



T-News INDIA

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Chandigarh | Delhi | Gujarat | Haryana | Maharashtra | Madhya Pradesh | Punjab | Uttar Pradesh



THALASSAEMIA INTERNATIONAL FEDERATION

TIF Vision

TIF's vision is to establish equal access to quality health care for every patient with thalassaemia and other haemoglobin disorders across the world.

TIF Mission

TIF's mission is the development and establishment of National Control Programmes for the prevention and quality treatment of thalassaemia and other haemoglobin disorders in every affected country.

Supported in India by Federation of Indian Thalassaemia (FIT)

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Best Wishes for 2016!

BACKGROUND

Thalassaemia International Federation (TIF) is a global non-profit, non-governmental patient-driven organisation founded in 1986. It is working in official relations with the World Health Organization (WHO) since 1996. As umbrella organization TIF now represents 192 national thalassaemia associations and other members from over 60 countries across the world. One of the main purposes of TIF is the establishment of new and strengthening of existing national patient/parent associations for a strong patient/parents voice

Following the visit by senior officials of Thalassaemia International Federation (TIF) in November 2012 to the Ministry of Health and Family Welfare in New Delhi, an expression of interest was initiated by the Directorate General of Health services of the Ministry of Health and Family Welfare to support and improve services provided to patients with haemoglobin (Hb) disorders.

We began working together in 2012 knowing that the work we do would affect the future of children with thalassaemia in India. In 2013 the working groups formed in seven states mapped the thalassaemia landscape and created the database of patient, NGOs, treatment facilities and Govt. support and the gaps in treatment and care. In 2014 each State, developed the COP was developed along with the a National Charter by Delhi Task force to advocate with the health policy makers on nine key Priorities to put Thalassaemia on the National Health agenda. From end of 2014 and through 2015 the State Task Forces have successfully presented advocated with various Government and Health policy makers to garner support. This has generated strong support and commitment in some States and generated the momentum to provide care and support in others. We are deeply proud of what we and our supporters accomplished.

In this edition of T-News let's look at the progress made and celebrate the success, share the best practices to learn from each other and foster a collaborative way forward.

Achievements in COP recommendations for Thalassaemia Care and Support

Charter of Priorities (COP) Recommendations	Delhi	Gujarat	MP	MH	Punjab	UP	Haryana	Chandi.
Prevention, screening* & awareness	↑	↑	→	↑	↑	→	→	→
Blood availability & Safety	↗	↗	↑	↗	↑	↗	→	→
Free Iron chelators	↑	↑	↗	↑	↗	↗	→	→
Multi-disciplinary care	↗	↗	↗	↗	→	→	→	↗
Establishment of State Registry	↗	↗	→	↗	→	→	→	→

↑ Excellent Progress (at State/Policy Level). ↗ Fairly good Progress. → Yet to make headway
*Screening & awareness being done by NGOs of State Task Forces and not the Govt.

Best Practices & Achievements

DELHI UPDATE

- Working with Association of Obstetricians & Gynecologists of Delhi (AOGD) by attending their monthly meetings and distributing thalassemia material to the doctors to promote screening / Pre-natal diagnosis.
- Display boxes with pamphlets and book marks are being kept at more than 100 Gynecological Clinics. Letters and emails sent to over 40 Delhi Hospitals requesting them to screen all pregnant women.

GUJARAT UPDATE

- Population Screening is ongoing program, for students in Universities as well Community screening. Several thousands have been screened by now.
- Pre-natal diagnosis: So far more than 2.0 lakhs pregnant women screened & subsequently 135 Thalassemia Major fetus aborted.

Plans are afoot to replicate this Program in Vadodara district.

- Many blood banks, NGOs & parents have started forming specific blood group donors group linked to an individual Thalassemia Major child; to ensure that transfusion requirements are fulfilled by this dedicated repeat voluntary donors, to minimize the risk of acquiring HCV/HIV.

MADHYA PRADESH UPDATE

- Opening a new national level institute for Thalassemic and Sickle Cell Anaemia in Bhopal in collaboration of Global Research and welfare society Bhopal and Govt. of Madhya Pradesh: The institute will provide education/counseling, treatment, research etc. Discussion started with Govt offices like Education, Medical & Revenue dept.
- Introducing new course M.Sc Medical Biotechnology in collaboration of RKDF University and Global Research and Welfare Society Bhopal. The 20% of the revenue generated of this course will be used for treatment thalassemic and Sickle cell anemia patients.



HARYANA UPDATE

- Involving local administration in awareness and blood donation campaigns, where several high level Govt. Officials donated blood.

Recently Inspector General of Haryana Police Sri. Alok Mittal, IPS, donated blood and Deputy Commissioner motivated people to come forward assist in making an effort to eradicate Thalassaemia.



“Patients and parents enjoying a mud dance and mud bath; this was different experience for them”

at a Picnic organized
by Foundation Against Thalassemia

MAHARASHTRA UPDATE

Maharashtra Task Force - Building Advocacy Coalitions for Greater Action and Impact

The Maharashtra Task Force has moved leaps and bounds in providing sustainable models of Thalassaemia Care and Support that would significantly improve the quality of services across the State. The multi-stakeholder Task Force group in Mumbai is a coalition of persons from Govt., Health Dept., Medical fraternity, Civil Society Organization (CSOs) consisting of NGOs, Parents and Patient groups. This unique combination of stakeholders has enhanced the reach of the advocacy efforts; to enable greater success by combining commitment, resources and skills and leveraging the comparative advantage of each member.

The Achievements of Maharashtra Task Force in last six months:

- India's first Comprehensive Thalassaemia Centre;
- NAT Testing in 6 major government blood banks in Maharashtra supported by Governing Board of State Blood Transfusion Council;
- HLA Typing Of Thalassaemia Patients;
- Garnering support from Mr. Oscar Fernandes, Rajya Sabha member, for tabling and moving the Bill On 'Rights Of Persons With Disabilities' in the next session of Parliament;
- Inauguration of new Thalassaemia Day Care Centre at Jalna and Aurangabad;
- Registration Of 'Ledipasvir' and 'Daclatasvir' for Treatment of Hepatitis C;
- Awareness sessions in Management Institutes across the Country with Axis Bank.

A milestone in Thalassaemia Care in India

India's first Comprehensive Thalassaemia Centre is being setup in Mumbai, at the Pediatric Hematology-Oncology, LTMG Hospital. The Maharashtra Task Force spearheaded by Mr. Vinay Shetty and Dr. Rughwani played a key role in advocating for this one of its kind facility. The two storey facility was not has provided by the Additional Municipal Commissioner of inspection of building and the Brihan Mumbai Municipal Corporation (BMC).

The following services:

- Transfusion Centre and Blood Storage Unit;
- Pre-natal Diagnosis facility, Laboratory for Population Screening;
- Clinics for Multi-disciplinary Thalassaemia Care;
- Bone Marrow Transplant facility (10 beds + 5 step-down).

In addition it will also house a residential facility, administrative offices, cafeteria and other support services.

UTTAR PRADESH UPDATE

- Govt.order issued to all district hospitals to provide free blood to all Thalassemic children.
- Walk For Thalassaemia on 8th May.
- Prevention, awareness & screening by societies of Uttar Pradesh.
- 20 mobile buses approved for blood transfusion.



Awareness program on BMT for parents and care givers



News coverage by Amar Ujala on the BMT awareness camp

PUNJAB UPDATE

Serum ferritin done free of cost for children under NRHM scheme Filters, blood transfusion sets and iron chelators available free of cost.

Formation of committees

- Antenatal diagnosis involving FOGSI. Talk delivered to gynecologist about antenatal screening.
- Blood Safety Committee, talks on for making NAT screening compulsory for donated blood and all patients.



Dr. Priyanka Gupta, Paed. Haemato oncologist from SPS Hospital speaking to 200 students who attended the awareness campaign at the Govt. college



Students of the college signing the 'End Thalassaemia' pledge at the event

Successful Media Advocacy

Making the Case for Thalassemia with Media Advocacy – Uttar Pradesh

To garner support and make media partners to advocate, raise the profile and draw the attention of the Government and general public to the gap in services of care and support of patients with thalassemia, was effectively done through a media sensitization and advocacy at the Multi-stakeholder meeting held in Lucknow on the 29th of Dec '2014.

Over 25 senior journalist from both the National and local press were sensitised through one-on-one discussions and sharing the evidence gathered by the State task forces on the issues faced by the patients with thalassaemia and the care givers due to lack of facilities and support was highlighted.

The media gave an excellent coverage to the event and the issue and will continue supporting the cause by highlighting the needs of Thalassemia Patients in Uttar Pradesh.

Capability Building Training

Thalassemia Association Capability Building training at SP Jain Institute of Management(Mumbai) sponsored by Novartis –

The capacity building training was organized by SP Jain Management School Mumbai for building skills of organisations and persons working for Thalassemia treatment, care and awareness.

The training was attended by representatives from nine States that included TIF State Task Force Members from Delhi, Punjab, Gujarat, and Uttar Pradesh. The discussion was facilitated by Ms. Usha Menon.

Discussions

- Launch a Thalassemia National awareness campaign;
- Garner support from Corporate Social Responsibility (CSR) funds and volunteer of corporate sector;
- Build capacities of NGOs;
- Collaborate with UNICEF, Save the Children, Child Rights and You (CRY) and CCF for awareness campaign;
- Need for National data on Thalassemia and State wise registry;
- Step up screening.



States Representatives & Coordinators

Thalassaemia International Federation (TIF)

- Dr Androulla Eleftheriou - TIF Executive Director
- Dr Michael Angastiniotis - TIF Medical Advisor

The Federation of India Thalassaemics (FIT)

- Mrs Shobha Tuli (President)
- J.S. Arora (Secretary)

Country Facilitator

- Mrs Usha Menon

Delhi

- Mrs Shobha Tuli
- Dr J. S. Arora
- Dr V. K. Khanna
- Dr. V. P. Choudhury

Maharashtra

- Dr. Girish Chaudhari - Assistant Director, Directorate of Health Services (DHS)
- Dr. Sanjaykumar Jadhav, Assistant Director, State Blood Transfusion Council (DHS)
- Dr. P.G. Natrajan- Department of Pre-Natal Medicine, Nanavati Hospital, Mumbai
- Dr. Roshan Colah – Scientist F -Deputy Director, National Institute of ImmunoHaematology (NIIH), Mumbai;
- Dr. Mamta Manglani - Head of Department of Pediatrics, L.T.M.G. Hospital, Sion, Mumbai
- Mr. Jatin Sejpal-Thalassaemia patient
- Ms. Sangeetha Wadhwa - Thalassaemia patient
- Mr. Ashok Khatuja - Parent of thalassaemia patient, Ulhasnagar
- Mr. Anil Shah - Parent of thalassaemia patient
- Dr. Vinky Rughwani – State Coordinator - President, Thalassaemia Society of Central India, Nagpur
- Mr. Vinay Shetty – State Coordinator - Vice President, Think Foundation, Mumbai
- Dr. Sangita Lodha, Smile Thalassaemia Foundation, Nasik
- Mr. Surendra Sitani, Thalassaemia Society of Pune

Chandigarh

- Mr Rajinder Kalra – Chandigarh
- Mr Arjun Singh – Chandigarh

Gujarat

- Dr Ashwin Patel – President of the Haematology Association
- Dr Maheria – Paediatrics
- Dr Bipin Patel – President of the Paediatric Association
- Dr R. Z. Patel
- Dr D. C. Master
- Mr Mahesh Trivedi
- Dr Maulik Bakshi – Paediatrician
- Dr Anil Khatri – Paediatrician, President of the Thalassaemia Jagruti Foundation
- Dr Madhuben M. Naik – Honorary Secretary of the Indian Red Cross Society – Gujarat Branch

Haryana

- Mr Ravinder Dudeja
- Mr Ram Kumar
- Mr Sehrawat Ram Kumar

Madhya Pradesh

- Dr Chandra Bahadur Singh Chandra - Global Research Welfare Society – Bhopal
- Mr Girish Ahuja - Disha Welfare Association Samity
- Dr C. B.S. Dangi – Secretary of Global Welfare Research Society
- Dr Neel Kamal Kapoor - AIIMS- Bhopal
- Dr S. S. Kasmi-Retired Director of Health Services
- Dr D. C. Sharma – Madhya Pradesh Nodal Officer
- Ms Surbhi Chaudhary –Patient (Indore)
- Mr Ritesh Pamrani –Patient (Gwalior)
- Mr Ashok Kukereja - Parent(Gwalior)

Punjab

- Dr Praveen C. Sobti - Dayanard Medical College and Hospital
- Mr Rajesh Kapoor - Zindagi Live Foundation

Uttar Pradesh

- Dr. Jalabala Sardana, Bareilly
- Mr. Mukesh Agarwal, Bareilly
- Dr Sangeeta Kumar - Pediatrician - Varanasi
- Dr Nitu Nigam – Geneticist – Kanpur Rama Medical College, Hospital and Research Center, Kanpur
- Dr Toolika Chandra – St George’s Medical University
- Mr Pravir Arya – President of the Thalassemeice India Society, Lucknow
- Mrs Seema Arya – Parent
- Mr Manish Goel – Parent

Wishing Every One a Happy and Successful New Year

Grateful thanks to

 **NOVARTIS**

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