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Sankalp's Bone Marrow Transplant unit is now a reality



A new hope, a new silver lining has surfaced for little children suffering from the pain and burden of thalassemia. A new Bone Marrow Transplant unit (BMT) with an exclusive focus towards treating thalassemia children has been jointly established by Sankalp India Foundation, Cure2Children and People Tree Hospitals at Bengaluru. This unit is the one of the two centers in the country and first of its kind in South India, that has an exclusive focus on thalassemia and is setup on a Not For Profit basis.

The unit was inaugurated on the 27th of August 2015 by Dr Vamanadeva, Director of Health and Family Welfare Services, Government of Karnataka. The event was attended by several dignitaries treating thalassemia patients from across the country. Parents, families of thalassemia affected children were also present. Speaking at the occasion, Dr Vamanadeva highlighted the need for such centres that offer quality care and yet be affordable. He expressed delight that the facility is looking to cater to patients from all over the state and hoped that the pain and burden of thalassemia will be wiped out for several children.

The 4-bed unit is one of the two centers in the country that has an exclusive focus on thalassemia. The unit is being setup with philanthropic contributions from several individuals and organizations. Dr Lawrence Faulkner from Cure2Children

Italy is the consultant physician on board. Cure2Children, headed by Dr Lawrence is spearheading thalassemia care and management in several parts of Europe and Asia. Being a pediatric oncologist, he has taken special focus on thalassemia and has overseen several successful transplants at associated centres all over the world. He says "every child, suffering from thalassemia, must get an affordable and reliable cure". Under his able guidance, the team at People Tree Hospitals led by Dr Chetan Ginigeri is all geared up to Give Life A Better Chance to several children who are queued up for transplants.

"This joint venture is a conglomeration of three organizations, who believe in delivering high quality care to each & everyone. We are taking every measure to make sure that, subsidized cost does not mean compromised care" says Dr.Chandrasekar Chikkamuniyappa, CEO and Senior Joint Replacement Surgeon, People Tree Hospitals. 'In 3 years' time we



would like this center to become JCI Accredited, hence all the processes are accordingly being set and followed', he adds.

Every Bone Marrow transplantation done at this centre is highly subsidized. Regular cost of Bone Marrow transplantation elsewhere is generally over and above 15 lakhs. However, this joint venture is going to bring down the cost to around 8.5Lakhs to 10 Lakhs for needy children. To our knowledge this is going to be the lowest cost for Bone Marrow Transplantation in the country. Sankalp is taking care of the financial, socio-economic aspects and patient management aspects at the centre. Sankalp has forged relationships with several partners to be able to set up the unit at minimal cost and yet offer quality care. "No child with thalassemia should die,



"Try to be a rainbow in someone's cloud." - Maya Angelou



either because of lack funds or facilities, that's our mission. Our aim is to work towards effective prevention, management and cure for thalassemia and thereby ease the pain and suffering of children" says Lalith & Rajat from Sankalp India Foundation. A powerful and well-designed web based application, BMT Plus, developed by Sankalp's technology partner – Jagriti Innovations is being used as the platform where patient's daily treatment routines are tracked by all concerned.

The first set of patients have already been admitted and are on their treatment course. It is being planned that over the next one year more than 20 children will have been cured. It is also expected that in due course of time patients from several other centres in the country may be benefitted by the services offered by the centre.

Recently, one of the three little ones stepped out and took the first steps out of our BMT unit. The other two children are also packing their bags. Our dream of offering safe and quality oriented transplant to any and every child who suffers from thalassemia has started taking shape.



"We know what we are, but know not what we may be." - William Shakespeare

Emergency Wing Team Report - 2014-15

The year began with merger of Project Disha and Emergency Wing, the two teams inclined towards making blood accessible and available to the needy. It was felt that it would be logistically easier if the two, otherwise separately perceived teams, worked in cohesion.

The Helpline Situation

The helpline is believed to be critical to Sankalp's progress as an organisation. Running the helpline without problems means that the basic purpose of the organisation gets fulfilled – helping people with blood. To this extent the team did perform. But, when it comes to simplifying blood search for the needy at large, the team did not meet the expectations it had set for itself. Although the number of calls coming to the helpline dropped over the year, but come summer, the helpline's engagement picked up like never before.



Apart from calls to helpline getting handled, the other good things that happened include getting an extra employee to cover 12 hours of calls daily. Technology remained the biggest backbone in running the helpline. The newly integrated SMS gateway was well received both by callers and the team.

Locality	Calls %
Bangalore	67%
Dharwad	8%
Mysore	4%
Gulbarga	4%
Davanagere	4%
Bijapur	2%
Shimoga	1%
Belgaum	1%
Raichur	1%
Dakshina Kannada	1%
Hassan	1%
Chikamagalur	1%
Uttara Kannada	1%
Bagalkot	1%
Bellary	1%
Haveri	1%

The team was also able to actively provide skill development for Response Center Executive to handle more complex blood requests. Although the changing employee situation resulted in little of the knowledge transfer culminate into real work.

Among the not so good things, the biggest worry was a drop in the average number of calls which reached the helpline. A lack of initiative from the team to patch up the problem with proactive awareness campaigns was felt. 67% of all calls were

"The world is full of magical things patiently waiting for our wits to grow sharper." -

Bertrand Russell

from Bangalore, which is a sizeable increase from last year's 61%. The need for the helpline reach beyond the city in a big way was felt.

Due to frequent employee changes, the frequency of daily stocks update also fell significantly. The project to make the blood helpline a single point of contact for all Sankalp activities also suffered due to lack of a streamlined approach and changing RCEs. While the core task of managing the helpline and handling calls was done, the team plans to fix these loopholes in the upcoming year.

Handling Emergencies

Emergency Wing continued to take blood requests, fight summer shortages, build skill and potential for transfusion medicine research and build network for Bombay Blood Group.

What makes the team powerful is a functional helpline, a team of experienced volunteers who possess a thorough understanding of transfusion medicine, its credibility with donors and blood banks especially in cases of Bombay blood group requirements, availability of backup volunteers who can speak Kannada, 24*7 availability of at least one volunteer, strong database for Bombay blood group even from small cities, availability blood stock data publically, and platelets donors registry.

The team, however, witnessed a shortage of volunteers, insufficient meetings, lack of

documentation, and lack of active SDP database. While all emergency blood requests were catered to on time, the need to bring processes and train more volunteers was felt. The team plans to take this up in the upcoming year.

Bombay Blood Group Network



In total, 38 blood requests were received for the rare blood group from across the country. The team was successful this year in collaborating with other organisations to use Bombay blood group site for request and donor management and also making it a one stop information center and discussion forum for Bombay blood group individuals. The organizations which partnered include Mumbai's Think Foundation and several blood banks from Karnataka. The year also witnessed a scientific paper on Bombay blood group by the Emergency Wing getting accepted in Blood transfusion journal.

While the requests were managed, there are several other reasons why Bombay Blood

"Health is the greatest gift, contentment the greatest wealth, faithfulness the best relationship." - Buddha

Group Network continues to remain a success story -

Bombaybloodgroup.org was publicised in AP, TN, Pondicherry and Kerela. The team received response from around 30 Blood banks and also many new donors added to our list. There was also a spike in number of request being received from AP during January to March 2015. Requests were received not only from big cities like Hyderabad, Vizag but also from small towns like Ongle.



Paper on 'Managing Rare Blood Group Requests- Bombay Oh Phenotype: Our Experience with www.bombaybloodgroup.org' was submitted to 2 journals Asian Journal of Transfusion Science and Blood Transfusion. It was accepted by Blood Transfusion.

Bombay Blood Group Meet was organised on 15th June 2014. It was attended by 6 Donors. 2 of them had come for the first time. This meeting was organised with little resource and time.

3 units of Bombay Blood Group blood were transported to Jamshedpur to cater to an emergency.

Numerous Bombay Blood Group donors have started registering on the site. Few donated as well.

The Twitter handle for Bombay Blood Group has started attracting Blood group

Group	Total Requests
Bombay-	4
Bombay+	34

requests floating in social media.

Overall, the Emergency Wing had a fulfilling year. While all the basic tasks were done, a lack in proactive approach to bring processes and remain progressive was felt. As the team steps into another year, the volunteers have set clear roadmaps to take its learning from the previous year and define the years to come

State	Total Request
Andhra Pradesh	8
Chattisgarh	2
Delhi	3
Goa	1
Gujarat	1
Jharkhand	1
Karnataka	10
Maharashtra	2
Odisha	1
Telangana	2
Tamil Nadu	4
West Bengal	2
Others	1

"Clouds come floating into my life, no longer to carry rain or usher storm, but to add color to my sunset sky." - Rabindranath Tagore

Donor Counseling - the long road ahead

Counselling donors is an important and integral part of blood banking. Counsellors have various roles to play in the blood banking setup. In voluntary blood donation drives, a counsellor plays the role of speaking to the donor before blood donation where he/she encourages the donor to donate and gets an assurance that required pre donation criteria is met. Any questions/concerns related to blood donation (apart from medical issues which shall be addressed by the doctor), should also to be answered by the counsellor. Although not necessarily experienced to do this, many blood banks have a person in place for this.

However, counsellors are required to play a much more important role after the blood donation drive. Every unit collected is subjected to tests for HIV, Hepatitis - 2

dreadful sero positive conditions. A donor who tests positive for these must be referred to the Integrated Counselling and Test Centre (ICTC) where professional counsellors with requisite knowledge and experience of handling such donors speak to them and plan necessary next steps as required. However, these days blood banks are adopting a different approach. In this, if they find a donor who has tested positive for such diseases, they do the first level handling by their own blood bank counsellor

handling the donor and calling him/her to their blood bank for further tests. Whether this is right or wrong is a subject of a much wider debate.

This article summarizes the incidents over the last few months where the blood bank staff/counsellor have created much unwanted havoc. Handling donors who test positive for HIV or Hepatitis is quite challenging because of emotional and societal reasons. This is especially true when the information of a possible infection is to be communicated for the first time. It is also a well known fact that a few cases of False

Positive are seen. Over the last 6 months, Sankalp RK team has come across atleast 4 cases where the blood bank counsellor has created significant damage.

In 2/4 cases, the blood bank counsellor informed the donor that it is almost true that they have been tested positive for HIV and that they must come over to the blood bank for confirmation. This created a damaging effect with the donor under question going into a mental shock. The donors were given no other background information. It was not even told to them that the information must be kept confidential and that the donor need not panic. All these mistakes meant that the donor informed his/her friends and family.

!ncidence Report

"Believe you can and you're halfway there." - Theodore Roosevelt

They then went ahead with independent testing at a lab of their convenience. For one donor when the result was negative, the Sankalp camp coordinator was called and chided and abused saying that it is a plan to cause panic and extract money etc. One donor even threatened to take legal action for the mental trauma and financial losses incurred to get confirmatory tests done. After several attempts to pacify the donor and the HR of the organization the situation was under control.

In 2 other cases, the blood bank staff called up the Sankalp team and informed about 2 donors being tested as positive. The staff claimed that since they were unreachable on phone they wanted Sankalp to call them and inform. Despite requesting them to try alternative means to reach the donor like email or postal address etc, they just sent out the name and other details to Sankalp.

Such severe mistakes can come back to haunt us. Blood banks must educate their staff about the whole process. They must be made to realize the consequences of incomplete communication. Ideally the blood bank must never be involved and it must be solely left to ICTC to handle this. Even if they have to be involved, a well trained person must head the communication with donors. Counselling such donors is a different thing altogether. Soft skill training, training on communication techniques are very crucial for each member of the blood bank team.

We appeal to blood banks to follow correct practices. Blood banks must invest in training programs for their staff. This must include both technical and behavioural trainings. More importantly sero positive cases must be referred to ICTC. It is incorrect on the part of blood banks to take control of such situations by themselves.



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9480044444

"The best and most beautiful things in the world cannot be seen or even touched - they must be felt with the heart." - Helen Keller

News and Updates from August 2015

Lesser camps, better planning for Rakta Kranti

Due to a patriotic fervour gripping the city around Independence day the number of blood donation drives in were far too many. At such times, Sankalp takes a stand not to organise too many drives. This ensures a balanced supply of blood without overloading and leading to possible wastage. Hence in the month of August, the team organised only 7 blood donation drives leading to a collection of 603 units of blood. The rate of adverse events was quite high compared to other months in the year and was about 4%. The introduction of the deferral protocol has shown some promising results. The donor screening was done on a more pragmatic basis. We had about 17.75% deferrals in the month.

The first 15 days saw us organizing only 2 camps.

A drive was organized on 1 August 2015 at Taj Vivanta. Enthusiastic employees of the hotel came forward in good numbers and eagerly waited for their chance to donate. 33 units were collected by Victoria Hospital. A



drive at Tata Power on 12 August saw close to 100 employees coming in to donate. Plenty of donors who regularly donate in Sankalp camps were happy to be back again. Tata Power makes a significant contribution by organizing drives every 6 months.

Post Independence Day the team organized 5 drives to cater to the needs towards the end of the month. A drive at Temenos saw 46 units collected by ESI Hospital. The drive at Idea Cellular saw 54 blood donor heroes donating to Bowring Hospital and young students of Azim Premji University also made their contribution by having 87 units donated to Victoria Hospital blood bank. Good publicity saw a fair share of people come forward in all these institutions.

Sankalp also connected to Huawei Technologies this month. A blood donation drive there saw more than 200 donors turned up. Constant flow of donors throughout the day saw 180 units collected by Rashthrothana blood bank. The units collected was of immense help to our thalassemia kids at our Samraksha centre. Our final drive of the month was at AIG



"If opportunity doesn't knock, build a door." - Milton Berle

where again really good education and motivation saw more than 30% of the employees form a bee line at the camp. 131 units were finally collected by Narayana Hrudayalaya blood bank.

Sankalp would like to thank the support of all these organizations for their support to the cause of voluntary blood donation.



Thalassemia Management and Care

August turned out to be an exceptionally busy month at Indira Gandhi Institute of Child Health. There were 236 patient visits with a total of 319 transfusions. The capacity of the centre is being utilized fully and is being stretched. Thanks to plenty of blood being available in the city we had blood units which were 5 days old on an average being given to the patients with 2 hours of processing time. This was inspite of 1 in 6 units of blood being organised from blood banks outside the institute. However, thanks to the sheer quantum of transfusions, scheduling became difficult and the average pre-transfusion Hb fell to 8.17 gm/dl. Median hospitalisation duration continued to hover at 7 hours. The centre also completed the annual cardiac screening, thanks to Jayadeva Institute of Cardiology. Three children need special attention so far as their

cardiac health is concerned and they are being offered the same. In spite of the ever increasing workload and the stress due to capacity vs. demand, the team is committed to ensuring that each child receives the best treatment.

Project Samraksha had 191 visits with 236 units transfused in the month of August. However, generously contributing to the hustle bustle at the centre are the pre-transplant and post-transplant follow-ups. Like always, Rashtrottana blood bank made available all needed units with average age of blood units being 5 days old and the processing time being 3 hours. The overall hospitalisation was 7 hours. The centre has been able to do a great job maintaining the pre-transfusion hemoglobin levels at 9gm/dl. The centre made good progress with the DEXA scans and also initiated cardio-vascular screening. The team at Samraksha is putting in intense effort to early identify the first signs of complications and build capacity to initiate corrective actions.

As many transplanters would agree, most of the work which contributes to the success of bone marrow transplantations happens at the thalassemia centres. We had a capacity building program where there was discussion on how to ensure that the children who are undertaking management are maintained in best possible shape once they find a match. It's true that the outcome of BMT depends upon the physiological status of the child including the ferritin level, the liver size and the spleen size etc.

"The best way out is always through." - Robert Frost

However, what is also true is that using proper therapy, the damage caused to the body can be reversed and the child can be brought from higher risk to lower risk categories prior to proceeding for transplants. With this intention, our teams geared up for state of the art down-staging program and collaboration with the transplant teams.

In addition, the post transplant followup is also more effective if done in the friendly and more familiar environment of the day care centre rather than the hospitals themselves. With this intention, steps are being taken to ensure that the child who undertake BMT with Sankalp's support continue to receive best care post transplant through the day care centres.

The Emergency Team and the Blood Help-line

The blood help-line has consistently been receiving 30-60 blood requests and a total call load of about 100 calls per day (not to forget the 20% requests which come in the middle of the night). With such busy schedules, when an unfortunate event takes

away the person who is managing the calls on the help-line number for the day, it amounts to a very difficult day for the volunteers. August was one such month. On one hand the city was desperately seeking platelet and on the other hand we had difficulty organising for people to manage calls. Then Akshata, the new Response Centre Executive came in. She picked up the task at hand very quickly and learnt the intricacies of differentiating between blood requests and providing appropriate solutions.

Now, not only does she take the regular blood requests which can be handled with the blood stocks in the blood banks, she has also been taking care of requests which require donors, single donor platelets and even some rare blood groups. The option of getting informed advice on a single call when it comes to need of blood is a very strong asset. The information available through the help-line is becoming more elaborate and situationally accurate. With the option of reaching out to the help-line on a call, almost anyone can seek assistance.

Call when you collect or need a unit of Bombay Blood Group!



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"Whoever is happy will make others happy too." - Anne Frank

Onam: the color of god's own country

Onam is the biggest and the most important festival of the state of Kerala. It is a harvest festival and is celebrated with joy and enthusiasm all over the state by people of all communities. According to a popular legend, the festival is celebrated to welcome King Mahabali, whose spirit is said to visit Kerala at the time of Onam. Onam is celebrated in the beginning of the month of Chingam, the first month of Malayalam Calendar (Kollavarsham). This corresponds with the month of August-September according to Gregorian Calendar.

Carnival of Onam lasts from four to ten days. First day, Atham and tenth day, Thirunam are most important of all. Popularity and presentation of rich culture of the state during the carnival made Onam the National Festival of Kerala in 1961. Thiruvathira kali, a dance form with rhythmic clapping is performed during onam days. Elaborate feasts, folk songs, elegant dances, energetic games, elephants, boats and flowers all are a part of the dynamic festival called Onam. Government of India has taken due notice of this vibrant and colorful festival. It promotes

Onam internationally in a big way and celebrates 'Tourist Week' for Kerala during Onam celebrations. Thousands of domestic and foreign tourists visit Kerala to be a part of Onam.

Onam is also a harvest festival. It is celebrated at a time when everything appears so nice and good. The beautiful landscape of Kerala can be seen in its full radiance at this time of the Malayalam New Year. Weather, it seems, also seeks to be a part of the festival. It contributes by becoming pleasantly warm and sunny. Fields look brilliant with a bountiful harvest. Farmers feel on top of the world as they watch the result of their hard labour with pride.

Story goes that during the reign of mighty asura (demon) king, Mahabali, Kerala witnessed its golden era. Every body in the state was happy and prosperous and king was highly regarded by his subjects. Apart from all his virtues, Mahabali had one shortcoming. He was egoistic. This weakness in Mahabali's character was



"To the mind that is still, the whole universe surrenders." - Lao Tzu

utilized by Gods to bring an end to his reign as they felt challenged by Mahabali's growing popularity. However, for all the good deed done by Mahabali, God granted him a boon that he could annually visit his people with whom he was so attached. It is this visit of Mahabali that is celebrated as Onam every year. People make all efforts to celebrate the festival in a grand way and impress upon their dear King that they are happy and wish him well.

Rich cultural heritage of Kerala comes out in its best form and spirit during the ten day long festival. It is indeed a treat to be a part of the grand carnival. A typical onam sadya. People of Kerala make elaborate preparations to celebrate it in the best possible manner. Religious and traditional people of Kerala sincerely follow all the customs and traditions set by their ancestors. A number of cultural programmes, dances, songs and feasts mark the festival. The most impressive part of Onam celebration is the grand feast called Onasadya, prepared on Thiruonam. It is a

nine course meal consisting of 11 to 13 essential dishes. Onasadya is served on banana leaves and people sit on a mat laid on the floor to have the meal. Another enchanting feature of Onam is Vallamkali, the Snake Boat Race, held on the river Pampa. It is a colourful sight to watch the decorated boat oared by hundreds of boatmen amidst chanting of songs and cheering by spectators.

There is also a tradition to play games, collectively called Onakalikal, on Onam. Men go in for rigorous sports like Talappanthukali (played with ball), Ambeyyal (Archery), Kutukutu and combats called Kayyankali and Attakalam. Women indulge in cultural activities. They make intricately designed flower mats called, Pookalam in the front courtyard of house to welcome King Mahabali. Kaikotti kali and Thumbi Thullal are two graceful dances performed by women on Onam. Folk performances like Kummatti kali and Pulikali add to the zest of celebrations.



"From a small seed a mighty trunk may grow." - Aeschylus

Workshop on thalassemia prevention, management and cure

Just prior to the inauguration of our BMT unit on 27th August 2015, we organised a Workshop on Thalassemia Prevention, Management and Cure. People who have committed their lives to the cause of thalassemia from all over the country were generous enough to come all the way to participate in this workshop to discuss and deliberate on the best strategies being adopted all over the country.

The program had 3 sessions, one each on Thalassemia Prevention, Management and Cure. Each session started with experience sharing by individuals representing the organisations which we believed have done pioneering work followed by open house discussion. Mr Vinay Shetty from Think Foundation, Mumbai led the session on Thalassemia Prevention, Dr Reshma Srinivas from Project Samraksha, Rashtrathana Parishat, Bangalore led the session on Management and Dr Priya Marwah from South East Asia Institute of Thalassemia, Jaipur led the session on Cure. In spite of very interesting topics, insights and enthusiasm to deliberate more, the limited time available for the workshop became a huge bottleneck. However, this workshop, which was organised more in a round table manner with people getting an opportunity to discuss and debate has in the past shown better outcome compared to the traditional classroom like speeches and talks.

Few aspects which came out very clearly

included:

huge variation in the quality of care being delivered across the centres in the country.

huge variation in the cost of care.

the limited penetration of evidence based medicine in the healthcare delivery setup.

While all of these problems are common across all arenas of the public healthcare setup, in case of chronic disease management, especially for the children, the implications are very serious. It's not surprising that 90% of the children born with thalassemia die without access to proper care and management.

One way to hope for the resolution of the problems is wait for the Government to take some steps. There is a lot of focus on getting this done. However, as an organization Sankalp believes that there is scope for more to be done by the other stakeholders, including patient groups, non-profits, healthcare setups etc. which can add quality and reliability to the delivery of care even in resource limited setting. This is where innovation comes into picture. This is where networking and knowledge sharing is an enabler. with that intent in mind we have initiated such programs and hope to continue to organise more of these. Huge amount of capacity building and competency is needed at grass-root levels to fight thalassemia. The best time to do it was yesterday, the second best is *today*.

"I dwell in possibility." - Emily Dickinson

We are offering HLA Typing



At Sankalp India Foundation, We firmly believe that each child must be given an option for complete cure irrespective of their financial status. The HLA test is the first step which determines whether the sibling can be a matched donor to the child suffering from thalassemia. The cost of HLA typing in India is around Rs. 10,000/- per child making it inaccessible to most families. Unfortunately, most families suffering from thalassemia are unaware of the possibility of cure.

There is good news. Currently, we are offering free HLA typing to those children with thalassemia who have a healthy sibling donor in association with Cure2Children Foundation, Italy. So far this facility was available for the children taking transfusion at centres supported by Sankalp. We are

happy invite the families to make use of this opportunity. Please spread the word about the availability of this option for the families. The families can call our central help-line number 9480044444 for further information and appointment. We have limited number of free testing slots and we consider the eligibility of the family to avail free HLA typing on a case by case basis.

Supported by Cure2Children Foundation, Italy



"A compliment is something like a kiss through a veil." - Victor Hugo

Registered Newspaper

Registered RNP / KA / BGS / 2179 / 2015-17 | Cost of single copy Re. 1/- | Posted on 17th of every month at Bangalore-PSO. | RNI No: KARENG/2010/35892
Total Pages: 16

From:
Sankalp India Foundation
#460, "GOKULA",
8th Main, 4th Block,
Koramangala,
Bangalore - 560034.

Published for Sankalp India Foundation by Rajat Kumar Agarwal at #460, "GOKULA", 8th Main, 4th Block, Koramangala, Bangalore - 560034.
Printed by ShivaPrakash R at Saraswati Binding Works, 1/1, 3rd B Main, 13th Cross, Cholurpalya, Bangalore - 560023
Editor: Rakesh Dhanya. © All rights reserved. Reproduction in whole or in part without permission of the Publisher is prohibited.
RNI No: KARENG/2010/35892

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