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Background information on epilepsy

Epilepsy is a tendency toward recurrent, unprovoked seizures. The illness may be associated with other brain disorders, including learning disorders. Approximately 30,000 people in Finland have epilepsy. The prevalence under the age of 15 years is approximately 0.7/1000. The causes and manifestations of epilepsy are highly varied. Some children and adolescents have benign forms of epilepsy, which are either self-limiting or respond well to medication. One fourth have drug-resistant forms of epilepsy. The majority of difficult-to-treat epilepsies are characterized by onset in childhood or adolescence.

Therapy is based on accurate epilepsy syndrome diagnosis and determination of the underlying causes. These include many rare diseases. Inappropriate or excessive medication is not effective against seizures and may further impair functionality. Drug-resistant epilepsy is associated with increased risk of cognitive disorders, psychiatric comorbidity, accidents and death.

Abbreviations used

Children's epilepsy unit = Children's Epilepsy Ward L11 and video EEG and outpatient clinic
EEG = Electroencephalography
MEG = magnetoencephalography, a technique for mapping brain activity by recording magnetic fields produced by the brain
PET = positron emission tomography, a technique for measuring glucose metabolism in the brain
SPECT = single-photon emission computed tomography, a technique for measuring blood flow in brain tissue
Stereo-EEG = video EEG performed with stereotactically placed depth electrodes, used in planning epilepsy surgery
Video-EEG = an examination lasting several hours or days, in which EEG and video of the patient's symptoms are simultaneously recorded
VNS = vagus nerve stimulator, a treatment method based on the stimulation of the vagus nerve
HUS = Helsinki and Uusimaa Hospital District
HUH = Helsinki University Hospital
Children’s epilepsy unit

The children’s epilepsy unit includes the epilepsy ward L11, video-EEG and outpatient clinic. It is Finland’s largest unit specializing in the diagnostics, treatment and differential diagnostics of pediatric and adolescent epilepsy. Epilepsy surgery in Finland is centralized in two hospitals, Helsinki University Hospital (HUH) and Kuopio University Hospital, by virtue of Government Degree 336/2011 Section 5 (6 April 2011). HUH has the most extensive experience of epilepsy surgery in children and adolescents, of extratemporal operations and examinations carried out with intracranial depth electrodes. In 2016, nearly one third of the billed costs for patient care were attributed to hospitals outside the HUS catchment area (Figure 1).

The task of the children’s epilepsy unit is to perform diagnostics and treatment for children and adolescents with epilepsy within the HUS catchment area, in collaboration with the general pediatric neurology outpatient clinics (the Children’s Castle Hospital, Jorvi Hospital, Peijas Hospital, Hyvinkää Hospital). In addition, it provides nation-wide consultations on severe epilepsies in children and adolescents, pre-operative assessments and epilepsy surgery. The unit engages in international clinical and research cooperation regarding surgical and non-surgical treatments of severe and rare epileptic syndromes.

The epilepsy ward L11 and the video-EEG unit manage the care of all children and adolescents from all over the country who are undergoing a pre-operative assessment due to severe epilepsy. Post-operative care takes place at L11 from the first post-operative day. In addition, ward L11 manages patients with epilepsy who require inpatient care for a severe seizures or demanding examinations and treatments (onset of diatets, immunological treatments). All children and adolescents with drug-resistant epilepsies within the HUH’s specialized area of responsibility, and their treatment consultations, have been centralized in the children’s epilepsy unit. The video-EEG unit carries out all video-EEG examinations required for children and adults under HUH care; at least one third of these examinations are pre-operative assessments of severe epilepsy.

The treatment of severe epilepsy is multi-professional teamwork. The treatment of children and adolescents with epilepsy involves pediatric neurologists, neuropsychologists, neuroradiologists, neurosurgeons and nurses specialized in epilepsy (Figure 2). It also requires close collaboration with child and adolescent psychiatrists, paediatricians and nutritionists. The care of adult patients in video-EEG is managed in collaboration with HUH neurologists. All pre-operative assessments and recommendations are made by our joint epilepsy team. A psychiatrist is consulted when necessary.

Figure 1. Distribution (%) of billed costs by province attributed to in-patients at the epilepsy ward L11 and video-EEG in 2016. In addition, six patients were referred from Estonia.

Figure 2. Children’s epilepsy unit and the epilepsy surgery team at Helsinki University Hospital 2016

- Video-EEG (VEEG)
  3 monitoring beds,
  16-19 nurses with special training (minimum 1 year) for video-EEG,
  314 recordings in 2016: 116 >24 hours, 13 intracranial studies

- Epilepsy ward L11
  7 beds (one for polysomnography),
  13 nurses trained in pediatrics
  1260 admissions in 2016

- Outpatient clinic
  8 nurses (3 nurse specialists: vagal nerve stimulation, ketogenic diet, infantile epilepsy),
  Appr. 3500 visits in 2016

- Pediatric epileptologists 5 (2 docents): three trained in the US (18 months UCLA, 2x6 months Cleveland Clinic Foundation)

- Physicians in training
  One pediatric neurologist in research and epileptology training, one resident

- Epilepsy surgery team
  Pediatric neurology 3, neurology 3,
  neurophysiology 4, neuroradiology 3,
  neurosurgery 2-3, neuropathology 1,
  neuropsychology 4, nurse specialists 2

- National and international collaboration
  Kuopio University Hospital, Epilepsy Center
  Nordic epilepsy surgery teams
  Pediatric neurologists in Estonia
  ILAE pediatric epilepsy surgery task force
  E-epilepsy consortium, U-Task
The clinical guidelines for children and adolescents with epilepsy were defined in the 2013 Current Care Guidelines (http://www.kaypahoito.fi/web/kh/suositukset/suositus?id=eho50059), which were co-authored by two physicians from our unit. In addition, one of our physicians co-authored the 2016 update on Current Care Guidelines for prolonged epileptic seizure (http://www.kaypahoito.fi/web/kh/suositukset/suositus?id=hoi50059), which were co-authored www.kaypahoito.fi/web/kh/suositukset/suositus?id). The epilepsy unit has extensive expertise on orphan drugs, special permit drugs and immunological treatments used in severe epilepsies. Our unit has produced a care program for most rare forms of epilepsy.

Ketogenic diet

The efficacy of the ketogenic diet in the treatment of epilepsy was discovered as early as the 1920s, although it has been taken into more extensive use some 20 years ago. The ketogenic diet is based on obtaining energy mainly from fat and strict restriction of carbohydrates. According to the scientific literature, 40–50% of children benefit from the diet; a benefit is considered significant if the number of seizures is reduced by 50%. Serious complications are rare.

The use of ketogenic diets in the epilepsy unit increased in 2008, when physicians, nurses and nutritionists were provided with training in the dietary treatment of epilepsy and attended Nordic meetings focusing on the diet. Our own dietary guidelines were produced in 2010 and updated in 2017.

<table>
<thead>
<tr>
<th>Year</th>
<th>Started (median starting age range of variation)</th>
<th>Over 50% reduction in seizures</th>
<th>Serious adverse effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014</td>
<td>8 (4.5 yrs; 1-17 yrs)</td>
<td>4 (50 %)</td>
<td>0</td>
</tr>
<tr>
<td>2015</td>
<td>11 (6.2 yrs; 0.5-14 yrs)</td>
<td>5 (45%)</td>
<td>0</td>
</tr>
<tr>
<td>2016</td>
<td>13 (6.9 yrs; 0.8-14.9 yrs)</td>
<td>7 (55%)</td>
<td>1 (pancreatitis)</td>
</tr>
</tbody>
</table>

Table 1. Patients who were started on ketogenic diet in 2014 through 2016.
France and Italy currently have the leading expertise in stereo-EEG; in those countries, the method has been in use for decades. The neurophysiologists of our epilepsy surgery team participate annually in stereo-EEG training courses organized by three French and one Canadian epilepsy surgery centers (Marseille, Lyon, Grenoble, Montreal) covering different brain areas. The teaching includes theory and practical training in the planning, execution and interpretation of stereo-EEG examinations. When treating patients, we have been able to consult with three French epilepsy surgery and stereo-EEG specialists (in 2013 with Professor Philippe Kahnane, Grenoble, and in 2015 with Professor Patrick Chauvel, Marseille/Cleveland Clinic Foundation, 2016 professor Fabrice Bartolomei, Marseille).

We participate in Nordic and European collaboration to develop the care of epilepsy surgery patients. The common 2-day conference of the epilepsy surgery teams of Sweden, Norway, Denmark and Finland is organized every two years, latest in Helsinki in August 2016. We participate in the monthly teleconferences organized by E-epilepsy (European pilot network for epilepsy surgery) and in pediatric epilepsy surgery workshops (U-Task) 3–4 times per year. We also have regular teleconferences with the epilepsy surgery team of Kuopio University Hospital.

HUH has the most extensive experience in Finland of the surgical treatment of drug-resistant epilepsy in children and adolescents. By the end of 2016, 482 therapeutic epilepsy surgeries had been carried out, 12% of which were second operations. Of these, 305 (63%) were performed on patients under the age of 16 and 125 (26%) on patients under the age of 7 (Graph 2).

By the end of 2016, 18 pediatric patients from Estonia had been referred to us for pre-operative assessments. Three Estonian patients had epilepsy surgery in 2016.

Most of the studies reporting on the outcomes of operations on children and adolescents are based on the cohorts of single hospitals, probably with relatively poor representation of the general population. Our results can best be compared with a national prospective and longitudinal study carried out in Sweden (Edelvik et al, Neurology 2013; 81:1244–1251), which reported that 53% of the 88 children and adolescents operated on were seizure-free during the two-year follow-up period. Correspondingly, 52% of the patients operated on at HUH were seizure-free for at least two years following the surgery (Graph 3).

It should be noted that a smaller proportion of the patients underwent temporal lobe resections at HUH (24%) than in Sweden (43%), which by default decreases the likelihood of seizure-free outcomes.
The palliative operations in Graph 3 included 30 corpus callosotomies. At two years after surgery, over 50% seizure reduction was present in 13 patients (43%). Our results are comparable with those reported from Sweden. Stigsdotter-Broman et al. (Epilepsia, 55:316–321, 2014) observed over 50% seizure reduction of two years postoperatively in 12/31 patients (39%). The remaining palliative treatments in Graph 3 were four procedures targeting hypothalamic hamartomas and one multiple subpial transection.

Surgical complications at HUH (Table 2) can also be compared with studies conducted in Sweden: in the 865 operations performed in 1996–2010, complications occurred in 10.5% of patients (Bjellvi et al. J Neurosurg 122:519–525, 2015).

![Graph 3. Seizure free outcomes at two years postoperatively in patients who had surgery at HUH under age 16 years in 1992 through 2014. For those patients who had more than one surgery under age 16 years, the reported results refer to the latest operation.](image-url)

<table>
<thead>
<tr>
<th>Adverse effect</th>
<th>1991-2015</th>
<th>2015</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual field defect (hemianopia or inferior quadrantanopia)</td>
<td>10 (2.2%)</td>
<td></td>
<td>In one case probably present prior to surgery, not examined</td>
</tr>
<tr>
<td>Shunt</td>
<td>8 (2.0%)</td>
<td></td>
<td>All hemispherotomies</td>
</tr>
<tr>
<td>Hemiparesis</td>
<td>9 (2.0%)</td>
<td></td>
<td>Two very mild</td>
</tr>
<tr>
<td>Verbal dysfunction</td>
<td>9 (2.0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychiatric symptoms</td>
<td>4 (1.0%)</td>
<td></td>
<td>All adults</td>
</tr>
<tr>
<td>Visual dysfunction</td>
<td>1 (0.2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impairment of memory</td>
<td>1 (0.2%)</td>
<td></td>
<td>Predicted</td>
</tr>
<tr>
<td>Hypothalamic dysfunction</td>
<td>1 (0.2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bone infection</td>
<td>1 (0.2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cyst formation</td>
<td>1 (0.2%)</td>
<td></td>
<td>Required revision operation</td>
</tr>
<tr>
<td>Cranial nerve paresis</td>
<td>1 (0.2%)</td>
<td>1 (3%)</td>
<td>Associated with functional hemispherectomy</td>
</tr>
<tr>
<td>Total</td>
<td>44 (9.7%)</td>
<td>1 (3%)</td>
<td></td>
</tr>
</tbody>
</table>

Table 2. The adverse effects of surgical treatment still present at 6 months after surgery in all patients operated on at HUH (including adults).
Vagus nerve stimulation

A vagus nerve stimulator (VNS) can be used in the treatment of severe epilepsy together with drug therapies, in order to alleviate symptoms in patients who are ineligible for resective surgery. A neurosurgeon implants the VNS under the pectoral muscle, and the wires are coiled around the vagus nerve in the neck. The device sends electrical stimuli through the nerve, and can be adjusted using a sensor and small handheld computer through the skin. Based on controlled studies, VNS reduces the number of seizures in approximately half of all patients by at least 50% which is considered a significant benefit. The treatment response is difficult to predict at individual level. Adverse effects are usually rare and manageable by adjusting the electric current.

VNS therapies were started at HUH in 1998. By the end of 2016, a VNS had been implanted in 80 children or adolescents. Of the 46 patients who had VNS implantations in 2011 through 2016, 20 have had significant benefit (43%). In one case, the stimulator had to be removed due to an infection. There were no other major adverse effects.

Rare epilepsies and epileptic syndromes

Many severe forms of epilepsy belong to the group of rare diseases and to conditions known as epileptic encephalopathies, defined as epileptic activity causing or exacerbating cognitive dysfunction, sometimes leading to intellectual disability. In addition to prompt diagnostics and correctly targeted treatment, these patients also require monitoring and care by a multi-professional team and experts in a number of specialties. Some examples are presented below.

Infantile spasm syndrome is a severe form of epilepsy with onset in early infancy; when untreated, this condition may lead to a permanent arrest of the child's development and learning. Approximately 25 patients present annually with this syndrome in Finland. The underlying cause is the key determinant for prognosis, but delayed diagnosis and treatment also lead to learning disability even in those infants whose prognosis would be excellent with appropriate treatment. The first-line drugs are vigabatrin and ACTH, both of which are used almost exclusively for this specific syndrome. Our treatment protocol updated in 2016 is based on both our own and international research as well as international treatment guidelines. Tables 3–4 present treatment outcomes at two years of age over a ten-year period in 1997–2006 and over a shorter period in 2014–2016 for children treated at the epilepsy unit.

Epileptic encephalopathy with electric status epilepticus during sleep (CSWS syndrome) is a form of epilepsy which is extremely difficult to treat and causes learning difficulties in children of pre-school and primary school age. EEG monitoring typically reveals continuous spikes and waves during sleep. The syndrome is difficult to diagnose and no accurate data are available on its prevalence. The children's epilepsy unit has conducted the largest clinical follow-up study to date on patients with this syndrome (Liukkonen et al. Epilepsia 2010: 51: 2023–2032). The study included 32 patients treated at the epilepsy unit. The electric status during sleep was stopped by drug therapy in half of the patients. One third of them regained their previous intellectual capacity. The children's epilepsy unit has also published the first experience of surgical treatment of the syndrome (Peltola et al. Epilepsia 2011; 52:602–609). Based on our results and later research carried out elsewhere, surgery may significantly benefit some drug resistant patients with a structural abnormality as the underlying cause. The children's epilepsy unit is currently developing better EEG methods for diagnosing CSWS.

<table>
<thead>
<tr>
<th>Year</th>
<th>Underlying cause</th>
<th>New patients</th>
<th>Seizure-free latest by 3 months after treatment onset</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014-2015</td>
<td>Identified etiology</td>
<td>16</td>
<td>10 (63 %)</td>
</tr>
<tr>
<td></td>
<td>Unknown etiology</td>
<td>4</td>
<td>4 (100 %)</td>
</tr>
<tr>
<td>2016</td>
<td>Identified etiology</td>
<td>6</td>
<td>2 (33 %)</td>
</tr>
<tr>
<td></td>
<td>Unknown etiology</td>
<td>8</td>
<td>6 (75 %)</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>34</td>
<td>22 (65 %)</td>
</tr>
</tbody>
</table>


<table>
<thead>
<tr>
<th>Underlying cause</th>
<th>Seizure-free at the age of 2 years</th>
<th>Normal development at the age of 2 years</th>
<th>Mortality under the age of 2 years</th>
<th>Data not available</th>
<th>Patients total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identified #</td>
<td>14 (41 %)</td>
<td>6 (15 %)</td>
<td>5 (15 %)</td>
<td>2 (6 %)</td>
<td>34 (100 %)</td>
</tr>
<tr>
<td>Unknown</td>
<td>19 (100 %)</td>
<td>17 (89 %)</td>
<td>0</td>
<td>0</td>
<td>19 (100 %)</td>
</tr>
<tr>
<td>Total</td>
<td>33 (62 %)</td>
<td>23 (43 %)</td>
<td>5 (9 %)</td>
<td>2 (4 %)</td>
<td>53 (100 %)</td>
</tr>
</tbody>
</table>

Table 3. Treatment outcomes in patients with infantile spasms by the age of two years (HUH catchment area population-based 1997–2006, all infants treated at the epilepsy unit) # 28 had structural, three genetic and three metabolic underlying causes.
syndrome, in collaboration with the pediatric clinical neurophysiology unit (Peltola et al. Clinical Neurophysiology 2012; 123:1294–12 and 2014; 125:1639–1646). We participate in Rescue ESES, a randomized controlled multicenter European study comparing different treatments (http://www.isrctn.com/ISRCTN42686094). Our treatment program for CSWS is based on both our own previous experience and other available scientific evidence. In 2016, we had 48 patients with CSWS in our care.

Dravet syndrome is the most commonly recognized form of genetic epilepsy. Prevalence estimates indicate that 3–4 patients develop the condition each year in Finland. Typical symptoms include prolonged epileptic seizures (status epilepticus) provoked by fever and infection with onset in the first year of life, followed by polymorphic seizures and some level of cognitive dysfunction in the following years. An early diagnosis is important for starting appropriate drug treatment. The best response is usually achieved with the orphan medicine stiripentol (class B evidence from a randomized controlled trial) combined with other suitable drugs; this combination stops episodes of epileptic status in nearly all patients. Some commonly used antiepileptic drugs may exacerbate the symptoms.

By the end of 2016 the children’s epilepsy unit has been involved in the care of a total of 44 patients, of whom 37 (84%) were found to have the most common genetic abnormality associated with the syndrome, an SCN1A mutation. The SCN1A gene regulates the sodium channels within the neuronal membranes. Some other type of genetic etiology was identified in three patients and in four patients, genetic etiology remains unidentified. We have published research on Dravet syndrome (Gally ym. Epilepsia 2013; 54:1577-85) and have been involved in the multicenter study commissioned by the European Medicines Agency (EMEA) on the adverse effects of stiripentol. The epilepsy unit also participates in the Nordic working group which is developing treatment guidelines for Dravet syndrome. During 2016, we had a total of 22 patients in our care. Dravet syndrome was newly diagnosed in seven patients in 2014-2016 (Table 5).

### Table 5. New Dravet syndrome patients in 2014-2016.

<table>
<thead>
<tr>
<th>Key indicators/year</th>
<th>2014–2015</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of new Dravet syndrome diagnoses</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Identified genetic etiology (SCN1A)</td>
<td>5 (6)</td>
<td>1 (1)</td>
</tr>
<tr>
<td>Age less than 18 months at diagnosis</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Stiripentol therapy in use</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Patients with epileptic status after diagnosis</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

Others genetic epilepsies. During 2014–2016, the children’s epilepsy unit identified an etiological diagnosis by gene panels for 16 patients with severe forms of epilepsy (one third of those examined) and by conventional sequencing methods for two patients (Dravet syndrome patients described in Table 5 are not included). In addition, as part of our research project, we have identified new genes associated with severe epilepsy (Muona M ym. Am J Hum Genet 2016;99:683-94; Anttonen AK ym. Neurology 2015; 85:306-15) and determined a genetic diagnosis for 26 children or families. We collaborate with EuroEpinomics, a research consortium which identified new epilepsy genes and produced data on their phenotypes (Syrbe S ym.Nat Genet 2015;47:393-9; EuroEPINOMICS-RES Consortium et al. Am J Hum Genet. 2014;95:580-70; Sulis A ym. Am J Hum Genet 2013;93:967-75; Lemke JT ym.Nat Genet 2013;45:1067-72). We participate in the large international project (EP25, launched in 2016) which is looking for new genetic causes of epilepsy.

Tuberous sclerosis is a typical rare disease (incidence rate 17:100 000) caused by a gene defect. The symptoms include severe epilepsy (commonly infantile spasms), learning disabilities of varying degrees, and abnormalities in many other organs, such as renal angiomylipomas, rhabdomyomas, skin abnormalities and ocular disorders. Patients need the expertise of a multi-professional team. International guidelines are available for follow-up, with the purpose of promoting early diagnosis of dangerous manifestations (e.g. infantile spasms, growing giant cell astrocytomas and kidney tumors) before they lead to complications. In 2016, we have further streamlined the follow-up. We cared for 25 patients with tuberous sclerosis, of whom three infants were followed with repeated EEG-studies due to the risk of infantile spasms.

Rasmussen encephalitis is an autoimmune brain disease with typical onset at pre-school or primary school age. The symptoms include extremely drug-resistant epilepsy and gradually developing neurological deficits, most typically hemiparesis. The progression of neurological deficits can be delayed by immunological treatments, which do not, however, alleviate the seizures in most patients. Seizure freedom can only be achieved by hemispherectomy, i.e. disconnecting all neural connections of one hemisphere. The incidence rate of Rasmussen encephalitis is estimated at 0.017: 100,000, which in Finland means a maximum of one patient per year.

By the end of 2016, the children’s epilepsy unit had treated 12 patients with Rasmussen encephalitis. Ten of our patients (83%) have received or are receiving immunological treatment (with the exception of one patient diagnosed in 1991 and another patient diagnosed at the age of 20 years). Nine patients were treated surgically (75%). Hemispherotomies were performed for seven patients (58%) all of whom are now seizure-free and have retained ambulation. Resective surgery was performed for two patients resulting in alleviation of the seizures.

Limbic encephalitis, characterized by a clearly elevated level of GAD antibodies, responds poorly to immunological therapies and causes severe epilepsy. We have treated four patients, three of whom have undergone a temporal lobectomy during adolescence. Surgical treatment significantly alleviated the epileptic seizures.
Ongoing research projects (contact persons)

- Outcome of pediatric epilepsy surgery and factors predicting outcome (Eija Gaily, Aki Laakso, Heta Leinonen)
- Localization of epileptic foci using mathematical signal processing methods (Leena Lauronen, Maria Pettola)
- Noninvasive localization of linguistic functions in children (Henri Lehtinen)
- Localization of epileptic foci by MEG (Ritva Paetau, Juha Wilenius)
- Developmental effects of prenatal antiepileptic drug exposure (Mari Videman, Sampsa Vanhatalo, Eija Gaily)
- Cognitive development of children exposed to antiepileptic drugs at age 6 years; European multicenter study (EURAP/NCEP) (coordinator Eija Gaily)
- Genetic epilepsies, EPI25 project (Tarja Linnankivi, Anna-Elina Lehesjoki)
- Early infantile epilepsies (Henna Jonsson, Tarja Linnankivi, Eija Gaily)
- Development of EEG diagnostics for CSWS epilepsy (Maria Pettola)
- A European multicenter study on the treatment of CSWS, coordinated by UMC Utrecht (Rescue ESES) (Liisa Metsähonkala)
- NOPRES: Nordic Prospective study of outcome of Rare patient groups after Epilepsy Surgery (Liisa Metsähonkala, Eija Gaily)
- A randomized, double-blind, placebo-controlled study to evaluate the efficacy and safety of sage-547 injection in the treatment of subjects with super-refractory status epilepticus (dos, Eija Gaily, dos, Tuula Lönnqvist, LT Kirsi Mikkonen)


Doctoral students: Henna Jonsson, Heta Leinonen, Henri Lehtinen

Nine original articles in peer reviewed scientific journals in 2016 were published by the physicians of the pediatric epilepsy unit. In addition, four chapters in Finnish and international textbooks on epilepsy and one review on infantile spasms in the Finnish medical Journal (Suomen Lääkärilehti) were produced.

Summary and future plans

The children’s epilepsy unit at HUH is Finland’s largest unit specializing in the diagnostics, treatment and demanding differential diagnostics of epilepsy in children and adolescents. The unit has the most extensive experience of epilepsy surgery in children and adolescents in Finland, particularly in extratemporal operations, examinations carried out with intracranial depth electrodes and rare forms of epilepsy with onset in early childhood. Our investigation methods and treatment outcomes correspond to high international standards.

The Epilepsy Unit is situated at the Children’s Castle Hospital, separately from other acute pediatric care. This creates a challenge, particularly during out-of-hours service. With the completion of the new children’s hospital in 2018, a new acute pediatric neurology ward will be established. The current three video-EEG recording rooms will be replaced by 4–5 rooms. Increased capacity will further improve diagnostics and treatment. We will also have better resources for responding to the still existing treatment gap for patients with surgically remediable severe epilepsies. Patient safety will be improved by the proximity with the pediatric ICU and pediatric wards as well as the pediatric neurosurgery and adult neurology departments. The video-EEG unit will also continue to serve adult neurological patients at HUH, and collaboration with neurologists treating epilepsy patients will be further increased.

Maintaining a high standard in epilepsy surgery and the treatment and documentation of rare diseases will require substantial further efforts from our unit. We will apply for a membership in the European Reference Network for Epilepsy (EpiCARE) established in 2017. We will continue the efforts to develop and coordinate treatment of rare, severe and complex epilepsies in Finland in collaboration with the Kuopio University Hospital epilepsy team, other Finnish interest groups, other European networks and international partners. Teleconferences will be started in 2017 with new partners such as the Marseille epilepsy team and Tallinn pediatric neurology.

In 2017, we will launch our quality control epilepsy registry, first piloting at HUH and then extending to include all patients treated for epilepsy at the Helsinki and Uusimaa Hospital District. The registry will improve measurement of the efficacy of epilepsy treatments and accumulate data for the development of treatments and scientific research. Once the registry is established at HUH, we hope to collaborate with other university hospitals in Finland to create a national epilepsy registry.

In a country like Finland, with its small population, the number of patients with rare diseases or those needing epilepsy surgery are relatively low compared to epilepsy centers in many other European countries and the United States. The continuing education of specialists in international centers is crucial to maintaining high-standard practices within the unit, as well as regular attendance at the most important international congresses and the production of educational materials in the field of epilepsy.