

Sankalp joins hands with Government of Madhya Pradesh to enable thalassemia cure



16th November 2016, Indore

Sankalp India Foundation and Maharaja Yeshwant Rao Hospital, Indore, a unit of the state government of Madhya Pradesh joined hands to start bone-marrow transplantation centre to cure the children suffering from thalassemia and sickle cell disease.

Maharaja Yeshwant Rao(MY) Hospital, Indore is a Government Institute committed to the care of

children including ones with transfusion-dependent thalassemia. The hospital has initiated a project to setup a thalassemia BMT unit with an intention to treat children suffering from thalassemia and related haemoglobin disorders. The two organisations came together to leverage the expertise developed by Sankalp India Foundation together with its partner Cure2Children to enable high success rates, low complication rates and cost effectiveness to the new program initiated by the MY hospital.

On 16th November Mr Lalith Parmar visited Indore and met with the entire team including Divisional Commissioner - Sh. Sanjay Dubey, The Dean of Mahatma Gandhi Memorial Medical College - Dr Sharad Thora and the other members of the administration.

'Under our mission 'Thalassemia Free India', we will provide all possible help to MYH in starting BMT for thalassemia and sickle cell disease, treatment protocol, training of nurses and proper monitoring of each case through a software (BMTPlus management) to ensure higher success', Lalith Parmar the President of Sankalp India Foundation said.

Sankalp India Foundation will train the staff, provide

logistics support, treatment protocols and HLA typing. The two organisations will work closely together for scientific advancement of cure from thalassemia and regularly engage in clinical and outcome reviews. The construction work at the centre in Indore is in advanced stages. Soon, the nurses from Indore will come to Sankalp-People Tree Centre for BMT, Bangalore for training. During the initial phase of the program, a senior nurse from Sankalp team will visit Indore. The first transplantation is expected to commence in early 2018. Beside this, on 25th December 2017, the two organisations are planning to organise an HLA typing camp for the patients at MY hospital.

This collaboration takes the mission that Sankalp serves one big step forward. We keenly look forward to enabling access to reliable cure for little children in Madhya Pradesh.



"In attaining our ideals,our means should be as pure as the end!"

- Rajendra Prasad

Federation of Indian Blood Donation Organisations Meeting at Phagwara



10th-12th November 2017 - Phagwara, Punjab

BLODCON 2017 - FIBDO National Workshop & Conference of Blood Donor Motivator Organisations was held at Lovely Professional University(LPU), Phagwara, Punjab, India with 150 specially selected participants from home and abroad.

With the primary goal of bringing in 100% voluntary blood donation by the year 2020, the meeting which happens every 2 years is an attempt to synchronise the efforts of all

the organisations which are serious about their pursuit of 100% voluntary blood donation.

Hosted very warmly by Hindustan Welfare Blood Donors' Club, Phagwara, FIBDO organised the meeting in association with National Blood Transfusion Council (NBTC), MoHFW, Government of India. Beside the representatives of the various non-government organisations, this meeting was unique in the sense that there were several representatives of the Government from various states of the country.

"To love without role, without power plays, is revolution."

-Rita Mae Brown

The suffering of the people in the hands of blood banks who demand replacement for every blood unit they collect tends to push some individuals and new organisations from taking a stand against getting blood donated to the blood banks voluntarily. The fact that replacement based blood donations are an evil to the society and must be ended needs to be reiterated a million times over at all given platforms. The real problem of blood banks not taking the responsibility to put effort to mobilize community and get voluntary blood donation needs to be recognized and the society needs to ensure that enough mobilisation of blood donors happens to meet the demand.

FIBDO has been very effective in course correcting various organisations through the length and breadth of the country. FIBDO encourages its member organisations to strictly do away with evil practices like donor cards and sensitizes its members to seek quality assurance in blood donation very effectively.

As a next important step, even as days pass by there does not seem to be a concrete roadmap and action plan being worked upon by various stakeholders to actually achieve the goal of 100% voluntary blood donation by the year 2020. FIBDO, through its presence in the various national policy making forums is working towards fostering a meaningful and well directed dialogue to keep the real issue of replacement based blood donation on the table.

In this conference there was a session where the

representatives of the Government formed a panel to address the concerns of the various NGOs. The open house format of this session brought out the serious disconnect between the policy makers and what is being observed on ground. Both groups recognised the need to work closely together in the best interest of the common goal – to ensure each patient receives blood on time. Though it is left to be seen if this consensus actually reflects in the structure of the various State Blood Transfusion Councils. These state level bodies which were made to bring the stakeholders together by the order of the Supreme court are either non-existent, defunct, or constitute just the representatives of the state all over the country, though there are a few exceptional states.

The national executive of FIBDO agreed to intensify its efforts to foster in voluntary blood donation across the country. The state level groups have been encouraged to take the legislative support which has been made available after intense efforts of member organisations of FIBDO at a national level to the various state departments.

Team Sankalp is happy to be part of FIBDO, primarily because the forum provides a unique opportunity to exchange the key learning, ideas and resources with other organisations involved in blood donation.

* * *

Moving towards era of Haploidentical transplantation

In the last few years tremendous progress has been made to provide reliable and accessible cure from thalassemia. Patients who have a fully matched donors are getting cured with high success rates. Nevertheless, the families who do not have a match continue to wait for the right curative therapy. Unrelated bone marrow transplantations continue to be very



expensive. The rates of graft versus host disease, a complication which follows bone marrow transplantation continue to be very high in matched unrelated transplants.

continue to wait for the right curative therapy. Unrelated bone marrow transplantations continue to be very expensive. The rates of graft versus host disease, a complication which follows bone marrow transplantation continue to be very high in matched unrelated transplants.

An alternative option is haploidentical bone marrow transplantations – in which the parents are able to donate marrow to the patient. Rapid progress is being made in the field of haploidentical bone marrow transplantation. We have been confident for a while that haploidentical transplantations are going to be the way forward to offer transplantations from parents with reasonable chance of success. After several rounds of iteration, high amount of research and fine-tuning, we are at a stage when within our network South East Asia Institute of Thalassemia, Jaipur has been able to achieve sustained success with haploidentical transplantations. With at-least 6

consecutive patients doing well with the haploidentical transplantations, we are in the process of offering haploidentical transplantations to patients at our centres. Once haploidentical transplantation are taken up on a regular basis, the limitation of a matching donor will go away for all children who have at least one natural parent or sibling.

The first of the patients already undergoing transplantation and the next few patients queued up. The future looks brighter than ever before. Nevertheless we will continue to take baby steps forward safeguarding both safety and clinical outcomes as much as possible.

For families who are keen to consider haploidentical transplantations as an option, please do keep in mind that we strongly recommend that regular management is undertaken under proper guidance. Only those children who are well managed could expect to have good transplant outcome.

PERFORMANCE REPORT

Sankalp Program For Thalassemia Management

| Centers | Total Patient Visits (patients) | Number of units of blood transfused (units) | How many day old blood units were transfused (days) | Time taken to process blood components (hours) | Pre-transfusion Hemoglobin Median (g/dl) | Share of blood units from attached blood bank (%) |
|---|---------------------------------|---|---|--|--|---|
| | | | <7: Good 7-10: Average >10: Bad | <2: Good 2-3: Average >3: Bad | >9: Good 8-9: Average <8: Bad | >95%: Good 90-95%: Average <90%: Bad |
| Indira Gandhi Institute of Child Health | 313 | 362 | 6 | 2.0 | 9.4 | 100% |
| Project Samraksha | 452 | 530 | 4 | 3.0 | 9.3 | 100% |
| KLE Belgaum | 248 | 238 | 3 | 2.8 | 9.0 | 100% |
| Wenlock Mangalore | 54 | 69 | 6 | 4.3 | 8.0 | 100% |

Rakta Kranti - The Blood Revolution

| | Blood Donation Camps | Total Donors | Total Units Collected | Rate of Post Donation Complications | Rate of Donor Deferral |
|------------|----------------------|--------------|-----------------------|--|--|
| | | | | <2%: Good 2-4%: Average >4%: Bad | <10%: Good 10-15%: Average >15%: Bad |
| This month | 9 | 719 | 617 | 3.7% | 14.9% |
| This year | 114 | 10078 | 8510 | 3.9% | 15.5% |

Thanks to the following organisations for having supported us to ensure continued supply of safe blood to the needy

AMD
Azim Premji University
Burger King

Microsoft
Mphasis
PayPal

Robert Bosch
RBL bank
Suncity

November 2017



Sankalp Program For Thalassemia Cure

| | Total Transplants Done | Overall Survival | Disease Free Survival |
|------------------------|------------------------|------------------|-----------------------|
| People Tree, Bangalore | 67 | 91% | 84% |
| CIMS, Ahmedabad | 20 | 100% | 95% |
| Other Centres | 11 | 91% | 82% |
| Total | 98 | 80% | 87% |

Bombay blood group network

| | Total bombay blood group requests | Number of units organised off the shelf | Number of units donated |
|----------------------------------|-----------------------------------|---|-------------------------|
| Last month | 14 | 4 | 1 |
| This financial year (cumulative) | 85 | 34 | 19 |
| Last financial year | 71 | 18 | 21 |

Disha Statewide Blood Helpline - 9480044444

| | Total Blood requests on the statewide help-line | % of blood requests satisfied by existing blood bank stocks | % of blood requests from outside Bangalore |
|----------------------------------|---|---|--|
| Last month | 505 | 77% | 23% |
| This financial year (cumulative) | 5064 | 80% | 21% |
| Last financial year | 6348 | 84% | 27% |

Story of little Tanvi - from pain to health and wellbeing



Manish and Meena met in a family function, fell in love, got married and their sweet married life started. Manish was a photographer by his profession. Since childhood he was fond of doing photography. At the young age he started doing photography in family function and later on he became a professional wedding photographer. Living in a small town of Bhavnagar, his business was seasonal. Despite low income they were living happily.

After 2 years of marriage their first child arrived named Tanvi. At the time of delivery Meena was at father's house as it was her first delivery. After 3 months, during the vaccination process the medical person found that she was looking pale. The doctor advised

them to go for hemoglobin check-up. The report of hemoglobin was low. The doctor then advised for thalassemia test as the test facilities was not available in the town they came to Ahmedabad for the test. After a day the report came, unfortunately the report was positive. It means she was suffering for a life threatening disease called thalassemia.

The doctor explained about the disease and told that now onwards, she will be needed a regular blood transfusions. He also added that the only cure of the disease is Bone Marrow Transplantation which costs Rs 12 to 15 lakhs. It was not possible to even think about the BMT as the cost was too high. Now she was taking regular blood transfusion in Bhavnagar.

Two years has passed and Meena got pregnant again. But this time they were cautious. She underwent for thalassemia test during her pregnancy. Fortunately the coming child was Thalassemia minor. After few months the child arrive. Her name was Dhani. When Dhani became 3 yrs old at that time they heard about opening a new Bone Marrow Transplant centre at Ahmedabad, which was started by Sankalp India Foundation. They inquired about it and found Free HLA matching program at Sankalp's CIMS Hospital centre.

They went there and met the coordinator. The coordinator explained about entire BMT process. They went for HLA test and after 5 months the report arrived. Fortunately it was full matched with her sister Dhani. But when they found about the cost they were depressed as it was not possible for a person who is doing photography work in a small town to bear the cost. When the Sankalp found about this they told not to worry for the cost. Sankalp assured them that it will

assist them in raising funds for the remaining cost. They worked hard for the contribution but could manage for only Rs. 5 lakhs. The remaining amount was contributed by donors from Sankalp side.

And the day arrived. After proper down-staging process she got admitted in CIMS hospital, Ahmedabad. She was small and mischievous. But BMT staff took her care and treated her very well. After completing the procedure she was discharged from the hospital.

Currently she is under step down process and doing well. Soon she will become a normal kid and will live her life with joy. We wish her a happy and healthy life.

We are offering free HLA Typing

At Sankalp India Foundation, We firmly believe that each child must be given an option for complete cure irrespective of their financial status. The HLA test is the first step which determines whether the sibling can be a matched donor to the child suffering from thalassemia. The cost of HLA typing in India is around Rs. 10,000/- per child making it inaccessible to most families.

There is good news. Currently, we are offering free HLA typing to those children with thalassemia who have a healthy sibling donor in association with Cure2Children Foundation, Italy. We are happy invite the families to make use of this opportunity. Please spread the word



about the availability of this option for the families. The families can call our central help-line number 9480044444 for further information and appointment.

Our multi-institutional review of the blood transfusion practices and their effectiveness for treating



Pediatric Hematology Oncology Journal



Available online 5 December 2017

In Press, Accepted Manuscript — Note to users



Open Access

Multi-institutional, retrospective review of blood transfusion practices and outcomes in a large cohort of thalassemia patients in South India






Rajat Kumar Agarwal^{a, b},  , Amit Sedai^{a, b}, Kumari Ankita^a, Lalith Parmar^a, Rakesh Dhanya^a, Sunil Dhimal^b, Dr Reshma Shriniwas^c, Dr Sumithra P^c, Dr Hemanth V Iyer^c, Ashwini Gowda^c, Dr Pooja Gujjal^d, Dr Pradeep R^d, Pushpa H^{a, d}, Dr Suman Jain^e, Dr Saroja Kondaveeti^e, Dr J. Dasaratha Ramaiah^f, Dr Raviteja^f, Dr Hariharanatha Sharma^f, Dr Sujata Jali^g, Shrikant Viragi^g, Dr Shreedevi Bobati^g, Neelawa Rayappa Tallur^g, Dr Stalin Ramprakash^h, Dr Lawrence Faulkner^{h, i}

Our work “Multi-institutional, retrospective review of blood transfusion practices and outcomes in a large cohort of thalassemia patients in South India” has been accepted for publication in Pediatric Hematology Oncology Journal, the official journal of Journal of the Pediatric Hematology Oncology Chapter of the Indian Academy of Pediatrics.

Not many large multi-institutional studies have been published in India. As a consequence we continue to base our management practices on anecdotal findings, generalised guidelines or individual perception of the clinicians. To our knowledge, this is the largest study which has systematically analysed various issues around blood transfusion needs of thalassemia patients over a period of 1 year prospectively from 5

different centres in Karnataka and Telangana. The evidence and findings of this study are likely to provide a benchmark for assessment of blood transfusion practices for chronically transfused thalassemia patients.

The key findings of the study included:

-  Mean pre-transfusion Hb was 8.8 g/dl.
-  99% of blood was available on-site.
-  Saline washing of red cells seems to be effective in controlling transfusion reactions.
-  Rate of transfusion reactions was 0.7% without pre-medication.
-  Low rates of transfusion-transmitted infections were seen.

✍ Voluntary blood donation may reduce transfusion transmitted infections.

✍ Median duration of entire day care stay was 8 hours (inter quartile range 6–8).

“This is a well written paper, detailing the transfusion practices at five major thalassemia care centers in South India. The authors have extracted and analyzed data collected through a web-based transfusion management software tool that is used to facilitate the care of these patient. Therefore, this is a retrospective, non-interventional study of clinical practice. The information provided is comprehensive and

presented in a lucid manner which allows the reader to negotiate the large amounts of data presented with clarity and comprehension. I believe that this paper provides a benchmark for how thalassemia patients could and should be cared for, not just in LMIC, but everywhere.” – remarked one of the reviewers of the manuscript.

We would like to take this opportunity to congratulate teams from Project Samraksha, Rashtrorathana Parishat - Bangalore, Indira Gandhi Institute of Child Health - Bangalore, Thalassemia and Sickle Cell Society - Hyderabad, Rural Development Trust Hospital - Ananthpur and Jawaharlal Nehru Medical College - Belgaum for participating in the study.

**“We protect in more than one way!”
- Blood Donors at one of blood donation camps.**



“We are what our thoughts have made us; so take care about what you think. Words are secondary. Thoughts live; they travel far.”

-Swami Vivekananda

Hi Sankalp!

Please get in touch for any of the following

Sankalp Emergency Team

- Seek assistance for arranging blood in extremely difficult situations
- Donate platelets voluntarily and help ensure platelets on shelf all the time.
- Learn about strategies and technologies for conservative and rational management of blood.

Bombay blood group network

- Register if you are a person with Bombay blood group
- Inform if you have Bombay blood group on your self
- Request if you need Bombay blood group

Statewide Blood Helpline

- Call 9480044444 when in need of blood anywhere in Karnataka

Rakta Kranti

- Organise blood donation camps
- Learn about organising safe and effective blood donation camps
- Form a Team Red - a team of volunteers who help propagate the message of blood donation
- Volunteer in our blood donation camps

Thalassemia Prevention

- Opt to get tested for thalassemia and other related hemoglobin disorders
- Organise a drive to get people around you tested
- Assistance for antenatal testing for parents who are at risk of getting a child with thalassemia

Thalassemia Management

- Support the treatment and management of a child suffering from thalassemia
- Refer a patient who is in need of help for thalassemia treatment at our centers
- Seek advice on management of thalassemia

Thalassemia Cure

- Refer a child suffering from thalassemia for free HLA typing
- Refer a child for Bone Marrow Transplant
- Donate towards Bone Marrow Transplant of a child
- Seek advice on options for cure for families with thalassemia

Contribute

- Make a donation - help us do more of what we do
- Volunteer - join us to make a difference!
- Share your experience and problems

From:

Call: 9480044444 | Visit: www.sankalpindia.net

Mail: contact@sankalpindia.net

Address: #460, "GOKULA", 8th Main, 4th Block, Koramangala, Bangalore - 560034

To: