Annual Report 2016
CARE FOR HEART CHILDREN
Jaana Pihkala, Ilkka Mattila, Paula Rautiainen
Contents

Presentation of operations ........................................ 3
Pediatric Cardiac Ward K4 ........................................ 4
Heart surgery ....................................................... 5
Pediatric Intensive Care Unit K9 ............................... 8
Catheterization laboratory ...................................... 10
Cardiac patients according to their hospital districts in 2016 11
Cardiac outpatient care ......................................... 12
New in 2016 .......................................................... 13
Research work ..................................................... 17
Summary ............................................................. 20

For pediatric cardiological patients, the most usual diseases are congenital structural heart defects, arrhythmia and myocardium-related diseases such as myocarditis and cardiomyopathies. Heart surgery, catheterizations and heart transplantations for children and youth are centralized nationally to the Children's Hospital (Helsinki).

Pediatric Cardiac Ward K4 is a pediatric cardiac ward with 14 beds, six of which are intended for intensive monitoring. Patients are admitted to the ward for cardiac catheterizations and heart surgeries. Additionally, patients are admitted to the ward for medical examinations and establishment of medication. One to two pediatric cardiologists work on the ward as well as a pediatric resident, 30 nurses and one ward secretary. Heart surgeons act as consultants on the ward.

At the operating unit one operating room is allocated for open heart surgery and equipped with mobile angiography device for hybrid procedures (surgery requiring perioperative angiography). The pediatric cardiac surgical team consists of four cardiac surgeons, ten cardiac anesthesiologists, four perfusion nurses, and several nurses trained for pediatric cardiac surgical care. This team (with pediatric surgeons) also performs all pediatric organ transplantations in Finland.

The Pediatric Intensive Care Unit K9 is a heavy mixed pediatric intensive care unit with 12 beds. The majority of patients have undergone cardiac surgeries or require intensive care for congenital cardiac disease. Cardiac patients account for two thirds of the unit’s Therapeutic Intervention Score (TISS).

In the catheterization laboratory, diagnostic hemodynamic and angiographic examinations are performed as well as interventional catheterizations, electrophysiological examinations, arrhythmia ablation treatments and endocardial pacemaker installations. Transesophageal echocardiographic and electrophyslogic examinations are also performed under anesthesia. In the catheterization laboratory at a time there are always two pediatric cardiologists as well as two catheterization registered nurses, an anesthesiologist and anesthetic nurse.

Pediatric cardiac outpatient care is carried out in the Cardiac Outpatient Unit (three receptions, five days a week), in Children’s Hospital Pediatric Outpatient Clinic (one reception, three days a week) and in Jorvi Hospital Pediatric Outpatient Clinic (one reception, three days a week). A fetal cardiac outpatient clinic is at the Cardiac Outpatient Unit twice a week. Cardiology consultations for the wards and other subspeciality outpatient clinics are conducted daily, and a cardiology consultant also works in the heart operating room as well as in K9 and in Neonatal Intensive Care Unit K7. Six pediatric cardiologists work at the outpatient clinics and perform the consultations and eight registered nurses work at the Cardiac Outpatient Unit.

Training to nursing and medical students is provided to a considerable extent in the unit, and active scientific research is also performed.
Pediatric Cardiac Ward K4

The ward treats patients who have arrived to the hospital for catheterizations, surgeries, medical examinations, and medication, as well as patients who are recovering from catheterizations and heart surgery. In 2015, a job rotation began between nurses from Pediatric Intensive Care Unit K9 and Pediatric Cardiac Ward K4, and in 2016 a rotation began between ward K4 and Neonatal and Infant Surgery Ward K6. The job rotation is planned from the perspective of the heart child process and from the perspective of functional know-how while also keeping the processes of the new Children’s Hospital in mind. The most essential part of the job rotation is widening the range of expertise, obtaining new information and skills, and strengthening cooperation. Job rotation between the units will continue systematically in the future.

The ward’s occupancy rates and the number of treatment days have decreased significantly in 2016. This is partly due to the decreased number of heart surgeries and partly due to the fact that day visits (e.g., MRI and CT scans performed in general anesthesia, and tooth and ear procedures) now take place in the day hospital since it is now open for longer.

<table>
<thead>
<tr>
<th>Pediatric cardiac ward K4</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>In-patient periods (n)</td>
<td>1143</td>
<td>1028</td>
<td>1025</td>
<td>1046</td>
<td>1062</td>
<td>949</td>
</tr>
<tr>
<td>In-patient days (n)</td>
<td>4927</td>
<td>4616</td>
<td>5040</td>
<td>4688</td>
<td>4786</td>
<td>2934</td>
</tr>
<tr>
<td>Average hospital stay (days)</td>
<td>4.27</td>
<td>4.46</td>
<td>4.9</td>
<td>4.44</td>
<td>4.46</td>
<td>3.78</td>
</tr>
<tr>
<td>Average net occupancy rate (%)</td>
<td>68</td>
<td>66</td>
<td>72</td>
<td>64</td>
<td>69</td>
<td>57</td>
</tr>
</tbody>
</table>

Table 1. Total number of Cardiac ward K4’s treatment periods, treatment days, hospital stay and net occupancy rate during 2011–2016.

Heart surgery

Pediatric cardiac and transplantation surgery in Finland is centralized at the Children’s Hospital in Helsinki. In addition, approximately 5 to 10 heart operations are performed on Estonian patients at the Children’s Hospital annually. The annual level of approximately 300 operations became established already 25 years ago. In the following 10 years, the current wide spectrum of procedures and good results were achieved through general and local development. The percentage of newborn patients (approx. 25%) and repeat surgeries (approx. 30%) have also remained constant. In 2016, the operative mortality rate in heart surgeries was 1%.

Our aim is to correct any heart defects as early as possible and as completely as possible to achieve the usual age-appropriate heart status while also taking the child’s health status into consideration. Currently, the average age of operated patients is 2.4 years. The proportion of children under the age of one year is approximately 55%. The proportion of repeat surgeries is expected to stay constant because some defects need to be repaired in several stages either due to the child’s growth or the nature of the defect. The long-term prognosis of pediatric patients undergoing heart surgery in Finland is good (Figure 4).

The following figures depict the key numbers of our operations.

Figure 1. Open and closed heart surgeries at the Children’s Hospital annually from 2010 to 2016.
Figure 2. Operated newborn and infant patients from 2010 to 2016.

Figure 3. Operative mortality rate development from 2010 to 2016, all patients.

Figure 4. Late follow-up results of all children operated in Finland 1953–2009 of childhood age (< 15 years), 13 876 operations on 10 964 children. Follow-up comprehensiveness 98 %. (Raissadati A, Nieminen H, Jokinen E, Sairanen H. Progress in Late Results Among Pediatric Cardiac Surgery Patients: A Population-Based Six-Decade Study with 98 % Follow-Up. Circulation 131(4): 347–53, 2015).
Pediatric Intensive Care Unit K9

The Pediatric Intensive Care Unit holds 12 beds. The Pediatric Intensive Care Unit K9 is a so-called heavy pediatric intensive care unit where a significant portion of the patients are heart surgery patients, or patients suffering from cardiac insufficiency or arrhythmia. These patients produce two thirds of the unit’s Therapeutic Intervention Score (TISS).

Figure 5. Total number of patients treated in the Pediatric Intensive Care Unit K9 and the numbers of heart surgery patients, cardiological patients and cardiac transplantation patients from 2012 to 2016.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart surgery patients</td>
<td>49</td>
<td>56</td>
<td>55</td>
<td>57</td>
<td>48</td>
</tr>
<tr>
<td>Cardiological patients</td>
<td>15</td>
<td>14</td>
<td>17</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>Heart transplantation patients</td>
<td>0</td>
<td>3</td>
<td>3</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Others</td>
<td>36</td>
<td>27</td>
<td>25</td>
<td>26</td>
<td>39</td>
</tr>
</tbody>
</table>

Table 2. Distribution of Therapeutic Intervention Scores (TISS) at the Intensive Care Unit K9 during 2012–2016.

Figure 6. Length of stay in the Intensive Care Unit K9: total number of patients (Hoidetut potilaat) and the numbers of cardiac surgical patients (Sydänkirurgiset potilaat), cardiological patients (Kardiologiset potilaat) and cardiac transplantation patients (Sydäntransplantotopilaat) during 2012–2016.
Catheterization laboratory

All invasive pediatric cardiology in Finland – i.e. heart catheterizations – is centralized to the Children’s Hospital, Helsinki University Hospital. These procedures comprise diagnostic hemodynamic and angiographic examinations, interventional catheterizations, electrophysiological examinations and arrhythmia ablation treatments as well as endocardial pacemaker installations. Additionally, pre- and post-operative cardiac catheterizations are performed on Estonian patients annually (about 5–10). In the figure below, the key figures describing procedures from the years 2010–2016 are presented.

Cardiac patients according to their hospital districts in 2016

Figure 7. Total invasive procedures performed in the cardiac catheterization laboratory at the Children’s hospital from 2010 to 2016.

Figure 8. Distribution of treatment days of cardiac and heart surgery patients in HUH Children and Adolescents according to hospital districts in 2016.
Cardiac outpatient care

Pediatric cardiologic outpatient visits take place in three locations: Cardiac Outpatient Clinic at the Children’s Hospital (Helsinki), Pediatric Outpatient Clinic at the Children’s Hospital (Helsinki), and Jorvi Hospital Pediatric Outpatient Clinic. The fetal cardiac outpatient clinic takes place at the Cardiac Outpatient Clinic two days a week. Cardiologist consultation services are provided for all outpatient clinics, hospital wards, intensive care units K7 and K9, and for the OR.

In 2015, the Fetomaternal Medical Center began holding case meetings every other week. In these meetings, a multiprofessional team discusses patients who have a prenatal diagnosis of structural congenital anomalies. The meetings are partaken by specialists in perinatology, neonatology, pediatric surgery, pediatric neurology, and pediatric cardiology.

In 2015, the Fetomaternal Medical Center began holding case meetings every other week. In these meetings, a multiprofessional team discusses patients who have a prenatal diagnosis of structural congenital anomalies. The meetings are partaken by specialists in perinatology, neonatology, pediatric surgery, pediatric neurology, and pediatric cardiology.

Figure 9. Total numbers of patients: pediatric cardiology outpatient visits (blue), cardiology consultations (orange) and fetal cardiac visits (grey) during 2010–2016.

Figure 10. Total number of non-invasive examinations performed by pediatric cardiologists during 2010–2016: exercise tests (light blue), 24-hour ECG-recording (orange), event monitor (grey), pacemaker control (yellow), transthoracic echocardiography (dark blue).

New in 2016

Rare Cardiac Diseases Programme

The Rare Diseases Center (HAKE) was founded within HUS in 2015. Rare cardiac diseases have been a part of the HAKE programme of HUH Children and Adolescents since the beginning of 2016 when Markku Mäkijärvi, Chief Medical Officer of HUS, validated the HUH HAKE Rare Cardiac Diseases Programme application. Head of Department Jaana Pihkala was appointed as programme director. The programme is aimed at strengthening the networks of professionals who have experience in rare diseases and bringing patients’ experiences into the development process for better care.

The pediatric cardiology team has participated in the planning and development of HAKE. In 2016, the programme only covered congenital heart defects, but it is intended to expand to cover all rare heart diseases that manifest in childhood or in adulthood.

In June 2016, HUS’s Rare Cardiac Diseases Programme applied for a membership in the ERN’s (European Reference Network) GUARD-Heart, a network of experts in rare cardiac diseases. The programme was accepted for the application in all aspects of the network, which consists of rare
familial electrical heart diseases in adults, rare familial electrical heart diseases in children, and cardiomyopathies in adults and children (Figure 11). For 2017, our aim is to include congenital heart defects as well. ERN will offer services and co-operation to the patients, patient organizations, and professionals. The network also provides possibilities for developing patient registers and research.

Pediatric cardiologists have also participated in the development of the net portal Terveyskylä.fi [Health Village] and its sub portals Lastentalo.fi [Children’s House] (upcoming) and Harvinais-sairaudet.fi [Rare Diseases]. These portals provide digital services and information for both patients and professionals. The team has, for example, produced material to the pages concerning rare cardiac diseases. Other university hospitals also participate in the development of these portals.

Figure 11. Members of the ERN’s GUARD-Heart and their areas of expertise.

Intensive Unit Indicators

The intensive unit’s team has created indicators to measure the effectiveness of treatment. We began using these indicators in 2016. The indicators have been used to measure waiting list (figure 12) and treatment times of patients, surgery cancellations due to patients or resources, and patient transportations from intensive care to regular wards. Also, we have monitored the efficient use of the cardiac operation room. Figure 13 shows the number of heart surgeries and cancellations in 2015 and 2016. The figure shows, for example, that the number of cancellations due to resources has decreased.

Figure 12. Total number of patients on the waiting list for catheterization, transesophageal echocardiogram, and cardiac surgery in 2016.
### Research work


Summary

During 2016, 203 open heart surgeries and 79 closed heart surgeries were performed in the Children’s Hospital. 74 (26%) of the surgeries were performed on children under the age of one month, and 167 (54.2%) on children under the age of 12 months, in total. Four heart transplants were performed. The large share of infants and demanding cardiac surgery place special challenges on surgical care as well as on intensive care and ward care. This is also illustrated by the fact that the share of heart patients in intensive care unit according to Therapeutic Intervention Scoring System (TISS) points has in recent years been in the approximate two thirds. The total number of reoperations is significant: more than 30 % of all operations. This frequently derives from the fact that the patient’s heart defect is initially planned for correction in several stages: e.g. as a series of three-stage palliative operations for a univentricular heart defect. Occasionally residual defects require a reoperation.

Surgical mortality in Finland in recent years has been below the average European level – last year in the range of one per cent, regardless of the fact that even the most complicated defects have come within the sphere of surgical treatment. The late prognosis of heart children who have been operated on is monitored with comprehensive follow-up research study. The long-term follow-up results of patients who have been treated surgically during the years 1953–2009 published recently (Raisasadat et. al Circulation 2015) reflect procedures performed with early perfusion and surgical techniques. It does appear that with the modern techniques, the long-term results from operations performed between 1990 and 2010 have improved.

Catheter procedures in the treatment of congenital heart defects were initiated during the 1960s. The quality and total number of procedures and instruments have developed rapidly, and these days within the sphere of catheter techniques-based treatment are even preterm infants. Currently in a large part of all the pediatric cardiology units, interventional catheterizations form the biggest group of catheterization procedures. At the Children’s Hospital (Helsinki), these totaled 185 last year.

Some diagnostic catheterizations are also conducted in interventional readiness. The number of invasive electrophysiological examinations and catheter ablations for the diagnostics and treatment of arrhythmia has constantly increased in recent years: their total number in 2016 was 90. The indications for catheter procedures are the same as for the surgical treatment of similar defects. The benefits of catheterization procedures compared to surgery are rapid recovery and smaller cosmetic detriment. Cost-wise as well, a catheter procedure is almost always more economical than the corresponding surgical operation. In addition, endocardial pacemaker installations and transesophageal echocardiograms are actively performed in the heart catheterization laboratory.

The net loading of the pediatric cardiologic ward K4 is continuously in the range of 60 %. Most of the patients come from outside the HUS catchment area for highly specialized medical care, which sets exceptional requirements on the arrangements. Approximately 4500 patients visit the pediatric cardiologist’s reception per year, and echocardiographic examinations are performed to the total of almost 6000 annually. Some of the patients are put under general anesthesia for the examinations, which sets exceptional requirements for the appointments.

A fetal heart clinic operates at the Cardiac outpatient unit in Children’s hospital two days a week. It employs three pediatric cardiologists who are specialised in fetal cardiology. The fetal cardiac clinic works closely together with the Fetomater nal Medical Center in Women’s Hospital. The total number of special examinations, such as exercise tests, pacemaker testing and Holter recordings, is high, which also imposes requirements on the special expertise of the care staff. The total number of visits to outpatient clinics has remained almost the same in recent years, and no significant changes are being planned with regard to the next few years.

National net portals Lastentalo.fi and Harvinais sairaudet.fi provide digital services and information for both patients and professionals. For pediatric cardiology, the contents of these pages and co-operation with patient organizations is actively developed together with other university hospitals. The Rare Cardiac Diseases programme will be approved as a part of European Reference Network that offers services and co-operation to patients, patient organizations, and professionals. The network also provides possibilities for developing patient registries and research.
Pediatric Cardiac Ward K4
Pediatric Intensive Care Unit K9
Operating and Anesthesia Unit
Cardiac Outpatient Unit

The Children’s Hospital (Helsinki)
Street address: Stenbäckinkatu 11, Helsinki
Postal address: P.O. Box 281,
FI-00029 HUS
Telephone: +358 (0)9 4711
www.hus.fi