LET’S MAKE
SICKLE CELL
DISEASE A PUBLIC-
HEALTH PRIORITY

FONDATION PIERRE FABRE
Recognised as being of public utility
Fifteen years after the Fondation Pierre Fabre’s first initiatives, it has become one of the most important actors in fighting sickle cell disease in Africa through its frontline involvement in treating patients and relieving their symptoms, coordinating prevention and research, supporting local entities, and continually raising the awareness of governments and international organisations involved in health care.

Sickle cell disease which is the world’s foremost genetic disease and the fourth-largest pandemic in Africa is a poorly understood illness that is largely absent from major international aid programmes, each year, an estimated 300,000 children are born with the disease, two-thirds of them in sub-Saharan Africa. While its symptoms can be significantly alleviated with early treatment, it remains a major cause of infant mortality; without treatment, half of all children born with the disease will not live to the age of five. And the future looks grim; the demographic evolution of Africa – which the WHO declares will be home to more than 40% of world births in 2050 – presages an explosion in the number of cases on a continent that already bears the heaviest sickle cell disease burden.

LAYING THE FIRST STONE IN 2006 IN MALI
For more than 15 years, the Foundation has worked to ensure recognition, research, screening and treatment of the disease. Our first concrete initiative was in Mali. In 2006 the Foundation convened public and private partners, established a financial blueprint and created the Sickle Cell Disease Research Centre (CRLD) in Bamako, part of a collaboration agreement with the Ministry of Health and Public Hygiene. In January 2010, the CRLD opened its doors to fulfill several missions: patient screening and treatment, raising public awareness, training healthcare professionals and implementing research projects.

PROGRESSIVE WORLDWIDE EXPANSION
Based on the work carried out in Mali, the Fondation Pierre Fabre has been operating since 2011 in the Central African Republic and the Democratic Republic of Congo, extending programmes into Madagascar, Cameroon and Burkina Faso. Our objective each time is to provide on the ground assistance and scientific expertise. This is done not only to improve prevention, early diagnosis and treatment, but also to support research programmes and establish the necessary conditions for an effective, sustainable and coordinated health response by all entities involved in combatting this disease.

SICKLE CELL DISEASE IN AFRICA AND AROUND THE WORLD

World’s leading genetic disease according to the WHO. 4th largest pandemic in Africa 50% infant mortality before the age of 5 in some African countries

50 Million individuals affected, mostly in Africa and the Caribbean Up to 40% prevalence of the sickle cell gene in sub-Saharan Africa

SICKLE CELL DISEASE
Sickle cell disease is a genetic disorder of the haemoglobin. It primarily manifests in the form of anaemia, susceptibility to infections and very painful seizures caused by poor blood circulation and insufficient tissue oxygenation.
GLOBAL ADVOCACY
"AFRICAN SICKLE-CELL INITIATIVE"

In Paris, on 26 March 2019, in an effort to alert the international community and support the mobilisation dynamics of the various countries affected by the disease, the Fondation Pierre Fabre brought together the Nigerian and Central African Ministers of Health, representatives of the Ministers of Health of Togo, Kenya, Burkina Faso and Burundi, WHO representatives and fourteen experts from eleven African and Indian Ocean countries.

At the end of this gathering, dubbed the “African Sickle-Cell Initiative,” the participants adopted a joint declaration calling for the disease to be taken into account on the global health agenda. They formalised six priorities for action to respond to the urgent need to act to assist the millions of sickle cell sufferers and their families.

These priorities include the need to Institutionalise systematic neonatal or early screening in legal and national frameworks, to integrate screening and treatment for sickle cell disease on all tiers of the health pyramid and to promote coordination of policies and strategic plans to combat sickle cell disease at national, pan-African and international levels.

MEETING
On 15 June 2022 in Paris, the Foundation is hosting the second meeting of the African Sickle-Cell Initiative, bringing together 33 participants from 13 French-speaking and English-speaking African countries.

The meeting’s objective is to take stock of progress made in the fight against sickle cell disease in each country and to assess the needs and priorities that would lead to sickle cell disease being officially considered a public health priority. This brainstorming session will be broadened through a joint working session with The American Society of Hematology.

This event is being held in parallel with the Fourth Global Congress on Sickle Cell Disease, taking place in Paris for the first time and uniting more than 400 specialists from across the globe (16-18 June). The Fondation Pierre Fabre is one of the major partners of the congress, facilitating the participation of more than thirty experts, specialists and physicians from Africa.

AN INTEGRATED APPROACH TO INCREASE PROJECT IMPACT AND SUSTAINABILITY

Today, our programmes cover ten African countries and are structured in an increasingly globalised approach designed to build solid institutional frameworks as springboards for implementing effective policies to fight the disease.

In several African countries, we provide support to public authorities such that the conditions for a national strategy for treating the disease are maintained, as they are for HIV or malaria.

In 2020, this systemic approach became more concrete in the Democratic Republic of Congo when a national plan to fight sickle cell disease was established. The objective of the pilot project supported in three health zones in the DRC is to integrate treatment of the disease into the essential health services package. This commitment was further strengthened in 2021 with the “Drép.ACCI” programme covering Central Africa and Côte d’Ivoire, which places the Fondation Pierre Fabre among the world’s experts in fighting sickle cell disease.

THE IMPORTANCE OF EARLY SCREENING

The first symptoms of sickle cell disease appear in infants when they are three or four months old. But if it is detected too late, after a serious seizure, it can cause irreversible clinical manifestations. Neonatal screening coupled with early treatment, however, can lead to lasting improvement in the condition of young patients.

It is a major lever for reducing the disease’s complications and infant mortality rate.
For more than 15 years, the Fondation Pierre Fabre has been joining forces with local structures involved in the prevention, diagnosis and treatment of sickle cell disease, with a sole conviction: the need to build a structured institutional framework with national health authorities.

**CURRENT PROGRAMMES**

8 PROGRAMMES IN 9 COUNTRIES:

- **Mali**: Creation and development of the Sickle Cell Disease Research Centre (CRLD) in Bamako.
- **Burkina Faso**: National programme supporting the Ministry of Health and CSOs.
- **Guinea Conakry**: Support in equipping and operating the centre in Conakry, managed by the NGO SOS Driépanocytaires.
- **Haiti**: Neonatal screening at the Saint Damien Pediatric Hospital in Port au Prince.
- **Madagascar**: Support for treatment and screening of new-borns (in partnership with the IMRA).
- **RDC, Cameroun, RCA, Côte d’Ivoire**: Multi-country project co-financed with the AFD.
- **RCA**: Support for the sickle cell disease research and treatment centre in Bangui.
- **E-drepanocytose**: A free training platform for healthcare professionals.

**CONTEXTUALISE RESEARCH**

Pr Aldiouma Guindo, Deputy Director of the Sickle Cell Disease Research Centre in Mali.

“Thanks to the support of the Fondation Pierre Fabre, we have begun using software to collect and analyse clinical data to prepare for clinical research projects. These advances will help inform national strategies and policies to fight sickle cell disease.”

**DISSEMINATE KNOWLEDGE**

The CRTD organises remote training sessions in peripheral areas to create a “sickle cell ecosystem” in the CAR and to improve treatment of the disease at the bottom tiers of the health pyramid.

**Malu**

The Foundation provides technical and financial support to the Sickle Cell Disease Research Centre (CRLD), which covers screening, treatment and hospitalisation activities (more than 14,000 patients), research, training and awareness-raising.

**Central African Republic**

The Fondation Pierre Fabre supports the Sickle Cell Research and Treatment Centre (CRTD) in Bangui.

The CRTD is the country’s only referral institution and receives financial support for training and purchasing medicines and equipment.
Burkina Faso

Cofinanced by the Agence Française de Développement, the Drépa-Faso programme is designed to support the Burkinabè Ministry of Health in developing a specific framework for the fight against sickle cell disease and implementing a national programme that helps improve living conditions for sickle cell patients.

Over the three years that this project will be rolled out, it is expected to screen more than 53,000 new-borns, 18,000 children and 7,000 pregnant women.

This means that more than 1,200 new-borns and children will benefit from medical treatment thanks to early detection.

Guinea

The Foundation supports the Sickle Cell Disease Control Centre in Conakry to increase the centre’s human and technical capacities and ensure its financial autonomy.

**RESPOND TO A PUBLIC HEALTH EMERGENCY**

According to statistics published in 2019 by the Donka National Hospital in Conakry, 20% of the Guinean population carries the sickle cell trait.

DRC, Cameroon, Central African Republic, Côte d’Ivoire

Launched in 2021, Drép.ACCI is a new milestone in the fight against sickle cell disease and its integration into the global health agenda.

The main objective of this large-scale programme co-financed by AFD is to support state governments in developing national policies to combat the disease.

Haiti

The project initiated in Haiti is achieved through the Saint Damien Pediatric Hospital, the Hôpital Universitaire de la Paix and the State University of Haiti Hospital.

**SYSTEMATISE EARLY SCREENING**

Jacqueline Gautier, general manager of Saint Damien Hospital in Haiti.

“It is essential that the children of Haiti benefit from the early screening that has been in place for more than 30 years in Europe and North America. Our first objective is to make this service available to as many people as possible, because it greatly improves the prognosis and quality of life.”

**INTEGRATE THE DISEASE IN NATIONAL HEALTH STRATEGIES**

Léopold Nzambimpungu, Deputy National Director of the National Sickle Cell Disease Control Programme of the DRC Ministry of Health.

“The objective is to integrate sickle cell disease into the essential health services package, as is already the case for HIV-AIDS, malaria and tuberculosis. With one priority: children, whose mortality rate is particularly high in remote rural areas.”
**E-DREPANOCYTOSE: FREE ONLINE COURSES FOR NURSES AND DOCTORS**

E-drépanocytose is a free training space designed in 2020 with the help of the Université Numérique Francophone Mondiale (World Francophone Digital University) to help healthcare professionals in French-speaking Africa detect and treat sickle cell patients.

It is the first training platform dedicated to the disease and anticipates the coming rise in the sickle cell population linked to demographic growth in Africa and an increased need for personnel trained in treating the disease.

The platform currently offers nearly six and a half hours of lessons divided into two levels, with 305 professionals from 21 countries registered on the platform. Creation of E-drépanocytose was on the initiative of the Fondation Pierre Fabre and the European Institute for Cooperation and Development with the support of the Coopération internationale de la Principauté de Monaco, RAFT (Réseau en Afrique Francophone pour Telemedicine) and the Agence Française de Développement.

https://e-drepanocytose.org/

**Béatrice Garrette,**
Executive Director of the Fondation Pierre Fabre

"E-drépanocytose does not replace a university degree, but it is a tool upon which health authorities in African countries can rely in the initial and/or continuous training of healthcare personnel."
RESEARCH PROGRAMMES

To Improve the degree of awareness and understanding of the disease and to generate data in an African context, we are acting as promoter and/or investigator for several research programmes.

**Infant Mortality - MIDAS Study**
Mali, Côte d’Ivoire, Senegal, DRC, Burkina Faso

MIDAS, an epidemiological study conducted with Inserm Unit 970 and the Institut Necker, assesses infant and child mortality attributable to sickle cell disease in five sub-Saharan African countries (sample of more than 8,000 children).

In 2020, the results showed 25% excess mortality in children under 10 born to families with sickle cell disease.

**Rapid-screening tests - Drépatest III project**
Mali

Drépatest is designed to evaluate the diagnostic performance of two rapid-screening tests and compare the results with those from the reference testing technique used at the Sickle Cell Disease Research Centre (CRLD) in Bamako (samples from 4,000 new-borns). The results will confirm the feasibility of widespread use in sickle-cell screening programmes at birth.

**Pharmacological evaluation – Traditional medicinal plants**
Madagascar

The Foundation is working in collaboration with the Malagasy Institute for Applied Research as part of a pharmacological and toxicological evaluation of medicinal plants traditionally used in treating sickle cell disease.

**IMPAS study – Sickle cell disease and malaria**
Cameroun

Conducted with the Centre Pasteur in Cameroon, IMPAS assesses the impact of the sickle cell trait on malaria transmission (cohort of 5,000 individuals). Laboratory tests began in 2021.

PROVISION OF HYDROXYUREA THERAPY

To combat the underuse of hydroxyurea, whose effectiveness in preventing and alleviating the symptoms of sickle cell disease has been established by multiple studies, the Foundation is studying several partnership avenues to ensure access to the therapy on the African continent. Clinical studies show a drastic reduction in the frequency and intensity of chest syndromes, with a direct impact on quality of life and life expectancy.
Created by Pierre Fabre, founder of the laboratories of the same name, the Fondation Pierre Fabre was awarded charitable status on 6 April 1999, declared by the French State as working in the public interest. The Foundation’s head office is in Castres, France, and its administrative headquarters are in Lavaur, in that country’s Tarn département. The Fondation Pierre Fabre acts disinterestedly and independently to achieve its strictly humanitarian goal. Its mission is to enable communities from the world’s less-advanced and emerging countries, as well as those plunged into severe crises by political or economic upheaval and/or natural disaster, to access the quality and levels of everyday healthcare and the widely used drugs defined by the WHO as being essential to human health.

The Fondation Pierre Fabre is also the main shareholder of the Pierre Fabre Group, with an 86% share. This organisation, unique in France at this level of commitment, makes it possible to endow the Foundation with sustainable means to finance its work. The Fondation Pierre Fabre is not directly involved in the operational management of the Group, devoting itself exclusively to performing the work set forth in its statutes. The Fondation Pierre Fabre is an operating foundation that designs and develops its own programmes in close collaboration with local partners. In 2022, it is leading more than 35 programmes in some twenty countries in Africa, Southeast Asia, Lebanon and Haiti.

It has structured its initiatives around five areas of intervention:
Training pharmaceutical specialists to strengthen health systems and increase the availability of quality medicines. Main countries of intervention: Laos, Cambodia, Vietnam, Togo, Madagascar.
Combating sickle cell disease, the world’s leading genetic disease and the fourth-largest pandemic in Africa. In this fight, the Foundation supports local treatment facilities, helps institutions set up disease-control programmes, promotes research and performs advocacy work. Main countries of intervention: Mali, Burkina-Faso, DRC, Cameroon, Côte d’Ivoire, CAR, Conakry-Guinea, Senegal, Haiti.
Access to quality healthcare, for vulnerable communities in crisis contexts. This commitment is particularly focused on two fronts: in Lebanon, access to healthcare for Syrian refugees and underprivileged Lebanese. In the DRC and CAR, treating victims of sexual and gender-based violence through support for the staff of Dr Mukwege, winner of the 2018 Nobel Peace Prize.
EHealth, which provides a tremendous opportunity to reduce healthcare inequalities. Since 2016, the Fondation Pierre Fabre has been honing its expertise in this realm, which it uses to enhance the skills and capacities of health authorities and entities working in the field. Each year, through its Global South eHealth Observatory (www.odess.io), the Foundation identifies and supports the most promising initiatives designed to serve poor populations in Africa and Asia.
Dermatology: skin diseases are a neglected public health problem in the Global South. The Foundation primarily focuses on developing two model programmes: 1) Applying telemedicine in the realm of dermatology for teleconsultations, connecting health workers and specialists to make remote diagnoses possible and to compensate for the lack of dermatologists. 2) Prevention and treatment of skin cancer in people with albinism in Africa. Main countries of intervention: Mali, Togo, Mauritania, Tanzania, Malawi, Burkina-Faso, Niger, Côte d’Ivoire.