FEDERATION of Indian Thalassemics

NATIONAL THALASSEMIA BULLETIN

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Hon'ble Chief Minister of Delhi Mrs. Sheila Dikshit Addressing the Audience.

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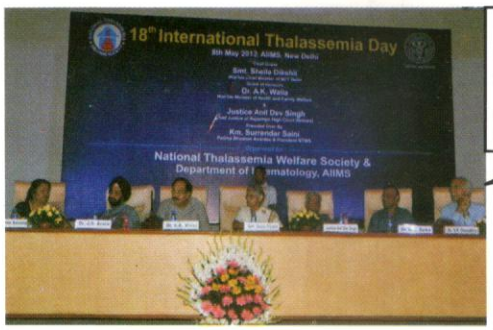
18th International Thalassemia Day, 8 May'12



Left to right Dr. Renu Saxena, Dr. J.S. Arora, Dr. A.K. Walia, Smt. Sheila Dikshit, Justice Anil Dev Singh (Retired) Dr. R.C. Deka & Dr. V.P. Choudhry

Dr. A.K. Walia announcing schemes on 18th ITD.

Dr. V.P. Choudhry giving a token of appreciation to Hon'ble CM

Dr. J.S. Arora receiving a memento from Dr A.K. Walia.

Dr. N.K. Mehra discussing Bone Marrow registry with Dr. Walia.

Dr. J.S. Arora explaining problems of Thalassemia to Hon'ble Chief Minister of Delhi Mrs. Sheila Dikshitt and Hon'ble Health Minister Dr. A.K. Walia

Anil Dev Singh retired Cheif Justice of Rajasthan High Court giving his views on providing disability status to Thalassemics.

Hon'ble CM of Delhi Mrs. Sheila Dikshit giving autograph to Baby Muskaan.

Dignitaries among the audience.

Dr. Renu Saxena, Dr. Deepika Deka, Dr. R.C. Deka amongst audience.

EDITORIAL

Dr. J.S. Arora

India leads US, YESS world's first oral iron chelator Deferiprone [KELFER] was first launched in India on 5th April 1995. Europe followed and allowed restricted use of Deferiprone [Ferriprox] in 1999. Pressure of world thalassemia community forced US FDA to approve this drug for the treatment of iron overload in thalassemics on 14th October, 2011. Cooley's Anaemia Foundation and UK Thalassemia Society played lead role while other thalassemia associations world over further energized their efforts. Many studies have substantiated the cardio-protective effect of Deferiprone. UKTS official bulletin "Thalassemia Matters" Jan 2012 issue number 119, has quoted an observation in support of this. In 2003, 20 adult thalassemics from USA and 20 adult thalassemics from UK attended TIF conference at Palermo, Italy. In 2012 out of those 20 US adult thalassemics only 2 are alive and rest 18 died of cardiac problems [who were on Desferrioxamine and never took Deferiprone, because it was not available there] and out of those 20 UK adult thalassemics only 2 died, that too causes unrelated to heart.

UKTS, which funded the research on Deferiprone and CIPLA, which made Deferiprone [KELFER] available here in India at affordable cost deserve a standing ovation.

Fruits of adequate care have started pouring in India too. Now in India too, thalassemics are not only getting higher education, getting good employment, doing business but also marrying and having their own children.

Thalassemia Major is really not a big thing to deal with and Yes Mr. Mohit Munjal (A Thalassemic Major) & Dr. Mrs. Indu Arun Sharma are living example of it.

On 15th Feb 1983 The Munjal Family of Fatehabad, Haryana was filled with Joy. A cute little boy named Mohit was born in the family. Both Mrs & Mr Suresh Munjal were overjoyed. After 3 months the whole family turns into standby mode when they came to know that their son Mohit is having Thalassemia Major a daunting disease.

Mohit had that courage to face every situation of life. Now he runs his own business of C & F Nokia in Haryana .

The day when he realised that he is no less than any Normal Human Being was the day when he found his Soulmate Taruna Munjal (Normal –not even Thalassemia carrier). He got married on 12th June 2011 and exactly 374 days after you know what happened Mohit & Taruna blessed with a cute little angel on 21st June 2012. "Hridya Munjal".

Happy family photo at page No. 10.

And now Mohit Munjal is a proud father. We wish the family a long happy, healthy future.

Ms. Indu Bala (A Thalassemic major) from Charkhi Dadri (Haryana) born on 2nd Sept. 1985 and now Dr. Mrs. Indu Arun Sharma after doing his BAMS & marrying to an MBBS Doctor on 28-11-2011. Her thalassemia status was clearly told to all the members of the boy family right at the first meeting. She is currently running her own clinic in rural area of Haryana.

Please share you success stories with us.

Take your treatment Full
Enjoy your life Wonderful.

Bone Diseases in Thalassemia

Dr. J.S. Arora

Bone is resorbed by osteoclasts and rebuild by osteoblasts. Bones are continuously undergoing a dynamic process of resorption and formation. Osteoclast and Osteoblast work hand in hand in bone metabolism. Osteoporosis/Osteopenia though manifest in adults, it starts in childhood & adolescence. Several bone abnormalities, including the enlargement of the cranial and facial bones, spinal deformities, scoliosis, nerve compression, spontaneous fractures, and bone loss are present in Thalassemia major [TM] patients.

The incidence of osteopenia or osteoporosis is around 70-80%. Even in well treated TM patients it has been found to be approximately 40–50%.

Pathogenesis of osteoporosis in thalassemia :

Several genetic and acquired factors are responsible for bone destruction in TM. The typical delay in sexual maturation, diabetes, hypothyroidism, parathyroid gland dysfunction, accelerated hemopoiesis with progressive marrow expansion, direct iron toxicity on osteoblasts and the deficiency of growth hormone (GH) or insulin growth factor I (IGF-I) have been indicated as possible causes for thalassemia induced osteoporosis. There is a problem in quantity of bone geometry, architecture and osteo-dystrophy because of aberrant Vit D metabolism.

Iron overload has correlation with growth failure and bone abnormalities. High desferrioxamine dosage has been associated with cartilage alterations. It has been observed that, despite normal hemoglobin level, effective iron chelation and adequate hormone replacement, patients continue to show an unbalanced bone turnover with an increased resorptive phase resulting in seriously diminished bone mineral density (BMD). This imbalance can be caused by estrogen deficiency, gluco-corticoids exposure, inflammatory diseases and T cell activation. Osteoporotic tumors like myeloma & osteolytic metastases create situations favouring bone loss.

Genetic Factors :

Genetic factors seem to play a role in the development of low bone mass and osteoporotic fractures. The study of COLIA 1 polymorphism may help in identifying thalassemia patients who are at higher risk to develop osteoporosis and pathologic fractures. Vitamin D receptor (VDR) has been reported to correlate with bone mineral damage in thalassemics.

Acquired Factors :

Endocrine

Hypothyroidism, hypoparathyroidism, diabetes mellitus, and mainly hypogonadism (delayed puberty and/or secondary hypogonadism) are considered as major causes of osteopenia/osteoporosis in TM. Hemosiderosis of the pituitary gonadotrophic cells and iron deposition in the testes and ovaries are involved in the pathogenesis of endocrine complications in TM. Hypogonadism is a well-recognized cause of osteoporosis and osteopenia and is characterized by high bone turnover with enhanced resorptive phase. Estrogen and progesterone appear to inhibit osteoclast activity and promote bone formation, whereas testosterone has a direct stimulatory effect on osteoblast proliferation and differentiation.

Iron overload & Chelation

The iron overload interferes in osteoid maturation and mineralization, including incorporation of iron into crystals of calcium hydroxyapatite, which consequently affects the growth of hydroxyapatite crystals and reduces the bone metabolism unit tensile strength. Desferrioxamine [DFO] inhibits DNA synthesis, osteoblast, and fibroblast proliferation, and collagen formation, especially in patients who receive inappropriately high doses of desferrioxamine. DFO also chelates Mg, Ca, Zn. Cal chelation leads to reduction in bone density. DFO can cause truncal shortening, bone deformity and arthropathy.

Bone marrow expansion has also been considered as a major cause of bone destruction.

Vitamin Deficiency

Vitamin C deficiency in iron overloaded patients induces the risk of osteoporotic fractures. Vitamin D deficiency is implicated in the pathogenesis of osteoporosis in TM patients due to the regulatory effect of vitamin D in both osteoclasts and osteoblasts. Vit D insufficiency leads to Genu Valgus or rickets and dysmorphic bones.

Physical Activity

Thalassemia patients have reduced physical activity due to the complications of the disease and the overprotection by their parents who do not encourage muscle activity. Muscle activity should be encouraged in these patients.

DIAGNOSIS :

Diagnosis is done by Bone Densitometry. According to the World Health Organization, osteoporosis is a disease characterized by low bone mass and micro-architectural deterioration of bone tissue, leading to enhanced bone fragility and a consequential increase in fracture risk. The cut-off of 2.5 standard deviations below the normal mean in BMD for the

respective age is used for the defining osteoporosis, whereas the decrease of BMD between 1.5 and 2.5 standard deviations below the normal mean for the respective age is defined as osteopenia.

Osteoporosis

BMD > 2.5 SD below the young normal mean (T score) or standard deviations in relation to patient's age (Z score)

Osteopenia

BMD >1.5--2.5 SD below the young normal mean (T score). For every SD > -2.5 there is further increase in fracture risk. Osteopenia may behave like osteoporosis in presence of concomitant bone disease.

Treatment Options for TM Induced Osteoporosis :

Blood transfusions + Chelation + Hormone replacement therapy [HRT] are sheet anchors of treatment.

Prevention and general principles

Adequate calcium & zinc intake and small amounts of vitamin D administration during skeleton development can increase bone mass in adolescence and decrease bone loss in adult life. However in most studies reduced serum levels of 25-hydroxyvitamin D in TM patients has not been observed. Annual checking of BMD starting in adolescence helps in early management.

Physical activity must always be encouraged. Moderate and high impact activities are to be supported. Exercise improves cardiovascular system, reduces the risk of diabetes and prevents depression.

Smoking should be discouraged.

Early diagnosis and treatment of diabetes mellitus is also important.

Sufficient blood transfusions inhibit uncontrolled bone marrow expansion and adequate iron chelation prevents iron toxicity in the bone. Minerals and trace elements must be given prophylactic to all patients. Cal & Zn depletion is preventable by adhering to therapeutic ratio of DFO

Hormone replacement therapy [HRT]

Prevention of hypogonadism seems to be the most effective way for preventing osteoporosis and other bone deformities in TM patients. Continuous hormonal replacement therapy with transdermal estrogen for females and human chorionic gonadotrophin for males improves bone density parameters.

Calcitonin is a potent inhibitor of osteoclasts. 100 IU three times a week for 1 year in combination with 250 mg calcium daily helped in disappearance of bone pains, radiological findings of osteoporosis improved, and decrease in number of fractures.

Bisphosphonates are potent inhibitors of osteoclast function. They inhibit differentiation of osteoclast precursors. They also inhibit the action of matured osteoclast. Enhance the apoptosis of mature osteoclast and prevent their attachment to the bone surface. Most commonly used bisphosphonates in thalassemics are oral Clodronate and oral Alendronate. Daily treatment with alendronate normalized the rate of bone turnover, and resulted in a rise in BMD of the spine and the hip. 30 & 60 mg iv Pamidronate every month in TM increased BMD in lumber spine, femoral neck, and forearm reducing markers of bone resorption & formation. Zoledronic acid is the most potent third generation bisphosphonate to-date and has been found to be extremely efficacious in increasing BMD and reducing bone resorption in thalassemia-induced osteoporosis with no serious side effects.

Conclusion and future perspectives :

Osteoporosis is a progressive disease; thus, prevention and early diagnosis are very important. Adequate hemoglobin levels, effective iron chelation, calcium and vitamin D supplementation, physical activity and hormonal replacement are the main to-date measures for the management of this disease.

Caution :

However, despite hormonal replacement, calcium and vitamin D administration, effective iron chelation, and normalization of hemoglobin levels, patients with TM continue to lose bone mass.

Key reference Treatment options for thalassemia patients with osteoporosis
Evangelos Terpos and Ersi Voskaridou Ann.
N.Y. Acad. Sci. 1202 (2010) 237–243

NTWS Activities

On 26th April 2012 Mr Gautam Seth (PRO NTWS) briefed about Thalassemia on AIR FM Rainbow Programme "*Hum Kissi Se Kam Nahi*" he also briefed about our preparation for 8th May 2012 "International Thalassemia Day". In continuation to this there was a broadcast on Thalassemia on 3rd May 2012 same programme "*Hum Kissi Se Kam Nahi*" in which Ms Tanu Verma Thalassemic Major a journalism student briefed about her journey with Thalassemia and the obstacles she faced and still facing. Her words derived a big source of motivation for lots of thalassemics like her.

As usual this year also DD News on the occasion of International Thalassemia Day dedicated it's much sought health programme "Total Health" for thalassemia on Sunday, 6th May'12. It was a live telecast, from 8:30 am to 9:30am, panelists were Dr J.S. Arora, alongwith Dr Renu Saxena, professor & head, department of haematology, AIIMS and Dr Deepika Deka, professor of obstetrics & gynecology AIIMS. Focus of this programme was on screening of pregnant women by obstetrician during 1st visit. Phone calls were received from places as far as Tripura & Karnatka. Another phone in programme was aired by All India Radio on Monday 7am to 8am at its Indraprastha channel 819 Khz/366.3 meter. Dr J.S Arora and Dr Bhawna Dhingra Asst. professor of paediatrics at Kalawati Saran Children Hospital were invited experts.

18th International Thalassemia Day Celebration :

National Thalassemia Welfare Society (NTWS) Observed 18th International Thalassemia Day on 8th May 2012 with great fervor at Jawahar Lal Auditorium AIIMS 5:30 pm Onwards. The show started with a big bang. It started with Ganesh Vandana by Jhonny Sufi followed by Punjabi-Haryanvi mix song by Lalit Baba & Mr. B., Mimickery by RJ Gaurav and laughter fillers by Mr Gautam Seth.

As soon as our Chief Guest arrived Mrs. Vandana Arora took over the reins of mike to manage the stage. To mark the 18th ITD, NTWS planned to felicitate adult Thalassemic achievers. Hon'ble Chief Minister of Delhi Mrs. Sheila Dikshit was the Chief Guest. During her speech she stressed the need of prevention and said Delhi Govt. in association with NTWS will plan a strategy for prevention and control of Thalassemia. Dr A.K. Walia Hon'ble Minister of Health and Family Welfare who was Guest of Honour highlighted steps taken by his Government for the benefit of Thalassemics. He said we already have separate Thalassemia wards in 5 Delhi Govt. hospitals, now two new Thalassemia units will be started at Sanjay Gandhi hospital & Hedgewar hospital.

He said, keeping in mind the need of adult Thalassemics we have decided to start transfusion services all seven days a week i.e. all 365 days a year including all Sundays and holidays.

Dr. Walia assured the audience that Delhi Govt. is committed to provide safe blood to all who need it. He said we are already doing 4th generation ELISA test, now soon NAT [nucleic acid testing] facility will be added in all Delhi Govt. hospital blood banks. He said he has also waived of VAT on drugs and equipments used in the treatment of Thalassemia when he was Finance Minister. He echoed the voice of Hon'ble Chief Minister to control the menace of Thalassemia.

Justice Anil Dev Singh retired Chief Justice of Rajasthan high court who was also Guest of Honour stressed that, Thalassemics both major and minor should not face any discrimination in life, be it education, employment or social. He said though the disability act can be amended by the parliament but state Govt. can reserve some seats for thalassemics in education and employment by notification. He requested the Hon'ble Chief Minister to look into it. While welcoming the guests, Dr J.S. Arora, General Secretary of NTWS requested the Hon'ble Health Minister to initiate the Thalassemia registry in Delhi and including Thalassemia in marriage registry. He also requested Dr R.C. Deka, Director AIIMS and Dr. Renu Saxena (HoD, Dept. of Hematology AIIMS) to once again allocate a separate ward & free chelating agents for Thalassemics at AIIMS. Dr. V.P. Choudhry's main thrust was on prevention & control of Thalassemia involving all stake holders including DHS, Govt. hospitals, private hospitals and NGO's. Dr R.C. Deka Director and Dr Renu Saxena HoD Haematology AIIMS appreciated efforts put forward by NTWS in organizing this activity at AIIMS and promised to provide better services to Thalassemics at AIIMS.

Hon'ble Chief Minister felicitated our great achievers who have won the battle in wide ways and achieved great heights defeating the "Thalassemia". Mrs. Swaran Anil invited one by one great warriors elucidating their achievements. Sukhsohit Singh is first Thalassemia Major to clear Indian Civil Services. He joined the Indian Civil Services under the Ministry of Defence, Government of India as an IdAS [Indian defence Accounts Services] Group A Officer in Nov. 2011.

Swati Miglani passed from IIT Roorkee, M. Phil. Maths now working as a Lecturer at Aravalli College of Engineering & Management, Faridabad Dr. Indu Bala a medical doctor by profession recently got married to a medical doctor who is not a Thalassemia carrier.

Mrs. Swaran Anil then invited Ms. Jyoti Arora, a young emerging novelist from Ghaziabad. A post graduate in English literature and applied psychology, she has been working as a freelance writer since 2007. All these despite she had to leave the school at 7th standard due to medical complications.

Surbhi Jain a Lawyer enrolled under Bar Council of India, practicing at Tis Hazari Courts, New Delhi.

Tanu Verma pursuing MSc in Journalism Advertising and Mass Communication and working for Thalassemia patients with NTWS.

Nitin Kumar a graduate from Delhi University completed GNIIT course from NIIT Dwarka now working as an office assistant at Upper Yamuna River Board a Government organisation.

Lipika Dureja a science graduate had given her final exam of MSc. in Textile & Clothing.

Shivali Arora has done BA Maths Honours, B.Ed and now she is pursuing MSc. Maths.

Mrs. Swaran Anil could not stop her tears while introducing Ms. Sangeeta Bhola to the audience that she had lost her both parents at very young age, and in-spite of this, she manage to look after her treatment herself and also supported other family members by working at BPO. Everyone was touched by her story.

After the felicitation ceremony of the young talented Thalassemics, some of our beautiful Thalassemia Major girls performed a bollywood dance number. A poem on save a girl child was recited by Priya, a Thalassemic from Bhiwani, Haryana. Ayush, 10 yrs old performed a Michael Jackson dance. The complete aura of the function was in a festive mood. The audience, parents, patients doctors & invited guests enjoyed cultural evening to its fullest.

As the cultural show came to an end there was a lucky draw waiting for the adult Thalassemics. Four names were picked up and were given cash prize of Rs. 2500 each.

After the cultural programme all the participants were given return gifts, a traveler's mug with a slogan on Thalassemia. A very delicious mouth licking dinner was served to all by 9 PM.

World Blood Donor Day 14th June 2012

A day dedicated to all the Blood Donor with theme "EVERY BLOOD DONOR IS A HERO" was celebrated with complete joy and feeling of Enthusiasm. On this eve DSACS [Delhi State AIDS Control Society] organized a painting competition for the thalassemics at Delhi University on 13th June 2012. The result was declared on 14th June 2012 with great zeal and fervor. Three thalassemics Tulika Dey, Swadheen Jain and Radhika Khatter bagged 1st, 2nd and 3rd prize comprising of cash Rs. 5,000, 3,000 & 2,000 respectively. The event comprised of honouring the centurian blood donors and the NGOs organizing regular blood donation camps. Ms Tanu Verma on behalf of NTWS and all thalassemics appreciated and expressed gratitude to all the voluntary blood donors for sharing their gift of life. Her words made everybody spell bound and created a desire of donating blood amongst the participating youth. The event ended with mouth relishing food.

On the same day, the department of transfusion medicine of Indraprastha Apollo Hospitals, along with State Blood Transfusion Council, Govt of NCT Delhi and Blood for All (B4A), organised a 'National Seminar on Promotion of Voluntary Blood Donation' to commemorate the world blood donor day 2012 at Le Meridian, New Delhi. The event comprised of honouring the centurian blood donors and the NGOs organizing regular Blood donation camps. Mst Ayush performed a Punjabi Bhangra dance on the occasion. The function ended with mouth watering food.

NTWS expands its wings

On 23rd June 2012 NTWS held a Workshop for the employees of an NGO Child Survival India (CSI). A team of 15 to 20 people headed by Ms Deepa & Ms Sarabjeet Kaur were trained by Dr. J. S. Arora to spread awareness of Thalassemia amongst the rural and lower middle class urban population. Dr J.S. Arora explained them about Thalassemia, how to do testing of Thalassemia & how to convince them to go for prenatal screening of Thalassemia. CSI is already working on creating awareness on HIV now they have also decided to join hands with NTWS for creating awareness on Thalassemia. CSI will also hold educational camps at NTWS Dispensary Gurgaon for the rural folks of nearby places.

Blood Donation Camps organised by NTWS

NTWS organized 70 blood donation camps in association with Govt. blood banks from June 2011 to June 2012 and collected around 3000 units of blood to strengthen supply of blood.

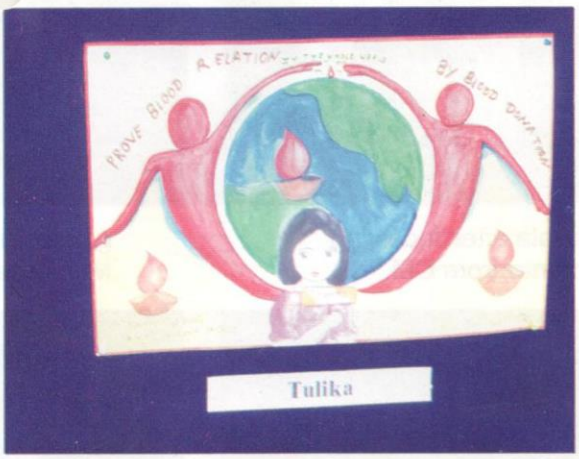
Some of the camps are given below

Date	Name of Organisations	Blood Banks	No. of Units Collected
26-07-11	MDI, Gurgaon	LNJP	101
20-08-11	Pacific Mall, Subhash Nagar	AIIMS	50
27-08-11	IITM, Janakpuri	DDU	100
03-10-11	Convergys, Gurgaon	LNJP	101
11-10-11	ZS Associates, Gurgaon	RML	100
12-10-11	DLF Pramerica, Gurgaon	DDU	105
13-10-11	Vatika Towers, Gurgaon	AIIMS	74
15-10-11	Mc Donalds, Gurgaon	RML	56
20-10-11	Smart Cube, Gurgaon	LNJP	130
17-11-11	Vertex, Noida	LNJP	75
28-11-11	Vertex, Noida	LNJP	66
05-03-12	Mahindra Finance, Rajendra Place	RML	57
06-03-12	SRF Ltd., Bhiwadi	DDU	90
21--3-12	Vatika Tower, Gurgaon	AIIMS	59
05-04-12	Alcatel Lucent, Sigma	DDU	55
02-04-12	Convergys, Gurgaon	LNJP	79
01-06-12	Ciena, Gurgaon	AIIMS	73
07-06-12	Director General Prisons, Tihar	DDU	119
17-06-12	Arora Polyclinc, Vikas Puri	DDU	69
20-06-12	Fluor, Gurgaon	AIIMS	220

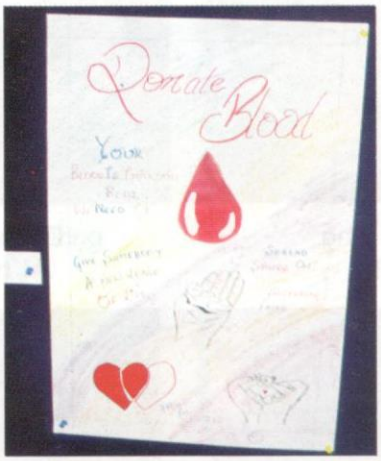
World Blood Donor Day, 14th June, 2012

Ms. Tanu Verma addressing on the occasion of World Blood Donor Day 14th June, 2012.

Winner family.



1st Prize winner painting by Tulika Dey.



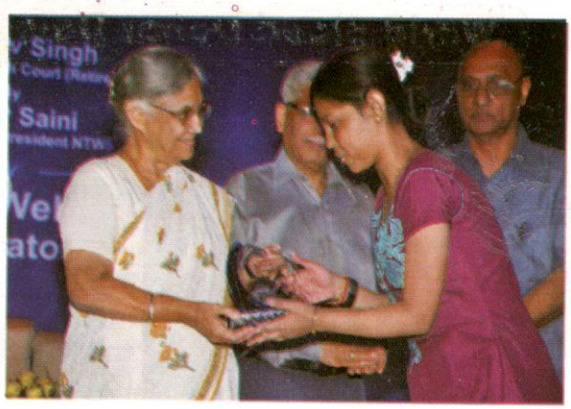
2nd Prize winner painting by Swadheen Jain

Radhika Khatter
3rd prize winner
with her drawing

Dr. J.S. Arora explaining Thalassemia to Ms. Deepa, Ms. Sarabjeet Kaur and their team of "Child Survival India" at NTWS Office.

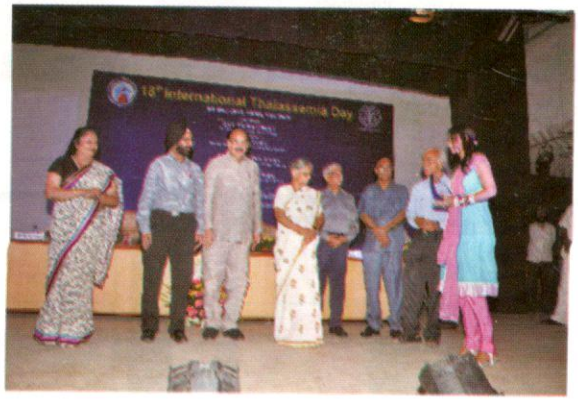
Dr. J.S. Arora receiving a memento for organizing maximum blood donation camps from Dr. S.P. Agarwal Secretary Gen. Indian Red Cross Society on the occasion of World Blood Donor Day.

Ms. Surbhi Jain receiving memento from CM.

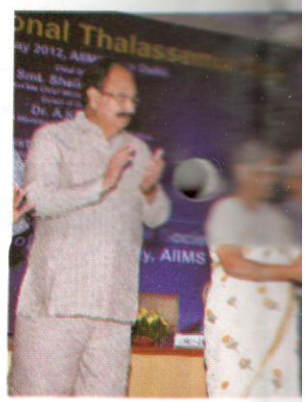


Ms. Tanu Verma receiving memento from CM.

Ms. Shivali Arora receiving memento from CM.

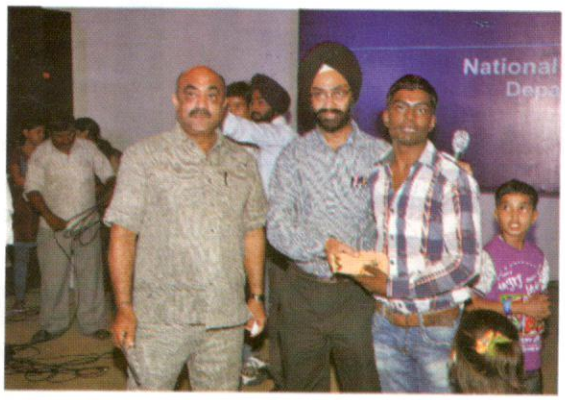


Dr. Indu Bala after receiving memento from CM.

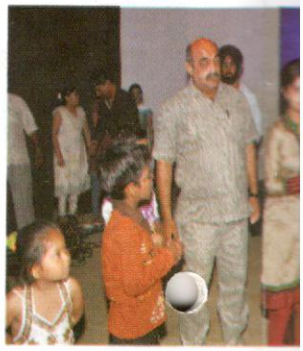


Ms. Lipika Dur
memento from

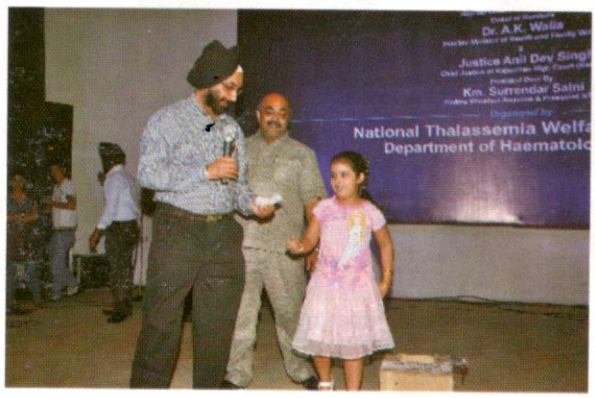
Ms. Priya Girdhar the Lucky Draw Winner receiving a cheque of Rs 2500.



Mr. Nitin the Lucky Draw Winner receiving a cheque of Rs 2500.



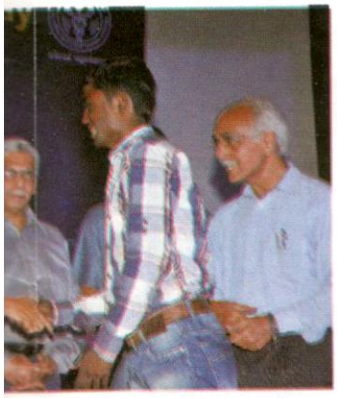
Ms. Shivali
Lucky Draw
receiving a cheq



Cute Saanvi taking out Lucky Draw of 4 Adult Thalassemia Major patients.

Cultural performance.

Group Dance per
Keerti, Saanvi,



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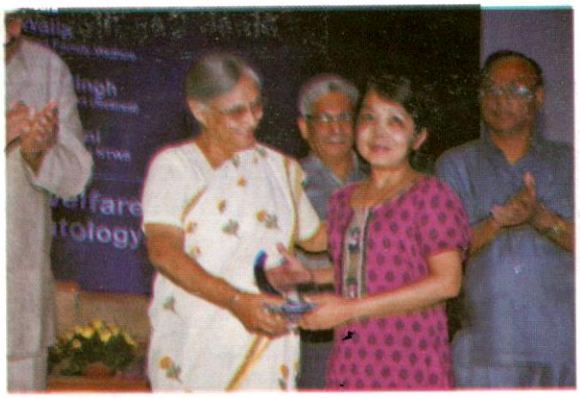
Mr. Sukhsohit Singh after receiving memento from CM.



Jyoti Arora receiving memento from CM.

a Dureja receiving
from Hon'ble CM.

Ms. Swati Miglani receiving memento from CM.

Mr. Gautam Seth receiving a token of appreciation from Dr. J. S. Arora.

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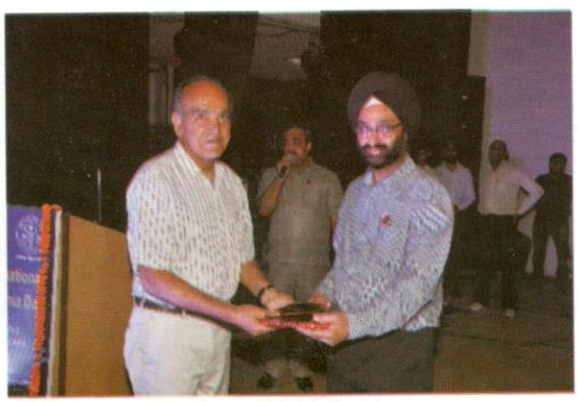
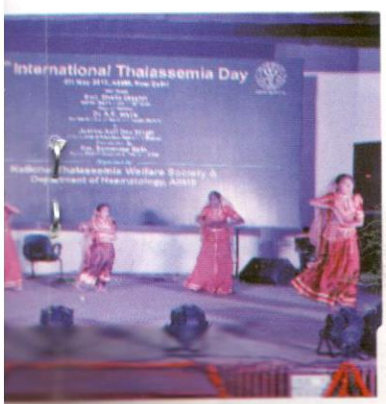
y Draw Winner
cheque of Rs 2500.



Retd. Air Marshall Bharat Kumar receiving a token of appreciation from Dr J.S. Arora.

Dr. J.S. Arora giving memento to Mr. Hansraj Ahir, MP Lok Sabha.



performed by Radhika,
Gunjan & Yashika.

Vandana Arora inviting the guests.

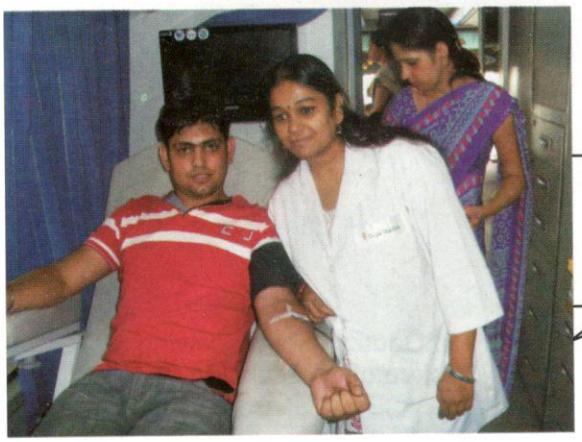
Ms. Surbhi Jain motivating thalassemics .

Ayush performing a dance.

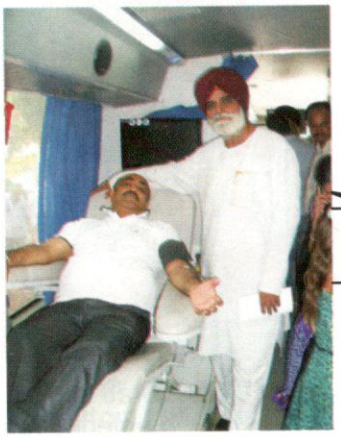
Blood Donation Camp at NTWS Office & Rajouri Garden

Mr. C.R. Garg
Deputy Commissioner
West Zone, MCD,
Mr Gautam Seth
& Dr. J.S. Arora
encouraging Blood Donor
Mr. Gulshan Sachdeva.

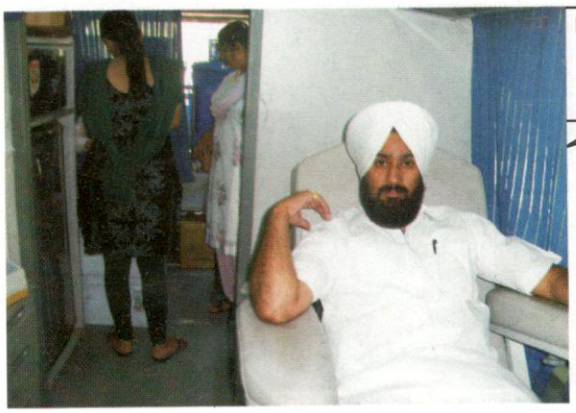
Mr. Vinod Mittal &
Sd. Surinder Singh
encouraging the donor



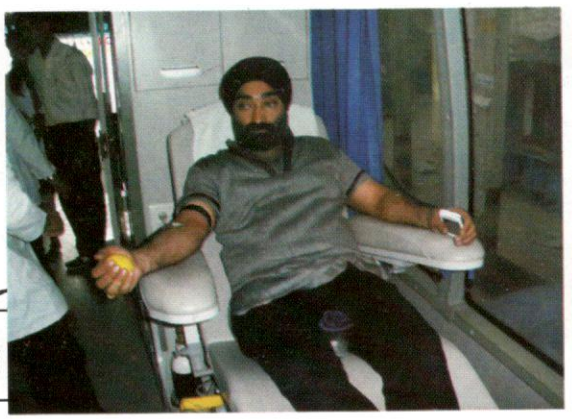
Mr. Praveen Tanwar
donating blood
flanked by his wife
Mrs. Divya Tanwar



Mr. Gautam Seth
donating blood.



Mr. Gagandeep Singh
donating blood
on 17th June'12
at NTWS Office.



S. Gurpreet Singh
Gandhi donating blood

Blood Donation Camp
on 22nd July, 2012
in the memory of
Late Sd. Surjeet Singh
Gandhi organised by
Sd. Gurpreet Singh Gandhi
& Sd. Dilpreet Singh Gandhi

Mohit Munjal with
his sweet family.

NTWS interaction with the Government of Delhi.

A meeting was called by Hon'ble Health Minister Dr. A.K. Walia on 26th April 2012 in which Medical Superintendents, Blood Bank Officers and in-charge Thalassemia Units were invited to discuss to improve the facilities at Thalassemia Wards and take more effective steps for prevention of thalassemia. Dr J. S. Arora coordinated the meeting. Following important steps have been taken in response to the above meeting held under the chairmanship of Hon'ble Minister of Health.

1. DDU, GTB, BSA & CNBC hospital will provide transfusion services all 7 days a week, 365 days a year. LNJP i s already providing these services since June 2011.
2. Soon NAT (Nucleic Acid Testing) in donors blood will be provided in all Delhi Government Hospital Blood Banks.
3. Red Cell Antibody Screening will be extended to all Blood Banks.
4. New Thalassemia Units will be started at Sanjay Gandhi Hospital and Hedgewar Hospitals.
5. More thrust will be given on Thalassemia Awareness and Screening.

News from Other Societies :

CME on Thalassemia and Sickle Cell Anemia at Bhilai :

Department of Peadiatrics, Jawaharlal Nehru Hospital & Research Centre, Bhilai organised a CME on Thalassemia & Sickle cell anaemia on 18th Mar'2012. On the eve of CME Dr Dinesh Bhurani addressed on leukaemia to a gathering organized by Deptt of Paediatrics Jawahar Lal Nehru Hospital Bhilai. On 18th March Dr V.P. Choudhry gave lecture on Influence of Malaria & guidelines for chronic transfusion in Thalassemia. Dr Dinesh Bhurani's topic was on BMT in Thalassemia & sickle cell anaemia (SCA). Dr J.S Arora gave lecture on clinical consequences of iron deposition & chelation therapy in Thalassemia. Dr V.P. Choudhry's post lunch session was on prenatal diagnosis of Thalassemia & sickle cell anaemia, newborn screening of SCA. Dr. J.S. Arora highlighted on sickle cell crisis and chronic organ damage in SCA & therapy. Dr V.P. Choudhry ended the session by discussing on preparation of surgery in SCA & management of pregnancy in SCA. There were around 120 doctors from different stream and 20 thalassemic parents who attended the CME.

Thalassemia clinic at Bareilly :

Thalassemic Children Welfare Society, Bareilly organizes special thalassemia clinic every year on the occasion of International Thalassemia Day. This year it was organized on Sunday 6th May'12. A free thalassemia checkup camp was organized where Dr. V. P. Choudhary examined around 80 thalassemic children. As most of the Thalassemics are now adolescent, Dr. Choudhary's interactive talk on "Management of Thalassemia in Adolescence" was very much beneficial and appreciated by patients and parents. Members of the Sakhi Club and Inner Wheel, who have adopted Thalassemic children, were honored. In the evening, all the Thalassemic patients, parents and doctors joined hands together and united to form a human chain to spread the message of prevention of Thalassemia and voluntary blood donation.

North Eastern Thalassemia Society, Dibrugarh :

The North-Eastern Thalassemia Society celebrated World Thalassemia Day on 8th May with a seminar held in the Medicine complex of Assam Medical College and Hospital. The seminar was attended by Physicians, Paediatricians, Pathologists, Gynaecologists as well as P.G. students from different departments. Different aspects of Thalassemia care including oral chelators and blood safety were discussed.

A blood donation camp was also held on the same day, at the blood bank of Assam Medical College Hospital, where a large number of students donated blood as well as pledged their support towards Thalassemic children by future donations whenever needed. A roster of the names of these donors is being maintained.

Cochin: Blood disorder patients took out High Court march

Due to State government and Central government lack of interest and negligence towards the blood disorder patients "Blood Patients Protection Council" {BPPC} Kerala, India,

organized a High court march on 23rd Feb'2012 in Cochin. BPPC had filed two public interest litigation petitions in Kerala High court for the expert treatment and life saving drug for blood disorder patients in 1999. Even after a long period of litigation, poor patients didn't get justice so far. Even though a significant verdict issued by the Hon'ble High court in 1999 in favor of blood disorder patients, the state government didn't took any fruitful action. Following the negligence of state government, council filed again a PIL in 2008. The much-awaited patients and their hapless families worried in this negative stance of health authority. Patients and their parents intensified their agitation. They organized many strikes including a march towards Indian Parliament. The central and state government continued their merciless negligence.

Pune Red Cross celebrates Children's Day with Thalassemic Children :

The Indian Red Cross Society, Pune District Branch celebrated the Children's Day with Thalassemic children. Over 100 Thalassemic children attended the program with their parents. The children enjoyed drawing and painting, expressing their skills with them.

Children's Day was celebrated with lamps and cake cutting. The children celebrated Diwali on this auspicious day. Gifts were given to all the children. The Thalassemic children facing the agony of repeated blood transfusion and complicated treatment throughout their life relaxed today and enjoyed with volunteers of youth Red Cross. They sang, danced and lit Diwali lamps. Lunch was followed by a magic show for the children.

Parent's education meet was held simultaneously. Dr. Vijay Ramanan, a renowned haemato-oncologist conducted the meet. Parents were updated on advancements on medical treatment and their doubts were cleared. Mr. Jatin Sejpal, the social worker of Indian Red Cross Society's Thalassemia Centre and Mrs. Nayana Doshi, the secretary of Thalassemia association spoke to the audience. Parents repeatedly expressed their gratitude to the IRCS for their noble services.

The program was also attended by the team of Red FM 93.5 who organized massive blood donation camps at the following blood banks, viz. Sahyadari Hospital Karve Road, Janakalyan Swargate, Ruby Hall Clinic and KEM Hospital. Approx. 400 units of blood were collected through their awareness program and blood donation drive on air. The Chairman of IRCS Mr. N.A.P. Nanavati, counselors and Red Cross youths of IRCS were present on the occasion. Hon Secretary IRCS Prof. R.V. Kulkarni thanked everybody for their cooperation.

Jatin Sejpal honoured

Every year on 10th February the Muktangan Rehabilitation Center, Pune, felicitate two persons working for Community Service with "Sangharsh Sanman" award in the memory of Late Dr Anita Awachat. This time the foundation honoured Mr Jatin Sejpal for his commendable services towards Thalassemia.

News from Gurgaon

Pahuja Trust for Blood Disorders & Gurgaon Thalassemia Society observed International Thalassemia Day on 20th May 2012 at Paras Hospital Gurgaon. A drawing Competition was held among young thalassemics followed by a CME on Thalassemia in which Dr VP Choudhry highlighted the important points on diet in Thalassemics, Dr Jagdish Chandra stressed the need of maintaining Hb above 10 gm & Dr JS Arora asked the patients to initiate the chelation as early as after 12 to 15 transfusions and keep it regular and maintain ferritin less than 1000ng/ml. Winning Thalassemics were given prizes by Mr & Mrs Air Marshall Bharat Kumar.

CME at Dehradun

A CME program was organise at Dehradun under the aegis of Department of Health & Family Welfare Uttarakhand an initiative to improve maternal and child health outcomes in congenital defects. A thalassemia clinic was also organized on this occasion Dr Nancy Oliveri examined and advice the thalassemic patients. Dr J.S. Arora gave a talk on management of thalassemia to a gathering of patients and doctors at Guru Ram Rai Hospital Dehradun. Dr. Sujata Sinha was back bone of the CME and Thalassemia Clinic.

News from Jammu

Dr. (Prof) Ashok Kumar Gupta gave a talk on thalassemia on "Take One" channel (J&K) on 8-5 2012. It was a 45 minutes talk/interview which has been telecasted five times, which helped in creating awareness of Thalassemia in Jammu.

News from Jabalpur

Mr. Girish Ahuja informed that on the occassion of International Thalassemia Day 8th May 2012 Jabalpur Thalassemia Society organised a Thalassemia Clinic for thalassmia patients in Jabalpur in which they had done free Serum Ferritin Test of 12 Thalassemia Children.

थैलासीमिया में अस्थि रोग

यथा संभव चिकित्सा के उपरांत भी थैलासीमिया मेंजर रोगियों की अस्थियों में कमजोरी व खोखलापन पाया जाता है। इसके मुख्य कारण हैं प्रजननांगों में देरी से विकास, मधुमेह, थायराईड व पैराथाराईड ग्रंथी में विकृति व निरंतर अस्थि मज्जा का विकास होना तथा अस्थिकणों पर अतिरिक्त लोहे का विषप्रभाव, ग्रोथ हारमोन व इंसुलिन ग्रोथ फैक्टर की कमी इत्यादि। लोह निष्कासक दवाओं का भी विकास व अस्थिविकृति पर प्रभाव देखा गया है, विशेष रूप से डैस्फराल का अधिक मात्रा में प्रयोग।

इससे भी बड़ी पहेली यह है कि कई बार उचित हीमोग्लोबिन तल, लोह निष्कासक दवाओं का समुचित प्रयोग तथा हारमोन का प्रयोग करने पर भी बोन मिनरल डैन्सिटी में कमी पायी जाती है।

विश्व स्वास्थ्य संगठन के अनुसार यदि बोन मिनरल डैन्सिटी सामान्य मानक स्तर से 2.5 अन्तराल से अधिक गिर जाता है तो इसे ओस्टीयोपोरोसिस कहते हैं और यदि यह 1.5 से 2.5 स्तर तक गिरता है तो इसे ओस्टीयोपीनीया कहा जाता है।

डा. वोन्की व उनके साथियों ने पाया कि 30% थैलासीमिया मेजर रोगियों में कोलिआ जीन एकक् रूप में तथा 4% रोगियों में जोड़े के रूप में पाया जाता है पुरुष रोगियों में इसकी उपस्थिती होने पर रीढ़ व कूल्हे की हड्डी में तीव्र ओस्टीयोपोरोसिस पाया जाता है। इसके अतिरिक्त विटामिन डी रिसैप्टर, कैल्सीटोनिन रिसैप्टर, इस्ट्रोजन तथा इंटरलयुकिन आदि जीन में व्रिकृती होने पर ओस्टीयोपोरोसिस की सभांवना बढ़ जाती है।

थैलासीमिया मेंजर रोगियों में अतिरिक्त लोहा जमा होने के कारण जहां विटामिन डी की कमी ओस्टियोपोरोसिस का एक विकृति कारक है वहां विटामिन सी की कमी होने से विकृत अस्थि के टूटने की सभावना बढ़ जाती है रोग की अपनी समस्याओं के कारण तथा माता-पिता के अति संरक्षण के कारण शारीरिक व्यायाम में कमी भी ओस्टियोपोरोसिस को बढ़ावा देती है।

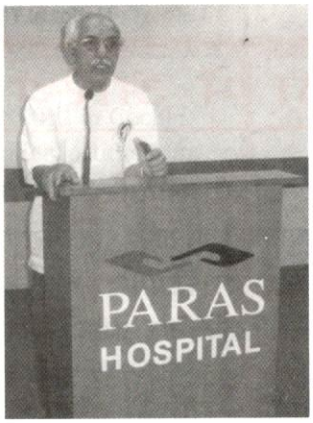
चिकित्सा

ओस्टियोपोरोसिस की चिकित्सा में बचाव ही उपचार है एक सामयिक उक्ती है। किशोरावस्था में बोन मिनरल डैन्सीटी की जांच वर्ष में एक बार आवश्यक है शारीरिक व्यायाम के लिये बच्चों को प्रोत्साहित करना चाहिये। कठिन व्यायाम को उचित सहायक की देख-रेख में ही करना चाहिये। व्यायाम करने से हृदय रोग, मधुमेह व माानसिक तनाव आदि का अंदेशा कम होता है। कैल्शियम को थोड़ी मात्रा में विटामिन डी के साथ लेनेसे अस्थि में छीणता व टूटने की संभावना कम हो जाती है।

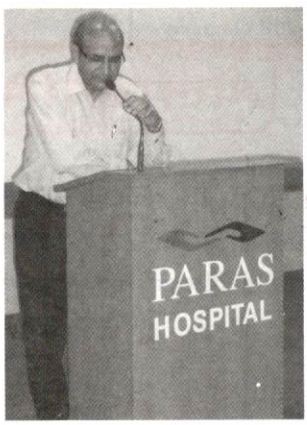
पिट्रयुटरी ग्रंथी पुरुषों में अंडकोश व स्त्रीयो में अंडाशय में लोहे का जमना भी ओस्टीयोपोरोसिस कारक है। स्त्रियों में इस्ट्रोजन व परोजेस्ट्रान अपरोक्ष रुप से तथा पुरुषों में टैस्टोस्ट्रान परोक्ष रुप से अस्थि निमार्ण मे सहायक होते हैं। रक्त की मात्रा कम होने पर रीढ़ की कमर वाली अस्थियों में बोन मिनरल डेन्सिटी की कमी पाई जाती है। अस्थि में लोह एकत्रित होने से अस्थि के खनिजकरण में बाधा पहुंचती है जिससे हड्डी कमजोर होती है आवश्यकता से अधिक मात्रा में लिया गया डैस्फराल अस्थिकरण में बाधक है ।

थैलासीमिया मेजर विशेष रूप से थैलासीमिया इंटरमीडिया में खून की कमी को पूरा करने के लिये अस्थि भज्जा अतिरिक्त रक्तकण बनाने के कारण फैल जाती है। यह भी अस्थि विनाश का एक विशेष कारण है।

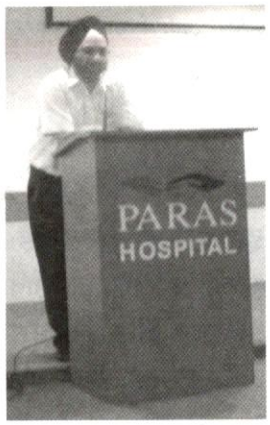
Mrs. & Mr. Bharat Kumar giving prizes to winning Thalassemics.



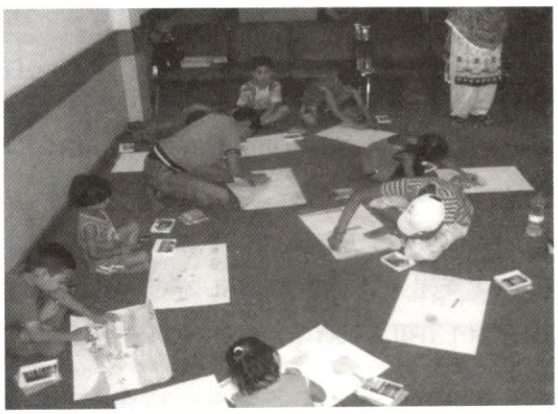
Dr. V.P. Choudhry speaking on diet in Thalassemia.



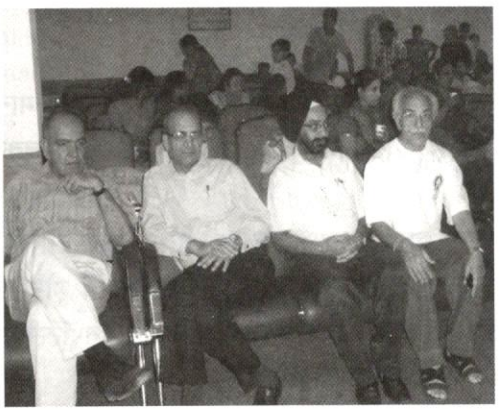
Dr. Jagdish Chandra speaking on Blood Transfusion in Thalassemics.



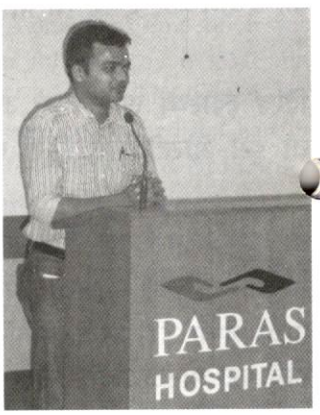
Dr. J.S. Arora speaking on importance of Chelation.



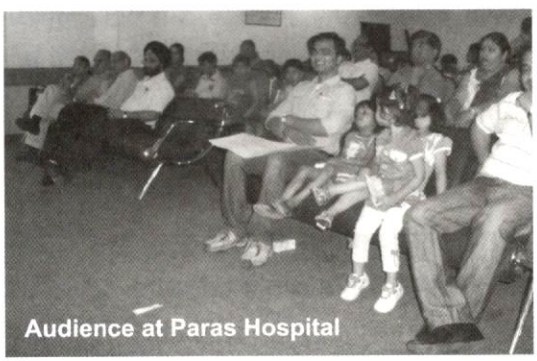
Drawing Competition organised by Gurgaon Thalassemia Society.

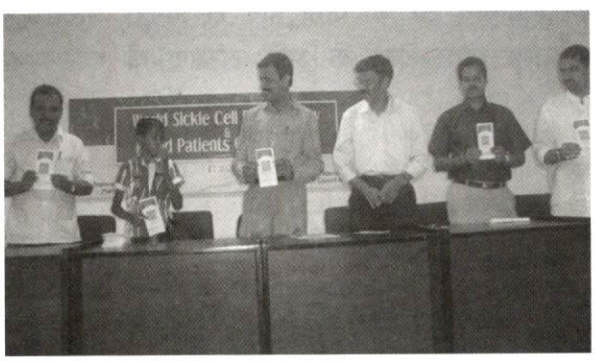


Air Marshal Bharat Kumar, Dr. Jagdish Chandra, Dr. J.S. Arora & Dr. V.P. Choudhry among audience at Paras Hospital.

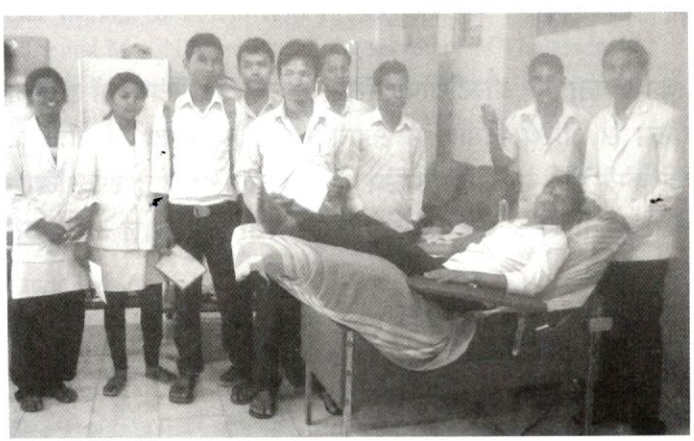


Mr. Latesh Jain announcing the prizes.





World Sickle Cell Day Observed by BPPC Kozhikode.



Blood Donation Camp being organised at Dibrugarh on ITD'12.

Dr. J.S. Arora and Dr. Alok Ahuja discussing current status of Thalassemia in Dehradun with Dr. Nancy F. Oliveri.

अपने हौसलों के बल पर हम
अपनी प्रतिभा दिखा देंगे,
भले कोई मंच ना दे हमको,
हम मंच अपना बना लेंगे।
जो कहते खुद को सितारा है,
जगमगा कर उनके सामने ही:
चमक कर देंगे उनकी फीकी,
और सूरज खुद को बना लेंगे।

सावधानी हटी, दुर्घटना घटी।

आज Chelation को भुला दिया
कल को मत कहना
Diabetes ने रूला दिया।

NATIONAL THALASSEMIA WELFARE SOCIETY (Regd.)

KG-1/97, Vikas Puri, New Delhi-110018 Tel: 9311166711-712, 25511795
E-mail: ntws08@gmail.com

MEMBERSHIP

Any person can become life membership of the society by filling a form & Sending a DD of Rs. 500 in favour of : **National Thalassemia Welfare Soceity.**

For **NRI & Foreigners** Life membership fee US$100

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Address

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1. Data on file
2. Taher A, El-Beshlawy A, Daily M, et al. efficacy and Safety of Deferasirox, an Oral Iron Chelator, in Heavily Iron-Overloaded Patients with β-Thalassaemia: from the ESCALATOR Study. Eur J Haematol. 2009;82:494-99.
* Liver Iron Concentration

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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