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Dear Thalassemia family and friends,

Welcome to the 46th issue of our newsletter!

Ever since its formation in 1987, Thalassemics India has worked tirelessly in this field, with the innate desire to improve treatment facilities for thalassemics and to spread awareness about thalassemia in the country.

I am reminded of both the challenges and milestones our NGO has come across since its inception.

This year our agenda is to promote awareness programmes, as well as to collect more funds for our underprivileged thalassemics who are looking upon us to support their treatment. We will persistently reach out to look for opportunities to extend our network, in order to make sure that we are able to move ahead in this direction and meet our demands.

Inside, you’ll find features, news and regular columns. The editorial team has tried their best to make this issue different as compared to the earlier issues. A number of our thalassemics have contributed to this newsletter. We hereby extend our thanks to all of them, for their feedback, reports, personal experiences and their inspiring stories.

Congratulations to all those who have received accolades!

Special thanks to our Scientific Advisory Board members! We are short of words to express our gratitude for all of them, for the great work that they have been doing in this field.

I am proud to share with you that I have been re elected on the TIF board as TIF’s Vice- President for another term. I will make sure to do my very best.

Having this opportunity, I would like to thank the donors and our CSR partners for their support.

Thalassemics India’s executive team always strives to serve better the members. I hope you enjoy reading this issue. Do let us know if there are any topics you’d like to see covered in the next issue. Your feedback is very important for us.

With sincere warm regards,

Shobha Tuli
Secretary, Thalassemics India
I thank

Ministry of Health and Family Welfare
Government of India

&

Ministry of Coal
Government of India
(An IS/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
MESSAGE

I am happy to know that Thalasemmics India is organizing a seminar on 8th May on the topic “The Basics of Thalassemia Management: Safe Blood Transfusions, Investigations, Iron Chelators, Prevention Strategies" at New Delhi and also releasing ‘Thalassemia Update’ at the event.

I am hopeful that the seminar will provide a platform to exchange the expertise, experience of medical fraternity to update their knowledge and skills improving quality of health service delivery. This will also help in updating their knowledge regarding the latest methodologies and standards of management and prevention of thalassemia.

I congratulate the organizers and the participants of the seminar and extend my best wishes for its success.

(Preeti Sudan)
New Team of Thalassemics India (2017-2022)

Deepak Chopra  
President

Dr Gautam Bose  
Vice President

Dr V.K. Khanna  
Vice President

Shobha Tuli  
Secretary

Rekha Arora  
Joint Secretary

Anubha Taneja Mukherjee  
Joint Secretary

Arun Sehgal  
Treasurer

Deepak Dhingra  
Joint Treasurer

Rita Jain  
Executive Member

Shivangi Amrit  
Executive Member

Nehal Dhingra  
Executive Member

Viresh  
Executive Member

Gagandeep Singh  
Social Media & Event Advisor

Ashwini Malik  
Financial Advisor

Rajiv Chibber  
Media Advisor

www.thalassemicsindia.org
Meet our Scientific Advisors

Dr M.B. Agarwal
Department: Haematology
Bombay Hospital Inst of Med Sc, Mumbai, India

He is one of the reputed haematologists in the area, and has earned the distinction of being one of the best haematologists.

Maria Domenica Cappellini
University of Milan & Policlinico Foundation IRCCS, Milan, Italy

Maria Domenica Cappellini is Professor of Internal Medicine at the University of Milan and Chief of the Hereditary Anaemia Centre at the Policlinico Foundation, Milan. She qualified as an MD in 1974 at the University of Milan, Italy and has been active in the fields of thalassaemia, haemoglobinopathies, and the haem biosynthetic pathway for over 35 years. Dr. Cappellini has published a large number of peer-reviewed original articles in these areas and is a regular contributor and invited speaker at national and international meetings. In addition, she developed an erythroid liquid culture system from peripheral erythroid progenitors in order to study molecules with the potential capability of reversing hemoglobin switching, or inducing fetal hemoglobin production in view of therapeutic application. Dr. Cappellini is a member of a number of societies, including the European Hematology Association (EHA), the American Society of Hematology (ASH), the Italian Society of Hematology (SIE), the American Society of Hematology (ASH), the Italian Society of Internal Medicine (SII), and Bioiron Society.

Dr Mammen Chandy
Department: Director
Tata Medical Centre, Kolkata, India

He has been a pioneer in the field of haematology and bone marrow transplantation in India and has led the largest and most successful bone marrow transplant services in India at CMC Vellore. He is the director of TMC, Kolkata.

Dr Allan Cohen
Department: Hematologist in the Division of Hematology at Children's Hospital of Philadelphia, USA

He is an active member of numerous professional and scientific societies. He is the former chair and a current member of the Medical Advisory Board of the Cooley’s Anemia Foundation; Chair of the Board of Directors of the American Board of Pediatrics; and President-elect of the Association of Medical School Pediatric Department Chairs (AMSPDC).

Dr Ved Prakash Choudhry
(M.D. FIAP, FIIMSA, FIACM, FISHTH), Sr. Consultant, Department of Hematology, Fortis Escorts Hospital, Faridabad Batra Hospital & Medical Research Center, Tughlakabad Institutional Area, New Delhi, India

He retired as Professor & Head of Hematology, AIIMS, New Delhi. He has clinical experience of over 50 years of managing various blood disorders. He has worked extensively in the field of thalassemia. He has published over 100 chapters in various books, and over 350 papers in National & International Journals. He has been awarded multiple International & National awards for his contribution in the field of hematology. He initiated DM hematology program at AIIMS.

Dr Ratna Chatterjee
Department: Reproductive Medicine Unit University college of London, UK

She is a consultant in reproductive health of adolescent and adult survivors of chronic and serious disease with special interest in haemoglobinopathy, chronic renal disease and recipients of chemotherapy for cancer - IFWH of UCL/UCLH.
and has been member of various advisory committees in ICMR, Ministry of Health, Government of India.

Dr Suthat Fuchareon  
Department: Thalassemia Research Centre, Mahidol University, Thailand

Dr. Fuchareon is internationally recognized for his work on thalassemia in Thailand and Southeast Asia. His scientific interests encompasses the spectrum of basic, translational, clinical and epidemiological research. Work from the Thalassemia Research Center at Mahidol University has set the standard for defining the molecular genetics, genomics, and genotypic/phenotypic correlations of thalassemic syndromes.

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

He is appointed member of Project Advisory Committee on Anemia in ICMR, New Delhi. He is also a scientific expert in consultative advisory committee on Anemia Indian council of medical research.

He is also an Expert for selection of Candidates for Fellowship in Hematology-Oncology, by National Board of Examinations

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

He is the Chairman, Child Health Institute, Sir Ganga Ram Hospital. He has over 40 years’ experience. His main interest is Thalassemia. The doctor is known to take care for the patients with an immense amount of sensitivity not just for their concerns but that of the family too.

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

She is giving paediatric services at Apollo Hospital for over 20 years. Offering an exemplary care and medical help to infants, children and adolescents, she as a renowned medical practitioner has earned a wide recognition over the years.

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

Dr. Antonio Piga developed and leads the reference Centre for Hemoglobinopathies, endorsed by Italian Ministry of Health and European Rare Diseases Network.

His research activities are focused on novel diagnostic and therapeutic approaches for thalassemia and iron overload, academic teaching and medical librarianship. He is an author of more than 180 scientific publications in peer-reviewed journals.

Dr Farrukh Shah  
Department: Haematology, University College London, London, UK

She has a special interest in the management of transfusion iron overload and haemoglobinopathies. She is actively involved in clinical research in iron chelation and is a local investigator and national investigator for a number of clinical trials. She also works as a medical adviser to the UK Thalassaemia Society.

John B. Porter  
MA, MD, FRCP, FRC Path, Department of Haematology, University College London, London, UK

John Porter is a Professor of Haematology and Consultant Haematologist at the University College London Hospitals in London, UK and head of the joint Red Cell Unit for UCLH and Whittington Hospitals.
He is Professor of medicine at the division of Hematology- Oncology of the American University of Beirut Medical Centre, Lebanon where he is also associate chair of research.

In addition, he is a consultant hematologist at the Thalassemia Department of the chronic care centre in Hazmieh, Lebanon and a fellow of the Royal college of Physicians

Dr I C Verma
Department: Advisor, Institute of Genetics and Genomics, Sir Ganga Ram Hospital, New Delhi, India

He is a Geneticist. He practices at Sir Gangaram Hospital in Old Rajinder Nagar, Delhi. He has an experience of 52 years in this field.

Dr. Verma has been awarded various recognition, including prestigious FRCP Fellowship, Ranbaxy Science Award, ICMR, NAMS and BC Roy Medical Council award etc. In the year 2003, he made a successful entry in LIMCA book of records as a pioneer in genetic, in India. Dr. Verma is a member of the advisory body of the World Health Organization Committee of Genetic Disorder.

Dr John Malcolm Walker
Department: Consultant Cardiologist, Hatter Cardiovascular Institute, London, U K

He is a physician and cardiologist with nearly 40 years of experience. He is having improved understanding of heart problems in individuals with blood disorders leads to better outcomes for patients.

Thalassemia treatment and compliance could be challenging, especially with adult thalassemics. Don't lose hope-there is hopeful news round the corner:

- A new treatment to increase the blood transfusion gap.
- Gene Therapy within the next 2-3 years.
Behind the Desk of Thalassemics India

Rashmi Kalra

Job Title: Office Administrator
Ed Qualification: B. Com, Delhi University
Job Description: Attending to thalassemia parents & patients; maintaining official records of all projects & handling day to day official work. Looking after all administrative needs of the office.

Sonam Madaan

Job Title: Head - Communications
Ed Qualification: B.A (Hons) English, Delhi University
Diploma in French Language, AFD, Pursuing M.A (English)
Job Description: Managing the website; handling Social Media initiatives and activities and providing creative content and digital assets.

Sangeeta Mittal

Job Title: Care giver at Thalassemia Unit, St. Stephen's Hospital
Ed Qualification: B.A, Ranchi University
Job Description: Assisting thalassemia patients and their families in the Thalassemia unit at St. Stephen's Hospital & maintaining their medical records.

Indu Sughal

Job Title: Co-ordinator Bone Marrow Transplant Project.
Ed Qualification: BDS, Post Graduate in Nutrition Science, Post Graduate Diploma in Public Health
Job Description: Co-ordinating the Bone Marrow Transplant maintaining Project data & Handling corresponding of BMT cases.

Swati Tuteja

Job Title: Associate
Ed Qualification: B.A (Economics & Office Management), Delhi University
Job Description: Assisting in communications; recording membership data and handling all medical couriers.

Sheela Davis

Job Title: Care giver at “Preeti Tuli Thalassemia Unit”, Sir Ganga Ram Hospital
Ed Qualification: Senior Secondary
Job Description: Assisting thalassemia patients and their families in the Thalassemia unit at Sir Ganga Ram Hospital & maintaining their medical record and coordinating with the families for the Thalassemia Clinic held every Wednesday at the hospital.

Mahtab Alam

Deviram Pokherel

Kishan Prasad

Surya Pal

other staff members
Congratulations...

**Buddhadev Goswami**

He has qualified GATE 2018 exam in Biotechnology with All India Rank 963...

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**Kartik Dhingra**

He has completed his 12th Class Education (CBSE) from Oxford School, Vikas Puri securing 91.6% marks.

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**Pooja Chawla**

She is working in Muthoot Fincorp Limited and recently got promotion in the company as a Assistant Branch Manager. She has participated in Ramp Walk Competition in Muthoot Fincorp Limited at National Level and won 1st position there.
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<th>Name</th>
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<td>Sonny Iqbal</td>
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<td>D. K. Narula</td>
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<td>Yogender Kumar Arora</td>
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<td>Nalin Goel</td>
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<td>A. Haque</td>
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<td>Sonia Narula</td>
<td>2100.00</td>
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<td>Anita B Ramchandani</td>
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<td>Manit Singh</td>
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It is owing to the massive strides in the field of medicine and the relentless efforts of the government, that we are witnessing the start of a whole new era in the area of thalassemia and advocacy related to its various aspects. The recent inclusion of thalassemia in the list of disabilities under The Rights of Persons with Disabilities Act, 2016, has given an unprecedented boost to the spirit of thalassemics in India and the Supreme Court’s interpretation of thalassemia as a benchmark disability for the purpose of admission to a medical seat has further empowered the patients of thalassemia to dream and do bigger – for themselves and for the country. In this background, a group of seven adult thalassemics accomplished in the field of IT, Education, Law & Psychology, came together to form the Thalassemia Patients Advocacy Group in June 2017 under the umbrella of Thalassemics India.

In recognition of the fact that there remains a considerable ground to cover though, particularly with regard to the Availability and Safety of blood; Management & Care of Thalassemia; and Prevention of Thalassemia, the Group is ready to take up advocacy around these important issues and organized its first half-day long Seminar on the Policy Interventions for the Evolving Needs of Thalassemics in India, on 16th September 2017, at Tamarind, India Habitat Centre, Lodhi Road, New Delhi. The programme started at 9.00am. The Seminar also marked the Launch of Thalassemia Patients Advocacy Group, which is the first of its kind in the world.

On behalf of Thalassemics India, the welcome address was given by Mrs. Shobha Tuli, Secretary - Thalassemics India, whereas Mr. Deepak Chopra, President-Thalassemics India, along with the other dignitaries officially launched the Thalassemia Patients Advocacy Group. Thalassemics India is the umbrella organisation for the PAG, which has been doing pioneering work for the cause of Thalassemia and thalassemics in India, for more than 30 years. The session also addressed the demands of Thalassemics for safe blood, Blood on call facility without replacement, NAT screening, pre-storage filtered blood, free medicines for Iron Chelation and request for registration of thalassemia patients who have crossed the count of 2000 in Delhi NCR region. The Hon’ble Deputy Chief minister of Delhi, Mr. Manish Sisodia, was the chief guest for the occasion, who graced the event with his presence and emphasised the need for initiating and creating awareness and supporting the needs of thalassemics. He promised to ensure that the information on thalassemia would be disseminated in all the schools in Delhi. He also appreciated and lauded the efforts of the Thalassemia Patients Advocacy Group and Thalassemics India and assured to organise prevention programmes and meetings in collaboration with the state health department and Delhi NHM. He further discussed idea of expediting the process of taking things ahead.

The session was also attended by Shri B.N. Satpathy, Principal Advisor, NITI Aayog. Shri Satpathy committed complete support to the Patients Advocacy Group and stressed on the need for the development of a National Policy for Thalassemia along with development of a Strategic Plan for the same.
Further, Ms. Vinita Srivastava, National Consultant, Blood Cell (NHM), shared the initiatives for prevention and management of Thalassemia across the country. She also took the opportunity to suggest the formulation of an advisory committee for responding to the needs of thalassemics in Delhi. The chief guest Shri Manish Sisodia, assured her of the necessary support and action, at his end.

The Special Guest for the occasion was Dr. Kamlesh Kumar Pandey, The Chief Commissioner for Persons with Disabilities, who assured the support of his Department and stressed on the need for eliminating stereotypes and sensitizing the society towards the needs of thalassemia patients.

The seminar was also attended by Dr. Vanshree, Director - Blood Bank, Indian Red Cross Society, who addressed the session on Availability and quality of blood for Thalassemia patients. She accepted the importance of safe and NAT Tested blood for thalassemics by seeking support through the medium of Corporate Social Responsibility and the Central and the State government.

The Annual General meeting was held on 03 December, 2017 at Constitution Club, New Delhi. The meeting was attended by more than 100 members. After a brief welcome by the President, Secretary’s report was shared followed by 2016-2017 audited accounts.

Dr. V. K Khanna gave a talk on “New Chelation Drug- Oleptiss “ followed by questions & answers session. The meeting ended with vote of thanks followed by lunch.
Participation in the 14th International Conference on Thalassaemia & Haemoglobinopathies and 16th TIF International Conference for Patients and Parents, Greece

Thalassemics India was well represented by Shobha Tuli, Gagandeep Singh, Anubha Taneja, Hemant Bellani, Viresh Piplani, Shivangi Amrit, Nehal Dhingra and Anuj Wadehra. Anubha Taneja’s talk was part of the opening ceremony and was very well received by all. There was also a stall of Thalassemics India which had information material on Thalassemia and other literature printed and published by Thalassemics India. This conference saw a large representation of patients and parents from all over India.

The conference spoke about the newer drugs and their stages of research among many other newer protocols in management of Thalassemia.

We are happy to announce that Mrs. Shobha Tuli, Secretary, Thalassemics India has been re-elected Vice President of Thalassaemia International Federation.

Special Thalassemia Clinic held at “Preeti Tuli Thalassemia Unit”, Sir Gangaram Hospital, New Delhi

A special Thalassemia Clinic was held at Sir Gangaram Hospital, New Delhi on 10th March & 11th March, 2018. We had invited the expert doctors in Obstetrics and Gynaecology from UCLH, London. The doctors did consultation for over 40 Thalassemia patients who came from Delhi, Kolkata, UP, Haryana & Nepal.

As part of Thalassemics India ongoing activities to improve thalassemia care. This clinic was planned to give an opportunity to our adult thalassemics to discuss their issues in private. As per the feedback received by us all parents and patients who visited the clinic seems to be satisfied and pleased with the arrangements done by Thalassemics India and Gangaram Hospital.

Thalassemics India would like to thank the invited doctors for their time and diligence.

We feel really very thankful to Dr. V.K. Khanna and his team at the hospital for their kind support.
14th International Conference on Thalassaemia & Haemoglobinopathies and 16th TIF International Conference for Patients and Parents, Greece

“Who if not you? … for the stake in decision making for thalassemics” as well as the whole-hearted acceptance to PAG’s keynote presentation by almost everyone – patients, doctors, administrators alike!

“Grass is always greener on the other side”. So True!!

With respect to medical care and treatment, there is a common belief that India is way behind as compared to developed countries. This is not always the case and Greece conference reaffirmed it. In Greece, we met patients impacted by some rare diseases requiring frequent transfusions just like thalassemia. These patients were from some of the developed nations and were struggling to get adequate blood transfusions and maintain the minimal Hb levels due to lack of medical expertise, care and awareness. While patients in India are performing so well in all spheres of life, such patients experience poor Quality of Life due to inadequate transfusions. I feel sad for them and so proud regarding the specialized care and treatment we receive from our doctors. So, CHEER UP for the good things we have and keep working towards a better future!!

“Greece was special for me! Not only because it was my first International speaking engagement, but also because I was delivering the Key Note Address before the doctors and professionals I owe my life to. For me, it was an absolute privilege to speak on a unique topic like “Patients as Equal Partners in Decision-Making: A Global Reality”. My presentation focused on the roles that patients can play in decision making related to their treatment and other aspects related to their condition. During the presentation, I relied on examples of Patients Organisations across the globe. I felt proud to share the Indian experience and the start that we have made with Thalassemia Patients Advocacy Group in India. The response from the audience was overwhelming. I was particularly delighted to note that India stands ahead of many developed countries in terms of policy making, amongst other aspects related to management of thalassemia. In this particular sense, the conference was an eye opener for me and I will cherish its memories for years to come.”

“I am not afraid of storms, for I am learning to sail my ship.”

If I have to summarize about my experience or takeaways from the conference held in Thessaloniki, I would say that it was exhilarating and eye opening.

As far as the sessions were concerned they were really informative wherein I
realized that everything boils down to how we manage our chelation. The moment we have a condition where iron is excessively deposited in the various organs of our body, it will affect them whether in terms of the heart, kidney, liver, etc. On a personal front I have had some renal issues and eventually it all boils down to the point that we need to be regular instead of being reckless in terms of our medication.

Additionally, I was also amused with the idea of infusion pumps which could be used for travel for longer period of time. But when we did try the sample, we comprehended that if a person is working and traveling, then it may suit the needs for chelation but on a regular basis they are slightly inconvenient unless the person is ready to spare 36 hours or solely for this purpose. Since I have been used to the Venogliss or the JMS needles, we came across certain samples of needles which apparently were being claimed as painless, even in comparison to Thalasets.

The conference was a great way to meet and interact with people, not only from different societies but also from diverse backgrounds and engaging with them over technologies and approaches followed globally for the management of Thalassaemia. These conferences also let us brainstorm not only amongst each other but enables us to have a conversation with each other through the Patient’s and Parent’s sessions, making you aware of the innumerable possibilities and technological developments in as far as Prevention, care and management of Thalassaemia is concerned.

Last, but certainly not the least, was another significant development which interestingly gave a new perspective to the present and upcoming conferences on Thalassaemia and Hemoglobinopathies, initiated by the PAG Thals (Patients Advocacy Group for Thalassaemia) which was represented by Anubha. She was a speaker at the session related to Public policy and Advocacy which was extremely well received by one and al. The idea being that who else better than the patients themselves to represent their needs and interests in the field of policy making and advocating the needs for certain right and benefits that shall not only aid the ones affected in the present day but also help the future generation where we all shall lead each other by example. It has to be patients themselves who now not only be aware of the policies but also should learn to take a stand an be vocal about their rights and needs by being pro-active when it comes to policy making. If we won’t stand up for ourselves, who will?

Lastly I would really like to conclude by quoting Nicholas Kristof (an American journalist and political commentator and a winner of two Pulitzer Prizes) who stated that, “One of the most crucial kinds of intervention is in advocacy. We can think about charities in the context of delivering services, and indeed that is part of their job, but advocacy is also getting governments to step up the plate. They can also give more voice to those who don’t have one.”

“...”

Viresh

“It was a wonderful experience to attend 16th TIF conference for Patients & Parents. I received lot of information around how the future is going to be for Thalassemics, what researches are going on and the progress made so far.

We are very close to some of the major breakthrough in the area of Thalassemia treatments. In my opinion one of the key aspect about the new and advanced treatments is that it should be affordable and available for all the Thalassemics across the globe.

Many important topic were covered as part of this conference. One of them was was “Patients as equal partners in decision-making”. In this Anubha Taneja Mukherjee from Thalasemia Patients Advocacy Group discussed about the importance of active participation of patients in multiple areas not only related to their health and well-being but also the government policies impacting them. The need and importance of including patients in the decision making for their treatements, policies etc. and how Patients advocacy groups are working globally and how they are benefitting the lives of the patients.

We all know about Iron Overload and damages caused by it and importance of Iron Chelation therapy. This is one of the most important topic in any conference about Thalassemi. This session talked about complications of Iron overload in Transfusion dependent and Non Transfusion Dependent Thalassemi. Based on recommendations, to test Iron levels, MRI using T2* (in milliseconds) and R2* imaging techniques are considered the best for liver iron concentration quantification. Serum ferritin results in correlation with the liver iron concentration quantification will give proper insights about the condition of Iron in the body.

There were many other interesting topics covered on Gene-Therapy, Osteoprosis in Thalassemi, Hepatitis C treatments etc.

Apart from these sessions, we got the chance to meet and make many Thalassemics friends across the globe. We visited stalls displaying new devices like disposable pumps, Infusion Set etc.

This conference gave us a glimpse of future and a ray of hope. We are filled with optimism and hope for a better live for all our Thalassmic friends.”
**Feedback from Parents/ Patients**

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<thead>
<tr>
<th>Feedback</th>
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<tbody>
<tr>
<td>“Thalassemics India is the best NGO”</td>
<td>Nikhil Vaid</td>
</tr>
<tr>
<td>“Very good service from society-Thalassemics India”</td>
<td>Mandeep Singh Suri</td>
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<tr>
<td>“Very helpful society”</td>
<td>Juhi Thakkar</td>
</tr>
<tr>
<td>“Thanks to Thalassemics India for taking good care of the children”</td>
<td>Minty Baroota</td>
</tr>
<tr>
<td>“It is great help of medicines at Thalassemics India”</td>
<td>Mehak Bhasin</td>
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<tr>
<td>“Thalassemics India is doing good work”</td>
<td>Nimish Malik</td>
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<tr>
<td>“Very good service”</td>
<td>Mughdha Verma</td>
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<tr>
<td>“Thank you so much Thalassemics India... for being with us... and helping us like any thing... we are so thank full to you all”</td>
<td>Deepak Singhania</td>
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<tr>
<td>“I will never forget your help...in this costly world and your this kind of help giving boost us to live easy”</td>
<td>Baidya Nath Ghosh</td>
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<tr>
<td>“We would like to pass my sincere thanks for providing support”</td>
<td>Renu Sapra</td>
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<tr>
<td>“I would like to thank you for the help given by you for blood transfusions filter and other medicines”</td>
<td>Suresh Behl</td>
</tr>
<tr>
<td>“Warm wishes to the society”</td>
<td>Jeetendra Kathpalia</td>
</tr>
<tr>
<td>“Through this message, I want to pass my sincere thanks for providing help &amp; support”</td>
<td>Sahil Bansal</td>
</tr>
<tr>
<td>“It’s a very helpful and co-operative action from Thalassemics India to forward the hand for the thalassemic patients in providing filters and day care services at the hospital. I am really very thankful for your help and hope for more extended services from the Thalassemics India in future for the betterment of patients &amp; parents”</td>
<td>Sonia Jain</td>
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<td>“Thalassemics India has always been helpful”</td>
<td>Pooja Ahuja</td>
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<td>“You have helped me a lot by providing me the facilities”</td>
<td>Praneeta Mittal</td>
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<td>“I am very grateful to the society for the facilities”</td>
<td>Sunman Singh</td>
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<td>“I feel very proud of Thalassemics India”</td>
<td>Lakshay Arora</td>
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<td>“Best wishes for the society”</td>
<td>Nikhil Jain</td>
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<td>“I feel really obliged to the society”</td>
<td>Karmanpreet kaur.</td>
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<td>“Authority are requested to continue doing best for treatment”</td>
<td>Yogesh Lalit</td>
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<td>“Thalassemics India is doing a marvellous job”</td>
<td>Prem Kataria</td>
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<td>“You are doing really good...keep it up”</td>
<td>Kartik Dhingra</td>
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<td>“Thalassemics India is a supportive society”</td>
<td>Asha Ahuja</td>
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<td>“Very good service”</td>
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<td>“Very supportive society”</td>
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Hematopoietic Stem Cell Transplantation Project

Criteria
1. Patient’s age to be less than 12 yrs.
2. Patient should have 100% HLA matched sibling donor (minimum matching ratio: 6/6)
3. Patient’s family income to be less than 5 lakhs per annum.
4. Resident of India.

Bone Marrow Transplant Centres
1. CMC, Vellore
2. TMC, Kolkata
3. AIIMS, New Delhi
4. Rajiv Gandhi Cancer Institute and Research Centre, New Delhi

Any thalassemic patient fulfilling this criteria can get financial aid upto Rs. 10 lakhs from Coal India Ltd.

Submit your application to:

Thalassemics India
A-9, Nizammudin West, New Delhi - 110013
Tel. 41827334, 46595811
Email: thalcind@yahoo.co.in, info@thalassemicsindia.org
www.thalassemicsindia.org
Increase chances of speedy recovery

Leukocytes in donated blood can cause

- Febrile non-hemolytic transfusion reactions (FNHTR)
- Transmission of infectious agents like CMV
- HLA alloimmunization and immunosuppression

Which may lead to

- Postoperative infections and complications
- Unnecessary investigations and tests
- Increased cost of treatment

Use of leukodepleted blood can help reduce these complications

with Leukodepleted blood

For more details contact your blood bank

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THALASSAEMIA UPDATE

Straight from The Heart

With the way the current world revolves, diseases have become more common than ever. From awareness campaigns for AIDS to marathons for cancer awareness to driving polio eradication through mandatory home visits, people are striving to gain knowledge and prevent harm.

But what about silent killers? The diseases that you don’t even know about? The one that can be easily prevented, if only you knew about them in the first place? If only your doctor had asked you to get that one test? The one that my parents wish their doctor had asked them to get.

It’s a Thalassemia trait test – one that detects whether a person is Thalassemia minor and if their partner has the same trait, their child is susceptible to be a Thalassemia major patient. And it’s a 25% chance that this may happen. Like it happened with me.

I was only 3 months old when my grandfather looked at my pale face, and concerned, rushed me to the hospital. Inquiries, painful tests and tense hours later led to the conclusion that I was suffering from an inherited genetic blood disorder, and I was a Thalassemia major patient.

Thalassemia is a disease that affects the human body’s ability to create hemoglobin and red blood cells. In other words, your body cannot create it naturally. This is why my mom associated the word transfusion and not troublesome with me, when I was just two years old. It wasn’t tantrums that led me to skip school but the basic need for blood, something your body creates naturally.

The next couple of months meant being in and out of the hospital every day. I was too young to know the consequences of my disease, but for my family it was a fight with destiny, cursed of luck and the last resort of having hope.

And yet I remember my early school years as beautiful. Labeled as ‘Little Miss Sunshine’ girl in my junior school, to me even my fortnightly transfusions were normal. It was obviously not a process that I enjoyed or even understood but I accepted it.

As the years passed, I realized that this situation I had landed up in, was for no fault of my own, made me unique. Unlike my classmates, I was not reprimanded for missing classes or even missing a few days of school. Everyone understood me and were always helpful. And most importantly, I still made friends and attended all the birthday parties. Smiling, and enjoying my life, the obstacles that lay ahead of me were something that I was prepared to tackle, head on. Life has taught me, albeit in a hard way, that no quality is more important than that of resilience and the spirit of refusing to give up.

Always interested in pretty little things, I decided to pursue my passion to be a jewelry designer. I joined the Gemological Institute of America (GIA) and was conferred a Diamond Graduate and Jewelry Designer, and I constantly work towards achieving my dream of starting my own jewelry line.

But it is only because of the support that I get, each day, from my parents, my brother, my whole extended family and group of friends, that I still blissfully dream of building my kind of future.

And in this future a very important part is to ensure that as many people are aware about Thalassemia as possible. Let me tell you why!

Thalassemia is something that is EASILY PREVENTED. All it takes is 1 test when you conceive to know if your child is a carrier. All it takes is one medical test of your prospective partner to know if he or she is a minor carrier. Remember all the kundli tests that you think of getting done? Add just 1 medical test to that list.

Lack of awareness is a bigger reason for the spread of thalassemia than even genetics. I want people to be aware because I am blessed that I have a family that could support me and provide me with the right medical support and financially afford the care that I needed.

But imagine the kind of financial strain, the emotional trauma and the physical problems that my family would not have to go through, if my mother would have got the chance to take that one test. A test, that costs the same as an ultrasound. A test that my mother’s doctor did not even ask her to take! One that my mother herself, did not ask to take. And why did this happen? Because no one was aware.

And I wish there were efforts to create more awareness. From campaigns, to regular meetings (yes there is Thalassemics India and we meet often!), to even a Bollywood rom com, because why not! We had the movie Salaam Namaste (remember the reason why Saif Ali Khan had to take a blood test) so why not another?

Thalassemia has made me aware of how fragile someone’s life can be, and how the right support system can make that same life a beacon of strength. I live a normal life today, one filled with regular outings, dresses to try, weddings to attend and maybe someday get married myself.

Regular medicine intake, like you would do when you’re diabetic, is all that we need to take care of. And
with the advancements in science, such medicines have developed that I no longer need to put injections for 12 hours, I just need to pop a tablet in 2 minutes.

I could tell you much more of what I went through, but I’d rather tell you of what I look forward to. I look forward to transfusions because I get to talk to my favorite doctor, I look forward to my aunt coming over and cooking my favorite dish and I look forward to continue dreaming.

But I am constantly aware of the fact that I am different. And somedays I wish for certain things, just like I am sure you do. But while you have days where you wish that your life was replicating a movie or a novel, I wish for normalcy. Which is when I do what every other female does - cry a little, grab a tub of popcorn and let Ranbir Kapoor take me to a better place. And chocolate, of course!

Lastly, more than my family, more than my closest friend or my latest crush, even more than my ever patient mother or my sometimes irritating but forever understanding brother or my strength – my father, more than all of them, I would like to thank blood donors.

The random person who was willing to donate even a drop of blood, you have given me and many other patients like me, hope. You have given us a chance at survival. It is patients like me, hope. You have given me and many other donors.

of them, I would like to thank blood

The thalassemia's are a heterogenous group of hemoglobin disorders in which the production of normal Hb is partly or completely suppressed as a result of defective synthesis of one or more globin chains. All patient with thalassemia requires ABO and Rh(D) compatible blood. As you would be aware that the recommended treatment for thalassemia major involves lifelong regular blood transfusions, usually administered every two to five weeks, to maintain the pre-transfusion haemoglobin levels above 9-10.5 g/dl. But in other ways, blood transfusions expose the patients to a variety of risks. Thus, it is vital to continue to improve blood safety and to find ways of reducing blood transfusion requirements and number of donor exposures. Another aspect to worry about is accumulation of excess iron in the body because of RBC transfusions which further causes iron over load in the patient. In the absence of any mechanism of human body to excrete excess iron, chelation therapy is essential and constitutes the second important arm besides the transfusion therapy towards the clinical management of such patients. Bone marrow Transplantation from HLA-identical siblings has been increasingly adopted for curing Thalassemia. The general applicability of a bone marrow transplantation is limited by the availability of a related HLA matched donor. There is one in four chances that any given sibling will be HLA identical. Because most patients with thalassemia do not have a compatible sibling donor, there is interest in using matched unrelated donors. Unfortunately, the complications rate of transplants in such cases are generally higher than a sibling matched transplants. Stem cells have the remarkable potential to develop into many different cell types in the body during early life and growth. In some organs, such as the gut and bone marrow, stem cells regularly divide to repair and replace worn out or damaged tissues. The use of stem cells obtained from umbilical cord blood collected at the time of delivery has received considerable interest across health care industry or in other words transplant surgeons. There are several possible advantages to this approach. First stem cells can be easily obtained at birth, and often in sufficient quantity for a successful donation – thus avoiding the bone marrow harvest of a donor at a later stage which would depend case to case. Secondly, GVHD – Graft Versus Host Disease would be less as stem cells are obtained at this early stage in life. More importantly, I believe the routine collection of cord blood stem cells from all births would provide a wider pool of donors for BMT therapy specially for unrelated matched donor requirements. Cord blood when used with Bone marrow
provided significant successful results as in my own case. The same combination has been used in treating as well as curing successfully for my daughter who had been a patient of Thalassemia major. We had a long fight in life for battling with Thalassemia Major and having a matched sibling with a right approach towards preserving Stem cells at the time of birth has supported us now to win over thalassemia major and striking it out of my daughter’s as well as our family forever. Cells being the building blocks of human body has proven to have significant importance. For me it’s like a Term insurance which we all buy but never want to be used, same way stem cell banking should be performed, where in no one should have such chance in life to use it but unfortunately, if one must use it then fortunately serves as a backup. The utmost support in managing/curing such disorders is via skilled doctors who are serving to cure this ailment from the society via BMT procedures. I am very much thankful to Dr. Sunil Bhat (Consultant & Head of Pediatric Hematology, Oncology and Bone Marrow Transplantation Service at Mazumdar Shaw Medical Center of Narayana Health City) for his continued support and carrying out the BMT for my daughter. Also, with great respect, thanking Dr. Amita Mahajan (Senior Consultant in the department of Pediatric Oncology and Hematology at Indraprastha Apollo Hospital, New Delhi.) for supporting us in initial days for fighting with such a deadly disorder and educating us with a right path to be followed in managing such ailment going forward. In addition to the support from the doctors we came across, Cryoviva has played a very significant role in my tough phase of life. Cryoviva seems to be best in industry for stem cell banking as processes and approaches followed in management of stem cells from initial stage till ordering are of world class standards. Most importantly the company has a robust support during retrieval process & has several success stories like ours. Many heartfelt thanks to Thalassemics India for their continued efforts for last 30 years in supporting via needed educations, conferences, subsidized rate offerings on drugs and equipment for needy families/patients, spreading awareness among public & facilitate screening and prevention programmes for control of Thalassemia. Most importantly helping mankind as an aim to make India Thalassemia free.

Niyati Arora

I vaguely remember reading in the previous thalassemia magazine edition where my friend wrote that “My life is as normal as any other of my age, Its just that you go to movies once a month and i go for transfusions”. I could totally relate with the thought because we are born with it and have lived with it. So going for blood transfusion every 21-25 days has become a part of life. From our perspective its a necessity like you have Five basic necessities food, water, shelter, clothes & education, we have one more; blood and we need to fulfil it as normally as you do the other Five. So i don’t understand why my story or my struggles and success are more important than any other and to be covered in a magazine article. If i have achieved somethings in life until now its because i have been blessed with all the 6 necessities i need that not everyone is lucky enough to have. And even much more including my parents support. That doesn’t mean there are no problems in my life. No one’s life is perfect. I have had downs in life infact many of them, but i have learned to live with them to face them and if they cannot be solved then make them a part of your life just like Thalasemia.

So if i were to write something to inspire my fellow friends who have 6 basic needs i will tell them that everyone has problems some or the other and everyone has a reason to live and smile. Its just that which one you choose to focus and talk about more. I strongly believe that life is like a mirror if you smile at it it definitely smiles back. If you must know about me.

I am 24 years old. I have done masters and 3 years of japanese language and currently doing japanese interpretation job. I have been on scholarship to japan for 10 days as i stood first in North India japanese language speech contest and then stood First in The All India Japanese language speech contest recently. These are some my current achievements. I love to travel and have been blessed with opportunity to travel alot in life. Travel is my passion and japanese language is my skill. I love to make travel vlogs, watch japanese and english movies, read inspirational books, draw and spend time with family and friends in my free time. I am happy with my life, being able to live and have enough to run after my dreams.

I have full acceptance to My life because its MY LIFE if you have not given your life acceptance yet then please do it that way Thalassemia will be your strength not weakness.

Jayati Goswami

No one can make you feel inferior without your consent. So, ignore that kind of people. Only surround yourself with people who will lift you higher. Do what you can, with what you have, where you are. Enjoy the whole part of life. Be Happy………

www.thalassemicsindia.org
I knew I will get married to the best person on earth and it did happen. My husband is a beta Thal major patient & I am normal, not even carrier. My family was unaware of such disease in nature.

Rahul is from Kolkata and I am from Mumbai. We got friendly before marriage.

We have a long story about our marriage. It was very difficult for me to convince my parents specially my father for me to get married to Rahul. But I tried and tried until success. And so it happened. Now I am happily married to my love Rahul.

My parents and family like him more than to me.

Rahul, is a gem of a person. He is very loving and caring. I am really blessed to have him as my life partner. He has taken very good care of himself. Also his good health credits goes to my mother in law, who has struggled so many times, in his childhood, for his healthy life. Now after marriage Rahul has also started good care of himself with proper & regular medication. He has changed personally towards himself. He has set life goals and higher aims to achieve. We see improvement in his every report.

I believe, we should accept people as they are. Everyone just need love in this world. To love and be loved, is the most wealthy person on earth. Spread love, take care of the surrounding and people and see the change.

To all NON Thal people who reading this. Thalassemic people can also live a very normal life like ours. They not different.

Accept them the way they are. They only demand for love and support from you. Those who do not accept them thinking they are sick, I am sorry I think you are mentally sick to not accept them.”

Shivam Upadhyay

“Art is something that makes you breathe with different kind of Happiness”

Somya Malik
Mother Nature and It Essence

Nature, in the simplest sense, is a natural, physical, or material world or Universe. It is the most precious and beautiful gift “GOD” has given us. Nature has a power of healing, peace, noise free, calmness and an attitude to foster all the living beings in our ecological system so that everyone survives.

Nature has a lot of colorful variations that even our most expensive cameras would shy away. Listening to birds chirping, singing and seeing them enjoy breeze is a blissful moment. Trees, leaves and branches dancing to the tunes of the breeze flowing around. The flowers are ready to bloom and some have already smiling and glorifying the whole aura around. The birds are flying high to catch the most height and swimming in the open sky. Squirrels travel from one branch of tree to another, happy in little bites of happiness. Observing them, gives blast of happiness and glitter in eyes. Also, gives me a pinch of fear that we are losing this beauty at a faster rate. In the middle of this glorified presence, all the Why’s, how’s questions oscillated in my thought process.

FROM a tree that has a long way to go, still standing straight, providing home to hundreds of living beings, helping in rain, good quality air and so on, teaches the struggling attitude even in the roughest environmental conditions and still gives us fruit without asking for anything. And, building that attitude and putting it forward to help secure nature and its components so that it glorifies for years to come and TO a short lived flower that teaches us gentleness, calmness and spreading different colors and fragrance. Nature in whichever form teaches us, heals every emotion, body and lives.

In this gadget locked world confined within the digital boundaries, fact paced urbanization and industrialization; we have forgotten to nurture and care for our Mother Nature who gives everything but never ask anything in return. And, are moving faster towards its destruction and destroying surroundings in such a way a little will be left for future lives. Ecological system is getting disturbed at a rapid rate like increased earth temperature, melting of glaciers, extinct of species, deforestation and so on, and a never ending list.

Conserve nature and its resources, so that the ecological balance stays maintained and far from further damages. The worth and its value for everyone’s survival stay intact. A bit by bit towards her can make her once again and she can be ready to teach and heal us more. It is “Better late than Never”.

Gift a plant to be a grown as tree for future lives, Nature’s beauty not be deprived of and everyone survives.

“Mornings”

The widely spread sky have lot to say,
And, open the doors for the sun ray.
The warmth of sun and tunes of cold breeze that touches everyone,
Everyone is ready to immerse them in this breezy sun.
The flowers are ready to bloom,
Some are ready to groom.
Birds and trees make some noise,
The descending breeze enlightens them twice.
Squirrels chirping making everyone happy,
Seeing them enjoy, no one can be unhappy.
In middle of this, I just observed and stood still,
Nature and its components need to be conserved and not to be killed.
Ecological disturbance has reached its peak,
Need to conserve her with every possible natural technique.

----------------------
Sana Sardana

‘It runs in the family.’
‘It’s a hereditary problem.’
‘It is a lifelong disease.’

These were only few of the orthodox thoughts when I disclosed to my prospective in-laws that my brother is a Thalassemic major. If her brother has an incurable issue, then she must also be carrying some defect. Matrimony in India comes with its own clauses. An arranged marriage is often not the decision of bride and groom alone but involves a magnanimous affair of accepting the thought process of the two families involved. There are countless agree to disagree situations for which both parties must come to a consensus. Disclosure of a medical situation like the carrier of thalassaemic gene tends to complicate this familial situation further. After getting rejected by a few prospective grooms, on the grounds of Thalassemia, I realized it isn’t going to be easy, you’re being judged on prospects beyond your control. The fact is that it is natural for humans to be ignorant of the situations that they are not themselves dealing with. But the irony is that in Indian context, they are more than ready for a horoscope match, but an electrophoresis blood
test will scare them to the extent that they would rather call off the alliance. It is quite clear that compatibility between two people is not enough for a marriage to take place. It is also evident that the world of “normal” people (non-carriers) needs more education on the science and daily life of a thalassaemic. That there is a difference between a disease and a disorder. They need to accept that we are as normal as them, that we are also one of them. And I believe, it also becomes our duty to shed some light on the subject matter. The more vocal we become, the better we accept our own situation. It is not only for the purpose of marriage or securing a job, but in a way giving back to the society by the means of our life experiences. We live in an age where we can prevent the occurrence of a ‘major condition’ by spreading awareness and creating a positive attitude towards thalassaemics. As they say, it is a road full of challenges, but we should look for a way and not a way out.

Accept: The phenomena of every human being is to understand and understand correctly and positively. It doesn’t matter what - be it a way of lifestyle, be a disability, be a relationship or the activity of surroundings, but important is to accept. In fact it is not only a compulsion but a sign of mental stability or readiness for the hurdles.

Hurdles: When we ask a child the meaning, he would surely answer as the object on race track, but only a person with it (hurdles) as life experiences will tell us the true meaning. Every hurdle is different from the one crossed. Many maybe more difficult, just like the race track, but when accepted it and faced with determination can be overcomed. Maybe not at single attempt and maybe by falling many times but what helps to cross it is the determination.

Determination: This time it’s not the word but the feeling of what the word means which is important. It is the one word that keeps one going. Although, not all is roses and for some it is not even a single rose but if tried with determination, self-confidence and strength, and remember them at the lowest times, then one can get a chance to pick a few roses for himself. And the most easiest way to remember at lowest time is remembering the reason and source for the need of determination. As it is also said, ‘God Helps Those Who Help Themselves.’ Have faith in ourselves and God, not to have pity on ourselves and not to let others feel pity, find and look at the brighter side of life, overcome weakness, be positive and never loose hope. Try and try until you climb the wall just like the spider, until there is a ray of hope which leads to sunshine.

Conqueror: With few words, not just words but along with their meaning and lessons attach to it lets be determined to be positive and WIN THE RACE - life and competition, and be the conqueror. No matter what path, unless correct and true, no matter the number of attempts and no matter the number of hurdles, lets just focus on winning cause this is Life. And as they say, ‘When Life Gives You Lemons, You Make Lemonade.’

Happy Lemonade!

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Rahul Wahi

“Art is not a handicraft, it is the transmission of feeling the artist has experienced.”
Dr. Soumya Santra
MBBS, MD

• We don’t tell that we have Thalassaemia but proclaim that we are Thalassaemics.
• We do not need to exchange blood frequently but we are required to be transfused with packed red cells when our engine gets down.
• Yes, we can hear, see and can speak loud. We have emotions, feelings and can think as well as you do. We can run, fight for existence and work with confidence for the entire time frame of mine.
• We feel bad but blow it away with a deep sigh, when we request our relatives or acquaintances to do a premarital thalassaemia screening test but they neglect by saying they are too pious and good to have such abnormal genes.
• We can wake up early, go to school and take studies as seriously as our extracurricular activities. We can play around with you during breaks and can even perform on stage.
• During exams, we don’t need isolated exam area or even extra time and yet can keep high scores and excel.
• After school days, we can join any stream for higher education or can study in any part of the globe and add feathers to our hats.
• We can eat anything and everything provided our ferritin is low and other lab parameters are in normal range.
• We waste entire day during transfusions, spend sleepless nights during all-night injections, feel nausea on swallowing bland medicines and quite a many number of pills. We don’t let these hamper our lives as we can manage our available time, plan well and stay prepared.
• We spend months at home with added illness and weakness. Our dreams feel shattered when we are down with malaria, dengue or huge spleen. Yet we fight back and meet and face you again on life’s playground with more gusto.
• We sympathize on those who shows sympathy on us. We love them who care for us and support us through tough times.
• If we get donors or extra manpower support, we are thankful to them and the Almighty. If we don’t get, we are indifferent and never count it as our misfortune.
• At job, we have no parallel entries. We work shoulder to shoulder with all our efforts and even our achievements are commendable. We are sincere more than serious with all jobs we do.
• In love, marriage and love-making, many hitches and separations are ought to come. But its always the best for you who comes last and stay with you forever.
• We don’t let future bother us, instead we do the best and keep the rest. This attitude of ours makes the people around us to bother much.
• We give a smile wherever we go and leave behind a mark from where we return. As we grow we learn more and be stronger to face the world.

If you have important news you want to share with the thalassemia community, let us know. We also encourage people to share their stories about their personal experience that may touch other thalassemics, parents and societies.
Interview with Maria by Sonam Madaan

Sonam: Maria tell us something about Ganesha Night?

Maria: Ganesha Night happened when I thought of spreading awareness in Italy. In my island, the percentage of thalassemia children is very high. And I feel really proud on telling this that India stands ahead in the treatment for Thalassemia. Back in Italy, for creating awareness and embarking Thalassemia. I thought of organizing an event with the help of my friends in the humdrum of my hometown. The event covered puppet shows, dance performances etc.

Event was massive hit and people supported it full-heartedly. The entire money collected against selling of tickets was a benefaction to thalassemics India.

Sonam: What do you think about Thalassemia Management in India?

Maria: In India, thalassemia management is profoundly good. Proper monitoring of each patient is observed here.

Sonam: What do you feel for Thalassemics here?

Maria: I feel they are very intelligent... (Laughs) I mean like they know about themselves a lot. They take extremely good care about their chelation, timely transfusions.

Thank you so much Maria, her friends & the people who supported the cause and collected funds for our Thalassemia children in India....

God Bless You!
News Across India

Odisha
National Workshop on Voluntary Blood Donation at Sambalpur, Odisha, Organised by Tyaga, Burla

Haryana
Blood donation camp by Bannuwal Biradri Faridabad for Thalassaemic kids where 112 blood donors came to donate blood

Chattisgarh
रायपुर छत्तीसगढ़ में श्री कृष्णा सिंह बैरिटेच ट्रस्ट द्वारा 19 नवम्बर को ढोंक दिनेश बुरानी जी (हेमाटोलॉजिस्ट, राजीव गांधी केंसर हासपितल) का निशुल्क चेकअप केम्प रखा गया, जिसमें पूरे छत्तीसगढ़ ही नहीं, मध्यप्रदेश के 172 बच्चों की जांच हुई, 102 HLS टेस्ट हुए।

अयान गुप्ता जी अहलूला, HOD कालेज समिति और ढोंक दिनेश बुरानी जी के नेतृत्व में के बच्चे बीमारी के लक्षण दर्शाते हैं, ताकि निशुल्क बच्चे के व्यवस्था हो सके, कार्यक्रम के संबंध में निरंतर फ्री दवाईयों के लिए प्रयास कर रही हैं, छत्तीसगढ़ में मो राष्ट्रीय दवारा निशुल्क दवाईयों के ऑर्डर आ चुके हैं, जल्द ही जिला अस्पताल में आयरन बिल्लियों दवाईयों की बी जाएगी।

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Medical Books are available in limited numbers at Thalassemics India office. Hard copies can be order directly from Thalassemics India which are distributed free of cost (only one copy per publication).

1. Patients’ Rights
2. Guidelines for the Clinical Management of Thalassaemia - 2nd revised edition
3. About Thalassemia in Hindi
4. Beta Thalassemia Books in Hindi
5. Sickle Cell Thalassemia Books in Hindi
6. Prevention of Thalassaemias and other Haemoglobin Disorders – vol 1 & 2

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

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- Asunra 100mg tablets
- Asunra 400mg tablets
- Desirox 250mg tablets
- Desirox 500mg tablets
- Kelfer 500mg capsules
- Kelfer 250mg capsules
- Defrijet 250mg tablets
- Defrijet 500mg tablets
- Oleptiss FCT 90mg tablets
- Oleptiss FCT 180mg tablets
- Oleptiss FCT 360mg tablets
- Bio –R filter (for 1 unit of blood)
- Bio –R2 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, Greece made

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LR blood transfusion in Cardiac Surgery Patients reduced mortality rates by half.

Patients given LR blood had a much lower incidence of Bacterial Contamination as compared to those given non-LR blood.