6th International Conference on Thalassemia

24th - 25th September, 2016
New Delhi, India

Announcement

Conference Venue:
Eros Hotel, Nehru Place, New Delhi

Important Dates:
Early Bird Registration
31st May, 2016

Accommodation Reservation:
31st July, 2016

Organised by:
www.thalassemicsindia.org
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* LIC: Liver Iron Concentration
Dear Friends,

We have come to the end of 2015. This year our motto was to: strengthen collaboration with important bodies to address Thalassemia. Our actions and the activities held during this year helped in making an impact, along with preparing us to face 2016 to take up the ongoing activities and to address the new challenges.

Our strength comes from our members. We expect you to become active partners in our ongoing activities. We also request for your suggestions, before we plan our activities, so that all of us can work together. We encourage healthy discussions. Sometimes you may not agree on the decisions taken by us. Feel free to give your suggestions and feedback. We warmly welcome your views on the issues that concern you.

Through our next issue of Thalassemia Update, we will share with you the list of activities for 2016 so that you are able to plan accordingly and support the activities as per your capability.

We are preparing for the 6th International Conference on Thalassemia in New Delhi for which the first announcement is being made in this issue.

We will soon share with you our plan of action for the International Thalassemia Day.

We will continue to work closely with Thalassaemia International Federation, Federation of Indian Thalassemics and other thalassemia NGOs to build up the partnerships to strengthen us to make an impact to address our demands as a unified body.

As you may agree, there is a lot of ongoing work at one time as such, it becomes difficult to communicate with you through the Thalassemics India’s newsletter. But we are constantly at the job of realizing our dream – treatment for all, and no future births of children with thalassemia major.

As always, I would like to thank all for supporting Thalassemics India and the affected families. I do hope to receive the same response from our donors and well wishers in 2016 and the forthcoming years.

Wishing you all a very happy, healthy and a prosperous new year!

Sincerely,

Shobha Tuli
2nd Pan-Asian Conference on Haemoglobinopathies
Hanoi, Vietnam 26th-27th September 2015

The conference was held at JW Marriott Hotel, Hanoi and attended by more than 700 delegates spanning 19 countries. The importance attached to this educational event is reflected through the participation of His Excellency, the Minister of Health of Vietnam, Representative of ASEAN and SEARO WHO, Her Highness Sheikha Sheikha Bint Seif Al-Nahyan, a distinguished member of TIF’s Board of Directors.

The programme was divided into two parts running concurrently: the Scientific programme and the Patients'/Parents’ programme.

Thalassemics India is grateful to TIF for sponsoring four thalassemics from India.

More information about this conference is available on TIF’s website - www.thalassaemia.org.cy
It was both by a stroke of luck and genuine intent that I happened to be chosen for the 2nd Pan Asian Conference on Haemoglobinopathies in Hanoi organised by TIF on the 26-27th September, 2015. The journey of it all began with a planned meeting with Mrs Shobha Tuli, Secretary, Thalassemics India when my mother along with my brother and myself called on her for a scheduled meet in the scorching heat of May at her New Delhi office, travelling from Jaipur-which happens to be my second home in India after Kolkata.

As a thalassemic patient and the guardians of the patient there are many thoughts racing through one’s mind which at times is hard to understand unless you have been in their shoes. Mrs Tuli had been in those shoes and felt almost every emotion which a mother of a terminally diseased patient can feel. Not only that, having helped on daily basis countless number of such patients and their families for their treatment, she had experienced a lot more. Various stages in the life of an individual pose different challenges for everyone, for a thalassemic patient only these situations are more accentuated and acute. I have reached a stage where I consider myself well managed with my Beta Thal major disease, (thanks to my Doctor Mrs. Sharmila Chandra, all the nursing staffs, family, and others), have work that provides me with more than I can live on and take care of my treatment, have grown into an adult with 29 years behind me and many other things that I can be indeed be grateful for. However to find a life partner for me has become increasing difficult with little awareness about the disease in the general population and the mere mention of the disease a taboo to prospective partner and their family. After many disappointments for us, my mother decided to seek counsel of Mrs Tuli, with the faith that something meaning will come out it. This meeting not only led us into the knowledge about many other patients who have successfully got married but also enlightened us on range of topics from how thalassemic patients are making a difference in their respective field of work and passion to contributing significantly to others by being of help to other patients. This touched and motivated me and my family. It was during this discussion that I was offered by her to participate in the Hanoi conference and I was more than happy to choose to go for it. Sometimes all it takes is to show some confidence in someone to take the first step. Mrs Tuli never fails in that.

Being in conference was one of my life’s most wonderful experiences till date. Right from the time I landed at the Hanoi airport with my mother and Dr Chandra accompanying me; to the last step out of Vietnam was a magical journey in many ways. The feel of it all started with meeting delegates of the conference from various countries- both patients and medical professionals- in the vehicle itself which escorted us to the stunning place of our accommodation and conference venue- Hotel J. W Marriot. Patients & Doctors from India, Pakistan, Indonesia, Malaysia, Thailand, Sri Lanka, Maldives, Mauritius, Iran, UK, Cambodia, Vietnam and many other countries had congressed and the whole atmosphere was buzzing with enthusiasm and hope of better future for the patients as well as meeting and making new friends from all over the world. The welcome party hosted by NIHBT on arrival that included traditional Vietnamese dance and music concert followed by dinner was an amazing ice breaker and absolute delight in itself. The two days that followed were filled with learning and networking opportunities which were jam packed with sessions of presentations by doctors & executive members of TIF sharing their knowledge and expert advice on the latest and the best disease management approach. The topics ranged far and wide from Blood safety, Treatment- Iron load, Monitoring and Infections, Treatment Updates, Common Endocrine, Cardiac and Liver Complications, HSCT & Quality and efficacy of drugs, Quality of life & Measuring Iron Overload, Capacity building associations, Clinical trials in Gene therapy.

Apart from all the above presentations which were really in depth and marvellously enlightening what was most motivating to me from the patient’s perspective was the Key note presentation by the Executive Director of Thalassemia International Federation, Mrs Androulla Eleftheriou on “Haemoglobin Disorders: Access to Care and Prevention- The Global Picture” and her various moderation of panel discussion peppered with words of encouragement and assurance of her help to all the thalassemics on behalf of Thalassemia International Federation (TIF).

The highlights and the success of the conference for me were the following:
1. The opportunity to update myself on complete range of emerging and new approaches to the treatment of thalassemia.
2. To feel assured that some cure could be on the horizon with ongoing trials and research in Gene Therapy.
3. To be able to meet, make friends and network with other thalassemia patients, support groups, organisers, medical professionals & doctors.
4. Feel inspired and motivated in learning that tremendous effort is being made by lot of selfless people
who are constantly contributing in eradication, awareness, management and finding cure for Thalassemia.
In my opinion these conferences play a great equaliser in terms of providing opportunity to both patients and doctors to discuss challenges and solutions face to face and being accessible to each other in a friendly environment as opposed to regular clinical set-up.

When the two day conference came to an end it was a bittersweet feeling. The happiness of newly acquired hope and motivation along with many fond memories was highly invigorating while the feeling of going back to our own different paths back again, away from new friends with whom we shared such amazing moments was equally disappointing. Perhaps we will meet again at another conference with new stories to share.

My journey after the conference continued for several more days in Vietnam, vacationing with my mother and Doctor in enchanting places of this beautiful country that included Hanoi, Ho Chi Minh city & Ha Long bay. The most noticeable and laudable virtue of the people of Vietnam in my experience was their humility, forgiveness, resilience, polite and warm welcoming nature despite their disturbing past.

I would like to place on record my heartfelt and sincere gratitude to Mrs Shobha Tuli, Thalassemics India & Thalassemia International Federation for nominating and choosing me as a sponsored delegate for this conference. I also convey my thanks to all the people and associations/groups involved in organising the conference so brilliantly. It was such a memorable event.

- Rahul Balasaria
Kolkata

- Sangeeta Wadhwa
Mumbai

The conference

I have attended many conferences but this conference was planned and executed differently and I would like to thank the organizers for coming up with the changes and making it even more engaging for patients and parents. Some changes were:

- Having 2 tracks, one for medical experts and other for Patients and Parents.
- Both tracks had very relevant and important topics focused on targeted audience (Medical/ General).

In Sept 2015, TIF gave me an opportunity to participate in the 2nd Pan Asian conference to be held at the JW Marriott Hotel in Hanoi, Vietnam. Vietnam is a Southeast Asian country on the South China Sea known for its beaches, rivers, Buddhist pagodas and bustling cities. Hanoi is its capital.

The conference was very professionally managed and the travel and accommodation facilities was appreciated by one and all.

The best part of the conference was the Patients/ Parents & Doctors scientific session which, being less technical, was also easy to understand.

I have been attending Thalassemia conferences since the age of ten, as such understand the challenges most Parents & Patients face when communicating with Doctors and Experts.

Many Parents/Patients are initially shy & confused with so many mind boggling questions, looking for a remedy for treatment; a hope for the future.

Here, I could unreservedly ask personal questions and discuss various individual problems during and after the session. The Doctors were also very patient in listening and responding.

I had a firsthand experience in meeting Doctors and Patients from across the World, as such have an insight into the scenarios in various countries & institutions; also the level of interactions and knowledge sharing was deeply enriching which has been a great boost to my confidence.

Being a patient and a counselor, I can confidently say that my knowledge & perspective towards being a thalassemic has changed abundantly.

Working as a PRO in healthcare, I have now a platform to share my knowledge and experience with patients, parents & Doctors likewise. I heartily thank TIF (Thalassaemia International Federation) Mrs. Shobha Tuli, (Thalassemics India), and Dr J. S Arora for giving me a chance on this platform.

I will continue to strive to do more in the field of Thalassemia, specifically counseling and motivating the patients to consider Thalassemia as a part of life and not the ONLY part of Life.

- Sangeeta Wadhwa
Mumbai
I attended sessions from “patients and parents program”. Its motto was “Empowering Patients” and the sessions completely justified the motto. Many topics were discussed and advanced knowledge was shared in these sessions, with the difference that the information was simplified for non-medical people like patients and parents. We were all engaged in learning and relating things with our experiences and asking questions whenever we had a query.

The Sessions
The sessions provided very useful information about many important topics related with health and well being of Thalassemics. Apart from medical, they also covered social and psychological aspects and guided the patients’ parents on those aspects. I would like to share some points from my memory:

- Blood transfusion and blood safety, Iron load monitoring and chelation

Blood transfusion is the primary treatment for Thalassemics. Some important points discussed here were related with when the blood transfusion is needed, how much blood is required and what Hb levels should be maintained.

These topics were related with the overall health of the patients, but there are many other aspects and among them, the most important would be Blood Safety. Every year many people suffer from different reactions during and post blood transfusions and some Thalassemics are infected with life threatening diseases.

WHO recommends that all blood donations should be screened for infections prior to use. Screening should be mandatory for HIV, hepatitis B, hepatitis C and syphilis. Blood screening should be performed according to the quality system requirements.

It’s important that Blood Safety is given high importance as it plays a major role in long and healthy life of Thalassemics.

One major research is happening in the field of increasing the interval between 2 transfusions. By 2017, we can expect some results, which may prolong the gap between 2 transfusions for up to 6 months.

Another important topic was monitoring iron overload. In this it was discussed that how iron deposited in different organs can cause many complications and what are the different ways to measure, monitor and control iron overload.

Serum ferritin, which is used widely to monitor the iron level can sometimes be an unreliable predictor of iron loading in as the result can be impacted by some other conditions, but this is so far the widely used and recommended test for measuring the iron level.

Liver Iron Concentration (LIC) provides a good measure of total body iron stores and helps in initiation and adjustment of chelation therapy. FerriScan is a way to have an accurate, validated MRI-based measurement of liver iron Concentration, which can be discussed in more details with your physician.

- Growth and other challenges and coping strategy

The life is very difficult for a Thalassemic. There are various stress factors affecting patients like:
- Altered appearances, poor growth
- Delayed puberty
- Sense of being different from peers
- Uncertain future (health/ death, work etc.)
- Possible guilt feelings for being a burden
- Poor medical care

Some psychological disorders described in patients are:
- Low self esteem, poor self image
- Emotional and conduct disorders
- Attention deficit disorders
- Impulsive, uncontrolled temper
- Dysphoric mood
- Dependency
- Fears, anxiety

There were also following and more ways suggested for patients/ parents to cope with the various challenges:
- Positive adaptation and good quality of life
- Autonomy, to grow from passive acceptance to self care – independence
- Participation in decision taking
- Stable family relationships
- Sense of normality

Good thing is that lot of support is available these days in many forms like:
- Professional Support – Doctors, Nurses, psychologist - the multi disciplinary team
- Society, patient and parent support groups
- Internet communities

- Gene Therapy, Clinical Trials and more

Luckily, I met “Philippe Leboulch” in the cab taking us from the airport to the hotel. He is a scientific founder of bluebird bio and serves as the co-chairman of its Scientific Advisory Board. This is the company behind the wonderful results in the field of Gene Therapy for Thalassemia. We talked about the company, the people who are working in it, the people who have been treated and lot more.

The first guy treated by gene therapy in France is of Thai origin. The results of clinical trials are really promising.

Currently clinical trials are in progress and more patients are invited to receive the treatment as part of clinical trial.

Some good news is expected around 2018. Keeping our fingers crossed for this ray of hope and
looking forward to the launch of this treatment for everyone at an earliest.

**Vietnam, People we met and more**

I did not know anyone who had been to Vietnam and can share any information about the country, so there were some apprehensions. To know more about the country, I visited several travel websites and gained more information about the country, culture, restaurants providing vegetarian food and learned a few words in Vietnamese.

My experience in Hanoi was fantastic from the moment I landed. The team from event organizing company was present to pick up the guests. It was around 45 minutes journey to hotel on wide and clean Hanoi roads little weekend traffic. Overall it’s a beautiful country with friendly people. They love Indian People. “Balika vadhu” the Indian TV shows is broadcasted in Vietnamese language and it’s their favorite TV show.

On our first evening, we visited Hanoi hospital where a cultural program was organized. Next evening we attended the opening ceremony with some more cultural programs.

The songs they sang, their dances and the musical instruments they played were just wonderful. They were very different from what we usually see and everyone loved it.

It was a wonderful experience, meeting Thalassemics from Vietnam and many other countries like Pakistan, Nepal, Sri Lanka, Bangladesh, Maldives, Indonesia, Myanmar, Hong Kong, Iran, Malaysia, Thailand and more. Everyone was very friendly and we discussed many things like issues we usually face, facilities available in different countries, medicines and government support etc. Communication was sometimes difficult with non-english speaking friends, but in all groups there were some people who knew English so we didn’t faced difficulty in conversations.

Overall it was a wonderful experience. We have gained a lot of information about new developments in the field of Thalassemia, met the experts working hard to make a difference in our lives.

I would like to thank TIF for organizing this conference and bringing all the experts together to share the latest information, which will benefit many Thalassemic patients, parents and societies.

- Viresh Piplani
  
  Delhi

After a long expectation the day came with full of joy and enthusiasm. I was filled with more dreams and hopes. Started my journey from my home to attend 2nd pan-Asian conference at Hanoi on 24th September. My parents and my husband gave me send-off in the Chennai airport. After the check-in procedure I boarded my flight to Malaysia by 12.30am. The journey was so pleasant.

Usually a travel to foreign country will be for various purposes like tour, business or studies a journey to attend a medical conference by a patient was so different and travelling alone gave me so many thoughts. I looked back my life journey though it was a tough one it was so colorful and surprising with lot of twist and turns. So many times I survived from death, repeated transfusions and constant treatment did not make me tired. My quest to explore the life kept me so strong and energetic. So many good memories poured into my mind and it gave me lot of hope I was so surprised that I’m travelling to a foreign country alone because even to my nearby school my father will accompany me and hold my hand because of my health issues. In my childhood I was so dependent and now I felt that I’m totally independent.

I reached Malaysia by 7'o clock. I had my connecting flight to Hanoi by 9am. Reached Hanoi by 12 noon after getting my visa on arrival, the program organisers took me to JW MARRIOT hotel. They gave me a sophisticated room to stay. After a rest went to a Gala dinner in Vietnam national thalassemia centre. Enjoyed the cultural program and Vietnamese cuisine. The next morning 26th September conference started by 10.30am. Morning sessions were very useful to all parents and patients such as blood safety, blood transfusion on thalassemia, iron load monitoring& chelation, infections in thalassemia, we clarified so many doubts to the doctors and they patiently addressed all our queries.

By 12.30pm we had lunch break during that time I made so many friends from different parts of the world. The Vietnamese people were so friendly and affectionate. Then after lunch we had sessions like growth and skeletal changes, sexual development problems, cardiac complications and liver complications through these sessions myself and all the patients and parents felt the importance of continuous monitoring the heart and liver iron overload through T2* and ferriscan and we had the hope that longevity of life is possible if we regularly monitor heart and liver and take chelation.

By 6 in the evening we had opening ceremony in that I enjoyed the traditional dance and music of Vietnam.

The program ended by 8 PM myself and my friends from other parts of India, Pakistan, Nepal, Bangladesh went for an outing we had food in an indian restaurant in Hanoi and had a great time there. Then we returned to the hotel and we had a get together and shared our life experiences, it was so eye opening. We felt that we
all are genetic brothers and sisters.

On the second day of conference we had so many knowledge widening sessions such as stem cell transplant, quality and efficacy of life saving drugs, new advances in treatment of thalassemia, MRI technologies for measurement of tissue iron concentration. The topic which was very close to my heart and which is most important for thalassemics was psychosocial support by doctor Michael Angastiniotis. In the panel discussion I clarified my queries related to child birth in thalassemia as I’m married and expecting to have a baby soon.

After lunch we had sessions relating to the role of associations in educating and advocacy by Androlla Eleftheriou and organizing an association and building up the infrastructure by Shobha Tuli Maam which inspired me to have an idea of starting an association in South India because here there is no adequate awareness about thalassemia and its treatment.

A session by our friend Viresh Piplani ‘A day in patients life’, represented all patients experience in having thalassemia. At last the sessions about clinical trials in gene therapy gave a ray of hope to all the thalassemics.

Finally in the panel discussion I raised a question regarding passing of the person’s with disability bill 2014, Mrs. Shoba Tuli ma’am gave the hope that it will be passed in a short time. The conference as per the schedule ended by 5.45 PM. After that we made some shopping in Hanoi.

The next day I left the hotel at 10 in the morning. While travelling from hotel to airport, I enjoyed a wonderful view of Vietnam. While crossing a graveyard one of my friend from Nepal said, “at last we have to come here only”, I said “if we live for the people like Hochiminh the leader of Vietnam who fought for the people. We will be kept in the museum”.

The trip to Vietnam, more than knowledge and experience it gave me wisdom. I felt that traveling to Vietnam was a great opportunity and thalassemia is a gift in my life, if I have been a normal girl I would not even crossed the border of India.

I felt thalassemia is a blessing in disguise because of that I’m strong, knowledge full, bold, caring, having love towards all in the world and at last I got my wisdom. I realized what life is.

I thank Thalassemia International Federation and Thalaseemics India for providing me this great and valuable opportunity.

Mumtaj Surya M.A.,M.L
Advocate - Chennai.

Our new members

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| Oindrina Mitra    | West Bengal |
| Pradeep Poddar    | Maharashtra |
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| Rajarshi Nath     | Karnataka   |
| Rajesh Raigudia   | Chennai     |
| Rajat Kamboj      | Madhya Pradesh |
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| Satish Jeganrao Deshmukh | Maharashtra |
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| Viren Kalubhai Vala | U.P        |
| Vivek Kapoor      | Maharashtra |
| Yash Bhatat Gandhi| Gujarat     |
| Yogesh Makkana    | Gujarat     |
| Yogesh Makkana    | Gujarat     |

www.thalassemicsindia.org
Dear Friends,

The 2nd Pan-Asian Conference on Hemoglobinopathies was held in Vietnam on 26th & 27th September 2015. It was a scientific feast with a brainstorming session all through these two days. It gives me immense pleasure to present the highlights of this conference.

Dr. Yesim Aydinok, Paediatric Haemato-Oncologist from Ege University Children’s Hospital, Turkey, talked about mitigating infection risks in transfusion practices. There are more than 200 known organisms that can be transmitted by blood transfusion and many more infections are being added to the list each year. Remarkable reductions have been achieved in the risk of serious infection through donor screening methods. It has been realized that all recognized threats have not been addressed adequately. It is impossible to detect infectivity of the donor during the window period. Inactivating pathogen present in the blood rather than just testing for them represents a different approach to blood component safety. It also represents the only practical means of dealing with many pathogens for which no testing measure, has as yet been developed. There are some concerns regarding the clinical effectiveness and avoidance of unwanted side effects of products thus obtained. Methods are being widely used for platelets and plasma derived products and are being developed for red blood cells.

Prof. Philippe Leboulch updated regarding gene therapy in thalassemia during the opening ceremony of the event. Professor Leboulch has made pioneering contributions to the field of gene therapy. He informed the audience that, 15 patients of thalassemia major have been treated so far with gene therapy. It seems that gene therapy is soon going to be a reality rather than a distant dream.

Dr. Paul Kwo, Professor of Medicine & Medical Director of Transplantation at Indiana University School of Medicine, Indianapolis, USA. He presented his magnificent work on safety & efficacy of oral therapy with Grazoprevir & Elbasvir for chronic hepatitis C. The study is of immense importance to us, as we see a large number of patients who are suffering from chronic hepatitis C. With the combination regimen, cure rates of >95% have been achieved. As the regimen is ribavirin free, there were no concerns regarding hemolysis. We are also thrilled to know that the regimen has been used in children as young as 6 years old without any significant adverse effects (Personal communication).

Dr. John B Porter, Professor of Hematology & Consultant Haematologist at University College of London, UK. He enlightened the audience regarding novel erythropoiesis stimulating agents in thalassemia. Sotatercept (ACE-011) & Lustatercept (ACE-536), activin receptor traps, are being tried in phase-2 trials. It acts on late stage erythropoiesis to increase the release of mature erythrocytes into the circulation.

Dr. Roshan Colah, Ex-Director, National Institute of Immunohematology, Mumbai gave the current status of management of thalassemia & sickle cell disease in India. It is estimated that there are more than 100,000 patients with thalassemia & around 1,50,000 of sickle cell disease. The mainstay of management of β thalassemia major patients in India involves safe and adequate blood transfusions and iron chelation. It has been estimated that 2 million units of packed red cells would be required for transfusion of thalassemia patients in India. Due to the consistent efforts of thalassemia societies and health professionals, care and management of thalassemia has been included in the 12th Five Year Plan by the Government of India. As health care is looked after by the state, diagnosis and management of Thalassemia patients is done by respective State Governments in providing health care services including the establishment of blood transfusion services. According to the guidelines of the National Blood Transfusion Council under the National Aids Control Organization, blood is provided free of cost to patients with thalassemia and sickle cell disease. Yet, studies show that only around 15% of patients receive optimum management. Although many thalassemia day care centres have been established in different cities both in Government and private hospitals as well as by the Indian Red Cross Society, there is a great urban-rural divide with majority of patients in rural areas being inadequately managed.

Dr. Shruti Kakkar, Assistant Professor, Department of Pediatrics, DMCH, Ludhiana presented the work on “Efficacy & Safety of deferasirox in single vs divided dosage in thalassemia patients” done under the supervision of Professor Praveen C. Sobti. In our population, once daily dosage appears to be more efficacious than twice daily. This could be due to poor compliance with twice a day dosage, interaction with food or the pharmacokinetics in our population.

We look forward to similar conferences in future and increased participation from various centres in India.

by Dr. Shruti Kakkar
Assistant Professor
Department of Pediatrics, DMCH, Ludhiana
bluebird bio is developing next-generation products based on the transformative potential of gene therapy to treat patients with severe genetic and rare diseases.

TRANSFORMING THE LIVES OF PATIENTS WITH SEVERE GENETIC AND RARE DISEASES

Learn more about bluebird bio at www.bluebirdbio.com
Contact us about participation in our clinical studies at clinicaltrials@bluebirdbio.com
Artificial blood set for first human trial by 2016

London: In a ground-breaking trial, researchers in the UK will test artificial blood made from human stem cells in patients for the first time. The research, planned for 2016, could manufacture industrial super red blood cells.

New road map for thalassemia management

Thalassemia is a blood disorder passed down through families (inherited) in which the body makes an abnormal form of hemoglobin. Hemoglobin is the protein in red blood cells that carries oxygen. The disorder results in large numbers of red blood cells being destroyed, which leads to anemia across the body.

Thalassemia care is available at the tertiary care centers; however, the need to identify and upgrade the treatment is still needed. The guidelines under the National Program on Thalassemia are implemented to improve the detection and management of patients suffering from the inherited blood disorders.

The guidelines under the National Program on Thalassemia provide a detailed road map focusing on creating registries, screening, and offering adequate care by setting up well-equipped infrastructural facilities such as labs at hospitals and primary health centres.

The move to frame guidelines is significant at a time when the country is facing a major public health challenge with the rising burden of thalassemia. The disease affects people of all ages and has a significant impact on their quality of life. The guidelines are crucial in ensuring that patients receive timely and effective care.

Another winner from ICMR; dirt-cheap test kits for thalassemia

NEW DELHI: India on Tuesday launched a diagnostic kit for blood disorder — thalassemia, which is expected to bring down the testing cost by 95 per cent.

The kit developed by scientists at The Indian Council of Medical Research (ICMR) is in the line of technological advancements that were made in the health sector over the last five years, with the launch of HIV, influenza, swine flu, and mosquito-borne Japanese encephalitis vaccines.

“The test costs roughly ₹4,000 at a government hospital or ₹15,000 if done private may go up to ₹15,000. The production cost of our kit is merely ₹400 that will bring down the cost drastically,” said Dr VM Katoch, Director General, ICMR.

The test is expected to bring the generic version of these drugs, which are available from the brand names, and the local market will witness a cheaper alternative. The test will be made available to hospitals and blood banks.

Hepatitis C could also benefit

The test is expected to bring the generic version of these drugs, which are available from the brand names, and the local market will witness a cheaper alternative. The test will be made available to hospitals and blood banks.

Bangalore: A school in Thrissur has a global achievement. An 11-year-old girl, Anjali, has been declared the best student in India.

Drugs control agency has granted a waiver of local trials for crucial new antiviral drugs

The drug control agency has granted a waiver of local trials for crucial new antiviral drugs.

According to the WHO, about 12 million people in India are infected with Hepatitis C in India, which leaves the country at risk. The drug control agency has granted a waiver of local trials for crucial new antiviral drugs.
India may get first-ever thalassaemia medicine

which is making the drug, sees India as it has a huge number of patients

Perinatal home at hand for thalassemia patients

For Treatment

Killer on the prowl

Oral tablets a sweet pill for Hepatitis C

www.thalassemicsindia.org
This program began on 18th April 2015, with a clear object to enhance the capacity of all Thalassemia NGOs for a better society.

Supported by Novartis, this program was spread into four modules. The last module was held on 19th-20th December, 2015.

All Thalassemia NGOs had the opportunity to learn a lot from the lectures given by Prof. Rukaiya Joshi, Prof. Malay Krishna, Dr. Sumita Datta, Mr. Vijay Nadkrani, Prof. Shreenivas Kunte, Prof. Raja Roy Choudhury, Dr. Anjail Kanitkar, Ms. Rekha Kuruvilla, Ms. Merine John, Mr. Noshir Dadrawala, Mr. Dharmedra Jethwani, Prof. P. Prabhakaran & Ms Usha Menon (on skype).

Some of the important features of the program agenda were: Fundraising, Project Writing, FCRA, Policy Advocacy in Thalassemia, Project Management, Networking, Management of Volunteers, Presentations by NGO’s Participants, Leadership for Growth, Budgeting & Concepts of Finance and Sustainability.

This event also gave an opportunity to the delegates attending these workshops to share their common issues & the problems they encounter in their regions.

The last session of this ‘module four’ was encouraging when the delegates were addressed by Dr. Ranjan Banarjee Dean, SPJIMR and Senior Faculty members, Mr. Amitabh Dube, Head Novartis Oncology India, Mr. Prabhat Kumar Sinha and Senior Executives from Novartis.

I am confident that all 14 Thalassemia NGOs selected by Novartis from India for this workshop would have learnt a lot through this learning program. This will definitely help them to improve their way of working and also to run their Societies more professionally.

Thanks to Novartis and SPJIMR for conducting such an event.

- Shobha Tuli
Stem Cells are the most Precious Gift of God.

Bless Your baby with protection of a lifetime
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# Lifetime Protection

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- Inherited Metabolic Disorders
- Histiocytic Disorders
- Lymphoproliferative Disorders
- Other Inherited Disorders
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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
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Leukoreduction and Clinical outcomes:

Pre-storage WBC reduction significantly reduced the rate of Febrile Non-Hemolitic Transfusion Reactions from 61% to as low as 2.5% in patients receiving multiple transfusions\(^1\)

Leukoreduced transfusions reduced post-operative infections by about 10% (from 33% to 23%) in Surgical Patients\(^2\)

After implementation of universal leukoreduction in transfused patients, the Line Related Infections were seen to reduce by 35%\(^3\)

For patients undergoing Bone Marrow Transplantation filtration of the blood products was effective for the prevention of transfusion-associated CMV infection\(^4\)

LR blood transfusion in Cardiac Surgery Patients reduced mortality rates by half\(^5\)

Patients given LR blood had a much lower incidence of Bacterial Contamination as compared to those given non-LR blood\(^6\)
AMBULATORY SYRINGE DRIVERS FOR THALASSAEMIA TREATMENT

THALAPUMP 20

- Digital programming (Screw Driver free)
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Pitampura, Delhi-110034, Ph:- 9810052179
The meeting began at 11.30 am with the President’s welcome address. This was followed by the Secretary’s report for 2014-2015, which provided a summary of all the major activities undertaken during the year showing the transparent framework, composition, funding and focus of the society. Accounts for the year ended 31st March, 2015 was presented by the Treasurer.

The meeting was attended by over 100 parents and thalassemics. A special session was held on the request of thalassemia families, the same conducted by Dr. V. K. Khanna, Dr. Amita Mahajan and Dr. Nirmal Kumar. Dr. Amita Mahajan gave an update on the recent status of thalassemia and also about the new research to improve the treatment and the cure of thalassemia.

The meeting ended with a vote of thanks, followed by luncheon.
Thalassemics India’s upcoming events

1. 6th International Conference on Thalassemia - 24th - 25th September, 2016
2. International Thalassemia Day - 8th May, 2016
3. Annual Picnic - TBA

Congratulations!

Congratulations to Swati Tuteja for scoring 84.25% in BA. Programme in third semester at Satyawati College (Delhi University).

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

- Desferal
- Asunra
- 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)
Haemonetics Purecell™ RC
High efficiency leucocyte removal filter for blood transfusion

- 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

The blood filters business of PALL® is now a part of Haemonetics
News Across India

Kerala
Blood Patients’ Protection Council observed Patient Solidarity Day before Medical college hospital, Calicut, Kerala, India. In this part a Rally of blood disorder patients, a public meeting in Medical College town street and a protest fast was also organized. Council General Convener, Kareem Karassery inaugurated the program. Moideen Poovaduka, K.K.Nizar, prasidhan, A. N. Lissi. Vahab, Sulu Ashraf were spoke. Ummer Ali and Maqsood led the Rally.

Nasik
Nasik Thalassaemia Foundation along with touchwood foundation did screening camp at Bhagatwadi Adiwasi village, and did many activities for the grand festive.
Nasik Thalassaemia Foundation did screening camp at Bhagatwadi Adiwasi village, and did many activities for the grand festival Diwali. Distributed sweets, drawing book, clothes and many more competition held amongst kids.
On the occasion of 14th November thalasæmia screening camp held in adiwasi village with the help of Touchwood Foundation and thalassaemia foundation Nasik under esops activity of Mahindra n Mahindra and rangoli competition, drawing competition held at “Nasik thalassaemia foundation”. Prize distribution done by president of Rotary Dr Awesh Palod.

Chandigarh
Prize being given to winners of Cycle Rally and Awareness Camp which was organized to celebrate the International Thalassaemia Day.

Dr. Neelam Marwha, HOD, Deptt. of Transfusion Medicines, PGIMER, Chandigarh addressing the audience in CME dated 25th Sept. 2015

144th Blood Donation Camp held on 9th May, 2015 by TCWA
Inaugurated by Dr. Savita Malhotra, Dean PGI, Chandigarh

145th Blood Donation Camp held on 23rd May, 2015 by TCWA
Inaugurated by Sh. Ashok Garg, Government Contractor, Panchkula

147th Blood Donation Camp held on 14th June, 2015 by TCWA at GMCH-32, Chandigarh
Inaugurated by Dr. Atul Sachdev, Director /Principal, GMCH-32, Chandigarh

Memento being given to the Donors by Mrs. Neelam Sikka in the presence of Bank Staff and Sh. Rajinder Kalra (General Secretary)
Blood Donation Camp held on 18th August, 2015 by TCWA and Market Dealer Association, Sector 18, Chandigarh Inaugurated by Sh. Vijay Kumar Dev (IAS) Advisor to Governor Chandigarh

Memorandum and Profile of the Association being given to Advisor by Sh. Rajinder Kalra (General Secretary, TCWA)

Ajmer

Ajmer 29 November 2015, Ajmer Ration Thalassemics Thalassemic Donations Camps held on 1st November 2015 by TCWA and Market Dealer Association, Sector 18, Chandigarh Inaugurated by Sh. Ramesh Kalra, AGM, State Bank of India, PGIMER, Chandigarh

Memento being given to the Donors by Sh. Vikas Pratap in the presence of Sh. Rajinder Kalra (General Secretary) and Staff

148th Blood Donation Camp held on 20th June, 2015 by TCWA
Inaugurated by Sh. Ramesh Kalra, AGM, State Bank of India, PGIMER, Chandigarh

149th Blood Donation Camp held on 4th July, 2015 by TCWA
Inaugurated by Sh. Vikas Pratap, I.A.S. Secretary Personnel to CM, Govt. of Punjab

150th Blood Donation Camp held on 18th May, 2015 by TCWA
Inaugurated by Sh. Anurag Agarwal, I.A.S., Home Secretary, Chandigarh

151th Blood Donation Camp held on 18th August, 2015 by TCWA and Market Dealer Association, Sector 18, Chandigarh Inaugurated by Sh. Vikas Pratap, I.A.S. Secretary Personnel to CM, Govt. of Punjab

Memorandum and Profile of the Association being given to Advisor by Sh. Rajinder Kalra (General Secretary, TCWA)

The Editorial Committee reserves the right to change the text of the articles sent for publication where necessary, in good faith.
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www.thalassemicsindia.org
Thalassemics India

Thalassemics India: Thalassemics India is a 'not-for-profit' registered organization established in 1987 with the sole purpose of serving and caring for thalassemia affected children. A journey that began in 1987 (under the Societies Registration Act 1860) has come a long way.

Mission & Vision: Our mission is to ensure that all Thalassemia patients receive the recommended treatment at no cost. Our vision is to see the country free of new thalassemia births.

Thalassemics India aims to:

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