FEDERATION of Indian Thalassemics
NATIONAL THALASSEMIA BULLETIN

VOL. 21 No-1 | EDITORIAL BOARD | September, 2015

Upcoming Events

8th National Thalassemia Conference

Sat. & Sun. 17th & 18th December 2016

at

Jawahar Lal Auditorium, AIIMS, New Delhi

Corresspondence Address :

Dr. J.S. Arora (General Secretary)

FEDERATION OF INDIAN THALASSEMICS

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Leukoreduced transfusions **reduced post-operative infections by about 10% (from 33% to 23%) in Surgical Patients**.[2]

After implementation of universal leukoreduction in transfused patients, the **Line Related Infections were seen to reduce by 35%**.[3]

For patients undergoing **Bone Marrow Transplantation** filtration of the blood products was effective for the **prevention of transfusion-associated CMV infection**.[4]

LR blood transfusion in **Cardiac Surgery Patients reduced mortality rates by half**.[5]

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Editorial Magnetic resonance Imaging (MRI T2*) is essential for normal life in Thalassemics

Dr. V.P. CHOUDHRY

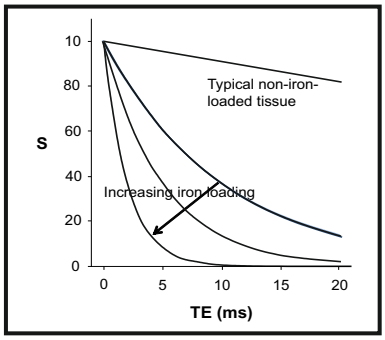
Life of children with thalassemia is dependent on regular red cell transfusions. Each unit of blood transfusion carries 200-220 mg of iron along with it. This iron accumulates in the body over years. This iron overload is a major cause of morbidity & mortality in children with thalassemia. Major cause of death is heart failure besides liver disorders due to iron overload. Growth failure along with diabetes, hypothyroidism & sexual development disorders result from iron overload in various endocrine glands of the body.

Among various tests to assess the iron overload serum ferritin is simple, cheap, most practical, and cost effective method. However it has its own multiple problems besides various technical aspects. Serum ferritin is also an acute phase reactant & its levels increases following minor infections such as common cold, fever, immune disorders, following even minor surgeries etc. Most important serum ferritin does not truly reflect the iron overload in various parts of the body such as heart, liver, endocrine glands etc. Therefore many thalassemic children who are even able to maintain serum ferritin between 2000-2500 ng/ml may develop various problems involving heart, liver, growth failure delayed puberty, diabetes etc.

Scientists all over the World have been doing their best to evolve tests which could provide true status of iron overload. Liver biopsy became the gold standard method to reflect the true status of iron overload in the body. Since liver biopsy is an invasive procedure and serial estimation is not practical thus it is not in general practice. **Over the year magnetic resonance imaging has evolved as practical method which is able to measure true iron overload status in the heart & liver precisely. It has helped the physicians to select the most appropriate chelating agents for each patient to improve the quality of life and long term survivals.**

To perform accurate MRI one needs 1) MRI machine. 2) Necessary software to take proper images of heart & liver and 3) Software to quantify and interpret the images. **Mostly 1.5 tesla MRI machines has been recommended.** Software which takes the images is called sequences and among various sequencesT2* is commonly used. These sequences have been standardized across different platform (T2*). The images thus acquired are interpreted for the quantification of iron content in different organs by dedicated software. Liver & heart iron are measured with T2* MRI sequences.T2* measurement represents the transverse relaxation of a signal. Iron deposits in the organs disrupt the homogeneity of the magnetic field. If the iron in the tissue is more the signal intensity in the organs drops rapidly (Fig 1).

In a tissue with significant iron overload, the decay curve will drop very fast and the image will have little signal after a short time, generating black images. Thus high T2 numbers represent less iron and lower T2* numbers represent more iron.*



The decay curves are generated for each organ and thus many organs can be evaluated in same time by changing the imaging plane (for details one can refer to reviews). The whole MRI test for iron overload is a quick process & can be completed in 10-20 minutes depending upon the software. The images generated by the manner are analyzed by the software such as CMR tools , CV 142, Medis Q mass etc to obtain T2* valves. Then the T2* numbers is converted to liver iron concentration (LIC) and myocardial iron concentration (MIC). The calibration curves have been obtained simultaneously by performing MRI of liver & heart to measure iron levels which have been corelated with iron content of liver & myocardical biopsies over the years. Standardized tables for heart & liver have been obtained (table 1)

Table 1: Classification table for Iron Overload in the liver & heart

	HEART				LIVER			
Parameter	Normal	Mild	Moderate	severe	Normal	Mild	Moderate	severe
T2*	>20	15-20	10-15	<10	>11.4	3.8-11.4	1.8-3.8	<1.8
R2*	<50	55-66.5	66.6-100	>100	<88	88-263	263-555	>555
MIC(mg/gm)	<1.16	1.16-1.65	1.65-2.71	>2.71	<2.0	2.0- 7.0	7-15	>15

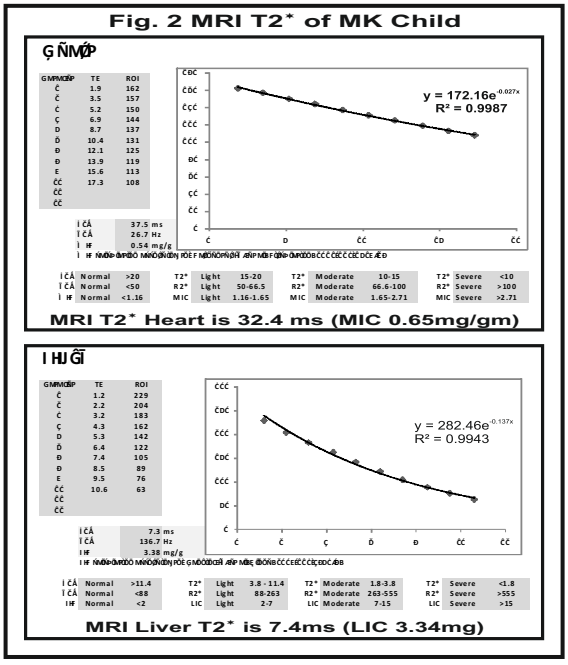
MRI for iron overload assessment has become very simple, standardized, fast and provides very accurate assessment. More important its results are reliable and are of great help to hematologist and your doctors to advise the required chelation therapy. The centers who have been using MRI T2* for last one decade have significantly improved the survivals and quality of life of thalassemic children. Now this facility is available in Metros

Magnetic resonance Imaging (MRI T2*) is essential for normal life in Thalassemics

& big cities in India. Following cases are being presented that how MRI has helped us to change the treatment and improve the quality of life and survivals.

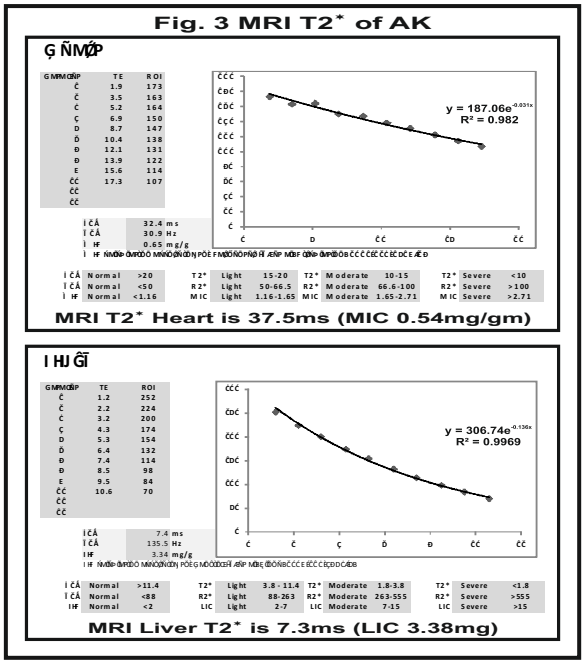
Case 1: Eighteen year MK child with thalassemia major has been on regular transfusion therapy. His serum ferritin was 4000 ng/ml in 2001. He was being treated on Kelfer and the ferritin could not be brought down inspite of Kelfer (110mg/kg/day) for last 3years. He was treated with combination of Desferal (45 mg/kg daily sc over 10 hours) along with daily Kelfer (80mg/kg/day). His serum ferritin came down & varied between 600-800 ng/ml during 2013. At this point of time his physician was planning to stop Desferal & continue Kelfer. MRI T2* for heart revealed T2* of 32.4 ms while liver T2* 7.4 ms with iron content of 3.39mg/gm.

This data clearly showed that his liver had significant iron overload (Fig 2).



Based on this data he was advised to stop Desferal and Kelfer and start Asunra 30mg/kg/day. He followed the advice & one year later his serum ferritin was 700ng/ml and MRI T2*of liver 13.2ms and thus by changing therapy iron overload in the liver was managed successfully.

Case II: AK thalassemia major child born in 1993 was on regular transfusion & maintained his hemoglobin between 7-9 gm/dl (average Hb level over last one year was 7.4gm/dl). His parents did not give any chelation therapy inspite of doctor's advice. When child was 10 year old he developed breathlessness, palpitation and growth failure. His serum ferritin was 14000ng/ ml with LVEF of 23% . Now parents agreed for chelation. Child was given Desferal (40mg/kg/day) for initial 4 months & later 4 days a week along with Kelfer (100mg/kg/day). Over the next four year child improved. His S. ferritin came down to 4570ng/ml. In 2010 he was treated with same dose of Desferal along with daily Defrassirox (40mg/kg/day). In May 2014 his serum ferritin was 950ng/ml. MRI T2* heart was 37.5ms while that of liver was 7.3ms (LIC 3.38mg). Child was completely normal and had no evidence of iron overload over heart and various other glands. With this MRI T2* data (fig 3)



child was advised to stop Desferal & continue Deferasirox . Child remained well and his serum ferritin varied between 800-1000 ng/ml. In May 2014 the MRI T2* was of great help to us in advising to stopping Desferal and continue the Desferasirox. Thalassemia center doctor who was managing this child wanted to start Kelfer before MRI T2* was done.

Above cases have clearly shown that how MRI T2* helped us in treating these children more effectively . **Most important, MRI T2* now is more reliable than S.ferritin levels. It is strongly advised that all children over 10 years should get MRI T2* at least once a year besides getting serum ferritin levels at 3-4 months interval. I assure you that MRI T2* will be of great help to your doctor in planning the chelation therapy .** There is no doubt that proper chelation therapy in your child will prevent all the complications of iron overload & will result into their long survival and better quality of life.

Dr. V.P. CHOUDHRY

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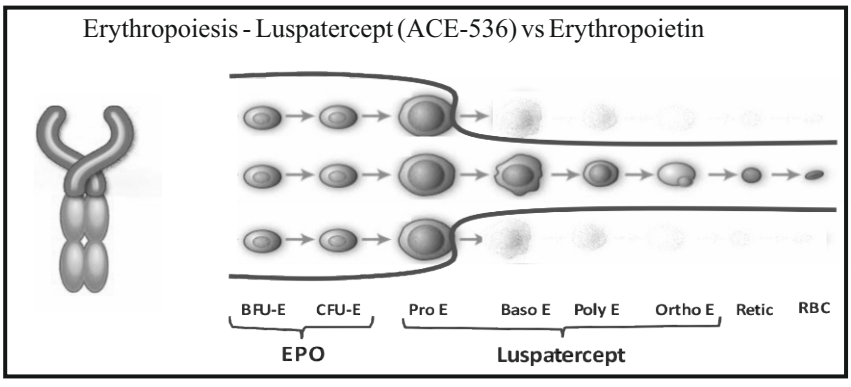
A New Drug in Offing to treat Thalassemia

Dr. J.S. Arora

Beta-thalassemia is an inherited disease due to mutations in the beta globin gene leading to deficient hemoglobin production and serious anemia. There is an over production of red blood cell (RBC) precursors in the bone marrow, often resulting in bone deformities, decreased bone mineral density and bone strength, and pathologic fractures. These abundant RBC precursors fail to properly mature into functional RBCs, which is known as ineffective erythropoiesis. Besides severe anemia, patients also suffer from multiple organ dysfunction, due to iron overload, resulting from the ineffective erythropoiesis as well as the repeated packed cells transfusions. Iron overload can lead to heart failure, liver fibrosis, diabetes, thyroid and many other complications. Current clinical management for beta-thalassemia includes regular RBC transfusions and daily iron chelation therapy, which is associated with toxicities. Till now there are no approved drug to treat beta-thalassemia.

The FDA granted fast track status to luspatercept (ACE-536) for patients with transfusion- dependent beta-thalassemia and non-transfusion-dependent beta-thalassemia, according to a press release dated 18th May 2015

Luspatercept (ACE-536) is an investigational protein therapeutic agent that increases red blood cell (RBC) levels by targeting molecules in the Transforming Growth Factor-Beta (TGF-β) superfamily involved in the late stages of erythropoiesis (red blood cell production). Luspatercept regulates late-stage erythrocyte (red blood cell) precursor cell differentiation and maturation. This mechanism of action is distinct from that of erythropoietin (EPO), which stimulates the proliferation of early-stage erythrocyte precursor cells.



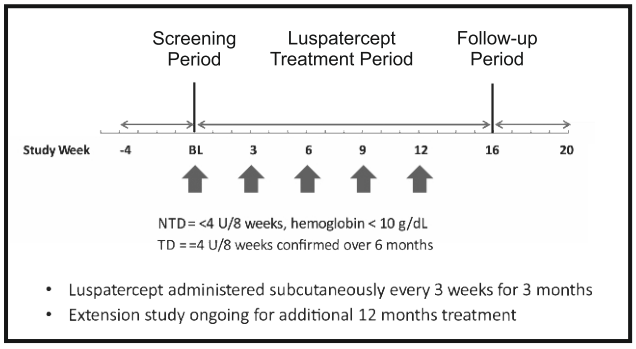
In preclinical studies, luspatercept promoted red blood cell (RBC) formation in the absence of erythropoietin (EPO) signalling, had distinct effects from EPO on RBC differentiation, and acted on a different population of progenitor blood cells than EPO during RBC development. In these studies, luspatercept did not promote significant increases in bone mass.

Clinical Trials

Luspatercept Phase 1 study in healthy volunteers, produced a dose-dependent increase in RBC and hemoglobin levels.

Luspatercept Phase 2 multicenter, open-label, dose escalation study in adults with β-thalassemia presented at the 56th American Society of Hematology (ASH) Annual Meeting and Exposition 2014, revealed Luspatercept increased hemoglobin levels, reduced transfusion burden and improved measures of iron overload in beta-thalassemia patients. A therapy, that could potentially benefit most patients, regardless of the genetic background. Extension study is ongoing for additional 12 months treatment.

In the phase 2 study, luspatercept was evaluated in transfusion-dependent beta-thalassemia (TDT) and non-transfusion-dependent beta-thalassemia (NTDT) patients. A total of 30 patients were treated in the dose escalation stage of this study, in which luspatercept was administered subcutaneously, once every 3 weeks for up to 5 doses with a 2-month follow-up. Study design includes sequential cohorts (n=6 patients/cohort) at dose levels of 0.2, 0.4, 0.6, 0.8, 1.0, 1.25 and 1.5 mg/kg.



Preliminary data for the 30 patients (23 NTDT & 7 TDT) enrolled in the first 5 cohorts. Median age was 34.5 yr (range: 20-57 yr), 16 (53%) were male and 83% had prior splenectomy. Mean (SD) baseline Hb for the NTD patients was 8.3 (0.9) g/dL.

Improvement of anaemia and transfusion burden:

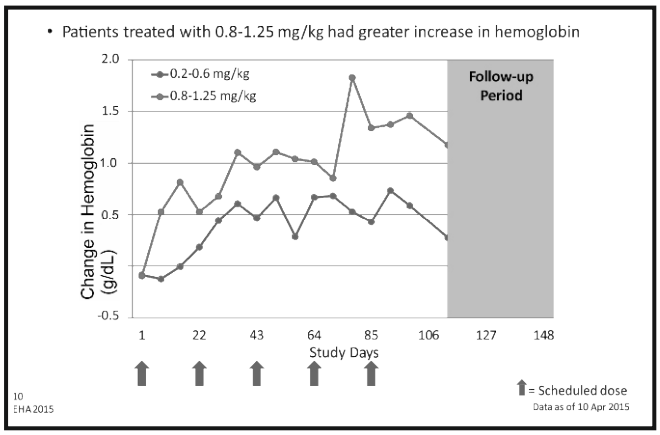
- 9 of 12 patients (75%) treated with dose levels of 0.8 or 1.0 mg/kg of luspatercept met the study primary endpoint of an erythroid response

A New Drug in Offing to treat Thalassemia

- 6 of 6 (100%) transfusion dependent patients achieved a reduction in transfusion burden of at least 60% over a 12 week period

- 3 of 6 (50%) non-transfusion dependent patients had a sustained hemoglobin increase of at least 1.5 g/dL for ≥ 2 weeks.

Mean Hemoglobin Change in NTD Patients



Reduction in iron overload:

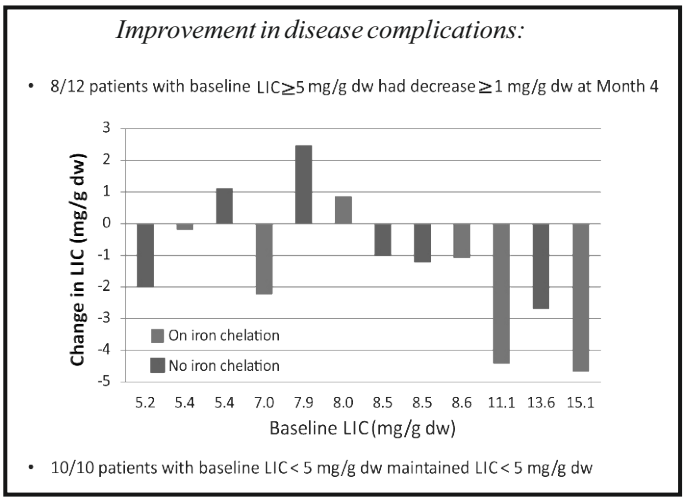
Reductions in liver iron concentration (LIC), were observed in both non-transfusion dependent and transfusion dependent patients.

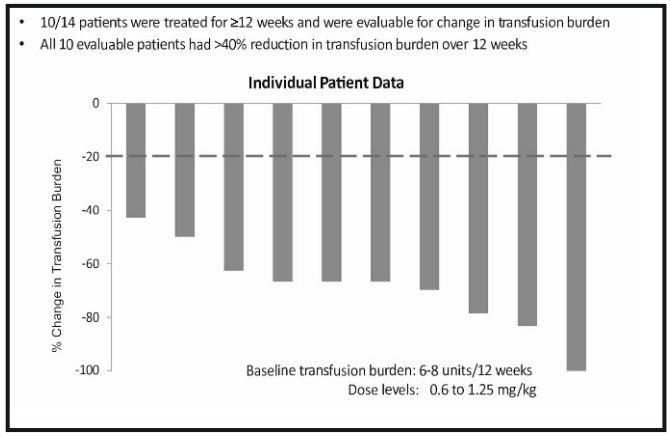
- In NTDT patients with baseline LIC ≥ 5 mg/g dry weight, 8 of 12 (67%) patients had a reduction in LIC of ≥ 1 mg/g dry weight in this 16 week study

- In TDT patients with baseline LIC ≥ 5 mg/g dry weight, 4 of 5 (80%) patients had reductions in LIC ranging from 0.7 to 4.7 mg/g dry weight

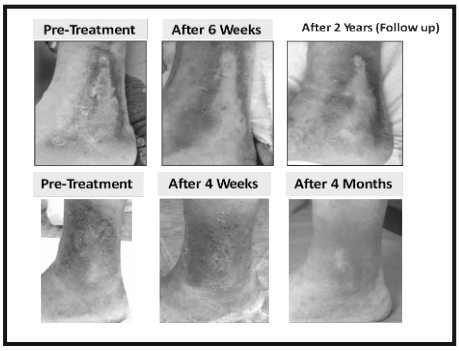
- TDT patients also had reductions in serum ferritin, ranging from 12-60%

Improvement in disease complications:





- 2 of 2 patients, who had persistent leg ulcers, experienced rapid healing of the ulcers.



Side Effect :

The most common adverse events were bone pain, headache, myalgia, asthenia, influenza, macule and pain in extremity. There were no drug-related serious adverse events and no patient developed anti-drug antibodies on treatment. No notable changes in platelets or WBC were observed.

- No related serious adverse events

- 2 patients had related grade 3 adverse events: bone pain (n=2), asthenia (n=1)

- 6/39 (15%) patients discontinued early, associated with an adverse event: headache, ankle pain, back pain, spider nevi, superficial thrombosis, and bone pain

Related Adverse Events (all grades) in ≥ 5% Patients, n (%)

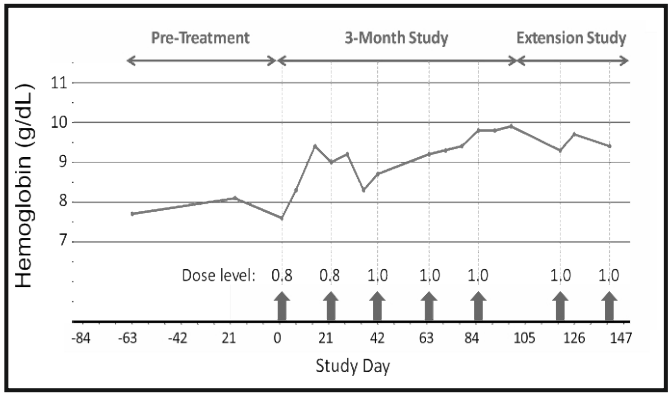
Preferred Term	NTD N=25	TD N=14	Overall N=39
Bone pain	3 (12%)	6 (43%)	9 (23%)
Myalgia	3 (12%)	4 (29%)	7 (18%)
Headache	2 (8%)	4 (29%)	6 (15%)
Asthenia	1 (4%)	3 (21%)	4 (10%)
Pain in extremity	1 (4%)	2 (14%)	3 (8%)
Influenza	1 (4%)	1 (7%)	2 (5%)
Macule	2 (8%)	0	2 (5%)
Musculoskeletal pain	1 (4%)	1 (7%)	2 (5%)

A New Drug in Offing to treat Thalassemia

June 2015 Update : Acceleron Pharma one of the two companies jointly developing luspatercept announced new preliminary results from the ongoing phase 2 clinical trials in patients with beta-thalassemia in oral presentations at the 20th Congress of the European Hematology Association June 11 - 14, 2015; Vienna, Austria. Luspatercept has demonstrated positive effects on multiple complications of the disease by increasing haemoglobin levels, reducing transfusion burden and reducing iron overload in the majority of beta-thalassemia patients.

NTDT patients

● For patients who received luspatercept 0.8–1.25 mg/kg, 38% had a mean haemoglobin increase ≥ 1.5 g/dL maintained for at least 9 weeks.



● For 8 of the 12 iron overloaded NTDT patients, luspatercept reduced liver iron concentration by 1 - 4.6 mg/g dry weight over the 16 week period.

TDT patients

● All ten evaluable patients who received luspatercept 0.6–1.25 mg/kg had more than a 40% reduction in transfusion burden.

● For 2 of the 3 iron overloaded TDT patients, luspatercept reduced liver iron concentration by 1.96 and 4.7 mg/g dry weight, respectively.

Luspatercept phase 2 study started in January 2013, under the supervision of USFDA and health authorities of Greece, Italy & Turkey. Estimated date of completion is March 2016. Patients from both genders above the age of 18 were recruited from Greece, Italy and Turkey.

Inclusion Criteria included prior splenectomy or spleen size < 18 cm in the longest diameter by abdominal ultrasound. Aspartate aminotransferase (AST) or alanine aminotransferase (ALT) < 3 x upper limit of normal (ULN) and serum creatinine ≤ 1.5 x ULN.

Exclusion Criteria include any clinically significant, cardiovascular, endocrine, neurologic, hepatic, gastrointestinal, infectious, immunological or genitourinary disease. Folate deficiency, symptomatic splenomegaly, positive for human immunodeficiency virus (HIV), active infectious hepatitis B (HBV) or active infectious hepatitis C (HCV), known history of thromboembolic events ≥ grade 3, ejection fraction < 50% , uncontrolled hypertension, heart failure class 3 or higher, platelet count < 100 x10^9/L or > 1,000 x10^9/L, proteinuria ≥ Grade 2, patients on hydroxyurea treatment and major surgery (except splenectomy)

Luspatercept is currently in phase 2 clinical trials in patients with beta-thalassemia and in patients with myelodysplastic syndromes. "Celgene and Acceleron" are working diligently to initiate a phase 3 clinical program in 2015 to treat patients with beta-thalassemia

यथा संभव उचित चिकित्सा उपरांत भी 70 से 80% थैलासीमिया रोगीयों में अस्थी रोग (osteoporosis) होने की संभावना रहती है। अत: उचित मात्रा में कैल्शियम तथा विटामिन डी का सेवन करें तथा 18 वर्ष की आयु पश्चात प्रति 1 से 2 वर्ष में डैक्सा स्कैन करवांए।

हर समय अपना हीमोग्लोबिन 10g/dL या उससे अधिक रखने से आपकी शारीरिक वृद्धि तो सामान्य होती ही है इसके अतिरिक्त तिल्ली के बढ़ने की संभावना भी नही रहती।

7th National Thalassemia Conference 19th & 20th April 2014

"ADVANCES IN THALASSEMIA", the 7th National Thalassemia Conference organized by National Thalassemia Welfare Society & Department of Haematology AIIMS in association with IAP Delhi, Delhi Society of Haematology & Federation of Indian Thalassemics on Saturday & Sunday 19th & 20th April 2014 at Jawahar Lal Auditorium AIIMS on a large scale.

The three days mega event started off with the 7th National Thalassemia Conference on 19th & 20th April 2014 and was followed by a workshop on Thalassemia in association with Dept of Paediatrics, GTB Hospital on Monday 21st April 2014 at UCMS & GTB Hospital.

The conference started with full zeal with the case presentations by various eminent medical professionals. Dr. VIP Viprakasit from Thailand briefed delegates about the clinical perspective of Diagnostic Enigma. The Laboratory perspective of Diagnostic Enigma was explained and briefed by our very own Indian Haematologist Dr. H. Pati.

Then the time came for a very much awaited talk The Power of Ten /Dus Ka Dum by Dr AP Dubey The talk was highly appreciated by patients, parents and doctors. He emphasized on the need of maintaining pre transfusion Hb>10gm/dl. After that Dr. V.P. Choudhry briefed the importance of Alloimmunisation He said Allo – immunization is more common in Thalassemia Intermedia and in Thalassemia Major who start Blood Transfusion after the age of 3 years.

This was followed by formal inauguration.

The conference was inaugurated by Dr. N.K. Mehra, Dean AIIMS Dr P.K. Dave Director Rockland Hospital, Former Director AIIMS & Dr. D.K. Sharma Medical Superintendent AIIMS Hospital were the guest of honours.

Dr Renu Saxena while welcoming audience mentioned the association of National Thalassemia Welfare Society with Department of Hamematology AIIMS since its inception in 1991. She said jointly we have been doing major activities on Thalassemia every 2 to 3 years. Dr. D.K. Sharma Medical Superintendent, AIIMS mentioned in his address that Department of Haematology and National Thalassemia Welfare Society are working in Hand in Gloves for the Welfare of Thalassemia.

Dr. Michael Angastiniotis Thalassemia International Federation Medical Advisor informed that TIF had a series of meeting with FIT (Federation of Indian Thalassemics) & Thalassemia Association of 8 states Maharashtra, Gujarat, MP, Delhi, Punjab, Haryana, Chandigarh & UP. In a series of brainstorming sessions. We have prepared a charter of priorities to be submitted to Govt. of India & Governments of 8 identified states. Even today we are having a parallel session with state taskforce to finalize the charter of priorities. **Today TIF in association with NTWS is organizing a Patient Capacity Building Workshop. We are happy to note that over 300 thalassemia patients are participating in this workshop.**

Dr. P.K. Dave Former Director AIIMS recollecting his association with Dr. V.P. Choudhry & Dr. J.S. Arora mentioned that during his tenure a state of art Thalassemia Ward was inaugurated and he happen to be the part of every Thalassemia Activity in AIIMS. Dr N.K. Mehra, Dean, AIIMS mentioned that permanent cure of Thalassemia lies with Bone Marrow Transplantation but due to non-availability of HLA matched donors many thalassemics have to survive on repeated blood transfusion & iron chelation. He said that AIIMS has started Asian Indian Donor Bone Marrow Registry though the data is less but we intend to improve so that more and more thalassemics can undergo BMT especially those who do not have HLA matched donor within the family. While talking to the audience Dr. N.K. Mehra shared his experiences and said that we all should step up to work together for the betterment of Thalassemia Patients.

The inauguration ceremony was presided over by Km. Surrendar Saini Padma Bhushan Awardee & president, NTWS. In her presidential address Km. Surrendar Saini exhorted the dignitaries on the Dias & Doctors to pursue the Govt. to include Thalassemia in the list of disability. Patients, parents & doctors present in the hall acknowledged her gesture with a standing ovation. She recommended that this public applaud be passed as resolution and handed over to the appropriate authority.

Dr NK Mehra released the Souvenir of 7th National Thalassemia Conference. A poster designed by Dr. V.P. Choudhry on benefits of ideal thalassemia management was released by Dr. P.K. Dave Director Rockland Hospital. Dr. Michael Angastiniotis TIF Medical Advisor released the Book written by Dr. J.S. Arora **"Florilegium of Thalassemia"**. This is a concise book which contains information on practical management in simple, clear, easy to understand language.

NTWS has initiated Dr. B.N. Dara Award to an Indian medical doctor for dedicated work in the field of Thalassemia & Haemoglobinopathies. Award carries a cash prize and a citation along with a memento. Dr. B.N Dara was a leading Pediatrician of Jaipur. This award has already been given to Dr. Mammen Chandy followed by Dr. V.P. Choudhry, Dr. M.B Agarwal, Dr. M.R. Lokeshwar & Dr. Roshan Colah during the deliberations of our previous National Thalassemia Conferences. Dr. V. P. Choudhry gave background of the awards and introduced the awardees. He

said this time the executive of NTWS has conferred this Award to Dr. I.C. Verma. Dr. I.C. Verma qualified in Medicine from Amritsar Medical College. Dr. Verma has been honored with numerous national awards, such as that from ICMR, NAMS, Ranbaxy Science Foundation and BC Roy award of MCI. He has over 300 original papers published in indexed journals.

The Best Social Worker Award was conferred to Dr Mrs Madhuben R Naik for her incredible work for the cause of thalassemia in her state. She is M.D. (Gynecology, presently, Honorary Chairman, Indian Red Cross Society, Gujarat State. In 1974, a Red Cross branch was established in Navsari and looked after it as its Honorary Founder. Under Dr. Madhuben Naik's stewardship, IRCS National Headquarters, ICRC and IFRC have recognized Gujarat Red Cross as one of the strongest State Red Cross Branches in the whole Country. A number of prestigious Awards – for Toping in voluntary blood donation, Fund Raising etc. were received by Gujarat Red Cross from the National Headquarters. Dr. Madhuben Naik was awarded "Red Cross Gold Medal" for the year 2007.

Dr. Arora thanked Km. Surrendar Saini for always been vocal on the issue of including Thalassemia in the list of disability. He also made an appeal to his fellow doctors as well. Thalassemics need their gentle care and support. He pleaded before the blood bank authorities to be more sympathetic towards thalassemics while issuing the blood. Dr. Arora appealed the heads of transfusion centres to take extra steps to extend transfusion timings in the evenings, holidays and Sundays so that grown up Thalassemics can adjust the transfusion timings with education, exams and profession. This service is already provided by a few of Thalassemia Centres in Delhi Govt. hospitals. He advised to the thalassemic patients and parents that they should work with their society in organizing blood donation camps and creating awareness in public Dr. Arora specially thanked Dr. Renu Saxena & Dept of Haematology for associating with NTWS & helping us in organizing this conference.

Inauguration ceremony was followed by belly filling breakfast. After that Dr. Amita Mahajan spoke on monitoring of Iron Overload while Dr. J.S. Arora elaborated on New Technology MRIT2*. He informed that MRIT2* iron study is a gold standard for measuring Iron Overload in Thalassemics. He presented 5 cases of Iron Overload & depicted in 1 case that in Thalassemia Intermedia serum ferritin has no correlation with iron overload. Even with low ferritin there can be sever iron overload in Thalassemia Intermedia patients. In Thalassemia Major also Serum ferritin reading may be misleading.

Dr. Praveen Sobti highlighted the benefits of the oldest and safest chelator Desferal. Dr. Maria D Cappellini spoke on the pros and cons of Oral Chelator Deferiprone & Defrasirox. Dr. Sunil Gomber emphasized on the Combination Chelation Therapy in highly iron overloaded patients.

Dr. Michael Angastiniotis stressed on the need of NAT (nucleic acid amplification test) in donor's blood. He said that the Blood Banks should narrow window period of TTI markers and stress on providing safest blood to all the thalassemics. Dr. S.K. Sarin spoke on the treatment of Transfusion Transmitted Infections Hepatitis B & C in thalassemics. Dr. Maria D Cappellini stressed on when and why a thalassemic should go for splenectomy. Dr. Vikas Kohli emphasized on the Cardiac Complications in Thalassemia Major and Intermedia. Dr. Rajiv Bansal spoke on the need of regular monitoring of all the thalassemic patients. Dr. Michael Angastiniotis stressed on the need for Multidisciplinary Care he stressed that each transfusion center should have all the medical facilities under one roof.

We also have a very special session by thalassemics for thalassemics. Thalassemic Major Ms Sangeeta Wadhwa and Dr. Rimjhim Bakshi shared their experiences with all. They both were the real source of Inspiration for all the thalassemic families. Dr. J.S. Arora highlighted the tips of maintaining a Thalassemia Major.

On 20th April 2014 in the morning we have a special session for the thalassemia patients and parents seeking personal advice from the respective doctors: Dr. M.D. Cappellini & Dr. V.P. Choudhry for Chelation. Dr. Viprakasit & Dr. Jagdish Chandra for Challenges in transfusion in both Thalassemia Intermedia and Major. Dr. V.K. Khanna & Dr. Dinesha Bhurani regarding transplant and Hydroxy Urea.

Dr. Madhulika Kabra highlighted on the Antenatal diagnosis. She informed as soon as the lady becomes pregnant she should consult a Gynecologist and Genetics Unit. Dr. Sujata Sinha informed about Thalassemia Control Programme in Dehradun under her guidance. She said that it was a successful programme and can be implemented in whole of India. Dr. IC Verma talked about Carrier Diagnosis. He highlighted if the patient is found to have low MCV & MCH and high RBCs then he/she should be suggested HbHPLC.

Dr. Sangeeta Gupta spoke on the Antenatal diagnosis. Cordocentesis was explained by Dr. Renu Saxena. She informed if a pregnant women has not gone for CVS in first trimester then she can opt for cordocentesis.

Dr. Prantar Chakrabarti highlighted the treatment of Thalassemia Intermedia. He informed that Thalassemia Intermedia require equal amount of care and attention like thalassemia major. Dr. V.K. Khanna talked about the Thrombophilia Complications in Thalassemics. He said that now these complications are frequently seen in adult thalassemics.

Then Dr. Anju Seth made adolescent boys and girls stuck to her next lecture Growth and Puberty. Dr. Rashid Merchant stressed on the Bone Diseases in Thalassemia.70 to 80 % thalassemia suffer from Osteopenia or osteoporosis. These patients require adequate Calcium and Vitamin D and regular testing of BMD/ Dexa every year. Dr. Anju Virmani highlighted about Diabetes & Thyroid in Thalassemia. She informed that it can be taken care if correct treatment is given at initial point of time. Dr. Vatsala Dadhwal talked about the fertility and pregnancy in Thalassemia Major & Intermedia. She informed that with adequate treatment thalassemics can plan a child and we have thalassemia major who have completed their family.

Dr. Vikram Mathew stressed on Stem Cell Transplantation. Dr. Ajay Sharma (Brig) talked about the Life after BMT. He informed that one can have a normal life after BMT. Dr. M.B. Agarwal spoke on much awaited Gene Therapy. He informed that one case has been reported with positive response, more studies are in the offing

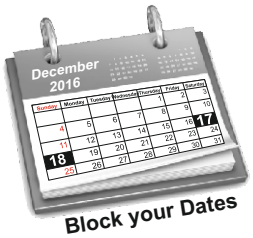
Simultaneously we also had a separate Doctor session for all the Doctors.

Dr. VIP Viprakasit talked about the Molecular Aspect of NTDT patients. Dr. V.K. Khanna spoke on the treatment given to the NTDT patients including the Blood Transfusion, Chelation and regular monitoring. Dr. M.D. Cappellini talked about the Complication of Thalassemia Intermedia. Dr. V.P. Choudhry emphasized on the overall management of thalassemia major. Dr. Jagdish Chandra emphasized on switch over from Pediatrician to Physician. He informed the doctors that Lady Harding Hospital is the first to start with adult thalassemia ward. He stressed the thalassemia doctors to open up with an adult thalassemia ward in their hospitals, as now we have many of adult thalassemics. Dr. Prantar Chakrabarti highlighted the Thalassemia intermedia scenario in India. Dr. Dinesh Bhurani spoke about the infection involved in the Bone Marrow Transplantation. After that we had a much awaited debate between Dr. V.P. Choudhry & Dr. Dharma Ram Chaudhary Care vs Cure.

TIF patient Capacity Building workshop was a finest initiative taken to motivate the patients for a better treatment, to live a near normal healthy life.

On 21st April 2014 a workshop was conducted on Thalassemia in association with UCMS & Guru Teg Bahadur Hospital, Dilshad Garden. The main idea behind the workshop was to highlight the various aspects of thalassemia. Eminent Doctors present case studies on different aspects of thalassemia.

The three days celebration ended with lovable memories that can be treasured for the whole life & with a burning desire to come up with new ideas next time.



CELEBRATING 25 Years
1991-2016

8th National Thalassemia Conference
17th & 18th Dec. 2016
at
JL Auditorium, AIIMS, New Delhi

National Thalassemia Welfare Society is entering its 25th Year of inception this December. A series of big events have been chalked out to observe 25th year of its foundation. It will conclude with a mega event by organizing 8th National Thalassemia Conference & Workshop. Many new developments have taken place since our last conference in April 2014. Cure for all is noticeable by the end of next year. It will be a golden opportunity to know, learn, understand & practice new developments.

Some patients who were given FREE Infusion Pump & Medicines


Amrit Kaur


Ayush

Bidisha Ghosh


Divya Narang

Infusion Pump given to Bobby by Hon' ble Minister of Health Sh. Satyender Jain & Mr. Kanwar S. Relan (Jaquar)


Lalit


Kapil Nagpal


Liyakat & Sajakat


Ravi Grover


Sourabh


Tanu Verma


Sangeeta Bhola


Ketan Verma


Prateek


Deepak Kapoor

7th National Thalassemia Conference 19th & 20th April 2014

Dr. Michael Anganstiniotis, Medical Advisor TIF Releasing a Handbook on Thalassemia "Forilegium of Thalassemia" Authored by Dr J.S. Arora

Dr. P.K. Dave Released Thalassemia Management Boards , at JLN Auditorium, AIIMS, New Delhi

President NTWS Km Surrendar Saini conferring Best Social Worker Award to Dr Madhuben R Naik

Dr NK Mehra honouring Dr IC Verma with Dr.BN Dara Award

Dr PK Dave felicitating MDI Samaritans for incredible work on Thalassemia

Dr Renu Saxena giving a token of appreciation to School of Inspired Leadership, Gurgaon

7th National Thalassemia Conference Audience

Dr. M.D. Capellini, Dr JS Arora & Dr DK Sharma, MS, AIIMS amongst the audience

Group of Thalassemia Major Patient

7th National Thalassemia Conference Audience

Thalassemia patients & parents at 7th National Thalassemia Conference, 19th & 20th Apr 2014, JLN Auditorium, AIIMS, New Delhi

Thalassemia Patients/Parents at TIF Capacity building Workshop, New Delhi, 19th Apr 2014

Thalassemic families enjoying cultural evening

Thalassemia patients enjoying the DJ night at AIIMS

Thalassemia patients from Maharashtra, Gujarat, UP

Thalassemia patients from Delhi

7th National Thalassemia Conference 19th & 20th April 2014

Dr MD Cappellini

Dr VIP Viprakasit

Dr Michael Angastiniotis addressing the audience at TIF Patient Capacity Building Workshop, 19th Apr 2014

Dr NK Mehra

Dr MB Aggarwal

Dr IC Verma

Dr VP Choudhry

Dr Jagdish Chandra

Dr SK Sarin

Brig Dr Ajay Sharma

Dr Sunil Gomber

Dr AP Dubey

Dr Prantar Chakrabarti

Dr Rajeev Bansal

Dr Rashid Merchant

Dr Dinesh Bhurani

Dr JS Arora

Dr H Pati

Dr. V.K. Khanna

Dr Renu Saxena

Dr Anju Seth

Dr Amita Mahajan

Dr Praveen C Sobti

Dr Sangeeta Gupta

Dr Sujata Sinha

Dr Anju Virmani

Dr Madhulika Kabra

Dr. Vatsala Dadhwal

Dr Mrs. Swaran Anil addressing the Audience of 7th NTC 2014 at Jawaharlal Auditorium AIIMS

Dr Rimjhim Bakshi

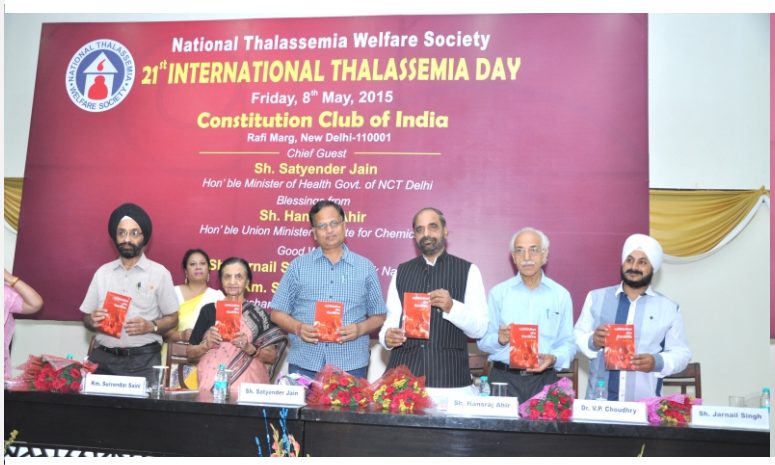
Mrs Sreelata Rudra

Ms Sangeeta Wadhwa

21st International Thalassemia Day 8th May 2015

Hon'ble Union Minister of Chemical Mr. Hansraj Ahir lighting the lamp

Hon'ble Minister of Health addressing the audience



Hon'ble Minister of Health released Hindi version of Florilegium of Thalassemia authored by Dr. JS Arora

Tanu Verma (Thalassemia Major) singing a song

VISITS

Defrijet Conclave organised by Sun Pharma

NGO Excellence Programme at SP Jain Institute, Mumbai

Thalassemia Check Up Camp at Hissar on 7th June 2015

Thalassemia Welfare Association Patna organised a Thalassemia Check Up Camp in Patna on 28th June 2014

Dr. Harshwardhan awarding NTWS for organising maximum number of Blood Donation Camps on 14th June 2014 World Blood Donor Day

World Blood Donor Day 14th June 2014

Mr. Arun Jain CEO Flour Donating Blood for the Thalassemia Patients

Blood Donation Camp Flour Gurgaon

Blood Donation Camp Red Fox, Aerocity

Blood Donation Camp at Pacific Mall Subhash Nagar with DDU Blood bank Team

Blood donation organised at Shankardev Bhavan

Blood Donation Camp at Radison Blu Dwarka

Thalassemia Screening Camp at Vivekanand College on 11th Feb 2015, 100 samples were collected

NTWS running in ADHM 2014

A Team of Delloite Nukkad Natak enjoying with a Thalassemic

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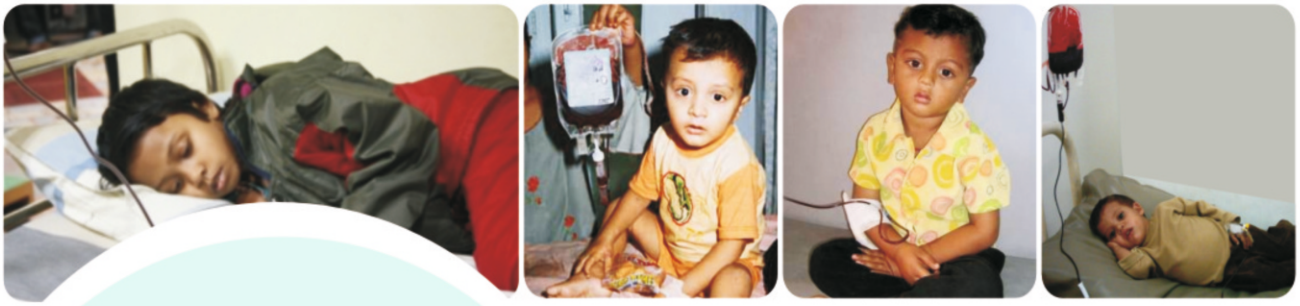
MRI T2 for assessment of iron overload in Heart and Liver in Thalassemic patients. Iron overloads in Heart and Liver leads to Heart failure & Cirrhosis of Liver.*



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To know more ask our Thalassemia Helpline No(s) : 9991119101,102, 9811182359

Clinical Meetings outside Delhi

Dr. Arora visited Jabalpur Thalassemia Society on 4th February 2014. Fifty patients were examined and advised treatment.

Dr. J.S Arora visited Gwalior on 18th May 2014 and examined Thalassemia patients there. Same day Dr. V.P. Choudhry visited Bareilly and examined Thalassemia patients.

National Thalassemia Welfare Society in association with Haryana Thalassemia Welfare Society, Rohtak organized a Camp on 25th May 2014. Dr. J.S Arora, Dr. V.P. Choudhry, Dr. Narender Agarwal and NTWS staff visited the Camp and examined large number of patients and distributed medicines at subsidized rates.

World Blood Donors Day 14th June 2014 was celebrated by NACO at RML Hospital Auditorium. NTWS was honored by then Health Minister Dr. Harshvardhan for organizing maximum numbers of Blood donation Camps.

Dr. J.S Arora visited Patna on 28th & 29th June 2014 to inaugurate Bihar Thalassemia Welfare Association, Patna. All the Thalassemia patients of Bihar and Jharkhand were invited for check-up. There was a large gathering of patients and parents. Mr. N.N Vidhyarthi secretary Thalassemia Society of Bihar thanked and appreciated Dr. Sunil Kumar for assisting in organizing thalassemia camp at has Saroj Hospital.

National Thalassemia Welfare Society associated with Amritsar Thalassemia Welfare Society, and organized a Patient check up camp on 6th of July 2014. Dr. J.S Arora was invited from Delhi. 67 patients visited the free check-up camp. Medicine were distributed by NTWS at subsidized rate with support from Mr SS Khattar former general secretary of Thalassemia Children Welfare Society Chandigarh to all the patients who came for the check-up.

National Thalassemia Welfare Society associated with Thalassemia Society Jalandhar, organized a Patient check-up camp on 2nd Nov 2014. Medicine were distributed by NTWS at subsidized rate to all the patients who came for the check-up. The funds were raised by Mr. S.S. Khattar and family.

Airtel Delhi Half Marathon on 23rd Nov 2014 (Great Delhi Run of 6Km) around 15 runners run to promote our cause thalassemia.

National Thalassemia Welfare Society in association with Thalassemia Society Jabalpur organized a Patient check up camp on 7th Dec2014. Medicine were distributed by NTWS at subsidized rate to all the patients who came for the check-up.

Radisson Blu Hotel Dwarka associated with us for organizing Blood Donation Camps for our patients. They have also organized a Christmas party on 25th Dec 2014 to entertain and bring smile on the face of the thalassemia patients.

A picnic was organized by Lucknow Thalassemia Society on 26th Jan 2015. The thalassemia patients participated in games & drawing competition. Prizes were given to the winners, Dr. J.S. Arora also examined the patients and gave advice. Thalassimic Society Lucknow is regularly organizing such activities to create liaison between patients and doctors.

On 1st Feb 2015 a check-up camp was organized by Thalassemia Society Bareilly in Association with National Thalassemia Welfare Society. Dr. J.S. Arora and Dr. Rayaz Ahemad visited to check-up the patients. Samples for HLA typing were also taken. Same day a check-up camp for thalassemics was organized at Gwalior. Dr V.P. Choudhry visited and examined the patients

On 15th Feb 2015 a check camp was organized by Thalassemia Society Jalandhar in Association with National Thalassemia Welfare Society where Dr. J.S. Arora examined around 80 to 90 patients.

National Thalassemia Welfare Society in association with Thalassemia Society Jammu organized a thalassemia check-up camp on 21st & 22nd Feb 2015. A CME on Thalassemia for doctors was also organized on 21st Feb'15

Thalassemia Society Dehradun organized a check-up camp for thalassemia patients on 1st Mar 2015. Dr J.S. Arora and Dr. V.P. Choudhry visited to examine the patients.

Thalassemia Society Dhanbad, Jharkhand organized a check-up camp for thalassemia patients on 29th Mar 2015. Dr J.S. Arora visited and examined the patients

Thalassemia Society of Rohtak organized a check-up camp for thalassemia patients on 5th April 2015. Dr J.S. Arora and Dr. Vikas Dua visited and examined the patients. Dr. Alka Yadav also examined the patients. All the three doctors enlightened the patients/parents about latest trends in the field. Mr Ram Kumar president Thalassemia Society Rohtak thanked the visiting faculty for the cooperation

National Thalassemia Welfare Society in association with Thalassemia Society Jabalpur organized a check up camp for thalassemics on 19th April 2015. Dr J.S. Arora examined about 50 patients.

On 26th April 2015 a CME on thalassemia as well as a patient check-up camp was organized by JN Medical College and Hospital Aligarh in Association with National Thalassemia Welfare Society where Dr V.P. Choudhry, Dr Jagdish Chandra, Dr. J.S. Arora & Dr. Rayaz Ahmed from Delhi highlighted various aspects of thalassemia. Dr. Zeeba thanked all the eminent Doctors for their precious time & expertise

Clinical Meetings outside Delhi

National Thalassemia Welfare Society in association with Thalassemia Society Hissar organized a check up camp for thalassemics on 7th June 2015. Dr. J.S. arora and Dr. Dinesh Bhurani visited and examined the patients. A CME for doctors was also organized on this day. Dr. J.S. Arora spoke on overview of Thalassemia and Dr. Bhurani on Stem Cell Transplant in Thalassemia.

National Thalassemia Welfare Society in association with Thalassemia Society Bihar organized a check up camp for thalassemics on 28h June 2015 to mark the first anniversary of formation of Thalassemia Society of Bihar.

National Thalassemia Welfare Society in association with thalassemia society Sirsa organized a checkup Camp for thalassemia patient at IMA Hall Sirsa on 6th September 2015 Dr. J.S. Arora & Dr. Vikas Dua examined around 60 thalassemia patient.

Free Thalassemia Clinic at Tilak Nagar, New Delhi.

Every 2nd Sunday of the month free Thalassemia clinic is held at second floor, DUSIB (Delhi Urban State Improvement Board) building, Block 12, Tilak Nagar. Timings 9 am onwards till all patients are examined. Patients from all parts of India visit this clinic for free counseling and advice. Medicines are distributed at subsidized cost. Renowned faculty from various institutions visit and give their free services on that day. In past three months we have given free medicines to around 20 patients including the Infusion pumps.

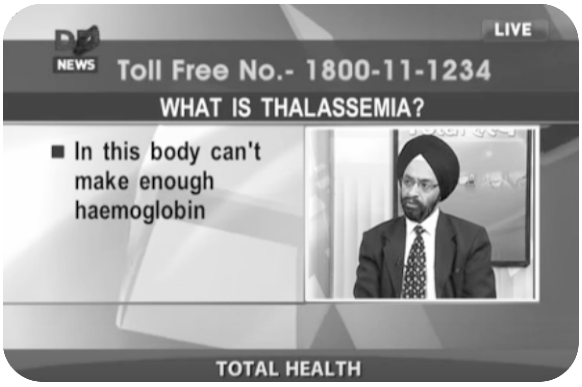
Other Activities

On 3rd February 2014 a huge rally was organized at India Gate by the Disability Rights NGO's. NTWS also participated to impose the demand to pass the Disability Rights Bill in the Parliament.

Thalassemia patients of NTWS were invited by Reliance Communication on 11th February 2014 to celebrate the Employee Day. Children were given gifts and shared special moments with the Employees of Reliance Communications, New Delhi.

Fluor Daniel, Gurgaon invited NTWS on 6th March to give lecture on Thalassemia and other blood disorders along with stress management. Dr. V.P. Choudhry, Dr. Vineeta, Dr. Tiwari and Mrs. Vandana Arora visited Fluor Daniel to deliver the lectures. The employees were delighted to gain knowledge from learned faculty.

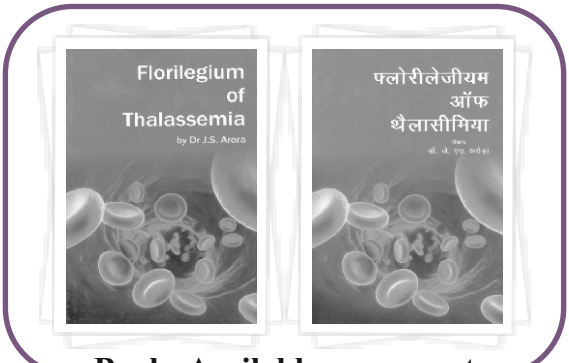
DD News invited Dr. J.S Arora, General Secretary NTWS, Dr Dinesh Bhurani & Dr. A.P. Dubey on 4th May 2014 to one hour live health programme "Total Health" to mark the 'International Thalassemia Day



Youtubelink https://www.youtube.com/watch?v=srKjqLXSjAk

On 5th May, All India Radio, New Delhi invited Dr. J.S. Arora for an "on air" discussion about Thalassemia and its prevention.

8th May 2014 International Thalassemia Day was celebrated at GTB Hospital in association with National Association of Reproductive Child Health of India, Delhi Branch. National Thalassemia Welfare Society celebrated ITD by distributing gifts among the Thalassemia patients on 8th May.



Books Available on request

21st International Thalassemia Day 8th May 2015

National Thalassemia Welfare Society (NTWS) observed 21st International Thalassemia Day (ITD) at Constitution Club of India, Rafi Marg New Delhi 110001 on 8th May 2015. Around 250 Thalassemia patients, parents and Thalassemia experts gathered to discuss the problems faced by thalassemics and to find means to solve those problems.

From 6pm to 7pm patients open their heart under the session "Dil Ki Baat". Most of the patients demanded that transfusion services should be available on all 7 days a week including Sundays and holidays. Only DDU Hospital is providing transfusions on Sundays and holidays but other hospitals are not. Patients were also complaining about break in supply of medicines and filters.

After that from 7pm to 8pm there was panel discussion by doctors, in which Dr. V.P. Choudhry former professor and head of haematology AIIMS moderated the session while Dr. A.P. Dubey, Director professor & head department of pediatrics, LN hospital, Dr. Jagdish Chandra Director professor & head department of pediatrics, Kalawati Saran Children Hospital, Dr Mausumi Swami head blood bank DDUH and Dr. Dinesh Bhurani Chief of transplant unit Rajiv Gandhi Cancer Research Institute participated. Experts asked the thalassemia patients and parents to maintain pre-transfusion hemoglobin above 10gm/dl and serum ferritin <1000ng/ml for optimum growth and puberty. Parents were also asked to search for HLA matched donor early in life because if bone marrow transplant is done early, success rate is high.

It was followed by welcome of dignitaries from 8pm onwards. While welcoming the guests Km. Surrendar Saini a noted social worker, Padma Bhushan Awardee and president of NTWS stressed the need of inclusion of Thalassemia in the list of disabilities for the purpose of "Disability Act". Ms Tanu Verma a thalassemia major patient sang a melodious song "Eh mere vatan ke logo" in which she portrayed every aspect of Thalassemia. Dr. J.S. Arora general secretary of NTWS explained the problems of thalassemia to the audience and highlighted the actions need to be taken by Ministry of Health Govt. of Delhi. He requested the chief guest Sh. Satyender Jain, Hon'ble Health Minister Govt. of NCT to initiate transfusion services 365 days a year in Delhi Govt Hospitals which include GTB hospital, LN hospital, CNBC hospital, BSA hospital, Sanjay Gandhi hospital and Hedgewar hospital. He requested the Hon'ble Minister to procure the medicines and blood filters at DHS level to avoid break in supply, initiate thalassemia screening of all pregnant women at all hospitals and maternity centres of Delhi, introduce NAT testing by individual donor testing (IDT) method in donors blood at all blood banks in Delhi to save all blood recipients from transfusion transmitted hepatitis B, C and HIV infections. He stressed the need of a sequencer for genetic lab at LN hospital, bone marrow transplant (BMT) unit in a Delhi Govt. hospital and a grant of Rs. 5 lacs for thalassemia patients undergoing BMT till we don't have BMT unit at any Delhi Govt. hospital. He said all these decisions were taken during the regime of previous Govt. but were not implemented due to administrative reasons. He requested the Hon'ble Minister to revitalizing Thalassemia cell under DHS of which he was coordinator since inception; it will help in improving the facilities for care & control of Thalassemia. Dr. Arora again requested the Hon'ble Minister of State for Chemicals Mr Hansraj Ahir to pursue with central Govt. to pass the disability bill which has already been tabled in Rajya Sabha. Hon'ble Union Minister of State for Chemicals Sh. Hansraj Ahir gave his blessings by promising to bring the iron chelators being used by thalassemics under National Pharmaceutical Pricing Authority (NPPA) and manufacturing of leucocyte filters in India to reduce the cost of these drugs and equipment. He also promised to discuss the disability issue with Minister of Social Justice and Empowerment

Before delivering his speech chief guest Sh. Satyender Jain Hon'ble Minister of Health Govt. of Delhi released the Hindi edition of **Florilegium of Thalassemia** authored by Dr J.S. Arora. In his speech he promised speedy follow ups of the proposals put forward by Dr. J.S. Arora and will specially look for safe blood, uninterrupted regular supply of medicines, screening of pregnant women, open BMT centres in the Delhi Govt. Hospitals. He also promised to rejuvenate Thalassemia cell and asked Dr. Arora to continue to coordinate Thalassemia Cell for rapid implementation of Govt. decisions.

Sh. Jarnail Singh, MLA Tilak Nagar, said that he is aware of noble work done by NTWS and has already given a building for thalassemia center to NTWS at Tilak nagar.

Dr. V.P. Choudhry thanked the guests and delegates.

In the end all the participants relished the delicious food and thalassemics were given return gift.

Lucknow

Thalassemic Society Lucknow organized a walk for thalassemia on 8th May 2015. It was started with a rally and various performances by thalassemia major patients. It was a nice initiative to boost the morale of Thalassemia patients and to make the mass aware about the daunting disease Thalassemia.

Kanpur

An International Thalassemia Day was organized at Rama Medical College-Hospital and Research Centre, Mandhana, Kanpur on 8th May 2015. Research Officer Dr. Nitu Nigam was the force behind this activity. She provided detailed information regarding the genetic disorder. This was followed by an interaction session in which doubts and queries were clarified by Dr. Nitu Nigam and Dr. D.K. Shukla who is Vice Principal of Rama Medical College. Thalassemia affected families of Kanpur and adjoining areas were invited for this day. A free blood transfusion and check-up camp was conducted for all the families. This Event was a great success with the co-operation of the families who attended this International Thalassemia Day 2015.

Ajmer

Ajmer Region Thalassemia Welfare Society organized a Voluntary Blood Donation Camp on 13th April 2014 and collected 421 units of Blood to augment safe supply of blood to 141 registered thalassemia patients in Ajmer. International Thalassemia Day was observed on 9th May 2014. The Event comprised of a picnic organized at Bidla City Water Park. Thalassemic Families enjoyed a lot and had a great time with each other. The Celebration ended with a Cake cutting ceremony by all 141 Thalassemia registered patients of Ajmer.

Ludhiana

Zindagi Live Foundation organized a thalassemia awareness campaign alongwith a blood donation drive on Sunday 26th July 2015. Thalassemia Children Welfare Association celebrated its 18th anniversary on 11th August 2015 by organizing a blood donation camp.

Patiala

Dr. Kanchan Bhardwaj was awarded by Hon'ble Finance Minister of Punjab Sh Parminder Singh on 15th August 2015, as head, Rajindra Hospital Blood Bank for being the most dedicated Blood Bank

Jalandhar

Jalandhar Thalassemia Welfare Society celebrated the Independence week by organizing chain of blood donation campsin Aug 2015 and collected more than 300 units of Blood.

⊙ All the societies are request to send there activity report along with photographs/press coverage for the bulletin.

⊙ Thalassemia patients/parents should come forward to contribute for bulletin in the form of stories/poems experience and suggestion.

ਐੱਸ. ਪੀ. ਐੱਸ. ਹਸਪਤਾਲ ਨੇ 50 ਥੈਲੇਸਿਮਿਕ ਬੱਚੇ ਗੋਦ ਲਏ

ਪ੍ਰੋਗਰਾਮ 'ਚ ਮੌਜੂਦ ਬੱਚਿਆਂ ਨੂੰ ਦਵਾਈਆਂ ਦੀ ਵੰਡ ਕਰਦੇ ਹਸਪਤਾਲ ਪ੍ਰਬੰਧਕ ਤੇ ਸਟਾਫ। (ਤਸਵੀਰ ਬਾਜਵਾ)

ਲੁਧਿਆਣਾ, 17 ਅਗਸਤ (ਸਹਿਗਲ)- ਸ਼ਹੀਦ ਭਗਤ ਸਿੰਘ ਨਗਰ (ਐੱਸ. ਬੀ. ਐੱਸ.) ਹਸਪਤਾਲ ਨੇ ਜ਼ਿੰਦਗੀ ਲਾਈਵ ਫਾਊਂਡੇਸ਼ਨ ਦੇ ਸਹਿਯੋਗ ਨਾਲ ਜੀਓ ਜ਼ਿੰਦਗੀ ਅਭਿਆਨ ਤਹਿਤ ਥੈਲੇਸੀਮੀਆ ਨਾਲ ਪੀੜਤ 50 ਬੱਚਿਆਂ ਨੂੰ ਗੋਦ ਲਿਆ ਹੈ। ਹਸਪਤਾਲ ਇਨ੍ਹਾਂ ਬੱਚਿਆਂ ਨੂੰ ਮੈਡੀਕਲ ਮਦਦ ਦੇਵੇਗਾ। ਸ਼ੁੱਕਰਵਾਰ ਦਿਵਸ ਮੌਕੇ ਸ਼ਹੀਦ ਭਗਤ ਸਿੰਘ ਫਾਊਂਡੇਸ਼ਨ ਵਲੋਂ ਹਸਪਤਾਲ ਵਿਚ ਆਯੋਜਿਤ ਪ੍ਰੋਗਰਾਮ ਦੌਰਾਨ ਪਰਿਵਾਰਾਂ ਦੇ ਨਾਲ ਆਏ ਇਨ੍ਹਾਂ ਬੱਚਿਆਂ ਨੂੰ ਦਵਾਈਆਂ ਵੰਡੀਆਂ ਗਈਆਂ।

ਹਸਪਤਾਲ 'ਚ ਥੈਲੇਸੀਮੀਆ ਨਾਲ ਪੀੜਤ ਬੱਚਿਆਂ ਦੇ ਇੰਸੈਂਟਿਵ ਕੇਅਰ ਵਿਭਾਗ ਦੀ ਐਸੋਸੀਏਟ ਕੰਸਲਟੈਂਟ ਡਾ. ਮਹਿਰ ਬਾਂਸਲ ਮੁਤਾਬਕ ਇਹ ਬੀਮਾਰੀ ਬੱਚਿਆਂ ਨੂੰ ਵਿਰਾਸਤ ਵਿਚ ਮਿਲਦੀ ਹੈ, ਜਿਸ ਵਿਚ ਰੈੱਡ ਬਲੱਡ ਸੈੱਲ ਦੀ ਕਮੀ ਦੇ ਕਾਰਨ ਹੀਮੋਗਲੋਬਿਨ ਐਨੀਮੀਆ ਥੈਲੇਸੀਮੀਆ ਦਾ ਕਾਰਨ ਬਣਦਾ ਹੈ। ਮੰਜਰ ਥੈਲੇਸੀਮਿਕ ਕਿਹਾ ਜਾਂਦਾ ਹੈ। ਇਸ ਤਰ੍ਹਾਂ ਦੇ ਮਰੀਜ਼ਾਂ ਨੂੰ 3-4 ਹਫਤੇ ਬਾਅਦ ਬਲੱਡ ਚੜ੍ਹਾਉਣਾ ਪੈਂਦਾ ਹੈ।

ਹਸਪਤਾਲ ਦੇ ਪ੍ਰਬੰਧਕ ਨਿਰਦੇਸ਼ਕ ਸੁਰਜੀਤ ਸਿੰਘ ਨੇ ਕਿਹਾ ਕਿ ਐੱਸ. ਪੀ. ਐੱਸ. ਹਸਪਤਾਲ ਦਾ ਪ੍ਰਬੰਧਨ ਤੇ ਕਰਮਚਾਰੀ ਇਸ ਨੇਕ ਕੰਮ ਵਿਚ ਆਪਣਾ ਯੋਗਦਾਨ ਦੇ ਕੇ ਖੁਸ਼ੀ ਮਹਿਸੂਸ ਕਰ ਰਹੇ ਹਨ। ਉਨ੍ਹਾਂ ਨੇ ਉਮੀਦ ਜਤਾਈ ਕਿ ਜ਼ਿੰਦਗੀ ਲਾਈਵ ਦੀ ਟੀਮ ਹਮੇਸ਼ਾ ਉਨ੍ਹਾਂ ਨੂੰ ਇਸ ਤਰ੍ਹਾਂ ਦੇ ਕੰਮਾਂ 'ਚ ਸਹਿਯੋਗ ਦਿੰਦੀ ਰਹੇਗੀ।

राजिंदरा अस्पताल के ब्लड बैंक को सूबे में बेस्ट वर्किंग का अवॉर्ड

पटियाला | राजिंदरा अस्पताल के ब्लड बैंक को सूबे में सबसे डेडिकेटेड और बेस्ट वर्किंग का अवॉर्ड मिला है। ब्लड बैंक हेड डॉ. कंचन भारद्वाज को यह अवार्ड 15 अगस्त को जिला स्तरीय कार्यक्रम में वित्तमंत्री परमिंदर सिंह ढींडसा ने दिया। डॉ. भारद्वाज ने बताया कि उनके ब्लड बैंक में ब्लड वालंटियर्स डोनेशन के काम में 3 से 4 साल से बेहतर काम कर रहे हैं। यहां एमएस डॉ. बीएल भारद्वाज मौजूद रहे।

शिविर में थेलेसिमिया की निःशुल्क जांच

पटना (एसएनबी)। थैलेसेमिया वेलफेयर एसोसिएशन, बिहार की ओर से सरोज हॉस्पिटल में थैलेसिमिया का निःशुल्क जांच शिविर आयोजित किया गया। शिविर में बिहार, नेपाल, झारखंड एवं पश्चिम बंगाल के करीब 130 रोगियों की जांच की गई। प्रसिद्ध हेमेटोलॉजिस्ट एवं नेशनल थैलेसिमिया वेलफेयर सोसाइटी, नई दिल्ली के जेनरल सेक्रेटरी डॉ. जेएस अरोड़ा ने शिविर का उद्घाटन किया। इस मौके पर उन्होंने कहा कि थैलेसिमिया के मरीजों को इस बात का ध्यान रखना चाहिए कि उनका हीमोग्लोबिन दस ग्राम से कम न हो। इसके साथ ही नियमित रूप से दवा एवं पैथोलॉजिकल टेस्ट करवाना चाहिए। इस मौके पर मुख्य अतिथि के रूप में मुख्य लोक अभियोजक एवं बिहार स्टेट बार काउंसिल के सदस्य जयप्रकाश सिंह, डॉ. सुनील कुमार, एएन विद्यार्थी, मिताली सेन गुप्ता समेत अन्य लोग मौजूद थे।

Blood Donation Camps organized by NTWS

Date	Place	Blood Bank Team	Date	Place	Blood Bank Team
11-01-14	Reliance Communications, Vaishali	RML	10-10-14	Lily, Gurgaon	LNJP
19 01 14	Todays Blossom, Gurgaon	RML	19-10-14	B-1 Gurdwara, Janakpuri	DDU
06-02-14	Management Development Inst. Gurgn	DDU	04-12-14	Pacific Mall, Shubhash Nagar	DDU
15-02-14	Sarita Vihar,Delhi	AIIMS	31-10-14	IITM, Janakpuri	DDU
16-02-14	Oriental Bank of Commerce,Vikaspuri	LHMC	13-11-14	DHFL Pramerica, Gurgaon	DDU
28-02-14	IITM, Janakpuri	DDU	09-12-14	Mercer, Noida	RML
06-03-14	Bechtel, Gurgaon	LNJP	10-12-14	Mercer, Gurgaon	DDU
06-03-14	Bechtel, Gurgaon	AIIMS	17-12-14		DDU
09-03-14	Jwala Heri Market, Paschim Vihar	RML	20-12-14	Reliance Communication, CP	LNJP
12-03-14	SRF, Bhiwadi	RML	11-01-15	Nirvana Country, Gurgaon	DDU
13-03-14	Vatika Towers, Gurgaon	DDU	16-01-15	Bharti Airtel Ltd, Gurgaon	DDU
21-03-14	Karam Industries, Noida	LNJP	05-02-15	MDI, Gurgaon	DDU
25-03-14	Minda , Greater Noida	LNJP	23-02-15	Airtel, Manesar	DDU
09-05-14	TDI Centre, Jasola	DDU	04-03-15	Bechtal, Gurgaon	DDU
04-06-14	Ciena, Sector 32, Gurgaon	RML	28-03-15	Assam Association Delhi	DDU
04-06-14	Ciena, Sector 32, Gurgaon	LNJP	07-04-15	Shiv Hanuman Mandir, Ladrawan	DDU
05-06-14	Larsen & Toubro, Noida	DDU	16-04-15	Ansal University, Gurgaon	DDU
12-06-14	Vatika Triangle, Gurgaon	DDU	19-04-15	Guru Teg Bahadur Sahib Gurudwara, Ambala	Ambala
13-06-14	Tower Vision, Gurgaon	DDU			
17-06-14	First India Place, Gurgaon	DDU	23-04-15	Karam Industry, Noida	LNJP
19-06-14	Vatika Bussiness Park, Gurgaon	DDU	25-04-15	Aam Aadmi Office, Tilak Nagar	DDU
29-06-14	Vatika City, Gurgaon	RML	20-05-15	Ciena, Gurgaon	LNJP
20-06-14	Vatika City Point, Gurgaon	DDU	28-05-15	Fluor Daniel	DDU
16-07-14	Red Fox Hotel, Mayur Vihar	RML	28-05-15	Fluor Daniel	LNJP
22-06-14	Arora Polyclinic, Vikaspuri	DDU	28-05-15	Fluor Daniel	LHMC
11-07-14	Red Fox Hotel, Aerocity	DDU	15-06-15	Vatika Triangle	DDU
12-07-14	Vertex, Noida	LNJP	19-06-15	Hyatt Place Gurgaon	AIIMS
23-07-14	Aristocrat Technologies	LNJP	21-06-15	Arora Polyclinic, Vikas Puri	RML
30-07-14	SOIL, Gurgaon	RML	22-06-15	First India Place	DDU
01-08-14	Fluor, Gurgaon	LHMC	23-06-15	Vatika Tower	RML
07-08-14	MDI, Gurgaon	DDU	24-06-15	Vatika City Point	DDU
13-08-14	Mc Donald's, Paschim Vihar	RML	25-06-15	Vatika Business Park Gurgaon	RML
24-08-14	Vipul Greens, Gurgaon	RML	26-06-15	Vatika Professional Point	DDU
02-09-14	Aricent, Electronic City, Gurgaon	RML	28-06-15	Vatika City	RML
03-09-14	Aricent, Udyog Vihar,Gurgaon	LNJP	29-06-15	Vatika Mindscape	RML
04-09-14	Aricent, Presidency Tower,Gurgaon	RML	30-06-15	Red Fox	RML
05-09-14	Aricent, Infotech Gurgaon	LNJP	5-07-15	Jail Road	IRCS
13-09-14	Raddison Blu Hotel, Dwarka	DDU	14-07-15	Alcatel Lucent Gurgaon	DDU
27-09-14	AAM Admi office, Patel Nagar	LNJP	14-07-15	Alcatel Lucent Cyber Greens	LNJP
27-09-14	AAM Admi office, Patel Nagar	LHMC	15-07-15	Alcatel Lucent Plot No 25	LNJP
			17-07-15	Reliance Communication, Rafi Marg	LNJP

- **Total 80 Blood Donation Camps organized from 11 Jan. 2014 to 17 July 2015**
  Total Number of Units Collected 5241
- **Maximum Units collected in one day 483 units in Fluor Daniel on 28th May 2015**
- **Number of Camps >100 units collected in one day is 13**

महत्वपूर्ण जानकारी :

☛ किसी के लिए ब्लड जब चाहिए ब्लड बैंक में जाने से पहले पता कर लेना चाहिए कोनसा ब्लड ग्रुप लगेगा जो ब्लड ग्रुप चाहिए वो ब्लड ग्रुप उनके पारिवार में से किसी का है या नही, अगर है तो वो क्यों नही देना चाहते।

☛ कितने यूनिट लगेगी, एक्सचेंज चलेगा की नही, अगर एक्सचेंज चलेगा तो अनके परिवार वाले दे सकते है या नही।

☛ जिन्हे ब्लड चाहिये वो कहाँ के रहने वाले है। अगर लोकल है तो फिर उन्हे अपने दोस्तो को ब्लड डोनेट करने के लिए बुलायें। अगर नही है तो हमें फोन लगाए

☛ हमारे उद्देश्य जरूरत मंदो की सहायता करना और आप सभी हमारे साथ देंगे तो ब्लड बैंको में कभी ब्लड की कमी नही होगी।

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- Preparing long-term detailed sustainability plan for the NGO.

NATIONAL THALASSEMIA WELFARE SOCIETY (Regd.)

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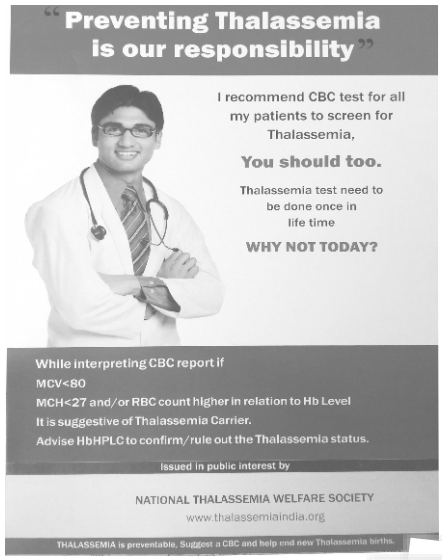

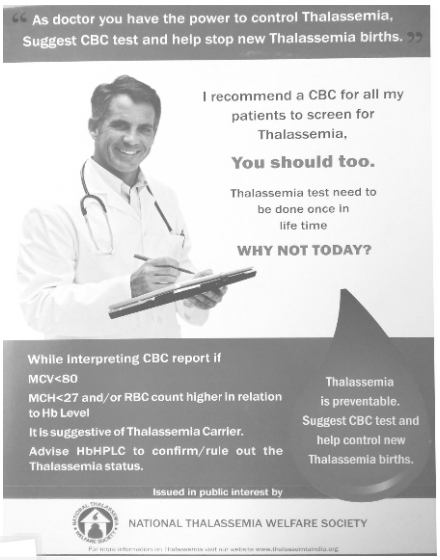

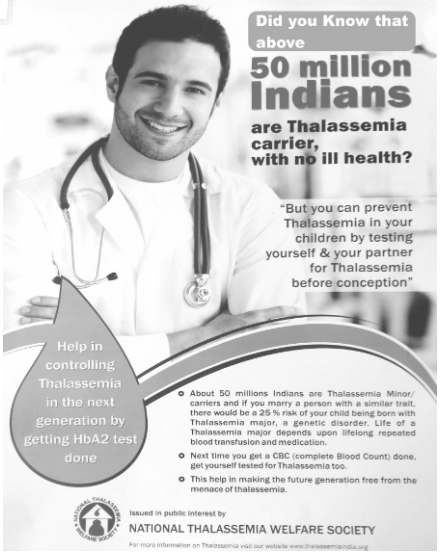

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Deferasirox 250/500mg

Inspire Life with a Difference

- Introduced with added orange flavour
- Achieves significant control of iron overload
- Improves patient compliance

For further information write to:

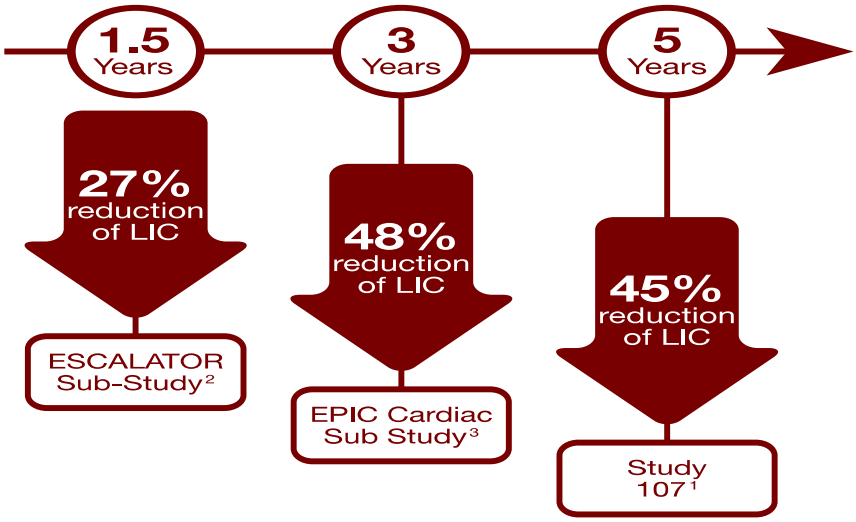
SUN ONCOLOGY
a division of Sun Pharmaceutical Industries Ltd
Acme Plaza, Andheri Kurla Road, Andheri (E), Mumbai-400 059
Tel.: 66969696 Fax.: 28212013.

L2157442

For the use of an Oncologist or a Cancer Hospital or a Laboratory only.

Significant

reduction
of liver and total body iron overload with long-term Deferasirox treatment in patients of β Thalassemia[1]



The most frequent reactions reported during chronic treatment with Asunra in adult and pediatric patients include gastrointestinal disturbances in about 26% of patients (mainly nausea, vomiting, diarrhea, or abdominal pain), and skin rash in about 7% of patients. These reactions are dose-dependent, mostly mild to moderate, generally transient and mostly resolve even if treatment is continued. Mild, non-progressive increases in serum creatinine, mostly within the normal range, occur in about 36% of patients. These are dose-dependent, often resolve spontaneously and can sometimes be alleviated by reducing the dose [4]

Asunra®
deferasirox 100mg/400mg Tablets
A novel once a day oral iron chelator

Pediatric Patients are classified as 2 years and above

1. Cappellini MD, et al. Blood. 2011;118:884-93; 2. Pathare A, et al. Ann Haematol. 2010;89:405-9;3. Cappellini MD. et al.Haematological 2010: 95(4) 557 – 566
4. India package Insert dated 16th Aug, 2013 based on the IPL dated 15th July, 2013

Basic Succinct Statement
ASUNRA®
Presentation: dispersible tablets containing 100 mg and 400 mg of deferasirox.
Indications: •for adults and pediatric patients aged 2 years and over with chronic iron overload due to blood transfusions (transfusional hemosiderosis).
Dosage: Transfusional iron overload •Starting daily dose: recommended initial daily dose is 20 mg/kg body weight; consider 30 mg/kg for patients receiving >14 mL/kg/month of packed red blood cells (>4 units/month), and for whom the objective is the reduction of iron overload; consider 10 mg/kg for patients receiving ~7 mL/kg/month of packed red blood cells (<2 units/month), and for whom the objective is the maintenance of the body iron level; for patients already well-managed on treatment with deferoxamine, consider a starting dose of ASUNRA® that is numerically half that of the deferoxamine dose. •50% starting dose reduction in moderate hepatic impairment (Child-Pugh B). Should not be used in severe hepatic impairment (Child-Pugh C). •Monthly monitoring of serum ferritin for assessing patient's response to therapy. •Dose adjustment if necessary every 3 to 6 months based on serum ferritin trends. Dose adjustments should be made in steps of 5 to 10 mg/kg. In patients not adequately controlled with doses of 30 mg/kg, doses of up to 40 mg/kg may be considered. In patients whose serum ferritin level has reached the target (usually between 500 and 1000 microgram/L), dose reductions in steps of 5 to 10 mg/kg should be considered to maintain serum ferritin levels within the target range. ASUNRA should be interrupted if serum ferritin falls consistently below 500 micrograms/L. •Maximum daily dose is 40 mg/kg body weight.
Administration: ASUNRA must be taken once daily on an empty stomach at least 30 minutes before food. •ASUNRA tablets to be dispersed in water or apple or orange juice.
Contraindications: •Hypersensitivity to deferasirox or to any of the excipients. •Creatinine clearance <40 mL/min or serum creatinine >2 times the age-appropriate upper limit of normal. •High risk MDS patients and patients with other hematological and non-hematological malignancies who are not expected to benefit from chelation therapy due to the rapid progression of their disease.
Women of child-bearing potential, pregnancy, breast-feeding and fertility: •Pregnancy: No clinical data on exposed pregnancies are available for deferasirox. Studies in animals have shown some reproductive toxicity at maternally toxic doses. The potential risk for humans is unknown. As a precaution, it is recommended that ASUNRA not be used during pregnancy unless clearly necessary. •Breast-feeding: It is not known if deferasirox is secreted into human milk. Breast-feeding while taking ASUNRA is not recommended. •Fertility: ASUNRA did not affect fertility or reproduction in rat studies even at toxic doses.
Warnings/Precautions: •Caution in elderly patients due to a higher frequency of adverse reactions. •Caution in patients with creatinine clearance between 40 and less than 60 mL/min, particularly in cases where there are additional risk factors that may impair renal function. Monthly monitoring of creatinine clearance, serum creatinine and proteinuria: dose reduction may be needed in some cases of non-progressive increase in serum creatinine; ASUNRA should be interrupted if serum creatinine shows a progressive rise beyond the age-appropriate upper limit of normal. More frequent creatinine monitoring recommended in patients with an increased risk of renal complications. Rare reports of acute renal failure, some of which required dialysis. Reports of renal tubulopathy mainly in children with beta-thalassemia and serum ferritin levels <1,500 microgram/L. •Not recommended in patients with severe hepatic impairment (Child-Pugh C). Monitoring of serum transaminases, bilirubin and alkaline phosphatase: before the initiation of treatment, every 2 weeks during the first month and monthly thereafter. ASUNRA should be interrupted if persistent and progressive unattributable increase in serum transaminases levels. Post-marketing cases of hepatic failure have been reported. •Gastrointestinal irritation may occur. Upper gastrointestinal ulceration and hemorrhage have been reported in patients, including children and adolescents. Multiple ulcers have been observed in some patients. There have been rare reports of fatal GI hemorrhages, especially in elderly patients who had advanced hematologic malignancies and/or low platelet counts. Caution in patients with platelet counts <50 x 109/L. • Cases of Stevens-Johnson syndrome (SJS) have been reported during the post-marketing period. If SJS is suspected ASUNRA should be discontinued. •Skin rashes: ASUNRA should be interrupted if severe rash develops. •Discontinue if severe hypersensitivity reaction occurs. •Annual ophthalmological/audiological testing. •Should not be used during pregnancy unless clearly necessary. •Not recommended when breast-feeding. •Must not be combined with other iron chelator therapies. •Product contains lactose.
Interactions: •Should not be taken with aluminium-containing antacids. •Caution when combined with drugs metabolized through CYP3A4 (e.g. ciclosporin, simvastatin, hormonal contraceptive agents, midazolam). •Increases in the dose of Asunra should be considered when concomitantly used with potent UGT inducers (e.g. rifampicin, phenytoin, phenobarbital, ritonavir). •Careful monitoring of glucose levels should be performed when repaglinide is used concomitantly with ASUNRA. Interaction with other CYP2C8 substrates like paclitaxel cannot be excluded. •Consider monitoring of theophylline concentration and possible theophylline dose reduction. Interaction with other CYP1A2 substrates may be possible. •Caution when combined with drugs with ulcerogenic potential (e.g. NSAIDS, corticosteroids, oral bisphosphonates) or with anticoagulants.
Adverse reactions: •Very common: blood creatinine increased. •Common: nausea, vomiting, diarrhea, abdominal pain, abdominal distension, constipation, dyspepsia, rash, pruritus, transaminases increased, proteinuria, headache. •Uncommon: anxiety, sleep disorder, dizziness, early cataracts, maculopathy, hearing loss, pharyngolaryngeal pain, gastrointestinal hemorrhage, gastric ulcer (including multiple ulcers), duodenal ulcer, gastritis, hepatitis, cholelithiasis, pigmentation disorder, renal tubulopathy (Fanconi's syndrome), pyrexia, edema, fatigue. •Rare: optic neuritis, erythema multiforme, esophagitis. •Adverse drug reactions from post-marketing (frequency unknown): Stevens-Johnson syndrome, acute renal failure, tubulointerstitial nephritis, hepatic failure, leukocytoclastic vasculitis, urticaria, alopecia, hypersensitivity reactions (including anaphylaxis and angioedema), aggravated anemia and cytopenia (relationship with ASUNRA uncertain).
Packs: 5 strips of 6 dispersible tablets.
Before prescribing, please consult full prescribing information available from Novartis Healthcare Private Limited, Sandoz House, Dr. Annie Besant Road, Worli, Mumbai- 400 018, Tel: 022 2495 8888
For the use only of a registered medical practitioner or a hospital or a laboratory
India BSS dated 10 Oct 2013 based on international BSS dtd 15 July 2013

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Sandoz House, Dr. Annie Besant Road, Worli, Mumbai- 400 018, Tel: 022 2495 8888

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