

[AS INTRODUCED IN THE SENATE]

A

BILL

to provide compulsory blood test for proposed spouse for Thalassaemia

WHEREAS it is expedient to take concrete steps for controlling the hazardous disease of Thalassaemia and to make a law for testing of proposed spouses who have Thalassaemia and manifest the disease;

It is hereby enacted as follows:-

1. Short title, extent and commencement.— (1) This Act may be called the Compulsory Blood Test of the Spouses and Proposed Spouses for Thalassaemia Disease Act, 2018.

(2) It extends to the whole of Islamabad Capital Territory.

(3) It shall come into force at once.

2. Definitions.— In this Act, unless the context requires otherwise, —

(a) "Thalassaemia" means a disease in which a child or an adult becomes anaemic because of a genetic defect of haemoglobin;

(b) "Thalassaemia major" means a stage of Thalassaemia which clinically manifests itself as severe anaemia requiring treatment with repeated blood transfusion and medicines;

(c) "Thalassaemia minor or trait" means Thalassaemia which results in mild anaemia and is often misdiagnosed as an iron deficiency anaemia if appropriate blood tests are not carried out; and

(d) "Prenatal diagnosis" means test carried out during pregnancy.

3. State Obligation for Affirmative Action.— (1) The Government shall design and follow a strong and effective system and shall introduce and set up system of Genetic Counselling and diagnostic facilities for the citizens of Islamabad Capital Territory and shall encourage the citizens to take necessary counselling and blood test to diagnose Thalassaemia trait status.

(2) The Government shall ensure easy access to facilities provided for diagnosis of Thalassaemia carriers and safe blood transfusion as well.

(3) The Government shall also ensure that Non-Governmental Organizations are providing safe blood transfusion to the Thalassaemia patients.

4. Blood Test before Marriage.— (1) The Citizens shall be advised and counselled to obtain the premarital blood screening to ensure that they are not carrying the trait.

(2) All clinics, hospitals and centres treating the Thalassaemia patients shall ensure that they shall provide necessary counselling to the proposed spouses and their parents before marrying and inform them clearly about the risks of consanguineous marriage and on their chances of having Thalassaemia children.

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

(4) All Non-Governmental Organizations (NGOs) running centres dealing with Thalassaemia shall ensure that they spend at least 10% of their budget on developing facilities for prenatal diagnosis of Thalassaemia.

(5) In case a non-Governmental Organization, clinic or hospital fails to carry out the necessary action they shall face administrative action from the concerned Ministry. A fine amounting to rupees fifty thousand shall be imposed on the non-Governmental Organization, clinic or hospital which fails to carry out the test.

5. Reporting of test result.— (1) The test results are to be reported to those who are tested and if they are carriers (have Thalassaemia minor or trait) they are to be given counselling regarding their marrying someone with the same trait and the risk of passing on the disease to their offspring. The test results are to be entered into a data bank for registration of carriers of the trait.

(2) Antenatal test result are to be reported to the women tested and her partner and if the test is positive the parents are to be advised about the condition of the fetus and offered an option of terminating the pregnancy.

6. Preventive Measures.— Notwithstanding anything to the contrary contained in any other law or rule for the time being in force, every marriage in the Islamabad Capital Territory before solemnizing shall fulfil the following precautionary / preventive health measures that:

(a) Nikkah Registrar shall obtain test reports of premarital screening of spouse for Thalassaemia;

(b) The result whatever it may be shall have no effect on the marriage being solemnized.

(c) The Nikah Registrar shall keep and maintain these reports for at least two years from the date marriage is solemnized;

(d) If marriage is solemnized in contravention of these provisions or paragraph (c) is violated, the license of such Nikah Registrar shall be cancelled or whoever, other than Nikah Registrar, solemnized such marriage shall be fined Rs.10,000.

7. Power to make rules.- The Government shall make rules for carrying out the purposes of this Act within six months of the commencement of this Act and shall be placed before the Parliament for information.

STATEMENT OF OBJECTS AND REASONS

Thalassaemia is a hereditary genetic disorder causing impaired production of haemoglobin. It is a dangerous disease which kills a large number of children in Pakistan every year. It is very much needed to take appropriate steps to stop further spread of this disease and arrange for proper precautionary measures control its spread.

2. The Bill seeks to achieve the aforesaid objectives.

SENATOR MIAN MUHAMMAD ATEEQ SHAIKH
Member-in-Charge