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FEDERATION of Indian Thalassemics

National Thalassemia Bulletin

Vol. 5 No. 2

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IMPORTANT

Now you can visit and get more information at your website: **thalassemiaindia.org**

Good news for Thalassemic children taking transfusion at Mata Chanan Devi Hospital, Janak Puri. Now onwards these patients don't have to go and procure blood from Red Cross Blood Bank; the hospital will arrange blood itself for them.

Prepare for a major activity on National Thalassemia Day i.e. 14th November. For details contact your society.

INTERNATIONAL THALASSEMIA DAY

Hon'ble Minister of Health Govt. of Delhi Dr. Ashok Walia during International Thalassemia Day Celebrations at Lajpat Bhawan, Lajpat Nagar, New Delhi; Dr. J.S. Arora (Gen. Sec.) and Ms. Surrendar Saini (President) NTWS also seen on Dias.

Report Inside

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MEMBER SOCIETIES

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 **Burdwan**
Thalassemia Society of India, **Calcutta**
Thalassemic Children Welfare Assoc., **Chandigarh**
National Thalassemia Welfare Society, **Delhi**
Thalassemics India, **Delhi**
Thalassemia Welfare Society of **Hisar**
Thalassemia & Sickle Cell Society of **Hyderabad**
Thalassemia & Sickle Cell Society of **Indore**
J&K Thalassemia Welfare Society, **J&K**
Thalassemia Society of Jaipur & SDMH, **Jaipur**
Indian Academy of Paediatrics, Marwar, **Jodhpur**
The Thalassemia Society of **Kota**
Thalassemic Society of U.P., **Lucknow**
Patient's Asssoc. Thalassemic Unit Trust, **Mumbai**
Thalassemia & Sickle Cell Anaemia Welfare Soc., **Orissa**
Haryana Thalassemia Welfare Society, **Rohtak**

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Prof. & Head – Histocompatibility Lab, A.I.I.M.S.
Dr. I.C. Verma
Prof. & Head – Genetic Unit, S.G.R.H.

EDITORIAL

In eighties Thalassemia was a word of dictioneries and some sophisticated medical text books. At the start of this decade there were some groups doing their bit to bring Thalassemic families closer to each other and help mutually. In 1994 when National Thalassemia Welfare Society organised first National Thalassemia Conference there were only 7-8 known Thalassemia societies in India, and half of them were just for name sake. With the formation of Federation in February, 1994 there was a sudden spurt in activities in Thalassemia. And we saw Thalassemia societies coming up in major cities of India. Now we have over 25 Thalassemia societies in India, 21 are already members of FIT. The satisfying feature is that most of them are active and some of the new societies are even more active than the older ones. Activity report of TASWELS, Orissa and Mumbai Thalassemia Society reflex their commitment and efforts made by them in this direction. Some of the IAP branches have also shown interest in welfare of Thalassemia and have approached us for membership.

Thalassemia movement in India has now crossed its infancy and started walking with support. We can see more coverage in press and electronic media, more involvement of celebrities like film stars, sportspersons, bureaucrats and politicians. Regular National/International/State level conferences, seminars and workshops are held. Thalassemia is one of the topic at the meeting organised by Paediatric and Haematology groups. In some states societies have been able to involve Govt. agencies for providing better management services and attract the media's attention to create awareness in public. Now more blood donation camps are organised to reduce the burden on thalassemic families. Societies are doing their best to provide free/subsidised treatment to few of poor needy Thalassemics.

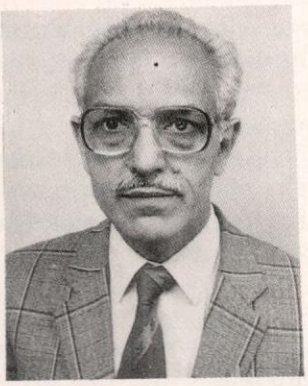
These are good signs but as I told you earlier its just walking with support; this is not enough, we have to run and win. For this we have to ensure that:

- Thalassemia should be part of curriculum in schools.
- Thalassemia screening should be an annual activity in schools and colleges.
- Antenatal screening for Thalassemia must be made mandatory atleast in all Govt. Hospitals.
- Obstretricians should be "TAUGHT" that Thalassemia is a seroius problem and it needs their "ATTENTION".
- At some places media has become tired of word "Thalassemia" in such a short period. Media should be convinced that it is just take-off and we cannot fly without their wings. They should lend us their full support otherwise our dreams of "Zero Thalassemia" is bound to crash.

Dr. J.S. Arora

Thalassemia Screening and Control Programme

— Dr. V.P. Choudhry, Prof. of Haematology, AIIMS



Prevention & Control of Thalassemia

ß Thalassemia is a heterozygous inherited disorder characterised by reduced or absent ß globin gene expression. Thalassemia along with haemoglobinopathies are globally widespread. As per WHO estimates 4.5% of the world's population are carriers of haemo-globinopathies (about 250 million). Nearly 300,000 infants are born every year with major haemoglobinopathies. It is believed that the genetic mutation for haemoglobinopathies had taken place as the healthy carriers were protected against the lethal effects of falciparum malaria. This genetic disorder was most prevalent in the tropics and subtropics. Fast transport system has resulted in global migration of carriers and world wide distribution of haemoglobinopathies. In North-West Europe and USA, 2-10% of the population is at risk for various haemoglobinopathies. Prevalence of Thalassemia carrier state in Asia is next to Africa but nearly 59% of the world's population with Haemoglobinopathies reside in Asia.

In India also ß Thalassemia is the commonest among haemoglobinopathies. Nearly 30 million people are carriers of ß Thalassemia and 8-10 thousands babies with major Thalassemia are born every year. Carrier rate varies between 0-17% in different ethnic groups. Frequency of the Thalassemia gene among Gujratis, Sindhis, Punjabis specially who have migrated from West Pakistan, Lohanas etc. is quite high. Prevalence of Thalassemia in Delhi varied between 2.3% to 9.2% with an average of 5.5% in a multicentric study conducted under the aegies of Indian Council of Medical Research.

The current treatment of Thalassemia involves regular blood transfusions to maintain haemoglobin above 10 gm/dl and chelation therapy. Cost of therapy per child per year is nearly Rs. 1.25 lakhs. It is expected that atleast 50,000 to 100,000 Thalassemic children are on irregular blood transfusion and chelation therapy in India. Cost of optimal therapy for 50,000 thalassemic children will be 625 crores (6.25 billion). This staggering cost of therapy is beyond the reach of our country. Cost is expected to rise further by Rs. 100 crores every year for additional 8,000-10,000 Thalassemic children born annually. Forty-five percent of health budget in Cyprus was spent only on chelation therapy for thalassemics. Birth rate of Thalassemia major has been brought down to a negligible level as a result of Thalassemia Control programme. An ICMR pilot study conducted in Faridabad proved that Thalassemia Control Programme is cost effective in India. Thalassemia Control can be achieved by marriage counselling, prenatal diagnosis and abortion of affected fetus among the thalassemia carriers. Thus the thalassemia carrier detection is an essential component for its control.

Carrier Detection: It is not adequate to carry out the prenatal diagnosis in known carriers or families having given birth to thalassemic children. The organisation of the programme for identification of thalassemia carrier in the community is a herculean task. In the developed countries it has been achieved by the various red cells indices by an electronic red cell counter which is an expensive method. A simple test based upon the lowered osmotic fragility of red cells has been applied widely with equal sensitivity and specificity. This test is called NESTROFT (Naked Eye Single Tube Red Cell Osmotic Fragility Test) and has been effectively used for the carrier detection in the community. However some other authors feel that this test is of not much utility and needs further evaluation or improvements in the technique. Haemoglobin A2 estimation is essential to confirm the carrier status which can be carried out by column chromatography, haemoglobin electrophoresis on cellulose acetate and densitometry. Thalassemia screening programme can be initiated as short term programme to yield immediate result or as long term programme which will have its impact later.

Short Term Programme

In the short term programme, all pregnant women attending the hospitals/centres for antenatal examination need to be screened for thalassemia carrier. Spouse of pregnant women who are detected as carrier should undergo Haemoglobin A2 estimation for immediate confirmation of thalassemia status. Antenatal diagnosis becomes essential if both wife and husband are carriers. The drawback of such a screening programme in our country is that large number of women attend the hospitals/centres for antenatal examination quite late when the antenatal diagnosis may not be feasible. Therefore, such a screening programme will have some immediate impact, but it cannot completely control the birth rate of thalassemic children. Organisation of antenatal check-up and screening programme during early pregnancy for a country of our size itself is a problem of greater magnitude. The other strategy could be to screen the high risk population and extend the screening facilities to family members of parents who have given birth to thalassemic children but such a programme may not succeed as it may result in identification of ethnic groups having high prevalence of thalassemia carrier. Large number of thalassemic families consider thalassemia disease as a course rather than a genetic disorder. Therefore, the initiation of screening programme in such communities may result in a social stigma and non cooperation of these ethnic group.

Long term programme

In long term programme all children either in school or colleges may be screened for thalassemia status. Children and their parents need to be informed about the thalassemia carrier status along with the risks of birth of thalassemic children if a carrier marries a carrier. Marriage counselling is likely to be successful in educated families. All women will know about their thalassemia status before pregnancy and the need for antenatal diagnosis in case their spouse are also carriers. Family physicians can also review the risk of thalassemic child with the family either prior to pregnancy or during early pregnancy when the antenatal diagnosis will be feasible. The drawback of such a programme is its organisation throughout the country and the high investment. The advantages of such a programme is that it will control thalassemia and improve the general health status.

Prenatal diagnosis

Any screening programme without the prenatal diagnosis and option of abortion of affected foetus cannot be successful to control thalassemia in the community. Two techniques are available for prenatal diagnosis. In the first technique, fetal blood is withdrawn at 18-20 weeks of gestation to assay alpha, beta and gamma chain synthesis. The disadvantages of this technique are:

a) use of radioisotopes
b) prolonged uncertainity to the family as the diagnosis is established late
c) greater emotional stress to mother
d) difficult abortion between 22-24 weeks of gestation and
e) greater risk of fetal loss

Second method for prenatal diagnosis is DNA studies using chorionic villus sample, obtained between 10-12 week of pregnancy. DNA diagnosis was earlier being made by polymorphism at different loci of ß globin gene. So far nearly 200 mutations have been detected world wide. Luckly each centre need not identify all these mutations. It has been seen that five to seven mutations account for nearly 95% of mutation of any region.

Strategy for control of Thalassemia

Various components for control of Thalassemia which are very essential include the following:

1. *Political and Government will*

Any control programme can have its impact only when it is initiated at the National or State level. The effective programme can be initiated by the Central or State Governments. The implemention of programme depend on the will of the Government & commitment of the implementing agency. Every person has to be responsible and accountable for his work and responsibility. Such a programme will not succeed in the absence of accountability and periodic evaluation of the programme.

2. *Awareness in the community*

No community programme can be successful without involving the community for which the general awareness of the programme in the community is the initial step. This oan be achieved easily through media such as newspapers, radio, television etc. There is a need to emphasize the prevalence and adverse effects of the disease. cost of treatment and associated problems. Various measures for the prevention and control of the disease need to be communicated through various medias and in the school and college health programmes. It is essential to involve the various thalassemic societies. Presently there are 25 thalassemic societies in India and many of them have joined Federation of Indian Thalassemics (FIT) with the prime objective of increasing the awareness of the disease and to initiate the measures for its control.

3. *Screening of community*

It is essential to identify the carriers of beta thalassemia gene and to recognise the couples at risk. Carrier screening can be done at birth, in school or colleges, before marriage, soon after marriage or during pregnancy. Various strategies under short term and long term can be undertaken. Short term strategies will have immediate impact but itself cannot control as majority of women attend the hospitals/centres late during their pregnancy. It is essential to have short and long term programmes together along with the involvement of the non Governmental organisation committed for thalassemia.

4. *Establishment of prenatal diagnostic facilities*

There is need to have 7-8 regional centres in different parts of the countries which should initially screen for 5-7 common mutations. These centres should have frequent communication and interaction with each other and to have internal and external quality control. One of the centres should have upgraded facilities to identify the uncommon mutations for all the centres.

5. *Optimal treatment of Thalassemic children*

It forms a major component of any Thalassemia Control Programme. Centres with antenatal diagnostic facilities could serve as regional centres to provide ideal management of Thalassemic children. All these regional centres should have link with various day care centres in their regions. Thalassemic children should get the current management from the day care centre. Regional centres should have facilities to investigate and manage the difficult and complicated cases of Thalassemia from the regions besides having facilities for prenatal diagnosis. Close association of regional centres with day care units will facilitate better co-operation and early referral of cases for antenatal diagnosis. These day care units could also serve and participate in the community programme for Thalassemia control.

6. *Control Programme*

It is essential that all components of the programme should be well planned and in place for proper implementation. Success of such a programme will depend upon the strong political will and active participation of the community specially the parents of thalassemic children. Involvement of various thalassemic societies and Federation of Indian Thalassemics is of utmost importance. A strong bureaurocratic support is essential to provide necessary funds for such a programme. But all this will not be enough. Medical & paramedical fraternity has to rise to the occasion to sensitize the community, the neccesary push and to maintain the momentum for the movement. Health education at all levels such as schools, colleges, politicians, bureaucrats, health professionals and the community is the key to the success of such a programme. All media of communication such as radio, news papers and audio visuals (TV) need to play a vital role in increasing the awareness of the disease in the community. Community/religious leaders specially from the communities with higher prevalence of Thalassemia will have to shoulder the major responsibilities of awareness of the disease and advantages of the programme.

The technology of the community control of Thalassemic which is affordable and cost effective is available in India. It is high time to initiate the community control programme by initiating multi centric pilot projects in few selected regions with a high prevalence and later extend the programme throughout India.

International Thalassemia Day May '99

Delhi

National Thalassemia Welfare Society observed International Thalassemia Day on 9th May at Lajpat Bhawan, Lajpat Nagar, New Delhi. Over 200 Thalassemic families participated. Thalassemic children predominated the show.

Dr. Ashok Walia, Hon'ble Minister of Health, Govt. of NCT Delhi inaugurated the event.

While speaking on the ocassion he said Delhi Govt. has taken steps to improve facilities for Thalassemics. The long standing demand to screen the Hepatitis C in Donor's blood will be shortly implemented atleast in 5 Regional Blood Banks. He also said that he will look into improving facilities at Regional Blood Transfusion Centres so that packed cells be made available at all the centres. While welcoming the Minister Ms. Surrendar Saini, President of the Society requested him to lay stress on Thalassemia Screening in all the Govt. Hospitals of Delhi.

Dr. Anupam Sachdeva, Ms. Surrendar Saini and Dr. Tulika Seth among the audience on International Thalassemia Day at Lajpat Bhawan.

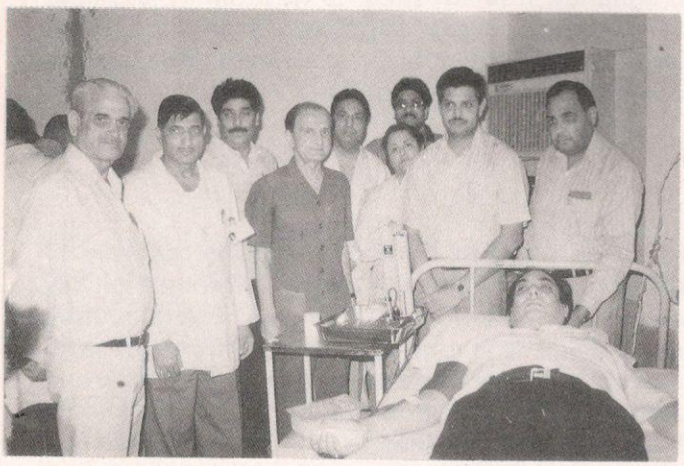
Eminent doctors also participated to satisfy the feast of Thalassemic parents. Dr. Tulika Seth who is performing First Cord Blood Transplantation in Thalassemia in India thanked National Thalassemia Welfare Society for sponsoring the treatment of SUGAM, a 2 year old Thalassemic Major. She said, if HLA matched fetus is available, Cord Blood Transplantation is comparitively much more safer than conventional Bone Marrow Transplantation. In this, Cord Blood is collected at the time of delivery and stored for transplantation in future. Dr. Anupam Sachdeva spoke on Depot Desferal, the newer technique of Desferal therapy.

Dr. V.P. Choudhry, Prof. of Haematology at AIIMS mentioned some newer techniques to raise the Hb level with drugs in some selected categories of Thalassemics. Dr. J.S. Arora, General Secretary of National Thalassemia Welfare Society appealed the Minister to start Thalassemia Awareness & Screening in schools and colleges.

Jamshedpur

Dr. S.P. Chatterjee, Memorial Health Association conducted a meet at Bistupur office to mark the International Thalassemia Day. A veteran medico Dr. P.P. Banerjee described the importance of observing the day. Dr. N.K. Sinha said that most of the children in our country die because of ignorance and superstitious practices. Dr. Harjeet Singh said that it is more important for us to identify the disease as it is more than any other disease caused by blood deficiency. Dr. T.K Chatterjee said that in our country most children fall victim to the disease due to ignorance of the disease and its late identification.

J&K



Blood donation camp organised by J&K Thalassemia Welfare Society. L to R- Sh. G.M. Pathak, Dr. R.D. Minhas, SMGS Hospital. Er. Sudhir Sethi, Sh. K.L. Dubey, Regional Secretary, IRCS, Jammu. Dr. Ashok Gupta, Dr. (Mrs) Kum Kum Sharma, Dr. K.K. Kaul, Sh. P.K. Tripathi, I.A.S., Dy. Commissioner, Jammu- Chief Guest, Dr. H.L. Goswamy, Principal, G.M.C., Jammu.

International Thalassemia Day was celebrated by J & K Thalassemia Welfare Society on 8th May, 99. A blood donation camp was organised at S.M.G.S. Hospital, Jammu which was inaugurated by Dr. H.L. Goswami, Principal, Govt. Medical College. Sh. P.K. Tripathi, IAS, Deputy Commissioner, Jammu was the Chief Guest. The camp was conducted by Dr. Kum Kum Sharma, Professor and H.O.D. of Blood Transfusion Medicine, Govt. Medical College, Jammu. Interaction between Thalassemia patients, chief guest and eminent doctors was held. Principal, Govt. Medical College informed the chief guest about the facilities being extended to the Thalassemics. Deputy Commissioner, Jammu assured full support and co-operation to the society in its activities.

Afternoon a panel discussion was held in the hospital auditorium in the presence of patients and their family members. The proceeding was conducted by Er. Sudhir Sethi, Vice President and General Secretary, Mr. G.M. Pathak, Brigadier Retd. K. Jagmohan Singh, President welcomed the dignitaries. Dr. D.B. Sharma, Dr. Kum Kum Sharma, Dr. Ashok Gupta and Dr. K.K. Kaul participated in the discussion.

Later Dr. Ashok Gupta gave away the prizes to the outstanding Thalassemic students. Gifts were also given to all the Thalassemic children, snacks and cold drinks were served to all. In the end Er. Sudhir Sethi and Mr. G.M. Pathak also addressed the gathering and proposed a vote of thanks to the guests. The day long programme was covered by Siti cable and telecasted in the evening news Bulletin.

Burdwan

Thalassemia Awareness Walk organised by Thalassemia Welfare Society of Burdwan

The Thalassemia Welfare Society of Burdwan celebrated 8th May, the International Thalassemia Day by holding a seminar amongst the patient-guardians, giving Desferal free of cost to twenty patients and conducting a walk on the Prevention of Thalassemia for public awareness.

My Column — A SATURDAY EVENING

What a wonderful shot! I exclaimed while enjoying Sachin Tendulkar's batting on a Saturday afternoon. Suddenly the door bell rang. It was my mother with the blood bag in her hand. I was reminded that its a Saturday of Needles, Pricks i.e. The Blood Transfusion day for me. I had to leave all the match in its most exciting phase and go to the clinic for the transfusion. A new nurse had joined the clinic that day & so I was suspicious that will she be able to prick me properly at once. Finally the tense moment & as the needle, that was handed over to the new nurse neared by hand my mother's face grew painful but what the sister nurse couldn't find was an appropriate vein! So, it meant that I had to be pricked thrice on that Saturday. Imagine out of the year's 48 Saturdays, I have to be transfused on 24 of those and if 6-12 of those turn out to be like the Saturday narrated above then how can one be peaceful. That's not all, sometimes during the transfusion the vein gets thrombed and I have to be pricked all over again in a new vein. But still I am very positive like my positive hero "Sachin Tendulkar" that putting all the bouncers & yorkers aside I will be cured by any of the new treatments & researches being undertaken and I will again exclaim "What a wonderful Saturday it is!"

The above incident is my true experience.

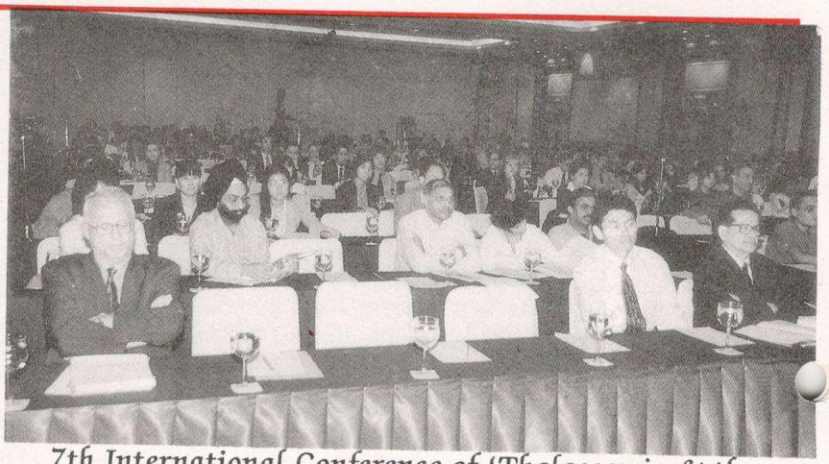
Hemant
S/o. Shri. T.R. Bellani
A-4/93, Priyadarshni Apts., Paschim Vihar, New Delhi–63

NOTE:-

- Articles and experiences from Thalassemic patients/ parents are invited to be published in this column.
- Any questions? Pick up a pen, write on a paper, mail it and find answer from the experts in the forthcoming bulletin.
- Publications at the discretion of editorial board.

7th INTERNATIONAL CONFERENCE OF "THALASSEMIA & THE HAEMOGLOBINOPATHIES" AT BANGKOK & 9TH THALASSEMIA PARENT & THALASSEMICS INTERNATIONAL CONFERENCE

As I received the first information that **7th International Conference of Thalassemia & the Haemo-globinopathies** is being organised at Bangkok, I was delighted and made up my mind to attend this conference.



7th International Conference of 'Thalassemia & the Haemoglobinopathies' at Bangkok, Thailand in progress

I had thought of attending the last conference at Malta in 1997 but could not make it, so I did not want to lose this opportunity. Air fare and other expenditure did apply breaks to my mind to think twice but my commitment to Thalassemia and encouragement & support from my family, Mr. Ashok Sikka and specially Dr. V.P. Choudhry made my dreams true to attend the International Thalassemia Conference. We left Indian Airport at 00.05 hrs IST and reached at Bangkok airport at 5.30 local time (4 hrs. journey and 1 hour 30 minutes difference). We were delighted to see the galaxy of International faculty and participants. India was largely participated. Participants included Dr. V.P. Choudhry, Dr. V.K. Khanna, Dr. I.C. Verma, Mrs. Shobha Tuli and myself from Delhi; Dr. R.K. Marwah from Chandigarh, Dr. Mammen Chandy from Vellore, Dr. Rajeev Bansal from Jaipur; Mrs Sharmila Chandra, Ms. Sushma Bhatacharya & Mr. Kaniya from West Bengal, Dr. Deepika Mohanty, Dr. Roshan Kolah & Dr. Lele from Maharashtra. Dr. M.B. Agarwal who was one of the speaker at symposium could not make it due to his father's illness so Dr. A. Gogtay from Cipla presented his data. The real pride came to India when Mrs. Shobha Tuli received **"George Englezos Award"** during the inauguration ceremony.

Mrs. Shobha Tuli receiveing the 'George Englezos Award' during the inauguration ceremony of 9th TIF Conference 30th May'99, Bangkok, Thailand

Dr. Wonke received the **"Panos Englezos Award"** for her dedicated services for Thalassemics.

The 'Panos Englezos Founders Award' presented to Dr. Beatrix Wonke

The news of the conference was indication of approval of Deferiprone in USA and Canada. This has set to rest all the controversies created by its adversaries for its early launching in India.

The important topics discussed were:

- *New Trends in transfusion therapy in Thalassemia: Alternative to minimise blood requirements*
- *The dynamics of ß-globin gene switching*
- *Haemoglobin F Stimulation with Hydroxyurea, Butyrates and Erythropoietin*
- *Prenatal diagnosis of Haemoglobinopathies by using fetal cells in the maternal circulation*
- *Assessment of iron status with MRI*
- *Preclinical studies for the gene therapy of Thalassemia & Sickle Cell disease*
- *Hormonal disorders, Fertility and Reproduction in Thalassemia*
- *Cardiac Complications in Thalassemia*

Dr. V.P. Choudhry chairing a session on "Management of Thalassemia in the next millennium" at 7th International Conference of Thalassemia & the Haemoglobinopathies

Important topics will be published in the forthcoming Bulletins.

6 days of brain storming sessions have made up every participant more wise and enlightened to deal with Thalassemia. Indian Thalassemics will be highly benefitted from the large participation of experts from different parts of the country.

Message from Mrs. Shobha Tuli

I am deeply touched to receive the **"George Englezos Award"** from Thalassemia International Federation, Cyprus. It is a matter of great honour for me to receive such an appreciation & I am extremely grateful to TIF for recognising my dedication and love for Thalassemia.

On this occasion I would like to tell all my Thalassemics, their parents & associations that this special Award is not only "my achievement" but "our achievement". We all have worked hard, we all have come a long way and we still have to go miles. At least at this stage we should now be hopeful of taking along with us T.I.F., W.H.O., other benevolent organisations & the respective Governments.

Let us all commit to help our Thalassemics in whatever way we can do to make their lives more comfortable & happy.

The Thalassemia Society, Kota

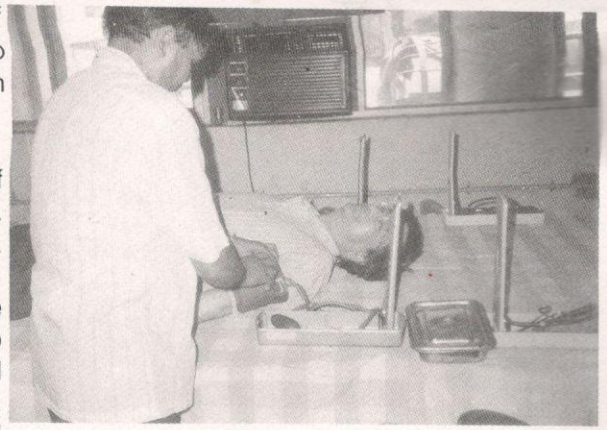
The Thalassemia Society, Kota has also started "Thalassemia Care Clinic" at Jay Kay Lon Hospital, Kota on every 2nd Saturday w.e.f. 12th June, 1999. Samples for serum ferritin has also been collected during this clinic. Our society has arranged eleven Blood Donation camps from 13-12-98 to 30-5-99 at different places in Kota and collected 273 unit blood for Thalassemics and now we are giving blood to patients without any replacement. B.T. set canula etc. are being given to patients on wholesale price at Jay Kaylon Hospital.

National Thalassemia Welfare Society

National Thalassemia Welfare Society organised a series of Thalassemia Awareness & Blood Donation Camps this year to augment the supply of safe blood and create awareness in public.

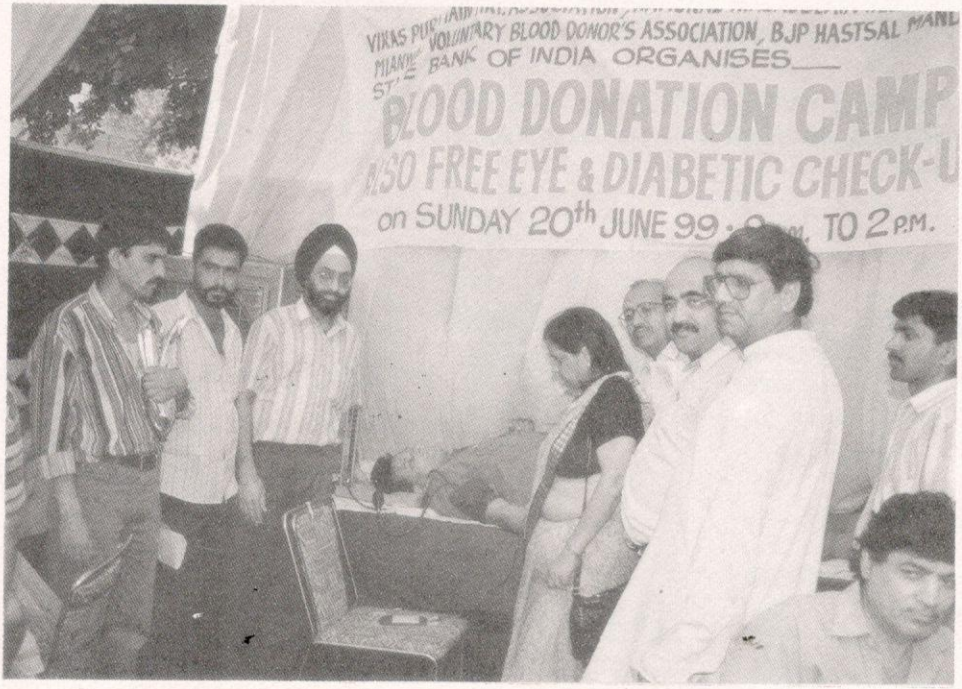
First of this kind this year was organised with the help of Mr. Mohinder Dhingra, a Thalassemic parent at South Extn. Part-I on 20th April '99. Fifty nine units of blood was collected.

On 29th April '99, the Hon'ble Chief Commissioner of Income Tax, Shri Raj Narain inaugurated the Blood Donation Camp organised by NTWS in association with Income Tax Office and Lion's Club of Delhi. 52 units of blood was collected. Shri Siddharth Mukherjee, Addl. Commissioner and Shri Kamal Kapur, Assistant Commissioner of Income Tax and Shri T.R. Bhalla, President, Lion's Club of Delhi, Mr. K.R. Wahi, Secretary, Lion's Club of Delhi and Mr. Ashok Sikka were the key persons in holding this camp.



Shri Raj Narain, Chief Commissioner of Income Tax donating blood at ITO, New Delhi

Then came the turn of hatrick with the help of Engineer's India Ltd. on 9th, 10th and 11th June'99 at Bhikaji Cama Place, PTI Building, Connaught Place and R&D Centre, Gurgaon respectively, wherein 120 units of blood were collected.



Mr. Gurbachan Singh S.H.O., Vikas Puri donating blood at Vikas Puri Besides Dr. J.S. Arora; Dr. Usha Gupta, Blood Bank officer, AIIMS; Mr. R.K. Agarwal, Asstt. Gen. Secretary, SBI Officer's Association; Mr. Gautam Seth, President, Vikas Puri Main Market Assoc.; Mr. Ravinder Anand, President, BJP, Hastsal Mandal also seen in the picture

A BUMPER BLOOD DONATION CAMP was organised by National Thalassemia Welfare Society in association with State Bank of India, Vikas Puri Branch, Mianwali Voluntary Blood Donors' Association, Vikas Puri Main Market Association & BJP Hastsal Mandal for the brave soldiers injured during the "Operation Vijay" fighting with Pakistan supported intruders at Kargil, Kashmir, on Sunday, the 20th June, 1999. Eye Donation and Free Diabetic Check-up Camp was also organised alongwith. 225 voluntary donors donated blood. The main attraction of the camp was that inspite of 10 beds for bleeding, 5-6 donors were waiting throughout the camp i.e. from 8.30 AM to 3.00 PM in the scorching

heat of June. Shri Mange Ram Garg, President, Delhi BJP unit inaugurated the camp. Queue were seen at all the counters i.e. registration counter, blood grouping counter and bleeding area.

Once again Mr. Ashok Sikka was at the foremost to help us in organising a blood donation camp. He convinced Mr. Gulshan Gulati, President of Azad Market Traders Association to organise a Blood Donation Camp at Shri Sanatan Dharam Mandir, Library Road, Azad Market, Delhi-110006 on 22nd June'99. 150 units of blood were collected. Mr. Pradeep Malik & Yash Pal Chhabra motivated the donors.

Thalassemia Awareness was given due importance at all the above camps. As usual Mr. Ashok Sachdeva and Ms. Monisha were our frontline warriors at all the camps. Three more camps, one again through Mr. Mohinder Dhingra at Gurudwara Shri Guru Singh Sabha at Kotla Mobarakpur on 3rd July, 2nd at ITI, Pusa in association with Lion's club of Delhi and 3rd at PNB Bhikaji Cama Place are in the offing. This is not the end, we are in touch with many other organisations to hold many more Blood Donation Camps. Thalassemic parents are once again requested to use their contacts and help us in organising Blood Donation Camps.

Mumbai Thalassemic Society

First Annual Report

On 26th January'98 some dedicated parents and well wishers decided to form the Mumbai Thalassemic Society (MTS) under the dynamic leadership of Ms. Shilpa Ruparelia and Ms. Purna Sheth.

The following programmes/activities were conducted by the Society:-

1. **FUN-N-FAIR (Entertainment)**-MTS observed International Thalassemia Day at the National college ground Bandra on 8th May, 1998 with the help of "WE CARE TRUST". 350 Thalassemia children along with their parents enjoyed whole evening with many games, dances, housie and chatpata delicious food and cold drinks etc. Many celebrities like Neelam, Deepti Naval, Nishigandha Vad, Swapnil Joshi, Tiku Talsania, Rajeshwari and famous cricketers like Sanjay Manjrekar, Jatin Paranjpe, Paras Phambrey, Nilesh Kulkarni and Amol Mazumdar attended and played with the children. Dr. Lokeshwar, Dr. Mangalani and Dr. Nitin Shah also attended and encouraged all of us.

2. **Children, Doctors & Parent's Meeting (Scientific)**:- On 9th May, 1998 MTS arranged meeting and panel discussion with the help of Thalassemia Research Centre, Sion Hospital. This was attended by 125 children and parents. Eminent personalities like Dr. M.R. Lokeshwar, Dr. Mamta Mangalani, Dr. Deepika Mohanti, Dr. N.B. Jaju, Dr. Bharat Agarwal, Dr. Rashmi Dalvi, Dr. Nitin Shah, Harsha Yagnik (and on behalf of parents/ Society Anil Shah) were on the panel to discuss the questions and queries raised by the parents. Mrs. Purna Ashani's efforts for this meeting were commendable.

MTS is extremely grateful to Dr. Mamta Mangalani and her team for the whole arrangement for this very informative meeting.

3. **Blood Donation Camp**:- With the help of Rotary Club of Queen city and Naigaon Police Head Quarters Blood Donation Camp was organised for the children affected by Thalassemia. 150 young policeman donated blood for Thalassemic children. Every individual blood donor was given cap and pen as gift. Mrs. Shilpa Ruparelia arranged this camp whereas gifts were arranged by Mr. Vijay Shah.

4. **Participation in Quiz Contest (Awareness)**:- Association of Voluntary Blood Donation Organisers (AVBDO) conducted a quiz contest on blood donation. About 32 thousand students from Sr. colleges in Mumbai and around had participated in this contest dealing with blood and related disorders mainly Thalassemia. The total arrangement for this unique contest was done by Dr. N.B. Jaju.

5. **Parents Get-together (Awareness Parents Education)**:- A small get-together was arranged with parents in K.E.M. Hospital on 9th October, 1998 with association of Blood Bank and Paediatric Dept. Staff

Dr. Jayashri Kamat, Dr. Diwte and Mr. Simuel addressed the parents on proper management of Thalassemic children. Anil Shah on behalf of MTS explained the various activities undertaken by the society and appealed for participation of the parents. Mr. Rajan Punjabi had made all the arrangements for this meet.

6. **Felicitation and cultural programme (Motivation & Entertainment):-** In order to encourage and motivate the Thalassemic children for their performance in studies and in other extra activities. MTS had organised a programmme on 25th Oct, 1998 and they were offered different gifts by the celebrities Arbaz Khan & Smita Jaikar. On this occasion Thalassemic children presented an excellent and wonderful stage performance by Bijal Vora, Sangita Wadhwa, Rashi Arora, Pradnya Sonawane, Nimesh Shah & Zeeshan Ali, Nikita Vanwari entertained audience by jokes whereas Punit Jobanputra played Tabla.

Eminent doctors like Dr. Sunil Parekh, Dr. Mangalani, Dr. Roshan, Dr. Jaju, Dr. J. Kamat, Dr. Swati Kanakia & Dr. J. Sharma were present. They appreciated the children's performance and also the society for undertaking this activity. This unique and very special programme was possible and successful only with the efforts taken by Mrs. Purna Sheth, Mrs. Ritu Ruparelia, Mrs. Mrudulaben, Mrs. Sunita, Ms. Chanda and Mrs. Bharti.

7. **Workshop for the parents (Parents Education):-** With the courtesy of Division of Paediatric Haematology. Sion Hospital, MTS organised a one day workshop specially for the parents on 26th Dec'1998. This was a very special and unique workshop arranged for the first time in the city. During the workshop Dr. S.H. Adwani (Tata Hospital) delivered an excellent speech on BMT in Thalassemia. This was followed by a panel discussion. Dr. Mangalani, Dr. Roshan, Dr. Farah, Dr. Jaju, Dr. Punjwani, (and on behalf of parents and society- Anil Shah) were on the panel. Dr. Rachna Sharma was the moderator. In the last session of the workshop, parents were divided in six groups, they were circulated in six stations (rooms) on the very important topics namely Blood transfusion, Chelation, Diet in Thalassemia. Recent Developments, Psychological Support- Awareness & Prenatal Detection. All the parents were given proper guidance and information on the topics by experts in the field.

On this occasion Committee members who are working wholeheartedly to propagate activities of the society Mrs. Sunita Shahani, Mrs.Purna Ashani, Ms.Chanda and Mrs. Ali helped a lot to make this event a great success.

8. Thalassemic children enjoyed the Republic Day evening with fun & excitement. MTS organised a visit to Astro Mischief Games Parlour run by actor Sunil Shetty, with courtesy of Rotary club of Bombay Metropolitan specially Rotarian Mr Rajen Mehta. Rotary club arranged this visit and also breakfast for the children. Mr. Shabbirbhai of Astro Mischief not only allowed children to enjoy whole evening but also served cold drinks to all. It was really a wonderful to see our children extremely happy.

Hepatitis B Vaccination For Thalassemic and Siblings (Scientific); This very important and essential project was under taken with personal efforts by Ms. Shilpaben for the society. It is to be conducted in other 4/5 transfusion Centres. It has started already in Red Cross and St. George Hospital.

Other Activities:

a) **Thalassemia Awareness & Detection Drive (Awareness):** MTS participated in such drive on 9th Nov.1998 organised by Lions International at Worli Sports Club. This was supported by Lions Club of Dadar(W). Similar Drive was organised by Tarun Mitra Mandal at Velji at Lakhamsi Nappu High School Chinchpokli on 10th January, 1999. This was a great camp in which 900 bottles of blood was collected within six hours with full enthusiasm. Most of the population was Kachhi Jain (High Risk). In both the above campaigns the organisers appreciated the work done by our members and activities undertaken by the society. They offered full support and help to the society.

b) **Adoption of thalassemic children for Kelfer (Support):** Some magnanimous people came forward to adopt Thalassemic children for buying Kelfer. So far 2 children were adopted. We Care Trust and Amit Iyer Foundation are also supporting a few children in buying Kelfer. MTS is extremely grateful to them for their noble support.

c) **Helping (Support):** With the courtesy of Sapna Jeswani, "The Ohm Trust" supported three poor thalassemic children for education.

d) **Participation In T.V. Programmes On Thalassemia (Awareness):** **Zee T.V.**covered episode on Thalassemia in their renowned programme **"Junior Horlicks Chhoti**

Chhoti Batein" in June 1998.on behalf of MTS and parents Anil Shah Participated with Dr. Mangalani & Dr.Lokeshwar.

Door Darshan (National Channel) also telecasted one episode on Thalassemia in the favourite programme" **Apaki Shanti"** in Jan'99. Hemang Thakkar, Anil Shah, Sapna Jeswani, and many parents & children participated. The activities of the MTS were explained and Highlighted in the show. this was covered in parts on 4th and 5th Jan'1999.

e) Availability of Filters at reduced rates (Support): With the courtesy of Mr. Vijay Shah a stock of 20 Leucocyte filters is kept with the society to meet the urgent need of the parents.

f) T.V. Cassette (Awareness & Support): Producers of famous serial Shapath, Mr. Homi Wadia, Nikita Shah & Kiran Kumar were extremely happy to know about stage performance presented by Thalassemia Children. They have kindly agreed to make one cassette on this entirely at their cost, for the society. Shooting is already over. This was possible only by the efforts taken by Ms. Jasmine Majethia.

g) Day Care Centre at K.E.M. Hospital: Thalassemic children taking treatment in K.E.M. Hospital have to be admitted for 2 or 3 days for single transfusion whereby parents are put to many difficulties. The office bearers of MTS had meeting with Dean and other doctors in K.E.M. Hospital in this regard & requested them to start facility of "Day Care Centre". This is being considered favourably and the arrangements are under process.

Thalassemia & Sickle Cell Anaemia Welfare Society (TASWELS) Orissa, Bhubaneshwar

1. *Periodic Check-up Camps*

i) The Society started its activities by arranging free check up camp to Thalassemics by Prof. G. Sarangi of S.C.B. Medical college, Cuttack on 3-5-98 at the Municipal Corporation Hospital,Bhubaneshwar.

ii) Colonel Dr. D.K. Mishra, Reader in Haematology Dept., AFMC, Pune also examined the patients on 27-5-98 and 27-1-99.

2. *Public Awareness*

In order to create public awareness regarding Thalassemia:

i) On 14th Nov'98 to commemorate "National Thalassemia Day" a rally was arranged with 500 school children and 40 Thalassemic children with banners and play-cards, pamphlets were distributed to the public. Important dignitaries, Life members, Rotarians and Inner-Wheel Members participated in the rally.

ii) At all Blood Donation Camps organised by Red Cross Blood Bank, a write up on AWARENESS for Thalassemia is being distributed to each donor.

3. *Vaccination Programme for Hepatitis-B*

Three doses of vaccination against hepatitis-B was given to twenty three Thalassemics, free of cost which was sponsored by the Rotarians. Mass vaccination on Hepatitis-B was given momentum by our society which spread like wild fire and thousands were vaccinated.

4. *Blood Testing Facility*

In order to ensure correct testing of Hb level society has purchased a Haemoglobin Photometer. Steps have been initiated to get some assistance from resource persons/ donors for purchase of an ELISA reader and electrophoresis instrument so as to provide facility for periodic blood testing e.g. Serum Ferritin. To confirm diagnosis samples of ten children have been tested at CCMB, Hyderabad.

5. *Enrollment of life Members*

Seventy four Life Members have been enrolled into the Society. Request letters for being Life Members have been sent to U.S.A. for participation of NRI.

6. *Registration of Society*

The Society has since been registered as per the Societies Registration Act 1860 with Inspector General registration, Cuttack on 16-2-99.

7. *Facilitating Splenectomy Operation*

Negotiation is in progress with Surgeons at S.C.B.

THE NATIONAL CENTRE FOR PROMOTION OF EMPLOYMENT FOR DISABLED PEOPLE'S (NCPEDP) POSTGRADUATE SCHOLARSHIP SCHEME 1999

Eligibility

1. The candidate should be an Indian national between 18 and 35 years of age. However, the age can be relaxed at the discretion of the awarding authority.
2. The candidate should be either persuing or should have gained admission to a full time course in a university established by law or in a recognised equivalent institution.
3. The income of the candidate or his parents/guardians should not exceed Rs. 5,000/- per month.
4. Applications could be made for any one of the following courses/subjects:

   MBBS/MD/MS/or an equivalent or higher course in Medicine or Surgery, Mechanical, Civil, Electronic or any other branch of Engineering, Computer Science, Business Administration, Management, Jurisprudence, Journalism, Architecture, Fine Arts, and any other course that may be notified by the awarding authority from time to time.
5. At the discretion of the awarding authority, a scholarsip may also be awarded for a professional course of IGNOU or any other recognised Open University.

Rates of Scholarship:–The basic rate of scholarship shall be Rs. 1,000 per month.

NOTE: The forms are available with Dr. J.S. Arora, General Secretary, Federation of Indian Thalassemics or Contact:

North Zone:	Shri Salil Chaturvedi, B-1, Sector 53, Noida–201301
Tel:	011-91581445
South Zone:	Ms. Jayshree Raveendran
Fax:	044-4413013
West Zone:	Dr. Meenu Bhambani, 2/502 Malviya Nagar, Jaipur-302017
Tel:	0141-522667
East Zone:	Dr. Sruti Mohapatra
Fax:	0674-409158
North-East Zone:	Smt. Zeenat Ali
Fax:	0364-221811

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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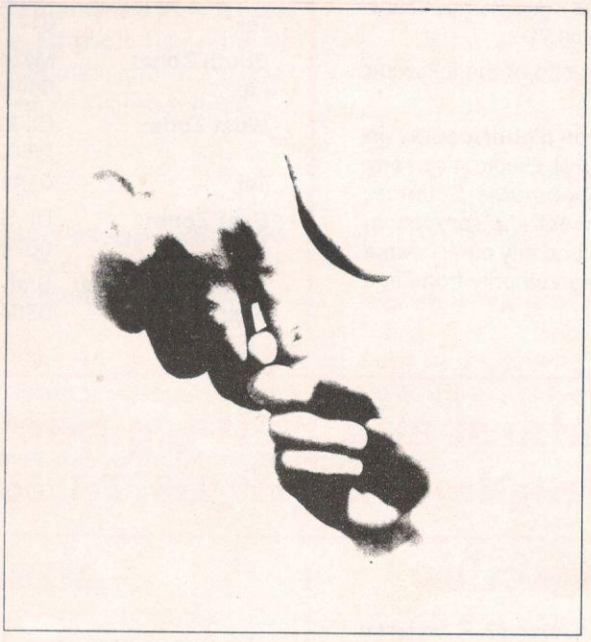
A GLOBAL BREAKTHROUGH IN THALASSAEMIA



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.

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