INSIGHT AND HOPE FOR PEOPLE LIVING WITH HAEMOPHILIA
Imagine...

...a future where all people living with haemophilia have the opportunity to lead the life they desire. Novo Nordisk is changing haemophilia by developing and nurturing partnerships across the haemophilia community in order to support better access to expert care. Central to these efforts is the HERO initiative.

Giving haemophilia a voice

THE GOAL OF HERO IS TO:

- Advance the understanding of psychosocial issues related to living with haemophilia.
- Provide a strong platform for building advocacy and supporting improvements in care.
- Facilitate patient-oriented monitoring and better practice sharing to promote improvements in quality of life and health outcomes for people with haemophilia.
At the heart of the HERO initiative is the HERO study. Completed in 2012, the HERO study surveyed 1,386 people in 11 countries, making it the largest ever multi-national, multi-method study of life with haemophilia.

The HERO study has given us some key insights into the challenges facing people living with haemophilia, particularly in the following areas:

**WORK LIFE**
- **RELATIONSHIPS & SUPPORT**
- **KNOWLEDGE & UNDERSTANDING**
- **ACCESS TO CARE**
- **PSYCHOSOCIAL WELL-BEING**

### CHALLENGES AT WORK

A number of people living with haemophilia, as well as the parents of children with haemophilia, experience challenges in the workplace. They report that haemophilia may affect their chances of employment or a promotion. They also believe haemophilia may have been a reason for losing a previous job. Although more than half of the people with haemophilia in the survey report being employed, 80% of them say the condition has a negative impact on working life.

**AMONG PARENTS OF CHILDREN WITH HAEMOPHILIA,** 63% report that the condition negatively impacts their work life.

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1. Demographic Characteristics of People with Haemophilia in the HERO Study, Poster #199, WFH Congress 2012
2. Demographic characteristics of parents in the HERO Study, Poster #200, WFH Congress 2012
Challenges in relationships

People with haemophilia may also experience challenges when forming intimate relationships. Among the survey’s adult respondents, 36% report that haemophilia affects their opportunities to develop close relationships with prospective partners. The reasons cited include concern about the impact of haemophilia and the ability to support a family in the future, as well as feeling different and being faced with a lack of understanding about their condition.

IMPACT ON INTIMACY

More than half of the respondents who replied to questions on sexual health report that haemophilia has a negative effect on the quality of their sex life. Reasons cited were limitations in movements, HIV, tiredness and pain.

CONFIDING IN OTHERS

Almost a third of people with haemophilia and 41% of parents of children with haemophilia report having a negative experience when telling someone about their or their son’s haemophilia.

Knowledge and understanding

People with haemophilia and parents of children with haemophilia reported an overall satisfaction with the support and understanding shown by their partners, family, friends, other schoolchildren and teachers. And although the majority of school teachers are made aware of a child’s haemophilia, parents report that a lack of knowledge was the main source of dissatisfaction with those who care for their child.

59% of parents report that other children treat their son differently because of his haemophilia.

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6. Not all respondents, n=324, 59% reported that other children treat their son differently because of his haemophilia.
Access to care

Despite advances in treatment options, many people around the world are still dependent on others, such as family members or healthcare professionals, to help them manage their haemophilia. Parents report that they have the main responsibility for managing their son’s haemophilia care, but reliance on healthcare professionals at a hospital or clinic is also a reality.

Managing treatment in the home setting varies by country, with the majority in France managing treatment always or mostly at home, but with just under one fifth of people in Algeria reporting the same.¹

32% OF PEOPLE WITH HAEMOPHILIA ARE FACING DIFFICULTIES ACCESSING A HAEMOPHILIA TREATMENT CENTRE. ²

¹ Clinical Presentation and Management of People with Haemophilia Responding to the HERO Study, Oral presentation, WFH 2012
² OF PEOPLE WITH HAEMOPHILIA ARE FACING DIFFICULTIES ACCESSING A HAEMOPHILIA TREATMENT CENTRE.
Psychosocial issues

The HERO Study has confirmed that haemophilia can negatively impact people’s quality of life in the form of decreased mobility, pain or discomfort, depression and anxiety. In fact, 89% of people with haemophilia report that pain has interfered with their daily life in the last four weeks, and 50% say they experience constant pain. Despite these challenges, few people with haemophilia report receiving counselling.

A child’s haemophilia may also impact parents’ well-being. Parents of a son with haemophilia report feelings of guilt, disappointment and a desire to increase society’s understanding of haemophilia. Just under a quarter of the parents report that they have received counselling to help cope with their son’s haemophilia. Among those who have not received support, nearly half would like to.

Only 22% of people with haemophilia in the HERO study say that they have received counselling in the past five years.

Greater understanding for a better future

The HERO study has brought to light the many challenges that people living with haemophilia experience in their daily lives. However, it also shows that people with haemophilia remain optimistic about the future. HERO aims to improve outcomes in haemophilia by increasing awareness and stimulating discussion in the medical community about how to better address the psychosocial needs of people with haemophilia.

GET INVOLVED

Together, we can help support better access to expert care, enabling people with haemophilia to lead the life they desire. If you would like to find out more about the HERO initiative and how to get involved, please visit our website: changinghaemophilia.com or contact your local Novo Nordisk representative.
Novo Nordisk is changing haemophilia. Every step of our journey is focused on improving treatment and care for people. Our formulation for haemophilia with inhibitors was an innovation of its time, but our commitment is not limited to just one innovation. With our strong pipeline and our partnerships with the haemophilia community around the world, we will continue to drive fundamental and ongoing change for people with haemophilia in the future.

Learn more at changinghaemophilia.com