

Celebration of 50 transplants at our Sankalp-People Tree Centre for Paediatric BMT



When someone asked about the vision for our thalassemia centres – we remarked – we hope to close them! The intention behind the statement was to reach a point where every child who is likely to do better with the option of permanent cure – gets the transplants and enough is done to prevent new births with thalassemia.

As an organisation we are focussed upon improving the curative option for thalassemia to be able to offer reliable cure to as many patients as possible. Though several options are available like transplantation from unrelated donors, partially matched donors, from sources like cord blood etc. one must keep in mind that

the curative option must compete and score higher than the option of long term supportive care.

As Sankalp - Cure2Children Network, we are fortunate to be in a situation where we are able to offer reasonable quality management in cure of thalassemia to all patients irrespective of their financial status – thus raising the bar for transplantations still higher.



As we crossed the 50 transplantations mark, we thought that it was a good time to come together with the families to mark the occasion. A small function was organised on 16 September 2017 at People Tree Hospitals to mark the occasion. Speaking on the occasion Dr Stalin shared how he was initially apprehensive about the working of the Indian healthcare setup when he came back from UK. He had never had patients whose treatment was interrupted for want of funds and he expressed happiness that at the Sankalp-People Tree Centre for Pediatric BMT he could treat the patients without having the worry about the financials even when the bills shot up astronomically.

Dr Lawrence Faulkner expressed his happiness on reaching the milestone. He made the day very special for several families who so far do not have a related match by sharing the good outcomes that are being seen in the haploidentical BMT context. He explained the whole process, and potential complications to the families and answered their questions patiently. Several patients and their families recollected their journey through the transplantation process.

It was a coincidence that several of the patients who had a stormy transplantation course happened to

attend the program. The doctors were amazed to see that the children had recovered completely and were now living a life with the chapter of thalassemia closed and put far behind. Kids had a wonderful time at the event, meeting their favorite nurses and doctors and enjoying each other's company.

Dr Supraja and Dr Chandrashekhar from People Tree Hospitals expressed their happiness reviewing the progress of the program and promised all needed support in the time to come.

Mr Lalith Parmar from Team Sankalp thanked all the donors, patient families, partner institutions and everyone else who have contributed to realising the objectives of Sankalp program for thalassemia cure. He also expressed confidence that together with the support of all involved, we will reach out to more children with cure.

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Our findings related to paternal vs maternal fully matched donors published in BMT - Nature Group

Bone Marrow Transplantation

OPEN

Bone Marrow Transplantation (2017), 1–2

www.nature.com/bmt

LETTER TO THE EDITOR

Rejection of paternal vs maternal fully matched bone marrow grafts in children with thalassemia

Bone Marrow Transplantation advance online publication, 18 September 2017; doi:10.1038/bmt.2017.199

The bidirectional passage of cells across the placenta during fetal life is a well-described phenomenon which may result in a state of reciprocal persistent tolerance towards unshared histocompatibility antigens.^{1–3} On the other hand sera of multiparous women were pivotal in the initial discovery of new HLA antigens and donor parity may increase the risk of GvHD.⁴ In the partially matched related (haploidentical) context many centers may prefer the mother as a donor for T-cell depleted grafts^{5,6} and for non-malignant conditions,^{6,7} while for T-replete grafts for malignancies the mother might be the last choice.⁸ This could be related to the much lower

0. Bone marrow was G-CSF-primed in all cases by treating the donor with filgrastim 5 µg/kg/dose twice daily for either 3 or 5 days prior to harvest. GvHD prophylaxis consisted of cyclosporin A combined with methotrexate or mycophenolate mofetil.¹¹ All patients and parental donors had sequence-based high-resolution extended 6-loci HLA typing (DKMS Life Science Lab, Dresden, Germany, www.dkms-lab.de) which was confirmed in a second independent laboratory (Jeevan's HLA Laboratory, Chennai, India, <http://www.jeevan.org/ngs-hla-lab/>).¹⁰ Patients' characteristics are summarized in Table 1. Sibling number and gender were included since the mother may have developed immunization against inherited paternal minor histocompatibility antigens during previous pregnancies.¹² This retrospective study was approved by institutional review boards.

For those patients who have related fully HLA matched donors (apart from siblings), does the relationship with the donor influence the outcome? We observed that there was a significant difference in outcomes between those patients who received bone marrow from a fully matched father and those who received it from their mother. Our findings were published in Bone Marrow Transplantation of the Nature group in September 2017. As always, the findings are open access and available for anyone to read.

The focus on a particular disease condition, collaboration across institutions, extensive data management, real-time analysis and most of all a keen

eye for quality and safety has put us in a unique situation where we are observing trends and patterns which remained unexplored so far. We consider it important to share our findings - irrespective of whether it reflects our success or whether it is a case where we face unusual challenges with the larger scientific and clinical community. The eventual aim of our team is to contribute to transplantation safety. This publication is yet another leap forward for us.

We aim at minimizing mortality and providing long-term improved quality of life through our transplantation program. Small steps like this one help in accelerating the journey towards our goal!

"Status quos are made to be broken."

- Ray Davis



Happy National Voluntary
Blood Donor Day 2017

Big Salute to the blood donors



In quest for every improving transplantations 2nd Sankalp Cure2Children Network meeting held



22-23 September 2017, Ahmedabad

The second meeting of the Sankalp Cure2Children Network was held on 21-22 September 2017 at Ahmedabad. The meeting was attended by representatives from South East Asia Institute of Thalassemia - Jaipur, Sankalp-People Tree Centre for Pediatric BMT - Bangalore, Sankalp-CIMS Centre for Pediatric BMT - Ahmedabad, J M Wadia Children's Hospital - Mumbai, Dr Jyotishankar Raychaudhuri, Cure2Children Foundation - Italy and Sankalp India Foundation - Bangalore.

The goals of the meeting were to review the performance of the transplantation program so far, deliberate on the challenges which the teams are facing and develop common ground for the work to be done in the near future.

The meeting happened at a time when the latest addition to the network, the Ahmedabad unit just completed 12 transplants – with each of the children doing well. It was also well timed for the new program director for the Sankalp-CIMS centre – Dr Vikramjit Kanwar who joined the team in September to get introduced to everyone involved.

BMTPlus, the information technology platform which is used across our network continues to evolve. The event also allowed for a refresher training and introduction to the latest features of the system. The users also shared requests for new features.

The group has vast experience with transplants for thalassemia and has been able to contribute several publications. Nevertheless, there are limitations to retrospective analysis of data. A need was felt to get started with clinical studies. With the ethics committee of Sankalp in place the group deliberated on some ideas one of which would be selected for a multi centre

"Only he who attempts the absurd is capable of achieving the impossible."

- Miguel de Unamuno



study. The group hoped to get started with this by the end of the year.

With positive outcomes from the haploidentical transplantations been done at SEAIT, other centres planned to adopt the protocol. At the same time there was further discussion on making the current protocol – which already seems to be doing very well, as less toxic as possible on a longer term for the patient. There was also discussion on further simplifying the current protocol to make the transplantation course smoother for the families.

Regular meetings like these one allow for comprehensive review of the work being

done across the centres. It allows for various viewpoints to be placed before the group and deliberated upon.

The synergy that gets built in these meetings gives proper direction and force to the group.

We would like to thank all the people who participated in the meetings and everyone who worked to make it possible.

* * *

"There is only one thing that makes a dream impossible to achieve: the fear of failure."

- Paulo Coelho

Experience of a volunteer from our drive



The following is the experience shared by a Meshita, a student volunteer from Ammucare charitable trust at Mantri Espana blood drive on 29th July 2017. We thank her for the great share!

"Blood donation today is a growing need in India. The requirement being four times the current availability, many children suffering from thalassemia don't receive blood transfusions on a monthly basis due to availability. I feel in today's day and age we need a lot of more awareness and information sharing about the benefits of donating blood. The last time I volunteered to help for a camp, I expected people to be in pain, feeling dizzy and nauseated. But I was pleasantly surprised as to how the whole camp was organized.

The registration was simple and not time-consuming, the people were friendly and made you feel comfortable in the environment. Proper arrangements such as refreshments and cots for people to lie down, were arranged.

The whole process was smooth and comfortable. When I turn 18, I would definitely want to give blood, now knowing that the process is so simple and pain-free and also towards a good cause.

So I encourage all of you to do the same because it will save a life."

















Meshita Advani (Student Volunteer)

"Don't find fault - find a remedy."





- Henry Ford

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	325	409	 12	 2.5	 9.3	 97%
Project Samraksha	410	468	 3	 2.8	 9.4	 100%
KLE Belgaum	252	248	 5	 3.0	 9.0	 100%
Wenlock Mangalore	42	59	 9	 3.3	 8.0	 100%

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	15	674	569	 2.1%	 16.2%
This year	106	9359	7893	 3.9%	 15.6%

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

Artech
Blue Dart
Blue Ocean
Chola Group
Directi

Epsilon
Helping Hand
IndeComm
Knolskape
SmartERP

Softtek
Stanley Black and Decker
Swiggy

September 2017



Sankalp Program For Thalassemia Cure

	Total Transplants Done	Overall Survival	Disease Free Survival
People Tree, Bangalore	58	91%	83%
CIMS, Ahmedabad	15	100%	100%
Other Centres	11	91%	91%
Total	84	93%	86%

Bombay blood group network

	Total bombay blood group requests	Number of units organised off the shelf	Number of units donated
Last month	15	7	5
This financial year (cumulative)	63	26	18
Last financial year	71	18	21

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	574	80%	20%
This financial year (cumulative)	3715	79%	22%
Last financial year	6348	84%	27%

Rollercoaster September for Bombay Blood Group



The month of September has been a roller coaster ride for us in managing multiple Bombay Blood Group requirements from all across the country. All thanks to the real life heroes whose timely donated blood and helped the patients.

Thanks to Mr Sheethal, Mr Raju, Mr Gautam Chandra, Mr Satish Kumar, Mr Sameer, Mr Shridhar Bindiganavile, Mr Suhas Hegde, Ms Medha Vaidya, Dr. Suresh Kolekar and Mr Pari. Patients in Bangalore,

Hyderabad, Siliguri, Pune, Thiruvapur, Chennai and Mangalore were helped.

We would also like to thank all the blood banks who timely reported the available/unused units and helped us in packaging and moving them.

Month ends on a good note when we know few precious lives were saved and 2 new lives came to this world safely.

Correction in Vol 7 Issue 9 September 2017 Issue

We made 2 major errors in last month's Patrika. We reported transplanted related mortality as 100% in the table on page 4 which was actually 0%.

We also seemed to have flipped the total donors and

total donations in the table reporting the performance of Team Rakta Kranti on page 7 for last month.

We apologise to the readers for the same.

"Growth is never by mere chance; it is the result of forces working together."

- J.C. Penney

Message by a Regular Voluntary Blood, Platelets and Bone Marrow Donor on the National Voluntary Blood Donor Day



Mr Chandrakanth Acharya is a voluntary blood donor and a donor motivator who is close to completing 100 donations with 32 single donor platelets donations and 1 stem cell donation. An inspiration to all of us, ever willing to donate blood, he is ready to come whenever there is someone in need of blood. A must read for everyone in blood banking.

Greetings on the National Voluntary Blood Donor Day!
Here are a few thoughts of the voluntary donor!

As a voluntary donor, what crosses the donors mind are shared in the paragraphs below. If they are addressed in right earnest,

I believe the goal of 100% voluntary blood donation with no forced or replacement donation can be achieved earlier.

A person coming out to donate blood for the first time needs to be treated well and be informed of what to expect be it 1% or less of donors fainting/ feeling light headed/ giddy/ black out as also the venipuncture site hurting/ turning black to blue because of blood leakage etc and very rare case of hyper ventilation. I have seen donors feeling relieved when told what to expect and take measures to avoid it too! This has to happen at the time of donor form filling, which is not happening currently in most blood banks. Front office personnel

can double up as counsellors to neo donors. It is in the interest of blood banks to put the donor at ease and make his experience memorable one as this leads to him or her coming back again for donations.

If a person has arrived at the blood bank means someone must have cajoled him/her into that by sufficiently motivating. It is blood bank's duty to sustain it further.

I will intersperse here with a few of negative experiences here. In one of the blood banks, donor was deferred on seeing grey color of hair!! It could have been avoided in the first place, if there is a dedicated front office staff who can double up as counsellor too. And training in the best practices, NACO/WHO guidelines and etiquette make the whole affair simpler.

We are all humans. prone to errors. But minimising errors is one of the best practices. Blind pricks and its consequences leave a bad memory and may deter neo donors. Latest devices like vein illuminator help in this but nothing beats a good training and confidence.

And if for reasons, some donor may have to be temporarily deferred, announce it with dignity. I have seen female donors going away sadly as though the temporary deferral on account of low haemoglobin makes them permanently deferred. If possible, suggest ways of improving Hb which helps them in enjoying life to the full too. Temporary deferrals should



be said so and when can it be lifted also to be told.

If the blood flow is slow or stops, (during donation) donor comfort and safety is priority and not the saving of the bag/kit. Do not jiggle the needle to increase flow!!

If for any reason (non availability of bed/machine, waiting for test results) there is going to be delay, please tell the donor so. Their time is precious and they would have come to help someone putting their important work on hold. It really irritates to wait, while blood bank personnel chit chat and gossip.

A cheerful disposition and professional attitude is something which can definitely be inculcated and is expected by each donor when he visits a blood bank for donation.

Happy blood donation day once again!!!

Rakta Kranti Schools - Preparing Future Blood Donors



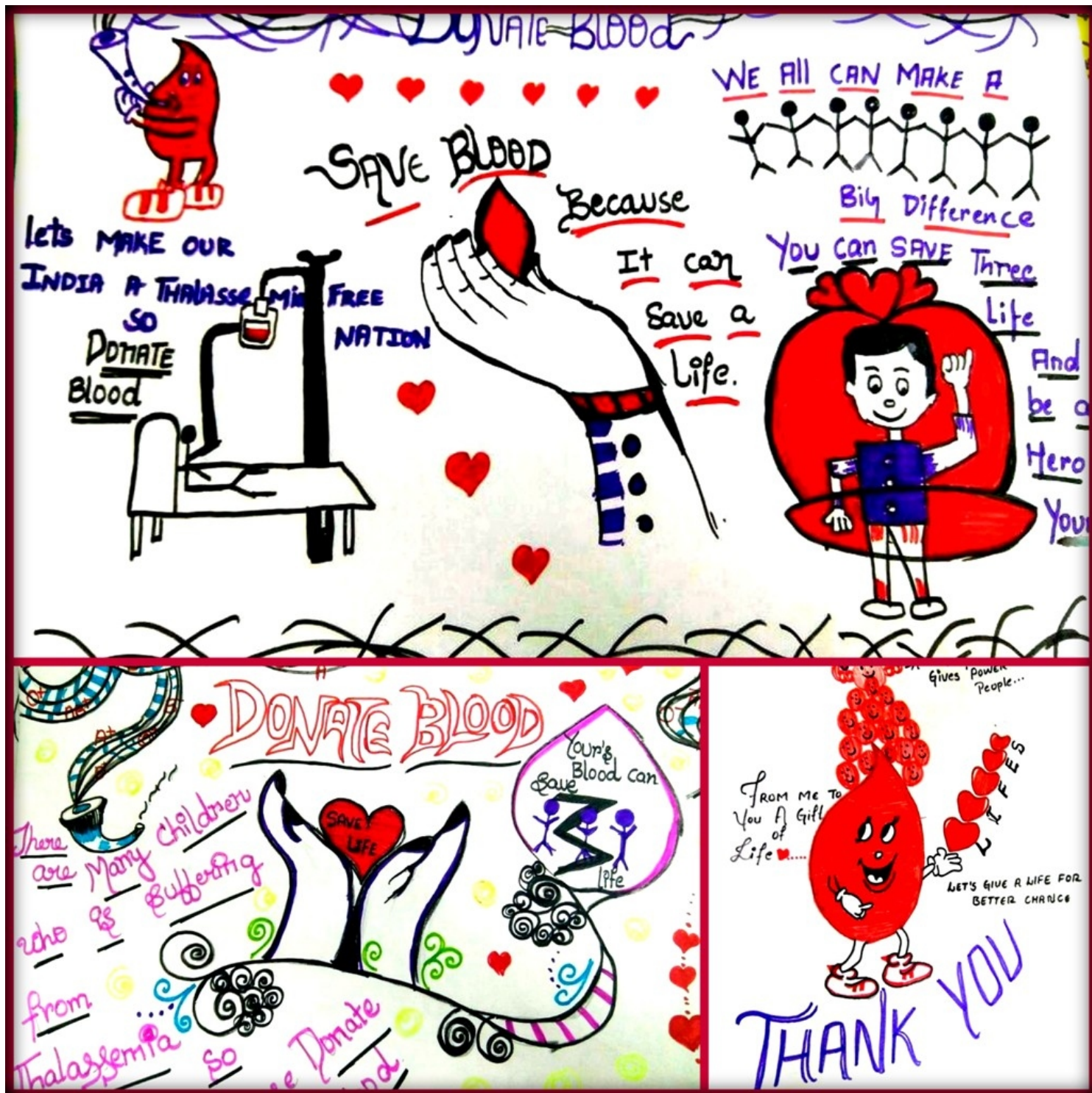
Rakta Kranti – the Blood Revolution movement of Sankalp has a special program for school children aimed at sensitizing the young minds towards blood donation. The students of class VIII, IX and X are educated on various facts regarding blood through their school curriculum, but they are unaware about the process of blood donation as such. This is the right age to make them aware of the blood donation

process, as they are the future potential donors. Proper education imparted to the right people at the right time has shown to make a BIG DIFFERENCE in this context.

This year the Rakta Kranti team cooled their heels after the summer marathon as the stock of blood in blood banks rose with large number of monsoon blood donation drives. They decided to redirect their time to the Rakta Kranti School Program once again. In the month of September they were able to organise small programs followed with thought provoking and

"A leader must have the courage to act against an expert's advice."

-James Callaghan



involving competitions for 2000 children spread across 6 schools in Bangalore. Programs were organised in Citizen's High School (Tannery Road and Hosakote branches), Gurukula Academy, St Joseph's High School, Reddy Jana Sangha High School and St Charles High School.

The immediate outcome of this exercise is visible from the writings and artwork the kids came up with post the sessions. We are confident that these young ones are on their way to become model blood donors, thoroughly sensitised, properly educated and motivated to ensure that they make the choice to ensure no one suffers due to shortage of blood.

"There are always obstacles and competitors. There is never an open road, except the wide road that leads to failure."

-Herbert Casson



We thank all the participating students, teachers and schools.

Excerpts from the essays: *'Real bliss can be achieved through love, fellowship, selfless service and sacrifice, and not by amassing wealth alone. One must try to donate blood and see what joy, happiness and satisfaction one will experience at the mere thought that this gesture may save somebody's life one day.'*

- Arun YH, VIII, Gurukula Academy

'One cannot make blood. It is a gift we have inside us to give to those who are injured, sick or in need. Those are the best reasons to donate blood.'

- Akshaya P, VIII, St Joseph's High School

'Please donate blood. We know that we can also save lives, but we don't do it. Many people in the world keep a healthy timetable to be healthy. If they donate blood every 3 months,

they may save a child who needs blood. Please donate blood not for anything like money, but for helping others, caring, love and humanity.'

- Aasiya Khatoon, VIII, Citizens' High School

'Most of the time, pressure and responsibilities force us to overlook how important life is. We rarely take the time to consider the small things to do for others and how these things can affect someone else's lives. Having an important effect is human blood. And blood is something that can not be produced. For people in need, we have to donate blood.'

- Abirami P, VIII, Citizens' High School

'Our Pledge- India is my country. All Indians are my brothers and sisters. I love my country. We will donate blood and we will be a hero for my country.'

- Arfa Kousar, VIII, Citizens' High School.

Hi Sankalp!

Please get in touch for any of the following

Sankalp Emergency Team

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

Bombay blood group network

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

Statewide Blood Helpline

- Call 9480044444 when in need of blood anywhere in Karnataka

Rakta Kranti

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

Thalassemia Prevention

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

Thalassemia Management

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

Thalassemia Cure

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

Contribute

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

From:

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Mail: contact@sankalpindia.net

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To: