

PROGRAM FOR

DETECTION OF THALASSAEMIA MINOR AMONGST COLLEGE STUDENTS

ORGANISED BY



UNDER THE AEGIS OF



IS ABOUT HEALTHY YOUNGSTERS

Thalassaemia may be an alien word for you. But, the fact is that if there is any segment of the population that needs to know about Thalassaemia, it is the student population. Thalassaemia is about healthy youngsters.

For every youngster, doing a Blood Test for Thalassaemia Minor could be as important as getting a Bachelor's Degree. In fact it could be the most important decision of a student's life.

DEAR PRINCIPAL

College prepares a student to face the challenges that lie ahead. The student is carefully moulded into a well-rounded personality. The student is endowed with knowledge in his area of academic interest, which equips him to take up a profession and earn financial stability. The extra-curricular activities help the student in developing skills of interaction with society.

After getting out of college, the student would have reached an age when he/she will have to settle down in life including raising a family. Life should not throw any surprises or shocks at your student.

The birth of a Thalassaemia Major child who will survive only through regular blood transfusions, could be one such shock. This can happen if both partners in a marriage are Thalassaemia Minor. Doing a Blood Test for Thalassaemia Minor is very important for every student.

This test, when done outside, can be very expensive. The money apart, we know that inertia will prevent most of us from going to a laboratory and doing the test. Life has its own way of making us busy enough to forget to do the test.

You could organize a Thalassaemia Minor Detection Camp in your college. We would do the test free of cost for you, thanks to well-intentioned sponsors. We would target the final year student of your college and come to you every year. You could then very proudly say that every student who has passed out from your college has been tested for Thalassaemia Minor. You would be doing a great service to your students, and securing their future.

We would like the NSS unit of your college to undertake the following activities:

Thalassaemia Awareness & Detection Camp in college

Our objective here is to ensure that the students of your college are tested for Thalassaemia Minor. This Camp, which would involve testing of the final year students, would be held every year.

Thalassaemia Awareness Camp in your neighbourhood

The NSS students of your college could choose any residential area, office or railway station near the college. The Awareness Camp would be a one-day activity having the objective of creating awareness about Thalassaemia amongst the general public. Awareness would be created through posters, leaflets and one-to-one interaction. All support will be provided by CITIZEN for this activity.

IS A MISERABLE DISORDER

Thalassaemia Major is a serious genetic blood disorder, which affects more than 1 lakh children in our country. Children suffering from the disorder have it from birth, and are normally detected to be Thalassaemia Major when they are between 3 to 6 months of age. Unless monitored properly these children will not survive for long.

One of the most important components of blood is Red Blood Corpuscles (RBCs). RBCs contain a substance called haemoglobin, which plays the vital role of carrying the oxygen that we breathe in, to the various parts of the body. A Thalassaemia Major child is not able to produce haemoglobin. Therefore life-giving oxygen is not supplied to the various tissues, which will die as a result.

In order to survive one has to ensure that haemoglobin is present in the Thalassaemic child's blood. The child therefore needs blood transfusions, which have to be given throughout life-on an average every 15 days.

Repeated transfusions result in a build-up of iron in the body of the child. This undesirable iron, if allowed to accumulate, will ultimately kill the child. To dispose off this excess iron, the child needs to take an injection of "Desferal" every day. The injection is delivered by an 'infusion' pump over a period of 8 to 10 hours. The child thus is hooked to the needle every day for 8 to 10 hours.

The life of the child is one of great misery.

WHO IS RESPONSIBLE?

A Thalassaemia Major child is born only if both parents are Thalassaemia Minor. The parents do not know that they are Thalassaemia Minor because Thalassaemia Minors are healthy people leading normal lives.

There are more than 40 million Indians who are Thalassaemia Minor. Almost all of them do not know of this. Therefore, there is every chance of two Thalassaemia Minors getting married and not knowing about it. In such an event there is chance that the child born to them will be a Thalassaemia Major.

Most people come to know that they are Thalassaemia Minor only after giving birth to a Thalassaemia Major child. By then, it is too late, and there is nothing they can do about it. If only one of the two partners in a marriage is a Thalassaemia Minor, there is no risk to their future child.

Lack of awareness about Thalassaemia is the cause of the misery and suffering of a Thalassaemia Major child. Had the two partners in a marriage known that they were Thalassaemia Minor, they could have prevented the birth of a Thalassaemia Major child. There is nothing wrong in being a Thalassaemia Minor. There is everything wrong in not knowing that you are one.

Thus, two healthy youngsters, who were not aware that they were Thalassaemia Minor, were responsible for this misery.

ALL YOU NEED TO DO IS...

Knowledge of Thalassaemia is very important for youngsters who are not married. Every youngster must know whether he/she is a Thalassaemia Minor before marriage. And for this every youngster must do a blood test for Thalassaemia Minor.

If the Blood Test indicates that you are not a Thalassaemia Minor, then it does not matter who your spouse is. Even if your spouse is a Thalassaemia Minor, there is no risk to your future child.

However, if the Test indicates that you are a Thalassaemia Minor, it is very necessary for the partner to be tested. If the partner is not a Thalassaemia Minor, there is no risk to your future child.

But if both partners are Thalassaemia Minor, you must realise that the child born to you can be a Thalassaemia Major. There is a 25 % chance of the child being a Thalassaemia Major. It is possible to do a Pre Natal test very early in the pregnancy, and find out if the foetus is Thalassaemia Major or not. You can then decide whether to continue with the pregnancy or not. Ofcourse, you could choose to not have children, but to adopt a child.

Knowing whether one is a Thalassaemia Minor is very important for every student.

IS A BLOOD DISORDER

Thalassaemia Major is a blood disorder. To understand what this means we need to understand Blood.

Blood is life. Blood plays the role of creating, conserving and protecting life. The different components of blood have different roles to play. We therefore need to understand these different components.

Blood is made up of:

Plasma: the fluid part which carries all the nutrients to the tissues of the body and takes away all the waste matter. Plasma is the 'carrier', which enables the blood to flow.

Platelets: ensures that, in the event of bleeding, a clot is formed to prevent further loss of blood.

W.B.Cs: the defence mechanism of the body. They protect the body from external attacks and are also called as the 'soldier' cells.

R.B.Cs: contain haemoglobin, which carries the oxygen that we breathe to the different parts of the body. In fact the red colour of blood is due to RBCs.

Thalassaemia Major is a blood disorder caused due to the inability to produce haemoglobin, leading to premature destruction of RBCs.

IS A GENETIC DISORDER

For each physical characteristic and function of the body there is a pair of genes, one given by the mother and the other given by the father.

One of the genes tends to be dominant and the other recessive. The child takes the characteristic of that parent whose gene is dominant. A child may have the mother's gene being dominant for one characteristic and the father's gene dominant for another characteristic.

There is a pair of genes, which determines how haemoglobin is produced.

If both genes for haemoglobin are normal, the person is normal with respect to Thalassaemia.

If one gene is normal and the other is 'altered', the normal gene dominates. Such a person is called a Thalassaemia Minor. The good gene being dominant, a Thalassaemia Minor is healthy and will remain so.

If both genes are 'altered', the child is a Thalassaemia Major. This can happen only if both parents pass on the defective gene, meaning that both parents are Thalassaemia Minor.

Thalassaemia Major is thus, a disorder, where both genes for haemoglobin are 'altered'. In other words, Thalassaemia Major is a disorder caused due to both parents being Thalassaemia Minor and passing on the 'altered' gene to the child.

AWARENESS & DETECTION CAMP IN YOUR COLLEGE

The 'Awareness & Detection Camp for Thalassaemia Minor' in college will ideally comprise of:

Lecture for NSS & final year students

There could be one or more lectures fixed ideally 4 days before the camp. The lecture (1 hour) would be followed by a "Question & Answer" session.

Poster Exhibition

Poster Exhibition to be displayed in the college from the day of the lecture to the day of the Camp.

Class-to-class announcements

NSS volunteers should go classroom to classroom for all final year students, a day before the camp. Announcement of the Camp and a brief talk on Thalassaemia should be made.

Detection Tests

This is the day of actual activity. A laboratory team will come and carry out the blood tests. One large room, four tables and a few chairs will be required.

Counselling

The results of the test will be available after 10 days. A Counselling session will have to be fixed where all Thalassaemia Minors will be called.

Follow up with family

NSS volunteers to ensure testing of siblings of Thalassaemia Minors.

INTIMATION OF CAMP

Date:

The NSS Programme Coordinator
Mumbai University,
Mumbai

Dear Sir,

We wish to undertake an "Awareness & Detection camp for Thalassaemia Minor in our college.

The schedule is as follows:

a. 1 hour lecture on: _____

b. Detection camp on: _____

Yours sincerely,

Programme Officer

cc: Secretary, CITIZEN - 98201 46448

Contact details:

	NAME	Tel
Prog. Officer		
Student Leader		
College		

REQUIREMENTS OF CAMP

Layout

Requirements:

4 tables

20 chairs

3 Dustbins

Volunteers

2 for explaining filling of forms

1 for registration

1 for handing test bulb

1 for assisting technicians

1 for fixing plaster and handing booklet

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If you are a Sindhi, Punjabi,
Gujarati, Muslim or Bengali-

READ ON!

If you belong to
any other community,

READ ON!

While Thalassaemia is most prevalent among the communities mentioned above, people from ANY community may suffer from it. So get informed, get smart and save yourself from unnecessary suffering...

**Thalassaemia Major
is a serious problem...**

Thalassaemia Major is a genetic, life threatening blood disorder. There are more than 100,000 children in India who suffer from this disorder. This number increases by over 10,000 every year. If these children are not monitored and treated properly, they do not survive.

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Blood, genes and Thalassaemia

To understand more about Thalassaemia you need to know a little about blood and genes.

Blood is made up of red blood cells (RBCs), white blood cells (WBCs), platelets and plasma. The red blood cells contain a substance called haemoglobin. Haemoglobin carries the oxygen that we breathe in to wherever it is needed in the body.

For every characteristic and function of our body there is a pair of genes. One gene is given by each parent. There is a pair of genes that controls how haemoglobin is produced.

- In the case of a **normal** person both genes for haemoglobin are normal.
- In the case of a **Thalassaemia Minor**, one gene for haemoglobin is normal and the other is defective.
- In the case of a **Thalassaemia Major**, both genes for haemoglobin are defective.

This status is inherited and will not change throughout one's lifetime. A Thalassaemia Minor can never become a Thalassaemia Major and vice-versa.

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Major? Minor? Confused?

There are 30 million Thalassaemia Minor people in India. These people, also known as carriers, are completely healthy and normal except for slight anaemia in some cases. Because they are absolutely healthy, most people with Thalassaemia Minor do not even know that they are carriers. Even you could be a Thalassaemia Minor and not know about it!

So if a Thalassaemia Minor is perfectly healthy, why worry?

There is no reason to worry if you are a Thalassaemia Minor, unless your spouse is one too. However, if both parents are Thalassaemia Minor, there is a 25% chance in every pregnancy that the child born to them will be a Thalassaemia Major. **And that** is cause for concern.

What is Thalassaemia Major?

Children with Thalassaemia Major cannot make normal haemoglobin. Therefore the oxygen they breathe in does not reach the various parts of the body. This can be fatal. A Thalassaemia Major child needs to take blood transfusions every 15 days throughout his life in order to survive. These transfusions result in excess iron in the body. This too can be life threatening. To regulate the amount of iron, the child needs to take an injection of Desferal every day of his life.

The constant medication and transfusions cause enormous mental, physical and financial strain on the child and the family.

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Is there a cure for Thalassaemia Major ?

The only permanent cure presently available for Thalassaemia Major is a Bone Marrow Transplant (BMT). This requires an identical donor (which is rare), is prohibitively expensive and carries a high risk. In most cases, BMT is not an option.

How do you prevent Thalassaemia Major ?

Every person should do a Blood Test for Thalassaemia Minor preferably before getting married, but definitely before having a child.

If both partners in a marriage are Thalassaemia Minor, the mother-to-be should do a Pre-Natal test very early in the pregnancy to determine the status of the foetus. If the foetus is Thalassaemia Major it is medically advised to terminate the pregnancy.

Remember

- **Do a test for Thalassaemia Minor even if you are healthy.**
- **If you are Thalassaemia Minor, check if your spouse/spouse-to-be is a Thalassaemia Minor.**
- **If both you and your spouse are Thalassaemia Minor, do a Pre-Natal test very early in the pregnancy.**

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You could be a
Thalassaemia Minor and
not know about it.
Do a blood test and
find out if you are one.

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If you are a
Thalassaemia Minor,
you should find out
if your spouse/spouse-to-be
is also a Thalassaemia Minor.

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If both you and your spouse/spouse-to-be are Thalassaemia Minor your child may be born a Thalassaemia Major.

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If both you and your spouse are Thalassaemia Minor, do a Pre-Natal test very early in the pregnancy.

