

## A #ThisWay Story: William McKeown

*"It's not 'I have to exercise,' it's 'I need to learn to love exercise and find what is right for me.'"*

In the framework of our **#ThisWay Campaign**, the EHC interviewed **William McKeown** (32) from the United Kingdom, a patient with severe haemophilia A, who shared with us how he improved his mental and physical health and built sustainable healthy habits by changing his mindset and getting involved with patient communities.

We hope you find William's story inspirational and his insights helpful. If you have any questions or would like to get in touch with William, please do not hesitate to drop us an email.

### **William McKeown (32), United Kingdom**

"I live near Belfast, Northern Ireland, and I have severe haemophilia A. I work as a doctor specialising in the Care of the Elderly and Stroke Medicine. As part of my work, I care for people who have had a stroke caused by either bleeding or by blood clots. I also treat older people who are living with complications of ageing such as dementia, frailty, and poor mobility.

I love my work and my care for others is very much informed by my own experiences living as a patient with a chronic condition. I am a member of the EHC Youth Committee, and it has been an absolute pleasure to meet so many inspiring people affected by bleeding disorders like me over the past 3 years in this role, which comes to an end this autumn."



### **CHILDHOOD**

"As a baby, my parents found I was bruising spontaneously quite a lot, which led to numerous trips to the doctors and subsequently, I was diagnosed with severe haemophilia A. It must have been quite a shock and a stressful time for my family as we had no family history of bleeding disorders. In the first few years, prophylaxis didn't exist yet so every fall we would drive to the hospital to get an injection and the whole process would take hours.

My number of trips to the hospital fell considerably when I finally got prophylaxis around age 6. However, I did not learn to self-infuse until age 13 which significantly limited me. For instance, I chose not to go on school trips, or if I did, my parents had to come and do

the injection for me. This is why I believe it's critical for the independence of a person with a severe bleeding disorder to learn that skill at a young age.

In elementary school, my teachers meant well but unfortunately, they didn't understand my condition and sometimes their reactions were disproportionate. They even assigned a special assistant to me who came with me to the playground. As a child, I hated feeling different, being watched all the time instead of just letting me be a kid. Fortunately, it's common practice now for schools to have proper information about children with bleeding disorders."

## PHYSICAL AND MENTAL HEALTH



"As a child, I was very overweight, I didn't like sports and hated any kind of exercise. Only in my early 20s did I start doing exercise when I got involved with the patient community. Basically, a switch flipped in my head – I knew I was going to have joint problems if I didn't get physically active so I started going to the gym.

In the beginning, I deliberately chose to do low-impact activities only such as the cross-trainer and weight-machines, then I moved on to more impactful activities. Once I developed a good, solid technique, I also started using free weights. I was able to lose the extra weight and keep it off too!

The critical thing for me was to learn to love exercise. It's not 'I have to exercise', it's 'I need to learn to love exercise and find what is right for me'. Now I love running, cycling, sailing, and hiking. My haemophilia and my joint health are much better as a consequence – I get almost no bleeds.

If I haven't been out for a run or haven't been to the gym for a few days, I feel restless. I enjoy that time: it's 'me-time', a very liberating experience, just exercising and not thinking about anything else. While I don't have a lot of free time, my 'secret' is to have a calendar, put relax time in the calendar, and actually keep to the calendar.

I believe that forming habits, and learning to love good habits, not just exercise but also healthy foods, are key, and the more something is a habit the less you have to think about it.

Lastly, I wasn't involved with any patient community for most of my life and didn't know anyone else with a bleeding disorder until around age 22. When you live with a rare condition and you are only surrounded by people who don't understand what you are

going through, you have a real sense of difference so it was transformative for me to get involved with various patient groups and patient organisations. I would encourage anyone with a bleeding disorder to connect with a patient community to be surrounded by people who know what it's like to have a bleeding disorder.”

*Disclaimer: always consult with a healthcare professional before beginning a new exercise program.*