



THALASSEMIA SOCIETY PUNE CHAPTER

Registration No. 2057/2014

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

Newsletter Date-08-May-2019 Volume 1, Issue 3

Index

- Mission Statement
- President's Message
- Secretary Message
- Message from Jackie
- The Goddess of Humanity!
- Patient Stories
- Awareness Campaign
- Know Thalassemia
- Research & Updates

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. The foundation maintains a strong relationship with the medical community that provides diagnosis, treatment and care.

GOAL: “Our aim is Prevention of Thalassemia and the people in society should be educated about it”.

Hello and welcome to the Thalassemia Society Pune Chapter (TSPC) newsletter!

Prevention-ZERO Thalassemia

My goals that I wanted TSPC to accomplish

- Improved care and better quality of life for our patients.
- Increase volunteerism within the organization.
- Create an even better relationship between TSPC and our patients.



President

Through awareness and education, we strive for longer and healthier lives for all patients with thalassemia until a universal cure is found.



Secretary

ZERO Thalassemia New Patients in Pune by year 2020

As a TSPC team we are committed to achieve ZERO thalassemia new patients in Pune by year 2020 and we are determined to have existing thalassemia mates in Pune with best of treatment and facilities to achieve everything in life.

DID YOU KNOW?

IN INDIA, EVERY Hour
ONE Child is born with

THALASSEMIA

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

Message from Brand Ambassador Jackie Shroff **Prevention of Thalassemia- A Major task on Hand**
Everyone should be a brand ambassador for Thalassemia so that everyone is aware of it.



He said in a statement: "This subject is very close to my heart as my younger daughter Krishna was prevented from being thalassaemic due to awareness and tests. I appeal to the government to reduce the charges of medicines and take active steps towards prevention of this disease as it is a preventable disease. "From my side, I along with Tiger Shroff and Akshay Kumar will do the best to increase awareness. The message has to percolate not only in towns but to the villages also."

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.

मूल तथ्य यह है कि अगर
माता-पिता दोनों को भी कुछ
हद तक थैलेसीमिया है तो
बच्चा इसकी उच्च दर से
प्रभावित हो सकता है।
इसलिए मैं उन सभी नए
युवा जोड़ों से आग्रह करता हूँ
जो बच्चे की योजना बना रहे
हैं, वे पहले अपने खून की
जांच कराएं। - जैकी श्रॉफ

Thalassemia Patient- What they go through for the rest of their lives?

- Thalassemia patient, most of the time, shows the disease manifestation few months after birth. The child is typically pale (anaemic) and have failure to thrive.
- They are blood transfusion dependent for survival-**MONTHLY** basis and at times it maybe on weekly basis, depending on the individual.
- Due to the frequent blood transfusions, they are at risk of iron overload that leads to vital organs damage such heart and liver failure.
- Bone marrow transplantation is the only cure, but finding a suitable donor is challenging and very much depending on the medical expertise available.

Big Movement - TSPC Association - 7th Thalassemia Lunch-On Symposium on Saturday, 27th April 2019 in Bombay Hospital, Mumbai

In association with



Youth Thalassemia Alliance
Mumbai



Thalassaemic Gujarat
Ahmedabad



Thalassemia Society Pune Chapter
Pune



7TH

THALASSEMIA
LUNCH-ON
SYMPOSIUM

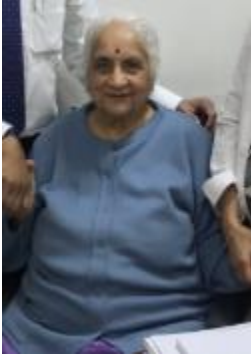
Saturday, 27th April 2019
from 08.30 am onwards

Venue:
S P Jain Auditorium
4th Floor, New wing,
Bombay Hospital,
Marine Lines, Mumbai

Agenda:

1. Lecture - Curative options in thalassemia : BMT & Gene therapy
2. Challenges & New horizons
3. Lecture: Iron chelation
4. Lecture: Fertility & Pregnancy in thalassemia
5. Lecture: Endocrinology of thalassemia
6. Lecture: Emerging therapies in thalassemia

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



The Goddess Of Humanity!

Mrs. Jasmine Majethia

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.

This 80 year old lady works 24/7 to raise financial aid for Thalassaemic patients and create awareness about prevention of this disease.

AT THE age of 80, Jasmine Majethia doesn't use a smartphone and relies on her grandchildren to book a cab for her when she steps out of her home in the Pune suburb of Bavdhan. But when it comes to helping children affected with thalassaemia – a genetic blood disorder – Majethia is a wall of support for hospitals and charitable trusts across Maharashtra over the last 40 years.

“There are so many shocking stories. Once, I came across a family from Rajkot where the woman committed suicide as all her three children were detected with thalassaemia and required blood transfusions every month,” says Majethia. “These stories trouble me a lot.”

Majethia started as a liaison officer at the LTM Medical College and Hospital in Mumbai's Sion before becoming the chairperson of Mumbai Thalassaemic Society while helping to set up blood-cell counter machines at civic-run hospitals in the city.

She is now an advisor with the Pune chapter of the Thalassaemic society. And on the way, she has played a key role in pushing the cause of thalassaemia for organisations, such as the Parent's Association Thalassaemic Unit Trust (PATUT).

Thalassaemia affects more than 1 lakh children in the country, according to a paper published in the Paediatric Hematology Oncology journal.

The disorder appears in two types, according to Dr Nita Munshi, Thalassaemia Society, Pune chapter. “Thalassaemia major patients suffer excessive destruction of red blood cells (RBCs) leading to severe anaemia. The disease is life-threatening, if untreated. Thalassaemia minor is a less serious form, and normal people would not know unless they undergo special tests,” says Munshi.

Huge wave in favour of BJP, claims PM; Sonia says don't forget 2004 results

“Bone marrow transplant (BMT) is a permanent cure for thalassaemics, but that comes at a cost. Typically, the cost of treating one patient could reach nothing less than an approximate Rs 15-20 lakh. Apart from raising awareness, here is where Jasmine has played a vital role,” says Rashmikant Shah, a trustee at PATUT, which is run by ghazal legend Pankaj Udhas.

A recent success story scripted by Majethia is that of six-year-old Chetasree Mukane, the daughter of Avinash, a house painter from Palghar district. “My daughter underwent repeated blood transfusions and doctors advised us about BMT. We fell short of the cost by a couple of lakhs. But PATUT managed the funds,” says the father.

Living with Thalassemia: Patient Stories



Jyoti Arora

Hope is hardest to keep when it is most needed. For people suffering with serious ailments like Thalassemia, it is very hard to keep hopes alive. But we must never let out troubles blight away the light of hope. Because no matter how hard things get, tomorrow might still be a better day.

That is what I believe in. That is what I hold on to. Hope! It's not just a four letter word. It is the power that can light your way through the darkest times. Some may say that Hope gives false promises that may never come true. But they forget that even then, Hope can be the life spring of strength, courage, and the determination to go on. And together, these can achieve a lot, even if not all.

Note about Thalassemia:

Thalassemia is a very serious and debilitating disorder. So far, the only cure available is Bone Marrow Transplant, and that is out of reach of most patients. However, Thalassemia can be prevented. If all people get their Thalassemia status checked (it only takes a blood test), then they can prevent their children from acquiring Thalassemia.



Priya - My journey!

Born in Kanpur, U.P – Diagnosed as a thalassemic major at the age of 3 months.

It was like a shock for parents to accept it, as they had never heard of this before.

Shifted from U.P to Pune.

Since then till today I am taking blood transfusion, the transfusion frequency increased as I started growing up.

My age now is 22.
This 22 year time period had its own set of ups and downs in my life.

As my bones were weak I got a couple of fractures, got admitted in hospital due to severe pneumonia and other infections.

So it became like a challenge for my parents to keep me fit – physically and emotionally

Despite of all this I properly coped up with my secondary and higher secondary education.

Wanted to be a doctor so that I could have found a boon medicine for Thalassemia – A dream

But failed! – another turning point- decided to study pure sciences then and currently pursuing my master's degree in microbiology.

Also trying on my part to help and spread awareness for the cause of Thalassemia.



Challenges of a Thalassemic

Emotional and mental difficulties are the consequences of physical unfitness in the life of a thalassemic kid.

1st- childhood – he/ she is restricted to play around like other kids do, because Hb maintenance is the parents concern; taking medical leaves from school due to illness or blood transfusion.

2nd – Society being biased with such kids because they don't have proper information about Thalassemia or they have misconceptions.

3rd – As the kid grows its difficult for him to accept his medical condition.

4th – Deal with iron accumulation and iron chelation problems.

5th – Delayed puberty

6th – Uncertain to get good jobs or develop a good career.

Other challenges- financial burden on parents, lack of support from society.

"The good physician treats the disease; the great physician treats the patient who has the disease. - William Osler"



On 26 Dec' 2018

SRPF officers invited Dr Munshi (President of TSPC) to give an awareness talk to all the police staff of Pune. There were around 400 people of police department sitting in the audience, Dr explained them about Thalassemia, it's transmission, treatment, about life of thalassemic kid and why is prevention and awareness important. After the presentation and Dr's talk, we answered the questions of officers followed by Priya Vaswani's motivational talk as in her talk she made an appeal to all the police people to get tested. Asha Borker another volunteer of TSPC talked her heart out and said awareness is very important. After the awareness talk program, on the spot we began with screening program for testing their thalassemia trait. No doubt this Awareness program was a big success in itself as the audience on their own came forward for getting their selves tested and we could do the test.

Looking forward to screen many more people in 2019 and achieve the goal of thalassemia free India.

#TSPC #Thalassemia_Not_A_Taboo #Awareness #Prevention #To_get_screened_contact_us

On 10 Dec' 2018

Symbiosis institute of information technology had organise for a Thalassemia Awareness talk on Monday and invited Thalassemia Society Pune Chapter team for the same.

Dr Nita Munshi being a speaker spoke about Thalassemia, it's types, how is it transmitted, how is it managed and lastly Why it's awareness and prevention is so so important. Ms. Priya Vaswani our volunteer appealed all the students by her talk to get tested for Thalassemia. It was a great session and interaction with students there.

We thank symbiosis for helping us in our Motto!

Looking forward to aware more and more people about Thalassemia!

#Thalassemia #Its_Not_A_taboo #Talk_About_it #Get_Yourself_Tested_before_Marriage #Spread_the_word #Looking_Forward_for_Thalassemia_Free_India..



On 17 Nov, 2018.

Thalassemia Society Pune Chapter (TSPC) did Awareness Drive at Pune University Signal.

Our team stood at various points with placards saying "#Prevent_Thalassemia" at the signal and approached people to our best to let them know about Thalassemia by giving pamphlets. We came across a young guy who had no clue about Thalassemia, he saw the word and asked what is it exactly, Priya Vaswani - volunteer explained him about the disorder and solved his doubts of what? How? When? The other person we met is a CBSE tutor, being a teacher he knew about disorder but he got more clarity when he came to know about symptoms and treatment. These people we met supported the cause and appreciated us by words of "Good Work, Good Job and smiles".

Many more drives to do, many more people to be made aware about Thalassemia

#TSPC #Signal_Awareness_Drive

#Looking_Forward_Towards_Thal_Free_India..!



"LET YOUR SMILE CHANGE THE WORLD BUT DON'T LET THE WORLD CHANGE YOUR SMILE"



On 14 Oct 2018- Sunday!

Sunday morning spent well 😊

We did Thalassaemia Awareness drive at Wadia College signal, Pune.

The drive started at 9am, we distributed in a team of 2 and stood on different signal around that road. Everytime there was a red light, I went and stood in front of the vehicles and spoke shortly about Thalassaemia and it's prevention! In between we got motivation by hearing to encouraging words from the passerby's saying "Wonderful work" "Good job" "Thumbs ups 👍".

And we ended our drive at 11am.

Indeed it was a Happy Sunday and a Happy Start to such Awareness Drive! With the same spirit and determination we'll be doing many more awareness campaign in upcoming months 😊!

#Thalassaemia_Awareness #Talk_About_It #It_is_not_A_Taboo #Team #TSPC #Motto
#Thal_Free_Pune_by_2020 🙌 😊

Drive Program to help Thalassaemia Patients to give the information about Disability Certificate



On Sunday, 27th January

Thalassaemia Society Pune Chapter organized program to help **Thalassaemia** patients to give the information about disability certificate for thalassaemia patients and to help them file online application.

Mrs. Jasmine Majethia and Society President – Dr. Nita Munshi started the program by lightening the lamp. Dr. Munshi welcomed the patients and explained the purpose of the program.

Ms. Priya Vaswani conducted the session about filing the online application and explained the overall process. The program was attended by approx. 200 patients and parents. Online applications for more than 50 patients were filled up and upload to government site; rest of the application filing process is going on for remaining patients.

Purpose of this program was to help patients fill and send the form as most patients don't have the knowledge and/or access to that.

The program was held at cancer building auditorium at Ruby Hall Clinic and volunteers from various organizations participated in the program to help patients.

The society secretary, Surendra Sitani presented votes of thanks to all volunteers and attendees.



“Challenges are what make life interesting and overcoming them is what makes life meaningful.”

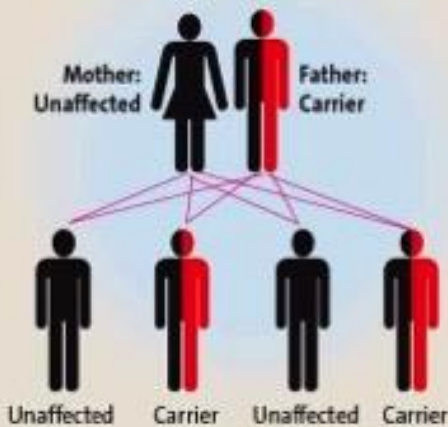
Interesting Facts about Thalassemia Carriers

How the thalassaemia trait is inherited

This diagram shows the inheritance patterns of beta thalassaemia, where you will need two altered genes to get beta-thalassaemia major or intermedia. Other thalassaemias have similar inheritance patterns.

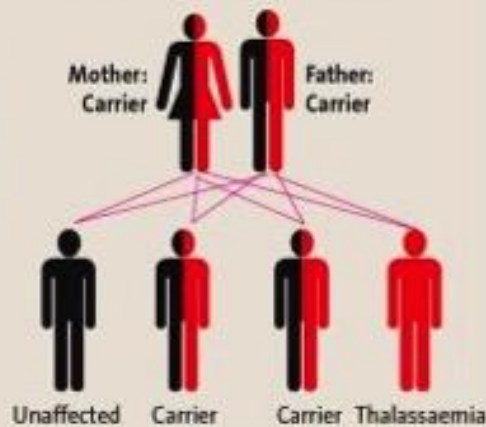
When one parent is a carrier

Risk for child to:
> Have thalassaemia: 0%
> Become a carrier: 50%



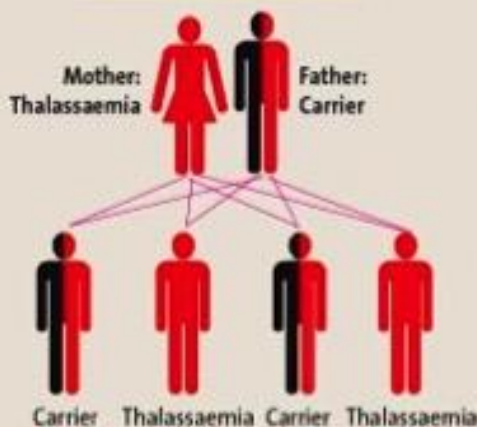
When both parents are a carrier

Risk for child to:
> Have thalassaemia: 25%
> Become a carrier: 50%



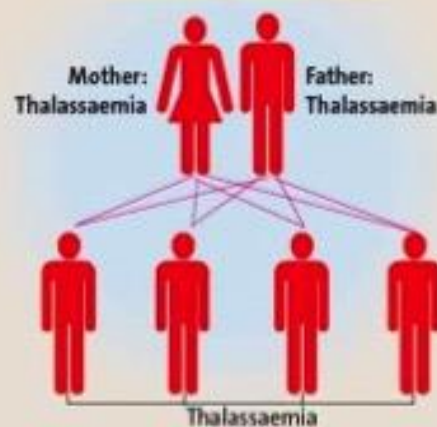
When one parent is a patient and another a carrier

Risk for child to:
> Have thalassaemia: 50%
> Become a carrier: 50%



When both parents are patients

Risk for child to:
> Have thalassaemia: 100%
> Become a carrier: 0%



■ Without thalassaemia trait ■ With thalassaemia trait

What you need to know about thalassaemia?

Thalassaemia is preventable. Screening is easily and widely available.

Thalassaemia carriers are most of the time perfectly healthy individuals, **BUT** are capable of transferring the genes to their offspring.

Thalassaemia **CAN ONLY** be detected and confirmed by **blood test**.

Regular blood transfusions with other treatment (iron-chelation) ensure the survival of thalassaemia patient. The only cure for thalassaemia patient is bone marrow transplant.

Even though treatment is available, we believe that **“Prevention Is Always Better Than Cure”** and thalassaemia is definitely a highly preventable condition.



“Once you replace negative thoughts with positive ones, you'll start having positive results.”

President

Dr. Nita Munshi

Vice President

Mr. Ramesh Arora

Secretary

Mr. Surendra Sitani

Treasurer

Mr. Shrichand Tejwani

Patron

Mrs. Jasmine Majethia

Members

Mrs. Nayana Doshi

Mr. Kailash Tile

Ms. Shilpa Arora

Mr. Ashok Waswani

Mr. Ashutosh Thaokar

Mr. Jatin Sejjal

Mr. Nilesh Shah

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We're on the Web!

See us at :
<http://thalassemiapune.co.in>

Research & Updates

Gene Therapy:

bluebird bio Receives Positive Opinion from CHMP for ZYNTEGLO™ (autologous CD34+ cells encoding β A-T87Q-globin gene) Gene Therapy for Patients 12 Years and Older with Transfusion-Dependent β -Thalassemia (TDT) Who Do Not Have β 0/ β 0 Genotype

First gene therapy recommended for approval in the EU for TDT

Treatment with ZYNTEGLO has been shown to help eliminate the need for chronic blood transfusions in patients with TDT

ZYNTEGLO is bluebird bio's first gene therapy submitted for regulatory approval

<http://investor.bluebirdbio.com/news-releases/news-release-details/bluebird-bio-receives-positive-opinion-chmp-zynteglotm>

For Other Trial Updates

Visit - <https://www.thalassemia.org/learn-about-thalassemia/clinical-trials/> for all the clinical trial updates related to Thalassemia

Association

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

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

Thalasseemics India - <http://www.thalasseemicsindia.org/>

Maharashtra Blood Transfusion Council - <http://mahasbtc.org/sbtc/>

Patients/Parents/Associations/Doctors/Caregivers

Please share your valuable thoughts, suggestions, feedback, and comments if any on our official address or email.

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.



For Private Circulation Only