

Bill No. 170 of 2019

THE FREE AND COMPULSORY PRE-MARITAL GENETIC
TESTING BILL, 2019

By

DR. SHRIKANT EKNATH SHINDE, M.P.

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BILL

to provide for free and compulsory pre-marital genetic testing for couples planning to get married or start a family in order to identify common genetic blood disorders like sickle cell, anemia and thalassemia and for matters connected therewith or incidental thereto.

BE it enacted by Parliament in the Seventieth Year of the Republic of India as follows:—

1. (1) This Act may be called the Free and Compulsory Pre-Marital Genetic Testing Act, 2019.

5 (2) It extends to the whole of India.

(3) It shall come into force on such date as the Central Government may, by notification in the Official Gazette, appoint.

Short title,
extent and
commencement.

Definitions.	<p>2. In this Act, unless the context otherwise requires,—</p> <p>(a) "appropriate Government" means in the case of a State, the Government of that State and in other cases, the Central Government;</p> <p>(b) "couple" means a male above the age of twenty years and female above the age of eighteen years or a person belonging to the third gender having valid identity and birth certificate, planning to get married under any personal law as is applicable or willing to start a family including those persons who are in a live-in relationship;</p> <p>(c) "health centre" includes Government or private hospitals, pathology centres, dispensaries, clinics, hospital on wheels and such other centres meant for pre-marital genetic testing established by the appropriate Government;</p> <p>(d) "pre-marital genetic test" means tests for detecting common genetic blood disorders like sickle cell anemia and thalassemia primarily aimed at giving medical consultation on the odds of transmitting these diseases to the other partner/spouse or children including their lab investigation, consultation and counselling; and</p> <p>(e) "prescribed" means prescribed by the rules made under this Act.</p>	5 5 10 15
Policy for compulsory pre-marital genetic testing of couples.	<p>3. (1) The appropriate Government shall, as soon as may be, after commencement of this Act, by notification in the Official Gazette, frame a policy for compulsory pre-marital genetic testing of couples intending to get married.</p> <p>(2) The policy framed under sub-section (1) shall include the provision of pre-marital genetic testing free of cost at health centres specified under this Act, in such manner as may be prescribed.</p>	20
Responsibility of appropriate Government.	<p>4. The appropriate Government shall—</p> <p>(a) appoint or hire required manpower and other materials or services, from time to time, for carrying out the purposes of this Act; and</p> <p>(b) ensure effective and timely advertisement and due publicity to the policy framed under section 3.</p>	25
Duty of couples.	<p>5. It shall be the duty of every couple to—</p> <p>(a) schedule a pre-marital genetic testing at least three months before the marriage date;</p> <p>(b) produce the pre-marital compatibility certificate issued under section 5 to the Registrar of marriage before issuance of marriage certificate or such other documents.</p>	30
Pre-Marital Compatibility Certificate.	<p>6. Every health centre shall, after the pre-merital genetic test of couple, issue pre-marital compatibility certificate in such form and manner as may be prescribed, which shall be valid for only six months.</p>	
Confidentiality.	<p>7. The medical and screening records of the couple or individuals shall be dealt with extreme confidentiality and in compliance with Information Technology (Reasonable Security Practices and Procedures and Sensitive Personal Data or Information) Rules, 2011 framed under the Information Technology Act, 2000 and the Indian Medical Council (Professional Conduct, Etiquette and Ethics) Regulations, 2002 framed under the Indian Medical Council Act, 1956 or any other Act of privacy for the time being in force.</p>	35 40
Central Government to provide adequate fund.	<p>8. The Central Government shall, after due appropriation made by Parliament by law in this behalf, provide, from time to time, adequate funds to the State Government for carrying out the purpose of this Act.</p>	
Power to remove difficulty.	<p>9. If any difficulty arises in giving effect to the provisions of this Act, the Central Government may make such order or give such direction, not inconsistent with the provisions of this Act, as may appear to be necessary or expedient for removing the difficulty:</p>	45

Provided that no such order shall be made after the expiry of the period of two years from the date of commencement of this Act.

11. (1) The appropriate Government may, by notification in the Official Gazette, make rules for carrying out the purposes of this Act.

Power to
make rules.

5 (2) Every rule made under this Act shall be laid, as soon as may be after it is made,
before each House of Parliament, while it is in session, for a total period of thirty days which
may be comprised in one session or in two or more successive sessions, and if, before the
expiry of the session immediately following the session or the successive sessions aforesaid,
both Houses agree in making any modification in the rule or both the Houses agree that the
10 rule should not be made, the rule shall thereafter, have effect only in such modified form or be
of no effect, as the case may be; so, however, that any such modification or annulments shall
be without prejudice to the validity of anything previously done under that rule.

(3) Every rule made by the State Government under this Act shall be laid, as soon as
may be after it is made, before the State Legislature.

STATEMENT OF OBJECTS AND REASONS

Marriage is the union of two souls, a fundamental building block of our society and the cornerstone in building emotional and healthy family relationship. It is given prime importance in Indian societies and a lot of efforts are put to ensure that the marriage results in a happy and satisfactory life for the partakers. Usually in Indian circumstance, financial and social aspects are scrutinized before selecting a matrimonial partner however health scrutiny is not given as much importance, seldom-times resulting in exigent challenges for lifetime for the betrothed. Thus the need of a healthy marriage arise to ensures that no family member suffer from hereditary and infectious diseases.

India today, is confronting a unique problem of growing number of genetic blood disorder cases like that of sickle cell anemia and thalassemia. Thalassemia is a genetic blood disorder commonly characterized by the abnormal production of hemoglobin in the body. The abnormality results in improper exgen transport and destruction of red blood cells. It has wide-ranging effects on the human body like iron overload, bone deformities and in severe cases heart disease also. The disease has no cure and people living with thalassemia major require regular blood transfusions as an effective measure to prolong life. A thalassemia major child is born out of the marriage of two thalassemia minor patients. Therefore, the only way to prevent the spread of thalassemia major is to avoid the marriage of two thalassemia minor patients.

Thalassemia has one of the highest incidents rates in India, with close to ten thousand to twelve thousand children being born with thalassemia (in India) per year. This makes India officially the thalassemia capital of the world. India is estimated to have ten thousand patients with a Beta thalassemia (β thalassemias) syndrome and around one lakh and fifty thousand patients with sickle cell disease, but few among them are optimally managed. Allergenic stem cell transplant is unaffordable for the majority of families. Thus, feasible option for control is to intensify pre-marital screening of such diseases along with micro-mapping to assess the true burden; develop adequate facilities for such diseases along with micro-mapping to assess the true burden; adequate facilities for genetic counseling and pre-marital diagnosis in public sector Institutions. At least one lakh rupees is the cost of treatment per patient every year. The total burden of diseases born out of genetic disorder is estimated to stand at fifty thousand crore annually. A developing country like India cannot afford this burden and thus it is the most opportune time to draft a national policy for a free and compulsory pre-marital genetic screening for all residents irrespective of their financial or social background as it cannot be left optional for long.

The Bill, therefore, seeks to:—

- (a) mitigate the spread of genetic blood disorders like sickle cell, anemia and thalassemia by providing free and compulsory pre-marital genetic testing for couples who are planning to get married or start a family;
 - (b) promote awareness about the concept of the comprehensive healthy marriage;
 - (c) reduce pressure over health institutions and blood banks;
 - (d) aoid social and psychological problems for families whose children suffer;
- and
- (e) reduce the family and nation's financial burden of treating such children.

Hence this Bill.

NEW DELHI;
June 26, 2019.

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FINANCIAL MEMORANDUM

Clause 4 of the Bill provides for appointment of manpower, material and services for carrying out the purposes of this Act. It also provides for due publicity of pre-marital genetic testing policy by the appropriate Government. Clause 8 provides that the Central Government shall provide adequate funds for carrying out the purposes of this Act. The Bill, therefore, if enacted, would involve expenditure from the Consolidated Fund of India. It is estimated that a recurring expenditure of rupees five hundred crores will be involved from the Consolidated Fund of India.

No non-recurring expenditure is likely to be involved.

MEMORANDUM REGARDING DELEGATED LEGISLATION

Clause 11 of the Bill empowers the appropriate Government to make rules for carrying out the purposes of the Bill. As the rules will relate to matters of detail only, the delegation of legislative power is of a normal character.

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