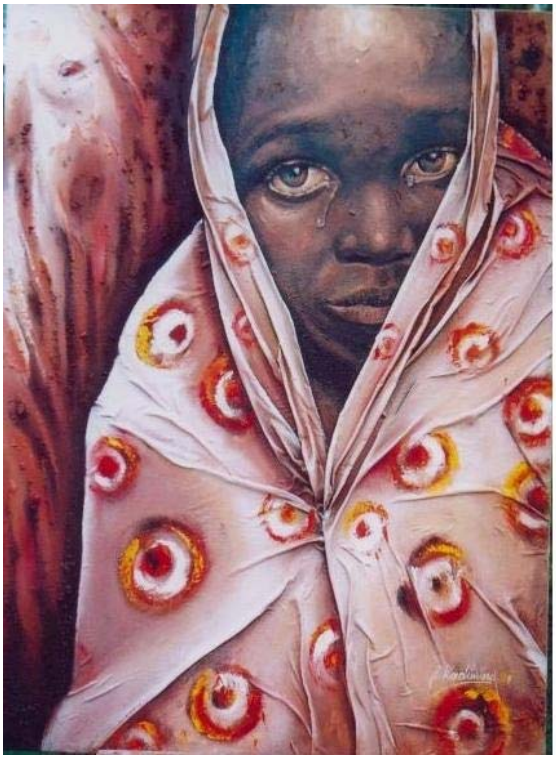
UN Permanent mission
Of Congo

OILD

The 1st World Sickle Cell Day
19 June 2009 United Nations, New York



A painting by a Congolese artist

NOVARTIS

BACKGROUND

On December 22, 2008, the General Assembly of the United Nations unanimously adopted Resolution A/63/L63 recognizing sickle cell disease as a public health problem

Among the objectives envisaged by this resolution, proposed by the delegation of the Congo in collaboration with OILD and 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 in collaboration with OLID (l'Organisation Internationale de Lutte contre la Drépanocytose) will organize in partnership with the World Health Organization (WHO), the United Nations Children's Fund (UNICEF), and the World Bank, the first Sickle Cell Awareness Day to take place at the United Nations on June 19, 2009.

OBJECTIVES

1. To sensitise member States and the international community to the objectives of resolution A/63/L63.

2. 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 (NSTPN) in areas around the United Nations
- Discussion panels and round tables
- Round table of the First Ladies and Heads of State
- Reception

Program :

08h30 – 08h45 Registration

09h00- 09h10 Opening welcome by the Secretary General of the United Nations

09h10- 09h20 Address by the President of the General Assembly of the United Nations

09h20-09h30 Addresses by representatives of WHO/UNICEF

09h30-09h40 Address by the President of OILD

09H40-09h50 Address by the First Lady of the Congo

09h50-10h00 Address by the Head of State

10h00-10h15 Experience of patients and their families

10H15-10h30 Tour of exhibition 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

10h30-10h50
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)

10h50-11h10
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 Padreep Patra (India); representing UN/Aids*

11h10-11h30

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 (Brésil)

11h30-11h50
Sub-topic 4: Strategies for prevention : Role of Reference Centres and research

Professor Graham SERJEANT (Jamaica), Professor Ohéné FREMPONG (USA)

11h50-12h10
Sub-topic 5 : Strategies to mobilise resources and financial support

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

Professor Elira Dokékias ; Representatives of the United Nations, Goodwill ambassadors for sickle cell ; FIFA*

12h10-12h30 Discussions

12h30-14h00 Lunch break

14h00-16h-00

Round table 1

Moderators : Doctor Léon Tshilolo (Congo RDC)
Teresa Ginger Davis (USA)

Topic :

1) Preventing spread of the sickle cell gene around the world
2) Summarising the best practice for management of the disease
3) Improving transfusion services for sickle cell patients

Speakers :

- Professor Ohéné Frempong
- Professor Elira Dokékias
- Professor Graham Serjeant
- Doctor Elena Ginzburg

14h00-16h00

Round table 2

Moderators : Professor Ibrahima Diagne (Sénégal)
Joice Aragao de Jesus (Brésil)

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
- First Ladies and Ministers of Health (? Of African Countries)
- Research Scientists

16h00-16h30

Closing of Meeting and Press Conference

17h00
Reception

Partners :

- United Nations
- WHO
- UNICEF
- UNESCO
- UNAIDS
- SCDAA (Sickle Cell Disease Association of America)
- SCTPA (Sickle Cell & Thalassemia Patient Network)
- NOVARTIS