

Thalassemia Society Pune Chapter.

Registration No: 2057/2014

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Our society The Thalassemia Society Pune Chapter (TSPC) was founded by patients, parents of Thalassemia Major a genetic disorder, along with Dr Nita Munshi (President-TSPC). The foundation provides hope, comfort and encouragement to those battling this disorder. We are working on care of Thalassemics, their Chelation, Blood Transfusion, BMT, Awareness and Prevention drives in Thalassemia Major.

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.

Thalassemia Major is a genetic disorder in which a person needs Blood Transfusions in every 2-3 weeks from the age since they are diagnosed as a Thalassemic Major. Due to rapid Blood Transfusions, the iron level in the body rises gradually and to reduce this level, they need to take medication (chelation). Injections and oral medicines which are iron chelating drugs are available, these drugs reduce the overloaded iron level in body. There is no cure to thalassemia as of date. The only cure is Bone Marrow Transplant, but that has its own limitations apart from the cost constants- it costs Rs 15-20Lacs.

Can you imagine a 2 yr kid taking blood transfusions, injections, and tablets just to enjoy a near normal life? This causes a lot of financial as well as emotional burden on the family. An ideal treatment plan costs Rs10,000/- per month. The fact is these children can grow up as normal kids a lead a long life provided they get the right treatment.

Our GOAL is to achieve ZERO New Thalassemia Births in Pune. "Our aim is Prevention of Thalassemia and the people in society should be educated about it". Thalassemia Major is one such condition about which people are not so aware and we can prevent new Thalassemic births by making people aware and spreading the word.

Below reports covered the work for betterment of thalassemia patients as well as the events attended and organized by TSPC.

- 1. International Thalassemia Day, 8th May 2018-** On the occasion of International Thalassemia Day, TSPC had organized a musical event- "Unchained melodies" presented by DOCS- Doctor's orchestra for Charity and Social Service. DOCS is a team of 18-20 doctors who are passionate about singing and music and are professionally involved into this since past 20 years, they play orchestra and sing for social causes. 8th evening was made beautiful by their melodies voice and music. 🎵😊!
Around 300+ people were a part of that evening. #Jackie_shroff sir once again was with TSPC and he spoke to the audience about thal awareness. Patients and parents enjoyed the evening completely and we all were mesmerized with the beautiful old melodies 🎵❤️!



2. TSPC Participation in Mumbai 2nd June 2018.

5th Dinner Symposium (by Dr M.B.Agarwal) at ITC Grand, Mumbai. Attended by committee members and Dr Nita Munshi (President) of TSPC. The program was informative and fruitful.

Many doctors including Dr Nita Munshi, Dr Antonio Piga (Haematologist, Italy), Dr Sanjeevan Sharma, Dr Amita Mahajan, Dr JS Arora were a part of the program.

It began with introductory session of all the guests followed by a mind-blowing session presented by Dr Ravi Dhanani (PhD in Thalassemia) on the topic Rajkot- An example of community control of Thalassemia. Dr Ravi has done a wonderful work for Thalassemia in Rajkot, Gujarat. He himself being a Thalassemic major took an initiative for working for the betterment and improving the lives of rest of the Thalassemics in Rajkot. He and his team is working selflessly for the treatment, education and growth & development for Thalassemics there. Also Dr Ravi and his team has taken an initiative for creating Thalassemia awareness in Rajkot by spreading the word in local places (schools, colleges, parks, etc). Their hard work is being paid off, no Thalassemic child is born since a couple of years in Rajkot. Truly Dr Ravi Dhanani is a great inspiration.

The program was then followed by the next session presented by Dr Antonio Piga (Haematologist, Italy). He explained very well about different Iron Chelators and its toxicity, the compliance and compatibility of all the three iron Chelators, the way of functioning in Thalassemia Intermediate and Thalassemia Major, markers for monitoring iron overload. The session was then followed by various questions coming from patients and parents. Questions on Wheatgrass, thalidomide, hydroxyurea, Iron Chelators, Iron chelating substances, on increasing hemoglobin levels, diet for thals.

Overall the session was informative and interactive, the take away message for all thals was Keep Chelating regularly, do not worry as life is a balance between risks and benefits. Trust yourself and your doctor.



3. TSPC Participation in FIAT EVENT 13th July 2018

FIAT has taken an initiative to help for the cause of Thalassemia. They have been of a great help to us since past 2 years. These people are helping Thalassemic kids through their CSR funds and have been organizing blood donation camps on regular intervals with majority of their employees donating blood each time. Thalassemia society of Pune Chapter with other Thalassemic kids were invited. It's completely a blessing to see people who really know the importance of donating blood and are voluntarily & happily contributing a little to save lives and giving smiles.

Overview of program: Kids were provided with refreshments followed by a talk from Jatin Sejpal, who spoke about importance of blood donation and Thalassemia awareness, Dr Midha, Dr Kulkarni were other speakers who spoke about the work they have been doing for the cause of Thalassemia.

#Thank_You_FIAT..😊! #Keep_spreading_Hope_And_Sharing_Happiness..😊!
#We_are_Grateful_to_You..😊!



4. TSPC President felicitation

A big shout-out for our dear Dr. Nita Munshi- president of Thalassaemia Society Pune Chapter.

Recently she was felicitated by Mr Maulik for all the good work she has been doing in pune for the cause of Thalassaemia through TSPC..😊



5. Thalassaemia Awareness drive 14'Oct 2018- Sunday

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. Every time there was a red light, We 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👍". We ended our drive at 11am. Indeed it was a Happy Sunday for such an Awareness Drive! With the same spirit and determination, we'll be doing many more awareness campaign. #Thalassaemia Awareness #Talk_About_It

#It_is_not_A_Taboo #Team #TSPC #Thal_Free_Pune_by_2020👏😊

A big Thank You to Local traffic police for permission and cooperation.😊 Looking forward towards Thalassaemia Free India👏😊!



6. Thalassemia Awareness drive 17 Nov, 2018.

Thalassemia Society Pune Chapter (TSPC) did an 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..🙌!



7. TSPC Participation in Delhi on 24th and 25th Nov' 2018

9th National Thalassemia conference was held at Delhi on 24th and 25th of Nov' 2018. Our committee members Mr Jatin Sejpal and Ms Priya Vaswani attended the conference.

The discussion in conference covered the topics like Transfusion reaction, Iron overload problems, iron chelation and its dosage, growth monitoring, endocrine complications, Roles of NGO and organizations for working for thalassemia, how can thalassemia be prevented, role of social networking in prevention and help for thalassemia welfare, Puberty in thalasseemics, and healthcare in future aspects. We now see that many Thalasseemics are getting married this is like a hope to many, and another good news is Thalassemic majors can also go for planning a baby and become parents.

We met many people (patients and parents) who came from different parts of India for conference.
It was indeed an informative conference.
Thanks and Good job #NTWS for organizing this great meeting.
#Delhi #9th_NTC #Thalassemia #it_is_preventable 😊



8. Thalassemia Awareness drive 10th December, 2018.

Symbiosis institute of information technology had organised 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, its types, how it is transmitted, how it is managed and lastly why its 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!

#Its_Not_A_taboo #Talk_About_it

#Get_Yourself_Tested_before_Marriage #Spread_the_word

#Looking_Forward_for_Thalassemia_Free_India..👍😊



9. Christmas party 20th Dec for Thalassemic Kids

Christmas party was held at The Ladies Club on 20th Dec. All the kids enjoyed watching the magic show, puppet show. Kids had fun by dancing on the beat of music, and had joy munching the delicacies. It's always lovely to see kids happy and smiling 😊:) 🍷🥰



10. Thalassemia Awareness drive SRPF 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 thal 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 thal free India.

Thalassemia awareness session in SRPF, and on that day even our Ambassador Mr. Jackie Shroff took out time for police officers.



11. TSPC Disability Certificate Seminar 27th anuary,2019-

Thalassemia 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 Majhethia 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.

Special thanks to Shyam, Vijay, Gaurav, Amol, Priya, Surendra, Dipesh, Sahil, Nilesh, Dr Munshi, Nayana Madam, Asha, Harshala and all volunteers for the successful execution.

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.

TSPC appreciate the help of Sassoon Hospital and staff members for Disability Certificates for Thalassemia Children.



12. Annual Medical Test with concession

Dr Munshi (President – TSPC and Director Laboratory, Ruby Hall Clinic) has assisted in Ruby Hall clinic & TSPC in doing Annual medical tests for patients at 50 % concession, 25 % of cost bear by TSPC so just 25% cost to patients.

13. Funds for BMT

Arranging Funds and Help for Patients and parents for BMT through collaboration with Ruby Hall Medical Social Worker Department and others. Mrs. Majethiya, our patron is helping in this through her Mumbai experience.

14. Blood Filters in Concession rate

Leucocyte Blood Filters to remove white Blood cells are provided to patients at the nominal cost of Rs. 700 which costs mrp 2700 by collaborating with Thalassemic India, Delhi.

15. TSPC Support to Thalassemia Patients for Chelation

TSPC Support Thalassemia patients for chelation (Iron removal) for patients who requires financial support to follow appropriate treatment protocol.

16. WebSite - <http://thalassemiapune.co.in/>

TSPC maintain their own website where all the details regarding the program and current updates are shared which can be used by various thalassemia members.

17. Future Goals.

We are planning to have seminars and workshops for Pune patients and parents in every quarter. We will have discussion on curing thalassemia along with some gifts and medical kit distribution through get together events. We are having regular interactions with Corporates to help us with their CSIR budgets. We are also planning to have medical workshops for all the doctors and blood banks for thalassemia awareness. We also have a thought of organizing thalassemia screening programs in colleges and companies and work to our level best for the welfare of the patients.