



**Permanent Mission of the Republic
of Congo to the United Nations**



**Sickle Cell Disease International
Organization**

**THE 1ST WORLD SICKLE CELL DAY
19TH JUNE 2009 UNITED NATIONS OFFICE, NEW YORK**

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BACKGROUND

On December 22, 2008, the General Assembly of the United Nations unanimously adopted Resolution A/63/237 recognizing sickle cell disease as a public health problem

Among the objectives envisaged by this resolution initiated by the Sickle Cell Disease International Organisation (SCDIO), proposed by the delegation of the Congo and cosponsored by 24 Member States was the recognition that June 19 of each year be designated Sickle Cell Day to increase awareness of this problem at national and international levels.

To recognise this event, the permanent mission of the Congo to the United Nations in New York and the SCDIO (OILD in French) will organize in partnership with the World Health Organization (WHO), the United Nations Children's Fund (UNICEF), the UNAIDS and the World Bank, the first Sickle Cell Awareness Day to take place at the United Nations on June 19th, 2009.

OBJECTIVES

- To sensitise Member States and the international community to the objectives of resolution A/63/237
- To mobilise the resources necessary to create centres of excellence for treatment and research in the disease in Africa and India.

EVENTS

- Exhibition of Associations and international organisations at the United Nations building
- Art exhibition on sickle cell disease
- Festival organised by the Sickle Cell & Thalassemia Patients Network (SCTPN) in areas around the United Nations
- Discussion panels and round table
- Round table of the First Ladies and Royal Highnesses
- Reception

DATE AND PLACE

June 19th, 2009 - United Nations Office in New York

PROGRAM :

08:30 – 08:45 Registration



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09:00- 09:45 Opening Ceremony

- Address Secretary General of the United Nations
- Address by the President of the U.N. General Assembly
- Addresses by representatives of WHO/UNICEF
- Address by the President of OILD
- Address by the First Lady of the Congo

09:45-10:00 Experience of patients and their families: *Mrs Marie-France TIROLIEN (Guadeloupe, FRANCE), SCDA (USA)*

10:00-10:25 Tour of exhibition stands and coffee break

MAIN TOPIC

A century since the discovery of sickle cell disease: review and perspectives. General presentation on sickle cell disease: recent discoveries

10:30-10:50 *Sub-topic 1:*

Progress achieved: *obstacles to universal access to prevention, treatment, care, information and education; the developed world and Africa.*

Professor Jacques ELION (France), Professor Jean KOKO (Gabon)

10:50-11:10 *Sub-topic 2:*

The perspective of sickle cell disease in relation to other public health priorities such as malaria, HIV/Aids and malnutrition

Professor Dappa DIALLO (Mali), Professor Pradeep PATRA (India)

11:10-11:30 *Sub-topic 3:*

Reducing the disparities between North and South in the treatment of sickle cell disease: What solutions are available in wealthy countries?

Professor Pierre BÉGUÉ (France), Professor Aderson ARAUJO (Brazil)



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11:30-11:50 *Sub-topic 4:*

Strategies for prevention: Role of Reference Centres and research

Professor Graham SERJEANT (Jamaica), Professor Kwaku OHÉNE-FREMPONG (USA)

11:50-12:10 *Sub-topic 5*

Strategies to mobilise resources and financial support

- Opportunities through the United Nations
- Increasing awareness through sport and culture.
- Others

Representatives of the United Nations Agencies, Goodwill Ambassadors for sickle cell; FIFA

12:10-12:30 **Discussions**

13:00-15:00 **Lunch break**

15:00-17:00 **Round table 1 NGOs and Civil Society's entities**

Moderators: Mrs Jenny HIPPOCRATE-FIXY (France), Mrs Teresa GINGER DAVIS (USA)

Topic:

- Preventing spread of the sickle cell gene around the world
- Summarising the best practice for management of the disease
- Improving transfusion services for sickle cell patients

Speakers:

- Professor Kuaku OHÉNE-FREMPONG
- Professor Elira DOKÉKIAS
- Professor Graham SERJEANT
- Doctor Elena GINZBURG
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15:00-17:00 **Round table 2**

Moderators: Professor Ibrahima DIAGNE (Senegal) Mrs Elisabeth SIMPSON (USA), Dr Joice ARAGAO DE JESUS (Brazil)

Topic: An international appeal for a draft resolution to supplement diplomatic efforts for further resolutions. Identifying financial resources for sickle cell disease world wide

Speakers

- Representatives of the United Nations



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- First Ladies and Royal Highnesses
 - Ministers of Health
 - Research Scientists

17:00-18:00 Closing of Meeting and Press Conference

18:30-20:00 Reception

PARTICIPATION

- UN General Assembly;
- UN Secretariat General;
- UN Economic and Social Council
- UN Security Council (Presidency of the month)
- UN Agencies (WHO, UNDP, UNICEF, FNUAP, UNIFEM, UNESCO, FAO, UNAIDS etc.)
- Regional Institutions (africaine Union, européenne Union etc.)
- International Financial Institutions (IMF, World Bank, IFC etc.)
- Development Key Partners
- Members States and Permanent Missions to the United Nations
- Heads of States or Government
- Royal Highnesses
- First Ladies
- NGOs and Civil Society's Entities
- International experts