Summary report
HERO SUMMIT 2013
27–28 June, The Hague, Netherlands
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Executive summary

HERO (Haemophilia Experiences, Results and Opportunities) is an international initiative that aims to build a solid understanding of life with haemophilia, as seen from the perspective of people with haemophilia, their families and their healthcare providers.

The HERO initiative was established in 2009 with the formation of the HERO International Advisory Board (IAB). At the heart of the HERO initiative is the HERO study, the largest ever multinational, multi-method study consisting of:

• An extensive literature review to assess the existing literature and establish gaps in knowledge
• Qualitative research among 150 people with haemophilia, parents and healthcare professionals from 7 countries
• Quantitative research among 1236 people with haemophilia (≥18 years of age) and parents of children with haemophilia (<18) from 10 countries

THE HERO SUMMIT 2013
On 27 and 28 June 2013, 48 delegates from 18 countries and from a range of backgrounds within haemophilia research and care gathered at the HERO Summit in The Hague, the Netherlands. The first summit of its kind, the meeting brought together international experts from a variety of different fields and recognised organisations, including psychology, physiotherapy, nursing, haematology and patient organisations, to share and discuss the results of the HERO study. In particular they discussed how best to:

• Share HERO insights and experiences into the challenges, especially psychosocial issues, faced by people with haemophilia
• Work at a ‘grass-roots level’ to come up with priorities and actions which could benefit people with haemophilia and those who care for them

THE HERO SUMMIT 2013 FACULTY
The content and facilitation of the meeting was guided by the HERO Summit 2013 Faculty, a sub-group of the HERO International Advisory Board comprised of the following multi-disciplinary group of experts from the field of haemophilia:

• Alfonso Iorio (Canada), Associate Professor of Clinical Epidemiology and Medicine at McMaster University, Ontario
• Andrea Buzzi (Italy), President of Fondazione Paracelsio
• Angela Forsyth (USA), Physiotherapist, chair of the Musculoskeletal Committee of the World Federation of Hemophilia
• Ann Marie Stain (Canada), Retired, previously Hemophilia Nurse Coordinator at the Hospital for Sick Children in Toronto
• Frederica Cassis (Brazil), Psychologist at the Hemophilia Center, University of São Paulo Faculty of Medicine Clinics Hospital and member of the WFH Psychosocial Committee
• Diane Nugent (USA), Hemophilia Treatment Center Director, Children’s Hospital of Orange County, California
• Werner Kalnins (Germany), President of the German Haemophilia Society

THE PROGRAMME
The meeting programme consisted of plenum presentations and feedback sessions along with multi-country, multi-disciplinary workshops based on key insights from the HERO study. There was a high level of engagement among all participants and the two days of discussion and group work resulted in a number of ideas for addressing some of the issues within haemophilia uncovered by the HERO study.
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<td>Improve disease education to empower patients and families, and increase physicians’ understanding of daily needs of people with haemophilia</td>
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<td>Improving access to expert care – measuring</td>
<td>Use specific metrics to document and assess outcomes related to education, employment, quality of life, age distribution, pain and mobility.</td>
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<td>Apply pilot approaches across countries to document the burden of life with haemophilia and the complications associated with haemophilia and its treatment.</td>
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DAY 1, SESSION 1. OPENING SESSION:
HERO results and key insights

DR DIANE NUGENT
Hemophilia Treatment
Center Director, Children’s
Hospital of Orange County,
California and member of
the HERO International Advisory Board

Opening the meeting as Chair, Dr Diane
Nugent communicated the purpose of
the meeting: listening and sharing ideas.
She stressed that the HERO initiative takes
us beyond access to factor and broadens
perspectives to consider psychosocial
components as an essential part of care.

“The strength of HERO is that it comes from the person with haemophilia and the family. We have to focus only on this. We have to listen to what people with haemophilia and their loved ones are telling us are barriers.”

DR ANGELA FORSYTH
Physiotherapist, chair of the Musculoskeletal Committee of the
World Federation of Haemophilia and member of the HERO
International Advisory Board

Dr Angela Forsyth presented the results and key insights from the HERO study. The presentation focused on the results from the quantitative research, through which the following key insights have been drawn:

EMPLOYMENT: People with haemophilia and parents are often educated and working but haemophilia challenges job options.
• 80% of people with haemophilia reported a negative impact of haemophilia on employment

RELATIONSHIPS: People with haemophilia face challenges in forming relationships and haemophilia influences the quality of their sex lives.
• 36% reported a negative impact of haemophilia on forming close relationships and 53% reported that haemophilia negatively affected the quality of their sex lives

KNOWLEDGE: Gaps in knowledge among schoolteachers and others caring for a child with haemophilia is a source of parental dissatisfaction.
• 73% of parents reported that a lack of knowledge about haemophilia was a source of dissatisfaction in terms of teacher support

BARRIERS: There is considerable country variation when it comes to access to care and in-home treatment.
• In Algeria, 18% of people with haemophilia reported receiving treatment always or mostly at home, while in France, 94% reported the same

BURDEN: Respondents reported psychological or psychiatric conditions, yet few have received treatment. Many people with haemophilia reported being in constant pain.
• 89% of people with haemophilia reported that pain interfered with daily life in the past four weeks, and 50% reported constant pain
Day 1, Session 2. Country Presentations:

Key insights and priorities

China

Professor Renchi Yang
Institute of Hematology and Blood Diseases Hospital, CAMS & PUMC, in Tianjin

Professor Renchi Yang presented highlights from the Chinese HERO results (first presented at ISTH 2013):

- People with haemophilia and parents of children with haemophilia in China reported a larger impact of haemophilia on quality of life compared to other participating countries.
- In China, few people with haemophilia or parents reported receiving psychological support and treatment.
- People with haemophilia and parents in China were not as optimistic about their future compared with other participating countries.

Going forward, a priority for China is to gather further information on psychosocial issues and to provide guidance for improving support.

Germany

Dr Carmen Escuriola-Ettingshausen
MD, PhD, HZRM – Haemophilia Centre Rhein Main, Frankfurt-Mörfelden

Dr Carmen Escuriola-Ettingshausen presented some background on haemophilia care in Germany and highlighted the findings of interest from the HERO study.

In Germany, haemophilia care standards are high, with consumption levels of approximately 7 IU FVIII per capita. There may be regional differences, however, when it comes to accessing expert care.

Highlights from the German HERO data were:

- 56% reported extreme/moderate pain, which is similar to other Western European countries.
- Pain interfered more with daily life in Germany compared with other countries.
- 17% reported treatment for psychological conditions vs. an average of 20% for Western Europe. This was the lowest of all Western European countries.

Priority initiatives for Germany include: 1) advanced education and networking between pain specialists and haematologists to better address pain in haemophilia; and 2) a symposium for sharing treatment recommendations and patient education materials and for discussing requirements for patients of different ages.

Spain

Professor Felipe Querol
PhD, MD, University of Valencia, Haemostasis and Thrombosis Unit, LA FE Hospital, Valencia

Professor Felipe Querol presented perspectives on haemophilia care and ambitions for HERO in Spain.

41% of Spanish parents in the HERO study reported difficulty in accessing haemophilia treatment centres, compared with a study average of 23%. Distance to a haemophilia treatment centre can be a challenge. Travel times are reported as less than two hours and the goal is to reduce this to less than 30 minutes in order to ensure access to quality care.

The following focus areas have been identified to further the HERO project and benefit people with haemophilia in Spain:

- Analyse opportunities for improving access to care, such as home delivery solutions.
- Identify best practices, ensuring they are communicated through guidelines, protocols, courses and educational materials.
Professor Claude Négrier presented the background and priorities for France.

Access to haemophilia treatment centres and/or comprehensive care centres and the standards of haemophilia care (access to physiotherapy, counselling, and social workers) are good in France. Highlights from the following studies were presented:

- Molho et al, Haemophilia 2000: Increased bleeding frequency reduces quality of life
- Gringeri et al, Haemophilia 2004: Prophylaxis improves quality of life and improves pain management

Looking ahead, the following focus areas were highlighted for development: 1) practical workshop concepts to help patients adapt body movements and physical activities to haemophilia; and 2) more relevant pain questionnaire/evaluation tools to help healthcare professionals.

ALGERIA

Dr Meriem Bensadok presented some challenges and developments within haemophilia care in Algeria, as well as the top-level findings from the HERO study and the next steps for the project locally.

In Algeria, there is access to physiotherapists, counsellors and social workers in most haemophilia treatment centres and treatment is free in public hospitals. Treatment mainly takes place at the hospital, but in-home treatment has started to be implemented. For people with haemophilia, quality of care is improving and hospital budgets are increasing each year. However, barriers still remain, including limited hospital budgets in some regions and the lack of a strong national haemophilia programme. Observations from the Algerian results of the HERO study include:

- 60% of patients reported always receiving treatment at the haemophilia treatment centre. This is considerably lower than the study average.
- 84% of people with haemophilia experienced difficulty accessing factor.
- Only 16% of parents reported mostly or always treating their sons at home. This was the lowest score of all countries in the HERO study, compared with 92% in France, for example. Similar results were reported by people with haemophilia.

The following priority areas arising from local HERO discussions were highlighted: set up a national haemophilia register and encourage in-home treatment at an early age.

USA

Dr Diane Nugent took the stage again to zoom in on the status of haemophilia care and the recent discussions involving HERO from a US perspective.

With approximately 140 federally-designated haemophilia treatment centres funded through government grants and other programmes, the set-up of haemophilia care in the US presents a diverse picture. In-home treatment is the norm and prophylaxis has expanded after the results of the Joint Outcome Study. From the US cohort of the HERO study, publications have been presented at NHF 2012 and ASH 2012. Results include:
• Relationships: People with haemophilia and parents of children with haemophilia reported a high level of perceived support from their spouses, families, friends and colleagues, yet 82% and 67%, respectively, reported a negative impact on work. Among people with haemophilia, 37% reported a negative impact on relationships and said that there are knowledge gaps among teachers, coaches, other children and friends.

• Access to care: Approximately 1/4 of people with haemophilia and parents reported difficulty obtaining factor products.

• Quality of life: EQ5D scores among people with haemophilia showed that haemophilia has an impact on quality of life similar to other chronic diseases, but the impact is felt at a much earlier age.

• Pain: 92% of people with haemophilia reported pain (100% of those with inhibitors), and those who were unemployed or with self-reported arthritis reported more chronic pain. Those with inhibitors reported more acute bleed-related pain.

Since autumn 2012, HERO results have been presented to a variety of stakeholder groups, most recently at the HERO Summit for Solutions held in May 2013. Potential initiatives identified through such discussions include: Education, employment and advocacy specific educational materials for different audiences (career counselling, school interactions; a mentoring programme for families; development of a scale to measure burden on caregivers, and exploring and validating assessment/screening tools for pain and functional impairment).
Delegates were divided into six workshop groups, based on interest. The workshops were facilitated by experts within the different themes and split into two sessions, with opportunities for the groups to share and discuss in between. The objective of the first session was to identify and prioritise a key issue for each of the six workshop themes. During the second session, the groups focused on identifying strategies for addressing this issue, and they then presented their results in the plenum. After a discussion period, the group voted on the relevance and feasibility of each proposal.
Workshop 1: Empowering people with haemophilia and their families

FACILITATOR
Frederica Cassis, Psychologist, member of the Psychology Committee of the Brazilian Federation of Haemophilia

CO-FACILITATOR
Andrea Buzzi, President of Fondazione Paracelso, a non-profit foundation working within haemophilia

BACKGROUND
Haemophilia is a lifelong disease, and patients and caregivers are strongly supported by spouses and family. However, haemophilia also puts stress on relationships between spouses, siblings and families.

APPROACH
The group identified a need to strengthen communication skills within and beyond the family, starting from the time of diagnosis. The group further identified several challenges during the process: 1) that there is a time lapse between diagnosis and the onset of treatment; 2) that available information can be misunderstood; and 3) that people with haemophilia and their families are not necessarily prepared to be able to communicate well about life with the condition.

Solutions identified were to:
• Ensure that the time after diagnosis is used well in order to create a supportive environment for learning, to provide expert support to the family in terms of haemophilia and communication skills, and to provide physicians with guidelines that can help them manage specific situations post-diagnosis.
• Collect and share credible information sources (websites and manuals) and to develop protocols for haemophilia treatment centres that can help facilitate communication at each life stage (e.g. check lists and referral criteria for psychologist support).
• Facilitate workshops on effective communication beyond treatment, to facilitate peer sharing and support programmes to share best practices and experiences between countries and hospitals, and to collaborate with haemophilia societies.

“Teaching a family how to express their needs so that they can better find the information they need. Either through the centre or through the educational booklists that are given to them, so they can write their questions and get back to us in a more creative way.”

- Diane Bissonnette
Workshop 2: Addressing psychological challenges, pain and functional limitations

FACILITATOR
Werner Kalnins, President of the managing board of the German Society for Haemophilia

CO-FACILITATOR
Angela Forsyth, Physiotherapist and chair of the Musculoskeletal Committee of the World Federation of Haemophilia

BACKGROUND
For most people with haemophilia, pain and functional impairment interfere with daily life, and for more than half, pain is constant. Many people with haemophilia experience psychological challenges and few receive treatment for these.

“Probably, for a lot of people, what they require is not a psychologist but maybe a health professional who has good listening skills, who finds out what their problem is and knows when to refer them on to others.”

– Martin Bedford

APPROACH
In this workshop, two focus areas were identified: 1) the need to develop pain assessment tools that are specific to haemophilia, and 2) the need to ensure access to appropriate psychological experts.

With regard to developing pain assessment tools, several barriers were identified, primarily related to reaching a consensus concerning the need for a pain assessment tool and thereafter developing and implementing a tool that can be used locally. Steps towards gaining a consensus were proposed, such as evaluating the current evidence base and creating awareness of the problem within haemophilia. This could be achieved by establishing an expert group, conducting and publishing a systematic literature review, and identifying local champions to promote the cause.

In terms of ensuring access to appropriate psychosocial professionals, several challenges were identified: 1) there is a lack of awareness, expertise and communication among professionals, 2) there is a lack of awareness among patients and a lack of acceptance of psychological intervention, and 3) there are limited resources available to secure psychological expertise.

The group proposed that these challenges could be addressed by:

• Using HERO results as a way of initiating awareness and communication (through education, congresses and events) and as a way of encouraging the development of guidelines.
• Working together with patient organisations and establishing patient advisory groups to investigate why there is poor patient acceptability and identify how best to intervene.
• Helping to facilitate solution-oriented interventions via the development of a screening tool, referral criteria, and more in-depth psychological interventions by training non-specialist staff in advanced communication skills.
Workshop 3: Engaging with the outside world and care networks

FACILITATOR
Ann Marie Stain, Former Hemophilia Nurse Co-Ordinator in the Comprehensive Care Hemophilia Clinic at The Hospital for Sick Children, Toronto

CO-FACILITATOR
Chris Guelcher, MS, PNP-BC, Pediatric Nurse Practitioner at the Center for Cancer and Blood Disorders, Children’s National Medical Center, Washington, USA

BACKGROUND
Knowledge gaps around haemophilia among teachers and other adults (for example: sports teachers, coaches) and peers might limit their ability to fully support children with haemophilia as they strive to manage their disease and fully engage in life.

“We recognise that it’s not just developing tools, it’s also how to get the tools out to the coach or the teacher or providing it to the parent.”

– Chris Guelcher

APPROACH
The group identified the need to improve the awareness and use of existing educational materials and to continually assess the educational and support needs of at-risk families. There was a consensus that a lot of credible resources and materials already exist that can help facilitate collaboration and communication between people with haemophilia, their families and the peers and professionals that they engage with on a daily basis.

A solution to this could be to develop an international library of materials and tools, collated from existing materials and reviewed and evaluated by committees of experts within the relevant topics. Guidelines and templates could be provided for the development of future materials. Geographical, cultural, political and resource challenges were identified related to the distribution and implementation of such materials, and various channels were identified in order to help facilitate the dissemination, such as peer-to-peer, social media, emails from patient organisations, text messages, camps, society meetings and though the haemophilia treatment centres.

Finally, there was a focus on the challenges related to supporting at-risk families. The group recommended that the needs of these families be continually assessed. Targeted ‘train the trainer’ sessions for nurses, social workers, psychologists and parents or people with haemophilia were identified as ways of providing individualised education and counselling, providing improved psychosocial support and intervention at the haemophilia treatment centres, and helping to prepare peer-to-peer mentors for at-risk families. This could take place through the treatment centre or via a partnership with the haemophilia society.
Workshop 4: Engaging in the workplace

FACILITATOR
Matt Gregory, member of the UK Haemophilia Society and the Haemophilia Alliance

CO-FACILITATOR
Michelle Rice, Director of Public Policy, the National Hemophilia Foundation; mother of two sons with haemophilia, USA

BACKGROUND
People with haemophilia and their caregivers face issues in the workplace in terms of choosing a job, engaging with colleagues, job performance, and job retention.

“As far as I’m concerned, employment is simply the most important thing in anybody’s life. It is something we do day-in and day-out for most of our lives and people with haemophilia should be allowed to access that as easily as possible.”

– Matt Gregory

APPROACH
The group identified that it was imperative to support people with haemophilia and carers across all stages of the career lifecycle. For young adults, before their first job, it is important to map interests and potential career paths early on and take part in courses, programmes and scholarships to build a strong CV. When searching for the first job, the young man needs to become self-sufficient and equipped with the right communication skills, and he also needs to know how to research companies and prepare for interviews. Key questions will be when and how to disclose haemophilia and what will the physical requirements of the job be?

Parents may need support with work/life balance, and they need to choose a job that is right for themselves and for the family as a whole. Options to investigate here may be flex time and working from home.

For adults with haemophilia established on the employment market, there may be considerations with regard to career progression, and short-term versus long-term goal setting. There may also be a need to support retirement planning later on in the career.

Guided by a working group to evaluate what is currently available, how it is used and to ensure monitoring and follow up, examples of how this could be done are:

- Peer-to-peer interactive presentations
- Templates for guidance for social workers and career counsellors
- Best practice examples across countries
- Camp programmes
- Professional training opportunities
- Online download centres
- Mentor programmes
- Internships
- Job shadowing
- Distant twinning sessions (i.e. via Skype) to provide employment counselling and support
SUMMARY REPORT

WALID KOBISI

Walid has haemophilia A
**Workshop 5: Improving access to expert care**

**FACILITATOR**
César Garrido, Treasurer of Asociación Venezolana para la Hemofilia (AVH), and father of a son with haemophilia

**CO-FACILITATOR**
Susanne Brandl, General Manager, Novo Nordisk Haemophilia Foundation

**BACKGROUND**
While patients and caregivers perceive good disease control and have a positive outlook for the future, issues remain in securing access to expert care and in-home treatment.

“What we want to achieve is to have some standards of care that are international, national, local and that are tailored to the appropriate region that the patient might present in.”  
– Kate Khair

**APPROACH**
Participants in this workshop were mainly haematologists and nurses from very different geographical backgrounds, including the UK, Germany, France, Lebanon, China and Libya. Despite these differences, and the varying standards for haemophilia care, common issues and areas for improvement within the care delivery system were identified. The group agreed that there was a need to increase awareness among primary care and emergency room physicians with regard to diagnosis, treatment and referral, and they also believed that improving disease education would empower patients and families, thereby increasing physicians’ understanding of the daily needs of people with haemophilia.

Proposals for how to achieve this included:

- Tailoring standards of care to guide recognition, diagnosis, treatment and referral in primary and emergency care. More specifically, this could be done by creating an expert group to guide topics, materials, standards and guidelines and to ensure follow up. The early involvement of authorities/decision-makers would ensure processes are anchored in the health care system.

- Educating and empowering physicians by identifying country-specific targets and by using peer-to-peer sessions by the haemophilia treatment centre team. Sessions would include the topics in the standard curriculum and at national congresses and meetings, via case studies and workshops. 24hr hotlines, e-learning materials and posters could be used to support physicians in decision-making and referrals.

In addition, the group agreed that educated and empowered patients and families, as well as a strong patient voice through the haemophilia society, were important elements in ensuring that physicians understand the needs and care requirements of people with haemophilia. This could be achieved via group sessions for patients, carriers and relatives, and through strong leadership in the haemophilia community, either by establishing a society, providing leadership training or planning succession.
**Workshop 6: Improving access to expert care – measuring outcomes**

**FACILITATOR**
Mark Skinner, CEO and President, Institute for Policy Advancement, USA

**CO-FACILITATOR**
Alfonso Iorio, Associate Professor Department of Clinical Epidemiology and Biostatistics with Clinical Service at the Hemophilia clinic at McMaster University

**BACKGROUND**
There is a lack of consistent data and assessment tools to make the case for access to expert care and in-home treatment for people with haemophilia.

**APPROACH**
In order to secure access to expert care, decision-makers increasingly seek sound, evidence-based arguments. The workshop group took a pragmatic approach to investigating relevant existing measures within and between countries to track outcomes that were relevant for clinical decision-makers and that could build the case to convince authorities of the need to ensure quality care within haemophilia.

The group discussed how to document the burden of living with haemophilia and the complications associated with haemophilia and its treatment. This could be done by measuring outcomes related to education, employment, quality of life, age distribution, pain and mobility. Indicators could be used such as days lost from school/work due to haemophilia in the last defined number of months, EQ5D score versus comparator, population distribution by age, pain level with comparator, use of assistive devices and many others.

The group recommended taking a pilot approach across countries. A pilot study could test feasibility and could run in four English or French speaking countries (two developed and two developing) in about 300 adults with haemophilia A or B. The study could also involve a single assessment per patient, with two assessments per country (different patients at different times). Secondary outcomes could be the response rate, percentage of complete responses, time to completion and cost per completed survey.

“We identified what we thought would be reasonable metrics for measurements. So educational achievement would be looking at the highest educational level completed and the measure for that, the comparator – beyond comparing countries or looking at how it changes over the course of time – would be looking at what the national distribution of educational achievement is.”

– Mark Skinner
The HERO Summit was an important step in moving from insights to action.

A collaborative effort, contributed to by all HERO Summit 2013 delegates, this summary report aims to capture the spirit of the meeting and some of the ideas that may inspire action, benefitting people with haemophilia and those who care for them.

Novo Nordisk is committed to support the community in changing possibilities in haemophilia and will continue to take steps to better understand and raise awareness of some of the fundamental psychosocial challenges faced by people living with haemophilia.

For more information on the HERO initiative, please visit the HERO website: herostudy.org
HERO (Haemophilia Experiences, Results and Opportunities) is an international initiative guided by the HERO International Advisory Board and supported by Novo Nordisk. HERO aims to build a comprehensive understanding of life with haemophilia as seen from the perspective of people with haemophilia, their families and their healthcare providers.