

Thalassemics in Dakshina Kannada receive a memorable Independence Day gift



This Independence Day brought a new cheer and new hope to the coastal city of Mangalore. Sankalp India Foundation took a new step towards providing systematic care and management for many more children by setting up a thalassemia day

care centre at District Wenlock Hospital. Adequate blood transfusion, medicines and supplements, routine investigation and consultation with national and international experts will all be provided to these children.

Although the district has 7 medical colleges (the most in Karnataka), there was no single centre of excellence for clinical management of thalassemia which is actually the biggest NCD affecting children. Now, there is one something that will change the lives of nearly 200+ thalasseemics in this region.

Aided by ThalCare, a world renowned thalassemia care technology platform, the centre will join into a network of thalassemia day care centres run by Sankalp India Foundation which already manages 3 other day cares in Karnataka supporting nearly 750 children. 25 children have already been enrolled and have started being managed under the Sankalp banner. The centre aims at having nearly 200 children enrolled in the next one year. The centre will operate on the second floor of the Regional Advanced Paediatric Care Centre. It will move to the ground floor of the hospital's new medical block that will be ready by October.

Seva Bharti Trust, Kalpa Trust both Mangalore based NGOs are lending their support to the program by helping with counselling and resources necessary to run the centre. Other NGOs like Indian Womens Association, Kuwait also is part of the team committed to provide chelators and other supplements.

Dr Rajeshwari, District Surgeon speaking on the occasion said "This is an important setup in Wenlock Hospital. Attending to NCDs is an important element of care. The hospital is happy and excited that in a PPP model we will be providing systematic care to children with thalassemia and related hemoglobinopathies.



Wenlock Hospital is committed to changing the life of all these children for the better"

Dr U V Shenoy, District Early Intervention Officer and Nodal Officer for Hemoglobinopathies said "The day care centre should become a centre of excellence for clinical management of Thalassemia. We intend to reach out to every child suffering from thalassaemia and help them lead a life free from such blood disorders,"

Sh Lalith Parmar, President, Sankalp India Foundation: "This is an important step in our journey. We intend to reach out to each child suffering from thalassemia and give them systematic care with standards as good as or better than in other parts of the world. With this centre, in about 1 year we will covering nearly 1000 children. Mangalore is an important medical hub and District Wenlock Hospital is a well known hospital. This partnership will be crucial to improve the overall quality of life of thalasseemics in this belt of the country".

Double milestones in Aug-2017 - Bangalore BMT unit crosses 50 mark and Ahmedabad unit crossed 10

In August 2017, team Sankalp crossed 2 major milestones. Sankalp-People Tree Center for Paediatric Bone Marrow Transplantation, Bangalore crossed the 50 mark of the number of patients transplanted. We were able to achieve this just before its second anniversary. By August end, we reached 55 number of transplants. In the same month the Sankalp-CIMS center for Paediatric BMT Centre, Ahmedabad completed its first 10 transplants. In a repeat of the Bangalore experience, all of the first 10 transplant patients are doing well.

We take pride in the fact that though our thalassemia management centers receive only 1 girl for every 2 boys for management, when it comes to transplants we almost have a 1:1 ratio between girls and boys. We are very proud of the fact that each candidate was selected for transplant irrespective of their family's financial status.

The selection criteria was purely based upon medical eligibility and preparedness. A big round of applause to all our donors and supporters whose magnanimous contribution has allowed each child who could benefit from transplant, have access to it.



Our BMT centres are delivering transplants with outcomes comparable to the best centers of the world. The teams are also very active in publishing the outcomes of the transplants to international community. This has enabled the team in making the transplant safer, the extra mile to make sure that the learning is shared and validated through a stringent peer review process in world class journals.

Most of all, for Team Sankalp, the journey to realize the option of reliable and not-for-profit cure from thalassemia has been a very fulfilling one. The faith of the families, the relentless effort to make transplants safer, innovation, support of the community, scientific outcome, designing a program which preempt problems, learning to effectively manage critical situations has made the last 2 years a very memorable one.

Nevertheless, we must stress that the experience of the last 2 years only reinforces our belief that every child suffering from thalassemia could potentially be cured. The journey is just beginning.

"If you don't know where you're going, you might not get there."

Yogi Berra

Transplant Outcomes

	Sankalp-PTH Centre, Bangalore	Sankalp-CIMS Centre, Ahmedabad
Date of First Transplant	4th August 2015	17th April 2017
ALL TRANSPLANTS		
Total transplants	55	11
Overall survival	91%	100%
Cured	82%	100%
Transplant related deaths	7%	0%
SIBLING DONOR TRANSPLANTS		
Total Transplants	45	11
Overall survival	93%	100%
Cured	89%	100%
Transplant related deaths	7%	0%
Female patients (%)	45%	64%
Medical Condition	Thalassemia: 53 Sickle Cell Disease: 1 Aplastic Anemia: 1	Thalassemia: 11
Nationality	Indian: 53; Afghanistan: 1; Nigeria: 1	Indian: 11
Cost of transplant	850000	900000

"You are your possibilities. If you know that, you can do anything."

Oprah Winfrey

My Experience at APHON Annual conference - Sandeep



My heartfelt thanks to all who supported and guided me to participate in one of the prestigious conferences for nurses, The APHON Annual Conference in Palm Springs, California, USA. APHON is the professional organization for paediatric haematology/oncology nurses and other paediatric haematology/oncology healthcare professionals. Its members are dedicated to promoting optimal nursing care for children, adolescents, young adults with cancer and blood disorders, and their families. My visit to this conference happened on 17 Aug 2017 to 20 Aug 2017. And I am overwhelmed to share that I was selected as a scholarship member for the conference out of numerous applicants.

To recall the experience gained over there is beyond words. If I have to brief out my major take home learning experiences, I was amazed to see nurses

showing notable interest in research works. The paper presentations by them were commendable and full of knowledge, which clearly portrays how nurses over there are confident in their field of practice. The next important thing which captured my mind is the empowerment of nurses. The western nurses are very well aware of the rationale behind each task they perform.













Attending this conference and getting to know nurses around the world, sharing the experiences and knowledge is really worthwhile. Seeing the passion in them drove me to implement significant changes in our way of practice and thinking. Conducting regular professional development classes, sharing experiences, attending conferences, involving in scientific research work will for sure help in the career development and professional outlook of our nurses.

“ Failure will never overtake me if my determination to succeed is strong enough.”

- Dr A P J Kalam

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 (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	327	408	 11	 2.5	 9.5	 98%
Project Samraksha	413	488	 4	 3.0	 9.4	 100%
KLE Belgaum	260	258	 4	 3.3	 9.0	 100%

Sankalp Program For Thalassemia Cure

	Total HLA typings	Total number of children offered Bone Marrow Transplantation	Total number of children cured of Thalassemia by Bone Marrow Transplantation
This financial year	1203	27	27
Total	4829	78	67

August 2017



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	14	639	755	5.6%	13.9%
This year	91	8685	7324	4.0%	15.6%

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

Directi
Swiggy
Gurukula Academy
Indegene

Indus Towers
Hilton Hotels
CPG Consultants
Microland

Schneider
National Instruments
Aegis
National Law School

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	644	73%	17%
This financial year (cumulative)	3114	80%	22%
Last financial year	6348	84%	27%

For any queries or suggestions, please write to sankalp.admin@gmail.com

Khushi The Symbol of Happiness

Though Pooja was the first child in the family of Gopal bhai and Jasu ben, Khushi brought more happiness to the family as one can always find a sweet smile on her small face. She was born to the GopalBhai family which was living in a small village called Jamjodhpur in Gujarat. Khushi's father is an unskilled labour in the village. Her mother was uneducated housewife.

The family lived within themselves with the minimum financial earnings they had. One day the family found that their younger daughter's needs are different from others. She needs blood to survive each month! When she was three months old the family went to a nearby government hospital for general vaccination. The on duty doctor found her face to be pale. Little Khushi was also suffering from fever. The doctor doubted for thalassemia and prescribed the test for the same. Unfortunately, they found that Khushi is indeed suffering from thalassemia.

For the next 10 years, the family had to get blood transfusion done nearly every 20 - 30 days for her. Sometimes they had to go to Jamnagar a city nearby their village for blood transfusion. Limited financial resources did not diminish the determination of the family. They loved the child and wanted a good future for her.

They had little knowledge there is a permanent cure. One day they found out that there is a Free HLA matching program for thalasseemics at Ahmedabad



which was organised by Sankalp India Foundation. Someone had mentioned that HLA test can help setup a path to cure the child. They registered their name and went to Ahmedabad for HLA matching. After 3 months the moment of truth had arrived - Khushi had a full HLA match with Pooja.

There were multiple challenges. They were informed that the cost of BMT will be 9 lakhs. For this poor family this was a very huge amount. They expressed inability to gather even half of the amount. Moreover, apart from the the parents no other family member from their family tree was ready to accept even 20% risk of BMT. They were also worried about the health and future of Pooja- the donor.

When the Sankalp team knew realized these problems, they counsiled the family properly. Proper information was provided that helped the parents speak to the other members in the family. They also told them the donor will remain safe for now and forever. They were also told to bring whatever amount they could managed and the rest would be fund raised by Sankalp. The family could barely manage one lakh rupees. Team Sankalp fund raised the rest.

Finally the day arrived. Khushi underwent BMT at the Sankalp-CIMS BMT center at CIMS hospital Ahmedabad. She stayed in hospital almost for one and

a half month. Her BMT was a challenge for the team, but it was all well managed. She was discharged with a confidence that things would be fine.

It has now been more than 3 months since her BMT the signs are good and she is on her way to complete cure. For the family, Khushi's smile now feels more assuring. They know that she will have a normal and beautiful childhood.

Sankalp get's a new office

Sankalp took birth in a hostel room - bringing to an end a tormenting helplessness which arose when a person lost his life waiting for blood in Bangalore. The young organisation took baby steps in the common spaces of the college premises after the regular college hours. Meetings happened under the trees and sometimes at the tea shops outside the nearby hospital where the incident had occurred that night.

Through the years, the organisation functioned from volunteers' homes, offices of the partner institutions and public places. Over the last few years, we did realise that the organisation had grown large enough to need some dedicated space for people to get together and work. Finally on a Saturday morning in August 2017, Sankalp India Foundation moved to it's new office at DHI Innovation Park, Near Honeywell, Arekere, Bannerghatta Main Road, Venugopal Reddy Layout, Arekere, Bengaluru, Karnataka 560076, India.

A nice cozy office which is right next to our technology

partner - Jagriti Innovation's office has since become a hub of interactions, meetings, building synergy - and also heated debates. This operations office is now the location of the statewide helpline for blood, the back end office of Rakta Kranti, thalassemia management and cure program and the administrative and financial activities of Sankalp.

This will also be the hub for stores and resources required to run the programs of Sankalp. With more and more technology being used across our projects and high emphasis on collaborations, this office will also act as the hub for routine interactions, web conferences etc.

New address:

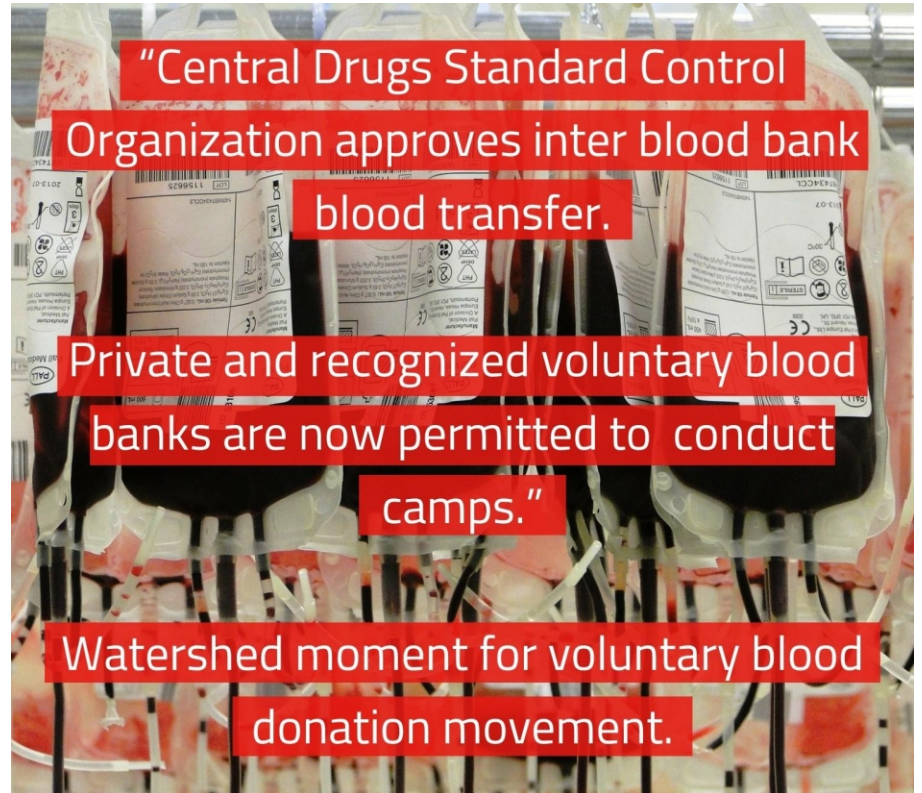
Sankalp India Foundation
DHI Innovation Park, Near Honeywell, Arekere, Bannerghatta Main Road, Venugopal Reddy Layout, Arekere, Bengaluru, Karnataka 560076, India.

Voluntary blood donation beginning to find place in private hospital based blood banks

It was a landmark event for the Government to take note of the fact that private hospitals must be allowed to participate in outdoor blood donation camps and amend the drugs and cosmetics act. Though there was an order by the National Blood Transfusion Council more than a year before the act was amended but little had changed till then. With a single government order, a major roadblock to 100% voluntary blood donation was removed.

Though private hospital based blood banks had for years complained about not being able to choose outdoor voluntary blood donation as against replacement because of the legal barriers, once those obstacles were removed, nothing seemed to change in the first few months. However, the buzz about the amendment gradually increased. We got several requests to share the government order. Media was helpful because every article related to the issue covered the need for private hospitals to now consider doing outdoor blood donation drives. For those who had long struggled for this change, the time for full of anticipation and uncertainty - to see when voluntary blood donation finally kicks in.

Fortunately, the month of August did see the first signs of change, at-least in Bangalore. A handful of private hospital



based blood banks led by progressive blood bankers decided to give the new opportunity a try. Over next few months, we plan to start with small blood donation camps for them so that they can get their teams in good shape for the unique needs of outdoor blood donation drives.

Finally, it's the time when some light is visible at the end of the tunnel.

Link to the order:

[http://www.cdsc.nic.in/writereaddata/GSR%20328\(E\)%20Dated%2003_04_2017.pdf](http://www.cdsc.nic.in/writereaddata/GSR%20328(E)%20Dated%2003_04_2017.pdf)

"All glory comes from daring to begin."

- Ruskin Bond

Transforming data in blood collection drives

Sankalp is committed to enabling delivery of better quality in each of the blood donation drives. A critical component in quality assurance is the systematic capturing of the data which could be used to quantify performance. Ever since 2007, when we started our blood donation drive, we evolved several tools which are used to assess the quality of the blood donation camp including feedback for each stakeholder, performance as against targets, noncompliance, complications, deferrals etc.

We are taking the data management associated with the blood donation camps to the next step. Rather than capture data on paper and then digitalize it later, we are keeping pace with the enhanced internet connectivity and performance on mobile devices and switching to a truly paperless blood donation camps

quality assessment scheme. We are working steadily to render the paper forms only as backups for the occasional outages.

One of the key benefits digitization brings in is reducing the delays and errors in transcribing the paper forms. This, in turn, feeds back into the quality process in a quicker manner - enabling shorter turn around times to see the impact of learning from a particular event. It also makes unnecessary the need to visit the same tasks again after the camp - taking the full quality management process to completion.

So, now you know why Sankalp folks are carrying more portable electronic devices.

Happy donating!

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.

"That man is strongest who stands alone!"

-Ruskin Bond

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: