[AS PASSED BY THE NATIONAL ASSEMBLY]

A

BILL

to provide compulsory blood test for proposed spouse for Thalassemia

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

It is hereby enacted as follows:—

1. **Short title, extent and commencement.**—(1) This Act may be called the Islamabad Capital Territory Compulsory Thalassemia Screening Bill, 2026.

(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) "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 Federal Government;

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

(d) "Thalassemia" means a disease in which a child or an adult becomes anaemic because of a genetic defect of haemoglobin which included thalassemia major & minor;

(e) "rules" mean rules made under this Act; and

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

3. **Informative and educational materials on thalassemia.**– 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.

4. **Blood test for thalassemia before marriage.** – (1) The health care facility treating the Thalassemia patients shall ensure that blood relatives of Thalassemia patients are all screened for thalassemia.

(2) The blood relatives of Thalassemia patients who are marrying shall be advised and counselled 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 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 Thalassemia.

(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 haemoglobin 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.

5. **Reporting of test result.** — (1) The test results are to be reported to those who are tested and if they are carriers (Thalassemia) 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.

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

(3) 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. **Compulsory test.**– All individuals who are or shall ever be in the reproductive phase (capable of bearing children) should have their Thalassemia status checked by a simple blood test called haemoglobin 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.

7. **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) the Nikkah Registrar shall obtain test reports of premarital screening of bride and the bridegroom to be married for Thalassemia;

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

(c) the Nikkah 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 Nikkah Registrar shall be cancelled or whoever, other than Nikkah Registrar, solemnized such marriage shall be fined one hundred thousand Rupees.

8. **Penalty.**– (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.

(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 healthcare facility does not provide written and oral counselling they shall be deemed to have been negligent of their duty and shall be penalized.

9. **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.

10. Offence to be punishable and triable.– 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.

11. Cognizance of an offence.– No court shall take cognizance of an offence under this Act, except upon a complaint in writing by the Federal Secretary Health Services or District Health Officer ICT, or any other officer in this behalf, authorized by him.

12. Act to over-ride other laws etc.– This Act shall have effect notwithstanding anything contained in any other law for the time being in force.

13. Indemnity.– 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.

STATEMENT OF OBJECTS AND REASONS

The aim of this Bill is to significantly reduce the prevalence and impact of Thalassemia in Pakistan, where the disease affects 3-8% of the population and leads to the birth of approximately 5,000 transfusion-dependent Thalassemia major children each year. This Bill seeks to implement a comprehensive approach that includes mandatory genetic screening and counseling for families with a history of Thalassemia, particularly those engaged in consanguineous marriages, which increase the risk of passing on the disease.

2. The proposed legislation will ensure the identification of carriers (individuals with one abnormal gene), the provision of genetic counseling, and the offering of prenatal diagnostic services to prevent the birth of affected children. With 30% of families with a history of thalassemia being carriers, it is critical to proactively screen and counsel at-risk couples.

3. Furthermore, the proposed Bill aims to strengthen healthcare systems to provide better access to life-saving treatments, including blood transfusions and iron chelation therapy, for those already diagnosed with the disease. By increasing public awareness about the inheritance patterns and prevention strategies, the law will empower families to make informed decisions, ultimately reducing the burden of Thalassemia on individuals, families, and the healthcare infrastructure.

4. This legislative proposal will help curb the spread of Thalassemia in Pakistan, ensuring better health outcomes for future generations and preventing the associated social and financial burdens.

5. The Bill seeks to achieve the aforesaid objectives.

SD/-

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