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FEDERATION of Indian Thalassemics

National Thalassemia Bulletin

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NATIONAL THALASSEMIA WELFARE SOCIETY (Regd.)
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Announcement

Long wait is over
L-1 to be launched on
Sunday, the 5th March 1995 !!!

TIF's AWARDS

Presented on 7th TIF Conference
6–8th September, 1994, London

Scientific Award in memory of
late George Englezos presented to

Prof. Bernadette Modell

The Panos Englezos Founders Award presented to

Mr. Elias Sofianos

(President of the Panhellenic Thalassemic Federation)

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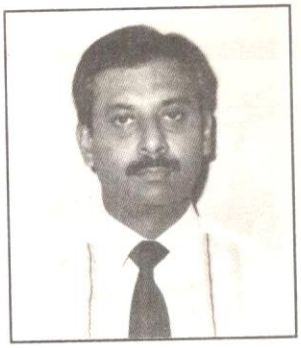
President's Pen



It could not have been a better beginning than wishing you all a Happy & Healthy 1995.

Moving ahead from a wish to reality is the fact that the long awaited & the much laboured effort has finally taken shape in the form of a Federation.

The prime activity & objective of this newly born Federation shall be to provide a wider canvass & pursue the struggle of individual societies. Knowing fully well that each one of us is not only committed to fight for self but also share with others in the same boat thought to provide a vehicle which could glide through the areas of hardship & make the living a bit simpler.

To enable us achieve the objectives it would be imperative that the fight & struggle against Thalassemia be now taken up in a united & concerted manner wherein the local issues be continued to be tackled by your efforts and problems of national & international magnitude be taken up by the Federation. It would not be out of place to mention here that in each sphere your role is going to be vital & we can assure you that a team spirit & renewed effort from our end would bring the desired results.

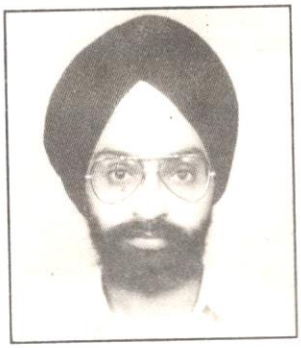
At this point of time what seems to be of immense importance is awareness & prevention hence 'Create Public Awareness'. A case in point would be the mass communication and the major role it has played in educating the common masses about the dangers, the do's & don't's of AIDS.

If a similar drive is launched for Thalassemia a day would not be far when we would be able to free the society of this dreaded blood disorder.

Let us all dedicate ourselves to take the burden off the Thalassemics & create a Thalassemia free society.

Deepak Chopra

Secretary's Desk



Wishing you all A Very Happy & Healthy New Year. I am confident that new year will be very bright for thalassemics.

A long time need was being felt to have a National Body which could represent all the Thalassemics and co-ordinate the activities of various Thalassemic societies in India. I greatly appreciate the efforts of National Thalassemia Welfare Society in forming the Federation.

The objectives of FIT are as follows:

1. to co-ordinate among various Thalassemia Associations of India & abroad.
2. to create greater awareness amongst public.
3. to serve as a medium for exchange of ideas, skill, knowledge, experience and information.
4. to pursue the Govt. Authorities for:
   a) improving facilities for screening, diagnosis and treatment of thalassemia.
   b) creation of thalassemia centres.
   c) starting National Thalassemia Eradication Programme.
   d) Income Tax rebate on expenditure.
   e) full reimbursement of treatment expenses by all Govt. and autonomous bodies.
   f) exemption in medical fitness for higher education and service purposes.
   g) handicap benefits for thalassemics.

I am confident that with the co-operation of all thalassemic societies, the federation will march ahead towards its major goals. Six societies have already got registered with the federation. I hope others will soon follow the suit.

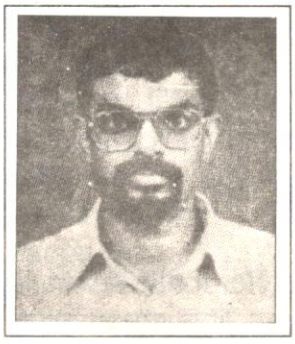
I greatly appreciate the co-operation of Dr. V.P. Choudhry who founded the idea and carved it into the shape.

I can't express my pleasure in informing you that long awaited wonder drug L-1 (Deferiprone) will be available for clinical use in thalassemia from mid of March 95. It will not only add years of life to thalassemics but will also improve quality of life.

Dr. J.S. Arora

BONE MARROW TRANSPLANTATION IN THALASSEMIA MAJOR: AN UPDATE OF THE VELLORE EXPERIENCE

—Dr. David Dennison
Assoc. Prof., Deptt. of Haematology, CMCH Vellore



Bone marrow transplantation is today the only curative treatment available for transfusion dependent thalassemia. However only patients with fully matched sibling donors are eligible for this treatment. Furthermore the outcome of BMT depends on the presence or absence of three risk factors:

1. Inadequate iron chelation.
2. Enlarged liver of more than 2cms.
3. Presence of liver fibrosis (damage to liver seen under the microscope).

Patients with none of these risk factors are categorized as Class I, those with one or two as Class II and those with all three as Class III. The latest results from Italy show that the post transplant disease free survival for patients in Class I, II & III is 93%, 85% and 64% respectively.

UPDATE OF THE RESULTS FROM VELLORE

Three years have passed since the first bone marrow transplantation for thalassemia major in the country in October 1991. Up till November 1994 a total of 27 BMTs for this disorder have been performed in Vellore.

Pre-transplant Patient Data

The median age of our patients was 6 Yrs. The youngest patient was 2.7 Yrs. and the oldest was 18 Yrs. There were 23 males and 4 females. The median number of blood transfusions received was 75 ranging from 20 to 275. Four percent of patients were positive for hepatitis B surface antigen and 23% were positive for hepatitis C antibody. The median serum ferritin value was 5,127 ng/ml (range: 980 ng/ml to 13,600 ng/ml) showing that most of our patients are heavily iron overloaded at the time of transplant.

Classification based on risk factors

There were no patients in Class I. There were 8 patients in Class II and 13 patients in Class III. Six patients were classified as either Class II or III because liver biopsies were not done at that time. Based on our experience these 6 patients would almost certainly be Class III. We are currently doing liver biopsies on all patients before the BMT in order to classify them and to find out the extent of liver damage. This is done under general anaesthesia at the time of Hickman catheter placement. This method eliminates pain and anxiety for the patient.

Results

The results of BMT in Vellore are summarized in table 1. The overall results suggest that about 74% of patients with thalassemia major can be cured by BMT. For purposes of analysis the six patients who were either Class II or III were designated as Class III. When the results were analysed on the basis of Class it is clear that patients with Class II have a better outcome than Class III patients. Two of our patients have rejected the graft. One patient at 10 months and the other after 1 yr. and 4 months post BMT. These patients have now become thalassemic again and require blood transfusions. The five patients who expired did so on an average of 16 days post BMT. Mortality due to BMT remains a significant problem in the Class III patients. Class II patients appear to withstand the transplant better.

Table 1

	OVERALL	CLASS II	CLASS III
No. of patients:	27	8	19
Alive & Disease Free:	20 (74%)	7 (88%)	13 (68%)
Alive but Rejected:	2 (7%)	1 (12%)	1 (5%)
Death due to BMT	5 (19%)	0	5 (26%)

Donors

There were 12 male and 15 female donors. The median age was 8 Yrs ranging from 2 to 25 years. Bone marrow is harvested from the donor under general anaesthesia. All the donors are well and there have been no problems during the harvest. The usual duration of hospital stay for the donor is about one week.

Cost

The average cost of BMT remains around Rs. 4 lakhs and can range from Rs. 3.5 lakhs to Rs. 6 lakhs if there are complications. Even though expensive it still remains much lower when compared to the cost in Italy making it affordable to many more patients.

Discussion

Bone marrow transplantation for thalassemia is now well established in India. This means that patients no longer have to go abroad to avail of this treatment.

Parents who are considering BMT for their children should be aware that it is all the more necessary to keep the child well transfused and chelated for the transplant in order to increase the chance for a good outcome. This is a very clear message from our results of the Class II and Class III patients as has also been shown by the Italian experience. Regular follow up with the doctor and interaction with the local thalassemia society will help achieve this goal.

INTRAVENOUS DELIVERY SYSTEM (PORT-A-CATH)

— From U.K.T.S. News

Treatment with subcutaneous (s.c.) Desferrioxamine (DFX) is burdensome, in many instances, painful and time consuming. Many thalassemia patients fail to comply to the recommended chelation treatment and they become iron overloaded. The result is damage to the endocrine glands, late sexual development, short stature, diabetes, hypothyroidism and hypoparathyroidism. Eventually iron is deposited in the heart muscles causing hypertrophy, dilatation, degeneration of myocardial fibres and cardiomyopathy. The extent of the heart damage is directly related to the transfusional iron overload in poor compliant or in non chelated patients. It is well known that in most patients iron induced cardiac disease can be reversed with more intensive chelation programme. For this an intravenous delivery device (Port-A-Cath) is implanted under general anaesthesia. The Port-A-Cath is inserted by general or cadio vascular surgeons. The system

consists of a small metal chamber sealed at the top with a septum made of self-sealing silicon and a thin flexible tube or catheter. The catheter is inserted into the neck veins (internal jugular or subclavian vein) and the tip is positioned in the major heart vein (superior vena cava). It is then tunnelled to the site of the subcutaneous pocket in which the portal is placed. The portal is connected to the catheter and is sutured in place. In female patients the system is sited in an area covered by the bra, in children and thin adult men a low profile Port-A-Cath is placed on the chest wall in an accessible position for treatment.

Who should have the Port-A-Cath?

1. Thalassemia patients who are sensitive to subcutaneous DFX treatment.
2. Iron overloaded thalassemia patients with heart complications.
3. Thalassemic patients who are unable to intensity s.c. DFX chelation in spite of rising serum ferritin levels.
4. In preparation for planned pregnancy with high serum ferritin.

Use of Port-A-Cath

Access to the Port-A-Cath is by no-coring Huber needle. For continuous 24 hour infusion of DFX a Gripper needle is inserted into the Portal which has a cushioned needle platform to protect the puncture site, eliminate the need for a bulky dressing and to give greater comfort for the patient. Insertion of the needle is done aseptically and is proceeded by cleaning the area up to 6 cm around the portal for 3 minutes with povidone iodone followed by alcohol.

After palpation of the portal the Gripper needle is inserted into the septum at 90 degrees until it touches the base plate. The clip from the Gripper needle is removed and the system is connected to an infusion set with luer lock devices either to the Graseby Desferal pump or to the single day infuser (Baxter). For long term infusion the needle is changed as per the local procedure. In the Whittington; we tend to change the needle every four to six weeks. A positive injection pressure must be maintained to prevent blood entering into the cathéter. When not in use the system must be flushed with 5-10 mls of heparinised saline.

Complications

Blockage, infection and mechanical failure are the commonest complications. Blockage occurs when positive pressure fails (pump stops working) and blood enters the system. With a 1ml syringe using heparin or urokinase the system can be unblocked. Infection–Septicaemia commonly caused by a skin organism Staphylococcus aureus or epidermidis. Blood cultures from the line are positive and attempts to clear the infection by using intraportal antibiotics are usually unsuccessful. If intraportal antibiotics do not clear the system the Port-A-Cath has to be removed.

Mechanical Problems

May result from the catheter being inserted into a small neck vein and not into the superior vena cava. The Port-A-Cath has to be removed in these cases.

Port-A-Cath implantable venus access system is a considerable advance in the management of iron overloaded thalassemic patients. Because the system is inserted under the skin it has fewer problem with infection but strict asepsis in all procedures is essential. It is cosmetically and socially acceptable and teenagers find no interference in their daily school activities. In thalassemia major patients with cardiac problems it is a life saving device.

Dr. B. Wonke

बोन मैरो ट्रांसप्लांट

थैलासीमिया रोग में आज के युग में बोन मैरो ट्रांसप्लांट ही एक मात्र पूर्ण इलाज़ है। यद्यपि यह लाभ केवल उन थैलासीमिकस को ही मिल सकता है जिनकी बोन मैरो सगे भाई या बहन से मिलती हो। बोन मैरो ट्रांसप्लांट का फायदा निम्न तीन बातों पर निर्भर है :-

1. अतिरिक्त लौहे का अपूर्ण निष्कासन
2. ज़िगर का 2 से॰मी॰ से अधिक बढ़ना
3. ज़िगर में फाईब्रोसिस होना।

यदि उपरोक्त में से कोई भी कमी नहीं है तो उसे श्रेणी 1 में रखा जाता है, यदि तीन में से एक या दो कमियाँ हों तो उसे श्रेणी 2 में रखा जाता है और यदि तीनों कमियाँ हों तो श्रेणी 3 में। इटली के अनुभव अनुसार श्रेणी 1, 2 व 3 में क्रमानुसार 93%, 85% व 64% सफलता पाई जाती है।

वैलूर में प्रथम बोन मैरो ट्रांसप्लांट अक्टूबर 1991 में किया गया। तब से नवंबर 1994 तक 27 ट्रांसप्लांट किये गये। इसमें 23 लड़के व 4 लड़कियां थी। सबसे छोटा बच्चा 2 वर्ष 7 माह व सबसे बड़ा बच्चा 18 वर्ष का था। इन बच्चों में 20 से 275 बार रक्त संचारण हो चुका था। 4% बच्चें हैपेटाईटिस बी व 23% हैपेटाईटिस सी से प्रभावित पाये गये। फैरीटिन की मात्रा 980 ng/dl से 13,600 ng/dl तक थी। उपरोक्त तीन श्रेणियों में बांटने पर 8 बच्चें द्वितीय श्रेणी में व 19 बच्चें तृतीय श्रेणी में पाये गये।

कुल मिला कर 75% बच्चों में पूरा फायदा हुआ व 4 थैलासीमिकस में graft rejection पाया गया। उनमें से एक बच्चें में बोन मैरो उपरान्त 10 माह पर व दूसरे बच्चें में 1 वर्ष व 4 माह पर यह प्रक्रिया देखने को मिली अब उनको पुन: रक्त संचारण पर निर्भर रहना पड़ेगा। पांच थैलासीमिकस की बोन मैरो ट्रांसप्लांट के कारण मृत्यु हुई यह सभी तीसरी श्रेणी के वर्ग में आते थे।

Donor — बोन मैरो देने वालों की आयु 2 से 25 वर्ष की थी। बोन मैरो पूर्ण संज्ञानाश की स्थिति में किया गया व किसी भी donor को कोई भी समस्या का सामना नहीं करना पड़ा। सामान्यतया donor को एक सप्ताह के लिए अस्पताल में रूकना पड़ा।

खर्चा — एक आप्रेशन में औसतन 4 लाख रूपये (3.5 लाख से 6 लाख रूपये तक) का खर्चा आया। इटली के मुकाबले यह बहुत कम पड़ता है तथा अधिक लोगों के आर्थिक दायरे में आ जाता है।

जो मां-बाप अपने बच्चों का बोन मैरो ट्रांसप्लांट करवाने के इच्छुक हैं उनको चाहिये कि अपने थैलासीमिक बच्चे का रक्त संचारण तथा लौह निष्कासन उचित प्रकार से करें। ताकि अच्छे परिणाम की आशा की जा सके।

अध्यापक सत्र के अन्तिम दिन: परीक्षा पत्र अब प्रिंटर के पास है और अब आप के पास दो सप्ताह बाकी हैं, यदि किसी ने कोई प्रश्न पूछना है तो पूछ सकता हैं।

राजदीप: सर, केवल एक प्रश्न? प्रिंटर का पता बता दीजिए।

PORT-A-CATH

त्वचा के नीचे डैस्फराल देने से कई समस्यायें आती हैं जैसे सूजन, दर्द आदि। इन कारणों से अक्सर थैलासीमिक पूरा डैस्फराल नहीं ले पाते तथा बाद में अधिक लौहे के कारण कई अंगों में विकृतियां उत्पन्न हो जाती हैं जैसे अन्त:स्रावी ग्रन्थियाँ, हृदय, ज़िगर आदि। हृदय में विकृति अतिरिक्त लोह की मात्रा पर निर्भर करती है, इस विकृति को ठीक किया जा सकता है यदि विशेष असरदार रूप में लोह निष्कासक दवा का प्रयोग किया जाये। इसके लिए एक विशेष उपकरण Port-A-Cath का प्रयोग किया जाता है इसको हृदय सर्जन द्वारा पूर्ण संज्ञानाश की अवस्था में छाती पर लगाया जाता है। इसमें ऊपर धातु का बना एक खोल होता है जिस पर स्वत: बंद होने वाली सिलीकोन की झिल्ली लगी होती है और नीचे एक पतली सी ट्यूब होती है। इस ट्यूब को शिरा द्वारा हृदय की मुख्य शिरा में पहुँचाया जाता है। 24 घण्टे लगातार डैस्फराल देने के लिए छाती पर जहाँ Portal लगा होता है उस भाग को अच्छी तरह जीवाणु रहित करके एक विशेष Gripper सुई को उसमें 90° पर डालते है और उसको Infusion पम्प से जोड़ दिया जाता है। 4-6 सप्ताह बाद सुई को बदला जाता है। इसका प्रयोग निम्नलिखित में किया जाता है :-

1. जिन थैलासीमिकस को त्वचा के नीचे डैस्फराल देने से प्रतिक्रिया होती हो;
2. अति लोह के कारण हृदय में विकृति आ गई हो;
3. फैरीटिन अधिक होते हुये भी अध:त्वक डैस्फराल की मात्रा न बड़ा सकते हो;
4. गर्भ धारण से पूर्व यदि फैरीटिन बहुत अधिक हो।

Port-A-Cath में Blockage व Infection का खतरा रहता है अत: बहुत सावधानी की आवश्यकता होती है। अति लोह द्वारा हृदय विकृति को ठीक करने में यह उपकरण जीवन रक्षक का कार्य करता है।

शुभ सूचना

अतिरिक्त लोह निष्कासक मौखिक दवा डेफरीप्रोन 5 मार्च, 1995 से उपयोग के लिए उपलब्ध।

नेशनल थैलासीमिया वैलफेयर सोसाइटी द्वारा इसी दिन एल-वन के बारे में पूर्ण जानकारी देने के लिए एक विशेष सभा का आयोजन जवाहर लाल आडीटोरियम, AIIMS में किया जा रहा है यह सभा प्रात: 10.30 बजे आरम्भ होगी जिसमें मुख्य वक्ता लंदन से डा॰ जार्ज, डा॰ वी॰ पी॰ चौधरी, डा॰ मारवाह व डा॰ चन्द्रा होंगे। अंत में प्रश्नोत्तर काल होगा तथा प्रश्नों के उत्तर हिन्दी में भी दिये जायेंगे। सभा के उपरान्त भोजन का भी प्रबंध है।

इस अवसर पर हम एक पुस्तिका का विमोचन करने जा रहे हैं जिसमें एल-वन के प्रति जानकारी होगी। सभा में आ कर एल-वन के बारे में जानकारी प्राप्त करें व पुस्तिका में विज्ञापन अथवा दान द्वारा धन एकत्रित करने में हमारी सहायता करें।

प्रवेश निशुल्क।

12 वर्ष से छोटी आयु के बच्चों का प्रवेश वर्जित है।

विशेष थैलासीमिया क्लीनिक

नेशनल थैलासीमिया वैलफेयर सोसाइटी की ओर से ***प्रति माह दूसरे रविवार को प्रात: 10.00 बजे से दोपहर 2.00 बजे तक चैरीटेबल मेडिकल क्लीनिक, लाजपत भवन,*** निकट विक्रम होटल, लाजपत नगर में थैलासीमिया बच्चों की जांच की व्यवस्था की जा रही है।

प्रथम बार यह क्लीनिक 12 फरवरी को होगी।

इस क्लीनिक में समय-समय पर डा॰ वी॰ पी॰ चौधरी, डा॰ शोभा बरूर, डा॰ ऐ॰ पी॰ दूबे, डा॰ सिद्धार्थ सेन व डा॰ ममता शर्मा आदि जांच करेंगे।

यहां पर फैरीटिन, थैलासीमिया माईनर/मेजर की जांच तथा रक्त के अन्य टैस्ट किये जायेंगे।

क्लीनिक पर आने से पूर्व प्रत्येक बार संस्था के कार्यालय से समय निर्धारण करना आवश्यक है।

MY EXPERIENCE OF PORT-A-CATH

I have been taking blood transfusions for last ten years. I didn't use to take Desferal regularly because of my negligence. I didn't even think about it. Result: My heart beat increased suddenly and I was admitted in Sir Ganga Ram Hospital. My brother consulted Dr. Khanna and Dr. Arora. Both of them had same opinion that in this situation only Port-A-Cath is the only way to control. But at that time I couldn't go for it because my heart was not normal. In August a meeting was held in Sir Ganga Ram Hospital in which Dr. M.B. Agarwal was also invited. On testing serum ferritin it was found that it had gone upto 7000. Dr. Agarwal told that my heart can be reverted only by giving regular and high dose of Desferal and that could be done only through Port-A-Cath in short time. So, we went Bombay in September 1993. Operation was done in Bombay Hospital by Dr. G.T. Hegde under local anaesthesia. We had to stay there for ten days and total expenses were around fifty thousand.

Port-A-Cath is a stethoscope shaped device which is fixed under my skin and attached to my blood vein. A specially designed needle is inserted into port and it remains in port until you take it out. We have to just fill the dose of Desferal after 24 hours. One needle can be used for 15 to 20 days. My brother does everything as inserting needle into port, filling Desferal into syringe and taking needle out. There is little pain when needle is inserted into port but after that there is no pain. I take 6 Desferal daily for 15 to 20 days regularly. After taking rest for 5 to 7 days we start the treatment again.

It is a very simple way to low SF level in 6 to 8 months. Only little patience is needed. I suggest everyone, whose SF is above 5000 and who can afford Port-A-Cath treatment, must go for it. It is little expensive but very fruitful. I have taken more than 500 Desferals by now and now I am feeling much better. I am very thankful to Dr. Agarwal, Dr. Khanna and Dr. Arora for all the things they have done for me.

ASHOK MAKHIJA

Message from Ahmedabad

I am sending my best wishes on occasion of formation of Federation. The birth of Federation will go a long way in improving welfare of thalassemic children.

Wishing you all Very Happy New Year.

Dr. R.B. Shaw
President
TSCS, Ahmedabad

In 1993, earning's by Tirupati temple of Lord Venkateshwara were 119.5 crore! "Kash" it could be used for welfare of thalassemia. We would have been able to manage all the thalassemics whole life and ERADICATE IT ONCE FOR ALL.

MOTIVATE YOUR DEAR & NEAR ONES TO DIVERT THEIR DONATIONS FOR WELFARE OF THALASSEMIA

Report from Chandigarh

Thalassemic Children Welfare Association, Chandigarh associated with the blood donation camp organised by Baba Sheikh Farid Blood Donors under the chairmanship of Dr. H.S. Aneja, Director Health Services, Punjab. Mr. M.S. Rekhi, Vice President of Association appealed the donors and visitors to donate liberaly in cash & kind and adopt some children of weaker section.

Mr. Ved Prakash Gupta celebrated the birth day of his grandson on 26-11-94 by holding blood donation camp. T.C.W.A. associated with it and distributed booklets on thalassemia. 225 persons voluntarly donnated blood. Mr. Suresh Arora, DIG Vigilence, Punjab, inaugurated the camp. Dr. Gurjeewan Grewal, Head of Haematology, P.G.I. also graced the occassion.

A talk on Thalassemia was given by Mrs. Gini Barth, Jt. Secretary of T.C.W.A., Chandigarh on AIR. Similar talks were also organised at a youth meeting in Vidya Bhawan and Govt. College for men.

Report from Delhi

National Thalassemia Welfare Society

National Thalassemia Welfare Society organised a picnic for Thalassemic families at Children Park near India Gate on 20-11-94. About 200 parents and well wishers attended and took part in various activities like races, tambola, musical chair etc. The picnic concluded with lunch. It was first of its kind for thalassemics. Everybody enjoyed and appreciated the idea.

General body meeting was also organised on this day and elections were held for next executives. Miss Surrender Saini, Chairperson Delhi Social Welfare Advisory Board and Mr. Harish Chawla, Director Cipla Ltd. consented and unanimously elected President and Vice President of the society. Dr. J.S. Arora was elected General Secretary of the society. Whole of the executive was elected unanimously.

Thalassemics India

An appeal was made to Hon'ble Finance Minister for waival of excise duty on Desferal and to grant adhoc exemption of custom duty on consignments of pumps and accessories; which were granted.

Dr. V.K. Khanna, Varun Chopra and Mrs. Shobha Tuli attended the 7th T.I.F. Conference in London. A project on awareness and prevention was presented, the issue of high price of Desferal was taken up with CIBA & T.I.F.

Dr. B. Wonke's Visit

On 28th December, 94 Dr. Wonke visited "Preeti Tuli Thalassemia Unit" at Sir Ganga Ram Hospital. Check up clinic were organised from 28th to 30th December, 94. Nearly 70 children were examined and given advise. On 29th December a symposium was organised at S.G.R.H. where besides Dr. Wonke, Dr. V.K. Khanna, Dr. V.P. Choudhry, Dr. I.C. Verma and Dr. Nidhi Vohra gave useful information. A seminar on "Prevention and anti-natal diagnosis of Thalassemia" was held at hotel Meridien on 31st December, 94. Nearly 130 gynaecologists attended the seminar. A seminar and check up clinic was also held at Santokhba Durlabjee Hospital, Jaipur on New Year Day.

Pall Biomedical sponsored Dr. Wonke's visit and her hospitality was taken care of by M/s Cezaria, Mr. Ravi Tuli and Mr. Arun Sehgal.

LAUNCHING OF L-1

Sunday, the 5th March, 1995.

Use of L-1 (Deferiprone), the oral Iron Chelator will require close monitoring and it will be available through specified centres only. Cost of treatment will be less than 1/10th to that of Desferal therapy.

TO KNOW ALL ABOUT L-1

National Thalassemia Welfare Society is organising a symposium on "Deferiprone" at

Jawahar Lal Auditorium

AIIMS, Ansari Nagar, New Delhi–29

on Sunday, the 5th March, 1995

10.30 A.M. to 1.00 P.M.

Scientific Speakers:

- Dr. George J. Kontoghiorghes
- Dr. V.P. Choudhry, AIIMS, New Delhi
- Dr. R.K. Marwah, P.G.I., Chandigarh
- Dr. S. Chandra, Calcutta

Question Answer Session Followed by Lunch

We are publishing a souvenir on this occasion which will contain all relevant information on L-1 (Deferiprone). Help us in collecting funds by advertisement/donation for souvenir.

NO REGISTRATION FEES.

Children below 12 years are not allowed.

RENOWNED SOCIAL WORKERS JOIN N.T.W.S.

MISS SURRENDER SAINI a noted social worker is Chairperson of Delhi Social Welfare Advisory Board, a statutory body to help voluntary organisations for promotion of social welfare activities by giving financial assistance. She is Chairman of Bharat Sewak Samaj Delhi Pradesh a voluntary social organisation working for welfare of down trodden and poor in slum and rural areas. She is also President of All India Federation of Deaf and Trustee of Kasturba National Memorial Trust which was set up by Father of India Mahatama Gandhi. She has also served as member of Metropolitan council of Delhi 1967-77.

She has many awards to her credit. Padma Bhushan in 1970 in appreciation of her social work.

"Community leaders of the world Award" by American Biographical Institute of USA.

"Priya Darshini (Indira Gandhi) Award" for 1990 for social work.

- Vice Chairman of Nari Niketan a statutory body setup of Delhi Govt.
- Chairman of governing body of Janaki Devi college and Laxmi Bai college.
- Vice Chairman of Bal Bhawan Board.

In her official capacity she had been visiting America and Russia many times.

HER INVOLVEMENT IN THALASSEMIA WILL HELP US IN RAISING THE ISSUE AT HIGHER LEVELS.

Mr. Harish Chawla is director of Cipla Ltd. a well known pharmaceutical company with 200 crore turnover and famous in thalassemics being manufacturer of oral and cost effective Iron chelator Deferiprone. **He is the key person in introducing L-1 for therapeutic use in thalassemics.** He has blessed us by being the Vice President of the society. He is also instrumental in getting us the blessings of Miss Surrender Saini a noted social worker as President.

He is West Pakistan born, very modest, soft spoken, self made person. At present he is also

1. Vice President of "Indian Federation of United Nations".
2. President of "Sabrang" (Music Society) which is almost 40 years old.
3. President of "Nrityaranjani" (objective to promote the Art of Bharat Natyam).
4. **Member "Central Advisory Council", Ministry of Industry, Govt. of India, he is the only member in his individual capacity while almost all others are either Govt. officials or union leaders.**
5. Office bearer of number of social, sports, cultural, religious organisations.

LAST BUT NOT LEAST HE IS COMMITTED TO THE CAUSE OF THALASSEMIA

REGULAR THALASSEMIA CLINIC

National Thalassemia Welfare Society plans to start Thalassemia clinic on every ***2nd Sunday, 10.00 A.M. to 2.00 P.M. at Charitable Medical Clinic, Lajpat Bhawan,*** Near Vikram Hotel, Mool Chand Flyover, Lajpat Nagar, New Delhi.

First such clinic will be held on Sunday, the **12th February, 1995.**

Experts:
- Dr. V.P. Choudhry
- Dr. A.P. Dubey
- Dr. Mamta Sharma
- Dr. Shobha Broor
- Dr. Siddharth Sen

Features:
- Proper Monitoring Record
- S. Ferritin Assay for Rs. 150/-
- Thalassemia Screening (Haemogram, HbF, HbA2) Rs. 150/-
- *Many more test will be added later on.*

To avoid any inconvenience please take **PRIOR APPOINTMENT.**

For appointment contact: **550 7483** between 12.00 Noon to 1.00 P.M.

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National Thalassemia Welfare Society (Regd.)

(R. No. S/26823, Registered under Societies Registration Act XXI of 1860)

KG-1/97, Vikas Puri, New Delhi-110 018. Phone: 550 7483 Fax: 91-11-559 1202, 559 8879

MEMBERSHIP

Any person can become a member of the society.

Charges	Inland	Foreign
Patron :	Rs. 5000	$ 500
Life :	Rs. 500	$ 50
Annual :	Rs. 50	– —

ADVERTISEMENT CHARGES

	Inland	Foreign
Sponsorship	Rs. 5000	$ 500
Inside		
Full Page	Rs. 1500	$ 150
Half Page	Rs. 800	– —
Back		
Full Page	Rs. 2000	$ 200
Half Page	Rs. 1200	– —

MEMBERSHIP FORM

Sir, I wish to be enrolled a Patron /Life /Annual member, Donor of National Thalassemia Welfare Society, and volunteer to promote its aims and objectives.

Name in Full (BLOCK LETTERS) .....

Correspondence Address (BLOCK LETTERS) .....

..... Ph: .....

I am sending here with Cash/Cheque/Draft No. ..... Date .....

Drawn on ..... for Rs. .....

Rs. (in words) .....

1. ..... 2. .....

Dated ..... (Signature)

Name of Patient ..... Date of Birth .....

Transfusion Centre ..... Blood Group .....