

**Lessons learned from one decade  
experience of the « Centre de Recherche  
et de Lutte contre la Drépanocytose  
(CRLD) » in Bamako, Mali**

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# Introduction

- **The CRDL "Centre de Recherche et de Lutte contre la Drépanocytose" is established in 2010 with:**
  - **The support of a consortium of partners set up and led by the Pierre Fabre Foundation;**
  - **A strong commitment from the Malian government;**
  - **And an active associative life ("Association Malienne de Lutte contre la Drépanocytose": AMLUD),**

# **The missions attributed to the Center**

- **Missions assigned to the were to :**
  - **Ensure access to quality care with equity**
  - **Develop medical research on sickle cell disease**
  - **Train medical staff on sickle cell disease**
  - **Develop information & awareness on sickle cell disease**
  - **Promote national and international partnership in research**

## **Recruitment and retention strategies for medical follow-up (minimization of drop-outs)**

- **The mission to ensure equity in access to care for all was based on three principals:**
  - **The non-payment of fees before care**
  - **Payment of fees according to the patient's convenience**
  - **Partial payment of the fees by the patient, i.e. 40% of the fees.**

## Some achievements in medical care

- ✓ Center has enrolled overall 1,000 new patients per year, achieving more than 12,000 in 2020
- ✓ Sickle cell mortality in the Center in 2020 as showed in this table is:
  - 👉 lower than those reported in Tanzania in 2011
  - 👉 and close to those reported in the United Kingdom in 2007 and the United States in 2010.

Age (group)	Number of patients	Nombre of deaph	Mortality rate (100 person-year)
≤ 5 years	1233	17	0.06 (0.34 – 0.90)
6-15 years	3972	36	0.18 (0.13 – 0.25)
≥ 16 years	7523	171	0.36 (0.31 – 0.42)
<b>Total</b>	<b>12728</b>	<b>224</b>	<b>0.32 (0.28 – 0.36)</b>
Tanzanie (Makani et al, 2011)			1,9
UK (Telfer et al, 2007)			0,15
USA (Quinn et al, 2010)			0,6

# Major difficulties

- Three major difficulties :
  - A low ratio of healthcare workers /number of patients;
  - A low number of researchers' staff;
  - No significative strengthening of research staff
  
- While the Center has trained more than 200 healthcare workers and more than 300 communicators, it has published only **26 scientific papers** versus **a minimum of 70** over 10 years

Human ressources	2010	2019	Balance
General Practitioner	3	6	+ 3
Hematologist	3	3	0
Pediatrician	0	2	+ 2
Biologist	2	2	0
Psychologist	0	1	+ 1
Researcher	3	4	+ 1
Biostatistician	0	1	+ 1
Clinical Research Associate	0	2	+ 2
Data entry Technician	0	3	+ 3

# The Center's Challenges & lessons

- **Two major challenges :**
  - **First : How can CRLD maintain quality and equity of care with a limited number of staff in the face of continuous annual enrolling of more than 1,000 new patients?**
  - **Secund : How can the CRLD best conduct its research mission?**
- **👉 We propose to re-define the missions of CRLD in the framework of healthcare pyramid as this diagram shows.**

# Sickle Cell Network

## HEALTH CENTERS

## MISSIONS

### Third level

Referral Centers

EPH

- Training +++
- Research +++
- Conception
- Program coordination
- Organization/Follow-up/evaluation
- Specific care

### Second level

Competency Centers

CSREF ou Hôpitaux de District

Hôpitaux régionaux

- Diagnosis +++
- Screening (NBS +++)
- management of emergencies +++
- Follow up +++
- Information/awareness

### First level

Competency Units

CSCOM

CLINIQUES

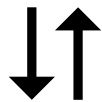
Infirmieries de Garnisons

CMIE

Structures confessionnelles

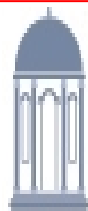
Accoucheuses traditionnelles

- Screening (NBS ±)
- Diagnosis and Care +++
- Follow up +++
- Information/awareness





# Aknowledgements



FONDATION PIERRE FABRE



GROUPE BANK OF AFRICA

