

Haemophilia Chartered Physiotherapists' Association

The HCPA consists of specialist physiotherapists working in haemophilia and allied bleeding disorders services across the UK and Ireland. 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
Elizabeth Bradshaw & Sarah Jones	Secretary
Joanne Minshall	Treasurer

Peer Review

The peer review process has highlighted inadequate levels of physiotherapy provision in 60% of the haemophilia services reviewed across the UK. HCPA members have been able to use the reports to raise the profile of this problem to local senior managers and commissioners. To date, of the 22 centres where provision was assessed as inadequate, 9% have achieved a significant improvement, 59% are in progress with on-going meetings and business cases being put in place, and 32% remain with significant barriers.

Research

The HCPA is proud to support and facilitate a thriving research environment. Members have successfully received NIHR and commercial grant funding. Current NIHR funded research includes:

- Haemarthrosis of the ankle in haemophilia A and B: prevalence, impact and intervention.
NIHR Academy HEE/NIHR ICA Clinical Doctoral Academic Fellowship, ICA-CDRF-2015-01-012
Richard Wilkins
- Developing a rehabilitation intervention for the management of chronic arthritic joint pain in people with haemophilia.
NIHR Academy HEE/NIHR ICA Clinical Doctoral Academic Fellowship, ICA-CDRF-2017-03-050
Paul McLaughlin
- Development of a haemophilia physiotherapy intervention for optimum musculoskeletal health in children (DOLPHIN-II) - a randomised controlled trial.
NIHR Research for Patient Benefit (RfPB) Programme, NIHR-201588
David Stephensen, Melanie Bladen, Liz Carroll, Ferhana Hahsem, Tracy Pellat-Higgins, Eirini Saloniki

The annual meeting includes a half-day session focussed on sharing and developing research activity, as well as a free papers session for members to showcase their work in the format of a five minute assessed oral presentation. The HCPA encourages collaboration and members continue to initiate, present and publish key papers on an international level. Melanie Bladen has been invited to join the International Prophylaxis Study Group (the IPSTG), a collaborative group of health care professionals involved with the assessment and care of individuals with inherited bleeding disorders, which is currently exploring the utility and modification of the Haemophilia Joint Health Score (HJHS).

At EAHAD in February 2020, HCPA members contributed 20 posters and six presentations. In the Physiotherapy SLAM Oral presentation session five of the seven abstracts selected were from HCPA members.

- Physical activity and cardiometabolic risk profiles amongst Irish adults with severe haemophilia: the Irish personalised approach to the treatment of haemophilia (iPATH) study, M Kennedy
- Project gym: promoting fitness in haemophilia, P McLaughlin
- DOLPHIN: development of a haemophilia physiotherapy intervention for optimum musculoskeletal health - interim results of a randomised controlled trial, D Stephensen
- Identifying performance-based outcome measures of physical function in people with haemophilia (IPOP), M Bladen
- Reliability of the i-step in children with haemophilia, D Chugh
- Prevalence of haemarthrosis and clinical impact on the musculoskeletal system in people with haemophilia in the United Kingdom; evaluation of NHD and Haemtrack patient reported data, R Wilkins.

Melanie Bladen won first prize for her presentation on the IPOP (Identifying Performance-based Outcome measures of Physical function in people with haemophilia) study and David Stephensen second prize for the interim results of the DOLPHIN study which explored feasibility of a randomised controlled trial of an exercise programme for children with haemophilia. Megan Kennedy won third prize for her poster on Physical activity and cardiometabolic risk profiles amongst Irish adults with severe haemophilia: The Irish Personalised approach to the treatment of Haemophilia (iPATH) study.

Publications in 2020:

1. Flannery T, Bladen M, Hopper D, Jones S, McLaughlin P, Penn A, Sayers F, Wells A & Stephensen D (2020). Physiotherapy after COVID-19 - "Zoom or room". *Haemophilia*, Early view. <https://doi.org/10.1111/hae.14166>
2. McLaughlin P, Aspdahl M, Matlary RED, Grinda N, Katzerova M, O'Mahony B, Stephensen D, Lobet S. (2020) Comprehensive care on paper only? The challenge for physiotherapy provision in day to day haemophilia practice. *Haemophilia*. Early view. <https://doi.org/10.1111/hae.14150>
3. Kuijlaars IAR, van der Net J, Feldman BM, Aspdahl M, Bladen M, et al. (2020) Evaluating international Haemophilia Joint Health Score (HJHS) results combined

- with expert opinion: Options for a shorter HJHS. *Haemophilia*. Early view. <https://doi.org/10.1111/hae.14180>
4. Wells AJ & Stephensen D (2020). The role of the physiotherapist in the management of people with haemophilia: defining the new normal. *Br J Hosp Med*, 81(8). <https://doi.org/10.12968/hmed.2020.0016>
 5. Bladen M, Carroll L, Dodd C, Drechsler WI, Hashem F, Patel V, Pellatt-Higgins T, Saloniki E, Stephensen D (2020). Results of feasibility and safety of randomised controlled trial of a musculoskeletal exercise intervention versus usual care for children with haemophilia. *Haemophilia*. 26(5): e223-225. <https://doi.org/10.1111/hae.14026>
 6. McLaughlin P, Hurley M, Chowdary P, Khair K & Stephensen D (2020). Physiotherapy interventions for pain management in haemophilia: a systematic review. *Haemophilia*, 26(4):667-684. <https://doi.org/10.1111/hae.14030>
 7. Taylor S, Room J, Barker K (2020). Physical activity levels in men with Haemophilia—A single centre UK survey. *Haemophilia*, 26(4): 718-725. <https://doi.org/10.1111/hae.14009>
 8. Hashem F, Bladen M, Carroll L, Dodd C, Drechsler WI, Patel V, Pellatt-Higgins T, Saloniki E, Stephensen D (2020). Muscle strengthening intervention for children with haemophilia: co-designing a best-practice exercise programme with children, families and healthcare professionals. *Health Expectations*. <https://doi.org/10.1111/hex.13119>
 9. O'Donovan M, Buckley C, Benson J, Roche S, McGowan M, Parkinson L et al. (2020). Telehealth for delivery of haemophilia comprehensive care during the COVID-19 pandemic. *Haemophilia*, 00:1-7. <https://doi.org/10.1111/hae.14156>
 10. Bradshaw E, McClellan, Whybrow P, Cramp F (2019). Physiotherapy outcome measures of haemophilia acute bleed episodes: What matters to patients? *Haemophilia*, 25(6): 1066-1072. <https://doi.org/10.1111/hae.14180>

Covid-19

At the beginning of lockdown HCPA members worked quickly to provide online resources for both patients and fellow clinicians. Members have supported one another with the move to virtual consultations, alongside the challenges of redeployment and for some, significant changes to departmental infrastructure. The adaptability and positivity shown is a credit to HCPA members whose focus is always on providing the highest quality of patient care.

Meetings

1. 5th -6th March 2020 Annual educational meeting & AGM, Birmingham. Brenda Buzzard award & CPD bursary winner for best free paper: Steph Taylor 'Past the tipping point: a qualitative study of the views and experiences of men with haemophilia regarding mobility, balance and falls'.
2. 2nd July 2020 Virtual educational meeting
3. November 2020 Virtual educational meeting

4. 5th March 2021 Virtual annual educational meeting & AGM

UK Standards of Care

- <http://www.ukhcdo.org/wp-content/uploads/2020/06/2020v1-Children-Service-Provision-of-Physiotherpay-in-Haemophilia.pdf>
- <http://www.ukhcdo.org/wp-content/uploads/2020/06/2020v1-Adult-Service-Provision-of-Physiotherapy-in-Haemophilia.pdf>

HCPA Constitution

- http://www.ukhcdo.org/wp-content/uploads/2019/01/FINAL_HCPA_Constitution.pdf

Anna Wells,
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