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FEDERATION of Indian Thalassemics

National Thalassemia Bulletin

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MARCH AGAINST THALASSEMIA

organised by Federation of Indian Thalassemics
on *"National Thalassemia Day"* the14th November, 1999

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EDITORIAL

As we enter into the new millenium, let us look back and view the status of Thalassemia in our country for the last few years. The families who could bear the cost of expensive drugs and equipments are in a position to receive best of the treatment. Filters, pumps and infusion sets are available with Thalassemia associations all the times, that too at cost prices. Free Thalassemia clinics are arranged from time to time with the help of National & International experts in Thalassemia. Workshops, seminars and conferences (both at National & International levels) are held atleast once in two years. Associations have been working hard to collect funds, equipments and drugs from all corners of the world to offer medical support to needy Thalassemics. Talks on Thalassemia and free screening camps are also held in schools & colleges.

But what I still feel is that we have not been able to reach that stage where we should have been by now. One of the main reasons is that the major input into the above mentioned success story has come from a few Thalassemia associations only. So it has not been an overall growth on the Thalassemia front. In some states the facilities for Thalassemics are still a bare minimal. Parents are not taking enough interest in association's activities and so the organisations are still struggling. Well, let us all realise that we have to move quicker till it is too late and our Thalassemics start demanding for their rights to live and not exist. It is not good to say that alone we cannot do so much. Individual efforts are required in order to have more hands around us. One may encounter difficulties. But our eyes have to be set on our ultimate goal of cure & control of Thalassemia.

Thus as we enter into the new millenium let all of us concentrate for "less pains and more gains" in the years to come.

May 2000 be happy, healthy and joyous new year for you and your family. On behalf of FIT family I wish you all the best and look forward to our continued relationship throughout the coming year.

Mrs. Shobha Tuli
President

Fetal Haemoglobin induction by Butyrate Lessons from Sickle Cell disease

— G.F. Atweh, M.Sutton, I.Nassif, S.P. Perrine

High levels of fetal haemoglobin protect from many of the complications of sickle cell disease and lead to better survival. Butyrate and other short chain fatty acids were previously known to increase fetal haemoglobin production in erythroid cells in vitro and in animal models in vivo. We investigated the effect of butyrate therapy on fetal globin gene expression in 15 patients with sickle cell disease. We first tested a regimen of weekly butyrate therapy in 6 patients who received infusions of arginine butyrate for 8-10 hrs/day, 5 days a week. Three of the six patients had a good response to butyrate and the mean fetal haemoglobin level of this group increased from 1.8% to 8.6%. However, the high levels of fetal haemoglobin could not be sustained with prolonged continuous therapy. We hypothesized that this loss of fetal haemoglobin response may be a result of the well-known antiproliferative effects of butyrate. We designed an alternative regimen consisting of intermittent or "pulse" butyrate therapy where the drug is given for 4 days followed by 10 to 24 days with no drug exposure. This pulse regimen induced fetal globin gene expression in 7 out of 9 patients and the mean fetal haemoglobin in this group increased from 6.3% to 20.1% ($p<0.0015$). The total haemoglobin levels also increased by a mean of 1.2 gm/dl above baseline ($p<0.004$). Interestingly, all responders had baseline fetal haemoglobin levels above 2% and all non-responders had baseline levels below 2%. The high levels of fetal haemoglobin were sustained in all responders including a patient who has been on pulse butyrate therapy for more than 40 months. This regimen was well tolerated with no adverse side effects reported by any of the enrolled patients. Thus, pulse administration of butyrate resulted in marked and sustained increases in fetal haemoglobin levels in approximately two-thirds of adult patients with sickle cell disease that were enrolled in our study.

Of the five butyrate non-responders, three were treated with hydroxyurea either before or after their butyrate treatment. All three increased their fetal haemoglobin levels above 20% while on hydroxyurea. This demonstrates the absence of cross-resistance to the fetal haemoglobin including activities of butyrate and hydroxyurea. This also suggests that the two drugs probably work by different mechanisms. Hydroxyurea is the first pharmacologic inducer of fetal haemoglobin that was shown in a control randomized clinical trial to ameliorate the clinical severity of sickle cell disease. However, the amelioration was incomplete and the incidence of vaso-occlusive crises was decreased by about 50% and acute chest crises by about 30%. We have also seen partial clinical and fetal haemoglobin responses in some of the patients that were enrolled in our butyrate study. This suggested to us the possibility that combination therapy with butyrate and hydroxyurea may be advantageous, particularly in patients who achieve a partial response to either drug alone. We have recently enrolled three patients on a combination therapy protocol consisting of hydroxyurea for several months followed by simultaneous administration of hydroxyurea and butyrate. All three patients increased their fetal haemoglobin levels following butyrate administration above their baseline levels on hydroxyurea alone. In one patient who was totally resistant to butyrate following both weekly and intermittent therapy, introduction of butyrate after hydroxyurea therapy resulted in a big increment in the feta haemoglobin level. This demonstrates that resistance to butyrate is not absolute and that it may be possible to reverse butyrate-resistance by pre-treatment with hydroxyurea. It is still not clear whether this "acquired" responsiveness to butyrate could be sustained following withdrawal of hydroxyurea.

The mechanism(s) by which hydroxyurea and butyrate stimulate fetal haemoglobin production are still not entirely clear. It is believed that butyrate induces fetal globin gene expression, atleast in part, by inhibition of histone deacetylase. Histone deacetylases are believed to be recruited to specific DNA sequences by binding to transcriptional complexes consisting of transcription factors, adapters and co-repressors. This may explain the striking correlation between the baseline fetal haemoglobin level and the response to butyrate that was observed in our patients. This hypothesis is also supported by earlier observations in animals in which totally silent globin genes required atleast partial activation by 5-azacytidine in order to respond to butyrate. If this correlation between baseline fetal haemoglobin and response to butyrate is substantiated, the baseline fetal haemoglobin level may serve as a good predictor of response to butyrate. These observations in a small number of patients require confirmation in a larger randomized controlled study that should also assess the clinical efficacy of this new form of therapy.

The Clinical Trial of Hydroxyurea in Beta Thalassemia Intermedia

Mehrnoush Kosaryan, Ghasem Yousefy, Mohammad Reza Mahdavi, Nasser Vallaei, Davoud Farzin
Mazandaran University of Medical Sciences

Purpose: To evaluate the therapeutic effect of Hydroxyurea on milder phenotypes of our Thalassemics, we conducted a clinical trial in Bou Ali Sina Hospital, Sari, Islamic Republic of Iran.

Patients and method: it was an open clinical trial. Participants were Thalassemic patients who had their first blood transfusion after 5 years old or were not transfusion dependent. The patients or parents signed the informed consent. Outcome variables were: need to blood transfusion (clinical signs of anaemia or Hb under 8 g/dl), the changes in mean of Hct, Reticulocyte count, HbF, before and during the 6 months period treatment. Renal function tests (urea or BUN and creatinine) and CBC were performed before the treatment and every week at the beginning and every month thereafter to detect the side effects of the drug. Oral hydroxyurea (Syrea, Medac,Germany 500 mg capsules), 15-30 mg/Kg/day was administered. The statistical tests have been used were t-test and Ms Nemar.

Findings: Patients were 13 females (76.5%) and 4 males (23.5%). The mean and SD of age at the diagnosis, the first transfusion and the trial was 5.9±5, 9.8±9.8 and 19.2±7.4 years respectively. About 88% of the patients who had 5-6 blood transfusions during the last 6 months had no transfusion during the trial period. The mean and SD of Hct changed by Hydroxyurea from 26.5±2 to 31.2±2.2 perdent. Changes in HbF (%), Retic. (%) and MCV (fl) were (mean±SD) 47±20 to 72±12, 2.3±1.5 to 5±6.7, 82±5 to 86±8.2 respectively. The follow up period was 8 to 10 months.

Conclusion: Hydroxyurea has a beneficial effect in Thalassemia Intermedia and no serious side effects at least in short period of time.

Long term erythropoietin therapy in children with Thalassemia Major

Y. Aydinok, K. Kavakli, G. Nisli, M. Kantar, N. Cetingul
Ege University Hospital, Dept. of Paediatric Haematology, Izmir, Turkey

Erythropoietin (EPO) alone or in combination with other HbF modulating agents represents a new modality of treatment for the haemoglobinopathies.

In a randomized study of 27 children with transfusion dependent Thalassemia Major (TM) which started in 1994 (Nisli et al, 1997), we found 4 good responders to EPO therapy. We now present the long term follow up of these 4 patients. Genotypic characteristics of the patients are shown in the table.

No.	Age	Sex	ß-mutation	α-mutation	Xmnl
1	13	M	IVS1-6/IVS1-6	αα/αα	-/-
2	12	F	IVS1-110/IVS1-6	αα/αα	-/-
3	4	M	IVSII-1/FSC8	αα/αα	-/-
4	17	F	IVS1-110/IVS1-110	$-\alpha^{3.7}\alpha/\alpha\alpha$	-/-

EPO was administered at the dose of 500 IU/Kgx 3 times a week for the first 6 to 12 months, and half this dose subsequently. Three patients showed sustained haemoglobin levels of 8 gm/dl without transfusion for 5 years. An increase in the percentage of F cell levels of the patients was noticed after the first month of EPO and sustained thereafter. The initial HbF levels did not change significantly during the first year. However administration of EPO beyond 1 year was associated with a definite 2.5 to 6 fold increase in the percentage of HbF in all patients. The 4th patient only responded to a higher dose of EPO (1000 IU/Kg x 3/wk) leading to a hyperexpanded bone marrow by the 18th month of therapy. Following the discontinuation of EPO, this patient returned to a regular transfusion program for 1 year until the combined use of EPO (600 IU/Kg x 3/wk) and HU (20 mg/Kg x 4/wk) was initiated. She has now been on combination therapy for 2 years without adverse effects and also has not required transfusion. In conclusion, the transfusion dependency of a proportion of TM patients, homozygous for mild ß-mutations (and perhaps also a few with severe mutations) will respond to EPO or EPO combined with HU.

हीमोग्लोबिन बढ़ाने वाली दवाओं पर प्रयोग–एक समीक्षा

— डा॰ जे॰ एस॰ अरोड़ा

ऐसा देखा गया है कि Foetal हीमोग्लोबिन अधिक होने से सिक्कल सैल रोग का दुष्प्रभाव काफी कम हो जाता है। यह भी ज्ञात है कि ब्यूट्रेट व अन्य इसी प्रकार के योग Foetal हीमोग्लोबिन को बढ़ाते है। इसी से प्रेरित हो कर कुछ विशेषज्ञों ने इस को सिक्कल सैल व थैलासीमिया में प्रयोग किया।

सिक्कल सैल रोग में ब्यूट्रेट देने से 50% तक दुष्प्रभाव कम होते देखे गये। जिन में यह लाभ नहीं दिखाई दिया अथवा कम मिला उनमें हाईड्रोक्सीयूरिया साथ देने से काफी फायदा हुआ। ब्यूट्रेट व हाईड्रोक्सीयूरिया साथ-साथ देने से 20% तक Foetal हीमोग्लोबिन बढ़ जाता है तथा हीमोग्लोबिन की मात्रा में 1-2 gm/dl तक की वृद्धि होती है। ब्यूट्रेट व हाईड्रोक्सीयूरिया दोनों अलग-अलग विधि से Foetal हीमोग्लोबिन बढ़ाते हैं। एक की नाकामी दूसरे पर प्रभाव नहीं डालती, अपितु उसमें सहयोग देती है। 5 Azacytidine नामक दवा भी सुप्त ग्लोबिन ज़ीन को सक्रिय करने में सहायता करती है।

ब्यूट्रेट से थैलासीमिया में बहुत अधिक लाभ देखने को नहीं मिला। लेकिन हाईड्रोक्सीयूरिया से Foetal हीमोग्लोबिन बढ़ते हुए देखा गया है। विकृत रक्त बनाने के कारण हड्डियों में जो फैलाव आ जाता है और उससे होने वाली पीड़ा को रोकने के लिये हाईड्रोक्सीयूरिया का प्रयोग थैलासीमिया में किया जा चुका है।

डा॰ डी॰ लूकोपोलोस के प्रयोगानुसार इस दवा के प्रयोग से Foetal हीमोग्लोबिन तो बढ़ता है लेकिन हीमोग्लोबिन में कोई विशेष अंतर नहीं आता। इसके बावजूद रोगी पहले से अच्छा महसूस करता है। इसका कारण बोन मैरो में विकृत रक्ताणुओं को हाईड्रोक्सीयूरिया द्वारा बनने से रोकना माना जाता है। HbE/ß थैलासीमिया तथा HbS/ß थैलासीमिया में इसके बहुत अच्छे परिणाम देखने को मिले हैं। दो चीनी थैलासीमिया रोगियों में हाईड्रोक्सीयूरिया से हीमोग्लोबिन की मात्रा बढ़ने की एक रिर्पोट प्रकाशित हुई है। इससे प्रेरित हो कर साईप्रस में 12 थैलासीमिया रोगियों में हाईड्रोक्सीयूरिया का प्रयोग किया गया। इससे Foetal हीमोग्लोबिन तो 50% से 80% बढ़ गया लेकिन हीमोग्लोबिन व अन्य परिमाणों में कोई विशेष अंतर नहीं आया। थैलासीमिया इंटरमीडिया में हाईड्रोक्सीयूरिया से बहुत अच्छा लाभ देखने को मिला।

तुर्की में 27 थैलासीमिया मेज़र बच्चों में एरिथ्रोपोयटिन अकेले व हाईड्रोक्सीयूरिया के साथ देने से 4 रोगियों में बहुत अच्छा लाभ देखने को मिला। इसमें से 3 बच्चों में केवल एरिथ्रोपोयटिन देने से हीमोग्लोबिन 5 वर्ष तक बिना रक्त चढ़ायें 8 ग्राम से अधिक स्थापित रहा। चतुर्थ रोगी को 18 माह पश्चात हाईड्रोक्सीयूरिया भी साथ में दिया गया।

कुल मिला कर यह कहा जा सकता है कि ब्यूट्रेट, हाईड्रोक्सीयूरिया व एरिथ्रोपोयटिन आदि दवाओं से सिक्कल सैल रोग, थैलासीमिया इंटरमीडिया, HbE/ß थैलासीमिया तथा HbS/ß थैलासीमिया अथवा कुछ विशेष म्यूटेशन वाले थैलासीमिया मेज़र रोगियों में लाभ की आशा की जा सकती है।

उपरोक्त प्रभाव को सिद्ध करने के लिये अभी और अधिक रोगियों में लंबे समय तक प्रयोग की आवश्यकता है। इन दवाओं का प्रयोग केवल रक्त रोग विशेषज्ञ की देख-रेख में ही करना चाहिए।

National Thalassemia Day – 14th November, 1999

Federation of Indian Thalassemics organised **"March Against Thalassemia"** on National Thalassemia Day, the 14th November, 1999 from Barakhamba Road to Jantar Mantar. Thalassemic patients and parents from Chandigarh, Hisar, Rohtak, Jammu, Pune, Orissa, Jodhpur, Hyderabad ventured to participate along with their counterparts in Delhi to tell the public and to get the attention of Govt. and media that ***"see we are suffering,take necessary steps so that you should not suffer"***. Around 200 children from different schools of Delhi also "Marched" shoulder to shoulder with their peer Thalassemics to voice their solidarity to **"Fight against Thalassemia"**. Dr. Ashok Walia, Health Minister, Govt. of NCT, Delhi flagged off the **"March"** from Barakhamba Road. While speaking on the occasion he said that every year over 30,000 units blood is utilised for survival of Thalassemics in Delhi alone. If we do not take steps now our blood banks will go dry and we would not be left with any blood even for emergency purposes. He said that Delhi Govt. is aware of problems of Thalassemia and has launched Thalassemia Screening Programme in three of its major hospitals. He also said free chelation therapy would be provided at Delhi Govt. Hospitals.

Dr. Ashok Walia also released sticker carrying the message **"Check your Thalassemia status before marriage"**. It was sponsored by Sapra Invertors. He appreciated the slogan and asked the participants to propagate the theme.

Dr. Ashok Walia, Hon'ble Health Minister, Govt. of NCT, Delhi releasing a sticker on prevention of Thalassemia. The sticker reads CHECK YOUR THALASSEMIA STATUS BEFORE MARRIAGE

Earlier Thalassemic Children along with their parents met Prime Minister Sh. Atal Bihari Vajpayee on 10.11.99 and submitted a memorandum stressing the need for prevention and control of Thalassemia on the following lines:

Health Ministry may be directed to open up a Thalassemia Control Cell similar to NACO (National AIDS Control Organisation).

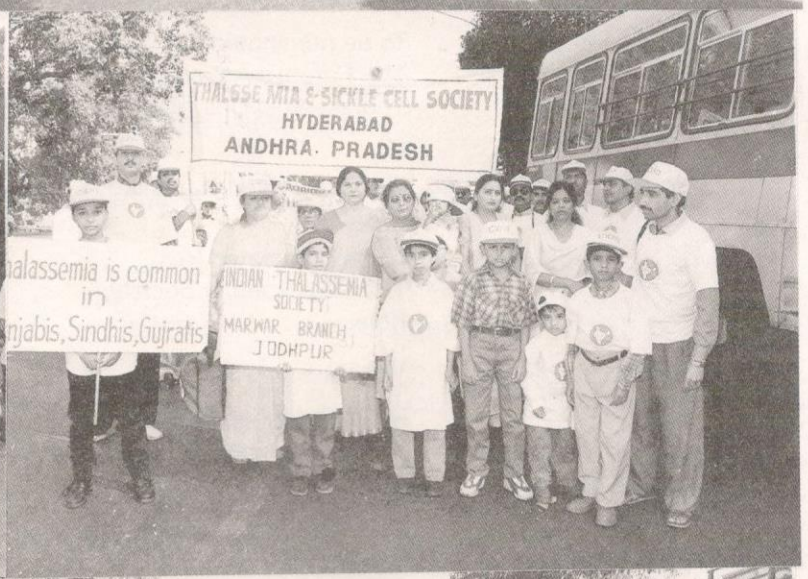
National Thalassemia Eradication Programme may be launched on the lines of National Malaria Eradication Programme.

Information and Broadcasting Ministry may be geared up to spread the awareness on Prevention & Control of Thalassemia.

The participants marched from Barakhamba road to Jantar Mantar through Tolstoy Marg carrying banners, playcards showing slogans on prevention & control of Thalassemia. They were to wear T-shirts bearing Control Thalassemia & logo of Novartis on back and logo of FIT with Fight Against Thalassemia on front. Caps were sponsored by Cipla, while Britania biscuits were served in the middle of the **"March"**. Pepsi, chole bhature & rasgulla were waiting for them at the end.

Dr. Walia set to flag off the "March".

National Thalassemia Day – 14th November, 1999



NEW EXECUTIVE ELECTED

General Council Meeting of the Federation of Indian Thalassemics was held on 14th November '99 at AIIMS. The following executive was elected unanimously.

President	:	Mrs. Shobha Tuli
General Secretary	:	Dr. J.S. Arora
Treasurer	:	Mrs. Neelam Khurana
Vice President		
North	:	Mr. S.P. Ajmani (Chandigarh) Mr. Sudhir Sethi (Jammu)
South	:	Dr. A. N. Krishna Kumari (Hyderabad)
East	:	To be nominated from Thalassemia Society of India, Calcutta
West	:	To be nominated from The Parent's Assoc. Thalassemic Unit, Bombay
Joint Secretary		
North	:	Mr. Tara Chand Kaushik (Rohtak)
	:	To be nominated from The Thalassemia Society, Kota
South	:	Vacant
East	:	Mr. C.S. Mohapatra (Bhubaneshwar)
West	:	To be nominated from M.P. Thalassemia Welfare Society, Indore

Thalassemia Society of Hisar

Prevention and clinical management of Thalassemia is still not advanced in our state. Our society is actively engaged in fighting this dreadly disease. Patients from far off places like Bhadra, Rajgarh, Taranagar (Rajasthan) and Bhulada, Bhiki, Munak, Fazilka (Punjab) and Dabwali, Sirsa, Fatehbad, Bhuna, Uklana, Tohana, Barwala, Hansi and other remote areas of Haryana come to our Society for repeated blood transfusions. We provide them B.T. set, Blood unit, hepatitis B vaccinations free of cost. We are unable to provide Desferal/Kelfer free of cost inspite of our best efforts.

I-CARDS DISTRIBUTED

Members of following societies who have submitted the requisite forms are requested to collect their I-Cards from their respective societies:

- ✔ The Thalassemia Society of Kota
- ✔ Thalassemia & Sickle Cell Society (Hyderabad)
- ✔ J&K Thalassemia Welfare Society
- ✔ Thalassemia Society of Hisar, Haryana
- ✔ Thalassemia Welfare Society of Burdwan
- ✔ Thalassemia Welfare Society, Rohtak
- ✔ National Thalassemia Welfare Society, Delhi
- ✔ Thalassemia Society of Pune

Members of above societies who have not submitted their forms may use the photocopy of the form published in this Bulletin and submit the complete information along with two photographs to their respective societies.

It is regretted that following societies have not taken pains to take information from their members for the I-cards:

- ✘ Thalassemics India, Delhi.
- ✘ Thalassemia & Sickle Cell Society of Ahmedabad.
- ✘ Ajmer Region Thalassemia Welfare Society, Ajmer.
- ✘ Thalassemia Society of India, Allahabad.
- ✘ M. P. Thalassemia Kid Care Society, Bhopal.
- ✘ Thalassemic child Health Care Society, Burdwan.
- ✘ Thalassemia Welfare Society of India, Calcutta.
- ✘ Thalassemic Children Welfare Assoc., Chandigarh.
- ✘ Thalassemia & Sickle Cell Society of Indore.
- ✘ Thalassemia Society of Jaipur & SDMH, Jaipur.
- ✘ IAP, Marwar-Thalassemia Society, Jodhpur.
- ✘ Thalassemia Society of U.P., Lucknow.
- ✘ Patient's Assoc. Thalassemic Unit Trust, Mumbai.
- ✘ Thalassemia & Sickle Cell Anaemia Welfare Society, Orissa.

Members of these societies are requested to pursue their office bearers to take up the matter for speedy action. However members of these societies may also send the duly filled forms printed in this Bulletin along with two photographs to the undersigned.

Dr. J.S. Arora
General Secretary
Federation of Indian Thalassemics
Post Box No. 6627
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FEDERATION of Indian Thalassemics

P.O. Box No. 6627, New Delhi–110 018, Phones: 5507483, 5511795
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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 _____

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.

Thalassemic Children Welfare Association, Chandigarh

Thalassemic Children Welfare Association was formed in 1987 and registered under Registration Act 1960, to look after more than 100 Thalassemics in 1987 which presently increased to 340. Some of the major achievements and its activities are as under:

1. 765 sq. ft. room in Advanced Paediatrics Centre (APC) provided by P.G.I. Chandigarh was furnished by the Association with ultra modern facilities like Air conditioners, music system, water cooler, large sizes T.V. sets and 25 comfortable beds for Thalassemics who have to spend the whole day for blood transfusion.

2. National level conference National Update on Thalassemic 1995 was organised by the Association, Dr. R.K. Marwaha and his team.

3. Association has got prepared Documentary film on Thalassemia captioned "Fighting for red in the Blood" by Technical Teachers Training Institute, Chandigarh who were awarded International Award (Gold Medal) at a film festival held in Japan in 1998.

4. To give maximum facilities to our children who come for blood transfusion at an interval of 15 days in Thalassemia room under the supervision and guidance of Dr. R.K. Marwaha. Some of the facilities given are as under:

   a) No need for each patient to go to Blood Bank etc. for giving samples and taking blood.
   b) Sampling and blood transfusions are being done by our two well experienced staff members and a doctor under supervision of medical experts of P.G.I., Chandigarh in the Thalassemia room itself.
   c) Samples for tests of Hb, TLC, DLC, Serum Ferritin and all other tests are being taken in room itself.
   d) Music systems & T.V. sets, air conditioners, refrigerators and other such facilities are made available in the room.
   e) Medical items for blood transfusions are made available free of cost to more than 70 poor patients out of 340 and at "No profit No Loss" to others.
   f) In addition to extension of telephone of P.G.I., a separate direct personal telephone has been installed in the room for convenience of patients.

5) Since 1990 the Association is organising Blood Donation Camps. This year in summer, the Association had organised 6 blood donation camps in which more than 1200 donors (most of them from far off places e.g. Amritsar, Ganga Nagar, Ludhiana, Jalandhar, Bilaspur, Sirsa and Mandi Dabhwali) donated blood. All donors were welcomed and honoured with a momento with thanks and regards.

6) The Association is organising Awareness Programmes in School/College to create awareness amongst public about the disease for preventing the disease from further spread.

7) More than 70 meritorious children who have performed well in Drawing, Poems, Stories were honoured and presented awards/gifts.

8) The Dept. of Blood Bank have kindly agreed to start test of Hepatitis -C for the blood to be provided for our children with our persuasion through Dr. R.K. Marwaha.

9) The services of a doctor have been arranged by the association for the convenience of the patients.

10) We are in liaison with FIT (Federation of Indian Thalassemics at National level and with TIF (Thalassemia International Federation) at International level for the benefits of our children.

11) U.T. Chandigarh Administration has kindly sanctioned Rs. 5 lacs for providing medical items to our children of Chandigarh and further Rs. 1 lac for other purposes to our Association.

12) The 24 hours Cardiac Test for Thalassemic children of Chandigarh and its surroundings have since been introduced.

In addition to above six blood donation camps six more camps were arranged by our members in co-ordination with clubs & societies. Dr. R.K. Marwaha and his team, plan to organise special clinics on Endocrnology, Cardiology & Dental in co-ordination with our Association.

Association also participated in the Thalassemia March/ Rally organised by Federation of Indian Thalassemics on the occasion of National Thalassemia Day on 14th November, 1999.

National Thalassemia Welfare Society

Perfect Health Mela '99

National Thalassemia Welfare Society participated for 6th time in the Perfect Health Mela '99 organised by **Heart Care Foundation of India from Oct. 29th – Nov. 2nd, 1999 at Archery Ground, Jawaharlal Nehru Stadium, New Delhi.**

Even though the crowd was less due to festival season and concurrent Diwali Melas. Good rush was seen at our stall. Around 400 visitors were screened for Thalassemia by MOFTI (Miscro Osmotic Fragility Tests India). Screening was sponsored by our all season sponsorer Cmdr Sawhney.

Blood Donation Camps

National Thalassemia Welfare Society in association with Management & Development Institute organised a Blood Donation Camp on **Saturday, the 9th October '99 at 9.30 AM to 4.00 PM at MDI, Sukhrali, Gurgaon, Haryana.** Thalassemia screening was also done along with. Around 90 volunteers were screened for Thalassemia status.

Another blood donation camp was organised in association with Institute of Hotel Management, Catering & Nutrition on **Friday, the 19th November 1999 at the Institute, Pusa, New Delhi-110012, wherein 80 volunteers donated blood.**

J&K Thalassemia Welfare Society

A regular special Thalassemia clinic has been started by the Dept. of Paediatrics, S.M.G.S. Hospital on every last Thursday of each month, where all the thalassemics are checked-up, vaccinated for Hepatitis B virus and Kelfer is issued to Thalassemics free of cost. Serum Ferritin assay also done free after every three months.

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

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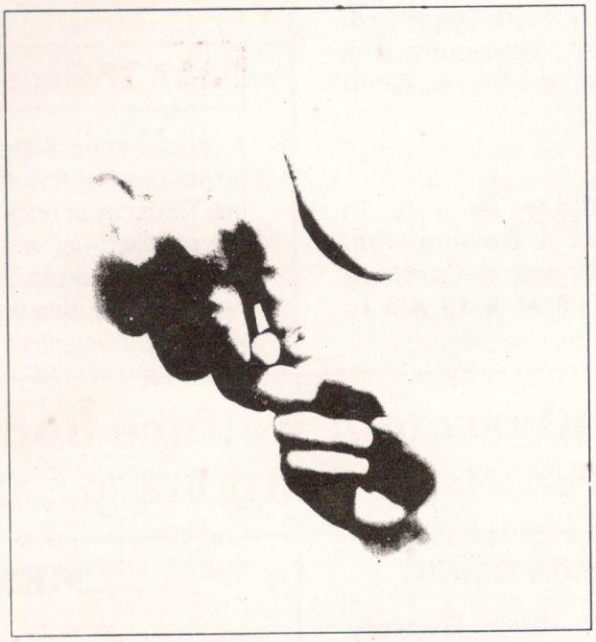
A GLOBAL BREAKTHROUGH IN THALASSAEMIA



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.

For further information contact:
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