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PROVINCIAL ASSEMBLY OF THE PUNJAB

REPORT OF THE STANDING COMMITTEE ON SPECIALIZED HEALTHCARE & MEDICAL EDUCATION REGARDING "THE PUNJAB PREVENTION AND CONTROL OF THALASSEMIA BILL 2024 (BILL NO. 13 OF 2024)".

The subject Bill was referred to the Committee on October 15, 2024 and the same was considered by the Committee in its meetings held on March 4, 2025 and April 16, 2025.

2. The following attended:

1.	Mr Adnan Afzal Chattha, MPA (PP-36)	Chairperson
2.	Ms Rushda Lodhi Parliamentary Secretary for Specialized Healthcare & Medical Education	<i>ex-officio Member</i>
3.	Ms Sunbal Malik Hussain, MPA (W-316)	Member
4.	Ms Hina Parvez Butt, MPA (W-302)	Member
5.	Ms Nargis Faiz Malik, MPA (W-336)	Member
6.	Ms Uzma Kardar, MPA (W-322)	Member
7.	Mr Ali Hussain Khan, MPA (PP-83)	Member
8.	Ms Zarnab Sher, MPA (PP-40)	Member
9.	Mr Faisal Jamil, MPA (PP-259)	Member
10.	Syed Ali Haider Gilani, MPA (PP-213)	Member Incharge

3. Mr Zeeshan Shabbir, Special Secretary, Government of the Punjab, Specialized Healthcare & Medical Education Department and Mr Shan ul Haq, Special Secretary, Law & Parliamentary Affairs Department, represented their Departments as Expert Advisors. Mr Faisal Bilal Buttar, Additional Secretary (Committees), Provincial Assembly of the Punjab, functioned as Secretary to the Committee.

4. Syed Ali Haider Gilani, MPA (PP-213) Member Incharge apprised the Committee about the aims and objects of the Bill. He requested the Committee that the Bill, as introduced, may be recommended for passage by the Assembly.

5. After detailed discussion the Committee decided to recommended that the Bill may be passed by the Assembly with certain amendments.

6. A copy of the Bill, as introduced in the Assembly and as recommended by the Committee, is given at Annexure-A and Annexure-B respectively.

(ADNAN AFZAL CHATTHA)

Chairperson

Standing Committee on

Specialized Healthcare & Medical Education

Lahore

April 16, 2025

(CH AMER HABIB)

Secretary General

Lahore

April 16, 2025

(Bill as introduced in the Assembly)

PROVINCIAL ASSEMBLY OF THE PUNJAB

Bill No. 13 of 2024

THE PUNJAB PREVENTION AND CONTROL OF THALASSEMIA BILL 2024

A

Bill

to provide for prevention and control of thalassemia.

WHEREAS it is expedient to provide for prevention and control of thalassemia in the Province of The Punjab.

Be it enacted by the Provincial Assembly of the Punjab as follows:

1. Short title, extent and commencement.— (1) This Act may be called the Punjab Prevention and Control of Thalassemia Act, 2024.

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

(3) It shall come into force at once.

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

(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 The Punjab;

(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-carecenter;

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

(e) "thalassemia" means a disease in which a child or an adult becomesanemic 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. 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. State obligation to take affirmative action.— (1) Government shall design and follow a strong and effective system and shall introduce and setup system of Genetic Counseling and diagnostic facilities for the citizens of The Punjab, and shall take measures to encourage the citizens to take the counseling and blood test to diagnose thalassemia trait status.

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

(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 thalassemia.

(5) The health care facility shall provide counseling 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.

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

(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. Compulsory test.— 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.

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 counseling with information on pattern of disease and trait transmission, and if the health care facility does not provide written and oral counseling they shall be deemed to have been negligent of their duty and shall be penalized.

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

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 Secretary Health Services or District Health Officer or any other officer on his 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

Thalassemia can be prevented using a combination of treatments such as prenatal screening and genetic counseling. Genetic Counseling - Couples with a family history of thalassemia or who belong to ethnic groups at higher risk should consider genetic counseling before planning a pregnancy. Hence this Bill.

SYED ALI HAIDER GILANI, MPA (PP-213),
MEMBER INCHARGE

Lahore:
October 15, 2024

CH AMER HABIB
Secretary General

(Bill as recommended by the Standing Committee on Specialized Healthcare & Medical Education)

A

Bill

to make provisions for the control and prevention of Thalassemia and other genetic orders.

Preamble.— WHEREAS early detection, prevention and management of thalassemia and related genetic disorders are essential to reduce the burden of these conditions on the healthcare system;

It is hereby enacted as follows:

1. Short title, extent and commencement.— (1) This Act may be cited as the Punjab Thalassemia Prevention Act 2025.

(2) It extends to whole of the Punjab.

(3) It shall come into force at once.

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

- (a) “Board” means the Board of Intermediate and Secondary Education established under the Punjab Boards of Intermediate and Secondary Education Act, 1976 (XIII of 1976);
- (b) “Chairperson” means the Chairperson of the Council;
- (c) “Council” means the Council notified under section 3 of this Act;
- (d) “data” means the data generated in consequence of a sample or test;
- (e) “Department” means the Specialized Healthcare and Medical Education Department;
- (f) “Government” means Government of the Punjab;
- (g) “Institution” means a public or private school or college and includes Deeni Madaras either registered with any board in the Punjab;
- (h) “laboratory” means a public or private sector laboratory notified under this Act;
- (i) “member” means a member of the Council;
- (j) “PITB” means the Punjab Information Technology Board established under the Punjab Information Technology Board Ordinance 1999 (XLIV of 1999);
- (k) “PPC” means Pakistan Penal Code;
- (l) “prescribed” means prescribed by the rules or the regulations;
- (m) “regulations” means the regulations framed under this Act;
- (n) “rules” means the rules made under this Act;
- (o) “school” means a public or private school and includes Deeni Madaras registered under the relevant laws; and
- (p) “student” means a student registered with any Board.

3. Advisory Council.— (1) There shall be an Advisory Council to be notified by the Department after approval by the Government comprising the following:

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|-----|---|--------------------|
| 1) | <u>Minister for Specialized Healthcare & Medical Education</u> | <u>Chairperson</u> |
| 2) | <u>Minister for Health & Population Department</u> | <u>Member</u> |
| 3) | <u>Parliamentary Secretary, Specialized Healthcare & Medical Education</u> | <u>Member</u> |
| 4) | <u>Two members, including one female member, of Provincial Assembly of the Punjab to be nominated by the Speaker of the Assembly;</u> | <u>Members</u> |
| 5) | <u>Secretary, Specialized Healthcare & Medical Education Department</u> | <u>Secretary</u> |
| 6) | <u>Secretary/Special Secretary (Operations), Health & Population Department</u> | <u>Member</u> |
| 7) | <u>Secretary/Special Secretary (Operations), Higher Education Department</u> | <u>Member</u> |
| 8) | <u>Secretary/Special Secretary (Operations), School Education Department</u> | <u>Member</u> |
| 9) | <u>Secretary/Special Secretary (Operations), Local Government and Community Development Department</u> | <u>Member</u> |
| 10) | <u>Secretary/Special Secretary (Operations), Auqaf & Religious Affairs Department</u> | <u>Member</u> |
| 11) | <u>Additional Secretary (Technical) Specialized Healthcare & Medical Education Department</u> | <u>Member</u> |
| 12) | <u>Vice Chancellor, University of Child Health Sciences, Children's Hospital, Lahore</u> | <u>Member</u> |
| 13) | <u>CEO, Punjab Healthcare Commission</u> | <u>Member</u> |
| 14) | <u>DG, Punjab Thalassemia & other Genetic Disorders Prevention Program</u> | <u>Member</u> |
| 15) | <u>Director, CEMB</u> | <u>Member</u> |
| 16) | <u>One Representative of Public & Private Schools (to be nominated by SED)</u> | <u>Member</u> |
| 17) | <u>One Professor of Hematology, nominated by the Department</u> | <u>Member</u> |

(2) Ten Members, including Chairperson or the person presiding the meeting, shall constitute the quorum for a meeting of the Council, and the Council shall make a decision by majority of its members present and voting, and in case of a tie, the Chairperson or the member presiding the meeting shall have a casting vote.

(3) The Council shall meet at least once in three months and its meeting shall be held at such place, date and time as the Chairperson or the person nominated to preside over the meeting may determine.

(4) The Chairperson or, in his absence, any member nominated by him shall preside over the meeting of the Council.

4. **Powers and functions of the Council.—** (1) The Council may recommend to the Government for effective system of genetic counseling and diagnostic facilities accessible to the students of Punjab and take such measures to encourage them to fully utilize it.

(2) All individuals tested for the disease(s), if found carrier of trait, shall be given counseling regarding their marrying someone carrying rate and risk of passing on the disease(s) to their offspring.

(3) Advisory Council will facilitate early diagnosis, management, complication and prevention of disease(s) through updated education about the latest tests, active role of Punjab Healthcare Commission in the whole process and creation of huge data bank for further policy making.

(4) Advisory Council will place a substantive mechanism for formulating tests to be done for the said disease(s) and the referred laboratories, either public or private.

(5) Accreditation of the said laboratories will be the sole responsibility of the Advisory Council.

(6) The target population and the age group who are to undergo testing will be determined by the Advisory Council.

(7) Advisory Council will ensure check on the quality control of Laboratories.

(8) The Council will regulate rate of the tests prescribed for the said disease(s).

(9) A mechanism will be devised by the Advisory Council for proper referral system.

(10) The Council may recommend inclusion of thalassemia diagnosed children in the list of special children and may also recommend issuance of special health cards for their treatments at public and private hospitals.

(11) The Council will further recommend registration of thalassemia diagnosed children in NADRA at the time of issuance of form-B or smart card or CNIC and would recommend to make arrangements for provision of financial assistance to the thalassemia children.

5. **Remuneration.—** No remuneration shall be paid to the members of the Council.

6. **Technical Advisory Committee.—** The Council shall, for a specified period, constitute a Technical Advisory Committee, consisting of the following:

- a) Additional Secretary (Technical) of the Specialized Healthcare and Medical Education Department;
- b) Additional Secretary (Technical) of the Health & Population Department;
- c) a representative of Secretary, School Education Department not below the rank of Deputy Secretary;
- d) a representative of Secretary, Higher Education Department not below the rank of Deputy Secretary;
- e) Secretary, Punjab Blood Transfusion Authority, Punjab;

- f) Director, Institute of Blood Transfusion Services, Punjab;
- g) a representative of Punjab Healthcare Commission;
- h) One Professor of Medicine to be nominated by Advisory Council;
- i) One Professor of Hematology to be nominated by Advisory Council;
- j) One Professor of Pediatrics to be nominated by Advisory Council;
- k) a representative of the Thalassemia organizations, to be nominated by the Advisory Council;
- l) a representative of PITB; and
- m) a legal expert.

7. Category of a test.— The Department shall, after approval by the Government, on the recommendation of the Advisory Council, notify a category of test or more than one category of test, as the case may be, in the official Gazette.

8. Consent Form.— Advisory Council shall formulate the proforma containing all the parameters required for the informed consent.

9. Fee.— Price fixation shall be done through the Punjab Healthcare Commission under provision of “PRICING OF HEALTHCARE SERVICES REGULATION 2021”; provided that the Government may make arrangements for free of cost testing facility for the purpose.

10. Laboratories.— (1) No laboratory or its authorized person shall take sample or conduct test of a student under this Act unless it is notified by the Department on the recommendation of the Council.

(2) The laboratory shall conduct the test in accordance with the standards and procedures as may be prescribed by the Department on the recommendation of the Council.

(3) A laboratory shall, after taking the sample or conducting the test, as the case may be, issue acknowledgment receipt to the student at once and forward its duplicate copy to the head of the concerned institution within three working days.

(4) The laboratory shall conclude the test within ten days from taking the sample and forward its result to the Punjab Information Technology Board electronically within five days after its conclusion.

(5) The laboratory shall maintain the confidentiality of the results and shall not share it or any relevant information with any unauthorized person.

11. Confidentiality of information.— No one shall share the information whether personal or medical, with any other individual or collective, personal or medical to any Medical Company, Pharmaceutical company, local donor, international donor, local/international NGOs/INGOs or any other entity without the approval of the Government.

12. Responsibility of PITB.— (1) The PITB shall establish a separate portal for receiving and maintaining the data from the laboratories under this Act.

(2) The data of the test received from the laboratories shall be kept in the custody of the PITB and its secrecy shall be maintained.

13. Responsibility of head of an Institution.— The head of an institution shall ensure that students enrolled in the institution, has provided the sample or

undergone a test under this Act by a notified laboratory at the time of enrollment or submission of forms to the Board, whichever is earlier.

14. Responsibility of a Board.— A Board shall, before registration of student, ensure that the receipt regarding provision of a sample or conduct of test under this Act is enclosed with the form for registration.

15. Implementation and Monitoring.— The Council, Specialized Healthcare and Medical Education Department, School Education Department, Higher Education Department, Punjab Healthcare Commission and Board shall be responsible for implementation of the provisions of this act and monitoring thereunder.

16. Violation of provisions of this Act.— (1) If a Government employee is found involved in violation of any provision of this Act, he shall be proceeded against under the Punjab Employees Efficiency and Disciplinary Accountability Act 2006 (XII of 2006).

(2) If a Government employee is found involved in unauthorized release of information of the data or generation of a fake result, he shall be liable to be prosecuted under this Act and the Punjab Employees Efficiency and Disciplinary Accountability Act 2006 (XII of 2006).

(3) In case an employee of a private laboratory notified under this Act is found involved in unauthorized release of information of the data or generation of a fake result, he shall be liable to be proceeded against under PPC and the Labs involved in any malpractice shall face proceedings which may include blacklisting.

17. Fund of the Council.— (1) The Government shall establish a fund.

(2) The Council shall maintain the fund in the prescribed manner.

(3) The fund shall consists of:

- (a) grants received from the Government through budgetary allocations;
- (b) income received from tests fees and all other sums received by the Council;
- (c) money received from the Federal Government or any international organization by way of grant, loan, advance or others;
- (d) money received from the disposal of movable and immovable property of the Council;
- (e) and any other money received by the Council.

18. Audit and Accounts.— (1) The Council shall maintain complete and accurate books of accounts of its actual expenses and receipts in the manner prescribed.

(2) The Council shall approve the annual budget of the Authority in the prescribed manner.

(3) The accounts of the Council shall be audited annually by the Auditor General of Pakistan.

19. Delegation of powers.— The Council may delegate any of its functions to committee or any other officer of the Council except the following functions:

- (a) framing of regulations;
- (b) approval of budget of the Council in addition to the budget allocated by the Government; and
- (c) making of policies.

20. Power to make rules.— (1) The Government may, by notification in the official Gazette, on the recommendation of the Council, make rules for carrying out the purposes of this Act.

(2) Notwithstanding the generality of the power provided under sub-section (1), Government may make rules for the purposes of this Act.

21. Power to frame regulations.— The Council may, subject to the provisions of this Act and the rules made thereunder, and after approval by the Government, frame regulations for conduct of its business.

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

23. Cognizance of an offence.— No court shall take cognizance of an offence under this Act except upon a complaint in writing by the Secretary, Specialized Healthcare and Medical Education Department or Chief Executive Officer, District Health Authority or any officer on their behalf authorized by them.

24. Act to override other laws.— This Act shall have effect notwithstanding anything contained in any other law for the time being in force.

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

26. Removal of difficulties.— If any difficulty arises in giving effect to any of the provisions of this Act, Government may, by notification in the official Gazette, make such order not inconsistent with the provisions of this Act, as it may consider necessary for the purpose of removal of difficulty.
