

NOTIFICATION

Dated Quetta, the 21st October, 2015.

No.PAB/Legis:V(13)/2015. The Balochistan Prevention and Control of Thalassemia Bill, 2015, (Bill No. 13 of 2015) having been passed by the Provincial Assembly of Balochistan on 09th October, 2015 and assented to by the Governor, Balochistan on 16th October, 2015 is hereby published as an Act of Balochistan Provincial Assembly.

THE BALUCHISTAN PREVENTION AND CONTROL OF THALASSEMIA
ACT 2015 (ACT NO.XIV OF 2015)

AN

Act

to provide for prevention and control of Thalassemia in Balochistan.

Preamble.

WHEREAS it is expedient to provide for prevention and control of Thalassemia in the Province of Balochistan.

It is hereby enacted as follows:-

Short title, extent and Commencement.

1. (1) This Act may be called the Balochistan Prevention and Control of Thalassemia Act, 2015.

(2) It shall extend to the whole of Balochistan, except the Tribal Areas.

(3) It shall come into force at once.

Definitions.

2. In this Act, unless there is anything repugnant in the subject or context

- (a) **“Act”** means the Balochistan Prevention and Control of Thalassemia Act, 2015;
- (b) **“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 siblings of the patient;
- (c) **“Government”** mean the Government of Balochistan,
- (d) **“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 patients of Thalassemia and include a day care center;
- (e) **“Rules”** mean the rules made under this Act;
- (f) **“Thalassemia”** means a disease in which a child or an adult becomes anemic because of genetic defect of hemoglobin; and
- (g) **“Trait”** mean 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,

Informative and educational material on Thalassemia

consistent informative and educational material on Thalassemia and trait, and may by notification in the official Gazette, publish such instruction, guideline/policies as it deems necessary or appropriate to achieve the purpose of producing and distributing informative and educational materials.

State obligation to take affirmative action.

4. (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 Residents of Balochistan and shall take measures to encourage the citizens to take the counseling and blood test to diagnose Thalassemia trait status.

(2) A non-Government organization may provide blood transfusion to Thalassemia patients.

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

Blood Test for Thalassemia before marriage.

5. (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 go for a pre-marital blood screening to ensure that they are not carrying the trait.

(3) Antenatal test shall be carried out on pregnant women who are known carriers and whose spouse are also carrier for the trait, subject to approval having been

obtained from the pregnant women and their spouses.

(4) All non-Government organization centers 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 purpose of premarital 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 test 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 chorionic 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.

Reporting of test result.

6. (1) The test result should 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 to their offspring.

(2) The test result shall be entered

into a data bank for registration of carriers of the trait.

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

Compulsory test.

7. 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 hemoglobin electrophoresis. No test shall be conducted or samples obtained from any individual in compliance 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.

Penalty.

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.

(2) In case health care facility or any health care provider or medical practitioner or any other person conduct any test for Thalassemia screening or obtain any samples from any person for the purpose 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 should 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, departmentally as well under the penal provisions of law.

**Establishment of the
Thalassemia and
Haemoglobinopathy
Board.**

9. (1) Government shall by notification establish a foundation to be known as the "Thalassemia and Haemoglobinopathy Foundation".

(2) The Government shall constitute a board by notification on such composition as determine by the Government.

(3) The Head office of the Board shall be at Quetta.

(4) The Board shall take all measures which it deems necessary for the promotion, development and financing of Thalassemia and Haemoglobinopathy centers across the province for the prevention and treatment of Thalassemia and to implement the provisions of this Act.

(5) The Board shall establish a Fund to be known as the Thalassemia and Haemoglobinopathy Board Fund, which shall vest in the Board and to which shall be credited

- (a) Grants made by Government, Federal Government and Local bodies;
- (b) Income from investment made by the Board;
- (c) Donations and endowments;
- (d) Revolving funds placed by Government at the disposal of the Board; and
- (e) All other sums received by the

Board and income from other sources.

Power to make rules.

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

Offence to be Punishable and Trial-able.

11. Notwithstanding anything contained in the Code of Criminal Procedure, 1898, an offence punishable under this Act shall be bail-able and trial-able by a Judicial Magistrate 1st class.

Cognizance of an offence.

12. No court shall take cognizance of an offence under this Act except upon a complaint in writing made by the Secretary Health, Director General Health or District Health officer or any other officer duly authorized by him to exercise such powers by a notification in official Gazette.

Act to override other laws.

13. This Act shall have overriding effect notwithstanding anything contained in any other law for the time being enforce.

Indemnity.

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

(Secretary)

Balochistan Provincial Assembly
