

# SICKLE CELL DISEASE (PREVENTION, CONTROL AND MANAGEMENT) BILL, 2021

(SB. 166)

A BILL FOR

AN ACT TO PROVIDE FOR THE PREVENTION, CONTROL AND MANAGEMENT OF SICKLE CELL *DISEASE* AND FOR OTHER PURPOSES CONNECTED THEREWITH, 2021

FIRST READING

SECOND READING

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## SICKLE CELL DISEASE (PREVENTION, CONTROL AND MANAGEMENT) BILL, 2021



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#### A BILL FOR

AN ACT TO PROVIDE FOR THE PREVENTION, CONTROL AND MANAGEMENT OF SICKLE CELL DISEASE AND FOR OTHER PURPOSES CONNECTED THEREWITH, 2021 (SB. 166)

{ Commencement.

ENACTED by the National Assembly of the Federal Republic of Nigeria as follows-

PART 1: GOVERNMENT INVOLVEMENT AND PRIVATE PARTICIPATION IN THE PREVENTION, CONTROL AND MANAGEMENT OF SICKLE CELL DISEASE.

1. The Government of the Federation of Nigeria shall engage in and encourage the prevention, control and management of the occurrence, spread and effect of Sickle Cell Disease, hereinafter called "the disease", in the manner provided for in this Bill.

Objectives/Obligations

2. (1) Any person in the federation may, subject to any restriction or requirement under this Act, freely participate in the prevention, control and management of the occurrence, spread and effect of the disease.

2. Private Participation

- (2) Subject to any law relating to information in the federation any person may give, disseminate or distribute advice, information or literature useful in the prevention, control and management of the disease.
- 3. (1) The prevention, Control and Management of the disease as provided for under this Act shall be directed, coordinated and supervised by the ministry of the government of the federation in charge of health, hereinafter referred to as "the Ministry".

3. Functions and duties of the Ministry

- (2) The functions and duties of the Ministry in respect of the prevention, control and management of the disease shall include —
- (a) the collection of data, statistics and information as to the number or quantum of cases of the occurrence of the disease for the purpose of effectively planning and executing its prevention, control and management;
- (b) to carry out researches, studies and findings as to the immediate, secondary and remote causes and effects of the disease;
- (c) to statistically evaluate or detect the degree of susceptibility to the disease of various ages, genders or aspects of the community for the purpose of effectively planning and executing special attention and handling for the purpose of preventing, controlling or managing the disease among them;
- (d) the active prevention, control and management of the occurrence, spread and effects of the disease in the federation directly and through its appropriate agencies;
- (e) to encourage and co-ordinate participation in the prevention, control and management of the disease in the federation by private persons, organisations and foreign governments;
- (f) to directly or through its appropriate agencies procure, receive or obtain and distribute, give

out or administer drugs for the prevention, control and management of the disease in the federation;

- (g) to directly or through its appropriate agencies procure, receive or obtain and disseminate, give or distribute advice, information or literature useful in the prevention, control and management of the disease;
- (h) to carry out awareness education and enlightenment campaigns and other forms of enlightenment activities necessary for the prevention, control and management of the disease either directly or through its appropriate agencies;
- (i) to encourage and impress on members of the public, including but not restricted to intending couples, to undergo blood genotype tests for the purpose of knowing, discovering or ascertaining their blood genotype and for the avoidance of marriages or matrimonial unions that will or are likely to produce children prone or susceptible to the disease; and
- (j) such other functions and duties that are provided for it under this Act.
- (3) Any of the foregoing functions or duties of the ministry in respect of the prevention, control and management of the disease may be performed or discharged by the ministry directly or through any appropriate agency thereof.
- (4) Nothing precludes the Houses of Assembly of the States of the Federation to make laws in respect of these functions.

PART I! - ACCREDITED PARTICIPANTS

- 4. (1) In furtherance to Section 3 (2)(e) of this Bill, the Ministry may accredit federal hospitals and clinics to act or function as accredited participants in the prevention, control and management of the disease in the federation, and such accredited hospitals or medical clinics shall –
- 4. Accreditation of Hospitals and clinics
- (a) i. serve as accredited centres for the provision of medical treatment for the disease,
- ii. provide advice, guidance and counselling on the causes, effects, prevention, control and management of the disease; and
- iii. serve as blood genotype testing centres for members of the public free of cost or charge to such members of the public;
- (b) keep and transmit to the Ministry, monthly or periodic records regarding members of the public who have received medical treatment, advice, guidance and counselling and who have undergone blood genotype testing and to whom or on whom drugs have been dispensed or administered at such hospitals or clinics for the prevention, control and management of the disease, which records shall include the names, addresses and ages of such members of the public and —
- (i) the dates of the treatment, advice, guidance or counselling; or

- (ii) the kind and quantity of drugs administered and the results of the blood genotype tests conducted or carried out in the respective cases.
- (2) In accrediting hospitals under this Section, the Ministry shall ensure that -
- (a) adequate number of hospitals are accredited in each state of the federation; and
- (b) the hospitals accredited in a State are so selected or distributed according to their location in the state as to ensure their proximity to members of the public in that State and to ensure the easy access of people from every part of that State to the services rendered at such hospitals or medical clinics regarding the prevention, control and management of the disease.
- (3) No action or claim shall lie against the ministry for any refusal to accredit any hospital or medical clinic under this Bill.
- 5. (1) The Ministry may pursuance to section 3 (2)(b) of this Bill accredit local or foreign non-governmental or private organizations or bodies to act or function as accredited participants in the prevention, control and management of the disease.

5. Accreditation of Organizations, bodies

- (2) The organizations or bodies accredited under this section may be partners with the Ministry in the prevention, control and management of the disease, and may without cost or charge to any member of the public -
- (a) procure, obtain or acquire and disseminate, give out or distribute information or literature pertaining or relating to the prevention, control and management of the disease;
- (b) procure or receive and distribute, administer or cause to be administered drugs for the prevention, control or management of the disease;
- (c) carry out enlightenment campaigns and other forms of enlightenment activities approved by the Ministry for the prevention, control and management of the disease;
- (d) advocate for and encourage the carrying out of blood genotype tests by members of the public including but not restricted to intending couples;
- (e) with the approval or upon the request of the Ministry carry out any special function or activity necessary for the prevention, control or management of the disease.

#### PART III: DONATIONS

6.

.-(1) The Ministry may, subject to Section 7 of this Bill, receive donations of funds, drugs, literature or other materials from persons, organizations, bodies or governments for the prevention, control and management of the disease.

6. Donations

(2) The Ministry shall, before spending or utilizing any funds, drugs, literature or other materials donated to it under this Bill, make a report of such donation or donations to the National Assembly and obtain approval and directive of same for the spending, or utilization of such

funds, drugs, literature, or other materials.

- (3) The reports by the Ministry to the National Assembly mentioned in subsection (2) of this section may be monthly or quarterly and shall include, among other details, —
- (a) in the case of funds the name and address of the donor or donors, the amount donated and the date and place of such donation;
- (b) in the case of drugs, literature or other material, the brand and quantity of the drugs or the kind and quantity of literature or material donated, the name and address of the donor or donors and the date and place of such donation.
- 7. (1) The Ministry shall, before receiving or accepting any donation of drugs, literature or other material —

7. Restrictions regarding donations

- (a) in the case of drugs, test the drug or drugs in order to prove its or their relevance, genuineness, efficacy or quality; and
- (b) in the case of literature or other materials verify their relevance to or efficacy in the prevention, control and management of the disease.
- (2) The Ministry shall not accept any funds donated or intended or sought to be donated to it if it knows or has reason to believe that the funds are illegally or unlawfully acquired.
- (3) The Ministry shall not accept or receive any literature or other material donated or intended or sought to be donated to it if it knows or is of the opinion or has reason to believe that such literature or other material —
- (a) are illegally or unlawfully acquired or acquired with illegal or ill-gotten funds; or
- (b) are not relevant or useful in the prevention, control or management of the disease.
- (4) The Ministry shall not accept any drugs donated or intended or sought to be donated to it if
- (a) it knows or has reason to believe that the drugs are unlawfully or illegally acquired or acquired with ill-gotten funds; or
- (b) before or after testing them in accordance with subsection (1) of this section it discovers or is of the opinion that such drugs are expired or irrelevant to or of such low quality or so ineffective that they cannot be useful in the prevention, control or management of the disease.
- (5) Where the Ministry refuses or declines to accept any donation by reason of any of the foregoing provisions it shall in writing inform the donor or donors concerned of the fact of such refusal and the reason or reasons for it.
- 8. (1) In its directive to the Ministry on or regarding the use, spending or utilization of funds, drugs, literature or other materials donated or available to the Ministry, the National Assembly shall have regard to and apply the principles of fairness and federal character.

8. Mode of directive by National Assembly on donations (2) Notwithstanding anything to the contrary that may be inferred from subsection (1) of this section, the National Assembly may by resolution direct that a certain amount or quantity of funds, drugs, literature or other material donated or available to the ministry be spent or utilized in or on the prevention, control or management of the disease in a particular part of the federation due to the observed or discovered peculiar trend or frequency of occurrence, spread or effect of the disease in that particular part of the federation.

#### PART IV: OFFENCES

- .-(1) Any person who diverts to his or another person's private use, sale or appropriation any 9. funds, drugs, literature of material donated, procured or available for the benefit of the public for the prevention, control or management of the disease under this Bill commits an offence.
- 9. Offence of diverting or converting donated available Funds, drugs, etc.

- (2) Any person who commits an offence under this section shall be liable -
- (a) on first conviction to a term of imprisonment which may extend to three years or a fine of five hundred thousand Naira (₩500,000); and
- (b) on subsequent conviction to a term of imprisonment which may extend to six years or a fine of eight hundred thousand Naira (\\$00,000).

### PART V: MISCELLANEOUS PROVISIONS

- 10. (1) The Ministry may, subject to subsection 3 of this section, either upon a directive of the National Assembly under section 8 (2) of this Bill or in its normal course of operation specially assign or request any non-governmental organization or body accredited by it under section 5 of this Bill to carry out awareness and enlightenment education campaigns or other forms of education or advocacy or to perform any specified function or activity permitted by this Bill for the prevention, control or management of the disease in the federation or any part thereof.
- 10. Special assignments accredited organizations.
- (2) Where the Ministry specially assigns or requests an accredited organization or body to perform or carry out any specified function or activity in accordance with this section, it shall make available to the organization or body the funds and materials or resources which the ministry considers necessary for the performance or the carrying out of that function or activity.

The Ministry shall, except upon a directive of the National Assembly under section 8 of this Bill, not assign or request any organization or body to specially carry out any function or activity in a specific part of the federation unless-

- (a) there is a report or complaint from that part of the federation of or concerning a peculiar high trend of occurrence, spread or effect of the disease and a demand or request for intervention of the Ministry; and
- (b) following such request for intervention there is a corporate decision of the Ministry to that effect.
- (1) The hospitals and medical clinics accredited by the Ministry under this Bill shall each maintain 11. Special services to

- (a) go through or carry out blood genotype tests;
- (b) receive advice or counselling on the causes, effects and prevention of the disease;
- (c) in appropriate cases obtain medication or treatment necessary for the prevention, control and management of the disease.
- (2) Where it is learnt either from any party or parties to an intending couple or is realized or discovered through a medical test that the blood genotype composition of any or two of the persons intending to marry each other is such as would render children born in such marriage prone or susceptible to the disease, the hospital or medical clinic or the doctor or medical personnel thereof attending to the intending couple or person or persons concerned shall -
- (a) advise such intending couple or person or persons concerned not to go into the intended marriage due to the likelihood of occurrence of the disease in children that may be born thereunder:
- (b) reduce such advice in writing and issue the written advice to the person or persons; and
- (c) record the full names, addresses, and other particulars and case of such person or persons and the advice given thereto as well as the date of such advice.
- (3) No action or claim for breach of promise to marry shall be brought or maintained against any person withdrawing from an intended, planned or pending wedding or marriage in compliance with or following a written advice of a doctor or appropriate medical personnel under subsection 2 of this Section.
- (4) Nothing in this section or any provision of this Act shall be construed to warrant, support or justify any divorce or withdrawal by any person from an already subsisting lawful marriage or from any obligation thereunder.
- The accreditation by the Ministry of any organization or body under this Bill may be withdrawn 12. or cancelled where such organization or body —
- Withdrawal Cancellation accreditation

or

- (a) does not satisfactorily perform its functions or those assigned to it by the Ministry under this Bill; or
- (b) has become affected by any of the disqualifications from accreditation under this Bill or was not qualified for accreditation under this Bill at the time it was accredited; or
- (c) diverts to its private use or is found to be unfair in the dispensation or administration of any drugs or material or any part thereof made available or donated to it for the benefit of the public by the Ministry or donated or available to it; or
- (d) is in breach of or acts contrary to any clear provision of this Bill or the terms or any of the

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terms of its accreditation under this Bill; or

- (e) is in breach of any of its functions or duties or the terms of any specific or special function or duty assigned to it by the Ministry under this Bill.
- 13. The Ministry may directly or through any of its agencies make available, administer or distribute all drugs, literature or materials available to it for the prevention, control and management of the disease or make some or any quantity thereof available to the hospitals, clinics, organizations or bodies accredited by it under this Bill to administer, make available or distribute to members of the public.

13. Ministry to decide mode of Utilizing drugs, materials etc.

14. Where an offence is committed under this Bill in respect of any funds, drugs, literature or material, such funds, drugs, literature or material shall be forfeited to the government of the federation which shall remit same to the ministry and the funds, drugs, literature or material shall be deemed and treated as donated to the Ministry.

Forfeiture of diverted funds, drugs, etc.

15. (1) In this Bill —

15. interpretation

"the disease" means Sickle cell Disease;

"the Ministry" means the Federal Ministry in charge of Health; and

"words imputing the masculine gender" refer to and include both the masculine and feminine gender.

16. This Bill may be cited as Sickle Cell Disease (Prevention, Control and Management) Bill, 2021.

16 Citation

EXPLANATORY MEMORANDUM

This Bill seeks to provide for a legal framework for the prevention, control and management of Sickle cell Disease, in Nigeria.

THIS BILL WAS PASSED BY THE SENATE ON TUESDAY, 21st SEPTEMBER, 2021

President.

Senate of the Federal Republic of Nigeria

Clerk,

Senate of the Federal Republic of Nigeria