



PAE

Projeto Atenção Especializada

Workshop:

Projeto Atenção Especializada para Doença Falciforme

REALIZAÇÃO:



UFMG



APOIO:



Ministério da
Saúde





*Newborn Screening and the Healthcare System for
Sickle Cell Disease in Minas Gerais*

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Federal University of Minas Gerais - Brazil





Minas Gerais - Brazil

National Brazilian Newborn Screening Program

Implemented in 2001 for:

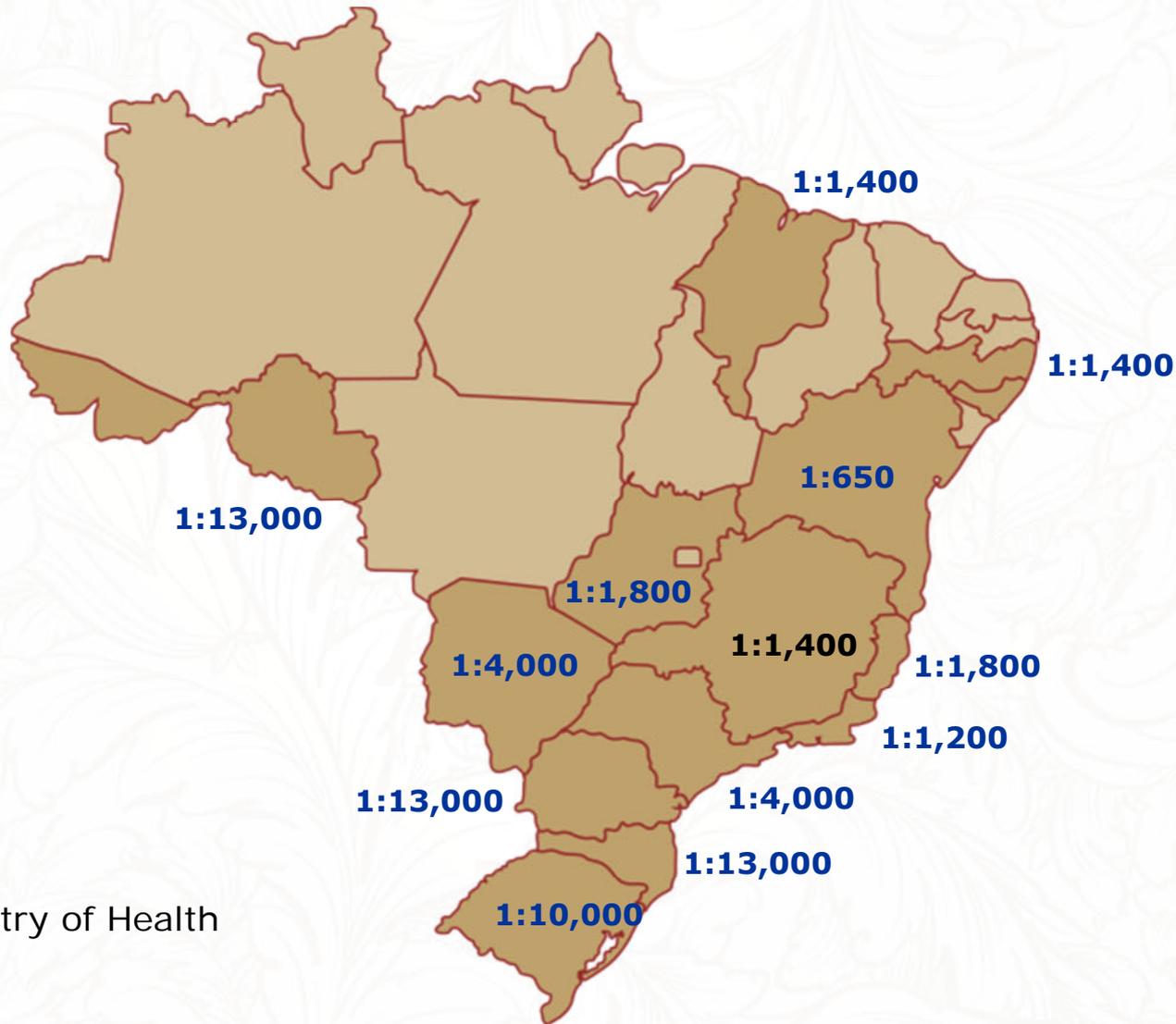
- Phenylketonuria
- Congenital Hypothyroidism
- Sickle Cell Disease (1998 in Minas Gerais)
- Cystic Fibrosis

Expanded in **2013** for:

- Biotinidase Deficiency
- Congenital Adrenal Hyperplasia

Sickle Cell Disease in Brazil

Incidence in newborns per State



Source: Ministry of Health



20 million inhabitants

590,000 km²

853 counties

Live Births (LB) 2009

CALIFORNIA
527,000 LB

TEXAS
402,000 LB

NEW YORK STATE
248,000 LB

MINAS GERAIS
260,000 LB

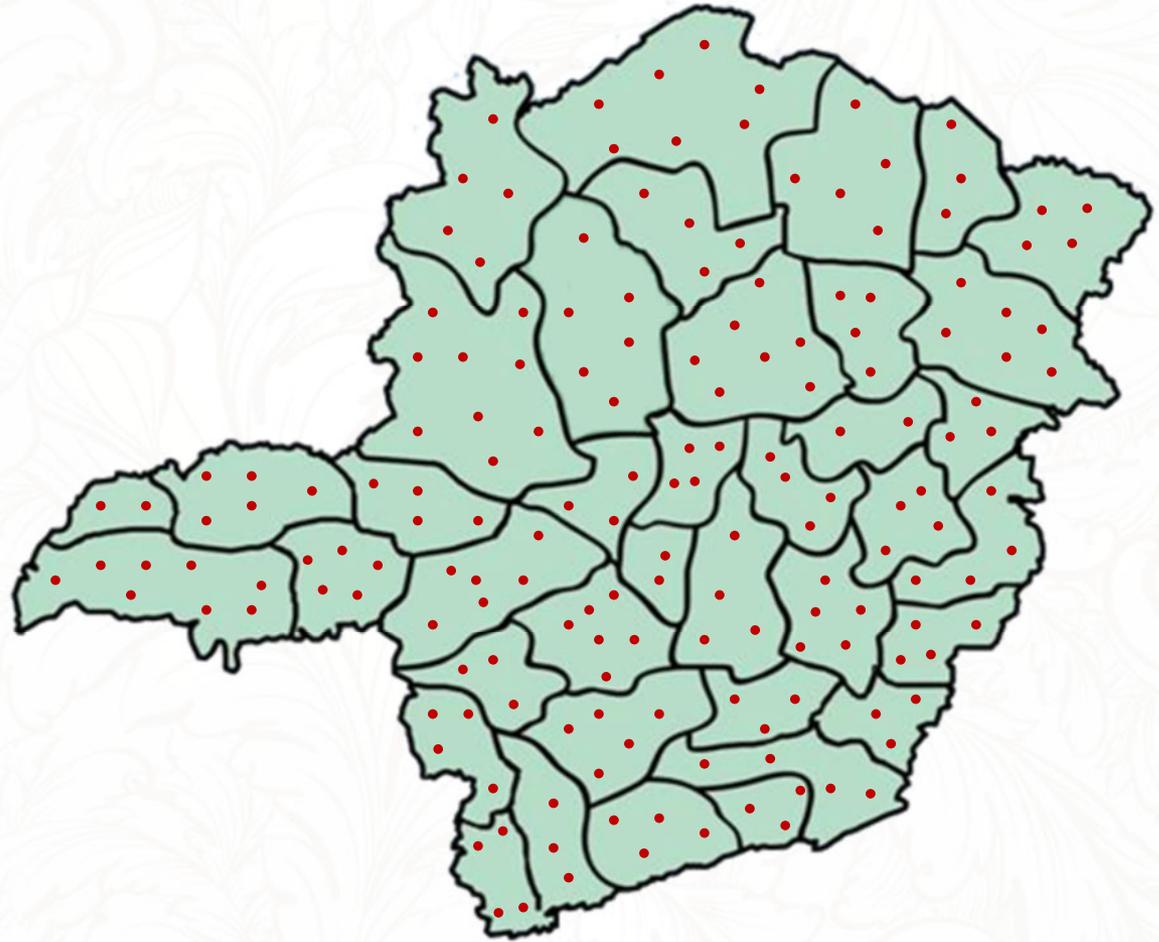


Screened babies

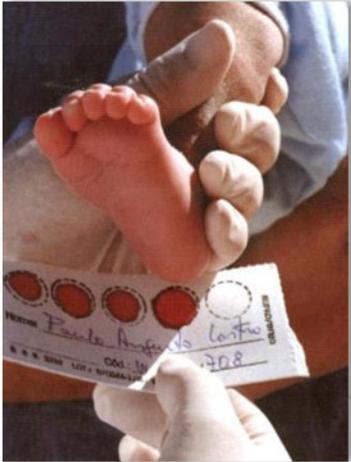
sept/1993 to feb/2014

Congenital hypothyroidism	4,9 million	(since 1993)
Phenilketonuria	4,9 million	(since 1993)
Sickle Cell Disease and other hemoglobinopathies	4,1 million	(since 1998)
Cystic Fibrosis	2,6 million	(since 2003)
Biotinidase Deficiency	185,000	(since 2013)
Congenital Adrenal Hyperplasia	185,000	(since 2013)

**Collection of specimens at the 3th-5th day of life in
2,468 primary care centers throughout the state**



Collection (free of charge)



**Collections are made in
853 counties**



Tests for:

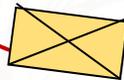
PKU

Congenital Hypothyroidism

Sickle Cell Disease

Cystic Fibrosis

Mail



**Single
Laboratory -
School of
Medicine**

Fundação Hemominas

Minas Gerais State Center of Hematology and Blood Transfusion

- **Founded in 1985**
- **23 facilities in Minas Gerais State**
- **260,000 units of blood collection/year**
- **Referral State Service for the treatment of sickle cell disease and hemophilia**



Hemominas network: regional units

Protocols

- **Transfusion: phenotype matching of donor red blood cell for red cells antigens C, E and K leukodepletion of red cells**
- **Hydroxyurea: protocol of Brazilian Ministry of Health**
- **Stroke: chronic transfusion**
- **Chelation**
- **TCD**

Teaching Hospital - UFMG



A leader in treatment of medium-and high-complexity diseases, HC/UFMG stands out in several activities, such as oncologic treatments, graft, hemodialysis, chemotherapy, high-risk maternity and nursery, and human reproduction

Total capacity: 466 beds

Sickle Cell Disease and other Hemoglobynopathies - Minas Gerais

Phenotype	Number
Hb SS	3.319
Hb SC	2.128
Hb Sβ-thal	366
Hb CC	307
Outras	194
Talassemia	123
TOTAL	6.437

Performance measures

Step	Days (median)
Age at collection	5
Sample transportation (mail)	4
Laboratory processing	2
Age at first appointment for SCD	35

Source: Nupad/UFMG

Incidence for all types of SCD out of 2.9 million children (newborn screening)

HbS group-specific data	Number	Incidence
SS or Sβ⁰thal	1,151	1 : 2,530 (0,04%)
Hemoglobinopathy SC	825	1 : 3,530 (0,03%)
Hemoglobinopathy SD	12	--
Probable Sβ⁺thal	75	--
ALL TYPES SCD	2,072	1 : 1,400

Source: Nupad/UFMG

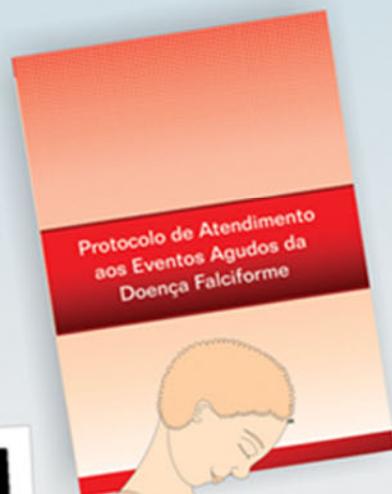


Center of Education and Aid on Hemoglobinopathies



CEHMOB-MG

Centro de Educação e Apoio para Hemoglobinopatias



**Projeto
Aninha**

Cuidando da Gestante
com Doença Falciforme

CEHMOB-MG



CEHMOB
ATENDE

Service provided for all state

**ANY DOUBTS
ON SCD?**

Call:



0800 • 722 • 6500

Toll free
24 hours - 7 days



Brazil-Africa Cooperation Project



Ghanaian technicians training at Minas Gerais Program



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Projeto Atenção Especializada

Specialized Care Project for Sickle Cell Disease

Why?

Diagnosis, tracking and follow-up control

**Center for Newborn Screening
NUPAD/Federal University**

**State Blood Centers (12)
(Hemominas)**

- Screening-Diagnosis
- Sample tracking
- Patient tracking
- Follow-up control
- Training-Education
- Research

- Hematologic Care
- Secondary care
- **“Primary care”**
- Training-Education
- Research

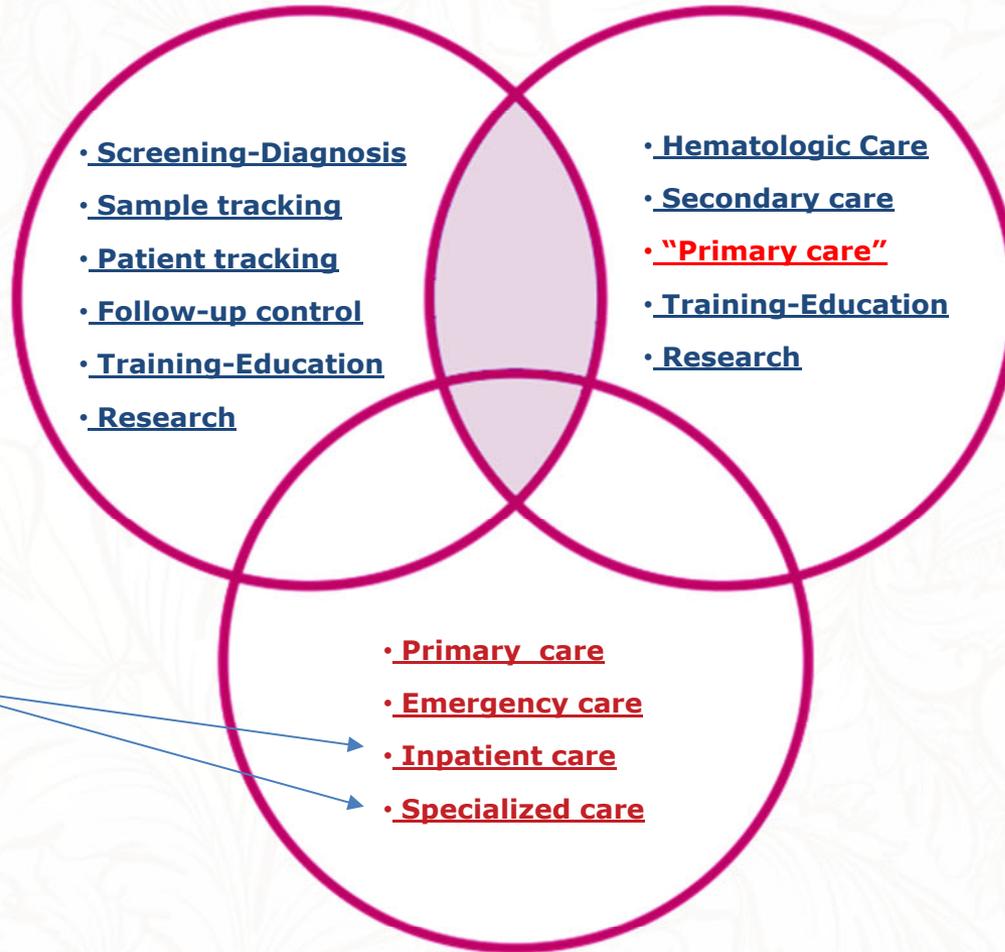
- **Primary care**
- **Emergency care**
- **Inpatient care**
- **Specialized care**

**853 County Health Departments
(including capital and metropolitan areas)**

Diagnosis, tracking and follow-up control

**Center for Newborn Screening
NUPAD/Federal University**

**State Blood Centers (12)
(Hemominas)**



PAE Project



**853 County Health Departments
(including capital and metropolitan areas)**

PAE Project (first step:2 years)

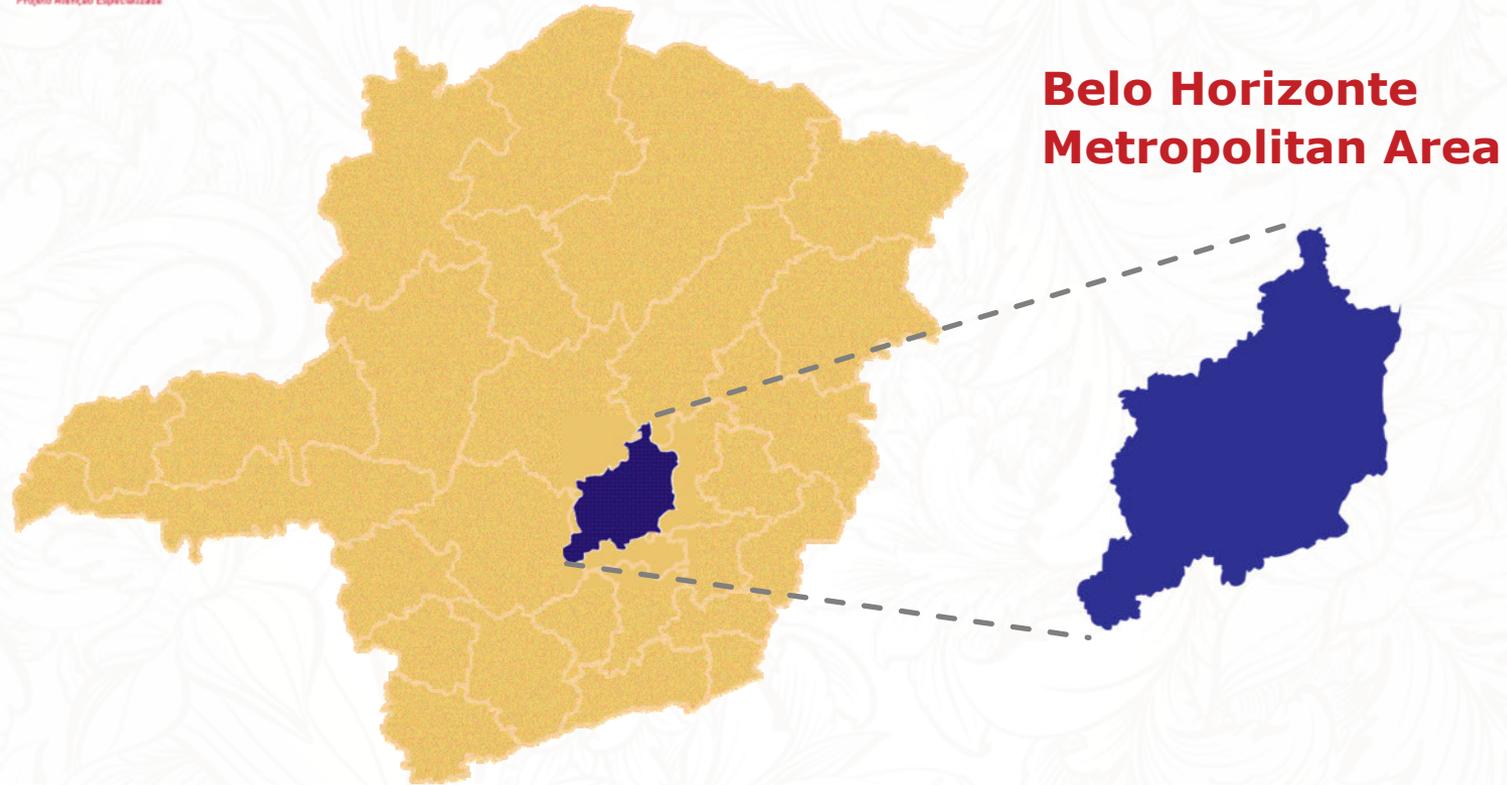
Goals:

- Critical mass on SCD
- Sharing knowledge on SCD – Electronic Database Support
- Performing Brazilian Protocols
- Comprehensive Care
- Contribute to establish referral services network in Minas Gerais
- Sharing single SCD Database for researching
- Research
- Difusion SCD knowledge at Medical Schools

PAE Project (first step:2 years)

Medical Specialties Selected

- Women's health
- Orthopedics
- Ophthalmology
- **Nephrology (October, 2013 workshop)**
- Cardiology
- **Pulmonology (October, 2013 workshop)**
- **Neurology (October, 2013 workshop)**



34 counties
4,9 million inhabitants
40,000 Km²

SECOND STEP

**Expanding experience
to whole Minas Gerais
state**



Main concerns

- Number of patients enrolled after one year project.
- Sharing clinical issues (ex: Aninha)
- Application – underestimated.
- “special research system” or integrated system within SUS?