



# FEDERATION of Indian Thalasseemics NATIONAL THALASSEMIA BULLETIN

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Release of Souvenir, Left to Right Dr. J. S. Arora (General Secretary-NTWS), Dr. D.K. Sharma (MS-AIIMS), Km. Surrender Saini (President-NTWS), Mr. Hansraj Ahir (MP-Lok Sabha), Dr. V.M. Katoch (Director General-ICMR & Secretary Health Govt. of India), Dr. V.P. Choudhry (Former Prof. & Head Dept. of Haematology-AIIMS and Mr. D.P Yadav (Former Deputy Union Minister).

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# 6th National Thalassemia Conference, 21st & 22nd Nov.' 2010



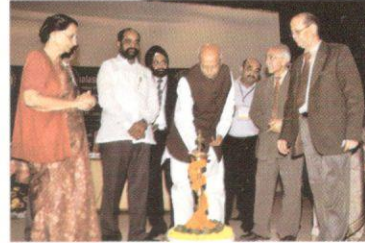
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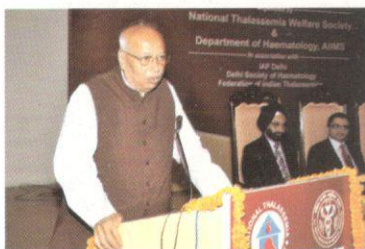
Chief Guest  
Dr. V. M. Katoch  
lighting the lamp



Dr. V. M. Katoch  
addressing the  
audience



Mr. D. P. Yadav  
Former Union Minister  
& Vice President, NTWS  
lighting the lamp



Mr. D. P. Yadav  
giving his address



Km. Surrender Saini  
alongwith other  
dignitaries lighting  
the lamp



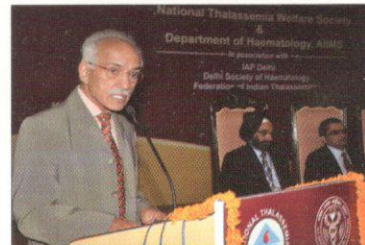
Km. Surrender Saini  
Padma Bhusan Awardee,  
President, NTWS, giving her  
presidential address



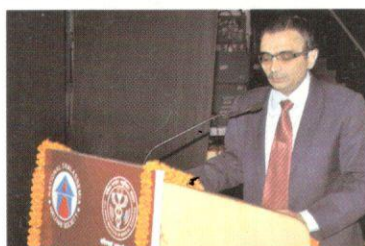
Dr. J.S. Arora  
General Secretary  
(NTWS) lighting  
the lamp



MP, Mr. Hansraj Ahir  
sharing his idea



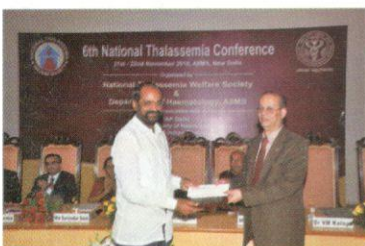
Dr. V. P. Choudhry  
giving his address



Dr. D.K. Sharma  
MS AIIMS  
addressing the  
audience



Km Surrender Saini  
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Dr. Katoch

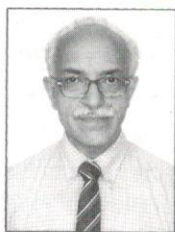


Dr. V.M. Katoch  
giving Best Social  
Worker Award to  
MP, Mr. Hansraj Ahir



Dr Roshan Colah  
recieving  
Dr. B.N. Dara Award  
from Dr. Katoch



**Dr. V. P. Choudhry**

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Former professor & head Hematology AIIMS  
Director

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## MOVING MOUNTAINS

It is indeed a heartening news for 5 crore Thalassemic carriers in India that Government will launch a National Programme for the Eradication of Thalassemia. Policy decision of major importance has been taken during a three day meeting held between 11<sup>th</sup> & 13<sup>th</sup> January, 2011 under the chairmanship of the Union Minister of Health & Family welfare Sh. Ghulam Nabi Azad, Ministers of Health & Medical Education from 16 states and principal/ secretaries and directors of Health & Medical education from 28 states/ Union territories and senior officials of the Central Ministry of Health & Family Welfare were present. In this meeting under non communicable diseases the resolution states. "Government will launch a national programme for eradication of thalassemia ". This decision has come as a result of pursuance for Thalassemic eradication programme by several bodies such as Indian Council of Medical Research Ministry of Biotechnology and various NGO such as National Thalassemia Welfare Society, Federation of Indian Thalassemic etc. Several countries such as Cyprus, Sardinia, Greece etc have shown to the World that Thalassemia has been successfully eradicated in their countries. Several muslim countries such as Iran, Saudi Arabia where termination of pregnancy is against their religion along with UK & other countries have initiated thalassemia control programme in their countries several years back. It is amply clear that such a programme is very cost effective and essential if pursued with total sincerity, commitment and with clear targets.

With the above resolution the technocrats, medical fraternity and officials of Ministry of Health & Family welfare need to plan out a clear programme for eradication of thalassemia in our vast country while keeping in view the complexities of hemoglobinopathies and its various combinations. It is essential to follow principles of success which include a). To increase the awareness of the disorders in the community. b). To educate the community regarding the problems of thalassemia, its management & it's cost to get their co-operation c). To initiate training of large number personal for screening programme. d). To develop laboratories and train laboratory personal for molecular diagnosis. e). Training of doctors for techniques such as chorionic villus sampling. f). To maintain internal & external quality control. g). Complete involvement of the community leaders, religious bodies and all N.G.O associated with thalassemia care & control in different regions. Adequate funds need to be made available along with very strong political will for the success of the programme and accountability at all levels. In addition it will be essential to develop day care services to provide regular blood transfusions, adequate chelation

## EDITORIAL

therapy and to carry monitoring of thalassemic patients for early detection of complications of the disease and their management. Such a step will ensure complete co-operation of all thalassemic families for the eradication programme. We need to learn from Thalassemia eradication programme of other countries regarding several difficulties faced and errors committed by those countries.

Several National Programmes have been conducted under Ministry of health Government of India since independence. All of them have been well planned & sound excellent on paper to control various diseases. But in reality many of them have failed to achieve their objectives. The strategies of these programmes were modified in subsequent years and even the objectives were re-defined for their success. The National malaria control programme was initiated in 1953. National leprosy programme in 1955, National Tuberculosis programme in 1962 etc are still continuing and all these diseases are still rampant with significant morbidity & mortality. Nutritional anemia control programme which was launched in 1970 but its evaluations under ICMR Task Force study in 1989 revealed that prevalence of anemia in certain population had increased while in other area it was almost same inspite of the fact that the programme was being executed for over 18 years. Universal Immunization Programme for Polio was initiated in 1985. Subsequently the Pulse Polio Immunization (PPI) was launched in 1995-96. To achieve the global goal of reaching zero incidence of polio by 2000 A.D. PPI programme was intensified in 1999-2000. However the programme is still continuing & till date we have not yet achieved zero incidence of polio. It is a matter of great concern that government plans excellent National Health programmes but the success of the programme is poor due to several difficulties in execution of these programmes. The major factors for failure for these health include a).health being state subject & many states possibly donot cooperate for various reasons. b).Community for which the control programme are meant is never involved at any stage & therefore the participation of the community is negligible. c). poor training and apathy of the staff. d). poor roads & transport problems in remote areas. e). poor quality of drugs, equipments etc which are purchased at lowest cost. f) politics in health issues & in execution of programmes. Other most important factor being that neither there are any targets nor accountability of any one involved for the success of programmes. Similarly community leaders, NGO of the areas and religious bodies are never involved whom people follow with great faith. It appears that the success of National Health Programmes seems as difficult as **Moving Mountains**. However if there is strong will power of government of India with community involvement with definitive goals and accountability of all concerned then the mountains can be moved. India which is emerging as great power in the World can eradicate Thalassemia. Let us all join our hands irrespective of our caste, religion, politics, etc to work for the success of the eradication of thalassemia to

*"Chak de India and mita de Thalassemia."*



## THALASSEMIA WE CARE

Tanu Verma

"THALASSEMIA WE CARE" was the theme of the 6<sup>th</sup> National Thalassemia Conference organized by National Thalassemia Welfare Society & Department of Haematology AIIMS in association with IAP Delhi Society of Haematology & Federation of Indian Thalassemics on Sunday & Monday 21<sup>st</sup> & 22<sup>nd</sup> Nov 2010 at Jawahar Lal Nehru Auditorium AIIMS with a BIG BANG.

*The conference was a four days celebration of our 20<sup>th</sup> anniversary. The four days mega event started off with a workshop on "Prenatal Diagnosis of Thalassemia" in association with Dept of Obs. & Gynae AIIMS on Saturday 20<sup>th</sup> Nov 2010 at LT-2 teaching block AIIMS. It was like a dream come true to organize a workshop for gynecologists.*

The workshop comprised of various lectures by Prominent Medical Professionals. Some of the interesting one were:

Dr. Nishi Madan Former Prof & Head Dept of Pathology UCMS & GTB Hospital spoke on Thalassemia Screening in Pregnancy. She herself was a part of the ICMR study on Epidemiology of Thalassemia. She briefed the participants about various screening methods for beta Thalassemia Trait, a recessively inherited heterozygous disorder with few or no symptoms.

Dr Suman Mendiratta, specialist Gr I Obstt. & Gyane Department Hindu Rao has done a large scale Thalassemia screening in MCD Hospitals & Schools. She is also the project coordinator Thalassemia Control Project, MCD since 05-09-2008 & Incharge Pre-marriage Counseling Clinic at Hindu Rao Hospital. She has also organized number of blood donation camps. She revealed her future plan under Thalassemia Control Project:

- Introduction of Prenatal Diagnostics Techniques and genetic laboratory in Hindu Rao Hospital.
- Installation of Automated Hematology Analyzers in maternity homes and zonal units of school health services in a phased manner.
- Introduction of Thalassemia Screening in Maternity Homes.

A lecture on counseling of Prenatal Diagnosis was taken by Dr Madhulika Kabra Additional Professor, Genetics division, Department of Pediatrics, AIIMS. She is also

member Task force for Genetic disorders, ICMR. She said that Thalassemia trait couples should contact the genetic dept as soon as the lady becomes pregnant or even before conception for timely detection of DNA mutations.

While talking on Chorionic Villus Sampling, Dr Nutan Agarwal Prof. of Obs & Gynae at AIIMS said that CVS is the safe procedure & chances of fetal loss is equal to that of prevalent in normal pregnancy.

Dr Vatsla Dadhwal Asst Prof. of Obs & Gynae at AIIMS explained Cordocentesis by video. She informed that Cordocentesis is performed at 16 - 18 Weeks of pregnancy. She added need of Cordocentesis arises only if lady reports in second trimester or DNA mutations could not be found during early pregnancy.

At the end of this workshop a panel discussion was held with the panelist Dr J S Arora, Dr Vandana Chaddha, Dr Anita Kaul, Dr Madhulika Kabra & Dr Nishi Madan to discuss various interesting cases put by Dr Nutan Agarwal. Panel discussion was followed by lunch. It was followed by a two days conference. The conference was inaugurated by Dr V.M. Katoch Hon'ble Director General ICMR & Secretary Ministry of Health, Govt of India. Mr. D.P. Yadav former Deputy Union Minister & Mr Hansraj Ahir MP, Lok Sabha were the guest of honours. The inauguration ceremony was presided over by Km. Surrender Saini Padma Bhushan Awardee & president, NTWS.

While, welcoming the delegates Dr J S Arora requested Dr V M Katoch to initiate fresh epidemiological studies on haemoglobinopathies in India on large samples as now with migration of population from one state to another state and inter community marriages in fashion the earlier studies have outlived their relevance. Dr Arora pleaded Dr Katoch to use his good office to pursue to declare Thalassemia as a National Disease under a separate section/department just like those of Malaria, leprosy, Tuberculosis etc.

Dr Arora thanked Km Surrender Saini for always been vocal on the issue of including Thalassemia in the list of disability. He reminded Ms Saini & Mr Yadav ji that both are very close to the corridors of power at centre & Delhi, so both of them should spare some time and forcefully pursue this issue.

He also made an appeal to his fellow doctors that.



Thalassemics need their gentle care and support. He pleaded before the blood bank authorities to be more sympathetic towards thalassemics while issuing the blood. Dr Arora appealed the heads of transfusion centres to take extra steps to extend transfusion timings in the evenings, holidays and Sundays so that grown up Thalassemics can adjust the transfusion timings with education, exams and profession.

He advised to the thalassaemic patients and parents that they should work with their society in organizing blood donation camps and creating awareness in public.

Dr Arora specially thanked Dr Renu Saxena, Dr Seema Tyagi & Dept of Haematology for associating with NTWS & helping us in organizing this conference.

NTWS has initiated Dr B N Dara Award to an Indian medical doctor for dedicated work in the field of Thalassemia & Haemoglobinopathies. Award carries a cash prize and a citation along with a memento. Dr B.N Dara was a leading Pediatrician of Jaipur.

This award has already been given to Dr Mammen Chandy followed by Dr V.P. Choudhry, Dr M.B Agarwal & Dr M.R. Lokeshwar during the deliberations of our previous National Thalassemia Conferences.

This time the executive of NTWS conferred this Award to Dr Roshan Colah. She is Scientist F (Deputy Director {SG}) at the National Institute of Immunohaematology under the Indian Council of Medical Research at Mumbai. She received a Ph.D in Biochemistry from Bombay University in 1984 and has been the Head of the Dept. of Haematogenetics at the Institute since 1988. Her group works on Red Cell Disorders in particular the Hemoglobinopathies, Red Cell Enzymopathies and Membranopathies. Her main area of research has been on the epidemiology of the Thalassemias and Sick Cell disease, understanding the molecular basis of the Thalassemias and developing prevention programmes in India. She has received several awards and has been invited to participate in many National and International meetings. Her research has resulted in 170 publications in National and International journals.

NTWS has also initiated Best Social Worker Award alongwith Dr B N Dara Award for a person who has been deeply involved for the welfare of Thalassemia & Haemoglobinopathies, this time it was awarded to Mr Hansraj Ahir, three times Member of Parliament, Lok Sabha. He started Dr Ganga Ram Ahir Charitable Trust to improve the medical services. Under this trust he organized 3-4 Thalassemia & Sick Cell camps. In each camp 3000 to 6000 persons were screened for

Thalassemia & Sick Cell. Faculty from AIIMS provided expert advice during these camps. He is actively persuading for separate Thalassemia & Sick Cell wards & free medicines for Thalassemics & Sick Cell patients with the state govt. of Maharashtra Mr Ahir organized a meeting of office bearers of NTWS with Union Social Welfare Minister Mr Mukul Wasnik to include Thalassemia in the list of disabilities. He is also pursuing with the Govt of India to establish a satellite centre under the aegis of ICMR for Haemoglobinopathies at Chandrapur. He has also raised issues on Thalassemia in the Parliament.

In her presidential address Km Surrender Saini exhorted the dignitaries on the Dias & Doctors to pursue the Govt. to include Thalassemia in the list of disability. Patients, parents & doctors present in the hall acknowledged her gesture with a standing ovation. She recommended public applaud up this suggestion be passed as resolution and handed over to the appropriate authority.

Though the inauguration was held at 10:30 am the registration of delegates had already started at 8:00 am. Two parallel sessions one for the doctors at LT 3 & another for patients & parents were held at Jawahar Lal Nehru Auditorium AIIMS.

In the Doctor's Session Challenges in Diagnosis of Thalassemia was covered by Dr V K Khanna Senior consultant pediatrician Sir Ganga Ram Hospital, New Delhi. Transfusion Therapy including Leucodepletion was explained by Dr A.P. Dubey Director Prof. & Head Dept of Paediatric MAMC & Associated LN Hospital. This session was chaired by Dr Amit Banerjee MS LN Hospital & Dr D.N. Virmani former head Dept of Paediatrics Kasturba Hospital. Session II comprised of lectures on stem cell transplantation by Dr Alok Srivastav. Iron overload & Conventional Iron Chelation by Dr Sunil Gomber Director, Professor Department of Pediatrics UCMS & G.T.B Hospital. Indian experience in Deferasirox by Dr V P Choudhry, Endocrine Problems by Dr Ratna Chatterjee, Protocol for Thalassemia monitoring by Dr Jagdish Chandra. The session was chaired by Dr D K Sharma Medical Superintendent AIIMS

The parents session opened with a talk by Dr K Ghosh Director, National Institute Of Immuno-haematology (ICMR), on Haemoglobinopathies in India. Dr Jagdish Chandra apprised the patients & parents how to monitor their Treatment. This Session was Chaired by Dr Bharat Singh Director State Blood Transfusion Council and Head, Blood Bank GTB Hospital.



The session was followed by inauguration & mouth relishing breakfast. Hygienic nutritious relishing breakfast forced Dr K Ghosh to stress on hygienic blood i.e. blood free from viral infections. Since, Dr S K Sarin could not make it due to some other commitment he deputed his learned colleague Dr Pankaj Tyagi Asst Prof. Institute of Liver & Billiary Diseases to speak on Hepatitis C infection in thalassemics. The session was chaired by Dr Neelam Mohan DM Gastroenterology, senior consultant at Medanta, Gurgaon & Dr R N Makroo Head of Transfusion Medicine, Apollo Hospital.

Proceeding further Dr Rajiv Bansal senior pediatrician and in charge of Thalassemia unit at Santokhba Durlabhji Hospital, Jaipur enlightened on, one of the basic arm of the treatment i.e the chelataion therapy. Dr Alok Srivastav Pof. & Head Dept. of Haematology CMC Vellore talked about the most demanding part of treatment i.e. Cure with stem cell transplantation. The session was chaired by Dr Dinesh Bhurani Hemato-Oncologist at Rajiv Gandhi Cancer Hospital who is doing Bone Marrow Transplantations in thalassemia.

The session was followed by extremely delicious food which was highly cherished by everyone. Post lunch dozy audience were awaken by Indian born UKite scholar Dr Ratna Chatterjee. Consultant in reproductive health of adolescent and adult survivors of chronic and serious disease with special interest in haemoglobinopathy. She emphasised on Bone Disorders, in local Hindi language, which was highly appreciated by everyone present their. Then Dr Chatterjee made adolescent boys and girls stuck to her next lecture Growth and Puberty. Now, it was the turn of fatherly figure Dr V P Choudhry to draw the attention of each and every parent of all young and old Thalassemics by his breaking news "Gene Therapy has emerged successful treatment in thalassemia". The session was chaired by Dr Mohini Kumari Head of Dept of pediatrics, DDU Hospital & Dr N V Kamath Medical Superintendent Sanjay Gandhi Hospital. Both are very concerned about the well beings of thalassemics.

The next session comprised of success stories of the legends affected by Thalassemia. Dr J S Arora General Secretary of NTWS open the session by touching every ones role be it a patient, parent, extended family, neighborhood, school, doctor, institute, Govt & general public. He emphasised on three points :

- **Thalassemics don't need to be 100 times better than others, to be considered equal to them.**
- **Thalassemic do not differ significantly from healthy young people in their ability to cope with life's difficulties.**
- **Well treated Thalassemics can challenge life's difficulties, in the same way as any other "normal person".**

Dr Anjali Sardana, a thalassemia major yes Doctor Anjali Sardana, a thalassemia major did her PhD in computer science from IIT Roorkee challenging TCS when TCS refused to give her a job on medical grounds though she had been selected on merits. She made the thalassemics feel that nothing is impossible & thalassemia is advantage. And today if she is addressing big audience its just because of thalassemia. Ms Nitya Dawra an MBA in finance said that she comes from a small town in Haryana, a state where girls are not allowed to live an independent life but after her 12<sup>th</sup> standard she lived alone in Delhi & did her graduation from prestigious Lady Shriram College & then MBA. Being eldest in the family now she has joined her family business & leading a productive life. Ms Tanu Verma who has done Bachelor in Journalism motivated the audience with her experience being a Thalassemic. She said that thalassemia is really not a big deal to crack with. It is not at all our weakness rather than its our power. She concluded her talk with a nice quote "WAVES ARE INSPIRING NOT BECAUSE, THEY RISE AND FALL BECAUSE, EACH TIME THEY FALL, THEY NEVER FAIL TO RISE AGAIN" the trio young girls motivated the masses to fight back the battle and win it with dignity. The session was chaired by Mrs Shobha Tuli President of FIT.

*The day ended with good memories & a cup of tea.*

**Representatives of various societies stayed back to discuss various issues under the banner of FIT (Federation of Indian Thalassemics) to improve awareness & treatment facilities all over India.**

**Miss Your Dose (Chelation) Today  
Compromise Your Health Tomorrow.**



## PARTICIPANTS DURING QUESTION ANSWER SESSION









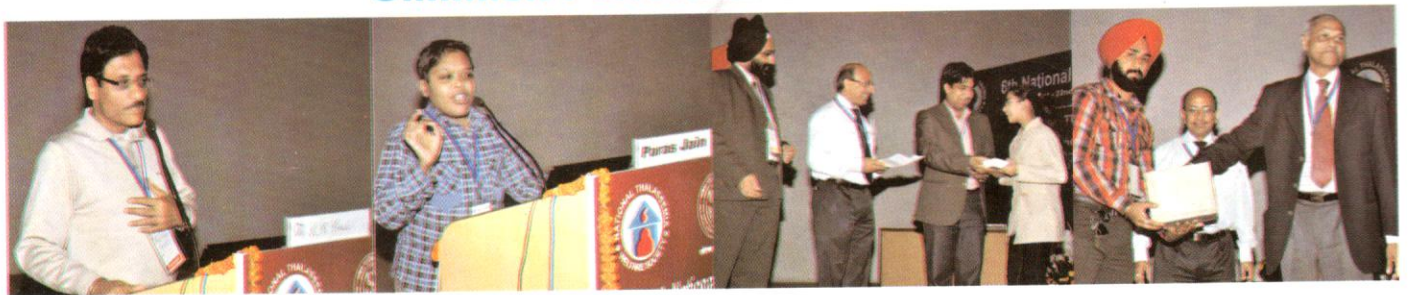




## Group Photographs of Patients & Doctors at 6<sup>th</sup> NTC



## Gimmick Performances and Quiz



## Workshop on challenges in diagnosis of thalassemia on 23<sup>rd</sup> Nov' 2010





The second day started with more passion and a burning desire to know more about different aspects of Thalassemia. The day comprised of 4 sessions by various doctors like Interesting cases of Diagnoses discussed by Dr H Pati Professor of Hematology at AIIMS, Cardiac Problem in Thalassemia by Dr Arun Mohanty working as Interventional Cardiologist at Sir Ganga Ram Hospital, Hb HPLC in Thalassemia & Haemoglobinopathies by Dr Seema Tyagi Associate Prof. AIIMS, Thrombophilia in Haemoglobinopathies by Dr Renu Saxena Professor & Head Dept. of Hematology, AIIMS. The session was chaired by Dr Madhur Kudesia Medical superintendent, Kasturba Hospital & Dr Tejinder Singh Prof. & Head Dept of Pathology, MAMC.

After a short break for the breakfast again the participants sat on their seats to gain more knowledge through lectures like Anemia in Pregnancy, IDA and Thalassemia Screening by Dr Meera Sikka Prof of Obs.& Gynae at UCMS, Management of pregnancy in Thalassemias by Dr Rekha Bajoria Clinical Senior Lecturer in Medical Education (Obstetrics and Gynaecology) at Institute For Women's Health at University of London, UK. CVS and Cordocentesis were explained by Dr Nutan Agarwal, Prevention & Control by Dr Madhulika. The Session was headed by Dr Rita Ranjan Head of Department of Obstetrics & Gynaecology DDU Hospital & Dr Mohini Kumari.

Dr V.P. Choudhry filled the gap of Dr Sharmila Chandra to cover Thalassemia Intermedia and Hb E disease, Diabetes & other endocrine issues were discussed by Dr. Nikhil Tandon Prof. & Head Dept of Endocrinology, AIIMS. The session was chaired by Dr Veena Dhoda Head Blood Bank RML Hospital & Dr Sangeeta Pahuja Head Blood Bank Lady Harding Medical College & Hospital.

*Then, it was followed by mouthwatering food.*

And then, the time came for last session Indian experience in Defrasirox by Dr V P Choudhry, cord blood transplantation by Dr Sandeep Shah Part Time Associate professor Gujarat Cancer & Research Institute and in-charge of Bone Marrow Transplantation Unit & last but certainly not the least the time came for what the participants were wanting to know Life after BMT by Dr Mammen Chandy the director of the Tata Medical

Center, Rajarhat Kolkata. The session was chaired by Dr N K Mehra Head of Histo- Compatability Department at AIIMS & Dr Dharma Choudhry heading Haemato-oncology unit at BL Kapoor Hospital, who has done over 15 successful transplantations in thalassemia in Delhi.

Mrs Neelam Khurana proudly narrated the bold & successful story of her son Mudit Khurana who himself took initiative to immigrate to US for higher studies.

And now the time came for entertainment, a mimicry by Mr Raj Kapoor (Dr K K Kaul) & a gimmick by Paras Jain a Thalassemia himself.

The Celebration was still not over. On 23rd November 2010 we had a workshop on Challenges in Diagnosis of THALASSEMIA at Deptt of Haematology, 1st floor IRCH Building, AIIMS. The workshop comprised of 2 sessions. The session I comprised of Introduction by Dr Renu Saxena, Screening of Thalassemia by Dr Seema Tyagi, HbHPLC by Dr H Pati.

The session II comprised of Hands on Training, in this the 30 Participants were divided into 3 groups A, B & C. At a time each group was suppose to attend one lab section. In this there were 3 lab stations. Station 1 CBC by Dr. Mrinalini, Dr. Sabina, Station 2 Hb Electrophoresis/ Molecular Diagnosis By Dr Gurpreet Singh, Dr. Jasmita, Mr. Sanjay. Station 3 on HPLC Dr. Monika & Dr. Sonal.

And then the doctors filled their Tummy with the south Indian Yummy.

*Cipla was the chief sponsor of the event other main sponsors were Hemogenomics Pvt. Ltd., Astra Zenca Pharma, Roch Scientific India, Pall India Pvt.Ltd., Sun Pharmaceutical, Biorad.*

*The 4 days celebration ended with lovable memories that can be treasured for the whole life & with a burning desire to come up with a more organized conference next time.*

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## Patient/Parent Section

### Thalassemia : A major curse upon Mankind

Dr. Ravi Dhanani

Human Psychology says that every man born on earth has basic instinct of survival, strives for the accomplishment of excellence. This is the case of Ravi, now Dr. Ravi B. Dhanani, a young and dynamic Prof. Dept. of Social Work, Rajkot (Gujarat). He presented his research papers, on Thalassemia Major, as he is Thalassemia Major and has been undergoing the long and tiresome treatment of Blood transfusion.

Ravi provides a unique and unparallel example to all the Thalassemics, parents and guardians that what tremendous miracles can be brought about in the lives of Thalassemic patients provided they should have firm determination to live normal life and to convert the

miserable life into sweet garden of pleasure and success.

Born in the famous Patel Family of Gujarat, Amreli District, in August 1984 with Thalassemia major, neither the small child [Ravi] nor his parents had lost the abounding faith in God. Ravi's Thalassemia major condition has never been a constraint in his studies and career. Being a Commerce student, he did his Master's in Social Work. Dr. Ravi accepted Thalassemia smilingly and positively. He decided to do his doctoral degree on **"Thalassemia Major and its multi dimensional implications upon the Parents and guardians of the Thalassemic patients"** and he did an excellent work on it and won Ph.D. from Saurashtra University, Rajkot.

#### **"A STUDY OF THE PROBLEMS OF PARENT'S OF THALASSAEMIA PATIENT'S"**

A sample of 200 respondents has been selected out of the universe of Rajkot District in particular and Saurashtra in general. My Research Work contains the below mentioned problems of the guardians.

1. 65% guardians have monthly income of Rs. 5000/-
2. 79% guardians do not give any other medicine and treatment to their Thalassemic children other than Blood Transfusion because of economic condition.
3. Approx more than 60% guardians feel depression and stress because of Thalassemic children.
4. Approximately 30% guardians conceal Thalassemic disease of their children.
5. More than 40% guardians do not give adequate attention to their other children due to the Thalassemic child.
6. More than 70% guardians have to infuse budgetary control over their expenditure and are not in the position to spend money in shopping, entertainment, religious and social functions
7. Besides, they have also to face the problems of matrimonial arrangements of their normal children.
8. More than 90% Thalassemic children could study up to the primary or secondary level of education only.
9. It is significant to note that there is the absence of social organization to help the Thalassemic children.
10. The Parents and guardians have constant worry about their Thalassemic child.

Summing up the Research work, I would like to

emphasize that Thalassemia test before marriage is compulsory and the Thalassemia minor should marry only a normal person because if both the partners are Thalassemia minor, there is 1 in 4 possibility that their child may be Thalassemic major

According to the estimate of Indian Red Cross Society, more than 8000 Thalassemia major are born. The current figure of Thalassemics in Gujarat is 7000. Indian Medical Research Foundation says that Rs. 20 lac is being spent for the treatment of a Thalassemic major in 20 years. The family is completely ruined yet they cannot save their child. One significant thing should be noted at this stage that where the curative measures are very rare and not available, preventive measures should be resorted to. The carrier testing before marriage would certainly prevent the marriage of Thalassemia minors and can save Rs. 20 Lacs means Rs. 1 Lac every year which amount can be constructively utilized for the purpose of solving number of other social-problems which would lead to the creation of healthy-society. WHO warns that if appropriate preventive measures are not taken to prevent Thalassemia, it would be a deadly disease, a curse in the 21<sup>st</sup> century. The Govt. should come forward and create awareness among the people about the tragedy of this deadly disease, with the co-operation and co-ordination of Non-Govt. organizations, educational institutes and the media. We should follow the example of Cyprus and enact & implement strict law regarding Thalassemia-prevention.



## HOW TO USE PALL FILTER. [RC1VAE & RC2VAE]

### INSERVICING RC FILTERS AVOIDING SLOW FLOW AND BLOCKAGE PROBLEMS

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

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

- It is vital that the squeeze of the bag is maintained throughout the prime. If the squeeze is released, air will be entrained back into the filter from the drip chambers. It is not so important to have a strong squeeze, especially if it means that the nurse is getting tired. The key is to have a steady and continuous squeeze. If the nurses find this difficult, then a pressure infuser bag should be used to prime the filter. This can be left on throughout the transfusion and it could potentially prevent some of the slow flow problems later on.
- It is vital that the filter is maintained in the vertical position while the drip chambers are inverted. Our leucocyte depleting filters have been designed so that they prime from the bottom to the top without having to invert the filter (unlike our competitors). However, if the filter is accidentally tilted there is the potential to leave pockets of air.

#### In addition:

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

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

Raise head height of bloodbag,

Check patency of cannulae,

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

## NATIONAL THALASSEMIA WELFARE SOCIETY (Regd.)

KG-1/97, Vikas Puri, New Delhi-110018 Tel: 9311166711-712, 25511795

URL: [thalassemiaindia.org](http://thalassemiaindia.org), E-Mail: [ntws08@gmail.com](mailto: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 Socieity.**

For NRI & Foreigners Life membership fee US\$100

#### READILY AVAILABLE

Filters Single & Double Unit  
Kelfer, Desferal, Desirox, Asunra  
Infusion Pump AND S.V Set

#### Medicines

#### Rate

Asunra 400mg	1750/-
Desirox 500mg	900/-
Single Filter	470 - 500/-
Double Filter	660/-
<b>For any information</b>	
Contact. 9311166710-711, 9810020829	

#### ADVERTISEMENT CHARGES

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#### NTWS Thalassemia Centre

**Thalassemia Clinic, 2<sup>nd</sup> Sunday every month**  
**Reporting time: 9am to 12 noon**

#### Address

NTWS Thalassemia Centre,  
2nd Floor, Community Centre,  
Slum & JJ Dept. of MCD,  
Near Gurudwara Singh Sabha,  
Block- 12, Tilak Nagar  
New Delhi-110018  
Ph. 9311166710-711-712

#### Facilities:

- \* Growth Monitoring
- \* Chelation Therapy
- \* Serum Ferritin Test **Rs.150/** only
- \* Thalassemia testing (HPLC) **Rs.300/** only



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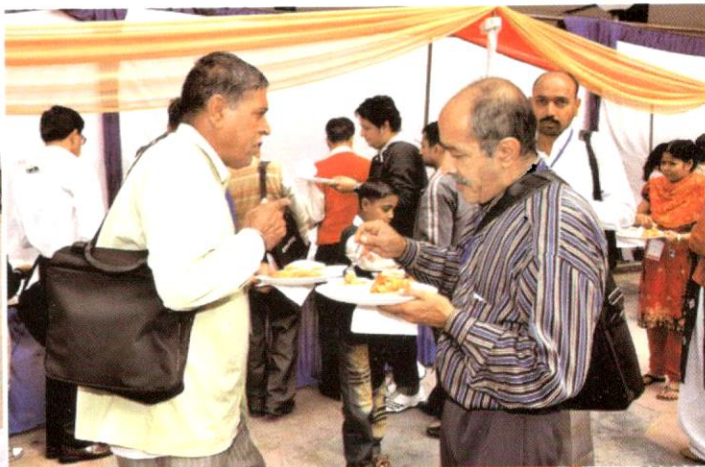
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High efficiency leucocyte

# removal

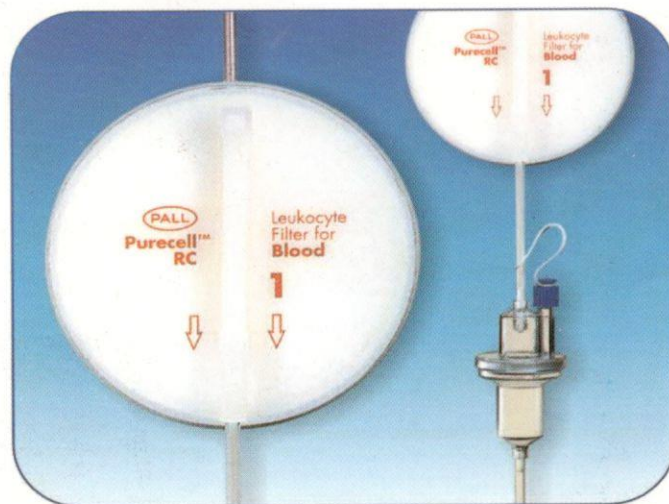
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- ▶ Clinically proven media technology
- ▶ Enhanced ease-of-use with self-levelling drip chamber
- ▶ High red cell recovery
- ▶ Minimal filter hold-up volume
- ▶ Rapid priming without saline
- ▶ Bedside filtration of one unit of red cells
- ▶ For standard or rapid flow applications

w: [www.pall.com/blood](http://www.pall.com/blood)

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