FEDERATION OF INDIAN THALASSEMICS
NATIONAL THALASSEMIA BULLETIN

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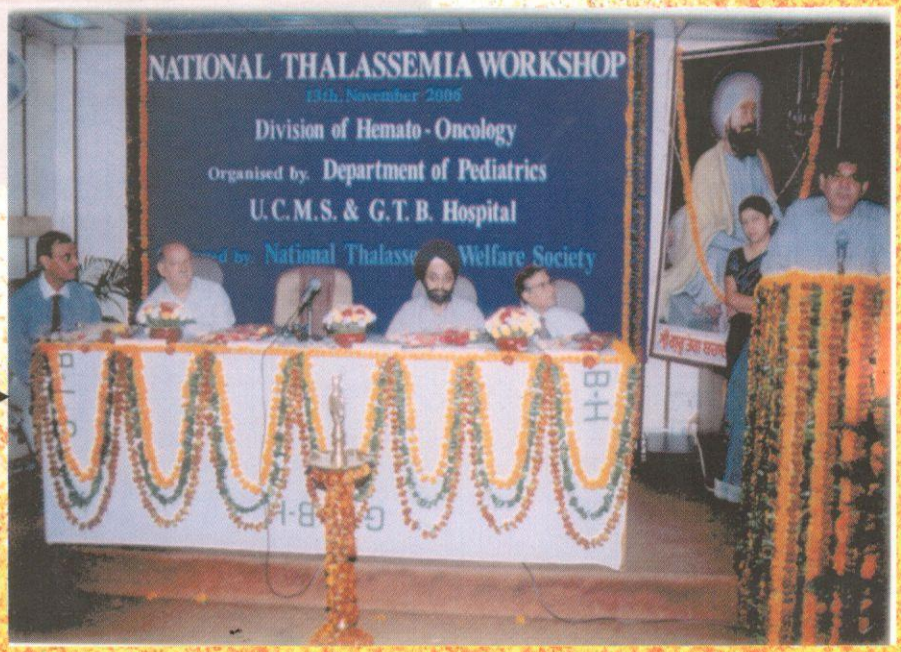
<= Dignitaries at the Dias Left to Right, Dr. A.P. Dubey, Km.. Surrendar Saini, Dr. Ashok Walia Chief Guest (Hon'able Minister of Finance Govt. of Delhi), Dr. V.K. Ramteke & Dr J.S. Arora, During the inauguration of 5th National Thalassemia Conference organized by National Thalassemia Welfare Society at MAMC Auditorium on 11th Nov. 2006



=> Inauguration of National Thalassemia Workshop at GTB Hospital on 13th Nov. 2006 Left to right Dr. Sunil Gomber Dr. L.C. Thakur Dr. J.S. Arora, Dr. M.M.A. Fridi . Mr K.S. Wahi, additional secretary, (Health), Govt. of Delhi addressing the audience

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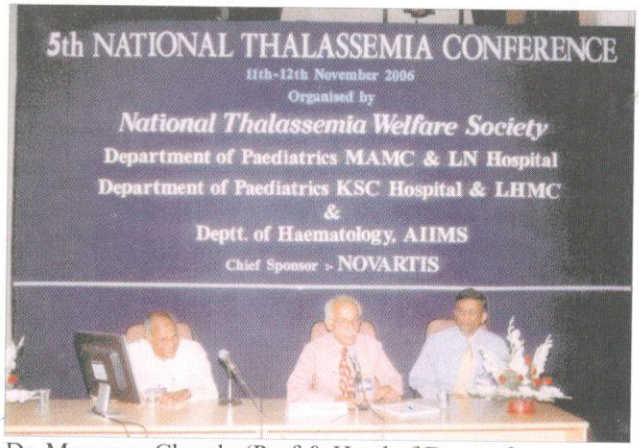
Dr Ashok Walia Lighting the lamp to mark the inauguration of 5th National Thalassemia Conference

Dr Ashok Walia releasing CD of 2nd documentary film on Thalassemia awareness "Jagriti". Ist documentary was "Chetna"

Dr. M.R. Lokeshwar receiving Dr. B.N. Dara award from Dr. A.K. Walia



Dr. Mammen Chandy (Prof & Head of Dept. of Haematology, CMC Vellore), Dr V.P. Choudhry (Prof & Head of Hematology, AIIMS), Dr Rajat Kumar (Prof of Hematology at AIIMS), clearing doubts about Bone Marrow Transplantation

Km. Surrendar Saini (President NTWS) awarding "Best Social Worker Award" to Mrs. Vandana Arora

Ms Anubha Taneja (Thalassemia Patient) addressing the crucial issue of "Expectations & obligations of a Thalassemic" at 5th NTC

EDITORIAL

Exemption of VAT on Leucocyte Filters by the Delhi Government

Once again we have been able to get another benefit for Thalassemics in Delhi. Delhi Government has already exempted Kelfer & Desferal from VAT for last few years. Now Dr. A.K. Walia Hon'ble Minister of Finance, Government of NCT Delhi once again showered blessings on us by exempting VAT on Leucocyte Filters. It will not only help Delhi patients but also Thalassemic patients/societies who are getting filters from NTWS. Now they can have Leucocyte Filters without VAT.

Prof. Dr. V.P. Choudhry, Medical Advisor to National Thalassemia Welfare Society & Federation of Indian Thalassemics has superannuated from the post of Professor and Head Department of Hematology at AIIMS. He was also former Director Indira Gandhi Institute of Child Health Kabul, Afghanistan.
Medical Advisor Armed Forces Medical Services.
President Indian Society of Hematology & Transfusion Medicine.
President Delhi Society of Hematology
Chairperson Pediatric Hemato-oncology IAP

Prof. V.P. Choudhry has now joined Sun Flag-Pahuja Centre for Blood Disorders as Director at Sun Flag Hospital Faridabad. Pahuja Foundation is also an NGO committed for cause of Thalassemia and provides special care facilities for: -
Thalassemics at Sun Flag Hospital at subsidized rates.
Prof. V.P. Choudhry will be available at :-
Pahuja centre for Blood Disorders Sun Flag Hospital. Sector 16 A Faridabad
95129-2263584-85-86 Extn. 2210
95129-4075184 Fax: 95129-4076962
Timings => 9:00 am to 5:00 pm
and at his private clinic
Hematology Clinic
A-26 Shivalik, Near Malviya Nagar,
New Delhi 110017
011-64532813, 09811073904
Timings => 5:30 pm to 7:00 pm

He will continue to provide his services at NTWS run special Thalassemia clinic on 2nd Sunday of every month at Community Centre, 12 Block Tilak Nagar, New Delhi 18

All Thalassemics salute him for the personnel care provided by him during his tenure at AIIMS. He has promised to help the Thalassemics in future also.

Dr Ashok Walia and Dr V.P. Choudhry are two legends of Thalassemia; National Thalassemia Welfare Society pays special Tribute to both of them to acknowledge their services for the welfare of Thalassemia

छपते-छपते हमे समाचार मिला है कि एक्सजैड(असुनरा) का भारत आगमन एक बार फिर कम से कम 6 मास के लिये टल गया है। ऐसा देखने मे आया है कि बहुत से रोगीयो ने डेस्फ़राल या कैल्फर लेना बन्द कर दिया है या कम कर दिया है या जिनको कैल्फर से दुष्प्रभाव हो रहे है उन्होने पम्प लेने का विचार इसलिये त्याग दिया है कि जुलाई, अगस्त मे तो एक्सजैड (असुनरा) आने ही वाला है पहली बात तो यह है कि इसमे बार-बार विल्म्भ हो रहा है दूसरी बात शरीर मे अतिरिक्त लौह एक जीर्ण विष की तरह ऐसे ही काम करता है जैसे लकड़ी को अंदर-अंदर दीमक खा जाती है या फिर लोहे को जंगाल खा जाता है अत: मेरा सभी थैलासीमिक्स को विशेष अनुरोध है कि एक्सजैड (असुनरा) की उम्मीद मे कैल्फर या डेस्फराल कम न करें।

डा॰ जे. एस. अरोडा

भविष्य तभी उज्जवल होगा यदि हम आज ज्योति जलायेगे।
उस प्रकाशमय भविष्य की क्या विश्वसनीयता यदि आज के अंधकार मे हम अपना अस्तित्व ही खो बैठें।

Practical Approach to Desferal Administration at Home

Dr J.S. Arora

Desferal is the time-tested medicine for iron chelation in the world market for over 35 years. It is the gold standard in iron chelation. Deferiprone (Kelfer) though a good oral iron chelator, could not make a significant dent in its market share. Even with the launch of new much safer oral iron chelator Defrasirox (Exjade). Desferal is going to stay; specially in Indian scenario where most of the Thalassemics are highly iron overloaded, combination therapy will be best option to bring their ferritin level near normal. Although Novartis has prepared "Guidelines for home infusion of Desferal" and every patient is taught how to give Desferal injection whenever he is handed over pump and again by transfusion specialist at Thalassemia units: but still some patients keep coming to us for problems arising due to wrong injection administration techniques.

Due to repeated pain & swelling, at times patients stop taking Desferal therapy. A review of Desferal administration technique has been presented which incorporates procedure published by Novartis.

Step-1. The water for injection is drawn into a syringe. Use water for injection of good quality, **plastic ampoules** are preferred over glass ampoules.

One vial of Desferal injection can be mixed with 2.5 to 5 ml of water for injection. For convenience it can be calculated as follows.

One Vial of Desferal	5 ml of water for injection
Two Vials of Desferal	5 to 10 ml of water for injection
Three Vials of Desferal	10 -15 ml of water for injection
Four Vials of Desferal	10 20 ml of water for injection

Step- 2. After cleaning the rubber stopper of the Desferal vial with alcohol,the content of the syringe is injected into the vial.

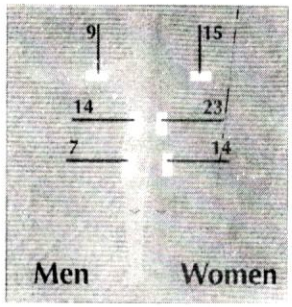
Step-3. The vial is well shaken to dissolve the drug.Do not shake vigorously. It takes more time to dissolve in winter than in summer.

Step - 4. After re-cleaning the stopper with alcohol, the dissolved drug is drawn into the syring

Step - 5. The butterfly type needle (27G short needle long tubing Scalp Vein Set) is attached to the syringe and the empty space in the tube is then filled with the injection solution.

Step - 6. The syringe is placed into the infusion pump. Adjust the timing of the pump in such a way that it finishes in 8-12 hours. Longer the better. Adjustment of time is different in different models, which can be learnt from the Thalassemia specialist.

Step - 7. For infusion, the needle may be inserted under the skin of the abdomen, the arm, upper leg or the thigh.



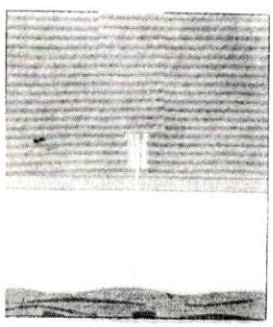
Skin to muscle fascia

Numbers = mean distances (in mm) from skin to muscle fascia (i.e. depth of the subcutaneous tissue)*

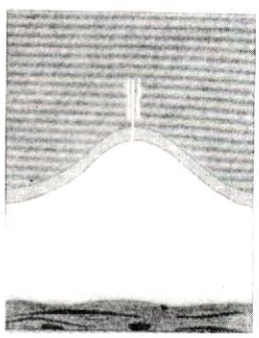
It is important to clean the skin very thoroughly with alcohol before the needle is inserted firmly up to the wings into a fold of the skin formed by the free hand.

The best way to ensure a subcutaneous injection rather than an intramuscular injection is to PINCH-UP and inject into the fold.

No pinch-up



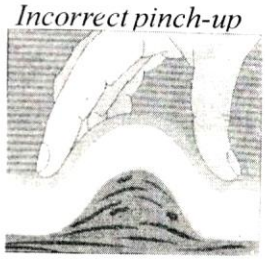
Pinch-up



A correct pinch up should be done only with the thumb and index finger/middle finger, taking up dermis and subcutaneous tissue but leaving the muscle behind.

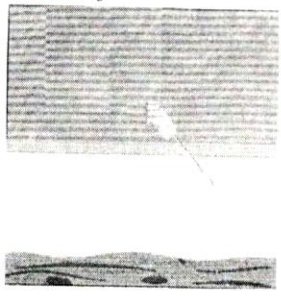
Correct pinch-up

Incorrect pinch-up



It is recommended that injections be given at a 45^0 angle, except for injections with SV sets having perpendicular needle which can be given at a 90^0 angle. Release the grip on the skin fold slowly once the needle has been removed (releasing the grip too soon could provoke an intramuscular injection).

An injection at 45^0



Abdomen is preferred site?

There is usually abundant subcutaneous tissue, and thus less risk of an intramuscular injection. Pinch-up is easier in the abdomen than in the thigh or arm. The fastest absorption of medicine is from the abdomen. However, one must inject within a hand's breadth on either side of the umbilicus. Injections more lateral than this, risk going into the muscle. Even in obese persons, the subcutaneous space narrows considerably when moving laterally.

Special precautions for thigh injections?

Injections in the thigh should only be performed anteriorly and laterally. The femoral vessels and nerves lie medially and can easily be traumatized by the needle. However, there is very little subcutaneous tissue laterally sometimes less than 3 mm. Therefore, all injections in the thigh must be performed with a pinch-up.

Arm the least preferred site?

Like the thigh, the arm has very thin layers of subcutaneous tissue in many people. Therefore, a pinch-up is necessary for each injection.However, it is nearly impossible for an individual to perform a pinch-up and inject at the same time.

Buttocks?

There is abundant subcutaneous tissue in the buttocks, even in children and thin individuals. Therefore, injections can safely be given there without a pinch-up.

Step - 8. The tip of the needle should move freely when the needle is waggled. If it does not move freely, the needle should be inserted in a new site after cleaning with alcohol.

The needle is then fixed and taped. While fixing tape on SV set, ends of the tap should be folded. Folding makes easier to remove the tape when the injection is over, you don't have to scratch the skin to remove the tape. If a paper piece is placed on the wings of SV set., wings of SV set do not stick to tape so it become easier to remove the tape since SV set is not pulled up while removing the tape at the end of injection.

tep - 9. The pump is usually carried on the body using a belt or shoulder holster, however shirt or "kurta" with two big pockets to hold the pump is better option.. Overnight use is the most convenient for the patient.

Step 10 At the end of injection remove the SV set while keeping a spirit swab at the injection site, leave it as it is and tape for some more time

There may be redness or swelling at the injection site, which usually disappears within 24hrs. If it does not reduces or causes discomfort Thrombophob cream may be applied. If pain or swelling increases consult your Doctor.

Iron Chelation is as important for regularly transfused Thalassemic as passing of urine, stool for a normal individual. Do not withhold it just because some thing convenient will be available in future

If you don't utilize your today sensibly, don't expect a brighter tomorrow.

थैलासीमिया न्याय

शिराज (ईरान) के द्वारा प्रकाशित ओमिड पत्रिका में प्रकाशित लेख (Thalassemia Justice) में मोजदेह गधेरी द्वारा लिखित नाटक का हिन्दी रूपान्तरण

पिछले बुधवार को हमने एक थैलासीमिया न्याय नाटक में भाग लिया जो कि इस प्रकार है

शिकायतकर्ता अतिरिक्त लोह
अभियुक्त डैस्फराल
न्यायधीश

न्यायधीश :सभी शान्त हो जाए । शिकायत कर्ता कृपया अपनी शिकायत दर्ज करें।

शिकायतकर्ता :मेरा नाम अतिरिक्त लोह है, मैं जालिम डेस्फराल के विरूद्व शिकायत दर्ज कराना चाहता हूँ । इसने मुझे बेघर, बंजारा बना दिया है ।

न्यायधीश :कृपया विस्तार से बताए ।

शिकायतकर्ता :आप विश्वास किजिए, मैं एक बहुत अच्छी जिन्दगी जी रहा था । मैं रक्त वाहिनी नदी में रहता था । जब मुझे भूख लगती, मैं दिल के होटल में चला जाता, रोज शाम को मै जिगर के उद्यान में जाता, जुम्मे के दिन हम दोनों गुर्दो पर पिकनिक मनाने जाते । एक दिन हमने जिगर के उद्यान में एक सुन्दर महल बनाने का सोचा । धीरे धीरे हमने उसे निर्मित कर उसमें कुछ समय खुशी से व्यतीत किया । अचानक ही थोडे थोडे आक्रमणों से मेरे बहुत से दोस्त मारे गए । ज्यादातर आक्रमण रात के समय होते थे जब हम गहरी नींद में होते थे । मुझे जांच करने पर मालूम हुआ कि हमारा दुश्मन दुष्ट डैस्फराल है । इसने हमारा महल ढा दिया और मेरे बहुत से दोस्तो को भी मार डाला । आप को इसे जरूर सजा देनी चाहिए । यदि आप न्यायधीश है तो इसे अवश्य फॉसी दीजिए ।

न्यायधीश :नम्रता से बात कीजिए । श्रीमान डेस्फराल आप अपने बचाव में क्या कहना चाहेगे ?

डैस्फराल :मैं एक अन्तर्राष्ट्रिय जांच अधिकारी हूँ । अतिरिक्त लोहा और उसके दोस्त मिलकर अनाधिकृत महल बना लेते है । उनके पास निर्माण करने का कोई लाइसेन्स नहीं है । ना ही पंजीकरण का कोई अधिकार है । इसके अतिरिक्त ये लोग दिल और जिगर को ठीक से काम नहीं करने देते, और उनको चैन से रहने नहीं देते । आप तो जानते है कि ये हमारे शरीर के प्रमुख अंग है और यदि ये नष्ट हो जाए तो.....मेरा मुख्य कार्य इन सभी अंगो का ध्यान रखना है ।

शिकायतकर्ता :तुम कायर हो, तुमने मेरे दोस्तो को मार डाला और तुम कहते हो कि तुम इंस्पेक्टर हो, तुम .....

न्यायधीश :शान्त रहिए, न्यायलय में एक घण्टे का अन्तराल रहेगा ।
(एक घंटे पश्चात) अतिरिक्त लोहे को दूसरो की जमीन पर अतिक्रमण और उनकी क्रिया में व्यवधान डालने के लिए दोषी पाया गया । और सभी थैलासीमिकस को मशवरा दिया गया कि वो डेस्फराल इंस्पेक्टर की सेवाएं अधिक से अधिक प्राप्त करें । ताकि अतिरिक्त लोहा हमारे किसी भी अंग पर अतिक्रमण न कर पाए और उनके निश्चिंत कार्यो में कोई अवरोध न हो । अगला मुकदमा आने तक आज के लिए यह न्यायलय खारिज किया जाता है ।

National Thalassemia Welfare Society

National Thalassemia Welfare Society was first to hold symposium on Bone Marrow Transplantation on 24th jan'1993 at Sir Ganga Ram Hospital, created another milestone by holding first National Thalassemia Conference on 4th Feb'1994. The Third milestone was created by launching of "**Kelfer**" by organizing a symposium on thalassemia and Defriprone on 4th Apr'1995.

In this series of milestones National Thalassemia Welfare Society, kept its promise to educate the thalassemic families and update the medical fraternity on newly launched oral iron chelator "**EXJADE**" in the world market, by organizing "**5th National Thalassemia Conference**" on 11th & 12th Nov'06.

The "**5 National Thalassemia Conference**" was inaugurated by the Hon'ble Minister of Finance Dr. Ashok Walia. In his inaugural address he said that Delhi Govt is providing free iron chelating agents Kelfer and Desferal to all the thalassemics registered with the Delhi Govt hospitals and we will also provide new oral iron chelator (**EXJADE**) to our thalassemics free of cost as soon as it is available in the market. He added that at the request of National Thalassemia Welfare Society we have also waived off VAT (sales tax) on Kelfer & Desferal. He said "**We would allocate a 50 beded ward for thalassemics under the supervision of National Thalassemia Welfare Society for better management of thalassemic patients**".

Km. Surrendar Saini, President National Thalassemia Welfare Society, in her presidential address thanked Dr. Ashok Walia for sparing his valuable time out of his busy schedule to inaugurate the conference, and urged Delhi Govt to include Thalassemia in the list of disabled, so that thalassemics can avail of benefits extended to physically challenged persons.

Thalassemia though first diagnosed as early as in 1925, adequate transfusion therapy came into existence in 70's. Earlier the blood was transfused when the haemoglobin level droped to as low as 4-5 gms. This was the time when the need was felt to maintaine haemoglobin around 10 gms. This transfusion regimen increased life span from early childhood to adolescent and thalassemics succumbed to iron overload, due to repeated blood transfusions and not anaemia. In early 70's Desferal was also launched in west. Transfusion & Desferal changed the life of thalassemics so much so that, the thalassemics started looking towards quality life and normal adulthood. It was only because of adequate transfusion & chelation therapy that we have now thalassemics who are touching 6th decades of their active meaningful life.

Desferal being available only in injection form and very short half life (excreted from the body within 5 minutes) has an inherited problem of poor compliance. This made the scientist to look for an oral iron chelator and L1/Deferiprone was launched in Indian market as Kelfer in 1995 and as Ferripox in 1997 in Europe. Introduction of Kelfer in Indian market changed the scenario of thalassemics in India. It had dual advantage of being oral and cost effective. Side effects of Deferiprone like leucopenia, neutropenia and arthritis could not make it the drug of choice for the iron chelation.

On November 3rd' 2005 Defrasirox was approved by US FDA, it had undergone extensive clinical trial and found to be much more safer than Deferiprone and effective as good as Desferal.

Defrasirox (EXJADE) can be dissolved in the water and taken orally, it is given just once a day. It is 5 times more potent from Desferal and 10 times more potent than Kelfer. It takes out iron from the blood and excreted through faeces. It does not extract other minerals like Zinc and Copper. It causes intermittent mild nausea, occasional abdominal pain and constipation. It does not cause any serious side effect and is well tolerated. It has also being shown to have additive effect when given along with Desferal.

Defrasirox (EXJADE) was launched in 25 European Union countries on 30th Aug'06, the promoter of this drug NOVARTIS has already planned to launch it in India. It will be shortly available in the Indian market. We have already requested the company to price it keeping in mind the affordability of Indian thalassemics.

Defrasirox (EXJADE) will be known as **ASUNRA** in India. It will revolutionize the treatment of thalassemia. Indian Thalassemics will have an added advantage of ASUNRA being oral and cost effective as compared to Desferal. Its one daily dose will save the thalassemics from repeated dose of 2-3 times a day as in Kelfer. The low cost, once a day dosage, and oral administration will certainly improve the compliance and thus improving the life span and quality of life of Indian Thalassemics.

Dr. M B Agarwal, Head of Department of Haematology, Mumbai Hospital Institute for Medical Sciences, explained nitty- gritty of EXJADE and most excited but far from reality, cure for all, " Gene therapy."

Dr. Rajat Kumar, Prof of Haematology, AIIMS, explained step-by-step Bone Marrow Transplantation and Dr Mamen Chandy, Prof & Head Department of Haematology, CMC Vellore, highlighted the necessary precautions & care to be taken after the transplantation. He stressed the need of post BMT care, since at times we loose patient even after successful transplantation, due to negligence post BMT Dr. V P Choudhry, Prof & Head, Department of Haematology, AIIMS, explained how to maintain Thalassemia Intermedia. Dr. Sahrmila Chandra, Senior Consultant in Medicine, at Kothari Medical Centre, Kolkatta, talked of thalassemia E Disease which is more prevalent in eastern India.

Besides EXJADE "Adult Thalassemia" was another hot topic of the conference. Dr. Jagdish Chandra, Prof of Paediatrics Kalawati Saran Children Hospital, exhorted professionals of Internal medicines to start adult thalassemia units in medical department.

Grown up Thalassemics, Anjali & Anubha shared their views on "Adult Thalassemics: adjustment & acceptance, Education & Employment" and "Expectations & Obligation of a Thalassemic" respectively. Their presentations were so much exciting & enthusiastic that adult thalassemics present among the audience cheered and applauded their every quotation to the extent that their talks transformed into interactive sessions.

While Dr. A. P. Dubey, Prof of Paediatrics at Maulana Azad Medical College, stressed the need of maintaining Hb above 10gms, his treatment advice was complimented with need of regular iron chelation by Dr. Sunil Gomber, Prof of Paediatrics UCMS & GTB Hospital.

Dr. S. K. Sarin, Director, Prof & Head Dept of Gastroentrology, G.B. Pant Hosp, Delhi, while updating us on management of Hepatitis B & C promised to hold Hepatitis B & C screening camps under the aegis of National Thalassemia Welfare Society, at Thalassemia Center, Tilak Nagar at regular intervals. He also promised that Thalassemics found positive by screening test will undergo Hepatitis B & C RNA qualitative and quantitative test free of cost and if required we would also try to give free interferone therapy. He also advised thalassemics to contact Dr J. S. Arora, General Secretary of NTWS, for the appointment and guidance.
Dr. Nikhil Tondon, Prof of Endocrinology at the AIIMS & Dr. Deepika Deka, Prof, Dept fo Obstetrics & Gynaecology, AIIMS, also agreed to organize a dedicated growth and puberty clinic once a month at AIIMS.

Dr. Ashok Gupta, Prof & Head Paediatrics ,Jammu Medical College stressed that use of Leucodepleting filters during blood transfusion is a necessity and not a luxury.

Dr. A. D. Tiwari Prof & Head of Paediatrics, PGI, Rohtak, said that life-long antibiotic cover is must for splenectomized thalassemics.

National Thalassemia Welfare Society has initiated Dr B N Dara award since 1997. This award is given to an Indian Doctor who has dedicated his services for th thalassemia for long time. Dr. B. N. Dara was a leading Paeditrician of Jaipur with a special interest and sympathy towards thalassemics. National Thalassemia Welfare Society has already honoured Dr. Mammen Chandy, Dr. V. P. Choudhry and Dr. M. B. Agarwal with this award in 1997, 2001 & 2003 respectively. This time the award was conferred upon Dr. M. R. Lokeshwar by the Hon'ble Finance Minister of Delhi Dr. Ashok Walia. Dr. M. R. Lokeshwar was formally Prof and Head of Peadiatrics. Presently he is consultant to Hinduja Hospital. He has been General Secretary and President of Indian Academy of Paediatrics and Indian Society of Haematology and Transfusion Medicine. He started Thalassemia unit at Sion Hospital. He is editor of Pediatric clinics of India and several books. He has received several International & National Awards to his credit.

National Thalassemia Welfare Society also initiated be Social Worker Award at the same time i.e.1997. This award is being given to social worker who selflessly devotes his time and energy for the welfare of Thalassemia. Km Surrendar Saini noted Social Worker and President of National Thalassemia Welfare Society bestowed this prestigious award to Mrs. Vandana Arora. Mrs. Vandana Arora came in contact with National Thalassemia Welfare Society for a project on Thalassemia for her daughter Apurva in 1998 and since then she has never looked back and continuously & tirelessly working for Thalassemia specially by organizing Blood Donation Camps and Awareness & Screening Camps.

NATIONAL THALASSEMIA WELFARE SOCIETY

ACTIVITY REPORT

National Thalassemia Welfare Society in association with **KARSTADT QUELLE & VATIKA GROUP**, Sushant lok I block A, Gurgaon, organized a Blood Donation Camp on **4th Oct'06**. **96 units** of blood were collected by AIIMS blood bank team.

On 2nd Nov'06 NTWS organised a blood donation camp at LIC branch no. 128 C 26-27, Janak Puri, Pankha Road, New Delhi, where **37-units** of blood were collected byAIIMS blood bank team.

On 17th Nov'06 NTWS organised a blood donation camp at Deen Dayal Upadhyaya College, Karampura, New Delhi 15. Where DDU blood bank team collected **92 units** of blood.

On 26th Nov'06 NTWS organised a blood donation camp in association with ART OF LIVING at Society's premises KG-1/97, Vikas Puri, New Delhi. Where DDU blood bank team collected **77 units** of blood.

On 28th Nov'06 NTWS organised a Screening Camp in association with MVBDA at Arya Samaj Mandir, Tilak Nagar 75 students were screened.

On 6th Dec'06 NTWS organized a Blood Donation Camp in association with Ballar Pur Industries Ltd, at **1st** India Place, Mehrauli, Gurgaon Rd, Gurgaon. Where AIIMS blood bank team collected **30 units** of blood.

On 1st Jan'07 NTWS organized a Blood Donation Camp in association with Naraina & Rajinder Nagar Block Congress Committees on the occassion of Birthday of Sh. Ram Babu Sharma, President DPCC, at Jain Sthaan Chowk, Budh Nagar, J J Colony, Inderpuri. Where, LNJP Hospital blood bank team collected of bloods.

On 6th Jan'07 NTWS organized a " **Serum Ferritin Estimation**" & "**Hepatitis B Vaccination**" camp in association with Sun Flag-Pahuja Centre for Blood Disorders & Thalassemia, at Faridabad, Haryana. Ferritin samples of 68 children were taken & 58 children got vaccinated for Hep-B.

On 11th Jan' 07 NTWS organized a blood donation camp at Chandiwala Estate Okhla New Delhi where 104 units of blood were collected by AIIMS blood bank team.

On 8th of 9th Feb'07 a 24 hour blood donation camp was organised by NTWS at **Keane Gurgaon** where 166 units of blood were collected by AIIMS & LNJP blood bank team.

On 14th Feb' 07 NTWS organized a blood donation camp at Art Faculty Gate, Nr. DUSU' Office, North Campus, Delhi University where 60 units of blood were collected by AIIMS blood bank team.

On 23th Feb'07 NTWS organized a blood donation camp at FICCI. blood was collected by LNJP blood bank team.

On 14th April 2007 Sai Charitable trust Rohini in association with NTWS organized blood donation camp where 81 units of blood were collected.

On 19th April 2007 NTWS organize a blood donation camp in association with Sarla Fabrics Ltd. Ghaziabad, where DDU blood bank team collected 37 units of blood.

On 22nd April 2007 NTWS organized Blood Donation Camp in association with EKTA Ladies Club, at Sarita Vihar, B' Block Community Centre where AIIMS blood bank team collected 46 units of Blood.

On 26th April 2007 NTWS organized Blood Donation Camp in association with DLF Square, Gurgaon, where AIIMS blood bank team collected 106 units of Blood

On 27th April 2007 NTWS organized Blood Donation Camp in Bechtel India, Gurgaon where 121 units of blood were collected by AIIMS Blood Bank.

NTWS has participated in Gynae Conference "FOGSI 07" by putting up a stall & distributing brochures, posters. The stall was very attractive with display of flexi Thalassemia panels. Dr. J.S. Arora organized an on the spot Thalassemia Quiz for the Gynae Doctors. Most of the obstetrician were unaware of the impact of the desease. Mr. & Mrs. Hemant Gera both software engineers & Thalassemic parents took actively part in creating awareness in the conference.

DISABLED

DRG has organised a meeting on Friday, 19th January'2007, at AADI- Action for Abilities Development & Inclusion (formerly Spastic Society of Northern India),, 2, Balbir Saxena Marg, Hauz Khas.

It was a great opportunity to meet and listen to Mr. Riku Virtanen of Finland. Riku is Deafblind, but inspite of the severe nature of his disability, he is a secondary school graduate and now a student of law at the University of Turku since 2002. Rinku was actively involved in the process on UN Convention on the Rights of Persons with Disabilities.

It was a great pleasure to welcome Mr. Rinku Virtanen to our country and to be able to meet him and to listen to him. This at a time, when merely being deaf is punishable in 21st Century India (Maniram Sharma denied IAS and given an Accounts Service instead) and being totally blind means that all employment doors are shut upon you because people with partial blindness will be preferred.

THE THALASSEMIA SOCIETY OF INDIA KOLKATA

A Synopsis

Dr. Taraknath Mukhopadhyay

In 1984, a group of wild-eyed but determined parents of the unfortunate thalassemic patients formed "The Thalassemia Society of India" to combat the onslought of the dreaded disease "Thalassemia".

The activities of the society revolve around two theme areas
(a) assisting the existing patients by providing state -of-the- art treatment management protocol.
(b) Prevention of this disease by creating greater awareness through effective counseling.

Among other activities, society runs its own treatment center in a rented premises at 18, Raja Rammohan Sarani, Kolkata. To provide treatment, two basic requirements of the society are safe blood and effective chelation. Towards this end, the society organized around 300 voluntary blood donation camps thereby collecting around 18000 packets of blood in a year. The society also organizes carrier detection camps through which around thousand persons per year are tested for Thalassemia carrier status.

Society also organizes different orientation camps about Thalassemia regularly in different places to aware the public about the risk of the Thalassemia and way to prevent it.

Society also organized International Seminar on Thalassemia one year ago. It is also member of the Thalassemia International Federation, Cyprus. Presently around 250 patient are given treatment in this center who come from various parts of West Bengal. Owing to paucity of accommodations these unfortunate patients have to come all the way form far off places and go back.

The Objectives:

The objectives of the society are as following: To provide assistance to the affected Thalassemic patients in the treatment of the disease. To generate awareness about Thalasemia and to prevent it. To carry on with research activities to bring about a cure for this dreaded disease and other allied haemotological disorders.

TREATMENT STATUS AT A GLANCE

The Thalassemia Society of India , Kolkata is running its own Treatment Center. Society provides blood to all the patient at a very low cost, & to some of them free of cost.Society also collects funds from the people to provide chelators free of cost as frequently as possible.

Society also has its own laboratory, where patients get the facilities for testing Hb, TLC, DLC, platelets, LFT, Ferritin and other routine haematological investigations at a very low cost or free of cost.

As a result of our sincere efforts and with the blessings of the God a better standard of the patient is achieved. Average pretransfusion Hb is maintained around 8-9 gm. Within 200 patients around 60% are E-ß Thalassemia among 200 patients

1. 15 patients are transfused at interval of 8-10 days.
2. 15 patients are transfused at interval of 2 months.
3. 70 patients are transfused at interval of 3 months.
4. 20 patients are transfused at interval of 1 month.
5. 50 patients are transfused at interval of 2-6 month.
6. 30 patients ate transfusion free.

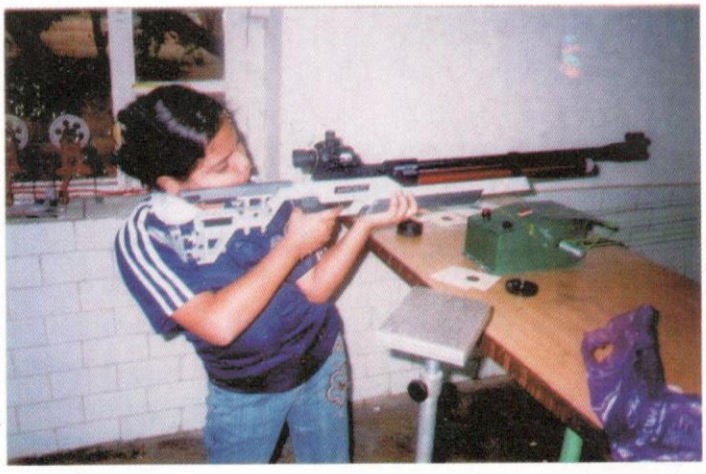
AGE DISTRIBUTION

1. Upto 5 yrs.	10 patients.
2. 5-10 yrs.	40 patients.
3. 10-20 yrs.	100 patients.
4. 20-30 yrs.	30 patients.
5. Above 30 yrs age	10 patients.

Among our patient 1) Two of them mothers,
2) Two of them fathers.

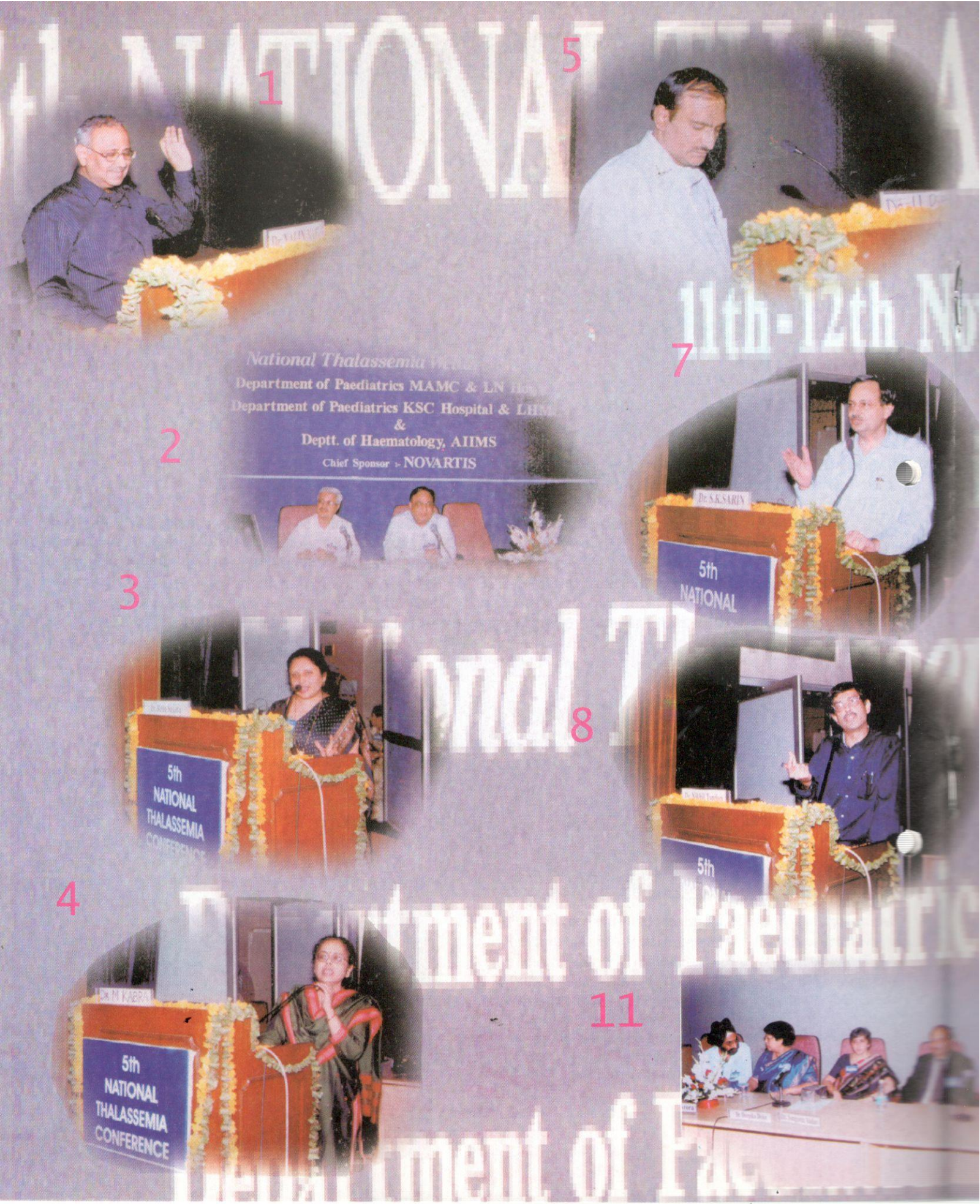
Among our patients serum ferritin maintained below 2500 ng/c.c. is approx. 40% of patients. Due to poor financial condition all cannot afford chelation properly. Besides conventional treatment of blood transfusion and chelation other modern treatment facilities are also in practice. About 32 patients of this treatment centre are on Hydroxyurea therapy and results are very encouraging. Wheatgrass juice therapy is also given in our treatment center, the results are still awaiting. I was also involved personally in Bone-marrow transplantation, conducted in Kothari Medical Centre, Kolkata a few years back.

Dr. Sunil Gomber Professor of Paediatrics, incharge Heamato-oncology division of department of Paediatrics at UCMS & GTB Hospital receiving "DELHI STATE AWARD" for service doctors for meritorious services in the field of Paediatric medicine from Smt Sheila Dixit Hon'ble, Chief Minister of Delhi and Dr. Yoganand Shastri, Hon'ble Health minister of Delhi on 29/8/06 at MAMC Auditorium New Delhi.



Ms Gargi Sarker D/o Sh. S.P.Sarker bagged the Gold Medal in all India Kendriya Vidyalayas Sanganthan National sports meet, 2006-2007 organized by Mumbai Region held at Pune, 9-13 Oct. 2006
Showing her in shooting position

Ms Gargi Sarker D/o Sh. S.P.Sarker bagged the Silver Medal in Shooting Competition organized by Kendriya Vidyalayas Delhi Region at Tughlakabad 6-8 Sep. 2006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2
National Thalassemia
Department of Paediatrics MAMC & LN
Department of Paediatrics KSC Hospital & LHM
&
Deptt. of Haematology, AIIMS
Chief Sponsor :- NOVARTIS
3
5th
NATIONAL
THALASSEMIA
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CONFERENCE
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Dr.S.K.SARIN
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NATIONAL
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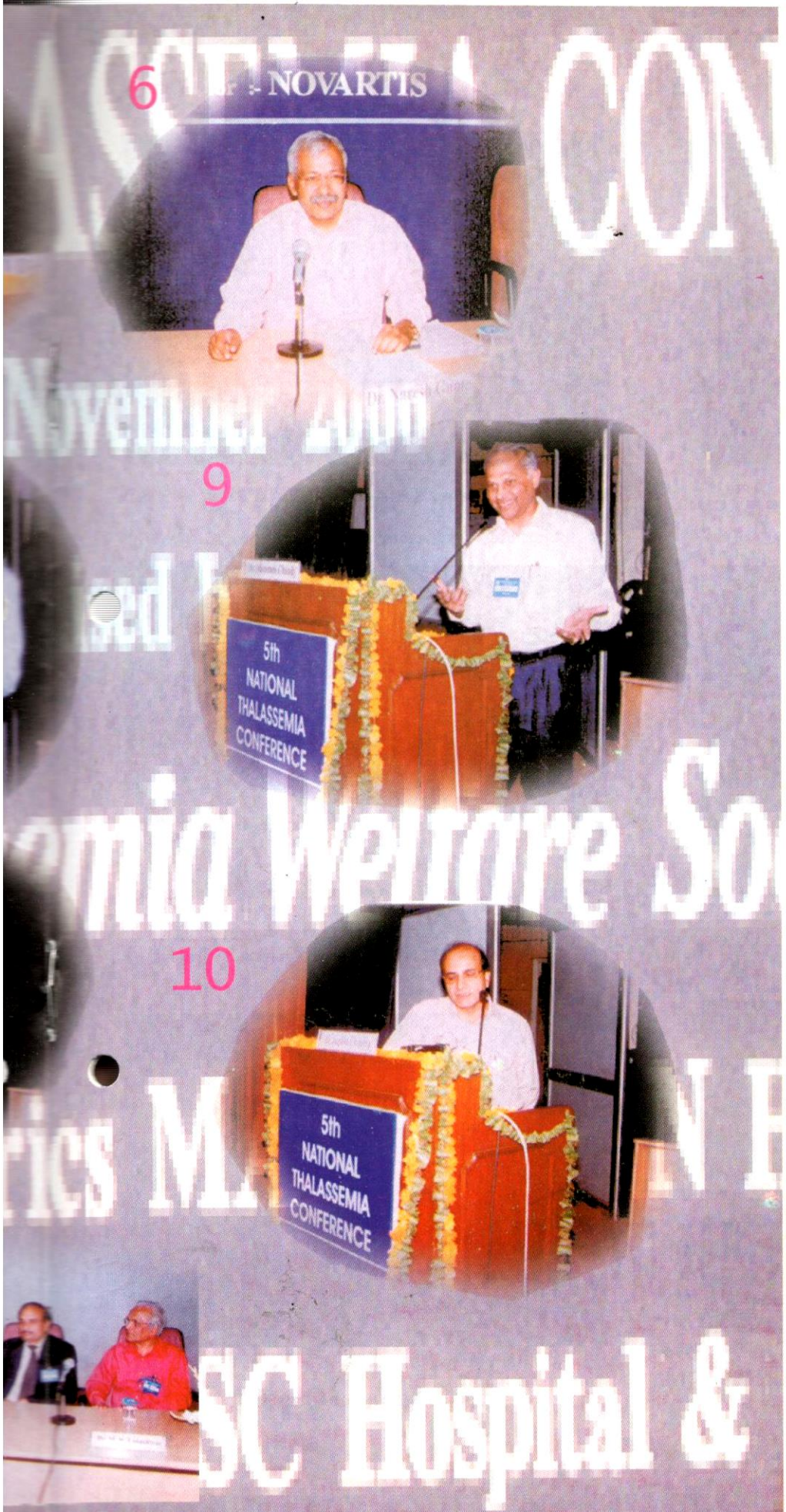


1. Dr M.B. Agarwal elucidates the new Oral iron chelator Exjade

2. Mr Anil Shah (Secreary Citizen NGO),
   Dr. R.B. Shah (President TSCS Ahemdabad) chairing a session

3. Dr. Renu Saxena (Prof of Hematology at AIIMS), explicates the coagulability in Thalassemia at 5th NTC

4. Dr. Madhulika Kabra (Prof. of Paediatrics & incharge, Genetic Unit at AIIMS) illuminating on prevention of Thalassemia at 5th NTC

5. Dr H.Patti (Prof of Hematology at AIIMS), edifying issues in Diagnosis

6. Dr. Naresh Gupta (Prof. of Medicine LN Hospital) Chairing a session on adult Thalassemia

7. Dr. S.K. Sarin (Prof. & Head of Gastro-entrology GB Pant Hospital) expound Hepatitis B & C infection in Thalassemics

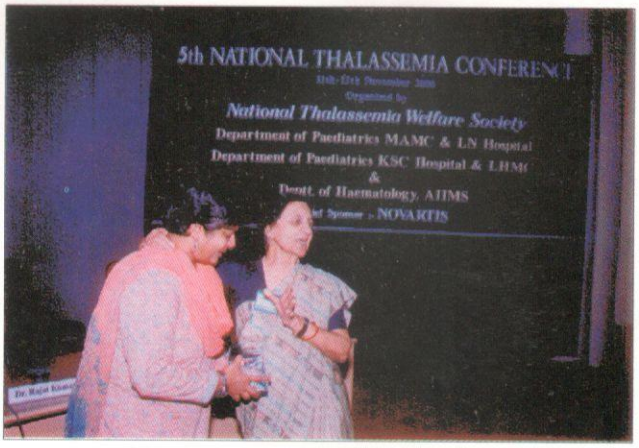
8. Dr. Nikhil Tandon (Prof. of Endocrinology at AIIMS) enlightening the audience on Calcium & Bone disease

9. Dr Mammen Chandy enlightening on post BMT Care

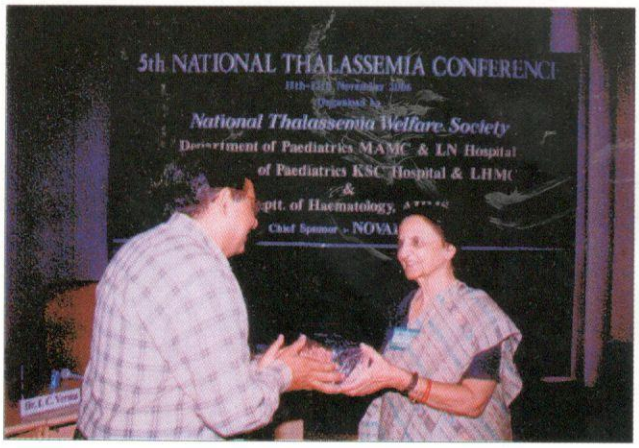
10. Dr Jagdish Chandra presenting highly informative lecture on adult Thalassemia

11. Dr. J.S. Arora, Dr. Deepika Deka Prof of Obs. & Gynae at AIIMS),
    Dr Sangeeta Yadav
    (Prof of Pediatrics LN Hospital and MAMC),
    Dr A.P. Dubey (Prof & Head of Pediatrics LN Hospital and MAMC)
    & Dr. M.R.Lokeshwar during panel discussion

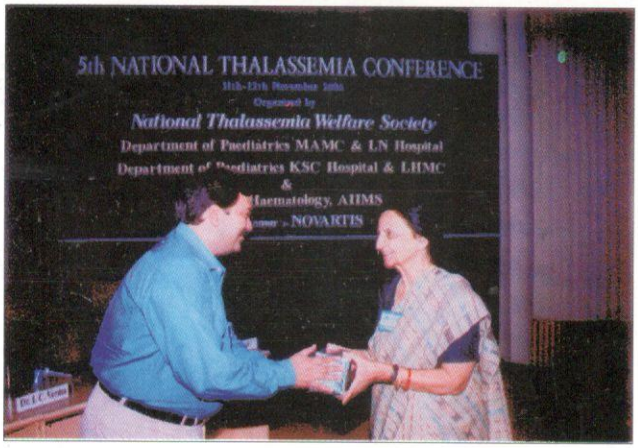
Km Surrendar Saini (President NTWS) presenting Mementoes to executive members of NTWS



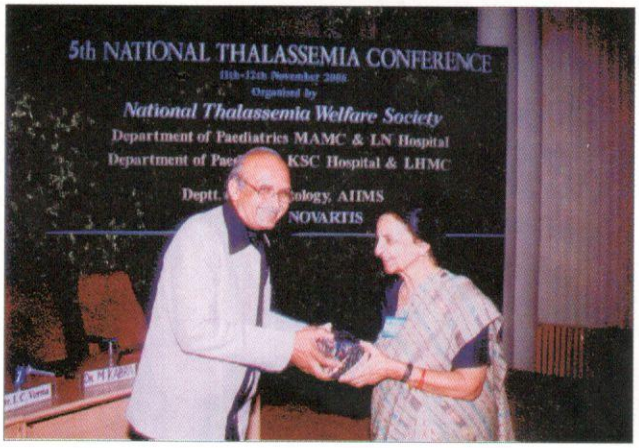
Mrs Sreelata Rudra



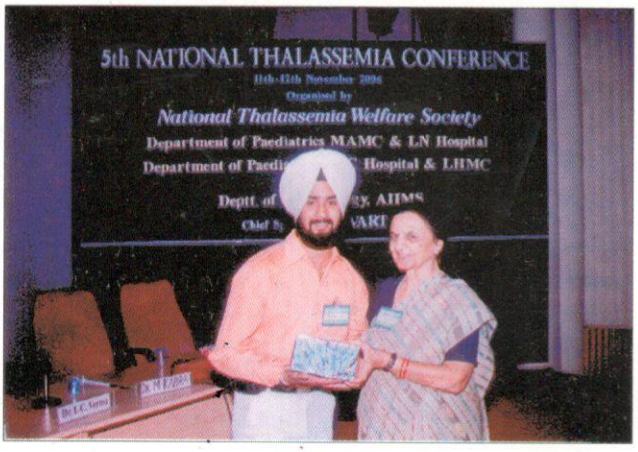
Mr. V.K. Meglani



Mr. Neeraj Tripathi



Mr. Ashok Sachdeva



Mr. Gagan Deep Singh

Mrs. Monisha Gogoi

SERUM Thalassemia Prevention Federation

Sanjib Acharya

Serum Thalassemia Prevention Federation is a Kolkata based registered Society. We are providing extensive services for control & prevention of Thalassemia. We are doing our job at the District as well as at the Block level in the entire eastern India under the banner of "SERUM THALASSEMIA PREVENTION FEDERATION" with the co-operation of different organizations and institutions.

M/s S. Serum Analysis Center(Pvt) Ltd. is one of the leading associates of our Society and it is also a leading referral Laboratory in India. It not only helps in screening the blood through HPLC process for detecting Thalassemia Carrier at a very subsidized rate, but also extend hands for the awareness of Thalassemia disorder.

The main objectives of our Society are as follow:

To conduct seminars, conferences and counseling for prevention of Thalassemia disease.

To publish brochures and reports for the mass awareness on Thalassemia disease.

To encourage tests at pre-marital stage for detection of Thalassemia carrier in order to prevent Thalassemia disease.

To do anything necessary and proper for the control of the Thalassemia disease.

To consider and deal by all lawful means with the common problems involved in Thalassemia disease.

In this noble cause we are not alone we are associated with **Mohonbati Health Care Welfare Society, Sristi Nursing Home & Karukrit Advertising Private Ltd.** organizations and institutions for the mass communication on Thalassemia.

We are planning to expand our services in the field of Thalassemia extensively throughout the country. In this context we express our desire to associate and also to provide our services in the awareness of Thalassemia to highly esteemed organization NTWS. We assure you for our best co-operation and support to your attempt in the burning issue of deadly Thalassemia disease.

THALASSEMIA PREVENTION ACTIVITIES OF WEST BENGAL VOLUNTARY BLOOD DONORS FORUM

Why we are in this business

West Bengal Voluntary Blood Donors Forum, a voluntary organization, working for the promotion of voluntary Blood Donation in the state of West Bengal since 1977. In 1980, 2493 units of Blood were collected in West Bengal, but in 2005 the same has crossed 5,00,000 unit. Still shortage of blood is experienced.

It is observed that among the many reasons demand of Blood in West Bengal has been increasing due to growing number of Thalassemics. Every year 5 to 8 percent extra blood is needed for the new thalassemia patients. To minimize the growing demand of blood and to restore light and hopes of many dying patients, WBVBDF has launched Thalassemia free West Bengal Project in 2003 to eradicate the disease by way of awareness activities.

Thalassemia Annual Day Celebration on 14th Nov'06 (Childrens' Day) at Kasturba Hospital

Consecutively third year anniversary of TDCC was celebrated at Kasturba hospital on 14th November 2006. This is done every year in association of Rotary Club Uptown.

Dr. Madhu Jain, DHA, MCD was the Chief Guest and other persons on the Dias were Dr. P. Bhatia, M.S., Kasturba Hospital, Dr. J. S. Arora, General Secretary, National Thalassemia Welfare Society, Mr. V.K. Jain and Mr. Sushil Gupta from Rotaty Uptown, Dr. D. N. Virmani, HOD(Paed) and Dr. Leela Pant, HOD(Path). All the dignitaries on the dias said few words of encouragement & appreciation.

Dr. S. Mehta, I/c T.D.C.C, anchored the programmed..

Dr. Virmani presented the annual report of TDCC & highlighted the fact that in 2006, 408 transfusion were given without any untoward reaction.

Vote of thanks given by Dr. Mahar (BTO).

All 33 registered Thalassemic children attended the occasion. They were given gifts by the Rotary Club and there was an entertainment programme organized by the School of Nursing, Kasturba Hospital for these children.

The parents of the Thalassemia children were also given an opportunity to address the gathering & all of them were happy

JAMNAGAR THALASSEMIA WELFARE SOCIETY

Mr. Vaman Jani

In memory of my late daughter and with honest intention to serve humanity, Priti Jani Memorial Trust was formed in the year 1995. There was very little or no awareness about this genetic blood disorder. It took me some time to understand. Started meeting parents, visiting Government Hospitals, collecting literature on Thalassemia from various sources. Afterwards, started distribution of leaflet on thalassemia as a part of awareness program. Simultaneously, arranged blood for individual Thalassemics by finding donor, supplied B.T. set, arranged blood transfusion and fund permitting supplied Desferal also. Due to paucity of funds, I was able to offer to one or two children maximum. Since fatality occurred due to iron overload, I was under terrible frustration but undeterred.

I continued distribution of leaflet on Thalassemia for awareness, frequently meeting thalassemic parents and motivating them, ultimately able to convince them to have their active involvement, as a result of which Jamnagar Thalassemia Welfare Trust was established and registered as Public Charitable Trust in the year 2004. By then, with continued pursuance with the Government Hospital authorities, a separate ward for thalassemics was established and close family atmosphere developed with parents and doctors which gave us better co-ordination.

We have 200 Thalassemics receiving blood transfusion at the Government Hospital who maintains the patient register. By virtue of regular visit at the ward by the Trustees who are the Thalassemic parents, we have developed better understanding. Blood transfusion is carried out at the Government Hospital to almost all the Thalassemics and the hospital authorities do not charge any money. We get 100% screened blood. Since the Hospital is run by the Government, the Doctors keeps on changing due to transfer but we do have a Pediatrician on our Board of Trustees whose guidance is sought if required.

Appreciating Government Blood Bank services especially for Thalassemic, we pursue locally and arrange blood donation camps at a regular interval to ensure that there is no shortfall in blood supplies. Hospital supply complete B.T. administration set free of cost which is much appreciated.

We have four private Blood Banks in town who suppling blood free or against replacement donor but they charge for blood analysis and most of the parents being poor they do not opt this alternative except one or two affording parents who pay to private Hospital for blood transfusion as well which is a costly affair.

A few patients are on regular iron chelating Desferal who can afford having a pump of their own since no infusion pumps are available at the Hospital. Most parents are so poor that they can't even afford Kelfer. Five to ten parents use filters which are procured on subsidized payment for which the patient becomes member of Mumbai Thalassemia Welfare Society. Members also recieve50% concession on Kelfer. Patients who are not the members, procure Kelfer from Ahmedabad Depot for which cumbersome forms are required to be filled, giving ferritin level, preparation of Demand Draft as advance payment etc., makes the scenario worst and unpleasant.

Prior to the formation of this Trust, we have carried out blood test of individuals from the high risk communities with electophoresis free of charge since we tied up with the Reliance Life Sciences, Mumbai which has met with great success. We do have antinatal diagnostic facilities available with local gynaecs. Few couples at risk having undergone CVS sampling are blessed with normal babies. We regularly conduct massive awareness program during blood donation camps as well as distributing leaflets on Thalassemia. We do have all blood testing facilities available but with no Government support. Even to measure the serum ferritin level, we are asked to go to other laboratories in the town. We are pursuing hard to commence use of the cells separetor and opt for blood component therapy since Thalassemics require only RBC, while other useful components go waste.We are also pressing hard on supplying Kelfer free of charge to all thalassemics. Gynaecologists are fully aware of this disorder and screening regularly during pregnancy-particularly people from high risk communities. We also help poor patients with vaccines before spleen removal.

We are launching a massive screening program for female students from 8th standard to 12th standard from high risk communities very shortly with CBC. We intend to cover all the Girls Schools in Jamnagar town provided the funds permit. Those found positive, will further be tested on electrophoresis since we firmly believe that in our country cure is unaffordable by all and therefore it will be in the interest of the society to conduct mass screening program. We do not have any political celebrity attached, to getting things done.

We have two bone marrow surviving transplant Rinku and Shikha - who are both enjoying normal health. Rinku is over 18 years of age. Dr.Mammen Chandy performed bone marrow transplantation at Vellore on both these patients successfully. Rinku suffered GVHD after the marrow transplant but could overcome the entire hurdle while Shikha is normal.

We have Payal - 21 year old female - and most properly managed surviving child with regular blood transfusion and iron chelation with combination therapy.

A BIG CHERRY ON AN ICE-CREAM

By-: Jasmeet Singh Ahuja

One Sunday, I went for morning walk. As I am a patient of allergy, my doctor has advised me to go for morning walks for fresh air. I start it from the main road near my house and jog till the park ends, which is about two miles away. I was all in sweat because of continuous jogging. The weather was quite hot; July is the most humid month. Whenever I go for this morning walk, I just curse my doctor, my parents, my allergic life and also God, for making me so defective.

There was no one around me in the park. Far ahead, I could see some guys playing football. I took out my bottle of water and was drinking it when a girl came jogging and she sat down on the next bench.

I looked at the girl beside me. She was heavily breathing and was using an inhaler. It looked as if medicine was not coming and she was desperately in need of it. She was becoming more and more impatient. I even noticed her body shivering. Something was definitely wrong. I enquired, " Can I help you?"

She looked at me, " Get me some water."

I got up but realized that I had just finished up my bottle. I went to the roadside to see if I could get some help. There was no one. I decided to go to the guys playing football. May be somebody has water. Fortunately, they helped. The girl was feeling better when I reached with water. Water ameliorated her problem. She thanked me. " Anything wrong with you." I asked.

She was about to tell me when a big car stopped in front of us on the road with loud music from 'Rang De Basanti' going on, 'Loose Control'. The speakers of the car were great. Seeing the car, she smiled and ran towards it. While going she turned back and said, "Thank you". Within a minute, she reached the car and the next thing, which I saw made me more surprised. This girl climbed to the top of the car and sat on the roof and started shouting and enjoying with the music. The car was gone within a second, spreading the loud music everywhere.

That whole day, I couldn't forget her. At heart, I really loved her attitude to life. She was, what we call these days, in a wrong spelling, KOOOOOOOL!

" I am fine. You disappeared yesterday. I hope you are fine now." I said.

" Ya. It's part of my life." She said smilingly.

" What are you doing here?"

" Well" she handed me a pamphlet, " We're organizing a blood donation camp for thalassemia patients, tomorrow."

Next day, my sister asked me to drop her to The City Hall. She was going to that blood donation camp with her school group, to donate blood. I looked at her, wondering, it was such an easygoing thing for her. I accompanied her.

" What is this Thalassemia?" I asked my sister on way.

" It is some kind of a blood disorder. I don't know much about it." She replied.

Seeing the visitor tag on my pocket, she asked, "Just a visitor? not donating?"

" No. My sister is donating."

" What about you?"

" Well...I am not...actually I don't feel like."

" You are not ready for donating, right?" She said.

I realized she was right. I nodded.

" Don't worry, it's ok. It takes time for people to get ready. But I'm glad you came. It'll give you an idea." I nodded again.

" Tell me what is this 'Thalassemia'. I mean everywhere it's written. What is it?"

" You don't know what is Thalassemia?" She asked. I shook my head.

We were walking in the garden. She started, " Thalassemia is a genetic blood disorder. It is a hidden disorder. Thousands and even millions of people in certain communities and countries carry the thalassemia gene but have no knowledge or awareness about it. It is only after the fact that they get married to another person carrying the same gene and have kids, they hear about it."

" What kind of disorder?"

" Actually, the Hemoglobin producing gene of parents is defective, so when a child is born of such a marriage, the Hemoglobin producing gene is missing in him."

" Oh! Then how does the child lives?"

"Hemoglobin maintenance, that is to say, maintain a mean Hemoglobin of 9-10gm to keep the child alive. And this is only reached by blood transfusion every 3rd week."

" What! Are you serious?" I asked her.

" Yes I am. I am one of them."

I stood where I was, looking at her. "Yes, I had been undergoing blood transfusions since I was a kid. It has become part of my life now. But this is just one sort of thalassemia. There are other types also, which are not so severe."

She looked at me and said, "You're wondering if that is true then why do I look so ok and so fine." I nearly nodded.

"After blood transfusion, the patient becomes ok. Although, there are lot of other problems but ..who doesn't have problems. It is just part of it you see. It doesn't stop you from living your life."

" I don't know how to react. You've told me something, I feel so shocked. I mean, such big thing had been there and I didn't know about it. I mean. I had never ever heard about it."

"It is normal. Our Government has not taken it seriously. Actually, there are lots of patients but not enough blood and this result in death of so many patients. Thalassemia's prevalence in India is so so high that according to one statistical data, 1 in every 20 Indian is a carrier of a potentially pathological hemoglobin gene or in other words a defective hemoglobin-producing gene. If we look at it, it is quite common." "Exactly, that's what came to my mind." I said. Both of us walked with some steps of silence. " I really want to thank you for that day."She said

It's ok." I said. " Was that also due to this Thalassemia thing?"
"Not exactly. Actually, due to continual blood transfusions the body develops some problems. It can be due to that that I am asthmatic. I'm not sure."
Before we could continue our conversation further, somebody called her. She had to go. Within an hour, my sister was also free. She was ok. I had been worried about her. I saw a feeling of pride on her face to be a donor. She came to me and said, " I feel so good. Atleast, I have helped someone. I have given life to someone." I patted her back. She showed me another pamphlet, " This is a party ticket."
" Party ticket?" I asked.
"All donors and all patients are invited for a party in Hotel Taj." She said. " Isn't great?"
I wondered how courageous these people were. " Ya. It's great."
Before I was going, that girl met me at the exit, she handed me the same ticket. I was surprised, " But I am not a donor."
" I know you'll be one soon." She smiled and hugged my sister.
My sister lateron said, " She is too good." And I just nodded.

On the party night, I was stunned to see people rocking the party just like a normal party. I mean to say, no one could say they were ill or they had a serious blood disorder and for that they keep getting blood transfusions every third week. My sister found her friends and she got mixed up with them. I rather sat on the stool to have a drink. People dancing were all youngsters. The music was quite loud and girls dancing on the floor were not bad, either. DJ was awesome. My feet were tapping and my shoulders were moving with the beats. After a long time, I had been to a nightclub. I was enjoying the crowd.
In between, announcements were also going on to thank all the blood donors. Donors and guests were asked to take floor too.
After an hour, I found that girl sitting with some elder people. She looked at me and smiled. It looked as if she had been looking at me for a long time. She came to me.
" Why aren't you dancing?"
" I don't feel like."
" Don't hesitate. Don't you like this party?" she asked.
" Yes, I do."
" DJ is great." I nodded.
" All of these are thalassemia patients?" I enquired.
" Most of them. But don't think that everyone here gets blood transfusions."
I chuckled. " They don't look like patients."
" I know. That's what we teach them in our community. To live life as much as you can."
" Community?"
" We have a Thalassemia community."
" Ok." I said. " It's great."
" So now you want to be a donor."
" Well, my mind is drifting to that side."
" That's good."
Suddenly the music stopped. She said getting up, " Oh! That's my turn. Watch it." There was an announcement about a special dance sequence by Thalassemia Community Counselors. She with two more girls and one boy went on floor. The music started and it was "Koi Kahe Kehta Rahe" from Dil Chahta He. The dance was splendid. People just couldn't stop themselves. Every single person in the party danced with them. I wondered again, were they really patients!
After the party was over, she met me outside. My sister was still with her friends, so I had a bit of conversation with her again.
" I loved it. I think that's the best party I have ever attended." I said.
" I can't tell you how many people have said the same thing today. I am so happy."
" You guys are really...amazing. I mean, you exactly do what you want."
" I know what you mean. Yes, we do what we want to do. We enjoy life to the full."
" It's so different...you are so different...you sit on top of a moving car and enjoy, you dance great, you are always so happy, you are always into some activity...I mean how do you get the energy?"
She laughed. " It comes automatically. Look, everyone has to die. You, me, everyone else. No one will live forever. So what's the difference? I believe in try fulfill all your dreams, try everything you want to try, I mean, if you want to sit on top of a moving car, just sit. Sing like a rock star. Dance like as if no one is watching. Be part of everything you want to. Talk to everyone. Be good to everyone. How long are you going to condemn God for giving you such a miserable life? Isn't it enough that he atleast gave you a chance to be born like a human being?"
" You are amazing."
She smiled. " You believe in dreams?" She asked me.
" Yes I do."
" What's your biggest dream?"
" I want to be known."
" Then start working on it, coz life is too short. You never know when the chances are given. You have to grab them to make your dream come true...coz the stock is always limited. You know what I mean?" She said.
" I know. What's your dream?"
" I want to be the best in everything I try. Be it dance, singing, games, anything. I just want to be at the top. Just like a big cherry on an ice cream."

The Walk to the Base Camp of K2

The Thalassaemia Society of Pakistan is a torchbearer in the lives of Thalassaemic patients. It is a streak of hope for the ailing souls of young children who are doomed forever to pain and suffering.The Society's aim is to create awareness and consciousness about this inherited disorder. Thalassaemic children often feel that they are incapableof performing daily activities like normal children, let alone the strenuous activities. This singular misconception in their minds was replaced by self-confidence by one inspirational idea of the Society. The children, who have the strength to face such bitter anguish in life with smiling faces, can accomplish anything! The challenge was to walk to the base camp of the second highest mountain in the World K2. The idea was a head turner from the very beginning. How can children who are already anaemic and incapacitated, surmount such a great obstacle? Its true that people sit up and listen to the most crazy ideas - the challenge was well supported by the Thalassaemia International Federation and took a final shape. So, with the guidance and support of the Society, five Thalassaemics took it up themselves to accomplish this Herculean task. They, along with their parents and with the help of the Society began the arduous toil of preparing for the walk. The walk to the Base Camp of K2 took a better part of a month but the preparation took nearly a year. The enthusiasm of these children renowned our faith in the power of conviction. They blissfully underwent constant physical training, stress tests and regular monitoring to confirm their endurance for the physical conditions at the base camp of the "Second highest mountain in the World".The goal of this test of endurance was to spread awareness about Thalassaemia, but the most important message these children wanted to give to the world was "IF WE ARE LOOKED AFTER PROPERLY, WE CAN DO ANYTHING IN THE WORLD!"

These courageous children eloquently expressed their heartfelt emotions and gave the world a golden chance to be a part of their lives. From here, a new chapter of infinite hope and conviction begins. The tedious journey started with generating funds for the walk, training the participants, a 10 day trek and final culmination at the base of the mighty K2, which stood to honour the dedication of our little soldiers. These Thalassaemic children, began their journey by road on July 2, 2001.

After two days, they reached the highest desert region in the world, the valley of Skardu. The children and other participants, stayed in Skardu for a week, walking every single day so that they could become acclimatized to the thin air. Finally the 10th of July dawned upon this group of 32 people, who set off for Thungal by jeep. Where they camped for the night. On the 11th of July the group started walking for the next destination which was Korfung. The first day walk lasted for 12 hours for these children, every step was exhausting and required great conviction and motivation for the noble cause

.

One of the toughest terrains in the world lay unfathomed and the miles ahead were tormenting. Beautiful landscape turned into a real life drama as these children traveled with their full perseverance. Perils were numerous but the hopes soared higher. Many a time the Society members were intimidated by the intensity of the perils that lay ahead but faced it skillfully and bravely. Gushing, ice cold waters roared below bridges made of wooden logs. Atreacherous path ascended into the mountains and onto the glacier; the air grew thinner and breathing was laboured ? energy levels were sapped ? But hopes never shattered. Watching these children toil for their sick friends was heartwarming.The world watched in amazement as the walk continued unabated to Jula, Paiyo, Khobrste, Urdukas, Gore 1 & finally Concordia. The Walk came to an end at the base camp of K2 on the 19th of July. Exhausted children, their parents and volunteers rejoiced at their achievement. Emotions soared high. Tears of happiness rolled down cheeks. They had set new standards of courage and endurance. They had proved to the world that though ailments weaken bodies, souls are immortal and can reach any height if there is the will to do so. We are sure you have enjoyed this beautiful experience of our brave soldiers. Our world is definitely more complete and perfect with the dedication and courage shown by these children. Our venture was not possible without the help of our generous sponsors. They have illuminated the lives of Thalassaemics with their cooperation and assistance. We express our heartfelt gratitude to our friends at: Bank Alfalah, Lipton Yellow Label, World Call, Hang Ten, Servis Shoes, Punjab Horticulture Society, CDL Foods, McDonalds, Salt 'N Pepper, Rafhan Best Foods, Nirala Sweets, Seasons Canola & Punjab Horticulture Authority. We are especially indebted to Align Technology. With their gracious help, our courageous team of heroes came home safely and comfortably by helicopter. All our beneficial sponsors made our journey to the base camp of K2 more than a mere dream and Align Technology completed it with the perfection and grace such an endevour deserved. We would also like to thank Millennium Tours for organizing the walk for us and for all the support and help they have provided.Last but not least we extend our thanks to our friends from the UK, Mr.Gerald Mason, Dr. Robert Mueller, Ms. Irna Qureshi, Ms. Gulshan Karbani & Dr. Tasleem Tariq for contributing very generous donations to the society

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*SUNNYSINGLA
T.C.W.A

THALASSEMIA SURVEY / थैलासीमिया सर्वेक्षण

Name
नाम ..... D.O.B.
जन्म तिथि..... Sex
लिगं .....

Father's Name
पिता का नाम ..... Occupation
व्यवसाय.....

Address
पता .....

Resi. Phone No. (with STD Code)
घर का फोन नं ..... Office Ph. No.
दफ्तर फोन नं .....

E.mail
ई मेल..... Fax No.
फैक्स नं .....

Education (Basic)
शिक्षा (मूल) .....

Vocational / Professional (Education/Knowledge)
व्यवसापिक (शिक्षा / ज्ञान) .....

Registered with which Society (Name of Society)
किस सस्था मे पजीकृत है (संस्था का नाम) .....

.....

How you (Individual/Family) can help the Society
आप (स्वंय / परिवार) सस्था को किस प्रकार से सहयोग दे सकते है .....

.....

What you expect from your Thalassaemia Society
आप अपनी सस्था से क्या अपेक्षा रखते है

.....

.....

Do you use Filer ? (Yes/No) क्या आप फिलटर प्रयोग है ? हां / नही

Do you use Kelfer ? (Yes/No) [250/500] _____ Cap/day
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How much you can afford for chelating agents ?
आप लोहा निकालने की दवा पर कितना खर्च कर सकते है ?

Kelfer/Desferal/Exjade (Asunra) कैलफर / डैस्फराल / एक्सजेड (असुनरा)..... / Per Month प्रति माह

☞Do you want Thalassemics should be declared disabled Yes/No
☞क्या आप चाहते है कि थैलासीमिया रोगीयो को कानून्न विक्लांग सूची मे दर्जा किया जाना चाहिए हां / नही

☞आपका मत Exjade(असुनरा) की कीमत कम रखने तथा थैलासीमिया को विक्लांगता की सूची मे रखने मे सहयोग देगा तथा उचित व्यवसाय उपलब्ध कराने के लिये सरकार पर दबाव डालने मे सहायक होगा

☞अतः अधिक से अधिक थैलासीमिक इस को फार्म भर कर निम्न पते पर भेजे । उपरोक्त फार्म को फोटो-कापी किया जा सकता है ।

Federation of Indian Thalassemics , KG-1/97, Vikas puri New Delhi- 110018

हस्ताक्षर
Signature

☞ All societies are requested to make maximum copies of this form and get it filled from every Thalassemic patients / parents.

M.P. THALASSEMIA KID CARE SOCIETY

Dr. Sajid Khan

Madhya Pradesh Thalassemia Kids Care Society, Bhopal formed in 1996-97 (NGO's) Charitable Society is exempt under Section 80-G of I.T. Act.

74 Thalassemia Children registered with the society.
Transfusion facilities available within

Hamidia Hospital Gandhi Medical College, Bhopal	Free
Syush Hospital, Jahangirabad, Bhopal	Concessional Charges
LBS Hospital, Motia , Talab, Tajul Masajid, Bhopal	Concessional Charges
Paliwal Hospital, Nr Bhopal Talkies Qazi Camp Road, Bhopal.	Concessional Charges
Sewa Sadan, Bairagarh, Bhopal	Free
Guwlani Clinic, Bairagarh, Bhopal	Concessional Charges
Chirayu Hospital,Bhopal	Concessional Charges

Blood Bank associate with us are:

Bhopal Blood Bank & Component Centre Near Hamidia Hospital, Bhopal	Free Testing, PRBC
Hamidia Hospital, Gandhi Medical College	Testing Fee, Whole Blood.
New Bhopal Blood Bank, Arera Colony,	Concession Charge, Whole Blood
Arpan Blood Bank, M.P. Nagar, Bhopal	Concession Charge, Whole Blood

Society provide Poor Thalassemics only blood transfusion set, scalp vein & medicines. We do not provide Desferal, Kelfer, and Pumps.

We organize Awareness Screening Program in Schools, Colleges, Offices etc., We are not getting any facilities from State Government & Health Department. And even we do not have HbHPLC test for pregnant women. Electrophoresis test available at Adity Lab, Bhopal Blood Bank & Path for Rs. 350

No facilities available for Anti-natal diagnosis.

No political/social entity/Celebrity attached with our organization. We organized Blood Donation Camps with the help of private sectors.

NATIONAL THALASSEMIA WELFARE SOCIETY (Regd.)

KG-1/97, Vikas Puri, New Delhi-110018 Tel : 65491151, 25511795
URL: thalassaemiaindia.org

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 Soceity.**

For **NRI & Foreigners** Life membership fee US$ 60

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Half page	Rs. 3,000	- -
Back		
Full page	Rs 20,000	US$ 1,500

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, Block 12, Tilak Nagar, Near Gurudwara Singh Sabha, New Delhi-18
For Appointment Contact: Dr. J. S. Arora Tel: 25507483, 25511795

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* Serum Ferritin Assay for Rs. 150/- only
* Hepatitis B Vaccine: Rs. 50/- for children below 10 years. Rs.100/- for children above 10 years.
* Thalassemia Screening / Diagnosis with HPLC Rs. 300/- only.

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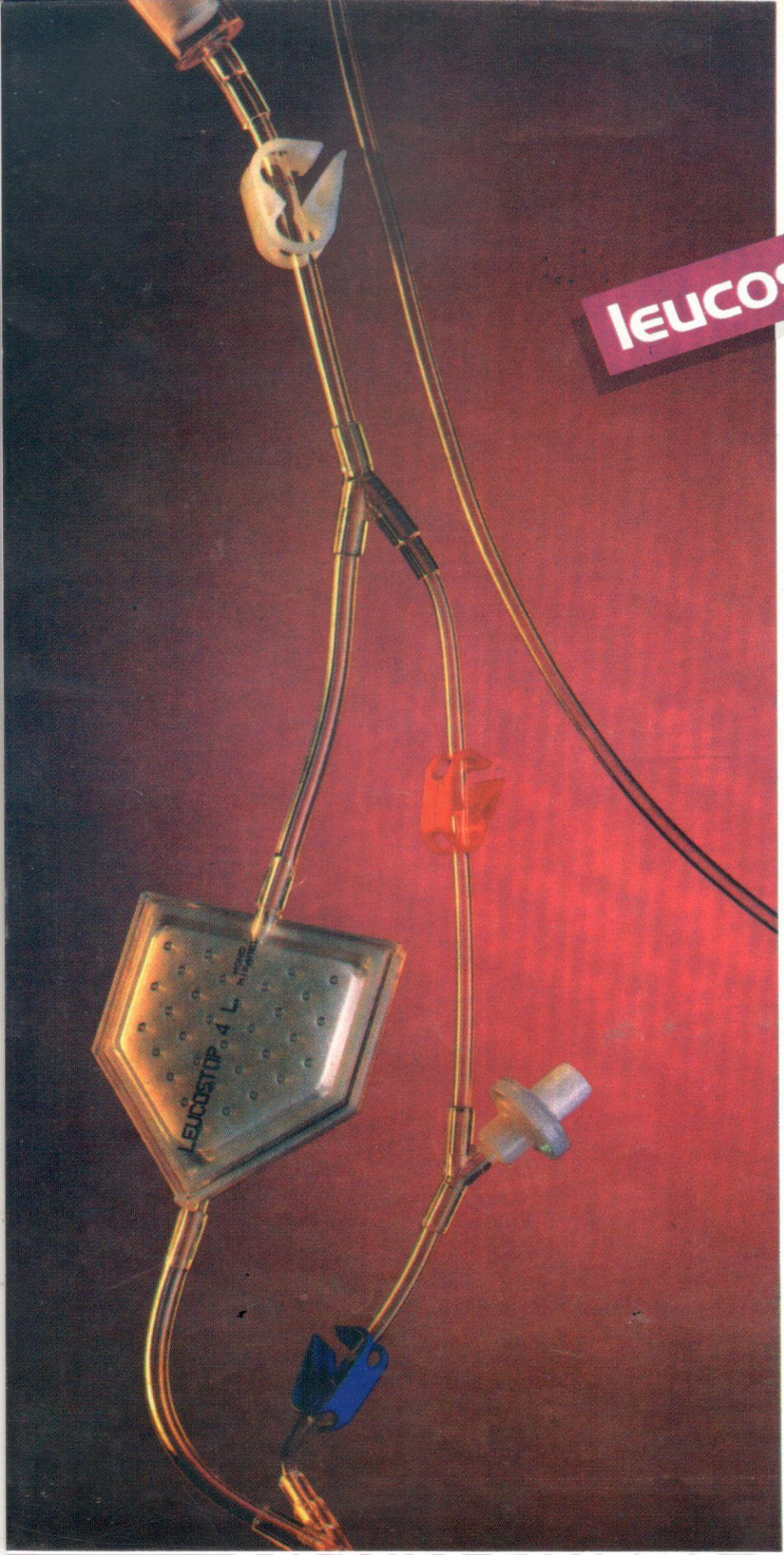

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