

# New and emerging issues in physiotherapy

*Abi Polus*

I was extremely lucky to be supported to attend the **17th Annual Congress of the European Association for Haemophilia and Allied disorders (EAHAD)** meeting in Frankfurt in February 2024. I felt it was important to attend further education as the management of haemophilia and other bleeding disorders is rapidly changing and it is vital that clinicians keep up with the changes in real time so that we can best treat the people we look after.

## CHANGES TO BLEEDS

I am seeing people with bleeding disorders in the haemophilia clinic and on the hospital ward who are having a different presentation of bleeding to what we had traditionally seen. People who are on non-factor therapies, extended half-life products, and gene therapy now report significantly fewer bleeding episodes, but bleeds they do have can be more difficult to identify, or as a few of my patients have described as 'feel weird'. This can lead to late presentation and an increased period of dysfunction. We are also seeing increased presentations of people who are having muscle bleeds and we need to consider why this may be.

It was extremely interesting to attend the Congress and note that this is an issue around the world and that many, many musculoskeletal health

professionals and other members of the multi-disciplinary team are all seeing this. Lectures and formal and informal discussions all discussed this phenomenon.

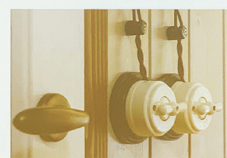
An entire day prior to the Congress was devoted to physiotherapy management and was extremely informative for me. An interdisciplinary session combined with nursing and psychosocial services had a discussion of non-factor therapies, with very relatable and pertinent case studies, leading to an interactive and informative discussion about what we are now seeing and how it has changed. In particular, and extremely relevant was senior physiotherapist and patient advocate Dr Paul McLaughlin from the UK demonstrating a case of joint decision making in choosing treatment and presentation of musculoskeletal issues. >

The third case:  
Moving from FVIII to Efficizumab (and back again...)



Paul McLaughlin

Royal Free London NHS Foundation Trust



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Further talks by some key Haemophilia Physiotherapy researchers addressed perspectives on how bleeding has changed with new therapies (Prof David Stephensen, UK), difficulties in recognising bleed or not bleed (Merel Timmer, Netherlands) and a further case presentation interview with a patient using non-factor therapy (Paul McLaughlin, UK).

## LATEST RESEARCH

This was followed by a SLAM session, where 10 minute presentations of 6 recent musculoskeletal related trials were presented. These were very interesting and included using light-up pods to improve balance and reaction time, developing an allied health program with an occupational therapist (which I have personally been advocating for, for a long time!!). Utilisation of local physiotherapists (those outside haemophilia treatment centres/HTCs) in the Netherlands was discussed. I agree with this concept, but it made me smile that they emphasised that some patients had to travel up to an hour to get to their centre, where we know that is minimal for most of our patients, where 4 hours or more to access HTCs is not unusual. A systematic review of outcome measures was interesting.

The SLAM session I found of most interest was one that was using evidence to co-design (physio and patients) to develop a virtual-based program that aims to increase confidence to exercise for people with haemophilia by Stephanie Taylor, a UK-based physiotherapist. She described the collaboration with patients about what they really wanted in an exercise program, which was then delivered. The final session was a return to sport lecture by Dr Thomas Hilberg (Germany), using principles of healing times and stressing the need to find the delicate balance of not returning too early so re-bleeding and re-injury risk is high, and not too late where loss of range and strength and muscle and bone mass may be difficult.

Throughout the rest of the congress there were various interesting sessions with themes including von Willebrand disease (VWD), women and bleeding disorders, novel therapies, acquired haemophilia, artificial intelligence (AI) and pain. The following is a summary of those sessions of particular interest.

## ARTIFICIAL INTELLIGENCE (AI)



An AI Session by various doctors was very informative, with the message that this is not a topic that we can ignore or shy away from: it is the present and the future and is going to be around and we need new skills and literacy in AI. We are using technology with electronic medical records, registries, telehealth, apps, internet platforms and various other media. We need to use it with ethical principles of transparency and responsibility. Prof Mike Makris, a haematologist in the UK, was enlightening in his talk on AI in scientific communication and gave us quite frighteningly real examples of deep fakes - and the trust we may need to challenge. One example he gave is there could potentially be a circulating video of him/us with same face/voice - saying something that he/we have never spoken about. They could have us saying anything - how would we know what is truth? He stated that we cannot avoid it by ignoring it; it is already mainstream.

He also discussed Generative pre-trained Transformer (Chat GPT) and how it can be used ethically and how it should not be used. He highlighted the inadequacies in AI: in general it is prone to mistakes and cannot currently assess quality. It can 'hallucinate and fabricate' (i.e., make things up) and AI tools do not cite their sources and make up references. He told us of a site called Retraction Watch that has tracked 14,000+ papers retracted in last 5 years. This is great in that papers are being authenticated, but worrying that we may read something incorrect that has been made up and not yet validated. All peer-reviewed professional journals have rules on AI and you have to declare use of AI in a research paper. We need to use AI ethically and vigilantly.



## JOINT HEALTH AND PAIN

An excellent session was on joint health in haemophilia in an evolving treatment landscape.

Dr Annette Von Drygalski (USA) discussed the clinical implications and joint bleeding, joint remodelling, chronic pain and reduced quality of life (QOL) and noted that poor joint health is a globally reality. Dr Hortensia de la Cortez-Rodriguez (Spain) discussed current joint health measures and emerging challenges including the subclinical bleeding being undetected. In a study of people with non-severe haemophilia A and no history of a joint bleed, haemosiderin (residual blood) deposits were found in 14% of people who did not report any symptoms. >

Prof David Stephensen (UK) discussed the biomechanical and neuromuscular changes in joint and muscle bleeds, the perception of pain and psychological impacts. He reiterated that pain does not directly correlate with structural damage. He presented various studies in haemophilia that addressed this. He discussed the study by McLaughlin who interviewed patients with pain regarding their views of management and exercise and of note mentioned a patient comment of ‘[it is] difficult to score out of 10 as something you live with’, which certainly made me think and consider my practice and questioning.

## IMPACT OF NEW THERAPIES

A session on non-factor therapies for haemophilia and VWD by Dr Steve Pipe (USA) discussed new therapies like emicizumab and some in advanced clinical trials. Dr Andreas Tiede (Germany) discussed change in acquired (non-hereditary) haemophilia, which was very interesting. A session on the optimised outcome of haemophilia treatment, ‘Towards a haemophilia free mind’ by Dr Cedric Hermans (Belgium), included thought on people with haemophilia who may no longer bleed needing physical coaching to get them where they want to be. In discussing long term joint health, Dr Roberta Gualtierotti (Italy), noted that originally >1 % of circulating factor level was thought to be protective, then 3-5%, and now it is considered the factor level may be even be higher. She discussed synovitis (inflammation of the joint lining) and the unmet needs we still have - tools to collect early detection of joint damage.

Professor and physiotherapist David Stephensen highlighted the need for more uniform assessment tools and identified the need for more meaningful

and guided rehabilitation. He is involved in current research - which I have been contributing to – and is aiming for a core set of performance-based tests to monitor physical function across lifespan. He has identified 7 tests - tests that are widely used in other musculoskeletal conditions. Another outstanding talk was by Anna Wells, a UK-based physiotherapist, who explored post-traumatic stress symptoms and pain memories in people with haemophilia and the influence on their current pain. It was extremely interesting. She found perceptual and emotional parts of pain were difficult to verbalise. People with haemophilia could recall and relive pain and trauma even in presence of no painful stimuli. She suggested that HTCs need to be trauma informed and management may need to include reprogramming memories. She discussed how psychosocial input can be extremely valuable here. This may become even more relevant in the future for children who may not have ever needed intravenous (IV) access but may in the presence of a rare bleed when they are in an acute situation that is already scary and painful.

I was also able to discuss ideas for research and general patterns of presentation with my global colleagues and took comfort in we are all experiencing similar issues with novel therapies and bleed identification, different bleed presentation to what we have experienced previously and different management, and various other changes. I was able to bounce ideas for collaboration and be inspired by the amazing research my colleagues are doing overseas and ponder how we may do similar in Australia to identify need and improve services in Australia.

I am extremely grateful to have been supported in having the in this opportunity to attend, which has reassured me that my work with patients is similar to my colleagues around the world and can challenge me to improve my skills and better help those around me.

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*Photos: Abi Polus*

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