

## DKMS-Germany, Cure2Children Foundation-Italy and Sankalp India Foundation-Bangalore come together to find ways to increase access to cure from thalassemia



*On 9-10th January 2018, we at Sankalp were honoured and excited to host a delegation from DKMS Germany including Dr Thomas Klingebiel, a very well known person in the pediatric BMT and hematology community.*

DKMS is an international nonprofit organization, founded 25 years ago in Germany by Dr. Peter Harf

when he lost his wife to leukemia. Today, DKMS has offices in several countries and has registered over 6 million potential donors worldwide. DKMS is driven by innovation and invests in our people's ideas in order to be the premier provider of assistance to blood cancer patients throughout the world.

Since 2014, DKMS has been supporting Sankalp-Cure2Children Network with high resolution HLA typing. The delegation from DKMS came to meet the team at Bangalore and see the work being done. Over the two days, the delegation visited the Sankalp-

People Tree Centre for Pediatric BMT, and Project Samraksha - the thalassemia day care centre at Rashtrottthana Parishat. Intense deliberations were organised to understand the details of how we have been able to reach-out with world class cure for patients irrespective of their background, and yet in a cost conscious way. At the end of the two very fruitful days, the three organisations, DKMS, Cure2Children and Sankalp agreed to work together to find ways to reach out to more patients with the option of cure. We are happy to share that as the very first step towards the shared goal, DKMS committed to contributing part of the transplantation cost for next 100 children to be

transplanted.

*The opportunity that this coming together of three organisations sharing common goal brings is unprecedented. These two days have left us filled with optimism to be able to lessen unnecessary suffering. This puts greater responsibility on our teams to convert the possibilities into action.*

\* \* \*

## 1st CME on Thalassemia Organised at RDT Ananthpur



On 3rd December 2017, Department of Pediatrics, Rural Development Trust, Ananthpur organised the 1st CME on Thalassemia. Attended by pediatricians from Ananthpur and nearby districts, the event was very well received and productive.

The team at Rural Development Trust is doing

exceptional work in ensuring that world class protocol driven care for thalassemia is made available to the patients in rural areas. Be it blood transfusions, investigations, chelation therapy or transplants, team RDT makes the impossible happen. The aim of this CME was to raise awareness about blood disorders and ensure that early detection and proper

"The test of a first-rate intelligence is the ability to hold two opposed ideas in the mind at the same time and still retain the ability to function. One should, for example, be able to see that things are hopeless and yet be determined to make them otherwise. F. Scott"





management reaches all the patients.

Dr Raviteja introduced the audience to the program for thalassemia at RDT. Dr Dhanyalakshmi from the Centre for DNA Fingerprinting and Diagnostics spoke about the preventive strategies. Dr Suman Jain from Thalassemia and Sickle Cell Society spoke about the role of blood transfusion medicine in thalassemia care. Dr Raghavaiah from RDT spoke about the essentials of thalassemia management.

Dr V P Choudhury, Former Professor & Head Department of Hematology, AIIMS, New Delhi spoke about preventing complications. With his exceptional ability to simplify complicated medical concepts and effective communication, he kept the audience deeply interested in the subject. Dr Choudhary was deeply impressed by the work which was being done. Dr Stalin Ramprakash, the Program Director of Sankalp-People Tree Centre for Pediatric BMT spoke about the

diagnostic issues and curative options for thalassemia. Rajat Kumar Agarwal from team Sankalp spoke about patient centric delivery of care.

*A key outcome of the CME and the discussion with Dr Sudheer Katumalla the Director of RDT Hospital, Bathalapalli, Dr Dasarath Ramaiah the HOD Pediatrics and Team Sankalp was the decision to pilot screening of all pregnant women in Ananthpur for hemoglobinopathies. This is a major step forward in the direction of prevention.*

We congratulate the management and team at RDT for the fantastic work they are doing. At Sankalp, we are very proud to be associated with such a committed and energetic team.



# HLA typing paves the way for cure from thalassemia in Madhya Pradesh



In December 2017, 3 camps were organised in Indore, Bhopal and Gwalior by Government of Madhya Pradesh together with Team Sankalp. As per the memorandum of understanding signed between Sankalp India Foundation and MY Hospital, Government of Madhya Pradesh and Sankalp, we organised HLA typing. In all, about 200 families were offered HLA typing.

*All three events saw great enthusiasm from the families. Dr Prakash Satwani participated in the events to guide the families. While HLA typing happens, the doctors and nurses are visiting Bangalore and Ahmedabad to be trained at our*

*centers. The first of the transplants is expected to start in March 2018.*

Sankalp India Foundation has been offering HLA typing to families who have a good prospect of cure from thalassemia together with Cure2Children Foundation and supported by DKMS Germany.

The teams from Indore are already at Bangalore and Ahmedabad working together with our BMT teams learning the nuances of transplantation for thalassemia.

Team Sankalp is happy to play a role in enabling more children to be cured from thalassemia.

# "Can inequity in healthcare be bridged in LMICs – Multicentre experience from thalassemia day care centres in India" published in PHOJ

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## Can inequity in healthcare be bridged in LMICs – Multicentre experience from thalassemia day care centres in India

Lalith Parmar <sup>a,\*</sup>, Amit Sedai <sup>a,b</sup>, Kumari Ankita <sup>a</sup>, Rakesh Dhanya <sup>a</sup>,  
Rajat Kumar Agarwal <sup>a,b</sup>, Sunil Dhimal <sup>b</sup>, Reshma Shriniwas <sup>c</sup>, Hemanth V. Iyer <sup>c</sup>,  
Ashwini Gowda <sup>c</sup>, Pooja Gujjal <sup>d</sup>, H. Pushpa <sup>a,d</sup>, Suman Jain <sup>e</sup>, Saroja Kondaveeti <sup>e</sup>,  
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Stalin Ramprakash <sup>h</sup>, Lawrence Faulkner <sup>a,h,i</sup>

<sup>a</sup> Sankalp India Foundation, Bangalore, India

<sup>b</sup> Jagriti Innovations, Bangalore, India

<sup>c</sup> Project Samraksha, Rashtrottana Parishat, Bangalore, India

<sup>d</sup> Indira Gandhi Institute of Child Health, Bangalore, India

<sup>e</sup> Thalassemia and Sickle Cell Society, Hyderabad, India

<sup>f</sup> Rural Development Trust Hospital, Ananthpur, India

<sup>g</sup> Jawaharlal Nehru Medical College, Belgaum, India

<sup>h</sup> Sankalp-People Tree Centre for Pediatric BMT, Bangalore, India

<sup>i</sup> Cure2Children Foundation, Florence, Italy

Delivering equitable healthcare is a global challenge. There are certain groups of patients which continue to perform poorly on clinical indicators compared to other patients. Gender, socio-economic status, distance from treatment centre and parental education are well established factors which influence the treatment outcomes.

Sankalp India Foundation, together with its partner organisation strives to ensure that each child gets proper care irrespective of their background. We measured and compared clinical parameters on various determinants of social inequity to see how effectively the thalassemia management program has

been able to deliver care equitably. The results were recently published in the special edition on Thalassemia of the Pediatric Hematology Oncology Journal of the Pediatric Hematology Oncology Chapter of Indian Academy of Pediatrics titled "Can inequity in healthcare be bridged in LMICs – Multicentre experience from thalassemia day care centres in India".

The following are the key highlights of the paper:

- ✍ Participating centres seemed to have achieved reasonable equity in delivery of transfusion therapy.
- ✍ No sex based inequity is seen though fewer girls get enrolled for treatment compared to boys.

"The world is full of willing people - some willing to work, the rest willing to let them."

- Robert Frost



✍ Centres offering transport support do not see the impact of distance from hospital on patient care.

✍ Despite absence of inequity for the factors reviewed, chelation therapy remained suboptimal.

*The paper concludes "The centres included in this survey have been able to achieve health equity based on social determinants including economic status, sex, travel distance to the centre of treatment, and education level of parents. This experience shows how health outcomes could be measured based upon factors contributing to inequity and that health equity can be*

*achieved even in resource-limited setting for management of chronic diseases like thalassemia."*

The fact that 5 different centres across different states which delivered care to 1507 patients were able to do so equitably is very encouraging. We congratulate the staff, management and donors of these centers for having made this possible. This is a model to be emulated in all centres in the country and abroad.

The paper is open access and the full paper is available free of charge to download and share.

*Please download the paper at the following URL: <https://goo.gl/zKqwMU>*

\* \* \*

Manjunath came a long way with us from being one of the first Thal child registered at our centres in 2011 to getting cured.



"Experience is not what happens to a man; it is what a man does with what happens to him."

- Aldous Huxley

# Experience of a volunteer from our drives



I am Deepak, a student at IIT Delhi, and I volunteered for Sankalp in December 2017. I came to know about Sankalp through my father, who has worked with Sankalp.

I assisted in organizing blood donation camps, aimed at providing blood for Thalassemia patients. There is always a feeling of satisfaction obtained from working for something that matters. There are children who depend on regular blood transfusions for their survival, and we must assist where we can.

It was an enlightening experience. I learned about several aspects of blood donation, and also donated blood for the first time. Starting from helping donors fill forms, to advising them on post donation precautions, every component of a blood donation camp must function like clockwork for best results, and Sankalp ensures this in the best possible way.

I helped at around 6 camps, in offices, universities, residential societies and schools as well. I was pleasantly surprised by the turnout at each and every camp. Although some donors were not eligible to donate, they almost always promised to come back and try the next time, which was really nice to hear. Everyone wanted to help and contribute in some way or the other.

This was a great learning experience for me, as I managed to learn about various aspects such as the pre-requisite conditions required for a donor to be eligible to donate, various precautions to take during post donation, and a general idea of how a blood donation camp is organized. Hopefully with some more experience in the future, I will be able to organize a blood donation camp myself and help those in need.

I look forward to volunteering with Sankalp again.

"We cannot do everything at once, but we can do something at once."

- Calvin Coolidge



# 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	553	653	6	2.8	9.1	98%
Project Samraksha	907	1043	3	2.5	9.5	100%
KLE Belgaum	517	480	3	2.5	8.9	100%
Wenlock Mangalore	125	145	4	4.0	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
Last two months	38	2452	2039	3.2%	16.6%
This year	152	12530	10549	3.8%	15.7%

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

**Applied Materials**  
Aramex  
Cargill  
CGI  
Coviam  
Faurecia  
FedEx  
Felder  
Grant Thornton

**Icon**  
InfyBPO  
ITPB  
JNCASR  
Mahaveer's Place  
McDonald's  
Medi Assist  
National Instruments  
NCBS

**Rainbow Residency**  
Riya Tours  
Sankalp  
St. Theresa  
Treebo  
Uttishta Bharatha  
VIBGYOR  
Volunteers for a Cause  
Wipro



# Jan-Feb 2018



## Sankalp Program For Thalassemia Cure

	Total Transplants Done	Overall Survival	Disease Free Survival
People Tree, Bangalore	73	92%	86%
CIMS, Ahmedabad	25	100%	96%
Other Centres	11	91%	91%
Total	109	93%	89%

## Bombay blood group network

	Total bombay blood group requests	Number of units organised off the shelf	Number of units donated
Last month	8	1	4
This year (cumulative)	42	7	15
Last year	68	30	50

## 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 two months	1150	89%	20%
This financial year (cumulative)	6270	81%	21%
Last financial year	6348	84%	27%

# "Low-cost matched sibling bone marrow transplant for standard-risk thalassemia in a limited-resource setting" - Published in PHOJ

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<sup>h</sup> Sankalp-People Tree Centre for Pediatric BMT, Bangalore, India

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Bone marrow transplantation continues to be the only cure from thalassemia. However, there are several challenges including the high cost of treatment, the treatment associated complications and outcomes. Sankalp-Cure2Children Network has done pathbreaking work in this direction to enable BMT for thalassemia patients with good outcomes, low toxicities, and yet at a lower cost to the society.

In our intent to share the knowledge acquired, recently we summarised and published our experience in the special edition on Thalassemia of the Pediatric Hematology Oncology Journal of the Pediatric

Hematology Oncology Chapter of Indian Academy of Pediatrics titled "Low-cost matched sibling bone marrow transplant for standard-risk thalassemia in a limited-resource setting". This was the third paper accepted for publication in this edition from our team.

*The paper concludes - 'Our results suggest that it is possible to achieve good outcomes without significant long-term morbidity with simplified and cost-conscious BMT in children with thalassemia. We believe that*

"Don't wait for extraordinary opportunities. Seize common occasions and make them great."

-Orison Swett Marden



*patient selection purely based on medical eligibility criteria, emphasis on simple and well-proven infection control measures, judicious use of antibiotics, intensive use of information and communication, technology-assisted quality assurance, and close collaboration with thalassemia centers during down staging, pre- and post-transplant, as well as continued effective follow up support are critical components to the delivery of good outcomes with reduced overall costs.'*

Last year the Government of India made funds available selectively to only 4 centers for transplantation from thalassemia. In spite of 10000 kids being born each year and a huge population living with thalassemia, there were only about 60 transplants done from the available budget in premier institutes against the provision of funds for 100 transplants. In a presentation made at a conference

organised by the Government of Karnataka in February 2018 in Bangalore it was shared that there was no mortality. Yet, the data on the overall cost of transplant to the patient, the disease free survival rates and complications rates is not available in public. Email and calls to the ministry and the ministry designated NGO representative have failed to provide any insight into this matter. In-spite of several centers clearly demonstrating good outcomes with low costs, gaps in the system continue to put the patients through avoidable suffering. The current paper is an example of how data from the centres could be reported scientifically and transparently.

The paper is open access and the full paper is available free of charge to download and share.

*Please download the paper at the following URL: <https://goo.gl/zKqwMU>*

*Sankalp-Cure2Children Network's guide for cure from thalassemia is available at <http://sankalpindia.net/cureguide>.*



# Looking For **Blood?**

## ರಕ್ತಕ್ಕಾಗಿ ಹುಡುಕಾಟವೇ?

**Mail: [sankalp.admin@gmail.com](mailto:sankalp.admin@gmail.com) | Visit: [www.sankalpindia.net](http://www.sankalpindia.net)**

# 9480044444

# Beyond fully matched related donor transplants - Team Sankalp goes Haplo to help children

The month of December saw yet another milestone for Team Sankalp. We took two strides forward in our mission to give life a better chance.

*We undertook a haploidentical BMT for a little girl from Philippines at Sankalp People Tree Centre with alpha-thalassemia for Pediatric BMT.*

DKMS Germany, our partner organisation which has been supporting us with HLA typing kindly offered to cover the cost of transplantation. Under the watchful eyes of Dr Stalin Ramprakash, the Program Director of Sankalp-People Tree Centre and Dr Lawrence Faulkner, the Medical Coordinator of Team Sankalp, the transplantation process went as planned and the child has fully engrafted. Currently the child is in the 3rd month post transplantation and the experience with her transplant brings in promise to numerous families who may not have a matched related donor.

*The mother and father are at least half matches to the child. A new method of transplantation called haploidentical transplant has now become mainstream as a result of a large body of evidence pointing to increased safety and effectiveness compared to other alternative donor sources such as volunteer*

*unrelated donors or cord blood banks. We believe that at present the use of unrelated donors is ethically questionable.*

*While the team at Bangalore were busy with the haploidentical transplantation, our team at Sankalp-CIMS centre for Pediatric BMT came across a child who was in need for autologous transplantation to cure Neuroblastoma.*

Cure2Children foundation pitched in with part of the funds needed and we were happy to have the transplantation done at our centre. Like the Bangalore experience, the transplantation happened by the book and the child is doing well. Contrary to thalassemia, the chances of success of transplantation are low in neuroblastoma and the patient has limited time. Nevertheless, coordinated efforts are being made all over the globe including the Global Neuroblastoma Network to improve the outcomes. We are happy to see the little one cured and on track for a normal life ahead.

We thank our partner organisations for putting their faith in our people, systems and processes. Together we are making a difference!

\* \* \*



# Sankalp and KLE-Belgaum come together to start a new Bone Marrow Transplantation Centre



Sankalp is in collaboration with Dr Prabhakar Kore KLE Hospital and Jawaharlal Nehru Medical College, Belgaum to help strengthen the the delivery of care to the thalassemia patients. Jai Shiv Shakti Thalassemia Day Care Centre has provided immense relief to the patients. As part of the regular management process, we have additionally offered HLA typing to the eligible families and found several matches. Some of these kids came to Bangalore for BMT and are now cured from thalassemia.

Taking the collaboration to the next level, Team Sankalp and Team KLE have agreed to come together to start a Bone Marrow Transplantation centre at KLE, Belgaum. This is a big leap forward to offer reliable cure

to patients from North Karnataka and border districts of nearby states. Sankalp-People Tree Centre at People Tree Hospitals, Bangalore is already busy enough and this new centre will accelerate the delivery of cure to the patients. The newly established thalassemia day care centre at Wenlock Hospital, Mangalore will also benefit from the new transplant unit. This would be the third BMT unit for Team Sankalp.

The details of the unit are being worked out. Within the first half of 2018 we expect to have the first few transplantations completed.

"Better to do something imperfectly than to do nothing flawlessly."

-Robert H. Schuller

# Skill building nurses for Pediatric Hematology / Oncology and Bone Marrow Transplantation - the next big initiative



Sankalp-People Tree Centre for Pediatric BMT is happy to enable Ms Elizabeth Arku from BMT Ghana to receive 20 days of intense training. BMT Ghana is planning to setup what is probably going to be the very first BMT centre in Sub-Saharan Africa later in 2018.

Within the short duration of time that she had, Ms Arku was very keen to learn and worked hard. Ms Arku noted that "the experienced doctors, nurses and other health personnels involved in the delivery health care to patients at the BMTU all work in unity to achieve one positive goal. I have gotten to know that the more I practice, the more I learn the more I become experienced in this particular field." She considered her training program a successful one. More importantly, she built professional and personal relationship with her colleagues in Bangalore and knows that she could connect to them whenever needed in future.

Ms Arku's visit set into motion a series of actions which are paving the way for a structured training program for nurses in pediatric hematology oncology. There is a wide gap between the skill set of the new recruits and the needs of bone marrow transplantation which this training will seek to bridge. All nurses who will join the program and those who come to our centre for training will go through this training process.

So far, it seems like have been able to put together a program which is contextually suited and immediately impactful in skill building nursing teams. Sandeep, the Nursing coordinator of Sankalp is working together with Association of Pediatric Hematology/Oncology Nurses (APHON) from USA to strengthen this program and make it world class. In two years we aim at having a formal training program in this direction.

"Creativity is allowing yourself to make mistakes. Art is knowing which ones to keep."

- Scott Adams



## Wishing Jayashree a happy journey ahead

Ramesh was earning his bread by working as a private driver in Mumbai. He and his wife Adeshwari, lived in a chawl in Mumbai. Within a year of their marriage, they were blessed with a baby girl who was named Jayshree. Within few months of her birth, it was clear that Jayshree was not growing normally and seemed to have some medical problems. She was looking pale and ill. Adeshwari's father took them to a doctor and mentioned the whole situation. The doctor immediately suspected thalassemia. Jayshree underwent HPLC test and it was confirmed that she was suffering from thalassemia.



With a lot of difficulty Jayshree started getting blood transfusions regularly at a government hospital. Her maternal grandfather was taking care of her, doing whatever they could with their limited means. Ramesh was a private driver and could not afford to take a day off regularly and struggled to keep the child going.

Seven years later Adeshwari got another pregnancy. This time they were aware and during the pregnancy she underwent for antenatal screening and found that the child was not a thalassemia major. When Jayshree was twelve years old, the family heard about Bone Marrow Transplantation, a permanent cure for thalassemia when they got an opportunity to get registered for HLA typing with Sankalp India Foundation. After 4 months the report came and fortunately the report showed that the sibling was a full match.

With the newfound hope Jayshree underwent primary checkup for BMT. Unfortunately her serum ferritin was very high. Doctors said that this could adversely impact

the transplant and put her on a aggressive downstaging therapy to control iron load before the procedure. Team Sankalp was involved in her downstaging through weekly follow-up and even support for chelation therapy. The bundled cost of transplant at Sankalp's centres is the lowest in the country, the amount however was not affordable of the family. The family contributed what they could and requested for help with the remaining amount. Team Sankalp fundraised for the child from its donors. A year later the doctors were of the opinion that Jayshree had been downstaged as much as possible and agreed to take her up for transplant at Sankalp-CIMS Pediatric BMT Program at CIMS Hospital, Ahmadabad. She did have a relatively stormy transplant course but after a month and a half, emerged with a fully engrafted marrow from her sibling. She was discharged from the hospital and moved to an apartment nearby. Currently she is in step down process and doing well. Her recovery is slow but steady.

We wish her good luck and a happy journey on the road of life!

# Hi Sankalp!

Please get in touch for any of the following

## Statewide Blood Helpline

- Call 9480044444 when in need of blood anywhere in Karnataka

## 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

**From:**

**Call: 9480044444 | Visit: [www.sankalpindia.net](http://www.sankalpindia.net)**

**Mail: [contact@sankalpindia.net](mailto:contact@sankalpindia.net)**

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

**To:**

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None

I, Rajat Kumar Agarwal, hereby declare that the particulars given above are true to the best of my knowledge and belief

Rajat Kumar Agarwal

15 Feb 2018