

Together  
improving  
access to  
haemophilia  
care

Self-infusion training in Samarinda, Indonesia will help people with haemophilia manage their condition at home.



Gabriel and his mum visit nurse Luz Graciela Villalaz, a member of the multidisciplinary care team at the Hospital del Niño in Panama City, Panama.

A young boy with dark hair, wearing a dark blue hoodie and light-colored pants, is sitting on a hospital bed. He is looking down at a medical device connected to his arm. The room is decorated with colorful wall stickers, including a lion and a fish. A television is mounted on the wall above him, displaying the number '52'. The bed has a white sheet and a patterned border. A stainless steel pot is visible on the right side of the bed.

**Our vision:  
All people with  
haemophilia or  
allied bleeding  
disorders receive  
care and treatment  
wherever they live.**

## 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 haemophilia. However, only 25% of the global patient population has been identified. Many of those living with the condition – even when they have received a diagnosis – are not receiving adequate care. 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 Novo Nordisk Haemophilia Foundation was established as a non-profit organisation in 2005 to join the journey to make this a reality. 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.



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, is saving lives by spreading the knowledge and creating awareness during World Haemophilia Day, as part of the NNHF Uganda 2 project.



Ismail learns physiotherapy techniques for rehabilitation to help reduce bleeds and strengthen joints at the haemophilia treatment centre in Tashkent, Uzbekistan.

# 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.

## 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



Prof Ampaiwan Chuansumrit teamed up with Dr Rungrote Natesirinikul and international expert physiotherapists to deliver MSK training, as part of the NNHF Thailand 2 project.

## 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, patient organisation, 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 Natesirinikul, 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, 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.



'Unity is our way to find solutions', an exercise during the formation of the Women's group as part of the NNHF Pakistan 6 project.

## Our governance and principles

The Novo Nordisk Haemophilia Foundation (NNHF) is a non-profit organisation. Adhering to high governance standards is key for our organisation and its operations as a grant-making foundation.

The NNHF is an associated partner of Swiss Foundations and orients its organisational governance to the principles and recommendations of the 'Swiss Foundation Code'. It is governed by the NNHF Council, which comprises globally renowned experts in the field of bleeding disorders and members from Novo Nordisk drawn from the company's experience in haemophilia and management of operations in emerging countries. NNHF Council members exercise their duty without remuneration except for the reimbursement of their expenses.

### Roles and responsibilities

The NNHF Council ensures that the foundation's goals, activities and structures are transparent and appropriate to the foundation's purpose. The Council convenes twice each year and is the supervisory and main decision body of NNHF to ensure proper handling of funds and their distribution.

The NNHF Council entrusts daily management to the NNHF management team. This team is responsible for the operational management of the NNHF and supports partners to deliver results-oriented projects.

The annual financial statements of NNHF are audited by PricewaterhouseCoopers AG. Swiss authorities ensure that the proceeds of NNHF are spent in accordance with its objectives and inspect proper financial and liquidity planning along with financial reporting.

### NNHF in brief

Founded in 2005 and situated in Zurich, Switzerland, the Novo Nordisk Haemophilia Foundation (NNHF) is a non-profit organisation dedicated to defining and funding sustainable projects which improve access to quality care benefitting people with haemophilia and allied bleeding disorders in developing and emerging countries. With partners in the countries and international experts, we address three focus areas: capacity building; diagnosis and registry; education and empowerment.



At an MSK workshop delivered through the NNHF Chile 2 project, Rafael Jeldez Díaz learned how to prevent joint complications.

# Engage with us

**Website:** [www.nnhf.org](http://www.nnhf.org)

**Facebook:** [www.facebook.com/novonordiskhaemophiliafoundation](http://www.facebook.com/novonordiskhaemophiliafoundation)

**LinkedIn:** [www.linkedin.com/company/novo-nordisk-haemophilia-foundation](http://www.linkedin.com/company/novo-nordisk-haemophilia-foundation)

**Youtube:** [www.youtube.com/novonordiskhaemophiliafoundation](http://www.youtube.com/novonordiskhaemophiliafoundation)

**NNHF Activity update:** Subscribe by email: [info@nnhf.org](mailto:info@nnhf.org)

**Biennial Better Practice Sharing Forum**



Michael learned how to better manage his condition, thanks to training organised as part of the NNHF project in Ghana.