

BREAK THE STIGMA FOR FAMILIES

Moving into Action when Psychiatry Got Personal

We the Dutch love our bicycles. With one quarter of all trips in the Netherlands made on two wheels, and with an average output of 2.5 km per person per day, we are a country of proud cyclists. The vast majority of Dutch citizens own or ride a bicycle. And it is not only 'the masses' who ride: the internet is rife with pictures of different generations of our royal family riding their own, and a 2017 photo of our Prime Minister parking his bicycle at the King's palace went viral. Cycling is part of our daily routine and family life. From early on we teach our children to ride on two wheels. In the process, we connect them to different generations within their families and our nation.

My father taught me how to ride. I have clear memories of that day: it was my grandfather's birthday; I remember my relatives' voices in the background, the sun warm on my skin, my father's hand on my shoulder. Most of all, I remember the excitement and sense of freedom when my father let go and I cycled on my own for the very first time. It is true that I had not yet learned the finer points of slowing down, so my maiden voyage soon ended in the bushes. But that initial taste of freedom made me want to try again and again.

I am Dutch and I am a cyclist. I live and work as a child psychiatrist in Drenthe, the quintessential cycling province of the Netherlands. Bicycles are part of my daily life. In my work as medical director of the department of family psychiatry I even compare becoming a 'good enough' parent to teaching a child how to ride a bicycle.

Native and enthusiast cyclist that I am, it still caught me by surprise that a bicycle, of all things, helped me address the stigma I was so deeply and unknowingly embroiled in.

Among the countless pictures that include bicycles in my family's photo album, my favorite was taken on July 21, 2018, at the Regional Velodrome in Assen, during the launch of the campaign **Break the Stigma for Families**. The picture in the next page spans three generations: my father Rikus Aardema, my husband Johan Prins and me, and our adolescent children, Caya and Ivar. The cyclist in the background is my mentor,

colleague and dear friend, Andrés Martin.

The story behind the picture began on October 16, 2017. On that day, Johan was hospitalized for a serious and potentially life-threatening illness. For our young family, this represented an entirely new challenge. We were lucky, as we recognized some symptoms and were able to ask for urgent medical care. That day remains in a fog, but I do remember the relief we all felt when his disease was recognized, named, and taken seriously. Johan was diagnosed with major depression, and given the symptoms he

presented with, had to be admitted urgently.

I am a child psychiatrist and have learned that mental illnesses are real, common and treatable conditions. On that day I also recognized, while 'walking the talk', of the profound impact mental illness has on the families of the patients we care for. It was also a reminder that being caregivers does not immunize us from being afflicted ourselves.





The Prins-Aardema family at the Northern Regional Velodrome in Assen. Pictured from left: Rikus, Ivar, Cecil, Johan, and Caya – as Andrés Martin (behind, right) heads into the curve.

Mental illness changes behavior: it affects *personhood*, more than just the person. My husband had struggled before, and we were diligent in seeking help during the months leading to his hospitalization. The symptoms of his illness were not subtle then, and in retrospect are quite clear today. Still, we felt confused, alone and not fully understood at the time. In our initial conversations with professionals there seemed to be a relentless emphasis on our underlying personalities, on our putatively dysfunctional relationship, on our limited parenting skills. We felt blamed and ostracized by family, friends and professionals – all of them well-meaning, no doubt. At our time of greatest need, stigmatized views of mental illness and psychiatric care had permeated through and posed an enormous additional burden on our nuclear family. I am a psychiatrist by training, and struggled with such views (others', as much as my own, for sure). If this was the case for me, what could I expect for the countless others who are not professionally trained but suffer just as much as we did?

The feeling of relief at the moment of Johan's hospitalization had everything to do with reconceptualizing his symptoms and our struggles as a family. Once his illness was named, it was as if he had become

visible once again. It helped me to explain to our children and our families what had ailed Johan, to give words to his suffering, and to explain why treatment in a hospital setting was required. Seriously ill people go to hospitals for treatment, and Johan was no exception to that rule.

In the weeks after his admission I learned more about the stigma surrounding mental

illness, including the one that I had been unwittingly harboring. After his hospital stay, Johan wanted to be able to talk openly about his experience. I supported him in this, as we wanted to provide a good example of openness for our children. Despite such candor in the family, I struggled with being equally open at work. I felt embarrassed and guilty: that as a psychiatrist I, of all people,



Country riding. From left: Ivar, Emmen City Mayor Eric van Oosterhout, Caya, Cecil and Andrés. Sitting on his hand-bike, Simon Henk Luimstra rode with us, representing riders of all disciplines and abilities embraced by the UCI.



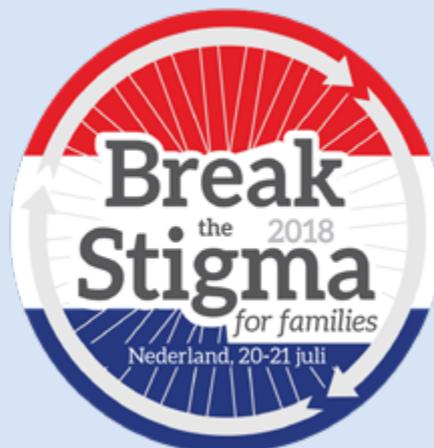
had not been able to prevent or recognize my husband's depression and its impact on our family. It was only when I engaged in the thought experiment of comparing myself to an oncologist whose partner is diagnosed with cancer, that I discovered how deeply I had been struggling with internalized stigma around mental illness. From that day on it became much easier to communicate and share information about Johan's illness and his admission to hospital.

Our communication was open and clear, and the response immediately overwhelming. Many colleagues and friends shared their personal stories about the burden they had carried within themselves in having a loved one affected by mental illness. The stories were at times intense and filled with pain and suffering, just as much as by relief at finally being able to share and unload. Most of these stories were new to me, even as I had long known the colleagues sharing them.

During those same days in late October 2017, Andrés Martín was about to finish his cross-country *Break the Cycle* tour across the United States. I shared my personal story with Andrés, who not only supported us as a family, but also gave us hope by sharing his personal history confronting recurring episodes of depression. His openness made me realize that when it comes to mental illness, we have a shortage of hopeful examples, that the shared lived experience of professional colleagues and friends can make an enormous difference.

While still on his endorphin rush, Andrés told me of his hopes to repeat the feat of synergizing cycling with mental health awareness-building and destigmatization efforts. I contributed the family angle to the equation, and we both added our international commitment. And so was born *Break the Stigma for Families – Netherlands 2018*.

I wanted a campaign aimed not at elite cyclists, but rather at any and all family members. I had learned that mental illness is a family affair, and that just as the entire family suffers, it is that selfsame family that supports and scaffolds the affected member back to health. It was also important for me to cycle with families without knowing who exactly was the ill member, the so called 'identified patient'. Some physical illnesses have family groups who cycle together; I was yearning for a similar campaign for mental illnesses, and committed to making one happen.



Over the course of two days, we cycled first in a cycling center, where young athletes showed us the finer points of BMX, mountain and velodrome racing, and where the local authorities welcomed our campaign with great enthusiasm. On the second day, we rode in the bucolic Dutch landscape, joined by a group of families, many children, riders of different abilities, and even the Honorable Emmen City Mayor in tow. We linked our campaign to international cycling networks, including that of UCI (*Union Cycliste Internationale*), even making it to the top of their website on the week of the event. Cycling is central to our campaign: we want to share with families that same sense of independence and joy we feel while riding.

This campaign has already proven transformative for my family and me. The velodrome picture reminds me of the freedom that comes with cycling, and of the power of sharing openly as we strive to help others. It is my fervent hope that Drenthe was just the start of an ambitious and heartfelt vision to help *Break the Stigma for Families* the world over.

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