

संकल्प पत्रिका

A monthly newsletter by Sankalp India Foundation
Volume 7 | Issue 06 | June 2017



Sankalp celebrates 14th Anniversary





As we stepped into our 15th year, we felt the need to commemorate the event with a small celebration to share the joy with the people involved with Sankalp in different capacities. The event was organized on the afternoon of 20th May 2017 at People Tree Hospital, Bangalore. In the morning the members of the executive committee of Sankalp met the members of the advisory board to chalk out the broad work strategies for the next year.

The event in the afternoon was attended by friends, well wishers, partner organisations. Lalith Parmar, President Sankalp India Foundation presented the annual report highlighting the work done and progress made by all teams. The audience was keen to see the numbers and excited to know that each project had reached greater milestones. Mr S V Iyer, member of the advisory board spoke about the immediate and pressing need for effective screening of pregnant ladies to prevent birth of more thalassemics. He urged regulatory authorities and the medical fraternity to take up thalassemia prevention at a massive scale.

Robert Bosch, Rambus, Qualcomm and National Instruments - the 4 corporate organisations who have

supported Sankalp with several blood donation drives were thanked and honored for their generous support. These organisations stand testimony to the fact that voluntary blood donation movement has really been well adopted by the general public.

ed and honored for their generous support. These organisations stand testimony to the fact that voluntary blood donation movement has really been well adopted by the general public.

A booklet on thalassemia cure - authored by Dr Lawrence Faulkner was released. This booklet is a one point reference to understand the world of low cost yet fully quality conscious bone marrow transplants for thalassemia. Copies of this booklet were handed over to several people.

The online version of the booklet is available at www.sankalpindia.net/cureguide

"We must believe that we are gifted for something, and that this thing, at whatever cost, must be attained."

Marie Curie

The progress made in technology, scientific research and publications are all proud achievements of Sankalp. Rajat Kumar Agarwal presented details of this progress to an engrossed audience. Many people later expressed satisfaction about the fact that Sankalp is also contributing learnings back to the medical community. Mr Vinod, CFO of Jai Shiv Shakti Health and

Education Trust, the organisation that has been a pillar of support to the thalassemia activities of Sankalp shared his views on working with the organisation.

Finally as the National Anthem was being sung, there was glitter in everyone's eyes. The room was filled with the energies of people who dream of a better India. For

Meeting of the Advisory Board



On 21st May 2017 we also had the annual meeting of Sankalp's advisory board. Mrs Jasmine Majethia, Dr Lawrence Faulkner, Dr Shankar, Mr S V Iyer, Mr J M Maheswariji and Mr Yogeshbhai Lakhani (special invitee) attended the meeting beside the board members of Sankalp.

The meeting started with the presentation of the performance of the organisation in the last financial year. The board expressed satisfaction on the work

done last year.

This was followed by the review of the discussion done in the last advisory board meeting. There was vibrant discussion on several challenges. This was followed by the discussion on few key topics on which the Sankalp board requested for advice for the year to come. The advisory board brings in a huge amount of multi-disciplinary expertise and experience which has been the guiding light for the Team Sankalp.

Stop the harassment in the name of Replacement Blood by Hospitals - Petition on CHANGE.ORG



This **World Blood Donor Day**

let us

#StopReplacement



Sign petition on change.org

This World Blood Donor Day - 2017, let us take steps to Stop Replacement

On this World Blood Donor Day, we need to take a stand to protect voluntary blood donation from a massive threat posed by the brazen and rampant demand for replacement of blood units by hospital based blood banks.

The reason why numerous blood donors donate blood is because they believe that the units they donate will

be available to any and every needy patients without any discrimination or barrier. The message that many hospitals will not accept blood which is readily available on the shelves, and yet continue to demand replacement is a serious deterrent for regular voluntary blood donors.

The family of the patients continue to suffer under the coercive demands of the hospitals that are treating their patient. They continue to be blackmailed and harassed into getting blood donors.

"You can have the nine greatest individual ballplayers in the world, but if they don't play together, the club won't be worth a dime."

Babe Ruth

The government has removed the known roadblocks as far as the law is concerned in order to ensure that every hospital based blood bank is able to participate in voluntary blood donation camps. This has paved the way for the implementation of the national blood policy which envisions that blood be sourced from voluntary non-remunerated blood donors without any coercion into action. Yet, majority of hospital based blood banks show no sign of moving from replacement to voluntary blood donation.


Blood donors are at loss to understand why their peers continue to suffer - looking for blood units even when the blood banks continue to tell them that they have enough stocks and are happy to provide blood to anyone. This is breaking the trust relationship between the donors and the blood banks.


Blood donated by voluntary non-remunerated blood donors is the safest. It is high time that the onus of organising blood products is shifted from the patient to the hospitals. Sufficient blood should be collected, tested and be kept ready well in advance. The family of the patient should not be involved in the process of organizing for blood. This is the case in most countries which have a well established blood donation program. The Government must intervene to stop the practice of blood banks asking the patient's family to bring in blood donors.


The fact that voluntary blood donation has shown steady rise across the country is testimony to the commitment of the common man's willingness to participate in ensuring there is enough safe and sustainable supply of blood. Majority of hospital based blood banks do not put effort to participate in voluntary blood donation camps and at the same time they do not accept blood units donated by voluntary blood

donors from other blood banks. The demand for replacement blood units is making it impossible for large number of patients to receive blood from truly voluntary non-remunerated blood donors, and thus the voluntary blood donation movement is being suppressed from being able to ensure blood for all.

20 years after the reforms for blood donations were set in motion by the Supreme Court of the country and only 2.5 years are left to achieve the national and global goal for 100% voluntary blood donation by the year 2020 across the country. It is high time that the regulatory bodies take note of the real issues threatening to derail the vision 2020 and take the following steps to systematically eliminate replacement blood collection.

 Each hospital must be made to publicly disclose the collection of blood from truly voluntary blood donors versus blood donors who have been forced to donate because the hospital asked the family to organise donors (whatever name the hospitals choose to give to cover up this grave malpractice).

 Each blood bank must be asked to share a plan on how they are going to move from their current level of replacement donation to zero replacement in a time bound manner and the reporting of this should be integrated with the existing systems of monitoring blood banking.

 There should be clear messaging from National Blood Transfusion Council and other regulatory bodies strongly condemning, discouraging and wherever possible legally limiting the process of replacement blood donation.

If the government fails to offer protection to patients and allow unrestricted exploitation of the patients - it will cause serious and irreversible damage to the voluntary blood donation movement.

Celebration of International World Thalassemia Day

Sankalp India Foundation dedicated 8th of May to commemorate both the thalassemia patients who are no longer with us but are always close in our heart and to celebrate with all those patients who are alive and fighting everyday for their right to a better quality of life.

India, considered to be the capital of thalassemia, sees around 10,000 children born with the condition every year. However, the disease is still overlooked when we talk about the burden of the disease in the country. Many of these die before the age of 20 due to poverty and lack of treatment. Unfortunately, there is no prevention and control programme at the national level.

Cathay Pacific had partnered with us to give the kids of our Thalassemia day care center a day of Joy and Hope. There were 16 kids who had spent a wonderful day at Flight4 Fantasy, Forum Mall, Koramangla, experiencing flight simulation. Flying a plane is one of the most desired, but unfulfilled dream that most have. Flight 4 Fantasy is the only flight stimulation center in India, providing an experience of virtual flying to non-pilots.

The kids had a joyous flight in the Boeing 737-Commercial Jet, Fighter Jet-Military and Cessna-



General Aviation. Certificates and goodies were also given to them. The kids were delighted when they started flying along with the pilots. The kids were excited to put on the 3D glasses and fly the fighter jet, which was the most attractive of all, with accentuated pitch and roll movement, to provide an unmatched fun filled time. They were challenging each other for an aerial combat too with missiles!

Taj Sats Air Catering limited had provided food packets to the kids with lots of chocolates to relish on. The kids had a gala time roaming around in the mall with their parents. We would like to take the opportunity to thank Cathay Pacific to give these kids wings to fly.

These kids come regularly to our day care centers for Blood transfusion. It was amazing to see them so vibrant and full of life!

"Perseverance is not a long race; it is many short races one after another."













Walter Elliott

Thank you blood donors for a fantastic May 2017



PERFORMANCE REPORT

Sankalp Program For Thalassemia Management

Centers	Total Patient Visits (patients)	Number of units of blood transfused (units)	How many day old blood units were transfused (days)	Time taken to process blood components (hours)	Pre-transfusion Hemoglobin (g/dl)	Share of blood units from attached blood bank (%)
			<7: Good 7-10: Average >10: Bad	<2: Good 2-3: Average >3: Bad	>9: Good 8-9: Average <8: Bad	>95%: Good 90-95%: Average <90%: Bad
Indira Gandhi Institute of Child Health	322	415	 6	 2.0	 8.7	 97%
Project Samraksha	396	451	 3	 3.0	 9.3	 100%
KLE Belgaum	243	238	 3	 2.3	 9.0	 100%

Sankalp Program For Thalassemia Cure

	Total HLA typings	Total number of children offered Bone Marrow Transplantation	Total number of children cured of Thalassemia by Bone Marrow Transplantation
This year	910	11	11
Total	2742	62	52

Bombay blood group network

	Total bombay blood group requests	Number of units organised off the shelf	Number of units donated
Last month	11	3	1
This year (cumulative)	24	7	5
Last year	71	18	21

May 2017



Rakta Kranti - The Blood Revolution

	Blood Donation Camps	Total Donors	Total Units Collected	Rate of Post Donation Complications	Rate of Donor Deferral
				<2%: Good 2-4%: Average >4%: Bad	<10%: Good 10-15%: Average >15%: Bad
This month	20	1999	1833	2.9%	15.4%
This year	37	3218	2936	3.1%	15.4%

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

Aegis
Alcon
Bosch
Deutsche Bank
ECI
Envoy

General Motors
Grant Thornton
Icon
Mathworks
Microsoft
Novo Nordisk

Rambus
Star Bazaar
Sutherland
Xerox

Disha Statewide Blood Helpline - 9480044444

	Total Blood requests on the statewide help-line	% of blood requests satisfied by existing blood bank stocks	% of blood requests from outside Bangalore
Last month	692	90%	23%
This year (cumulative)	1090	89%	27%
Last year	6348	84%	27%

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

Karnataka Government announces support for Thalassemia and other hemoglobin disorders

Since last year Sankalp India Foundation had been requesting the Government of Karnataka to come up with a comprehensive policy for support for thalassemia.

The first major step in the direction of adequate support for patients suffering from thalassemia was taken in the form of a review meeting of State Blood Cell on 31st March 2017 where various stakeholders were invited to share their inputs for a

state-wide proposal. The secretary to the Government, Health and Family Welfare Department, Government of Karnataka, has issued two circulars - one for the setting up of day care centres for the treatment and care of hemoglobinopathies and the other one for compulsory and universal screening of pregnant women for hemoglobinopathies.



A simple blood test can help save your child from a lifetime of suffering!

"With confidence, you have won even before you have started."

Marcus Garvey

We congratulate the Government of Karnataka on taking these progressive steps. This is a very welcome departure from the situation where the state did not recognize hemoglobinopathies as an area of concern at all. While the circular shows the intent of the Government, the percolation of the message through the healthcare system and the laying out of a delivery mechanism is the current challenge at hand.

This circular also brings Karnataka a step closer to its neighboring states of Tamil Nadu, Maharashtra, Telangana and Andhra Pradesh beside several other states in the country who have comprehensive support for thalassemia care. Blood, the heart of the care for thalassemia continues to be a challenge and the need to have centres created around facilities which can ensure adequate supply of safe blood for these patients is paramount. Neighboring states have found much success in models where the state supports the patient population coming from families with income less than Rs 2,00,000 with cost of treatment often in public private partnership with organisations which have already been working for care and management of these children. Voluntary Health Services-Chennai, Thalassemia and Sickle Cell Society-Hyderabad and Comprehensive Thalassemia

Care Centre- Mumbai are examples of such models.

An important shift in policy is the focus on prevention. By mandating to screen all pregnant women in the state the Government has taken a huge step forward which comes with equal amount of challenges. Will the screening be restricted to those who get maternal screening done in public healthcare setup alone? Will the screening facility at the district level be well networked with the last mile sample collection and transportation teams? How effective will the further screening of the couples who are identified as carriers be? These are all questions which are to be answered. But with enough tracking mechanism in place and a strong will to drive in the change, this is doable especially with the very well invested upon network which has been created for care and management of pregnant women.

It's time that the various stakeholders work in tandem with each other towards two goals; ensure that the kids living with thalassemia get best option for care and management and ensure that we stop thalassemia and other hemoglobinopathies completely by way of effective prevention.

Did you know?

**Postpartum hemorrhage
(bleeding after child birth) is
a leading cause of maternal death?**

Can something be done?



"Once you become self-conscious, there is no end to it; once you start to doubt, there is no room for anything else."

Mignon McLaughlin

My experience working to keep the shelves full

By Soumi Datta

Blood and Blood products are needed 24 hrs a day, 365 days a year- for emergencies, surgeries, organ transplants, to treat burns, injuries, heart disease, thalassemia, sickle cell anemia and many other medical conditions. Transfusion is the only option for survival for many patients, but many patients do not have access to safe blood on the shelves when they need it the most. Blood Availability depends on the selfless and heroic act of people who donate blood- the most precious gift of life.

At Rakta Kranti, Sankalp has a very dedicated and self motivated team, which is constantly working hard to reach out to people and disseminate the knowledge and goodness of voluntary blood donation. There are three main areas of work for the team to focus on:

1. Getting donors

The team is responsible for ensuring that the maximum planned number of donors attend and donate blood. Depending upon what population segment is expected for the drive, as the publicity materials are made accordingly. For e.g. If the target is residential community, then it is best done on holidays. If the segment is educational institutions, then it has to be done keeping exam schedules in mind. Similarly, a camp for the office goers may be held on a working day at the work place to make it convenient for the donors. Once the team has decided on holding the camp, prospective donors need to be contacted and persuaded to come to the camp. A communication plan is designed accordingly. IEC Materials- Banners, Posters are displayed, Email blast- mailers are sent across, floor talks and open sessions are done to



motivate donors. It generally evokes better interest. SMS campaign has also become an integral part of the publicity campaign. After the camp, thank you note is sent across to the organizations. Well planned and organized drives with focus on quality is what we promise to the donors.

2. Working with our partners

The team of Rakta Kranti, interfaces with stakeholders like the blood banks, organization, authorities etc. The team needs to keep the blood bank updated with the time and venue that have been chosen. A list of requirements is sent across to the organization along with the material, staff list and vehicle no. by the team so that we have all the necessary clearance on the day of the drive to set up the camp.

3. Camp Management

The team has to reach an hour before the camp is scheduled to start. Along with the help of the partnering blood bank's resources, the Sankalp coordinators set up the various areas for:

✍ Registration

✍ Waiting

"Whatever can be done another day can be done today."

Michel de Montaigne



- ✎ Medical check up
- ✎ Donation
- ✎ Post donation area for refreshments

Site management coordinators need to guide the donors to feel them relaxed. They ensure that people do take rest and refreshments after donation. In case there are any complications, it is the prime duty of the coordinator to ensure that the donor is attended by the Medical officer who is present for the camp. The reaction is captured and followed up the next day or unless the donor has totally recovered.

"Rakta Kranti has always planned to organize Blood donation drives in the time of shortage, and does not focus on the days of national importance, when there are too

many drives happening across the city. This helps in better management of the supply of Blood."

Blood knows no caste, creed, color, race or religion. Rakta Kranti aims to meet the requirement of the precious drug of Blood by organizing voluntary blood donation drives, but with a strict quality control and very efficient and quality oriented Blood Banks.

As an individual I feel more responsible now! It is amazing to work with such a group of dedicated individuals whose tireless exertion, commitment and passionate concern is making difference in the lives of so many people.

* * *

A journey from the Dark to the Brightness



Rajnikant and Minakshi, living in a small village near Junagadh in Gujarat, were filled with joy when their first son was born. All the senior family members were also happy. They named him Ronak which meant grace, and by the grace of God he was their gift. Truly he brought "Ronak" in their family.

But after the first few months of his birth the "ronak" on Ronak's face gradually started disappearing. Both the parents started worrying as his health was getting bad. They began to wonder what was happening suddenly, why was their little boy looking so pale and dull? They took him to a nearby doctor in their town. Initially the doctor gave the child some iron supplements and tonic, but there was no improvement in his health. Later he suggested the family to go to Junagadh city and consult a hematologist.

In Junagadh, the hematologist examined the child and asked the family to get a HPLC test done and come back with a report. Unfortunately, the report confirmed what the doctor had feared. The report indicated that Ronak was suffering from a blood disease called thalassemia major. They were informed that this was a genetic blood disorder and now he would require blood transfusion at regular intervals all his life. They were also informed that the only way to be permanently cured from thalassemia is Bone Marrow Transplant which would be possible if there is a fully HLA matched donor. When all this was explained to the family and they were informed about the fact that the cost of BMT is INR 14,00,000, they lost all hope of his permanent cure and accepted all this as God's wish.

After few years Minakshi delivered a second child.

They named the child as Harshad, which meant "Joy Giver". After few months, they went to Junagadh and got his HPLC test done. Fortunately, he was not Thalassemia Major. However, he was a thalassemia carrier.

On the other side, thalassemia management through blood transfusions and chelation was on for Ronak on a routine basis. Although it was free, it was hard for the family to go and spend one entire day for blood transfusion once in every 25 to 30 days. Gradually as he grew up the periodicity decreased as it was very difficult to get blood every time. It was hard for Ronak to be pricked so often. But he accepted this as a part of his routine life and he had learnt to be happy.

In September 2016, the family found out that there is a HLA testing program by Sankalp India Foundation at a blood bank in Rajkot city. They registered their name to be tested and gave buccal swab samples of Ronak and Harshad. After few months, they got the news that Ronak and Harshad have a full HLA match. Harshad truly proved himself as 'Harshad'.

A Sankalp team member explained about the entire project of Bone Marrow Transplantation to the family which was about to be started in CIMS Hospital at Ahmedabad, under the title of Sankalp-CIMS Pediatric BMT Program. The program was on a Not for Profit basis and the cost of transplant was Rs. 900000. The team member also explained about the procedure of BMT to the patients. This meant nearly 3 months away

from home for the child and the parents.

Financially, it was impossible for them to imagine how they would manage even half the amount. Moreover, Ronak's grandparents were aged. His grandfather was partially paralyzed and grandmother was unable to do entire household work in the absence of Rajnikant and Minakshi. But thanks to Rajvi, the elder sister of Rajnikant, who though being married promised to manage the house in the absence of Minakshi.

After much struggle, Ronak's family could manage only for Rs. 50000 by seeking help from their friends, relatives and employers. When the Sankalp team realized that the family is poor and unable to manage the finances, they went to their donors like Cipla, Tata Trust, JSS and explained the financial condition about Ronak. Through the support from these institutions funds for Ronak were managed.

Finally, on 31 March 2017, Ronak was admitted to CIMS hospital, Ahmedabad. His treatment started and the staff realised that Ronak is a very active kid. All the activities for his time pass be it indoor games, TV, story books, sketch books and color boxes were available in the BMT unit. Ronak spent around a month and half in the unit. After completing the first stage of treatment at the unit, (which included conditioning and marrow transplantation) he was discharged and sent to the step-down facility for post-transplant management. Now he is on the path to complete recovery. Soon he will be sent home with a new life and hopes of a better future. We congratulate him for fighting the battle of thalassemia and getting a new lease of life. Our best wishes are with him for a healthy, happy and bright future.

Hi Sankalp!

Please get in touch for any of the following

Sankalp Emergency Team

- Seek assistance for arranging blood in extremely difficult situations
- Donate platelets voluntarily and help ensure platelets on shelf all the time.
- Learn about strategies and technologies for conservative and rational management of blood.

Bombay blood group network

- Register if you are a person with Bombay blood group
- Inform if you have Bombay blood group on your self
- Request if you need Bombay blood group

Statewide Blood Helpline

- Call 9480044444 when in need of blood anywhere in Karnataka

Rakta Kranti

- Organise blood donation camps
- Learn about organising safe and effective blood donation camps
- Form a Team Red - a team of volunteers who help propagate the message of blood donation
- Volunteer in our blood donation camps

Thalassemia Prevention

- Opt to get tested for thalassemia and other related hemoglobin disorders
- Organise a drive to get people around you tested
- Assistance for antenatal testing for parents who are at risk of getting a child with thalassemia

Thalassemia Management

- Support the treatment and management of a child suffering from thalassemia
- Refer a patient who is in need of help for thalassemia treatment at our centers
- Seek advice on management of thalassemia

Thalassemia Cure

- Refer a child suffering from thalassemia for free HLA typing
- Refer a child for Bone Marrow Transplant
- Donate towards Bone Marrow Transplant of a child
- Seek advice on options for cure for families with thalassemia

Contribute

- Make a donation - help us do more of what we do
- Volunteer - join us to make a difference!
- Share your experience and problems

From:

Call: 9480044444 | Visit: www.sankalpindia.net

Mail: contact@sankalpindia.net

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

To: