FEDERATION OF INDIAN THALASSEMICS

NATIONAL THALASSEMIA BULLETIN

Vol. 8 No. 2 July, 2002

Ms Surrendar Saini (Centre), President NTWS and Dr. J.S. Arora (holding recipient child Akshita) giving a cheque of Rs. 2,00,000 to Dr. P. K. Dave, Director AIIMS, New Delhi and Dr. Vinod Kochupillai, Prof. & Head IRCH, AIIMS, for the Bone Marrow Transplantation of Akshita. Advocate Mr. Ashok Sikka witnessing the donation.

Rs. 1,15,000 more sent to ARSH after receiving on SOS from him making it total of Rs. 3,25,000

Arsh underwent BMT at Vellore on 27th March 2002.
He was discharged from Hospital on 25th June 2002.
He is O.K. now. The total cost went up to Rs. 17,00,000
(Rupees Seventeen Lac) due to various complications.

We pray the almighty to give him a disease free long life

Address all correspondence to :
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KG-1/97, Vikas Puri, New Delhi-110 018 Tel : 5507483, 5511795 Fax : 91-11-5513576

INTERNATIONAL THALASSEMIA DAY

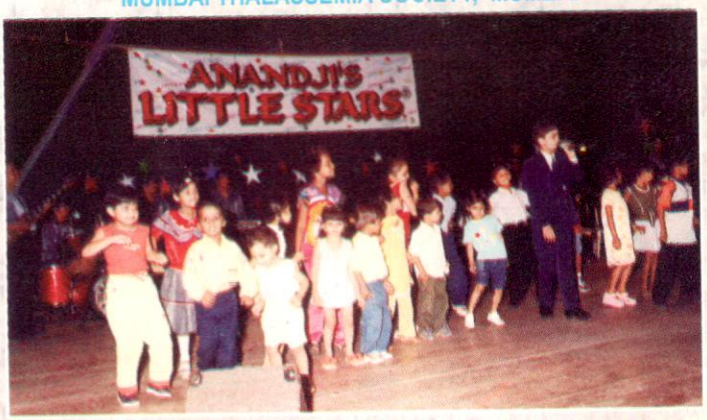
National Thalassemia Welfare Society At APPU GHAR & Attached OYESTERS

THALASSEMICS INDIA

BLOOD PATIENT'S PROTECTION COUNCIL, CALICUT-KERALA

Mr. Kareem Karassery, Gen. Sec. Malabar Thas Society addressing at Vyapara Bhawan, Calicut on 08-05-02.

MUMBAI THALASSEMIA SOCIETY, MUMBAI



Thalassemic children dancing in full zest to the tunes of Anandji (of famed Kalyanji Anandji music directors duo) and "Little Stars"

EDITORIAL

INTERNATIONAL THALASSEMIA DAY, 8 May 2002

Message from the World Health Organisation

It gives me great pleasure, on behalf of the World Health Organisation, to greet you on the occasion of the International Thalassemia Day, which will focus on public awareness concerning the prevention and clinical care of Thalassemia.

As you know, the World Health Organization's main objective is the attainment of the highest possible level for all people. To this end, we must take up the challenges provided to us by the new genetic knowledge now available, as stated in the recently published report on *Genomics and World Health*. WHO supports activities towards the development of medical genetics services at the international level? Thalassemia remains a serious genetic disorder and, although it is now well-understood and controllable with effective medication available worldwide, children continue to suffer, either because of the failure to detect the disease, its tardy recognition, or through lack of access to treatment.

In order to improve the management of haemoglobin disorders in developed and developing countries, WHO continues to collaborate closely with the Thalassemia International Federation. Our collaboration has been oriented towards improving disease diagnosis and care, as well as to educating the public and health care workers.

I wish you a successful and rewarding International Day. May it mark the acceleration of progress towards improved care for patients with Thalassemia and further stimulate country activities.

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Gene Therapy

— Dr. Michael Antoniou
Division of Medical and Molecular Genetics
GKT School of Medicine, King's College London
(Source UKTS)

The announcement of the "care" of Rhys Evans from South Wales by gene therapy is certainly heartening news. The story of Rhys's apparent successful treatment by gene therapy reproduces the results obtained over the last 3 years with what is now a total of 8 boys with the same disease in France (and which we reported on at the time of the first successful announcement in UKTS News back in 2000). Rhys was born with a type of inherited immune system disease called SCID-X which only affects boys. Without an immune system children like Rhys cannot fight infections and would soon die if they did not live a special clean chamber or plastic "bubble" as it is called. **The successful treatment of children with SCID-X disease is encouraging news for those of us trying to develop gene therapy for the haemoglobinopathies (thalassemia and sickle cell disease). This is because the cells within the body one needs to treat by gene therapy in thalassemia and sickle cell disease is the same as in SCID-X, namely the bone marrow stem cells from which all blood cells are produced.** The first step in the treatment of the boys with SCID-X, was achieved by taking a mini but otherwise normal copy of the gene (known as ?C) which is defective in these individuals and inserting this into a type of virus gene delivery vehicle known as a "retrovirus". The second step involved using this therapy virus to infect bone marrow stem cells taken from these boys. The now treated and "corrected" bone marrow stem cells carrying a normal copy of the ?C gene were then returned to the individual from where they originally came from. This is exactly the type of gene therapy strategy groups such as my own are trying to develop for the treatment of thalassemia and sickle cell disease.

So, I'm sure the question you are all asking is if it can be done for SCID-X why not for thalassemia? The reasons are many and complex. Firstly, the number of bone marrow stem cells that you need to correct to have a therapeutic effect in boys with SCID-X are far fewer than in the case of thalassemia and sickle cell disease. Secondly, the efficiency with which the ?C therapy gene needs to function to have a corrective effect in SCID-X is a great deal less than in thalassemia and sickle cell disease. A few percent of the normal level of ?C is sufficient whereas in thalassemia and sickle cell disease we need to achieve 25% of normal levels of ?-globin protein to see a therapeutic effect. Lastly and most importantly, the gene corrected cells in SCID-X have a survival advantage over those that were not corrected. What this means is that only gene corrected bone marrow stem cells in the case of SCID-X will give rise to normal immune system cells; those that are not gene corrected do not produce any immune system cells. As a result over a period of several months the SCID-X boys accumulated normal functioning immune system cells in their blood until a therapeutic level was reached. This has allowed them up to now to live a normal life outside of their clean "bubble". This survival advantage of gene corrected immune system cells after bone marrow stem cell gene transfer is a special situation to the SCID-X condition. Unfortunately, this survival advantage of gene corrected cells does not apply to thalassemia and sickle cell disease. Here both corrected and non-corrected bone marrow stem cells will survive giving rise to normal and abnormal red blood cells. As a result, in thalassemia and sickle cell disease we need a much more efficient delivery of the therapy gene to the bone marrow stem cells and a much higher level of gene function to see a therapeutic effect than was required for the SCID-X boys.

In addition, what remain as an unanswered but important issue are certain long-term safety concerns with the type virus gene delivery system as used in the treatment of the boys with SCID-X. Only time will tell if there are unsuspected side effects from this type of treatment. This justifies efforts for the

development of technology that will allow the introduction of therapy genes into bone marrow stem cells using chemical rather than virus delivery vehicles.

So, although the success so far in treating SCID-X with gene therapy is very encouraging, general problems of using this type of approach to deliver genes to bone marrow stem cells to address other conditions such as thalassemia and sickle cell disease still remain largely unresolved. However, these are areas of intense research by many groups around the world and with steady progress being made.

जीन चिकित्सा

इवन्स को मिला कर SCID-X नामक रोग से पीड़ित 8 बच्चों का जीन चिकित्सा द्वारा सफलतापूर्वक इलाज किया जा चुका है। SCID-X नामक रोग केवल लड़कों को ही प्रभावित करता है। इसमें रोगी को प्रतिरोधक क्षमता नहीं होती। अत: यदि उसे किसी जीवाणु रहित कक्ष में न रखा जाये तो कोई भी संक्रमण होने से मृत्यु हो जाती है। SCID-X रोगी की सफलतापूर्वक चिकित्सा से थैलासीमिया जगत में खुशी की लहर दौड़ना स्वाभाविक था क्योंकि SCID-X में जीन चिकित्सा द्वारा जिन कोशिकाओं को ठीक किया जाता है थैलासीमिंया व सिकल सैल एनीमिया में भी उन्हीं कोशिकाओं को ठीक करने की आवश्यकता होती है, अर्थात् बोन मैरो में बनने वाली मूल कोशिकाओं (stem cells) की। ये मूल कोशिकायें ही सभी प्रकार की रक्त कोशिकाएँ बनाती हैं।

SCID-X में जीन चिकित्सा की प्रक्रिया इस प्रकार है:

1) ?C नामक जीन (जो SCID-X रोगियों में प्रभावित होती है) के एक छोटे सामान्य (रोगरहित) प्रतिरूप को लेकर जीन प्रवाहक विषाणु माध्यम जिसको "रिटरोवाईरस" कहते हैं उसमें डाल दिया जाता है।

2) इस "चिकित्सीय विषाणु" से रोगी बच्चे से निकाले गये बोन मैरो stem cells को संक्रमित कर देते हैं।

3) चिकित्सीय विषाणु द्वारा संक्रमित कर ठीक किये गये बोन मैरो stem cells जोकि सामान्य (रोगरहित) ?C जीन से युक्त होती है को रोगी में पुन: वहीं डाल देते है जहाँ से इसे निकाला गया था।

जीन चिकित्सा की यही वह प्रक्रिया है जिसको थैलासीमिया व सिकल सैल एनीमिया में विकसित करने के प्रयास किये जा रहे हैं।

अब आपके मन में यह प्रश्न उठ रहा होगा कि यदि SCID-X में सफलतापूर्वक जीन चिकित्सा की जा सकती है तो थैलासीमिया में क्यों नहीं। इसके कई कारण हैं।

1) SCID-X में अपेक्षित प्रभाव प्राप्त करने के लिये थैलासीमिया तथा सिकल सैल की अपेक्षा बहुत कम बोन मैरो stem cells को ठीक करने की आवश्यकता होती है।

2) SCID-X में उचित प्रभाव प्राप्त करने के लिये परिष्कृत चिकित्सीय ?C जीन की बहुत कम मात्रा की आवश्यकता पड़ती है जबकि थैलासीमिया तथा सिकल सैल एनीमिया में कम से कम 25% ?-ग्लोबिन प्रोटीन के सामान्य (रोगरहित) कोशिकाओं की आवश्यकता होती है।

3) SCID-X जीन चिकित्सा में एक और विशेष बात यह है कि इसमें जीन चिकित्सा उपरान्त केवल (चिकित्सा से) ठीक किये गये जीन ही सामान्य अविकृत कोशिकाएँ बनाते हैं जबकि (चिकित्सा से) ठीक नहीं की गई कोशिकाएँ कोई अविकृत कोशिकाएँ नहीं बनाती। जबकि थैलासीमिया तथा सिकल सैल एनीमिया में (चिकित्सा से) ठीक किये गये व (चिकित्सा से) न ठीक किये गये दोनों ही अपनी-अपनी क्षमतानुसार क्रमश: अविकृत (रोगरहित) व विकृत (रोगी) कोशिकाएँ बनाती हैं, अत: थैलासीमिया में ठीक की गई कोशिकाओं की अधिक मात्रा की आवश्यकता पड़ती है।

इन सबके अतिरिक्त अभी एक विशेष बात और जानने योग्य यह है कि कुछ समय उपरान्त इस चिकित्सा पद्धति में प्रयुक्त विषाणु का शरीर पर क्या प्रभाव पड़ेगा, यह भी एक रहस्य है। इसलिए विषाणु के बजाय रसायनिक जीन प्रवाहक को विकसित करने के प्रयास किये जा रहे हैं। यद्यपि SCID-X रोग में जीन चिकित्सा से लाभ देखा गया है परन्तु थैलासीमिया व सिकल सैल में कब व कितना लाभ होगा यह भविष्य ही बतायेगा।

Clinical and Laboratory Evaluation Checklist - TIF

Monthly

- CBC

Every 3 months

- **serum ferritin**
- **clinical chemistry:**
  - glucose
  - urate
  - urea
  - creatinine
  - iron
  - TIBC
  - alk. phosphatase
  - γ-GT/GGTP
  - ALT/SGPT
  - AST/SGOT
  - LDH

Every 6 months

- **cardiac evaluation:**
  - cardiac echo
  - EKG
  - heart chamber dimensions
  - systolic function
  - diastolic function
  - fractional shortening

Yearly

- **virology:**
  - Hepatitis C panel (anti-HCV, anti-HCV RIBA)
  - Hepatitis B panel (HBsAg, anti-HBs, anti-HBc IgG)
  - anti-HIV 1+2
- **liver biopsy:** to evaluate liver iron concentration and histology
- **endocrine function evaluation:**
  - free T4 & TSH
  - parathyroid hormone
  - FSH
  - LH
  - testosterone
  - estradiol
  - DHEA-S
  - fasting A.M. cortisol
  - oral glucose tolerance test/GTT
  - bone age and bone density
  - zinc, copper, selenium, vitamin C, vitamin E
- **complete physical exam**
- **ophthalmology examination**
- **audiology examination**

As indicated

- 24-hour Holter monitor
- cardiac stress test (EST)
- anti-HBc IgM
- anti-HBe
- HBeAg
- anti-HDV
- HCV-RNA

The above list provides an indication of the recommended examinations and frequencies, but **each patient's case is unique**. Examinations may be required more frequently than indicated here, and additional examinations not listed may also be necessary.

National Thalassemia Welfare Society

International Thalassemia Day

This year Thalassemic children had a unique experience of FREE UNLIMITED Rides & Water Games at Appu Ghar and attached Oysters. 11th May, 2002 being the first holiday of the summer vacation NTWS observed the International Thalassemia Day instead of 8th May, at Appu Ghar. Around 400 Thalassemia patients, parents and siblings enjoyed Rides & Water Games. Most of the children were from poor economic strata who would have never dreamt of visiting Appu Ghar or Oysters.

Children gathered at the gate by much earlier to the stipulated time of 9.00 a.m. Free food packets were served to all by 9.30 a.m. then they were directly taken to the **Oysters** (water games at Appu Ghar). Children along with their parents enjoyed Rainfall Dance, Snow Dance, Water Glides & Swimming Pool with the tune of top Punjabi and English music. They stayed there up to 11.30 a.m. All the participants were also given Free Coke, after that they enjoyed all other rides to their fullest feast.

Thanks to Mr. Rakesh Babbar, President, International Amusement Ltd. (Appu Ghar Management) Thalassemic Children could forget their pains & worries, could smile & dance in snow & rain in the scorching heat & sweat of summer. Mr. Babbar was so impressed by the "wide smile with discipline" of the Thalassemics that he promised us similar facilities in future. The credit of the unlimited N'joyment also goes to Mr. Syed Sameen Anwar Dy. Manager who managed the show very well. The co-operation of Mr. Jasra was also admirable. Mrs. Swaran Anil and Mr. Gautam Seth were instrumental in getting us this enjoyment.

Blood Donation Camps

National Thalassemia Welfare Society associated with Delhi Vidyut Board and Mianwalli Volunteer Blood Donors Association to organize a Blood Donation camp at Shankar Road Delhi Vidyut Board office on 18th February 2002. **Transport Minister Govt. of Delhi, Shri Ajay Makan**, was the guest of honour. **Shri Jagdish Sagar, Chairman Delhi Vidyut Board**, inaugurated the Blood Camp. A lecture was also arranged on safe Blood Donation.

The chairperson Shri Hiralal Sharma, President General Secretary Delhi State Electricity Workers Union chaired the occasion. Special Invitee Shri Alok Kumar President, Dadhichi Dehdan Samiti, Kumari Tanuja Joshi, Vice President, Eye Bank Association of India, Director Venu Eye Bank also graced the occassion. Donors were given mementos and certificate. The camp was a super success, which collected 64 units of blood.

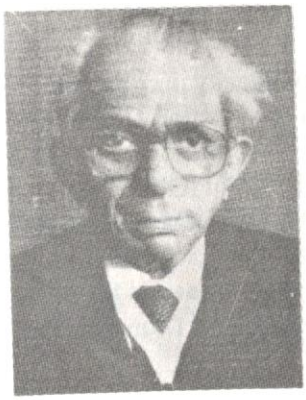
National Thalassemia Welfare Society organized two blood donation camps in association with **Huges Software System**, at their offices at **Electronic City, Gurgaon** on 31-05-02 & 07-06-02. Ms. Rashmi & Ms. Bindu Nair motivated their colleagues for voluntary blood donation. Total 100 & 70 units of blood were collected respectively. Mrs. Vandana Arora a Social Worker from Gurgaon helped us in organizing these camps.

National Thalassemia Welfare Society in collaboration with Vikas Puri Main Market Association & Mianwali Voluntary Blood Donors' Association organized THALASSEMIA BLOOD DONATION CAMP on **Sunday, the 16th June, 2002, 9.00 AM to 2.00 PM at Society office premises.** 89 donors donated blood in this camp. **Donors enjoyed donating blood in special air-conditioned mobile Blood Donation Van of AIIMS.**

After lot of persuasion we could convince **Mr. Jewesh Manuja** (father of a Thalassemia patient Mayank Manuja, a patient from NDMC) to organize a **"Thalassemia blood donation camp"** in collaboration with the Jail Road Shopkeepers Association and Anand Vihar Welfare Association at Dashmesh Hospital, Jail Road, on 22nd June 2002.

His efforts were so fruitful that in his first attempt we could collect 125 units of blood. Red Cross team also appreciated his hard work in making the camp a super success. Now he and his collaborators Jail Road Shopkeepers Association, Anand Vihar Welfare Association and Dashmesh Hospital, Jail Road, are so thrilled and energized that they have promised to hold at least one blood donation camp every year in the month of June.

Editorial Comment: If more Thalassemic parents come forward to organize "Thalassemia blood donation camps" specially in summer then there would not be much problem to Thalassemics in getting blood. As far as funds are concerned these can be arranged from local sources or any Thalassemia society will be too willing to sponsor such activity.



Dr. Vinod Behari Lal
17.10.1915 – 26.03.2002

A Tribute

A Trail Blazer in Blood Banking Movement in India. Dr. Lal was not only the Founder Chairman of the Blood Bank Organisation, Pusa, New Delhi; he was a highly qualified scientist and multi-faceted personality. In six decades of professional career he won many laurels for himself and had many achievements to his credit, the most notable among them being his work on HLA system under Prof. J. Asset, Nobel Laureate, in 1959 and his work at the Institute of Human Genetics at Gottingen University, under Prof. Becker from 1969 to 1977.

The credit of performing the first Bone marrow Transplantation in India on a lady, Aplastic Anemia belongs to Dr. Lal. The patient lived for 5 yrs – a good survival time (referred in the proceedings of International Blood Transfusion Congress-1962). The Visionary in Dr. Lal came to the fore again in 1966, when he established the Institute of Haematology in Delhi with a view to training Para- Medical Staff in Blood Banking and Laboratory Medicine.

Dr. Lal was a great philanthropist who was constantly engaged in various social activities and was always at hand to help the downtrodden and the needy, He was felicitated with Indira Gandhi Priyadarshini Award 1992, National Unity Award 1993, Hind Ratna Award 1993, Man of the Year 1998 and 2000 Millennium Gold Medal Honour by American Biographical Institute, U.S.A. Not but least he was guiding force behind our organization as patron of the society.

May God rest his soul in peace.

Dr. J.S. Arora
General Secretary
National Thalassemia Welfare Society

Mumbai Thalassemic Society

From January 2001 M.T.S. is publishing a regular newsletter **"Smiley"** with views pertaining to Thalassemia. 50% subsidy on Kelfer therapy is provided to Thalassemic patients. The society organized a stage show by Anandji's "Little Stars" in an air-conditioned Bhaidas hall, Vile Parle (West) on Sat 4th May 2002.

On May 8, 2002 created a "Thalassemia Day Care Centre" in association with K.E.M. hospital. More than 100 Thalassemics are getting their blood transfusions in the hospital.

BLOOD PATIENT'S PROTECTION COUNCIL

(Leukemia, Thalassemia, Hemophilia, Sickle Cell Anemia & Aplastic Anemia)

MALABAR ZONE, Tel: 0495-296182, Phoenix, Salem, KARASSERY CALICUT-673602, KERALA

Thalassemia day observed dated 8th May, 2002

World Thalassemia day was observed at Vyapara Bhawan, Kozhikkod under the aegis of Malabar THAS Society. Related to this various programs like free Hepatitis-B Vaccination, Medicine distribution, Medical camp and awareness classes were organized. It was the most advantageous that the Kelfer (LI Deferiprone) capsules could be given to all needy patients free of cost on the occasion.

Dr. C.K. Sasidharan, Head Department of Paediatric wing of Calicut Medical College inaugurated the programme Shri P. Damodharan, special correspondent Malayala Manorama the most leading newspaper in India distributed free Kelfer capsules to the poor patients, Society President Dr. P.M. Kutty presided over the function.

Mr. Kareem Karassery, Secretary Malabar THAS society put the report about the past activities of the society. Shri A. Sajeevan, senior correspondent Kerala Kairuli daily, Dr. V.P. Kannan, Asst.Professor Govt. Dental colleges Kozhikkod, Advocate Sivam Madathil counsel, Kerala high court, Mr. P.C. Kishore, Secretary Kerala State Medical Technician Association also spoke.

Mr. K. Hassankoya Gen. Secretary Vyapari Vyavasari Ekopana Samathi welcomed the gathering and Mr. V. Akbar, Joint Secretary of THAS society proposed the vote of thanks.

In his speech Dr. C.K. Sasidharan and Dr. P.M. Kutty mentioned about the possibilities and advantages of cord blood transplantation. In Calicut Medical College hospital 28000 (Twenty Eighty Thousand) child birth takes place in each year. It will facilitate to get the matched cord blood for each patient. They said that the operation would perform only after through discussion with experts like Dr. S.H. Advani Director, Tata Memorial Hospital Mumbai, who arrives on 16th May 2002.

Thalassemia Patient Arrested dated 2nd June, 2002

Calicut: (Kerala) Following an agitation against the hospital fee imposed by the Kerala Government a number of Thalassemia patients and their parents were arrested with other patients like Leukaemia, Haemophilia and sickle cell anaemia. The agitation took place at the cash counter of Calicut Medical College Hospital (Institute of Maternal and Child Health) on 01-06-02. Owing to heavy crowd the fee collection was completely disrupted. After a two-hour agitation Medical College Police rushed to the hospital cash counter and arrested all patients and their parents and removed them to Medical College Police Station. The patients who were arrested had been admitted in the hospital for chemotherapy or blood transfusion and receiving other treatment also. The Malabar zone blood patient's protection council organized the strike.

The patients and their parents had staged a similar strike in front of the office of the superintendent of the Hospital on 06-04-2002. Then the superintendent of Medical College Hospital Dr. K. Sasidharn exempted all Hemeto-oncology patients from remitting the hospital fee for a period of one month. After a month the hospital authorities restarted to collect hospital fee from these patients. In lieu of that the patients organized a strike again in front of the hospital cash counter.

In a special order Kerala Government had directed for complete free treatment to Leukaemia patients in 1996. Besides the Central Government had given direction to Health Secretaries of different States and UTS not to charge any fee for issue of blood/blood component from Thalassemia and Haemophilia patients, who required repeated blood transfusions as life saving measures (S12015/9/96NACO dated: 17-08-98). But now Kerala Government is collecting fee from these patients also, even for the blood/blood components, which is against the above order.

The blood patient's protection council has been demanding for a separate Hemeto-oncology unit at

Calicut Medical College Hospital and distribution of free life saving drugs including Desferal for the blood disorder patients for ten years. Numerous agitations had staged for this purpose. Even a march to Kerala State Secretariat which is 400 (Four hundred) Km away from Calicut also was organized. Consistent negligence of the Government towards these patients has enhanced the fury of the patients and their parents. Mr. Kareem Karaserry, Convenor Blood Pateint's Protection Council, Mr. K.P. Ashokan, Mr. K.V.A. Raheem and Mr. Medavampat Krishna Das led the agitation.

The agitation will be continued till the order to charge from Thalassemia and Haemophilia patients is cancelled.

Thalassemia and Sickle Cell Society, Hyderabad

CME (Continued Medical Education) programme was organized by our society on March 17, 2002 specially for Obstetricians, Gynaecologists and Paediatricians.

Eminent speakers of National repute were invited to speak. Dr. Mammen Chandy, Prof. and Head of Haematology CMC, Vellore spoke on "Present and future trends in the Management of Thalassemia". Dr. P.G. Natarajan of Nanavathi Hospital, Mumbai spoke on "Prenatal Diagnosis of Haemoglobinopathies". Dr. M.P.J.S. Anand Raj of Institute of Genetics, Hyderabad spoke on "Conventional and Molecular Diagnosis of Thalassemia" the focus being on comprehensive management of Thalassemia and its prevention.

Our Patron-In-Chief was beloved Dr. Harpriya Rangarajan, the lady Governor. About 200 medical personnel attended the meeting and it was a grand success.

A Blood Donation Camp was organized by the Vice President of the society, Mrs. Ratnavali near her residence on 21st April and 33 donors donated blood. Bharath Biotech also organized a blood donation camp at their premises on 2nd May and 70 persons donated blood.

On 9th June Dr. Sreedhar Rao gave a talk on Alternative Therapy of Acupuncture and Naturopathy to help Thalassemia patients.

The Badminton player Mr. P. Gopichand visited our society and was presented with a badge, which he has promised to display whenever he plays.

New Thalassemia Society Formed

Indian Red Cross Society, Ahmedabad District Branch

- Champaben Chudgar Blood Foundation
- Seth Kanaiyalal Blood Bank

"J.L. Thakore Red Cross Bhavan"
18, Gujarat Brahmkshatriya Society
Mahalaxmi, Paldi, Ahmedabad-380007
Ph: (079) 6643833, 6643855
E-mail: ahmedabadredcross@hotmail.com

I am a Centurion Blood Donor and Secretary of Red Cross. I was instrumental in starting of Thalassemia clinic at Red Cross Ahmedabad. Dr. Sasiben Vani, Dr. Ramesh Shah and Dr. Anil Shah all Paediatricians have helped us in putting this service to the state where it is today.

We have been transfusing blood to 8 Thalassemia children every day without asking for replacement. On our register, today we have more than 400 such children ranging from age group of 1 to 23. We want to extend our service to more children and, therefore we are proposing to start Sunday Thalassemia service also.

We propose to educate the parents of Thalassemic for prenatal diagnosis, diagnostic test for their relatives for confirmation that they are not Thalassemia minor so that marriage counselling can be provided to them.

Dr.Chaitanya Vora
Executive Director

Mr. Mahesh C. Trivedi
Hon. Secretary

The Hematology Foundation, Kolkata

(Review of the objectives and activities- 2001-02)

Objectives

1. To support and uplift the treatment facilities for the patients suffering from Thalassemia.
2. To promote awareness in general public about Thalassemia and to provide assistance as may be considered necessary, so that this disease may be eradicated in near future.

Activities during 2001-02

1. Blood Transfusions:

Ensuring availability of Blood for transfusions, continued to be priority and a number of Voluntary Blood Donation Camps were organized on regular basis. However it is experienced that proper planning in advance will further improve the situation. The following statement may be relevant in this connection.

A. Total number of patient Members requiring Blood Transfusions on regular basis – 74 (31/03/02)

B. Blood Units required for above – 1332

C. Blood Units available – 1160

D. Shortfall met from other sources – 172

E. Particulars of Voluntary Blood Donation Camps:

	2000-01		2001-02	
	Nos.	**Units**	**Nos.**	**Units**
Repeat Camps	20	1270	13	691
New Camps	11	385	19	901
Total	31	1655	32	1592
Less for Organizers		470		332
Balance		**1185**		**1260**

F. Financial Involvements:

Total amount spent during 2001-02 for organising Blood Camps Rs. 43,184 against which a sum of Rs. 38,700 was collected as Donation. Net amount spent from other fund is therefore Rs. 4,404.

2. Laboratory Services:

Pathological Test facility from our Laboratory was availed by 60 members (out of 83 as on 31/03/02) and 40 non-members, on regular basis and total collections are Rs. 97,510/- (Members Rs. 58,510 and Non members Rs. 39,000/- on pro-rata basis).

Total expenses for running the Laboratory (Administration, salary of Pathologist & Technicians, Consumables etc.) being Rs. 1,33,294/- there is a shortfall of Rs. 35,784/, which has been met from Donation collected for the purpose.

Cost of having pathological tests at our Laboratory being much less from the market rates, benefits from this service are well appreciated. Some poor patients avail the test free of cost. However the equipments in the laboratory needs up gradation, for which we have a pending commitment for further Donation.

3. Day Care of Transfusion Facilities:

Day Care Centre at Kothari Medical Centre being overcrowded, we have initiated and persuaded Lions Club – Dist. 322B to have a transfusion centre for our patient members. Accordingly they have opened a centre in Feb. 2001 and 39 members have since shifted at this centre.

However the centre at Lions Club did not come up well as expected. It is therefore imperative that we must explore possibility of having some alternative arrangements.

4. Medical Assistance:

We continued to provide medical assistance to the members by way of:

A. Bulk purchase of Leukocyte Filters and Desferal by the Foundation to make them available as and when required.

B. Reimbursement of transfusion expenses and free supply of Desferal/Kelfer to poor and needy patients.

C. Collection of Donation for reimbursement of expenses on BMT of one patient member.

D. Supply of Infusion Pump on loan as and when required.

The total expenses for the above assistance during 2001-02 are Rs. 79,000/-, which has been met mainly from Donation collected for this purpose.

5. Other Activities:

A. Thalassemia Awareness:

Lecture/Talk was delivered to create awareness whenever any opportunity was available in the seminar/meeting held primarily along with Blood Donation Camp. However, it is felt that such activity was much below than its need. Thalassemia carrier detection programme could not be undertaken on sustained basis in view of the fact that most of the times HPLC system at Lion Club was not available.

B. Fund raising Activities:

An amount of Rs. 44,000/- was collected through organising a cultural function at Mahajati Sadan in February 2002. This was utilized in clearing some of the liabilities. A further sum of Rs. 31,000/- was made available from Drama Utsav.

C. Donation:

Most of the Donation collected during 2001-02 was against specific issues and used accordingly.

Particulars of Donation:

	(Rs.)
Donation to support Blood Donation Camp	38,780/-
Donation to support BMT of a patient	44.000/-
Donation to support Laboratory services	36,000/-
Donation to support Medical Assistance	33.500/-
Donation to support Cultural Function	70,500/-
Total	**2,22,780/-**

6. Acknowledgement:

We must acknowledge the support and guidance given by Dr. (Mrs.) S. Chandra, our consulting Haematologist, in running the Foundation. All the patients registered with the Foundation are monitored on regular basis.

Support received from Dr. M.K. Das, Genetist and Research Scientist in keeping the patients well and in prevention of birth of Thalassemic child, is also worth mentioning.

Letter to Editor

Mukesh Ahuja
684/25 Patel Nagar
Rohtak 124001

Q 1. At this stage is any treatment available, by which my son may live his life without blood transfusion?

As of today the conventional treatment available is repeated blood transfusion to maintain Hb 10gm/dl and above along with iron chelation with Desferal/Kelfer to maintain serum Ferritin level around 1000 mg. However the child can be saved of repeated blood transfusions & iron chelation with permanent cure called Bone Marrow Transplantation. It requires HLA identical donor usually sibling which is possible only in 30 % cases. It costs around 8-10 lac in India and is also very risky.

Q 2. We are not going any DNA test, is it a time to go for DNA test?

DNA test is not required at this time. How ever it will be required at the time of antenatal diagnosis if you go for next pregnancy.

Q 3. Is Cord blood transfusion is successful in India or abroad?

Q 4. If we go for Cord blood transfusion can you provide us full details of the hospitals and doctors, which is successfully doing this job?

&

Q 5. I heard that the doctors of AIIMS New Delhi has done one Cord Blood Transplantation what is the result?

Cord Blood Transplantation has shown some success abroad but there is not much experience in Cord Blood Transplantation India. Only one Cord Blood Transplantation has been done in India that was in AIIMS in April 2000. The disease relapsed after some time.

1. Procedure cost and risk is the same, both in BMT & CBT except the source of donor's Stem cells.
2. As stated above the CBT done at AIIMS was not successful. It relapsed after sometime.

Preliminary Invitation

To all Thalassemia Associations and persons
The First National Thalassemia Conference

Organised by:
Thalassemia Welfare Society of Burdwan

With Collaboration of FIT

27-28th October, 2002

For details contact:
Kanai Bairagya
Secretary
Thalassemia Welfare Society of Burdwan
Gosaipara, Near Agriculture Farm
Burdwan (West Bengal), India
Phone: 91-342-564069 ● Fax: 91-342-564069
E-mail: twsbdn@vsnl.net

National Haematology Update-III
January 17-18, 2003

Jawaharlal Nehru Auditorium
AIIMS, New Delhi

Department of Haematology
AIIMS, New Delhi

In association with
Delhi Society of Haematology
Indian Society of Haematology & Transfusion Medicine and
National Thalassemia Welfare Society

Mailing Address:
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National Thalassemia Welfare Society (Regd.)

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URL: thalassemiaindia.com E-mail: ntws@thalassemiaindia.com

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Half Page	Rs. 1,800	– —
Back		
Full Page	Rs. 10,000	US $ 1,000

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MEMBERSHIP

Any person can become a member of the society.

Charges	Inland	Foreign
Patron:	Rs. 5,000	US $ 500
Life:	Rs. 500	US $ 50

READY AVAILABLE

	(Rs.)
Filter Single Unit	430/- each
Filter Double Unit	530/- each
Infusion Pump	12,000/- each
Scalp Vein Set 27G	15/- each

SPECIAL THALASSEMIA CLINIC

National Thalassemia Welfare Society organises Thalassemia Check up Clinic ***on 2nd Sunday*** of every month at ***Charitable Medical Clinic, Lajpat Bhawan,*** Near Vikram Hotel, Near Mool Chand Flyover, Lajpat Nagar, New Delhi.

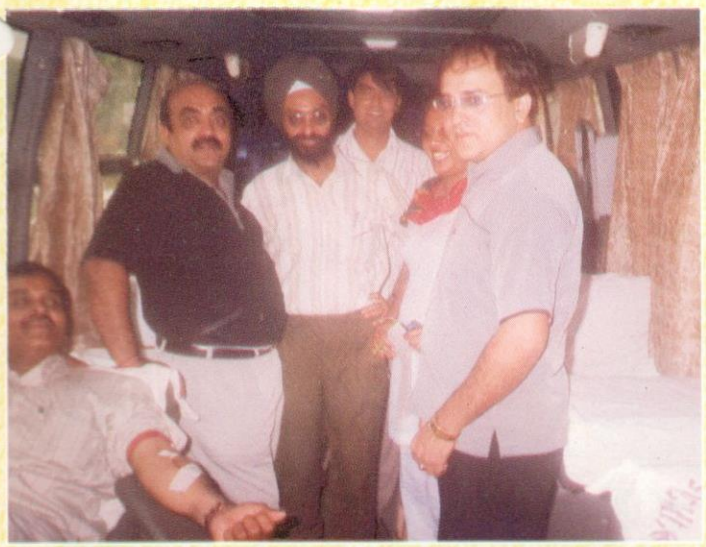
Facilities:

- Growth Monitoring
- Chelation Therapy
- Serum Ferritin Assay for Rs. 150 only
- Hepatitis B vaccine: Rs. 50/- for Children below 10 years
  Rs. 100/- for Children above 10 years
- Thalassemia Screening/Diagnosis with HPLC Rs. 300/- only

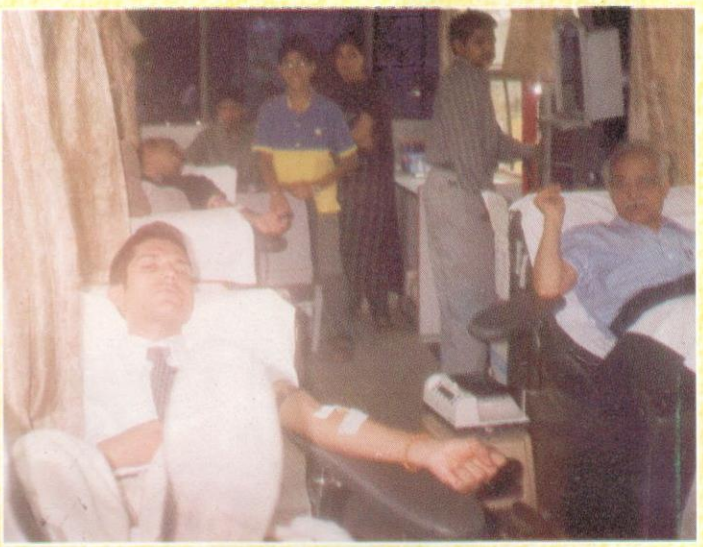
For appointment contact: Dr. J.S. Arora, Tel: 91-11-5507483

Dr. J. S. Arora giving an interview to a reporter for a Website, at Hughes Software Systems, Gurgaon Mrs. Vandna Arora social worker seen in the picture

Ms. Rashmi Soni donating Blood at Hughes Software Systems, Gurgaon, while Bindu Nair & Monisha looking at



Dr. J.S. Arora, Gautam Seth and Pop Star Lucky Singh with blood donor in AIIMS's Mobile blood donation van at Vikas Puri on 16th June 2002



Dr. V. P. Choudhary donating blood in AIIMS's Mobile blood donation van at Vikas Puri on 16th June 2002

Dr. Krishna, President of TSCS, Mrs. Ratnavali, Vice President of TSCS, Lady Governer, Mrs. Rangarajan, Dr. Anand Raj and others lighting the lamp at the C.M.E. inauguration

Dr. Mammen Chandy, Prof. & Head Dept. of Haematology CMC, Vellore being presented a bouquet by Thalassemic child at CME organised by TSCS, Hyderabad


With your help
I will live.
Provide
Thalassaemics
with the full
treatment
Desferal
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Desferal
Desferal
0,5 g
Desferal
NOVARTIS
Novartis India Limited
Pharmaceuticals Sector, Royal Insurance Building,
14 Jamshedji Tata Rd., Mumbai -400 020.(INDIA).
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