

press release

Novo Nordisk announces new data on psychosocial impact of people living with hemophilia B

Findings from the B-HERO-S study presented at the World Federation of Hemophilia 2016 World Congress

Plainsboro, N.J., July 26, 2016 – Novo Nordisk today announced the first results from the Bridging Hemophilia B Experiences, Results and Opportunities into Solutions (B-HERO-S) study, which found that many adults and children living with even mild or moderate hemophilia B in the United States experience a negative impact on their career, education and recreational activities as a result of the disorder. These findings were presented today in Orlando, Florida at the largest international meeting for the global bleeding disorders community, the World Federation of Hemophilia (WFH) 2016 World Congress.

“B-HERO-S builds upon Novo Nordisk’s HERO legacy, which is grounded in gaining a better understanding of the daily challenges people living with hemophilia face,” said Robert Gut, MD, PhD, VP Clinical Development & Medical Affairs Biopharmaceuticals, Novo Nordisk. “Findings like these help further identify unmet needs and inform how we as a company can better serve the community.”

Overall, the B-HERO-S study has provided extensive information on the psychosocial impact of hemophilia B, particularly on people with mild/moderate hemophilia and those who care for them. A large number of respondents with mild/moderate hemophilia B completed the survey, including affected women and parents of affected girls. Survey questions for women were distinctly tailored to include the types of bleeding symptoms unique to women, making B-HERO-S an unprecedented opportunity to study the psychosocial impact of mild-moderate-severe factor IX deficiency in both women and men.

“The B-HERO-S study brought to light many challenges faced by some patients with mild/moderate hemophilia B, including affected women and girls,” said Michelle Witkop, DNP, FNP-BC, Northern Regional Bleeding Disorder Center. “With hemophilia treatment centers (HTCs) and local hemophilia chapters focused on proactive education in people with severe hemophilia and their families, B-HERO-S data tells us we need to make sure that those with mild/moderate hemophilia B come to the HTC for routine visits so that we can proactively address issues that might come up in school, activities and career choice.”

Key data highlights to be presented at the meeting include:

- **Impact on Disorder Management (P-W-199 and MP-W-198)**
 - While 79% of adults with hemophilia B were on some form of routine factor infusions, only 27% were responsible for their own care, with many relying on hematologists (55%) and nurses (12%) for regular care.

- Sixty-five percent (65%) of children with hemophilia B were taking routine infusions. Responsibility for care was typically with the responding caregiver, family member or child themselves (73%).
 - Fifty-two percent (52%) of the adults with hemophilia B have had issues with access to factor due to availability or affordability in the past five years; 78% have concerns about access in the next five years.
 - Approximately half (53%) of caregivers of children with hemophilia B have had difficulties obtaining factor in the past 5 years due to concerns about the availability or affordability; 69% have concerns in the next five years.
- **Impact on Recreational Activities (P-T-174 and P-T-173)**
 - Nearly all of the adults (98%) with hemophilia B reported a negative impact on engagement in recreational activities. A majority made moderate to significant changes around their treatment plan in order to participate in particular recreational activities.
 - Most caregivers (90%) reported a negative impact of hemophilia B on their child's engagement in recreational activities, and a majority reported making significant to moderate changes to treatment to accommodate particular recreational activities.
 - **Impact on Education and Work (P-T-64)**
 - Nearly all participating adults (94%) with hemophilia B reported a negative impact on education including difficulty concentrating, attending school or participating in activities due to their disorder.
 - Nearly all participating adults (95%) described a negative impact of hemophilia B on their working life. Most caregivers (89%) and their partners (84%) also reported that caring for a child with hemophilia B had a negative impact on their work.

"The data show some patients with mild/moderate hemophilia B and their caregivers may have more challenges than we would expect," said Chris Guelcher, PNP, Children's National Medical Center. "From the pediatric treatment perspective it highlights the need to emphasize the importance of routine comprehensive care visits to the hemophilia treatment centers particularly during transition to make sure the family plans appropriately."

About the B-HERO-S Study

B-HERO-S was designed to better understand the psychosocial impact of hemophilia on adults and children with mild-moderate-severe hemophilia B, as well as their caregivers. B-HERO-S was completed with the collaboration of three organizations – the National Hemophilia Foundation (NHF), the Coalition for Hemophilia B and the Hemophilia Federation of America (HFA) – who helped distribute study information, and the active engagement of a multi-disciplinary group of healthcare professionals, patients, caregivers and advocacy organizations that contributed to the design, analysis and communication of the results.

B-HERO-S is an extension of HERO, a global initiative that launched in 2009 and culminated with the HERO quantitative study with over 1,200 patients and caregivers in 10 countries and was completed in late 2011. HERO and other ongoing projects aim to build a more comprehensive understanding of life with hemophilia as seen from the perspective of people with hemophilia, their families and their healthcare providers.

More information about **B-HERO-S** can be found at [clinicaltrials.gov](https://clinicaltrials.gov/ct2/show/NCT02568202) under NCT02568202 (<https://clinicaltrials.gov/ct2/show/NCT02568202>)

More information about **HERO** can be found at clinicaltrials.gov under NCT01322620 (<https://clinicaltrials.gov/ct2/show/NCT01322620>) and at www.herostudy.org.

About Novo Nordisk

Novo Nordisk is a global healthcare company with more than 90 years of innovation and leadership in diabetes care. This heritage has given us experience and capabilities that also enable us to help people defeat other serious chronic conditions: hemophilia, growth disorders and obesity. With U.S. headquarters in Plainsboro, N.J., Novo Nordisk Inc. has more than 5,000 employees in the United States. For more information, visit novonordisk.us or follow us on Twitter: @novonordiskus.

Further information

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