SECRETARY'S REPORT
(1st April, 2015– 31st March, 2016)

To the Annual General Body Meeting of Thalassemics India
Held on November 6th, 2016 at Constitution Club of India, New Delhi.

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Dear Friends,

Our last AGM was held on 15th November ,2015. We are meeting again after almost a year at today's AGM. We have experienced during the year success stories, achievements, various activities and things that are still to be done. We learnt from past disappointments to consider ways to develop and to expand our activities.

Before I present the annual report for the year 2015, I would like to share with you some information on the 2 areas which I feel are very important for an NGO to plan their activities which reflects later the success and struggle of the NGO.

- **Funding pattern:**

1. No fixed grant received from Govt /s or any other official body/ies
2. Funds collected on one to one basis
3. Funds collected against project/s
4. Membership fee
5. Advertisements

- **Composition of the society:**

1. Executive members -13 (all volunteers)
2. Permanent salaried staff – 8
3. Part time – 1 for accounts
4. C.A

Our focus throughout 2015 has been to increase awareness about thalassemia, to help the under privileged thalassemics and to build up partnerships with the Govt. bodies.

Summary of 2015 activities:-

1. "Helping Hands Project" :-

1. Supported the treatment of more than 200 thalassemics **(144+58)** by giving them at no cost chelation drugs, filters, pumps and blood transfusions :
   Filters :2167
   Desferal : 420 boxes
   Asunra : 295 boxes
   Kelfer :- 254 boxes
   Desirox :- 426 boxes

Defrijet :- 38 boxes
Pumps :- 2 pumps
Blood transfusions : 658

2. Catering to thalassemics 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 22 States across the country (Jammu, Haryana, Punjab,Chandigarh, Himachal Pradesh, Uttar Pradesh, Uttrakhand, Madhya Pradesh, Gujarat, Maharashtra, Odisha, Jharkhand, Bihar, Chattisgarh, Andhra Pradesh, Karnataka, West Bengal, Kerala, Tamil Nadu, Assam, Nagaland & Delhi).

3. Supported **14** BMT cases, arranging financial support through another NGO - Rs. 1 lac per patient.

2. Communication:-

1. Through e-newsletters, Thalassemia update(news magazine) letters, emails and social media (face book & twitter).

2. Distribution of material on thalassemia, at no cost to thalassemia families and thalassemia ngos.

3. Collection and dissemination of information about the latest therapies and of the research in progress.

4. Information to members on the activities taking place in and out of the country.

5. Contacted schools & colleges for arranging awareness talks and blood donation camps.

6. Acting as an informative body between thalassemia families and doctors.

7. Letters sent to a number of colonies for collection of funds.

3. Building & strengthening relationships with thalassemia familes:-

1. 100 Thalassemics and their parents were taken to Kingdom of Dreams, Gurgaon for the show 'Jhumroo".
2. Our 10 thalassemics performed on the stage at the Shaimak Summer funk held at Sri fort Auditorium .
3. Fund Raiser event on April 18th, 2015 at Siri fort auditorium Musical Evening with Sonam Kalra & The Sufi Gospel Project. This evening saw an audience of around 350 people.

4. The International Thalassemia day was observed on 8th May at Sri Sathya Sai International Centre.The Chief Guest was Mrs. Maneka Sanjay Gandhi, Union Minister for Women and Child Development. The programme was attended by more than 500

people including doctors, senior sisters, social workers, a number of people from blood banks and thalassemia families.

5 Some of our thalassemics were invited at the blood donation camp held at Nirman Bhawan.

4. Towards Awareness :-

1. Took the initiative to convince the Govt. of NCT of Delhi to release advertisements for public awareness in main dailies newspapers on International Thalassemia Day.
2. Students from Hansraj College visited the Thalassemia Unit of St.Stephen's Hospital .
3. A talk was given on thalassemia at the INDO US Conference - "Realizing the Potential of Rare Disorders in India" held in New Delhi- Shobha Tuli
4. We used the medium of the radio to share messages about thalassemia on May 6th, 7th and 8th.
5. Keeping the momentum going, thalassemia information material was distributed in the monthly meetings of AOGD. Material is also being kept in the clinics of Gynaecologists & Obstetricians throughout the city of Delhi.
6. Additional material in the form of book marks, leaflets, posters and pamphlets on thalassemia awareness is printed for free distribution in hospitals and private clinics.
7. As part of Thalassemics India awareness campaign , Dr. V.K.khanna was invited by Doordarshan for a live chat "Good Evening India".
8. Mrs. Shobha Tuli was Invited by AIR to speak on thalassemia in one of their programmes.
9. Decision was taken to make a small film on thalassemia.
10. A number of letters were sent to Hospitals in Delhi to begin Thalassemia screening.

5. Important meetings:-

1. Attended Novartis's NGO Excellence programme held at SPJIMR ,Mumbai on April, July, October & Dec (4 moduels)-Shobha Tuli , Gagandeep Singh & Anubha Taneja.
2. Meetings with the Health Minister, Govt. of NCT of Delhi
3. Help Committee Meetings held to meet and review 42 thalassemics taking free of cost medical help from Thalassemics India – Rita Jain, Rekha Arora & Poonam Anand.

4. Managed to take 4 thalassemics from India for the TIF conference with the support of TIF.(Sangeeta Wadhwa/Mumbai, Mumtaj Surya/ Tamilnadu, Rahul Balasaria/Kolkata & Viresh Piplani/Delhi.

5. Attended the TIF Board of Directors meeting held in London-Shobha Tuli

6. A no. of meetings were held with Govt. officials at the Ministry of Health and Family welfare, Govt.of India to prepare “Prevention and control of Hemoglobinopathies in India –Thalassemias, Sickle cell Disease and other variant hemoglobins”- Dr.V.K.Khanna & Shobha Tuli

7. A no of meetings took place to prepare for the 6th International Conference on Thalassemia.

8. A no. of meetings were held with the Ministers at Govt of India regarding the disability bill.

6.C.S.R Funding :-

We received a grant under C.S.R to support the treatment of underprivileged thalassemics.

7. Others

1. Blood Donation camps -12

2. AGM

3. Executive committee meetings (9)

4. New members (93)

5. I – Cards (935)

While overlooking the events in my mind that occurred during the year, I can say without bias, that we at Thalassemics India should be satisfied and contended with what we have achieved in 2015.

Finally I would like to thank the staff , my colleagues at Thalassemics India and all the doctors in India and abroad for their commitment and time.

Thanks to each one of you for joining us today.

Shobha Tuli

Secretary