A summary of some of the activities of Thalassemics India in 2017 (Jan – Dec)

• Services Rendered to Thalassemia patients:
Thalassemics India rendered help and support to Thalassemia societies and parents in more than 23 States in India providing them with chelation drugs, infusion pumps, filters, needles at extremely subsidized rates. We have also helped over 200 thalassemics by providing them medicines, filters, and pumps free of cost.

• NGO Refresher Training Programme:
Thalassemics India took part in the “NGO Refresher Training – Thalassemia” programme held at the S.P.Jain Institute of Management & Research, Mumbai on 28th & 29th April, 2017. 14 representatives from the different Thalassemia NGO’s from across the country participated in this unique programme. This workshop gave an opportunity to learn and to share the best practices and to learn from each other how to work best in the care and control of Thalassemia. Mrs. Shobha Tuli and Mrs Gagan attended this from Thalassemics India.

• Seminar on Thalassemia:
A thalassemia awareness seminar was organized by Rotary District 3011 on 29th April at India Habitat Centre, New Delhi. Thalassemics India was represented by Dr. V.K.Khanna, Mrs Shobha Tuli, Mr. Ashvini Malik & Ms. Nishtha Madan. Presentations were given by Dr. V.K.Khanna on “Thalassemia – The Medical Aspects”. Shobha Tuli talked about the future “Thalassemia Control Progamme” and Nishtha Madan gave a brief about her
Thalassemia journey sensitising the Rotarians about the practical problems faced by thalassemics.

- **Sunday Clinic at the Thalassemics India office with Dr. Khanna and the “Help Committee”:**

  Help Committee, comprising of Rita Jain and Rekha Arora, held a clinic at Thalassemics India’s Nizamuddin office on 30\textsuperscript{th} July and 27\textsuperscript{th} August. Dr V K Khanna clinically examined the patients and advised them on better management and treatment protocol. Thalassemics India invited 8 patients from Hindu Rao Hospital and 6 patients from St Stephen’s hospital. These children are receiving free medical support from Thalassemics India.
An Evening with Kutle Khan- Fund Raising Event:

Thalassemics India organised a fund raiser musical evening with the famous Maestro of Kartal and Sufi and Rajasthani Folk Fusion artist- Kutle Khan, on 6th May at Orana Resorts, New Delhi. The Chief Guests at the function were the well-known Kuchipudi dance performers Dr. Raja Reddy, a Padma Shri & Padma Bhushan awardee, and his wife Radha Reddy.

The evening compered by Nehal Dhingra, started with the lamp lighting & Saraswati Vandana, sung by Shivangi Amrit. Nishtha Madan spoke about the issues and concerns of thalassemics at different points of time. Mr. Deepak Chopra, the President of Thalassemics India, welcomed the chief guests, the invited faculty, the guests and the artists, doctors, nurses, blood banks, supporters & Thalassemics were felicitated for their outstanding work and support for thalassemia patients.

The proceeds from this fund raiser were used towards supporting the treatment of underprivileged thalassemia patients.

We, at Thalassemics India, would like to thank the Orana Hotels and Resorts for their support for this fund-raising evening.
National Thala Meet in Gujarat:

Thalassemia Society of Gujarat organized a thalassemia guidance program called “National Thala Meet” for the children and parents of 11 states of India, in Ahmedabad Gujarat, on 28th May, 2017. Dr V K Khanna was invited to give a talk on Thalassemia and Mrs Shobha Tuli was invited as the Guest of Honour for the occasion.
• **Blood Donation Camp and talk at WHO office on 14th June:**

A blood donation camp was organized at the WHO office in Delhi, in collaboration with the Indian Red Cross Society and Thalassemics India. Viresh Piplani, Umesh Nagpal, Aastha Chhabra, Mohit Sharma, Vaishnavi, Gaurav and Gagan attended this camp. Viresh and Aastha gave a short talk on what is Thalassemia and how it can be prevented, and the importance of blood donation was emphasized. They collected close to 100 units of blood.

• **"Thalassemia" - A live discussion program on Delhi Doordarshan:**

An interview with some doctors and patient and parent members of Thalassemics India was held at the Delhi Doordarshan studio. The subject of discussion was
treatment and awareness about Thalassemia. This program has been telecast multiple times. First one was on 28th August 2107, from 4.30 pm to 5.30pm.

- **Thalassemia Update, organized by Mumbai Hematology Group, headed by Dr M B Agarwal, on Saturday, 9th September, Hotel Taj Mahal Palace, Mumbai:** Attended by Mrs Shobha Tuli, Mrs Gagandeep, Mr Ashvini Malik. This was a well-organized half day workshop where topics discussed were BMT, MRI T2*, Bone health and exercise in Thalassemia among many others. Mr Jackie Shroff came in as a special guest and spent some time with the patients and parents and promised to spread awareness about Thalassemia. For more photos go to our facebook page.
• Launch of the PAG (Patients Advocacy Group) and a Seminar on the Policy Interventions for the Evolving Needs of Thalassemics in India, on 16th September 2017, at Tamarind, India Habitat Centre, Lodhi Road, New Delhi:

It was a well-attended program by senior government officials from the state and central government, patients, and parents from all over north India. The chief guest was Mr Manish Sisodia, Dy Chief Minister of Delhi.

A group of 7 Adult Thalassemics announced the formation of the Patient Advocacy Group, under the banner of Thalassemics India, where this patient body will represent the concerns and issues of all the patients in the government and work towards a solution with the government support.
• 40 Students of BSc. Hons Zoology from Hansraj College, studying Immunology & Genetics, visited Indian Red Cross Society Blood Bank on 16th October:

Dr Neelam Gandhi, Associate Professor, Hansraj College, Delhi University, brings a team of student every year to introduce them to the different aspects of Thalassemia. In 2016 it was transfusion and this year it was the blood bank.

• 16th TIF International Conference for Patients & Parents, 17 – 19 November, 2017, Thessaloniki, Greece:
Thalassemics India was well represented by Shobha Tuli, Gagandeep Singh, Anubha Taneja, Hemant Bellani, Viresh Piplani, Shivangi Amrit, Nehal Dhingra and Anuj Wadhera. Anubha Taneja’s talk was part of the opening ceremony and was very well received by all. There was also a stall of Thalassemics India which had information material on Thalassemia and other literature printed and published by Thalassemics India. This conference saw a large representation of patients and parents from all over India.

The conference spoke about the newer drugs and their stages of research..among many other newer protocols in management of Thalassemia.

We are happy to announce that Mrs. Shobha Tuli, Secretary, Thalassemics India has been re-elected Vice President of Thalassaemia International Federation.
• **Photographic Exhibition held on 25th and 26th November, 2017:**

An initiative of Tina Basuray from The Wishing Factory: "Smiles Despite Everything", a one of its kind photographic exhibition on the life of Thalassemic Children. Mrs Shobha Tuli was invited to inaugurate the Exhibition and Dr V K Khanna was invited to give a talk on Thalassemia.

• **AGM of Thalassemics India, held on 3rd December at the Constitution Club, New Delhi:**

Thalassemics India AGM was held on December 3rd. Over 100 Thalassemia patients and families well attended it. Mr. Deepak Chopra, President Thalassemics India, gave a welcome speech for all the members, after which Mrs Shobha Tuli, Secretary Thalassemics India gave the report on year gone by. Then Dr.V K Khanna shared information about the new oral Chelator by Novartis: Oleptiss. The society’s accounts were shared with all and open discussion on many concerns of thalassemia patients. The meeting ended with a lunch.
• **Meeting with Jackie Shroff, 8\textsuperscript{th} December:**

Shobha Tuli, Ashvini Malik, Deepak Dhingra, Vinita Srivastava and Gagandeep Singh met with Jackie Shroff to take on Thalassemia Awareness as a project.

• **Thalassemia Update, organized by Mumbai Hematology Group, headed by Dr M B Agarwal, on Saturday 16\textsuperscript{th} December, at ITC Grand Central, Mumbai:**

The second in the series of Thalassemia Update workshops. Dr Agarwal’s effort was to bring, in simple language, for the patients and parents the latest in the management of Thalassemia and help patients to share their concerns and have them resolved. Mrs Gagan attended the workshop.
Dr Smita Koppikar (Endocrinologist) Mr Anil Shah (Parent) Ms Sangeeta Wadhwa (Patient) Dr Ameet Mandot (Hepatologist)

Dr M B Agarwal (Hematologist) Dr Piyush Desai (Diabetologist) Dr Bhakti Samant (Chief Dietician) Ms Gagandeep Singh (Thalassemics India)
• For the year 2017, Thalassemics India has been able to provide partial support to 4 thalassemia patients for their BMT procedure.

• Under the Coal India Limited and the Ministry of Health and Family Welfare, Govt. Of India Project of BMT Support, more than 55 Thalassemia patients’ applications have been approved by the Ministry for financial support for their procedure. Thalassemics India is humbled to be the coordinator for this project.

• A new film on Thalassemia, management, awareness, and prevention has been made for public awareness. Thanks to all the partners who gave their time and support.

• Representatives from Thalassemics India have been meeting up with officials from the Ministry of Health, Govt. of NCT of Delhi, the Ministry of Health & Family Welfare, Govt. of India, the Ministry of Tribal Affairs, Govt. of India and the Ministry of Social Justice and Empowerment, Govt. of India.