THALASSEMIA SOCIETY PUNE CHAPTER

Registration No. 2057/2014

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

Newsletter Date-01-Dec-2020 Volume 1, Issue 4

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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. 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".

Dr. Nita Munshi - President TSPC & Director Laboratory, Ruby Hall Group of Hospitals

President
Dr. Nita Munshi

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

Pune - being one of the fastest growing cities in India, has a significant burden of Thalassemia. A local, purely voluntary social, welfare organization that has been at the forefront of efforts to help cater to unmet needs of affected families in and around Pune, is what the Thalassemia Society Pune Chapter (TSPC) represents.

It is led by a group of individuals from diverse professional backgrounds.

Our goal is simple: every patient, anywhere, deserves the opportunity to live their fullest life possible with a good quality of life.

I thank you deeply for the support you have given us over the years, and hope we together can find ways to continue this task of fulfilling our dreams which TSPC has brought to the Thalassemia community.

Secretary
Surendra Sitani

Thalassemia is a treatable disorder that can be well-managed with blood transfusions and chelation therapy. A person with thalassemia will need to receive medical care on a regular basis from a hematologist or a doctor who specializes in treating patients with thalassemia.

These patients need you more than ever before. The economic conditions caused by the global pandemic have adversely affected the funds being collected to provide *quality care* to our patients.

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

The COVID-19 Pandemic and TSPC

Living through the COVID-19 pandemic has been an added stress for the general population, but particularly those who live with a chronic health condition

TSPC has been very active to assist our needy patients during such tough pandemic times. We have provided financial help to patients. We also helped to arrange blood donors for our patients.

Due to lock down, some of our patients were unable to commute for blood transfusions and TSPC arranged transportation. We also helped patients by delivering Leukocyte reduction Filters (Blood Filters).to them during their transfusions.

Our office staff, Mrs. Reshma continues to be available in office to ensure that patients' needs are met.
Our TSPC committee members are also available on WhatsApp/ Phone to guide our patients.

Having thalassemia makes some things harder, but it isn't something that has to limit you in life.

The most important thing a person with thalassemia can do is stick to their transfusion and chelation schedules to prevent severe anemia and possible organ damage from iron overload, respectively.

Hiral's Quarantine &Me

"Life is not easy for any of us. But what of that? We must have perseverance and, above all, confidence in ourselves. We must believe that we are gifted for something, and that this thing, at whatever cost, must be attained."

This year we all heard of the corona, pandemic, covid-19, quarantine everywhere. Where many people take this negatively, I took the lockdown positively & did the things, that I really wanted to do, but couldn't do earlier , because of my busy schedule of German classes. This lockdown I have started to take my classes online. Just after 3rd day of lockdown there was requirement of Blood & I told 3 friends to donate Blood on 26th March in Inlaks Budhrani hospital for Thalassemia warrior. My friend Priya Vaswani and I went live on International Blood Donors Day on Instagram to create awareness about Thalassemia and Blood donation. I have also talked about Thalassemia & briefed people what it is on International Thalassemia Day - 8th May on Facebook by going live. I have encouraged 3 donors to donate blood in July.

I got a chance to give my Interview on legendary Podcast show of Abby Yoong Fast Forward your Entrepreneur Journey from Singapore to share my story.

I also got chance to give talk to Yuva Asmita Social Work group where I created awareness about Thalassemia. I feel honored to get featured for their Interview taken on Instagram where I have shared many important topics related to Thalassemia & how we can stay Positive. I have shared what is Thalassemia? What difficulties Thalassemia warriors face in their lives? What Thalassemia warriors need to do regularly? I have also talked how we can prevent Thalassemia by just doing one simple Test -HbA2 . Why people need to donate Blood? How frequently they can donate? I have also shared that I started working with Team Funwithredbloodcells Team on Instagram who create awareness about Thalassemia and Blood Donation through memes & jokes. Where our Myth Busters help people to forget old myths & believes about Blood donation & motivate people to donate. I have also talked about TSPC & how they help Thalassemia warriors by providing Filters, Annual Blood Tests, medicines, etc.

I just want to tell all of you, that never underestimate youself. Always have faith & believe in yourself and God. Whenever you think Positive, you will always get Positive results in whatever you do. Keep in mind. All is well. God is always there & we can achieve anything in our life, once we decide to do so.

Sighgad College Pune Visit

TSPC ZERO 2022 Thal Awareness

Our committee member Mr Kailash and Secretary Mr Surendra visited the Sighgad College on Feb 10th 2020, to create awareness in society and young college students. That is a sure way and the first step of preventing Thalassemia.

Gynecologists can be very useful and effective in creating awareness in people and prevent thalassemia. They can include the test for thalassemia trait in routine check-up of pregnant women. Gynecologists Dr.Amit Patankar and Dr.Leena Patankar are willing to help us prevent and eradicate Thalassemia.

Meeting with Dr.Amit Patankar

"Maintaining thalassemia treatment routine is top priority. It can be challenging at times, but it's worth it."

मेरा नाम हर्षला प्रविण खरात है। मैं महाराष्ट्र के पुणे जिल्हे मे रेहती हू। थॅलेसिमीया के साथ मेरा संघर्ष बच्चपन सेही चल रहा है। जब मैं छोटी थी तब मेरी रोग प्रतिकारक शक्ती कम थी। इसलीये छोटेसे छोटा इन्फेक्शन भी मुझे जलदी हो जाता था। इसलीये बहोत बार हॉस्पिटल मे ऍडमिट हो जाती थी। घरवाले बहोत ध्यान रखते थे। पर स्कुल मे, दोस्तों के साथ खेलते समय कोई ना कोई इन्फेक्शन होई जाता। इस वजहसे मेरी स्कुल मे कई बार पढाई छूट जाती थी। उस टाइम ब्लड ट्रांस्फुशन के लिये 3 से 4 दिन लगते थे। मतलब महिने के 7/8 दिन तो मेरी स्कुल की छुटी निश्चित होती थी। छुटी मतलब पढाई का नुकसान होता था। जब मैं 6 कक्ष मे थी तब मैं मम्मी - पापा से जिद्द कर के स्कुल पिकनिक पर गई और उस पिकनिक पर मेरा accident हो गया। उस accident मे मेरे spin मे gap हो गई। और मेरी चलती - फिरती, हसती - खेलती जिंदगी बेड रेस्ट पर चली गई। पुरे एक साल मेरे उपर ट्रीटमेंट चलता रहा। ब्लड ट्रांस्फुशन और स्पाईन मे हुई गॅप का इलाज दोनो साथ साथ चल रहा था। ये दोनो इलाज करणे में मम्मी पप्पा को बहोत तकलीफ हूइ। मेरे स्कुल का भी एक साल निकल गया । पर मैने हार ना मानी, मैं ने एक साल स्कुल मे गॅप ली अपनी ट्रीटमेंट पुरी की, आईस्था आईस्था अपने पैरों पर फिर से चलना सिखा और अगले साल मैने फिर से 6 कक्ष मे ऍडमिशन लिया। मुझे स्कुल मे फिरसे जाने के लिये मेरे डॉक्टर, मेरे स्कुल के शिक्षक और मेरे फॅमिलीने मुझे बहोत प्रोत्साहन दिया। और मैने मेरी पढाई जारी रखी। प्रॉपर ट्रीटमेंट, सेहत का ध्यान रखते हूए मैने अपनी आगे की पढाई जारी रखी और मैने अपना post graduation तक की पढाई पुरी की। 2012 मे मैने भारत के महाराष्ट्र, मुंबई मे "महाराष्ट्र स्टेट इलेक्ट्रिसिटी डिस्ट्रीबुशन"MSED.CO.LTD सरकारी कम्पनी मे आऊट सोर्सिंग के तौर पर जॉब करना शूरु किया। वहा पुरे 5 साल मैने सर्व्हिस की। उस के बाद हम सब पुणे शिफ्ट हो गये। और अब मैं यह एक ऑफिस मे काम कर रही हू।

Osteoporosis के वजहसे मेरे bone weak होगये है। और बच्चपन में हुए accident के वजहसे spin हुई gap से मुझे travling के time support belt use करना पड़ता है। 2016 मे heart में iron deposit होने से में hospitalized होगई और उसकी ट्रीटमेंट आगे 6/7 months चली उसके चलते मुझे अपना जॉब छोड़ना पड़ा।

जैसे जैसे मेरी आयु बढ रही है। वैसे वैसे थॅलेसिमीया के साथ नऐ नऐ बिमारियां, परेशनिया बढ रही है।

थॅलेसिमीया के वजह से बहोत कुछ सीखना मिल रहा है। दुनिया के हर कोनेसे थॅलेसिमीयाग्रस्त लोगो से मिलने का मोक मिल गया है। बहोत सारे दोस्त बन गये है। इस थॅलेसिमीया के वजह से।

अब मै अपने दोस्तांनो के साथ "द विशिंग फॅक्टरी" नामक NGO मे काम कर के दुसरे थॅलेसिमीयाग्रस्त लोगो की मदत कर रही हू।

मे एक थॅलेसिमीयाग्रस्त हो के भी मैने अपनी शिक्षा पूर्ण की, एक अच्छि ऑफिस में काम कर रही हू। साथी मे अपने जैसे थॅलेसिमीयाग्रस्त लोगो की मदत कर रही हू।

मैं एक थॅलेसिमीयाग्रस्त हो के भी एक नॉर्मल जिंदगी जी रही हू वो भी खुशी से।


Living with Thalassemia: Harshala

Our Patrons

The Goddess Of Humanity!
Mrs. Jasmine Majethia

A Special Salute to80 year old lady works 24/7 to raise financial aid for Thalassemic patients and create awareness about prevention of this disease.

Save your CHILD from Life Long Blood Transfusion - "Get Tested for Thalassemia"

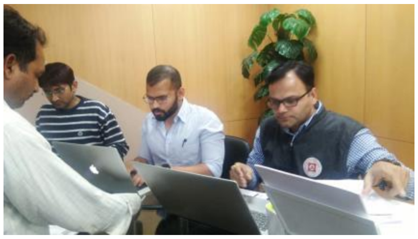
Annual Health Testing

TSPC is committed to the wellbeing of Thalassemia Patients. We conducted annual health check of at Ruby Hall in December 2019. Based on patient's age group and gender, various tests were prescribed to patients. In collaborations with Ruby Hall, Pune, TSPC offered very subsidized rates, upto 75% discounts on blood tests, Dexa Scan, 2D Echo, T2 MRI. Patients paid 25% and TSPC paid 25% for blood tests. We had hassle free process in Ruby Hall.. Post report collections, patients were referred to various doctors to do free consultations. We had approximately 100+ patients who benefited from this initiative.

Diwali Mela

TSPC continues to celebrate various festivals to get together our patients/parents like Diwali, Christmas including 8th May International Thalassemia day. Last Diwali – Oct 2019, we had a wonderful entertainment program at Boat Club, Pune. We had approximately 300 member's attendance and it was a superb event. It was a unique event as we had our own Thalassemia family members doing stage performances like singing, dancing, flute etc. Program anchoring was done by Mrs. Doshi and her relatives. We had a forum for the Thalassemia children to talk about their career aspirations and are happy to inform that many of them are dreaming to become Engineers, Doctors, and do Social Service. Very promising future indeed!. We had dinner for everyone. And Diwali gifts were distributed to all. TSPC also issued newly designed TSPC identity cards to all the members. Overall it was a very gratifying event.

"Thousands of candles can be lighted from a single candle, and the life of the candle will not be shortened. Happiness never decreases by being shared."



Thalassemia Disability Certification Registration

TSPC organized help desks to enable our society patients to fill the Maharashtra govt. disability certification forms, and guide them to get it registered. Help Desks were organized at Ruby Hall in January 2019. We had more than 100 patients registered on that given day and later on TSPC did follow up to ensure all of them got their disability certification from Sassoon Hospital, Pune. We are also helping on an ongoing basis with the registration from our TSPC office. All patients are educated on benefits of having disability certificate like education assistance, jobs and travel assistance, etc

Testing For Thalassemia
A SIMPLE Blood Test called Hb ELECTOPHORESIS / Hb A2 will tell you whether you are a carrier or have a trait of thalassemia minor.


It's almost time that I
Can test my thalassemia status before marriage .
#International thalassemia Day

Medical Guidance from Doctors

TSPC is fully aware of importance of communicating latest trends in medical world for Thalassemia patients. We had organized sessions from prestigious doctors from Pune to have interactions with our patients, to educate them as well as an opportunity to have open dialogues. We had a great program at Ruby Hall in August 2019. We had informative sessions from Dr. Vibha Bafna, Dr. Meghana Chawala, Dr. Vijay Ramanan, Dr Mujumdar, Mrs Sumedha and Dr. Nita Munshi. Patients were guided about Iron Chelation, Diet, and importance of regular tests along with challenges of patients in growing phase.

Thalassemia Awareness Program
In INDIA, each year,7000-10000 children are born with Thalassemia Major

In Oct 2019, TSPC along with a Bengali social community in Kharadi, Pune organized an awareness program for Thalassemia on the occasion of Durga Puja. It was a blood donation camp and TSPC, President Dr. Nita Munshi addressed an audience of over 75 members. She helped them understand what Thalassemia is, how to prevent it, and how as a society they can help Thalassemics by regular blood donations, spreading awareness, providing financial help, and much more.

A RECENT SUCCESS ….by Kailas Tile

We had a very successful awareness drive for SRPF personnel stationed in Pune. Our Ambassador Mr. Jackie Shroff graced the occasion and made it a big & successful event where more than 1000 people benefited from the informative session. Earlier, a drive at IT giant Infosys Limited was also very successful. Hundreds of employees participated in the session and more than 500 employees actually got tested for Thalassemia Trait (carrier status).
TSPC organized Traffic Signal Shows, Corporate/ College Drives for awareness.

Always a warrior, and never a victim to this disorder (Thalassemia)

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

Common terminology that you may find in textbooks which describe beta thalassemia.

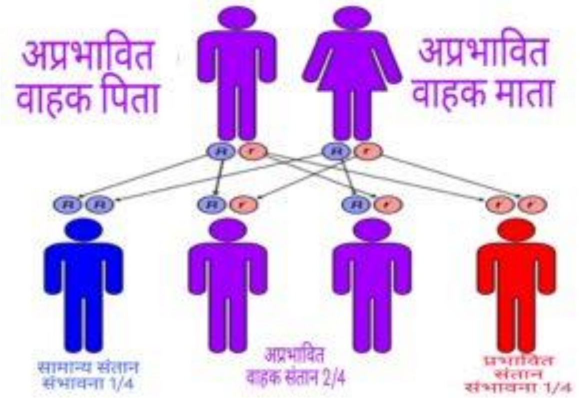
Beta-0 thalassemiarefers to the absence of production of beta globin. When patients are homozygous for beta Thalassemia gene, they cannot make any normal beta chains (hemoglobin A).

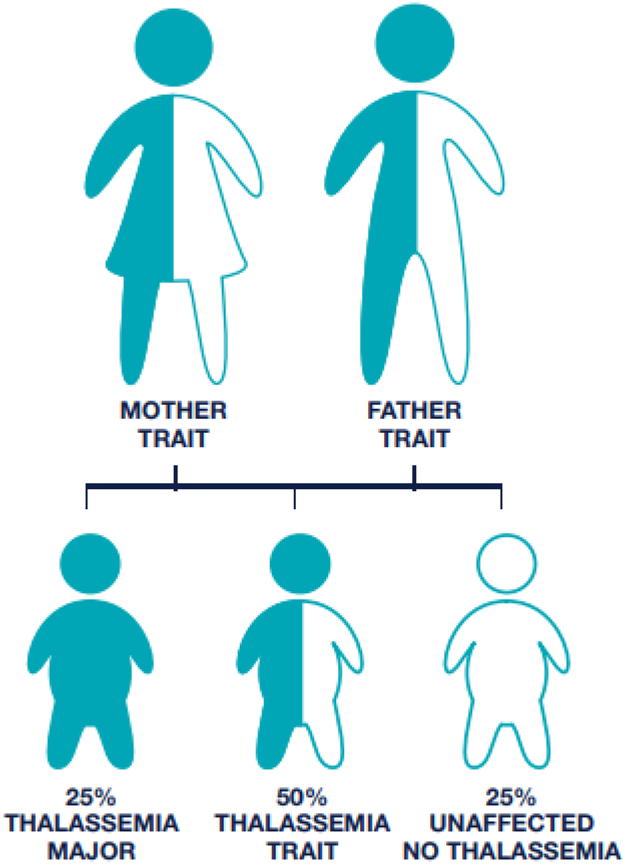
Beta + thalassemia indicate a mutation that presents decreased but not absent production of beta globin. Thalassemia patients in which one or both of their beta thalassemia mutations are beta+ mutations make some hemoglobin A, and the disorder may be less severe.

Thalassemia trait, also called **thalassemia minor**, is when a person carries the trait for thalassemia major – there is no clinical significance when a person carries the trait and likely to be normal.

Beta thalassemia major is a clinical diagnosis referring to a patient who has a severe form of the disease and requires chronic transfusions early in life.

Beta thalassemia intermedia is a clinical diagnosis of a patient characterized by a less severe chronic anemia and a more variable clinical phenotype.





थैलेसीमिया तब होता है जब हीमोग्लोबिन के उत्पादन में शामिल किसी एक जीन में असामान्यता या उत्परिवर्तन होता है। आपको यह आनुवांशिक असामान्यता अपने माता-पिता से विरासत में मिलती है।

यदि आपके माता-पिता में से केवल एक थैलेसीमिया का वाहक है, तो आप थैलेसीमिया माइनर नामक बीमारी का एक रूप विकसित कर सकते हैं। यदि ऐसा होता है, तो संभवतः आपको लक्षण नहीं होंगे, लेकिन आप एक वाहक होंगे। थैलेसीमिया माइनर वाले कुछ लोग बहुत मामूली लक्षण विकसित करते हैं।

यदि आपके माता-पिता दोनों थैलेसीमिया के वाहक हैं, तो आपके पास बीमारी के अधिक गंभीर रूप को विरासत में प्राप्त करने की अधिक संभावना है।

"Get Tested, before it Tests You"
Timely diagnosis of Thalassemia can save us from enormous problems and challenges.

“When faith replaces doubt, when selfless service eliminates selfish striving, the power of God brings to pass His purposes.”

Being a Thalassemic, JatinSejpal help the Thalassemia Patients……..

I am regularly working for Thalassemia patients in and around Pune; but I had a different experience during Covid pandemic for the past several months.
Availability of blood was a difficult task for our patients and I was getting many calls and messages for blood donors.
Starting to work on this had many hurdles like convincing donors during covid was very difficult task and if there were any then arranging their travel pass was one more task for me. I started working on arranging donors; police pass for their travel permission.

Organized some small camps during covid with following all norms of government for blood donation.
One more challenge was for patients and parents to go to hospital. So I was helping many of them with police travel permission. Also attended many webinars on Thalassemia organized by TIF, Thalassemic India and YTA. Getting timely guidance from Dr. Nita Munshi Madam, Surendra Sir and all committee members was a great learning experience for me. Definitely we all will win this covid war.

God keep and bless our ever loving parents. – By Shilpa

This is addressed to all our thalassemia majors, their parents, family, and well-wishers. I have seen a lot of change in the world of Thalassemia. I am of course, referring to the Indian scene. It has only changed for the better for Thalassemia warriors, as the term I have always used, rather than patients. I had come across the phrase “Iron warrior" back in the 90's. I was for the first time, and to my joy, learning of online support groups. It was a term that quickly caught on with all of us, and it was so apt! * Warrior is the attitude we all imbibe, and which defines our battle and struggle. Always a warrior, and never a victim to this disorder. Positivity has only increased with time. In terms of longevity, medical advances, awareness and support groups including our very own TSPC.

TSPC, which at its inception was a mere handful of worried parents and very young children and few adult thals, Today has become an NGO...and with the able support and guidance of our wonderful president Dr Munshi, we have gained both structure and direction. Many other organizations have come up which only add to the benefits and support available to the community. However, of course, TSPC is and will remain unique as that small group that was the first line help and proud platform towards uniting the community and providing the base. Though often short on funds but never the will... It remains the pioneer to many a Thalassemia warrior who struck out independently or further. So thank you to our TSPC society and each one who stayed loyal and committed to its aims and efforts□. There are other groups which patients have made 'only for patients' (rather warriors);..Which really fill the need we had, of support groups. In all this, I do have a point and bottom line. Which, I am getting to....

We must, and we must all over India, as far and as much as possible, keep our cause united and pure. Let not the different groups, political differences or even politics take away from or become a distraction to reaching a commitment to our cause.."Uniting thals" which will make the difference to the very situation and position of Thalassemia, from an Orphan to adopted happily. Let us not get divided by being part of different groups, all paths reach the same goal. All are parts of one whole. Please just keep in mind the last para, as we go ahead in our life and it's battles.

"Get Tested, before it Tests You"
Timely diagnosis of Thalassemia can save us from enormous problems and challenges.

“Life with Thalassemia” - Simran Tejwani

I'm a Thalassemic since I was 3 months of age and now I am 34 years old. Life has not been easy for any Thalassemic and everyone has had their fair share of struggles in maintaining a good health and trying to beat the odds; but I am very grateful to God and my family for every bit of support that they have given me because Thalassemia hasn't deterred me from doing what I wanted to!

I did my B com and then worked for a year after which I pursued MBA in Finance, interned for Development Bank of Singapore and today I have my own set up in the business of Corporate Gifting and I've been married for almost 4 years now to a Wonderful guy and in a beautiful family !

I have undergone a Bone Marrow Transplant at the age of 8, been independent of transfusion for 10 months and after my case relapsed, I have gone back to being dependent on Blood transfusions and taking desferal injections. Life is tough, but Thalassemia has taught me to be Tougher.

Life with Thalassemia does not come easy, but at the end of the day- Life hasn't been too easy on anyone. With this attitude I have embraced it and have taken charge of my health and I am living a life as any other non thal person.

With proper medical care and the latest medical advancements, thals can have great careers, can get married and also have kids. We just need the support and need empathy- We do not need Sympathy!

Yes, there are a lot of challenges, but we need support groups and we need a lot of support from Govt in terms of subsidies free medical supplies/ iron chelators so that we can cope up with these challenges.

We do not have insurance here in India and as an adult a lot of my expenses go in medicals. I don't want to be dependent on my parents or my husband for medical bills, so I would love for support groups and Government to help us with free medical supplies/subsidies, so that the burden is less on us financially.

A book can be written on my experiences, but this is a glimpse of my life and I have a long way to go :)

To all my fellow thals - Life is going to be tough, but we have to be Tougher and if you take charge of your health, nothing can stop you from achieving what you want!!!

As a Thal Committee member

- ➔ As a patient and as a member of the Thalassemia society, it's been one of our dreams to have our own Thalassemia daycare center with dedicated nurses and doctors who can take care of us and with amenities that will help us sail through our pain in a better way.
- ➔ In hospitals and other centers, Thalassemia day care is seen more from a commercial angle than otherwise. Our endeavor is to have a center where the painful experience can be made pleasant and where the patients know that they are taken care of by good doctors and nurses.
- ➔ As a member of the committee, my contribution has been there for organizing and executing events, attending seminars as a Thalassemia society together to know about the latest developments in the field of Thalassemia.

To achieve this, efforts are being made to ask Gynecologists to make the test for Thalassemia, mandatory. Government needs to make this mandatory.

“Life is going to be tough, but we have to be Tougher and if you take charge of your health, nothing can stop you from achieving what you want !!!”

थॅलेसेमिया सोसायटी पुणे चॅप्टर (TSPC)

सौ.नयना दोशी (पुणे)

TSPC ही एक NGO आहे. ही संस्था 1991 मध्ये पुण्यात स्थापन झाली. या संस्थेसाठी मी गेली 23 वर्षे काम करत आहे. मी सुद्धा एक 'थॅलेसेमिया मुलाची' पेरेंट आहे. त्यामुळे 'थॅलेसेमिया' असणाऱ्या मुलांच्या आयुष्याचा प्रवास कसा असतो, याची मला पूर्ण जाणीव आहे. मुला-मुलींची शारिरीक वाढ, मानसिकता, आर्थिक प्रश्न, आरोग्य वगैरे गोष्टी मी जवळून पाहिल्या आहेत, अनुभवल्या आहेत.

TSPC साठी माझे वर्षातून 4 ते 5 ब्लड कॅंप असतात. मी पेशंट व त्यांच्या पेरेंटस्‌ना कौन्सिलिंग करते. पालकांची मनस्थिती खचू नये म्हणून त्यांना या सर्व गोष्टींना सामोरे जाण्यासाठी धीर देते. संस्थेतर्फे पेशंटस्‌ना औषधे, फिल्टर उपलब्ध करून देते. तसेच शिक्षणासाठी मदत करते. पेशंटस्‌नाही यामुळे खूप दिलासा मिळतो.

8 मे या 'थॅलेसेमिया आंतरराष्ट्रीय दिनानिमित्त' माझी रेडिओवर (एफ.एम.) मुलाखत प्रसारित झाली. यात मी 'Thalassemia Prevention' साठी योग्य ते मार्गदर्शन केले.

आणखी एक गोष्ट म्हणजे केवळ आजाराच्या दबावाखाली न राहता मुलांनी त्यांचे आयुष्य इतरांप्रमाणे मजेत घालवावे म्हणून त्यांच्यासाठी मनोरंजनाचे कार्यक्रम आयोजित करते. यात पेशंटस्‌चा खूप सपोर्ट मिळतो. वयाने मोठे असलेले पेशंट स्वतःच्या अडचणी मांडतात, त्या सोडविण्यासाठी त्यांना मदत व मार्गदर्शन करते.

थॅलेसेमिया पेशंटस्‌साठी मला खूप काही करायचे आहे, चांगल्या योजनाही मनात आहेत. हे काम मी करतच राहणार आहे. आणखी सांगण्यासारखे खूप काही आहे, पण मी इथेच थांबते. धन्यवाद!

Mrs. Nayana Doshi

– सक्रिय कार्यकर्ते –

1. सुवर्णा गांधी
2. शिवम गांधी
3. गौरव येनपुरे
4. अनुराग जगताप
5. तेजस राका
6. अथर्व ढेरे
7. ईश्वरलाल परमार
8. किरण
9. हिमांशू बंगाळे
10. मिहीर गुजर
11. श्रुती नेवे
12. सिद्धी कदम
13. समृद्धी कदम

Mrs. PreetiKulkarni

थॅलेसेमिया सोसायटी पुणे चॅप्टर (TSPC)

सौ. प्रीती कुलकर्णी
(प्रोप्रा. पालवी ग्राफिक्स्)

TSPC या संस्थेसाठी मी गेली 8-9 वर्षे काम करत आहे. 'थॅलेसेमिया' पेशंटस्‌साठी कार्यरत असणाऱ्या या संस्थेमध्ये माझ्या कामाचा सहभाग असणे, ही माझ्यासाठी अतिशय अभिमानाची बाब आहे. पेशंटस्‌साठी अनेक उपक्रम ही संस्था राबवत असते. TSPC संस्थेचे डिझाईनिंग व प्रिंटींगचे काम आमच्या संस्थेकडे (पालवी ग्राफिक्स) असते. हे काम माझ्यासाठी फक्त व्यावसायिक काम नसून, या संस्थेसाठी केलेल्या सेवेचा खारीचा वाटा आहे असे मी समजते. व्यावसायिक कामाव्यतिरिक्तही मी या संस्थेत कार्यरत असते. भविष्यामध्ये पेशंटस्‌साठी काही योजना मनात आहेत. त्या पूर्ण करण्याचा मी नक्कीच प्रयत्न करणार आहे.

“TSPC FUTURE PROJECT - CENTER OF EXCELLENCE”

Some months back a group of our Committee members went down to Mumbai for a study on Center of Excellence which is rendering a yeoman service to all Thalassemia patients. All of us were really impressed with the infrastructure of the institution with all possible top of the line facilities available for Thalassemia patients.

After discussing with our members I am glad to say that this is a dream project for all of us and we will put in all our efforts for achieving this for our patients. Yes we will need all possible help from everyone but let us all willingly put our shoulder to the wheel.

Our Project Report will be ready soon so please being prepared to put in all your efforts.

Vice President - TSPC
Mr. Ramesh Arora

“Life is going to be tough, but we have to be Tougher and if you take charge of your health, nothing can stop you from achieving what you want !!!”

“Big Thank You to all who help and support us”

FinOlex PIPES

Mukul Madhav
Foundation
Established 1999

Dear Mrs. Munshi,

We are happy to support the Thalassemia Society and support the needy patients. It has opened our eyes to the need, the expenses and increase the possibilities of a better life for them.

We have recently connected with The Wishing Factory in Baroda headed by Parth Thakur a young Thalassemia patient himself striving hard to support fellow patients. We would be soon moving to support patients in Mumbai too.

I am truly honored to be on a crusade along with likeminded friends and partners to support the society of Thalassemia patients and ensure they have a good well being.

Wishing you all my very best.
Warm Regards
Ritu Prakash Chhabria

I believe your work will bring joy to many people in future. May your creativity shine bright in the days to come.

Arun Markale
Advocate & Tax
Advisor

Strange but truth is husband or wife having a defective gene is safe. Not both same defect. That is why we have children with Thalassemia, a life-long burden for the child, parents and society. It costs only Rs.200 to avoid such a big, costly calamity. Please note, anyone who intends to get marry, should think of finding out if they by any chance carry a defective gene that will lead to Thalassemia if they marry a person with same defect. Full stop, It is that simple to avoid this and put an end to this in next 100 years. Do not ignore it before marriage and if married, before coming pregnant. It is simple blood test. Affordable.

T

I thank and appreciate Mrs. Jasmine Majethia even for contributing her entire life in and for Children with Thalassemia and continuing the same even at this age. She is an inspiration for inspirers.

Dr A Velumani.
Creator, Thyrocare.
Focus! Be Consistent!!

Thyrocare®
Think Thyroid. Think Thyrocare.

You’ll never find a rainbow if you’re looking down - Charlie Chaplin

“Thank you from the bottom of our heart to all our doctors, nurses, technicians you went above and beyond to make us comfortable, you are all amazing, we appreciate you all.”

Blood Donors Thank you. Although, we do not know each other, but your precious blood gives our patients a new life. Thank you for being such a supportive human being.

THANKY YOU to All Blood Banks for your contribution toward the noble cause.

Thank you Symbosis Institute for organizing the Thalassemia Awareness and conducting workshops sessions.

Thank you Bajaj group for helping the Thalassemia Patients.

Thank you Manikchand Group for helping the Thalassemia Patients.

Thank you Infosys for helping blood drive efforts.

To All volunteers Thank you for all your hard work. And we could never ask for a more. Words actually cannot express how grateful we are to have you here. May God bless you!

Thank you Ruby Hall for conducting blood test for Thalassemia patients in concessional rates.

Thank you Rotary Club Pune for your generous support to our society and Thalassemia patients. We greatly appreciate it.

“Sending you good thoughts—and hoping you believe in yourself just as much as I believe in you”

Thalassemia - I don't feel like this word is a disorder to me anymore but it has turned out to be an opportunity in my life to make a difference! - Priya

Here, I am and here's my story.
I was diagnosed with thalassemia major when I was of 3months and today I am 24. This 24 years period has its own sets of ups and downs. You can call it as a rollercoaster ride which gradually I started enjoying. I was born in Kanpur, U.P, my parents didn't know anything about thalassemia then and tried there best to keep me healthy. Since Kanpur didn't have good hospital, they used to take me to SGPGI - Lucknow for blood transfusions. When I was 6 they took a decision to shift to Pune just because I should get proper education and treatment.

I have always been a jolly kid and with my parents support I was moulded into brave kid. When I was of 8, I got badly infected with pneumonia, was admitted in hospital for a couple of months, doctors were unable to find out why wasn't I responding to treatment as my condition got worsen day by day, they told my parents that they are trying their best but can't guarantee whether I would survive or not. But I am a child of my brave parents, mumma and papa gave me all strength and love to me and I recovered and was out of the ICU soon. I completed my secondary and higher secondary education with flying colors, though I got fractures in between but I continued to study. I wanted to pursue MBBS but failed to score well in entrance so I decided to take pure sciences and did my graduation in microbiology. Currently I am pursuing post-graduation in Microbiology. I am passionate about thalassemia, as I said I take it as an opportunity. With the help of my family i have built up enough confidence that now I give speeches on thalassemia awareness and positivity in colleges, Institutes and conferences. I am volunteering with TSPC and The Wishing Factory NGO, both these organizations are working towards wellness of thalassemics and aim to eradicate thalassemia. I believe- that life is a reflection of our thoughts, we attract what we think and believe in, hence I say let's always stay positive and be an optimistic in life, because pessimistic thoughts never work!

- Priya Vaswani (Thalassemia Major Warrior & a Social Activist for Thalassemia)

TSPC would like to thank all blood banks in Pune and Pimpri Chinchwad area.

Thalassemia patients are completely dependent on blood for regular transfusions. Blood banks have played pivotal to make blood available to our Thalassemia patients.

Below blood banks who have been super helpful and we appreciate their help.

- **Ruby Hall Clinic Blood Bank, Pune 411001**
- **KEM Hospital Blood Bank Pune 411001**
- **Jankalyan Blood Bank , , Pune 411002**
- **Inlaks & Budhrani Hospital Blood Bank , Pune 411001**
- **Akshay Blood Bank, Pune 411028**
- **Om Blood Bank, Pune 411011**
- **Deenanath Mangeshkar Hospital Blood Bank, Pune 411004**
- **Pimpri Serological Institute Blood Bank, Pimpri-Chinchwad 411018**
- **Bharati Hospital Blood Bank, Pune 411043**
- **Blood Bank Sassoon Gov Hospital, Pune 411001**
- **Sahyadri Hospital Blood Bank, Pune 411004**

Often when you think you're at the end of something, you're at the beginning of something else.

“There’s something in you that the world needs.”

If proper care has taken the thalassemic child will live the life normally. Up to 6 yrs the proper match of suitable donor within the blood relation (siblings or parents) then one must go for Bone Marrow Transplant. Then the child will be free from Thalassemia. At Ruby Hall Clinic since 2008 till date more than 50 thalassemic patients underwent transplant.
But I think each one should get themselves tested for minor Thalassemia so that it will prevent the birth of Major Thalassemia children.

Surekha Joshi - Transplant Coordinator - Ruby Hall Clinic

Clinical Trial Updates - https://www.thalassemia.org/learn-about-thalassemia/clinical-trials/

Gene Therapy:First gene therapy approved in Europe for the treatment of transfusion-dependent beta thalassemia

ZYNTEGLO is indicated for the treatment of patients 12 years and older with TDT who do not have a β0/β0 genotype, for whom haematopoietic stem cell (HSC) transplantation is appropriate but a human leukocyte antigen (HLA)–matched related HSC donor is not available. **https://www.zynteglo.eu/**

1. **Clinical Trials of Gene Therapy in Transfusion-Dependent Beta Thalassemia**
    a. LentiGlobin:

       Further information is available in the press release at: http://investor.bluebirdbio.com/news-releases/news-release-details/majority-evaluable-patients-across-genotypes-achieve-transfusion

2. **Clinical Trials of Gene Editing in Transfusion-Dependent Beta Thalassemia**
    a. CTX-001
       Two Patients Become Transfusion Independent After Gene Editing Therapy
       Further information about these findings is available in the press release at: http://ir.crisprtx.com/news-releases/news-release-details/crispr-therapeutics-and-vertex-announce-new-clinical-data
    b. ST-400:
       Further information is available in the press release at: https://investor.sangamo.com/news-releases/news-release-details/sangamo-announces-preliminary-results-first-three-patients-phase

3. **Clinical Trials for Patients with Non-Transfusion-Dependent Thalassemia**
    a. Mitapivat:
       Agios Pharmaceuticals Provides Update on Phase 2 Study of Mitapivat in Non-Transfusion-Dependent Thalassemia
       The Phase 2 study of mitapivat in non-transfusion-dependent alpha- and beta-thalassemia has been fully enrolled. Further information about the preliminary Phase 2 findings can be found at: https://www.globenewswire.com/news-release/2020/06/12/2047266/0/en/Agios-First-in-Class-PKR-Activator-Mitapivat-Demonstrates-Sustained-Hemoglobin-Responses-in-Non-transfusion-dependent-%CE%B1-and-%CE%B2-Thalassemia-in-Phase-2-Study.html
    b. IMR-687
       Imara has Dosed the First Thalassemia Patient in Its Phase 2b Forte Clinical Trial
       Further information can be found in Imara’s press release at: https://www.globenewswire.com/news-release/2020/10/16/2109779/0/en/Imara-Announces-First-Patient-Dosed-in-Forte-Phase-2b-Clinical-Trial-of-IMR-687-in-Beta-Thalassemia.html
4. **Clinical Trials of PDE9 Inhibition**
       Imara has Dosed the First Thalassemia Patient in Its Phase 2b Forte Clinical Trial
       Further information can be found in Imara’s press release at: https://www.globenewswire.com/news-release/2020/10/16/2109779/0/en/Imara-Announces-First-Patient-Dosed-in-Forte-Phase-2b-Clinical-Trial-of-IMR-687-in-Beta-Thalassemia.html

जो कुछ भी तुमको कमजोर बनाता है – शारीरिक, बौद्धिक या मानसिक उसे जहर की तरह त्याग दो।

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thalassemiapune14@gmail.com

We’re on the Web!
See us at :
http://thalassemiapune.co.in

We couldn’t do what we do without our volunteers and donors. Together, we’re making a difference – and you can, too. There are countless ways you can help us lead the fight against thalassemia.

Association

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

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

Thalassemics India - http://www.thalassemicsindia.org/

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

TSPC would like to take this opportunity to sincerely thank The Management at ***Ruby Hall Clinic*** *for their kindness and concern for Thalassemia children over the years! Thanks again for your dedication to patient care.*

Big Thank You to all who help and support us. Together we are making a difference! Your continued support of our mission is deeply gratifying to us, and we hope it is the same for you. We would love the opportunity to thank you again!

Patients/Parents/Associations/Doctors/Caregivers

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

Email - thalassemiapune14@gmail.com

About our Organization - Thalassemia Society Pune Chapter is a purely voluntary, social, welfare organization committed for the cause of Thalassemia. TSPC formed as 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.