



European Reference Network on Pediatric Transplantation

Network Presentation



**European
Reference
Network**

for rare or low prevalence
complex diseases

 **Network**
Transplantation
in Children
(ERN TRANSPLANT-CHILD)

Your Date Here



TransplantChild focuses on a **low prevalent and complex clinical conditions** in children, both solid organ transplantation (SOT) / hematopoietic stem cell transplantation (HSCT), multiple or combined procedures, with a **specific `cross-cutting approach`**:

**`A PROCESS APPROACH INSTEAD OF
A DISEASE/ORGAN APPROACH`**

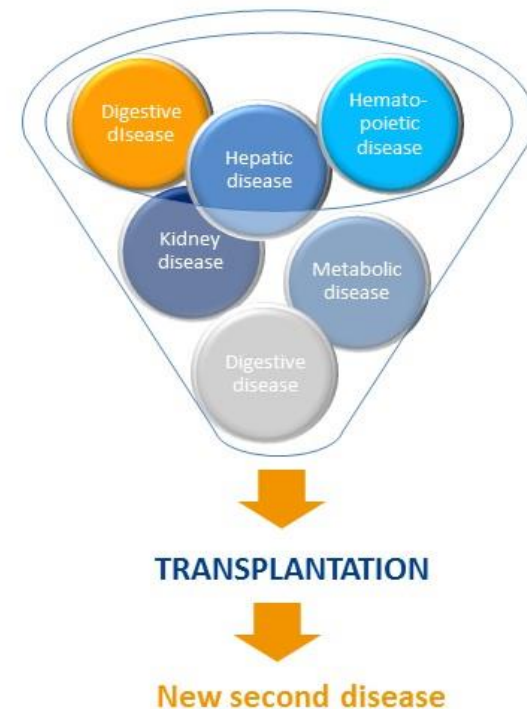


TRANSPLANTCHILD
proposes a holistic
procedure with a **cross-**
cutting approach.

The **cross-cutting** approach

- Transplanted children **shift** their primary disease to **lifelong chronic condition** or ‘disease’, mostly **imposed** by the immunosuppression.
- The new lifelong medical condition is **common** in many aspects to **all** transplanted children.
- **Standardization** of the most recent **improvements** in the transplantation process as a whole

Transplantation as a needed funnel where rare diseases merge to be transformed in a second new disease



Network added value



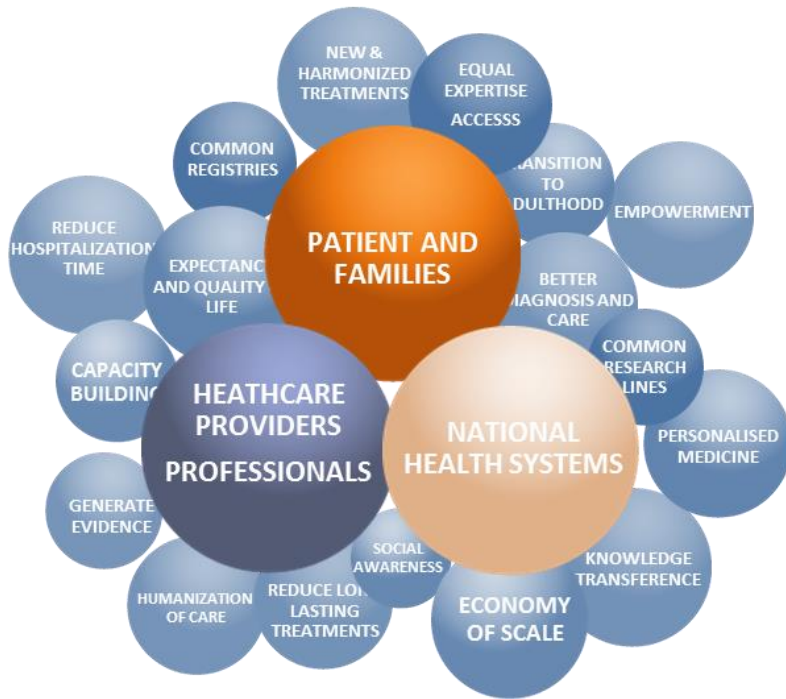
Patients, families and patient organizations

- Giving **patient voice** and involvement
- Facilitating awareness, **self-control**, training and participation
- Providing latest knowledge
- **Psychosocial support** (at school age and transition to adulthood)
- **Information** on clinical trials and research projects
- Minimising hospitalisation time and long-term treatments and **humanising patient's care**

HCPs and multiprofessionals teams

- Reducing related mortality and morbidity
- Favoring **higher amount of cases** with multicentre efforts
- Identifying and establishing **synergies** for all transplantation types
- Access to **clinical excellence** and support and training at all levels
- Providing **guidelines** for clinical practice
- **Harmonising** care and use of preventive practices
- Allowing the development of **personalised medicine**

Network added value



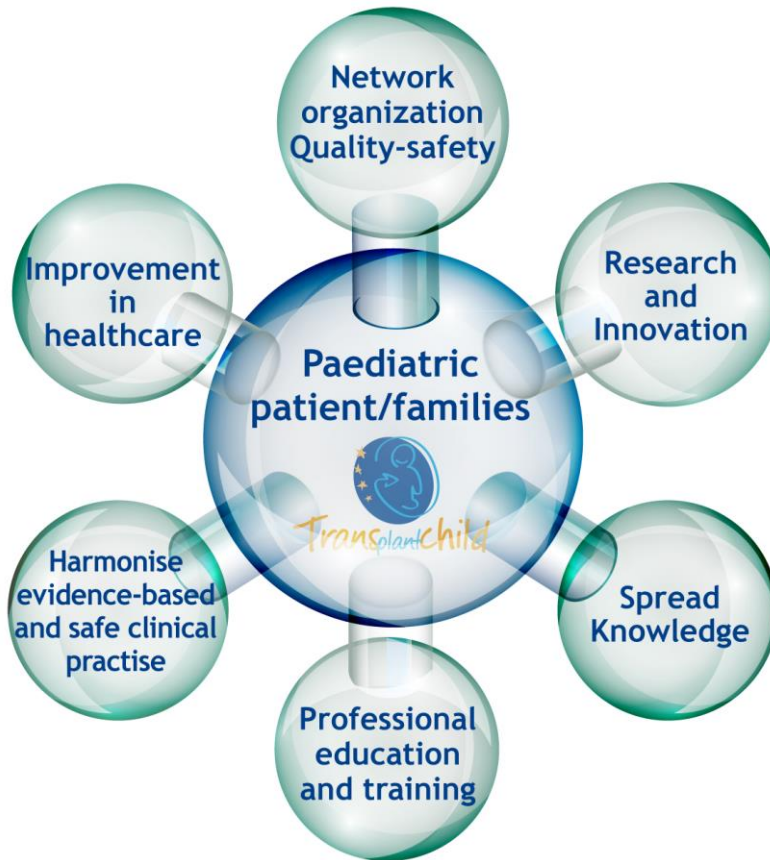
Health Systems

- Reducing costs
- **Improving health outcomes** (quality and safety in health care and satisfaction of patients and their families)
- Providing the highest standard of care
- Providing harmonised clinical practice guidelines
- Providing specialised professionals in high complex procedures
- **Sharing information** with other stakeholders

Other stakeholders

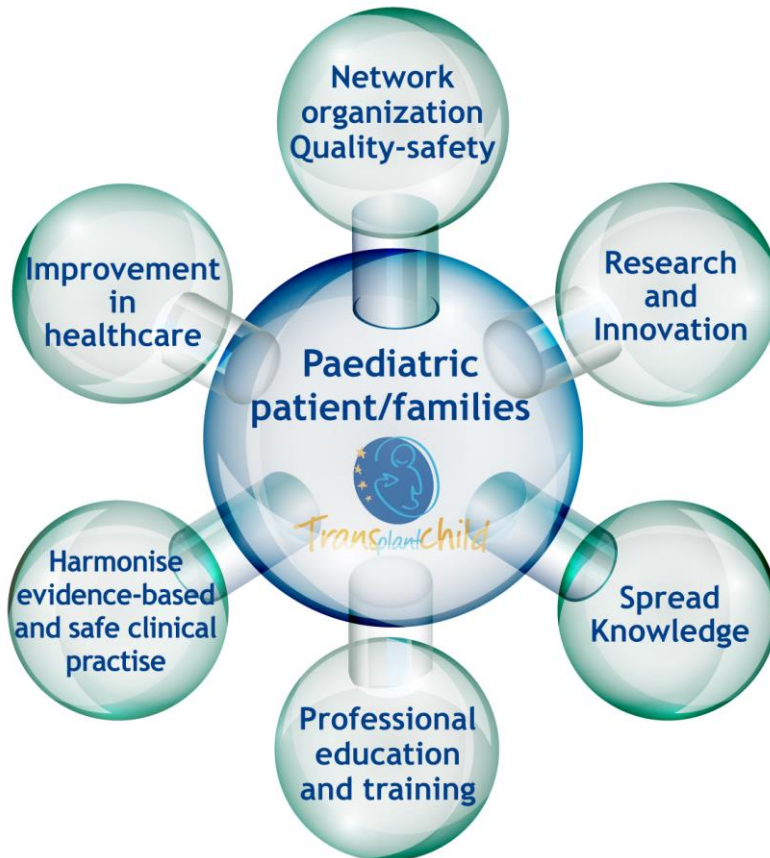
- Involving **patients' organizations, associations and scientific societies** in the improvement of clinical practice and the dissemination of best practices
- Establishing **partnerships** with industry and research centres
- Promoting **harmonised policies** across the EU
- **Establishing synergies with other networks and affiliated centres**

Network Strategic lines



1. Facilitate the **patient empowerment** through its participation in the activities of the network, access to information, dissemination of experience, research, exchange of necessary knowledge to facilitate their decision-making.
2. **Improvements in healthcare**: prevention, surgical interventions, patients' follow-up and health care for transplanted patients.
3. **Improve health outcomes** regarding the immune transplant process and phenomena of rejection and tolerance through the use of **clinical practice guidelines** by multi-professional teams involved in care.

Network Strategic lines



4. The gaps identification, alignment and prioritization of **areas of research and innovation** facilitate continuous improvement in transplant patient care and health outcomes.

5. **Disseminate knowledge** through society and other stakeholders, and clinical teams at different levels (including education and training activities).



Pediatric Transplantation : Survival rates

% survival	1 year	5 year	10 year
Liver	95 %	85 %	80 - 85 %
Kidney	95 – 100 %	95 %	90 %
Intestinal	78 %	66 %	60 %
Cardiac	85 %	75 %	60 - 75 %
Lung	80 %	50 %	
HSCT			60 - 70 %

Successful medical procedure

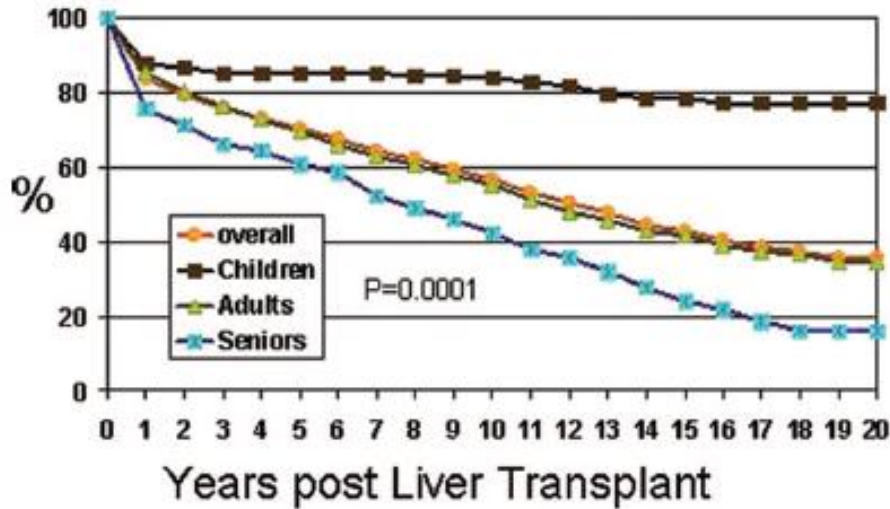
Long expectancy of life

- Chronic clinical condition (immunosuppression related)
- Higher risk of adverse effects (prolonged)
- Longer demand of care
 - Family
 - Health care providers / Health Systems
- “Changing patient” : infant → child → teenager → adult
continuous development : physical / psychological / cognitive
- Transition childhood to adulthood

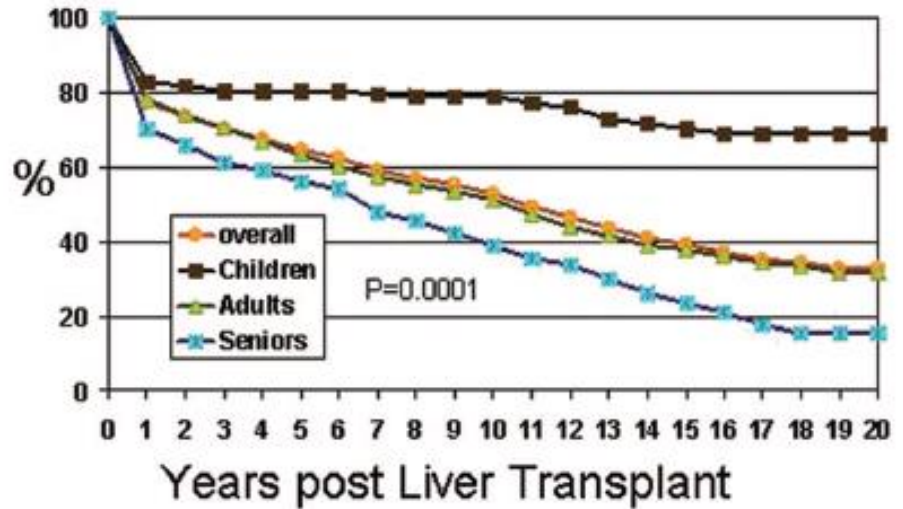


Pediatric Liver Transplantation

Patient Survival



Graft Survival



- 50 % candidates at transplant < 2 years old
- 80 % indications : chronic liver disease diagnosed at first weeks/months of life
- Type of donor
 - Living donor : 20-50 %
- Few centers
- 10-15 % combined grafts (liver-kidney, liver-intestinal, multivisceral)
- PT numbers are low(< 10 % adult activity) → negative impact (research, education, experience)

PLT first 1 year

Re- Transplant 10 – 15 %

Primary Graft
non-function
2-5 %

Vascular Thrombosis
HA 5-10%
PV 5 %
HV 5%

Graft Complications

- Biliary 20 %
- Acute rejection 20-30%
- Vascular 10 -15 %

General Complications

- Renal dysfunction : 10-30 %
- EBV related PTLTD 5-10 %

Infections (bacterial , fungal) 60-70%

Viral Infections (CMV/EBV) 60-70 %

ICU (2-4 weeks)

ICU physicians / nurses
Hepatologist
Hepatic Surgeon
Radiologist
Microbiologist
Pharmacologist
Physiotherapist

Transplant Ward (0,5 – 3 month)

Hepatologist and Hepatic Surgeon
Specialized nurses
Radiologist (follow – up or interventional)
Microbiologist
Pharmacologist
Nutritionist
Physiotherapist

Outpatient clinic follow-up (controls / 2-3 months)

Re-admissions in hospital (50%)
(repeated 25% : biliary/vascular)

Impact on Family

Emotional
positive : transplant
negative: fear , uncertainty
Laboral
Economical
Clinical (living donor)

Discharge from hospital
Increasing role in care
Dosing medications
Nutrition
General care

Professional psychological support

Parents education
Parents surveillance
Social Resources

Labor benefits (attendance)
Financial assistance

Primary health care providers/Social workers : key role

PLT in the long term > 1 year

-Low mortality (5 %)

- Chronic rejection 10 %
- Tumor (PTLD) 35 %
- Infection 20 %

- 10 years

- Graft function 80 % normal
- Histological lesions 65 %

-Clinical stability

Graft Complications

- Biliary 10 %
- Vascular 10 -15 %
- Rejection 5%

General Complications

- Renal dysfunction : 10-30 %
- Growth failure :30 % final height < 10th percentile
- Food allergy : 15 – 20%
- Diabetes 10 % (CF 70%)
- Overweight : 10 – 30 %
- Hyperlipidaemias : 7- 26 %
- Tumors / PTLD : 5 – 10 %
- Deafness (toxic) : 10-15%
- Neurocognitive difficulty 30 %** (intellectual , language)

“ideal survivor “ : 1/3 patients

(clinical profile: no re-LT, IS monotherapy, No PTLD/renal dysfunction7growth impairment, no prednisone /other drugs)

Healthcare

- Outpatient clinic / 3 – 4 months
- Low frequency of hospital admissions

Basic (Specialized) Care

hepatologist / surgeon
nurses
nutritionist
pharmacologist
microbiologist
radiologist

Other Specialized care

endocrinology
allergology
onco-hematology
neurology
interventional radiology
others

Impact on family

- Day to day caregivers (medication , basic care)
- Accepted and adapted to the situation
- Normal incorporation to work

Additional educational support (30%)
Social support (selected cases)

Adolescence

Non-adherence to treatment

Incidence 25 %
Risk of Rejection

Decreased quality of life perception

Significantly decreased across multiple domains
(Physical, psychological, social, family and school functioning)
Anxiety (37%) ; Depression (up to 17%)

Transition to adulthood

Transfer to an adult-care transplant unit

Basic (Specialized) Care

hepatologist / surgeon
nurses
nutritionist
pharmacologist
microbiologist
radiologist

+

Psychological attention to patients

-Information
-Clinical situation / future risk
-Medications (+/- effects)
-Detection / prevention (PeLTQL specific tool) Peer-mentoring models
-Treatment

Transition Units and protocols

Impact on family

Stress , anxiety , uncertainty
Care failure (non adherence)
“New beginning” (transition)

Progressive increase the role
of children in self-care



conclusions

- Pediatric transplantation can be considered as a successful clinical procedure that offers to most patients a long expectancy of life.
- We still have a great margin to improve the results of transplant in
 - Clinical issues
 - Psychosocial care (patients and families)
 - Adolescence
 - Transition to adulthood



JGdD

Transplantchild

Transplantation (SOT & HSCT) in Children

THANK YOU!

Do you have any questions?

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