

sankalp patrika

A monthly newsletter by Sankalp India Foundation
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Sankalp India Foundation celebrates a Double Milestone

Sankalp India Foundation, a Bangalore based voluntary organization started in 2003, achieved a double milestone of having completed 100 Bone Marrow Transplants for children with thalassemia, and have collected 100,000 units of blood through voluntary blood donation drives.

Back in 2003, Sankalp started on a night when an unknown person came to a group of students requesting them to donate blood for his relative. By the

time the students donated, the life was lost. The group then began a journey of setting up a mechanism to help people with blood in emergencies, also establishing a statewide helpline for blood – a single number connected to the most quality-oriented blood banks in the state guiding people to places where safe blood is available in 2006.

In the year 2007, Sankalp started organizing voluntary blood donation drives in order to compensate lack of stocks in blood banks. Since then Sankalp has organized over 1200 voluntary blood donation drives collecting 100,000+ units in more than 150 corporate organizations. Most of these blood units have been



collected in periods of extreme need of blood thereby ensuring availability of safe blood all through the year in the most reputed blood banks of Bangalore. The blood donation drives are characterized by absolute focus on quality and giving donors a unique and comfortable experience during blood donation. Sankalp has published its findings in the field of voluntary blood donation through various scientific publications in reputed international journals.

Since 2011, Sankalp started working in the field of thalassemia. The organization today manages 5 thalassemia day care centres in Karnataka and Maharashtra looking at the systematic management of nearly 1200 children. These 5 day care centres in Indira Gandhi Institute Of Child Health (IGICH), Project Samraksha at Rashtrottana Parishat, District Wenlock Hospital, Mangalore and KLE Hospital in Belgaum have been setup by Sankalp in partnerships with the institutions. Using technology platforms

highly customized for thalassemia management, knowledge sharing and trainings by national and international experts, and generous contributions by philanthropic individuals, the organization has setup mechanisms to ensure that each child receives the best optimal care possible irrespective of their background. This has brought in a noticeable change in the quality of lives of these children.

Bone Marrow Transplant (BMT) is today the only mechanism of cure from thalassemia. Due to escalated costs BMT is often inaccessible in most hospitals in India. In 2015, Sankalp setup a unique transplant centre at Bangalore in collaboration with People Tree Hospitals and knowledge, and resource support from Dr Lawrence Faulkner from Cure2Children in Italy. A group of donors generously funded the facility and the transplants started on a not for profit basis at an overall cost of INR 8.5 lakhs including post-transplant supportive care upto 1 year. The commitment to



support and quality at this cost is nearly 50% cheaper than any other BMT facility in the country. 3 years now, the centre has completed more than 100 BMTs for thalassemia with an overall survival of over 92% and a disease-free survival of more than 85%. These results are at par with international outcomes and are by far the best in the country.

Over these years, the cost of transplant has been maintained the same. Most of the costs are fund raised by Sankalp via generous contributions from several organizations and individuals. The facility is also the first in the country to be lined up for an international accreditation from FACT-JACIE. IN 2017, Sankalp setup another BMT facility at Ahmedabad where 50 transplants have been completed with equally good results. With over 150,000 thalasseemics in the country and about 10,000 being born each year, thalassemia needs special focus.

With focused management and cure facilities, Sankalp has set up a mechanism where each child receives the most appropriate care thereby making thalassemia care accessible to all.

“Our aim is to see that each child suffering from thalassemia receives the most optimal and appropriate care. As an organization, we are working on all 3 fronts – prevention, management and cure of thalassemia to achieve our goal of building a Thalassemia Free India. On the voluntary blood donation front, we have created a system where voluntary drives with excellent quality are conducted in periods of extreme emergencies thereby ensuring safe blood availability all through the year, taking rapid strides towards taking India towards 100% voluntary blood donation” says Lalith Parmar, President Sankalp India Foundation.

“Life is about making right things and going on.”

R.K. Narayan

Thalassemia Day Care Centre supported by Sankalp India Foundation started at Abu Road



A new step forward has been made in our mission to ensure that children suffering from Thalassemia get proper care and management with the inauguration of the new Thalassemia Day Care Centre at RMM Global Hospital Trauma Centre at Abu Road in Rajasthan on 1st October 2018.

What started as a discussion on the sidelines of a conference in July took the shape of a day care centre very quickly with the management of GRCH keen to provide systematic care to the kids around Abu Road. The day care centre has been started with 25 kids. What could have been a more befitting occasion for inauguration than the National Voluntary Blood Donation Day.

With this day care centre - systematic blood

transfusions, iron chelation therapy, regular monitoring, complication prevention, counselling, and consultation with pediatric hematologists oncologists will be available for the kids at the centre. The centre will also promote prevention and cure and will forward the vision of Thalassemia Free India.

Coordinated care and management assisted by technology and driven by the intent to achieve measurable outcome has transformed the lives of several families who are receiving equitable care at our centres. We are very happy and proud to have partners who share the common vision and join hands to reach out to the most needy.

" I am full of ambition and hope and of full charm of life. But I can renounce all at the time of need"

- Shaheed Bhagat Singh

Enabling cure - Sankalp offers more HLA typing



The end of month of September was particularly busy for Team Sankalp as we geared up to offer HLA typing to about 200 families. Thanks to the support of Cure2Children Foundation - Italy and DKMS Germany, Sankalp has pioneered access to free HLA typing in a systematic and impactful way over last few years.

These events are not one off and serve as the first major step in the journey towards better management and cure. The events enable proper counselling of families and the need to ensure that systematic care continues to reach their child. On the other hand, for those families who get a good HLA match, the organisation provides support to get transplantations. At Jai Shivshakti Centre for Thalassemia Management at KLE Belgaum, the enthusiasm in the families was high since several kids from the centre who had got HLA typing done earlier in similar event were getting cured. The team at KLE had ensured all necessary preparation and 38 families came in for HLA typing.

The next event was organised on 29th September 2018 at Thalassemia Society, Goa. About 90 kids in

Goa are coming to Goa Medical College to receive regular care and 29 families were HLA typed. A short program was held by the Society which is incidentally headed by the HOD of Pediatrics from GMC and has the treating doctor as one of the main decision makers. Experts in the field of thalassemia management and cure were available to answer questions from the families.

A HLA typing event was also held at Jalaram Abhuday Centre in Ahmedabad. Little children who come for regular care at Civil Hospital, Ahmedabad who can be clinically prepared for transplant were offered HLA typing. In all, about 30 families were covered. On similar lines, HLA typing was also offered to another 15 children in Mumbai. These children are taking transfusions in either Wadia Children Hospital or at Samarpan Blood Bank and the families are now thinking about the possibility of cure.

For Team Sankalp, the greatest satisfaction is in seeing these events come all the way from HLA typing to cure for these kids.

“India may be a land of over a 100 problems, but it is also a place for a billion solutions. ”

-Kailash Satyarthi

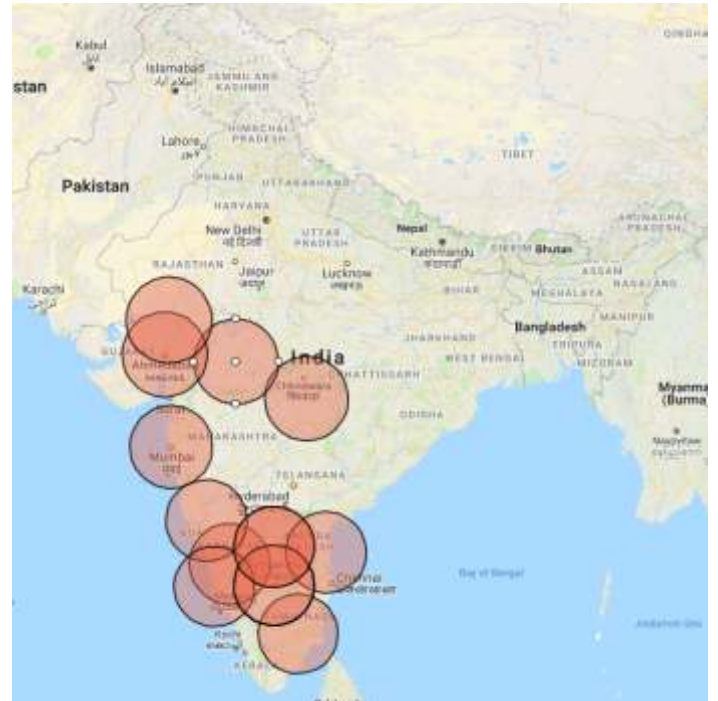
Mission “Thalassemia Free India” strengthened with the signing of MOUs to setup and strengthen day care centres

In September 2018, we took our mission for “Thalassemia Free India” further by signing up the MoUs to replicate our model of comprehensive care and management for thalassemia in more regions.

The first MOU was signed between Kauvery Hospitals, Trichy and Sankalp for the establishment of 8 bedded day care centre. While the hospitals will organise for all the resources, Sankalp has taken up the responsibility of training the staff, provide access to information technology platform for thalassemia - ThalCare, provide technical expertise, consultation with the experts and regular monitoring for the centre. The centre is due to be inaugurated in October. Dr Chandrakumar the MD and CEO of Kauvery Hospitals is very keen on ensuring that comprehensive and quality care for thalassemia is made available for a large population around Trichi.

Another MOU was signed between Samarpan Blood Bank, represented by Sh Nitin Bhai Maniar and Sankalp for strengthening the existing day care centre at Mumbai. Mumbai serves a large population of thalassemia patients from Maharashtra and yet the options for comprehensive care of thalassemia are limited. Sankalp is looking forward to augment the good work already being done by Samarpan so that each child may receive quality care for thalassemia and Samarpan may be able to accommodate more patients. The team from Samarpan including Dr Pallavi and Darshana came over to Bangalore to visit our centres.

Collaborations have also been setup with Adani Group & Rotary Wall City Charitable Trust in Bhuj, Indian Red



Cross in Rajkot and Indian Red Cross in Nellore to establish day care centres where systematic care is delivered. All of these centres are building up steam to register patients on ThalCare and look at organizing the basics. With availability of safe blood not a challenge at any of these places, good support of labs being available, ground level coordinators being trained by the Sankalp team it is a matter of time by which things will be streamlined to be at par with the existing centres managed by Sankalp in Karnataka.

We are happy to have participated in the Equitable Healthcare Access Consortium meeting in Madurai earlier this year, which helped build connections with like minded organisations across the country. It is through this forum that the conversation for daycare centres at Trichy and Abu Road started.

Map shows circles of 200 km radius around day care centres where Sankalp is supporting thalassemia care.

Voluntary Blood Donation continues to ensure shelves in blood banks are well stocked

Sankalp India Foundation have always focused on strategic planning of blood donation drives to ensure availability of blood throughout the year. As the months of August and September, witnesses a good number of blood donation drives due to the celebration of Independence Day, we have cautiously chose to plan the drives and ensured that there is even number of stocks distributed to all the Blood Banks as the need demanded and not over burden them with stocks. 32

blood donation drives have been organized in the two months, collecting 1442 units of blood.

We would like to thank all the donors who have rolled up their sleeves to donate blood and save lives! You bring smile and hope to our little ones at the Thalassemia Day Care Centres. #theneedisconstant #thegratificationisinstant #fightagainstthalassemia



“Excellence is a continuous process and not an accident. ”

A. P. J. Abdul 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 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	615	711	11	2.8	9.6	100%
Project Samraksha	938	1097	3	2.5	9.0	100%
KLE Belgaum	532	506	3	2.5	8.7	100%
Wenlock Mangalore	216	235	4	4.0	8.2	100%
TSCS of Central India, Nagpur	193	193	4	3.0	8.3	0%

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	2
2018-19	61	42	4
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	671	82%	34%
2018-19	2724	89%	26%
2017-18	6977	82%	21%

April-May 2018



Sankalp Program For Thalassemia Cure

Total Transplants Done	Overall Survival	Disease Free Survival
102	91%	80%
52	96%	92%
11	91%	82%
165	93%	84%

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	32	1896	1513	🚩 2.5%	🚩 20.2%
2018-19	130	11384	9611	🚩 3.2%	🚩 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

APU
Artech
Awfis
Cipla
CPG Consultants
Dell EMC
Faurecia

Groupon
HDFC ERGO
Indegene
ITPB
Mantri Espana
National Law School

Rainbow Residency
Sakha Global
SBD
Sigma Infosolutions
Societe Generale
Volunteer for a Cause

How are the transplants becoming safer - good news for patients who seek cure from thalassemia

It has been three years since the time Sankalp started the program for thalassemia cure. We started our bone marrow transplantations for patients who had a matched related donor only. Even in this selected group of patient, recent data shows that the team has achieved 95.5% disease free survival and 98.3% overall survival last year, building upon the success of previous years. Specially in the matched sibling context, the team improved disease free survival from 89.1% across the years to 98.3% for last year alone.

One of the key reasons for steadily improving outcomes is the stringent review of the data that the organisation accumulates. For our Sankalp program for Thalassemia Cure, it is no different. Recently we reviewed our data for the transplantations again after a gap of 3 months from the last Sankalp-Cure2children network meeting. We are happy to share some of the key findings which have huge implications on enabling cure for all kids.

At the beginning of this year, Sankalp has started accepting patients who had a partial match with the parents for transplantation. These haploidentical transplantations(also referred to as haplo) are relatively new and there is very limited context appropriate published data available.

With the positive experience at South east Asia Institute of Thalassemia Jaipur and with the good

outcome with the first haplo in Bangalore, we proceeded with a limited number of transplantations with partially matched parental donors. Now, when we review the outcomes we can see that in a selected group of patients the outcome of haplo is probably as good as matched sibling transplants. There are two major risk factors beside the usual risk factors associated with transplantations for thalassemia which have shown to contribute to poorer outcomes (transplant failure). The first one is the nature of mismatch. Some matches are such that there is a increased risk of the patient's cells destroying the incoming bone marrow (host vs graft reaction). The other issue that has been uncovered is the presence of donor specific antibodies in the patient prior to transplant. The patients who had neither of these issues performed extremely well. The fact that these issues have now been identified, targeted work is being undertaken to see how they can be addressed.

Nevertheless, the experience confirms that we can expand the number of children who can be offered transplants as a curative choice. Now, we will begin the process of systematically preparing more low-risk kids for routine haploidentical transplants.

It is a known fact that thalassemia transplants do not do well if the patient has severe organ damage. Enlarged liver and spleen are key risk factors. A key differentiator in our approach to transplants in the

huge investment of time and effort we make together with the thalassemia families to undo the damage done by years of improper care to the extent possible. This process call downstaging is undertaken for each child and only once the medical team is confident that no further improvement can be achieved is the child taken up for transplant.

Recent review of our data shown that the intent to downstage has worked very well and an overwhelming majority of patients go into the low risk category just prior to transplant. As a consequence and also thanks to the improved protocols we have improved the outcomes significantly. With the latest protocol for all patient put

together we saw an overall survival of 98% and disease free survival of 94% in our two centres.

With outcomes that set a benchmark, the next focus for fully matched related transplants is to reduce the chemotherapy to the minimum so as to spare the detrimental impact on fertility.

Both these findings give us greater confidence in our mission for a thalassemia free India. The journey of last few years have seen pathbreaking improvements which have made available reliable transplantation to patients with higher risks, more age and those who did not have matched related donors. While some challenges remain, the fact that they have been identified is a promise of solutions soon.

I'm absolutely happy that I could contribute a bit to the well-being of society. Congratulations to you for this wonderful initiative. This time I had a sense of relief that the blood donated by me was used for a good cause.

Thank you for the opportunity.

-Prashanth Chiplunkar

Glad to have started donating blood with Sankalp. I am not scared now :)

-Pulkit Lal

The safest blood - No blood!

Let's share a scenario. A person is anemic with a Hb of 9 gm/dl and brought in for a surgical procedure. The doctors agree that the chances of bleeding are low and yet to be on a safer side they request for a unit of blood to be kept ready. They proceed with the surgery and fortunately the patient did not need any blood. Now, the patient is brought back to recover and doctor comes to see the patient during rounds. The doctor is informed that there is still a unit of blood crossmatched for this patient available - which if unused will need to be discarded. The doctor has two options at this point in time:

- 1) Since the patient is surely anemic, the doctor orders for the blood unit to be transfused. Why waste the precious unit of blood?
- 2) The doctor refuses to transfuse and emphasizes that unless absolutely unavoidable the patient must not be transfused.

Pause and think what would you choose?

More often than not, the first choice is made. Many people transfuse patients preemptively. While wastage of blood is a big issue in itself, the immunological impact of a blood transfusion on a recipient is underestimated and not widely appreciated.

Whenever a person receives any tissue from a foreign source, the body develops antibodies to the antigens of the donor. On receiving blood for the first time, since there are no pre-existing antibodies, there is no immediate complication. But, should the person need blood products in future or if the person is a potential

3Rs for Rational Blood Use



REDUCE

Using alternatives like erythropoietin, volume expanders and assurance of getting a unit donated in a short while, the demand for rare blood units to be donated is reduced. Proper advance planning with hemoglobin corrector and use of advance surgical techniques also enables reducing the amount of blood needed.



REUSE

Intra-operative cell salvage is a technique which allows purifying the blood which is collected during surgical procedures and transfuse that back to the patient. Also keeping blood units on a standby, ready for issue to a patient never to be taken back can help use the same unit to cover multiple patients.



RECYCLE

For planned surgeries it is recommended for the patient to donate blood for themselves - autologous donation. It is also possible to collect the blood lost during surgery and process it to be transfused back to the patient. Minimum exposure to other person's blood is best.

donor or recipient of hematopoietic stem cell or solid organ transplantation in future, there is a risk of having ready antibodies against the donor's tissue which can cause complications ranging from destruction of donor tissues, rejection of the transplanted tissue and consequently even death. A seemingly harmless transfusion received years back has the potential to wreak havoc in the person's life.

As science has progressed, and our ability to connect the dots has increased, it is very evident that no allogeneic transfusion is safe. Each transfusion from an unknown person is associated with risks ranging

from the risk of acquiring infections to complications associated with the immune system. As we make progress in blood transfusion medicine, there is significant progress on both arms - the one which seeks to make transfusions safer and the one which seeks to reduce the need for allogenic blood transfusions (blood transfusions from donor's blood). The sheer complexity involved in reducing the risk of complications from allogenic blood and the associated costs all point towards the need for greater adoption of relatively simpler strategies to minimise transfusions.

For a while it was believed that filtering blood products before transfusion can protect the recipient from getting antibodies (allo-immunisation). However randomised controlled trials done with cardiac surgery patients, those who are potential candidates for renal transplants and surgery patients have shown the futility of using expensive blood filtration techniques. At the same time, the debate around the cost-benefit of using techniques like nucleic acid amplification test to reduce the risk of exposure to infections continues to rage.

There are several centres which do elective surgeries like cardiac surgeries which have started routinely using several rounds of autologous blood collection. Infact patients who receive these "bloodless" surgeries tend to recover faster and have smaller hospitalisation duration. Autologous blood collection is nothing but the person giving blood at an interval of 1 weeks upto 4 weeks before their surgery for the same blood to be transfused back when needed. Supplementation given both through injections, syrups and tablets ensure that the patient recovers both quantitatively and qualitatively even after donating blood quickly before the surgery. All units can

be transfused safely at the time of surgery, thereby reducing, if not eliminating, the need for blood from other donors. Several patients like those who are undergoing hemodialysis has switched to growth factors like erythropoietin rather than get blood transfusions. These synthetically manufactured growth factors contribute to rapid production of red cells by the donor's own marrow. Even simple techniques like fighting anemia in the general population by iron fortification and supplementation may drastically reduce the need to transfuse blood.

The safest strategy is to try and avoid use of donor's blood as far as possible. While it is becoming clear that eventually the awareness around harm done to the patients with blood transfusions will increase and the health systems will employ means to minimise allogenic blood transfusions as a standard practice, until that happens, patients must also start asking their doctors if there is a way to avoid blood transfusions.

For the society in general there is another major advantage of minimising allogenic blood use. Medical advancements and increase in access of care have lead to the steady increase in demand for allogenic blood. With number of patients on unavoidable chronic blood transfusion therapy (like those suffering from thalassemia) steadily increasing, rationalising and minimising the use of blood will ensure that adequate supply of blood continues to be available for all patients. Not to forget the huge cost saving which will result from the fewer infections and complications associated with minimising blood use.

The rule of thumb is - "Safest Blood Transfusion is No Blood Transfusion".

Traveling 2000 km every month for 6 years - Gowtham's families journey of cure



This is a story of a boy who is 14 year old and very smart. He belongs to a very small village of Bihar.

Vrijabihari and Pushpa were married to each other and from their marriage they had 4 children. Vrijabihari was working in a small factory as helper and with his little earnings he used to take care of entire family. Both Vrijabihari and Pushpa were uneducated and their livelihood was not that stable. The family lives in a small but kind of house which has no extra facilities like proper electricity and water. Vrijabihari due to some personal issues could not continue to work in the factory and he started farming.

After 3 months of Gowtham's birth he suddenly turned unwell and parents took him to a small clinic nearby and for about 2 months he was treated there. His diagnosis was unidentified their and Gowtham's father

spent 20,000 for no reasons. Then an auto driver in Bangalore who knew this family asked them to come down Bangalore and suggested them to visit Indira Gandhi Hospital. Gowtham's father took him to Indira Gandhi Hospital and he was suspected Thalassemic by Doctor there, his samples were drawn to investigate and the reports confirmed that he was Thalassemia Major. Then the father was first sent to Day Care Centre for Thalassemia in the hospital which is managed by Sankalp.

Initially father was counselled by day care coordinator that Gowtham will have to receive blood 15 days once for which every time they should travel from Bihar to Bangalore. Gowtham's father was first in a shock later he agreed to come. Till 2016 father used to get Gowtham for transfusion in every 15 days once without fail. Attempts were made to try and get him

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

- Robert Frost



transfused in Kolkata and Durgapur but the family preferred to come to Bangalore.

In-between his entire family was called for general counselling towards cure of the disease and suggested HLA Typing test, all family members had come and the samples were collected. The family had good news few months later that Gowtham has fully matched Donor and the Donor was his younger sibling Evraj.

Gowtham was transferred to Samraksha another Day Care managed by Sankalp which involves preparing the children for transplant. At the same time only Gowtham and his father shifted to Bangalore. He was a high risk candidate as he had huge spleen and liver with Iron overload so aggressive medication was mandatory to prepare him medically good to go for transplant and it took a little time.

Mean while father was counselled in brief on risks and benefits of having transplant and was also told about the cost. The father was keen on Transplant but after shifting to Bangalore he joined as helper at tailor shop and earned only Rs. 6000 per month in which he had to take care of Gowtham and the other family members. He said NO to transplant only because of finances but

Sankalp team motivated him and also verified his financial status and took initiative to help the family. They helped the family by fund raising and for this they had to approach many of them and somehow managed to collect the required amount. The other side medical team worked really well to make him medically eligible. Gowtham was then proposed for transplant and the transplant team still considered him as a risky candidate. But the team decided to take him up for the transplant and we'll plan his treatment. He was taken up for transplant and his transplant went well.

As he was a high risk patient the team expected little complications after the transplant but there were no such major complications apart from some minor issues. The nursing team and transplant physician were happy. One more beautiful change that happened is bringing in a play therapist exclusively for these children when they are inside the unit for days to just make their mind set stable and keep them happy.

Gowtham was very happy attending sessions on various activities done like drawing, sketching and puzzle building.

His counts engrafted sooner than later and the entire Sankalp team is happy for his transplant. Family is thankful to the entire team of Sankalp and happy now for Gowtham.

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.

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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

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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 propogate the message of blood donation

Volunteer in our blood donation camps

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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

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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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