

PROFESSIONAL DEVELOPMENT

UK physiotherapy and haemophilia: A future strategy built on past success

Melanie Bladen, David Stephensen, Paul McLaughlin

From its humble beginnings in 1990, the UK's Haemophilia Chartered Physiotherapists Association (HCPA) has led the development of haemophilia physiotherapy in the UK and increasingly across Europe too. Over the past 10 years, the growth of the group has centred on an annual professional meeting that facilitated educational opportunities and professional networking, and has increasingly promoted research among members. The HCPA has now established a Clinical Studies Group, an open forum designed to identify and support research needs and to promote a collaborative approach to research that will answer some of the important questions that remain about haemophilia care.

Keywords: physiotherapy, HCPA, research

The Haemophilia Chartered Physiotherapists Association was formed in the UK in 1990. A notice was posted by Brenda Buzzard in the journal *Physiotherapy* announcing a recently formed group established "to promote the interchange of ideas about the management of patients with congenital bleeding disorders". She and four colleagues – Karen Beeton, Ruth Bolton, Fiona Hall and Fiona McChesney – had already held one meeting, a few months earlier at the Royal Free Hospital, London, and they wished to develop a forum for communication via a newsletter and regional meetings. Indeed, a series of meetings were then organised at haemophilia centres around the UK, allowing participants to share experience of current practice and particularly to discuss complex clinical cases. This was in the difficult era of the medical management of patients infected with HIV and hepatitis C; many were very sick and management of haemophilia often took a secondary place to those diseases. But over time, the HCPA began to flourish. Members became involved in the WFH musculoskeletal committee;



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they networked with international colleagues; and they put together programmes for meetings that would develop clinical standards.

The impetus to take the group to the next level and to establish a national meeting of haemophilia physiotherapists came from the then Medical Director of Bayer, Professor Ian Hann, formerly Professor of Paediatric Haematology and Oncology at Great Ormond Street Hospital. He identified the need to provide CPD and support for physiotherapists in haemophilia, similar to that which was available to the specialist nurses. He offered to sponsor a meeting, which would give an opportunity for physiotherapists to identify their own learning needs, allowing the invitation of external speakers and worldwide experts in the field. The offer was enthusiastically accepted by physiotherapists.

Those leading its development (Melanie Bladen, David Stephensen and later Paul McLaughlin) identified a clear set of aims. At a time when very little current practice was evidence-based or research-orientated, and was instead largely based on individual case studies and "on-the-job" learning, the physiotherapists felt there was a clear need to establish a regular supported meeting that would seek to improve and ensure academic content. The meeting would also provide an excellent opportunity for peer-support and networking, so that physiotherapists who were working with complex clinical presentations could discuss management approaches with others. Finally, the meeting would also seek to promote research among physiotherapists.

The first meeting was held in Birmingham in 2007, the year in which it was prospectively demonstrated for the first time that prophylaxis with recombinant factor VIII can prevent joint damage and decrease the frequency of joint and other

Melanie Bladen MSc
Physiotherapist, Great Ormond Street Hospital for Children NHS Foundation Trust, Great Ormond St, London WC1N 3JH, UK
Email: Melanie.Bladen@gosh.nhs.uk

David Stephensen PhD
Physiotherapist, Kent Haemophilia & Thrombosis Centre, Canterbury, UK
Email david.stephensen@nhs.net

Paul McLaughlin MSc
Physiotherapist, Katharine Dormandy Haemophilia Centre and Thrombosis unit, Royal Free Hospital NHS Foundation Trust, Pond St, London, NW3 2QG, UK
Email: p.mclaughlin@nhs.net

haemorrhages in young boys with severe haemophilia A [1]. On the basis of this publication, prophylaxis came to be accepted as the gold standard treatment for haemophilia.

Several eminent specialists were invited to speak at the inaugural meeting. They included Frank van Genderen, who had devised the Haemophilia Activities List (and later the PedHAL), Pam Hilliard, who had been instrumental in the development of the Haemophilia Joint Health Score, Bjorn Lundin who discussed MRI and joint pathology, and Natalie Jansen, who had worked with Goris Roosendaal and been involved in the studies that had provided evidence to support current advice on PRICE and non-weight-bearing in the early days of haemophilic bleeding [2]. This meeting established a tradition that continued with subsequent meetings (Table 1), which have now covered a comprehensive range of clinically relevant topics, all of which have been based on the group's own identified learning needs as well as feedback received from meeting attendees. It is notable that in the early HCPA meetings, the lack of expertise in the UK meant there was a need to invite international speakers to speak at meetings. This is no longer the case. The expertise in physiotherapy globally is now well represented in the UK.

The 2007 meeting was attended by 20 physiotherapists; by 2016 there were 34 physiotherapists in regular attendance. As the number of physiotherapists employed (or with protected hours) within the UK's haemophilia centres has grown, so too has the level of professionalism of those in practice.

Key achievements in the last decade have included:

- An established annual national meeting
- Inclusion of a 'free paper' session at the annual meeting, allowing members of the HCPA to present ongoing research work, as well as provide a safe and supportive forum in which to develop the skills required to submit such work to international meetings. Meeting sponsorship has allowed for a CPD bursary to be allocated to the winning free paper at the meeting, and so those HCPA members who get the opportunity to go to the international meetings to learn and network are able to bring back new information to share with our colleagues
- Standardised HJHS teaching
- Development of Standard of Care documents for adult and paediatric physiotherapy services, based on the Chartered Society of Physiotherapy (CSP) professional standards framework.
- Increasing engagement in clinical research enhancing the knowledge base of the profession
- Collaboration between physiotherapists at different centres has grown as a result of the network forged by the HCPA, leading to a more cohesive professional group
- An established web-based peer-support forum on Haemnet (www.haemnet.com) where members can meet and share problems and issues. It also has a platform within *The Journal of Haemophilia Practice* in which members can present cases
- Strengthening interdisciplinary relationships with the UK

Table 1: Topics addressed at HCPA meetings and invited speakers, 2007-2015

Year	Topics	External Speakers
2007	Classifying sports by risk / HAL / Prophylaxis and joint outcomes / HJHS / MRI and joint pathology / Pathogenesis of haemophilic arthropathy	Frank Genderen / Pam Hilliard / Bjorn Lundin / Nathalie Jansen
2008	ICH in children / ICH in children with haemophilia / Ankle pathology / Update on gait study / Podiatry / Physio service / Haemophilic pseudotumors / Tissue healing times	Elizabeth Chalmers / Nick Goddard / Piet de Kleijn / Lee Short / Suzanne Docherty
2009	Normal gait/ Adult gait and ankle gait parameters / 3D gait analysis / Physical activity in boys with haemophilia/ Obesity / Activity participation / Case studies / Future of physiotherapy	Sebastian Lobet / Frank van Genderen / Emma Sherlock / Danielle Douma / Kathy Mulder
2010	Prophylaxis/ Synoviorthesis / Sex and the psoas / Pain management /case studies	Peter Collins / Nick Goddard/ Greig Blamey
2011	Outcome measures (adult and child) / Obesity and nutrition /Obesity and foot/ lower limb /Case studies	Marjoleine Stafford / Stewart Morrison
2012	Muscle haematomas and sports medicine / Haematomas and haemophilia / Pseudotumors and imaging/ Rehabilitation / Debate on plyometrics and electrotherapy	Zoe Hudson / Emma Sherlock
2013	NHS Clinical Reference Group for Haemophilia / Future of commissioning / HJHS study day	Gerry Dolan / Pam Hilliard / Nichan Zourikan
2014	Joint scoring / Coagulation mechanisms / Lab investigations / Ultrasound /abstracts	Keith Gomez / Jane Needham / Peter Collins
2015	Research / Inhibitors (medical and acquired) / management of children and adults / abstracts / Foot and ankle problems	Mike Makris / Mary Mathias / Peter Briggs
2016	Psychology 0-18 / 18+ / Case studies	Zoe Berger / Lindsay Hughes/ Nicola Dunne

Haemophilia Nurses Association, which in turn is helping to identify and develop better models of patient-centred care and research opportunities (such as the SO-FIT study [3])

- Greater national influence on care pathways and guidelines through HCPA representation on the NHS England Clinical Reference Group, being part of the development of the service specification for care in England, as well as UK Haemophilia Doctors Organisation (UKHCD) Outcomes and Musculoskeletal working parties
- Membership of the UK Clinical Research Network Bleeding Disorders Clinical Studies Group.
- Closer collaboration and support through the above activities has resulted in a wider acceptance and appreciation of the role and status of the haemophilia physiotherapist in the UK, with a greater national voice and an increased presence within the international haemophilia community and global haemophilia meetings. It is acknowledged that there is always more work to do. There remains an ongoing need to establish standardised outcomes for the different age groups in

haemophilia. This should be a cradle-to-grave approach, whereby for example, if a child has an ankle bleed there are set outcomes that will assess and monitor changes from a clinical and patient perspective. Likewise those clinical and patient identified problems in the elderly population can be systematically identified and monitored. The HCPA has identified outcomes, both as a measure of the disease process, and a measure of intervention success, as a key point for development in the coming years.

The HCPA Clinical Studies Group

One very tangible demonstration of the rise in professionalism of the UK's physiotherapists can be seen in Table 2 that lists the 32 papers published in the past 10 years that included UK haemophilia physiotherapists in their authorship. By contrast, from 1996 to 2005, there were just 15 papers published that included UK physiotherapists as authors. This rise in publications has been made possible as a direct result of regular meetings that have facilitated collaboration, sharing of ideas and peer support.

The 15 papers prior to 2006 primarily focussed on case

Table 2: Publications involving HCPA members, 2006-15

Citation

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studies and anecdotal evidence. There was a need for studies to utilise robust methodologies. The increased academic support and collaboration facilitated by the HCPA Annual Meeting, has led to an increase in research focussed work published by UK physiotherapists, with more than half of the 32 papers published in the past decade utilising diverse robust research methodologies.

The challenge now is to harness and to build on that

dynamism for research in a collaborative manner in order to answer some of the important questions that remain about haemophilia care. For this reason the HCPA has established a Clinical Studies Group, an open forum designed to identify what needs to be done, and provide support and mentorship for those interested in research in their area of practice. Clinicians must be involved in research in order to provide the best practice to our patients. Research for

Haemophilia Group

MADAM — The Haemophilia Chartered Physiotherapists Association is a recently formed group which has been established to promote the interchange of ideas about the management of patients with congenital bleeding disorders. The group aims to develop a forum for communication via a newsletter and meetings, the first of which was held in June this year at the Royal Free Hospital, Hampstead.

Anyone who would like to be added to the mailing list is invited to write to Brenda Buzzard MCSP, Physiotherapy Department, Royal Victoria Hospital, Newcastle.

**KAREN BEETON MCSP
RUTH BOLTON MCSP
BRENDA BUZZARD MCSP
FIONA HALL MCSP
FIONA McCHESNEY MCSP**



physiotherapists can take many forms, from individual-initiated research, systematically reviewing existing evidence to find the best approaches, to participating in research for others. The primary aim of the group is to support research and build capacity (Table 3). One way the group can support activity is to function as a forum to enable physiotherapists with an idea to bring it to the Clinical Studies Group, which would in turn help the physiotherapist develop that idea into a worthwhile research project. The group would also provide a support network for those already undertaking research to assist with recruitment to multi-centre research. By working within a group forum rather than in isolation, the hope is that physiotherapists can encourage each other to participate in each other's research. This should lead to robust clinically relevant studies of high quality and sufficient numbers.

Table 3: Aims of the Clinical Studies Group

To develop a haemophilia physiotherapy research group
To identify research priorities and generate evidence on which care is based
To build research capacity within physiotherapy and increase research activity by physiotherapists in haemophilia
To develop a support network
Support a good research experience and recommending it to others
To identify and deliver research of the highest quality
Collaborate with colleagues, patients and other clinicians
Include them in the way research is prioritised, designed and delivered

Looking to the future

There is increasing support available for physiotherapists to attend international meetings, such as those of the international Musculoskeletal Congresses of the World Federation of Haemophilia. In addition, physiotherapists are increasingly represented on the organising committees for WFH meetings, as well as being invited speakers at both the WFH world congress and the MSK congresses. At the more local level, the needs of continual professional development (CPD) and education pose challenges for the HCPA, which must work to ensure its annual meeting contains a scientific element while also remaining relevant to practising clinicians whether they manage adults or children on a day-to-day level.

At a professional level, across the UK, haemophilia physiotherapists are gaining more hours and greater representation in haemophilia centres. They are increasingly recognised as key members of the haemophilia multidisciplinary team, and the best-placed profession to deal with the musculoskeletal issues that patients present with. As a group, HCPA needs to further promote itself, highlighting to stakeholders in haemophilia care what haemophilia physiotherapy can do and more clearly define the role. Clearly, active participation in research is a key element of this in what is a golden age for musculoskeletal research in haemophilia, both in adult and paediatric care. Physiotherapists should no longer simply support other people's research and publications by generating data but are in an ideal position to identify research priorities and questions and lead research programmes that are designed to really benefit patient care. This will be greatly facilitated by the work of the Clinical Studies Group and the collaborative principles upon which it is predicated.

At an international level, HCPA members are represented on the physiotherapy groups of both the European Association for Haemophilia and Allied Bleeding Disorders (EAHAD) and the WFH, and are collaborating with a worldwide expert team in developing and writing teaching packs for physiotherapists new to haemophilia care.

There is a case for redefining the role of the physiotherapist within the haemophilia multidisciplinary team, and extend the boundaries of that role. Indeed, boundaries are already being pushed with the use of point-of-care real-time ultrasound, performing steroid injections, independent

prescribing rights and the use of diagnostic radiology in clinics. The very specific musculoskeletal components of haemophilia make this a logical development for physiotherapists. The aspiration should be to see the development of a consultant physiotherapist in haemophilia. Such a role should allow the profession to take the lead in developing pathways and care protocols, and driving research.

It is conceivable that in the future physiotherapists and nurses could facilitate patient review clinics, with medical colleagues being involved only when there is a medical emergency. For patients who report to be generally well and are well-treated in regards to prophylaxis, this is certainly a model that is likely to develop within the next few years, as the main issues being identified are MSK-related and/or treatment-related. It is likely that the UK could drive forward this model, due to the quality of both nursing and physiotherapy practice in haemophilia care.

Haemophilia physiotherapy care together with the work of the HCPA in the UK has continued to develop since the HCPA was established in the early 1990s. There have been clear benefits of establishing a close working, collaborative group focussed on research and evidence-based practice. It is important that this work continues to enhance the musculoskeletal health of people with haemophilia and ensures that those with the condition receive the best and most appropriate care now and in the future.

Disclosures

The authors have advised no interests that might be perceived as posing a conflict or bias.

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