FEDERATION of Indian Thalassemics
NATIONAL THALASSEMIA BULLETIN

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8th National Thalassemia Conference

"Cure in Sight"

Saturday & Sunday 17th & 18th December, 2016

शरीरमाद्यं खलु धर्मसाधनम्

organized by National Thalassemia Welfare Society

in association with Department of Haematology, AIIMS

Learn How to Live a Normal Life at NTWS

Mr. Sidharth Bajaj (Thalassemia Major) & his lovely family

at **JAWAHAR LAL AUDITORIUM**

All India Institute of Medical Sciences Ansari Nagar, New Delhi-110029

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Corresspondence Address :

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Activities of 25th Foundation Day 22nd Nov. 2015 & Raahgiri on Valentine's Day 14th Feb. 2016

Live Thalassemia Discussion on DD News Total Health on 8th May 2016

https://www.youtube.com/watch?v=MA3CVVaNBMM&spfreload=5

All halassemics & their parents in our country will be excited to know that National Welfare Society is organizing 8th International Thalassemia Conference on 17th & 18th December, 2016 at AIIMS. The theme of conference has been very rightly chosen as **"Cure in Sight"** after reviewing all the new development and research studies in progress. We are confident that over the next 5-10 years every thalassemic child will be cured forever with any of the following modalities.

Present Status

Over last two decades with the advent NAT testing blood has become very safe and risk of transfusion transmitted infection has reduced significantly. With wide spread use of hepatitis B vaccine administration at diagnosis and its periodical administration every five years has prevented the occurrence of hepatitis B. Prevalence of hepatitis C has greatly reduced in those children who are getting NAT tested blood transfusion from diagnosis onwards. Now the treatment of hepatitis C is readily available and with the current treatment hepatitis C infection can be cured very effectively. Those times have gone when only one chelating agent (Desferal) was available. Now we have two oral chelators such as deferasirox and deferiprone which are very effective and safe drugs. Both these agents are affordable and many state government are making these drugs available free of cost. **With continuous monitoring of serum ferritin, liver and renal functions, MRIT$_2$* these children can be effectively chelated.** A multi centric study by Borgna – Pignatti has shown that over 90% children born after 1995 are alive and have normal life with current protocol regimens.

Transfusion Free Life

Various genetic mutations in thalassemia results (a) ineffective erythropoiesis and (b) increased signaling of Smad 2/3 path way. Now a molecule ACE-536 has been developed which binds with Smad 2/3 signaling ligands GDF II and GDF-18 with high affinity and results in normalization of hematopoiesis. ACE-536 (Luspatercept) not only corrects the ineffective erythropoiesis, but reduces the hemolysis, complications of the thalassemia (leg ulcers) and iron overload. Recently results of phase II study were presented in ASH.[3] Blood transfusion requirement was reduced in 40% of transfusion dependent thalassemic children besides reduction in liver iron content. Among 25 patients of non-transfusion dependent thalassemia (thalassemia intermedia) hemoglobin levels increased in majority of patients with healing of leg ulcers in all three cases. Further studies are in progress to determine its effective dose, safety and long term results.

By antisense technology a new drug has been developed which suppresses hepcidin (a peptide hormone which controls the iron homeostasis in the body) in the blood. Low levels of hepicidin increases the iron absorption there by it increases the morbidity and mortality in thalassemic children. Antisense oligionucleatides (ASO) mouse TMPRSS-6 has been developed which is resulted in reduction of serum iron and ferritin levels in mouse model of beta thalassemia. By this therapy anemia was corrected along with reduction in iron levels. Studies are in progress to develop the drugs for human TMPRSS-6. Similarity other drugs Pleckstrin-2 has been found to be effective β-thalassemic mouse model studies.

Development of such drugs may increase the hemoglobin levels significantly in subsets of thalassemic children to offer them complete cure.

Chelation Therapy

Presently available chelators are being further modified to make them more thalassemics friendly. Novartis has improved the Deferasirox and launched its product which is more effective and can be taken any time of the day even with food. Similarity Deferiprone with sustained release formulation have been developed and thus it can be administered in a single dose. Combination of Deferiprone and Deferasirox have now been evaluated in multiple studies which have clearly shown that combination of these two drugs is safe and effective in reducing the serum ferritin and normalization of cardiac and liver MRIT$_2$* values. **Multiple strategies based upon serum ferritin, liver and cardiac T$_2$*, transfusional iron burden have been suggested with the aim to maintain serum ferritin of 1000 ng/ml for long term survivals.**

A novel iron chelator SP-420 has been found to be very effective, safe and with reduced renal toxicity. Another agent Eltrombopag has been found to be very effective and strong in mobilizing cellular iron and reducing the serum ferritin levels greatly. Studies are in progress to evaluate its efficacy and safety as oral chelator either alone or in combination with other available oral chelators. **Development of such chelator will prolong the life of thalassemic children.**

Bone Marrow Transplantation / Stem Cell Transplantation

Professor Guido Lucarelli has demonstrated beyond doubt that the sibling bone marrow transplantation (BMT) offers complete cure for thalassemic children. They had developed risk stratification based on three criterias such as

1. Chelation status, **2.** Hepatomegaly **3.** Hepatic fibrosis

Class I: Children, who are well chelated, have no hepatomegaly or hepatic fibrosis

Class II: Children with one or two above risk factors

Class III: Children with presence of all three risk factors

Results from Pesaro in large number of patients are given in table 1

Table 1: Results of Bone Marrow Transplant from Pesaro[8]

Risk Status	Survivals (%)	Thalassemia Free Survivals (%)
1	93	90
2	87	84
3	79	58
Adults	66	62

Results of bone marrow transplant were best when performed at young age and children are well chelated and have no evidence of either hepatomegaly or hepatic fibrosis. The major problem of BMT in that HLA matched sibling donor is available only in 30% of cases. Over the last few years with better understanding of B &T lymphocytes, changes in conditioning regimen and with manipulation of lymphocytes now it is possible to carry haplo (half matched) bone marrow transplants. Parents and siblings of thalassemic children will have 50% of HLA match. Thus every thalassemic child can undergo haplo BMT. Major problems with haplo BMT at present are (a) At present the results of haplo BMT are poorer as compared with fully matched sibling BMT (b) Cost of haplo BMT is nearly two to three times that of the conventional BMT and (c) Only few centers have initiated this facility and also have limited experience. Presently most centers in the World prefer to do conventional bone marrow transplant. **Over the years it is expected with further improvement in T & B cell manipulation and further improvement in the conditioning regimens the results of haplo BMT will become comparable with fully matched BMT.** Thus the complete cure for all thalassemic children is in sight with haplo BMT in near future.

Gene Therapy

Over the last two decades scientists at multiple centers have been working hard with commitment to develop gene therapy so that mutation of beta thalassemia can be corrected in hematopoietic stem cells of thalassemic children. The major hurdle was to develop a vector which could slice the mutational gene from stem cells and insert the normal gene. Among various vectors lenti viral gene (lenti globin BB 305) has been developed by team of research workers at Harward Medical School and Boston Children Hospital. In the ongoing Northstar study 13 children with β-thalassemia major have undergone gene therapy till 28th Oct, 2015. No major complications were observed in these patients and there was no evidence of clonal dominance or replication of lenti virus up to 19 months follow up.

Similarly at Ramathibodi hospital, Mahidol University Bangkok Thailand 34 patients have been enrolled for gene therapy. Twelve patients with β-thalassemia major and two with sickle cell disease have already undergone gene therapy. Their first patient has been transfusion independent for 8 years. Twelve patients of β-thalassemia have become transfusion independent or needing much reduced transfusion than before. Several other centers in the World have also initiated their studies on gene therapy. American Society of Hematology (ASH) in their 57th Annual meeting the abstracts on gene therapy were selected as Best of ASH and were featured in the presidential symposium. Dr. Marcela Maus Director of cellular immunotherapy at the Massachusetts general hospital cancer center stated **"I am thrilled with these results. It seems that gene therapy is becoming a clinical reality"**

Approach for gene therapy is potentially safer because it requires milder conditioning regimens. Patients own stem cells are removed, manipulated in the laboratory with the insertion of corrected gene in place of the defective gene and subsequently these stem cells are transfused back to the patients. It is expected over the next few years that the procedure of gene therapy will be further perfected and will be available at multiple centers in the World including India. **Thus all thalassemic children over the World will be cured of thalassemia.**

In conclusion there have been advances in all aspects of management of thalassemia such as (a) transfusion therapy, (b) chelation therapy, (c) monitoring of therapy, (d) early detection of complications and their management, (e) development of haplo BMT, (f) gene therapy etc. With these developments all thalassemic children will be greatly benefitted. The pace of development in haplo BMT and gene therapy has been so fast that the medical professionals at present strongly feel that the **"Cure is in Sight"** for thala ssemia in near future.

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How to select iron chelators

By Chi Kong Li

Vice-chairman, Paediatric Haematology Committee, China

Abstract: With three iron chelators available in many countries, a great number of thalassaemia patients now have a selection of therapies to choose from. For many, the long-sought after option is oral, doing away with the need for invasive injections. However, other aspects of treatment are also important, including socio-economic factors, patient age, severity of iron overload and the organs affected—not to mention availability. New oral iron chelators currently under study offer the hope that such therapy will one day be a reality for all thalassaemia major patients, irrespective of age or income.

The three iron chelators currently available are deferriox- amine, deferiprone and deferasirox. Deferrioxamine, which is administered sub-cutaneously, has the longest history of clinical use, and its efficacy and side effects are well known to clinicians. The oral chelator deferiprone has gained in popularity following its approval by the European Medicines Agency (EMA) and boasts a superior ability to protect the heart, which has been shown to improve survival in many studies. The combined use of deferrioxamine and deferiprone is now recommended by many clinicians for patients who have severe iron overload, especially cardiac overload as demonstrated by MRI. The third chelator, deferasirox, is also oral, providing patients and their doctors with a further alternative for the removal of excess body iron.

In most western countries, the number of new cases of thalassaemia major is decreasing or is maintained at very low incidence. However, in countries lacking comprehen- sive prenatal screening programmes, the number of new cases born each year remains significant. These transfu-sion-dependent children usually develop excess body iron and begin chelation therapy at 2-3 years of age.

The standard treatment is the subcutaneous administra- tion of deferrioxamine in the region of the abdomen, demanding a great deal of young patients and of the par- ents who must come to terms with the difficult task of inserting a needle into their child.

The oral chelator deferasirox can be given to children as young as 2. However, the drug remains prohibitively expensive for most families in developing countries, despite the manufacturer's efforts to reduce costs.

The other oral chelator, deferiprone, is not suitable for children under the age of 5. Previously only available in tablets, deferiprone has recently been introduced in solu- tion form. A six-month clinical study of deferiprone solu- tion administered to 59 children under the age of 6, con-ducted in Egypt, Malaysia and Indonesia, demonstrated short-term efficacy in reducing serum ferritin. Assuming the same biological efficacy as the tablet form, deferiprone solution certainly benefits young children most, and they may not require injectable iron chelation in the future. However, the long-term effects on young chil- dren of deferiprone, including side effects, are still unknown. Two of the 59 children receiving deferiprone solution developed agranulocytosis within the six month period, while 6% developed mild neutropenia. It is not known whether the incidence of agranulocytosis increas- es with longer duration of deferiprone treatment.1 Joint pain or arthralgia occurred in 4% of patients; one patient experienced severe joint pain that required discontinua- tion of deferiprone treatment. Whether young children with growing skeletal system will be more prone to joint toxicity is a question that requires further study. The accu- mulation of more clinical data over a longer period are therefore required before recommending deferiprone as first-line treatment in young children.

A number of studies of older patients over the past 10 years have concentrated on the prevention of cardiac toxicity and thus improved survival. The administration of deferiprone alone or in combination with deferrioxamine has been shown to be more effective in removing excess iron from the heart. Deferasirox has also been the subject of careful study regarding cardiac protective effect. A one-year study showed that mild to moderate cardiac iron overload patients benefit more from deferasirox as the T2* meas- ured on cardiac magnetic resonance with better improve-ment of T2*. Follow-up studies indicated further improve- ment in cardiac iron status at two and three years.2,3

The process of removing iron from heart cells is slow and it may take several years to achieve very good clearance of heart iron. In patients with severe heart iron overload, as demonstrated by T2* < 6ms, the chance of developing heart failure is 47% in one year.4 Such patients should receive intensive iron chelation to prevent heart failure, with most experts recommending a combination of deferiprone and deferrioxamine. However, studies have shown that about 25% of patients on combination treat- ment have to stop combined treatment, with agranulocy- tosis cited as one of the main reasons. The combined uses of deferrioxamine and deferasirox, or deferasirox and deferiprone, have not been subject to full investigation, with the exception of a few individual cases. However, patients are more likely to comply with a treatment of combined oral iron chelators, making it an option that may thus improve survival. Deferiprone has better cardiac pro- tective effect, while deferasirox appears to provide good clearance of liver iron. The combined use of both agents may therefore achieve better overall control of total body iron. Lower doses of either agent used in combination may be possible. However, careful study is required into the optimal recommended dosage of each, and the toxicity profile of combined chelators

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25th Foundation Day 22nd Nov. 2015

National Thalassemia Welfare Society observed its 25th Foundation Day on Sunday, 22nd Nov 2015 at 8 Dr BD Marg, New Delhi 110001 at the residence of Sh. Hansraj Ahir, (Hon'ble Union Minister of Chemicals & Fertilizers). The function started in the evening by 5:00 pm and ended by 9:00 pm. Around 250 thalassemia patients/parents gathered to showcase their talent and raise their voice for better management & prevention of Thalassemia disease.

Dr. Soumya Swaminathan, Director General ICMR inaugurated the function by lighting the lamp. Unfortunately Sh Hansraj Ahir Ji did not make to the event due to some other commitments. Dr. Soumya Swaminathan was really happy to grace the occasion. She committed to work on the prevention of Thalassemia. She said that she would love to associate with National Thalassemia Welfare Society for the care and control of Thalassemia.

Km. Surrendar Saini (President, NTWS), Padma Bhushan Awardee and a role model for social sector of our country illustrated the journey of NTWS. While addressing the audience Dr. JS Arora (General Secretary NTWS) highlighted the achievements of society during last 24 years, the hurdles overcome, and the future goals.

Dr. VP Choudhry (Medical Advisor, NTWS) imparted about his remarkable association with National Thalassemia Welfare Society for past 24 years. Dr. Choudhry expressed gratitude to our President Km. Surrendar Saini for her honorable contribution towards the society.

After that a very little angel Arushi Mishra (Thalassemia Major) performed Kathak Dance which was highly appreciated by all. Her dances made the audience enjoy the lovely evening ambience sitting in the open.

Ms. Jyoti Arora a Thalassemia Major patient and author of two novels 'Dreams Sake' & 'Lemom Girl' showed her concern that in spite of best possible treatment Thalassemia patients are unable to compete with their peers on one hand and on other hand even if they are eligible by competition & deserve their due they are refused jobs on one pretext or the other. If they are covered under Disability Act then they will be in a position to achieve desired level of competence and will be able to livelihood without support of their parents or after parents (expired). A very young boy Sarthak Chabra (Thalassemia Major) sang a song alongwith his guitar. His performance completely changed the aura of whole evening to a very soothing note.

And then all the dignitaries felicitated the performers of the day & 3 Lucky Draws were released out of all the 50 coupons.

The last item and much awaited attraction of the day, DJ got started for all the thalassemics. Each and every Thalassemic patient and parents shake their boots on the dance floor with full zeal which added the cherry on the cake of the Foundation Day evening.

After that scrumptious dinner was served for all and then the event got ended with mouth relishing sweets and a wonderful memorable return Gift for all.

Raahgiri on Valentine's Day 14th Feb. 2016

Thalassemia Awareness Campaign was conducted at Raahagiri, Connaught Place on 14th February, 2016 on Sunday. Delhi from all corners of the city started pouring in from 6 am onwards. An hour later, the stage was crowded, there was music in the air with happy Delhi Raahgiris. It was the freedom to walk on the streets of Connaught Place that was important. Mrs. Vandana Arora, Mr & Mrs Rajesh & Neelam Khurana also spend their time with Raahgiris. Dr. Swarana Anil had brought her dog Maximus, who was also spreading message on Thalassemia prevention.

Thalassemia Awareness Campaign involved the enthusiastic participation of students who performed dance on the stage. Little master Ayush perfomed his favourite MJ dance. Ankur Theatre Group from SBTB Khalsa College Delhi University performed a street play on Thalssemia Prevention lead by Ammucare. This Campaign began enthusiastically with welcome speech by Dr. J.S. Arora.

It was followed by various events lined up for cool air. The students actively participated on D.J. Stage show, Mass awareness, Nukkad natak, Quize & Prizes, Comedy Show and Walkathon. The students took great effort and ensured that public enjoy every minute.

Dr. J.S Arora, Dr. A P Dubey, Dr. Jagdish Chander & Dr. Dharma Choudhry highlighted the tips of maintaining a Thalassemia Major and appealed all the audience for Thalassemia Test before marriage. It was a nice initiative to create mass awareness about the dreaded disease Thalassemia.

The winner of the various events were awarded with mementos, certificates & PVR cinema tickets. The main idea behind the Campaign was to highlight the various aspect of thalassemia. Mrs. Vandana Arora, Dr. Swaran Anil, Mrs. Neelam Khurana and Rajesh Khurana thanked the guested and delegates. This event was a great success.

Swasthay Sanjivini

Dr. J.S Arora and Dr. Jagdish Chandra were invited to Swasthay Sanjivani Phone in program of AIR on Monday Ist February 2016 from 7.05 am to 7.55 am. The theme of program was. थैलासीमिय चिकित्सा प्रबंध Almost every aspect of the Thalassemia management and prevention were covered. Many Questions were put up by the listeners.

Ahmedabd

Dr Nikhil Sekth and Dr Anil Kahtri organized a CME at Lions Club Hall, Mithawadi, Ahmedabad on 26th June 2016. Dr V.K Khanna from Ganga Ram Hospital Delhi and Dr J.S Arora from National Thalassemia Welfare Society were invited faculty. Dr J.S Arora Spoke on the management of Non-Transfusion dependent Thalassemia. Dr Anil Khatri delivered a lecture on Transfusion Therapy in Thalassemia Major. Dr Nikhil Sekth stressed the need of MRI T2* for Iron overload monitoring. Dr V.K Khanna enlightened the audience how to manage adult Thalassemics. Ms Sangeeta Wadhwa specially flew from Mumbai to manage the stage.

Free INFUSION PUMPS to the underprivileged patients











Thalassemia ward, Civil Hospital, Jalandhar, Punjab

3 Lucky draw winners of free PVR couple movie tickets

Free Thalassemia Checkup Camps on 19th March & 28th June 2016, Patna

Thalassemia Checkup Camp, Hisar

Thalassemia Checkup Camp, Jammu

CME at Ahmedabad

Christmas Carnival at Radisson Blu, Dwarka



Sh. Rajiv Babber & Sh. Mahendra Yadav, MLA Vikaspuri & Councillor Sh. Ashok Saini donating blood




World Blood Donor's Day, 14th June 2016

Workshop on Thalassemia

Diagnostic Dilemma

On Friday, 16th December, 2016 *at* AIIMS, New Delhi

Stem Cell Transplantation

On Monday 19th December 2016 at Army R & R Hospital, Dhaula Kuan, New Delhi-10

REGISTRATION FORM FOR WORKSHOP

Name.....

Qualification.....Designation.....

Field (Paediatrician, Physician, Pathologist, Blood bank officer, Gynaecologist, other)…….....

Hospital/Clinic Address.....

.....

Mobile No. :..... Email.....

Residential Address.....

.....Mobile No. .....

I wish to register for Workshop Diagnostic Dilemma/Stem Cell Transplantation/Both. I am submitting a

Cheque/DD No.....Dated.....for Rs…….....……

Rupees in Word .....

Drawn on bank ..... Branch .....By Cash .....…against

Receipt No……

Dated .....

Signature

Secretariate :

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KG-1/97, Vikas Puri, New Delhi-110018
Mob. : 9311166710-711-712
E-mail : ntws2015@gmail.com
Website : www.thalassemiaindia.org

Note :

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

Please fill separate form for conference and workshop. However total amount can be paid by through single DD/Cheque

REGISTRATION FEES

WORKSHOP (One WORKSHOP)	:	**Rs. 500**	**before 15th August 2016**
		Rs. 700	**15th Aug. to 30th Nov. 2016**
		Rs. 1000	**On the spot Registration (1st Dec. to 15 Dec. 2016)**
Both WORKSHOP	:	**Rs. 800**	**before 15th August 2016**
		Rs. 1200	**15th Aug. to 30th Nov. 2016**
		Rs. 1800	**On the spot Registration (1st Dec. to 15 Dec. 2016)**

NOTE : Workshop registration will close as soon as the required number of doctors have registered

Mode of Payment :

Drafts/Cheques should be drawn in favour of **"National Thalassemia Welfare Society"** payable at Delhi.

Add Rs.50/- for outstation cheques. Please write **your Name and Phone No.** on back of the DD/Cheque.

Send registration fee by Demand Draft/Cheque or Cash against receipt

For Bank transfer. Bank details are as under :

Bank - YES BANK, Vikaspuri, New Delhi, India
Account No - 038894600000162
IFSC Code-YESB0000388
PAN - AAATN 2048P

General Information

Wise Folks-Upto 8th May, 2016

Patient 12yrs & above	**Rs. 100.00**
Parent/Doctor/Friend	**Rs. 300.00**

Nice Folks-Upto15th August, 2016

Patient 12yrs & above	**Rs. 150.00**
Parent/Doctor/Friend	**Rs. 400.00**

Precise Folks-Upto30th November, 2016

Patient 12yrs & above	**Rs. 200.00**
Parent/Doctor/Friend	**Rs. 500.00**

Modernise Folks-1st December, 2016 onwards

Patient 12yrs & above	**Rs. 300.00**
Parent/Doctor/Friend	**Rs. 600.00**

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 15th October, 2016.

Accommodation Charges :

Class A	**Rs. 1500/-approx. per day**
Class B	**Rs. 5000/-approx. per day**
Class C	**Rs. 11000/-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 **National Thalassemia Welfare Society** payable at Delhi/New Delhi. Please add Rs. 50/- for outstation cheques.

IMPORTANT CUT OF DATES :

8th May, 2016 Nominal Charges
15th August, 2016 Concessional Registration
15th October, 2016 Last date for Accommodation

NOTE :
Children below 12 are not allowed.
Additional members will not be provided a Conference Kit.

CONFERENCE SECRETARIATE :

Dr. J.S. Arora (Organising Secretary)
KG-1/97, Vikas Puri, New Delhi-110018
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E-mail : ntws2015@gmail.com, drjsarora2016@gmail.com
URL : www.thalassemiaindia.org

REGISTRATION FORM

1) Patient/Parent/Doctor_____Age/Sex_____

2) Patient/Parent/Doctor_____Age/Sex_____

3) Patient/Parent/Doctor_____Age/Sex_____

Address :_____

_____Pin Code_____

Mobile 1)_____ 2) _____

E-mail : _____

Accommodation required : Yes/No No. of Persons :_____

Category : A B C

Arrival Date & Time :_____

Departure Date & Time :_____

Registration Fee_____Accommodation Charge_____

Total Rs._____Rupees (in words)_____

_____

D.D./*Cheque in favour of* ***"National Thalassemia Welfare Society"***

D.D./Cheque No :_____Date_____

drawn on :_____

for Rs. :_____Rupees_____

Please specify "Your Interest & Concern"_____

_____

Date_____Signature_____

NOTE :

- **Registration form can be photostated.**
- **No cancellation is allowed once the registration fee/accommodation charges are paid.**
- **No refund/adjustment will be entertained.**

For Office Use Only.
R.No. _____
Date _____
Reg. No. _____

Bareilly

Thalassemia Checkup Camp was Organized on 28th February 2016 By Thalassemia Children Welfare Society of Bareilly at IMA Blood Bank Bareilly. Dr. J.S. Arora & Dr. Dinesh Bhurani Visited from Delhi to check the Patients. 25 Patients were examined. Dr. J.S. Arora gave a lecture stressing the need of maintaining Hb above 10gm & ideal Chelation. He advised the patient above 10 Year of age should undergo MRI T2* Iron studies once in a year, only serum ferritin is not reliable. Dr. Dinesh Bhurani told the audience that patients below 7 years of age if adequately transfused and chelated have best success rate so plan for BMT as early as possible.

Dr. J Sardana thanked IMA Blood Bank for helping Thalassemia Patients by Providing blood free of cost. She extorted Thalassemia families to be Blood Donors & Organize Blood Donation Camps. so that our Thalassemic Children should not face shortage of Blood.

International Thalassemia day, Bareilly

International Thalassemia day was celebrated in Bareilly on 8th May 2016 As soon as our Chief guest Mrs. Vrunda Desai Joint Commission Income Tax and Wife of Sh. Gaurav Dayal , DM Bareilly arrived all the children gathered and presented rose to her. She really enjoyed the moment with Thalassemic Children more than to Children with Parents attending the Camp. Drawing and Painting Competition was held among thalassemic Children. Mrs. Vrunda Desai enjoyed the wonderful poem and speech by thalassemic children. Gift were given to all the children. Free Chelation medicine, Folic acid and calcium were distributed to poor and needy Children sponsored by Golden Era Society Bareilly and inner wheel Club. Mrs. Vrunda Desai took keen interest to help Thalassemia Children. As promised Dr. Ravish Agarwal President of IMA Bareilly, the IMA Bareilly started the Thalassemia Screeninig Camp at subsidzed rate for Docters and their Families on 8th May 2016. Dr. Anju Uppal Director of IMA Blood Bank assured to provide safe blood to all who need it. Programme ended with Cake Cutting and Lunch sponsored by IMA, We are thankful of Dr. Ravish Agarwal president IMA, Dr. Anju Uppal , Dr. Parul Priya, Dr. SK Sardana, Mr.. Mukesh Agarwal, Dr. Amit Jindal for their Co-operation.

Patna

Thalassemia Checkup camp was organized on 19th & 20th March 2016 at Patna High Court Premises by Thalassemia Society of Bihar, General Secretary Mr NN Vidhyarthi . Dr J.S Arora examined around 50 patients. Patients of outside Patna were examined on 19th March 2016 local city patient were asked to come on Sunday. 29 year old Thalassemia Major Mitali was introduced by Dr J.S Arora as one of the best maintained Thalassemic in patna. She has been adequately treated by the parents. She Said "I am well maintained and a teacher in a school. I would like to advice to all the parents to provide adequate transfusion and chelation to their children since beginning and always be in touch with thalassemia specialist Doctors.

On 28th June 2016 Thalassemia Society of Bihar celebrated its 2nd anniversary by organizing free thalassemia checkup camp at Saroj Hospital, Kankarbagh, Patna. Dr J.S Arora from Delhi was invited to check up the patients and give advice for adequate treatment. Dr Archna Jain practicing gynaecologist, Dr SK Agarwal medical specialist Patna Medical College and Dr Sunil Kumar director Saroj Hospital also graced the occasion. Mr N.N Vidyarthi General Secretary of Society invited the parents to join him to improve facilities at Patna.

Jalandhar

Free Thalassemia Checkup camp was orgnanised on Sunday 27th March 2016 at Civil Hospital Jalandhar. Dr JS Arora & Dr Dinesh Bhurani examined 46 patients. 24 patients were given FREE medicines courtesy Mr SS Khattar and Mr Gagandeep Singh Khattar. Mr TS Bhatia, Mr MS Thapar and other members of Jalandhar Thalassemia Welfare Society organised the camp. Civil Hospital Jalandhar Thalassemia ward is one of the most decorated ward. concepted, created and maintained by Jalandhar Thalassemia Welfare Society General Secretary, 80 Years Sd.TS Bhatia

Jodhpur

Thalassemia health checkup and awareness camp organize by department of pediatrics S.N. Medical College Jodhpur in association with Marwar thallassemia society, VHFRC and SEAIT JAIPUR in Jodhpur, on 24 April 2016. Dr. V.P. Choudhary checked the thalasemics and aware them about the proper chelating agent and advised to give blood in adeqate quantity to maintain S.feritin in control. He also awared them to maintain Hb more than 10 gm to have proper growth. Dr. Priya (SEAIT JAIPUR) also checked the patients and enlightened them about BMT. The camp was sponsored by Vasundhra Hospital. Dr. Pramod Sharma HOD deptt of pediatrics S.N. Medical College also addressed to the patients.

Gurgaon

Dr. J.S Arora was invited by Ciena India Pvt. Ltd to creat awareness about thalassemia and blood donation among their employees. A webinar was arranged where the employees participated the seminar from the comfort of their workstation. This was followed by blood donation camp on the 18th May 2016.

Jammu & Kashmir

Jammu & Kashmir Thalassemia Welfare Society organized a thalassemia checkup camp on 14th & 15th May 2016. Patients from outside Jammu. Were examined on 14th May 2016. A CME was also organized on Saturday at Maharaja Gulab Singh Govt. medical college Jammu

Dr. V.P Chaudhry spoke on conventional management while Dr. J.S Arora enlighten on permanent Cure during this activity executive of Jammu and Kashmir Thalassemia Welfare Society and staff of MGSGMC Hospital paid homage to their departed leader Mr. G.M Pathak the founder General Secretary, and presented a memento to his family.

Local Jammu Patients were examined on 15th May 2016. Dr. J.S Arora and Dr. V.P Choudhry examined 76 patients during their visit in this camp.

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Blood Donation Camps organized by NTWS

Date	Venue	Blood Banks	Units
06-08-2015	MDI, Gurgaon	LHMC	84
19-08-2015	Walmart, Gurgaon	RML	64
30-09-2015	Radisson Blu, Dwarka	DDU	34
01-10-2015	Delhi Metropolitan, Noida	AIIMS	75
06-10-2015	E4E Health Care, Noida	AIIMS	59
09-10-2015	E4E Health Care, Noida	RML	48
28-10-2015	SPM Autocomp, Manesar	AIIMS	81
02-11-2015	IITM, Janakpuri	RML	83
04-11-2015	IINTM, Janakpuri	RML	104
29-11-2015	Nirvana Country, Gurgaon	DDU	49
03-11-2015	SOIL, Gurgaon	LHMC	41
16-12-2015	DHFL Pramerica, Gurgaon	RML	72
20-02-2016	Mc Donald's, Rajendra Place	DDU	40

Date	Venue	Blood Banks	Units
04-03-2016	Bharti Care, Worldmark-2 Aerocity	DDU	76
10-03-2016	Bechtel India, Gurgaon	DDU	105
10-03-2016	Bechtel India, Gurgaon	LNJP	18
22-04-2016	Shiv Mandir, Ladrawan	DDU	41
13-05-2016	Walmart, Gurgaon	DDU	62
18-05-2016	Ciena, Gurgaon	RML	50
18-05-2016	Ciena, Gurgaon	LHMC	55
19-06-2016	Arora Polyclinic, Vikaspuri	DDU	82
21-06-2016	Vatika Triangle, Gurgaon	DDU	39
23-06-2016	Vatika First India Place, Gurgaon	DDU	54
25-06-2016	Vatika City, Gurgaon	DDU	16
27-06-2016	Vatika City Point, Gurgaon	DDU	62
30-06-2016	Vatika Professonal Point, Grugaon	DDU	67

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NATIONAL THALASSEMIA WELFARE SOCIETY (Regd.)

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Free Thalassemia Clinic, 2nd Sunday every month
Registration time : 9am to 12 noon

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Near Gurudwara Singh Sabha,
Block – 12, Tilak Nagar, New Delhi-110018
Ph.: 9311166710-711-712

MEMBERSHIP

Any person can become Member of the Society by filling up the requisite form and sending a DD in favour of :

National Thalassemia Welfare Society

Form can be download from **website : www.thalassemiaindia.org**

Life Member	**Indian**	**INR**	**500**
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