



Completing 100 transplants at Ahmedabad

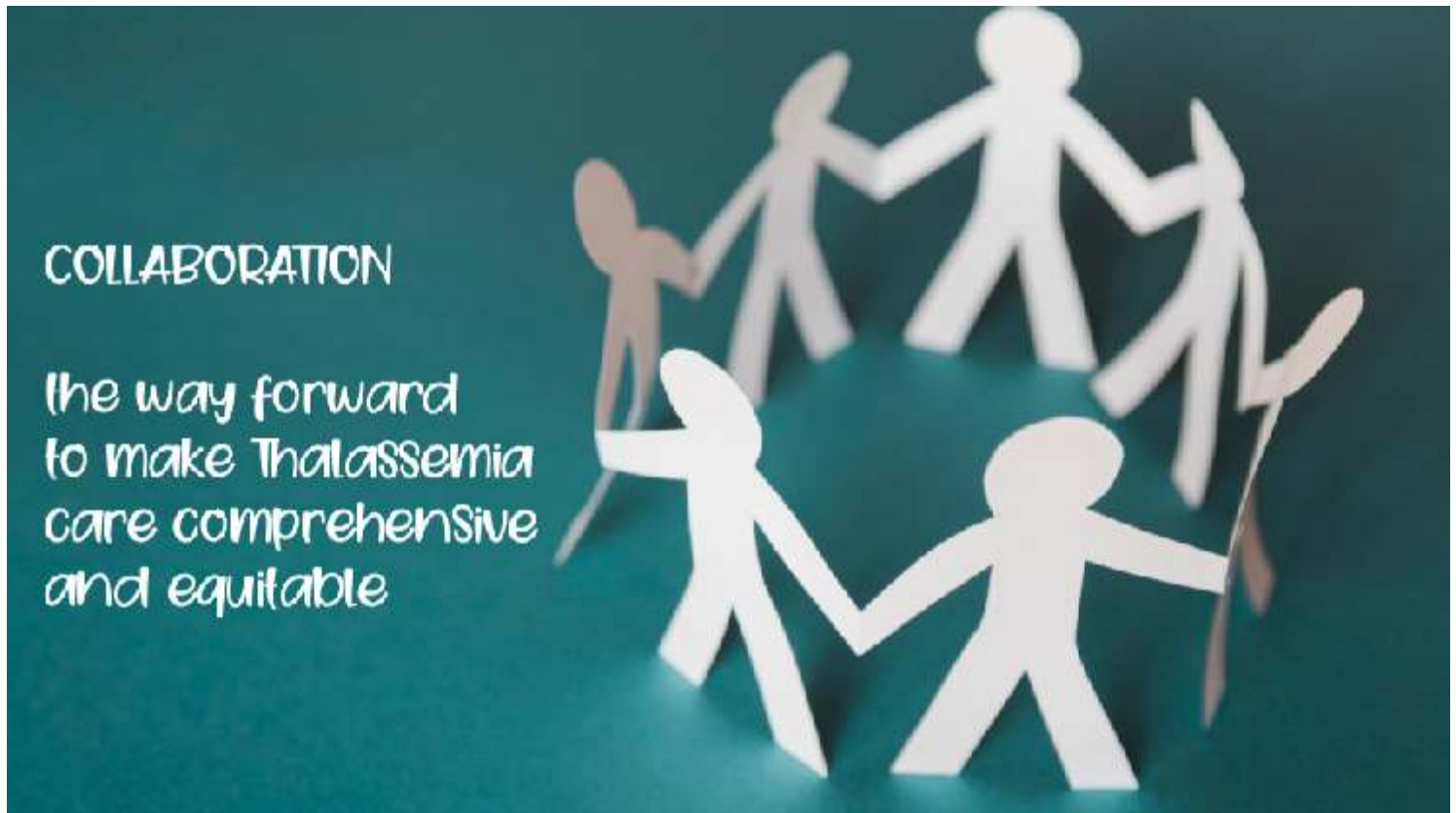
With about 3 transplants a month, Sankalp-CIMS Centre for Pediatric BMT has achieved the milestone of 100 bone marrow transplants within 3 years of the program being started with a few more months to spare. The milestone holds greater significance considering the excellent outcomes at the centre in both matched related and now haploidentical transplants.

This centre was unique in the sense that the transplant centre came first, followed by the network of day care centres. The organisation already had a large number

of HLA matched patients waiting to be transplanted with Sankalp's program prior to the finalisation of the program at Ahmedabad. Since then the transplant program has not only brought in a reliable option of cure for the kids in Western and even Central and Northern parts of the country, but also helped strengthen care and management of thalassemia.

We congratulate all the donors, families, team members and everyone else who has made this possible.

Power of Collaboration - A Thalassemia Care Centre is Revived



3 months ago, we received a call from one of the day care centres where we had teamed up with a blood bank to provide systematic and holistic care. While on one side were 2 people from Sankalp, on the other side there was the entire thalassemia day care team, some patients and their parents and staff from the blood bank. The intention of the sudden call – to thank Sankalp for joining hands with the team. Each one of them said that the collaboration has only yielded good. While the day care staff mentioned how procedural things have become, the patients and their mothers were filled with joy that their children are getting healthier.

The entire team narrated that earlier it was unbelievably difficult to maintain a pre transfusion Hb of 9 gm/dL or above. Even if a few of them did, it was

mainly thanks to the compliance and alertness of the families themselves. Now, with ThalCare, a very large percentage of the patients maintain this level. What makes the case more interesting is the fact that the day care has 84% or more patients who are above the age of 15 years. Another parent went on to comment upon the reduction in time during the visit. The 'day care' was essentially now able to deliver care in a day – be it transfusions, lab investigations, counselling, chelation. The management team of the blood bank and day care seemed elated that the goals with which the daycare was setup are being realized.

Although the daycare was formed sometime back, the team did not have the knowhow and methodology to manage the specifics well. The collaboration with Sankalp helped them get that in place. Being situated

in the financial capital of the city, there was no dearth of either patients or resources. Of late, many individuals and groups known to Sankalp have expressed awe at the turnaround of the situation there. One senior member working in the city mentioned that despite years of efforts it never looked like this daycare is a place for systematic care and that with the new collaboration things have turned on its head in a few months.

For the 2 people on call from Sankalp, this felt like

another small step in the right direction. With local resources, safe blood and the technology, knowhow and systematic framework available with Sankalp, regular systematic management of thalassemia and related hemoglobin disorders is today a reality. Every couple of months there is a new request to collaborate in a new city. 5 years ago, Sankalp dreamt of 20 thalassemia day cares in the country all working with the same principles. Nature seems to be leading us there!

Bill to increase current gestational age for Medical Termination of Pregnancy to 24 weeks approved



29 Jan 2019 Press Information Bureau - Government of India: The Union Cabinet has approved the Medical Termination of Pregnancy (Amendment) Bill, 2020 to amend the Medical Termination of Pregnancy Act, 1971. The amendment has increased the current limit of 16 weeks for termination of pregnancy to 24 weeks of gestation. The bill also proposes not to have an upper gestation limit in cases of substantial foetal abnormalities diagnosed by Medical Board. The composition, functions and other details of Medical Board are to be prescribed subsequently in Rules under the Act. The bill will be presented in the upcoming session of the Parliament.

Although it is possible to screen the foetus for blood disorders like thalassemia, a major challenge has been the identification and screening of at risk pregnancies in time. Screening on time gives the family the choice to have affected foetus terminated. Many families report new pregnancies only after the first trimester. The

sample from the foetus is taken by experts predominantly in major cities (Chorionic villus sampling). The report then take a few weeks to come back. In Sankalp India Foundation's experience, there were cases where the reports came back after legal allowed time for termination of pregnancy was over. This bill brings a huge relief in that context.

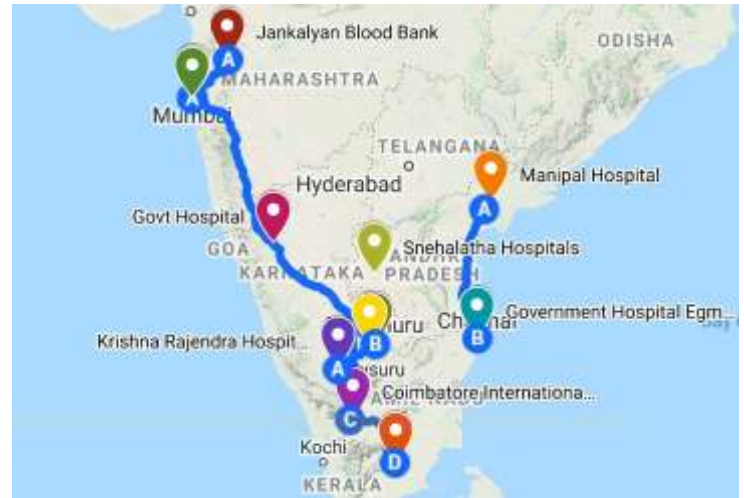
In India, we continue to see an estimated 12,000 new births with thalassemia each year. Prevention is the most meaningful response to inherited blood disorders. Sankalp India Foundation with all its partner organisations firmly believes that universal screening of pregnancies for blood disorders must be enforced - in order to achieve a Thalassemia Free India. In that context, this proposed bill will give a longer window of opportunity to screen the pregnancies and provide longer window to the family to make informed choice.

15 days, 6 requests, 4 transfers: Examples to emulate for rational use and power of collaboration

We share the story of 6 blood requests which were handled between 17th Jan and 2nd Feb 2020 by Sankalp's Emergency Team.

17 Jan 2020 Rational blood use averts unnecessary donation for delivery in Bangalore: We received a request for Bombay blood type for a pregnant lady due to deliver at Rajarajeshwari Hospital, Bangalore. She had a hemoglobin of 12gm/dl. In spite of healthy Hb count, the treating doctors insisted on having one unit ready on the shelf considering the rare blood type. One unit was available in K R Hospital, Mysore which we recommended to be transferred (blood bank to blood bank transfer). The treating doctors instead advised the family to shift the lady to KR hospital. The family did not agree to transferring to Mysore. Fortunately, the family was acquainted with a known specialist who spoke to our team. The specialist confirmed that with the hemoglobin on 12 gm/dl the chances of needing the transfusion are remote. The family is now all set for delivery together with the medical team and for now no one is insisting on the unit being made available on the shelf.

17 Jan 2020 Teamwork and planning avert needless donation in Ananthpur : Bombay blood type was requested from Snehalatha hospital, Ananthpur for a lady with gynaecological complications with a hemoglobin of 5 gm/dl. The doctors informed that they anticipated getting one unit from Ananthpur and one more donor may be coming in to donate. We requested the team to keep the donor on hold unless the situation was very critical and instead transfer the unit from Guntur. They transfused one unit and thankfully kept



the donor on hold. The patient improved and neither more donation nor blood transfer was needed.

21 Jan 2020 Blood unit from Guntur transferred as backup for delivery in Chennai: A pregnant lady, due for delivery, admitted in Egmore Hospital - Chennai was detected with Bombay Blood type and a low hemoglobin. The treating doctors insist on having a blood unit on the shelf. Meanwhile Platelets donors club Chennai also came across the request and with their local support things became more manageable. It was a requirement to be "on a safer side" and hence we suggested that the ready unit on shelf in Guntur which was collected on 5th Jan 2020 be transferred (blood bank to blood bank transfer). Platelets club Chennai could locate a person traveling from Guntur who helped transfer the unit from Manipal Hospital Guntur to Egmore Hospital Blood Bank. The lady was not transfused and had a safe delivery. NOW the unit is reserved for a kid who is being treated in the same hospital with a hemoglobin less than 5 gm/dl.

22 Jan 2020 Unit from Mysore and Mumbai come in for

surgery in Bangalore: A request for Bombay blood type was made from St John's Hospital Bangalore for a patient who was due to undergo amputation with a hemoglobin of 10 gm/dl. We recommended that the available unit from K R Hospital Mysore be transferred. For some time there was some confusion over whether the medical team would accept a unit from K R Hospital Mysore. On 29th Jan 2020, the unit was collected to be used for this patient and the surgery happened. Post-surgery, one more unit was requested for which we recommended that a unit which is available in Mumbai be transferred in. On 2nd Feb 2020, the unit was also transferred from Sion Hospital Blood Bank – Mumbai, with the help of Team Sankalp – Mumbai and Think Foundation.

23 Jan 2020 Unit donated even though another one was available on the shelves: We received a request for a Bombay blood type from District Hospital Dharwad for a patient who was bleeding with a hemoglobin of 5.5 gm/dl. A unit which was available at Janakalyan Blood Bank, Nasik was recommended to be used for this patient. The medical team sought some time to confirm that they were willing to accept the transferred unit. After our discussion the medical team became unresponsive. They were apprehensive about the transferring blood unit. Later we realized that they found a donor from Gadag who donated. Patient has received the transfusion and is said to need no more units.

26 Jan 2020 Unit from Nasik makes its way to Madurai: We received a request for multiple units of Bombay blood type for a patient being treated at Velammal Medical College Madurai. The patient was reported to have a hemoglobin of 4.5 gm/dl through Platelets donors club - Chennai. At the same time, we had 2 requests for Bombay blood type for 2 patients in

Bangalore with one unit available on the shelf in Mysore. There was another patient in Coimbatore who requested for at least 2 units. Family was screened and there were no donors found. At the same time there were units reported from Mumbai and Nasik on shelf. One unit was donated locally. Decision was taken to transfer the unit available with Janakalyan Blood Bank - Nasik with interim help of Samarpan Blood Bank - Mumbai to maintain the cold chain. It helped since we had Sankalp associates on ground in both the cities. There were logistics issues in using air connectivity to Madurai and hence the unit was shipped to Coimbatore on 30 Jan 2020 where a volunteer of Platelets club collected it and transferred to Madurai with reinforced cold chain.

While these requests were being addressed there were 3 other requests which came in with partial information and no clear contact points, which we could not do much about. Gradually improving networking for rare blood types has vastly improved the collective ability to ensure right blood is available to the right patient irrespective of the regional limitations and challenges. The direction of work we have chosen is to rationalising blood use and collaborate and this seems to be paying rich dividends.

Structurally within team Sankalp we are happy that now we have multiple fully acquainted people specializing in managing rare blood type requests. This enhances our capability to ensure timely and appropriate steps are taken for each request.

We would like to thank all the involved blood banks, medical teams, patient families, logistics providers, Platelets Club Chennai and Sankalp friends who worked together to let better sense prevail and continue to ensure rational use of rare blood types.

PERFORMANCE REPORT

Sankalp Program For Thalassemia Management

Centers	Total Patient (patients)	Number of units of blood transfused (units)	How many day old blood units were transfused (days)	Time taken to process blood components (hours)	Pro-transfusion Hemoglobin Median (g/dl)	Serum Ferritin (%)
			<7: Good 7-10: Average >10: Bad	<2: Good 2-3: Average >3: Bad	>9: Good 8-9: Average <8: Bad	<2000: Good 2000-3000: Average >3000: Bad
Indira Gandhi Institute of Child Health	245	367	▶ 4	▶ 4.0	▶ 9.6	▶ 1915
Project Samraksha	366	657	▶ 4	▶ 2.3	▶ 9.7	▶ 1958
KLE Belgaum	217	305	▶ 2	▶ 2.5	▶ 8.2	▶ 2764
Wenlock Mangalore	103	164	▶ 6	▶ 4.0	▶ 9.6	▶ 2930
TSCS of Central India, Nagpur	93	115	▶ 4	▶ 2.3	▶ 8.7	▶ 3557
RMMG Abu Road	32	56	▶ 5	▶ 0.5	▶ 9.3	▶ 3486
IRCS Rajkot	71	167	▶ 7	▶ 1.8	▶ 9.3	▶ 3041
Samarpan, Mumbai	123	445	▶ 18	▶ 3.8	▶ 10.4	▶ 4902
SJAST Ahmedabad	282	146	▶ 6	▶ 3.3	▶ 9.3	▶ 3511
IRCS Nellore	46	54	▶ 3	▶ 0.5	▶ 8.5	▶ 4513
IRCS Elluru	166	110	▶ 4	▶ 2.0	▶ 7.9	▶ 4307
HST Dehradun	102	27	▶ 9	▶ 2.0	▶ 7.9	▶ 1460
TOTAL	1846	2613	▶ 6.0	▶ 2.4	▶ 9.0	▶ 3195.3

Disha - The Blood Helpline

	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	816	72%	19%
2019-20	5180	64%	28%
2018-19	5256	84%	24%

Jan 2020



Sankalp Program For Thalassemia Cure

	Total Transplants Done	Overall Survival	Disease Free Survival
People Tree, Bangalore	165	87%	74%
CIMS, Ahmedabad	104	98%	96%
Other Centres	11	91%	82%
Total	280	92%	82%

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 month	19	1331	1106	3.9%	16.9%
2019-20	201	16295	13582	3.8%	16.6%
2018-19	216	17627	14869	3.5%	15.6%

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

ACI
Aegis
AIG
Applied
Aratt

Cargill
Disha Central Park
Faurecia
Icon
Jawahar Lal Nehru Centre For Advanced
Scientific Research

National Center For Biological Sciences
National Instruments
Sriram Samruddhi Apartments
Volunteers for a Cause
VR Mall

BMT Annual follow up meet on 28th January 2020

We at Sankalp believe in permanent cure for all our patients irrespective of their financial condition. As a part of this process, we have been calling in our patients who underwent Bone Marrow Transplantation since 2015 for their annual checkup.

The first Annual follow up meet of 2020 was held on 28th January 2020 at People Tree Hospital. It was a great joy to see the children completely recovered and leading a normal life post their BMT. We had patients who had come from different locations like Kodagu, Madurai and Telegana with different backgrounds and stories to share.

Sukrana and her Farzana both had Thalassemia. Family moved from Bihar to Bangalore for the medical treatment 5 years ago. With the help and support from various quarters, transplant for both the siblings was successful. Today both the siblings are healthy and going to school like other children. The elder sibling is in 10th and the younger one is in 8th standard. The family is happy that they made the decision to move to Bangalore.

Harshith Kumar had undergone BMT twice in 2016. First time his father was a donor but due to some medical complication it was rejected and the second time his Sister was donor and it was successful and today he is healthy. There is no end to the joy of his parents' when they see him healthy and active.

Dhanush and Vamshi are from Kodagu, both the siblings had Thalassemia. Dhanush is the younger



sibling had HLA fully match with his sister and accordingly his BMT was done in 2016. But Vamshi did not have HLA match and hence he is still undergoing blood transfusion every month. Parents are satisfied to see atleast one child is completely cured and healthy. In days to come, we are hoping to cure Vamshi through haplo-identical bone marrow transplant.

Vaishnavi comes from a very small village in Madurai where they don't have a proper toilet facility in their village. They are 3 siblings, Vaishnavi is the second child who had Thalassemia. Vaishnavi's father never supported her treatment but her mother was emotionally very strong and determined to cure her. She struggled alone, stayed in Bangalore and took care of Vaishnavi during her transplantation. Today she is so happy to see Vaishnavi's smile on her face. Seeing that she forgets all the troubles, the mental and the physical torture she underwent with her husband.

Families had a wonderful time sharing their stories and interacting with Dr. Stailin and Sankalp team.

"I'm a great believer in luck, and I find the harder I work, the more I have of it."

- Thomas Jefferson

Wishing Hruthik all the best for his Exams!

Balakrishna was earning his bread by working as an Electrician in Bangalore. He was married to Roopa in 2002 in a close family circle and they lived in a joint family. Within a year of marriage Roopa conceived and their whole family was happy to welcome the new member. But when Roopa went for her pregnancy check up the doctors advised her to abort the baby as the baby had some complications, the couple were very disappointed and went ahead as per the doctors advise.

After one year Roopa conceived again and was blessed with a boy baby (Hruthik) who was healthy. However, the child did not have a thumb finger in both the hands but this did not bother the parents. Later again they were blessed with a girl child who was Autistic. Despite these difficulties, the couple took care of their children quite well

Hruthik was healthy and going to school. At the time that he was 13 years he fell ill several times with fever and fatigue. On the advice of local doctors he was being managed with antibiotics. But the fever did not subside and he used to feel tired every day after school. The family was very concerned about his health and took him to the clinic close to their house. The doctor gave him IV fluids and sent him back home. Despite all these interventions the fever did not subside. It was then suspected that he has Dengue and was referred to Bangalore. He was admitted in the hospital and was being treated, but the platelets were dropping to very low levels. He used to undergo platelet transfusions every 3rd day for nearly 2 months.. Slowly he was recovering from what people believed was dengue. During this time he started bleeding from gums and

passing blood in the stools. The family was shocked to see this and again they rushed him to the hospital. The doctors advised the family to meet the Sankalp medical team.

The medical team investigated his case and found that he was suffering from Fanconi Anemia and he has to undergo Bone Marrow transplantation immediately. The family was shocked and did not know what it is and financially also they were finding it difficult to afford the treatment as they had already spent their savings on Hruthik's dengue treatment. We counseled the family and gave them the required emotional support and also gave them the hope for financial support. The family agreed for a HLA typing test and it was revealed that he had a partially matched donor - his father. The medical team explained the risks and benefits of Bone Marrow transplant to the family. The medical team in Bangalore transplant center took it as a challenge as he was 16 years old and hence a candidate with relatively higher risk.

The Sankalp medical team started the pre transplant treatment and once he was clinically ready the transplant was done. The transplant was successful with some medical complications but the doctors and the nursing team worked hard day and night to treat him. Hruthik was discharged from the hospital and moved to an apartment nearby. Currently he is in step down process and doing well. He is waiting to become alright and want to go back to school to complete his 10th standard and continue his studies. We at Sankalp wish him all the best for his exams and come out in bright colors.

The Red Bus Brings In a Cheer!

On Republic Day 2020, the residents of Disha Central Apartment, Varthur came forward to give life a better chance by organizing a blood donation camp. The camp was organized in association with Indian Red Cross Society. It was a novel experience for the community as well as SIF coordinator as mobile blood donation vehicle was brought in for the camp.

Blood Mobile is a bus equipped with 4 cots and all necessary instruments required to conduct a blood donation camp. The camp organizers just need to provide a parking space and can concentrate only on publicising and encouraging donors.

This makes it fast, easy and simple to organise a blood donation camp and camps can be organized at places with limited space or at places where not many donations are expected.

This camp generated a lot of excitement, especially for children. Lot of kids came to see the bus and learned about the importance of blood donation in the process! It was a successful event where 36 units were collected with donor turnout being 45. As we did a camp in blood mobile after a gap of 6 years, it also provided us an opportunity to get better insights on blood mobile camps.

The biggest challenge for the vehicle was narrow roads and it was got stuck on the way when it could not pass a narrow railway under bridge. This caused an hour's delay in the start of camp. But camp organizers were very supportive, and donors waited with patience.



With a rate of 12 donations per hours, we were able to quickly finish the camp within stipulated time.

We hope that this is a new beginning in the RK chapter of Sankalp. We are looking forward to organizing many more such camps. Our target would be to plan blood mobile at apartment complexes, malls, tech parks in the coming months. Access to blood mobile has opened up a lot of possibilities for organizing camps at different avenues.

"Be as simple as you can be; you will be astonished to see how uncomplicated and happy your life can become."

- Paramahansa Yogananda

When Thalassemias turned out to be Sickie Thals!



One of the goals for 2019 across our day care centres was to retrieve the initial diagnosis documents for the kids receiving treatment. Often the documentation is missing or is incomplete, in which case we resolved to take a step-wise approach to be sure of the diagnosis. Once the transfusions begin the blood sample of the patient is mixed with the blood donor's blood. Hence as the first step the parents are tested to determine if the haemoglobin electrophoresis test shows that they are carriers of the disease which the child seems to have inherited.

A cluster of surprise came up at one of our centres where 3 patients who were being treated as thalassemia majors turned out to be sickle beta thalassemia patients. These kids have one parent who is a carrier of thalassemia and the other who is a carrier of sickle cell disease. The child inherits the defective gene from both the parents and consequently has symptoms of the disease.

The peculiarity with patients who are sickle beta –

thalassemia patients is that they tend to behave more like sickle cell disease patients. In our experience, we have all the patients who are diagnosed with sickle cell disease or who have a situation similar to these 3 patients become completely transfusion independent when given proper treatment. The treatment involves giving an inexpensive once daily tablet named hydroxyurea in the right dose and with proper monitoring. In effect, with this corrective exercise we identified that 3 kids were needlessly being transfused as they could have done well only on hydroxyurea tablets had the diagnosis been right.

The detection of these three patients with a condition which is far more manageable than their current diagnosis is a further motivator for the team to invest and work upon establishing the diagnosis. Genetic diagnosis is the most reliable technique but it comes at a huge cost. We are closely working with like minded folks from molecular laboratories to rationalise the costs.

Credits: This cover has been designed using Freepik.com

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

From:

Call: 9480044444 | Visit: www.sankalpindia.net

Mail: contact@sankalpindia.net

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

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

To: