



## Sankalp celebrates it's 15th birthday with the completion of 100 Bone Marrow Transplants

23 May 2018, Mumbai

The 15th birthday of Sankalp coincided with an important milestone in our journey. 100+ Bone Marrow Transplants were completed in the 2

transplant centres managed by Sankalp at Bangalore and Ahmedabad. After 100+ transplants, the team had a success rate of 85% as disease free survival and 94% overall survival, which is comparable to or even better than some of the best transplant centres across the



world. The event was attended by primary financial contributors of Sankalp, esteemed individuals from the Department of Health - Government of Maharashtra, children and parents who have been through the transplant process.

The program was presided by distinguished chief guests Dr Nitin Shah from Heart Foundation and Ms. Mala Vazirani from Transasia Bio-Medicals. Presentation on the Sankalp's journey of cure, and the organisation's work in the management and prevention of thalassemia were made by Rakesh Dhanya, CEO of Sankalp India Foundation. Members of the clinical team of Sankalp headed by Dr Lawrence Faulkner took questions by the audience on different aspects related to transplants, the current and future trends and how it was possible to achieve the exemplary result over the last 3 years. Several questions on haplo-identical transplants, gene therapy were also answered by the team.

The highlight of the event was the felicitation ceremony. Teams from Tata Trusts, Cipla, Kalapatru Foundation, Didwania Charitable Trust, Jai Shivshakti Health and Educational Foundation, Amit Iyer Memorial Foundation, Ranka Charitable Trust, Bhanushali Seva Samaj, Mr. Bharat Bhai Shah, Ghelani Charitable Trust, and KARO Trust were felicitated for their outstanding contribution to the success of the program. The program ended on a joyous note with all the little children gathering around the clinical team who have overseen the transplant and posing for photographs.

*For us at Sankalp, the journey of cure has just begun and we hope to be able to partner with several like minded individuals and organisations to head in the vision of Thalassemia Free India.*

# BlueOcean Market Intelligence and Sankalp organize "A Walk For Thalassemia Prevention"



8th May 2018, Bangalore

It is estimated that about 3000 patients continue to live with thalassemia in Karnataka. Thalassemia patients depend upon blood transfusions every few weeks for their entire lifetime for survival. More thalassemiacs continue to be born in spite of the fact that this disorder is preventable by screening parents at antenatal stage.

In order to raise awareness about the issue, Blueocean Market Intelligence joined hands with Sankalp India Foundation to organize "A Walk for Thalassemia Prevention" on 8 May 2018. The 6 km walk which started at Blue Ocean's campus in Embassy Tech Village, Marathahalli at 11:30 AM covered the distance from there until the EcoSpace Skywalk, Panathur underpass and concluded with a tour of Embassy Tech Village. It attracted over 150 people including working professionals, children suffering from thalassemia, apart from members of both Sankalp and Blue Ocean.

Thalassemia is a genetic blood disorder passed down through families in which the body makes an abnormal form of hemoglobin, resulting in an excessively rapid rate of destruction of red blood cells, which leads to severe anemia. Treatment necessitates lifelong regular periodic blood transfusions, medications all through their lives, which are painful and a physical, psychological, and financial burden to both patients and their families. It is estimated that every year nearly 10,000-12,000 children are born with this disorder. This is in addition to the estimated 200,000 children already living with this condition. Raising awareness about the disease, screening, and its prevention is extremely important. It is estimated that nearly 4% of the Indian population is said to have a thalassemia trait. Perennial blood shortage, absence of public funding in healthcare, lifelong suffering to the children, parents and families truly make Thalassemia a grave national health challenge.

A Walkathon was organized to raise public awareness



about this disease, prevention measures and measures to avoid its transmission. The children along with their parents and the adults, who come to receive systematic care and treatment at the Thalassaemia day care centers of Sankalp India Foundation came with a new vigor and hope to participate in the Walkathon.

It was the first CSR Initiative from Blueocean Cares and it was a huge success! The participation from the employees were overwhelming and it was fantastic to note that despite the smoldering heat, the work pressure, people took time out to walk a distance of 4 kms to show that they care as individuals and collectively as an organization. Their enthusiasm and commitment to the cause is truly laudable.

## Thalassemia can be prevented

Thalassemia prevention is a possibility. It requires a simple blood test of expecting parents to confirm that they have a trait. Unfortunately this is not part of the

routine investigations planned by gynaecologists. If every woman is checked for this at the time of her first pregnancy and is found to have a trait, the partner also could be tested. If both of them have the trait, then antenatal diagnosis can be carried out to determine if the foetus is positive for thalassemia major. If yes, there is an opportunity at hand to prevent the birth of a child with thalassemia and avoid potential suffering for a lifetime for the family.

"When our family received the news that we are going to have a baby, we went to the gynaecologists and did all the tests that they asked us to. A few months after the birth of our baby girl we were told that she had thalassemia. If only the gynecologist had screened us for thalassemia during early stage, the suffering that we are going through could have been avoided" - Sameer, father of a thalassemic child.

## Government needs to do more

In several forums both the Government of India and

Government of Karnataka has spoken of the need to start a strong campaign for thalassemia prevention. Unfortunately, nothing much has happened. For example, In March 2017, Government of Karnataka had announced that universal screening for thalassemia would be done for pregnant mothers in the state. Even after a year, this announcement has not converted into action on ground. In order to remind the Government of the need to urgently start the screening for thalassemia, the team also created an online petition aimed to be submitted to the Ministry Of Health & Family Welfare, Government Of India and Government of Karnataka appealing for the decision on thalassemia screening to be included in the set of routine investigations planned during the first pregnancy of a lady to be enforced. The petition is accessible at <http://change.org/p/ministry-of-health-family-welfare-let-s-make-india-thalassemia-free>.

It took Sankalp 6 years to build 4 day care centres and streamline management in 3 different cities. While of-course the government machinery thanks to the availability of resources and manpower can change things quickly, it is clear that orders and mandates don't work. A thalassemia day care centre for every 200 km is ideal. In that sense, Karnataka needs only 6-8. The story is same for antenatal screening as well. Another government order at the same time – March 2017 mentioned that antenatal screening would be available in each district. The fact remains that even in Bangalore, the state capital, economically weak families have nowhere to go.

Perhaps it is time that the authorities relook at their decisions and track progress. Strengthening existing centres by empaneling them and providing support should be considered. While Sankalp has been trying to pitch for this at several forums, it often falls on deaf ears!



**A GRAVE  
PUBLIC HEALTH  
CHALLENGE  
IN INDIA**

**Thalassemia**

**STOP  
THALASSEMIA**

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

**AMIT  
IYER**  
MEMORIAL  
FOUNDATION

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Twinkle Star Complex,  
Ghatla Road, Chembur,  
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Email: [iyersvi@yahoo.co.in](mailto:iyersvi@yahoo.co.in)  
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**Sankalp India Foundation**

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BTM 2nd Stage, Bangalore 560 076.  
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A booklet addressing the issues around thalassemia prevention was released on World Thalassemia Day 2018 at Mumbai. For copies, please email [contact@sankalpindia.net](mailto:contact@sankalpindia.net)

"I was looking for the key for years, But the door was always open" - Aravind Adiga

"To be able to laugh and to be merciful are the only things that make man better than the beast." - Ruskin Bond

# ThalMeet 2018 - Meeting of Thalassemia Centers Organised in Bangalore



*ThalMeet 2018, the meeting of thalassemia centre who aim at harmonising Thalassemia Care and strengthen last mile delivery was organised on 21 and 22 May 2018 in Bangalore. Eight centers including Indira Gandhi Institute of Child Health - Bangalore, Project Samraksha - Bangalore, Wenlock Hospital - Mangalore, Jai Shivshakti Centre for Thalassemia Management KLE Hospitals - Belagavi, Rural Development Trust - Ananthpur, Thalassemia Sickle Cell Society - Hyderabad, Gujarat Adani Institute of Medical Science - Bhuj and Indian Red Cross Society - Rajkot participated in the event.*

In-spite of the fact that these centers are connected electronically and meet frequently online to discuss patient specific matters and learn from each other, ThalMeet is an event which helps brainstorm idea, gain clarity, receive training on newer technologies and not to forget - to meet each other and develop connections which go a long way in building a strong network.

The event also introduced the teams to Dr Neema Bhat, Paediatric Hematologist Oncologist who recently joined our team with the specific intention of strengthening care and management of thalassemia across the centers where Sankalp is involved. With ThalCare and BMTPlus, we have the technology to ensure that the complete set of medical records of the patients are available for the consultants. Dr Neema is working to strengthen care and management at a grassroot level, provide patient specific advice to the local doctors, nurses and coordinators and oversee the progress of all the kids across the centres.

Working together with Mr Santhosh Hegde, the Project Manager of Sankalp Program for Thalassemia Management, the two of them are providing the much needed support to the teams to take care for thalassemia at a whole new level.

The main focus of this meeting was to build the capacity of our teams. There was a whole day dedicated for the training of nurses and coordinators while the second day was spent harmonising the medical management across the centers. This specific



focus on the people who are at the forefront is essential to ensure intent translates into outcome.

In the two day event, the group had vibrant discussions around thalassemia prevention, counselling patient families, use of technology, increasing research output, combination chelation therapy and how to deal with other blood disorders beside other topics.

Speaking on the event, Mr Rakesh Dhanya, the CEO of Sankalp said - "We are committed to ensuring that each child who is coming to any of our partner centers for care is giving quality care. The recent strengthening of our teams is an enabling step to ensure that not only the existing centers deliver better care, but we also have the capability to extend this to many more kids. Over next few months Sankalp will aim at finding ore partners and reach out many more kids with systematic, reliable and holistic care and management."

With clear lines of action for improving quality of thalassemia care, the teams are back to their own centres and busy giving life a better chance!



"Just as the fire is the direct cause for cooking, so without Knowledge no emancipation can be had. Compared with all other forms of discipline Knowledge of the Self is the one direct means for liberation." - Adi Shankara

# 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	542	627	7	2.0	9.1	100%
Project Samraksha	1015	1122	2	3.0	9.0	100%
KLE Belgaum	503	466	2	3.0	8.8	100%
Wenlock Mangalore	193	202	4	4.0	8.5	100%
TSCS of Central India, Nagpur	122	111	3	2.0	7.7	

## Bombay blood group network

	Total bombay blood group requests	Number of units organised off the shelf	Number of units donated
Last two months	21	7	1
2018-19	21	7	1
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	1345	96%	22%
2017-18	6977	82%	21%

# April-May 2018



## Sankalp Program For Thalassemia Cure

	Total Transplants Done	Overall Survival	Disease Free Survival
People Tree, Bangalore	86	93%	81%
CIMS, Ahmedabad	36	100%	94%
Other Centres	11	91%	82%
Total	133	95%	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	23	1376	1093	🚩 3.6%	🚩 20.6%
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

<b>Anarock</b> <b>Awfis</b> <b>AxioBio</b> <b>Campus Student Communities</b> <b>CMP Girls Hostel</b> <b>CMP JP Nagar</b>	<b>Helping Hand</b> <b>Hindustan Field Services</b> <b>Idea</b> <b>International Tech Park Bangalore</b> <b>Li &amp; Fung</b> <b>Mantri Espana</b>	<b>Mphasis</b> <b>Ola Cabs</b> <b>Prateek Apparels</b> <b>Schneider Electric</b> <b>Xerox</b>
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# Sankalp-Cure2Children Network Meeting Organised



Sankalp-Cure2Children Network meeting for BMT was organised on 28-29 May 2018 at People Tree Hospitals, Bangalore. The two day meeting held every six months is an opportunity for our transplant teams to get together and brainstorm - contributing to the fine outcomes. We had participation from the teams at Sankalp-People Tree Centre - Bangalore, Sankalp-CIMS Centre - Ahmedabad, South East Asia Institute for Thalassemia, MY Hospitals Indore, Cure2Children Foundation and Sankalp India Foundation. This time we were happy to have Dr Eugenios Goussetis, Pediatric Hematologist-Oncologist, from Aghia Sophia Children's Hospital - Athens, Greece join the team.

Beside reviewing the outcomes and challenges with the current protocol there was intense deliberation on the options available for patients who do not have a matched related donor. Early results with haploidentical transplants have been very encouraging

and the steps to strengthen the protocol further were discussed. After two productive days and a host of ideas to work upon, with renewed energy the teams are back to their units - to give life a better chance!

## Transplant Outcomes - Whole Group

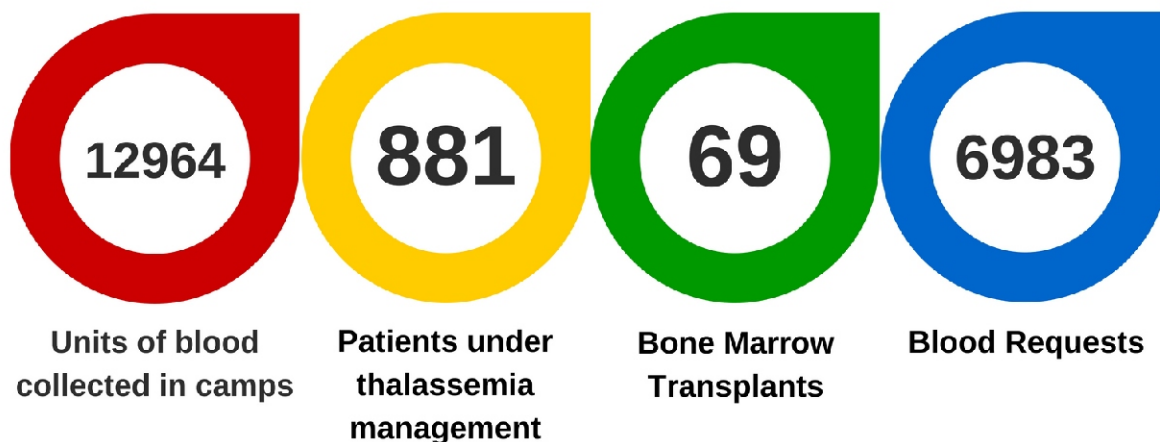
	Overall	Last Year
Disease Free Survival	84.4%	95.5%
Overall Survival	93.6%	98.5%

## Transplant Outcomes - Matched Sibling Donors

	Overall	Last Year
Disease Free Survival	89.1%	98.3%
Overall Survival	95.7%	100.0%

# Sankalp Annual Report 2017-18

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Given our quest to do full justice to our principle of Giving Life A Better Chance, it was essential that we spent some time on balancing rapid growth with consolidation of existing work. We dedicated almost the whole of last year strengthening ourselves. Having won the immense confidence of the community including patients, caregivers, financial donors it was time to look at how to build sustenance before taking off on the next growth trajectory.

Our numbers do show progress - we had about 13,000 units of blood collected, trained about 2000 children on voluntary blood donation, had nearly 900 children receiving systematic management of thalassemia, completed 69 bone marrow transplants, addressed nearly 7000 blood requests with about 150 of them for the extremely rare Bombay blood group. However, what we see as a bigger achievement is the fact this progress has been accompanied with growth in people and processes at Sankalp. A small 500 sq ft office space in Bangalore with different teams being groomed for specialized work as demanded by the variety of projects at Sankalp is testimony to the fact that internal strengthening is going on at full steam.

The year also saw us reach a few important milestones, each of which gave us the belief that we are pursuing the right track in our journey - we had the 1000th blood donation drive since the inception of the Rakta Kranti program a decade ago and the 50th bone marrow transplant in our Bangalore facility since the start about 30 months ago. We had a BMT unit and a thalassemia day care center added to the existing set of centers.

Each blood donor that walks into our drives to donate, each patient that calls on our helpline seeking blood, each child that comes into our thalassemia day care or BMT centers and every donor who contributes for the projects deserves nothing short of the best. Sankalp exists because of the trust these people have in us. They are and will continue to be the ones who will help us grow. The work and strength built over the last year has brought in more potential collaborations with different institutions to expand our boundaries of work. We feel humbled but poised to take flight to embrace these opportunities to fulfill our mission of 100% Voluntary Blood Donation and Thalassemia Free India.

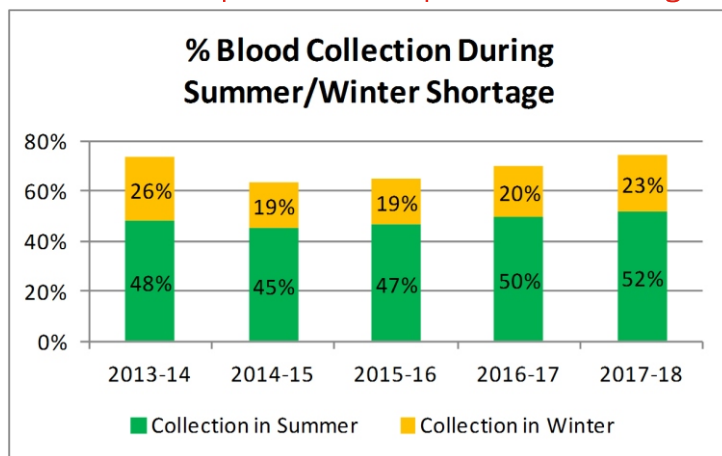
# The struggle and fight for blood shortage continues during this summer

The blood shortage during the summer months is a problem plaguing us from time unknown. The plummeting stocks of blood at the blood banks have always raised serious concern and like always the Rakta Kranti team of Sankalp India Foundation has been battling for organizing regular voluntary blood donation drives to meet the summer shortage.

*Sankalp had made a solemn vow 15 years back that no patient should die or suffer due to lack of blood and like every year we are ready to fight the critical shortage period. 50 voluntary blood drives have been organized in the two months of April and May, 2018 collecting 3709 units of blood.*

The crisis situation is alarming every year. The increase in demand far out spaces the increase in voluntary blood donation. It is important to remember that blood is perishable and cannot be stockpiled in advance, but

This chart shows how Sankalp focuses blood donation camps around the periods of shortage,

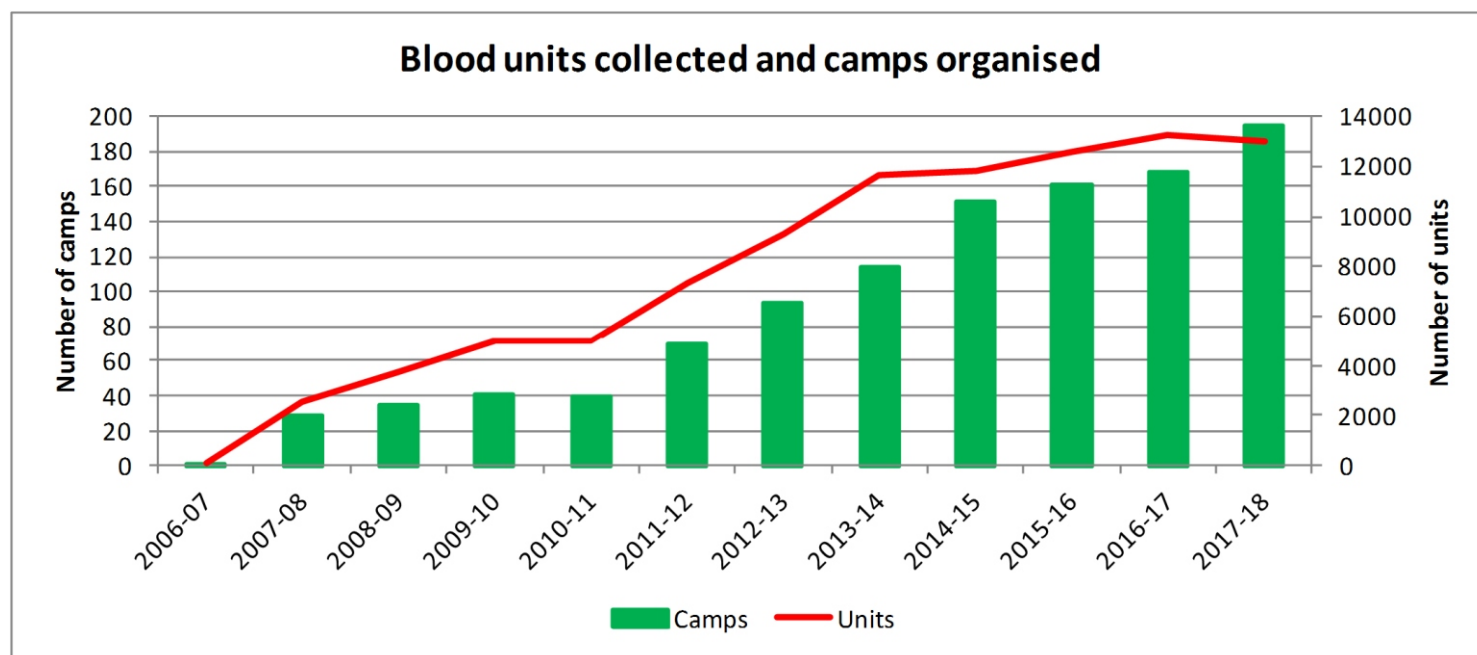


this situation can be replenished when generous voluntary blood donors roll up their sleeves to donate blood. These donations help to ensure that blood products are available for patients undergoing critical surgeries; patients suffering from thalassaemia, during the process of child birth, for cancer patients and the list goes on and on...

The blood banks across the city lack the process of better planning of blood drives throughout the year. Focusing on the critical periods of blood shortage plays a very important role rather than clustering drives on the days of National importance. This causes a serious imbalance in the blood stocks and brings along with it sufferings and misery for the patients and their family members.

On one hand, we are running a mission to "STOP REPLACEMENT" of blood stocks in the hospital by professional donors or replacement based donors and achieving 100% Voluntary Blood Donation by 2020 and on the other hand due to lack of effective planning of





Voluntary Blood Drives during the summer months, the blood banks reel under the blood shortage forcing and harassing patients and their family members to seek replacement based blood donations. This is a vicious cycle in which the response to one difficulty creates a new problem that aggravates the original difficulty.

Further to add to the scenario, the challenges have been very explicit. The election campaigns during the summer months this year have severely hampered public blood donation drives. Corporate Bodies are often reluctant to understand the gravity of the situation and hence do not provide adequate support to Blood Banks or Foundations organizing Voluntary Blood Donation drives. The common misconception among donors that donating blood in the summer months lead to more exhaustion also decreases the donor turnout in blood drives.

Summer months are historically the most difficult for blood centers with students on a break from university/colleges and donors away vacationing. But of course, the need for blood never stops.



Now the question is- how do we fight this period of blood shortage? The answer is very simple. Voluntary Blood Donation is the need of the hour. Spread this message around, creating awareness and sensitizing people that human blood cannot be manufactured. Another human being has to donate it.

*Take the charge of organizing Voluntary Blood Donation in your college, office, apartments. Stand up and be counted. "Make Blood Donation your Responsibility".*

## Story of Chinna -from darkness to light!



This is a story of a family who are extremely poor and who are also categorised as backwards, they are also treated very low in the society which they live. Pulappa and Muthyalamma were married to each other and from their marriage they had three children among them Chinna Pedanna is the youngest. Pulappa is a physically challenged due to his condition he couldn't work anywhere, Muthyalamma had to take responsibility of the entire family and also she became the only earning member of family. She is a wood picker, the family lives in a small village of Ananthpur district. Despite the poor condition Muthyalamma managed to take care of her family well.

After 4 months of Chinna Pedanna born, he turned up

showing bad health. Family took him to hospital nearby. The blood samples were drawn to know his condition and reports showed that his blood counts were very low. He was transfused immediately and two days later again there was a fall in his counts. Doctors screened the family for Thalassemia and the reports later confirmed that he was a Thalassemic. He got transfused in the local hospital for sometime and then started receiving transfusions at the Rural Development Trust Hospital in Bathalapalli - Ananthpur, a centre providing good care for thalassemia. The family just knew that there was something wrong with him and he is getting treated for that apart from this they couldn't understand anything about the disorder.

Few years later trust people counselled the family and also offered HLA typing test. It wasn't easy at all to convince them for the investigation but the efforts of team who counselled them did not go waste. Few months later the test reports revealed that he has a fully matched donor; it was Muthyalamma his second sibling. The team at RDT again counselled the family and explained the risk benefits of Bone Marrow Transplant. The family still found it difficult to understand things but they were just aware that whatever it is, it's going to be very expensive and they would never be able to afford it. The medical team at RDT understood the situation well and decided to help the family together with Sankalp India Foundation. Through regular meeting with medical team of Sankalp he was down staged exceptionally well - a process which reduces the risks associated with the procedure. Intense downstaging was needed because he had a large spleen and liver size which increase the chances of transplant failure. RDT and team Sankalp agreed to cover the cost of transplant.

He was referred to the transplant centre at Bangalore. Beside the liver and spleen he was also 16 years old and hence a candidate with relatively higher risk. The

transplant wasn't expected to be straight forward but the medical team took it as a challenge and admitted him. Eventually, the transplant went well in part because the team meticulously planned to mitigate any problems that were anticipated as a consequence of his condition. Fortunately, he did not get any kind of life threatening infections also. He engrafted soon and was discharged earlier than usual.

The transplant was particularly challenging because of the severe communication difficulties complicated further by illiteracy. With a lot of patience the nursing team found a way to communicate and the mother started taking care of the child well. Coming from a very different environment, getting the family to get used to the hygiene conscious setup of the bone marrow transplant unit.

*As the transplant came successfully without any complications, the family was very happy and grateful. When they visited RDT Hospital, the team there was also overjoyed.*



**Team RDT with more kids who have been supported by them for transplant at our centers.**

# 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](http://www.sankalpindia.net)**

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

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### To: