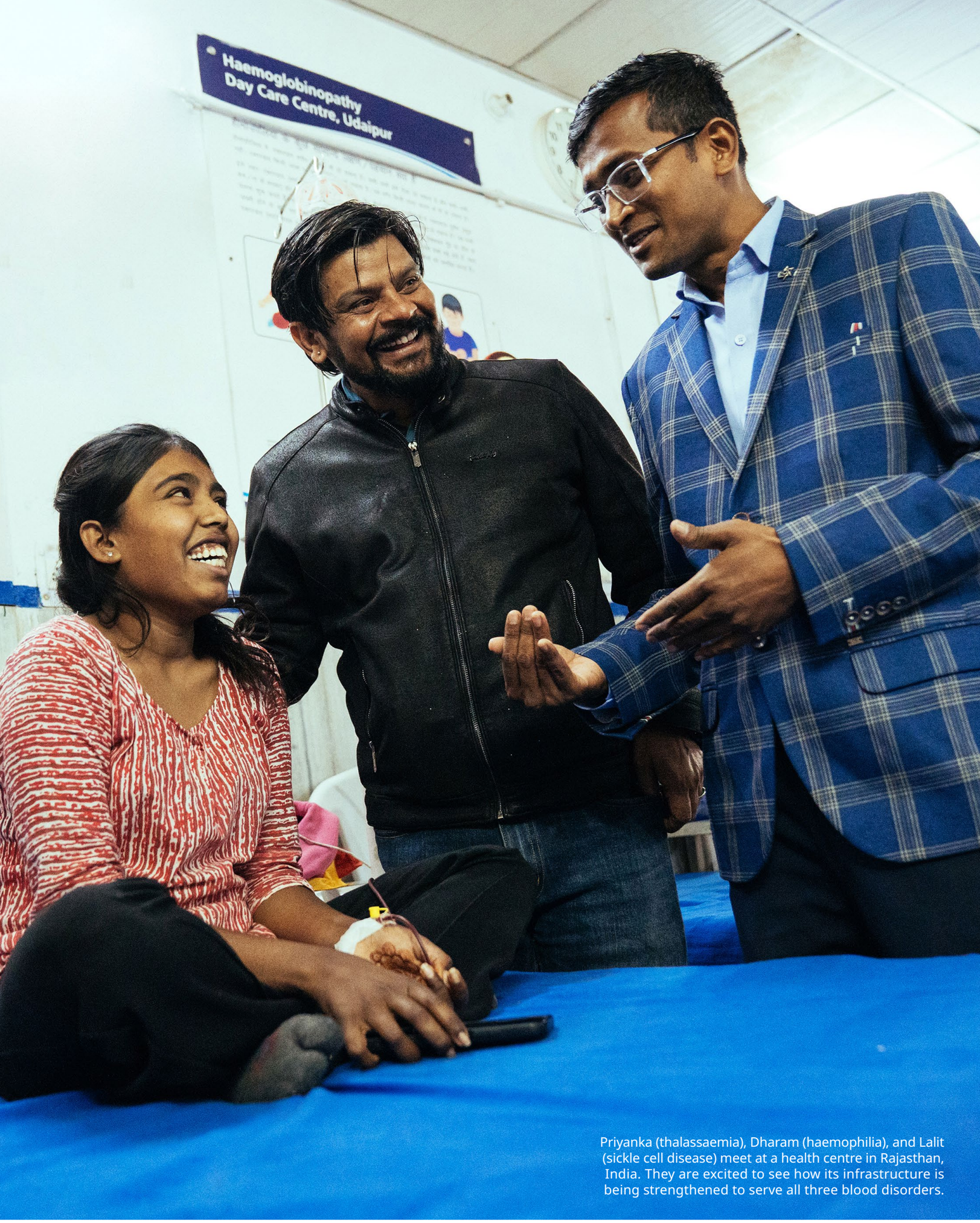


Priyanka (thalassaemia), Dharam (haemophilia), and Lalit (sickle cell disease) meet at a health centre in Rajasthan, India. They are excited to see how its infrastructure is being strengthened to serve all three blood disorders.

Impacting care. Together

novo nordisk haemophilia & haemoglobinopathies foundation

In a training organised by the World Federation of Hemophilia, NNHF Council Member Prof Margareth Ozelo (University of Campinas, Brazil) demonstrates treatment on Laércio Dias dos Santos Miguel. The training was held in Angola and NNHF funds enabled medical teams from Cape Verde and Mozambique to join as well.

VISION

All people with haemophilia and haemoglobinopathies access care and treatment, wherever they live.

MISSION

Together with our local partners, we improve access to care for people with haemophilia and haemoglobinopathies in low- and middle-income countries. Tailored to each country's unique context, our programmes grow from working alongside our partners. We go beyond funding. We co-define, co-create, and co-implement to pave the way to self-sufficiency. Always guided by our three areas of focus: building capacity and infrastructure, ensuring access to quality diagnosis, and advocating for systemic change.

Haemophilia is a rare, inherited bleeding disorder where the blood does not clot properly. The two main types are Haemophilia A (factor VIII deficiency) and Haemophilia B (factor IX deficiency). It primarily affects males, but females can be carriers and may experience bleeding symptoms. Globally, haemophilia affects over 836,000 males, yet fewer than half are diagnosed and registered.[1]

Haemoglobinopathies are blood disorders that affect the structure or production of haemoglobin – a condition that is lifelong, genetically inherited, and often underdiagnosed. The most common forms are sickle cell disease (SCD) and thalassaemia. According to the World Health Organization and Thalassaemia International Federation, an estimated 500,000 to 600,000 babies are born each year with SCD or thalassaemia.[2,3]

1. World Federation of Hemophilia, Annual Global Survey 2023: www1.wfh.org/publications/files/pdf-2525.pdf Last accessed: August 2025.
2. World Health Organization (2021) https://www.who.int/news-room/fact-sheets/detail/sickle-cell-disease. Last accessed November 2025
3. Thalassaemia International Federation (2023) https://thalassaemia.org.cy/publications/tif-publications/guidelines-for-the-management-of-non-transfusion-dependent-%ce%b2-thalassaemia-3rd-edition-2023/. Last accessed November 2025

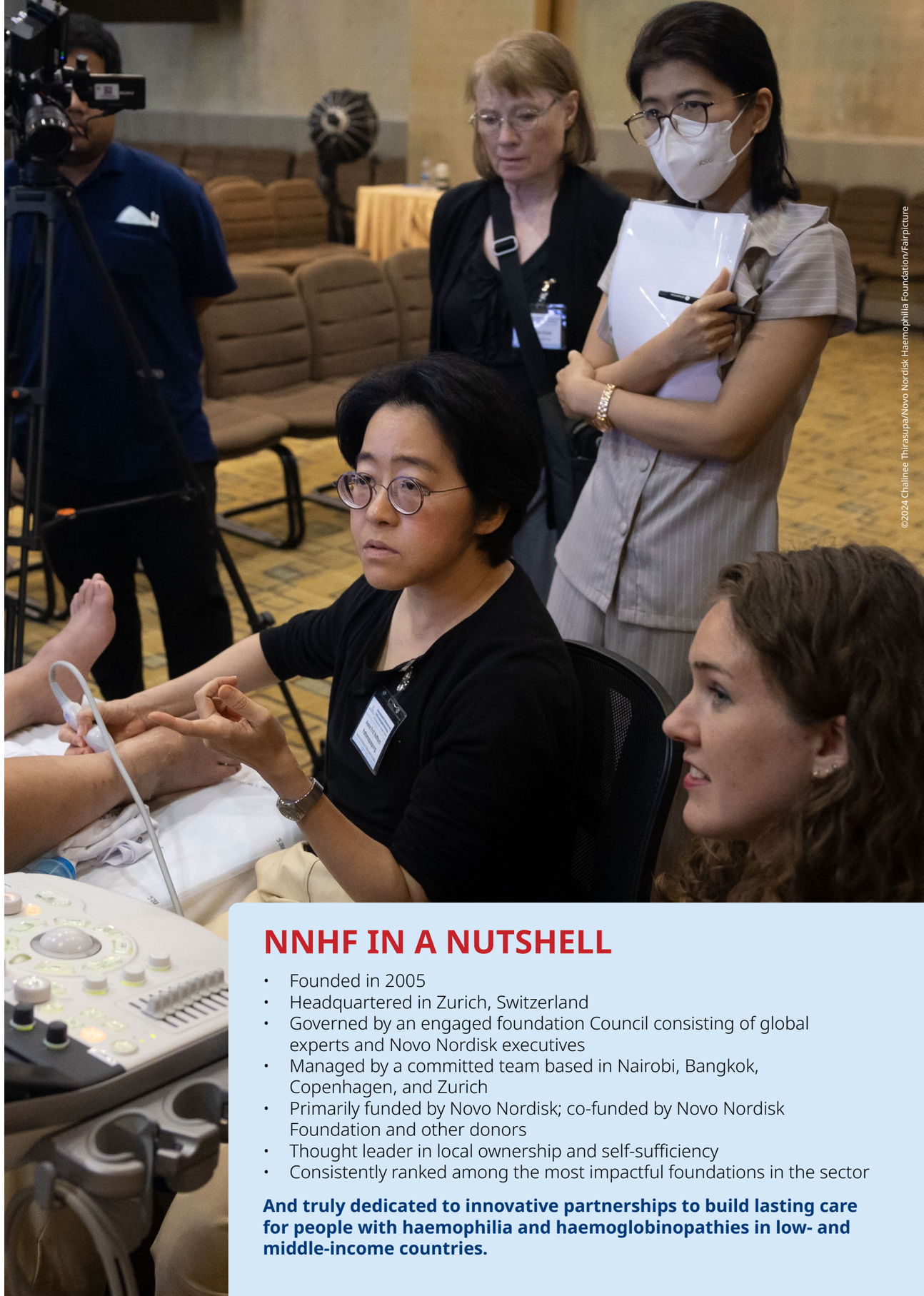
ADDRESSING CRITICAL HEALTH NEEDS

An estimated ten million people worldwide live with haemophilia or haemoglobinopathies. The vast majority reside in low- and middle-income countries.

These individuals face interconnected challenges that severely impact their health:

- **Limited access to comprehensive care:** Insufficient healthcare infrastructure and shortage of trained professionals prevent adequate care for the affected people.
- **Delayed diagnosis:** The lack of newborn screening and diagnostic facilities impede timely treatment.
- **Treatment gaps:** Limited availability and affordability of essential treatments lead to chronic pain.
- **Psychosocial impact:** Inadequate mental health and family support services hinder individuals to live up to their potential.
- **Policy barriers:** Insufficient healthcare policies and advocacy frameworks preserve stigma and misinformation.

By providing access to care and treatment, NNHF can prevent disability and death, and significantly improve the quality of life of people living with haemophilia or haemoglobinopathies.



A team from The Hospital for Sick Children (SickKids) of Toronto, Canada, teaches Thai haematologists, physiotherapists, and radiologists how to use point-of-care ultrasound to detect early signs of joint damage in a workshop in Bangkok, Thailand.

NNHF IN A NUTSHELL

- Founded in 2005
- Headquartered in Zurich, Switzerland
- Governed by an engaged foundation Council consisting of global experts and Novo Nordisk executives
- Managed by a committed team based in Nairobi, Bangkok, Copenhagen, and Zurich
- Primarily funded by Novo Nordisk; co-funded by Novo Nordisk Foundation and other donors
- Thought leader in local ownership and self-sufficiency
- Consistently ranked among the most impactful foundations in the sector

And truly dedicated to innovative partnerships to build lasting care for people with haemophilia and haemoglobinopathies in low- and middle-income countries.

PARTNERING TO EXCEL IN BUILDING LASTING CARE

Linking our global network with local expertise

Our partnerships have proven to be the seed for locally tailored solutions. Solutions that have grown roots to drive systemic change. No two programmes are identical. Our uniquely designed initiatives address the local context and lift local leaders while drawing from global best practices.

We excel in our partnering because we co-assess the needs and co-plan strategically, assist technically and build capacity, monitor regularly, manage adaptively, evaluate transparently, and share our knowledge.

We foster local ecosystems of funders, experts, and partners to create knowledge exchange, mentorship, problem-solving, and advocacy to amplify the impact of every programme. Because we believe in the power of network.

OWNERSHIFT

We equip our partners to take ownership and initiate necessary shifts:

- programmes led by our partners
- strategic support, resources, and expertise provided by NNHF

REAL INNOVATION

'Ownershift' creates true advancements:

- training hubs serving multiple countries
- regional coalitions for joint advocacy
- data-driven advocacy
- technology for innovative care

SELF-SUFFICIENCY

Locally rooted innovations create sustainable transformation:

- systemic change within the country's health care sector
- self-sufficiency in care delivery

Integrated care for bigger impact

Over two decades of partnerships on the ground have proven: we can achieve more comprehensive diagnosis and care, build stronger infrastructure, and generate more awareness when addressing multiple blood conditions simultaneously. Coordinated programming in low- and middle-income countries serve healthcare professionals and affected individuals in a more efficient way.

Depending on the regional context of the project, NNHF addresses one, two, or all three of the disorders - **haemophilia**, **sickle cell disease**, **and thalassaemia** - in a combined effort.

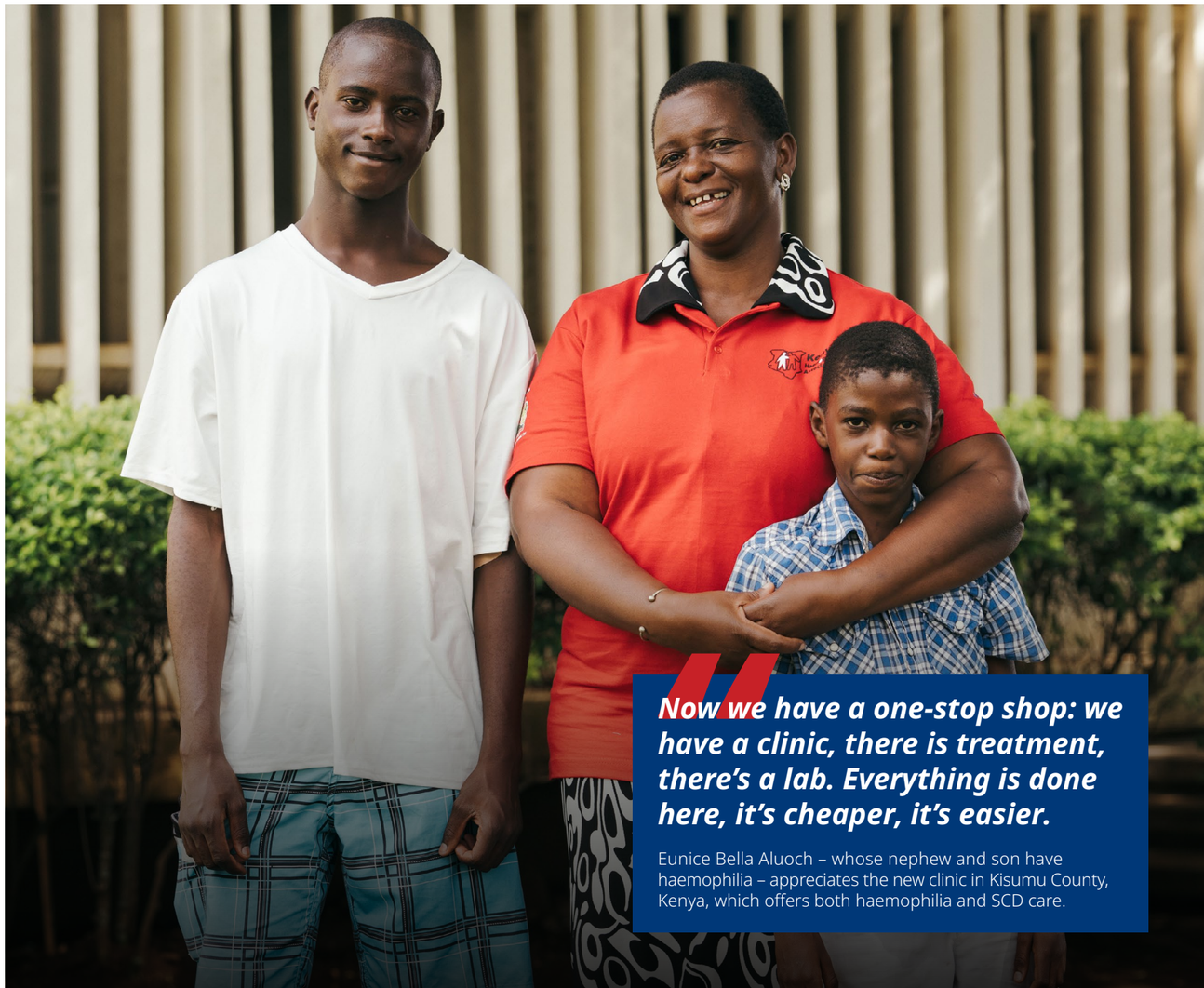
Triple focus for sustainability

Our projects focus on three areas to achieve systemic change. This framework has proven comprehensive in creating lasting transformation.

1. Capacity building and infrastructure
We strengthen infrastructure and train families, patient organisations, and healthcare professionals on-site or virtually.

2. Diagnosis and registry
We improve diagnostic skills and facilities, build registry systems to manage patient population, and implement quality assurance processes.

3. Awareness and advocacy
We equip the haemophilia and haemoglobinopathies community to raise awareness among the public and authorities to advocate for systemic change.



"Now we have a one-stop shop: we have a clinic, there is treatment, there's a lab. Everything is done here, it's cheaper, it's easier.

Eunice Bella Aluoch – whose nephew and son have haemophilia – appreciates the new clinic in Kisumu County, Kenya, which offers both haemophilia and SCD care.

Maria del Carmen Agurcia from Honduras, recipient of the NNHF Community Award in 2022: As the President of the Sociedad Hondureña Hemofilia from 2000 to 2013, she played a key role in strengthening the organisation and continues to serve as a source of inspiration for many.

GOVERNANCE AND TRANSPARENCY

We believe in solid governance structures to ensure the trustworthy functioning of our organisation.

The NNHF Council provides oversight and strategic guidance while ensuring alignment with our mission and values. It comprises Novo Nordisk executives alongside an equal number of renowned healthcare professionals from the regions we serve.

We adhere to Swiss Foundation Code principles to ensure the highest level of governance, accountability, and transparency in all our operations.

We value transparency in communicating:

What we do
- clear funding criteria
- our partner organisations

Honest learnings
- our successes and challenges
- our monitoring and evaluation practices for systematic improvement
- our proven best practices

Finances
- transparent financial reports
- independent annual audits

We are proud to be recognised by the Center for Effective Philanthropy (CEP) as a funder of highest transparency (2022).

AWARDING THE REMARKABLE

Annually, we celebrate outstanding achievements and honour exceptional work of our partners and within the haemophilia and haemoglobinopathies community.

Project of the Year Award

We recognise programmes that shine through excellent impact, leadership and true innovation.

Community Award

We honour individuals or groups for exceptional dedication and engagement in improving care.

JOIN OUR MISSION!

Partnership is the seed of everything we do. Because only together, can we combine knowledge and resources in unique ways to shape the specific solutions for the communities we serve.

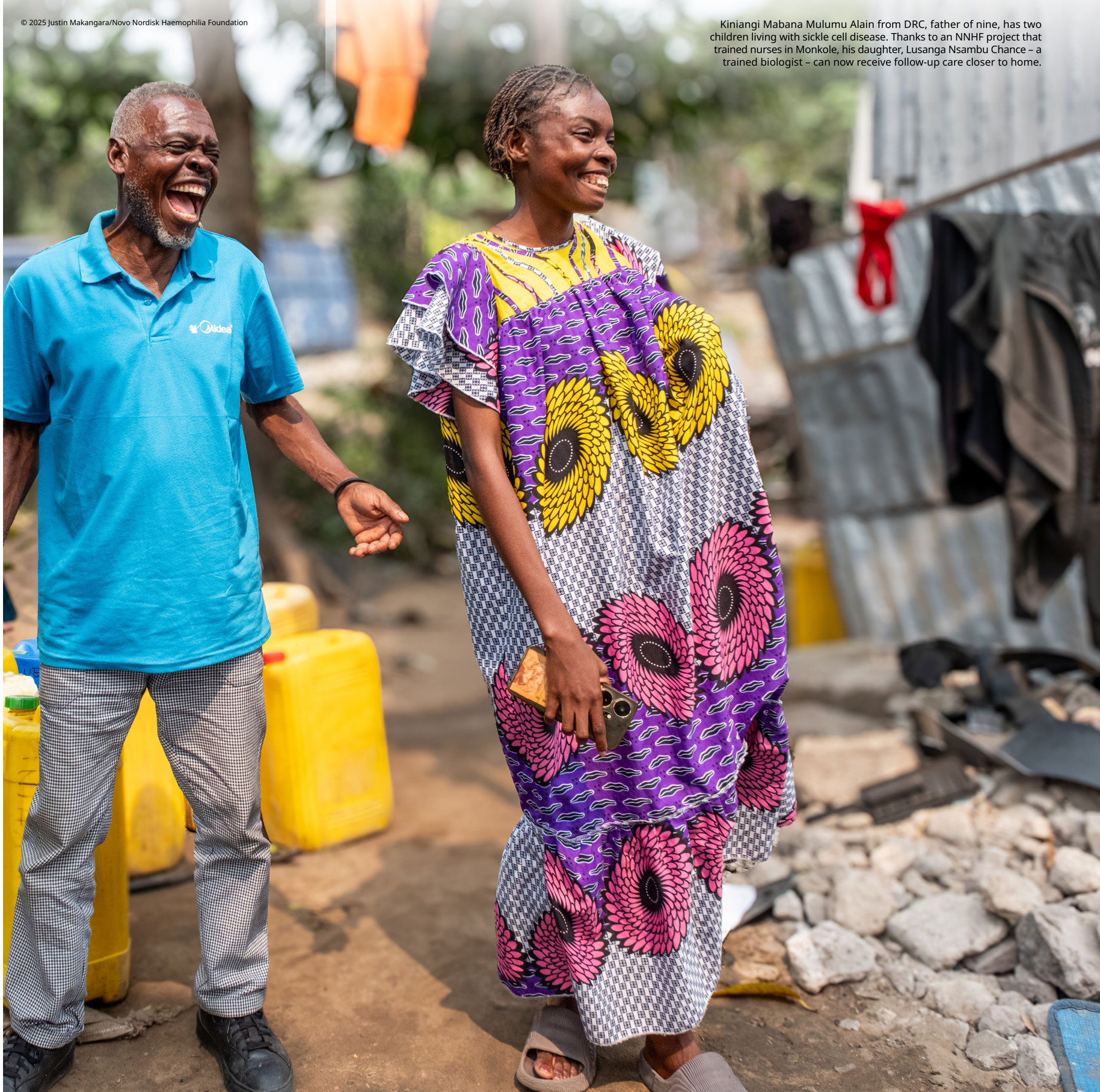
We call on you to join us in our mission.

As a potential project partner
We invite you to apply for a grant.

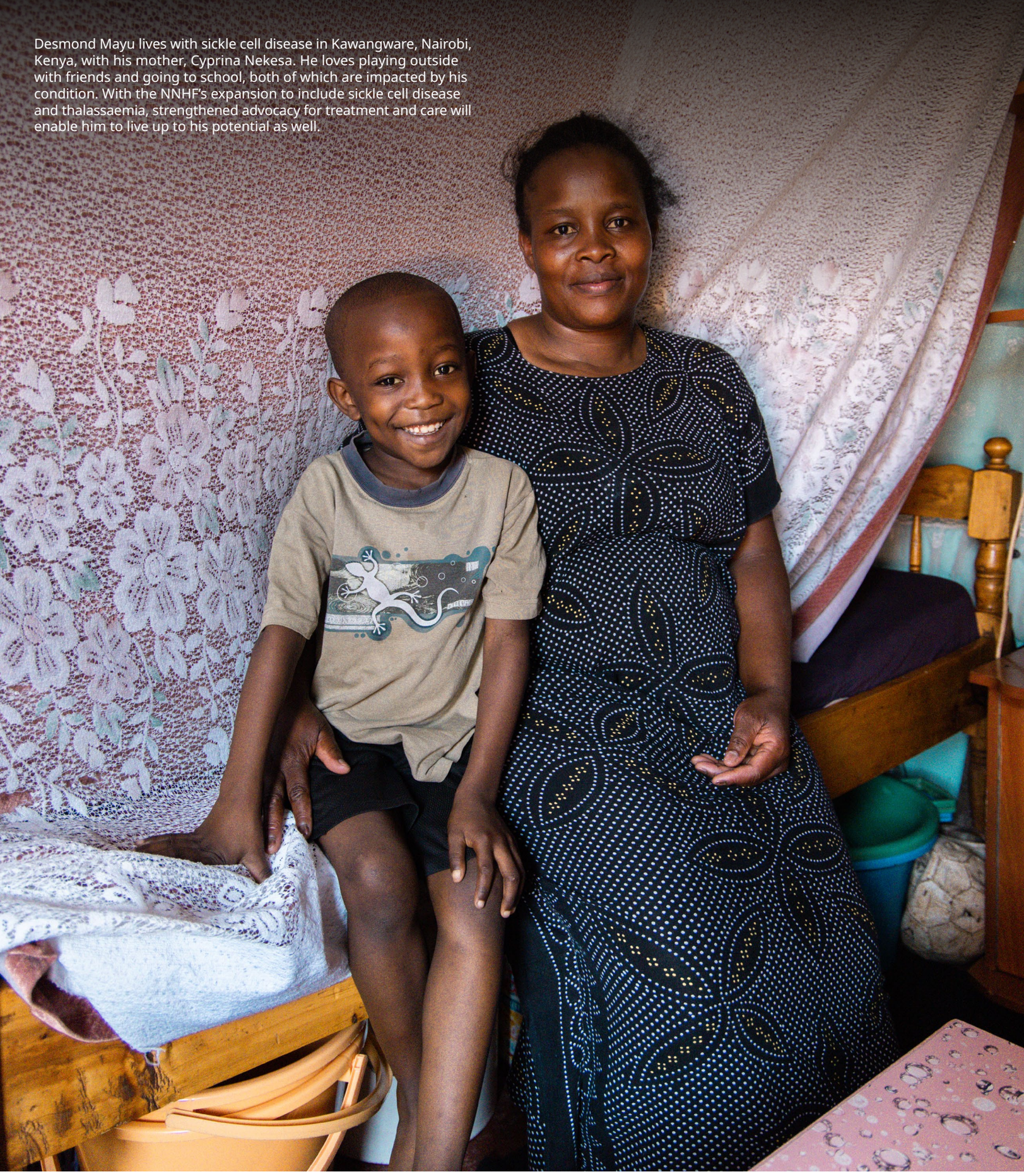
As global delivery or co-funding partners
We invite you to unite our efforts for even greater impact.

As expert volunteers
We invite you to become part of our global network and share your knowledge with our partner organisations.

Because we are impacting care.
Together



Kiniangi Mabana Mulumu Alain from DRC, father of nine, has two children living with sickle cell disease. Thanks to an NNHF project that trained nurses in Monkole, his daughter, Lusanga Nsambu Chance – a trained biologist – can now receive follow-up care closer to home.



Desmond Mayu lives with sickle cell disease in Kawangware, Nairobi, Kenya, with his mother, Cyprina Nekesa. He loves playing outside with friends and going to school, both of which are impacted by his condition. With the NNHF's expansion to include sickle cell disease and thalassaemia, strengthened advocacy for treatment and care will enable him to live up to his potential as well.

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