NNHF activity report 2018

Team up to reach out

Marrone, here with his brother, used to have to embark on 13-hour boat journeys to access adequate care. The Brazil 4 project trained healthcare professionals in several cities to reduce travel time for people with bleeding disorders and prevent them from developing severe arthropathy.

novo nordisk
haemophilia foundation

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

12-year old Soe Myat Kyaw and his mother await a consultation with a nurse who was trained through the Myanmar 3 project.

Contents

Produced by | NNHF
Editor and writer | Natasha Kopitsis
Design and graphics | SAKINA CONSEIL
Photos | William Leach Photography; Jesper Westley Photography; NNHF and programme partners.

2018: A year of teaming up to reach out

Dear partners, friends, community members and funders,

Teamwork and partnership have been core to our work at the NNHF since it was established in 2005. Building on these themes, this Activity Report shows how working with haemophilia experts, patient organisations, authorities, media, and other stakeholders brings positive change to the lives of people with bleeding disorders.

The China 4 project is an outstanding example of how a strong network of dedicated experts can generate incredible impact. Establishing multidisciplinary care in five centres across Shandong province, the team reached out to people with haemophilia who in the past had to travel up to 12 hours to access care. It was the team's dedication and collaborative approach that led us to select China 4 as winner of the 2018 NNHF Project of the Year Award.

Recognition was also given to 2018 NNHF Community Award winner Prof Johnny Mahlangu from Johannesburg, South Africa. For over 15 years, Prof Mahlangu has worked tirelessly to help improve diagnosis, increase knowledge and establish centres across ten countries in Africa. He is just one of the volunteers who make the envisaged impact of NNHF projects into tangible change. Read our 'Meet our expert volunteers' section of this report to see who else has dedicated their time and skills to NNHF projects this year.

As the NNHF network continues to grow, so do the opportunities for teaming up within and across this network. Since 2005, the NNHF has supported 268 programmes spanning 72 countries. In 2018, we welcomed Albania, Botswana, Madagascar and Namibia into our portfolio for the first time.

We would like to thank all of you for your ongoing commitment to our vision, that all people with haemophilia or allied bleeding disorders receive care and treatment wherever they live. We look forward to teaming up with you in the coming year in our joint pursuit to make this vision a reality.

Denise Brændgård presents Prof Zhang Xinsheng with the 2018 NNHF Project of the Year Award.

Jesper Brandgaard with NNHF Chile 3 project partner Dr Verónica Soto in Santiago.

Denise Brændgård
General manager

Jesper Brandgaard
NNHF Council President

About NNHF

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

The journey to improved care

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

One in 10,000 people is born with haemophilia[1]. However, less than half of the global patient population has a confirmed diagnosis[2]. Most of those living with the condition – even when they have received a diagnosis – are not receiving adequate care[3]. This is particularly true in developing and emerging countries. Here, the challenges faced by people with bleeding disorders include: a shortage of medical experts; limited facilities providing care and diagnosis; lack of knowledge about the condition amongst people with haemophilia and bleeding disorders, their families and communities; low awareness amongst authorities and the public. These challenges mean that people living with the condition may suffer from disabilities, pain, and in some cases, they may have fatal complications leading to early death.

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

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

[1] www.wfh.org/en/sslpage.aspx?pid=646
[2] WFH Annual Global Survey 2017 data. Accessed January 2019
[3] www.wfh.org/en/about-us

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

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

A focused approach to tailored projects

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

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

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

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

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

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

Capacity building

Diagnosis and registry

Education and empowerment

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, President of patient organisation, Pará, Brazil

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

> "Our efforts in engaging and working together with authorities led to the Ministry of Health allocating space for a comprehensive care clinic, waiving taxes on treatment donations, and allocating healthcare professionals to work at the haemophilia clinics."
>
> James Kago, Secretary General of patient organisation, Kenya

Achieving sustainable goals

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

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

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

Impact assessment 2018

Self-infusion training in Samarinda as part of the Indonesia 2 project will reduce the number of hospital visits required in case of a bleed.

Impact assessment 2018 methodology

The 2018 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 2018 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 43 NNHF programmes across 32 countries which were running or completed in 2018. Representatives from 41 programmes responded, meaning 95% 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 2018 partner survey.

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

Following the NNHF Leadership workshop in Egypt, participants from the Ethiopia 1 project put their new skills into practice at a workshop to empower the youth group.

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

41,500
healthcare professionals trained[1]

Care facilities

493
centres established or strengthened[1]

198
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 85% of partners

"The training on management of haemophilia included aspects of how haemophilia patients can perform first aid at home, so we are now better placed to advise them how they can care for themselves before they report to hospital."

Dr Yohannie Mlombe
haematologist,
Malawi

Reduced distance to receive care
according to 81% of partners

"In the state of Pará, many people with haemophilia live in remote locations and have no immediate access to care and expertise. Our training activities throughout the state mean that first level care is now available outside the capital "

Christianne Oliveira Costa
President of patient organisation, Pará,
Brazil

Improved quality of care
with 77% of partners with national guidelines using them to provide better care

"The national physiotherapy protocols we produced will be used by our network of physiotherapists across India, meaning those in tier 2 and even less than tier 2 towns know what to do for a haemophiliac who has had an acute joint bleed."

Dr Pamela Narayan
physiotherapist, India

[1] Source: NNHF programme portfolio data 2005-2018.

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

3,100
lab technicians trained[1]

Diagnosis facilities

287
labs established or strengthened[1]

Quality data

25,500
patients have been re-tested or newly diagnosed[1]

40
countries developed or improved registries[1]

Improved quality of diagnosis

through NNHF supported activities, say 100% of partners

“We are now able to test for factor levels free of charge. Before this project in Mandalay, we had to travel over 500km to be screened”

Myo Aung
President of patient organisation (Mandalay Chapter),
Myanmar

Increased diagnosis rate

observed by 100% of partners

“After establishing a new haemostasis lab outside of the capital city, we have been able to diagnose more people with haemophilia, and these patients are able to get this diagnosis quicker than before.”

Dr Teresa Faguaga
transfusional medicine specialist,
Uruguay

Informed policy makers

with 91% of partners saying they have gained commitment for the continued support of diagnosis activities

“We have used the data from the registry to lobby the county government of Garissa to allocate space for setting up of a haemophilia clinic due to the many numbers of patients travelling the 350 km to Nairobi to seek treatment.”

James Kago
Secretary General of patient organisation, Kenya

---

[1] Source: NNHF programme portfolio data 2005-2018.

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

42,500
people with haemophilia and family members educated[1]

Strong patient organisation

Empowered leaders within the patient organisation
say 86% of partners

Engaged authorities and community network

Members active in engaging with authorities
say 91% of partners

Improved understanding of the condition

leading to overall health improvements, observed by 93% of partners

"Parents and people with haemophilia now see that treatment with coagulation factor is important but quality of life will be better if we develop a rehabilitation programme to strengthen their musculoskeletal system."

Dr Nancy Loayza
Head of Clinical Haematology Service, Peru

Stronger organisational structure

according to 80% of partners

"Our Hemophilia Foundation-Pakistan (HFP) activities have had the greatest impact as the organisation in Pakistan is matured and in a position to lobby more effectively with health authorities for the rights of the bleeding disorders community in the country."

Masood Fareed Malik
President of patient organisation, Pakistan

Changes in policy around bleeding disorders

say 86% of partners

"With the help of meetings in the framework of projects supported by NNHF, the authorities changed their attitude towards haemophilia and decided to improve the comprehensive approach to treatment in the regions."

Gulnara Huseynova
President of patient organisation, Azerbaijan

[1] Source: NNHF programme portfolio data 2005-2018.

Regional highlights: Africa

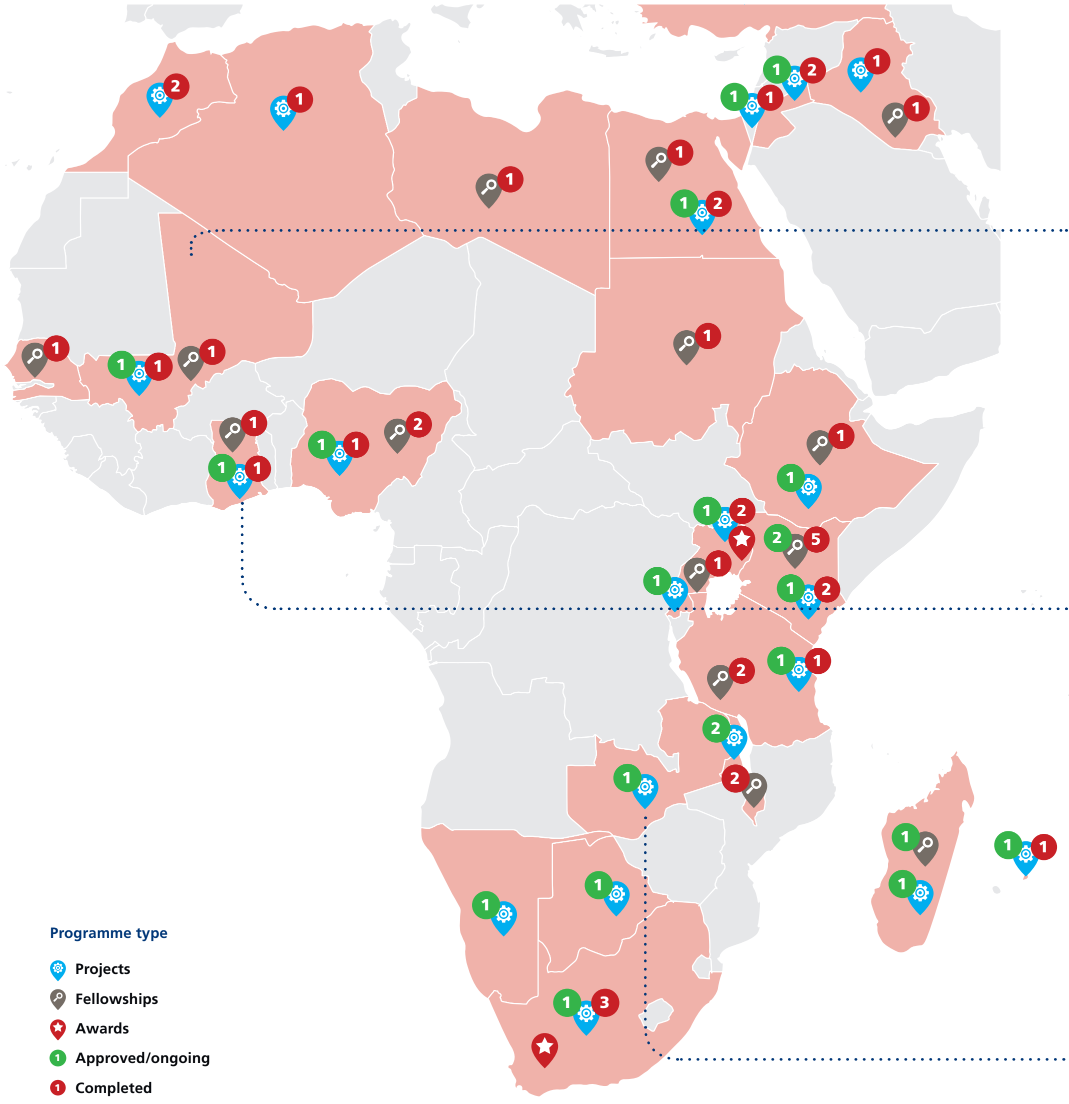
Members of the patient organisation attend the opening of the Zambia's first Haemophilia Treatment Centre in Lusaka, which was established through the Zambia 1 project.

Africa:
Establishing care and improving diagnosis

In 2018, 19 programmes were approved, running or completed in Africa. New countries in the NNHF portfolio are Botswana, Madagascar and Namibia. The region is also home to the 2018 NNHF Community Award winner, Prof Johnny Mahlangu from South Africa.

			Capacity building		Diagnosis and registry			Education and empowerment		Awareness and advocacy	
Projects	Approved/ongoing in 2018	Completed in 2018	Health workforce	Service delivery	Diagnosis skills	Laboratory infrastructure	Registry	Education of patients and their network	Empowerment of patient organisation	Awareness raising	Advocacy
Botswana 1	●		●	●	●						
Ethiopia 1	●		●	●	●	●		●		●	
Ghana 2	●		●		●	●		●	●	●	●
Kenya 3		●	●	●	●	●		●	●	●	
Kenya 4	●		●	●	●	●	●	●	●	●	●
Madagascar 1	●		●	●	●	●		●	●	●	
Malawi 1	●		●	●	●	●	●	●	●	●	●
Malawi 2	●		●	●	●	●		●	●	●	
Mali 1		●	●				●	●			●
Mali 2	●		●		●	●	●	●		●	
Mauritius 1		●	●		●	●	●	●		●	●
Mauritius 2	●		●					●	●	●	
Namibia 1	●		●					●	●	●	
Rwanda 1	●		●	●		●		●		●	
South Africa 4	●		●		●		●		●		
Tanzania 2	●								●	●	●
Uganda 2		●	●					●		●	●
Uganda 3	●		●	●	●	●	●	●	●	●	●
Zambia 1	●		●	●				●	●	●	

Africa: Regional map



Mali 1: Collaboration is key

Overcoming stigma and raising awareness by teaming up with experts at home and in Kenya.

Ghana 2: Expanding care to more regions

Bringing care and support closer to people living in the Central and Northern regions.

Zambia 1: Building the foundations of care

Establishing the first haemophilia clinic and reaching out to the medical and patient communities.

Mali 1

Collaboration is key

As in previous years, NNHF programmes in Africa have focused on increasing the low diagnosis rate which proves a challenge in many countries in the region. One of these countries is Mali, where the first NNHF project ran from 2016 to 2018.

A key element of the project was teaming up across and within borders. This included project partner Dr Yacouba Diallo visiting Dr Kibet Shikuku, a haematologist from Kenya who has collaborated with NNHF since 2012. By exchanging experiences within the same region, Dr Diallo gained an understanding of how to address the haemophilia challenges specific to African populations.

Overcoming stigma and isolation

One of these challenges relates to traditional circumcision practices, and the belief that haemophilia is a result of witchcraft. Through a series of educational and capacity building workshops in five regions (Bamako, Kayes, Sikasso, Segou and Mopti), Dr Diallo and his team helped people with haemophilia, family members and traditional practitioners understand that the condition is a medical one, and how to manage it accordingly. As a result, people with haemophilia and family members who were once isolated from their communities are empowered to share their experiences in their regions, in a drive to identify more people with haemophilia.

Benefitting from media and social networks

Addressing the low diagnosis rate through awareness creation was a priority for the project team. With only 42 people diagnosed when the project started, the team undertook a series of media interviews which resulted in consultations with those who had seen these interviews and recognised that they were experiencing the symptoms being described. By the end of the project, the number of diagnosed patients almost tripled to 123.

To ensure newly identified patients received the right support, even if they lived far away from their clinic, the team established a Whatsapp group to answer questions, provide support, and make referrals when needed.

> “Our integrated strategy of including families, healthcare professionals and traditional practitioners in the project showed positive results. We were able to make traditional and current medical knowledge co-exist, thus allowing each party to understand the need and the dangers for the people with haemophilia, especially in Africa. Now, each actor knows they have a key role to play as an important partner to create change”
>
> Dr Yacouba Diallo, haematologist, Mali

The team presented the results of their project at the WFH Congress in Glasgow, UK in May 2018, showing the remarkable progress that has already been made in the country. The Mali 2 project was approved in November 2018 and will focus on training healthcare professionals and educating people with haemophilia in three regions, as well as further increasing the diagnosis rate.

Ghana 2

Expanding care to more regions

Another project taking a regional approach is Ghana 2. With Ghana 1 focusing on Southern Ghana, this project aimed to expand care further by focusing on the Central and Northern regions. Led by patient organisation president Martin Boakye in close collaboration with the medical team from Kumasi, activities ranged from strengthening the patient association, training healthcare professionals, improving diagnosis and identifying more patients through awareness raising activities.

By creating three more regional patient organisation chapters in Kumasi, Tamale and Koforidua, people living with haemophilia in these areas are closer to a network that can provide education, support and advice.

Building knowledge amongst the medical community

To improve care in these regions, the project team undertook a series of training workshops. In total, more than 200 healthcare professionals were trained including midwives, nurses, circumcision practitioners and physiotherapists. Post-test questionnaires from the first workshop in Kumasi showed there was already an average of 20% increase in knowledge of how to manage haemophilia.

To increase the diagnosis rate, the project is working to improve the quality of diagnosis and identify more patients through awareness raising activities. 40 biomedical scientists have been trained as of the end of 2018, and a further 12 will receive in-depth training in Kumasi from Angus McCraw, a lab specialist from the UK.

To help identify those who may not realise they have haemophilia, the team has delivered lectures in training schools in Koforidua and Accra, alongside a targeted media campaign and awareness raising activities in public places such as outdoor markets. In addition, training workshops mean that more healthcare professionals are equipped to identify patients through family trees. As a result, the number of people with haemophilia that have been identified increased from 142 to more than 250.

Lab technicians in Ghana will now be able to conduct accurate diagnosis following training from Angus McCraw, a lab specialist from the UK.

Zambia 1

Building the foundations of care

Raising awareness is one of the key objectives of the Zambia 1 project, a country which has a diagnosis rate of just 5%. This forms part of the effort to build the foundations of haemophilia care in the country. Led by Chilufya Pikiti from the patient organisation in collaboration with the medical community, in less than two years the project has established the country's first haemophilia clinic.

To reach out to newly diagnosed patients and ensure they understand their condition and care options, the team conducted a series of home visits. This was accompanied by training for healthcare professionals, including traditional circumcisers.

Whilst facing many similar challenges, NNHF programmes in Africa show that there are many ways to address these challenges, but all rely on building a strong team with the ability to reach out to those who can benefit from improved knowledge, skills and diagnosis in the region.

Final project communications

Project	Title	Summary
Kenya 3	Enhancing capacity for haemophilia care delivery	Establishing a treatment centre in Mombasa whilst strengthening care in Nairobi
Malawi 1	The power of collaboration in establishing care and diagnosis	An international team of experts supported the team to create a lab and deliver training in three regions.
Mauritius 1	Establishing multidisciplinary care	Watch the film from the Mauritius 1 team to see why their activities in this project gained international recognition.
Nigeria 2	Improving diagnosis alongside self-esteem	Awareness raising activities, workshops and a lab upgrade led to an increased diagnosis rate alongside improved self-esteem.

Regional highlights: Americas

Lab technicians in Santiago are implemeting screening techniques learnt in Spain through the Chile 3 project.

Americas:
Utilising regional and international expertise

Four projects were approved in 2018 in this region, bringing the total number of running or completed programmes in the year to 17. Decentralisation of care has been a strong theme amongst projects, with activities aiming to bring care closer to home for people with haemophilia.

			Capacity building		Diagnosis and registry			Education and empowerment		Awareness and advocacy	
Projects	Approved/ongoing in 2018	Completed in 2018	Health workforce	Service delivery	Diagnosis skills	Laboratory infrastructure	Registry	Education of patients and their network	Empowerment of patient organisation	Awareness raising	Advocacy
Argentina 2	●		●					●		●	
Argentina 3	●		●	●		●	●	●		●	
Argentina 4	●		●	●				●		●	
Brazil 4		●	●					●	●	●	●
Brazil 5	●		●	●	●	●				●	
Chile 3	●		●	●	●	●	●				
Colombia 2	●		●					●		●	
Colombia 3	●		●	●				●		●	
Cuba 2		●	●	●	●	●	●	●		●	
Dominican Rep. 2	●		●		●	●	●	●		●	●
Mexico 4	●		●	●			●			●	
Mexico 5	●		●	●	●	●	●	●			
Mexico 6		●	●					●		●	
Mexico 7	●		●	●	●	●				●	
Nicaragua 2	●		●		●	●		●	●	●	●
Peru 3	●		●	●	●	●	●			●	
Uruguay 3	●		●	●	●	●		●		●	

Americas: Regional map

Mexico 6: Inspired through knowledge sharing

Collaborating with members of the NNHF Mexico 2 project leads to improved health outcomes in the State of Yucatán.

Cuba 2: Establishing comprehensive care

Bringing care to the East of the country and creating a national haemophilia network through collaboration and better practice sharing.

Brazil 4: Strengthening the care network

Decentralising care and capacity building activities bring care closer to home for those living in the State of Pará.

Programme type

- ⚙ Projects
- 🔍 Fellowships
- ★ Awards
- 🟢 Approved/ongoing
- 🔴 Completed

Brazil 4

Strengthening the care network

Reaching out to more people with haemophilia often starts with decentralisation of care. For those living in remote areas and with limited economic resources, the absence of care close to home can have devastating consequences. This was the case for Telma and her son Marrone, who has haemophilia A. From their home town of Bagre in the state of Pará, the only option for receiving care in cases of a bleed was to make a 13-hour boat trip to the city of Belem, 300km away. When the economic and emotional cost of this became too much, Telma made the heartbreaking decision to move with Marrone and two of his siblings to Belem, whilst her husband and three other children remained in Bagre.

It was to address challenges like this that the Brazil 4 project, led by Christianne Maria Oliveira Costa from the State of Pará patient organisation, was created. By training more than 340 healthcare professionals across four cities in the state, primary level care is now available for those living outside of Belem.

> This project is very important not only for the State of Pará but also as a model for other states. And it is rewarding to see the personal impact the project has had on people with haemophilia and their families."
>
> Christianne Maria Oliveira Costa, President of patient organisation

Reducing hospitalisations

As well as receiving appropriate care, the trained nurses can teach self-infusion – a legal right for people with haemophilia in Brazil, thus reducing the need for hospital visits. The team also conducted research into the psycho-social aspects affecting adherence to treatment regimes, taking into consideration socio-economic factors, which will guide healthcare professionals in advising and supporting their patients accordingly.

The team have also cascaded their learnings further afield, presenting their findings on haemophilia treatment barriers and adherence at the HEMO 2018 congress in Sao Paulo.

A World Haemophilia Day in Belém brought together local authorities, members of the Brazilian Federation of Haemophilia, healthcare professionals and people with haemophilia and their families.

Cuba 2

Establishing comprehensive care

Decentralisation of care has also been the theme of the Cuba 2 project. The project focused on bringing care closer to the vulnerable population living in the East of the country.

In 2008, care was only available in the capital city Havana. The NNHF Cuba 1 project established comprehensive care centres in Pinar del Rio in the West and Villa Clara in the centre. Applying their learnings and methods from this project, the team set out to bring comprehensive care to two more cities - Santiago de Cuba and Holguín - in the East.

Alongside the creation of haemophilia clinics, the labs in both centres were equipped and lab technicians trained to conduct accurate diagnosis. More than 60 healthcare professionals were trained and educational materials targeting dentists, teachers and people with haemophilia were produced.

Creating a national network

Whilst most activities focused on the East, the project has a national element. National treatment guidelines and informational posters were developed and have been distributed to hospitals across the country.

By the end of the project in December 2018, a national haemophilia network had been created, which culminated in a workshop involving the centres that were established through the Cuba 1 and Cuba 2 projects. During the workshop, the team showed how the results from the centres established in Cuba 1 are continuing to demonstrate sustainable impact in improving health outcomes for those living with haemophilia.

A workshop in December 2018 brought together members of the Cuba 1 and Cuba 2 projects.

Mexico 6

Inspired through knowledge sharing

Like Cuba, NNHF projects in Mexico are based on a culture of knowledge sharing across the different project teams that NNHF has supported in the country. Inspired by the NNHF 2015 Project of the Year Award winner Mexico 2 (Monterrey), the Mexico 6 project has focused on outreach in the State of Yucatán.

Project partner Dr Eric Gutierrez is head of the haemophilia clinic at the Hospital General Agustin O'Horan in Mérida, State of Yucatán. As the only public hospital in the state accredited to provide haemophilia care under the national social security system, Dr Gutierrez sought to improve health outcomes by empowering people with haemophilia and their families to provide self-care, and training the healthcare professional network around them.

Improved health outcomes

In collaboration with the Mexico 2 project team, two nurses have been trained in Monterrey in 2017, who went on to support educational sessions with more than 50 people with haemophilia and family members. Self-infusion was a key part of these sessions, meaning that people with haemophilia no longer have to visit the hospital in cases of a bleed. As of late 2018, the number of hospital admissions for bleeds had reduced by a half compared to the previous year, and a reduction in joint complications has also been observed.

> "We are proud that one hundred percent of the families that were trained adequately demonstrated how to apply intravenous treatment to their children. They have learned about the condition, and we have disseminated information about it to the general public and healthcare professionals."
>
> Dr Eric Gutierrez, head of haemophilia clinic

The project team's activities to reach out to more people with haemophilia included the publication and distribution of educational materials, some of which were translated into Yucatec Maya, a Mayan language spoken in Yucatan. Haemophilia has been featured in local television and radio broadcasts and on social media.

Final project communications

Project	Title	Summary
Argentina 2	The art of better care	Bringing a comprehensive approach to the Southern Buenos Aires province.
Argentina 3	Planting the seeds of progress	Outreach to people with haemophilia living in the province of Jujuy.
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

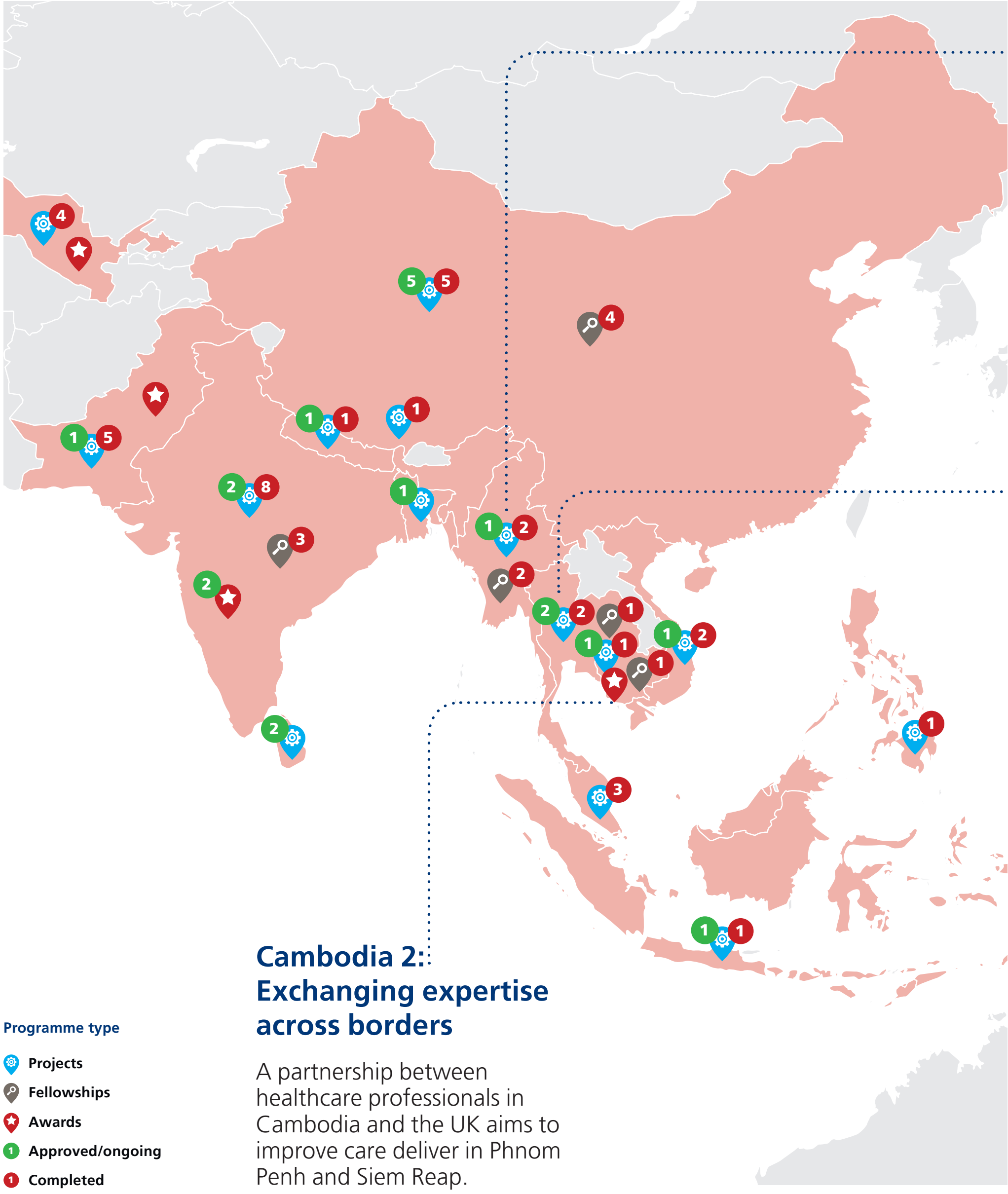
Physiotherapists Pheng Vann from Phnom Penh, Cambodia and Tracey Dandy from Nottingham, UK assess the joints of Li Jing Li, who has haemophilia A. Before Tracey's visit to Cambodia, Vann had undertaken four weeks of in-depth training at Nottingham University Hospital.

Asia:
Exchanging knowledge across borders

18 programmes were approved, running or completed in Asia in 2018. Many projects across the region rely on the power of networks to spread knowledge and reach out to more people with haemophilia. The 2018 NNHF Project of the Year Award winner, China 4, demonstrated this by establishing comprehensive care in five cities across Shandong province.

			Capacity building		Diagnosis and registry			Education and empowerment		Awareness and advocacy	
Projects	Approved/ongoing in 2018	Completed in 2018	Health workforce	Service delivery	Diagnosis skills	Laboratory infrastructure	Registry	Education of patients and their network	Empowerment of patient organisation	Awareness raising	Advocacy
Bangladesh	●		●	●	●			●		●	
Cambodia 2	●		●	●	●	●		●	●	●	●
China 5	●		●	●	●		●	●	●	●	
China 6	●		●	●	●		●	●		●	●
China 7	●		●	●	●	●	●	●		●	
China 8	●		●	●	●	●	●	●		●	●
China 10			●	●				●			
India 7	●		●				●	●			
India 8	●								●		
India 9	●		●	●			●	●		●	
Indonesia 2	●		●	●				●			
Myanmar 3	●		●	●		●		●	●	●	●
Nepal 2	●		●	●	●	●		●	●	●	●
Sri Lanka 1		●	●					●	●	●	●
Sri Lanka 2	●		●	●	●	●		●	●	●	
Thailand 2	●		●	●			●	●	●	●	
Thailand 4	●		●	●				●	●	●	
Vietnam 3	●		●	●	●	●		●	●	●	

Asia:
Regional map



Myanmar 3: Nurses as a key player in haemophilia care

Teaming up with an international nurse expert to increase capacity to deliver care in Mandalay and beyond.

Thailand 2: Expanding musculoskeletal care

Training and international collaboration leads to a wider musculskeletal (MSK) care network and development of a MSK registry.

Cambodia 2: Exchanging expertise across borders

A partnership between healthcare professionals in Cambodia and the UK aims to improve care deliver in Phnom Penh and Siem Reap.

Programme type

- ⚙ **Projects**
- 🔍 **Fellowships**
- ★ **Awards**
- 🟢 **Approved/ongoing**
- 🔴 **Completed**

Cambodia 2

> This is an opportunity to develop the next generation of healthcare professionals in the country. We need to expand our expertise in haemophilia to reach those who really need it - not just now, but in the years to come."
>
> Prof Chean Sophal, haematologist, Cambodia

Exchanging expertise across borders

In 2018, the project saw healthcare professionals from the National Pediatric Hospital (NPH) in Phnom Penh and Angkor Hospital for Children (AHC) in Siem Reap team up with Nottingham University Hospital in the UK, forming a partnership based on sharing experiences in the pursuit of improved haemophilia care. Following eight weeks of in-depth training in Nottingham, the two nurses, two haematologists and one physiotherapist returned to their hospitals in Cambodia to devise ways to implement their learnings. The team from the UK – comprising a haematologist, nurse and physiotherapist - then visited Cambodia to see the teams in action and provide further practical advice on improving the management of haemophilia care in both hospitals.

Developing a long-term partnership

What struck the UK team was the learning that they gained through the experience. "We joined this project expecting to teach healthcare professionals from Cambodia about how to deliver haemophilia care. What we found was that we were also the ones doing the learning – despite the limited resource environment, we saw how innovation and teamwork can help overcome some of the challenges raised" explained Michelle Kightley, haemophilia nurse.

Now that the UK team has returned to Nottingham, they will continue their dialogue with AHC and NPH to support the development of training materials for healthcare professionals and people with haemophilia.

Alongside these activities, the Cambodian Haemophilia Association (CHA) is also working to strengthen its capacity to reach out to more people with haemophilia and improve the diagnosis rate. The first step has been forming a youth group, which will work to encourage more active members to join CHA, and raise awareness of the condition.

Dr Charlotte Grimley and nurse Michelle Kightley from the UK with Dr Pechkethia Lam from Cambodia during a consultation at the National Pediatric Hospital, Phnom Penh.

Myanmar 3

In Mandalay, Myanmar, haematologist Dr Moe Hein invites his next patient in for a consultation. The queue outside his consultation room stretches the length of the corridor and beyond to the stairwell. Dr Moe Hein is the only haematologist in northern Myanmar. His weekly haematology clinic is one of the few opportunities that people with haemophilia have to access specialist care.

> As the only adult haematologist in the region, we need to investigate other options to ensure people with haemophilia are receiving care. That's why we identified nurses as playing a key role in this project. They are usually the first point of contact, so being able to identify symptoms, provide appropriate care and support psycho-social needs are just some of the skills they need".
>
> Dr Moe Hein, haematologist, Myanmar

Nurses as a key player in haemophilia care

Jennifer Maahs, haemophilia nurse practitioner from the Indiana Hemophilia and Thrombosis Center in the US, kicked off the chain of learning by delivering a 3-day workshop to 14 haemophilia nurses in October 2018. Each participant was given a train-the-trainer pack, translated into Burmese, so that they can train their peers at their centres. Not only will this mean more healthcare professionals are able to provide haemophilia care, it also means those living outside of Mandalay don't need to travel so far to receive this care.

Other highlights in 2018 include the recognition of the Mandalay Chapter of the patient organisation by authorities. Led by the organisation's President Myo Aung, the Chapter can now engage in fundraising and awareness creation activities which will help them identify and reach out to more people living with haemophilia in the region.

14 nurses participated in haemophilia training delivered by Jennifer Maahs from the US. They will now cascade what they have learnt to their colleagues at their centres.

Thailand 2

Physiotherapists are also key players in haemophilia care. Physiotherapy can help reduce and prevent the musculoskeletal (MSK) complications associated with haemophilia.

Expanding MSK care

The Thailand 2 project is expanding MSK care beyond the hubs of Bangkok and Chiang Mai, bringing physiotherapy closer to home for people with haemophilia. In 2018, four MSK training sessions have been held for physiotherapists in Lampang, Chiang Rai, Phitsanulok and Chiang Mai. The training is built around the use of internationally recognised MSK evaluation tools, which have been translated into Thai. The data collected during consultations will be entered into a MSK registry, which is also being developed through the project.

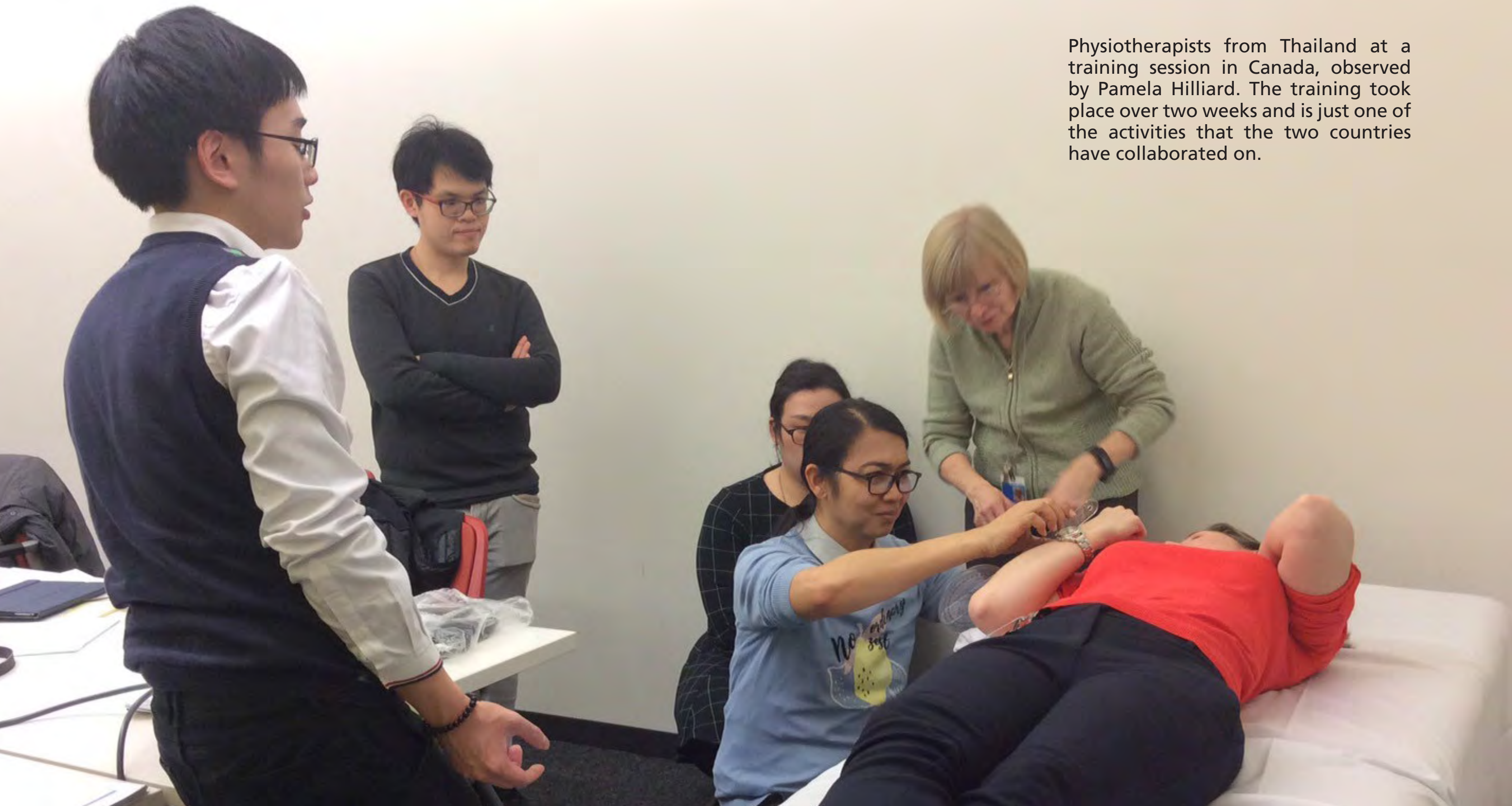
Benefitting from collaboration

Throughout its activities, this project has benefitted from a long-term collaboration between Dr Rungrote Natesirinilkul from the Faculty of Medicine, Chiang Mai University, Prof Ampaiwan Chuansumrit from IHTC Bangkok and the team of Dr Victor Blanchette from SickKids Hospital in Toronto, Canada. As well as providing practical training onsite and advising on the development of the registry, in 2018 four physiotherapists and one haematologist from different regions across Thailand undertook in-depth training at SickKids. To gain experience working with adults, they also received training at St Michael's Hospital during their stay.

Those who received training are now part of the team training other physiotherapists in Thailand, ensuring that learning is cascaded to more centres.

Final project communications

Project	Title	Summary
China 4	Improving access to comprehensive care	Strengthening care through training, awareness raising and network creation in Shandong province.



Physiotherapists from Thailand at a training session in Canada, observed by Pamela Hilliard. The training took place over two weeks and is just one of the activities that the two countries have collaborated on.

Regional highlights: Europe and Caucasus

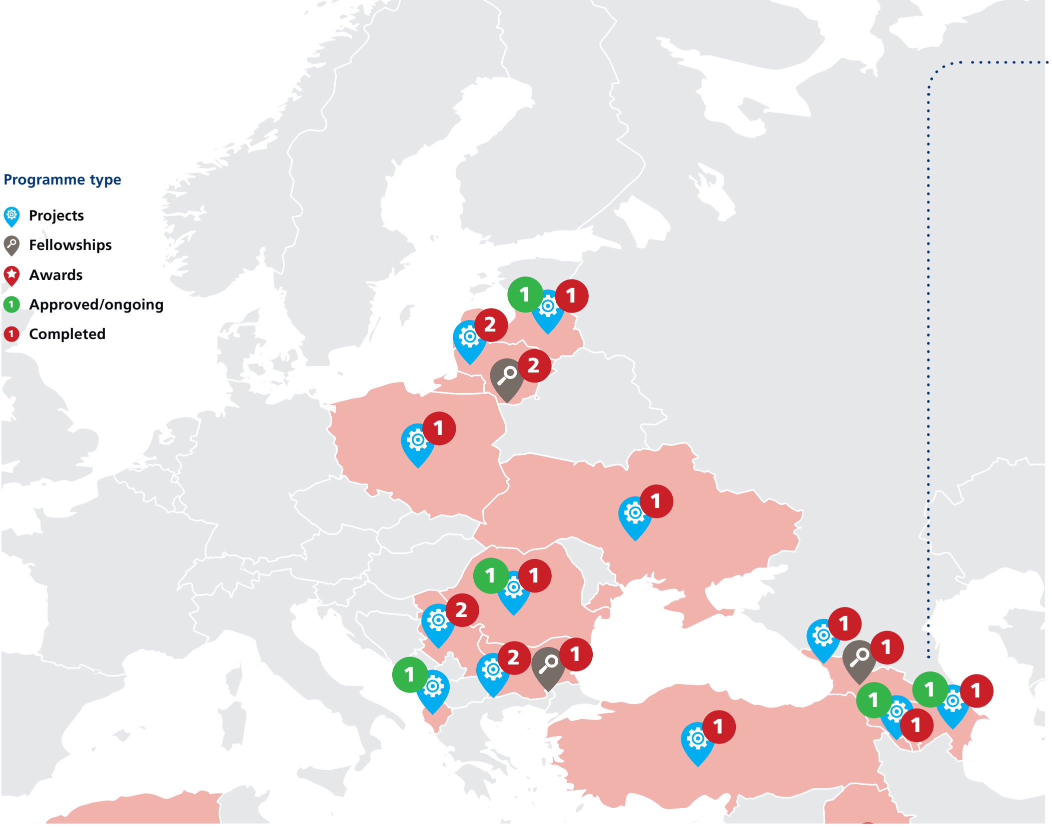
In the Armenia 1 project, Dr Hegine Khacehatryan and the multidsciplinary team from Yerevan undertook outreach visits to Gyumri to support the team to deliiver haemophilia care.

Europe and Caucasus: Improving rehabilitation services and engaging the community

We are delighted that Albania joined the NNHF portfolio in 2018, which along with Romania will unite the haemophilia and medical communities to raise awareness of the condition. Our collaboration with Armenia and Azerbaijan continues, with both projects focusing on rehabilitation.

			Capacity building		Diagnosis and registry			Education and empowerment		Awareness and advocacy	
Projects	Approved/ongoing in 2018	Completed in 2018	Health workforce	Service delivery	Diagnosis skills	Laboratory infrastructure	Registry	Education of patients and their network	Empowerment of patient organisation	Awareness raising	Advocacy
Albania 1	●		●	●	●	●		●	●	●	●
Armenia 1		●	●	●			●	●		●	
Armenia 2	●		●	●	●	●		●		●	
Azerbaijan 2	●		●	●	●			●		●	●
Latvia 2	Cancelled*						●				
Romania 2	●							●	●	●	●

*This project was cancelled due to the need to seek a different partner to collaborate with for the technical aspect of the registry development.



Azerbaijan 2: Improving physiotherapy care through collaboration

Expanding physiotherapy care to new regions through healthcare professional training, education of people with haemophilia and engaging with authorities.

Azerbaijan 2

Building on a successful track record

In Azerbaijan in 2012, there was almost no haemophilia care outside of the capital city of Baku. This was a challenge that Gulnara Huseynova, president of the patient organisation, sought to address through the Azerbaijan 1 project. By collaborating with authorities, international experts and healthcare professionals, the project helped establish two satellite centres and provided training to healthcare professionals across 12 regions.

To build on this impressive track record, Gulnara is putting her collaborative approach into action again through the Azerbaijan 2 project. This time, the project is focusing on strengthening physiotherapy to reduce and prevent musculoskeletal complications caused by bleeding, and decentralising care to Nakhchivan.

Expanding physiotherapy to new regions

Having established satellite clinics in Shirvan and Ganja through the Azerbaijan 1 project, this second project is again working with these centres to establish physiotherapy units through healthcare professional training and provision of equipment. With the long-term goal of standardising physiotherapy care across the country, the team started by strengthening the unit in Baku.

Another centre involved in this collaboration is the Central Hospital in Nakhchivan. Nakhchivan is a landlocked Autonomous Republic isolated from the Azerbaijan mainland. Located more than 400km from Baku, it is vital that people living with haemophilia in the region can access appropriate care close to home.

Through a series of discussions with the Minister and Deputy Minister of health, the hospital's multidisciplinary team, parents and people with haemophilia in the region, the project team are now working together to ensure specialist physiotherapy adapted to haemophilia needs are delivered as part of the comprehensive care service.

Reducing MSK complications through education and training

In Lankaran – a coastal city 250km south of Baku – a physiotherapy unit is also being established and equipped. So far, 80 children with haemophilia and family members have received education from a core team from Baku, explaining the importance of physiotherapy in reducing MSK complications.

As of the end of 2018, 180 people with haemophilia and family members have received education on MSK care, and 17 physiotherapists have been trained.

Participants of an education session in Lankaran, where a the team from Baku are supporting the establishment of a physiotherapy unit through the Azerbaijan 2 project.

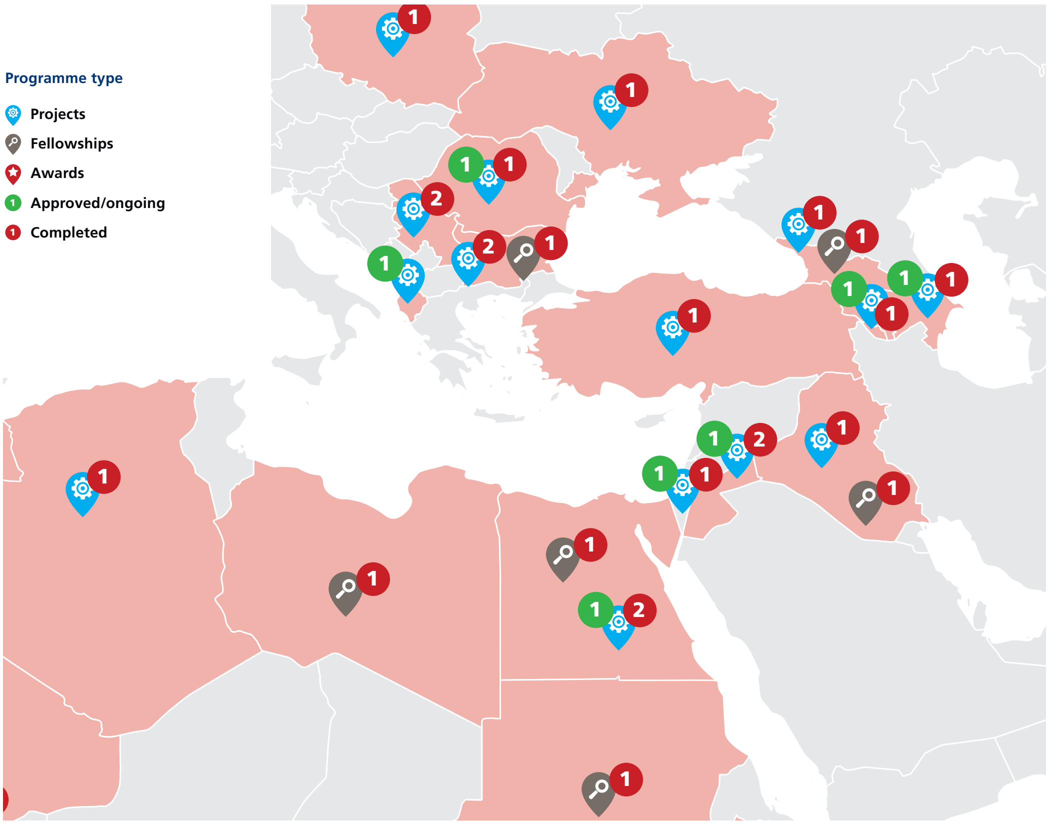
Regional highlights: Middle and Near East

The Pakistan 6 project is strengthening the patient organisation through activities such as capacity building and orientation workshops.

Middle and Near East : Empowering communities and building care capacity

Four projects were approved, running or completed in this region in 2018. After focusing on musculoskeletal care in Egypt 2, the current project now aims to decentralise care across the country. Activities in Pakistan and Palestine seek to empower the bleeding disorders community, with Palestine also establishing care in the Gaza Strip.

			Capacity building		Diagnosis and registry			Education and empowerment		Awareness and advocacy	
Projects	Approved/ongoing in 2018	Completed in 2018	Health workforce	Service delivery	Diagnosis skills	Laboratory infrastructure	Registry	Education of patients and their network	Empowerment of patient organisation	Awareness raising	Advocacy
Egypt 2		●	●	●			●	●			●
Egypt 3	●		●	●	●	●	●	●	●	●	●
Pakistan 6	●										
Palestine 2	●				●	●		●	●	●	



Thank you to our expert volunteers

Dr Laura Villarreal from Mexico City collaborated with the Mexico 6 project team to deliver self-infusion training to people with haemophilia and their family members.

International experts teaming up to reach out

Along with our project partners, the impact of NNHF programmes would not be possible without the voluntary contribution of our network of international experts. Whether through sharing knowledge, hosting trainees or providing support remotely, we thank all of our volunteers who have supported NNHF programmes in 2018.

Argentina 4:

Team members from Unicamp, Campinas, Brazil:
Dr Alessandro Rozim Zorzi, traumatologist
Dr Samuel de Souza Medina, haematologist
Glenda Feldberg Andrade, physiatrist
Dr Jhovany Belmont Sánchez
Paediatric rehabilitation specialist, Hospital Infantil de México Federico Gómez, Mexico City, Mexico

> Working with the Argentina 4 team, we were able to show how multidisciplinary teams can interact and share knowledge while providing high quality assistance to people with hemophilia suffering from early or advanced joint disease."
>
> Dr Samuel de Souza Medina

Cambodia 2

Team members from Nottingham University Hospital, Nottingham, UK:
Tracey Dandy, physiotherapist
Dr Charlotte Grimley, Associate Specialist in Haematology
Michelle Kightley, Haemophilia Clinical Nurse Specialist

> Despite the challenges of limited resources in Cambodia, I've seen really good examples of care provision: excellent medical, nursing, social work, psychological support and especially physiotherapy."
>
> Michelle Kightley

Ghana 2

Angus McCraw
Lab specialist, London, UK

Seck Hong from Cambodia receives care in Siem Reap from a team trained in the UK.

India 7

Greig Blamey
Physiotherapist, Health Sciences Centre, Winnipeg, Canada

> The India 7 project is extremely unique and the model represents something I have never seen before in any country in all of the travels I have done."
>
> Greig Blamey

India 8

Ed Kuebler
Social worker, Gulf States Hemophilia & Thrombophilia Center, Houston, US

Mauritius 1 and Sri Lanka 1

Dr Alok Srivastava
Haematologist, Christian Medical College and Hospital, Vellore, India

Mauritius 1

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

> In addressing the challenges of bleeding disorders in Africa, it is the team work and multiple partnerships that will take us far. It is indeed a pleasure for many of us living in Africa to work with the NNHF and people with haemophilia."
>
> Prof Johnny Mahlangu

Mexico 4

Dr Eric Gutierrez
Haematologist, Hospital Agustin O'Horan, Mérida, Mexico

Laura Paez
Social worker, Hospital Universitario "Dr. José Eleuterio González", Monterrey, Mexico

Dr Laura Villarreal
Haematologist, Hospital Universitario "Dr. José Eleuterio González", Monterrey, Mexico

> Volunteering with NNHF projects in Mexico is my way of spreading the knowledge I gained through leading the Mexico 2 project. It is a pleasure to be inspired by and provide inspiration to those who share a vision to improve haemophilia care."
>
> Dr Laura Villarreal

Prof Johnny Mahlangu has volunteered for numerous projects across Africa and is the recipient of the 2018 NNHF Community Award.

Mexico 5 and Mexico 7

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

Myanmar 3

Jennifer Maahs
Nurse practitioner, Indiana Hemophilia and Thrombosis Centre, Indianapolis, US

Peru 3

Prof Miguel Escobar
Associate Professor, Haematology, University of Texas Health Science Center, Houston, US

Luz Villalaz
Nurse, Hospital del Niño, Panama City, Panama

Sri Lanka 1

Dr Kate Khair
Clinical Academic Careers Fellow, Centre for Outcomes Research and Experience in Children's Health Illness and Disability (ORCHID) Great Ormond Street Hospital for Children NHS Trust, London, UK

Thailand 2

Audrey Abad
Clinical Research Project Manager, Hospital for Sick Children (SickKids), Toronto, Canada

Prof Victor Blanchette
Paediatric haematologist, Medical Director, Hospital for Sick Children (SickKids), Toronto, Canada

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

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

Pamela Hilliard
Physiotherapist, Toronto, Canada

Dr Jerry Teitel
Consultant haematologist, Medical Director Adult Comprehensive Care Haemophilia Programme, St Michael's Hospital, Toronto, Canada

> "The long-term nature of our partnership with the Thailand 2 project team has given us a deep understanding of the challenges they are trying to address, and we can adapt the support we provide to them as these challenges evolve over time."
>
> Prof Victor Blanchette


Marión Echenagucia from Venezuela delivered training to lab technicians in the Mexico 5 project.

Our governance and accounts

As part of the project planning process in Botswana, healthcare professionals, people with haemophilia and family members came together for a strategic planning workshop.

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.

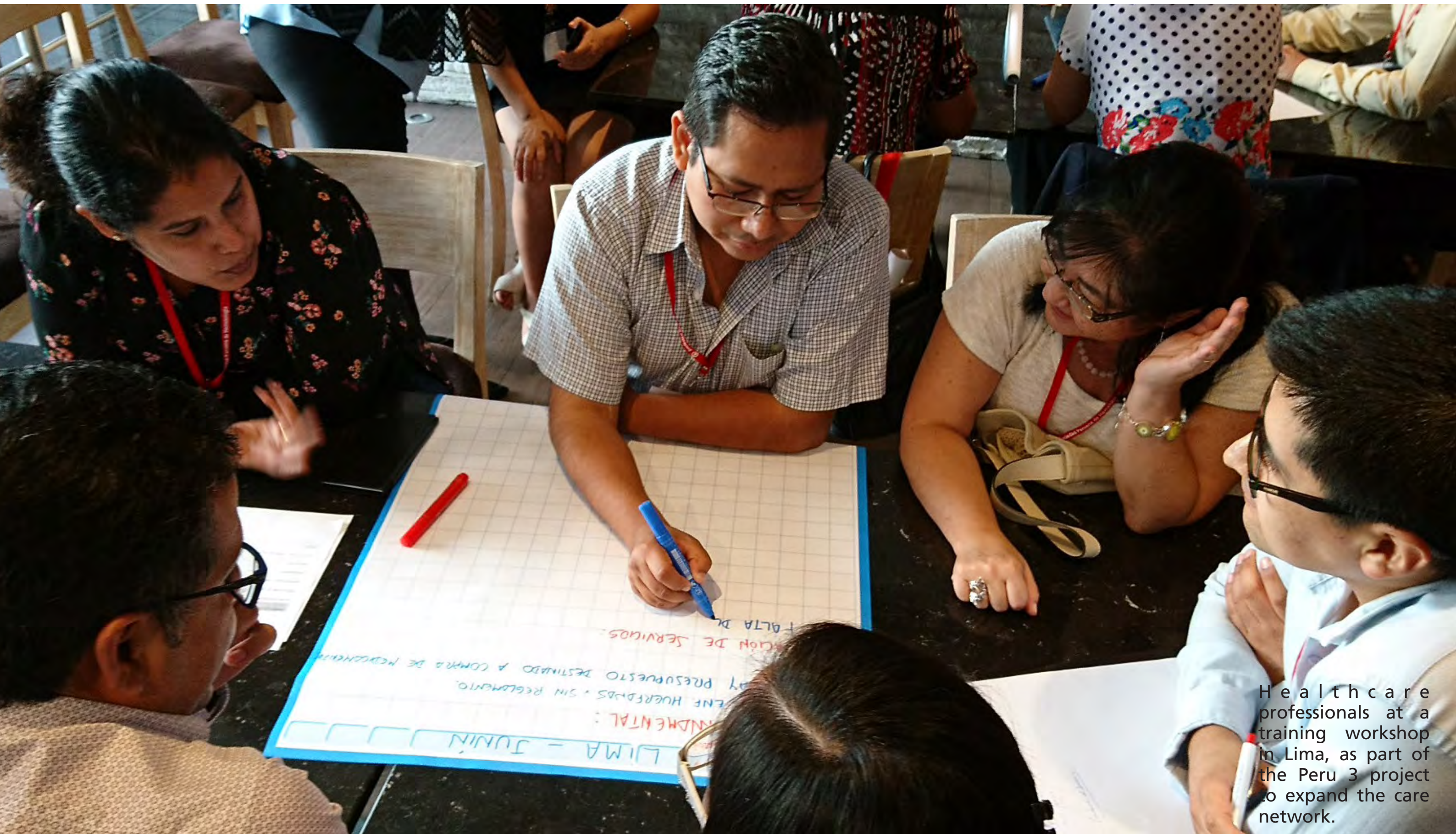
The NNHF is an associated partner of Swiss Foundations and orients its organisational governance to the principles and recommendations of the 'Swiss Foundation Code'. It is governed by the NNHF Council, which comprises globally renowned experts in the field of bleeding disorders and members from Novo 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.



Healthcare professionals at a training workshop in Lima, as part of the Peru 3 project to expand the care network.

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)

Changes to the NNHF Council in early 2019

Jan Hoff replaced Christian Kanstrup from January 2019
Jesper Brandgaard replaced Mike Rulis as Council president from February 2019
Ludovic Helfgott joined as vice president in April 2019

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

Novo Nordisk Haemophilia Foundation

Zurich

Report of the statutory auditors to the Board

on the financial statements 2018

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 2018.

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

Joanne Burgener	David Stauffer
Audit expert Auditor in charge	

Zürich, 22 February 2019

Enclosure:

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

PricewaterhouseCoopers AG, Birchstrasse 160, Postfach, CH-8050 Zürich, Switzerland
Telefon: +41 58 792 44 00, Telefax: +41 58 792 44 10, www.pwc.ch

novo nordisk
haemophilia foundation

Financial Statements

Company	**Novo Nordisk Haemophilia Foundation, Zurich**
Financial year	**2018**
Closing date	**31.12.2018**

Financial statements 2018:
Balance sheet

Novo Nordisk Haemophilia Foundation, Zurich

Balance sheet as at 31 December
(in Swiss francs)

Assets	Note	2018	2017
Current assets			
Cash and cash equivalents		3’888’798	3’502’147
Other receivables -		70’228	0
due from third parties		70’228	0
Total current assets		3’959’026	3’502’147
Total assets		**3’959’026**	**3’502’147**

Balance sheet as at 31 December
(in Swiss francs)

Liabilities	Note	2018	2017
Short-term liabilities			
Trade payables -		90’492	0
due to third parties		90’492	0
Accrued expenses	1.2, 2.2	2’967’572	2’587’498
Total short-term liabilities		3’058’064	2’587’498
Long-term liabilities			
Long-term provisions		74’570	69’657
Total long-term liabilities		74’570	69’657
Total liabilities		3’132’634	2’657’155
Equity			
Locked-up capital		200’000	200’000
Statutory retained earnings		644’992	686’897
Gain/(loss) for the year		-18’600	-41’905
Total equity		826’392	844’992
Total liabilities		**3’959’026**	**3’502’147**

Financial statements 2018:
P&L by nature of expense

Novo Nordisk Haemophilia Foundation, Zurich

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

	Note	2018	2017
Donation income	1.1	2'828'967	2'875'129
Net grants		-1'515'665	-1'570'767
Approved grants		-1'613'000	-1'921'000
Cancelled and closed grants		97'335	350'233
Personnel costs		-1'044'261	-1'010'998
Other operating expenses		-118'222	-177'661
Project result		150'819	115'703
Administration costs	2.3	-157'704	-160'027
Operating result		-6'885	-44'323
Financial income		-11'715	2'419
Result for the year		**-18'600**	**-41'905**

Financial statements 2018:
Notes NN

Novo Nordisk Haemophilia Foundation, Zurich

Notes to the financial statement 2018
(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	2018 profit and loss statement	Balance sheet as at 31 December 2018
EUR	1.15	1.12
DKK	0.15	0.15
USD	0.98	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 2018 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

	2018	2017
Grants for development programmes:	2’842’409	2’424’377
Accrued bonus and pension costs	100’867	127’402
Other accruals	24’296	35’719
Accrued expenses	**2’967’572**	**2’587’498**

2.3 Administration costs

	2018	2017
Rental and lease costs	65’951	57’284
Office costs	33’277	32’772
SLA costs	19’347	20’597
Legal and consulting fees	27’360	33’084
Audit fees	5’906	6’480
Other expenses	5’863	9’810
Administration costs	**157’704**	**160’027**

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

	2018	2017
Car Leasing	11’074	27’846

2.5 Significant events occurring after the balance sheet date

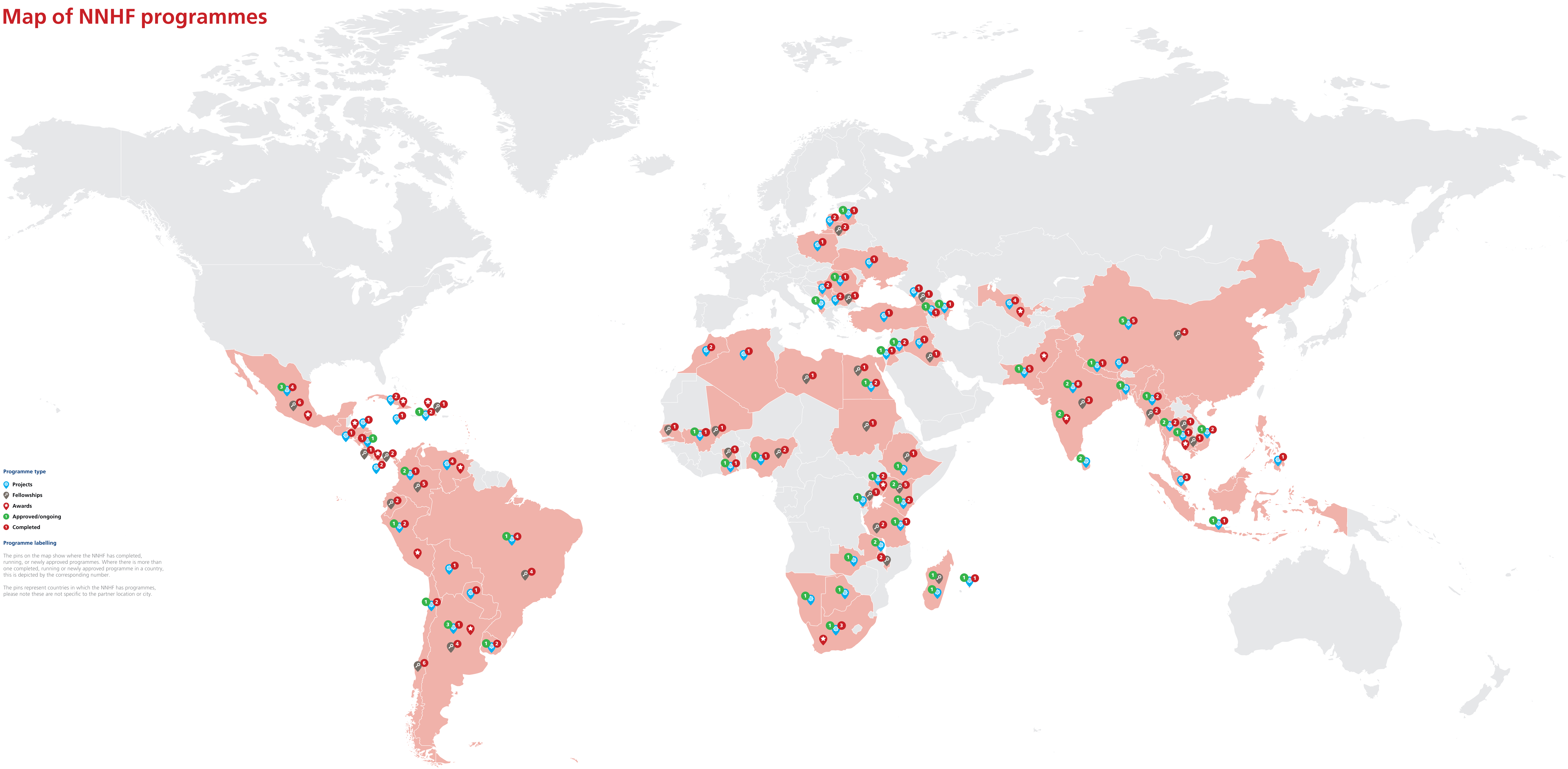
None

Map of NNHF programmes

●

Albania ·
Algeria ·
Argentina ·
Armenia · Azerbaijan
· Bangladesh · Bolivia
· Botswana · 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 · Namibia · 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.

Patient organisation President Christianne Oliveira Costa visits Marrone and his family in Belem, Brazil. Marrone is living with severe haemophilia A.

Novo Nordisk Haemophilia Foundation
Thurgauerstrasse 36/38, 8050 Zurich, Switzerland
info@nnhf.org
www.nnhf.org
Facebook
LinkedIn
YouTube
Instagram

novo nordisk
haemophilia foundation