



TO BE INTRODUCED IN YOUTH PARLIAMENT OF PAKISTAN

A

Bill

To make blood screening mandatory for getting Nikkah NAMA

It is hereby enacted as follows:

CHAPTER I PRELIMINARY

1. Short title and commencement:-

- (1) This Act may be called the compulsory blood screening Act, 2012.
- (2) It shall come into force at once.

2. **Definitions.-**

- (a) “Chairperson” means the Chairperson of the Health Board.
- (b) “Health Committee” means Health Committee on blood screening under the auspices of the Federal health department.
- (c) “Member” means a member of the health board and includes the Chairperson;
- (d) “Prescribed” means prescribed by rules made under this Act; and
- (e) “Blood bank” means certified and registered blood bank by ministry of health
- (f) “hospital” means certified and registered hospital by ministry of health.
- (e) “Thalassemia” means a disease in which a child or an adult becomes anemic because of genetic defect of hemoglobin

CHAPTER II. ESTABLISHMENT OF HEALTH COMMITTEE

The Federal Government shall constitute a health committee to exercise the powers and perform the functions under this Act.

The health committee shall consist of,-

3. .- The health committee shall consist of:

- (a) Federal Secretary of health
- (b) Four senior doctors selected by the federal health department

The office of the Commission shall be at Islamabad.

CHAPTER III. MANAGEMENT AND PROCEDURES OF THE COMMITTEE

4. Formation of a Health Board to regulate blood screening process.

- a) The board will be authorized to formulate regulations in order to carry out the functions smoothly.
- b) Undertake and promote research in the field of blood screening and maintain data base on the complaints on violation of law.
- c) Direct investigation and inquiry in respect of any incident of violation of law;
- d) Submit independent reports to the Government on the state of human rights in Pakistan for incorporation in reports to WHO (World Health Organization)
- e) Such other functions as it may consider necessary for the awareness of blood screening's importance.

CHAPTER IV. COMPULSORY BLOOD SCREENING BEFORE NIKKAH

5:- Blood screening shall be mandatory before Nikkah. A couple shall get a “protect blood from Thalassemia” certificate from a registered blood bank or a registered and certified hospital before Nikkah.

- b) The blood screening test shall be of Rs.200/- per person.
- c) The Qazi (Nikkah facilitator) shall not provide his services for Nikkah unless a couple present “protect blood from Thalassemia” certificate.

CHAPTER V. PROCEDURE OF GETTING BLOOD SCREENED

- a) A person shall make a pay order of Rs. 200 in favor of Ministry of Health account
- b) Request for blood screening shall be made in blood bank or a hospital
- c) The blood bank or the hospital shall screen blood of the person who shows the pay order.
- d) The blood bank or the hospital shall provide “protect blood from **Thalassemia**” certificate or vice versa to the person who requested for blood screening.

CHAPTER VI: PROCEDURE OF GETTING NIKKAH NAMA FROM UNION COUNCIL

6:- In order to get Nikkah nama, the joint blood screening certificates or individual certificates “protect blood from **Thalassemia**” shall be presented to the court.

- b) The court or the Union Council shall not provide Nikkah Nama to the person who does not present the certificate.

CHAPTER VII PENALTY IN CASE OF VIOLATION

7:- A penalty of Rs. 2500/- shall be announced if Nikkah offered without the screening test, that shall be authorized by the Health Board. If in case the penalty is not paid, the Ministry of Health can authorize a period of sentence for the violation of the law.

CHAPTER VII ALLOCATION OF FUND FOR HEALTH COMMITTEE

8:- The Ministry of health shall announce a certain amount for the health committee on blood screening in budget that shall be dealt by the Ministry of Finance.

STATEMENT OF OBJECT AND REASON

Realising the fact that 50,000 to 100,000 patients are suffering from Thalassemia in Pakistan and every year 5,000 babies are born with the deadly disease. The numbers of the patients are increasing day by day. According to Patients Welfare Association (PWA) 100,000 children are being born with the disease of Thalassemia due to not getting blood screened before marriage. Furthermore, about 25 per cent children are born with the disease of Thalassemia as a consequence of cousin marriage. Therefore, it is very necessary to promulgate a law to see Pakistan a Thalassemia free country.

The bill seeks above mentioned objective.

MOVERS

Siraj Memon (YP57-Sindh09)

Anum Mohsin (YP22-Punjab 02)

BACKGROUND PAPER

Realising the fact that 50,000 to 100,000 patients are suffering from Thalassemia in Pakistan and every year 5,000 babies are born with the deadly disease, the World Thalassemia Day is

being observed today (Friday) with a solemn pledge to treat every patient.

In Pakistan, 5 out of 100 people are Thalassemia patients and around 8 million population is Thalassemia carrier. Thalassemia is an inherited characteristic of blood. It reduces the amount of haemoglobin in a human body leading to anaemia.

Thalassemia International Federation has designated May 8, as World Thalassemia Day to show solidarity with patients and ever year like other parts of the world, this day is observed in Pakistan, said Dr Tahira, Director PIMS Thalassemia Centre and Associate Professor of Haematology while talking to TheNation.

While defining the term Thalassemia carrier, she said it means a person having the gene that causes this blood order.

However, carriers of this disease can live a healthy life but if they marry another person having the disease gene then they are chances of that they can transmit it to next generation, which may cause the Thalassemia, she added.

She said that around 650 patients were currently register with Thalassemia Centre PIMS and all kind of required medical facilities were being provided to them, including blood transfusion.

About Thalassemia, she said; It is an inherited blood disorder that causes the body to produce less haemoglobin.

Haemoglobin helps red blood cells spread oxygen throughout body. Low levels of haemoglobin may cause anaemia, an illness that makes feel weak and tired. Severe cases of anaemia may damage organs and result in death, she added. (THE NEWS)

BACKGROUND PAPER-II

Prevention of Thalassemia: Law on blood tests before marriage soon

FEDERAL Social Welfare Minister Samina Khalid Ghurki has said the federal government would soon pass legislation for mandatory blood tests of couples before marriage at federal and provincial level to avoid preventable blood complications and other disorders in children.

She was speaking at a public health seminar on "Thalassemia - its prevention, awareness and social responsibilities" organised by the Mir Khalil-ur-Rehman Memorial Society in collaboration with Sundas Foundation in connection with World Thalassemia Day at the auditorium of Lahore Chamber of Commerce and Industry on Friday.

Samina Ghurki said Islamic countries such as Saudi Arab and Iran had already made legislation in this regard. She also stressed to create awareness among masses for prevention of thalassemia by conducting blood screening tests.

The federal minister said that cousin marriages were also a major cause of emergence of a large number of thalassemia patients every year in the country, and this trend should be discouraged to avoid blood diseases and other physical disorders. She said the government would stand by thalassemia patients despite the fact it government was entangled in a host of crises. Like modern facilities in public sector hospitals in the cities, she also stressed the need to provide facilities of blood transfusion in public sector health institutions in smaller districts across the country.

Punjab Law Minister Rana Sanaullah also stressed the need to create awareness among masses to prevent thalassemia among the next generation. He proposed to incorporate an article of mandatory blood test of prospective couple in Nikahnama to avoid the spread of thalassemia.

He said the Punjab government would take every step to provide preventive and curative health facilities to the people in the province, and in this regard, he added the government could stem the spread of thalassemia by providing blood screening facilities in public sector hospitals and BHUs in remote areas of the province.

CM's Task Force for Elementary Education and Punjab Education Foundation Chairman Raja Muhammad Anwar said mankind had never bowed before natural and unnatural calamities and diseases, and added that human beings had discovered cures of deadly diseases such as plague, malaria, chicken pox, TB, etc, which had killed hundreds of thousands of people around the world. Similarly, he said, the Thalassemia disease also required prevention more than treatment and cure.

While working with an NGO for the rehabilitation of deaf and dumb people, he informed that it was observed that parents of over 90 per cent patients were cousins. "Several medical and blood complications can be prevented through blood tests before marriages between cousins," he asserted.

LCCI President Mian Muzaffar Ali said that people could prevent a lot of problems and diseases with a slight improvement in lifestyles, as he believed that most of the problems and diseases were self-created hence preventable.

Renowned columnist and Sundas Foundation Chairman Munnoo Bhai said that Sundas Foundation was working in three cities, where screened blood transfusion was carried out upon over 5,000 thalassemia patients twice a month. He said the organisation was providing blood and safe blood transfusion services to thalassemia patients free of cost after getting donations of safe blood from healthy donors.

According to a safe estimate, he said, the people of Pakistan gave Rs 140 billion in charity every year and half of which had been going to professional mendicants. "If this charity is properly used then most of the problems of people could be resolved and country's progress ensured. The people are very passionate about ameliorating the lot of the needy people in the country," he added.

King Edward Medical University (KEMU) Vice-Chancellor Prof Dr Zafarullah Khan said that developed countries had made legislation to control the spread of thalassemia disease, while it was multiplying in our country in the absence of legislation for prevention of this deadly disease. "It could easily be transmitted from parents to their children," he said.

Qazi Abdul Qadeer Khamosh urged the government to provide diagnostic and treatment facilities to the thalassemia patients in public sector hospitals.

Rakhshanda Naveed suggested that there should a separate channel to create awareness regarding prevention, control and treatment of diseases among the people in the country. She also appealed to philanthropists to adopt a thalassaemic patient for their effective treatment to enable them to lead a normal life.

Besides, Pakistan ENT Association Vice-President Dr Nasrullah Rana, TV artiste Kanwal and others also spoke on the occasion.

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Legislation suggested to contain thalassaemia

PESHAWAR: Speakers at a seminar Friday urged the government to make special legislation to prevent rapidly spreading thalassaemia disease in the country, particularly the Frontier province.

The event was arranged by Hamza Foundation, a non-governmental organisation working for rehabilitation of thalassaemic children. It was attended by a considerable number of children hit by the disease and their parents.

Notable among those who spoke on the occasion were Hamza Foundation Chairman Ijaz Ali Khan, literary figure Abaseen Yousafzai, Project Director of Tanzim Lissail-wal-Mahroom Farrukh Ser and Dr Fakhar Zaman.

The speakers said the main reason for the rapid spread of thalassaemia was cousin marriages. They urged the government to make thalassaemia test compulsory for both men and women before marriage so that two persons having the gene of the disease could not marry.

This method, they said, had been adopted in Saudi Arabia, the United Arab Emirates, the Maldives, Iran and some

Western countries where the spread of the disease was controlled to a great extent after the introduction of the law.

The speakers said some 10 million people across the country were suffering from minor thalassaemia and 88,000 children from acute thalassaemia. They said it was unfortunate that the number of thalassaemic children was much higher in NWFP than other parts of the country. The very reason for that was the lack of awareness among the people, they pointed out.

The speakers said the very purpose of marking the World Thalassaemia Day was to create awareness among the masses to take preventive measures against the fatal disease. They urged the well-off people and philanthropists to extend maximum cooperation to the charity-based organisations working for eradication of thalassaemia.

They suggested that the government should launch special publicity campaigns through print and electronic media to do away with the disease as had been done in case of polio, HIV/AIDS and TB, etc.

The well-to-do people should also extend financial support to the non-profit organisations working for treatment of thalassaemic children so that they could provide better facilities to the infected children, they added.

The speakers were of the opinion that the thalassaemic children could lead a healthy life, if they were provided proper medication and other facilities. This is the practice in many countries across the world, they added.

The permanent treatment of thalassaemic children is bone marrow transplant, which not only cost about Rs20 million but there are only eight per cent chances of their recovery from the disease. As majority of the people of Pakistan, particularly NWFP, hail from poor backgrounds, the infected children should be provided proper medication so that they could be able to lead a normal life, added the speakers.

http://www.thenews.com.pk/daily_detail.asp?id=176545

Clauses :

- 1. Blood screening should be mandatory before Nikkah.*
- 2. Blood Screening shall be done from Government registered blood banks or hospitals.*
- 3. The blood screening test shall be of Rs.200/- per person.*
- 4. Formation of a Health Board to regulate blood screening, consisting of members affiliated with the Union Council.*
- 5. The Union Council should be responsible to provide blood screening slips with a systematic and mechanized process with the Nikah nama.*
- 6. The process shall be in such an order that the pay order should be to the State Bank of Pakistan directed to the Health Board, than the slip shall be given to the blood bank/hospital to attain the certificate that shall be submitted with the Union Council.*
- 7. The Ministry of Health would be authorized to regulate the Health Board for an effective and transparent system.*

8. *The Health Board shall comprise of the members as Head Officer of Union Council, Qazi/Islamic scholar, senior doctor of respective government hospitals.*
9. The Qazi affiliated with the Union council only shall have the authority to certify the Nikkah Nama of the respective areas offered by other Qazi's.
10. *The certificate from the Health Board shall certify as "protected blood from Thalassemia"*
11. A penalty of Rs. 2500/- shall be announced if Nikkah offered without the screening test, that shall be authorized by the Health Board. If in case the penalty is not paid, the Ministry of Health can authorize a period of sentence for the violation of the law.
12. The Ministry of health shall announce a certain amount for the screen tests in budget that shall be dealt by the Ministry of Finance.