THALASSEMIA SOCIETY PUNE CHAPTER

Registration No. 2057/2014

"Life has two rules: #1 Never quits #2 Always remember rule #1"

Newsletter Date-16-Feb-2015 Volume 1, Issue 1

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Mission Statement

The Thalassemia Society Pune Chapter was founded by patients, parents and friends affected by Thalassemia. The foundation provides hope, comfort and encouragement to those battling this disorder. At the heart of the organization is a strong desire to help improve the quality of life for all patients with Thalassemia. We volunteer our time to organize conferences, raise funds to educate the community, ensure patients and parents know the latest in care, and donate to the work of researchers. The foundation maintains a strong relationship with the medical community that provides diagnosis, treatment and care.

"Our aim is Prevention of Thalassemia and the people in society should be educated about it".

Message from Jackie Shroff

Prevention of Thalassemia- A Major task on Hand

Message from Mr. Jackie Shroff – A well-known actor par excellence, a philanthropist, and above all a good soul & an excellent human being!!!

Today we have so many children born with Thalassemia Major in India.

Why is it that we have not been able to reduce the number of births?

Why have we not reduced the burden of families who go through the agony of a child born with Thalassemia Major?

The answer is "US" – We have not taken it upon ourselves to do something for society, to reduce that burden.

The only way we can help these families is by preventing the birth of a Thalassemia Major Child.

If countries Like Cyprus and Iran can do it, I am sure we too can!

Let us all work towards Prevention of Thalassemia by creating awareness amongst our people by screening students, & pregnant women. Let us tell young couples planning to get married to match their Thalassemia status before matching their horoscopes.

I pledge to work for the Prevention of Thalassemia and hope you all will join me in this endeavor.

All good wishes to the Thalassemia Society of Pune Chapter.

Save a life
Give Blood

"Thalassemia doesn't just impact the patient; it impacts everyone that knows them"

President's Message

Hello and welcome to the first issue of the Thalassemia Society Pune Chapter (TSPC) newsletter! Since this is our first issue, I would like to use this space to talk about our organization.

TSPC was founded in 1991 by a group of people (patients, parents, and loved ones) who have over 30 years of non-profit experience in previous organizations. Our organization was founded on the belief that there is more to helping a patient than through research, drugs, and blood tests. We believe that none of this will be helpful if the patient doesn't have hope. Hope that they can live a fun, productive, and happy life. Hope that being normal is not a fantasy but can truly be a reality. Once they have this hope instilled in them, any obstacle can easily be conquered with support and a helping hand along the way.

It is our belief that the support of family, friends, and a committed non-profit organization is vital to the quality of life for all Thalassemia patients. And we are committed to providing this one-on-one, local support for the Thalassemia community in Pune and around. We want to help people in their own backyard and put hope back in their hearts. If you believe what I believe, we need your help! Please go to our website http://www.TSPC.org and join our mailing list, so we can keep you updated on our organization and how you can help. If you would like to be a volunteer, please click 'Yes! I am interested in volunteering' when joining the mailing list, or e-mail me at joinme@tspc.org with your ideas of how you can help.

Thank you for taking the time to learn about our organization. With your help, we can ensure a bright future for Thalassemia patients everywhere.

Patient Message

Yes, I would love to say that living with thalassemia is not easy. I wasn't always a beacon of light for people. I spent most of my life angry, sad, and ashamed of having a blood disorder. Then I realized that I was the one designing my life. I decided early on that I could either choose to live a life of misery or I could choose to live a life of happiness. I took the high road. We all have this choice and sometimes it takes an enormous amount of inner strength to push through our own negative momentum, but I know it's possible. I'm living proof of this fact. I'd love to see you try one small step towards happiness each day. We are so much stronger than we sometimes allow ourselves to be in all areas of life. Let's show the world what we're made of.

The best way to prevent Thalassemia

All it requires is willingness of young couples to voluntarily undergo the blood test to check their carrier status. A small prick for them today can ensure that their child is not subjected to a lifetime of needles and painful transfusions

and they do not have to share the child's pain.

Awareness Drive @RM Dhariwal Foundation Blood

Awareness Drive @ Pune

थॅलेसिमिया म्हणजे काय?

शरीरामध्ये ऑक्सिजनचा पुरवठा होण्यासाठी हिमोग्लोबिन आवश्यक असते. मात्र अनुवंशिकतेमुळे होणाऱ्या थॅलसेमिया या आजारात हिमोग्लोबिनची निमिर्ती होण्याचे प्रमाण कमी होते किंवा काही वेळा अजिबातच निमिर्ती होत नाही. त्यामुळे वेगवेगळ्या प्रकारचा कमी अधिक पातळीवरील ॲनिमिया होतो.

थॅलसेमिया चे दोन प्रकार असतात. –
थॅलसेमिया मेजर,
थॅलसेमिया मायनर

थॅलिसिमिया मायनर हा अनेकदा सौम्य पातळीवर असतो. त्यामुळे लोह कमी असलेल्या ॲनिमियाशी त्याची गफलत घातली जाते. थॅलेसेमिया मायनर असलेल्या मुलांमधील रक्ताचे प्रमाण हे त्याच्या वयाच्या इतर मुलांपेक्षा कमी असते. पण त्याची कोणतीही लक्षणे दिसत नाहीत. या आजारासह जन्माला येणाऱ्या माणसासोबत हा आजार आयुष्यभर राहतो. या व्यक्तीचे लग्न थॅलेसिमिया मायनर नसलेल्या व्यक्तीशी झाले तर त्यांच्या काही मुलांना हा आजार नसण्याची शक्यता असतेे. थॅलेसिमिया मायनरसाठी उपचारांची आवश्यकता नसते आणि अनुवंशिकतेमुळे हा आजार असलेल्या अनेक माणसांचेही आरोग्य चांगले राहते.

दोन्ही पालकांना थॅलेसेमिया मायनर असेल तर मात्र जन्माला आलेल्या मुलाला थॅलेसेमिया मेजर असण्याची शक्यता २५ टक्के असते. म्हणजे चारामधील एकाला थॅलेसिमिया मेजर, दोघांना थॅलेसिमिया मायनर तर एक मूल हे निरोगी जन्माला येऊ शकते. थॅलेसिमिया मेजर झालेल्या मुलाला नियमितपणे रक्त बदलण्याची गरज पडते. सहा ते नऊ महिन्यांपासून संपूर्ण आयुष्यभर ही प्रक्रिया करावी लागते. ही मुले मोठी होत असताना अशक्त होत जातात. पहिल्या-दुसरया वर्षांपासूनच त्यांची वाढ खुंटते. यकृत आणि प्लीहा (स्प्लीन- रक्तातील बाहेरचे घटक काढून ते गाळून घेणारी ग्रंथी, यकृताखाली असते) मोठे होत असल्याने त्यांचे पोट ओघळल्यासारखे वाटते. डोळे खंगतात आणि गालाची हाडे उठून दिसतात.

एचपीएलसी सारख्या साध्या रक्तचाचणीतून या आजाराचे निदान होऊ शकते.

उपचार : चार ते सहा आठवड्यांनी शरीराला नव्याने रक्त देणे गरजेचे ठरते. मात्र बाहेरून रक्तपुरवठा करतानाही समस्या येतात. लोहाचे प्रमाण जास्त झाल्यास मधुमेह, यकृताचे आजार तसेच हृदयविकार होण्याची शक्यता असते. लोहाचे प्रमाण मर्यादेत ठेवण्यासाठी DEFEROXAMINE AND DEFERASIROX औषध नियमित द्यावे लागते. बोन मॅरो ट्रान्सप्लांटचा पर्यायही सध्या थॅलेसिमियासाठी वापरला जातो.

"Obstacles are valuable lessons cleverly disguised…Obstacles will never crush you as long as you have the resolve to overcome them."

The Iron Maiden

"People fear volunteering their time in a government hospital due to the risk of communicable diseases; tuberculosis, for instance. I want to tell them how my lifelong asthma disappeared without any intervention, while working year on year with people at a government hospital, in Mumbai. When you dedicate your life energy to others, obstacles to your work vanish on their own.

So what does a middle class, married at twenty-three, enthusiastic, sensitive, gregarious lady from a conservative family, do with her large network of family friends, when she is told explicitly, that having a career is not an option? Unperturbed by the need for financial compensation or public gratification, one would assume they get on with life, have and raise kids; and look forward to playing with grandchildren in their old age.

Not if they are Jasmineben. This seventy seven year old spunky lady did not challenge her familial boundaries, or seek a career, title, fame or recognition. She simply used the combined skills of her network (she knows the who's who at government bodies, trusts, and also corporate houses such as Novartis, Transasia, Cipla, Voltas) and her characteristic empathy towards changing the circumstances of the poor, unwell, and needy.

Why?

"I was a thalassemia carrier (minor) with 8g haemoglobin at any point of time, shares Jasmineben. "Luckily, I was exposed to good doctors who explained to me that a thalassemia carrier does not, in fact, need iron supplements, since they already have iron in their bodies. They lack enough folic acid, a vitamin that our bodies need to produce new blood cells. "Lay people, or even some inexperienced general practitioners, she adds, "and a lot of quacks believe that thalassemia can be treated by increasing the amount of iron in the body. I have seen cases where unsuspecting patients have followed the advice of quacks, ingested more iron thereby causing internal damage to their bodies." Iron is not at all recommended in the case of moderate thalassemia (Thyrocare, 2014.)

Her visits to Sion hospital inspired her to start a Thalassemia unit in the hospital itself, with Dr Lokeshwar, a paediatric haematologist, whom she knew personally.

"When I was a student, says Jasmineben, I read about Florence Nightingale. I wanted to be like her, but this want had no way of reaching fruition, since I was married as soon as I finished graduation. Also, through childhood, I was told very specifically, that I cannot have a career, hence social work at the grassroots level just wasn't an option."

"Neither was I," she continues, "from a medical background nor did I have access to the kind of fund that could make me a donor. So I just did whatever I could."

Slowly, the dedication and commitment to make things happen for the public good, made Jasmineben a popular name in the healthcare sector.

In the year 1981, her neighbour and friend, Dr Rebello, Assistant Dean of Sion Hospital, asked Jasmineben to officially join the thalassemia unit as Liaison Officer. She accepted the honour and also assisted her in creating a Cancer – Leukemia Children's ward, a Trauma Ward, NIC (Neonatal Intensive care unit), and facilitated the total refurbishment of the Resident medical officer's quarters.

A total of fifty rooms on the fifth floor were refurbished only with Jasmineben's donor friend's funds.

"Till date, I start my day by calling up donors," she continues. "I refuse to accept cheques of amounts lower than a lakh – because that means to get a single job done, I will have to approach anywhere between two to twenty people. "It is just ineffective to work this way," she adds. "Today, a single bone marrow transplant to completely cure a single patient, requires between eight to ten lakhs. I also work at making funds accessible from the Prime Ministers relief fund and Sir Ratan Tata trust to the needy, by helping them with the application process. Thereafter, the patient then only needs to raise about twenty percent, or approximately rupees two lakhs for treatment."

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The Iron Maiden Continue

"A few years ago, to bring about cognisance and awareness of international Thalassemia day, she also tirelessly approached many media houses over years to globally telecast the message, that simple awareness of thalassemia is key to eradicate it. Puneet Goenka of Zee TV, convinced with her cause, telecasted her campaign free, for over a decade, on all his channels and also proactively created specials for this day. "I owe immense gratitude towards people such as Mr Goenka, who support my intention and invest in me," she says with an unarguable tinkle in her eye.

Her advice to social sector professionals?

"I live my life by three P's:

1) Proper Project: Your work should be real and good. Donors are smart, educated and intelligent. You cannot fool them. They will respond only to honest and sincere work.
2) Perseverance: Try and try till you succeed. There is no obstacle, which cannot be surmounted.
3) Passion: Don't give up. Have a goal, pursue it with all you have. My goal is to see the birth rate of thalassemia become zero, by 2020. I may not be around until then, but I will do what I can till I'm around. "

How does she keep motivating herself to do this day after day? Without seeking compensation for her work. Charitable funds aren't easy to come by in today's consumerist world, and philanthropy is really, voluntary.

Finally her advice is at a macro level. Thalassemia is not contagious, and can be eradicated by strong government will. She shares the example of the small Mediterranean nation of Cypress with an extremely high incidence of thalassemia. The Church got involved, and priests refused to conduct a matrimonial service without verifying that the necessary blood tests are done, Jasmineben explains. Hence today, in Cyprus number of children born with thalassemia in Cyprus is virtually zero. "We have to follow the same example, where blood tests become as critical as horoscopes in matchmaking, and no union is permitted, without a blood test."

Did you Know?

Red cells make up about 45% of the total volume of blood. Their main constituent is the protein "haemoglobin". Their main role is to carry oxygen from the lungs to tissues and cells around the body, through the oxygen-carrying "haemoglobin".

Thalassaemia major is a disorder of the blood. More specifically, a disorder of the haemoglobin molecule inside the red blood cells.

Thalassaemia is an inherited genetic disease, passed on from parents to children through the genes. It is not an infectious disease.

Carriers of thalassaemia are perfectly healthy individuals. The risk of giving birth to a child affected with thalassaemia is 25% when both parents are carriers and 0% when only one parent is a carrier.

β-thalassaemia major is today preventable and treatable. It is treated with regular blood transfusions and iron chelation and total cure is on the near horizon.

Today there is ample scientific evidence for appropriate diagnosis, monitoring and treatment of other, previously defined as 'milder' clinical thalassaemia syndromes, collectively given now the name "Non Transfusion-Dependent Thalassaemias". These include β-thalassaemia intermedia, HbE/β-thalassaemia and HbH (α-thalassaemia).

Thalassemia Society Pune Chapter,
Row House No. C-9,
Silver Orchards,
Sr. No. 127/175,
Wakad Road,Pune
MS - 411057

PHONE:
91-976-651-1371

E-MAIL:
contact@tspc.com

Important Contacts

Blood Filters
Mrs. Doshi – 9270049248

Asunra
Siddhi Distributers
020-65208852

We're on the Web!

See us at:

www.tspc.org.in

Our Team

Dr. Nita Munshi - **President**

Mr. Ramesh Arora – **Vice President**

Mr. Surendra Sitani - **Secretary**

Mr. Shrichand Tejwani - **Treasurer**

Mrs. Jasmine Majethia - **Patron Member**

Members
Mrs. Nayana Doshi
Mr. Kailash Tile
Ms. Shilpa Arora
Mr. Ashok Waswani
Mr. Ashutosh Thaokar
Mr. Jatin Sejpal
Mr. Nilesh Shah
Ms. Priya Ashok Waswani
Mrs. Chitra Joshi
Ms. Simaran Tejwani

Association

Thalassemia International Federation (TIF) - http://www.thalassaemia.org.cy/

National Thalassemia Welfare Society - http://www.thalassemiaindia.org/

Achievement

Successfully organized the 25 Blood camps as well as same number of awareness drive across Pune in Year 2014.

Dates to Remember – 2015

Month - ***May***
#International Thalassemia Day

Month - April to August
 # Annual Tests - @ Ruby Hall Clinic
 # Patient – Parent Program

Month - October - November
 # Diwali
 # Children's Day

Month - December
 # Christmas

About Our Organization…

Thalassemia Society Pune Chapter is a purely voluntary, social, welfare organization committed for the cause of Thalassemia. TSPC formed in 1992 is a voluntary, social, welfare organization committed for the cause of Thalassemia.5 crore Indians are carriers of Thalassemia gene and 10,000 Thalassemia Major are born every year. Thalassemia can be prevented by awareness & screening before marriage or before planning for family. Survival depends upon life-long repeated blood transfusions and costly medicines.

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