



# FEDERATION OF INDIAN THALASSEMICS NATIONAL THALASSEMIABULLETIN

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Souvenir of Thalassaemia Symposium - III.

Thalassaemic Children Inaugurating  
the Symposium



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# Speakers of Thalassemia Symposium - III





## Editorial

Defrasirox was launched in April 2008 preceded by a video conference amongst experts from all over India, followed by a Seminar held by P.H.O. chapter of Indian Academy of Pediatrics. Most of the doctors involved at major centers providing Thalassemia care participated in these meetings. We thought it necessary to trickle this knowledge amongst doctors, working in the periphery, small towns, patients and parents. This prompted us to organize 3<sup>rd</sup> Thalassemia Symposium on 31<sup>st</sup> August 2008. Details of which are mentioned inside.

*Thalassemia patients have been longing for inclusion of Thalassemia in the list of disability for the purpose of the PWD Act. One more step in this direction has taken place i.e. the estimate committee of Lok Sabha of which Km Surrender Saini, President of NTWS, is also a member, emphasized the need to include people with Thalassemia to be recognized among Persons With Disability Act with 1995.*

*An Italian Study has revealed that 65% of Thalassemic Major Patients were alive at 35 years of age. Lower Ferritin was associated with low probability of experiencing heart failure and with prolonged survival. It has been demonstrated by Italian & Cypriot Studies that Deferiprone alone or in combination with deferoxamine improves cardiac disease free survival.*

*A newspaper headlines "30,000 units of blood gone down the drain". The report proceeded to calculate the cost of wasted blood as Rs. 1.32 Crores that would have saved at least 28,499 lives. If one read total report it will reveal that above wastage was in 4 years from 2002 - 06, that included blood tested positive for Hepatitis B, VDR L and HIV, which is less than 2% of the total collection, This is acceptable as per as standard norms. The purpose of highlighting this report is the people should not be carried away by sensational headlines and start accusing one or the other. Volunteer blood donors and Philanthropists are requested not to form opinion just by reading headlines but read full report and then interpret and to continue support the noble cause of Volunteer Blood Donation.*

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## The First Study Comparing Cardiac Iron Load And Cardiac Function In Patients Treated With Deferiprone, Deferasirox And Deferoxamine

Comparison of deferasirox, deferiprone, and deferoxamine effectiveness on myocardial iron concentrations and biventricular function by quantitative MR in beta-thalassaemia major by Pepe *et al.* as presented at the 13<sup>th</sup> Congress of the European Hematology Association, June 2008<sup>1</sup>

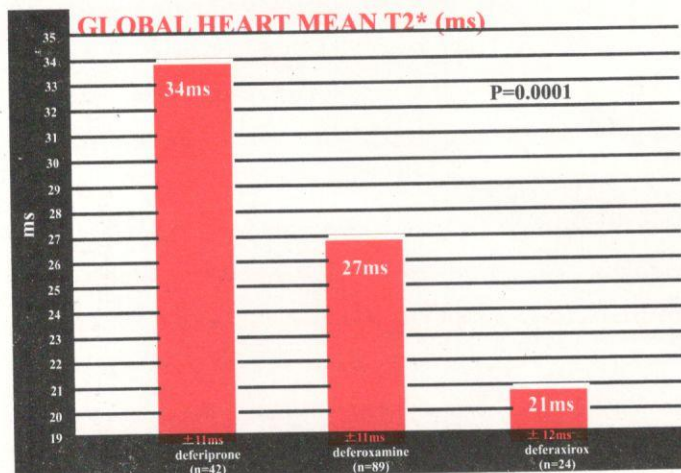
### Background and Methods

• This cohort study compared myocardial iron concentration, myocardial function and liver iron concentration in thalassaemia major patients treated with deferiprone, deferasirox or deferoxamine for one year or longer.

• MIOT (Myocardial Iron Overload in Thalassaemia) is a network of 6 magnetic resonance centers in Italy where cardiac and liver iron status are assessed by a standard procedure.

• Patients in the three treatment groups were matched for gender, pre-transfusion haemoglobin levels, age at starting chelation therapy, and compliance with treatment.

• Myocardial iron concentration and distribution were measured by an MRI T2\* multislice multiecho technique. Biventricular function parameters were quantitatively evaluated by cine-dynamic MRI imaging. Liver iron concentration was measured by MRI T2\* multiecho technique.

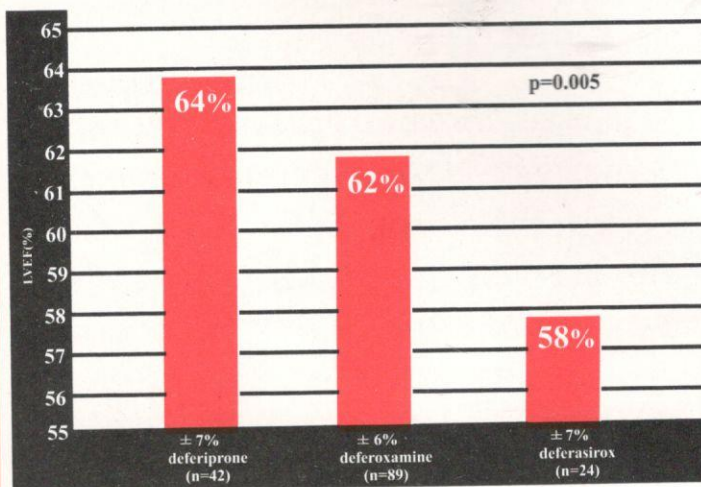


### Results

• The lowest myocardial iron load and highest left ventricular ejection fraction (LVEF) were found in the patients treated with deferiprone.

• The global cardiac T2\* value was significantly higher in the deferiprone group ( $34 \pm 11$  ms) -versus: deferoxamine ( $27 \pm 11$  ms) ( $p=0.002$ ) and deferasirox ( $21 \pm 12$  ms) ( $p=0.0001$ )

### CARDIAC FUNCTION AS MEASURED BY LEFT VENTRICULAR EJECTION FRACTION (LVEF)



• LVEF was highest in the deferiprone group ( $64 \pm 7\%$ ) -versus: deferoxamine ( $62 \pm 6\%$ ) and deferasirox ( $58 \pm 7\%$ ) ( $p=0.005$ )

• The deferasirox-treated group was significantly younger ( $26 \pm 7$  years) than the groups treated with deferiprone ( $32 \pm 9$  years) or deferoxamine ( $33 \pm 8$  years) ( $p=0.0001$ ) and had significantly higher mean serum ferritin levels ( $2516 \pm 2106$  ng/ml) than the groups treated with deferiprone ( $1493 \pm 1651$  ng/ml) or deferoxamine ( $987 \pm 915$  ng/ml).

### Conclusion

IN THIS LANDMARK COMPARATIVE STUDY THE AUTHORS CONCLUDED, BASED ON THE MRI RESULTS THAT FERRIPROX (DEFERIPRONE) SEEMS TO BE MORE EFFECTIVE THAN ORAL DEFERASIROX OR SUBCUTANEOUS DEFEROXAMINE IN REMOVAL OF MYOCARDIAL IRON, WITH CONCORDANT POSITIVE EFFECT ON LEFT GLOBAL SYSTOLIC FUNCTION.

Source:- Ferriprox literature

# MANAGEMENT OF THE “Difficult” IRON OVERLOADED PATIENT

Source- Symposium 7, 11<sup>th</sup> International Conference on Thalassemia & Haemoglobinopathies, TIF Conference, October 2008, Singapore

	Condition	Treatment
<b>A</b>	Increasing of ferritin levels >2500 ng/ml or Liver Iron Concentration > 7mg/gr/dry weight	Changing chelation treatment (increase of deferoxamine dosage, deferiprone, associated or combined deferiprone-deferoxamine, Sequential or alternating deferiprone-deferoxamine, deferasirox)
<b>B</b>	Decreasing of left ventricular ejection fraction < 50%, right ventricular dysfunction	Associated or combined deferiprone-deferoxamine or continuous s.c. or i.v. deferoxamine treatment show clear cut documentation.
<b>C</b>	Global or septum left ventricle heart T2* signal <20ms	Addition of deferiprone with or without deferoxamine according to the findings of heart failure is the main alternative
<b>D</b>	Glucose metabolism disturbances (GMD)	Associated or combined deferiprone-deferoxamine is the only documented choice

If deferoxamine intolerance is present, the two options are possible : deferiprone or, if the patient has more than 7mg/gr/dw of Liver Iron Concentration, deferasirox.

Monitoring of specific side effects during all these chelation treatment is mandatory.

## डैफरीप्रोन, डैफरासिरोक्स और डैफरोक्सामाईन (कैल्फर, असुनरा/डैसिरोक्स, डैस्फैराल) का थैलासिमिया रोगियों पर पहला तुलनात्मक परीक्षण।

जून 2008 में तेरहवें यूरोपिए रूथिर विज्ञान संस्थागत सम्मेलन में पेपे और उसके साथियों द्वारा डैफरीप्रोन, डैफरासिरोक्स और डैफरोक्सामाईन चिकित्सा द्वारा हृदयगत लोहे और वैन्ट्रीकल कार्य क्षमता का बीटा थैलासीमिया मेजर में तुलनात्मक प्रभाव पर अध्ययन प्रस्तुत किया।

### प्रक्षेप और प्रक्रिया

1. इस अध्ययन में थैलासिमिया मेजर रोगियों पर हृदयगत लोहे की मात्रा, हृदय की कार्य क्षमता एवम जिगर में लोहे की मात्रा का डैफरीप्रोन, डैफरासिरोक्स और डैफरोक्सामाईन के तुलनात्मक प्रभाव को एक वर्ष या अधिक कार्य काल के लिए देखा गया।
2. एम.आर.आई.टी2\* का, इटली में चुम्बकीय परीक्षण केंद्रों का नेटवर्क है। जहाँ पर हृदय व जिगर में लोहे की मात्रा को जाँचने की प्रमाणित प्रक्रिया है।
3. रोगियों को 3 चिकित्सीय विभागों में लिंग, रक्त संचारण पूर्व हीमोग्लोबिन, लोह निष्कासन चिकित्सा के समय आयु तथा चिकित्सा में नियमितता में समानता रखी गई।
4. हृदय में लोहे की मात्रा, जिगर में लोहे की मात्रा तथा हृदय के वैन्ट्रीकल की कार्य क्षमता को एम.आर.आई.टी2\* द्वारा मापा गया।

### परिणाम

1. जिन रोगियों में डैफरीप्रोन से चिकित्सा की गई उनमें हृदयगत लोहे की मात्रा सबसे कम और हृदय की कार्य क्षमता सबसे अधिक पाई गई।
2. वैष्वीय हृदयिक टी2\* की मात्रा डैफरीप्रोन वर्ग में  $34 \pm 11$  ms, जब की डैफरोक्सामाईन में  $27 \pm 11$  ms और डैफरासिरोक्स में  $21 \pm 12$  ms पाई गई।
3. एल.वी.ई.एफ ( हृदयगत कार्य क्षमता) डैफरीप्रोन वर्ग में सबसे अधिक  $64 \pm 7$ , डैफरोक्सामाईन में  $62 \pm 6$  तथा डैफरासिरोक्स  $58 \pm 7$  पाई गई।

डैफरासिरोक्स वर्ग में रोगी सबसे कम उम्र  $26 \pm 7$ , जब की डैफरीप्रोन वर्ग में  $32 \pm 9$  तथा डैफरोक्सामाईन वर्ग में  $33 \pm 8$  थे। इसके अतिरिक्त डैफरासिरोक्स वर्ग में सीरम फेराटिन सबसे अधिक  $2516 \pm 2106$  ng/ml जब की डैफरीप्रोन वर्ग में  $1493 \pm 1651$  ng/ml तथा डैफरोक्सामाईन वर्ग में  $987 \pm 915$  ng/ml पाया गया।

### निर्णय

इस अहम तुलनात्मक अध्ययन में परीक्षकों ने एम.आर.आई के परिणाम के आधार पर पाया कि डैफरीप्रोन, हृदयगत लोहे को निकालने के अतिरिक्त हृदय की कार्य क्षमता को बढ़ाने में डैफरासिरोक्स अथवा डैफरोक्सामाईन की तुलना में अधिक प्रभावशाली है।

## Thalassemia Symposium - III, 2008

**National Thalassemia Welfare Society** in association Dept. of Pediatrics Kalawati Saran Children Hospital & Dept. of Haematology, AIIMS organized "*Thalassemia Symposium-III 2008*" at Swaran Jayanti Auditorium at Lady Harding Medical College on 31<sup>st</sup> August, 2008.

### Over 500 Thalassemics patients/parents and doctors participated the symposium.

Session on transfusion therapy for doctors was held in a separate hall. **Dr. Anupam Sachdeva** explained minute details of transfusion requirements and **Dr. V. K. Khanna** enlighten on monitoring of Thalassemic patients. **Dr. Ravi Reddy** COO, South Africa National Blood services (SANBS) emphasized the need of individual donor Nucleic Acid Testing. He said *NAT* is the best to reduce the risk of these infections to almost zero. He said that this technique is already in vogue in west for over a decade and even in south east asia for more than 5 yrs. He looked a worried person to know higher incidence of transfusion transmitted infection due to blood transfusions specially in Thalassemic Patients in India.

Session on transfusion was followed by clinical workshop for doctors. Use of filters was highlighted by **Dr. Manoranjan Mahapatra**. **Dr. J. S. Arora** elucidated step-by-step use of infusion pump in Desferal therapy. While doctors were busy in seminar hall on first floor patients were getting there academic feast from **Dr. Sunil Gomber**, **Dr. S. K. Sarin** and **Dr. Jagdish Chandra**. They gave tips on transfusion therapy, liver infections and growth respectively in Hindi. Dr. Sarin's talk was based on children's favourite medium of understanding cartoons and sketches.

Young Thalassemics Isha, Tanu, Jyoti, Vandana marked the inauguration of the symposium by lightning the lamp, many more thalassemics mounted the dais and shared their joy. **Dr. Jagdish Chandra** Prof. of Pediatrics Kalawati Saran Children Hospital welcomed the audience and thanked the speakers specially who had come from far and wide to share their expertise. During her inaugural address Padam Bhushan Awardee and President of NTWS **Km. Surrender Saini** said that Thalassemia should be included in the list of disability so that Thalassemics can also avail off benefits extended to other disabilities and they can also earn their lively hood to support their treatment & live a near normal life with self-esteem and dignity. She also released the souvenir and CD of documentary film "*New Pinch*". This documentary is a hard work put up by Anjali Sardana and her colleagues, Lata Chauhan, Pallavi Dwivedi & Kushuma Bisht from IIT Roorkee. Anjali, Lata & Pallavi who had specially come for this occasion were duly honored and presented mementoes by Km. Surrender Saini.

**Dr. J. S. Arora** General Secretary of National Thalassemia Welfare Society gave a brief account of activities of the society. He said that we worked hard & liaised with all the Govt. hospitals to start Thalassemia wards/units in their hospitals, as a result now we have separate Thalassemia wards in all the major Govt. hospitals in Delhi. He stressed that there is an urgent need to implement *NAT* (Nucleic Acid Testing) in donor's blood to save Thalassemics from high risk of being affected with transfusion transmitted infections like Hepatitis B, Hepatitis C & HIV.

Dr. Arora informed the audience that Govt. of Haryana has allotted us a huge 4000 sq. ft. built up area with over 1 acre of vacant land for running a primary health care centre at C-2 block, Palam Vihar. Now NTWS is also providing general health care to poor women & children from villages & unauthorized localities around Palam Vihar. In the due course of time facilities for Thalassemia will also be added.

"*New Pinch*" was shown to the audience during tea & lunch breaks. It was highly appreciated by all.

**Dr. Anita Saxena** Prof. of Cardiology at AIIMS, who has done maximum work on cardiac problems in Thalassemia, presented her data on iron overload related heart problems in Thalassemics. **Dr. Anju Seth** Prof. of Pediatrics at Kalawati Saran Children Hospital has done excellent work on endocrinopathies in Thalassemia; she shared her experience with the audience.

Bone diseases are very common in Thalassemics, **Dr. Rashid Merchant** consultant pediatrics Nanawati & Hinduja Hospitals, Mumbai presented his data on his clinical studies on osteopathies in Thalassemia. He emphasized adequate Vit. D supplementation with calcium.

**Dr. V. P. Choudhry** Director Pahuja Center for Blood Disorders Sun Flag Hospital Faridabad and former Prof. & Head of Haematology, AIIMS cautioned that though Defrasirox is comparatively safe but it needs regular monitoring specially kidney function. Before switching over to new drugs some basic tests are performed and repeated at regular interval. He said Defrasirox should not be used along with Kelfer or Desferal.

**Dr. Sandeep Shah** who have specially flown to Delhi from Ahmedabad to share his experience with unrelated cord blood transplantation said now young Thalassemics can be cured of Thalassemia even if they don't have HLA matched sibling in the family because now some private cord blood banks like cryobanks are storing cord blood which if found HLA identical with any patient, can be

transfused and cured. Cord blood is the blood discharged from the placenta at the time of delivery which goes waste. It contains naive (basic) cells which can be transformed into any organ and used to cure a number of incurable disorders including Thalassemia.

**Dr. Jagdish Chandra** while delivering his lecture on growth & development in Thalassemia said that most children under 10 yrs. are normal for age and children between 10-20 yrs. show growth impairment particularly in height while some catch-up and attain normal height after 20 yrs. Optimum transfusion & adequate chelation alongwith good nutrition is key to normal growth & development.

**Dr. Sarmila Chandra** Sr. consultant hematologists from Kolkata highlighted the importance of Desferal & monitoring of Kelfer and said that Kelfer & Desferal are going to stay and will continue to be used in Thalassemics for various reasons.

**Dr. Madhulika Kabra** Prof. of pediatrics, in charge genetic unit AIIMS asked the prospective Thalassemia carrier

couples to contact genetic dept. immediately after the pregnancy to confirm for mutation analysis so that CVS can be performed well in time that is 9 to 11 weeks of pregnancy.

**Dr. Renu Saxena** Prof. & Head Dept. of Haematology AIIMS, informed that in those couples where mutations could not be identified or CVS sample is inadequate or contaminated or pregnant women reports in second trimester fetal blood sample is collected at 18 weeks of pregnancy and subjected to Hb HPLC to know the Thalassemia status of the fetus.

**Anjali Sardana** a Thalassemia major from Bareilly, pursuing PHD from IIT, Roorkee has always been a source of encouragement and motivation. She informed that she visits her home town every two weeks to take her transfusions and taking Desferal injections regularly to rein in her serum ferritin. She takes her visits to Blood transfusion as picnics.

**Tarun Nanda** a tall, smart Thalassemic from Chandigarh, pioneer in Wheat Grass Juice therapy in India shared his experience with the audience. He said he is still taking Wheat

## NTWS Activities

1. AIIMS Preventive and Social Medicine Department organized two days Seminar on "Pre Marriage Training Course" for Happy Married Life at **AIIMS** Sushruta Seminar Hall on 29<sup>th</sup> & 30<sup>th</sup> July 2008. Dr. J.S. Arora was invited for lecture on Thalassemia & other genetic disorder. Dr. Bir Singh H.O.D Preventive Medicine was the Brain behind this new concept. Thalassemia Screening Test was conducted for all the participants present for the training session.

2. **NTWS** organized a Blood Donation Camp at MDI on 06<sup>th</sup> August, 2008 from 3 PM to 11 PM. It was a very successful camp where Hindu Rao Hospital Blood Bank collected **109 Units** of Blood.

3. **Convergys** India Ltd. Gurgaon organized a Health Mela on 08<sup>th</sup> August, 2008. Many NGO's participated in this Mela. **NTWS** was also invited to create awareness on Thalassemia. Mr. Gagandeep Singh and Mr. Rajesh participated in this Health Mela and made a good effort to spread the message about Thalassemia and how to prevent this disease.

4. **MetLife** Noida organized Blood Donation Camp for the first time on 12<sup>th</sup> August, 2008 from 6 PM to 12 midnight. It was a very successful camp where **103 Units** of Blood were collected by AIIMS Blood Bank.

5. **Convergys** India Ltd. Gurgaon organized a Night Blood Donation Camp on 13<sup>th</sup> August, 2008. The staff and Executives of Convergys are regular Blood Donors. The LNJP Hospital and AIIMS Blood Banks collected **111 Units** of Blood in Gurgaon. This was for the first time the Convergys people organized Blood Donation Camp in all over India Branches, Bangalore Mumbai & Pune on the eve

of the Independence Day, 14<sup>th</sup> of Aug, for the Thalassemic Children. It was a remarkable event and we thank the Convergians for their special effort for this noble cause.

6. Staff of National Thalassemia Welfare Society and its subsidiary NTWS Dispensary, Palam Vihar celebrated the Independence Day, 15<sup>th</sup> Aug, 08 by organizing a Blood Donation Camp at Rajindra Park, Palam Village. **30 Units** of Blood were collected by DDU Hospital Blood Bank.

7. National Thalassemia Welfare Society organized Thalassemia Symposium - III on Sunday 31st August, 08 at Swaran Jayanti Auditorium, Lady Harding Medical College New Delhi. A separate report is published in this Bulletin.

8. Delhi Students Union Joint Secretary, Mr. Ashish Gahlot organized a Blood Donation Camp in association with NTWS, for the Delhi Bomb Blasts victims on 19<sup>th</sup> Sept' 08. DDU Hospital Blood Bank Team collected **27 units** of blood.

9. Acharya Narender Dev College, Kalkaji invited Dr. J. S. Arora on 15<sup>th</sup> of September, 08 for a talk on Thalassemia. The Principal & Staff of college participated in Documentary, lecture & interactive session organised in the Seminar room which was over packed with students of A N D College. The Documentary film "Chetna" was shown followed by Dr. Arora's lecture. The students asked number of queries regarding Thalassemia & Blood Donation and promised to donate blood for the Thalassemia patients. The blood donation & Thalassemia screening was organized on 26<sup>th</sup> of September, 08 where **150 volunteered** for Thalassemia screening test.

10. The **NCPED** organized National awareness workshop for implementation of the United Nations Convention on The

Rights of Person with Disabilities (UNCRPD) & XI<sup>th</sup> Five year plan at USI Residency from 30<sup>th</sup> Sep. to 1<sup>st</sup> Oct., 2008. Dr. J. S. Arora & Mrs. Manisha attended the Seminar. Dr. Renuka Choudhary Minister of Women & child Development was a chief guest of the Seminar. Various discussions on disability sector were discussed and the National Policy on human rights was reviewed. Schemes for the disables identified. It was felt that monitoring should be done and guidelines be set up at Ministry level and see that they are followed.

**11. ISBTI** organized National Seminar on Promotion of Voluntary Blood Donation and felicitated Centurion Blood Donors on Voluntary Blood Donation Day 1<sup>st</sup> Oct., 08 at India Habitat Centre. Thalassemia patient Mst. Tushar sang two songs on Blood Donors & stole the heart of the audience. Dr. Makroo, Secretary General ISBTI said, "We should be well prepared for the Terror activities for Blood Donation at this time. We should have adequate supply of Blood for emergencies. Blood Donation is one way to fill the life happy. God is present every where but God in true form is in donors who have donated more than 100 times.

**12. SRF Ltd.,** Gurgaon organized for the first time a Blood Donation Camp on 20<sup>th</sup> Oct., 2008 in association with NTWS. It was very successful venture where AIIMS blood bank team collected **54 units** of blood. Number of volunteers came forward for Thalassemia screening test. Samples were taken during the blood donation camp.

**13. Keane India Ltd.,** organized a 24 hours Blood Donation Camp at Gurgaon Head Office and on the same day they organized a Blood Donation Camp for the first time at

Noida branch. Total **195 units of blood** were collected on the same day by RML, Hindu Rao & GTB Hospital Blood Banks. Thalassemia screening test was also done. 58 volunteers came forward and gave their samples for the test. Keane has promised to organize regularly Blood Donation Camp for the Thalassemics.

**14. Heart Care Foundation of India** organized a *Perfect Health Mela* from 17<sup>th</sup> to 27<sup>th</sup> of Oct., 2008 at Laxmi Bai Nagar, stadium New Delhi. NTWS put up a stall and distributed brochures & posters among the visitors who came to see the mela. Mr. S. N. Arora, Rajesh Kumar & Monisha Gogoi explained to the visitors that Thalassemia is preventable. A blood test known as HbA2/HPLC can detect the carriers of the defected Thalassemia gene. It is very important to know the Thalassemia status before marriage or before the family is completed.

**15. AIIMS centre** for community medicine organize **Pre-Marriage Training Course** for "Happy Married Life" at Sushruta Seminar Room, CCM (Old O.T. Block, AIIMS) from 21-22<sup>nd</sup> Oct 08 in presence of Health Communication Unit. The programme started with introduction of participants and a pre-test by Dr. Bir Singh. Dr. J.S. Arora, General Secretary of National Thalassemia Welfare Society was invited to speak on Thalassemia and other genetic disorder. He stressed the need of Thalassemia Awareness for prevention. He also spoke how simple it is to prevent Thalassemia. Thalassemia screening for all the participants was done by NTWS on 22<sup>nd</sup> Oct.

## TCWA, Chandigarh

6 Blood Donation Camps were held from 10<sup>th</sup> May, 2008 to 19<sup>th</sup> July, 2008 by TCWA during summer when there is extreme shortage of blood every year.

### Brief of each camp is given as under:

1<sup>st</sup> Blood Donation Camp held on 10<sup>th</sup> May, 2008 and was inaugurated by Dr. K. K. Talwar, Director, PGIMER, Chandigarh in which 295 units were collected. International Thalassemia Day was observed on that day.

2<sup>nd</sup> (100<sup>th</sup> Camp) was held on 25<sup>th</sup> May, 2008. The camp was inaugurated by Hon'ble Sh. Pawan Kumar Bansal, Union Minister of State for Finance and Parliamentary Affairs, Govt. of India. 302 persons donated blood.

The 3<sup>rd</sup> camp dated 7<sup>th</sup> June, 2008 was inaugurated by Mrs. Pushpinder Kaur AGM (SBI) Main Branch, Sector-17, Chandigarh, in this camp 210 persons donated blood.

The 4<sup>th</sup> camp dated 22<sup>nd</sup> June, 2008 was inaugurated by A.P.S. Sarkaria, Joint Director, State Transport, Punjab in which 172 persons donated blood.

The 5<sup>th</sup> Blood Donation Camp dated 6<sup>th</sup> July, 2008 was inaugurated Sh. Pardeep Chhabra, Mayor Chandigarh in which 224 persons donated blood.

The 6<sup>th</sup> and the last camp dated 19<sup>th</sup> July, 2008 was inaugurated by Dr. Sunit Singhi, Prof. & Head Dept. of Pediatrics, PGIMER, Chandigarh in this camp 202 persons donated blood.

Mrs. Shobha Tuli, visited PGIMER, Thalassemia Ward on 08<sup>th</sup> July, 2008 along with her husband. She appreciated the arrangements being made and facilities being provided to Thalassemics. She also donated Rs. 10,000/- for this noble cause.

Some of other facilities provided to Thalassemics are as under:-

✍ The association is providing free of cost Kelfer to about 60 poor people and Desirox to about 10 people, those whom Kelfer does not suit.

✍ Bus fare free to all Thalassemics along with one attendant from place of stay of PGI, Chandigarh for treatment.

✍ Kelfer/Desirox is being provided free of cost/concessional rate to more than 70 Thalassemics.

✍ Prizes are being given to meritorious Thalassemics every year.



Dr.J.S. Arora, Mr. Gautam Seth & Surender Singh with Chief Guest ACP Mr. Gurbachan Singh at BDC Vikas Puri,



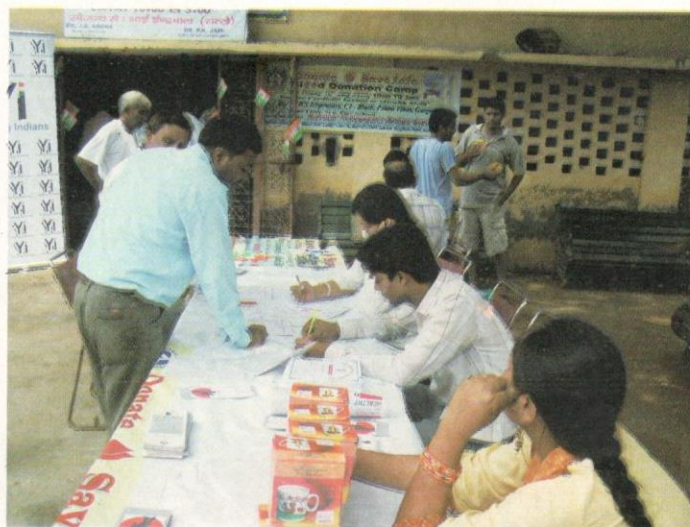
Dr. Arora addressing the participants in the Pre-Marriage Counselling Seminar at AIIMS



BDC at Alcatel, Gurgaon



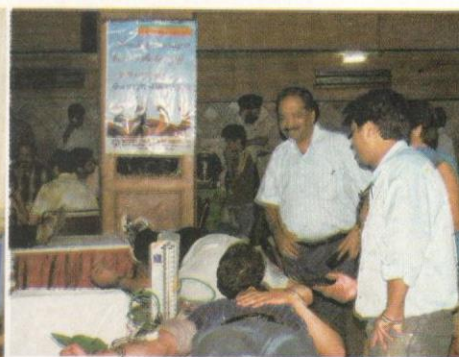
Dr.P.K.Jain & Preeti Ahuja, organising a Blood Donation Camp on 15th August'08 at Palam Vihar



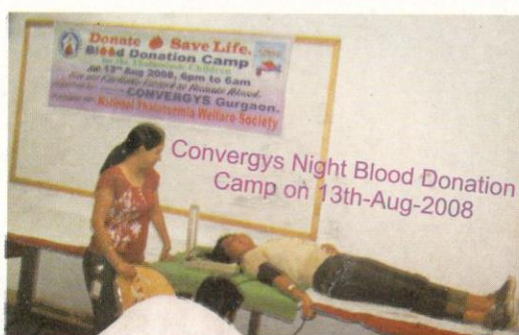
Ajay & Monisha taking samples for Thalassemia Screening at a Seminar at AIIMS



DDU Blood Bank Team at HCL



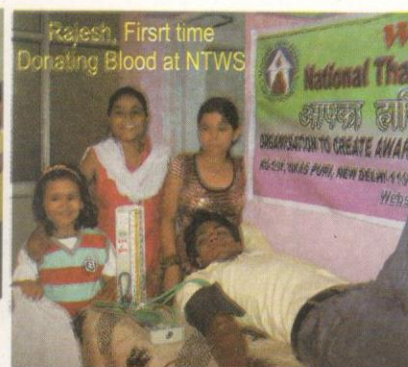
Mr.J. Manuja motivating donors during the BDC at Jail Road



Convergys Night Blood Donation Camp on 13th-Aug-2008



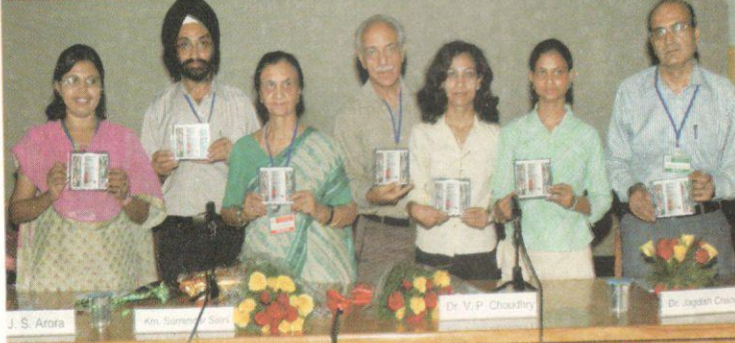
Sarala Fabrics, Ghzbd



Rajesh, First time Donating Blood at NTWS

# National Thalassemia Symposium - III, August 2008

## Organizers & Volunteers

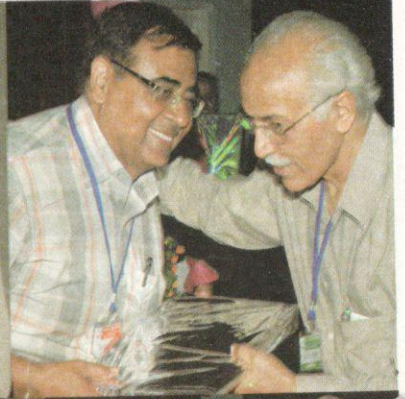
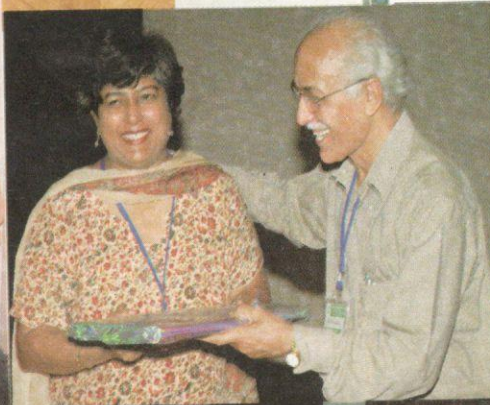


Release of "New Pinch" Documentary made by iITians of Roorkee

## ENTISIPARENTS REGISTRATION



## NTWS-PATIENTS/PARENTS REGISTRATION



# Parents/Patients & Doctor's at Thalassemia Symposium - III





Thalassemia Cell launched at Hindu rao Hospital.



Dr. K. K. Talwar, Director PGIMER being received by the Thalassemia for the inauguration of 1st Blood Donation Camp.



Mrs. Pushpinder Kaur, AGM. SBJ inaugurating the 3rd Blood Donation Camp.



Dr. J.S Arora receiving live time services award from Dr. N.K. Ganguly, Dir. I.C.M.R under the aegis of Paediatrics Haemato-oncology, branch of IAP.



Sh. A. P. S. Sarkaria, Joint Director, State Transport Punjab inflicting with the Blood Donor.



Dr. Neelam Marwaha, Head of the Blood Transfusion and medicine along with Dr. Sunil Singh, President, Gen. Secretary and other Doctors and executive members of TCWA.



Sh. Pawan Kumar Bansal, Union Minister of Finance & Parliamentary affair along with Director PGI, President, Gen. Secretary & other Doctors and members of TCWA on 100th Blood Donation Camp.



Dr. Neelam Marwaha, Head of the Blood Transfusion and medicine along with Dr. Sunil Singh, President, Gen. Secretary and other Doctors and executive members of TCWA.

## Thalassemia Control Project under MCD, Delhi

Dr. Suman Mendiratta  
Sr. Consultant Gynae (Hindu Rao Hospital)

### **Introduction**

Thalassemia is a serious genetic blood disorder in which body is unable to make adequate Haemoglobin. About 35 million people in India are carriers of Thalassemia gene and more than 10,000 Thalassemics are born every year. About 5.5 percent of the Delhi's population is carrier of the Thalassemia gene and over 200 Thalassemia major are born in Delhi every year.

The only curative treatment available is complete bone marrow transplantation from a matching sibling donor which is not always possible. Moreover the facility for such transplantation is not available everywhere in the country. The only method for survival of a Thalassemia major patient is regular blood transfusion. The annual cost for the treatment varies between Rs. 50,000 to Rs. 2 Lacs, which is beyond the reach of a common man.

It is, therefore, essential to prevent the birth of children with Thalassemia major. In spite of best possible treatment the life span of Thalassemia major child is very small and majority of patients die in their early childhood.

Prevention of marriage between two Thalassemia carriers is an ideal way of preventing transmission of this disease to next generation.

However, if not screened at premarital stage then screening for Thalassemia trait can be done at antenatal stage and if both parents are detected to be having Thalassemia trait, they can be counseled and prenatal tests can be offered to them to determine if yet unborn child is affected with Thalassemia major. Medical termination of pregnancy can be offered if couple so desires to prevent birth of Thalassemia major baby.

Keeping above factors in mind MCD launched a project called Thalassemia Control Programme, in all 32 Maternity Homes, four Colony Hospitals and four major Hospitals namely HRH, SDN, KH & GLMH Maternity Hospitals.

**It was inaugurated by Chief Guest** Sh. K.S. Mehra Hon'ble Commissioner, MCD. **Guest of Honour** Dr. V. K. Monga Chairman, Health Committee, MCD on 20<sup>th</sup> September, 2008 at Hindu Rao Hospital

### **The objective of above project is as under**

- ✍ To have pre-natal screening of the expecting mothers to detect Thalassemia trait.
- ✍ To create awareness among the prospective couples/general public.
- ✍ To offer pre-natal counseling/test to Thalassemia trait couple.
- ✍ To prevent birth of children with Thalassemia major.

### **Process of Implementation of Project**

The MCD has a large network of Maternity Homes, Maternity Centers, 06 major Hospitals and 04 Colony Hospitals. It is, therefore, proposed to implement this project in phased manner.

A pilot project started in HRH on 20<sup>th</sup> September, 2008. The Hospital is already having all facilities and equipments for this project. Doctors, Lab Technician/Lab Assistant, LHVs, Nurses & ANMS of 32 Maternity Homes were trained for screening of Thalassemic patients in the Maternity Homes through a simple technique called NESTROFT.

- Thalassemia Screening will also be organized for school children in all MCD Schools at the time of admission and routine check-up.
- Awareness program for school children and their parents will be organized under School Health Scheme.
- Awareness program will also be organized for general public in Maternity Homes and rural areas.
- Pre-marriage/marriage counseling Clinic will be started in HRH.
- Mass Screening Camp will be organized in the Maternity Homes every three months

A Thalassemia Control Cell under the charge of a Project Coordinator has been set up in the zonal office premises of Civil Line Zone for implementation of this project. The project will be implemented under the direct supervision and control of the **Sh. Janak Dugal** Addl. Health Commissioner and **Dr. Madhu Jain** DHA

Dr. Suman Lata Mendiratta has been made the project coordinator for implementation of the Thalassemia Control Project in MCD. Dr. Sangeeta is the training officer.

## ACTIVITY REPORT OF THALASSAEMIA SOCIETY OF INDIA (TSI) West Bengal FOR THE MONTH OF JUNE 2008

12 Blood Donation camps where 1190 units of Blood were collected.

Date	Club/Association	No. of Units
01.06.08	New Tarun Sangha, Singur, Hooghly	100
01.06.08	Yuba Bharti Club, Sodepur, 24 pgs (N)	100
03.06.08	Youth Star, Dadpur, Hooghly	80
07.06.08	Green Park, Netaji United Club, Green Park, 24 pgs (N)	100
08.06.08	Kalikapur Hasanpur Sahajatri Sangha, Kalikapur, 24 Pgs (S)	100
08.06.08	Sree Sangha, Salkia, Howrah	80
15.06.08	Belegkata Palyers Corner Association, CIT Building, Kolkata-700010	100
15.06.08	Kolbagab Sporting Club, Kolkabagan, Kolkata-700009	150
15.06.08	Jagriti Tarun Sangha, Salkia, Howrah	100
22.06.08	Babudanga Athletic Club, 95/5 Sree Ram Dangha Road, Salkia, Howrah	80
22.06.08	Nabaday, Baranagar, 7 Motilal Mullick Lane, Kolkata-700035	100
22.06.08	Sanskritik Parishad, Master Para, Konnagar, Hooghly	100

Total number of patients received Blood transfusion at our treatment centre	219
Total number of Blood units transfused to the patient	250
Total number of Blood transfusion with IV Chelation	14
Total number of Hb. Testing done	352
Total number of TC/ DC/ Platelet testing	27
Total number of LFT tests done	01

### JULY 2008

12 Blood Donation camps where 1240 units of Blood was collected.

Date	Club/Association	No. of Units
06.07.08	Micheal Nagar, Netaji Sangha, Kolkata-133	100
06.07.08	Yubak Brinda, Club, Salkia, Howrah	80
06.07.08	Mahila Samiti, 1 Tara Sankar Sarani, Kolkata-37	100
13.07.08	D.Y.F.I, Tarkeshwar, Hooghly	100
13.07.08	Smriti Sangha Club, Barasat, 24 Pgs (N)	80
13.07.08	Naba Yubak Brinda, Ghatal, Midnapore	150
13.07.08	Kalabagan Sporting Club, Kalabagan, Kolkata-90	100
20.07.08	D.Y.F.I, New Barrackpore, 24 Pgs (N)	80
20.07.08	Vivekananda Sporting Club, Sheoraphully, Hooghly	100
20.07.08	Aghnisekha Club, Champahati, 24 pgs (S)	100
27.07.08	Salt Lake, BJ Block Committee, BJ-415 A, Sec-II, Salt Lake, Kolkata-91	100
27.07.08	Jagriti Club, Baranagar, Kolkata-700035	150

Total number of Blood units transfused to the patient	320
Total number of Blood transfusion with IV Chelation	06
Total number of IV Chelation	433
Total number of TC/ DC/ Platelet testing	55
Total number of LFT tests done	

## A letter from **Serum Thalassemia Prevention Federation (West Bengal)**

**Dear Dr. Arora**

We are very much happy to learn that the entire programme of 31<sup>st</sup> August was fruitful and successful. Unfortunately I have failed to participate due to one very important event in our State for preventing Thalassemia at the State level.

You will be happy to know that we approached to our West Bengal Assembly and proposed Government of West Bengal for taking initiative for Mandatory Thalassemia carrier Test which was held on 31<sup>st</sup> August, 2008. One of our MLA Dr. K. D. Ghosh made an appeal to the Assembly House for accepting this prayer for further course of action.

The prayer was granted by the Assembly and ultimately the matter was sent to the Health Standing Committee of the Assembly for further course of Action.

**I am very much happy to inform you that I was invited at the Assembly before Health Standing Committee for briefing the matter to the 20 MLA Members of the Standing Committee and ultimately to motivate further.**

**Now the matter will be sent to the Legal Dept. for further course of action. By this time I went to NACO and discussed about the NAT test matter with Dr. Debasish**

**Gupta where I have found your prayer letter also in this context.**

I have requested National Blood Transfusion Council for looking into the matter for the interest of Thalassemics of India.

Thank you very much for your letter and your suggestion for ensuring Safe Blood Transfusion in the Country in the coming years.

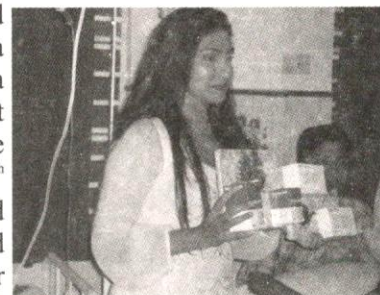
I will send this in News form for publication of the same in

- We also publish and distribute different informative papers about Thalassemia.
- We offer pre/post transfusion blood investigation at a subsidies rate (e.g. Ferritin, Iron, TIBC, CBC, SGPT, SGOT etc.)
- We observed Thalassemia awareness week from 8<sup>th</sup> to 14<sup>th</sup> May in West Bengal with the decorative and informative tableue.
- We organize blood donation camps on every year.
- We also take responsibility of blood transfusion of a limited number of patient at free of cost.

Thank you very much for your kind suggestion.

### TREATMENT CENTRE VISIT

The noted film actress Ms Rituparna Sengupta who has long been associated with Thalassemia Society of India paid a visit to the treatment centre of the organization on 16<sup>th</sup> April 2008. She handed over the much awaited oral iron Chelator (Asunra and Desirox) for the first time to the patients of the society at our treatment centre at 48A Muktabambabu Street, Kolkata 700 007.



She spent some quality time with the children providing them hope, comfort and encouragement. The media covered the occasion where Ms Sengupta ventilated the causes and concerns of this dreaded illness. It is through her opinion the facts about Thalassemia reached through various echelons of the society.

### Screening Camps organised by Serum Thalassemia Prevention Federation

Total Test	24162
Normal Pattern	21476
Heterozygous State of Beta Thalassemia	968
Beta Thalassemia	355
HBE Beta Thalassemia	394
HBE Trait	619
Sickle Beta Thalassemia	54
Sickle 'D' Trait	71
Haemoglobin 'E' Disease	114
Haemoglobin 'D' Trait	59
Sickle Cell Disease	52

## ORIENTATION SESSION ON ORAL CHELATOR BY NOVARTIS AND CIPLA TO THE PATIENT GURDIAN OF THE SOCIETY

On 15<sup>th</sup> April two representatives from Novartis conducted a session to enlighten the patient guardians about the newly introduced iron Chelator - Asunra. The session was quite educative for the parents as all their queries were answered. Cipla conducted a similar session on 22<sup>nd</sup> April 2008. These two sessions conducted by the pioneer medicine companies placed an interesting choice before the patients.

## BLOOD DONATION AWARENESS CAMP AT OIL AND NATURAL GAS CORPORATION'S (ONGC) OFFICE

The Thalassemia Society of India organized a Blood Donation awareness camp at ONGC (Taratolla office) on 16<sup>th</sup> April 2008. The camp was mainly organized to raise awareness on the importance of donating blood. A Thalassaemic patient survives on regular blood transfusion-so to meet up this demand organizing blood donation camps is an utter necessity. This message was conveyed to the employees of ONGC. Mr. C. R. Baidy Basin manager, ONGC graced the program. Dr. P. R. K Raju- GM- HR of ONGC also attended the program. The Thalassemia Society of India's endeavour to conduct such awareness camps is solely aimed at reaching to each and every corner of the society and aspires to conduct more such camps in the near future.

## Kozhikkod Celebrated Thalassemia Day

World Thalassemia day was observed under the auspicious of Malabar Thalassemia Society at Portland hospital, Kozhikkod. Hepatitis B, vaccination, Haematology medical camp, awareness, cultural activities also were organized.

Kerala Assembly legislator advisor P.M.A Sclams MLA inaugurated the International Thalassemia Day celebrations. Dr. P. M. Kutty, president of the society presided over the function. P. T. Abdul Latheef, Dy. Major Corporation of Calicut distributed the medicine. K. Rajan station director all India radio, Kozhikkod distributed the food grains Dr. C. A. Abdul Kareem, Director, Portland hospital, South Beach, Kozhikkod inaugurated the vaccination program.

Dr. V. T. Ajith Kumar treasurer of the society and the chief consultant in Haematology clinic MCH, Kozhikkod, P. Mamukkoya, opp. Leaders Calicut Corporation, M. A. Johnson, Social activist felicitated the function.

**Adv:** M. Mujeebulla manages Madyamam Health Care Program (A charity foundation under a newspaper daily called "Madyamam") declared sponsorship of Asunra free. Dr. Nazeem Shereef Psychologist took a class related to the Psycho Social issues.

After the program meals were served to all participants.

Kareem Karassery Secretary, Malabar Thalassemia Society welcomed the gathering. P. C. Kishore Vice-President expressed the vote of thanks.

## Successful people help others Who are slow?

It was a sports stadium. Eight children were standing on the track to participate in the running event.

- \* Ready!
- \* Steady!
- \* Bang!!!

With the sound of toy pistol, all eight girls started running. Hardly have they covered ten to fifteen steps, one of the smaller girls slipped and fell down. Due to bruises and pain she started crying. When other seven girls heard this sound, stopped running, stood for a while and turned back, they all ran back to the place where the girl fell down. One among them bent, picked and kissed the girl gently and enquired 'Now pain must have reduced'. All seven girls lifted the fallen girl, pacified her, two of them held the girl firmly and then all seven joined hands together and walked together and reached the winning-post. Officials were shocked. Clapping of thousands of spectators filled the stadium. Many eyes were filled with tears and perhaps it had reached the GOD even!

YES. This happened in Hyderabad [INDIA], recently! The sport was conducted by National Institute of Mental Health. All these special girls had come to participate in this event and they are spastic children. Yes, they were mentally retarded / challenged. What did they teach this world?

Teamwork? Humanity? Equality among all Successful people help others who are slow in Learning so that they are not left far behind. This is really a great message...

# DEFRASIROX / EXJADE - ASUNRA / DESIROX

का प्रयोग करते समय निम्न बातों का ध्यान आवश्यक है।

1. दवा आरम्भ करने से पहले, **SGOT, SGPT, SAP, Urea, Creatinine** का टेस्ट करवाना चाहिये तथा दवा आरम्भ करने के पश्चात प्रति माह भी ये जांच आवश्यक है।
2. **Ferritin** की जांच 2 महीने में एक बार करवानी चाहिए।
3. मूत्र में प्रोटीन की मात्रा माह में एक बार जांच करवानी चाहिए।
4. दवा को खाली पेट खाने से आधा घंटा पहले 100 - 200ml पानी, संतरे या सेब के जूस में हिला कर लेना चाहिये। साबुत या चबा कर नहीं खाना। गिलास में बची हुई दवा को पुनः थोड़े पानी में हिलाकर पी लेना चाहिये।
5. शरीर पर चकत्ते अथवा अतिसार (**Diarrhoea**), होने से थैलासीमिया चिकित्सक से सम्पर्क करें।

## NATIONAL THALASSEMIA WELFARE SOCIETY (Regd.)

KG-1/97, Vikas Puri, New Delhi-110018 Tel: 9311166711-712, 25511795

URL: [www.thalassaemiaindia.org](http://www.thalassaemiaindia.org)

E-Mail: [ntws08@gmail.com](mailto:ntws08@gmail.com)

### MEMBERSHIP

Any person can become life membership of the society by filling a form & Sending a DD of Rs. 500 in favour of : **National Thalassemia Welfare Society.**

For **NRI & Foreigners** Life membership fee US\$100

### READILY AVAILABLE

Filters Single Unit  
Filters Double Unit  
Kelfer  
Desferal  
Infusion Pump  
S.V Set  
Desirox & Asunra

### ADVERTISEMENT CHARGES

	<u>INLAND</u>	<u>FOREIGN</u>
Sponsorship	RS. 50,000	US\$ 5,000
Cover Page		
Inside Front	Rs. 15,000	US\$ 1,500
Inside Back	Rs. 15,000	US\$ 1,500
Inside		
Full page	Rs. 5,000	US\$ 500
Half page	Rs. 3,000	-
Back		
Full page	Rs. 20,000	US\$ 2,000

### Special Thalassemia Clinic

N.T.W.S. Organises Thalassemia check up Clinic on 2nd Sunday of every month at N.T.W.S Thalassemia Centre, 2nd Floor, Community Centre, Slum & JJ Dept. of MCD, Near Gurudwara Singh Sabha Block 12, Tilak Nagar New Delhi-18  
For Appointment Contact: Dr. J. S. Arora Tel: 25507483, 25511795

#### Facilities:

- \* Growth Monitoring
- \* Chelation Therapy
- \* Serum Ferritin Assay for **Rs.150** only
- \* Hepatitis B Vaccine: **Rs. 50** for children below 10 years.  
**Rs. 100** for children above 10years.
- \* Thalassemia Screening / Diagnosis with HPLC **Rs. 300** only
- \* CBC (complete blood count) **Rs. 70** only

कैल्फर प्रयोग करने वाले रोगी अपनी CBC (Hb, TLC, DLC, Platelet) की रिपोर्ट जो (एक हफ्ते से ज्यादा पुरानी ना हो) को लाना ना भुले। जो रोगी असूनरा अथवा डैसीरोक्स का प्रयोग करते हैं वो CBC, SGOT, SGPT, SAP, Urea, Creatinine, Urine Routine) आदि रिपोर्ट जो (एक हफ्ते से ज्यादा पुरानी ना हो) को लाना ना भुले। यदि आप उपयुक्त रिपोर्ट नहीं लाते हैं तो दवा का पर्चा नहीं दिया जा सकता।

## **FIT EXECUTIVE:**

### **PRESIDENT**

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Ishwar Parwani (Rajasthan) Ph: 0145-2621082  
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Sajid Khan (MP) Ph. 9826057909  
Nisha Yadav (UP) Ph. 0532-211003

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Satnam Singh (Punjab)  
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**Dr. George J. Kontoghiorghe**  
Prof. of Heam. Cyprus  
**Prof. Benadette Modell**  
Prof. of Community Genetics, London  
**Dr. Nancy F. Olivieri**  
Director- Thalassemia Program, Toronto  
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Cancer Research Centre, Boston U.S.A  
**Dr. Vincenzo De Sanctis**  
Day Hospital of Endocrinology, Italy  
**Dr. Cogero Vullo**  
Div. of Pead. Centro della Microcitemia, Italy  
**Dr. Beatrix Wonke**  
Haematologist, Formerly at Whittington Hospital, London

## **MEMBER SOCIETIES:**

Thalassemia & Sick Cell Society of **Ahmedabad**  
Ajmer Region Thalassemia Welfare Society **Ajmer**  
Thalassemia Society of India, **Allahabad**  
Amritsar Thalassemia Welfare 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 Assoc, **Chandigarh**  
National Thalassemia Welfare Society, **Delhi**  
Thalassemics India, **Delhi**  
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**  
Indian Academy of Paediatric Marwar, **Jodhpur**  
Thalassemia Society of India, **Kolkata**  
The Hematology Foundation, **Kolkata**  
West Bengal Voluntary Blood Donors Forum,  
The Thalassemia Society of Kota, **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**  
Haryana Thalassemia Welfare Society, **Rohtak**  
Thalassemia Haemophilia Sickle Cell Anaemia Prevention,  
Counselling & BT Centre, **Surat**  
Varanasi Region Thalassemia Welfare Society, **Varanasi**

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**Dr. V.P. Choudhry**  
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**Dr. Deepika Deka**  
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Prof. & Head - Deptt of Path. G.T.B. Hospital  
**Dr. R.K. Marwah**  
Prof.- Deptt of Paediatrics, PGI, Chandigarh  
**Dr. N.K. Mehra**  
Prof. & Head-Histocompatibility Lab, A.I.I.M.S  
**Dr. I.C. Verma**  
Prof. & Head-Genetic Unit, S.G.R.H

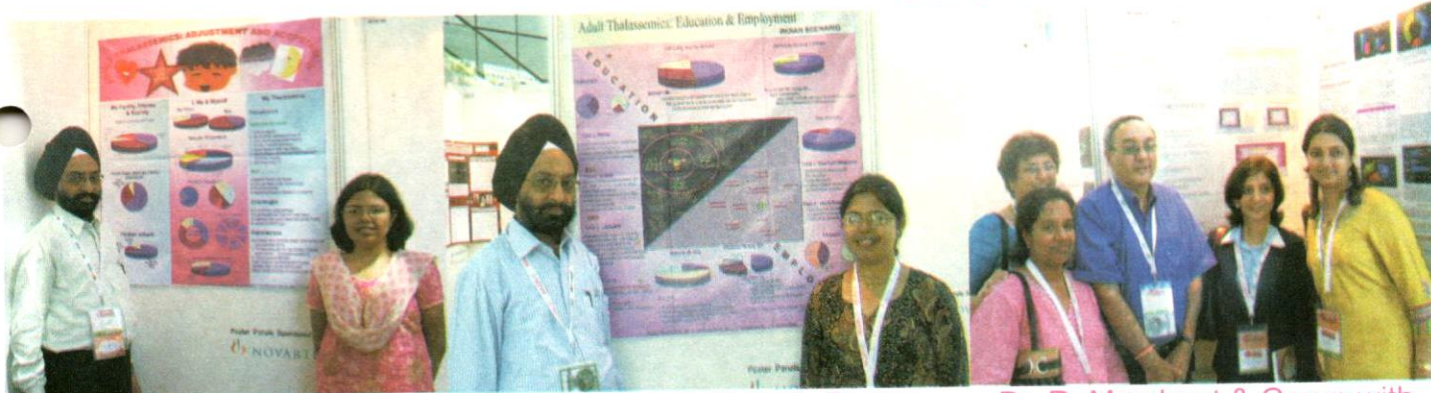
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YOU are rich when you never more than what you have.



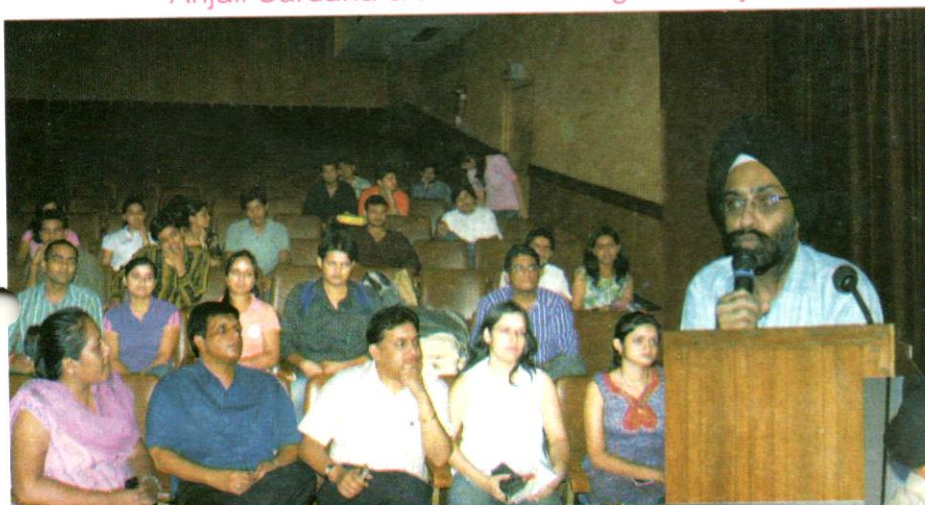
Doctors from India at TIF Conference Singapore

The Group from India who visited Singapore during the TIF Conference



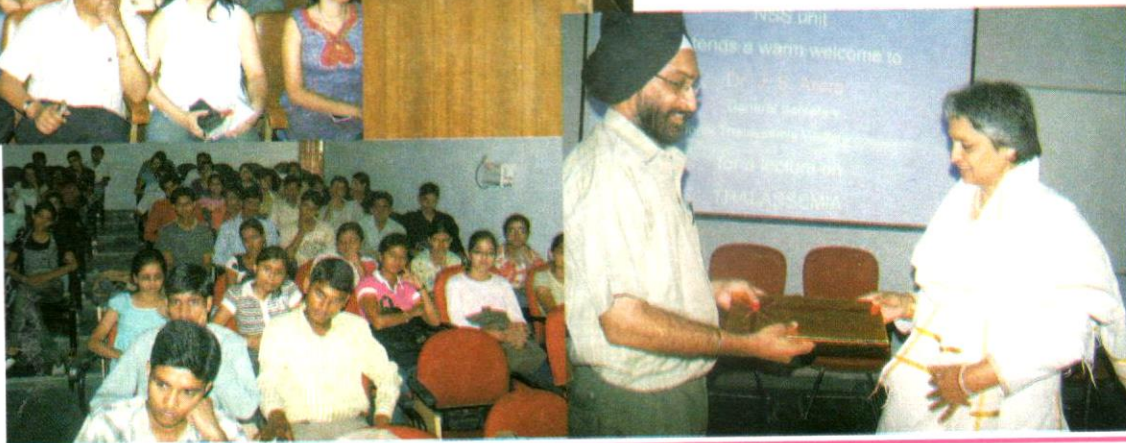
Anjali Sardana & Dr. Arora along with Anjali's Poster

Dr. R. Merchant & Group with their Poster display



Dr. Arora delivering lecture at Apeejay Management Institute Dwarka

Dr. Arora & Principal of AND College DU, Kalkaji



YOU are you when you are at peace with who you are not.

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