Lives that take care of Lives

Testimonies from transplantation teams across Europe

TransplantChild

European Reference Network | Transplantation in Children (ERN TRANSPLANT-CHILD)

Funded by the European Union

TransplantChild is the European Reference Network on Paediatric Transplantation, encompassing Hematopoietic Stem Cell and all Solid Organ Transplant programmes - namely Heart, Lung, Kidney, Liver, Intestinal and multi-organ.

Established in 2017 by the European Commission, its aim is to connect 40 healthcare providers, multidisciplinary teams and patients across 21 countries in the EU and Norway by addressing the rare and complex procedure of paediatric transplantation, which requires a pool of experts and highly specialised resources and that is, in most cases, the only life-saving treatment option.

In 2023 a booklet titled "A Brighter Future" was created collecting several stories of transplanted children, adolescents and young adults and their families with the precise purpose of sharing their experiences with those anxiously waiting for a transplant.

Moving from the request of patients and families to get to know the other side of the story, we are now giving voice to healthcare professionals working in the field of paediatric transplantation.

We truly believe this booklet will contribute to address some common professional and emotional issues, to allow some time for reflection, both at the individual level and inside the teams, and to acknowledge the different - but all necessary - professional roles, supporting the consolidation of cohesive and motivated teams.

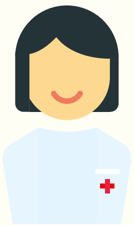
We also hope it will contribute to spread the enthusiasm and the passion for working in paediatric transplantation among the new generations of healthcare professionals.

Index

Suomi / Finland

Ulla

lastenhoitaja



Rooli ja maa:
Olen lastensairaanhoitaja ja olen työskennellyt elinsiirtolasten kanssa siitä lähtien, kun elinsiirto-ohjelma aloitettiin sairaalassamme vuonna 1986.

Kokemus lasten elinsiirroista:
Melkein 40 vuotta.

Elinsiirroista:
Sairaalassani suoritamme Suomen kaikki lasten elinten siirrot (munuainen, maksa, sydän, keuhko ja suolisto).
Meillä on Suomessa synnynnäinen munuaissairaus nimeltä CNF. Nämä lapset tarvitsevat dialyysihoitoa ennen elinsiirtoa. Olen myös peritoneaalidialyysihoitaja ja olen kouluttanut näiden lasten vanhempia kotona tehtävään dialyysihoitoon. Olen tehnyt kotikäyntejä eri puolilla Suomea näiden dialyysipotilaiden luona osana opetusohjelmaa.

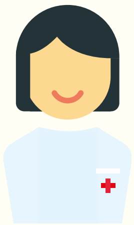
Miksi valitsit elinsiirtoa käsittelevän terveydenhuollon ammattilaisen?
Minusta tuli elinsiirtohoitaja, koska samat dialyysipotilaat saivat munuaisensiirron ja jatkoivat seurantaa samalla osastolla. Itse asiassa Suomessa kaikki lapset, jotka saavat kiinteän elinsiirron, hoidetaan elinsiirtolääkäreiden seurannassa, jotka kaikki ovat nefrologeja. Siksi kaikki potilaat ovat samalla osastolla ja vastaanotolla elinsiirron jälkeen. On kiehtovaa ja palkitsevaa nähdä, kuinka merkittävästi elinsiirto vaikuttaa näiden lasten terveyteen ja elämään.

Neuvoja hyvien suhteiden luomiseen potilaiden/perheiden kanssa:
Monilla potilaistamme on synnynnäisiä sairauksia ja he tulevat meille pikkulapsina. Seuraamme heitä, kunnes he siirtyvät aikuisten puolelle 18–20-vuotiaina. Tämä tarkoittaa monia erittäin pitkiä suhteita potilaidemme ja perheidemme kanssa. On tärkeää kuunnella potilaita ja heidän vanhempiaan ja sisaruksiaan sekä jakaa tietoa siitä, mitä sairaalassa tehdään. On myös tärkeää, että heidän on helppo olla yhteydessä hoitohenkilökuntaan ongelmien ilmetessä.

Muistatko jotain erityistä tapausta? Jos niin, miksi?
Olen tehnyt useita koulukäyntejä, kun elinsiirtolapset ovat aloittaneet tai palanneet kouluun. Vierailujen tarkoituksena on ollut kertoa luokkatovereille ja opettajille elinsiirroista yleensä ja miten se näkyy arjessa. Esimerkiksi elinikäinen lääkitys, näkyvät arvet ja koulusta poissaolo sairaalakäyntien vuoksi. On tärkeää jakaa tätä tietoa ja siten yrittää vähentää mahdollista kiusaamista, jota joskus ilmenee tilanteen ymmärtämättömyydestä.

Ulla

pediatric nurse



Role and country:
I am a pediatric nurse, and I have been working with transplanted children since the transplant program started at our hospital in 1986.

Experience in the field of pediatric transplantation:
Almost 40 years.

Type of Transplant Program:
In my hospital we perform all solid organ pediatric transplantations (kidney, liver, heart, lung and intestine) for the whole country.
In Finland we have a congenital kidney disease called CNF: these children need dialysis care before transplant. I am also a peritoneal dialysis nurse and have educated many of these children's parents to do dialysis at home. I have made many home visits all around Finland to the dialysis patients, as a part of the educational program.

Why did you choose to become a healthcare professional dealing with transplant?
I happened to become a transplant nurse as the same dialysis patients received kidney transplants and continued to be followed up on the same ward. In fact, in Finland all children who receive a solid organ transplant are taken care of our transplant doctors who all are nephrologists. And that's why all patients are on the same ward and outpatient after transplant.
It is fascinating and rewarding to see how a transplant makes a huge difference for their health and lives.

Advice on how to establish a good relationship with patients /families:
Many of our patients have congenital diseases and come to us as infants. We follow them up until they transfer to the adult care at the age of 18-20. This means very long relationships with our patients and families.
It´s important to listen to the patients and their parents and siblings and to share information about what is being done in the hospital. It is also important that it is easy for them to be in contact with us caregivers when problems come up.

Any particular case your recall? If so, why?
I have made several school visits when our transplanted children have started or have gone back to school. The aim of these visits is to tell the classmates and teachers about transplantations in general and what it means in everyday life. For instance, lifelong medication, scars and absence from school due to hospital visits. It's important to share this information and thus to try to reduce possible bullying that sometimes occurs due to not understanding the situation.

Ulla

Muistan kouluvierailut lämmöllä. Yhdellä 7-vuotiaalla pojalla oli erittäin jännittävä munuaisensiirtoarpi, joka näytti liskolta. Hän oli siitä niin ylpeä ja päätti näyttää sen luokan edessä käyntini yhteydessä.
Tulin luokkahuoneeseen ja olin juuri esittäytynyt, kun hän nosti kätensä ja kysyi: "Saanko nyt näyttää arpeni?" Kysyin häneltä, voisinko aloittaa kertomalla luokalle jotain siitä, mitä hän on kokenut ennen näyttämistä? "Ok" hän sanoi. Aloin siis kertoa luokalle sisäelimistämme ja mitä ne tekevät, kun sama kysymys toistui: "Voinko näyttää sen nyt?"
Ymmärsin, että hän oli niin innoissaan saadessaan näyttää arpensa luokalle, että minun piti antaa hänen tehdä se heti alkuun. Ja voi miten iloinen ja ylpeä poika nosti paitaansa ja näytti arpeaan luokalle. Luokkatoverit olivat vaikuttuneita, mutta heti sen jälkeen monta kättä nousi, sillä melkein kaikilla oli jonkinlaisia arpia, joista he halusivat näyttää ja kertoa. Tämä teki vierailusta tärkeän koko luokalle! Jokainen sai jakaa omia kokemuksiaan tunnin mittaisen vierailun aikana. Pojan oli mukava kuulla ja nähdä, että muillakin lapsilla on arpimuistoja ja he ovat käyneet lääkäreillä ja syöneet lääkkeitä. Heillä oli paljon yhteistä!

Viesti, jonka haluat jakaa potilaiden/perheen tai muiden terveydenhuollon ammattilaisten kanssa:
Elinsiirtolasten ja heidän perheidensä hoitaminen vaatii moniammatillista osaamista. Moniammatillisen tiimin kanssa on tärkeää pitää säännöllisiä tapaamisia, joissa on mahdollista jakaa ajatuksia ja keskustella siitä, miten potilasta ja perheitä hoidetaan parhaalla mahdollisella tavalla.
Eräs potilas on todennut että "Elinsiirto ei ole koko elämä, mutta vaikuttaa koko elämään".

Ulla

I remember these school visits warmly. One 7-year-old boy had a very exciting kidney transplant scar that looked like a lizard. He was so proud of it and had decided to show it in front of the class when I visited them. I came to the classroom and had just presented myself when he lifted his hand and asked: "Can I show my scar now?" I asked him if I could start by telling the class something about what he has experienced first before showing. "Ok" he said. So, I started telling the class about the organs we have inside and what they do, when the same question came: "Can I show it now?"
I understood that he was so excited to get to show his scar to the class, so I had to let him do it as a starter. And oh, what a happy and proud boy he was lifting his shirt and showing his scar to the class. The classmates were impressed, but immediately after that, lots of arms were lifted, because almost all of them had some kinds of scars they wanted to show and talk about. This made the visit important for the whole class! Everybody got to share their own experiences during the one-hour visit. It was nice for our patient to hear and see that other children also have scar-memories and have been to doctors and taken medicine. They had much in common!

Message you want to share with patients /family or other health professionals:
Taking care of transplanted children and their families require multiprofessional knowledge. It's important to get to know each other and have regular meetings with the multiprofessional team where it is possible to share thoughts and discuss how to take care of the patient and families in the best possible way.
A patient said once "A transplant is not the whole life, but it affects everything in life".

Anna

kliininen farmaseutti

Sairaanhoitaja v.1998, Farmaseutti v. 2006.

Ammattiryhmä:
Osastofarmaseutti (clinical pharmacist).

Kokemus lasten elinsiirroista:
10-20 vuotta (v. 2009 alkaen).

Elinsiirto-ohjelmat:
Kaikki lasten kiinteät elinsiirrot Suomessa = munuainen, maksa, sydän, keuhkot, suolensiirrot.

Miksi ryhtynyt työskentelemään lasten elinsiirtojen parissa?
Olen taustaltani myös sairaanhoitaja, ja myöhemmin opiskellut farmaseutiksi. Työskentelin aikaisemmin sairaanhoitajana aikuisten hemodialyysiyksikössä, josta useammat potilaat saivat munuaissiirron hoitojen edetessä. Tällöin tutustuin ensimmäisen kerran elinsiirtojen maailmaan Suomessa, ja koin erikoisalan mielenkiintoiseksi. Kun myöhemmin valmistuin farmaseutiksi, hakeuduin töihin taas sairaalaan ja pääsin työskentelemään lasten elinsiirtojen parissa HUS Lastenklinikan elinsiirto-osastolla.

Pääasialliset muutokset lasten elinsiirroissa oman työurani aikana:
- Lääkehoitojen protokollat ovat muuttuneet ja muokkaantuneet vuosien varrella.
- Omaissiirrot lisääntyneet munuaissiirroissa.
- Potilasryhmät ja diagnoosit johtaen elinsiirtoon ovat muuttuneet monimuotoisimmaksi johtuen esimerkiksi maahanmuuton lisääntymisestä Suomeen.
- Uusia elinsiirtoja aloitettu lapsilla (mm. suolensiirrot).
- Uusia lääkehoitoja ja valmisteita on tullut markkinoille ja aloitettu käyttämään lasten elinsiirroissa Suomessa.
- Oma työnkuvani osastofarmaseuttina kehittynyt logistiikasta ja lääkkeen valmistuksesta sairaalassa enemmän kliiniseen suuntaan. Nykyään työnkuvaani kuuluvat useat lasten ja perheiden lääkeohjaukset, moniammatilliset työryhmät, uusien lääkkeiden ohjeiden tuottaminen ja moniammatillinen työskentely useiden eri ammattiryhmien kanssa koskien lasten elinsiirtoja.

Neuvoja hyvään kommunikaation lasten ja perheiden kanssa:
- Huomioi aina perheen tausta ja aikaisempi kokemus esimerkiksi lääkehoitoon liittyen.
- Ota itse potilas/lapsi aina mukaan keskusteluun, jos ikä/ko-operaatio on riittävällä tasolla yhteistyöhön.

Anna

clinical pharmacist

Nurse (graduated 1998), Pharmacist (graduated 2006).

Profession:
Clinical pharmacist.

Experience in children’s organ transplants:
10-20 years (from 2009).

Transplant programs:
All solid organ transplants for children in Finland = kidney, liver, heart, lung, intestinal transplants.

Why did you start working with children’s organ transplants specialty?
My other profession is a nurse, and I later studied to become a pharmacist. I previously worked as a nurse in the adult hemodialysis unit, where most of the patients received kidney transplants as the treatments progressed.
That was the first time I got to know the world of organ transplants in Finland, and I found the specialty interesting. When I later graduated as a pharmacist, I applied for a job at the hospital again and I got to work with children’s organ transplants at the Paediatric Organ Transplant Department.

Main changes in children’s organ transplants during my own career:
- Medical treatment protocols have changed and modified over the years.
- Familial living donor transplants have increased in kidney transplants.
- Patient groups and diagnoses leading to organ transplantation have become more diverse, for example due to the increased immigration to Finland.
- New organ transplant programmes started in children (e.g. small bowel transplants).
- New medication treatments and preparations have entered the market and started to be used in children’s organ transplants in Finland.
- My job description as a clinical pharmacist has evolved from logistics and drug preparation in the hospital to a more clinical direction. Today, my job description includes medication counseling and guidance for children and families, multi-professional working groups, producing instructions for new medicines and collaboration with several different professions regarding children’s organ transplants.

Your advice for good communication with children and families:
- Always take into consideration the family’s background and previous experience with medication treatment.
- Always include the patient/child in the discussion if the age/cooperation is at a sufficient level for communication.

- Ota huomioon/kuuntele vanhempien ja lapsen mielipiteitä sekä toiveita lääkehoidon toteutuksessa (esimerkiksi voiko lääkkeen muotoa vaihtaa tabletista liuokseen tai päinvastoin, voiko lääkkeen pahaa makua jotenkin poistaa/peittää, voiko lääkkeiden antoajankohtia muokata helpottamaan kotona annettavan lääkehoidon onnistumista).
- Kerro lääkehoitoon liittyvät asiat mahdollisimman selkokielellä ja anna perheen esittää kysymyksiä vapaasti.
- Ole valmis muuttamaan omaa suunnitelmaa lääkehoidon toteuttamisesta, jos perheellä on hankaluuksia/ongelmia tai ohjattu lääkehoidon toteutus ei olekaan hyvä kyseiselle lapselle tai perheelle.

Mieleen painunut potilastapaus:
Yksi ensimmäisistä suolensiirtopotilaista, jonka lääkehoidossa olen vuosien varrella ollut toistuvasti mukana.
Jäänyt mieleen erityisesti siksi, että olen itse ollut alusta alkaen mukana ensimmäisissä lasten suolensiirroissa, ja lääkehoidon käytännön toteutus ja ohjeet olivat osittain omalla vastuullani sekä mietittävänä.
Lisäksi on ollut sekä mielenkiintoista, haastavaa että opettavaista seurata kyseisen potilaan matkaa ja kehitystä vuosien mittaan lasten erikoissairaanhoidon asiakkaana.

Viesti, jonka haluan jakaa perheiden ja muiden ammattiryhmien kanssa:
- Lääkehoito elinsiirroissa voi joskus tuntua monimutkaiselta ja jopa hankalalta toteuttaa kotona, mutta hyvällä yhteistyöllä ja jatkuvalla kommunikaatiolla saadaan lääkehoito usein sujuvaksi osaksi lapsen/nuoren elämääo.
- Muistakaa hyödyntää farmasian alan ammattilaisten osaamista osana lääkehoidon suunnittelua ja käytännön toteutusta!

- Take into account/listen to the parents' and the child's opinions and wishes in the implementation of medication treatment (for example, if the formulation of the medication can be changed from a tablet to a solution or vice versa, if the bad taste of the medication can be somehow removed/concealed, if the times of administration of medications can be modified to enable successful medication treatment at home).
- Explain the issues related to medical treatment in a language as clear as possible and let the family ask questions freely.
- Be ready to change your own plan for the implementation of medication treatment if the family has difficulties/problems or the proposed implementation of medication treatment is not applicable for the child or family in question.

A memorable patient case:
One of the first small bowel transplant patients, in whose medication treatment I have been repeatedly involved with over the years. It's memorable especially because I myself have been involved in the first pediatric small bowel transplant from the beginning, and the practical implementation and instructions of the medication treatment were partly my own responsibility and development. In addition, it has been both interesting, challenging and educational to follow the journey and development of the patient in question over the years as a patient of children's specialised medical care.

Messages you want to share with families and other professional groups:
- Medication treatment in organ transplants can sometimes seem complicated and even difficult to implement at home, but with good cooperation and constant communication, medication treatment can often become an integral and flexible part of a child's/youth's life.
- Remember to use the expertise of pharmacy professionals as part of the planning and practical implementation of medication treatment!

Timo

lasten nefrologi / elinsiirtopediatri

Rooli ja maa:

Olen lastennefrologi ja elinsiirtolastenlääkäri Helsingin yliopistollisessa sairaalassa. Olen työskennellyt yksikössämme lähes 20 vuotta eri tehtävissä.

Kokemus lasten elinsiirroista:

30 vuotta.

Elinsiirto-ohjelma:

Suomessa kaikki lasten kiinteiden elinsiirrot on keskitetty Helsinkiin. Väestömme on pieni, vain 5,5 miljoonaa asukasta, ja se on tärkein syy keskitettyyn hoitoon. Kaikki elinsiirrot, mukaan lukien leikkaus ja tehohoito, tehdään Uudessa lastensairaalassa. Meillä on erityinen lastensiirtokirurgitiimi, joka suorittaa leikkauksen ja siirron jälkeisestä hoidosta vastaavat lastennefrologit, joilla on asiantuntemusta myös elinsiirroista.

Miksi päädyit työskentelemään elinsiirtojen parissa?

Aloitin väitöskirjatyöprojektini lääketieteen opiskelijana, ja ohjaajani oli erikoistunut lasten nefrologiaan. Tutkimusprojektillani ei ollut mitään tekemistä nefrologian tai elinsiirron kanssa, mutta koska "altistuin" nefrologialle, kiinnostukseni siihen suuntaan lisääntyi vähitellen. Nähtyäni, miten suuri vaikutus elinsiirrolla oli lapsen terveydentilaan ja elämänlaatuun, kiinnostuin erityisesti elinsiirroista.

Kuinka saavutetaan toimiva yhteys potilaisiin/perheisiin:

On tärkeää ymmärtää vaikeasti sairaan lapsen huoltajien valtava huoli. Näissä vaikeissa tilanteissa huoltajien on joskus vaikea erottaa, mitkä tekijät ovat lapsen hoidon kannalta merkittäviä ja mitkä vähemmän merkittäviä. Meidän ammattilaisten on tehtävä on pyrkiä huomioimaan myös nämä "vähemmän" merkittävät asiat ja suhtautua niihin vakavasti.

Onko mieleesi jäänyt jokin erityisen tapaus? Jos on, miksi?

Yksi ensimmäisistä keuhkonsiirtopotilaistamme oli toipumassa leikkauksesta. Eräänä päivänä hän pyysi minut potilashuoneeseen ja alkoi laulaa suomalaista iskelmää. Rehellisesti sanottuna se kuulosti melko epävireiseltä, mutta potilas oli niin onnellinen, että hän pystyi laulamaan. Ennen siirtoa se ei ollut mahdollista huonon keuhkojen toiminnan vuoksi. Olimme molemmat todella iloisia ja liikuttuneita tästä tilanteesta.

Viesti, jonka haluat jakaa potilaiden/perheen tai muiden terveydenhuollon ammattilaisten kanssa:

On tärkeää muistaa, että elinsiirto ei tee lapsista täysin terveitä. Jatkuva lääkitys ja kliiniset kontrollit vaaditaan koko elämänsä ajan. Elämä elinsiirron jälkeen voi kuitenkin olla melko normaalia.

Timo

pediatric nephrologist / transplant pediatrician

Role:

I am a pediatric nephrologist and transplant pediatrician in Finland. I have been working in our Unit for almost 20 years in different positions.

Experience in the field of pediatric transplantation:

30 years.

Type of Transplant Program:

In Finland, all pediatric solid organ transplantations are centralised to Helsinki. Our population is small, only 5.5 million inhabitants, and that is the main reason for centralised care. All transplantation, including surgery and intensive care, are performed at the New Children's Hospital. We have a special team of pediatric transplant surgeons and the post-transplant care is handled by pediatric nephrologists, who have expertise on organ transplantation.

Why did you choose to become a healthcare professional dealing with transplant?

I started my PhD project as medical student, and my supervisor was specialised in pediatric nephrology. My PhD project did not have anything to do with nephrology or transplantation, but since I became "exposed" to nephrology my interest in that field gradually increased. After seeing the enormous change in the quality of life due to transplantation, I became especially interested in SOTs (Solid Organ Transplantations).

Advice on how to establish a good relationship with patients/families:

It is important to be aware of the enormous worry that the parents of a severely ill child carry. It is sometimes difficult for parents to differentiate which issues are important and which are less important. We should have patience to explain also the "less" important aspects and take them seriously as well.

Any particular case you recall? If so, why?

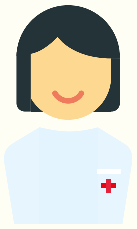
One of our first lung transplanted patient was recovering from the operation. One day she asked me to go to her room and started to sing a Finnish pop song. To be honest, it sounded a bit out of tune, but the patient was so happy being able to sing. Before transplantation it was not possible because of her poor lung function. We were both happy and touched about this situation.

Message you want to share with patients/family or other health professionals:

It important to remember that transplantation does not make children totally healthy. Continuous medication and clinical check-ups are required throughout their life. However, life after transplantation can be near to normal.

France

Marie
infirmière de coordination



Rôle:
Infirmière de coordination du parcours patient greffe de moelle osseuse.

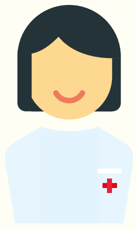
Expérience en transplantation de cellules souches hématopoïétiques:
Inférieure à 1 an.

Pourquoi avez-vous choisi de devenir un professionnel de la santé s'occupant de transplantations?
Je suis infirmière depuis 18 ans et j'ai déjà travaillé dans de nombreuses spécialités pédiatrique. Je souhaitais changer de registre professionnel, être plus dans l'accompagnement et l'éducation des enfants et de leurs familles.
Il s'agit d'une création de poste avec beaucoup de possibilité créatives, c'est intellectuellement enrichissant et stimulant. J'accompagne les patients et leur aidant dans une étape délicate mais très importante de leur parcours de soin.
La greffe de cellules souches hématopoïétiques n'est pas une procédure d'urgence. Comme il s'agit d'une greffe provenant d'un donneur vivant, la date est fixée plusieurs jours à l'avance.
Avant la greffe, il est nécessaire de préparer le corps à la recevoir: cette période, appelée conditionnement, consiste à administrer une chimiothérapie au patient.

Conseils pour établir une bonne relation avec les patients/familles:
S'assurer d'une bonne compréhension de la langue parlée et écrite, prendre le temps d'expliquer les choses et être disponible à la demande.

Un cas particulier dont vous vous souvenez?
Le cas de deux frères, le cadet a été diagnostiqué d'un déficit immunitaire sévère avec une indication de greffe de cellules hématopoïétiques rapidement.
Lors du dépistage de la fratrie pour déterminer les compatibilités, découverte que le frère ainé est lui aussi porteur de cette maladie avec indication de greffe à moyen terme. Le cadet a été greffé avec un donneur fichier, car pas de compatibilité familiale, l'ainé a été greffé deux mois plus tard avec le frère cadet.
Pour l'instant ils vont tous bien.

Marie
coordinating nurse



Role:
Bone Marrow Transplant Patient Pathway Coordinating Nurse.

Experience in hematopoietic stem cells transplantation:
Less than 1 year.

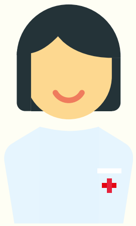
Why did you choose to become a healthcare professional dealing with transplants?
I have been a nurse for 18 years and I have already worked in many pediatric specialties; I wanted to change my professional role, in order to be more involved in supporting and educating children and their families. It is a job with a lot of creative possibilities, it is intellectually enriching and stimulating.
I accompany patients and help them through a delicate but very important stage of their care journey.
Hematopoietic stem cell transplantation is not an emergency procedure. Since this is a transplant from a living donor, the date is planned several days in advance. Before the transplant, it is necessary to prepare the body to receive it: this period, called conditioning, involves administering chemotherapy to the patient.

Advice on how to establish a good relationship with patient/families:
Ensure a good understanding of spoken and written language, take the time to explain things and be available when needed.

Any particular case you recall?
The case of two brothers: the younger was diagnosed with a severe immune deficiency with an indication of urgent hematopoietic cell transplantation.
During the screening of the siblings to determine compatibility, it was discovered that the older brother was also a carrier of this disease, with indication of transplant in the medium term.
The youngest received a transplant from an unknown donor, as there was no family compatibility; the eldest received a transplant two months later from the middle brother. For now they are all doing well!

Djamilla

infirmière de coordination



Rôle:
Infirmière de coordination du parcours patient greffe hépatique.

Expérience en Transplantation hépatique:
Depuis 15 ans.

Conseils pour établir une bonne relation avec les patients et leurs familles:
Ecoute, transparence et disponibilité.

Un cas particulier dont vous vous souvenez?
C'était au tout début de ma prise de poste en transplantation hépatique. Nous avons accueilli une famille libyenne venue avec un visa touristique: les deux parents, leurs deux fils, et une petite fille gravement malade. Rapidement, la mère a dû repartir avec les garçons, laissant le père seul en France avec leur fillette de moins d'un an, atteinte d'une atrésie des voies biliaires compliquée par l'échec de la procédure de Kasaï. Son état s'est rapidement dégradé, nécessitant une greffe en super urgence. Un mois après leur arrivée, la petite a été greffée, mais les suites opératoires ont été marquées par de lourdes complications. Le père, épuisé mais déterminé, a dû faire plusieurs allers-retours pour permettre à la mère de revenir. Elle a pu arriver seule pendant la période de réanimation, mais a été contrainte de repartir peu de temps après. Durant cette attente, nous leur envoyions régulièrement des photos pour les tenir informés de l'évolution.

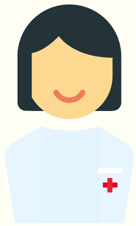
Petit à petit, la situation s'est améliorée. Le père est revenu auprès de sa fille, et a finalement réussi à faire revenir la mère. Après un long séjour à l'hôpital et de nombreuses démarches, les frères ont pu, eux aussi, rejoindre la famille.

Aujourd'hui, ils vivent en France. Ils se sont pleinement intégrés: les parents travaillent, les enfants vont à l'école. La petite fille a maintenant 13 ans et elle va très bien.

Cette histoire m'a profondément marquée. Voir une famille déchirée, séparée dans une situation aussi critique, avec un risque vital pour leur enfant … C'était très dur. Mais aujourd'hui, tout s'est bien terminé. C'est cela qui donne tout son sens à mon travail: faire tout ce qui est en mon pouvoir pour rendre possible l'impossible, et accompagner les familles à chaque étape de cette épreuve.

Djamilla

coordinating nurse



Role:
Liver Transplant Patient Pathway Coordinating Nurse.

Experience in liver transplantation:
15 years.

Advice on how to establish a good relationship with patients/families:
Listening, transparency and availability.

Any particular case you recall?
It was at the very beginning of my liver transplant position. We welcomed a Libyan family who came with a tourist visa: the two parents, their two sons and a seriously ill little girl. The mother had to leave quickly with the boys, leaving the father alone in France with their little daughter, who was less than one year old, suffering from biliary atresia complicated by the failure of the Kasaï procedure.

Her condition deteriorated rapidly, requiring an emergency transplant. A month after their arrival the little girl received the transplant, but the post-operative course was marked by serious complications. The father, exhausted but determined, had to make several trips back and forth to allow the mother to return. She was able to arrive alone when the child was at the Intensive Care Unit, but she was forced to leave shortly after. During this time, we regularly sent them photos of the child to keep them informed of developments.

Little by little, the situation improved. The father returned to his daughter and finally managed to bring the mother back. After a long hospital stay and many steps, the brothers were also able to join the family.

Today they live in France. They have fully integrated: the parents work, the children go to school. The little girl is now 13 years old and she is doing very well.

I was deeply impressed by this story. Seeing a family torn apart, separated in such a critical situation, with a vital risk for their child... It was very hard. But everything turned out well.

This is what makes my work meaningful: doing everything in my power to make the impossible possible, and accompanying families at every stage of this ordeal.

Carmen

chirurgien hépatobiliaire et intestinal pédiatrique

Je suis chirurgien pédiatre spécialisée dans la chirurgie hépatobiliaire et de l'insuffisance intestinale. Dans ce cadre, je réalise des transplantations de foie et d'intestin chez l'enfant depuis 10 ans.

J'ai découvert cette spécialité particulière lors de mon clinicat de chirurgie, où j'ai eu l'occasion de me former dans la prise en charge de ces malades ci particuliers, faire en sorte qu'un foie «s'allume» puis ensuite réflechir chaque jour à améliorer son geste jusque atteindre la légèreté et la délicatesse du mouvement que cette spécialité exige. Avec le temps, je tends maintenant à «raffiner» encore nos prises en charge et c'est dans ce cadre que j'ai souhaité mi'nvestir dans les reseaux européens.

L'hôpital dans lequel je travaille, est membre, entre autres, de l'ERN Transplantchild. Les ERN ont pour vocation de garantir une équité de soins pour les maladies rares au sein de l'Union européenne. Cela passe par la mutualisation de nos protocoles cliniques, de nos recherches, et par la construction progressive d'un standard de prise en charge commun aux différents pays européens. L'ERN TransplantChild vise à améliorer la prise en charge des enfants transplantés. Les centres qui la composent sont répartis en groupes de travail thématiques (appelés work packages), qui se réunissent tous les deux mois pour faire le point sur les avancées réalisées.

Cette collaboration régulière favorise une interaction riche entre les différents acteurs européens du soin pédiatrique en transplantation, et permet, à terme, de mettre en place un réseau efficace au service de nos jeunes patients et de leurs familles. À titre personnel, je collabore activement au work package 10, qui a notamment pour objectif de tisser un réseau d'associations européennes engagées autour de la transplantation.

Un autre axe de travail que nous développons concerne les adolescents et jeunes adultes transplantés (groupe AYA – Adolescents and Young Adults), avec l'ambition de lancer des programmes de mentorat à l'échelle européenne, de concevoir des outils de diffusion à destination des patients et de leurs familles.

De nombreux défis sont encore devant nous comme par exemple les grandes disparités de règles d'allocation des greffons hépatiques au sein de l'Europe et notamment pour les enfants.

Certains pays en effet vont avoir des règles d'attribution favorisant les enfants et d'autres non. Ce défi conduit au développement de techniques d'amélioration de la préservation des greffons hépatiques et peut être même d'amélioration de la qualité à terme de ces greffons.

Carmen

pediatric hepatobiliary and intestinal surgeon

I am a pediatric surgeon specialised in hepatobiliary surgery and intestinal failure. In this context, I have been performing liver and intestinal transplants in children for the past ten years.

I discovered this unique specialty during my surgical residency, where I had the opportunity to train and learn how to care for these very specific patients - to make a liver "light up," and then, day after day, refine my technique until I reached the delicacy and precision that this specialty demands.

Over time, I have sought to further refine our approaches to care, and it is within this framework that I chose to become involved in the European Reference Networks. The hospital where I work is a member - among others - of the ERN TransplantChild.

ERNs (European Reference Networks) aim to ensure equitable care for rare diseases across the European Union. This is achieved through the sharing of clinical protocols, research efforts, and the gradual development of a common standard of care among European countries. ERN TransplantChild focuses on improving the care of transplanted children.

The centers involved are organised into thematic working groups (called Work Packages), which meet every two months to review progress. This regular collaboration fosters rich interaction among European professionals involved in pediatric transplantation and ultimately helps build an efficient network serving our young patients and their families.

Personally, I am actively involved in Work Package 10, which aims to build a network of European Patients Associations engaged in transplantation. Another area we are developing concerns adolescents and young adults (AYAs group), with the goal of launching European mentorship programs and creating communication tools for patients and their families.

Many challenges still lie ahead, such as the significant disparities in liver graft allocation rules across Europe, especially for children. Some countries have allocation policies that prioritise children, while others do not.

This challenge has led to the development of techniques to improve graft preservation and potentially enhance graft quality over time. Perfusion machines are at the heart of these new technologies and are currently the subject of numerous studies in adult transplantation — and increasingly in pediatrics as well. Another challenge I see is improving access to transplantation training for younger professionals, who often

Ce sont les machines de perfusion des greffons qui sont au cœur de ces technologies nouvelles et qui font l'objet de nombreuses études actuellement en transplantation adulte mais aussi de plus en plus en pédiatrie.

Un autre défi que je vois est l'amélioration de l'accès à la formation en transplantation pour les plus jeunes, qui, bien souvent, ne découvrent la spécialité que s'ils ont la chance d'effectuer des stages dans des services ultraspécialisés. Ceci est le cas partout en Europe et il serait probablement intéressant de développer des programmes de formation commun à l'adresse des plus jeunes pour susciter l'envie précocement d'embrasser cette belle spécialité médicochirurgicale.

Sur la thématique du suivi à long terme et de la qualité de vie, les échanges avec certains adolescents et jeunes adultes transplantés m'ont amenée à réfléchir à la place particulière qu'occupe ce groupe. Ils ne relèvent plus tout à fait de la pédiatrie, mais ne sont pas encore prêts à franchir pleinement le cap vers la médecine adulte.

Peut-être que, nous pédiatres, ne les préparons pas suffisamment tôt à cette transition? Peut-être faudrait-il envisager la mise en place d'équipes mixtes dès les premières étapes du suivi, afin de permettre aux patients et à leurs familles d'aborder ce passage plus sereinement. C'est une thématique qui m'interpelle particulièrement en ce moment, et je suis convaincue que les échanges avec les collègues européens, les associations et les patients eux-mêmes permettront d'orienter la création de programmes dédiés.

Un autre sujet récurrent dans les discussions avec ce groupe concerne les voyages: comment anticiper les soins à l'étranger ? Qui contacter en cas de besoin dans un pays où l'on se rend pour des vacances ou pour travailler, parfois sans ses parents? Ces interrogations sont légitimes et montrent à quel point il est nécessaire de penser un accompagnement global.

Je crois que les ERN, grâce au réseau qu'elles constituent et aux échanges qu'elles favorisent, ont le potentiel d'apporter des réponses concrètes et innovantes à ces enjeux, au service des patients.

Enfin, si je devais résumer notre activité ce serait peut-être de dire que les équipes soignantes partagent avec les familles leurs joies, mais aussi leurs peines, sur ce chemin difficile qu'est la transplantation. C'est une spécialité exigeante qui, lorsqu'elle aboutit, redonne un élan de vie incroyable - à l'enfant, à sa famille, et à nous aussi! Ce sont ces instants d'intensité, qui nous portent et nous donnent la force de continuer, jour après jour, un peu plus loin…

only discover the specialty if they are fortunate enough to do rotations in highly specialised departments.

This is true across Europe, and it would likely be beneficial to develop shared training programs aimed at younger professionals to spark early interest in this beautiful medico-surgical specialty.

On the topic of long-term follow-up and quality of life, discussions with some adolescent and young adult transplant recipients have led me to reflect on the unique position of this group.

They are no longer fully pediatric, yet not quite ready to make the leap into adult medicine. Perhaps we, as pediatricians, do not prepare them early enough for this transition?

Maybe we should consider forming mixed teams from the outset to help patients and their families navigate this transition more smoothly. This is a topic I am currently deeply engaged with, and I am convinced that exchanges with European colleagues, associations, and patients themselves will help guide the development of dedicated programs.

Another recurring topic in discussions with this group is travelling: how to anticipate care abroad? Who to contact in a foreign country when traveling for vacation or work, sometimes without parents? These are legitimate concerns and highlight the need for a comprehensive support system.

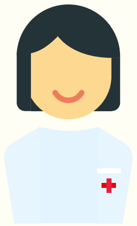
I believe that ERNs, through the networks they build and the exchanges they foster, have the potential to offer concrete and innovative solutions to these challenges - all in service of the patients.

Finally, if I had to summarise our work, I would say that healthcare teams share with families both their joys and their sorrows along the difficult path of transplantation. It is a demanding specialty that, when successful, brings an incredible surge of life - to the child, to their family, and to us as well! These intense moments are what carry us forward and give us the strength to continue, day after day, a little further…

Deutschland / Germany

Marie

Gesundheits - und Kinderkrankenpflegerin



Seit 2009 bin ich als Gesundheits - und Kinderkrankenpflegerin in verschiedenen Bereichen der pädiatrischen Gastroenterologie und Hepatologie tätig.

Schon früh wusste ich, dass ich einen Beruf ergreifen möchte, in dem der Mensch im Mittelpunkt steht - ein Beruf, in dem ich helfen, begleiten und unterstützen kann. Deshalb begann ich 2006 meine Ausbildung zur Gesundheits - und Kinderkrankenpflegerin, die ich 2009 abschloss. Unmittelbar danach startete ich auf einer Station, auf der Kinder und Jugendliche vor und nach einer Lebertransplantation sowie mit komplexen gastroenterologischen Erkrankungen betreut werden.

In dieser Zeit durfte ich viele Familien durch die oft intensive und emotionale Phase einer Transplantation begleiten. Trotz der Herausforderungen habe ich diese Arbeit mit großer Hingabe gemacht. Besonders wertvoll war das starke Miteinander im Team: Wir haben uns in stressigen Momenten gegenseitig unterstützt, in ruhigeren Zeiten gemeinsam gelacht und auch außerhalb der Klinik Freundschaften gepflegt. Die Arbeit war für mich einfach immer schon mehr als ein Beruf - eher eine Berufung.

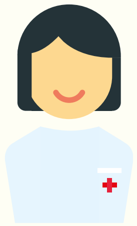
Dank der Unterstützung des Leiters der Abteilung für Kindergastroenterologie und Hepatologie und der Freistellung meiner ehemaligen Stationsleitung erhielt ich 2013 die Möglichkeit, drei Monate in einem Kinderkrankenhaus in Großbritannien zu arbeiten. Diese Erfahrung war für mich sehr prägend - sie hat meinen Blick geschärft und meine Begeisterung für die Schulung von Familien und Patient:innen geweckt. Ob im Umgang mit Ernährungssonden, Medikamententrainings oder bezüglich der Alltagsstruktur nach einer Lebertransplantation: Die individuelle Unterstützung in diesen Bereichen ist essenziell wichtig für den Langzeitverlauf - und leider fehlt im Stationsalltag oft die nötige Zeit und das Personal dafür.

Im Jahr 2018 übernahm ich zunächst stundenweise, später vollständig die Position der Lebendspendekoordinatorin und wechselte in das psychosoziale Team der Abteilung. Diese neue Rolle ermöglichte mir einen Perspektivwechsel auf den komplexen Bereich der Organtransplantation. Besonders bereichernd war es für mich, Familien in dieser herausfordernden Lebensphase begleiten zu dürfen - ein Prozess, der nicht nur medizinisch, sondern auch emotional und sozial einschneidend ist. Ein offenes Ohr, ausreichend Zeit, Unterstützung bei behördlichen Angelegenheiten oder die Begleitung zu den notwendigen Untersuchungen, spielerische Aufklärung - all das sind nur einige der vielen Dinge, die das psychosoziale Team abdeckt.

In den vergangenen Jahren habe ich viele junge Pflegekräfte kennengelernt. Bei einigen zeigte sich bereits früh eine gewisse Resignation - und das ist nur allzu nachvollziehbar. Der Fachkräftemangel ist ein Problem, das unser Gesundheitssystem

Marie

pediatric nurse



I have been working as a pediatric nurse in various areas of paediatric gastroenterology and hepatology since 2009.

I knew very early that I wanted to take up a profession that puts people first - a profession where I could help, accompany and support people. That's why I started my education course as a paediatric nurse in 2006, and I graduated in 2009.
Immediately afterward, I started working in a ward where children and adolescents are cared for before and after a liver transplant, as well as those with complex gastroenterological diseases.

During this time, I was able to accompany many families through the often intense and emotional phase of a transplant. Despite the challenges, I have done this work with great dedication. Particularly valuable was the strong cooperation within the team: we supported each other in stressful moments, laughed together in quieter times and also cultivated friendships outside the hospital. For me, my job has always been more than a profession - more of a vocation.

In 2013, thanks to the support of the Director of the Paediatric Gastroenterology and Hepatology Unit and the leave of absence of my former ward manager, I was given the opportunity to work for three months at a Children's Hospital in the UK.
This experience was very formative for me - it has sharpened my eye and aroused my enthusiasm for training families and patients in dealing with nutritional problems, medications and the everyday structure after a liver transplant. Individual support in these areas is essential for the long-term progression - and unfortunately there is often a lack of time and staff in the day-to-day work to be dedicated to such a purpose.

In 2018 I took over the position of living donation coordinator, initially part time and later on full time, and I moved to the psychosocial team of the Unit.

It was particularly enriching for me being able to accompany families in this challenging phase of their lives - a process that is not only medically but also emotionally and socially incisive. An open listening, sufficient time, support on official procedures, accompanying to the necessary investigations, playful education - all these aspects are just a few of the many things that the psychosocial team covers.

In recent years, I have met many young nurses. Some showed some resignation at an early stage - and this is all understandable. The shortage of skilled workers is a problem that has accompanied our healthcare system for decades. At the same time, modern medical advances enable the survival of patients whose care is sometimes seit Jahrzehnten begleitet. Gleichzeitig ermöglichen moderne medizinische Fortschritte das Überleben von Patient: innen, deren Versorgung mitunter sehr aufwendig ist. Der Pflegebedarf wächst - die Ressourcen hingegen nicht im gleichen Maß.

Deshalb ist es mir ein Herzensanliegen, allen Kolleg: innen zu sagen: Achtet auf euch. Sorgt gut für eure seelische Gesundheit. Lasst die Geschichten der Klinik nach Feierabend - so gut es geht - am Arbeitsplatz. Und vor allem: Sprecht es aus, wenn ihr euch überfordert oder erschöpft fühlt. Ich selbst habe lange versucht, immer mehr zu leisten, immer besser zu funktionieren - bis ich 2021 an einem Punkt angekommen war, an dem nichts mehr ging. Ein Burnout zwang mich zu einer anderthalbjährigen Auszeit.

Dass ich diesen Text geschrieben habe zeigt, mit der Unterstützung von besonderen Menschen - sowohl im beruflichen als auch im privaten Umfeld - habe ich meinen Weg zurück ins Team und in meine Kraft gefunden. Zur Zeit arbeite ich stundenweise in der Elternzeit für die Abteilung, aktualisiere Informationsmaterial für die Familien, unterstütze den Verein Billy Rubin e.V. und plane gerade ein Interviewprojekt mit betroffenen Familien.

Ich wünsche mir, dass wir auf uns selbst mit der gleichen Fürsorge schauen, mit der wir unseren Patient:innen begegnen. Denn nur so können wir auf Dauer den Herausforderungen die dieser Beruf mit sich bringt und den Patient: innen gerecht werden.

very complex. Care needs are growing, but resources are not growing at the same rate.

It is therefore a matter of heart to me to say to all my colleagues: Take care of yourselves. Take good care of your mental health. Leave the hospital's stories at work after work, as much as possible. And most importantly: Say it when you feel overwhelmed or exhausted. I myself tried for a long time to do more and more, to work better and better - until I arrived in 2021 at a point where nothing worked anymore. A burnout forced me to take a year and a half off.

The fact that I wrote this text shows that, with the support of special people - both in my professional and private life - I have found my way back into the team and that I have fully regained my strength. At the moment I work for the Unit part time, updating educational and informative materials for the families, supporting the Patients Association we work closely with and I am currently planning an interview project with the families of transplanted children and adolescents.

I hope that we look after ourselves with the same care with which we look after our patients. This is the only way we can meet the challenges of this profession in the long term and meet the needs of our patients.

Johanna

Pädiatrische Gastroenterologin und Hepatologin

Kinderärztin - pädiatrische Gastroenterologin und Hepatologin.

Erfahrung:
5-10 Jahre in der pädiatrischen Transplantationsmedizin.

Spezialisierung:
Pädiatrische Lebertransplantation.

Warum haben Sie sich entschieden, sich im Bereich pädiatrischen Lebertransplantation zu spezialisieren?
Ich bin im 3. Jahr meiner Weiterbildungszeit zur Kinder - und Jugendfachärztin an die Medizinische Hochschule gekommen. Dort hatte ich bereits studiert und wusste daher, wie spezialisiert die einzelnen Abteilungen sind und dass hier schwerkranke Kinder betreut werden. Für mich war es am Anfang vor allem das Interesse mehr über die Kindergastroenterologie und -hepatologie zu lernen. Schon bald musste ich jedoch feststellen, wie viele Kinder an seltenen Lebererkrankungen leiden, bei denen derzeit nur eine Lebertransplantation das Überleben ermöglichen kann.
Ich habe das Gefühl, in diesen besonderen Bereich hineingewachsen zu sein. Am Anfang betreut man auf Station neue Patientinnen und Patienten, die aus anderen Kliniken verlegt werden. Die Diagnosestellung ist dabei manchmal wie Detektivarbeit: Alle suchen nach dem entscheidenden Hinweis, der den Weg zur Diagnose weist. Viele Patienten sind Säuglinge, oft nur wenige Monate alt. Für die Familien ist es eine schwere Zeit, so kurz nach der Geburt mit einer chronischen, lebensbedrohlichen Lebererkrankung ihres Kindes konfrontiert zu werden.
Man lernt die Familien in dieser Ausnahmesituation sehr gut kennen und braucht viel Fingerspitzengefühl und Fachwissen, um sie in dieser ersten Phase gut zu begleiten. Im weiteren Verlauf betreut man die Kinder und ihre Eltern über viele Monate, manchmal Jahre, in der Ambulanz. Man sieht die Kinder älter werden und darf miterleben, wie sie sich zu kleinen Persönlichkeiten entwickeln. Und doch kommt es immer wieder zu Situationen, in denen man mit den Familien über ernste gesundheitliche Probleme sprechen muss - etwa wenn ihr Kind auf die Warteliste für eine Lebertransplantation aufgenommen werden muss.
Ruft man die Eltern dann an, um mitzuteilen, dass es ein Organangebot gibt, spürt man unmittelbar die Freude, die Aufregung und zugleich die Sorge vor dem, was nun bevorsteht: Wird alles gut verlaufen? Passt das Organ? Gibt es Komplikationen bei der Transplantation? Wie wird es meinem Kind danach gehen? In diesen Momenten spürt man das große Vertrauen, das die Familien dem medizinischen Team entgegenbringen, wenn sie ihr Kind an der OP-Schleuse verabschieden.
Das erste Mal bei einer Lebertransplantation dabei sein zu dürfen, war für mich ein Schlüsselmoment.

Johanna

pediatric gastroenterologist and hepatologist

Pediatrician – Pediatric Gastroenterologist and Hepatologist.

Experience:
5–10 years in pediatric transplantation.

Specialization:
Pediatric liver transplantation.

Why did you choose to become a healthcare professional dealing with transplants?
In my third year of training as a pediatrician, I joined the Medical School where I had previously studied. I already knew how specialised the single Departments were and that some of the most seriously ill children were treated there. Initially, my motivation was to deepen my knowledge of pediatric gastroenterology and hepatology.
It quickly became clear to me how many children suffer from rare liver diseases for which, at present, only a liver transplantation offers the possibility of survival. I feel as I have grown into this highly specialised field step by step. At first, I cared for newly transferred patients on the ward.
Diagnosing their condition often resembled detective work - searching for the crucial clue that would lead us to the right diagnosis. Many patients were infants, only a few months old.
For the families, it is an incredibly difficult time to be confronted so soon after birth with a severe, chronic liver disease in their child.
In these exceptional situations, you get to know families closely. Supporting them well through this initial phase requires great sensitivity as well as expertise.
Over time, we continue to follow these families for months or even years in the outpatient clinic, watching the children grow up and develop their own personalities. Yet, serious conversations are often unavoidable - sometimes about deteriorating health, sometimes about the need to be placed on the waiting list for a liver transplant.
When the moment comes to call and inform a family that there is an organ offer, you can feel their mixture of joy, excitement and concern for what lies ahead. Will everything go well? Will the organ be a match? Will there be complications during the transplantation? How will the child be afterwards? The trust families place in us when they hand their child over at the operating theatre door is profound.
Being present at my first liver transplantation was a defining moment. The procedure had an almost magical quality: the diseased, nodular, greenish liver was removed and in its place the donor liver - smooth, delicate, and healthy - was carefully positioned. It is remarkable that such a complex intervention has become so established and successful today, and an incredible blessing for families. It is no surprise that many of our patients celebrate their "liver birthday" - the gift of a second life.

Johanna

Die Transplantation hatte fast etwas Magisches: Die kranke, knotig-grünliche Leber wurde entfernt und die Spenderleber - so zart, glatt und fein - an ihrer Stelle eingesetzt. Was für eine herausragende medizinische Leistung, dass dies heute so etabliert und erfolgreich möglich ist - und was für ein Glück für die Familien. Nicht umsonst feiern viele unserer Patientinnen und Patienten ihren „Lebergeburtstag“: Sie haben ein zweites Leben geschenkt bekommen.

Das Schönste ist, dass den Kindern durch die Lebertransplantation in der Regel ein weitgehend normales Leben und Aufwachsen ermöglicht wird. Die Familien von der ersten Diagnosestellung über die Monate und Jahre bis zur Transplantation, während des stationären Aufenthaltes und anschließend oft über viele Jahre bis zur Transition in die Erwachsenenmedizin begleiten zu dürfen, empfinde ich als absolutes Privileg. Ich bin überzeugt, dass eine gute und vertrauensvolle Kommunikation dabei entscheidend ist. Eltern und Kinder müssen gut informiert sein. Natürlich läuft nicht immer alles glatt. Auf dem Weg einer Transplantation gibt es viele Stolpersteine, und über mögliche Komplikationen offen zu sprechen ist unverzichtbar. Manche Situationen vergisst man nie: Wenn bei der Transplantation Probleme auftreten und zum Beispiel die Blutversorgung der Spenderleber nicht hergestellt werden kann. Was für ein schwerer Moment, wenn die eigentlich heilbringende Transplantation nicht erfolgreich war und alles Hoffen der Eltern und alle Bemühungen des Transplantationsteams nicht zum Ziel geführt haben. In diesen Momenten ist eine klare, offene Kommunikation mit den Eltern entscheidend. Erfahrungsgemäß können Eltern diese schlimmen Nachrichten/Situationen am besten verarbeiten, wenn Probleme benannt und Lösungswege aufgezeigt werden. Manche verstummen in ihrer Verzweiflung, andere suchen wiederholt das Gespräch. Zum Glück gibt es in den meisten Situationen eine Strategie - wie die High-Urgency-Listung für ein neues Organ, wenn die Blutversorgung des Transplantats nicht gelingt. Auch wenn der Weg beschwerlich und lang ist, gibt es in der Regel eine Lösung.

Und man weiß es vorher nie: Manche Patientinnen und Patienten, bei denen man einen schwierigen Verlauf erwartet, erholen sich erstaunlich schnell und verlassen zwei Wochen nach der Transplantation unsere Station. Andere erleben nahezu jede mögliche Komplikation und bleiben monatelang bei uns, doch auch sie sind irgendwann wieder zuhause, kommen nur noch zur Kontrolle in die Ambulanz und schicken Postkarten aus dem Urlaub oder von der Konfirmation.

Diese Arbeit ist sehr intensiv, und ich nehme sie oft mit nach Hause. Die Gedanken sind bei den Familien, den Problemen, den Entscheidungen - habe ich es gut gelöst? Sie fordert viel, denn es geht um das Leben der Kinder und ihrer Familien, und man möchte sein Bestes geben. Zugleich ist es eine sehr erfüllende Arbeit, weil man Kindern und Familien eine lebensverlängernde Therapie anbieten kann. Möglich ist das nur in einem guten Team, in dem man sich aufeinander verlassen kann. Ebenso wichtig ist, dass die Familien Vertrauen fassen und sich als Teil dieses Teams sehen, das für die Gesundheit ihres Kindes sorgt.

Dies ist und war mein Antrieb: Die Zusammenarbeit und Kommunikation mit den Eltern immer weiter zu verbessern, die Familien zu stärken und ihnen Fähigkeiten an die Hand zu geben, schwierige Situationen zu meistern - und gemeinsam mit uns zu den Expertinnen und Experten für die Erkrankung ihres Kindes zu werden.

Würde ich mich wieder für diesen Bereich entscheiden? Ja. Trotz aller Belastungen und Entbehrungen ist es ein großartiger Beruf. Die vielen Erfahrungen und Erlebnisse mit den Kindern und Familien sind das, was trägt und immer wieder bestätigt: Es lohnt sich.

Johanna

The most rewarding part is that a liver transplant usually enables children to live and grow up in a largely normal way. Being able to accompany families from the first encounter, through the pre-transplant months or years, during the hospital stay for the transplant, and afterwards until the transition to adult medicine, is an absolute privilege.

Good, trusting communication is essential. Parents and children need clear, honest information - especially because the transplant journey is rarely without obstacles. Complications can arise, and it is vital to speak about them openly. Some moments remain unforgettable, such as when a donor liver cannot be adequately supplied with blood during transplantation, causing the procedure to fail despite all hopes and efforts. In these conversations, openness helps families process the situation.

Parents need time and space to express their disappointment - some withdraw in their grief, while others seek repeated discussions.

Fortunately, there are often solutions. In the example of insufficient blood supply, the option is a high-urgency listing for a new donor organ. Even then, we must be transparent about possible complications. Many times, there is a way forward, even if it is long and challenging. Some children, against all expectations, recover swiftly and are walking off the ward just two weeks after transplantation. Others face every possible complication, spending months in hospital, but eventually return home and later send postcards from holidays and family events.

This work is intense and stays with me beyond the hospital walls. My thoughts often remain with the children and families - wondering whether we resolved a problem well or whether we could do more. It is demanding because so much is at stake, and we strive to ensure the best possible outcome for each child entrusted to our care.

Yet it is a deeply fulfilling work. We can offer children and families a life-extending therapy, and this is only possible with a strong, reliable team. It is equally important that families can trust us and feel part of this team dedicated to their child’s health.

This trust has always been my motivation - to continually improve collaboration and communication with parents, to empower families with the knowledge and skills to face difficult situations, and to help them become true experts in their child’s condition, working alongside us for the best possible future.

Would I choose to work in this field again? Absolutely. Despite all the challenges and sacrifices, it is a truly rewarding profession. The many experiences and moments shared with the children and their families are what sustain me and continually reaffirm my decision.

Italia / Italy

Maria

nefrologa pediatrica

Sono una Nefrologa Pediatra presso il Centro Trapianti di Rene Pediatrico di un ospedale universitario in Italia, lavoro in questo ambito da oltre tre anni. Il mio interesse per il trapianto renale pediatrico, tuttavia, è nato già durante gli anni della formazione specialistica ed è diventato il fulcro della mia attività clinica e di ricerca, portandomi a realizzare diversi contributi scientifici e a partecipare a congressi nazionali e internazionali.

La dimensione del trapianto renale mi ha sempre affascinata per il suo profondo significato umano e simbolico: la possibilità di ridare vita attraverso l'esperienza del "dono". È un gesto che trasforma la perdita in speranza, la morte in vita. Questo è ciò che cerco di trasmettere ai nostri pazienti e alle loro famiglie: che ogni trapianto porta con sé la memoria di un altro bambino che non ce l'ha fatta, e che questo non dobbiamo dimenticarlo mai.

Una delle più grandi soddisfazioni del mio lavoro nasce proprio dai bambini, molti dei quali sono segnati fin dalla nascita da una malattia renale cronica e dalla prospettiva della dialisi. Vederli rifiorire dopo il trapianto, tornare a mangiare, a correre, a ridere e a vivere come tutti i loro coetanei è una gioia indescrivibile. E confesso che, davanti a certe scene, durante le visite ambulatoriali o le telefonate per il trapianto, faccio spesso fatica a trattenere la commozione.

Negli ultimi anni ho iniziato a occuparmi con particolare attenzione del tema della "transizione" dall'età adolescenziale a quella adulta. Lavorare con questi ragazzi significa affrontare nuove sfide: accompagnarli verso una maggiore autonomia, aiutarli ad accettare la malattia, anche di fronte ai compagni, e a gestire la paura di non sentirsi "come gli altri". Eppure, sorprendentemente, molti di loro si rivelano più maturi e consapevoli di quanto ci si aspetterebbe, con interessi, passioni e sogni che meritano di essere ascoltati e valorizzati.

Di recente ho iniziato anche a seguire i percorsi di "donazione da vivente", nella maggior parte dei casi da parte dei genitori. Questa attività mi ha permesso di entrare ancora più a fondo nelle vite delle famiglie, di toccare con mano le loro preoccupazioni, la loro fragilità, ma anche la loro straordinaria forza e speranza in un futuro migliore per i propri figli.

Nonostante le difficoltà e il carico emotivo che spesso accompagna il nostro lavoro, sento ogni giorno una profonda gratitudine per la fiducia che le famiglie ci accordano, per i sorrisi dei bambini e per il privilegio di poter assistere alla loro rinascita. Sono questi i momenti che ripagano di ogni fatica, che ricordano il senso profondo di questa professione e il motivo per cui, se potessi, la sceglierei ancora, senza esitazione.

Maria

pediatric nephrologist

I am a Pediatric Nephrologist at the Pediatric Kidney Transplant Center of a University Hospital in Italy, and I have been working in this field for over three years. My interest in pediatric kidney transplantation, however, began much earlier - during my residency years - and since then has become the core of my clinical and research activity, resulting in several scientific contributions and presentations at national and international conferences.

Kidney transplantation has always fascinated me for its profound human and symbolic meaning: the chance to give new life through the experience of "donation". It is a gesture that transforms loss into hope, death into life. This is what I try to convey to our patients and their families: that every transplant carries the memory of another child who could not make it, and we must never forget that.

One of the greatest satisfactions in my work comes directly from the children themselves - many of whom are born under the shadow of chronic kidney disease and dialysis. Seeing them flourish again after transplantation, regain their appetite, start running, laughing and simply living like any other child is a joy beyond words. There are moments, especially during follow-up visits or the emotional phone calls before a transplant, when I find it hard to hold back tears.

In recent years, I have also become particularly interested in the process of "transition" - the delicate journey from adolescence to adulthood. Working with these young people means facing new challenges: learning to hand them the responsibility for their health, witnessing their struggle for autonomy and sometimes their difficulty in accepting the disease, especially in front of peers. Yet, it often surprises me how mature and resilient they can be, full of interests and dreams, both individual and shared.

More recently, I have started to follow the "living donor kidney transplant program", in most cases involving parents donating to their children. This experience has allowed me to enter even more deeply into the intimate stories of these families - to touch their fears, their fragility, and their extraordinary strength.

Despite the challenges and emotional burden that this work can sometimes bring, I feel immense gratitude every day - for the trust of the families, for the smiles of the children, and for the privilege of being able to witness their rebirth. These are the moments that make every effort worthwhile, that remind me why I chose this path, and why I would choose it again, without hesitation.

Paola

epatologa pediatrica

Prendermi cura dei bambini sottoposti a trapianto di fegato è un viaggio che ho intrapreso dieci anni fa. Come epatologa pediatrica l'ho percorso al fianco di colleghi, famiglie e, soprattutto, pazienti. Come ogni viaggio, il mio è pieno di ricordi, sia gioiosi che strazianti. Vorrei condividere questi momenti sotto forma di istantanee, una per ogni anno, catturando l'essenza di questa straordinaria esperienza.

2015

Una bambina cinese di un anno è stata sottoposta a trapianto di fegato per malattia epatica allo stadio terminale causata da atresia biliare. È stata la prima paziente trapiantata di fegato che ho curato come specializzanda in pediatria, e rappresenta in qualche modo una pietra miliare che ha plasmato il mio viaggio nell'epatologia pediatrica.

2016

Un bambino di nove anni con epatoblastoma è stato sottoposto a un trapianto di fegato. Nel corso degli anni ha affrontato due ricadute della malattia, si è coraggiosamente sottoposto alle cure e ha vinto la battaglia. Ora, a 18 anni, è pronto ad abbracciare il prossimo capitolo della sua vita.

2017

A un bambino di cinque mesi proveniente dall'estero è stata diagnosticata l'atresia biliare. Abbiamo contribuito a garantire la copertura sanitaria in Italia, dandogli la possibilità di ricevere un trapianto di fegato salvavita. Oggi, a otto anni, sua madre condivide con noi orgogliosamente che eccelle in matematica!

2018

Un ragazzo di tredici anni con leucinosi è stato sottoposto a trapianto di fegato. Sei mesi dopo la sua dimissione, i suoi genitori ci hanno inviato una foto commovente di lui che dà un grosso morso ad un hamburger, una gioia semplice che una volta era impossibile per lui.

2019

Un trapianto domino che coinvolge un donatore deceduto, un bambino con leucinosi e un altro con malattia epatica allo stadio terminale a causa di atresia biliare. A volte raddoppiare il lavoro significa raddoppiare il successo!

2020

Una bambina di 1 anno con atresia biliare è stata sottoposta a trapianto di fegato all'inizio della pandemia di COVID-19.

Paola

pediatric hepatologist

Caring for children undergoing liver transplantation is a journey, one that I embarked on ten years ago. As a Pediatric Hepatologist I have walked this path alongside colleagues, families, and, most importantly, patients. Like any journey, mine is filled with memories, both joyful and heartbreaking. I would like to share these moments as snapshots, one for each year, capturing the essence of this extraordinary experience.

2015

A one-year-old Chinese girl underwent a liver transplant for end-stage liver disease caused by biliary atresia. She was the first liver transplant patient I cared for as a pediatric resident and represents somehow a milestone that shaped my journey in pediatric hepatology.

2016

A nine-year-old boy with hepatoblastoma underwent a liver transplant. Over the years, he faced two disease relapses and bravely underwent treatment and won the battle. Now, at 18, he is ready to embrace the next chapter of his life.

2017

A five-months-old boy from abroad was diagnosed with biliary atresia. We helped secure Italian healthcare coverage, giving him the chance to receive a life-saving liver transplant. Today, at eight years old, his mother proudly shares that he excels in mathematics!

2018

A thirteen-year-old boy with maple syrup urine disease underwent a liver transplant. Six months after his discharge, his parents sent us a heartwarming photo of him taking a big bite of a hamburger, a simple joy that was once impossible for him.

2019

A domino transplant involving a deceased donor, a child with maple syrup urine disease and another with end-stage liver disease due to biliary atresia. Sometimes, doubling the work means doubling the success!

2020

A 1-year-old girl with biliary atresia underwent a liver transplant at the very onset of the COVID-19 pandemic.

While the world came to a halt, organ donation never ceased, and we continued treating children with end-stage liver disease, ensuring they received the care they needed.

Paola

Mentre il mondo si è fermato, la donazione di organi non è mai cessata e abbiamo continuato a curare i bambini con malattia epatica allo stadio terminale, assicurando che ricevessero le cure di cui avevano bisogno.

2021
Una bambina di nove anni con epatoblastoma ha subito un trapianto di fegato. Purtroppo, è morta di recente a seguito di una recidiva della malattia oncologica. Il suo viaggio rimane un promemoria sia della speranza che della fragilità che accompagnano queste battaglie.

2022
Una bambina di quattro anni con la sindrome di Alagille è morta tragicamente poco dopo un trapianto di fegato di emergenza a causa dello scompenso acuto della malattia epatica. In sua memoria, i suoi genitori hanno fatto una sentita donazione al nostro ospedale. Recentemente hanno condiviso con noi la gioia per la nascita di un figlio.

2023
Un ragazzo di diciassette anni con colestasi intraepatica familiare progressiva di tipo 3 è stato sottoposto a trapianto di fegato. Prima dell’intervento ci ha fatto promettere che avrebbe potuto farsi il tatuaggio di una fenice che risorge dalle sue ceneri, come simbolo della sua stessa rinascita.

2024
Un rifugiato palestinese di cinque anni con diagnosi di atresia biliare è arrivato in Italia con la sua famiglia a giugno. Durante le vacanze di Natale ha ricevuto un trapianto di fegato salvavita, segnando un nuovo inizio per lui e i suoi genitori.

2025
Quest’anno è appena iniziato. Aspetto di vedere cosa porterà!

Paola

2021
A nine-year-old girl with hepatoblastoma underwent a liver transplant. Sadly, she recently passed away following a relapse of her disease. Her journey remains a reminder of both the hope and the fragility that come with these battles.

2022
A four-year-old girl with Alagille syndrome tragically passed away shortly after an emergency liver transplant due to acute liver disease decompensation. In her memory, her parents made a heartfelt donation to our institution. Recently, they shared the joyful news of the birth of their son.

2023
A seventeen-year-old boy with progressive familial intrahepatic cholestasis type 3 underwent a liver transplant. Before surgery, he made us promise that he could get a tattoo of a phoenix rising from its ashes as a symbol of his own rebirth.

2024
A five-year-old Palestinian refugee diagnosed with biliary atresia arrived in Italy with his family in June. During the Christmas holidays, he received a life-saving liver transplant, marking a new beginning for him and his parents.

2025
This year has just begun. I am looking forward to seeing what will come next!

Nicola
cardiochirurgo

Ilaria
segretaria

Cardiochirurgo: Buongiorno Ilaria, come sta?

Segretaria: Molto bene dottore, si ricomincia la settimana a pieno ritmo. Ho sentito che ieri avete trapiantato il cuore a una bambina di pochi anni…

Cardiochirurgo: Sì, è stata davvero una giornata molto dura e fisicamente provante. Sai, abbiamo ricevuto la segnalazione il giorno prima e da quel momento la mia testa e il mio cuore si sono concentrati esclusivamente su queste due persone: da una parte il bambino che ha donato e la tragedia che i suoi genitori stanno vivendo, dall'altra la grande possibilità per questa bambina che finalmente potrà tornare alla vita se supererà la fase acuta del post-trapianto. Al momento sembra che stia andando bene e che il cuore stia funzionando alla grande.

Segretaria: Questa è la notizia più bella e che ci riempie più di gioia. Immagino la sua emozione nel comunicare ai genitori questa notizia…

Cardiochirurgo: Già! Da quando sono genitore è molto più difficile scindere la parte professionale da quella umana, specie quando si tratta del trapianto di un bambino. Da un lato mi sentivo un supereroe all'idea che avrei ridato la speranza di una vita nuova alla loro bambina, dall'altro la paura che il trapianto potesse non andare bene, e quindi la difficoltà a dire loro che un intervento di questo tipo è gravato da tante possibili complicanze, inclusa la possibilità di non sopravvivere.

Segretaria: Qual è il momento più facile per un cardiochirurgo in un trapianto?

Cardiochirurgo: Ce ne sono fondamentalmente due: quando il cuore riparte con l'attività elettrica e vedi la vita che riprende, e quando finalmente l'intervento è finito, tutto è andato per il verso giusto, vai incontro ai genitori e mentre parli con loro il volto pieno di paure e insicurezze si riempie di un colore nuovo, felice, ricco di speranza. I familiari dei pazienti adulti spesso mi ringraziano con parole molto accorate, mentre per i genitori dei bambini che ho trapiantato è nel loro sguardo e nei loro gesti, nei loro sospiri e nell'abbraccio da mamma e papà che sta tutta la loro immensa riconoscenza. E questa è una cosa che sperimento ad ogni visita, in ogni momento in cui vedo quel bambino o quella bambina crescere, cominciare a camminare, a parlare. La vita di un individuo che cresce e si spera diventerà adulto.

Segretaria: Caro dottore, questa non è solo una speranza ma una realtà. In questi miei lunghi anni di esperienza, aggiornando carte o rispondendo al telefono, ho visto tanti genitori vivere quello che ora vivono i genitori di cui parla lei, e ho visto altrettanti bambini così indifesi e così indeboliti da molte complicanze anche post trapianto che oggi sono finalmente grandi, adulti, felici, spensierati, amanti della

Nicola
cardiac surgeon

Ilaria
secretary

Cardiac surgeon: Good morning Ilaria, how are you?

Secretary: I am very well doctor, we have started the week at full speed. I heard that yesterday you transplanted the heart of a few years old girl...

Cardiac surgeon: Yes, it was a very hard and physically trying day. You know, we got the report the day before and from that very moment my head and my heart focused exclusively on these people: on the one hand, the donor child and the tragedy his parents are experiencing, on the other hand, the great possibility for this little girl who will finally be able to return to life if she overcomes the acute phase of post-transplantation. So far it seems she is doing well and that the heart is working great.

Secretary: This is the best news, it fills us with joy. I can imagine your emotion in telling her parents the news...

Cardiac surgeon: Yeah! Since I became a father it is much more difficult to separate the professional side from the human one, especially when it comes to the transplant of a child. On the one hand, I felt like a superhero to the idea that I would give the hope of a new life to their child, on the other hand, the fear that the transplant might not go well, and therefore the difficulty in telling them that such an intervention is burdened with so many possible complications, including the possibility of not surviving.

Secretary: What is the easiest moment for a cardiac surgeon in a transplant?

Cardiac surgeon: There are basically two: when the heart starts again with the electrical activity and you see the life that starts flowing back, and when the surgery is finally over, everything went well, you go to meet the parents and as you talk to them their faces full of fears and uncertainties are filled with a new, happy, hopeful color. Parents of adult patients often thank me with very heartfelt words, while for the parents of the children I transplanted it is in their eyes and gestures, in their sighs and in the embrace as a mother and a father that all their immense gratitude lies. And this is something that I experience at every follow-up visit, when I see that child growing up, starting to walk and talk. The life of a person that grows up and hopefully becomes an adult.

Secretary: Dear Doctor, this is not just a hope but a reality. In my many years of experience, working in this Unit updating papers or answering the phone, I have seen so many parents going through the same as those parents you are referring to now, and I have seen so many children so helpless and so weakened by many vita; certo con le loro sofferenze e le loro difficoltà, ma sono arrivati ben oltre i traguardi che i suoi colleghi prima di lei avevano previsto.

Cardiochirurgo: Ilaria, quali sono le qualità che dovrebbe avere o sviluppare secondo lei un cardiochirurgo per essere prima di tutto un bravo medico?

Segretaria: È una domanda molto difficile... Ma vede, io credo che la verità più grande stia in questa frase: ''Fa' agli altri quello che ti piacerebbe che gli altri facessero a te''. Il medico deve trattare i più deboli, gli ultimi, i soli, i più indifesi, e quindi anche e soprattutto i bambini più in difficoltà, magari senza un supporto familiare, come se fossero figli o nipoti suoi.

Cardiochirurgo: Ha perfettamente ragione…

Segretaria: Le dirò di più: c'è una bellissima fiaba di Esopo, quella del topo e del leone, che calza a pennello. Una volta il leone borioso si pavoneggiava davanti al topolino di quanto fosse forte e altero rispetto a lui. Finché un bel giorno il leone fu imprigionato e incatenato dai cacciatori. Il topolino, passando, lo vide sofferente. Il leone cominciò a piangere e gridare ''Topo, aiutami, fai qualcosa sono imprigionato ti scongiuro'' e il topolino mosso da pietà cominciò a rosicchiare le corde fino a liberare il leone, che gli fu riconoscente per la vita. Ecco, anche la persona più indifesa e piccola nella società può salvarti e aiutarti; così anche i più piccoli pazienti possono diventare un giorno fonte di aiuto per gli altri.

Telefono che squilla, il cardiochirurgo risponde e poi riattacca.

Cardiochirurgo: Grazie Ilaria, le sue parole mi toccano molto… Ora devo andare perché, come lei sa bene, il cardiochirurgo che sono io oggi è stato molti anni fa un bambino trapiantato e mi aspettano per fare un prelievo di monitoraggio. In questo caso, la fiaba che ci insegnano da bambini è diventata realtà!

complications, even after transplantation, that today are finally well, adults, happy, light-hearted, lovers of life. Of course with their sufferings and difficulties, but they have gone far beyond the goals that your colleagues before you had foreseen.

Cardiac surgeon: Ilaria, what are in your opinion the qualities that a cardiac surgeon should have or should develop in order to be a good doctor?

Secretary: It's a very difficult question... But you see, I believe the greatest truth lies in this sentence: 'Do to others what you would like others to do to you'. The doctor must treat the weakest, the last, the lonely, the most defenseless, and therefore also and above all the most difficult children, perhaps without family support, as if they were his children or grandchildren.

Cardiac surgeon: You're absolutely right...

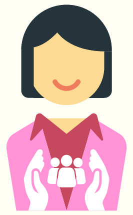
Secretary: I'll tell you more: there is a beautiful fairy tale of Aesop, that of the mouse and the lion, which fits like a glove. The lion was showing off in front of the mouse for how strong and tall he was in comparison to him. Until the day the lion was imprisoned and chained by the hunters. The mouse, passing by, saw him suffering. The lion started crying and shouting ''Mouse, help me, do something, I am imprisoned, I am begging you'' and the mouse moved by pity began to gnaw the strings until the lion was freed and grateful for his life. You see, even the most defenseless and weakest person in society can save and help you: even the smallest patient can one day become a source of help for others.

Phone ringing, the cardiac surgeon picks up and then hangs up.

Cardiac surgeon: Thank you Ilaria, your words touch me a lot... Now I have to go because, as you know well, the cardiac surgeon I am today was many years ago a transplanted child and they are waiting for me to take a monitoring blood sample. In this case, the fairy tale they teach us as children has become reality!

Alessio
assistente sociale

Francesca
assistente sociale



Siamo Alessio e Francesca, assistenti sociali di un ospedale pediatrico. Il nostro Servizio Sociale collabora con i reparti di degenza e con tutti gli altri servizi presenti nella struttura per assicurare una presa in carico globale ed integrata del paziente e della sua famiglia.

In questo contesto forniamo, a supporto dell’equipe multidisciplinare ospedaliera, la nostra consulenza anche nei programmi di inserimento in lista di trapianto, dove nello specifico, ci occupiamo di approfondire l’organizzazione familiare, identificando le risorse di cui il nucleo dispone e le eventuali necessità e/o fragilità dei genitori connesse alla complessità di ciascun caso.

Attraverso lo strumento professionale del colloquio, ci poniamo l’obiettivo di costruire un rapporto di fiducia con la famiglia che si fonda sull’accoglienza, l’ascolto e l’empatia. Nel nostro lavoro infatti al centro viene posta la famiglia del paziente, che deve essere sempre coinvolta per identificare il reale bisogno, stimolata, responsabilizzata e resa protagonista delle azioni ad essa destinate. Si cerca di favorire una riflessione congiunta sul percorso prospettato dai sanitari, sensibilizzando, nello specifico, il caregiver sull’ importanza del suo ruolo per la buona riuscita del percorso di cura.

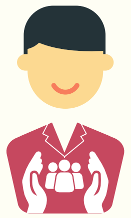
Laddove necessario, proponiamo il coinvolgimento dei servizi territoriali non solo per garantire una continuità terapeutica tra ospedale e territorio ma anche per migliore le condizioni di vita quotidiana e garantire al bambino, compatibilmente alla patologia, una vita scolastica, sportiva, relazione e sociale.

Proprio di recente abbiamo seguito il caso del minore F., un adolescente appartenente ad una famiglia monogenitoriale con tre sorelle più piccole; questa situazione ha rappresentato un chiaro esempio di quanto l’integrazione socio-sanitaria, interna al contesto ospedaliero ma anche con i servizi territoriali, costituisca un elemento fondamentale per una presa in carico efficace e globale del nucleo familiare.

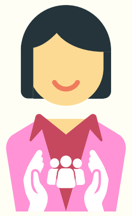
Sin dal primo incontro con la madre del ragazzo, è apparso evidente che la situazione familiare fosse caratterizzata da diverse criticità afferenti all’ambito socio-familiare, economico ed abitativo. La Signora inizialmente mostrava scarsa consapevolezza circa la complessità clinica del figlio tanto che in alcune circostanze ha anche disatteso le visite programmate presso il nostro ospedale. Si mostrava ostile e diffidente rispetto al nostro coinvolgimento, percepito come intrusivo e punitivo nei suoi confronti, e alla possibilità di attivare una collaborazione con i servizi territoriali.

Abbiamo cercato di offrire alla Signora uno spazio di ascolto, per conoscere la sua storia e comprende le sue difficoltà. Si è tentato di rassicurarla sul fatto che l’obiettivo del nostro intervento era di cercare di sostenerla nella ricerca di un equilibrio nella

Alessio
social worker



Francesca
social worker



We are Alessio and Francesca, social workers at a pediatric hospital. Our Social Service team collaborates with the inpatient departments and all other services within the facility to ensure a global and integrated care for patients and their families.

In this context, we provide support to the hospital’s multidisciplinary team, including consultancy in transplant list placement programmes. In particular, we focus on analysing the family’s organisational structure, identifying its available resources and any needs and/or vulnerabilities of the parents related to the complexity of each case.

Through the professional tool of the interview, we aim to build a relationship of trust with the family based on welcoming, listening and empathy. Indeed our work places the patient’s family at the center, always engaging them to identify their true needs, encouraging them to be empowered and to take ownership of the actions addressed to them. The aim is to encourage joint reflection on the care plan outlined by healthcare professionals, specifically raising caregiver awareness of the importance of their role in the success of the treatment process.

Where necessary, we propose the involvement of community services not only to ensure therapeutic continuity between the hospital and the community, but also to improve the daily living conditions and ensure that the child, compatibly with his/her condition, has a fulfilling academic, sports, relationship and social life.

Just recently we followed the case of F., a teenager from a single-parent family with three younger sisters; this situation has been a clear example of how social and healthcare integration, both within the hospital setting and with community services, is a fundamental element for effective and comprehensive family care.

From the first meeting with the boy’s mother, it was clear that the family situation was characterised by several critical issues related to social, family, economic and housing conditions. The mother initially showed little awareness of her son’s clinical complexity, to the point that on same occasions she even missed the scheduled visits to our hospital. She was hostile and wary of our involvement, which she perceived as intrusive and punitive, and of the possibility of establishing a partnership with local services. We attempted to offer the mother a space to listen, to get to know her history and understand her difficulties.

We attempted to reassure her that the aim of our intervention was to support her in finding balance in the situation she was facing: her son’s illness combined with managing all the other daily demands of a family where she was the sole parent. We tried to help her recognise the family resources already present and that, situazione che si trovava a fronteggiare: la malattia del figlio associata alla gestione di tutte le altre esigenze di vita quotidiana di una famiglia dove lei era l'unico genitore presente. Abbiamo cercato di aiutarla a riconoscere le risorse familiari già presenti e che, di fatto, nonostante alcune tensioni dovute a questioni passate, queste erano disponibili ad aiutarla. Approfondendo la conoscenza del caso è emerso, inoltre, che il contesto abitativo del nucleo non risultava idoneo alla domiciliazione del minore per la presenza di criticità strutturali e la condizione economica disagiata (la Signora non aveva un reddito fisso) non le permetteva di farsi carico di lavori di ristrutturazione.

Per questo, con il suo consenso, è stata avviata una formale collaborazione con il servizio sociale territoriale che, tra l'altro, ha provveduto ad erogare misure di sostegno al reddito con le quali sono state apportate le necessarie modifiche all'abitazione per metterla in sicurezza anche in vista di un rientro a casa del bambino post-trapianto.

Il lavoro dell'intera équipe ospedaliera ha monitorato costantemente la situazione socio-familiare con la partecipazione attiva di tutta rete dei servizi socio-sanitari territoriali con la quale periodicamente sono stati programmati anche degli incontri per un raccordo/aggiornamento sul progetto integrato definito. Gli interventi mirati che sono stati previsti e poi attuati, ciascun servizio per quanto di competenza, hanno consentito di raggiungere una piena compliance familiare al percorso terapeutico proposto dai curanti.

Questo ha portato quindi all'inserimento del bambino in lista d'attesa e successivamente al trapianto con un lungo periodo di ricovero, durante il quale, F. è stato sempre sereno con accanto la mamma e gli altri parenti che, in piena armonia, si sono alternati in reparto. Una volta dimesso ha continuato il suo follow up senza alcuna particolare criticità.

Il successo di questo caso dimostra quanto l'integrazione tra équipe medico-sanitaria, servizio sociale ospedaliero e servizi territoriali sia una modalità imprescindibile nella presa in carico di pazienti affetti da malattie croniche e complesse soprattutto quando poi sono presenti delle fragilità familiari.

despite some tensions due to past issues, were available to help her. Further investigation of the case revealed that the family's housing situation was not suitable for the child's residence due to structural issues, and the difficult economic condition (the woman had no fixed income) prevented her from undertaking renovation work.

For this reason, with her consent, a formal collaboration was initiated with the local social service, which, among other things, provided income support measures with which the necessary modifications were made to the home to make it safe, also in preparation for the child's return home post-transplant.

The entire hospital team constantly monitored the family's social and emotional situation with the active participation of the entire network of local health and social services, with which periodic meetings were also scheduled for coordination and updates on the defined integrated plan.

The targeted interventions that were planned and then implemented, each service according to its scope of expertise, allowed to achieve full family compliance with the treatment plan proposed by the treating physicians.

This led to the inclusion of the child on the waiting list and subsequent transplant, with a long period of hospitalisation, during which F. was always serene, with his mother and other relatives at his side, who harmoniously took turns caring for him at the ward. After his discharge, he continued his follow-up without any particular critical issues.

The success of this case demonstrates how integration between the healthcare team, hospital social services and community services is essential in caring for patients with chronic and complex diseases, especially when family fragility is present.

Benedetta
psicologa

Silvia
psicologa

Lavorare come psicologa in un'unità di trapianto epatico pediatrico significa entrare in contatto con famiglie che stanno attraversando una fase estremamente delicata del loro percorso di cura.

Molti dei bambini e degli adolescenti che incontriamo convivono da anni con una malattia epatica o metabolica cronica che ha influenzato il loro sviluppo, le loro relazioni sociali e la loro qualità della vita. I genitori hanno affrontato lunghi periodi di monitoraggio clinico, ricoveri frequenti e prolungati, e una costante incertezza rispetto all'evoluzione della malattia, cercando ogni volta di adattarsi e di far fronte alla complessità attingendo alle proprie risorse personali.

Quando arrivano al percorso di trapianto, portano con sé una storia già complessa e faticosa. Fondamentale è accogliere questa storia, creando uno spazio sicuro in cui la famiglia possa condividere ciò che ha vissuto, ciò che teme e ciò che spera rispetto al trapianto. Nei colloqui emergono aspettative, dubbi, domande rimaste sospese e un ventaglio di emozioni che va dalla paura al sollievo, dall'incertezza alla speranza. Lo psicologo rappresenta una presenza costante lungo tutto il percorso creando uno spazio sicuro in cui i vissuti possano essere espressi, elaborati e riformulati.

Con bambini e adolescenti il fine è concentrarsi sul dare senso a ciò che accade nel loro corpo, supportandoli nel riconoscere e modulare le proprie emozioni. L'obiettivo è aiutarli a sviluppare strategie pratiche per affrontare le diverse fasi del trapianto con maggiore consapevolezza e minore ansia.

Parallelamente, anche i genitori necessitano di ascolto e sostegno per affrontare un carico emotivo e decisionale molto significativo: la paura dell'intervento, l'incertezza della lista d'attesa e la necessità di restare presenti in una quotidianità già complessa. Attraverso i colloqui psicologici, esploriamo timori e risorse, favoriamo una comunicazione efficace con l'équipe clinica e sosteniamo modalità adattive che preservino l'equilibrio familiare.

Una delle storie che portiamo più nel cuore è quella di due fratelli gemelli di 16 anni con acidemia metilmalonica, la cui vita fin dai primi mesi era stata segnata da frequenti crisi metaboliche e, negli ultimi anni, da una progressiva insufficienza renale. Quando sono arrivati al nostro ospedale, erano provati - fisicamente ed emotivamente - da una dieta rigidissima, controlli medici continui e la consapevolezza crescente che la loro condizione stava progressivamente peggiorando. Durante i colloqui, parlavamo delle loro paure, della fatica di accettare un corpo con la cicatrice e della complessità di un trapianto combinato fegato-rene. Ma parlavamo anche dei loro sogni: frequentare la scuola senza dover passare mesi in ospedale, andare in pizzeria con gli amici, immaginare un futuro simile a quello dei loro coetanei.

Benedetta
psychologist

Silvia
psychologist

Working as a psychologist in a Pediatric Liver Transplant Unit means engaging with families who are going through an extremely delicate phase of their care journey.

Many of the children and adolescents we meet have been living for years with a chronic liver or metabolic condition that has affected their development, their social relationships and their overall quality of life. Parents have been facing long periods of clinical monitoring, frequent and prolonged hospitalisations, and constant uncertainty regarding the progression of the disease, each time trying to adapt and cope with the complexity of the situation by drawing on their own personal resources.

When they enter the transplant pathway, they bring with them an already complex and tiring story. It is essential to acknowledge and welcome this history, creating a safe space in which the family can share what they have experienced, what they fear and what they hope for in relation to the transplant. During the interviews, expectations, doubts, suspended questions and a range of emotions emerge, ranging from fear to relief, from uncertainty to hope. The psychologist provides a constant presence along the entire process, creating a safe space where experiences can be expressed, processed and reframed.

With children and adolescents, the focus is on helping them make sense of what is happening in their bodies, supporting them in recognising and regulating their emotions. The goal is to help them develop practical strategies to navigate the various stages of transplantation with greater awareness and less anxiety.

At the same time, parents also need to be listened and supported to manage a significant emotional and decision-making burden: the fear of the surgery, the uncertainty of the waiting list and the need to remain present in an already complex daily life. Through psychological sessions, we explore their fears and resources, foster effective communication with the clinical team and support adaptive strategies that help maintain family balance.

One of the stories closest to our hearts is that of two 16-year-old twin brothers with methylmalonic acidemia, whose lives had been marked from their earliest months by frequent metabolic crises and, in recent years, by progressive kidney failure. When they arrived at our hospital, they were exhausted - physically and emotionally - by a very strict diet, continuous medical monitoring and the growing awareness that their condition was steadily worsening. During our sessions, we talked about their fears, the challenge of accepting a body marked by a scar and the complexity of a combined liver–kidney transplant. But we also talked about their dreams: attending school without having to spend months in the hospital, going out for a pizza with friends, imagining a future like that of their peers.

Nel marzo 2023 le loro condizioni sono peggiorate rapidamente, sul piano neurologico, cognitivo e fisico, generando grande preoccupazione in tutta la famiglia. Poi, pochi giorni dopo, è arrivata la telefonata che ha cambiato tutto: era stato trovato un donatore compatibile. Grazie all'immensa generosità di un'altra famiglia, entrambi i fratelli sono stati sottoposti, nello stesso giorno, a un doppio trapianto fegato–rene - una vera e propria doppia rinascita.

A un anno dal trapianto, dopo 16 anni, la prima pizza con gli amici e un lungo elenco di piatti da provare. Oggi frequentano la scuola con entusiasmo, partecipano attivamente alla vita sociale e fanno progetti per il futuro. Uno sogna di diventare cuoco e finalmente può assaggiare i piatti che prepara; l'altro immagina una carriera da barman. La loro qualità di vita è notevolmente migliorata, così come quella dell'intera famiglia, che può finalmente vivere una vita "normale".

Nel trapianto epatico pediatrico, la cura non è mai solo medica: è un processo condiviso, che intreccia dimensioni cliniche, psicologiche e relazionali. In questo contesto, le vite si prendono cura di altre vite, costruendo insieme un percorso possibile.

In March 2023 their condition deteriorated rapidly - neurologically, cognitively and physically - causing great concern for the entire family. Then, a few days later, the phone call arrived that changed everything: a compatible donor had been found. Thanks to the immense generosity of another family, both brothers underwent, on the same day, a double liver-kidney transplant - a true double rebirth.

One year after the transplant, after 16 years, they celebrated their first pizza with friends and a long list of dishes to try. Today, they attend school with enthusiasm, participate actively in social life and make plans for their future. One dreams of becoming a chef and can finally taste the dishes he prepares; the other envisions a career as a bartender. Their quality of life has significantly improved, as has that of their entire family, who can finally live a "normal" life.

In pediatric liver transplantation, care is never solely medical: it is a shared process that intertwines clinical, psychological and relational dimensions. In this context, truly lives take care of lives, building together a path forward.

Rachele
cardiologa pediatrica

Da più di vent’anni mi occupo, in qualità di cardiologa, del trattamento e della cura di bambini affetti da ipertensione polmonare e che richiedono un trapianto di polmone. Lavoro presso l’Unità di Scompenso, Trapianto e Assistenza Meccanica Cardiorespiratoria del nostro ospedale, dove, insieme al team multidisciplinare, negli ultimi anni abbiamo integrato i percorsi di questi piccoli pazienti, dal momento della diagnosi fino alla gestione post-operatoria e alla transizione al follow-up per adulti.

Nel nostro centro, il team per il trapianto toracico è coinvolto in ogni fase della vita del bambino, affrontando la progressione delle malattie affiancando le famiglie da quando i bambini sono molto piccoli, o addirittura da neonati. Accompagniamo i bambini lungo il loro percorso terapeutico, dalle fasi iniziali della malattia, alla necessità di un trapianto, fino alla gestione post-operatoria. In questi anni, ho avuto il privilegio di vedere bambini affrontare e superare sfide incredibili, diventando adulti sani e attivi, per poi vederli proseguire la loro vita con i propri figli.

Il mio lavoro si è evoluto negli anni, e oggi posso affrontare con maggiore sicurezza le varie problematiche legate al trapianto di polmone, ma ciò che non è cambiato è la difficoltà di gestire le decisioni delicate riguardo a quando un bambino debba entrare in lista per il trapianto. Quando la malattia è avanzata, la decisione è quasi inevitabile, ma quando la condizione è grave ma non terminale, il momento giusto per il trapianto è una scelta che può fare la differenza tra una vita migliore e rischi inutili. A volte alcuni pazienti precipitano nell’insufficienza d’organo acutamente, necessitando di un supporto meccanico quale la macchina dell’ECMO (sistema di ossigenazione meccanica a membrana).

Ogni bambino è diverso, e anche se la medicina ci aiuta a guidarci nelle decisioni, è sempre l’esperienza umana che ci insegna a vedere ogni bambino come una persona, non solo come un paziente.

Una delle cose che mi motiva nel mio lavoro è il legame che si crea con le famiglie. Non ci si occupa solo della malattia fisica, ma si entra a far parte della vita della famiglia, si impara a conoscere le loro tradizioni, i loro sogni, le loro preoccupazioni, e si lavora insieme per dare ai bambini la possibilità di vivere una vita il più possibile normale.

Un’esperienza che mi ha segnato profondamente è stata il nostro ultimo caso, M, una ragazza affetta da una rara patologia polmonare e che è stata sottoposta a trapianto di polmone a 16 anni, dopo una lunga lotta per l’insufficienza ventilatoria e che la costringeva a vivere isolata in casa. Dopo 4 anni di attesa, all’ultimo controllo, M. presentava una necessità di trattamento in ECMO per il deterioramento grave. Inizialmente sembrava che non ci fossero speranze, ma poi è arrivata l’offerta adatta

Rachele
pediatric cardiologist

For more than twenty years, as a cardiologist, I have been treating and caring for children with pulmonary hypertension who require a lung transplant. I work at the Failure, Transplant and Mechanical Cardiopulmonary Assistance Unit of our hospital, where, together with the multidisciplinary team, in recent years we have integrated the care of young patients, from diagnosis to post-operative management and transition to adult follow-up.

At our center, the thoracic transplant team is involved in every stage of a child’s life, dealing with the progression of disease by supporting families from a very young age of their child, or even as newborns. We accompany children along their therapeutic path, from the initial stages of the disease, to the need for a transplant, up to post-operative care. Over these years, I have had the privilege of seeing children face and overcome incredible challenges, becoming healthy, active adults, and then seeing them move on with their lives with their own children.

My work has evolved over the years, and today I can more confidently address the various issues related to lung transplantation. What has not changed is the difficulty of managing delicate decisions about when a child should be placed on the transplant list. When the disease is advanced, the decision is almost inevitable, but when the condition is severe but not terminal, the right timing for transplantation is a choice that can make the difference between a better life and unnecessary risks. Sometimes some patients fall into acute organ failure, requiring mechanical support such as the ECMO machine (mechanical membrane oxygenation system).

Every child is different, and although medicine helps guide our decisions, it is always the human experience that teaches us to see every child as a person, not just a patient.

One of the things that motivates me in my work is the bond that is created with families. We do not just deal with physical illness, but we become part of family’s life, we learn about their traditions, their dreams, their concerns, and we work together to give children the chance to live a life as normal as possible.

An experience that deeply affected me was our last case, M, a girl suffering from a rare lung disease who underwent a lung transplant at 16 years of age, after a long struggle with ventilatory insufficiency that forced her to live in isolation at home. After a four year wait, at her last checkup, M. required ECMO treatment due to severe deterioration. Initially it seemed that there was no hope, but then the right offer arrived for her and we hoped that the transplant would bring an extraordinary change. After a long period in intensive care due to surgical complications, M. made an incredible recovery, managing to run, enjoy life and resume her studies.

a lei ed abbiamo sperato che con il trapianto ci fosse un cambiamento straordinario. Dopo un periodo lungo in terapia intensiva per complicanze chirurgiche, M. ha fatto un recupero incredibile, è riuscita a correre, a godersi la vita e a riprendere gli studi. Quella trasformazione è una delle soddisfazioni più grandi che posso ricordare.

Tuttavia, non è sempre tutto rose e fiori. Dopo 1 anno, è comparso un linfoma metastatico, non rispondente a tante terapie, anche d'avanguardia. Ricordo con dolore M. quando abbiamo affrontato ulteriori complicazioni gravi che non siamo riusciti a gestire. La sua morte, avvenuta pochi mesi dopo, è stata un colpo difficile da accettare, e nonostante il nostro impegno, rimarrà sempre nel mio cuore.

Ogni volta che un bambino non ce la fa, ogni volta che si perde una battaglia, è come se il cuore stesso del nostro lavoro fosse messo alla prova. La difficoltà di accettare la perdita e di essere lì per le famiglie in momenti così tragici è ciò che ci spinge a fare sempre meglio, ma anche a imparare che non tutte le storie possono avere un lieto fine.

L'elemento che rende davvero speciale il nostro lavoro, però, è il continuo apprendimento e la crescita che deriva dal rapporto diretto con i pazienti e le loro famiglie. Molto spesso, i genitori diventano anche una risorsa fondamentale: la loro forza e determinazione sono fonte di ispirazione. Ho imparato molto da loro, tanto quanto ho imparato dai miei pazienti.

Una cosa ho imparato, che il dolore, la malattia può essere anche un momento di grande trasformazione e di apertura verso una comprensione più profonda della vita e delle relazioni umane, nelle quali anche noi medici ci troviamo coinvolte.

Oggi, come in passato, ci sono sempre nuove sfide, nuove tecnologie e nuovi trattamenti da esplorare, e questa continua ricerca mi motiva ogni giorno. Tuttavia, la vera forza del nostro lavoro sta nel saper lavorare insieme come team, nell'offrire ai bambini e alle famiglie non solo le nostre competenze mediche, ma anche la nostra umanità, empatia e dedizione. La vera forza risiede nella profonda connessione spirituale che instauriamo ogni giorno con i bambini, i genitori e tra noi colleghi. La medicina non è solo un lavoro scientifico: è un'arte che va vissuta con il cuore e con l'anima.

That transformation is one of the greatest satisfactions I can remember.

However, it is not always all sunshine and roses. After one year, metastatic lymphoma appeared, unresponsive to many therapies, even cutting-edge ones. I remember M. with sorrow, when we faced further serious complications that we could not manage. Her death, a few months later, was a difficult blow to accept, and despite our efforts, she will always remain in my heart.

Every time a child doesn't make it, every time a battle is lost, it is as if the very heart of our work is tested. The difficulty of accepting loss and being there for families in such tragic moments is what drives us to always do better and better, but also to learn that not all stories have a happy ending.

What makes our work turly special, however, is the continuous learning and growth that comes from direct relationships with patients and their families. Very often, parents also become a fundamental resource: their strength and determination are a source of inspiration. I have learned a lot from them, as much as I have learned from my patients.

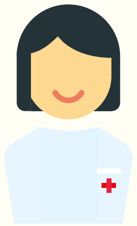
One thing I have learned is that pain and illness can also be a moment of great transformation and opening towards a deeper understanding of life and human relationships, in which we doctors also find ourselves involved.

Today, as in the past, there are always new challenges, new technologies and new treatments to explore, and this ongoing research motivates me every day.

However, the true strength of our work lies in our ability to work together as a team, offering children and families not only our medical expertise, but also our humanity, empathy and dedication. The real strength lies in the deep spiritual connection we establish every day with children, parents and each other as colleagues. Medicine is not just a scientific endeavor: it is an art that must be lived with heart and soul.

Roberta

infermiera pediatrica



Il coordinamento infermieristico:
Nel percorso dei bambini pre e post trapianto è un anello organizzativo fondamentale, un ruolo che è parte integrante di un percorso che coinvolge tutte le professionalità dell'Ospedale.

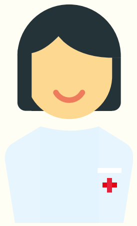
Quale è il vostro ruolo? Quali sono le vostre responsabilità?
Il nostro ruolo inizia con la presa in carico dei bambini individuati come possibili riceventi di trapianto. È un ruolo attivo all'interno di un gruppo di professionisti, ciascuno dei quali ha il proprio compito ma collabora con gli altri. Il percorso inizia con la conoscenza della famiglia del bambino o del ragazzo candidabile al trapianto e da una prima valutazione che prevede diverse attività, tra cui l'organizzazione degli esami e delle visite necessarie, definiti da protocolli e standard nazionali e internazionali, a cui faranno seguito una serie di altri controlli clinici, consulenze e visite specialistiche. La valutazione per l'inserimento in lista d'attesa avviene in regime di ricovero ordinario o di day hospital; mediamente servono 7 - 8 giorni di ricovero ordinario o 15 giorni in caso di day hospital. Il passaggio successivo alle valutazioni dei risulta da parte di tutti i professionisti coinvolti è il colloquio con la famiglia e con il paziente per l'inserimento in lista per il trapianto. Si tratta di una fase molto delicata che termina con un nuovo colloquio con la famiglia e il paziente, che sono chiamati anche a firmare (il paziente solo se adolescente) i consensi previsti.
Dopo il colloquio e la firma dei consensi si procede con l'inserimento nelle liste di attesa diversificate per ciascun organo, gestite dal Centro Nazionale Trapianti e dal Centro Regionale Trapianti.
Un'importante fase del colloquio è rappresentata dalla comunicazione alle famiglie che esiste la possibilità per i bambini o ragazzi che hanno bisogno di un trapianto di fegato o di rene, di poter ricevere l'organo da un donatore vivente, quindi da un loro familiare. Se dalla possibilità si passa all'azione, viene attivata una procedura precisa che segue protocolli specifici finalizzati a stabilire l'idoneità alla donazione. Anche questa è un'attività molto articolata che noi organizziamo, con valutazioni cliniche peculiari e collegiali, interne ed esterne all'Ospedale, e che ci impegna professionalmente ed umanamente.

Come viene gestita la lista di attesa?
Le liste di attesa sono gestite in base ad algoritmi, specifici per ciascun organo, che in modo oggettivo e trasparente definiscono sulla base dei dati clinici e immunologici la priorità di ciascun paziente rispetto agli altri presenti in lista. Per questo è fondamentale aggiornare i da clinici dei pazienti in lista, attività di cui ci occupiamo costantemente.

Quando avviene il trapianto?
Il trapianto da donatore vivente viene organizzato e programmato in modo elettivo.

Roberta

pediatric nurse



Nursing coordination:
In the pre- and post- transplant journey of children, it is a fundamental organisational link, a role that is an integral part of a process that involves all the hospital's professionals.

What is your role? What are your responsibilities?
Our role begins with taking care of children identified as potential transplant recipients. It is an active role within a team of professionals, each with their own specific tasks but working all together. The path begins with meeting the family of the child or young person eligible for a transplant and with an initial assessment that involves various activities, including the organisation of examinations and necessary visits, defined by national and international protocols and standards, followed by a series of other clinical checks, consultations and specialist visits.
The waiting list assessment takes place in ordinary hospital or day hospital; on average, it takes 7 to 8 days of hospitalisation or 15 days in the case of a day hospital. After the evaluations of the results by all the professionals involved, the next step is the interview with the family and with the patient for inclusion on the transplant list. This is a very delicate phase that ends with a further discussion with the family and the patient, who are required to sign the expected consents forms (the patient only if an adolescent).
After the interview and the signing of the consent forms, the patient is inserted in the waiting list, different for each organ, managed by the National Transplant Centre and the Regional Transplant Centre. An important step in the discussion is informing the families that there is the possibility for children or young people who need a liver or kidney transplant to receive the organ from a living donor, i.e. a family member.
If the possibility leads to action, a precise procedure is activated that follows specific protocols to determine eligibility for donation. This is also a highly complex process that we organise, with specific and collegial clinical assessments, both internal and external to the hospital, and which engages us professionally and humanely.

How is the waiting list defined?
Waiting lists are managed according to algorithms, specific to each organ, which objectively and transparently define, on the basis of clinical and immunological data, the priority of each patient over the others on the list.
For this reason, it is essential to update the clinical data of patients on the waiting list, an activity that we constantly take care of.

When does the transplant take place?
Living donor transplants are organised and scheduled on an elective basis.

Per i trapianti da donatore deceduto, invece, attendiamo la generosità delle persone che hanno fatto l'importantissima scelta di essere donatori d'organo.

Per questo, un infermiere fra noi è sempre reperibile e quando arriva la prima telefonata che segnala la disponibilità di una donazione è sempre un'emozione.

Da lì inizia un'attività di organizzazione e informazione di tutti i professionisti coinvolti: la direzione sanitaria, i clinici, il personale dei laboratori, chi si occupa dei trasporti, il centro regionale e quello nazionale.

Viene quindi organizzato il prelievo d'organo nella sede dove si trova il donatore, e dove i nostri chirurghi si recheranno; successivamente viene definito l'orario di discesa in sala operatoria del bambino e tutta la squadra si organizza per ridurre i tempi e ottimizzare i percorsi. Altre volte viene organizzato il trasporto dell'organo, prelevato da un'equipe esterna. E, naturalmente, chiamiamo la famiglia del ricevente. Si tratta di una fase molto delicata perché può capitare che il ricevente si trovi fuori regione e i tempi del trapianto siano stretti, quindi dobbiamo organizzarci e accordarci poi con la famiglia. In taluni casi è necessario, causa una distanza troppo ampia per permettere al paziente di giungere in ospedale nei tempi richiesti (solitamente poche ore), che si debba attivare un servizio di trasporto con voli dedicati.

Il trapianto è veramente un lavoro di squadra…

Sì, assolutamente. Sono tantissime le professionalità coinvolte in una catena in cui anche un singolo anello fa la differenza! Ciascun professionista mette a disposizione la propria preparazione e la propria competenza per cambiare la vita di una persona, per dare una nuova possibilità di vita!

Siamo tutti parte di un qualcosa molto più grande di noi.

Non c'è nessuno che sia protagonista, solo il bambino che deve ricevere l'organo nel più breve tempo possibile, per ridurre i tempi di ischemia e aumentare le possibilità di ripresa funzionale dell'organo trapiantato. Di questo abbiamo tutti percezione: quando si attiva una donazione per trapianto, sentiamo di essere tu una cosa sola, pronta a muoversi ed è questo che ci riempie di un coraggio e di una forza superiori, tanto da farci dimenticare a volte la fatica dell'impegno costante e concentrato.

Quali sono le reazioni dei familiari alla vostra chiamata?

Entusiasmo, misto spesso a preoccupazione determinata essenzialmente dalla paura dell'intervento, a cui subentra poi la paura della famiglia di non riuscire ad arrivare nel tempo previsto quando risiede fuori regione. Noi infermiere siamo chiamate a dare anche un supporto propriamente emotivo, a tranquillizzare i genitori. L'ansia spesso prende il sopravvento nei genitori che vedono davanti una prospettiva di attesa; in questi casi, forniamo tutte le informazioni necessarie perché si possa raggiungere con successo un traguardo così importante, in piena collaborazione.

E poi arriva il momento del trapianto…

Prima che l'organo arrivi, noi seguiamo l'intero iter con l'equipe del prelievo. C'è una cascata di informazioni costante: quando inizia l'intervento di prelievo, quando l'equipe parte per il ritorno, quando sta per arrivare. Tutto deve essere minuziosamente seguito per la buona riuscita del trapianto. Dobbiamo organizzare la discesa in sala del ricevente mentre l'organo sta arrivando per poter rispettare i tempi previsti.

For transplants from a deceased donor we await the generosity of those who have made the very important choice to be organ donors.

For this reason, a nurse among us is always available and when the phone call arrives telling the availability of a donation it is always an emotion.

From there we start organising and informing all the professionals involved: the management, clinicians, laboratory staff, transportation personnel, regional and national centres.

Organ harvesting is then organised at the donor site, where our surgeons will travel to; other times it is done by an external surgery equipe there available. The time for the child's arrival in the operating room is then determined and the whole team plans the path to reduce time and optimise the processes. And, of course, we call the recipient's family. This is a very delicate phase because the recipient may be living outside the region and the transplant schedule is tight, so we must organise things and then make a plan with the family. In some cases, due to the distance being too wide to allow the patient to reach the hospital in the required time (usually a few hours), it is necessary to activate a transport service with dedicated flights available.

Transplantation is truly a team effort…

Yes, absolutely. There are so many professionals involved in a chain where even a single ring makes the difference!

Each professional provides his/her knowledge and expertise to change someone's life, to give a new chance at life. We are all part of something much bigger than ourselves. There is no one who is the protagonist, only the child who must receive the organ as quickly as possible, to reduce ischemia times and increase the chances of functional recovery of the transplanted organ.

We all perceive this: when a transplant donation is activated, we feel that we are as one, ready to move, and this is what fills us with greater courage and strength, so that we sometimes forget the fatigue of constant and focused commitment.

How do family members react to your call?

Enthusiasm, often mixed with concern mainly due to the fear of the procedure itself, followed by the fear of the family not being able to arrive on time if they live outside the region. We nurses are also called upon to provide emotional support, to reassure parents. Anxiety often takes over parents faced with the prospect of waiting; in these cases, we provide all the necessary information to successfully achieve such an important goal, in full collaboration.

And then the time for the transplant comes…

Before the organ arrives, we follow the entire process with the collection equipe.There is a constant cascade of information: when the organ harvesting procedure begins, when the team leaves for the return, when it is about to arrive. Everything must be carefully monitored for the success of the transplant.

We must organise the recipient's arrival in the operating room while the organ is on its way to ensure we meet the scheduled deadlines. Only when the organ arrives in the operating theatre its suitability can be confirmed. Families are informed, but when the organ is found to be not suitable, their disappointment is ours too.

Solo quando l'organo arriva in ospedale e in sala operatoria, è possibile confermare l'idoneità. Le famiglie vengono informate, ma quando l'organo risulta non idoneo il loro dispiacere è anche il nostro.

Dopo il trapianto…

Il cammino continua, tutti i professionisti sono coinvolti, in modo diverso, e noi affianchiamo pazienti e famiglie con colloqui, con controlli clinici, con professionalità e umanità. I bambini trapiantati devono essere seguiti costantemente dopo il trapianto, sino a quando verranno affidati alle cure dei centri che seguono i pazienti adulti. Quindi la "famiglia" di cui ci occupiamo aumenta e si modifica costantemente. Un'altra attività molto importante e impegnativa è quella di raccogliere tutti i dati relativi al follow up successivo al trapianto, dati che devono anche essere costantemente comunicati al Centro Nazionale Trapianti. Tutto questo è molto importante per contribuire a mantenere alta la qualità dell'attività di trapianto nel nostro Ospedale e a livello nazionale.

Il trapianto, la famiglia e noi…

Viviamo il successo con un entusiasmo sentito e condiviso. Una cosa che ci fa felici è la gratitudine delle famiglie verso il donatore. In molti casi ci chiedono quanti anni aveva, che cosa faceva, come si chiamava chi ha ridato la vita al proprio figlio o alla propria figlia. Non possiamo rispondere a tutto naturalmente, ma percepiamo da parte dei genitori la consapevolezza di un gesto d'amore che genera vita. Capita persino che le famiglie siano felici ma che nello stesso momento provino dispiacere perché sanno che alla loro gioia corrisponde il dolore di un'altra persona che ha dovuto dire addio a un proprio familiare o amico. E poi siamo felici nel periodo post operatorio. Vediamo mamme e papà trasformati. Li vediamo arrivare sorridenti, ben curati, le mamme truccate. Manifestano gioia anche così. Sono rinati. E questo ci fa riflettere, ci gratifica, ci fa emozionare. Perché è in quel momento che siamo spettatori del miracolo di come una vita purtroppo interrotta sia fonte di una vita nuova per tante persone.

È una grande soddisfazione vedere i bambini crescere e stare bene, molti di loro non ricordano il percorso; gli abbracci dei genitori, a distanza di anni dal trapianto, ci fanno capire che invece loro non ci dimenticheranno mai!

After the transplant…

The journey continues, with all professionals involved in different ways, and we support patients and families with discussions, clinical check-ups, with a professional but also a compassionate approach. Transplanted children must be monitored closely after the transplant until they are transferred to the care of the centres that follow adult patients. Therefore, the 'family' we are dealing with is constantly growing and changing.
Another very important and demanding task is collecting all transplant - related data during the post-transplant follow-ups. These data must be constantly communicated to the National Transplant Centre. All of this is crucial to maintaining the high quality of transplant activity in our hospital and at national level.

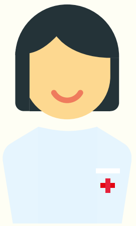
The transplant, the family and us…

We experience success with heartfelt and shared enthusiasm. One thing that makes us happy is the families' gratitude toward the donor. In many cases they ask us how old they were, what they did, what was the name of the person who brought their son or daughter back to life. We cannot answer everything, of course, but we sense from the parents the awareness of a gesture of love that generates life.
It can even happen that families are happy but sad at the same time, because they know that their joy corresponds to the pain of another person who had to say goodbye to a family member or friend.
And then we are happy in the post-operative period. We see moms and dads transformed. We see them coming smiling, well-groomed, the mothers wearing makeup. They express joy even like this. They're reborn. And this makes us reflect, gratifies us, moves us deeply. Because it is in that moment that we witness the miracle of how a life, sadly interrupted, is the source of a new life for so many people.

It is a great satisfaction to see children grow up and thrive, many of them do not remember the journey; their parents' hugs, years after the transplant, make us understand that, on the other hand, they will never forget us!

Alessandra

infermiera pediatrica



Sono un'infermiera pediatrica e lavoro dal 2010 nel reparto di Nefrologia e Gastroenterologia di un ospedale pediatrico in Italia.
Mi hanno assegnato a questa unità operativa per caso quando sono stata assunta, ma io ho capito subito che fosse il posto giusto per me.
Quello che mi ha da subito colpito e affascinato è stato il mondo dei trapianti, che ho potuto negli anni approfondire con passione.

Nel mio reparto assistiamo pazienti cronici con insufficienza renale ed epatica che vanno incontro a trapianto d'organo e che seguono un percorso simile fatto di ricoveri, esami, inserimento in lista e attesa.
I ricoveri sono lunghi e ripetuti, e con le famiglie abbiamo sempre cercato di instaurare un rapporto di fiducia: sappiamo bene che una buona riuscita del trapianto inizia ben prima dell'intervento chirurgico stesso.

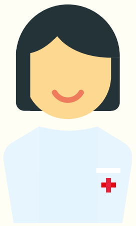
Ho impresso nel mio cuore e nella mia mente tantissimi ricordi, tantissime storie di bambini ricoverati, ma quello che più mi piace condividere è il momento in cui riceviamo la "chiamata", perché tutti sappiamo che quel momento tanto atteso è arrivato e che da lì in poi tante cose cambieranno.
La speranza di un cambiamento diventa concreta, la frenesia di mettersi all'opera per preparare tutto quello che serve, il coordinare tante persone ma soprattutto quel clima che si crea, l'emozione proprio tangibile da parte di tutti, paziente e famiglia ma anche di noi operatori, che in quel momento ci sentiamo parte di una rete che sta facendo qualcosa di bello.

Il mio pensiero in quel momento (anzi quello di tutti) è sempre di profonda ammirazione e gratitudine verso chi in un momento tragico come la morte di una persona cara acconsente al prelievo degli organi per salvare la vita di qualcun altro... Questa la "cosa in più" che rende questo meccanismo così delicato ed importante... Questa è la motivazione che spinge tutti a fare il nostro lavoro per bene; io lo faccio con grande orgoglio e incredibile rispetto verso i donatori e verso la rete trapianti che permette il realizzarsi del dono in modo trasparente.

Ecco la trasparenza è l'altro aspetto che ammiro di questa branca della medicina.
Vedere tornare in reparto dopo pochi giorni dal trapianto i nostri pazienti già molto "diversi" nel colore (nel caso dei bambini trapiantati di fegato) o con una diuresi attiva (nel caso dei trapianti di rene) ci gratifica e ci commuove.
In seguito inizia un'altra parte importante del nostro lavoro, cioè quella di trasmettere tutte le informazioni necessarie a preservare l'organo il più a lungo possibile.
Quello che trovo difficile è accettare che qualche volta nonostante i nostri sforzi alcuni pazienti (pochi) talvolta smettono di assumere le terapie antirigetto... In questi casi anche io mi interrogo come professionista se e cosa avrei potuto fare di diverso.

Alessandra

pediatric nurse



I am a pediatric nurse and I have been working since 2010 in the Nephrology and Gastroenterology Department of a pediatric hospital in Italy.
I was assigned to this unit by chance when I was hired, but I immediately realised that it was the right place for me.
What immediately struck and fascinated me was the world of transplants, which I was able to explore with passion over the years.

In my Unit we assist chronic patients with renal and hepatic failure who undergo organ transplantation and who follow a similar path of hospitalisation, examinations, inclusion in the transplant waiting list and waiting.
Hospital stays are long and repeated, and we have always tried to establish a relationship of trust with families: we are well aware that a successful transplant begins well before the surgery itself.

I have so many memories in my heart and in my mind, so many stories of hospitalised children, but what I like to share most is the moment when we receive the "call", because we all know that the long-awaited moment has finally arrived and from then on many things will change.
The hope for change becomes concrete, the frenzy of getting to work preparing everything needed, the coordination of many people but above all the atmosphere that is created, the very tangible emotion on the part of everyone, patient and family but also us professionals, who in that moment feel part of a network that is doing something beautiful.

My thoughts at that moment (and indeed everyone's) are always of deep admiration and gratitude to those who, in a tragic moment such as the death of a loved one, consent to donate organs to save someone else's life... This is the "extra" that makes this process so delicate and important... This is the motivation that drives everyone to do our job well; I do this with great pride and incredible respect for the donors and the transplant network that allows donations to be made transparently.

Transparency is the other aspect I admire about this branch of medicine.
Seeing our patients returning to the ward a few days after transplantation, already very "different" in their colour (in the case of liver transplant) or with active diuresis (in the case of kidney transplant) is gratifying and moving.
Then another important part of our work begins, providing all the information necessary to preserve the organ for as long as possible.
What I find difficult is to accept that, despite our efforts, some (few) patients sometimes stop taking anti-rejection therapies... In these cases, I also question myself as a professional whether and what I could have done differently.

Alessandra

Ormai sono 15 anni che lavoro con pazienti trapiantati di rene e fegato e la gratificazione più grande è vedere che i pazienti mi riconoscono e ricordano bene quanto tempo abbiamo passato insieme, l'impegno dedicato… Come se fossimo stati famiglia per un po' di tempo, e dentro di me so bene che lo siamo stati per davvero.

È bello vedere che tutti i professionisti che ruotano attorno a questi bambini hanno a cuore soprattutto il loro ritorno ad una vita "normale". Mi piace farmi raccontare dai ragazzi trapiantati cosa fanno, che scuole frequentano, che interessi hanno.

Alcune storie non sono andate bene… Bisogna dirlo… E non solo perché c'è stata poca compliance da parte dei pazienti o delle famiglie, ma perché il livello di complessità di malattia era così elevato che il susseguirsi di complicanze hanno portato a gravi peggioramenti clinici e in alcuni casi alla perdita del paziente.

Ho in mente alcune storie che mi hanno toccato molto… Una è quella della morte di una ragazzina trapiantata di rene e cuore... Aveva una malattia difficile, ma il coinvolgimento nella sua storia era stato davvero alto e il dispiacere ce lo siamo portati dentro per tanto tempo... Ancora adesso, anche a distanza di anni, penso a lei con molta tenerezza.
Questo è solo uno degli episodi tristi che mi hanno toccato nel profondo.

A volte penso che manchi un po' il confronto tra noi personale della stessa equipe su questi aspetti più emotivi. Apprezzo questa opportunità di racconto e testimonianza!

Termino la mia riflessione con la condivisione del forte senso di appartenenza a questo mondo e la voglia di continuare a mettermi in gioco per i miei pazienti e le loro famiglie!

Alessandra

I have been working with kidney and liver transplant patients for 15 years now, and the greatest reward is seeing that patients recognise me and remember well the time we spent together, the dedication I put in... As if we were a family for a while, and deep down I know we truly were.

It is wonderful to see that all the professionals working with these children are concerned about their return to a "normal" life. I enjoy hearing the transplanted children tell me what they do, what school they attend, what interests they have.

Some stories did not go well... It must be said... And not only because there was poor compliance by patients or families, but because the level of complexity of the disease was so high that the succession of complications led to serious clinical worsening and in some cases to the loss of the patient.

I can think of a few stories that have touched me deeply… One is the death of a young girl who had received a kidney and heart transplant... She had a difficult disease, but we were deeply involved in her story and we carried the pain with us for a long time... Even now, years later, I think of her with great tenderness.
This is just one of the sad episodes that touched me deeply.

Sometimes I think we, as members of the same team, are lacking the chances to talk about these more emotional aspects. I appreciate this opportunity to share my experiences and testimony!

I'll end my reflection by sharing my strong sense of belonging to this world and my desire to continue putting myself out there for my patients and their families!

Mara

epatologa pediatrica

È da quindici anni - venti, se includo i miei anni di specialità - che mi dedico, in qualità di pediatra, alla cura dei bambini affetti da malattie del fegato che richiedono o che sono già stati sottoposti a un trapianto di fegato presso l'Unità di "Gastroenterologia, Endoscopia Digestiva, Epatologia e Cura del Bambino con Trapianto di Fegato" del nostro ospedale.

Nel nostro centro, il pediatra epatologo si prende cura dei bambini affetti da malattie epatiche lungo il loro intero percorso di cura. Conosciamo i nostri pazienti dalla diagnosi - spesso fin dalla nascita - e li accompagniamo in tutte le fasi della malattia: dalla gestione clinica pre-trapianto, al trapianto di fegato e poi attraverso il follow-up post-trapianto fino alla transizione ai colleghi epatologi dell'adulto.

Nel corso degli anni molte cose sono cambiate nella mia pratica clinica. Oggi sono decisamente più sicura nella gestione dei diversi aspetti del trapianto. I problemi clinici, e in particolare le complicanze post-trapianto, sono ora più facili da affrontare e la ricerca di soluzioni è più rapida ed efficace.

Tuttavia, alcuni aspetti rimangono complessi. Il primo tra tutti è decidere quando inserire un bambino nella lista di attesa per il trapianto di fegato. Ciò non è difficile quando la malattia è grave e il trapianto è un'opzione inevitabile. Ma nei casi in cui la malattia del fegato è presente ma non ancora terminale, decidere le tempistiche del trapianto rimane una delle scelte più difficili. Troppo presto significa esporre il bambino ai rischi del trapianto prematuramente, privandolo dell'opportunità di crescere, essere vaccinato e vivere una vita senza immunosoppressori un po' più a lungo.

Troppo tardi, al contrario, può aumentare il rischio di mortalità in lista d'attesa, aumentare i rischi chirurgici, e compromettere l'efficacia stessa del trapianto. Anche dopo tanti anni, questa decisione è sempre estremamente ragionata. Ogni volta ricordo i bambini (la maggioranza) a cui il trapianto ha regalato una seconda possibilità e una qualità di vita profondamente migliorata. Ma penso anche a quelli, per fortuna pochi, che non ce l'hanno fatta. Ricordo tutto di loro, ogni dettaglio, e non posso negare che le loro foto sono tutte appese nel mio ufficio per non dimenticarli mai.

A., è stata sottoposta a trapianto di fegato a 5 anni di età per prurito intrattabile, ma è deceduta pochi giorni dopo l'intervento a causa delle co-morbidità correlate alla sua malattia di base, la sindrome di Alagille.
K., affetto da leucinosi, è mancato a 2 anni dopo essere stato sottoposto a due trapianti epatici, entrambi falliti per gravi complicanze vascolari.
Dopo due trapianti nel primo anno di vita per atresia biliare, L. non è riuscito a sopravvivere al terzo all'età di 16 anni.

Mara

pediatric hepatologist

It has been fifteen years - twenty if I include my years of residency - that I have dedicated myself, as a pediatric hepatologist, to caring for children with liver diseases who require or have already undergone a liver transplant at the Unit of "Gastroenterology, Digestive Endoscopy, Hepatology, and Care of the Child with Liver Transplantation" at our Hospital.

At our center, the role of the pediatric hepatologist is central. We get to know our patients from diagnosis - often from birth - and accompany them throughout their journey with liver disease, to liver transplantation and then through the entire post-transplant follow-up until their transition to adult hepatology care.

Over the years, many things have changed around my professionality. Today, I am much more confident in managing different aspects of transplantation. Clinical problems - particularly transplant complications - are now easier to approach, and finding solution has become more straightforward.

Yet, some aspects remain difficult. The first is the decision to place a child on the liver transplant waiting list. This is not difficult when the disease is severe, and transplantation is an unavoidable option. But in cases where liver disease is present but not yet terminal, deciding on the timing of transplantation remains one of the hardest choices. Too early means exposing the child to transplant-related risks prematurely, depriving him/her of the opportunity to grow, be vaccinated, and experience a life without immunosuppression for a little longer.

Too late increases the risk of mortality while on the waiting list, raises surgical risks and may ultimately reduce the transplant benefit. Even after all these years, this decision is always burdensome. Every time, I reflect on the children (the majority) who have been given a second chance through transplantation and have experienced a renewed quality of life. But I also think of those - thankfully very few - who died for transplant-related complications. I remember everything about them, every detail, and I cannot deny that their photos are all pinned up in my office so that I never forget them.

A., underwent transplantation at 5 years of age for intractable cholestatic pruritus, but passed away a few days later due to the co-morbidities of Alagille syndrome.
K., affected by maple syrup disease, died at 2 years of age after failure of two liver transplants due recurrent hepatic artery thrombosis.
After two transplants in the first year of life for biliary atresia, L. could not survive the third one at the age of 16.

Queste esperienze mi hanno insegnato che, al di là dei protocolli clinici e dell'esperienza individuale, ogni decisione che prendiamo ha un peso immenso.

È per questo che sono convinta che, anche se non esiste sempre una decisione giusta in senso assoluto, la combinazione di un approccio multidisciplinare, di confronti attenti e ponderati, e di un profondo impegno nel voler offrire ad ogni bambino l'opzione migliore sia la chiave per poter compiere per ogni paziente la scelta più giusta possibile.

L'altra grande sfida è sapere quando dire "no": quando un trapianto o un re-trapianto non sono più un'opzione perché la malattia è incurabile o la situazione è ormai troppo compromessa. Scegliere di procedere con un re-trapianto, nonostante minime possibilità di successo, espone al rischio etico di un accanimento terapeutico; d'altro canto, decidere di non intervenire e orientare il percorso verso cure di supporto o palliative comporta il rischio di rinunciare a una potenziale opportunità di cura.

Ciò che rende questa decisione ancora più difficile è l'assenza, nella maggior parte dei casi, di linee guida a cui fare riferimento. Ci occupiamo di malattie rare e il trapianto di fegato pediatrico è di per sé una procedura rara: questo significa che spesso esistono pochi casi analoghi su cui potersi basare. L'unico conforto risiede nella consapevolezza di seguire un approccio scientifico e metodologico rigoroso, condiviso con l'intero team trapiantologico, fondato sull'ascolto attento della famiglia e, quando necessario, supportato dal parere del Comitato Etico. Queste decisioni multidisciplinari, per quanto dolorose, trovano una loro solidità nella condivisione, in quanto emergono da uno sforzo collegiale incentrato sull'interesse superiore del bambino.

Detto questo, non c'è privilegio più grande dell'amare il proprio lavoro. Nonostante la fatica, le responsabilità e le inevitabili preoccupazioni, non ho alcun dubbio di essere fortunata. Fortunata ad aver incontrato così tanti pazienti straordinari - e anche genitori, talvolta impegnativi - che mi hanno insegnato molto. Fortunata per aver potuto contribuire alla guarigione di molti, anche se non di tutti. Fortunata per poter lavorare accanto a colleghi appassionati e generosi, con cui condivido successi e fallimenti, con cui ci sosteniamo nei momenti difficili e continuiamo ad imparare ogni giorno, tenendo sempre al centro la cura e il bene dei bambini.

These experiences have taught me that, beyond clinical protocols and medical expertise, every decision we take carries immense weight.

This is why I believe that, even though there is not always an absolutely right decision, the combination of a multidisciplinary approach, thoughtful deliberation and a deep commitment to giving each child the best possible chance is the key to making the best possible choice.

The other great challenge is knowing when to say 'no' - when transplantation or re-transplantation is no longer an option because the disease is incurable, or the situation is too severe. The decision to proceed with a (re)transplant despite minimal chances of success carries the ethical risk of therapeutic obstinacy, while choosing to redirect the treatment path toward palliative or supportive care brings the risk of overlooking a potential opportunity. What makes this even more difficult is the absence of clear guidelines in most cases.

We often deal with rare diseases - and pediatric liver transplantation itself is a rare procedure - meaning there is often little precedent to rely on. The only solace is adhering to a rigorously scientific and methodological approach, engaging the entire transplant team, listening carefully to the family, and, in some cases, consulting the ethics committee. These multidisciplinary decisions, though painful, provide some reassurance, as they emerge from a collective effort centered on the child's best interests.

That being said, there is no greater privilege than loving one's work. Despite the fatigue, the responsibilities and the worries, I have no doubt that I am fortunate. Fortunate to have met so many extraordinary patients and parents (sometimes difficult ones, too). Fortunate to have contributed to the healing of many - though not all. And fortunate to work alongside dedicated colleagues who have shared both successes and failures - supporting each other, learning together and always staying committed to our patients.

Licia

nefrologa pediatrica

Sono una nefrologa pediatrica e sono responsabile del programma di trapianto pediatrico di rene e combinato rene-fegato. Sono anche coinvolta come consulente nel programma di trapianto pediatrico di cuore, fegato e cellule staminali ematopoietiche.

La mia attività principale è prendermi cura di bambini affetti da malattie renali croniche, congenite o acquisite, che portano all'insufficienza d'organo e alla necessità di una sostituzione della funzione renale con un trapianto di rene.
A volte conosco le famiglie anche prima che i loro figli nascano e condivido con loro tutto il viaggio fino a raggiungere i 18 anni, passando attraverso la diagnosi della malattia, le cure - tra cui spesso la dialisi - fino al trapianto. Seguo i bambini e le loro famiglie in tutti i passaggi necessari per vederli diventare adulti, quindi ho la possibilità di vederli come pazienti ricoverati - spesso per lunghi periodi soprattutto quando sono molto piccoli - e poi come pazienti ambulatoriali, molto spesso per telefono, messaggi whatsapp ed e-mail.

Ho iniziato questo lavoro nel 1990, quando mi sono trasferito dai laboratori di ricerca immunogenetica, dove stavo conducendo ricerche sugli anticorpi monoclonali, alla clinica perché ero stufa di lavorare su topi e sulle cellule.

Ho scelto di cambiare e cominciare a lavorare invece sugli esseri umani e, sfruttando la mia esperienza manuale nel fare procedure in creature estremamente piccole come i cuccioli di topi, ho scelto i bambini, e ho scelto la nefrologia per sfruttare il mio background immunologico.

La passione per la scienza e le nuove tecnologie per migliorare la vita delle persone sono ciò che mi guida.

Il motivo principale per cui mi piace questo lavoro è l'esperienza umana di accompagnare un neonato malato a diventare adulto, vedendolo crescere con la propria famiglia fino ad avere poi figli propri. Ripensare al difficile viaggio che abbiamo condiviso fa sentire che ne vale davvero la pena.
La soddisfazione più grande che abbia mai avuto dal mio lavoro è stata vedere il secondo neonato di uno dei pazienti più complessi mai trapiantati nel nostro centro. Questa bambina era arrivata da un altro paese per un trapianto di rene dopo aver completamente mancato i trattamenti di base per la sua malattia renale, sviluppando la peggiore osteodistrofia uremica e lesioni ossee che io abbia mai visto che la costringevano su una sedia a rotelle. Ora è una bellissima madre di due ragazzi che cammina perfettamente, dopo un lungo percorso di interventi e infine un trapianto di rene.

Licia

pediatric nephrologist

I am a pediatric nephrologist and I am responsible for the pediatric kidney transplantation and combined kidney-liver transplantation program in my hospital. I am also involved as a consultant in the heart, liver and hematopoietic stem cells transplantation program for children.

My main activity is the care of children affected by congenital and acquired chronic kidney diseases leading to organ failure and in the need for a substitution of the function with a kidney transplantation.
Sometimes I know the families even before their children are born and I share with them all the journey until they reach 18 years of age, passing through disease diagnosis, cures - including often dialysis - until transplantation. I follow the children and their whole families in all the steps necessary to see them becoming adults, therefore I have the chance to see them as inpatients - often for long periods especially when they are very small - and then as outpatients, very often by phone, whatsapp messages and emails.

I started this job in 1990, when I moved from the immunogenetics research laboratories, where I was conducting research on monoclonal antibodies, to the clinic because I was fed up with working on mice and cells.

Therefore, I chose to move to work on humans, but taking advantage of my manual experience in doing procedures in extremely small creatures like puppy mice, I chose children and I chose nephrology not to waste my immunology background.
My strongest drivers are the passion for science and new technologies to improve people's life.

The main reason why I like this job is the human experience of leading a diseased newborn to become an adult, seeing him/her becoming a grown-up adult with his/her own family and children. Looking back at the difficult journey we shared is really worth it.
The biggest satisfaction I ever got from my job was to see the second newborn child of one of the most complex patients ever transplanted in our center. She arrived from another country for a kidney transplantation after having completely missed the basic treatments of the renal disease she was affected by, developing the worst uremic osteodystrophy, bone lesions I ever saw and on a wheelchair. She is now a beautiful mother of two boys, with straight legs and walking perfectly after a long journey of interventions and finally a kidney transplant.
The main recognition of my job comes on a daily basis from children who do not care at all of their clinical exams because they just want to eat and run and have fun as their peers.

Il riconoscimento principale del mio lavoro viene ogni giorno da bambini che non si preoccupano affatto dei loro esami clinici perché vogliono solo mangiare, correre e divertirsi come loro coetanei. Se penso alla mia carriera le principali difficoltà sono state quando ho dovuto comunicare la prognosi del termine vita senza alcuna possibilità di altra cura a causa di tumori non rispondenti a nessuna linea di terapia, dopo complicanze neonatali, interventi, dialisi e infine un trapianto. La fine della vita per un PTLD. In questi momenti stavo quasi per arrendermi, ma poi i genitori si sono dimostrati più forti di me e mi hanno sostenuto più di quanto fossi in grado io di sostenere loro.

Un episodio particolarmente difficile per me è stato vedere che dopo tutto l'amore, la passione e gli sforzi spesi per cambiare la vita di una ragazza molto sfortunata, lei ha completamente interrotto tutte le terapie e sviluppato un rigetto d'organo che non rispondeva a nessuna terapia. Ha perso il suo secondo trapianto in meno di due anni, dopo essere stata trasferita al setting assistenziale dell'adulto quando sembrava abbastanza responsabile per prendersi cura di sé stessa. Non ho valutato abbastanza bene il suo grado di maturità e la sua capacità di essere responsabile, e le ho dato la possibilità di comportarsi da adulta, ma mi sbagliavo.

Una cosa che mi è davvero mancata/avrei amato nella mia pratica quotidiana e che vorrei suggerire per considerazioni future è di offrire agli operatori sanitari del tempo di consulenza con professionisti che sappiano dare indicazioni su come comportarsi con gli adolescenti (troppo stretti, troppo perdenti, troppo fiduciosi o chissà come...). Una cosa che voglio dire a collaboratori, pari e superiori, e non ho mai osato, è che non lavoriamo per il riconoscimento e la compensazione, ma il riconoscimento di ciò che facciamo sarebbe molto gratificante e utile per superare le difficoltà.

Ho raccontato la mia storia perché mi aspetto che condividere le nostre storie possa essere di aiuto per:
- Costruire team motivati in grado di auto-rafforzarsi e sostenersi a vicenda;
- Suggerire di creare team più multidisciplinari;
- Allocare il giusto tempo per parlare all'interno del gruppo di lavoro;
- Fare brainstorming sulle nostre difficoltà con i bambini e le famiglie.

If I think about my career the main difficulties have been when I had to communicate prognosis of life ending without any possibility of other cure after tumors not responsive to any line of therapy after newborn complications, interventions, dialysis and finally a transplant. Ending life for a PTLD. In these circumstances, I was almost to give up but then parents were stronger than me and they were supporting me more than I myself was able to be with them.

One episode that was particularly difficult/stressing/negative for me was to see that after all the love and the passion and the efforts spent to change a very unfortunate girl's life, she completely stopped all therapies and developed a horrible rejection non-responsive to any therapy. She lost her second transplant after less than two years, after she was transferred to adult care and seemed responsible enough to care for herself. I did not understand well enough her maturity and responsibility and gave her the chance to behave as an adult, but I was wrong.

Something I really missed/would have loved in my daily practice and would like to suggest for future considerations is to have some dedicated time for healthcare professionals with external professionals trained for counselling to discuss how to behave with adolescents (too tight, too lose, too trusty or who knows how…).

Something I want to tell collaborators, peers and superiors, and I have never dared to, is that we do not work for recognition and compensation, but recognition and acknowledgement of what we do would be very gratifying and useful to stand over the difficulties.

I told my story because I expect that sharing our stories may be of help for:

- Building motivated teams able to self-strengthening and support each other;
- Suggesting to build more multidisciplinary teams;
- Allotting time for speaking within our teams;
- Brainstorming on our difficulties with children and families.

Elisa

nefrologa pediatrica

Sono una nefrologa pediatra e sono responsabile del Centro di Trapianto di Rene Pediatrico di un Ospedale Universitario in Italia.

Lavoro come nefrologa pediatra da circa 20 anni e mi occupo specificamente del trapianto di rene pediatrico da più di 10 anni.

All'inizio della mia carriera, mi occupavo soprattutto di malattie renali rare e genetiche, ma il campo del trapianto di rene mi affascinava molto, anche perchè i due medici più anziani di me (di due generazioni diverse) che mi hanno insegnato la nefrologia pediatrica si occupavano di trapianto e mi hanno in qualche modo trasmesso la loro passione per questo ambito clinico. In particolare, la mia prima mentore è stata la nefrologa pediatra che ha iniziato il trapianto di rene pediatrico in Italia (infatti, il Centro in cui lavoro è stato il primo Centro Trapianto di Rene Pediatrico in Italia, nel 1987) e mi raccontava spesso delle emozioni e delle paure del primo trapianto eseguito. In seguito, ho iniziato anche io ad occuparmi dei bambini trapiantati e successivamente mi è stato affidato il ruolo di responsabile del Centro Trapianti.

Nei primi anni, ero molto concentrata sugli aspetti più strettamente clinici, probabilmente perché anche io avevo bisogno di fare esperienza ed aumentare le mie conoscenze in un ambito di cui prima non mi occupavo. Poi, però, nel tempo, ho iniziato a capire come far si che un bambino trapiantato stia bene richieda necessariamente di curare tutto, non solo il suo rene, e non solo il bambino, ma tutta la sua famiglia.

Spesso, all'università o durante la scuola di specializzazione, ti consigliano di non "familiarizzare" troppo con i pazienti, perché rischi di essere troppo coinvolto emotivamente. Io ho avuto però la fortuna di conoscere dei colleghi, che pensavano invece che "familiarizzare" con i pazienti sia proprio la via preferenziale per prendersi cura di loro, specie quando i pazienti sono dei bambini o degli adolescenti, che non hanno bisogno di ricevere "ordini" da un estraneo, ma piuttosto dei consigli o delle indicazioni da persone di cui si fidano e con cui sentono di avere un rapporto personale. Spesso noi medici chiediamo molto ai nostri pazienti e alle loro famiglie (genitori, ma anche fratelli sani): assumere farmaci, fare o non fare certe cose, mangiare in un certo modo, ecc.

Circa 15 anni fa, nel nostro Centro Trapianti abbiamo iniziato ad organizzare dei "campi", cioè delle brevi esperienze residenziali extra-ospedaliere con i pazienti e/o le loro famiglie. Queste esperienze sono state preziosissime, perchè mi hanno permesso di conoscere meglio, al di fuori dell'ospedale, i "miei" bambini e le loro famiglie, capendo abitudini, usanze, tradizioni, rapporti ecc. di ciascuna.

Elisa

pediatric nephrologist

I am a Paediatric Nephrologist and the head of the Paediatric Kidney Transplant Center at a University Hospital in Italy.

I have been working as a Paediatric Nephrologist for about 20 years and I have been specifically involved in Paediatric Kidney Transplantation for over 10 years.

At the beginning of my career, I focused mainly on rare and genetic kidney diseases, but I was always deeply fascinated by the field of kidney transplantation. This was also because the two more senior physicians (from two different generations) who taught me paediatric nephrology were both involved in transplantation, and they passed on their passion for this area of clinical care.
In particular, my first mentor was the pioneer Paediatric Nephrologist who started Paediatric Kidney Transplantation in Italy (in fact, the hospital where I work was the first Paediatric Kidney Transplant Center in Italy in 1987); she often told me about the emotions and fears surrounding the very first transplant she performed, and this inspired me somehow. Eventually, I myself began to care for transplanted patients, and later I was entrusted with the role of head of the Transplant Center.

In the first few years, I was very focused on the strictly clinical aspects, probably because I also needed to gain experience and deepen my knowledge in an area I had not previously worked on. Over time, however, I began to realise that helping a transplanted child to do well means taking care of everything, not just the kidney, and not just the child, but the whole family!

At university or during residency, we are often advised not to "get too close" to patients, to avoid becoming overly emotionally involved. However, I was fortunate to meet colleagues who believed the opposite: that forming close bonds with patients is actually the best way to truly care for them, especially when the patients are children or adolescents. They don't need to receive "orders" from a stranger, but rather advice and guidance from someone they trust and with whom they feel a personal connection.
As physicians, we often ask a great deal of our patients and their families (parents, but also healthy siblings): to take medications, to follow or avoid certain behaviors, to eat in specific ways, etc.

About 15 years ago, our Transplant Center began organising "camps," that is to say, short residential experiences outside the hospital with our patients and/or their families. These experiences have been incredibly valuable to me, as they allowed me to get to know "my" children and their families better outside of the hospital, learning about their habits, customs, traditions, relationships and more.

Tale conoscenza è fondamentale per curare, perchè permette di capire quali sono gli obiettivi raggiungibili e quali no: per esempio, chiedere ad una famiglia del Sud Italia di rinunciare a certi cibi o a certe tradizioni culinarie, è una richiesta impossibile e inutile, che fa molta fatica ad essere rispettata!

Ugualmente, vietare ad un bambino che abita in alta montagna ed i cui genitori sono maestri di sci, di stare sulle piste perchè potrebbe essere pericoloso, è una richiesta che metterebbe in crisi l'intero nucleo familiare!

Ma questo si può capire solo conoscendo i contesti ambientali, sociali e culturali in cui un bambino vive ed è importantissimo conoscerli, se si vuole davvero prendersi cura di quel bambino.

Penso infatti che la cura passi solo attraverso un rapporto di fiducia e affetto reciproco, in cui il medico può fidarsi al 100% del paziente e dei suoi genitori ed essi possono essere assolutamente certi che il medico, in tutto ciò che dice e fa, ha come unico obiettivo quello di restituire il bambino malato e tutta la sua famiglia ad una vita normale!

This kind of understanding is essential for providing care, because it helps you recognise what goals are realistically achievable and which are not. For example, asking a family from southern Italy to give up certain foods or culinary traditions is an unrealistic and ineffective request: it is extremely hard for them to comply!

Similarly, forbidding a child who lives in the mountains and whose parents are ski instructors from going on the slopes because it might be dangerous would destabilise the entire family.

But this kind of understanding only comes from knowing the environmental, social, and cultural contexts in which a child lives, and it is absolutely crucial to know them if you truly want to take care of that child!

I truly believe that care can only happen through a relationship of trust and mutual affection, in which the physician can trust the patient and his/her parents completely, and they, in turn, can be absolutely certain that everything the doctor says and does has one single goal: to give the sick child, and his/her entire family, a chance at a normal life!

Silvia
dietista

Alessia
dietista

Nel nostro ospedale pediatrico, il percorso dei pazienti affetti da malattie metaboliche ereditarie, candidati a trapianto di fegato o a trapianto combinato fegato-rene, è prima di tutto un percorso umano, sociale, affettivo. Ogni bambino che incontriamo porta con sé una storia complessa, un bagaglio di restrizioni dietetiche, di diversità, spesso iniziato molto precocemente, caratterizzato da diagnosi difficili, lunghi tempi di attesa, decisioni delicate e da un legame particolarmente stretto con la propria famiglia.

Ecco, noi dietiste del reparto di Malattie Metaboliche Ereditarie - Silvia, dedicata in questo ambito da quasi 40 anni, e Alessia - abbiamo accompagnato nel tempo numerosi bambini e adolescenti lungo l'intero iter trapiantologico, dalla diagnosi precoce, alla valutazione dell'indicazione al trapianto, fino al follow-up a lungo termine. Questo percorso condiviso ci ha permesso di osservare da vicino non solo l'evoluzione clinica delle patologie, ma anche il significativo carico emotivo e organizzativo che il trapianto comporta per i bambini e per le loro famiglie.

Il trapianto di fegato, e in alcuni casi il trapianto combinato fegato-rene, non rappresenta semplicemente una sostituzione d'organo, ma una vera e propria terapia metabolica in grado di correggere il difetto enzimatico alla base della patologia. L'indicazione al trapianto deriva da una valutazione attenta, meticolosa e condivisa, che considera non solo i parametri clinici e biochimici, ma anche lo sviluppo neurologico, lo stato nutrizionale e la qualità di vita del bambino. Si tratta spesso di un momento complesso, che richiede un dialogo aperto, chiaro e basato sulla reciproca fiducia con le famiglie.

Durante la fase pre-trapianto il nostro impegno è rivolto a garantire la migliore stabilità metabolica possibile, atta a prevenire le complicanze acute e a preparare il paziente e la famiglia a un intervento che viene vissuto con timore, paura, ma anche con grande speranza. In quanto dietiste del team metabolico, il nostro contributo si concentra in modo particolare sulla gestione nutrizionale delle prescrizioni dietetiche difficili da gestire a domicilio che rappresentano un elemento centrale della terapia. In questa fase, la relazione, che si costruisce giorno dopo giorno, diventa parte integrante del percorso di cura, con continui monitoraggi nutrizionali anche nelle fasi di scompenso acuto metabolico.

I ricoveri, i controlli in follow-up, i contatti telefonici con le famiglie ci permettono di istaurare un rapporto di fiducia e di ascolto. Le loro domande, le loro paure … Un futuro, una nuova vita da affrontare, a volte impreparati.

Il trattamento nutrizionale nei pazienti affetti da malattie metaboliche ereditarie si basa sull'impostazione di una dieta ipoproteica strettamente controllata, con un

Silvia
dietitian

Alessia
dietitian

At our pediatric hospital, the journey of patients suffering from hereditary metabolic diseases, candidates for liver transplant or combined liver and kidney transplant, is first and foremost a human, social and emotional one. Every child we meet brings with them a complex history, a baggage of dietary restrictions and diversity, often started very early, characterised by difficult diagnoses, long waiting times, delicate decisions and a particularly close bond with their family.

We, dietitians in the Department of Inherited Metabolic Diseases - Silvia, who has been working in this field for almost 40 years, and Alessia - have accompanied many children and adolescents throughout the entire transplant process, from early diagnosis to assessment of the indication for transplant, up to long-term follow-up. This shared journey has allowed us to closely observe not only the clinical evolution of diseases, but also the significant emotional and organisational burden that transplantation entails for children and their families.

Liver transplantation, and in some cases combined liver and kidney transplantation, is not simply an organ replacement, but a true metabolic therapy capable of correcting the underlying enzymatic defect. The indication for transplantation is based on a careful, meticulous and shared evaluation, which considers not only clinical and biochemical parameters, but also the child's neurological development, nutritional status and quality of life. This is often a complex process which requires an open, clear dialogue based on mutual trust with families.

During the pre-transplant phase, our commitment is to ensure the best possible metabolic stability, preventing acute complications and preparing the patient and the family for a procedure that is experienced with fear, apprehension, but also with great hope. As dietitians of the metabolic team, our contribution focuses particularly on the nutritional management of the difficult-to-manage dietary prescriptions at home, which are a central element of therapy. During this phase, the relationship that is built day by day, becomes an integral part of the care path, with continuous nutritional monitoring even during the phases of acute metabolic decompensation.

Hospitalisations, follow-up visits, telephone contacts with families allow us to establish a relationship of trust and listening. Their questions, their fears... A future, a new life to face, sometimes unprepared.

Nutritional treatment for patients with hereditary metabolic diseases is based on a strictly controlled low-protein diet, with a natural protein intake tailored to the individual enzyme deficiency and the patient's individual tolerance. Protein restriction is compensated by using amino acid mixtures (extremely unpalatable protein equivalents or synthetic proteins) formulated to ensure adequate amino acids intake apporto proteico naturale calibrato sul singolo difetto enzimatico e sulla tolleranza individuale del paziente. La restrizione proteica viene compensata mediante l'utilizzo di miscele aminoacidiche (proteine equivalenti o sintetiche estremamente non palatabili), formulate per garantire un adeguato apporto di aminoacidi (per evitare la malnutrizione e la cachessia), e di prodotti dietetici "speciali" (pane-pasta-latte-biscotti ecc… aproteici). In base alle patologie e alle fasi cliniche, può essere necessario l'utilizzo di integratori calorici, fondamentali per prevenire il catabolismo proteico endogeno e mantenere un adeguato equilibrio metabolico.

Spesso, poiché l'alimentazione e gli alimenti prescritti rappresentano la cura insieme alla farmacoterapia e devono essere sempre assunti in modo costante, si può ricorrere a somministrazioni alimentari più invasive, quali il posizionamento del SNG e in casi più complessi al confezionamento PEG.

Dal 2009 ad oggi, presso la nostra Unità Operativa di Malattie Metaboliche ed Epatologia, 69 pazienti pediatrici sono stati sottoposti a trapianto. Dietro a questo dato numerico si collocano volti, famiglie, fotografie, eventi e percorsi di cura e di vita che proseguono nel tempo. Nella maggior parte dei casi il trapianto ha consentito una significativa riduzione degli scompensi metabolici e delle ospedalizzazioni, con un conseguente miglioramento della qualità di vita non solo dei pazienti, ma dell'intero nucleo familiare. I bambini, in dieta fortemente restrittiva nella fase pre-trapianto, possono finalmente assaporare la convivialità di un pasto sereno e soprattutto "uguale" ai fratellini o ai genitori o ai compagni di scuola, poiché non più "diversi".

Questi bambini portano un bagaglio di anni di rinunce, di feste di compleanno mancate, di viaggi non goduti, di gite scolastiche alle quali non si è partecipato poiché si mangiava diverso… Tutto meticolosamente pesato su un bilancino di precisione da portare sempre appresso, dieta impossibile da attuare fuori casa. Le paure e la voglia o il bisogno di mangiare di più, di assaggiare alimenti non consentiti, proibiti, tante privazioni.

Uno degli aspetti più gratificanti del nostro lavoro è stato osservare, negli anni, che alcuni bambini conosciuti in condizioni di estrema fragilità hanno acquisito progressivamente maggiore stabilità clinica, autonomia nelle scelte alimentari, la possibilità di una vita quotidiana e sociale serena, uguale ai pari. Questo evidenzia come il trapianto non rappresenti un punto di arrivo, ma l'inizio di un nuovo percorso di vita, più sereno da condividere nel contesto sociale.

In conclusione, l'esperienza del nostro ospedale pediatrico dimostra come il trapianto di fegato e fegato-rene nei pazienti pediatrici affetti da malattie metaboliche ereditarie sia il risultato di un percorso complesso, fondato sull'integrazione di competenze cliniche, chirurgiche e umane. Per noi, questo percorso rappresenta anche un'esperienza professionale e personale di immenso valore… Che continua a rafforzare il senso del nostro lavoro quotidiano accanto ai piccoli pazienti e alle loro famiglie.

(to prevent malnutrition and cachexia), and "special" dietary products (protein-free bread, pasta, milk, biscuits, etc.). Depending on the pathology and clinical stage, the use of caloric supplements may be necessary, as they are essential for preventing endogenous protein catabolism and maintaining adequate metabolic balance.

Often, since the diet and prescribed foods represent the treatment along with pharmacotherapy and must always be taken consistently, more invasive nutritional administrations can be used, such as positioning a SNG and, in more complex cases, PEG.

Since 2009, 69 pediatric patients have undergone transplantation at our Metabolic Diseases and Hepatology Unit. Behind these numbers there are faces, families, photographs, events, paths of care and life that continue over time. In most cases, transplantation has led to a significant reduction in metabolic crises and hospitalisations, resulting in an improvement in the quality of life not only of the patients but of the entire family. Children on a highly restrictive diet in the pre-transplant phase can finally enjoy the conviviality of a serene meal and above all "just like" their siblings, parents or schoolmates, since they are no longer "different".

These children carry a baggage of years of renunciations, missed birthday parties, unenjoyed trips and school they missed because they ate differently... Everything meticulously weighed on a precision scale to be always carried around, a diet impossible to follow outside the home. The fears and the desire or need to eat more, to taste foods that are not allowed, forbidden, so many deprivations.

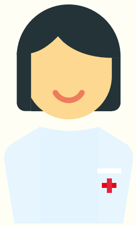
One of the most rewarding aspects of our work has been observing, over the years, how some children we met in extremely fragile conditions have progressively gained greater clinical stability, independence in their dietary choices, and the opportunity to lead a serene daily and social life, equal to peers. This highlights how transplantation is not a point of arrival, but rather the beginning of a new, more peaceful life journey, shared in the social context.

In conclusion, the experience of our pediatric hospital demonstrates how liver and liver-kidney transplantation in pediatric patients with inherited metabolic diseases is the result of a complex process, based on the integration of clinical, surgical and human expertise. For us, this process also represents a professional and personal experience of immense value... Which continues to strengthen the meaning of our daily work alongside young patients and their families.

Nederland / Netherlands

p. 88
Yvonne

Yvonne
kinderverpleegkundige



Ik ben kinderlongverpleegkundige en werk sinds 20 jaar met kindertransplantatie, waarvan de eerste zeven jaar op de verpleegafdeling. Dertien jaar geleden kreeg ik de kans om mij volledig op kinderlongtransplantatie te richten vanuit de rol verpleegkundig consulent.

Transplantatie heeft mij vanaf het eerste moment dat ik er mee in aanraking kwam geïnteresseerd.

Er gebeurt veel vanaf de screening totdat een kind over gaat naar de volwassen afdeling. De ontwikkeling van het kind tot een volwassene gaat daarbij ook door. Het mooie van mijn beroep vind ik dat ik op een laagdrempelige manier het kind en de ouders hier in kan ondersteunen.

Ik heb ongelofelijk veel respect voor de manier waarop kinderen en ouders het longtransplantatietraject doorstaan. De kracht en de manier waarop ze met eventuele tegenslagen omgaan blijft indrukwekkend.

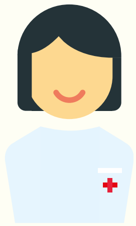
De meeste kinderen die ik vooraf aan een longtransplantatie spreek hebben een bescheiden wens. Gewoon naast hun vriendje kunnen lopen naar de gymles in plaats van bij juf achter op de fiets. Mee kunnen doen met leeftijdsgenootjes, dat is alles wat ze willen.

Dit maakt het extra bijzonder als ze na een transplantatie in staat zijn om dit soort dingen weer op te pakken. De eerste schooldag, een diploma, een studie kiezen, een dansoptreden, de eerste vakantie en de eerste verliefdheid… We zien hoe ze stap voor stap vooruit gaan en plannen maken voor de toekomst. Het is heel waardevol om dat vanaf de zijlijn mee te mogen maken.

Als ik op de werkvloer ben ga ik helemaal op in de patiëntenzorg en vergeet ik alles wat daar buiten speelt. Zodra ik na mijn dienst het ziekenhuis verlaat moet ik soms echt even bewust schakelen. Welke dag is het ook alweer en wat staat thuis op de planning? Er zijn dagen dat ik de overgang van de werkvloer naar privé best lastig vind. Als je een kind hebt zien vechten voor zijn leven op de Intensive Care en ouders wensen je na het gesprek een fijne vakantie… Ik kan het niet helpen dat ik soms met een schuldgevoel het ziekenhuis verlaat.

Een deskundig, fijn en betrokken team is heel belangrijk als je je met deze complexe zorg bezighoudt. We zijn het enige centrum in Nederland dat longtransplantaties uitvoert bij kinderen. Ik ben trots dat ik deel mag uitmaken van dit team en dat ik sinds kort ook ervaringen kan uitwisselen met verpleegkundigen uit Europa die ik heb ontmoet via ERN Transplantchild.

Yvonne
pediatric nurse



I am a paediatric lung nurse and I have been working in paediatric transplantation for 20 years, the first seven of which were spent in the nursing ward. Thirteen years ago, I was given the opportunity to focus entirely on paediatric lung transplantation in the role of nursing consultant.

Transplantation has interested me from the very first moment I encountered it.

A lot happens between the screening and the child growing up becoming an adult: his/her physical and mental development continues during the time of illness. What I love about my job is that I can support the child and their parents in an accessible way.

I have incredible respect for the way children and parents go through the lung transplant process. Their strength and the way they deal with any setbacks is so impressive.
Most of the children I see before a lung transplant have modest wishes. Just being able to walk alongside their friends to gym class instead of riding on the back of their teacher's bike. Being able to participate with their peers is all they want.

This makes it even more special when, after a transplant, they are able to do these kinds of things. The first day of school, the moment they graduate, choosing a course of study, a dance performance, the first holiday and the first crush... We see how they progress step by step and make plans for the future. It is very valuable to be able to experience this from the sidelines.

When I'm at work, I'm completely absorbed in patient care and forget everything else that's going on. As soon as I leave the hospital after my shift, I sometimes have to make a conscious effort to switch gears. What day is it again and what's on the agenda at home? There are days when I find the transition from work to private life quite difficult. When you've seen a child fighting for his life in intensive care and the parents wish you a nice holiday after the consultation... I can't help feeling guilty when I leave the hospital sometimes.

A skilled, pleasant and committed team is very important when you are involved in this complex care. We are the only centre in the Netherlands that performs lung transplants on children. I am proud to be part of this team and that I have recently been able to exchange experiences with nurses from across Europe whom I met through the ERN Transplantchild.

Because we often see the children again after a lung transplant, we have time to build a relationship and explain and repeat everything calmly. I hope that this will

Doordat we de kinderen vaak terugzien na een longtransplantatie hebben we tijd om een band op te bouwen en alles rustig uit te leggen en te herhalen. Ik hoop daardoor sneller te herkennen als er iets speelt en hoop dat ze het vertrouwen hebben om het te vertellen als het even niet gaat. Maar ik besef me ook dat we niet iedereen kunnen helpen en dat we niet overal invloed op hebben.

Ik herinner me een jongen die na zijn longtransplantatie vaak niet op afspraken verscheen en soms onaangekondigd ineens wél kwam. Ik zal nooit vergeten dat hij vanuit de taxi belde met de vraag wat onze favoriete hamburger was. Een half uur later stond hij bij de balie met een zak burgers van de Macdonalds. ‘Samen opeten?’ zei hij. We maakten altijd tijd voor hem vrij omdat we het belangrijk vonden om contact met hem te houden. De gesprekken die we toen hadden - tijdens het eten van een hamburger - zijn me altijd bijgebleven. Hij gaf me een kijkje in zijn wereld waar ik veel van heb geleerd.

Mijn boodschap aan kinderen en ouders zou zijn: stel alle vragen die je hebt, ook als je twijfelt. Onbelangrijke vragen bestaan niet. Dit leert ons wat bij jullie speelt en helpt ons om jullie zo goed mogelijk te begeleiden. Voel je onderdeel van het team. Samen gaan we voor de beste zorg.

En aan zorgverleners: wees geduldig. Durf te vragen, ook als het niet de goede kant op gaat. Luister naar ze. Leer van ze.

enable me to recognise more quickly when something is wrong and that they will feel confident enough to tell me when things are not going well. But I also realise that we cannot help everyone and that we cannot influence everything.

I remember a boy who often didn’t show up for appointments after his lung transplant and sometimes suddenly turned up unannounced. I’ll never forget him calling from the taxi to ask what our favourite hamburger was. Half an hour later, he was at the reception desk with a bag of burgers from McDonald’s. ‘Want to eat together?’ he said. We always made time for him because we knew it was important to stay in touch with him. The conversations we had back then - while eating a hamburger - have always stayed with me. He gave me a look into his world, from which I learned a lot.

My message to children and parents would be: ask all the questions you have, even if you are unsure. There are no unimportant questions. This teaches us what is going on with you and helps us to guide you the best we can. Feel part of the team. Together, we strive for the best care.

And to healthcare providers: be patient. Dare to ask questions, even if things are not going well. Listen to them. Learn from them.

Polska / Poland

Julita

pediatra, neonatologiem

Neonatolog czy transplantolog? Lekarz, którego pacjenci urodzili się na nowo.

Jestem lekarzem pediatrą, neonatologiem. Od 20 lat pracuję w dużym szpitalu dziecięcym w stolicy Polski, Warszawie. Większość mojego zawodowego życia spędziłam na oddziale intensywnej terapii dla noworodków. Leczyłam najmniejsze, niedojrzałe dzieci, których narządy wewnętrzne nie funkcjonowały prawidłowo. Noworodki urodzone z wadami wrodzonymi, ciężkimi zakażeniami, poważnymi uszkodzeniami neurologicznymi, chorobami metabolicznymi. Praca lekarza na takim oddziale wymaga ogromnej wiedzy i zaangażowania, umiejętności zachowania zimnej krwi. Jednak najtrudniejsze są rozmowy z rodzicami dziecka o tym, że czasem jesteśmy bezsilni, że przegraliśmy z chorobą. Patrzenie im w oczy, bycie przy nich to trud, ale też nasza powinność.

Jak neonatolog znalazł się w oddziale transplantacyjnym? Potrzebowałam zmiany w życiu. Jednak takiej zmiany, która pozwoli mi na wykorzystanie mojej wiedzy i doświadczenia lekarza intensywisty. Wydawało mi się, że właśnie w pracy z pacjentami po przeszczepieniu będę mogła się odnaleźć. Pracy z dziećmi, które dzięki dawcy, rodzą się na nowo. Pracy z pacjentami, którzy potrafią nas zaskoczyć, którzy chorują nieschematycznie, przy których lekarz na pewno nie popadnie w rutynę. Tacy właśnie są moi podopieczni po przeszczepieniu wątroby i nerek. To co dodatkowo łączy ich z niedojrzałymi wcześniakami to niewydolny układ odpornościowy ze wszystkimi tego konsekwencjami.

Co mnie zaskoczyło? Że pacjent może być większy od lekarza. I że zamiast mikrodawek niektórzy potrzebują całej ampułki leku.

Co jest trudne? To się nie zmieniło. Nadal poważne rozmowy z rodzicami, i dodatkowo z dzieckiem. Rozmowy o tym, że nie widzimy poprawy, że będziemy po raz kolejny próbować innej metody leczenia, ale nie mamy pewności czy przyniesie ona efekt. Wiem jednak, że dla rodziców gorszy od tak trudnej rozmowy jest jej brak.

Co jest wspaniałe? Radość i wdzięczność dzieci. Ufność jaką nas obdarzają, szczególnie jeżeli uda nam się w trudzie do nich dotrzeć. Z niektórymi pacjentami, którzy są długo hospitalizowani zaczyna nas łączyć specyficzna więź. I czy tego chcemy czy nie kawałek tej pracy zabieramy do domu.

Na koniec muszę podkreślić jak ważne w naszej pracy jest działanie zespołowe. Nawet perfekcyjna operacja przeszczepienia skończyłaby się fiaskiem bez całego sztabu lekarzy i pielęgniarek, którzy wspólnie walczą o utrzymanie funkcji przeszczepionego narządu. Choć czasem ta praca może wydawać się niewidzialna.
Jestem dumna, że jestem członkiem tego zespołu.

Julita

pediatrician, neonatologist

Neonatologist or Transplantologist? A doctor whose patients have been reborn.

I'm a pediatrician, a neonatologist. For 20 years I have been working in a large children's hospital in the capital of Poland, Warsaw. I spent most of my professional life in the neonatal intensive care unit. I treated the smallest, immature children whose internal organs were not functioning properly. Newborns with birth defects, severe infections, severe neurological damage, metabolic diseases. The job of a doctor in such a ward requires great knowledge and commitment, the ability to maintain cold blood. However, the most difficult thing is to talk to the child's parents about the fact that sometimes we are powerless, that we have lost against the disease. Looking at them into their eyes, being with them is such an effort, but it is also our duty.

How did the neonatologist end up in the transplant ward? I needed a change in my life. However, such a change would allow me to use my knowledge and experience of an intensive pediatrician. It seemed to me that it was in working with transplanted patients that I would be able to find myself. Working with children who, thanks to the donor, are born again. Working with patients who can challenge us, who suffer from unconventional diseases, with whom the doctor will certainly not fall into the routine. These are my patients after liver and kidney transplants. What additionally connects them to immature premature babies is a failing immune system with all the consequences.

What surprised me? A patient underage can be bigger than a doctor. And that instead of microdoses, some people need a whole ampoule of the drug.

What's hard? That hasn't changed. Still difficult conversations with parents, and additionally with the child. Talking about the fact that we do not see an improvement, that we will try another method of treatment again, but we are not sure whether it will bring any effect. I know, however, that for parents, the lack of such a hard conversation is worse than the conversation itself.

What's great? The joy and gratitude of the children. The trust they give us, especially if we manage to reach them. With some patients who are hospitalised for a long time, we begin to have a specific bond. And whether we like it or not, we take a piece of this work home.

Finally, I must stress the importance of teamwork in our work. Even a perfect transplant operation would fail without a whole staff of doctors and nurses fighting together to maintain the function of the transplanted organ. Although sometimes this work may seem invisible.
I am proud to be a member of this team.

Malgorzata

chirurg dziecięcy, transplantolog kliniczny

Rola:
Chirurg dziecięcy, transplantolog kliniczny.

Doświadczenie w dziedzinie transplantacji:
>20 lat.

Rodzaj programu transplantacji narządów:
nerka, wątroba.

Dlaczego zdecydowała się Pani zostać pracownikiem służby zdrowia zajmującym się transplantacjami?
Odkąd pamiętam zawsze chciałam zostać lekarzem, w trakcie nauki na wydziale medycznym zaczęłam swoją przygodę z chirurgią dziecięcą, a następnie na stażu podyplomowym bardzo duże wrażenie zrobiła na mnie transplantologia. W trakcie studiów medycznych zaczęłam odkrywać, jak ogromne znaczenie ma chirurgia w ratowaniu życia i poprawie jakości zdrowia pacjentów. Chirurgia dziecięca sprawia, że ciężko chore dzieci wracają do pełnej sprawności. Początkowo, gdy zaczęłam pracować w szpitalu, miałam możliwość uczestniczyć w zabiegach chirurgicznych, obserwować, jak przełomowe technologie i medycyna współczesna potrafią zmieniać losy pacjentów. Jednak to, co ujęło mnie najbardziej, to moment, kiedy po udanym przeszczepie widziałam, jak mały pacjent wraca do zdrowia, wstaje z łóżka, zaczyna się śmiać, bawić i normalnie funkcjonować jak jego rówieśnicy. Zajmowanie się transplantacjami to dla mnie nie tylko praca, ale i misja – dawanie dzieciom szansy na nowe życie. Często to moment, kiedy rodziny doświadczają ogromnego lęku i niepewności, a ja muszę pomóc im przejść przez ten trudny moment w ich życiu. Praca w Centrum Zdrowia Dziecka to nieustanne wyzwanie - każde dziecko, każda historia to inny przypadek, co sprawia, że moje kompetencje są nieustannie rozwijane.

Jak połączyć swoje życie osobiste z pilnością transplantacji, gdy narząd jest nagle dostępny?
W pracy transplantologa kluczowa jest elastyczność i umiejętność szybkiego podejmowania decyzji. Choć sytuacje związane z dostępnością narządu wymagają natychmiastowego działania, staram się zorganizować życie osobiste w sposób, który umożliwia mi szybkie reagowanie. Praca w zespole i wsparcie rodziny pozwala mi utrzymać balans. W chwilach, kiedy otrzymuję informację o dostępności narządu, potrafię skupić się na zadaniu, wiedząc, że mam odpowiednie wsparcie. Takie wyważenie pozwala mi skutecznie łączyć profesjonalizm z życiem osobistym, co jest niezbędne, by w pełni angażować się w ratowanie życia pacjentów.

Malgorzata

pediatric surgeon, clinical transplantologist

Role:
Pediatric surgeon, clinical transplantologist.

Experience in the field of transplantation:
>20 years.

Type of organ transplantation program:
Kidney, Liver.

Why did you decide to become a transplant health professional?
Ever since I can remember, I have always wanted to become a doctor. During my studies at the medical faculty I started my adventure with pediatric surgery and later, during my postgraduate internship, transplantology impressed me very much. During my medical studies, I began to discover the importance of surgery in saving lives and improving the quality of patients' health. Children's surgery makes seriously ill children return to full fitness.
Initially, when I started working in the hospital, I had the opportunity to participate in surgical procedures, observe how breakthrough technologies and modern medicine can change the fate of patients. However, what captivated me the most was the moment when, after a successful transplant, I saw a little patient recover, get out of bed, laugh, have fun and function normally like his peers. For me, dealing with transplants is not only a job, but also a mission - to give children a chance at a new life. Often this is when families experience tremendous fear and uncertainty, and I have to help them go through this difficult moment in their lives. Working at a Children's Hospital is a constant challenge - every child, every story is a different case, which means that my competences need to be constantly developed and adjusted.

How do you combine your personal life with the urgency of transplantation when an organ is suddenly available?
In the work of a transplantologist, flexibility and the ability to make decisions quickly are crucial. Since organ availability requires immediate action, I try to organise my personal life in a way that allows me to react quickly. Working in a team and being supported by my family allows me to maintain a balance. In the moments when I receive information about the availability of an organ, I can focus on the task, knowing that I have the right support. This balance allows me to effectively combine my profession with my personal life, which is necessary to fully engage in saving patients' lives.

Malgorzata

Jak przekazać informację Rodzinie o nieudanym przeszczepie?
Przekazanie rodzicom tak trudnej informacji to zawsze moment, który wymaga delikatności i pełnej empatii. Staram się rozmawiać w spokojny sposób, wyjaśniając dokładnie, co się stało, unikając technicznego żargonu, aby rodzice mogli zrozumieć sytuację. Ważne jest, by w tej chwili dać im przestrzeń na emocje, pozwolić im wyrazić ból i rozczarowanie. Przekazuję, że mimo nieudanej próby, nie rezygnujemy z dalszego działania i szukania rozwiązań. Stawiam na wsparcie i współpracę - informuję, jakie kroki będą podejmowane w przyszłości, aby dać dziecku jak najlepszą szansę. W takich chwilach najważniejsze jest być obecnym i zapewnić rodzinę, że nie zostaną sami w trudnym procesie, jaki ich czeka.

Porady, jak nawiązać dobre relacje z pacjentami/rodzinami:
Aby nawiązać dobre relacje z pacjentami i ich rodzinami, kluczowe jest okazywanie empatii i zrozumienia. Ważne jest, by słuchać ich obaw i pytań, a także wyjaśniać sytuację w sposób jasny i spokojny. Budowanie zaufania opiera się na szczerości, cierpliwości oraz dostępności, tak aby rodziny czuły się komfortowo i wiedziały, że mogą liczyć na nasze wsparcie. Dobre relacje to także okazywanie szacunku dla emocji i potrzeb rodziny, oferowanie wsparcia zarówno medycznego, jak i emocjonalnego.

Czy pamięta Pan/Pani jakiś konkretny przypadek? Jeśli tak, dlaczego?
Odpowiedź na to pytanie jest niezmiernie trudne, nie pamiętam jednego konkretnego pacjenta. Każdy przypadek przebiegu choroby, każdy pacjent jest inny i najczęściej pozostaje na długo w pamięci. Praktycznie od każdego pacjenta i jego rodziny można nauczyć się czegoś nowego, co może poprawić relacje z kolejnymi osobami, a także sprawia, ze staję się lepszym lekarzem.

Wiadomość, którą chce Pan/Pani przekazać pacjentom/rodzicom lub innemu pracownikowi służby zdrowia:
Najważniejsi w naszej pracy są pacjenci i ich rodziny. Istotne jest to, aby odczuwali, że mamy wspólny cel dobro i zdrowie dziecka. Dodatkowo musimy pamiętać, że aby osiągnąć ten cel konieczna jest współpraca wielu osób - lekarzy, pielęgniarek, dietetyczek, rehabilitantów, laborantów, diagnostów, nauczycieli w przedszkolu - pojedyncza osoba nie jest w stanie osiągnąć sukcesu.

Malgorzata

How do you communicate a failed transplant?
Giving parents such difficult information is always a moment that requires delicacy and full empathy. I try to talk in a calm way, explaining exactly what happened, avoiding jargon so that parents can understand the situation. It is important in that moment to give them space for emotions, to allow them to express their pain and disappointment. I tell them that despite the unsuccessful attempt, we do not give up looking for further action and search for solutions. I focus on support and cooperation – what steps will be taken in the future to give the child the best possible chance. In such moments, the most important thing is to be present and assure the family that they will not be left alone in the difficult process that awaits them.

Your advice on how to establish good relationships with patients/families:
In order to establish good relationships with patients and their families, it is crucial to show empathy and understanding. It is important to listen to their concerns and questions, as well as to explain the situation in a clear and calm way. Building trust is based on honesty, patience and availability, so that families feel comfortable and know that they can count on our support. Good relationships also mean showing respect for the emotions and needs of the family, offering both medical and emotional support.

Do you remember a specific case? If so, why?
The answer to this question is extremely difficult, I do not remember one particular patient. Each case of the course of the disease, each patient is different and most often remains in memory for a long time. Practically every patient and his/her family teach me something new, which can improve relationships with other people and also makes me a better doctor.

Message you would like to send to patients/parents or other healthcare professionals:
The most important focus in our work are patients and their families. It is important that they feel that we have a common goal for the well-being and health of the child. In addition, we must remember that to achieve this goal, many people need to work together - doctors, nurses, nutritionists, physiotherapists, laboratory technicians, diagnosticians, teachers in kindergarten - a single person is not able to succeed.

Portugal

Conceição

nefrologista pediátrica

Trabalhei em transplante renal pediátrico cerca de 3 décadas e a minha atividade nesta área da Medicina determinou e preencheu uma significativa parte da minha vida profissional. Após a realização do exame final de especialidade de nefrologia, tive a oportunidade de concorrer a um Hospital Pediátrico onde pretendiam que fosse implementado o programa de transplante renal pediátrico.

Deparei-me com um desafio estimulante: trabalhar com crianças e desenvolver uma atividade interessante e complexa, que é a transplantação. Agarrei com entusiasmo esta tarefa que exigiu liderança, preparação técnica, estudo e trabalho constante, ao longo da minha vida profissional.

O responsável pela equipa de transplantação tem um papel fulcral no êxito do programa, tendo sob a sua responsabilidade o planeamento eficiente da atividade e o desenvolvimento de estratégias que promovam a consolidação de equipas motivadas, coesas e atualizadas.

A participação dos diferentes elementos da equipa em atividades formativas e de investigação devem ser estimuladas, assim como a participação em fóruns de discussão de boas práticas clínicas e de novas estratégias terapêuticas.

O transplante pediátrico é considerado um procedimento complexo e raro, e a integração do Programa de Transplantação Pediátrica em Redes de Referência Nacionais e internacionais é de grande importância. Estas Redes ocupam um espaço vital para a troca de ideias, colaboração e desenvolvimento de estratégias conjuntas, encorajando o desenvolvimento interpares de soluções inovadoras.

Todos temos a consciência de que a atividade de transplantação é exigente no tempo disponibilizado para o trabalho, desenvolvendo-se muitas vezes em horas ou dias incómodos, que motivam sacrifício. Um conselho que dou aos colegas de trabalho, particularmente às gerações mais novas: procurem sempre manter um equilíbrio entre a vida pessoal e profissional, pois um médico saudável e equilibrado é um médico melhor.

Uma das grandes dificuldades em transplantação é lidar com a perda, seja a morte do doente, seja a falência do enxerto.

Conceição

pediatric nefrologist

I have been working in pediatric kidney transplantation for about 3 decades and my activity in this area of Medicine has determined and filled a significant part of my professional life.

After passing an end-of-specialty nephrology exam, I had the opportunity to apply to work in a pediatric hospital where they wanted the pediatric kidney transplant program to be implemented. This opportunity was for me a stimulating challenge: working with children and developing an interesting and complex activity, which is transplantation.

I enthusiastically embraced this task which required leadership, technical preparation, study and constant work throughout my professional life.

The Director of a transplant team has got a central role in the success of the program, having under his responsibility the efficient planning of the activity and the development of strategies that promote the consolidation of motivated, cohesive and up-to-date teams.

The participation of the different team members in training and research activities should be stimulated, as well as participation in forums to discuss good clinical practices and new therapeutic strategies.

Paediatric transplantation is considered a complex and rare procedure, and the integration of the Paediatric Transplantation Program into national and international Reference Networks is of great importance.

These Networks occupy a vital space for the exchange of ideas, collaboration and development of joint strategies, encouraging the peer-to-peer development of innovative solutions.

We are all aware that transplantation activity is a demanding part of our working time, often meaning uncomfortable shifts in terms of hours or days, which motivate sacrifice.

A piece of advice I give to co-workers, particularly younger generations: always seek to maintain a balance between your personal and professional life, as a healthy and balanced doctor is a better doctor.

One of the great difficulties in transplantation is to deal with the loss, either the death of the patient or the failure of the graft. The tragedies we take home, enclosed in our

Os dramas que levamos para casa, encerrados nos nossos silêncios, são difíceis, causam sofrimento.

Autoproteção é obrigatório, estabelecer fronteiras, separar a vida profissional/pessoal de forma a diminuir o impacto emocional. Aprender a aceitar a perda, processar as emoções de forma saudável pode ajudar a continuação do exercício de medicina com equilíbrio.

O apoio interpar, assim como celebrar pequenas vitórias, ajudam a superar a dor das perdas.

E por último, na era da inteligência artificial, relembro que a medicina é uma ciência, mas também é a arte de tratar. A relação de confiança a estabelecer com a criança doente e respetivos pais, através de uma eficaz capacidade de comunicação, de respeito, de empatia e de compaixão, exigem um contacto humano que a tecnologia não pode disponibilizar.

silences, are difficult and cause suffering.

Self-protection is mandatory, establishing boundaries, separating professional/personal life in order to lessen the emotional impact. Learning to accept the loss, processing emotions in a healthy way can help continue the exercise of medicine with balance.

Peer support, as well as celebrating small victories, help overcome the pain of losses.

And finally, in the age of artificial intelligence, I remind that medicine is a science, but it is also the art of treating.

The relationship of trust established with a sick child and his parents, through an effective power for communication, respect, empathy and compassion, requires a human contact that technology cannot ever provide.

Angélica

educadora de infância

Durante a minha atividade profissional, enquanto educadora de infância em contexto hospitalar, tive muito tempo - tempo para cuidar, para escutar, para acarinhar, para rir, às vezes para chorar.

Tive o privilégio de partilhar vivências com crianças portadoras de doença crónica, às quais dediquei o melhor de mim, mas também foram elas que muitas vezes me proporcionaram os maiores e melhores momentos profissionais.

Acompanhei diversas situações marcantes em hemodiálise, das quais destaco a experiência vivida num dia de abril de 2021, em que entrei no quarto da criança, à qual dou o nome de "Esperança", que me disse com entusiasmo, «já sei fazer xixi».

Era a voz de uma criança carregada de futuro, num corpo franzino de quatro anos. Estava sentada no bacio, e tão feliz, que fazia dele um trono. Tinha sido transplantada renal, e estava com o enxerto funcionante. Até então, não sabia o que era fazer xixi, daí, o grande feito!

Esta criança, era a mesma que refazia histórias, apropriando-se das personagens, referido "que era engraçado entrar nas pessoas". A doença não a incapacitou nesta competência, nem noutras relacionadas com diversas aprendizagens. Sempre entusiasmada, e com vontade de fazer coisas.

Estabeleci com esta criança, uma relação de proximidade. Conheci-a ainda não tinha dois anos, estava anéfrica, fazia hemodiálise crónica e quimioterapia para um tumor de Wilms. Revelou-se sempre, uma criança com vontade de aprender. Cedo descobriu que tinha vida para além da doença.

Dizia, muito a sério, que no hospital, eu era a professora, e fora do hospital, era a melhor amiga. Gostaria eu, de ter a humildade, a alegria, o amor e a sabedoria feita de simplicidade desta, e, de tantas outras crianças portadoras de doença crónica.

Angélica

kindergarten teacher

During my professional career as a kindergarten teacher in a hospital setting, I had plenty of time - time to care, to listen, to cherish, to laugh and sometimes to cry.

I had the privilege of sharing experiences with children with chronic illness, to whom I dedicated the best of myself, but they were also the ones who often provided me with the greatest and best professional moments.

I have witnessed several remarkable situations during hemodialysis, and I would like to recall one of them: one day in April 2021, I walked into the room of a child I named "Hope" who enthusiastically said "I can pee now!". It was the voice of a child full of hope, in a frail four-year-old body.

She was sitting on the potty, so happy she made it her throne. She had been kidney transplanted, and she had a working graft. "I didn't know what it was to pee", hence the great achievement!

This child was the same one who remade stories, appropriating the characters, saying that "it was funny to be in other peoples' shoes". The disease did not incapacitate her in this skill, nor in others related to various learnings. Always excited and eager to do things.

I have established a close relationship with this child. I met her when she was not yet two years old, she was anemic, had chronic hemodialysis and chemotherapy for a Wilms tumor. She always revealed herself to be a child eager to learn. She soon discovered that there was life beyond her illness.

She said, very seriously, that in the hospital I was her teacher and outside the hospital I was her best friend. I wish I had the humility, joy, love and the wisdom that she, and so many other children with chronic diseases, simply have.

La Salete

nefrologista

Cargo:

Nefrologista e responsável pela transplantação renal.

Experiência:

A minha experiência na área da transplantação renal tem já mais de 25 anos e, igualmente, cerca de 25 anos na transplantação reno-pancreática em doentes com diabetes tipo 1. Nos primeiros anos em que trabalhei na transplantação, a transplantação renal pediátrica era realizada no serviço de adultos onde sempre trabalhei. Era um grande desafio, e de facto, faz todo sentido que os programas se tenham separado e que a transplantação renal pediátrica se tenha passado a fazer num local com estrutura própria para acolher as crianças e para as acompanhar.

Escolha Transplantação:

A minha decisão de optar pela transplantação renal dentro das áreas da nefrologia prendeu-se com os excelentes resultados da transplantação e o modo como esta pode mudar a vida dos doentes francamente para melhor. É de todos os tipos de tratamento para a doença renal crónica terminal ou avançada aquele que proporciona melhores resultados e melhor qualidade de vida. E é tão bom ver os doentes mudarem a sua vida para melhor não só em termos de saúde, mas em termos sociais, profissionais e familiares!

Como eu combino a minha vida familiar e pessoal com urgência de trabalhar uma situação de transplante que está prestes a ocorrer?

Pois, com sacrifício pessoal, mas com muita satisfação também por ver o quanto mudamos a vida dos doentes. E ainda mais nas vidas das crianças. É claro que deixamos muitas vezes a nossa família, o convívio social para gerir uma situação que é sempre urgente porque os órgãos não esperam. Mas com compreensão, com empenho e algum espírito de sacrifício, tudo se consegue!

Avanços/Dificuldades:

Ao longo dos anos, e desde que trabalho na transplantação renal, houve de facto muitos avanços quer em termos de imunossupressão, quer em termos de evolução da técnica cirúrgica e também no próprio seguimento dos doentes.

Dar ao doente e à família a notícia da falência do enxerto renal é sempre difícil e penoso - quer para o doente, quer para a equipa que o trata. O melhor modo é irmos mantendo o doente e a família sempre informados, ganhar a sua empatia, saber que confiam na equipa que o trata e que tudo fez para que o transplante tivesse sucesso, mas que infelizmente não aconteceu. Quando o doente acompanha todo este percurso e o vamos mantendo sempre informado é mais fácil para ele aceitar esta desfecho, ainda que seja sempre doloroso para todos.

La Salete

nephrologist

Position:

Nephrologist and responsible for kidney transplantation.

Experience:

My experience in kidney transplantation is over 25 years old, and also about 25 years in rhine-pancreatic transplantation in patients with type 1 diabetes.

In the early years that I worked in transplantation, pediatric kidney transplantation was performed in the adult service where I had always worked. It was a great challenge, and in fact, it makes perfect sense that the programs were separated and that pediatric kidney transplantation began to be performed in a location with its own structure to accommodate and monitor the children.

Choice for Transplantation:

My decision to opt for kidney transplantation within the areas of nephrology was related to the excellent results of transplantation and how it can change the lives of patients, frankly for the better. Among all types of treatment for chronic end-stage or advanced kidney disease it is the one that provides better results and better quality of life. And it is so good to see patients changing their lives for the better, not only in terms of health, but in social, professional and family terms!

How do I combine my family and personal life with urgency to work out a transplant situation that is about to occur?

With personal sacrifice, but also with the great sense of satisfaction in seeing how much we have changed patients' lives. And especially children's lives. Of course, we often leave our families and social life behind to deal with this situation which is always urgent because the organs do not wait. But with understanding, with commitment and with some spirit sacrifice, everything is achieved!

Advances/Difficulties:

Over the years, and since I have started working in kidney transplantation, there have indeed been many advances both in terms of immunosuppression, in terms of the evolution of surgical technique and also in the follow-up of patients. Giving the patient and family the news of renal graft failure is always difficult and painful - both for the patient and for the team that treats him/her. The best way is to keep the patient and family always informed, gain their empathy, make sure they trust that the healthcare team did everything to make the transplant successful, but unfortunately it did not happen. When the patient follows this path all along and we keep him/her informed it is easier for him/her to accept this outcome, although it is always painful for everyone.

As razões acima, são as mesmas que nos levam a cultivar uma relação de proximidade com o doente e a família, que é fundamental ao longo do processo de evolução do seu transplante renal. Ganharmos a sua confiança e mantermos com eles uma relação de proximidade.

Caso particular:

Um caso que frequentemente recordo é o de uma criança a quem era sempre muito difícil fazer as colheitas de sangue para análises. A única maneira de a convencer a deixar fazer a colheita era dar-lhe pequenos presentes em cada dia: fossem lápis de cor, livros para desenhar ou para pintar, lápis de cera, etc. Nunca era fácil, mas estes pequenos "subornos" permitiam-nos aceder à criança com mais facilidade, para uma situação que lhe era sempre traumática.

Mensagem final:

A mensagem final que gostava de deixar é que na transplantação renal temos tanto para dar que todos os sacrifícios valem a pena! E vamos também ficar mais felizes quando virmos o resultado do nosso empenho: uma vida que se transformou, uma criança que cresceu mais saudável e mais feliz!

Those reasons are the same that lead us to cultivate a close relationship with the patient and the family, which is fundamental throughout the kidney transplantation process. We gain their trust and maintain a close relationship with them.

Particular case:

One case I often recall is that of a child who always had a very difficult time in taking blood samples for analysis. The only way to convince her to let us do the test was to give her small gifts each day: they were coloured pencils, drawing or painting books, crayons, etc. It was never easy, but these small "bribes" allowed us to access the child more easily, in a situation that was always traumatic for her.

Final message:

The final message I would like to leave with is that in kidney transplantation we have so much to give that all the sacrifices are worth it! And we will also be happier when we see the result of our commitment: a life that has changed, a child that has grown healthier and happier!

Sameiro

nefrologista pediátrica

O transplante renal pediátrico é uma das intervenções médicas mais transformadoras, oferecendo às crianças com doença renal crónica a possibilidade de viver uma vida quase normal.

Como nefrologista pediátrica com mais de 20 anos de experiência em transplantes renais, tive o privilégio de participar de inúmeras jornadas de transplantação pediátrica. Ao longo desse tempo, estive envolvida em todas as etapas do processo - desde as avaliações pré-transplante até os cuidados pós-transplante - e posso afirmar com confiança que o sucesso de um transplante renal pediátrico é o resultado direto do esforço coletivo de uma equipa multidisciplinar dedicada.

Embora a recuperação física seja um aspeto a ter em conta, é igualmente essencial apoiar a criança e a família emocionalmente.

Para as famílias, o caminho para um transplante é repleto de incertezas, e nosso papel é oferecer tanto conhecimento médico quanto orientação compassiva.

Nenhuma criança é igual a outra, e o percurso de cada uma é único. O sucesso de um transplante reside nesse cuidado individualizado, que garante que as necessidades de cada criança sejam abordadas de forma abrangente.

Ao longo dos anos, testemunhei avanços notáveis nas terapêuticas imunossupressoras que melhoraram os resultados dos transplantes e reduziram as complicações.

Graças aos avanços no controlo da rejeição imunológica e na prevenção de infeções, as taxas de sucesso dos transplantes renais pediátricos melhoraram dramaticamente, trazendo a todos nós uma renovada esperança para um futuro mais brilhante.

Um dos aspetos mais difíceis do meu trabalho é comunicar quando um transplante começa a falhar. Abordo essas conversas com grande cuidado, oferecendo uma comunicação clara e transparente, enquanto demonstro empatia e compreensão.

Asseguro que tanto a criança quanto a família recebam total apoio, permitindo que processem as informações e façam perguntas, para que possam tomar decisões informadas sobre os próximos passos.

O bem-estar emocional das famílias é tão importante quanto os cuidados médicos que oferecemos. Um diagnóstico de insuficiência renal pode ser devastador, e apoiar as famílias durante esse desafio é crucial.

Sameiro

pediatric nephrologist

Paediatric kidney transplantation is one of the most transformative medical interventions, offering children with chronic kidney failure the possibility of living a near-normal life.

As a paediatric nephrologist with over 20 years of experience in kidney transplantation, I have had the privilege of being part of countless paediatric transplant journeys. Throughout this time, I've been involved in every step of the process - from pre-transplant assessments to post-transplant care - and I can confidently say that the success of a paediatric kidney transplant is a direct result of the collective effort of a dedicated, multidisciplinary team.

While physical recovery is one aspect of the journey, it is equally essential to support the child and his/her family emotionally.

For families, the path to a transplant is filled with uncertainty and our role is to offer both medical expertise and compassionate guidance.

There are not two children alike each other, each child's journey is different. The success of a transplant lies in individualised care, which ensures that each child's needs are addressed comprehensively.

Over the years I've witnessed remarkable advances in immunosuppressive therapies that have enhanced transplant outcomes and reduced complications.

Thanks to advances in immune rejection control and infection prevention, the success rates of paediatric kidney transplants have dramatically improved, giving us all the renewed hope for a brighter future.

One of the most challenging aspects of my job is communicating when a transplant is failing. I approach these conversations with great care, offering clear and transparent communication while showing empathy and understanding.

I ensure that both the child and his/her family are fully supported, allowing them to process the information and ask questions, so they can make informed decisions about the next steps.

The emotional well-being of families is just as important as the medical care we provide. A diagnosis of kidney failure can be devastating, and supporting families through this challenge is crucial.

Sameiro

Sabemos que o transplante é uma jornada longa e frequentemente difícil, e nosso objetivo é fornecer não apenas cuidados clínicos, mas também uma fonte constante de força emocional para os pais e crianças.

No meu trabalho, sou constantemente inspirada pela resiliência das crianças, pelo forte apoio das suas famílias e pelo poder coletivo de uma equipa multidisciplinar.

Ver as crianças prosperarem após o transplante, sabendo que desempenhamos um papel para tornar isso possível, é uma das maiores recompensas.

O nosso papel como cuidadores vai muito além dos procedimentos médicos; trata-se de ver cada criança como um indivíduo e de colaborar com suas famílias para lhes proporcionar a oportunidade de um futuro repleto de possibilidades.

Sameiro

We know that transplant is a long, often difficult, journey and our aim is to provide not only clinical care but also a steady source of emotional strength for parents and children.

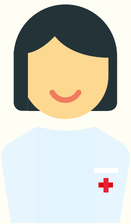
In my job I am constantly inspired by the resilience of children, the strong support of their families and the collective power of a multidisciplinary team.

Seeing children thrive after their transplant, knowing we played a part in making that possible, is one of the greatest rewards.

Our role as caregivers extends far beyond just medical procedures: it is about seeing each child as an individual and collaborating with their families to give children the opportunity for a future full of possibilities.

Rute

enfermeira pediátrica



Sou enfermeira na Pediatria há 23 anos e trabalho mais de perto com doentes renais crónicos há 14 anos.

E sinto o mesmo que nos primeiros dias: trabalhar com crianças e adolescentes com doença renal é viver diariamente um encontro entre a ciência, o cuidado e a esperança!

Cada nova família que chega aos nossos cuidados carrega não apenas um diagnóstico, mas uma história marcada por desafios, resiliência e força. Cada uma delas trilha o seu caminho consoante os obstáculos que vão surgindo, sempre connosco ao lado para ajudar a ultrapassar cada um deles! O nosso cuidado começa muito antes da administração de medicamentos, da avaliação de sinais vitais... Inicia-se no olhar atento, na escuta ativa e no acolhimento de medos e incertezas.

Para muitas dessas crianças e adolescentes, o transplante representa uma nova oportunidade na vida, é a luz ao fundo do túnel. Mas depois de atingida esta etapa, começa outra, que exige um novo compromisso diário com o tratamento, com a prevenção de complicações e com a adaptação a um novo corpo que agora abriga um novo órgão.

Nesta área específica, o meu papel continua a ir muito para além do conhecimento técnico. Passa por reforçar a importância da adesão ao regime terapêutico, pela vigilância de sinais de complicações, mas também por segurar a mão, por ajudar a limpar as lágrimas, por celebrar pequenas vitórias, por continuar a estar presente nos momentos difíceis… Passa por ensinar crianças, adolescentes, famílias, para que compreendam o próprio cuidado, ajudando-as a desenvolver a autonomia, especialmente na adolescência, quando surgem novos desafios relacionados com a aceitação e responsabilidade com o seu estado de saúde.

Todos os dias aprendo com cada um deles sobre coragem, resiliência e amor à vida. Acompanhar a sua evolução, ver a cor voltar ao rosto, a energia voltar às brincadeiras e os sonhos ganharem força, é a minha maior recompensa!

Ser enfermeira nesta área é viver intensamente! É reconhecer que cada transplante é mais do que um procedimento cirúrgico… é um recomeço! É compreender que, cuidar de um rim transplantado é, na verdade, cuidar de uma vida inteira que se renova… e vivenciar que, de alguma forma, nós (os profissionais de saúde) nos renovamos com eles!

Rute

pediatric nurse

I've been a pediatric nurse for 23 years and I've been working more closely with patients with chronic kidney disease for 14 years.

And I feel the same way as in the early days: working with children and adolescents with kidney disease is living an encounter between science, care and hope every day!

Every new family that comes into our care carries not only a diagnosis, but a story marked by challenges, resilience and strength. Each one forges its own path according to the obstacles that arise, always with us by its side to help overcome each one of them! Our care begins long before administering medications, assessing vital signs... It starts with attentive observation, active listening and welcoming fears and uncertainties.

For many of these children and adolescents, transplantation represents a new opportunity in life, it is the light at the end of the tunnel. But after reaching this stage, another begins, which requires a new daily commitment to treatment, prevention of complications and adaptation to a new body that now houses a new organ.

In this specific area, my role continues to go far beyond technical knowledge. It involves reinforcing the importance of adherence to the therapeutic regimen, monitoring for signs of complications, but also holding the hand, helping to wipe tears away, celebrating small victories and remaining present during difficult times... It involves teaching children, adolescents and families, so that they understand their own care, helping them to develop autonomy, especially during adolescence when new challenges arise related to accepting and taking responsibility for their state of health.

Every day I learn from each of them about courage, resilience and love of life. Witnessing their progress, seeing the color return to their faces, the energy return to their playfulness and their dreams gain strength, is my greatest reward!

To be a nurse in this area is living life to the fullest! It's recognising that each transplant is more than a surgical procedure... It's a new beginning! It's understanding that caring for a transplanted kidney is actually caring for a whole life that is renewed... And experiencing that somehow we (healthcare professionals) are renewed along with them!

Teresa

nefrologista pediátrica

Sou médica, nefrologista pediátrica e trabalho na área da transplantação renal há mais de vinte anos. Sinto que foi e é um privilégio fazer parte do programa de transplantação renal pediátrica, da multidisciplinaridade de valências e equipas necessárias para a concretização com sucesso de cada transplante.

Escolhi este caminho porque acredito que a medicina pode ser um ato de transformação, de que o transplante renal pediátrico pode ser uma das suas mais claras expressões. O transplante representa, para mim, um ato de fé, um elogio ao sonho e ao olhar atento, um desafio de renovação perante os labirintos da existência humana.

É um voto de confiança e de esperança na ciência, uma segunda oportunidade, um recomeço, uma vida que se estende para lá da insuficiência e da limitação. Cada criança que volta ao seu imaginário infantil e momentos alegres, a correr e a rir sem fadiga e a sonhar sem medo, faz valer cada hora minha perdida de sono ou em família, cada preocupação silenciosa que por vezes me acompanha. É, também, muito gratificante a emoção e a alegria que testemunhamos nos pais, quando projetam num transplante bem sucedido, um futuro de menos sofrimento e mais radiante para os seus filhos.

Atualmente, os avanços da ciência e tecnológicos permitem-nos diagnósticos mais precoces, tratamentos mais eficazes e precisos, cirurgias menos invasivas e um acompanhamento mais rigoroso dos doentes. Ao longo dos anos pude acompanhar os avanços nas terapêuticas imunossupressoras, na prevenção da infeção e no controlo da rejeição, o que permitiu melhores taxas de sucesso e de sobrevida do órgão. Este é o caminho para um futuro mais feliz e seguro para cada criança transplantada.

No entanto, nem sempre é fácil abraçar a evolução técnica sem perder a humanização. Num tempo em que as vivências e gestos se pautam pelo imediatismo e estereotipias, pelos avanços tecnológicos e inteligência artificial, será possível a individualidade, as mensagens subtis, o poder das emoções e da empatia com o doente e seus pais? A relação constrói-se na escuta atenta, na transparência de cada explicação, no tempo dedicado, na entrega e na confiança mútua.

Por outro lado, também vivemos tempos em que a informação corre sem filtro, em que o medo e a insegurança podem ganhar espaço e em que as redes sociais podem ser palco de angústias para os doentes e respetivos pais. Aqui, o transplante pediátrico não é apenas uma intervenção médica, pode ser também um processo de educação e de sensibilização.

Teresa

pediatric nephrologist

I am a pediatric nephrologist and I have been working in the field of kidney transplantation for more than twenty years. I feel that it was and still is a privilege to be part of the paediatric renal transplantation program, the multidisciplinary expertise and team required to successfully perform each aspect of transplantation.

I chose this path because I believe that medicine can be an act of transformation, and paediatric kidney transplantation can be one of its clearest expressions. Transplantation represents, for me, an act of faith, a tribute to dreams and attentiveness, a challenge of renewal in the face of the labyrinths of human existence. It is a vow of trust and hope in science, a second chance, a new beginning, a life that extends beyond insufficiency and limitation.

Every child who returns to his childhood imagination and joyful moments, running and laughing without fatigue and dreaming without fear, makes every hour of lost sleep or lost family time worthwhile, as makes every silent worry that sometimes accompanies me worth it. It is also very gratifying the emotion and joy that we witness in parents when they project a successful transplant into a less suffering and more radiant future for their children.

Advances in science and technology allow us today to make earlier diagnoses, to provide with more effective and accurate treatments, to perform less invasive surgeries and to follow-up patients more rigorously. Over the years, I have been able to follow advances in immunosuppressive therapies, infection prevention and rejection control, which allow better rates of success and survival of the organ. This is the path to a happier and safer future for every transplanted child.

However, it is not always easy to embrace technical evolution without losing human touch. In a time when experiences and gestures are driven by immediacy and stereotypes, technological advances and artificial intelligence, will individuality, subtle messages, the power of emotions and empathy with the patient and his/her parents still be possible? The relationship is built on attentive listening, the transparency in each explanation, dedicated time, committment and mutual trust.

On the other hand, we also live in times where information flows unfiltered, fear and insecurity can gain ground and social networks can be a source of anguish for patients and their parents. Here, pediatric transplantation is not only a medical intervention, it can also be a process of education and awareness.

Sometimes it is necessary to communicate the bad news of a kidney transplant failure, which is always very hard for me.

Por vezes é necessário comunicar a má notícia da falência do rim transplantado, o que é sempre muito árduo para mim. Não há forma fácil de o fazer, e nunca haverá. Cada palavra e cada silêncio pesam.

Procuro ser cuidadosa, precisa e transparente na explicação, escolher palavras simples e diretas, dar espaço à tristeza, mas também à esperança.

Sobretudo é crucial para mim criar espaço para que as crianças e os seus pais, sintam apoio e empatia e possam exprimir as suas dúvidas e emoções, para que se possam projetar nas etapas seguintes com mais segurança e otimismo.

As crianças e os seus pais são os principais motores de cada ato de transplantação, pela sua coragem e, sobretudo, pela sua enorme força de superação.

São eles que nos inspiram, pela forma intrépida e tantas vezes silenciosa como vivem as suas fragilidades e mantêm a sua identidade, alegria, determinação, projetos ambiciosos e expetativa de lugares seguros e muito felizes.

Cabe-nos a nós, profissionais de saúde, ajudar a construir o caminho, fornecendo o melhor apoio possível, médico, social e emocional, o que só é possível com uma equipa de trabalho multidisciplinar muito coesa. Cada desafio, cada obstáculo, deve ser enfrentado em conjunto, partilhado, criando pontes entre a dor e o receio e a confiança e a esperança num futuro brilhante, cheio de oportunidades.

There is no easy way to do it, and there will never be. Every word and every silence weigh heavily. I try to be careful, precise and transparent in the explanation, choosing simple and direct words, allowing space for sadness, but also for hope.

Above all, it is crucial for me to create space for children and their parents to experience support and empathy and to express their doubts and emotions.

It is important that they feel supported and trusted by the whole team, so that they can project themselves into the next steps with greater confidence and optimism.

Children and their parents are the driving force behind every transplant, for their courage and, above all, for their enormous resilience.

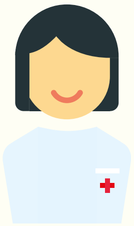
They inspire us with the intrepid and often silent way in which they face their weaknesses and maintain their identity, joy, determination, ambitious projects and expectation of safe and very happy places. It is up to us, as healthcare professionals, to help build the way by providing the best possible medical, social and emotional support, which is only possible with a very cohesive multidisciplinary team.

Every challenge, every obstacle must be tackled together, shared, building bridges between pain and fear and trust and hope in a bright future, full of opportunities.

España / Spain

Paloma

enfermera pediátrica



Soy enfermera especialista en pediatría y trabajo en la Consulta de Transición de Trasplante de Órganos Sólidos de mi hospital. Llevo menos de cinco años trabajando en este campo. Actualmente llevamos a cabo un programa de apoyo y seguimiento para niños y adolescentes que han recibido un trasplante. Además, organizamos talleres de Transición para pacientes a partir de los 12 años, preparándoles para el paso a la atención de adultos. Es un reto, pero cada vez estamos mejor preparados para que los jóvenes trasplantados afronten esta etapa con las herramientas necesarias para salir adelante.

Desde que empecé en enfermería, me ha interesado el cuidado de los pacientes pediátricos. El trasplante es un campo muy especial porque implica apoyar a los niños y a sus familias en momentos de gran incertidumbre, pero también de esperanza. La posibilidad de ofrecerles una nueva oportunidad de vida me motiva cada día.

Cuando un trasplante no va bien, es uno de los momentos más duros de nuestra profesión. No hay un enfoque único, pero siempre intento ser sincera, empática y estar disponible para responder a las preguntas de la familia. Es crucial comunicarles que no están solos y que haremos todo lo posible por ofrecerles alternativas.

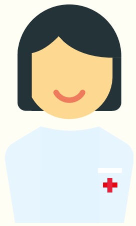
Escuchar es la base de todo. A menudo, las familias y los pacientes sólo necesitan ser escuchados y comprendidos. También es importante explicar las cosas con claridad, sin tecnicismos innecesarios, y asegurarse de que tienen toda la información que necesitan en cada fase del proceso.

Recuerdo a un adolescente que, tras recibir su trasplante, estaba muy preocupado por el impacto que el tratamiento tendría en su vida cotidiana. Temía no ser capaz de llevar una vida normal o de administrar correctamente su medicación. A lo largo de los talleres de transición, pudimos hablar de sus miedos y de cómo gestionarlos. Con el tiempo, ganó confianza en sí mismo y en su capacidad para manejar su tratamiento. Al final, se convirtió en un líder entre sus compañeros, ayudando a otros pacientes a entender que, aunque el camino era difícil, con el apoyo adecuado podían llevar una vida plena. Ese proceso de crecimiento fue muy significativo para mí, tanto profesional como personalmente.

A los pacientes y sus familias les diría que no están solos. La espera puede ser difícil, pero hay todo un equipo detrás de ellos, luchando con ellos y por ellos. A los profesionales, les animaría a seguir mejorando la comunicación con los pacientes y a no olvidar nunca que detrás de cada historia clínica hay una familia y un niño con sus miedos, esperanzas y sueños.

Paloma

pediatric nurse



I am a pediatric nurse specialist, working in the Solid Organ Transplant Transition Clinic of my hospital. I have been working in this field for less than five years, and we currently run a program of support and follow-up for children and adolescents who have received a transplant. Additionally, we organise transition workshops for patients starting at age of 12, preparing them for the transfer to adult care. It is a challenge, but we are becoming increasingly better prepared to ensure that young transplant recipients face this stage with the necessary tools to succeed.

Since I began my job as a nurse, I have been interested in the care of pediatric patients. Transplantation is a very special field because it involves supporting children and their families during moments of great uncertainty, but also of hope. The possibility of offering them a new opportunity for life motivates me every day.

When a transplant doesn't go well, it is one of the hardest moments of our profession. There is no one-size-fits-all approach, but I always try to be honest, empathetic and available to answer the family's questions. It is crucial to let them know that they are not alone and that we will do everything we can to offer possible alternatives.

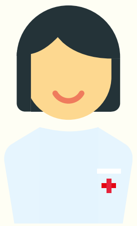
Listening is the foundation of everything. Often, families and patients just need to be heard and understood. It is also important to explain things clearly, without unnecessary technicalities, and to make sure they have all the information they need at each stage of the process.

I remember a teenager who, after receiving his transplant, was very worried about the impact the treatment would have on his daily life. He was afraid he wouldn't be able to lead a normal life or manage his medication correctly.

Throughout the transition workshops, we were able to talk about his fears and how to manage them. Over time, he gained confidence in himself and in his ability to handle his treatment. In the end, he became a leader among his peers, helping other patients understand that although the journey is challenging, with the right support they could lead a full life. That process of growth was very meaningful to me both professionally and personally.

I would want to tell patients and their families that they are not alone. The wait can be difficult, but there is a whole team behind them, fighting with them and for them. I would encourage healthcare professionals to continue improving communication with patients and never forget that behind every medical record is a family and a child with their fears, hopes, and dreams.

Maria
enfermera pediátrica



Soy enfermera pediátrica de España. Empecé a trabajar en el campo del trasplante pediátrico de órgano sólido hace 32 años. Inicialmente solo se hacían trasplantes de riñón e hígado, más tarde llegaron el de intestino, el cardiaco, el pulmonar y el multivisceral.

¿Por qué decidió convertirse en un profesional de la salud que se ocupa de trasplantes?
Llegué al trasplante por casualidad, hacía falta una enfermera en la Unidad de hospitalización de trasplantes pediátricos, pero enseguida descubrí que quería seguir aprendiendo sobre ello.

Principales cambios a lo largo de los años:
Los cambios a lo largo de los años han sido muchos. Dificil elegir, pero si hay que elegir destacaría el cambio de la ciclosporina por el tacrólimus, el alojamiento y manutención del cuidador junto al niño, incluso en la PICU, el programa de actividades recreativas durante los ingresos, el apoyo de las Asociaciones de Pacientes y el último de ellos, el Programa de acompañamiento a la Transición para adolescentes y jóvenes trasplantados.

Consejos sobre cómo establecer una buena relación con los pacientes/familias:
La herramienta principal para establecer una buena relación con los niños y sus familias es ESCUCHAR. Escuchar cómo se sienten y qué necesitan. Y, a partir de ahí, tratar de dar respuesta a esas necesidades en la medida de nuestras posibilidades, y ser honestos: no ofrecer aquello que no está en nuestras manos conseguir.

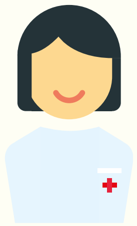
¿Recuerdas algún caso en particular? Si es así, ¿por qué?
Imposible referirme a un solo caso, son muchos los nombres de niños y familias que han dejado huella en mí, cada uno de ellos me ha enseñado algo que me ha hecho mejor enfermera y mejor persona.

Un mensaje para otros profesionales:
Dejaos enseñar, tenemos mucho que aprender de cada familia que tenemos el privilegio de cuidar y enseñar a convivir con un trasplante.

Un mensaje para los padres:
Confiad en vuestros hijos cuando llegue el momento, dejadles volar y aprender a vivir con su trasplante y ser independientes. La sobreprotección no ayuda, sólo limita.

Un mensaje para los pacientes:
Y un mensaje para esas personas maravillosas que aprenden desde niños a sobrellevar su condición de trasplantados, como dice la canción de El KanKa: "Mírate, creételo / Sal de ahí, afróntalo/ Tómalo, confía en ti/ Sí que puedes, que nadie te diga que no/ Porque sí que puedes" ¡Disfruta de la vida y sé feliz!

Maria
pediatric nurse



I'm a pediatric nurse specialist from Spain. I began working in the field of pediatric solid organ transplantations 32 years ago. At first, only kidney and liver transplants were performed, but later also intestinal, cardiac, pulmonary and multivisceral transplant programmes started.

Why did you choose to become a healthcare professional dealing with transplants?
I got into transplantation by chance, when they needed a nurse for the Pediatric Transplant Ward, but soon I realised I wanted to keep learning about it.

Main changes over the years:
There have been many changes over the years. It's hard to choose, but if I had to pick some up, I would highlight the improvements in immunosuppressive medication, the accommodation and support of the caregiver with the child, even in the Intensive Care Unit, the program of recreational activities during admissions, the support from Patient Associations and, recently, the Transition Program to help adolescent and young adult transplant patients.

Advice on how to establish a good relationship with patients/families:
The main tool to build a good relationship with children and their families is to LISTEN. Listen to how they feel and what they need. Then, we will try to respond to those needs as much as possible and it is really important to be honest, not offering what we can't provide them with.

Any particular case you recall? If so, why?
It's impossible to pick just one case; there are so many children and families who have left a mark on me. Each one has given me something that has made me a better nurse and a better person.

A message for other professionals:
Let yourself learn. We have a lot to learn from every family that we have the privilege of caring for and teaching how to live with a transplant.

A message for parents:
Trust your children when the time comes. Let them fly, learn to live with their transplant and be independent. Overprotection doesn't help; it only limits them.

A message for patients:
A message to those amasing people who grow up learning to live as transplant recipients, as the song by El KanKa says: "Look at yourself, believe in yourself / Step out, face it / Take it on, trust yourself / You can do it, don't let anyone tell you otherwise / Because you truly can." Enjoy life and be happy!

Luis

cardiólogo pediátrico

Fui cardiólogo pediátrico durante muchos años en un gran hospital, ahora estoy jubilado.

En estos años he aprendido que las actitudes positivas de los profesionales sanitarios ayudan a construir relaciones únicas con los pacientes. Los médicos de trasplantes pediátricos son muy importantes en la vida de los niños. Todo lo que haces por ellos, especialmente si no está directamente relacionado con su enfermedad, puede crear grandes lazos, a veces incluso duraderos.

Tuve un paciente que tenía más o menos 4 años cuando llegó para ser tratado por un defecto cardíaco congénito. Resultó que necesitaba un trasplante y tuvo que permanecer ingresado mucho tiempo.

El era hincha de uno de los equipos madrileños de fútbol, el Atlético de Madrid. Yo todos los días, durante mis rondas, le pedía que se hiciera seguidor del Real Madrid, el equipo rival del suyo. El siempre me respondía con una gran sonrisa diciendo: "de ninguna manera".

Yo tenía una relación cercana con una organización sin ánimo de lucro llamada "Pequeño Deseo". Trabajan con niños enfermos haciendo que un deseo elegido por ellos se haga realidad. "Pequeño Deseo" los llevó entonces, a él y a su padre, a un entrenamiento del Atlético de Madrid donde conoció a los jugadores y le firmaron una camiseta. También pudo asistir a un partido de su amado equipo. Quería que yo fuera con él, pero no fue posible en ese momento.

Han pasado 10 años. El pasado año me jubilé, pero he mantenido el contacto con él y con su familia. Un familiar mío trabaja en la empresa de marketing del Atlético de Madrid y, al contarle esta historia, ella se ofreció a conseguir entradas para un partido. Así que le llamé. Ahora tiene 14 años, y nos fuimos, junto con su padre, a un partido de su querido Atlético de Madrid con muy buenos asientos. Volvió a conocer a los jugadores, consiguió una nueva camiseta y obtuvo la firma de cada jugador en una bufanda del equipo. Estaba realmente feliz,... y yo también aunque no apoye a su equipo;)

Siento que los niños con enfermedades crónicas enfrentan muchas dificultades a lo largo de su vida, especialmente durante sus primeros años, y he observado un efecto muy positivo de estas recompensas en su evolución. También ayuda a construir un vínculo sólido con el equipo de trasplantes.

Luis

paediatric cardiologist

I was a paediatric cardiologist for many years in a large hospital, now I am retired.

Positive attitudes from healthcare professionals help building proper and unique relationships with patients. Paediatric transplant physicians are very important in kids' life and whatever you do for them, especially things not directly related to their disease itself, may build great ties, sometimes even everlasting.

I had a patient who was more or less 4 years old at the time he arrived to be treated for a congenital heart defect, but he needed a transplant instead and he was admitted for a long time.

He was a fan of Atlético de Madrid football team and I would ask him every day in my rounds to become a Real Madrid supporter. He always replied with a big smile saying: "No way!".

I had a close relationship with a non-profit organization called "Little wish". They work with sick kids, fulfilling a desire chosen by them.
"Little wish" took him and his father to a training day where he met the players and to a game of his loved team. He wanted me to go with them but it was not possible at that time.

Years later I retired but I had kept contacts with him and his family. A relative of mine worked with Atletico de Madrid marketing company and, as I told her his story, she offered to get tickets for a game so I called him, then 14 years old, and took him and his father again to a game with very good seats. He met the players, got a new jersey, got every player's signature in a team´s scarf and was really happy. So was I, even though I am not a supporter of his team.

Children with chronic diseases face many difficulties during their life, especially during their early years, and I have observed the very positive effect those rewards have on their outcome, as building a solid link with the transplant team also does.

Marta

pediatra

La pediatría es, ante todo, una vocación. Es mirar la enfermedad desde los ojos de un niño y entender que detrás de cada diagnóstico hay una familia que espera, un futuro que aún puede escribirse y una vida que merece desplegar todo su potencial.

En este contexto, el trasplante hematopoyético pediátrico representa uno de los mayores actos de fe en la medicina moderna: un puente entre la fragilidad y la fuerza, entre la ciencia y la esperanza.

El trasplante de médula ósea en niños es mucho más que un procedimiento médico. Es un compromiso profundo con la vida, una segunda oportunidad que combina conocimiento, precisión y ternura. Cada trasplante implica un acto de valentía - del niño que lo enfrenta, de la familia que confía, y del equipo que lo acompaña con la convicción de que la ciencia y el cuidado pueden cambiar destinos.

Yo he dedicado mi vida profesional a este ámbito, donde el rigor científico convive con la emoción de ver renacer. Licenciada en Medicina, realicé mi residencia en Pediatría y me subespecialicé en Hematología y Oncología Pediátrica en un hospital pediátrico de España, un centro que respira historia, compromiso y excelencia. Allí encontré no solo mi lugar de trabajo, sino un espacio donde la vocación se transforma en propósito.

Hoy soy Jefe de Sección en la Unidad de Trasplante Hematopoyético, una unidad acreditada por CSUR y JACIE, que representa un referente nacional e internacional. En ella, la ciencia se une al cuidado más humano, y la medicina se practica con la sensibilidad que solo los niños inspiran.

A lo largo de mi trayectoria, he participado en más de 1000 trasplantes en pacientes pediátricos, acompañando a cada niño en un proceso que es tan técnico como emocional. Cada uno de esos trasplantes es una historia única: el pequeño que vuelve a sonreír, la familia que recupera la esperanza, el equipo que celebra silenciosamente cada recuperación. Son momentos que recuerdan por qué elegimos ser médicos.

El trasplante hematopoyético en niños no solo salva vidas; también enseña lecciones profundas. Enseña paciencia, humildad y respeto ante la naturaleza humana. Enseña que la inmunidad no solo se reconstruye en el laboratorio, sino también en el alma de quienes acompañan el proceso. Y enseña que, incluso en los días más difíciles, la medicina tiene un poder inigualable: el de devolver la posibilidad del mañana.

Porque en pediatría, cada gesto cuenta. Una palabra, una caricia, una mirada de confianza pueden ser tan terapéuticas como el tratamiento más complejo. En el trasplante, esta sensibilidad se multiplica: los niños que afrontan esta experiencia se

---

Marta

pediatrician

Pediatrics is first and foremost a vocation. It is to look at the disease from the eyes of a child and understand that behind every diagnosis there is a family that waits, a future that can still be written and a life that deserves to unfold its full potential.

In this context, pediatric hematopoietic transplantation represents one of the greatest acts of faith in modern medicine: a bridge between fragility and strength, between science and hope.

Bone marrow transplantation in children is much more than a medical procedure. It is a deep commitment to life, a second chance that combines knowledge, precision and tenderness. Each transplant involves an act of courage - from the child who faces it, from the family who trusts it and from the team who accompanies them with the conviction that science and care can change fates.

I have dedicated my professional life to this field, where scientific rigor coexists with the emotion of seeing rebirth. Graduated in Medicine, I did my residency in Pediatrics and subspecialised in Pediatric Hematology and Oncology at a pediatric hospital in Spain, a center that breathes history, commitment and excellence. There I found not only my workplace, but a space where vocation is transformed into purpose.

Today I am Head of Section in the Hematopoietic Transplant Unit, a unit accredited by CSUR and JACIE, which represents a national and international reference. In it, science joins the most humane care, and medicine is practiced with the sensitivity that only children inspire.

Throughout my career, I have participated in more than 1000 transplants in pediatric patients, accompanying each child in a process that is both technical and emotional. Each of those transplants is a unique story: the little one who smiles again, the family who regains hope, the team who silently celebrates every recovery. These are moments that remind us why we choose to be doctors.

Haematopoietic transplantation in children not only saves lives, it also teaches profound lessons. It teaches patience, humility and respect for human nature. It teaches that immunity is not only rebuilt in the laboratory, but also in the soul of those who accompany the process. And it teaches that, even on the most difficult days, medicine has unparalleled power: to return the possibility of tomorrow.

In pediatrics every gesture counts. A word, a caress, a look of trust can be as therapeutic as the most complex treatment. In transplantation, this sensitivity multiplies: the children who face this experience become true teachers of resilience, everyday heroes who teach that life, even fragile, can be immensely strong.

convierten en verdaderos maestros de resiliencia, en héroes cotidianos que enseñan que la vida, aun frágil, puede ser inmensamente fuerte.

El trasplante hematopoyético en pediatría es un canto a la esperanza. Es la unión entre ciencia, compasión y trabajo en equipo. Es un ejemplo de lo que la medicina puede lograr cuando se practica desde la excelencia técnica y el compromiso humano.

Curar no es solo eliminar la enfermedad, sino acompañar, aliviar, sostener y devolver la ilusión. Que la medicina pediátrica no se mide solo en estadísticas, sino en sonrisas recuperadas. Y que el trasplante de médula ósea es, en realidad, una celebración de la vida misma, la prueba de que la ciencia puede ser profundamente humana.

Cada niño trasplantado lleva consigo un pedacito del esfuerzo de todo un equipo, la entrega de una familia y la visión de profesionales que creen, cada día, que la medicina puede transformar el destino. Y esa convicción, que ha guiado mi carrera, seguirá impulsando el futuro del trasplante pediátrico, un futuro donde la ciencia y la ternura seguirán caminando de la mano, devolviendo a los niños aquello que más merecen: la vida, la risa y el mañana.

Hematopoietic transplantation in pediatrics is a song to hope. It is the union between science, compassion and teamwork. It is an example of what medicine can achieve when practiced from technical excellence and human commitment.

Curing is not only eliminating the disease, but accompanying, relieving, sustaining and restoring hope. Pediatric medicine is not measured only in statistics, but in recovered smiles. And bone marrow transplantation is actually a celebration of life itself, the proof that science can be profoundly human.

Each transplanted child carries a piece of the effort of an entire team, the dedication of a family and the vision of professionals who believe, every day, that medicine can transform destiny. And that conviction, which has guided my career, will continue to drive the future of pediatric transplantation, a future where science and tenderness will continue to walk hand in hand, giving children back what they most deserve: life, laughter and tomorrow.

Paloma

hepátologa pediátrica

Soy pediatra especializado en enfermedades hepáticas.

Comencé mi carrera en 1969 en uno de los pocos hospitales de Europa que desarrollaba especialidades pediátricas en aquel momento y desde 1975 me he especializado en el tratamiento de niños con enfermedades hepáticas. He trabajado durante 55 años en salud pública con diversas responsabilidades.

Esta profesión convirtió mi vida en un sueño y puso a mi alcance un universo inmenso y apasionante, porque no hay nada tan importante como la vida y el bienestar de las personas. Decía Hipócrates "Donde quiera que se ame el arte de la medicina, se ama también a la humanidad".

La medicina es una ciencia de la incertidumbre, y un arte de la probabilidad. La ciencia se ocupa de sanar el cuerpo, y el arte de mantener al paciente con buen estado de ánimo. Estos dos aspectos tienen que guardar un equilibrio perfecto. El buen profesional de la medicina no debe pensar solo en la enfermedad, sino en el paciente que la padece. No solo debe estar vinculado a la adquisición de conocimientos científicos, tiene también que adquirir el compromiso con su lugar de trabajo, los pacientes y sus familiares.

Hacer pediatría tiene una connotación especial: es una manera de vivir con ilusión, esperanza, alegrías y penas, peleando con la enfermedad y explorando el conocimiento para mejorar la salud de los niños, que son el bien más preciado de nuestra sociedad. Los factores que han contribuido al desarrollo de la medicina, y de la hepatología en concreto, son: el avance en el conocimiento científico, las innovaciones tecnológicas, la investigación por parte de entidades públicas y privadas, el énfasis en el desarrollo de estudios clínicos y experimentales controlados y la accesibilidad a las redes de comunicaciones científicas.

La eficacia del trasplante ha motivado cambios profundos. La posibilidad de resolver con trasplante la mayoría de las hepatopatías severas indujo un mejor estudio y cuidado de éstas. La enfermedad hepática del niño tiene connotaciones de etiología y evolución distinta a las hepatopatías del adulto, lo que hace inapropiado que sea atendida en un programa de Hepatología y Trasplante Hepático del adulto.
El trasplante hepático en niños resulta la actividad más compleja y la que requiere del mayor consumo de tiempo y habilidades de los profesionales de los Servicios implicados. Los pacientes y sus padres necesitan la atención médica y el apoyo humano necesario ante la presencia de una enfermedad grave antes del trasplante, un proceso inicial post-trasplante de alto riesgo con habitual incidencia de complicaciones médicas y quirúrgicas y una evolución a largo plazo con necesidades

---

Paloma

pediatric hepatologist

I am a pediatrician specialised in liver diseases.

I started my career in 1969 in one of the few hospitals in Europe that developed pediatric specialties at that time, and since 1975 I have specialised in treating children with liver diseases. I have worked for 55 years in public health with various responsibilities.

This profession turned my life into a dream and opened up an immense and exciting universe because nothing is more important than the life and well-being of people. Hippocrates said, "Wherever the art of medicine is loved, there is also a love of humanity."

Medicine is a science of uncertainty and an art of probability. Science focuses on healing the body, and art on maintaining the patient's good spirit. These two aspects must be in perfect balance. A good healthcare professional should not only think about the disease but also about the patient who suffers from it. Professionals should not only be connected to acquiring scientific knowledge but also committed to their workplace, patients and their families.

Paediatrics has a special connotation: it is a way of living with enthusiasm, hope, joys and sorrows, fighting diseases and expanding knowledge to improve the health of children, who are the most precious asset of our society.

The factors that have contributed to the development of medicine, and hepatology specifically, are advances in scientific knowledge, technological innovations, research by public and private entities, the emphasis on developing controlled clinical and experimental studies and accessibility to scientific communication networks.

The effectiveness of transplants has brought profound changes. The possibility of solving most severe liver diseases with a transplant led to better study and care of these diseases.
Children's liver diseases have different causes and evolutions compared to adult liver diseases, making it inappropriate for children to be treated in an adult Hepatology and Liver Transplant program. Liver transplantation in children is the most complex activity and requires the most time and skills from the professionals involved.
Patients and their parents need the necessary medical attention and human support during the presence of a severe disease before the transplant, a high-risk initial post-transplant process with frequent medical and surgical complications, and long-term follow-up with changing needs as the patient grows and approaches adulthood.
The transplant activity is subject to immunosuppression and infection prevention

cambiantes a medida que el paciente crece y se aproxima a la edad adulta. La actividad del trasplante está sujeta a protocolos de inmunosupresión y profilaxis de infección. La investigación es esencial para la mejor atención del paciente.

En 1986, realizamos el primer trasplante de hígado en un niño de 4 años con colestasis intrahepática familiar progresiva. El equipo, compuesto por un cirujano principal y un equipo básico de Hepatología Pediátrica, Cirugía Pediátrica, Anestesia, Reanimación y Cuidados Intensivos Pediátricos, Banco de Sangre, Coordinación de Trasplantes y el personal de enfermería y auxiliares de Reanimación y la unidad de hospitalización, se mantuvo siempre entusiasta y altamente dedicado.

El número acumulado de procedimientos de trasplante hepático y hepatorrenal desde 1986 hasta Diciembre de 2024 es de 908, con una supervivencia del niño del 88% a los 15 años del trasplante y del 95% en los casos en los que la indicación del trasplante fue la atresia biliar, la colestasis o alguna enfermedad metabólica.

La labor de la enfermería es esencial, no solo en la atención médica, sino en la formación de los familiares en los cuidados necesarios y en el apoyo psicológico durante la hospitalización y el seguimiento en consulta.

Desde 2022, logramos una consulta de enfermería de Transición que atienden adolescentes desde los 12 años de edad para hacerles progresivamente autónomos en el cuidado de su salud y ayudarles a que afronten el paso al cuidado de especialistas de adultos de una manera óptima.

Siempre mantuvimos una relación estrecha con nuestros pacientes y sus familias. Lo fundamental fue siempre escuchar sus deseos, sus problemas, las dificultades en la relación padres-hijo y orientarles sobre cómo manejar la situación, sin ser sobreprotectores.

Los padres deben saber que la mejor forma de que la salud de sus hijos vaya bien es el trabajo en equipo, una relación cercana entre el equipo sanitario, ellos y el niño según edad. Lo fundamental: escucharnos unos a otros y tratar de solucionar los problemas.

Me preguntáis sobre un caso particular que recuerde; eso me parece difícil, han sido tantos niños que me dejaron recuerdos …

Pero quizás citar algo que me impactó, el detalle del primer trasplante: aquel niño de 4 añitos, que estableció una relación muy cercana conmigo. Le gustaban las ranas. Después de la vuelta de un Congreso, fui inmediatamente a verle y me regaló una "ranita de goma" que él tenía, en señal de que se encontraba feliz y bien. Todavía guardo esa ranita en mi dormitorio.

protocols. Research is essential for better patient care.

In 1986 we performed the first liver transplant in a 4-year-old boy with progressive familial intrahepatic cholestasis, with a lead surgeon and a basic team involved from Pediatric Hepatology, Pediatric Surgery, Anesthesia, Resuscitation and Pediatric Intensive Care, Blood Bank, Transplant Coordination and the nursing and auxiliary staff. The team was always enthusiastic and highly dedicated.

The transplant program led to the expansion of services within the hospital. The total number of liver and liver-kidney transplant procedures performed from 1986 to December 2024 is 908, with an 88% child survival rate at 15 years post-transplant and 95% in cases where the transplant was indicated for biliary atresia, cholestasis or a metabolic disease.

The role of nurses is essential, not only in medical care but also in training family members in necessary care and in providing psychological support during hospitalisation and follow-up appointments.

Since 2022 we have established a Transition nursing clinic for adolescents from 12 years old to gradually make them autonomous in managing their health and to support them in the transition to adult care specialists optimally.

We have always maintained a close relationship with our patients and their families. The fundamental aspect is always listening to their wishes, problems and difficulties in the parent-child relationship and guiding them on how to handle the situations without being overprotective.

Parents should know that the best way for their children's health to be well is teamwork: a close relationship between the healthcare team, them and the child according to his/her age. The fundamental thing is to listen to each other and try to solve problems.

You ask me about a specific case I remember; that seems difficult, there have been so many children who left memories... But maybe I will mention something that impacted me, the detail of the first transplant: that 4-year-old boy who established a very close relationship with me. He liked frogs. After returning from a conference I immediately went to see him and he gave me a rubber frog he had, as a sign that he was happy and well. I still keep that frog in my bedroom.

Marta

nefróloga pediátrica

Hola a todos.

Soy pediatra y trabajo como nefrólogo infantil en un gran hospital en España, desde hace más de 25 años. Durante todo ese tiempo he atendido de manera directa o indirecta a muchos niños con insuficiencia renal y una parte de ellos han necesitado un trasplante renal o varios a lo largo de su infancia.

Como la causa más frecuente de insuficiencia renal en el niño son las anomalías congénitas , en muchos casos mi relación con los niños y sus familias ha comenzado incluso antes de que nacieran, con el diagnóstico prenatal. Informar a una pareja de que su hijo va a tener una enfermedad renal durante toda su vida, que no va a curar y que en los casos más graves en algún momento necesitarán un tratamiento que sustituya al riñón es muy duro, pero acompañarles en el proceso y poder ofrecer el trasplante como una opción de tratamiento que en la mayor parte de los casos va a permitir al niño una buena calidad de vida, abre una puerta de esperanza.

Y precisamente eso, el poder contar con opciones cuando los órganos, en este caso los riñones, ya no dan más de si, es uno de los motivos por el que decidí dedicarme a esto.

A lo largo de estos años he visto cómo avanzaban las técnicas de diálisis, cómo avanzaban los fármacos inmunosupresores y la individualización de los mismos, cómo mejoraba nuestro control de las infecciones y de las distintas complicaciones del trasplante.

He visto cómo muchos padres y madres han donado riñones a sus hijos para poder ofrecerles esa nueva vida, cómo conseguíamos trasplantar pacientes incompatibles de grupo, pacientes que necesitaban dos o más órganos, pacientes con problemas vasculares antes intrasplantables…

Y lo que es más importante, en el futuro se abren muchas nuevas opciones que ya están en marcha y muchas que aún ni siquiera imaginamos pero que sabemos que mejorarán la vida de nuestros pacientes.

El camino no es fácil y seguro que las complicaciones aparecerán en algún momento, antes o después del trasplante.

Establecer una buena relación con los pacientes y sus familias es fundamental para poder afrontarlas juntos desde la confianza en que el profesional que te atiende está haciendo todo lo que sabe y puede por solucionarlas.

Marta

pediatric nephrologist

Hello everyone.

I am a pediatrician and I have been working as a pediatric nephrologist in a large hospital in Spain for more than 25 years.

I have directly or indirectly cared for many children with kidney failure and some of them have needed a kidney transplant or several throughout their childhood.

As the most frequent cause of kidney failure in a child is congenital abnormalities, in many cases my relationship with children and their families begins even before they are born, with prenatal diagnosis.

Informing a couple that their child will have a kidney disease throughout his/her life, that it will not cure and in the most serious cases at some point they will need a treatment that replaces the kidney is very hard, but accompanying them in the process and being able to offer the transplant as a treatment option - which in most cases will give the child a good quality of life - opens a door of hope.

And precisely that, being able to have options when the organs, in this case the kidneys, cannot function anymore, is one of the reasons why I decided to dedicate myself to transplantation.

Over the years I have seen how dialysis techniques have advanced, how immunosuppressant drugs and their individualisation have advanced, how our control of infections and the various complications of transplantation has improved.

I've seen how many fathers and mothers have donated kidneys to their children to give them a new life, how we managed to transplant incompatible patients, patients who needed two or more organs, patients with vascular problems that were previously not transplantable...

And what is more important, many new options will open up in the future, some of which are already underway and many that we have not even imagined yet, which we know will improve the lives of our patients.

The path is not easy and it is certain that complications will appear at some point, before or after the transplant. Establishing a good relationship with patients and their families is essential to be able to face them together, starting from the confidence that the professional who treats you or your child is doing everything he/she knows and can in order to solve them.

Pero por muy brillante que sea el médico, es el paciente (y en el caso de los niños su familia) el que tiene que cuidarse, el que tiene que tomar sus medicinas y hacer sus controles, el protagonista de su enfermedad.

Y si el paciente no se cuida, y en este punto me acuerdo de los adolescentes que dejan su medicación y que pierden los trasplantes a pesar de todos nuestros esfuerzos, no hay nada que hacer.

Ver cómo mis “niños” terminan sus estudios o empiezan a prepararse para distintas profesiones, cómo disfrutan con la música, el arte o el deporte, que me cuenten sus proyectos y planes me compensa de todas esas guardias en las que no pude dormir o de todos esos fines de semana que no pude descansar.

Y en los casos en los que las cosas no fueron bien, espero que tanto ellos como sus familias sintieran que también en esos momentos estaba a su lado.

But as brilliant as the doctor is, it is the patient (and in the case of children their family) who has to take care of themselves, the one who has to take their medications and do their checks, the protagonist of their disease.

And if the patient is not taking care of himself/herself - and at this point I am reminded of the teenagers who stop taking their medication and lose their transplants despite all our efforts - there is nothing we can do as doctors.

Seeing how my “children” complete their studies or start getting ready for different professions, how they enjoy music, art or sport, listening to their projects and plans compensates me for all those guards in which I could not sleep or for all those weekends that I could not rest.

And in those cases where things did not go well, I hope that both they and their families felt that I was also by their side at that time.

United Kingdom

Khalid

paediatric hepato-biliary and transplant surgeon

Role:
Paediatric hepato-biliary and transplant surgeon.

Experience in the field of pediatric transplantation:
20 years.

Type of Transplant Program:
Paediatric transplant programs providing Liver, Bowel, Kidney, Combined Liver-Kidney and multivisceral transplant.

Why did you choose to become a healthcare professional dealing with transplants?
When I was trained as a paediatric surgeon, I was rotated to the paediatric transplant team as a trainee: I found it challenging, different to day to day paediatric surgery and life saving.

How can you combine your personal life with the urgency of a transplant when an organ is suddenly available?
There were times when I was the only onsite paediatric transplant surgeon and also mainly on cadaveric transplant programmes, so I did not have the luxury to plan my personal life. When an organ became available, I made myself available.

How do you communicate a failing transplant notice?
We review patients and meet their families daily; if I had to share the bad news, I would organise a sit down meeting with the hepatologist and the specialist nurse and then brief the family on what is happening, what can be done, the risks etc.

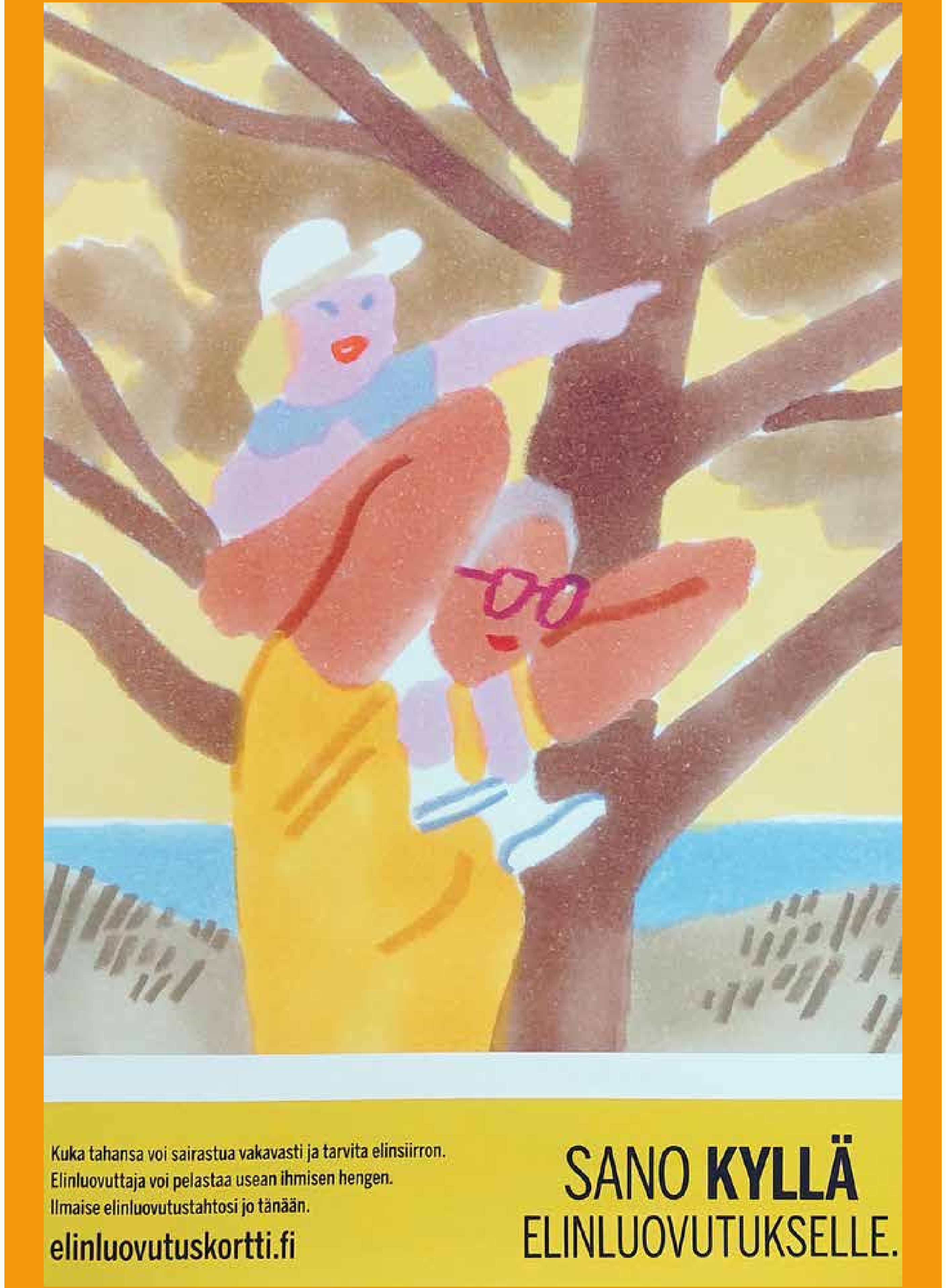
Advice on how to establish a good relationship with patients/families:
Be honest and open.

Any particular case you recall? If so, why?
Many and the reason is because they were challenging.

Message you want to share with patients/parents or other healthcare professionals:
This a field where we have to work as a team, including the family, to celebrate the success and share the failure.
We can only try and make the best possible management plan which must be realistic.

Tietoa elinsiirtoa odottaville, elinsiirron saaneille ja heidän läheisilleen.

Elinsiirtotalo.fi on osa Suomen yliopistosairaaloiden Terveyskylää.



Kuka tahansa voi sairastua vakavasti ja tarvita elinsiirron.
Elinluovuttaja voi pelastaa usean ihmisen hengen.
Ilmaise elinluovutustahtosi jo tänään.

elinluovutuskortti.fi

SANO **KYLLÄ**
ELINLUOVUTUKSELLE.


Manu
Aida


Quando chega
o outono
solta-se a
folhinha!
Historias de
DINOSSAUROS

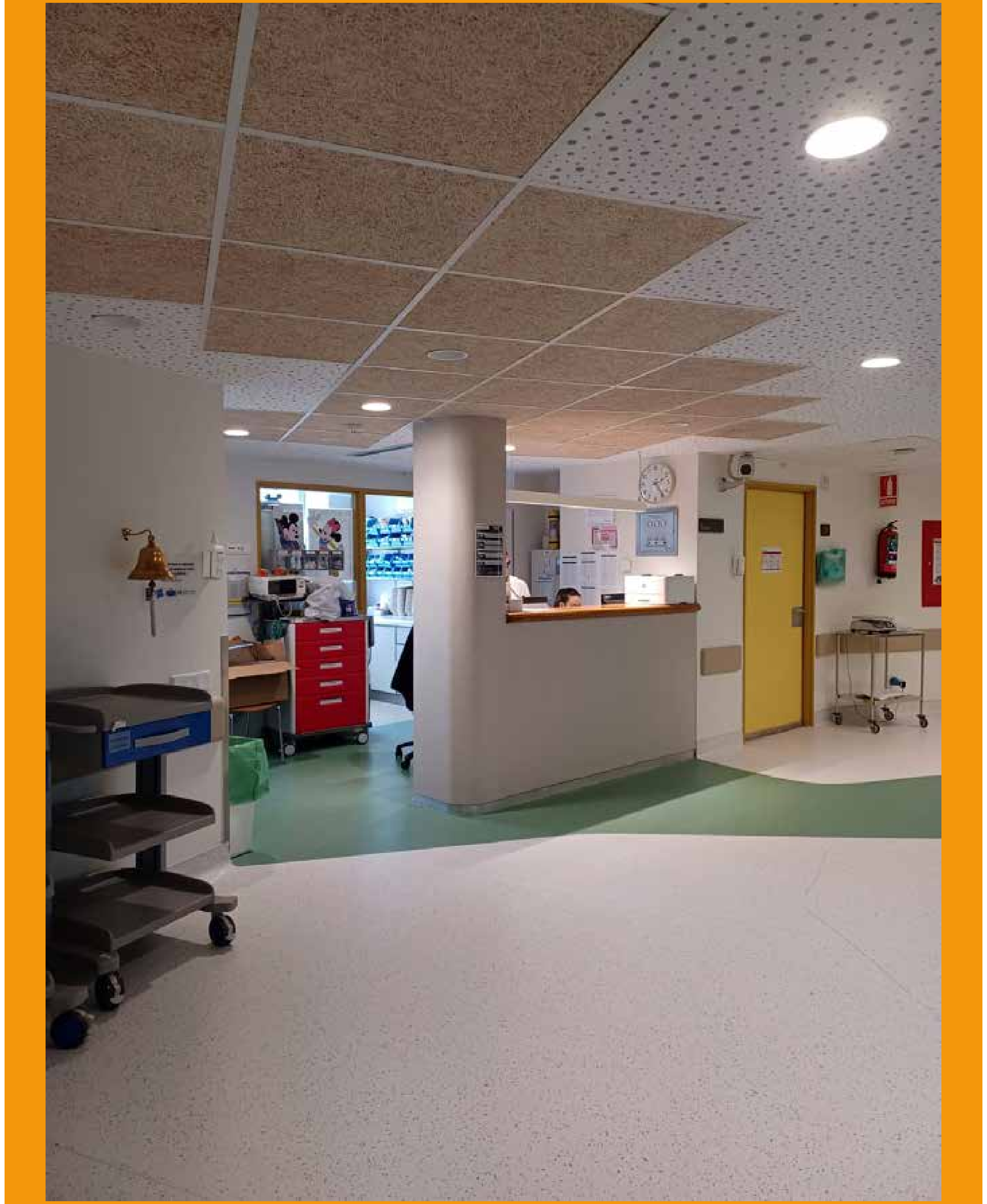

piano
4
piano
• Chirurgia Generale
• Chirurgia Specialistica
3
piano
• Nefrologia e Dialisi
• Malattie Rare
• Gastro-Enterologia
• Centro Trapianto Organo Solid
2
piano
• Neurologia e Neurofisiologia
• Neuropsichiatria
• Malattie Metaboliche Ereditar
1
• Pediatria d'I

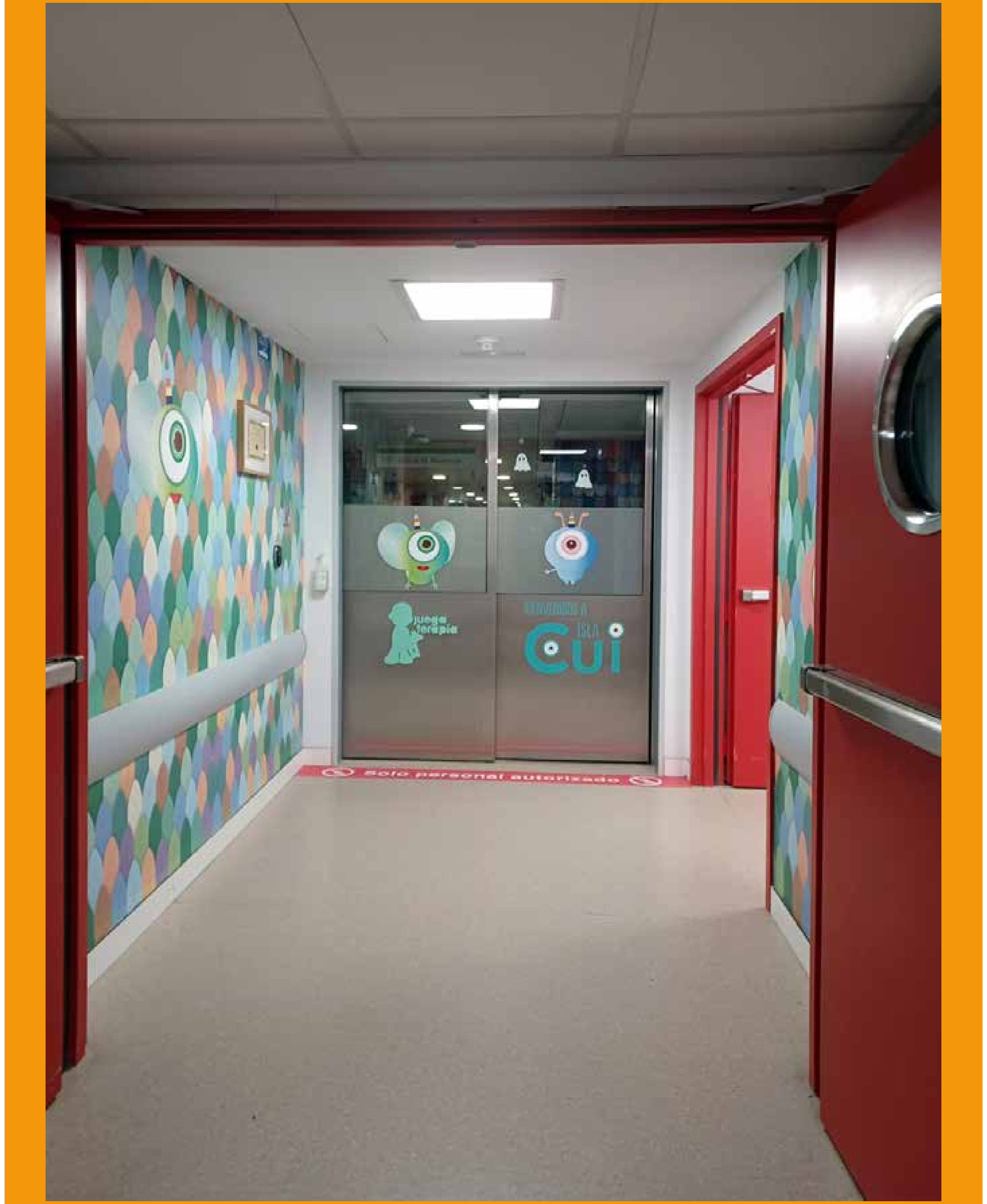

7
6
5
4
3
2
1
0
3
3

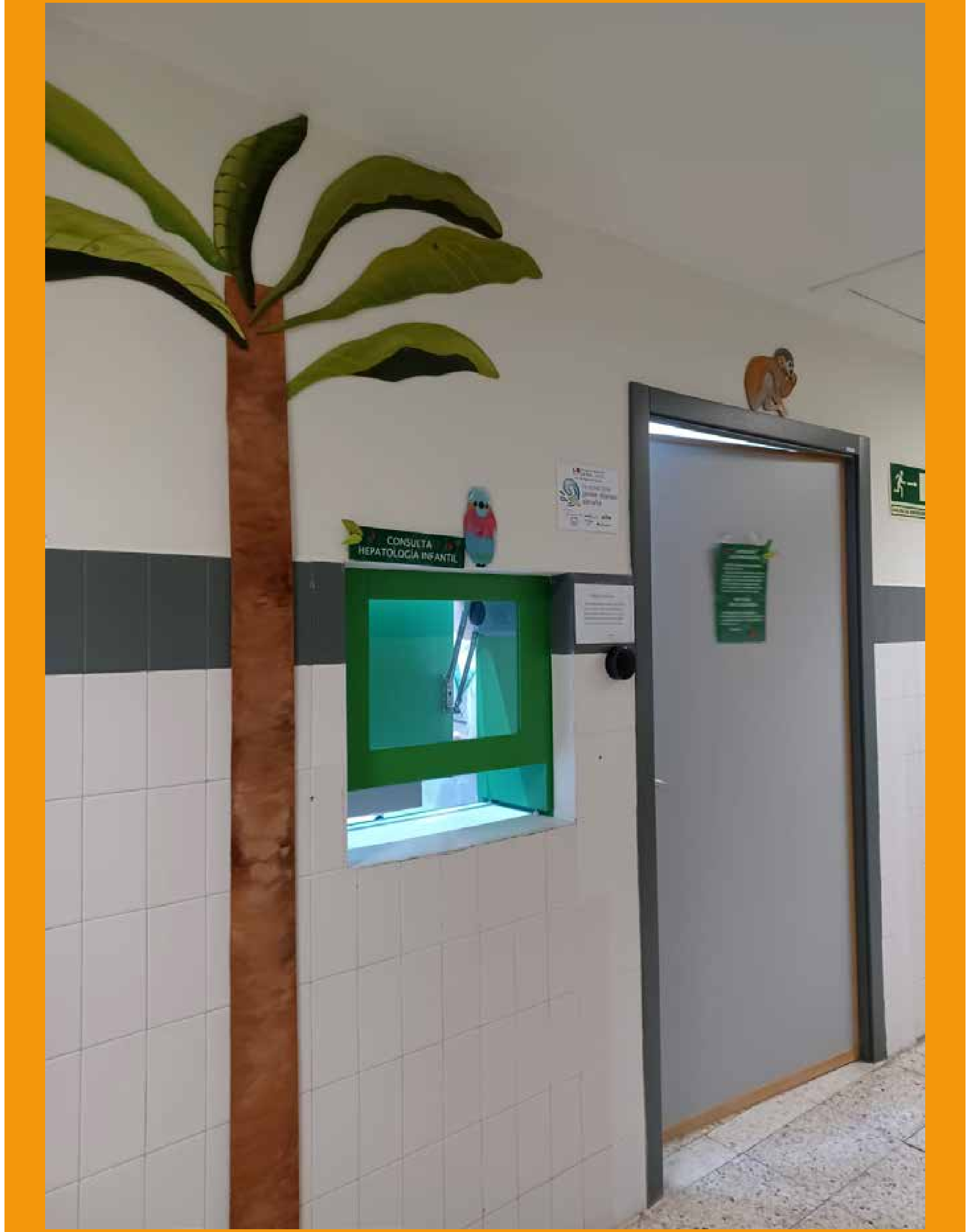

Centro Hospitalar do Porto, E.P.E.
Centro de Referência
Transplantação Renal Pediátrica
European Reference Network
FOR RARE OR LOW PREVALENCE COMPLEX DISEASES
This hospital belongs to
the European Reference Network
for Transplantation in Children (ERN-TransplantChild)
TransplantChild
CENTRO DE REFERÊNCIA TRANSPLANTAÇÃO RENAL PEDIÁTRICA

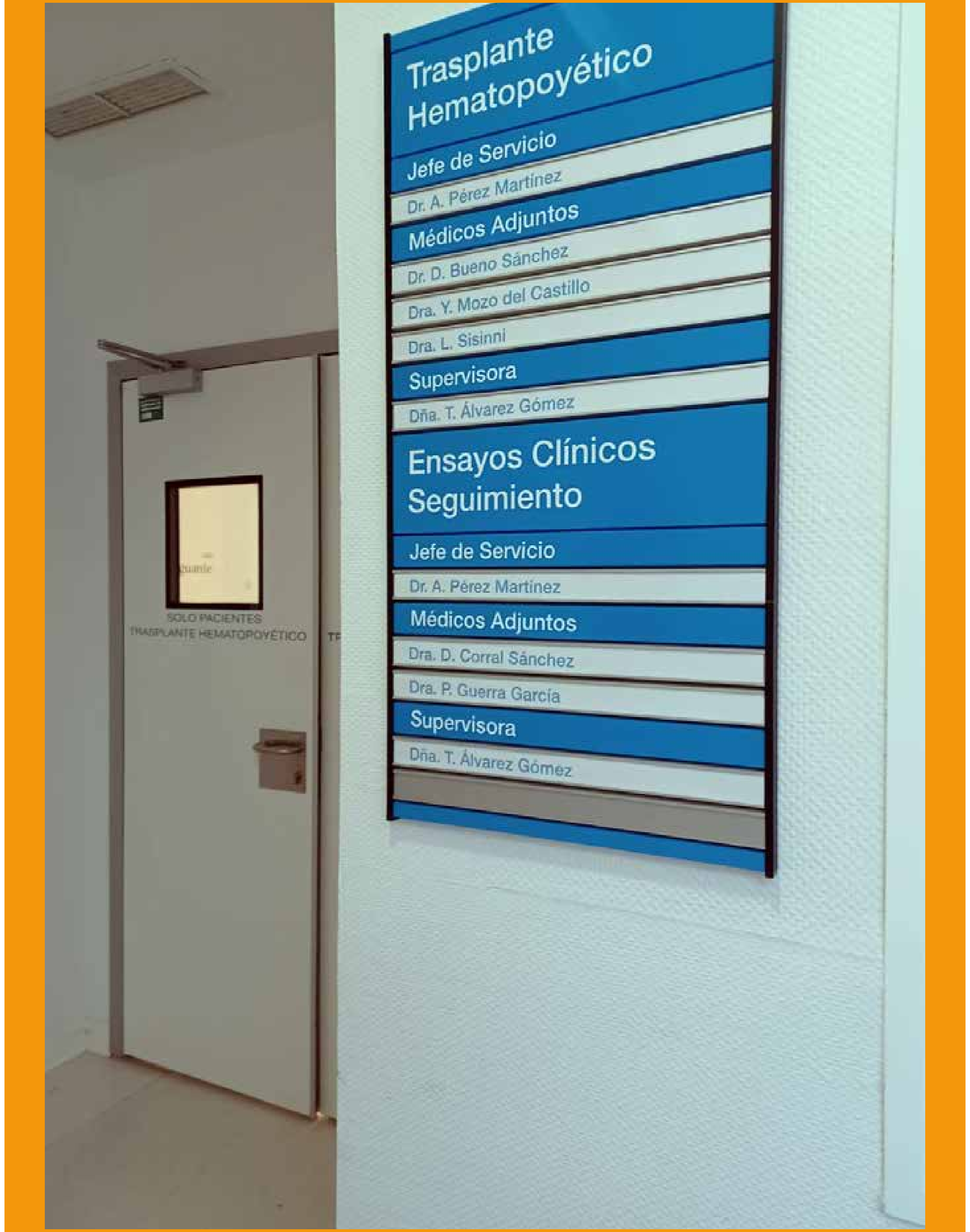

European Reference Network
FOR RARE OR LOW PREVALENCE COMPLEX DISEASES
TransplantChild


UOC NEFROLOGIA PEDIATRICA
we love kidneys
NEFROLOGIA PEDIATRICA
AMBULATORIO TRAPIANTI
Vivere con un TRAPIANTO:
SCOPRI TRANSPLANTCHILD!




juega terapia
BIENVENIDOS A
ISLA
Cui
Solo personal autorizado


CONSULTA
HEPATOLOGÍA INFANTIL


Trasplante
Hematopoyético
Jefe de Servicio
Dr. A. Pérez Martínez
Médicos Adjuntos
Dr. D. Bueno Sánchez
Dra. Y. Mozo del Castillo
Dra. L. Sisinni
Supervisora
Dña. T. Álvarez Gómez
Ensayos Clínicos
Seguimiento
Jefe de Servicio
Dr. A. Pérez Martínez
Médicos Adjuntos
Dra. D. Corral Sánchez
Dra. P. Guerra García
Supervisora
Dña. T. Álvarez Gómez
SOLO PACIENTES
TRASPLANTE HEMATOPOYÉTICO


Cris
8


AULA
LA PAZ EN ORBITA
6


Consulta de Enfermería


SaludMadrid
Nefrología
Consultas
Diálisis
Comunidad de Madrid

Rodrigo

"An enriching and highly relevant document to understand the philosophy of care in pediatric transplantations among different countries, which emphasises the need for communication and listening to be as open, honest, clear and simple as possible between the medical team, the patient and the family.

Thanks to these testimonies I have got to know some initiatives across Europe that I particularly appreciated: doctors and nurses who go to schools to speak with teachers, staff and students, thus contributing to reduce issues related to teachers' lack of understanding about repeated absences and the bullying or questioning from classmates; recreational camps outside the hospital to build relationships between children, families and medical staff; Transition programs from pediatric to adult services.

Let us not forget that healthcare professionals, beneath their uniforms, are human too. They feel the weight of pain, fear, and exhaustion - just like us and our families. Their dedication doesn't shield them from emotion; it often deepens it.

This booklet could inspire future medical professionals to join the field of pediatric transplantation. Reading it made me feel even more grateful to the medical team who cared for me."

Terry

"This booklet highlights a Europe united in a shared vision of care, despite diverse practices. These testimonies aren't just informative - they're inspirational.

I was struck by the passages where caregivers speak about themselves - their fatigue, doubts and emotions. It's a powerful reminder: caring for others begins with caring for oneself.

Those testimonies tell a multiprofessional model, where each actor — doctors, pharmacists, nurses, teachers, social workers, psychologists, families — contributes to the child's overall well-being. They show that transplantation goes far beyond the medical field - it also involves social, emotional and sometimes administrative aspects, especially for families coming from far away: it is not just a treatment, but an emotional and educational partnership.
This booklet shows that beyond borders pediatric transplantation is above all a story of love, trust and shared resilience between healthcare professionals, children and families.

I felt immense gratitude toward medical teams for their humanity, listening and total commitment. Reading these stories reminded me how we, transplant patients, are connected to them by an invisible but powerful thread.

A beautiful initiative - bravo to all who contributed to this project!"

Charlotte

"I like that you get different insights from the perspectives of various personalities. I also appreciate that it's written in different languages. People who feel alone with the topic can feel even more understood as a result!"

Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or European Health and Digital Executive Agency (HADEA). Neither the European Union nor the granting authority can be held responsible for them. 101156607 — TransplantChild23-27 — EU4H-2023-ERN2-IBA.