FEDERATION of Indian Thalassemics

National Thalassemia Bulletin

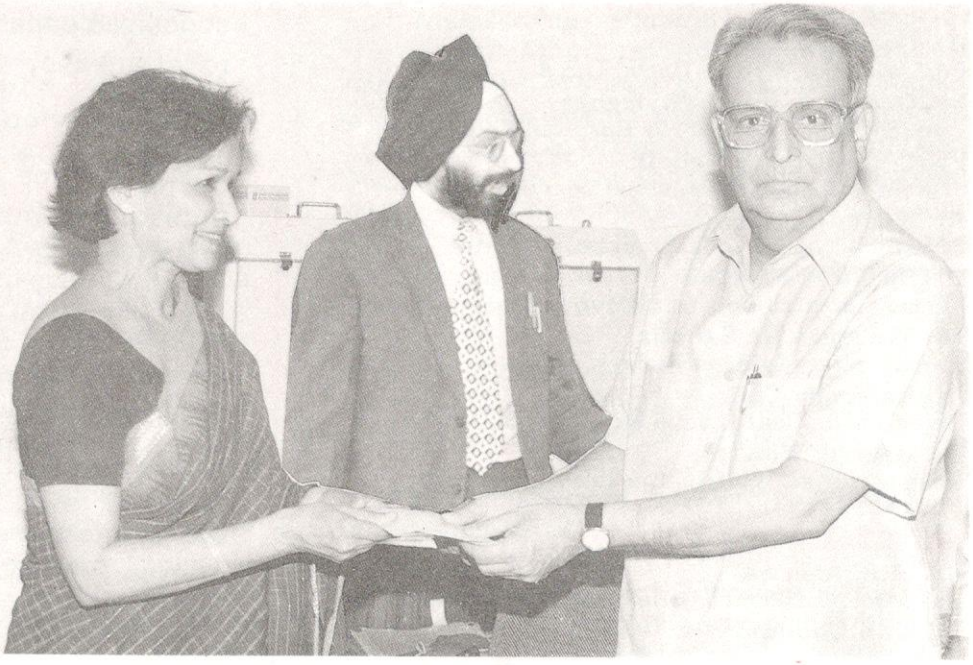
Vol. 5 No. 1 April, 99

International Thalassemia Day, 8th May 1999

International Thalassemia Day, will be observed at Constitution Club, Rafi Marg, New Delhi from 4 pm onwards. Cultural activities and prizes to outstanding children will mark the occasion. A symposia on recent advances in Thalassemia will be highlight of the evening. Thalassemics who have secured more than 80% marks in 1998-99 examination or want to participate in cultural activities are requested to contact Dr. J.S. Arora or Mrs. Shobha Tuli before 30th April, 99

May God bless Sugam a long disease free happy life

National Thalassemia Welfare Society makes an humble effort to sponsor the expenses of the first Cord Blood Transplantation in Thalassemia in India.



On behalf of National Thalassemia Welfare Society, Dr. Manorama Bhargava, H.O.D., Haematology, AIIMS giving a cheque of Rs. 1,00,000 to Dr. P.K. Dave, Director, AIIMS for the treatment of SUGAM

Address all correspondence to:
Dr. J.S. Arora, General Secretary, Federation of Indian Thalassemics
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For Registered letters & couriers: KG-1/97, Vikas Puri, New Delhi–110 018

the patients medical records and from personal interviews. Mostly all patients were assessed for their endocrine status with measuring T4, TSH, Prolactin, FSH, LH, Estradiol and a.m. Cortisol before pregnancy and in a number of them the GnRH test was performed using the standard method. All patients were annually evaluated with oral glucose tolerance test.

Nine patients had evaluation of their cardiac function Echocardiography (M-Mode, two-dimensional, Doppler) during pregnancy and following delivery where the following indices were measured: End Systolic Dimension (ESD), End Diastolic Dimension (EDD)and Ejection fraction (EF).

Results

Number of Patients

Sixty two women were able to achieve ninety pregnancies and give birth to eighty four babies. The mean age when pregnancy was achieved for group I was 24 years, for group II 27 years, for group III 28.2 years and for Group IV 24.6 years. The ferritin levels at the ages of 9 to 14 years when puberty develops in females is significantly higher in patients of group III, compared to the patients of groups I and IV. There were no endocrine complications in the patients of Groups I and II. In the patients of Group IV, apart from Hypogonadism no other endocrinopathy was present. Patients in the Group III had additionally IDDM (28.8%), impaired glucose tolerance (28.8%), Hypothyroidism (28.8%) and Hypoparathyroidism (14.4%). There were two twin pregnancies in patients of Group III (induced) and two twin pregnancies in patients of group I (one induced and one spontaneous). There was also a triple pregnancy in one patient (XD) with Primary Amenorrhoea, which was induced with HMG and conceived with intercourse.

Stimulation with GNRH

The patients of Group I had a normal rise of both FSH and LH as expected. The patients who belonged to Groups III and IV had a minimal rise and most interestingly patients with Primary Amenorrhoea and other additional endocrinopathies showed absolutely no elevation of the basal value indicating the severity of the long standing haemosiderosis of the Pituitary and the Hypothalamus.

Conception and outcome of the pregnancies

Out of the seventy three pregnancies in the patients of Group I and II, sixty-six were spontaneously achieved and eight following induction. All pregnancies of the patients in the Groups III and IV were achieved following induction. There were overall twenty-four induced pregnancies which were achieved by intercourse (41.6%), insemination (25%) and by IVF (33.3%). Seven pregnancies (7.7%) resulted in spontaneous abortions and two (2.2%) in stillbirth. Sixty-nine babies (76.6%) were born at full-term and twelve (13.3%) were born prematurely.

Delivery

There is an overall relatively high incidence of Caesarian sections performed (32%), and mainly in Group III (71.4%) which was attributed to safety reasons. The mean birth weight of the full term babies born to the mothers of Group I was 2,540 grams, to those of Group III 2,880 grams and to those of Group IV 2,670 grams. There were overall only four babies, which were characterized as small for their gestational age.

Transfusion requirements

As expected pregnant Thalassemics required significantly larger amount of total blood transfusion during pregnancy. In all three groups there was no difference between the amount of blood required before pregnancy compared to that required after delivery. There was also no difference between the haemoglobin level before, during and after pregnancy in all three groups.

Ferritin levels

There was a statistically significant increase of the ferritin levels during pregnancy when they were compared to those before for Group I and for Groups III and IV taken together. Their ferritin levels remained significantly increased after pregnancy when they were compared to the levels before in all three groups. Interestingly in all three groups there was no statistically

significant difference between the ferritin levels of the first trimester compared to those of one year before.

omplications

Complications of pregnancy were rare. There were neither endocrine complications noted nor any case of Gestational Diabetes. None of the patients showed impairment of renal function. Two patients with Primary Amenorrhoea, the one being that with the triple pregnancy developed pre-eclampsia for which they had a premature delivery with Caesarian section. Our patient with the triple pregnancy also developed severe cardiac failure due to cardiac tamponade, which was successfully treated. Pericarditis was noted in two patients without any impairment of their cardiac function. In all nine patients that had the opportunity to examine with cardiac echo there was a transient increase of the ESD, and EDD which both decreased to normal values after delivery.

oth partners Thalassemics

Seven couples consisted of Thalassemic patients. Following genetic counselling five couples (three women with SA, one woman with NM and one woman with TI) decided to proceed to sperm donation. One couple where the female partner suffered PA and IDDM proceeded to ovum donation after failure of conception with sperm donation. In the remaining couple where the female was NM, pregnancy was spontaneously achieved and their wish was to give birth to a Thalassemic baby who is now 3 years old.

iscussion

Thalassemic females who are regularly transfused and well chelated can now become pregnant either spontaneously or following induction of ovulation. Following the first described case of pregnancy in a female with Thalassemia Intermedia by Walker in 1969, ninety additional cases have been subsequently reported in the literature by several studies. The small number of reported pregnancies most of which were in women with Thalassemia Intermedia is the consequence of the shortened life expectancy which no longer exists and the reduced fertility rated resulting from dysfunction of the Hypothalamic Pituitary Gonadal axis. The number of Thalassemic mothers in our series is the larger reported so far which clearly reflects the good quality of medical care which these patients receive.

Hypogonadotropic Hypogonadism in Thalassemics is the result of combined damage of the gonadotroph cells of the anterior pituitary and the Hypothalamus as demonstrated from the blunted response of both FSH and LH after acute and chronic stimulation with GnRH. One patient however was able to achieve pregnancy following induction with clomiphene citrate, which indicates adequate pituitary function. Ovarian function is well preserved despite hemosiderosis as all our amenorrheic patients are able to ovulate following induction with HMG. In previous studies however a number of amenorrheic females were not able demonstrate an Estradiol rise after stimulation with HMG. The absence of Estradiol rise to HMG in some patients with Amenorrhoea indicates either simultaneous ovarian dysfunction or increased requirements of the HMG to result in stimulation. In 90% of our patients with TM and TI, the pregnancies were spontaneously achieved which indicates normal ovarian function.

A small number (8.8%) of our patients developed Secondary Amenorrhoea after delivery although they attained menarche and had normal menstrual cycles before the pregnancy and were able to conceive spontaneously. Pregnancy cannot be implicated as the causative factor as most of our women develop SA at some stage in their life, which has also been reported in other studies.

Chronic maternal anaemia in the Thalassemic pregnant woman may result in fetal hypoxia, which predisposes to poor fetal outcome such as death, premature labor and intrauterine growth retardation. In our patients we observed 7.7% first trimester abortions, 2.2% still births, and 7.7% premature labor in singleton pregnancies. The incidence of the above mentioned complications is smaller compared to a study which reviewed a number of 17 pregnancies, and reported two abortions, two stillbirths and three pre-term deliveries, one of which was in a twin pregnancy. The number of

babies born small for their gestational age is also less compared to other reports. In our series, the incidence of IUGR babies is 4.5% which is smaller from 11.7% shown by Savona-Ventura and 60% by Tampakoudis et al. In the most recent study by Kumar, which reported the outcome of thirty-two pregnancies, there were no similar complications observed.

The Thalassemic pregnant faces possible deleterious consequences in her cardiac function as a result of myocardial hemosiderosis and changes in her hemodynamic state, which occur during pregnany. Accelerated erythropoesis and expansion of the total red cell volume occur that increase the cardiac output which may potentially lead to cardiac failure. There have been no severe cardiac complications reported except for one case with early infiltrative cardiomyopathy. In our series we had only one 28 year old patient with PA who carried a triple pregnancy following induction with HMG and conceived with intercourse, who developed congestive cardiac failure, which was the consequence of cardiac tamponade following pericarditis. She was successfully treated with medications and an elective premature Caesarian section was performed. Another patient with NM and no severe hemosiderosis had an uneventful episode of pericarditis. One patient with PA and singleton pregnancy with severe hemosiderosis had a transient increase of ESD and EDD and decrease of EF as seen in the cardiac echo. The transient increase of EDD seen in all nine patients examined by cardiac echo is the result of the increased blood volume, which is associated with pregnancy. Careful monitoring of the transfusion regime to avoid overload and periodical evaluation of the cardiac function should be done in the pregnant Thalassemic.

Two of our patients both with PA developed pre-eclampsia for which an emergency Caesarian section was performed. One of these two patients was the woman who was carrying the triple pregnancy and obviously was in high risk. Despite the fact that pregnancy in Thalassemia is considered as high risk, the cases of reported pre-eclampsia are not frequent, as only another similar patient was seen. Nevertheless, it is advisable to have this potentially deleterious complication in mind in any thalassemic pregnant woman. Other complications that have been reported but not seen in any of our patients are thrombovlevitis and hypersplenic crisis in splenectomized individuals.

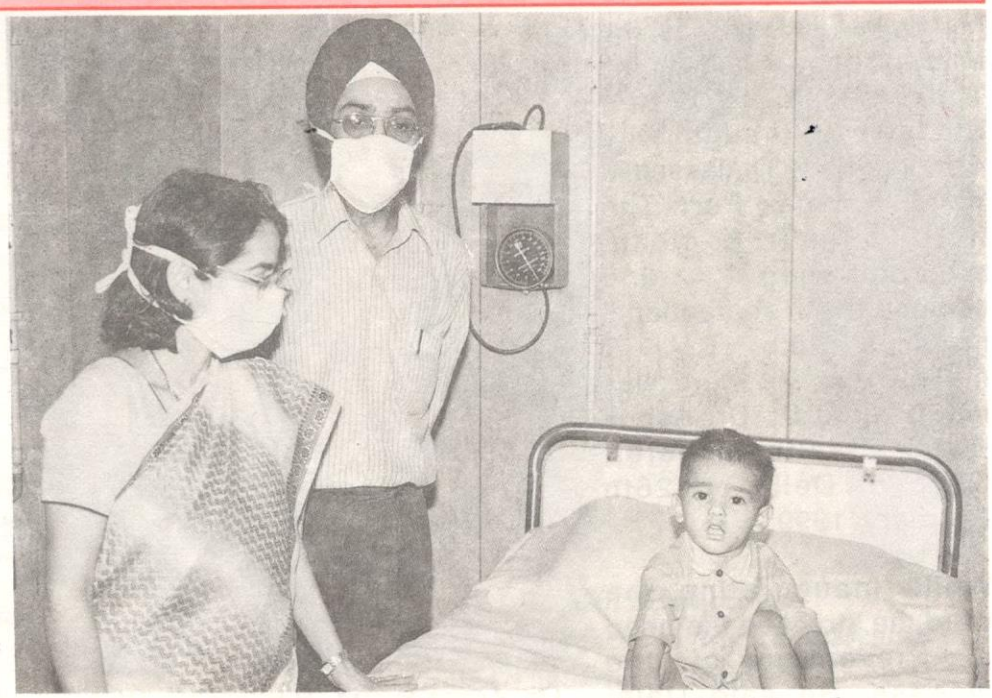
Except for the two cases of pre-eclampsia no other severe obstretic complications were seen. The high incidence of 32% in caesarian sections performed is in agreement with previous findings and can be mostly attributed to cephalopelvic disproportion. Except for the isolated cases reported, the incidence of caesarian section was 25% in the thirty two patients studied by Kumar and 76% in the sixteen pregnancies reported by Jensen.

Our pregnant patients had increased transfusion requirements to maintain the haemoglobin level at 10 gm/dl as expected. Desferioxamine therapy due to its possible teratogenic effects was withheld as soon as the pregnancy was diagnosed. The Ferritin levels were significantly increased during pregnancy particularly in the last trimester and after delivery, which is in agreement with previous studies but not found in other reports where no patient had more than 10% increase in serum ferritin levels after delivery compared to the pre-pregnancy level. In our patients there was an overall 32% increase in serum ferritin in the last trimester and 41% after delivery. It has been assumed that pregnancy is an efficient chelator of iron due to its hemodilution effect and the fetal consumption of the free iron because the ferritin levels were found to remain stable. Although Desferioxamine therapy has not been implicated for deleterious effects on the fetus, we advice that the medication be discontinued once pregnancy is diagnosed or during the induction period.

In summary, women with Thalassemia Intermedia and Major in our days can become pregnant and give birth to healthy babies even if they suffer Hypogonadism with chronic anovulation. Pregnancy doesnot have a deleterious effect on the course of their disease and there are no severe obstretic complications except for the high incidence of Caesarian section. This collected data clearly reflects our patients strong desire to have a family, which becomes nowadays a reality.

LONG LIVE SUGAM

Hundreds of Thousands of philanthropists who have contributed small & big for Cord Blood Transplantation of SUGAM have sent their good wishes and are praying for his transfusion free life. At the time of printing intracath line has been put up and conditioning has been started.



Dr. J.S. Arora visits Transplant Unit to wish SUGAM early recovery Dr. Tulika Seth accompanies him.

Bone Marrow Transplantation is the only time tested permanant cure available to transfusion dependant Thalassemics with a pre-condition of availability of HLA-matched donor. Over 1,000 BMTs have been performed at World's most experienced centre, Pesaro, Italy. In India, Dr. Mammen Chandy and his team has performed about 100 BMTs at Vellore at almost 1/5th cost with comparable results with that of Italy.

Lately a new technique Cord Blood Transplantation has been developed in which placental blood is collected at the time of delivery, stored and later on transplanted into the affected child. Complete HLA matching is the basic requirement for better results. However, some transplants with Cord Blood have been successfully engrafted even in partially matched (with difference of 2-3 allele or antigens) donors.

Dr. Tulika Seth in association with Dr. Lalit Kumar and Dr. Vinod Kuchupalli at IRCH, AIIMS, New Delhi has endeavored to perform the first Cord Blood Transplantation in India. However, she has enough experience in Cord Blood Transplantation abroad. Over 200 such transplants have been undertaken in Europe and U.S.A. successfully without exposing the recepient to a high risk of graft vs host disease.

Two years old SUGAM was lucky enough to get HLA matched donor (sibling). HLA matching was done by Dr. N.K. Mehra from the same CVS material collected for antenatal diagnosis for Thalassemia at 9-11 weeks of pregnancy. Sugam's parents, migrants from Bihar were not in a position to bear even the highly subsidised cost (Rs. 1,00,000 only as against Rs. 6-9 lacs for BMT at Vellore) of treatment. The family approached the Society for help. We are proud to inform that we could collect the necessary funds with the support from philanthropists.

Let us all wish a great success to the medical team and transfusion free normal life to SUGAM.

Planning for Bone Marrow Transplantation; Keep an eagle eye on your Serum Ferritin

THALASSEMIA WARD INAUGURATED

Mata Chanan Devi Hospital in association with National Thalassemia Welfare Society inaugurated 4 bedded Free Thalassemia Ward in Janak Puri. The ward is neat & clean, airconditioned and equipped with recreational material like T.V. & magazines. The ward was inaugurated by Dr. Ashok Walia, Health Minister, Govt. of Delhi on 26th February, 1999.

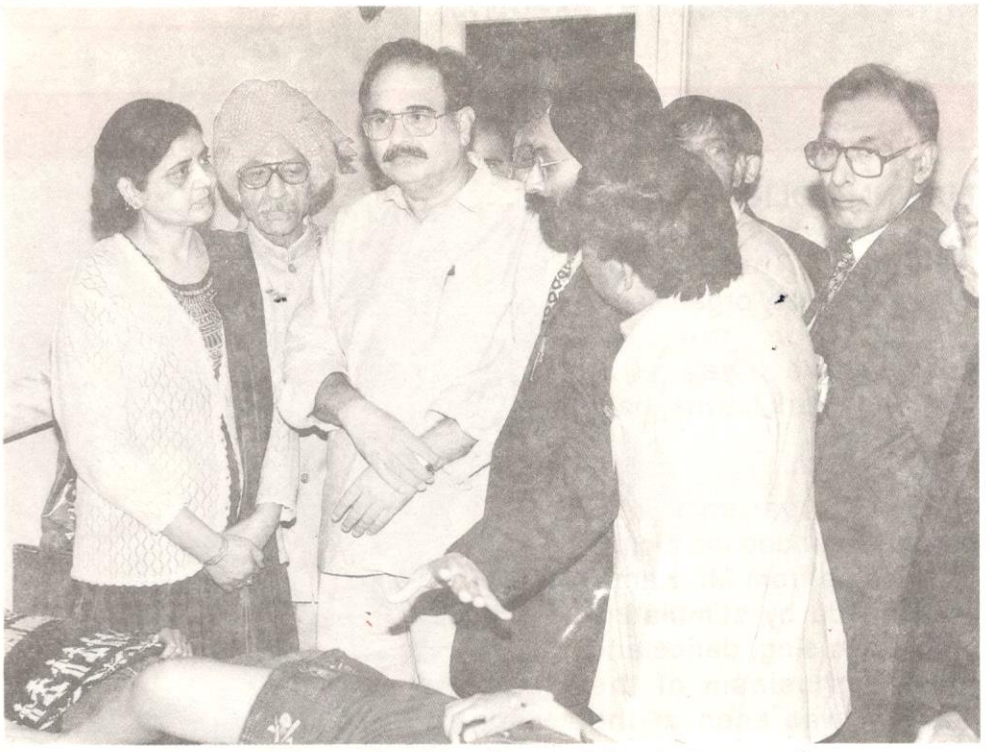
Dr. Ashok Walia, Hon'ble Health Minister of Delhi inaugurating the Thalassemia ward at Mata Chanan Devi Hospital, Janak Puri; Mahashya Dharampal ji assisting him.

While inaugurating the ward, he stressed the need of Prevention of the disease. He said Delhi Govt. has already allocated Rs. 15.25 lacs to three major hospitals of Delhi vise Deen Dayal Upadhaya Hospital, Guru Teg Bahadur Hospital & Lok Narayan Jai Prakash Hospital. All expectant mothers visiting antenatal clinics of these hospitals will be screened for Thalassemia and those found positive would be advised accordingly. He appreciated the role of National Thalassemia Welfare Society in spreading awareness and helping the Thalassemics.

Mahashya Dharampal ji, Chairman of Mata Chanan

Dr. Sudhir Chabbra, Medical Superintendant of the Hospital explaining the facilities available for Thalassemic patients at Mata Chanan Devi Hospital to Dr. Ashok Walia, Mahashya Dharampal ji and Dr. Arora.

Devi Hospital, promised to provide more facilities at a subsidised cost. Dr. P.S. Bawa, Medical Advisor of the Hospital said that **transfusion charges will be just Rs. 150/- including cross match, haemoglobin & meals during stay at the hospital.** Dr. Sudhir Chabbra while speaking on the occasion said that **hospital will provide Hepatitis C screening of donor's blood at a nominal cost of Rs.110/- only.**



Dr. Arora explaining the Health Minister and Mahashya Dharampal ji the problems faced by the Thalassemics in just inaugurated Thalassemia ward

Dr. J.S. Arora, General Secretary of National Thalassemia Welfare Society while appreciating Mahashya Dharampal ji for providing subsidised services for Thalassemics specially Hepatitis C screening attracted the attention of Dr. Walia towards problems of Thalassemia and requested him to involve NGO's and take a lead to start a Thalassemia screening programme in all the schools of Delhi.

Dr. Ashok Walia addressing during the inauguration ceremony.

NATIONAL THALASSEMIA WELFARE SOCIETY

FUN 'N' FROLIC

National Thalassemia Welfare Society organised a PICNIC for the 5th consecutive year at Childrens Park Lawns, near India Gate.

Ms. Surrendar Saini along with Dr. Arora sharing with the Thalassemic parents the past activities of the Society and the future plans.

Over 200 patients and parents attended the picnic. Start came from Mr. Kamal Manchanda by stimulating children to sing, dance and joke. Enthusiasm of the children was seen at the end of the cultural session when almost all the children danced to their heart to the tune of Ta-Ra-Ra-Ra. It was followed by races. Children were divided into 3 age groups and the races for Thalassemics & their siblings were organised separately. Then it was the time of the "On the Spot Painting" competition. While children below the age of 5 years were asked to draw Their surroundings; topic for 6-10 years was "The present state of the city" and for 11 and above was "Dream city". While children were busy with their paintings, parents were discussing the past activities and the future plans in the concurrent General Body Meeting. While presenting the annual report Dr. Arora stressed the need of holding Blood Donation Camps specifically in the months of summer. He asked the members to contact Resident Welfare Associations/Market Associations or any other Political/Non-Political group for holding Blood Donation Camps. He specifically said that if the funds cannot be generated by local efforts, society will reimburse for any expense incurred on these camps. While welcoming the members Ms. Surrendar Saini, President of Society said that we hope to get Disability status for the Thalassemics which may eventually help in getting benefits under The persons with Disabilities (Equal opportunities, protection of Rights and full participation) Act 1995 No. 1 of 1996.

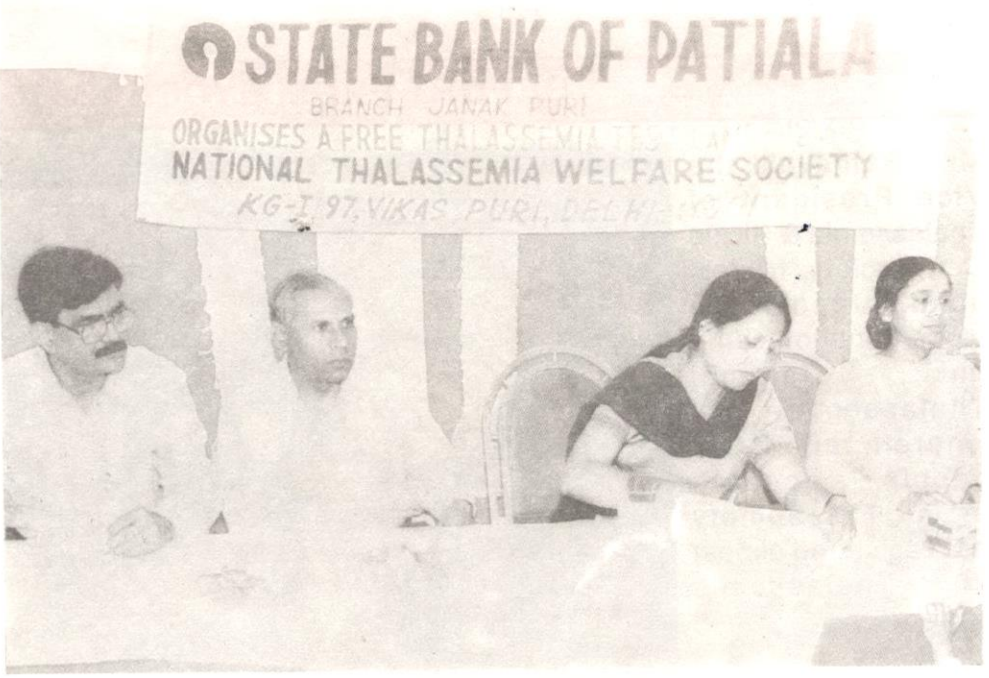
Then came the turn of Tambola which was equally enjoyed by both young & old. By this time everybody was hungry and a delicious heavy feast was served in a "pangat".

After the lunch, a fierce fight broke between children & mothers on one side and adult males on the other in the form of TUG OF WAR. Alas! In this era of male dominance, the females & children got an easy win.

At the end of the day the winning children from all the activities were duly rewarded. Before dispersing everybody rejoiced Mrs. Khurana's innovative game "Egg throw".

THALASSEMIA AWARENESS & SCREENING CAMPS

National Thalassemia Welfare Society in association with State Bank of Patiala organised Thalassemia Awareness & Free Thalassemia Screening Camps at Janak Puri, Shiv Nagar & Bali Nagar on 12th, 13th and 15th March'99 respectively.



Mr. S.K. Saggar, Manager (Planning), State Bank of Patiala looking at the Free Thalassemia Screening being done at Janak Puri Camp

Volunteers were screened with MOFTI. Positives were advised HbA_2 for confirmation. Mr. S.K. Saggar, Manager (Planning) was the brain behind the organisation of these camps. Mr. S.P. Mehtani, Deputy Manager was the chief co-ordinator and Branch Managers, Mr. S.P. Rajan, Mr. R. M. Singh and Mr. G.K. Sapra of Janak Puri, Shiv Nagar and Bali Nagar respectively were the actual executors of these camps.

CLINICAL MEETING

National Thalassemia Welfare Society organised a clinical meeting at Deen Dayal Upadhaya Hospital on 27th March'99 which was attended by over 100 patients and parents besides many doctors from the hospital. Dr. Mamta Sharma, H.O.D., Paediatrics delivered a lecture on "Blood transfusion Therapy in Thalassemics". She stressed the need of transfusing only packed cells and maintaining the Hb above 10 gm. Dr. V.K. Khanna, Sr. Consultant, Paediatrics, Sir Ganga Ram Hospital enlightened the audience on "Chelation Therapy". He said, "Chelation is as important as transfusion" and emphasized early initiation of Chelation therapy i.e. immediately after 15-20 transfusions or when the serum ferritin level crosses 1000 ng. While informing about activities of National Thalassemia Welfare Society, Dr. J.S. Arora, General Secretary of the Society exhorted the audience to help the Society in holding blood donation camps. He said, full financial assistance may be provided for these camps. He also invited the poor patients to avail off free/subsidised chelation therapy from the Society.

Summer–Once again Blood Shortage

Organise Blood Donation Camps
&
get financial help from the Society

Fever – Sore Throat

No Kelfer – No Desferal

REPORT FROM HYDERABAD

Mrs. Ratnavalli the Vice President of Thalassemia & Sickle Cell Society, Hyderabad, organised a blood donation camp on National Thalassemia Day wherein about 42 people donated blood. The Society has registered almost 70 Thalassemic patients.

Thalassemia & Sickle Cell Society, Hyderabad in association with Niloufer Hospital, Institute of Transfusion Medicine & Research and IAP Twin cities organised the "Paediatric Haematology Update" on 10th January, 1999 at Green Park Hotel, Hyderabad. The scientific programme was convened with the idea of generating awareness among the Paediatricians as well as Obstretricians and General Physicians about the functioning of the Thalassemia and Sickle cell Society. Dr. Mamta Manglani from Mumbai spoke on "Haemoglobinopathies". About 200 delagates from the twin cities and districts attended the scientific programme.

The 7th International Conference of Thalassemia and the Haemoglobinopathies
&
The 9th Thalassemia Parent and Thalassemics International Conference
31st May – 4th June 1999
The Imperial's Queen's Park Hotel, Bangkok, Thailand

Registration Fee (After 15th March)

Conference Participant	16,000 THB
Accompanying Guest	6,000 THB
Patient and Parent	6,000 THB
Processing Fee (for all categories)	4,000 THB

Exchange Rate: 36–40 THB per 1 US$

Opening Ceremony & Welcome Reception
Sunday, 30th May 1999, 6 PM to 9 PM

Closing Ceremony
Friday, 4th June 1999, 3.30 PM to 5.00 PM

Registration Form mail or fax to:

Dr. Pathom Sawanpanyalert
Bureau of Medical Technical Development
Department of Medical Services
Ministry of Public Health
Tivanon Road, Nonthaburi 11000
Thailand
Tel/Fax: 662 591-8265 Fax: 662 818-4061
E-mail: pathoms@loxinfo.co.th

Registration Forms available with FIT

REPORT FROM HISAR

The various activities of Thalassemia Society of Hisar during the year 1998 (from Jan'98 to Dec'98)

The Society held four blood donation camps during the year.

Sh. Ved Jhandai, Secretary of the Thalassemia Society, Hisar being awarded by the Industries Minister, Haryana on 26th January, 1999.

The Society donated 445 B.T. sets and the same number of scalp vein sets to the Thalassemic patients free of cost and 372 units of blood free of testing charges and without replacement. All the Thalassemic patients were given Hepatitis B vaccination (all three doses) free of cost by the Society. The society is trying to distribute Kelfer capsules free of cost to the Thalassemic patients. The President of the Society has met the Hon'ble Minister of Haryana in this regard.

A talk on Thalassemia was telecasted on the city channel, Hisar, Mr. Ved Jhandai was the main speaker.

Mr. Ved Jhandai, General Secretary of Thalassemia Welfare Society, Hisar was honoured by the Haryana Govt. and was also chosen for Red & White Bravery Award in the Social Service category. The honour was presented by Industrial Training and Education Minister of Haryana, Mr. Brij Mohan Singla on 26th January'99.

He was awarded for his distinct services being a blood donor for 51 times, organising 21 blood donation camps in the city & a crusader against the dreaded disease "Thalassemia". Wrecked by the death of his children due to Thalassemia he started his crusade against the disease in 1991 and intensified his efforts in 1995 after the death of his 10 year old son. He organises a blood donation camp every year on 26th June in memory of his son.

He was also honoured in the Regional Annual Conference of 19 Lions Clubs on 28-2-99 for his dedicated social services.

FEDERATION of Indian Thalassemics

P.O. Box No. 6627, New Delhi–110 018, Phones: 5507483, 5511795
Fax: 91-11-5513576

Name (Patient): _____ Date of birth _____ Sex _____

Education/Occupation (Patient): _____ Diagnosed at the age of: _____

Father's Name: _____ Address: _____

_____

Phone No. with STD code (Resi.): _____ Office: _____

Registered with (Name of Society): _____

_____ **Membership No.** _____ **Blood Group** _____

Blood Bank from where you are taking blood: _____

Transfusion Centre _____ Name of Consultant _____

Average Pre-transfusion Hb maintained during last year _____ Using Filters: Yes/No

Chelation-Kelfer/Desferal/Any other (please specify) _____ Dose per month _____

Hepatitis B vaccination: Yes/No (Yes means 3 doses at 0, 1, 6 months and Booster after 5 yrs)

Hepatitis B Positive/Negative/Not known

Hepatitis C Positive/Negative/Not known

HIV Positive/Negative/Not known

Brother(s)/Sister(s) Name, Age, Thalassemia status (Minor/Major/Intermedia/Not known)

1. _____
2. _____
3. _____

Date

Signature

Name _____

NOTE: 1. Please send two photographs of the patient along with this form.
2. If you are registered with more than one society, name(s) of other society(ies) along with membership No. on back side of photocopy of duly filled form may be sent directly to 'FIT' at above address.

Volunteers needed for Gene Therapy Research!

Dr. Punam Malik, a physician scientist in Children's Hospital Los Angeles, is performing research in gene therapy for Thalassemia. She needs small quantities of bone marrow samples from Beta-Thalassemia adult patients to be able to assess the effect of genetic correction of Thalassemia.

If you are Beta-Thalassemia patient (18-year or older) and are willing to donate small quantities of bone marrow samples, please send e-mail to:

<mail to: tmcheng@prodigy.net>

National Thalassemia Welfare Society invites applications from amongst its members for free/subsidised chelation therapy. Subsidy forms are available with Doctor/Sister-incharge of all Govt. transfusion centres in Delhi or contact Society office.

National Thalassemia Welfare Society (Regd.)

KG-1/97, Vikas Puri, New Delhi–110 018 Tel: 5507483, 5511795

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. 150/- for Children below 10 years
  Rs. 300/- for Children above 10 years
- Thalassemia Screening

For appointment contact:

Dr. J.S. Arora, Tel 550 7483

MEMBERSHIP

Any person can become a member of the society.

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

ADVERTISEMENT CHARGES

	Inland	Foreign
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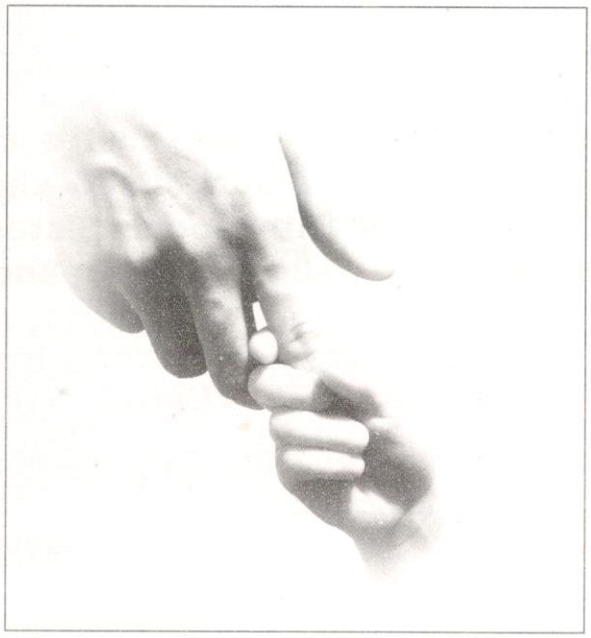
Half Page	Rs. 1,200	– —
Back		
Full Page	Rs. 3,000	$ 300

Published by: National Thalassemia Welfare Society (Regd.) on behalf of Federation of Indian Thalassemics, Printed by: Deepika Printers Ph: 559 5893.

A GLOBAL BREAKTHROUGH IN THALASSAEMIA



The world's first oral iron chelator

Deferiprone

Abridged Prescribing Information **Composition: Kelfer-250/500** Each capsule contains Deferiprone 250 mg/500 mg. **Indications:** Transfusion haemosiderosis, especially in cases of thalassaemia, other haemolytic anaemias, aplastic anaemia and myelodysplastic syndromes, acute iron poisoning, siderosis associated with liver cirrhosis and for the diagnosis of iron-storage diseases. **Dosage and Administration:** 50-75 mg/kg body weight daily in 2-4 divided doses. **Contraindications:** Hypersensitivity to deferiprone. **Warnings and Precautions :** Kelfer should be administered with caution in patients whose serum ferritin levels are below 1000 ng/ml and in patients with impaired hepatic and renal function. Kelfer is not recommended in children below 2 years of age. Reversible impairment of cardiac function may occur in patients with severe iron overload undergoing combined treatments with Kelfer and vitamin C. **Pregnancy:** Deferiprone is not recommended for use in pregnant women. **Side Effects:** GI disturbances, joint pains and swelling are reported. Agranulocytosis, neutropenia and zinc depletion may occur. **Patient Monitoring:** The minimum monitoring essential for deferiprone therapy: (1) Haemoglobin, total and differential white cell counts and platelet counts at 3-4 weekly intervals or whenever clinically indicated (2) Serum ferritin at 3-4 monthly intervals. ***Note:*** *If the total white cell count drops to less than 3000/cmm or Absolute Neutrophil Count (ANC) falls to less than 1000/cmm or platelet count falls to less than 1,00,000/cmm, the drug should be discontinued. In case the patient develops severe joint pain, swelling or difficulty in squatting/walking and no relief is obtained by administering ibuprofen/diclofenac or any other suitable NSAID, the therapy should be discontinued. The drug should not be restarted if joint pains recur.* **Presentation:** Container of 50 capsules.

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