THALASSEMIA UPDATE

Thalassemics India
ISSUE 50
AUGUST 2021

INAUGURATION OF BLOOD COLLECTION VANS & NAT SCREENING LAB

Hon'ble Health Minister Dr. Harsh Vardhan unveils the Blood Collection Vans & NAT Screening Lab on 20th March, 2021 at IRCS, National Headquarters, New Delhi

HIGHLIGHTS OF THIS ISSUE

THALASSEMICS INDIA
A-9, NIZAMUDDIN WEST, NEW DELHI-110013
TEL: 011-41827334, 011-46595811
info@thalassemicsindia.org | thalcind@yahoo.co.in

SPECIAL THANKS

We thank Mrs. Kohli for supporting the treatment of 8 thalassemics:
Yogesh, Anchal, Naina, Nikhil, Chandni, Manisha, Pooja K, Pooja G since October, 2019.
All patients were given Desferal Injections, Desirox, Kelfer, Asunra and Filters.

Secretary's Message

Dear friends,

Hope you all are keeping well!

2020 was a remarkably difficult year for all of us. The new normal was lockdowns, masks, travel bans & fear of getting covid infection. Most of us thought 2021 would be a better year. However, it turned out to be the worse year as compared to 2020 due to the second wave of Covid-19 pandemic.

Between 2020-21, we got in touch with all experts from India & Abroad to know more & more about covid & its possible effect on thalassemics. Each day came with a new challenge. Some we could handle, but for rest we had to contact govt. authorities, blood banks, hospitals & media. Individual workloads strengthly became heavier as staff was working from home. Time constrains were very real. Thus, we had no option but to move faster, than ever before. Believe us it was worth attempting. Immediate correspondence with the Ministry, phone calls to blood donors, virtual meetings with patients, parents & doctors, counselling thalassemics on Covid-19 testing & vaccination, holding & participating in webinars, helping underprivileged patients by giving them medical travel & other support, holding blood donation camps, preparing project for grants & working on existing/new projects brought desirable results.

The team of Thalassemics India worked day & night incredibly fast to make sure that we could match patients' expectations & stand with them during this difficult period. We know times are still hard for many of us but hopeful for better times ahead.

This issue of thalassemia update will give you an insight about the work accomplished by TI during these testing times.

Hope you will appreciate our efforts & abilities! We will continue to do our very best as per our resources & capabilities by working together with our friends, donors, doctors, hospitals, TIF & Govt. health authorities.

Our priority & commitment remains with government authorities to start national control programs for thalassemia & provide quality health care & services to thalassemia patients country wide.

Meanwhile, we are working hand in hand with Patient Advocacy Group (TPAG). Today, the patients' voices are more impactful than ever before.

If there is anything that you would like us to intervene or help with, write to us. We are always there as a group to help find you the answers.

We would like to extend our most sincere appreciation to doctors, nurses, healthcare workers, Indian Red Cross Society, Thalassaemia International Federation, donors and members. Special thanks to our CSR partners. Your support is making a big difference to our projects & patients' lives.

Stay safe & healthy!

Sincerely,
Shobha Tuli

DR. HARSH VARDHAN UNVEILS THE BLOOD COLLECTION VANS & NAT SCREENING LAB ON 20TH MARCH, 2021 AT INDIAN RED CROSS SOCIETY, NATIONAL HEADQUARTERS, NEW DELHI

The Union Health Minister, Dr. Harsh Vardhan inaugurated 3 Blood Collection vehicles- 2 mobile buses funded by DXC Technology and 1 bus funded by LIC Golden Jubilee Foundation. During this Inauguration ceremony, Thalassemics India formally handed over the three vehicles to IRCS Blood Bank. The Hon'ble Minister also inaugurated the NAT Screening LAB which is an initiative of Thalassemia Patient Advocacy Group (TPAG), the patient wing of Thalassemics India.

DR. HARSH VARDHAN UNVEILS THE BLOOD COLLECTION VANS & NAT SCREENING LAB ON 20TH MARCH, 2021 AT INDIAN RED CROSS SOCIETY, NATIONAL HEADQUARTERS, NEW DELHI

During the inauguration ceremony, Dr Harsh Vardhan said, "Blood is a life-saving resource in the healthcare system especially for Thalassemia patients who regularly require blood transfusion. While the Government of India is taking relevant steps towards prevention and better management of Thalassemia in the country, these steps to initiate blood collection vans and advanced blood-screening technology are just in the right direction to support safe-blood availability for the patients.

Mr. R.K. Jain spoke about IRCS's activities & thanked the Hon'ble minister for his time. He also mentioned about the donation of the mobile collection blood vans by Thalassemics India to Indian Red Cross Society. Mr. Deepak Chopra, President, Thalassemics India while thanking the Minister for inaugurating the Mobile Collection Vans & NAT testing Lab, appreciated the support given by Red Cross Blood Bank.

SPECIAL THANKS

DXC TECHNOLOGY

LIC
भारतीय जीवन बीमा निगम
LIFE INSURANCE CORPORATION OF INDIA

ANNUAL GENERAL MEETING

Thalassemics India held its 33rd Annual General Meeting on 31st January,2021. The meeting was held virtually and attended by more than 100 members.

The meeting started with a welcome address by the President, Mr Deepak Chopra. Secretary report was presented by Mrs Shobha Tuli. While sharing the report, she said that the work of Thalassemics India in addressing effectively the needs of the thalassemia families & achieving its mission, has been based on 4 pillars:

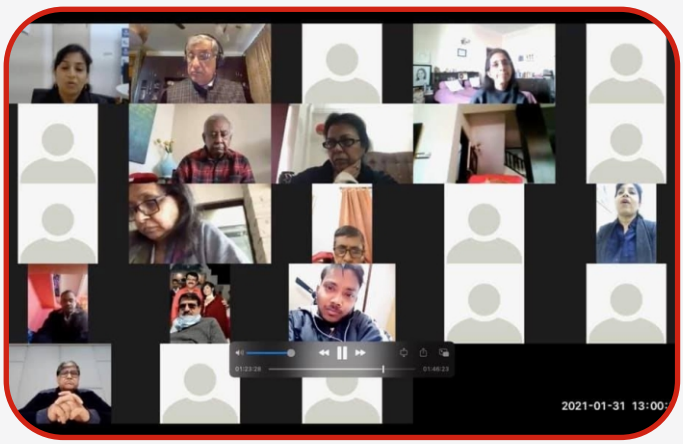
- Collaborations/ Partnerships with health authorities & other related health institutions or associations at the national & international level to improve health care & to increase thalassemia awareness.
- Supporting & contributing to the health care of underprivileged patients to improve their quality of life.
- Participating in educational events both at the national & international level to gain knowledge and to update our members with the correct and latest information on thalassemia.
- Supporting patient groups across the country aiming to transform the effected groups into productive & equal partners.

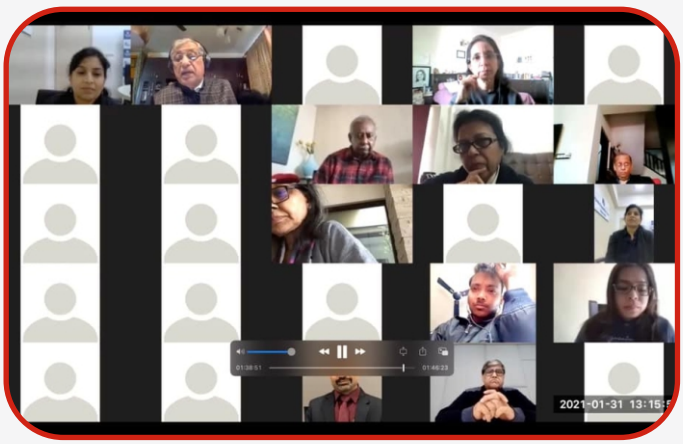
She further gave a brief report about association's activities for the year 2020.

Financial report was presented by the Treasurer Mr. Arun Sehgal.

After the AGM official work, there was a session with Dr V K Khanna & Dr Amita Mahajan who talked about the "Thalassemia Care in the Pandemic".

The meeting ended with the Vote of Thanks.





INTERNATIONAL THALASSEMIA DAY

''WEBINAR ON RECENT ADVANCES IN THALASSEMIA''

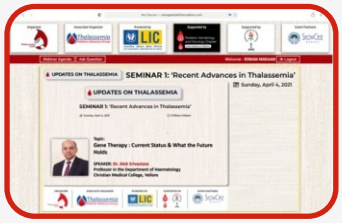
The program started with a welcome address by Dr. V.K Khanna, Vice President of Thalassemics India.

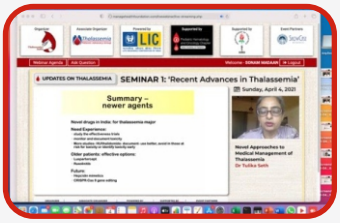
Dr. Mamta Manglani gave the Chairperson's note and introduced all the invited speakers. Dr Tulika Seth talked about the ''Novel approaches to Medical Management''. Dr Revathi Raj talked about ''Bone Marrow Transplant Challenges & Triumphs''. Dr. Alok Srivastava gave a presentation on ''Gene Therapy - Current Status & What the Future Holds''

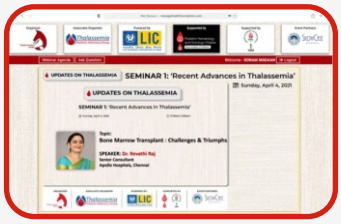
This was followed by the panel discussion. The program was moderated by Dr. Amita Mahajan.

The program ended with a vote of thanks by Deepak Chopra, President of Thalassemics India.

WATCH IT HERE



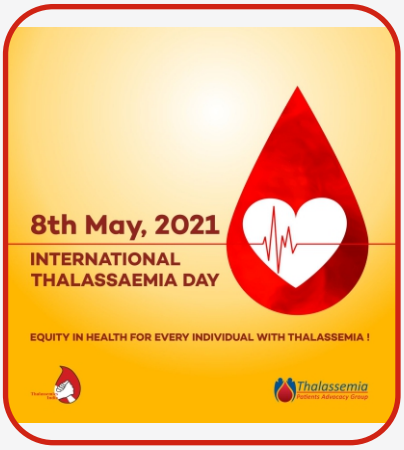


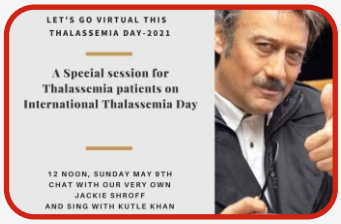


Thalassemics India is grateful to Rotary Club of Delhi Safdarjung for their generous donation of 3 Oxygen Concentrators.

INTERNATIONAL THALASSEMIA DAY

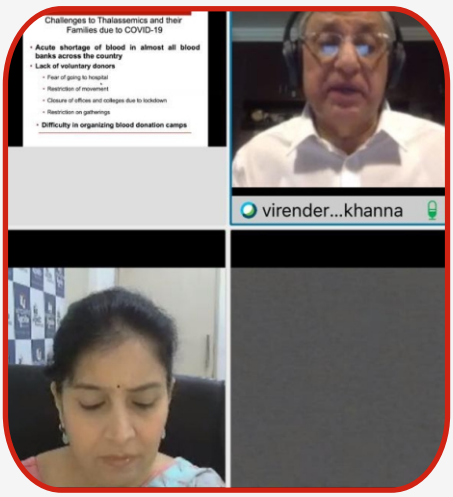
- We are happy & grateful to Bollywood Star Mr. Jackie Shroff & Rajasthani folk singer Kutle Khanji for the fun interactive session with and for Thalassemia patients on May 9, 2021. Thalassemics across the country joined the session and chatted and sang with both the guests.





WEBINAR ON THALASSEMIA AWARENESS

- We are thankful to **DXC Technology** & team for hosting a webinar on Thalassemia Awareness on May 7,2021. Dr. V.K. Khanna briefed about Thalassemia & its Prevention. Dr. Amita Mahajan highlighted the importance of Blood Donation.



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.

PHOTOGRAPHY COMPETITION

On International Thalassemia Day 2021, Thalassemics India had organized a Photography competition to celebrate the various emotions of a Mother & Child. The response was overwhelming and a lot of good talent surfaced. The results were announced on 12th May on all Thalassemics India's social media platforms.

A big thank you to each and every participant for taking part in this competition. Thalassemics India is extremely grateful to the Ahuja family for sponsoring the prizes.

1st PRIZE

SOMYA MALIK,
DELHI

2nd PRIZE

MAYANK MANUJA,

DELHI

3rd PRIZE

SHIVIKA GARODIA

LUCKNOW

Consolation Prize

RAHUL WAHI

DELHI

Life is all about being grateful and spreading happiness, and your love and generous contribution is always helping our thalassemics in all possible ways. We are thankful to our sponsors for encouraging Thalassemics!

BAL SEWA YOJNA
THALASSEMIA & APLASTIC ANAEMIA HSCT CSR PROJECT BY COAL INDIA LTD.

Dr Harsh Vardhan, Union Minister for Health and Family Welfare launched the second phase of "Thalassemia Bal Sewa Yojna" for the underprivileged Thalassemia patients as well as Aplastic Anaemia patients.

This is a great CSR initiative by Coal India Limited and MoHFW under which financial assistance upto Rs. 10 lakhs will be given to each patient to cover the transplant costs.

To ensure that benefits reach the intended beneficiaries, Thalassemics India is appointed for providing administrative and promotional support with coordination and liasioning of "Thalassemia & Aplastic Anaemia Bal Sewa Yojna" as envisaged in MoH&FW guidelines.

Eight treating hospitals are empanelled under " Thalassemia & Aplastic Anaemia Bal Sewa Yojna"

- AIIMS, New Delhi
- CMC, Vellore
- Tata Medical Center, Kolkata
- PGIMER ,Chandigarh
- Rajiv Gandhi Cancer Institute, Delhi
- SGPGI ,Lucknow
- Narayana Hrudayalaya , Bangalore.
- CMC ,Ludhiana

Eligibility Criteria for Thalassemia:

- Resident of India
- Patient must have transfusion dependent thalassemia.
- Patient's age to be 12 years or less
- Patient should have 100% HLA matched sibling donor (minimum matching ratio: 6/6)
- Patients whose yearly family income is Rs. 5 lakhs and or less(on the basis of income certificate verified by competent local authorities, or the employer)
- Such patients must be other than Class III B patients
- Liver size of the patient to be less than 5cms below the coastal margin

Eligibility Criteria for Aplastic Anaemia :

- Resident of India
- Patient's age to be 18 years or less
- The patient must have severe aplastic anaemia as documented by a bone marrow
- examination at one of the HSCT centres and a full 6/6HLA matched related donor(Matched unrelated, Unrelated cord blood and Haploidentical transplants are not eligible for this support)
- Patients whose yearly family income is Rs. 8 lakhs and or less (on the basis of income certificate verified by competent local authorities, or the employer
- Necessary test for ruling out inherited bone marrow failure syndromes are to be done

For More Information Contact Thalassemics India at:
Thalassemics India : A-9, Nizamuddin West, New Delhi-110013
(O) 011-41827334,46595811 (M) 9871445595

WEBINAR ON
"CHALLENGES IN DAY-TO-DAY MANAGEMENT OF THALASSEMIA"

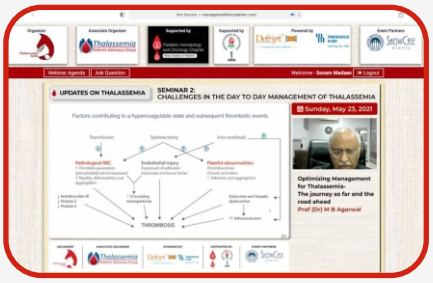
In continuation with the series of webinars, Thalassemics India & Thalassemia Patient Advocacy Group (TPAG) organized another webinar on ''Challenges in Day-to-Day Management of Thalassemia'' on 23rd May,2021 from 4-6 pm.

The program started with a welcome address by Dr. V.K Khanna, Vice President of Thalassemics India.
Dr. V.K. Khanna gave introduction of Dr. Lalit Mehndiratta. Dr. Sunil Bhat - Director & Clinical Lead Pediatric Haematology, Oncology and Blood & Marrow Transplantation, Narayana Health Network Hospitals, Bangalore gave a brief introduction of the Guest of Honour Dr. M.B. Agarwal. He is the President, Mumbai Hematology Group, Prof & Head, Bombay Hospital Institute of Medical Sciences, Mumbai. Dr. M. B. Agarwal talked about the Challenges in the Clinical Management of Thalassemia.

Dr. John Porter is the Consultant Haematologist, UCL Hospitals, London, UK. He gave a presentation on COVID-19 & Thalassemia. Dr. Amita Mahajan introduced all the panelists: Prof Deepak Bansal, Prof Anju Seth, Dr Shruti Kakkar, This was followed by the panel discussion & QA session. The program was moderated by Dr. Amita Mahajan, Senior Consultant - Apollo hospital, Delhi.

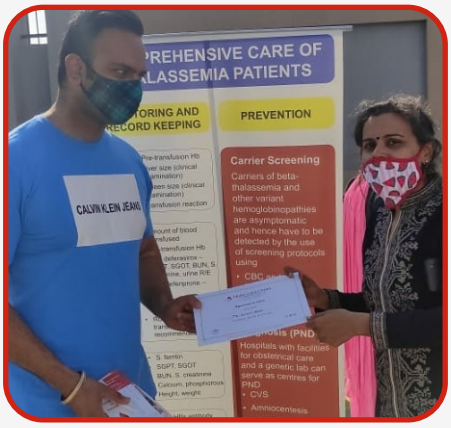
The program ended with a vote of thanks by Deepak Chopra President of Thalassemics India. This webinar is powered by Sun Pharma & Fresnius Kabi.

WATCH IT HERE



BLOOD DONATION CAMPAIGN

Eight blood donation camps were organized by Life Savers in collaboration with Thalassemics India & Indian Red Cross Society. 689 units of blood were collected.



BLOOD DONATION CAMPAIGN

Two Blood donation camps were organized by Aditi & Sunil in collaboration with Thalassemics India & Indian Red Cross Society. 132 units of blood were collected.

Blood donation camp was organized by KAB Welfare Foundation in collaboration with Thalassemics India & Indian Red Cross Society. 11 units of blood were collected.

Special thanks to the Organisers, Blood donors & the team of Indian Red Cross Society for their support.

**Come forward & help us in arranging talks on Thalassemia, blood donation camps &
funds for underprivileged thalassemia children**

CURE FOR THALASSEMIA MAJOR – GENE THERAPY?

Alok Srivastava
Centre for Stem Cell Research & Department of Haematology
Christian Medical College, Vellore

Curative therapy for beta thalassemia major (TM) has been possible through allogeneic haematopoietic stem cell transplantation (HSCT), first carried out in Pesaro, Italy in 1981. This therapy was made available in India in 1991 at the Christian Medical College (CMC), Vellore and has been a life changer for those who have been able to access and had a successful outcome. Now there are more than 25 centres offering this service in the country. Unfortunately, there are many limitations of this approach. Starting with only about a third of all patients having a suitable donor, results being best with a HLA matched related donor, to issues related to access to an appropriate HSCT centre or the costs associated with it. Many patients are also excluded as they are much older and have developed severe dysfunction of major organs.

Though accurate estimates are not available, the result of these challenges are that <10,000 HSCTs have been performed for TM in the world over the last 40 years. Compare this to the incidence of this disease at >50,000 births with TM in the world every year, about 1/5th of those being in India. In fact, <2500 HSCTs have been done in India since 1991 (>650 of those being in CMC, Vellore) with about 300 being done every year at present in the country. It is clear therefore that allogeneic HSCT is not the most practical option for curative treatment for most patients with TM.

This is why there has been great interest in developing gene therapy (GT) as another option for curative therapy for TM. What GT for this kind of a genetic disease implies is to provide a functional gene instead of the mutated non-functional form which is causing the disease. This can be done by gene replacement or, more recently, by gene repair. The most common approach at present is to use a lentiviral (LV) vector (transport system) to carry this artificially constructed beta globin gene (the transgene) into HSCs collected from the patient (therefore no donor is needed) through apheresis in a blood bank (no surgery of any kind). The process of integration of the transgene into HSCs is carried out in the laboratory and then the product is tested to ensure that it has acceptable quality.

The treated HSCs are then transplanted into the patient after conditioning like a bone marrow transplant but being autologous HSCs, the treatment is much less complicated and therefore safer from the transplant perspective compared to an allogeneic HSCT. Once these gene corrected HSCs engraft, they start making haemoglobin which they could not make earlier. There are also ways now to repair the patient's own gene through gene editing techniques (CRISPR-Cas9 and base editing being two of them). This is somewhat like editing a word in a document – cutting out the wrong letter and pasting the right one there to let the word make sense. Gene editing may be thought of as molecular cutting and pasting to repair the mutated non-functional gene.

According to the results from several clinical trials, once engrafted, these HSCs make enough transgene haemoglobin to provide near normal levels to cure the disease in most but not all patients treated. Currently, one product has been licensed (ZyntegloTM) for the treatment of B+ TM, where the disease is not as severe, but it costs about Rs. 15 crores/dose. Further trials are ongoing for the more severe forms of TM. While these are very promising, we must recognize that these are early days of this kind of therapy in clinical use. There is much promise with all patients having the option of cure but there are also many challenges. The most important of those is the safety of this approach. As the HSCs are being gene modified with an integrating vector, there is a potential for them to undergo mutations in unrelated genes and cause new disease.

CURE FOR THALASSEMIA MAJOR – GENE THERAPY?

In the past, some patients with immune deficiency disease treated LV vector gene therapy had developed leukemias. This has also happened more recently in patients with sickle cell disease (SCD) treated with such vectors but not among patients with TM so far. In SCD, it is not clear whether the complication is due to the LV vector. Nonetheless, this is a major long-term complication to watch. Further clinical trials are ongoing to assess the safety and efficacy of GT in TM. However, once safety is established, this treatment will be possible for the almost the entire spectrum of patients – the very young, within the first 1-3 years of life and also those who are much older, with appropriate precautions.

In India, the Centre for Stem Cell Research, a unit of in Stem, Bengaluru, based at the CMC, Vellore has several scientists working on developing different GT products for TM and SCD. (www.cscr.in) This research is supported by the Department of Biotechnology, Government of India. Several products are at an advanced stage of pre-clinical development and should be ready for clinical trials in 18-24 months. The technology for production of vectors, which is a major limitation in the country at present, is also being established. The goal is make GT accessible to all patients with TM in India.

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)**
- **Defrijet FCT 360 MG**
- **Defrijet FCT 180 MG**
- **Micrel infusion pump**

OUR WORTHY DONORS

Manoj Jain	1,00,000
Pradeep Diwan	1,00,000
Shabnam Chhabra	50,000
Indus Valley	50,000
Vishakha Amit Kishore	50,000
Vishakha Amit Kishore	50,000
Brindavan Agro	45,000
Ravinder Ghai	41,000
DM Exports Pvt. Ltd.	40,000
Jugjiv Singh	25,000
National Institute of Computer Education Engineering & Technology	21,000
Surya International	15,000
Anita Kumari	15,000
Neelam Gandhi	11,000
Devendra Kumar Narula	11,000
Deepak Dhingra	10,000
Meghna Sharma	10,000
Nasscom Foundation	6,652
Debabrata Saharay	6,412
Viresh Piplani	6,000
Riddhi Arora	5,100
Ruchi Shah	1,224

MAKE A DONATION

- **Visit our website for making online donation.**
- **Write a cheque favouring 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.

OUR NEW MEMBERS

Aayat Nishat	Delhi
Akhilesh Kumar Pandey	Delhi
Anurag Seth	Madhya Pradesh
Asad Khan	Delhi
Baani Sawhney	Delhi
Bablu Chaurasia	Madhya Pradesh
Deep Naskar	West Bengal
Dipan Ghosh	West Bengal
Dr. Mithlesh Kumar Choubey	Madhya Pradesh
Janardhan Saini	Delhi
Jayendra Sadhuram Motwani	Gujarat
Jivan Jyot Blood Bank	Maharashtra
Kirti Ranjan Mishra	Uttar Pradesh
Lakshman Mahato	West Bengal
Lalit Agrawal	Madhya Pradesh
Leena Kartha	West Bengal
Mohammad Noor Islam	Uttar Pradesh
Mohammad Talib Mazhar	Uttar Pradesh
Muskan Maheshwari	Delhi
Nihal Raju Desai	Maharashtra
Nirvaan Borah	Karnataka
Pawan Kumar	Delhi
Pradeep K. Ludhani	Delhi
Prasheel Chopra	Haryana
Prithvi Kumar	Kerala
Pushkar	Jharkhand
Rajeev Ranjan Chaurasia	Madhya Pradesh
Rajesh Kumar Singh	Uttar Pradesh
Ravinder Kumar Palai	Delhi
Sahil Piyush Shah	Gujarat
Sanjay Kumar	Delhi
Sanjib Datta	West Bengal
Saurabh Khurana	Jaipur
Shambhavi Jha	Jharkhand
Shivani Mundada	Telangana
Shivin Grover	Delhi
Shree Jalaram Abhyudaya Sadbhavana Trust	Gujarat
Simar Preet Singh	Punjab
Sunny More	Assam
Sushmita Tiwari	Uttar Pradesh
Swijal Ajay Kumar Prabtani	Gujarat
Syed Abdul Hafeez	Maharashtra
Vishnu Pratap Singh	Uttar Pradesh
Vivek Bhaskar	Haryana

HELPING HANDS PROJECT

Under this project, we continued to help more than 100 patients by giving them free of cost chelation medicines & blood leucocyte filters. Thalassemics India also supported some of the patients by covering their hospital charges including covid testing & the transportation charges.

THALASSAEMIA INTERNATIONAL FEDERATION

About TIF

Thalassaemia International Federation (TIF), a non-governmental, patient driven umbrella organisation, established in 1986, supports the rights of patients for access to quality health, social and other care through its work with over 230 national thalassaemia associations in 62 countries across the world. Founded by a small group of doctors and patients/parents who represented National Patient Associations, mainly from Cyprus, Greece, Italy, UK and USA i.e. countries where thalassaemia had been recognized early as a genetic, hereditary disorder with huge medical, public health, social and economic repercussions if left unaddressed in terms of both effective prevention and management.

Our Mission

The prioritisation of thalassaemia on national health agenda's and the development and implementation of effective disease-specific control (prevention and clinical management) programmes within national healthcare systems based on universal coverage.

Our Vision

To support the provision of equal access of every affected patient to high quality health, social and other care in a truly patient-centred healthcare setting.

Our Work

Education | Advocacy | Collaborations/ Networking | Research | Raising Awareness

For more information about TIF's activities & future programs, please visit the website: www.thalassaemia.org.cy

WATCH HERE **READ MORE**

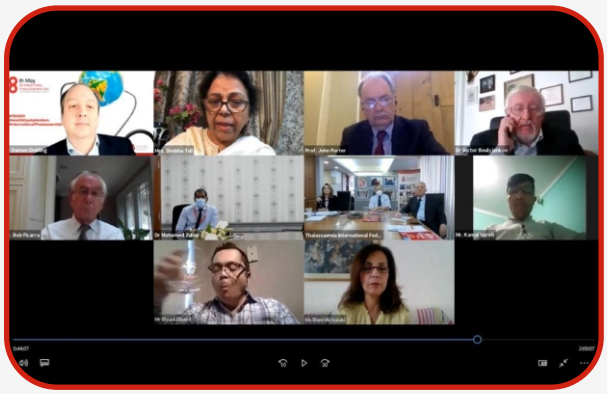
- **Thalassaemia Parent/Patient Associations from India thank TIF for its Support & Guidance**
- **Informative material received from Thalassaemia International Federation (TIF) is shared with our registered beneficiary members across the country through mails & social media.**

WEBINARS

Thalassemics India's participation in webinars held in India and Overseas.

[READ MORE]

[READ HERE]



Thalassemics India website [www.thalassemicsindia.org] continues to be updated on a weekly basis with noteworthy information, deriving from T.I's day to day work.

- **Website's analytics: 515 visitors per month**
- **Facebook: 4,968 friends & we have 3,207 followers on our FB page. We are also connected with people through 20-30 groups.**
- **Twitter: 1900 tweet impressions per month.**
- **Instagram: 1314 followers. Follow us on @thalassemicsindia**

www.facebook.com/thalassemicsindia
www.twitter.com/thalassemics
www.thalassemicsindia.org

NEWS ACROSS INDIA

अमर उजाला

अपनी बीमारी की परवाह नहीं, दूसरों की जान बचाने में जुटीं हैं डॉ. पियासी

थैलेसीमिया से पीड़ित हैं पीजीआई सर्जरी विभाग की जूनियर रेजीडेंट, महीने में दो बार चढ़वाती हैं खून

अपराजिता

पहले ऊटी फिर अपना इलाज

कोविड मरीजों के बीच अपनी पीत छिपा कर रहीं काम, खून पर तनाव को हावी नहीं होने देती

बचपन में ही तय कर लिया था कि डॉक्टर बनना है

दोनों बेटियों पर माता-पिता को नाज

Thalassemia patients seek inclusion in priority group for vaccination

SushmiDey@timesgroup.com

New Delhi: As the government is gearing up to roll out the vaccination drive against Covid-19 and plans to cover the high-risk population in the initial phase, thalassemia patients have urged the government to include them in the priority group for early inoculation.

Thalassemia patients – who are mostly young – sometimes even as young as three months' old – often have multiple complications including diabetes, cardiac and respiratory diseases and hepatitis. Besides, such patients have to routinely undergo hospitalisation for blood transfusion that increases risk of infection for them.

In a letter to the National Expert Group for Vaccine Administration for Covid-19 (NEGVAC), the Thalassemia Patients Advocacy Group has raised these concerns and urged the government to treat them as priority population for Covid immunisation.

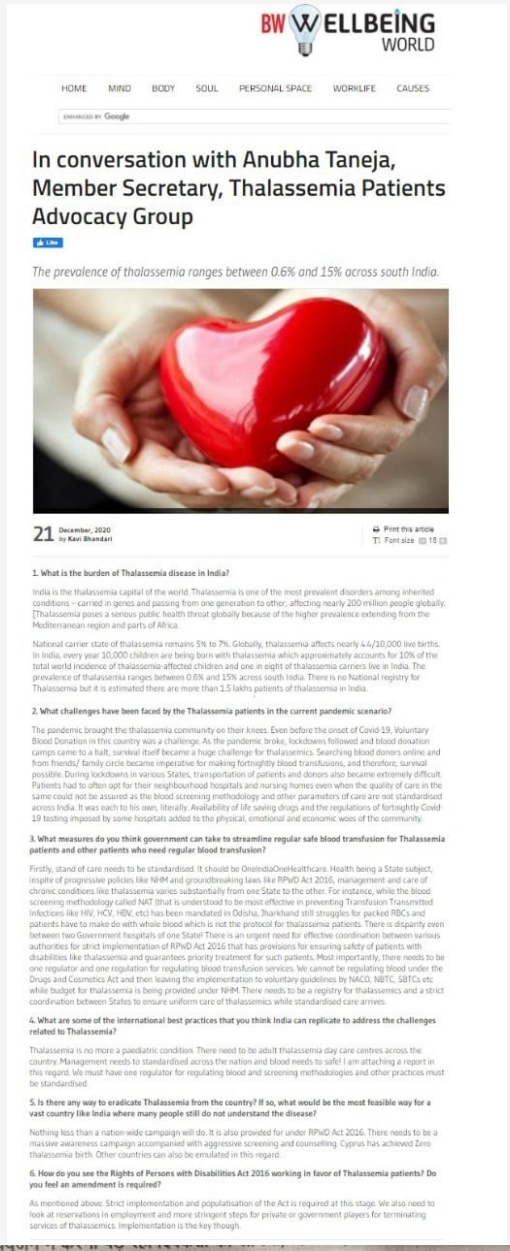
"Thalassemia patients stand out in the situation of the pandemic because of their need to frequently (every 2-4 weeks) visit healthcare facilities for blood transfusion. This makes the need for protection measures such as vaccination imperative as hospital environments may be regarded as "hotspots" for viral transmission," the Group's member-secretary Anubha Taneja-Mukherjee said in the letter.

The Group has also underlined that thalassemia has been identified as a disability under the Rights of Persons with Disabilities (RPWD) Act, 2016 and such patients are prioritised by the Act under Section 25 as far as healthcare is concerned.

The government plans to vaccinate around 30 crore priority population in the first phase of Covid vaccination. Apart from healthcare and front-line workers, the list includes elderly above 50 years of age and those below 50 years with specific co-morbidities that may lower the immunity and poses higher risk mortality in case of infection.

"Thalassemia patients suffer various co-morbidities and this renders these patients vulnerable to bacterial infections that may lead to serious illness or life-threatening sepsis. When infected by SARSCoV2, these patients may also develop secondary bacterial infections," Anubha said.

Thalassemia patients – who are mostly young – have to routinely undergo hospitalisation for blood transfusion that increases risk of infection for them



BW WELLBEING WORLD

HOME MIND BODY SOUL PERSONAL SPACE WORKLIFE CAUSES

In conversation with Anubha Taneja, Member Secretary, Thalassemia Patients Advocacy Group

The prevalence of thalassemia ranges between 0.6% and 15% across south India.

21 December, 2020 by Kavi Bhandari

Print this article Font size

1. What is the burden of Thalassemia disease in India?

India is the thalassemia capital of the world. Thalassemia is one of the most prevalent disorders among inherited conditions – carried in genes and passing from one generation to other, affecting nearly 200 million people globally. Thalassemia poses a serious public health threat globally because of the higher prevalence extending from the Mediterranean region and parts of Africa.

National carrier state of thalassemia remains 5% to 7%. Globally, thalassemia affects nearly 4.4/10,000 live births. In India, every year 10,000 children are being born with thalassemia which approximately accounts for 10% of the total world incidence of thalassemia-affected children and one in eight of thalassemia carriers live in India. The prevalence of thalassemia ranges between 0.6% and 15% across south India. There is no National registry for Thalassemia but it is estimated there are more than 1.5 lakhs patients of thalassemia in India.

2. What challenges have been faced by the Thalassemia patients in the current pandemic scenario?

The pandemic brought the thalassemia community on their knees. Even before the onset of Covid-19, Voluntary Blood Donation in this country was a challenge. As the pandemic broke, lockdowns followed and blood donation camps came to a halt, survival itself became a huge challenge for thalassemics. Searching blood donors online and from friends/ family circle became imperative for making fortnightly blood transfusions, and therefore, survival possible. During lockdowns in various States, transportation of patients and donors also became extremely difficult. Patients had to often opt for their neighbourhood hospitals and nursing homes even when the quality of care in the same could not be assured as the blood screening methodology and other parameters of care are not standardised across India. It was each to his own, literally. Availability of life saving drugs and the regulations of fortnightly Covid-19 testing imposed by some hospitals added to the physical, emotional and economic woes of the community.

3. What measures do you think government can take to streamline regular safe blood transfusion for Thalassemia patients and other patients who need regular blood transfusion?

Firstly, stand of care needs to be standardised. It should be OneIndiaOneHealthcare. Health being a State subject, inspite of progressive policies like NHM and groundbreaking laws like RPwD Act 2016, management and care of chronic conditions like thalassemia varies substantially from one State to the other. For instance, while the blood screening methodology called NAT (that is understood to be most effective in preventing Transfusion Transmitted Infections like HIV, HCV, HBV, etc) has been mandated in Odisha, Jharkhand still struggles for packed RBCs and patients have to make do with whole blood which is not the protocol for thalassemia patients. There is disparity even between two Government hospitals of one State! There is an urgent need for effective coordination between various authorities for strict implementation of RPwD Act 2016 that has provisions for ensuring safety of patients with disabilities like thalassemia and guarantees priority treatment for such patients. Most importantly, there needs to be one regulator and one regulation for regulating blood transfusion services. We cannot be regulating blood under the Drugs and Cosmetics Act and then leaving the implementation to voluntary guidelines by NACO, NBTC, SBTCs etc while budget for thalassemia is being provided under NHM. There needs to be a registry for thalassemics and a strict coordination between States to ensure uniform care of thalassemics while standardised care arrives.

4. What are some of the international best practices that you think India can replicate to address the challenges related to Thalassemia?

Thalassemia is no more a paediatric condition. There need to be adult thalassemia day care centres across the country. Management needs to standardised across the nation and blood needs to safe! I am attaching a report in this regard. We must have one regulator for regulating blood and screening methodologies and other practices must be standardised.

5. Is there any way to eradicate Thalassemia from the country? If so, what would be the most feasible way for a vast country like India where many people still do not understand the disease?

Nothing less than a nation-wide campaign will do. It is also provided for under RPwD Act 2016. There needs to be a massive awareness campaign accompanied with aggressive screening and counselling. Cyprus has achieved Zero thalassemia birth. Other countries can also be emulated in this regard.

6. How do you see the Rights of Persons with Disabilities Act 2016 working in favor of Thalassemia patients? Do you feel an amendment is required?

As mentioned above. Strict implementation and popularisation of the Act is required at this stage. We also need to look at reservations in employment and more stringent steps for private or government players for terminating services of thalassemics. Implementation is the key though.

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रक्त केन्द्र में न्यूक्लिक एसिड टेस्टिंग जांच सुविधा का शुभारंभ

केन्द्रीय स्वास्थ्य और परिवार कल्याण मंत्री जोकि इंडियन रेडक्रास सोसाइटी के अध्यक्ष भी हैं, ने आईआरसीएस के मुख्यालय के रक्त केन्द्र में न्यूक्लिक एसिड टेस्टिंग (NAT) जांच सुविधा का उद्घाटन किया. वहीं, दो रक्त संकलन वाहनों समेत तीन पूर्ण रूप से सुविधा संपन्न वाहनों का भी शुभारंभ किया. इनका इस्तेमाल रक्तदान शिविर आयोजित करने और रेड क्रास रक्त केंद्र में रक्त के यूनिट जोड़ने में किया जाएगा. आईआरसीएस के महासचिव आर.के जैन थैलेसिमिक्स इंडिया के अध्यक्ष दीपक चोपड़ा और दोनों संगठनों के वरिष्ठ पदाधिकारी इस अवसर पर उपस्थित रहे.

Blood Donation | corornavirus | COVID 19 | Health Minister Dr Harsh Vardhan | Health News | population

Thalassaemia, cancer patients suffer blood challenge during Covid-19

PNS ■ NEW DELHI

From shortage of blood in blood banks to unavailability of transportation and transfusion facilities, thalassaemia patients, cancer patients and dialysis recipients among others, who need regular blood transfusions, have been facing multiple challenges in the wake of the Covid-19 pandemic.

Added to their agony has been the Central and State governments' failure to give priority to their needs, lamented an advocacy group as they shared their views at a Webinar "Illness to Wellness' organised by ASSOCHAM on International Day for Persons with Disabilities 2020 marked on Thursday.

"On our own, with the help of organisations like Life Savers, Khoon and Giving Is Living in addition to support from Indian Red Cross Society, have been organizing blood camps during the pandemic. However, the State governments did not do much to spread awareness around blood donation" rued Anubha Taneja-Mukherjee, Member Secretary, TPAG (Thalassemics Patients Advocacy Group).

It is estimated that there are about 65,000-67,000 thalassemia patients in the country with around 9,000-10,000 cases being added every year.

Anubha also alleged disparity in rules for the sector pointing out that currently the Drug and Cosmetic Act regulates blood while National Blood Transfusion Council (NBTC) guidelines are voluntary. Similarly, National Health Mission (NHM) is responsible for thalassemia while NACO is responsible for BTS. There is too much confusion, she said.

In the long run, the Government should consider having a consolidated blood regulation separate from the Drugs and Cosmetics Act that does not give adequate power to NBTC, she suggested.

The experts also deliberated on the Rights of Persons with Disabilities Act 2016 and how its implementation can ensure availability and safety of blood transfusion services, the demand which was backed by Anil Rajput, Chairman, ASSOCHAM CSR Council.

The panel also included Dr Pawan Kumar Singh, Head of Oncology, Organ Transplant, Hematology Hematopoietic Stem Cell Transplant Department, Artemis Hospital, Dr Amita Mahajan, Senior consultant, Pediatric Hematology & Oncology Indraprastha & Apollo Hospitals, Delhi, Chetan Manchegowda, Founder, Khoon; Rajesh Mittal, President, Rotary, Deepak Chopra, President-Thalassemics India, George Contantinou, Board member of Thalassemia International Federation.

Dr Sunil Gupta, Additional Director General, Blood Transfusion Services at NACO, said that a Committee is considering whether there should be a separate body and legislation even as the experts called for timely availability of medicines, accessibility of generic drugs at a cheaper cost and bringing down the cost of stem cell and bone marrow treatment so that more and more thalassaemia patients can be benefitted.

थैलीसीमिया के मरीजों का कोविड ने बढ़ाया दर्द

■ विशेष संवाददाता, नई दिल्ली

डिसएबिलिटी डे आज

- कोविड से न केवल उन्हें संक्रमण का डर है, बल्कि ब्लड ट्रांसफ्यूजन नहीं होने पर यह बीमारी बढ़ने का भी खतरा है
- डिसएबिलिटी एक्ट में शामिल होने के बाद भी थैलीसीमिया से पीड़ित बच्चों को उनका हक नहीं मिल रहा है

कोविड महामारी का असर पूरे जनमानस पर देखा जा रहा है। पहले से बीमार लोगों के लिए यह किसी आफत से कम नहीं है। हर महीने दूसरे के ब्लड से आगे का जीवन पाने वाले थैलीसीमिया से पीड़ित लोगों को ब्लड ट्रांसफ्यूजन में हर रोज दिक्कतों का सामना करना पड़ रहा है। कोविड से न केवल उन्हें संक्रमण का डर है, बल्कि ब्लड ट्रांसफ्यूजन नहीं होने पर यह बीमारी बढ़ने का भी खतरा है। डिसएबिलिटी एक्ट में शामिल होने के बाद भी थैलीसीमिया से पीड़ित बच्चों को उनका हक नहीं मिल रहा है।

गुरुवार को डिसएबिलिटी डे है। एक्सपर्ट का कहना है कि डिसएबिलिटी एक्ट के क्लॉज 8 के अनुसार इन बच्चों को इलाज में तवज्जो मिलनी चाहिए। अगर महामारी का दौर है तो उसमें उनके इलाज का और खयाल रखना चाहिए। उन्हें हर जरूरी सुविधा मुहैया करानी चाहिए। मगर, ऐसा हो नहीं रहा है।

थैलीसेमिक इंडिया की सचिव शोभा तुली ने कहा कि दिल्ली-एनसीआर में 2500 ऐसे बच्चे हैं, जिन्हें हर महीने ब्लड की जरूरत होती है। अगर एक महीने ब्लड ट्रांसफ्यूजन नहीं कराया तो उनकी परेशानी बढ़ जाती है। उन्होंने कहा कि जब से कोविड आया है, तब से उन्हें ब्लड मिलने में दिक्कत हो रही है। अब उनके माता-पिता को खुद से डोनर लेकर आने पड़ते हैं, तभी उनके बच्चे का समय पर ट्रांसफ्यूजन हो पाता है। कई अस्पताल कोविड के हो गए हैं, इसलिए कई बच्चों का अस्पताल बदल गया है। उन्हें दूसरे अस्पताल जाना पड़ता है। आने-जाने में उनका खर्च बढ़ गया है। रिस्क ज्यादा हो गया है। उनकी परेशानी बढ़ गई है।

शोभा तुली ने बताया कि कई ऐसे बच्चे हैं, जिनके घर में सिर्फ एक ही कमाने वाले थे। कोविड की वजह से उनकी नौकरी चली गई। इन बच्चों को सरकार की तरफ से हर महीने मदद के तौर पर 2500 रुपये मिलते हैं, लेकिन अभी ऐप्लिकेशन जमा नहीं हो पा रहा है तो उन्हें यह सुविधा नहीं मिल रही है। उन्होंने कहा कि डिसएबिलिटी एक्ट के तहत जितनी सुविधा उन्हें मिलनी चाहिए, वह नहीं मिल रही है। सरकार से मांग है कि वह इन बच्चों का जो हक है, उसे पूरा करे।

दिल्ली और एनसीआर की ताजा खबरें सबसे पहले पढ़ने के लिए ट्विटर पर फॉलो करें @NBTDilli

NEWS ACROSS INDIA

https://www.healthwire.co/dr-harsh-vardhan-unveils-a-state-of-the-art-blood-screening-lab-by-thalassemia-patients-advocacy-group/amp/?__twitter_impression=true

https://orissadiary.com/dr-harsh-vardhan-inaugurates-nat-testing-facility-at-the-red-cross-society-headquarters/

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Govt proposes amendment in Rehabilitation Council of India Act 1992

OUR CORRESPONDENT

NEW DELHI: The government has proposed an amendment in the Rehabilitation Council of India Act 1992, saying the need for it has arisen in view of developments in the rehabilitation and education sector.

In a public notice, the Ministry of Social Justice and Empowerment (MSJ&E) proposed that the amendment in the act will make the Rehabilitation Council of India (RCI) provide accessible, quality and affordable habilitation and rehabilitation education, regulate the conduct of such education, meet the demand of high quality professionals and personnel in all parts of the country.

The RCI will encourage professionals to adopt latest research in their work and contribute to research, to maintain and enforce high ethical standards in services provided by professionals and personnel, and for matters connected therewith or incidental thereto in line with provisions of the Rights of Persons with Disabilities Act, 2016, the notice said.

"The need for amendment to the said Act has arisen in view of developments in the rehabilitation and the education sector in the intervening years from 1992 onwards," it said.

"Further, in view of introduction of the National Education Policy, several changes would be warranted in existing programme and course objectives, deliverables, curriculum, design, content, pedagogy, duration, evaluation criteria etc." it added.

A need has also arisen to benchmark all programmes and courses with those being conducted at the national and international levels to ensure quality in rehabilitation education and to bridge the gap in quality rehabilitation care human resource, the notice further said.

Keeping this in view, the government said the Department of Empowerment of Persons with Disabilities has prepared the draft amendment to RCI Act, 1992.

The department has invited comments of all the stakeholders, including state governments/UT administrations, civil society/non-government organisations, academicians, public and private sector organizations, multilateral institutions and members of the public to submit their comments on proposed amendments within a period of 21 days. Stakeholders may submit their suggestions by mail at mailto:kvs.rao13@nic.in"kvs.rao13@nic.in latest by December 23, it said.

Under the amendment, the notice said, the council should assess demand of professionals and personnel, and develop a roadmap for meeting such demand, map programmes and courses in habilitation and rehabilitation being conducted at the national and international levels and prescribe benchmark standards for the same.

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सीएम सिटी सबसे बड़ा ब्लड बैंक, फिर रक्त की कमी से जूझ रहा

पटियाला, 8 जुलाई (धीर) : ब्लड बैंक के सूत्रों के अनुसार यह कमी भीषण गर्मी स्कूल कॉलेज का बंद होने से कैंप कम लग रहे हैं जो लग रहे है उनमें डोनर कम आ रहे हैं और डिमांड में एक दम से बड़ोतरी हो रही है जिससे से सबसे ज्यादा प्रभावित थैलेसीमिया से पीड़ित बच्चे हो रहे हैं। पटियाला थैलासिमिक चिल्ड्रन वैल्फेयर एसोसिएशन के महासचिव विजय पाहवा ने बताया हमारी एसो. के पास 250 से ज्यादा पीड़ित बच्चे हैं जो अलग-अलग शहरों से रोजाना बीस के करीब बच्चे बल्ड ट्रांसफ्यूजन करवाने आते हैं लेकिन बल्ड की कमी के कारण कई बच्चों को वापस जाना पड़ता है। इन्हीं बच्चो के लिए एसो. द्वारा 10 जुलाई दिन शनिवार को बल्ड बैंक राजिंद्रा अस्पताल में सुबह 9 बजे से रक्तदान कैंप लगाया जा रहा है। उन्होंने सभी रक्तदान शिविर लगाने वाली संस्थाओं को अपील की ज्यादा से ज्यादा रक्तदान शिविर लगाए।

दैनिक सवेरा Fri, 09 July 2021 epaper.dainiksaveratimes.org/c/6

The Indian Express - Ahmedabad Edition (25-05-2021)

Thalassemia patients struggle as blood donations decrease

EXPRESS NEWS SERVICE
VADODARA, MAY 24

FOR OVER six weeks, the parents of a nine-year-old girl scouted blood banks across Vadodara and neighbouring towns, looking for a bottle of AB+ blood for her regular transfusion for Thalassemia. They could manage it only last week, after the girl's haemoglobin level dropped drastically.

Anshul Goel of Vadodara-based Boond Thalassemia Foundation, who himself is a Beta-Thalassemic Major and helped the parents find a donor, says, "By the time she found a donor, her haemoglobin levels were under seven. Due to the Covid pandemic and vaccination drive, finding donors has become extremely difficult. The availability of blood in the city has dropped to alarming levels, causing difficulty to Thalassemia major patients and others who are dependent on transfusions every 15-20 days."

Goel's foundation, in association with its partner blood bank Shree Jalaram Blood Bank of Vadodara, is organising a blood donation camp on May 30 at the Parsi Agyiari compound in Sayajigunj, to gather at least 50 units of blood for Thalassemia patients. The event is backed by local organisations like Aastha Thalassemia Trust and Friends Society, and groups of youngsters from Scientific Community and We are the Future Group.

"The idea is to gather donors as many donors as possible, following Covid protocols... Although the blood bank will prioritise Thalassemia transfusions, it will not be out of reach for anyone in need of blood," Goel said.

He added that in addition to the pandemic and the government health guidelines restricting persons taking vaccine shots from donating blood for 14 days, the holy month of Ramzan also added to the shortage. "A lot of regular donors from the Muslim community could not donate blood due to the month-long fast... We are hoping that in the coming weeks, it will be easier to find blood."

Dr Vijay Shah, Vadodara city BJP president, who also runs Indu Blood Bank, said, "Very few people voluntarily donate blood during this pandemic. Covid guidelines do not allow gathering at a blood camp. We conducted 75 smaller blood donation camps but it does not meet the need... The requirement of blood has increased over the past few days and finding plasma donors is more difficult."

Shah says that the increased demand for blood may also be due to surgeries that were deferred in non-Covid hospitals being taken up now. "There is no demand for blood in Covid hospitals. But in non-Covid hospitals, where planned surgeries were postponed due to the second wave, the demand is picking up," Shah said.

According to Shah, AB+ and all Rh-negative blood groups are difficult to find even in regular times and the pandemic and vaccination drive have only widened the gap. "As far as shortage of blood for Thalassemia patients is concerned, at our blood bank, we adopt the recipient between a group of four donors of the same blood group so that one of them is available every two to four weeks." Currently, nearly 100 Thalassemia patients are in need of regular transfusions in Vadodara.

रक्तदान से तीर्थयात्रा जैसा पुण्य : हर्षवर्धन

जनसत्ता संवाददाता
नई दिल्ली, 20 मार्च।

केंद्रीय स्वास्थ्यमंत्री डॉ हर्षवर्धन ने शनिवार को रेड क्रॉस सोसाइटी मुख्यालय में एनएटी (न्यूक्लिक एसिड टेस्टिंग) जांच सुविधा का उद्घाटन किया। थैलेसीमिया स्क्रीनिंग के बारे में उन्होंने कहा कि विवाह पूर्व रक्त कुंडली मिलाना जन्म कुंडली से अधिक महत्त्वपूर्ण है। उन्होंने कहा कि रक्तदान से भी विभिन्न तीर्थ यात्रा जैसा पुण्य मिलता है।

उन्होंने कहा कि कोविड-19 महामारी के चरम के दौरान आइआरसीएस के 80 रक्त केन्द्रों ने उल्लेखनीय भूमिका निभाई। उन्होंने दो रक्त संकलन वाहनों समेत तीन पूर्ण रूप से सुविधा संपन्न वाहनों को भी हरी झंडी दिखाई। इनका इस्तेमाल रेड क्रास रक्त केंद्र में रक्त जुटाने में किया जाएगा। मंत्री ने कहा कि एनएटी जांच से एचआइवी, हेपेटाइटिस बी-सी जैसे जोखिम में कमी आएगी।

3 THE SUNDAY EXPRESS, JULY 5, 2020 THE CITY

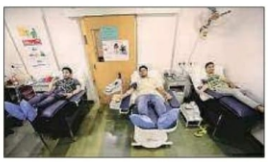
Pandemic leaves blood banks parched, hospitals rely on in-house donations

ASTHA SAXENA
NEW DELHI, JULY 4

THE COVID-19 pandemic has left blood banks in the capital running dry, with the number of voluntary donations falling significantly given the fear of transmission. Plus expanding containment zones in the city have left little space for the blood banks to hold camps. There are over 70 blood banks in the capital, which collects 95% of the blood through regular donation drives by organising camps at schools, colleges and private institutions.

The Indian Red Cross Society (IRCS), a voluntary organisation with a network of blood banks across the country, has been able to hold 57 camps in Delhi from April 14 till date. The organisation, which used to hold 25 blood donation camps a month, was able to arrange just 2,500 units of blood during these three months.

"The containment zones in Delhi have increased over the last few months due to which the blood donation drives cannot be carried out in those areas. Many volunteers are not able to donate as they reside in these areas. At present, we are able to meet 50% of the demand," said IRCS director Vanashree Singh. Every year, the society organises a mega blood donation camp on April 24 in which 1,200-1,500 units of blood is collected. This year, the event was canceled.



There are over 70 blood banks in the capital. Archive

Corporate houses, schools and colleges, which are shut nowadays, are major sources of blood collections for several NGOs. "We are now coordinating with RWAs for holding blood donation camps in their areas," said Singh.

To meet the supply, those visiting the hospitals are being motivated to donate blood. The in-house donations at hospitals, though, are relatively more stable.

"The voluntary donations have dropped significantly during the lockdown while the in-house donations have gone up. The situation was grim when the lockdown started as there was a complete ban on movement. But we are somehow motivating the donors to come forward and donate. In the last three months, we have organised 25-30 camps in areas like Najafgarh, Vikaspuri and Paschim Vihar. We are making extra efforts and increasing in-house donations in hospitals. Doctors are regularly motivating attendants to donate," said Dr Mausami Swami, director of Delhi's blood transfusion council.

Blood cancer patients, thalassemia patients, pregnant women, road accident victims and people needing elective surgeries suffer the most due to the lack of blood donations.

"Even patients and their families have exhausted all possible donors. The number of panic calls from families has increased. If someone requires two units of blood, then we are only able to provide him one unit. We have requested the Delhi government to step in and motivate people to come forward and donate blood. The government can also start organising camps by following the social distancing rules," said Shobha Tuli, secretary of NGO Thalassemics India.

THAL MATRIMONY

NEWS FROM MUMBAI

WE BELIEVE IN HELPING THALASSEMICS TO FIND THEIR PERFECT SOULMATE.

Journey started since 2012. Ms. Sangeeta Wadhwa initiated the idea of thalassemia marriage and she was able to make six thal to thal couples from all over India. After that she started the project with YTA matrimonial, in 2018. In 2019 Youth Thalassemia Alliance in association with Let's help some1 started working on this project because currently our mission is to to help find dream patner because we feel everyone has right to fulfill their dream of marriage. Our portal and service provide services in professional manner.

In January 2020 we got good response from candidates all over India and in this one and half year we have six success stories, we believe many will be followed in future.
We understand the importance of personal data and that's why we work with confidentiality in data handling.

Our project coordinator Mrs. Shobha Arora have worked tirelessly to make this success. We first understand the expectations of candidates and help them find their perfect soulmate.

We do not charge anything from anyone.
Candidates just have to register themsleves

We welcome all other thalassemics who haven't yet registered with us and are willing to get married

CONTACT
Shobha Arora 8087648004
Sangeeta Wadhwa 9930632928

OPEN PLATFORM FOR RARE DISEASES (OPFORD)

NEWS FROM BANGALORE

It was originally an online resource hub for patients and families with rare diseases to access information on rare diseases, symptoms, diagnosis, treatment, available cures, list of geneticists, diagnostic centers and hospitals. It was incubated at the healthcare not-for-profit Centre for Health Ecologies and Technology (CHET), Bengaluru. OPFORD.ORG was inaugurated by Dr. Kiran Mazumdar-Shaw in March 2018 at the Blue-Ribbon Rare Diseases Symposium organized by CHET. Over time, it became clear that there was a need to go beyond a digital repository and improve health outcomes in the real world. This led to the establishment of the OPFORD foundation in 2019. OPFORD now stands for Open Platform for Orphan Diseases.

OPFORD foundation's primary aim is to improve health outcomes for people with an orphan or neglected disease. In India, there are an estimated 1,50,000 patients with thalassemia, 100,000 patients with sickle cell disease and 50,000 patients with bleeding disorders. Despite the staggering numbers, these diseases continue to be neglected in the public health care system and also suffer from political neglect. Though approved therapies exist for these diseases, patients are unable to access treatment due to public healthcare gaps and economic constraints. Consequently, such diseases have high mortality and morbidity rates.

OPFORD's goal is to improve outcomes for people affected with these diseases by bringing together expertise in medicine, biotechnology and information technology through a unique organizational platform model. Since the platform is an open model, we can leverage the expertise and solutions provided by a range of stakeholders to ensure maximum reach to patients.

OPFORD is also uniquely poised to create a platform which can facilitate participation in the current advances in genomic medicine. Gene therapeutics may revolutionize treatment and curatives for genetic disorders and OPFORD intends to create pathways to participate in this scientific and technological revolution.

OPFORD's initial areas of focus are the blood and bleeding disorders because of the high prevalence and the need to urgently provide solutions to these patient communities. To support patients, we have developed a dedicated helpline with trained expert counselors and peer counselors to help patients with information, knowledge and handholding to deal with the condition. We help patients connect with well-curated key resources like clinicians, geneticists, diagnostic laboratories, treatment centers and patient organizations. This enables and empowers patients to seek timely medical interventions and pre-empt serious co-morbidities.

OPFORD supports patients to proactively take charge of their health and work towards improving their overall health.

Our help line number is 77956 65149
Patients can also reach out to us on WhatsApp – 87925 05400
Our website – www.opford.org

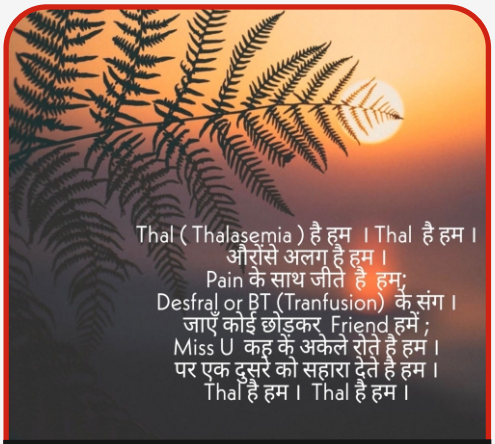
CREATIVE SIDE OF OUR THALASSEMIA WARRIORS

Deepika Guptha

Shubhi Saxena

Ek Bharat Shresta Bharat
Vaibhavi - 5th C

CA - Yogesh Chawla



Harshala Malti Pravin Kharat

Shruti Batra

Rahul Wahi

QUARANTINE - A POEM

By : Anshul Goel

Quarantine – A Poem

Quarantine is not so fine when it comes to good food and wine,
it makes you sit and whine for the sun to shine,
it makes you crave the beautiful mine of people of your kind,
who are all quarantined!

Quarantine is not much kind when it comes to the devils of our minds,
they hop and hop all day and night until they are fed with an self-enforced thought of you,
finally being fine.

It is different for each one of us
as it never came in a size,
that fits all 1.3 billion at a time
for some it is the time to bring on their hobbies right out of their minds,
and for some it is the time to light up being one with the divine.

The nature has healed its broken spine,
each and every day the conditions becoming
more and more stable and fine,
the sky has never been seen this refined
in this dusty parade of time.

Nevertheless this quarantine will be full of new and exciting discoveries worthy of every dime,
for people have once again believed in the power of unity and to just trust be aligned.

For in this now being written,
mighty history of valour of the real warriors of time - doctors, workers, vendors and the ever vigilant
police of our beautiful nation being together,
to fight against one virus of Covid 19,
keeping hand in hand intertwined.

YOU'LL NEVER FIND A RAINBOW IF YOU'RE LOOKING DOWN- CHARLIE CHAPLIN

Team FunWIthRedBloodCells is proving it correct. Spreading thalassemia awareness in the lightest way on Instagram. Follow @TeamFunWithRedBloodCells on Instagram

In the movie '3 Idiots', Chatur Ramalingam defines 'What is a machine' in a complex statement while Rancho explains it with the example of a trouser zip as 'anything that simplifies human work is a machine'. Now let's try to explain you 'What is Thalassemia' in the Chatur way: Thalassemia is a genetic blood disorder in which the body is unable to produce healthy red blood cells and the person has to transfuse blood after every 10-15 days. After reading the above statement, how much did you understand?

Did you understand better? Yes? This concept is technically called a Meme. This was the primary reason 'why' we started the page. To simplify awareness about Thalassemia we came together as a team to create this Instagram page called funwithredbloodcells. As the name suggests, 'fun' element is the most important part of our awareness mission. Now that you know the 'what' and 'why' about us let us tell you 'how' we started. It was the year 2020 'when' the world was locked down, we got bored enough to let lose our creative minds and created our first meme to start off this journey. We then created our page officially on 8th May 2020 and uploaded our first meme. We were immensely supported by our Thalassemia community and that encouraged us to dream big. Talking about 'why' we started the page, it was primarily to simplify awareness about Thalassemia and make it fun for the reader to understand the concept. Our work over the year has also expanded in creating awareness about Blood Donation, through memes and MythBusters.

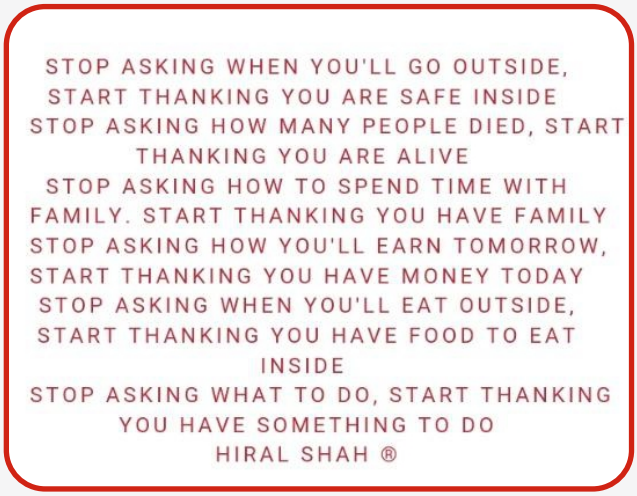
We have also started taking live sessions on Instagram talking to Thalassemia Warriors across India and the world and shared their Thriving with Thal journey with our viewers. We also created a step-by-step guide to fill disability certificate and posted it on YouTube for the benefit of our Thalassemia Warriors and are now a 1000+ family on Instagram.

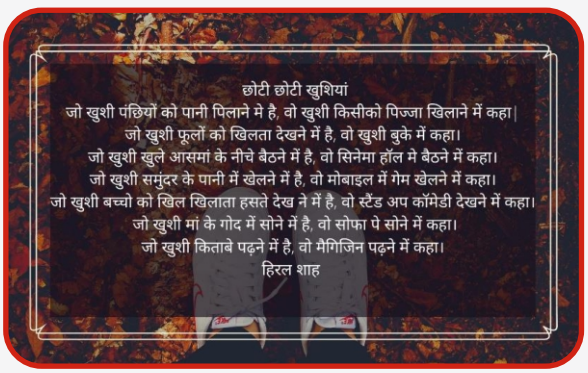
In summary, we are a bunch of Thalassemia Warriors who started this page for the benefit of our community and hope to share all the necessary information with everyone in a fun way.
You can reach out to us on Instagram, Facebook and,YouTube if you search for the word **Funwithredbloodcells**.

MOTIVATIONAL STORY
-BY HIRAL SHAH

Hello!
I'm Hiral Shah. Thalassaemia major warrior. Thalassaemia didn't hold me back from achieving my higher education or any other dreams. I have done my Masters in German language & also C1 in German. I have also worked as a German language practitioner in IBM Daksh. I just loved my job so much. I worked there for 1 year & 4 months. I had to left that job, because the rotational shifts affected my health badly. After that I was Hospitalized thrice & 2 times I was in ICU. One time it was very critical & doctor told my parents, that she has only 72 hrs left. If she fights, than only there is chance of her survival. This 72 hrs changed my whole life. I got my purpose to fight back as a true warrior. I have already decided I will dedicate my life to serve the society & to help others. In 2018 I have joined The Wishing Factory as a volunteer and I have been doing great work spreading awareness about Thalassaemia, blood donation etc. I am also connected with many other social organisations such as Thalassaemia Society Pune Chapter, Yuva Asmita & also working as a core team member of Funwithredbloodcells. Since 4+ years I am running my own German language Classes. Recently I have also started my small business #fashionhub i.e. online Shopping group. I am really thankful that I was featured in Times of India, Pune Mirror for my thriving with thal story many times also I got the chance to give Radio Interview to RJ Sangram & spread awareness about Thalassaemia & blood donation. I also got featured in legendary Podcast show of Abby Yoong from Singapore. I always believe in Positivity & I really like to inspire people. I really like to spend my free time doing something creative. Creativity makes me happy. I believe Thalassaemia is not my weakness, but it's my strength that made me so strong. I always believe we can achieve anything & everything, if we just have faith in yourself. You just need to decide what you want in your life & take action accordingly. Nothing can't stop us from achieving our Goals.


Hiral Shah





THALASSEMICS INDIA

A-9, NIZAMUDDIN WEST, NEW DELHI-110013

TEL: 011-41827334, 011-46595811

Email:- info@thalassemicsindia.org

Email:- thalcind@yahoo.co.in

www.thalassemicsindia.org