

Haemophilia Chartered Physiotherapists' Association

We aim to define, promote and encourage best practice for physiotherapy within haemophilia care, providing professional leadership and directing national physiotherapy policy.

Executive Committee

Anna Wells	Chair:
David Hopper	Vice-Chair
David Stephensen	Research Lead
Hannah Harbidge	Secretary
Joanne Minshall	Treasurer

Research

Over the past 12 months HCPA members have continued to support and facilitate a thriving research and innovative environment. The annual meeting includes a half-day session focussed on sharing and developing research activity. As well as contributing joint score data to a multitude of observational and interventional studies, HCPA members have actively published and initiated several single and multi-centre musculoskeletal studies. Key papers published by the group this year include a thorough review of recent advances in musculoskeletal physiotherapy for haemophilia [Stephensen, Bladen & McLaughlin, *Therapeutic Advances in Hematology*; 2018; 9(8):227-237], and inter-rater reliability of physiotherapists performing the Haemophilia Early Arthropathy Detection with Ultrasound (HEAD-US) protocol to evaluate synovitis and joint arthropathy [Stephensen, Classey, Harbidge, Patel, Taylor, Wells; *Haemophilia*; 2018; 24(3):471-476]. At the WFH Congress this year in Glasgow, three of the eight musculoskeletal abstracts selected for the free paper presentation session were submitted by UK physiotherapists. Hannah Harbidge presented a study evaluating the *inter-rater variability of global gait score assessment using the HJHS criteria*; Vishal Patel presented a paper reporting a novel physiotherapy-led musculoskeletal clinic for people with haemophilia and their perceptions of this clinic; and Steve Classey presented interim results of a real-world study on the use of *point of care ultrasound imaging to guide treatment decision in people with haemophilia*. Elizabeth Bradshaw will be presenting her work on *measuring change following an acute bleed episode - what outcome measures do haemophilia patients think are of most value* at the national Chartered Society of Physiotherapy 2018 congress. Based on this work, Elizabeth has secured funding from the NIHR Pre-doctoral Clinical Academic Fellowship scheme to develop a *proposal to investigate the effectiveness of pulsed shortwave diathermy (PSWD) in the treatment of acute bleeds, with a view to conducting a trial researching home-based versus hospital based delivery*.

NIHR Research Fellow, David Stephensen has led NIHR funding grants to investigate a *feasibility study exploring the benefits of a muscle strengthening programme for children*

with haemophilia and a Novo Nordisk Access to Insight Clinical Research Grant to explore use of home ultrasound to empower the haemophilia patient to distinguish between bleeding and non-bleeding episodes. David Hopper will undertake a PhD linked to this work. Steve Classey has received a Pfizer Investigator Initiated Research grant to explore the use of point of care ultrasound imaging to guide treatment decision in people with haemophilia. Paul McLaughlin was successfully awarded a NIHR clinical doctoral research fellowship to complete a PhD in which he will investigate a rehabilitation intervention for the management of chronic arthritic joint pain in people with haemophilia. Paul McLaughlin in collaboration with Haemnet have received a Pfizer Investigator Initiated Research grant to bring together haemophilia professionals (nurses and physiotherapists) and personal trainers to develop a disease-specific fitness programme that can be delivered to young men with haemophilia to increase levels of participation in exercise and physical activity. Melanie Bladen was successfully awarded funding from the Sir William Coxen Trust to investigate the feasibility and sensitivity of using the i-STEP (an incremental step test standardised for height) to monitor physical function in boys with haemophilia.

An international collaboration led by the HCPA has been established to identify and standardise a core set of performance-based outcome measures of physical function in people with haemophilia (IPOP). The rationale for this work is based on the comprehensive evaluation and description of health recommendations of the World Health Organisation via the International Classification of Function (ICF) framework that suggest severity of health conditions are best described in terms of “Body Structures and Functions”, “Activities” and “Participation”. Activity reflects ability to perform daily tasks while participation reflects involvement in life situations. Current physical assessment of haemophilia focuses on joint structure, with little information on function or ability to perform and participate in activities. Furthermore, patients report little benefit from the HJHS in understanding their health. Standardising a core set of outcomes is necessary whilst minimising patient burden of multiple assessments. A consensus-based, decision analysis approach will be used to select the performance-based measures of physical function. This will be achieved through focus groups utilising Nominal Group Techniques as well as a series of online decision surveys.

In collaboration with the EAHAD Physiotherapy Committee, we have completed a survey of the role and scope of practice of haemophilia physiotherapists in Europe. This information will be used to establish principles of physiotherapy practice for people with haemophilia to support professional education strategies and self-governance of physiotherapists.

Anna Wells,
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September 2018