Thalassemia Patients Advocacy Group (TPAG) joins Thalassemics India in wishing you

#Ye Diwali Suraksha Wali

“To Protect the overall interests of Thalassemics and prevent Thalasemia”

“To advocate for a Thalassemia Free India where all Thalassemics are cured or healthy.”

HIGHLIGHTS OF THIS ISSUE:
- Special Thanks
- On-going Projects
- Activities
- Articles
- New Members
- TIF News
- Worthy Donors
- News Across India
- Forthcoming Activities

www.thalassemicsindia.org
Special Thanks

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National Association for Reproductive & Child Health of India
P&G Leathers
BRINDAVAN AGRO IND PVT LTD
Dear Member,

Greetings from Thalassemics India!

It is my privilege to share a brief of our activities through this newsletter.

Our focus has been to take more Thalassemics under our care. Our experience shows that their growth and empowerment benefits not only the beneficiaries but the whole community. At the same time, we are well aware that we are not able to help all the deserving patients but our focus is always to help a child in need and to defeat Thalassemia.

We look forward to have more CSR partners for continuing this work to ensure that in 2020 we can help more thalassemics.

Our hands are strengthened by the Patients Advocacy Group (TPAG). Having them around, it looks like that we ushering in a period of novel ideas, sense of urgency, important conversations and meaningful actions.

Today, our Thalassemic children stand as inspiring examples of their transformation from kids to young achievers in their own fields. Thanks to their families and doctors.... Thalassemics India is both humbled and proud, in being a part of their journey. You will always inspire us and empower us. God bless each one of you!

Thalassemics India is in the care of Thalassemics since 1987. Despite the stormy challenges, we are making sure to sustain and to make progress. Also learning from the years of experience, we are poised to walk the road to a promising future as per your expectations.

Thalassemics India’s supporters and partners are the heartbeat of our organization. Generous support from individuals, companies and other partners make our work possible. Thank you for being there for our children.

Apart from what we have been doing, we are going to concentrate more on GST, RPWD Act, National Policy, Awareness / Thalassemia Screening, Blood availability and its safety in the coming year.

As always, we welcome your suggestions and comments you may have.

Sincerely,

Shobha Tuli
Secretary, Thalassemics India
THALASSAEMIA UPDATE

Helping under privileged thalassemics

Under this project, Thalassemics India has been supporting underprivileged thalassemia patients since the year 2000.

From January to October 2019, seventy seven patients were given free of cost blood leucocyte filters, chelation drugs, infusion pumps and needles amounting to Rs. 34 Lakhs.

T2* MRI:

Under this project, we got 23 MRI's done for the needy patients from Mahajan Imaging Centre, Hauz Khas, New Delhi. The patients are from Hindu Rao, St. Stephens, Sir Gangaram, Charika Palika, Kasturba hospitals. Thalassemics India paid for these MRI's - Rs. 80,500/-.

Sunday Clinics

The clinic was held on 03 Feb, 2019 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 society.

Dr. V.K. Khanna, Chairman, Institute of Child Healthcare, Sir Ganga Ram Hospital was invited to hold this clinic.

8 thalassemia patients from St. Stephen's Hospital, NDMC, LNJP, Kasturba, Hindu Rao Hospital were counselled for the recommended treatment.

Thanks to Maria Grazia Lintas for donating Euro 4000.00 to Thalassemics India in support of our appeal to help a few thalassemia children who cannot afford their chelation medicines & blood leucocyte filters.
Through our socials & website, we are able to connect with a huge no. of thalassemics and general masses. Till date, we have around 7,000 followers & 4968 Friends on Facebook, around 1,500 tweet impressions on our Twitter account, & approx 237 visits per month on our website.

- www.facebook.com/thalassemicsindia
- www.twitter.com/thalassemics
- www.thalassemicsindia.org
Under this project, Thalassemics India helped in the organisation of 8 blood donation camps held in Delhi/NCR. Thalassemia awareness material was distributed during the camps.

Blood donation Camp at Macquarie Group

Blood donation camp at Bharat Vikas Parishad

Blood donation camp at Dr. Akhilesh Das Gupta Institute of Technology and Management

Blood donation camp at Bestech Towers

Blood donation camp at DXC Technology

Project ‘Pahunch’
Blood donation camp at Indian Hotel Academy

Blood donation camp at Macquarie

Talk given by Ms. Shobha Tuli at Hotel Park on society's activities

Talk on Thalassemia Awareness by Dr. V.K. Khanna at Mater Dei School

www.thalassemicsindia.org
Talk on Thalassemia Awareness by Dr. Gautam Bose at Govt girls school, Hamilton Road, Mori Gate

Talk at SGRH by Dr. V K Khanna & Ms. Shobha Tuli for team Macquarie Group

Stall at Macquaire for Thalassemia awareness & fund raising

Hoardings at prominent metro stations & billboards on roads across Delhi

Thalassemia Awareness Talk given by Ms. Anuradha Sinha & Ms. Swati Tuteja at IHA
“Thalassemia Bal Sewa Yojna” is a unique project initiated by Coal India & Ministry of Health & Family Welfare, Government of India to provide financial assistance to underprivileged patients. Thalassemics India, the coordinating agency for this project has received around 203 cases from across the country eg. Uttar Pradesh, Maharashtra, Andhra Pradesh, West Bengal, Madhya Pradesh, Gujarat, Rajasthan, Karnataka, Bihar, Jharkhand, Punjab, Delhi, Chhattisgarh, Telangana and Haryana.

Out of these applications, 158 applications got approved by the Expert Screening Committee at the Ministry of Health & Family Welfare.

So far 119 transplants are done till now.

Selected Bone Marrow Transplant Centers:
- Christian Medical College, Vellore
- Tata Medical Center, Kolkata
- All India Institute of Medical Sciences, New Delhi
- Rajiv Gandhi Cancer Institute & Research Centre, New Delhi
- Post Graduate Institute of Medical Education & Research, Chandigarh
- Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow

We are extremely grateful to Madam Jyoti Ghai, Anuj Wadehra & Swati Tuteja for extending their timely support to Arun Yadav, a thalassemia major patient who is undergoing Bone Marrow Transplant at CMC Vellore. An amount of Rs.1,07,300/- was transferred by Thalassemics India to patient’s account at CMC Vellore.
On Moving Mountains

“You have been assigned this mountain to show others it can be moved.”

I remember reading this line many years ago. I never had the disposition of a flagbearer, but something about the possibility of moving mountains seemed very exciting. What was more important was the idea that once one person moves a mountain, others come to believe that mountains, no matter how big, how imposing, how menacing, can be moved. This, among many other such inspirations was where the idea of researching resilience in children with debilitating chronic illnesses germinated in my mind. What makes us not give up? What makes us thrive despite all adversities? Most importantly, how can this wonderful capacity be protected and fostered, especially in the young?

Research reveals that despite pervasive difficulties, children with thalassemia and other debilitating conditions, often do surprisingly well, especially when supported adequately by their physical and social ecology, comprising their family, school and the larger community. A well-known adage of the disability rights community has been “Nothing about us, without us.” What this means is that it is the affected community that has the closest, insider’s view of what the lived reality of any debilitating condition is. Over 34 years of overcoming struggles of a life with thalassemia, my conviction has grown stronger that any impetus for change will have to begin within the thalassemia community.

Over the past couple of decades, efforts of the medical community, parent bodies, welfare organisations, researchers and policy advocates have borne fruit with the inclusion of Thalassemia as a benchmark disability in the rights of persons with disabilities act of 2016. Continued efforts of this coalition are required to strengthen this community and to pave the way for a better, stronger and brighter future for children and adults with thalassemia. It is my sincere belief that research on thalassemia with an ‘insider’s view’ will help administrators, families and policy makers understand the needs of children with thalassemia and understand the complex aspects of their development and education. After all, we know our mountains the best.

In keeping with this spirit of the community, the Patient Advocacy Group at Thalassemics India has provided invaluable support for my research endeavour. Recently, a series of sessions were held with children with Thalassemia and their parents at Thalassemics India. These sessions aimed at understanding what kind of psychosocial difficulties were faced by children with Thalassemia and what kind of support systems could be identified and drawn from. Further, the sessions provided psycho education to the parents about creating the right conditions of caring relationships, realistic yet high expectations, meaningful participation and future directedness for the children’s natural resilience to be fostered.

As I move ahead with this research, it is my hope that more stakeholders from the thalassemia community would join me, share their stories of struggles and victories and shape my perspective. Let us co-create a model that future advocacy efforts may be built on. Together, let us move mountains.

Priyanka Padhy is Assistant Professor of Psychology at Lady Shri Ram College, Delhi University. She is currently pursuing PhD in Early Childhood Development from Jamia Millia Islamia. Ms Padhy has diverse teaching and research experience spanning a decade.

-Priyanka Padhy
TPAG Member

Come forward and help us in arranging talks on Thalassemia & Blood Donation Camps
Journey of My Life

Today when I look back I see those nineteen years that built me and evolved me. Standing today in the midst of the world and working hard to make a place for myself, I sometimes stop and look at those past nineteen years that led me here. Of course, I don’t remember all but what I do is enough to trace the journey of my life.

It all started with a simple shrill of cry. My parents were there carrying million dreams in their eyes and hoping that their daughter is going to be special one. I was a special person but the only difference was that the speciality or peculiarity I had was something no one asked for. It was when I got diagnosed with a blood disorder called Thalassemia. Those million dreams in the eyes of my parents turned into tears.

I was put on regular transfusions and medicines. Every time that needle pierced into my body I always asked ‘why me’. Things went on this way many years and my family always had a worry in their eyes which they tried to hide allot but couldn’t.

Then at some point of time I realised that this is a part of my life and I have to accept it and just live through it. All people around me got happy to know that I started living my life happily, but it wasn’t the end to the problems at all. I grew up but not with the pace I should and then started getting bullied by some and some who hasn’t bullying showed sympathy, which actually hurt more than bullying. I was upset, I was angry, I was depressed but all I could do is cry and live by.

Few years later I got around really good people. People who taught me that you will always get critics around you but that doesn’t mean they are the only one left in this world and if you don’t live by their expectations you will die. This made me realise that it wasn’t me who was flawed but it were the people.

Today looking back at all those angry days and cries I feel that all of them has taught me lessons. All those laughter I shared got me beautiful memories. I have realised that those sufferings and pains only made me strong person and I am proud of it. This pace has got me people for life who gave me a forever. There are problems of course there are times when I get upset or feel low but now I never ask “why me”. I today can easily say that I am in love with my life and I can’t ask for more as I am very thankful to what I have got. I am just being happy and trying to make this journey a memorable one.

-Aarti Batra

Forthcoming Events:

- Annual General Meeting, 24 November, 2019 at Constitution Club, New Delhi
- Dr. Ratna Chatterjee & Dr. Rekha Bajoria clinic at Sir Gangaram Hospital on 7- 8 December, 2019
- International Thalassemia Day, 8 May
- Pan-Asian Conference on Thalassemia in September, 2020 in Delhi (date yet to be announced)
- Dr. Malcolm Walker’s visit to New Delhi for UCL T2* MRI Project
Hello, my name is Shayan Basuray and today I am going to tell you a story. A story from my life.

Born on 8th August 2004 to the coolest couple Amurto and Tina Basuray. Memories of my childhood have always been wonderful. Being the only one I was the biggest attention seeker of the family. But out of all the happiness and pampering their used to be 2 days every month in my life which would be extremely painful. Those two days were the sudden absence of my Mother. Everything would be fun and frolic but suddenly my Mother would disappear. I used to tell my Teacher that my Mother is a tourist mom”. Those two days used to be nightmarish for me. I would miss Mom so much.

My Mother is a power house of laughter, fun, and coolness. She has a huge number of friends. The entire family loves her. I have always seen her smile and not get angry ever.

When I was 10 my Mom took me out and told me her story. My Mother is a Thalassemia Warrior. Thalassemia is a genetic blood disorder which parents pass on to their children unknowingly. My Mom needs blood transfusions every 4 weeks as her body does not produce enough blood. She told me everything about Thalassemia and how it can be prevented by a simple blood test. If only my Grand parents had got themselves tested, Ma would not have to suffer so much. Throughout her life she has been poked and punctured hundreds of times for blood transfusion and get tested for other related illness. She has never given up and she never will.

My parents were conscious enough not to make me go through the same painful life so they got tested before getting married. They have made sure I live a happy and smooth life. It is now my turn to help my Ma to spread awareness about Thalassemia everywhere. I am a Thalassemia soldier.

On this International Thalassemia day, I request you all to be like my parents. Don’t pass on a life full of pain to your next generation. Get tested for Thalassemia today.

-Shayan Basuray

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

- Desferal 0.5g injections
- 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)
- BB Imugard Filter (for 1 unit of blood)
- RC1VAE (Pall) filter (for 1 unit of blood)
- RC2VAE (Pall) filter (for 2 units of blood)
- Venogliss G-27 Short Needle, length 60 cm
- JMS Needle G-27 Short Needle, length 80 cm
- TI-needle G-28 8mm, length 60 cm
- Micrel infusion pump, made in Greece
Exercise is important. Individuals with thalassemia should not wait to exercise until they feel they have enough energy; regular exercise will create the energy to continue. The benefits of exercise may actually be greater in thalassemia as studies have shown patients have reduced muscle mass. Exercise can stimulate both muscle and bone growth and increase bone strength.

Frequently engage in light and moderate intensity activities; these have numerous benefits for individuals with thalassemia. Experiment with exercise, and find activities that work for you. Make exercise a priority in your life; you will be rewarded through a healthier body and a happier mind. If you have questions about exercise, ask your healthcare team about how to get started!

-Sonam Madaan

"Current Perspectives in Thalassemia"

Seminar on "Current Perspectives in Thalassemia" was held on 18th August at Hotel Le Meridien, New Delhi attended by 150 delegates. The main topics were: Safe Blood, Transfusion reactions, Pubertal Delay & Combination chelation therapy. The main highlights were: Panel discussion on higher education & employment, Finding a life partner: Challenges & Triumphs. The panellists were adult thalassemics with invited experts from Ministry. We are grateful to Dr. Sanjay Kant Prasad, Dr. Renu Saxena, Dr. Bharat Singh, Ms. Vinita Srivastava, Dr. Anjali Hazarika, DR. Vanshree Singh, Dr. Sangeeta Pahuja, Dr. Amita Mahajan, Dr. V.K Khanna, Dr. S.Sudha, Dr. Anju Seth, Dr. V.P Chaudhary, Dr. Sunil Gomber, Dr. Jagdish Chandra & Dr. Roma Kumar for their time and active participation.

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.
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| **A H. One** | Rs. 10,000.00 |
| **Yogesh Gursahani** | Rs. 10,000.00 |
| **Tejinder Kaur** | Rs. 7,500.00 |
| **Madhu Bhagat** | Rs. 6,160.00 |
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### Our New Members

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TIF Board Meeting held at Fujairah, UAE on 7-8 April

After the quorum was confirmed, meeting started with a welcome address by the President, Mr. Panos Englezos. Minutes of the last board meeting were approved. Accounts were shared by the Treasurer and the same were passed by the board.

Dr. Androulla Eleftheriou presented a briefing of TIF’s activities for the period of Jan- March, 2019.

During the board meeting, some of the members gave briefing about their country’s progress made in Haemoglobinopathies. Mrs. Shobha Tuli, Vice-President- TIF also briefed the members about Thalassemics India’s activities & MoHFW, Govt. of India’s achievements in the field of thalassemia.

Fund raising was discussed in length where members shared their thoughts about raising funds from different avenues.

Some of the other important topics were also discussed like new members approval, replacement of one of the board members etc.

The arrangements made by Her Highness were excellent & their hospitality was great. Special thanks to Mr. Saeed Jafaar Al-Awadhi for looking after all the board member’s travel & accommodation arrangements.

Thalassaemia International Federation & SAM Deutschland, Germany organised a two day workshop which was focused on building the three C’s for patient organisation (Capacity, Competence & Confidence). The workshop was open for patients & patient organisations participated by almost 100 delegates. During the workshop, attendees shared opinions, thoughts and suggestions for building better society for thalassemics and to uphold recommended treatment.

Panos Englezos, President, Thalassaemia International Federation & Prof. Regine Grosse, Head Thalassaemia clinic, University Hospital Hamburg- Eppendorf gave the opening speeches.

The keynote speaker was Dr. Androulla Eleftheriou spoke about “the role of patient associations in improving the quality of services for haemoglobin disorders”.

There were 3 sessions each day including: 1. Scientific Symposium focused on “Improving the quality of services in practice.” 2. Knowledge, Power & Impact focused on reaching out to patients, enabling global patient networking, Knowing your disease etc.

3. Patient Associations: essential elements for effective functioning & service provision targeted on building a robust legal infrastructure, fundraising for patient association: how to gain supporters, the value of developing a strategy and plan of action etc.

From India, Anubha Taneja Mukherjee, Member Secretary of TPAG presented her thoughts on “Reaching out to Patients effectively communicating the value of joining a local/national associations”. Sonam Madan, Hemant Bellani, Shivangi Amrit & Nehal Dhingra were the other delegates.
Thalassemics India organised a seminar on 31st March, 2019 at Hotel Le’ Meridien, New Delhi from 9:30 am to 2 pm followed by lunch. It was held under the banner of Indian Academy of Pediatrics, Delhi & Apollo Hospitals.

The seminar started with a session on **Nutritional Anemia in India: The Burden and Way Forward** by Dr. Jagdish Chandra. It highlighted the different types of Anemia typically found in India. It was chaired by Dr. Anupam Sachdeva, Dr. Chandra Tripathi, Dr. Rajiv Garg, Dr. Ajay Gupta.

The next session was conducted by Dr. Amita Mahajan on **Recent Advances in Management of Thalassemia** chaired by Dr. V.K Khanna, Dr. S. Sudha & Dr. Alka Mathur.

Dr. Anil Khatri shared information on **Clinical Case Scenario- Thalassemia** in a Panel discussion. The panelists were Dr. Praveen Sobti, Dr. Anupam Prakash, Dr. Vikas Dua, Dr. Shruti Kakkar & Dr. Piali Mandal.

After the tea/coffee break, a Plenary discussion on **Optimising Management of Pediatric CML** took place participated by Dr. Deepam Pushpam, Dr. Sameer Bakshi, Dr. Alok Hemal, & Dr. Rachna Seth.

Dr. Nita Radhakrishnan gave a talk on the **Challenge in ITP Management: Role of Oral TPO agonist B**. This session was chaired by Dr. V.P Chaudhary, Dr. Sandeep Sharma & Dr. K.C Tamaria.

Dr. Manas Kalra moderated the panel discussion on **Clinical Case Scenario- ITP**. The panelists were Dr. S. P Yadav, Dr. Gaurav Kharya, Dr. Vipin Khandelwal, Dr. Sandeep Jain & Dr. Neha Rastogi.

Lastly, we had a very empowering session on **BMT for Thalassemia: Cure for Life** by Dr. Vikram Mathews, chaired by Dr. Tulika Seth, Dr. (Brig) Ajay Sharma & Dr. Shishir Seth.

The seminar ended with a vote of thanks by Shobha Tuli, Secretary, Thalassemics India. All speakers & chairpersons were felicitated with token of appreciation.

We are very grateful to Dr. Amita Mahajan, all speakers & chairpersons for making this seminar a grand success.

**Finally, a big thanks to our sponsors!**
On the occasion of International Thalassemia Day, the team of Thalassemics India visited Deen Dayal Upadhyay, GTB, St. Stephens, Lady Harding Medical College, AIIMS, Kalawati Saran Hindurao, Gangaram, RML Hospitals to distribute gifts to thalassemia children.

The Editorial Committee reserves the right to change the text of the articles sent for publication where necessary, in good faith.

The Editorial Committee or Thalassemics India do not accept any responsibility for any inaccuracies or omissions.

The views expressed are not necessarily that of Thalassemics India.

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Thalassemics India supported the organisation of the **Intercity Health Symposium- 2019** organised by Rotary Club of Delhi Safdarjung in association with other 4 clubs of Rotary Zone 1. The event held at Teen Murti Auditorium from 3 to 6 pm followed by High Tea was attended by a large no. of Rotarians.

The purpose of this event was to raise awareness about Thalassemia, Cardiac Care & Unrelated Bone Marrow donor registry.

The function was graced by DG Vinay Bhatia as the Chief Guest and Bollywood star Mr. Jackie Shroff as Guest of Honour.

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**Workshop on Resource Mobilisation and Digital Media Effectiveness**

Ms. Sonam Madan from Thalassemics India attended the workshop on 22nd February, 2019 at SPJIMR, Kasturba Gandhi Marg, Delhi. Workshop opened with the lecture “From Surviving to Thriving” of Ms. Usha Menon, Executive Chairman, UM-MC Singapore. She is being a renowned international practitioner. The lecture was all about the fund raising. It was an overall learning experience.

The next topic of the Agenda was “Are you using digital media effectively”? by Prof. Kaustav Majumdar, Head of Startups and Incubation, SPJIMR. This topic included all the relevant information about digital media.

As an NGO, gathered the learning and it was really helpful in the mentioned attributes.
Concert for a Cause was held on August 17, 2019, at Jawaharlal Nehru Stadium, New Delhi.

Organised by Show Case Events & Miran Productions, the concert was being held to raise funds for underprivileged thalassemia patients under the patronage of the Delhi Govt. & Delhi Tourism.

ABBA Tribute has been performed worldwide with great appreciation—music for all generations.

The concert was further supported by Starbucks, Mother Dairy, Nestle India and XO Catering.

We would like to extend our sincere gratitude to Delhi Govt., ShowCase Events, Miran Productions & others for making this event possible.

Life is like a dream..., all our dreams can come true if we have the courage to pursue them.

I am Pooja 37 years old blood depend patient thalassemia patient. Life is not easy for me and challenges are always waiting for me. And in all between i got selected for Shravan Kumar Awards 2019 I would like to thank Thalassemics India, my doctors and my parents because of all support I was able to achieve this. I am very thankful to Rajasthan academy who consider me for this award.

This will help me to boost my confidence and inspire me to fight further in life with any situations. I would like to thanks to my office and my seniors who helped me, encourage me so I can grow in my life.

Congratulations to Ms. Pooja Gupta!
We would like to extend our sincere thanks to Narch’s initiative for supporting Thalassemia & our NGO Thalassemics India.

The function was held on 23rd February, 2019 at Hotel Eros from 7 pm to 10 pm followed by dinner.

Five thalassemics sang a few inspiring songs which were applauded by the audience. This was followed by bollywood songs by a group of musicians.

Special thanks:
Dr. Achla Batra & her team for arranging this event.

We look forward of doing a lot more together.

Help us to help our underprivileged thalassemics by supporting Thalassemics India!

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.
What does Thalassemia Mean to me?

Thalassemia to me is a serious medical condition to carry, which does involve quite a lot of attention towards healthcare! Having stated this I can vouch that it is manageable and I am witness to wonderful healthy citizens of various countries of the world including India and they are merely coincidentally Thalassemics by medical condition!

So all you need is a built in family towards the notion that it’s just a part of life and not the life itself. So keep at keeping well the way it works for you the best.

-Hemani Bellani

Thalassemia is a blood disorder which everyone can save from this if they have a knowledge about this. It is a preventable.

Being a thalassemic sometimes it is challenging how you can fight from physical pain which you are getting from thalassemia. For me it is a big challenge being a thalassemic. I am not so much active physically as compared to other people. I want to be active like other people but I am not able to this creates a problem for me. But overall it is an experience which I am experiencing in this life which taught me the importance of blood. But looking at this whole thing I will say that thalassemia is a disease. It’s upon you how a tackle it. I never see myself as not physically active but then also I am very mentally active, I set many goals in my life and I achieved my goals. I love to learn music and dance.

I have many goals in my academic area and I am working on it so that I get success from that area too.

Being a thalassemic you should not stop yourself. If you have dreams and goals like other people you can achieve it. It’s just a disease, if you are not physically active you should be active mentally. Don’t stop yourself by just saying that I’m suffering from this problem and I cannot do it. You should push yourself whatever goals you have worked on.

-Mukshita Kaur Arora

Thalassemia has always been challenging for me. Dealing with it is not an easy task. With growing age, more problems evolve.

As a Thalassemic, I sometimes feel like a little difficult to matchup with the energy of non-thalassemic people. But yes it has not for years, now and I am happily dealing with it and becoming stronger.

-Bhumika Luthra

Maintaining my treatment routine is my top priority. It can be challenging at times, but it’s worth it. The future looks bright, and I’m looking forward to having the opportunity to give back to the thalassemia community.

- Swati Tuteja

Thalassemia is a part of me, I’m not a survivor of this disorder. I feel I’m a warrior who fights a daily battle to manage my chelation therapy, transfusions, regular checkups and day to day tasks. The strength I have gained today is all because of the pain I have gone through, so I cherish every single thing thalassemia has given to me. I would like to thank everyone around me who have helped me in fighting these daily battles of mine.

-Rahul Wahi

For me it is a way of life. I don’t consider it as a disease; I consider it as my strength.

Managing regular transfusion and chelation with my normal work is a challenge that I want to win always. I am not having a disease I am managing it...

-Kishika Sachar
Thalassaemia does not mean bad to me. It is just a normal feeling for me. Transfusion day is the day when I feel relaxed and refreshed. I enjoy whole day by doing nothing and have my blood transfusion. And I am proud to be a Thalassemic.

- Pratham Dhawan

As a Thalassemic, I feel I am living three lives. I am a soldier who is fighting on three different battlefields. Managing my three lives is challenging. Hope and will to fight has kept me going. I have accepted the fact that society does not give that much of understanding and support that we expect. We need to be strong. It is not an easy life we live. We have done a PhD in pain. We have been underestimated by the world but we shock them every time. My parents, my younger brother Amrit, close friends and close family have always encouraged and supported me to fight. Try your best and leave the rest. Do things which makes me happy. Yes I do not get to do all the things I want due to my medical condition but that is life. After a dark night there is always a bright day.

- Gagandeep Singh Chandok

After a painful and long struggle now Thalassemia is a lifestyle to me. Taking transfusion & chelation therapy has become a routine part of my day to day life.

We should not hide our Thalassemic status from everyone. Be cause if we are a Thalassemic, we will not speak about this disorder. Then how our society will get rid of this lifelong painful disorder? It is our duty to help society, our country, we should talk & make people understand, its preventable!

- Ashish Vadera

What does thalassaemia mean to me? Thalassemia for me is a way of life. I am now so used to my transfusions & chelation regime, that I have now started looking for plans around it. For me it is not a burden nor do I need to fight. It all depends on you! You can make it a habit or can sit and complain. But at the end of the day, you need to take charge of your own health. So stay positive and manage yourself well, and there’s no one stopping you.

- Sonam Madian

I take regular blood transfusions every 15-18 days. There is nothing that a thalassemic can’t do. Sometimes it’s very tough to manage all, but still, I manage. I try to maintain my Hb level & also low ferritin. As well as stay healthy.

- Umesh Nagpal

I was born with high ambitions in a very supportive family. For me being Thalassemic is not a limiting factor, rather it is my plus point that imparts positive vibes in me and encourages me to perform out of box. Apart from my professional life I love to do painting as well. I am University gold medalist in that. Other hobbies include Photography and Writing. I live patient life only once in 20 days i.e., during my transfusion day.

I urge all to never let this disease take over your dreams. Fear will never determine your destiny. Regular dose of chelation therapy apart from regular blood transfusions is what we require to lead a normal life.

- CA Yogesh Choudhary
Govt hospitals, clinics to report thalassemia cases

NEWS ITEM

All government hospitals, dispensaries, and clinics in Delhi now have to report suspected and confirmed cases of thalassemia to the state health department every month. The disease is a hereditary blood disorder that results in the production of abnormal red blood cells and causes anemia.

The new policy, introduced by the Delhi government, requires all government hospitals to send monthly reports to the health department. The reports must include details of patients diagnosed with thalassemia, as well as information on their treatment and follow-up care.

“Under the national programme, a test for early detection of thalassemia was done in 24 NGOs, which also provided free blood transfusions and medications. The NGO urged all patients with thalassemia to visit government hospitals,” said Dr SK Arora, additional director of health and family welfare.

Healthy life with a positive mind

The teachers-in-charge of Interact Club of Guru Tegh Bahadur 3rd Century Public School, Mansarover Garden attended the District Interact Health Symposium, 2019. It was organised by the Interact Club of Delhi, Sub-An, Shalimar Bagh. The chief guests were Vijay Bhatia, District President, and Jackie Shroff, Bollywood Actor and Brand Ambassador of Thalassemics India. The panel of guest speakers comprised of Dr HK Chopra, Sr Consultant Cardiology, Dr Anil Handoo, Sr Consultant and Director Pathology, and Gayatri Verma, Head of Tuberous Telangiectasia, DATRI. Through their lectures, they threw light on Thalassemia and its prevention. They urged the audience to bring the community and the experts to bring about a massive transformation in the Global Health Status. This was followed by a questionnaire round which was answered by the panel of speakers.

Later, Jackie Shroff stole the show by voicing his deep-rooted desire to reach the common masses and to create a registry of committed voluntary donors for Thalassemic patients.

Experts threw light on Thalassemia and its prevention

GTB 3RD CENTENARY PUBLIC TEACHERS TAKE PART IN HEALTH SYMPOSIUM

The district chapter of Interact Club of Guru Tegh Bahadur 3rd Century Public School, Mansarover Garden attended the District Interact Health Symposium, 2019. It was organised by the Interact Club of Delhi, Sub-An, Shalimar Bagh. The chief guests were Vijay Bhatia, District President, and Jackie Shroff, Bollywood Actor and Brand Ambassador of Thalassemics India. The panel of guest speakers comprised of Dr HK Chopra, Sr Consultant Cardiology, Dr Anil Handoo, Sr Consultant and Director Pathology, and Gayatri Verma, Head of Tuberous Telangiectasia, DATRI. Through their lectures, they threw light on Thalassemia and its prevention. They urged the audience to bring the community and the experts to bring about a massive transformation in the Global Health Status. This was followed by a questionnaire round which was answered by the panel of speakers.

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THALASSAEMIA UPDATE

INBRIEF

OVER 200 UNITS OF BLOOD COLLECTED

Chandigarh: The Thalassaemic Children Welfare Association collected 238 units of blood during a blood donation camp organised at the PGI here on Saturday. Rajinder Kalra, general secretary of the association, said it was the 183rd blood donation camp organised in coordination with the Blood Bank, PGI, under the supervision of Dr Ratti Ram Sharma, Head, Department of Transfusion Medicine, PGI.

Blood donors were also honoured. Kalra said next blood donation camp would be held on August 3 at Zakir Hall, Research Block A, PGI.

THALASSAEMIA UPDATE

News Across India
JULY 20 BLOOD DONATION

To meet the shortage of blood during the summer months at the PGIMER Blood Bank, The Thalassaemic Children Welfare Association, Chandigarh, will be organising its 183rd blood donation camp on July 20. The organisers have requested voluntary blood donors and social organisations to participate in the camp and help thalassaemics and other needy patients.

When: 10:30 am onwards. Where: Zakir Hali, Block A, PGIMER, Chandigarh.

EVENING OF GHAZALS.

Free travel for thalassaemia patients in state-run buses

Fellately available to patient, attendant only for blood transfusion.

Blood donors facilitated

Over 200 donate blood at PGI

Blood donation camp organised at PGI

Chandigarh: Thalassemic Children Welfare Association organised its 183rd blood donation camp on Saturday at the Postgraduate Institute of Medical Education and Research (PGIMER) in Chandigarh. In coordination with PGIMER Blood Bank, Post Graduate Institute of Medical Education and Research (PGIMER) at the hospital premises on Saturday.

Over 200 donate blood at PGI

Chandigarh: Thalassemic Children Welfare Association organised its 183rd blood donation camp on Saturday at the Postgraduate Institute of Medical Education and Research (PGIMER) in Chandigarh. In coordination with PGIMER Blood Bank, Post Graduate Institute of Medical Education and Research (PGIMER) at the hospital premises on Saturday.
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 annual income to be less than 5 lakhs.
4. Resident of India.
5. Patient should not come under risk category III B (Liver size of the patient below the coastal margin should be less than 5 cms).

Selected Bone Marrow Transplant Centres
1. Christian Medical College, Vellore
2. Tata Medical Centre, Kolkata
3. All India Institute of Medical Sciences, New Delhi
4. Rajiv Gandhi Cancer Institute and Research Centre, New Delhi
5. Post Graduate Institute of Medical Education and Research, Chandigarh
6. Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow

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