

SINDH ACT NO.I OF 2014

THE SINDH PREVENTION AND CONTROL OF THALASSEMIA ACT, 2013

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[27th January, 2014]

An Act to provide for prevention and control of thalassemia.

WHEREAS it is expedient to provide for prevention and control of thalassemia in the Province of Sindh. **Preamble.**

It is hereby enacted as follows:-

1. (1) This Act may be called the Sindh Prevention and Control of Thalassemia Act, 2013. **Short title, extent and commencement.**

(2) It shall extend to the whole of the Province of Sindh.

(3) It shall come into force at once and shall be deemed to have taken effect on and from 8th August, 2013.

2. In this Act, unless there is anything repugnant to the subject or context - **Definitions.**

(a) "blood relatives" means directly related aunts and uncles including sisters and brothers of mother and father of the patient, the children of these uncles and aunts and the siblings of the patient;

(b) "Government" means the Government of Sindh;

(c) "health care facility" means a Government, non-Government, semi-Government or private institution or organization, or private medical practitioner engaged, directly or indirectly, in the provision of health care to the patients of thalassemia, and includes a day-care center;

(d) "rules" means rules made under this Act;

(e) "thalassemia" means a disease in which a child or an adult becomes anemic because of genetic defect of hemoglobin;

(f) "trait" means thalassemia which is heterozygous and results in mild anemia and is often misdiagnosed as iron deficiency anemia if appropriate blood tests are not carried out.

3. Government shall arrange for and approve the dissemination of objective and consistent informational and educational materials on thalassemia and trait, and may, by notification in the official gazette, publish such instructions, guidelines or policies as it deems necessary or appropriate, for the purposes of producing and distributing informational and educational materials. **Informative and educational materials on thalassemia.**

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4. (1) Government shall design and follow a strong and effective system and shall introduce and setup system of Genetic Counselling and diagnostic facilities for the citizens of Sindh, and shall take measures to encourage the citizens to take the counselling and blood test to diagnose thalassemia trait status.

State obligation to take affirmative action.

(2) A non-governmental organization may provide blood transfusion to thalassemia patients.

(3) Government shall ensure easy access to diagnostic facilities for diagnosis of thalassemia carriers.

5. (1) The health care facility treating the thalassemia patients shall ensure that blood relatives of these children are all screened for thalassemia.

Blood test for thalassemia before marriage.

(2) The blood relatives of thalassemia patients who are marrying shall be advised and counseled to obtain a pre-marital blood screening to ensure that they are not carrying the trait.

(3) Antenatal tests shall be carried out on pregnant women known who are known carriers and whose spouses are also carrier for the trait, subject to approval having been obtained from the pregnant women and their spouses.

(4) All Non-governmental organization centres dealing with thalassemia shall ensure that ten percent of their budget shall be spent on developing facilities for thalassemia and prenatal diagnosis of thalassamia.

(5) The health care facility shall provide counselling facilities for relatives of patients on risk of consanguineous marriages and on their chances of having thalassemia children.

(6) For the purposes of pre-marital testing the partners shall have their blood indices done if both the partners have blood indices showing microcytosis their hemoglobin electrophoresis should be undertaken to ensure that they are not carrying the trait.

(7) Antenatal testing shall be carried out, with the consent of the person being tested, in all pregnant women who are known carriers and whose spouses are also known carriers. Diagnosis of the disease shall be carried out by chronic villous sampling and polymerase chain reaction to be carried out in first trimester at a center or hospital which has the facility to carry out such test and procedure.

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6. (1) The test results shall be reported to those who are tested and if they are carriers of trait, they shall be given counselling regarding their marrying someone carrying trait and the risk of passing on the disease of their offspring. **Reporting of test result.**

(2) The test results shall be entered into a data bank for registration of carriers of the trait.

(3) Antenatal test results shall be reported to the women tested and their spouses.

7. All individuals who are or shall ever be in the reproductive phase (capable to bearing children) should have their thalassemia status checked by a simple blood test called hemoglobin electrophoresis. No tests shall be conducted or samples obtained from any individual on reliance of anything contained in this Act, without consent of the person on whom such test is being conducted or from whom the sample is being obtained. **Compulsory test.**

8. (1) In case a health care facility fails to carry out the necessary screening, the health care facility shall be held negligent to perform its duty and shall be charged a penalty of rupees one hundred thousand. **Penalty.**

(2) In case any health care facility or any health care provider or medical practitioner or any other person conducts any tests for thalassemia screening or obtains any samples from any person for the purposes of thalassemia screening, without the consent of the person on whom such tests are being conducted or from whom such samples have been collected shall be punishable under section 337E of the Pakistan Penal Code, 1860.

(3) It shall be compulsory for health care facility to provide detailed genetic counselling with information on pattern of disease and trait transmission, and if the health care facility does not provide written and oral counselling they shall be deemed to have been negligent of their duty and shall be penalized.

9. (1) Government shall by notification establish a Foundation to be known as the Thalassemia and Hemoglobinopathy Foundation. **Establishment of the Thalassemia and Hemoglobinopathy Foundation.**

(2) The Foundation shall be a body corporate having perpetual succession and a common seal with power to acquire, hold and dispose of property, both movable and immovable, and shall by the said name sue and be sued.

(3) The Head Office of the Foundation shall be at Karachi.

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(4) The Foundation shall take all measures which it deems necessary for the promotion, development and financing of Thalassaemia and hemoglobinopathy Centres across the Province for the prevention and treatment of Thalassaemia and to implement the provisions of this Act.

(5) The composition and governance of the Foundation shall be notified by Government.

(6) The Foundation shall establish a Fund to be known as the Thalassaemia and Hemoglobinopathy Foundation Fund which shall vest in the Foundation and to which shall be credited -

- (a) grants made by Government and the Federal Government and Local Bodies;
- (b) income from investments made by the Foundation;
- (c) donations and endowments;
- (d) revolving funds placed by Government at the disposal of the Foundation; and
- (e) all other sums received by the Foundation and income from other sources.

10. Government may by notification in official Gazette, make rules for carrying out the purposes of this Act. **Power to make rules.**

11. Notwithstanding anything contained in the Code of Criminal Procedure 1898, an offence punishable under this Act shall be bail able and triable under the provisions of this Act by a Judicial Magistrate. **Offence to be punishable and triable.**

12. No court shall take cognizance of an offence under this Act except upon a complaint in writing by the Secretary Health Services or District Health Officer or any other officer on his behalf authorized by him. **Cognizance of an offence.**

13. This Act shall have effect notwithstanding anything contained in any other law for the time being in force. **Ordinance to override other laws etc.**

14. No suit, prosecution or other legal proceeding shall be made against any person for anything which is in good faith done or intended to be done under this Act. **Indemnity.**