

**Bill No. 65 of 2022**

THE THALASSEMIA PREVENTION BILL, 2022

By

SHRI RAHUL SHEWALE, M.P.

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BILL

*to promote awareness to prevent passing of thalassaemia from parents to children through mutated haemoglobin genes and for matters connected therewith.*

BE it enacted by Parliament in the Seventy-third Year of the Republic of India as follows:—

1. (1) This Act may be called the Thalassaemia Prevention Act, 2022.

(2) It extends to the whole of India.

5 (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.	2. In this Act, unless the context otherwise requires:—	
	(a) “appropriate Government” means in the case of a State, the Government of that State, and in all other cases, the Central Government;	
	(b) “educational institution” means a primary or a middle or a secondary school imparting education to children, by whatever name such institution is called;	5
	(c) “Fund” means the Thalassemia Prevention and Awareness Fund; and	
	(d) “prescribed” means prescribed by rules made under this Act.	
Thalassemia Prevention and Awareness Fund.	<b>3. (1) The Central Government shall, by notification in the official Gazette, constitute a Fund to be known as the Thalassemia Prevention and Awareness Fund.</b>	10
	<b>(2) The Fund shall be utilised to:—</b>	
	(a) create awareness about thalassemia at bus stands, railway stations and government hospitals in urban and rural areas; and	
	(b) organise blood donation camp in such manner as may be prescribed.	15
Compulsory Teaching of thalassemia in educational institutions.	4. From such date, as the Central Government may, by notification in the official Gazette, specify, thalassemia and preventive measures therefor shall be taught as a compulsory subject in all educational institutions.	
Compulsory Thalassemia Test Report.	5. The appropriate Government shall ensure that the testing for thalassemia is made compulsory,—	20
	(i) at the time of taking admission in Educational Institutions;	
	(ii) at the time of being appointed in Government establishment and Nationalised Bank:	
	Provided that mere testing positive for thalassemia shall not be a ground to deny admission in educational institutions or appointment in Government establishments and nationalised banks, as the case may be.	25
Thalassemia Test Report before marriage.	6. Each party to marriage shall, before solemnisation of marriage, submit thalassemia test report to the appropriate Government in such manner as may be prescribed:	30
	Provided that mere testing positive for thalassemia of either party to the marriage shall not be a ground for denial of registering or solemnisation of a marriage.	
Central Government to provide funds.	<b>7. The Central Government shall, after due appropriation made by Parliament by law in this behalf, provide adequate funds, from time to time, for carrying out the purposes of this Act.</b>	35
Act to have overriding effect.	8. The provisions of this Act shall have effect notwithstanding anything inconsistent therewith contained in any other law for the time being in force.	
Power to remove difficulties.	9. (1) If any difficulty arises in giving effect to the provisions of this Act, the Central Government may, by order published in the Official Gazette, make such provisions not inconsistent with the provisions of this Act as may appear to it to be necessary or expedient for removing the difficulty:	40

Provided that no order shall be made under this section after the expiry of a period of two years from the commencement of this Act.

(2) Every order made under this section shall be laid, as soon as may be after it is made, before each House of Parliament.

5           **10.** (1) The Central Government may, by notification in the Official Gazette, make rules for carrying out the purposes of this Act.

Power to make rules.

10           (2) Every rule made under this section 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 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 annulment shall be without prejudice to the validity of anything previously done under that rule.

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(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

Thalassemia is a disease caused by a defect in the blood. Most people are unaware of this disease. The disease is fully genetic. In other words, it is the parents who cause the disease in children. This disease is of two types, minor and major. Children get this serious disease only because of ignorance of their parents about the disease. Thalassemia minor are carriers and can live their lives like everyone else. But if two thalassemia minors are married to each other there are twenty five per cent chances of getting thalassemia major child. To stop all this a simple procedure is to get tested for thalassemia before marriage. This test can be carried out at any pathology lab. If the person carries out the test for thalassemia and tests negative or positive, the result remains same for the rest of life. That's why it is must that the person should get tested once.

The Bill provides for creating awareness about thalassemia so as to prevent passing of thalassemia from parents to children.

Hence this Bill.

NEW DELHI;  
19 *January*, 2022.

RAHUL SHEWALE

## FINANCIAL MEMORANDUM

Clause 3 of the Bill provides for the constitution of a Thalassemia Prevention and Awareness Fund, which shall be utilised for creating awareness about the disease in urban and rural areas and for organising blood donation camps. Clause 7 provides that the Central Government shall provide adequate funds for carrying out the purposes of the Act. The Bill, therefore, if enacted, would involve expenditure from the Consolidated Fund of India. It is estimated that a recurring expenditure of about rupees ten crore per annum would be involved from the Consolidated Fund of India.

No non-recurring expenditure is likely to be involved.

## MEMORANDUM REGARDING DELEGATED LEGISLATION

Clause 10 of the Bill empowers the Central 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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