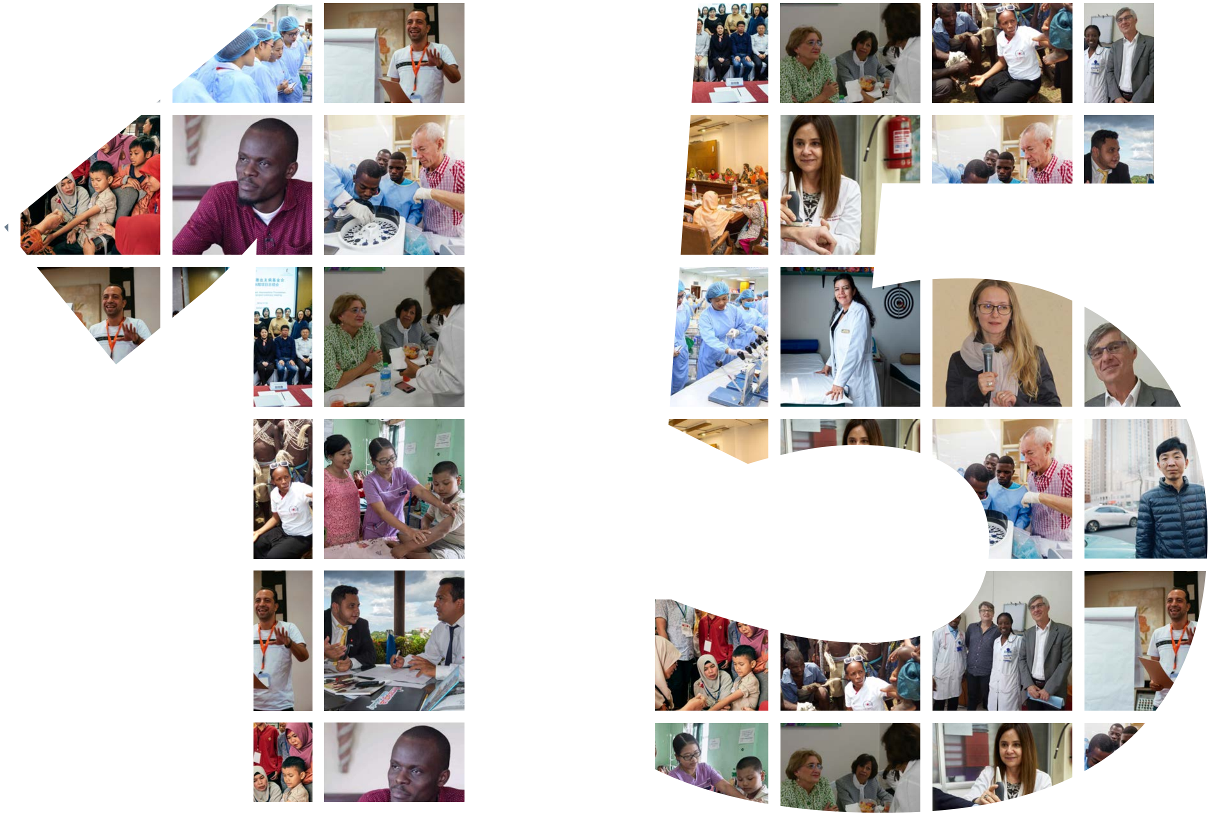

15 years, 15 stories

novo nordisk
haemophilia foundation

2020 marked the Novo Nordisk Haemophilia Foundation's 15th anniversary. The 15 inspirational stories in this book were published online as part of the NNHF '15 years, 15 stories' series and illustrate the impact that individuals associated with NNHF have had in facilitating better care for people with haemophilia, wherever they live. The stories in this book appear in the order they were shared online throughout 2020.

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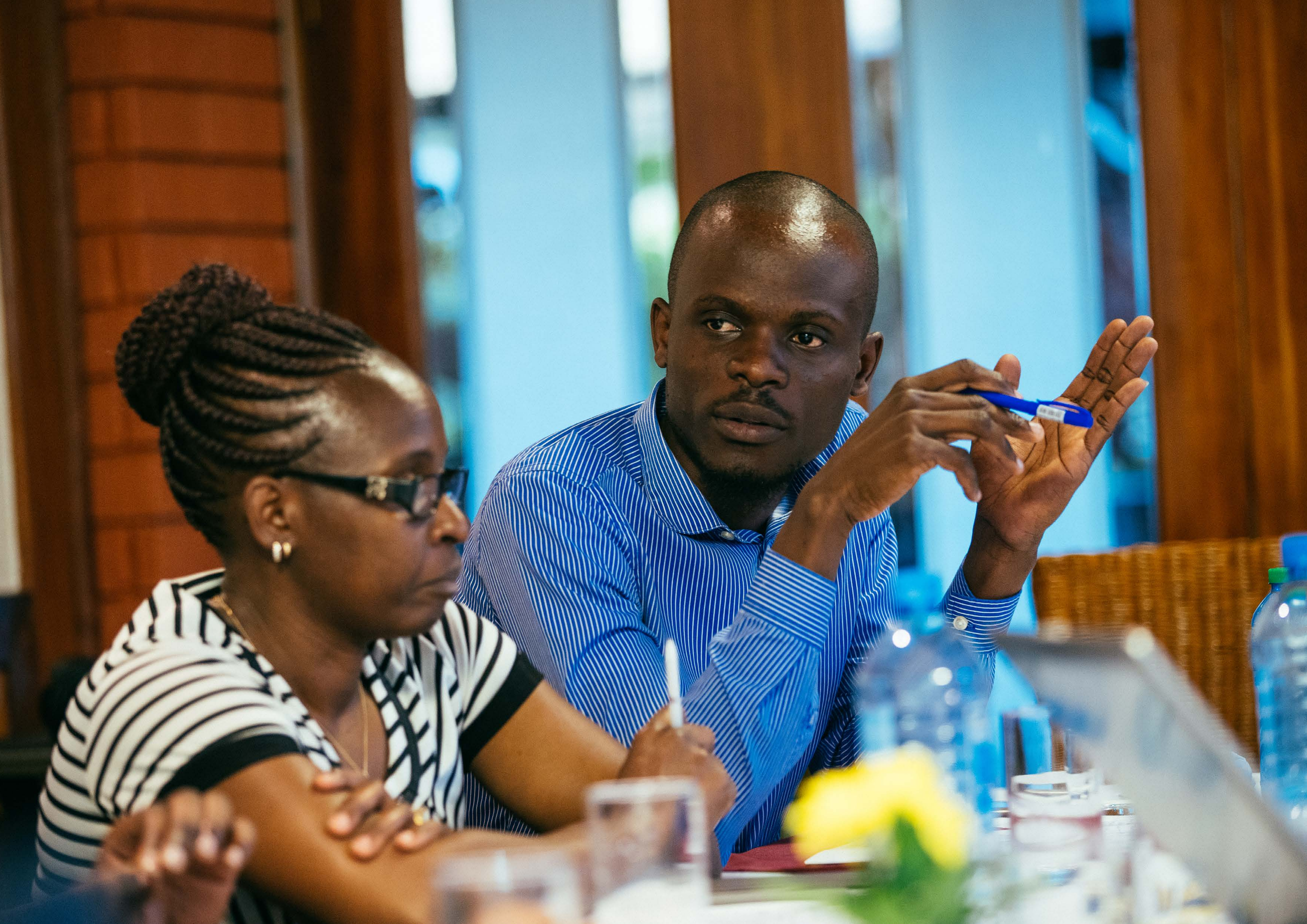
CARLOS MAUBE, KENYA

A TALE OF SELFLESS DEVOTION TO SUPPORT OTHERS



Born in Mombasa, Kenya, Carlos Maube grew up with a mystery condition that would define his childhood. From a very young age, he suffered a series of internal and external bleeds that seemingly never stopped. The doctors simply could not figure out what was causing them nor how they could be prevented.

Things came to a head one day when Carlos was admitted to hospital after vomiting blood. At a loss as to what to do, one of his doctors decided to carry out investigative surgery. It was a decision that would see Carlos fall into a coma for two weeks, when no precautions were taken to control his bleeding.

“The doctor who was taking care of me in the hospital told my mother that he didn’t know what else to do with my condition and, for that reason, he washed his hands of the case,” recalls Carlos, thinking back to that episode in his life. “I’d actually lost hope of living again because haemophilia had brought hell in my life and I gave up.”

A chance diagnosis

Fortunately for Carlos and his family, a nurse at the clinic witnessed what he was going through and recalled treating a boy with similar symptoms. She recommended the doctor take Carlos’ blood sample for a haemophilia test.

The result confirmed her suspicions: Carlos was diagnosed with haemophilia. Doctors adjusted his treatment accordingly and within days, there was a marked difference in the way Carlos’ blood was clotting. Soon he was out of hospital and, receiving appropriate care, able to lead a normal life.

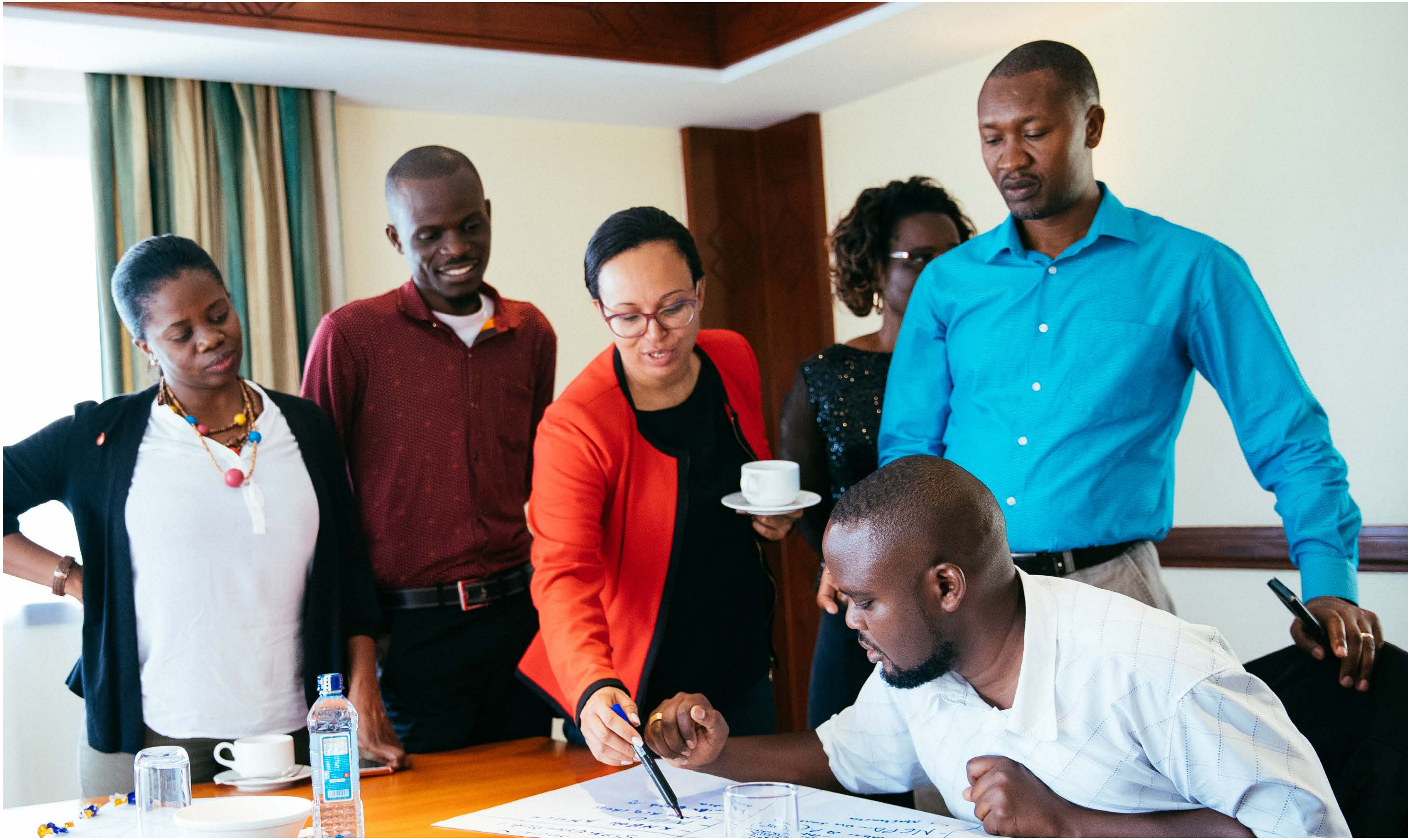
While most people would probably distance themselves from the suffering they’d experienced, Carlos embraced it for the greater good. It became his mission to help other people in Kenya who might be living through a similar experience.

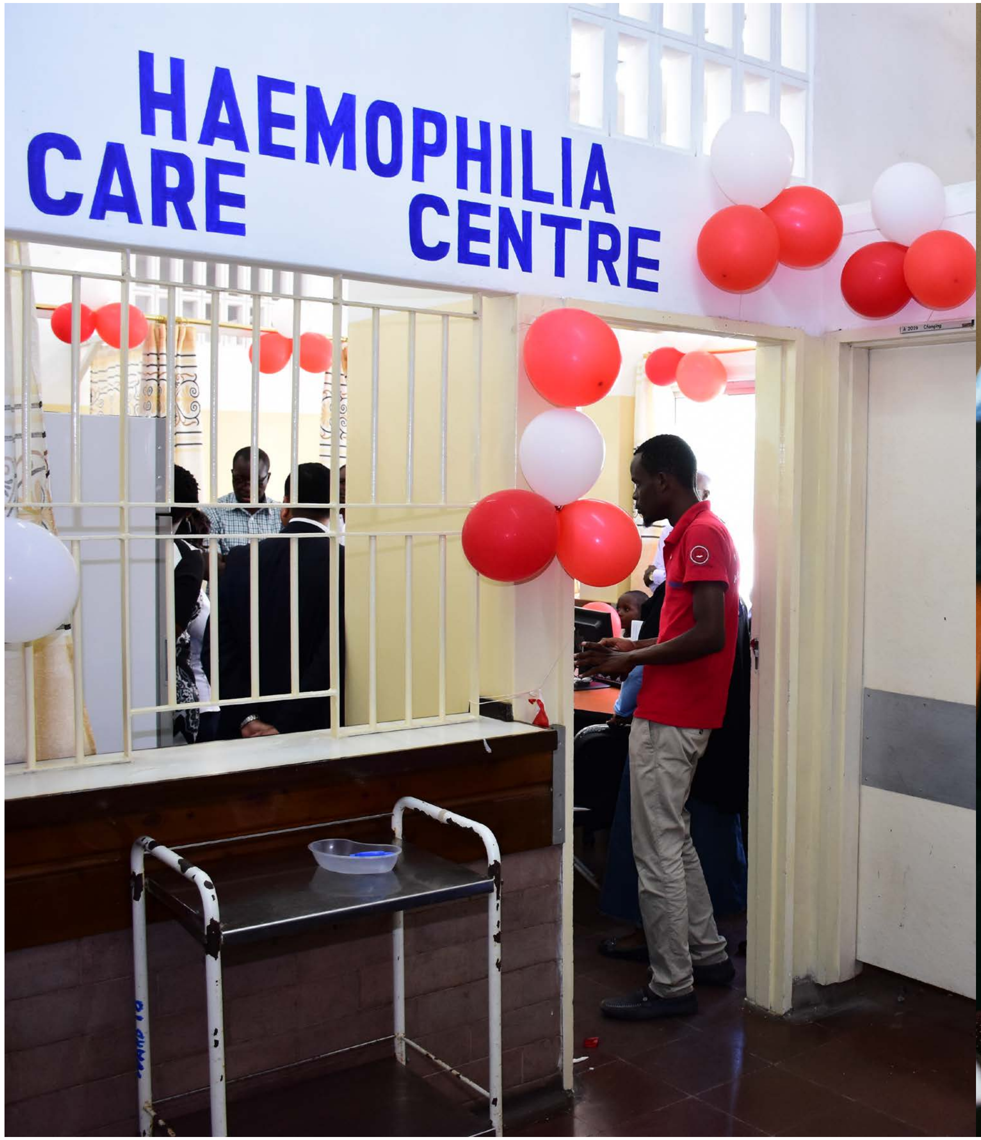
“After my own experience, I decided never will I allow someone on this earth – be it a child or an old person with haemophilia – to suffer. That’s why I decided I would volunteer with the Kenyan Haemophilia Association.”

A fundamental challenge

When Carlos was young, haemophilia care in Kenya was only available in Nairobi and Eldoret. But outside of these two cities, care remained basic and diagnosis rates remained low because of a lack of knowledge and appropriate equipment.

Even in cases where people had a diagnosis, they often had to travel long distances to receive care. Many people could only afford to travel in an emergency, which drastically increased the chances of disability and even death.




HAEMOPHILIA
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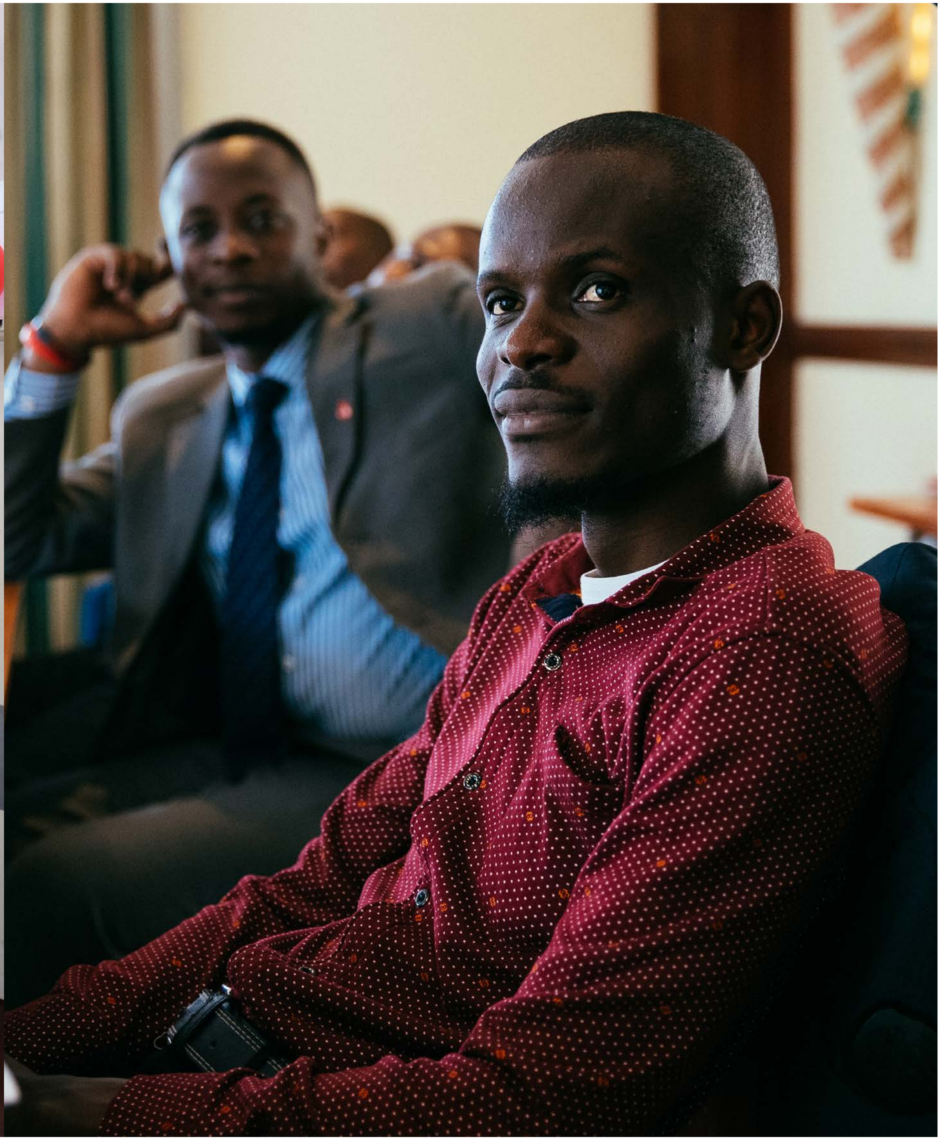


Working with the Kenya Haemophilia Foundation

To help address these challenges, Carlos became a volunteer at the Kenya Haemophilia Association, a NNHF project partner. He is an administrator for them and plays a key role in organising and delivering awareness raising events, clinic openings and educational sessions.

Since he started volunteering, Carlos has helped set-up the first haemophilia care clinic in Mombasa, Coast Province. The clinic has had a huge impact on those living with haemophilia in the region, who no longer have to travel vast distances to access care and pay the costs associated with that travel.

The newly established clinic also includes diagnosis facilities. Within the first year of the Kenya Haemophilia Foundation's work in Coast Province, the number of diagnosed patients had increased from three to 20.

But Carlos' ambitions aren't restricted to Kenya. He has also established himself as a spokesperson for haemophilia, helping set-up a regional youth group for Africa, where he hopes sharing his experiences and ideas will help improve care across the whole region.

Spreading knowledge for the greater good

Carlos serves as an inspiration to others, thanks to his selfless commitment to improving haemophilia care for other people in Kenya and beyond. His devotion to helping others shows us that even people who had once lost hope can become positive ambassadors for the condition.

Teaming up to reach out

His story is also an example of where knowledge sharing and collaboration can improve care drastically. If the nurse hadn't shared her experience, Carlos might never have received the proper diagnosis.

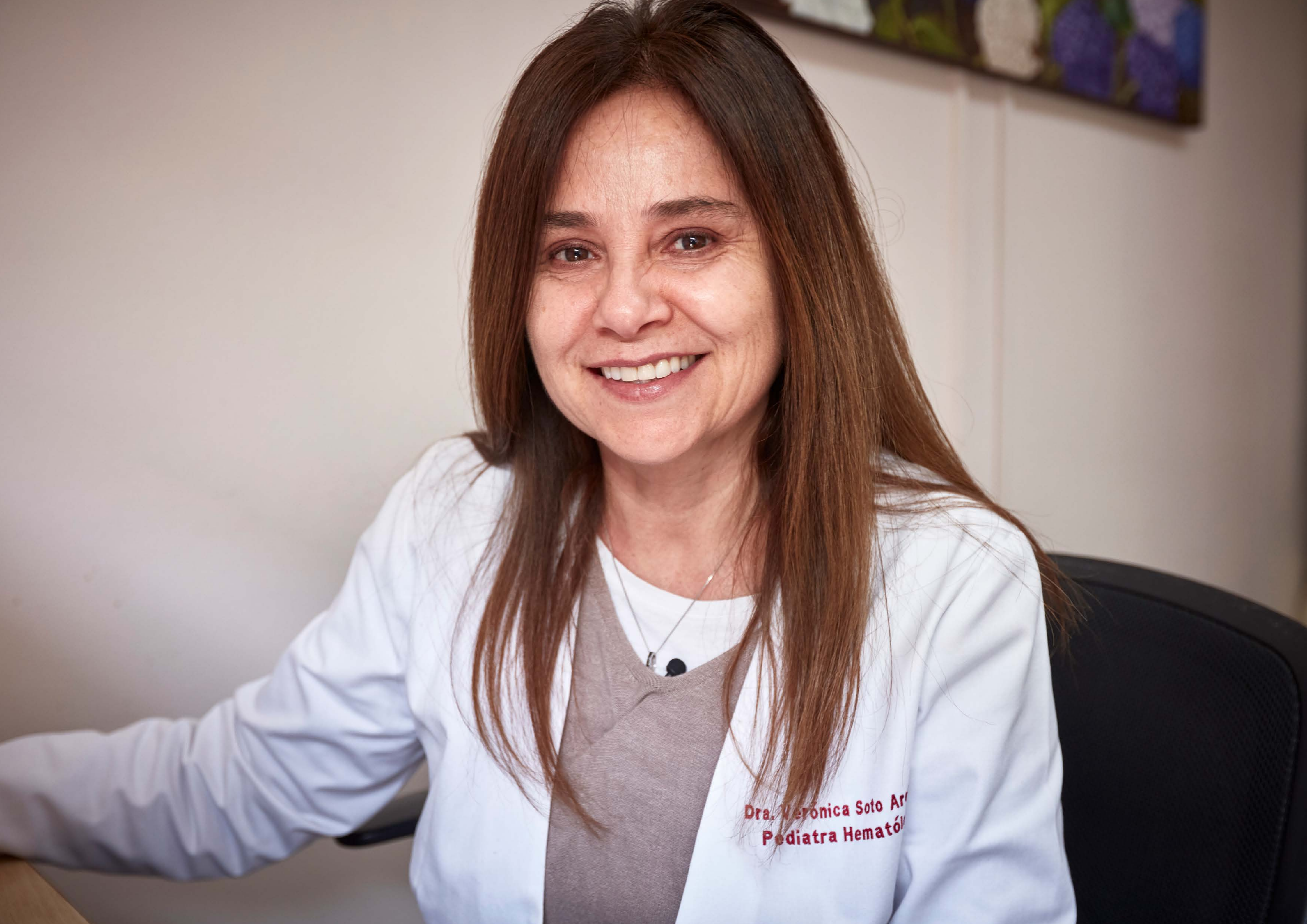
Recognising the importance of teaming up, the Kenya Haemophilia Association has brought together three associations which were not previously aligned in their activities and messages. Now that the Association is working as one, they are making clear strides in improving haemophilia care.

WATCH CARLOS' STORY

To watch Carlos' story please scan this QR-code
or visit nnhf.org/15-years-15-stories

DR VERÓNICA SOTO, CHILE

INNOVATION AND TECHNOLOGY LEAD TO TAILORED CARE


Dra. Verónica Soto Ar
Pediatra Hematól

Chile's Dr Verónica Soto had a vision for haemophilia care in the country, one that would mean all people with haemophilia had an accurate diagnosis, and received tailored care based on long-term monitoring of their condition and joint status. With the completion of the NNHF Chile 3 project, Dr Soto is part of a network that has brought the country closer to that vision.

Dr Soto, a paediatric haematologist from Santiago's Hospital Roberto del Rio, began collaborating with NNHF in 2009. This included undertaking the huge task of conducting laboratory assessments of people with haemophilia, alongside an evaluation of the medical knowledge of healthcare professionals and educational materials.

Addressing the challenges

The project team found that many people with haemophilia were not only misdiagnosed from the perspective of their coagulopathy, but also their type of haemophilia. In such cases, any treatment being prescribed would be ineffective.

The team therefore set about creating a national registry to collect the revised data. Alongside this, educational materials were developed for families and healthcare professionals, and healthcare professionals were guided on how to evaluate and monitor their patients and the efficacy of their treatment regimens.

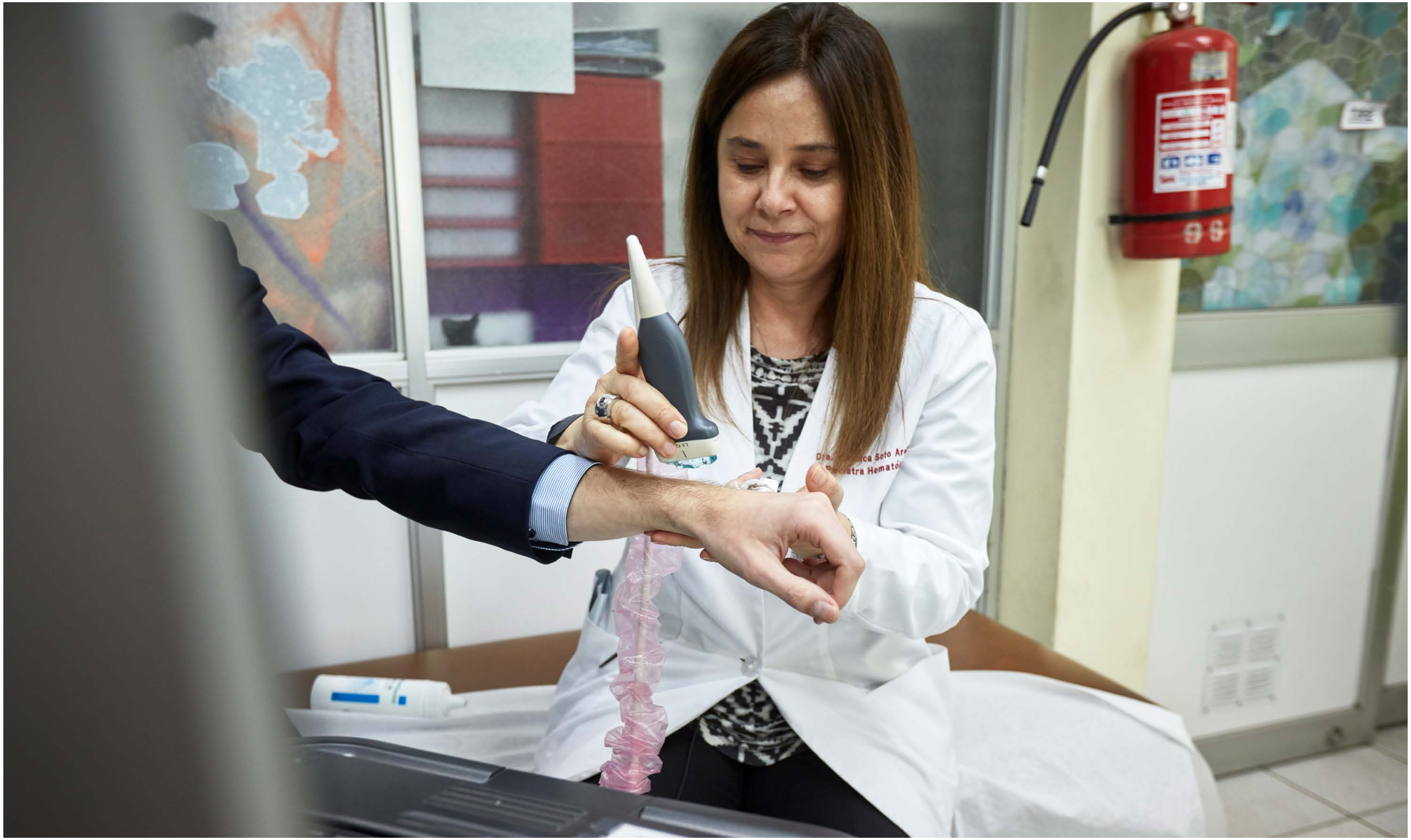
Following this project, the team identified two further opportunities to create change. Firstly, varied standards of multidisciplinary care were resulting in joint damage and disability. Secondly, they felt that moving the registry to an online platform would help overcome the difficulties faced when people with haemophilia transitioned from paediatric to adult care, or if they moved region. An online registry would also be easier to use than an Excel based one and would provide a more efficient way of collecting and maintaining up-to-date national data for advocacy activities.

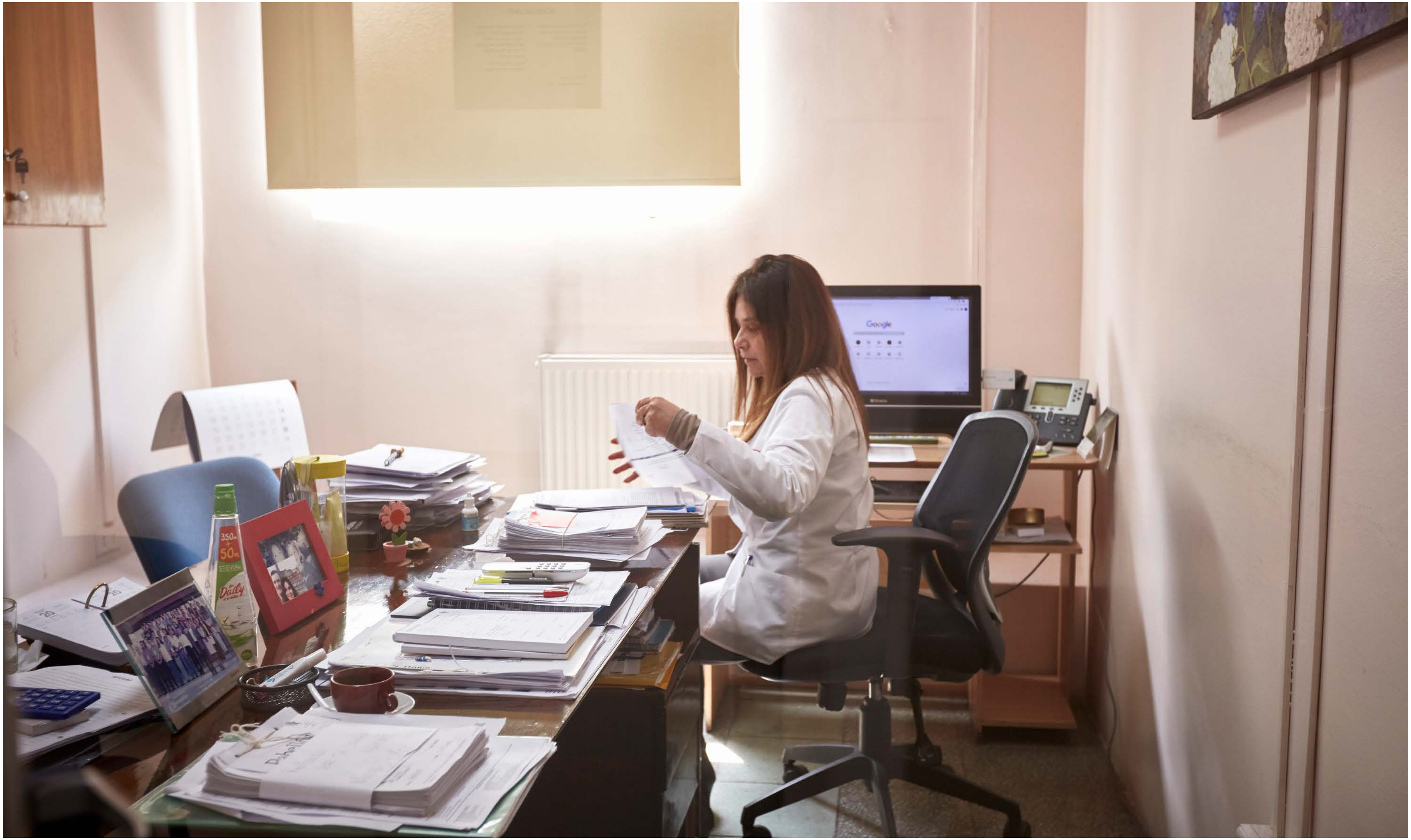
Monitoring health outcomes through technology

Dr Soto's follow-up project therefore involved building up a team to utilise technology to create an innovative approach to care delivery and management. Two of the key outcomes from this project are a mobile app and an online registry.

The mobile phone app focuses on musculoskeletal (MSK) health, prescribing balance based exercises as a form treatment. The app rates the users' performance as they undertake these exercises, so that their physiotherapist can then adapt the exercise programme accordingly, without having to wait until the monthly consultation.

The app is already producing positive results. Jaime Ricardo Tapia, who has severe haemophilia A, has been using it for 11 weeks: "It has helped me to be more rigorous when it comes to doing the exercises...It also





helps me to want to improve more every time, and you know instantly if you are not doing the exercise well" he explained.

The user-friendly online registry that was created will, alongside the mobile phone app, help track arthropathy and joint health, so that care and treatment which help prevent MSK complications can be prescribed. The development of the registry and the mobile app also serves as a stepping stone for the development of future complementary tools, as further needs of healthcare professionals and people with haemophilia are identified.

Dr Soto worked closely with Dr Juan Cristobal Morales from Hospital Sotero del Río to develop the registry. As a family doctor working with adults, Dr Morales's experience complemented that of Dr Soto's paediatric haematology background; "He was able to provide a different perspective, so we've been able to come to agreements and organise all issues as they are most relevant to patients as a whole. Which is why it's so important to work with individuals who have a different viewpoint than your own" explains Dr Soto.

Accurate data leading to tailored care

The online registry is now being rolled out across Chile, with 34 centres aiming to use it from early 2020. Once implemented, people living with haemophilia will receive care and treatment that is tailored to their individual needs, whilst the medical community will have long-term data that will ensure they and government authorities acquire the appropriate resources required for effective haemophilia care. The registry was developed with a view to being utilised not just across Chile, but potentially the whole region. "Indeed, if as a country, or as a Latin American region, we could establish the same registry everywhere, this would be a tremendous achievement," concludes Dr Soto.

Award winning innovation and collaboration

The innovative and collaborative approach taken by the team has resulted in their Chile 3 project being named the NNHF Project of the Year 2020. This award goes to the project which has demonstrated outstanding dedication, excellent project management, stakeholder involvement and sustainable impact.

WATCH DR SOTO'S STORY

To watch Dr Soto's story please scan this QR-code
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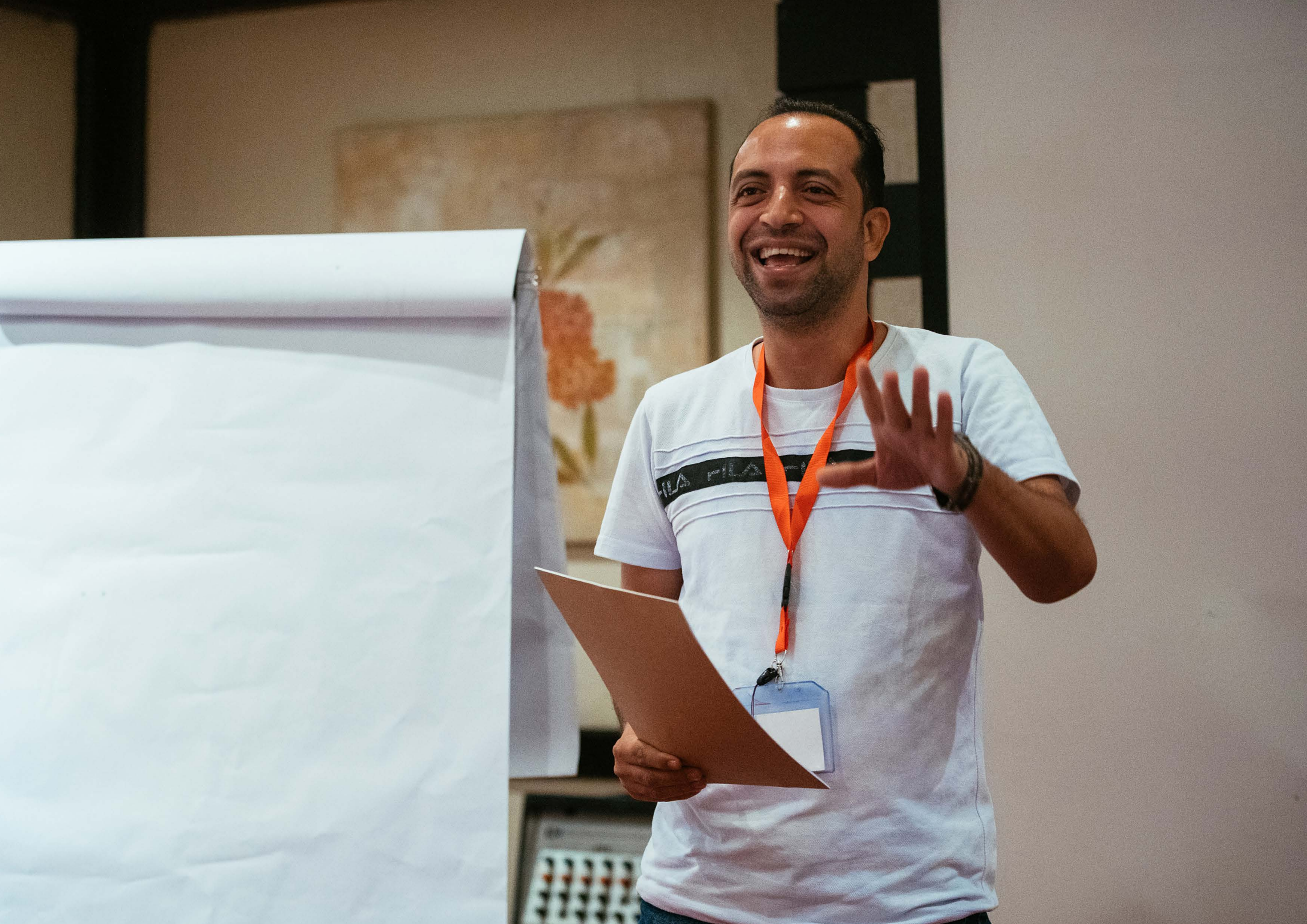
MOHAMED ABOHAGAR, EGYPT

CREATING A NETWORK FOR CHANGE THROUGH SOCIAL MEDIA


FILA FILA

Throughout his life, Mohamed Abohagar has taken a positive view of haemophilia. Despite missing many days of school due to bleeds, he went on to gain a university degree. His positivity today hides the trauma he went through 14 years ago: in 2006, Abohagar's younger brother, who also had haemophilia, passed away following a brain haemorrhage. This experience proved to be a turning point for Abohagar.

Abohagar recalls the day he took his brother to the hospital with a brain bleed. Once there, he found there was neither the knowledge nor the treatment that could help him. In the period after losing his brother, he realised he didn't know anyone he could reach out to or who could relate to what he was going through. By 2010, this sense of isolation led to the idea of creating a group for people with haemophilia.

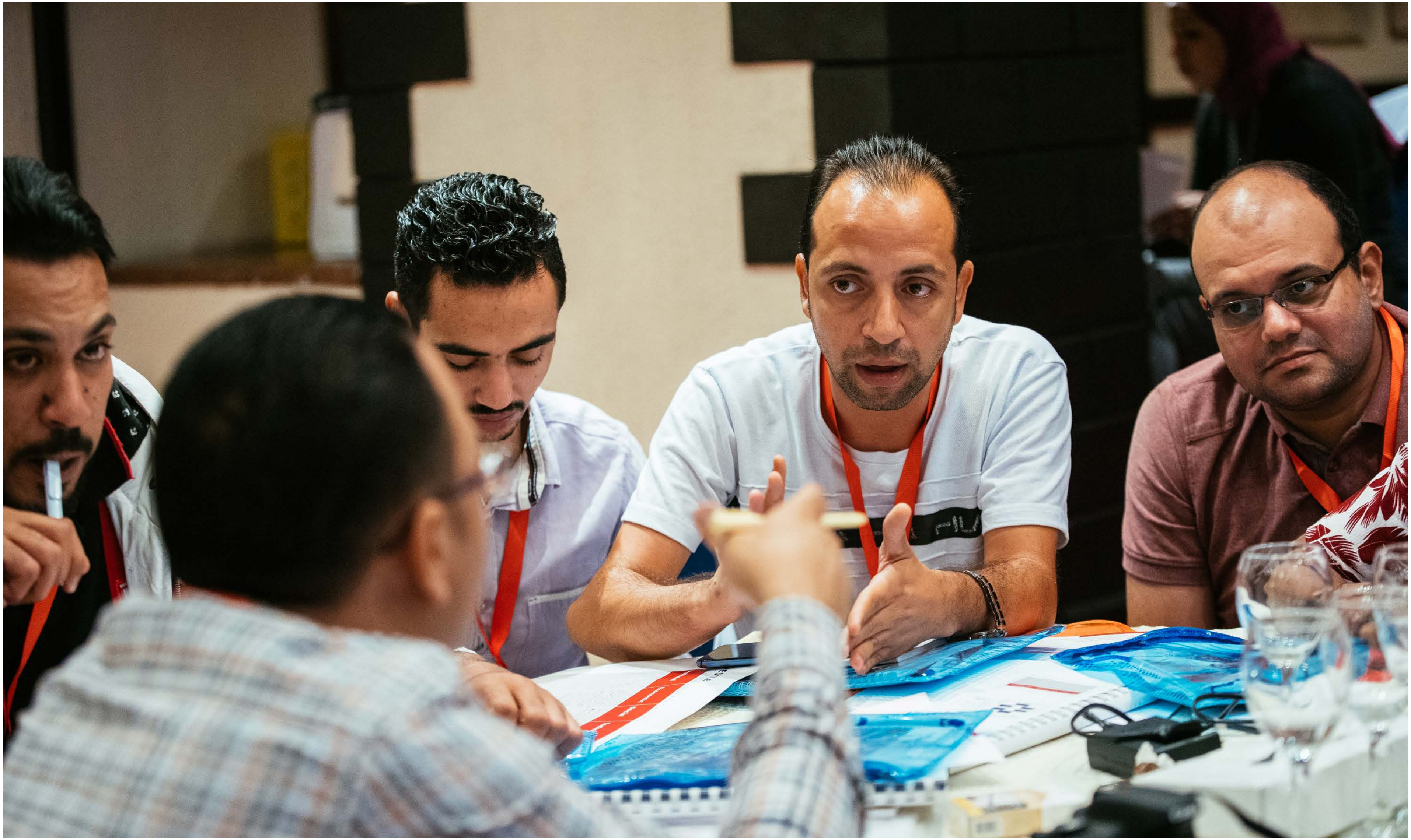
The power of social media

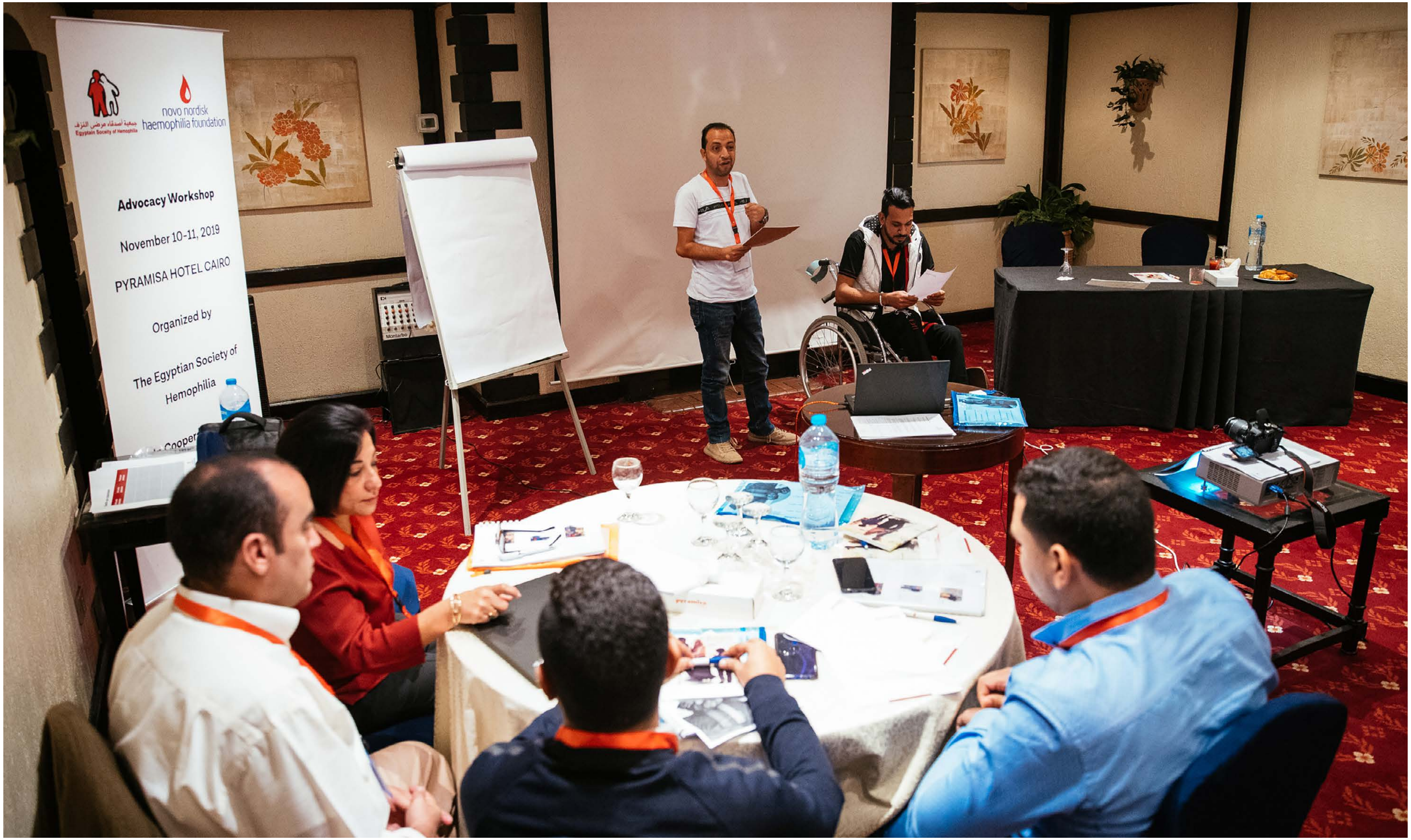
It was important to Abohagar that the group should be accessible to people across Egypt. As a regular user of social media, Abohagar was aware of its power in spreading messages and creating change, prompting him to turn his thoughts to Facebook. There, he found there was a small haemophilia group based in Alexandria. After numerous talks and visits, Abohagar joined with them to seek ways to attract new members, soon doubling their numbers from 10 to 20. Over time the group expanded to include more and more provinces. Today, the group encompasses more than 5,000 members from all of Egypt's 27 provinces.

The Facebook group is more than a support forum for its members. Members have agreed roles and responsibilities – for example one member translates the latest scientific research into haemophilia to ensure all members can keep informed about the condition. The group also raises awareness of haemophilia beyond its members. As well as flagging issues and topics through hashtags, its activities enabled it to connect with more traditional forms of media, leading to interviews with some of the biggest names in Egyptian broadcasting.

Raised awareness leads to action

Their combined efforts drew the attention of two key stakeholders: medical representatives from the Egyptian Society of Haemophilia (ESH) and healthcare authorities. In 2013, the first NNHF supported project in Egypt increased the active involvement of people with haemophilia in the organisation. The Facebook page built on this by providing a direct route of communication between the medical community and those with haemophilia across Egypt, enabling them to tailor ESH efforts to improve the knowledge of healthcare professionals. "Because the ESH's doctors started to know about the problems posted on the page, they started to set a plan...to organise medical or educational convoys for both patients and doctors," explains Abohagar. He also believes that the awareness created amongst healthcare authorities has had a substantial impact in creating improvements to haemophilia care policies between 2011 and 2019.




جمعية أصدقاء مرضى النزف
Egyptian Society of Hemophilia
novo nordisk
haemophilia foundation
Advocacy Workshop
November 10-11, 2019
PYRAMISA HOTEL CAIRO
Organized by
The Egyptian Society of
Hemophilia

It is clear to Abohagar that the success of the group is due to its members passion for working hand in hand to drive change. After two members attended a NNHF leadership skills workshop in 2018, they have attracted and trained many more youth leaders from across Egypt through the NNHF Egypt 3 project. "From all provinces there appeared young adults who were motivated to help and they started spreading in provinces to raise awareness."

A story of friendship

Abohagar is testament to the importance of sharing stories within the haemophilia community and beyond, "As a person with haemophilia, I usually talk about what I see myself. Because I am an eyewitness, I have to share my testimony."

One of the unforeseen outcomes of this group is the creation of not just a network, but of friendship. Before his brother passed away, Abohagar describes himself as having little involvement with haemophilia. Now, when talking about the haemophilia community in Egypt, he proudly proclaims, "Thankfully we're now so interlinked...Whatever province I visit in Egypt, my brother is replaced by ten wherever I go."

WATCH MOHAMED'S STORY

To watch Mohamed's story please scan this QR-code
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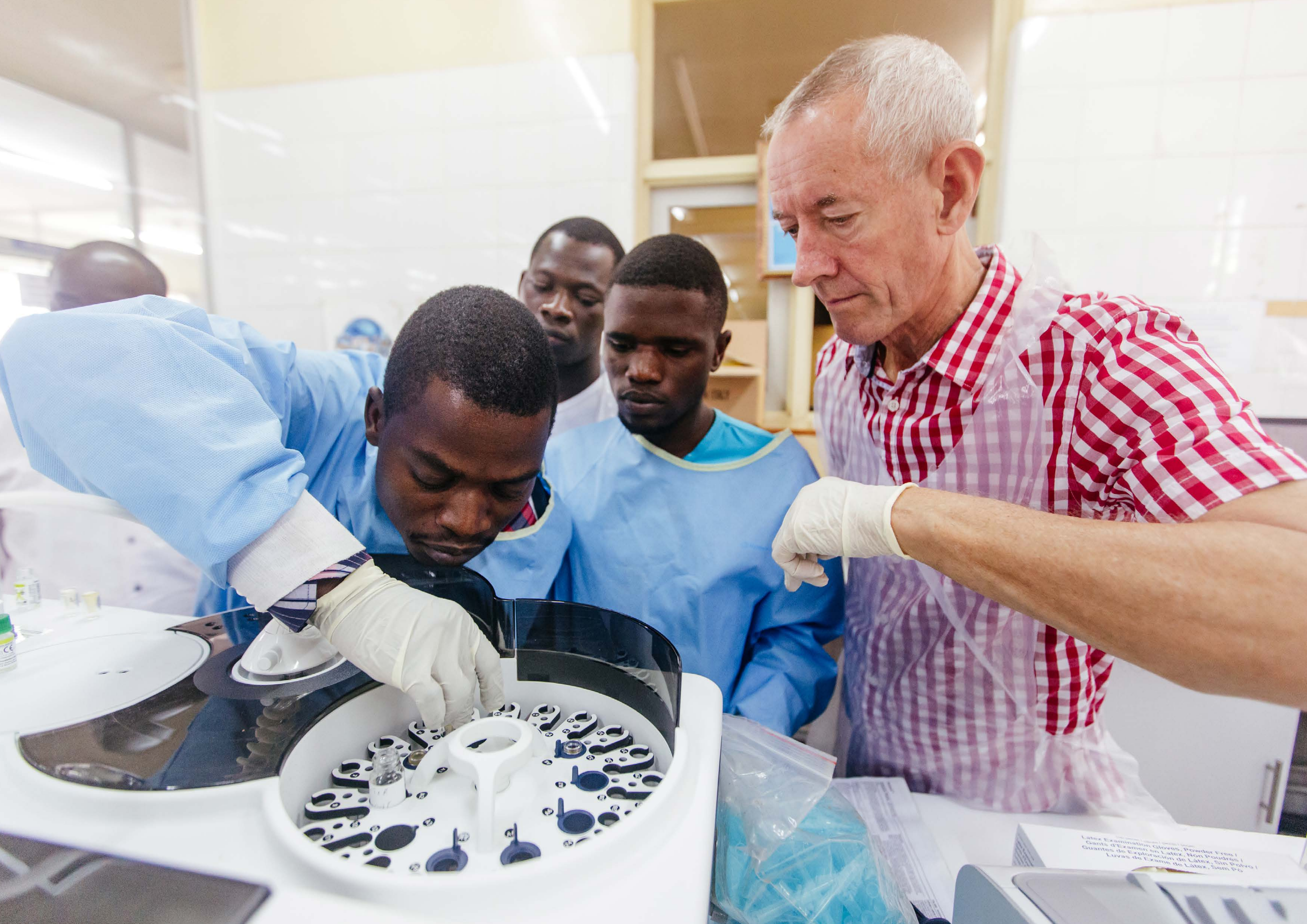
ANGUS MCCRAW

TAKING ACTION TO IMPROVE DIAGNOSIS


Latex Examination Gloves, Powder Free /
Gants d'Examen en Latex, Non Poudres /
Guantes de Exploración de Látex, Sin Polvo /
Luvas de Exame de Látex, Sem Pó

When biomedical scientist Angus McCraw began collaborating with the NNHF in 2011, his aim was to address a very specific set of challenges: the lack of skills, personnel and facilities to diagnose haemophilia in developing countries. Today, Angus has trained more than 190 lab technicians from 31 countries and provides ongoing advice to NNHF partners.

The consequences of a lack of adequate diagnosis are numerous. People living with haemophilia do not realise they have the condition. For those that are diagnosed, their diagnoses can be inaccurate, leading to incorrect care and treatment. Without the data to demonstrate accurate numbers of people with haemophilia, healthcare authorities are reluctant to allocate resources to ensure appropriate care.

Combining expertise with a tailored approach

Angus started working with the NNHF to develop a training programme focused on lab diagnosis in developing countries, explaining, “the people in these countries benefit from training because they very often don’t have the opportunity to have a specific training in the field of diagnosis of haemophilia and indeed the diagnosis of bleeding disorders.”

As a biomedical scientist, Angus has the technical expertise to deliver the training. Beyond this, Angus adapts his approach to suit the environments of those receiving the training. In some countries for instance, the frequency of power cuts could be problematic, therefore he advises some partners to purchase freezers capable of lower temperatures than those used in developed countries, to ensure reagents remain at the optimum temperature. He undertakes research before each training to understand which equipment and computer systems are available to participants.

Sustainable and tangible impact

Angus knows that sustainability is key to creating long-term change. He ensures those he trains have the knowledge and skills to go on to train others in their countries. From his long experience volunteering with NNHF, he has many post-training success stories to share, from numerous countries across continents: China has introduced an external quality assessment scheme for its labs; after training with Angus in South Africa, David Ofusu from Ghana arranged a locally led workshop covering six regions of his home country; Sem Samey is now training his peers in Cambodia following his training.

Those he has trained frequently comment on Angus’ patience, humour and kindness, as well as the tangible impact of the training: “Thanks to his efforts, we are now able to diagnose haemophilia cases in Malawi. This has literally saved the lives of many people with haemophilia, not to mention the improvement in the health-related quality of life of all confirmed cases,” says Dr Yohannie Mlombe from Lilongwe, Malawi.

Although he retired from his role at the UK’s Royal Free Hospital in London seven years ago, Angus has no intention of slowing down his efforts to improve diagnosis. “My dream for haemophilia is for all countries across the developing world to be able to diagnose haemophilia and bleeding disorders with confidence and to give a unified approach to diagnosis.”

WATCH ANGUS’ STORY

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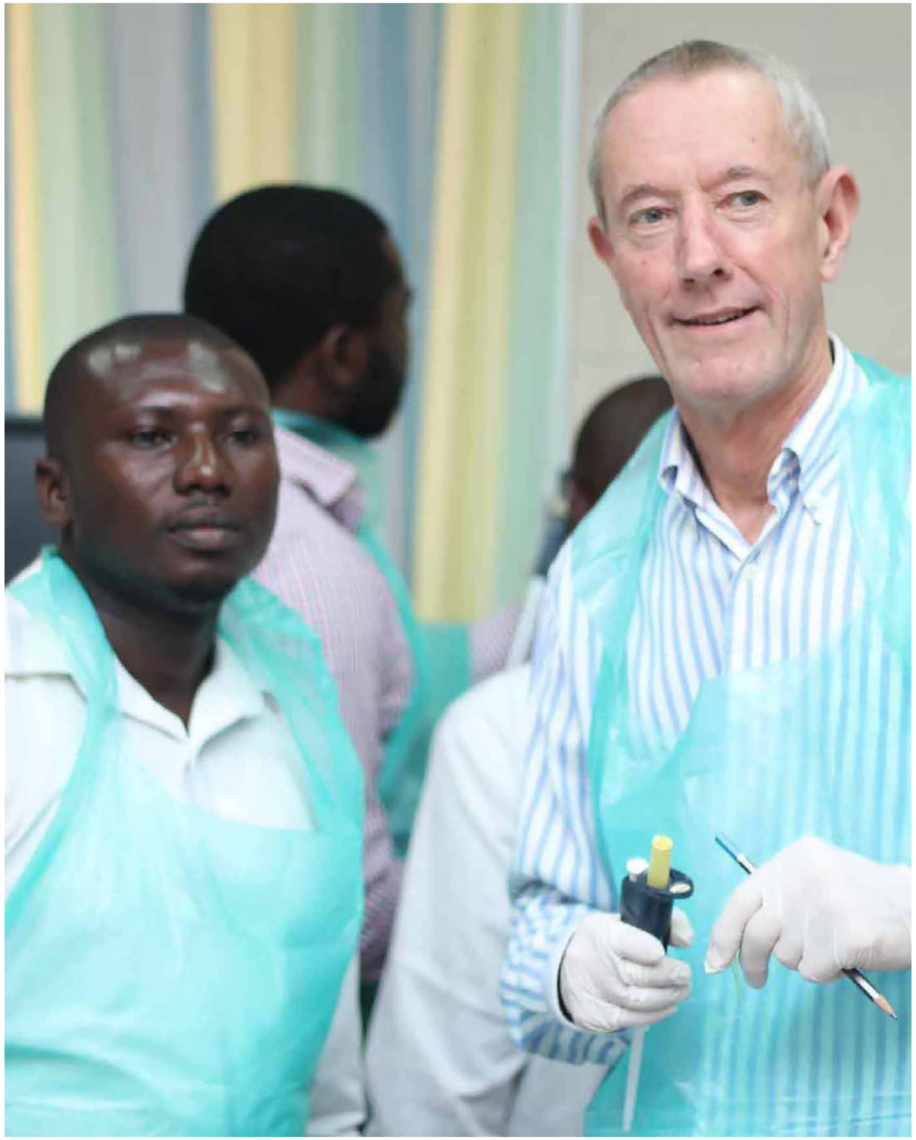
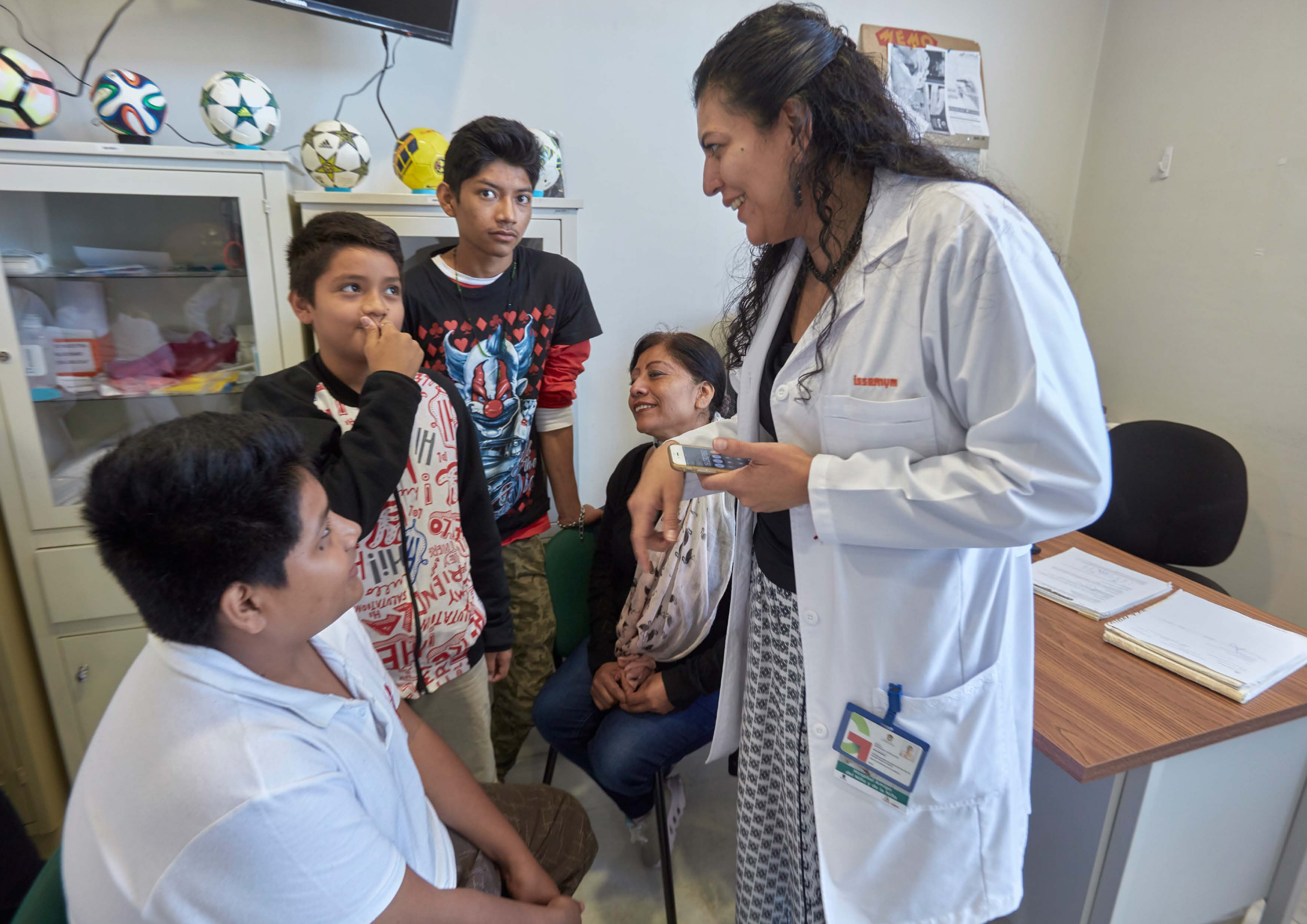


DR CECILIA RODRÍGUEZ CASTILLEJOS, MEXICO

INSPIRED TO IMPLEMENT MULTIDISCIPLINARY CARE


MEMO
issemym

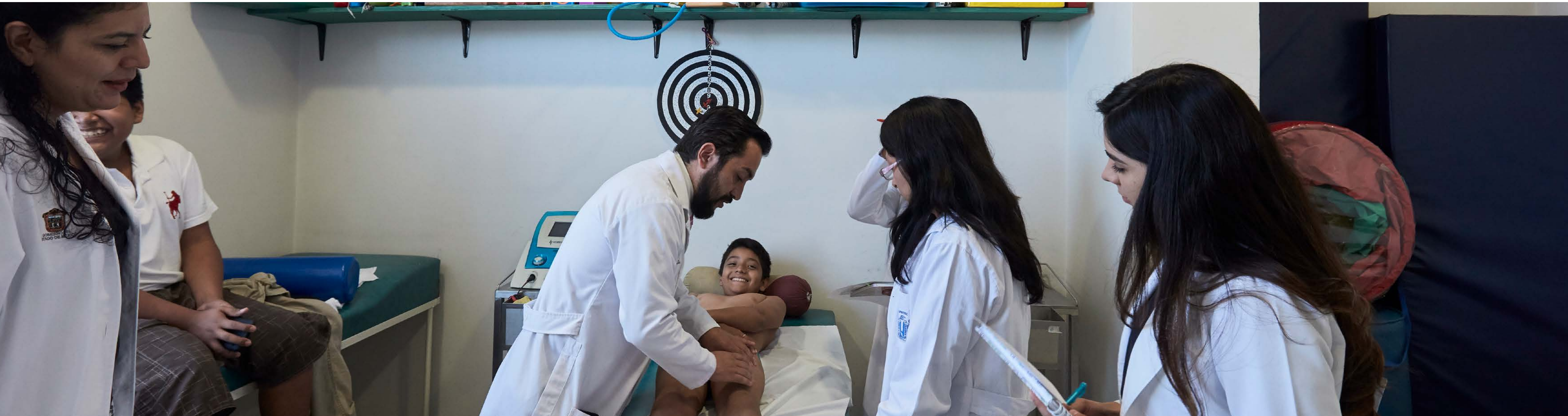
In 2016, Dr Cecilia Rodríguez Castillejos from the State of Mexico's Maternal-Infant ISSEMyM hospital was clear that a multidisciplinary team would bring multiple benefits to people with haemophilia.

Firstly, Dr Rodriguez Castillejos wanted haemophilia care to be holistic. This meant looking at what care would benefit the whole family as well as the individual, and at which other specialities could contribute to the person's health and well-being. She wanted to improve the confidence of healthcare professionals who were sometimes uncertain on how to effectively provide care for people with haemophilia. Most importantly her objective was to ensure that people with haemophilia, who were sometimes travelling for up to four hours to reach the hospital, were gaining the maximum benefit from each visit and avoiding multiple trips wherever possible.

Learning across borders

To find the best way to achieve these outcomes, Dr Rodríguez sought inspiration from elsewhere in Mexico and further afield. "I had the chance to visit the UT Physicians Gulf States Hemophilia and Thrombophilia Center in Houston, with Dr Escobar, and I learned that patients stayed in one place but the physicians rotated instead. In Tabasco, it is designed so that all doctors converge around a patient. In Monterrey there's a designated clinic day, and on that day, all specialists see patients with haemophilia. I just went looking for the arrangement that would fit us best. Kind of like searching for a dress!" she recalls.

Through the Mexico 5 project activities which started in 2018, Dr Rodríguez is implementing a single consultation model, where multiple trained specialists consult with the person with haemophilia and family members in one single visit, based on this search. She has continued to utilise expertise from outside of the state. For example,



Lic Marion Echenagucia from Venezuela trained lab technicians in Mexico, a physiotherapist, social workers and nurses were trained at the University Hospital in Monterrey and most recently, Dr Rodríguez and an orthopaedist received training at UNICAMP in Campinas, Brazil.

Optimised outcomes for people with haemophilia

The single consultation model is proving beneficial for all concerned. "We have optimised time for ourselves, time for patients and in general, time for the institution," explains Dr Rodríguez. As for people with haemophilia and their parents: "They have liked it a lot. The moment we introduced the idea, it was received with immediate acceptance. For them it meant less travel time, they knew that in a single appointment they'd be able to integrate several visits into one. When their treatment is taken to multidisciplinary meetings, patients can hear stories from other people in their same condition. They can meet adults who have become professionals and have their condition. This helps them create a goal."

WATCH DR RODRIGUEZ'S STORY

To watch Dr Rodriguez's story please scan this QR-code
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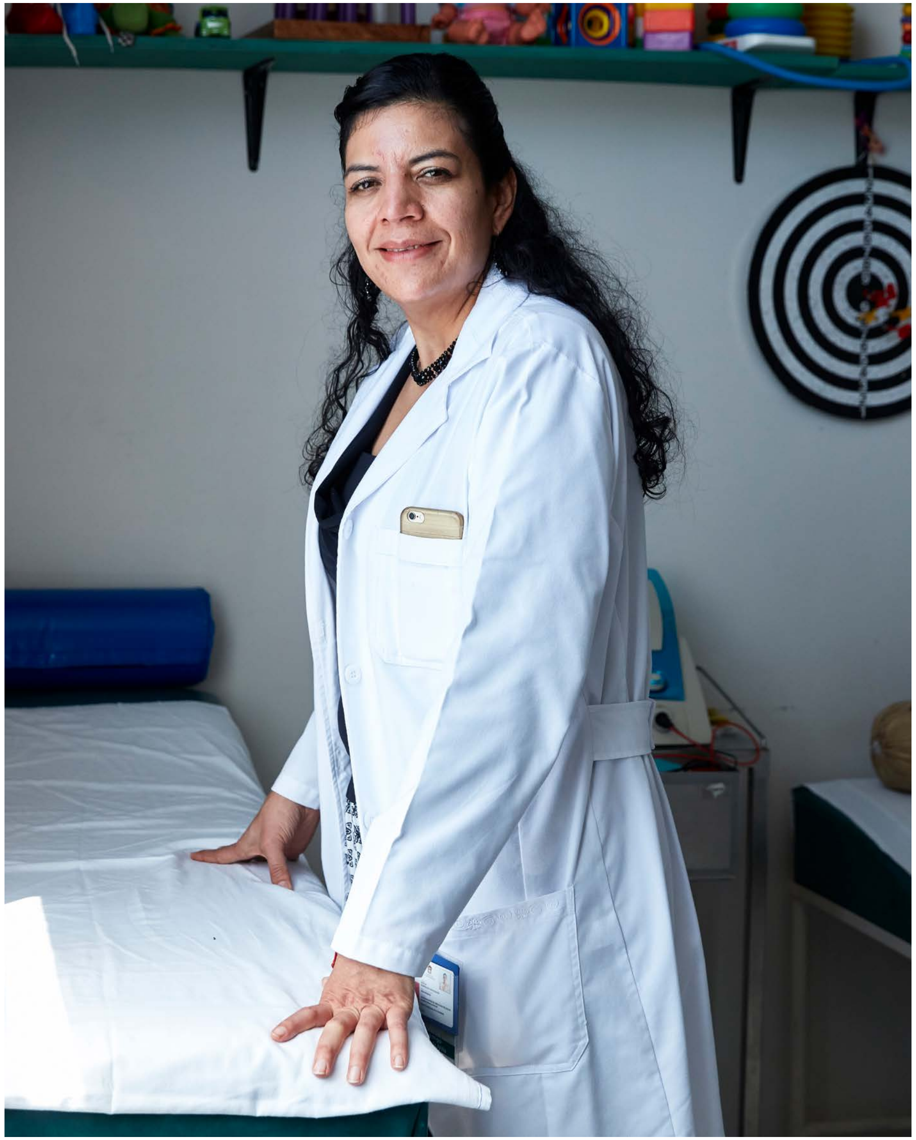
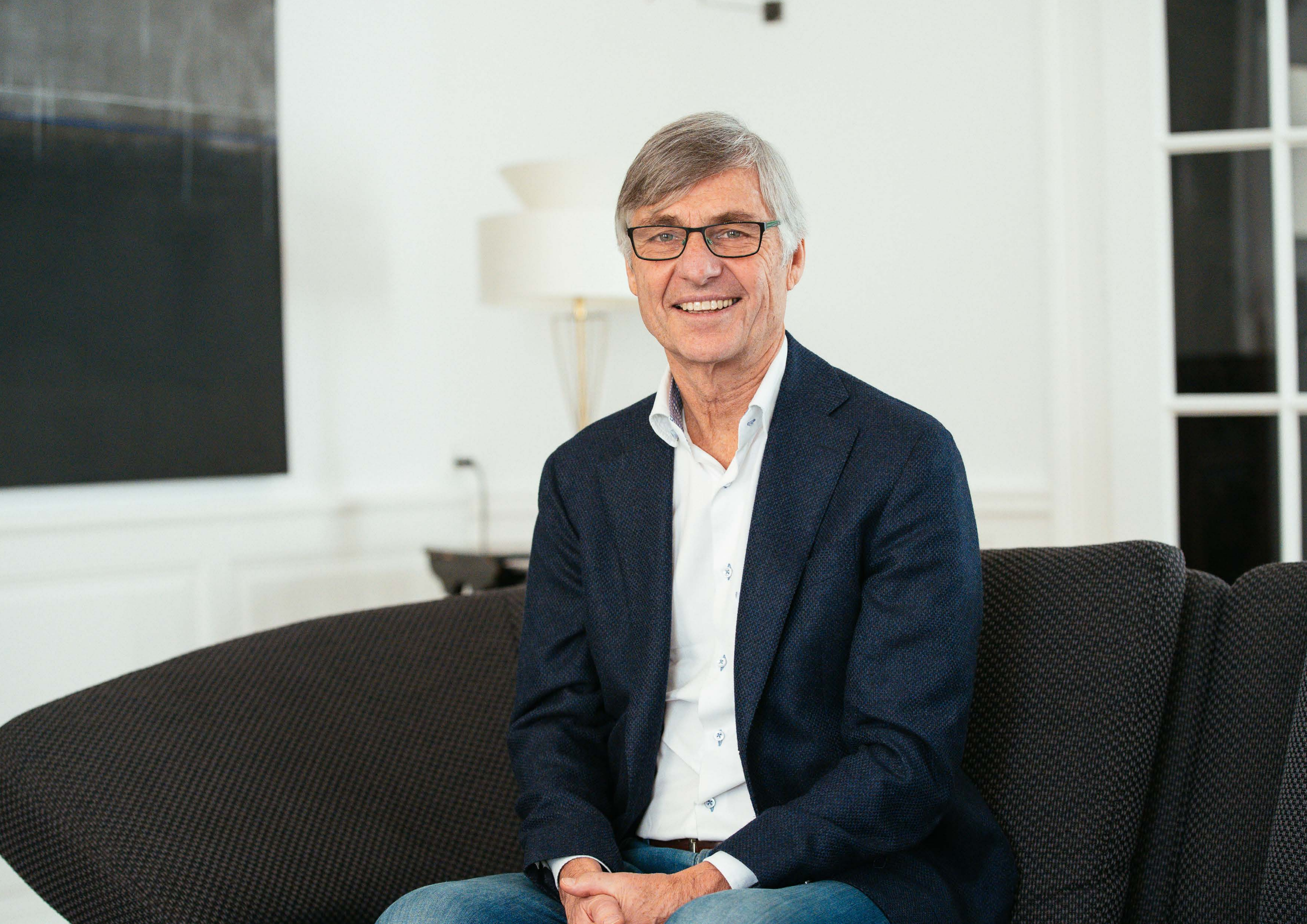


PROF PHILIPPE DE MOERLOOSE, RWANDA

PARTNERING TO ENHANCE IMPACT



For more than ten years, Prof Philippe de Moerloose has played a fundamental role in establishing partnerships that improve haemophilia care in Africa. Bringing his experience to the NNHF Rwanda project, Prof de Moerloose emphasises the importance of a multi-partner collaborative approach.

Taking a partnership approach to haemophilia care comes naturally to Prof de Moerloose: “Haemophilia and bleeding disorders are a special area. As it’s a lifelong condition, we get to know our patients. Close relationships are built, and healthcare professionals and people with haemophilia are viewed as equals,” he explains.

Keen to apply this approach in Rwanda, Prof de Moerloose is one of a team of collaborators working to improve knowledge and diagnosis in the country and to decentralise care beyond the capital city of Kigali.

Joining forces for long-lasting impact

Prof de Moerloose is a representative of the French African Alliance for the Treatment of Haemophilia (AFATH), which partners with French speaking African countries to improve haemophilia care. In Rwanda, AFATH’s role includes the education of healthcare professionals and people with haemophilia, and the development of quality diagnosis. “AFATH was really created with the objective to help with education and diagnosis at a certain level, but with the idea that other international and local organisations will take the lead after us to ensure sustainability.”

AFATH joined forces with the Rwanda patient organisation, NNHF and Save One Life, an organisation providing aid to people with haemophilia in developing countries, to build the strategy and skills required to improve haemophilia care.

Activities were identified as complementary to those of the World Federation of Hemophilia (WFH), which was supplying humanitarian aid in Rwanda, and who would provide support for education, diagnosis and registry on a wider scale once the Rwandan patient organisation was registered as a National Member Organisation.

“Sometimes we see cases of international organisations starting activities in developing countries, it lasts one or two years and after that they leave and everything stops. By involving the local patient organisation and healthcare professionals from the start, and empowering them to become a WFH member, we’re ensuring the impact of what we do lasts in the long-term.”

Building skills across borders

To build the skills of the local Rwandan team, Prof de Moerloose introduced them to the Centre de Traitement de l’Hémophilie Hôtel Dieu in Nantes, France. Supported by NNHF, three healthcare professionals and a representative from the patient organisation travelled from Rwanda to undertake training and experience sharing in Nantes. The NNHF project also provided laboratory equipment to the team in Kigali to begin the process of establishing quality diagnosis.

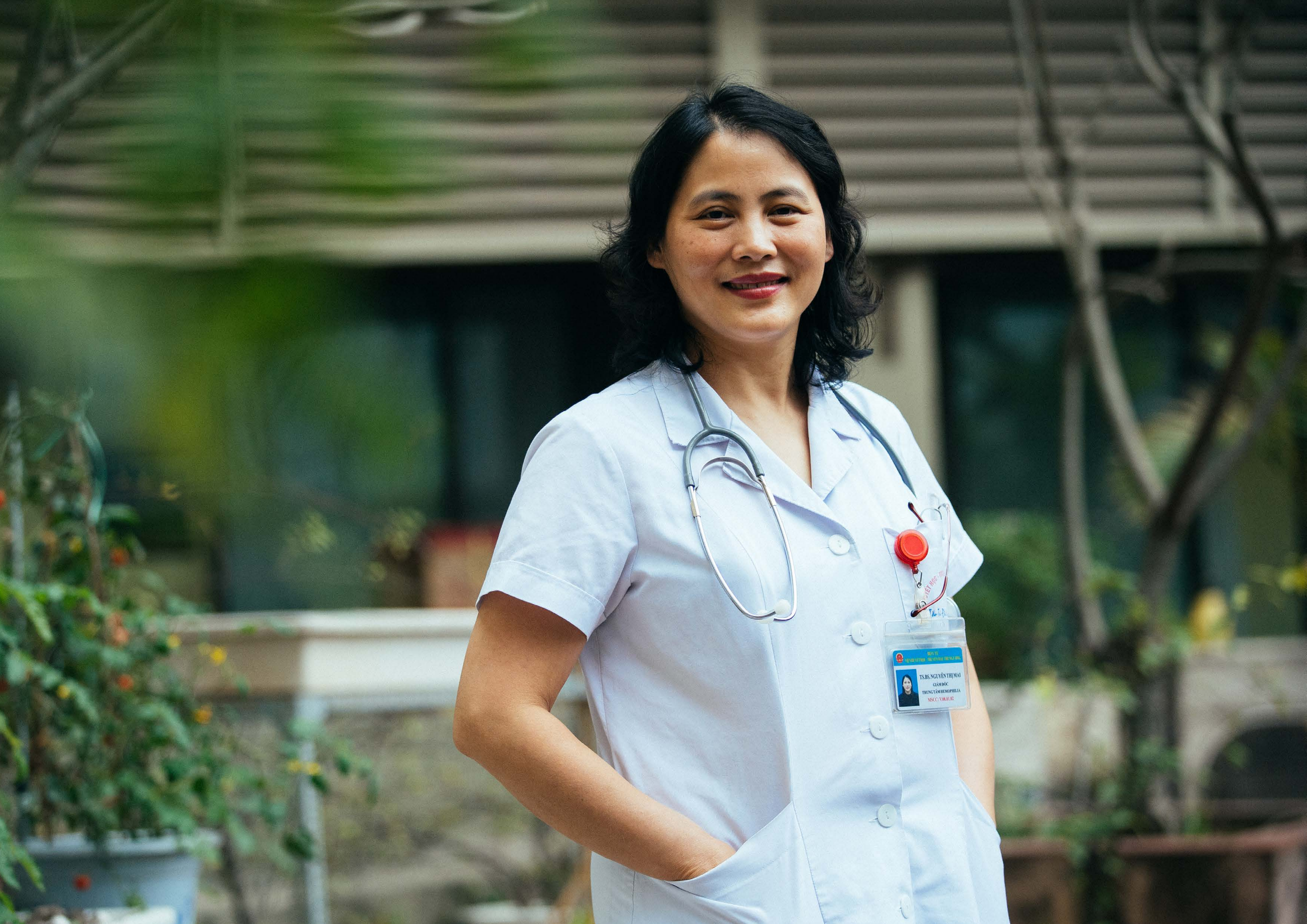
Throughout all these activities, Prof de Moerloose emphasises that it is the people and vision behind the partnering organisations that lead to success: “The quality for people involved in these types of projects are multiple, but it’s a vision of solidarity. You need to have people who are open but also realistic. In French, we say to be an active pessimist - I mean to be realistic about what you can reach, but despite the difficulties, to commit yourself to the long-lasting impact – knowing that when you start you have to run.”

WATCH PROF DE MOERLOOSE’S STORY

To watch Prof de Moerloose’s story please scan this QR-code
or visit nnhf.org/15-years-15-stories

DR NGUYEN THI MAI, VIETNAM

A STEP-BY-STEP APPROACH TO EXPANDING HAEMOPHILIA CARE


BỘ Y TẾ
TS.BS. NGUYỄN THỊ MAI
GIÁM ĐỐC
TRUNG TÂM HEMOPHILIA
MSCC: V.08.01.02

In the seventeen years that Dr Nguyen Thi Mai has worked in haemophilia, she has seen care expand from pockets of basic provision to a network that encompasses the whole country.

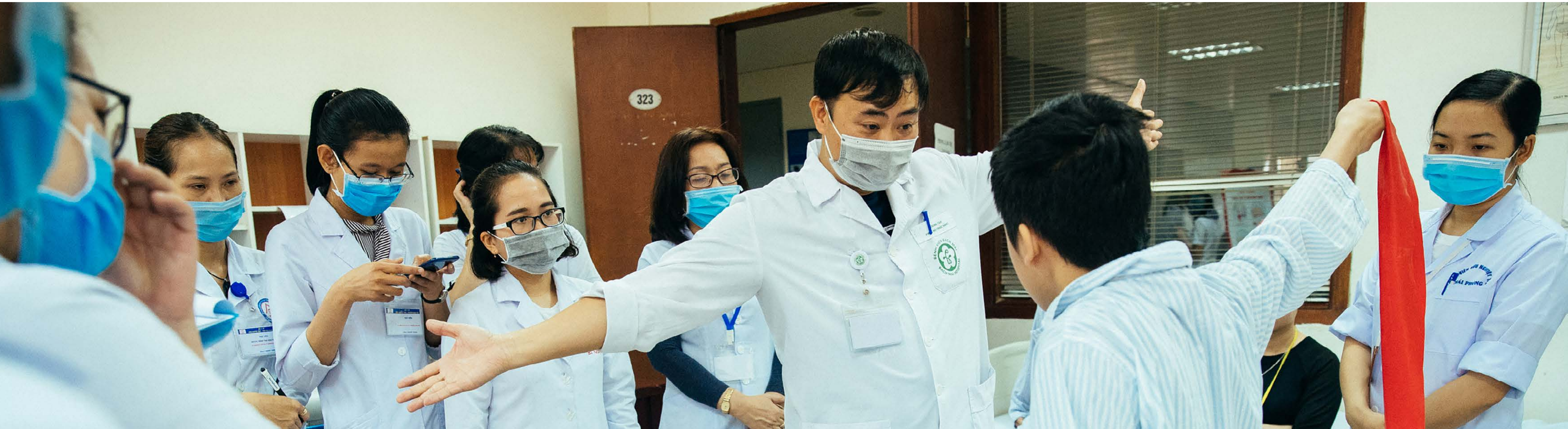
"I remember one man who came in with abdominal bleeding. He was operated on six times during his eight month stay with us, still no-one knew what was causing the bleeding." Dr Mai is reminiscing from the Haemophilia Centre in Hanoi, Vietnam. "Eventually he was diagnosed with haemophilia, referred to a consultant and was able to access regular advice and care. Now he works as a teacher and lives a relatively normal life."

Enabling people with haemophilia to live normal, quality lives is the driving force behind the efforts of Dr Mai and her colleagues to improve care at a national level in Vietnam. Involved in NNHF projects in Vietnam since 2008, Dr Mai is one of a team that has worked tirelessly to build care across the country using a step-by-step approach.

Overcoming challenges in haemophilia care

When Dr Mai started working in the field, she encountered many people with haemophilia who were experiencing complications and high rates of disability, caused by barriers to diagnosis and a lack of knowledge about the condition amongst communities and healthcare professionals. With haemophilia care only available in Hanoi, it was clear that people living outside of the city were at risk of even greater challenges.

Through training for healthcare professionals and partnering with the Vietnam patient organisation, the project team strengthened care in Hanoi as well as Hue and Ho Chi Minh City, "We established in



these haemophilia centres a complete care model which ensured the provision of multidisciplinary care, and collaborated with them to build a training model and patient organisation clubs that could be replicated across the country," explains Dr Mai.

Creating a haemophilia network

With the training hubs, national diagnosis and treatment guidelines, and a mobilised patient community in place, the project team has now started to create ten satellite centres across the country. For the very first time, people with haemophilia will have access to a national haemophilia care network.

Summarising the change that she has witnessed, Dr Mai says, "the quality of diagnosis, treatment and care for people with haemophilia in Vietnam, not only in Hanoi, has improved significantly. This is the source of great pride for everyone who has helped to make this happen."

WATCH DR MAI'S STORY

To watch Dr Mai's story please scan this QR-code
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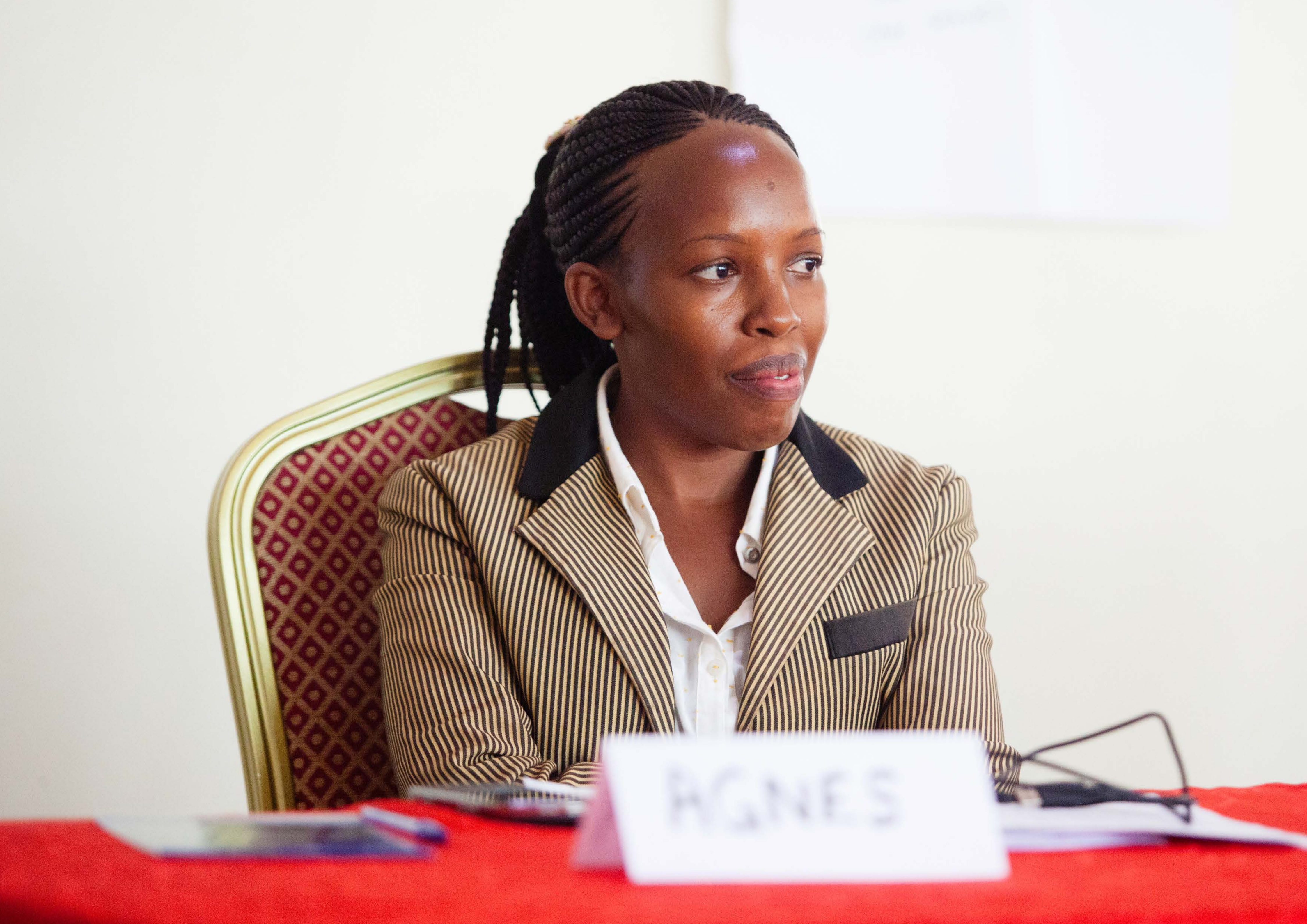
AGNES KISAKYE, UGANDA

A JOURNEY TO SYSTEMIC CHANGE IN UGANDA


AGNES

Agnes describes her journey with haemophilia as one of despair followed by hope. Despair that, when her nephew started showing symptoms of haemophilia in 2004, there were no diagnosis facilities in Uganda, and care and treatment were only available through international organisations. Hope thanks to the changes that she is now seeing across the country.

“The trouble we went through as a family to save the life of my nephew led us to look out for other families in Uganda with this condition,” explains Agnes. With the philosophy that ‘every life matters and is worth saving’, Agnes and the Haemophilia Foundation of Uganda (HFU) have worked tirelessly to identify people with haemophilia, refer them to appropriate care and advocate for haemophilia to be included in national healthcare policies.

Engaging communities, media and authorities

Much of Agnes’s work involves a hands-on approach to supporting people with haemophilia and their families: giving advice on how to manage the condition, linking them with the right doctor, and counselling mothers who have been stigmatised by their families and communities.

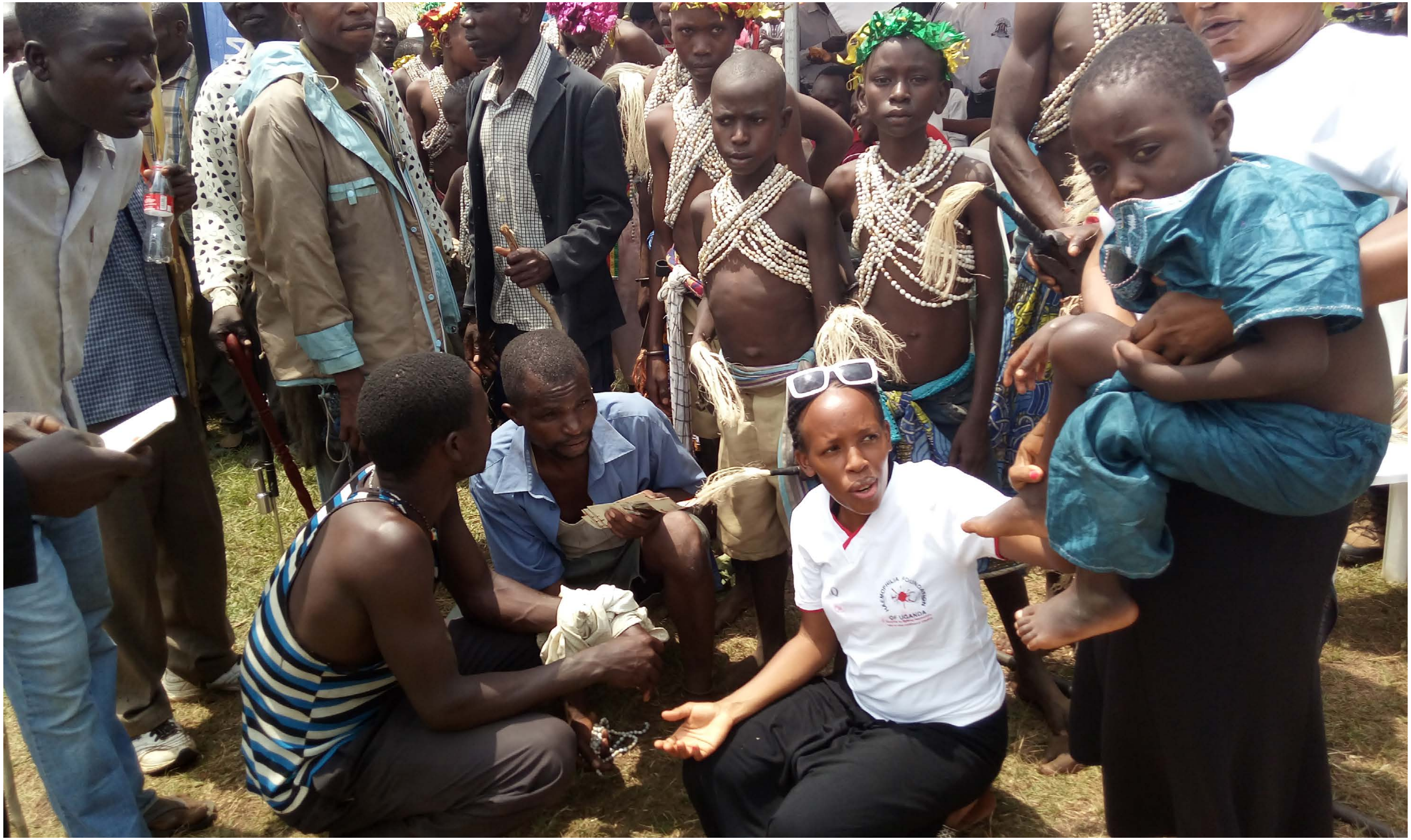
Combined with this have been efforts to create systemic change. Since partnering with the NNHF in 2015, Agnes has engaged media in a strategic way, ensuring they helped spread tailored messages that helped raise awareness whilst emphasising the need for authorities to support haemophilia care.

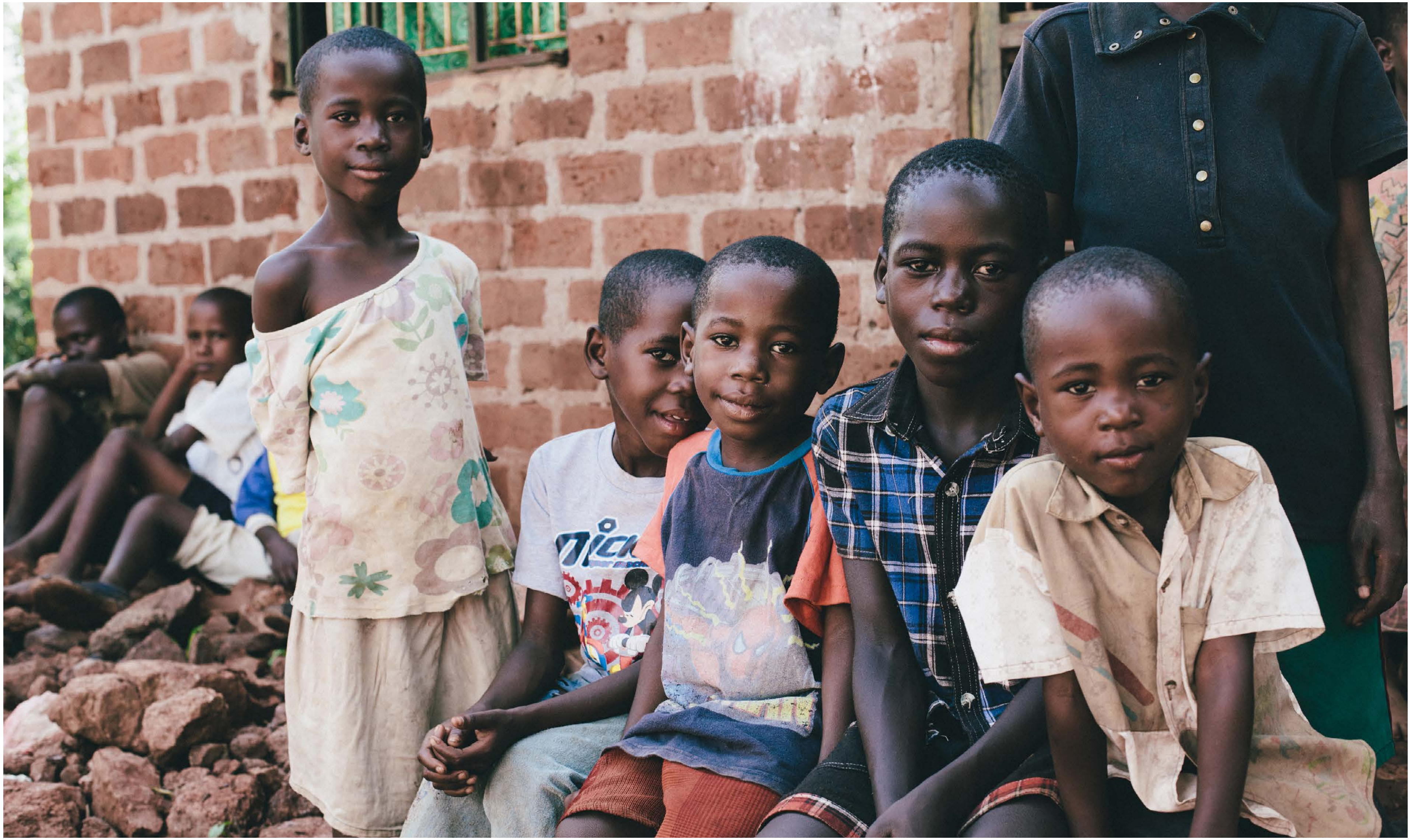
HFU’s achievements so far have been impressive: haemophilia testing and treatment is now free at the national hospital, the diagnosis rate has increased thanks to outreach programmes and the capacity of healthcare professionals has been enhanced through trainings both locally and abroad. These feats, and the exceptional project management shown throughout, are some of the reasons why the Uganda 2 project was selected as the NNHF Project of the Year 2017.

Expanding haemophilia care beyond Kampala

“Most of the patients I meet come from impoverished homes, some of them cannot even afford transport to go to hospitals. But when I give them assurance that diagnosis and treatment is free, they do everything within their means to access the treatment in the hospitals,” explains Agnes. However, this highlights an ongoing challenge that has now become a focus of HFU’s advocacy efforts – despite significant progress in the regions, haemophilia care outside of the capital city remains limited.

Agnes has been one of the key players in HFU’s advocacy activities, which have resulted in a motion on haemophilia being discussed in parliament for the first time in 2019. It has now been escalated to the Ministry of Health, and if approved would lead to the government supporting the expansion of haemophilia care across the country.


HAEMOPHILIA FOUNDATION
OF UGANDA



A sustainable advocacy roadmap

Agnes lays out their advocacy strategy, saying, "having a national policy on haemophilia is the most sustainable way of ensuring healthy living and productivity for people living with haemophilia. The government should also have a nationwide sensitisation plan to create awareness and also integrate people with haemophilia into the national education policy and production activities."

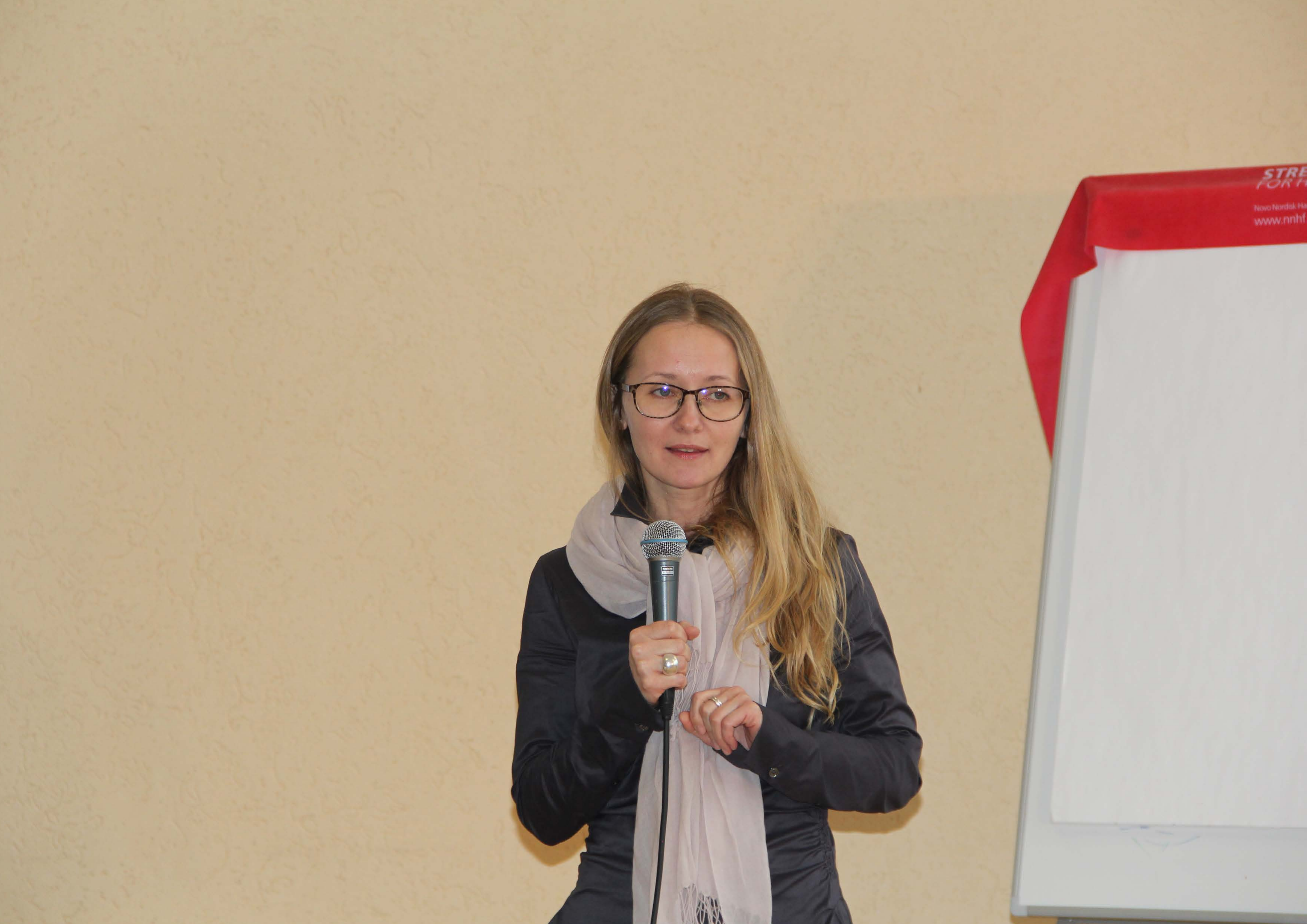
With the progress made so far and a clear strategic direction ahead, Agnes has more reason than ever to be hopeful in her journey to improve haemophilia care in Uganda.

WATCH AGNES' STORY

To watch Agnes' story please scan this QR-code
or visit nnhf.org/15-years-15-stories

DR SONATA SAULYTE TRAKYMIENE, LITHUANIA

INSPIRED TO IMPLEMENT MULTIDISCIPLINARY CARE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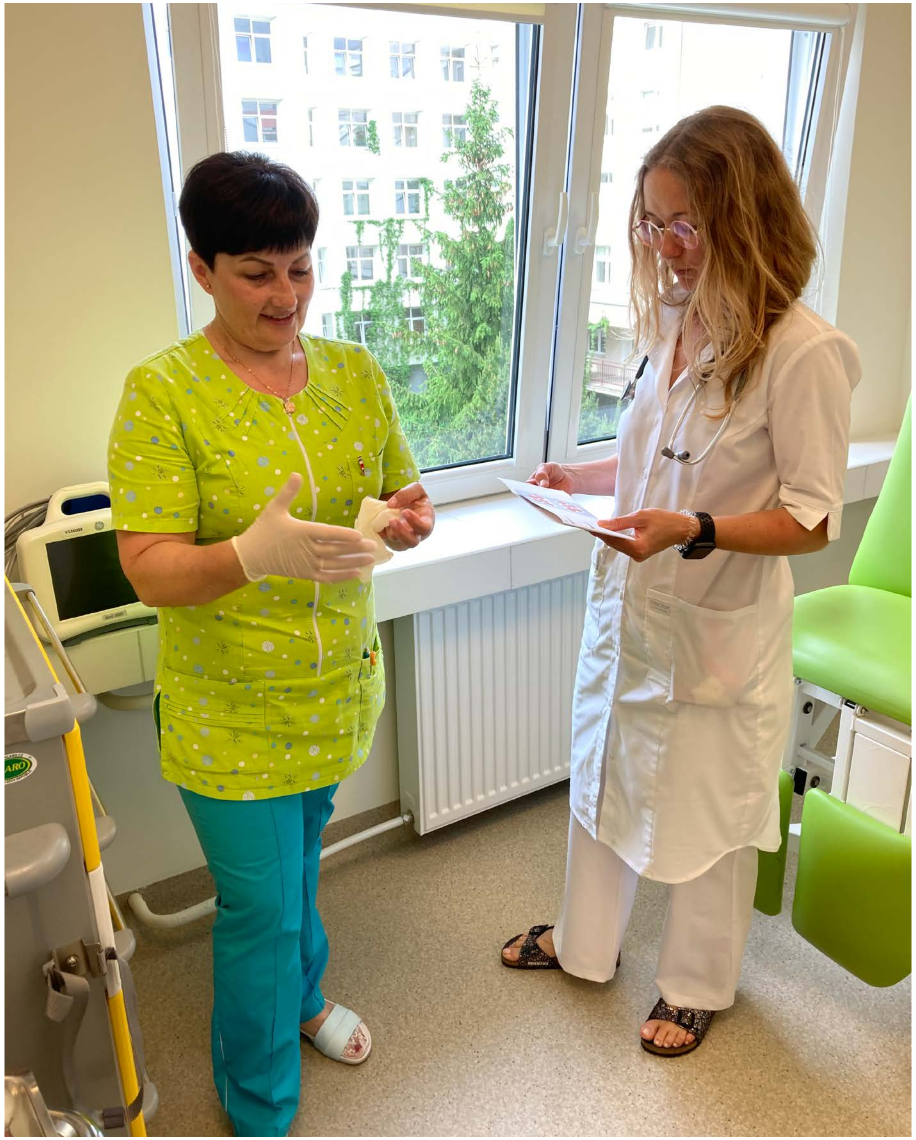
For Dr Sonata Saulyte Trakymiene, providing the best care to people with haemophilia is an ongoing process: "Despite quite good prophylaxis in Lithuania, people with haemophilia did not feel able to be physically active, they were afraid to impair their health by doing something wrong or not recommended for haemophilia patients," she explains.

Dr Trakymiene and the patient organisation knew the solution was to establish a physiotherapy service tailored to the needs of people with haemophilia. How to achieve this with limited resources within Lithuania was the challenge they needed to address. "We knew what we would like to improve in haemophilia care, however we did not have ideas how to start and be brave with physiotherapy for our patients. That's when we decided to use our contacts to reach out to experts beyond Lithuania."

Multi-international collaboration

This marked the beginning of an international collaboration that started with physiotherapists and a psychologist being trained at the SickKids Hospital in Canada. Physiotherapists Piet de Kleijn, Natasa Jankovic and Prof Adly Sabbour from the Netherlands, Serbia and Egypt joined the expert team, providing guidance and on-site training in Lithuania.



Having seen the benefits of sharing expertise across borders, the project team went on to create a north-eastern European network encompassing seven countries across the region. Dr Trakymiene and members of the project team passed on the knowledge they gained to this international group of healthcare professionals through regional symposia and the creation of a joint resolution on physiotherapy for people with haemophilia.

Inspiration for personal and professional growth

Within Lithuania, Dr Trakymiene is seeing the impact of these efforts: "A lot of people with haemophilia, who were not very active physically, finally became engaged and motivated to do physical activity. Physiotherapy is now in our routine regular services for haemophilia patients that helps to evaluate treatment outcomes."

Beyond the health benefits for people with haemophilia, Dr Trakymiene's story is one of personal growth, inspiring her to continue to strive for the best outcomes for the haemophilia community: "Through these NNHF projects I grew as a haemophilia care provider, they helped me understand my patients more deeply and develop very tight contacts, that always helps to fight all obstacles in our way when trying to improve haemophilia care in our country. I also met so many wonderful people dedicated to haemophilia care who inspired me so much and I still have warmest memories from these projects days."

WATCH DR TRAKYMIENE'S STORY

To watch Dr Trakymiene's story please scan this QR-code
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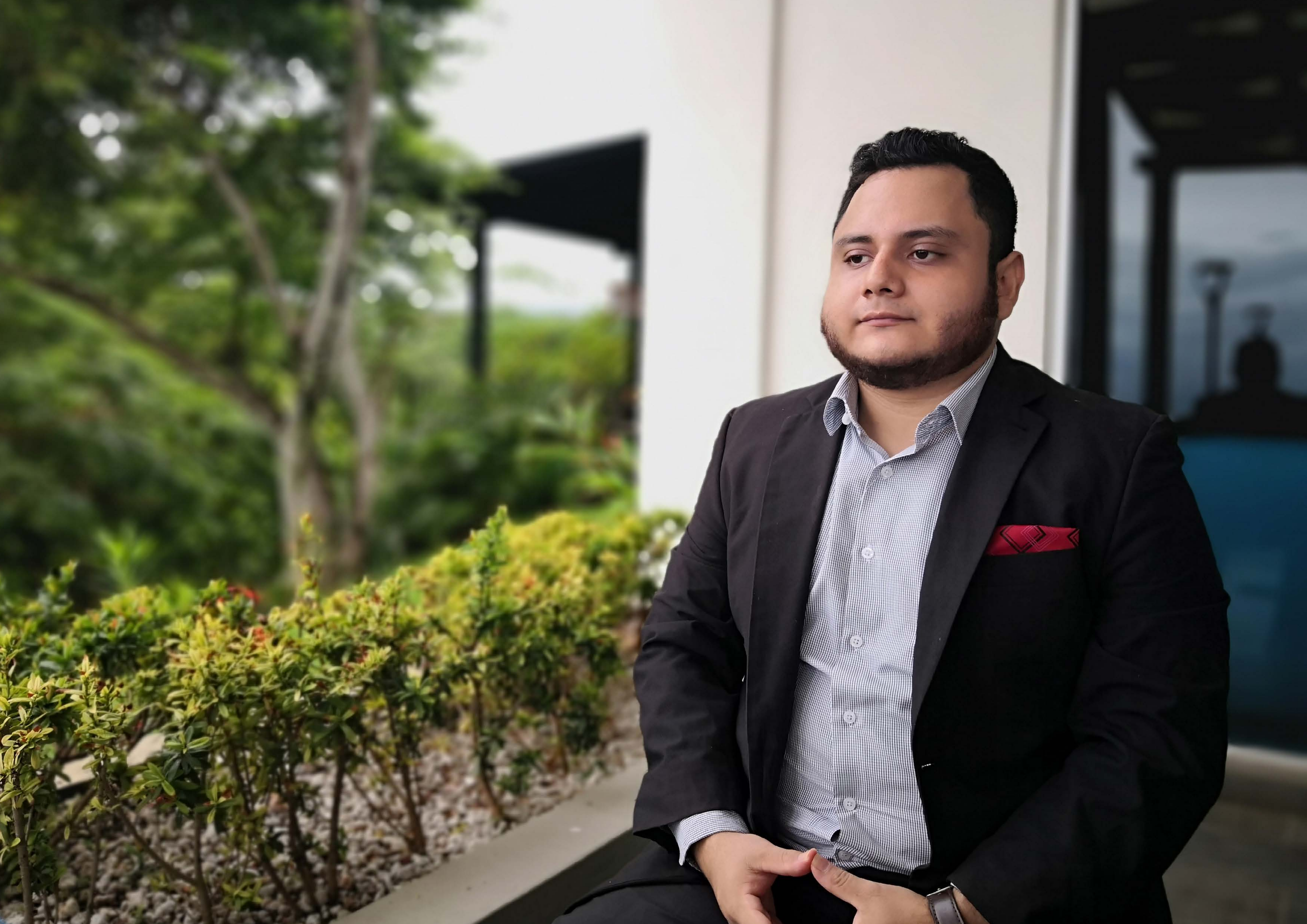
ENGELS REYES, NICARAGUA

A LEADER'S INCLUSIVE APPROACH TO PURSUING SHARED GOALS



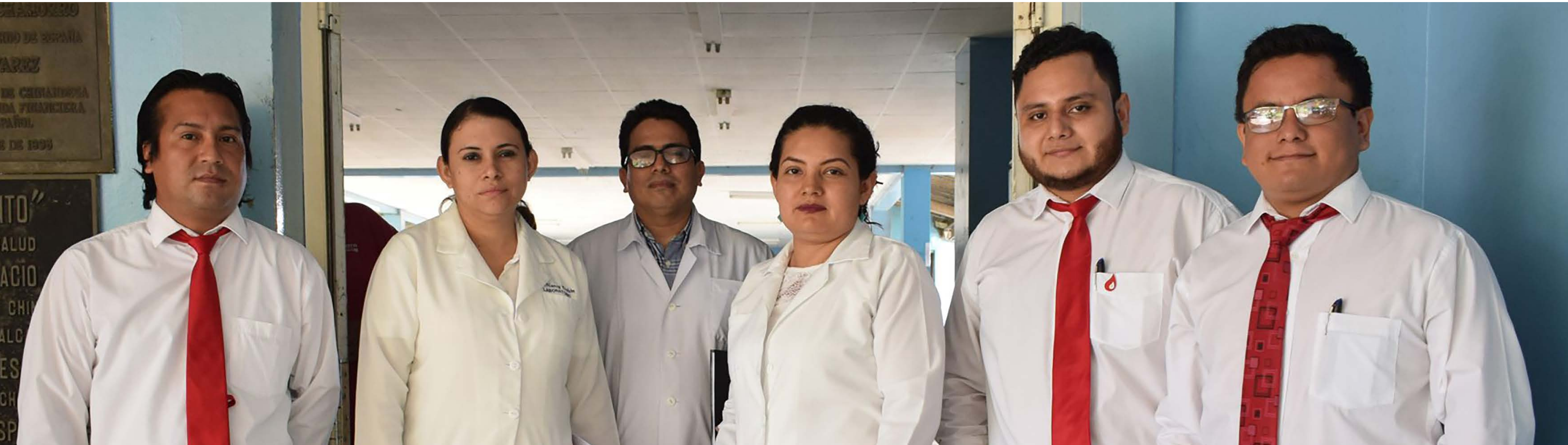
The desire to be an agent for change came at a young age for Engels Reyes. By developing his leaderships skills, Engels, who is living with severe haemophilia A, is turning this desire into a reality together with the haemophilia communities of Nicaragua and Central America.

It was when Engels became engaged in the international haemophilia community that he realised the challenges he recognised from growing up in Nicaragua – namely limited knowledge about the condition and lack of access to care – had been successfully addressed elsewhere. This vision of a better future motivated Engels to improve the situation in his home country.

Addressing shared challenges

As well as seeing the achievements of haemophilia communities abroad, Engels also became aware of shared challenges between countries. This is particularly the case for Nicaragua's neighbours Honduras, El Salvador and Guatemala. The NNHF Nicaragua 2 project therefore includes activities to collaborate with these countries and strengthen their respective patient organisations.

As a key player in devising and delivering the practical activities of the patient organisation through his role as President, Engels has also refined his leadership skills, enabling him to become a spokesperson for haemophilia at a national level. A key thread that runs through Engels' approach to leadership is that of collaboration and dialogue, "I have learned to always be there to listen to my community to know the very particular needs of our health system, and to understand how it works so that I can make suggestions, always in a spirit of dialogue and respect for the persons and the institutions."



Creating a solid team

This approach is being applied in the Nicaragua 2 project, which seeks to decentralise diagnosis, expand haemophilia knowledge across the country and share best practices between neighbouring countries, objectives that require the engagement and support of various stakeholders including health authorities.

Continuing the theme of collaboration, Engels also emphasises the importance of teamwork in pursuing their goals: "I have learned to recognise my limitations and the aptitudes and potential of others. This is how we have achieved a solid team with professionals from different areas, all working towards the same objective, to improve the care of haemophilia in Nicaragua."

WATCH ENGELS' STORY

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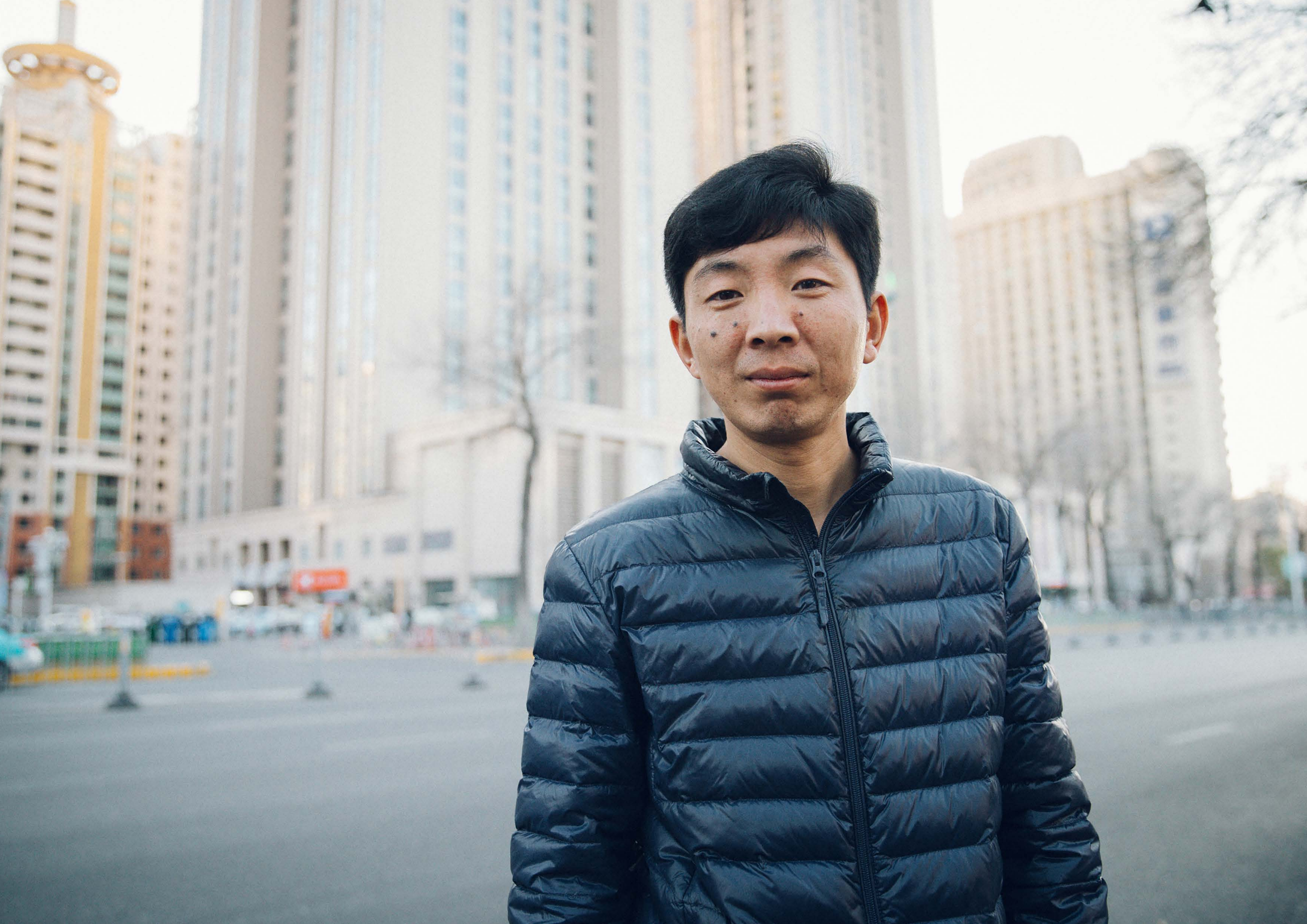
HUA WEI LIN, CHINA

AFFORDABLE CARE, CLOSER TO HOME



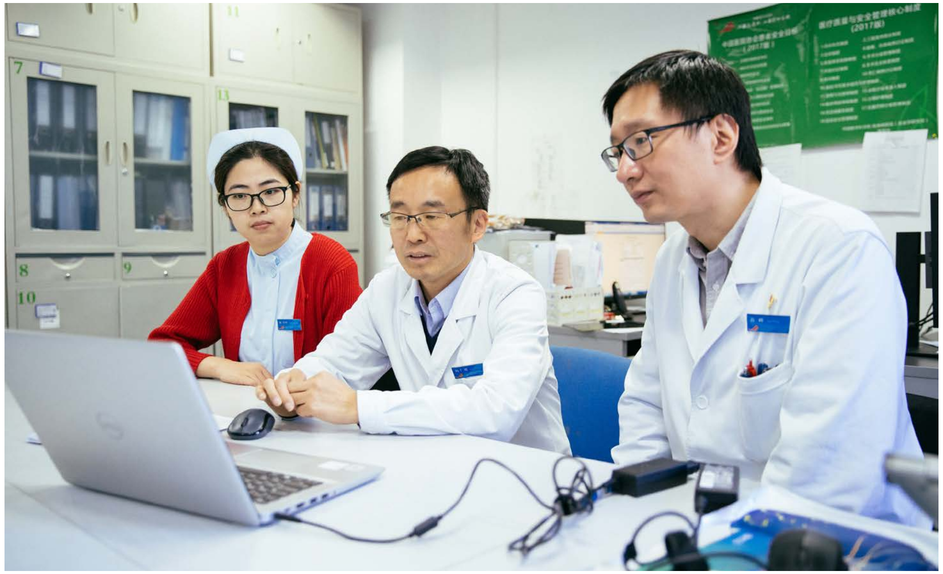
As 37-year old Hua Wei Lin boards the train in his home province of Hebei, China, it is difficult to believe that he was once unable to walk. Repeated bleedings in his knees as a young adult meant he had to rely on a wheelchair. Despite being diagnosed with severe haemophilia A at 19, without a job, he couldn't afford the care and treatment he knew he needed. The activities of the NNHF China 8 project helped to change the life of Hua Wei Lin, and thousands like him.

Hua Wei Lin's parents were aware he had bleeding tendencies since the age of two, when a childhood accident resulted in a cut on the chin that nearly caused him to bleed to death. Unable to afford to take him to hospital on this and subsequent occasions, his parents became accustomed to Hua Wei Lin spending days in bed throughout his childhood, waiting for his bleeds to subside. A particularly severe bleed, caused after a schoolteacher insisted he participate in a sports lesson, led him to receiving a diagnosis of severe haemophilia A at the age of 19.

A multi-faceted approach

At this time, the cost of haemophilia care was not fully reimbursed by insurance in Hebei. Hua Wei Lin could eventually only move with the support of a wheelchair, and he was unable to work on the family farm. Stories like Hua Wei Lin's were not uncommon in the North East of China. This is why the NNHF China 8 project focused on seven provinces in this region, taking a multi-faceted approach to improving care.

The project established one of seven new Haemophilia Treatment Centres in Hebei, and trained healthcare professionals in diagnosis, care and treatment. Leveraging on the increased interest of healthcare professionals in haemophilia, the project team provided targeted support to them on how to engage local healthcare authorities on the issue of health insurance reimbursement.



Collaboration leads to improved care

Alongside this, the project team collaborated with local chapters of the patient organisation, so that they could educate more members, raise awareness of haemophilia and join the efforts to engage local healthcare authorities. The team credits this network of healthcare professionals, people with haemophilia and local authorities for the achievements of the project.

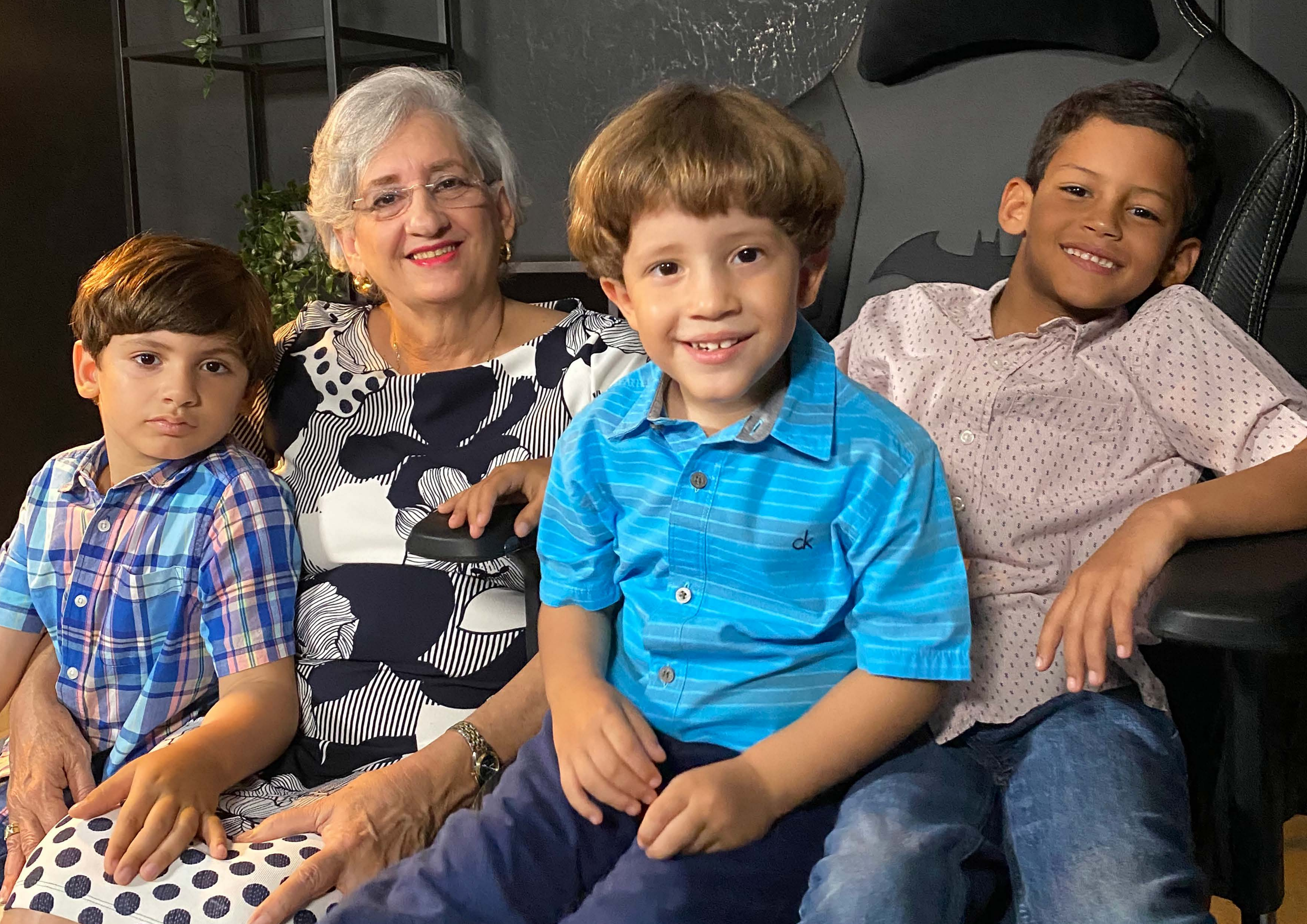
The benefits of these activities are clear to see in Hua Wei Lin's life. His haemophilia care is now fully reimbursed by insurance. Instead of undertaking a 2-hour train journey to receive care in Tianjin, he can visit his local Haemophilia Treatment Centre in Hebei. Through the NNHF project, he was taught to self-infuse. Today, Hua Wei Lin is on low-dose prophylaxis. He no longer requires a walking aid and is able to work as a delivery person: "My life has totally changed. Before, I had recurrent pain and I couldn't work. Now I can go to work and I have no pain."

WATCH HUA WEI LIN'S STORY

To watch Hua Wei Lin's story please scan this QR-code
or visit nnhf.org/15-years-15-stories

HAYDÉE BENOIT DE GARCÍA, DOMINICAN REPUBLIC

A PASSION FOR DEVELOPING TOMORROW’S HAEMOPHILIA LEADERS



When her son was diagnosed with severe haemophilia A in Toronto at six months old, Haydée Benoit de García received the support and information she needed to understand the condition and how her son could live his life to the full. On returning to her home country of the Dominican Republic, Haydée set out to ensure families affected by haemophilia in her home country could receive the same level of support.

The challenges Haydée saw amongst the haemophilia community in the Dominican Republic were many: there was little dialogue between people with haemophilia and the medical community, and the lack of information available to parents meant they prevented their children from participating in activities with their peers.

Establishing a support and knowledge network

Determined to provide the same support she had received, in 1996 Haydée teamed up with Dr Rosa Nieves Paulino, Dr Joanne Taveras, nurse Maria Espinal and a small group of parents to create the Fundación Apoyo al Hemofílico (FAHEM), the national patient organisation. This enabled Haydée to pursue one of her ambitions: to hold youth leadership camps for people with haemophilia.

Inspired by the summer camps her son had attended in the USA, Haydée wanted these camps to provide boys with haemophilia the opportunity to learn, play and socialise – experiences that had often been denied them because of misconceptions about their condition.

Mixed emotions and developing friendships

Haydée recalls the first camps, which started in 1999, led to mixed emotions for those involved. For many mothers it was the first time they had been separated from their sons. For the participants, it was the first time some were able to eat three meals a day or sleep in their own bed. “It was so rewarding to see the happiness on their faces when they played baseball or basketball. Through the years, the tears turned into laughs of joy, because at the camp they met friends who shared this experience like brothers,” she recalls.

Besides learning to participate safely in certain sports, the main purpose of the camps was to instil in participants the skills and confidence to become haemophilia leaders, ensuring that the next generation would be ready to continue and build on the work of FAHEM. Describing their approach to leadership development, Haydée says, “The camp has become a laboratory where we have been transforming and analysing the attitudes and skills of our young people.”

Her role in devising the youth camps was instrumental in Haydée winning the NNHF Community Award in 2012. The following year, the NNHF Central America, Caribbean and Venezuela project began, led by Fendi Valdez Bisono, a FAHEM member who had demonstrated promising leadership qualities. The project established a regional network of patient organisations covering nine countries.

Dedicated to pursuing a vision

Throughout the years Haydée has shown an incredible dedication to families affected by haemophilia. Summarising what fuels her, Haydée says, "My son Dámaso and my grandson Enzo have made me renew my energy every day so that the Dominican haemophilia community continues to move forward. My love for them has unleashed this passion that I feel for Dominican people with haemophilia to continue advancing, to continue progressing and above all to have one day the immense joy of knowing that our vision of a better quality of life for all is truly fulfilled."

Haydée's vision is now pursued by a new generation of haemophilia leaders who will continue sharing knowledge and building networks for generations to come.

Haydée together with FAHEM is currently working to expand diagnosis and establish a registry in the Dominican Republic through the second NNHF project in the country. It builds on the first NNHF project, which strengthened care in the capital city of Santo Domingo.

WATCH HAYDÉE'S STORY

To watch Haydée's story please scan this QR-code
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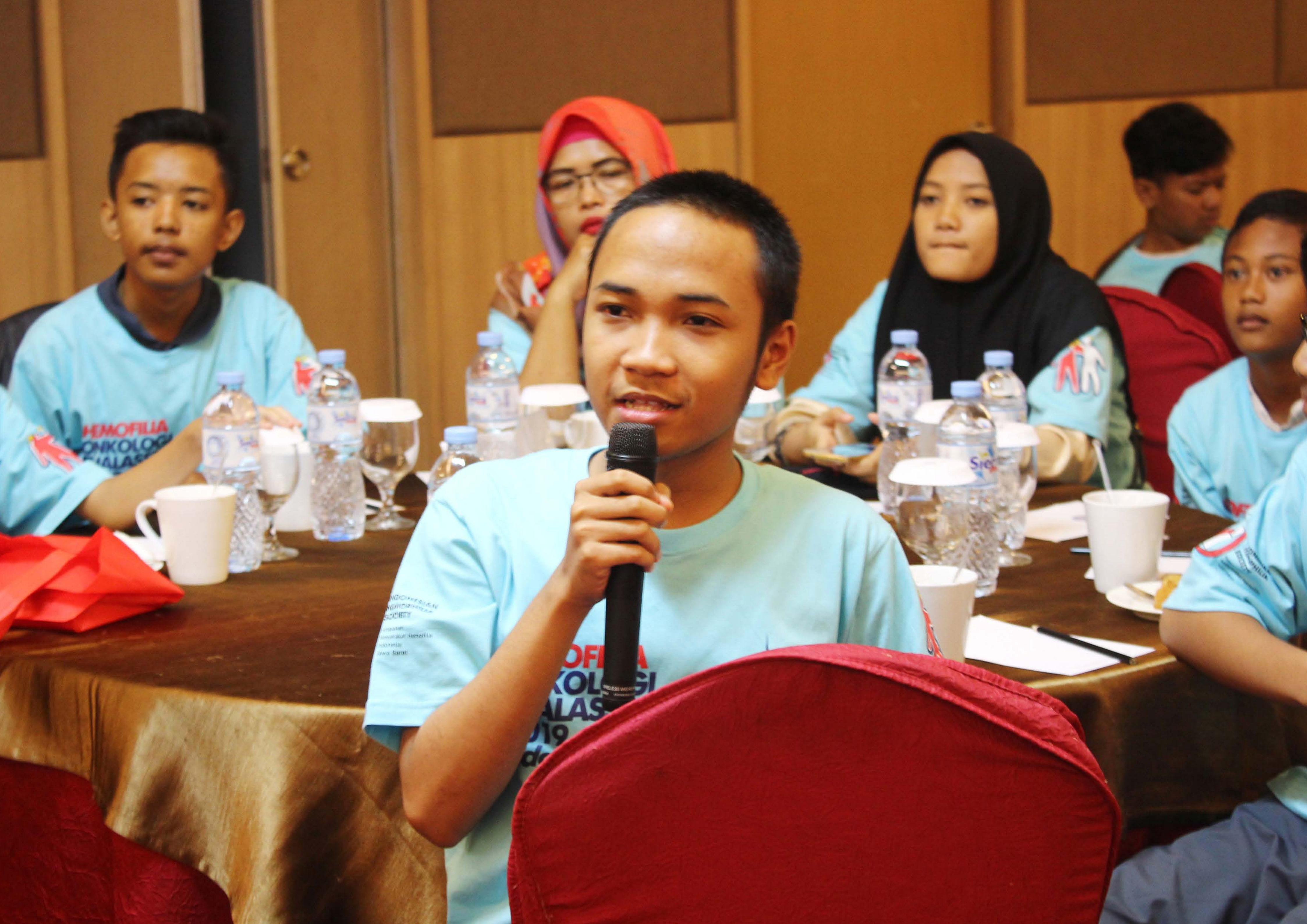
REKA SHAKIRALHAMDI LATIEF, INDONESIA

SELF-INFUSION AS A ROUTE TO INCREASED INDEPENDENCE


HEMOFILIA
ONKOLOGI

Until last year, travelling for hours through heavy traffic to reach the local clinic whenever he had a bleed was the norm for 17-year old Reka Shakiralhamdi Latief. Reka lives in Bandung, Indonesia, a city whose traffic is worse than the infamously congested Jakarta. Reka was one of many people with haemophilia facing this challenge across Indonesia.

At the age of three, Reka had to undertake this journey on a motorcycle with his father whilst experiencing an intercranial bleed. The delay in receiving treatment was potentially fatal. Even upon release from hospital after 14 days, Reka and his parents still had to undertake the difficult journey every day for the following week, so that he could receive his treatment. From this point on for Reka, who has severe haemophilia A, this journey became an integral part of his life.

Empowerment through education

In 2019, Reka participated in a self-infusion workshop organised as part of the NNHF Indonesia 2 project by the Indonesian Society of Hematology & Blood Transfusion and the Indonesian Hemophilia Society. The workshop was one of a series being held across ten provinces in the country, as part of the project team's objective to empower people with haemophilia and their parents, through education and skills development. The workshop changed Reka's life.

A newfound confidence

"At first, I was scared to insert the needle into my arm, but the workshop gave me confidence because it was very practical and the nurses were very patient and supportive," recalls Reka.

After the self-infusion workshop, Reka attended several supervised practise sessions with nurses at the hospital to ensure he would be able to correctly self-infuse. "Now I am less scared of having a bleed because I know I can deal with it at home and I don't have to spend hours travelling to the clinic," explains Reka. This has been fundamental in enabling him to live more independently and focus on doing the things he enjoys as a typical 17-year old – playing computer games, reading and teasing his sister.

WATCH REKA'S STORY

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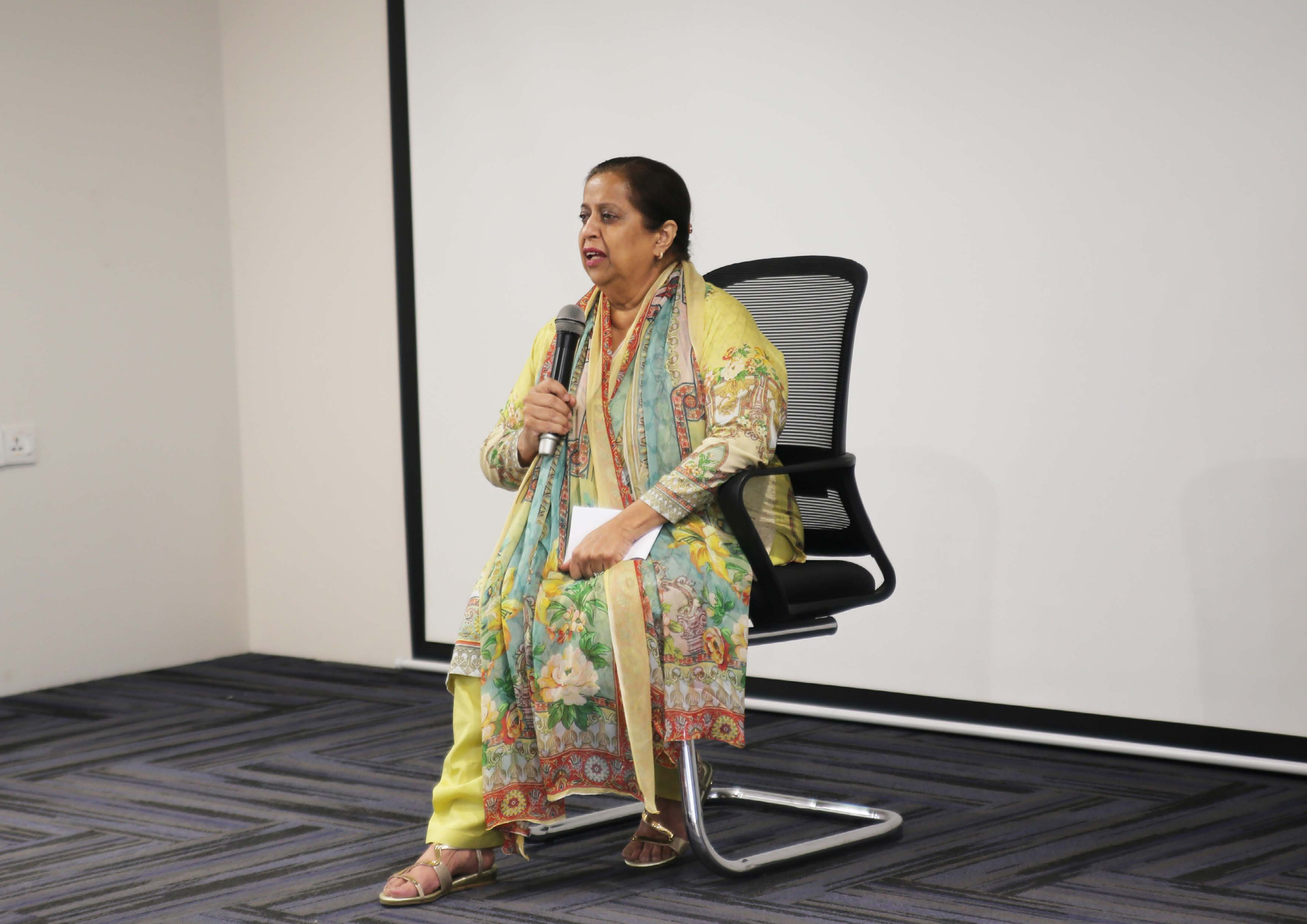
SOSIALISASI APLIKASI
HEMOFILIA INDONESIA
ONLINE REGISTRY
BANDUNG, MEI 2019
WFH
WORLD FEDERATION OF HEMOPHILIA
INDONESIAN HEMOPHILIA SOCIETY
WORKSHOP SELF INFUSION
Alat-alat bebas suntik dibuang kemana?
Yankes : ada safety box
diolah di insinerator

DR SHAHLA T. SOHAIL, PAKISTAN

A ROLE MODEL FOR WOMEN WITH BLEEDING DISORDERS



After being told their daughter had an ‘abnormal bleeding disorder’, Dr Sohail’s parents were determined that she would go on to live an independent and successful life. Now a doctor specialising in bleeding disorders, Dr Sohail is dedicated to ensuring women affected by bleeding disorders in Pakistan are empowered to overcome the challenges associated with the condition.

Being told their daughter had an ‘abnormal’ condition was initially devastating for Dr Sohail’s parents, but they soon decided to dedicate their energy to ensuring she would live a fulfilled life. They enrolled her into a good school and focused on building her confidence so she could follow her dream of becoming a doctor. Living with a bleeding disorder meant that every time she had a bleed, Dr Sohail had to go to the hospital to receive treatment, often remaining there for days until she was well enough to return home. But she successfully completed her education and travelled to the UK as part of her medical training.

Global differences in bleeding disorders care

It was during her time in the UK that, 20 years after her parents were first told she had a bleeding disorder, Dr Sohail received a definitive diagnosis of type III von Willebrand disease. It was also at that time that she saw evidence that people with bleeding disorders could live a normal life.

It therefore came as a shock when Dr Sohail returned to Pakistan to find that bleeding disorders care remained limited. “There was still no care for persons with bleeding disorders, whether they were boys or girls,” she recalls. A desire to change this led Dr Sohail and a group of peers and colleagues to establish Hemophilia Foundation - Pakistan (HFP).

A close community of support

Twenty years on, Dr Sohail plays a key role in the Hemophilia Patients Welfare Society, one of HFP’s chapters, focusing particularly on counselling and empowering women affected by bleeding disorders. Having known many of these women since childhood in her capacity as a paediatrician, Dr Sohail is now a source of guidance and support beyond her medical role: “These girls have grown up with me and over the years they have started to consider me as a role model. I do my best to support them, including acting as a family counsellor, genetic counsellor, psycho-social counsellor and they can come to me for anything that bothers them and discuss it with me because we are all very close,” she explains.

Establishing a national women’s group

The HFP established a national women’s group through the NNHF Pakistan 6 project in 2017. The group aims to ensure that girls and women receive early, accurate diagnosis, leading to better health outcomes and to provide women affected by bleeding disorders with the education, support and skills to advocate for their health and social support needs.

Describing her role in the group, Dr Sohail says, “Girls or women with bleeding disorders in Pakistan, as elsewhere in the world, are facing a struggle. At this point in time I would like to strive and make these young girls and women feel that there is no challenge for them in this disorder, that instead they can take it along with them and live a life in comfort.”

WATCH DR SOHAIL’S STORY

To watch Dr Sohail’s story please scan this QR-code
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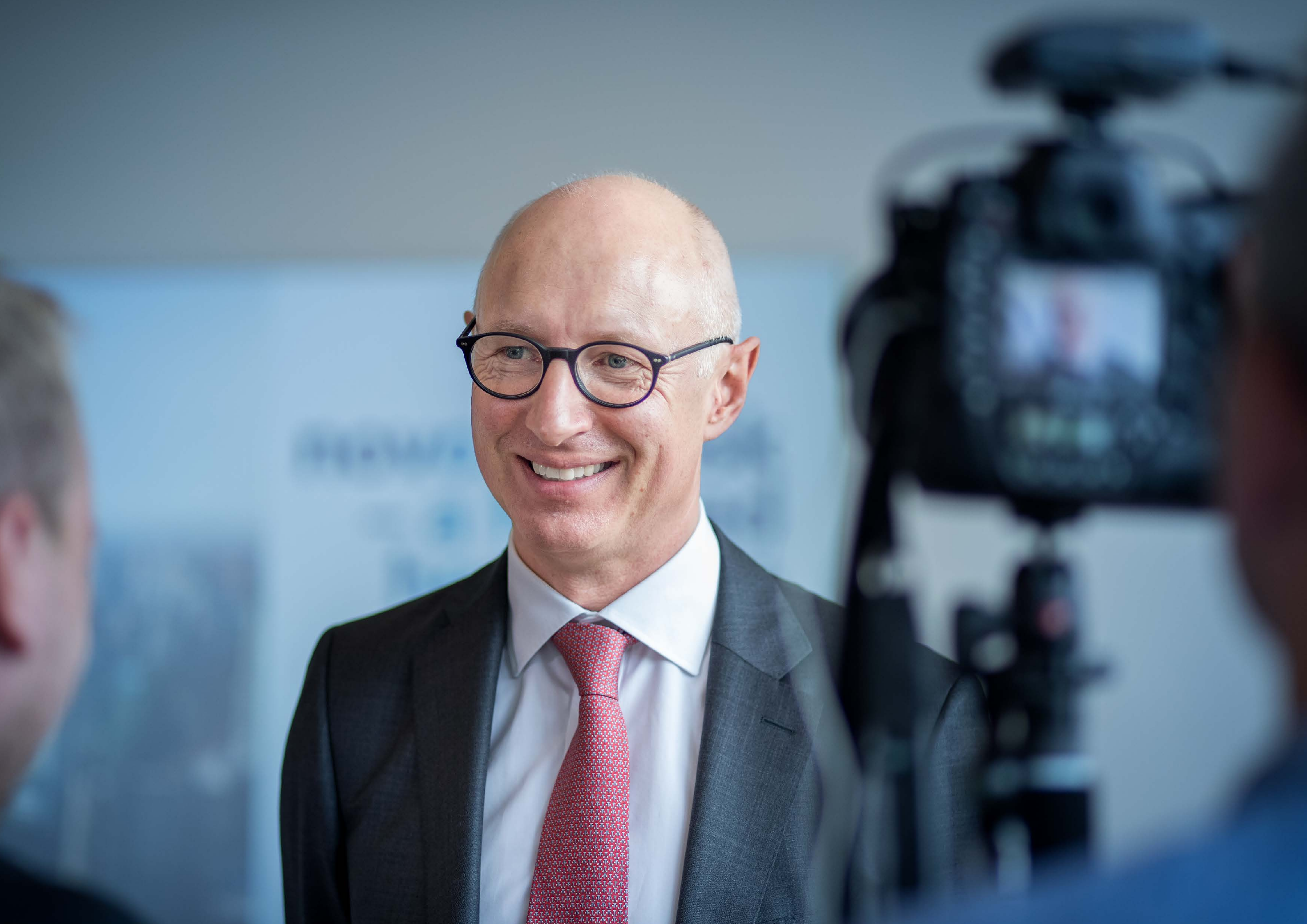
LARS FRUERGAARD JØRGENSEN, DENMARK

LEADING A COMPANY COMMITTED TO IMPACTING CARE. TOGETHER



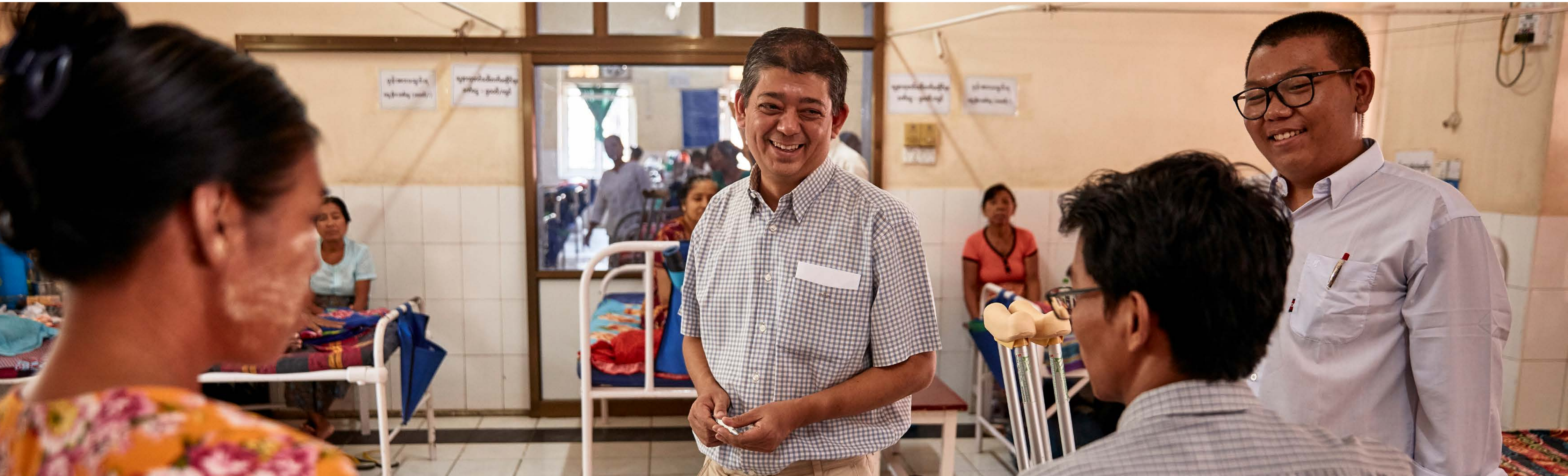
In 2005, Novo Nordisk established the Novo Nordisk Haemophilia Foundation with the vision that all people with haemophilia or rare bleeding disorders receive care and treatment, wherever they live. 15 years on, Novo Nordisk CEO Lars Fruergaard Jørgensen explains how the company's commitment to this vision remains as strong as ever.

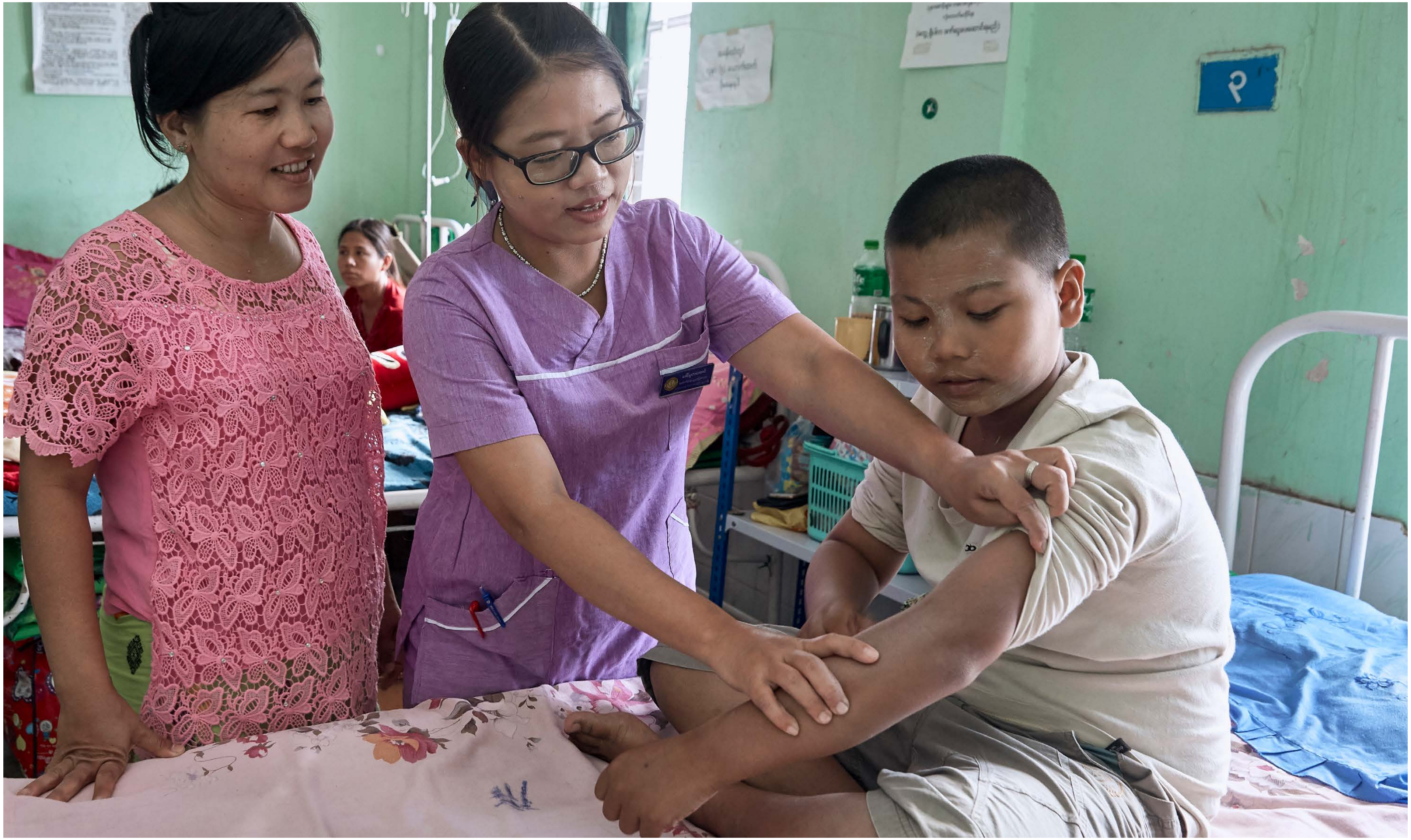
As the NNHF's founder and funder, Novo Nordisk has been fundamental in enabling the NNHF to improve access to care in over 78 countries to date. One of these countries is Myanmar, where in 2017, at the start of the NNHF project in the northern part of the country, only one haematologist and one paediatrician were providing haemophilia care, and diagnosis facilities were limited.

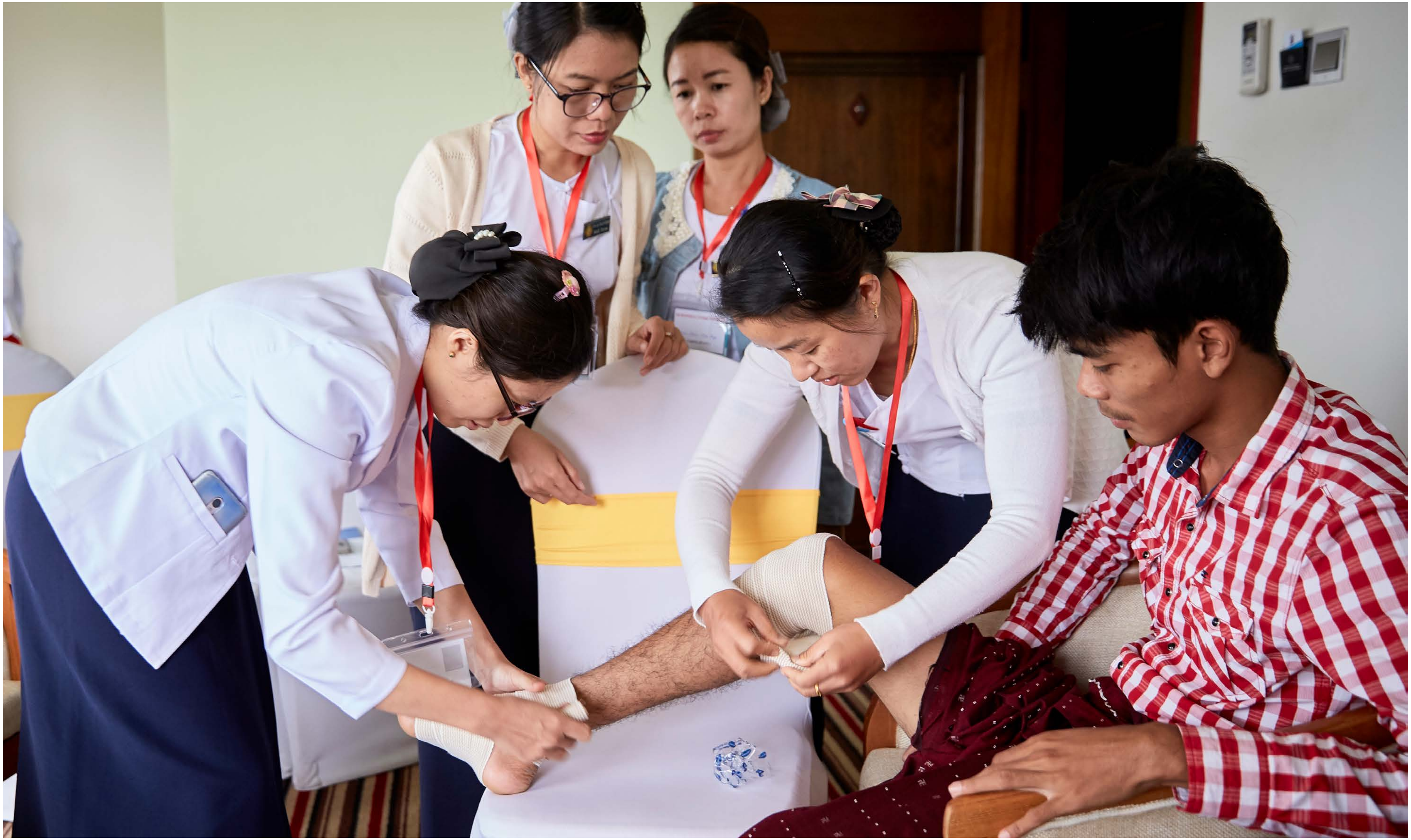
The NNHF project has brought together international experts and institutions to train nurses, physiotherapists and haematologists. Diagnosis equipment has been purchased and the regional patient organisation has been strengthened to improve its capacity to provide education and support.

Companywide commitment to improving care

As Lars Fruergaard Jørgensen explains, some of the key activities of the project, such as the training of three haematologists in the UK, have been made possible thanks to the fundraising efforts of Novo Nordisk employees across the world. Myanmar is not the only NNHF project to benefit from Novo Nordisk employees' generosity. Globally, they have also volunteered their skills to build capacity amongst project teams on topics such as advocacy and process optimisation.



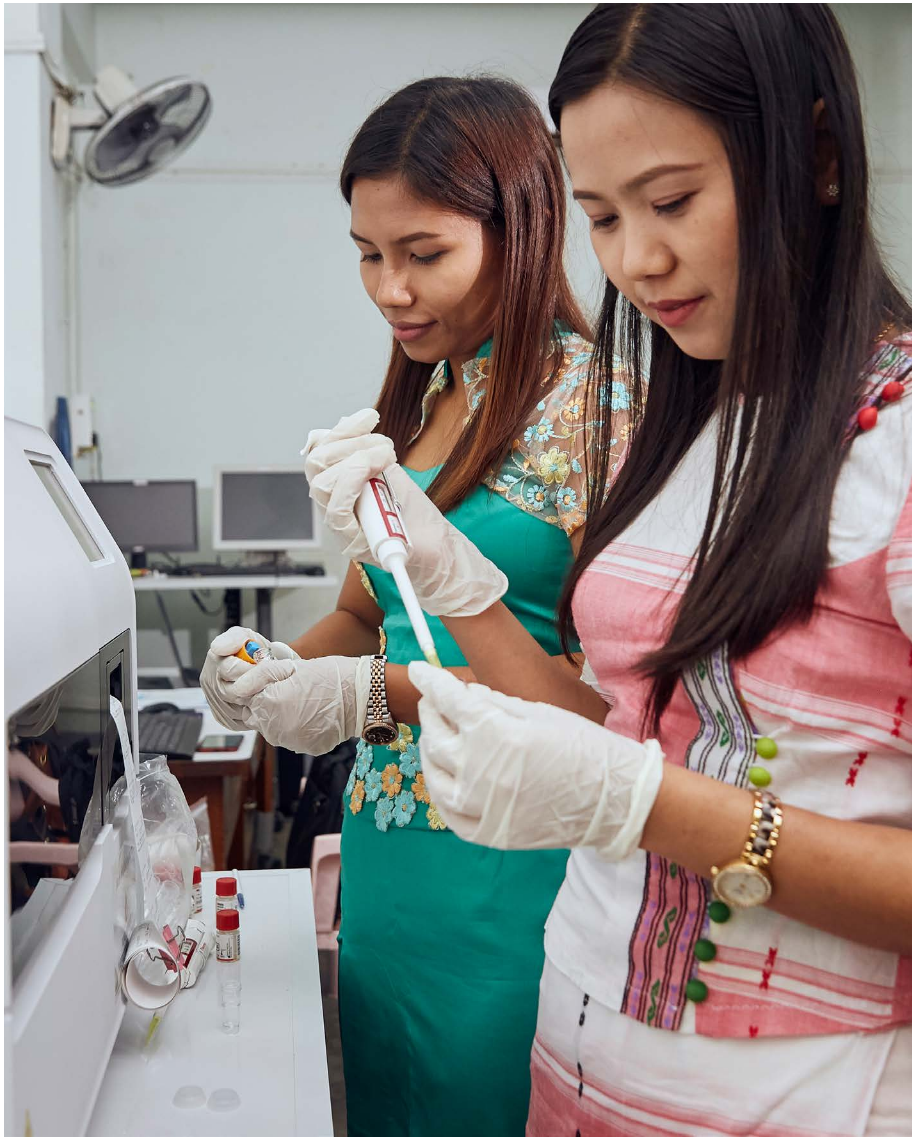




Additionally, the NNHF Council comprises representatives from Novo Nordisk executive management alongside globally renowned medical professionals, who provide strategic guidance to the NNHF.

Achieving a sense of pride

Reflecting on the achievements of the NNHF Myanmar project so far, Lars Fruergaard Jørgensen says "I am proud to lead a company that is helping to create such a change," reflecting a pride that resonates across the organisation. Alongside NNHF's partners, Council members, international volunteers and representatives from the global bleeding disorders community, the dedication and commitment of Novo Nordisk's management team and employees have contributed greatly to the NNHF in impacting care. Together.



WATCH LARS' STORY

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Impacting care. Together