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A new liver for the baby

Heidit Kaio (26.11.2010)

The death of a tiny baby demonstrates the difficulty Estonians experience in finding transplant organs for young children.

"When we received a letter of guarantee from the Health Insurance Fund for 3.5 million kroons, it was such a good feeling! This really is a great country!" says Marge. The money was intended for a liver transplant operation in London for seven-and-a-half-month old Valter. Organ transplants are performed on such small babies, although it does seem like performing surgery on a doll.

Little Valter's liver wasn't working as it should. Infants don't grumble, and Valter didn't cause a fuss either – his illness was discovered when doctors noticed that the boy's skin was too yellow. At that point Valter was two and a half months old. Other than that, Valter was a cheerful young lad, lively and babbling away. From time to time he tried to scratch his ear – itchy ears are one of characteristic symptoms experienced by those with liver problems. As his illness progressed over several months, Valter began to get tired quickly and sleep a lot, he became increasingly weak, and he started to pick up infections more frequently from his older brothers.

Valter's doctor, Katrin Luts at the Tallinn Children's Hospital, made it clear to the child's parents that their son would need to have a liver transplant.

A new liver is available, but in England

Valter is Estonia's second known case of a child with Alagille's syndrome – it is rare illness, but not necessarily life-threatening. Doctors in both Tallinn in Tartu did everything they could. Marge, Valter's mother, researched her son's illness on the Internet and communicated with other parents in similar situations from all over the world.

"I went on to internet forums in English, and there I found people praising the work of a doctor at the King's College Hospital in London named Alex Knisley. So I sent him a letter containing Valter's test results," says Marge.

From there everything progressed quickly: Knisley gave them a consultation, and together with Valter's doctor in Tallinn they started to move things forward.

The Valter family requested money from the Estonian Health Insurance Fund (which they got) and they looked for a way to fly the whole family to London and stay there in a hotel while Valter was in hospital.

Six weeks after sending the first letter to London, they received a letter from Kings College setting an appointment for the initial examination. But little Valter didn't have the strength to go to London – a week before the flight, he succumbed to a chance viral illness.

Valter's parents donated all the money they had collected for the journey to the Tallinn Children's Hospital Support Fund, so that in future it can be used by another family in need of help.

Every child in need of a transplant is an important lesson for our healthcare system. Each case is like a snowplough, gradually clearing the road ahead. In countries with larger populations, parents with children in need of help go onto a conveyor belt – there are a lot of patients and the finding of solutions is routine. In Estonia things are not the same. Finding a new organ depends on the initiative of the child's parents and the doctor.

"It should also be the case in Estonia that we notify a transplant centre that a child of such and such an age is in need of an organ, and the system starts to look for a solution" says Doctor Katrin Luts, who has helped babies get treatment abroad.

Last year two children received new organs in foreign countries. Overall there have been six such cases since 2006. Children have gone to England, Germany, Sweden and Austria for treatment. Babies are forced to go abroad for transplants not so much due to a lack of surgical capabilities in Estonia, but rather because suitable organs are too difficult to come by here.

However, organ transplants abroad are a privilege reserved for small babies in Estonia. For adult patients the future is still at home, says Tanel Laisaar from the Tartu University Clinic. In October he performed Estonia's first lung transplant operation.

Estonia would benefit from joining the Scandinavian system

Why should each country have to cope with its sick adults by itself? There is always a shortage of organs, and at foreign centres there is no interest in sharing these scant resources. In addition, patients find it difficult to cope in a foreign country, communicating in a foreign language in an intensive care ward.

Cooperation between countries is important, if only so that precious organs provided by donors don't go to waste. A kidney survives outside the body for 24 hours and a liver for 8 hours. Estonia is currently involved in cooperation in the exchange of kidneys, mainly with Latvia. So far fewer than ten kidneys a year have been exchanged.

Katrin Luts from the Children's Hospital is hopeful that the Estonian State will sign up to the European donor organ allocation service Eurotransplant.

"We hope that during the coming year we will join Eurotransplant", says Mart Einasto, member of the management board of the Tartu University Clinic.

For accession, however, a number of requirements must be fulfilled – just like for joining the European single currency. Even working together, Estonia, Latvia and Lithuania are still too small to operate effectively in the field of child organ donation. Membership of the larger system would give sick babies in Estonia a greater chance of survival.

A transplant may be the cheapest treatment

- The transplant of a new organ is the most cost-effective method of treatment for kidneys, according to data collected by the European Commission, who recently adopted a directive on organ transplantation.

- The most frequently transplanted organ is the kidneys. A kidney transplant costs an average of EEK 190 000.

- There is also another method for kidney treatment: the patient sits in a chair for five straight hours twice a week while his or her blood is cleaned of waste substances. This type of treatment costs EEK 448 400 per year.

- A liver transplant costs an average of EEK 552 000. No other treatment option is possible for these patients.