Annual Report 2014
Pediatric kidney, liver and organ transplantation unit

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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.
INTRODUCTION

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 management 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 totally around 2000 days/year for hospital stays. Thousand visits at the day hospital are annually registered and the outpatient clinics serve for 1200-1500 patient visits a 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 gives training in dialysis 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 18 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.

PEDIATRIC ORGAN TRANSPLANTATIONS

1. TRANSPLANTATIONS IN 1986-2014

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 (Figure 2) Twenty-two children underwent transplantation in 2014. Thirty percent of the recipients come from the Helsinki University Hospital and 70% are from the other the Finnish university hospitals (Figure 1)
Table 1. Development of children’s organ transplantation in 1986-2014. Nine percent of the operations were re-transplantations.

<table>
<thead>
<tr>
<th>Organ</th>
<th>Year</th>
<th>First transplantation</th>
<th>Patients</th>
<th>Transplantations</th>
<th>% of transplantations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney</td>
<td>1986</td>
<td>241</td>
<td>267</td>
<td></td>
<td>54.8 %</td>
</tr>
<tr>
<td>Liver</td>
<td>1987</td>
<td>108</td>
<td>126</td>
<td></td>
<td>25.9 %</td>
</tr>
<tr>
<td>Liver-kidney</td>
<td>1993</td>
<td>13</td>
<td>13</td>
<td></td>
<td>2.7 %</td>
</tr>
<tr>
<td>Heart</td>
<td>1991</td>
<td>71</td>
<td>72</td>
<td></td>
<td>14.8 %</td>
</tr>
<tr>
<td>Heart-lung</td>
<td>2007</td>
<td>2</td>
<td>2</td>
<td></td>
<td>0.4 %</td>
</tr>
<tr>
<td>Lung</td>
<td>2009</td>
<td>4</td>
<td>4</td>
<td></td>
<td>0.8 %</td>
</tr>
<tr>
<td>Small intestine</td>
<td>2009</td>
<td>3</td>
<td>3</td>
<td></td>
<td>0.6 %</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>442</td>
<td>487</td>
<td></td>
<td>100 %</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Transplant</th>
<th>Helsinki</th>
<th>Turku</th>
<th>Tampere</th>
<th>Kuopio</th>
<th>Oulu</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney (241 patients)</td>
<td>31%</td>
<td>12%</td>
<td>24%</td>
<td>21%</td>
<td>12%</td>
</tr>
<tr>
<td>Liver (108 patients)</td>
<td>27%</td>
<td>16%</td>
<td>29%</td>
<td>15%</td>
<td>13%</td>
</tr>
<tr>
<td>Heart (68 patients)</td>
<td>31%</td>
<td>4.4%</td>
<td>31%</td>
<td>21%</td>
<td>13%</td>
</tr>
</tbody>
</table>

Figure 1. Distribution of transplant recipients according to university hospital areas in 1986-2014.

Figure 2. Pediatric organ transplantations annually 2005-2014.
2. 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).
Figure 4. 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 5. The proportion of family member and cadaver donors in kidney transplantations.
3. 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 6. Patient survival rate after kidney, liver, and heart transplantation patients 1987-2014](image)

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 in EDTA- and Scandiatransplant registries (Figure 7). In liver and heart transplantations the survival rates are equivalent to the best registry information.

![Figure 7. 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.](image)
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 2014

A total of 22 organ transplantations, including

- 14 kidney transplantations,
- 4 liver transplantations,
- 3 heart transplantations,
- 1 heart-lung transplantation

Dialysis treatments (number):

- HD 429
- PD 119
- PF 89
- MARS 5
- ECP 2

Ward:

- in-patient periods 481
- in-patients days 1973
- average in-patient care time 3.8 days
- use of capacity 90.1 %

Visits:

- day hospital 1006
- out-patient visits of kidney and liver patients 653
- out-patient visits of transplant patients 781

RESEARCH ACTIVITY

Ongoing research projects:

- Pathogenesis of proteinuria in renal disorders
- Cardiovascular problems of young adults who received kidney transplant as a child
- Long-term prognosis for children who received a kidney transplant for congenital nephrotic syndrome
Quality of life of adults transplants as a child.
Pathogenesis of tubulointerstitial nephritis and uveitis
Early diagnostics of allograft nephropathy after kidney transplantation
Early diagnostics of fibrosis in liver transplantation
Liver and kidney changes in patients with Mulibrey nanism
Biomarkers for kidney damage in children undergoing open-heart surgery

Twenty-four original international articles were published in 2014.

**SUMMARY AND FUTURE PROSPECTS**

Pediatric organ transplantation is an established mode of therapy in severe organ failure. Concentrating all transplant children 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 participation of the transplant center in the long-term follow-up guarantees continuity in treatment.

The ABOi transplantations in heart and kidney patients may reduce waiting time and can be seen as steps forward. So far we have conducted three ABOi heart transplantations successfully. The first ABOi kidney transplantation is planned for year 2015.

Dialysis treatment is constantly being developed. CVVHD became a routine treatment in 2014 hemodynamically unstable patients. In 2015, Tuula Hölttä will spend a month at the Great Ormond Street Hospital in London studying the use of intermittent hemofiltration on kidney patients.

Collaboration with the oncology unit has begun 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.

In 2014 we took part in the drafting of a guidebook aimed at improving the availability of donors in our country. 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.

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 an event in Barcelona in 2016.

In 2014-15 we will serve 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). This takes place on the basis of visits and return visits with the aim of launching children's kidney transplantation in Moscow.

To fund our own research activities, we have received about €150,000 in support (the EVO fund, the Juselius Foundation, the Research Foundation for Children's Diseases, the Sohlberg Foundation). Two new doctoral dissertations and 10-20 original articles are expected in 2015.
**Pediatric renal, liver, and organ transplantation unit**

K3 Children's renal and organ transplantation ward
Day hospital
Transplantation office

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