2025 AT A GLANCE

novo nordisk
haemophilia &
haemoglobinopathies
foundation

At Kaolack Regional Hospital, Senegal, with Dr Diarietou (Biologist, CNTS Dakar), Amadou Cheikhou Niang (Representative, Kaolack Regional Chapter of ASH), and Abdou Lahi Badiane, uncle to Ousmane Thioub, a young boy with haemophilia.

47 programmes running in 51 countries

In 2025, we strengthened the reach and momentum of our programmes. Our third coalition project in **East Africa** was launched, while partners in **Portuguese-speaking African and Latin American** countries initiated new activities to foster cross-border collaboration. A new regional project in West Africa was also approved, further expanding our impact.

Our partnership with the **Novo Nordisk Foundation (NNF)** was strengthened through a new co-funding agreement, guiding collaboration through 2030 and accelerating our strategic expansion **into haemoglobinopathies whilst deepening our commitment to haemophilia**. At the community level, the Community Award recognised **Agnes Kisakye** for her leadership and tireless advocacy within the Haemophilia Foundation of Uganda (HFU), which continues to identify and support people with haemophilia nationwide.

IMPACT **IN 2025**

Dr Anupam Dutta from Assam Medical College with Naresh (whose brother lives with sickle cell disease), Janardan (living with haemophilia) and Dr Ahmed (whose son lives with thalassaemia) discuss how their communities could benefit from an integrated approach to haemophilia and haemoglobinopathies.

KEY ACTIVITIES

159 treatment centres established or strengthened

2,868 healthcare professionals trained, 333 of whom received in-depth training

1,018 people with haemophilia and
3,277 people with sickle cell disease
re-tested or newly diagnosed

KEY OUTCOMES

An average **26-hour** reduction in travel time to receive care[1]

An average increase of **83%** in the number of people diagnosed[2]

SYSTEMIC CHANGE

One third of NNHF partners reported advocacy uptakes in 2025[3]

Total beneficiaries

64,049

NNHF programmes running in 2025 benefited people across three conditions:

52,143 people with haemophilia

11,506 people with sickle cell disease

400 people with thalassaemia

References: **1.** Average reduction in travel time across all running projects in 2025 based on partner reporting **2.** Across all running projects with diagnosis activities in 2025 based on partner reporting **3.** Examples of advocacy uptakes: Policy development, national blood disorders programmes, increase in annual budget allocated to haemophilia and/or haemoglobinopathies

PORTFOLIO HIGHLIGHTS

2025 saw the completion of 16 NNHF programmes, spanning four continents. Here are some of the highlights.

Improving rehabilitation and care for people with haemophilia in Honduras

Honduras successfully completed its three year NNHF supported Healthy Joints programme, expanding rehabilitation and strengthening haemophilia care nationwide. Key achievements include:

- A national physiotherapy network through partner organisation Teletón, specialised equipment, and international training for three physiotherapists, improving access across six centres
- 100% of surveyed participants reported better quality of life, with major improvements in mobility, adherence, and physical activity
- Two haematologists trained abroad to support the next generation of leaders, 178 medical students reached, and a new national patient registry established to support long term planning and sustainability

Uncover more

Strengthening coalitions for haemophilia and sickle cell disease in East Africa

In East Africa, one of our longest running coalition projects completed its second phase. Spanning Kenya, Tanzania, Uganda and Rwanda, achievements in this phase include:

- Expanded haemophilia and sickle cell care through the strengthening/ establishment of 28 centres across the four countries, reducing journeys to receive care by up to 10 hours
- A 28% average increase in the number of people diagnosed with haemophilia, with 538 people diagnosed and haemophilia registries in place across all countries
- Government commitments secured for haemophilia, including endorsement of national treatment guidelines, budget allocation to reagents, and the establishment of a regional training hub at Kenya Medical Training College

The project's third phase began in June 2025, aiming to further integrate the approaches for haemophilia and sickle cell disease, with a focus on screening, diagnosis and policy advocacy.

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Decentralising haemophilia care in Indonesia

Indonesia is comprised of over 17,000 islands. For people with haemophilia living in East Nusa Tenggara, West Kalimantan, West Sumatra and Papua, accessing care and treatment could mean travelling to provinces located up to 3,700 km away. Through the third NNHF project:

- Basic care in all four provinces is available for the first time, due to the establishment and training of multidisciplinary teams (haematologist, nurse, physiotherapist)
- Lab technician training enabled the first diagnoses in Kupang, the capital of East Nusa Tenggara, and two provincial hospitals began procuring reagents

The team will continue to drive diagnostic efforts through family-tree tracing, whilst exploring strategies to further standardise care across provinces.

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