FEDERATION of Indian Thalassemics
NATIONAL THALASSEMIA BULLETIN

VOL. 17. No. 2 | SEP. 2011

Hon'ble Health Minister Dr. A.K. Walia Presenting a Memento to an IAS Thalassemic Major Sukhsohit Singh on World Blood Donor Day 14th June 2011.

CORRESPONDENCE ADDRESS :

Dr. J.S.Arora

(General Secretary)

FEDERATION OF INDIAN THALASSEMICS

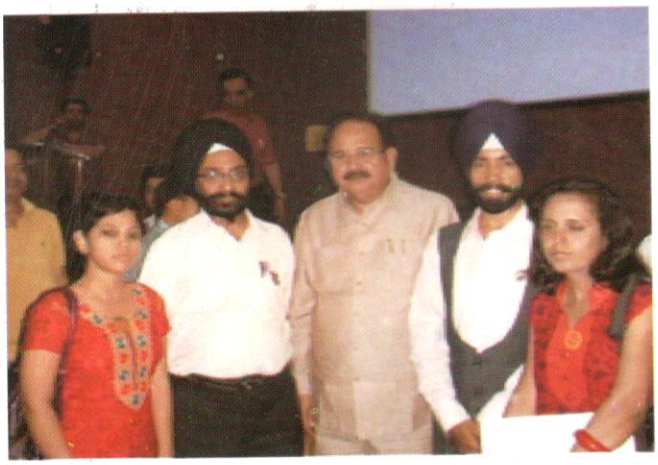
KG-1/97 Vikas Puri, New Delhi - 110018

Tel : 9311166710-711-712, 25507483,25511795

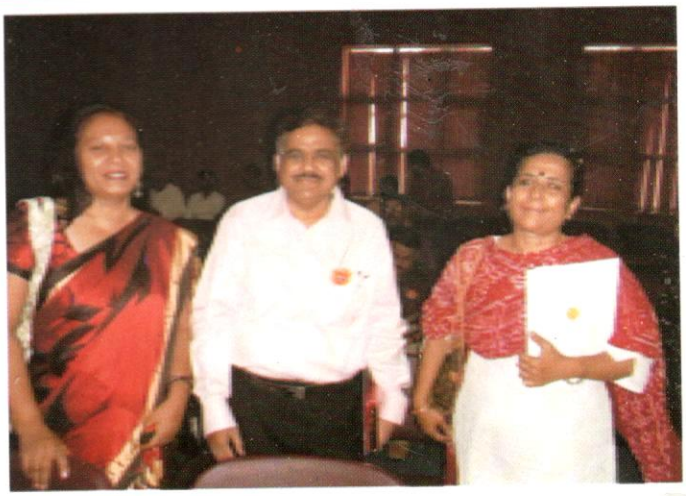
FAX : 91-11-28543576

E-mail : drjsarora@bol.net.in, drjsarora@gmail.com

EVENTS PHOTOS

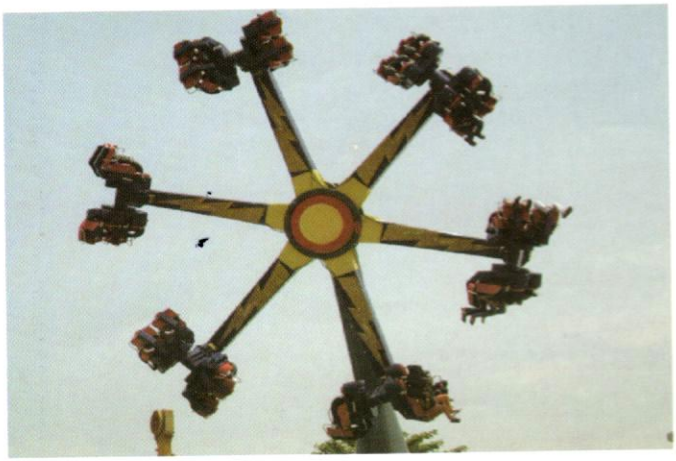


Hon'ble Health Minister Dr A.K. Walia & Dr J.S. Arora alongwith Thalassemia Major Children on World Blood Donors Day 14th Jun'11.

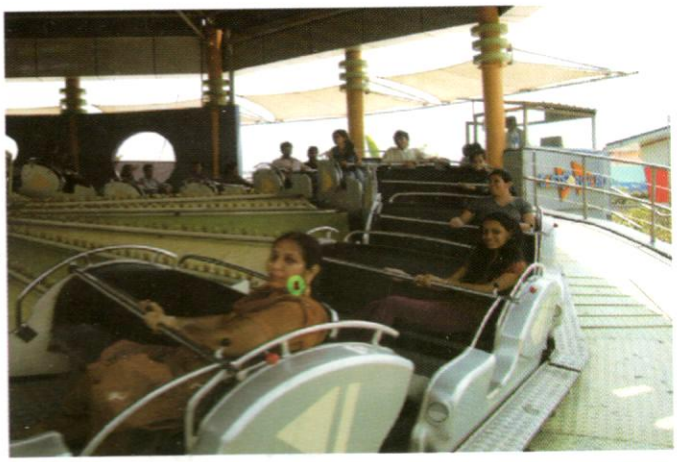


Dr. U.C. Verma, HoD Blood Bank Hindu Rao Hospital alongwith Ms. Monisha Gogoi and Ms. Vandana Arora on World Blood Donors Day 14th June'11.

Dr. V.P. Choudhry, Dr. V.K. Khanna & Delegate Discussing Case Studies at TIF Turkey Conference, 11 to 14th May, 2011

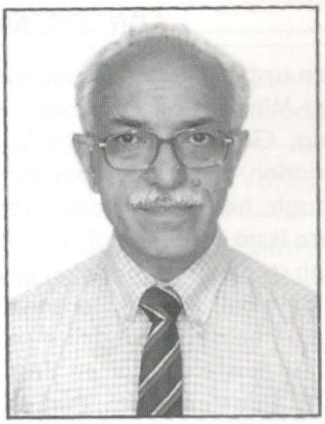


Patients enjoying on a Ride at Worlds of Wonder, Noida on Occasion of ITD, 8th May, 2011.



Patients & Parents enjoying on a Ride at Worlds of Wonder, Noida on Occasion of ITD, 8th May, 2011.

EDITORIAL



Dr. V. P. Choudhry
(M.D. FIAP, FIMSA, FIACM, FISHTM)
Former Professor & Head Hematology, AIIMS
Director
1- Sungflag Phuja Centre for Blood Disorders
Sunflag Hospital, Sec-16, A Faridabad
2. Hematology Division : Paras Hospital, Gurgaon
E-mail : vedpchoudhry@yahoo.co.in, Ph. : 09811073904

WHAT A SHAME

News of a very bright Thalassemic child Sukshohit Singh being denied a job of civil services who was ranked 48 as per list of Union Public Service Commission is a shame on the country. He has been declared unfit just because he is having Thalassemia Major, There is no medical evidence that person with thalassemia major. If treated well like Sukshohit Singh in any way affects the capabilities of person such as physical, mental, technical, administrative etc. Among various jobs opportunities in life, the administrative role is the easiest to perform. Life of children with Thalassemia major depends upon on regular transfusion which can be undertaken at night without affecting the office schedule. These children all over the developed World are doing various jobs of even highest caliber & lead a normal life. They even marry & have normal children. A person with anyother major permanent disabilities would have got the job on either reserved seats or on humanitarian grounds to rehabilitate him. On the contrary Sukshohit Singh who has a brilliant academic record as he topped the Central Board for Secondary Education from Chandigarh region and was also a topper in Masters in Public Administration in Punjab University has been denied the opportunity to serve the nation. In fact it is matter of pride that Mr. Sukshohit Singh has performed much better in academics than normal persons inspite of his disability. Many medical conditions have been enlisted under disability then why cannot Thalassemia major be included in which person is disabled for life from early childhood. There is an urgent need for the government to enact the law to include Thalassemia under the disability.

I fail to understand that why a person with a such a academic record is being denied Civil Services. If it is due to Law in that case why cannot the law be modified. If he has been declared medically unfit because of Thalassemia. Then my worthy colleagues need to be blamed as they themselves do not know the ins & outs of Thalassemia major. It is possible that in the medical board there was no hematologist who would have provided all the necessary information to the medical board to ensure that this bright boy would have served as an officer in civil services. If it so then it is shame on the medical profession on whose ignorance the career of a bright boy is being murdered in a democratic Country.

I appeal to the government to come to the rescue of Mr. Sukshohit Singh to ensure that he gets this job which he deserves on his academic grounds and right of every citizen in our Country.

Ray of Hope

HT news item dated 5th July 2011, that Prime Minister of India Sh. Man Mohan Singh has intervened is a welcome news. But no one knows that how long it will take him to get the job. Even if he gets the job, he will become junior to many who appeared with him, will haunt him throughout his life. All this happened when journalist Mr. Chetan Chauhan, who followed the case in the media. However he has still not got the job and P.M Office need to pursue the progress of his case.

Fit for cracking IAS exam but unfit for appointment .....

DR. J. S. ARORA

Sukhsohit Singh cleared the much prestigious civil services (IAS) exam- 2008, with the all India rank of 833. (42nd rank in the second merit list declared by the Union Public Service Commission on sep. 03.2011), but several hundreds of the candidates clear it every year, so what's so special and extraordinary about him.... Well nothing much.... He is first patient of Thalassemia major, throughout India, and throughout the history of this IAS exam to have cracked this examination along with other illustrious academic career record; he is still out of the services. He was rejected for the Civil services on the grounds that he is a patient of Thalassemia major. Some arbitrary rules have jeopardized his dream of bureaucratic career.

He has lost count of the blood transfusions done on him but has never lost sight of his mission in life ... to be a career civil servant, his dream job.

He was diagnosed to have Thalassemia major, at the age of one and a half years, a rare genetic disorder where the only chance of survival is frequent and regular blood transfusions, yet he has never allowed this disability to come in the way of his success. **"a disability in fact comes with a different ability, with deeper insights into the possibilities of what life may bring to us"** as is said... disease is inevitable, but whether it causes disease or not is altogether optional, just as pain is inevitable, but suffering is optional. His father Wg. Cdr. M. S Bawa, a retired officer of the Indian Air Force has been a perennial source of encouragement, and constant motivation for carrying out a quest for perfection and achieving excellence. His mother Mrs. Gursharan Kaur Bawa, a retd. School teacher epitomizes faith & sincerity.

Sukhsohit Singh has a series of records to his credit... He had topped the entire Kendriya Vidyalaya Chandigarh region, in the class 12th CBSE Examination in commerce stream in 2002. Did his B.Com with honors in Business Economics in 2005 from GGDSD College, Punjab University, Chandigarh and scoring highest marks in Income Tax subject. Scored the First position and the gold Medals, in Masters in Public Administration from Punjab University in 2010, cleared the UGC JRF exam in Dec 2009, and cleared the civil services (IAS) exam 2008, with the all India rank of 833. Cleared the Rajasthan Civil Services Exam 2008 with 94th rank. And is presently pursuing his PhD in Public Administration as a Junior Research Fellow, at Punjab University, Chandigarh.

However now, his civil services career seems to be in a state of turmoil, after the medical examination conducted in Feb 2010 at Vardhaman Mahavir College & Safdarjung Hospital, New Delhi, have declared him as medically unfit for all services [Technical (Police) as well as non technical] on account of Thalassemia Major.

However in preferring an appeal, to the Department of Personnel and Training, Ministry of Personnel, Public Grievances and Training, Government of India, New Delhi for the reconsideration of the medical status he pleads: that even though he is a known case of Thalassaemia major there is no evidence of any obvious ill-effect on overall health status. The Condition does not in any way affect the physical, mental, technical and administrative capacities of the person and that he is in a good mental and bodily health and free from any physical defect likely to interfere with the efficient performance of the duties on his appointment, and is fit in all other respects.

That the Medical Board has erred in its judgement about his fitness as per the certificate issued by Dr. R.K. Marwaha, Professor of Paediatric-Haematology Oncology, Advanced Paediatrics Centre, Postgraduate Institute of Medical Education and Research, Chandigarh-160012 , India. Dr. R. K Marwaha further opined that he is an example of what can be achieved by a Thalassemic patient, his dedication, determination and hard work has helped him to achieve this success, and that he shall excel, and will be an asset to any organisation which provides him an opportunity to work.

Our constitution ensures us a fundamental right to equality of opportunity in public services, and an equal participation, thus barring him from entering into public services on this basis shall be grossly unfair, unjust and unreasonable. And this goes against the constitutional spirit. The medical board questioned the continued and effective discharge of my services to the government. **But if he may argue to the contrary, & have come so far and so long and have dealt with this for 25 years and all so well, there is no reason why he cannot do this for the coming years in his official capacity in the government position. The authorities need to answer these questions. And had he not been efficient and continuous in his efforts he would not have come so far and achieved so much. What else is the definition of efficiency and continuity?**

We need answers to all these questions.....we have quota's for physically handicapped, while rejections for those who have no physical deformity, but a genetic disorder something over which they have no control.

He must pay back what he got from our society. Education he believes is a real empowerment & He greatly encourages Thalassemic parents to make their children to complete their formal education. He is also a devout reader, love skating, and playing table tennis, cooking is his all time favourite hobby.

His ultimate objective is to contribute to the society in the greatest possible way.

BLOOD DONATION CAMPS ORGANISED BY NTWS IN 2011

S.No.	Date	Group Organising Blood Donation Camp	Blood Bank	Blood Units collected
1.	17- 22 Jan	Vatika Group Gurgaon	AIIMS	351
2.	2 Feb	Smart Cube, Noida	DDU Hospital	110
3.	6 Feb	Nirwana Country, Gurgaon	AIIMS	61
4.	14 Feb	Delhi University	AIIMS	66
5.	28 Feb	Mac Donalds	AIIMS	36
6.	4 March	SRF Bhiwadi	AIIMS	109
7.	7 & 8 April	Aricent Gurgaon	LNJP , BSA, RML Hospital	242
8.	8 April	Convergys Gurgaon	DDU Hospital	46
9.	15 April	Fluor Daniel Gurgaon	AIIMS	122
10.	11 May	ZS Associates Gurgaon	AIIMS	49
11.	13 May	Ciena Gurgaon	AIIMS	61
12.	20 May	SAP India, Gurgaon	AIIMS	55
13.	25 May	Teleperformance, Gurgaon	LNJP	80
14.	27 May	Bechtel India	DDU Blood Bank	84
15.	8 June	Keane India Gurgaon & Noida	LNJP & RML	132
16.	5 June	Vikaspuri C Block Gurudwara	DDU	46
17.	19 June	Shubham Banquet, Hari Nagar	Red Cross Society	102
18.	22 June	Dunnhumby, Gurgaon	AIIMS	45
19.	26 June	NTWS office Vikaspuri	DDU	84

Executive of NTWS convey the heart felt thanks to various blood banks for their co-operation and all volunteers who offered their services and organized the blood donation camps to save lifes.

Disable

A Meeting organised by NCEPDP on Disability

Disabled Meeting at Vishwa Yuva Kendra, Chanakya Puri on 15th January 2011 was attended by Dr. J.S Arora & Monisha.

Airtel Delhi Half Marathon 2010

Monisha Gogoi thanked the Corporate Support Team ICICI Lombard, Delhi Branch & I pledger Mr. Akash Moondhra for choosing the cause Thalassemia in the Charity Award Function organized by Concern India Foundation at Le Meridian on 9th February, 2011.

Thalassemia Awareness

Dr. J.S. Arora was invited by SAP India, Gurgaon on 11th February, for a lecture on Thalassemia. All the employees showed keen interest in conducting a Blood Donation Camp along with a Thalassemia Screening Camp as soon as possible.

Dr. V P Choudhry was invited for a meeting by Dr. Shukla, Genpact, Gurgaon on 18th March and discussed about Thalassemia and its Prevention.

Dr. J.S. Arora & Tanu visited Apollo Hospital on 27th March for a Seminar on Genetics.

On 26th April Dr. Arora attended a seminar on thalassemia at BSAH.

Swami Dayanand Hospital Thalassemia Unit organized Thalassemia week from 3rd to 7th May 2011, NTWS also participated in International Thalassemia week by Swami Dayanand Hospital to mark the International Thalassemia Day celebration.

Ms Tanu Verma, Mr Gagan and Ms. Monisha attended a function at Maternity Home in Seemapuri on 6th May 2011. Where Ms Tanu Verma (Thalassemia Major) spoke about Living With Thalassemia and Motivated the Masses to go for Thalassemia Carrier Test before marriage to save their children from thousands of pricks. Her talk was highly appreciated by Hon'ble Chief Guest Mayor of Delhi Mrs. Rajni Abbi.

International Thalassemia Day 2011

National Thalassemia Welfare Society observed International Thalassemia Day 8th May on Saturday 7th of May at Worlds of Wonder, Noida. There was a gathering of 300 Thalassemia families. The day started with a Magic Show. The children enjoyed the show very much. After that the joy rides started. Parents along with their children enjoyed all the rides as much as they can. Thalassemia children and their brothers & sisters all were very happy and delighted to spent the whole day at the Worlds of Wonder. Snacks & refreshment was served at the beginning. To beat the heat all parents & children enjoyed the rain dance very much with the latest numbers of the DJ. Lunch was served by 2pm.

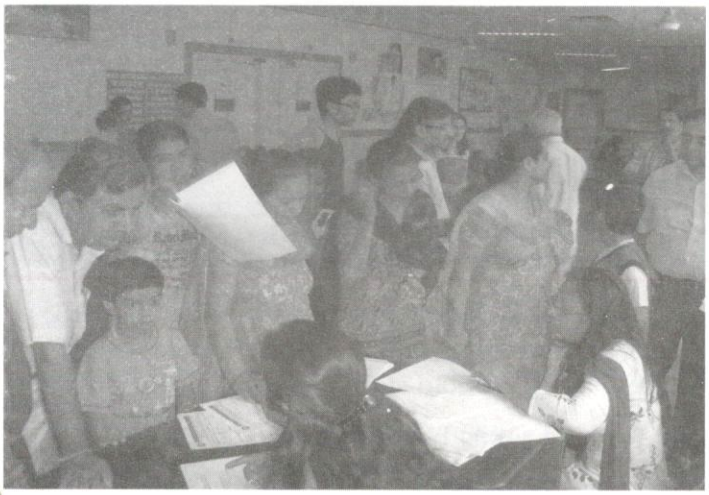
World Blood Donors Day 2011, NTWS participated in WBD 14th June at Apollo Hospital

All the RBTC's Blood Banks, NGO's and the Blood Donors who have donated more than 50 times were involved to observe the World Blood Donor's Day 2011 at Apollo Hospital Auditorium. Hon'ble Health Minister Delhi Govt. Dr. Ashok Walia was the Chief Guest of the function. The Blood Bank staff of Apollo Hospital started the function by citing the Saraswati Maa Vandana. The Hon'ble Health Minister and the other invited guest, from NACO & SBTC lighted the Lamp and inaugurated the function. Our three Thalassemia singers Tanu, Jyoti & Vandana sang a beautiful song written by Dr. J.S. Arora, honouring the Volunteer Blood Donors. There was a small play written by Dr. Makroo on Blood donation & the staff of Apollo Blood Bank acted very well and made all the audience laugh. After this presentation a Thalassemia young intelligent lad who has succeeder other and IAS was denied job in the Indian Civil Service. Gave a small talk about his carrier & future in front of the Hon'ble Health Minister and appealed to do justice. He also thanked all the volunteer blood donors for donating blood for the Thalassemics.

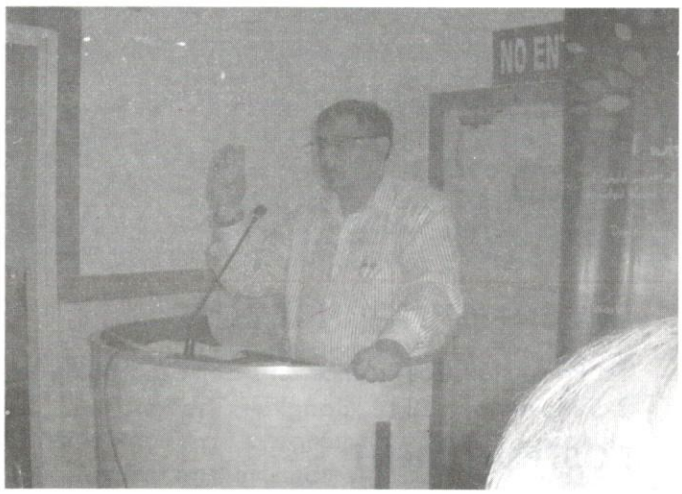
FARIDABAD - THALASSEMIA MEET AT PAHUJA TRUST SUNFLAG HOSPITAL

Pahuja Trust for Blood Disorders organized a CME on 22nd May 2011 at Sunflag Hospital Faridabad. There was a good gathering of Parents & patients. Blood samples were taken of all the Thalassemic patient for HIV, Hep B & C, Serrum Ferritin & Red Cell Allo- Immunisation free of cost. Subsequently the results were communicated to the children. These tests facilitated the management of Thalassemia. Dr. V.K Khanna, Dr. V.P. Choudhry & Dr. Amita Mahajan gave lecture on various aspects of Thalassemia management. Thalassemic children were given awards who had excelled in Academics. The Trust is committed for the Thalassemia care in Faridabad. The Center is keen that all children should maintain their Serum ferritin levels below 2000 ng/ml. It was announced that children with serum ferritin below 2000 ng/ml will be given all chelating agents free of cost for three months. Children with serum ferritin levels below 1000 ng/ml will get the drugs for 6 months. This prime object was to encourage children to take regular chelation therapy.

Dr. V.P. Choudhry, Dr. Jagdish Chandra, Dr. J.S. Arora & Mr. Ravinder Dudeja alongwith Thalassemia patients at Sunflag Hospital.



Patients being Screened for Virus Markers.



Dr. V.K. Khanna addressing the Parents .

DEFRASIROX EXJADE - ASUNRA

का प्रयोग करते समय निम्न बातों का ध्यान आवश्यक है।

1. दवा आरम्भ करने से पहले तथा पुन: हर महीने **UREA, CREATININE, SGOT, SGPT, SAP, URINE ALBUMIN** तथा **CBC (Hb, TLC, DLC, Platelet)** की जांच आवश्यक है।
2. प्रति माह **Ferritin** की जांच करवानी चाहिए।
3. दवा को खाली पेट खाने से आधा घंटा पहले **100 - 200ml** पानी, संतरे या सेव के जूस में हिला कर लेना चाहिए। साबुत या चबा कर नहीं खाना चाहिए। गिलास मे बची हुई दवा को पुन: थोड़े पानी में हिलाकर पी लेना चाहिए।
4. शरीर पर चकत्ते अथवा अतिसार **(Diarrhoea)** होने से घबराने की आवश्यकता नहीं, थैलासीमिया चिकित्सक से सम्पर्क करें।

"Thalassemia Activist" and "The Media" have shakened the Bureaucracy and the Legislature without disturbing the Judiciary.

hindustantimes | 09

nation

PM intervenes, thalassemic to join civil services

ht IMPACT

BETTING HIS DUE

Thalassemia disrupts his civil service dreams

Medical board says youth affected by blood disorder not fit for civil services

Thalassaemic man denied a job that was 'rightfully' his

A CHRONIC DISORDER BUT NOT HINDRANCE TO LIFE

Sunday Hindustan Times New Delhi, June 19, 2011

Medical experts back thalassemic IAS aspirant

HOPE FLOATS Doctors from AIIMS and PGI, Chandigarh say Singh is capable of carrying out his duties as a civil servant

ht FOLLOW-UP

HT Correspondent

NEW DELHI: Top medical experts and politicians have come out in support of Sukhsohit Singh, a patient of rare genetic blood disorder. Thalassemia major.

ice job," said Dr VP Choudhury, former head of Department of Haematology at AIIMS. "If it is due to law, then the law should be changed".

Both Dr Choudhury and Dr RK Marwaha of the Post Graduate Institute (PGI), Chandigarh, another Central government institution, have

Sukhsohit Singh

He (Sukhsohit Singh) should not be denied a chance to serve the country and ways to help him to achieve his dream should be taken

AMBIKA SONI
I&B minister

demic record should be considered not his disease," Marwaha had said.

Not just the medical fraternity, even information and broadcasting minister Ambika Soni has also spoken in favour of Singh.

"He should not be denied a chance to serve the country and ways to help him to achieve his

Service Commission, he was ranked 48, meaning he should have been selected an Indian Administrative Service officer.

A medical board of Safdarjung Hospital declared him unfit to join the civil service, either on technical or non-technical side. The decision is now being reviewed at RML hospital

Wednesday Hindustan Times, New Delhi, June 15, 2011

Thalassemia disrupts his civil service dreams

SINGH IS PROBABLY THE FIRST THALASSEMIC MAJOR PATIENT IN INDIA TO HAVE CRACKED THE CIVIL SERVICES EXAM

URGENT ANNOUNCEMENT

1st Pan-Asian Conference on Haemoglobinopathies
3-5 November 2011, Bangkok, Thailand

POSTPONEMENT

We would like to sadly announce, that after extensively discussing and evaluating the current extraordinary climatic conditions that prevail in Thailand, the Board of Directors of the Thalassaemia International Federation (TIF) decided to postpone the 1st Pan- Asian Conference on haemoglobinopathies, scheduled for 3-5 November 2011, at the Royal Orchid Sheraton Hotel and Towers in Bangkok, Thailand.

As the safety and well-being of our participants is of primary importance to TIF, the TIF Board has decided to move the event to 8-10 February 2012. We apologize for any inconvenience that these changes may have caused you and we are confident that you understand why this action had to be taken.

Sincerely
On behalf of the Board of TIF
And the local organising committees
Panos Englezos
President
Thalassaemia International Federation
Co-chairman of the
1st Pan-Asian Conference on Haemoglobinopathies

FDA NEWS RELEASE (Oct. 14, 2011)

FDA approves Ferriprox to treat patients with excess iron in the body

The U.S. Food and Drug Administration today approved Ferriprox (deferiprone) to treat patients with iron overload due to blood transfusions in patients with thalassemia, a genetic blood disorder that causes anemia, who had an inadequate response to prior chelation therapy.

Patients with thalassemia have excess iron in the body from the frequent blood transfusions (transfusional iron overload), a condition that is serious and can be fatal. These patients also have a risk of developing liver disease, diabetes, arthritis, heart failure or an abnormal heart rhythm.

The standard of care to treat transfusional iron overload is chelation therapy chemical agents that are used to remove heavy metals from the body. Ferriprox is intended for use when chelation therapy is inadequate.

"Ferriprox represents the first new FDA-approved treatment for this disorder since 2005," said Richard Pazdur, M.D., director of the Office of Hematology and Oncology Products in the FDA's Center for Drug Evaluation and Research.

The safety and effectiveness of Ferriprox is based on an analysis of data from twelve clinical studies in 236 patients. Patients participating in the study did not respond to prior iron chelation therapy. Ferriprox was considered a successful treatment for patients who experienced at least a 20 percent decrease in serum ferritin, a protein that stores iron in the body for later use. Half of the patients in the study experienced at least a 20 percent decrease in ferritin levels.

The most common side effects seen in patients who received Ferriprox included nausea, vomiting, abdominal and joint pain, urine discoloration (chromaturia), a decrease in the number of white blood cells (neutropenia), and an increase in the level of a liver enzyme that may be indicative of tissue or liver damage at unsafe amounts.

The most serious side effect seen in about two percent of patients treated with Ferriprox was the development of agranulocytosis, a serious and potentially life-threatening reduction in the number of granulocytes (a type of white blood cell that fights infection).

The therapy is being approved under the FDA's accelerated approval program, designed to provide patients with earlier access to promising new drugs followed by further studies to confirm the drug's clinical benefit.

The accelerated approval program allows the agency to approve a drug to treat a serious disease based on clinical data showing that the drug has an effect on an endpoint that is reasonably likely to predict a clinical benefit to patients, or on an effect on a clinical endpoint other than survival or irreversible morbidity (illness).

ApoPharma has agreed to several post-marketing requirement and commitments. One commitment includes further study of the use of Ferriprox in patients with sickle cell disease who have transfusional iron overload.

Earlier this year, the U.S. Department of Health and Human Services (HHS) launched the Sickle Cell Disease (SCD) Initiative bringing together HHS agencies to enhance the quality and quantity of SCD data, develop best practice guidelines and quality of care metrics, improve health care delivery and coordination of care for patients with SCD, facilitate approval of new medical products, and expand research on SCD. The post-marketing requirement for further study of Ferriprox aligns with the goals of the SCD Initiative.

Ferriprox is marketed by ApoPharma Inc. of Toronto.

Kerela Blood Disorder Patients took out Medical College March (26-2-2011)

Kozhikkode. Blood patients' protection Council took out a march to the institute of Maternal and child health at Calicut Medical college hospital on 26th Feb 2011 demanding free life saving drugs for patients stricken with Thalassemia, Haemophilia, Sickle cell anemia and leukaemia. The march was organized in protest against the stark neglect of the state government towards these fatal diseases afflicting the poor patients. Hundreds of patients with blood disorder and their relatives took part in the march.

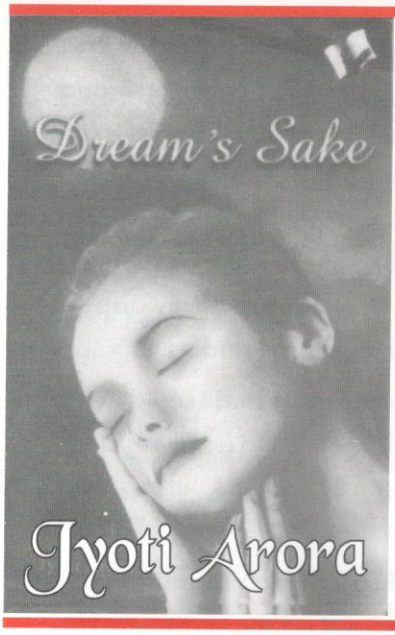
Thalassemia Awareness Campaign by BPPC Kerala

After the march a memorandum comprising thirteen points demand was submitted to the Superintendent of the hospital. Earlier the copy of the memorandum was submitted to Sri Mullappali Ramachandran, the Hon'ble State Minister of Home affairs of India. The following day on 27th feb.2001 Sri. Mullappali Ramachandran had an inauguration programme of a newly set up building at MCH under the NRHM programme. Then the minister passed the order to the principal to implement 13 point demand raised by the BPPC as soon as possible. Minister also sent a copy of the order to the Convenor of the BPPC. Patients and their parents are eagerly waiting for the implementation of the order.

Get together of Thalassemia patients (9-4-2011)

Blood Patients Protection Council organized a get together of Thalassemia patients with the joint auspicious of Paradise orchestra, a musical team led by Dr.V.P. Sasidharan, Dy. Superintendent MCH, Calicut at Vallikkunnu Beach garden resort on 9th April 2011saturday. Many cultural programs were organized. Noted Malayalam language poet Ravanaprabu inaugurated the function. Kareem Karassery, joint secretary, Federation of the Indian Thalassemics was the chief guest. Sudheer Kadalundi the two time world Guinness book record winner in tabala, played the tabala for the song of Thalassemia patients in the concerted program. Noted Malayalam film singer Ms. Sisily channel artist Nishad, M. Krishnan participated in the orchestra. Dr. V. T. Ajith Kumar, physician of Thalassemia patients also participated in the program. The program was great relief and enjoyment to the patients and their parents especially in the wake of previous day's police arrest and related incidents. A sumptuous food and free life saving drug were distributed to all participants.

Kareem Karassery
Gen.Convener,
Blood Patients Protection Council (BPPC)



REACH OUT BY

Among the winding lanes of life
Roads that take us high and low
Let there be a hand to hold the light
And kill the gloom with love's glow.

Behind the facades that we all create
Beneath the masks that all do wear
Let someone peek in and see
The lonely heart, trembling with fear.

Reach out, for we are all alone
Let us share the smiles and tears
Reach out, for the world's a dreary place
And we all need someone who cares.

Someone who hears what we can't say
Someone who knows what we won't show
Come, let's join our hands together
And seeds of togetherness let us sow.

To add a cheer, to spread a smile
And reflect in darkness a gentle beam
Of friendship, of care and of love
And give someone courage again to dream...

A battle it is that we all are fighting,
A battle that we all do share.
So let's join our hearts together
And find comfort in each other's care.

ARTICLE

"Life is like a game of cards. The hand that is dealt you is determinism; the way you play it is free will," said Jawaharlal Nehru.

Not all of us have been given the best of chances in life. But a true winner is one who makes use of whatever God gives and tries to live life to the fullest.

And that's exactly what I try to do, always.

Life may not be perfect, but it isn't for anyone else either. God may have given me Thalassemia, but He has also given me lots of great gifts. It would be just foolishness if I let go of all God's blessings and concentrate on just nursing my sores.

One of the greatest gifts that God has given me is the skill to write well. And right now, I'm trying all I can to use it to the best advantage and carve out a happy future for myself.

Living with Thalassemia is not easy. It wasn't for me either. If I look back at my childhood, my memories are more crammed with hospital visits than visits to parks or playgrounds. Because of Thalassemia, I even had to drop out of school after class seventh.

My serum ferritin was way too high and Desferal still out of our reach. Life had become too unpredictable and hospital visits too frequent. I could no longer manage to go to school and was forced to quit. For two years, I battled against iron overload. During those years, my education took a back seat.

There never was any pressure from my parents for me to study. But not studying further was not an option I could allow myself. I had far too big dreams for me to remain uneducated. I wanted to become a writer. And for that, I knew I needed to study.

So, after a gap of couple of years, I started studying again. I didn't go back to the school though. Instead, my parents enrolled me in class tenth of the Patrachaar Vidyalaya of CBSE Board. I started preparing for my board exams. I had to do it all on my own as there were no teachers to teach me. And even all my friends from the school had become busy in a circle of which I was no longer a part. But I studied as well as I could.

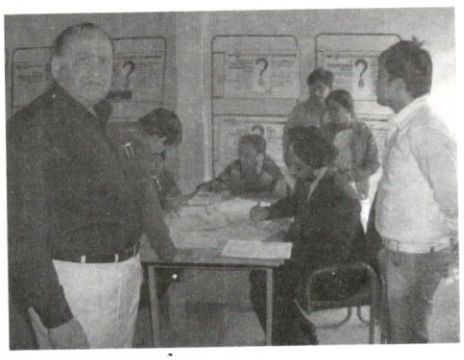
Unfortunately, things started going out of control when I started having high fever. For more than three months, several tests and medicines were tried. But nothing worked. I grew worse and worse and finally ended up in AIIMS. My kidneys had stopped working. I had to spend nearly a month there. With God's grace, the doctors there succeeded in pulling me back into life. But when I was discharged from the hospital, I had become so weak that I could not even lift a glass of water. That was the end of January. The board exams were just one month away. Now, there was no time left for detailed studies. But as soon as I could, I started going through my books. Though I did not get very good marks, but I cleared all my papers comfortably and even got 85% in English. After that, I never let anything interfere with my studies.

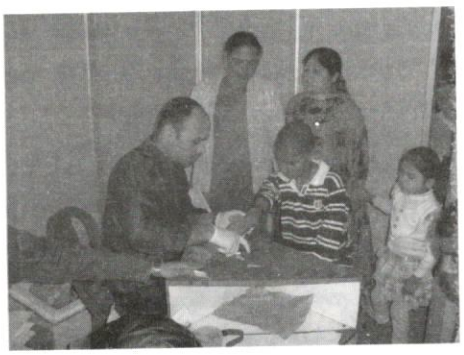
That was also the year when Kelfer was launched. It improved things a lot for me and I could live a more comfortable life. I continued studying through correspondence courses and went on to do graduation in English (Hons.) from Delhi University, and then M.A. in English Literature and also M.A. in Applied Psychology, both from the Annamalai University.

While I did post graduation, I also taught English as a personal tutor. But that did not satisfy me. I wanted to become a writer. So, in 2007, I started working as a freelance writer and editor. I have worked with Star Publishers and Distributors Pvt. Ltd. and also Reading Treasure of the GRG Consultants and Authors Pvt. Ltd. For both of them, I worked at developing books for kids. For Star Publishers, I abridged 24 English classics; these include great works like Huckleberry Finn, Great Expectations, Jane Eyre, Kim and Moby Dick. Meanwhile, I also started writing a novel. That novel, titled 'Dream's Sake,' has been recently published by V&S Publishers.

With the publishing of this book, my most cherished dream has come true. But it's still not the end of my ambition. It's only the beginning. I have yet to win the readers' hearts. I have yet to create for myself a name in the literary field. That's what my ambition is. And if God gives me time, I'm determined to work hard to achieve it. Thalassemia may have put bars on my life. But I will not let it imprison my dreams and ambition. Never. ●

Tilak Nagar Camp Photos





HOW TO USE PALL FILTER. [RC1VAE & RC2VAE]

INSERVICING RC FILTERS AVOIDING SLOW FLOW AND BLOCKAGE PROBLEMS

a) Blood bags should always be carefully agitated, and particular care should be taken to dislodge aggregates from the bloodbag ports and edges of the bag.
b) If problems are encountered with priming of filters, bloodbags should be left to rest (warm) for 10 minutes.
c) Close the roller clamp on the administration set. Hang and then spike the blood bag. Adjust the height of the drip stand to ensure that a comfortable grip is achieved, squeeze the blood bag, open the roller clamp and tilt the drip chamber.

There are two very important issues that should be discussed at this stage and they can be reviewed while the filter is priming.

1. It is vital that the squeeze of the bag is maintained throughout the prime. If the squeeze is released, air will be entrained back into the filter from the drip chambers. It is not so important to have a strong squeeze, especially if it means that the nurse is getting tired. The key is to have a steady and continuous squeeze. If the nurses find this difficult, then a pressure infuser bag should be used to prime the filter. This can be left on throughout the transfusion and it could potentially prevent some of the slow flow problems later on.

2. It is vital that the filter is maintained in the vertical position while the drip chambers are inverted. Our leucocyte depleting filters have been designed so that they prime from the bottom to the top without having to invert the filter (unlike our competitors). However, if the filter is accidentally tilted there is the potential to leave pockets of air.

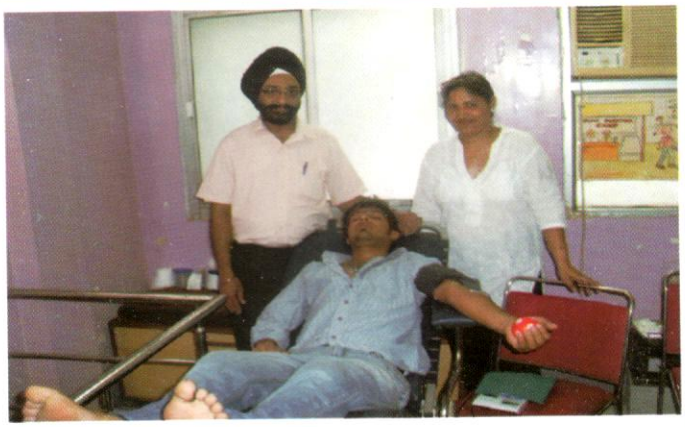
In addition:
Customers should be told that gravity priming is absolutely contraindicated. It has been noted, with filters that have been gravity primed, that significant amounts of air is left in the layers of the filter. This will contribute to slow flow problems. If the nurses find squeezing the bag too difficult, then once again, recommend that a pressure infuser bag can be used to ensure correct priming.

If, during the transfusion, flow stops or is too slow, the nurses should:

Raise head height of bloodbag,
Check patency of cannulae,
Check the volume in the bag. Occasionally, some bags contain more blood than others up to 100ml more. If the flow rate is set at 100ml/hr, for example, this can add at least another hour to the transfusion time. Whether the flow rate is increased to compensate is dependant on the clinical condition of the patient and will be decided by the nurses.

Published by: National Thalassemia Welfare Society (Regd.) On behalf of Federation of Indian Thalassemic.

Blood Donation Camps Organised at various MNC'S Institutions & Malls in Delhi-NCR



Cipla

Pioneers
in Thalassaemia therapy

Oral
Iron Chelator

Desirox

(Deferasirox – 250/500 mg Tablets)

Simple... Once Daily... Dispersible

Kelfer

Deferiprone-250 / 500 mg Capsules

World's First Oral Iron Chelator