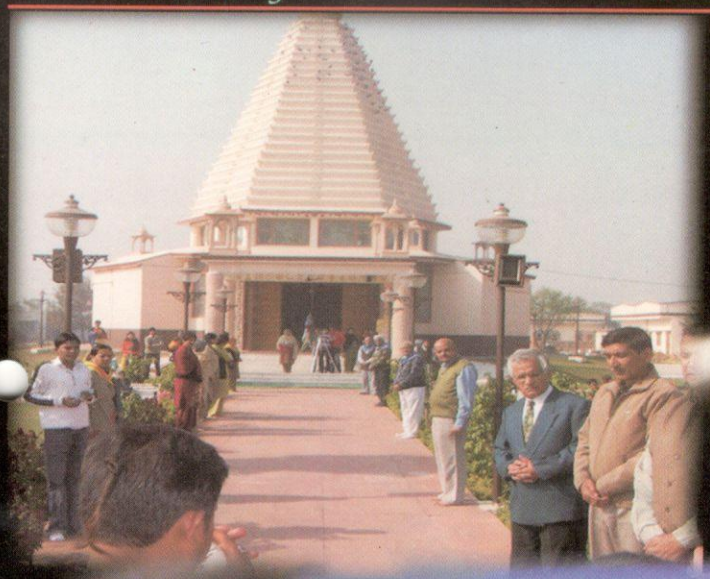
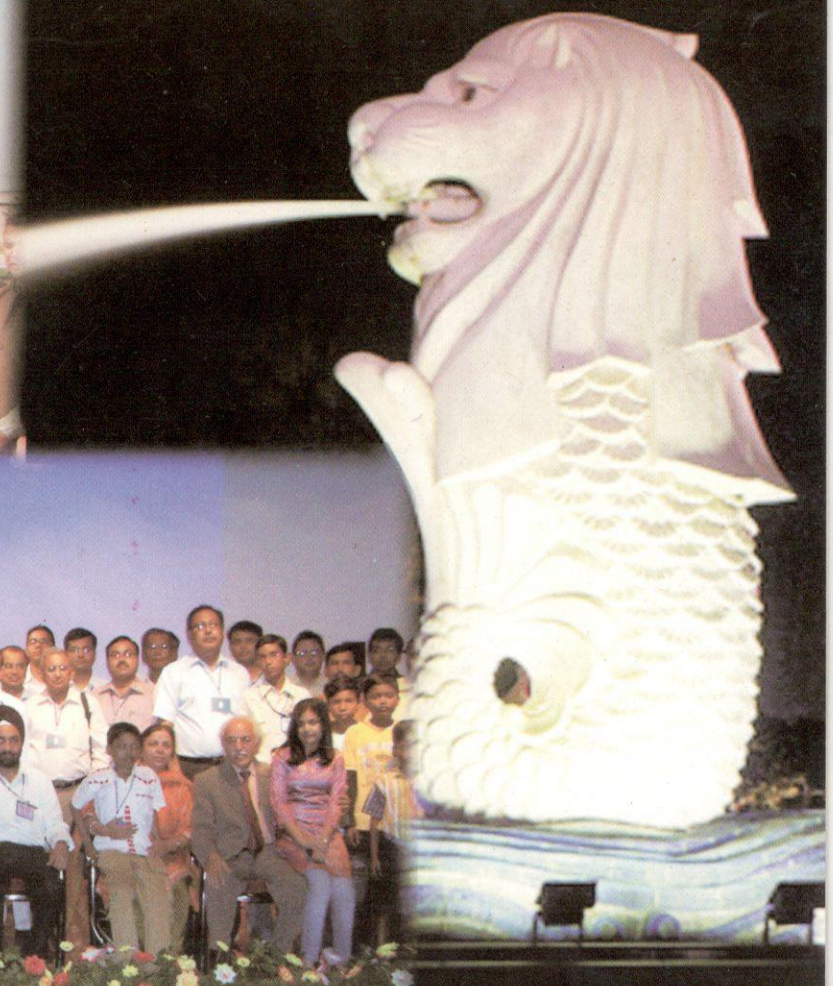
FEDERATION OF INDIAN THALASSEMICS

NATIONAL THALASSEMIA BULLETIN

EDITORIAL BOARD





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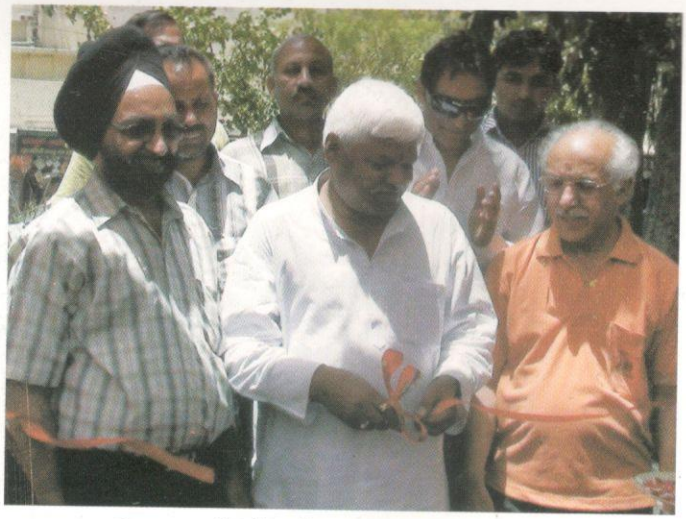


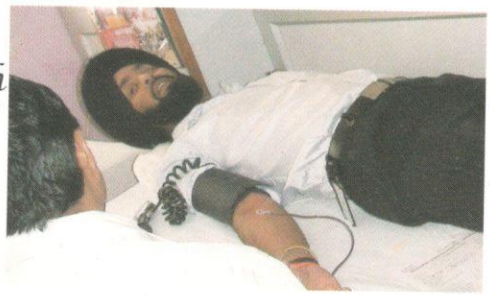
Annual Blood Donation Camp at Vikaspuri NTWS office, inaugurated by Hon'ble MP Sh. Mahabal Mishra

Dr. Arora encouraging first time donor, Dipti saxena

Dr Arora discussing problems of Thalassemia with M.P. Mr. Mahabal Mishra

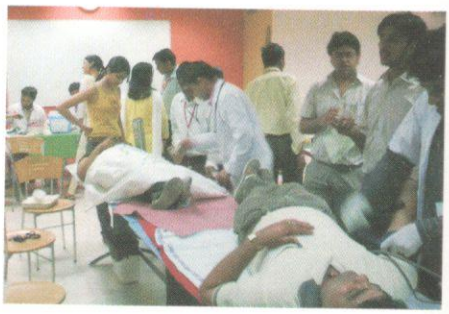
Annual Blood Donation Camp at Vikasuri 21st June 2009

Gagandeep Singh donating blood at NTWS office



Blood Donation Camp at CIENA

NTWS Blood Donation Camp at Convergys, Gurgaon



Dr. VP Choudhry
Director*
• Sunflag Pahuja Center for Blood Disorders
Sunflag Hospital Sector 16 A, Faridabad.
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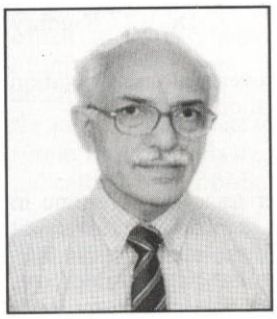
Formly Prof & Head Departmnet of Hematology,



Editorial

Present National Thalassemia bulletin has come late but carries the comprehensive treatment for thalassemia. It provides information which is state of art which will ensure a long life with out any complications if it is followed strictly. It is my sincere request to all parents to ensure that their dear children get the best care as they love them most. There are nearly sixty thalassemia societies in the country who are doing their best to provide support to these children. All parents should feel free to discuss their problems with their societies and should work with them closely to improve the facilities for Care & Control of Thalassemia in their regions. In return it will improve the treatment of their own child which is their ultimate goal. One must know that "**God help those who help themselves**". Thus it in your interest to insure that these societies work effectively. Your contribution will be of great help in improving the services of Thalassemic societies.

Pahuja Trust in collaboration with Paras Hospital has opened "A Thalassemia day Care Centre" at Paras Hospital, Gurgaon. National Thalassemia Welfare Society, Thalassemia Society Gurgaon have also become partner in this programme. Paras Hospital is providing the care for thalassemic children at highly subsidized rates which include blood transfusions, chelation therapy along with monitoring of thalassemia care for these patients. Gurgaon welfare society has come forward by placing a social worker who will facilitate & provide help to thalassemia children, inform of filters, chelating & other drugs. All these facilities are now available under care of an expert hematologist to all thalassemia patien in Gurgaon & around.

Some thing more to cheer for thalassemics as they will soon be able to meet the experts from all over the world who have spent their life time for care of thalassemics. Some of them have been involved in development of iron chelators, such as Asunra / Desirox, heart care, gene therapy and so on. All these World famous doctors will be meeting you, during the 4th International Conference on Thalassemia on 30th & 31st October in Delhi. The 4th International Thalassemia conference is being organized by Thalassemics India. You should make all out efforts to attend this conference. Such golden opportunities are rare and you can not miss it. You should make best use of this conference by learning from them & interacting with them. You may contact Mrs. Shobha Tuli, Secretary of Thalassemics India or Dr. Amita Mahajan, the Organizing secretary of this conference for further details.

Management of Thalassemia Major

Dr. VP Choudhry

Introduction

Thalassemia is the most common single gene disorder in the world and represents a major health burden worldwide. Its prevalence in India varies between 0-18% with a mean of nearly 3.5 percent. Nearly fifty million people carry this gene in India. It is a recessively inherited disorder resulting from various mutations of genes which code for globin chains of Hemoglobin (Hb), leading to reduced or absent synthesis of alpha or beta globin chains. The first case of beta-thalassemia in India was reported from Calcutta in 1938. One lakh children with Thalassemia major are born in the world. Nearly twelve thousand children are born in India every year. The frequency of thalassemia trait is 3 to 18 percent in Northern India and 0 to 3 percent in South. It is very common in certain communities such as Sindhis, Punjabis, migrants from Pakistan to North India such as Khatris and Multanis, Bhanushalis, Lohanas, Baniyas from Gujrat, Mahars, Kolis, Goud Saraswats from Maharashtra, Gouds and Lingayat from Karnataka, etc.

Clinical Manifestations of Beta-thalassemia

The spectrum of clinical manifestations of Beta-thalassemia varies widely. One end of the spectrum is the serious homozygous form (thalassemia major) that presents itself early in infancy (6 to 18 months) with progressive pallor, hepatomegaly, splenomegaly and bony changes early symptoms present in infants with are persistent anemia, excessive crying, poor weight gain, irritability, anemia not responding to various therapies the other end of the spectrum is a heterozygous form (thalassemia minor) in which the people have a normal life. In between these two forms there are patients with a varying degree of clinical manifestations of anemia, splenohepatomegely and bony changes, who maintain their life comfortably and are not dependent on blood transfusions such patients are a case of thalassemia-intermedia. Patients with thalassemia Intermedia can be homozygous or heterozygous.

Management of a Thalassemic Child

Basic principles of Management include

1. Correction of the anemia
2. Removal of excess iron with iron chelating agents
3. Treatment of complications
4. Cure of the disease by bone marrow transplantation

Transfusion therapy in thalassemia has two goals:

1. To prevent anemia
2. To suppress endogenous erythropoiesis to avoid ineffective erythropoiesis & bony changes

Blood transfusion is mandatory for all children with thalassemia major and for those children with thalassemia Intermedia, who cannot maintain their Hb at 7 gm/dl. for patients who have progressive evidence of growth retardation, severe bony changes, and significant hepatoslenomegaly regular blood transfusions are presently the mainstay of treatment of thalassemia major.

Packed cell Transfusion (RBCs)

Transfuse these children with coombs' cross matched packed RBCs. It is preferred to give leucodepleted blood which can be done by bed side filters or by prestorage leucoreduction systems. Pre storage filtration is better than bed side filters. Blood from near relatives should be avoided to prevent alloimmunization and for possible bone marrow transplantation in future.

How much to Transfuse

The ideal transfusion regimen is hyper transfusion regime in which the aim is to maintain mean hemoglobin levels at 12.5gm/dl and pre-transfusion hemoglobin level not less than 10gm%.This regimen permits normal growth and development, prevents skeletal changes and gastrointestinal iron absorption. It also prevents the liver & spleen enlargement hypersplenism.

Frequency of Transfusion

It is desirable that children should receive 10-15 ml of packed cells/kg/day, which raises Hb level by about 3.5 gm/dl. Packed cell transfusions every 2-4 weeks is adequate to maintain a pre-transfusion baseline Hb level (10 to 11 gm / dl). Blood should be transfused over 4-6 hours & its frequency varies from case to case. In patients with cardiac insufficiency, packed cell transfusion in small amount should be given frequently to maintain the hemoglobin above 11 gm/dl. Blood should be given slowly over 6 hours. The Patients should be assessed annually for mean hemoglobin levels, overall blood requirement, physical growth and development, evidence of hypersplenism, iron overload and development of antibodies.

Complications of Transfusions

Complications of repeated blood transfusions include increased non-hemolytic febrile reactions; transfusion transmitted infections like HBV, HCV, HIV, Malaria, etc. Other major problem encountered in the management of thalassemia is the iron overload. Screening of the blood for HIV, HBV, HCV viruses and Malaria by sensitive tests such as ELISA is mandatory to prevent these infections. Screening of blood, by nucleic acid testing (NAT) for various viral infections have reduced the prevalence of these infections. All Thalassemics who are negative for the hepatitis B, surface antigen should receive hepatitis B vaccine. Hepatitis B booster vaccination should be given to these children every five years.

Iron Overload And Chelation Therapy

Two factors contribute to iron overload in a thalassemic child.

A. Transfusional iron overload

B. Enhanced gastrointestinal iron absorption.

Each unit of pack cell releases 180-200 mg of elemental iron. The body accumulates nearly 200 mg/kg of iron every year. One mg of iron is absorbed daily from the gut in a normal person while in a thalassemic child it may be as high as 10mg/day. However, iron overload from the gut is minimal. Transfusion iron overload leads to deposition of iron in the heart leading to multiple heart problems. Its deposition in the pancreas causes diabetes, while in the liver and spleen may result in hepatosplenomegaly, hepatic fibrosis and cirrhosis of liver. The iron overload in the pituitary gland causes growth retardation and delayed puberty. Iron deposition in other glands causes their dysfunction. Its deposition in the skin leads to black discoloration.

Monitoring for Iron overload:

Iron levels of thalassemics can be monitored by serum ferritin levels which are readily available and easy to monitor. When its level is above 1000 ng/ml, the chelation therapy should be

initiated. The level of serum ferritin above10,000 ng/ml is found to be associated with significant organ dysfunction. A limitation of serum ferritin is that its levels are falsely very high in presence of infection, Vitamin C deficiency, hepatic damage, hemolysis and ineffective erythropoiesis. Till date, serum ferritin remains the most practical test to access the iron overload. The trend in serum ferritin levels over a period (rise or fall) serves as a good indicator of body iron burden.

Other methods to detect iron overload are Liver biopsy, MRI and SQUID & Star 2 images of the heart. Liver biopsy is the gold standard but it is invasive, expensive, & associated with the risk of internal bleeding. Presently this is used for research only.
SQUID (*Superconducting Quantum Interference Device*) is an imaging modality & it directly measures the body ferritin and hemosiderin. However, it is not preferred to evaluate the myocardial iron.

MRI provides a non-invasive, quantitative method of measuring tissue iron concentration indirectly. Liver iron level determined by using MRI, shows excellent correlation with liver iron. MRI has the ability to evaluate the entire organ. It is a more accurate method to measure liver iron content. Presently Ferrisean has been developed using MRI which is a simple & effective method to assess iron overload in different organs & total body iron. T2* MRI which is becoming the new standard for measuring cardiac iron levels, is better than MRI. In general, the lower the T2* value, the higher the risk of cardiac dysfunction. T2* value below 8 ms is suggestive of severe cardic iron overload.

DESFERRIOXAMINE (DFO/ Desferal)

Desferrioxamine is a hexadentate; one molecule of DFO binds with one molecule of iron. It has a short half life and is not absorbed from the gut. Therefore, it needs to be given continuously with the help of an infusion pump. Desferal should be started before the age of 2 years. It is given on a daily basis, for a minimum of 5 to 6 days per week, over 8 to 12 hours per day with the help of a subcutaneous infusion pump. The daily dose of desferal is 30 to 50 mg/kg and its dose needs to be tailored according to the patients need. It is advisable to keep the serum ferritin level between 1000-1500 ng/ml. Nearly two thirds of the iron is chelated through stools and the remaining through urine. It benefits various organs such as liver, heart & endocrine glands. it needs to be administered by slow subcutaneous or intravenous infusion, the compliance decreases with the advancing age.

It is fairly safe and has minimal toxicity. Its subcutaneous administration causes local pain, and redness. Visual abnormality may occur and includes decreased acuity of vision, peripheral field vision defects, and defective dark adaptation. A high incidence of high frequency sensori-neural hearing loss has also been observed. Auditory and visual toxicity are reversible if detected early. Therefore slit lamp and audiometry examination are advised annually.

Vitamin C

Ascorbic acid deficiency increases insoluble iron hemosiderin. Vitamin C helps in conversion of hemosiderin into ferritin from which iron can be chelated. Addition of vitamin C 100 mg daily prior to DFO therapy increases iron excretion. It is given only with DFO therapy.

Deferiprone (Kelfer)

This was the first oral drug developed. It mobilizes iron from transferrin, ferritin and hemosiderin. It has undergone extensive trials in USA, UK, Canada & India and has been found to be an effective iron chelating agent. It is given in dose of 75 to 100 mg/ kg body weight. It has been found to be more effective in mobilizing intracellular iron from the heart. Nearly 20 percent of children develop gastrointestinal symptoms like nausea, vomiting, pain in the abdomen and diarrhea. Advent of deferiprone has improved the compliance. Twenty to thirty percent children develop arthropathy, which is reversible after reducing the dose or on stopping deferiprone. Absolute neutropenia and thrombocytopenia also have been reported in occasional cases.

Combination Therapy

Desferal and Deferiprone have different actions. Both have been used together to improve the compliance, efficacy to reduce the side effects & cost of therapy. Deferiprone (75 mg/kg/day) is given for 5 to 7 days in a week and desferal (30-40 / kg / day) is given subcutaneously 2-3 days a week. This combination has been found to be good and an acceptable regimen. Combination regimen is recommended for patients with high ferritin levels and patients having cardiac or endocrine problems.

Deferasirox/ICL-670(Exjade/ Asunra/ Desirox)

ICL 670 is a new class of tridentates, which is a synthetic iron chelator. Two molecules of the chelator are required to form a complex with ferric iron. It is twice as effective as DFO. The iron excretion is predominantly fecal. Chelated iron is cleared by the liver and excreted through the bile. It also has the ability to chelate iron, from the reticulo-endothelial cells (RE cells) as well as various organs. It is highly selective for iron and does not excrete zinc or copper. Its oral bioavailability is 70% and can be given once a day as it has a long half life. In comparative studies 20 mg/kg of Deferasirox is found to be as effective as 40 mg/kg of DFO. Maximum dose recommended is 30 mg/kg. The most common side effects noted are transient GI disturbances like abdominal pain, nausea and vomiting, diarrhea etc and skin rashes.

SPLENECTOMY

It has been proved that if the hemoglobin level is maintained above 10gm/dl. Then the spleen does not get enlarged & evidence of hypersplenism does not appear. However, in our country many children develop splenomegaly and hypersplenism because of poor facilities for the proper management of thalassemia. If the child has already developed splenomegaly and signs of hypersplenism, splenectomy should be undertaken after 6 years of age.

Splenectomy is indicated if the yearly requirement of packed cells is 200 cc / kg or more. Decrease in WBC and platelet count are late manifestations of hypersplenism. All children needing splenectomy should receive pneumococcal, H influenzae and meningococcal vaccine at least 3 to 4 weeks prior to surgery. The family should be counseled regarding the risks & benefits of splenectomy prior to surgery. Prophylactic penicillin therapy must be continued life-long after splenectomy. Parents should start amoxycillin or ciproflox at start of fever V2. The child should be taken to the hospital at the earliest. All infections should be treated promptly with broad spectrum antibiotics at the hospital.

BONE MARROW TRANSPLANTATION

It offers a permanent cure and better future for children. The credit of the first bone marrow transplantation in thalassemia major goes to E Donald Thomas who performed this procedure on a 18 months old thalassemic child in 1982 using HLA matched with the elder sister as a donor. This child was cured of thalassemia. Since then many centers in the world and few in India have initiated BMT facilities. The principles of bone marrow transplantation include

(a) To destroy and prevent regeneration of defective stem cells,

(b) Sufficient immune suppression for good engraftment of donor bone marrow cells.

(c) To infuse normal stem cells.

(d) To prevent GVHD with high dose therapy of busulphan, cyclophosphamide, total and other modalities.

The three most important adverse prognostic factors for survival and event free survival that have been observed in large studies & includes

a) Presence of hepatomegaly (Hepatomegaly of 2 cm. below costal margin.)

b) Portal fibrosis and

c) Iron overload (S ferritin > 1000 ng/ml).

Based upon these factors children have been divided into three classes. Class I when all above three factors are absent. Class II when one or two factors are present and children with presence of all factors are termed as class III. Results of bone marrow transplantation is best in class I children with event free survival of more than 95 percent of cases. The cost BMT in India is around 8 to10 lacs and is regularly being done at Christian Medical College Vellore, Tata Memorial Hospital Mumbai, AIIMS in Delhi, SGPGI Lucknow & several other centres.

Key Messages

1. *Management of thalassemia is life long.*
2. *Regular packed cell transfusion to maintain pretransfusion hemoglobin above 10gm/dl is most Important.*
3. *It is essential to monitor serum ferritin levels regularly at 3-4 months interval.*
4. *Chelation therapy should be started as soon as serum ferritin level is >1000ng/ml.*
5. *Chelation treatment is necessary as long as the child is getting blood transfusions.*
6. *Among various chelating drugs the Asunra / Desirox is most effective. It needs to be given once daily and is a total body iron chelator.*
7. *Dose & form of chelation therapy should be selected to maintain serum ferritin levels around 1000ng/ml.*
8. *Splenectomy should be undertaken with all precautions & only when indicated.*
9. *Bone marrow transplantation offers complete cure. It is only a one time procedure.*

इसका हिन्दी रूपान्तर अगले संस्करण मे प्रकाशित किया जायेगा।

NTWS Activities

1. Swami Dayanand Hospital, Shahdara organized **Thalassemia Week** from **4th Feb'09 to 13th Feb'09** in association with **NTWS**. Lectures were given by Ms. Monisha to all the OPD Patients (Pregnant ladies, Staff of SDH etc). **Chetna & Jagriti, two Thalassemia Documentaries**, were shown on a big LCD Screen. Brochures were distributed and exhibition panels were displayed for the public. **The Obst. & Gynae Dept. of SDH, referred some cases to Hindu Rao Hospital for HPLC test.**

2. NTWS in association with DUSU organized a **Blood Donation Camp at Delhi University North Campus on 14th February 2009 Valentine's Day.** It is an annual event, the Hindu Rao Hospital Blood Bank team collected blood. **Mc Donalds, Kamla Nagar Branch** sponsored the refreshments of the volunteer blood donors. The Thalassemia Control Project of MCD, Hindu Rao Hospital conducted Thalassemia Screening & Anemia detection test of the voluntary blood donors & DU students. Dr. Suman Mendiratta H.o.D, Gynae, Hindu Rao Hospital introduced **"Sangini"** pre-marriage counseling clinic and asked the Student Union leaders to send the students for counseling & guidance. There was also a Slogan writing competition & Thalassemia Quiz competition, during the Blood Donation Camp. Dr. P.P. Singh, M S , Hindu Rao Hospital was the Chief- guest of the camp. He gave away the prizes to the best Slogan writers & winners of the quiz competition.

3. On **24th of April'09 a CME** was organized **at Paras Hospital, Gurgaon**. All the Thalassemia Patients of **NCR** were invited. **Dr. V.P Choudhry & Dr. J.S. Arora** addressed the meeting & thanked **Air Marshall Mr. Bharat Kumar, Founder Trustee of Pahuja Trust & The M.S Of Paras Hospital** for their kind Co operation for opening a Thalassemia Day Care Unit at Paras Hospital. Gurgaon patients are happy to have a Day Care Centre under the guidance of Dr. V.P. Choudhry who has joined as Director Hematology at Paras Hospital. On 24th March' 09 CME on Thalassemia was organised for Medical Faculty which was addressed by Dr. V.P. Choudhry, Dr. J.S. Arora, Dr. V.K. Khanna (Pediatrician, Gangaram Hospital), Dr. Vatsala (Dept of Obs & Gynae, AIIMS) . It was attended by over 100 doctors of Gurgaon. Here the Thalassemia Patients will get a comprehensive therapy at highly subsidized rates.

4. This year **International Thalassemia Day** was observed by **NTWS** on **9th of May'09** at **Metro Walk Adventure Island, Rohini.** It was a cool pleasant day of this summer season and around **600 Thalassemia families** came together to enjoy the **ITD** at Adventure Island. It was a beautiful place to enjoy with ones family. The day started with some Magic Shows, which the children enjoyed very much. The high- tech rides overjoyed the Thalassemic children. The parents also enjoyed seeing their children happy and thanked Dr. J.S Arora for bringing them to such a beautiful place. All the rides were very fast & thrilling & children were very happy to see this new world of entertainment. There were water games & rain dance. It was lot of fun and frolic & a great way to beat the heat. Lunch was served and the food was also very tasty.

The Current Status of Gene Therapy for Thalassemia and Sickle Cell Disease

Gene therapy is the long awaited "final cure" for thalassemia and sickle cell disease. To cure means to render a patient free of disease and the need for treatment. Such a cure can currently only be achieved in hereditary hemoglobin disorders by haemopoetic stem cell transplantation.

Because stem cells ("master cells" of the human body, which are able to produce copies of themselves or other types of cells in this case red blood cells) are usually taken from the bone marrow the procedure is popularly known as bone marrow transplantation (BMT).

Other sources of stem cells are also being used such as those derived from the umbilical cord, or the circulating blood of the donor. This procedure requires a suitable matched or histocompatible donor (one who has the same HLA antigens in his/her white cells) who is related to the patient. However, only around 16-20% of patients have an ideal donor. Patients must also be in good condition regarding iron overload and the resultant complications. So the numbers of patients, who can benefit from this treatment are very limited.

Gene therapy, on the other hand depends on the auto-transplantation of the patient's own stem cells which were previously treated outside the body with the transfer of a functional β-globin gene. This means that no donor is required and complications such as graft rejection and graft versus host reactions are practically eliminated. The patient's condition is still a factor in success, since the whole process of autologus transplant includes partial or total marrow ablation (i.e., destroying the patient's own bone marrow to allow the new stem cells to settle and produce healthy Hb)

Years of experimentation have demonstrated that transferring the functional gene into the patient's stem cell can be successfully done using a virus (viral vector). The most successful family of viruses to achieve this are the lentiviruses. In experimental mice it has been demonstrated that once introduced into very young red cells (stem cells, nucleated red cells and reticulocytes), they produce β- globin which is sustained over time, and so the anaemia is corrected.

Several research groups have developed lentivirus gene delivery systems, using various section of the functional beta-globin gene to include regions that control the expression of the gene (locus control region). However these vectors do not all express β- globin at the same level. Two research groups have felt enough confidence in their lentivirus vectors, as a result of their animal experiments that they have decided to proceed to trials in humans.

Human trials

Human trials are the exciting new development that everybody has been waiting for. This update is based on the latest information made available to TIF during the 1st Pan-Middle East Conference on Haemoglobinopathies in Damascus, Syria on 1-2 May 2009.

The first of the two groups to decide on human trials is the one led by **Prof. Philippe Leboulch**, based at Harvard University with several collaborators, including Prof. Arthur Bank (Columbia University). Prof. Elaine Gluckman and Prof. Yves Buzard (Paris University).

A patient has been treated in a phase I/II trial in Paris. The patient, whose name is Paul Louis Beauchesne, has completed the treatment and is doing well. (See CAF Medical Update No. 15, September 2008.) There is a positive selection of the corrected stem cells in his bone marrow, so that over time there has been an increase in the production of normal hemoglobin. His transfusion requirements gradually came down, and he is now producing 8.5g/dl of functional Hb without any transfusions since June 2008. Paul Louis had received monthly transfusions for his entire life, so the result is judged to be a success.

A second research team is preparing for clinical trials. This team is led by Prof. Michael Sadelain of the Memorial Sloan kettering Cancer Centre in New York, whose collaborators include Dr. Aurelio Maggio (University of Palermo). Dr. John Tisdale (NIH). Dr Leszeck Lisowski and Dr. Stefano Rivella (Well Cornell medical College). Dr. Farid Boulad, a member of the Slone Kettering team, was a speaker at the Conference and presented current developments.

This team has also been working with lentivial vectors, and one has been selected for human trials and labelled "Thalagen", It is supported by a company called Errant Gene Therapeutics (EGT). The research proposal for the human gene transfertrial has been reviewed by the Recombianant DNA advisory Committee (RAC) in the USA, and FDA approval is expected in April 2009. The trial, involving 5-10 patients, is expected to go ahead in the autumn of 2009. TIF is in close contact with Pat Girondi, the CEO of EGT.

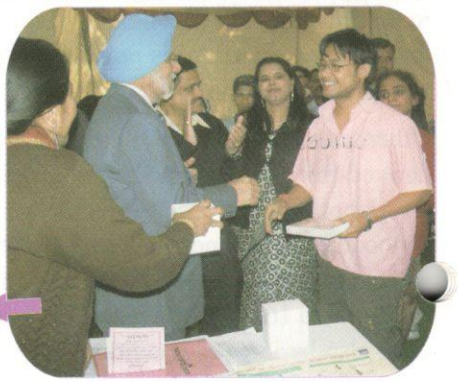
Several other teams are also making progress with their viral vectors and are investigating both efficacy and safety. One team is based at the St Rafael hospital in Milano, and the clinical application of gene therapy, when trials start, will be the responsibility of the transplantation team which is headed by Dr. Sarah Marktel. She was also present at the conference and gave an update to the TIF Board.

Mr. Diggal additional Commisioner MCD addressing during Inagration of Thalassemia Control Project

Dr. Suman Mendiratta, Dr. Sangita Popli, Ms. Monisha along with Mc Donald Staff of Kamala Nagar Branch during Blood Donation Camp on Valentine day

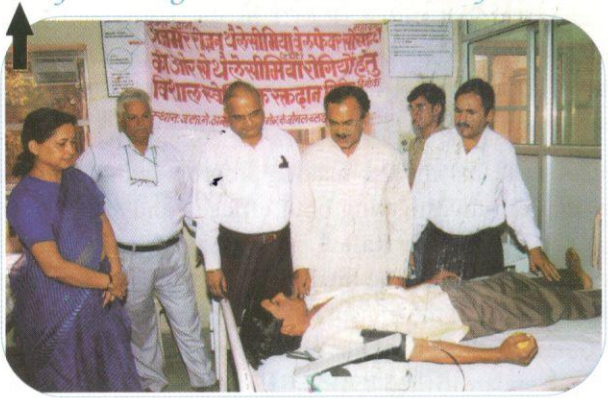
Dr. Verma In-charge Thalassemia Unit & Blood Bank Swami Dayanand Hospital along with Dr. Mohanti & Matron In-charge

Dr P.P Singh MS Hindu Rao Hospital encouraging Blood Donors during Camp organised by NTWS on Valentine Day 14th feb'09 at Delhi University Student Union Office



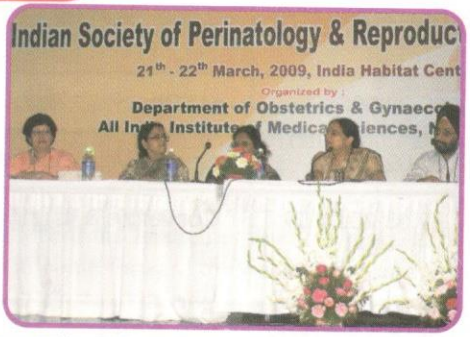
International Thalassemia Day Celebration by Ajmer Region Thalassemia Welfare Society

International Thalassemia Day Celebration by Punjab Thalassemics Welfare Society, Ludhiana

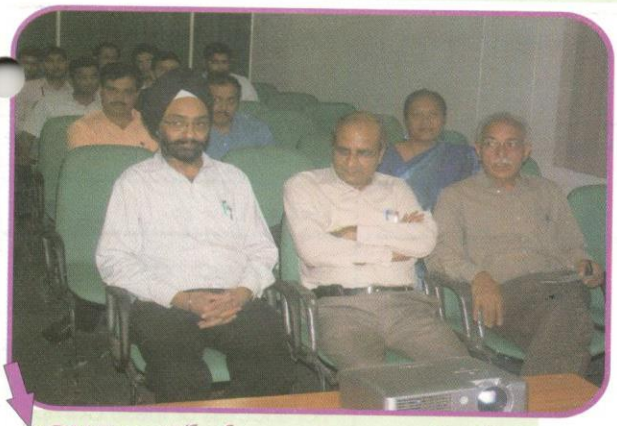


Dr. Ratna Chatterji, Mrs. Shobha Tuli, Dr. Arora & Dr. Choudhry at 2nd International Workshop on Thalassaemia in Eastern India Held at, Kolkata on 7th. & 8th. March 2009.

Dr. J. S Arora receiving a memento from Principle of Guru Nanak Dev Khalsa College, DU

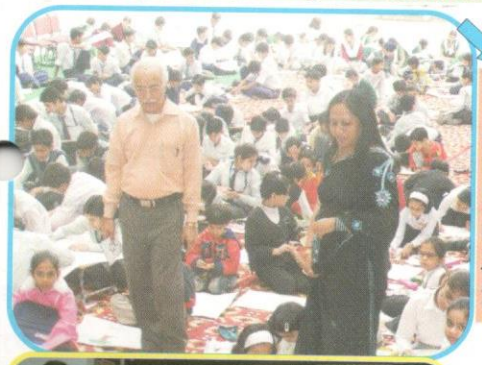


Dr.Deepika Deka Prof. Gynae AIIMS, Dr. Madhulika Kabra Incharge genetics AIIMS, Dr.Renu Saxena HoD Hemat. AIIMS, Dr. Sunita Mittal HoD Gynae AIIMS & Dr. J.S. Arora during Pannel discussion on planning Motherhood at India Habitat Centre, 22 March 2009



CME on Thalassemia organised at Maharishi Balkmiki Hospital, Poot Khurd, Delhi, on 25th March 2009

Dr. Sunita Mittal, Dr. J S Arora, Dr. Deepika Deka & Dr Neena Malhotra during Cultural Activity of ISOPARB March'09



Dr. V.P. Choudhry & Monisha inspecting Children during Drawing Competition at Chacha Nehru Hospital on Bal Diwas 14th Nov'08

Free Thalassemia camp at Sun Flag Pahuja Center for Blood Disorders on 28th December 08 Ferritin samples are being taken by NTWS team

Mst. Tushar singing a song based on Hit song of Oscar Award Wining Film Slum Dog - JAI HO

Blood Donation Drive by NTWS for easy Availability of Blood

Date	Organization	Blood Bank	No. of Units Collected	Highlights
31.01.09	Aricent, Gurgaon	AIIMS	128	First time with record Collection.
06.02.09	Ciena, Gurgaon	AIIMS	127	Free Thalassemia Screening at camp.
20.02.09	Mc Donalds, Vikaspuri	AIIMS	45	Good start.
22.02.09	Arora Polyclinic, Vikaspuri	DDU Hospital	84	In association with Art of living
19.03-30.03.09	Convergys & its units	DDU Hospital, Hindu Rao Hospital, LNJP Hospital	251	Convergys & its various units deserve special Thanks from all Thalassemics.
08.03 - 20.03.09	HCL, Noida	DDU Hospital, Hindu Rao Hospital, RML, AIIMS	145	Day & night camps their constant support of great value to Thalassemia.
22.04 - 23.04.09	Fluor Daniel, Gurgaon	AIIMS	280	Annual event with records.
06.05.09	Aegis, Gurgaon	AIIMS	89	Regular Donors.
08.05.09	Aegis, Noida Keane India Ltd. Keane India, Gurgaon Aegis, Gurgaon	DDU AIIMS GTB & Hindu Rao RML	45 45 82 57	Record breaking in Camps to celebrate International Thalassemia Day Mrs.S Rudra, Mr. Neeraj Tripathy,Mrs. Neelam Kohli, Mr. Neeraj Kumar worked For Success of these Camps.
14.05.09	Cushman & Wakefield India, Gurgaon Ltd.	LNJP Hospital	39	Organized for the first time.
22.05.09	Teleperformance Ltd.	Hindu Rao Hospital	101	First time successful camp.
28.05.09	Aegis, Gurgaon	Hindu Rao Hospital	48	Regular Donors.
30.05.09	Manya Education Pvt.Ltd	RML Hospital	43	Their first attempt. Good Beginning.
10.06.09	C-Block Gurudwara, Vikaspuri	DDU Hospital	47	Their annual event source of constant Support.
21.06.09	Arora Polyclinic, Vikaspuri	DDU Hospital	70	Mr. Mahabal Mishra (MP) was chief guest.
21.06.09	Shubham Banquet, Hari Nagar	DDU Hospital	112	Efforts of Mr. Jewesh Manuja brought Grand success.

*We would like to appeal to all the **Corporates & BPOs,** to come forward and help the Thalassemics by organizing more **Blood Donation Camps.** As there is an acute shortage of blood during the summer months we need to organize more and more camps to beat the shortage and keep the **reservoir** of the **Govt. Blood Banks** full.*

Gwalior

Thalassemia Society of Gwalior organised a clinical meeting on 26th July '09 at Gwalior. Dr. J S Arora and Dr. Dinesh Bhurani Hematologist Rajiv Gandhi Cancer Hospital, New Delhi visited and examined around 30 patients. Dr. J S Arora explained General management in detail while Dr. Bhurani enlightened on Bone Marrow Transplantation. Mr. K.L.Bhambani President of Thalassemia Society of Gwalior and Mr. Pavan Agarwal secretary made strong efforts for its success.

In the evening Dr Rashmi Gupta president of IAP branch, Gwalior organised a CME where a comprehensive talk on approach to anemia was given by Dr. Dinesh Bhurani while Dr. Arora spoke on Haemolytic Anemia.Around 50 paediatricians attended the CME.

Report from Patiala Thalassemic Children Welfare Society

Patiala Thalassemic Children Welfare Association organised free Medical checkup at Mata Shri Kali Devi Temple, Patiala on 28th June '09. Dr. J. S. Arora gave an elaborative talk on Thalassemia to Thalassemic patients & parents. Dr. Arora along with Dr. Gursharan Singh HoD Paediatrics, Rajindra Hospital, Patiala also examined around 60 patients & advised appropriate treatment. President Sd. Davinder Singh and Secretary Mrs. Manjinder K. Walia of Patiala Thalassemic Children Welfare Association were force behind the success of this activity. Mr. Vijay Kumar Chopra Chairman of Punjab Kesri also visited and blessed the Thalassemic Children. Mr. Davinder Singh Mehta President of Society informed that 130 Thalassemic children are registered with them, who required Blood Transfusion every 15-20 days & medicines for Iron Chelation. He said all the Children were offered free testing before the camp but most of the children can not afford the medicines due to high cost. He appealed the public to come forward to donate blood and help financially so that adequate treatment can be given to all patients. Mr. Vijay Pawah, Mr. Dinesh Batra, Mr. Harinder Kumar, Mr. Harpal Singh, Mr. Rajiv Arora, Ms. Sunita, Mrs. Manjinder Kaur Walia and many other members were present on the occassion

थैलेसीमिया पीडित बच्चों हेतु स्वेच्छिक रक्तदान शिविर मे 281 युनिट रक्तदान

अजमेर 12 अप्रेल 2009 (वि.) अजमेर रीजन थैलेसीमिया वेलफेयर सोसायटी के तत्वाधान में दिनांक 12 अप्रेल रविवार को ब्लड डोनेशन कैम्प जोनल ब्लड बैंक, जवाहर लाल नेहरू चिकित्सालय अजमेर में आयोजित किया गया।

प्रो. वासुदेव देवनानी, विधायक अजमेर उत्तर के मुख्य आतिथ्य में शिविर प्रारम्भ किया गया। उक्त शिविर में डा. आनन्द माथुर अधीक्षक, ज.ला.ने.चिकित्सालय, अजमेर, डा.अजय यादव, डा. नानक जेठानी एवं डा. ओम प्रकाश पचौरी भी उपस्थित थे।

संस्था के सचिव श्री परवानी के अनुसार उक्त शिविर में लगभग 281 स्वेच्छिक रक्तदाताओ के द्वारा रक्तदान किया गया। जिसका उपयोग सोसायटी में रजिस्टर्ड अजमेर सम्भाग के 84 थैलेसिमिक बच्चों के निरंतर रक्त संचरण हेतु किया जायेगा। स्वेच्छिक रक्तदाता अजमेर, भीलवाडा, नागौर, किशनगढ, ब्यावर, बिजयनगर, डेगाना, शाहपुरा, आसीन्द, भीम आदि से रक्तदान करने के लिए बडी संख्या में ज.ला.ने. चिकित्सालय के जोनल ब्लड बैंक में रक्तदान के लिये आये।

श्री परवानी ने बताया कि उक्त शिविर में अधिक से अधिक नवयुवकों, महिलाओं के द्वारा रक्तदान किया गया तथा रक्तदाताओं का उत्साह देखते ही बनता था। उक्त अवसर पर अस्पताल प्रशासन के द्वारा अतिरिक्त वरिष्ठ तकनीशियनों एवं नर्सिंग स्टाफ की व्यवस्था की गई थी जिसमें श्री सुशील खण्डेलवाल, गंगासिंह, श्याम सुंदर शर्मा, धर्मप्रकाश, जी, बलवन्त सिंह, तरून सैनी, लोकेश, शाहबाज, राधावल्लभ, ईश्वर तथा विक्रम के द्वारा रक्तदान के दौरान अपनी अमुल्य सेवाएं प्रदान की गई।

सोसायटी के अध्यक्ष श्री अमित अग्रवाल, श्री सुर्य प्रकाश टांक, श्री हरमेन्द्र छाबडा, श्री जगदीश चेलानी, श्री विजय निचानी, श्री हितेष मलुकानी, श्री राजेश मंघवानी, श्री ईशारत अली, प्रवीण गुप्ता तथा समस्त पदाधिकारियों ने जनहित के कार्य को सफल बनाने हेतु तन-मन-धन से सहयोग प्रदान किया।

Workshop

Thalassemia & Sickle cell disease Around the World:
Burden, Prevention and Control
At The All India Institute of Medical Sciences, New Delhi
4 October, 2009; 8:30 AM to 3:45 PM

18th International Thalassemia Day, at Dayanand Medical College and Hospital, Ludhiana

In view of 18th International Thalassemia Day, the departments of Transfusion Medicine and Pediatrics jointly organised 10th annual medicos voluntary blood donation camp at Dayanand Medical College and Hospital on 8th May 2009. The day is observed all over the world to commemorate the death anniversary of George. Englesoz of Cyprus, who died at the age of 26. Despite being a Thalassemic, he was an active member of the Thalassemia International Federation and worked for the welfare of Thalassemic patients all over the world. The camp got started with an impressive inaugural ceremony, where Mr. Prem Gupta, Secretary of DMCH Managing Society, DMCH, was the chief guest while Principal of DMCH Dr. Daljit Singh was the guest of honor. About 150 units of blood were collected during the camp. The president of Punjab Thalassemia Welfare Society, Ms Rama Kapoor elaborated on the functioning of the society and monetary and other benefits being provided to the Thalassemic children by the society. Professor and Head of Transfusion Medicine, Dr. Amarjit Kaur extended a warm welcome to the dignitaries, faculty, voluntary blood donors, NGOs including Ms Rashmi Karwa, Social Welfare Society, Mandi Ahmedgarh, Salaam Zindagi and Har Har Astha Sewa Parivar & the Thalassemic Children were present on the occasion. A group of Thalassemic children also put up a solo and group song performance. Professor of Pediatrics and In-charge of Thalassemia Unit at DMCH, Dr. Parveen C Sobti informed that presently, the Thalassemia Unit at DMCH was catering to the needs of 215 children, who were regularly getting blood transfusions. The faculty who donated blood started with Medical Suptd, Dr. Sandeep Puri, who holds the distinction of being the leading blood donor from DMCH faculty and was honored with a gold medal on the occasion. Other members, including Dr. Gautam Ahluwalia, Dr. Navjot K Bajwa, Dr. G.S. Bajwa, Dr. Rajesh Arya, Dr. PPS. Gill and Dr. Gautam Biswas also donated blood. The contribution of the staff of the Transfusion medicine department along with the doctors and technicians were also acknowledged for their efforts. The monetary contributions were made by Mr. Sunila Gupta, Mrs. Rama Munjal and Mrs. Nandita Gupta for the treatment of those Thalassemic Children whose parents were not able to bear the cost of their Medical treatment.

शादी से पहले थैलेसीमिया जांच जरूरी

नेहरू अस्पताल के शिशु रोग विभाग मे थैलेसीमिया स्वास्थ्य केन्द्र का उद्घाटन, प्रख्यात चिकित्सक डॉ. सचदेवा ने बताए बचाव के उपाय

अजमेर, 27 अप्रैल। लाइलाज बीमारी थैलेसीमिया से बचने का एकमात्र उपाय शादी से पहले लड़के-लड़की का थैलेसीमिया वाहक का टेस्ट कराना है। यदि इस तरह सभी लोग टेस्ट कराते रहे, तो देश से बीमारी खत्म हो जाएगी। यह बात सर गंगाराम चिकित्सालय दिल्ली मे शिशुरोग विभागाध्यक्ष डॉ. अनुपम सचदेवा ने तोपनोवाल इंडस्ट्रीज के सहयोग से जवाहर लाल नेहरू चिकित्सालय के शिशुरोग विभाग मे निर्मित थैलेसीमिया स्वास्थ्य केन्द्र का उद्घाटन कराने के पश्चात पत्रकारो से बातचीत करते हुए कहा। उन्होने बताया कि सम्पूर्ण भारत मे 35 लाख लोग थैलेसीमिया के केरियर है और 8-10 हजार बच्चों का जन्म इसी विकार के साथ होता है। इससे बचाव के लिए गर्भवती महिलाओ को गर्भावस्था के 10-11 वें सप्ताह मे कोरियोनिक विलाई सैम्पलिंग टेस्ट करवाना चाहिए।

जवाहर लाल नेहरू अस्पताल के शिशु रोग विभाग में थैलेसीमिया हैल्थ सेंटर शुरू हो गया है। यह सेंटर खुलने से अब शहर के थैलेसीमिया पीड़ित बच्चों को महत्वपूर्ण सलाह एवं जांच आदि की त्वरित और विशेषज्ञ सुविधाएं उपलब्ध हो सकेंगी। इससे पहले विभाग में थैलेसीमिया पीड़ितों के लिए केवल ब्लड ट्रांसफ्यूजन की सुविधा ही थी। थैलेसीमिया सेंटर के प्रभारी डॉ. संजीव जैन होंगे। जेएलएन अस्पताल के शिशु रोग विभाग परिसर में स्थित सेंटर हर महीने के दूसरे व चौथे शनिवार को खुलेगा। सेंटर का उद्घाटन दिल्ली के सर गंगाराम अस्पताल के वरिष्ठ हीमोटोलॉजिस्ट डॉ.अनुपम सचदेवा ने किया, वही विशिष्ट अतिथि के रू मे इनर व्हील क्लब की अध्यक्ष मंजू तोषनीवाल व प्रतिभा गहलोत मौजूद थी। इस अवसर पर 35 बच्चों के रक्त की जांच की गई। कार्यक्रम में डॉ. जैसवानी ने थैलेसीमिया की जांचों की दर पचास फीसदी कम करने की घोषणा की। रोटरी क्लब के हरेंद्र कुमार ने थैलेसीमिया पीड़ित बच्चों के लिए विशेष शिविर आयोजित करने की घोषणा की।

Celebration of National Voluntary Blood Donation Day

1st October 2009 is being celebrated as National Voluntary Blood Donation Day to promote the voluntary blood donation program in the country.

Indian Society of Blood Transfusion & Immunohaematology, State Blood Transfusion Council NCT Delhi & Department of Transfusion Medicine Indraprastha Apollo Hospital, New Delhi is going to organize a National seminar on the promotion of safe blood Programe to commemorate this day. The seminar will be conducted at **Gulmohar Hall India Habitat Centre New Delhi on 1st October, 2009 at 10A.M**

All are to requested to attend the function & add grace to the occasion.

THE HEMATOLOGY FOUNDATION, KOLKATA, INDIA

ON SECOND INTERNATIONAL WORKSHOP ON THALASSAEMIA IN EASTERN INDIA, HELD AT RAMKRISHNA MISSION SEVA PRATISTHAN AUDITORIUM, KOLKATA ON 7TH. & 8TH. MARCH 2009.

Sushital Mitra (Secretary)
The Hematology Foundation

It is most heartening to report that the Second International Workshop on Thalassaemia was concluded very successfully at Kolkata with about 300 delegates comprising of Physicians, Patients and their Parents from different parts of West Bengal and other states as well as from neighbouring country like Bangladesh.

It is really extremely satisfying to receive feedbacks from learned Faculties and all others participated as delegates that the Workshop was organized absolutely in a professional manner and it really served the purpose with most contemporary and relevant subjects covered in a most well dedicated platform.

Thanks to Dr. (Mrs.) S. Chandra, Convenor and Chairperson in the Organising Committee, who has left no stone unturned to ensure that the Workshop gives maximum benefit of updating the knowledge in most of the relevant areas, covered by learned faculties in the respective areas from the country and abroad.

INAUGURATION

Inauguration of this important event was addressed by dignitaries like Mr. Chittotosh Mukherjee, Retired Chief Justice, Kolkata High Court as Chief Guest and Mrs. Shobha Tuli, Vice President of Thalassaemia International Federation, Cyprus, as special guest.

Dr. (Mrs.) Chandra described briefly the very purpose of having such Workshop at regular intervals so that the physicians dealing with thalassaemic patients are updated with various developments taking place on regular basis all over the World. Adult patients and their parents are also required to be made aware about various developments taking place in this respect. She most cordially welcomed Chief Guest, Special Guest, All Faculties from the country & abroad and all delegates present in the workshop.

Mrs. Tuli also clarified further in her speech that such workshop must be held at regular intervals and TIF is prepared to support all such activities for the cause of Thalassaemia. She thanked the organiser The Hematology Foundation for taking this important venture and wished all success of their endevour.

Mr. Mukherjee, in his address mentioned that the organisers should also attempt to improve treatment & other facilities for thalassaemic children, in particular from poor communities, along with arranging such workshop with learned faculties for exchange of ideas and updating their knowledge in the respective fields.

A Souvenir published on the occasion was also released.

Mr. Sushital Mitra, Secretary of The Hematology Foundation, who also acted as Organising Secretary of the Workshop, proposed most hearty vote of thanks to all dignitaries on dais for spending their most valuable time for the cause of Thalassaemia, the Thalassaemia International Federation for their active role in making this Workshop possible, Authorities of Ramkrishna Mission Seva Pratisthan for lending their beautiful Auditorium for this important event, the learned Faculties from the Country and abroad and all delegates / children present on the occasion. He also gratefully mentioned about the untiring efforts by members in the organizing committee and various sub-committees in presenting this event in most befitting manner and conveyed sincere thanks to all of them.

TECHNICAL SESSIONS

Technical sessions started with Global Epidemiology Hb Disorders. Deliberations were made by Prof. M. Ghosh (Kolkata) and Prof. S. Fucharoen (Thailand). Transfusional Management of Thalassaemia was covered by Prof. U. Choudhury (Kolkata). All the subjects drew attention of all present with many pertinent questions from the floor.

An Overview of Sickle Cell Disease in Orissa was presented by Dr. R. K. Jena of Orissa and highlights of this presentation got further clarified by the delegates.

The paper on Stem Cell Transplants in Thalassaemia as a matter of permanent cure of this disorder, presented by Dr. Andrew Wu of Singapore, was well received by the audience.

Prof. Ratna Chatterjee from U. K. covered (i) Endocrine & Bone Problems (ii) Growth & Pubertal Problems and (iii) Pregnancy in Thalassaemia with her academic as well as practical knowledge in the respective fields. She also took part in examining a few critical patients and gave her valued opinion.

Prof. S. Fucharoen also covered Cardiac Complications in Thalassaemia. Dr. Andrew Wu from Singapore emphasized the current development on Stem Cell Transplants in Thalassaemia and how important this is for permanent cure of the disease.

Prof. V. P. Choudhury (Delhi) spoke about the Conventional Iron Chelation and Prof. M. B. Agarwal (Mumbai) covered the Indian experience for use of Deferasirox for an effective iron chelation. Both the sessions attracted the audience to get clarified on certain important issues related to iron overload.

A very important subject (as described by many delegates) like Safe Blood was covered by Dr. P. Bhattacharya (Kolkata), Prof. N. Marwah (Chandigarh) and Prof. G. Choudhury (Lucknow). Prof. D. Banerjee and Prof. K. Mukherjee of Kolkata chaired the session and summarized the presentations.

Psychosocial Problems in Thalassaemia presented by Prof. P. Chakraborty (Kolkata) was considered very much appropriate in case of adult thalassaemics and all present agreed that such problems can not be ignored.

Mrs. S. Tuli and Dr. J. S. Arora (Delhi) chaired the session on Ideal Living for Thalassaemia Patient Welfare. Representatives of various Thalassaemia Associations at Kolkata and other parts of West Bengal and Bangladesh also took part on the discussions. Growth & Nutritional Status of E-beta Thalassaemia and Diet in Thalassaemia were covered by Prof. J. Banerjee and Ms. K. Roy respectively, both being from Kolkata.

After hearing the submissions from the representatives of various Thalassaemia Associations, Mrs. Tuli opined that every Association should take more concern to improve the treatment and other matters relating to Thalassaemia. TIF is working hard towards this goal and all are requested to submit their recommendations to TIF to achieve the goal much faster.

A cultural Function was presented by children under The Hematology Foundation and everybody admired the attempt and really enjoyed the function.

NTWS Initiates Three New Thalassemia Centres in Delhi under Delhi Govt.

Chacha Nehru Hospital, Geeta Colony, Maharishi Balmiki Hospital, Poot Khurd & Baba Saheb Ambedkar Hospital, Sector 5, Rohini have also started transfusion services.

A new Thalassemia Unit at Chacha Nehru Hospital, Geeta Colony started functioning from January 2009. Dr. K K Kalra MS of the Hospital took special interest in starting the centre. NTWS also donated a chair cum bed for the unit. CNBC is the first Govt. Hospital accredited by NABH. Principal Secretary Health Mr. J P Singh visited Thalassemia unit during NABH accreditation ceremony of the hospital.

A CME on Thalassemia was organized at Maharishi Balmiki Hospital on 25th March '09. Doctors of all the departments attended the meeting Dr. V P Choudhry delivered a talk on Transfusion Therapy, Dr. Jagdish Chandra highlighted the need of Iron Chelation. Dr. J S Arora emphasized on prevention of Thalassemia. Dr. N V Kamat MS of the Hospital announced to start Transfusion services in their pediatric department, however the patient has to bring blood from Red Cross or Baba Saheb Ambedkar Hospital. Dr. Sushil Shrivastava HoD Pediatric department offered his full support for the care of Thalassemics. Dr. Vandana Goyal Gynecologist said that "We will initiate screening of pregnant women during anti-natal check up."

On 19th May a CME on Thalassemia was organized at Baba Saheb Ambedkar Hospital by dept. of Pediatric Dr. Jagdish Chandra emphasized on important clinical issues in the diagnosis of Thalassemias, Ms Madhu Chandnani of Biorad spoke on role of HPLC in the diagnosis of thalassemia. Dr. Rahul Nathani consultant at dept. of Hematology, Rajiv Gandhi Cancer Hospital, Rohini gave a talk on transfusion therapy for thalassemia major. It was followed by a panel discussion on Chelation therapy in Thalassemia major. The discussion was moderated by Dr. Jagdish Chandra and the panelist were Dr. Sunil Gomber, Dr. Sudha, Dr. J. S. Arora and Dr. Kirti Nanal. FAQs about allogeneic BMT in thalassemia major were answered by Dr. Dinesh Bhurani RGCI.

Dr. R K Gupta HoD Pediatric, BSAH and Dr. Gauri Kapoor HoD Pediatric Hemato-oncology, RGCI introduced the scientific session and Dr. G P Kaushal consultant dept. of Pediatric gave vote of thanks. Dr. Gupta and Dr. Kaushal promised to start transfusion services in their department. Dr. Meenakshi incharge blood bank offered her full support in providing the blood for Thalassemics.

Published by: National Thalassemia Welfare Society (Regd.) On behalf of Federation of Indian Thalassemic.

Picnic Rohtak Lake, 25th December'08