A Brighter Future

TransplantChild, testimonies for life

TransplantChild

European Reference Network

Transplantation in Children
(ERN TRANSPLANT-CHILD)

Funded by the
European Union

TransplantChild is one of 24 European Reference Networks, which includes the participation of 40 different hospitals spanning 21 countries. Its main objective is to connect patients, healthcare providers and professionals across the European Union, specifically focusing on paediatric transplantation.

The main aim is to address rare or complex diseases that require highly specialised treatment and a pool of experts and resources.

TransplantChild focuses on Hematopoietic Stem Cell and Solid Organ Transplant programmes such as Heart, Intestinal and multi-organic, Kidney, Liver or Lung.

The organ transplant, whatever the organ may be, is, in most cases, the last resort to save a life.

The basic concept for this book was created due to the need to share the several experiences of families and children that have endured or experienced one or more transplants with those who anxiously await a transplant. The purpose of this book is to help and support our healthcare universe such as professionals, families, children, and adolescents.

The testimonials were requested to all hospitals, with those testimonials being gathered here in this publication.

Through this initiative, we hope to explain some of the doubts and fears that our patients and families have. Truthfully, we would like to gather more testimonials from more hospitals and countries.

In conclusion, we would like to thank all the children, adolescents, families, and healthcare professionals for their participation.

This book is from everyone to everyone!

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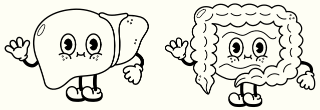
Stories

France

Sophie



« Je suis née deux fois, le jour de mon anniversaire et le jour de la transplantation »

La transplantation a eu lieu alors que je n'avais que 3ans et demi. Personne ne savait comment ça allait se passer car en plus d'être une double transplantation, c'était une première en Europe.

J'ai très peu de souvenir de cette période au vu de mon âge à cette période-là mais je sais que j'avais peur, peur de n'a pas me réveiller et d'être « encore » malade, peur d'avoir mal et de rester encore longtemps à l'hôpital … mais je savais aussi que c'était une chance pour moi et que je devais continuer de me battre. Ma famille, surtout mes parents, étaient très présents et me disaient de ne pas baisser les bras car après cette opération j'aurais une belle vie, que je pourrais retourner à la maison avec mes sœurs, retourner à l'école, retrouver mes copains… je me suis battue malgré la peur et les complications qui ont suivi mais j'ai toujours gardé ma joie de vivre, mon sourire et ma bonne humeur. Aujourd'hui, 28 ans après, je me rends compte de la chance que j'ai eu d'avoir pu bénéficier de cette double transplantation, je vis comme une femme de mon âge, sans trop regarder en arrière et tous les jours je me dis, malgré la prise de traitement quotidienne, que j'ai de la chance d'être encore en vie et que tous les jours c'est un jour de plus de gagner.

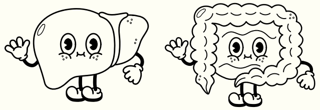
A tous les parents, restez positif, ne lâchez rien, et continuez à « vivre » malgré l'attente, la peur, et les contraintes de la pathologie de votre enfant. Malgré beaucoup d'appréhension et de peur, mes parents ont toujours fait confiance à l'équipe médical et ils ont eu raison. Ils se sont battus ensemble et ça a payé. Le fait d'avoir été très entouré par leurs amis et la famille, ça les a beaucoup aidés et ils ont pu me soutenir au quotidien.

A tous les enfants n'ayez pas peur ce n'est qu'un petit moment à passer mais après la vie sera beaucoup plus belle, et vous allez vous sentir « différents » tout en restant vous-même. Dites-vous que la vie est belle et qu'il faut sourire tous les jours malgré la peur et la douleur. Mais ne craignez pas de craquer, ça fait du bien parfois et surtout, parlez de ce que vous ressentez, de vos appréhensions et n'hésitez pas à poser toutes les questions que vous voulez au personnel soignant et à vos parents.

Dès que j'ai un petit coup de mou, je me rappelle ces deux phrases qui me permettent d'avance « je suis née deux fois, le jour de mon anniversaire et le jour de la transplantation » et puis « je n'ai jamais rien fait comme tout le monde et ce n'est pas aujourd'hui que je vais changer »

Si je me base sur mon expérience, l'hôpital était pour moi ma deuxième maison et donc l'équipe médical ma deuxième famille. Ils m'ont accompagné jusqu'au bout de la transplantation et bien longtemps après. Merci à eux d'être ceux qu'ils sont et même si ce n'est pas tous les jours facile, ils sont là pour rassurer les enfants ainsi que les parents et effectuent un travail formidable.

Sophie



"I was born twice on my birthday and on the day of the transplant"

The transplant took place when I was only 3 and a half years old. Nobody knew how it was going to go because in addition to it being a double transplant, it was a first in Europe.

I have very little memory of this period, given my age at that time, but I know that I was afraid; afraid of not waking up, of still being sick, and of having pain and staying in the hospital for a long time. But I also knew that it was an opportunity for me and that I had to keep fighting. My family, especially my parents, were very present and told me not to give up because after this operation I would have a good life; that I could go home with my sisters, go back to school, find my friends. Despite the fear and complications that followed, I always kept my joie de vivre, my smile and my good mood. Today, 28 years later, I realize how lucky I was to have been able to benefit from this double transplant. I live like any other woman of my age, without looking back too much, and every day I tell myself, despite taking daily treatment, that I am lucky to still be alive and that every day it is one more day to win.

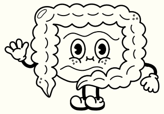
To all parents, stay positive, do not let go, and continue to "live" despite the expectation, fear, and constraints of your child's pathology. Despite a lot of apprehension and fear, my parents always trusted the medical team, and they were right. They worked together and it paid off. The fact that they were very supported by their friends and family helped them a lot, and so they were able to then support me on a daily basis.

To all children, do not be afraid. It is only a short moment to spend in treatment, but afterward, life will be much more beautiful, and you will feel different while remaining yourself. Tell yourself that life is beautiful and that you should smile every day despite fear and pain. But do not be afraid to crack — it feels good sometimes. Above all, talk about how you feel, including your apprehensions, and do not hesitate to ask all the questions you want of your caregivers and parents. As soon as I have a little free time, I remember these two sentences

"I was born twice on my birthday and on the day of the transplant" and then "I have never done anything like everyone else, and it is not today that I will change that."

Based on my experience, the hospital was my second home, and therefore, the medical team was my second family. They accompanied me to the end of the transplant and long after. Thank you to them for being who they are and even if it is not easy every day, they are there to reassure children as well as parents and they do a great job.

Pierre



« Penser positivement à votre situation »

Je m'appelle Pierre, j'ai 27 ans et j'habite à Fasano, dans le sud de l'Italie. En décembre 1998, à l'âge de 3 ans, j'ai reçu une greffe d'intestin.

Je ne me souviens pas beaucoup de cette époque, mais je sais que j'ai eu la chance d'être l'un des premiers bébés à subir une greffe d'intestin sans aucune complication.

En juillet 2021, j'ai terminé mes études à l'université des langues de Bari. Je parle couramment l'italien (ma langue maternelle), le français (la première langue que j'ai commencé à parler), l'anglais et l'espagnol. J'ai toujours été passionnée par les langues et j'ai toujours voulu appliquer ces connaissances.

À la question « Qu'aimeriez-vous faire dans la vie ?», j'ai toujours répondu « Quelque chose en rapport avec les langues ».

Après l'université, j'ai commencé à chercher du travail et, en mai 2022, j'ai commencé mon premier emploi : réceptionniste dans un hôtel à Cisternino, une petite ville près de Fasano, travaillant de nuit pendant tout l'été.

Voilà un peu ce que je suis et comment vous pouvez voir qu'après la transplantation, tout s'est amélioré. Je peux confirmer que j'ai maintenant une vie comme la majorité de la population.

Bien sûr, je dois faire attention à mon corps: Je ne peux pas faire de travaux physiques extrêmement lourds, je dois éviter certains aliments auxquels je suis allergique ou intolérant (poisson, lait, œufs et viandes blanches).

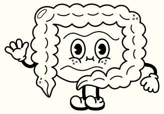
En parlant avec des patients ou avec leurs parents qui vivent ou ont vécu une situation comme la mienne, je comprends que ces personnes me considèrent comme une sorte de modèle pour eux. En fait, lorsque j'étais bébé, mes parents ont rejoint une association italienne appelée « Un filo per la vita» pour les enfants ou les adultes qui ont eu une maladie de l'intestin, dans le but que ces syndromes soient reconnus comme une maladie rare en Italie.

En ce qui concerne ma transplantation, j'ai toujours des cicatrices sur le ventre. Elles me rappellent d'où je suis partie, et combien le chemin a été long, pour pouvoir enfin dire que, pas à pas, j'ai réussi à mener une vie indépendante. Aujourd'hui, je n'ai plus à me rendre que deux fois par an à l'hôpital pour m'assurer que tout fonctionne encore bien, et c'est le cas.

J'espère que ce simple texte pourra aider chaque personne qui vit cette situation difficile dans l'attente d'une transplantation.

Ce que je peux vous suggérer, c'est de penser positivement à votre situation et de vous rendre compte qu'elle finira par s'améliorer.

Pierre



"Think positively about your situation"

My name is Pierre, I'm 27 years old and I live in Fasano, in southern Italy. In December 1998, when I was 3 years old, I received a bowel transplant.

I don't remember much about that time, but I know how lucky I am to be one of the first babies to undergo a bowel transplant with no complications.

In July 2021, I finished my studies at the University of Languages in Bari. I speak fluent Italian (my mother tongue), French (the first language I started to speak), English and Spanish. I always had a passion for languages and have wanted ever since to apply this knowledge.

My answer to the question, "What would you like to do for a living?" has always been "Something to do with languages". After university, I started looking for work, and in May 2022 I began my first job receptionist in a hotel in Cisternino, a little city near Fasano, working nights throughout the summer.

That's just a little about me, and how you can see that, after transplantation, everything became better. I can confirm that I now have a life like the majority of the population.

Of course, I have to care about my body I can't do extremely heavy physical work, I need to avoid some foods to which I am allergic or intolerant (fish, milk, eggs and white meats).

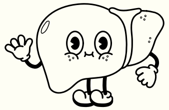
Speaking with patients or with their parents who live or have lived in a situation like mine, I understand that these people see me as a kind of role model for them. In fact, when I was a baby, my parents joined an Italian association called "Un filo per la vita" for children or adults who have had bowel disease, with the goal that these syndromes will be recognized as a rare disease in Italy.

In terms of my transplantation, I continue to have scars on my belly. They remind me of where I started, and how long was the path, to be able to finally say that, step by step, I have achieved an independent life. Now, I only need to undergo hospital follow-ups twice a year, to be sure that everything continues to function well, and it has.

I hope that this simple text can help each person who is living in this difficult situation while waiting for transplantation.

What I can suggest is to think positively about your situation, and realize that it will eventually be better.

Margot



« Profitez de votre vie intensément et de chaque moment de votre renaissance »

Margot, 5 ans 1/2. Greffe de foie à 18 mois pour Atrésie des Voies Biliaires.

En août 2022, admirer Margot profiter de la vie, à l'image de ses 2 aînées au même âge, est le symbole du succès de l'aventure de la greffe. Margot va à l'école, déjeune à la cantine, profite du centre de loisirs, de ses activités multisports, nage, et passe ses vacances chez Papy et Mamy. Elle voyage en Europe et en Asie. Elle adore danser et demeure une petite fille très gaie, pleine d'énergie.

La greffe est une aventure qui démarre dès l'inscription sur la liste d'attente. A partir de cet instant, chaque jour, chaque nuit sont synonymes d'angoisse et d'espoir… La patience atteint son comble… mais le jour J arrive finalement. Et une renaissance, une seconde chance pour profiter de la vie se présente. Le chemin est long et difficile… mais le résultat est incroyable. Comme pour une naissance, préparez votre valise qui vous accompagnera à l'hôpital : des vêtements confortables, livres, jeux, chargeurs, photos, musique, quelques douceurs etc… ces petites choses personnelles vous feront un bien fou.

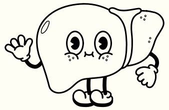
Que de chemin parcouru à travers l'aventure de la greffe…profitez de votre vie intensément et de chaque moment de votre renaissance.

Une tendre pensée aux parents, compagnons de galère, qui vivent des nuits blanches, dans des conditions pas très faciles et qui mettent leur propre vie entre parenthèse, essayant de jongler entre la vie pro, la vie familiale…Quel courage et quelle force vous portez pour accompagner votre enfant. C'est un marathon…ne lâchez rien !

Une pensée également au staff médical et paramédical, au staff de la crèche, de l'école, du centre de loisirs, des activités sportives qui gardent toujours un œil vigilant et bienveillant.

Que ferions-nous sans l'accompagnement et le soutien sans faille des pédiatres, hépatologues, chirurgiens et tous les autres professionnels de santé ? Vous êtes nos guides à travers tout le long chemin de la greffe et du post-greffe. Nos questions et inquiétudes de parents sont parfois redondantes mais vous seuls êtes en mesure de nous rassurer sur le parcours. Merci de votre accompagnement sans faille…et de votre patience.

Margot



"Enjoy your life intensely and every moment of your rebirth"

Margot, 5 ½ years. Liver transplant at 18 months for biliary atresia.

In August 2022, looking at Margot enjoying life like her 2 older sisters, at the same age, is the greatest success of the transplant adventure. Margot goes to school, eats at the canteen, goes to the leisure centre, participates in sports activities, swims, and spends holidays with Grandpa and Grandma. She travels to Europe and Asia, loves to dance and remains a very greedy and cheerful little girl.

The transplant adventure begins as soon as you register on the waiting list. During this period, every day and night is synonymous with anguish and hope. Patience reaches its limit, but the big day finally arrives. And then a rebirth, a second chance to enjoy life presents itself. The journey is long and difficult, but the result is incredible. Like a birth, prepare your overnight bag for hospitalisation comfortable outfits, books, games, chargers, photos, music, etc. You will appreciate these little personal belongings.

How far we have come through the adventure of transplantation — enjoy your life intensely and every moment of your rebirth.

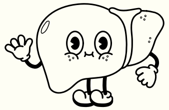
A tender thought for the parents and friends of the transplant recipient, who endure sleepless nights, in not very easy conditions and who put their own life on hold, trying to juggle professional life and family life.

What courage and strength you have to support your child!

A warm thought also to the staff of the hospital, nursery, school, leisure centre, and the sports coaches, who always kept a vigilant and benevolent eye on our daughter.

What would we have done without health professionals' dedication and support? You are our guide through the long journey of transplantation and post-transplant. Our questions and concerns as parents are sometimes redundant, but only you are able to reassure us on this journey. Thank you for your unfailing support, and your patience.

Chloé



« Quoiqu’il arrive, il faut faire confiance aux équipes médicales »

Age au moment de la greffe
2 ans
Organe greffé
Foie

Inquiétudes principales
Notre principale inquiétude face à cette opération de greffe était la survie de notre enfant. Elle n’avait que 2 ans à l’époque et les risques existaient. Nous avons eu la chance d’avoir été suivi par une équipe extraordinaire qui nous a accompagné, du début à la fin, avec professionnalisme et humanité.

Bénéfices
Une fois l’opération réalisée, la greffe nous est rapidement apparue comme une magnifique opportunité pour notre enfant. Cela lui permet aujourd’hui d’avoir une vie bien plus normale qu’avec sa pathologie initiale. Le suivi de greffe n’est pas un long fleuve tranquille mais il y a des solutions à chaque problème.

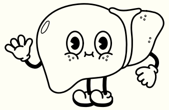
Message pour ceux qui attendent une greffe
L’opération, en terme chirurgical, n’est pas insurmontable. On se remet bien plus vite que ce que nous pouvons imaginer. Nous avons la chance en France d’avoir les plus grands spécialistes. L’après opération est une résurrection !

Message pour les autres greffés
Dans beaucoup d’autres pays, les greffes ne sont pas pratiquées et les chances de survie réduites, souvent inexistantes. Apprécions la qualité de nos soignants et soyons heureux d’être français !

Message pour les parents
Quoiqu’il arrive, il faut faire confiance aux équipes médicales et aller dans le même sens pour les aider à soigner nos enfants. C’est un travail d’équipe et notre rôle est essentiel ! Ensuite, il me semble qu’il faut garder espoir! C’est très important pour nous, en tant que parents, mais aussi pour notre enfant, qui ressent nos craintes.

Message pour les professionnels de santé (médecins, infirmières, assistantes sociales, etc)
Merci du fond du cœur d’être là pour nous !

Chloé



“Whatever happens, we have to trust the medical teams”

Age at time of transplant
2 years
Transplanted organ
Liver

Top concerns
Our main concern with this transplant operation was the survival of our child. She was only 2 years old at the time, and there were risks. We were fortunate to have been followed by an extraordinary team who treated us, from beginning to end, with professionalism and humanity.

Benefits
Once the operation was completed, the transplant was quickly shown to be a magnificent benefit for our child. This now allows her to have a much more normal life than her initial pathology suggested. Transplant follow-up is not entirely smooth sailing, but there are solutions to every problem.

Message for those waiting for a transplant
The operation, in surgical terms, is not insurmountable. We’re recovering much faster than we could have imagined. We are fortunate in France to have the greatest specialists. Life after the operation is like a resurrection!

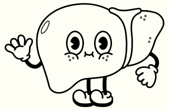
Message for the other transplant recipients
In many other countries, transplantation is not practiced and the chances of survival are reduced, or even non-existent. Enjoy the quality of our caregivers and be happy to be French!

Message for parents
Whatever happens, we have to trust the medical teams and aid in helping them care for our children. It is a team effort, and our role is essential! Second, it seems to me that we must maintain hope! This is very important for us, as parents, but also for our child, who feels our fears.

Message for health professionals (doctors, nurses, social workers, etc.)
Thank you with all my heart for being here for us!

Deutschland/Germany

Helga



«Es kann sehr hilfreich sein, mit Familien von transplantierten Kindern in Kontakt zu treten»

Grunderkrankung des Kindes
Sekundär sklerosierende Cholangitis mit biliärer Zirrhose
Alter des Kindes jetzt
5
Alter des Kindes bei Transplantation
2 Jahre und 5 Monate

Was waren Ihre Hauptsorgen in der Zeit um und nach der Transplantation?
Unsere größte Befürchtung war, dass eine Transplantation viele Komplikationen mit sich bringen könnte und dass wir Helga verlieren könnten. Wir waren verängstigt und hofften lange Zeit, dass sie keine Transplantation benötigen würde.

Was waren Ihrer Meinung nach die größten Erfolge?
Der größte Erfolg war die Transplantation. Unsere Tochter bekam ein ganzes Organ(kein Split) und alles verlief gut, ohne Komplikationen. Heute ist sie ein gesundes kleines Mädchen, das seine Kindheit genießt.

Was hat Ihnen in der Zeit um die Transplantation am meisten geholfen?
Das gesamte Transplantationsteam des Krankenhauses war großartig. Die Lebertransplantation von Helga war für unsere Familie ein sehr traumatisches Erlebnis. Ich bin sehr dankbar, dass wir im Transplantationsprogramm die Möglichkeit hatten, mit dem gesamten Team über alles zu sprechen. Sie haben unsere Sorgen verstanden und uns geholfen, unsere Angst zu überwinden.

Was würden Sie anderen Kindern, die aktuell auf eine Transplantation warten, gerne sagen?
Sprecht mit euren Eltern und Ärzten über eure Bedenken. Es ist normal, in dieser Situation Angst zu haben. Vertraut den Ärzten und befolgt ihre Ratschläge, besonders nach der Transplantation. Die regelmäßige Einnahme von Medikamenten wird eines Tages zu eurer Verantwortung werden. Das ist das Mindeste, was ihr für euch selbst tun könnt und es istein Zeichen der Dankbarkeit für das große Geschenk des Lebens, das ihr erhalten habt.

Was würden Sie den Eltern der Kinder gerne sagen?
Kümmern Sie sich gut um sich selbst. Ihr Kind braucht Sie, um gesund und stark zu sein. Scheuen Sie sich deshalb nicht, um die Hilfe zu bitten, die Sie brauchen. Es kann sehr hilfreich sein, mit Familien von transplantierten Kindern in Kontakt zu treten. Sie werden sich weniger allein fühlen und mehr Hoffnung haben. Wappnen Sie sich mit viel Geduld und Zuversicht und vergessen Sie nicht, dass sich all dies eines Tages lohnen

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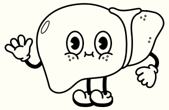
Helga



“Getting in touch with families of transplanted children can help a lot”

Underlying disease of the child
Secondary sclerosing cholangitis with biliary cirrhosis
Age of the child now
5
Age of the child at transplantation
2 years and 5 months

What were your main concerns during the time around and after transplant?
Our biggest fear was that transplantation could bring lots of complications and that we could lose her. We were terrified, and for a long time hoped that she would not need a transplantation.

What do you think were the greatest successes?
The biggest success was the transplantation. Our daughter got a full organ and everything went well, without complications. Today, she is a healthy little girl who enjoys her childhood.

What helped you the most during the transplant period?
The whole transplant team at the hospital was amazing. Helga’s liver operation was a deeply traumatic experience for our family. I am very grateful that in the transplant program we had the opportunity to talk with the whole team about everything. They understood our concerns and helped us overcome our fear.

What would you like to tell other children who are currently waiting for a transplant?
Speak about your concerns with your parents and doctors; it is normal to be afraid in this situation. Trust the doc- tors and follow their advice, especially after transplantation. Taking medication regularly will one day become your responsibility. It’s the least you can do for yourself as a sign of gratitude for the huge gift of life you’ve been given.

What would you tell the children’s parents?
Take good care of yourself. Your child needs you to be healthy and strong. Therefore don’t be afraid to ask for the help that you need. Getting in touch with families of transplanted children can help a lot. You will feel less alone and more hopeful. Arm yourself with a lot of patience and faith and don’t forget that all this will one day be worth it because your child will get a new chance for life.

What would I like to say to the healthcare staff involved (doctors, nurses, psychologists, social workers, service workers)?
Thank you very much for your patience, dedication, and the love that you put into giving our

wird, weil Ihr Kind eine neue Chance auf Leben bekommt.

Was würden Sie gern dem beteiligten Gesundheitspersonal (z.B. Ärzt*innen, Krankenpfleger*innen, Psycholog*in- nen, Sozialarbeiter*innen, Servicemitarbeiter*innen) gerne sagen?
Vielen Dank für Ihre Geduld, Ihre Hingabe und Ihre Liebe, die Sie aufbringen, um unseren Kindern eine zweite Chance für das Leben zu geben. Sie werden für immer in unseren Herzen und Gebeten sein.

Möchten Sie und sonst noch etwas miteilen?
Vielen Dank für Ihren Beitrag!

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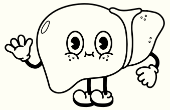
children a second chance at life. You will be forever in our hearts and prayers.

Anything else you would like to share?
Thank you for your contribution!

Ingrid



«Niemals aufgeben und immer ein sich Glauben»

Wir alt bin ich jetzt
13
Wie alt war ich bei der Transplantation
Bei der ersten 8 um bei der zweiten 13,5

Was waren meine Sorgen in der Zeit um und nach der Transplantation?
Dass die Leber nicht so funktioniert wie sie soll oder dass in der OP etwas schief läuft dass ich danach nicht „normal" bin dass sie starke Schmerzen habe dass ich vielleicht Freunde verliere oder so das sich lange nicht richtig was machen kann.

Was war mein größter Erfolg nach der überstandenen Transplantation? Worüber habe ich mich am meisten gefreut?
Dass ich nicht mehr immer so ein dicken Bauch habe und deswegen weniger ins Krankenhaus muss dass ich fitter und motivierter bin.

Dass ich kein Juckreiz und kleine Adern im Gesicht habe und dass ich die OP gut geschafft habe.

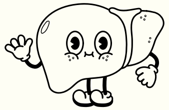
Es hat mir derzeit um die Transplantation am meisten geholfen?
Dass ich mich mit einem anderen Mädchen austauschen konnte dass ich viel mit meinen Geschwistern geschrieben habe dass ich einen sehr tollen Arzt habe und eigentlich immer mit meiner Psychologin reden konnte dass meine Mutter mich so unterstützt hat.

Was würde ich anderen Kindern die aktuell auf eine Transplantation warten keine sagen?
Niemals aufgeben und immer ein sich Glauben. Ihr seid so stark.

Was möchte ich anderen schon transplantierten Kindern keine sagen?
Dass sie auch immer weiterkämpfen sollen und dass sie sehr stark sind und dass sie sich nicht schämen müssen (Narben).

Was würde ich gern beteiligten Gesundheitspersonal (z. B. Ärzt*innen Krankenpfleger*innen Psycholog*innen & Sozialarbeiter*innen Servicemitarbeiter*innen) gerne sagen?
Dass man kranke Kinder ernst nehmen sollte aber auch dass sie alle einen wichtigen ernstzunehmenden Beruf machen. Danke!

Ingrid



"Never give up, and always believe in yourself"

What were my main concerns around the time of the transplant and afterwards?
That my new liver won't function the way it's supposed to. That the operation goes bad and i will be in a lot of pain. That i will not feel "normal" again or will lose my friends. That i will have to take it easy for a long time and can't do anything interesting.

What was my greatest success after having a transplant? What made me the happiest?
That I don't have such a big belly anymore and therefore don't have to go to hospital so often. That I am more energetic and motivated. That I no langer have the itching or small veins on my face, and that I have managed to get through the operation.

What helped me the most during the time around the transplant?
That I was in touch with another girl who had gone through the same and messaged me a lot with my sib lings. That I have a very great doctor and could always talk to my psychologist. That my mother supported me so much.

What would I like to tell other children who are currently waiting for a transplant?
Never give up, and always believe in yourself! You are so strong!

What would I like to say to other children who have already been trasplanted?
That they have to keep on fighting and that they are so strong! They don't have to be ashamed of any- thing (scars, etc).

What would I like to say to the healthcare staff involved (doctors, nurses, psychologists, social workers, service workers)?
That you should take sick children seriously. And that you all have an important and serious job, thank you!

Ingrids Mutter

Was waren ihre Hauptsorgen in der Zeit um und nach der Transplantation?
Bei der ersten Transplantation waren meine größten Sorgen, ob sie das überleben wird. Sie hatte innerhalb 1 Woche „akutes Leberversagen“. Es ging ihr sehr schlecht, sie war nicht mehr ansprechbar und wurde künstlich am Leben erhalten bis zur Transplantation. Ich hatte Angst, dass sie bleibende Schäden behält. Ich hatte große Sorge, dass jetzt die Kraft und den Mut verliert weiterzuleben. Es war eine Zeit mit vielen Höhen und Tiefen. Sie hat ein ganzes Jahr gebraucht bis sie wieder ihrem großen Hobby nachgehen konnte (das Turnen).

Was waren ihr Meinung nach die größten Erfolge?
Ein Kind selbst war in dieser Situation der größte Erfolg! Ingrid hat nie aufgegeben zu kämpfen und ist ins Leben zurückgekehrt. Sie hat ihre Ziele verfolgt und immer weiter gemacht, obwohl es ein langer schwerer Weg war. Die Hilfe und das Glück bekommen zu haben, dass Ingrid weiter leben kann. Fünf Jahre hat Ingrid mit dieser Leber gelebt, bis sie im April 2022 wieder transplantiert wurden. Wir geben nicht auf, Ingrid kämpft weiter für ein ganz normales Leben!

Was hat Ihnen in der Zeit um die Transplantation am meisten geholfen?
Hartnäckig zu sein und sich ein eigenes Netzwerk aufzubauen. Einen festen, kompetenten Arzt zu haben, der uns auf Augenhöhe begegnet und uns seit 5 Jahren begleitet. Ein toller Kinderarzt, der zu jeder Tages- zur Nachtzeit erreichbar ist. Eine Psychologin, die Vertrauen aufbauen konnte und meine Tochter immer wieder Mut zugesprochen hat und der Ingrid da abholt wo sie sich gerade befindet und ein professioneller Operateur. Das Personal auf der Station das Ingrid ernst genommen hat. Der Rückhalt meiner Familie, besonders meiner Mutter, die mir sehr viel Durchhaltevermögen Optimismus und Kraft entgegengebracht hat und mich aufgemuntert hat. Ingrids Zwillingsschwester, die sehr schnell „groß“ geworden ist in dieser schweren Zeit und vieles allein managen musste und mein Sohn, der sofort wieder bei uns einzog und viel unterstützt hat.

Was würden sie anderen Kindern, die aktuell auf eine Transplantation warten, keine sagen?
Verliert nicht den Mut. Haltet durch und seid immer präsent. Es lohnt sich zu kämpfen! Haltet den Kontakt zu euren Freunden, auch wenn es manchmal schwer fällt. Holt euch Hilfe (Gesprächstherapie). Unternimmt Dinge die noch möglich sind. Es gibt immer einen Weg, den jeder „für sich“ finden muss und mit Hilfe auch finden wird!

Was würden Sie den Eltern der Kinder gerne sagen?
Immer wieder den Kontakt zur Klinik aufnehmen. Das intensive Gespräch mit den entsprechenden Ärzten suchen. Sich Hilfe holen, um neue Kräfte zu entwickeln. Dem eigenen Kind Mut zu sprechen und Kraft geben. Das Leben so lebenswert wie möglich zu gestalten. Gemeinsame Ziele erfolgen. Fordert eure „Rechte“ und „Hilfen“ ein, die euch in dieser Zeit zustehen. Baut euch euer eigenes Netzwerk auf, mit den Personen, denen Ihr Vertrauen könnt.

Was würden Sie gern dem beteiligten Gesundheitspersonal (z. B. Ärzt*innen Krankenpfleger*innen Psycholog*innen & Sozialarbeiter*innen Servicemitarbeiter*innen) sagen?
Schon. Ich wünsche mir von einigen des Gesundheitspersonales etwas mehr Empathie gegenüber der Erkrankten. Die angesprochenen Leiden des Patienten ernst nehmen. Wir wissen alle nicht, wie es dem betroffenen Kind vor- während und nach einer Transplantation geht, wir können es nur vermuten! Reicht das?

Möchten Sie sonst noch etwas mitteilen?
In den Händen, in denen wir uns aufgehoben fühlen, ist vieles leichter! Danke!!!

Mother of Ingrid

What were your main concerns during the time around and after transplant?
During the first transplant, my biggest concerns were whether she would survive this. She had ‘acute liver failure’ within a week. She was very unwell, unresponsive and was kept alive artificially until the operation. I was afraid that she would suffer permanent damage, and I was very worried that Ingrid would lose the strength and courage to go on living. It was a time with many ups and downs. It took her a whole year before she was able to pursue her great hobby (gymnastics) again.

What do you think were the greatest successes?
My child herself was the greatest success in this situation! Ingrid never gave up fighting and returned to life! She pursued her goals and always kept going, even though it was a long, hard road. And to have received the help and the luck so Ingrid can continue to live. Ingrid lived with her first liver for 5 years, until she was transplanted again in April 2022. We will not give up; Ingrid continues to fight for a normal life!

What helped you the most during the transplant period?
To be persistent and build our own network; having a constant, competent doctor who sees eye-to- eye with us and has been with us for 5 years, a great paediatrician who is available at all hours; having a psychologist who has been able to build trust and who has always encouraged my daughter, raising Ingrid’s morale; having a professional surgeon; the staff on the ward, who took Ingrid seriously; and the support of my family, especially my mother, who gave me a lot of stamina, optimism and strength and cheered me up. Ingrid’s twin sister, who “grew up” very quickly during this difficult time, had to manage a lot on her own, and my son, who immediately moved back in with us, provided a lot of support.

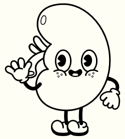
What would you like to tell other children who are currently waiting for a transplant?
Do not lose heart. Hang in there and always be present. It is worth fighting! Keep in touch with your friends, even if it is sometimes difficult. Get help (therapy). Do the things that are still possible. Everyone has to find the way “for themselves”, and will find it with help!

What would you tell the children’s parents?
Always keep in touch with the clinic. Seek intensive discussion with the relevant doctors. Get help to develop new strengths. Encourage and give strength to your child. Make life as worth living as possible. Pursue common goals. Claim the “rights” and help that you are entitled to during this time. Build your own network of people you can trust.

What would I like to say to the healthcare staff involved (doctors, nurses, psychologists, social workers, service workers)?
I would like to see more empathy from some of the healthcare staff towards the ill. Take the patient’s suffering, which he shares with you, seriously. We don’t all know how an affected child is doing before, during and after a transplant, we can only guess!

Anything else you would like to share?
Many things are easier when we feel cared for — thank you!

Lena



«Das Leben ist so toll ohne Dialyse»

Grunderkrankung des Kindes
Niereninsuffizienz
Alter des Kindes Jetzt
16
Alter des Kindes bei Transplantation
16

Was waren meine Sorgen der Zeit um und nach der Transplantation?
Ob die Niere von meinem Körper aufgenommen wird?. Wie lange ich auf der Intensivstation liegen muss?. Wie lange der Blasenkatheter und die Drainagen drinne bleiben?. Wie lange ich insgesamt im Krankenhaus bleiben muss?

Was waren meine größten Erfolge nach der überstandenen Transplantation? Worüber habe ich mich am meisten gefreut?
Als sich auf die Normalstation durfte. Als der Blasenkatheter und die Drainagen gezogen wurde. Ich endlich nach Hause durfte. Ich wieder normal auf Toilette gehen konnte.

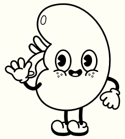
Bessert mir in der Zeit und die Transplantation am meisten geholfen?
Der Gedanke bald wieder ein „fast“ normales. Leben führen zu können. Keine Dialyse mehr machen zu müssen.
Das würde ich anderen Kindern, die aktuell auf eine Transplantation warten, gerne sagen?
Macht euch keine großen Sorgen, alles wird gut. Habt keine große Angst davor, bleibt gelassen. Euch wird es danach viel besser gehen. Ihr könnt wieder „fast“ ein normales Leben führen.

Was möchte ich anderen schon transplantierten Kindern gerne sagen?
Das Leben ist so toll ohne Dialyse. Es ist ein Wunder wieder fast normal essen zu können. Das Medikament nehme gehörten zum Alltag.

Was würde ich gern beteiligten Gesundheitspersonal (z. B. Ärzt*innen Krankenpfleger*innen Psycholog*innen & Sozialarbeiter*innen Servicemitarbeiter*innen) gerne sagen?
Vielen herzlichen Dank. Hier war alles so nett und hilfsbereit.

Möchte Stuhl sonst noch etwas mitteilen?
Die Zeit zwischen der Dialyse bis zur Transplantation wird schnell vorbeigehen.

Lena



“Life is so great without dialysis”

Primary disease
Renal failure
Age of the child now
16 years
Age of the child at transplantation
16 years

What were my concerns during the time around and after the transplant?
Whether my body accepts the kidney. How long I would have to stay in intensive care. How long the bladder catheter and drains would have to stay in How long I would have to stay in hospital in total.

What was my greatest success after having a transplant? What made me the happiest?
When I was allowed to go to the regular ward. When the bladder catheter and the drains were pulled.When I was finally allowed to go home. When I was able to go to the toilet normally again.

What helped me the most during the time around the transplant?
The thought of soon being able to lead an “almost” normal life again. No more dialysis.

What would I like to tell other children who are currently waiting for a transplant?
Don’t worry too much, everything will be fine. Don’t be very afraid of it, stay calm. You will feel much better afterwards. You can “almost“ lead a normal life again.

What would I like to say to other children who have already been trasplanted?
Life is so great without dialysis. It’s a miracle to be able to eat “almost” normally again. Taking medication is now part of everyday life.

What would I like to say to the healthcare staff involved (doctors, nurses, psychologists, social workers, ser- vice workers)?
Thank you very much. You were all so nice and helpful.

Anything else you’d like to share?
The time between dialysis and transplantation will pass quickly.

Lenas Mutter

Was waren ihre Haupt Sorge in der Zeit um und nach der Transplantation?
Wie wird die Transplantation verlaufen? Wird die Transplantat gut verlaufen?
Ob das Organ angenommen wird?
Wird der Heilungsprozess gut verlaufen?
Komme ich als Elternteil als Spender infrage?
Wie schnell bekommt man eine Spender Niere?

Was waren ihrer Meinung nach die größten Erfolge?
Die Translation ist gut verlaufen!
Das Organ wurde angenommen!
Dialyse war nicht mehr notwendig.
Es gibt kaum Einschränkungen beim Essen.

Was hat Ihnen in der Zeit und die Transplantation am meisten geholfen?
Aufklärungsgespräch mit den Ärzten.
Gespräch mit Familie und Freunden.

Was würden Sie anderen Kindern, die aktuell auf eine Transplantation warten, gerne sagen?
Die Diagnose und Krankheit ist zwar blöd/doof, aber es ist nicht lebensbedrohlich, da man sie durch die Dialyse und Transplantation behandeln kann.

Man ist in dieser Situation nicht alleine, man kriegt viel Unterstützung und Zuspruch durch Ärzte, Familie und Freunde.

Was würden Sie den Eltern der Kinder gerne sagen?
Die Kinder sind durch die Krankheit nicht weniger wird sie brauchen in dieser Zeit besondere Unterstützung.

Der Umstand der Krankheitsschweiß das Leben durcheinander, man passt sich jedoch schnell an die Situation an.

Was würden Sie gern dem beteiligten Gesundheitspersonal (z. B. Ärzt*innen Krankenpfleger*innen Psycholog*innen & Sozialarbeiter*innen Servicemitarbeiter*innen) sagen?
Ein sehr großes dann geschickt für die Unterstützung für die Begleitung durch die Zeit für die Ratschläge ohne euch wäre das alles nicht möglich gewesen.

Möchten Sie sonst noch etwas mitteilen?
Man weiß nicht was die Zukunft bringt es ist jedoch gut zu wissen das es eine Zukunft gibt.

Mother of Lena

What were your main concerns during the time around and after the transplant?
How will the transplantation proceed?
Will the transplantation go well?
Will the new organ be accepted?
Will the healing process go well?
As a parent, am I eligible to be a donor?
How quickly can one get a donor kidney?

What do you think were the greatest successes?
The transplant went well!
The organ was accepted!
Dialysis was no longer necessary.
There are very few restrictions on eating.

What helped you the most during the transplant period?
Educational conversation with the doctors.
Talks with family and friends.

What would you like to tell other children who are currently waiting for a transplant?
The diagnosis and disease sucks, but it is not life threatening because it can be treated with dialysis and transplantation.

You are not alone in this situation, you get a lot of support and encouragement from doctors, family and friends.

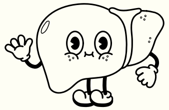
What would you tell the children's parents?
The children are not less valuable because of the disease; they need special support during this time.

The circumstance of the disease throws life upside down, but one quickly adapts to the situation.

What would you like to say to the healthcare staff involved (doctors, nurses, psychologists, social work- ers, service workers)?
A very big thank you for the support, for the company through the time, for the advice. Without you none of this would have been possible

Anything else you would like to share?
You don't know what the future holds, but it is good to know that there is a future.

M



«Die Krankenhauszeit für mein Kind „bunt“ zu gestalten»

Grunderkrankung des Kindes
Gallengangatresie
Alter des Kindes Jetzt
6
Alter des Kindes bei Transplantation
6 Monate

Was waren ihre Haupt Sorge in der Zeit um und nach der Transplantation?
Mich hat oft die Frage gequält, ob mein Kind auch irgendwann wie die Geschwister durch den Garten toben wird. Wird sie nach all den Strapazen auch so herzhaft lachen können und das Leben genießen? Hoffentlich wird sie später auch eine Familie gründen können, habe ich mir gedacht. Hoffentlich verängstigt sie das alles nicht fürs Leben und sie wird trotzdem eine selbstbewusste Frau, waren manchmal meine Gedanken.

Was waren ihrer Meinung nach die größten Erfolge?
Als die Geschwister nach der Transplantation das erste Mal zu ihr durften und alle Kinder einfach nur glücklich und zufrieden waren, sich zu haben. Das drumherum war allen in diesem Augenblick egal. Es war emotional und magisch. Das erste Lachen danach und der erste Spaziergang waren weitere Meilensteine, die mir viel bedeutet haben.

Was hat Ihnen in der Zeit und die Transplantation am meisten geholfen?
Das waren und sind ganz klar Erfolgsgeschichten von Menschen, die das gleiche erlebt haben. Ich habe mich auf die Suche nach positiven Geschichten gemacht, z. B. nach Frauen, die als Kind transplantiert wurden, jetzt Familien haben glücklich sind. Ich habe eine Menge solcher Menschen gefunden und bin sehr glücklich darüber.

Was würden Sie anderen Kindern, die aktuell auf eine Transplantation warten, gerne sagen?
Halte durch es wird wieder schön. Jetzt fühlt sich alles vielleicht sehr verängstigend an, doch irgendwann vergisst euer Kopf zum Glück etwas diese schwere Zeit und er werde wieder lachen, toben und das Leben genießen können, Schwimmen Fahrradfahren, Trampolinspringen, Reiten, Tanzen, all dies ist möglich noch vieles mehr.

Was würden Sie den Eltern der Kinder gerne sagen?
Die Tränen die fließt, ist berechtigt. Es ist eine so große Sache und das kann man nicht runter spielen. Doch habe versucht, die Krankenhauszeit für mein Kind „bunt“ zu gestalten. Der Bettchen habe ich mit fröhlichen ???? geschmückt, mit ihr mit bunten Ballons gespielt, Seifenblasen gepustet,

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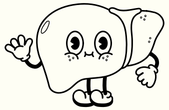
M



“I tried to make the hospitals ‘colourful’ for my child”

Primary disease
Biliary atresia
Age of the child now
6 years
Age of the child at transplantation
approximately 6 months

What were your main concerns during the time around and after the transplant?
I have often been tormented by the question of whether my child will someday be able to romp through the garden like her siblings. Will she also be able to laugh as heartily and enjoy life after all the hardships? I was hopeful that she would be able to start a family later on, that all this would not scar her for life, and that she would still become a self-confident woman.

What do you think were the greatest successes?
When her siblings were allowed to see her for the first time after the transplant, all the children were just happy and content to have each other. No one cared about the “trappings” at that moment. It was emotional and magical. Her first laugh afterwards and the first time she walked after the transplant were other milestones that meant a lot to me.

What helped you the most during the transplant period?
There were and are clearly success stories of people who have experienced the same. I went looking for positive stories, for example, women who were transplanted as children and now have families and are happy. I have found a lot of people like that and am very grateful for the strength they give me.

What would you like to tell other children who are currently waiting for a transplant?
Hang in there, it’s going to be beautiful again. Everything may feel very scary now, but fortunately, at some point your head will forget about this difficult time and you will be able to laugh, romp and enjoy life again. Swimming, cycling, jumping on the trampoline, horseback riding, dancing, all this is possible. And much more.

What would you tell the children’s parents?
Every tear that flows is justified. It’s a big deal and you can’t downplay that. But I tried to make the hospitals “colourful” for my child. I decorated her bed with happy photos, played with colourful balloons with her, blew soap bubbles and let children’s songs resound through the room. Of course, I cried with her sometimes, but from day to day we laughed more, played more and whenever it was possible, we went out into nature.

und Kinderlieder durch Zimmer schallen lassen. Natürlich habe ich auch mit ihr geweint, aber von Tag zu Tag haben wir mehr gelacht, mehr gespielt und wann immer es ging, sind wir raus in die Natur.

Was würden Sie gern dem beteiligten Gesundheitspersonal (z. B. Ärzt*innen Krankenpfleger*innen Psycholog*innen & Sozialarbeiter*innen Servicemitarbeiter*innen) sagen?

Danke für die liebe Art, die sie meinem Kind und mir entgegenbringen. Danke für jedes Lächeln, jede Erklärung und all die Geduld bei Untersuchungen, Blutabnahmen beim Zuganglegen. Mein Kind wurde immer freundlich behandelt und das hat ihr in all der Zeit etwas die Angst genommen. Danke für jeden „Small Talk“, selbst das hilft, sich nicht so allein zu fühlen. Danke an die Clowns und an die Herzkasper. Ihr seid so wertvoll für uns.

Möchten Sie sonst noch etwas mitteilen?

Vorbereitung für die Kinder kindgerecht auf die Eingriffe z. B. anhand von Kuscheltieren durch Ärzte z. B. wäre toll. Wenn die Kinder ständig gepiekst werden wäre ein „Anti- Angst Workshop“ vor Spritzen und Zugängen toll, wo die Kinder es auch mal spielerischen erklärt bekommen und Tricks lernen, wie es vielleicht weniger schmerzhaft ist. Und die Kinder vielleicht erfahren was dann mit ihrem Blut passiert.

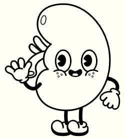
What would you like to say to the healthcare staff involved (doctors, nurses, psychologists, social work- ers, service workers)?

Thank you for the kind way you treat my child and me. Thank you for every smile, every explanation and all the patience with examinations, blood tests and IV. My child was always treated kindly, which took away some of her fears over the years. Thanks for every “small talk”, which made us not feel so alone. Thanks to the clowns. You are so valuable to us.

Anything else you would like to share?

Preparing the children for the interventions in a child-friendly way, e.g., using cuddly toys by doctors, would be great. Since the children are constantly being pricked, an “anti-anxiety workshop” about injections and IVs would be useful, where the children can have it explained in a playful way and learn tricks that might make it less painful (e.g., breathing techniques, Emla-patch, holding still) and perhaps learn what happens to the blood at that point. Childcare during educational talks would be great.

Lisa



«Wir Kinder sind stärker als manche Erwachsenen denken»

Name des Kindes oder Pseudonym
Lisa
Grunderkrankung des Kindes
IgA-Nephritis
Alter des Kindes jetzt
15
Alter des Kindes bei Transplantation
9

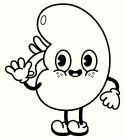
Was waren Ihre Hauptsorgen in der Zeit um und nach der Transplantation?
Ich weiß noch, dass ich in der Nacht vor der Transplantation nicht schlafen konnte. Meine Mutter war bei mir und mein Vater war in einem anderen Gebäude des Krankenhauses. Ich kann mich auch noch daran erinnern, dass ich meine Mama gefragt habe, ob ich bei der Operation sterben könnte. Ansonsten habe ich mich eher gefreut, dass ich die große Chance, nach neun Monaten Dialyse, auf die neue Niere bekomme.

Was waren Ihrer Meinung nach die größten Erfolge?
Das ich endlich nicht mehr an der Dialyse (PD) sein musste, dass ich wieder essen konnte, worauf ich Lust hatte ohne Einschränkungen und dass meine neue Niere angenommen wurde.

Was hat Ihnen in der Zeit um die Transplantation am meisten geholfen?
Der Kontakt zu anderen bereits erfolgreich Transplantierten und deren Geschichten. Meine Eltern, der Zu-sammenhalt der Familie und meiner Freunde.

Was würden Sie anderen Kindern, die aktuell auf eine Transplantation warten, gerne sagen?
Haltet durch! Wir Kinder sind stärker als manche Erwachsenen denken und ihr schafft das.

Lisa



“We kids are stronger than some adults think”

Child’s name or pseudonym
Lisa
Primary disease
IgA nephritis
Age of the child now
15 years
Age of child at transplantation
9 years

What were your main concerns during the time, around and after the transplantation?
I remember that I couldn’t sleep the night before the transplantation. My mother was with me and my father was in another building at the hospital. I also remember asking my mom if I might die during the operation. Apart from that, I was rather happy to have the big chance, after 9 months of dialysis, to get a new kidney.

What do you think have been the biggest successes?
That I finally didn’t have to be on peritoneal dialysis (PD) any more, that I could eat whatever I felt like again without restrictions, and that my new kidney was accepted.

What helped you the most during the time around the transplantation?
The contact with other already successfully transplanted people and their stories. My parents and the solidarity of my family and friends.

What would you like to tell other children that are currently waiting for a transplantation?
Hang in there. We kids are stronger than some adults think, and you can do it.

Hans and Sabine, Lisas Eltern

Was waren Ihre Hauptsorgen in der Zeit um und nach der Transplantation?
Für uns, als Eltern, war es die größte Sorge, dass das neue Organ nicht angenommen wird. Gerade für Hans, als Lebendspender, war die größte Angst, dass es nicht helfen wird, sein Organ nicht gut genug ist. Ein Satz, den Hans ggü. den Ärzten geäußert hat in dieser Zeit, ist auch heute noch sehr präsent „Bitte helfen Sie meinem Kind.“ Diese Angst, begleitet mit den Gedanken, dass am Tag der Transplantation der Anruf kommt, dass Lisa weiterhin an der Dialyse ist, weil die Transplantation nicht erfolgreich war, haben für zahlreiche unruhige, sorgenvolle Momente gesorgt. Diese Sorge war auch selbst nach der erfolgreich verlaufenen Transplantation immer noch vorhanden. Der Blick auf die Werte, die Schritte die Lisa gehen wird und die Gedanken, wie sich Lisas und unser Leben nach der Transplantation entwickeln wird, waren die bestimmenden Faktoren rund um die Transplan- tation. Welche neuen Einschnitte wird es geben auch in Bezug auf die Vielzahl an Medikamenten, die nach der Tranplantation auf einmal notwendig waren und sind.

Was waren Ihrer Meinung nach die größten Erfolge?
Das die neue Niere von Lisas Körper angenommen wurde und die Lebensenergie wieder in Lisa zurückge- kehrt ist. Dies auch verbunden mit Lisas großem Willen - trotz neuer Niere - so schnell wie möglich ein vergleich- weises normales Leben zu führen. Sie hat wieder an Gewicht gewonnen, hat wieder mehr gelacht und war im wahrsten Sinne des Wortes lebendiger. Und ganz klar auch nicht mehr durch die PD in unserem Familienleben zeit- lich limitiert zu sein, freier in unseren Entscheidungen zu sein, Urlaube ohne PD zu planen und wieder spontan sein zu können.

Was hat Ihnen in der Zeit um die Transplantation am meisten geholfen?
Akzeptieren was ist. Das Gefühl und das Wissen, dass wir so viele Dinge in der Hand haben und die, die wir nicht beeinflussen können, lernen zu akzeptieren. Auch das Vertrauen in unsere Ärzte und das gesamte Team, of- fene, klare Worte von deren Seite und die Zuversicht, dass alles gut werden wird. Auch der Rückhalt unserer Familie und Freunde hat uns in der Zeit gestützt.

Was würden Sie den Eltern der Kinder gerne sagen?
Stellt den Ärzten Fragen, denn in unserer Situation ist keine Frage „zu blöd“, um nicht gestellt zu werden. Jede Unsicherheit, jede Sorge hat ihre Berechtigung. Nehmt euch auch wichtig, gönnt euch eure Auszeiten. Auch als Eltern darf man Ängste haben, Tränen dürfen geweint werden auch – je nach Alter - mit den Kindern. Wir können so viele Dinge beeinflussen und so vieles leider auch nicht. Setzt gleichermaßen auch euer Vertrauen in euer Ärzteteam und hört auf euer Bauchgefühl. Und vertraut euren Kindern.

Im Speziellen bei einer Lebendspende - auch aus der eigenen Erfahrung heraus – redet miteinander. Egal wer, jeder trägt in diesem Prozess, dieser Ausnahmesituation, gleichermaßen seinen Beitrag.

Was würden Sie gern dem beteiligten Gesundheitspersonal (z.B. Ärzt*innen, Krankenpfleger*innen, Psycholog*in- nen, Sozialarbeiter*innen, Servicemitarbeiter*innen) sagen?
Zeit und Empathie sind kostbare Güter in Krankenhäusern und der Druck wird zunehmend größer. Dies haben wir in den Jahren und den vielen Krankenhausaufenthalten gelernt. Die Sorgen, von uns Eltern, sind real und damit verbunden auch der Wunsch, zu verstehen, was passiert mit unserem Kind, warum passieren die Dinge. Wir haben Ängste und Sorgen, um unser Kind und die sind präsent. Je besser wir, als Eltern „mitgenommen“ werden, umso stärker können wir diese Entscheidungen mittragen und gleichermaßen unsere Kinder stärken. Aber und dies ist ein ebenso wichtiger Punkt. Wir, die Eltern von Lisa, sagen unserem KfH und dem Krankenhaus „Danke“ dafür, dass sie genau das ermöglicht haben.

Möchten Sie sonst noch etwas mitteilen?
Vielen Dank für Ihren Beitrag!

Hans and Sabine, parents of Lisa

What were your main concerns during the time, around and after the transplantation?
For us, as parents, the biggest concern was whether the new organ would be accepted. Especially for Hans, as a living donor, the biggest fear was that it won’t help and that his organ is not good enough. One thing Hans said to the doctors during this time, which is still very present today, is “Please help my child.” This fear, accompanied with the thoughts of what if, on the day of the transplantation, the call would come that Lisa would still need to be on dialysis because the transplant was unsuccessful, was responsible for numerous anxious, worry-filled moments. This worry was still present even after the transplantation was successful. Looking at the values, the steps that Lisa would need to take, and thinking about how Lisa’s and our lives would develop after the transplantation were the main thoughts around the transplantation. What new changes would there be, also in terms of the multitude of medications that were and are necessary, suddenly after the transplantation.

What do you think have been the biggest successes?
That the new kidney was accepted by Lisa’s body and that her life energy returned. This is also combined with Lisa’s great will — despite the new kidney — to have a comparably normal life as soon as possible. She gained weight again, laughed more, and was literally more alive. And clearly, one success is that she is no longer limited by PD in our family life. We have more freedom in our decisions, we can plan vacations without PD, and can be spontaneous again.

What helped you the most during the time around the transplantation?
Acceptance of what is. The feeling and knowing that we have so many things on our hands and learning to accept those we can’t control. Also, trust in our doctors and the entire team, with open and clear discussion from their side, and confidence that everything will be okay. The support of our family and friends also helped us a lot during that time.

What would you like to tell other children that are currently waiting for a transplantation?
Ask the doctors questions, because in our situation no question is “too stupid” to be asked. Every uncertainty, every concern has its justification. Also treat yourselves well; allow yourself some timeouts. As parents, you are also allowed to have fears. Tears may also be shed — and depending on their age – also with the children. We can influence so many things, but unfortunately, we cannot influence many other things. Put your trust in your medical team and listen to your feelings.

And trust your children.

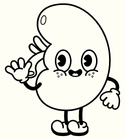
Especially in the case of a living donation — also from our own experience — talk to each other. Remember that everyone has an equal contribution to make in this process in this exceptional situation.

What would you like to say to the healthcare staff involved (e.g., doctors, nurses, psychologists, social workers, service staff)?
Time and empathy are precious commodities in hospitals, and the pressure is increasing. We have learned this over the years during the many hospital stays we have had. The worries of us as parents are real, and with that comes the desire to understand what is happening to our child and why are things happening. We have ever-present worries about our child. The better we, as parents, are “taken along” in the course of treatment, the better we can support treatment decisions and strengthen our children. But we want to stress this equally important point

We, as Lisa‘s parents, say „Thank you“ to our KfH and the hospital for providing exactly that.

Ireland

Oisin



“Thank you are two words that mean so much”

Primary disease (cause of transplant)
Hemolytic Uremic Syndrome (HUS)
Age
16 years
Age at transplant
10 years

Successes
Transplant with HUS controlled with eculizumab.

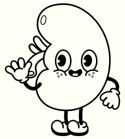
Message for the ones waiting for transplant
Keep your head up high, when you get your transplant, life will be so much better.

Message for other transplanted peers
You still need to work to keep your new organ.

Message for parents/caregivers
Take every day as it comes. Life will change for the better. Try to do something for yourself after the patient is stable.

Messages for health professionals
“Thank you” are two words that mean so much. There are so many people that have helped us whom we have never met.

Connor



“Even though it can be scary, there are doctors and nurses to take good care of you”

Primary disease (cause of transplant)
Chronic renal failure
Age
15 years
Age at transplant
9 years

Main concerns
My main concern was how long I would have to stay in Hospital and if they would have any food I like.

Successes
Even though I was in and out of hospital a lot during the first year of my transplant, I am doing well.

Message for the ones waiting for transplant
Even though it can be scary, there are doctors and nurses to take good care of you. Asking lots of questions can help you understand what is happening.

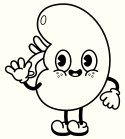
Message for other transplanted peers
Make sure to listen to the nurse and take your tablets.

Message for parents/caregivers
Give you child a present.

Messages for health professionals
Thank you for all your help.

Other topics
Remember to bring something special with you to hospital to remind you of home that can bring you comfort.

Patrick



“It is very hard to wait, but it all comes together”

Primary disease (cause of transplant)
Nephrotic syndrome (FSGS) Podocine gene

Age at transplant
13 years

Main concerns
We were hopeful for a successful transplant, we were hopeful for a living donor, we were hopeful all would go according to plan. We were concerned about general life, health and the impact of the condition.

Successes
Very successful transplant that went according to plan. Recovery for the patient (13-year-old) and dad (donor) went extremely well. After 14 weeks, back to school, feeling lots of energy and feeling like a regular kid.

Message for the ones waiting for transplant
It is very hard to wait, but it all comes together. The living donor program is fantastic but it needs a lot of time and patience. If you are restricted on fluids while on dialysis, we hugely sympathize and want to assure you it will feel amazing on the other side; stay strong.

Message for other transplanted peers
It is so important to take your medicines, as these are vital, and also mind your water intake. Appreciate your second chance at life and be mindful in daily activities so as not to damage or hurt your kidney.

Message for parents/caregivers
Do all you can to support your child, let them vent and be a safe haven for them. It will all be better on the other side. Make sure to talk about all that is going on and also try to make time for yourself.

Messages for health professionals
Try to put yourselves in our shoes as a family. Try to remember we are doing our best and to always show empathy and a caring nature. Fortunately, we were blessed with amazing professionals.

“Thank you” are two words that mean so much. There are so many people that have helped us whom we have never met.

Other topics
Talk to your doctor about any issue you may have; never assume it is wrong or too small. Everyone and every issue are important. We were extremely lucky to have an amazing doctor who took everything on board and helped in any way possible.


RINS
RINS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Faz acompanhamento médico.
Evita a automedicação.
DIA MUNDIAL DO RIM
Reduz o consumo de sal.
Faz uma alimentação saudável.
Diminui o consumo de açúcar.
10 Março 202
LUDMILA PAXE


Dia Mundial
do Rim


DIA MUNDIAL
DOS RINS


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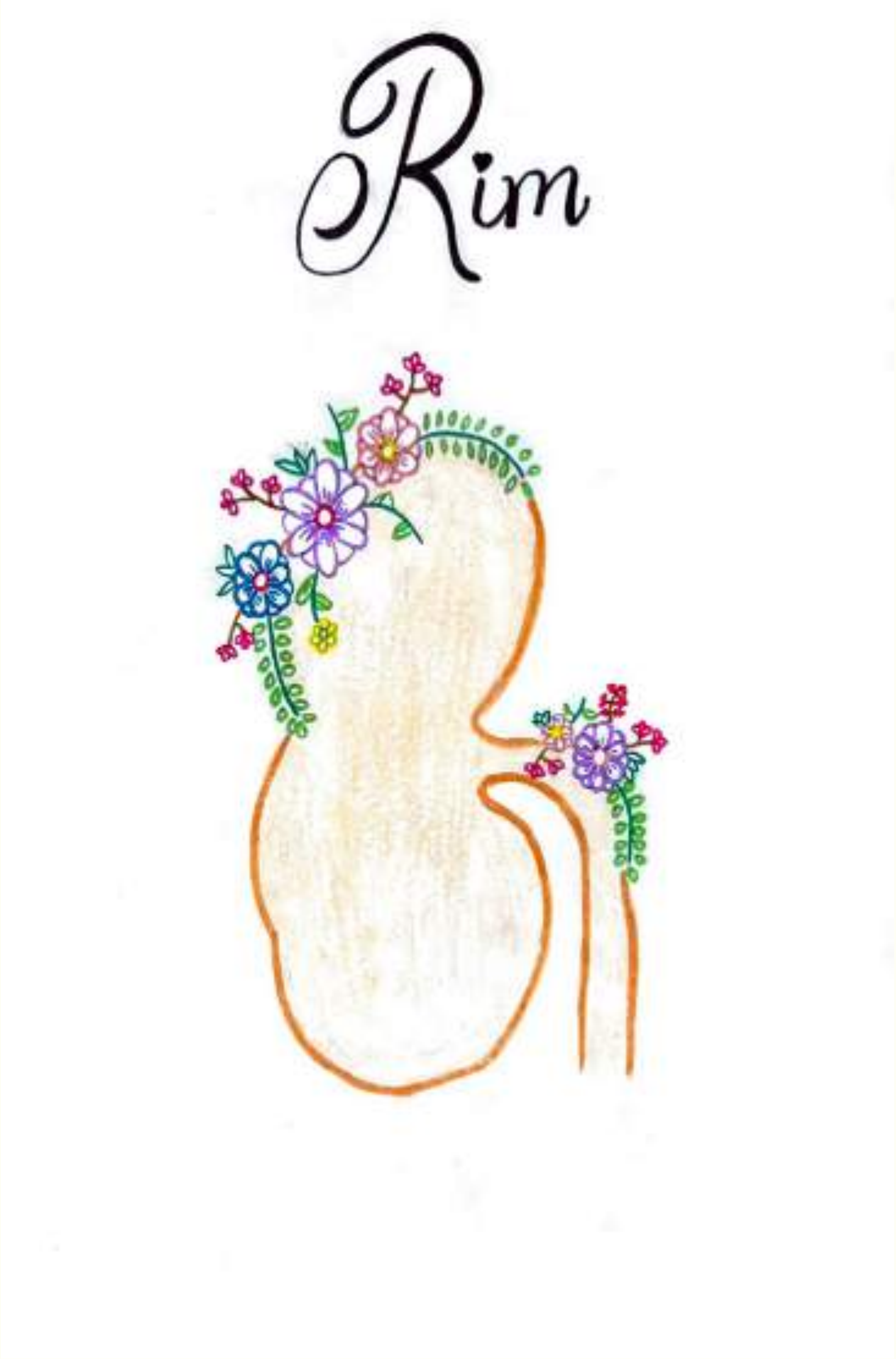

Rim


CUIDAR DOS RINS
MAL
BEM
Droga
Água


DIA MUNDIAL
DOS RINS
Rita Sousa 4ºB
José Simão [illegible] 4ºB


DIA
MUNDIAL
DO
RIM!
Dia
do
Mundial
Rim
Miguel
Melo

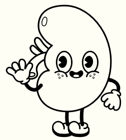

O Rim é o meu melhor amigo


Pela Saúde dos teus
Rins
Rins são
para toda Vida!


Dia mundial do Rim.
05/03/2023
Catarina

Italia/Italy

Anna



«Fidatevi del vostro medico e dei paramedici»

Età
16 anni
Diagnosi/tipo di trapianto
Displasia e ipoplasia renale/trapianto di rene
Età al trapianto
Primo trapianto a 4 anni, secondo trapianto a 14 anni

Principali preoccupazioni
Complessità dell'intervento. Rigetto del rene.

Risultati
Primo trapianto 2010. L'intervento è stato eseguito con successo. Abbiamo dovuto affrontare un rigetto del rene dopo una settimana, ma è stato prontamente gestito dai medici. Il secondo trapianto nel 2020 è stato un successo. Nessun rigetto.

Messaggio per gli altri pazienti che sono in lista trapianto
Quando ho scoperto di aver bisogno di un altro trapianto, non mentirò, avevo paura che qualcosa potesse andare storto, ma soprattutto ero stanco. Siate pazienti. Anche se siete sempre stanchi e assetati. Le buone notizie arriveranno, come è successo a me.

Messaggio per i pazienti che hanno eseguito trapianto
Godetevi il senso di liberta'.

Messaggio per i genitori
Non arrendetevi mai e poi mai. Mai! Dico sul serio! All'inizio è dura, molto dura. Accettare il fatto che vostro figlio/a è affetto da una malattia terribile che richiede cure mediche costanti, ricoveri e interventi chirurgici è un compito molto difficile. Fidatevi del vostro medico e dei paramedici. Lavorano per il bene di vostro figlio.

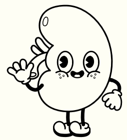
Abbiamo visitato gli ospedali di tutto il mondo, letteralmente Surabaya, Jakarta, Singapore, Kuala Lumpur, Parigi e in Italia. Abbiamo trovato un gruppo di medici ultra-esperti e molto professionali. Sono anche molto premurosi e comprensivi, un aspetto da non dare per scontato.

Tutta la fatica che state sopportando durante la dialisi, le innumerevoli corse al pronto soccorso, il costante desiderio di essere messi in lista d'attesa e poi la speranza che arrivi un organo compatibile, saranno alleviati una volta eseguito l'intervento. Dopodiché, tutto si svolgerà in modo più agevole e semplice, sia dal punto di vista logistico che psicologico.

Il lato positivo di questa vita diversa (eppure folle) è che incontrerete molte persone nella vostra stessa situazione con molte storie diverse. Parlate con loro e ascoltate le loro storie. Alcune sono incredibili e potrete fare delle belle amicizie.

Messaggio per il personale sanitario
Come ho già detto in precedenza, abbiamo avuto la (non) fortuna di visitare diversi ospedali in tutto il mondo, con tanti bravi medici e paramedici, e li ringrazio tutti. Se ho un consiglio da dare è questo: siate gentili e pazienti con i pazienti - perdonate il gioco di parole - e soprattutto con noi genitori. Stiamo attraversando un periodo molto stressante e frustrante. A volte quello che diciamo non è quello che intendiamo veramente.

Anna



"Trust your physician and paramedics"

Age
16
Primary disease/transplant type
Renal dysplasia and hypoplasia / Kidney transplant
Age at transplant
First transplant at 4 years old, second transplant at 14 years old

Main concern
Complexity of the operation and kidney rejection.

Outcome
First transplant 2010. The surgery was successfully done. We faced a kidney rejection after a week, but has been promptly managed by doctors. Second transplant in 2020 was a success. No rejection.

Message for the ones waiting transplant
When I found out I needed another transplantation, I'm not going to lie, I was scared that something could go wrong, but mainly I was tired. Be patient. Even if you are always tired and thirsty. Good news will arrive as it did for me.

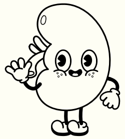
Message for the other transplanted peers
Enjoy the sense of freedom.

Message for parents/caregivers
Never ever give up. Ever! I mean it! At first it's hard, very hard. Just accepting the fact that your son/daughter is affected by a terrible disease that demands constant medical care, hospitalisations and surgery is a very hard task. Trust your physician and paramedics. They work for the good of your child.

We've toured hospitals all over the world, literally: Surabaya, Jakarta, Singapore, Kuala Lumpur, Paris and Italy We found a group of ultra-experienced and very professional doctors. They are also very considerate and sympathetic, which is an aspect not to be taken for granted. All the struggle that you are enduring during dialysis, your countless rushes to the emergency room, the constant desire to have your name put on the waiting list and then the hope for a compatible organ to come, will be relieved once the surgery is performed. After that, everything will run more smoothly and easily, both logistically and psychologically. The bright side of this different (yet crazy) life is that you'll meet a lot of people in your same situation with a lot of different stories. Talk to them and listen to their stories. Some are incredible, and you can make some good friends.

Message for health professionals
As I've previously mentioned, we had the (un)fortunate chance to visit quite a few hospitals around the globe, including loads of good doctors and paramedics, and I thank them all. If I have one word of advice, it is this: please be kind and patient with the patient – forgive the pun — and especially with us parents. We're going through a very stressful and frustrating time. Sometimes what we say is not what we really mean.

Gaia



«Che non perdano la speranza e continuino a lottare»

Diagnosi/tipo di trapianto
Insufficienza renale cronica
Età al trapianto
5 anni

Principali preoccupazione
Per quanto riguarda l'intervento, si è sempre pensato a come si sarebbe sentito, se avrebbe sofferto molto.

Risultato
Il trapianto è stato un successo.

Messaggio per gli altri pazienti che sono in -lista trapianto
Che non perdano la speranza e continuino a lottare.

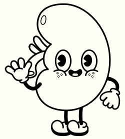
Messaggio per i pazienti che hanno eseguito trapianto Message for the other transplanted peers
Che si prendano cura di lui, che prendano le medicine al momento giusto, che vivano una vita sana il più possibile.

Messaggio per i genitori
Che continuiamo ad essere attenti ai nostri figli, che non abbassiamo la guardia, hanno bisogno di noi. Che ci prendiamo cura anche di noi stessi, se stiamo bene loro staranno meglio.

Messaggio per il personale sanitario
Non potrò mai ringraziarvi abbastanza per tutto quello che avete fatto per mia figlia. Saremo sempre grati.

Grazie mille per tutto, la vita di mia figlia è cambiata per meglio.

Gaia



"Don't lose hope and keep fighting"

Primary disease/transplant type
Chronic renal insufficiency
Age at transplant
5 years old

Main concerns
My main concern was always if my little baby will feel pain.

Outcome
The transplant was very successful.

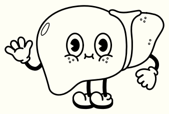
Message for the ones waiting trransplant
Don't lose hope and keep fighting.

Message for the other transplanted peers
Take care of your new transplanted organ. Take your meds at the right time and have a normal, healthy life as much as possible.

Message for parents/caregivers
We need to be always aware of our children; let's not lower our guard, because they need us. We also need to take care of ourselves. If we are good they will be better.

Message for health professionals
I have no words to thank you all for everything you did for my daughter. We will always be grateful. Thank you so much for everything, my daughter's life has changed for the better.

Lucrezia



«Sono tutte azioni che hanno un loro prezzo, l’energia e la forza che richiedono per essere affrontate»

Mi chiamo Lucrezia e nel 2019 mi sono operata di trapianto di fegato; ebbene sì, circa tre anni fa ho iniziato questo percorso consapevole che non sarebbe stata una passeggiata ma che sicuramente mi avrebbe restituito tanti anni di avventure ed emozioni perse.

Ho 20 anni e sono in cura da quando avevo pochi mesi di vita; i primi 17 sono stati anni che ammetto avrei preferito vivere diversamente, come una ragazza “normale” - come erroneamente pensavo fossero gli altri e non io - e non da un ospedale all’altro o da una colangite all’altra, ma poi penso anche che è grazie agli ostacoli che ho superato con grinta e alla forza che ho avuto, che la mia famiglia e i miei amici mi hanno sempre dato, che ora sono qui a raccontare di un passato che sento più leggero.

Non finirò mai di ringraziare abbastanza le persone intorno a me che hanno fatto tanti ma tanti sacrifici. Ringrazio i medici, che hanno un posto speciale nel mio cuore e che mi hanno restituito una vita splendente ed emozionante che credevo potesse essere quasi un sogno. Ringrazio la mia famiglia, i miei genitori e mia sorella, che mi sono stati a fianco sempre e che nonostante le piccole difficoltà non hanno mancato di darmi tutto ciò di cui una bambina (e poi ragazza) avesse bisogno, e di più. Ringrazio i miei amici per non avermi mai fatta sentire diversa o inferiore, e con i quali mi sono sempre confidata; ormai siamo un bel gruppo solido da anni!

Settembre 2022: sto per iniziare il secondo anno di università: mi piacerebbe specializzarmi in questioni ambientali e di sostenibilità, magari approfondendo all’estero! Alcune volte non poter essere partecipe e presente giorno per giorno alle attività di classe con gli amici e gli insegnanti mi demoralizzava un po’; penso non sia facile per nessuno stare lontano da certi ambienti e in certi momenti della vita per così tante volte; ciò detto non nego di aver vissuto i miei anni di scuola tra una risata e qualche pianto sui libri…

Confermo di non essere riuscita a scappare dai miei doveri da studentessa! Chiaramente a mancarmi non è stata solo la scuola - insomma a chi è che piace così tanto la scuola! - ma il semplice stare con mia sorella o i miei genitori senza preoccupazioni ed in serenità.

Il trapianto lo aspettavo con ansia, un’ansia non negativa, direi una via di mezzo: i timori c’erano, forse non tanto da parte mia quanto per la mia famiglia. So bene che sono stati anni che ci hanno messo a dura prova e forse per loro anche di più: vedere, capire, aiutare, sopportare, sono tutte azioni che hanno un loro prezzo, l’energia e la forza che richiedono per essere affrontate sono enormi, lo sforzo è collettivo.

Convivere con questa situazione un po’ ballerina tra giorni in cui mi sentivo forte e raggiante a giorni in cui lo ero meno, giorni in cui stavo male, mi ha portata a convivere con un’ansia forse anche esagerata e che mi porto dietro ancora

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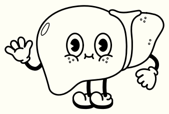
Lucrezia



“We need all our energy, strength and effort to understand and to endure the situation”

My name is Lucrezia and in 2019, I underwent to a liver transplant.About 3 years ago, I started my path. At that time, I was aware that it would be not a “nice” journey for me; however, I was sure that it would give me back a new, exciting life.

I am 20 years old and have been in treatment since I was a few months old; my first 17 years were very hard. I would have preferred to live differently, as a “normal” girl! I was in and out of hospitals for many episodes of cholangitis. However, I got through my difficulties and approached my obstacles with courage and strength, with the help of my family and friends. Now I can talk about my past with nice feelings about what I have experienced.

I will never stop thanking all the people who have sacrificed so much for me. I thank all the doctors, they have a special place in my heart because they have given me back my bright and exciting life. I thank my family, my parents and my sister, who have always been by my side, and despite the difficulties, have always given me everything I needed as a little girl (and then as a bigger girl), and more! I thank my friends, who never made me feel different, and to whom I always showed my real self; we have been a strong group for many years!

In September 2022, I started my second year of university. I would like to specialize in Environmental Studies; perhaps I could do it abroad! In the past, sometimes I felt sad because I was unable to always participate in class activities. During my school years I have laughed and cried; however, I did not escape my scholastic duties! Of course, it was not just school life that I missed — I missed living my life together with my sister or my parents without worries.

I was looking forward to the transplant; although I had fears, my family had even more. They were such difficult years for all of us. We need all our energy, strength and effort to understand and to endure the situation. Some days I was strong and happy, while other days I was sick and sad; this condition made me feel very anxious, and it does even now. Nevertheless, I am working on it.

At the beginning I had fears and doubts about the surgery I was going to undergo; I thought it was too risky. My brain probably did not accept the change. I thought I was in a glass bubble, too delicate and easily broken. But I was not, and I am not even now.

I am deeply grateful for the treatments I have received, and I’m not going to waste everything I have. I will live my life without fear. I believe that psychological support is an essential part of paths like mine. I thank the psychologist at the hospital who helped me to better understand my feelings, my fears and my problems. All this helps me to continue to live my life with joy and serenity.

I was asked to write about 300-400 words about myself — and, oops — I wrote just “little” more than that! I am grateful for the opportunity that gave me this wonderful hospital. I hope my story adesso. Ci sto lavorando su, il fatto di aver affrontato un'operazione così importante è stato quasi peggio inizialmente: mi sono riempita di paure e dubbi per tutto, senza motivo, convincendomi che sarei stata più a rischio in quel momento che dopo. Probabilmente il mio cervello non aveva ancora ingranato e accettato il cambiamento, pensavo di essere in una bolla di vetro, troppo fragile. Così non era e così non è.

Sono infinitamente grata delle possibilità e delle cure che mi sono state date e non ho intenzione di gettare nulla al vento, ma questo non vuol dire vivere nella paura di semplicemente vivere. Ritengo che il sostegno psicologico sia parte integrante di percorsi come il mio, e di tanti altri ed altre persone, e che suggerisco sempre.

Grazie alla dottoressa con la quale ci vediamo in ospedale ogni tanto mi sono messa faccia a faccia con me stessa, nuda davanti a tutto quello che pensavo, e questo mi aiuta tutt'ora a continuare con più piacere e placidità. Detto questo mi era stato consigliato di raccontarmi in 300 - 400 e ops! diciamo sono leggermente di più, ma d'altronde ognuno ha la sua storia da dire e le sue parole da usare, e ringrazio di questa bellissima opportunità che l'ospedale mi ha presentato. Con la mia storia vorrei far arrivare tanta fiducia e supporto alle famiglie che hanno vissuto o vivono esperienze difficili, di continui up and down, come ho detto prima lo sforzo è collettivo è di unione!

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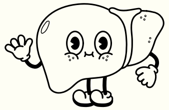
conveys trust and support to the families who lived or are living difficult experiences. I strongly believe the effort must be shared and that there is strength in unity!

Elisa



«Una particolare parola di speranza vorremmo trasmettere a chi è in attesa di trapianto»

Siamo i genitori di Elisa, una bambina di quasi 11 anni che vive appieno la bellezza e la spensieratezza della sua età.

A meno di cinque mesi dalla nascita Elisa ha ricevuto un trapianto di fegato, pochi giorni fa ha eseguito la biopsia di controllo a 10 anni dal trapianto e tutto funziona perfettamente.

Ricordiamo sempre lucidamente le preoccupazioni dei momenti più bui e delicati dei giorni precedenti al trapianto, ma con la consapevolezza attuale possiamo affermare che anche in quei momenti non abbiamo mai perso la speranza.

E' proprio questa parola: speranza, che vorremmo trasmettere a tutti coloro, bambini e genitori, che oggi si trovano nella nostra stessa situazione di dieci anni fa.

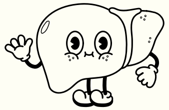
La speranza non è una cosa astratta o un modo di dire, ma qualcosa che abbiamo costruito lentamente, con sforzo, insieme a tutte le persone che ci sono state vicine, innanzitutto gli operatori sanitari dell'ospedale, i quali ci hanno preso per mano fin dal primo giorno e guidato materialmente, psicologicamente, ed emotivamente verso la nuova condizione che ci aspettava,rieducandoci con pazienza e dedizione mentre nel frattempo riportavano in vita la nostra Elisa.

Poi sono seguiti i controlli, qualche ricaduta, iniziali difficoltà con la gestione della bambina piccolissima a casa senza il supporto di medici e infermieri, sicuramente con qualche preoccupazione in più della norma ma sempre con grandissima fiducia è continuato e continua il nostro cammino.

Una particolare parola di speranza vorremmo trasmettere a chi è in attesa di trapianto, dicendo che gli siamo vicini avendo vissuto quelle esperienze e che presto anche per loro arriverà il momento della rinascita, dato che le donazioni sono sempre in aumento e la sensibilità delle persone riguardo a queste tematiche è in costante crescita.

Per concludere vorremmo lasciare un messaggio di ringraziamento a qualcuno che non lo leggerà mai, ma è sempre nei nostri pensieri, la famiglia che con generosità, in un momento di grande dolore ha deciso di donare gli organi.

Elisa



"We would like to send a special word of hope to those waiting for a transplant"

We are Elisa's parents, a girl of almost 11 years old who lives the beauty and the light-heartedness of her age. At 5 months of age, Elena received a liver transplant. Then, a few days ago, she underwent a 10-year post-transplant liver biopsy protocol, and found that everything is going well!

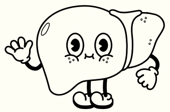
We clearly remember the concerns we had during the darkest and most delicate days before transplant, but we can say that even throughout those challenging moments, we never lost hope. It is precisely the word, hope, which we would like to convey to all those children and parents who are now in the same situation as we were 10 years ago.

Hope is something that we have built slowly, with effort, together with the people who have been close to us throughout Elisa's journey: first of all, the hospital's health workers, who have taken our hand since day one and greatly guided us, psychologically and emotionally, through the ups and downs of Elisa's condition, helping us with patience and dedication while at the same time bringing our Elisa back to life. Later, we had some difficulties in managing a small child at home without the support of doctors and nurses; however, we continued our journey, with some concerns, but always with great confidence.

We would like to send a special word of hope to those waiting for a transplant. We feel close to them because we have had the same experience. Soon the moment of "rebirth" will come for them too, because the number of donations is increasing as well as people's awareness about this issue.

To conclude, we would like to send a thank you message to the donor who will never read it, but who is always in our thoughts, and to the family of this person who generously, in a moment of great pain, decided to donate his/her organs.

Carlo



«Tenendo sempre custodia di colui che mi ha dato la mia nuova vita»

Ciao, mi chiamo Carlo e voglio raccontarvi la mia storia. Premetto che è un pochino lunga quindi armatevi di pazienza! Scherzo. Iniziamo!

Ero piccolo quando mi fu diagnosticata la malattia al fegato e cominciai ad affrontare quel calvario con tanta forza. Ricordo avevo un pancione enorme dovuto all’ascite sembrava che aspettassi un bambino e quando entravo nello studio del dottore per la visita medica entrava prima la pancia e dopo tutto il resto. Da qui cominciò tutto e i dottori erano in procinto di inserirmi in lista trapianto subito perché le condizioni erano allarmanti e quindi bisognava affrettarsi. Passò del tempo e gli esami davano segni di miglioramento e allora non fui più inserito nella lista ma continuavo a fari i vari controlli di routine e tutto era sempre stabile per due/tre anni.

Arrivò l’anno 2019 e a fine agosto mi ricoverai per un controllo più approfondito e da li a pochi giorni mi dimisero poiché tutto era stabile. Alla dimissione mi comunicarono i dottori che dopo dieci giorni sarei dovuto tornare per un nuovo ricovero ad effettuare un altro accertamento. Durante questi giorni mi sentivo strano, la pancia dura, gonfia e conati di vomito ma non mi allarmai tanto perché io mi agito molto quando devo recarmi in ospedale e pensai che era dovuto a quello, ed invece mi sbagliavo. L’11 Settembre 2019 si scatenò il peggio, mi portarono urgentemente all’ospedale con l’elicottero perché la situazione era veramente tragica. Arrivato in ospedale fui immediatamente portato in camera intensiva ed intubato. I giorni seguenti continuavano ad essere tragici fino a quando i dottori non arrivarono alla conclusione che avevo in corso un’emorragia interna con innalzamento dell’ammonio dovuto al mio fegato malato e allora mi operarono di urgenza. Dopo questo accaduto i dottori mi dissero che era arrivato il momento di mettermi in lista trapianto e durante la degenza di ripresa dal lungo intervento cominciai ad effettuare i vari esami per l’inserimento in lista. Rimasi ricoverato per tre mesi e poi venni dimesso e quando tornai a casa continuai a fare i controlli fino a quando un giorno non mi chiamò l’ospedale per comunicarmi che avevano programmato l’appuntamento per firmare l’inserimento in lista. Io prò non ero d’accordo, non volevo fare il trapianto ma con l’aiuto della mia famiglia e di altre persone mi convinsi ed andai a firmare. Dopo alcuni giorni l’inserimento in lista andò a buon fine e ora si doveva solo aspettare la chiamata ed è stata molto dura aspettare. Il mio tempo di attesa fu di sei mesi: a Maggio mi chiamarono per dirmi che c’era un fegato che poteva essere compatibile con me, che momento!! Stava per finire tutto il mio calvario, stavo soffrendo tanto, per me non era più vita e quella chiamata era per me la nuova vita. Di corsa e con l’acqua alla gola insieme ai miei genitori partimmo e ci recammo all’ospedale dove mi fecero mille esami per verificare l’idoneità e la compatibilità del fegato. Dovetti aspettare delle ore prima di sapere il risultato e quelle ore non

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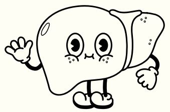
Carlo



“I’m always thinking of the person who gave me this new life”

Hello, my name is Carlo, and I want to tell you my story. It is a little long, but please be patient with me!

I was little when I was diagnosed with a liver disease and I had to face up to my troubles with strength. I remember I had a huge tummy due to the ascites; it looked like I was expecting a baby! When I would go to the doctor’s office for my medical examinations, my tummy entered the office before the rest of my body. Because my conditions were alarming, at the beginning, the doctors urgently wanted to put me on the transplant list. Then the exams showed signs of improvement, so the doctors decided to wait for a transplant. But I continued my follow-ups, and everything was stable for 2 or 3 years.

At the end of August 2019, I was hospitalized for few days and then discharged because everything was stable. I was supposed to return to the hospital 10 days later. However, while at home I did not feel well, my tummy became hard and swollen, and I had nausea. I was not too worried, but I was wrong not to be. On the 11th of September 2019, I was air-lifted to the hospital by helicopter because the situation was really bad. I was immediately brought to the paediatric intensive care unit and intubated. The following days were terrible; hence, I was brought straightaway to the operating theatre due to an abdominal hemorrhage. After the surgery, the doctors decided to put me on the transplant list, but I was not happy about the decision. I did not want to undergo a transplant. I was hospitalized for 3 months and continued my follow-ups. One day doctors tried to persuade me to sign the consent to be on the transplant list, but I was not ready, so I refused to sign it. Later, I was encouraged to sign by my family and friends and I finally signed the consent.

It was very difficult for me to be on the transplant waiting list. I impatiently waited for “the call” for 6 months. Then in May, they finally called me! A possible compatible liver had been found, what great news! My agony was going to end! A new life was going to start. Together with my parents, we rushed to the hospital, where I had to wait the results of the tests to verify the compatibility of the liver. I had to wait hours before the outcome, and I was very anxious during that time. However, at 5 o’clock in the morning, the nurse came to tell me that the organ was 100% compatible and I said with tears in my eyes, “Finally!” Shortly afterwards, I was in the operating theatre, and I had the thought that a whole new life was coming. Everything went well, although the surgery lasted many hours. The hospitalization was very long because I unfortunately felt bad and had to be returned to the operating theatre due to a complication. Yet, when I returned home was able to take my life back, always thinking of the person who gave me this new life.

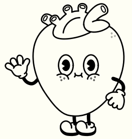
To the people waiting for a transplant, I can say that numerous things change positively after passavano mai, ma verso le cinque ecco che arrivò l'infermiera a dirmi che l'organo era compatibile al 100% ed io con le lacrime agli occhi esclamai finalmente! Da li a poco mi portarono in sala dove niente era sicuro ma con la consapevolezza che se tutto fosse andato bene avrei iniziato una nuova vita, quella che fino ad allora era stata per me sconosciuta. Fortunatamente andò tutto bene, l'intervento duro molte ore, la degenza fu molto lunga perché purtroppo mi sentì male nuovamente e rientrai una volta ancora in sala operatoria. Dopo tutto ciò ritornai a casa e cominciai a riprendere la mia vita in mano tenendo sempre custodia di colui che mi ha dato la mia nuova vita.

Da trapiantato posso dire che molte cose cambiano naturalmente in positivo perciò per chi dovrà affrontare un trapianto io dico andate sicuri e vincenti perché il trapianto è vita!! Io adesso voglio essere una fonte di testimonianza come mi dicono anche i miei genitori.

Penso di aver detto tutto o meglio abbastanza. Ringrazio chi ha permesso di testimoniare queste storie, ringrazio i miei dottori, la mia famiglia e soprattutto te, mio angelo custode.

transplant; so don't worry, because the transplant is life! Now I think I have said it all, or rather enough. I thank the people that have let me share my adventure, and I thank all doctors, my family, and above all, my guardian angel.

Gabriele



«Mi auguro di sì per proseguire questa avventura chiamata vita»

Diagnosi/tipo di trapianto
Cardiomiopatia con ventricolo sinistro ipocinetico / Trapianto di cuore
Età al trapianto
3 anni

Ciao sono Gabriele ho 6 anni e sono nato la prima volta il 22 aprile 2016, vi chiederete come mai la «prima volta», beh, perché in realtà io ho due compleanni: sono rinato tra il 4 e il 5 giugno 2019. Due compleanni?!? Sì! Io sono un trapiantato cardiaco.

L'equipe dell'ospedale a 3 mesi dalla mia nascita, mi ha inserito in lista trapianti. Ho atteso circa 3 anni fatti di alti e bassi e di tanto altro… E non avrei potuto aspettare di più. Di questi tre anni uno e mezzo è trascorso a casa ed uno e mezzo in ospedale dove mi accompagnava il mio fidato Berlin Heart e dove mi son fatto una seconda famiglia.

Sapete, la storia di ognuno di noi trapiantati è singolare e speciale ed è quello che mette alla prova ogni singola equipe, perché non siamo una formula matematica, ma siamo persone che reagiscono in modo diverso a terapie che i medici hanno da linee guida internazionali.

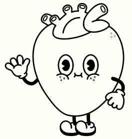
Tornando a noi io ero un Cardiomiopatico Ipocinetico Sinistro (succesivamente hanno scoperto che fosse un problema genetico). Il mio cuoricino non ce la faceva, ha retto per un po', ma poi i medici hanno proposto il Berlin Heart per avere una speranza in più di arrivare al trapianto: questo ha voluto dire vivere in ospedale assumendo farmaci per niente semplici da gestire ma necessari. Io nel mentre crescevo e mi hanno dovuto cambiare il ventricolo (VAD) con uno più grande.

È arrivato il giorno tanto atteso, con tanta paura per me (anche se me lo si leggeva solo negli occhi perché ero piccolo), e tanta paura per chi mi stava vicino. Non è stata una passeggiata, perché, siamo sinceri, non tutti i trapianti vanno benissimo e non tutti i trapianti si possono dire riusciti. Infatti purtroppo il mio nuovo inquilino non è ripartito subito, ci ha messo un po' a capire se si sarebbe trovato bene nella nuova casa e quando è ripartito è rimasto ipocinetico destro. Ma vale sempre la pena provare!

Arriverò a un secondo trapianto? Mi auguro di sì per proseguire questa avventura chiamata vita… Infatti purtroppo il trapianto non è a vita… Almeno per ora. Care famiglie, come avrete capito la strada non è facile in nessun momento e per nessun attore presente nella storia di ognuno di noi, compreso per chi dona che fa un gesto di altruismo ogni oltre immaginazione, perché un figlio è un figlio sia da una parte che dall'altra della barricata.

Cari medici, non è semplice quello che fate, ma non abbiate paura ad affezionarvi ai Vostri piccoli e grandi pazienti, perché nell'imparare a conoscerli meglio potete affinare la medicina dal generale al particolare, anche se è rischioso per l'oggettività e la freddezza delle decisioni!

Gabriele



"I want to carry on with this adventure called life"

Primary disease/transplant type
Cardiomyopathy with a hypokinetic left ventricle / Heart transplant
Age at atransplant
3 years old

Hi, my name is Gabriele, I'm 6 years old, and I was born on 22 April 2016, for the first time. You may ask why I said "for the first time". Well, I've got 2 birthdays: I was reborn in 2019 between 4 and 5 June. Two birthdays? Yes, I had a heart transplant.

The hospital team decided to include my name on the transplant waiting list when I was 3 months old. I waited for about 3 years and couldn't have waited any longer. I spent one-and-a-half years at home and the other one-and-a-half at the hospital, where my beloved Berlin Heart supported me and where I found a second family, too.

The story of a person with a transplant is unique and special. Every single medical team is tested by our different reactions to the therapies that are suggested by the international guidelines.

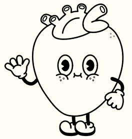
I had a cardiomyopathy with a hypokinetic left ventricle (later discovered to be a genetic problem). My little heart didn't work properly; it beat for a while, but then doctors thought it was better to use the Berlin Heart to give me a greater chance of survival until the transplantation. I had to live at the hospital and undergo major treatments that were essential to stay alive. In the meantime, I was growing, and my ventricular assist device had to be replaced with a larger one.

Finally, the long awaited day arrived and I was afraid (you could easily see it in my eyes), and those who were close to me were frightened, too. Not all transplants are successful. Unfortunately, my new heart didn't beat at first; it took a while and when it started working it still remained hypokinetic.

Will I have a second heart transplant? I hope I will, because I want to carry on with this adventure called life. Sadly, transplants don't last a lifetime. Families, your pathway is not an easy one, either for those who donate an organ or for those who receive it. The donors are very generous, but they have parents just like the recipients do.

Doctors, your job is hard, but don't be afraid to grow fond of both your pediatric and adult patients. Getting to know them better will help you to perfect your techniques from general to specific, even if loving them could affect your objectivity!

Emma



«Il suo sorriso è stato il comune denominatore durante tutto il suo lungoricovero»

Diagnosi/tipo di trapianto
Grave malformazione cardiaca/trapianto di cuore
Età al trapianto
6 anni

Sono la mamma di Emma e sono una mamma fortunata. Emma nasce nel 2010 con una grave malformazione cardiaca, un solo ventricolo e coartazione aortica.

L'iter chirurgico prevede tre interventi, un percorso difficile ma necessario per avere la possibilità di condurre una vita di buona qualità. Emma affronta i tre interventi, ma non mancano le complicazioni, soprattutto dopo il terzo intervento. Tutto è in precario equilibrio e l'insufficienza della sua valvola atrio-ventricolare mette in discussione il risultato della Fontan. La situazione peggiora velocemente e l'unica opzione diventa il trapianto di cuore.

Durante uno dei suoi numerosi ricoveri per fronteggiare lo scompenso cardiaco, il cuore di mia figlia si ferma, improvvisamente, mentre passeggia nel reparto. E' la sera del 15 gennaio 2016. Dopo più di due ore di rianimazione, le viene impiantato l'ECMO, che funziona bene e Emma si sveglia dopo due giorni senza danni neurologici.

Risentire la sua voce e vedere la luce nei suoi occhi azzurri è stato un regalo inestimabile dopo interminabili ore di angoscia. La situazione di Emma, seppur stabile rimaneva molto grave. I giorni passavano nel reparto di cardio-rianimazione ma la donazione non arrivava e così, attraverso un percorso di step intermedi si arriva al Berlin Heart.

Ogni passaggio era un rischio, ma l'organismo di Emma si adatta, combatte, si stabilizza e a fine marzo viene trasferita in reparto di cardiologia attaccata al cuore artificiale. I mesi passano, Emma recupera le forze, ritorna a camminare, ride, gioca, addirittura balla...sempre attaccata al Berlin Heart.

Emma capisce che quello strano macchinario attaccato con due tubi nel suo torace la fa stare bene, inizia a fidarsi dei medici che le sono stati sempre accanto, delle infermiere e di tutti coloro che ormai facevano parte della sua quotidianità.

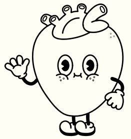
Non era più spaventata, era consapevole della sua situazione, l'aveva accettata scegliendo di affrontare le giornate con il sorriso.

Ricordo una sera, una delle poche in cui ero presente, (poichè normalmente era il papà a starle accanto di notte) la vidi sorridere mentre dormiva serena...un sorriso bellissimo che non avevo mai visto prima. Può sembrare normale a molti ma era straordinario..mi emozionai perchè finalmente Emma si sentiva bene, non faticava più a respirare, non si svegliava più piangendo perchè si sentiva il cuore in gola. Ora riusciva a sognare e sorridere.

Il suo sorriso è stato il comune denominatore durante tutto il suo lungo ricovero. Ci ha insegnato con quanta intensità bisogna vivere ogni giorno. Un esempio di forza e coraggio incredibile per una bimba di soli 5 anni e mezzo che non si è mai arresa ma che si è attaccata a questa vita con tutta sè stessa.

La notte del 5 luglio arriva la donazione. Felicità

Emma



"Her smile was the common denominator throughout his long hospitalization"

Primary disease/transplant type
Severe heart malformation/ Heart transplant
Age at transplant
6 years old

I'm Emma's mom, and I'm very lucky. Emma was born in 2010 with a severe heart malformation, a single ventricle and coarctation of the aorta. The surgical procedure involved 3 operations, a difficult but necessary path for her to have the opportunity for a good quality of life. Emma underwent the 3 surgeries, but complications arose, especially after the third surgery. Her situation was extremely precarious, and the insufficiency of her atrioventricular valve put the Fontan procedure result into question. The situation worsened quickly, and the only option became a heart transplant. During one of her many hospitalizations to deal with her heart failure, my daughter's heart suddenly stopped as she walked around the ward. It was the evening of January 15, 2016. After more than 2 hours of resuscitation, an extracorporeal membrane oxygenation machine was attached, which worked well, and Emma woke up after 2 days, with no neurological damage.

Hearing her voice and seeing the light in her blue eyes was a priceless gift after endless hours of anguish. However, Emma's situation, although stable, remained very serious. Days passed in the cardio-resuscitation ward, but given that no heart was yet available, through a number of intermediate steps, she received a Berlin Heart.

Each step was a risk, but Emma's body adapted, fought, and stabilised, and at the end of March, 2016, she was transferred to the cardiology ward attached to the artificial heart. Months passed during which Emma regained her strength and began to walk, laugh, play, and even dance again — always attached to her Berlin heart.

Emma understood that that strange machine attached with two tubes in her chest made her feel good, and she began to trust the doctors and nurses who had been treating her for so long, who were now part of her daily life. She was no longer afraid, she was aware of her situation, and she accepted it by choosing to face each day with a smile.

I remember one evening, one of the few in which I was present (since normally it was her father who stayed with her at night) I saw her smile while she was sleeping peacefully — a beautiful smile that I had never seen before. It may seem normal to many, but I found it extraordinary. I became emotional because Emma was finally feeling good, she no longer struggled to breathe, and she no longer woke up crying because her heart was in her throat. Now she could dream and smile.

Her smile was the common denominator throughout his long hospitalization. She taught us how intensely we must live every day; an example of incredible strength and courage for a girl of only 5 and a half years who had never given up but e paura. Mentre in piena notte guidavo per raggiungere l'ospedale, emozioni contrastanti mi assalivano.

Speri sempre di prendere la decisione giusta, hai la responsabilità di decidere sulla persona che come genitore ami di più e non è mai semplice.

Qualsiasi mio dubbio viene dissolto appena arrivata in ospedale. Erano le 5.30 del mattino e Emma era già sveglia, intenta a pettinarsi i capelli. Mi ha salutato come sempre e con il suo splendido sorriso mi ha comunicato che era arrivato il cuoricino fucsia con i brillantini che tanto aveva desiderato. Era straordinariamente pronta, più di tutti noi.

Quanta forza in un essere così piccolo.

Nel tardo pomeriggio di quel giorno le porte della sala operatoria si aprirono. Guardai gli occhi dei due eccezionali medici che venivano verso di noi e capii subito che una nuova vita era iniziata per Emma. Il trapianto era riuscito. Il 13 agosto, dopo più di 8 mesi, Emma viene dimessa.

Questa è la storia di un'avventura incredibile, fatta di incontri che ci hanno cambiato la vita, fatta di forti legami nati nelle corsie di un ospedale, fatta di persone straordinarie che abbiamo avuto la fortuna di avere al nostro fianco, un'equipe medica d'eccellenza che ha reso possibile l'impossibile, un primario fuori dall'ordinario.

Sono trascorsi più di 6 anni dal giorno del trapianto. Emma ha vissuto più anni con il cuore che le è stato donato che con quello con cui è nata.

Proprio per questo, mi rendo conto, più degli altri anni, del regalo inestimabile che ci è stato fatto, una vita di possibilità.

Chi ha trascorso anni fra le corsie di un ospedale fra ricoveri, operazioni e continue cure desidera solo tornare alla normalità, alla sana spensieratezza per vivere pienamente ogni giorno.

Emma mi ha insegnato in questi anni più di quanto io possa insegnarle in una vita intera. Esempio di forza, tenacia e coraggio.

Vorrei poter raccontare ai genitori del donatore, della luce che si rifletteva sul suo viso quando è uscita dopo 8 mesi dalla camera dell'ospedale, del vento che le accarezzava la pelle la prima volta che è salita in montagna senza che le mancasse il respiro o del suo sorriso che illumina chiunque ha la fortuna di averla vicino e vorrei raccontargli di come brillano i suoi occhi e di quanto è straordinaria, perchè è soprattutto grazie a loro che Emma è qua oggi.

Lei è Vita. Donare è vita. Ecco perchè sono una mamma fortunata.

who had fully embraced life. The donated heart arrived on the night of July 5th. I felt both happiness and fear. As I drove to the hospital in the middle of the night, mixed emotions assailed me.

You always hope to make the right decision. You have a responsibility to make decisions for the person you love the most as a parent, and it's never easy. Any doubt I had vanished as soon as I arrived at the hospital. It was 5:30 in the morning and Emma was already awake, combing her hair. She greeted me as always, and with her splendid smile told me that the fuchsia heart with glitter she had so desired had arrived. She was extraordinarily ready, more than any of us. How much strength in such a small being.

In the late afternoon of that day, the doors of the operating room opened. I looked into the eyes of the two exceptional doctors who came towards us and I knew immediately that a new life had begun for Emma. The transplant was successful. On August 13th, 2016, after more than 8 months, Emma left the hospital.

This was an incredible adventure, filled with encounters that changed our lives, having forged strong bonds born in the wards of a hospital, made up of extraordinary people who we were lucky enough to have by our side: an excellent medical team that made the impossible possible, including an extraordinary Chief of Cardiology.

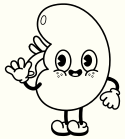
As I write this, more than 6 years have passed since the day of the transplant. Emma has lived more years with the heart she was given than with the one she was born with. Precisely for this reason, I am aware, more than in other years, of the priceless gift that has been given to us — a life of possibility.

Those who have spent years in the wards of a hospital between hospitalisations, operations, and continuous treatments, just want to return to normalcy, to their healthy carefree life, to live fully every day. Emma has taught me more over the years than I can teach her in a lifetime. She is an example of strength, tenacity, and courage.

I would like to tell the donor's parents about the light that reflected on her face when she left the hospital room after 8 months, about the wind that caressed her skin the first time she walked up a mountain without shortness of breath, and of her smile that delights anyone who is lucky enough to have her near. I would like to tell them how her eyes shine and how extraordinary she is, because it is above all thanks to them that Emma is here today.

She is alive. Giving is life. That's why I'm a lucky mom.

Paola



«La vita è un ciclo continuo, sempre in movimento»

Diagnosi/tipo di trapianto
Glomerulosclerosi focale.
Trapianto di rene.
Età al trapianto
12 anni

Principali preoccupazione
Prendere le pastiglie.

Risultato
Ottimo, sono come prima ma con le pastiglie!

Messagio per gli altri pazienti che sono in lista trapianto
Buona fortuna, spero che abbiate presto il trapianto come me. Coraggio e molta speranza!

Messaggio per i pazienti che hanno eseguito trapianto
Sono contenta per tutte le persone che hanno superato questo problema come me.

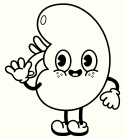
Messaggio per i genitori
La vita è un ciclo continuo, sempre in movimento, se i bei tempi passano, passeranno anche i tempi difficili.

Messaggio per il personale sanitario
Ringrazio per la disponibilità, gentilezza, professionalità e pazienza che avete!

Mi sono sentita da subito, come in una grande famiglia, e ogni visita di controllo è anche l'opportunità di rivedere le persone e poter sorridere. Ammiro, per la professionalità ed umanità con cui portate avanti il compito, a volte in condizioni non facili, senza mai dimenticare che noi pazienti siamo persone e non un numero, avendo sempre una parola, un sorriso, un gesto di attenzione che a volte sono la medicina migliore.

Grazie mille di tutto!

Paola



"Life is a continuous cycle, always in motion"

Primary disease / Transplant type
Focal segmental glomerulosclerosis (FSGS)
Kidney transplant
Age at transplant
12 years old

Main concerns
Take my meds every day.

Outcome
Successful transplant. I'm the same as before but now it's me and my meds!

Message for other patients who are on the transplant list
Good luck, I hope you have the transplant soon like me. Courage and much hope!

Message for the other transplanted peers
I'm happy for all the people who have overcome this problem, as I have.

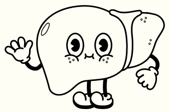
Message for parents/caregivers
Life is a continuous cycle, always in motion; if the good times pass, the hard times will pass, too.

Message for health professionals
Thank you for the availability, kindness, professionalism and patience you have!

I immediately felt like I was part of a big family, and now every follow-up visit is also an opportunity to see all the medical staff again and smile. I admire the professionalism and humanity with which everyone on the team performed their job, sometimes in difficult conditions, without ever forgetting that we patients are people and not just a number, always with a word, smile or gesture of attention that sometimes for us is the best medicine.

Thank you so much for everything!

Elena



«A volte ricevere un conforto è meglio di qualsiasi terapia esistente»

Sono G.P, mamma di una splendida ragazza di 12 anni, che alla tenera età di quasi sette mesi ha avuto la fortuna di poter ricevere in dono un nuovo fegato, poichè il suo fegatuccio purtroppo sembrava quello di una novantenne fumatrice a causa dell'atresia delle vie biliari. Le nostre preoccupazioni iniziali ovviamente erano legate al timore che la nostra bambina non potesse riuscire a rimanere in vita, ma grazie al sostegno della splendida equipe dell'ospedale e alla condivisione delle esperienze di altri genitori, siamo riusciti a trasformare il terrore, in fiducia, il panico si è trasformato in coraggio e la Paura è stata giorno per giorno placata dalla competenza, la pazienza e la presenza di tutto lo staff del centro trapianti.

Un messaggio per chi è in attesa di trapianto? Abbiate fiducia, non cercate colpevoli, un po' di leggerezza, tanta pazienza ma soprattutto Tanto Amore Per La Vita E Rispetto per chi ci circonda.

Le nostre soddisfazioni? Riuscire a non far sentire nostra figlia una persona "malata" nonostante tutto e farle fare un vita il più possibile "normale" e credo che il segreto per far questo sia principalmente il non piangersi mai addosso, ma rimboccarsi le maniche anche dopo essere caduti e rialzarsi sempre con il sorriso.

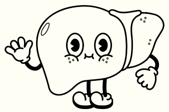
Un messaggio ai professionisti che assistono? A volte ricevere un conforto è meglio di qualsiasi terapia esistente (e noi l'abbiamo sempre ricevuto).

Noi ci riteniamo persone paradossalmente molto fortunate e godiamo giorno per giorno ogni attimo con i nostri figli, anche quando la sera la qui presente si trasforma in un cerbero quando le bambine alle 22 ancora non si sono lavate i denti…." Un attimo mamma"… (la leggerezza che dicevo pocanzi la sera si perde anche nelle migliori famiglie …eh eh) …ovviamente scherzo.

Starei qui ore ed ore a scrivere ma temo che le 400 parole siano ormai superate.

Vorrei mandare un augurio di buona vita a tutti, soprattutto dopo gli ultimi 2 anni vissuti.

Elena



"Sometimes receiving comfort is better than any other therapy"

I'm G.P, the mother of a beautiful 12-year-old girl who, at the tender age of almost 7 months, was lucky enough to be able to receive a new liver as a gift, because hers, unfortunately, was like that of a 90-year-old due to atresia of the bile ducts. Our initial concerns were of course the fear that our little girl would not be able to remain alive, but thanks to the support of the beautiful team of the hospital and the sharing of other parents' experiences, we managed to transform doubt into faith, panic became courage, and our fears were calmed daily by the competence, patience and presence of all the staff of the Transplantation Centre.

A message for those who are waiting for a transplant? Trust, do not blame, maintain some light-heartedness and patience, but above all, have a love for life and for those around you.

Our satisfactions? Being able to not make our daughter feel like a "sick" person despite everything, and to provide her with as "normal" a life as possible. I think the secret to achieving this was mainly not to cry about her, but to pick her up after falling, and always with a smile.

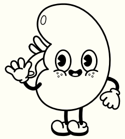
A message to the professionals who assist? Sometimes receiving comfort is better than any other therapy (and we have always received it).

We think we are, paradoxically, very lucky people, and we enjoy every day with our children, even when in the evening the girls have still not brushed their teeth at 22:00…."Wait for a moment mummy"… heh heh… obviously, a joke.

I'd be here for hours and hours writing, but I'm afraid the 400 words would be exceeded.

I would like to send everyone a wish for a good life, especially after the last 2 years we have lived through.

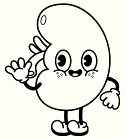
Giovanna



«Con il trapianto non finisce il nostro viaggio, ne inizia un altro»

Cari compagni di viaggio, mi chiamo Giovanna ho 29 anni e nel 2007 dopo circa 2 anni di dialisi, ho effettuato un trapianto di rene. Un percorso spigoloso che spesso ho paragonato ad un videogioco costituito da infiniti livelli: ogni volta che ne superavo uno, il successivo era più difficile. Un percorso il mio, il nostro che ci vuole pronti a combattere senza allenamento contro nemici sconosciuti ma che prima o poi sconfiggeremo perché la Vita trionfa sempre. Nonostante le vicissitudini infatti, la partita più importante l'ho vinta io e vorrei svelarvi qualche trucchetto. In questo gioco, la speranza è come Virgilio per Dante dunque non separatevene mai. I consigli dei medici seguiteli, abbiate fiducia in loro che sono la nostra seconda famiglia e lottano per noi e con noi. I loro no accoglieteli come un investimento e domani si tramuteranno in si. Non dimenticate mai dopo il trapianto, il cammino che avete affrontato, le persone che vi hanno accompagnato ma soprattutto non dimenticate di essere trapiantati e dunque vivi ad abitare il mondo grazie a chi ha superato la morte per la vostra salvezza. Siamo, siete portatori di una seconda possibilità, custodi di una parte di qualcuno che qualcun altro amava e che magari un giorno potrà ritrovare in voi. Con il trapianto non finisce il nostro viaggio, ne inizia un altro.

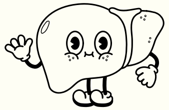
Giovanna



"Transplantation does not end our journey, another one begins"

Dear travel companions, my name is Giovanna. I am 29 years old, and on 2007, after about 2 years of dialysis, I received a kidney transplant. It has been difficult path that I have often compared to a video game made up of infinite levels: every time I passed one, the next was more difficult; a path, like mine and ours, which requires us to be ready to fight without training against unknown enemies but that sooner or later we will defeat because Life always triumphs. Despite the vicissitudes, in fact, I won the most important game, and I would like to reveal some tricks. In this game, hope is like Virgil to Dante, so never separate from him. Follow the doctors' advice; trust them, because they are our second family and they are fighting for us and with us. Welcome their "no" as an investment in your future, so tomorrow the answer will turn into a "yes". After transplantation, never forget the path you have taken, the people who accompanied you, and above all do not forget that you are transplanted. You are a living person capable of inhabiting the world thanks to those who have had to suffer their loved ones' death in order to give you life. We possess a second chance, and we are guardians of a part of a person whom someone else loved and who maybe one day they will find in you. Transplantation does not end our journey, another one begins.

Alberto



«Ma soprattutto è fiero della sua cicatrice»

Alberto è finalmente arrivato e mai avremmo immaginato di trovarci di fronte a una diagnosi di malattia genetica rara in cui l'unica speranza era il trapianto di fegato.

Spaventati e sconvolti ci siamo affidati ai medici e infermieri che fin da subito si sono presi cura del nostro piccolo e ci hanno aiutato a capire il percorso a cui saremmo dovuti per forza andare incontro.

Un anno dopo arriva il fegato per Alberto e la speranza per lui e per noi di una rinascita.

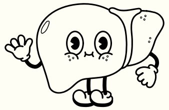
Ringrazieremo per sempre la famiglia del donatore e tutte le figure professionali che hanno ruotato intorno a noi in questi anni e che continuano tutt'ora a prendersi cura di Alberto.

La paura è stata tanta ma la condivisione con le famiglie che avevano già vissuto tutto quello che sarebbe successo a noi ci ha permesso di essere più consapevoli e più sicuri.

Alberto non ricorda nulla di quel periodo, era molto piccolo, ma gli abbiamo raccontato tutto e guardiamo spesso foto e video di quel periodo. Oggi è un bambino che sta bene, pieno di energie, simpatico, ma soprattutto è fiero della sua cicatrice.

La mostra sempre a tutti con orgoglio, perché lui è un supereroe, il nostro.

Alberto



"Above all, he is proud of his scar"

Alberto arrived finally, and we would never imagine we would face a diagnosis of genetic rare disease for which the liver transplantation was the only hope.

Scared and upset we trusted the doctors and the nurses who cared for Alberto since the very first moment and helped us to understand the path we would necessarily have to go through.

One year later a liver for Alberto arrived, and with it the hope for a rebirth for our child and for us.

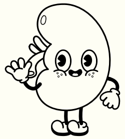
We will be forever thankful to the donor's family and to all the healthcare professionals who has surrounded us in those years and who are still taking care of Alberto.

We were very scared but sharing our story and our feelings with other families who had already experienced what would happen to us let us be more conscious and confident.

Alberto has no memory whatsoever of that time, he was too little, but we told him everything and we often watch phots and videos of those days.

Today he is well and full of energy; he is a nice kid but above all he is proud of his scar. He always shows it off, because he is a superhero. Ours.

E.



«Alla fine cerchiamo di cogliere tutte le opportunità che abbiamo e vivere ora ed quì»

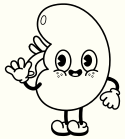
Sono la mamma della piccola E., una bambina di 7 anni. E. aveva una malattia rara e subito dopo la nascita eravamo costrette a passare molto tempo in ospedale.

Dopo tantissime complicazioni abbiamo cominciato con la dialisi, per 2 anni. Il tempo trascorso in dialisi sembrava un'eternità, ma d'altra parte, nonostante molte difficoltà, eravamo grati perchè questo apparecchio significava la salvezza. Finalmente all'eta di 3 anni, E. ha fatto il trapianto di rene da donatore vivente. Questo è stato l'inizio di una nuova vita piena di libertà e di tante possibilità, ma vissuta ancora con nuovi problemi e preoccupazioni. Anche se all'inizio non sembrava così, oggi posso dire che l'ospedale è diventato la nostra seconda famiglia. Parlare d'ospedale ogni volta prima del ricovero in modo fantastico ed allo stesso tempo molto reale, fare un favola piena di dettagli ogni volta quando dobbiamo fare diverse procedure diagnostiche o trovare in reparto amici con lo stesso rene speciale, rende i nostri giorni in ospedale più divertenti. Poi ci sono i nostri medici di nefrologia sempre presenti e comprensivi. Gli infermieri e tutto il personale dimostrano sempre una umanità che ci commuove ogni volta.

Abbiamo imparato ad apprezzare la vita con quelle piccole cose e sfruttare al massimo ogni giorno sia brutto o bello. Alla fine cerchiamo di cogliere tutte le opportunità che abbiamo e vivere ora e qui.

La mia piccola E. ci ha insegnato che per questi piccoli bambini coraggiosi con un rene speciale non c'è nessun limite!

E.



"We try to seize any opportunity we see and to live fully here and now"

I am E.'s mum, a 7 year old girl. E. suffers from a rare disease and since she was born we had to spend a long time in hospital.

After many complications we started dialysis, for 2 years. Dialysis seemed to last forever, but at the end of the day that machine meant the life for us.

Finally when E. was 3 years old she underwent kidney transplantation from a living donor.

That was a new life for us, with freedom and many opportunities, even though we had to face new problems and fears.

At the beginning it did not seem so, but today I can say out loud that the hospital has become our second family.

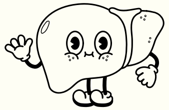
We come up with fantastic yet real stories before the hospitalisation, we invent tales full of details every time we need to take new diagnostic tests, we meet up with friends with the same special kidney as ours: all of this makes our days at the hospital good fun.

Our nephrologists are always there for us and caring. Nurses and all the health care professionals always reveal a very touching humanity.

We have learnt to value life from the small things and to make the most out every single day, regardless it is a good or bad day. We try to seize any opportunity we see and to live fully here and now.

My little E. has taught us that for those little brave kids with a special kidney there is no limit!

B.T.



«I bambini insegnano a noi adulti a non mollare mai e a lottare sempre»

Ciao sono la mamma di B.T.

Al rientro da una vacanza al mare la mia bambina comincia ad essere stanca, a voler dormire in ogni posto. La porto dalla pediatra, pensando che forse il pesce mangiato in vacanza le avesse fatto male, ma solo guardandola negli occhi mi dice "Questa bimba sta male" e mi manda a fare poche analisi mirate.

In meno di ventiquattro ore mi trovo ricoverata d'urgenza all ospedale pediatrico della mia regione. Il tempo di una banale ecografia dove vedono una massa nel fegato e ci catapultano d'urgenza in un altro ospedale. Qui conosciamo due dottori meravigliosi. Ricordo ancora quando uno dei due mi disse "Signora, sono un papà anche io, la capisco, ma stia tranquilla che adesso capiamo cosa ha la bimba". In brevissimo tempo l'esito: B. aveva un tumore al fegato chiamato epatoblastoma, si sarebbe salvata solo con un trapianto. Ma il suo tumore era troppo grande per poter essere asportato, così ci mettono in chemioterapia. Un altro angelo ci ha seguito in tutto quel percorso; dovevamo solo sperare che quelle terribili chemio riducessero il tumore per poter portare al trapianto la nostra bimba.

Dopo circa 5 mesi di chemioterapia finalmente la buona notizia: le chemioterapie avevano funzionato, B. poteva essere trapiantata entro trenta giorni. Nel frattempo io e mio marito ci sottoponiamo ad analisi precise dove ci viene confermato che entrambi eravamo compatibili per donare a B. un pezzetto del nostro fegato; i medici ci spiegano che questo sarà possibile solo nel caso in cui non arrivi un organo compatibile.

Ci mandano a casa in attesa e in meno di ventiquattro ore suona il telefono: il fegato compatibile era arrivato. L'ultima notte a casa e alle sei del mattino eravamo già in ospedale insieme ai nostri angeli custodi, che ci hanno accompagnato in ogni istante di questo terribile cammino. Lì ci aspettava il chirurgo con tutto il suo staff tra infermieri e anestesisti. Un po' la gioia di fare entrare B. finalmente in quella sala operatoria, un po' la paura per quello che sarebbe potuto succedere…

L'attesa è stata infinita, mi è passata davvero davanti tutta una vita. Finalmente dopo dodici ore vengono a dirci che l'intervento era finito e che era andato tutto bene.

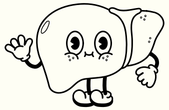
B. era rinata grazie a una giovane donna donatrice che ha salvato la mia bimba e un'altra signora. B. ha ricevuto uno split, cioè metà fegato, perchè essendo un organo che si rigenera hanno potuto salvare due vite con un solo organo.

Rivederla quel giorno è stato come vederla la prima volta che è venuta al mondo.

Oggi B. ha 11 anni, è una ragazzina piena di vita, solare e allegra, più matura di altri ragazzi della sua età perché quello che le è successo a due anni l'ha comunque segnata. È stata una grande guerriera e ancora lo è. I bambini insegnano a noi adulti a non mollare mai e a lottare sempre.

Questa testimonianza è solo un breve riassunto di quello che abbiamo passato; ma secondo la mia esperienza credete nella medicina e credete in quei medici che dedicano la loro vita, mettono tutta la loro passione, passano giorni e notti a studiare la soluzione per i loro piccoli pazienti. CREDETECI SEMPRE fino all ultimo istante.

B.T.



"Kids teach us not to give up and always fight"

Hello, I am B.T.'s mom.

Coming back from a sea holiday my girl begins to be always tired, to sleep everywhere all the time. I take her to the pediatrician, thinking she is sick because of some bad fish eaten on holiday, but the doctor just looking at her says "This girl is not well at all" and she prescribes few but very specific tests.

In less than twenty-four hours I find ourselves hospitalised of urgency at our regional pediatrician hospital. With an ordinary ultrasound the doctors can see a mass in the liver and they send us to another hospital in a rush, and here we get to know two amasing specialists. I still remember when one of them told me "I am a father myself, I understand you, but do not worry, we will find out what the matter is with your daughter". In a very short time the answer: B. had a liver cancer called "Epatoblastoma", only a transplant could save her. But the tumor was too big to be removed, and therefore we were prescribed chemotherapy. Another guardian angel followed us in that journey; our only hope was that terrible chemotherapies reduced the tumor so that our girl could be transplanted.

After more or less 5 months the good news: chemotherapies worked. B. could be transplanted within thirty days. In the meantime my husband and I undergo tests which confirm we both can be donors and give B. a portion of our liver; doctors explain to us that this will be done only if there is no compatible organ available.

They send us home ad in less than twenty-four hours the phone rings: the compatible liver is there. We spend our last night at home and at six a.m. we are at the hospital together with our guardian angels, who have never left us alone during this terrible journey. The surgeon was waiting for us there too, with his team of nurses and anesthetists.

We were so happy that B. could finally enter that operating theatre, but at the same time so scared for what could happen….

The waiting was endless, I could relive my entire life. Finally after 12 hours they told us the surgery was over and that everything went well.

B. was reborn thanks to a young girl donor, who saved my daughter and another lady. B. received a split liver, that is to say a portion; since the liver can regenerate itself the doctors could save two lived with one organ only.

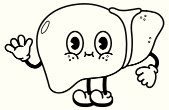
See B. that day was like seeing here for the very first time when she came into the world.

Today B. is eleven, she is an energetic, lively and cheerful girl, more mature than the kids of her same age because what happened to her when she was only 2 affected her. She was a fighter, and still she is. Kids teach us not to give up and always fight.

Our testimony is just a short summary of what we had to face; according to my experience trust medical science and doctors who dedicate their lives, give their passion and spend their days and night looking for the best solution for their little patients.

ALWAYS BELIEVE, until the very end.

Giorgio



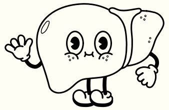
«Un evento immenso che genera speranza e forza»

Quella di nostro figlio Giorgio è una storia piena di speranza. L'abbiamo desiderato tantissimo. Durante gli ultimi mesi ci siamo chiesti più volte come avremmo reagito nel caso in cui si fossero presentate delle difficoltà, ma la nostra mente non immaginava nulla di quello che sarebbe accaduto. La diagnosi della malattia metabolica genetica rara di Giorgio è stata chiara da subito, dalla stanza del reparto di maternità piena dei nostri sogni siamo stati trasferiti con estrema fretta nel reparto di terapia intensiva. La luce in un attimo si è spenta, ci siamo ritrovati al buio senza sentiero.

Abbiamo iniziato a fare mille domande a tutti i medici con cui siamo entrati in contatto, ma non ci bastava e così abbiamo cercato qualsiasi appiglio anche online. La speranza, appresa come attitudine giornaliera, ci ha permesso di recuperare le forze e di trovare un nuovo punto di partenza. Un articolo online parlava di uno specialista esperto di malattie metaboliche e tra i primi a dare indicazione di trapianto di fegato come cura.

È così che è tornata la luce. Il percorso di messa in lista è stato tortuoso e più lento anche a causa della pandemia, il Covid ci ha più volte messo i bastoni tra le ruote. Dalla nostra città abbiamo fatto la spola con un'altra e ad ogni viaggio si aggiungevano incontri preziosi. Il gastroenterologo pediatrico che ad oggi è la nostra stella polare, il suo collega che non ci ha mai lasciati soli e un'altra dottoressa che con la sua professionalità ci ha fatto sentire sicuri in tanti momenti difficili. Impossibile non ricordare il chirurgo e tutte le infermiere che sono state supporto concreto e costante. Quando raccontiamo la storia di Giorgio a volte abbiamo quasi paura di essere fraintesi. Tendiamo a tralasciare il racconto della fatica, della paura e della complessità di quello che abbiamo vissuto, perchè come quando una madre partorisce poi dimentica il dolore e ricorda solo la felicità della vita che è nata. Assistere al trapianto di un figlio è un'esperienza potentissima che racchiude la morte di chi dona e la nuova vita di chi riceve. Un evento immenso che genera speranza e forza in chi lo vive da vicino e in chi gli sta attorno.

Giorgio



“A huge event which brings hope and strength”

The story of our son Giorgio is a full of hope one. We had been longing for him. During the lost months of the pregnancy we wondered many times what we would do in case of problems, but we simply could not imagine anything of what actually happened.

The diagnosis of Giorgio's metabolic rare disease was immediately evident, from the maternity ward full of our dreams we were sent to the NICU in a rush.

The light was off in a second, we found ourselves lost in the darkness with no path.

We started to question all the doctors we met, but it was not enough for us, and therefore we searched online. Our hope, as a daily attitude, helped us to regain strength and find a new starting point.

An online article was about a specialist in metabolic rare diseases and one of the first indicating liver transplantation as the cure.

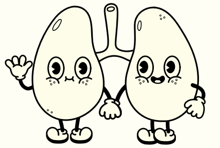
The light was back on. The transplant waiting list procedure was complicated and slow due to the Covid pandemic.

From our town we went back and forth another city so many times, and during every journey we met other valuable specialists: a pediatric gastroenterologist who is our polar star, one of his colleagues who has never left us alone, another doctor who reassured us in many difficult times with her professionalism. We cannot forget the surgeon too, and the nurses who were a concrete and constant support.

When we tell Giorgio's story, sometimes we are afraid of being misunderstood. We tend to neglect the part of the story about the struggle, the fear and the complexity of what we went through: as when a mother gives birth then she forgets the pain and remembers only the happiness for the life born.

Witnessing your kid's transplant is a very powerful experience, which includes the donor's death and the recipient's new life. A huge event which brings hope and strength in those who live it and those who are involved.

Michele



«Oggi siamo insieme, anche a tutto il resto del mondo»

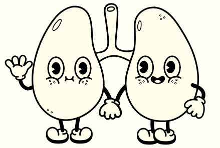
È bello poter esserci a raccontare la sconfitta che la vita ti ha riservato. Ti senti meglio quando racconti la tua storia, e allo stesso tempo aiuti qualcun altro che magari può trovare speranza nelle tue parole e riconoscersi un po' nelle tue vicende. Quello che abbiamo passato ci ha insegnato tante cose, come affrontare le difficoltà che la vita ti mette davanti. In questa sconfitta molte persone si sono unite a me, che oggi considero mandate dalla Provvidenza, perché hanno dato al mio bambino una seconda vita.

Le mani e l'amore dei medici che fanno l'impossibile per noi, li ringraziamo per ogni minuto dedicato a nostro figlio. Non è facile vivere le ore di attesa: sono piene di ansia, stress, difficoltà, a tal punto che ti si spezza il cuore e ti manca il respiro mentre aspetti che passino. Ma quando l'attesa finisce e capisci che tutto sta andando bene, senti allora il sangue che riprende a scorrere, ritorni in te, fai un respiro profondo, ti siedi da qualche parte un attimo e dici: ne è valsa la pena.

Si può sopportare la fatica, il sacrificio. Ecco perché voglio dirlo ogni volta che ne ho l'opportunità, per offrire il meglio che posso agli altri. Non riusciamo a salvare il mondo, ma alcune vite sì.

Ringraziamo tutti coloro che ci sono stati nel nostro difficile viaggio: grazie a questo oggi siamo insieme, e siamo insieme anche a tutto il resto del mondo.

Michele



"Today we are together, with the rest of the whole world too"

It is good to be there and be able to tell the defeat that life has reserved for you. You feel better when you tell your story, and at the same time you help someone else who could find hope in your words and who could recognize himself a bit in what you have gone through. What we've lived has taught us so many things, such as to face the difficulties that life throws at you. In this defeat many people have joined me, whom today I consider sent by Providence, because they gave my child a second life.

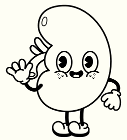
The hands and the love of the doctors who do the impossible for us, we thank them for every minute they dedicate to our son. It's not easy to deal with the waiting: they are hours full of anxiety, stress, difficulties, to the point that your heart breaks and you can't breathe while you wait for them to pass. But when the wait is over and you realize that everything is going well, you feel the blood starting to flow again, you come back to yourself, take a deep breath, sit down somewhere for a moment and say: it was worth it.

You can bear the effort, the sacrifice. That's why I want to say it whenever I have the opportunity, to offer the best I can to others. We can't save the world, but we can save some lives.

We thank all those who have been there in our difficult journey: thanks to that today we find ourselves together, and we are together with the rest of the whole world too.

Lietuva / Lithuania

Jonas



„Geresnis rytojus visada ateina“

Pacientas

8 metų berniukas Jonas Čiupala.

Pirminė liga

Įgimti obstrukciniai inkstų geldelės defektai ir įgimtos šlapimtakio formavimosi ydos. Lėtinis inkstų nepakankamumas. Inksto transplantacija, kai vaikui buvo 5 metai metų amžiaus.

Problemos ir rūpesčiai

Buvo pagrindiniai mūsų šeimos palydovai nuo vaiko gimimo iki pat transplantacijos. Labai liūdna, kai po sėkmingo vaikelio atėjimo į šį pasaulį visos mamos keliauja su naujagimiais namo. Deja, bet ne mūsų atveju, mums teko persikelti į naujagimių skyrių ir mamai visiškai nenutuokiančiai apie rimtas ligas tenka išgyventi baisų periodą. Matyt baisiausia, kai 6 dienų naujagimį išveža operuoti, tiesiog plyšta širdis. Laukimas, nežinia, blogi tyrimai vaistų gausybė kas kart tas pats per tą patį. Galiausia tyrimų rezultatai tokie, kad vaikas atsiduria reanimacijoje. Kaip baisu tėvams, kai sužinai jog tavo vaikas nebegali gyventi be dializių. 9 mėnesiui vaikeliui implantuojamas peritoninės dializės (PD) kateteris į pilvaplėvę ir pradedamos dializės. Daug visko naujo, kelionės tik su dializės aparatu, visi vakarai ir rytai praleisti prie šio aparato. Adaptuojiesi, pripranti atrodo džiaugiesi gyvenimu ir staiga naujiena, kad pilvaplėvėje sąaugos todėl šis dializavimo būdas nebetinka. Tad trimečiui vaikui implantuotas hemodializės (HD) kateteris. Vėl naujas periodas, kas antrą dieną esame pririšti prie klinikų, išvykos net ir į kaimą sustabdytos, nes mažamečių vaikų bet kuriame Lietuvos mieste nedializuoja. Permainos, pokyčiai prie visko reikia priprasti iš naujo. Galiausia skambučio laukimas su pakvietimu ir transplantacijos centrą. Sulaukėme keleto skambučių, visi jie buvo naktį, jie baisūs, nes pažadina, išsigąsti, bet tuo pat metu turi greit pradėti ruoštis nes nėra laiko laukti.

Sėkmės istorija

Pagaliau sulaukėme to laiko tiksliau vaikas pasiekė tą svorio kategoriją, kai galėjom stoti į laukiančių transplantacijos gretas. Pasiūlymų ir skambučių sulaukėme nedaug, tad gydytojai pasiūlius mums tėvams būti donorais nedelsiant sutikom. Po gausybės tyrimų išaiškėjo, kad tėtis inksto donoru vaikui būti negali, mamos inkstas vaikui tiko. Pamenu tą dieną, kai su džiaugsmo ašaromis išeinu iš gydytojų konsiliumo ir negalvoju apie save, bet džiūgauju, kad galėsiu suteikti savo vaikui geresnį gyvenimą. Transplantacija atliko patys geriausi šios srities profesionalai, viskas pavyko puikiai. Vaiką gydantys nefrologai tai gydytojai iš didžiosios raidės, jų dėka net sveikimo laikotarpis buvo labai greitas ir sėkmingas.

Žinutė laukiantiems transplantacijos

Nenustokit tikėti, po didelių rūpesčių ir po begalės išbandymų visada ateina geresnis rytojus.

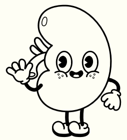
Žinutė kitiems tėvams

Kas mūsų nenužudo padaro mus stipresniais.

Žinutė sveikatos priežiūros specialistams

Šiems žmonėms žinutę pasiųsti sunku, jiems nuolat norisi dėkoti, dėkoti ir dėkoti už tai, kad jie yra, už tai ką jie daro, už tai kad jie traukia iš mirties gniaužtų, už tai, kad jie rūpinasi ir už tai, kad neleidžia palūžti. Ačiū!

Jonas



“A better tomorrow always comes”

Congenital obstructive renal defects and congenital malformations of the urinary tract. Chronic kidney failure. Kidney transplant when the child was 5 years old.

Problems and worries were the main companions of our family from Jonas’ birth until the transplant. It is very sad when after the successful arrival of a child into this world, not all mothers can go home with their newborns. In our case, we had to move to the neonatal unit and the mother has to go through a terrible period away from her sick infant. The worst thing was when our 6-day-old newborn was taken for surgery. Waiting, not knowing, bad test results, a lot of medications, it was the same thing over and over again. Finally, our child was hospitalized in intensive care. How scary it is for parents when you find out that your child can no longer live without dialysis. At 9 months, a peritoneal dialysis (PD) catheter was implanted into Jonas’ peritoneum and dialysis was started. We had to learn a lot of new things, such as always traveling with a dialysis machine, spending all evenings and mornings with it. We adapted, became accustomed to it, began to enjoy life, and suddenly we got the news that there were adhesions in Jonas’ peritoneum, so the dialysis method was no longer suitable. Therefore, a haemodialysis (HD) catheter was implanted in our 3-year-old child. It was a new period again. Every second day we were tied to the hospital; trips even to the village had to be stopped, because young children cannot receive dialysis many Lithuanian cities. With all the changes, you have to get used to everything all over again. Finally, we were waiting for a call with an invitation to the transplant centre. We received several calls, all of them at night; they are scary because they wake you up and startle you, but at the same time you have to start preparing quickly because there is no time to waste.

A success story

Jonas finally reached the weight category where he could join the transplant waiting list. We received few offers or calls, so when the doctor suggested that we be the donors, we immediately agreed. After genetic testing, it became clear that Jonas’ father could not be a kidney donor, but my kidney was suitable. I remember the day when I left the doctor’s office with tears of joy. I didn’t think about myself, I was just so happy that I would be able to give my child a better life. The transplant was performed by the best professionals in the field, and everything went perfectly. The nephrologists treating Jonas are the greatest professionals; thanks to them, even the recovery period was very quick and successful.

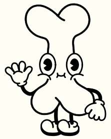
A message to those waiting for a transplant

Don’t stop believing; after great troubles and endless challenges, a better tomorrow always comes.

A message to health professionals

Thank you for being there, for everything you do, for pulling patients from the clutches of death, for caring, and for not letting patients break down. Thank you!

Jurgis



„Jūs tiesiog turite tikėti savimi“

Sunkus kombinuotas imunodeficitas (SCID) T ir B limfocitinių ląstelių trūkumas. Atlikta alogeninė kaulų čiulpų transplantacija.

Transplantacija atlikta 2022 m. sausį. Jokūbui buvo 4.5 metų. Jokūbą nuo 4 mėn. amžiaus puolė įvairios infekcijos, virusai, bakterijos ir uždegimai. Nuolat buvo gydomas dėl bronchito, plaučių uždegimo, įvairių odos ligų, sepsio, cistos operacija. Transplantacija pavyko itin sėkmingai. Prigijimas ląstelių buvo 100%. Būklės eiga buvo neįtikėtinai sėkminga ir po 1.5 mėn Jokūbas grįžo namo.

Žinutė laukiantiems transplantacijos

Nors laukia sunkus gydymo etapas, bet svarbu suvokti, kad tai medicinos ir medikų dovanojama galimybė gyventi. Jei jau pasiekta ta linija, kuomet lieka vienintelis ar paskutinis gydymo kelias transplantacija, vadinasi jau įveikta neįtikėtinai daug sunkumų, belieka įveikti ir šį.

Žinutė kitiems transplantuotiems bendraamžiams

Jūs visi esate labai ypatingi, nes nuo transplantacijos dienos švęsite du gimtadienius. Tai nepaprastai didelė dovana. O toliau belieka tikėti savimi, kad kūnas susidraugautų su ta dovana, kad nekiltų komplikacijų ir, kad kaip įmanoma greičiau galėtumėte grįžti į savo įprastą gyvenimo ritmą.

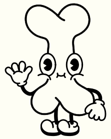
Žinutė tėvams/globėjams

Laukia tiek fiziškai, tiek emociškai sunkus periodas visai šeimai. Kylančios baimės ir nerimas būna kasdienis palydovas. Asmeniškai mums sunkiausias laikas buvo iki sužinojom diagnozę, nes sūnus sirgo daug, nuolat ir sunkiai. Kai sužinojom, kad jis turi SCID ir vienintelis gydymo būdas yra transplantacija buvo baisu, bet iš kitos pusės palengvėjo, nes mes pagaliau žinojom kuo jis iš tiesų serga ir kaip galima jam padėti. O tada belieka koncentruotis į tai, kaip išlikti ramiems, kad tai jausdamas vaikas nebijotų to gydymo, kuris laukia. Ir tikėti. Tikėti medicinos pažanga, gydytojų atsidavimu, savimi, kad išbūsi stiprus lydėti savo vaiką šiame kelyje, o labiausiai savo vaiku, kad padedamas mūsų visų jis įveiks savo ligą.

Žinutė sveikatos priežiūros specialistams

Didelė padėka visiems darbuotojams, su kuriais susipažinome sutikome ligoninėje per šiuos 5 gydymo metų. Visas personalas transplantacijos metu buvo ypač dėmesingas. Visi tai darė su dideliu atsidavimu ir rūpesčiu. Vėliau atsiradus komplikacijoms matėme, kaip nuoširdžiai visi stengiasi, kad sūnus greičiau pasveiktų. Tai be galo sunkus, daug žinių, nuolatinio mokymosi ir ne tik vietinio, bet ir tarptautinio bendradarbiavimo reikalaujantis darbas. Dėka to, šiandien transplantacijų rezultatai tokie puikus. Ačiū mokslui, medicinai ir profesionaliems gydytojams bei slaugytojams už dovanotą sūnui antrą gyvenimo šansą.

Jurgis



«You just have to believe in yourself»

Severe combined immunodeficiency (SCID) T and B lymphocyte deficiency. Allogeneic bone marrow transplantation.

The transplant took place in January 2022. James was 4.5 years old. From the age of 4 months, Jacob had been plagued by various infections, viruses, bacteria and inflammation. He was constantly treated for bronchitis, pneumonia, various skin diseases, sepsis and cyst surgery. The transplant was a great success. Cell engraftment was 100%. The course of the condition was incredibly successful, and after 1.5 months, James returned home.

A message to those waiting for a transplant

Although there is a difficult phase of treatment ahead, it is important to realise that this is a chance to live, granted by medicine and medical professionals. If the line has been crossed where transplantation is the only or the last treatment option, then an incredible number of difficulties have been overcome, and this is the last one you will need to endure.

A message to other transplanted peers:

You are all very special because you will have two birthdays from the day of your transplant. This is an incredibly big gift. And now you just have to believe in yourself, that your body will make friends with this gift, that there will be no complications and that you will be able to get back to your normal routine as soon as possible.

Message to parents/guardians

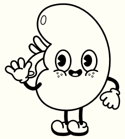
It's going to be a physically and emotionally difficult period for the whole family. Fears and anxiety are a daily companion. For us personally, the most difficult time was before we received the diagnosis, because our son was sick a lot, and had great difficulties. When we found out that he had SCID and the only treatment was a transplant, it was scary, but on the other hand it was a relief, because we finally knew what we were dealing with and how we could help him. And then we just had to concentrate on staying calm for our child's sake, so he was not afraid of the treatment that was coming. And believe. Believe in medical progress, in the dedication of the doctors, in yourself, that you will be strong enough to accompany your child on this journey. Believe most of all in your child, and that with everyone's help, he will overcome his illness.

Message to health professionals

A huge thank you to all the staff we have met at the hospital during the 5 years of treatment. All the staff were extremely attentive during the transplant. They all worked with great dedication and care. Even after the complications later on, we could see how sincerely everyone was trying to make my son's recovery faster. It is an extremely difficult job, requiring a lot of knowledge, constant learning, and not only local but also international cooperation. Thanks to this, transplants today are very successful. Thank you to science, medicine and professional doctors and nurses for giving my son a second chance at life.

Portugal

João



«Felizmente, o trasplante chegou e passámos a uma fase diferente»

Doença primária
Síndrome nefrótica, insuficiência renal
Idade aquando do trasplante
6 anos
Principais preocupações
Rejeição renal
Sucessos
Normalização da função renal

Mensagem para quem está à espera de um trasplante
É difícil ver a função renal do nosso filho diminuir diariamente, esperar e não poder fazer nada; mas de repente, quando surge a oportunidade, tudo muda de uma só vez. Tentámos todo o tipo de tratamentos até descobrirmos que só um trasplante de rim faria a diferença. Desde que ele tinha 1 ano de idade que andávamos a tentar vários tratamentos e nada parecia resultar até aos 6 anos. Com este novo rim, ele pôde deixar de fazer diálise e começar a viver uma vida normal.

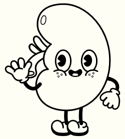
Mensagem para outros colegas transplantados
Desejamos-vos as maiores felicidades para o período de recuperação que se aproxima e temos de estar sempre atentos aos imunossupressores e agir em conformidade para nos mantermos seguros e reduzirmos os riscos.

Mensagem para os pais/cuidadores
Quando as coisas começaram a complicar-se e ele teve de começar a fazer diálise, era tudo novo para mim e pensei que não seria capaz de o fazer. Mas aprender sobre o processo e fazer a formação no hospital só foi possível graças ao apoio que recebi do centro de diálise. Durante cerca de duas semanas, aprendemos a lidar com a situação no futuro. Felizmente, o trasplante chegou e passámos a uma fase diferente, mas não posso esquecer todo o trabalho realizado e estou muito grato pela ajuda e atenção pessoal.

Mensagem para os profissionais de saúde
Estamos eternamente gratos pelo vosso esforço e apoio constantes durante este longo e stressante processo. No hospital, as pessoas trabalham diariamente para prestar os melhores cuidados de saúde possíveis. Os médicos trabalham em conjunto com enfermeiros, pessoal auxiliar e apoio logístico para cumprir a sua missão. Sentimos que tudo foi muito bem coordenado e facilitou o processo para o nosso filho.

Mensagem especial para os médicos que acompanharam o meu filho nos últimos 6 anos
Ficarei eternamente grato pelo vosso trabalho. Tenho 100% de certeza que todos fizeram tudo o que podiam durante este processo e, tendo isso em conta, não teria mudado nada. Por isso, agradeço-vos do fundo do coração.

João



«Luckily the transplant arrived and we moved to a different stage»

Primary disease
Nephrotic Syndrome, kidney failure
Age at transplant
6 years
Main concerns
Kidney rejection
Successes
Kidney function normalized

Message for the ones waiting for transplant
It's difficult to see your child's kidney function decrease daily, waiting and not being able to do anything about it; but suddenly, when the opportunity presents itself, everything changes all at once. We tried all kinds of treatments until we discovered that only a kidney transplant would make a difference. We had been trying various treatments since he was 1 year old, and nothing seemed to work until the age of 6. With this new kidney, he could stop dialysis and start living a normal life.

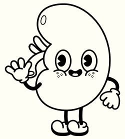
Message for other transplanted peers
We wish you all the best for the upcoming period of recovery, and we need to consistently be aware of immune suppressants and act accordingly to stay safe and reduce risk.

Message for parents/caregivers
When things start getting more complicated and he had to start dialysis, it was all new for me and I thought I wouldn't be able to do it. But learning about the process and doing the training at the hospital was only possible due to the support I received from the dialysis center. For about 2 weeks, we learned about how to deal with the situation in the future. Luckily the transplant arrived and we moved to a different stage, but I cannot forget all the work done and I have so much gratitude for the personal help and attention.

Message for health professionals
We are eternally grateful for your consistent efforts and support during this long and stressful process. At the hospital, people work on a daily basis to provide the best healthcare possible. Doctors work together with nurses, auxiliary personnel and logistics support to achieve their mission. We felt that everything was very well coordinated and made the process easier for our child.

Special message for the doctors that have been with my son for the last 6 years
I will be eternally grateful for your work. I am 100% sure that you all did everything that you could during this process, and having this in mind, I wouldn't have changed a single thing. So, thank you from the bottom of my heart.

Ana



«Coexistindo também momentos de muita revolta e frustração compreensíveis»

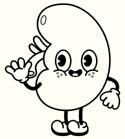
A minha filha Ana foi transplantada aos 14 anos de idade. Após todo um processo de exames, vários internamentos, cirurgias e tratamentos clínicos, eis que fomos finalmente abençoadas por um dador neste caso cadáver. O diagnóstico de Síndrome Nefrótico corticorresistente teve o seu episódio inaugural aos 4 anos de idade. A partir desse momento a nossa vida mudou completamente. Como mãe procurei manter-me informada sobre a doença e mantive o meu foco em ajudar a minha filha a manter uma vida praticamente normal, aliando sempre a minha fé e esperança nos resultados e na equipa médica e de enfermagem que tivemos o privilégio de encontrar nesta árdua caminhada. Nem sempre tudo correu bem, contudo com uma dieta equilibrada (alimentação sem sal), hábitos e rotinas saudáveis em conciliação com a medicação que segui sempre com rigor, a Ana durante 10 anos manteve-se estável, embora sempre acompanhada clinicamente em várias valências (nefrologia, pneumologia, cardiologia, pedopsiquiatria, endocrinologia, nutrição pediátrica).

A Ana aos 13 anos começou numa primeira fase por fazer diálise peritoneal, tivemos de aprender com rigor todos os procedimentos inerentes, de seguida teve de ser submetida a uma cirurgia e teve de suspender e passar a fazer hemodiálise, três vezes por semana, no hospital, durante quatro horas e, por último, voltou à diálise peritoneal com a ajuda de uma máquina (cicladora) que fazia as trocas noturnas, até ao dia em que foi transplantada, após alguns meses em lista de espera.

Sinto um tremendo orgulho na minha filha, pois apesar destes tratamentos, os cateteres dos quais era portadora, as cicatrizes que cobrem o seu corpo enfrentou tudo de forma resiliente, sem complexos, coexistindo também momentos de muita revolta e frustração compreensíveis. Apesar disto tudo frequentou sempre a escola com bastante sucesso escolar e cumpriu com os objetivos a que se propôs. O nosso lema sempre se pautou por manter sempre uma vida como qualquer outro adolescente da sua idade, aliando e gerindo sempre a doença nas nossas vidas o melhor possível.

Aos pais destas crianças não sei como expressar e só quem vive algo semelhante é capaz de sentir verdadeiramente o nosso estado de frustração, impotência, ansiedade e a constante procura por respostas, enquanto se aguarda pelo derradeiro e último passo que se trata do trasplante, aí encontramos força quando menos esperamos e temos de aceitar essa condição e viver um dia de cada vez, é difícil, mas não há outra maneira. São os nossos filhos, encarar e enfrentar os obstáculos, não há outra solução. Alcançamos finalmente o sucesso que tanto almejávamos em 29-07-2021. Sejam corajosos e vivam felizes!

Ana



«There were also moments of understandable anger and frustration»

My daughter, Ana, received a transplant at the age of 14. After a whole process of exams, several hospitalizations, surgeries and clinical treatments, behold, we were finally blessed by a donor; in this case, a cadaver.

The diagnosis of corticosteroid-resistant nephrotic syndrome had its inaugural episode at 4 years of age. From that moment, our life changed completely. As a mother, I tried to keep myself informed about the disease and kept my focus on helping my daughter to maintain a practically normal life, always combining my faith and hope in the results and in the medical and nursing team that we were privileged to meet during this arduous journey.

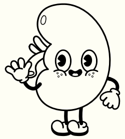
Not everything always went well; however, with a balanced diet (no salt), healthy habits and routines in combination with the prescribed medication that I always followed strictly, Ana remained stable for 10 years, although she was always clinically monitored in several aspects (nephrology, pulmonology, cardiology, child psychiatry, endocrinology and paediatric nutrition).

At the age of 13, Ana started initially by undergoing peritoneal dialysis. We had to rigorously learn all the inherent procedures, then she had to undergo surgery, stop peritoneal dialysis and start haemodialysis in the hospital 3 times a week, for 4 hours. Finally, she returned to peritoneal dialysis with the help of a machine (cycler) that performed the nightly changes, until the day she was trasplanted, after a few months on the waiting list.

I feel tremendous pride in my daughter, because throughout those treatments, the catheters she had and the scars that covered her body, she faced everything in a resilient way, without complexes. There were also moments of understandable anger and frustration. Despite all this, she always attended school, achieving great academic success and fulfilling the objectives she set for herself. Our goal has always been for her to maintain a life like any other teenager of her age, always integrating and managing the disease in our lives as well as possible.

It is difficult to express to the parents of children undergoing this procedure something that only those who experience something similar are able to truly feel: our state of frustration, impotence, anxiety and the constant search for answers, while waiting for the final step, which is the transplant. We found strength when we least expected it and learned to accept this condition and live life one day at a time. It's difficult, but there's no other way. They are our children, who are facing obstacles, and there is no other solution. We have finally achieved the success we had waited so long for on 29-07-2021. Be brave and live happily!

Manuel



«Sinto que o meu estilo de vida melhorou bastante desde que fui transplantado»

Eu sou o Manuel, tenho 18 anos e fui transplantado aos 5 anos!

Já não me recordo muito bem de como era a minha vida antes do trasplante, mas lembro-me que tinha diversos cuidados devido às infeções que podia apanhar no cateter e respetivo orifício. Recordo ainda que antes do trasplante tinha uma vida muito ocupada porque necessitava de ir muitas vezes ao hospital. Sinto que o meu estilo de vida melhorou bastante desde que fui transplantado.

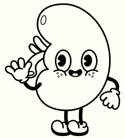
Tenho consciência de que os cuidados no dia-a-dia são fundamentais para eu manter a minha qualidade de vida e o meu rim saudável; bebo cerca de 2,5 L de água por dia, tomo a medicação de forma dedicada, diariamente, sem falhas e com o rigor horário que é exigido, ou seja, sempre à mesma hora.

A alimentação tem de ser rigorosa e não devo ingerir muita gordura ou muito açúcar. Em minha casa todos comemos comida sem sal, por isso a quantidade de sal que ingiro também acaba por ser reduzida. Relativamente ao álcool, nunca bebi nem nunca tive autorização médica para beber álcool antes dos 18 anos. Mesmo hoje, com 18 anos completados, continuo a não ingerir álcool.

Os cuidados com uma boa recuperação diária através do descanso noturno é também um hábito que tento manter no meu dia a dia. De momento, tem-se tornado mais difícil de manter longas noites de sono devido à faculdade.

Atualmente estou a estudar na Universidade, para me licenciar em Fisioterapia; a minha situação de transplantado renal tem-me causado algumas limitações, no enanto, são quase insignificantes. Apesar do trasplante já ter mais de 12 anos, continuo a ter consultas de rotina e por vezes acabo por faltar a algumas aulas importantes; no entanto, quando chego a casa tento rever a matéria que dei na aula, diminuindo assim o impacto das faltas; por isso, não existem ou quase não sinto limitações.

Manuel



"I feel that my lifestyle has improved a lot since the transplant"

I am Manuel, I am 18 years old and I underwent a kidney transplant when I was 5 years old!

I don't remember very well how my life was before the transplant, but I remember that I had several precautions due to the infections that I could catch in the catheter and respective orifice. I also remember that before transplantation I had a very busy life because I needed to go to the hospital so often. I feel that my lifestyle has improved a lot since the transplant.

I am aware that daily care is fundamental to maintain my quality of life and the health of my kidney; I drink about 2.5 L of water per day, I take my medication in a dedicated way, daily, without fail, and with the strict schedule that is required, that is, always at the same time.

The diet has to be strict and I shouldn't eat too much fat or sugar. In my house we all eat food without salt, so the amount of salt I ingest is also reduced. Regarding alcohol, I never drank and never had medical permission to drink alcohol before I was 18. Even today, at the age of 18, I still don't drink alcohol.

The care for a good daily recovery by resting at night is also a habit I try to maintain in my daily life. At the moment it has become more difficult to maintain long nights of sleep due to college.

I am currently studying for a degree in Physical Therapy at University; my kidney transplant situation has caused me some limitations, but they are almost insignificant. Although the transplant is now more than 12 years old, I still have routine appointments and sometimes I end up missing some important classes; however, when I get home I try to review what I have taught in class, thus decreasing the impact of the absences, so there are no or almost no limitations.

Mãe do Manuel

O Manuel nasceu com insuficiência renal, às 30 semanas, 2 minutos antes do seu irmão gémeo Dinis.

Hoje, o Manuel tem 18 anos, está a estudar para terminar a sua licenciatura em Fisioterapia, e vive com a sua família nuclear: os seus 3 irmãos, pai e mãe. Na minha opinião, pouco independente, claro, o Manuel é um jovem feliz, a trabalhar diariamente para o futuro que procura!

O Manuel esteve internado desde o nascimento até aos 4 meses, fez diálise peritoneal desde as 3 semanas de vida até aos 5 anos e 7 meses, quando foi submetido ao trasplante renal.

O trasplante marcou claramente duas fases na vida do Manuel, o antes e o depois; no entanto, a vida é sempre um continuo de mudanças e adaptações permanentes e constantes, e isso aconteceu também na vida do Manuel. Assim, muitas são as fases e etapas que podem ser contadas e descritas: a ida para o jardim escola ainda em Diálise, a entrada na escola 1º ano no imediato pós-trasplante, a passagem para o 5º ano e entrada numa grande escola com milhares de colegas, a adolescência e a evolução para o ensino secundário, e atualmente a maioridade e a entrada na universidade.

A grande diferença entre a vivência do Manuel e a vivência de qualquer outro jovem, como por exemplo os irmãos, tem sido a importância de personalizar e adaptar em cada fase, os detalhes e particularidades que a insuficiência renal/transplantado impõem. Esta adaptação foi sempre feita com base em dois pressupostos: - conhecimento detalhado e consciente das particularidades que a situação de insuficiência renal/transplantado exige, por parte do Manuel e de toda a família; exemplos disso são os cuidados com a alimentação, água, cuidados especiais de higiene, consciência da imunossupressão e suas implicações, cuidado e rigor com a toma da terapêutica, valor da relação honesta e respeitosa com a equipa de profissionais da saúde (equipa clínica) que acompanha o Manuel ainda hoje;

- todos os seres humanos têm especificidades próprias relativas ao seu equilíbrio físico e saúde; uns têm mais limitações, outros menos, umas com mais impacto no dia-a-dia outras com menos impacto; uns atualmente, outros no passado, ou eventualmente no futuro; ter uma situação diferente, não tem que ser assim "tão diferente"!

Com estes pressuposto em mente, a família foi criando adaptações, em perfeita sintonia com a equipa clínica que acompanhou o Manuel desde o nascimento, aprendendo, evoluindo, questionando, procurando alternativas e fazendo o melhor possível no contexto, sempre num espírito positivo e colaborativo, buscando o melhor para o Manuel, atendendo ao equilíbrio entre saúde e bem-estar, presente e futuro.

Sou a mãe do Manuel, feliz e muito grata!

Mother of Manuel

Manuel was born 2 minutes before his twin brother, Dinis, and had kidney failure at 30 weeks.

Today, Manuel is 18 years old, is studying to finish his degree in Physiotherapy, and lives with his nuclear family: his 3 brothers, father and mother. In my opinion, he is not very independent; however, Manuel is a happy young man, working daily for the future he is aiming for!

Manuel was hospitalized from birth to 4 months, and he underwent peritoneal dialysis from 3 weeks of age to 5 years and 7 months, when he underwent a kidney transplant.

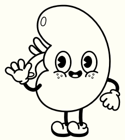
The transplant clearly marked 2 phases in Manuel's life, before and after; however, life is always a continuum of perpetual changes and adaptations, and this also happened in Manuel's life. Many phases and events stand out in memory: going into the school's garden while still undergoing dialysis; entering the first year of school immediately after the transplant; moving up to the fifth year of school and entering a large building with thousands of peers; adolescence and progress to secondary education; and currently adulthood and university entrance.

The big difference between Manuel's experience and the experience of any other young person, such as his brothers, has been the importance of personalizing and adapting, at each stage, to the details and particularities that renal failure/transplantation impose. This adaptation has always been made based on 2 assumptions: – Detailed and conscious knowledge of the particularities that the situation of renal failure/transplant requires, from Manuel and the whole family. Examples of this are care with food and water; special hygiene care; awareness of immunosuppression and its implications; care and rigor with taking the therapy; and the value of an honest and respectful relationship with the team of health professionals (clinical team) that accompanies Manuel even today; – All human beings have their own specificities regarding their physical balance and health. Some have more limitations, others fewer; some with more impact on the day-to-day, others with less impact; some currently, others in the past, or possibly in the future. Having a different situation doesn't necessarily mean you have to be "so different"!

With these assumptions in mind, the family adapted, in perfect harmony with the clinical team that followed Manuel from birth. We are continually learning, evolving, questioning, looking for alternatives, and doing the best possible in the context, always in a positive and collaborative spirit, seeking the best for Manuel, attending to the balance between health and well-being, for the present and future.

I'm Manuel's mother, happy and very grateful!

Maria



«Acreditamos que lhe foi dada a dádiva da vida, uma segunda oportunidade»

Uma malformação renal foi diagnosticada à nascença à nossa filha. Quando ela começou a ter problemas com a função renal, foi muito assustador. Sempre nos tinham dito que, devido aos seus outros problemas de saúde, ela não poderia receber um trasplante nem sequer ser elegível para fazer hemodiálise. Isto foi muito difícil, porque parecia que tínhamos uma parede à nossa frente e não sabíamos para onde nos virar.

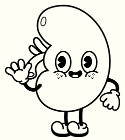
Aos 5 anos, foi encaminhada para o Hospital, onde nos foi apresentada uma nova e fantástica equipa de médicos. Depois de falar com eles, foi como se se tivessem aberto novas portas. Sempre quisemos que a nossa filha pudesse receber um trasplante e quando nos disseram que isso era uma possibilidade e que, a dada altura, ela ia ser adicionada à lista de espera de trasplante, foi um grande alívio, mas também nos deixou muito nervosos porque não sabíamos bem o que esperar. A equipa de nefrologia conseguiu manter a função renal da Maria estável, sem terapia de substituição renal, durante quase 6 anos.

Quando nos disseram que a sua função renal tinha diminuído ao ponto de ser necessário inserir um cateter para a preparar para a diálise peritoneal, pensámos que estávamos a dar um enorme passo atrás. Perguntámos se podíamos fazer o teste para sermos dadores, mas disseram-nos que não era a melhor opção. Após discussões com as equipas médicas, alguns dos nossos receios foram dissipados, embora continuássemos muito nervosos.

No dia 19 de Junho de 2021, recebemos um telefonema do hospital a dizer que tinham um rim e que tínhamos de nos dirigir imediatamente ao hospital para iniciar os últimos testes de compatibilidade para o procedimento. Ficámos em choque! Apesar de sabermos que era o que sempre quisemos e que era o melhor para uma melhor qualidade de vida, estávamos aterrorizados. Todos os testes correram bem e, no dia seguinte, 20 de Junho, foi o dia do trasplante. Em Portugal, este é o “Dia Nacional da Doação e Transplantação de Órgãos”, pelo que não podia ter sido um dia melhor para o procedimento.

A mãe da Maria esteve com ela durante todo o processo. Foi-lhe permitido estar com ela na sala de operações até ser sedada. Antes de a Maria ser operada, a enfermeira-chefe e o anestesista explicaram tudo o que ia acontecer, para que pudéssemos estar um pouco mais descontraídos enquanto esperávamos. A operação parecia estar a demorar uma eternidade. Quando finalmente nos foi permitido vê-la na sala de recobro, os nossos receios começaram a diminuir. Depois disso, ela ficou alguns dias na unidade de cuidados intensivos. A Maria adora música, por isso, enquanto esteve nos cuidados intensivos, o seu iPad nunca parou de tocar; era a única coisa que lhe dava algum conforto, permitindo-lhe até dormir.

Maria



“We do believe that she was given the gift of life”

Our daughter was diagnosed with kidney malformation at birth. When she started to have issues with her kidney function, it was very scary. We had always been told that, due to her other health issues, she would not be able to receive a transplant or even be eligible to undergo haemodialysis. This was very hard, because it looked as though we had run into another wall and we didn’t know where to turn.

At age 5, she was referred to the Hospital, where we were introduced to an amazing new team of doctors. After talking with them, it was as though new doors had opened. We always wanted our daughter to be able to receive a transplant, and when we were told that this was a possibility and at some point and that she was going to be added to the transplant list it was a great relief, but it also made us very nervous because we didn’t really know what to expect. The nephrology team managed to keep Maria’s kidney function stable, without renal replacement therapy, for almost 6 years more.

When we were told that her kidney function had declined to the point where she would need to have the catheter inserted to ready her for peritoneal dialysis, we thought that we were taking a huge step backwards. We asked if we could be tested to be her donors, but were told that was not the best option. After discussions with her teams of doctors, some of our fears were allayed, although we were still very nervous.

On 19th June 2021, we received a call from the hospital saying that they had a kidney and that we needed to go to hospital straightaway to begin the final compatibility tests for the procedure. We were in shock! Although we knew that this was what we had always wanted and it was the best thing for a better quality of life, we were still terrified. All the tests were fine, so the next day, 20th June, was transplant day. In Portugal, this is the “National Organ Donation and Transplantation Day”, so it couldn’t have been a better day for the procedure.

Maria’s mom was with her for the entire process. She was allowed to be with her in the operating theatre until she was sedated. Before Maria went into surgery, the head nurse and the anaesthesiologist explained everything that it was going to happen so we could be a little more relaxed while waiting. The operation seemed to take forever. When we were finally allowed to see her in the recovery room, our fears started to lessen. After that, she stayed a few days in the intensive care unit. Maria loves music, so while she was in intensive care her iPad never stopped playing; it was the only thing that would give her some comfort, even allowing her to sleep. Maria’s recovery was amazing. That little girl is a fighter, and she teaches us so much every day.

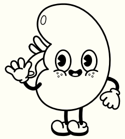
Since the surgery, there have been some challenges, and things have not always been easy. However, I am sure it was the best thing for our daughter, the quality of her life is so much better.

A recuperação da Maria foi espantosa. Esta menina é uma lutadora e ensina-nos muito todos os dias. Desde a cirurgia, têm surgido alguns desafios e as coisas nem sempre têm sido fáceis. No entanto, tenho a certeza de que foi a melhor coisa para a nossa filha, a qualidade da sua vida é muito melhor. Ela já viajou por todo o mundo e o seu novo rim tornou muito mais fácil continuar a fazer o que nós, como família, gostávamos de fazer. Tudo isto foi muito assustador, não vou mentir, e para tornar as coisas ainda mais angustiantes, tudo isto aconteceu no meio de uma pandemia. Acreditamos que lhe foi dada a dádiva da vida, uma segunda oportunidade, e por isso estamos gratos. Estamos gratos a todos os que acreditaram e a todos os que ajudaram a que isso acontecesse.

She has travelled all over the world, and her new kidney has made it so much easier to keep on doing what we as a family have loved to do. All of this was very scary, I’m not going to lie, and to make it even more nerve-wracking, all this happened in the middle of a pandemic. We do believe that she was given the gift of life, a second chance, and for that we are grateful. We are grateful for everyone who believed and for everyone who helped make it happen.

España / Spain

Sergio



«La vida no consiste en esperar a que pase la tormenta, sino en aprender a bailar bajo la lluvia»

Edad
9 años
Enfermedad base
Síndrome de Denys Drash
Años (al momento del trasplante)
1º trasplante 3 años, 2º trasplante 6 años y 10 meses

Principales problemas
Infecciones varias y rechazo del órgano.

Logros
Tener una vida feliz con pocos ingresos hospitalarios.

Mensaje para los que esperan un órgano
El periodo de espera puede generar muchos interrogantes ¿cómo será el momento en el que recibiremos la llamada?, ¿será pronto?, ¿cómo será el postoperatorio? Es inevitable atravesar este «*mar de emociones*». Las ganas de que llegue esta posibilidad de una vida más plena, y también la incertidumbre de cómo irá todo. Esperamos que la esperanza los acompañe en la espera del proceso. El cambio es realmente increíble, finalizan muchas limitaciones, y hay verdaderas posibilidades de compartir con nuestra familia y seres queridos muchas aventuras.

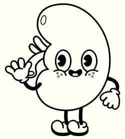
Mensaje para otros trasplantados
¡Esperamos que vuestro trasplante vaya muy bien!, que se reduzcan las visitas y controles al hospital y que puedan disfrutar de todas las oportunidades que se les presenten.

Hay que tener en cuenta unos cuidados especiales, medidas de higiene y prevención, la constancia con la toma de las medicaciones, y también procurar llevar una vida sana. Resaltamos la importancia de agradecer el gran acto de amor que ha realizado nuestro donante y su familia, y la responsabilidad por nuestra parte de honrar este acto.

Mensaje para los padres y madres
¡Lo primero que queremos trasmitirles es: no estáis solos! Hemos compartido los mismos sentimientos y temores con respecto a los trasplantes y a cómo afrontarán nuestros hij@s su futuro.

El trasplante y la donación de órganos nos ha hecho cambiar nuestra percepción de la vida, nos hizo entender y valorar cada momento como único, y estamos felices de poder disfrutar una vida familiar completa. El trasplante no solo abrió la posibilidad de que nuestro hijo disfrutase de su infancia, sino que también lo pudiéramos hacer todos nosotros. A veces se siguen transitando momentos difíciles o nuevos retos, pero no son comparables con las dificultades que surgen antes del trasplante (por ejemplo con la diálisis). Por último, os dejamos una bonita frase que una vez leímos: *«La vida no consiste en esperar a que pase la tormenta, sino en aprender a bailar bajo la lluvia».*

Sergio



“Life isn’t about waiting for the storm to pass. It’s about learning how to dance in the rain”

Age
9 years old
Primary disease
Denys-Drash Syndrome (Congenital Nephrotic Syndrome). Kidney transplant
Age at transplant
1st transplant 3 years old, 2nd transplant 6 years old and 10 months

Main concerns
Infections, organ rejection.

Successes
Living a happy life, with limited hospital stays.

Message for the ones waiting for transplant
The waiting list period can trigger many questions and doubts how would it be when we receive the call? Would it be soon? What about the post-surgery period? It’s inevitableto go through this “sea of emotions”; the desire to possibly live a full life, but also the uncertainty of the outcome. We wish for hope to accompany you throughout the process. The change is truly unbelievable; many limitations are overcome, and there is the chance of sharing a complete life with your loved one.

Message for other transplanted peers
We hope your transplant goes very well, that your hospital stays and follow-ups are reduced, and you can enjoy all the opportunities that come with it. You’ll need to take special careof hygiene and prevention, realise the importance of promptly taking the medicines prescribed according to the medical indications, and practice healthy habits.

We highlight the importance of appreciating the great act of love that has been shown by our donor and family, and the responsibility on our part to honour this action.

Message for parents/caregivers
First, we’d like to say, “You are not alone!!” We share the same feelings, emotions, and fears regarding transplantation, and our concern about how our kids will face their future.
The transplant and organ donation has made us change our perception of life it has made us understand and value every moment as unique, and we are happy that we can now enjoy a complete family life.

The transplant opened not only the possibility for our son to enjoy his childhood, but for the other family members to be part of it as well. There will still be difficult moments and new challenges, but they are not comparable to the complications before transplant. And here’s a wonderful quote we once read: “Life isn’t about waiting for the storm to pass. It’s about learninghow to dance in the rain.”

Message for the health professionals
Our eternal gratitude to the extraordinary professionals which not only looked after the health and well-being of our son, but also our whole family.

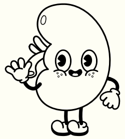
Mensaje para profesionales sanitarios

Nuestra inmensa gratitud a los grandes profesionales que no solo velan por la salud y el bienestar de nuestro hijo, sino el de toda la familia.

Tenemos mucha suerte de poder contar con ellos con toda su dedicación y vocación de excelencia, tratando de hacer siempre lo mejor posible para cuidar a nuestro hijo, entendiendo no solo los aspectos clínicos, sino también el impacto emocional que representa para un niño y su familia atravesando una grave enfermedad crónica. Estos grandes seres humanos se vuelven realmente parte de nuestra familia, y les estaremos eternamente agradecidos.

We are very lucky to be able to count on them. They are fully dedicated and aim for excellence, trying always to do the best they can to take care of our son, understanding not only the clinical issues, but also the emotional impact on a child and family dealing with a serious chronic disease. These great human beings have really become part of our family, for whom we'll be eternally grateful.

Marta



«Cuídate para poder cuidar»

Edad
7 años y 3 meses

Edad en el momento del trasplante
18 meses

Principales preocupaciones
Rechazo renal, pérdida de función renal con el tiempo e infecciones derivadas de la inmunosupresión.

Éxitos
Gracias al trasplante puede llevar una vida normal acorde a su edad.

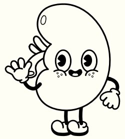
Mensajes para pacientes a la espera de trasplante
Cuídate mucho, debes tratar de cuidar la función renal residual durante este tiempo para que tu calidad de vida sea la mejor posible. La etapa de diálisis y de espera es dura, pero con el trasplante tu vida dará un giro de 180 grados.

Mensaje para otros trasplantados
Disfruta tu nueva vida y cuida ese regalo, tomando tus inmunosupresores, bebiendo mucha agua y cuidando tu alimentación.

Mensaje para padres y cuidadores
Cuídate para poder cuidar.

Mensaje para profesionales sanitarios
Gracias a médicos, enfermeras y auxiliares. Tanto por el cuidado técnico como emocional. Nuestra pequeña perdió sus riñones tras una complicación en una cirugía. Después de 9 duros meses de diálisis en los que su vida dependía de una máquina 12 horas al día llegó la esperada llamada. Sus primeros dos años post trasplante fueron muy complicados debido a infecciones que requirieron muchos meses de hospitalización, pero afortunadamente hoy en día dichas infecciones no suelen requerir hospitalización y su vida es plena y feliz. Por este motivo nos gustaría dar un mensaje de agradecimiento a todos los donantes especialmente a los padres que en un momento tan delicado deciden dar una nueva oportunidad a otros niños.

Marta



“Taking care of yourself is important in order to be able to take care of others”

Age
7 years old

Age at transplant
18 months

Main concerns
Transplant rejection, loss of kidney function and bacterial infection due to immunosuppressive state.

Successes
Normal life carried on according to her age.

Message for the patients waiting for transplant
Take a great care of yourself. You’ll need to preserve your remaining kidney function during this waiting time in order to improve your wellbeing in the near future. Dialysis and the waiting is tough, but after the transplant, your life is going to have a 180-degree transformation.

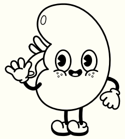
Messages for other transplanted peers
Enjoy your life, keep that gift in good condition by taking your immunosuppressants, drinking water frequently and eating healthy food.

Message for parents and caregivers
Taking care of yourself is important in order to be able to take care of others.

Message for the health professionals
To the doctors, nurses and all the staff involved, thank you all, from a professional as well as an emotional point of view.

Other additional topics
Our little daughter lost both kidneys due to complications after another surgery. After a long and hard 9 months of dialysis, during which her life relied on a machine 12 hours a day, one day the long-awaited phone call arrived. The 2 years after the procedure were complicated, with a lot of bacterial infections. We spent many nights at the hospital. Fortunately, hospitalizations for bacterial infections don’t happen any more, and she has a happy and full life. We would like to express our gratitude to all the organ donors, especially to all the parents who have decided, during the saddest time of their lives, to help other children in need.

Sara



«Te devuelve las ganas de vivir»

Me llamo Sara y tengo 16 años. Me diagnosticaron el síndrome de Denys-Drash cuando tenía 5 años. Esta enfermedad provoca un tumor en el riñón y una enfermedad renal. Al principio recibí tratamiento para el tumor (cirugía, quimioterapia y radioterapia), pero después desarrollé una enfermedad renal terminal que me llevó a un trasplante de riñón de donante fallecido cuando tenía 10 años.

En los primeros meses después del trasplante, me preocupaba mucho tomar toda la medicación y cuidarme para cuidar lo mejor posible mi nuevo riñón.

Tener un trasplante de riñón tiene muchas ventajas, te cambia la vida por completo, te permite crecer mejor, comer más, sentirte mejor y hacer todo lo que quieras; y, por supuesto, no necesitas diálisis ni tantos medicamentos. Después del trasplante, empecé a hacer todas las cosas que echaba de menos: salir sin estar cansada, hacer deporte, seguir estudiando… En resumen, te devuelve las ganas de vivir.

Mensajes para pacientes a la espera de trasplante

Si estás en lista de espera para un trasplante, te envío mi apoyo y mi ánimo. Sé que te enfrentas a un momento difícil, pero debes ser paciente y optimista. Estoy segura de que tendrás suerte y de que te recuperarás pronto. Puede parecer que estás entrando en un túnel oscuro, pero debes confiar en que muy pronto verás la luz al final del mismo.

Mensaje para otros trasplantados

Si tienes la suerte de que el trasplante sea un éxito, debes cuidarte al máximo para que el nuevo riñón que llevas dentro dure mucho tiempo. Debes ser siempre optimista, tomar tu medicación y seguir las recomendaciones que te dé tu médico. Cuanto más te cuides, más te durará el riñón trasplantado, porque estoy segura de que no te gustaría volver a pasar por el mismo proceso. Pero si, por desgracia, tuvieras que someterte a otro trasplante, intenta no preocuparte; sé valiente y hazlo. Nos puede pasar a cualquiera.

Mensaje para padres y cuidadores

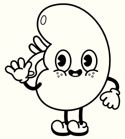
Nuestros familiares, que siempre nos hacen compañía, son un pilar muy importante durante nuestra enfermedad. Sólo quiero darles las gracias por cuidarnos y por el sufrimiento que sienten cuando estamos enfermos. Nunca se rinden y siempre están ahí para darnos todo lo que necesitamos con una sonrisa, lo que hace que el camino sea más tolerable.

Mensaje para profesionales sanitarios

Por último, quiero agradecer a todos los profesionales sanitarios el gran trabajo que realizan a los cirujanos que nos operan, a las enfermeras que nos cuidan y a los nefrólogos pediátricos que nos acompañan durante todo el proceso. Quiero darles las gracias porque quieren lo mejor para nosotros y siempre intentan animarnos. Recuerda que sin ellos ahora no nos sentiríamos tan bien.

Espero que mi testimonio sirva para que otros niños y niñas que vayan a pasar por un trasplante no tengan miedo y se sientan confiados y valientes para afrontar el proceso del trasplante.

Sara



“It brings back your will to live”

My name is Sara, and I am 16 years old. I was diagnosed with Denys-Drash syndrome when I was 5 years old. This disease causes a kidney tumour and kidney disease. Initially, I received treatment for the tumour (surgery, chemotherapy and radiotherapy), but later I developed end-stage kidney disease that led to a deceased-donor kidney transplantation when I was 10.

In the first months after the transplantation, I felt very worried about taking all my medication and looking after myself, in order to best care for my new kidney.

There are many advantages to having a kidney transplant it changes your life completely, allowing you to grow better, eat more, feeling better and do everything you want; and of course, you don’t need dialysis or so many medications. After the transplant, I started to do all the things I had missed going out without being tired, practicing sports, continuing my studies — to sum up, it brings back your will to live.

Message for the patients waiting for transplant

If you are on the transplantation waiting list, I send you my support and encouragement. I know you are facing a difficult time, but you must be patient and optimistic. I am sure that you will be lucky and that you will recover soon. It may seem like you’re entering a dark tunnel, but you should trust that very soon you will see the light at the end of it.

Messages for other transplanted peers

If you are lucky to have a successful transplantation, you should look after yourself as much as possible so that the new kidney you have inside will last for a very long time. You must be always optimistic, take your medication and follow the recommendations given by your doctor. The more you look after yourself, the more your transplanted kidney will last, because I am sure that you wouldn’t like to go through the same process again. But if, unfortunately, you would have to undergo another transplantation, try not to worry; be courageous and have it done. It could happen to any of us.

Message for parents and caregivers

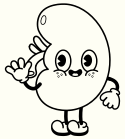
Our family members, who always keep us company, are a very important pillar during our disease. I just want to thank them for the care they provide us and the suffering they feel when we are sick. They never give up and are always are there to provide everything we need with a smile, which makes the journey more tolerable.

Message for the health professionals

Finally, I want to thank all the health professionals for the great work they do the surgeons who operate on you, the nurses who look after you and the paediatric nephrologists who accompany you throughout the process. I would like to thank them because they want the best for us and they always try to cheer us up. Remember that without them we wouldn’t feel so good now.

I hope my testimony will be useful for other boys and girls who are going through a transplantation so that they will not be afraid but feel confident and courageous to face the process of transplantation.

Juan



«El momento de su trasplante llegará, todo irá mejor»

Me llamo Juan y tengo 16 años. Recibí un trasplante de riñón de donante fallecido cuando tenía 12 años en el hospital.

Al principio, tuve unas pequeñas complicaciones con unas venas rotas y tuve que volver al quirófano, donde se solucionó el problema satisfactoriamente.

Éxitos

Antes de entrar en quirófano, estaba preocupado y temía que algo pudiera salir mal, pero los médicos me ayudaron a tranquilizarme.

Mensajes para pacientes a la espera de trasplante

Las ventajas de tener un trasplante son tener una vida mucho mejor, no estar conectado a una máquina de diálisis para tener algo de calidad de vida y disfrutar de todo en cada momento, como salir a pasear, comer de todo (pero con cuidado), practicar deporte y tener una vida tranquila acompañado de mi familia.

Mensaje para otros trasplantados

Mi consejo a los niños que están en lista de espera es que tengan paciencia y fe. El momento de su trasplante llegará, todo irá mejor y podrán disfrutar de una nueva vida. Y a los niños trasplantados, les aconsejo que disfruten todo lo que puedan de esta maravillosa vida, pero que no olviden cuidarse y tomar puntualmente su medicación todos los días.

Mensaje para padres y cuidadores

Mi mensaje para los padres y cuidadores es que disfrutéis de la maravillosa vida que Dios os ha dado, bendiciendo a vuestros hijos por recibir un trasplante, y que os relajéis después del estrés que habéis sentido mientras atravesábamos nuestra enfermedad.

Quiero agradecer especialmente a mi familia el apoyo que me ha dado cuando lo he necesitado, porque sin ellos no lo habría conseguido.

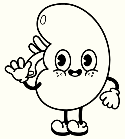
Mensaje para profesionales sanitarios

También gracias de corazón a los profesionales sanitarios por el cuidado que tuvieron conmigo tanto durante la operación como en la planta del hospital, porque estos cuidados me ayudaron a recuperarme antes de lo que pensaba. Quiero agradecer especialmente al equipo de nefrología pediátrica del hospital y a mi doctor, que fue como un ángel para mí durante el ingreso para el trasplante.

Mis padres también agradecen a todos por los cuidados que recibimos el día de la cirugía del trasplante (7 de diciembre de 2018) y el apoyo que nos dieron ese día los médicos, enfermeras y auxiliares.

Gracias de nuevo de todo corazón y deseo que Dios os bendiga a todos. Con mucho cariño.

Juan



“Your transplant moment will arrive, everything will be better”

My name is Juan, and I am 16 years old. I received a deceased-donor kidney transplant when I was 12 years old at the hospital.

Initially, I had some minor complications involving some broken veins, and I had to go back to the operating theatre, where the problem was fixed satisfactorily.

Successes

Before entering the surgery, I was worried and afraid that something might go wrong, but the doctors helped me to calm down.

Message for the patients waiting for transplant

The advantages of having a transplant are having a much better life, not being connected to a dialysis machine so as to have some quality of life and enjoying everything in every moment, like going for a walk, eating everything (but with care), practising sports and having a quiet life accompanied by my family.

Messages for other transplanted peers

My advice to the children on the waiting list is to be patient and have faith. Your transplant moment will arrive, everything will be better and you will be able to enjoy a new life. And to the transplanted children, I advise you to enjoy as much as you can of this wonderful life, but don’t forget to look after yourself and take your medication punctually every day.

Message for parents and caregivers

My message for parents and caregivers is to enjoy the wonderful life that God has given you, blessing your children who have received a transplant, and to relax after the stress you have felt while we were going through our disease.

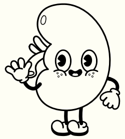
Message for the health professionals

I want to especially thank my family for the support they gave me when I needed it, because without them I wouldn’t have made it. Also thanks from the bottom of my heart to the health professionals for the care they took of me both during the surgery and on the hospital floor, because this care helped me to recover sooner than I thought. I want to give a special thanks to the paediatric nephrology team from the hospital and to my doctor, who was like an angel for me during the transplant admission.

My parents also thank everyone for all the care that we received the day of the transplant surgery (7th December 2018) and the support that the doctors, nurses and nursing assistants gave us that day.

Thank you again with all my heart, and I wish for God to bless all of you. Lots of love.

Laura



«El miedo a que mi vida cambiara después del trasplante se ha convertido en gratitud»

Me llamo Laura, tengo 17 años y recibí un trasplante de riñón el 12 de abril de 2022.

Todo empezó en 2019. Cuando tenía 14 años me diagnosticaron una glomerulonefritis rápidamente progresiva, probablemente desarrollada tras una infección vírica. La glomerulonefritis causó una rápida disminución de mi función renal; después de un año, era de aproximadamente el 20%. Durante los tres años siguientes, estuve en prediálisis; en ese periodo de tiempo, mi función renal siguió disminuyendo, por lo que supe que me encaminaba directamente a un trasplante de riñón.

A pesar de mi estado de salud, seguí con mi vida normal en la medida de lo posible practicando deporte, estudiando, saliendo con mis amigos. Intenté asumir mi futuro trasplante como un paso normal que tenía que llegar, aunque intentaba no pensar demasiado en ello.

Mantenía mi filosofía de disfrutar todo lo posible antes del trasplante hasta que me dijeron que tenía que empezar con la hemodiálisis. Durante ese periodo en diálisis me incluyeron en la lista de espera para el trasplante. Empecé a ser consciente de que se acercaba el momento del trasplante, y tengo que admitir que tenía miedo. Tenía miedo de la operación, pero sobre todo me preocupaba la posibilidad de que mi vida después del trasplante no fuera la misma.

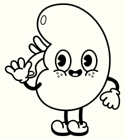
Estuve en hemodiálisis durante 3 semanas, y durante ese tiempo este miedo estuvo oculto; pero salió a la luz el lunes 11 de abril. Ese día, después de mi sesión de diálisis, recibimos una llamada del hospital, informándonos de un posible donante. Nada más llegar a casa llamé a mis amigos para darles la noticia, preocupada pero también ilusionada, y confiada en que iba a ser mi oportunidad para una nueva vida. Viajamos durante la noche desde mi ciudad, Almería, hasta Sevilla, y el miedo pudo conmigo durante ese trayecto. Cuando llegamos al hospital, el médico me confirmó que el trasplante estaba confirmado y, sorprendentemente, el miedo desapareció. Seguía nerviosa, pero sentía que todo iba a salir bien, y finalmente así fue.

Mi primer sentimiento tras el trasplante fue de gratitud hacia esa persona generosa que donó sus órganos para dar vida a personas como yo. Mi estancia en el hospital fue de 10 días, y no tuve ninguna complicación durante este tiempo en el hospital. Intenté hacer todo lo posible para volver a casa lo antes posible, y lo conseguí.

Por último, el miedo a que mi vida cambiara después del trasplante se ha convertido en gratitud por ese cambio. Gracias al trasplante, he aprendido a quererme y a valorar las pequeñas cosas de la vida que normalmente no apreciamos. El trasplante me ha ayudado a conocerme mejor.

Se podría decir que he empezado a leer el primer capítulo de mi nueva vida, y por ahora me está encantando.

Laura



"The fear about my life changing after the transplant has become gratitude"

My name is Laura, I am 17 years old and received a kidney transplant on 12th April 2022.

Everything started in 2019. When I was 14, I was diagnosed with rapidly progressive glomerulonephritis, probably developed after a viral infection. The glomerulonephritis caused a rapid decline in my renal function; after a year, it was about 20%. For the following 3 years, I was a pre-dialysis patient; in that period of time, my renal function kept decreasing, so I knew that I was heading straight for a kidney transplantation.

Despite my health situation, I went on with my normal life as much as possible practicing sports, studying, going out with my friends. I tried to assume my future transplant was a normal step that had to come, although I tried not to think too much about it.

I maintained my philosophy of enjoying as much as possible before the transplantation until I was told that I had to start on haemodialysis. During that period on dialysis I was put on the transplant waiting list. I began to be aware that the moment of the transplantation was nearing, and I have to admit that I was afraid. I was afraid of the transplant surgery, but mainly I was worried about the possibility that my life after the transplant would not be the same.

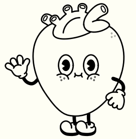
I was on haemodialysis for 3 weeks, and during that time this fear was hidden; but it came out on Monday, 11th April. That day, after my dialysis session, we received a call from the hospital, informing us of a possible donor. As soon as I arrived home I called my friends to give them the news, worried but also excited, and confident that it was going to be my opportunity for a new life. We travelled overnight from my city, Almeria, to Sevilla, and fear got the better of me during that trip. When we arrived to hospital, the doctor confirmed that the transplant was confirmed, and surprisingly, the fear disappeared. I still was nervous, but I felt that everything was going to be ok, and ultimately, it was.

My first feeling after the transplantation was gratitude to that generous person who donated his organs for giving life to people like me. My stay in the hospital was 10 days, and I had no complications during the my time in hospital. I tried to do my best to return home as soon as possible, and I achieved it.

Finally, the fear about my life changing after the transplant has become gratitude for that change. Thanks to the transplant, I have learnt to love myself and to value the small things in life that normally we do not appreciate. The transplant has helped me get to know myself better.

One could say that I have started reading the first chapter of my new life, and for now I am loving it.

Julen



«Sí, estoy enfadado con el mundo»

Me llamo Julen, tengo 12 años. A los 6 recibí un trasplante de corazón en el hospital.

Al principio no asimilaba completamente lo que pasaba, tampoco me fiaba de los médicos. Mis principales preocupaciones eran saber qué me iban a hacer y si todo saldría bien. Aquella mañana me quedé solo, me llevaron al quirófano, un sitio frío, lleno de aparatos extraños que nunca había visto.

Otro momento difícil fue la UCI (Unidad de Cuidados Intensivos). Estaba solo con las enfermeras, mis padres solo podían estar una hora por la mañana y otra por la tarde; cuando se iban me quedaba llorando, no entendía nada. Recuerdo que mis padres me preguntaban: «¿te pasa algo?». Yo, con esa edad, no pensaba nada bueno y les decía: «Sí, estoy enfadado con el mundo».

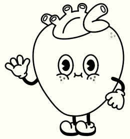
Bueno, dejo los malos recuerdos, los positivos son muchos y más interesantes.

Tras la UCI, ingresé en la habitación 715. Empecé a darme cuenta que había cosas que estaban cambiando: andaba sin cansarme; comía con normalidad y los alimentos tenían sabor y olor; recibía mensajes de mi familia y de mis amigos de clase; estudiaba con mi padre en la habitación y hacía mis deberes en el colegio de la sexta planta del hospital; médicos y personal eran amables, siempre preocupados por ayudarme en lo que necesitase. Cuando pude salir de la habitación descubrí un triciclo que me quitaban en la hora de la comida, ¡estaba tan emocionado…! Nunca había tenido esa experiencia. Pedaleando es cuando de verdad comprendí que todo era mejor.

Antes del trasplante estás limitado, el miedo y la preocupación te rodean; después, llevas una vida normal, eres un niño como los otros. Ahora no estoy siempre cansado, practico deportes, hago excursiones con mi familia, salgo con mis amigos y hasta voy a ir de viaje de fin de curso, como cualquier persona de mi edad. Sé que tengo que ver a mis médicos de vez en cuando y no olvidarme nunca de tomar mis medicamentos.

Mis médicos son estupendos, recuerdo a mi cirujano, siempre con una sonrisa para mí, incluso al quitarme los apósitos de un tirón; especialmente a mi doctor, a quien quiero mucho, cercano, siempre está ahí para lo que necesito, incluso consiguió que a través de la Fundación Make a Wish fuera a ver a mi equipo de fútbol, el Atlético de Madrid; al equipo de enfermería y su PlayStation con la que juego cada día; a todos… Sin dejar de olvidar a todos los profesionales que hacen que, cuando estamos en el hospital, estemos como en casa. Junto a mi familia, estaré siempre agradecido a todo el personal de los hospitales, por su estudio, trabajo y profesionalidad; también, por supuesto, a la familia de mi donante, que, en uno de sus peores momentos, tomaron la decisión de salvar varias vidas, entre ellas la mía.

Julen



"Yes, I'm angry at the world"

My name is Julen, I am 12 years old. At 6, I received a heart transplant.

At the beginning, I didn't fully assimilate what was happening, nor did I trust doctors. My main concerns were to understand what they were going to do to me and whether everything would go well. The morning of the transplant, I was left alone; they took me to the operating room, a cold place, full of strange devices that I had never seen before.

Another difficult moment was the ICU (Intensive Care Unit). I was alone with the nurses. My parents could only spend an hour with me in the morning and another in the afternoon. When they left, I started crying; I didn't understand anything. I remember my parents asking me, "Did something happen to you?" I, at that age, didn't think of anything good and said, "Yes, I'm angry at the world".

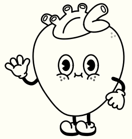
Well, that's enough of the bad memories, the positive ones are many and more interesting.

After the ICU, I was admitted to room 715. I began to realize that some things were changing I walked without getting tired; I ate normally and could taste and smell the food; I received get-well messages from my family and class friends; I studied with my father in the room and did my homework at the school on the sixth floor of the hospital; and the doctors and staff were friendly, always worried about helping me get what I needed. When I was able to leave the room, I discovered a tricycle; I was so excited! I've never had that experience before. Pedalling is when I really realised that everything was better.

Before the transplant, you are limited; fear and worry surround you. Then, you lead a normal life, you are a child like all others. Now I'm not always tired, I play sports, I go on excursions with my family, I go out with my friends and I will even go on an end-of-year trip like anyone else my age. But I know I have to see my doctors from time to time and I never forget to take my medications.

My doctors are great. I would like to thank my surgeon, who always had a smile for me, even when ripping off the dressings; my doctor, whom I love a lot, and who is always there when I need him, who even contacted the Make a Wish Foundation to make it possible for me to watch my football team, Atletico Madrid; the nursing team and her PlayStation with which I play every day; to everyone, without forgetting all the professionals who make us feel at home when we are in hospital. My family and I will always be grateful to all the staff of the hospitals, for their study, work and professionalism; also, of course, to my donor's family, who, at one of their worst moments, made the decision to save several lives, including mine.

Alejandro



«Tenían que cambiar mi corazón porque estaba muy sucio y casi no botaba»

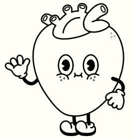
Hola, soy Alejandro y tengo siete años y medio (o algo más de cuatro si contamos desde que recibí mi nuevo corazón). Fui trasplantado cuando apenas tenía tres años y medio y, a pesar de que era muy pequeño cuando ingresé en el hospital, sí que tengo recuerdos de aquella época, y todos son buenos.

Recuerdo muy bien cómo empezó todo, el día en que los médicos me dijeron que me tenían que «cambiar mi corazón porque estaba muy sucio y casi no botaba». La verdad es que yo, cuando oí la noticia y durante toda mi estancia en el hospital, nunca tuve miedo. Y no lo tuve porque, como me dicen mis padres, soy un niño muy fuerte y valiente. Durante mi estancia en el hospi siempre estuve acompañado de mi familia, que me cuidaron como a un rey y siempre estaban conmigo. Además, al hospital siempre venía mucha gente a visitarme y todos me trataban muy bien. El tiempo que duró la espera fue muy divertido y guardo muy buenos recuerdos. Recuerdo que en esa época me gustaba mucho la canción de «*Baby shark*» y tenía locos a todos los médicos y enfermeras. También me gustaba disfrazarme de superhéroe, de caballero, de médico, de fantasma…tenía el armario del hospi lleno de disfraces y ¡hasta tenía un coche y una moto! De todos modos, como más me gustaba desplazarme, era subido a mi portasueros; me daba unos paseos increíbles ya que, además, no podía separarme de él porque ¡estaba siempre enchufado a una máquina que no dejaba de pitar!.

A todos los sanitarios que cuidaron de mí quiero decirles que les quiero mucho y que son mis héroes. Guardo mucho cariño a las enfermeras, auxiliares, médicos, cirujanos, a los de la UCI, a todos los del personal de limpieza… todos me querían mucho y siempre estaban pendientes de mí. Ahora, cada vez que voy al hospital a las revisiones, me encanta verlos y comprobar que me siguen queriendo igual.

A los niños que están esperando un trasplante en el hospi, me gustaría desearles muy buena suerte, que pronto les llegue el órgano y que todo vaya muy bien. Que estén tranquilos, que la recompensa después es muy buena. Yo ahora estoy disfrutando a tope de mi nueva vida, de mi corazón nuevo y ¡hasta me he apuntado a un equipo de fútbol! ¡Los primeros goles que meta os los dedicaré a vosotros y a todos los donantes del mundo!

Alejandro



"They had to change my heart because it was so dirty and hardly bounced"

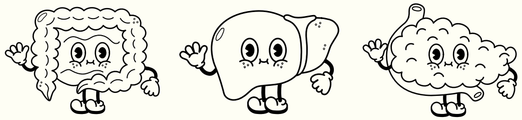
Hi, I'm Alejandro, and I'm seven-and-a-half years old (or a little over 4, if we count the time since I received my new heart). I received a transplant when I was only three-and-a-half years old and, although I was very small when I was admitted to hospital, I do have memories of that time, and they are all good.

I remember very well how it all started, the day the doctors told me that they had to "change my heart because it was so dirty and hardly bounced." The truth is that, when I heard the news and throughout my stay in the hospital, I was never afraid. And that was because, as my parents tell me, I'm a very strong and brave child. During my stay at the hospital, I was always accompanied by my family, who took care of me like a king and were always with me. In addition, many people came to the hospital to visit me and everyone treated me very well. The time while waiting for the transplant was a lot of fun, and I have very good memories. I remember that at that time I really liked the "*Baby shark song*" and I drove all the doctors and nurses crazy. I also liked to dress up as a superhero, as a gentleman, as a doctor, as a ghost — I had a hospital closet full of costumes and even had a car and a motorcycle! Anyway, the way I most liked to move around was on my IV pole; I used to go for amazing walks because I was always attached to a machine that kept beeping!

To all the healthcare workers who looked after me, I want to tell you that I love you very much and that you are my heroes. I love the nurses, assistants, doctors, surgeons, the ICU, all the cleaning staff — they all loved me very much and were always aware of me. Now, every time I go to the hospital for check-ups, I love to see them and see that they still love me just the same.

For the children in hospital waiting for a transplant, I would like to wish you very good luck, may your organ arrive soon and may everything go well. Be calm, because the reward afterwards is worth it. I am now enjoying my new life, my new heart, and I have even signed up for a football team! The first goals I score will be dedicated to you and to to all the donors in the world!

Elena



«Todo es un aprendizaje, duro, pero muy positivo»

Esta es la historia de una preciosa niña llamada Elena. En la actualidad tiene 9 años. Desde que nació le tocó luchar para vivir, fue prematura. A los cinco días de su nacimiento se tuvo que enfrentar a una enterocolitis necrotizante que le destrozó el intestino. Pero ella puso todas sus fuerzas para seguir en este mundo y después de unas cuantas operaciones, sus doctores (para nosotros sus ángeles) decidieron que debía entrar en lista de espera de un trasplante.

Elena tuvo mucha suerte y gracias a la generosidad de unos papás (a lo que estaremos eternamente agradecidos) a los 7 meses tuvo un donante y se le realizó el trasplante de cinco órganos.

Una vez trasplantada, nuestra mayor preocupación ha sido el rechazo, así como virus, bacterias y demás bichitos. En definitiva, la salud de Elena.

Pero Elena es muy fuerte y puede con todos los bichitos y contratiempos que surgen en su camino. Su mayor éxito es lo feliz que es disfrutando de una vida como cualquier niño (exceptuando su medicación y revisiones).

Le encanta ir al cole, a sus extraescolares, jugar en los parques, viajar…Lo disfruta todo con mucha intensidad y con una gran sonrisa pícara en su cara. Una de sus mayores características es su risa.

Por todo esto queremos transmitir a los familiares en lista de espera fuerza hasta que llegue y, cuando eso ocurra, podrán disfrutar de una nueva vida. Y, por otro lado, que siempre confíen en los médicos y la ciencia.

Elena y sus compañeros trasplantados son héroes y nuestro mensaje es que vivan cada momento, den importancia a lo realmente importante, que rían y que sean muy felices porque lo merecen.

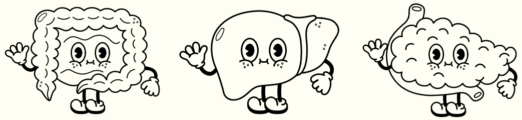
Una parte importante que les acompañan en sus vidas son los cuidadores, a los cuales les pedimos energía positiva, fuerza y que siempre luchen, porque aún en situaciones difíciles ellos no se rinden.

Por último, queremos agradecer a los donantes su generosidad. Y a los profesionales de la salud transmitirles toda nuestra admiración, cariño y gratitud. Creemos que deberíamos darles de una vez el lugar que merecen, pues son nuestros ángeles.

«Todo es un aprendizaje, duro, pero muy positivo».

Feliz vida.

Elena



“Everything is a learning experience, sometimes hard, but very positive”

This is the story of a beautiful little girl named Elena. She is currently 9 years old. Since the day she was born, she had to fight to live, because she was preterm. Within 5 days of her birth, she had to face a necrotising enterocolitis that destroyed her intestine. But she put all her strength into continuing in this world, and after a few operations, her doctors (for us her angels) decided that she should be on the waiting list for a transplant.

Elena was very lucky, and thanks to the generosity of some parents (to whom we will be eternally grateful), at 7 months she had a donor and had 5 organs trasplanted.

Once trasplanted, our biggest concern has been rejection, as well as viruses, bacteria and other bugs. In short, Elena’s health.

But Elena is very strong and can handle all the bugs and setbacks that come her way. Her greatest success is how happy she is to be able to enjoy a life like any other child (except for her medication and check-ups).

She loves going to school, her after-school activities, playing in the park, travelling — she enjoys everything with great intensity and with a big mischievous smile on her face. One of her greatest characteristics is her laughter.

For all this, we want to transmit strength to the families with children on a waiting list, because when the moment of the transplant arrives, their child will be able to enjoy a new life. And they should always trust in doctors and science.

Elena and her fellow transplant recipients are heroes, and our message to them is to live every moment, to concentrate on what is really important, to laugh and to be very happy, because they deserve it.

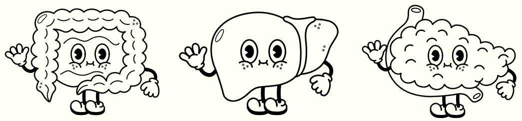
Caregivers are an important part of our lives, from whom we ask for positive energy, strength and to always fight, because even in difficult situations they don’t give up on us.

Finally, we would like to thank the donors for their generosity. And to the health professionals we convey all our admiration, affection and gratitude. We believe that we should give them the thanks that they deserve, because they are our angels.

“Everything is a learning experience, sometimes hard, but very positive.”

Have a happy life.

José



«Aprovechen esta segunda oportunidad que les da la vida»

José nació en abril del 2008. Tiene 14 años. Al nacer le diagnosticaron un vólvulo intestinal y le tuvieron que quitar todo el intestino delgado y parte del intestino grueso. No nos daban ninguna esperanza de vida y, tras estar casi un mes ingresado sin ninguna solución posible, nos enteramos buscando en internet que en un hospital estaba la unidad de rehabilitación intestinal y trasplante, pionera en toda España. Conseguimos hablar con sus doctores y nos dijeron que en cuanto el niño estuviera estable lo lleváramos allí. Después de estudiarlo y realizarle una intervención para ver en qué situación se encontraba, nos dijeron que la única solución era un trasplante intestinal.

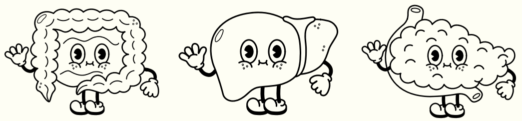
Lo pusieron en lista de espera, y durante unos tres meses ingresados nos enseñaron todo lo necesario para desde casa, saber manejar la parenteral y cuidados que conllevaba la situación. Al año recibimos la llamada del doctor de que había un posible donante para José (junio del 2009).

En el momento que entras en lista de espera, pasas a vivir pendiente de una llamada que parece no llegar nunca, pero llegó. La preocupación es inmensa, tener la incertidumbre de cómo irá todo, es muy angustioso. Pero todo fue bien. Sabíamos que estábamos en las mejores manos y así fue. A los tres meses nos pudimos ir a casa a empezar una nueva vida. José pudo hacer una vida casi normal. El primer año aún con la parenteral. Pudo compaginar el colegio con las horas nocturnas de parenteral hasta que se la quitaron. Luego con la ileostomia fue muy pesado el tener que estar pendiente de sus cuidados tanto en el cole (el cual tuvimos mucha suerte con el profesorado ya que colaboraron en todo lo que pudieron sin ponernos ninguna pega) como por las noches cuando no había manera de que le aguantara el disco pegado a su tripita. Lo mejor de todo es lo bien que supo llevar José esta situación. Era un niño muy extrovertido y feliz, eso nos lo trasmitía a toda la familia y nos ayudó mucho a sobrellevarlo todo.

A los 5 años (2014) tuvo un rechazo y toda nuestra vida se desvaneció. Teníamos que volver a empezar de cero, con el miedo en el cuerpo que eso conlleva; volver a entrar en lista de espera. Esta vez el trasplante sería multivisceral, ya que en estos cinco años habían comprobado que había menos riesgo de rechazo. La preocupación era extrema ya que si este volvía a fallar, ya no había más posibilidades para él. Y al año, en el 2015, le realizan el 2º trasplante y hasta ahora. José lleva una vida normal, con su medicación y sus revisiones pero es totalmente independiente, es muy deportista, juega a balonmano y estudia 2º de la E.S.O. Mi mensaje para las familias que estén esperando un trasplante es que tengan esperanza porque llega. Gracias a Dios hay cada vez más conciencia con las donaciónes. A los trasplantados que aprovechen esta segunda oportunidad que les da la vida y que aprendan a valorar las pequeñas cosas.

Y a los profesionales de la salud, gracias por la gran labor que hacen a las personas, en especial, a los médicos del Hospital que han cuidado de José y nos han transmitido desde el primer momento, tranquilidad y paz interior, al saber que estábamos en las mejores manos; cirujanos, gastroenterólogos, enfermeras, etc…

José



"Take advantage of this second chance of life"

José was born in April 2008. He's 14 years old.At birth, he was diagnosed with an intestinal volvulus, and they had to remove all of his small intestine and part of the large intestine. They gave us no hope of life, and after almost a month without any possible solution, we found on the internet that one hospital had an intestinal rehabilitation and transplant unit, the first of its kind in Spain. We talked their doctors and they told us that as soon as José was stable we should take there. After examining him and performing an intervention to see what the situation was, we were told that the only solution was an intestinal transplant.

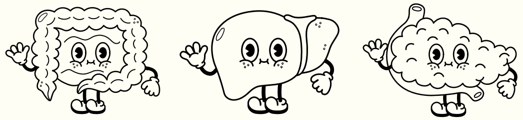
He was put on the waiting list, and for about 3 months we were taught everything we needed to know about how to manage the parenteral feeding and care involved in the situation. After a year, we received a call from the doctor that there was a possible donor for José (June 2009).

The moment you get on the waiting list, you are waiting for a call that never seems to come. But it did arrive. The worry was immense, to live with the uncertainty of how everything will go was very distressing. But, everything went well. We felt we were in the best hands, and we were. After 3 months, we were able to go home and start a new life. José was able to lead an almost normal life. The first year, even with the parenteral nutrition, he was able to combine school with the night-time parenteral hours until it ended. With the ileostomy, his care both at school (which we were very lucky with the because they collaborated as much as they could) and at night was difficult, when there was no way he could keep the disc stuck to his stomach. The best part was how well José was able to weather this situation. He was a very extroverted and happy child, which transmitted to the whole family and helped us cope with everything.

At age of 5 (2014), he unfortunately had a rejection, and our whole life vanished. We had to start again from scratch, with the fear that this entails; José had to be put back on the waiting list. This time, the transplant would be multivisceral, because over the previous 5 years, they had found that there was less risk of rejection. The concern was extreme because if it failed again, there was no more chance for him. A year later, in 2015, he underwent his second transplant, and has been fine until now. José leads a normal life, with his medication and his check-ups, but he is totally independent, is very sporty, plays handball and is in his second year of secondary school. My message to families who are waiting for a transplant is to have hope, because the day will arrive. Thankfully, there is more and more awareness of the need for donations. I would like to tell transplant recipients to take advantage of this second chance of life that has been given them and to learn to value the little things.

And to the health professionals, thank you for the great work you do for people, especially the doctors, surgeons, gastroenterologists, nurses, etc. who have taken care of José and who have transmitted to us peace of mind, knowing that we were in the best hands.

Luis



«Los padres tenéis que ser muy fuertes y estar muy orgullosos»

Luis tiene 3 años. Él tenía 1 año y 8 meses cuando se le realizó el trasplante multivisceral.

Una de las principales preocupaciones relacionadas con el trasplante es el rechazo de los órganos.

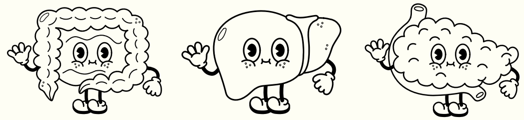
Las cosas positivas son ver a Luis comiendo, corriendo y jugando y haciendo una vida casi normal.

A los pacientes en espera de un trasplante, les quiero decir que siempre hay una luz al final del túnel. A otros compañeros trasplantados quiero decirles que sois héroes, por todo lo que estáis luchando. Los padres tenéis que ser muy fuertes y estar muy orgullosos de lo que estáis luchando por vuestros hijos.

Al final, queremos dar las gracias a la familia donante y al equipo de médicos. Gracias a ellos, nuestro hijo está ahora llevando una vida nueva.

Muchas gracias.

Luis



“Parents, you have to be very strong and should be very proud”

Luis is 3 years old. He was 1 year and 8 months when he had a multivisceral transplant.

One of the main concerns related to transplant is organ rejection.

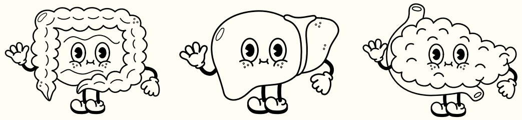
The positive things about the transplant are seeing Luis eating, running and playing, and that he now lives an almost normal life.

To the patients waiting for a transplant, I want to say that there is always a light at the end of the tunnel. To other fellow transplant recipients, I want to say that you are heroes, for all that you are fighting for. And parents, you have to be very strong and should be very proud of fighting for your children.

Finally, we want to thank the donor family and the team of doctors. Thanks to them, our son is now living a new life.

Thank you very much.

Daniel



«Aunque hay una parte que se escapa a nuestro control, hay que pensar que hay opciones»

Mi nombre es Daniel y actualmente tengo 16 años. Me hicieron un trasplante multivisceral sin bazo (estómago, páncreas, hígado, intestino delgado y duodeno) cuando tenía 2 años y medio. Aunque yo no recuerdo mucho de aquella etapa, por lo que me han contado mis padres, familiares, médicos y por fotos y vídeos que he visto, tuve una segunda oportunidad de vivir.

Al parecer tenía un fallo intestinal secundario a un síndrome de depleción de ADN mitocondrial con déficit del complejo IV de la cadena respiratoria, es decir, una enfermedad poco frecuente, que hacía que todo lo que comía por boca, no lo absorbiera mi intestino. Así que estuve desnutrido y conectado 24 horas al día a una máquina de nutrición parenteral (NP) durante 2 años y medio, ya que si intentaban ciclarme la NP, entraba en hipoglucemia, por lo que parece que eso aceleró mi entrada en lista de trasplante, ya que mi hígado comenzó a deteriorarse poco a poco.

Por lo que me han contado iban a hacerme un trasplante hepato-intestinal, que la misma noche de la intervención se convirtió en multivisceral. Durante aquella época mis padres y yo convivimos no solo con la NP, sino con sondas nasogástricas para nutrición enteral y con iliostomías que, según mis padres, me dejaban la piel del abdomen bastante mal.

En marzo de 2009, gracias a la generosidad de una familia, llegó la esperada llamada para el trasplante, después de casi un año en lista de espera. Unos meses antes nos llamaron también, pero en aquella ocasión, el trasplante no fue viable y tuvimos que volver a casa a esperar de nuevo. Eso puede pasar, pero a veces hay contratiempos que no pueden controlarse.

En aquel tiempo de espera, mis padres cuentan que había que estar localizables 24 horas al día allí donde estuvieran. Así que, con el consentimiento de los médicos, fuimos de vacaciones fuera de Madrid (donde vivimos), ya que un servicio de catering nos llevaba las bolsas de NP donde estábamos. También me cuentan que durante esa espera, trataron de ser optimistas, pese a que sabían que no era fácil que apareciera un donante para mí. Aún así, trataban de hacer vida familiar y que yo tuviera una situación lo más «normalizada» posible dadas las circunstancias.

Durante ese tiempo, conocimos una asociación llamada NUPA, en la que otras familias con una situación similar a la nuestra, nos brindaron su apoyo, y pudimos conocer a otros niños trasplantados y con fallo intestinal. A día de hoy, es como nuestra segunda casa, al igual que el hospital.

Pero en esa etapa de espera, también hubo momentos complicados, de ingresos repetidos, infecciones graves, etc. que hacían que el ánimo de mis padres variase mucho. Mi madre dejó su trabajo para cuidar de mí y mi padre hacía malabares para ir del trabajo al hospital cada día cuando estábamos ingresados. Aún así, mis padres dicen que tenemos suerte porque otras familias que

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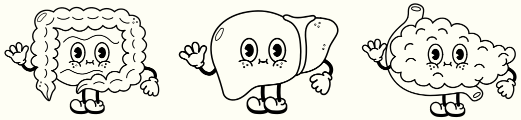
Daniel



“Although there is a part that is beyond our control, you have to remember that there are options and you can get better”

My name is Daniel and I am currently 16 years old. The following is my experience as a multivisceral transplant recipient.

I had a multivisceral transplant without a spleen (stomach, pancreas, liver, small intestine and duodenum) when I was two-and-a-half years old. Although I don’t remember much of that stage, I have been told by my parents, relatives, doctors and through photos and videos that I now have a second chance to live.

I had secondary intestinal failure to a mitochondrial DNA depletion syndrome with deficiency of IV complex of the respiratory chain, that is, a rare disease, which meant that whatever I ate by mouth was not absorbed by my intestine. So, I was malnourished and connected 24 hours a day to a parenteral nutrition (PN) machine for two-and-a-half years, because without it, I would have gone into hypoglycaemia. This accelerated my entry on the transplant list, as my liver began to deteriorate little by little.

From what I have been told, they had planned to do a hepato-intestinal transplant, which on the night of the intervention turned into a multivisceral transplant. During that time, my parents and I lived not only with PN, but also with nasogastric tubes for enteral nutrition and with ileostomies, which according to my parents, made my abdominal skin look pretty bad.

In March 2009, thanks to one family’s generosity, the long-awaited call for transplant came after almost a year on the waiting list. We had also been called a few months earlier, but on that occasion, the transplant was not viable and we had to return home to wait again. That can happen, but sometimes there are setbacks that can’t be controlled.

During that waiting time, my parents say that they had to be reachable 24 hours a day wherever they were. So with the doctor’s consent, we went on holiday outside Madrid (where we live), because a catering service could bring the PN bags to us where we were. They also told me that during this wait, they tried to be optimistic, even though they knew that it was not easy to find a donor for me. Even so, they tried to make family life and for me as ”normal” a situation as possible under the circumstances.

During that time, we found an association called the Association of Help for children with Intestinal Failure, Parenteral Nutrition and Multivisceral Transplant, where other families in a similar situation to ours gave us their support, and we were able to meet other children who had been transplanted and with intestinal failure. Today, it’s like our second home, just like the hospital.

But during that waiting time, there were also difficult moments; repeated hospital admissions, serious infections, etc., which made my parents’ mood vary greatly. My mother left her job to take care of me and my father juggled getting from work to the hospital every day while I was there.

no son de Madrid, tenían que estar separadas durante mucho tiempo.

En mi caso después del trasplante, todo cambió para mejor. Me fueron quitando poco a poco la NP…¡fuera tubitos! Y empecé a comer por boca y coger peso. Con 3 años empecé a andar y aunque me ha costado entrar en los «percentiles», ¡por fin lo conseguí!

En estos 13 años he ido al cole con mascarilla, mucho antes de la pandemia, he podido experimentar muchas cosas como un chaval de mi edad, aunque también he tenido que aprender a vivir con mis limitaciones y una vida ligada a unos medicamentos imprescindibles, aunque a veces me cueste un poco.

Hemos contado con un equipo médico excepcional (médicos, cirujanos, enfermeros…) que nos han apoyado y llevado de la mano y al que estamos muy agradecidos.

Nuestra experiencia en general, ha sido muy positiva, pese a etapas complicadas física y psicológicamente, y esa idea es la que queremos transmitir a aquellas personas que a día de hoy, esperan un trasplante.

Aunque hay una parte que se escapa a nuestro control, hay que pensar que hay opciones y se puede salir adelante. Además, las técnicas médicas evolucionan cada vez más y permiten logros increíbles.

Yo doy gracias por estar hoy donde estoy, con ayuda de quienes me han acompañado en estos años y quiero dar las gracias a quienes generosamente donan vida a quienes se les acaba.

Still, my parents say we were lucky because other families who were not from Madrid had to be separated for a long time.

In my case, after the transplant everything changed for the better. Little by little, they removed the NP — no tubes! I started to eat by mouth and put on weight. At 3 years old, I started to walk, and although it took me a while to reach the correct “percentiles”, I finally made it!

Over these 13 years I have gone to school with a mask, long before the pandemic, and I have been able to experience many things just like any other a kid of my age, although I have also had to learn to live with my limitations and a life linked to essential medicines, even if it sometimes costs me a little.

We have had an exceptional medical team (doctors, surgeons, nurses) who have supported and guided us and to whom we are very grateful.

Our experience in general has been very positive, despite the complicated physical and psychological stages, and this is what we want to transmit to those people who are currently waiting for a transplant.

Although there is a part that is beyond our control, you have to remember that there are options and you can get better. Moreover, medical techniques are evolving more and more and allow for incredible achievements.

I give thanks for being where I am today, with the help of those who have accompanied me throughout these years, and I want to thank those who so generously donate a chance at life to those who are running out of time.

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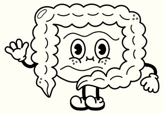

«Lo que ha de suceder, sucederá»

El trasplante le llegó a los 9 meses, tras tan solo 3 meses en lista de espera. Nuestro temor inicial fue la inclusión en lista de trasplante, lo cual significaba que no existía otra solución para él y, por tanto, la imposibilidad de seguir adelante sin él. Una vez en lista, el siguiente temor era que jamás llegara un injerto adecuado y nos quedáramos en el camino. Sabíamos que era muy complicado debido a su corta edad y bajo peso (pesaba 4 kg cuando recibió el injerto). Me leí las últimas estadísticas de la ONT acerca del porcentaje de fallecimientos en lista de espera, el tipo de donante óptimo y las características tan específicas del mismo, la dificultad de encontrar un donante así, la culpabilidad por desear un injerto adecuado a expensas de saber que implicaba el fallecimiento de otro niño tan pequeño o más que él.

Además, como todo coincidió con la época covid, pensaba que encontrar un donante sería más complicado debido a todos los protocolos hospitalarios, que la gente salía menos de casa, etc. Nunca leí nada sobre la cirugía necesaria, por estimarla demasiado compleja y con muchos elementos que podrían fallar. Decidí que sería un proceso mágico donde los cirujanos obraban de manera inimaginable haciendo todo encajar a la perfección. Otro temor era cómo tendría que vivir nuestro hijo con la inmunosupresión. Depender de una medicación de por vida no es grave, mucha gente necesita medicación, pero con el temor siempre a no contagiarse de nada era otra cosa, y más para un niño que explora todo sin temor. Tras el trasplante alcanzó en pocos meses la talla y peso adecuados para su edad, tras permanecer meses en percentiles ínfimos que casi ni aparecían en las tablas. Al fin tuvo fuerzas para mantenerse sentado, gatear, caminar. Fue alcanzando poco a poco todos los hitos del desarrollo, «floreciendo» al fin a nivel psicomotor. Verle crecer y sobre todo engordar fue una auténtica alegría, que rellenara la ropa y la usara de su talla o incluso de más mayor no tenía precio. Dejar de necesitar la nutrición parenteral fue el éxtasis, cogerle de cualquier manera y montarle en el carro o en el coche sin preocuparnos por el cable, la bomba y la bolsa y que algo pudiera fallar y soltarse y contaminarse. Y darle un baño sumergido, entrar en una piscina. A «A» le encanta el agua, no hemos pasado un verano más feliz que este pasado. El cierre de la ostomía fue también un gran paso. Sentir que al fin es independiente de máquinas y grandes cuidados es una tranquilidad enorme. Pensar que se le abren las puertas de casi las mismas oportunidades que al resto de niños, poder pensar en él en futuro «cuando sea mayor….» (antes del trasplante no nos lo imaginábamos de mayor), etc.

Al paciente en lista de trasplante, mucho ánimo y mucha suerte. Nadie que no haya estado en lista de trasplante se imagina lo que es. Es estar 24h pendiente de un teléfono, evitar viajar lejos del centro donde podría llegar a hacerse el trasplante, es cuidarse para evitar estar enfermo si llegara el momento, es confiar en lo mejor de la

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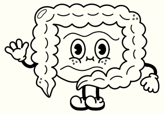
A



“What is to be will be”

The transplant was received at 9 months, after only 3 months on a waiting list.Our initial fear was A’s inclusion on the transplant list, which meant there was no other solution for him and, therefore, the impossibility of his health improving without it. Once listed, the next fear was that a proper graft would never arrive and he would remain critically ill. We knew that transplantation was very complicated due to his young age and low weight (he weighed 4 kg when he received the graft). I had read the latest statistics from the Spanish Transplant Organisation about the death rate for those on the waiting list, the type of optimal donor and the very specific characteristics needed, the difficulty of finding such a donor, as well as feeling the guilt for wanting an appropriate graft, knowing that it would mean the death of another child as young as or younger than him.

In addition, because everything coincided with the COVID era, I thought that finding a donor would be more complicated due to all the hospital protocols, that people went out less, etc. I never read anything about the necessary surgery, its complexity, and with many elements that could fail. I decided that it would be a magical process where surgeons worked in an unimaginable way, doing everything perfectly. Another fear was how our son would have to live with immunosuppression. Depending on a medication for life is not serious, many people take regular medication; but there was a fear of him catching something else, particularly for a child who explores everything without fear. After the transplant, our son finally reached the appropriate height and weight for his age after a few months, after small incremental increases in percentiles. At last, he had the strength to sit, crawl, and walk. He was gradually reaching all the milestones of development, “flourishing” at last at the psychomotor level. To see him grow and especially to gain weight was a real joy; that he filled his clothes and wore an appropriate size or even larger was priceless. To stop needing parenteral nutrition was ecstasy, to hold him in any way and having him be able to ride in the car without worrying about the cable, the pump, and the bag or that something would break or become contaminated. He could finally go into a pool. “A” loves water; we haven’t spent a happier summer than this last one, post-transplant. Closing the ostomy was also a big step. To feel that at last he is independent of machines and the need for constant care gives us an enormous sense of tranquillity. We are thrilled to think that he now has almost the same opportunities as other children, and to be able to think of him in the future, “when he is older” (before the transplant, we did not dare imagine him as older).

For patients on transplant list, good luck, and hang in there. No one who has not been on the transplant list can imagine what it is like to wait 24 h a day waiting for a phone call; to be unable to travel far from the centre where the transplant would be performed; to take constant care of yourself to avoid being sick when the transplant vida (la bondad y altruismo de unos desconocidos, la pericia de unos médicos dedicados a salvar vidas, es soñar con con un futuro personal y mejor calidad de vida) cuando otra vida se apaga. Pero ante todo, es un momento de espera que nosotros decidimos convertir en disfrutar el presente y el ahora.

Nunca un día tuvo más valor que dentro de esa espera. Las horas se nos hacían cortas para mostrar a nuestro hijo todo lo que queríamos que conociera, lo mucho que le quieren sus padres, su familia, lugares bonitos que merecía la pena ver y, ante todo, música que jamás se podría perder. Los despertares, baños, juegos, iban siempre acompañados de nuestra mejor música y muchos muchos bailes. «Lo que ha de suceder, sucederá», mientras tanto, que cada día merezca la pena.

A otros compañeros trasplantados poco que decir. Somos afortunados por el mero hecho de haber llegado hasta aquí. Aprovechemos esta oportunidad de la mejor manera. Tenemos mucho que aprender de vosotros y estamos disponibles para aquellos que nos pudieran necesitar.

El paciente fue nuestro bebé, pero, de haber sido uno de nosotros, hubiéramos querido aquello que nosotros intentamos aportar a nuestro hijo. Aparcamos nuestros miedos en un cajón para darle a nuestro hijo lo mejor de nosotros mismos, no perder la oportunidad nunca de decirle lo que le queremos y adaptarnos a sus rutinas en la medida de lo posible para que nunca se sintiera solo o fuera de lugar en la familia. Al no ser consciente de su propia situación, nunca tuvimos que abordar sus temores ni consolarle en momentos de dificultad, lo cual es una tarea muy dura que otros padres y cuidadores habrán sufrido y que nosotros no. Escuchar, apoyar y no angustiar con lo que nosotros ni siquiera sabemos que ocurrirá es lo que hacíamos mi pareja y yo entre ambos, junto con algún pequeño momento de flaqueza en el que hacíamos todo lo contrario y acabábamos derrumbados.

En nuestro caso tan solo es un mensaje de agradecimiento, ya que nos trata un equipo soñado. La cercanía, humanidad y profesionalidad son claves para las familias que pasamos por todo este proceso. Saber que conocen a fondo su campo, que contamos con la información necesaria, el apoyo siempre disponible (NUPA fue pieza clave, tanto del equipo profesional como de las familias que, al otro lado del chat, comparten su situación y te ayudan, haciéndote sentir siempre acompañado y comprendido) y una comunicación directa en caso de dudas y urgencias (sea por teléfono, por email o en consulta) aporta una inmensa tranquilidad y confianza durante todo el proceso pre y postrasplante, que a su vez se traduce en mejor calidad de vida para el paciente y su familia.

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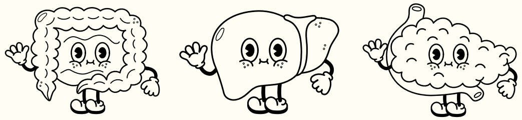
arrives; and to trust in the best of people (the kindness and altruism of strangers, the expertise of the doctors dedicated to saving lives, and dreaming of a personal future and better quality of life), always remembering that another life has ended. But above all, it is during the waiting time that you should enjoy the present moment to its fullest. Every day we waited was precious; the hours were short to show our son everything we wanted him to know how much his parents and family love him, beautiful places worth seeing, and above all, music that should never be missed. The awakenings, baths, games, were always accompanied by our favourite music and lots of dancing. “What is to be will be,” meanwhile, make every day worthwhile.

We have little to say other than we are fortunate for the mere fact that we have come this far. Let’s seize this opportunity in the best way. We have a lot to learn from you and we are available to those who may need us.

You need to put your fears aside so as to give your child the best of yourselves; never miss the opportunity to tell your child you love them, and adapt to your child’s routines as much as possible so they never feel alone or out of place in the family. Given that our son had not been aware of his situation, we never had to address his fears or comfort him in times of fear, which is a very difficult task that other parents and caregivers will have suffered that we did not. Listening, providing mutual support, and trying not to stress about not knowing what will happen is what my partner and I did, along with some times of weakness in which we did the opposite and ended up collapsing.

We would like to express our gratitude, because you treated us wonderfully. Closeness, humanity, and professionalism are key for the families who go through this whole process. Knowing that you are experts in your field, that we receive the necessary information, that support is always available (the Spanish Transplant Organisation was key in this, both of the professional team and of the families who, on the other side of the chat, share their situation and helped make us feel supported and understood), and having direct communication in case of doubts or emergencies (either by phone, email, or in consultation) provides immense tranquillity and confidence throughout the pre- and post-transplant process, which in turn translates into better quality of life for the patient and their family.

Pedro



«Tengan mucha esperanza y paciencia»

Pedro tiene 8 años. Cuando solo le faltaban cuatro días para cumplir los tres, le hicieron un trasplante multivisceral. Desde ese momento, nuestra vida cambió y, poco a poco, hemos ido alcanzando logros que nos han permitido mejorar la calidad de vida de Pedro y la nuestra como familia. Ya no tiene nutrición parenteral, no tiene enteral, ni botón gástrico y, ahora, los médicos estudian su caso para lo último que tenemos, la colostomía.

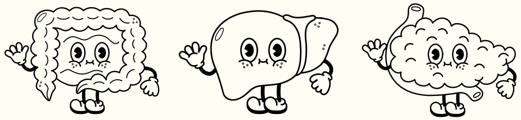
A quienes se encuentran en lista de espera de trasplante, decirles que tengan mucha esperanza y paciencia. Ojalá algún día les pueda llegar un donante compatible.

Para los compañeros trasplantados, que tengan fe y que se cuiden mucho para tener las menores complicaciones posibles.

Para los padres y cuidadores, paciencia también, y poco a poco ir aprendiendo para saber en todo momento cómo reaccionar. Eso se va a aprendiendo con el paso del tiempo.

A los profesionales que nos tratan. Gracias por todo lo que hacen, por seguir investigando para que estos niños tengan futuro y por dedicarse en tiempo y alma a las segundas oportunidades.

Pedro



“To have a lot of hope and patience”

Pedro is 8 years old. When he was only 4 days shy of his third birthday, he underwent a multivisceral transplant. From that moment, our life changed, and little by little, we have been reaching achievements that have allowed us to improve Pedro’s quality of life and ours as a family he no longer receives parenteral or enteral nutrition, has no gastrostomy button, and now doctors are studying his case for the last thing to be removed, the colostomy.

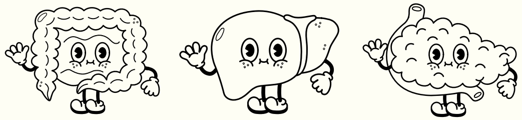
To those on the transplant waiting list, I want to tell them to have a lot of hope and patience. I hope that a compatible donor will be found soon.

For other patients with a transplant, I want to tell them to have faith and take great care of themselves so as to have the fewest possible complications.

For parents and caregivers, I also advise patience, and learning little by little how to react at all times. That is something you learn over time.

To the professionals who treat us, thank you for everything you do, for continuing to investigate so these children have a future and for dedicating your time and soul to giving us second chances.

Alberto



«Todos juntos, hacen que este milagro sea posible»

Alberto es un niño de 9 años trasplantado múltiple a los 14 meses.

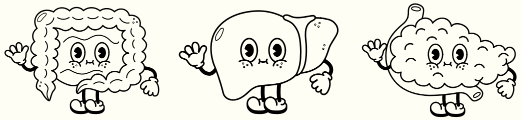
La máxima preocupación mientras esperas, es que no llegue a tiempo, y cuando ya ha llegado, existe el miedo constante al rechazo. Pero a la vez, sabes que es la única opción de vida que te queda, y ese miedo se ve compensado con la alegría de tener esa oportunidad.

Para todos los pacientes que se encuentran en espera, mucho ánimo y no desesperarse. Afortunadamente las donaciones llegan, y aunque el proceso es duro, los beneficios son enormes. Alberto hace una vida totalmente normal, va al cole, juega, ríe, llora… como cualquier otro niño de su edad, y nos da, a todos los que estamos a su alrededor, una lección de vida diaria.

Nadie dice que esto sea fácil, pero tampoco más difícil que otras circunstancias de la vida, por eso, todos los trasplantados tenemos que saber que durante el camino podemos encontrarnos obstáculos, pero que se pueden salvar gracias al gran equipo médico, que lucha cada día por ello y por mejorar la calidad de vida, y por supuesto, por la la valentía de los pacientes.

Desde que todo esto empezó, sólo puedo sentir gratitud. Cada día al acostarme doy gracias a los donantes, al equipo médico, a todas las personas que te acompañan durante todo este proceso. Todos juntos, hacen que este milagro sea posible.

Alberto



“Together, they made this miracle possible”

Alberto is a 9-year-old child, with multiple transplants at 14 months.

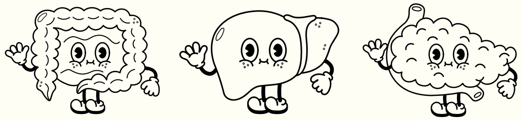
The greatest concern while you wait is that the donated organ will not arrive in time; then, when it has finally arrived, there is a constant fear of rejection. At the same time, however, you know that it’s the only chance for life that you have left, and that fear is compensated with the joy of having the opportunity for a second chance.

For all patients who are waiting, a lot of encouragement and do not despair. Fortunately the donations arrive, and although the process is tough, the benefits are huge. Alberto now lives a totally normal life, goes to school, plays, laughs, cries — just like any other child of his age. He gives us, and everyone around him, a daily lesson in life.

Nobody says that this is easy, but it is also no more difficult than many other circumstances in life. All you need to know is that you will find obstacles along the way, but they can be overcome thanks to a great medical team, who fight alongside you every day to improve your child’s quality of life, and of course, by your child’s courage.

Since all this started, I can only feel gratitude. Every day when I go to bed I thank the donors, the medical team, and all the people who accompanied us throughout this process. Together, they made this miracle possible.

Patricia



«Nunca se den por vencidos, luchen, siempre hay una luz al final del túnel»

Hola, soy Ana, madre de Patricia, ella tiene 15 años. En febrero del 2023 hace 16 años.

Su primer trasplante fue a los 17 meses de edad, cuando pesaba apenas 4 kilos. Esta vez fue solo de intestino delgado. Lastimosamente este trasplante se echó a perder por la presencia de linfomas No Hodking tipo B.

El segundo trasplante fue cuando tenía 4 años. También fue solo de intestino delgado, con la falta de suerte que también se le hizo el linfoma No Hodking tipo B y tuvieron que retirarlo a los dos meses de trasplantarla.

El último trasplante fue cuando tuvo seis años y esta vez fueron siete órganos del aparato digestivo. Aquí también se le hizo un linfoma No Hodking tipo T. Aquí tuvieron que ponerle dos años de tratamiento de quimioterapia que gracias a Dios y al equipo maravilloso de profesionales del hospital la sacaron adelante y todo fue muy bien hasta el día de hoy.

Mi principal preocupación con el trasplante fue el rechazo o complicaciones postrasplante, como que se contagie de enfermedades que tengan complicaciones con el sistema digestivo, como por ejemplo la gastroenteritis, infecciones intestinales.

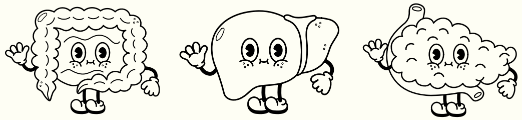
El mayor éxito que hemos tenido con mi niña es que desde el último trasplante ella hace una vida completamente normal. Puede comer de todo, va al instituto, cursa el año escolar que le toca de acuerdo a su edad, hace todas las actividades como cualquier niña normal, asiste a las reuniones sociales con sus amigas. Ha crecido y ha tenido un desarrollo normal en su etapa de pre adolescente. Ella es feliz cumpliendo sus sueños y metas uno a uno, sueña con ser psicóloga para ayudar a las personas que necesitan de alguien que les escuche y les brinde su cariño y apoyo.

Ya no está conectada y atada a ninguna máquina para alimentarse. Es el mayor logro para ella que, aunque fue muy difícil que aprendiera a comer por boca, lo logró. Gracias a que su trasplante funciona perfectamente, ahora mismo tiene el peso y talla normal para su edad, cosa que hubiese sido imposible sin el trasplante.

El mensaje que podemos dar para los padres y niños que están a la espera de un trasplante es que sean perseverantes y confíen que todo va a salir muy bien porque hay un equipo de profesionales muy preparados y cuentan con una tecnología punta en estos tiempos para llevar a cabo estos nuevos tratamientos y trasplantes. Nunca se den por vencidos, luchen, siempre hay una luz al final del túnel y la solución está muy cerca.

El mensaje para mis compañeros trasplantados es que disfrutemos la nueva oportunidad que Dios y la vida nos ha dado mediante los trasplantes. Hemos vuelto a nacer para ser felices disfrutando cada momento con sabiduría, responsabilidad y conciencia. Hay que ser fuertes y valientes y confiar que todo va a estar muy bien.

Patricia



"Never give up the fight. There is always a light at the end of the tunnel"

Hello I am Ana, Patricia's mother; she is 15 years old and will be 16 in February 2023.

Patricia's first transplant was at 17 months, when she weighed just 4 kilos, this time it was only the small intestine. Unfortunately, this transplant was ruined by the presence of non-Hodgkin B-cell lymphoma. The second transplant was when she was 4 years old, also only a small intestine transplant, with the misfortune that she once more had non-Hodgkin B-cell lymphoma, and it had to be removed 2 months after being trasplanted.

The last transplant was when she was 6 years old. This time, she received a transplant of 7 organs of the digestive system, after which she developed non-Hodgkin T-cell lymphoma. She had to undergo 2 years of chemotherapy treatment, which, thanks to God and the wonderful team of professionals at the hospital, has been successful to the present day.

My main concern with the transplant was rejection or post-transplant complications, such as catching diseases related to the digestive system, like gastroenteritis or intestinal infections.

The greatest success we have had with my girl is that since the last transplant she has been living a completely normal life. She can eat anything, goes to high school, does all activities like any other girl, and attends social gatherings with her friends. She has grown up and has had normal pre-teen development. She is happy fulfilling her dreams and goals one by one, and dreams of being a psychologist to help people who need someone who listens to them, to whom she can give her affection and support.

That she is no longer attached to any feeding machine is her greatest achievement. Although it was very difficult for her to learn to eat by mouth, she achieved it thanks to the fact that her transplant works perfectly. She is now at a normal weight and height for her age, which would have been impossible without the transplant.

The message that we would like to give to parents and children who are waiting for a transplant is to persevere and trust that everything will turn out well, because you have a team of highly trained professionals fighting for you, and they have the latest technology for performing these new treatments and transplants. Never give up the fight — there is always a light at the end of the tunnel, and the solution is very close.

The message for my fellow transplant recipients is to enjoy the new opportunity that God and medicine have given us through transplants. We have been reborn, so be happy and enjoy every moment with wisdom, responsibility, and conscience. We have to be strong and brave and trust that everything will be fine.

The message for parents and caregivers is to refuse to surrender; you have to fight every day with great strength and confidence, and have faith that

El mensaje que podemos dar para los padres y cuidadores es que está prohibido rendirse, que hay que luchar cada día con mucha fuerza y confianza, tener mucha fe que todo va a estar muy bien.

Que luego de grandes luchas hay grandes victorias y que luego todo solo es un gran recuerdo para ser la luz para otras familias que están empezando en el camino.

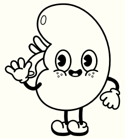
Mi mensaje para los profesionales de la salud es que sin ellos no podríamos estar vivos disfrutando de este maravilloso mundo de oportunidades.

Que sigan adelante con ese mismo esfuerzo, dedicación amor y perseverancia a pesar de las circunstancias adversas que a veces se les presente en la vida, que nosotros los necesitamos tanto como a nuestras familias, que les amamos porque son parte importante para nuestras vidas porque su gran lucha es nuestra salud y bienestar.

everything will be fine. After great struggles come great victories, and you can shine the light for other families who are just starting on the path.

My message to health professionals is that, without you, we would not be alive to enjoy this wonderful world of opportunity. May you go forward with the same effort, dedication, love, and perseverance despite the adverse circumstances that sometimes come your way in life. We need you as much as we need our families, and we love you because you are an important part of our lives. Your greatest struggle is our health and well-being.

Rubén



«El trasplante nos ha cambiado la vida a mejor»

Edad en la que se realizó el trasplante
11 años

Principales preocupaciones relacionadas con el trasplante
Nuestra mayor preocupación antes del trasplante fueron las horas que pasaba conectado a la máquina de diálisis peritoneal sin apenas poder tener vida, con analíticas muy seguidas para ver la situación crítica de sus riñones. Después del trasplante nos preocupa la gran cantidad de fármacos que debe de tomar «de por vida» para conservar dicho órgano y también que en nuestro caso el órgano trasplantado tiene «fecha de caducidad» y nuestro hijo deberá volver a ser trasplantado en unos años... pero estamos súper contentos por lo bien que ha salido todo.

Éxitos, logros, cosas positivas, metas que has alcanzado hasta la fecha
Ha ganado calidad de vida al no estar conectado a la diálisis, ha mejorado su aspecto, su peso, su fuerza, su autoestima y poco a poco va mejorando otros aspectos. El trasplante nos ha cambiado la vida «a mejor».

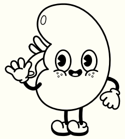
Mensaje para pacientes en espera de trasplante
Que tengan mucha paciencia, todo llega. La donación de órganos es necesaria para salvar otras vidas. Me gustaría que la donación de órganos fuera instaurada como algo de sentido común para que casi toda la población estuviera dispuesta a donar (sin tener que esperar a que sea tu familiar directo el que necesita un órgano). Que todo el mundo cuando cumpliera los 18 años se registrara como donante de órganos. Nuestros órganos no nos sirven (después de la muerte) y pueden salvar muchas vidas y mejorar la vida de muchas familias. Es posible que el órgano que esperamos no llegue a la primera... pero tranquilos... con un poco de paciencia llegará el correcto en poco tiempo y todo irá a mejor. Cada día somos más los que estamos dispuestos a donar.

Mensaje para otros compañeros trasplantados
Están vivos gracias a gestos solidarios de familias que tuvieron que tomar la difícil decision de donar los órganos (en el peor momento) con la muerte de su familiar directo. Deben cuidar su salud al máximo para que ese órgano recibido altruistamente pueda vivir muchos años en su cuerpo.

Mensaje para padres y cuidadores
Paciencia para llevar el trabajo con tesón para darle los máximos y mejores cuidados al trasplantado, los va a necesitar «de por vida».

Mensaje para los profesionales de la salud
Millones de gracias. Sobre todo a los que «por vocación» disfrutan día a día con su trabajo. Gracias a ellos por mejorar la salud de nuestros familiares. Y que sigamos luchando por nuestra sanidad pública.

Rubén



“The transplant has changed our lives for the better”

Age at the time of transplantation
11 years

Main Transplant Concerns
Our biggest concern before the transplant was the hours Rubén spent connected to the peritoneal dialysis machine barely living, with frequent blood tests to check the critical situation of his kidneys. After the transplant, we were concerned about the large amount of drugs that he would have to take “for life” to preserve the organ, and that in his case the transplanted organ has an “expiry date” and our son will have to be transplanted again in a few years; however, we are very happy with how well everything has gone so far.

Successes, achievements, positive things, goals you have achieved to date
Rubén has gained quality of life by not being connected to a dialysis machine; he has improved his appearance, his weight, his strength, his self-esteem, and little by little, he is improving other aspects as well. The transplant has changed our lives for the better.

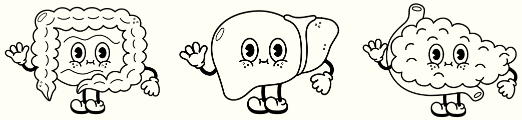
Message for patients waiting for a transplant
Be very patient, everything will come. Organ donation is necessary to save other lives. I would like organ donation to become more common, so that almost the entire population would be willing to donate (without having to wait until it is your immediate family member who needs an organ). Everyone should register as an organ donor at the age of 18. Our organs do not serve us after death and can save many lives and improve the lives of many families. It is possible that the organ we are waiting for will not arrive at first — but don’t worry — with a little patience the right one will arrive in a short time and everything will improve. More and more people every day are willing to donate.

Message for other transplanted colleagues
You are alive thanks to gestures of solidarity from families who had to take the difficult decision to donate the organs (at the worst possible moment) on the death of their direct family member. You must take care of your health as much as possible so that this altruistically received organ can live for many years in your body.

Message for parents and caregivers
Have patience to carry out the work ahead of you with tenacity in order to give the maximum and best care to the transplanted person because he/she will need it “for life”.

Message for health professionals
Thanks a million times over. Especially to those who “by vocation” enjoy their work on a daily basis. Thanks to them for improving the health of our families. And may we continue to fight for our public health.

Jon



«Un mensaje grande grande de esperanza»

Jon, 15 años. Trasplante con 4 años. Principal preocupación: evitar el rechazo y los efectos secundarios de la medicina inmunosupresora.

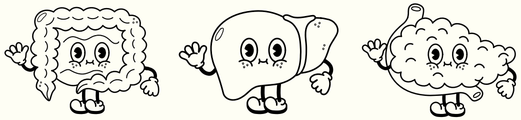
El mayor éxito sin duda fue el propio trasplante porque fue un milagro que llegasen tan rápido los órganos. Fue una situación de vida o muerte. Si hubieran tardado unos días más mi hijo ya no estaría aquí.

Así que al hilo de esto, un mensaje grande grande de esperanza para las familias. Si Jon pudo salir adelante, otros niños y niñas también. Nunca perdamos la esperanza.

Para los profesionales de la salud, sólo un mensaje. Profundo y eterno agradecimiento. Ellos le salvaron la vida a mi hijo. Ni más ni menos. Junto con la maravillosa ONT. Esa gran coordinación permitió la rapidísima llegada de los órganos para Jon.

Así que enormes gracias a todos.

Jon



“A great message of hope for families”

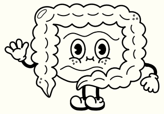
Jon, 15 years; transplant at 4 years old. My main concern was to avoid organ rejection and the adverse effects of immunosuppressive medicine.

The greatest success was undoubtedly the transplant itself, because it was a miracle that the organs arrived so quickly. It was a life or death situation. If they had taken a few more days to arrive, my son would no longer be here.

Therefore, I have a great message of hope for families. If Jon was able to pull through, so will other children. Let’s never lose hope.

Just a short message for the health professionals. My deep and eternal gratitude. They saved my son’s life — no more and no less. Along with the wonderful ONT(National Transplant Organisation). This great coordination allowed for the very rapid arrival of organs for Jon, so huge thanks to everyone.

Noelia



«Compartir experiencias nos ayuda a todos»

Noelia, 18 meses.
14 meses cuando el trasplante.

Preocupación
Rechazo del trasplante, pero sin obsesionarse.

Éxitos
¡Muchos! Aún es algo pronto, pero lo de gatear ha sido todo un regalo que nos ha hecho Noelia.

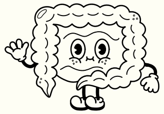
Mensaje
No perder la esperanza, en el momento menos esperado llega esa llamada.

Mensaje para otros
Compartir experiencias nos ayuda a todos.

Mensaje para padres
Que no pierdan la esperanza y que sean muy pacientes.

Mensaje para los profesionales
Gracias por la gran labor, que sigan teniendo mucha paciencia con los papás.

Noelia



“Sharing experiences helps us all”

Noelia, 18 months.
She was 14 months old when she had the transplant.

Worry
Rejection of the transplant, but without obsessing.

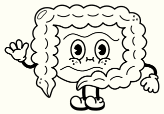
Successes
Many! It’s still early, but crawling has been a gift Noelia has given us.

Message
Don’t lose hope, the call comes when you least expect it.

Message for others
Sharing experiences helps us all.

Message for parents
Don’t lose hope, and be very patient. 8. Message for professionals Thank you for the great work you do, and may you continue to be patient with the parents.

Juan Carlos



«Estaremos agradecidos de por vida»

Juan Carlos se trasplantó con 2 años. Lo que más miedo nos daba era que no hubiera un donante compatible para él o que rechazara los órganos al realizarle el trasplante.

A los que están esperando para un trasplante les diría que tengan esperanza, que sean fuertes porque aunque vaya a ser un camino duro, al final su calidad de vida mejorará. Habrá días de desesperación pero poco a poco verán la luz al final del túnel y todo valdrá la pena.

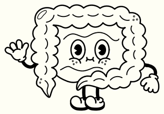
A todos los que están trasplantados, les diría que son personas que han venido al mundo para darnos una lección a todos los que los rodeamos, que tienen una magia especial y que disfruten de la vida cada segundo ya que han tenido una nueva oportunidad de vivirla.

A los padres y cuidadores, esta es la vida que nos ha tocado vivir, no es fácil y aunque hay días en los que se hace cuesta arriba seguir adelante, al final siempre merece la pena. Nuestros hijos nos han elegido y tienen la suerte de que siempre estaremos a su lado. Ellos nos han enseñado lo que de verdad importa en la vida.

A los profesionales de la salud, nunca podremos agradeceros lo suficiente todo lo que hacéis por nosotros. Os debemos la vida. Gracias por la magnífica labor que hacéis no sólo en lo profesional, sino en lo personal. Por acompañarnos en los días difíciles y celebrar cada mejora de nuestros hijos como si de los vuestros se tratase. Estaremos agradecidos de por vida.

A las familias de los donantes. Gracias de corazón por ser tan generosos en el peor momento de vuestra vida. Gracias por darnos esta oportunidad de vivir.

Juan Carlos



"We'll be grateful for life"

Juan Carlos was transplanted at 2 years of age. What we feared most was that there would not be a compatible donor for him or that he would reject the organs when the transplant took place.

To those who are waiting for a transplant, I would like to tell you to have hope, to be strong, because even if it is going to be a hard road, in the end, your quality of life will improve. There will be days of despair, but little by little you will see the light at the end of the tunnel and everything will be worth it.

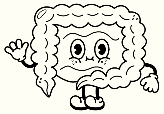
To all who are transplanted I would say that you have come into the world to give a lesson to everyone, you who have a special magic and who enjoy life every second because you have received a new opportunity to live it.

To parents and caregivers, this is the life that we have to live. It is not easy, and although there are days when it is an uphill battle to move forward, in the end, it is always worth it. Our children have chosen us and they are lucky that we will always be by their side. They have taught us what really matters in life.

To health professionals we can never thank you enough for everything you do for us. We owe you our lives. Thank you for the magnificent work you do, not only in the professionally, but personally. For accompanying us on the difficult days and celebrating every improvement in our children's lives as if they were your own. We'll be grateful for life.

To the families of donors. Thank you from the bottom of our hearts for being so generous at the worst moment of your life. Thank you for giving us this chance to live.

Olga



«No estás solo»

Hola, soy Olga y tengo 17 años. Nací en Lima, Perú, y me trasplantaron el 8 de junio de 2019.

La verdad es que fue una etapa de mi vida muy difícil. Yo pensaba que todo se iba a acabar, que nunca me iban a llamar y que la lista iba a ser eterna, pero finalmente me llamaron. Estaba súper nerviosa, las cosas al principio no fluían en mí porque tenía mucho miedo a que algo me pasara, pero finalmente confié en los doctores y en mí porque yo creo que cualquiera no pasa ese tipo de situaciones, el hecho de despertarte y no poder moverte o sentirte mal, o estar un verano entero en el hospital no es fácil, y allí en el hospital me apoyaron psicológicamente muchísimo, me ayudaron los médicos, las enfermeras, mi cirujano. A sentirme plena y, lo más importante, a no perderme a mí, porque fue muy difícil y yo soy una persona muy sensible y sí que hubo un momento donde dije: no puedo más. Pero ahí estuvieron mis médicos, mis padres, mi familia para levantarme y que sean la razón por la que pueda seguir adelante. Después de eso, salí a final de verano y al principio me costó mucho porque fue una situación de pastillas, cuidados, no podía salir mucho por la contaminación, porque estaba recién operada, dietas y tenía que ir al médico cada mes.

Después se fue acortando todo eso y yo fui acostumbrándome más y me mentalicé de que tenía que cuidarme y seguir para adelante. A día de hoy hago cosas que antes no podía hacer; por ejemplo, hago deporte, me estoy preparando para debutar en powerlifting, estoy en primero de bachillerato de artes escénicas porque me gusta mucho el arte y el teatro, también estoy en una academia de inglés, tengo amigos y tengo pareja. Él sabe todo lo que he pasado y me siento muy completa, todo gracias a los médicos, a mi familia y mi psicóloga y se lo agradezco mucho. A día de hoy voy poco al hospital, no voy como antes, pero me parece bien tener que ir porque es algo que ya he normalizado, entonces no me cuesta mucho. Es verdad que preferiría no ir, pero bueno, tengo muy pocas pastillas y todas esas cosas… A día de hoy hago todas esas cosas que he nombrado anteriormente. Estoy bastante feliz y con muchas ganas de seguir para adelante. Si no hubiese sido por los médicos no hubiese sido posible, y niños como yo, personas como yo, creo que deberían de ser fuertes siempre porque estas situaciones solo las pasamos los guerreros y a la gente que tienen que trasplantarla yo la considero muy fuerte. A toda esa gente que tiene que pasar por quirófano, a la gente que tiene que pasar situaciones psicológicas que no deberían pasar con su edad…etc y siempre con el apoyo de tu familia y de gente externa como los médicos que se preocupan mucho por ti y no solo por tu salud.

El mensaje que puedo daros a vosotros es mucha fuerza, sois más fuertes de lo que creéis, todos somos capaces de superar lo que nos propongamos.

También quería añadir un mensaje para los padres. Son lo más importante en esa etapa para nosotros, de hecho en mi caso la única razón por la que luché cuando me trasplantaron fueron ellos,

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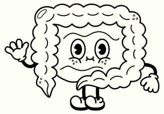
Olga



«You are not alone»

Hello, I am Olga, and I am 17 years old. I was born in Lima, Peru, and I received a transplant on June 8, 2019.

The truth is that it was a very difficult stage of my life. I thought that everything was going to end, that they would never call me, and that the list was going to be eternal; but I finally got a call. I was super nervous. At first, I was very afraid that something bad would happen to me, but I ultimately trusted the doctors. This situation does not happen to everyone

waking up and feeling bad, not being able to move, or spending a whole summer in the hospital. It isn't easy, but in the hospital, everyone supported me psychologically

the doctors, the nurses, and my surgeon helped me to feel fulfilled, and most importantly not to lose myself. It was very difficult for me, and I am a very sensitive person, so there was a moment where I said, "I cannot do this any more". But my doctors, my parents, and my family all raised my spirits and increased my determination and are the reason I can keep going. I left hospital at the end of summer, but at the beginning it was very difficult for me because I had to deal with pills, take special care, I could not get out much because of the risk of contamination due to being newly operated, I had a special diet, and I had to go to the doctor every month.

Then I gradually became used to it and I realised that I had to take care of myself to make progress. Today, I do things that I could not do before; for example, I play sports, am preparing to debut in powerlifting, and am in the first baccalaureate for the performing arts because I love art and theatre. I am also in an English academy, have friends, and I have a partner, who knows everything I've been through. I feel my life is very complete, all thanks to the doctors, my family, and my psychologist whom I thank very much. Now I don't go to the hospital as much as I used to, but it's good that I have to go because it has become a normal part of my routine. I am quite happy and very eager to move forward. If not for the doctors, it would not have been possible. I always think we transplant recipients are strong, because only warriors get through these situations. We have to go through surgery, with the emotional and psychological effects that entails, which should not happen at our age. But always with the support of our family and others, like doctors, who care a lot about you as a person and not only about your health.

The message I can give you is that you have a lot of strength, you are stronger than you think, and we are all able to succeed at what we set out to do.

I also wanted to add a message for parents

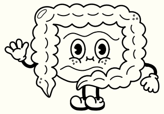
You are the most important thing at that stage for us. In fact, the only reason I agreed to the transplant was for them; I didn't want my health to affect my mother any more than it already had, and for my father not to mourn or have a heart filled with sadness. Parents are the most important no quería que a mi madre le afecte más de lo que ya le estaba afectando, y a mi padre no decepcionarle y pasar el duelo, no llenarles el corazón de tristeza. A lo que quiero llegar con esto es que los padres son lo más importante y el mayor apoyo, por lo menos en mi caso. Ya sean tus padres, tu primo, tu hermano o tu amigo, quien te acompañe en ese momento es la pequeñita luz que ves para salir adelante, tu fuerza, tu salvavidas. Aparte de querer salir tú adelante y conseguir todos esos objetivos que te quedan por cumplir en la vida, porque somos muy jóvenes y aunque tengamos ese problema de salud, después de la intervención podemos seguir cumpliendo nuestros sueños.

Que te recuerden que no estás solo y que desde ese mismo momento te acompañarán en todo el proceso. También intentar ser pacientes porque no siempre estaremos de buen humor en ese estado, y nos pueden herir fácilmente con pocas palabras… así que las personas o la persona que te acompañe que cuide sus palabras y que sean pacientes con nosotros.

and most supportive part of the whole process, at least in my case. Whether it is your parents, your cousin, your brother, or your friend who is accompanying you at that moment, they are your strength, your lifesaver. We also want to feel better and achieve all the goals we have yet to reach in order to live a full life. Even if we have some health problems, after the intervention we can continue to fulfil our dreams.

Remember that you are not alone, and that you will be accompanied throughout the process. For caregivers, try to be patient with us, because we will not always be in a good mood in our condition, and we can easily be hurt.

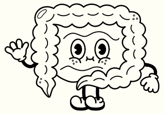
Alicia



«Todo llega y para bien»

Al principio lo que más preocupación me daba era que no tuviera rechazo. Lo que hemos conseguido después del trasplante: mejor calidad de vida, con más energía y más contenta. Que todo llega y para bien. Para mí, todo el equipo que está antes y después del trasplante son geniales y muy cercanos a la familia y, sobre todo, cualquier duda, cualquier miedo, te lo resuelven. Hacen que todo sea más fácil.

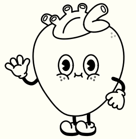
Alicia



«Everything happens for the best»

At the beginning, what worried me the most was that the transplant would be rejected. What we have achieved after the transplant is a better quality of life; Alicia has more energy and is happier. Everything happens for the best. For me, the whole team before and after the transplant were great and became very close to the family. Above all, they resolve any doubts or fears and make everything easier for you.

Irene



«Una vida llena de ilusión»

Ya han pasado casi 6 años desde que mi vida cambió para siempre; es lo mejor y lo más bonito que me ha pasado en la vida, aunque también lo más duro. Sin embargo, si no hubiese sido por todo lo que tuvimos que pasar, mi vida ya no hubiese sido la misma.

Soy Irene, vivo en Valladolid y, al mes de nacer, me diagnosticaron una cardiopatía compleja con comunicación interventricular grande, cabalgamiento tricúspide, insuficiencia moderada de la válvula AV derecha, estenosis pulmonar y funcionalmente corazón univentricular con insuficiencia valvular AV derecha.

Para arreglar este desastre, me realizaron una serie de cirugías que permitieron que mi corazón siguiese funcionando hasta los 17 años: me realizaron la cirugía de Glenn a los 8 meses, cirugía de Fontan a los 4 y al poco tiempo un marcapasos por bloqueo AV, además de unos cuantos arreglos más debido a una desinencia de la válvula tricúspide y me implantaron stents en el Fontan por una estenosis en el mismo, además de otro en la rama pulmonar izquierda.

Cuando tenía 17 años comencé a sentirme muy muy cansada, este cansancio ya venía de hace años más o menos desde los 14, todos los años ingresaba en los meses de otoño por el mismo cansancio que me impedía realizar una vida normal como la de mis compañeros y compañeras de clase. Mis médicos siempre mediante fármacos o diversos cateterismos conseguían que volviese a estar mejor. Sin embargo, ese año fue diferente, el simple hecho de ir a clase me costaba mucho, ingresé en octubre de 2015 porque la calidad de vida que tenía era mala, estuve dos meses ingresada, hablé con muchos médicos sobre mi cansancio extremo, era incapaz de realizar esfuerzos mínimos como caminar, comer sola o vestirme, necesitaba ayuda de mi familia las 24 horas del día.

Después de algún tiempo y unos cuantos cateterismos me diagnosticaron un cuadro de insuficiencia cardiaca progresiva. Cuando salí del hospital iba en silla de ruedas y al principio me esforcé en ir a clase, pero en febrero, cuando ya tenía 18 años tuve que dejar de asistir porque no podía aguantar las horas de clase seguidas sin ponerme mala. Tenía tal cansancio que ir andando desde mi habitación al salón me costaba demasiado, me esforzaba mucho por comer porque el simple hecho de hacerlo me cansaba, tenía muchos dolores de estómago además de un dolor fortísimo en la zona del diafragma (ese dolor era intermitente, aparecía cuando hacia algún pequeño esfuerzo). Es muy difícil de explicar esa astenia ya que el simple hecho de respirar era un esfuerzo.

Una de las veces que fui para cambiar el marcapasos, el 1 de abril del 2016, me encontré con la noticia de que necesitaba un trasplante de corazón. Para mí fue algo que me impactó demasiado ya que nunca había oído que yo en algún momento de mi vida iba a necesitar “eso”. Cuando subimos a planta para ingresar el doctor y el cirujano

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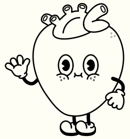
Irene



«A life full of ilusion»

It’s been almost 6 years since my life changed forever; it was the best and the most beautiful thing that has happened to me in my life, although also the hardest. However, if it hadn’t been for all we had to go through, my life would no longer have been the same.

I am Irene. I live in Valladolid, and 1 month after birth, I was diagnosed with a complex heart disease with large interventricular communication, tricuspid riding, moderate insufficiency of the right auriculoventricular (AV) valve, pulmonary stenosis and functionally univentricular heart with right valve failure.

To fix this mess, they performed a series of surgeries on me that allowed my heart to continue working until I was 17: I had Glenn’s surgery at 8 months, Fontan surgery at 4 years and shortly a pacemaker due to AV block. There were also a few more procedures due to a discontinuance of the tricuspid valve, and stents were implanted due to a stenosis in the Fontan, in addition to another found in the left pulmonary branch.

When I was 17 years old, I began to feel very tired. This tiredness had begun around the time I was 14, and every year I had to be admitted to hospital during the autumn months due to this tiredness that prevented me from carrying out a normal life like my classmates. My doctors always managed to make me feel better again through prescribing medicines or performing various catheterizations. However, that year was different; something as simple as going to class was very difficult for me. I was admitted to hospital in October 2015 for 2 months because my quality of life was poor. I spoke with many doctors about my extreme tiredness. I told them I was unable to make minimum efforts like walking, eating alone or getting dressed, and I needed help from my family 24 hours a day.

After some time and a few catheterizations, I was diagnosed with progressive heart failure. When I left the hospital, I did so in a wheelchair. At first I tried to go to class, but in February, when I was 18 years old, I had to stop attending because I couldn’t endure the long hours of class without getting sick. I had such fatigue that walking from my room to the living room was too hard for me. I struggled a lot to eat because of the simple fact that doing so tired me. I had frequent stomach aches, in addition to a very strong pain in the area of the diaphragm (that pain was intermittent; it appeared when making some small effort). It is very difficult to explain asthenia; even the simple act of breathing was an effort.

Once when I went to have my pacemaker changed, on April 1, 2016, I received the news that I needed a heart transplant. I was shocked, because I had never heard that at some point in my life I was going to need “that”. We went up to the hospital floor to admit me, and the doctor and the surgeon were the ones who told me the news with the greatest humanity and delicacy that fueron quienes me lo dijeron con la mayor humanidad y delicadeza que os podáis imaginar. Para mí aquello fue muy duro al principio, lo único en lo que podía pensar era que una persona tenía que morir para que yo siguiese con vida, pero después de hablar con mis médicos, mis enfermeras y mis padres, lo entendí todo, no era lo que yo imaginaba con la edad que tenía.

Durante el tiempo que estuve esperando el corazón, iba cada dos semanas al hospital desde Valladolid, para ponerme Levosimendan y creo que hizo su efecto, porque me ayudó a poderme presentar a la selectividad, aunque con muchísimo esfuerzo. Yo pensé que después de todo el esfuerzo que estaba haciendo no iba a conseguir lo que quería estudiar, pero al final pude entrar en medicina.

El verano pasó muy lentamente, cada día me empezaba a encontrar peor que el anterior, aunque por suerte estaba en casa, pero en septiembre me ingresaron para ponerme un fármaco de infusión continua por vía intravenosa pues comencé a empeorar. Estuve hasta finales de octubre en el hospital y por suerte me pudieron enviar con el fármaco a mi casa. En aquel momento es cuando más triste me sentía pues dependía de todas las personas de mi entorno: si quería salir a la calle tenía que salir con la silla de ruedas y el palo del suero y me daba mucha vergüenza ya que la gente me miraba durante mucho tiempo como si fuese un bicho raro, pero por suerte solo tuve que esperar 15 día desde que salí del hospital, ya que el día 2 de noviembre llegó mi GRAN SUERTE.

Todo pasó muy rápido para mí, aunque supongo que para mi familia que estaba fuera no tanto. Yo estaba convencida de que todo iba a salir bien en cuanto a la cirugía, confiaba muchísimo en todos los cirujanos, pero me daba mucho miedo pensar cuando volvería a despertar en la UVI o si volvería a despertar alguna vez, cuánto tiempo habría pasado desde que me dormí y en qué condiciones lo haría. Además, para mí la UVI me supone mucho estrés por los malos recuerdos que tengo de cuando tenía 4 años que estuve meses en ese lugar. Cuando entré en el quirófano me despedí de mi familia y recuerdo que mi madre me dijo: “venga, ahora te toca luchar a tí, te espero aquí afuera, te quiero cariño” y me dormí en el quirófano dando la mano a una enfermera, pensando que estaba en la playa sentada en la orilla con mi familia, mientras de fondo en ese momento sonaba una canción de Malú.

Recuerdo que el despertar no fue nada traumático, tengo muchos recuerdos de ver a mi familia, aún cuando estaba con la anestesia, de intentar hablar con ellos cuando estaba aún intubada y de la propia desintubación, pero lo peor de todo esto fueron las pesadillas que tuve durante una temporada y que a día de hoy todavía tengo alguna.

Estuve 5 días en la UVI muy cuidada y con todas las atenciones que me pudieron dar y aunque para mí era un lugar muy traumático gracias a todos lo pude llevar muy bien. Lo más impresionante de todo es cuando comencé a despertarme y a ser consciente de lo que había pasado yo me encontraba llena de vida, me encontraba bien, ya no estaba cansada, ni me encontraba mal debido al cansancio.

A los 15 días ya estaba en casa, todo estaba bien. Una de las veces antes del trasplante pregunté cuánto tiempo iba a tener que estar en el hospital después de la intervención y me dijeron que iba a ser duro, que necesitaría tiempo, pero por suerte desafié las estadísticas y a los pocos días estaba en casa.

Desde entonces mi vida ha cambiado, ahora soy más feliz de lo que ya era antes, ahora puedo hacer las cosas por mí misma, aunque me siguen pasando muchas secuelas que me ha dejado el trasplante. Tengo infecciones cada cierto tiempo que me obligan a volver a depender de mi familia porque me hacen encontrarme muy mal y necesito ayuda para desplazarme, aunque a veces sea un simple catarro, padezco de dolores musculares a

you can imagine. For me, that was very hard at the beginning; the only thing I could think about was that a person had to die in order for me to remain alive. But after talking to my doctors, my nurses and my parents, I understood everything. It wasn’t what I had imagined at the age I was.

While I was waiting for the heart, I went from Valladolid to the hospital every 2 weeks to receive levosimendan, and I think it made a difference, because it helped me to pass my university entrance exams, although it took a major effort. I thought that after all the effort I was making I wasn’t going to get into the area that I wanted to study, but in the end I was able to get into medicine.

The summer passed very slowly. Every day I began to feel worse than the previous one, although luckily I was at home. In September I began to get worse, so was admitted to hospital to get a continuous intravenous infusion drug. I was in hospital until the end of October, and luckily they were able to send me home with the medicine. It was at that point I felt saddest because I was so dependent on all the people around me: if I wanted to go out on the street I had to go out with the wheelchair and the serum stick, and I was very embarrassed because people looked at me for a long time as if I were a freak. But luckily, I only had to wait 15 days after leaving the hospital, since on November 2 my GREAT LUCK arrived.

It all happened very quickly for me, although I guess for my family, not so much. I was convinced that everything was going to go well in terms of the surgery. I trusted all the surgeons a lot, but I was very afraid to think about waking up again in the intensive care unit (ICU) or if I would ever wake up again, how long it would have been since I fell asleep and in what conditions I would do it. In addition, for me, the ICU is a lot of stress because of the bad memories I had of when I was 4 years old, when I was months in that place. When I walked into the operating room, I said goodbye to my family and remember my mother telling me: “Come, now it’s your turn to fight; I’ll wait for you out here, I love you baby,” and I fell asleep in the operating room holding a nurse’s hand, thinking I was on the beach sitting on the shore with my family, while a Malú song was playing in the background.

I remember that waking up was nothing traumatic, I have many memories of seeing my family, even when I was under anaesthesia, of trying to talk to them when I was still intubated and of the disintubation itself, but the worst of all were the nightmares I had for a while, and today I still have some.

I spent 5 days in the ICU, well cared for and with all the attention that they could give me. Although for me it was a very traumatic place, thanks to everyone there, I was able to withstand it very well. The most impressive thing of all is when I began to wake up and began to realise what had happened, I was full of life; I felt good, I was no longer tired, nor was I ill due to tiredness.

After 15 days, I was home, and everything was fine. One time before the transplant I asked how long I was going to have to be in hospital after the intervention, and they told me that it was going to be hard, that I would need time. Luckily, I challenged the statistics, and a few days later I was home.

Since then, my life has changed. Now I am happier than I was before, and I can do things by myself, although I still have many sequelae that the transplant has left me. I get infections from time to time that force me to depend again on my family because they make me feel very bad and I need help moving. Although sometimes I only have a simple cold, I sometimes suffer from very strong muscle pains due to the positions of the interventions, I have tremors in the upper and lower limbs that sometimes prevent me from holding a cup of coffee or dancing, and digestive and hepatic problems that affect my daily life. But what has affected me the most is attention deficit and memory loss since the transplant that makes me veces muy fuertes debido a las posiciones de las intervenciones, tengo temblores en las extremidades superiores e inferiores que me impiden a veces coger una taza de café o bailar, también problemas digestivos y hepáticos que me condicionan el día a día. Pero a mí lo que más me afecta es el déficit de atención y la pérdida de memoria desde el trasplante que me hace ir “a mi ritmo” en la universidad. Yo antes no tenía problemas de este tipo y al principio lo llevé un poco mal hasta que lo acepté. En cuanto a la astenia ahí sigue, pero ya no es la misma que antes, hay días que me encuentro mejor que otros, pero a veces me impide hacer una vida normal y necesito ayuda de mi familia y la silla de ruedas. Por suerte desde hace un año me ponen una infusión intravenosa de hierro cuando estoy más cansada de lo normal y me vuelvo a estabilizar.

Sin duda, aunque tenga estos problemillas que a veces se juntan unos cuantos a la vez y se convierte en una bola gigante, soy muy muy feliz y afortunada de estar aquí y de la familia que tengo que siempre me ha apoyado en todo y me ha hecho la vida tan fácil, que he podido disfrutar de ella aun cuando no me podía valer por mí misma.

Creo que lo que me ha permitido poder con todo lo que me ha ocurrido a lo largo de la vida y lo que está por llegar, es la fortaleza mental que tengo gracias a lo que me han enseñado todos los que están a mi lado: lo importante es el presente, hay que disfrutarlo y lo que tenga que venir ya se afrontará. Yo por suerte no he necesitado nunca la ayuda de psicólogos ni psiquiatras, pero si en algún momento lo necesitase no dudaría en pedirlo. Por ello pido que toda la gente que esté pasando por esto le pregunten si necesitan hablar porque hasta los que parecen más fuertes lo necesitan.

Con todo esto, me gustaría dar las gracias a todos los médicos y cirujanos que siempre me habéis ayudado y atendido. Porque, aunque os volviese locos con mi cansancio siempre me habéis hecho caso, aún cuando parecía que todo estaba bien, pero sobre todo gracias por haberme regalado esta vida.

go “at my own pace” in college. I had no problems of this kind before, and I had a hard time dealing with them at first until I accepted it. As for the asthenia, it is still there, but it is no longer the same as before. There are some days that I feel better than others, but sometimes it prevents me from leading a normal life and I need help from my family and the wheelchair. Luckily, for a year, I get an intravenous infusion of iron when I am more tired than normal and I become stable again.

Without a doubt, even if a few of these problems come together at the same time and it becomes a giant ball of issues, I am very happy and fortunate to be here, and my family has always supported me in everything and has made my life so easy that I have been able to enjoy it even when I couldn’t stand on my own.

I believe that what has allowed me to face everything that has happened throughout my life and what is to come is the mental strength that I have thanks to what everyone around me has taught me: the important thing is the present; you have to enjoy it, and you will face whatever is to come. Luckily, I have never needed the help of psychologists or psychiatrists, but if I ever needed them, I wouldn’t hesitate to ask. That is why I advise anyone going through this to ask if they feel they need to talk, because even those who seem strong need help once in a while.

With all this, I would like to thank all the doctors and surgeons who have always helped me and cared for me. Because even if I drove you crazy with my tiredness, you have always listened to me, even when it seemed that everything was fine; but most of all, thank you for giving me this life.

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