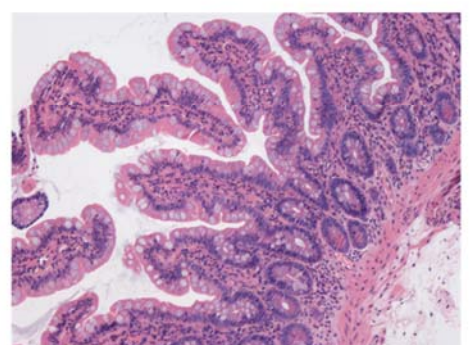
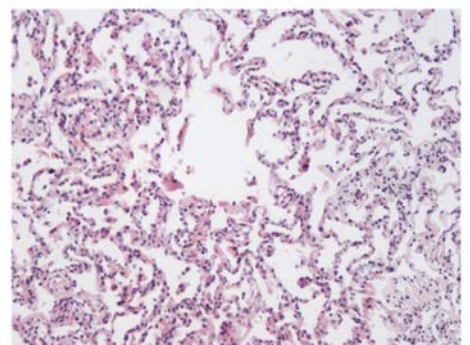
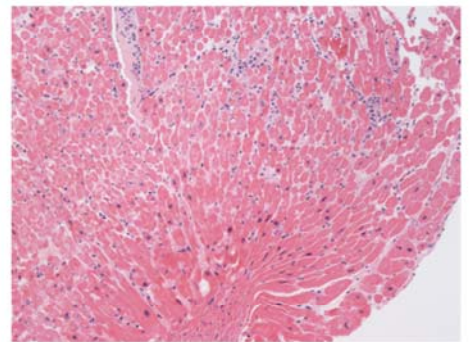
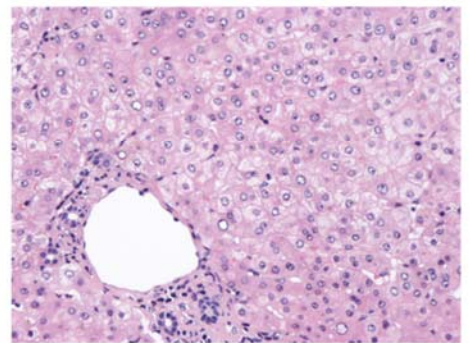
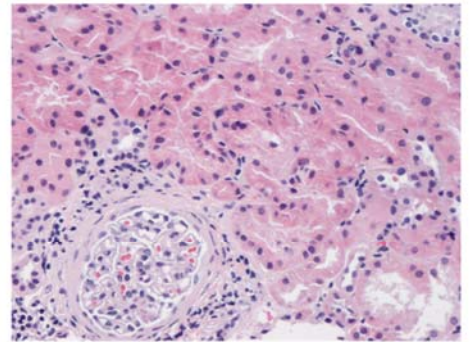


# Annual Report 2015

Pediatric kidney, liver  
and organ  
transplantation unit  
Hannu Jalanko, Paula Seikku



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### Abbreviations

ABOi	Organ transplantation across blood types
ARPKD	Autosomal recessive polycystic kidney disease
BA	Congenital biliary atresia
CAD	Cadaver donor
CAKUT	Congenital anomalies of the kidney and urinary tract
CNF	Finnish type of congenital nephrotic syndrome
CVVHDF	Continuous veno-venous hemodiafiltration
ECP	Extracorporeal photopheresis
HD	Hemodialysis
LRD	Living related donor
MARS	Molecular Adsorbent Recirculating System
PD	Peritoneal dialysis
PE	Plasma exchange

The cover photo shows biopsy findings from kidney, liver, heart, lung, and intestinal transplants.

## Pediatric Kidney, Liver and Organ Transplantation Unit

The unit for organ transplantation at the Children's Hospital, Helsinki University Hospital, is in charge of children's solid organ transplantations, dialysis treatments, and diagnostics and treatment of severe renal and liver diseases in Finland. The unit includes an in-patient ward (K3), a day hospital, and outpatient clinic for transplant and renal patients. Consultations, training, and maintenance of registers for transplantation and dialysis activities are taken care by the transplant office located in the unit. The ward provides approximately 2,000 in-patient days/year in total and just under a half of these are stays in intensive care. A thousand day hospital visits are registered annually, and there are 1,200-1,500 outpatient clinic visits per year.

All pediatric transplant patients (kidney, liver, heart, lungs and small bowel) are taken care by the same unit in collaboration with the department of thoracic and transplant surgery and the intensive care unit at the Children's Hospital as well as with the adult transplantation units. Centralizing transplantations into a single unit has been beneficial in order to achieve and maintain the required know-how.

The staff includes three transplant pediatricians and, as of the beginning of 2015, one part-time (50%) specialist. The unit is responsible for training of pediatric nephrology residents for the whole country. The unit has 30 nurses, two secretaries and specialist employees, such as a part-time pharmacist and a nutrition therapist. Also taking part in the activities is a rehabilitation coordinator, adolescent psychiatrist, psychiatric nurse, social worker, preschool teacher. The unit provides dialysis training for doctors and nurses from other central hospitals, as well as round-the-clock consultation.

Research work is active. The unit has supervised and produced 19 doctoral PhD theses, more than 150 scientific original publications, as well as numerous review articles in international textbooks and journals during the past 20 years.

## Transplantations in 1986-2015

The pediatric organ transplantation program was launched in 1986 at the Children's Hospital in collaboration with the adult transplantation units. The development of the program is shown in Table 1. For the time being, 10–25 pediatric transplantations are conducted in Finland annually. Twenty children underwent transplantation in 2015. Thirty percent of the recipients come from the Helsinki University Hospital area and the remaining 70 % are from the other the Finnish university hospitals.

Table 1. Development of children's organ transplantation in 1986-2015. Nine percent of the operations were re-transplantations.

	First transplantation	Patients	Transplantations
Kidney	1986	248	275
Liver	1987	14	132
Liver-kidney	1993	13	13
Heart	1991	75	78
Heart-lung	2007	2	2
Lung	2009	4	4
Small intestine	2009	4	4
<b>Total</b>		<b>442</b>	<b>487</b>

By the end of 2015

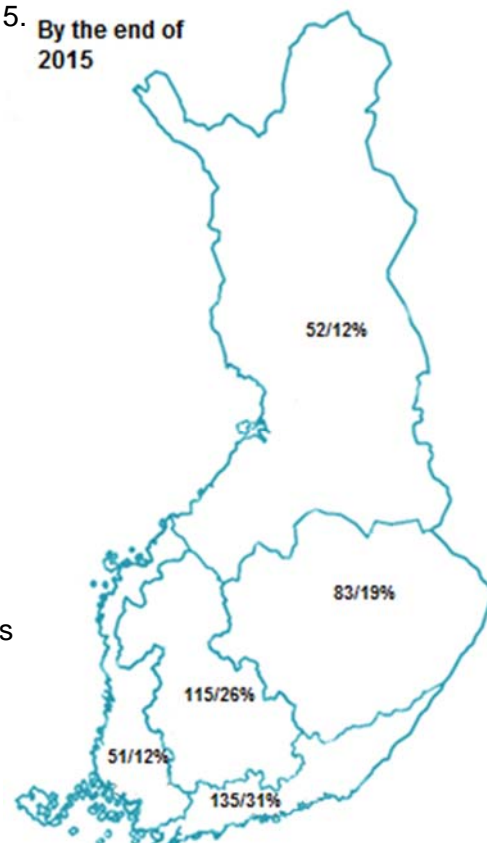
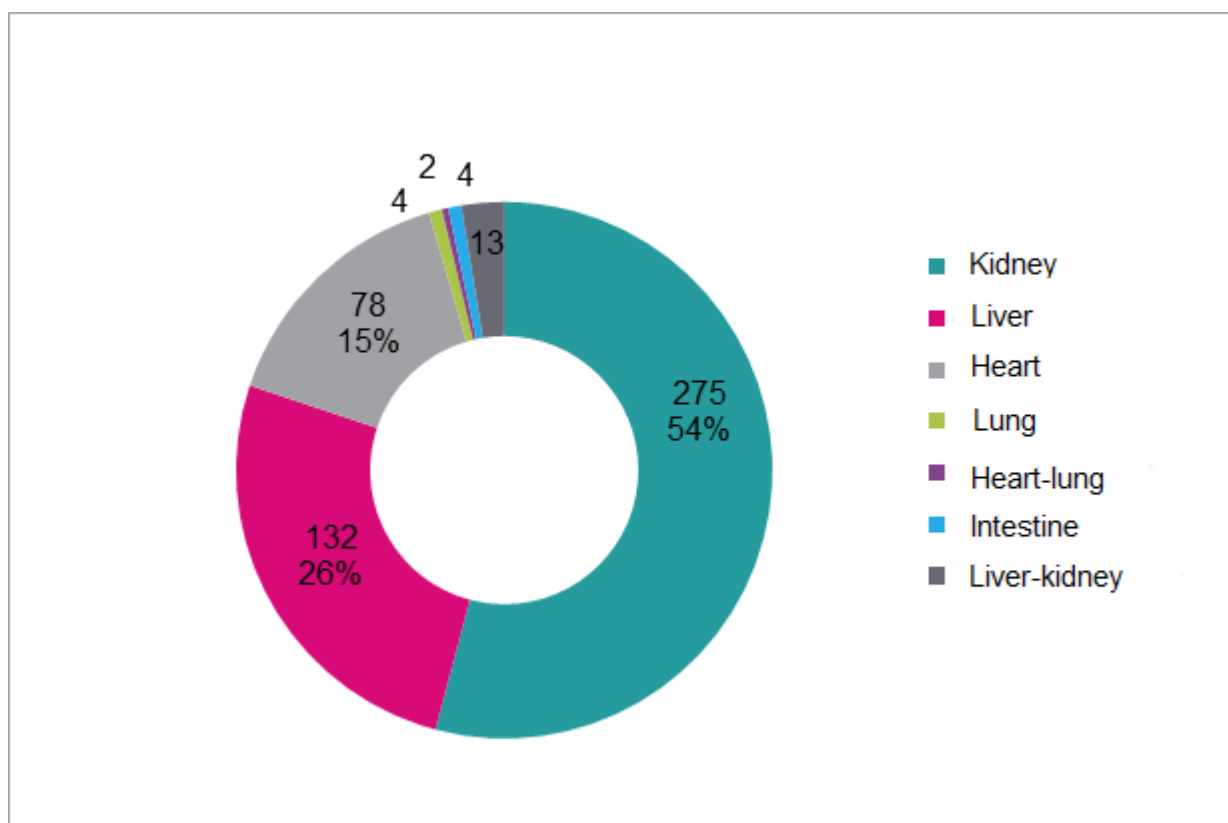


Table 2. Geographical distribution of kidney, liver, and heart recipients classified by university hospital area.

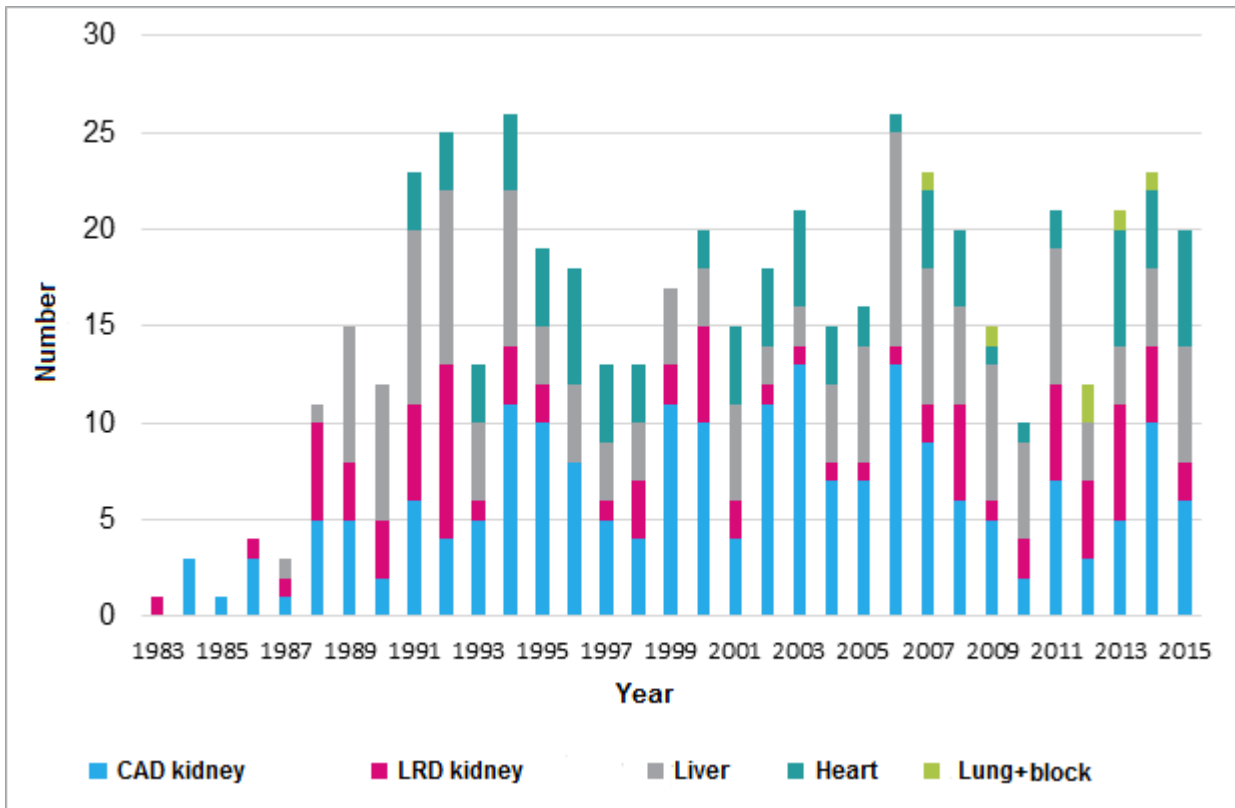
Transplant	Helsinki	Turku	Tampere	Kuopio	Oulu
Kidney (248 patients)	31%	12%	24%	21%	12%
Liver (114 patients)	28%	15%	28%	15%	13%
Heart (75 patients)	33%	7%	28%	19%	12%

Figure 1. Distribution of transplant recipients by university hospital areas in 1986-2015.



Figure

2. Pediatric organ transplantations by organ in 1986-2015



Figure

3. Pediatric organ transplantations annually 2005-2014.

## Indications for transplantation

The major group of kidney recipients in our country are infants with the Finnish type of congenital nephrotic syndrome (CNF) who are transplanted at the age of 1–2 years. The second-largest group comprises children with congenital anomalies of the kidney and urinary tract (CAKUT). The primary indication for liver transplantation is congenital biliary atresia (BA) followed by metabolic diseases, liver tumors, and acute liver failure. Cardiomyopathy and congenital cardiac defects account for the majority of heart transplantations (Figure 3) which is also true globally.

### Kidney

Congenital nephrotic syndrome	44 %
Congenital defects	28 %
ARPKD, nephronophthisis, etc.	18 %
Infectious	11 %
Other	6 %

### Liver

Congenital biliary atresia	39%
Metabolic disease	22%
Tumors	14%
Acute liver failure	11%
Liver-kidney transplantations	8%

### Heart

Congenital defects	60 %
Cardiomyopathy	40 %

### Lungs

Cystic fibrosis	50 %
Pulm. hypertension	50 %

### Small intestine

Intestinal aganglionosis	100%
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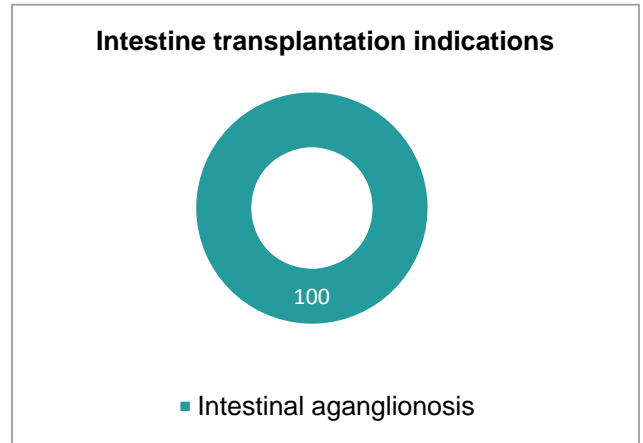
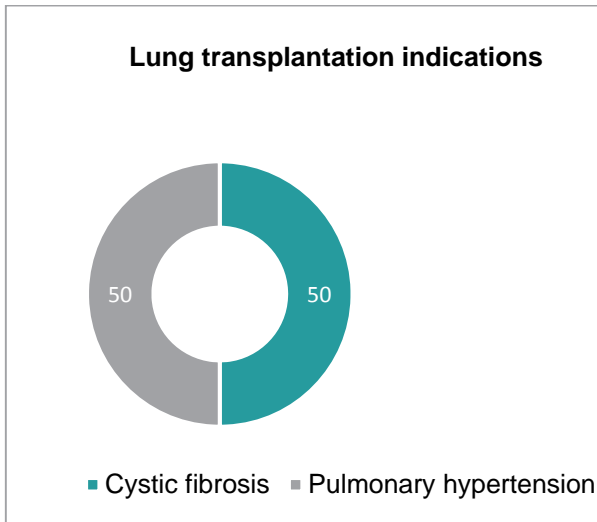
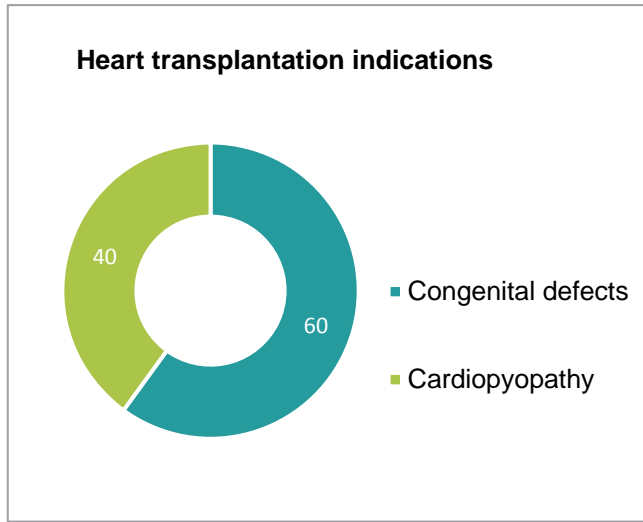
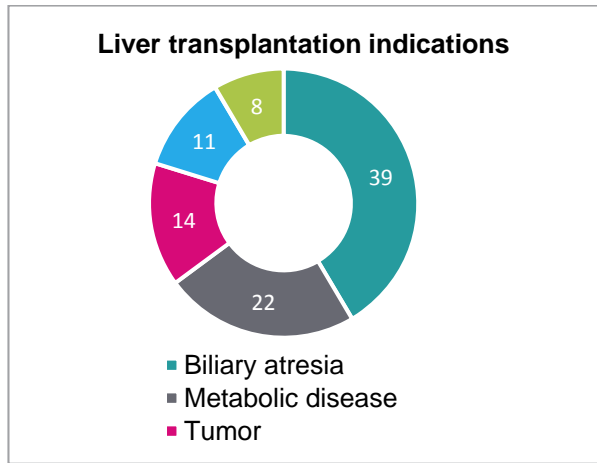
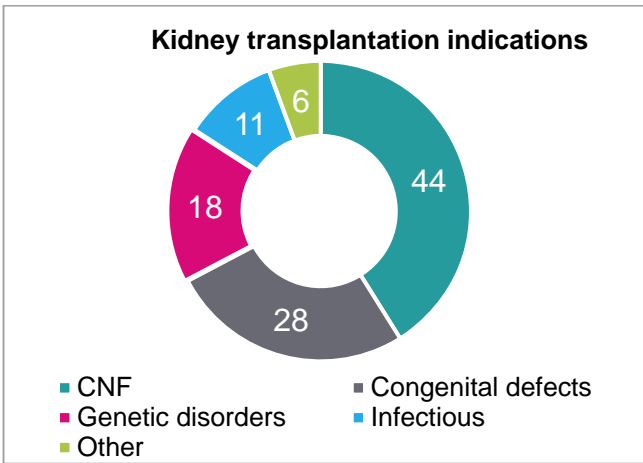


Figure 4. Indications for organ transplantation

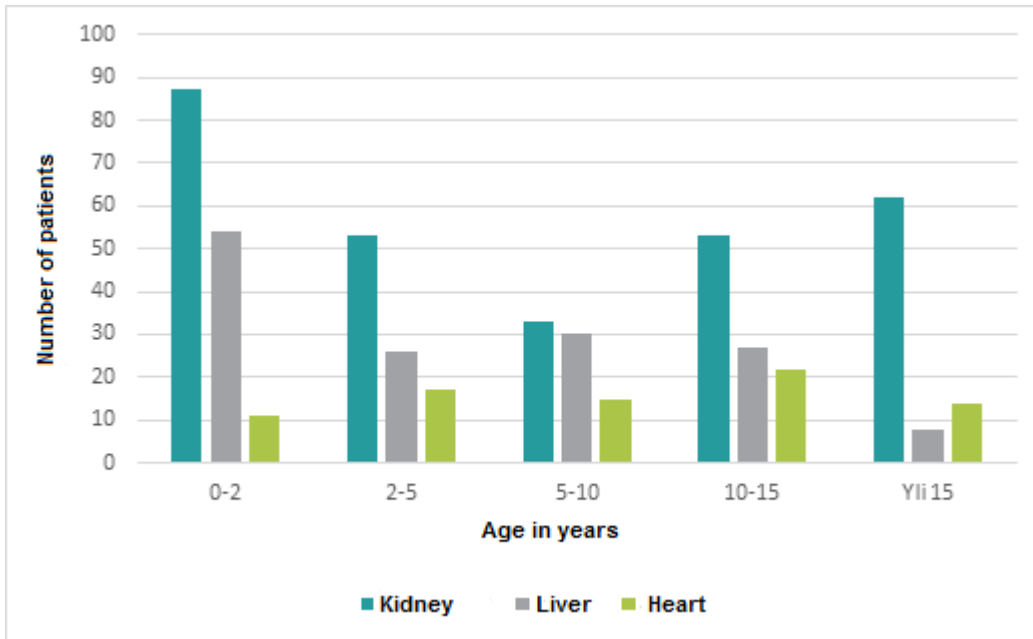


Figure 5. Age distribution of pediatric kidney, liver and heart recipients at the time of the transplantation.

The great majority of organs in pediatric transplantations come from adult cadaver donors (CAD) supplied by the national organ allocation organization and Scandiatransplant. In kidney transplantations living related donors have been used in 30 % of all operations. However, during the recent years this proportion has increased to 50 %.

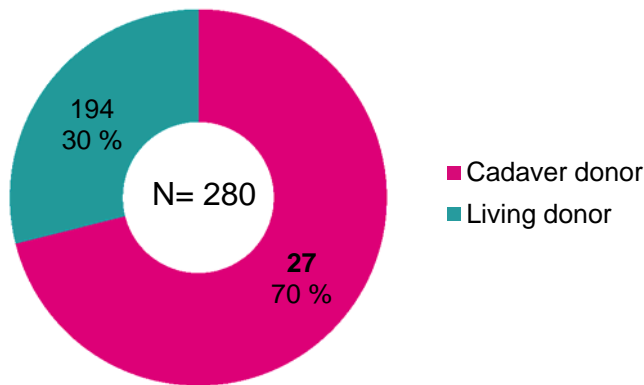


Figure 6. The proportion of family member and cadaver donors in kidney transplantations.

## Long-term outcomes of organ transplantations

The outcomes of organ transplantations are constantly improving. Of all Finnish children receiving kidney transplants, 95 % are alive ten years later. The patient survival rate in liver and hearts transplantations is about 70 % (Figure 6).

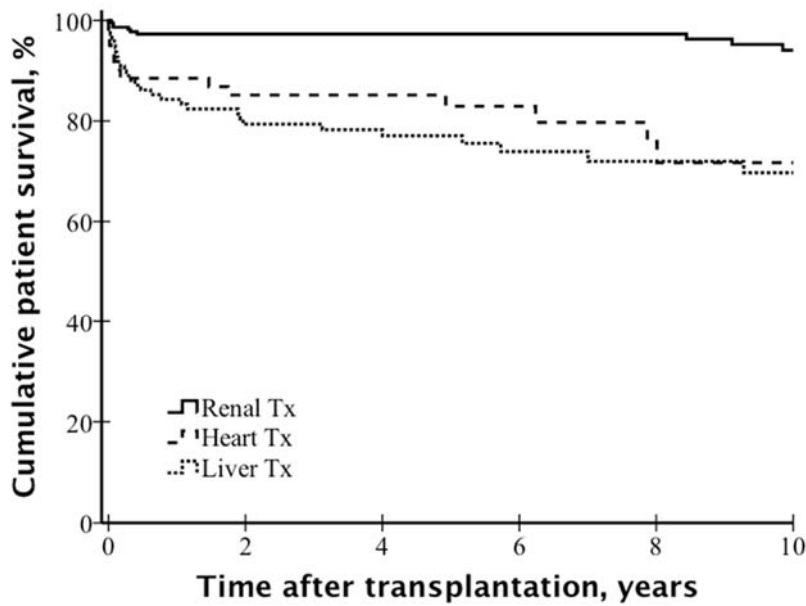


Figure 7. Patient survival rate after kidney, liver, and heart transplantation

The survival rates for the Finnish transplant recipients are at a high international level. After kidney transplantations, the long-term graft survival is the best according to the EDTA registry (Figure 7). In liver and heart transplantations the survival rates are equivalent to the best registry information

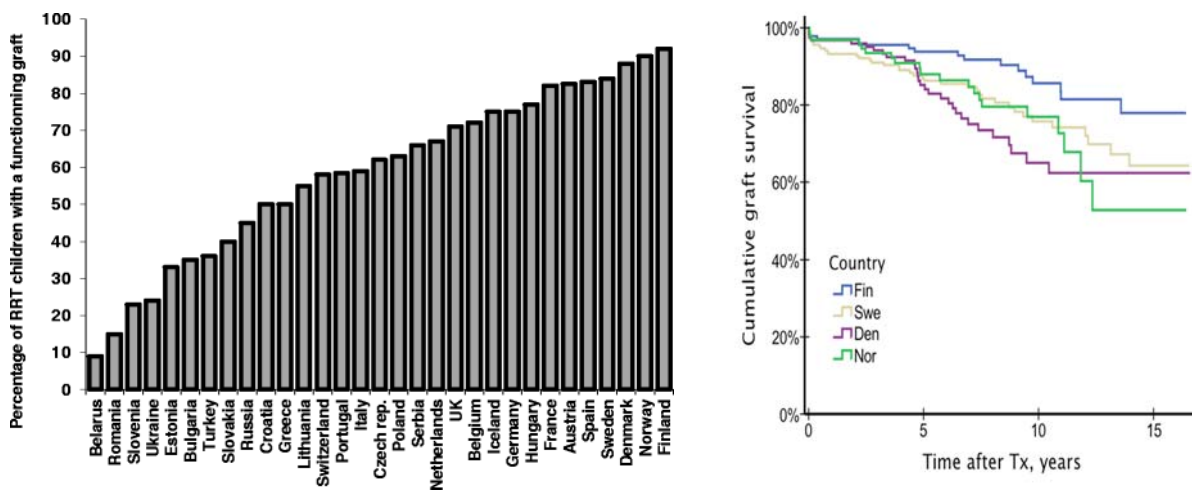


Figure 8. The columns on the left indicate the long-term survival rates of children receiving kidney transplantations in Europe, in which Finland is in first place (column on the right). In a more detailed comparison of the Nordic countries, Finland's proportion of functioning transplanted kidneys is highest. The data are from 2013.

## Other activities

The transplantation unit takes care of the diagnostics and treatment of children suffering from serious liver insufficiency caused by metabolic illnesses, acute liver failure, poisonings, and autoimmune diseases, among others. MARS dialysis treatment is given, if needed, in collaboration with the pediatric intensive care and adult liver units.



The unit is responsible for children's dialysis therapy in Finland on a 24/7 basis. Treatments include peritoneal dialysis (PD), hemodialysis (HD), as well as continuous veno-venous hemodiafiltration (CVVHDF). The last of these is used especially to support hemodynamically unstable patients in intensive care unit. Dialysis treatments are also conducted on patients on other wards. Most PD therapies are home-based CCPD treatments, for which the family receives training during a 1–2 week treatment period on the ward.

Our unit offers also plasma exchange treatment (PE) in autoimmune diseases and in antibody-mediated rejection episodes

## Key figures for 2015

A total of 20 organ transplantations, including

- 8 kidney transplantations,
- 6 liver transplantations,
- 6 heart transplantations,
- 1 small intestine transplantation

Dialysis treatments (number):

- HD 429
- PD 119 (majority as in-home treatment)
- PF 89
- MARS 5
- ECP 2

Ward:

- in-patient periods 392
- in-patients days 2,171
- average in-patient care time 5.5 days
- capacity utilization 85%

Visits:

- day hospital 949
- out-patient visits of kidney and liver patients 599
- out-patient visits of transplant patients 523

## Auditing

In November 2015, an audit of the Finnish organ transplantation activity, including the pediatric organ transplantations, was performed. The audit was performed by experts from Germany and Norway in addition to two Finnish auditors. The main focus of the audit was on the transplantation organization. The auditors did not find anything to dispute with in pediatric organ transplantations, and we received positive feedback especially regarding the centralization of our operations and regarding our transplantation research. Item number 5 from the final summary:

*5 Pediatric transplantation functions well as a multidisciplinary organization with joined involvement of transplantation surgeons, heart surgeons, committed heart anesthesiologists and pediatricians with special expertise in transplantation. The pediatric transplantation office has their own coordinators and collaboration with the adult transplantation office is perceived as feasible. Patient follow up is centralized to HUH and is well organized. Research is productive and active. A future challenge is the education of new experts (transplant physicians) to the field.*

In connection to the auditing process, the quality of life of transplantation patients was discussed, which is especially crucial when it comes to pediatric patients. We have surveyed child and adolescent transplantation patients in regards to their quality of life for several years now and it has become clear that a transplantation operation increases quality of life significantly. The need to observe quality of life in proportion to treatment costs was brought up, which will be looked into.

## Research activity

Research in the transplantation unit is active. In 2015, 23 original articles were published in addition to several international review articles. One doctoral thesis was completed (Juuso Tainio).

Research subjects include the pathogenesis of nephrosis, interstitial nephritis, and infections and long-term problems in pediatric transplantation patients. Two doctoral theses are to be completed in 2016 (Maija Suvanto, Jenni Miettinen). Our two key review articles are:

Jalanko H, Mattila I, Holmberg C. Renal Transplantation in infants. *Pediatr Nephrol*, 2015, epub ahead of print

Holmberg C, Jalanko H. Long-term effects of pediatric renal transplantation. *Nature Rev Nephrol*, 2015, epub ahead of print

## Summary and future prospects

In Finland, pediatric organ transplantation is centralized to HUH Children's Hospital. Concentrating all pediatric transplantation surgery, anesthesia and follow-up care into the same unit is unique on an international scale, but in a country with a small population base, it guarantees the best results. Also, the fact that the transplantation center participates in the long-term follow-up guarantees continuity in treatment.

One of the recent steps forward in organ transplantation development has been the crossing of the A, B and O blood type borders. The ABO-incompatible transplantations will increase the availability of transplants and reduce waiting time. So far we have conducted four ABOi heart transplantations successfully at Children's Hospital. We have the required readiness for ABOi kidney transplantations but none have been performed yet. For the so-called composite tissue transplantation (facial and limb transplants) treatment protocols were prepared in 2014 together with the adult transplantation units and operations have now begun with the first adult facial transplantation.

Dialysis treatment is constantly being developed. CVVHD has become a routine treatment which was greatly helped by a brochure compiled through collaboration. In 2015, a project was begun to consider using home-based hemodialysis treatments also in school-aged children and adolescents. Results from the past years show that home-based HD treatment five to six times a week ensures a better therapeutic equilibrium than HD treatment in hospital three times a week. In addition, intermittent HDF treatments have also begun.

Collaboration with the oncology unit began in 2014 and will continue in the future in the form of shared training events. A collaborative project was the introduction of photopheresis (ECP) at the Children's Hospital in late 2014. ECP is used in the treatment of patients suffering from chronic rejection or graft versus host rejection. The plan is to travel to Boston in June of 2016 to explore the combination treatment of a haploidentical stem cell transplant and a kidney transplantation.

During 2014–2015 we took part in the drafting of a guidebook aimed at improving the availability of donors in our country. We also continue to collaborate with the Kidney and Liver Society of Finland to improve the availability of donors.

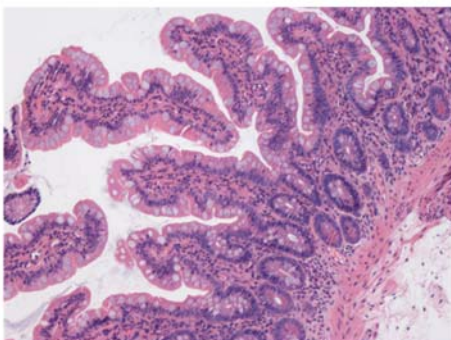
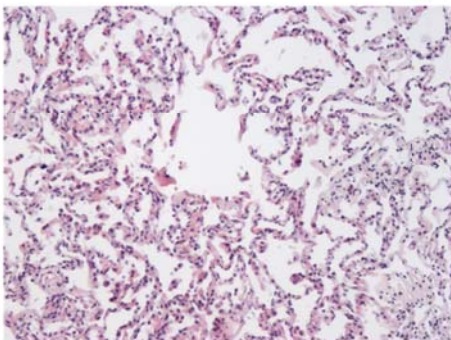
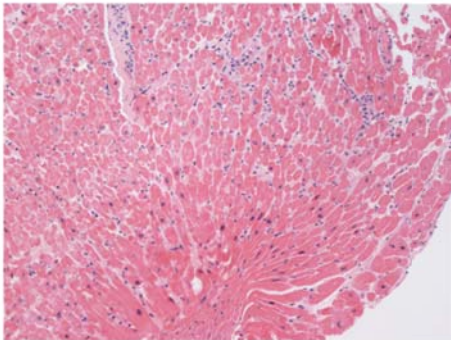
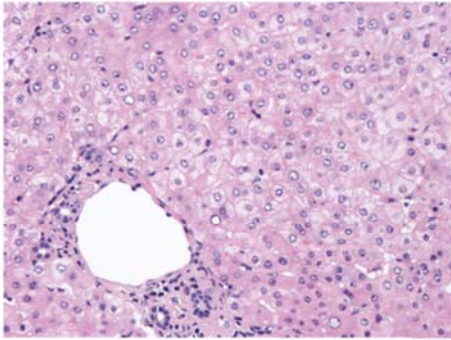
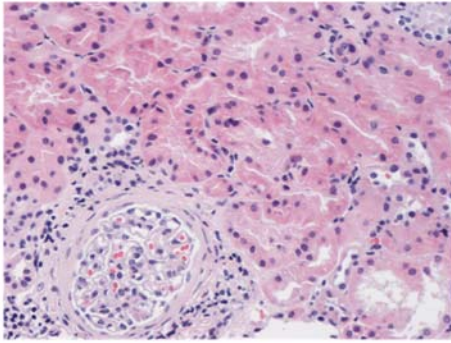
The results of organ transplantation and dialysis activities are compiled annually into several registries. These are the Finnish Registry for Kidney Diseases, the Nordic Scandiatransplant and NPRTSG registries, as well as European kidney and liver registries (EDTA, ELTR) and the international ISHLT registry for heart and lung transplants.

To ensure further development, our unit actively participates in European and global kidney and organ transplantation conferences (ESPN, IPTA, IPNA, EDTA, ISHLT). In nursing, the yearly EWOPA conference is significant. Pediatric nephrologists in Finland receive further training at the national training events organized twice a year.

The personnel organization LELSI has organized several study trips for our entire unit to key European kidney units (Lille, London, Essen, Gothenburg, Rome). The next visit will be to Barcelona in October 2016.

In 2014–15, our unit has served as a teaching hospital for the kidney unit of Moscow's leading children's hospital within the framework of the sister program of the International Society of Nephrology (ISN). Funding has increased for 2016 and we will also increase our collaboration. Our aim is to launch pediatric kidney transplantation operations in the leading pediatric kidney unit in Moscow.

In nephrology, the HAKE project for rare diseases will be launched in 2016 in collaboration with the adult nephrology unit. At the same time our unit will take part in the European ERN project in rare pediatric kidney diseases. The aim for both of these projects is to complete the first stage during summer 2016.



## Pediatric kidney, liver and organ transplantation unit

K3 Pediatric kidney and transplantation ward  
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Transplantation office

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