

DISSEMINATION WG Testimonies e-book

From the TransplantChild Dissemination WG we are aiming to gather testimonies from patients from all around Europe.

In some cases, receiving a transplantation is the only treatment for a person living with a Rare Disease, but paediatric transplantation is a highly complex process which brings forth many uncertainties for the families.

In an attempt to ease the families' minds, we want to collect the experience of those that are or have been in the same situation.

With this in mind, we would like to ask for the cooperation of all the centres of the ERN TransplantChild in the task of gathering testimonies from patients and producing and publishing an e-book to be used as support material by the families that have to undergo a paediatric transplantation.

Each centre should contribute with written testimonies of 5 patients or families in their native language and in English (translated by their HCP). A drawing is acceptable in the case of younger patients. Do not forget to include the written informed consent signed by the patient to publish their contribution!

Suggested format for the contributions:

- > 300-400 words
- Patient ID (name or pseudonym; age)
- Age at transplant
- Main concerns
- Successes
- Message for patients waiting for transplant
- Message for other transplanted peers
- Message for parents and caregivers
- ➤ Message for the Health professionals
- Other additional topics?

Please send us your contributions by September 15th, 2022:

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If you have any question or doubt, please do not hesitate to contact us.

Watch our informative webinar for more information!

