THALASSEMIA SOCIETY PUNE CHAPTER

Registration No. 2057/2014

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

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GOAL

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

Thalassemia - you can help….prevent....

The Thalassemia Society Pune Chapter (TSPC) was founded by patients, parents and friends affected by Thalassemia Major . The foundation provides hope, comfort and encouragement to those battling this disorder. The foundation maintains a strong relationship with the medical community that provides diagnosis, treatment and care.

We at the Thalassemia Society are committed for Prevention and Awareness drives in and around Pune. We have set a goal to achieve ZERO Thalassemia birth of new Patients in Pune by the year 2025.

President
Dr. Nita Munshi

As a part of this, we are planning to cover all corporates and colleges. We have conducted major awareness campaign in Infosys, Wipro, Fiat, VW, to name a few- where we have collected more than 500 samples for screening and are in process of counselling affected people with Thalassemia Trait. We are in process of similar mass awareness campaign / screening for prevention in various communities to create awareness of the disease condition. We are also collaborating with like-minded organisations for awareness. We collaborated with Ishanya Foundation to spread awareness among all Assamese individuals staying in Pune since there is a high prevalence of a type of Thalassemia in the east.

We help needy patients to ensure they are following effective treatment protocol to lead a perfect life. We have a lot of poor patients who can't afford treatment and it is our endeavor to ensure help to them to battle the disease.

We Organize blood donation drives to procure blood required for transfusion to.maintain normal hemoglobin of the Thalassemia children.

We also arrange forums & get together of patients and Parents for the welfare & treatment updates and cascading screening for future prevention in their Families.

We require funds to manage all the activities we are doing and request your kind help to inspire us to do more and more in the Field of Thalassemia through our Thalassemia Society Pune Chapter (TSPC).

We have the 80G exemption certificate for donations to our society

It is our earnest plea to request financial help in our noble cause and become our partners in PREVENTING Thalassemia in Pune.

DID YOU KNOW?

IN INDIA, EVERY Hour ONE Child is Born with

THALASSEMIA

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.

LET'S MAKE THIS WORLD THALASSEMIA FREE

"Be Aware. Share. Care.: Working with the global community as one to improve thalassaemia knowledge."

Be part of the International Thalassaemia Day 2022 and help transform the lives of millions of people across the globe!

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

Today, despite the ever-rising global incidence of thalassaemia and in the absence or lack of effective, nationally-coordinated prevention programmes in most countries affected by the disorder, awareness and knowledge about even the basics of the condition's prevention and management remain largely confined amongst the general public, including carriers of the disorder and/or patients themselves

Unawareness, lack of disease-specific knowledge and poor health literacy are even more striking in developing countries of the world, where more than 80% of patients with thalassaemia are born and live! They not only have a major impact on health outcomes, but can also be divisive in society and affect quality of life.

We must enable patients and the community at large to have equitable access to knowledge and resources that will strengthen their capacity to take preventative action, change attitudes towards carriers and/or patients with the disease, and better safeguard and manage their own health.

थॅलेसेमिया सोसायटी पुणे चॅप्टर कार्य

थॅलेसेमिया ब्लड डिसऑर्डर आहे हे आपणास माहिती आहेच पण याबद्दल फारसा अवेअरनेस नाही यासाठीच थॅलेसेमिया सोसायटी पूने चाप्टर एनजीओ काम करत आहे आणि मी त्याचा एक भाग आहे या संस्थेमध्ये पेशंटसाठी वेगवेगळे उपक्रम चालू असतात आठ मे हा इंटरनॅशनल थॅलेसिमिया डे आहे त्यानिमित्ताने अवेअरनेस प्रोग्राम आखला जातो आमच्या सोसायटीमध्ये पेशंट्सना औषध रुपाने फिल्टर च्या रूपाने वेगवेगळ्या प्रकारे मदत केली जाते पेशंटच्या पालकांचे आणि पेशंट चे ही कौन्सिलिंग केले जाते त्यायोगे हा आजार सहन करणे थोडे त्यांना सोयीचे होते टी एस पी सी संस्थेतर्फे मुलांना शिक्षणासाठी देखील थोडीफार मदत करण्यात येते थॅलेसिमिया चे मोठे पेशंट एकमेकांचे ग्रुप करून एकमेकांना मदत करतात ते वेगवेगळ्या स्पर्धांमध्येही भाग घेतात उच्च शिक्षण ही घेतात त्यांनादेखील सामाजिक प्रवाहामध्ये सामील होण्याची इच्छा आहे ही संस्था यांना प्रगती करण्यासाठी प्रोत्साहन देते व त्यासाठी वेगवेगळ्या ठिकाणाहून फंड देखील गोळा करते जास्तीत जास्त पेशंटला याचा लाभ घेता यावा

Mrs. Nayana Doshi

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
Thalassaemia is my strength or weakness?

"Life is not easy for any of us. But what of that? We mu st 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."

Living with Thalassaemia becomes easy, once you accept the truth fully. Indeed living with Thalassaemia given me lot of toughest problems like going to hospital every 15 days, requesting blood donors to donate Blood, taking medicines every single day, taking Desferal injection every night, adjusting in School, college, IBM office etc, but although all these problems it makes me stronger. Without having Thalassaemia I couldn't understand the importance of blood donation. The reason I am doing social work with various social organisations, is to spread awareness about Thalassaemia & blood donation. It doesn't matter for which or with which organisation I am working, but what matters is to just continue the good work about awareness. I am Proud to say that on 8th May 2021 I was felicitated by Pune's Mayor Murlidhar Mohol for my contribution in the field of Thalassaemia awareness.

Thalassaemia taught me to have patience in all my life, whether it's while pricking the needle, taking the chelations every single day or working in a corporate. It has never been my weakness & it never stopped me to achieve my Goals in life. I always believe if God gives you one problem, he will always gives you the Direction to solve the problem with supporting people.

When I was hospitalized more than 7 times till now, except for blood transfusion, I have learnt

The 2 biggest lessons, one is to take care of yourself first, (good health) and living the life fullest, because we never know when will our time come to leave this world. So before you leave the world, do something good, inspire people, add value to others.

I am grateful to each & every person in my life for supporting me in my journey till now. I am so thankful to Thalassaemia Society Pune chapter for always supporting Thalassaemia warriors & giving me chance to write today.

I want to tell all the young parents of Thalalassemics warriors; please raise your children as a Normal person, never stop them from learning or doing whatever they like, just because of Thalassaemia. Always remember, that Thalassaemia is just one part of our life not our whole life.

TSPC ZERO 2022 Thal Awareness

Thalassemia Awareness on International Women's Day 06 Mar 21" -Mr Surendra, Mrs. Chitra, Mrs. Doshi, Miss Priya had a great success of Thalassemia awareness TSPC team participation on 06 Mar 21 Savitri Forum Blood donation program during International Women's day IWD

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 Natarajan Mumbai, Dr. Amit Patankar and Dr. Leena Patankar Pune working with TSPC to help us prevent and eradicate Thalassemia.

Our committee member Mr Kailash and TSPC Secretary Mr Surendra will restart Sighgad College with continue support from Mrs Dhariwal Manikchand, to create awareness in society and young college students. That is a sure way and the first step of preventing Thalassemia

Dr Munshi, Tspc President set a Target/Goal to get 10 K pune people tested in 2022 with support from Mr Velumani Thyro care through support of TSPC Patron Mrs Majhethia along with Pune Hospitals who can help in test to eradicate new Thal Born in Pune

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

"ZERO THALASSEMIA BIRTHS BY 2025." – Dr. Munshi

2022….. A year of Hope and Positivity…. Let's pray that the last 2 years was like a bad dream never to be seen again.2021 ....What a year! It will surely go down in history and remembered as the year of the pandemic. The Covid Sars COV-2 year but not for the children with Thalassemia Major.

We, the members of TSPC (Thalassemia Society Pune Chapter) ensured that the children with Thalassemia Major don't suffer due to the lockdown or the covid restrictions.

The parents and a few good samaritans like Sahil Kejriwal made multiple trips in their cars to take children for their regular blood transfusions to the respective blood banks.

We ensured that all children got their filters and their medicines on time. Prakash medicals and Kalyani medicals in Pune came forward and offered heavy discounts to these children for their medicines which helped reduce the financial burden on the parents.

Though we could not organize any fun event for the children, we sent gift hampers to all during Diwali.

Mukul Madhav Foundation under the leadership of Mrs. Ritu Chhabria has been a constant mode of support for many children.

Mrs. Shobha Dhariwal and Shri Rahul Bajaj ji have always supported the cause of these children.

We have been fortunate and blessed to have the good wishes and blessings of many well wishers ….. however, good work cannot survive only on good wishes….we need funds too to sustain.

We had a fund raiser event in 2018, thereafter haven't been able to organize any function

OUR FOCUS REMAINS WELFARE OF ALL THE CHILDREN WITH THALASSEMIA MAJOR.
(I DON'T LIKE TO CALL THEM PATIENTS).
AND ZERO THALASSEMIA BIRTHS BY 2025.

I REQUEST YOU TO PARTICIPATE IN THIS ENDEVOUR TO MAKE IT A SUCCESS.

TOGETHER WE CAN

With thalassemia, you can't afford to wait for your heart to tell you it has too much iron.

Iron can start building up in the heart for a long time before a person with thalassemia feels any effects. But getting iron out of the heart as early as possible is important for the best health outcome.

That's why people with thalassemia need to have regular T2* cardiac scans performed, so that their doctors can take steps to keep their hearts healthy.

Life Long Association Transasia Bio-Medicals Ltd for Thalassemia Free India

A Vision for Thalassemia-free India

Transasia Bio-Medicals Ltd. works towards building a stronger and inclusive India by going beyond its business initiatives to enable lives, living and livelihoods. The company is helping to create change at the ground level across the nation, supporting especially the most vulnerable and marginalised communities. Through its ever evolving and inclusive development approach, Transasia supports meaningful activities to address some of India's most pressing development challenges.

Prevention of Thalassemia is a cause we are closely associated with. With a vision for a thalassemia-free India, Transasia's CSR arm, Vazirani Foundation, has been closely associated with Parents Association of Thalassemia Unit Trust (PATUT) to raise funds for the treatment of thalassemic children needing bone marrow transplant (BMT).

For over a decade, Transasia and PATUT have organised awareness and screening camps for college students, helping them understand their role in preventing thalassemia. Further, Transasia organizes regular blood donation camps and have collected about 10000 Blood Units to provide fresh blood. We also support thalassemia patients by providing bedside filters or chelation.

Further, Transasia has developed sophisticated blood analyzers that help in early detection for a number of fatal diseases that are a threat to not just the present, but future generations of this country. In the Hematology segment, the company offers fully automated three and five part range of differential hematology analyzers that integrate an array of features for enhanced clinical insights to save time and labour, while enhancing patient care. The instruments can help patients in screening of hemoglobinopathies as well as diseases such as MALARIA, DENGUE, CANCERS and HIV, apart from contributing to the fight against COVID-19.

In the recent past, Transasia has donated a few sophisticated ERBA fully automated hematology analyzer to PATUT as well as to large hospitals and medical colleges across India during the COVID-19 pandemic.

Mr. Suresh Vazirani, Founder Chairman of Transasia-Erba International Group of companies strongly believes that there is a lot more we can do for a healthier India, in addition to just offering the latest in medical technology. He is driven by the passion to make diagnostics more accessible as well as affordable, thereby contributing to the growth of the industry. – Mr. Suresh Vazirani who has spearheaded the Transasia - Erba group to be renowned, as India's leading In-vitro Diagnostic Company and a fast emerging player in the global IVD arena.

A leader in the In-vitro Diagnostic segment in India, Transasia Bio-Medicals Ltd., is a world-class solutions provider in Blood Banking, Clinical Chemistry, Critical Care, Coagulation, Diabetes Management, Hematology, Immunology, Urinalysis and Molecular Diagnostics.

Headquartered in Mumbai, it is a part of the global Transasia-Erba group, which serves millions in over 100 countries through its 12 now overseas subsidiaries.

With a legacy of over four decades, Transasia's foray into indigenous research has resulted in development of state-of-the-art products and technologies, enabling Transasia's deliverables to be synonymous with the best in the world. All products manufactured by Transasia are USFDA registered for their quality and implementation of GMP.

A strong endorser of the 'Make in India' concept, Transasia's Founder Chairman, Mr. Suresh Vazirani strongly believes that manufacturing in India is the only answer to address the country's needs for quality and affordable diagnostic solutions.

In fact, Transasia is the first Indian company to manufacture and export state-of-the-art blood analyzers and reagents, way back in the 1990s. The latest technologies from its European subsidiaries at Czech Republic and USA, are adopted and customized in India at the five manufacturing facilities at Baddi, Daman, Sikkim, Mumbai and Visakhapatnam, to develop products and solutions that aid in timely diagnosis. Today, Transasia has an impressive installed base of 70,000 equipment across India. Over 150 crore blood tests are done on a Transasia equipment every year benefitting more than 200 million people. In fact, one test every two seconds is conducted on a Transasia product!

On the global front, the Transasia-Erba group is focused on developing technologies specifically for the emerging markets. A truly multinational corporation, the group houses a transnational team of experts. With a strong distributor network, Transasia-Erba's products are made available in Italy, Germany, France, China, Turkey, USA, Latin America, Russia, Middle East, South Asia, South East Asia and Africa.

Erba Molecular, UK, is among the first few in the world to own a patented technology for molecular testing. Further, its USA subsidiary, Calbiotech, is strong in ELISA and CLIA assays for human and animal research, including specific assays for autoimmune disorders, cancer and infectious diseases.

With its 'Customer First' policy, Transasia has a network of 350+ service engineers, 400+ sales and marketing team, 25 zonal offices, and 450+ distributors who reach out to customers in over 5000 tier II-IV cities, towns and villages including the farthest north-eastern regions in a record time of just 4-5 hours. In fact, Transasia boasts of the largest team of sales and service personnel in the Indian IVD Industry!

All along its journey, the Transasia-Erba group has been recognized for its commitment to healthcare. Among its numerous accolades, Transasia most recently won the India Medical Devices Leader of the Year 2021 (2nd Runner Up) by the Dept. of Pharmaceuticals, Ministry of Chemicals and Fertilizers, Govt. of India. In 2021, Transasia ranked among the 500 most valuable companies in India by Hurun India in co-ordination with Burgundy Private and Axis Bank's Private Banking Business and also won the Economic Times Healthcare Award 2021 for COVID-19 testing solutions.

In the past the company has also won the 'The Economic Times Best Brand 2019', 'Brand of the Decade', 'Best Company in Medical Devices - IVD by Medgate Today magazine, 'Export Company of the Year – Indian Medical Devices' by the Government of India.

Transasia is also the first Indian IVD Company to receive the ICMED 13485 quality certificate in 2018, the country's first indigenous QA system for India manufactured medical devices. Transasia is also the first IVD Company in India to be awarded the ZED Diamond Quality rating from the Ministry of MSME, Government of India and the Quality Council of India for its manufacturing facility at Mumbai (Seepz).

Mr. Suresh Vazirani was adjudged the Topmost (Healthcare Leader Global) by World Health and Wellness Congress in 2022. He has also been felicitated by Dr. Harsh Vardhan, Hon'ble Minister of Science & Technology, Govt. of India as the 'Pioneer for Make in India Concept' initiative in 2015.

Under his able leadership, the Transasia - Erba group continues to increase the number of lives it touches, in its Commitment to a Healthier and Happier World!

Be part of the International Thalassaemia Day 2022 and help transform the lives of millions of people across the globe!

Thalassemia Prevention Drives - Kailas Tile

Thalassemia must be avoided at any cost for obvious reasons. Cost a side, it puts significant pressure on blood supply system, and there are always some duration every now and then when blood availability becomes an issue. At TSPC, we carry out number of various initiatives to increase the awareness and get people screened for Thalassemia. There are various possibilities where someone can be screened for the trait and few of these are:

At the time of marriage.
At the time of pregnancy.
At the time of collage admission.
At any other time, as a part of any routine checkup

Out of these times, the **marriage** is best time when one should get tested for thalassemia so that possibility of thalassemia child can be avoided. But the major blocker for this is, people are afraid to do that. Many of those who contacted shared the feedback that if we test ourselves and found positive, people will start rejecting us, most of the folks doesn't really understand the consequence etc so they tend to leave it to the luck/naseeb and prefer to get married and don't want any complexity of medical situation at this point in time. Hopefully public will become mature at some point in future to understand the need of this, but at this time, its difficult.

Next best time is at the time of pregnancy, but the issue here is, many gynecologists don't advise such testing. Reason could be either ignorance or lack of clarity in their mind itself. Or it could be just they only want to focus of happy path to avoid the risk of losing patient and potential earnings. If fetus is tested for thalassemia in early phase, an option can be provided to the couple to abort it. Its too emotional decision for many, so that's additional problem.

Rest of the options are just options of hope. If we test college students, they may of may not pay attention because they aren't in family mode but nevertheless we are targeting college students since they aren't skeptical about getting tested and we hope by putting word "Thalassemia" in their head, it will be move in right direction.

When awareness camps are conducted in organizations, we do see people/workers coming forward to get themselves tested but for this class, most of the times, its lost cause anyway. They already passed the risk or already in it. Only positive outcome of testing this class is, anybody who is planning family can be benefitted.

Love is the strongest force the world possesses. - Mahatma Gandhi

Jatin Sejpal

As I am regularly working for Thalassemia patients in Pune and surrounding Pune but we had different experience during covid pandemic from last few months .

Availability of blood was a difficult task for our patients and I was getting many calls and messages for blood donors.

Starting working on this had many hurdles like convincing donors during covid was very difficult task and if any then arranging their travel pass was one more task for me.
I started working on arranging donors , police pass for their travel permission .
Also organized some small camp 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 for police travel permission to them .
Also attended many webinars on Thalassemia organized by TIF, Thalassemia India and Yta .
Getting timely guidance from Dr Nita Munshi Madam , Surendra sir and all committee members was a great learning experience to me .

Definitely we all will win this covid war .

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.

TSPC Patient Welfare committee is committed to look after wellbeing of Thalassemia Patients and Family members. We at TSPC are super focused to enhance quality of life of our patients by driving many initiatives related to Awareness, Counseling, Annual health testing programs, subsidized rate Leukocyte reduction Filters, Medicines reimbursement to need patients. TSPC Welfare committee is driven by passionate members of TSPC who are Thalassemia Patients and Parents. We have members like Mr. Nilesh Shah, Mrs. Naina Doshi, Mrs. Rita Shah, and Mr. Jatin Sejpal actively working for TSPC Welfare committee. We are well guided by our team members including our President, Dr. Nita Munshi. We are also well supported by Mrs. Priti Kulkarni for our digital marketing like posters, WhatsApp graphics, standees and booklets.

Here are some highlights of TSPC Welfare committee

Leukocyte Filters:

TSPC continues to provide Leukocyte Filters to our patients who need blood transfusions. We have provided an average monthly 90 filters to our various patients at subsidized rates. Patients are connecting with our TSPC office and collecting these filters as per requirement.

Medicine Reimbursement:

TSPC is very happy to share that we are providing financial help to more than 45 patients. Patients are getting their Thalassemia related medicine cost reimbursed from our office. We have identified these patients based on their family needs and using stringent criteria.

Patient Medical Discount Program:

As a Thalassemia patient, there are recurring huge expenses on medicines like iron chelation. TSPC stepped forward to help and provide financial relief to our patients. We leveraged our relationship with 2 of the medical stores who have been involved for many years to help Thalassemia patients. TSPC has worked on special discounts on most commonly used Thalassemia medicines. Discounts vary by medicines and medical shops. We launched a discount program in September 2021. We have received very positive responses from our patients and they are saving high amounts with quality & timely medicine availability at these medical shops.

Medical Shops:

1. Prakash Medical Centre, Opp Railway Station, Pune -01. Ph: +91 9112111847
2. Kalyani Medicals, Opp Ruby Hall Clinic, Pune-01. Ph: +91 9049952598

How to avail benefits:

1. Patient to visit TSPC office; carry original medicine prescription & TSPC Card
2. Carry 2 Xerox copies of medicine prescriptions as you visit TSPC office
3. Medicine Prescription can be maximum 3 months old
4. Collect stamped prescription Xerox and visit medical shop
5. Show stamped prescription and pay discounted money to Medical shop
6. Collect Medicines and Bill

Please note medicines will not be provided at a special discount rate unless your prescription has TSPC stamp, date and signature

We are grateful to Mrs Ritu Chhabria and MMF for taking care of 29 children for their medications.

“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.

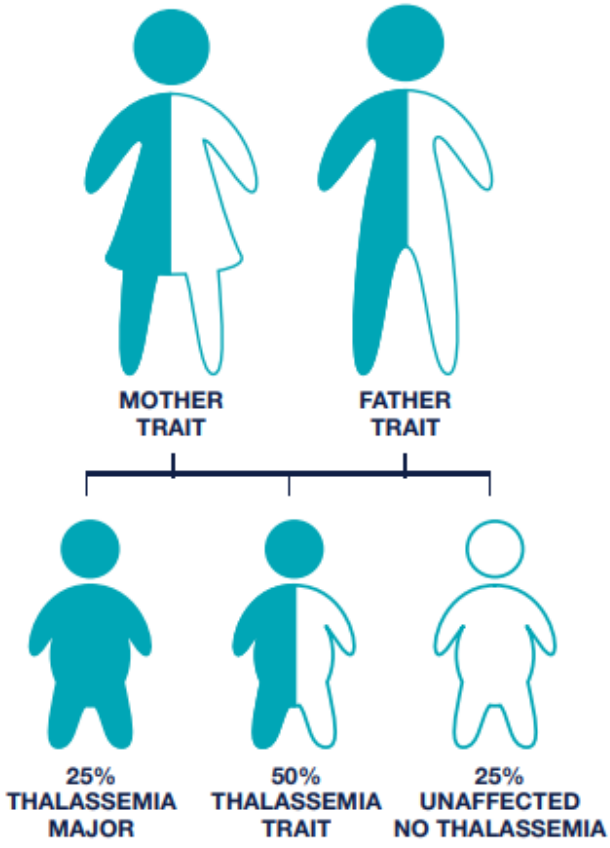
Beta-0 thalassemiarefers to the absence of production of beta globin. When patients are homozygous for beta Thalassemia gene, they cannot make any normal beta chains (hemoglobin A).

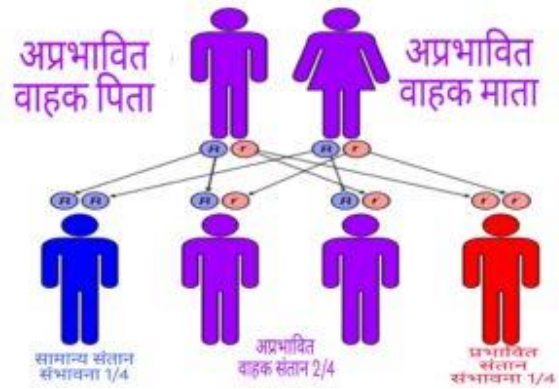
Beta + thalassemia indicate a mutation that presents decreased but not absent production of beta globin. Thalassemia patients in which one or both of their beta thalassemia mutations are beta+ mutations make some hemoglobin A, and the disorder may be less severe.

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.”

Diwali Gift to Thalassemia Patients……..

TSPC continues to celebrate various festivals to get together our patients/parents like Diwali, Christmas including 8th May International Thalassemia day. This year was tough to arrange any in-person gatherings due to covid situation. So TSPC patient welfare committee worked on nice fire cracker shaped chocolates box, Diya’s and shipped with “Happy Diwali” messaging to all patience residence. Our social groups were flooded with overwhelming appreciation messages with such pleasant Diwali gifts

Annual Health Testing

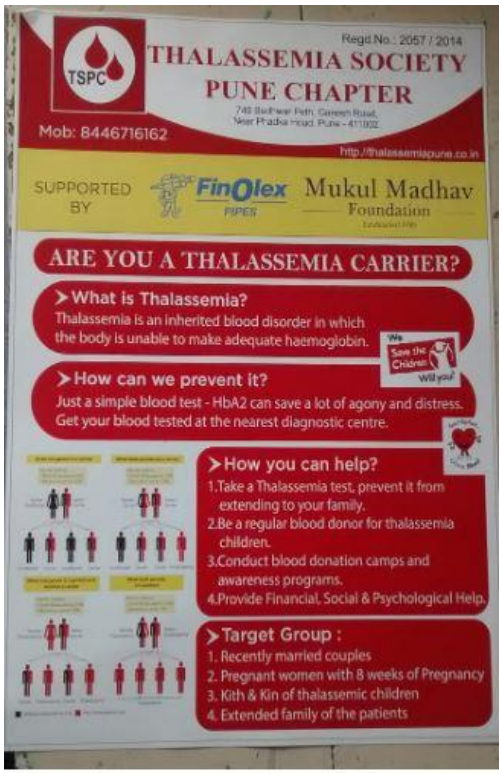
TSPC is committed to wellbeing of Thalassemia Patients. We conducted annual health check of at Ruby Hall based in the February 2022. Based on patient’s age group and gender, various test were prescribed to patients.

In collaborations with Ruby Hall, Pune, TSPC offered very subsidized rates on blood tests, Dexa Scan, T2 MRI. Dr. Kedar Munshi graciously agreed to do Sonography and 2D Echo tests at his clinics.

We had hassle free process to visit Ruby Hall, get all test done and reports were collected by our patients. Post report collections, patients were offered to visit doctors at ***Rudhir- The Lifeline, Thalassemia Day care center***. We had approximately 80+ patients to be benefited of this initiative.

Thalassemia Awareness Posters

TSPC in collaboration with Madhav Mukul Foundation, designed posters for Thalassemia Awareness. We printed these posters and distributed to various hospitals and blood banks. This has helped to reach out to wider audience for awareness of Thalassemia



Rudhir The lifeline

Comprehensive Thalassaemia Day Care Unit

Rudhir- The lifeline ~Daycare centre’s motto is care-curb-cure thalassemia. Along with the care of thalassemic warriors, we are stepping towards a cure with a Free HLA Test Camp

https://www.cancerpune.com/rudhir-the-lifeline/

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

"Big Thank You to all who help and support us"

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

Did you know that beta thalassemia major is the most severe form of thalassemia? By staying committed to long-term treatment, people with thalassemia can enjoy a full life.

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.

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.

Tough Times Never Last But Tough People Do! Stay Positive…..

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

TRANSITIONING TO ADULT HEALTHCARE IN THALASSEMIA: Q&A with Dr. Farzana Sayani

What responsibilities do thalassemia patients take on as they transition to adult healthcare?

As young adults with thalassemia transition to adult healthcare settings, it is important for them to become comfortable with several new responsibilities, including;
• Scheduling their own medical appointments with the thalassemia provider and any subspecialists
• Scheduling blood transfusions and necessary medical tests
• Understanding the reasons why they may need blood transfusions and why they must take particular Medications
• Being familiar with the complete list of medications that they take, knowing how to obtain these medications, and keeping track of when medications must be re-ordered
• Knowing how to contact their medical providers if they have any questions
• Knowing which emergency room they would go to if needed, and how to contact their regular providers in emergency situations
• Learning about health insurance and what is involved in obtaining coverage
• Learning to advocate for their own healthcare needs to help ensure that they receive the best possible care

Go to Full interview at
https://www.thalassemia.org/boduw/wp-content/uploads/2021/01/QA-with-Dr.-Sayani-Transitioning-to-Adult-Healthcare-in-Thalassemia-v2.pdf

OPTIMAL GROWTH IN PATIENTS WITH THALASSEMIA: Q&A with Dr. Tariq Ahmad

How often should growth be assessed in pediatric patients with thalassemia? Which particular measurements should be performed (standing height, sitting height, etc)?

Appropriate height velocity (the increase in height during a given period) is an important indicator that growth is adequate from a hormonal standpoint. Pediatricians typically have multiple visits with newborns to make sure that they are growing at an appropriate rate. Growth is very rapid in the first couple years of life and then by 5 years of age slows down to approximately 5 centimeters (2 inches) per year until puberty starts – at which point, the peak height velocity can almost double. In general, there are two important factors that influence final adult height: (1) the time at which an individual enters puberty and (2) how quickly they progress through puberty. Most females enter puberty between 9 to 10 years of age, begin to menstruate around 12.5 years of age, and then stop growing around 15 years of age. Estrogen is a hormone that causes the closure of the growth plates which is why girls stop growing sooner than boys. About 25% of boys enter puberty by 10 years of age, while 50% of boys enter puberty by 11 years of age. Subsequently, boys will stop growing around 16 years of age. An important concept, however, is that the bones may have a different age than the child.

Go to Full interview at
https://www.thalassemia.org/boduw/wp-content/uploads/2019/09/QA-with-Dr.-Ahmad-Digital-Version.pdf

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

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Opp. Ruby Hall Clinic
Sasoon Road,Pune 411001

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

UPDATES ON NOVEL TREATMENTS IN THALASSEMIA - LUSPATERCEPT (REBLOZYL)

The effect of long-term luspatercept use on iron levels and on utilization of iron chelation therapy was assessed in the Phase 3 BELIEVE trial of luspatercept in adult patients with transfusion-dependent beta thalassemia. After 24 weeks of treatment, 17.0% of patients who took luspatercept showed a reduction in serum ferritin levels from ≥ 1,000 µg/L to below 1,000 µg/L, compared with only 5.0% of patients treated with placebo. After 48 weeks of treatment, 9.7% of patients taking luspatercept showed a reduction in Liver Iron Concentration (LIC) from >3 at baseline to ≤3 mg/g dry weight, compared with only 5.9% of patients treated with placebo. Also after 48 weeks of treatment, 20% of patients taking luspatercept showed an improvement in cardiac iron T2* from ≤ 20 ms at baseline to > 20 ms, compared with only 9.1% of patients treated with placebo. No significant difference in iron chelation therapy was observed between luspatercept- and placebo-treated patients during the first 48 weeks of the study. However, the proportion of patients taking 1 or more iron chelation medications gradually declined in luspatercept-treated patients relative to patients taking placebo over longer time periods. Luspatercept-treated patients also experienced a gradual decrease in mean daily dose of deferasirox over time. In summary, a higher percentage of luspatercept-treated patients compared to placebo-treated patients experienced reductions in serum ferritin levels, Liver Iron Concentration, and cardiac iron levels in the first 48 weeks of the BELIEVE Study. This suggests that luspatercept-treated patients may be at lower risk of the complications associated with iron overload. Long-term luspatercept treatment also led to decreasing trends of iron chelation therapy use and deferasirox dosage.

Read More at - https://www.thalassemia.org/boduw/wp-content/uploads/2021/09/LifeLine-Newsletter-Summer2021.pdf

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

Clinical Trials of Gene Editing in Transfusion-Dependent Beta Thalassemia

b. 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

c. 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

Clinical Trials for Patients with Non-Transfusion-Dependent Thalassemia

d. 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

e. 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

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

https://www.thalassemia.org/clinical-trial-updates/

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Email - 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!

For Donation – Contact office or scan below QR code

SCAN & PAY

UPI ID: thalsoc@ucobank

BHIM UPI

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.


THALASSEMIA SOCIETY PUNE CHAPTER
TSPC
TSPC NEWSLETTER 2021
Registration No. 2057/2014