1. Opportunities and Challenges of networks

2. What is REDAC and CHARTA

1. Vision and Mission

2. Membership/Organization

3. Activities
What is a Network?

**Verb**
To cultivate people who can be helpful to one professionally, especially in finding employment or moving to a higher position.
Networks there, and Networks here....

Do we need (all these) these networks?
Global Distribution of Hemoglobin Disorders

Births per 1000 infants
( WHO estimates)

< 0.1
0.1 – 0.19
0.2 – 4.9
1 – 4.9
5.0 – 9.9
10 – 18.9
> 19

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Ofori-Acquah and Ohene-Fempong, 2007

Data from 1995-2004
1. Different networks come together with different purposes.

2. Networks should work to complement each other…not against/competition with each other
Networks there, and Networks here….

- Each network can focus on one area
- Leverage resources
- Lessons from HIV
  - Many networks, One voice

- Duplication of efforts
- Competing for the same resources
- Lessons from Hemophillia
  - Few Networks, One Powerful Voice
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Focus on Sickle Cell Disease Networks in Africa

(A historical perspective)

1995 International African Sickle Cell Symposium Series
2000
2005
2010
Sickle Cell Disease Networks in Africa: REDAC

What is REDAC?

The Sickle Cell Disease Research Network of Central Africa (REDAC)
Sickle Cell Disease Networks in Africa: REDAC

Vision

To Promote advocacy, education and dissemination of information about SCD
Sickle Cell Disease Networks in Africa: REDAC

Mission

6. Promote networking and sharing resources, information and data at national, regional and global levels
Sickle Cell Disease Networks in Africa: REDAC

- Independence 50 years ago
- Malaria is endemic
- AS prevalence – 20-50%
- High morbidity and mortality
- Limited resources

Secretary permanent:
Gylna Loko, MD (Martinique)
Gulillaume Wamba, MD (Cameroon)
Baron Ngasia, MD (DRC)
Sickle Cell Disease Networks in Africa: REDAC

Activities: Regional Scientific Meetings

Sickle Cell Disease Networks in Africa: Sickle CHARTA

What is Sickle CHARTA?

Consortium for Health Advocacy, Research, Training in Africa
Sickle Cell Disease Networks in Africa: Sickle CHARTA
Sickle Cell Disease Networks in Africa: Sickle CHARTA

Membership/Organization

Founding Members
Ambroise Wonkam, MD (Cameroon)
Solomon Ofori-Acquah, PhD (Ghana)
Oby Nnodu, MD (Nigeria)
Julie Makani (Tanzania)

> 30 affiliated investigators in Africa, UK and USA

Industrial Partners
PerkinElmer
Illumina
Sickle Cell Disease Networks in Africa: Sickle CHARTA

Vision

To establish a comprehensive health programme for the screening, management, treatment and prevention of SCD in Africa.
Sickle Cell Disease Networks in Africa: Sickle CHARTA

Mission

1. Promote advocacy, information, education and awareness in SCD in Africa.

2. Develop research programmes for SCD in Africa.

3. Develop training and educational programmes for SCD in Africa.
Sickle Cell Disease Networks in Africa: Sickle CHARTA

H3Africa Genomics Initiative

• Submitted application to
  – NIH (P.I. Ofori-Acquah)
  – Wellcome Trust (P.I. Makani)
    Pre-application award ($30,000)
    Full application due Tomorrow (03/15/012)
Overall scientific objective: Discover critical molecular mechanisms of hemolysis biology, including adaptation, and its influence on the natural history of SCD in Africa, by understanding the phenotypic consequences of human genetic variation.
Sickle Cell Disease Networks in Africa: Sickle CHARTA

H3Africa NIH Application

Countries

Cameroon
Democratic Republic of Congo
Ghana
Nigeria
Tanzania
South Africa
USA