NNHF
Activity Report 2016

Together delivering life-changing impact

novo nordisk
haemophilia foundation

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haemophilia foundation

About NNHF

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

About the NNHF logo

The NNHF logo is an expression of our vision that all people with haemophilia or allied bleeding disorders receive care and treatment wherever they live.

- The drop creates an association with haemophilia and bleeding disorders
- The white spot in the drop represents the missing protein, which causes the coagulation defect
- As a corporate foundation, the NNHF logo displays the name of its founder, to reflect on the corporation's commitment to haemophilia and its corporate responsibility.

NNHF Better Practice Sharing Platforms

Website: www.nnhf.org
Facebook page:
www.facebook.com/novonordiskhaemophiliafoundation
Activity update: subscribe through info@nnhf.org
Biennual Better Practice Sharing Forum

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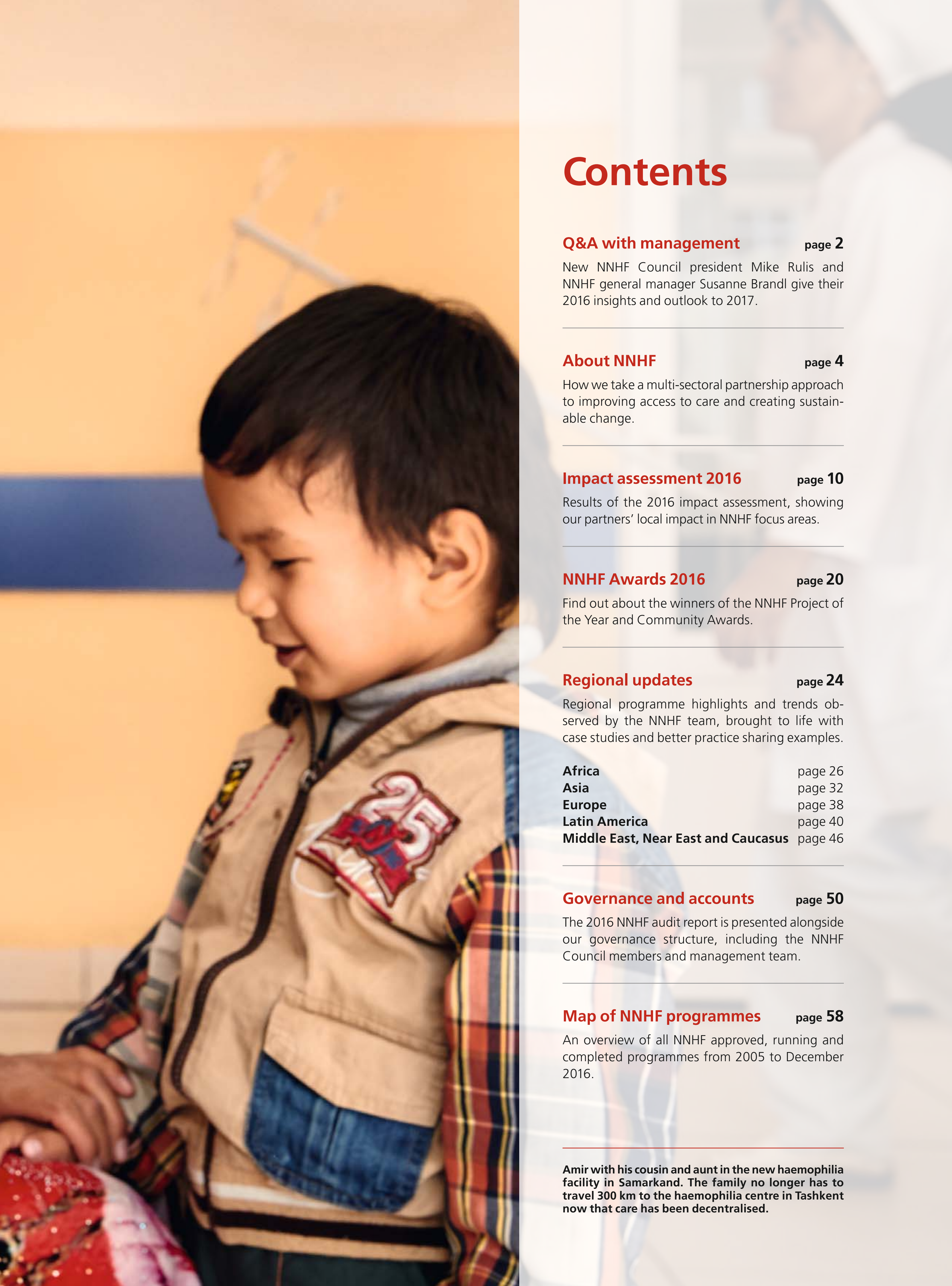
Front cover: Seven year old Amir is assessed at his home in Samarkand by haematologists Dr Zokir from his local hospital and Dr Mukhammadiev from Tashkent.

Back cover: Amir has moderate haemophilia A and lives with his mother and aunt, whose son also has haemophilia. Their local hospital has improved haemophilia facilities and trained healthcare professionals due to the activities of the NNHF project in Uzbekistan.



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An overview of all NNHF approved, running and completed programmes from 2005 to December 2016.

Amir with his cousin and aunt in the new haemophilia facility in Samarkand. The family no longer has to travel 300 km to the haemophilia centre in Tashkent now that care has been decentralised.

Susanne Brandl welcomes Mike Rulis as the new president of the NNHF Council and plans together with him for her succession and handover to Denise Brændgård in 2017.

Continuing to drive sustainable impact

Presenting the NNHF Activity Report 2016, new NNHF Council president **Mike Rulis** and general manager **Susanne Brandl** look back on an eventful year and join the future leader **Denise Brændgård** in giving their outlook for 2017.

What were the key achievements of 2016?

Susanne: An incredible year for the NNHF saw us extend our impact through 26 new and 60 running programmes in 2016, bringing our total number of programmes as of December to 228, covering 68 countries. During this time our efforts to improve quality diagnosis reaped impressive results – 21% of the global haemophilia population that have a complete diagnosis were diagnosed as a result of projects supported by NNHF.

Another highlight was the second Haemophilia Leadership Forum with 12 countries from Latin America, which showcased how common cross-sectoral understanding and strategising leads to local change. The World Federation of Hemophilia (WFH) Congress once again proved another excellent platform for exchanging experiences and better practices as well as testing out new ideas with our partners and the global haemophilia community.

A comprehensive review of NNHF activities and strategy was undertaken throughout 2016 which has, together with our previous impact assessments, provided insights and guidance to shape our work going forward.

What have your highlights been since becoming NNHF Council president in September 2016?

Mike: I am immensely honoured and proud to join the NNHF on its journey of improving haemophilia care. I have been consistently impressed by the Foundation's work before taking on this role, and having now gained more in-depth understanding of how they empower local partners to create change has only served to reinforce this impression.

The challenges facing those with haemophilia in developing and emerging countries are immense, and the NNHF has developed a strong position as one of the valued partners who can drive local, sustainable and systemic change which helps address these challenges.

Susanne, as you prepare to move on after more than ten years at NNHF, what is your message to NNHF partners, the team and community members?

Susanne: I would like to thank everyone for this exciting journey, which I know will continue based on what we have built up and created on local, regional and organisational levels. None of the achievements of the last 11 years would have been possible without our partners, global expert network and team, who never cease to amaze

creation through strong leadership

me with their unbending commitment to improving the lives of people with haemophilia.

Leading a highly dedicated, diverse and fast-paced NNHF team has been an ongoing source of inspiration for me in my daily work. Our passion for learning and openness to new ideas has been key to the growth and success of the NNHF and its activities.

A huge thank you also goes to the NNHF Council for guiding, challenging and supporting us on our journey and, of course, to Novo Nordisk, our founder and main funder whose ongoing support demonstrates its commitment to people with haemophilia across the world.

I can only encourage each of you to stay persistent and pursue your vision which will guide you in delivering life-changing impact through the good and the challenging times. All the best for you and your future!

> **"None of the achievements of the last 11 years would have been possible without our partners, global expert network and team, who never cease to amaze me with their unbending commitment to improving the lives of people with haemophilia."**
>
> **Susanne Brandl,**
> **NNHF general manager**

In what direction do you see the NNHF heading in 2017?

Mike: Firstly, I would like to thank Susanne very much for her invaluable leadership in shaping the NNHF to where it stands today and preparing it for a promising future. Personally, I look forward to another exciting year for the NNHF and for our partners, whom I look forward to getting to know better. Under Denise's leadership, the engaged and dedicated NNHF team will continue the Foundation's successful journey of delivering life-changing impact together with its partners.

As you take on leadership of the NNHF, what do you envisage for 2017 and beyond?

Denise: I am very excited to embark on this new era for myself and the NNHF, which will see us continuing to develop and build strong relationships with our partner network through our development programmes. The streamlined approach we are taking will ensure we optimise the impact of these programmes and the effectiveness of our services, so that our partners receive the right support through the right channels. One aspect of this is a new web-based programme management and information system, which we are implementing to support our partners and the NNHF team to efficiently manage, measure and follow-up on local impact creation on an individual programme as well as NNHF portfolio level.

A key part of my role will be to ensure a smooth transition. We will remain true to our dedication of empowering and working together with our partners to drive sustainable impact creation.

About NNHF

A tailored approach to improving access to haemophilia care

As of December 2016, the NNHF has supported 214 development programmes and 14 awards in 68 countries since it was founded in 2005.

This section describes the types of programmes we support and how our cross-sectoral approach to doing so empowers our partners to create sustainable change.

Examples from our international network illustrate how this relies on building alliances and strategic partnerships.

NNHF programmes in Uzbekistan span ten years and include strengthening haemophilia care in Tashkent and establishing regional care. Here, Said Ahmadov Aziz learns how to exercise with a stretch band at the haemophilia centre in Tashkent.

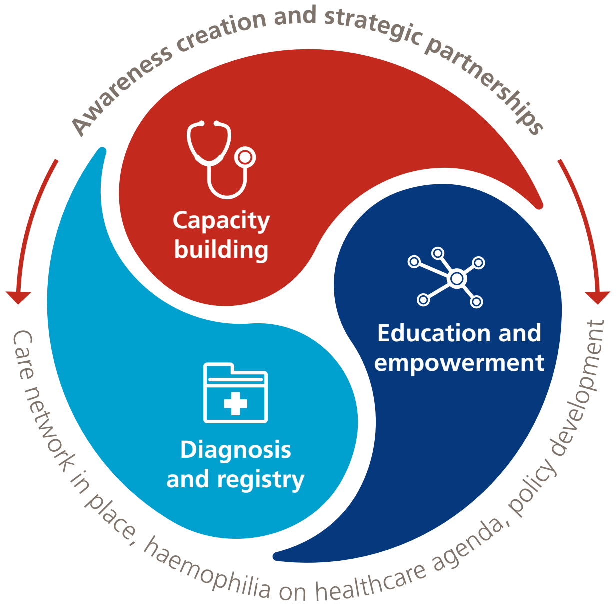
A focused approach to delivering better access to care

Since 2005, we have been driving efforts to address haemophilia care needs, in pursuit of our vision that all people with haemophilia or allied bleeding disorders receive care and treatment wherever they live.

1 in 10,000 people is born with haemophilia[1]. However, only 25% of the global patient population has been identified, and only half of these have a confirmed diagnosis[2], meaning they know the type and severity of their haemophilia.

According to University of London Emeritus Professor and founding editor of the Haemophilia journal Christine Lee, "With proper care, haemophilia is treatable and patients can lead normal lives." However, only 25% of the global patient population has access to treatment. This issue is particularly pressing in developing countries, where three quarters of the haemophilia patient population live.

In developing and emerging countries, the challenges in gaining access to care include: a lack of medical experts providing quality care; a lack of facilities delivering adequate care and diagnosis; a lack of knowledge and support networks amongst patients and their social environment; and a lack of awareness amongst authorities and the general population. These challenges have a tremendous impact on people with haemophilia and their families, and include disability, pain, stigmatisation and even death.



About the NNHF

The Novo Nordisk Haemophilia Foundation (NNHF) is a non-profit organisation established in 2005 to address these challenges through its **vision that all people with haemophilia or allied bleeding disorders receive care and treatment wherever they live**.

The NNHF was founded by Danish pharmaceutical company Novo Nordisk as a reflection of the company's commitment to improving haemophilia care. Establishing 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.

The NNHF vision is aligned to the United Nations (UN) Global Compact's human rights and equality principles. We are committed to contributing to the UN Sustainable Development Goals (SDGs) in line with our NNHF approach.

Our focus areas

All NNHF funded programmes include at least one of our focus areas:

- **Capacity building**: medical experts are equipped with knowledge and required facilities, organisation of care is optimised;
- **Diagnosis and registry**: diagnosis expertise and facilities are in place, quality data is available;
- **Education and empowerment**: patients, their social environment and patient organisations are informed, empowered and active to engage with healthcare professionals and authorities.

Underpinning these focus areas are targeted awareness creation activities and the development of strategic partnerships, which work to get haemophilia onto the healthcare agenda, influence policy and ensure a care network is in place.

Our programmes

To create change we support two types of programmes:

Projects: Projects are locally managed and typically run for one to three years. The NNHF funds projects which align with our focus areas and seek to:

- Establish and anchor multidisciplinary haemophilia care in the local healthcare system through a **comprehensive** national approach;

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[1] www.wfh.org/en/page.aspx?pid=646

[2] WFH Annual Global Survey 2015 data. Accessed January 2017

[3] Developing countries as defined by OECD Development Assistance Committee; low- and middle-income countries, except G8 members, EU members and countries with a firm date of entry into the EU: https://www.oecd.org/dac/stats/documentupload/DAC%20List%20of%20ODA%20Recipients%202014%20final.pdf

[4] NNHF is also engaged in so-called transition countries which are those European Union member countries or candidate countries where improvements of access to care are of high importance: http://europa.eu/about-eu/countries/index_en.htm

- Set-up **basic** haemophilia care and disease awareness, and/or;
- Pilot **innovative** approaches to grassroots care development with potential for scaling.

Awards: Each year the NNHF presents two 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 to benefit the haemophilia community.

Strong local leadership, co-creation and cross-sectoral partnerships lead to successful programme execution and sustainable impact. In such a set-up, the NNHF is only one player in the cross-sectoral partnership. Our partnership approach is outlined in the following pages.

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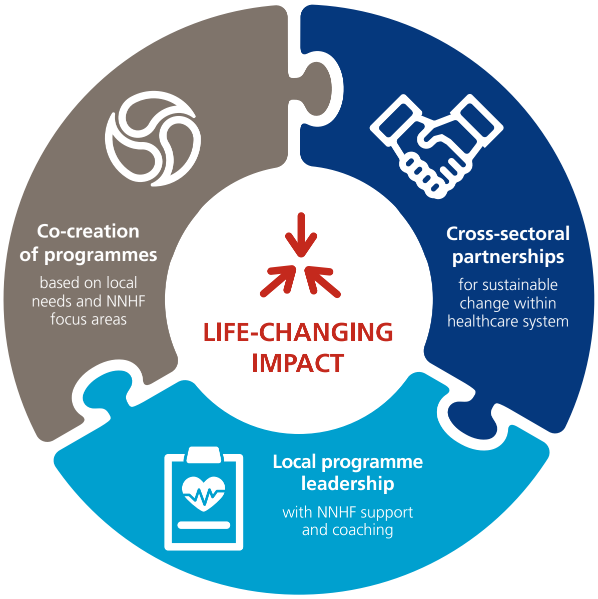

Contributing to the Sustainable Development Goals

Four of the 17 UN Sustainable Development Goals (SDGs) are reflected in the NNHF vision and approach to defining and funding sustainable programmes in developing[3] and emerging[4] countries.

The NNHF is working to improve access to healthcare, reduce inequalities, and build sustainable communities while working in partnership with local representatives from the community, international experts and authorities. The goal of this work is to overcome access barriers for many patients around the world and make communities inclusive and empowered to drive local sustainable change.

We believe that building on available knowledge and infrastructure and developing local leaders to anchor haemophilia and allied bleeding disorders with the existing healthcare system set the basis for policy development and equal inclusion of haemophilia and allied bleeding disorders in the healthcare agenda. Subsequently, measurable and sustainable results with life-changing benefits for people with haemophilia and allied bleeding disorders are made possible.

To date, the NNHF has provided grants, services and programme management support to 214 programmes and 14 awards in 68 countries resulting in improved access to care and quality of life for people with haemophilia and allied bleeding disorders, reduced inequalities in access to adequate diagnosis and care and empowered members of the medical and patient community as well as engaged authorities.

214 programmes
14 awards
68 countries

Improved access to care and quality of life

Reduced inequalities in access to adequate diagnosis and care in developing countries

Empowered community and engaged authorities

Cross-sectoral contribution to the SDGs

Upon request of African delegates at the WFH Congress in Orlando, the NNHF organised a regional meeting for Africa sharing better practices and inspiring ideas on how to generate further life changing impact in the region.

Cross-sectoral partnerships create sustainable change

As one of the cross-sectoral partners involved in a NNHF programme, our key role is to empower partners to create sustainable change. We support them to drive that change through better practice sharing, utilising expert networks and ongoing coaching and project management support.

NNHF programme partners are members of the haemophilia community in developing and emerging countries and include patients, healthcare professionals, patient associations and authority representatives. What unites them is their visionary approach and ability to lead, inspire, and drive change.

The wider NNHF partner network goes beyond this and includes international experts, healthcare institutions and sector representatives, lab companies, and non-governmental organisations as well as other stakeholders related to bleeding disorders and/or other chronic diseases.

Our approach to empowering partners

The NNHF grassroots approach involves bringing the expertise of these cross-sectoral stakeholders together to create sustainable benefits for people living with haemophilia in their local community.

In addition to introducing partners to our international network, we support them to drive change through coaching, facilitating partnership creation, and building specific skills – such as leadership or strategic media engagement skills – according to local needs. We also support partners to measure the progress of their activities and collate data showing their impact – enabling them to demonstrate to decision-makers the tangible benefits of their activities.

Inspiring partners through Better Practice Sharing

As well as hands-on coaching, partnering and project management support, we also facilitate Better Practice Sharing (BPS) as a way of providing inspiration and practical tools to those wishing to improve access to haemophilia care.

NNHF BPS platforms include:

- **Biennial BPS Forum**: an interactive day of workshops and experience sharing for all active project partners;
- **Online platforms and printed materials** such as our website, newsletter and materials such as this Activity Report;
- **Events and meetings** for people to exchange experiences across borders, specialties and sectors and to learn about common needs, topics and trends.

In 2016, we gained feedback from our active partners through our annual impact assessment, which was conducted as part of a review to improve the NNHF programme and service offering. All partners agree that the NNHF enhanced their ability to raise their voice and drive change, and in addition:

- 97% confirm the NNHF brings expertise that leads to lasting change;
- 95% say their collaboration with NNHF built or developed their leadership and/or communication skills.

We will continue to engage our partners in ongoing dialogue which allows us to ensure our services respond to their needs. It is this dialogue that inspires us to continue working across sectors and borders for improved access to care.

If you would like to collaborate with the NNHF and our partners in our efforts to improve haemophilia care, contact **info@nnhf.org**

The NNHF team and partners at the biennual Better Practice Sharing Forum in Orlando in 2016.

Building alliances to improve access to care

At the Haemophilia Leadership Forum in Peru in September 2016, we spoke to Prof Eduardo Missoni, a Global Health and Development expert from University Bocconi, Milan, Italy (pictured right) about the importance of creating alliances to address haemophilia care needs.

Despite health being a fundamental human right, access to healthcare is not guaranteed in many countries. What is your view on this in relation to haemophilia?
If health is expressed as a fundamental human right, we cannot exclude patients with haemophilia, or patients with diseases even rarer than haemophilia, and instead of talking about patients we should talk about people – citizens – who must have the guarantee of this fundamental right and make this right enforceable. In other words, we must recognise the responsibility of the public authorities in guaranteeing this aforementioned right.

What are the major challenges and opportunities that arise when developing access programmes for haemophilia care?
When working across a wide range of healthcare systems, programmes must be adapted to different contexts.

Countries with highly fragmented healthcare systems have greater difficulty and higher costs in dealing with rare diseases such as haemophilia. Therefore, the main response to the need to reach all patients with haemophilia and guarantee access to treatment comes from integrated systems, single healthcare systems.

How can this be achieved?
The answer is coordination as it involves the transformation of the healthcare system. The challenge is to ensure that the different sections of the system can not only communicate, but also coordinate, under an effective, clear and solid leadership of the national health authority.

Aside from health authorities, who else should be involved in healthcare system transformation?
One of the strategic elements in transforming healthcare systems is not just coordination within health sector entities, but also cross-sectorial coordination. This means involving levels of government that are very important to guarantee the right to health; sectors that are not only within the health services system. This is fundamental – because of the limited numbers involved. The rarer a disease is, the bigger the necessity to increase coordination among all systems.

How can we engage the different key players to coordinate on the issue of haemophilia care?
Typically we have three major forces in any society: government forces, civil society forces and market forces. In these components there are different interests, but the ability to grasp those forces to collaborate for the public interest, a common interest, is very important.

The fundamental right to health is one of those elements of aggregation on which we can build alliances. When dealing with a very specific problem such as haemophilia, it is even more important to build alliances that have this sensitivity to provide common answers. The key is ensuring all partners know how to work together ensuring the fundamental right to health.

Impact
assessment
2016

Engaging through impact measurement and communication

At the NNHF, impact measurement means providing our partners with the tools and coaching to measure and communicate the tangible impact of their programme activities.

In addition, our annual impact assessment allows us to measure how NNHF supported activities lead to local impact and review how we can improve our service offering to our partners.

The results of our latest annual impact assessment are presented in the following pages and show our partners' impact in three focus areas: capacity building; diagnosis and registry; and education and empowerment. We encourage our partners to use these results to engage with local authorities, decision makers and the haemophilia community in their efforts to improve haemophilia care.

Physiotherapist Leonardo Rodríguez during a rehabilitation session with a patient at the Complejo Hospitalario Sótero del Río, Santiago, Chile. The Chile 2 project included workshops for patients about the importance of musculoskeletal care in preventing bleeds.

The starting point for local impact creation in Malawi was a measurable awareness campaign, one of the results being the opening of the haemophilia centre in the presence of Health Minister Dr Peter Kumpalume MP and media.

Measuring and demonstrating local impact creation

Our key objective is to create sustainable value together with our partners. To ensure this is captured effectively, we provide partners with the skills and tools to measure and demonstrate local impact creation.

Demonstrating local impact facilitates partners' engagement and collaboration with local authorities, decision makers and the haemophilia community. One tool that supports this is the NNHF annual impact assessment.

The first impact assessment began in 2014, and covered all NNHF programmes since we were founded in 2005. The results of this assessment, which are summarised in the 2014/2015 Activity Report, were used by partners to demonstrate to their communities and decision makers the value of their work, and the importance of continued investment of time and resources in improving haemophilia care.

Using this data as part of their awareness raising activities has proven beneficial to partners:

- In 2016, 85% of partners said these activities raised awareness at authority level/amongst policy makers.
- 73% said that these activities led to changes in haemophilia healthcare policy.[1]

Recognising this value and using the 2014 impact assessment results as a baseline, we have conducted an impact assessment on an annual basis since. Alongside this, we support project partners to measure the impact and value of their activities on an ongoing basis as part of our monitoring processes and programme and service offering.

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[1] NNHF 2016 impact assessment survey, January 2017

The impact assessment also allows us to review our service offering, related activities, partnerships and programme management procedures to ensure we are driving local change together in the best possible way, and identifying areas where partners seek further support. As such, our impact assessment survey gains partner feedback on areas where further support is needed, and how NNHF can provide this support.

Impact assessment 2016 methodology

The 2016 impact assessment primarily uses data from three sources: a partner survey; NNHF programme portfolio data; and programme partners' progress reports containing quantitative and qualitative information.

Partner survey
The partner survey was developed by NNHF and distributed online using Survey Monkey. Questions are categorised by NNHF three focus area: capacity building; diagnosis and registry; and education and empowerment.

The survey was sent to 82 representatives from 40 countries, which represented the 60 NNHF programmes which were running or completed in 2016. Responses were received from 57 representatives of 43 programmes, meaning 72% of NNHF programmes are represented in the results. Respondents were given the option to provide their name or stay anonymous.

Programme portfolio data
The NNHF uses programme modules to categorise activities taking place within its programmes, as a means of facilitating Better Practice Sharing and tracking the distribution of funds per activity type. Programme portfolio data enables the extraction of data either on a cumulative basis (i.e. all data since the NNHF was founded in 2005) or an annual basis.

Programme partners' progress reports
To support the tracking of their activities and the measurement of their impact, NNHF project partners complete progress reports throughout their projects. We use these reports to highlight successes and areas for Better Practice Sharing, and to identify areas where we can provide further support. Quantitative data is extracted from these reports to allow for cross-portfolio data analysis.

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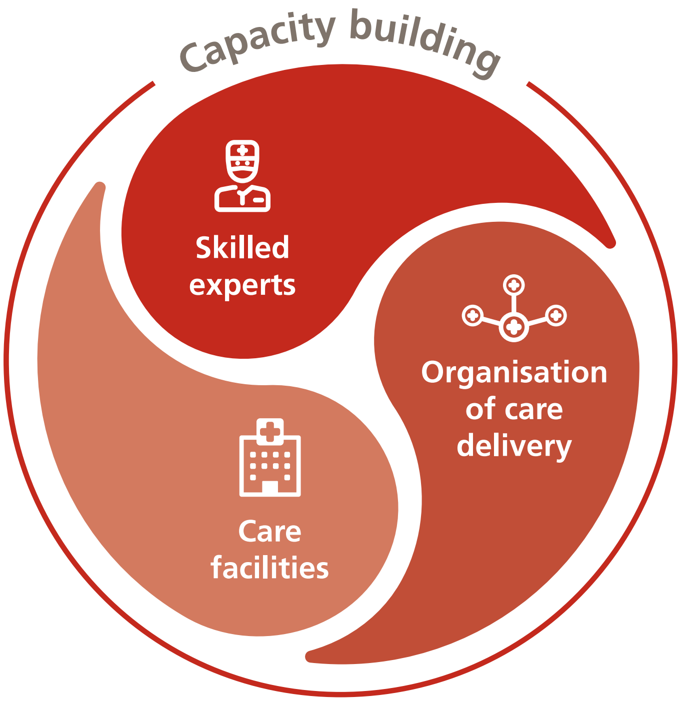
Registries such as the one developed in the Armenia project provide accurate patient population data which can help improve management and delivery of care for patients as well as inform and engage authorities.



Capacity building

Activities in this area improve access to care by developing expertise, creating medical networks and establishing or strengthening care centres, facilities and organisation of care.

Building skills amongst healthcare professionals comprises basic as well as in-depth training which is delivered in the project country or abroad. It can be tailored to one medical specialty or incorporate multiple specialties if it is being delivered as part of a multidisciplinary care approach. Where useful, follow-up visits from the training teams ensure new skills are being applied correctly and help to identify further training needs.

In addition, NNHF projects strengthen infrastructure through provision of equipment, creating or updating national guidelines, and training on the set-up and organisation of care to ensure the delivery of quality care.

Based on the results of our latest impact assessments and partner feedback, our NNHF fellowships and Basic Coagulation Courses which ran as standalone programmes until end 2016, will be incorporated into NNHF projects as of 2017. This means that activities requiring a period of training abroad and regional training courses will now be integrated into NNHF projects. This ensures newly acquired skills and experiences can be immediately embedded into project activities. As well as ensuring resource efficiency, this reflects the streamlined and holistic approach that we are encouraging our partners to take.

In 2016, NNHF supported training led to improved quality of care for patients, and with that improved health outcomes and a reduction in the number of hospitalisations per patient. The majority of NNHF partners observed an increase in the number of healthcare professionals providing haemophilia care, across specialties including haematologists, nurses, physiotherapists and social workers.

Partners stated a need for support in setting-up and organising care, implementing multidisciplinary care, and train-the-trainer concepts. We will continue to collect Better Practice Sharing examples on these topics and distribute them to our partner network for inspiration and replication.

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>30,350
healthcare professionals trained

Increase in number of expert staff
providing haemophilia care

427
centres established or strengthened

164
of these are satellite and primary care sites

251
labs established or strengthened

National care guidelines
are used to standardised care according to **38%** or partners

Reduced number of hospitalisations
per patient observed by **87%** of partners

Improved health outcomes
according to **97%** partners

Improved quality of care
thanks to NNHF supported training say **95%** of partners

Sources: NNHF data on file, December 2016; NNHF 2016 impact assessment survey, January 2017.

Reduced number of hospitalisations

"We have together trained over 600 healthcare professionals in comprehensive care supporting the NHSO in establishing the Chronic Care Model in 6 provinces. Leading nurse case managers said this led to a decrease in hospitalisations. We are expanding the training to a further 8 provinces. We are also training master trainers in musculoskeletal care, to further reduce hospitalisations."

Prof Ampaiwan Chuansumrit
haematologist, Thailand

Improved health outcomes

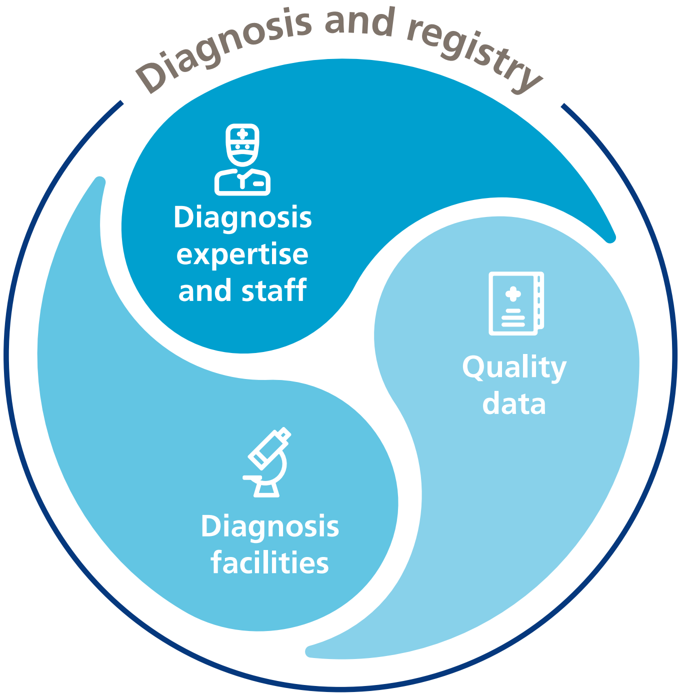
"In 2005, people with haemophilia were not expected to live beyond the age of 40. Today, our oldest patient is 60 years old, and many of our patients reach their 50s. Since 2005, the percentage of patients with haemophilia related disabilities has reduced from 80% to 55%."

Dr Aziza Makhmudova
haematologist, Uzbekistan

Improved quality of care

"We updated the national treatment guidelines and presented them to the Ministry of Health, who has approved them in September 2016 including new treatment options highlighting home treatment and specific prophylaxis schemes for defined patient groups."

Prof Nguyen Anh Tri
National Haemophilia Committee Chair, Vietnam



Diagnosis and registry

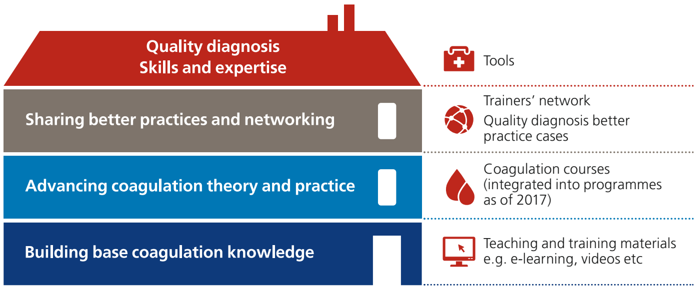
Only 1 in 4 of those living with haemophilia has been identified, and many who have been identified do not have a diagnosis which shows the severity or type of their haemophilia.

In addition to the low diagnosis rate, a lack of accurate data about the haemophilia population makes it difficult to engage authorities on the importance of haemophilia care.

NNHF activities to improve quality diagnosis include training, improving lab infrastructure and sponsorship of the World Federation of Hemophilia (WFH) International External Quality Assessment Scheme (IEQAS). The IEQAS, which the NNHF has sponsored since 2011, monitors and improves laboratory performance in haemophilia treatment centres worldwide.

The NNHF also promotes the importance of registries to generate the data needed to engage decision makers and allocate resources adequately.

A huge gap remains between the number of expected patients and those with a diagnosis. In countries such as Malawi, where the diagnosis rate is less than 1 %, NNHF projects focus on setting-up basic care, which includes establishing diagnosis skills and facilities. The



The NNHF lab module shows the activities and tools that are integrated into programmes focusing on quality diagnosis.

NNHF project in China is taking a comprehensive approach to improving quality diagnosis and registry, through the creation of the National External Quality Assurance Scheme of China.

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2,700
lab technicians trained

251
labs established or strengthened

22,000
patients have been re-tested or newly diagnosed since 2005

64
registries developed or improved in 41 countries

Improved quality of diagnosis
through NNHF supported activities, say **96%** of partners

Increased number of PwH diagnosed globally
21% of PwH in the world received diagnosis or complete diagnosis as a result of the projects supported by NNHF

Confirmed rising of local diagnosis rate
according to **96%** of partners

Medical information collected in the local registry,
say **85%** of partners

Sources: NNHF data on file, December 2016; NNHF 2016 impact assessment survey, January 2017; Calculation of global haemophilia population with complete diagnosis based on WFH Annual Global Survey Data 2015. Accessed February 2017.

Improved quality of diagnosis

"Through our national External Quality Assurance (EQA) Scheme we aim to achieve quality diagnosis and data across China. So far, the Haemophilia Treatment Centre Collaborative Network of China and the Clinical Laboratory Centre of the Ministry of Health have trained 228 laboratory technicians from more than 113 centres in coagulation techniques and pursue EQA surveys throughout the year."

Prof Xuefeng Wang
haematologist, China

Increased number of patients diagnosed globally

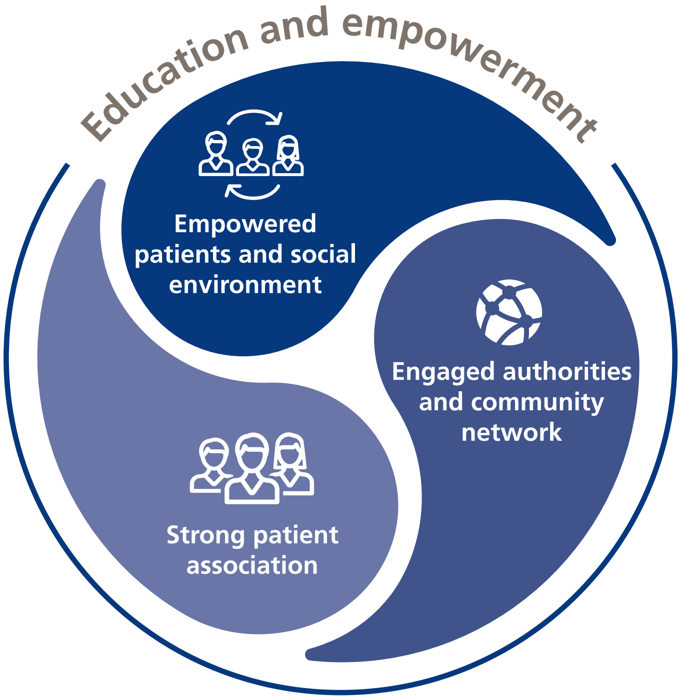
"Having trained lab technicians in their local settings and seen how these efforts are combined with awareness campaigns and education initiatives that help identify new patients, I am sure the global diagnosis rate can be raised further."

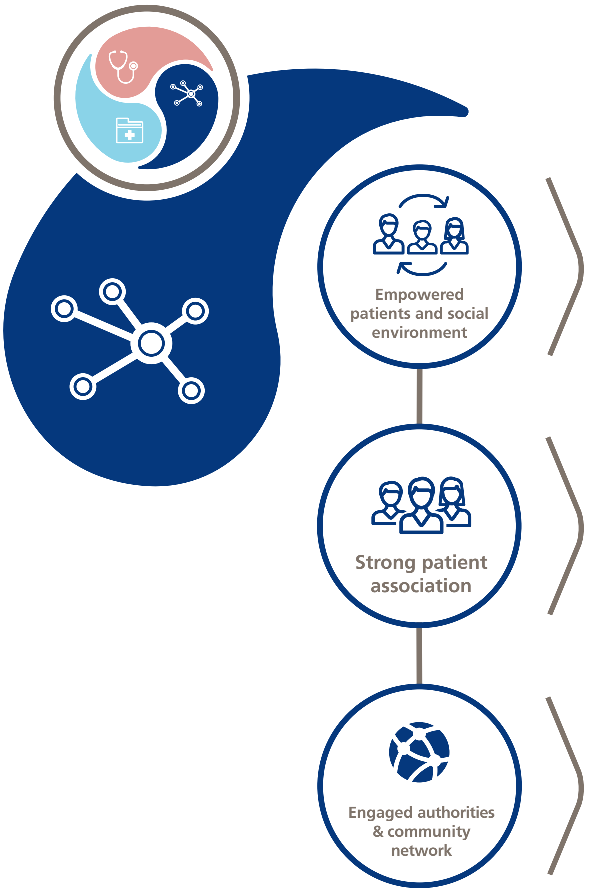
Marión Echenagucia
lab specialist and expert trainer, Venezuela

Improved local diagnosis rate

"In January 2016 we had only identified 9 patients – meaning our haemophilia diagnosis rate was less than 1%. Our project established the lab in Lilongwe and trained lab technicians to diagnose haemophilia. As a result, we diagnosed 35 patients in just one day."

Dr Yohannie Mlombe
haematologist, Malawi





Education and empowerment

Educational sessions unite patients and family members to learn, voice their community needs and form a support network. Activities with patient associations include developing skills and organisational capacity.

NNHF supported education activities bring patients together at national gatherings or in smaller groups, to provide information about haemophilia and how to cope with the condition in daily life, provide psycho-social support, or focus on a specific area of haemophilia care such as how to exercise safely at home.

As well as imparting practical advice and knowledge, these sessions introduce patients and family members to others in the same situation – sometimes for the first time – which provides an invaluable network of support. In 2016, these activities increased understanding of haemophilia and led to a better quality of life for patients and family members.

Activities with patient associations have helped to empower leaders, increased the level of activity and attracted more association members. Additionally, these activities led to a stronger collaboration with healthcare professionals, and members became more active in engaging authorities, decision makers, experts and other partners.

Areas in which partners would most like to develop more in 2017 onwards are sharing better practices as well as identifying and addressing educational needs within the community. NNHF activities are also continuing to address the gaps identified in previous surveys around the isolation and stigmatisation experienced by people with haemophilia. These include increased outreach activities like those in Georgia and Armenia (see page 48 for more information) and reaching out to different community groups as in Uganda (see page 29).

To ensure these better practices are increasingly easy for partners to retrieve going forward, we will be capturing and cataloguing such examples on the NNHF website.

Visit **nnhf.org** for more information about all NNHF programmes
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>33,750
patients and family members were educated since 2005

Better self-management
of the condition and in case of a bleed

Empowered leaders within the patient association
thanks to NNHF supported activities according to **93%** of NNHF partners

51%
of countries with NNHF programmes include activities relating to the patient association in their programmes

Stronger collaboration with healthcare professionals,
say **96%** of partners

Better quality of life
for patients and family members

Overall health improvements
according to NNHF partners

Members active in engaging with authorities
say **89%** of partners

Changes in policy around haemophilia
according to **73%** of partners

Sources: NNHF data on file, December 2016; NNHF 2016 impact assessment survey, January 2017.

Better quality of life

"We now have a consolidated structure with regards to the care offered to the patients. There is an emergency chain and thanks to the education that the patients and their carers receive, we have no hospitalisations. The patients have a better quality of life, they go to school and in general can participate in the activities they wish."

Dr Laura Villareal
haematologist, Mexico

Overall health improvements

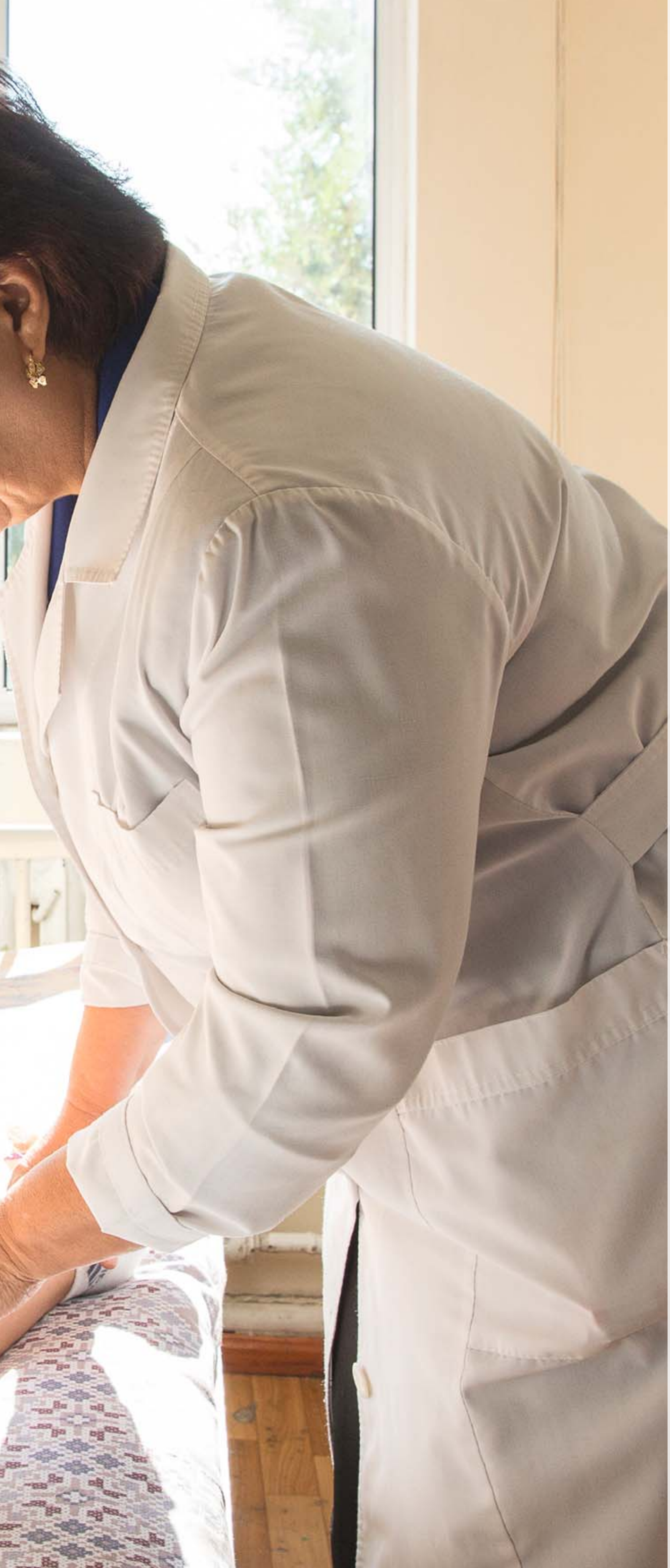
"After establishing a network of youth leaders from nine patient associations, we gained 128 new youth members. Young leaders in each country are taking an active role and are ready to take on the reigns and ensure a smooth transition when the current generation of leaders moves on. A network has been established across the region allowing experience sharing and learning across borders."

Fendi Valdez Bisono
patient association member, Dominican Republic

Engaged authorities

"We have delivered an awareness campaign in collaboration with healthcare professionals, which helped us to develop a dialogue with the Ministry of Health and hospital directors. Since the campaign started, the authorities have agreed to fund haemophilia diagnosis, and we have an ongoing exchange with the National Health Committee as part of our efforts to advocate for better haemophilia care."

Kisakye Agnes, executive secretary,
Haemophilia Foundation of Uganda



NNHF
Awards
2016

Recognising excellence and dedication to the haemophilia community

Each year the NNHF presents its Project of the Year Award and the Community Award.

In 2016, we were delighted to present the NNHF Project of the Year Award to the Pakistan 5 project for their innovation, transformational leadership, sustainability and excellence as a NNHF project partner.

The NNHF Community Award was presented to Dr Aziza Makhmudova from Uzbekistan, who has tirelessly dedicated herself to the improvement of haemophilia care across the country and is now engaging haemophilia communities beyond these borders.

This section describes more about the awards and why the Pakistan 5 project and Dr Makhmudova were deserved winners in 2016.

NNHF Community Award 2016 winner Dr Makhmudova examines 13-year old Brunbaev at the haemophilia treatment centre in Tashkent. Dr Makhmudova is renowned for her energy and is very close to her patients, with many requesting consultations with her when they visit the centre.

NNHF Project of the Year Award 2016: Pakistan 5

The NNHF Project of the Year Award goes to the project partner and team who have demonstrated outstanding dedication, excellent project management, stakeholder involvement, and sustainable impact.

The Pakistan 5 Project has been a remarkable journey. It started with a unique and bold vision of uniting the patient association chapters throughout Pakistan.

They knew that an energised, united, well-coordinated patient association could have tremendous impact. Their ability to register patients, raise awareness, and reach out to patients would be magnified exponentially. Led by Masood Fareed Malik, a former President of the Pakistan Hemophilia Patients Welfare Society (PHPWS), this project has stood out as a shining example of a model NNHF project partner.

In selecting the Pakistan 5 project for the award, four qualities stood out:

Innovation

No one had ever seen Haemophilia Day Celebrations like the ones led by this team. They started by instituting high-energy brainstorms where the sky was the limit. This energised membership and brought community ownership and participation to a new level – which led to highly successful celebrations.

One of the most innovative ways they found to address the stigmatisation of people with haemophilia was to produce The Positive Diaries. They presented profiles of people with haemophilia who were accountants, doctors, shop keepers and more. These diaries showed patients that they could live normal lives and showed Pakistani authorities that they can be productive and independent members of society when given proper support. The success and replicability of the Positive Diaries has inspired other countries and organisations to consider producing similar materials to be used as a stakeholder engagement and educational tool.

Transformational leadership

Masood and the Pakistan 5 team took remarkable steps to transform the patient support landscape in Pakistan. They began with a dynamic 2-day planning session to lay out a long-term strategic plan for the PHPWS. They established a National Haemophilia Youth Group, which brought together ten youth leaders from five chapters. They established an executive committee that included people with haemophilia from each chapter to encourage empowerment and communication.

Sustainability

The focus on youth and young leaders was extremely important. This was a project designed to last. Not only have they put into place a strong leadership structure for today, but they are grooming the leaders of tomorrow as part of their succession planning.

Pakistan 5 project partner Masood Fareed Malik accepts the NNHF Project of the Year Award from NNHF general manager Susanne Brandl and programme manager Shady Sedhom.

A remarkable testament to the focus on sustainability was Masood's deliberate choice not to run for PHPWS President. The goal was empowerment, and this was the ultimate example of that goal in action.

Excellence

In their reporting to NNHF, the team took pains to provide accurate, detailed assessments of their activity, and worked to ensure transparency in everything they did. It was clear that this group had outstanding teamwork and they were a pleasure to work with from start to finish.

For all of these reasons and more, we are proud to have supported the Pakistan 5 Project. Congratulations on being named the NNHF Project of the Year 2016!

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NNHF Community Award 2016: Dr Aziza Makhmudova, Uzbekistan

The NNHF Community Award goes to a person or group whose engagement is making an outstanding contribution to the haemophilia community. We consider nominees from all over the world for this honour.

It was 2005 when the first meeting between the NNHF and Dr Aziza Makhmudova occurred. Practically the first thing Dr Makhmudova said was: "I will not give up until my government supports and provides adequate care for people with haemophilia in my country."

At the time, basic care for people with haemophilia in Uzbekistan was only available in Tashkent and health outcomes for patients were poor. But just over ten years later, Uzbekistan stands as an example of excellence to countries across Central Asia. These great strides in care have come largely because of the persistent dedication of Dr Makhmudova, and we are proud to recognise her contribution with the NNHF Community Award 2016.

Creating impact through dedication and leadership

Dr Makhmudova has been an NNHF partner for over a decade. She has led four highly successful projects and with each project, her reach and impact has expanded. Take a look at the remarkable progression of her work on pages 37, which has encompassed four projects and resulted in the decentralisation of care. This has been a remarkable progression that has dramatically changed the haemophilia landscape in Uzbekistan.

Over the years, Dr Makhmudova has shown more than just dedication. She is a master of collaboration, sharing her experiences at congresses and building a foundation of a care community throughout Asia. She is also a dynamic manager, giving younger physicians the opportunity to act as leaders.

Dr Makhmudova with her award in her office at the haemophilia centre in Tashkent.

Dr Makhmudova (second from left) receives the Community Award from NNHF general manager Susanne Brandl and programme manager Shady Sedhom.

Driving change for a better future

A child born with haemophilia in Uzbekistan today will have better care, better education, and a better chance of a normal life as compared to a child 15 years ago – and that change is largely driven by Dr Makhmudova. She is a remarkable example of the wide-ranging impact that a person can have. We are proud to be her partner, and proud to present her with the NNHF Community Award 2016.

Visit **nnhf.org** for more information about all NNHF programmes
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> **"I cannot say what I am most proud of – all I know is that I cannot go without this work and cannot imagine working anywhere else. For me, the 1,500 patients are my children and my hope is that there will be a day when, through good care and treatment, we have eliminated the complications caused by haemophilia."**

Dr Makhmudova
NNHF Community Award 2016 winner

Regional updates

Sharing regional trends and better practices in improving care

In 2016, 86 NNHF programmes were completed or ongoing. The activities of each programme align with NNHF focus areas. Additionally, NNHF projects seek to:

- Establish and anchor multidisciplinary haemophilia care in the local healthcare system through a comprehensive national approach;
- Set-up basic haemophilia care and disease awareness, and/or;
- Pilot innovative approaches to grassroots care development with potential for scaling.

The following pages give an overview of completed and ongoing programmes divided by region, and describe programme highlights and trends observed by the NNHF team, brought to life with case studies and better practice sharing examples.

China 4 project partner Prof Zhang at a patient consultation with members of the team from the Shandong Rehabilitation Centre. The project is working to incorporate comprehensive care into the offering of five haemophilia centres in Shandong province.

Chimwemwe Chande is president of the patient association in Malawi. Until the NNHF Malawi project in 2016, her two sons were the only people in the country with a confirmed haemophilia diagnosis.

Africa regional update

In 2016, 18 programmes were approved, running or completed in Africa, the region with the most rapid growth in NNHF programmes.

					Capacity building		Diagnosis and registry			Education and empowerment		Awareness and advocacy	
Projects	**Project category**	NNHF partner since	Approved/ongoing in 2016	Completed in 2016	Building HCP skills	Building organisational capacity/infrastructure	Diagnosis skills/training	Establishing laboratory	Registry creation/strengthening	Education of patients and their network	Patient association strengthening	Awareness raising	Building advocacy skills
Kenya 3	Comprehensive	2010	⊙		⊙		⊙						
South Africa 3	Comprehensive	2008	⊙		⊙					⊙	⊙	⊙	
Ghana 2	Basic	2011	⊙		⊙		⊙	⊙		⊙	⊙	⊙	⊙
Mauritius	Basic	2015	⊙		⊙		⊙	⊙	⊙	⊙		⊙	⊙
Malawi	Basic	2015	⊙		⊙	⊙	⊙	⊙	⊙	⊙	⊙	⊙	⊙
Mali	Basic	2014	⊙		⊙				⊙	⊙		⊙	
Nigeria 2	Basic	2012	⊙		⊙		⊙	⊙		⊙		⊙	
Tanzania 2	Basic	2009	⊙								⊙	⊙	⊙
Uganda	Basic	2014		⊙			⊙	⊙	⊙	⊙		⊙	⊙
Uganda 2	Basic	2014	⊙		⊙					⊙		⊙	⊙

Fellowships	**Fellow profession**	NNHF partner since	Approved/ongoing in 2016	Completed in 2016	Building HCP skills	Building organisational capacity/infrastructure
Ghana	Biomedical scientist	2011		⊙	⊙	
Kenya 4	Paediatric nurse	2010		⊙	⊙	
Kenya 5	General Practitioner	2010		⊙	⊙	
Libya 1	Lab technician	2014	Cancelled			
Malawi 1	Medical officer	2015	⊙		⊙	
Malawi 2	Lab technician	2015	⊙		⊙	
Sudan	Physiotherapist		Cancelled			
Tanzania 1	Nurse	2009		⊙	⊙	
Tanzania 2	Nurse	2009	⊙		⊙	
Uganda	Paediatrician	2014		⊙	⊙	

From 2017, the NNHF will incorporate 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, ensuring resource efficiency and reflecting the streamlined approach we are encouraging our partners to take in their efforts to improve haemophilia care.

NNHF project partner Kisakye Agnes (centre) has played a fundamental role in engaging media in Uganda, resulting in an ongoing dialogue with health authorities.

Making progress on the haemophilia care journey in Africa

Efforts to improve haemophilia care in Africa have focused on establishing basic care by awareness raising, setting-up diagnosis, training healthcare professionals, and educating patients and their families.

A lack of disease awareness, care facilities and healthcare professionals trained in haemophilia mean that the diagnosis rate in Africa is low and haemophilia is not on the healthcare policy agenda. This is particularly true of East and West Africa, where we work with local partners to address this situation by building basic care with a focus on awareness raising activities.

Because awareness raising creates positive impact in all three NNHF focus areas, these types of activities were included in 67% of NNHF programmes worldwide in 2016. In many African countries where basic care is not established, increased awareness is the common thread running through all activities aiming to establish this care. Increased awareness of haemophilia symptoms amongst the public helps to identify new cases. Increased awareness of the condition amongst healthcare professionals means they are more likely to refer suspected patients for diagnosis. Raising awareness of the numbers of patients identified through these activities helps generate the data required by authorities to invest in haemophilia care.

In 2016, awareness raising activities have been particularly successful in demonstrating how strategically planned and integrated initiatives can help achieve overall programme impact such as authority engagement and improved diagnosis.

Empowerment through strategic media engagement

NNHF projects in Africa such as **Malawi**, **Nigeria 2**, **Kenya 3**, **Uganda** and **Ghana 2** have embraced media engagement activities, and benefited from tangible outcomes.

In **Kenya**, **Malawi** and **Uganda**, the NNHF supported the development of media engagement skills and communications planning through its strategic media engagement course. This 2-day course incorporates group workshops and practical training from NNHF team members in collaboration with local journalists, resulting in targeted local media action plans. Additionally, the course helps build confidence amongst participants – who comprise patients, parents and healthcare professionals – to become spokespeople for haemophilia, and many go on to become ambassadors within their projects. The course and its follow-up activities are integrated into project plans to support the achievement of overall project objectives.

In **Uganda**, media engagement has played a key role in every step of the journey to improving haemophilia care. The first part of the campaign engaged media to help raise awareness of haemophilia symptoms, and together with diagnosis improvement activities resulted in 49 new patients being diagnosed.

Authority engagement through targeted campaigning

The Uganda team, under the leadership of NNHF project partner and patient association executive secretary Kisakye Agnes, continued to leverage on its media connections and the momentum of journalists' interest in haemophilia, by engaging them in an ongoing campaign to engage authorities in improving haemophilia care. In 2016, this resulted in the Ministry of Health approving the inclusion of haemophilia care in the public healthcare budget, following the Minister of Health's attendance at the project's patient camp.

With the Uganda 2 project, approved in 2016, Agnes and the project team will continue to work with decision makers including the National Health Committee, Ministry of Health and hospital directors to advocate for improved haemophilia care. Alongside this, the project will continue its awareness campaign to identify patients and reduce stigma, and expand it to the Eastern, Central and Northern regions.

Prof Grace Ndeezi from the Uganda 2 project team delivers an awareness raising session for healthcare professionals.

The symbiotic relationship between media and high profile political figures – where politicians are attracted to events with a media

Consultant haemophilia nurse Dr Kate Khair from the UK delivers healthcare professional training in Blantyre, Malawi.

President of Mauritius Her Excellency Dr Ameenah Gurib-Fakim (third from left) with members of the patient association and NNHF during World Haemophilia Day celebrations in April 2016.

presence and vice versa – has been demonstrated in **Malawi** and **Mauritius** in 2016.

In Malawi, surrounded by journalists from some of the country's biggest broadcasters, Minister of Health Dr Peter Kumpalume MP officially opened the haemophilia clinic and newly equipped lab at Kamuzu Central Hospital.

In Mauritius, a week-long series of awareness raising events marking World Haemophilia Day was launched by the country's president, Her Excellency Dr Ameenah Gurib-Fakim. Dr Gurib-Fakim – addressing the audience in the Municipal Council building which had been lit-up in red to mark the occasion – also announced her patronage of the Mauritius Haemophilia Association at the event, where she was joined by patient association president Asraf Caunhye. With the week's events reaching a national audience thanks to coverage on television, radio and in newspapers, the country's population became aware of haemophilia and the challenges around equal access to quality care.

Minister of Health Dr Peter Kumpalume was interviewed by journalists at the inauguration of the haemophilia clinic in Lilongwe, Malawi.

Increased disease awareness enables quality diagnosis

One of the objectives of many awareness raising activities in Africa is the identification of patients. This is through tailored campaigns targeting patients, their community networks and healthcare professionals who may not realise the symptoms of haemophilia and therefore do not seek or refer to appropriate care.

In order to refer these patients for diagnosis, appropriate facilities need to be in place, and lab technicians need to be trained to use them. Such activities have been a key part of projects in **Malawi** and **Ghana** as well as in two regional basic coagulation courses held in **South Africa** and **Morocco** in 2016. In **Malawi**, the project team collaborated with UK lab specialist Dr Angus McCraw who delivered theoretical and practical training sessions to lab technicians in Lilongwe.

Ghana's approach utilised the skills gained by fellow David Ofuso, a biomedical scientist, who undertook his fellowship overseen by Prof Johnny Mahlangu at the Haemophilia Treatment Centre in Johannesburg in early 2016. David used his newly acquired skills to develop Standard Operating Procedures (SOPs) for his lab in Kumasi, and train other lab technicians in the city. He will play an active role in the **Ghana 2** project, where he will continue to train lab technicians in ten other cities.

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A team approach to establishing care in Malawi

In Malawi, it is expected that there are 1,600 people living with haemophilia. In January 2016, only nine had been identified. This is because there were no facilities or trained staff in public hospitals to diagnose haemophilia and a lack of awareness amongst the public.

With such a low number of identified patients, awareness of haemophilia was very low. People living with the condition did not know they had it. When healthcare professionals examined a patient with haemophilia symptoms, they did not always realise what was causing them.

The Society of Haemophilia and Allied Disorders (SHAD) teamed up with a diverse network of partners to address these issues. SHAD President Chimwemwe Chande and haematologist Dr Yohannie Mlombe from Kamuzu Central Hospital in Lilongwe partnered with the NNHF to establish diagnosis, train healthcare professionals, and deliver a national awareness campaign in collaboration with local and international experts.

Planning the awareness campaign began with a 2-day strategic media engagement workshop for members of the patient association, delivered by NNHF in collaboration with Malawian journalists Jane Hauya and Tiya Kathewera. Jane played a hands-on role throughout the duration of the project, utilising her media expertise and contacts to ensure media presence at the opening of the haemophilia clinic in November 2016.

To build expertise amongst local healthcare professionals, the project team collaborated with lab specialist Dr Angus McCraw and consultant haemophilia nurse Dr Kate Khair, both from the UK. Both experts in their field, Dr Khair and Dr McCraw have extensive experience of working in developing countries through initiatives with NNHF and the World Federation of Hemophilia (WFH).

16.3 million people live in Malawi

1,600 people suspected of having haemophilia

>35 patients diagnosed

Haemostasis and haemophilia clinic established and inaugurated by the Ministry of Health

1 diagnosis facility established in Lilongwe

14 lab technicians trained

>70 healthcare professionals trained in Lilongwe, Blantyre and Zomba

Representatives from organisations collaborating to improve care in Malawi: Laurie Kelley from Save One Life, Shady Sedhom from NNHF, Susan Warren from Haemophilia Scotland; Chimwemwe Chande from the Malawi patient association, Dr Kate Khair from Great Ormond Street Hospital.

Dr McCraw trained 14 lab technicians in basic coagulation theory and techniques in Lilongwe, whilst Kate delivered healthcare professional training in Blantyre, Zomba and Lilongwe. During a screening and diagnosis day in November 2016, both were on hand to oversee the newly trained practitioners during consultations and in the lab. 35 new patients were diagnosed as a result.

Alongside all of this, SHAD has built up a partnership with Haemophilia Scotland, where activities were undertaken in alignment with the NNHF project and included creating informational posters, running awareness activities and establishing a SHAD Facebook page and website.

"Teaming up with expert trainers from the UK, patients and healthcare professionals across Malawi, and organisations like the WFH, NNHF and Haemophilia Scotland has been key to our success in establishing haemophilia care. It means we have been able to train lab technicians and healthcare professionals to diagnose and care for patients, and that patients and family members are now acting as ambassadors to raise awareness of haemophilia. Teaming up has definitely helped create this change" explained Dr Mlombe.

Through all of these initiatives, SHAD has gone from strength to strength, with members using their newfound knowledge and confidence to build their network and move forward on the journey to improved haemophilia care.

Watch a short film about this project at **nnhf.org**

The NNHF project in Myanmar is supporting the patient association to raise awareness and educate patients and parents about the condition, with the aim that patients like Han Myo Htet (second from right) will no longer miss out on school due to bleeds.

Asia regional update

20 NNHF programmes were approved or running in 2016, while a further seven were completed.

Projects	Project category	NNHF partner since	Approved/ongoing in 2016	Completed in 2016	Capacity building		Diagnosis and registry			Education and empowerment		Awareness and advocacy	
					Building HCP skills	Building organisational capacity/infrastructure	Diagnosis skills/training	Establishing laboratory	Registry creation/strengthening	Education of patients and their network	Patient association strengthening	Awareness raising	Building advocacy skills
China 3	Comprehensive	2006	⊙		⊙	⊙	⊙	⊙	⊙	⊙		⊙	
China 4	Comprehensive	2006	⊙		⊙	⊙	⊙		⊙	⊙		⊙	
China 5	Comprehensive	2006	⊙		⊙	⊙	⊙		⊙	⊙	⊙	⊙	
China 6	Comprehensive	2006	⊙		⊙	⊙	⊙		⊙	⊙		⊙	⊙
India 2	Comprehensive	2008		⊙	⊙	⊙				⊙		⊙	⊙
India 7	Comprehensive	2008	⊙		⊙				⊙				
India 8	Comprehensive	2008	⊙							⊙	⊙		
Indonesia	Comprehensive	2012		⊙	⊙	⊙			⊙	⊙	⊙	⊙	⊙
Malaysia 3	Comprehensive	2008	⊙							⊙	⊙	⊙	⊙
Phillippines	Comprehensive	2011		⊙	⊙	⊙	⊙	⊙	⊙	⊙		⊙	
Thailand 1	Comprehensive	2008		⊙	⊙	⊙				⊙	⊙	⊙	
Thailand 2	Comprehensive	2008	⊙		⊙	⊙			⊙	⊙	⊙	⊙	
Thailand 4	Comprehensive	2008	⊙		⊙	⊙				⊙	⊙	⊙	
Vietnam 2	Comprehensive	2007	⊙		⊙	⊙	⊙	⊙	⊙	⊙	⊙	⊙	⊙
Uzbekistan 4	Comprehensive	2005	⊙		⊙				⊙				
Bangladesh	Basic	2015	⊙		⊙	⊙	⊙			⊙		⊙	
Cambodia	Basic	2011	⊙		⊙	⊙	⊙	⊙		⊙	⊙	⊙	
China 7	Basic	2006	⊙		⊙	⊙	⊙	⊙	⊙	⊙		⊙	
India 3	Basic	2008	⊙		⊙	⊙		⊙		⊙		⊙	
India 5	Basic	2008		⊙	⊙					⊙	⊙	⊙	
India 6	Basic	2008	⊙		⊙	⊙	⊙			⊙	⊙	⊙	
Myanmar	Basic	2013	⊙		⊙			⊙		⊙			
Myanmar 2	Basic	2013		⊙	⊙					⊙	⊙	⊙	
Nepal	Basic	2014	⊙		⊙						⊙	⊙	⊙
Sri Lanka	Basic	2009	⊙		⊙					⊙	⊙	⊙	⊙
Thailand 3	Innovative	2008		⊙		⊙							

Fellowships	Fellow profession	NNHF partner since	Approved/ongoing in 2016	Completed in 2016	Building HCP skills	Building organisational capacity/infrastructure	Diagnosis skills/training	Establishing laboratory	Registry creation/strengthening	Education of patients and their network	Patient association strengthening	Awareness raising	Building advocacy skills
Myanmar 2	Pathologist	2013	⊙				⊙						

Representatives of the Haemophilia Treatment Centre Collaborative Network of China at the NNHF project closing meeting in China at the end of 2016. The meeting included workshops to discuss learnings and identify further areas of need.

Collaborative networks for care, diagnosis and patient empowerment

NNHF activities in this vast region are diverse and for the purposes of this update have been divided into the sub-regions of China, South East Asia, India and Sri Lanka, and Central Asia.

NNHF engagement in Asia began in its founding year, when the Uzbekistan project started in 2005. Engagement in Uzbekistan continues to this day, with the fourth project in the country approved in 2016. This long-term engagement is also reflected in China and India, where the NNHF has supported seven and eight projects respectively as of December 2016. A key theme in these countries, as well as others in the region, is the creation of collaborative networks in pursuit of improved haemophilia care.

China – national quality assurance for improved diagnosis and data

The **China 3** project, which completed in 2016, trained more than 113 centres in quality diagnosis through a National External Quality Assurance (EQA) Scheme. More than 2,000 patients were diagnosed as a result. The project was instrumental in upgrading and consolidating the national registry based on software used by the UK Haemophilia Data Manager Forum Group (MDSAS-HCIS), and 26 centres were trained to use it – representing more than 50% of the 43 centres currently using the registry.

An exciting result of this is that China is now on its way to participating again in the World Federation of Haemophilia's global survey. As the most populace country in the world, this is a substantial step forward in improving the quality of global patient population data.

One of the last outcomes of the China 3 project has been the mapping of the Haemophilia Stakeholder Network of China. Such mapping formed by hundreds of stakeholders such as 3rd and 2nd level Haemophilia Treatment Centres, diagnostic laboratories and patient associations (Haemophilia Home of China) illustrated the great progress made in improving access to quality care by the Haemophilia Treatment Centre Collaborative Network of China (HTCCNC) together with the expanded care network over the last decade and supported by different organisations and partners including the NNHF.

Together with patient associations and other stakeholders, HTCCNC and NNHF will be expanding their long-standing collaboration to continue strengthening haemophilia care within China's healthcare system.

Read the full report at nnhf.org

South East Asia – building cross-border and cross-sectoral alliances

Collaboration has continued to be a strong theme in the projects across this region.

Project activities in **Myanmar** contributed to the development of the Myanmar Haemophilia Patient Association (MHPA) which achieved official recognition by the Myanmar government in early 2016 and by the World Federation of Hemophilia (WFH) as an associate National Member Organisation during the WFH congress in Orlando 2016.

A dedicated core team consisting of Professor Htun Lwin Nyein from Yangon General Hospital, Dr Aye Aye Khaing from Yangon Paediatric Hospital and Dr Moe Hein from Mandalay Hospital collaborated to train 209 healthcare professionals and deliver patient education workshops in Yangon and Mandalay.

The project is now focusing its activities in northern Myanmar in collaboration with the medical community and newly established patient association chapter in Mandalay. These activities are being undertaken in alignment with the stakeholders in Yangon, WFH and twinning partner Dr Thynn Thynn Yee from Katharine Dormandy Haemophilia and Thrombosis Centre at the Royal Free Hospital, London, who plays a central role in orchestrating the different partners in Myanmar.

In **Indonesia**, six haemophilia treatment centres collaborated to train 90 specialist doctors in multidisciplinary care, 900 physicians in basic disease knowledge, and educate more than 750 patients and family members.

The project team's efforts to engage and collaborate with authorities throughout the 2-year project led to incredible impact at policy level. Resulting policy changes include access to treatment for outpatients, factor coverage for orthopaedic and emergency surgery, and approval of on-demand home treatment. Read the full report at nnhf.org.

Based on these successful first steps, a second NNHF project has been approved to conduct further outreach activities and consolidate and strengthen these six haemophilia treatment centres together with four new ones.

Physiotherapist Paul McLaughlin from the Royal Free Hospital in the UK delivers training on MSK care and how to evaluate and consult a patient in Mandalay, Myanmar.

Vietnam 2 project partner Prof Tri (front row, fourth from right) at a national strategy meeting attended by the Vietnamese haemophilia committee and representatives from WFH, NNHF and industry.

Authorities have also been successfully engaged in **Vietnam**, where the Ministry of Health approved new treatment options highlighting home treatment and low-dose prophylaxis for severe haemophilia patients under the age of 15. This decision was based on the recommendations of a national haemophilia committee established through the **Vietnam 2** project, who updated the treatment guidelines developed in the Vietnam 1 project.

Other activities in the country included establishing multidisciplinary care teams and organising care delivery in Hanoi, Hue and Ho Chi Minh, and developing a haemophilia treatment centre in Can Tho General Hospital.

Through the project activities, more than 900 healthcare professionals have been trained, 2,400 patients and family members have been educated and more than 200 new patients have been diagnosed.

At a recent national strategy meeting with the national haemophilia committee, WFH, NNHF and industry representatives, Prof Nguyen Anh Tri presented the national haemophilia strategy for Vietnam, with NNHF committing to support the decentralisation of care.

A two-stream approach to improving comprehensive care is being taken in **Thailand**, with the first focusing on expanding access to quality care based on the chronic care model and the second focusing on musculoskeletal (MSK) care.

The **Thailand 2** project is working to establish MSK care in Chiang Mai and Bangkok through a train-the-trainer programme. The initial master trainer session was delivered by international expert physiotherapists Pamela Hilliard from the Sick Kids Hospital in Canada and Sharon Funk from the University of Colorado in the US. Participants will now return to their respective centres to put their new knowledge into practice by acting as master trainers.

The **Thailand 3** project, which started in 2016, developed a strategy to build healthcare professional knowledge, establish the chronic care model in eight regions and develop young patient association members as leaders.

This strategy will be implemented in the **Thailand 4** project, a collaborative project led by a cross-sectoral team consisting of Mr Hathaiwut Lamthean from the National Health Security Office (NHSO), Prof Ampaiwan Chuansumrit from IHTC Bangkok and Dr Rungrote Natesirinilkul from the Faculty of Medicine at Chiang Mai University, together with Mr Ekawat Suwantaroj of the Thai Haemophilia Patient Club.

The **Malaysia 3** project focuses on empowering the patient association through empowering dedicated women leaders and developing leadership tools.

India and Sri Lanka – empowering patients and replicating better practices

Empowering women is also one of the activities in the **Sri Lanka** project, which set-up a women's group as part of its activities and ran a workshop for 120 participants to address the issues facing women who are parents, carriers or have a bleeding disorder. This was alongside patient education sessions for 455 patient and family members which were supported by Brian O'Mahoney from the patient association in Ireland. In addition the project has conducted MSK training with 13 physiotherapists on a national level, which was identified as a key need by the patient association. The association is now looking to improve care further through stronger collaboration between the medical and patient communities.

In **India**, project activities are being scaled up to increase their geographical reach. Examples include the India 8 project in South and West India, which replicates the Parents Empowering Parents (PEP) activities originally part of the India 6 project that trained 40 parents in the North East to become PEP trainers. Similarly, India 7 will delve deeper into the topic of MSK which was a focus of the India 5 project in Karnataka. Through 100 patient evaluations, this project showed a direct correlation between exercise and improved joint health. The India 7 project will cover South India and will establish an MSK registry to collect outcome data.

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Long-term engagement creates local impact in Uzbekistan

Uzbekistan was one of the first countries to join the NNHF portfolio, with the first project starting in 2005. A total of four projects have been supported since, resulting in strengthened care in Tashkent and decentralisation of care to all regions.

In 2005, haemophilia care and diagnosis in Uzbekistan were only available in the capital city of Tashkent. For people with haemophilia living outside the city, access to care was time consuming and costly, and children would miss long periods of their education due to lengthy hospital visits.

It was this situation that drove haematologist Dr Aziza Makhmudova from Tashkent haemophilia centre to approach the NNHF with a project idea, which would mark the start of an 11-year partnership.

Strengthening and decentralising care

Dr Makhmudova and the project team began by strengthening care in Tashkent by training healthcare professionals, equipping the lab and training lab technicians to perform complete haemophilia diagnosis for the first time.

The team then set about establishing care for patients in other parts of the country. Haematologists from 12 regions participated in in-depth training in Tashkent, with the core team then visiting the regions to identify further training needs and train an additional 200 lab technicians, nurses and doctors in these regions. To improve access to diagnosis, labs were established in the cities of Fergana, Samarkand and Nukus.

Supporting educational activities

Whilst care was now available in the regions, children with haemophilia would still stay for long periods at the centre in Tashkent in cases of complications. To minimise the impact on their education the NNHF supported the creation of a school at the centre. Since it was established in 2008, each child attending the school has avoided missing on average a total of 10 days of schooling per year.

Ismail and Said are two of the pupils who have attended the school at the Tashkent haemophilia centre since it was established in 2008.

13-year old Brunbaev and his grandmother no longer need to make the 24-hour journey to Tashkent to receive care, as it is now available in their home city of Nukus.

Award winning impact

Decentralisation activities in Uzbekistan have led to a 92% reduction in the distance patients have to travel to receive care, and all patients are within 80km of their nearest care provider. 60% of haemophilia cases are now dealt with in regional centres instead of being referred to Tashkent. Over 1,500 patients have received complete diagnosis and haemophilia related disabilities have reduced by 25%.

To support the improvement of haemophilia care beyond her country's borders, Dr Makhmudova has shared her experiences in Turkey, Moscow and Azerbaijan. Her ongoing efforts have helped engage authorities, which now fund haemophilia treatment.

In recognition of her tireless dedication to people with haemophilia, Dr Makhmudova was presented with the NNHF Community Award 2016 (see page 23). She and the project team are now working on the fourth NNHF project which aims to improve joint health by establishing rehabilitative care across the country.

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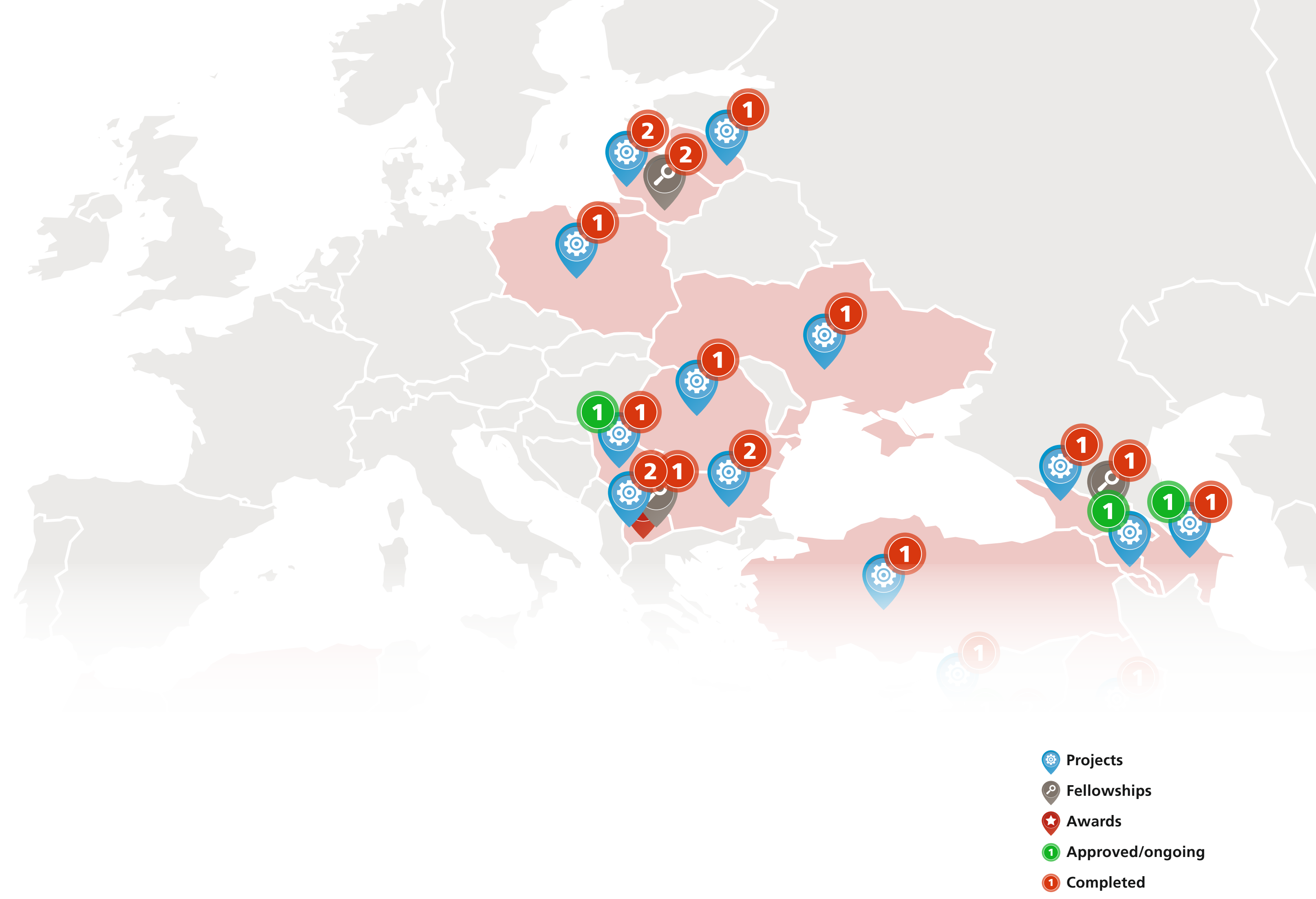
The Serbian Haemophilia Society is empowering patients to become more active and includes educational activities with parents and young people.



Europe regional update

As well as funding programmes in emerging countries, the NNHF occasionally funds programmes in transition countries[1]. In 2016, these included Serbia and Latvia, where unmet needs in haemophilia remain significant in specific areas of care.

In both countries, the patient associations are playing a fundamental role in addressing haemophilia needs together with the medical community. The Serbian Haemophilia Society is aiming to empower the patient community to become more active and take responsibility for self-care through the **Serbia 2** project. Here, activities to widen the Society's reach and impact include creating a network of regional educators and targeting specific audiences through educational activities, such as parents and young people.

In **Latvia**, the patient association is leading a project to create a registry that will monitor patient data and health outcomes. Once established, this will improve the quality of care and treatment and ensure a smooth transition for patients moving from paediatric to adult care systems.

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[1] See page 6 for NNHF geographic scope and definitions

					Capacity building		Diagnosis and registry			Education and empowerment		Awareness and advocacy	
Projects	**Project category**	NNHF partner since	Approved/ongoing in 2016	Completed in 2016	Building HCP skills	Building organisational capacity/infrastructure	Diagnosis skills/training	Establishing laboratory	Registry creation/strengthening	Education of patients and their network	Patient association strengthening	Awareness raising	Building advocacy skills
Serbia 2	Comprehensive	2011	⊙		⊙					⊙	⊙	⊙	⊙
Latvia 2	Basic	2011	⊙		⊙				⊙				

Dr Juan Cristobal Morales assessing a patient at the haemophilia clinic of Complejo Hospitalario Sótero del Río, Santiago, Chile.

Latin America regional update

With 25 approved, running or completed programmes in 2016, Latin America continues to be the region with the highest number of NNHF programmes, reflecting its size and diversity.

					Capacity building		Diagnosis and registry			Education and empowerment		Awareness and advocacy	
Projects	**Project category**	NNHF partner since	Approved/ongoing in 2016	Completed in 2016	Building HCP skills	Building organisational capacity/infrastructure	Diagnosis skills/training	Establishing laboratory	Registry creation/strengthening	Education of patients and their network	Patient association strengthening	Awareness raising	Building advocacy skills
Brazil 3	Comprehensive	2006		⊙	⊙	⊙				⊙			
Brazil 4	Comprehensive	2006	⊙		⊙				⊙	⊙	⊙	⊙	
Chile 2	Comprehensive	2007		⊙	⊙	⊙				⊙		⊙	
Chile 3	Comprehensive	2007	⊙		⊙	⊙	⊙	⊙	⊙				
Cuba 2	Comprehensive	2007	⊙		⊙	⊙	⊙	⊙	⊙	⊙		⊙	
Guatemala	Comprehensive		Cancelled		⊙	⊙	⊙	⊙	⊙	⊙		⊙	
Jamaica	Comprehensive	2014	⊙		⊙	⊙	⊙	⊙	⊙	⊙		⊙	
Mexico 2	Comprehensive	2010		⊙	⊙	⊙	⊙		⊙	⊙		⊙	
Mexico 3	Comprehensive	2010	⊙		⊙	⊙				⊙		⊙	
Peru 3	Comprehensive	2014	⊙		⊙	⊙	⊙	⊙	⊙			⊙	
Argentina 2	Basic	2012	⊙		⊙					⊙		⊙	
Argentina 3	Basic	2012	⊙		⊙	⊙		⊙	⊙	⊙		⊙	
Bolivia	Basic	2014		⊙	⊙	⊙	⊙	⊙	⊙	⊙	⊙	⊙	⊙
Mexico 5	Basic	2010	⊙		⊙	⊙			⊙	⊙	⊙	⊙	⊙
Nicaragua	Basic	2014	⊙		⊙	⊙	⊙	⊙	⊙	⊙	⊙	⊙	
Paraguay	Basic	2014	⊙		⊙	⊙	⊙	⊙	⊙	⊙	⊙	⊙	⊙
Peru 2	Basic	2014		⊙	⊙					⊙		⊙	
Brazil 2	Innovative	2006		⊙	⊙	⊙			⊙	⊙	⊙	⊙	
Central America, Caribbean and Venezuela	Innovative	2013		⊙						⊙	⊙	⊙	⊙
Mexico 4	Innovative	2010	⊙		⊙	⊙	⊙	⊙	⊙	⊙		⊙	

Fellowships	**Fellow profession**					
Chile 4	Physiotherapist	2007		⊙	⊙	
Chile 5	Social worker	2007	⊙		⊙	
Colombia 5	Physiotherapist	2011		⊙	⊙	
Mexico 5	Physiatrist	2010	⊙			
Mexico 6	Physiatrist	2010	⊙			
Panama 2	Haematologist	2007	⊙		⊙	

From 2017, the NNHF will incorporate 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, ensuring resource efficiency and reflecting the streamlined approach we are encouraging our partners to take in their efforts to improve haemophilia care.

The Haemophilia Leadership Forum in Peru was supported by the NNHF international expert network including Dr Laura Villareal from Mexico (centre).

Improving multidisciplinary care through collaboration

A key theme in this region is establishing multidisciplinary care, which was an element in all NNHF projects across Latin America in 2016. Other common activities were the creation and updating of registries and the utilisation of networks to improve haemophilia care.

In **Mexico**, haemophilia care has been attracting increasing attention from healthcare professionals and authorities, reflecting developments in the country's overall healthcare system. In 2016, the number of NNHF projects more than doubled in Mexico – increasing from two to four – and two new fellowships were approved.

Establishing multidisciplinary care in Mexico

Establishing multidisciplinary care was a key component of the NNHF Project of the Year award winning **Mexico 2** project in Monterrey, which was completed in 2016 (see the Mexico 2 completed project article at nnhf.org and the Project of the Year Award article in the NNHF Activity Report 2015 page 40).

With a team of eight healthcare professionals now able to provide care for people with haemophilia, project partner and haematologist Dr Laura Villarreal from the University Hospital Dr José Eleuterio González is now sharing the better practices she observed with the **Mexico 3** project team.

Like Mexico 2, this project led by paediatric haematologist and Head of Paediatric Haematology Dr Io Daiela Castillo from Hospital Infantil de México Federico Gómez (HIMFG) is working to improve musculoskeletal (MSK) care for paediatric patients in two key public hospitals – The National Paediatric Institute in Mexico City and the Civil Hospital in Guadalajara – through training healthcare professionals, educating patients and families, and collecting outcome data to demonstrate the efficacy of MSK care.

Whilst the value of establishing multidisciplinary care teams in these projects cannot be underestimated, one of the most impressive outcomes is the change in mindset that has resulted from these activities. The benefits of increased understanding of the importance of organising care with clear processes, roles and responsibilities amongst healthcare professionals, patients and authorities has already seen the Mexico 2 project team observing a decrease in the number of hospitalisations caused by haemophilia related complications – with only one hospitalisation occurring in the last two years.

The **Mexico 4** and **Mexico 5** projects, approved in 2016, mark a new era for NNHF projects in the country by focusing on standardising care. Mexico 4 will do this on a national scale, with Mexico 5 building on the Mexico 2 and Mexico 4 projects in the State of Mexico. In both projects, the teams are working to improve and standardise care across institutions and healthcare systems, which necessitates a cross-sectoral approach where healthcare professionals, authorities, decision makers and patients play a role in strengthening care.

In addition, the Mexico 4 project will include upgrading the national patient registry to include medical data. Similar activities involving registries will be undertaken in the **Chile 3** and **Peru 3** projects, which will start soon, as a means of engaging decision makers in dedicating resources to haemophilia care.

Regional collaboration across borders and sectors

Dr Villarreal from the Mexico 2 project also embodies the culture of collaboration seen across Latin America. As well as sharing experiences with the Mexico 3 team, she supported the delivery of the second NNHF Haemophilia Leadership Forum (HLF), held in Lima, Peru in September 2016.

Building on the success of the first HLF held in Panama in 2014 (find out more in the NNHF Activity Report 2015 page 39), this Forum was organised by NNHF, co-hosted by the Danish embassy for Chile, Peru and Ecuador, and sponsored by Novo Nordisk. It brought together over 50 representatives covering authorities, international experts, healthcare professionals and presidents of patient associations from 12 countries across Central America, the Caribbean and South America.

Speakers included Prof Miguel Escobar from Houston, USA, and Prof Eduardo Missoni from Italy who inspired attendees with their thoughts on comprehensive haemophilia care and challenges in the integration of haemophilia care in the health system.

One key theme arising from the HLF workshops was the need for a national strategy in each participating country, meaning the creation of national networks striving for the improvement and standardisation of care. Chile, Peru and Uruguay have since developed NNHF project plans to turn these ideas into action.

The spirit of collaboration seen in the two Forums held so far is also evident in the **Central America, Caribbean and Venezuela** project. The first regional NNHF project, activities were undertaken to

The NNHF Chile 2 project included workshops on musculoskeletal care which featured exercise sessions for adults and children.

empower patient association members with leadership skills, become active members of their organisations and be prepared to take over responsibilities in their organisations. See page 45 for more information.

Better practice sharing and outreach in Argentina

Whilst some projects in the region are at inception stage, others have demonstrated their sustainability, with haemophilia care continuing to improve after NNHF funded activities end.

Salta in Argentina is one example of this. NNHF engagement in Salta began in 2011 through the first Argentina project. Under the leadership of Dr María Sol Cruz, President of the Haemophilia Foundation of Salta, the project delivered outreach to patients and families across the region. Its impressive achievements led to it being granted the NNHF Project of the Year Award in 2013 (see NNHF Activity Report 2012/2013 page 44). The project team continued in their endeavors to improve haemophilia care beyond the lifespan of the project, and in 2016 the health authorities in Salta approved the establishment of a haemophilia service at the local hospital, dedicated to diagnosis and multidisciplinary care of people with haemophilia living in the province.

"When I look back at what we achieved during the past five years I realise the impact and extent of our activities. The NNHF project gave us confidence and confirmed that we were moving in the right direction and finally… made our dream come true, as today we have a service dedicated to haemophilia care at the local hospital," said Dr Cruz.

The **Argentina 2** project led by haematologist Dr Susana Garbiero from the patient association and healthcare centre in Bahía Blanca, is using a similar model in the Southern Buenos Aires province to create a network providing quality care, working together with all relevant healthcare institutions and strengthening them through healthcare professional training. In addition, outreach visits and educational sessions for patients and families will help to empower them and create networks.

Likewise, the **Argentina 3** project in Jujuy led by Dr Susana Gastaldo, haematologist from the haemophilia clinic of the Children's Hospital in San Salvador de Jujuy, is focusing on outreach using a similar model to that established by the Salta project team.

The Salta project team in Argentina at the newly inaugurated haemophilia service.

A healthcare professional training session in Espirito Santo as part of the Brazil 3 project.

Expanding the Brazil 2 MSK registry

The MSK registry is an example of an innovative idea piloted through a project, with a long-term view of being rolled out and adapted on a local level worldwide. Developed through the NNHF **Brazil 2** project (see NNHF Activity Report 2015 pp47-48), the registry sets a standard for MSK outcome data collection and is so far being adapted and utilised in other NNHF projects such as Egypt 2, India 7, Mexico 2 and Thailand 2.

As part of its work in encouraging partners to utilise the registry in their efforts to establish and promote MSK care, the NNHF is supporting an MSK group of international experts for the development of a practical MSK guidance document to facilitate the selection and application of the most relevant MSK assessment tools and scores to specific situations. The manuscript is planned to be released in 2017.

Elsewhere in Brazil, the **Brazil 3** project, led by Dr Alessandra Prezotti and the team from Hemocentro do Estado do Espírito Santo (HEMOES), also developed tools to improve haemophilia care. In this case, the tools comprised updated guidelines and educational materials aimed at enabling local healthcare professionals to confidently deliver treatment so that patients could receive quality care close to their homes, and improving patients' understanding of the condition so they would utilise their right to home treatment. By the end of the project, the percentage of patients who treat at home had risen from about 50% to over 70%. Read the full report at nnhf.org.

The project team received the Inoves Award which recognises innovation initiatives in the public management of Espírito Santo, for the value their work brings to the community, acknowledging their successful collaboration leading to the improvement of haemophilia care in Brazil. The NNHF congratulates the team and all who collaborated for their dedication and remarkable achievements.

Based on the lessons learned through this project, and the accomplishment of cross-functional collaboration, the **Brazil 4** project is now underway under the leadership of Christianne Oliveira from the Brazilian Federation of haemophilia. The project aims to strengthen the care and education network for haemophilia in the state of Pará in Brazil.

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Developing leaders through a regional approach

In 2014, Fendi Valdez Bisono was designated by his peers from Central America, Caribbean and Venezuela to become the project leader of this first NNHF project to be undertaken on a regional basis.

Realising the phenomenal level of co-ordination that would be required to ensure the nine participating countries would remain aligned throughout the project, the group felt he had the skills to lead them on this journey.

These skills we developed under the guidance of Haydée Benoit de García from the Dominican Republic, who used her 2012 NNHF Community Award grant to train future leaders of the patient association, having observed a lack of new leaders and succession planning for the association. It was with the aim of addressing this challenge that this project was instigated.

The project led to a leadership development programme which was instigated in each country and has so far trained 18 future leaders. Through the engagement efforts of this new generation of leaders, the region's patient associations now have 128 new active youth members, with all associations seeing an increase in members.

"This project has strengthened collaboration, we have seen similarities and differences and this experience allows that in future we can have better communication and better results in any project that takes place in the region," observed one participant.

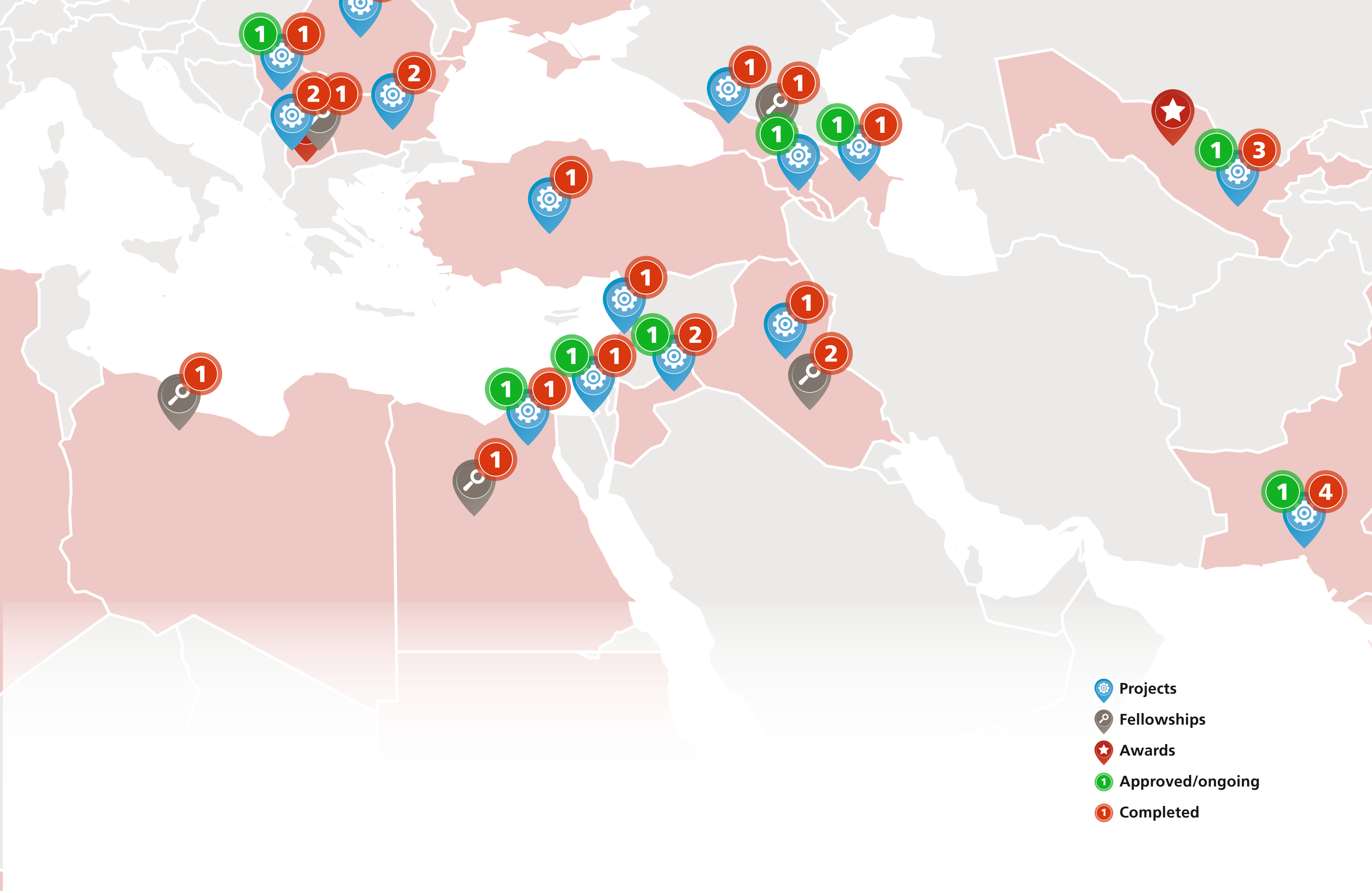
Fendi Bisono Valdez was selected as the project leader due to his experience working with youth in the Dominican Republic.

Overall, young leaders in each country are taking an active role and will ensure a smooth transition when the current generation of leaders moves on. A network has been established allowing experience sharing across borders. The project's activities were recognised by the WFH, who invited Fendi to present at their Latin America meeting.

Visit nnhf.org to read the full report of the project.

All participants of the regional training came together for in-depth training in the Dominican Republic in June 2015.

Prof Adly Sabbour at a patient education session in Qena, as part of the Egypt 1 project. The subsequent Egypt 2 project is currently running, and focuses on musculoskeletal care.



Middle East, Near East and Caucasus regional update

Six projects were running in this region in 2016, whilst one was completed. The NNHF Project of the Year Award 2016 was won by the Pakistan 5 project – marking the first NNHF award for the region.

					Capacity building		Diagnosis and registry			Education and empowerment		Awareness and advocacy	
Projects	**Project category**	NNHF partner since	Approved/ongoing in 2016	Completed in 2016	Building HCP skills	Building organisational capacity/infrastructure	Diagnosis skills/training	Establishing laboratory	Registry creation/strengthening	Education of patients and their network	Patient association strengthening	Awareness raising	Building advocacy skills
Georgia	Comprehensive	2011		⊙	⊙			⊙		⊙			
Armenia	Basic	2014	⊙		⊙	⊙		⊙	⊙	⊙		⊙	
Azerbaijan 2	Basic	2012	⊙		⊙	⊙	⊙			⊙		⊙	⊙
Egypt 2	Basic	2011	⊙		⊙	⊙			⊙				⊙
Pakistan 5	Basic	2006	⊙						⊙		⊙	⊙	
Palestine	Basic	2013	⊙		⊙		⊙	⊙	⊙	⊙		⊙	
Jordan 3	Innovative	2006	⊙							⊙	⊙	⊙	

Dr Levani Makhaldiani and the Georgia project team conducted outreach visits and educational sessions in six regions.

Expanding care provision through outreach and decentralisation

With care being significantly stronger in capital cities compared to other areas, outreach and decentralisation are common themes in this region. Initiatives cover both general haemophilia care as well as focused activities such as patient empowerment and musculoskeletal care.

Activities in **Armenia**, **Georgia**, **Jordan 3** and **Palestine** have all included outreach initiatives to expand care provision to different regions. In Armenia and Georgia, haemophilia care had so far been concentrated in the respective capital cities of Yerevan and Tbilisi.

Regional outreach and national guidelines

One of the six regions included in the **Armenia** outreach visits is Gyumri, where physiotherapists, haematologists and an ultrasound specialist were trained in haemophilia and supported to examine patients. 600 patients will receive education across these regions. The project is also establishing national guidelines and a registry to standardise care across the country.

Project partner Prof Smbat Daghbashyan, Director of the Haematology Centre of Armenia in Yerevan, observed: "These activities have 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."

In **Georgia**, project partner and haematologist Dr Levani Makhaldiani, Head of the Treatment Centre in Tbilisi, has led the project to strengthen skills and diagnosis facilities in Tbilisi, as well as conduct a series of multidisciplinary outreach visits in six regions. Over 300 patients and family members – including those with mobility challenges or living in rural areas – have benefited from home consultations, educational sessions and have now established links with their closest care centres. As in Armenia, the newly updated guidelines will help to standardise care across regions.

Decentralising musculoskeletal (MSK) care

The **Egypt 2** project, led by the Egyptian Haemophilia Society and represented by Dr Magda Rakha, has continued to strengthen the physiotherapy facilities established at five centres through the first Egypt project. Haematologists from these centres have been trained in the importance of physiotherapy, and physiotherapists from each clinic have been trained to evaluate people with haemophilia and utilise the MSK registry created through the NNHF Brazil 2 project.

Expanding patient empowerment

The NNHF award winning **Pakistan 5** project aimed to strengthen the patient association, raise haemophilia awareness and develop a national registry. To ensure the sustainability of the patient association and that it served all patients across the country, the team focused on establishing a National Youth Group. Through a series of visits to regional chapters, the project brought together ten youth leaders whose roles would ensure association activities would reach patients from across their five regions.

All project objectives were achieved in 2016 and the team is currently developing a new project to build on its success, which will focus on increasing awareness and advocating for better care at a regional level. Read more on why Pakistan 5 was named NNHF Project of the Year 2016 on page 22.

Outreach in Gyumri brings care closer to patients

Gyumri is the second largest city in Armenia, and is 130km from the country's capital, Yerevan. It is one of six regions benefiting from outreach support from the NNHF project team.

In October 2016, the multidisciplinary project team – which comprises a haematologist, physiotherapist, psychologist, ultrasound specialist and two nurses – travelled from Yerevan to Gyumri as part of a series of outreach visits across the country.

During the visit, they undertook a series of consultations with patients and families and delivered haemophilia training to the Gyumri team. Each team member was observed by members of the Gyumri team during the consultations, to ensure appropriate follow-up care would be provided.

One of the patients they met was 5-year old Matsakyen Armen, who had his first brain bleed at 3 years old, followed by a second in January 2016. Each time, he had to go to the hospital in Yerevan by bus, 190km from his home.

As a result of the outreach visits conducted by the project team, patients like Matsakyen can receive basic care closer to home and do not have to travel to Yerevan as often.

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

Top: Matsakyen and his mother attend a session with psychologist Naira Simoryan.

Centre: Ultrasound specialist Ruzanna Avagyan undertakes an examination using equipment provided through the NNHF project.

Bottom: Haematologist Dr Hegine Khacehatryan in a consultation session with Matsakyen, observed by nurse Areg Hazutyunyan.

Governance and accounts

Adhering to foundation governance standards and operating principles

The NNHF is established as a non-profit organisation and is governed by a Council of Members comprising eight representatives from Novo Nordisk management and the expert haemophilia community.

Operational management is the responsibility of the NNHF management team of seven staff members.

In the following pages, we present the 2016 NNHF audit report alongside our governance structure, management team and Council.

The NNHF management team pictured in the NNHF office in Zurich, Switzerland in February 2017.

Governance: The rules we live by

The NNHF is established as a non-profit organisation. Adhering to high foundation governance standards is a key objective for our organisation and its operations as a grant-making foundation.

The NNHF is an associated partner of Swiss Foundations and orients its corporate governance to the principles and recommendations of the 'Swiss Foundation Code'.

The NNHF is governed by the Foundation Council, chaired until 1 September 2016 by Jakob Riis, Executive Vice President, North America Operations, Novo Nordisk A/S (formerly Executive Vice President, Marketing, Medical Affairs and Stakeholder Engagement during his NNHF Council presidency) and from 22 September 2016 by Mike Rulis, Senior Vice President for Communication, Relations & Sustainability. Along with globally renowned external experts in the field of haemophilia, the Council consists of members from Novo Nordisk drawn from the company's global experience in haemophilia, as well as management of corporate social responsibility and 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 as transparent as possible and appropriate to the foundation's purpose. The Council convenes at least twice each year and is the supervisory and main decision body of NNHF to ensure proper handling of funds and their distribution. It makes decisions on submitted programmes and strategic direction, supervises financial and liquidity

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The NNHF Council

Mike Rulis, president (appointed 2016)
Leif Fenger Jensen, vice president (appointed 2009)
Ulla Hedner (appointed 2005)
Paul Huggins (appointed 2016)
Emil Kongshøj Larsen (appointed 2015)
Margareth Ozelo (appointed 2012)
Stephanie Seremetis (appointed 2015)
Amy Shapiro (appointed 2011)

The NNHF Council members execute their duty without remuneration except for the reimbursement of their expenses.

The NNHF Council pictured in March 2017. From left to right: Ulla Hedner, Mike Rulis, Stephanie Seremetis, Paul Huggins, Amy Shapiro, Margareth Ozelo, Emil Kongshøj Larsen.

The NNHF Council and management team thank the following former Council and team members for their dedication and contribution in 2016:

Former NNHF Council members
Jakob Riis, president (until September 2016)
Charlotte Ersbøll (until October 2016)

Former NNHF management team members
Alexandre Bento Costa Alencar, senior project manager (until April 2016)
Natasha Kopitsis, communications manager (until February 2016)

planning, approves the annual budget as well as the reporting on risk and financial management as submitted by NNHF Management. The NNHF Council entrusts daily management to NNHF Management, a team of seven employees. NNHF Management is responsible for the operational management of the NNHF and submits received programme applications to its Council for decision with appropriate recommendations according to NNHF programme guidelines. NNHF Management also ensures results-oriented programmes management, allocation of funds and budget controlling and is obliged to regularly update the Council on the financial and operative situation.

Clear operating principles and processes aim at achieving efficient and sustainable results fulfilling the purpose of the foundation to improve access to care for people with haemophilia and allied bleeding disorders. Our project management principles and tools are available on our website as well as upon request to ensure the highest transparency and quality standards when selecting, monitoring and controlling 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.

Susanne Brandl and Denise Brændgård preparing the handover of leadership in March 2017.

The NNHF management team

Susanne Brandl
general manager

Denise Brændgård
senior programme manager

Rubén García Santos
programme manager

Sara Motka
programme manager
(since June 2016)

Shady Sedhom
programme manager

Milena Marra
communications manager
(since August 2016)

Xio Fong Vilaysane
project coordinator

Lab technicians in Yerevan use equipment provided through the NNHF Armenia project to diagnose new patients.

Audit report

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

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 2016. Our limited statutory examination was completed on 1 March 2017.

These financial statements are the responsibility of the Board of the Foundation. 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 company personnel and analytical procedures as well as detailed tests of company 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

Kai

Joanne Burgener
Audit expert
Auditor in charge

Kai Mauden
Audit expert

Zürich, 1 March 2017

Enclosures:

Financial statements (balance sheet, income statement and notes)

Financial statements 2016

Balance sheet as at December 31
(in Swiss francs)

	Note	2016	2015
ASSETS			
Current assets			
Cash and cash equivalents		**3,415,774**	3,352,375
Trade receivables		**627,291**	620
due from third parties		**0**	620
due from group companies		**627,291**	0
Total current assets		**4,043,065**	3,352,995
Total Assets		**4,043,065**	3,352,995
LIABILITIES			
Short-term liabilities			
Trade payables		**70,103**	38,420
due to third parties		**70,103**	38,420
Accrued expenses	1.2, 2.2	**3,034,761**	2,412,160
Total short-term liabilities		**3,104,864**	2,450,580
Long-term liabilities			
Long-term provisions		**51,304**	80,985
Total long-term liabilities		**51,304**	80,985
Total liabilities		**3,156,168**	2,531,565
Equity			
Locked-up capital		**200,000**	200,000
Statutory retained earnings		**621,430**	500,208
Gain/(loss) for the year		**65,467**	121,222
Total equity		**886,897**	821,430
Total liabilities		**4,043,065**	3,352,995

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

	Note	2016	2015
Donation income	1.1	**3,101,909**	3,071,829
Net grants		**-1,287,857**	-1,239,203
Approved grants		**-1,501,056**	-1,280,500
Cancelled and closed grants		**213,199**	41,297
Personnel costs		**-1,353,303**	-1,273,429
Other operating expenses		**-242,108**	-260,563
Project result		**218,641**	298,634
Administration costs	2.3	**-162,372**	-151,553
Operating result		**56,269**	147,081
Financial income		**9,198**	0
Financial expenses		**0**	-25,859
Result for the year		**65,467**	121,222

Financial statements 2016

Notes to the financial statement 2016
(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	2016 profit and loss statement	Balance sheet as at 31 Dec. 2016
EUR	1.09	1.07
DKK	0.15	0.14
US$	0.99	1.02

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 2016 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

	2016	2015
Grants for development programmes	**2,207,559**	2,195,389
Accrued bonus and pension costs	**192,926**	176,598
Other accruals	**634,276**	40,173
Accrued expenses	**3,034,761**	2,412,160

2.3 Administration costs

	2016	2015
Rental and lease costs	**64,257**	65,881
Office costs	**31,993**	28,439
SLA costs	**21,463**	20,617
Legal and consulting fees	**22,289**	28,669
Audit fees	**6,480**	6,380
Other expenses	**15,890**	1,567
Administration costs	**162,372**	151,553

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

	2016	2015
Car leasing	**0**	2 236

2.5 Significant events occurring after the balance sheet date

None

Map of NNHF programmes

Defining and funding sustainable programmes

As of December 2016, the NNHF has supported 214 development programmes and 14 awards in 68 countries since it was founded in 2005. Completed, running and newly approved programmes are presented on the map on the following page.

An interactive version of this map which includes details of all programmes listed can be found at nnhf.org.

Three of Nayiga Justine's sons have haemophilia – two were diagnosed through the NNHF Uganda project. The family also attended a patient education camp through the project. Meeting with other families affected by haemophilia has given Justine hope of a brighter future for her sons.

Map of NNHF programmes

As of December 2016, the NNHF has supported 140 projects, 74 fellowships and 14 awards in 68 countries.

Programme type

- ⚙ Projects
- 🔑 Fellowships
- ★ Awards
- 1 Approved/ongoing
- 1 Completed

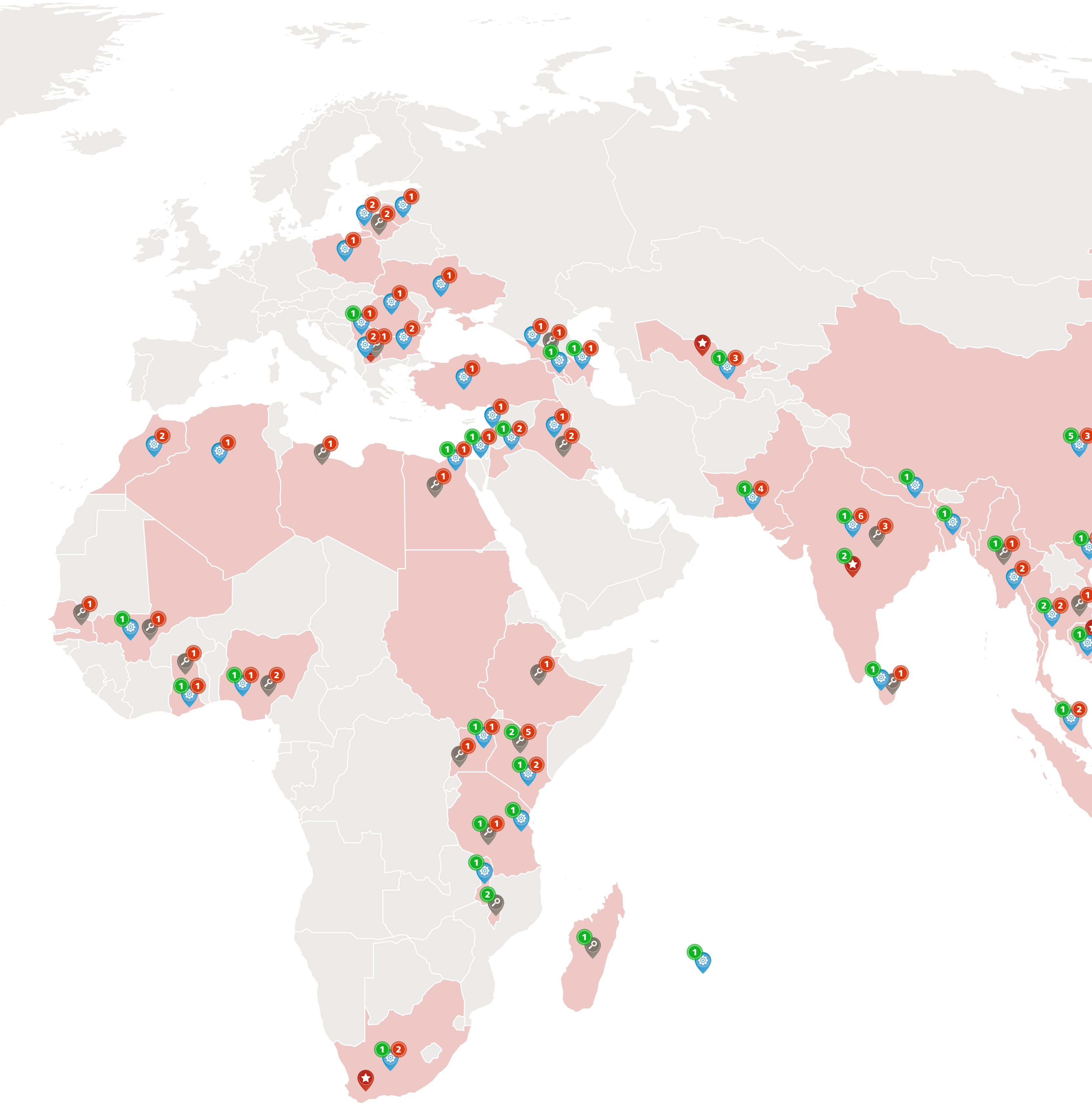
Programme labelling

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.

To find out more about all NNHF programmes and their status, visit the programmes pages of www.nnhf.org or download the quarterly updates from the homepage.

Note: NNHF supports initiatives in developing countries, preferably in the low, lower middle and upper middle income categories, as defined by the Organisation for Economic Co-operation and Development's Development Assistance Committee (OECD DAC) list. Furthermore, it can become active in transition economies as defined by the World Bank and IMF.

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About haemophilia and allied bleeding disorders

Haemophilia

Haemophilia is a hereditary bleeding disorder that affects males. Approximately 1 in 5,000 males is born with haemophilia. According to the World Federation of Hemophilia, only 25% have been identified, and only half of these have a confirmed diagnosis, meaning they know the type and severity of their haemophilia. Furthermore, only 25% of the global haemophilia population has access to adequate treatment. An estimated 75% of people with haemophilia live in the developing world. Patients with haemophilia A have either decreased, defective or absent production of the blood clotting protein, factor VIII. Those with haemophilia B have similar deficiencies with clotting factor IX. For people with haemophilia, bleeds often occur in the joints, particularly knees and ankles. Bleeds can also occur in the muscles, soft tissues, gastrointestinal tract or even the brain. Trauma, major surgery, tooth extractions or other minor surgery requires medical intervention to manage the associated bleeding. Without treatment bleeds are painful and can cause lasting damage and lead to impaired mobility. Haemophilia A and B can be treated by substituting the missing clotting factor by intravenous injection, either when bleeding occurs or prophylactic. The replacement clotting factors have typically been obtained from human plasma or, more recently, from recombinant technology.

von Willebrand Disease

Although more common than haemophilia, von Willebrand Disease (vWD) is often less serious. Many people with vWD have very mild symptoms. Often the first signs come during surgery or after a serious injury, when bleeding will not stop. Women with vWD tend to have more symptoms than men because of menstruation and childbirth. vWD is most often caused by genetic mutations that either impair the ability to make vW factor or lead to the production of defective forms of the protein. There are three different types of vWD with type 1 being the most common form, affecting 75% of those who have the disorder.

Rare Bleeding Disorders

Among inherited bleeding disorders, haemophilia A and B along with vWD, represent 95–97% of bleeding disorders. Deficiency of the remaining coagulation factors like fibrinogen, factor II, V,V+VIII, VII, X, XI and XIII are classified as Rare Bleeding Disorders (RBDs). They affect one person out of 500,000–2 million, depending on the deficient factor and are inherited in an autosomal recessive fashion. Heterozygous carriers may have less severe symptoms. The most common symptoms reported in all the deficiencies of any severity are mucocutaneous bleeding and bleeding during or after surgery. Excessive bleeding during the menstrual period and miscarriage is often found in women with deficiency of any coagulation factor, regardless of severity.

Novo Nordisk Haemophilia Foundation
Thurgauerstrasse 36/38, 8050 Zurich, Switzerland

www.nnhf.org
www.facebook.com/novonordiskhaemophiliafoundation

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