

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

David Hopper	Chair
Stephen Classey/Stephanie Taylor	Vice-Chair
David Stephensen	Research Lead
Sarah Jones	Secretary
Joanne Minshall	Treasurer

The committee was re-elected at the 2021 AGM in March and the positions will be held for a two year period before another election at the 2023 AGM.

Peer Review

The peer review process 2019/20 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.

Work is currently ongoing with the HCPA working closely with the CRG and the Haemophilia Society to raise the profile of the importance of physiotherapy within haemophilia care. Raising the profile will hopefully help address the disparity in care across the UK. A Checklist for centres to audit their physiotherapy service against current UKHCDO guidelines and a comprehensive information sheet with documenting the importance and benefits of adequate physiotherapy provision for all CCC is currently in draft, waiting to be signed off.

Work has also been ongoing with individual centres helping them prepare business cases to present to their centre directors.

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. This will take place again next year 2022 as we intend to host this meeting face to face if possible.

The HCPA encourages collaboration and members continue to initiate, present and publish key papers on an international level. Melanie Bladen was 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) this is ongoing.

At EAHAD in February 2021, despite the challenges faced HCPA members contributed to numerous poster presentations and 5 presentations three of which were in the main programme. In the Physiotherapy SLAM Oral presentation session two of the six abstracts selected were from HCPA members.

- PANEL PRESENTATION BY THE DUBLIN HAEMOPHILIA CENTER, Sheila Roche, Shona Brady, Patricia Byrne & Mairéad O'Donovan
- DIFFERENTIATING JOINT BLEEDING AND HAEMOPHILIA ARTHROPATHY - A QUALITATIVE STUDY, David Hopper.
- FEASIBILITY STUDY OF AN EDUCATION AND EXERCISE CLASS FOR HAEMOPHILIA PATIENTS ATTENDING THE NATIONAL COAGULATION CENTRE DUBLIN, Sheila Roche.
- MOTIVATION FOR PHYSICAL ACTIVITY IN THE AGE OF NEW TREATMENTS - PAEDIATRICS, YOUNGER ADULTS, OLDER ADULTS - OLDER ADULTS, Fionnuala Sayers.
- WEARABLE SENSOR TECHNOLOGY FOR MUSCULOSKELETAL AND PHYSICAL HEALTH, David Stephensen.

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.

As the pandemic has continued during 2021 we have worked to continue to strive to provide high levels of patient care throughout this period. Face to face consultations returned for regular clinic reviews which was important to monitor joint health and identify any other psychosocial issues that may be underlying, some virtual consultations have continued. We have continued to support each other virtually and our contribution to research is ongoing. The adaptability and positivity shown is a credit to HCPA members whose focus is always on providing the highest quality of patient care.

Quality Health 2020 Haemophilia Survey

This survey was conducted in 2020. The survey includes 96 responses from people with Haemophilia A, Haemophilia B, Von Willebrand Disease and Acquired Haemophilia, with data collected in areas including quality of life, involvement in treatment and care, self-management and the impact of COVID-19. Results from one of the questions related to physiotherapy is shown below;

Q39e - How would you rate the support you received for haemophilia or other bleeding disorders from these professionals in the last year? Clinical specialist physiotherapist

- Excellent 71%
- Good 20%
- Not Available 9%

Meetings

- 5th March 2021 Virtual annual educational meeting & AGM
- Northern Physiotherapy Group - Monthly CPD sessions 2021
- Southern Physiotherapy Group - Monthly CPD sessions 2021

Planned Meetings

- March 2022 – HCPA AGM (Face to Face)

UK Standards of Care

- <http://www.ukhcdo.org/wp-content/uploads/2020/06/2020v1-Children-Service-Provision-of-Physiotherapy-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

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