

About NNHF



A workshop for people with haemophilia and family members as part of the Mexico 6 project. The project provided self-infusion training to people with haemophilia, delivered by two nurses trained in Monterrey by the Mexico 2 project team.

The journey to improved care

Since 2005, together with our partners, we at the Novo Nordisk Haemophilia Foundation (NNHF) have been striving to improve access to care for people living with haemophilia and allied bleeding disorders.

One in 10,000 people is born with haemophilia¹. However, less than half of the global patient population has a confirmed diagnosis². Most of those living with the condition – even when they have received a diagnosis – are not receiving adequate care³. This is particularly true in developing and emerging countries. Here, the challenges faced by people with bleeding disorders include: a shortage of medical experts; limited facilities providing care and diagnosis; lack of knowledge about the condition amongst people with haemophilia and bleeding disorders, their families and communities; low awareness amongst authorities and the public. These challenges mean that people living with the condition may suffer from disabilities, pain, and in some cases, they may have fatal complications leading to early death.

This can be changed. With proper care, knowledge and support, people with bleeding disorders can live fulfilling lives with normal life-expectancy. The NNHF was established as a non-profit organisation by Danish pharmaceutical company Novo Nordisk as a reflection of the company's commitment to improving haemophilia care. Supporting the NNHF is part of Novo Nordisk's commitment to the Triple Bottom Line, which considers the financial, environmental and social impact of the company.

At the NNHF, we work with an international network of partners who support and deliver projects that create a systemic change, impacting the lives of people with bleeding disorders. Together, we work towards our vision that all people with haemophilia or allied bleeding disorders receive care and treatment, wherever they live.

¹ www.wfh.org/en/sslpage.aspx?pid=646

² WFH Annual Global Survey 2017 data. Accessed January 2019

³ www.wfh.org/en/about-us



In Uganda there was a misconception about bleeding disorders that cut across both the community and health workers. The community thought it was witchcraft, whilst health workers presumed that the patients were suffering from sickle cells or other diseases. That led to a lot of mismanagement of the condition. The work we have done together since then means that this has greatly changed. Both health workers and the community are now able to identify people with bleeding disorders based on the knowledge they have acquired through our activities.”

Agnes Kisakye, patient organisation, Uganda



Agnes Kisakye creating awareness among traditional circumcisers in Uganda to identify potential boys with haemophilia.

A focused approach to tailored projects

Our development projects are tailored to address the challenges faced by bleeding disorders communities in developing and emerging countries.

We do not take a 'one size fits all' approach in our development projects. We work with our partners to tailor their project activities to their community's specific needs. However, we have seen shared challenges across the global bleeding disorders population and our projects each address at least one of three focus areas:

Capacity building: equipping healthcare professionals with skills and knowledge, strengthening facilities and optimising service delivery.

Diagnosis and registry: enabling quality diagnosis through expertise and facilities, ensuring quality data is available.

Education and empowerment: informing and educating people with bleeding disorders and their families to be able to better manage the condition, empowering the bleeding disorders community to engage with healthcare professionals, authorities and decision-makers.

Awareness and advocacy activities are a thread which runs through all three focus areas. Such activities aim to get haemophilia on the healthcare agenda, influence policy and ensure a care network is in place.

NNHF projects

Through our projects, our partners aim to improve access to care, depending on the needs and challenges in each country or region.

NNHF development projects are managed by partners in the countries. To ensure sustainable impact, they are tailored to specific country needs and driven by an engaged team of community members. Successful programmes rely on three key factors:

1. Tailored project plans that ensure systemic and sustainable outcomes
2. Leadership from dedicated and motivated partners in the countries
3. Strong project management support from the NNHF team.

In all our projects, partnership is key. It is our partners who deliver change on the ground and ensure that the benefits for the bleeding disorders community last beyond the lifespan of any NNHF project. Creating sustainable impact is at the heart of what we do.

NNHF awards

In addition to our projects, we present two annual awards:

- The **NNHF Project of the Year Award** goes to the project which has demonstrated outstanding dedication, excellent project management, stakeholder involvement and sustainable impact.
- The **NNHF Community Award** is presented to an individual or group who makes an excellent voluntary contribution that benefits the bleeding disorders community.



Capacity
building



Diagnosis and
registry



Education and
empowerment

Teaming up to create sustainable impact

Our partners come from many sectors, backgrounds and countries. By teaming up, they bring together the skills and experience that lead to long-term benefits for people with bleeding disorders and their families.

An African proverb states “if you want to go fast, go alone. If you want to go far, go together.” We believe that this provides the key to creating sustainable impact. That is why teamwork is critical in all that we do.

From the project application phase, our partners work with multiple stakeholders to ensure each relevant group has a voice. Throughout the project delivery, they collaborate with experts from their country or abroad to develop skills and strengthen care networks. We empower partners to team up with those who can help them be heard, through activities such as strategic planning, media engagement, advocacy and leadership training. When a project ends, partners remain active members of our international network to benefit from better practice sharing and opportunities to team up within and beyond borders.

Delivering results through teamwork

The power of teaming up is evidenced across all NNHF programmes, which have seen patient organisations strengthened, national care networks created or reinforced and authorities engaged, to name just a few examples of the sustainable impact that has been created.



We encouraged direct dialogue between people with bleeding disorders and doctors during healthcare professional training, by including patients in the sessions.”

Christianne Oliveira Costa, President of patient organisation, Pará, Brazil



We partnered with international experts for physiotherapy training and support to develop our musculoskeletal (MSK) registry. Furthermore, participants of the training session became trainers in their region. This will help us cascade knowledge and increase healthcare professionals’ and patients’ understanding of the importance of their joint health.”

Dr Rungrote Natesirinilkul, haematologist, Thailand



Our efforts in engaging and working together with authorities led to the Ministry of Health allocating space for a comprehensive care clinic, waiving taxes on treatment donations, and allocating healthcare professionals to work at the haemophilia clinics.”

James Kago, Secretary General of patient organisation, Kenya

Achieving sustainable goals

Through our projects, our partners are empowered to take a long-term view to improving care for people with bleeding disorders, so that the impact of their activities continues beyond the lifespan of the project.

Our grassroots approach is aligned with the United Nations Sustainable Development Goals. We refer to these goals when, together with our partners, we plan, monitor and assess how our programmes lead to a sustainable future for haemophilia care in the countries in which we operate. For examples of how our programmes are meeting these goals, see the results of our latest impact assessment.

In April 2018, NNHF partners and selected young members of the African haemophilia community from six countries met in Cairo to take part in the NNHF Leadership Training workshop.

