SOCIETY

‘In that waiting room I knew: the cards had been dealt’



Four years ago, both the partner and the daughter of Jorg van Gent (43) were diagnosed with MD. Van Gent immersed himself in the hereditary muscle disease and founded the MD Nederland foundation. ‘If my daughter is in a wheelchair by the age of thirty, I want to be able to say that I tried everything.’

> **‘It was such an innocent scene, and such a stark contrast with the misery that was to come’**

Setback

In Setback, entrepreneurs, executives, politicians and artists talk about the low points in their careers. And how they bounced back.

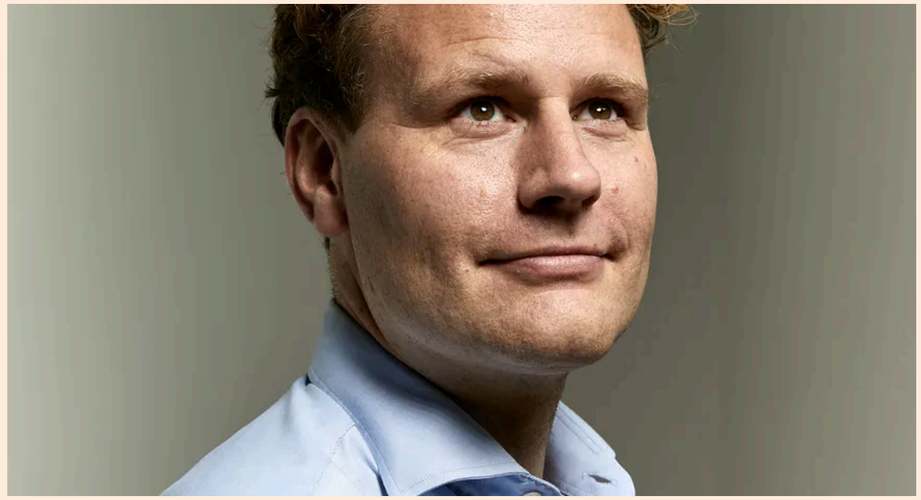
A summer’s day in August 2017. Jorg van Gent, investment manager at ABN Amro, is on the train to an appointment in Driebergen. Shirt on, briefcase on his lap. He is daydreaming. Then the ringtone of his mobile phone blares through the packed carriage. He answers and hears his girlfriend Kirsten (34) crying: ‘She’s got it.’

Van Gent knows at once what she means. ‘She’ is Kirsten’s sister. And ‘it’ is the diagnosis myotonic dystrophy (MD), a muscle disease. Van Gent doesn’t know what to say. Kirsten spent the afternoon at the beach with the children. So he simply asks: ‘Did the kids have a nice day?’ He gets off at Zeist and takes the train to Utrecht. There, at UMC Utrecht, his in-laws gather.

SAME DIAGNOSIS

In a dated consulting room, with fluorescent lighting and peeling paint, the family waits for the neurologist. He walks in, turns to Kirsten first and says: ‘Your sister was diagnosed with MD this morning. I have asked you all to come because this disease is passed on through the genes. That means your father will receive the same diagnosis. And there is a good chance that you have it too. And your daughter.’

For Van Gent, everything falls into place. Kirsten developed cataracts at a young age and has long suffered from cramping in her hands. Their daughter Anieke, then three years old, was late to start walking and talking. ‘Innocent in themselves, but all symptoms of MD. When we sat in that room, I knew: the cards had been dealt. The chance that they had MD too was 99%.’ He also knows that the disease becomes more severe with each generation, and that life expectancy is limited.



Jorg van Gent: ‘The economist in me woke up; I saw a market. There is already a promising gene therapy. It just needs to be turned into a medicine that is proven safe.’

PHOTOS: MARK HORN FOR HET FINANCIEELE DAGBLAD

The next day Van Gent and his family fly to the south of France, as planned. There he stands barefoot in the warm sand. Clear blue sky. Brightly coloured parasols. Anieke jumps over the waves in her pink swimsuit, squealing with delight. The ten-month-old twins lie behind him on a towel on the beach. Van Gent looks at his daughter and tears stream down his cheeks.

‘It was such an innocent scene, and such a stark contrast with the misery that was to come. I mourned the loss of our carefree existence.’ He knows that Anieke will deteriorate, just not how fast or how badly. ‘You see your child’s future falling apart.’ Slowly, the impact on his own life sinks in too. ‘When I’m seventy, I may have a severely disabled child, and I don’t know how things will be with Kirsten by then.’

NASHVILLE

In November 2017, genetic testing officially confirms the disease in Anieke, and therefore in Kirsten as well. Van Gent starts immersing himself in the muscle disease in the evenings. ‘I dropped biology in my fourth year of secondary school, so I had some catching up to do.’ At a medical congress in Nashville, he learns that MD affects 1 in 2,100 people. ‘The economist in me woke up; I saw a market. There is already a promising gene therapy. It just needs to be turned into a medicine that is proven safe.’

In 2019, Van Gent and friends set up the MD Nederland foundation. It is still in its infancy. ‘Ultimately, I want to bring scientists, investors and pharmaceutical companies together. That way I hope to help speed up the journey from science to a pill.’ It gives him something to hold on to. ‘If Anieke is in a wheelchair by the age of thirty, I want to be able to say that I tried everything.’ It may not change the outcome. ‘But then I can make peace with fate.’

His ‘mourning process’ is at odds with Kirsten’s. ‘She couldn’t talk about it at all in the first year.’ A social worker who heard their story ominously predicted: ‘You two will split up.’ Nothing could be further from the truth. Van Gent asked Kirsten to marry him at the end of 2017.

CAREFREE CHILDHOOD

Meanwhile, ‘the circus just keeps on going’. Anieke is now seven, the twins four. ‘Like any girl, Anieke spends twelve months getting excited about her next birthday.’ The family spent two months travelling through Africa. ‘We put things off less and do the things we want to do while we still can.’

Yet the diagnosis is never far from his mind. Last summer Anieke had a heart examination. ‘The conclusion was that there is something wrong with her heart, even though she isn’t troubled by it yet. Those are difficult moments. You realise once again that she is on the sliding scale of losing functions.’ The twins have not yet been tested for MD. ‘Doctors are reluctant, because what would you do differently if you did have the diagnosis? So far, nothing suggests the boys have inherited the disease, but I can’t rule it out.’

Van Gent and Kirsten do everything they can to give Anieke a carefree childhood. ‘She sometimes has to go to hospital for tests, but we don’t want MD to become who she is.’ That seems to be working. ‘When she sits on the rug playing with her dolls, I see how innocent and happy she is. I know that not knowing can’t last forever, but I hope we can keep it up for as long as possible.’ Anieke’s brothers want to become a firefighter and a pilot. ‘If you ask Anieke what she wants to be, she says: “I’ll just be Anieke.” Isn’t that wonderful?’

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- **2004** Studies economics and political science at the University of Amsterdam
- **2004–2015** Corporate finance advisor at ABN Amro
- **2012–2018** Director of Stichting Vitalis
- **2015–present** Investment manager at ABN Amro
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English translation of ‘In die wachtkamer wist ik: de kaarten zijn geschud’ by Floortje Gunst, Het Financieele Dagblad, 11 October 2021.

Original Dutch article: fd.nl/samenleving/1414977