FEDERATION OF INDIAN THALASSEMICS

NATIONAL THALASSEMIA BULLETIN

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The patient requires respect for his/her time, respect for the priorities of his/her life, and honesty on the part of the doctor. The patient hopes that the doctor will get out of her/his routine in order to help, accepting the patient's "good" and bad" days, their fears and uncertainties. The patient expects the doctor.....

Chris Sotirellis with his airplane
(he is a certified pilot)

Thalassemia Major, an aeronautical engineer & Vice President, UK Thalassemia Society

Thalassemia WE CARE

National Thalassemia Welfare Society
&
Department of Haematology AIIMS

Organises

6th National Thalassemia Conference

Sunday & Monday, 21st - 22nd November, 2010

in association with

IAP Delhi
Delhi Society of Haematology
Federation of Indian Thalassemics

at

Jawaharlal Nehru, Auditorium
All India Institute of Medical Sciences
New Delhi-110029

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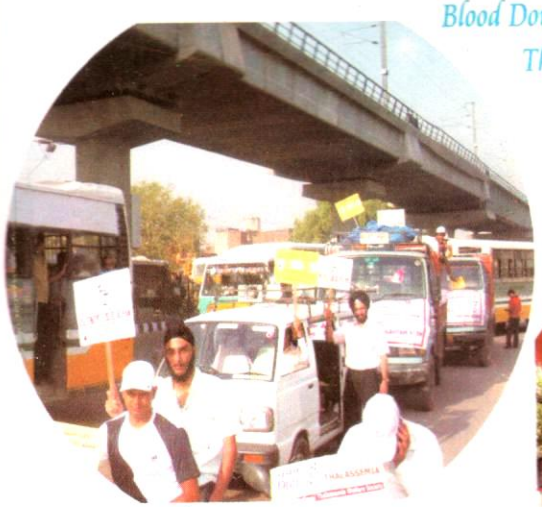
Blood Donation Camps held on 16th & 20th Jun at Vikas Puri and Thalassemia Awareness Rally organized by NTWS on 20th June'10



Mayor of Delhi Mr. Prithvi Raj Sawhney innaugrating Blood Donation Camp at society office on 20th June 2010 Mr Gautam Seth assisting him

Guests at NTWS Blood Donation Camp

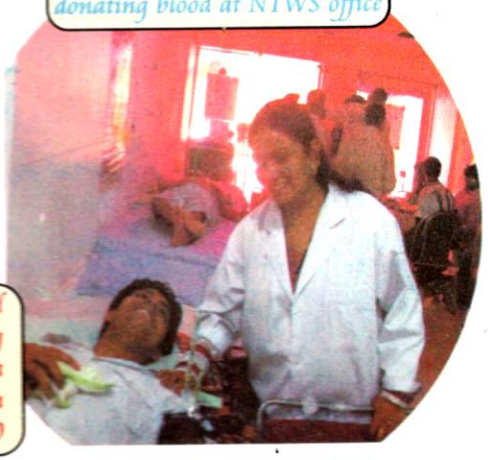
Mr. Anil Dubey , Dr. Arora, Mr. Prithvi Raj Sawhney and Mr. OP Arya at BDC 20th June 2010

NTWS Staff Rajesh Singh donating blood

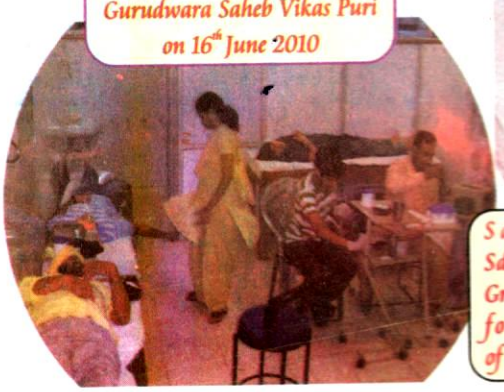
NTWS Staff Gagandeep Singh donating blood

Mr. Gautam Seth donating blood. Mr Surinder Singh encouraging him

1st time donor Nitin Tanwar donating blood at NTWS office



Blood Donation Camp at Gurudwara Saheb Vikas Puri on 16th June 2010



Sd. Jagdev Singh President and Sd. Rupinder Singh Secretary encouraging Granthi Sheb Vikas Puri C Block Gurudwara for donating blood on the occassion of Guru Arjun Dev Ji Martydom Day 16th Jun 2010

Editorial

पिछले संस्करण में आपने पढ़ा कि अहमदाबाद निवासी सपन शेट ने विपरीत परिस्थितीयों में (बचपन में ही उसके पिता उसे छोड़कर चले गये थे और उसकी माता ने अकेले ही सपन को न केवल अच्छी शिक्षा दी बल्कि उसके स्वास्थ्य का भी पूर्ण ध्यान दिया) पहले बारहवीं कक्षा में पूरे अहमदाबाद में अंग्रेजी विषय में प्रथम स्थान प्राप्त किया व फिर एम बी ए में तीन-तीन स्वर्ण पदक भी प्राप्त किये और अब एक बडी कम्पनी में उच्च पद पर प्रबंधक के रूप में कार्यरत है ।

इंग्लैड के एक व्यस्क थैलासीमिक डा. किस का फोटो उसके अपने विमान के साथ इस संस्करण के मुख पृष्ठ पर छपा है, वह एक प्रमाणिक पायलट तथा विमान उड्यन अभियंता है।

क्या आपने कभी सोचा है कि सपन व डा. किस की जीवन में सफल होने का रहस्य क्या है इनके अभिभावको ने आरंभ से ही इनको उचित चिकित्सा दी जिससे थैलासीमिया रोग इनकी उन्नती में बाधा न बनें।

किसी भी जीर्ण रोग जैसे थैलासीमिया में आवश्यक है रोगी जब छोटा हो तब उसके अभिभावक तथा बड़ा होने पर उसमें स्वंय भी रोग संबधी जानकारी प्राप्त करने की लालसा हो। इसके लिए आवश्यक है कि वो थैलासीमिया संस्था का न केवल सदस्य बनें बल्कि संस्था द्वारा छपने वाले पत्रों को ध्यान से पढ़े तथा विशेष रूप से संस्था द्वारा आयोजित विभिन्न सभाओं में शामिल हो कर स्वयं प्रश्न पूछकर अथवा दूसरे द्वारा पूछे गये प्रश्नो के उत्तर सुनकर अपनी शंका को दूर करें।

यहाँ यह जानना बहुत आवश्यक है कि किसी भी विषय पर प्रश्न अथवा शंका दिमाग में तभी आ सकती है यदि उसके बारे में कुछ पढ़ा अथवा सुना जाये। यदि आप अपने व्यवसाय के बारें में बाजार पर नजर न रखें जैसे आपके व्यवसाय संबंधी कौन कौन से नये उत्पाद आ रहे है अथवा भाव कितना कम या अधिक हो रहा है अथवा किसी विशेष उत्पाद का उत्पादन कम या खपत बड रही है तो आप अपने व्यवसाय में पिछड जायेंगे और यह प्रक्रिया आपको निरंतर करनी पड़ती है तभी आप आर्थिक तरक्की कर सकतें है।

इसी प्रकार यदि समय-समय पर आयोजित विशेष सभाओं, सम्मेलनों में आप भाग नहीं लेते तो थैलासीमिया की चिकित्सा में क्या नये परिवर्तन आ रहे है आप उससे वंचित रह जायेंगे और अपने बच्चों में रोग बढ़ने अथवा उससे होने वाले गंभीर दुष्ट परिणामों के स्वंय जिम्मेवार होंगें। बड़े होने पर आपके बच्चे ही आपको कहेगें कि आपने समय रहते उनकी उचित चिक्त्सिा नहीं की। एक बार एक अंग खराब हो जाये तो पुनः उसको पूर्वः स्थिति में लाना बहुत कठिन है। कुछ अभिभावक सोचते है कि इलाज तो चिकित्सक ने करना है तो उनको जानकारी होने से क्या लाभ। जैसे एक शिक्षक एक साथ 40-50 बच्चो को पड़ाता है परन्तु वहीं 5-10 बच्चे निपुण होते है जो स्वयं भी शिक्षा में ध्यान देते है। इसलिये इसी प्रकार आपके चिकित्सक के पास भी 50-100 रोगी हैं, वही रोगी अच्छा स्वास्थ्य प्राप्त कर सकते है जो स्वंय भी रोग व उसके इलाज के विभिन्न पहलूओं से अवगत हो।

आपको रोग के हर पहलू से अवगत कराने के लिए भारत वर्ष तथा विदेशो से वरिष्ठ चिकित्सक 21 व 22 नवम्बर को छठे राष्ट्रीय महासम्मेलन में रूबरू होगें। इस तरह के किसी भी स्वर्ण अवसर को कभी भी नहीं खोना चाहिये।

कुछ अभिभावको के अनुरोध पर रिआयतीं दरों पर पंजीकरण की तिथी 25 सिंतबर तक बड़ा दी गई है अतः इसका लाभ उठाने के लिए जल्दी से जल्दी पंजीकरण करवाये।

Dr. J.S Arora
General secretary

Transition of Patients with Thalassemia and sickle cell disease from paediatric to adult medicine

Based on a presentation given at the 2nd Pan European Conference on Hamoglobinpathies.

By Dr. Holger Cario Department of Paediatrics and Adolescent Medicine, University Hospital Ulm, Germany

Source TIF Magazine- April 2010

More than 30 years ago, the majority of chronically ill children did not survive in to adulthood. With the advent of innovative technologies and medical advances, many chronically ill adolescents- including patient with haemoglobinopathies- cross the threshold into adulthood every year. Successful transition of chronically ill adolescents from paediatric to adult medical care continues to be a challenging process. Often, the transitioning experience consists of an abrupt transfer, which leaves the youth unprepared for the movement to adult health care. Because adolescents and young adults with haemoglobinopathy are at risk of developing severe medical complications, obstacles that impede transition to adult care must be identified to promote an uninterrupted transfer.

The transition of patients with haemoglobinopathies from paediatric to adult health care is complex and multisided process. The consideration of the following "sides", or aspects, of this process is of particular importance for its successful management and, finally, for an optimal continuous medical care for patients with Thalassemia major (TM) or sickle cell disease (SCD).

1. Medical Treatment

This comprises all aspects of intrinsic medical treatment, i.e. treatment with regular medical drugs (for instance analgesics and hydroxycarbamide in SCD, chelation therapy and drugs for secondary complications in TM), emergency treatment, and transfusion in TM or exchange transfusion/ erythrocytopheresis in SCD. It is of particular importance for the patients' adherence and compliance, and thus for treatment success, that medical care for a specific disorder in both paediatric and adult health care is based on common standards. Depending on national or regional conditions, the degree of implementation of such common standards is currently varying.

2. Education and training of Medical staff

This aspect is very closely related to the first. **Apart from the central medical care provider, the paediatric or adult haematologist, many other persons involved in the medical care need adequate training to meet the needs of these complex disorders. This group comprises subspecialists such as cardiologists and endocrinologists, nurses, educators, psychologists, social workers and others. A very close collaboration of these caregivers is essential for a successful treatment.**

In countries where haemoglobinopathies affect primarily patients with a background of migration, and where migration occurred rather recently, patients only started to enter adulthood, and to look for treatment by adult health care services, during the last ten or fifteen years. Thus, adult health care providers inevitably had limited experience in the management of these rare disorders. In order to pass over knowledge and experience, not only is it important to have a close collaboration between different subspecialists and health care professionals within a medical care unit, but also a very close collaboration between paediatric and adult haematologists.

3. Health care Setting

The health care setting varies from country to country, sometimes even between regions within a country. For many patients, the transition from paediatric to adult care will be associated with transition form a rather familiar ambience within an in-patient clinic to an out-patient clinic focused on The care for self-managing individuals. Even patients treated in paediatric out-patient clinics will feel such fundamental change, since they got used to the ambience and to individual health care providers, particularly nurses and other supporting staff, knowing them for their whole life. Therefore, transition

to adult health care must include the careful preparation of patients to these changes to avoid frustration and retraction.

4. Adolescence and puberty

At the time of transition, patients usually are at the end of their puberty. Classic adolescent rebellion can be an added problem for patients with chronic illness. Actually, puberty certainly represents one of the most vulnerable periods in the life of each patients with haemoglobinopathy. Adolescents with Thalassemia begin to challenge the need to continue chelation treatment, even after the introduction of alternative medical drugs without the physical burden of deferoxamine. They stop adhering. Patients become aware of physical problem caused by their disease or its treatment. And puberty itself can be disturbed by hypogonadism caused by iron overload representing a major burden for affected patients. All these problems have to be considered within the transition process, which should follow a standardized plan but has to be realized in an individualized way. In addition to hypogonadism, other complications of iron overload, such as cardiac disease or diabetes mellitus, may occur in the same period. In these cases it has to be weighed very carefully where (in paediatric or adult medicine) treatment of such complications should be initiated. The ideal way, of course, would be the collaborative approach.

5. Social activities

At the end of adolescence, there are other issues besides the transition from paediatric to adult medical care that predominate the life of young adult patients with TM and SCD. These include professional training, job-hunting, love, family planning and others. In some countries, personal responsibilities for health insurance and the payment for medical care are associated with additional problem for the patients. These aspects should be included in a transition programme. Both paediatric and adult health care workers have to develop possibilities to provide continuous support concerning these question before, during, and after the transition.

6. The Families

The role of the family in the medical care of patients with haemoglobinopathies, and the transition process, varies depending on national, regional and ethnic conditions, but everywhere it is of great importance. During infancy and childhood, the families and the parents in particular guarantee adequate medical treatment of their children. In adult medicine, the individual patient with self-care responsibility is the immediate partner of the physician or sub specialist. With regard to this aspect, an abrupt care would certainly have an adverse effect on further treatment, adherence and compliance.

The influence of the parents may decrease during puberty. In the positive case, patients develop self-efficacy and self-care responsibility. In the negative case, the lack of compliance and adherence result in a long period of inadequate treatment, which can have even fatal consequences. Thus, patients education concerning their diagnosis, treatment and preventive measures, but also psychological and social support, are of central importance within this period. Parents need encouragement to handle this situation, to acknowledge the increasing personal responsibility of their children, and to settle into their new role as accompanying partner and supporter.

The transition of patients with haemoglobinopathies and other chronic disorder is not a one-off event, but a long-lasting process. Transition programmes must be developed in collaboration between paediatric and adult health care providers. They should consider the above-mentioned aspects, and therefore include the availability of common treatment standards, the collaboration within a multidisciplinary team and between paediatric and adult haematologists, the training of health care professionals, the education of the patient, the integration of the patient into decision-making, and the help for the families to strengthen their ability to support the patient in and after the transition process. The administrative handling of the transfer from paediatric to adult medical care should be planned in advance, including the transfer of relevant records. The timing of transfer should be flexible, depending on the patient's developmental and social background. Thus, based on a standardized programme, the transition process should be tailored for each individual patient.

Excerpts from Compliance, adherence, concordance The Patient's perspective: Dr Chris Sotirellis

Source TIF Magazine- April 2010

Reasons for non-adherence

Thalassemia patients are asked to comply with many treatments, including blood transfusions, chelation, treatment for hepatitis, bone disease, diabetes, heart, hormones, etc. It can feel as if life is reduced to "getting treatment" There is need to respect the patient's "normal life" priorities and the patient's time to fulfill them. Do even so-called centres of excellence respect these needs, for example by providing after-hours transfusion with proper staffing and other support to minimize hospital visits? Is there a willingness to work with the patient? The patient can easily be marginalized and seen as a burden to society, yet with the right care he/she can contribute enormously to society.

Do even so-called centres of excellence respect these needs, for example by providing after-hours transfusion with proper staffing and other support to minimize hospital visits? Is there a willingness to work with the patient? The patient can easily be marginalized and seen as a burden to society, yet with the right care he/she can contribute enormously to society.

Non-adherence can be intentional or involuntary. It may relate to the quality of information (Clarity, evidence, source) the impact of the regimen on daily life (costly, painful), the physical and mental capacity of the patient, or his/her social isolation, his/her ability to absorb more of the burden of uncertainty and treatment, or his/her self image. The treatment offered cannot be predicated solely on the doctor's views, but also by an understanding of the real burden on the patient's life. This understanding comes by "listening" to the patient, and not keeping everything on a clinical level.

What patients expect from their doctors

Patients with chronic conditions use reasoning and judgment to make decisions. In doing so, they must grapple with irreducible uncertainty concerning their life, including its duration and its content (career, having a family, paying off a mortgage, etc.). Medical practitioners often ignore these long-term goals and the uncertainties that affect the daily lives of patient. Yet the practitioner is the only "buffer" the patient has between science, the health services and the pharmaceutical industry. This is the real privilege doctors have, and their power and status derives from it, so they should value it and use it wisely. The doctor's motivation should always be clear in seeking the optimum for their patients and in their role of buffer between the patient, services and industry.

Environmental and social factors which influence the patient include the interpersonal relationship between the doctor and patient, as well as the quality of support from family members and friends. Most patients intuitively know their doctor's attitude and willingness to understand these things.

The patient requires respect for his/her time, respect for the priorities of his/her life, and honesty on the part of the doctor. The patient hopes that the doctor will get out of her/his routine in order to help, accepting the patient's "good" and "bad" days, their fears and uncertainties. The patient expects the doctor to share in these battles and be an ally, helping to reduce the burden of the disease and the treatment. Chris says: "The doctor must accept that I am more than just a Thalassemia patient: I am just as complex a being (if not more complex) than she/he is!"

Activities of National Thalassemia Welfare Society

Thalassemia SCREENING CAMP ON 30TH Jan 2010 at Gurudwara Gurunanak Darbar, Rajouri Garden

Thalassemia Screening camp was organized at Gurudwara Gurunanak Darbar, Rajouri Garden in association with Dr. Tejinder Singh. 52 samples were tested.

NTWS PICNIC RAIL MUSEUM ON 31 ST JAN 2010

This year due to bitter cold & dense fog our Thalassemia annual picnic got delayed. But as the Thalassemia Children wait eagerly & look forward for this picnic we organized the picnic on 31st Jan'10 at the Rail Museum, Chanakyapuri, New Delhi. It was a beautiful place to enjoy the picnic and around 200 thalassemia parents & children gathered that Sunday sunny morning. The children took the joy-ride in the toy train which passed through the gardens and tunnels where the big engines and boggies were displayed. The Rail Museum authority was also celebrating their museum day so they were showing children films & magic shows which our children enjoyed very much. Children also enjoyed scientific stalls put by rail authorities. Many Thalassemia patients from Rohtak also enjoyed the Picnic. Mr. D.B. Sharma took the lead and brought the thalassemia families of Rohtak & they also went for other sight seeing at Delhi. Lunch was served to all & return gifts were distributed to all the children. Children clicked their photographs posing along the trains & beautiful landscapes.

BIOOD DONATION CAMPS

NTWS organized a blood donation camp at SRF, LTD. Gurgaon. 33 units of blood were collected by AIIMS team.

NTWS organised a blood donation camp at Mc Donalds, Vikas Puri on 18th February 2010. Mc Donalds vikas puri put hard work and also sponsored the refreshment to the volunteer blood donors. The AIIMS blood Bank team collected 58 unit of blood.

NTWS organised blood donation Camp at Arora Polyclinic Vikas Puri on 21st February 2010 in association with Art of Living. The Baba Saheb Ambadkar Hospital, Blood Bank team collected blood. We are very thankful to whole team of Art of Living for their kind support and hard work they also sponsored the refreshment of volunteer blood donors. The blood bank team collected 49 units of blood.

NTWS organised blood donation Camp at ALCATEL, GURGAON on 24.02.2010 The DDU HOSPITAL team collected 53 units of blood.

NTWS organised Blood Donation camp on 3rd March 2010 at Guru Nanak Khalsa College, Dev Nagar. 100 units of blood were collected by AIIMS team.

Guru Nanak Dev Khalasa College Delhi University Dev Nagar honored Dr. Arora for his distinguished work in the field of Thalassemia and Monisha Gogoi for organizing voluntary blood donation camps, during their Annual Award function on 18th March 2010.

NTWS organised BDC on 4th March 2010 for the first time in SRF Bhiwadi. It was very successful camp where 101 units of blood were collected by blood bank of Baba Saheb Ambadkar Hospital, Rohini. 54 volunteers were screened for Thalassemia carrier status by CBC

NTWS organised a blood donation Camp at Bechtel, GURGAON The AIIMS HOSPITAL team collected 54 units of blood

NTWS organised a blood donation Camp at Smart Cube The AIIMS Blood bank team collected 70 units of blood. 41 samples were collected for Thalassemia Screening Test.

NTWS organised a day night blood donation Camp at Convergys Orchid on 21st and 22nd April 2010. Blood bank teams from GTB, LNJP, DDU Hospitals collected 52 units blood.

NTWS organised a blood donation Camp at Unitech Convergys on 23rd April 2010. The AIIMS team collected 17 units of blood

NTWS organized a blood donation & Thalassemia Screening Camp at Flour Daniel on 30th April 2010. It is very successful camp where AIIMS team collected 127 units of blood and 22 samples were collected for Thalassemia Screening Test.

NTWS organized a blood donation Camp at Ernst & Young, Gurgaon on 6th May 2010 The Red Cross team collected 104 units of blood

NTWS organised a blood donation Camp at Vatika Tower on 7th May 2010. The AIIMS team collected 69 units of blood

NTWS organized a Blood Donation Camp at Ernst & Young, Connaught Place on 11th May 2010. 32 units collected by Red cross blood bank team.

NTWS organized a Blood donation camp at Ernst &

Young, Gurgaon on 12th May 2010. 20 units blood collected by Red cross blood bank team

NTWS organised a blood donation Camp at AEGIS on 18th May 2010. The DDU team collected 17 units of Blood

NTWS organized a blood donation Camp at AEGIS on 19th May 2010. The Hindu Rao team collected 57 units of Blood.
NTWS organized a blood donation Camp at Convergys Agora on 28th May 2010. BSA Hospital blood bank team collected 50 units of blood

NTWS organized a blood donation Camp at CUSHMAN & Wakefield Pvt. LTD on 10th Jun 2010. The LNJP blood bank team collected 25 units of blood

On the occasion of Guru Arjan Dev Ji's Shahidi Gurupurab NTWS & Gurudwara Management organized a Blood Donation Camp at Gurudwara Singh Sabha, C- Block Vikas Puri on 16th Jun 2010. DDU team collected 49 units of blood.

National Thalassemia Welfare Society in collaboration with Vikas Puri Main Market Association & Yog Avam Manav Seva Sansthan organized THALASSEMIA BLOOD DONATION CAMP on Sunday, the 20th June, 2010 at Vikas Puri. While inaugurating the camp, the chief guest Mayor of Delhi Mr Prithvi Raj Sahni assured Dr. Arora that he will pursue with the MCD to buy a Mobile bus for blood bank of Hindu Rao Hospital, MLA Mr O.P. Babbar the guest of honour said that there is need to organize more blood donation camps. Councilors Mrs RajeshYadav & Mr Yash Pal Arya also graced the occasion.

The camp was preceded by a rally in the Vikas Puri. Mr Gautam Seth a senior social worker lead the rally. The rally started at 6:30 am from Arora Polyclinic KG-1 Vikas Puri passing through M block, C, A & D blocks to societies in D block & H block after covering G & J block culminated at KG-1 at 9:am. Rally stopped at markets & parks to encourage the people to donate blood.

AIIMS blood bank team collected 82 unit of blood

NTWS in association with Jail road market association organized a blood donation Camp at Shubham Banquet Hall, Jail Road on 20th Jun 2010. Enthusiastic efforts of Mr. Jiwesh Manuja and overwhelming support of Jail Road Market helped Red Cross blood bank team collecting 137 units of blood.

NTWS organized a blood donation Camp at Converges Atria on 24th Jun 2010. 100 units blood collected by AIIMS Trauma Centre

INTERNATIONAL THALASSEMIA DAY

NTWS observed International Thalassemia day at World of Wonders, NOIDA on 8th May 2010. It was cool pleasant day of this summer and around 550 Thalassemia families came together to enjoy the ITD at NOIDA. The day started with some magic shows. The high-tech rides overjoyed the Thalassemic families. All the rides were very fast & thrilling. It was lot of fun and frolic. Lunch was served, the food was very mouth watering.

NTWS PARTICIPATION WITH OTHER SOCITIES

Bareilly

Society for Thalassemia care & Control, Bareilly observed ITD at IMA blood bank, Bareilly. Mr Praveen Aron M.P and his wife Mrs. Supriya Aron Mayor of Bareilly were invited as Chief guest & guest of honour Dr J.S. Arora was also invited on this occasion. During inauguration Dr Arora thanked Mrs. Aron for fulfilling her last promise made during their joint meeting on National Thalassemia Day 14 Nov. 2009 for putting up hoardings on Thalassemia awareness in Bareilly. He also requested the mayor to provide free treatment to Thalassemic patients in Bareilly and help the society in creating awareness and organizing more blood donation camps. Mayor Mrs. Supriya Aron reiterated her commitment for Thalassemia and said that she will proactively work for the awareness of Thalassemia and ask her husband to arrange some money from his MPLAD fund for the treatment of Thalassemics. Blood Donation camp was also organized on this occasion. Dr. Arora also examined the patients and gave advice for treatment. Dr S.K Sardana & Dr. Mrs. I.J Sardana were the force behind this activity. They are the guardians of all the Thalassemics in and around Bareilly.

SUNFLAG HOSPITAL, FARIDABAD

Pahuja trust for Blood Disorders, alongwith Sunflag Hospital, Faridabad organized a CME on Thalassemia on Sunday, 7th March 2010. Nearly seventy Thalassemic children along with their parents attended this CME. Dr. J.S. Arora enlightened the parents about Transfusion Therapy in Thalassemia and stressed the need of maintaining pre-transfusion hemoglobin level above 10 gm/dl. Dr. V.P. Choudhry informed about iron overload caused by repeated blood transfusion and how to bring out this extra iron. Dr. Jagdish Chandra said that now with improved transfusion and chelation

therapy we have many Thalassemics entering adulthood. They have different problems like endocrine & bone disorders. If these are managed properly at right time Thalassemics can grow normally and live a fruitful life.

A Free Thalassemia checkup Camp was also organized after the CME. All the patients were also screened for HBsAg, Anti HCV, HIV, ECHO & Serum ferritin level. Dr. Choudhry, Dr. Chandra and Dr. Arora examined the patients and advised accordingly. Thalassemics were thankful to Dr. Chandra Prakash and Air Marshal (Retd) Bharat Kumar, board members of Pahuja trust and management of Sunflag hospital for providing excellent services at affordable cost.

Gwalior

At the invitation of Thalassemia Society Gwalior and IAP branch of Gwalior Dr. J.S.Arora and Dr. Dinesh Bhurani visited Gwalior on 21st February 2010. In the morning session a meeting was organized with patients and parents of Thalassemic children, in which Dr. Arora gave a overview on Thalassemia management while Dr. Bhurani gave a talk on stem cell transplantation. Both of them examined around 40 patients. Mr. Kanihya lal Bhambani president of Gwalior Thalassemia society exhorted the parents to become of members of society and cooperate with the society to improve the facilities in Gwalior. In the evening IAP branch of Gwalior organized a CME which was attended by around 40-50 pediatricians Dr. Bhurani gave a lecture on interpretation of CBC and Dr. Arora spoke on Hemolytic anemia.

Chandrapur

Mr. Hansraj Ahir MP of Chandrapur organized a meeting to study the feasibility of opening an ICMR Satellite Centre for Sickle Cell Anemia and Thalassemia at Chandrapur on April 18, 2010. Prof. V.M. Katoch, Secretary Department of Health Research, Govt. of India and Director General, ICMR, New Delhi, Prof. N.K.Mehra, HoD Histocompitability Lab AIIMS, New Delhi, Dr. K. Ghosh, NIIH, Mumbai, Prof. V.P. Choudhry, Dr. Raj D Mehra, AIIMS, Dr. Vijay Kumar, ICMR and Dr. J.S. Arora were invited to visit the site for the proposed ICMR Satellite Centre for Sickle Cell Anemia and Thalassemia, Chandrapur and discuss with District Health Officer and IMA, Chandrapur.

In the evening IMA, Chandrapur felicitated Mr. Hansraj Ahir, M.P for his contribution in development and enhancement of Medical Services. All the guest spoke on different aspects of Thalassemia, Sickle cell anaemia and other haemoglobinopathies.

Kota

Dr. V.P.Choudhry and Dr. J.S. Arora visited Kota at the invitation of Kota blood bank society. They examined around 50 Thalassemic patients and advised treatment. Prior to that they enlighten the parents about Transfusion therapy and need of adequate chelation.

A CME was also organized with IAP branch Kota. Dr. Choudhry gave a talk on Febrile neutropenia and Dr. Arora spoke on recent advances in management of Thalassemia. Dr. C.B. Das Gupta was the force behind organisation of this event.

Dibrugarh

Dr. Jishan Ahmed Secretary Thalassemia Welfare Society, Dibrugarh, organized a CME in association with Assam Medical College, Dibrugarh on 28th & 29th May 2010. On 28th evening Dr J.S. Arora gave an overview of management of sickle cell anaemia and Dr V.P. Choudhry talked on approach to pancytopenia including secondary bone marrow failure. Next day morning Dr V.P Choudhry spoke on Approach to Anaemia and Management of Thalassemia: Problems of the Adult Thalassemic and Monitoring of the Thalassemic patient. Dr. Arora covered Diagnosis of Thalassemia and Antenatal screening for Thalassemia.

A lot of enthusiasm was seen in Post lunch Interactive session with Physicians, Nurses, Parents & Patients. Department of paediatric, Medicine and blood bank overwhelmingly attended the CME on both days. Dr. R.K. Kotokey HoD Medicine made special efforts for the success of these activities.

छठे राष्ट्रीय थैलासीमिया सम्मेलन की रिआयती दर पर पंजीकरण की तिथी 25 सितंबर तक बड़ा दी गई है। जल्द पंजीकरण कराकर लाभ उठाएं।

National Consultation Workshop on Patient Safety, Auditorium of Telemedicine Department, SGPGI, Lucknow, 10-12 May 2010

Directorate General of Health Services, Ministry of Health and Family Welfare, Government of India organized a three-day National Consultation Workshop on Patient Safety at Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow from 10th to 12th May, 2010, from World Health Organization (WHO) country fund. The workshop was inaugurated by Dr. R.K. Srivastava, Director General of Health Services, on 10th May.

Patient Safety is prevention of harm to patients during medical care. Focus areas of this workshop were Hand hygiene, Surgical Safety, Adverse Event Reporting, Medication Safety, **Role of patient in Patient Safety** and developing Action Plan & Guidelines for implementation of Patient Safety in India.

In this workshop Patient Safety Experts, Medical Superintendents of Tertiary Hospitals, District Hospitals Director of Health Services/Head of hospital services, District CMO, Head of the Department of Government Medical College / Hospital etc. participated.

In view of experience and expertise, Dr. JS Arora was invited to deliver a lecture on **"Patient for Patient Safety"**, and participate in this workshop to finalize the guidelines for implementation of Patient Safety in the country. Patient for patient's safety (PFPS) initiative has been taken by WHO to involve patients in their safe & informed treatment. PFPS is close to our heart Patient's (Thalassemics) involvement is must in the treatment since they are always prone to various preventable risks factors during their treatment

Hospitality of Dr. Hem Chandra, HOD Hospital Administration, Sanjay Gandhi Postgraduate Institute of Medical Sciences, Lucknow was highly appreciated. Dr. Anil Kumar Chief Medical Officer (NFSG), Directorate General of Health Services welcomed the delegates and Introduced the participants.

Dr. Geeta Mehta, Health Technology and Patient Safety Unit, WHO SEARO Global and Regional Perspectives of Patient Safety Initiative.

ALL INDIA INSTITUTE OF MEDICAL SCIENCES
CENTRE FOR COMMUNITY MEDICINE (CCM)
"Health Promotion & Health Communication Unit"

Community Medicine Deptt of AIIMS organized **"5th Pre-Marriage Orientation Counseling for Happy Married Life" on 16 17 March, 2010** and **"6th Pre-Marriage Orientation Counseling for Happy Married Life" 31st July & 1st August, 2010** at Sushruta Seminar Room, CCM (Old O.T. Block, AIIMS). Dr J.S. Arora was invited on both the occasions to enlighten the participants the prevalence and need of screening. Genetic Disorders specially Thalassemia. All the participants were also offered free Thalassemia

News from Kerala

A long journey for a multiple noble cause

They traveled three thousand km by train taking three days and two nights to reach New Delhi, the capital city of India to attend 4th International conference on Thalassemia, 31st oct and 1st Nov 2009, New Delhi. **Actually they came to New Delhi not for attending the conference. They couldn't speak or understand English or Hindi, the national language of the country. Most members of them were Thalassemia afflicted patients and their parents. Some were other blood disorder patients like Sickle cell anemia, Hemophilia, Aplastic anemia and Leukemia.**

Kerala is a small state with 3crore population in the utmost southern part of India. Kerala is not only a role model state of health services in India but also a complete literacy state in the nation. In the tourism map it is known as God's own country. In Kerala near about fifty percent of population belong to Hindu religion community. Above 20% are Christians rest of the above 25% are Muslims.

One of the major achievements in health sector is the low child mortality rate. But this phenomenon rises the morbidity rate of children same as the developed countries. But unlike the developed countries Kerala has no facilities to prevent or to avoid this like morbidity rate by using new technologies like antenatal diagnosis. These pathetic situation causes to raise various kinds of hereditary disorder disease like Thalassemia, Sickle cell

Tushar singing a song on the occasion of World Blood Donar Day

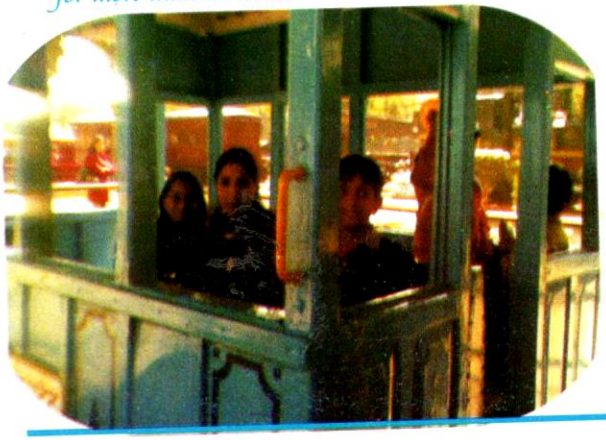
Dr JS Arora with Dr. Kabita Chaterjee , Dr.Veena Dhoda and Dr. Lalita Prashad at World Blood Donar Day 14 June 2010

Dr J.S. Arora receiving medal from MS GTB Hospital for donating blood for more than 50 times (Total 63), Dr. Bharat Singh Director State Blood Transfusion Council & HoD Blood Bank GTB Hospital taking out Certificate

Dr. Arora recieving appreciation award on behalf of NTWS for organising maximun number of blood donation camps in the capital

Mr Surider Singh recieving appreciation certificate on World Blood Donor Day for donating blood for more than 50 times

Dr JS Arora addresing the audience on World Blood Donors Day at UCMS& GTB Hospital



NTWS Team at World Blood Donar Day 14th June 2010

Thalassemia Aw
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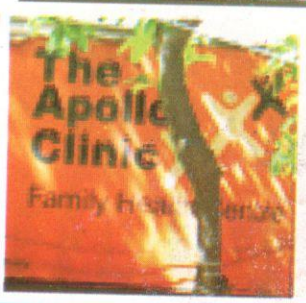
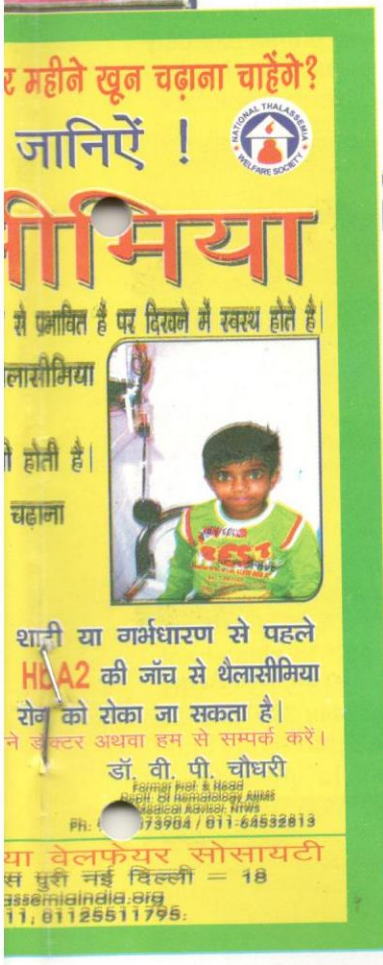
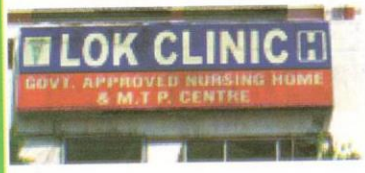
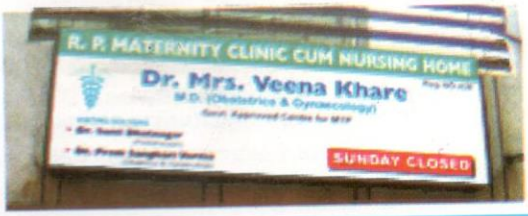


vareness Boards
Care Centers and Many More



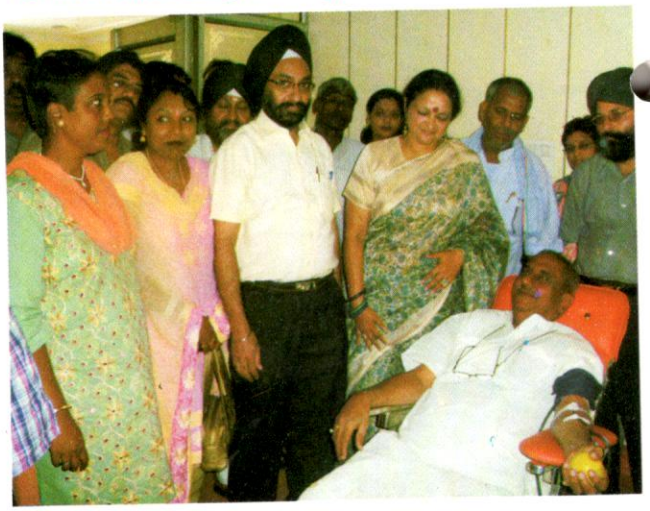




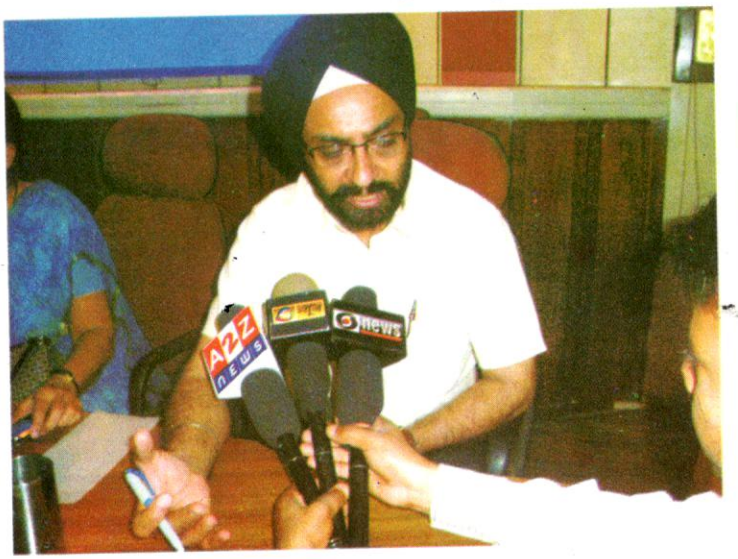
Dr. J.S Arora and Dr. VP Choudhary on the dias during the CME at Assam Medical College Dibrugarh

Sitting Left to Right Dr. Ahmed, Dr. Madhu Choudhary, Dr. VP Choudhary, Dr. Jishan, Dr. Kukrety And Dr. JS Arora alongwith medical doctors from Assam Medical College Dibrugarh

Dr. JS Arora addressing the audience at Assam Medical College Dibrugarh



Dr. Arora alongwith Mayor of bareily Mrs Supriya Aron at a Blood Donation Camp on ITD 8th May 2010 at IMA Blood Bank Bareilly.



Dr. Arora adressing the press at bareily ITD 8th May 2010

Dr I J Sardana & Dr Arora examining thalassemia patients at Bareily on the ocaasion of International Thalassemia Day 8th May 2010

anemia, Hemophilia and different kind of birth defects. In Wayanad, a hill district of Tribal people in north Kerala alone about five thousand persons are suffering from sickle cell disease among the tribal. Twenty thousand carriers among the tribal are the major threat in the health sector in the future years in hereditary disease.

Even though the prevalence of blood disorder patients is very high in north Kerala especially in Malabar region no sufficient facilities are available in hematology check up and no service of hematologist in this state.

Blood patients protection council is an organization of acutely blood disorder patients like Thalassemia, Hemophilia, Leukemia, Sickle cell anemia and Aplastic anaemia. Their parents have been fighting for the better treatment, life saving drugs and vital right of these patients for the past fifteen years. For achieving the birth right of patients many agitations were organized like road blockade including a state Secretariat march by traveling 800 km by BPPC. But the Govt. received a stubborn position against the patient's demand. That was the one reason compelling the patients to travel to New Delhi by declaring a parliament march.

They raised slogans demanding better treatment and life saving drugs for acutely ill patients and demonstrated towards the Indian parliament on 29th oct 2009. The patients raised 10 point demands including the set up of an antenatal screening facilities at Calicut medical college hospital. 1.5 crore people are dependent on this hospital for better treatment in Malabar area and some part of Karnataka and Tamilnadu state. Near about 100 blood disorder patients and their parents took part in the parliament march. Delhi police blocked their march with barricade at Jantar Mantar, New Delhi. The march was organised by Blood Patients Protection Council under the leadership of Kareem Karassery, the Gen. convener of BPPC.

Tom Vadakkan, Secretary, Indian National Congress, the ruling party of India inaugurated the march. Kareem Karassery, Gen; Convener of Blood patients' Protection Council took out the key note address. Dr. P. M. Kutty, president Malabar THAS Society, P.C Kishore, Ashraf Athikkode, M.V.Abdul Azeeze and K. Sunitha Kumari also spoke

After the march the agitated team rushed to All India Congress Committee Office New Delhi. Patients and their parents expressed their grievances and the miseries due to lack of expert treatment, life saving drugs and other ill feelings before the eminent leaders and office bearers of the ruling party (AICC) of India.

Dr. Shakheel Ahmed spokesperson of the ruling party took out an elaborate press conference with the blood disorder patients and their parents from Kerala at AICC office. AICC Secretary Tom Vadakkan was also present in the crowded press conference. Dr. Shakheel Ahmed assured the acutely ill children and their parents from Kerala that the Govt. OF INDIA and the health and family welfare department will take urgent step to solve the 10 points demand raised by BPPC Kerala. They would bring the matter before the Hon'ble president of Indian National Congress committee Ms. Sonia Gandhi, central health Minister Sri. Ghulam Nabi Azad and AICC gen. secretary Mr Rahul Gandhi immediately. Only after achieving the assurance from the ruling party head quarters the patients and the parents returned from there.

The following day patients visited all monumental and significant tourism places in Delhi with their parents including the inside of Indian Parliament. Some office bearers of BLOOD PATIENTS' PROTECTION COUNCIL and Malabar THAS Society from Kerala were the delegates of conference. Due to the medium of conference and instructions was English/Hindi only rest of the members of this team couldn't register or attend in the conference same day they went to Agra and visited the Taj Mahal, one of the seven wonders of the world and other world heritage monumental like Agra Fort well known pilgrimage center like Mathura Temple etc. This journey was very happy for the children, who are suffering from fatal disease. School going student and their parents also enjoyed this trip as great relief and relax from their painful fate of prolonged life.

Patients and their parents returned from NewDelhi after a week long tremendous mission and good feelings with significant knowledge to their home state by train. We reached on fifth of october without any inconvenience and harmfulness to and fro journey was very happy with songs, jokes and dance of children. When we reached at Calicut a letter from Union Health Minister Sri. Ghulam Nabi Azad reached to Calicut. He said in his letter that he has examined the matter and would get back to us shortly. In another letter send by the secretary of All India Congress Committee (AICC) Sri. Rama Chandra Kundiya MP mentioned that Ms. Sonia Gandhi, President, AICC, forwarded the application submitted by BPPC to the health minister. Among this responses a breakthrough occurred in the health field of Kerala. Ms. P. K. Sreemathi, health minister of Kerala declared that all acutely ill patients below eighteen years old will get free treatment from Jan 2010 without considering their income. Besides central health minister informed the local MP Sri. M.K. Ragavan that he sanctioned 3 crore rupees for the development of oncology department MCH Kozhikkode with immediate effect. The annual central budget allocated a considerable amount for the development of public health sector.

Blood disorder Patients and their parents believe that the multi purpose Journey of them to New Delhi was not spoiled. They are expecting more from the Central and State Government.

Kareem Karassery
Gen: Convener,
Blood Patients Protection Council Kerala,
Phoenix Sailam, P.O.Karassery, Via. Mukkam
Calicut. 673602
Email: bppckerala@gmail.com

अजमेर रीजन थैलेसिमिया वेलफेयर सोसायटी

अजमेर रीजन थैलेसिमिया वेलफेयर सोसायटी के तत्वाधान में दिनॉक 15-11-2009 से 29-11-2009 तक जन जागरूकता पखवाडा मनाया गया

22 नवम्बर 2009 के दिन प्रातः 9:30 बजे से दोपहर 3 तक आदर्श सी. सै. स्कूल न्यू मेजेस्टिक सिनेमा के पास, अजमेर में निःशुल्क चिकित्सा शिविर का आयोजन किया गया। उक्त शिविर में सोसायटी के अर्न्तगत रजिस्टर्ड समस्त कैरियर, इन्टरमीडिया एवं थैलसिमिया मेजर से पीडित 125 थैलसिमिक बच्चों के स्वास्थ्य की गहन जॉच की गई।

श्री ईश्वर पारवानी महामंत्री अजमेर रीजन थैलेसिमिया वेलफेयर सोसायटी के अनुसार उक्त शिविर का शुभारम्भ डा. वी.के. खन्ना आचार्य शिशु रोग विभाग, सर गंगा राम अस्पताल नई दिल्ली के कर कमलों द्वारा किया गया। समारोह की अध्यक्षता डा. अनिल जैन ने की तथा डा. आलोक गर्ग, डा. पंकज तोष्नीवाल एवं श्री प्रकाश जी विशिष्ट अतिथी थे। समस्त अतिथियों का स्वागत सोसायटी के अध्यक्ष श्री अमित अग्रवाल, पखवाडे के संयोजक श्री विजय निचानी, राजेश मंघवानी, श्री राजू मेंघानी, श्री हरमिन्दर सिंह छाबडा, श्री हितेष मलूकानी के द्वारा माल्यार्पण एवं शाल ओढा कर किया गया।

डा. वी.के. खन्ना के द्वारा थैलेसिमिक बच्चों के स्वास्थ्य का गहन परीक्षण भी किया गया। डा. अनिल जैन सह आचार्य जलाने चिकित्सालय अजमेर, डा. पंकज तोषनीवाल तथा डा. सतोष के द्वारा सहयोग प्रदान किया गया । उक्त शिविर में अजमेर, भीलवाडा, टोंक, नागौर, किशनगढ, ब्यावर आदि सम्पूर्ण विभाग के थैलेसिमिक बच्चों का परीक्षण किया गया। साथ ही 15 नवम्बर 2009 को पखवाडे के अन्तर्गत आयोजित जॉच शिविर में डा.खन्ना ने समस्त थैलेसिमिक अभिभावको को थैलेसिमिया रोग के उपचार एवं बचाव से अवगत कराते हुए बच्चों को सही समय पर आयरन चिलेशन देने तथा बिना लोहकण की खाद्यसामग्री भोजन में देने का सुझाव दिया। (अपने अध्यक्षीय व्याख्यान में डा.खन्ना के द्वारा 15 साल से छोटे बच्चों को बोनमेरो ट्रान्सप्लांट कराने हेतु अभिभावको को प्रेरित किया तथा उक्त बोनमेरो भाई-बहन के बोनमेरो से मिलान कराने की सलाह दी क्योंकि उसमें सफल आपरेशन का अनुपात 90 प्रतिशत होता है। डा. खन्ना ने थैलेसिमिक बच्चो की जांचे प्रतिवर्ष थाईराईड एच.आई.वी डैक्सा टेस्ट (15 वर्ष से अधिक आयु के बच्चों की) हैपेटाइटिस सी का टैस्ट अनिवार्य रूप से करवाने की सलाह के साथ साथ प्रत्येक बच्चे को प्रतिमाह सीबीसी तथा प्रत्येक 3 माह में एस.जी.टी., सीरम केटिनाईन एंव सीरम फेरेटिन टैस्ट कराने की भी सलाह दी। उन्होंने लोहकण विसर्जन की सबसे अच्छी दवाई केल्फर केप्सूल को बताया साथ ही नोवार्टिस कम्पनी की असुनरा टेबलेट एंव सिपला कम्पनी की डेजीरोक्स टेबलेट को भी अच्छी चिलेशन थैरेपी बताई।)

उक्त शिविर को सफल बनाने हेतु संयोजक श्री विजय निचानी, उप संयोजक हरमिन्दर सिंह छाबड़ा एंव सोसायटी के पदाधिकारी श्री अमित अग्रवाल, श्री जेठानन्द मलूकानी, श्री सूर्य प्रकाश टाक, श्री ईशारत अली, श्री रंजीत सिंह, श्री जगदीश चेलानी, राजेश मंघवानी एवं कमल पंजाबी द्वारा सहयोग प्रदान किया। जन जागरूकता पखवाड़े का समापन समारोह दिनॉक 29-11-2009 रविवार के दिन प्रातः 10 बजे से दोपहर 2:00 बजे तक संत कंवरराम धर्मशाला, पड़ाव अजमेर में थैलेसीमिया पीड़ित बच्चों की डांस एवं ड्राइंग प्रतियोगिता के आयोजन के साथ किया गया।

पुरस्कार वितरण समारोह का मुख्य अतिथ्य श्रीमान ज्ञानदेव आहूजा सरंक्षक एवं विधायक रामगढ़ अलवर के द्वारा किया गया अध्यक्षता प्रो. वासुदेव देवनानी विधायक अजमेर उत्तर, एवं श्री नरेन साहनी भगत अध्यक्ष सेन्ट्रल सिंधी पंचायत एवं समाज सेवी के द्वारा की गई। विशिष्ठ अतिथि कुमारी प्रवीन एवं नानकराम जयसिंघानी तथा धर्मू परवानी थे। मुख्य अतिथ्य के उद्बोधन में श्री ज्ञानदेव आहुजा ने पूरे प्रदेश के थैलेसीमिक बच्चो को आयरन चिलेशन की दवाई फ्री कराने हेतु माननीय मुख्यमंत्री के समुख प्रोजेक्ट बनाकर प्रस्तुत करने एवं तत्काल प्रभाव से दवाई हेतु बजट आवटिंत कराने हेतु सकारात्मक प्रयास करने का भी आश्वासन दिया। श्री वासुदेव देवनानी ने अपने उद्बोधन में बच्चों की दीर्धायु की कामना करते हुए संयुक्त प्रयासो से बच्चों को आयरन चिलेशन की दवाई सरकार से पूर्णतयाः फ्री कराने हेतु आश्वस्त किया। अध्यक्षीय भाषण में श्री नरेन साहनी ने थैलेसीमिया पीड़ितो की सेवा कार्य मानव सेवा का सर्वश्रेष्ठ कार्य बताया तथा बच्चो की दीर्घ आयु की कामना की ।

ड्राईंग प्रतियोगिता प्रातः 10 से 12 बजे तक आयोजित की गई तथा दोपहर 12 से 1:30 बजे तक डांस प्रतियोगिता आयोजित की गई। उक्त प्रतियोगिता में कुमारी दीपिका गुप्ता, वर्ष 12, प्रथम, कुमारी रद्धि अग्रवाल वर्ष 8 - द्वितीय तथा कुमारी हर्षा, वर्ष 4 तृतीय रही तथा डांस प्रतियोगिता में थैलेसिमिया जूनियर एवं सीनियर वर्ग में बच्चों ने बड़े ही आकर्षक रूप गीतों की सजीव प्रस्तुति की गई। डॉस प्रतियोगिता में जूनियर वर्ग में कु. सानिया टाक प्रथम, रिद्धी अग्रवाल द्वितीय, मुस्कान तृतीय तथा सीनियर वर्ग में हितेष मलूकानी प्रथम, दिपिका अरोड़ा द्वितीय, दीपिका गुप्ता तृतीय पुरस्कार विजेता रहे। यह वर्ष केयर एण्ड प्रीवेन्शन वर्ष के रूप में मनाया जा रहा है जिसका पुरस्कार प्रथम श्री विजय भट् द्वितीय शिवराज चौधरी, तथा तृतीय जगदीश चेलानी को दिया गया।

अन्त में सोसायटी के अध्यक्ष अमित अग्रवाल ने समस्त अतिथियों, अभिभावकों एवं बच्चों का हार्दिक आभार व्यक्त किया। पूरे पखवाड़े के दौरान श्री ईश्वर पारवानी महामंत्री, श्री विजय निचानी संयोजक्तव एवं हरमिन्द्रर सिंह छाबड़ा के उपसंयोजक्तव में सम्पूर्ण सम्भाग में थैलीसीमिया रोग के प्रभावी रोक एवं बचाव का सघन प्रचार प्रसार किया। साथ ही राजकीय महाविद्यालय किशनगढ़ में भी थैलेसीमिया रोग से बचाव एवं उपचार एवं स्वेच्छिक रक्तदान पर व्याख्यानमालाएं आयोजित की गई।

Patient Corner

Hi Friends,

I am Prateek Arya pursuing Chartered Accountancy Course from ICAI, Delhi. I am the one who starts his day thanking god for the beautiful life he has given me & to shower his blessings to all of us. I start my day taking blessings of my Ma & Pa who see their childhood in me every day. I am the most pampered child of my three sisters. My Elder sister had done MBA, other one is Chartered Accountant & youngest one is doctor. Today, I want to share my story with you. Why I am in this world....for whom I am in this world...there is always a reason behind everything God plans for us.

I was born on 15th February, 1993, a boy after three girls in the family, which provided everyone with a bigger reason for rejoicing my birth. Best wishes came pouring from all corners of the world. Celebrations were on but as no joy lasts forever neither did this. My health started deteriorating as I started turning pale & weak. My parent's got worried and a long process of doctor consultation, tests and medication commenced. My parent's world came falling when they came to know that I am a 'Thalassemic child'. I would like to request to everyone who is reading this article to spread message about awareness of Thalassemia as it can prevent the number of Thalassemic Childs in India. Our government is silent but why should we??????????? We are the actually the sufferers & can understand the pain of parents.

Nevertheless my father always had a hope inside him and I was taken to Homeopathic, Nadiveth, Aurvedic, Acupressure, Spiral therapy & least but not the last he also learned Reiki for me. Today also he is hoping for the miracle to happen in Allopathy. Ever parents tried their best for their children but nobody can win with the destiny. At the age of 10 I was been taken to ICU & doctors lost their hope in me & but not my family. Because of the needles prick ever day I never started the Chelation therapy ' Desfaral'. With increasing blood transfusion my serum ferritim raised above 15,000 & then it gave rise to problems such as heart function drastically dropped down to 25%, I was dyspneic for hours, my parents rushed to doctors across the cities but nobody was ready to handle my case. At last, Dr. JS Arora gave hope to my parents and after a month struggling in ICU with day long infusions & oxygen cylinders, I was stabilized with oral Kelfar & Desfaral. Since my childhood I had never taken a tablet & after this I had started 15-20 pills a day as there was no option left for me to survive & fight with the problems.

But the problems never stopped, just 2 days before my 8th Board exams, I got tingling and numbness in my fingers. My teacher advised to drop the year but the Doctors were after my exams.

Due to positive & optimistic nature of my parents , I got the treatment and was able to sit for my exams & scored the 1st Division.

I have always been the toppers in the class & among the favorite student of the teachers. In 12th standard I topped my School with 90%. It gave me the first chance to face interview with the local press. Today, my parents feel proud of giving birth to me.....The days has changed, I wake up early morning spend hrs in coaching & then came back home with tiring face but on seeing the smile on my Mom's face made me energetic & give me power and strength to go to library to spend the rest of the day. After 10-15 days I have to go to Delhi for getting my blood transfusion with my parents. Missing a day of coaching is a pain but where there is a hope, there is a will. With the support of my teachers & friends I cover the lessons which I missed. I want to give my wishes to all my friends. Nothings is impossible but it might be difficult to achieve but with the blessings, wishes and support of the elders nothing remains impossible if it's done with strong will & high spirit.

I think which means most important is that even after having awareness in my family & relatives one of my cousin's child is diagnosed as Thalassemia.

It's a humble request to spread the awareness of Thalassemia & get the test done which cost just a single prick but save the pain to get the needles pricked throughout the life of your children.

I would like to thank Dr. JS Arora who is always there to support the Thalassemic children and is joined with Thalassemic Society with a motive to help the poor n needy people.

I AM PRATEEK

I AM THE REFLECTION OF PROVIDENCE
AND VEST IN THE COAT OF HUMBLENESS;
I AM MYRIAD MY PARENTS FORSEE
AND CHERISH MY DREAMS IN MY DEEDS.

I HEARD A FABLE FROM MY SISTERS'
SWEET IS MY HOPE, INFINITE IS MY MASION;
I READ IN THE EYES OF MY ELDERS'
PRATEEK IS A FEATHER OF THEIR VISION.

I DO NOT REST TO RUST FOR
UNQUENCHABLE THIRST OF VIRGIN WORLD;
HATSOEVER IS WRITTEN ON MY SCROLL,
THE GODS FIND AND SHALL FIND ME BOLD.

I SAIL MY LIFE EVERYDAY
AND SATIATE MY NIGHTS;
I AM ONE LIKE THEE
SWIFT, TAMELESS & BRIGHT.

6th National Thalassemia Welfare Conference Sun, Mon 21, 22 Nov.2010

REGISTRATION FORM

Title-Doctor/Parent/Patient/Other: _____

Name: _____

Name of Additional Person Person (if applying): _____

Age/Sex _____

Address _____

_____

_____ Pin _____

Phone: _____

Fax: _____

E-mail: _____

Accommodation Required: Yes/No

Category: A B C

No. of Accompanying Persons: _____

Arrival Date & Time: _____

Departure Date & Time: _____

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

D.D./Cheque No : _____ Dated _____

Drawn on: _____

For Rs: _____ Rupees _____

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

Signature Date

NOTE:

1. **Registration form can also be downloaded from website :- www.thalassemiaindia.org**
2. **Registration form can be photostated.**
3. **No cancellation is allowed once the registration fee/accommodation charges are paid.**
4. **No refund /adjustment will be entertained under any circumstances.**
5. **Dully filled form be detached and sent to conference Secretariat along with requisite cheque.**

on the pressing demand by Patients/Parents Organising committee has agreed to extend concessional registration upto 25-Sep-2010

General information

Registration: Registration is open to all.

Registration Fees:

Early Birds Upto ~~31st Aug'2010~~ (20-Sep-2010)

Single	Rs. 300.00
Additional	Rs. 200.00
Patient	Rs. 100.00

Late Comers Upto 15th Nov'2010

Single	Rs.450.00
Additional	Rs.300.00
Patient	Rs.150.00

After **15th Nov'2010 & Spot Registration:**

Single	Rs.600.00
Additional	Rs.400.00
Patient	Rs.200.00

The Registration fee includes: Attendance to all sessions, literature, conference kit, lunch and tea/coffee for both the days.

Accommodation:

Limited accommodation will be made available on prior intimation and full advance payment **before 30th Sep'2010.**

Accommodation Charges:

Class A Rs.5000/-approx.per day
Class B Rs.2500/-approx.per day
Class C Rs.1500/-approx.per day

Mode of Payment:

Please send registration fee by Demand Draft/Cheque or Cash against receipt to the Conference Secretariat.

Drafts/Cheques should be drawn in favour of **"6th National Thalassemia Conference"** payable at Delhi/New Delhi. Please add Rs.50/- for outstation cheques.

NOTE:

Children below 15 are not allowed.
Persons registering as additional members will NOT be provided Conference Kit.

Conference Secretariat:

Dr. J.S. Arora,
Organising Secretary
6th National Thalassemia Conference
KG-1/97, Vikas Puri, New Delhi-18
Tel: 25511795, 796 Mb.: 9311166710,711,712
Fax: 91-11-28543576
Email: ntws08@gmail.com, drjsarora@bol.net.in
URL:-www.thalassemiaindia.org

PROGRAMME
WORKSHOP
on
Prenatal Diagnosis of THALASSEMIA in Pregnancy

on Saturday 20th Nov'2010

at

LT-2 teaching Block, AIIMS,
Ansari Nagar, New Delhi 110029

Thalassemia Screening in Pregnancy	11:00 am to 11:20 am
Counselling of prenatal diagnosis	11:20 am to 11:40 am
Live demo CVS & Cordocentesis	11:40 am to 01:20 pm
Case discussion & interactive session	01:20 pm to 02:00 pm
Lunch	02:00 pm

Dr Deepika Deka
Chairperson
Professor
Deptt. of Obs. & Gynae
AIIMS

Dr J.S Arora
Organising Secretary
General Secretary
NTWS

Maximum registration is limited to 30 persons only on first come first serve basis.

PROGRAMME
WORKSHOP
on
Challenges in Diagnosis of THALASSEMIA

on Tuesday 23rd Nov'2010

at

Deptt of Haematology,
1st floor IRCH Building, AIIMS,
Ansari Nagar, New Delhi 110029

Screening of Thalassemia	10:00 am to 10:30 am
HbHPLC	10:30 pm to 11:00 am
Hands on training	11:00 am to 02:00 pm
(CBC, Hb Electrophoresis, Hb HPLC, Cord blood HPLC for antenatal diagnosis, Molecular studies)	
Lunch	02:00 pm

Dr Renu Saxsena
Chairperson
Prof & Head
Deptt. Hematology,
AIIMS

Dr J.S Arora
Organising Secretary
General Secretary
NTWS

Maximum registration is limited to 20 persons only on first come first serve basis.

REGISTRATION FORM FOR WORKSHOP

Name.....Qualifications.....Designation.....

Hospital/Clinic Address.....

Ph.No..... Mobile No.....

Residential Address.....

Ph.No.....Email.....Cheque/DD.No.....

Dated.....Bank.....Branch.....

Tick one

Prenatal Diagnosis of THALASSEMIA in Pregnancy, Saturday 20th Nov'2010 ☐

Challenges in Diagnosis of THALASSEMIA, Tuesday 23rd Nov'2010 ☐

Registration Fees : Rs.300 (each workshop)
: Separate registration for conference as per brochure

Mode of Payment :

Drafts/Cheques should be drawn in favour of **"6th National Thalassemia Conference"** payable at Delhi/New Delhi. Please add Rs.50/- for outstation cheques. *Please write on back of the DD/Cheque.*

- ***"for workshop-*** **Prenatal Diagnosis of THALASSEMIA in Pregnancy"**
- ***"for workshop-*** **Challenges in Diagnosis of THALASSEMIA"**

Conference Secretariat:
National Thalassemia Welfare Society
KG-1/97, Vikas Puri, New Delhi
Tel: 25511795, 796, 9311166710,711,712
Fax 91-11-28543576
Email: ntws08@gmail.com,
drjsarora@bol.net.in
URL:- www.thalassemiaindia.org

Please send registration fee by Demand Draft/Cheque or Cash against receipt to the Conference Secretariat.

Last Date of Registration for workshop is 31st Oct'2010

TENTATIVE Programme

6th National Thalassemia Conference

Sunday 21st Nov. 2010

During Last 5 minutes of each Lecture, summary will be given in Hindi

SESSION I Prevalence & Protocol

S.no	Topic	Speaker	Timings
	Epidemiology of Haemoglobinopathies in India	Dr K. Ghosh	9:00 to 9:30
	Difficulties in maintaining Haemoglobin Level & Leuco-depletion	Dr V.P. Choudhry	9:30 to 10:00
	Protocol for Thalassemia monitoring	Dr Jagdish Chandra	10:00 to 10:30
Inauguration 10:30 to 11:30			
SESSION II	**Blood Safety**		
S.no	**Topic**	**Speaker**	**Timings**
	Hepatitis C Exposure and treatment	Dr Shiv Sarin	11:30 to 12:00
	Precaution and Management of HIV	Dr.	12:00 to 12:20
	Blood Safety Newer Technologies	Dr.	12:20 to 12:40
SESSION III	**Iron Chelation**		
S.no	**Topic**	**Speaker**	**Timings**
	Conventional Chelation Therapy	Dr Rajiv Bansal	12:40 to 1:10
	Indian experience in Defrasirox	Dr V.P. Choudhry	1:10 to 1:40
	LUNCH 1.40 PM – 2.30 PM		
SESSION IV	**Endocrine & Cardiac**		
S.no	**Topic**	**Speaker**	**Timings**
	Bone Disorder	Dr Ratna Chatterjee	2:30 to 3:00
	Diabetes & other endocrine issues	Dr. Nikhil Tandon	3:00 to 3:30
	Growth and puberty issues	Dr Ratna Chatterjee	3:30 to 4:00
	Cardiac problems	Dr Anita Saxena	4:00 to 4.20
SESSION V	**Thalassemia Intermedia**		
S.no	**Topic**	**Speaker**	**Timings**
	Thalassemia Intermedia and Hb E disease	Dr Sarmila Chandra	4.20 to 4:50
	Splenectomy Pre and Post	Dr Tulika Seth	4.50 to 5.10
	Management of RBC alloimmunisation in multitransfused thalassemics	Dr M Mahapatra	5.10 to 5.30
QUESTION ANSWER SESSION		**5:30 to 6:00**	

Sunday 21st Nov. 2010

Parallel - DOCTOR's Session

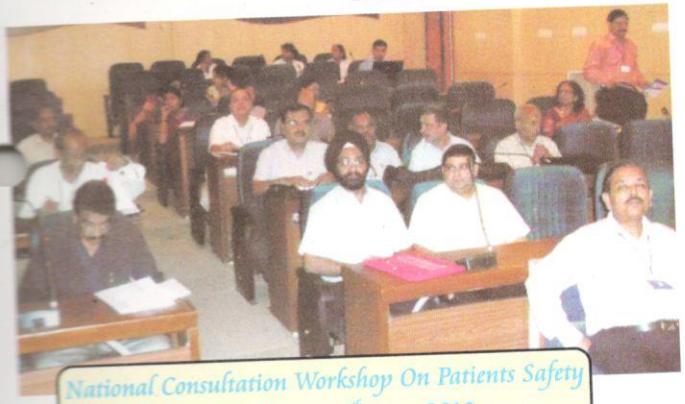
SESSION I			
S.no	**Topic**	**Speaker**	**Timings**
	Molecular Diagnosis of Thalassemia	Dr. S. Fucheron	9:00 to 9:30
	Challenges in Diagnosis of Thalassemia	Dr V.K. Khanna	9:30 to 10:00
	Transfusion Therapy including Leucodepletion	Dr A.P. Dubey	10:00 to 10:30
Inauguration 10:30 to 11:30			
SESSION II	**Blood Safety**		
S.no	**Topic**	**Speaker**	**Timings**
	Protocol for Thalassemia monitoring	Dr Jagdish Chandra	11:30 to 12:00
	Iron overload & Conventional Iron Chelation	Dr Sunil Gomber	12:00 to 12:30
	Indian experience in Defrasirox	Dr V.P. Choudhry	12:30 to 1:00
	Endocrine Problems	Dr Ratna Chatterjee	1.00 to 1.30
	Stem Cell Transplantation	Dr Dinesh Bhurani	1.30 to 2.00
LUNCH 2.00 pm			

Monday 22nd Nov. 2010

SESSION VII	INTERESTING CASES		
S.no	Topic	Speaker	Timings
	Diagnosis	Dr H. Pati	9.00 to 9.15
	Cardiac Problem	Dr Arun Mohanty	9.15 to 9.30
	Endocrine	Dr Anju Seth	9.30 to 9.45
	Thrombophilia in Haemoglobinopathies	Dr Renu Saxena	9.45 to 10.00
TEA BREAK	**10.00 AM – 10.15 AM**		
SESSION VIII	**Prevention**		
S.no	Topic	Speaker	Timings
	Anemia in Pregnancy, IDA and Thalassemia Screening	Dr Meera Sikka	10:15 to 10:45
	Management of pregnancy in Thalassemias	Dr Rekha Bajoria	10:45 to 11:10
	CVS and Cordocentesis	Dr Dipika Deka	11:10 to 11:30
	Prevention & Control	Dr Madhulika	11:30 to 11:50
SESSION IX	**Psycho-Social Issues panel Discussion in Hindi**		
S.no	Topic	Speaker	Timings
	Living with Thalassemia	Dr Manju Mehta	11.50 to 12.00
	Achievers/Success stories	Dr Anjali Sardana Mr Sapan Seth Ms Tanu Verma Ms Isha Adhlakha	12.00 to 12.10 12.10 to 12.20 12.20 to 12.30
	Panel Discussion Education, Employment & Marriage Counselling	All above + 2 Parents of adult Thalassemics	12.30 to 1.30
	LUNCH : 1:30 TO 2:30		
SESSION X - Transplantation			
S.no	Topic	Speaker	Timings
	Stem cell Transplantation	Dr Alok Shrivastva	2.30 to 3.00
	Cord Blood Transplantation	Dr Sandeep Shah	3.00 to 3.30
	Life after BMT	Dr.Mammen Chandy	3.30 to 4.00
QUESTION ANSWER SESSION		**4.00 to 5:00**	
TEA		**5.00 pm**	

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

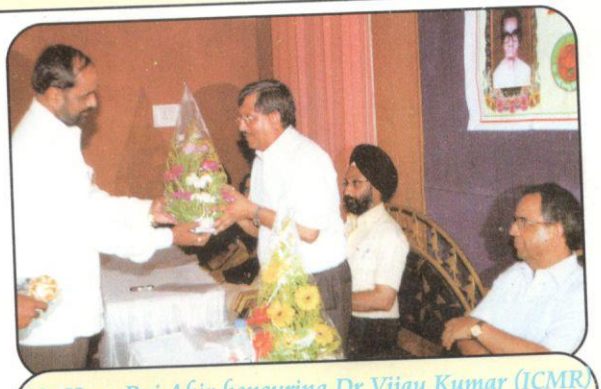
Delegates at National Consultation Workshop On Patient's Safety, Lucknow



National Consultation Workshop On Patients Safety in progress 10-12th May 2010

Dr Arora, PFPS Champion India WHO addresing at National Consultation Workshop On Patient's Safety, Lucknow

Left to right Dr M Khan, Dr Raj Mehra (AIIMS), Dr Madhu Choudhry, Dr Vinay Katoch (Secretary Dept. of health research & Dir. General ICMR), Mr Hans Raj Ahir (MP) Chandrapur, Dr K Ghosh (NIIH), Dr J S Arora, Dr N K Mehra, Dr V P Choudhry, Dr Vijay Kumar (ICMR), Discussing feasibility study for opening the ICMR Satellite Centre for Sickle Cell Anaemia & Thalassemia, Chandrapur.



Mr Hans Raj Ahir honouring Dr Vijay Kumar (ICMR) during CME at Chandrapur

Dignitaries at Dias during CME

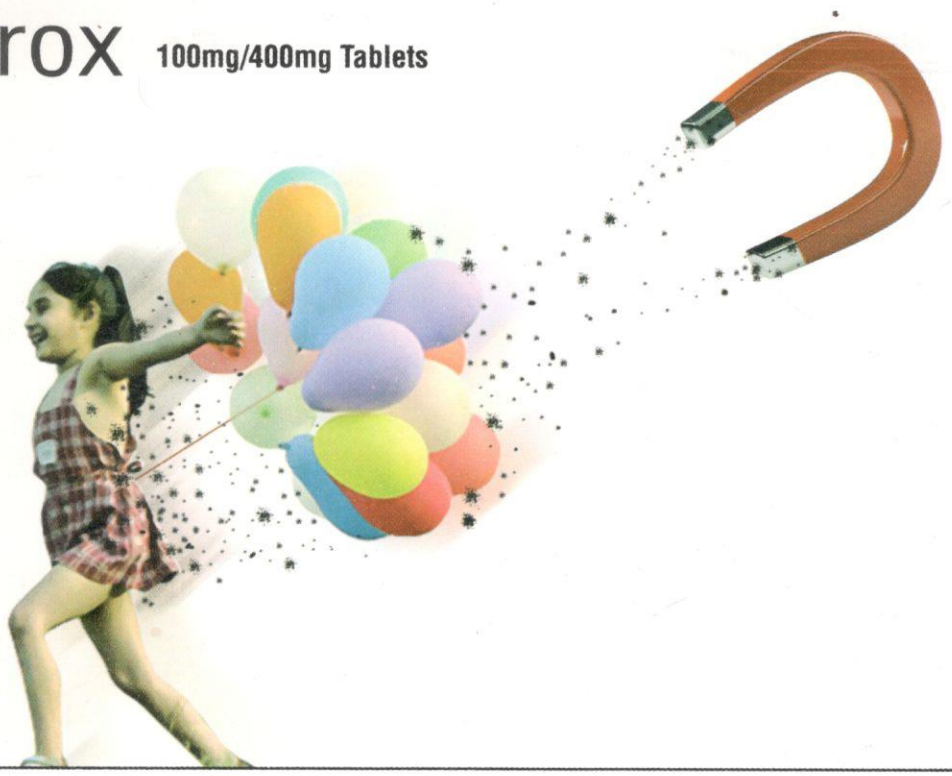
Mr Hans Raj Ahir honouring Dr J S Arora during CME at Chandrapur

REMOVE THE IRON OVERLOAD,

RELEASE THEIR CHILDHOOD WITH...

Asunra®

deferasirox 100mg/400mg Tablets



Abridged Prescribing Information

ASUNRA ® Presentation: dispersible tablets containing 100 mg and 400mg 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; consider 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; consider 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 patient's 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. In patients not adequately controlled with doses of 30 mg/kg, doses of up to 40 mg/kg may be considered. In patients whose serum ferritin level has reached the target (usually between 500 and 1000 microgram/L), dose reductions in steps of 5 to 10 mg/kg should be considered to maintain serum ferritin levels within the target range. Asunra should be interrupted if serum ferritin falls consistently below 500 micrograms/L • Maximum daily dose is 40 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 • Monitoring of serum transaminases, bilirubin and alkaline phosphatase: before the initiation of treatment, every 2 weeks during the first month and monthly thereafter. Asunra should be interrupted if persistent and progressive unattributable increase in serum transaminases levels. Postmarketing cases of hepatic failure have been reported • Asunra has not been studied in patients with renal and hepatic impairment and should be used with caution in such patients • Gastrointestinal irritation may occur. Upper gastrointestinal ulceration and haemorrhage have been reported in patients, including children and adolescents. Multiple ulcers have been observed in some patients • **Skin rashes:** Asunra should be interrupted if severe rash develops • Discontinue if severe hypersensitivity reaction occurs • Annual ophthalmological/audiological testing • 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 • Caution when combined with drugs metabolised through CYP3A4 (e.g. ciclosporin, simvastatin, hormonal contraceptive agents) • Increases in the dose of Asunra should be considered when concomitantly used with potent UGT inducers (e g. rifampicin, phenytoin, phenobarbital, ritonavir) • Careful monitoring of glucose levels should be performed when repaglinide is used concomitantly with Asunra. An interaction between Asunra and other CYP2C8 substrates like paclitaxel cannot be excluded • Caution when combined with drugs with ulcerogenic potential (e.g. NSAIDS, corticosteroids, oral bisphosphonates) or with anticoagulants. **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), renal tubulopathy, severe skin rash, maculopathy, hepatitis, hepatic failure, leukocytoclastic vasculitis, urticaria, optic neuritis, gastrointestinal haemorrhage, gastric ulcer (including multiple ulcers), duodenal ulcer, gastritis, oesophagitis. As with other iron chelator therapy, high-frequency hearing loss and early cataracts have been uncommonly observed. **Packs:** 5 x 6 Tablets of 100mg/400mg.

Note: Before prescribing, please consult full prescribing information.

For the use only of Registered Medical Practitioner or a Hospital or a Laboratory.

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ASUNRA/Onco/4/Qtr 3/2009