Haemophilia and sickle cell disease:
Increasing our impact together in Guinea

We are pleased to announce the signing of a new partnership agreement between the Novo Nordisk Haemophilia Foundation (NNHF) and the Fondation Pierre Fabre (FPF) to jointly improve awareness, diagnosis, care, and advocacy for blood disorders in Guinea. The two foundations have signed a Memorandum of Understanding (MoU) to leverage synergies through their respective programmes following a request by Guinea's Ministry of Health for a joint approach to haemophilia and sickle cell disease in the country.

The two-year agreement provides a framework for FPF and NNHF's collaboration and co-funding of activities in Guinea. The FPF has been involved in the fight against sickle cell Disease in Guinea since 2019 in partnership with SOS Drépano-Guinée that has set up a medical centre dedicated to sickle cell disease in the capital Conakry (following-up on 6 000 patients). FPF and SOS Drépano-Guinée now aim at decentralising diagnosis and care, making them available also in remote regions. NNHF leads a programme in the country designed to raise awareness and healthcare access for people with haemophilia, especially outside the capital city. Both programmes are advocating for blood disorders to be included in the national health policy.

Diagnosis rates remain low in Guinea: around 3% for haemophilia, with more than 1,300 people thought to live with the disorder. The estimated prevalence of carriers of the sickle cell trait is between 15 to 20% of the Guinean population. The incidence of sickle cell disease at birth is estimated to be 1.5%. The geographically diverse country stretches from the West African coast through tropical forests to the Sahel, with poor road systems making it even more challenging for people with blood disorders to travel to receive diagnosis and care.

The Fondation Pierre Fabre is striving to improve access to care for patients with sickle cell disease in Africa and Haiti since 2006, currently running 8 programmes in 9 countries. Being one of the world's foremost genetic diseases, sickle cell disease is believed to affect more than 250,000 newborns in sub-Saharan Africa each year. Guinea is one of the countries most severely impacted by the painful hereditary disease, which can be fatal if not properly treated. Patients often find themselves forced to seek care in other countries in the sub-region, such as Mali, Senegal or Côte d'Ivoire.

Véronique Teyssié, Programme Manager, FPF, says: "*We want to encourage greater screening of newborns and young children, as early treatment helps slow the disease's progress. The timing of our partnership with the NNHF is ideal for facilitating joint activities in terms of both advocacy at the national level and improvement of access to quality care for people living outside of Conakry*."

The NNHF is implementing its first project in Guinea in 2023 with the objective of raising awareness of haemophilia and increasing the diagnosis rate to 9% by 2024. The project will also advocate for integrated data of haemophilia and sickle cell disease to improve efficiency in providing care for rare blood disorders.

Denise Braendgaard, NNHF General Manager, said: "We look forward to a fruitful partnership with FPF based on our positive experience in Burkina Faso since 2021. By combining our efforts on blood disorders in Guinea, we are confident that we will be able to increase our impact together in order to benefit the greatest number of people."

The Novo Nordisk Haemophilia Foundation and Fondation Pierre Fabre will create a steering committee to secure a well-functioning partnership, oversee programme implementation, and jointly monitor outcomes and impacts of common initiatives.