

35th Annual General Meeting

12 February 2023

Secretary's Report 2022





Profile

- Thalassemics India is a non-governmental, non-profit organization established in 1987 with the aim of improving the treatment facilities, to promote community awareness, and to advocate for patients' rights.
- Its registered office is at C1/59, SDA, New Delhi and working office is at A-9, Nizamuddin West, New Delhi, a place given by Indian Red Cross Society, New Delhi under an MOU to TI.
- Through the years, Thalassemics India with its activities and collaborations, at the national, regional and international levels got recognition by State Government, Central Government, Indian Academy of Pediatrics and Thalassaemia International Federation.

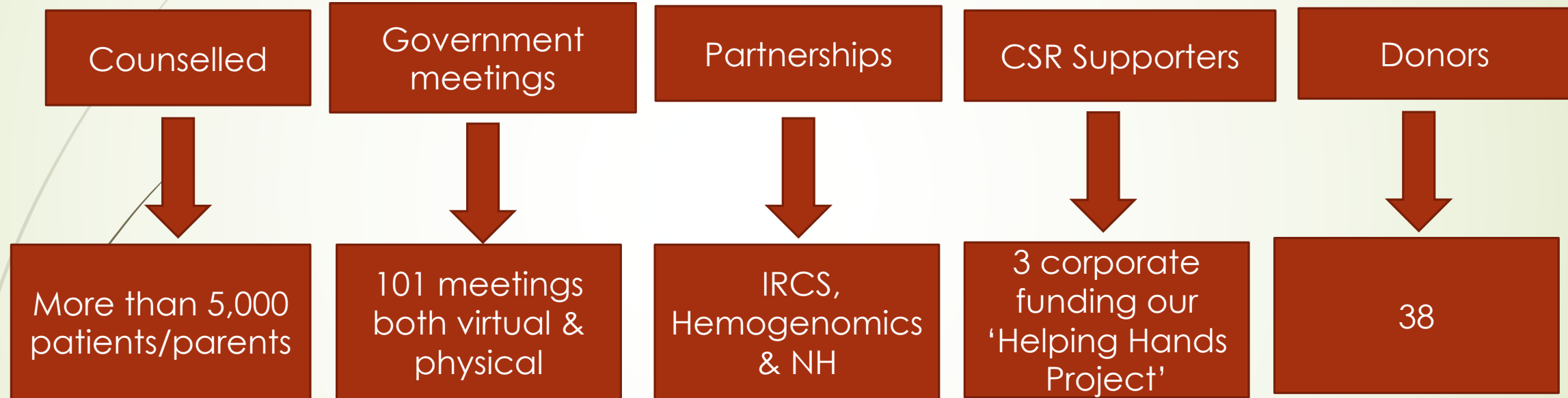
- To prioritise thalassemia on State and Central health agendas for both management and control of thalassemia
- To support the provision of quality health care to all patients with thalassemia and to advocate for a thalassemia-free India



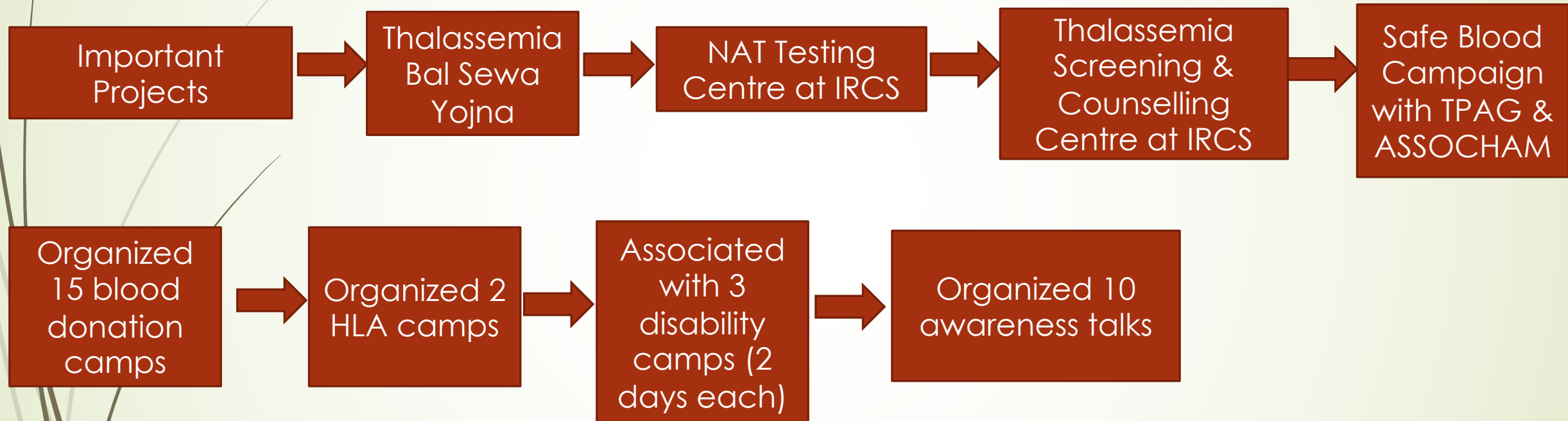
Scope of Work

- Organize and attend meetings, seminars, conferences and other academic symposiums to gain knowledge, share reliable information and experiences
- Strengthen the networking with government authorities and donors
- Procurement & distribution of iron chelation medicines, blood leucocyte filters, infusion pumps & infusion needles
- Conduct regular health checkup camps
- Collect funds
- Set up thalassemia care centres
- Launch new projects
- Connect with thalassemia associations and patients across the country
- Print, arrange and distribute reliable information about thalassemia
- Help in collection of blood
- Spread awareness about thalassemia

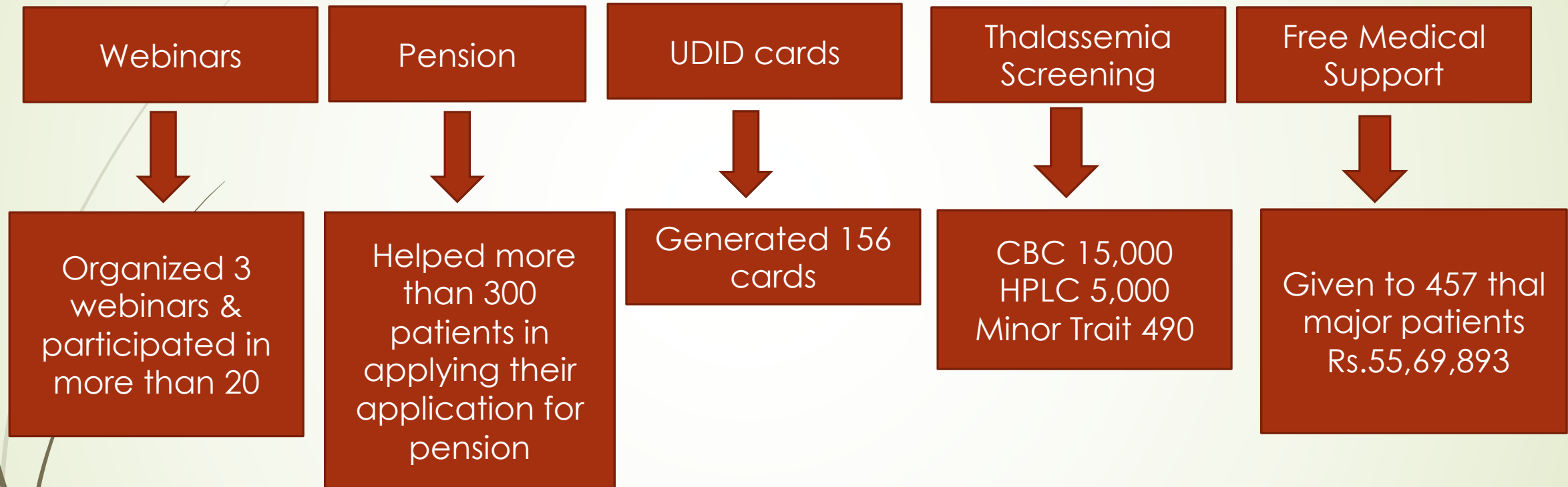
Quick Analytics-2022



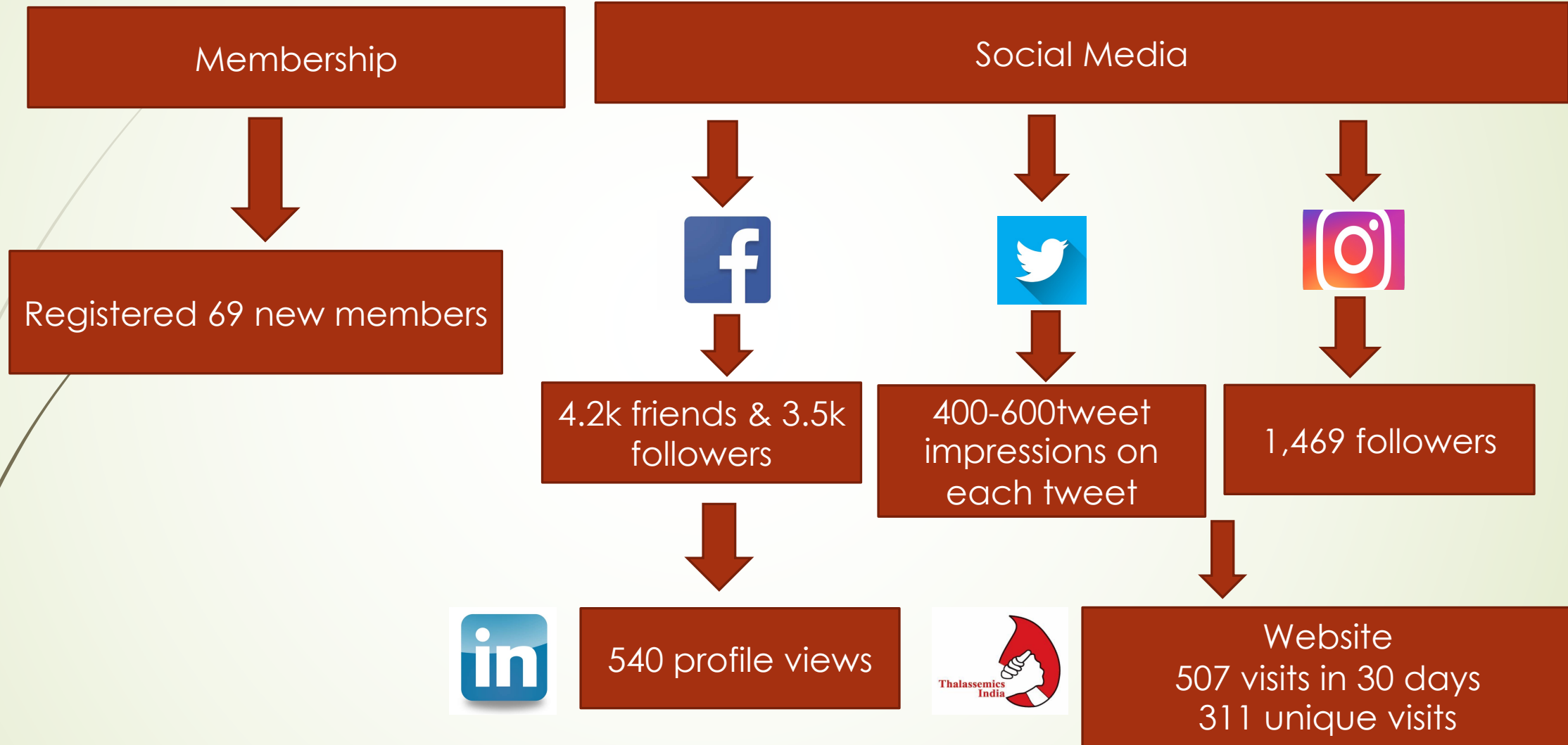
Quick Analytics-2022



Quick Analytics-2022



Quick Analytics-2022



International Thalassemia Day

- Thalasseemics India conducted a seminar in association with TIF & TPAG at Hotel Le Meridien, New Delhi. The seminar on Thalassemia was held with the spirit of “Be Aware, Share, & Care.”
- The event was held in a hybrid mode, attended by 230 participants. Some of the speakers joined virtually and some were present at the venue.





Thalassemia Bal Sewa Yojna

**Coal India Ltd CSR project
under the auspices of The
Ministry of Health and
Family Welfare, Govt. of
India.**



**139 Bone Marrow Transplants
done in the 1st phase.**

**187 Bone Marrow Transplants done in the
2nd phase.**

Thalassemia
154


Aplastic Anaemia
25

MUD
8




**For more information contact, Thalassemics India-the
appointed coordination body.**

Thalassemics India

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thalcind@yahoo.co.in
www.thalassemicsindia.org


AOGD Genetic & Fetal Medicine Subcommittee
 &
State Blood Cell, Delhi
PREVENTION OF THALASSEMIA & HEMOGLOBINOPATHIES
12th October, 2022 | 6:30 - 8:30 PM
Experts: Dr Ratna Puri, Dr Vandana Chadha
Organizing Chairpersons: Dr Seema Thakur, Dr Sangeeta Gupta
Chief Guest: Mrs Vinita Srivastava
Guests of Honor: Dr Asmita Rathore, Ms Shobha Tuli

Time	Topic	Speaker
6:30 - 6:35 PM	Welcome Address	Dr Sangeeta Gupta
6:35 - 6:40 PM	Inaugural Speech	Dr Asmita Rathore
6:40 - 6:45 PM	Inaugural Speech	Ms Shobha Tuli
6:45 - 6:50 PM	Address By Chief Guest	Mrs Vinita Srivastava
6:50 - 6:55 PM	State Blood Cell Initiative	Dr Seema Kapoor
Chairpersons: Dr Seema Kapoor, Dr Poonam Tara, Dr Upma Saxena		
6:50 - 7:05 PM	Which Screening Test to Use?	Dr Manisha Kumar
7:05 - 7:20 PM	How to Interpret HPLC?	Dr Ranjana Mishra
7:20 - 7:35 PM	Counselling for Thalassemia	Dr Seema Thakur
7:35 - 8:15 PM	Panel Discussion: Prenatal Diagnosis: Thalassemia & Hemoglobinopathies Panelists: Dr Sunita Bijaria, Dr Renu Arora, Dr Sumitra Bacarani, Dr Anubhuti Rana, Dr Jaya	Moderators: Dr Sangeeta Gupta Dr Reema Bhatt
Vote of Thanks		



 PRESENTS
Luspatercept
 in TDT and NTD
11th December 2022 | 3.00 pm - 4.30 pm

Webinar Agenda	
Chairpersons:	Dr. V.K. Khanna, Dr. Mamta Mangani, Dr. Tulika Seth
3.00 pm - 3.10 pm	Welcome and Introduction note - TI
3.10 pm - 3.30 pm	The Global Perspective - Dr. A Piga
3.30 pm - 3.45 pm	Practical considerations - Dr. Amita Mahajan
3.45 pm - 3.55 pm	Patients perspective - Dr. Namitha A Kumar
3.55 pm - 4.15 pm	Discussions & Questions/Answers
4.15 pm - 4.25 pm	Concluding remarks - Dr. Sunil Bhatt
4.25 pm - 4.30 pm	Vote of Thanks - TI

Register Now




Webinar on
Prevention Of Thalassemia- Challenges And Achievements
Saturday 26th February 2022 | 12.30 pm - 2.00 pm

 Dr. Nutan Mundaje Director General, Directorate General of Health Services, Govt. of NCT of Delhi and State Program Officer, Delhi State Health Mission	 Dr. S. Shantha Kumari President 2021-2022 Honorary Treasurer 2021-2022	 Dr. Androulla Eleftheriou Executive Director Thalassemia International Federation	 Ms. Vinita Srivastava Advisor Health Ministry of Tribal Affairs, Govt. of India
 Dr. Seema Kapoor Medical Officer State Blood Cell, Govt. of NCT of Delhi	 Dr. Tulika Seth Professor Haematology IIMB, New Delhi	 Prof. Maitreyee Bhattacharyya Professor & Director Institute of Haematology & Transfusion Medicine, Kolkata	 Dr. Reema Das Professor and Head of Department Haematology at the Postgraduate Institute of Medical Education and Research, Chandigarh
 Dr. Anil Khatri Consultant Pediatrician with Special Interest in Hemoglobinopathies	 Dr. Praveen Sobti Medical Director Guru Teg Bahadur Singh Hospital, Lucknow	 Prof. Achla Batra President, AGO VMMC & Safdarjung Hospital, New Delhi	 Dr. Reema Dua Puri Professor and Chairperson Institute of Medical Genetics and Research, Dr Bhanu Ram Hospital, New Delhi
 Dr. V.K. Khanna Chairperson Department of Pediatrics Dr Bhanu Ram Hospital, New Delhi New President Thalassemias India	 Dr. Amita Mahajan Sr. Consultant Pediatric Hematology & Oncology Indraprastha Apollo Hospital, New Delhi	 Mr. Deepak Chopra President Thalassemias India	 Mrs. Shobha Tuli Secretary Thalassemias India

WEBINAR
12 JUNE
THALASSAEMIA INTERNATIONAL FEDERATION

ADVANCES IN THE CARE & CURE OF THALASSAEMIA "NEW HOPE AND CHALLENGES"
 18:30 - 20:30 INDIA TIME
 15:00 - 17:00 CET TIME
IN COLLABORATION WITH THALASSEMIES INDIA & THALASSAEMIA PATIENTS ADVOCACY GROUP - INDIA

WELCOME ADDRESSES Mr. Deepak Chopra 18:30 - 18:35 President, Thalassemias India Dr. Androulla Eleftheriou 18:36 - 18:41 Executive Director, Thalassemia International Federation	IN HONOUR OF BLOOD DONORS DAY Assoc. Prof. Constantina Politis 18:42 - 18:48 Blood Safety The Global Perspective Ms. Vinita Srivastava 18:49 - 18:55 Safe Blood Saves Lives The Indian Perspective PROGRAMME Prof. John Porter 18:56 - 19:11 Gene Therapy - Current Status	Prof. Vip Viprakasit 19:12 - 19:18 Reblozyl (Luspatercept) in HbE/Thalassemia and Non Transfusion Dependent Thalassemia (NTDT) Prof. Antonio Piga 19:19 - 19:25 Reblozyl (Luspatercept) in Transfusion Dependent Thalassemia (TDT) Dr. Regine Grosse 19:26 - 19:31 Gene Therapy - Setting up for Gene Therapy Prof. Tulika Seth 19:32 - 19:38 The Indian Perspective on Innovative Drugs Prof. Alok Srivastava 19:39 - 19:45 The Indian Perspective on Innovative Curative Treatments
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INTERACTIVE DISCUSSION - Q&A
 19:45 - 20:20
VOTE OF THANKS AND FINAL REMARKS
 20:20 - 20:30
 Ms. Shobha Tuli













Some useful information about the on-going work

- NAT Testing Centre at IRCS running since March,2021
- Thalassemia Screening and Counselling Centre running since August,2020
- Under the Essential Drug List following up with MoHFW, Govt. of India for inclusion of two oral iron chelators in the EDL
- Revision of Disability Guidelines by the Govt. of India
- Ayushman Bharat Yojana
- Prevention of Thalassemia
- Insurance
- GST
- Custom duty

International Banner

- ▶ Thalasseemics India is a voting member of TIF since 1994. Shobha Tuli is representing TIF as its Vice-President



**THALASSAEMIA
INTERNATIONAL
FEDERATION**

- Shortage of Manpower
 - Regular Donations
 - Lack of Media Support
 - Government Funding
-
- Treatment For All
 - Increase Awareness
 - Safe Adequate Blood
 - Prevention Program



Executive Committee Members



Deepak Chopra
President



Dr. V.K. Khanna
Vice President



Dr. Gautam Bose
Vice President



Shobha Tuli
Secretary



Rekha Arora
Joint Secretary



Anubha Taneja Mukherjee
Joint Secretary



Arun Sehgal
Treasurer



Deepak Dhingra
Joint Treasurer



Gagandeep Singh
Social Media & Event Advisor



Ashwini Malik
Financial Advisor



Rita Jain
Executive Member



Viresh
Executive Member



Nehal Dhingra
Executive Member

Scientific Advisors



Dr. Alan Cohen



Dr. Ali Taher



Dr. Antonio Piga



Dr. Amila Mahajan



Dr. Farukh Shah



Dr. I.C. Verma



Dr. John Malcolm Walker



Dr. John Porter



Dr. Mammen Chandy



Dr. M.B. Agarwal



Dr. Nica Cappellini



Dr. Ratna Chatterjee



Dr. (Prof) Sunil Gumber



Dr. Suthat Fucharoen



Dr. Ved Prakash Choudhry



Dr. V.K. Khanna

Staff Members



Rashmi Kalra
Job Title: BMT Project Coordinator



Vijay Sharma
Job Title: Accountant



Sheela Davis
Job Title: Thalassemia Unit In charge,
Sir Ganga Ram Hospital



Sangeeta Mittal
Job Title: Thalassemia Unit In charge,
St. Stephens Hospital

Staff Members



Bijender Singh

Job Title: Senior Medical Laboratory Technician
at the “Thalassemia Screening and Counselling
Centre” IRCS



Munshi Ram

Job Title: Consultant at the “Thalassemia Screening and
Counselling Centre” IRCS



Mohit Dixit

Job Title: Laboratory Technician at the “Thalassemia
Screening and Counselling Centre” IRCS



Umesh Kumar

Job Title: Pharmacist



Let's work
together



CARE- Cooperate



CURE- Keep yourself healthy
and fit



CONTROL- Contact us for
screening camps and
awareness talks

- *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 looks difficult to accomplish*
- *Thanks to several individuals & organisations for their continued commitment to stand with us to work on 3 C's – Care, Cure & Control*
- *Thanks to our Scientific advisory members for sharing information from time to time*
- *Thanks to the Staff members for handling their job responsibilities which speaks volumes about their patience & dedication*

*Thank
You*