

# FEDERATION of Indian Thalassemics NATIONAL THALASSEMIA BULLETIN

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**EDITORIAL BOARD** 

December, 2013

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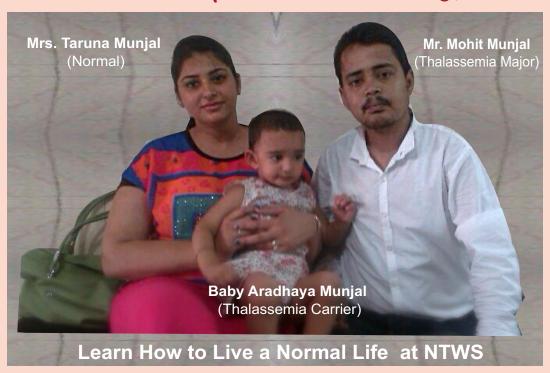


7<sup>th</sup>

# NATIONAL THALASSEMIA CONFERENCE

"Advances In Thalassemia Care"

Saturday, Sunday 19th & 20th April, 2014 organized by National Thalassemia Welfare Society in association with Department of Haematology AIIMS



# at JAWAHAR LAL AUDITORIUM

All India Institute of Medical Sciences Ansari Nagar, New Delhi-110029

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#### FEDERATION OF INDIAN THALASSEMICS

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# **BLOOD DONATION CAMPS**



Dr. V.P. Choudhry Examining a Patient Ms Priya Girdhar on 12th May, 2013



Dr. Jagdish Chandra Examining a Patient on 12th May, 2013



Dr. Anju Seth Examining Patient Ginni on 12th May 2013



Thalassemia Patients at Special Thalassemia Check-up Camp on 12th May 2013



The Term of Organisers of Blood Donation Camp on 16th June 2013



Dr. Rakhi Anand Psychologist at APOLLO Hospital Donating Bloodon 16th June' 2013 at NTWS Office



Mr. Rahul Kathuria Donating Blood on 16th June' 2013



Mr. Gagandeep Singh NTWS Staff Donating Blood on 16th June'13 at Arora Polyclinic

# **EDITORIAL**



Dr. V.P. Choudhry

(M.D. FIAP, FIMSA, FIACM, FISHTM)

Former proferssor & head Hematology AIIMS

Director

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#### **Thalassemia Camps**

Meenu (name changed) now 24 yr old girl, a thalassemia major diagnosed at 1½ year of age was seen with marked thalassemic faces and hepatosplenomegaly. Her parents were worried; she attended thalassemia camp in July 1995 where she was helped to register in a day care centre in Delhi for regular transfusions and therapy. She has been attending thalassemia camp regularly & following therapy as advised. She has no hepatoslenomegaly and started having normal menses at the age of 15 years. In December 2012, she got married. She has expressed her gratitude several times for help and support she got from the NTWS.

National Thalassemia Welfare Society (NTWS) since its inception has been holding camps. From Feb. 1994 to Sept 2002 on 2<sup>nd</sup> Sunday of every month initially at Lajpat Bhawan in Lajpat Nagar and from Oct 2002 to till date at 2<sup>nd</sup> floor Community Center, 12 Block, Tilak Nagar. The main objectives of these camps are:

- A) To ensure proper transfusion to maintain Hb>10gm/dl by education and by helping the children to get registered at various day care centers. NTWS pursued with various institutions & Delhi Government to initiate daycare centers in various hospitals so that every thalassemic child can be registered to receive the optimal management. NTWS has been organizing 60 to 70 blood donations camps in a year in association with Indian Red Cross and various Govt. blood banks to ensure that thalassemic children in Delhi & NCR areas are not denied of transfusions due to its non-availability of blood.
- B) To ensure proper chelation therapy with an attempt to maintain Serum ferritin levels around 1000 to 1200 ng/ml by education, increasing the awareness of complications of iron overload and by providing chelating agents free to very poor and at subsidized rates to the needy. NTWS has been providing even subcutaneous pumps for chelation therapy at no profit no loss basis. The facilities for Ferritin assay were made available at camps at subsidized rates to all and free for poor patients.
- C) Growth and development of these children are being maintained with early detection and treatment of growth failure and other problems.
- **D)** Monitoring for hepatitis markers, HIV, endocrine and cardiac tests were being conducted off and on, in association with various institutions such as AIIMS, Kalawati Saran Children Hospital, G B Pant Hospital, Institute of Liver & Billiary Sciences (ILBS), Apollo and Medanta Hospitals etc.
- E) Facility for thalassemia screening by HbHPLC is also available. In addition dietary advice, social & psychological support are being given to these children & their families. In these camps so far 1998

thalassemic children have been registered and 60-150 children have been attending these camps regularly since its inception.

NTWS in association with Thalassemic Societies of other states such as Bhillai, Bareilly, Burdwan, Faridabad, Gwalior, Kota, Jammu & Kashmir, Rohtak, Varanasi, Meerut, Agra, Dehradun, Gurgaon, Amritsar, Patiala, MP, Jabalpur, Jodhpur and Dibrugarh have been organizing thalassemia camps regularly at their centres. Faculty from NTWS besides local faculty have been taking active part in all these camps. Above activities are coupled with additional activities such as parents education on various aspects of thalassemia (transfusion, chelation therapy, need for regular monitoring, early detection of complications and their management, growth & development issues, bone marrow transplantation etc.) In addition public lectures on thalassemia awareness in schools, colleges, institutions are held by the visiting faculty. Continuing medical education programmes are also organized for doctors on thalassemia in association with Indian Academy of paediatrics, Association of Physician of India (API), Indian Medical Association (IMA) etc. with the objective of sharing the knowledge on thalassemia. Various consultants of NTWS Dr VP Choudhry, Dr. J.S Arora, Dr. Dinesh Bhurani, Dr. Jagdish Chandra, Dr. Amita Mahajan, Dr. AP Dubey, Dr. VK Khanna, etc. have been participating in these camps. These faculty members have been interacting with the staff of Day care centres and doctors providing thalassemia care along with the blood banks so that the optimal care of thalassemic children is made available at these centres. At several places faculty used their contacts & good will to facilitate the local societies to have more day care centres. However the commitment and active work of local thalassemic society played a major role in development of centres and their efforts resulted in improvement in thalassemia care.

These camps have contributed significantly in improving the thalassemia care as now thalassemic children are living in the third decade and few of them got married. Improvement in thalassemia care in our country has resulted better maintenance of hemoglobin level but the serum ferritin in most children are higher than expected because of high cost of chelation therapy. However few states such as Rajasthan, Delhi and J&K are providing free drugs for these patients while some states are providing at subsidized rates. Various complications such as hypothyroidism, growth retardation, cardiac & liver iron overload problems are being recognized early. The effectiveness of these camps will improve further significantly by

- a. Active participations of local faculty along with experts in thalassemia.
- $b. \ Regular \ monitoring \ of \ thal assemic \ children \ on \ designed \ performa.$
- c. Improving the facilities at day care centers.
- d. Easy availability of chelating drugs.
- e. Early detection and management of complications.
- f. Better relations and co-operation of various societies with NTWS/FIT.

It is expected that with the increasing education, contributions of various societies, more number of thalassemic camps and support from the medical professionals and government will result in improved survivals, better quality of life as in the developed countries.

# A Closer look at Beta Thalassemia Intermedia

Ali Taher, MD and Khaled Musallam, MD, Deptt. of Internal Medicine, American University of Beirut Medical Centre, Beirut & the Chronic Care Centre, Hazmieh, Lebanon. Source: TIF Magzine Issue No.- 60, December 2011

Abstract: Our understanding of the processes underlying the disease process in patients with  $\beta$ -thalassaemia intermedia (TI) has substantially increased over the past couple of decades. There are a number of options available for managing patients with TI, with several studies highlighting the benefits and risks of each approach. However, until solid evidence-based guidelines are available, individualised treatment should be maintained.

 $\beta$ -thalassaemia exhibits across a wide spectrum of clinical severity. At one extreme are patients with a clinically silent, mild anaemia, known as  $\beta$ -thalassaemia minor. At the other are patients with  $\beta$ -thalassaemia major, who present severe anaemia from an early age and require regular blood transfusions and iron chelation therapy throughout their lives The term  $\beta$ -thalassaemia intermermedia (TI) refers to those cases that fall between these two extremes, and who usually present the need for medical attention later in life.

The clinical characteristics of TI are very heterogeneous, making the understanding and management of the disease a challenging task. This article aims to assess significant advances made to that end over the past 20 years.

It is now known that in the case of TI, several genetic and environmental factors play a part in determining the severity of anaemia and clinical complications of the disease (phenotype). Examples of genetic factors modulating the severity of TI are:

- \*a broad diversity of mutations affecting the β-globin genes;
- \*co-inheritance of  $\alpha$ -thalassaemia;
- \*several newly discovered genes involved in modifying the  $\gamma$ -chain response (which alters the production of foetal haemoglobin);
- \*and genes directly involved in the expression of clinical complications.

Significant environmental factors may include malaria infection. The mechanism of disease in TI patients is attributed to three main factors: inability of the bone marrow to produce normal red blood cells (ineffective erythropoiesis); chronic anaemia and destruction of red blood cells (haemolysis); and increased absorption of iron from the gut. Recent work has identified several genetic mutations and internal factors that play a part in regulating these processes, which could be future targets for therapy. The combination of these mechanisms leads to several clinical complications in TI, which may not be as frequently observed in patients with  $\beta$ - thalassaemia major and which could cause significant morbidity, therefore warranting immediate attention.

Ineffective erythropoiesis is associated with skeletal deformities and osteoporosis, as well compensatory formation of masses elsewhere in the body (extramedullary haematopoiesis) that can cause mechanical problems.

Haemolysis has mainly been associated with enlargement of the spleen; however, recent evidence suggests that haemolysis, along with other factors, causes a high frequency of thrombosis in patients with TI and may explain other complications such as pulmonary hypertension (increased pressure in lung vessels) with secondary right heart failure. The extra iron absorbed from the gut can accumulate in the liver and (less so) in the heart, as recently observed through the application of MRI technology, and may eventually lead to significant liver disease.

The management of patients with TI remains a challenge. There are currently no solid, evidence-based guidelines for management, and treatment relies mainly on constant, expert observation of each individual patient.

Once a diagnosis of TI is established, the patient should be assessed over a period of several months before beginning any form of treatment. No treatment modality, especially transfusion therapy, should be embarked upon too hastily. Many patients with TI are unnecessarily subjected to a life-time of regular blood transfusions, particularly those that present an unusually low level of haemoglobin during a period of infection. In such situations, it is often appropriate to administer transfusions only in the acute case, and not to immediately commit to a longer-term transfusion programme. Moreover, the need for transfusion is dependent not only on the severity of the anaemia but also on the patient's general well being, particularly with respect to activity, growth, development and the early appearance of skeletal changes or other disease-related complications.

A recent study of 584 patients with TI from the Middle East region and Italy (the Optimal Care study) demonstrated the beneficial role of transfusions in decreasing various complications in TI, such as thrombosis, pulmonary hypertension, heart failure, leg ulcers and extramedullary haematopoiesis (4). The same study also highlighted a higher risk of many disease complications after splenectomy, suggesting that the recommendation of such a procedure in TI requires careful consideration. The study also showed a beneficial role for iron chelation therapy in TI. However, the efficacy and safety of this treatment is currently being evaluated in a large study using the oral iron chelator, deferasirox. Finally, the promising role played by agents that increase the production of foetal haemoglobin (such as hydroxyurea) has been documented in several studies, however further research in this area is essential.

Although TI is considered a milder form of the disease at initial presentation and diagnosis, TI patients are at risk of developing serious complications, especially as they grow older. Further clinical studies are therefore required, to assess the optimal type and timing of treatment to be offered to this group of patients, to avoid disease-related morbidity.

# **TIF-FIT NEWS**

Thalassemia International Federation came up with an objective to unite the voice of Thalassemia patients in India. In result, TIF organised three workshops, covering the States of Maharashtra, Gujarat, Madhya Pradesh, Punjab, Uttar Pradesh, New Delhi & Haryana.

The aims of this programme fall within TIF's commitment and mission to strengthen the voice of patients' associations, through identifying facts, weaknesses, strengths and risks, and building up capacities, highlighting the value of patient/parent engagement to health care, as equal stakeholders.

TIF in collaboration with India's umbrella organization Federation of Indian Thalassemics organised the 1<sup>st</sup> Capacity Building Workshop for patients, parents and patients associations on 18<sup>th</sup> and 19<sup>th</sup> May 2013 at Courtyard Marriott International Airport Hotel, Mumbai. The Worshop was organized for three major states Maharashtra, Gujarat and Madhya Pradesh.

The 1st Capacity Building Workshop had three major clear objectives:

- (i) To educate patients/parents and associations' representatives on the state-of-the-art management and prevention of haemoglobin disorders;
- (ii) To identify and discuss the strengths, weaknesses in the current health care within and between different cities/states;
- (iii) To build up competences and confidence of the participants enabling to take up the 'art' of lobbying and advocacy more effectively.

More importantly, in order to achieve point (iii), it was essential for the workshop to identify and put together the strengths and weaknesses of the different associations within and/or between the different states, so that they may learn from each other, with a view to identifying ways for a close and collective collaborative effort. This workshop was indeed an opportunity for the Thalassemia International Federation to identify specific ways and areas where it can provide support and achieve a measurable impact.

There were 75 participants. The workshop started with lighting of the lamp, and wishes that the proceedings of this workshop become fruitful. Dr Androulla Eleftheriou-TIF Executive Director addressed the audience with a welcoming message on behalf of the President, Mr Englezos, and the Board of TIF.

Thereafter, Mrs Shobha Tuli-President of the Federation of Indian Thalassemics, emphasized on the mission and commitment of both Federations for achieving further improvements and building on existing strengths and weaknesses in India.

Dr Androulla eluted on the objectives of the workshop and highlighted on the existing strengths, weaknesses and policies involved at the national and at each of the individual three states' levels.

Dr Amita Mahajan and Dr Rashid Merchant delivered excellent reviews on the current state-of-the-art management for thalassaemia.

Prof. Roshan Colah delivered an excellent review on the current status of Thalassemia prevention and management in India and Maharashtra State, referring to the studies undertaken by the National Institute of Immunohaematology (ICMR).

The Federation of Indian Thalassemics was represented by Mrs. Shobha Tuli and Dr. J.S. Arora.

The format of this workshop was structured in such a way, so as to provide support, guidance, information and knowledge, while at the same time allowing them to share knowledge and opportunities.

This was the first such event organised by TIF, and all the experience that has been gained or gaps/weaknesses identified in the course of the organisation and/or programme to be rectified in the ensuing workshops, planned for India.

# A Preliminary Meeting of 2<sup>nd</sup> Capacity Building Workshop on 16<sup>th</sup> Monday September, 2013

In continuation to the 1<sup>st</sup> Capacity Building Workshop in Mumbai TIF decided to hold the next workshop in Delhi covering the states of **Delhi**, **Haryana**, **Punjab and Uttar Pradesh**.

In this context TIF came up with a Preliminary Meeting on Monday 16<sup>th</sup> September, 2013 at the Kempinski Ambience Hotel, Yamuna Sports Complex, Delhi-32. Two representative of each state society were present in the meeting. Each society briefed about the Management of Thalassemia in their state and the facilities and privileges provided to Thalassemic patients.

# Follow-up meeting for Maharashtra-Tuesday 17<sup>th</sup> September, 2013

The Follow-up meeting for the 1st Capacity Building Workshop for the attendees from the State of Maharashtra of the Mumbai May 2013 workshop, took place on Tuesday 17 September 2013, at the Emerald Room of the Courtyard Marriott International Airport Hotel in Mumbai. This meeting was organised in order to evaluate the progress that was achieved pertaining to the 1st Capacity Building workshop in May 2013 and to plan more specifically for the future plans and actions in the context of a road map:

(i) Unifying the patients/parents associations' into one robust 'Voice'

- (ii) Assessing the propagation of awareness on haemoglobin disorders, initiation of collaboration between the associations and evaluation of the process of data collection, as agreed in the course of the 1st Capacity Building Workshop in Mumbai, in May 2013, and;
- iii) Identifying the next steps forward.

The meeting was honoured by the presence of His Excellency the Health Minister of the State Maharashtra, Mr. Suresh Shetty. In light of the objectives of this meeting, the following actions were agreed upon:

The creation of a State Steering Coordination Committee for Maharashtra state. The following individuals Mr. Surendra Kumar Sitani, Ms. Sangeeta Wadhwa, Dr. Vinky Rughvani, Mr. Vinay Shetty, Mr. Anil M Shah were assigned as its members and who are covering seven regions of the State - Konkan (Thane); Nashik; Amravati; Aurangabad; Pune, Nagpur and Mumbai.

It was agreed unanimously that the following actions/recommendations/suggestions and/or information on the quality care, awareness and prevention of haemoglobinopathies should be included in the Maharashtra State Charter to be handed to the Minister of Health.

# Follow-up meeting for Gujarat – Wednesday 18<sup>th</sup> September, 2013

The Follow-up meeting for the 1st Capacity Building Workshop for the attendees from the State of Gujarat took place on Wednesday 18 September 2013, at the Courtyard Marriott Ahmedabad, Hotel in Ahmedabad between 10.00 a.m. and 1.30pm. This meeting was organised in order to evaluate the progress that was achieved pertaining to the 1st Capacity Building workshop in May 2013

Mr. Ashish Desai – District Governor of Rotary Club Kankaria-Ahmedabad, congratulated TIF on its initiative to promote the control of haemoglobin disorders, and emphasized the Rotary Club's commitment to join 'forces' with TIF and develop various projects to promote the control of these disorders in India

Mr. Desai requested that TIF prepare a project proposal for the Rotary Club International, which he would undertake to promote at international Rotary Club level, in Evanston Illinois. Dr. Bipin Patel – Ex Rotary Club District Governor and current President of the Indian Paediatrics' Association, reinforced Mr Desai's commitment to assist in as many ways as possible in the development of joint projects with TIF in promoting the control of these diseases in India. In addition, Dr Patel has informed the audience that he would propose to the Paediatrics Association to prepare a module on the control and management of Haemoglobin disorders (Hb) to be included, in the Association's educational programme for paediatricians across India.

# Follow-up meeting for Madhya Pradesh – Thursday 19<sup>th</sup> September, 2013

The Follow-up meeting for the 1st Capacity Building Workshop for the attendees from the State of Madhya Pradesh took place on Thursday 19 September 2013, at the Courtyard Marriott Bhopal, Hotel in Bhopal between 10.00am – 2.30pm. This meeting was organised in order to evaluate the progress that was achieved pertaining to the 1st Capacity Building workshop in May 2013.

Dr. Pramod Chandra - Deputy Director of the Directorate of Health Services for Madhya Pradesh addressed the audience. He wholeheartedly expressed his personal commitment and interest to support, in as many ways as possible for the development and implantation policies pertaining to quality healthcare services provided to patients with haemoglobin disorders in the state of Madhya Pradesh. In this context, he requested TIF to prepare a proposal for a comprehensive control programme for these disorders as well as asked for the copies of the TIF 'Guidelines for the clinical management of thalassemia'. In reply, the TIF Board of Directors and the patients/parents community is indebted to Dr Chandra for his commitment and support.

During the course of the meeting, the different associations from the different cities were asked to present a summary of the activities/achievements of their respective associations, but more importantly to identify weaknesses and/or capitalize on their most urgent needs/demands:

During the meeting TIF has assigned job to all 3 states to compile information on the following:

- (i) Mapping of current State government support policies, acts, services and other documentation with respect to prevention, management and reimbursement schemes for these patients;
- (ii) A comprehensive database of thalassemia and sickle cell disease patients/parents' associations in the state, accompanied by all appropriate supporting documentation including a) Registration certificate; b) Constitution and c) names and capacities of their Board members;
- (iii) A database of NGOs and collaborating organisations such as the Rotary Club and Red Cross, working on the field of Thalassemia and Sickle Cell Disease;
- (iv) A database of medical specialists/academic advisors working in this field
- (v) A directory of Blood Banks, transfusion centres and thalassemia centres, across the State.

The Timeline for the above task was 15th October 2013.

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# **NTWS Activities**

#### International Thalassemia Day on 8th May, 2013

As in the past this time also total health programme of DD News was dedicated for thalassemia. A full one hour live telecast was aired on Sunday, 5<sup>th</sup> May, 2013. with Dr. J S Arora alongwith Dr Jagdish Chandra, Professor at Kalawati Saran Children Hospital and Dr Radhika AG, Professor of Obs & Gynae, GTB Hospital as experts. Anchors Sanjeev Upadhyay and Kiran Bharadwaj quized the panellist to discuss each and every aspect of thalassemia. Frequent questions were asked from viewers of all over India.

On the Occasion of International Thalassemia Day, National Thalassemia Welfare Society organised a Picnic for Thalassemia Patients and Families at Adventure Island Rohini Metro Walk on 8<sup>th</sup> May 2013. The Thalassemic Families had a great fun. They enjoyed the Rides and Rain Dance. Over 400 Thalassemic families enjoyed the day with great zeal and treasure. They were served with scrumptious Lunch.

The Thalassemic patients were blessed by the NTWS President Km. Surrender Saini Ji.

# Special Check Up Camp by a Team of Doctors from Medanta & Kalawati Saran Children Hospital on 12th May, 2013

In continuation to International Thalassemia Day celebrations on 12<sup>th</sup> May 2013 a Special Check up Camp was organised by NTWS at NTWS Thalassemia Centre. Besides Haematology, specialist from Cardiology & Endocrinology also examined the patients. Free ECG was done of all Thalassemics above 12yrs of age. The Team of Doctors from Medanta, LHMC & Kalawati Saran Children Hospital gave free consultation to all the thalassemics. Dr VP Choudhry, Dr Jagdish Chandra, Dr JS Arora, Dr Anju Seth, Dr Niraj Gupta and Dr Nupur examined the patients. During Lunch, Consultants discussed complicated cases.

#### World Blood Donor Day on 14th June, 2013

On the occasion of World Blood Donor Day, DSACS organised a function at Delhi Secretariat. It was inaugurated by Hon'ble Minister of Health, Dr. Ashok Walia. He honoured the centurion donors and blood donor organisations who have organised regular blood donation camps to support the blood banks. NTWS has organised 46 camps and collected 2700 units of blood during this period. On behalf of NTWS, Dr J S Arora, General Secretary of the society, received a memento of appreciation from Hon'ble Health Minister, Govt. of Delhi.

At a separate function organised by Appollo Hospital at India Habitat Centre, 3 young Thalassemic girls Ms Tanu Verma, Ms Shabri Ghosh & Ms Jyoti Gauri sang a song dedicated to Blood Donors and a young energetic Mst Ayush performed dance on Religious song and a Bollywood fusion.

Their performances were highly appreciated by public.

#### CME Obs and Gynae Gurgaon on 18th Sep., 2013

CME for orientation of Obs and Gynae was organised on Wednesday 18<sup>th</sup> September 2013 at Unitech Club, Gurgaon. Lectures were Delivered by Dr VP Choudhry, Dr Rahul Bhargava, Consultant Haematologist Artemis & Dr Aparna Sharma, Prof of Obs & Gynae, AIIMS on Pregnancy in Thalassemia, how to Diagnose Thalassemia Carrier, Antenatal Diagnosis of Thalassemia respectively. The lectures were highly appreciated by all the participants.

Each and every participant was given a Thalassemia Board, Posters & Brochures on Thalassemia as a token of Appreciation. The three respective speakers were felicitated by Gurgaon Obs and Gynae Society.

#### Voluntary Blood Donor Day on 1st October, 2013

Voluntary Blood Donor Day was observed at RML Hospital. Hon'ble Minister of Health, Govt. of India, Sh. Ghulam Nabi Azad was Chief Guest. He honoured the centurion donors with a token of memento. Ms. Olivia Culpo, Miss Universe 2012 was the Guest of Honour.

# Pradanya 2013, 3<sup>rd</sup>-6<sup>th</sup> October, 2013

Dr. J S Arora was invited by The Indian Institute of Health Management Research (IIHMR), Jaipur for International Conference 18<sup>th</sup> Pradanya 2013. The Conference was on three healthcare areas: Opportunities, Challenges and Innovations. Dr Nittita Prasopa, Programme Grant Manager, PFPS Manager, WHO and Dr J S Arora PFPS Champion WHO addressed the health management graduates on issues related to patient for patient safety.

#### ADRITH Health Mela on 4th October, 2013

Ahealth Mela ADRITH was organised by Kamla Nehru College on 4<sup>th</sup> October 2013. Wonderful Dance performances were given by our little Thalassemic Michael Jackson Ayush and another dance performance by 2 beautiful sisters Radhika and Sanvi. A talk on Thalassemia was delivered by Ms Tanu Verma. National Thalassemia Welfare Society participated by putting up stall for Thalassemia Awareness. The college crowd was motivated for the Thalassemia Carrier test before Marriage to save the future ones from the menace of Thalassemia

The Thalassemic performers Radhika & Ayush were given the free passes of Worlds of Wonder Noida as a token of appreciation by the organisers.

# Free Desirox Distribution Camp

National Thalassemia Welfare Society distributed 3500 boxes of Free Desirox 500mg Medicines to 560 NTWS member Thalassemia patients for 2 to 4 months from June 2013 to October 2013. Few societies from various states came to NTWS office to collect Free Desirox for their patients. Amritsar, Jabalpur, Hyderabad, Raipur and Gwalior Societies took the maximum benefit.



# 7<sup>th</sup> National Thalassemia Conference

A great academic feast is awaiting for you. International & National faculty of repute will provide state of art "Advances in Thalassemia Care".

We are delighted to invite you 7<sup>th</sup> National Thalassemia Conference on Saturday, Sunday 19<sup>th</sup> & 20<sup>th</sup> April 2014 at Jawahar Lal Auditorium, All India Institute of Medical Sciences.

Repeated blood transfusions and iron chelation are the basic principles of Thalassemia management. Easy availability of multiple iron chelating options has revolutionized the treatment of iron overload in multiple transfused Thalassemics. These basic principles have been further refined since the last conference in 2010 which have resulted in better quality and longevity of life. Special consideration will be given to concerns related to Thalassemia major in adolescence and adults.

Non Transfusion Dependent Thalassemia (Thalassemia Intermedia), management issues are altogether different than Thalassemia Major. In the present conference the scientific committee intends to cover their issues at greater depth.

Renowned International and National faculty will enlighten the participants. Experts will deliver the state of art care which will go a long way in improving thalassemia care in our country.

Your interest and concern will be our top priority in preparing the scientific programme. Please do specify "Your Interest and Concern" while registering for the conference. Early registration will help you in saving the money and help us to in making necessary arrangements to make your participation most comfortable.

Doctors who are interested in the management of Thalassemia will have golden opportunity to understand the practical management of thalassemia and to interact with the National & International faculty.

The Conference will be followed by a workshop on thalassemia on Monday 21<sup>st</sup> April 2014 at UCMS & GTB Hospital Shahdara. Since the registration of the workshop will be very limited, interested doctors are requested to register through a separate registration form at the earliest. The practical aspects on the management issues will be covered in greater depth. The participants in the workshop will have ample opportunity to interact with faculty.

Reputed Medical Professionals from India and some of the International Faculty are invited for the Conference to update the patients and parents on the correct management of the disease, which will further help them to increase the longevity of life.

Renowned **International Medical Professionals** invited for the conference are:

Professor MD Cappellini Department of Clinical Services and Community, University of Milan IRCCS Ca' Granda Foundation Maggiore Policlinico Hospital, Milan, Italy

Professor Ali Taher
Department of Internal Medicine,
Haematology and Oncology Division
American University of Beirut Medical Centre,
Beirut, Lebanon & Chronic Care Centre, Hazmieh,
Lebanon

Associate Professor VIP Viprakasit Division of Haematology and Oncology, Department of Paediatrics and Thalassemia Centre, Faculty of Medicine Siriraj Hospital Mahidol University, Bangkok, Thailand

Dr Suthat Fucharoen MD
Former Professor of Medicine
Thalassemia Research Centre,
Institute of Sciences and Technology
for Research and Development,
Mahidol University, Thailand.

### Reputed Medical Professionals from India are:-

Dr Ajay Sharma (Brig.)

Dr Amita Mahajan

Dr Anita Saxena

Dr A. P. Dubey

Dr Bharat Singh

Dr I. C. Verma

Dr Jagdish Chandra

Dr Mammen Chandy

Dr M. B. Agarwal

Dr M. R. Lokeshwar

Dr Neelam Mohan

Dr Nikhil Tandon

Dr Nita Munshi Dr Praveen Sobti

Dr Rajiv Kr. Bansal

Dr Renu Saxena

Dr Roshan Colah

Dr Sharmila Chandra

Dr S K Sarin

Dr Sunil Gomber

Dr V. K. Khanna

Dr V. P. Choudhry

# **General Information**

# **REGISTRATION FORM**

Registration: Registration is Open to all

**Registration Fees:** 

Early Bird Upto 15th December 2013

Patient Rs. 100.00
Parent/Doctor/Others Rs. 300.00

Regular Upto 15th February 2014

Patient Rs. 200.00
Parent/Doctor/Others Rs. 450.00

Late Comer Upto 31st March 2014

Patient Rs. 300.00
Parent/Doctor/Others Rs. 600.00

After 31st March & Spot Registration

Patient Rs 450.00
Parent/Doctor/Others Rs 800.00

The Registration fee includes: Attendance to all sessions, literature, conference kit, lunch and tea/coffee for both the days.

### **Accommodation:**

Limited accommodation will be made available on prior intimation and full advance payment before 31<sup>st</sup> Dec.,2013.

### **Accommodation Charges:**

Class A **Rs. 10,000**/-approx.per day Class B **Rs. 5000**/-approx.per day Class C **Rs. 2500**/-approx.per day

### **Mode of Payment:**

Please send registration fee by Demand Draft/Cheque or Cash against receipt to the Conference Secretariat.

Drafts/Cheques should be drawn in favour of "7<sup>th</sup> **National Thalassemia Conference**" payable at Delhi/New Delhi. Please add Rs.50/- for outstation cheques.

#### **NOTE:**

Children below 16 are not allowed. Additional members will not be provided Conference Kit.

### **Conference Secretariat:**

Dr. J.S. Arora (Organising Secretary)

KG-1/97, Vikas Puri, Delhi110018. Tel: 9311166710,11.12, 011- 25511795,796

E-mail: ntws08@gmail.com; drjsarora@gmail.com

URL: www.thalassemiaindia.org.

Name:	Age/Sex		
Name of Additional Mem	ber (if applying):		
Title-Doctor/Parent/Patien	nt/Other:		
Address:			
	Pin Code		
Phone No 1)	No 2)		
E-mail:			
Accommodation Required	d: Yes/No No. of Persons:		
Category:	A B C		
Arrival Date & Time:			
Departure Date & Time:			
Registration fee	Registration fee Accommodation charge		
Total RsRup	pees (in words)		
Please find enclosed			
D.D./Cheque No:	Ontad		
	Dated		
drawn on:			
for Rs:Rupee	es		
Dlagge gnesify "Wour Int	anat & Canaann'		
Please specify "Your Int	erest & Concern		
Date	Signature		

#### NOTE:

- 1. Registration form can be photostated.
- 2. No cancellation is allowed once the registration fee/accommodation charges are paid.
- 3. No refund /adjustment will be entertained

Note: At repeated demand of patients and parents, Early Bird has been extended to 15th Jan. 2014 for members of NTWS.

# **Blood Donation Camps organised by NTWS**

NTWS organized 81 blood donation camps in association with Govt. blood banks from June 2012 to November 2013 and collected 4462 units of blood to strengthen supply of blood.

List of Some of the camps are given below.

S.No	Date	Companies Name/Place	Blood Banks	No. Units Collected
1.	30-6-12	Mosaic, Noida	LNJP	19
2.	5-07-12	Smart Cube, Noida	DDU	100
3.	6-07-12	Vertex, Noida	LNJP	105
4.	22-7-12	Glittz Rajouri Garden	RML	81
5.	27-7-12	Agilent Technology, Manesar	DDU	103
6.	30-7-12	Agilent Technology, Manesar	RML	57
7.	8-08-12	Zee Network, Noida	LNJP	51
8.	9-08-12	Zee Network, Noida	LNJP	26
9.	11-8-12	Pacific Mall Subhash Nagar	DDU	18
10.	12-8-12	Sacred Heart Church, CP	RML	31
11.	23-8-12	Steria, Noida	RML	151
12.	25-8-12	St. Francis School, Janak Puri	DDU	42
13.	3-10-12	SK E&C, Gurgaon	DDU	121
14.	5-10-12	DLF Pramerica, Gurgaon	AIIMS	84
15.	10-10-12	Elillilly Gurgaon	LNJP	31
16.	11-10-12	Petron Engg. Pvt. Ltd., Gurgaon	AIIMS	95
17.	9-11-12	ALS Institute, Mukherjee Nagar	DDU	110
18.	28-11-12	Gurudwara, Vikaspuri	DDU	10
19.	4-12-12	NTT Date, Noida	LNJP	24
20.	6-12-12	NTT Data, Gurgaon	LNJP	45
21.	19-12-12	ALS Institute, Mukherjee Nagar	DDU	78
22.	30-12-12	Glittz, Rajouri Garden	AIIMS	31
23.	17-2-2013	Burari Camp	LHMC	56
24.	18-2-2013	Smart Cube	LNJP	17
25.	18-2-2013	Smart Cube	AIIMS	13
26.	28-2-2013	SRF Limited	LNJP	24
27.	4-3-2013	SRF Bhiwadi	DDU	76
28.	14-3-2013	Aricent Group	LNJP	25
29.	14-3-2013	Info Tech Centre	RML	75
30.	15-3-2013	Aricent Group Presidency Building	LNJP	62
31.	15-3-2013	Aricent Group Phase 4 Gurgaon	DDU	74
32.	17-3-2013	School of Inspired Leadership	LNJP	34
33.	25-4-2013	Flour Daniel	AIIMS	256
34.	9-5-2013	Vatika India Next	DDU	31
35.	10-5-2013	Vatika Triangle	RML	48
36.	17-5-2013	Ciena	AIIMS	84
37.	24-5-2013	Teleperformance	RML	45
38.	24-5-2013	Teleperformance	DDU	58

39.	27-5-2013	Alcatel Gurgaon DLF Cyber Green	DDU	25
40.	27-5-2013	Alcatel Gurgaon DIF Cyber Green	LNJP	35
41.	28-5-2013	Alcatel Gurgaon Fortune Tower	RML	33
42.	7-6-2013	Vatika Business Park Gurgaon	DDU	50
43.	12-6-2013	Gurudwara Vikas Puri	LHMC + RML	20 + 20
44.	15-6-2013	Vatika City Sohna Road	DDU	28
45.	16-6-2013	Arora Polyclinic Vikas Puri	DDU	65
46.	29-6-2013	MC Donalds	DDU	26
47.	5-7-2013	Vertex Noida	LNJP	120
48.	21-7-2013	Village Bamnoli Dwarka	RML	30
49.	22-7-2013	Ammu Care Trust	DDU	20
50.	23-7-2013	Dwarka ACP Office	DDU	29
51.	28-7-2013	Glitz Rojouri Garden	DDU	18
52.	31-7-2013	DCP West Rajouri Garden	DDU	30
53.	2-8-2013	Angelique International Limited	RMT	77
54.	7-8-2013	Vatika Tower	DDU	56
55.	8-8-2013	DCP Haus Khas	DDU	70
56.	9-9-2013	Mc Donalds Rajouri Garden	DDU	18
57.	10-8-2013	Mc Donalds Rajouri Garden	DDU	10
58.	11-8-2013	Mc Donalds Rajouri Garden	DDU	14
59.	16-8-2013	MDI Gurgaon	LNJP	16
60.	28-8-2013	Mc Donalds Vikas Puri	DDU	11
61.	29-8-2013	Mc Donalds	DDU	20
62.	27-09-2013	SKE & C, Gurgaon	RML	137
63.	12-09-2013	SOIL, Gurgaon	RML	37
64.	27-09-2013	SKE & C, Gurgaon	RML	137
65.	01-10-2013	Fluor, Gurgaon	RML	148
66.	01-10-2013	Flour, Gurgaon	LNJP	119
67.	03-10-2013	DCP Office, Central District, Daryaganj	RML	16
68.	05-10-2013	D.A.V. School, Vasant Vihar	LNJP	25
69.	09-10-2013	Lilly, Gurgaon	LNJP	42
70.	15-10-2013	DLF Pramerica, Gurgaon	RML	92
71.	18-10-2013	Bain & Company, Gurgaon	Lady Harding	34
72.	18-10-2013	Bain & Comapany, Gurgaon	LNJP	34
73.	20-10-2013	Nirvana Country, Gurgaon	RML	34
74.	23-10-2013	Red Fox Hotel, Mayur Vihar	RML	34
75.	25-10-2013	Lemon Tree Hotels, Aerocity	RML	58
76.	27-10-2013	Fitness Prime, Khirki Extension	LNJP	34
77.	28-10-2013	JIMS, Rohini	LNJP	46
78.	02-11-2013	Sai Mandir, Najafgarh	LNJP	28
79.	12-11-2013	John Keells BPO, Gurgaon	RML	56
80.	13-11-2013	John Keells BPO, Gurgaon	DDU	47
81.	20-11-203	Sai Mandir, Najafgarh	RML	72

# **News from Other Societies**

Thalassemia Children Society, Jaipur

# थैलेसीमिया रोग की रोकथाम संबंधी पोस्टर का विमोचन

जयपुर | थैलेसीमिया चिल्ड्रन सोसायटी से जुड़े बच्चे और अभिभावकों का प्रतिनिधिमंडल सोमवार को मुख्यमंत्री अशोक गहलोत से मिला। इस मौके



पर मुख्यमंत्री ने थैलेसीमिया रोग के प्रति जागरूकता के लिए जारी पोस्टर-होर्डिंग का विमोचन भी किया। प्रतिनिधिमंडल ने थैलेसीमिया रोगियों को सरकारी स्तर पर विशेष सहायता व व्यस्क थैलेसीमिया रोगी के लिए नौकरी का प्रावधान किए जाने

की मांग की। सोसायटी के अध्यक्ष नरेश भाटिया ने बताया कि पोस्टर में थैलेसीमिया रोग की गंभीरता और इसकी रोकथाम के लिए प्रत्येक नागरिक से थैलेसीमिया माइनर के लिए रक्त जांच करवाने की अपील की गई है।

# Thalassemia Awareness/ Check-up Camp at Ulhasnagar, Maharashtra

Thalassemia Awareness/ Check-up Camp at Ulhasnagar at Rotary Fete from 21.12.2012 to 01.01.2013 was a great success as more than 75000 persons visited our Thalasemia stall in the fete.

We checked 451 youngsters at this Camp, results are awaited. We have called all the youngsters to collect the reports personally as they may be counselled further with reports for Thalassaemia. This camp was attended by Thalassemia Major children who actively participated in the awareness drive, their presence proved to be fruitful in convincing the youngsters to come for Thalassemia test.

#### Thalassemia Camp Meerut

Krishna Mahajan Memorial & Thalassemia Welfare Trust organised Annual Thalassemia Welfare, Awareness and Blood Donation Camp at Lokpriya Hospital on 21<sup>st</sup> April 2013.

Dr V P Choudhry and Dr J S Arora were invited from Delhi to examine the patients. The event was inaugurated by Mr Hari Kant Ahluwalia (Mayor Meerut), Dr Atul Krishan (Founder and Director General Subharti Group), Dr V P Choudhry (Former Professor and Head Deptt of Haematology AIIMS) Dr J S Arora (General Secretary National Thalassemia Welfare Society) & Dr Rohit Arora (Director Lokpriya Hospital) shared the dias and addressed the public.

# Thalassemia Camp Jabalpur

A thalassemia camp was organised by Disha Welfare Association Samiti, Jabalpur, Indian Medical Association and Mahatma Gandhi Homeopathic Medical College in association with Muthoot Finance Ltd. on 1<sup>st</sup> September, 2013. 53 patients came for the check up. Dr J S Arora was invited from Delhi to examine the patients and gave advice for optimum treatment. Dr J S Arora also gave a lecture on thalassemia at this camp. Few patients were given free Desirox. In the evening, a meeting was held with IMA branch, Jabalpur where Dr. J S Arora gave a lecture on overview of thalassemia. Mr. Girish Ahuja and Mr. Sarabjeet Singh Narang from Disha Welfare Association, put their all out efforts for the success of this camp.

### News from Jammu & Kashmir

On 8th May, 2013, on International Thalassemia Day, a camp was organised by Dr. Mohammad Yaseen from Al-Amin Blood Bank, Jammu & Kashmir in association with Noora Hospital for spreading awareness in Thalassemia in both public and Govt. sectors. Dr J S Arora and Dr VP Choudhary was invited from Delhi. Minister of Medical Education (J & K) was Chief Guest in this camp. While addressing the audience, Minister of Medical Education informed that Rs. 5 Crore has been year marked for the thalassemia, haemophilia and other blood disorders for the State. Mr. Manzoor, Managing Director Noora Hospital announced that Noora Hospital will provide subsidized treatment for the thalassemic patients. On a way back, a meeting was held with Ms. Anna Syed Farkhanda of Mahindra Motors. She promised to organise a Blood Donation camp at Mahindra Showroom and support the treatment of thalassemic patients.

# Thalassemia Day celebration in IMA Bareilly on 5th May 2013

Thalassemia day was celebrated by IMA Bareilly on 5<sup>th</sup> May 2013. The day began with a rally. "Walk for Thalassemia" which covered a distance of 4 km was flagged off by Professor Dr. V.P. Chaudhary Director Center for Blood Disorder, Ex-Professor & Head Deptt. of Hematology AIIMS who had came especially to Bareilly to create awareness for thalassemia. Many thalassemic children and their parents also participated in it. This was followed by a medical check up camp of 74 thalassemic patients. Professor Dr. V.P. Chaudhary and Dr. Rahul Bhargava from Medanta Hospital examined the children and counselled the patients. It was followed by interactive session with thalassemics children & parents. A CME was organised in the evening. Lectures were delivered by Dr. Edna Dsouza, Dr. Nitin Dayal, Dr. Rahul Bhargava and Dr. V.P. Chaudhary from Delhi. IMA President Bareilly declared that IMA Bareilly will do its best for providing state of art care for thalassemics & soon will initiate thalassemia screening programme.

### **CONGRATULATIONS**

# Happily Married Thalassemic Major together

Jatin Sejpal 34 yrs Thalassemic got married to a Thalassemic girl Megha Naikode 25 yrs on 14<sup>th</sup> July 2013. Jatin and Megha together set one such example and inspiration for all those thalassemics who are dreaming of their happy future. Jatin and Megha both have a very positive approach towards their life and said they have similar issues and problems in life and will always help each other to cope with it.



# NATIONAL THALASSEMIA WELFARE SOCIETY (Regd.)

# KG-1/97, Vikas Puri, New Delhi-110018

E-mail: ntws08@gmail.com

### **MEMBERSHIP**

Any person can become Member of the Society by filling up the requisite form and sending a DD in favour of: **National Thalassemia Welfare Society.** 

Life Member Indian Resident	Rs.	500
Life Member NRI/Foreigner	USD	100
<b>Donor Member</b>	Rs.	5000
Patron	Rs. 50	,000

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# Special Subsidised Rates only for Thalassemics Registered with NTWS

Medicines	Rate
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Desirox 500mg (30 Tab.)	850
Desferal 500mg (10 Inj.)	1450
Deferijet 500mg (30 Tab.)	750
Kelfer 500mg (50 Caps.)	350
Single Filter BIO-R	550
Double Filter BIO-R	650
Single Filter Pall	600
Double Filter Pall	700

Rates are subject to change any time without Notice

# **NTWS** Thalassemia Centre

Thalassemia Clinic, 2<sup>nd</sup> Sunday every month <u>Reporting time: 9am to 12 noon</u>

### **Address**

NTWS Thalassemia Centre, 2<sup>nd</sup> Floor, Community Centre Slum & JJ Dept. Of MCD, Voter ID & Ration Card office Near Gurudwara Singh Sabha, Block – 12, Tilak Nagar, New Delhi-110018

Ph.: 9311166710-711-712

# **Facilities**

- \* Growth Monitoring
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# VICE PRESIDENT

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Phone: 011-255797370, 25797371

### **MEDICAL ADVISOR**

Dr. V.P. Choudhry (Delhi) Phone: 9811073904

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M. S. Rekhi (Chnadigarh) Phone: 0172-2570934

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Dr. George J. Kontoghiorghes

Prof. of Heam. Cyprus

**Prof. Bemadette Modell** 

Prof. of Community Fenerics, London

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Director-Thalassemia Programme, Toronto

Dr. Susan P. Perrine

Cancer Research Centre, Boston U.S.A.

**Dr. Vincenzo De Sanctis** 

Day Hospital of Encocrinology, Italy

Dr. Cogero Vullo

Div. of Pead. Centro della Micocitemia, Italy

Dr. Beatrix Wonke

Haematologist, Formerly at Whittington Hospital, London

# **MEMBER SOCIETIES:**

Thalassemia & Sickle Cell Society of Ahmedabad Aimer Region Thalassemia Welfare Society, Aimer

Thalassemia Society of India, Allahabad

Amritsar Thalassemia Welfaree Society, Amritsar

Thalassemia Welfare Society, Bhillai

M. P. Thalassemia Kid Care Society, Bhopal

Thalassemia Child Health Care Society, Burdwan

Thalassemia Welfare Society, Burdwan

Thalassemia Children Welfare Society, Bareilly

Thalassemia Children Welfare Association, Chandigarh

National Thalassemia Welfare Society, Delhi

Thalassemia India, Delhi

Pahuja Trust Centre for Blood Disorder, Faridabad

Thalassemia Society, Gwalior

Thalassemia Welfare Society of Hisar

Thalassemia & Sickle Cell Society of Hyderabad

M. P. Thalassemia Welfare Society, Indore

J & K Thalassemia Welfare Society, Jammu & Kashmir

Thalassemia Society of Jaipur & SDMH, Jaipur

Marwar Thalassemia Society, Jodhpur

Thalassemia Society of India, Kolkata

The Haematology Foundation, Kolkata

West Bengal Voluntary Blood Donors Forum, Kolkata

The Thalassemia Society of Kota

Thalassemia Society of U.P., Lucknow

Punjab Thalassemia Welfare Society, Ludhiana

Patient's Assoc. Thalassemic Unit Trust, Mumbai

We care Trust, Mumbai

Citizen NGO, Mumbai

Thalassemia & Sickle Cell Anaemia Welfare Society, Orissa

Patiala Thalassemic Children Welfare Society, Patiala

Thalassemia Society of Pune, Pune

Thalassemic Children Welfare Society, Ulhasnagar

Haryana Thalassemic Welfare Society, Rohtak

Thalassemia Haemophilia Sickle Cell Anaemia

Prevention, Counselling & BT Centre, Surat

Varanasi Region Thalassemia Welfare Society, Varanasi

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# BLOOD DONATION CAMPS



Dr. J.S. Arora & Mr Gautam Seth Police Inspector Rakesh Kumar During Blood Donation Camp at Arora Polyclinic



Blood Donation Camp at Ciena, Gurgaon on 17th May, 2013



Organisers of Blood Donation Camp at Begumpur Thana Rohini on 20th July' 2013



Red Fox Corporate, NTWS & RML Blood Bank Team



Dr. JS Arora addressing at Thalassemia Camp at Jabalpur on 1st September, 2013



Dr. J.S. Arora Examining a Patient at Jabalpur



Dr. J.S. Arora, Dr. Nittita Prasopa & Dr. Sanjay in International Conference 18th Pradanya 2013 Organised by IIHMR, Jaipur.



Dr. V.P. Choudhary Participating in Rally Organised by IMA Bareillyon Thalassemia Day Celebration



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