

SECRETARY'S REPORT
(1st April, 2016– 31st March, 2017)

**To the Annual General Body Meeting of Thalasseemics India
held on December 3rd, 2017 at the Constitution Club of India, New Delhi.**

Dear Friends,

On behalf of Thalasseemics India, it is my privilege to present to you the Annual report for 2016, which provides a summary of all major activities that our society has undertaken in the course of this year. Through this report, our framework, funding, composition, focus and our hopes will be unraveled in front of you.

Governance and membership

- Thalasseemics India's office is at A-9, Nizamuddin West, New Delhi. The team comprises of 12 executive members(all volunteers) & 9 persons as full and part time paid staff. TI is has a medical advisory committee of 16 members from India, Italy, U.K., Thailand, Lebanon & U.S.A.
- Thalasseemics India has 80G and FCRA .
- Thalasseemics India welcomes 113 new members from 23 States of India.

Associations

- Being the voting member of TIF, Thalasseemics India continued to work closely with TIF for their Indian project " Charter of Priorities".
- Attended the TIF Board meeting held in Jordan during the course of their thalassemia conference.
- Thalassemia Society Ajmer invited Dr. V.K.Khanna to hold a check-up clinic in Ajmer.
- Dr. V.K.Khanna delivered a lecture on "Quality of life in thalasseemics without BMT" in June at Ahmedabad.
- Dr. V.K.Khanna delivered public awareness lecture on thalassemia, in July at DAV School Pitampura, New Delhi.
- Thalasseemics Gujarat, Ahmedabad invited , Shobha Tuli to their Thalassemia meet as the Guest of Honour.
- Shobha Tuli was invited by Dr. C.B Dangi as one of the speakers in the 'Women Economic Forum'.
- Continuing the services given to Thalassemia families and thalassemia NGO's across the country by giving them Infusion pumps, Infusion needles, filters, chelation drugs at subsidized rates. In this year we catered to more than 23 States across the country (Jammu, Haryana, Punjab, Chandigarh, Himachal Pradesh, Rajasthan, Uttar Pradesh, Utrakhand, Madhya Pradesh, Gujarat, Maharashtra, Odisha, Jharkhand,

Bihar, Chattisgarh, Andhra Pradesh, Karnataka, West Bengal, Kerala, Tamil Nadu, Assam, Nagaland & Delhi).

Education and Awareness raising

- The 6th International Conference on Thalassemia was held with immense success in New Delhi. The conference was held under the Patronage of the Ministry of Health and Family Welfare, Govt of India. in collaboration with TIF, Sir Ganga Ram Hospital and Apollo Hospitals.
- This year's International Thalassemia day had a new theme, aiming to raise awareness and to collect funds for underprivileged thalassemia children. Thalassemics India organised many activities which included : a fund raising evening with the ever so eminent talented composer of Indian classical music, Shubha Mudgal, spots on thalassemia on F.M. channel, Interview on Webner and a talk at Doordharshan. The Delhi Govt. gave advertisements in Hindi and English newspapers to increase awareness of Thalassemia. Press conference was held at our office aiming to spread awareness about important facts regarding thalassemia.
- Invited by Doordharshan to take part in their two live programmes on Thalassemia in June.
- Took part in a 'Walk' on World Blood Donor Day at the India Gate in June.

Publications & Communications

- E –newsletter and Thalassemia Update are sent to all beneficiary members, donors, ngo's and all others who are connected with us. Two issues of Thalassemia Update & an abstract book were published in 2016.
- Social media and communication has gone through dynamic development inviting thalassemics to share updates through Face Book & Twitter.
- Website is updated from time to time with latest information and news.
- A short film on Thalassemia is made for public awareness.

Project and new initiatives

- Under our "Helping Hands" project , Thalassemics India supported the treatment of 200 thalassemics by giving them free of cost Desferal , Asunra, Desirox, Kelfer, Defrijet, Filters & Pumps amounting to Rs.29,67,465.00.
- Arranged financial support for 12 BMT cases by giving Rs.1 lac per patient.
 - "Guidelines on Hemoglobinopathies in India" is released by the Ministry of Health and Family Welfare, Govt. of India. Out of the 26 contributors, two of the contributors are from Thalassemics India.

- Thalasseemics India has been assigned an important role on the HSCT project started by the Coal India Ltd and the Mo HFW, Govt. of India in March, 2017. Thalasseemics India is given the task to coordinate this project as per the role defined by the MoH&FW, Govt. of India.
- Organised a thalasseemia camp at Sir Ganga Ram Hospital in the month of September. 45 Thalasseemics from Delhi, Harayana , Gujarat , Rajasthan & Maharashtra attended this clinic for their check up and counselling . Thanks to Dr. Malcolm Walker (London), Dr. John Porter (London) , Dr. Heba Elsedfy (Egypt) & Dr. V.K.Khanna for giving their time and valuable services.

Meetings

- A number of meetings were held with the Govt. officials at the MoHFW, Govt. of India and Delhi Govt. in the months of May, June (4), July , August, September (4) and November.
- Met the Additional Director, DGHS in August.
- Met the Hon'ble Minister of Social Welfare and Empowerment , Govt. of India in September.
- Had a meeting at IRCS in June to discuss Thalasseemia prevention programme.
- Our "Help Committee" had a meeting in June to discuss new applications.
- AGM was held in November.

Acknowledgement

Firstly, I would like to thank all our donors and sponsors for their generous contributions.

I would like to acknowledge the support given by two companies under "CSR".

Finally, I would like to thank our staff and committee members for their commitment and support.

Shobha Tuli

Secretary , Thalasseemics India