

β -THALASSEMIA MAJOR-FREE PAKISTAN

BY 2025

A FIVE POINT PLAN

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1. Know your thalassemia status

- All individuals who are or shall ever be in the reproductive phase (children) should have their thalassemia status checked by a simple blood test called hemoglobin electrophoresis. This is even more important if there is/was a family member with thalassemia minor/major. Since thalassemia status NEVER changes in life, it can be ascertained at capital ONE TIME at convenience, after the first sixth months of life.
- Those who are past the reproductive period need not get this test done
- All clinical laboratories and all thalassemia centers should offer this test at an affordable and subsidized rate as their moral obligation towards the society, the country and the mankind.

2. β -thalassemia minors must not marry each other

Since β -thalassemia major is the product of sexual contact between individuals with β -thalassemia minor, it is an absolute must that carriers of β -thalassemia gene should voluntarily decline marrying each other. Elders in the family should play their role to ensure compliance and enforce implementation.

3. Get antenatal diagnosis done

If marriage between two β -thal. minors is inevitable (for social, financial or other reasons beyond control), the couple should not produce its own children; it should adopt. If this too is unacceptable, the status of the fetus (the unborn child) must be verified between the 10th and the 12th week of pregnancy. This is possible through a technique called antenatal diagnosis which is now available in Pakistan.

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4. Decide on β -thalassemia major pregnancy

Result of antenatal diagnosis for thalassemia status of the unborn in each pregnancy in such marriages shall statistically be as follows:

- 25% chance : normal baby (better than the parents)
- 50% chance : β -thalassemia minor baby (same as the parents)
- 25% chance : β -thalassemia major baby (the dreaded outcome; bad news for the baby, the family, the nation and the mankind)

Pregnancies in the first two situations should be allowed to proceed naturally. The third option shall produce a baby with β -thalassemia major. To decide on the fate of such pregnancies is the prerogative of the parents and the family as a whole. To seek religious guidelines on this issue a copy of a fatwa from Maulana Taqi Usmani is reproduced at the back page. Decision may be made in the light of the contents of this fatwa. For further guidance parents are urged to consult other religious scholars while making a decision on the future of pregnancies which are likely to produce children with β -thalassemia major.

5. Law to prohibit marriages between β -thal.minors

Government should enact a legislation to make it mandatory for each citizen who is or shall ever be in the reproductive phase to have his thalassemia status defined. A certificate to this effect should be made a pre-requisite for admission to teaching institutions, NIC / driving license / passport / private and public employment and at the time of registration for marriage. Non-implementation/non-compliance or false certification should be declared a culpable offense against the society and the nation.

ہوا کے دوش پہ رکھے ہوئے چراغ ہیں ہم
جو بجھ گئے تو ہوا سے شکایتیں کیسی

Appendix-A

Reply from Molana Mohammad Taqi Othmani.

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الجواب

۱- حمل میں جب جان پڑ جائے (یعنی ۱۲ دن بعد) تو اسقاط حمل کی سزا عذاباً بائیں گنجائش نہیں، اگرچہ طبی تحقیق کے ذریعہ حمل میں کسی بیماری کا ظن غالب ہے کیوں نہ ہو عیال، کھوئے ہوئے جان پڑنے کے بعد اسقاط حمل قتل کے مترادف ہے اور زندہ بچہ کو فوہ وہ کتنا ہی شدید بیمار اور معذور کیوں نہ ہو قتل کرنا کسی صورت جائز نہیں ہے۔ اسی طرح حمل میں جان پڑ جانے کے بعد اسقاط کرنا اور کر دانا بھی جائز نہ ہوگا بلکہ ضرور جبکہ اسکان سوچ رہے کہ طبی رپورٹ پوری طرح درست نہ ہو یا رپورٹ درست ہو مگر پیدائش کے بعد اللہ کے حکم سے بچہ تندرست ہو۔

۲- البتہ حمل میں جان پڑنے سے قبل اگر طبی تحقیق سے حمل میں شدید بیماری یا نقص کا علم ہو جائے اور امانتدار طبیب کے اسقاط کا مشورہ رکھ کر والدہ کیلئے سزا عذاباً اسقاط کی گئی نہیں ہے۔

فی اثباتہ قال فی النہر بقی دل یناجی الاستسقاء بعد الحمل نعم یناجی ماہہ یتخلق منہ شیء ولن یکون ذلک الا بعد مائۃ وعشرین یوماً وهذا یقتضی انہم ارادوا بالتخلیق نفخ الروح واولا فہرغلط لأن التخلیق یتحقق بالثبوت ہرۃ قبل ہذہ المدة کما فی الفتح والاطلاق لغیرہ عدم توقف جواز اسقاطہا قبل المدة المذكورۃ علی اذن الزوج۔ وفی کراہیۃ الی نیتہ ولا أقول بالحمل اذا الحزن لو کسر یقین العیدہ فممنہ لأنہ اصل العیدہ فلما کان یؤخذ بالجزاء فلا أقول من أن یلحقہا یا ثم ہذا اذا اسقطت بغیر عذر قال ابن وہبان ومن الأعداء أن ینقطع لبنہا بعد ظهور الحمل ولیس ثوب الصبی ما لیس جربہ الطیر وخاف لہلاکہ۔ سنن ابی یوسف ۱۷۶/۳ ج ۳

شہدہ محمد شرف عفی عنہ

دارالافتاء - جامع دارالسلام کراچی

۱۸/۹/۱۴۱۵ھ



۱۸/۹/۱۴۱۵ھ

الجواب صحیح

احقر محمد تقی عثمانی

۱۹-۹-۲۰۱۵ء



Copy of this Fatwa was kindly provided by Brig. Suhaib Ahmed of the Armed Forces Institute of Pathology, Rawalpindi. His co-operation is greatly appreciated.