

Strategy for the Control of Sickle Cell Disease

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Define the Scope of the Problem

- Genetic
- Chronic
- Multiorgan, multisystem disease
- Morbidity/mortality
 - Pediatric
 - Adult

Health Education/Counseling

- Massive program
 - Major drives
 - Schools
 - Churches and mosques
 - media

Advocacy Groups

- NGOs
- Private companies
- Politicians and their families
 - Governors' wives association
- Celebrities
 - Film "Nollywood"
 - sports

Newborn Screening

- Ideally should be universal
- Proper training of technicians, counselors etc
- Availability of appropriate equipment
 - HPLC
 - Isoelectric focusing
- Should be done as soon after birth as practicable
- Confirmatory test at 6 months

Record Keeping

- Vital
- Should be computerized database

Follow-up Clinics

- All children identified in the screening program must be promptly enrolled in a dedicated SCD clinic
- Should be staffed by
 - Physicians
 - Nurses
 - Counselors
 - Technicians

Investigational Facilities

- Electronic cell counters for – CBC
- HPLC, Hb electrophoresis
- Radiography/ultrasonography
- Transcranial Doppler
- CT/MRI
- Nuclear Medicine

Treatment/drugs

- Malaria prophylaxis
- Penicillin prophylaxis
- Pneumococcal vaccine
- Folic acid
- Blood transfusion
- Hydroxyurea
- Others

Reality of the Nigerian Situation

- Big, diverse country
- Poor infrastructure
- Population of ~160 million
- Prevalence of HbS allele of ~ 30% = 48 million
- Prevalence of HbSS of ~2.0% = 3.2 million
- It's a huge problem which calls for a different strategy and innovative thinking
- It is indeed, a public health problem

Primary Health Care

- SCD has to be part of the primary health care program
- Has to be integrated into school curriculum at an early age
- Local government councils have to be involved
- Community health workers have to be trained to take the lead in health education and counseling
- A chain has to be established from the 1⁰ to the 2⁰ and 3⁰ levels of care
- Each state should have at least one center which has facilities for comprehensive care and diagnosis, including newborn screening where samples can be sent

National SCD Policy

- Nigeria is overdue for a clear well-articulated SCD policy
- In 2009/2010, a committee was set up in the FMOH to establish a NCD policy, to incorporate SCD
- The Nigerian SCD network was represented on this committee
- Policy is still to be passed by the national assembly



A BILL

FOR

An ACT To Provide For The Prevention,
Control And Management Of Sickle Cell
Disease And For Other Purposes Connected
Therewith

Sponsored by SEN. (DR) IFEANYI OKOWA
SEN. NENADI E. USMAN



Key Provisions

- Government shall provide support for SCD patients
 - Comprehensive treatment program
 - Encourage enhanced research
 - Encourage the active participation of all states and local governments
 - Encourage private participation subject to existing laws and regulations

Ministry Control

- The program shall be directed, coordinated and supervised by ministry whose functions include:
 - Establishment of newborn, childhood and adult screening programs
 - Provision of properly staffed and approved local health institutions
 - Raising awareness about the disease at local, national and governmental levels
 - Ensuring support from governmental and non-governmental agencies, including private companies
 - Developing a national database

Accreditation of Centers and Participants

- Public and private hospitals, medical clinics and primary health care centers will be accredited, which shall:
 - Provide medical treatment, as appropriate
 - Provide genetic counseling and diagnostic services
 - Keep, collate and transmit to the ministry, periodic records of all their activities
- There shall be a fair distribution of such centers in each ward, local government and state of the country

National Coordinating Center for the SCD Program

- This shall reside in the National Primary Health Care Development Agency
- Collect, coordinate, monitor and distribute data, best practices and findings regarding the program
- Develop a model protocol for the centers to follow with respect to prevention and treatment
- Develop educational materials
- Prepare annual reports for the Ministry and the National Assembly
- Liaise with other governmental agencies, NGOs or international bodies in furtherance of the program as required

Establishment of SCD Registry

- A SCD registry and surveillance system is authorized under this ACT
- Data will be used to describe the epidemiology of the disease in the country
- Can be used for research, information dissemination, policy decisions, health care planning etc

Strategic Components

- SCD newborn and population screening program
- Screening of families of probands
- Pre-marital screening
- 1^o and 2^o prevention strategies
 - Penicillin Prophylaxis
 - Pneumococcal and other vaccines as appropriate
 - Safe blood transfusion practices
- Training of health professionals (doctors, nurses, lab technicians, community health workers etc)
- Education and counseling
- Research including clinical, basic, genetic and molecular aspects of SCD

Governing Body

- This will be known as the Council
 - Responsible for the general supervision and provision of guidelines for the control of the expenditure of the program
- Members
 - Minister of Health – Chairman
 - Minister of State for Health – Vice Chairman
 - Executive Director, National Primary Health Care Development Agency
 - Head, National Coordinating Center – Secretary
 - Director, Planning Research and Statistics
 - Hematologist and pediatrician with expertise in SDCD from tertiary institutions
 - Two other members (one must be a woman) representing NGO
 - One individual with SCD

Financial Provisions

- A fund shall be established for running the program
- Derived from
 - Budgetary allocation from the Federal Government
 - Grants from State and Local Governments
 - Foreign aids and assistance from bilateral agencies and bodies

Conclusions

- This bill contains all the strategic components to commence a rational, logical planning for SCD in the country
- Unfortunately it was not favorably received when first presented to health committee of the senate
- The next steps are not quite clear
- We need all well-meaning professionals and other interested groups and individuals to support his bill
- It is a good starting point

Thank you