Congress: stories of challenge and resilience

Lenny

In April 2026 I was absolutely honoured to be invited to speak at the WFH (World Federation of Hemophilia) 2026 World Congress in Kuala Lumpur, Malaysia. I spoke at two separate workshops from the PWBD (People with Bleeding Disorders) psychosocial stream. In both sessions I was interviewed by Alfred Health Social Worker Jane Portnoy.

CHALLENGES AND COMPLICATIONS

In the first workshop, '*Psychosocial strategies in managing bleeding disorders*', I shared challenges and complications of living with haemophilia: the emotional struggles of dealing with intravenous treatments, the pain and the internal trauma with needle phobia and having to be treated very frequently. Thanks to the advancement of haemophilia treatment over the years, from on-demand, prophylactic, extended-half-life, and now, bypassing agents and changes from intravenous to subcutaneous mode of delivery, I can now take control of my own treatment and enjoy more freedoms, which is empowering. It is indeed amazing to see/experience firsthand how far haemophilia treatment has progressed.

The second workshop was the following day: '*The weight we carry: psychosocial realities of living with bleeding disorders*'. Although I attempted playing sports as a kid, being vision impaired meant I was always hit by the ball, and eventually, I developed a habit of running away from the ball/my team mates instead of catching it (needless to say, nobody wanted me on their team!). I was also very uncoordinated, having mild palsy, and was weaker on my left side.

FINDING MUSIC

From a young age, I already expressed a fascination and desire to play the piano, from listening to my cousins and aunts practicing at my grandmother's house. After much searching, mum eventually found a music school that was willing to give an uncoordinated, blind student a go.

When I began primary school, a teacher suggested that I should take up a group instrument, as I wasn't involved in sports. At the time, the only music instruments available were violin and cello. Because of my shunt being on my left side, violin was inadvisable, so the teacher had to find a group of students willing to be in a cello group. Although I was competent, I discontinued cello after one year as I found it cumbersome to carry.

I chose the clarinet as it was more portable (and I liked its mellow tone) and enjoyed being a member of school concert bands in my junior and senior years.

This allowed me to safely involve myself in a social activity as participating in sports and bush camps were dangerous for me as a person with comorbid vision impairment and haemophilia.

Lenny sharing his experiences with Jane Portnoy in their Congress presentation

STORIES OF RESILIENCE

Listening to other speakers talk about their experiences with haemophilia, three things that particularly resonated with me: the stigmas experienced by some haemophilia communities, the use of AI (artificial intelligence) for treating and discussing haemophilia in remote communities, and the willingness to reveal a haemophilia diagnosis when planning a family.

It was eye opening to hear about the incredible innovations, experiences and insights from various communities. Some participants revealed that getting tested for a bleeding disorder may negatively affect their employment, social, education and employment opportunities.

It's one thing to hear about dramatic stories, quite another to actually see the people who are telling their stories of their struggles.

L-R Tim (Australia), Michael (Malaysia), Lenny

An urgent need for language reforms were also discussed: currently, women are blamed for being 'carriers' of the haemophilia gene alteration. This overlooks the fact that about a third of haemophilia cases are caused by a spontaneous genetic mutation, and women can also be affected by a haemophilia diagnosis. Hopefully through better education and medical care such issues can be resolved.

It is amazing that AI is being developed to support, diagnose and treat bleeding disorders in remote communities such as Saytù Hemophilia, a chatbot developed by Dr. Awa Babbington-Ashaye for the Senegal community.

In the session '*Am I selfish for wanting a family? Family planning for people with bleeding disorders*', Taqrir Akramin Bin Khalib, a patient with severe haemophilia B, shared with us his story and various strategies about disclosing his haemophilia diagnosis with his partner/partner's family, such as sharing his treatment regime, inviting her to camps and haemophilia community meetings, so that she feels involved and realises that a life with haemophilia is nothing to be ashamed about. I was deeply moved by his talk.There were so many interesting talks happening concurrently that it was impossible to attend all of them, but I have definitely walked away with a greater appreciation of the courage of the haemophilia community and the wonderful medical and technological research and advancements that is happening all over the world.

Speaking at this event was an amazing experience. Thank you to WFH for encouraging me to speak at this event, share my experience, and most of all meet, learn and connect from the broader bleeding disorder community. They offer courage and positive attitude towards a better future.

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Lenny is a member of the Australian bleeding disorders community