



What's possible in haemophilia treatment?

Alison Morris

The 16th Annual Congress of the **European Association for Haemophilia and Allied Disorders (EAHAD)** was held in Manchester, UK between 7 and 10 February 2023. Taking as its focus *'Knowledge and treatment advances require us all to re-examine what's possible'*, the Congress explored the implications for both people with bleeding disorders and the Haemophilia Treatment Centre teams who manage their treatment and care.

The Congress was run in a hybrid format, allowing the European haemophilia community the opportunity to reconnect in person after two years of online meetings while at the same time promoting attendance from a broader global community through a virtual option. The Congress included a separate Allied Health Professionals Day with concurrent streams for nurses, physiotherapists and psychosocial professionals.

NEW THERAPIES AND PHYSIOTHERAPY

One of the overarching themes of the Congress related to the rapid advancement in new therapies for those with haemophilia, including improved extended half-life (EHL) products, non-factor therapies and gene therapy. There is optimism that this will result in a reduction in joint and muscle bleeds with a subsequent reduction in haemophilic arthropathy raising the question of whether physiotherapy will still be a necessary part of the multidisciplinary care team into the future. Many of the presentations demonstrated that the physiotherapy profession will continue to form an integral part of the care team in a

multitude of roles including:

- Developing new outcome measures that are more sensitive to subtle change
- Advocating for people with haemophilia to participate in a wider range of sporting and recreational activities and
- Ongoing education and support of people with haemophilia in both bleed and sport injury management and prevention.

HAEMOPHILIA PHYSICAL FUNCTION OUTCOMES

During the Allied Health Professionals day, renowned UK based physiotherapist David Stephensen gave a presentation on *Consensus on outcomes of physical function and activities for persons with haemophilia: results from the 'IPOP' Study*.

At their Annual Meeting in 2021, the Australia and New Zealand Haemophilia Physiotherapy Group (ANZHPG) were lucky to have David present the initial work in developing Performance Based Outcome Measures of Physical Function in patients with haemophilia. The aim was to determine a battery of physical function tests that would complement the current Haemophilia Joint Health Score (HJHS) and joint examination in future assessments. Using domains from the International Classification of Function (ICF), 11 activities were identified by persons with haemophilia as those they had the most difficulty with, of which the four most important were **walking long distances, running, hopping and undertaking a complex lower limb task**.

At EAHAD, David provided a project update and the team have now identified **seven clinical tests** that could potentially be used to measure performance in these activities. These tests have been considered meaningful to physiotherapists and importantly, practical and feasible to perform in clinical practice as they are quick and do not require specialist equipment.

They are:

- **Six minute walk test (6MWT)**
- **Timed up and down stairs**
- **30 second sit to stand**
- **Single leg balance**
- **Tandem stance**
- **Single hop for distance (children only)**
- **Timed up and go (adults only)**

The team are now undertaking the next stage of the project, which involves evaluating the psychometric properties of all these tests before proposing a core outcome set for the quantitative measure of physical function in people with haemophilia. David and his team were recipients of an EAHAD Research Grant at the conclusion of the conference to fund further work on this project.

SPORT AND HAEMOPHILIA

Another exciting session in the main congress was a multidisciplinary educational session on *Supporting sports in haemophilia*.

This session started with a presentation by German physician, Thomas Hilberg on *'tailored treatment for supporting sports in haemophilia.'* The opening message was the need for all people (including those with haemophilia) to be meeting the World Health Organisation (WHO) physical activity guidelines as this has proved to reduce risk factors for all-cause mortality.

He then went on to discuss the need for people with haemophilia to liaise with their Haemophilia Treatment Centre to ensure they choose sports and activities that are appropriate for them and that there is definitely no 'One Size fits All'. Consideration needs to balance risk of injury versus benefit but also allow for individual preference. This involves shared decision-making regarding choice and timing of prophylaxis, education regarding the most common injuries, differentiating these injuries from joint and muscle bleeds and implementing rehabilitation and prevention strategies.

This was followed by an inspiring presentation by Clive Smith – *'How running changed my life'*. Of all the excellent presentations over the course of

'Limits like fear are often only an illusion'

the congress this was probably the one that resonated most strongly with me. Clive is well known in the international bleeding disorder community

and is currently a Board Member of The Haemophilia Society UK. He is also a passionate patient advocate who has severe haemophilia A.

Clive described growing up in the 1980s, the era before regular prophylaxis, and spending much of his youth on crutches or in a wheelchair due to frequent joint bleeds. Once on regular prophylaxis, he was finally able to participate in physical activity and sport. He started running, later adding swimming and cycling into his regime to limit the repetitive load on his ankles, and this led him to 'dare to dream' - to complete an Ironman Triathlon. For those of you who aren't in the sporting sphere this entails a 3.8km swim directly followed by a 180km cycle, finished off with a marathon distance 42km run. Definitely not an event for the faint-hearted.

He described his apprehension in asking his HTC physiotherapist whether he would support him in his 'crazy' endeavour but was aware that to be successful he would need the expert advice that only someone experienced in haemophilia care could provide. He reflected that his physiotherapist's response was not perhaps what he was expecting with him being given the support that he needed and in 2014, he became the first person with severe haemophilia to complete an Ironman Triathlon.

The advice to allow your physiotherapist to work with you in achieving your goal rather than trying to do it alone is one that I echo. Especially now, in the times of changing treatment regimens and less haemophilia arthropathy, all people involved in haemophilia care need to shift their expectations with regards to what can be achieved in the physical activity domain.

Anything (well, almost anything) is possible.

I look forward to exploring these topics further when reconnecting with our community at the upcoming 21st Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders in Melbourne in August. See you there.

.....

Alison Morris is Senior Musculoskeletal Physiotherapist at the Haemophilia Treatment Centre at Perth Children's Hospital, WA

.....