

HERO – Haemophilia Experiences, Results and Opportunities



HERO is an international community inquiry initiated and supported by Novo Nordisk. This initiative will build a solid understanding of life with haemophilia, seen from the perspective of people with haemophilia, their families and their healthcare providers. It is our goal that their voices are heard to bring about action and change.

Psychosocial issues in haemophilia

Even with access to effective treatments, psychosocial issues affect the ability of people with haemophilia to manage their condition and live their lives as they would wish to. Important factors include

- Attitudes, including those of family members to diagnosis and treatment
- Wishes and aspirations as to how life could be better
- The social context of haemophilia – how the community understands and interacts with people with haemophilia

In September 2009 a multidisciplinary, multi-cultural group of experts met in Montréal to explore the unmet psychosocial needs of people with haemophilia, and all who care for them.

A detailed meeting report is available to download at www.changingpossibilities.com.

From Needs Assessment...

The meeting in Montréal explored the context for psychosocial issues in haemophilia – relationships between people with haemophilia and families, peers, carers, healthcare professionals and the general public.

It identified areas that potentially warrant priority focus – education and awareness beyond the patient and the specialist healthcare team, the importance of access to physical therapy, and self-management.

The meeting also recognised the importance of knowledge as a driver for change; the need to build evidence by engaging in structured research with the right methodology.

What does psychosocial support look like now and how do psychosocial aspects of life with haemophilia actually impact people around the world?

[...to Action and Advocacy](#)

How do we give everyone involved in haemophilia – people with haemophilia, families, carers, professionals from across the multidisciplinary team – a voice?

How do we translate global and local knowledge and evidence into local action and change?

[The Imperative to Build Evidence](#)

Research to build the evidence needed must be approached in a rational and objective way; the right

people must be asked, and they must be asked the right questions.

With this body of evidence, the community can further exchange experiences and solutions to the many shared challenges faced by people with haemophilia and their caregivers. Through publications and presentation of the findings, it will also be possible to engage in a productive conversation in the medical community about what can be done to provide care that encompasses the psychosocial needs of people with haemophilia. Lastly, it will provide a strong platform for approaching governments and other decision makers to encourage action and the development of powerful local initiatives.

“Without evidence you’re just a person with an opinion”



HERO Inquiry components

Literature Review

- Review existing body of knowledge into the psychosocial factors in haemophilia, ensuring that HERO provides new and valuable insights

Method:

- Discussions with key experts and conducting a professional literature review to capture the current knowledge and thinking

Initial investigation – insights and guidance

Face-to-face interviews with participants from across a broad spectrum of the haemophilia community to:

- Gather valuable and rich insight into life with haemophilia
- Provide guidance on developing a carefully structured investigation that reflects the experiences, attitudes, wishes and desired outcomes around life with haemophilia

Method:

- Triangulated approach involving in-depth interviews, auto-ethnography and discourse analysis with a sample of each section of the haemophilia community
 - 60 minute interviews with 150 people with haemophilia (A and B, with and without inhibitors), carers, physicians and other healthcare professionals across 7 countries. (Algeria, Brazil, France, Germany, Italy, UK, USA)
 - Discourse analysis, one of the most rigorous methods available for exploring how people express themselves and what they actually mean

Full investigation – providing a solid evidence base for action

A second stage of consultation that will provide distinguishable and quantifiable information to:

- Provide a robust evidence base on the impact of the issues identified in the initial investigation
- Inform future advocacy and the development of new solutions to improve lives across the haemophilia community

Method:

- On-line web survey, the most suitable method for reaching the widest audience of respondents from across the community
- 1200 participants from 12 countries (those listed above plus Argentina, Canada, China, Japan and Spain), providing a robust number across all countries and the full range of the community
- Findings to be available in 2011

International Advisors

- **Frederica Cassis** (Brazil) is a psychologist at the Haemophilia Center of the Hospital das Clinicas, São Paulo and a member of the WFH Psychosocial Committee
- **Eliane Sandoval** (Brazil) is a nurse coordinator specialising in haemophilia at the State University of São Paulo
- **Ann-Marie Stain** (Canada) is the haemophilia nurse coordinator for the bleeding disorder clinic at the Hospital for Sick Children in Toronto
- **Dr Werner Kalnins** (Germany) is President of the German Haemophilia Society, Deutsche Hämophilie Gesellschaft and has severe haemophilia A
- **Andrea Buzzi** (Italy) was General Secretary of the Italian Haemophilia Society and is now President of the Fondazione Paracelso
- **Dr Alfonso Iorio** (Italy) is Head of the Haemophilia Centre at the University of Perugia
- **Kentaro Kitamura** (Japan) - Vice President of the Kyoto Haemophilia Society

- **Professor Felipe Querol Fuentes** (Spain) specialises in physical therapy in haemophilia, working at the Unit of Congenital Coagulation Disorders at the University Hospital La Fe in Valencia
- **Matt Gregory** (UK) is Vice-Chair of the UK Haemophilia Society and has severe haemophilia A
- **Kerry Fatula** (USA) is Executive Director of the Western Pennsylvania Chapter of the National Hemophilia Foundation, and the mother of three sons with severe haemophilia A with inhibitors
- **Angela Forsyth** (USA) is a physiotherapist at the haemophilia centre of the University of Pennsylvania Medical Center, Philadelphia and Junior Vice-Chair of the WFH Musculoskeletal Committee
- **Dr Diane Nugent** (USA) is the Hemophilia Treatment Center Director at the Children's Hospital of Orange County, California, and head of Region 9, comprising California, Nevada, Hawaii and Pacific Rim, representing almost 15% of the haemophilia patients in the United States
- **Mark Peyrot** (USA) is a professor of sociology at Loyola College and has an appointment on the research faculty in the school of medicine at Johns Hopkins University
- **Sid Ramirez** (USA) has attended the inhibitor summits in the USA and has helps talk to young people with haemophilia. He has severe haemophilia A with an inhibitor
- **César Garrido** (Venezuela) is Vice President, National Member Organizations, World Federation of Hemophilia

HERO and Novo Nordisk

Changing Possibilities in Haemophilia® in action

Novo Nordisk is committed to Changing Possibilities in Haemophilia®, working towards a future where *all people living with haemophilia, with or without inhibitors, have the opportunity to lead the life they desire.*

Novo Nordisk has been engaged in serving the haemophilia inhibitor community for more than ten years and is now driving forward a clinical programme to deliver new product innovations for the broader haemophilia community.

At the heart of Novo Nordisk's efforts is the research that aims to improve the treatment choices for people with haemophilia. In addition Novo Nordisk is committed to investigating and improving the range of aspects of care that go beyond medical care. This includes a focus on psychosocial issues in haemophilia, not just for patients in every age group but also for families and healthcare professionals, and how understanding these issues can help communities to develop solutions leading to better outcomes and quality of life.