



Making 20 Thalassaemia Day Care Centres Happen

Ahmedabad Inauguration

26th January evokes patriotism from all Indians and is marked with several social and cultural events. For the team at Sankalp, patriotism is about honoring the promises we made - of building a country free of thalassaemia and striving towards 100% voluntary blood donation. While at Bangalore we had a public blood donation drive at a shopping mall evoking a grand response, we are happy to share that another significant step in the direction of improvement of care for thalassaemia has been taken with the extension of clinical services at the thalassaemia day care centre

setup by Jalaram Abhyuday Sadbhavana Trust (JAST) at Ahmedabad.

Effective management of thalassaemia for patients coming from diverse social backgrounds is sorely missing in our country. Most of the big cities often have facilities and teams to manage patients who can afford expensive therapies and treatment options but the ones coming from weaker financial and social backgrounds are left in a lurch. Over the years, Sankalp through its many ventures in this domain has been able to prove that systematic care delivery for a chronic



condition like thalassemia need not be dependent on the financial strength of the patient's family. Our own publication in the Pediatric Hematology Oncology Journal (PHOJ) proved that irrespective of gender, caste, economic or literacy background and distance from the centre, the quality of care extended to each child coming in for treatment can be uniform and be compliant to international guidelines. Sankalp is on a mission to root out the problems associated with thalassemia and has been actively looking at collaborations to setup care facilities for thalassemia.

Ahmedabad in Gujarat is a city well known for its rapid strides in the direction of development, especially in the recent years. Yet, the state of several 100 patients suffering from thalassemia, especially from the weaker financial sections of society remains concerning. More than a year ago, JAST recognized this situation and started a facility to provide food, play facilities and resting areas for several little children and their families coming in for regular blood transfusion at nearby hospitals. Over time, the centre matured into a zone for counselling, bonding between families and a place where children just loved to come just before the blood transfusion would start. On a thorough review it seemed like even though a lot of non-clinical issues for

the families were resolved with the establishment of this centre, clinically the children were not in great shape. That is when the team at JAST got in touch with Sankalp. Sankalp through its BMT unit at CIMS Hospital had setup its presence in Ahmedabad. The team at JAST were aware of the clinical outcomes and were very open to Sankalp taking over the responsibility for clinical care of children. The seeds of a holistic care centre for systematic care and management of thalassemia were sowed. With rapid coordination over the past few weeks to empower and add manpower and resources and the guarantee of safe blood coming in from the giants of blood banking in Ahmedabad – Prathama Blood Centre and Sarvodaya Blood Bank (Supratech), the missing blocks to setup a full clinical care facility were brought in place.

At 10 AM on 26th January 2019, Dr Lawrence Faulkner, Pediatric Hemato-Oncologist and the Medical Coordinator of Cure2Children, Italy and Sankalp India Foundation inaugurated the centre dedicating it to the several children in need of care. The event was attended by several well known figures at Ahmedabad – Mr Nitin Shah, Dr Deepa Trivedi, Pediatric HematoOncologist and BMT Program Director at the Sankalp CIMS Pediatric BMT Unit, heads of Prathama

"To live only for some unknown future is superficial."

- Dr.A.P.J.Abdul Kalam

Blood Centre and Supratech and all the honorary trustees, friends and members of JAST. We feel humbled at the love and admiration shown by the people from different walks of society who all contributed in their very small but important manner in the setup of this facility.

Dr Lawrence & Dr Deepa expressed happiness that many more children would get access to better management and eventually bring them in line for cure through BMT. Lalith Parmar, President, Sankalp India Foundation reiterated that Sankalp would build at least 20 day cares all over the country. He also challenged the whole team that the path is not easy and that should we work hard and do well, within a year there would be 400+ children at the centre. The JAST team was represented by Mr Rajiv Ravani, who is a trustee. He expressed immense satisfaction at building such a centre and echoed the notes of Mr Lalith and committed that JAST would take the ownership of driving the entire team to do the best for the children.

With 4 centres in Karnataka, 2 each in Maharashtra, AP, Gujarat and 1 in Rajasthan, Sankalp is now actively collaborating clinical care in 11 day care centres across the country.

Collaborations with Nellore, Rajahmundry, Eluru and Vijaywada

In the last week of December 2018, the thalassemia management team of Sankalp toured coastal AP to explore possible collaborations in setting up systematic care facilities for thalassemia. While the team has been working with several individuals in Rajahmundry to offer HLA typing, free consultation and BMT for children from the region, the possibilities of a day care were also explored.

At Nellore, the collaboration with Indian Red Cross Society finally materialized into a thalassemia day care facility being inaugurated on 28th December 2018. The team at Nellore, headed by Dr A V Subramanyam, the honorary chairman of IRCS and ably supported by Dr Yashvardhan, the blood bank medical officer worked overtime to secure necessary permissions from regulatory authorities and also get a 5 bedded facility in place in the premises of their blood bank. IRCS blood bank being one of the most sought after places for blood, there are several thalassemics who take blood from here. These families are being counseled and in the last one month 10 children have already been registered and transfusions have been started off. With collaboration for labs, chelation almost in place, the centre is at the cusp of taking full flight shortly.

IRCS Eluru and Mamata Foundation, Vijaywada have also joined hands with Sankalp. IRCS represented by Dr Prasad, a leading figure known for initiating several social projects and Mamata Foundation represented by Dr Sridevi were present in a HLA typing event organized on 24th December at Eluru. HLA typing was offered to 29 families. The doctors also expressed keen intention to collaborate with Sankalp. With ThalCare, the technology assisted tool for managing thalassemia, already being rolled out at their centres, the staff there are in the process of identifying the right patients and other resources for blood etc. By the month of April, MOUs with both organizations would be signed off to formally establish the collaboration leading into a complete thalassemia day care facility.

Partnerships with Samarpan (Sarvodaya Hospital), Mumbai and IRCS Rajkot

The collaborations with Samarpan Trust (Sarvodaya

Hospitals), Mumbai and IRCS Rajkot to streamline thalassemia management locally is also beginning to bear fruit. Over the last 2 months, intense focus on transfusions, investigations and regular review by hematologists have helped fix some basic problems.

With attention now shifting towards enabling regular lab investigations and starting chelation therapy for all eligible candidates, the centre maturity is improving rapidly.

Together with Jayadeva Institute of Cardiology - Cardiac Screening and Consultation organised for thalassemics



As kids with thalassemia progress into adulthood, cardiac complications pose a major threat. Early detection and aggressive management are the two key strategies. With this focus a cardiac screening event was organised at the thalassemia day care centre at Samraksha, Rashtrorathana Parishat in Bangalore on 17-November-2018 with support from

Jayadeva Institute of Cardiology. 105 patients participated in the program. Echocardiogram was done and Dr Bharat, the Pediatric Cardiology from Jayadeva reviewed all the reports. Thanks to Team Jayadeva, we are able to take the quality of care for patients with thalassemia.

"Great dreams of great dreamers are always transcended."

- Dr.A.P.J.Abdul Kalam

Two day training on Effective Management of Thalassemia



As part of the continuous learning initiatives adopted by Sankalp, a 2 day meeting for coordinators, nursing staff and doctors from the multiple thalassemia day care centres where Sankalp is involved was organized in Bangalore on the 23rd and 24th of January 2019

People from the following thalassemia Day Care Centre were present

1. Indira Gandhi Institute Of Child Health, Bangalore
2. Project Samraksha, Bangalore
3. Jai Shiv Shakti Centre for Thalassemia Management, KLE Hospital, Belgaum
4. District Wenlock Hospital, Mangalore
5. Thalassemia Society of Central India, Rughwani Hospital, Nagpur
6. Indian Red Cross Society, Rajkot

7. RMM Global Hospitals, Abu Road
8. Rural Development Trust, Ananthpur

The event saw active engagement of participants in several sessions. Dr Lawrence Faulkner, Pediatric Hemato-Oncologist and Lead Medical Coordinator of Cure2Children and Sankalp India Foundation, spoke about the need for care to be very organized and focused on quality. He reiterated that the success that Sankalp has seen with it's BMT initiative is down to the fact that care in the day care centres has been very focused.

Dr Stalin Ramprakash, Pediatric Hemato Oncologist and Program Director of the Sankalp People Tree Centre For Pediatric Bone Marrow Transplant spoke at length and enlightened the attendants on effective transfusion techniques by discussing the transfusion protocols and citing several example situations. Dr Raghuram, consultant Pediatric Hemato Oncologist at Sankalp People Tree Hospital spoke about methods of diagnosis and treatment for other hematological

"You can often find in rivers what you cannot find in oceans."

- Indian Proverb



disorders apart from thalassemia including usage of Hydroxyurea for different conditions.

We also laid out the protocols for chelation management, management of organomegaly, treating sero positive patients etc. Mr Santhosh Hegde, project manager of the Sankalp program for thalassemia management introduced all the new features in ThalCare and spoke about the regular errors and gaps seen in data entry.

Ms Rajeshwari Shastry, a play therapist, engaged the participants in activities of fun and games and touched upon the sensitive yet important subject of regular counselling, dealing with difficult families and children etc.

Overall, over the 2 days through constant questions and interactions, the participants went back with loads

of new things learnt. All of them expressed interest in participating in more such sessions in the future. By their own admission, it was a welcome break from day to day patient management – with the centres being thronged by patients everyday, the staff seldom have time for any introspection of work and opportunities to interact and learn new things.

“Information Technology-Assisted Treatment Planning and Performance Assessment for Severe Thalassemia Care in Low- and Middle-Income Countries: Observational Study” Published in JIMR

Technology helps improve care for thalassemia! That's our message in the prestigious Journal for Internet Medical Research published. Another step in the direction of "Thalassemia Free India".

Link: <https://medinform.jmir.org/2019/1/e9291>

DOI: 10.2196/medinform.9291 PMID: 30672740

Expanding the frontiers - Yogesh wins over Fanconi Anemia with his Bone Marrow Transplantation



Tracking each kid who came to our day care centres, we were sure earlier this year that a diagnosis of Severe Aplastic Anemia or Fanconis Anemia meant the child will not make it. These conditions are treatable and even curable. While we focussed on Thalassemia we had to admit that unless we stepped in, more young lives will be lost - leaving families devastated for a lifetime.

It was a big day as Yogesh gets discharged from our Transplant Centre in Bangalore. Over last few months the team has left no stone unturned to ensure that his fragile body tolerates and recovers from the intense treatment that was his only chance.

Yogesh has lit the lamp of hope for several others who eagerly await their transplants. As for the Sankalp - Cure2Children Foundation Network, we only wish that we replicate and exceed what little we have been able to do with thalassemia.

Another few kids are at various stages of their transplant for non-malignant blood disorders other than thalassemia as of date and more are joining the queue. A moment to pause. A moment to think. And a moment to redouble our commitment to "Give Life A Better Chance". Thank you so much everyone who joined hands to make this happen!

"I suppose leadership at one time meant muscles; but today it means getting along with people."

- Indira Gandhi

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	653	758	5	3.0	9.7	100%
Project Samraksha	923	1126	3	2.3	9.1	100%
KLE Belgaum	581	541	2	2.5	9.1	100%
Wenlock Mangalore	249	266	4	4.0	8.5	100%
TSCS of Central India, Nagpur	189	189	4	2.5	8.6	0%
Samarpan, Mumbai	189	205	15	2.5	9.0	100%
IRCS Rajkot	303	316	8	1.0	8.9	42%
RMMG Abu Road	83	83	5	1.0	8.8	100%
TOTAL	3170	3484	4.6	2.5	9.1	88%

Bombay blood group network

	Total bombay blood group requests	Number of units organised off the shelf	Number of units donated
Last two months	19	12	3
2018-19	110	62	15
2017-18	133	55	30

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	877	82%	22%
2018-19	4739	86%	23%
2017-18	6977	82%	21%

Dec18 -Jan 19



Sankalp Program For Thalassemia Cure

	Total Transplants Done	Overall Survival	Disease Free Survival
People Tree, Bangalore	122	91%	81%
CIMS, Ahmedabad	64	97%	94%
Other Centres	11	91%	82%
Total	197	93%	85%

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	37	3148	2622	3.0%	16.7%
2018-19	193	16686	14075	3.3%	15.6%
2017-18	195	15497	12964	3.7%	16.3%

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

Aegis
Amadeus
Artech
Aruba
AxioBio
Bosch
CGI
Disha Central Park
Evolute
Felder

Finastra
GM
Groupon
HH
JNCASR
Lovable Lingerie
Mahaveer's Place
Mantri Espana
Microchip
NCBS

Rainbow Drive
Swiggy
Tango India
Treebo
Trelleborg
TSS
Uttishta Bharatha
VFC
VR Mall
Zyme

How planning mitigated winter blood shortage?



Sankalp India Foundation has been strategically planning the blood donation drives to meet the critical hour of blood shortages both in the summer and winter months, instead of clustering the blood donation camps on the days of national importance or when the city has enough stocks. The winters of this year, has also been very challenging, specially the last week of Dec and the first week of Jan'2019.

While the city was busy celebrating festivals and the colleges were busy with exams and winter vacation, the need for blood did not come down. Each and every day, individuals across the city of Bengaluru, depend on blood donations for lifesaving treatments and emergency care. Hence, it is critical that regular

Voluntary donors donate blood to meet these needs.

52 blood donation drives have been organized between Nov- Jan, collecting 3745 units of blood. Drives were planned on every Sunday in the month of Dec 2018 and the first week of Jan'2019. The Blood Donation Drives have been distributed among 10 Blood Banks in Bengaluru to ensure proper distribution of blood in the city.

"A person can achieve everything by being simple and humble"

- Rig Veda



To mitigate this shortage, potential donors need to be educated about both the need and potential solutions. The supply of blood is like a cell phone battery, it constantly needs recharging. There is no substitute for human blood: the supply depends entirely on generous donations. Corporate Bodies, Voluntary groups and public associations have been sensitized about the need during this critical hour and they have been very supportive in their gesture of organizing Voluntary Blood Donation Drives.

To meet the fragile balance between blood supply and demand, Sankalp constantly search for more efficient ways to recruit blood donors. Efforts to achieve self-

sufficiency and to render blood supplies safely and make it manageable, focus has been laid on recruiting and retaining more volunteer donors. The constant concern with being able to meet the demands for blood is because of the fact that only a small percentage of the eligible population actually chooses to donate blood on a regular basis. Sankalp has been successful in organizing awareness session at corporate and creating TeamRed Volunteers for public drives to carry the message of Voluntary Blood Donation forward

Stand up and be counted. "Make Blood Donation your Responsibility!!"

"You can't change how people treat you or what they say about you. All you can do is change how you react to it."

- Mahatma Gandhi

Enrolling More Children for Bone Marrow Transplant HLA Typing Across The Country



Thanks to the generous support from DKMS, HLA typing which usually costs a significant amount is made very affordable for several families in India. Through their support, Sankalp has been actively identifying candidates for BMT across the country. Over the last 3 months, nearly 500 HLA samples have been collected. Here is a snapshot of HLA typing events held at different places.

Indore & Ujjain

Sankalp, DKMS are working together with MY Hospital Indore in helping them make BMT affordable and accessible to plenty of patients. Several rounds of HLA typing in the past led to the identification of 40+ patients with a HLA match. The activity was taken to the next level with HLA camps organized in Indore in late September and Ujjain in February. Nearly 120 families were offered HLA typing.

Rajahmundry, Eluru and Vijaywada

HLA typing for identifying candidates for haplo identical transplants were done at Rajahmundry in September and again in December 2018. 50+ families who do not have a full HLA match were eager to understand their prospects of cure. 29 families who had never known about the chances of cure were also offered HLA typing at Eluru and Vidaywada. Most of these families were excited to understand that there is a hope of cure.

Ahmedabad, Rajkot, Surat and Junagadh

The Sankalp Pediatric Bone Marrow Transplant Unit at CIMS Hospital Ahmedabad has been offering cure from thalassemia to several children from Gujarat. The team extended HLA typing to several cities within Gujarat to identify eligible candidates. Samples were collected for 100+ families across Ahmedabad, Rajkot, Surat and



Junagadh areas in Gujarat between November 2018
January 2019

RDT-Ananthpur

Sankalp and RDT have been working together for management and cure from thalassemia. 10 children from RDT have already undergone transplant at our centre in PTH, Bangalore. While all sibling and patient HLA samples were collected in the past, samples for parents were collected to identify any potential HLA matches with parents from consanguineous families or for haplo identical transplant. 100+ families were offered HLA typing in December 2018.

Karnataka and Goa

HLA typing has been regularly done over the last 3 months in the existing Sankalp thalassemia day care centres in Karnataka at KLE Hospital, Belgaum, Wenlock Hospital, Mangalore, Project Samraksha and Indira Gandhi Institute Of Child Health, Bangalore. Close to 120 families have been covered in this process.

Beside this in Goa 30 families typed with the support of Thalassemia Society of Goa and Goa Medical Council. No child from there has ever gone to BMT and this is the first event.

"The great are strongest when they stand alone, A God-given might of being is their force."

– Sri Aurobindo

An action packed Republic Day Celebration with Healing Touch Society



A single gesture can create million smiles!!

As we all celebrated the Republic Day with high patriotic spirit, there was a group of Volunteers from Healing Touch Society, who have stood out to make a difference!

On 26th Jan, 2019, a blood donation drive was held at VR Bengaluru, organized by Healing Touch Society in association with Sankalp India Foundation and ID Fresh Foods. 190 units of blood were collected in the event by Narayana Hrudayalaya Blood Bank. The event has set a new benchmark for public blood donation drives.

This camp proves that every individual can make an impact and save lives. The Healing Touch Group Volunteers are working professionals who took out time from their busy schedule to ensure that publicity

is done to reach out to the maximum number of people. The publicity campaign was started one month before to ensure increased participation from voluntary blood donors. Social Media- Facebook, WhatsApp, and Twitter were used extensively to reach out to maximum number of people. Pre-registration link was created to ensure that the team is well prepared to meet up the footfall of donors.

Extensive reach was created by publishing about the blood donation drives in newspapers- both in English and vernacular languages. 3000+ brochures were distributed in the nearby apartments, shops, malls etc. Brochures were also circulated in Whitefield residential area along with the morning newspapers. Standee banners were put up at all the floors at VR Mall. The campaign concept created was inclusive to all relevant audiences, engaging and personal; it highlighted the human touch to donating blood.

It's never too late to start over. If you weren't happy with yesterday, try something different today.

Don't stay stuck. Do better.

Sankalp India Foundation also helped out to reach to the maximum number of donors. SMS Campaign was used for reaching out to all the registered donors with Sankalp India Foundation, residing in the areas in and surrounding Whitefield.

The donors who came for donating blood were handed over certificates from Blood Bank and Healing Touch Society along with a sapling and gift box. VR Bengaluru made announcements using the PA system about the blood donation drive at regular intervals to inform the crowd at the malls.

RJ Kay had also come in for the inauguration program and motivated donors in the mall to donate blood. He also shared his experience of how he has been donating regularly and has helped save lives.

The donors had wonderful experience. Mr. Vasudev

Ballaney quotes "Had personally been yesterday- 26/01/19, at VR Bengaluru Mall, Whitefield for blood donation for 81st time. I am impressed the way the donation drive is taken care of. Very humble, polite, sympathetic and systematic approach to the drive."

An Anonymous donor quote- "I did not want to spend Republic Day celebrating it as a holiday and showing my patriotic spirit by posting on Facebook. I stay very nearby and I have seen the event on Facebook-that moment itself I took a decision to make a difference. Donate Blood and Save Lives!"

Gowtham Sampath Kumar states-" I came to donate blood to give back to the society in any way I can"

We continue to pursue excellence in care delivery and search for better and safer techniques for treatment. An essential part of this is peer review.

We are happy to share that several of our papers have been accepted to be presented both as oral presentations and posters in Transplantation and Cellular Therapy Meetings of ASBMT and CIBMTR 2019 - Houston (USA) and the 45th annual meeting of The European Society for Blood and Marrow Transplantation - Frankfurt (Germany).

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:

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