NNHF activity report 2017

Team up for change

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

novo nordisk
haemophilia foundation

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

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

Contents

Children commemorating World Haemophilia Day 2017 in Hanoi, Vietnam.

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2017: a year teaming up for change

Dear partners, friends, community members, Council and funders,

Our work at the NNHF would not be possible if it weren't for the passion and dedication of our international partner network. This year's Activity Report is all about how that network can 'Team up for change' in ways that have a sustainable impact on the lives of those with haemophilia and allied bleeding disorders.

Teaming up can take on many different forms. NNHF Community Award winner, Marión Echenagucia, for example has been teaming up with labs across Latin America on various educational and scientific activities, energised by her passion for sharing knowledge. The Project of the Year Award winning Uganda 2 project has been teaming up by creating networks with religious and community organisations so that they can work together to identify and provide support to people with haemophilia.

Denise presents the 2017 NNHF Community Award to Marión Echenagucia from Venezuela.

Throughout this report, which for the first time is only being published online, you will see and hopefully be inspired by stories from our partners that reflect elements of teaming up for change. We are also pleased to share the results of our 2017 impact assessment, which provides an overview and examples of the change being created by our partners. New features of the report include the 'Meet the teams' and 'Thank you to expert volunteers' sections, which provide more information about some of the people helping to drive forward NNHF project activities.

Since the NNHF was established in 2005, we have worked with partners on 230 programmes covering 69 countries. In 2017, we saw our long-term partnerships in countries such as China, Mexico and Uzbekistan continue to thrive, and developed new ones in countries such as Ethiopia, Rwanda and Zambia. Whilst our partners and their project activities may be diverse, what joins us together is our pursuit of the vision that all people with haemophilia or allied bleeding disorders receive care and treatment wherever they live.

Mike meets Enkhsuld Terbish, who has severe haemophilia A, during his first NNHF field visit to Mongolia.

2017 brought with it many changes and we are thankful to the NNHF team for their constant ability to adapt to new environments. With our respective experiences of a first year in the general manager role, and the first NNHF field visit as Council President, we have never ceased to be impressed by the positive spirit and commitment of all those we encounter in our roles.

We would like to thank you all for giving us the opportunity to team up with you for a change that has a great impact, and we are looking forward to continuing to collaborate with you all in the year ahead.

Denise Brændgård
General manager

Mike Rulis
NNHF Council president

Michael Rulis

About NNHF

‘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.

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 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

Diagnosis and registry

Education and empowerment

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.

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 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, 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.

Empowering women to become leaders and to activate regional chapters within the patient organisation in Malaysia was the aim of the NNHF Malaysia 3 project.

Impact assessment 2017

Dr Elizabeth Flores, biochemist, teamed up with Dr Susana Gastaldo to improve the laboratory infrastructure in the reference centre and improve quality of diagnosis in the province of Jujuy, Argentina.

Impact assessment 2017 methodology

The 2017 impact assessment uses quantitative and qualitative data from three sources: a partner survey, NNHF project portfolio data and project partners' progress reports.

Partner survey

Conducted in December 2017 and distributed using an online survey development tool[1], this survey collects data on impact creation in our three focus areas: capacity building; diagnosis and registry; education and empowerment.

The survey was sent to partners from 54 NNHF programmes across 38 countries which were running or completed in 2017. Representatives from 43 programmes responded, meaning 80% of NNHF running or completed programmes are represented in the results. Respondents were given the option to provide their name or stay anonymous.

Programme portfolio data

We use programme modules to categorise activities taking place within programmes, which facilitates Better Practice Sharing and tracking of the distribution of funds per category.

Project partners' progress reports

To monitor their activities and measure impact, our partners complete half-yearly progress reports throughout the duration of their projects. We use these reports to highlight success and areas for Better Practice Sharing, and to identify where we can provide further support. Quantitative data is extracted from these reports to allow for cross-portfolio data analysis.

Unless otherwise stated, the data presented in this impact assessment overview is from the 2017 partner survey.

[1] https://www.surveymonkey.com/

Young leaders present their action plan as part of the two-year leadership programme in the NNHF South Africa 4 project.

Capacity building

Our partners build capacity in their projects by developing expertise, creating medical networks and establishing or strengthening care centres, facilities and service delivery.

Building skills amongst healthcare professionals comprises basic as well as in-depth training which is delivered in the project country or abroad.

Skilled experts

36,000

healthcare professionals trained[1]

Care facilities

475

centres established or strengthened[1]

193

of these are satellite and primary care sites[1]

Organisation of care delivery

National care guidelines

updated, printed or distributed through NNHF projects by 60% of partners

Fewer hospitalisations

per patient observed by 90% of partners

Reduced distance to receive care

according to 80% of partners

Improved quality of care

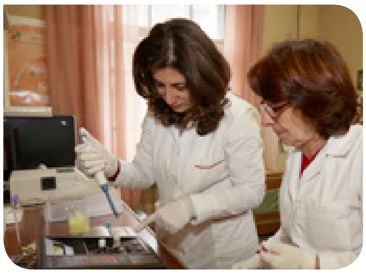
with 93% of partners with national guidelines using them to provide better care

"Physiotherapy training in 12 regions has contributed to a reduced risk of joint damage and means teams can offer rehabilitative treatment when joint damage has occurred, leading to a reduction in long hospital stays."

Dr Aziza Makhmudova
haematologist,
Uzbekistan

"We have managed to establish a health centre in the south of the country for the diagnosis of haemophilia without the need for patients to go to the capital of the country to certify the clinical suspicion."

Dr Carolina Molas
representative of healthcare authority,
Paraguay



"Our national treatment guidelines mean that centres across the country have a reference point to guide them in the delivery of appropriate haemophilia care. People with bleeding disorders no longer experience different quality of care depending on where they live."

Dr Hegine Khacehatryan
haematologist, Armenia

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[1] Source: NNHF programme portfolio data 2005-2017.

Diagnosis and registry

Only one in four of those living with bleeding disorders has been identified, and of these, many do not have a diagnosis which shows the type or severity of their disorder.

Our activities with partners in this area include training, improving lab infrastructure and sponsorship of the World Federation of Hemophilia (WFH) International External Quality Assessment Scheme (IEQAS). Our partners also develop and update registries through their projects, which provide the quality data needed to engage decision makers and allocate resources adequately.

Diagnosis expertise and staff

2,850
lab technicians trained[1]

Diagnosis facilities

283
labs established or strengthened[1]

Quality data

22,750
patients have been re-tested or newly diagnosed

69
registries developed or improved

Improved quality of diagnosis

through NNHF supported activities, say 96% of partners

"Previously most patients under our treatment centre had no confirmed laboratory diagnosis, so we had to send the laboratory for training. We are now excited, because we are able to add a correct diagnosis to the registry."

Dr David Silweya
epidemiologist,
Zambia

Increased diagnosis rate

observed by 93% of partners

"Thanks to the training of the Vietnam Hemophilia Association for doctors in haemophilia centres nationwide, many doctors have been provided with the knowledge to diagnose new patients. Based on this, 214 new haemophilia patients were diagnosed."

Dr Nguyen Thanh Mai
haematologist,
Vietnam

Informed policy makers

with 81% of partners using registry data for this purpose

"Our diagnosis and registry activities meant we could increase the funds allocated to treat people with haemophilia and provided data to help with our strategic planning and advocacy initiatives."

Magda Aly Rakha
representative of patient organisation,
Egypt

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[1] Source: NNHF programme portfolio data 2005-2017.

Education and empowerment

Educational sessions unite people with haemophilia and family members to learn, voice their community's needs and form a support network. Activities with patient organisations include developing skills and organisational capacity.

Topics covered in educational sessions include amongst others how to cope with the condition in daily life, psycho-social support and specific areas of haemophilia care such as exercise and self-infusion. We work together with patient organisation members to develop leadership, communications and advocacy skills.

Empowered people with haemophilia

38,150
people with haemophilia and family members educated[1]

Strong patient organisation

Empowered leaders within the patient organisation
say 91% of partners

Engaged authorities and community network

Members active in engaging with authorities
say 84% of partners

Improved understanding of the condition

leading to overall health improvements, observed by 98% of partners

"The knowledge acquired by patients, their families, teachers and caregivers leads to reduced discrimination, inequalities and a better understanding of the condition. People in the province of Jujuy now understand what haemophilia is."

Dr Susana Gastaldo
haematologist,
Argentina

Stronger organisational structure

according to 84% of partners

"The patient organisation is stronger in management and transparency; people with bleeding disorders and their families have been empowered to help each other."

Prof Chean Sophal
haematologist,
Cambodia

Changes in policy around bleeding disorders

say 86% of partners

"For the first time, haemophilia is mentioned in the 2018 draft health policy. We are proud of this achievement. Million thanks to our government and leadership, media engagement and advocacy activities supported by NNHF and other interested parties."

Richard Minja
patient organisation,
Tanzania

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[1] Source: NNHF programme portfolio data 2005-2017.

Regional highlights: Africa

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

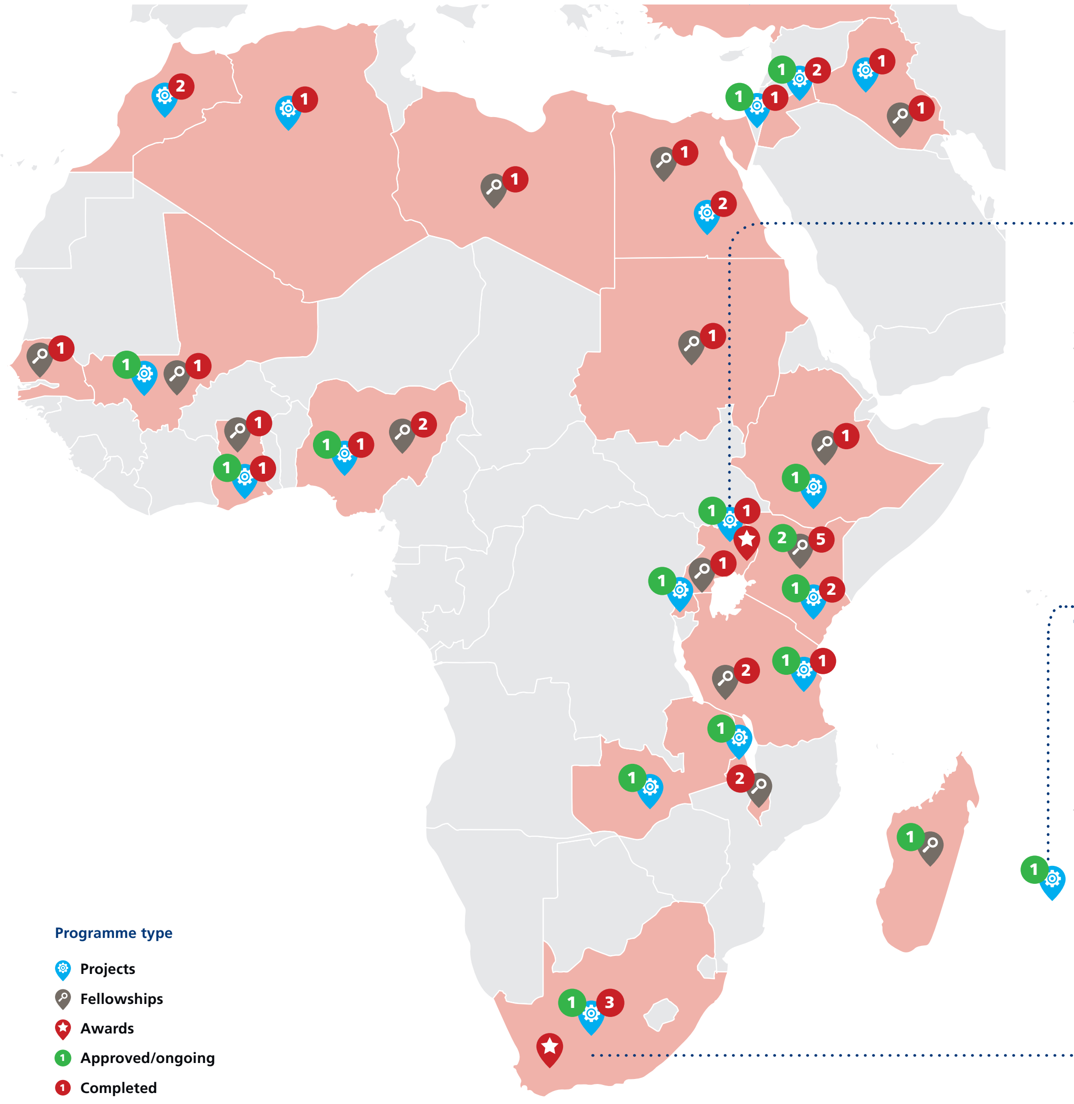
Africa:
Strengthening communities and basic care

In 2017, 16 programmes were approved, running or completed in Africa. We are delighted that Ethiopia, Rwanda and Zambia have joined our project portfolio, and that the region includes outstanding examples of better practices with the NNHF Project of the Year 2017, Uganda 2.

				Capacity building		Diagnosis and registry			Education and empowerment		Awareness and advocacy	
		Approved/ongoing in 2017	Completed in 2017	Health workforce	Service delivery	Diagnosis skills	Laboratory infrastructure	Registry	Education of patients and their network	Empowerment of patient organisation	Awareness raising	Advocacy
Projects	**Project category**											
Ethiopia 1	Basic	●		●	●	●	●		●		●	
Ghana 2	Basic	●		●		●	●		●	●	●	●
Kenya 3	Comprehensive	●		●	●	●	●		●	●	●	
Malawi 1	Basic	●		●	●	●	●	●	●	●	●	●
Mali 1	Basic	●		●				●	●		●	
Mauritius 1	Basic	●		●		●	●	●	●		●	●
Nigeria 2	Basic		●	●		●	●		●		●	
Rwanda 1	Basic	●		●	●		●		●		●	
South Africa 3	Comprehensive		●	●					●	●	●	
South Africa 4	Comprehensive	●		●		●		●		●		
Tanzania 2	Basic	●								●	●	●
Uganda 2	Basic	●		●					●		●	●
Zambia 1	Basic	●		●	●				●	●	●	
Fellowships	**Fellow profession**											
Malawi 1	Medical officer		●	●								
Malawi 2	Lab technician		●	●								
Tanzania 2	Nurse		●	●								

From 2017, the NNHF has incorporated the training elements previously covered through its fellowships into its projects. This means that training needs requiring a period of training abroad will now be delivered through NNHF projects.

Africa:
Regional map



Uganda 2: Connecting with community leaders

Award winning project engages with community leaders and organisations across the country to identify more people with haemophilia.

Mauritius: Teaming up across borders

Expert knowledge from India and South Africa means Mauritius now has a comprehensive care team, a well-equipped lab and a haemophilia network in place.

South Africa 4: Medical and patient communities form a joint force

The medical and patient communities are working together to build the capacity of healthcare professionals and strengthen the patient organisation.

Bringing people together for a common cause

The region continues to focus on establishing basic care, with many projects seeking to address low diagnosis rates by identifying more people with haemophilia. In Uganda, these efforts began with the Uganda 1 project, in 2015. This saw project partner Agnes Kisakye bring together an international team to set up the country's first public lab and train healthcare professionals in haemophilia and bleeding disorders. Agnes, who is the executive secretary of Uganda's patient organisation, is continuing to put her skills in bringing people together into action once again in the Uganda 2 project.

Connecting with community leaders

Given the important role of religious and community organisations in the country, the project is connecting with leaders from these organisations to engage them in their efforts to identify people with haemophilia and bleeding disorders. Involving these networks is crucial, as many people in Uganda – especially those living in rural areas – cannot easily access healthcare institutions. Those with haemophilia risk going undiagnosed because they are unable to recognise that their symptoms are being caused by the condition. This is where community leaders come in. As they have regular contact with their constituents, educating them to understand and recognise the symptoms of haemophilia means they can refer people who may have the condition to the patient organisation.

The project seeks to develop new leaders as well as work with established ones. 23 year old Peter Nangulu was diagnosed with haemophilia A at a patient camp organised by the Uganda 1 project in 2015. In the months following his diagnosis, Peter was reluctant to talk to anyone about his haemophilia, fearing rejection by his peers. However, with the patient organisation's encouragement he overcame these fears and began sharing his story at medical symposia and awareness events organised through the Uganda 2 project. In December 2017, Peter was elected as a youth leader and will team up with the patient organisation to empower young people in other regions. Alongside this, he will engage with healthcare professionals to increase their understanding of how it feels to be a person with haemophilia, as well as act as a media spokesperson to raise awareness of the condition.

> "This project has given me a platform to use my story and bring about positive change. The more people we can work together with, the more lives will be saved."
>
> Peter Nangulu, living with haemophilia A, Butaleja district, Uganda

Recognising achievements

The patient organisation assists those suspected of having haemophilia, ensuring they are referred for diagnosis and receive the right support throughout the process. The project team's efforts have so far seen them engage with traditional circumcisers, religious leaders and disability organisations, all of whom can be fundamental in improving the country's diagnosis rate. Additionally, the team is continuing to work with parliamentary networks to ensure haemophilia is given space on the national healthcare policy agenda. We are delighted that these efforts and impressive achievements so far led to the number of people with haemophilia diagnosed increasing from 4 to 170 since 2015, and to Uganda 2 being named NNHF Project of the Year 2017.
Find out more about the award.

Medical and patient communities form a joint force

In South Africa, the medical and patient communities identified a need to build capacity amongst healthcare professionals as well as strengthen the patient organisation. They knew they would be stronger if they teamed up, which is how the South Africa 4 project emerged. The team comprises the Medical and Scientific Advisory Council (MASAC) on the medical side and the South African Haemophilia Foundation (SAHF) which represents the patient community.

Building expertise and leadership

MASAC has developed a training curriculum which will be delivered in seven regions. SAHF is focusing on developing its next generation of leaders through a leadership training programme. The joint forces of knowledgeable healthcare professionals and an empowered patient community mean more people with haemophilia will be able to receive the care and support they need.

Long-term collaboration

The project team is also working together to set-up a registry. MASAC and SAHF have combined their significant knowledge of haemophilia to identify which demographic, medical and outcome data should be included. With both parties set to have access to the registry, the collaboration between the two will continue beyond the project's end.

Teaming up across borders

Mauritius looked further afield in its efforts to team up for change. As one of the smallest countries in Africa, the challenge in Mauritius was its limited capacity to build up its haemophilia care expertise and infrastructure. The team therefore partnered with Prof Johnny Mahlangu from the Haemophilia Treatment Centre in Johannesburg, South Africa. Prof Mahlangu visited Mauritius to support them in developing comprehensive care and a referral system. Alongside this, healthcare professionals from Mauritius underwent in-depth training at the Christian Medical College (CMC) in Vellore, India. As an international reference centre, CMC will further impart its expertise through onsite evaluation visits and as a point of reference to provide support.

As a result of this international collaboration, Mauritius now has a trained multidisciplinary care team, a fully equipped lab able to diagnose all bleeding disorders and a haemophilia referral system in place.

By teaming up with partners locally and internationally, NNHF projects in Africa provide an inspiring example of how much can be achieved when people work together for a joint cause.

Final project communications

Project	Title	Summary
Nigeria 2	*Improving diagnosis alongside self-esteem*	Healthcare professional training and awareness raising led to a 39% increase in the diagnosis rate, whilst motivational camps increased self-esteem, marriage and employment rates.
South Africa 3	*Expanding networks in the Eastern Cape*	Leadership and project management training supported the team's efforts to expand care to more regions and empower people with haemophilia and allied bleeding disorders.
Uganda 1	*Diagnosis and education for a better future*	Bringing free diagnosis to people with bleeding disorders for the first time, alongside a strategic media engagement campaign to identify more people with haemophilia and the country's first ever educational camp.

Orthopaedic training of Dr Beegoo at CMC Vellore, Chennai, to enable orthopaedic surgeons to perform operations on people with haemophilia in Mauritius, as part of the NNHF project in the country.

Regional highlights: Americas

Lic Marisol Soza, clinical bioanalyst from the Blood Bank in Managua, Nicaragua, shared her expertise with two lab technicians at the Blood Bank following the diagnosis training she received at Hospital del Niño in Panama City.

Americas:
Utilising regional and international expertise

Five projects were approved in 2017 in this region, bringing the total number of running or completed programmes in the year to 18. With a strong regional network, many projects have benefitted from utilising expertise across borders. Here we highlight a selection of projects that were completed during 2017.

				Capacity building		Diagnosis and registry			Education and empowerment		Awareness and advocacy	
		Approved/ongoing in 2017	Completed in 2017	Health workforce	Service delivery	Diagnosis skills	Laboratory infrastructure	Registry	Education of patients and their network	Empowerment of patient organisation	Awareness raising	Advocacy
Projects	**Project category**											
Argentina 4	Comprehensive	●		●	●				●		●	
Brazil 4	Comprehensive	●		●				●	●	●	●	
Brazil 5	Comprehensive	●		●	●	●	●				●	●
Chile 3	Comprehensive	●		●	●	●	●	●				
Colombia 2	Basic	●		●					●		●	
Cuba 2	Comprehensive	●		●	●	●	●	●	●		●	
Jamaica	Comprehensive		●	●	●	●	●	●	●	●	●	
Mexico 3	Comprehensive		●	●	●				●		●	
Mexico 4	Comprehensive	●		●	●			●			●	●
Mexico 5	Basic	●		●	●	●	●	●	●			
Mexico 6	Basic	●		●					●		●	
Nicaragua 1	Basic		●	●	●	●	●	●	●	●	●	
Paraguay 1	Basic		●	●	●	●	●	●	●	●	●	
Peru 3	Comprehensive	●		●	●	●	●	●			●	
Uruguay 3	Comprehensive	●		●	●	●	●	●	●		●	
Fellowships	**Fellow profession**											
Chile 5	Social worker		●	●								
Mexico 5	Physiatrist		●	●								
Mexico 6	Physiatrist		●	●								

From 2017, the NNHF has incorporated the training elements previously covered through its fellowships into its projects. This means that training needs requiring a period of training abroad will now be delivered through NNHF projects.

Americas: Regional map

Mexico 3: A multifaceted approach to teaming up

Working together within and across borders to set up paediatric rehabilitative care and improve adherence to treatment.

Meet the team from Mexico

Jamaica 1: Partnering for better care and a stronger community

Specialists from Canada deliver training covering multidisciplinary care, nursing and diagnosis.

Nicaragua 1: Building expertise and advocacy skills

Healthcare professional multidisciplinary training, advocacy activities and national level collaboration support the improvement of haemophilia care.

Paraguay 1: Bringing stakeholders together

With the guidance of experts from Mexico and Venezuela, the project team developed the technical knowledge and stakeholder management expertise required to improve care.

A multifaceted approach to teaming up

Teaming up often involves multiple partners, as demonstrated by the Mexico 3 project. The project, led by Dr Io Daiela Castillo, saw two paediatric hospitals in Mexico City – Hospital Infantil de México Federico Gómez and Instituto Nacional de Pediatría – working together to set up rehabilitative care in the two hospitals.

Inspired by Dr Laura Villareal, who built a multidisciplinary team in the State of Nuevo León from the bottom up in the NNHF Mexico 2 project, the Mexico 3 project team invited her to deliver healthcare professional training and provide ongoing guidance throughout the project. Looking further afield, the team sought the input of orthopaedist Dr Toribio Gómez from Panama and physiotherapist Naiari Fernández from Venezuela who shared their expertise by delivering MSK training.

An innovative approach to engaging people with haemophilia

Taking an innovative approach to education, the team developed materials and a web application aimed at children with haemophilia, their families and schools. With accessible language and colourful illustrations, the materials have been shared at various events and were translated into English.

Demonstrating further their creative approach to engage people with haemophilia, the team used Xbox One Kinect games in their physiotherapy sessions to improve coordination, balance and proprioception. The team also engaged with parents who are now taking an active role in the rehabilitation programme, as they motivate their children to exercise at home and monitor their adherence to treatment.

Following the project activities, the team has observed an improvement in joint health amongst people with haemophilia, and increased adherence to treatment and care regimens.

Read more about the project in the 'Meet the team' section.

Building expertise and advocacy skills

Leveraging on regional expertise was also a route taken by the Nicaragua 1 project, which sought to improve care. The project saw a strong collaboration between the patient organisation, the National Blood Bank and the hospital Manuel de Jesús Rivera "La Mascota" in Managua. Guadalupe Vivero from Panama trained a lab technician from Nicaragua's blood bank, whilst orthopaedist Dr Toribio Gómez visited the country to train healthcare professionals. In total 437 healthcare professionals and 235 medical students received training during the project.

Through the project, the blood bank has become the only institution in the country with the skills and facilities to offer quality diagnosis to people with bleeding disorders. This has led to a close relationship with the hospital Manuel de Jesús Rivera "La Mascota" to ensure referrals and follow-up are effectively carried out. The project team is now piloting a web application which will allow doctors to easily register and monitor patients whilst also enabling people with haemophilia and volunteers to reach out and connect with the national patient organisation.

Engels Reyes presents the impact created by the NNHF Nicaragua 1 project team in partnership with the Blood Bank, at the closing event in December 2017 in Managua, Nicaragua.

As the project partner, the Nicaraguan Association of Hemophilia has carved out an important role in leading these activities and becoming successful advocates for haemophilia care. Through their professionalism and dedication, the organisation has built a solid network with the National Blood Bank, local universities, the Ministry of Health and other key stakeholders and is viewed as a credible partner in improving the haemophilia situation in the country.

Bringing stakeholders together

Strong networks and gaining expertise from within and across borders have also proven a success factor in the Paraguay 1 project. The project team took the first steps to consolidating and decentralising care with a focus on two hospitals – the National Hospital of Itagua in Asunción and the Regional Hospital of Encarnación.

Marión Echenagucia, an expert lab technician from Venezuela delivered training in both hospitals. With the lab at the Regional Hospital of Encarnación being set-up from scratch through the project, this marks the first time that it can offer diagnosis to people with haemophilia. Both labs are now part of the World Federation of Hemophilia (WFH) International External Quality Assessment Scheme (IEQAS).

Sharing expertise on network creation

A multidisciplinary team from Hospital Universitario Dr José Eleuterio González in Monterrey, Mexico visited Paraguay to deliver training to 110 healthcare professionals. Aside from sharing their technical expertise, the Mexico team was fundamental in supporting the project team to build networks with national stakeholders. Both hospitals are now in regular dialogue with the patient organisation and the Ministry of Health’s national blood programme to pursue their common goal of improved care for people with haemophilia.

> "We are very proud because through this project we managed to unite more entities and hospitals so that we can work together, we achieved more communication and support with the national blood programme and a foundation for helping the haemophilia community, as well as with the hospitals involved.”
>
> Mayda Tamara Yasychyn, Fundacion de Ayuda al Hemofílico (Fundahemo), Asunción, Paraguay

Partnering for better care and a stronger community

Teaming up was the first step the Jamaica project made to address haemophilia challenges in the country. The project brought together haemophilia experts from the University Hospital of West Indies with a team of specialists from Canada, led by Dr Victor Blanchette.

Bringing the Canadian team to Jamaica for the education and training workshop enabled them to gain a first-hand understanding of local care conditions, and define and refine the training modules accordingly.

> "Having the opportunity to see the environment of clinical care in Jamaica assists in providing resources and education tailored to their reality. This is essential in providing the ‘best’ care for those living in Jamaica.”
>
> Vanessa Bouskill, nurse practitioner, Hospital for Sick Children (SickKids), Toronto, Canada

A united community engages authorities

The close collaboration and contact of team members with people with haemophilia throughout the project led to the reorganisation of a united patient organisation, the Haemophilia Society of Jamaica (HSJ). The HSJ was officially launched in Kingston in October 2017 at an event attended by a representative of the Ministry of Health, who made a public commitment to support people living with bleeding disorders. This public display of support was a huge step for haemophilia care in Jamaica, which has previously only received minimal government funding.

By working together with international experts, people with haemophilia and authorities, the project has improved the diagnostic infrastructure, developed healthcare professional skills, educated people with haemophilia and family members, and established a national haemophilia registry.

Dr Gillian Wharfe, NNHF Jamaica 1 project lead, with members of the Haemophilia Society of Jamaica at its official launch in October 2017.

Final project communications

Project	Title	Summary
Jamaica 1	*Collaboration builds better care and a stronger community*	Working with international experts to improve diagnosis, healthcare skills, whilst strengthening the patient organisation.
Mexico 3	*A playful approach to rehabilitative care*	Two paediatric hospitals integrate musculoskeletal care into their offering through healthcare professional training and education for children with haemophilia and their families.
Paraguay 1	*Consolidating care and creating networks*	Improving care and diagnosis in two hospitals through training from international experts and working with multiple stakeholders.
Nicaragua 1	Advocating for improved diagnosis and care	Using regional expertise and advocacy skills to improve multidisciplinary care and national level collaboration.

Regional highlights: Asia

Boys with haemophilia from Siem Reap join World Haemophilia Day celebrations in Phnom Penh, Cambodia, in April 2017.

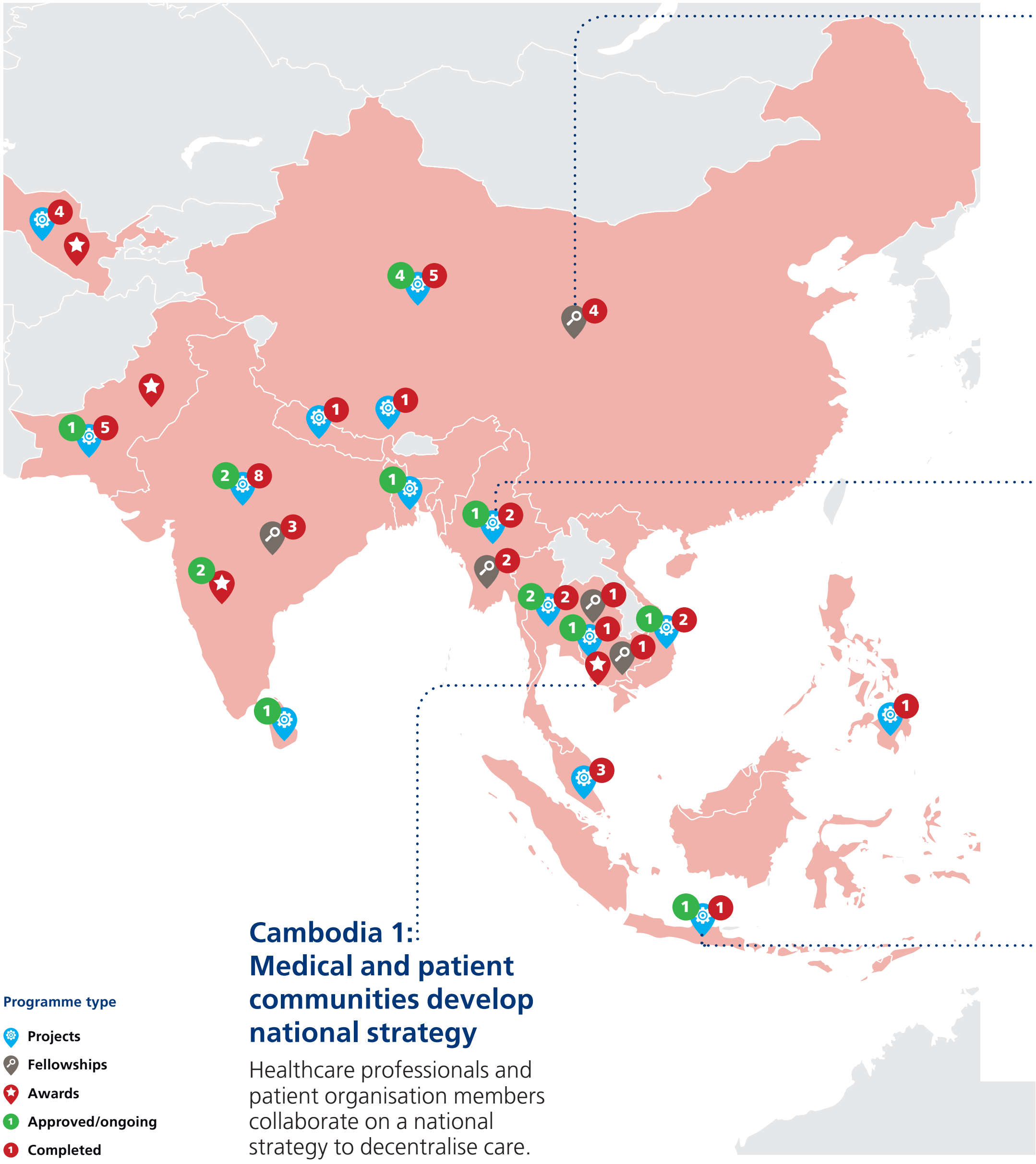
Asia:
Creating collaborative networks

25 programmes were approved, running or completed in Asia in 2017. The long-term nature of NNHF collaboration in this region is reflected in countries such as China, India, Vietnam and Uzbekistan, whose partnership with NNHF goes back at least nine years.

				Capacity building		Diagnosis and registry			Education and empowerment		Awareness and advocacy	
Projects	**Project category**	**Approved/ongoing in 2017**	**Completed in 2017**	Health workforce	Service delivery	Diagnosis skills	Laboratory infrastructure	Registry	Education of patients and their network	Empowerment of patient organisation	Awareness raising	Advocacy
Bangladesh 1	Basic	●		●	●	●			●		●	
Cambodia 1	Basic		●	●	●	●	●		●	●	●	
Cambodia 2	Comprehensive	●		●	●	●	●		●	●	●	●
China 3	Comprehensive		●	●	●	●	●	●	●		●	
China 4	Comprehensive		●	●	●	●		●	●		●	
China 5	Comprehensive	●		●	●	●		●	●	●	●	
China 6	Comprehensive	●		●	●	●		●	●		●	●
China 7	Basic	●		●	●	●	●	●	●		●	
China 8		●		●	●	●	●	●	●		●	●
India 3	Basic		●	●	●		●		●		●	
India 6	Basic		●	●	●	●			●	●	●	
India 7	Comprehensive	●		●				●				
India 8	Comprehensive	●							●	●		
India 9	Basic	●		●	●			●	●		●	
Indonesia 2		●		●	●				●			
Malaysia 3	Comprehensive		●						●	●	●	●
Myanmar 3	Comprehensive	●		●	●		●		●	●	●	●
Nepal 1	Basic		●	●						●	●	●
Sri Lanka 1	Basic	●		●					●	●	●	●
Thailand 2	Comprehensive	●		●	●			●	●	●	●	
Thailand 4	Comprehensive	●		●	●				●	●	●	
Uzbekistan 4	Comprehensive		●	●				●				
Vietnam 2	Comprehensive		●	●	●	●	●	●	●	●	●	●
Vietnam 3	Comprehensive	●		●	●	●	●		●	●	●	
Fellowships	**Fellow profession**											
Myanmar 2	Pathologist		●			●						

From 2017, the NNHF has incorporated the training elements previously covered through its fellowships into its projects. This means that training needs requiring a period of training abroad will now be delivered through NNHF projects.

Asia:
Regional map



China 4-5-6-7-8: Provincial approach strengthens multidisciplinary care

How teaming up on a provincial level creates networks of expertise and improved care across multiple provinces.

Meet the teams from the NNHF projects in China.

Thailand 4: Cross-sector collaboration at a national level

Bringing comprehensive care closer to people with haemophilia through a collaborative approach.

Cambodia 1: Medical and patient communities develop national strategy

Healthcare professionals and patient organisation members collaborate on a national strategy to decentralise care.

Indonesia 2: Empowering a volunteer network

Volunteers from the patient organisation build capacity and educate the haemophilia community across ten provinces.

Programme type

- Projects
- Fellowships
- Awards
- Approved/ongoing
- Completed

Medical and patient communities develop national strategy

Activities in this region comprise multiple levels of teaming up to create change – bringing together expertise from within provinces, countries and across borders. The Cambodia 1 project's two main streams were to improve diagnosis and care for people with haemophilia living outside of Phnom Penh and Siem Reap, and to educate those who had so far had limited access to information about their condition.

This required teaming up on two levels: firstly, Angkor Hospital for Children in Siem Reap partnered with the National Paediatric Hospital in Phnom Penh to train 122 healthcare professionals from across the country. "The long-term outcome is people with bleeding disorders will get more professional management in emergency before being referred to the specialised centres. Our colleagues will be able to respond adequately on the management of bleeding with or without final diagnosis," explained Prof Sophal from the National Paediatric Hospital.

Creating a knowledgeable and active community

The second stream of the project was overseen by the Cambodian Haemophilia Association (CHA). Over 300 people with haemophilia and family members attended educational workshops. "We feel supported and our boys know how to take care of their condition better, which ends up with less hospital visits as well as the boys feeling happier," shared one of the parents afterwards.

At the end of the project, CHA held a workshop for people with haemophilia and families to empower them to take an active role in defining CHA's needs and strategy.

The success of this project would not have been possible without the collaboration of haemophilia experts, volunteers, people with haemophilia and families from across Cambodia. The theme of 'Team up for change' was one of CHA's key messages on World Haemophilia Day and continues to define the work of the team, who have committed to continue working together to implement a strategy for the further decentralisation of care in Cambodia in the second project approved by the NNHF Council in November 2017.

Empowering a volunteer network

The patient community is also playing a vital role in the Indonesia 2 project. Given the scale of the project, which aims to improve care in 10 provinces across the country, the involvement of patient organisation members is key to its success.

On a voluntary basis, patient organisation members are delivering educational sessions for people with haemophilia and their families, covering topics such as self-infusion training, allowing them to self-manage their condition more effectively. Additionally, they are collaborating with the medical community to help organise healthcare professional training. By the end of 2017, the project team had trained 450 healthcare professionals and provided education to 260 people with haemophilia and their families.

Self-infusion training in Samarinda, Indonesia, as part of the second NNHF project in the country.

Cross-sector collaboration at a national level

The Thailand 4 project is taking a comprehensive multi-partner approach to improving care, with the project responsibilities divided between healthcare professionals, authorities and the patient organisation.

With the aim of bringing multidisciplinary care closer to people with haemophilia, every component of the project complements each other. It is being delivered by the National Health Security Office (NHSO) in collaboration with the International Haemophilia Treatment Centre in Bangkok, the Faculty of Medicine at Chiang Mai University and the Thai Haemophilia Patient Club.

At the end of 2017, healthcare professionals from eight provinces had been trained in multidisciplinary care and a referral system had been developed so that people with haemophilia receive the right care at the right time. Alongside this, the Thai Haemophilia Patient Club has delivered leadership training to five of its regional branches, with a view to empowering its members to play a more active role in strengthening the club and increasing its organisational capacity through fundraising and membership engagement activities.

Provincial approach strengthens multidisciplinary care

With five projects running in 2017, China provides an example of how teaming up on a provincial level creates networks of expertise and improved care across multiple provinces.

Building on the approach developed by the Haemophilia Treatment Centre Collaborative Network of China (HTCCNC) and adopted in the country since the NNHF China 2 project, the China 4, 5, 6, and 7 projects are each working in their respective provinces to strengthen multidisciplinary care, with one centre in each province responsible for cascading knowledge to other centres in their area. As a result, in each province an expert team will be created and the provincial medical network will have improved skills. In addition, thanks to the collaboration between centres in each province, the referral system will become more effective and able to respond better to the needs of people with bleeding disorders.

The China 8 project builds further on this approach by taking it to a multi-province level – with seven provinces in the north east of the country being included in the project.

> The network is a good model, without a strong network in place, we would not have been able to support people with haemophilia in those five cities, diagnose new patients, and make multidisciplinary care available closer to them.”
>
> Prof Zhang Xinsheng, director, Shandong Centre of Haemophilia Diagnosis and Treatment, Jinan, China

Final project communications

Project	Title	Summary
Cambodia 1	*Increasing the reach of haemophilia care*	Improving diagnosis and care outside of Phnom Penh and Siem Reap, and empowering people with haemophilia and bleeding disorders through education.
China 3	*Improving diagnosis through a national quality assurance scheme*	Creating a consistent system of testing and diagnosis resulting in quality data across China.
India 3	*Taking steps to standardise care in northern India*	Improving quality of care and community engagement through a multi-specialist training and awareness programme.
India 6	*Empowering parents and improving care*	Delivering a Parents Empowering Parents (PEP) programme in north and north east India.
Sri Lanka 1	*Improving care through international collaboration*	Improving musculoskeletal (MSK) care to prevent complications and disabilities, and educating and empowering people with haemophilia and allied bleeding disorders.
Uzbekistan 4	*Reducing joint complications through timely interventions*	Training healthcare professionals from 12 regions in rehabilitation techniques to help prevent joint damage.

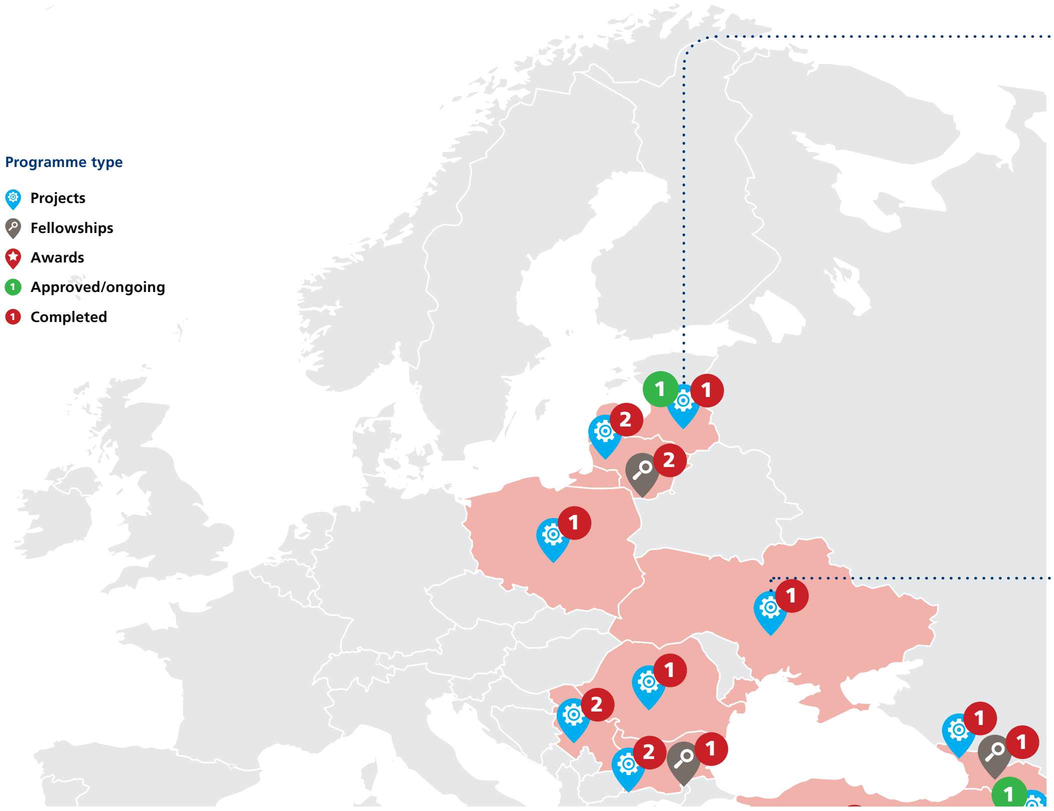
Regional highlights: Europe

Dr Miljic from the Adult Haematology Clinic in Belgrade, Serbia, during a consultation to assess the joints of a person with haemophilia.

Europe:
Improving data quality and engaging the community

In 2017, the NNHF funded two projects in this region: Latvia 2 and Serbia 2. Both projects see the patient organisations in each country taking a leading role in addressing unmet needs in haemophilia care.

				Capacity building		Diagnosis and registry			Education and empowerment		Awareness and advocacy	
Projects	**Project category**	Approved/ongoing in 2017	Completed in 2017	Health workforce	Service delivery	Diagnosis skills	Laboratory infrastructure	Registry	Education of patients and their network	Empowerment of patient organisation	Awareness raising	Advocacy
Latvia 2	Basic	●						●	●			
Serbia 2	Comprehensive		●	●					●	●	●	●



Latvia 2: Setting up a web-based registry

Establishing a registry to improve quality of data, care, and ensure a smooth transition from paediatric to adult care systems.

Serbia 2: Engaging the haemophilia community

Creating a network of regional educators to increase knowledge and community engagement.

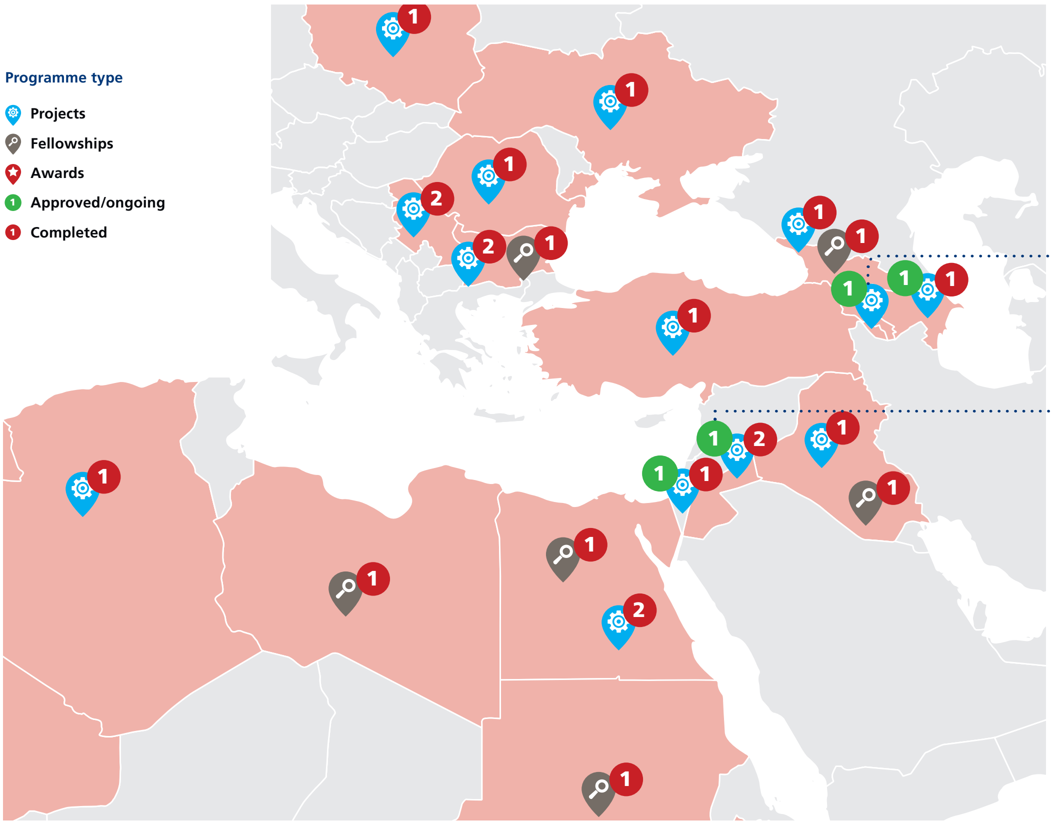
Regional highlights: Middle East, Near East and Caucasus

Nurses in Ramallah, Palestine receiving training on haemophilia care and how to use the national registry.

Middle East, Near East and Caucasus: Uniting stakeholders and improving expertise

Seven projects were approved, running or completed in this region in 2017. Project activities range from establishing web-based registries to training youth leaders, whilst project partners include patient organisations, healthcare professionals and authorities.

				Capacity building		Diagnosis and registry			Education and empowerment		Awareness and advocacy	
		Approved/ongoing in 2017	Completed in 2017	Health workforce	Service delivery	Diagnosis skills	Laboratory infrastructure	Registry	Education of patients and their network	Empowerment of patient organisation	Awareness raising	Advocacy
Projects	**Project category**											
Armenia 1	Basic	●		●	●			●	●		●	
Azerbaijan 2	Basic	●		●	●	●			●		●	●
Egypt 2	Basic	●		●	●			●	●			●
Jordan 3	Innovative		●						●	●	●	
Pakistan 5	Basic		●					●		●	●	
Pakistan 6	Comprehensive	●					●	●	●	●	●	●
Palestine	Basic		●	●		●	●	●	●		●	



Meet the team from Armenia

Palestine 1: Raising care standards through international collaboration

Teaming up with centres in Jordan and Egypt to train healthcare professionals.

Raising care standards through international collaboration

Teaming up across borders offers a solution to support activities in countries where resources are limited. This was the case in Palestine, which had a scarcity of haematologists in 2014, making it difficult for people with haemophilia to receive the specialist care they needed. The team formed by the Palestinian Ministry of Health therefore prioritised the training of healthcare professionals. Due to a lack of specialist centres within the country, they collaborated with Dr Magdy Elakiabi, Shabrawishi Hospital in Egypt, where two nurses and one physician attended an in-depth training course. In addition, six lab technicians were trained in diagnosis at Jordan University's Faculty of Medicine.

Furthermore, to ensure haemophilia was prominently positioned in the Ministry of Health's agenda, the team delivered an awareness raising workshop to their health educators which resulted in better knowledge of the condition amongst the Ministry's networks.

To raise the standard of care across the country, the team set about establishing national guidelines. A Ministry-appointed committee including haematologists, pharmacists and lab technicians from private and public sectors, together with a haematologist from the medical faculty at An-Najah University, developed care guidelines which are being distributed nationwide.

Through the project's activities, 146 people with haemophilia were retested and for the first time were able to receive correct information about their condition's severity and type.

Final project communications

Project	Title	Summary
Armenia 1	*Building a national haemophilia care network*	People with haemophilia are better informed and have access to an improved standard of care in the capital city as well as in other regions.
Pakistan 5	*Uniting patients to raise awareness*	Led by the national patient organisation, this project raised awareness, trained youth leaders and established a web-based registry.
Palestine 1	*Ministry of Health leads journey to improved care*	Care and resource planning was improved through healthcare professional training, lab equipment and the creation of a web-based registry.

Capacity building session for national women's group as part of the NNHF Pakistan 6 project.

Meet the teams

Rehabilitative hydrotherapy session at the Instituto Nacional de Pediatría in Mexico City, as part of the NNHF Mexico 3 project.

Armenia 1

An enthusiastic team in Yerevan sought to raise the national standards of haemophilia care in Armenia by strengthening their knowledge, expanding the care network outside of the city and improving diagnosis. Before the project people with haemophilia living outside of Yerevan only had occasional contact with healthcare professionals and lacked knowledge about the condition.

The team was trained and conducted a series of outreach visits to six regions. They also worked together to produce national treatment guidelines and a web-based registry. Alongside this, diagnostic facilities were improved and a series of educational events were held. Across the country, people with haemophilia are better informed and have access to an improved standard of care.

"The project has brought a young and dedicated haemophilia team together and shone a spotlight on haemophilia care – which we hope will attract more people to the specialty. Secondly, haemophilia patients now have trust that they can receive care here in Armenia and are less likely to leave the country like so many of their predecessors."
Prof Smbat Daghbashyan, director,
Haematology Centre, Yerevan

"The training of specialists was critically important for advancing haemophilia care in Armenia as specialists were not trained for a long time and training helped them to update their knowledge and be able to treat according to European standards."
Lusine Gigoyan, health programmes manager,
Haematology Centre, Yerevan

"My training in Lithuania gave me the expertise so that I can now deliver specialised physiotherapy care to people with haemophilia. This will help reduce musculoskeletal complications and the incidence of haemophilia related disabilities in the long-term."
Anahit Harutunyan, physiotherapist,
Haematology Centre, Yerevan

"Our national treatment guidelines mean that centres across the country have a reference point to guide them in the delivery of appropriate haemophilia care. People with bleeding disorders no longer experience different quality of care depending on where they live."
Dr Hegine Khacehatryan, haematologist,
Haematology Centre, Yerevan (left)

"Knowing that the care Matsakyen receives is gradually improving makes us hope that in future we'll be less fearful of letting him go to school and playing with friends, as if he does have a bleed, we don't have to travel so far to get help."
Mother of 5 year old Matsakyen who is living
with haemophilia, Gyumri

NNHF China projects

NNHF programmes in China span over 10 years and include eight projects and four fellowships. Five projects were running in 2017: China 4, China 5, China 6, China 7 and China 8.

The teams in China work on improving haemophilia care on a provincial, multi-provincial and national level. Since the NNHF China 2 project, the approach developed by the Haemophilia Treatment Centre Collaborative Network of China (HTCCNC) builds on the network model. The China 4 (Shandong), China 6 (Sichuan) and China 7 (Tibet) projects are working in their respective provinces to strengthen multidisciplinary care, with one centre empowered to cascade expertise to other centres in their area. The China 8 project further builds on this approach by including seven provinces in the north east of the country in the project.

“Compared to 11 years ago, haemophilia care has improved significantly in the country. In the beginning only six centres were able to provide haemophilia care in China. Today we count more than 30 centres. Over the last ten years, NNHF projects have greatly contributed to the improvement of access to haemophilia care.”
Prof Xuefeng Wang, Haematology Department, Ruijin Hospital, Shanghai – NNHF China 2 project partner

“The network is a good model, without a strong network in place and appropriate equipment, we would not have been able to support people with haemophilia in the five cities covered by the China 4 project and in the autonomous region of Tibet. Thanks to the teamwork we were able to diagnose new patients and make multidisciplinary care available closer to them.”
Prof Zhang Xinsheng, Shandong Centre of Haemophilia Diagnosis and Treatment, Jinan - NNHF China 4 and 7 project partner

"It is unfortunate to have haemophilia, but in Shandong we are lucky, because we have access to care and treatment. Before, people with haemophilia had to go to Beijing to receive care."

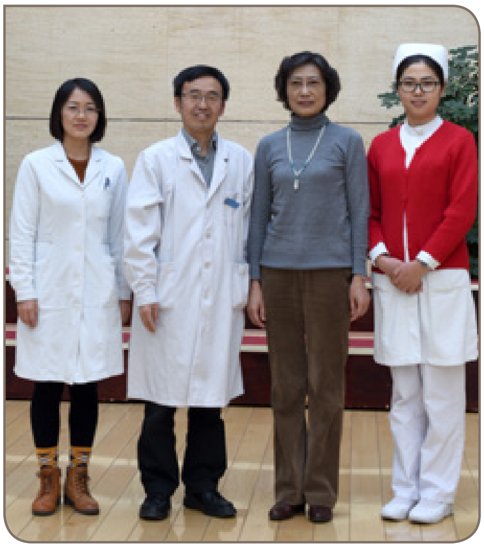
Qiang Wang, living with haemophilia A,
Jinan - NNHF China 4 project

"The most important result is that we established comprehensive care centres in five cities: Suzhou, Nanjing, Yangzhou, Xuzhou, Huai'an. More and more doctors want to collaborate in haemophilia treatment. Today patients can receive personal education by nurses and haematologists, joint assessment, physiotherapy and surgery, if necessary. This is thanks to a good teamwork."

Prof Ziqiang Yu, The First Affiliated Hospital of Suzhou University, Suzhou - NNHF China 5 project partner

"I met Prof Zhang and Prof Wang in 2012-2013 and started collaborating with them. I witnessed the benefits that the projects brought to the patients and therefore applied for a NNHF project. The great collaboration among members of the HTCCNC makes the transfer of patients easier, as we use the same management system and we exchange regularly during meetings and organise joint activities."

Prof Xiaojing Li, Sichuan Centre of Haemophilia Diagnosis and Treatment, Chengdu – NNHF China 6 project partner



"The collaboration among the centres in the provinces taking part in the China 8 project helped to improve expertise for diagnosis and treatment. Following the launch of the project, local professionals and patient groups sought support from local healthcare professionals, and the team was able to diagnose over 340 new people with haemophilia."

Prof Renchi Yang, Blood disease hospital, Chinese academy of medical science, Tianjin – NNHF China 8 project partner

NNHF Mexico 3 project

Dr Io Castillo, project lead, teamed up with healthcare professionals from Hospital Infantil de México Federico Gómez and from the Instituto Nacional de Pediatría, with healthcare professionals from other countries in Latin America as well as with people with haemophilia and their families, to improve musculoskeletal (MSK) care and decrease functional limitations.

Thanks to the great collaboration established, the NNHF Mexico 3 inclusive and innovative approach to paediatric rehabilitation has proven particularly impactful. All patients who have taken part in the rehabilitation programme reported improved mobility and muscular strength, and as they enjoyed the playful approach, they are keen to continue exercising to improve their quality of life.

Read more about the impact created by the NNHF Mexico 3 project.

"We work as a team: doctors, therapists, patients and parents, as we also exercise at home. Now that my children have received help to strengthen their muscles, their joints do not bleed anymore as they used to. With the exercises, therapy and the sports with the Kinect they realise that their joints are more flexible and, as they can do more movements, they foresee a healthier life for the future, just like anybody else."
Mrs Patricia Guzmán Altamirano, with her sons Brian and Leonardo, living with haemophilia

"It has been amazing to see the great teamwork that was done in each hospital for patients to complete their therapies and improve their strength, functionality, coordination, proprioception and so on. In implementing this therapy we observed an increased adherence to therapy for patients who showed motivation to continue to fight for better joint health."
Dr Io Daiela Castillo, haematologist,
Hospital Infantil de México Federico Gómez

"Sharing knowledge and learning from the experience of others helped us improve the care we provide to our patients in both hospitals. Before, the patients were not motivated to do physiotherapy. We made them work in a group, both in the pool and with the Xbox Kinetic; this created a great dynamic, making them feel good and motivated."
Dr Maria del Carmen García Cruz,
Instituto Nacional de Pediatría

"Throughout the project, we enhanced the collaboration between healthcare professionals, using the different competencies of each team member as strengths, for the benefit of the patients."
Dr Lourdes González Pedroza, haematologist,
Instituto Nacional de Pediatría

"When haemophilia affects the joints, in addition to affecting strength and mobility, it also affects other capacities like proprioception. Thanks to the use of Xbox Kinetic we worked with the patients to help them reduce limitations or recover faster."
Dr Jhovany Belmont Sánchez, paediatric physiatrist,
Hospital Infantil de México Federico Gómez

"Thanks to physiotherapy and physical activity, children with haemophilia recover their strength and joint health, allowing them to better manage daily activities."
Carla Eileen Lopez Herrera, physiotherapist,
Hospital Infantil de México Federico Gómez

"I am proud to be able to share my expertise on the treatment and care of people with haemophilia with the aim of ultimately improving the quality of life for the patients in our countries. I have also learned a lot during the days in Mexico, in regards to methodologies and guides, and this has been enriching for both parties."
Dr Toribio Gómez, consultant orthopaedist,
Panama City, Panama

"'Knowledge is power' we say. We worked to empower our patients to take care of themselves. They became more active, now they have less joint damage and can have a normal life."
Dr Oscar Daniel Isunza Alonso, orthopaedist,
Instituto Nacional de Pediatría

Find inspiration in the educational material *developed by the Mexico 3 project team.*

World Haemophilia Day celebration with 50 children and their families from Hospital Infantil de México Federico Gómez and Instituto Nacional de Pediatría during which the results of the Mexico 3 project were presented.

Events

The NNHF Kenya 3 project team celebrates the opening of the haemophilia clinic in Mombasa, in the presence of the hospital management and the haemophilia community.

Events

World Haemophilia Day – 17 April 2017

C.A.R.D.He. patient organisation and healthcare centre in Bahía Blanca, Argentina shared their messages on World Haemophilia Day.

As the major event for the haemophilia community, World Haemophilia Day is of particular focus for NNHF each year.

In 2017, to commemorate World Haemophilia Day, the NNHF engaged with the global community, mainly on its online Better Practice Sharing platforms. The NNHF invited its partners and the haemophilia community to take part in the 'Get Active for haemophilia - Team up for change' campaign, organising activities and sharing messages around the theme. The campaign proved engaging, with 20 NNHF project partners participating actively by sharing videos, photos and messages on Facebook.

On the same day, the NNHF launched its Activity Report 2016 and announced the winner of the NNHF Project of the Year Award - the Uganda 2 project - as well as the winner of the NNHF Community Award - Marión Echenagucia from Venezuela.

ISTH Congress, Berlin, Germany – 9-13 July 2017

At the ISTH Congress, held in Berlin from 9 to 13 July, the NNHF team welcomed delegates to its stand, inviting international experts as well as current and potential programme partners to 'Get Active for haemophilia – Team up for change'. The NNHF team held 98 productive meetings with delegates from 50 different nationalities discussing cross-border collaboration to improve haemophilia care and deliver life-changing impact.

Over 30 partners and delegates signed the 'Team up for change' wall, committing to work in partnership to improve haemophilia care in their regions and beyond.

The congress also provided a platform to recognise the exceptional voluntary engagement of Marión Echenagucia, winner of the NNHF Community Award 2017. The prize acknowledges her significant contribution to improving haemophilia care, strengthening diagnosis, training lab technicians and personnel in Venezuela and Latin America, always putting the patients at the centre of attention within multidisciplinary care.

CLAHT Congress, Punta Cana, Dominican Republic – 12-14 October 2017

The NNHF participated in the 25th edition of the CLAHT congress, held from 12 to 14 October in Punta Cana. Hearing about better practices from NNHF projects in the region and beyond inspired delegates seeking to improve haemophilia care in their countries. The event also provided the opportunity to meet with various NNHF project partners to discuss their project achievements as well as ideas of how to further work together to improve care for people with bleeding disorders in the region.

The NNHF team hosted a strategic planning workshop which saw the participation of doctors and patient organisations representatives and leading to a national project application (starting activities in 2018).

Marión Echenagucia receives the NNHF Community Award 2017, surrounded by colleagues and friends, at the ISTH Congress in Berlin, Germany.

Thank you to expert volunteers

Physiotherapist Sharon Funk from the US delivers physiotherapy training in Bangkok as part of the Thailand 2 project.

International experts teaming up for change

The NNHF expresses its gratitude to the following international experts who have volunteered during the year 2017, teaming up with NNHF partners to build or strengthen capacity and improve haemophilia care.

Continuous support on various projects in Latin America:

Marión Echenagucia,
lab specialist, Banco Municipal de Sangre, Caracas, Venezuela

Basic Coagulation Course, Morocco:

Christophe Nougier,
lab specialist, Hôpital Edouard Herriot Centre d'Hémophiles, Lyon, France

Cambodia 2 fellowship:

Dr Jameela Sathar and team,
consultant haematologist, Hospital Ampang, Kuala Lumpur, Malaysia

Chile 3 project:

Dr Felipe Querol,
physiatrist, Hospital Universitario y Politécnico La Fe, Valencia, Spain

Jamaica 1 project:

Dr Victor Blanchette,
paediatric haematologist, Hospital for Sick Children (SickKids), Toronto, Canada

Vanessa Bouskill,
nurse practitioner, Hospital for Sick Children (SickKids), Toronto, Canada

Pamela Hilliard,
haemophilia programme physiotherapist, Hospital for Sick Children (SickKids), Toronto, Canada

Dr Margaret Rand,
senior associate scientist, Research Institute, Hospital for Sick Children (SickKids), Toronto, Canada

Dr Nancy Young,
adjunct scientist, Research Institute, Hospital for Sick Children (SickKids), Toronto, Canada


Children with haemophilia learn more about their condition at an educational session in Santiago, as part of the NNHF Chile 2 project.

Audrey Abad,
clinical research project manager, Hospital for Sick Children (SickKids), Toronto, Canada

Koyo Usuba,
clinical research project assistant, Hospital for Sick Children (SickKids), Toronto, Canada

Dr Jerry Teitel,
consultant haematologist, medical director Adult Comprehensive Care Haemophilia Programme, St Michael's Hospital, Toronto, Canada

Georgina Floros,
haemophilia nurse, St Michael's Hospital, Toronto, Canada

Laurence Boma-Fischer,
specialist physiotherapist, Haemophilia Programme, St Michael's Hospital, Toronto, Canada

Dr David Lillicrap,
consultant haematologist, medical director, Queen's University, Kingston, Ontario, Canada

Angie Tuttle,
lab specialist, Queen's University, Kingston, Ontario, Canada

Malawi 1 and 2 fellowships:

Prof Johnny Mahlangu,
paediatrician and lab specialist, University of the Witwatersrand, Johannesburg, South Africa

Mauritius 1 project:

Dr Alok Srivastava and team,
haematologist, Christian Medical College, Vellore, India

Mexico 4 project:

Dr Laura Villarreal Martinez,
haematologist, Hospital Universitario Dr José Eleuterio González, Monterrey, Mexico

Mexico 5 and 6 fellowships:

Dr Felipe Querol,
physiatrist, Hospital Universitario y Politécnico La Fe, Valencia, Spain

Dr Santiago Bonanad,
haematologist, Hospital Universitario y Politécnico La Fe, Valencia, Spain


Osborne from Tongan, Malawi, now knows the type and severity of his haemophilia thanks to a newly equipped lab in Lilongwe.

Myanmar 2 project:

Paul McLaughlin,
physiotherapist, Royal Free Hospital, London, United Kingdom

Nicola Hubert,
physiotherapist, Great Ormond Street Hospital, London, United Kingdom

Myanmar 2 fellowship:

Dr Thynn Thynn Yee and team,
haematologist, Katharine Dormandy Haemophilia and Thrombosis Centre, Royal Free Hospital, London, United Kingdom

Nicaragua 1 project:

Dr Toribio Gómez,
consultant orthopaedist, Panama City, Panama

Paraguay 1 project:

Guadalupe Cavazos,
nurse, Hospital Universitario Dr José Eleuterio González, Monterrey, Mexico

José Ángel Garza,
physiatrist, Hospital Universitario Dr José Eleuterio González, Monterrey, Mexico

Laura Paez,
social worker, Hospital Universitario Dr José Eleuterio González, Monterrey, Mexico

Dr Laura Villarreal Martinez,
haematologist, Hospital Universitario Dr José Eleuterio González, Monterrey, Mexico

Tanzania 2 fellowship:

Dr Alok Srivastava and team,
Christian Medical College, Vellore, India

Thailand 2 project:

Dr Victor Blanchette,
paediatric haematologist, Hospital for Sick Children (SickKids), Toronto, Canada

Sharon Funk,
physiotherapist, University of Colorado, United States

Pamela Hilliard,
haemophilia programme physiotherapist, Hospital for Sick Children (SickKids), Toronto, Canada


Paul McLaughlin shares his expertise with physiotherapists at the Mandalay Hospital in Myanmar.

Our governance and accounts

Ismail learns physiotherapy techniques for rehabilitation from a physiotherapist at the haemophilia treatment centre in Tashkent, Uzbekistan.

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.

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

The NNHF Council

From left to right: (back) Amy Shapiro, Ulla Hedner, Mike Rulis, Jesper Brandgaard, Christian Kanstrup, (front) Paul Huggins, Margareth Castro Ozelo, Stephanie Seremetis.

Mike Rulis, president (appointed 2016)

Christian Kanstrup, vice president (appointed 2017)

Jesper Brandgaard (appointed 2017)

Ulla Hedner (appointed 2005)

Paul Huggins (appointed 2016)

Margareth Castro Ozelo (appointed 2012)

Stephanie Seremetis (appointed 2015)

Amy Shapiro (appointed 2011)

Former NNHF Council members

Leif Fenger Jensen, vice president 2009–2017

Emil Kongshøj Larsen 2015–2017

The NNHF management team

From left to right: Sara Motka, Xio Fong Vilaysane, Shady Sedhom, Milena Marra, Denise Brændgård, Stephan Destraz Morgan.

Denise Brændgård, general manager

Stephan Destraz Morgan, programme manager

Milena Marra, communications manager

Sara Motka, programme manager

Shady Sedhom, programme manager

Xio Fong Vilaysane, project coordinator

Former NNHF management team members

Susanne Brandl (until March 2017)

Rubén García Santos (until June 2017)

Audit report

Report of the statutory auditors on the limited statutory examination to the Board of Novo Nordisk Haemophilia Foundation
Zurich

As statutory auditors, we have examined the financial statements of Novo Nordisk Haemophilia Foundation, which comprise the balance sheet, income statement and notes, for the year ended 31 December 2017.

These financial statements are the responsibility of the Board. Our responsibility is to perform a limited statutory examination on these financial statements. We confirm that we meet the licensing and independence requirements as stipulated by Swiss law.

We conducted our examination in accordance with the Swiss Standard on Limited Statutory Examination. This standard requires that we plan and perform a limited statutory examination to identify material misstatements in the financial statements. A limited statutory examination consists primarily of inquiries of foundation personnel and analytical procedures as well as detailed tests of foundation documents as considered appropriate in the circumstances. However, the testing of the operational processes and the internal control system, as well as inquiries and further testing procedures to detect fraud or other legal violations, are not within the scope of this examination.

Based on our limited statutory examination, nothing has come to our attention that causes us to believe that the financial statements do not comply with Swiss law and the foundation's deed.

PricewaterhouseCoopers AG

J. Burgener

Ph. Gnädinger

Joanne Burgener
Audit expert
Auditor in charge

Philipp Gnädinger
Audit expert

Zürich, 23 February 2018

Enclosure:
- Financial statements (balance sheet, income statement and notes)

Financial statements 2017

Balance sheet as at December 31 (in Swiss francs)

	Note	**2017**	2016
ASSETS			
Current assets			
Cash and cash equivalents		**3,502,147**	3,415,774
Trade receivables		**0**	627,291
due from group companies		**0**	627,291
Total current assets		**3,502,147**	4,043,065
Total Assets		**3,502,147**	4,043,065
LIABILITIES			
Short-term liabilities			
Trade payables		**0**	70,103
due to third parties		**0**	70,103
Accrued expenses	1.2, 2.2	**2,587,498**	3,034,761
Total short-term liabilities		**2,587,498**	3,104,864
Long-term liabilities			
Long-term provisions		**69,657**	51,304
Total long-term liabilities		**69,657**	51,304
Total liabilities		**2,657,155**	3,156,168
Equity			
Locked-up capital		**200,000**	200,000
Statutory retained earnings		**686,897**	621,430
Gain/(loss) for the year		**-41,905**	65,467
Total equity		**844,992**	886,897
Total liabilities		**3,502,147**	4,043,065

Profit and loss statement for the financial year ended 31 December (in Swiss francs)

	Note	**2017**	2016
Donation income	1.1	**2,875,129**	3,101,909
Net grants		**-1,570,767**	-1,287,857
Approved grants		**-1,921,000**	-1'501,056
Cancelled and closed grants		**350,233**	213,199
Personnel costs		**-1,010,998**	-1,353,303
Other operating expenses		**-177,661**	-242,108
Project result		**115,703**	218,641
Administration costs	2.3	**-160,027**	-162,372
Operating result		**-44,324**	56,269
Financial income		**2,419**	9,198
Result for the year		**-41,905**	65,467

Financial statements 2017

Notes to the financial statement 2017 (in Swiss francs)

1 Accounting principles applied in the preparation of the financial statements

These financial statements have been prepared in accordance with the provisions of commercial accounting as set out in the Swiss Code of Obligations (Art. 957 to 963b CO, effective since 1 January 2013). Significant balance sheet items are accounted for as follows:

1.1 Donation income

Donation income represents the donations granted to the Novo Nordisk Haemophilia Foundation for the respective business year.

1.2 Grants

Grants are expensed when approved by the Novo Nordisk Haemophilia Council for development programmes. Grants get reversed when development programmes are cancelled or when development programmes are closed after objectives were achieved at lower than approved grant. Accrued project costs are included in accrued expenses.

1.3 Foreign currencies

Monetary and non-monetary items in foreign currency are translated into Swiss francs at the following exchange rates:

Foreign currency	2017 profit and loss statement	Balance sheet as at 31 December 2017
EUR	1.11	1.17
DKK	0.15	0.16
US$	0.99	0.98

The exchange rates used for balance sheet items are the rates prevailing on December 31; the exchange rates used for transactions conducted during the course of the year and for items in the profit and loss statement are average rates for the 2017 financial year.

2 Details, analyses and explanations to the financial statements

2.1 Employees

The number of full-time equivalents did not excced 10 on an annual average basis.

2.2 Accrued expenses

	2017	2016
Grants for development programmes:	**2,424,377**	2,207,559
Accrued bonus and pension costs	**127,402**	192,926
Other accruals	**35,719**	634,276
Operating result	**2,587,498**	3,034,761

2.3 Administration costs

	2017	2016
Rental and lease costs	**57,284**	64,257
Office costs	**32,772**	31,993
SLA costs	**20,597**	21,463
Legal and consulting fees	**33,084**	18,632
Audit fees	**6,480**	6,480
Other expenses	**9,810**	19,547
Administration costs	**160,027**	162,372

2.4 Lease liabilities (not terminable or expiring within 12 months of balance sheet date)

	2017	2016
Car leasing	**27,846**	0

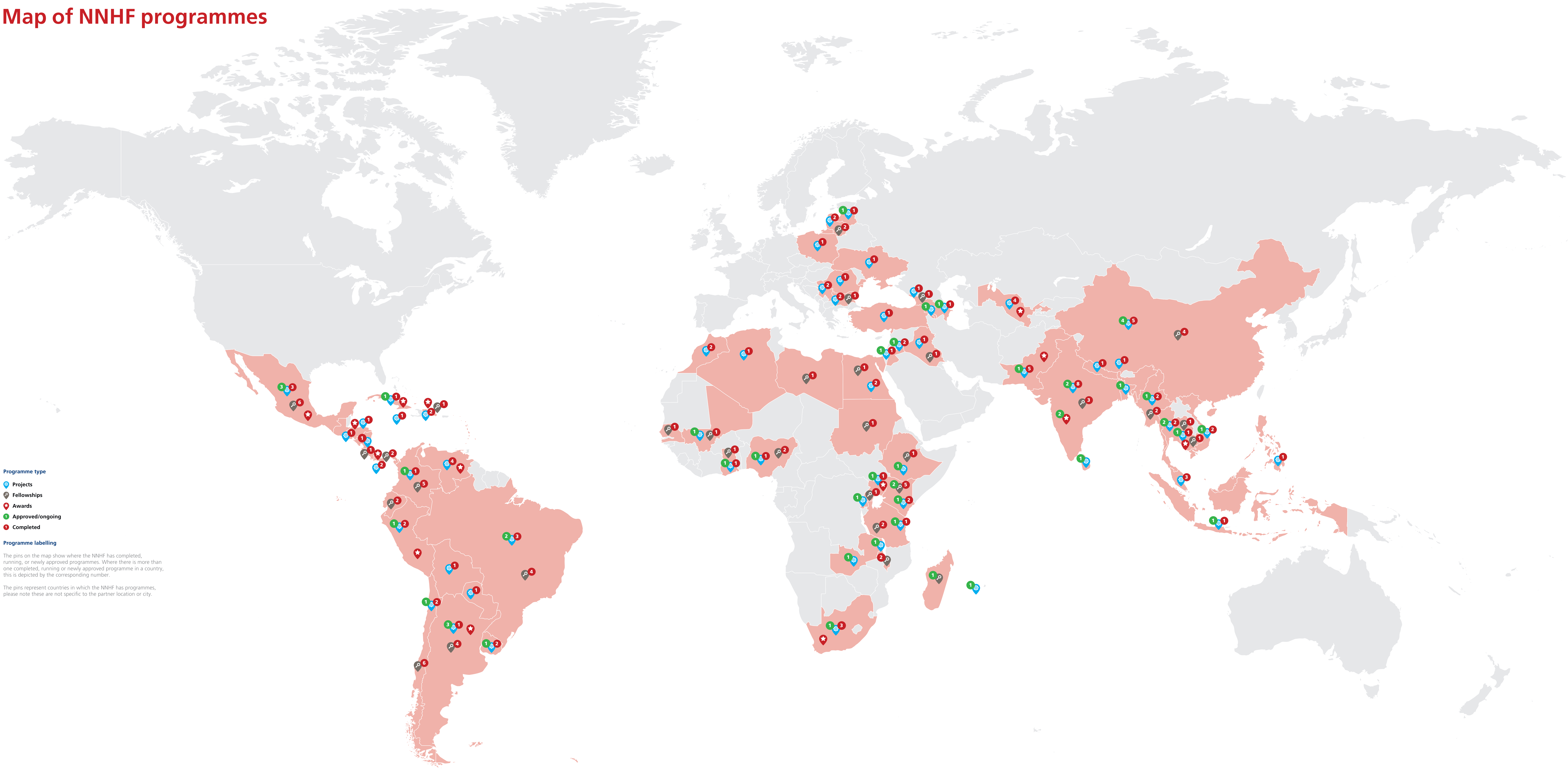
2.5 Significant events occurring after the balance sheet date

None

Map of NNHF programmes

•
Algeria •
Argentina
• Armenia
• Azerbaijan •
Bangladesh • Bolivia
• Brazil • Bulgaria •
Cambodia • Chile • China
• Colombia • Costa Rica • Cuba
• Dominican Republic • Ecuador
• Egypt • El Salvador • Ethiopia •
Georgia • Ghana • Guatemala • Honduras
• India • Indonesia • Iraq • Jamaica •
Jordan • Kenya • Latvia • Lebanon • Libya •
Lithuania • Macedonia • Madagascar • Malawi •
Malaysia • Mali • Mauritius • Mexico • Morocco
• Myanmar • Nepal • Nicaragua • Nigeria •
Pakistan • Palestine • Panama • Paraguay • Peru
• Philippines • Poland • Romania • Rwanda •
Senegal • Serbia • South Africa • Sri Lanka
• Sudan • Tanzania • Thailand • Turkey
• Uganda • Ukraine • Uruguay •
Uzbekistan • Venezuela •
Vietnam • Zambia

Map of NNHF programmes



Programme type

- 📍 Projects
- 📍 Fellowships
- ★ Awards
- 🟢 Approved/ongoing
- 🔴 Completed

Programme labelling

The pins on the map show where the NNHF has completed, running, or newly approved programmes. Where there is more than one completed, running or newly approved programme in a country, this is depicted by the corresponding number.

The pins represent countries in which the NNHF has programmes, please note these are not specific to the partner location or city.

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

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YouTube

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haemophilia foundation