THALASSAEMIA UPDATE

Thalassemics India
ISSUE 51
FEBRUARY 2022

Azadi Ka Amrit Mahotsav

Ministry of Health & Family Welfare
Government of India

Coal India

THALASSEMIA BAL SEWA YOJNA

Coal India Limited under its Corporate Social Responsibility is running "Thalassemia Bal Sewa Yojna" a scheme for curative treatment of Thalassemia and Aplastic Anaemia. Under this scheme, financial assistance upto Rs. 10 Lakh is provided for Bone Marrow Transplant in eight prominent hospitals spread across the country. Corpus fund has been provided to these hospitals for implementation of the scheme. The project is aimed at benefitting who are unable to afford the high cost of the transplants.

SELECTED TRANSPLANT CENTERS

- AIIMS, NEW DELHI
- CMC, VELLORE
- TATA MEDICAL CENTER, KOLKATA
- RAJIV GANDHI CANCER INSTITUTE, NEW DELHI
- NARAYANA HRUDAYALAYA, BANGALORE
- SGPGI, LUCKNOW
- CMC, LUDHIANA
- PGIMER, CHANDIGARH

HIGHLIGHTS

HSCT-2nd Phase Project, Articles, Worthy Donors, Screening & Counselling Centre at IRCS, TIF News, New Members, News Across India

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

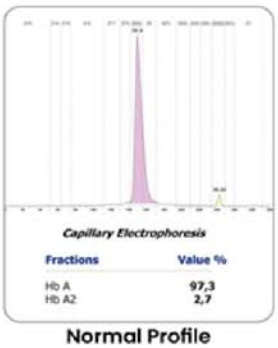
Hemoglobin Disorders Screening by *Capillary Electrophoresis*

For more than 20 years, Sebia has developed a strong expertise in the field of hemoglobin disorders screening and is a recognized partner of choice for all laboratories and scientists involved in hemoglobinopathies.

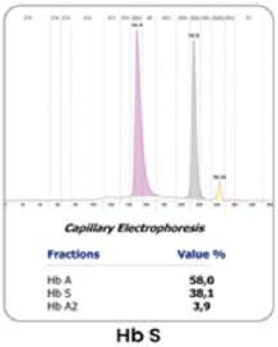
Key *Benefits*

High Resolution & Clean Profiles

CAPILLARYS instruments allow high resolution separation of the major hemoglobin variants (Hb S, Hb C, Hb D and Hb E) and accurate quantification of the Hb A2 and Hb F in presence of variants.



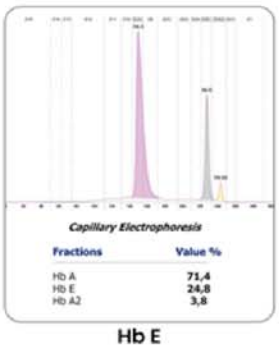
Normal Profile



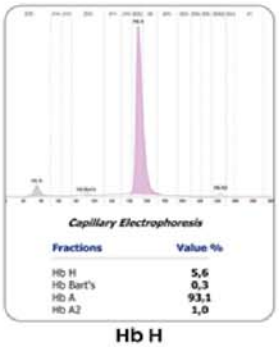
Hb S

Enhanced Detection

Capillary zone electrophoresis allows clean separation of Hb E from Hb A2 and facilitates easier detection & Quantification of Hb Bart's and Hb H.



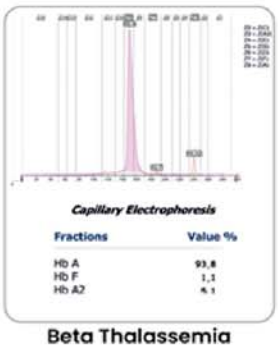
Hb E



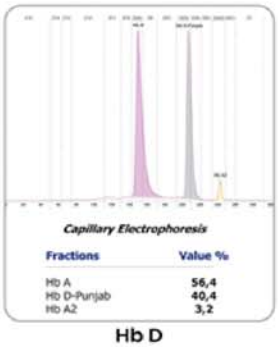
Hb H

Easy Interpretation

Easy interpretation through clear-cut and precise colour coded profiles, Rapid validation using Mosaic screen, On-board identification assistance



Beta Thalassemia



Hb D

Adapted to Each Laboratory

Thanks to the broad range of capillary instruments, the hemoglobin technique answers the needs and variable workload of all laboratories involved in abnormal hemoglobin screening.

Minicap flex piercing
8Test/hour

Capillary 3 OCTA/Tera
46/69 Test/hour

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Secretary's Message

Dear friends,

Greetings to one & all!

It gives me great pleasure to connect with you once again through this newsletter. This year has completely changed the role of all staff members including the Executive board members. To work virtually & yet give the best....During the Covid challenging times, we never lost hope. We kept going with care, love & compassion. We rather grew stronger and worked harder to handle the challenges that came to our attention from time to time.

This year, we'll be completing 35 years of our services. For more than 3 decades Thalassemics India has continued to champion patient's welfare. We are happy that we could deliver & improvise the services as per the available resources & patient's needs. Our mantras at T.I. are "Do More & More" to achieve 3 C's - Care, Cure & Control.

During the last 6 months, we have been focusing our attention on some very important areas as well as making sure that our running projects are doing well - Disability, helping the neediest by covering their treatment costs, awareness drives, blood donation camps, free NAT tested blood at IRCS & drawing Government's attention on free treatment for all and control of thalassemia.

You must have had heard about the 'Thalassemia Bal Sewa Yojana' initiated by Coal India Ltd and MoHFW to empower the BPL class patients to get cured. We are humbled to extend coordination support to this program. Inside you will find more information about this project.

TIF's contribution during these difficult times is huge by providing the timely and reliable information to Thalassemia families across the globe including India. We remain short of words to express our appreciation for their contribution and support.

Very specially, I would like to express my deepest appreciation to Thalassemia Patients Advocacy Group (TPAG) for their extraordinary efforts and the enthusiasm shown to improve those areas which really need attention and improvement.

35 years of unlimited support for the Thalassemia Patients and community awareness. Do keep encouraging us so that in the next few years, we are able to do much more as per patient's satisfaction.

With personal best regards,
Shobha Tuli

SPECIAL THANKS

"THALASSEMIA BAL SEWA YOJNA"
2ND PHASE OF THE HSCT PROJECT
A CSR INITIATIVE OF COAL INDIA LIMITED

ELIGIBILITY :

Criteria	Thalassemia	Aplastic Anaemia
Age	Up to 12 years	Up to 18 years
Family income	Up to Rs 5 lakh per annum	Up to Rs 8 lakh per annum
Matching donor	Matched sibling donor	Matched related donor

EMPANELLED CENTERS :


AIIMS, New Delhi


CMC, Vellore

TMC, Kolkata

RGCI, New Delhi


Narayana Hrudayalaya Bangalore


SGPGI, Lucknow

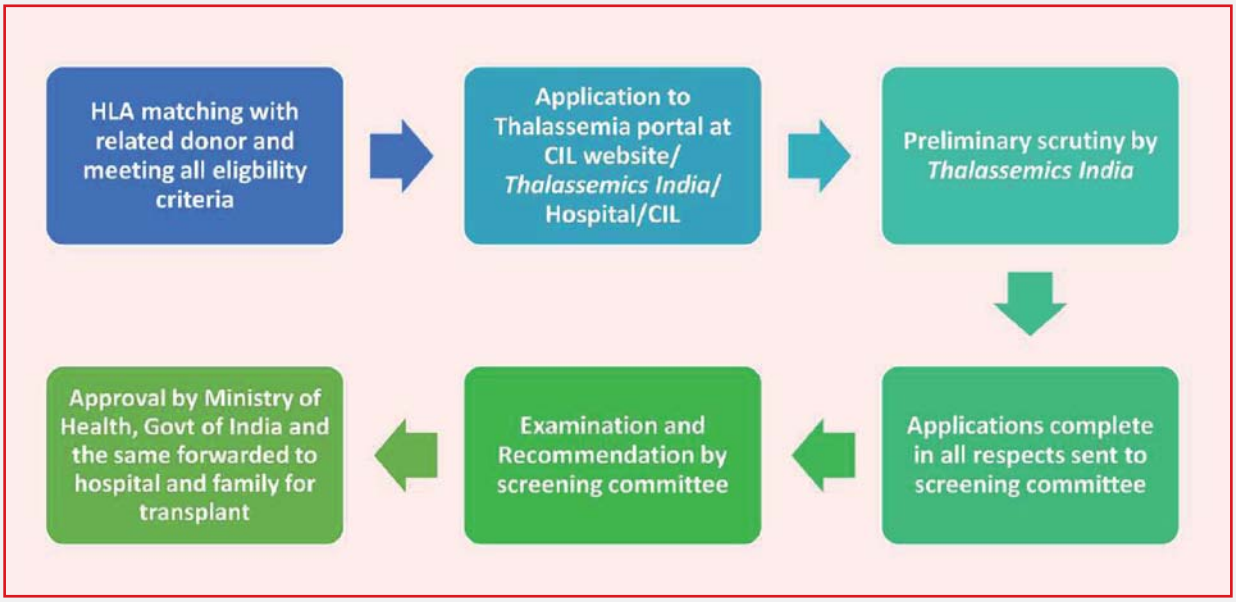

CMC, Ludhiana

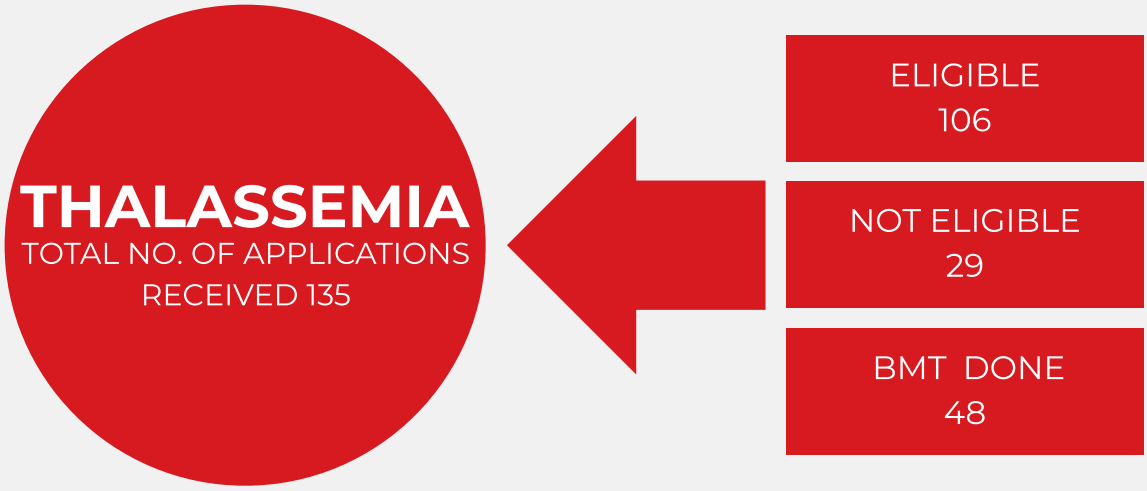

PGIMER, Chandigarh

CLINICAL REQUIREMENTS:

For Thalassemia	For Aplastic Anaemia
Patient should have transfusion dependent thalassemia.	Patient should have severe aplastic anaemia as documented by a bone marrow examination.
Patient should have 100% HLA (Human Leukocyte Antigen) matched sibling donor.	Full 6/6HLA matched related donor.
Such patients must be other than Class 111B patients, liver size of the patient to be less than 5 cm below the coastal margin.	Necessary test to be done for ruling out inherited bone marrow failure syndromes.

PROCESS FLOWCHART :





Applications were received from a number of States e.g. Andhra Pradesh, Bihar, Chhattisgarh, Delhi, Gujarat, Haryana, Jharkhand, Karnataka, Kerala,Madhya Pradesh, Maharashtra, Manipur, Odisha, Punjab, Rajasthan, Tamil Nadu, Uttar Pradesh and West Bengal.

Contact for more information:

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thalcind@yahoo.co.in | tulishobha@gmail.com

SACHIN B | ASST. MANAGER
Coal India Limited, Kolkata
+91- 9433007437
sachin.b@coalindia.in

Visit CIL website: https://www.coalindia.in/departments/csr/tbsy/

TOWARDS THALASSEMIA AWARENESS & SCREENING

HOARDINGS ON ROADS

An initiative by Thalassemics India to spread Thalassemia awareness in general masses through placing billboards & unipoles on prominent places with informative messages. This initiative is supported by **NTTD**.

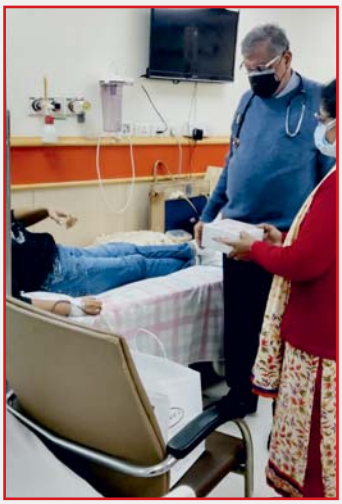
SCREENING CAMPS

- A screening camp held in collaboration with GIFT on 16 December at DAV Centenary College, Faridabad. 487 samples were collected.
- Another screening camp held in collaboration with GIFT on 21 December at K L Mehta Dayanand Women College, Faridabad. 986 samples were collected.

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

SPREADING SMILES PROJECT

Celebration at the thalassemia units of Sir Ganga Ram & St Stephen Hospital on 23rd & 24th Dec, 2021. Special thanks to the donor for making this happen. The team of **ICREON** made extra efforts to visit thalassemics india office on Christmas to meet some of their beneficiaries and distributed gifts and goodies.



WEBINARS

- **PROVISIONS, SCHEMES AND CONCESSIONS FOR THALASSEMICS :**

  GAPS AND THE WAY FORWARD

  A webinar was held on 26 June from 11.30 am to 2.30 pm on "Provisions, Schemes and Concessions for Thalassemics : Gaps and the Way Forward".

  Welcome address was given by Mr. Deepak Chopra, President of Thalassemics India. This was followed by 4 State presentations by Mrs. Shobha Tuli, Dr. Praveen Sobti, Dr. Vinki Rughwani and Dr. Anil Khatri. We had the honour of having Govt. officials from Maharashtra, Gujarat & MOTA. Dr V.K.Khanna & Amita Mahajan moderated the whole meeting.

- **BONE MARROW TRANSPLANT**

  A webinar on "Bone Marrow Transplant" was held on 13th November from 11.30am to 1.45pm. The webinar was held under the auspicious of the Ministry of Health and Family Welfare, Government of India . It was attended by 225 delegates from all over the country.

  Welcome address was given by Mr. Deepak Chopra. We were honoured to have Shri Vishal Chauhan, Joint Secretary (Policy) MoHFW as the Chief Guest and Shri. B.Sairam from Coal India as the Guest of Honour.
  Madam Vinita Srivastava, Advisor, Health Ministry of Tribal Affairs, Govt. of India spoke on "Programme to attain new heights".

  The invited guest speakers were Dr. Mammen Chandy, Dr. Sharat Damodar & Dr. Joseph John. Topics addressed by them were:- "The Transplant Procedure & Complications", "Preparing for a Transplant" and "Life after Transplant". Mrs. Shobha Tuli gave a brief about the HSCT project, Dr. V.K. Khanna extended the vote of thanks & Dr. Amita Mahajan moderated the whole session.


Webinar on
BONE MARROW TRANSPLANT
13th November 2021
Preparing for a Transplant
Dr Sharat Damodar
Clinical Director, Mazumdar Shaw Medical Center Narayana Health City, Bangalore
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Webinar on
BONE MARROW TRANSPLANT
13th November 2021
Welcome
Shri Deepak Chopra
President
Thalassemics India
Organised by :
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Webinar on
BONE MARROW TRANSPLANT
Saturday 13th November 2021 | 11.30 am - 1.30 pm
CHIEF GUEST
Shri Vishal Chauhan
I A S
Joint Secretary- Policy (NHM)
Ministry of Health & Family Welfare
Govt. of India
SPEAKERS
Dr M Joseph John
M M, MBA
Professor & Head of Clinical Haematology Haemato-Oncology and Bone Marrow Transplant Unit
Christian Medical College, Ludhiana
HOSTED BY
Mrs Shobha Tuli
Secretary
Thalassemics, India
Organised by :
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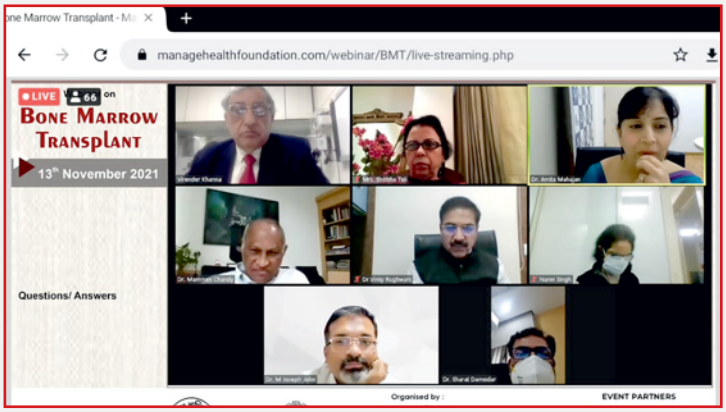
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LIVE 66 on
BONE MARROW TRANSPLANT
13th November 2021
Questions/ Answers
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Webinar Agenda
Ask Question
Welcome - RAJSHREE AGARWAL
Logout
LIVE 64 on
BONE MARROW TRANSPLANT
13th November 2021
CLICK TO UNMUTE
What happens to me over the years?
2009 – age of 1s
14 years
After 7 months
After 5 years
Life After Transplant
Dr M Joseph John
Professor & Head of Clinical Haematology
Haemato-Oncology and Bone


Webinar on
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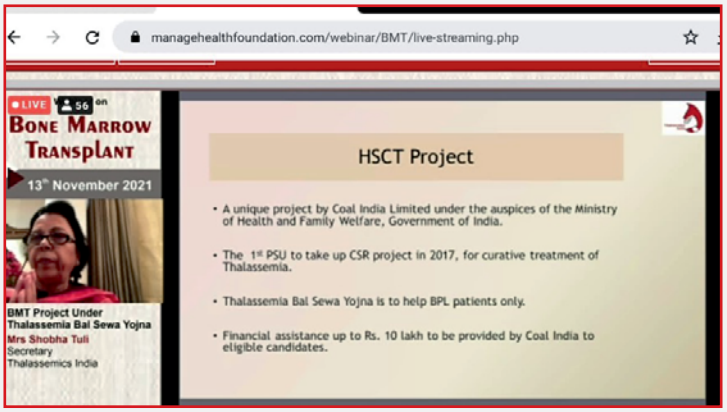
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LIVE 56 on
BONE MARROW TRANSPLANT
13th November 2021
BMT Project Under
Thalassemia Bal Sewa Yojna
Mrs Shobha Tuli
Secretary
Thalassemics India
HSCT Project
• A unique project by Coal India Limited under the auspices of the Ministry of Health and Family Welfare, Government of India.
• The 1st PSU to take up CSR project in 2017, for curative treatment of Thalassemia.
• Thalassemia Bal Sewa Yojna is to help BPL patients only.
• Financial assistance up to Rs. 10 lakh to be provided by Coal India to eligible candidates.

- **PREVENTION OF THALASSEMIA- CHALLENGES & ACHIEVEMENTS**

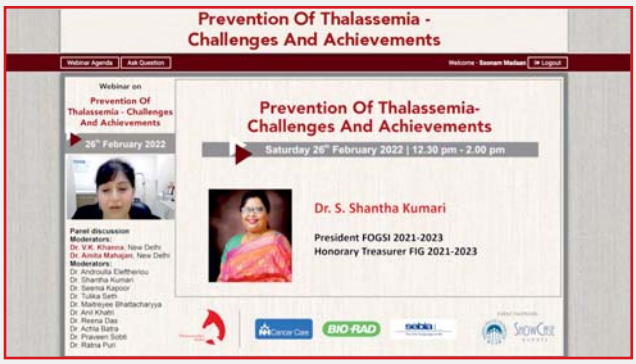
The webinar held on 26 February started with a welcome note by Mr. Deepak Chopra, President of Thalassemics India.

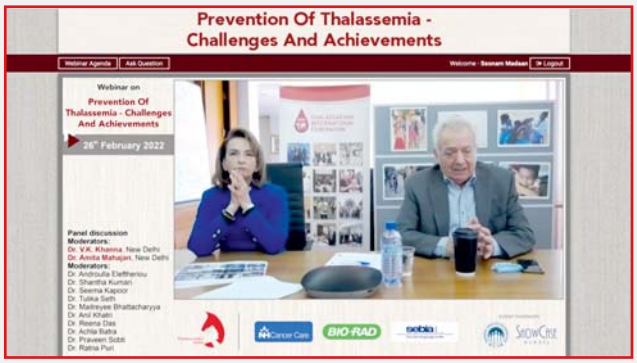
Ms. Shobha Tuli, Secretary of Thalassemics India gave a brief presentation on “Need of the Hour- Awareness & Prevention”. We were honoured to have with us Dr. Nutan Mundeja, Director General DGHS and State Program Officer- Delhi State Health Mission and Mr. Panos Englezos, President of Thalassaemia International Federation.

After the keynote addresses by the Hon'ble Guests, Dr.Amita Mahajan introduced all the invited guest speakers/panellists- Dr. Androulla Eleftheriou, Ms. Vinita Srivastava, Dr.Shantha Kumari, Dr. Seema Kapoor, Dr. Tulika Seth, Dr. Maitreyee Bhattacharyya, Dr. Anil Khatri, Dr. Reena Das, Dr.Achla Batra, Dr. Praveen Sobti & Dr. Ratna Puri.

The panel discussion was moderated by both -Dr. V.K. Khanna & Dr.Amita Mahajan. While talking about the “Future Roadmap”, Ms. Vinita Srivastava shared her experiences and gave her valuable input.

The webinar was attended by 140 participants from India & abroad. The meeting ended with a formal vote of thanks by Ms. Shobha Tuli.






Prevention Of Thalassemia - Challenges And Achievements
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Webinar on
Prevention Of Thalassemia - Challenges And Achievements
26th February 2022
Prevention Of Thalassemia- Challenges And Achievements
Saturday 26th February 2022 | 12.30 pm - 2.00 pm
Dr. Ratna Dua Puri
Panel discussion
Moderators:
Dr. V.K. Khanna, New Delhi
Dr. Amita Mahajan, New Delhi
Moderators:
Dr. Androulla Eleftheriou
Dr. Shantha Kumari
Dr. Seema Kapoor
Dr. Tulika Seth
Dr. Maitreyee Bhattacharyya
Dr. Anil Khatri
Dr. Reena Das
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Dr. Ratna Puri
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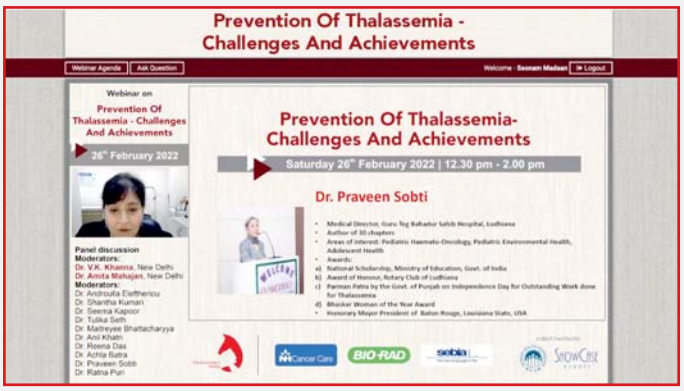
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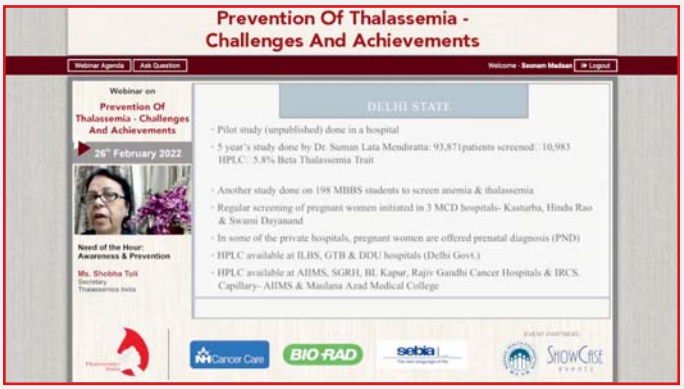
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DELHI STATE
Pilot study (unpublished) done in a hospital
5 year's study done by Dr. Suman Lata Mendiratta: 93,871patients screened.: 10,983 HPLC: 5.8% Beta Thalassemia Trait
Another study done on 198 MBBS students to screen anemia & thalassemia
Regular screening of pregnant women initiated in 3 MCD hospitals- Kasturba, Hindu Rao & Swami Dayanand
In some of the private hospitals, pregnant women are offered prenatal diagnosis (PND)
HPLC available at ILBS, GTB & DDU hospitals (Delhi Govt.)
HPLC available at AIIMS, SGRH, BL Kapur, Rajiv Gandhi Cancer Hospitals & IRCS. Capillary- AIIMS & Maulana Azad Medical College
Need of the Hour: Awareness & Prevention
Ms. Shobha Tuli
Secretary
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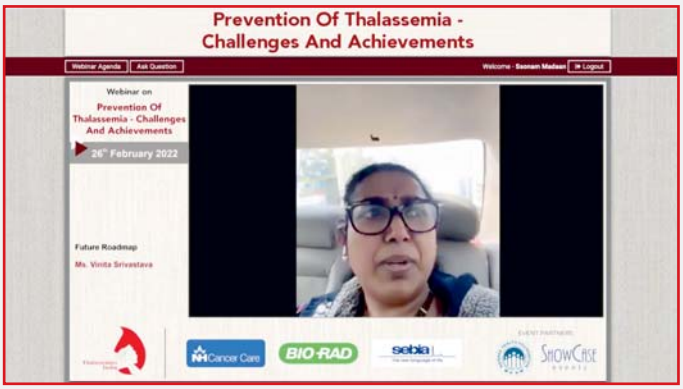
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Future Roadmap
Ms. Vinita Srivastava
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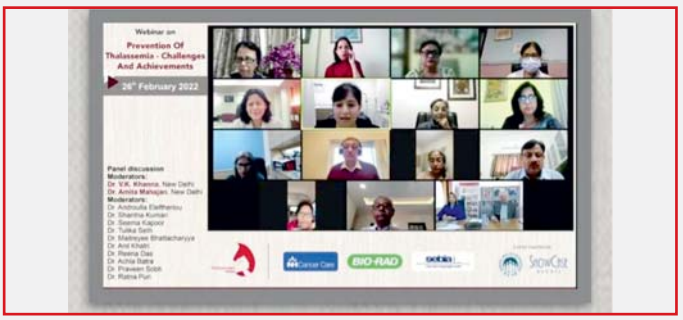
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Prevention Of Thalassemia- Challenges And Achievements
Saturday 26th February 2022 | 12.30 pm - 2.00 pm
KEYNOTE ADDRESS
Dr. Nutan Mundeja
Director General of the Directorate General of Health Services, Delhi &
State Program Officer of Delhi State Health Mission
Cancer Care
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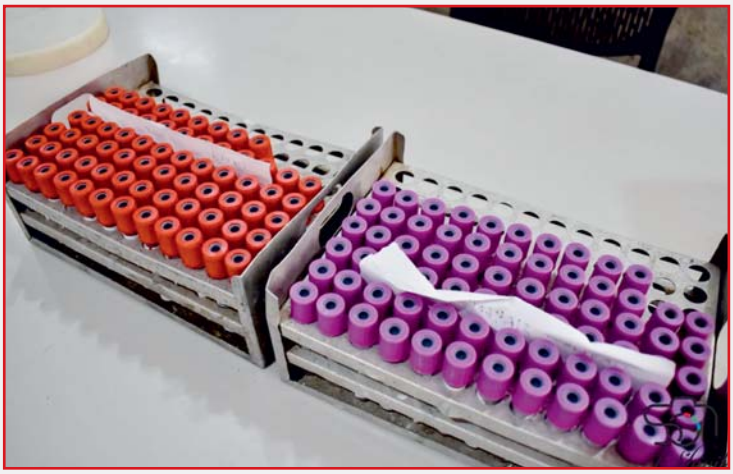
NAT TESTING LAB AT IRCS, NEW DELHI

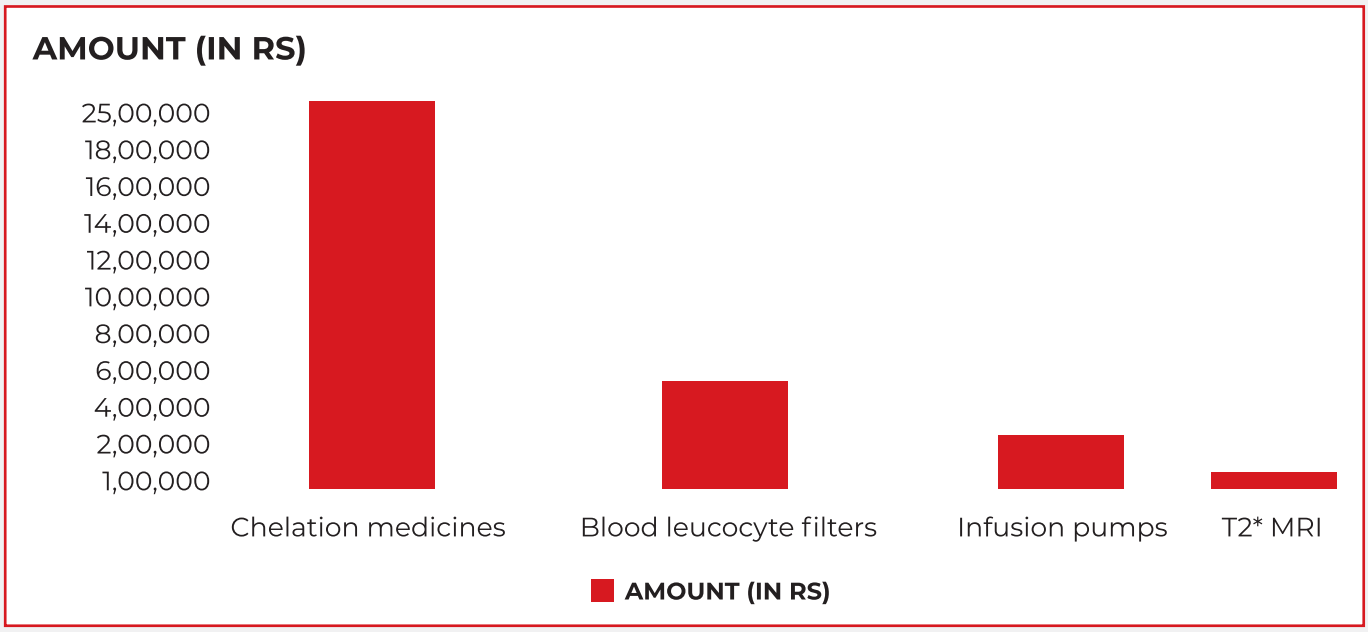
The lab was set up by TPAG & Thalassemics India at Indian Red Cross Society, National Headquarters, New Delhi. The lab has been running since March, 2021 in a PPP mode. Both thalassemics & non thalassemics are provided NAT tested blood from Red Cross.

Since the inception, total 13760 NAT tests were conducted and NAT tested blood was given free of cost by Indian Red Cross Blood Bank to all the recipients.



HELPING HANDS PROJECT
JANUARY 2021- DECEMBER 2021

Under this project, we helped more than 400 patients by giving them free of cost chelation medicines, blood leucocyte filters, infusion pumps and also covered their expensive investigations such as T2* MRI, DEXA SCAN and ECHO. Such patients are from Delhi, Haryana & UP.



A Check up clinic was organized at Sir Ganga Ram Hospital, New Delhi on 12 Dec,2021 to offer personalized patient care to those thalassemics who are receiving free medical support from our organization. Dr. V. K. Khanna & Dr. Amita Mahajan gave their time for which we are so grateful to them. 22 patients received consultations who came from DDU, Kasturba, Hindu Rao, St. Stephens, Ganga Ram & NDMC hospitals. Their lab investigations were also done on the same day.

We are trying our best to help patients in need by giving them recommended treatment free of cost and also supporting their timely medical interventions.

A group of 16 patients who came all the way from Lucknow to get their T2*MRI done at Mahajan Imaging Centre, New Delhi. Sponsored by : Thalassemics 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

NH CANCER CARE
NARAYANA HEALTH CITY – BANGALORE

"STATE-OF-THE-ART CARE FOR ADULT & CHILDREN WITH BLOOD DISORDERS AND CANCER"

NH Cancer Care at Narayana Health Bangalore is a center of excellence for care of cancer and blood disorders for over 15 years. It adopts a multidisciplinary team approach and it is a one-stop solution, which provides Comprehensive Cancer Care. Focus is on patient care, research, community education, and community outreach.

The center is one of the largest caring for patients with cancers and blood disorders. Few thousand patients with these conditions are looked after every year. Center offers quaternary care through "site specific" specialists and teams. Center is taking a big leap in providing immunotherapy based treatments in various cancer types.

BONE MARROW TRANSPLANT (BMT) EXPERIENCE AT NH CITY BANGALORE

- The transplant unit is 18 bedded state of the art with HEPA filtration system and en-suite facilities and is one of the largest in India.
- Done over 1500 plus transplantation till date which is the largest in Karnataka and one of the largest in the country.
- More than 400 Thalassemia Major transplants performed till now with excellent results.
- Center has dedicated teams to look after pediatric and adult patients.
- Center has one of the largest Asian experience in doing the Haplo-identical transplants especially with the TCR alpha-beta depletion.

NH Cancer Care

OUR WORTHY DONORS

Mandeep Singh	₹ 1,45,450
Vilad Bhushan	₹ 1,00,000
Paisley Exports Pvt Ltd.	₹ 1,00,000
Manoj Vipinchand Jain	₹ 1,00,000
Harpreet Singh	₹ 50,000
Brindavan Agro Industries Pvt Ltd.	₹ 30,000
Dr. Rajiv Chhibber	₹ 21,000
Siddhartha Talukdar	₹ 20,000
Ravinder Ghai	₹ 15,000
Sunita Dhingra	₹ 15,000
Shobha Marwah	₹ 9,000
Anand Singh	₹ 5,000
Manghulal Topan Bai Nangi Memorable Charitable Trust	₹ 4,000

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.
 # Thalassemics India is eligible to receive CSR funds.

EXPERIENCE OF BONE MARROW TRANSPLANT (BMT) FOR TRANSFUSION DEPENDENT THALASSEMIA IN RAJIV GANDHI CANCER INSTITUTE AND RESEARCH CENTER, DELHI.

DR. DINESH BHURANI - Director Haemato-Oncology & Bone Marrow Transplant Unit, Rajiv Gandhi Cancer Institute & Research Centre, Delhi

Hemoglobinopathies are inherited disorders of red blood cells. Being an important cause of morbidity and mortality, they impose a heavy burden on families and the health sector in our country. India has the largest number of children with Thalassemia major in the world – about 1 to 1.5 lakhs and almost 42 million carriers of ß (beta) thalassemia trait. About 10,000 -15,000 babies with thalassemia major are born every year. The only cure available for these children with thalassemia major is bone marrow transplantation (BMT). However, this can help only a few patients because of cost, paucity of BMT centers, or non-availability of a suitable HLA matched donor.

Therefore, the majority of the thalassemia patients in India are left with the option of regular blood transfusions followed by adequately monitored iron chelation therapy to remove the excessive iron overload-as a consequence of the multiple blood transfusions. Thus, it significantly affects the quality of life of a child and his/her family and places a great burden on healthcare services.

In India, the major obstacle to the availability of bone marrow transplant to every thalassemic child is the cost of transplant, even if the HLA matching donor is available in the family. The average cost of bone marrow transplant for thalassemia is around 12-15 lakhs.

We, at Rajiv Gandhi Cancer Institute and Research Centre, under the project initiated by Coal India Limited & Ministry of Health & family Welfare in coordination with Thalassemics India has performed 59 bone marrow transplants for transfusion dependent thalassemia patients (age ranging 1- 12 years) between April 2017 and March, 2022. Out of these 59 patients, 55(93.2%) patients are alive and 54 (91.5%) patients are free of thalassemia. Four (6.7%) patients died due to transplant related complications particularly infections. Only one patient had secondary graft rejection. With our constant efforts and urge to improve the outcomes, we have accomplished our goal of zero transplant related mortality and 100 percent thalassemia free survival. None of the patient had died in last three years (since March, 2019) and none of the patient had rejected the graft since then, and hence are thalassemia free. Our comprehensive thalassemia transplant program also includes pre transplant optimization of iron chelation therapy and downstaging of thalassemia risk stratification in case of high-risk patients and for all patients long term post-transplant follow up with focus on proper endocrine evaluation to achieve normal quality of life, which we think is the main purpose of bone marrow transplant.

With the financial aid provided by Coal India Limited we are able to perform four-five thalassemia transplants every month in our BMT unit. We encourage all parents having children with transfusion dependent thalassemia in their family, for HLA typing and matching with siblings and if HLA matched donor is available in family, to enroll under Thalassemia Bal Sewa Yojna Project to provide these patients the opportunity of permanent cure from thalassemia.

MY ROAD WITH REBLOZYL

MARIA HADJIDEMETRIOU

My transfusion regimen for the past 20 years has been two pints of blood every 14 days, prior to this because I am Intermediate many hematologists not only in America but around the world think they can leave their Intermediate Thalassemia patients untransfused with a hemoglobin of 8 even 7 and at times down to a 6. I ask you doctors if you are reading this CAN YOU FUNCTION ON A HEMAGLOBIN OF 8 OR 7 OR 6? Chances are NO so why do you expect your Thalassemia Intermediate patients to function on such low hemoglobin's. I try to maintain my hemoglobin above 10.5 because we need and deserve optimal health but that is quite challenging at times where my pre-transfusion hemoglobin on the 14th day can fall between a 10 and 10.3. Those days leading up to the 14th day are rough.

My body hurts so much and it doesn't start on day 14 for all the hematologists out there reading this UNDERSTAND that our hemoglobin starts to drop 5-7 days post transfusion little by little and every day a little bit more. My body starts hurting by Day 10. Because I have osteoporosis bone pain is the first, my ankles and pelvic bones where it makes it hard to walk but I still do...and sometimes a little run to catch the train; then Day 11 it is my bone marrow – that throbbing pain in my lower spine where it makes it harder to walk but I still do...and sometimes a little run to get home and start dinner; Day 12 it is my brain – that pain where I can't sustain a single thought; a fog so thick that makes my brain feel like mashed potatoes; Day 13 – I am so fatigue; my breathing has become slower, longer wanting so badly to take a 3 hour nap; my chest feels like it is going to jump out of my body making it the hardest to walk but I still do and sometimes a little run to get to an appointment which shows how much Thalassemia patients DO NOT GIVE UP. This shows our tenacity and our perseverance but imagine having to do all this on a 6 hemoglobin. Alas Day 14 – BLOOD DAY where I feel like crawling to the hospital for that miracle blood to seep deep into my vein bringing me life again for the next 14 days. REPEAT.

I NEED A BREAK

My veins need a break. All those sticks since I was diagnosed at 2 ½ years old (possibly over 20,000) caused so many scar tissues. Its like the needle hits a brick wall and many times where my veins blew up.

My organs need a break too. What comes with being chronically transfused is the iron overload. Sneaky iron making its ways into our organs, making them enlarged causing early organ failure. My spleen was removed at age 9; my gall bladder at age 11 and I find myself so blessed that my pancreas is still producing its own insulin because most Thalassemia patients have diabetes due to iron overload. Because of iron chelators and now thankfully an option of them we have been able to remove the iron from vital organs like our heart and liver still though we need to take our chelation medicine daily – as long as we are receiving our life saving blood we need to chelate. Message to my blood sisters and brothers around the world....if you have access to chelation be responsible and take your chelation. I understand how chelating can become cumbersome....I UNDERSTAND and at times I wish I never have to stick my tummy with a needle where that needle is in my tummy for 10 hours causing abscesses; massive black and blue marks; huge bumps. That wish came true and now my organs and my veins got the well-deserved break.

In November 2019 a new treatment was available for Thalassemia patients.....REBLOZYL. It is an injection that allows our red blood cells to go through its maturation stage. Once my hospital was approved for Reblozyl I believe around March 2020 I started my treatment. My very first injection was on May 13, 2020 – just when the coronavirus lockdowns came. The timing was a blessing as with the lockdowns came a halt to all blood drives depleting our supply of blood in our blood banks, the goal of Reblozyl is to keep extend our transfusion cycle depending on blood less. With the lockdowns also came school closures and everyone working from home where I would be able to rest should Reblozyl give me any side effects. I was told about the side effects of Reblozyl and the one that worried me the most was bone pain as I already have bone pain due to my severe osteoporosis. I was told the bone pain subsides as your body gets used to the drug as well the bone marrow pain subsides and this is a sign that the drug is working. Reblozyl is given to me every three weeks. Now remember my transfusion regimen was two pints of blood every 14 days, my chelation regimen at the time was Desferal 3-4 times a week and my oral chelator Deferiprone 3 times a day. I also want to note my ferritin fluctuating between 900-1,300 prior to starting Reblozyl. The first eight weeks I did have bone pain and bone marrow pain – it was manageable. What I did was rest; I took naps, I meditated; did yoga and this helped so much and just like my doctor said the pain subsided. My doctor and I set some guidelines for my hemoglobin levels and this was done because he understands how difficult it is for me to function with low hemoglobins and wants me to have optimum care – anything below 10.4 I receive two pints of blood and my injection; Anything above 10.5 I receive one pint of blood and my injection and anything above 11.5 I receive no blood and no injection and return to the hospital the following week and that would make it 4 weeks without blood. On May 13 my hemoglobin was 10.2 so I received two pints of blood and my first injection. On June 3rd I did a hemoglobin check and it was a phenomenal 11.5 so there was no blood and no injection. In this case I must return the following week for a hemoglobin check and on June 10 my hgb was 10.8 where I received one pint of blood and my injection.

Right now I am averaging around a 10.8 hemoglobin where I only receive one pint of blood every three weeks. This for me is like a cure. Not only did my veins get the well-deserved break they needed so did my organs. In November of 2020 another amazing thing happened; my ferritin went down to a 350 and it has been pretty much stabilized there except for a one off 650. November 2020 was the last time I used Desferal (desfaroxomine). I am currently only using one chelator – oral – Deferiprone. Other patients have been able to extend their transfusions regimen by 5 to 6 weeks and for a few other patients Reblozyl did not work. Each person is different.

I pray for all countries to approve of Reblozyl. For the countries that have socialized healthcare systems they will think of the cost of Reblozyl. What the Ministries of Health need to understand is the end result cost in providing Thalassemia patients with Reblozyl where they will save money. By giving patients Reblozyl it will cost them less. Less transfusions and less chelation medicines as the patients ferritin will drop but the most important is an incredible quality of life. This is what increases by giving patients optimum healthcare and that will be achieved by providing Reblozyl for Thalassemia patients. That at the end of the day does not have a price tag on it. IT IS PRICELESS!!!

LIFE IS: HOW YOU MAKE IT!!

Ssonam Maddan - A Thalassemia Warrior

Someone rightly said : You only live once, but if you do it right, once is enough. I strongly feel that it is your perspective of seeing life or your problems can change your attitude towards life. We all have different perspective about life. Some of us see positive aspects of whatever happens. While some keep blaming that life is hard. Why some sees beauty of the garden while some see, dry leaf and waste scattered along the way. Why some of us change the circumstances around them and some change themselves as per circumstances.

There is no set rule or protocol to live your life. God has given us the freedom how we can make it. So live a life that people will look up to you. I can explain this by narrating a short story from Bhagvad Gita. There was a rich man, having all opulence's in life was not happy because of this worrying attitude. He went to an astrologer & showed him horoscope, astrologer said there is no problem in your life, you should control your anxiety by learning Bhagvad Gita, he then went to an Acharya to learn the verses of Gita.

He said “OK. We'll start with first chapter and complete the whole book of 18 chapters in 3 months”. The man said, “No Swamiji. I'm busy with many things. So teach me the most important part”. The teacher said, “OK. Just learn 18th chapter. it is the summary of the Gita and it will take 2 weeks”. The man said, “Even 2 weeks is difficult. Teach me something more simple”. The teacher said, “OK. There is one sloka in the 18th chapter starting with sarva dharman parityajya. Just learn that one sloka and it will give you the essence of the Gita”.

The man said “One sloka is also difficult for me to learn. Tell me something more simple. “The acharya said, “There is one important word in that sloka 'ma shuchah', which means, “Do not worry”. Just understand this and Gita is understood.”

The man said “That's alright. But I'm already in anxiety and tell me how to remove it. Just telling “do not worry” will not help me. Please tell me what I should do to get rid of anxiety”.

The teacher said, “That is what the Gita is all about. If you want to know how to be free of worries then you should start from the chapter 1 of Gita. There is no shortcut to this process & in the Life itself. God has given different question papers to everyone. So live your life with zeal & enthusiasm. Help others in which way you can. Try to make everyone happy around you.

OUR NEW MEMBERS

Nitesh Bhawsar	Madhya Pradesh
Mohammad Anas	Delhi
Mohd. Mabood Alam	Uttar Pradesh
Jignesh Sevadas Nimbark	Gujarat
Mukesh Dubey	Uttar Pradesh
Sonam Chatterjee	West Bengal
Ashutosh Bose	Haryana
Deepak Longwani	Madhya Pradesh
Jaspreet Chohan	Maharashtra
Shubham Kumar	Haryana
Kaushalya Chainani	Madhya Pradesh
Manas Jhamb	Delhi
Ratan Jana	West Bengal
Abanta Kumar Dhal	Delhi
Lakshmikanth	Karnataka
Pooja Gupta	Delhi
Mohd. Kaushif	Delhi
Deepika Grover	Delhi
Gurmeet Singh	Punjab
Mosin Khan	Delhi
Apurba Dey	West Bengal
Prabhu Agya Foundation	Madhya Pradesh
Abhishek Choudhary	Uttar Pradesh

For more details about membership benefits, please visit our webiste : www.thalassemicsindia.org

To find out more about our organization, please contact the Thalassemics India office
Thalassemics India, A-9, Nizamuddin West, New Delhi-110013
Ph. :- 011-41827334,46595811, Email: thalcind@yahoo.co.in

THALASSAEMIA INTERNATIONAL FEDERATION

The 15th International Conference organised by Thalassaemia International Federation was held on 19-21 November, 2021. It was very heart-warming to witness that in these turbulent times, which do not allow for us to come closer to one another, our community remains united, resilient, and committed to moving forward despite challenges. We are very thankful to TIF for organising the conference.

It is a matter of privilege for us to be a part of the TIF conference.
Some glimpses of the TIF conference:-

CHALLENGES & UNMET NEEDS: THE PATIENT PERSPECTIVE

Chaired by: Ms. Shobha Tuli & George Constantiniou

The first session described a two-speed world, with a great number of inequalities between countries and patients, as large disparities between countries and regions and people with the same disease are a painful and unacceptable reality.

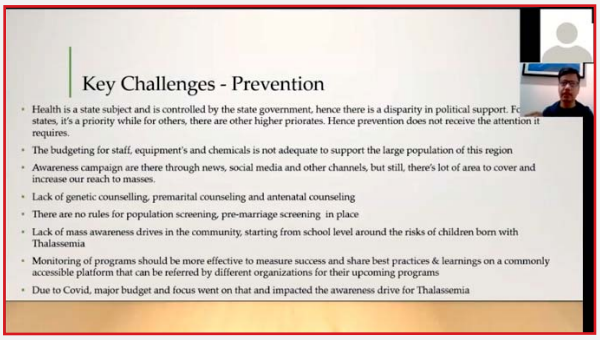
The distinction between privileged and disadvantaged patients was evident through the testimonies of patients from the six regions of the world, according to the categorisation of the World Health Organization. Through the plethora of challenges and unmet needs mentioned, the widening gap between patients in terms of care and social inclusion was easily understood.

Ms. Anubha Taneja talked about relationships and marriage, initially providing an overview of the situation in India from the 1980s to this day. Social stigma, but also practical problems brought about by the management of the disease used to be hurdles for relationships, as the primary concern of the patients was their very survival, while later on this changed to ensuring a healthy and dignified life with the disease.

Discussions on relationships and marriage for people with thalassemia are very recent in India and the result of education and interaction between patients in the context of national associations, which contributed to the strengthening of their self-confidence.

THALASSAEMIA INTERNATIONAL FEDERATION

Mr. Viresh K Piplani spoke about the key challenges including prevention.



Haematopoietic Stem Cell Transplantation : Experience from India presented by Dr. Vikram Mathews.

TIF BOARD MEETINGS

- Board meeting held on 17th October, 2021
- Board meeting held on 22nd November, 2021
- Board meeting held on 22nd December, 2021.

All meetings were held virtually

NEWS ACROSS INDIA

दिव्यांग छात्रों को अब 5% कोटा

पहले 3 फीसद था कोटा, से पीड़ित छात्रों को भी होगा लाभ

ऑनलाइन पोर्टल की समस्या नहीं हुई दूर

असुविधा

- टैब 2 न मुलने से एक भी छात्र नहीं का पाया पीटा का पुरस्कार
- इमेरेंसी सेंटर की हेल्पलाइन पर नहीं मिला जवाब

आपको हमारा Epaper कैसा लगा हमें बताएं

'HLA typing is very important to find donor, recipient whose cells most closely match'

Sarabjeet Singh Narang addressing the press conference on Thursday.

■ Staff Reporter

"HUMAN Leukocyte Antigens (HLA) serves as a unique identification marker for every individual. In organ and tissue transplantation, HLA antigens of the donor identified as invaders by the recipient, cause rejection. Careful selection of the matched donor and recipient critically affect the outcome of transplantation. HLA typing is therefore very important to find a donor and recipient whose cells most closely match," opined Dr. Sanjay Asati.

Dr Asati was addressing a press conference called by Disha Welfare Association on Thursday to inform about free HLA Camp to be organised at Pediatric ward of Netaji Subhash Chandra Bose Medical College and Hospital on March 27 from 9 am to 3 pm.

Patients suffering from thalassemia and sickle cell anemia will be largely benefited in the camp. Dr. Prakash Satnami from USA, Dr. Preeti Malpani from Indore, Joint Director, Health Services, Dr. Sanjay Mishra, Dr. Monika Lazrus, Head of Pediatric Department, NSCBMCH and Senior Pathologist, Dr. Sharad Jain will especially attend patients during the camp which will be supported by the volunteers of Disha Welfare Association, Thalassemia Janjagaran Samiti Jabalpur and other social organisations.

Sarabjeet Singh Narang from Disha Welfare, informed that Thalassemia and Sickle Cell are genetic diseases which spread its wings from one generation to another due to unawareness and ignorance. Hence, its important to conduct HBA2 test of the future couple before matching their Kundalis. During HLA camp, family members and parents of Thalassemia patients can give their samples free of cost for matching in the camp. If their samples matched, it will provide great relief to the Thalassemia patients who can defeat the life threatening disease.

According to experts, HLA typing is a rare process, hence, people must participate in the free HLA camp in large numbers to save the life of patients who are battling against Thalassemia and Sickle Cell.

Ajay Kumar Ghosh, Vikash Shukla, Chavi Thakur, Rahul Tiwari and Ashish Vishwakarma were also present.

Blood donation camp organised

Congress leader Nitin Bhansali donated blood in the camp.

■ Staff Reporter
RAIPUR, Dec 12

KASH Foundation on Sunday organised a blood donation camp in the state capital for children suffering from Thalassemia.

According to the information received, people actively participated in the blood donation camp. On the occasion, Congress leader Nitin Bhansali also donated blood for children suffering from Thalassemia. Meanwhile, blood donation certificates were given to donors.

Founder of KASH Foundation Kajal Sachdev, Suresh Sachdev, Ashish Makhija, Mindar Saluja, Divyanshu Jaiswal, Shweta Jaiswal, Heena Lehja, Satyendra

दैनिक भास्कर डूंगरपुर 02-02-2022

भास्कर एक्सक्लूसिव एमजी अस्पताल में ई-वेचर यूनिट तक नहीं, सामान्य वार्ड में ही बच्चों को भर्ती कर रहे, 77 बच्चे रेजिस्टर्ड

थैलेसीमिया पीड़ित बच्चों को बिना फिल्टर चढ़ा रहे खून, इससे दिल की बीमारी, लीवर डैमेज, हड्डियां हो रही कमजोर

जरूरी क्यों- शरीर में आयरन की मात्रा बढ़ने नहीं देता फिल्टर

दैनिक भास्कर बांसवाड़ा भास्कर 25-02-2022

पीड़ित बच्चों के परिजनों ने कहा-थैंक्स भास्कर, हर महीने औसतन 100 यूनिट खून बिना फिल्टर के ही बच्चों को चढ़ाया जा रहा था

17 साल बाद एमजी अस्पताल को मिली 300 ल्यूकोसाइट फिल्टर की सप्लाई, थैलेसीमिया पीड़ित बच्चों को खून चढ़ाने पर एलर्जी, संक्रमण का खतरा अब नहीं

भास्कर ने लापरवाही उजागर की तो विभाग ने जयपुर से 1.61 लाख रुपए के 300 फिल्टर भेजे

बांसवाड़ा: महात्मा गांधी अस्पताल में थैलेसीमिया पीड़ित बच्चे को खून चढ़ाने के दौरान फिल्टर का यह रिएक्शन।

थैलेसीमिया पीड़ित बच्चों के लिए अलग से ई-वेचर यूनिट बनाने की जरूरत

परिजन बोले- 500 रुपए में अहमदाबाद से मंगवाते थे

थैलेसीमिया पीड़ित बच्चों को बिना फिल्टर चढ़ रहे खून, इससे दिल की बीमारी, लीवर डैमेज, हड्डियां हो रही कमजोर

19 फरवरी को प्रकाशित खबर

दैनिक भास्कर

3 हजार थैलेसीमिया और हीमोफीलिया मरीजों को 10 तक दिव्यांग प्रमाण पत्र

'मेरा प्रमाण पत्र- मेरा सम्मान' नवाचार से पात्रों को प्रमाण पत्र उपलब्ध कराने के दिए निर्देश

जयपुर | चिकित्सा मंत्री परसादी लाल मीणा ने प्रदेश के हीमोफीलिया और थैलेसीमिया रोगियों को जल्द से जल्द दिव्यांग प्रमाण पत्र उपलब्ध करवाने के लिए 'मेरा प्रमाण पत्र-मेरा सम्मान' नवाचार करने के निर्देश दिए हैं। मीणा ने बताया कि प्रदेश में 3 हजार से ज्यादा थैलेसीमिया रोगी हैं, जिनमें से केवल 850 रोगियों को ही दिव्यांग प्रमाण पत्र जारी हुए हैं। इसी तरह हीमोफीलिया के 1 हजार मरीजों की तुलना में 400 रोगियों को ही प्रमाण पत्र जारी किए गए हैं। उन्होंने कहा कि दोनों बीमारियों से पीड़ितों को जल्द से जल्द प्रमाण पत्र उपलब्ध कराने के लिए यह अनूठा प्रयोग किया जा रहा है। राष्ट्रीय स्वास्थ्य मिशन के निदेशक डॉ. जितेंद्र कुमार सोनी ने बताया सभी मेडिकल कॉलेजों के अधीक्षकों को 10 फरवरी तक दोनों बीमारियों के मरीजों को प्रमाण पत्र दिलाने के निर्देश दिए जा चुके हैं।

डॉ. सोनी ने कहा कि प्रत्येक गुरुवार को संभाग स्तरीय मेडिकल कॉलेज स्तर पर विशेष रूप से थैलेसीमिया एवं हीमोफीलिया मरीजों की जांच कर पात्र व्यक्ति के लिए प्रमाण पत्र जारी करने के निर्देश दिए गए हैं। कोई भी पात्र व्यक्ति ई-मित्र के जरिए भी आवेदन कर सकता है। ई-मित्र के जरिए किया गया आवेदन बीसीएमओ, पीएमओ के पास जाएगा। वहां से आवेदन अग्रेसित होकर जांच उपरांत प्रमाण पत्र कर दिया जाएगा।

If you wish to share any important news with the thalassemia community, please let us know. We also encourage people to share their stories about their personal experience that may touch other thalassemics, parents and societies.

NEWS FROM THALASSEMIC CHAIRATABLE TRUST (REGD.), CHANDIGARH

THALASSAEMIC CHARITABLE TRUST (REGD) PGI-GMCH ORGANIZED ITS 241ST BLOOD DONATION CAMP ON 30.01.2022 IN PGIMER, CHANDIGARH TO COMMEMORATE MARTYRDOM DAY OF MAHATMA GANDHI. TOTAL 83 VOLUNTARY DONORS DONATED BLOOD IN THIS CAMP.

NEWS FROM THALASSEMIA & SICKLE CELL SOCIETY, HYDERABAD

Striving to check β-Thalassemia spread

CITY BUREAU
Hyderabad

Scientists have identified high-risk districts for the prevalence of beta-thalassemia and developed models to prevent the disease

Scientists from Hyderabad in a ground-breaking research titled 'Identification and Development of a High-Risk District Model in the Prevention of (Beta) β-Thalassemia in Telangana' have identified high-risk districts for the prevalence of beta-thalassemia and developed models to prevent the disease by conducting population-based screening programmes.

The researchers from the city-based Genome Foundation in collaboration with Thalassemia and Sickle Cell Society have identified four districts including Rangareddy, Sangareddy, Mahabubnagar and Khammam, as high-risk districts for the prevalence of Beta-Thalassemia in Telangana. The study on thalassemia, the genetic disease where a disorder in haemoglobin make up occurs at the genetic level and runs through families causing red blood cells and low levels of oxygen in the bloodstream, was sponsored by the TSCOST.

The group of scientists led by Dr Vadlamudi R Rao included Gaurav Gupta, Kondaveeti Saroja and Suman Jain, took 4 years to prepare a high risk-district model by compilation of data on age-sex distributions, parental and grand-parental ethnic affiliations, birthplaces, marital migrations, endogamy and consanguinity.

Among the endogamous subpopulations, five groups including Sunni, Lambadi, Madiga, Mala and Mudiraj contributed 69.5% and another 43 groups contributed 30.5% of beta-thalassemia patients of the study sample, the study said.

NEWS FROM KASH FOUNDATION, RAIPUR

दैनिक भास्कर रायपुर 14-12-2021

रक्तदान के लिए प्रेरित करने पहल...

खून दिया, शाबासी मिली

रायपुर | काश फाउंडेशन ने शंकर नगर स्थित एक फिटनेस क्लब में रक्तदान शिविर का आयोजन किया। फाउंडेशन की फाउंडर काजल सचदेव ने बताया कि हम थैलेसीमिया पीड़ित बच्चों की मदद के लिए रक्तदान अभियान चला रहे हैं। तुम हमें खून दो, हम तुम्हें शाबासी देंगे... जैसे नारों के साथ हमने रक्तदान की अपील की। बड़ी संख्या में लोगों ने ब्लड डोनेट किया। पीआईएसएफ के चेयरमैन नितिन भंसाली भी कैंप पहुंचे और 69वीं बार रक्तदान किया। सभी रक्तवीरों को प्रशस्ति पत्र देकर सम्मानित किया गया। इस दौरान सुरेश सचदेव, आशीष माखीजा, मिंदर सलूजा, दीव्यांशु जयसवाल, श्वेता जायसवाल आदि मौजूद रहे।

थैलासीमिया ग्रस्त बच्चों के लिए रक्तदान शिविर

पायनियर समाचार सेवा। फरीदाबाद

फाउंडेशन अगैंस्ट थैलासीमिया द्वारा आयोजित शिविर में रक्तदान करते समाज सेवी।

थैलासीमिया ग्रस्त बच्चों के लिए फाउंडेशन अगैंस्ट थैलासीमिया द्वारा एक रक्तदान शिविर का आयोजन भगवान महावीर हॉस्पिटल सैंट्रल ग्रीन फरीदाबाद में किया गया। इस अवसर पर थैलासीमिया ग्रस्त बच्चों को रक्त चढ़ाने के लिए फिल्टर इनर व्हील डिस्ट्रिक्ट 301 के सहयोग दिए गए। जिसके लिए इनर व्हील डिस्ट्रिक्ट 301 की गवर्नर अनीता जैन व डॉ. विनीता चोपड़ा का विशेष सहयोग रहा। गोल्डन लिओनेस क्लब फरीदाबाद ओल्ड द्वारा थैलासीमिया ग्रस्त बच्चों के लिए रिफ्रेशमेंट का प्रबन्ध किया गया।

इस अवसर पर क्लब की ओर से शैफाली, सरला व दिव्यांश उपस्थित रहे। रोटरी क्लब ऑफ दिल्ली साउथ सेंट्रल के मुकेश अग्रवाल का रक्तदान शिविर को सफल बनाने में बहु बड़ा सहयोग रहा। विष्णु सुरेखा मौर्या उद्योग द्वारा सभी बच्चों को उपहार दिए गए। जिन्हें पाकर बच्चे बहुत ही खुश थे। फाउंडेशन के प्रधान हरीश रतरा ने बताया की संस्था द्वारा समय समय रक्तदान शिविरों का आयोजन लगतार होता रहा है यही वजह है की फरीदाबाद में थैलासीमिया ग्रस्त बच्चों को रक्त की कमी का सामना नहीं करना पड़ रहा। संस्था के महा सचिव रविंद्र डुडेजा ने बताया की उनका हमेशा प्रयास रहा है बच्चे हमेशा स्वस्थ तो रहे खुश भी रहे। इस अवसर पर भारत अरोड़ा ने आश्वाशन दिया की आने वाली 23 मार्च को विजय रामलीला ग्राउंड में वो थैलासीमिया ग्रस्त बच्चों के लिए एक विशाल रक्तदान शिविर का आयोजन करेंगे।

NEWS FROM FOUNDATION AGAINST THALASSEMIA, FARIDABAD

FOR YOUR INFORMATION

The Rights of Persons with Disabilities (RPWD) Act, 2016 has recognized Thalassemia as a benchmark disability. Benchmark disability status ensures that all Thalassemics are recognized as persons with minimum 40% disability, and they are eligible to avail all benefits given to persons with benchmark disabilities under the RPWD Act.

UPDATED DISABILITY CARD VALIDITY

As per the new RPWD Act guidelines, Thalassemia patients with less than 80% disability shall be issued disability cards with three years validity & patients with more than 80% disability shall get permanent disability cards with lifetime validity.

KEY BENEFITS UNDER THE RPWD ACT

Many states offer financial assistance to patients via disability pension. For example, Delhi Govt. offers a monthly pension of Rs 2500/- to thalassemia patients who meet following criteria:

1. Aadhar card holder & Delhi resident for at least five years.
2. Annual family income of less than Rs 1,00,000 per annum from all sources.
3. Singly-operated account in any Bank in Delhi.
4. Not receiving financial assistance under any other Govt scheme.

- Every child with thalassemia between the age of six to eighteen years shall have the right to free education in a neighbourhood school, or in a special school, of his choice.
- All Government institutions of higher education and other higher education institutions receiving aid from the Government shall offer reservation not less than five per cent for persons with benchmark disabilities. Many Thalassemia patients are already getting benefited from this reservation and getting higher education in prestigious educational institutes like IIMs & IITs.
- Moreover, the persons with benchmark disabilities shall be given an upper age relaxation of five years for admission in institutions of higher education.
- Section 37(a) of RPWD Act recommends five per cent. reservation in allotment of agricultural land and housing. In Delhi, DDA Housing Schemes implements the recommendation via following measures:
  - 5% reservation for persons with disability (Divyangjan) as defined in Section 37(a) of the rights of persons with disability Act, 2016. Attempts shall be made to make allotment of flats to persons with disability at ground floor.
  - 5% rebate in the cost subject to a maximum of 1 lakh will be given to the persons with disability who are allotted flat under the above quota.

THALASSEMICS INDIA INITIATIVES

Thalassemics India is helping thalassemics in Delhi to avail benefits of RPWD Act by assisting them in:

- Disability Card Processing
- Disability Pension Processing

DISABILITY CARD PROCESSING

Disability card is needed to avail all benefits under the RPWD Act. Thalassemics India has taken the initiative to help Thalassemia patients with processing of disability cards. Till date, 349 disability cards have been successfully generated by Thalassemics India.

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To get assistance in applying for disability card, procedure is very simple. Try to apply on your own. If you need our help, contact Thalassemics India at its official email. Kindly mention your contact no., email & blood group in the email and attach scanned copy of Adhaar card, passport size photo & signature. The subject line for the mail should be "Scanned documents for UDID certificate".

DISABILITY PENSION PROCESSING

Thalassemics India is assisting eligible thalassemia patients in Delhi to enroll for disability pension. To get assistance in enrolling for pension, thalassemia patients / parents can send self-attested scanned copy of following documents on official Thalassemics India email or submit these documents in person at Thalassemics India office in New Delhi:

1. Address proof (for last 5 years): Voter I.D Card / Passport / Driving License
2. Disability Certificate
3. One Passport size photo
4. Bank Passbook
5. Self-declaration

The subject line for the mail should be "Scanned documents for Disability Pension".
To get more details on disability card and pension, please feel free to reach Swati Tuteja via official phone or email address of Thalassemics India.

FOR YOUR INFORMATION

Covid pandemic brought several challenges for everyone and even more for thalassemia patients & parents. Since the pandemic begun in 2019, every covid wave brought with it acute blood shortage, financial problems and commuting challenges for Thalassemics.
Thalassemics India demonstrated resilience to face this tough situation and worked with associated organizations & groups to support patients in overcoming covid challenges.

ENSURING BLOOD AVAILABILITY DURING PANDEMIC

During Covid, when there was acute blood shortage due to limited blood donations, Thalassemics India took initiatives by conducting around 24 Blood Donation camps (on an average 1 camp per month) & addressed severe blood shortage during the pandemic. This was not so easy without having the support of some voluntary organizations & committed people.

We are extremely thankful to following groups & volunteers who helped us arrange blood donations and camps during these difficult times:-

LifeSavers Blood Donor Group, specially Mr Ravi Mittal conducted the maximum number of blood camps during the pandemic. The group truly lived up to their name and saved lives of hundreds of Thalassemics during the pandemic.

TPAG VOLUNTEERS & ASSOCIATED ORGANIZATIONS

Thalassemia Patients Advocacy Group (TPAG), a patient group at Thalassemics India, created a blood donation helpline in collaboration with non-profit organizations like Khoon Khas & Giving is Living. 500+ individual units were arranged via the helpline. Blood donors were searched via social media & online portals like friends2support. Special thanks to following volunteers who contributed towards the helpline:

- Mr. Chethan M. Gowda & Ms. Charu Agarwal (Khoon Khas)
- Mrs. Varsha Sardana (Giving is Living)
- Mr. Madan Chawla (Globally Integrated Foundation for Thalassemia)
- TPAG Helpline Volunteers – Ms. Heena Khan, Mr. Gautam Sharma & Mr. Rishabh Lamba

KAB Welfare Foundation & other Volunteers: KAB foundation and other volunteers (Ms. Aditi & Mr. Gyanendra, Mr. Manuj Gakhar & Mr. Abhishek Kushwah)arranged few blood donation camps. Ms. Aditi & Mr. Gyanendra also helped in spreading awareness about Thalassemia in the community.

TRANSPORT ASSISTANCE & DOORSTEP DELIVERY OF MEDICINES

Public transport was shut down during the lockdowns. At such a time, going out for transfusion & buying chelators was a challenge for patients who didn't have their own conveyance. Thalassemics India in association with its patient group TPAG provided cabs and reimbursed transport expenses for many patients.

When everyone was scared to come out of their places, Thalassemics India staff facilitated the delivery of medicines & infusion pumps for Thalassemia patients in almost all states in India. More than 2100 courier requests for the chelation medicines & infusion pumps were successfully addressed during the pandemic.

PROVIDING FINANCIAL SUPPORT FOR MEDICAL EXPENDITURE

Many people lost their jobs or suffered losses due to the pandemic. Thalassemics India reimbursed medical expenses for such poor and needy families during the pandemic.

YES, WE HAVE OUTLIVED THIS PANDEMIC TOGETHER & HOPEFULLY THE PANDEMIC WOULD END SOON!!

FOR YOUR INFORMATION

INAUGURATION OF THE THALASSEMIA CENTER & BMT CLINIC AT DHARAMSHILA NARAYANA SUPERSPECIALITY HOSPITAL, NEW DELHI.

The centre was inaugurated by Mrs. Shobha Tuli, Secretary, Thalassemics India on December 4, 2021. This is the first Thalassemia centre in Delhi with a BMT clinic. The young thalassemics can take advantage of the BMT counselling as well. Both the centres are fully equipped with all the latest & necessary techniques used in the management of Thalassemia.

4 वीर अर्जुन, नई दिल्ली, 5 दिसम्बर, 2021

शादी के समय जन्मपत्री नहीं थैलेसीमिया के टेस्ट को आधार बनाएं : डॉ. खन्ना

वीर अर्जुन संवाददाता

नई दिल्ली। भारत सबसे ज्यादा थैलेसीमिया से पीड़ित बाला देश है यहां तकरीबन इनकी संख्या एक लाख से ज्यादा है अन्य अध्ययन बताते है कि हर साल दस हजार से अधिक बच्चे थैलेसीमिया के साथ पैदा होते हैं। रोग की गंभीरता की दृष्टि से थैलेसीमिया का मैनेजमेंट बहुत सावधानी भरा होता है, नियमित चलती दवाई हर दो से तीन हफ्तों में रक्त की आवश्यकता, मनोबल बनाए रखने के उपाय आदि एक थैलेसीमिया के मरीज के इलाज का हिस्सा है। धर्मशिला नारायण सुपर स्पेशलिस्ट हॉस्पिटल ने अपने परिसर में थैलेसीमिया सेंटर बीटीएम क्लीनिक की स्थापना की। इस मौके पर डॉ जे एस अरोड़ा, सरिता जयसवाल डॉक्टर सुपणो चक्रवर्ती आदि मौजूद थे। एक प्रेस वार्ता के दौरान एस खन्ना ने बताया कि जिस तरह परिवार के लोग शादी से पहले लड़का लड़की की जन्मपत्री से उनके गुणों का मेल करते है, उसी तरह शादी करने से पहले लड़का लड़की का थैलेसीमिया के लिए एक खून का टेस्ट करवा ले तो काफी हद तक थैलेसीमिया से होने वाले बच्चों को इस बीमारी से बचाया जा सकता है। उन्होंने कहा कि इस टेस्ट में पता चल जाएगा कि उन्हें थैलेसीमिया की बीमारी तो नहीं है उन्होंने कहा कि अब भारत में ट्रांसप्लांटेशन करवाकर उनकी उम्र हिंदुस्तान में 50 साल से ज्यादा हो रही है आने वाले समय में बोन मैरो ट्रांसप्लांटेशन कराने से बच्चों को जो ब्लड हर महीने या 15 दिन में चढ़ा करता है उससे छुटकारा मिल जाएगा उन्होंने कहा इसका खर्चा करीब 15 लाख रुपया आता है लेकिन केंद्र सरकार और राज्य सरकार भी थैलेसीमिया पीड़ित लोगों की मदद कर रही है और बोन मैरो ट्रांसप्लांटेशन में जो खर्चा आ रहा है वह मुहैया करा रही है इसलिए थैलेसीमिया से पीड़ित लोगों को बोन मैरो ट्रांसपेंटेशन करवाना चाहिए।

हर साल दस हजार से अधिक बच्चे थैलेसीमिया के साथ पैदा होते हैं

थैलेसीमिया के मरीजों के लिए खुला राहत केंद्र

जनसत्ता संवाददाता
नई दिल्ली, 4 दिसंबर।

धर्मशिला अस्पताल ने भारत का पहला ऐसा केंद्र खोला जहां थैलेसीमिया बोन मैरो ट्रांसप्लांट (बीएमटी) हो सकेगा। इससे थैलेसीमिया व रक्त कैंसर से पीड़ित बच्चों के संपूर्ण इलाज की सभी सेवाएं व सुविधाएं एक ही छत के नीचे उपलब्ध होंगी। अस्पताल के स्थापक डा एस खन्ना ने एक सम्मेलन में यह जानकारी दी।

एक अध्ययन के अनुसार भारत सबसे ज्यादा थैलेसीमिया से पीड़ित मरीजों की संख्या वाले देशों में से एक है। यहां मरीजों की यह संख्या तकरीबन 100,000 तक है। रोग की गंभीरता के नजरिए से थैलेसीमिया की देखभाल बहुत सावधानी भरा होता है। नियमित दवाएं चलती हैं, हर 2 से 3 हफ्तों में खून चढ़ाने की आवश्यकता होती है। मनोबल बनाए रखने के उपाय भी करने पड़ते हैं। यह सब एक थैलेसीमिया के मरीज के इलाज का हिस्सा होते हैं।

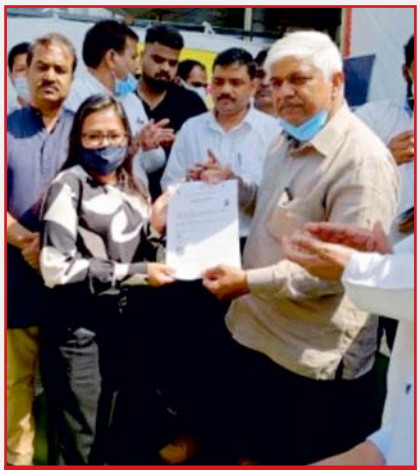
इस मौके पर थैलेसीमिक्स इंडिया की उपाध्यक्ष, थैलेसीमिया अंतरराष्ट्रीय फेडरेशन की अध्यक्ष डा शोभा तुली व राष्ट्रीय थैलेसीमिया वेलफेयर सोसाइटी एंड फेडरेशन आफ इंडियन थैलेसीमिक्स के महासचिव डा जे एस अरोड़ा ने विचार रखे। कार्यक्रम में डा सरिता रानी जैसवाल, प्रोग्राम डायरेक्टर,बीएमटी ने थैलेसीमिया बीएमटी के महत्त्व पर जागरूकता फैलाई।

DISABILITY CAMP HELD ON 10TH & 11TH MARCH, 2022

On 10th and 11th March, the Department of Social Welfare, Government of NCT of Delhi organized a General Disability- UDID Camp for PWD's in which Thalassemics India and a few other NGOs working for Persons with Disabilities were invited to take part in the 2 days camp.

The camp was organized for assisting patients with disabilities in obtaining their disability cards and some other aids from the government. The camp was held at GTB Hospital from 9:00 AM to 4:00 PM on both the days. Disability cards were issued after submission of documents and assessment by doctors to Forty Thalassemia patients at the Thalassemics India Booth.

Ms. Rashmi Singh (IAS, Director, Social Welfare, Govt. of NCT of Delhi), Mr. Ranjan Mukherjee (State Disability Commissioner) & Mr. T D Dhariyal (Ex. Dy. Chief Commissioner, Ministry of Social Justice & Empowerment) visited the camp.



Hon'ble Minister of Social Welfare, Sh. Rajendra Pal Gautam handed over Disability Certificate to Ms. Ssonam Maddan

Ms. Rashmi Singh (IAS, Director) Social Welfare, Govt. of NCT of Delhi. Met the NGO's reprsentatives by interacting with the volunteers She handed over wheelchairs to the needy

Mrs. Shobha Tuli Secretary Thalassemics India interacting with press

Thalassemics India stall attended by : Gaurav Jindal, Rishabh Lamba, Swati Tuteja & Namit Nagar

Thalassemics India is privileged to be a part of such an initiative which is really going to help the patients in obtaining their Disability certificates. Overall, it was a great experience and our work was highly appreciated by the applicants and the organizers.

MEDIA COVERAGE OF THE EVENT

थैलेसीमिया ग्रसित दिव्यांगों के विकलांग प्रमाण पत्र बनाने की प्रक्रिया शुरू

नई दिल्ली, (पंजाब केसरी): समाज कल्याण मंत्री राजेंद्र पाल गौतम शुक्रवार को दिलशाद गार्डन स्थित गुरु तेग बहादुर अस्पताल में दिव्यांगजन सहायता शिविर में शामिल हुए। समाज कल्याण विभाग के उत्तर पूर्वी जिला कार्यालय द्वारा आयोजित इस शिविर में दिल्ली सरकार व केंद्र सरकार सहित कई अन्य सामाजिक संस्थाएं भी शामिल हुईं। इस दिव्यांगजन शिविर में जिला शाहदरा सहित दिल्ली निवासियों को दिव्यांग जन से जुड़ी विभिन्न प्रकार की सेवाएं जैसे विकलांग प्रमाण पत्र, यूडीआईडी कार्ड, डिजिटल विकलांग प्रमाण पत्र, डीटीसी पास, रेलवे विभाग पास, लोन, सहायक उपकरण जैसी अनेक सेवाऐं ऑन दा स्पॉट दी गईं। शिविर में सभी को दिल्ली की केजरीवाल सरकार द्वारा चलाई गई कल्याणकारी योजनाओं के बारे में भी सभी को अवगत कराया गया। इसमें लगभग एक हजार लोगों का यूडीआईडी पंजीकरण हुआ। विकलांगता सहायता कैंप के अंतर्गत एक ही छत के नीचे दिव्यांग जनों को सभी सुविधाएं प्रधान की जाएं। जिससे उनकी समस्याओं का निराकरण जल्दी हो और उन्हें अपने छोटे छोटे कार्यों के लिए अलग-अलग दफ्तरों के चक्कर ना काटने पड़ें। इस शिविर के माध्यम से पहली बार दिल्ली की केजरीवाल सरकार ने थैलेसीमिया से प्रभावित लगभग 100 दिवांगजनों का विकलांग प्रमाण पत्र बनाने की प्रक्रिया की शुरुआत की। अभी तक यह सुविधा केवल दिल्ली के आरएमएल तथा एआईआईएमएस तक ही सीमित थी। अब यह सुविधा दिल्लीवालों को दिल्ली सरकार के जीटीबी अस्पताल में भी मिलेगी। इस अवसर पर समाज कल्याण मंत्री ने कहा कि दिल्ली की केजरीवाल सरकार पंक्ति में खड़े आखिरी व्यक्ति तक हर संभव मदद के लिए वचनबद्ध है। दिव्यांगजनों के लिए नई योजनाओं को उनके जीवन में और गुणवत्ता लाने के लिए दिल्ली सरकार प्रयास कर रही है और बहुत जल्द क्रियान्वित शुरू करेगी।

जीटीबी अस्पताल में किया गया विकलांगता शिविर का आयोजन

गौरव राय

दिल्ली। शाहदरा स्थित दिलशाद गार्डन के गुरु तेग बहादुर अस्पताल में योग्य चिकित्सा निदेशक डॉ. सुभाष गिरी के मार्गदर्शन में एमसीएच प्रखंड में गुरु तेग बहादुर अस्पताल एवं समाज कल्याण विभाग उत्तर पूर्व जिले की ओर से संयुक्त रूप से दो दिवसीय शिविर का आयोजन किया गया.

डॉक्टरों और समाज कल्याण विभाग की टीम ने 10/03/2022 और 11/03/2022 को डॉ रजत झाम्ब, अतिरिक्त चिकित्सा अधीक्षक जीटीबीएच, डॉ सत्येंद्र सिंह प्रोफेसर फिजियोलॉजी यूसीएमएस और सामाजिक कार्यकर्ता और जिला समाज कल्याण अधिकारी श्री पंकज की देखरेख में काम किया। शिविर को सफल बनाने के लिए। विकलांग व्यक्तियों की सुविधा के लिए हड्डी रोग, कान नाक गला, न्यूरोसर्जरी, न्यूरोलॉजी, मेडिसिन, बालरोग, थैलेसीमिया, बर्न एंड प्लास्टिक, न्यूरोलॉजी सहित सभी विशेषज्ञ डॉक्टर एक ही छत के नीचे मौजूद थे। इसे किसी भी प्रकार का विकलांगता प्रमाण पत्र जारी करने के लिए एक सर्व समावेशी शिविर बनाने के लिए मनोविज्ञान आईएचबीएएस की एक विशेष टीम को भी आमंत्रित किया गया था।

माननीय मंत्री महिला एवं बाल विकास एवं समाज कल्याण श्री राजेन्द्र पाल गौतम, सुश्री स्वाति शर्मा सचिव एचएफडब्ल्यू एवं पर्यटन, सुश्री रश्मि सिंह सचिव समाज कल्याण, सुश्री प्रांजल जिला मजिस्ट्रेट शाहदरा, श्री रंजन विकलांगता आयुक्त ने 02 दिनों के विशेष अभियान के दौरान शिविर का दौरा किया। गुरु तेग बहादुर अस्पताल और समाज कल्याण विभाग उत्तर पूर्व जिले के प्रयासों की सराहना की। उम्मीद की जा रही थी कि 50-60 व्यक्ति विकलांगता प्रमाण पत्र जारी करने के लिए आ सकते हैं, लेकिन लगभग 850 उम्मीदवार विभिन्न प्रकार की आवश्यकताओं के लिए आए जैसे विकलांगता प्रमाण पत्र / यूडीआईडी, रेलवे रियायत प्रमाण पत्र, डीटीसी पास, व्हील चेयर आवश्यकताओं और कुछ अन्य सेवाएं प्रदान करने के लिए। दो दिवसीय शिविर के दौरान कुछ सरकारी विभागों के साथ-साथ गैर सरकारी संगठनों को विकलांगता प्रमाण पत्र/यूडीआईडी कार्ड जारी करने के अलावा।

पंजीकृत विकलांग व्यक्तियों की संख्या लगभग दुगनी संख्या में, आसपास के राज्यों या दिल्ली के अन्य जिलों से आए, जिनके लिए इस शिविर में प्रावधान उनका नहीं था और उन्हें वापस करना पड़ा, जिससे ऊपर की तुलना में बहुत अधिक फुटफॉल हुआ।

विकलांगता प्रमाण पत्र निर्माण के अलावा शिविर में जीटीबी अस्पताल परिसर में विशेष रूप से डिजाइन किए गए क्यूबिकल में जरूरतमंद व्यक्तियों के लिए अपनी सेवाएं प्रदान करने वाली टीमें मौजूद थीं।

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