

Ministério da **Saúde**

G O V E R N O F E D E R A L

**BRASIL**

PAÍS RICO É PAÍS SEM POBREZA



**VII** Simpósio Brasileiro de  
**Doença Falciforme**  
Atenção à Saúde e Inovações Tecnológicas no SUS

VII BRAZILIAN SYMPOSIUM ON SICKLE CELL DISEASE

ENGLISH VERSION

SALVADOR

2013

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# INTRODUCTION

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## **Symposium discusses in Salvador attention, care and technological innovations for sickle cell disease**

The VII Brazilian Symposium on Sickle Cell Disease (SCD) will take place from 20 to 23 November 2013 in Salvador, in the Convention Center of Bahia. It continues with the integrated, multi-professional and multidisciplinary actions of the Ministry of Health (MS) within the care, attention and technological innovations normalized in the Unified Health System (SUS), aimed at people with SCD.

SCD is one of the most common genetic and hereditary disease in the world, with large incidence in Brazil. It is a genetic mutation that occurred in the African continent and that arrived in Brazil due to the sad story of African people brought here for slavery work. For its large incidence in this country, since 2005, the Ministry of Health (MS) developed a National Policy on Comprehensive Care for People with SCD, fulfilling a longstanding demand of the black movement, and established it in the SUS by ordinance GM / GAB No. 1,361, of August 16, 2005. The policy is implemented around the country by the Sickle Cell Disease Technical Advisor Team (ATDF), from the General Coordination of Blood and Blood Products (CGSH), that is linked to the Department of Specialized Care (DAE), in the Secretariat of Health Care (SAS).

Promoted by MS, in partnership with the University of Bahia (UFBA) and the State Secretariat of Health of Bahia (SESAB), this symposium takes place at an appropriate time due to the fact that the attention model that is advocated in it is being cited as an international reference. With multidisciplinary and multi-professional nature, it will address the theme that nowadays is essential to the improvement of care - the technological innovations that can offer people with SCD longevity with quality of life.

Besides international speakers and guests from Africa, where the disease originated, the symposium will be attended by the SUS workers and representatives of associations of people with SCD from all the Brazilian states, being this last aspect of great importance, because the user is the filter improvement in the implementation of the policy.

This symposium is held every two years in a different capital city and it is currently prioritized by CGSH to the Northeastern capitals, for that is the region with the highest incidence of the disease. This year the symposium is back to Salvador, capital of the state of Bahia, that has the higher incidence of SCD in Brazil. This is the place where it was created through the initiative of a group of experts who devoted themselves to the study of the disease in Brazil, and where it grew to be taken on by the MS.

The choice of Salvador has yet another reason: the city hosts the UFBA Center of Orthopedics and Traumatology of the *Hospital das Clinicas*, which is the hospital of the School of Medicine. The hospital maintains in partnership with the MS a center of studies and researches in the field of cell therapy in bone and skin lesions in SCD, which treats people from Bahia and from many other states.

The opening of the symposium will take place on the Day of Black Consciousness - November 20, in which Brazil pays respect to Zumbi dos Palmares, black hero that died in 1695, fighting against racism. It is a very significant day for the black movement and, of course, for people with SCD. This is a segment of the national population with which the country has a huge social debt. Africans and their descendants contributed to the formation of Brazil. The adoption of compensatory policies is a way to redeem the debt. It is this matter that, with great pride, this symposium is devoted to.

The Scientific Committee

## TARGET AUDIENCE

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- Medicine doctors and nurses;
- Health service professionals;
- Researchers and other scholars;
- Public managers;
- Social control representatives.

# EVENT AGENDA

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## OFFICIAL THEME: TECHNOLOGICAL INNOVATIONS IN THE SUS

**8 - 9:00 a.m. Presentation of papers - 03 rooms with 04 presentations of 10 minutes and five minutes for questions - total of 36 papers for oral presentation.**

**9 - 9:45 a.m. Conference (45 minutes - single room)**  
**auditório Oxalá**

1st. day - The Genome Project at Sickle Cell Disease - Jacques Elion (FRANCE)

2nd. day - Do we know the pain in sickle cell disease? - Samir Ballas (USA)

3rd. day - Hydroxyurea - are we using too little? - Kwaku Ohene Frempong (USA)

**10 - 11:30 a.m. Update course - 30 min for each theme**  
**room 1 - auditório Oxalá**

1<sup>st</sup> day - Critical events in Sickle Cell Disease

- in children - Jane Hankins (USA)
- in adults - Fernando Araujo (BAHIA)
- Pain approach - Samir Ballas (USA)

2<sup>nd</sup> day- The Hydroxyurea

- Physiopathologic Mechanisms - Kwaku Ohene Frempong (USA)
- Its use in chronic degeneration of organs - Clarisse Lobo (HEMORIO)
- Protocol of the Ministry of Health - Ana Cristina Silva Pinto (HEMOCENTRO Ribeirão Preto)

3rd. Day - Brain Vascular Disease

- Silent Infarction and Transient Ischaemic Attack - Rodolfo Cançado (School of Medical Sciences SANTA CASA DE SP)
- Diagnostic Approach - Ana Claudia C Bezerra Leite (HEMORIO)
- Therapeutic Approach - Celia Maria Silva (Hemominas)

**10 - 11:30 a.m. Update course - 30 min for each theme**  
**room 2 - auditório Xangô**

1<sup>st</sup> day - The Iron Chelation in Sickle Cell Disease

- Diagnosis of Iron Overload - Rodolfo Cançado (School of Medical Sciences SANTA CASA DE SP)
- Main Chelating Available - Aderson Araujo (HEMOPE)
- Chelation Protocol of the Ministry of Health - Ana Cristina Silva Pinto (HEMOCENTRO Ribeirão Preto)

2<sup>nd</sup> day - Modulating Agents in Sickle Cell Disease

- Genetic - Jacques Elion (FRANCE)
- Biochemicals - Eduardo Almeida (SAO JOSE DO RIO PRETO)

- Social - Miranete Arruda (SES/PE)

3<sup>rd</sup> day - The Cell Therapy for Sickle Cell Disease  
- Concept and Notes - Radovan Borojevic (UFRJ)  
- Its use in Leg Ulcers - Jose Lima Valber Meneses (UFBA)  
- Its use in Bone Injuries - Philippe Hernigou (FRANCE)

**10 - 11:30 a.m. Round table - 20 min to each theme with 30 min of debate**

**room 3 - conference room of the 3<sup>rd</sup> floor**

1<sup>st</sup> day - Full Care to Sickle Cell Disease I  
- Current Status of PNTN and New Perspectives - Ana Stela Goldbeck (CGSH)  
- Sickle Cell Disease in Continuing Education - Ana Paula Fernandes Pinheiro C (Cehmob-MG)  
- Importance of Hydration on the Clinical Course of Sickle Cell Disease - Claudia Copley (UERJ)

2<sup>nd</sup> day - The School in the Sickle Cell Disease Care Network  
- What, why and how? Molly Freeman (USA)  
- The Experience of Minas Gerais - Learn to Care - Cristiane Rust (Cehmob / UFMG / MG)  
- Social Control Expectations - Ilca Carmo (AMDAF/SES/RJ) and representative of Fenafal

3<sup>rd</sup> day - Assistance Networks in Sickle Cell Disease  
- Profile of Specialized Care and Primary Care in Sickle Cell Disease - Joice Aragão ATDF/CGSH/MS  
- “Rede Cegonha” and Sickle Cell Disease - Maria Esther Albuquerque - MS  
- Emergency Network and Sickle Cell Disease - Paulo de Tarso - Coordination of Urgency and Emergency/MS

**11:30 a.m. - 12 p.m. visit to presentation stands**

**12 - 12:45 p.m. official theme conference - 45 min (single room) auditório Oxalá**

1<sup>st</sup> day - Bone Marrow Transplantation in Sickle Cell Disease - Belinda Pinto Simões (FMRP-USP)

2<sup>nd</sup> day - Cellular Therapy for osteoarticular lesions. - Philippe Hernigou (FRANCE)

3<sup>rd</sup> day - Renal injury in Sickle Cell Disease and the use of Erythropoietin - Tereza Maria Nobrega (HEMORIO)

**12:45 - 2 p.m. - lunch - satellite symposia - 2 days - 2 symposia per day in two rooms - Total 4 symposia**

**2 - 3:30 p.m. round table - 20 min in each theme with 30 min of debate**

**room 1 - auditório Xangô**

1<sup>st</sup> day - Care for Women with Sickle Cell Disease  
- Maternal Mortality in Sickle Cell Disease - Vanessa Maria Fenelon da Costa (ANINHA PROJECT/UFMG)  
- Contraception - Myths and Truths - Mark Ymayo (SANTA MARCELINA-SP)



- Expectations of Women with Sickle Cell Disease - Representative of GN Gender in Sickle Cell Disease

2<sup>nd</sup> day - Adherence to Multidisciplinary Care and its Challenges

- Doctor's role - Jane Hankins (USA)
- Nurse's Role - Carmen C Mello Rodrigues (BOLDRINI CENTER Campinas-SP)
- Pharmacist's role - Ana Paula Queiroz (HEMORIO)

## **2 - 3:30 p.m. round table - 20 min in each theme with 30 min of debate**

### **room 2 - auditório Oxalá**

1<sup>st</sup> day - Full Care to Sickle Cell Disease II

- Quality of Life in Sickle Cell Disease - Silvia Lucia Ferreira (UFBA)
- Integrative Practices in Sickle Cell Disease - Cecilia Izidoro (UFRJ)
- Transition Clinic in Sickle Cell Disease - Jane Hankins (USA)

2<sup>nd</sup> day - Chronic Degeneration of Organs

- Role of the Physiotherapist in Sickle Cell Disease - Paulo Lessa (BAHIA)
- Therapeutic Itinerary for People with Leg Ulcer - Ana Luisa Dias (ISC-BA)
- Bone Mineral Density and Body Composition in Adults with Sickle Cell Disease - Karen Cordovil (UERJ)

## **3 - 4 p.m. visit to presentation stands - 1<sup>st</sup> and 2<sup>nd</sup> days**

## **4 - 5 p.m. what do I do? - 20 min in each theme**

### **room 1 - auditório Xangô**

1<sup>st</sup> day

- In Priapism - Samir Ballas (USA)
- In the Upper Right Quadrant Syndrome - Jessica Campos - (HEMORIO)
- In the Orthodontic Problems - Wellington Cavalcanti (HEMORIO)

2<sup>nd</sup> day

- In Alloimmunization in polytransfused - Denise Menezes Brunetta - (Hemoce)
- In the Sickle Cell Disease Preoperative - Cecilia Figueira (UFES)
- In the Treatment of Leg Ulcers - Mara Blanck (SOBENFE)

### **room 2 - auditório Oxalá (until 5:30 p.m.)**

1<sup>st</sup> day - Pain under Multiple Perspectives - Cecilia Izidoro (UFRJ) and Carmen Rodrigues (BOLDRINI CENTER Campinas-SP)

TARGET AUDIENCE: health professionals and users, maximum 40 people

1<sup>st</sup> moment: Expressing oneself and expressing the pain itself - 30 min.

2<sup>nd</sup> moment: Knowing and learning about the pain in Sickle Cell Disease - 15 min.

3<sup>rd</sup> moment: How to assess and treat the pain? - 30 min.

4<sup>th</sup> moment: Final Thoughts and evaluation - 15 min.

2nd. Day - Citizenship Workshop - Sergio Coelho Gomes (UFRJ), Candida Maria Queiroz (SMS/SALVADOR), Altair Lira (FENAFAL) and Miranete Arruda (SES/PE)

TARGET AUDIENCE: Healthcare professionals and users, maximum 60 people

1<sup>st</sup> moment: Introduction - 20 min.

2<sup>nd</sup> moment: Conversations Groups - 4 groups of 15 people - 30 min.

- Themes:

Group 1 - "Unequal Access to Health Services for People with Sickle Cell Disease"

Group 2 - "The Structure of SUS and Proper Attention to Sickle Cell Disease - critical points"

Group 3 - "The Path of the person with Sickle Cell Disease in SUS - Processes and Procedures"

Group 4 - "Humanization, Access, Shelter and Full Care as Health Rights"

3<sup>rd</sup> moment: Drafting the Charter of Services to Citizen with Sickle Cell Disease - 40 min.

## INTERNATIONAL EXPERTS

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### **Kwaku Ohene Frempong - EUA**

Activity type: Update course

You participate as: Speaker

Theme: The Hydroxyurea - Physiopathological Mechanism

Date: 11/22/2013

Time: 10 – 10:30 a.m.

Place: Auditório Oxalá

Activity type: Lecture

You participate as: Speaker

Theme: Hydroxyurea – do we use enough?

Date: 11/23/2013

Time: 9 – 9:45 a.m.

Place: Auditório Oxalá

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### **Jacques Elion - França**

Type: Conférence

Fonction: Panéliste

Thème: Le Projet du génome à la Drépanocytose

Date: 21/11/2013

Quand: 9 – 9:45 a.m.

Locale: Auditório Oxalá

Type: Mise à jour

Fonction: Panéliste

Thème: Les agents modulant dans la Drépanocytose – génétiques

Date: 22/11/2013

Quand: 10 – 10:30 a.m.

Locale: Auditório Xangô

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### **Samir Ballas - EUA**

Activity type: Update course

You participate as: Speaker

Theme: Critical events in Sickle Cell Disease – The Pain Approach

Data: 11/20/2013

Time: 11 – 11:30 a.m.

Place: Auditório Oxalá.

Activity type: What do I do?

You participate as: Speaker

Theme: At priapism

Date: 11/20/2013

Time: 04 – 04:20 p.m.

Place: Auditório Xangô

Activity type: Lecture  
You participate as: Speaker  
Theme: Do we know the pain of Sickle Cell Disease?  
Date: 11/22/2013 Time: 9 – 9:45 a.m.  
Place: Auditório Oxalá

**Philippe Hernigou – França**

Type: Conférence sur thème officiel  
Fonction: Panéliste  
Thème: Thérapie des lésions ostéo-articulaires  
Date: 22/11/2013 Quand: 12 – 12:45 p.m.  
Locale: Auditório Oxalá

Type: Mise à jour  
Fonction: Panéliste  
Thème: La thérapie cellulaire pour la Drépanocytose - Son utilisation dans les lésions osseuses  
Date: 23/11/2013 Quand: 11 – 11:30 a.m.  
Locale: Auditório Xangô

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**Jane Hankins – EUA**

Activity type: Update course  
You participate as: Speaker  
Theme: Critical events in Sickle Cell Disease – with children  
Date: 11/21/2013 Time: 10 – 10:30 a.m.  
Place: Auditório Oxalá

Activity type: Round table  
You participate as: Speaker  
Theme: Comprehensive care to Sickle Cell Disease - Transition Clinic in Sickle Cell Disease  
Date: 11/21/2013 Time: 02:40 – 03 p.m.  
Place: Auditório Oxalá

Activity type: Round table  
You participate as: Speaker  
Theme: Providing multi-professional care and its challenges – Physician's place  
Date: 11/22/2013 Time: 02 – 02:20 p.m.  
Place: Auditório Xangô

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**Molly Freeman**

Activity type: Round table  
You participate as: Speaker  
Theme: School in the care network of Sickle Cell Disease – What, why and how?  
Date: 11/22/2013 Time: 10 – 10:20 a.m.  
Place: Conference room, 3rd floor

# SUBMISSION OF SCIENTIFIC PAPERS

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## **Deadline for submission of proposals**

From June 30 registrations will be open for submission of scientific papers or experience reports, authored individually or collectively, in the knowledge field of Hemoglobinopathies / Comprehensive Care for People with Sickle Cell Disease. Deadline for submissions is September 30, 2013.

Entries must comply with the following guiding principles:

1. Care / Clinic
2. Public Policy, Planning and Management
3. Teaching and Research
4. Significant Experiences
5. Innovations in SUS
6. Participation and Social Control in SUS

## **General Instructions**

- Papers must be submitted online, on the website of the Symposium, in the participant restricted area. It is also through that area that the approval process of the paper must be verified.
- All papers must include title, main author, co-authors, institution, abstract, indication of theme and sub-theme, name and address of the submitter. The submitting author must be registered in the Symposium.
- Only unpublished papers can be submitted. Papers can be related to theses, dissertations, teaching or research projects in progress or completed in the last two years (2011-2013); and reports on significant experiences related to the fields indicated above, completed in the last two years (2011-2013).

## **Paper formatting**

All papers must contain a short abstract in accordance with the following indications:

- Character type: Times New Roman, size 12, with a space of 1.5 between lines;
- Paper margins: 2.5 cm on top, bottom, right and left;
- The total content of the abstract should contain up to 2,500 characters (including spaces and excluding title, author and institution);
- Do not include graphics, tables and photos.

## **BANNERS**

Banners must contain:

- Title
- Author (authors)
- Institution (s) of author (s), in abbreviated form
- Introduction
- Objectives
- Methodology
- Results (preliminary or final)
- Conclusions
- References

The final banner must be printed in the following format:

- Dimensions 90 x 100 cm with a unique layout, containing the name of the event at the top and the institutions supporting the base;
- References should be included.

## **ORAL PRESENTATION**

Criteria for selection of papers for oral presentation:

The Scientific Committee will select papers among all submitted for Oral Communication, according to its internal criteria. The remaining papers stay in the poster category.

In addition to complying with the requirements of explicit summaries of General Instructions, the process of evaluation and selection of papers follows the following criteria:

1. Relevance, innovation level (new applications / contribution to existing knowledge) and contemporaneity;
2. Theoretical consistency of the approached object and its relation to the theme and / or its coverage, methodological rigor.
3. Characteristics of the submitted abstract with respect to organization, synthesis capacity and clarity of presentation;
4. Inter-institutional, inter-sectoral and multidisciplinary Efforts, and of Social Control and Participation in the SUS.
5. Products, results, or arguments approaches and their effective contribution to the development of knowledge about the Haemoglobinopathies / Comprehensive Care for People with Sickle Cell Disease.
6. Contribution to the development of Care for People with Sickle Cell Disease.

### **Evaluation results**

The deadline for the announcement of results is August 30, 2013. Authors can check the status of their work by accessing the restricted area, according to the General Instructions. In time, date, time and location of each presentation of Posters and Oral Communication will be communicated to the authors.

## **Presentation of Papers**

The papers selected as banners will be exposed in reserved areas in date, time and place to be indicated by the Scientific Committee.

The papers selected for Oral Communication will be presented in accordance with the overall planning of the Symposium, with ten (10) minutes of presentation reserved for each author and (05) five minutes dedicated for debates after the presentations. Date, time and place will be set by the Scientific Committee.

## **Final recommendations**

By proposing a paper, participants agree to the following conditions:

- Oral communication will be presented exclusively by one of the authors;
- In case of withdrawal, it is requested that the participant of the Symposium to inform the Secretariat by November 1, 2013, via e-mail, so that other paper can be invited to present in its place.
- Certificates of presentation of papers (banner and / or oral communication) will be issued by the organization.
- Missed cases shall be decided by the Scientific Committee, whose decisions are final.



## EVENT ADDRESS

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# EXECUTIVE COMITEE

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## SCIENTIFIC COMITTEE

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## PRICE AND PAYMENTS

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The payment of the inscription of foreign participants is due in cash, in Brazil, in the first day of the seminar (November 20, 2013).

The value of the inscription is **XXXX** reais

# INFORMATIONS TO THE I SYMPOSIUM ON SICKLE CELL DISEASE LINES OF CARE OF BAHIA



**TERRA DE TODOS NÓS**

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**SECRETARIA DA SAÚDE**



*Symposium on Sickle Cell  
Disease Lines of Care of Bahia*

# INTRODUCTION

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# EVENT AGENDA

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# TURISM

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## BAHIATURSA

The Bahiatursa - Tourism Company of Bahia S / A - is a public and private owned company, linked to the Department of Tourism, responsible for the dissemination and promotion of tourism in Bahia, in Brazil and abroad; as well as the management of infrastructure and services to receive visitors in the state.

Acting in accordance with the policies of the Federal Government - National Tourism Plan - and the State Government, BAHIATURSA plays a key role in the attraction and expansion of the regional, national and international tourism; in obtaining regular flights and charters; and strengthening alliances and partnerships with the tourism industry, academic institutions, NGOs, development agencies and various public departments.

It is also responsible for the administration and marketing of the Convention Center of Bahia (Salvador), of Ilheus and of Porto Seguro, and the tourist information center of Pelourinho (SAT), of the Airport, of the Bus Station and of the Mercado Modelo.

<http://www.bahiatursa.ba.gov.br/>

# INSTITUTIONAL PARTNERS

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## **Official sponsors**

The VII Brazilian Symposium on Sickle Cell Disease and the I Symposium on Sickle Cell Disease Lines of Care of Bahia have the official sponsorship of the Ministry of Health

## **Management and execution**

- UFBA - Federal University of Bahia
- FMB - UFBA - School of Medicine of Bahia
- State Government of Bahia
- SESAB – State Department of Health (of the State Government of Bahia)
- HEMOBA - Hematology and Hemotherapy Foundation of Bahia
- APAE - Salvador - Association of Parents and Friends of Exceptional People
- FENAFAL - National Federation of Associations of People with Sickle Cell Disease
- Ministry of Health

## **Support**

- CGSH - General Coordination of Blood and Blood Products, Ministry of Health
- COMHUPES - University Hospital Professor Edgard Santos Complex
- FAPEX - RESEARCH AND EXTENSION SUPPORT FOUNDATION