FEDERATION OF INDIAN THALASSEMICS

NATIONAL THALASSEMIA BULLETIN

Vol. 14 - No. 1

August 2008

CHELATION MADE EASY

A new milestone in the treatment of Thalassemia

Thalassemia Symposium - III

What is new in Iron Chelation

Sunday, 31st Aug., 2008

organized by

NATIONAL THALASSEMIA WELFARE SOCIETY

in association with

Department of Paediatrics, LHMC & KSCH & Deptt. of Haematology AIIMS

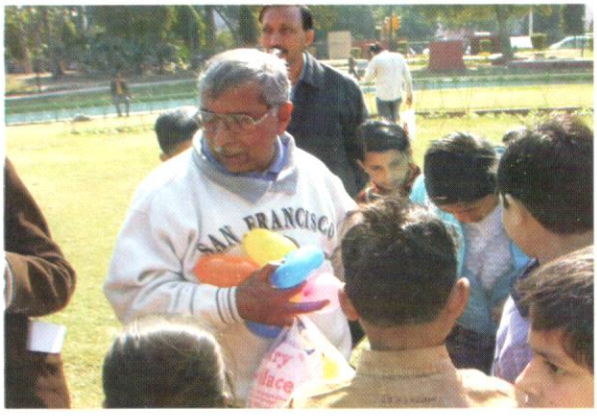
At

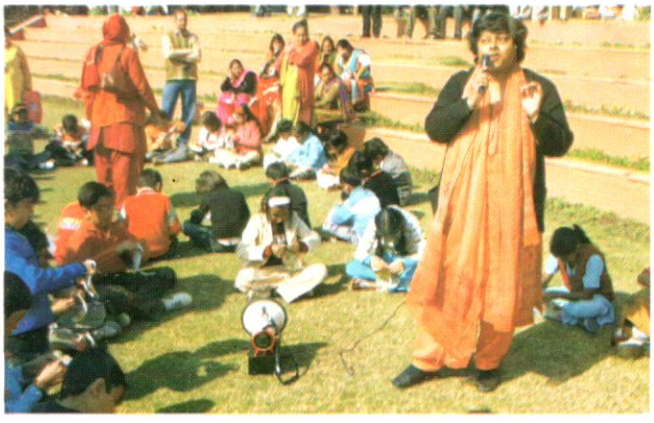
Swaran Jayanti Auditorium, Lady Harding Medical College,
Opp. Shivaji Stadium, New Delhi-110001

Address all correspondence to :

Dr. J. S. Arora, General Secretary, Federation of Indian Thalassemics
KG-I/97, Vikas Puri, New Delhi-110018
Tel : 9311166711-712, 25507483, 25511795 Fax : 91-11-28543576
E-mail : drjsarora@bol.net.in, ntws08@gmail.com

Thalassemic children enjoying Picnic on 20th Jan' 08 at Sanjay Gandhi Lake Park





Editorial

After improvement in transfusion facilities world over, iron overload has been a big challenge for survival of Thalassemics. Desferal introduced in early seventies did change the concept of treatment of Thalassemia, and the survival age increased gradually. Desferal's daily pricks restricted its use even in countries where it is free. The other short coming of Desferal is its ability to Chelate iron from heart, is debatable. Kelfer first introduced in India in 1995 raised a ray of hope among Indian Thalassemics. Later it was also launched in Europe for restricted use as Ferriprox. Though Deferiprone is known for its more effect on Cardiac iron but because of pain in joints & fear of leucopenia it could not become drug of choice.

Moment ICL 670C reached human trail Thalassemics were over vehemently waiting for its early lunch. When it received its marketing name 'Exjade', it looked dream come true. US FDA approval came on 03-11-05 & Europenean Union's nod on 30-08-06.

30th March'08 was the day of its 'bharat aagman'. Though through Video-Conferencing & Training of Trainers Workshop, Medical professionals were updated on its current status, still we thought our obligation to educate the Thalassemic families & Doctors and planned to organize Thalassemia Symposium-III on Sunday 31st Aug, 08. You should not miss this opportunity because every drug has unique mode of action, benefits & side effects. If you are a patient from a sub city or town do encourage your Doctor to attend this Symposium since ultimately he will be the person advising you on regular basis.

Looking forward to see you at the Symposium

Dr. J.S. Arora

आशा की नई किरण

डैस्फराल की सूईयों से छुटकारा,
कैल्फर के दुष्प्रभावों से निबटारा।

डैफ्रासिरॉक्स
{ ICL670C/EXJADE/ASUNRA/DESIROX }
अप्रैल 2008 से अब भारत में भी उपलब्ध।

डैफ्रासिरॉक्स व अन्य बहुत ही अहम् विषयों पर विस्तृत जानकारी प्राप्त करने के लिये 31 अगस्त को कलावती सरन अस्पताल से संलग्न लेडी हार्डिंग मैडिकल कालेज के स्वर्ण जयंती ऑडीटोरियम में आपका स्वागत है।

पंजीकरण विवरण पन्ना संख्या – 14

Asunra (Exjade, Deferasirox)

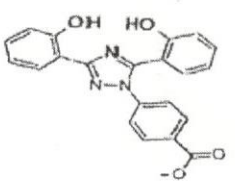
An oral, once daily, whole body iron chelator

Prof. M.B. Agarwal, MD
Haematologist, Bombay Hospital, Mumbai

So far, only Desferal and Kelfer have been used for treating iron-overloaded thalassaemia major. Desferal is inconvenient while Kelfer is less effective and has certain unwanted toxicities. Also, Kelfer has to be taken 3 times a day. Development of Asunra (Exjade, Deferasirox) is a major breakthrough for removing iron from the body of multi-transfused thalassaemia major as it is oral, once a day, whole body iron chelator with negligible toxicity and high efficacy.

Goals of chelation therapy include removal of iron from important organs (heart, liver, endocrine organs and others) as well as to keep the labile iron pool (LIP) to the minimum as it is toxic. The chief source of iron overload in thalassemia major is the blood that is. Transfused. With the help of iron chelator, the excretion of iron in urine or feces must keep pace with rate of iron accumulated from blood transfusion. As the blood transfusion is lifelong, the iron chelator has to be taken lifelong. Therefore, it must be safe, effective and must have a convenient route of administration.

Any drug which can be taken by mouth once a day is obviously the most convenient one. If it is effective and free from side-effects, it is wonderful. Asunra satisfies all these requirements. In addition, it removes iron from all sites i.e. liver, heart as well as LIP. Following is the structure of Asunra:



Asunra is indicated once 20 units of packed cells have been infused or S. ferritin is over 1000 ng/ml. It should be taken once daily on an empty stomach at least 30 minutes before food, preferably at the same time each day. The tablets are dispersed by stirring in a glass of water or apple or orange juice (100 to 200m) until a fine suspension is obtained. After the suspension has been swallowed, any residue must be resuspended in a small volume of water or juice and swallowed. The tablets must not be chewed or swallowed whole.

DOSAGE

The recommended initial daily dose of Asunra is 20-30 mg/kg body weight. For patients already well-managed with Desferal or Kelfer, Asunra may be given in the dose of 20 mg/k body weight. A dose of 30 mg/kg may be considered for those whose S. ferritin is high (>2000 ng/ml) as they have not received adequate iron chelation in past or their blood transfusion requirement is high i.e. >15 ml/k/month (approximately >4 units/month for an adult). For thalassaemia intermedia, even a dose of 10 mg/k may be good enough if transfusions are required occasionally, S. ferritin is not high and diet is not rich in iron.

Asunra dosing can therefore be very conveniently adjusted to meet the individual needs of the patient, i.e. 10 mg/k for maintaining S. ferritin in children needing <2 units of blood per month, 20 mg/k for maintaining S. ferritin in patients needing 2-4 units of blood per month and 30 mg/k for reducing S. ferritin, irrespective of what the transfusion requirement is. It is possible that in India, many patients, to start with, will require 30 mg/k of Asunra as their initial S. ferritin may be quite high due to lack of adequate iron chelation so far.

Asunra is available in India through Novartis as tablets of 400 mg and 100 mg. For a 20 kg child with S. ferritin between 1000-2000 ng/ml, a single tablet of 400 mg once a day is good enough. The same for a 40 kg child will be 2 tablets of 400 mg once daily and so on.

It is recommended that S. ferritin be monitored every 3 months and that the dose of Asunra be adjusted based on the S. ferritin. Dose adjustments may be made in steps of 5 to 10 mg/kg and are to be tailored to the individual patient's response and therapeutic goals. Doses above 30 mg/kg are not recommended because there has been no experience with doses above this level. If S. ferritin level is consistently below 500mg/ml, an interruption of treatment should be considered.

Adverse (toxic) effects:

The most frequent reactions reported during chronic treatment with Asunra include gastrointestinal disturbances in about 20% of patients (mainly nausea, vomiting, diarrhoea, or abdominal pain), and skin rash in about 5% of patients. These reactions are dose-dependent, mostly mild to moderate, generally transient and mostly resolve even if Asunra is continued.

For skin rashes of mild to moderate severity, Asunra may be continued without dose adjustment, since the rash often resolves spontaneously. For more severe rash, where interruption of treatment may be necessary, Asunra may be reintroduced after resolution of the rash, at a lower dose followed by gradual dose escalation. In severe cases this reintroduction may be conducted in combination with a short period of oral anti-histaminics or steroid administration.

Mild, non-progressive increases in S. creatinine, mostly within the normal range, occur in about 35% of patients. These are dose-dependent, often resolve spontaneously and can sometimes be alleviated by reducing the dose. It is recommended that S. creatinine be assessed before initiating therapy and monitored regularly thereafter. Patients with pre-existing renal conditions or patients who are receiving medicinal products that depress renal function may be more at risk of complications. Tests for proteinuria should also be performed intermittently. Care should be taken to maintain adequate hydration in patients who develop diarrhoea or vomiting.. For adult patients, the daily dose of Asunra may be reduced by 10 mg/kg if a non progressive rise in serum creatinine by >33% above the average of the pre-treatment measurements is seen. For paediatric patients, the dose may be reduced by 10 mg/kg if serum creatinine levels rise above the age-appropriate upper limit of normal. If there is a progressive increase in S. creatinine beyond the upper limit of normal, Asunra should be interrupted.

Elevations of liver transaminases were reported in about 2% of patients. These were not dependent on dose and most of these patients had elevated levels Prior to receiving Asunra Elevations of transaminase greater than 10 times the upper limit of the normal range, suggestive of hepatitis, are uncommon (0.3%). It is recommended that liver function be monitored every month. If there is a persistent and progressive increase in serum transaminase levels that can not be attributed to other causes, Asunra should be interrupted. Once the cause of the liver function test abnormalities has been clarified or after return to normal levels, cautious re-initiation of Asunra treatment at a lower dose followed by gradual dose escalation may be considered.

There have been post marketing reports (both spontaneous and from clinical trials) of cytopenias including neutropenia and thrombocytopenia in patients treated with Asunra.. Most of these patients had preexisting marrow disorders i.e. myelodysplastic syndrome or aplastic anaemia. Blood counts should be done intermittently and Asunra should be discontinued for those having unexplained cytopenia.

High frequency hearing loss and lenticular opacities (early cataracts) have been very rarely observed in patients treated with Asunra. Auditory and ophthalmic testing (including fundoscopy) is recommended before the start of Asunra treatment and at regular intervals thereafter (every 12 months). If disturbances are noted, dose reduction or interruption may be considered.

Asunra has not been associated with growth retardation in children. However, as a general precautionary measure, body weight and longitudinal growth in paediatric patients can be monitored at regular intervals (every 12 months).

Asunra must not be combined with other iron chelator (Desferal or Kelfer) therapies as the safety of such combinations has not been established.

Asunra has not been used in patients with kidney or liver disorders and must be used with caution in such patients.

Conclusions

Asunra is the new once daily orally active iron chelator. The 24-hour chelation coverage by Asunra will certainly improve the management of iron-overloaded patients. In addition, the flexible dosing will allow treatment to be adjusted according to iron intake. On the basis of published data till date, Asunra indeed appears promising for an effective, safe and convenient oral iron chelator suitable for long term use.

Table - 1 : Comparison of Asurna with existing iron chelators

Feature	Desferal	Kelfer	Asunra
Iron Selectivity	Highly selective	Highly selective	Highly selective
Regimen	SC or IV infusion	SC or IV infusion	SC or IV infusion
Tolerability issues	Local reactions	Local reactions	Local reactions
Long-term safety profile	Proven	Proven	Proven

Asunra (Exjade, Deferasirox)
An oral, once daily, whole body iron chelator

अभी तक केवल डैस्फराल और कैल्फर ही थैलासीमिया मेजर रोगीयों में चिकित्सा प्रयोग होता रहा है। डैस्फराल असुविधाजनक है तथा कैल्फर कम उपयोगी है तथा इसकी अवांछनीय विषाक्तता भी है और कैल्फर को दिन मे तीन बार लेना पड़ता है। बार-बार रक्त संचारण पर निर्भर थैलासीमिया मेजर रोगीयों में असुनरा (एक्स्जैड - डैफरासिरॉक्स) की व्युत्पति एक बहुत बड़ी खोज है क्योंकि यह डैफरासिरॉक्स दिन में एक बार लेने वाली निम्नतम विषाक्तता व उच्च प्रभाव वाली लोह निष्कासक है।

लोह निष्कासन चिकित्सा का उदेश्य है कि शरीर के प्रमुख अंगो (जैसे हृदय, जिगर अन्तस्रावी अंग व अन्य) से लोहे को निकालना तथा प्रगत लोहे की मात्रा को कम से कम रखना क्योंकि यह विषकारक है। थैलासीमिया मेजर में लोह प्रभार का मुख्य कारण रक्त संचारण है। लोह निष्कासक से, मल-मूत्र से लोहा निकलने की गति रक्त संचारण से लोहा जमने की गति से मेल खाती हो। क्योंकि रक्त संचारण जीवन भर करना पड़ता है अतः लोहनिष्कासक भी जीवन भर लेना पड़ता है। अतः यह सुरक्षित प्रभावी तथा आसानी से ग्रहण करने योग्य होना चाहिये।

कोई भी दवा जो मुँह से दिन में एक बार देने योग्य हो निःसंदेह वह सबसे सुविधाकारक होगी और यदि असरकारक व दुष्प्रभावों से रहित हो तो यह चमत्कारिक है। असुनरा में यह सभी गुण हैं इसके अतिरिक्त यह सभी स्थानों जैसे हृदय जिगर व प्रगत लोह भण्डार से लोहा निकालता है। असुनरा का प्रयोग 20 इकाई रक्त संचारण अथवा जब फैरीटिन 1000 से अधिक हो तभी इगिंत है। यह दिन में एक बार खाली पेट कम से कम भोजन से 30 मिनट पहले प्रतिदिन एक ही निश्चित समय लेना अधिक उपयुक्त है। गोली को 100 से 200 मि ली पानी, सेब का रस या संतरे के रस गें तब तक हिलायें जब तक उसका मिश्रण न बन जाये, बची हुई दवा को पुनः थोड़े से पानी मे मिला कर पी लेना चाहिये। गोली को चबा कर या साबुत नहीं निगलना चाहिए।

मात्रा – असुनरा की आरम्भिक मात्रा 20-30 मि.ग्रा. प्रति किलो शारीरिक भार के अनुसार है। जो रोगी कैल्फर या डैस्फराल पर उचित रूप से व्यवस्थित है उनमें असुनरा 20 मि.ग्रा. प्रति किलो भार के अनुसार तथा जिनमें फैरीटिन अधिक (>2000) है उनमें 30 मि ग्रा/प्रति किलो भार के अनुसार क्योंकि उन्होंने पहले उचित लोह निष्कासक नहीं दिया या उनकी रक्त संचारण की आवश्यकता अधिक (15 मि ली/ किलो प्रति माह) है । व्यस्क में औसतन >4 इकाई / प्रति माह रक्त की आवश्यकता होती है ।

थैलासीमिया मध्यमा में जिनमें रक्त कभी कभी चढ़ाना पड़ता है। फैरीटिन अधिक नहीं है तथा भोजन लोह तत्व समृद्ध नहीं है तो 10 मि ग्रा / प्रति कि लो की मात्रा काफी है।

असुनरा की मात्रा बहुत ही सुविधाजनक विधि से प्रत्येक रोगी की आवश्यकता के अनुसार निर्धारित की जा सकती है जैसे महीने में 2 इकाई रक्त संचारण करने वाले रोगीयों में फैरीटीन मात्रा स्थिर रखने के लिये 10 मि ग्रा/ किलो। 2-4 इकाई रक्त संचारण करने वाले रोगीयों में फैरीटिन स्थिर रखने के लिये 20 मिग्रा/किलो तथा 30 मि ग्रा/ किलो फैरीटिन कम करने के लिये चाहे रक्त संचारण की मात्रा कितनी भी हो। भारत वर्ष में आरम्भ में अधिकतर रोगीयों में 30 मिग्रा किलो मात्रा असुनरा की आवश्यकता बहुत से बच्चों में पड़ेगी क्योंकि पूर्व में लोह निष्कासन न करने के कारण उनका फैरीटिन अधिक होगा।

भारत में असुनरा नोवारटिस द्वारा 400 मिग्रा व 100 मिग्रा की गोली के रूप में उपलब्ध होगी। 20 किलो के बच्चे के लिए जिसका फैरीटिन 1000 - 2000 है एक 400 मिग्रा की गोली बहुत है। 40 किलो के बच्चे के लिये 400 मिग्रा की दो गोली और उसी तरह अन्य के लिये। फैरीटिन की प्रति 3 माह में जाँच करवानी चाहिये तथा असुनरा की मात्रा फैरीटिन के अनुसार निश्चित करनी चाहिए। प्रत्येक रोगी पर दवा के प्रभाव व चिकित्सीय लक्ष्य के अनुसार दवा की मात्रा 5-10 मिग्रा किलो की कमी या वृद्धि की जा सकती है 30 मि ग्रा/ किलो से अधिक मात्रा मे दवा प्रयोग इगिंत नहीं है। क्योंकि इसका कोई अनुभव नहीं है। यदि फैरीटिन लगातार 500ng/l से कम है तो कुछ समय के लिये दवा रोक देनी चाहिये।

दुष्प्रभाव (विप्रभाव)

असुनरा का दीर्घकाल तक प्रयोग करने से 20% रोगियों में उदर रोग संबधी विपरीत प्रभाव {मुख्यतया, जी मिचलाना छर्दि (उलटी), अतिसार (दस्त), पेट में दर्द } और 5% रोगियों में त्वचा पर चकत्ते पड़ना पाया गया। ये विप्रभाव दवा की मात्रा के

अनुपात में, अधिकतर निम्न से मध्यम प्रकार, सामन्यतया अल्पकालिक व असुनरा प्रयोग जारी रखते हुए भी स्वतः समाप्त हो जाते हैं। निम्न व मध्यम तीव्रता वाले चकत्तों के विप्रभाव में दवा की मात्रा को बिना बदले असुनरा का प्रयोग जारी रख सकते हैं क्योंकि यह चकत्ते स्वतः ही विलीन हो जाते हैं। अधिक तीव्र चकत्ते होने से कुछ समय के लिये दवा को रोक देना चाहिये तथा चकत्ते दूर होने के पश्चात पुनः दवा का प्रयोग कम मात्रा में आरम्भ करते हुए धीरे–धीरे बढ़ाना चाहिये। तीव्र चकत्ते होने पर अनूर्जक (anti allergic) अथवा स्टीरायड दवा का प्रयोग कुछ समय के लिये किया जा सकता है। 35% रोगीयों में अवृद्विशील Creatinine थोड़ा सा बढ़ जाता है। यह मात्रा के अनुपात से होता है तथा अक्सर स्वतः ही अथवा दवा की मात्रा कम करने से सामान्य हो जाता है। दवा आरम्भ करने से पूर्व तथा बाद में निरंतर अतंराल से Creatinine की जाँच वांछनीय है। जिन रोगियों में पहले से कोई गुर्दे का रोग हो अथवा कोई ऐसी दवा खा रहे हों जिससे गुर्दे की कार्य क्षमता पर असर पड़ता है, उनमें इस दुष्प्रभाव तथा मूत्र में प्रोटीन की जाँच भी समय-समय पर करवा लेनी चाहिए। यदि रोगी को उल्टी - दस्त लगे तो शरीर में पानी की कमी नहीं होनी चाहिए। व्यस्कों में यदि दवा आरम्भ पूर्व सतह से 33% से अधिक बढता है तो दवा की मात्रा 10 मिग्र/किलो के हिसाब से कम कर देनी चाहिए। बच्चों में यदि अपनी आयु के अनुपात से Creatinine अपनी अधिकतम सामान्य मात्रा से अधिक हो जाता है तो असुनरा 10 मिग्रा/किलो कम कर देनी चाहिए और यदि Creatinine लगातार बढ़ता जाता है तो असुनरा बंद कर देनी चाहिये। 2% रोगियों में जिगर के एंजाइम वृद्धि देखी गई। यह प्रभाव दवा की मात्रा से अनुबंधित नहीं था और इन रोगीयों में असुनरा आरंभ करने के पहले से ही एंजाइम बढ़े हुये थे। जिगर एंजाईम अपनी सामान्य अधिकतम सतह से 10 गुना अधिक जिगर रोग को इंगित करता है। यह बहुत ही कम 0.33% में पाया गया। माह में एक बार जिगर कार्यशक्ति की जाँच आवश्यक है। यदि जिगर के एंजाईम निरंतर वृद्धिशील हो और किसी और कारण का संदेह न हो तो असुनरा कुछ काल के लिय बंद कर देनी चाहिए। एक बार जिगर रोग के कारण पता लग जाये या जिगर ऐंजाईम पुनः सामान्य आ जाये तो ध्यान से असुनरा कम मात्रा में आरंभ कर देनी चाहिये और धीरे–धीरे मात्रा बढ़ानी चाहिये। बाजार में उपलब्ध होने के पश्चात असुनरा की चिकित्सा से सभी प्रकार के रक्त कणो में कमी (neutropenia, leucopenia) देखी गई है। इनमें से अधिकतर रोगीयों में पहले से ही अस्थिमज्जा का शमन या जैसे Mylodysplastic Syndrome व एप्लासटिक अनीमीया में रक्त कणों की गिनती समय-समय पर करवा लेनी चाहिये और यदि रक्त कणों की कमी असुनरा के कारण हो तो दवा बंद कर देनी चाहिये। असुनरा से चिकित्सा के दौरान सुनने की शक्ति में कमी व मोतीयाबिंद बहुत ही कम देखा गया है श्रवण शक्ती व आँख की जाँच (Fundoscopy) असुनरा आरंभ करने से पहले व चिकित्सा के दौरान निरंतर (प्रति 12 माह) करवानी चाहिये। यदि दुष्प्रभाव देखने को मिले तो दवा की मात्रा कम कर देनी चाहिये अथवा दवा बंद कर देनी चाहिये। असुनरा को दूसरी लोह निष्कासक दवा (डैस्फराल या कैल्फर) से मिला कर नहीं देना चाहिये क्योंकि मिश्रित चिकित्सा की सुरक्षा का अभी कोई प्रमाण नहीं है। असुनरा को जिगर व गुर्दे के रोगीयों में प्रयोग नहीं किया गया है अतः उन रोगीयों में इसे ध्यान से प्रयोग करना चाहिये।

निष्कर्ष :

असुनरा नवीन, दिन में एक बार प्रयोग करने वाली मौखिक लोह निष्कासक है। 24 घण्टे लोह निष्कासन प्रभाव से अतिरिक्त लोह प्रभारित रोगीयों का चिकित्सा प्रबंध पहले से अच्छा होगा। दवा की मात्रा में लचीलापन, लोहभार की मात्रा के अनुसार मात्रा का निर्धारण आसान होगा। अभी तक के प्रकाशित आंकड़ो के अनुसार असुनरा निश्चय ही एक प्रभावकारी, सुरक्षित व सुविधाजनक लोह निष्कासक दवा है जो लंबे समय तक प्रयोग की जा सकती है।

असुनरा का अन्य उपलब्ध लोहे निष्कासक दवाओं से तुलना

लक्ष्य	डैस्फराल	कैल्फर	असुनरा
लोह प्रति खिचाव	बहुत अधिक	जिंक का भी रिसाव	बहुत अधिक खिचाव
प्रयोग विधि	अधःत्वक या शिरा द्वारा	मौखिक, दिन में 3 बार	मौखिक, दिन में एक बार
सहनशीलता	स्थानीय विप्रभाव	जोड़ों में दर्द	त्वचा पर चकत्ते
दीर्घकालिक सुरक्षा	प्रमाणित	तीव्र न्यूट्रोपीनिया	अप्रमाणित

NATIONAL THALASSEMIA WELFARE SOCIETY

Activity Report

1. A Blood Donation Camp was organized in association with Mc Donald, Rajouri Garden, on 6th Nov '07. AIIMS Blood Bank team collected 32 units of blood.

2. NTWS organized continuous 4 days Thalassemia awareness and Blood Donation Camp at HCL, Sector - 60 and Sector- 58, Noida from 19th Nov to 22nd Nov'07. This was the first Camp of ours with HCL, and AIIMS Blood Bank team collected 183 units of blood. Number of Volunteers came forward for Thalassemia Test.

3.Path Infotech of Noida had organized a Blood Donation Camp, for the first time in association with our Society. AIIMS Blood Bank collected 30 units of blood. There was great enthusiasm among the staffs of Path Infotech and they promised to help us by organizing Camps regularly.

4. Mphasis, Noida also organized a 2 Days Blood Donation and Thalassemia Awareness Camp on 6th & 7th Dec'07, for the first time in association with our Society. **Dr. J.S. Arora was invited to deliver a talk on Thalassemia and Blood Donation**. 25 volunteers came forward for the Thalassemia HPLC test. LNJP Hospital Blood Bank Team collected 58 units of blood.

5. Convergys, Gurgaon organized 5 Night Blood Donation Camps on 16th & 18th Jan'08 at Orchid Square, on 24th & 25th Jan'08 at Atria building and on 8th Feb at Unitech building, in association with NTWS. 336 units of blood were collected by the LNJP and the Hindu Rao Hospital Blood Bank. Convergy's took a very strong step to eradicate Thalassemia by sponsoring the CBC test for all of their employees. Youngsters understood how important it is to know their Thalassemia Status before marriage and came forward to undergo this test. 480 volunteers from Convergys were screened during these camps

6. Mc Donald,Vikaspuri organized a Blood Donation Camp on 2nd Feb 2008, for the first time in association with NTWS and PVR Commercial Complex Welfare Association. 35 units of Blood were collected by the LNJP Hospital Blood Bank.

7.Colwell Salmon, Noida organized a Blood Donation and Thalassemia Screening Camp on 7th Feb., 2008 evening, for the first time in association with NTWS. It was a successful camp and number of volunteers came for their Thalassemia Screening test.

8. Delhi University Students Union organized a Blood Donation Camp in association with NTWS on the Valentines Day 14th Feb'08, Mc Donalds, Kamla Nagar sponsored the donors. AIIMS Blood Bank collected 35 units of blood.

9. On the occasion of 'Mahila Divas', Indian Sports and Cultural Society in association with NTWS organized a Blood Donation and a Thalassemia Screening Camp on 7th March 2008 at Income Tax Building I.T.O. Ms. Nafisa Ali, President ISCS and Film actress took active part in motivating the Blood Donors for Thalassemia Screening Test. She said it is due to our ignorance that Thalassemia disease is on high flame. In Thalassemia life long blood transfusion and expensive drugs to extract extra iron from the body is a trauma for the child and survival is very low for such patients. Nafisa Ali appealed to all the people present to check their Thalassemia Status before marriage and if their family is completed than get their children tested for thalassemia trait. Awareness can only prevent this disease. 50 volunteers got themselves Thalassemia screened during the camp.

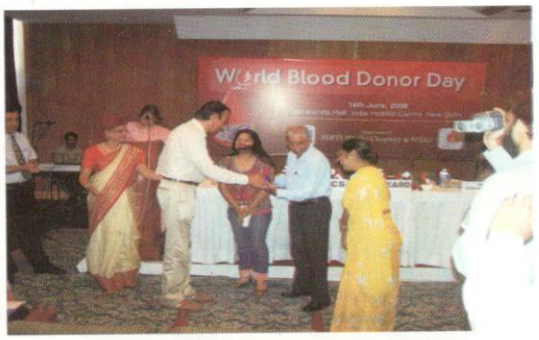
10. Guru Harkrishan Public School, Tilak Nagar invited NTWS to put up a Thalassemia awareness camp on 26th March during their Annual Day function. Brochures were distributed among the students, teachers and parents, Banners and exhibition panels were put up all around the school.

11. Convergys Atria, Gurgaon organized another two days Night Blood Donation and Thalassemia Screening Camp on 26th & 27th March 2008. It was a very successful camp where LNJP & Hindu Rao Blood Bank Teams collected 250 units of Blood. All the youngsters were aware of Thalassemia and came forward for the screening test to know their Thalassemia Status. Convergys has sponsored the Thalassemia Screening Test for their employees.

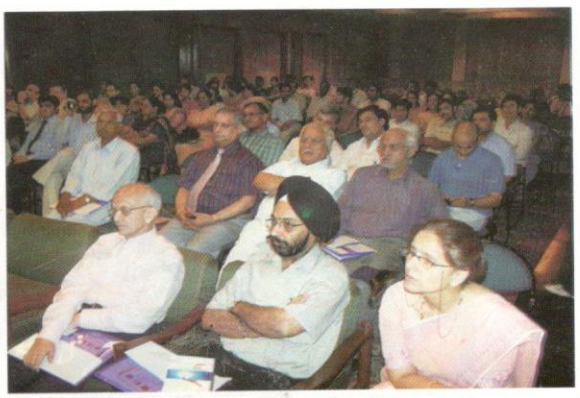
12. I.T.I, Arab Ki Sarai, Nizammudin organized a Blood Donation and Thalassemia Screening Camp in association with Mianwali Volunteer Blood Donation Association. NTWS collected the blood samples for

Dr. Jagdish Chandra, Dr. J.S. Arora and Dr. A.P. Dubey interacting with the Thalassemia Parents, patients in a Seminar on 3rd May'08 at Kalawati Hospital Hall.

Thalassemia patients & parents participating at Saminar on 3rd May' 08 at Kalawati Hospital during introduction of New Oral chelations drug.



Mr. & Mrs. Ashok Ahuja now joined with their daughter Nupur making a perfect blood donor family



ISBTI observed World Blood Donor's Day 14th June'08 at India Habitat Center.

Dr. A.P. Dubey & Dr.V.P. Choudhry discussing with patients about the new oral iron chelating drugs at Kalawati Hospital Seminar Hall

Dr. V.P. Choudhry addressing the gathering of Thalassemia Patients, Parents at Kalawati Hospital Seminar Hall on 3rd May'08.

ITD observed at Kalawati Saran Hospital 3rd May'08.

Tanu receiving a memento from organizers after giving a speech during the World Blood Donors Day at India Habitat Centre.

National Thalassemia Welfare Society's Participation

Dr. J.S Arora with Dr. Yatish Goel, President IAP Dehradun and Dr.B.S.Pandhi, President IMA Blood Bank Dehradun on 29-3-2008.

Dr Alok Ahuja putting up a querry to Dr. J.S. Arora during the CME organised at IMA Blood Bank Dehradun

Dr. J.S. Arora interacting with Thalassemia patients at Dehradun Blood Bank.

Dr. Sajid Khan briefing the press at Bhopal.

Dr. J.S. Arora addressing the Seminar at IMA Blood Bank, Dehradun, 29-3-2008

Audience at clinical meeting at Dehradun

Dr.J.S. Arora examining patients at Dehradun on 29th March'08.

Gagan giving medicines and Blood Filters to Patients at Dehradun Camp

at Dehradun, Agra, Bhopal & Bareilly

Dr. Arora examining patients at Bhopal

Dr. J.S. Arora delivering a lecture on Thalassemia Prevention at M.P Thalassemia Society on 17th May'08

V.P. Choudhry & Dr. J.S. Arora examining patients at Agra Society Camp.

Dr. Arora examining one of the best maintained Thalassemic Chinu at Bareilly

Dr. Choudhry examining patients at Bhopal

Dr J.S. Arora, Dr V.P. Choudhry and Dr. Sajid Khan at dias during a seminar on Thalassemia in Bhopal

Dr. V.P. Choudhry & Dr. J.S. Arora visited Samarpan Blood Bank Agra

Dr V.P. Choudhry examining patients at Bareilly

Dr Arora speaking on Iron Chelation at Bareilly

Anjali Sardana & Chinu the two stars of Bareilly

Desirox being introduced at Bareilly
by J.S. Tomar, Ex. Mayor of city

Audience at Clinical meeting at Bareilly

Mrs. Swaran Anil & Thalassemia patients doing
Pranayam at Tilak Nagar Centre

Patiala Thalassemic Children Welfare Association

Thalassemia Screening. 150 students were screened of Thalassemia. The students were aware of Thalassemia and were very happy to get themselves tested.

13. Members of the Bechtel Employees Club, Bechtel, Gurgaon, organized a Blood Donation Camp in association with NTWS on 11th April 2008. It was a successful camp where 94 units of blood were collected by the AIIMS Blood bank Team.

14. Bal Bharti Public School Ghaziabad organized a Thalassemia Screening camp on 16th April 2008.

15. Fluor Daniel, Gurgaon organized a very successful Blood donation and Thalassemia Screening camp at both the sites, DLF Square & DLF Cyber City on 17th & 18th April 2008. AIIMS blood Bank Team collected 264 units of blood.

16. Sarvodaya Enclave Ladies Club organized a Blood Donation & Thalassemia Screening Camp on 20th April 2008 at C- Block Mandir , Sarvodaya Enclave. It was their first attempt. LNJP Blood Bank Team collected 25 units of blood.

17. NTWS in association with Vatika's "Prayas" organized a Blood Donation Camp at Vatika Towers on 25th June2008. It was a very successful camp and the AIIMS Blood Bank Team collected 145 units of blood.

18. NTWS organized a Blood Donation camp at "Sarala Fabric Pvt. Ltd" Ghaziabad on 26th June 2008 . This is there third Blood Donation camp where 67 units of blood were collected by the AIIMS blood bank.

19. NTWS in association with Jail road shopkeepers association is regularly organizing Blood donation Camp at Hari Nagar, New Delhi. This year it was organised on 28th June '08, 134 units of blood were collected by the Red Cross Blood Bank. Mr. Jewesh Manuja a Thalassemic Parent is the force behind these camps.

20. NTWS organized a 23rd Blood Donation Camp at Society office on 29th June 2008; 86 units of blood were collected by the DDU Hospital Blood Bank.

21. HCL Technologies Pvt. Ltd gave us permission to organize 2 Blood Donation Camp at their 2 sites Section 58 & Sector 59, Noida on one day 16-07-08. AIIMS & DDUH Blood Bank Teams collected 111 units of blood. There were number of donors waiting to donate blood through out. It was a very successful Camp.

22. On 1-08-08 NTWS organized a BDC at Alcatel-Lucent, Gurgaon. Thalassemia Screening was also done along with Blood Donation. 53 units collected by AIIMS Blood Bank.

23. On 4th & 7th July 2008 Thalassemia Screening Camp was organized at Inter Globe Technologies Gurgaon where 125 volunteers were screened.

24. On 23-08-08 Thalassemia Screening Camp was organized at NDPL where 77 volunteers were screened.

25. Bal Bharti School invited NTWS on their Annual Day function to create awareness of Thalassemia among the Parents & Children Brochures & Posters were distributed & Exhibition panels were displayed.

NTWS celebrated Picnic this year on 20th Jan'08, at Sanjay Gandhi Lake Park, Sarojini Nagar, New Delhi. It was a sunny day and many Thalassemic Families from Delhi, Rohtak, Faridabad, Baghpat, Bhiwani etc enjoyed the Picnic. There were varieties of games for the children of different age groups. The children showed there talents in singing and dancing, cracked jokes which made the gathering laugh aloud. Mr. Gulati made the children play the funniest games which the children enjoyed very much. They were making monkey tail, blowing and tying balloons as fast as they can and decorating themself with all the glaze papers and balloons. Km. Surrender Saini welcomed the patients and parents and listened to their problems. Secretary's Report was read by Dr. J.S. Arora, (General Secretary, NTWS) meanwhile children were busy in the painting competition. The children were given three topics according to their age groups Holi Festival, Republic Day and Pollution & Environment. After this, lunch was served to all the members of the Thalassemic Families. Then prizes were distributed to the participants who won the races and the games. The last but not the least time came for Tambola Game. Tambola Tickets were distributed and Mr. Manchanda started announcing the numbers stylishly one after another. The Picnic ended with a sweet moment where childrens were left with gifts and chocolates distributed by Mr Kamal.

Foundation against Thalassemia, Faridabad celebrated Motivation Day on 6-01-2008. There was a live coverage by Delhi Aaj Tak. Parents shared there views, sorrows and pain due to ignorance and non - awareness of the disease "Thalassemia", their children are suffering today. These unfortunate parents appealed to the people through Media to go for Thalassemia test before marriage or if the family is not completed.

Clinical Meetings at Kalawati Saran & Kasturba Hospital

Kalawati Saran Hospital organized a Seminar to mark International Thalassemia Day on 3rd of May 2008. A scientific session was kept for medical and paramedical staff of LHMC & Kalawati Saran Hospital. Dr Harish Pemde spoke on diagnosis & management of Thalassemia, Dr Anju Seth talked on endocrine problems in Thalassemia, Dr Jagdish Chandra discussed adult Thalassemics challanges ahead, Dr Bhuriani elaborated on BMT and Dr J.S. Arora social aspect of Thalassemia.

The above seminar was followed by a talk by Dr V.P. Choudhry on new oral iron chelating drug Defrasirox ('Asunra' and 'Desirox'). All the Thalassemic patients of Delhi & NCR were invited for the function. The Lecture Hall was full with Patients, Parents, Doctors and Staff. Then their was question answer session with experts - Dr V.P. Choudhry, Dr A.P. Dubey, Dr Jagdish Chandra, Dr. Gauri and Dr. J.S. Arora. Who explained the querries put up by Thalassemia patients.

The Paediatrics Department of Kasturba Hospital observed the International Thalassemia Day on 7th May. All the patients, parents, doctors and paramedical staff attended enthusisticaly. Dr J.S Arora gave a lecture on Iron chelation with special emphesis on new drug Defrasirox. He also answered lot of queries raised by the participants. A small function was also Organized on 16th May 2008, where Thalassemia patients performed stage function and gifts were distributed to all the children present there. The children enjoyed very much, sang and danced along with the Doctors on stage. Packed lunch was given to all the members present in the function. The Medical Superintendent of Kasturba Hospital assured safe blood supply to the Thalassemics and every possible care, guidance and help.

NTWS Participation at Dehradun, Agra, Jodhpur, Bhopal, Bareilly and Kota

IMA Blood Bank Dehradun organized a seminar on Thalassemia on 29th Mar'08. Dr J.S. Arora examined the patients and gave an exciting news to Thalassemics that new oral iron chelator is being launched the next day i.e. 30th March. He apprised them about new drug Defrasirox in detail. In the evening members of IAP, IMA & Gynacologist attended the seminar. Dr. Aseem Tiwari incharge IMA blood bank, Dehradun spoke on rational use of blood and Dr. Arora elaborated on management of Thalassemia.

Agra Thalassemia Society organized a Seminar on 8th May International Thalassemia Day at Samarpan Blood Bank. Dr. V.P. Choudhry & Dr. J.S. Arora were the chief invitees. In the morning 70 patients were examined. Patients took the opportunity of free OPD and blood samples were taken for Serum ferritin test and HPLC test. It was followed by a lecture on arrival of new iron chelators "Defrasirox" by Dr. V.P. Choudhry and "Prevention and Control of Thalassemia" by Dr. J.S. Arora in the post lunch session. Doctors from IMA Agra also attended this session. Samarpan Blood Bank is a State of Art Blood Bank in Agra providing free of cost blood to Thalassemics. Dr. Anil Agarwal a senior paediatrician provides them free transfusion facility to all the Thalassemics. Many Thalassemic patients Started Defrasirox from that day onwards.

IAP Marwar Thalassemia Society, Jodhpur organized a Seminar on Thalassemia, Safe Blood Supply and Iron chelation Therapy on 23rd Dec'07, at Umed Hospital Auditorium, Jodhpur. Dr. V.P. Choudhury and Dr. Arora were the Chief Guest. They also examined Thalassemia patients and advised the treatment. Most of the Thalassemics were not maintaining the adequate Hb level & giving inadequate iron chelation. Their visit will stimulate them to adhere to optimum treatments.

Dr. Sajid Khan, Secretary, M.P Thalassemia Kid Care Society, Bhopal organized a Thalassemia Camp and CME on 17th May 2008. Dr. V.P. Choudhry and Dr. J.S. Arora examined 75 thalassemic patients. In the evening around 200 Patients, Parents, Doctors and Social Workers attended the Symposium. Dr. V.P. Choudhry delivered a lecture on the new chelating drug name "Defrasirox" and a lecture on "Prevention and Control of Thalassemia" by Dr. J.S. Arora.

Indian Medical Association Bareilly Branch, Indian Academy of Paediatrics, Bareilly and Society for Thalassemia Care & Control, Bareilly organized a Thalassemia Camp & CME on 25th May, 2008 at IMA Bhawan, Bareilly. Dr.V.P. Choudhry delivered a lecture on anaemia and interpretation of cell counter report while Dr. J.S. Arora highlighted iron chelation in Thalassemia.

थैलासीमिया बच्चों के अभिभावकों को दिया टिप्स

बरेली, आईएमए और थैलासीमिया सोसायटी की ओर से रविवार को आईएमए हाल में शिविर लगाया गया जिसमें मरीजों का परीक्षण करने के बाद अभिभावकों को टिप्स भी दिये गये। बच्चों का परीक्षण करने के बाद डा० वी.पी. चौधरी ने बताया कि अधिकांश बच्चों मे कमियां मिली हैं और इसका प्रमुख कारण ब्लड चढ़ाने के बाद डाक्टर से सलाह न लेना है। उन्होंने कहा कि थैलासीमिया बच्चों को सिर्फ खून चढ़वाने से ही काम नही चलेगा। उनकी बराबर मानीटरिंग होनी भी जरूरी है। बरेली के बच्चों मे ग्रोथ कम देखने को मिली। उनका हीमोग्लोबिन भी कम पाया गया। बच्चों का वजन और ऊंचाई अपेक्षा से कम थी। बच्चों के खून में लौह की मात्रा अधिक हो सकती है जो शरीर के अन्य अंगो पर प्रभाव डालती है। ऐसे में बच्चों का परीक्षण बेहद जरुरी है। डा. एस के सरदाना और डा. जे सरदाना के अनुरोध पर नेशनल थैलासीमिया वैलफेयर सोसायटी दिल्ली, आईएमए और सिद्धि विनायक अस्पताल ने एक-एक पंप भी बरेली थैलासीमिया सोसायटी को देने की घोषणा की। दोपहर तीन बजे तक चले शिविर में वयस्क थैलासीमिक अंजली व चीनु ने थैलेसीमिक अभिभावकों का उत्साहवर्धन किया। आईएमए अध्यक्ष डा. अजीत साहनी ने कार्यक्रम की अध्यक्षता की।

बढ सकती है उमर, सही इलाज हो अगर

अजमेर रीजन थैलासीमिया वैलफेयर सोसायटी के तत्वावधान मे रविवार को पड़ाव स्थित संत कंवरराम धर्मशाला में थैलासीमिया से पीडित बच्चों के लिए आयोजित चिकित्सा एवं रक्त जांच शिविर में 125 थैलासीमिया रोग से पीड़ित बच्चों की जांच की गई । शिविर में डॉ. ईश्वर जैसवानी, डॉ जे.सी. वैद व डॉ. मोतीलाल सोनी ने अपनी सेवाएं देते हुए पीड़ित बच्चों के अभिभावकों को बच्चों के कम्पलीट ब्लड टेस्ट, सिरम फेरीटिन व हेपेटाइटिस सी की समयानुसार जांच करवाने संबंधी परामर्श दिए। शिविर में ब्यावर किशनगढ, मसूदा, केकड़ी, पुष्कर, भिनाय व अजमेर से शिविरार्थियों ने भाग लिया। इससे पहले पूर्व विधायक ज्ञानदेव आहूजा एवं नगर परिषद के सभापति धर्मेन्द्र गहलोत ने शिविर का शुभारंभ किया। इस अवसर पर मुख्य अतिथि आहूजा ने थैलासीमिक रोग से पीड़ित बच्चों को राज्य सरकार व स्वयंसेवी सस्थाओ के माध्यम से निःशुल्क दवा व बोनमैरो ट्रासप्लांट सहयोग कराने की बात कही।
शिविर मे पार्षद जयकिशन पारवानी, इनहरव्हील क्लब की अध्यक्षा प्रतिभा गहलोत, ईश्वर पारवानी, मनोहर पंजाबी आदि उपस्थित थे ।

Story of Veenu

Name: Veenu
Age: 10 Years (D.O.B. 13th June 1997)
Address: Shiv Colony, Railway Station
Kosli, Rewari (Haryana)

बेबी वीनू को 3½ वर्ष की उम्र में बुखार हुआ था और बुखार काफी दिनों तक रहा। डा. ने हमें बताया कि इसके पेट मे गाठ लग रही है कहीं बाहर जाकर दिखाए। रेवाडी मे नर्सिंग होम में दिखाया जिन्होंने तिल्ली का बड़ा होना बताया। कुछ टेस्ट लिए। एक सप्ताह दवाई के बाद उन्होंने बताया कैंसर है । तब तक बुखार का रहना जारी था। यहाँ से गंगा राम (दिल्ली) हस्पताल ले गये । उनहोंने कुछ टेस्ट लिए वो टेस्ट नार्मल थे। उन्होंने बच्ची को एडमिट कराने की सलाह दी ताकि तिल्ली का सैम्पल लेकर जाँच कराए। लेकिन हम वहां से वापिस घर आ गये क्योकि उन्होने जो खर्च बताया उसका इन्तजाम नही था। धीरे-धीरे खून कम होना शुरु हो गया। हाथ पैर पतले, पेट बढ़ा हुआ लगने लगा। तब गंगा नगर के पास स्थित शाह स्तनाम हस्पताल में दिखाया वहाँ बच्चों के डा. नैन ने Hb Electrophoresis का टेस्ट लिया और उनहोंने बताया कि थैलासिमीया है इसे खून चढ़वाओ और इसका यही एक मात्र इलाज है। हमने सिरसा से खून चढ़वाना आरम्भ किया आज तक वहीं से खून चढ़वा रहे हैं। लेकिन उन्होंने कभी नही कहा कि इसका Serum Ferritin चेक कराओ या इसकी कोई आयरन निकालने की थेरेपी भी होती है। थैलासीमिया का एक केस जो National Thalassemia Welfare Society से जुडे हुए है सिरसा निवासी है उनसे बल्ड बैंक सिरसा मे मेरी मुलाकात हुई उन्होंने मुझे N.T.W.S. का पता दिया और मैं पहली बार 13.08.06 को तिलक नगर में Dr. J.S. Arora जी से मिला। डा० जी ने तिल्ली का फौरन आपरेशन कराने को कहा। यहां आकर मुझे थैलासीमिया क्या है इसके बारे में मालुम हुआ। M.A.M.C. मेडिकल में जो Conference हुई थी उसमें मुझे थैलासीमिया के विषय मे बहुत जानकारी मिली मैं धन्यवाद करता हूँ Dr. J.S. Arora जी का जिनकी वजह से सही इलाज और सही दिशा की तरफ चल रहा हूँ।

मनोहर लाल S/o श्री हन्सराज
शिव कालोनी, रेलवे स्टेशन,
कोसली, रेवाड़ी, हरियाणा

Thalassemia Symposium - III

GENERAL INFORMATION

Registration : Registration is open to all.

Registration Fees :
Registration Fees for Participants

Date of Deposit	Patient / Pareint		Doctors
	Single	Couple	
Upto 15th-Aug-2008	Rs. 150/-	Rs. 250/-	Rs. 200/-
Upto 25th-Aug-2008	Rs. 200/-	Rs. 350/-	Rs. 300/-
On the Spot	Rs. 300/-	Rs. 500/-	Rs. 400/-

The Registration fee includes: Attendance to all sessions, literature, conference kit, lunch and tea/coffee.
No kit will be issued to the additional Members.

Accommodation :
Limited accommodation will be made available on prior intimation and full advance payment before **10th Aug '2008.**

Accommodation Charges (without food) :

Class A	**Rs. 5000/-** approx. per day
Class B	**Rs. 2500/-** approx. per day
Guest House	**Rs. 1000/-** approx. per day

Mode of Payment :
Please send registration fee by Demand Draft/Cheque or Cash along with the registration form in favor of "**Thalassemia Symposium - III.**" To the Secretariat address.

Note
Please add **Rs.50/-** extra for outstation cheques.
Children below 15 are not allowed.

Special offer for Thalassemic Patients above 15 yrs. of age Rs. 50/- per head.

IMPORTANT
Seats are limited,
Last date for concessional Registration : Upto ~~15th~~ Aug, 2008
Extended upto 25th Aug, 2008

REGISTRATION FORM

Name:----------

Name of Additional Member(if applying)----------

Age/Sex:----------

Title-Doctor/Parent/Patient/Other

Address:----------

----------Pin ----------

Phone: ----------

Fax: ----------

E-mail: ----------

Accommodation Required : Yes / No

Category: A ☐ B ☐ Guest House

No. Of Accompanying Persons:----------

Arrival Date & Time: ----------

Departure Date: ----------

I would like to register for the symposium. Please find enclosed

D.D./Cheque No----------

Drown on ----------Date----------

For Rs.---------- Rupees ----------

.....

As Registration Fees and Accommodation charges (if applied for).

Signature.....Date.....

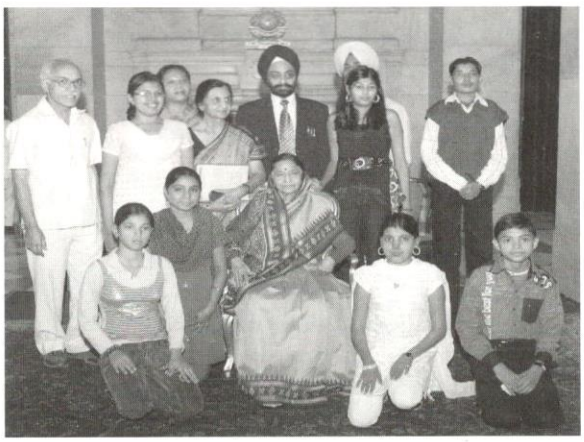
NOTE:

1. **Registration form can be photostated.**
2. **No cancellation is allowed once the registration fee/accommodation charges are paid.**
3. **No refund /adjustment will be entertained under any circumstances.**

Hon'ble President of India

Smt. Pratibha Devi Singh Patil

Blesses Thalassemic Children on Children day **14th Nov., 2007**



NATIONAL THALASSEMIA WELFARE SOCIETY TEAM

HARYANA THALASSEMIA WELFARE SOCIETY TEAM

NATIONAL THALASSEMIA WELFARE SOCIETY (Regd.)

KG-1/97, Vikas Puri, New Delhi-110018 Tel : 9311166711-712, 25511795
URL : www.thalassaemiaindia.org
E-Mail : ntws08@gmail.com

MEMBERSHIP :

Any person can become life member of the Society by filling a form & Sending a DD of Rs. 500 in favour of : National Thalassemia Welfare Society.

For NRI & Foreigners Life membership fee US$100

READILY AVAILABLE

Filters Single Unit
Filters Double Unit
Kelfer
Desferal
Infusion Pump
S.V Set
Special Discount on Desirox & Asunra

ADVERTISEMENT CHARGES

	INLAND	FOREIGN
Sponsership	RS. 50,000	US$ 5,000
Cover Page		
Inside Front	Rs. 15,000	US$ 1,500
Inside Back	Rs. 15,000	US$ 1,500
Inside		
Full page	Rs. 5,000	US$ 500
Half page	Rs. 3,000	-
Back		
Full page	Rs. 20,000	US$ 2,000

Special Thalassemia Clinic

N.T.W.S. Organises Thalassemia check up Clinic on 2nd Sunday of every month at N.T.W.S Thalassemia Centre, 2nd Floor, Community Centre, Slum & JJ Dept. of MCD, Near Gurudwara Singh Sabha Block 12, Tilak Nagar New Delhi-18

For Appointment Contact: Dr. J. S.Arora Tel : 25507483, 25511795

Facilities:

* Growth Monitoring
* Chelation Therapy
* Serum Ferritin Assay for **Rs.150** only
* Hepatitis B Vaccine: **Rs. 50** for children below 10 years. **Rs. 100** for children above 10years.
* Thalassemia Screening / Diagnosis with HPLC **Rs. 300** only
* CBC (complete blood count) **Rs. 70** only

Published by : National Thalassemia Welfare Society (Regd.) on behalf of Federation of Indian Thalassemics. Any reproduction of material contained in " National Thalassemia Bulletin" is welcome provided "FIT" is acknowledged.

NTWS Dispensary

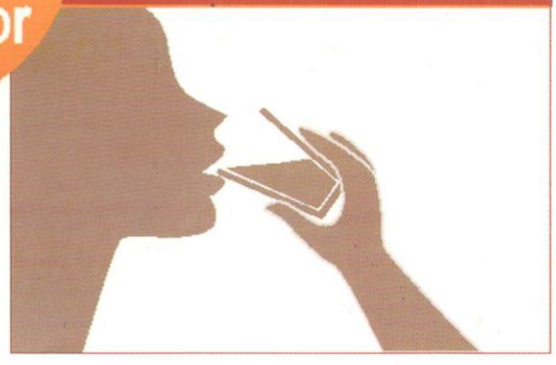
C-2 Block, Palam Vihar, Gurgaon

Iron chelation goes from injecting to ingesting

PLOP

The first once-daily oral iron chelator

GULP



Asunra®
deferasirox

Continuous protection for your patients with chronic iron overload due to blood transfusions

Formulation: Dispersible tablets containing 100 mg, 400 mg of deferasirox. **Indications:** For adults and paediatric patients aged 2 years and over with chronic iron overload due to blood transfusions (transfusional haemosiderosis). **Dosage:** • **Starting daily dose:** Recommended initial daily dose is 20 mg/kg body weight, except for 30 mg/kg for patients receiving >14 ml/kg/month of packed red blood cells (>4 units/month), and for whom the objective is reduction of iron overload; except for 10 mg/kg for patients receiving <7 ml/kg/month of packed red blood cells (<2 units/month), and for whom the objective is maintenance of the body iron level. For patients already well-managed on treatment with deferoxamine, consider a starting dose of **Asunra** that is numerically half that of the deferoxamine dose. • **Asunra** must be taken once daily on an empty stomach, at least 30 minutes before food. • **Asunra** tablets to be dispersed in water or apple or orange juice. • **Monthly monitoring of serum ferritin** for assessing patients response to therapy. • **Maintenance daily dose** to be adjusted if necessary every 3 to 6 months based on serum ferritin trends. Dose adjustments should be made in steps of 5 to 10 mg/kg. **Asunra** should be interrupted if serum ferritin falls consistently below 500 microgram/L. • **Maximum daily dose** is 30 mg/kg body weight. **Contraindications:** Hypersensitivity to deferasirox or to any of the excipients. **Warnings/Precautions:** • **Monthly monitoring of serum creatinine and proteinuria:** dose reduction may be needed in some cases of non-progressive increase in serum creatinine. **Asunra** should be interrupted if serum creatinine shows a progressive rise beyond the age-appropriate upper limit of normal. More frequent creatinine monitoring recommended in patients with an increased risk of renal complications. • **Monthly monitoring of serum transaminases:** **Asunra** should be interrupted if persistent and progressive unexplained increase in serum transaminase levels. • **Asunra** has not been studied in patients with moderate hepatic impairment and should be used with caution in such patients. • **Skin rashes:** **Asunra** should be interrupted if severe rash develops. • Discontinue if severe hypersensitivity reaction occurs. • Annual ophthalmological/audiological tests (e.g.). • Should not be used during pregnancy unless clearly necessary. • Not recommended when breast-feeding. • Must not be combined with other iron chelator therapies. • **Product contains lactose. Interactions:** • Should not be taken with aluminium-containing antacids. **Adverse reactions:** • **Most common adverse reactions:** nausea, vomiting, diarrhoea, abdominal pain, rash, non-progressive increase in serum creatinine, increased transaminases, abdominal distension, constipation, dyspepsia, proteinuria, headache. • **Less common adverse reactions but potentially serious:** acute renal failure, hypersensitivity reactions (including anaphylaxis and angioedema), severe skin rash, maculopapular, hepatitis, leukocytoclastic vasculitis, urticaria. As with other iron chelator therapy, high-frequency hearing loss and early cataracts have been uncommonly observed. **Packs:** Packs of 30 Tabs of 100 mg & 400 mg. **Note:** Before prescribing, please read full prescribing information.

NOVARTIS
ONCOLOGY

For further information write to:
Novartis Healthcare Pvt. Ltd.,
Pharmaceuticals Division, Sandoz House, Shivsagar Estate,
Dr. Annie Besant Road, Worli, Mumbai 400 018.
Tel.: 91 22 2495 8888 Fax: 91 22 2497 0454 www.novartisoncology.com

ASUNRA/ADVT/1