HSCT PROJECT

Thalassemics India is privileged to be given an opportunity to co-ordinate the HSCT project as per the role defined by the Ministry of Health & Family Welfare Govt. of India
Special Thanks

INFOGAIN INDIA PVT LTD

M/S ICREON FOR GOOD FOUNDATION TRUSTEE

AKM MEHRASONS JEWELLERS

BRINDAVAN AGRO IND. PVT.LTD

PREMA SAGAR

P & G ENTERPRISES PVT.LTD
Dear Friends,

Having this opportunity, I would like to assure you that Thalassemics India continues to move forward to promote the rights of thalassemics for their safe and effective care. Not only this, we are stepping up our efforts to work hand in hand with Public and Private sectors to seek their support for starting & implementing fruitful collaborations.

As I look back and compare them with the situation as it is today, I along with my colleagues at Thalassemics India, feel privileged to have witnessed dramatic improvements in almost every area of our work: awareness; management; cure; quality of life; recognition of patient’s rights and many others.

Through these years, we made sure to respect doctors who do their best for each and every one of their thalassemia patients; sisters who take extra personal care; all the public health professionals; donors who help us in our projects; our NGO friends and thalassemics who inspire and motivate us in our fight against thalassemia.

We had a very busy and successful 2016. The 6th International conference on Thalassemia, visit of expert clinicians from abroad, TIF meetings, fund raising event, support being continued to underprivileged patients and a number of visits and meetings with the Govt. officials.

The year 2017 started with a unique project started by Coal India Ltd and the Ministry of Health and Family Welfare, Govt. of India to cure thalassemics by offering them financial support for BMT. Thalassemics India is privileged to be given an opportunity to coordinate the HSCT project as per the role defined by the Ministry of Health & Family Welfare, Govt. of India for which we are extremely grateful to them. Guidelines on Hemoglobinopathies in India is being released by the Ministry of Health & Family Welfare, Govt. of India which will greatly help the medical professionals & State Governments in deciding the future policies on Hemoglobinopathies including thalassemia. After a long struggle, Thalassemia being included in the new categories of Disabilities by the Govt. of India. These moves by the Govt. India has come in from all - round praise from the Thalassemia ngo’s across the country.

Moving forward, very importantly, we are soon going to launch the Patients Advocacy Group. The Patients who have inspiring, guiding and motivating us will now stand with us hand in hand to take forward the legacy of Thalassemics India - HONESTY & GOOD GOVERNANCE & to take forward the unfinished tasks.

Enjoy reading this issue and please feel welcome to communicate and / or suggest whatever you feel we can do to make it better.

Shobha Tuli
Secretary
Under the banner of Rotary District 3011, Thalassemics India took the initiative of holding an awareness seminar which was held at Habitat Centre, New Delhi, attended by more than 100 senior Rotarians. The honourable invited guests from the Ministry were Ms. Vinita Srivastava, National consultant & coordinator, Blood cell - NHM, Govt. of India & Dr. S.K. Arora, Addl. Director (Public Health), Govt of Delhi. Dr. V.K. Khanna gave a talk on “Thalassemia – the medical aspects”, Shobha Tuli spoke about “Thalassemia Control Programme” & Nishtha Madan (an adult thalassemic patient) gave a brief about her “Thalassemia Journey”. This was followed by addresses from both the Ministries & the District Governor. The meeting ended with Hi-Tea.
On 6th May, Thalassemics India organised a fund raiser evening at Orana Hotels & Resorts, NH 8, New Delhi. We were honoured to have Dr. Raja Reddy, an Padma Shri & Padma Bhushan awardee as the Chief Guest of the function.

The function started with the lamp lighting & Saraswati Vandana sung by Ms. Shivangi Amrit (a thalassemic, an advocate by profession). Ms. Nishtha Madan (a thalassemic, a teacher by profession) spoke about the issues and concerns of thalassemics. Sh. Deepak Chopra, the President of Thalassemics India welcomed the Chief Guest, the invited doctors, senior sisters, blood bank officials & others. Having this opportunity, we felicitated the doctors, nurses, blood banks & our supporters. We also acknowledged some of our young talented thalassemics who have made us & their parents proud.

This was followed by an evening of music with the Maestro of Kartal and the master of Rajasthani Folk and Sufi Fusion- Kutle Khan.

The proceeds from this fund raiser will go towards supporting the treatment of underprivileged thalassemia patients.
Honouring Dr. Jagdish Chandra

Honouring Dr. A.P. Dubey

Honouring Dr. Anupam Prakash

Honouring Dr. Alok Hemal

Honouring Dr. V.P. Choudhary

Honouring Dr. Alka Mathur

Honouring Dr. V.K. Khanna

Honouring Dr. Amita Mahajan
THALASSAEMIA UPDATE

International Thalassemia Day

Honouring Dr. Ritu Chawla

Honouring Dr. Kamini Khillan

Honouring Dr. R. N. Makroo

Acknowledging Sister Siji

Acknowledging Sister Lavina

Acknowledging our supporters

Acknowledging our supporters

www.thalassemicsindia.org
THALASSAEMIA UPDATE _____________________________ International Thalassemia Day

Appreciating Nehal Dhingra

Appreciating Viresh Piplani

Appreciating Sumit Gupta

Appreciating Nishtha Madan

Kutle Khan’s performance

Group Photograph

Audience enjoying the Kutle khan performance

Audience enjoying the Kutle khan performance
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Hematopoietic Stem Cell Transplantation for Thalassemia Major in India
Alok Srivastava, Department of Haematology, Christian Medical College, Vellore

Allogeneic hematopoietic stem cell transplantation (HSCT) is still the mainstay of curative treatment for patients with thalassemia major and now offers very high rates of cure to patients who are able to access this therapy. In India, it was first done in 1991 and till date about 1000 HSCTs have been performed for this condition. Results have improved tremendously over the last decade with >90% success in well chelated young patients and nearly 80% survival even in higher risk patients. A combination of factors has led to this success but is predominantly related to better conditioning regimen and improved post-HSCT supportive care. The limited data available suggests that the long-term outcome is also excellent among those who undergo successful HSCT but the transplant should be performed early before any end organ damage occurs. The best results of HSCT are before 7 years of age in adequately managed patients but well transfused and chelated older patients including young adults can also have very good outcomes with the right treatment protocols.

While recognizing these successes of HSCT, it should also be mentioned that many challenges still persist. Significant morbidity and mortality is still associated with the procedure related to the uncertainties of HSCT itself from the point of view of toxicities of conditioning drugs, graft versus host disease, infections and graft rejection. Access to the therapy due to lack of suitable donors or just the availability of the service, as well as its cost, are also significant constraints in India. Matched related donors are generally available for about a third of patients with thalassemia major. At present, only about 250 to 250 HSCTs are being done for thalassemia major every year in the country in about 25-30 HSCT centers. With nearly 8-10,000 children born with thalassemia major every year in India, there clearly is need for more HSCTs to be performed along with an effective disease control program. While alternative donors (matched unrelated donors (both adults and cord blood), partially mismatched related donors and haplo-identical donors (HLA half matched family donors)) can increase the possibility of HSCT for more patients, there is still limited experience with such transplants in the world. Though good results have been achieved with such donors in some reports, concerns persist from the point of view of higher rates of rejections and graft versus host disease (GVHD) with such HSCTs. These issues must therefore be carefully considered before undertaking these HSCTs outside of a clinical study, particularly in centres with limited experience with such treatments.

Cost of HSCT is indeed the most significant barrier for access to HSCT for these patients in India. The cost of HSCT is generally about Rs. 10-15 lakhs depending on the condition of the patient. This can increase significantly in case of unexpected serious complications. It is imperative that health insurance cover the cost of such conditions without which many patients will never receive the treatment which can cure their condition. We need to create an environment where chronic diseases can be included within a family health insurance scheme. In the meantime, Thalassemics India in collaboration with the Ministry of Health of the Government of India has obtained support from Coal India Limited (CIL) through their corporate social responsibility program to provide significant assistance of up to Rs. 10 lakhs for the less affluent families to access this treatment. The effort from all the people in making this program a reality — the first of its kind in the country, needs to be applauded. Currently, this program aims to include only those children who do not have high-risk disease and have a matched sibling donor. While CIL is ready to support 200 or more such HSCT every year, the challenge is to find enough transplant centres which can offer this treatment in a non-profit model.

The aim of curative therapy for any disease is to not only eradicate it completely but to also ensure a normal life after that. After achieving high survivals in patients with thalassemia major undergoing HSCT, the next important question is their long-term results and late complications in such patients. Over 90% of patients who survive the first two years after HSCT would be generally expected to become long-term survivors. Since most of the HSCTs for thalassemia major are for children and adolescents, this issue becomes particularly critical as they would be expected to have several decades of life post-HSCT. It is also more relevant because in this condition most patients undergoing HSCT already have systemic complications related to chronic anemia, iron overload and resultant endocrine and metabolic dysfunction as well as transfusion-transmitted infections. The limited long-term outcome data on thalassemia major patients post HSCT (“ex-thalassemics”) has shown that at over 20 years after HSCT, patients who were well managed before transplant can have a quality of life as good as the normal population and certainly better than those being managed conservatively with hypertransfusion and iron chelation alone. Older age at HSCT and development of significant chronic GVHD were found to be factors leading to worse long-term outcome. Our goal should therefore be to offer HSCT to all children with thalassemia major and a suitable donor before they develop any transfusion / chelation related complications.

It should also be recognized that in >35 years since HSCT for thalassemia major was first done in the world
in 1981, less than 10,000 patients worldwide have been able to undergo this treatment due all the reasons mentioned above. From the community perspective therefore, there certainly is a need for an alternative cure which can be offered widely. Gene therapy for thalassemia major has been successful in the last 4-5 years and several clinical trials are currently progressing well in the world. In this treatment, the defective gene is corrected in the patient’s own stem cell followed by an autologous HSCT. It is likely that in the 2-3 years, gene therapy could become an approved treatment in Europe and North America. Research in this direction has also been initiated in India supported by the Government of India. Let us hope that patients in India will also have this option of treatment in a way that it is widely accessible giving more options to patients.

MRI for Quantification of Liver and Cardiac Iron in Thalassemia Major Patients: Pilot Study in Indian Population
Shantanu Mandal1, Kushaljit Singh Sodhi1, Deepak Bansal2, Anindita Sinha1, Anmol Bhatia1, Amita Trehan2, Niranjan Khandelwal1  
1Department of Radiodiagnosis and Imaging, 2Department of Pediatrics, Advanced Pediatric Centre, Post Graduate Institute of Medical Education and Research, Chandigarh, India

Abstract

Objective
To evaluate Magnetic resonance imaging (MRI) as a tool to quantify liver and cardiac iron in Indian population with thalassemia major, and correlate liver and cardiac iron values with that of serum ferritin (SF).

METHODS:
Fifty patients aged between 8 to 18 y, with thalassemia major on regular blood transfusions and oral iron chelation therapy were enroled in the study. Twenty patients within the same age group, having no history of blood transfusions and no liver or cardiac disease were taken as controls. T2* MRI of heart and liver and SF estimation was done for all the cases as well as controls. All MRI scans were done on a 1.5-T Siemens MRI scanner using body coil.

Results
The mean SF among cases was 2150 ng/ml (SD 2179). Significant correlation was found in patients between liver iron concentration (LIC, mean 15) and SF levels (r = 0.522; p < 0.001), and also significant but weaker correlation was found in patients between myocardial iron concentration (MIC, mean 1.3) and SF levels (r = 0.483; p < 0.001). Seventeen (34%) patients had a SF of <1000 ng/ml. Of these, 11 and 3 patients respectively had LIC and MIC more than normal range.

Conclusions
T2* MRI is a valuable non-invasive tool for quantification of liver and cardiac iron deposition in patients with thalassemia major. It can demonstrate high LIC and MIC, even though the targeted SF levels are low in thalassemia, indicating the need for escalation of the chelation therapy. This needs to be confirmed on full-fledged larger prospective studies.

Take home message regarding T2* MRI for patients with thalassemia major

• Besides serum ferritin, T2* MRI is a good test for assessing load of iron in the body
• It is typically recommended after 8-10 years of age
• It must be done from a center, where the calibration of MRI machine has been performed and validated for estimating iron load.
• It is possible that ferritin may be normal, however the T2* MRI may show a higher load in liver or heart.

Dr Deepak Bansal  
Professor, Hematology/Oncology unit  
Dept. of Pediatrics,  
Advanced Pediatric Center  
Postgraduate Institute of Medical Education & Research, Chandigarh, India  
dee takebansaldr@gmail.com

If you have important news you want to share with the thalassemia community, let us know. We also encourage people to share their stories about their personal experience that may touch other thalassemics, parents and societies.
“HELPING HANDS PROJECT”

1. Under this project Thalassemics India is extending help to underprivileged thalassemics by giving them at no cost iron chelation drugs, filters, pumps and blood transfusions:

   - From January to August 2017:

     Filters : 888 pcs
     Desirox : 405 boxes
     Desferal Inj. : 232 boxes
     Kelfer : 216 boxes
     Asunra : 214 boxes
     Blood transfusions : 142
     Infusion Pumps : 5 pumps

2. Chelation drugs and filters sent at subsidized rates to Thalassemia NGO’s & parents as per their requirement across the country. (Jammu, Haryana, Punjab, Chandigarh, Himachal Pradesh, Uttar Pradesh, Uttrakhand, Madhya Pradesh, Gujarat, Maharashtra, Odisha, Jharkhand, Bihar, Chattisgarh, Rajasthan, Andhra Pradesh, Karnataka, West Bengal, Kerala, Tamil Nadu, Assam, Nagaland & Delhi).

3. Arranged financial support for 4 BMT cases above the age of 10 years Rs. 1 lac per case.

4. Clinic held at Thalassemics India’s office. Eight thalassemics from the Hindu Rao Hospital were called upon for their medical check up. These 8 thalassemics are receiving free medical support from Thalassemics India. Thanks to Dr. V.K. Khanna for his time.
Gift of Life

Hematopoietic Stem Cell Transplantation Project

Coal India Limited

Ministry of Health and Family Welfare, Govt. of India

Criteria
1. Patient’s age to be less than 10 yrs.
2. Patient should have 100% HLA matched sibling donor (minimum matching ratio: 6/6)
3. Patient’s family income to be less than 5 lakhs per annum.
4. Resident of India.

Bone Marrow Transplant Centres
1. CMC, Vellore
2. TMC, Kolkata
3. AIIMS, New Delhi
4. Rajiv Gandhi Cancer Institute and Research Centre, New Delhi

Any thalassemic patient fulfilling this criteria can get financial aid upto Rs. 10 lakhs from Coal India Ltd.

For Further Information, Please contact:
Thalassemics India
A-9, Nizammudin West, New Delhi - 110013
Tel No. 41827334, 46595811
Email: thalcind@yahoo.co.in, info@thalassemicsindia.org
www.thalassemicsindia.org
The Deferiprone and Deferasirox Combination is Efficacious in Iron Overloaded Patients With -Thalassemia Major: A Prospective, Single-Center, Open-Label Study

Sidharth Totadri, Deepak Bansal, Prateek Bhatia, Savita V. Attri, Amita Trehan, R. K. Marwaha
Department of Pediatrics, Hematology–Oncology Unit and Biochemistry, Advanced Pediatric Center, Post Graduate Institute of Medical Education and Research, Chandigarh, India

Abstract

Background
The high cost, coupled with the need for continuous infusion, renders Desferrioxamine (DFO), a non-feasible option for iron-chelation in a large majority of patients with -thalassemia major in developing countries. Monotherapy with deferiprone (DFP) or deferasirox (DFX) may not always attain optimal control, particularly in heavily iron-loaded patients. Combination of DFP and DFX is a potential alternative.

Procedure
A prospective, single-center, open-label, uncontrolled study was conducted to evaluate the safety and efficacy of the combination in patients with -thalassemia major. Patients who had received either DFP or DFX for >1 year and a serum ferritin >2,000 μg/L were enrolled. Blood counts, liver/renal functions, and serum ferritin were monitored during the 1-year study period. Facilities for cardiac T2*-MRI were unavailable.

Results
Thirty-six patients with a mean age of 13 ± 6.9 years (range: 4-99) and a ferritin of 6,768 ± 4,145 μg/L formed the study cohort. Eight (22%) patients had transient gastrointestinal adverse effects. DFX was discontinued in one patient for persistent abdominal pain/diarrhea. Eight (22%) had joint symptoms; DFP was discontinued in two. Four (11%) patients had elevation in AST/ALT levels, managed with temporary interruption of DFX. Nine (25%) had an inconsistent elevation of creatinine to >33% of baseline; no intervention was done. One had transient proteinuria. None had neutropenia. At the end of 1 year, the serum ferritin reduced by a mean value of 3,275.3 ± 618.2 μg/L (P < 0.001).

Conclusions
The oral combination was found to be safe, efficacious, and a feasible option in patients with suboptimal response to monotherapy.

Take home message regarding combination oral chelation therapy for patients with thalassemia major
- One must use a single drug to reduce iron load as a first choice
- One must be regular with the intake of medicines, used for treating iron load
- If the load of iron cannot be controlled with a single medicine, a combination of 2 drugs can be tried.
- The oral combination therapy is generally safe in most patients. It should be administered on the recommendation of your doctor, and with monitoring of side-effects.

Dr Deepak Bansal
Professor, Hematology/Oncology unit
Dept. of Pediatrics,
Advanced Pediatric Center
Postgraduate Institute of Medical Education & Research, Chandigarh, India
deepakbansaldr@gmail.com

Upcoming Events
1. Seminar on the Policy Interventions for the Evolving Needs of Thalassemics in India & the Launch of the Thalassemia Patients Advocacy Group, 16th September 2017
2. Dr. Malcolm Walker’s visit to India - 29th - 31st October 2017
3. Annual General Meeting - 26th November 2017
Our new members

Abdul Takir Khan
Abhijeet Sathe
Abhiramanyu Chandra
Anees Khan
Anoop Maggu
Anupam Kumar Bansal
Ayesh Kanta Sahoo
Banishree Paul
Bhabajosh Patra
Bhaskar Parabahakar Guthe
Bipin Bihari Nandi
Brijesh Thakur
Chanchal Arora
Chandrashhekar Tukaram Pawar
Chintan Kumar Shaw
Chitranshu Jagggi
Debreta Malick
Deendayal Singh Parmar
Dinesh Diwan
Dinesh Kumar
Dipanjali Das
Dr. Kawaijeet Kaur
Dr. Sandeep B Kaia
Farha Afsar Chand
Gagan Madan
Gajanan Rambhaji Raundale
Gaurav Gulati
Hajarilal Meghani
Himanshu Goyal
Honey Ahuja
Jai Vanwari
Jharna Melick
Jignesh Balubhai Ahir
Kalash kotwani
Kajal Paul
Kalicharan Patel
Kalpesh Bhai
Kaushik Chakrabarti
L.VansikiShunya
Lalan Kumar
Lokesh K
Lokesh Tilwani
M.Ravi Kiran

Jharkhand
Maharashtra
Maharashtra
Haryana
U.P
Odisha
West Bengal
West Bengal
Maharashtra
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Madiya Pradesh
U.P
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Jharkhand
Haryana
West Bengal
Chattisgarh
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Delhi
Assam
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West Bengal
Andhra Pradesh
Jharkhand
Karnataka
Delhi
Andhra Pradesh

Madhusudan Sain
Manish Ghosal
Markush Tirki
Mukesh Pratap
Murlidhar Kukreja
N. Karuna Shree
Nafis Ahmed
Naryana Bhojne
Neeraj Jain
Nirmal Santwani
NRI Medical College & General Hospital
P.D.Sisodiya
Padam Raj Thanet
Pankaj C. Bhatia
Pankaj Kakkar
Pawan Kumar Anja
Piyush Agarwal
Pradeep Jena
Purnendu Rakshit
Raj Kumar Shewani
Rajat
Rajesh P. Kehra
Rajesh Rawli
Rakesh Singhai
Ram Sevak Sharma
Ranjit Singh
Ravinder Dhuie
Sachin Jain
Sahdev Singh Solanki
Samrath Kirti Shah
Sandeepr Pratap Ashani
Sandeepr S. Bewane
Sanjay Prabhakarao Nighot
Sanjeev Kumar
Sarfaraz
Shivaji Natha Alane
Shweta Punjabi
Simran
Sohit Katiyar
Sukhsohit Singh
Tarun Kr. Banerjee
Vikas Kumar

Odhisha
Delhi
Delhi
Gujarat
Chattisgarh
Karnataka
Mahashtra Pradesh
Maharashtra
Maharashtra
Maharashtra
Maharashtra
Maharashtra
Andhra Pradesh
West Bengal
Nepal
Gujarat
U.P
Haryana
U.P
Delhi
West Bengal
Maharashtra Pradesh
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Haryana
U.P
Maharashtra
Maharashtra
Punjab
U.P
Haryana
U.P
Punjab
Proud to share with you the profiles of our Patients Advocacy Group

Anubha Taneja
Public Policy Lawyer
Member Secretary, Patients Advocacy Group, Thalassemics India

Anubha is a lawyer by training and works as a Director in the Public Affairs & Advocacy Division of India’s leading integrated communications firm.

Anubha has been closely involved in the establishment of the Thalassemia Day Care Centre in the heart of India’s capital. This ward is a part of a central government hospital and provides end-to-end management and care for free.

Anubha is now driving Thalassemics India’s patients advocacy programme through the Patients Advocacy Group as its Member Secretary.

Anuj Wadehra
Software Architect

Anuj is a Software Architect with 10+ years of industry experience. He is currently working with a Software MNC.

His Idea for a “Smarter Delhi” was selected as one of the best ideas at the workshop conducted by IIIT, Delhi (in association with Delhi Govt.)

He intends to serve as a volunteer for the NGO- Thalassemics India and play his part in giving Thalassemics a better quality of life.

Nehal Dhingra

- Counseling Psychologist working as an Educational Counselor and Life Skills Trainer with DAV Public school.
- Specialisation at Child Guidance and Teenage counseling, and uses Theatre therapy to help children resolve conflicts.
- Volunteer at Thalassemics India, Delhi.
- Organised a number of blood donation camps and motivated children and parents.
- Love to Travel and explore different places, people, and food.
- Avid reader, and very adventurous.

Hemant Bellani
Technical Architect
(IT – Digital Marketing Services)

Hemant is a technical architect having over 9 years of experience in the design and development of IT based enterprise level digital marketing solutions primarily by making use of the world leading digital experience management and allied technology stacks.

He has been involved in volunteering duties for Thalassemics India namely in blood donation camps and delivering a pre-blood donation motivational talk in the same.

He has been an executive member for Thalassemics India and intend to serve as a volunteer for the said NGO and contribute towards the successful achievements of goals of the Patients’ Advocacy Group.
About

- Technologist specializing in the field of Digital Marketing, Web Content Management, E-Commerce, Social, Communities and Analytics
- Working in a leading software company
- Volunteering at Thalassemics India and earlier at Thalassemia Children Society, Jaipur for multiple activities like motivating people for blood donation, Blood donation drives, guiding children and parents and assisting at events.

Activities Interested in

- Guiding and motivating thalassemic children and parents on multiple topics like health, social, career etc.
- Blood Safety and blood donation
- Awareness
- Use of technology to help better and faster, connect with more people and share the knowledge and resources in far away areas
- Gene Therapy

Shivangi is currently working as a Senior Legal Associate with Novus Professional Services in Gurgaon for the past 1 year in the Service Delivery Department. Novus essentially is involved in providing services of document review, management and analysis services includes collecting, processing, reviewing, organizing, producing and analyzing documents for all types of matters, using award-winning processes, registered quality control programs, scientifically-based statistical analyses and cutting edge technologies.

Shivangi has been a part of the Legal outsourcing industry for around 4 years and is also a professional musician (vocalist) and has sung for the background score of Mohenjodaro, Jolly LLB (2) and has lent her voice for a couple of as jingles as well.

Shivangi has been actively involved in the activities of Thalassemics India and has performed at the International Thalassemia Day, attended international conferences and has been a part of the Patients Advisory Group and the recently formed Patient's Advocacy Group.

For your information:

The below mentioned drugs and equipments are available at Thalassemics India office at subsidized rates:

- Desferal
- Asunra
- Oleptiss
- Desirox
- Kelfer
- Defrijet
- Pall RC1VAE filter (for 1 unit of blood)
- Pall RC2VAE filter (for 2 units of blood)
- Bio –R filter (for 1 unit of blood)
- Bio –R2 filter (for 2 units of blood)
- JMS 27 G short needle, length 60 cm
- Veno gliss 27 G short needle, length 80 cm
- TI needle G-28, 8mm, length 60cm
- Thalapump-20, infusion pump
Parveiz Ali in Conversation with Author Pooja Khurana (Thalassemia Major)

Pervez Ali, Kashmiri born young and dynamic poet currently working as Principal in Radiant Model Public School, Khonmoh, Srinagar. His original poetry has gained him considerable appreciation in his nation but also internationally. Best known for touching on social and communal development, individual responsibilities in the welfare of society and long lasting peace.

Q) Tell us about yourself, what you are and for what you stand?
Ans) I am a teacher by profession and writer by passion. Apart from Master’s in English Literature, I have a diploma in creative writing and B. Ed.

Following the principle of being the disciple of love and messenger of peace, I am involved with many organizations working for the up keep of social fabric and I firmly believe in serving the humanity.

Q) Being thalassemic, what challenges you face daily from the society?
Ans) Of course, the society is always up with challenges for the people like me in different facets of life be it the employment, marriage or any other social gathering but as they say life is all about adjustments. Being the part of this society I managed to carve out a niche but still there are some compulsions especially from those who failed to learn the real essence of life. Let’s all join the hands for the betterment of a society. One thing I must add here, the way a thalassemic was living a life a decade ago is now altogether different, taking part in almost each sphere of life.

Q) From where you get the inspiration?
Ans) My parents. My family brought me up with clear intention that thalassemia is just a disorder, like any other. For parents to spend 6 hours in a day for their child to infuse the desired energy seems a normal job. I salute not only my parents but all those who have thalassemic children from the abysmal depths of my heart for the job they do unconditionally. Their selfless love is all that has changed my life.

Q) To become a writer was your childhood dream?
Ans) Can’t say in certain whether writing was my childhood dream or not but an affinity for reading was there from the very beginning. I always use to carry a book with me during transfusions to get rid of boredom and slowly this reading habit has put the firm base of my passion.

Q) Has writing helped you in your life to fight against the cause you stand for?
Ans) yes, indeed. It is this writing that helps me to convey my inner feelings and like my first story The Lifeline portrays my own story and the readers could realize that what challenges we are going through and having said that we are no less than a normal human being.

Q) What is your message to all thalassemic people in particular those living in India
Ans) Don’t let anyone tell you that you can’t do it. You are capable of every possible thing that exists on earth. Don’t die inside thinking that you are stuck with the duty of keeping yourself healthy.

Q) Define Author Pooja Khurana, in a single sentence.
Ans) A passion wrapped in a blanket of words.

Thank you so much for your time. Thanks Parveiz!

5. Behind the dark shadows
6. Lafzon se pare
7. Emerald Hues
8. Life as it happens

All are available on Amazon and Flipkart.
And still I feel miles to go before I sleep.

Q) Is there any responsibility to non thalassemic people towards thalassemic ones and how can we impart in them such feelings?
Ans) First of all let me clear, it is not only we thalassemic people but both thalassemic and non thalassemic have to pledge to free the country from thalassemia because no child deserves the pain of pricks every now and then. Those who are normal have a responsibility to boost the confidence in thalassemic people that they are equally capable of doing things be it living a good life, getting married or having children. Gone are those days when we had to fight with the question of survival.

Q) What is your message to all thalassemic people in particular those living in India

Ans) Don't let anyone tell you that you can’t do it. You are capable of every possible thing that exists on earth. Don’t die inside thinking that you are stuck with the duty of keeping yourself healthy.

Q) Define Author Pooja Khurana, in a single sentence.
Ans) A passion wrapped in a blanket of words.

Thank you so much for your time. Thanks Parveiz!
14th International Conference on Thalassaemia & Haemoglobinopathies & 16th TIF International Conference for Patients & Parents

The Thalassaemia International Federation (TIF) is delighted to announce the organisation of the 14th International Conference on Thalassaemia & Haemoglobinopathies & 16th TIF International Conference for Patients & Parents.

Date: 17-19 November 2017
Venue: Grand Hotel Palace, Thessaloniki, Greece
For Further Information, Please Contact: www.tifevents.org

TIF GENERAL ASSEMBLY

Date: 18 November 2017
Time: 13.15 – 15.00hrs,
Venue: Grand Hotel Palace, Thessaloniki, Greece
Conference website: www.tifevents.org

Medical Books are available in limited numbers at Thalassemics India office. Hard copies can be order directly from Thalassemics India which are distributed free of cost (only one copy per publication)

1. Patients’ Rights
3. About Thalassemia in Hindi
4. Beta Thalassemia Books in Hindi
5. Sickle Cell Thalassemia Books in Hindi
6. Prevention of Thalassaemias and other Haemoglobin Disorders – vol 1 & 2
Feedback from the Interns:

I am Drishti Asseja student of Amity University pursuing Masters in Development Studies, I worked as an intern in Thalassemics India. Working for this Ngo have made me more compassionate and empathetic. I have become more considerate and thoughtful and gained a lot of insight about the disease and its therapeutic measures and got to know the medicines taken and induced and filters used in treating of the disease.

I made a Information and feedback form where I got to know about the Blood transfusion centre, Doctor in charge, What medicine they take, which type of filters they use and also the patient’s last Serum Ferittin. However many parents did not know about their children’s serum ferittin and Some were also not aware about the doctor in charge, which was quite a setback.

After all these interviews I found out that Thalassemics children need special psychological and emotional care than any other child. The parents on the other hand need special emotional support from the caring professionals. Regular counseling sessions should be held.

I, Priyanka Manchanda, had this opportunity to intern with Thalassemics India’ for two weeks.The work to be done by me included delegate management for the seminar cum launch event from the day of joining to the final day itself. This majorly included calling and e-mailing the persons associated with the NGO and informing them about the event, taking their confirmations and following them back, providing them with their registration numbers etc. Backend data work was also included. The overall experience was astonishing. Apart from the defined role and duties, I learnt how to manage with multiple commands. There were times where I was receiving multiple commands over one thing and with this, I learnt how to be assertive and communicate effectively. I also explored myself as working in a proper work set up with proper working hours. I realised that it isn’t an easy task to do a desk job. I found myself good with the staff and that kept me going. The relationships at work matter a lot to the satisfaction in whatever we may take up. I didn’t get to stay there for long, but I am sure, I was happily working because of the support of Rashmi ma’am.

About the personal growth apart from work related behaviour, I learnt about Thalassemia about which, I didn’t know much. It sensitised me from within about how is it like to be a thalasemmic and enjoy a regular life. I would like to thank Nehal ma’am and all others involved in giving me this opportunity to learn and grow professionally as well as personally. If given an option, I would want to work here again.
Kerala

Blood Patients Protection Council (BPPC) Kerala organized a get together of Thalassemia patients from Kerala on the Republic Day at Regional science center, Calicut. In this part a free hepatitis B & C screening program, a feast in the wake of newly married Thalassemia couple were organized.

Dr. V.P. Sasicidharan, Principal, Medical College Hospital, Calicut inaugurated the program. V.S. Ramachandran, Director, Regional Science center, Calicut presided over the function. He also given a love gift to the newly wedded thalassemia couple Liba Mariam and Haneefa.

The program also given to a full respect to Dr. V.T. Ajith Kumar, chief physician, Pediatric Hematology Unit, Medical college hospital Calicut. K.M. Sunil also spoke in the function. Total 45 Thalassemia patients were screened for hepatitis B & C Only one Hepatitis C reported in the screening. Kareem Karassery, Gen.Convener of the Council welcomed the gathering. Moideen Poovoduka proposed the vote of thanks. After the program delicious food and ice-cream were served to all participant. All patients and their relatives allowed seeing the planetarium seen without tickets.

Blood Patients organized March to Medical College. Blood disorder patients took out a march to principal office of Medical college hospital, Calicut under the banner of Blood patients protection Council, Kerala. They demanded to provide life saving drugs to those who passed the age limit of 18 year old, provide differently able benefit to Thalassemia, Hemophilia and Sickle cell anemia patients and provide a separate treatment center to Thalassemia patients without considering their age. After the March Council submitted a 7 point demand to the Administrative Assistant of the principal. Take urgent step to post experts in Hemeto-Oncology ward and uplift the medical college hospital to AIIMS category are the other demands. Council Gen.Convener, Kareem Karassery inaugurated the March. K.C. Ashraf, M.K. Sajna, M.Hussain, spoke. Moideen Poovoduka welcomed the gathering. K.K. Nizar proposed the vote of thanks.

Ahmedabad

In Ahmedabad Gujarat, a thalassemia guidance program called “National Thalas Meet” for the children and parents of 11 states of India was organized by Thalassemics Gujarat. The society invited the experienced and genuine doctors who served many thalassemia patients, to share their knowledge and experiences with thalassemia children for their bright future. This programme was attended by 1000 patients and parents across the country.

Rajasthan

क्लेशसिमिक बच्चों का निशुल्क चिकित्सा एवं ज्ञान विकास सम्मेलन
क्लेशसिमिया जनजागरण कार्यक्रम पक्षवाद का समापन
अजमेर राजस्थान के जॉन बैलेंट्याँड़ सीसिएटी अजमेर के तत्वाधार में मनाया जा रहे क्लेशसिमिया
The Editorial Committee reserves the right to change the text of the articles sent for publication where necessary, in good faith. The Editorial Committee or Thalassemics India do not accept any responsibility for any inaccuracies or omissions. The views expressed are not necessarily that of Thalassemics India. Reproduction of the material published in Thalassaemia Update for Educational purpose is encouraged, provided it is accompanied by the following “According to Thalassaemia Update, the official newsletter of Thalassemics India”.
BioR and BioP Blood Filters

Leukocyte depletion filters for whole blood, red cell concentrate or platelet concentrate

**Leukocyte filters are characterized by:**

- High filtration efficiency and performance
- Easy handing
- Minimal volume loss
- Short filtration time

**Leukoreduction and Clinical outcomes:**

Pre- Storage WBC reduction significantly reduced the rate of Febrile Non-Hemolytic Transfusion Reactions from 61% to as low as 2.5% in patients receiving multiple transfusions.

Leukoreduced transfusions reduced post-operative infections by about 10% (from 33% to 23%) in Surgical Patients.

After implementation of universal leukoreduction in transfused patients, the Line Related Infections were seen to reduce by 35%.

For patients undergoing Bone Marrow Transplantation filtration of the blood products was effective for the prevention of transfusion-associated CMV infection.

LR blood transfusion in Cardiac Surgery Patients reduced mortality rates by half.

Patients given LR blood had a much lower incidence of Bacterial Contamination as compared to those given non-LR blood.
Thalassemics India

Thalassemics India: Thalassemics India is a non-profit registered organization established in 1987 with the purpose of serving and caring to thalassemia affected children. A journey that began in 1987 (under the Society's Registration Act 1860) has come a long way.

Mission & Vision: Our mission is to insure that all Thalassemia patients receive the recommended treatment at no cost. Our vision is to see our country free from Thalassemia.

Thalassemics India aims to:

- Educate and empower thalassemia patients/parents.
- Spread awareness about thalassemia amongst gynaecologists, health professionals and the community at large.
- Motivate and update patients and parents on latest developments.
- Help the underprivileged thalassemics.
- A network with decision makers and health authorities.

Thalassemics India
A-9, Nizamuddin West, New Delhi-110 013, INDIA
Tel No. 41827334, 4659811
Email: thalcind@yahoo.co.in, info@thalassemicsindia.org
www.thalassemicsindia.org