HIGHLIGHTS OF THIS ISSUE:

- World Thalassemia Day
- Projects
- Articles
- New Members
- Worthy Donors
- News Across India

www.thalassemicsindia.org
Special Thanks

ICREON COMMUNICATIONS (P) LTD

AKM MEHRASON'S JEWELLERS

BRINDAVAN AGRO IND PVT LTD

P & G ENTERPRISES PVT LTD

TAYAL SONS LTD
Dear Thalassemics India family,

Greetings and welcome to the 47th issue of Thalassemics India!

This issue marks the beginning of our new path that endeavours to keep our dreams alive of making India Thalasemia Free and helping the under-privileged and needy.

Inside, you will find updates about our project activities, success stories, Govt. of India’s initiatives, TIF News & special features about 8th May events.

This year AGM was indeed a successful event where we had a good turnout. We plan to promote the annual meeting in the coming year to have more attendance by making it an enjoyable and memorable event.

We are constantly updating our website to inform members about news & events. Our members receive newsletters by post & through email. In case you missed the newsletter, you will find it at www.thalassemicsindia.org

HSCT project by Coal India & MoHFW, Govt. of India has helped a number of Thalassemics to get cured through B.M.T. The selected centres are doing their very best by extending care & support to these children. We would like to thank the Ministry, Coal India & the medical fraternity for their exemplary work. The final draft of the National Policy by the MOHFW, Govt. of India is almost ready. We are expecting desirable changes in the Disability Act as per ours & other stakeholders suggestions.

TPAG is making progress and we are very proud of its leadership and work.

Changing the lives of children with Thalassemia is a continuous process. Nothing can be done in a limited period. The task is immense. Our organisation has been continuously working to bring change in the lives of underprivileged Thalassemics by offering them free medical care. For this we need donors/partners. Do let us know if you could help us in this area!

Thalassemia Update is a platform for you to share updates about your achievements & valuable suggestions with us. Therefore, I humbly encourage all of you to make use of this platform to remain connected with us. We hope you find this newsletter informative and useful.

Taking this opportunity, I wish each one of you a very happy & successful New Year. May you all stay healthy and reach new heights!

Shobha Tuli
Secretary, Thalassemics India
8th May
On the occasion of "World Thalassemia Day", Thalassemics India did a series of significant activities on 8th and 9th May in New Delhi.

On 8th May, a seminar on “The Basics of Thalassemia Management, Care and Prevention” was held at India Habitat Centre from 10 am to 4 pm with the expert haematologist group under the banner of the Ministry of Health & Family Welfare (MoHFW), Government of India.

The programme started with the welcome address by Mrs. Shobha Tuli, Secretary, Thalassemics India.

Dr. Roshan Colah gave a powerful talk on the “Road to making India Thalassemia free by 2025”.

A Panel Discussion on “Safe Blood Transfusion for Thalassemics: Current Status and Way Forward” was moderated by Dr. Amita Mahajan and the panelists were : Ms. Vinita Srivastava, Dr. Vanshree Singh, Dr. S. Sudha, Dr. Satyam Arora and Dr. Rahul Bhargava.

Dr. Tulika Seth threw more light on the new iron chelator drug - “Oleptiss”.

“Optimizing Chelation Therapy in Thalassemia” was very well put up in another Panel discussion moderated by Dr. V. K. Khanna with the expert panelists- Dr. Sunil Gomber, Dr. Anil Khatri, Dr. Praveen Sobti and Dr. Rajiv Bansal.

Mr. Deepak Chopra, President of Thalassemics India addressed the audience by giving an overview of the 30 years journey of Thalassemics India.

He also introduced and announced the Bollywood star Mr Jackie Shroff as the Brand Ambassador of Thalassemics India, supporting the mission of Thalassemia Awareness and Prevention.

Programme was officially inaugurated by the Hon’ble Chief Guest Sh. Rajendra Pal Gautam, Minister of Social Welfare, Delhi Govt., Dr. Kirti Bhushan, DGHS, Delhi Govt. & Ms. Vinita Srivastava, National Senior Consultant & Co-ordinator, Blood Cell- NHM, MoHFW, Govt. of India were the Guests of Honour.

During the inauguration function, the Hon’ble Minister unveiled the two posters on “Thalassemia Awareness and Prevention Campaign, with Jackie Shroff” and “The Patient Advocacy Group’s (TPAG) Newsletter”.

Some of the doctors who have contributed zealously in the field of thalassemia were felicitated for their dedication by Thalassemics India. The doctors received a token of appreciation from the Chief Guest.

Anurba Taneja, Member Secretary, TPAG, other group members and fellow thalassemics, along with our ambassador Jackie Shroff, took the pledge for “Thalassemia Free India by 2025.”

A brief press conference was held to introduce our Ambassador Mr Jackie Shroff.

A special address was given on “Disability” by the Deputy Chief Commissioner for Persons with Disabilities, Govt. of India - Sh. Sanjay Kant Prasad.

There was a special address on the “Indian Case Scenario: Management, Insurance & and various other significant issues” by Ms. Sangeeta Chatoo, Associate Professor Public Health and Society Research Group, Department of Health Sciences, University of York.

The programme attended by more than 300 participants was beautifully conducted by Ms. Nehal Dhingra, TPAG member.

The function concluded with a vote of thanks by Mrs. Shobha Tuli, Secretary, Thalassemics India.

9th May
Thalassemics India team members: Mrs. Shobha Tuli, Mr Deepak Dhingra, Mrs. Gagandeep Singh, Mrs Rita Jain, Mrs. Rashmi Kalra, Ms. Sonam Madaan and Ms. Swati Tuteja visited Deen Dayal Upadhyay Hospital and Sir Gangaram Hospital with our Brand Ambassador Jackie Shroff. Children felt ecstatic to meet Mr Shroff and receive back gifts from the Bollywood actor.

A very engaging press-conference was held at the board room of Sir Gangaram Hospital, New Delhi in the presence of Dr. D.S. Rana, Chairman, Board of Management, Dr. V. K. Khanna, Chairman, Child Health Institute, Dr. S.P. Byotra, Vice-Chairman Board of Management, and Mr Jackie Shroff. They addressed the press to take the message of thalassemia awareness and prevention forward and responded to their queries on Thalassemia.

A Live programme was telecast by Delhi DoorDarshan on Thalassemia, participated by Ms. Vinita Srivastava, Shobha Tuli and Dr. Rahul Bhargava.

We all, from Thalassemics India, would like to thank the MoHFW, Govt. of India, Ministry of Social Welfare, Delhi Govt., Directorate Government Health Services, Delhi Government, Sir Ganga Ram hospital, DDU hospital, Mr Jackie Shroff and the Donors who contributed to the success of this programme.
THALASSAEMIA UPDATE ____________________________________ World Thalassemia Day

Hon’ble Chief Guest Shri Rajendra Pal Gautam

Guest of Honour Dr Kirti Bhushan

Guest of Honour Ms. Vinita Srivastava

Group Song by Thalassemics

Deepak Chopra addressing the gathering

Sh. Rajendra Pal Gautam, Minister of Social Welfare Govt. of NCT of Delhi

Dr. Kirti Bhushan, DGHS, Govt. of NCT of Delhi

Poster launch by the Chief Guest & Jackie Shroff

Launch of TPAG Newsletter by the Chief Guest

Dr. Amita Mahajan with the panelists
Dr. V. K. Khanna Chairing the panel discussion

Honouring Dr. I. C. Verma

Audience

Honouring Ms. Vinita Srivastava

Honouring Dr. Jagdish Chandra

Honouring Dr. Vanshree Singh

Honouring Dr. Anil Khatri

Honouring Dr. Sunil Gomber

Honouring Dr. Tulika Seth

Honouring Dr. Roshan Colah
THALASSAEMIA UPDATE

World Thalassemia Day

Honouring Dr. V.P. Choudhry
Honouring Dr. V.K. Khanna
Honouring Dr. S. Sudha
Honouring Dr. Praveen Sobti
Honouring Dr. Rajiv Bansal
Honouring Dr. Satyam Arora
Honouring Dr. Rahul Bhargava
Honouring Rtn. Tejinder Kaur

Vote of thanks
Appreciation Notes received on the occasion of World Thalassemia Day

Thank you so much Mrs. Tuli for inviting me to this wonderful and inspiring meeting…

-Dr. Roshan Colah

The event was well organised and you spoke well. Very impressive speech.

- Thalassemic Parent

Please accept my sincere Congratulations for the grand success of International Thalassemia day function, involving Jackie as Ambassador for Thalassemia will have great effect on our sincere efforts to control Thalassemia. We all need to work together unitedly. Many thanks for all honours bestowed on me. I am willing to offer u all my services for this noble cause

-Dr. Ved Prakash Chaudhary

Excellent program. Congratulations

- Dr Tulika Seth

It was really a meaningful Seminar with a perfect blend. Glad that I could attend it.

Hearty Compliments

- Dr. Anil Khatri

I extend my congratulations to the entire team for organising such seminars.

- Pooja Kapoor

Dear Thalasemics India Team,

Everything was good arranged. Had a great time spent with my friends. Superb experience. Thank you

- Simarpreet

It was great experience meeting new people and the arrangements done by Thalassemic India was commendable.

- Bhumika Luthra

Very Informative Seminar!!

- Tisha

Talks of the doctors is really helpful! Thanks for arranging seminar.

- Umesh

The presentations and the achievements of those affected was even more admirable. God Bless one and all

- Thalassemic Parent

We at RCDS bow down to your spirit of service .. your dedication to the cause so dear to you !! God bless you

- RCDS

Shobha ji... your dedication towards the cause is admirable.

- Thalassemic Parent

Thanks for inviting me. Wonderful program, pleasure to attend. Regards.

-Dr. Rajiv Bansal

Thankyou shobhaji for such a fabulous programme.

- Thalassemic Parent
Message from Thalassemics India’s Brand Ambassador

I am delighted to be a part of Thalassemics India as the Brand Ambassador. Being associated with the organisation, helps me get to know more about the disorder. My humble request to everyone reading this, is that Thalassemia is a genetic blood disorder and it can be prevented by timely genetic screening. Please spread the word as much as you can, talk to everyone around you about the disorder.

Regards

Jackie Shroff
Actor Jackie Shroff meets children suffering from Thalassemia at Sir Ganga Ram Hospital on May 09, 2018.

Jackie Shroff Urges Government to Reduce Cost of Thalassemia Medicines

BOLLYWOOD PTI May 12, 2018 03:30 PM IST

New Delhi, May 12: Actor Jackie Shroff

The brand ambassador of Thalassemics India, visited the Sir Ganga Ram Hospital urged the Government to reduce the cost of medicines for thalassemia and take active steps towards prevention of the disease. Thalassemia is an inherited blood disorder in which the body makes an abnormal form of haemoglobin.

“This subject is very close to my heart as my younger daughter Krishna was prevented from being thalassemic due to awareness and tests,” he said.

“I appeal to the government to reduce the charges of medicines and take active steps towards prevention of this disease as it is a preventable disease,” Shroff said.

Dr. V. K. Khanna, the Chairman, Department of Pediatrics and Head of Thalassemia Unit at the Sir Ganga Ram Hospital, said that thalassemia broadly can be classified into major and minor.

Thalassemia major is an autosomal recessive blood disorder which gets transferred from parents to the children through the genes, he said.

Those who are affected with thalassemia major need regular blood transfusions, continuous monitoring and medications to survive, Khanna said.

“Approximate 3.4 per cent of the people are carriers of thalassemia and around 7,000 to 10,000 children are born with thalassemia major every year in India,” he said.

Jackie Shroff Gets Associated With An NGO

BOLLYWOOD Kanika Shrivastava
12:37 pm May 9, 2018

Most of the Bollywood actors are known for the charity they do or the NGOs they run. Jackie Shroff is the new entry in this list.

Jackie Shroff has become the face of an NGO, Thalassemics India, on the World Thalassemia Day. The actor will be flying to Delhi for a seminar including doctors and government officials.

The reason why Jackie has connected himself with this cause is that he and his wife Ayesha first became aware of this delicate health condition when they were expecting their daughter Krishna Shroff.

Jackie will be meeting the thalassemia patients and their parents today and will also announce a series of activities as a part of Awareness and Prevention Campaign.

That’s such a good deed, Jackie!

Jackie Shroff talks Thalassemia and why it must be prevented

Jackie Shroff with a Thalassemic kid in Ganga Ram Hospital, Delhi. Tribune photo

Aditi Tandon

Tribune News Service

New Delhi, May 9 Thalassemia can be a challenging medical condition for children affected with it but low awareness around the disorder has prevented its spread.

In a rare exercise of awareness building on Thalassemia on Wednesday, actor Jackie Shroff spent time with children suffering from the disorder and getting treated at Sir Gangaram Hospital in Delhi.

Efforts to get people about to get married get screened for Thalassemia to prevent their children from getting the disorder have not yielded much result.

Shroff today visited patients suffering
from Thalassemia and admitted, “This subject is very close to my heart. I appeal to the government to reduce the charges of medicines and take active steps towards prevention of this disease as it is a preventable disease. The message has to percolate to villages also.”

Gangaram’s Thalassemia unit has functioned since 1993 and many of the thalassemic children attending the hospital are adult now and 14 have got married.

Jackie Shroff has joined the mission of Thalassemics India as he had a deep connection with the cause. Dr VK Khanna, Chairman, Department of Pediatrics and Head of Thalassemia Unit, Sir Ganga Ram Hospital, said, “Thalassemia Major is an autosomal recessive blood disorder which gets transferred from parents to the children through the genes. It causes weakness and destruction of the red blood cells, affecting the formation of haemoglobin in the body and causes mild or severe anaemia causing complications like bone deformities, iron overload, cardiovascular illnesses, enlarged liver, jaundice, enlarged spleen, enlarged bones of cheeks or forehead, delayed puberty and many other complications.”

Shobha Tuli of Thalassemics India says there is a need to motivate the youths for the pre-marriage thalassemia screening and prevent this disorder from getting inherited among the next generations and to make the community, society, nation and world free of thalassemia.

Thalassemia has many types but broadly it can be classified into major and minor. Those who are affected with Thalassemia Major need regular blood transfusions, continuous monitoring and medications to survive. Approximate 3.4 per cent of the people are carriers of thalassemia and around 7,000 to 10,000 children are born with Thalassemia Major every year in India.

While the lifespan is increasing with better management and care but it is a tremendous challenge for both children and the parents to manage the disorder.

**On World Thalassemia Day Jackie Shroff to spread awareness about Thalassemia**

Wednesday, May 09, 2018 14:04 IST
By Santa Banta News Network

Actor Jackie Shroff has become the face of an NGO, Thalassemics India on the World Thalassemia Day

Bollywood actors are known to go out of the way for charitable activities. Now, Jackie Shroff also has participated in this noble act.

Thalassemics India has been working for the care of thalassemia patients and families for the last 30 years. Not just that, the actor on the World Thalassemia Day has also traveled to Delhi to raise awareness about the same.

Jackie Shroff has taken out time from his schedule to travel to Delhi. The NGO has planned a series of activities in the Capital. There’s a seminar involving senior doctors and government officials and also the launch of a host of initiatives involving him.

Interestingly, there’s a personal reason for Jackie to be connected with this cause. He has joined the mission of the NGO since he has a deep connection with the noble cause. Actually, not many are aware that he and his wife Ayesha first became aware of this delicate health condition, when they were expecting their daughter Krishna Shroff.

Today Jackie will be meeting thalassemia patients and their parents and also announce a series of activities that will be done as a part of the Awareness and Prevention campaign.

It’s believed that as a part of the same initiative, Jackie will also be visiting the thalassemia units at a couple of hospitals in Delhi, and will be meeting a few government officials along with the team from the NGO.

---

We sincerely thank the Indian Red Cross Society & Sir Ganga Ram Hospital for their continuous care & support.
Our Brand Ambassador Mr Jackie Shroff visited Thalassemia units and met thalassemic children on 9 May, 2018 with few members of Thalassemics India: Shobha Tuli, Gagandeep Singh, Rita Jain, Rashmi Kalra, Sonam Madaan and Swati Tuteja to Deen Dayal Upadhayay Hospital and Sir Gangaram Hospital with our Brand Ambassador Jackie Shroff. Children felt ecstatic to receive back gifts by the Bollywood actor.

A very engaging press-conference about Thalassemia was held at Sir Gangaram Hospital, New Delhi in the presence of Gangaram hospital authorities and Thalassemics India executive committee members. The press-conference was acknowledged by Dr. D.S. Rana, Chairman, Board of Management, Sir Gangaram Hospital, Dr. V. K. Khanna, Chairman, Child Health Institute, Sir Gangaram Hospital, Dr. S.P. Bayotra, Dr. Jayshree Sood & Dr. Ajay Swaroop.
Free Medical Support:
Under this project, we are always making efforts for the betterment of underprivileged thalassemic children. Thalassemics India has supported underprivileged thalassemia patients from St. Stephen’s, Sir Ganga Ram, Hindu Rao, NDMC, Kasturba and LNJP hospitals. From April to December, we managed to give free of cost chelation medicines and equipments to 200 thalassemics. We thank our donors for making this possible.

At Thalassemics India, A-9, Nizamuddin office.

At NDMC Hospital Thalassemia Unit

At Thalassemia Unit, Hindu Rao Hospital

Sunday Clinics:
The clinic was held on 30th July, 2018 from 3.00pm to 6.30pm at Nizamuddin office, this clinic was especially arranged for those patients who are receiving chelation drugs and filters free of cost from our society. Dr. V.K. Khanna, Chairman, Institute of Child healthcare, Sir Ganga Ram Hospital was invited to hold this clinic. Thalassemia patients from St. Stephen’s Hospital & NDMC Hospital came to attend this clinic for checkup & suggestions.
T2*MRI PROJECT:

As part of this project, Dr. Malcolm Walker & his team members from UCL, London, gave consultations to more than 100 patients on 10-14 November, 2018 in Delhi & Jaipur. Dr. V.K. Khanna, Dr. Amita Mahajan and Dr. Rajiv Bansal and the team of Thalassemics India helped in organizing the check up clinics and making all necessary arrangements at the imaging centres.

50 patients were selected from NDMC, Lady Hardinge, Apollo Hospital, GTB Hospital, St. Stephens Hospital, Deen Dayal Upadhyay Hospital for getting their T2*MRI done in Delhi at the Mahajan Imaging Centre and 50 patients were scanned in Jaipur.

Thanks to Dr. Malcolm Walker, Dr. V.K. Khanna, Dr. Amita Mahajan, Dr. Rajiv Bansal & Dr. Harsh Mahajan for their invaluable co-ordination in Delhi & Jaipur for the T2* MRI Project
Project “Pahunch”

The project is focused to work with Governments, thalassemia patients/parents, thalassemia centres, ngo’s, media, schools, colleges, corporate and hospitals for the purpose of sharing information & reaching out to them with our concerns & issues.

Blood Donation Camps:

"Press forward. Do not stop, do not linger in your journey, but strive for the mark set before you." - George Whitefield

Narchi Delhi organised an initiative with Thalassemics India for a cause that is so close to us. A Thalassemia Awareness Walk at Connaught Place, on 02 December, 2018 from 7 am-9 am more than 150 people participated in the walk. Members of Association of Gynaecologists of Delhi (AOGD), Dr. Jaideep Malhotra, President The Federation of Obstetric & Gynaecological Societies of India, Ms. Vinita Srivastava, National Senior Consultant & Co-ordinator, Blood Cell NHM also joined the walk. Thalassemics India is really grateful to NARCHI for the step they took for the cause. We need more such events and initiatives for Thalassemia Awareness.

Thalassemia Awareness Walk:

Narchi Delhi organised an initiative with Thalassemics India for a cause that is so close to us. A Thalassemia Awareness Walk at Connaught Place, on 02 December, 2018 from 7 am-9 am more than 150 people participated in the walk. Members of Association of Gynaecologists of Delhi (AOGD), Dr. Jaideep Malhotra, President The Federation of Obstetric & Gynaecological Societies of India, Ms. Vinita Srivastava, National Senior Consultant & Co-ordinator, Blood Cell NHM also joined the walk. Thalassemics India is really grateful to NARCHI for the step they took for the cause. We need more such events and initiatives for Thalassemia Awareness.

Thalassemia Awareness Talks:

Thalassemics India is extremely grateful to Red Roses Public School, Saket, Delhi for organizing awareness talk on Thalassemia on 13th October, 2018. We specially thank the faculty for their groundwork and efforts of taking the initiative. We request everyone to encourage and help us in spreading awareness for Thalassemia.

Thalassemia Awareness Campaign at DAV United:

Thalassemics India participated in DAV United at Indira Gandhi Institute for Arts, New Delhi.

A huge gathering of all DAV schools across India. Thalassemics India had a stall with information material on Thalassemia to help spread awareness among students, parents & teachers. There were interactive sessions with those that visited the stall. People got to know about the genetic blood disorder.

The event was over three days (21-23 December, 2018). Which was managed and participated by Rashmi Kalra, Swati Tuteja & Sonam Madaan... the initiative was taken by Nehal Dhingra.
Come forward & help us in arranging talks on Thalassemia, blood donation camps & funds for underprivileged thalassemia children
Coal India Limited under their Corporate Social Responsibility (CSR) in co-ordination with the Ministry of Health and Family Welfare, Govt. of India has started a "HEMATOPOEITIC STEM CELL TRANSPLANT" (HSCT Project), in 2017.

Hematopoietic Stem Cell Transplantation offers an alternative to life long transfusions and iron chelation for patients with Thalassemia Major. The Coal India CSR funded HSCT Programme titled "Thalassemia Bal Sewa Yojna" is intended to provide one time cure opportunity. The project is primarily intended to benefit those patients who have a matched sibling donor but do not have financial resources to bear the cost of the procedure.

I thank

Ministry of Health and Family Welfare
Government of India

&

Ministry of Coal
Government of India
(An ISO 9001:2008 Certified Ministry)

for giving my child a gift of life by helping us in Bone Marrow Transplant through Hematopoietic Stem Cell Transplantation Project
Visit to Kingdom of Dreams
This was our felicity to take 63 Thalassemia patients/parents to give them the pleasure of experiencing spectacular “Zangoora show” at Kingdom of Dreams, Gurgaon. This could not be possible without the help of Icreon and team. We are glad that children enjoyed very much. The pictures below say it all.

Visit to Taj Mahal, Agra
Thalassemics India has organized a visit to Taj Mahal, Agra on 8th Sept, 2018. A group of 41 thalassemia patients/parents has experienced the beauty of miraculous monument. They had sumptuous lunch at Hotel Radisson Blu, Agra.

Felicitating Thalassemics
### Our Worthy Donors

<table>
<thead>
<tr>
<th>Name</th>
<th>Amount</th>
<th>Name</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manoj Vipinchand Jain</td>
<td>₹130000.00</td>
<td>Mamta Bholia</td>
<td>₹10000.00</td>
</tr>
<tr>
<td>Indus Valley</td>
<td>₹25000.00</td>
<td>Rama Bholia</td>
<td>₹10000.00</td>
</tr>
<tr>
<td>Pushpa M Prashara</td>
<td>₹25000.00</td>
<td>Sonny Iqbal</td>
<td>₹7500.00</td>
</tr>
<tr>
<td>Vijay Kanchan</td>
<td>₹21000.00</td>
<td>Sunny Sachdeva</td>
<td>₹6000.00</td>
</tr>
<tr>
<td>A well wisher</td>
<td>₹21000.00</td>
<td>S.K. Sareen &amp; Rajni Sareen</td>
<td>₹5100.00</td>
</tr>
<tr>
<td>Bindu Bhalla</td>
<td>₹20000.00</td>
<td>Shailendra Singh Solanki</td>
<td>₹5001.00</td>
</tr>
<tr>
<td>Youshmann Bazaz Memorial</td>
<td>₹19530.00</td>
<td>Kuldip Raj Bedi</td>
<td>₹5000.00</td>
</tr>
<tr>
<td>Society</td>
<td></td>
<td>Saroj Choudhary</td>
<td>₹5000.00</td>
</tr>
<tr>
<td>Dr. V.P. Choudhry</td>
<td>₹15000.00</td>
<td>Kuldip Singh Madan</td>
<td>₹5000.00</td>
</tr>
<tr>
<td>Devendra Kumar Narula</td>
<td>₹11000.00</td>
<td>M. L.T.B. N.M.C. Trust</td>
<td>₹5000.00</td>
</tr>
<tr>
<td>Naveen Nand Keshwani</td>
<td>₹11000.00</td>
<td>Mannit Singh</td>
<td>₹4000.00</td>
</tr>
<tr>
<td>Neelam Gandhi</td>
<td>₹22000.00</td>
<td>Sonia Narula</td>
<td>₹2100.00</td>
</tr>
<tr>
<td>Nobina</td>
<td>₹10400.00</td>
<td>S. Usha</td>
<td>₹2000.00</td>
</tr>
<tr>
<td>Siddhant Enterprises</td>
<td>₹10000.00</td>
<td>Mrs. Jain</td>
<td>₹1100.00</td>
</tr>
<tr>
<td>Mirna Gambhir</td>
<td>₹10000.00</td>
<td>Poonam P Samani</td>
<td>₹1000.00</td>
</tr>
</tbody>
</table>
# Our New Members

<table>
<thead>
<tr>
<th>Name</th>
<th>State</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aarti Batra</td>
<td>Haryana</td>
<td></td>
</tr>
<tr>
<td>Abhijit Bartamuli</td>
<td>Assam</td>
<td></td>
</tr>
<tr>
<td>Abhishek Singla</td>
<td>Haryana</td>
<td></td>
</tr>
<tr>
<td>Ajay Chopra</td>
<td>Haryana</td>
<td></td>
</tr>
<tr>
<td>Akash Atamchand Kewal Ramani</td>
<td>Gujarat</td>
<td></td>
</tr>
<tr>
<td>Akhil Gupta</td>
<td>Pune</td>
<td></td>
</tr>
<tr>
<td>Akriti Goel</td>
<td>U.P</td>
<td></td>
</tr>
<tr>
<td>Amit Phutela</td>
<td>Delhi</td>
<td></td>
</tr>
<tr>
<td>Anurag Gupta</td>
<td>U.P</td>
<td></td>
</tr>
<tr>
<td>Arindam Bag</td>
<td>W.B</td>
<td></td>
</tr>
<tr>
<td>Arshdeep Singh</td>
<td>Punjab</td>
<td></td>
</tr>
<tr>
<td>Ashok Tholpadi</td>
<td>Karnataka</td>
<td></td>
</tr>
<tr>
<td>Atushree Pal</td>
<td>W.B</td>
<td></td>
</tr>
<tr>
<td>Bhargav Kishore Bhai Ajani</td>
<td>Gujarat</td>
<td></td>
</tr>
<tr>
<td>Deepak Sachdeva</td>
<td>Haryana</td>
<td></td>
</tr>
<tr>
<td>Devika Mathur</td>
<td>Haryana</td>
<td></td>
</tr>
<tr>
<td>Divanshu Wadhwa</td>
<td>Haryana</td>
<td></td>
</tr>
<tr>
<td>Gunam Singh</td>
<td>Punjab</td>
<td></td>
</tr>
<tr>
<td>Indrajit Sarkar</td>
<td>W.B</td>
<td></td>
</tr>
<tr>
<td>Kamal Kumar Pandey</td>
<td>U.P</td>
<td></td>
</tr>
<tr>
<td>Kapil Kewlani</td>
<td>M.S</td>
<td></td>
</tr>
<tr>
<td>Lalit Jain</td>
<td>Delhi</td>
<td></td>
</tr>
<tr>
<td>Late Ganpati Shanker Ichharam Majmudar Public Charitable Trust</td>
<td>Gujarat</td>
<td></td>
</tr>
<tr>
<td>Lekha Gupta</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mahadeva Swamy</td>
<td>Karnataka</td>
<td></td>
</tr>
<tr>
<td>Mahesh Ashok Karche</td>
<td>Pune</td>
<td></td>
</tr>
<tr>
<td>Manas Mukherjee</td>
<td>W.B</td>
<td></td>
</tr>
<tr>
<td>Manoj Yadav</td>
<td>Haryana</td>
<td></td>
</tr>
<tr>
<td>Mohit Gumber</td>
<td>Punjab</td>
<td></td>
</tr>
<tr>
<td>Mokshita Kaur Arora</td>
<td>Delhi</td>
<td></td>
</tr>
<tr>
<td>Neeraj Kumar</td>
<td>Delhi</td>
<td></td>
</tr>
<tr>
<td>Nilesh Shivismurti Tripathi</td>
<td>Maharashtra</td>
<td></td>
</tr>
<tr>
<td>Om Prakash Singh</td>
<td>Rajasthan</td>
<td></td>
</tr>
<tr>
<td>Parina Shah</td>
<td>Gujarat</td>
<td></td>
</tr>
<tr>
<td>Pooja Mukesh Kotecha</td>
<td>Gujarat</td>
<td></td>
</tr>
<tr>
<td>Pranav S. Waghe</td>
<td>M.S</td>
<td></td>
</tr>
<tr>
<td>Priyanka Roy</td>
<td>W.B</td>
<td></td>
</tr>
<tr>
<td>Puspender Bikash Acharya</td>
<td>W.B</td>
<td></td>
</tr>
<tr>
<td>Rahul Mehta</td>
<td>Telangana</td>
<td></td>
</tr>
<tr>
<td>Rajeshwari Majumdar</td>
<td>Odisha</td>
<td></td>
</tr>
<tr>
<td>Rajinder Kalra</td>
<td>Chandigarh</td>
<td></td>
</tr>
<tr>
<td>Ram Dulare</td>
<td>Delhi</td>
<td></td>
</tr>
<tr>
<td>Ritesh Awasthi</td>
<td>Chhattisgarh</td>
<td></td>
</tr>
<tr>
<td>Rupali Gajanan Bhadke</td>
<td>M.S</td>
<td></td>
</tr>
<tr>
<td>Sagar Chugh</td>
<td>Haryana</td>
<td></td>
</tr>
<tr>
<td>Saurabh Verma</td>
<td>Delhi</td>
<td></td>
</tr>
<tr>
<td>Sayed Khalid Rohani</td>
<td>Pakistan</td>
<td></td>
</tr>
<tr>
<td>Shaiyad Alam</td>
<td>M.P</td>
<td></td>
</tr>
<tr>
<td>Sri Dipankar Guha</td>
<td>W.B</td>
<td></td>
</tr>
<tr>
<td>Sudhir Mandwani</td>
<td>M.P</td>
<td></td>
</tr>
<tr>
<td>Sunil Arora</td>
<td>Uttarakhand</td>
<td></td>
</tr>
<tr>
<td>Sunil Durgesh Manik</td>
<td>M.S</td>
<td></td>
</tr>
<tr>
<td>Thalassaemia Welfare Association</td>
<td>Tamil Nadu</td>
<td></td>
</tr>
<tr>
<td>Thalassemia Children Welfare Association</td>
<td>Chandigarh</td>
<td></td>
</tr>
<tr>
<td>Thalassemia Welfare Society, Telangana State</td>
<td>Telangana</td>
<td></td>
</tr>
<tr>
<td>Uttam Santra</td>
<td>WB</td>
<td></td>
</tr>
<tr>
<td>Varsha Panwar</td>
<td>MP</td>
<td></td>
</tr>
<tr>
<td>Vijay M Kukreja</td>
<td>MS</td>
<td></td>
</tr>
<tr>
<td>Vikramjit Singh</td>
<td>Punjab</td>
<td></td>
</tr>
<tr>
<td>Vishal Pujara</td>
<td>Haryana</td>
<td></td>
</tr>
<tr>
<td>Vishal Shah</td>
<td>Maharashtra</td>
<td></td>
</tr>
<tr>
<td>Vivek Dilip Lodiya</td>
<td>Yavatmal</td>
<td></td>
</tr>
</tbody>
</table>
Thalassemics India’s 31st Annual General Meeting was held on 02 October, 18’ at Constitution Club, New Delhi from 11:30-2:00 pm followed by lunch. Meeting was attended by 143 members. Welcome Address was given by Dr. Gautam Bose, Vice-President, Thalassemics India. Audited accounts for the year 2017-18 were presented by Hemant Bellani. Secretary’s report was presented by Shobha Tuli. Queries on Luspatercept, Bone Marrow Transplant, Gene Therapy & Chelation therapies were addressed to the invited experts- Dr. V.K Khanna & Dr. Amita Mahajan. Members were also given necessary information about the Disability Act and GST. Viresh spoke about TPAG and its activities. Hemant Bellani addressed the audience by giving a motivational speech. Members appreciated the efforts of Thalassemics India for arranging such an interactive and informative meeting. Meeting ended with vote of thanks by the Shobha Tuli, Secretary, Thalassemics India.

Forthcoming Events:
1. Dr. V.K. Khanna’s clinic at A-9, Nizamuddin West on 03 February, 2019.
2. Outing under Project Spreading Smiles in February, 2019.
3. Dr. Ratna Chatterjee & Dr. Rekha Bajoria clinic at Sir Gangaram Hospital on 2-3 March, 2019.
4. TIF Board Meeting at Fujairah, UAE on 7-8 April, 2019.
8. 7th International Conference on thalassemia.
The idea of using gene therapy to treat the haemoglobinopathies (thalassaemia and sickle cell disease) is, in principle, straightforward. Red blood cells (RBCs) are continuously replenished by bone marrow haematopoietic stem cells (HSCs). Therefore, the stable transfer of a normal functioning copy of a β-globin therapy gene unit into the patient’s own HSC would result in the generation of normal rather than diseased RBCs for life. (Note: no donor bone marrow is needed).

A number of major discoveries and technical advances in gene therapy over the last 20 years, particularly since 2000, mean that, at long last, gene therapy for the haemoglobinopathies looks a serious possibility in the not too distant future.

In 1987, a group led by Prof Frank Grosveld discovered the master regulator of the β-globin gene family, known as the ‘locus control region’ (LCR). It was found that linking the LCR to a β-globin gene unit enables the gene to be efficiently and reproducibly switched on, and to produce a sufficiently high level of β-globin protein to be of therapeutic benefit, if reproduced in a gene therapy context (Levings and Bunger, 2002; Stamatoyannopoulos, 2005).

The stable introduction of the LCR-β-globin therapy gene unit into the patient’s HSCs is via a retroviral delivery vector, resulting in the permanent splicing or integration of the therapy gene into the HSC DNA, which is then retained for life. Overall, the gene therapy protocol employs an ‘ex vivo’ procedure. HSCs are isolated from the patient’s bone marrow and infected or transduced with the LCR-β-globin retroviral vector. The corrected cells are then returned to the patient, who in the meantime has undergone chemotherapy (as in a donor-derived bone marrow transplant) to partially or completely destroy their diseased bone marrow (Persons and Tisdale, 2004).

Early studies with LCR-β-globin gene retroviral vectors based on the mouse MoLV virus and using an ex vivo procedure in animal models, provided good proof of principle. However, it proved very difficult to accommodate LCR-β-globin gene units within MoLV retroviral vectors and manufacture them. In addition, the LCR-β-globin therapy gene units that could be incorporated into this vector system were ineffective at producing a consistent and sufficiently high level of β-globin protein to be of therapeutic value (Antoniou and Grosveld, 1999). However, a major breakthrough occurred in 2000, when the laboratory of Prof Michel Sadelain reported work involving the testing of an LCR-β-globin therapy gene unit within a class of retrovirus known as an HIV lentiviral (LV) vector (Figure 1; May et al, 2000). Prof Sadelain showed for the first time that the LV vector can readily accommodate a larger and more efficient version of the β-globin therapy gene linked to the three most powerful LCR elements (HS2, HS3, HS4), and that application of this vector in an ex vivo bone marrow transplant procedure could completely cure or rescue the β-thalassaemia condition in mouse models of this disease (May et al, 2000; Rivella et al, 2003).

Since then, a number of groups in the US and Europe have built their own versions of the LCR-β-globin gene LV vector (Persons and Tisdale, 2004; von Kalle C et al, 2004; Sadelain et al, 2006). The smallest version of the LCR-β-globin gene LV vector has included only LCR elements HS2 and HS3 in its design, which has significantly improved the ease of vector manufacture (Miccio et al, 2006).

In all these cases, researchers have shown good efficacy in rescuing disease in mouse models of β-thalassaemia or of sickle cell disease. In addition, some groups have shown that, under laboratory conditions, transduction of human HSC derived from bone marrow of severe β-thalassaemia major patients with the LCR-β-globin gene LV vector can correct the globin chain imbalance in resulting RBCs (Persons and Tisdale, 2004; Sadelain et al, 2006; von Kalle C et al, 2004; Roselli et al, 2006).

Remaining problems that need to be addressed in order to improve both the effectiveness and safety of the LCR-β-globin gene LV vector include: (i) reproducibility of function of the vector; (ii) insertional mutagenesis: the integration of the LCR-β-globin gene LV vector into the HSC DNA has the potential to disrupt host cell gene function causing, in the extreme situation, a leukaemia-type condition (von Kalle C et al, 2004), as has been observed in clinical trials using retroviral vectors for gene therapy of X-linked severe combined immune deficiency (SCID-X1; see Nienhuis et al, 2006), which also targets the HSC of the patient. Some researchers have therefore included the chicken β-globin LCR element cHS4 in their LV vector design to try and ‘insulate’ the LCR-β-globin gene unit, which has led to some improvement in the reproducibility of functioning (Persons and Tisdale, 2004; von Kalle C et al, 2004; Sadelain et al, 2006). In addition, it has been suggested that the cHS4 element may act to shield host genes within the HSC from interference by the LCR-β-globin therapy gene unit and therefore promote safety, although this has yet to be formally demonstrated.

These studies led to the...
commencement of the first Phase I/II gene therapy clinical trial for the haemoglobinopathies in 2006. The trial is led by Prof Philippe Leboulch in Paris and aims to treat five β-thalassaemia and five sickle cell disease patients within the age range of 5–35 years. The protocol, as expected, involves an ‘ex vivo’ approach, with patients receiving a full chemotherapy-conditioning programme with Busulfex to destroy their diseased bone marrow (Bank et al, 2005). Up to the end of 2006, two patients with β-thalassaemia had been treated. It is too early in the trial to know if any benefit has been derived.

The trial has not been without controversy, mainly related to the use of a high-risk full chemotherapy-conditioning programme as part of a protocol whose success is still far from certain, let alone in relation to what is currently achievable with a sibling-donor bone marrow transplant.

We eagerly await the outcome of these studies, as well as the commencement of future trials with LV vector designs with higher efficacy and safety profiles.

For your information:
The below mentioned drugs and equipments are available at Thalassemics India office at subsidized rates:

- Desferal 0.5g injection
- Asunra 100mg tablets
- Asunra 400mg tablets
- Oleptiss FCT 90mg tablets
- Oleptiss FCT 180mg tablets
- Oleptiss FCT 360mg tablets
- Desirox 250mg tablets
- Desirox 500mg tablets
- Kelfer 500mg capsules
- Kelfer 250mg capsules
- Defrijet 250mg tablets
- Defrijet 500mg tablets
- Bio –R filter (for 1 unit of blood)
- Bio –R2 filter (for 2 units of blood)
- BB Imugard Filter (for 1 unit of blood)
- RCIVAE (Pall) filter (for 1 unit of blood)
- RC2VAE (Pall) filter (for 2 units of blood)
- Venogliss G-27 Short Needle, length 60cm
- JMS Needle G-27 Short Needle, length 80 cm
- TI-needle G-28 8mm, length 60 cm
- Micrel infusion pump, made in Greece
Good news for patients with Thalassaemia (or Mediterranean Anemia) in view of a new injectable drug that reduces the need for frequent and lifelong blood transfusions. According to the patients, this means that their quality of life will be greatly improved. For example, a thalassaemic patient needs to be transfused approximately every 15 days. By taking this injectable medicine every 3 weeks, the patient will prolong the duration of the effect of blood transfusions.

**TIF's Newly Elected Board Team:**

- Mr Panos Englezos – President
- Ms Shobha Tuli– Vice President
- Ms Elena Mylona- Secretary
- Mr George Constantinou- Assistant Secretary
- Mr Riyad Elbard- Treasurer
- Mr Saeed Jaafar Al-Awadhi- Assistant Treasurer
- Her Highness Sheikha Sheikha Bint Seif Al-Nahyan- Board Member
- Mr Robert (Bob) Ficarra- Board Member
- Ms Romaine Maharaj-

**TIF’s Mission**

The promotion and implementation of national control programmes for the prevention and treatment of thalassaemia and other haemoglobin disorders in every affected country.

**TIF’s Vision**

Equal access to quality health care for every patient with thalassaemia and other haemoglobin disorders across the world.” At the forefront of the fight against thalassaemia and the haemoglobinopathies, TIF is actively involved in education, research and networking that revolve around the multitude of topics relating to thalassaemia and the haemoglobinopathies, through its constantly increasing number of projects.
Manika Kapoor, and Her Message of Hope

Manika Kapoor is a ten year old girl. Yes, she has Thalassemia. But she is so much more than her disease. She is a cheerful little beauty who can smile in any situation. She is hardworking and intelligent, and her only fear is not coming first in her class. She loves to dance. She also enjoys writing poems, some of which she never shows to anyone. She loves to play games, but on a smartphone. She also loves reading, but only comics. She makes the best tea in the world, but only in an electric kettle. She loves ice creams and knows the magic of doubling them by adding chocolates, cookies, jams, and anything else sweet that she can find. She is excellent at playing Monopoly. And if she cheats at it sometimes, you can never prove it.

Does she sound familiar? Well, she is much like you and me. She too is struggling against Thalassemia. She too is determined not to let it defeat her hopes and dreams. There’s only one difference. She’s fictional. She lives in the pages of my third novel YOU CAME LIKE HOPE (available on Amazon & Flipkart).

Mani is the sweetest character of this novel. She has lost her parents and she lives with her guardian. He is Mani’s world. And she is his greatest strength, and his only hope. She is the one whose smiles add rainbows to his dreary life, and whose laughter and merry words are the songs in his otherwise tuneless existence. It does not matter that she has Thalassemia. She is still a blessing. She’s still worth loving, worth fighting for, worth living for.

Although Mani is burdened by her disease, she is still the happiest person in the entire book. Because, you see, Thalassemia isn’t the greatest sorrow in the world. It’s just one among innumerable. Life is hard, maybe more for some and less for others. But it is hard for everyone. It throws challenges at everyone. What’s important is to not let these troubles blight away the light of hope. Because no matter how hard things get, tomorrow might still be a better day.

That is what I believe in. That is what I hold on to. Hope! It’s not just a four letter word. It is the power that can light your way through the darkest times. Some may say that Hope gives false promises that may never come true. But they forget that even then, Hope can be the life spring of strength, courage, and the determination to go on. And together, these can achieve a lot, even if not all.

Emily Dickinson wrote:

“Hope” is the thing with feathers -
That perches in the soul -
And sings the tune without the words -And never stops - at all –”

Don’t kill this little bird. Don’t silence its sweet, beckoning song. Hope on! Because when everything else fails, this voice of God can still give you the strength and will to go on.

Wish you all a happy life ahead,

Jyoti Arora

Jyotiarora.com
Three years ago, I started The Wishing Factory, TWF or The Wishing Factory, is a registered, ISO certified (ISO 9001:2015), not-for-profit organization that works for the welfare of Thalassemia Major and Blood Cancer patients. We aim to continue raising awareness about Thalassemia, a genetic blood disorder (i.e., passed down through families) in which the body makes an abnormal form of haemoglobin. India has been called as the ‘Thalassemia Capital’ with an estimated 300,000 patients suffering from Thalassemia Major and very few among them are optimally managed. Life is indeed difficult since even I’m a patient and I need blood transfusions every 15 days.

Thalassemia major is an inherited blood disorder in which the body makes an abnormal haemoglobin. Thus the patients’ bodies do not have healthy red blood cells and need blood transfusion every fortnight. They also need to take a daily dose of medication to control the level of iron in their bodies. The average life expectancy of a thalassemia patient is only 92-26 years. We support these underprivileged patients by making their wishes come true with individual and corporate philanthropic support. Our activities would not have seen light of the day if it weren’t for our dynamic volunteers. We have fulfilled over 350+ wishes that patients wished to have so far, along with supporting the healthcare and education of over 500+ patients spread across India. We have worked with IRCTC, Adlabs, Alembic Pharmaceuticals, Zomato, Jet Airways etc. in the

We have set up a blood transfusion centre in Vadodara providing free healthcare facilities to patients. We have refurbished a blood transfusion centre at BMST, Bangalore. Additionally, we have an iron chelation pump library providing infusion pumps and medicines for removal of iron from the body in Pune Mumbai, Vadodara and Jaipur.

Throughout these three years, there have been numerous stories which have touched my heart, but perhaps this one is the most special. I was on the Vadodara station waiting for my train to Mumbai, like any other normal day. I was going back to my hostel post my Diwali Break so I was carrying two trolley bags along with a few unpressed clothes. The first trolley bag was merely 7 days old so the wheels were literally gliding as I made my way to the platform from the parking, but the wheels of the other bag was rumbling with pain, barely rolling as they’re supposed to.

My dad offered to come inside and drop me till my coach, however, I never wanted him to make all the efforts of first finding space to park the car, then getting a parking slip and a platform ticket, so I simply asked him to go home instead. I told him that I’ll reach the coach and the luggage look manageable. Hence, I made my way to platform number 3, forcing my rumbling bag over the stairs. Just as I climbed my third stair towards the inquiry counter, the wheel of bag broke. I looked bag and saw my dad’s car slowly moving away towards the exit gate. I never wanted to call him back, so I decided to anyhow manage and drag it to my coach on platform no. 3. Just as I reached halfway through the stairs, something astonishing happened. A porter, more commonly referred to as a coolie, came past me and said, ‘You seem to be struggling with the bags, so why don’t you hand me the bags? I’ll take care of it.’

I am 22, so naturally the youthful energy in me replied that “Thanks, but leave it. I’ll manage and I really don’t need a porter’, besides, I was also skeptical that perhaps he would charge me exorbitantly for a distance that is already half traversed.

Before I could walk further, he simply took one the bag that was broken and ushered me to follow. He led me straight to my berth and then, just as I took out my wallet to pay, he said “I can’t take money from you. You probably don’t remember me, but I can never forget you”. While I was still trying to recollect, he politely told me, that “Sir, 8 months back, you fulfilled my child’s wish. He wanted a box of chocolates along with a toy. Today, he is no more, but I most certainly know that he was happy in the day’s that he lived and you certainly contributed to that in some way or another”. I looked at him, with watery eyes and smiled, thinking that perhaps life indeed is beautiful and whatever you do, eventually comes back to you. Hence, I urge every reader who reads this, please go out and do something beautiful today because the world now, needs more beautiful souls than ever.

-Parth Thakur
Thoughts about Life

Life is a dream Death is awakening someone told me this a long time ago, I don’t know what was in that person’s mind when that person told me this. However I have never forgotten it. According to me Life is like a World War, where every day we fight a battle. Every day I get up to hopes, challenges, excitement, fears etc. I get up every day and hope the day goes well and I survive. As like any battle there are always casualties of war. We win some and we lose some. It is only if there is a miracle we win a battle without casualties which is based on Luck, Destiny, blessings, good deeds of past life etc. Think what you want to however always respect life. Some say Life is test or punishment. Well I am not God so I do not have an answer to that. I get to hear from people that they have given up on life. Well only thing I can say is never give up have faith. Respect life. Everyone will need to fight their own battles with life sometime or the other. Your Parents, Loved ones and well wishers might come in like the UN, to help you and try to soften the impact of life. However at the end of the day you will need to fight your own battles well. It is easy to say however difficult to do I know this. Sometimes I also think lets leave everything and go and live in an isolated place. Well it is easy to say however difficult to do, we are humans being we cannot live isolated we will go mad and become animals. Never despair have faith. My dad always tells me “Try your best and leave the rest” and he is right.

However when you try the world says, ‘why try you need to win, you need to do it, no excuses no questions’. Well competition is talking here. There is cut throat competition in the world and the world says there is no place for weak people. If you want to survive you need to compete. Every man and woman for themselves. This attitude is the main cause for suicides as people feel it is better to end ones life rather than fight the pressures of life.

One should keep in mind there you are not respecting life, and you are not thinking about your parents and loved ones. What will they do after you are gone? The world will shed a tear or two and than forget you as they have to fight their own battles. “Out of Sight Out of Mind”. Everyone is expandable.

Life Never Goes according to plan there will always be speed breakers and obstacles on the way. And if there are no speed breakers and obstacles, the world and people around will create it for you and you know why, due to jealousy, competition etc.

Life Goes on after the end of a hard day a New day begins with a new beginning, hopes, desires, needs etc. Keep going don’t stop. Life is beautiful live every moment as time lost cannot be got back and respect life for what it is. Hard work, determination and strive to live life will take you places. There is no limit to what one can do.

When you are tempted to give up, your breakthrough is probably just around the corner. So just hold on as long as you can. Never give up have faith. Keep in mind if you do not get the breakthrough what you have been waiting for patiently and you have reached a dead end, than two doors will open. One door at your right and other door at your left. Choose carefully.

-Gagandeep Singh Chandok
Inside the doctor’s cabin:

“We are sad to share with you that your daughter has Thalassemia Major” said doctor

What is it doctor? asked the parents. Doctor explained with a calm voice, Unfortunately, it wasn’t as easy as how it was explained at the time of diagnosis. Nevertheless, life moved on, and days changed into weeks, months & years.

Thalassemia is an inherited blood disorder which was a gift from my parents to me :P. I was diagnosed with Thalassemia Major in 1989, almost three decades now. A Thalassemia major patient cannot make enough RBC’s which carry oxygen through the body. What their body produces are defective RBC’s thus they require regular RBC transfusions lifelong to be able to live. Though Thalassemia Major is a Preventable Blood Disorder, we couldn’t prevent it due to lack of awareness.

Nothing much seems to have changed since 1989. Sadly, we are still having new Thalassemia Major births in our country even today. This clearly shows that people are still not aware of this Genetic Blood Disorder. There are over 1 Lakh thalassemia major patients in our country alone and over 10,000 new births every year.

Living with Thalassemia is difficult and annoying. The treatment / management includes painful blood transfusions, regular chelation therapy and continuous lab investigations. The whole process of transfusion takes seven or eight hours, which means a full day, once every two weeks. There are a lot of complications associated with thalassemia, especially transfusion-related iron overload which requires chelation therapy on a daily basis, and this feeling of knowing that the excessive iron going into my body through the regular transfusions is compromising my organs and can damage my heart, liver and other organs, is intimidating.

My humble appeal to all those reading this article - please get yourselves tested for your Thalassemia status on-time, i.e before starting a family. Come for counselling, ask your gynaecologist. Its only when two thalassemia minors plan to have a baby, over each pregnancy, there is a 25% chance of Thalassemia Major child. A simple blood test-CBC & HbA2 will tell you whether you are a thalassemia minor / carrier.

Don’t let the future of your child suffer, and ask your doctor about the disorder, read about it! SHARE it with others and Prevent the birth of new thalassemia majors.

-Sonam Madaan
An article published in Suburb Gurgaon

Thalassemia is Preventable!
We couldn’t, but you must!!

Make a Donation

- Visit our website for availing online donation
- Write a cheque favoring Thalassemics India
- If you wish to send through bank transfer, please contact us.

#Donations to Thalassemics India (Regd.) are exempt under Section 80-G of the Income Tax Act.
Kerala

World Thalassemia day was observed at Regional Science Center & Planatarium, Calicut with various activities. Kozhikkode Mayor sri. Thottathil Ravendran inaugurated the function. Keralam Karassery, Gen. Convener of Blood Patients Protection Council, Kerala honored by the Mayor for his uncompromised fight and various achievements for the blood disorder patients for twenty-nine years. Mr. V. S. Ramachandran, director, Regional Science center, Calicut Presided over the function. The program was organized in the join auspicious of Caring for Childhood Cancer and chronic Illness(C4CCCI) and Regional science center, Calicut.

Dr. K. Suresh Kumar, noted palliative activist and the director of Institute of palliative medicine, Kozhikkode distributed the P.T. Anshif memorial cash award to Thalassemia patients who passed the SSLC public Examination this year.

Dr. O C. Indira, Retired Paediatric Professor, Medical college, Calicut took out a talk on Thalassemia. Mr. Jayendran Retd. Ass. Police commissioner, Mrs Deepa Ajith, Former Secretary C4CCCI also spoke.

Dr. V. T. Ajith Kumar. Head, and the professor of Pediatrics, Medical College, Manjeri, welcomed the gathering. K. M. Sunil proposed the vote of thanks. Various cultural activities were taking place in the function. Sunpharma sponsored the program.

Haryana

Haryana दूरीज दिवस के अवसर पर तेज यू हरसत सूरजकूंड पर भैलासिमिया ग्रास बच्चों को विद्यार्थी महाविद्यालय एडमिनिस्ट्रेटर तेज यू हरस तेज द्वारा हिस्ट्रूक्ट 301 की हिस्ट्रूक्ट ट्रांजर्स अखिल भारतीय जेन के आमंत्रित किया गया। इस अवसर पर बच्चों के लिए प्रयोग में दिखाई पड़ी शेयरेड न्यूज़, एक बच्चों की विशेष जागरूकता का अवसर कार्यकर्ता की गयी थी जिसका बच्चों के उपर निर्भर किया गया। बच्चों के लिए विशेष जपान का व्यवहार की गयी थी जिसका बच्चों के उपर निर्भर किया गया। शेयरेड न्यूज़ में दिखाई पड़ी शेयरेड न्यूज़, एक बच्चों की विशेष जागरूकता का अवसर कार्यकर्ता की गयी थी जिसका बच्चों के उपर निर्भर किया गया। बच्चों के उपर निर्भर किया गया।

Rajasthan

200 फ्लेडक्लाप्टेन! बेट लेंगी फ्लेडक्लाप्टेन

उत्तर प्रदेश: इस वर्ष भी अर्जुन राजस्थान भैलासिमिया दिवस के अवसर पर अर्जुन राजस्थान भैलासिमिया वेबसाइट अर्जुन के तलावाण में आये। दिनांक 08 मई 2018 में इंडियन टॉप टॉप फेरन में सफाई में एयर प्लेटफॉर्म की दुनिया वर्ल्ड ओवर इंडियन टॉप फेरन में सफाई में एयर प्लेटफॉर्म की दुनिया वर्ल्ड ओवर इंडियन टॉप फेरन में सफाई में एयर प्लेटफॉर्म की दुनिया वर्ल्ड ओवर इंडियन टॉप फेरन में सफाई में एयर प्लेटफॉर्म की दुनिया वर्ल्ड ओवर इंडियन टॉप फेरन में सफाई में एयर प्लेटफॉर्म की दुनिया वर्ल्ड ओवर इंडियन टॉप फेरन में सफाई में एयर प्लेटफॉर्म की दुनिया वर्ल्ड ओवर इंडियन टॉप फेरन में सफाई में एयर प्लेटफॉर्म की दुनिया वर्ल्ड ओवर इंडियन टॉप फेरन में सफाई में एयर प्लेटफॉर्म की दुनिया वर्ल्ड ओवर
The awareness camps are also organized from time to time to make public at large aware about the prevention and management of this hereditary disease.

In addition, the association use to distribute sweets/chocolates, juices etc. from time to time. This year on 8th May 2018 International Thalassaemia Day we distributed the sweets/ chocolates etc. to our thalassemics in both centres of PGIMER and GMCH-32. Photographs of this event also attached.

### Chandigarh

Thalassemic Children Welfare Association Chandigarh (Regd.) a Charitable Society, organizes Blood Donation Camps for the Blood Bank of PGI and GMCH-32, so that the thalassaemic patients can get blood for transfusion easily and regularly.

The association organized Blood Donation Camps throughout the year and approx. 30 Blood Donation Camps organized by the association within a year with the help/support of well wishers. In which 8 Blood Donation Camps individually organized by Thalassaemic Children Welfare Association every year in which 7 camps in PGIMER and one camp in GMCH-32. Every year in the series of 8 Blood Donation Camps, the first camp was organized to commemorate the International Thalassaemia Day and this camp always inaugurated by the Director of PGIMER Chandigarh. This year also we organized 8 Blood Donation Camps.

### Uttar Pradesh

Two events were organised on 15th of Sept 2018 at S.G.P.G.I., Lucknow. This was organised by Thalassemics India Society, Lucknow. First was HLA typing in association with Thalassemic Gujarat society. 103 samples were collected. Second, in association with Datri foundation 86 samples were collected.

On 22nd Sept, TIS had organized an awareness programme i.e. Annual Thalassaemia Update-2018 in association with cytogenetic unit, Dept of CFAR, KGMU. The main agenda of this programme was Clinical Management of Thalassemia.
Prenatal counselling, Role of BMT & finally a step towards eradication of this disease. This programme was conducted with full dedication by Dr Nitu Nigan Asstt. Prof. cytogenetic.

The speakers of the programme were Dr Jyesh Sheth, Prof A.K.Tripathi, Prof Inusha Panigarhi, Dr Vikas Dua.