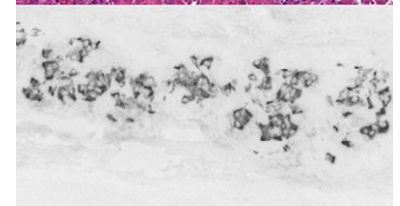
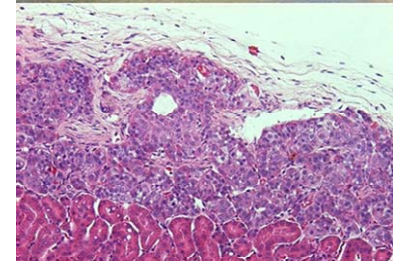
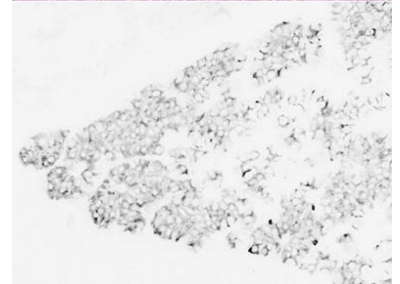
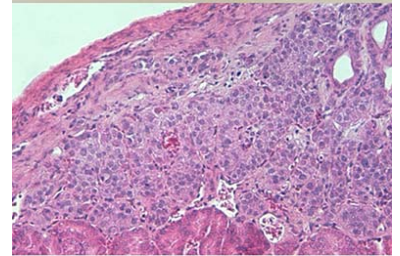


Annual report 2015

Children and diabetes
Päivi Miettinen



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Cover image: Insulin-producing cells differentiated from human stem cells (Prof. Timo Otonkoski Laboratory)

1. Pediatric Endocrinology Outpatient Clinic

The Pediatric Endocrinology Outpatient Clinic (ENDODIAB) provides outpatient and inpatient care for endocrinological disorders during childhood (including diabetes, with its rare forms) and consultations on endocrinological disorders for the entire Uusimaa region (Figure 1). In addition, it has national responsibility for training in the narrow speciality of children's endocrinology, provides training in children's endocrinology for central hospital pediatricians within the HUS area, physicians specializing in pediatrics, medical students and other health-care professionals, and performs research and development in its area of specialty.

The objective is to provide holistic care for patients and families, and to guarantee a high standard of care. Each patient has a designated doctor and nurse in charge of their personal care, enabling overall care for his or her family. ENDODIAB works in close collaboration with other pediatric units in the area.



Figure 1. Most patients at Jorvi and Children's Hospital diabetes clinics are referred from Espoo, Helsinki and Vantaa (red area) and they visit the clinic every 3–4 months. The number of patients from other municipalities may increase, owing to advances in digitalization and the resulting teleconsultations.

2. Diabetes care resources

In 2008, diabetes care for children and adolescents was centralized in the Helsinki Metropolitan Area to the pediatric outpatient clinics of Children's Hospital and Jorvi Hospital. Following this change, the care of around 150 children and adolescents (under the age of 16) with type 1 diabetes living in Vantaa and monitored by the Peijas Hospital Pediatric Outpatient Clinic was transferred to Jorvi Hospital, while those living in Kerava (approx. 40 patients) became patients of the Children's Hospital.

In 2015, the diabetes outpatient clinic at the Children's Hospital has been operated from the 6th floor of the Women's Hospital and the Jorvi unit in the Diabetes Center, on the same premises as adult diabetologists. The ward responsible for acute pediatric diabetology operated from the Women's Hospital until the summer of 2015, when it was moved to the Meilahti Tower Hospital Annex. Pediatric diabetes care at the Jorvi pediatric unit is provided on ward L1. At the moment, insulin pump treatments are started during the ward care within these units.

Staff resources:

1. At Jorvi, 1.1 pediatric endocrinologists and two pediatricians (diabetes care accounts for 30–70% of physicians' labor input) and a specializing diabetologist (EVAL; 80%), three diabetes nurses and a department secretary with a part-time role in the diabetes outpatient clinic. In addition, the unit works closely with social services, nutritionists and a rehabilitation instructor. A psychologist from the general pediatric psychiatric team is actively involved in the work of the diabetes team. Youth psychiatry consultations are referred to the regional outpatient clinics for examination, assessment and acute psychiatric care for adolescents (TAK clinics).
2. At the Children's Hospital, 3.2 pediatric endocrinologists and one specializing endocrinologist (diabetes care accounts for 60% of the physicians' labor input), one specializing diabetologist (100%) and two part-time professors with diabetes consultancy forming 10% of their labor input. There are 4.5 diabetes nurses, one part-time department secretary in addition to a nutritionist, social worker, children's psychologist/nurse (shared by the entire Children's Outpatient Clinic) and youth psychiatrist (shared by the entire Children's Outpatient Clinic and wards).

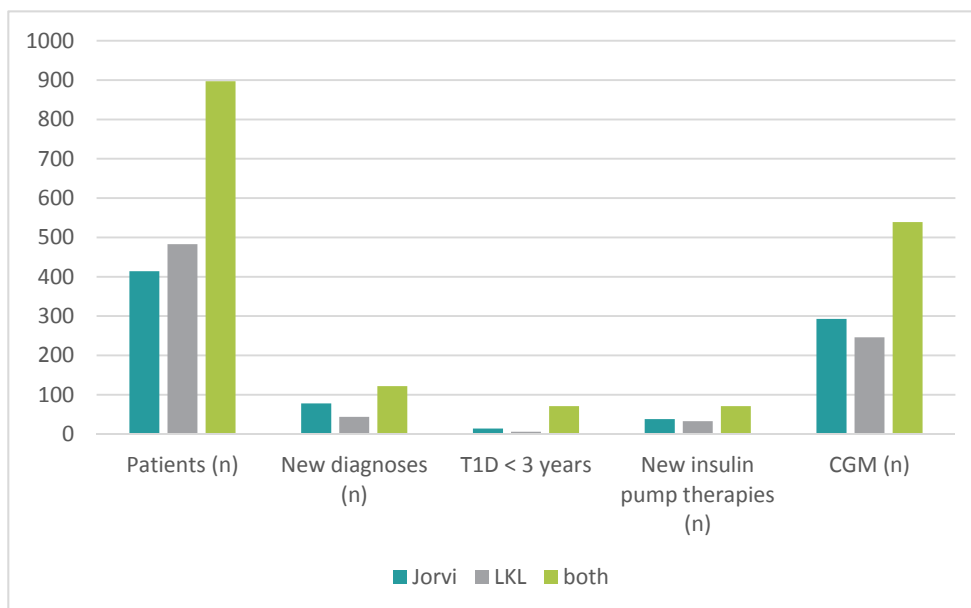
The Diabetes Outpatient Clinic provides a wide range of individual and group consultation for patients, their parents, medical students, specializing physicians and ward staff (departmental meetings). Group consultations for patients include annual theme weeks aimed at school-starters and evenings for families whose child has been recently diagnosed with diabetes. Recently diagnosed diabetics and their families are usually invited to two one-hour sessions with a physician, in addition to which they meet with a nutritionist and social worker and, in most cases, a youth psychiatrist. The child psychiatric team only meets with families if the recent diagnosis is expected to cause an acute crisis in the family; the future the aim is to develop care activities in a primarily pro-active direction.

3. Number of patients

In 2015, there were a total of 897 children and adolescents under monitoring (Figure 2). A small number of patients have been diagnosed with a condition other than T1 diabetes. These children and adolescents have either impaired glucose tolerance, Type 2 diabetes or cases of MODY diabetes, which have been diagnosed thanks to improved DNA diagnostics. The share of the above patient groups among all diabetics under treatment is only a few percent.

The incidence of diabetes has been increasing in the last few years by some 3% per year and the related morbidity is increasingly prominent in school-aged children. This means that the number of patients monitored by the pediatric unit is constantly rising.

Although the increase appears to have evened out, the ongoing demographic concentration of families with children in Espoo and Vantaa has increased the workload at Jorvi's diabetes outpatient unit more than at the Children's Hospital, with a particular increase in the number of recently diagnosed patients under the age of 3 (14 patients at Jorvi and 6 at the Children's Hospital).



Based on the facilities and staff resources available in 2015, the target frequency of three months control visit (according to national clinical guidelines) has been achieved to a fair degree. In relation to the nationwide quality control of diabetes care, diabetes control in the HUH Department of Children and Adolescents is close to the national average, as is the frequency of appointments with a nurse and doctor. Children's psychiatric services continue to be too rarely available, and more children's psychiatric services are required at the diabetes outpatient units at both Jorvi and the Children's Hospital, particularly during the first year of diabetes care.

4. Forms of treatment

Diabetic care is continuously developing and the introduction of new treatments and instruments requires well-trained staff. In order to deliver state-of-the-art care, these developments must be embraced independently and pro-actively. Insulin pump treatments are initiated for 70 patients per year (Figure 2). Treatment currently begins on a hospital ward, but there are plans to transfer this procedure to the day hospital, upon the opening of the new Children's hospital at the very latest. Day hospital operations are piloted at Jorvi Hospital in 2016. Almost half of our patients are currently in insulin pump therapy (Figure 3).

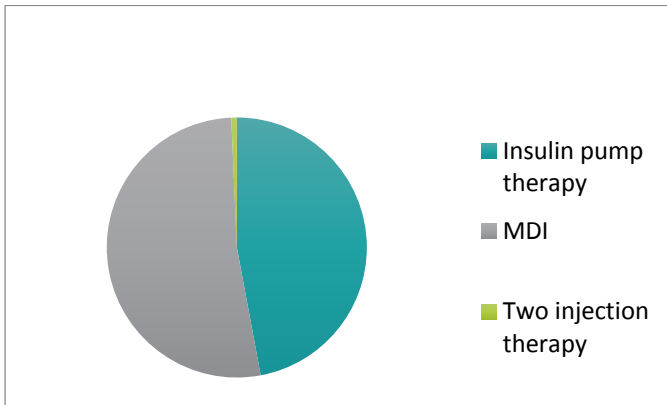


Figure 3. Forms of treatment for diabetics (%) in 2015 at the diabetes outpatient clinics of Jorvi and the Children's Hospital.

As a rule, infants under the age of 1 year are started on a CGM-enabled insulin pump treatment immediately after diagnosis, as is often the case with patients age of 1–3 years. Before a decision is taken to install a CGM-enabled insulin pump, the patient must undergo continuous glucose monitoring for at least one month to give the child and family a realistic picture of what CGM-enabled insulin pump therapy will be like.

CGM is a highly efficient tool for bringing poorly controlled diabetes under control, improving patient compliance and, through personal training, helping patients to understand the importance of insulin, exercise and nutrition physiology. The use of CGM has increased six-fold over a period of ten years (e.g. at the Children's Hospital 2015 vs. 2006: 246 patients vs. 40 patients) and there is a growing need for more equipment. Such instruments form an integral part of the treatment and research equipment of a modern diabetes clinic, but their use is labor intensive – installation of the instrument and data exports are performed by nurses, and a doctor is required to analyze the readings.

The future aim is therefore to increase the use of CGM and sensing insulin pumps and to engage patients and their families in handling weekly data exports at home. If the family requires assistance from the care team in adjusting the insulin dosage, they can send an e-mail to the diabetes clinic notifying that they have exported the data and a doctor or nurse can then give feedback and instructions on how to make the necessary changes. The installation of the CGM system is recorded as a procedure and e-mail feedback as a phone or letter consultation, since it replaces an appointment at the clinic. The aim is to set up a functioning cloud-based exporting service for CGM and, when necessary, electronic feedback for insulin dosage changes.

5. Quality of care

The objective indicator used for measuring treatment outcomes for diabetes is the HbA1c level (% or mmol/mol). Finland has no national diabetes register but unofficial quality statistics are compiled for each pediatric unit. Submitting data for the statistics is voluntary, for which reason the figures are not fully comprehensive. Ongoing project to improve quality of patient-care has produced positive results: The average HbA1c level for Jorvi and the Children's Hospital has dropped below the national average (in the units that had submitted their outcomes, the average HbA1c for patients under the age of 16 was 8.3%/67 mmol/mol) while they are in Jorvi 7.8% and in the Children's Hospital 8.1% (the average HbA1c level for patients over the age of 16 treated at Children's Hospital was 9.0%; Figure 4).

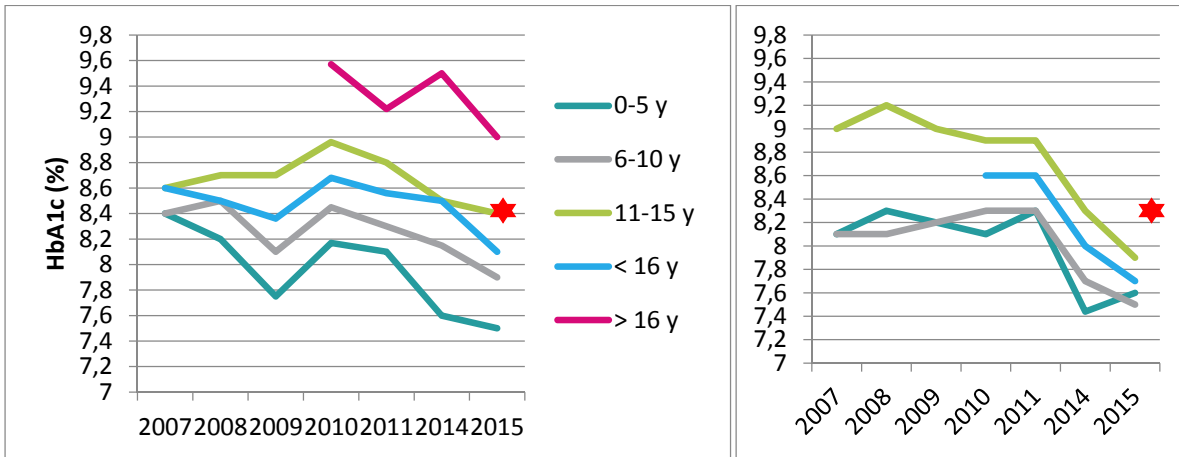


Figure 4. Changes in diabetic control by age for 2007–2015 at the diabetes clinics of the Children's Hospital (left) and Jorvi (right) (red asterisk = average HbA1c level at pediatric units in the whole of Finland).

A more crucial indicator of the quality of care than the overall HbA1c average is the share of patients with “well”, “poorly” or “reasonably” controlled diabetes (i.e., HbA1c below 7.5%, between 7.5–8.5% or over 8.5%); these figures are presented in Figure 5 and the positive overall trend in the Department of Children and Adolescents in 2014–2015 in Figure 6.

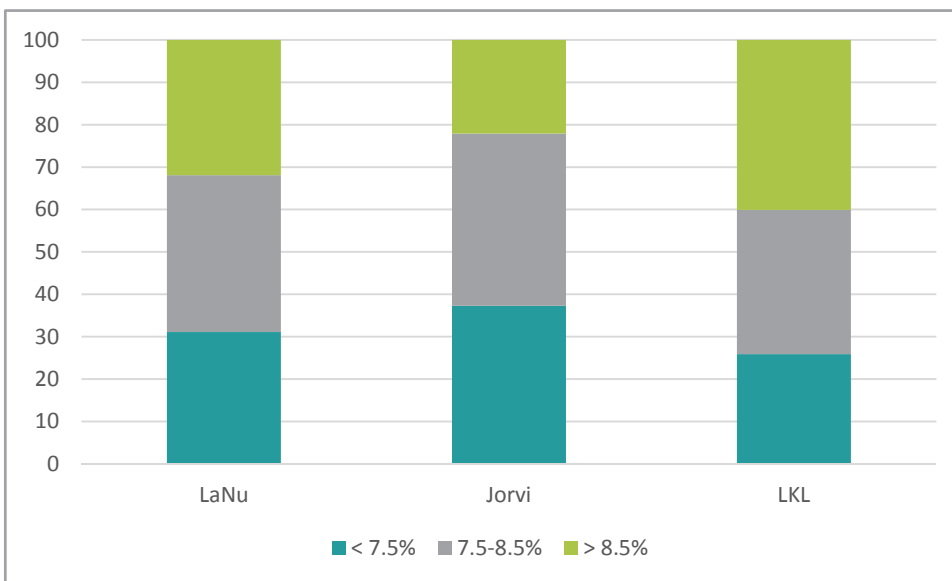


Figure 5. The distribution of controlled (HbA1c < 7.5%), reasonably (HbA1c 7.5–8.5%) and poorly controlled (HbA1c > 8.5%) diabetes patients (%) in 2015 (NB! The figures for the Children's Hospital also include patients over 16).

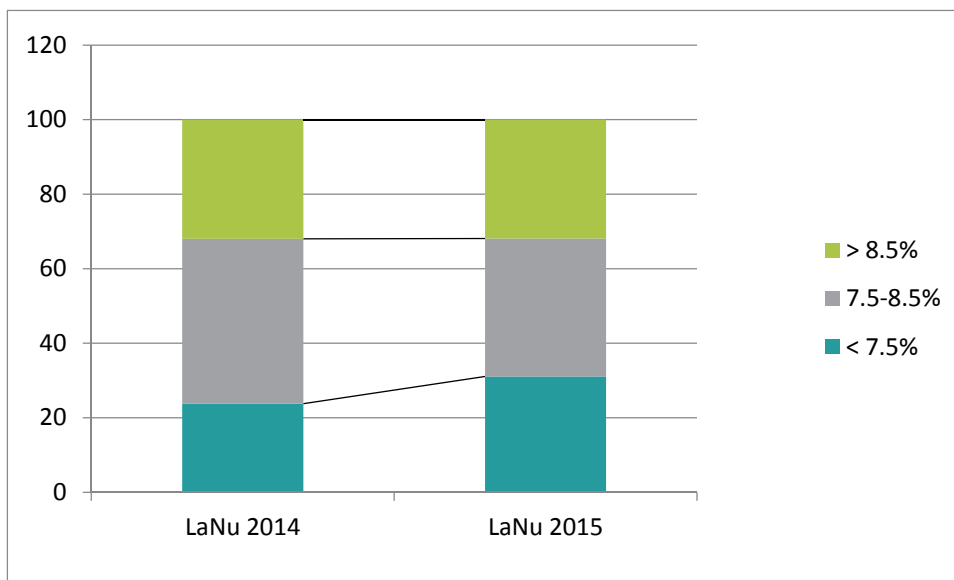


Figure 6. The percentage of patients with controlled (HbA1c < 7.5%) diabetes increased and that of patients with reasonably controlled (HbA1c 7.5–8.5%) diabetes decreased in 2014–2015, whereas the share of patients with poorly controlled diabetes remained unchanged (HbA1c > 8.5%).

6. Needs for change in 2016

HbA1c level is a significant factor in predicting the health of a young patient later in life. Increasing the share of patients with controlled diabetes is our main target for 2016.

Measures for achieving well controlled diabetes:

1. Increase benchmarking: The diabetes unit at Jorvi will begin systematic training to improve its operations and participate in training in Sweden as part of the FinnDiabkids project. Following the training, it will serve as an example for other units in Finland.
2. The diabetes team at the Children's Hospital will systematically monitor its operations through monthly reports.
3. Research on Motivational Interviews was begun in autumn 2015 at the Children's Hospital and will continue in 2016. The aim is to use interviews to improve patients' motivation for self-care.
4. General quality of patient guidance will be improved, with the target HbA1c level of <7.5% being emphasized in communications with patients and their families.
5. The initial care provided to recently diagnosed diabetics and their families will be improved. Structured consultations with physicians, possibly led by senior practitioners, will be increased at both units.
6. The availability of electronic services will be increased, covering the adjustment of insulin pumps, the first days at home with recently diagnosed diabetics, and the partial replacement of more frequent required consultations with teleconsultations.

7. Operative challenges

It is in the best interests of the patient to have a designated doctor and diabetes nurse. When a patient cancels an appointment, it is usually impossible to reschedule the appointment with the doctor in charge, owing to the limited number of consultation hours. We nevertheless aim to ensure that all nurse appointments are held by the same nurse. The Children's Hospital and Jorvi Hospital are teaching hospitals, where specializing doctors must receive adequate training in diabetes, which means that appointments are partly held by specializing doctors. The aim is to arrange appointments in such a manner that the physician in charge is available for consultation during appointments.

The initial treatment always takes place on a hospital ward, but shortage of space in the Children's Hospital has made the work of diabetes nurses increasingly challenging. This problem should be remedied once the space issues have been resolved.

The social and ethnic background of families can vary widely. Diabetes teams need additional training in understanding cultural conventions that differ from Finnish traditions, so that families can be advised on optimal lifestyle choices, which are central to treating diabetes (diet, exercise) and can be given the appropriate support in dealing with a chronic illness. In this, the role of the nutritionist, social worker and children's or youth psychiatrist on the diabetes care team is emphasized.

8. Research

Pediatric endocrinologists conduct extensive diabetes research; the key projects are research on the prevention of T1 diabetes led by Professor Mikael Knip and Professor Timo Otonkoski research group's work on beta stem cells. Other research topics at the unit include monogenic diabetes (Päivi Miettinen) and the improvement of diabetes control (Risto Lapatto, Matti Hero MD and Mari Pulkkinen MD)

9. Summary

Modern treatment and achieving the target HbA1c level <7.5% requires optimum resourcing for the diabetes team; the ongoing development of its operations (learning, benchmarking, increased efficiency and quality); the ability to respond to the demands of a changing society (supporting children and adolescents in their busy lives consisting of school, sports and family life); as well as the maintenance of high medical standards and expertise and the re-evaluation of practices (keeping up with technical innovations in insulin treatment and GCM and developing electronic services).

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