Welcome to our 32nd Annual General Meeting. It is my pleasure & a privilege to present to you Secretary’s report for the period 2018-19. This opportunity will help you to get an insight into the workings of Thalassemics India. The core activities in the year 2018-19 were aimed to consolidate the existing work & to make rapid growth. Having won the confidence of the community including caregivers, donors, policy makers and the work and strength built over the last year brought in more potential partners with different institutions to expand our boundaries of work.

SHOBHA TULI
Secretary, Thalassemics India
GOVERNANCE

• T.I. Executive Board: 14 members, all volunteers dedicated and committed

• T.I. Staff Members
  - Full time - 9
  - Part time – 1

• T.I. Scientific Advisors
  - National - 7
  - International - 9

• T.I. Brand Ambassador- Bollywood Actor Mr. Jackie Shroff

• TPAG: formed in 2017 under the aegis of Thalassemics India by 7 adult thalassemics accomplished in the fields of psychology, law, IT and education.
Thalassemics India is a voting member of TIF since 1992. Ms. Shobha Tuli, Secretary-Thalassemics India, is the elected Vice-president of TIF.
T.I. STAFF MEMBERS

Rashmi Kalra
Office Administrator

Indu Sughal
Co-Ordinator, Bone Marrow Transplant

Sonam Madaan
Head of Communications

Swati Tuteja
Associate

Sangeeta Mittal
Thalassemia Unit Incharge, St. Stephen’s Hospital

Sheela Davis
Thalassemia Unit Incharge, Sir Ganga Ram Hospital

Mahtab Alam
Pharmacist
T.I. SCIENTIFIC ADVISORS

Dr. M.B. Agarwal
Department - Haematology, Bombay Hospital & Medical Research Centre, Mumbai, India

Dr. Nica Cappellini
Department - University of Milan, Italy Policlinico Foundation IRCCS, Milan, Italy

Dr. Mammen Chandy
Department - Tata Medical Centre, Kolkata, India

Dr. Ratna Chatterjee
Department - Reproductive Medicine Unit, University college of London

Dr. Ved Prakash Choudhry
Department - Haematology Fortis Escorts Hospital, Faridabad, India

Dr. Alan R Cohen
Department - Division of Haematology at Children's Hospital of Philadelphia

Dr. Suthat Fucharoen
Department - Thalassemia Research Centre, Mahidol University, Thailand

Dr. (Prof) Sunil Gomber
Department - Paediatrics & Oncology, UCMS and GTB Hospital, Delhi, India

Dr. V.K. Khanna
Department - Paediatrics, Sir Ganga Ram Hospital, New Delhi, India

Dr. Amita Mahajan
Department - Paediatrics & Oncology, Indraprastha Apollo Hospital, New Delhi, India

Dr. Antonio Piga
Department - Clinical and Biological Sciences, University of Torino, Italy

Dr. John Porter
Department of Haematology, University College, London, UK

Dr. Farrukh Shah
Department - Haematology, University College, London, UK

Dr. Ali Taher
Department - Medicine, AUBMC & Chronic Care Centre, Beirut, Lebanon

Dr. I.C. Verma
Department - Institute of Medical Genetics & Genomics, Sir Ganga Ram Hospital, New Delhi, India

Dr. John Malcolm Walker
Department - The Hatter Cardiovascular Institute, London, UK
"Being the Brand Ambassador of Thalassemics India, I urge you to get Yourself Tested for Thalassemia before getting married or planning a family... Thalassemia is a PREVENTABLE Blood Disorder!!

Let’s PREVENT it."

JACKIE SHROFF
OUR WORK

Our past & existing work can be clustered into three major service lines:

CARE  CURE  CONTROL

Having 3 C's in view, Thalassemics India & the team are guided by a few principals:

- Humanity
- Impartiality
- Voluntary service & transparency
This year, we explored the possibilities of having partners to set up new facilities & to strengthen the existing ones.

CSR funds from Infogain, Icreon, NTTD & .......... (cannot disclose their name as per the MOU)

SOME MAJOR INTERVENTIONS ARE

Gave free of cost iron chelation medicines, leukocyte blood filters to those patients who cannot afford the costs.
Assessed the children who are not doing well with their current care & brought them to clinics specially arranged to decide specific treatment plans in consultation with their treating doctors. 4 clinics were held counselled by Dr. V.K Khanna, Dr. Ratna Chatterjee & Dr. Rekha Bajoria.
Taking requests from thalassemia parents/patients from across the country to send them filters, chelation drugs, infusion pumps & needles through courier at subsidized rates. Daily visits to our Nizamuddin office to pick up medicines & equipments are also attended 6 days a week.

Signed an MOU with UCL, UK for an Ultra-fast MRI Project. The first study is complete which was done in Delhi & Jaipur.
Helped in the organisation of blood donation camps.

Counselling thousands of patients & parents visiting our office on a regular basis & through phone calls & mails.
A seminar held on 8th May at IHC was attended by more than 300 delegates. Shri Rajender Pal Gautam, Minister of Social Welfare, Delhi Govt. was the Chief Guest. Guest of Honour Dr. Kirti Bhushan, Ms. Vinita Srivastava & Mr. Jackie Shroff.
An update on Pediatric Hematology seminar was held under the banner of IAP & Apollo Hospitals at Hotel Le Meridien, New Delhi. This meeting was attended by more than 70 doctors from Delhi, Punjab, Gujarat & Tamil Nadu.
HSCT Project under "Thalassemia Bal Sewa Yojna": 203 applications received from different parts of the country. 158 applications got approved by the Expert Screening Committee at MoHFW, Govt. of India. More than 119 transplants are done till now*

Under this project, financial help of Rs. 10 Lacs is given by Coal India Ltd. to each family.

*21.11.2019
Awareness Talks
Walk for Thalassemia
Hoardings & Billboards
Thalassemics India website www.thalassemicsindia.org continues to be updated on a weekly basis with noteworthy information, deriving from T.I.'s day to day work.

**Website's analytics:** 237 visitors per month

**Facebook:** 4,968 friends & we have 2,767 followers on our FB page. We are also connected with people through more than 20 groups.

**Twitter:** 1,193 tweet impressions per month.
UNDER SPREADING SMILES PROJECT

Visit to KOD
22nd June

Agra visit
8th Sept

Movie Time with thalassemics
6th Feb

Christmas & new year celebrations with thalassemia children
OTHER IMPORTANT EVENTS & ACTIVITIES

AGM held on 2nd October at Constitution Club

Fund raising evening organised by NARCHI on 23rd February at Hotel Eros

Attended the SPJIMR workshop held in New Delhi
OTHER IMPORTANT EVENTS & ACTIVITIES

Attended International Workshop held in Bangalore organised by National Health Mission

Internship at T.I. by 3 candidates
MEETINGS / IN ATTENDANCE

- Thalassaemia Meet in Ahmedabad on 21st November as Guest of Honour
- TIF Board Meeting in London on 28th & 29th April
- Gujarat Red Cross on 10th October
- 5th Thalassaemia symposium in Mumbai as Chief Guest on 11th July
- Govt. Thalassemia meetings in Varanasi in July & at Lucknow on HSCT Project on 5th December
- Govt. meetings on RPWD/ Disability Act
- Govt. meetings on National Policy
- Govt meeting on E-Rakth KOSH
- HSCT project meetings under the Chair of Health Secretary, Govt. of India
- Delhi Govt meetings on blood related & other Thalassemia issues
- Meetings with Finance Secretary and other officials on G.S.T
FORTHCOMING PLANS: 2019-20

- To do more Awareness Campaigns
- To start Thalassemia Screening Programme
- To help and counsel more patients
- To make sure that the new technology for T2 MRI is in place at affordable prices
- To put in more efforts to get GST rolled back or to get it reduced to 5%
- To follow up on the existing RPWD Act to get more benefits for Thalassaemics
- To bring in more Corporate Donors
- To hold 7th International Thalassaemia Conference or PAN Asian Conference in Delhi
- To follow up on the National Policy on Hemoglobin disorders which is under review
- To do seminars on Blood availability, safety, management of Thalassemia and BMT
Thanks to the persistent support of T.I. Board members & Thalassemia Patients Advocacy Group (TPAG) whose contribution in their own very unique & special capacities, no task looked difficult to accomplish.

Special thanks to our doctors, hospital authorities, blood banks and nurses for their continued support.

Our scientific advisory board has been very helpful to us.

Thanks to several individuals & organisations for their continued commitment to stand with us to work on 3 C's.

Thanks to the Staff members for handling their job responsibilities speaks volumes about their patience & dedication.