NEWS 3 hours ago

Katrine feared for her son's health – here she found help

For nine years, Katrine's son Theo has lived with a rare kidney disease. It has not only been hard for Theo to be in and out of hospitals – the disease has also had consequences for Katrine

Of Sebastian Myrup Hansen

For nine years, Katrine Maigaard has followed her son Theo's kidney disease. Photo: Private

For nine years, Katrine Maigaard's son Theo had lived a completely normal life.

But one summer day, the lives of both changed completely.

The family had grilled, and the menu was on chicken. After devouring the poultry, Theo felt bad.

Theo vomited, had an upset stomach and fever, and when he had to get up at night to pee, he knew right away that something was wrong.

Instead of a yellowish color, his pee was red. Katrine immediately raised the alarm and called the doctor.

After being examined by his doctor, Theo was hospitalized. It was reported that he had cystitis, but Theo kept peeing blood.

Instead, the report said that he had contracted food poisoning from the chicken, but that diagnosis turned out not to be correct either.

Since the age of nine, Theo has had a rare kidney disease that has taken time to diagnose and find the right treatment. Photo: Private

After a few months, Theo went to Rigshospitalet, where he was diagnosed with a rare kidney disease that affects only a few in Denmark and the world in general.

The disease has the name C3 Glomerulonephritis or simply C3GN.

For Theo, a life in and out of the hospital began to find the right treatment, while Katrine could follow her son's ailing health on the sidelines, resulting in high school absenteeism and hard days with fluctuating moods.

"For a long time, different treatments were tried and nothing worked.

"He was constantly tired and sick and constantly getting infections," Katrine tells SE og HØR.

Katrine herself is a trained doctor and therefore tried to find information and treatment for her son, but it was not encouraging words she found in the various research reports.

For Katrine Maigaard, it has been a tough period to follow her son Theo's illness. Photo: Private

"When you read them, you got depressed because it said there was no treatment, and half of the children had kidney failure within 10 years," she says.

Søren Rittig, professor and chief physician at the Department of Children and Adolescents at Aarhus University Hospital specializing in kidney diseases in children, conducts his own research into rare kidney diseases and confirms that the right treatment for C3GN can be difficult to find.

"Even larger centres abroad do not have enough patients to gain experience in finding out which treatment is best for the individual patient.

"The experience base is tenuous. Even though we think we can find the disease, people react differently to the treatment, says the chief physician, he explains to SE og HØR.

Can you play iPad in heaven?

For Katrine, it was hard to see her son's health deteriorate and how his mood was affected by it. She had to go down in time to care for Theo.

"I could tell Theo was wondering about death because he asked if I believed in heaven and if you could play iPad there," she says.

Theo's fear of death also affected Katrine.

"In the beginning, I took my sorrows in advance and thought a lot about whether Theo was getting so bad that he needed dialysis. Or whether he might die. There wasn't anyone to talk to it about.

Katrine continued her search for help for her boy, and she found hope on Facebook.

– I found a small Facebook group for parents with children with C3GN.

"We were probably 10 families from all over the world. It gave some to share experiences and concerns with. The group has grown – now with over 300 members, from many countries around the world.

– One of the happiest days of my life

Through international collaboration, consultant Søren Rittig has also gained knowledge about the rare kidney diseases.

Here, other doctors share knowledge and research that helps find the right treatment and diagnose the diseases.

"We enroll patients in a large registry worldwide so you can gain some experience.

"Abroad, they have major centres for research. There is a larger population base than the Danes, and we must lean on their experience to find solutions to this, he says.

After several examinations, the now 18-year-old Theo received the right treatment with the medicine ultomiris.

Theo was able to return to school, and his mood changed, so he no longer had long, sad days at home.

At the same time, Katrine was able to return to her job full-time.

Source: Aller Media
Ansvarshavende chefredaktør:
Niels Pinborg
pinborg@sh.dk
Adress:
Havneholmen 33
1561 København V
CVR.: 43325612
Tlf.: 72 34 20 00