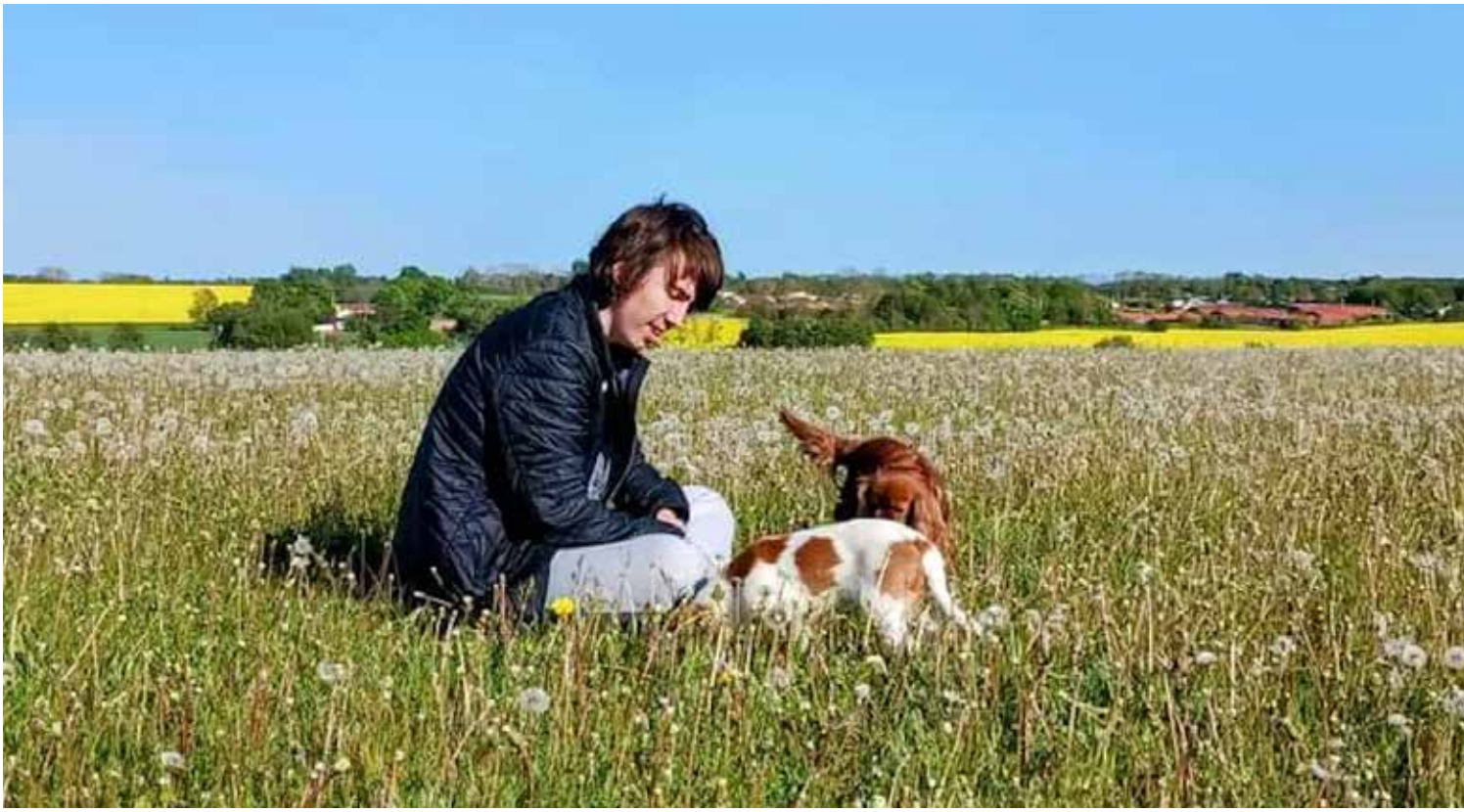
NEWS Yesterday

Theo is on life-saving medication – for six months it was about to go wrong

Theo knew something was wrong with him, but what it was, no one could tell him. It took time for him to be diagnosed and given the right treatment

Of Sebastian Myrup Hansen



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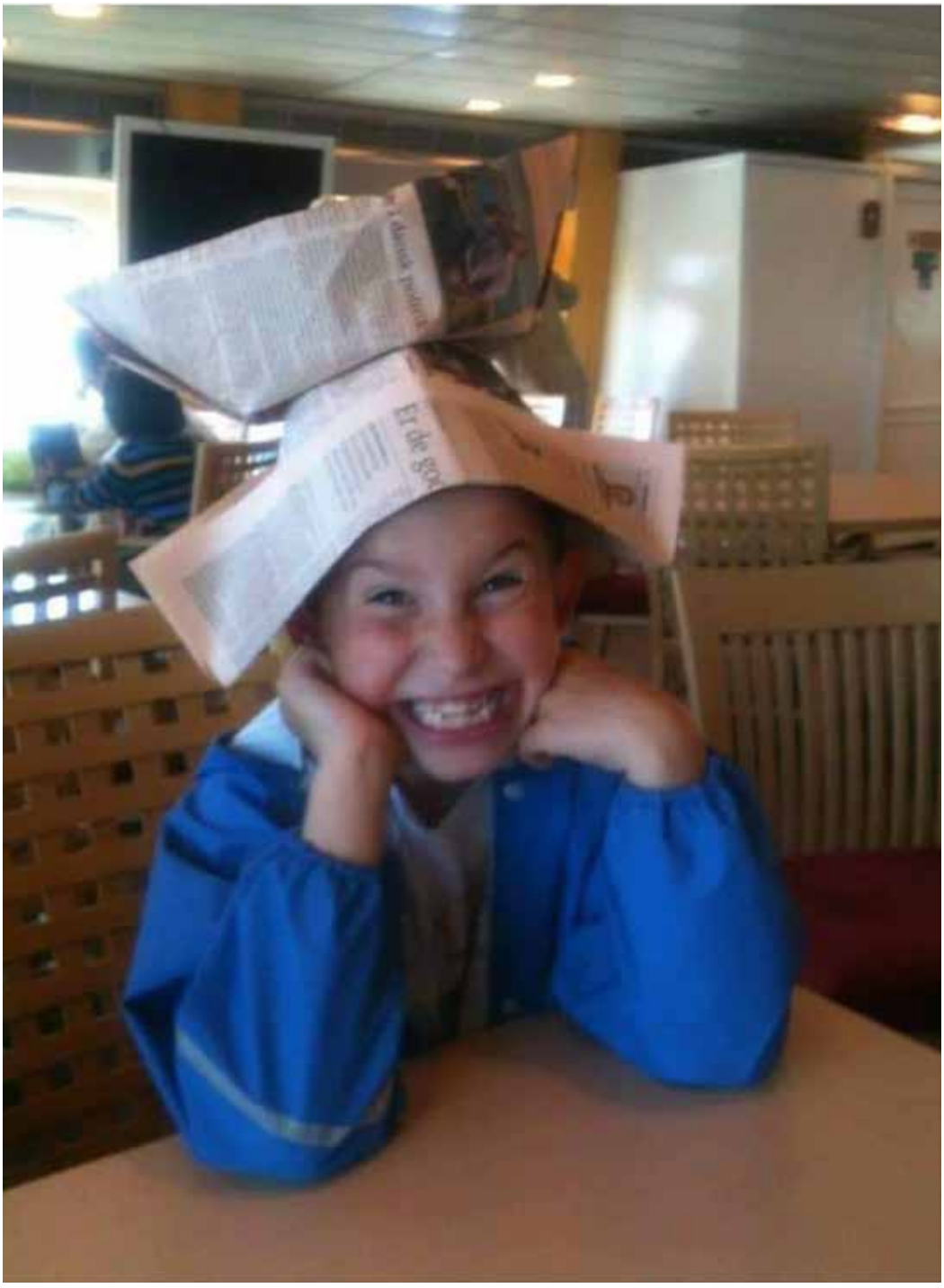
For Theo Maigaard, 18, life took a drastic turn at the age of nine.

A life full of energy and joy was replaced by regular trips to and from the hospital and a fear of dying. Theo has a kidney disease, but not just any kidney disease. A rare one, which affects only a few in Denmark and generally in the world. Its colloquial name is C3 Glomerulonephritis or simply C3GN.

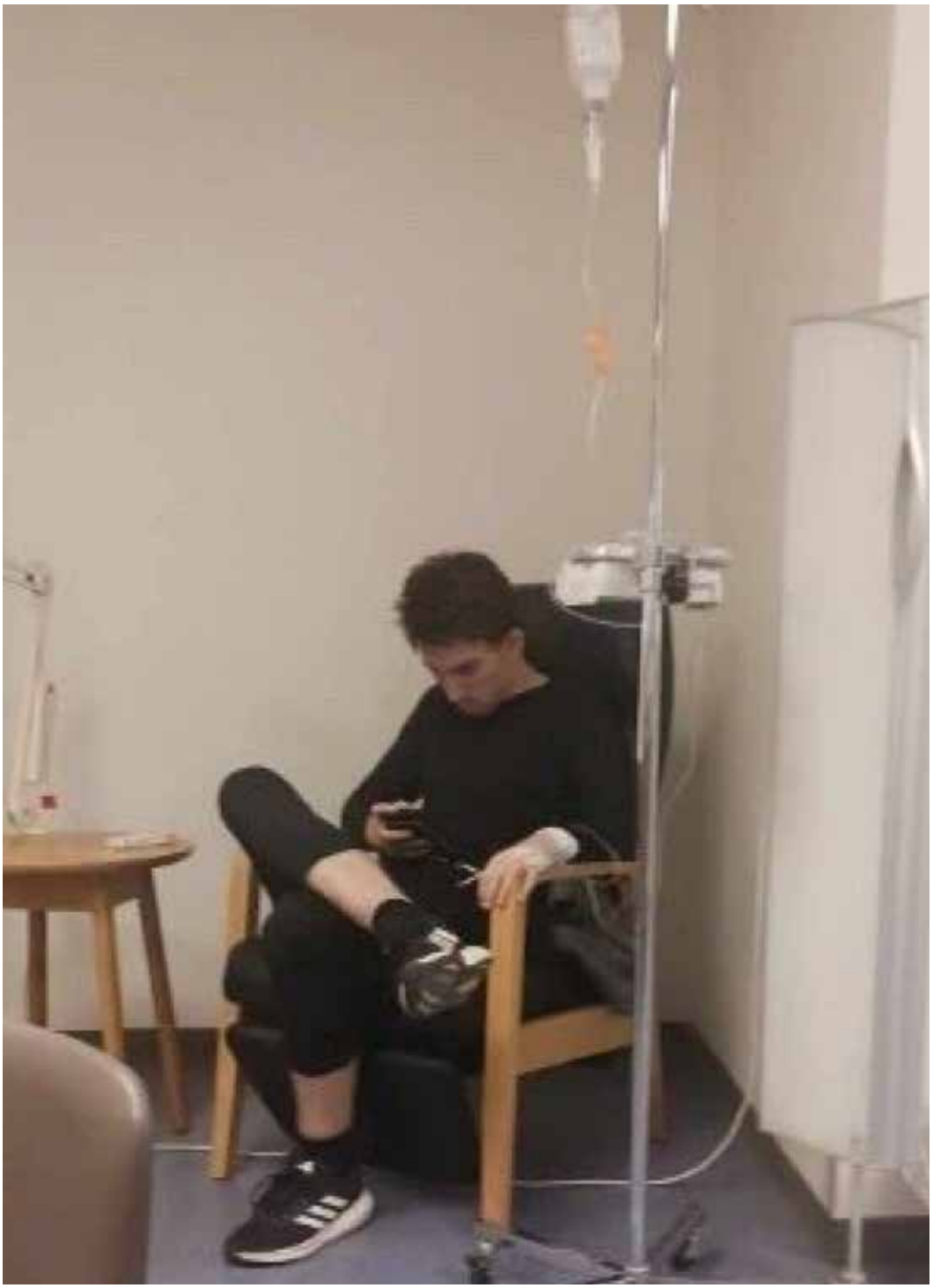
When Theo first peed blood, he knew something was wrong. It led to a worry at the age of just nine if he would ever see his dreams come true. “When I found out that it wouldn’t go away and there was no treatment, I thought I might die”, the now 18-year-old Theo tells SE og HØR.



At a young age, Theo became ill with a rare kidney disease. But it took time before the boy from Roskilde was given a final diagnosis, and it was hard for Theo. “I have been to the hospital so many times that it is difficult to remember one time from the other”. The medicine didn’t help. It is not unusual for a disease like C3GN to be difficult to diagnose. “It’s like finding a needle in a haystack, where you go on a detective hunt” explains Søren Rittig, professor and senior physician at the children and youth department at Aarhus University Hospital with a specialty in kidney diseases in children, to SE and HØR and elaborates. “On the one hand, we do not fully understand the mechanisms surrounding what is going on at the very bottom of the cell, and so it is difficult to diagnose the disease if it is in its infancy”.

When Theo was finally diagnosed, the next step was to find the right treatment, and where boys of Theo's age usually spend time with their friends and go to school, everyday life looked very different for him.

"I started on some medicine at a time that made me hungry all the time, I didn't go to school and was sad and angry for several years." According to Søren Rittig, there is a reason why it took a long time before Theo got the right medicine, as there are so few who have a kidney disease like Theo. Theo receives treatment with ultomiris here. He gets that every 8 weeks. "Even larger centers abroad do not have enough patients to gain experience in finding out which treatment is best for the individual patient. The basis of experience is tenuous. Even if we think we can find the disease, people react differently to the treatment" says the chief physician.



Close to going wrong

After several unsuccessful treatments and countless visits to the hospital, Theo was given the right medicine. The sad and bad days turned into happy, normal days filled with energy instead. He started secondary school and made friends. But the new life had a tight deadline, and when Theo turned 18, his health went downhill. Theo was no longer a child and transferred from the children's ward to the adult ward. "When I went to the adult nephrologists, they weren't sure that the medicine helped". Therefore, he was taken off his medication for a period of six months, and this had consequences for Theo. Theo rarely got out as he was very affected by the disease at a young age. Here, however, he has moved out for a wedding with his brother. "I got really tired again. I lacked energy and had to sleep more and couldn't cope with boarding-school in the same way". "I wanted to, but I got so tired, I slept through my alarm clock, and the teachers had to come and wake me up".

For Theo, the lack of medication could clearly be seen in the boy, as he gained 10 kilos in liquid, which is a clear symptom of the disease. Therefore, he was once again hospitalized.

Necessary to stop medication

The symptoms spoke their own language, and Theo came back on the same medication as before. "From one day to the next, the illness calmed down again and I began to recover. I was discharged from hospital after a few days, the following week I was back at school and could feel the energy coming back". It may sound like a startling decision to take Theo off his medication when he was living a normal life, but due to the rarity of C3GN it is necessary, according to Søren Rittig. "If things have gone well for a long period, then the question arises as to whether the disease could conceivably have calmed down, so that you no longer need the medicine. And there is only one way to find out, and that is by tapering down or stopping completely, and then we can see if there is still a need for the medicine", he explains.

Hoping for a cure

For Theo, the disease has left its mark on his dreams for the future. "I'm probably less scared than when I was a child. But honestly, I think it affects my future. If I could dream without it having to be realistic, I would wish there was a cure for my illness", says the now 18-year-old boy. Søren Rittig is also looking forward to the future of rare kidney diseases, where research in the field is undergoing a "rapid development", which gives hope. According to the chief physician, the big challenge is to understand the disease-causing mechanisms even better in the individual patient and thus be able to choose the best treatment.

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