

Thalassemia Society Pune Chapter.

Registration No: 2057/2014

Row House No. C-9, Silver Orchards, Sr. No. 127/175, Wakad, Pune-411057

Our society (TSPC) is formed by Patients and Parents of Thalassemia Major, a genetic disorder, along with Dr Nita Munshi (President-TSPC). We are working on care of Thalassemics, their Chelation, Blood Transfusion, BMT, Awareness and Prevention drives in Thalassemia Major.

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.

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.

Our GOAL is to achieve ZERO New Thalassemia Births in Pune.

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

1. International Thalassemia Day, 2017: TSPC had organize an entertainment program and party for all Thalassemic kids and their patients on 6 may 2017 at Boat club, Pune on the occasion of World Thalassemia day. The event was a true success, 260+ count of the people attended the event. Mrs Dhariwal and few more people were invited as our chief guest. The kids enjoyed to the fullest and participated actively in the program. It's happy to see that our kids are so very much talented. We have super dancing stars, we have little singers and few more wonderful kids who are a real magic as they sang the complete Sanskrit mantras and bhajans and one of them were Ganaraya.. 😊. The event included Orchestra music, dances, songs, magic show, games. The event was then followed by dinner and lastly we waved goodbyes to the kids by giving them gifts.

#Wonderful_event_it_was. 🎉👏😊..#Spreading_Happiness..

😊.#Sharing_Smiles



Our committee member Mr. Nilesh Shah giving a gift to a kid.



Our Thalassaemic Parents and Kids participating in Event.

- 2. CME on Thalassaemia:** TSPC in collaboration with Ruby hall had organized a CME on Thalassaemia for the Doctors, Nurses and other medical related people on 7th may, 2017 at Ruby Hall. It was a knowledgeable session attended by youth patients and parents listening and knowing about advance treatment and updates on Thalassaemia

regarding various aspects for a better life. All the doctors presenting their topic explained very well about the management of Thalassemia, treatment, bone marrow transplant, the importance of prenatal testing and novel therapies. All the sessions were very informative. After the doctor's sessions, Ms Priya Vaswani - Thal major presented our views as a patient's representative and Mr Surendra Sitani spoke & presented all the parents of Thal kids. The program was followed by lunch.. 😊!
#World_thalassemia_day #CME #Thalassemia_management#Zero_thalassaemia_by_2020...



TSPC President Dr Nita Munshi talk in session



TSPC Team and Ruby Hall Team in session



3. Medical Conference on Thalassemia, Mumbai: on Thalassemia in Tata Memorial Rotary club of Mumbai, Dist-3142 in collaboration with Dr M.B.Agarwal and YTA Mumbai had organize a Medical Conference on Thalassemia for thalasseemics patients on 11th June, 2017. Patients from almost all parts of India made it to the conference. Members from Thalassemia society of Pune Chapter (TSPC) including Youth Thalassemics (YTA) of Pune also attended this Conference.

Topics from food diet for Thalassemics to Pre implantation genetic diagnosis were very well explained by many reputed doctors of Mumbai, these sessions were then followed by Panel discussion of doctors and Open forum. All the queries and questions of patients and parents were beautifully answered in an easy language. The event was great and very informative. #Thank_You_Rotarians_Of_Mumbai , #Big_Thanks_To_Dr_Agarwal ,#ThankYou_YTA !



TSPC and YTA Pune team at Mumbai Medical Conference on Thalassemia.

4. TSPC visit to FIAT: TSPC team was invited by FIAT on 4th July, 2017 in FIAT Company, Rajangaon, Pune for a blood donation drive. Few of the TSPC members made it to FIAT, and actively participated in their entire event. TSPC team also spoke on the importance of blood donation and thalassemia awareness and prevention. 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. 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. Around 70 units of blood was donated, later the kids were sent for lunch and then they all were given some gifts at the time they were waved bye with a smile.

#Thank_You_FIAT.. 😊!

#Keep_spreading_Hope_And_Sharing_Happiness.. 😊!

#We_are_Grateful_to_You.. 😊!



TSPC and YTA Pune team with patients and parents participating in FIAT.

5. Thalassemia Conference, Pune: Thalassemia Society of Pune Chapter had organized a conference on Basic Management of Thalassemia on 22nd July, 2017 at Ruby Hall. Dr. M.B.Agarwal who is India's Top Most hematologist for Thalassemia was invited to give a talk and update all the patients and parents about proper and basic management of health. It was really great for the entire TSPC team to have Dr. M.B.Agarwal with us.


Regd.No.: 2057 / 2014

Thalassemia Society Pune Chapter



Dr. Neeta Munshi
President, TSPC

Golden Opportunity!!!



Dr. M.B.Agarwal
Haematologist

India's acclaimed and well known Haematologist
Dr. M.B.Agarwal(Mumbai)
to guide thalassemia patients about treatment protocols and address their queries and concerns.
Also talk by nutritionist and counselor.

Program is arranged for parents and patients above 10 yrs age.

* Registration is free but Pre-registration is compulsory *

Venue : Ruby Hall Clinic, Cancer Building Auditorium, Pune.
Date and Time : 22nd July, Saturday, 9.00 a.m. to 1 p.m.

: CONTACT :

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<http://thalassemiapune.co.in/>



TSPC and YTA members with Dr. Nita Munshi and Dr. M. B. Agarwal.

6. Thalassemia Conference, Mumbai: Thalassemia Society of Pune Chapter had attended a conference in Grand ITC Hotel on 16 Dec 2017. Topics such as diet, growth, maintenance of health, puberty and pregnancy of thal major woman were discussed. Oleptis/jadenu - new chelator in the market was discussed by Dr Agarwal. Discussion of several such topics was followed by an open forum session and later interactions between patients. The conference was very informative, and exchange of ideas, experiences and knowledge took place! Take Home Message of this conference was: to maintain Hb of a thal child up to 10, ferritin up to 1000 and also to regular monitor his/her growth...



TSPC and YTA Pune members with Dr. M. B. Agarwal and YTA Mumbai Sangeeta and Team

7. Pune conference at DMH on "An Update In Thalassemia"

Event was organized on 31 March 2018, it was really great for TSPC to have Dr M.B. Agarwal for the conference. The discussion done was basically on types of Thalassemia, Ferritin level and Hb level, blood reactions, chelators, Hormones, BMT, Gene therapy and importance of diet and exercise.. 🙌🙌😄😄! Oleptis the all new chelator in market was also discussed on the basis of its compliance and efficiency!

#An_Informative_Event_Organised_by_Tspc_in_collaboration_with_DMH
#ThankYou_Dr_Agarwal_For_Partnering





DMH Doctors , Dr Agarwal and TSPC Pune 31 March 2018

Future Goals.

We are planning to have seminars and workshops for Pune patients and parents in every quarter and help in discounted annual tests from TSPC. 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, Gynecologists 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. These Drives will help in ZERO new Thalassemic children by 2020.