Thalassaemia Update
Issue 44 • December 2016

SPECIAL EDITION

Pre and Post Thalassemia Conference, 2016

HIGHLIGHTS OF THIS ISSUE

- International Thalassemia Day
- Annual Picnic
- New Members
- Worthy Donors
- News Across India
- 6th International Conference on Thalassemia
- AGM
- Medical News

www.thalassemicsindia.org
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.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
Dear Friends,

Welcome to this special issue of Thalassemia Update! 2016, has been quite a busy year for us at Thalassemics India. The first half of the year was spent preparing for the 6th International Conference on Thalassemia.

A few talks on thalassemia at different platforms gave us an opportunity to share information & printed material with the general public.

International Thalassemia Day was celebrated on 8th May as a fund raising activity, details of which can be found in the newsletter.

One of our biggest achievements this year was receiving some funds under CSR which were best utilised by giving free of cost chelation drugs, filters & blood transfusions to the children in need.

I and the fellow colleagues at Thalassemics India are proud & happy to extend support to needy thalassemics children under our “Helping Hands Project”.

Keeping in view the importance of disability status, we had a number of meetings with the concerned govt. authorities.

Thankfully, our efforts were successful in holding another check up clinic on 23rd September for our thalassemics who had been demanding for such a clinic for quite some time. Our next super specialist clinic will be held in the coming year.

Our Annual General Meeting was held on 6th November which gave an opportunity to share our reports and to hear patients/parents feedbacks and their suggestions.

The long pending film on Thalassemia is finally complete which we plan to show in our awareness campaigns.

Every year, since Thalassemics India was established, we have been setting high standards and goals. Despite the difficulties and challenges we will move to 2017, with greater vigour & zeal for a very busy and yet another successful year to achieve our goal of improving the health and lives of Thalassemics across the country.

Among the many proud moments that Thalassemics India enjoyed in 2016, one of them is the success of the 6th International Conference on Thalassemia held on 24th -25th September which turned out to be our very best Thalassemia Conference ever held so far. You will find interesting information about the same inside this newsletter with some attractive pictures.

Finally, I would like to thank each and every person who took the time and trouble to assist us in our activities.

Wishing you and your family a successful, happy and healthy 2017. Stay blessed!!!

Sincerely,

Shobha Tuli
Special Thanks

MARIA GRAZIA LINTAS
INNER WHEEL CLUB OF FARIDABAD
NEW DELHI LAND CONSORTIUM PVT LTD
ROHIT NANDA
SUMIT GUPTA
MACQUARIE GLOBAL SERVICES PVT. LTD
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Thalassemics India celebrated 8th May this year by an awareness campaign & fundraising event under our “Helping Hands Project”.

The Press was invited to the meet with the aim to sensitise the general public and the concerned authorities. The Media was addressed about some of the important issues: incidence of thalassemia, high costs of treatment, disability, insurance and social issues. The news was very well covered by some of the prominent print and electronic media. The Govt. of Delhi also gave advertisements in Hindi and English dailies on 8th May, highlighting Thalassemia and its prevention and also informing thalassemia families about the treatment facilities available in five of the Government hospitals in Delhi.

Our “Helping Hands Project”, had already commenced enveloping underprivileged thalassemics under this programme, disbursing chelation drugs and filters at no cost. In order to continue with this programme, a fundraising event was held to collect more funds, inviting the ever so eminent, talented composer of Indian classical music, Shubha Mudgal. The evening began with the traditional lamp lighting, followed by “vandana” sung by our talented Shivangi Amrit. Thereafter, the artist took over in full flow singing, at a stretch for more than two hours, along with her team of instrumentalists, the audience acknowledging with appreciative hand-clapping.

The programme was compered by Nehal Dhingra and was attended by more than three hundred people.

The programme ended with a vote of thanks by the Secretary to Shubha Mudgal Ji and her team, as also the donors.
THALASSAEMIA UPDATE _____________________________ International Thalassemia Day

We would like to thank the donors who contributed to the 8th May function.
The annual picnic was organised by Thalassemics India on 28th March. Over 300 thalassemic children & their parents visited the “Worlds of Wonder” Noida. It was a day full of fun & interactions. The children & their families came in around 10.00 am and stayed on until 4.00 pm. They enjoyed the various rides and a sumptuous lunch.
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
## Our new members

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Kerala: Kareem Karassery

Blood Patients Protection Council (BPPC) Kerala has observed world Thalassemia Day at Regional Science Centre, Calicut with various activities with the support of regional Science centre, Calicut. Dr.P.K.Sasidharan, former professor and HoD of General medicine, Medical College hospital, Calicut inaugurated the function. He also released the special supplement related to Thalassemia Day celebration and distributed the P.T. Anshif memorial cash award for Thalasemia patients to those who had passed the SSLC public examination in 2016. V.S.Ramachandran, Director, Regional Science centre presided over the function. He honored Dr. Sasidharan for his year long services in the Hematology wing of Govt.Medical College hospital, Calicut. Kareem Karassery, General Convener of BPPC welcomed the gathering. K.C.Ashraf proposed the vote of thanks. After the inaugural function a patient's parent's session took place. In the Parents session Moideen Poovaduka,K.Raja Gopal,M.K.Sajna,Padma Kannan,C. Lasitha Rani,N.Hamza shared their experience from various angles. In the patients session Manjusha, Raheem Nandhi,Hasna,F.S,Fasila,Maqsood, C.Nayya and sabith shared their experience from various angles.

In the sessions patient's session Manjusha, Raheem Nandhi,Hasna,F.S,Fasila,Maqsood, C.Nayya and sabith shared their experience from various angles. After the function a painting competition was conducted for the Thalassemia affected children. Hafeef and Navya won the first and second prize in the competition. Kareem Karassery, Gen. Convener of Blood Patients Protection Council distributed the prize for the winners. Various cultural programs were also organized in the function. In this part of the function the Blood Patients Protection Council submitted a memorandum to the Hon'ble Parliament Member Sri.C.P .Narayanan for helping to get the disabled right for Thalassemia, Hemophilia and Sickle Cell Anemia.

Maharashtra: Dr. Sangita Lodha

On the occasion of world THALASSAEMIA day, a huge Thalassemia awareness cycle rally had been arranged, which has spread the massage about Thalassemia in the whole of Nasik city. Mahindra and Mahindra has taken this initiative along with many organisations, like the Jankalyan blood bank ,Thal Foundation Nasik, Touchwood Foundation,Nasik Cyclist Federation,Indian Medical Association, Indian Academy of Paediatrics, Arithan hospital, Rotary smart city etc. Dr Sangita Lodha addressed the people about Thalassemia. There was the Inauguration of a book "THALASSEMIA MANAGEMENT AT A GLANCE" compiled by Dr Sangita Lodha done on the same day.
Madhya Pradesh: Dr. Ravindra Kumar

On the occasion of world thalassemia day, 8th May 2016 Sri Aurobindo Medical College and PG Institute in association with Indian Academy of Pediatrics (Indore Branch) organized a one day CME program of doctors and interactive counselling session for patients and their parents. Our keynote speaker Dr. V. P. Choudhary, Director of Sunflag Pahuja Center for blood disorder and former Head of the department of Hematology AIIMS New Delhi gave an excellent coverage on clinical diagnosis of thalassemia also actively counselled the patients for better management of thalassemia. Other speakers Dr Rawat, Dr Siddhant Jain, Dr Tanmay Bharani & Dr. Preeti Shukla explained about the recent management, cardiological, endocrinological aspects & diet plans of thalassemia. Dr Aswini Dalal (Head of Diagnostic Division in CDFD, Hyderabad) explained gave an idea about the strategy and techniques for preventing thalassemia which is rather more important as prevention is always better than cure. Mrs Annaya Gosh aware us about the stem cell donor registry in India. Dr Kuldeep Singh, (HOD, Pediatrics AIIMS Jodhpur) was also connected via telemedicine facility and listened to the entire lecture presented here.

He also gave his talk on Social and ethical issues which thalassemia a patient faces every day. In the afternoon there was a patients parents and doctors interaction program in which thalassemia experts gave the knowledge about better management to thalassemic patients. Around 120 delegates participated in this event.

Jharkhand: Dr. T.K. Chatterjee

8 ebZ 2016 vkt "MAW h i h cut hZ MAW h , l- ny ky" MAW, i-ds cut hZ MAW, u- ds fl UY k MAW ds ds 'hekZ MAW i qik xgBld jir r MAW Loi uk B MAW eer k x ky j MAW i hkkd j i k hM MAW Q g p kn egr kJ MAW d vy he eMMI MAW vku k t k d MAWv k ral eMy MAW h i r egr kJ q PdHgH H ego lo egr lq vs r t cut hZ i g y oe kZ x fn h V h u fop ky j i kl bl vol j i t i m aj f d dl d aj u sv u h t i m aj ss n'k la ds ed dr fd; la /l o m K K u MAW h i h cut hZ usf d; la
Congratulations!

- Gouri Gupta for scoring 96.4% in class 12th CBSE Arts Stream.
- Chhavi Bajaj for scoring 93.2% in class 12th CBSE Commerce Stream.
- Sahil Bansal for scoring 92% in class 12th CBSE Commerce Stream.
- Akrit Jain for scoring 89% class 12th CBSE in Commerce Stream.
- Amav Choudhary for scoring 78.6% class 12th CBSE in Science Stream.
- Chetan Chandana for scoring 75% class 12th CBSE in Commerce Stream.

Special thanks to Genesis Foundation for supporting 7 of our thalassemics by giving them financial aid for undergoing Bone Marrow Transplant.

For your information:

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)

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.

Some time we must be hurt, In order to grow, We must loose, In order to Gain, Because some lessons are best when learnt through pain.
MESSAGE

I am happy to know that Thalassemia India along with Sir Ganga Ram Hospital, Thalassemia International Federation and IAP (Delhi) is organizing the 6th International Conference on Thalassemia from 24th – 25th September, 2016 at Delhi.

This specialty workshop, I am informed, will be conducted by the stalwarts of the field and will be attended by delegates not only from India but from around the globe.

I am hopeful that the Conference will provide a platform to exchange the expertise, experience of medical fraternity to update their knowledge and skills improving quality of health service delivery. This will also help in updating their knowledge regarding the latest methodologies and standards of management and prevention of Thalassemia.

I congratulate the organizers and the participants of the Conference and extend my best wishes for its success.

(Jagat Prakash Nadda)
The 6th International Conference on Thalassemia was held at Hotel Eros, Delhi on the 24th and the 25th September, 2016. The conference was held under the auspices of the Ministry of Health and Family Welfare, Government of India.

We were fortunate to have a galaxy of national and international experts who apprised us of the latest developments in the management of Thalassemia. The faculty included nine international, and over seventy national experts who shared extensive knowledge on a range of subjects. The conference was attended by over 600 doctors, parents, patients and Government health officials. The format of the conference was designed in a way that patient and parent queries were duly addressed, either during the presentations or panel discussions. The Chairpersons had been requested to summarize each of the presentations in Hindi at the end of each talk so that the essence and key messages reached all.

The tone for the conference was set by the first presentation by Dr. Androulla Eleftheriou, Executive Director, Thalassaemia International Federation who explained the current Global status of Thalassemia with specific focus on India. The next talk was on “Safety and Adequacy of Blood” by Dr. Poornam Srivastava of the Lions Blood Bank who highlighted the importance of the availability of adequate and safe blood products to thalassemic patients, as this is the mainstay of optimal management of these patients. This was followed by a session on Blood Transfusion Therapy by Dr. Mamta Manglani, Head of the Department, Sion Hospital, Mumbai who reiterated the principles of optimal transfusion of patients with thalassemia. She addressed the many issues encountered on a day-to-day basis when receiving transfusion therapy.

The conference was formally inaugurated before proceeding to further scientific sessions by the Chief Guest Dr. Arun Kr. Panda, Additional Secretary, Ministry of Health and Family Welfare, Government of India, along with H.E. Demetrios A. Theophylactou, Cyprus High Commissioner, Dr. Androulla Eleftheriou and Dr. Michael Angastiniotis. Shobha Tuli, Conference Secretary gave her welcome message. “Abstract Book” was officially released by the Chief Guest. The audience was apprised of the initiatives being taken by the Government bodies for patients with Thalassemia. A vote of thanks was given by Dr. V.K. Khanna, Chairperson Scientific Committee.

Short presentations from West Bengal, Gujarat and Uttar Pradesh highlighted the work being done at the State level both in terms of prevention and management of thalassemia.

Dr. Anupam Sibal, Pediatric gastroenterologist, Apollo Hospital, Delhi discussed the recent advances in the management of Hepatitis B and C. He informed the indications of starting treatment. The new medications now available for Hepatitis C make a cure or clearance of infection realistically possible for the majority of patients.

The next two sessions addressed the important area of Chelation. Dr. John Porter from UCL London shared the changing paradigm in chelation wherein we want all patients to have ferritin under 1000 so that there is no significant organ dysfunction in the long term. Deferasirox has truly made it possible for the majority of patients. Dr. Antonio Piga from Torino University, Italy took the proceedings further by deliberating on combination chelation therapy, which is needed in some patients who are unable to reduce iron overload by using a single agent. He shared his vast experience on when and how agents should be combined to yield the best results.

The sessions on Transfusion and Chelation were concluded by a Panel Discussion which covered many areas which parents and physicians find challenging. The session was moderated by Dr Deepak Bansal from PGIMER, Chandigarh. The questions were based on frequently asked by parents and patients and was found to be very advantageous by the audience.

The next segment was on endocrine issues. Dr. Heba Elseidfy from Ain Shams University, Egypt talked about growth problems, hypothyroidism, delayed puberty and poor bone health. She reiterated that optimal chelation is the cornerstone for prevention of endocrine dysfunction and the optimal management of these conditions. As it is difficult to discuss all issues in a single talk, this session was followed by a Panel Discussion format with Pediatric Endocrinologists from different hospitals and was moderated by Dr. Deepak Bansal. The practical aspects of monitoring for and management of endocrine issues in thalassemic patients were discussed.

This was followed by a session on cardiac management by Dr. John Malcolm Walker from University College Hospital, London. Once again, he emphasized that the only way to prevent cardiac complications by ensuring that excess iron overload does not get accumulated in the heart. He also shared tips for the doctors on managing cardiac complications.

The final session of the first day was an open forum for parents and patients moderated by Ms. Gagan Singh. This gave all attending to voice their own problems and also share their personal journeys and achievements with all.

The opening session on Day 2 was on T2* Imaging by Dr. Dr. Harsh Mahajan, Founder and Chief Radiologist of Mahajan Imaging, New Delhi and Dr. Amna Abdel Gadir from University College Hospital, London. It is widely accepted now that T2* MRI is the
best way to monitor iron overload in the heart and liver. Further progress in this area and the need to ensure accuracy and reliability of the test was highlighted.

The session on Monitoring was by Dr Antonio Piga who made us all aware, yet again of the need for optimal monitoring and for optimal management.

This was followed by the sessions on BMT, and questions around it that bother virtually all our patients. Dr Mammen Chandy, Director, Tata Medical Center, Kolkata very clearly addressed all the key areas. He shared data that the current outcomes for Thalassemia transplant with matched family donors and fully matched unrelated donors are excellent. However, based on current evidence transplants with half matched donors (haploidentical) or with even slightly mismatched unrelated donors can not be advised for these patients. All these issues were further addressed by a Panel of BMT experts who answered numerous patient queries.

In the next session Dr Philippe Leboulch, director of France’s Institute of Emerging Diseases and Innovative Therapies, France shared with the audience the progress made in the area of Gene therapy. A lot of exciting developments are happening in this area but it will still be a few years before the principles can be adopted in routine clinical practice. Dr Alok Srivastava from CMC Vellore, acknowledged their efforts to pioneer this in India also so that when the technology is ready for clinical use, Indian patients can benefit at affordable prices.

Following this was the section on Fertility and Pregnancy in Thalassemia. Dr Sanjivini Khanna, Director and Head, Dept. of Obs/Gyn, Fortis Hospital, New Delhi made everyone aware that fertility and pregnancy for thalassemia was a reality now as to how to manage the young pregnant woman with thalassemia. Dr Abha Majumdar from Sir Ganga Ram Hospital discussed about prenatal diagnosis which has made it possible to actually implant an embryo that is healthy and may even be fully matched with the patient. This is not, however, currently available in India.

The session on Thalidomide in Thalassemia: Hope or Hype was eagerly awaited by everyone as it is currently being prescribed widely for patients. Dr Amita Trehan, Pediatric Hematology Oncology unit, Chandigarh, discussed that whilst there were interesting case reports of four patients with thalassemia major and intermedia, who were given this drug in very difficult situations having benefited from this drug. However, it would be unwise to start prescribing this drug without further studies and detailed analysis. For now, patients should be continued on the standard management protocols.

The talk on New Drugs on the Horizon was delivered by Dr John Porter. There is a lot of excitement about Lusartercept which can prolong the transfusion interval. This drug is currently undergoing extensive trials and will now, more in the next couple of years or so.

Finally, the section on Patient Voices brought to the fore three young, dynamic, patients who highlighted the hopes, aspirations and the achievements of the young thalassemic and how a positive outlook more than anything can shape our destiny.

The conference was concluded on this favourable note. As organizers, it was a hugely rewarding experience for us and we hope that all attending found it to be an opportunity to learn, meet and make friends and move on to their personal journeys with the right knowledge and hopes in their hearts and dreams to achieve.

Dr Amita Mahajan
Secretary Scientific Committee
6th International Conference on Thalassemia

Shobha Tuli
Organizing Secretary
6th International Conference on Thalassemia
6th International Conference on Thalassemia 2016
2016, Conference Feed Back

Great meeting, very well organised. Thanks of the opportunity

- Dr. Anupam Sibal
Apollo Hospital

I enjoyed attending the meeting and organizing the two panels. The meeting was straightforward, educative, comfortable and world class arrangements. The thalassemia community is lucky to be led by you. Thank you for involving me.

- Dr. Deepak Bansal
Jaipur

Thank you for the opportunity to participate in the meeting.Well organised excellent meeting

- Dr. Amita Mahajan
Apollo Hospital

Congratulations for organizing such a wonderful conference. I really do not have words to appreciate the way the conference was organized in all fronts. Scientific Contents was very good. I could not afford to miss any session, as all the sessions were really chosen well. Rest of the arrangements were also very good. The team work of the society is really appreciable. My all best wishes.

- Dr. Alka Mathur
Hindu Rao Hospital

Thanks Thalassemics India and special thanks to Ms. Shobha Tuli for the excellent conference full of learning and blend of local with international experts.

- Dr. Omesh Kumar Bharti
Himachal Pradesh.

I would like to sincerely congratulate you for the excellent organisation and for the most productive conference. The efforts made to offer this truly unique educational experience to the participants were indeed impressive and remarkable.

- Dr. Androulla Eleftheriou
Executive Director, Thalassaemia International Federation

Very well organised, with lots of academic sessions, informative and interactive sessions from the dignitaries across the world who have covered each and every beat of Thalassemia. Feeling proud to be a part such an organisation and Conference.

- Dr. Sangeeta Lodha
Nasik

With due respect, happy diwali to you all, and also a big congratulations for organising such a useful conference on thalassemia for the people like me and others, thanks a lot.

- Deepak Singhana
M.P

Thank you so much for everything and congratulations for a really successful conference and work you are doing for thalassemic children. My very best wishes.

- Dr Heba Elsedfy
Cairo, Egypt.

Congratulations to you Mam and your entire team who pioneered the organization of such a huge and successful event. I do thank you and express my gratitude for giving us ‘The Thalassemics’ an opportunity to listen to some of the renowned clinicians from around the world who are making a significant difference to the life of Thalassemics.

- Samik Samadda
Kolkata.

Many many congratulations to you Mam and the entire team for the successful organisation of 6th International Thalassemia Conference. It was very well organised event and a scientific feast. I am grateful to all of you for inviting me and heartfelt thanks for the hospitality.

- Dr Poonam Shrivastava
Lions Blood Bank, Delhi

It was a great experience attending the 6th International Conference held on 24th & 25th September 2016 at New Delhi, India. The sessions I attended, were very informative and insightful on their particular subjects. I would like to take this chance to reflect upon my enriching experiences in the field of Thalassemia and the ways this conference has helped me to make a comparative study of medical practices and understand the international perspective on how to benefit from exchange of ideas, sharing of expertise, socializing with international patients, Doctors & Pharmaceutical companies. The Clinic which was held on 23rd September was really helpful for patients. Doctors gave their personal time to attend the patients very calmly. On the first day of the Conference i.e: 24th September, a Gala dinner was organized which was enjoyed with all the Doctors, NGO representatives, organizers and all other participants. I met many intelligent and sharp international and Indian Doctors from different countries. I enjoyed the presentations by Dr J M Walker from UK and Dr Amita Trehan from Chandigarh, India. The best part of the conference was the Patients/Parents & Doctors scientific session which was also translated in our national language which was easy to understand for the diverse crowd. Personally I think this conference was very well organized and very successful. Volunteers and team members were very active and hard working; specially the female volunteers. I would like to join them in their next conference and become part of their team. Heartily thanks to Mrs Shobha Tuli for her great efforts. I would like to share that whenever I met her I am inspired a lot and I am proud to say that she is my idol. Congratulations to Organizing Committee for your grand success in organizing this event. I fully enjoyed the two day event.

- Sangeeta Wadhwa
Maharashtra.

It was a very informative & very well organized Conference. All thanks to the organisers.

Yash Chawla
Delhi

Congratulations for a successful well organised conference! This was unique in all aspects, academics, social responsibility, even hospitality thanks to you and your team for all these.

- Prof. Maitreyee Bhattacharya
west Bangal
Check up Clinic

As a part of Thalassemics India activity, a ‘check-up’ clinic was organised on the 23rd of September at the Sir Ganga Ram Hospital, New Delhi.

Information on the clinic was sent to all our registered members, much in time. Finally, 45 thalassemics were shortlisted who came from Delhi, Haryana, Gujarat, Rajasthan & Maharashtra.

Thanks to Dr John B. Porter (London) Dr. J. Malcolm Walker (London) and Dr Heba Elsedfy, (Egypt), for giving their valuable time.

Thalassemics India is also thankful to Sir Ganga Ram Hospital authorities for organising this clinic.
The meeting was held on the 6th of November at the Constitution Club, from 11.00 to 2.00 pm followed by lunch. The same was attended by 95 members.

As per the agenda, of the meeting, the secretary’s report was presented after the welcome message by the President of Thalassemics India. Accounts for the financial year 2015-2016 were also presented by the treasurer.

As a part of this meeting, Dr. V.K. Khanna gave a brief about the 6th International Conference on Thalassemia highlighting some important issues & updates.

Some of the parents inquired about the status of the Disability Bill. Some of the members showed interest in arranging Blood donation camp/s in their areas. Some members also suggested that the society should take up the matter with IRCs for NAT screening.

The meeting ended with a vote of thanks by the Vice President, Dr. Gautam Bose.
upcoming events

14th International Conference on Thalassaemia & Haemoglobinopathies & 16th TIF International Conference for Patients & Parents, in October/November 2017 in Germany

2nd MEGMA Conference on Thalassaemia and Other Haemoglobinopathies, covering the Middle East (ME), Gulf (G), Maghreb (M) and African (A) regions was held on 11th & 12th November, 2016 at Le Royal Hotel, Amman, Jordan. The Conference was well organized in collaboration with the Jordanian Thalassemia & Hemophilia Society and the Ministry of Health - Jordan.

The Thalassaemia International Federation Board Meeting held on the 12th of November, 2016 at the Aman, Jordan was attended by Shobha Tuli.

TIF Books are available free of charge at Thalassemics India’s office:
A 9, Nizammuddin West,
New Delhi-110013
Thalassemics India Activities - A summary

- Services rendered to Thalassemia societies and parents, providing them with chelation drugs, infusion pumps, filters, needles at extremely subsidized rates to twenty-two States in India.
  - Desferal: 779 boxes
  - Asunra: 4327 boxes (400mg & 100mg)
  - Desirox: 966 boxes (250mg & 500mg)
  - Kelfer: 1491 boxes
  - Defrijet: 1001 boxes
  - Filters: 10,119 pcs.
  - Needles: 19,200 pcs.
  - Pumps: 47 units.
- Shobha Tuli as one of the panellists invited by the Dharashila Cancer Hospital for a panel discussion on "Thalassemia – An Unfinished Journey", on the 6th of February.
- Help Committee meeting held at the Nizamuddin office on 5th March to review help applications by the T.I executive members - Rita Jain and Rekha Arora.
- Annual Picnic held on 28th March, at the "Worlds of Wonder", Noida - The group was managed by Rekha Arora.
- Shobha Tuli invited by the "Thalassemics Gujarat" as the Guest of Honour, in Thalassemia meet, the same held on the 2nd of May at Ahmedabad.
- Shobha Tuli invited by the F.M Rainbow on the 5th of May, to take part in their one hour program to create Thalassemia awareness.
- The Press Meet conducted on the 6th of May, at the Nizamuddin office was addressed by Dr. V.K.Khanna and Shobha Tuli.
- A funding event was held to collect more funds, inviting the ever so eminent talented composer of Indian classical music, Shubha Mudgal on the 8th of May, International Thalassemia Day at Air Force Auditorium, Subroto Park.
- Shobha Tuli was invited by Dr. C.B Dangi on the 19th May, at Pullman Hotel (Aerocity Gurgaon) to take part in ‘Women Economic Forum’. Thalassemics India’s executive members Ashvini Malik & Deepak Dhingra also took part in this programme.
- Took part in a ‘Walk’ on World Blood Donor Day arranged by Dr.R.N Makroo at the India Gate on the 14th of June.
- A talk delivered on the 4th of June, by Shobha Tuli on Thalassemia & Thalassemics India’s Journey for Doordarshan.
- On World Blood Donor Day, Doordarshan invited Shobha Tuli to deliver a talk on Thalassemia.
Invited students from the Hansraj college to visit the Thalassemia unit of St. Stephen’s Hospital on 4th of August, for their ‘study program’. The group was managed by Thalassemics India’s joint treasurer, Deepak Dhingra.

The Zoological Society of Zoology department has organised an inaugural talk on “Thalassemia” by Dr. V. K. Khanna, Chairperson Thalassemia Unit, Sir Ganga Ram Hospital on 5th September . The lecture was very informative and well conveyed. The students and Teachers from inter-disciplinary subjects attended the lecture.

The lecture was followed by discussion where students asked different questions related to disease. He replied with his expertise.

Shobha Tuli was invited by the Innerwheel Club on 5th of September, to the MREI to talk about Thalassemia & BMT.

The Annual General Meeting of the Society was held on the 6th of November, at The Constitution Club, the same attended by 80 Thalassemia Members.

A ‘check up’ clinic was held on September at Sir Ganga Ram Hospital. 45 Thalassemics from Delhi, Haryana, Gujarat, Rajasthan & Maharashtra came to the clinic for counselling. Thanks to Dr. Malcolm Walker (London), Dr. John Porter (London) & Dr. Heba Elsedfy (Egypt) for giving their time and valuable services.

The 6th International Conference on Thalassemia was held at Hotel Eros, Delhi on the 24th and the 25th September, 2016. The conference was held under the auspices of the Ministry of Health and Family Welfare, Government of India.

Under “Helping Hand s Project” Thalassemics India gave free of cost chelation drugs, Infusion pumps, filters and blood transfusions to 208 thalassemics.

Blood Transfusions at St. Stephen’s Hospital :: 658
Filters :: 1756
Kelfer :: 244 boxes
Asunra :: 333 boxes
Desirox :: 415 boxes
Defrijet: 15 boxes
Desferal :: 402 boxes
Pumps :: 4 pumps

A film on Thalassemia is made for public awareness. Thanks to all the partners who gave their time and support.
New Drugs on the Horizon

Dr John B Porter
Professor of Haematology, University College London

The management of thalassaemia in the past three decades has focused on issuing increasingly safe blood and on improving the monitoring and treatment of iron overload. Curative therapy with bone marrow transplantation has also become increasingly safe and is now offered to a wider range of patients using haploidentical and Matched Unrelated Donor transplantation. Improvements in management with non-curative therapies are now on the horizon. Many of these aim to correct ineffective erythropoiesis that leads to leading to anemia, bone marrow erythroid hyperplasia, iron overload in severe thalassaemia syndromes. The effectiveness of erythropoiesis can be improved by correcting globin chain imbalance through promoting HbF synthesis, such as with hydroxyurea or butyrates. This approach has achieved variable and often only modest hemoglobin increments. However, new approaches to HbF promotion are under pre-clinical evaluation. Combination strategies, for example by using erythropoietin together with hydroxyurea, have shown encouraging hemoglobin increments and significant improvements in Quality of Life (QoL). A novel approach to improving erythropoiesis is by restriction of transferrin mediated iron delivery to the erythron. This has been achieved in preclinical studies using Tmprss6 inhibition, hepcidin manipulation or apotransferrin infusion. Although these approaches have not been proven clinically they have potential to improve anaemia by modulating ineffective erythropoiesis. Another approach is to manipulate Jak2. Inhibition of Jak2 corrects the proliferation/differentiation imbalance, decreases splenomegaly, and is under clinical trials in thalassaemias. Another novel approach to correcting IE which has now entered Phase III trials are the combination of the two molecules include sotatercept and luspatercept both of which appear to inhibit TGF-β signaling in the bone marrow and act mainly by inhibiting GDF11 and decreasing apoptosis of late erythropoietic progenitors. Preliminary phase II findings show hemoglobin increase of more than 1.5 g/dl in NTDT, and decreased transfusion requirement in transfusion-dependent thalassemia (TDT) of up to 50%, with an acceptable tolerability profile.


Combination Chelation Therapy

Antonio Piga, MD
Centre for Hemoglobinopathies
Dept. of Clinical and Biological Sciences, Torino University, San Luigi Gonzaga University Hospital, Orbassano, Italy.

Three drugs are worldwide available for iron chelation, deferoxamine (DFO), deferiprone (DFP) and deferasirox (DFX). In theory long term monotherapy using whichever of the three may be safe and effective, but in the clinical practice often a change of drug or a combination must be considered. The basic reason is the low efficiency of iron chelators: 80-98% of the drug is excreted or metabolized without iron binding. This happens because even in severe iron overload, only a very small proportion of excess iron is available for chelation at any moment. Removal of iron overload is then a slow process even in the absence of transfusional iron loading. Combination therapy has the potential to fill this gap as there is evidence that chelators together do not compete for the same iron, but have an additional or, sometimes, synergistic effect. In the literature the term combination is used often improperly. To lower ambiguity the following terms should be applied:

-Alternate therapy: in a single day a single chelator is taken, the two chelators take turn on a weekly, monthly or quarterly basis.

-Combination therapy: prescription of more than one chelator, to be taken in the same day at least for a significant part of the period.

-Sequential: in a single day two chelators are taken in sequence, with no substantial overlapping of the two drugs in the plasma.

-Simultaneous or concomitant: in a single day two chelators are taken at the same time, with substantial overlapping in the plasma.

Of many publications on combination, a few have a randomized controlled design, but evidence exists that combination, at least of DFO and DFP, is powerful and fast in lowering tissue iron, including heart iron. Interesting findings are emerging for the combination of the two oral (DFP+DFX) and DFO+DFX. Even if growing evidence indicate that the safety profile of combination is better than supposed in theory, this treatment should be deserved to expert doctors and applied to fully informed patients.
Haematopoietic Stem Cell Transplantation (HSCT) today offers an alternative to life long transfusion and chelation for patients with thalassemia major. In December 1981 the first allogeneic bone marrow transplant for thalassemia major was performed in Seattle. That patient is now alive and well 35 years post transplant. The team at Pesaro in Italy under the leadership of Professor Guido Lucarelli has since shown with 1003 patients that bone marrow transplantation is in fact a good alternative to transfusion chelation for thalassemia. However the procedure is associated with risk of infection, regimen related toxicity, graft versus host disease and relapse particularly in those patients who because of inadequate treatment and poor chelation have developed hepatomegaly and hepatic fibrosis. The team in Pesaro have developed a risk stratification based on these three criteria:

Class I: well chelated, no hepatomegaly, no hepatic fibrosis

Class II: one to two adverse risk factor

Class III: all three adverse risk factors

Data from Pesaro in Italy show that there is a 90% chance of disease free survival post transplant in patients who are in Class I, 85% in Class II and only 65% in Class III.

The decision that a family with a child with thalassemia has to make if there is a histocompatible sibling who can serve as the donor is whether they should continue transfusion chelation with its low present risk but significant late morbidity or have a transplant with its immediate risk but high probability of good quality life without the burden of life long transfusion and chelation. Transfusion and chelation can provide a near normal life expectancy in those children who remain compliant with the therapy.

Therefore there is little doubt that this is a time-tested form of treatment with little immediate risk. The difficulty is that it has to be continued life long and is expensive and sometimes the child becomes non-compliant with the chelation later in life.

In a country like India the economic advantage of a bone marrow transplant for thalassemia is compelling because many families can manage a one-time investment of RS 8-12 lakhs but a life long expenditure of RS 1-2 lakhs a year is a difficult proposition.

The question of whether to wait for gene therapy or accept the current risk of transplantation is a difficult one since there is some progress in this area.

Once the decision to have a bone marrow transplant has been made then the next step is to perform HLA typing on the patient and sibling.

If there are no matched siblings who can serve as a donor then the following alternative donors can be considered:

- Cord Blood
- Matched Unrelated Donors from registries
- Half matched donors: sibling or parent

If the parents are planning another baby then cord blood can be collected and stored: if the patient and the next baby are HLA matched, when the baby is two years old bone marrow and the stored cord blood can be used for transplantation. Matched unrelated cord blood transplants have a higher risk of rejection.

With the availability of large numbers of HLA typed donors in international registries, it is possible to find matched unrelated donors for patients with thalassemia. Currently these transplants should be done only if there is a 10/10 match: there is a higher risk compared to sibling matched related transplantation.

Some centers are offering half matched transplants for thalassemia: this must be considered experimental for the present till such time as more data is available.

This conference was a platform where patients and parents could resolve their queries and ask questions without being hesitant. The main highlight of the event was that each and every session was summarised and simplified making it convenient for the patients and parents to understand. The conference was very well executed and planned as the non medical people learned a lot and shared their personal experiences and could take back immense knowledge regarding the health and well-being of Thalassemics. It was a memorable event.

-Shivani Chugh
Delhi

Really it was good conference & we learnt a lot. Our best wishes always with you.

-Rajinder Kaia
Chandigarh

Heartfelt thanks for making me a part of wonderful conference. Perfect and flawless, updated my knowledge & I thoroughly enjoyed it.

- Raj Popli
Delhi

Congratulations for holding an excellent and well organised conference.

- Dr. Parveen Sobti
Punjab
### Transfusion therapy in thalassemia

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**Introduction**

Thalassemia syndromes are a heterogeneous group of inherited disorders known to be highly prevalent worldwide. It is an autosomal recessive disorder and is the commonest single gene disorder. The mainstay of therapy of thalassemia major is transfusion therapy and management of its complications. The transfusion therapy has undergone tremendous evolution since the early 60's when it was understood that thalassemic children cannot survive without blood transfusions.

**History of Transfusion Therapy in Thalassemia**

In the 1960's, Wolman proposed a palliative transfusion therapy for thalassemia major. It was aimed at maintaining the hemoglobin at 8.5 gms%. This led to improved survival, but the chronic illness, bone disease and cardiomyopathy persisted. To overcome these problems, Piomelli and workers suggested maintaining the hemoglobin above a minimum of 10 gms%. These vigorous regimens were termed as hypertransfusion, although normotransfusion may be a more descriptive term. Hypertransfusion promotes normal growth and development, prevents the onset of severe hepatosplenomegaly and hemolytic facies, lowers the absorption of gastrointestinal iron and reduces the anemic cardiomyopathy changes.

In 1980, Propper and colleagues introduced a further improvised regimen called supertransfusion, and maintained a pretransfusion hemoglobin of above 12 gms%. However, this did not prove significantly superior to hypertransfusions and was given up. Hypertransfusion remains the most accepted regimen in most parts of the world. However, in Europe, a yet newer regimen termed the "moderate transfusion regimen" was adopted and has been recommended by the Thalassemia International Federation. In this regimen, pretransfusion hemoglobin is maintained between 9 and 10.5 gms%.

**Transfusion Therapy**

It should be given with the following aims:

1. Fulfilling the goals in a thalassemic child
   - To alleviate anemia
   - To suppress ineffective erythropoiesis
   - To prevent serious growth and skeletal complication of thalassemia major
2. Ensuring optimal safety
   - Acute reactions
   - Transfusion transmitted infections
   - Delayed reactions

**Initiation of transfusions**

Transfusions should be started in all children with:

1. A confirmed diagnosis of thalassemia major (preferably by molecular techniques) with one of the following fulfilled:
   - Laboratory Criteria
   - If Hb drops < 7 gms% on 2 occasions > 2 weeks apart
   - Clinical Criteria irrespective of hemoglobin level
2. Hemoglobin > 7 gms% with any of the following clinical criteria
   - i. Facial changes
   - ii. Poor growth
   - iii. Fractures
   - iv. Clinically significant extramedullary haematopoiesis

2. Complete genotype of red cells is ideal to avoid alloimmunization.

**What to transfuse?**

Patients with thalassemia should receive leukocyte reduced packed red cells. What to transfuse?

**Transfusion Programs**

The volume and rate of blood transfusion depends on:

- The patient's age
- Clinical status
- Solutions added to preserve red blood cells.
- The hematocrit of the donor's RBCs.
- Target level of hemoglobin

There are various regimens for transfusing blood, but the best one is moderate as compared to hyper or super transfusion regimen.
Blood products for special situations:

<table>
<thead>
<tr>
<th>Irradiated blood cells</th>
<th>Washed red cells</th>
<th>Frozen red cells or deglycerolized red cells</th>
<th>Neocyte transfusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provided to patients who have received transplants or bone marrow transplant aspirants.</td>
<td>Suitable for IgA deficient patients and those who experience frequent allergic reactions.</td>
<td>Should be provided to patients with rare RBC antigens for whom it is difficult to cross-match donors.</td>
<td>May modestly reduce requirement as half life of RBCs would be more</td>
</tr>
<tr>
<td>It prevents a severe graft versus host disease</td>
<td>RBCs are frozen at -60°C in a 40% glycerol solution, can be stored up to 10 years.</td>
<td>Patients are exposed to higher number of donors, greater risk of infections and alloantibodies.</td>
<td>Cost is phenomenally high.</td>
</tr>
</tbody>
</table>

The moderate regimen is:

- 15 – 20 ml/kg body weight of concentrated red blood cell is given to the patient.
- Average time taken is 3-4 hours (unless patient has a lower hematocrit).
- Transfusion is carried out every 2-4 weeks.
- This regimen aims at maintaining Hb 9-10.5g/dl before transfusion, and < 15g/dl after transfusion.
- A non-splenectomized patient requires 180 ml of pure red blood cells/kg/year, while a splenectomized one 133 ml/kg/year.
- If cardiac problems are present or if Hb <5, slower rate of transfusion is adopted (2-3 ml/kg/hr).

Efficacy of a transfusion regimen

- Infections like malaria causing RBC destruction.

Outdoor transfusion services

In the past, a thalassemic child had to be admitted for blood transfusion alongside other sick children of the ward. Prolonged hospital stay, cross infections, increased cost, both to the parents and the institution as well as psychological trauma were the brunt of such therapy. With the advent of outdoor transfusion centers, transfusion can be well planned causing minimal psychological trauma to the child and parents as transfusion is given in a cordial compliant surrounding with other thalassemic children.

Advantages of outdoor thalassemia centers:

- It has made the therapy more convenient and compliant as it can be planned on school holidays and on the day convenient for the parents.
- Group therapy as a part of the intervention program has an important role and direct beneficial impact on outcomes.
- Parents exchange and share their experiences and feelings.
- It can be used as a platform to spread information, current knowledge and for genetic counseling.

Summary

In summary, transfusion therapy in thalassemia major should be initiated as soon as the diagnosis is firmly established. Baseline work-up should include screening for transfusion transmitted infections. Regarding the type of blood to be transfused, preferably leucocyte depleted (using leucocyte filters) packed red cells should be transfused. The amount to be transfused should not exceed 15 to 20 ml/kg administered at a rate of not > 5 ml/kg/hr. In presence of cardiac compromise, the rate of infusion should not exceed > 2 ml/kg/hr. Monitoring for adequacy of transfusions as well as transfusion related complications is mandatory. Outdoor centres should be encouraged as they offer great advantages to the patient and parents.
Effect of non-compliance on Thalassemia patients and social aspects of having this disease

Niharika Shinde

ABSTRACT

Introduction: Thalassemia patients have to take prescribed medications regularly and in specific ways. This article focuses on the regularity and compliance of the selected patients with taking medications, reasons for patients being non-compliant with their medications, whether or not the medications are administered in the correct way, and how treatments/other factors have an effect on their social life. Aim: To investigate the effects of the above mentioned aspects. Methods: The main method used in this study was to survey 50 patients to determine their compliance with their respective medications. Examination of medical files of each surveyed patient to determine effects of phases of irregularity or complete irregularity on each patient’s health were also done. Using these two methods, effects of using wrong methods for medication intake were also studied. Results and Conclusions: Most non-compliant patients showed a more increase in dosages and had a higher average frequency of blood transfusions than compliant patients. Social life, including school, was seen to be affected.

Keywords: Thalassemia, compliance, blood transfusions.

1. INTRODUCTION

Thalassemia is a genetically inherited blood disorder that falls under the category of ‘hemoglobinopathies’ in which the haemoglobin produced by the body is abnormal. There are numerous mutations that cause thalassemia. There are about 240 million carriers of β-thalassemia worldwide with 30 million in India. 1 in every 25 Indians is a carrier of thalassemia\[1\]. The IVS-1-5 mutation is the most common mutation found in the Indian population – the prevalence varies from 22.8 to 81.4% (as of 2014) in different regions of India, being the highest in Tamil Nadu in south-eastern India\[2\] and β-thalassemia is the most common single-gene disorder in the Indian population\[3\]. There are two main forms of thalassemia: Major and Minor. Minor patients do not require medications.

In the Lokmanya Tilak Municipal General Hospital, where the survey for this article was conducted, patients receive, according to their requirements, different combinations of the following medicines (or equivalent of the following types of medicines): Deferasirox, Deferiprone/Kelfer, Hydroxyurea Capsules, and supplements for Calcium, Zinc, Vitamins, Energy, Folic acid and bone structure.

2. METHOD

50 patients at the Lokmanya Tilak Municipal General Hospital (locally also known as Sion Hospital), which is located in Mumbai, India, were surveyed to gather information like: current age, height, weight, age at which treatment
began, current medications, changes in medications/medication dosages, compliance (and reason(s) if not compliant), number of blood transfusions per month, and whether or not the patient attends school. Correlations were drawn to find impacts of non-compliance on health and impact of disease on schooling.

3. RESULTS

Are the patients compliant?

68.2% of the surveyed patients were compliant.

Reasons for being non-compliant

The most common reason for being non-compliant (50%) was plain carelessness.

Changes in dosage (in the last year) for Compliant and Non-compliant patients

Social Aspects

From Figure 4, it can be seen that non-compliant patients usually require more blood transfusions which has an impact on school attendance. 91% of the patients, who don’t attend school, say they cannot attend due to frequent hospital visits/hospital admissions/falling sick as shown in Figure 5 below.

50% of the patient reported having fevers usually after blood transfusions.

Percentage of patients attending school and reasons for not attending

Figure 3: Dosages mean dosage of at least one type of medication.
Growth Charts for Male and Female Patients

On the following two weight-stature graphs for girls and boys (Figure 6 and Figure 7), data for each patient is plotted. Same coloured crosses represent data for the same patient.

55.6% of patients started their treatment at age 9 months or older. 44.4% patients started treatment when they were younger than 9 months of age.

Below 5th percentile in the two stature-weight charts above (Figure 6 and Figure 7) was considered as “Below Normal Stature” or “Below normal weight” any value above 5th percentile in the stature-weight charts above was considered as “Normal Stature” or “Normal Weight” in Figure 8 and Figure 9:
4. DISCUSSION/CONCLUSION
The most common reason for patients not being compliant with their respective medication(s) were simply forgetting and because they dislike having the required medicines (Figure 2).

Figure 3 and Figure 4 show the consequences of irregularity in administering medicines by comparison to the data of compliant patients.

In Figure 3, it can be seen that 29.5% more non-compliant female patients had an increase in their dosages than compliant patient and 44% more non-compliant male patients had an increase in their dosages than compliant male patients.

In Figure 4, it is seen that all non-compliant patients were required to have blood transfusions at least once a month whereas 7% of the compliant patients were required to have only one blood transfusion in two months. A significant 66% of non-compliant patients were required to have blood transfusions twice per month, which are 59% more patients than the compliant patients (7%).

Hence, being non-compliant can have an indirect negative impact on aspects like school attendance as a non-compliant patient most likely has to make more hospital visits. This correlates with Figure 5 which shows that 91% of patients that did not attend school due to being admitted in the hospital often. Having this disease could also affect attendance as Thalassemia patients are prone to get diseases like jaundice and usually experience fatigue, anaemia and sometimes fevers after blood transfusions (as mentioned before).

The patients surveyed belong to a relatively low social-economic background, and hence, due to lack of awareness of this particular disease, initiation of treatment began quite late for many of the patients. Thalassemia affects growth of the patient as it affects the endocrine system too. If diagnosis and treatment is done late, rate of growth can be significantly slower for that patient compared to a person with average growth of the same age.

As seen in Figure 8 and Figure 9, about 5% more patients showed below normal stature when treatment had begun after 9 months of age and about 10% more patients showed normal growth if treatment was initiated before the age of 9 months. The percentage of underweight patients, however, was very similar regardless of when the treatment had begun.

All prescribed medicines are crucial to maintain the stability of the patient’s health and there could be many repercussions, physical and social, if medication is ignored.

5. ACKNOWLEDGMENTS
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6. LITERATURE CITED
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Deferasirox reduces unregulated tissue iron loading and prevents further end-organ damage in β-thalassemia patients, suggesting 24-h protection from LPI.

**Mean LPI, pre and post deferasirox administration, at baseline and after repeat doses**

**EPIC Study**

**Pre-administration**

- Baseline
- Week 12
- Week 52

**Post-administration**

- Baseline
- Week 12
- Week 52

**Mean LPI, pre and post deferasirox administration, at baseline and after repeat doses**

**ESCALATOR Study**

**Pre-administration**

- Baseline
- Week 12
- Week 52

**Post-administration**

- Baseline
- Week 12
- Week 52

The most frequent reactions reported during chronic treatment with Asunra in adult and pediatric patients include gastrointestinal disturbances in about 29% of patients mainly nausea, vomiting, diarrhea, abdominal pain, and skin rash in about 7% of patients. These reactions are dose-dependent, mostly mild to moderate, generally transient, and most resolve even if treatment is continued. Non-progressive increase in serum creatinine, mostly within the normal range, occurs in about 35% of patients. These are dose-dependent, often resolved spontaneously and can be alleviated by reducing the dose.

Pediatric patients are close/receive 2 years and above.

**Asunra**

**Deferasirox**

100 mg/400 mg Tablets

A novel once a day oral iron chelator

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