

sankalp patrika

A monthly newsletter by Sankalp India Foundation
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BLODCON 2019 successfully organised

BLODCON 2019 the biennial 'National Workshop & Conference of Blood Donor Motivator Organisations' organized by the Federation of Indian Blood Donors Organisations- FIBDO, was hosted by Sankalp India Foundation, Bangalore together with National Blood Transfusion Council (NBTC), Ministry of Health And Family Welfare (MoHFW), Government of India. 60 representatives of blood donation organizations from India and abroad participated in the meeting.

This Conference and Workshop is of momentous significance for intensifying the voluntary blood donation movement. The event was aimed at providing a platform to our delegates to review the current activities and strategies for promoting voluntary blood donation movement. A key feature of this conference was on providing a significant thrust on education and training for the blood donation organizations to enhance their contribution to the

quality of blood donation camps. Dr Sundar Priyavan, Dr Girish C J, Dr Vijay Kumawat, Dr Ashish Dhoot, Dr Sumithra R and Dr Sandeepan Ghosh took the responsibility for the educational sessions. Their participation contributed not only to improving the readiness of the organisations to play an active role in enhancing quality of blood drives but also paved the way forward for closer and more meaningful organiser and blood bank cooperation.

The conference saw a leap forward on the donor side of National Haemovigilance Program of India with the participation of Dr.(Mrs) Reba Chhabra, the Director In-charge of the National Institute of Biologicals, Noida and Dr. Akanksha Bisht the in-charge of the National Haemovigilance Program of India. They highlighted how organisers should now begin to demand that the complications seen during the blood donation drives be reported to the NIB and in-fact consider this as one

Dr Swati Kulkarni from the National Institute of Immunohaematology Mumbai also attended the program. She spoke about the newly introduced detection of rare blood types and the activities / programs at NIIH which are of relevance to blood donors. With several key organisations who are involved in the management of rare blood types in India participating in the event, interaction with her has opened the doors for further collaboration.

A significant ongoing challenge continues to be the wide gaps between policy and ground reality. The fact that there is fragmentation at the Government level when it comes to matters relating to blood transfusion services has ensured that the Nation's Blood Policy has no single owner and implementer. The subject has come up for debate on various forums time and again and there have been discussions about addressing the concerns of the organisations actively working to ensure timely supply of voluntarily donated blood to the needy. Nevertheless, the progress continues to be very slow and consequently we are all set to miss the

mission 2020 deadline for achieving 100% voluntary blood donation. The meeting deliberated on this issue and finally decided to draw the attention of the Government at the highest level to this matter.

During the meeting, a decision was also taken to study the non-compliance in blood donation camps across the country. Sankalp has been entrusted with the responsibility for drafting and circulating the study proposal which is likely to be an eye opener on the quality and variability in blood drives across the nation.

A blood donation drive was organised by Narayana Health at the conference venue with the specific purpose of demonstrating the quality processes in action to the participants. A soulful and much appreciated performance by The Udupa Foundation, a registered charitable trust with the aim of promoting music, performing arts and culture contrasted well with the high intensity discussion and sessions.

Team Sankalp is thankful to FIBDO to give us the opportunity to host the event and to everyone who played a role in making this event a success.



Season's greetings
and wishing you a
very happy new
year - 2020.

Dr Charles Sklar visits us - New Chapter in handling Endocrine Complications Begins



In 2013, one morning a few weeks after the new day care cent with Rashtrathana Parishat started, a 24-year-old girl was brought into the day care supported by 2 people. She could not walk and her skin tone seemed abnormal - thanks to the heavy iron overload. Till this age she had never taken a medicine to remove iron. She was grossly under-transfused as her family had struggled to organise the AB- blood units that she had. She had brittle bones, pain and no confidence.

The situation looked very bleak and the same showed on her face. In our first conversation with her, the main goal was to give her confidence that things could potentially improve with proper care. Almost mindlessly, as part of a larger conversation one of us remarked - "someday you may even get married". There was silence in the room and that's when realization came that she may not even have started menstruation. The team got the right things going right away, and it showed results. A few months later, the same girl who was carried into the day-care told her mother not to come along for transfusions as now she was a big girl! Visibly she was happier. The doctor in-

charge shared with us that she has started her periods. On the next world thalassaemia day, the girl was all over the place, hopping around, chirping, ensuring that everything was perfectly organised for the little kids who she wanted to have a great day. The little girl got our team to appreciate the importance of development more than any book could have ever explained.

14-15th October 2019 have been marked with a lot of warm emotions and fondness in the book of Sankalp India Foundation and Cure2Children Foundation, as Dr Charles Sklar, Pediatric Endocrinology who was the Director of Long-Term Follow-Up Program at Memorial Sloan Kettering, New York spent time with us helping us take a leap forward in caring for abnormalities of physical growth and sexual development, and treatment of endocrine disorders both for those kids who have received bone marrow transplantation at our centres and those who continue to receive care for thalassaemia. This visit was an occasion to define the problem statement better and initiate work towards a strategy for comprehensive management.

The last three months were spent in anticipation and preparation of Dr Sklar's visit, getting kids to be examined for development and their hormone levels measured. Dr Sklar examined a selected group of kids along with our medical team which was followed by case discussions. It was an emotional moment to meet some kids who were so far off from transplant. Seeing them having restored some normalcy in life even with thalassemia and other disorders was quite moving. Now starts the journey to take the 'normalcy' beyond end of transfusions - and achieve more on growth and development front. One day was also spent with the kids who are likely suffering from endocrine issues because of thalassemia itself and associated iron overload. As the day progressed, it was clear that whatever strategy and system we have put in place for transfusion and chelation management could be extended to offer world class care for endocrine problems across our day care centres - a goal which is far too important to be delayed any further.

Deliberations on the wider issues of toxicity associated with treatment regimen, identification of source of problems, what to anticipate on a long term with the treatment that we use, what could be the best steps forward for our kids and several other topics happened to be discussed through the two days. Dr Sklar also promised to be involved on a regular basis to help setup monitoring and treatment guidelines, review specific complicated situations and periodically visit us to ensure that we continue to make good progress towards the lofty goal that we have opted to undertake.

Dr Lawrence Faulkner has been a strong advocate of ensuring that treatment regimens be designed taking into account the long-term interest of the patient

rather than just achieving success at transplants. With Dr Sklar's participation, the team is in a much more competent position to ensuring that our kids don't just get the best possible transplant outcomes but go back to society in best shape possible.

It's amazing that we are now talking about long term survivorship program - even with our limited resources and challenges! It's wonderful that the people who have spent their lives solving specific issues are joining in the team to make an overall integrated impact. No words of gratitude are enough for all those who in very unique ways have made this journey possible. The entire team feels more resolved and determined to do what is right - to give life a better chance!



"Great dreams of great dreamers are always transcended."

- Dr.A.P.J.Abdul Kalam

Thalassemia Minor test to be made mandatory in first pregnancy of every woman



AHMEDABAD : How Thalassemia major is a national health challenge caught the interest and attention of Dr Kirit Premjibhai Solanki, Member of Parliament, Ahmedabad West, when he paid a visit to a Thalassemia Day Care center and a Bone Marrow Transplant center at CIMS Hospital, followed by a Symposium on Thalassemia Prevention on Wednesday, 16th October 2019.

These events were organized jointly by Shree Jalaram Abhyudhaya Sadbhavana Trust, Ahmedabad; Sankalp India Foundation, Bangalore; and Amit Iyer Memorial Foundation, Mumbai; at CIMS Hospital auditorium.

Dr Solanki's interacted with Thalassemia major children and parents, made enquiries with each one of them and distributed small gifts to the children. He was overwhelmed to hear about the suffering these children go through and empathized with them.

Thereafter, he paid a visit to the Bone Marrow Transplant centre at CIMS Hospital and personally observed the manner in which this cure for Thalassemia is administered. He was quite impressed to know that this centre has cured over 90 children in the last two years and the success rate is 95%. He was also glad to know that BMT is being offered at a low cost of Rs 9 lakhs only on a not-for-profit basis.

In the following Symposium Mr S V Iyer, Trustee of Amit Iyer Memorial Foundation in his keynote address emphasized the importance and need for an effective prevention programme. He concluded that a targeted approach of screening every woman at her first pregnancy is the most effective and practical way forward. On behalf of Dr Kirit Solanki, who is also the Chairman of Indian Medical Parliamentarians Forum (IMPF), Mr Vinod Bhanu assured that IMPF will do all in their power to propagate and promote the prevention program.

Dr. Deepa Trivedi, Peadiatric Heamatology-Oncologist & Head of the BMT unit made an interesting presentation on the work the BMT centre is doing. Dr Lawrence Faulkner of Cure2Children, Italy, drew attention to the need for an effective prevention program for India and related his experience in other countries like Italy. The welcome address was made by Mr Lalith Parmar, President of Sankalp India Foundation, and a Vote of Thanks was extended by Mr Rajiv Ravani, trustee of Shree Jalaram Abhyudhaya Sadbhavana Trust. The program was attended by NGO's like TSCS, Hyderabad, Ved Foundation, Ahmedabad and many more.

"You can often find in rivers what you cannot find in oceans."

- Indian Proverb

Thalassemia and Sickle Society - Hyderabad and Sankalp come together for Cure



Thalassemia and Sickle Cell Society of Hyderabad is the single largest centre dedicated to care of patients from hemoglobinopathies in India. Sankalp and TSCS have worked together for several past years.

14th October was a very important day as the two organisations came together to join forces and redouble our efforts for a Thalassemia Free India. Mr Chandrakanth Agarwal the Chairman and Dr Suman Jain the CEO of TSCS came to Bangalore as we signed our MOU.

Once the MOU was signed the first batch of children were prepared for transplant. All the children who are likely candidates for transplants are being followed up on a weekly basis to prepare them as much as possible for the transplant. January 2020 came in with fresh cheers as the first 2 kids from TSCS got admitted to

Sankalp-People Tree Centre for Pediatric BMT under this MOU.

This is a new beginning for the numerous families who are receiving care offered by Thalassemia and Sickle Cell Society Hyderabad. For a thalassemia day care centre, having an option for reliable cure being made available systematically has had a positive impact on the wellbeing of all the patients, and contributes to increased compliance.



"Life is not a continuum of pleasant choices, but of inevitable problems that call for strength, determination, and hard work"

- Indian Proverb

When our kids got an opportunity to Make a Wish!

Make a wish Foundation and Cipla Foundation had jointly organized an event "Make a wish" on 27th September 2019 for 25 kids, who had undergone the Bone Marrow Transplantation at Sankalp-People Tree Centre for Paediatric BMT - Bangalore.

This event was mainly to fulfill the wishes of the children who are from an economically less fortunate background, who are diagnosed with a life-threatening medical condition. Make a Wish team and Cipla foundation identified such children and made their wishes come true by fulfilling their grants. Most of the children wished to have things like mobile phones, cycles, television sets, remote cars, dolls, tablets etc.

Kids from different locations had come for this program which was organized at People Tree hospital. The kids were given a chance to showcase their talents in drawing, coloring, building blocks and other fun activities were arranged for them.

Post that the kids received their gifts which they had wished and it was like their dreams coming true for them. Most of the kids forgot about their pain and were completely immersed in the joy of receiving the gifts.



" I suppose leadership at one time meant muscles; but today it means getting along with people."

- Indira Gandhi

PERFORMANCE REPORT

Sankalp Program For Thalassemia Management

Centers	Total Patient (patients)	Number of units of blood transfused (units)	How many day old blood units were transfused (days)	Time taken to process blood components (hours)	Pre-transfusion Hemoglobin Median (g/dl)
			<7: Good 7-10: Average >10: Bad	<2: Good 2-3: Average >3: Bad	>9: Good 8-9: Average <8: Bad
Indira Gandhi Institute of Child Health	236	737	7	3.0	9.5
Project Samraksha	381	1264	3	2.3	9.5
KLE Belgaum	215	528	3	3.5	8.7
Wenlock Mangalore	100	301	5	4.0	10.0
TSCS of Central India, Nagpur	92	266	4	1.0	9.2
RMMG Abu Road	31	129	4	0.5	9.3
IRCS Rajkot	72	309	4	1.5	9.2
Samarpan, Mumbai	123	880	7	3.5	10.6
SJAST Ahmedabad	279	285	6	3.0	9.1
IRCS Nellore	45	90	2	0.8	8.9
IRCS Elluru	172	271	3	2.0	7.8
HST Dehradun	85	38	12	2.0	7.7
TOTAL	1831	5098	5.0	2.3	9.1

Bombaybloodgroup.org

	Total bombay blood group requests	Number of units organised off the shelf	Number of units donated
Last two months	22	23	2
2019-20	119	89	15
2018-19	127	74	14

Nov - Dec 2019



Sankalp Program For Thalassemia Cure

	Total Transplants Done	Overall Survival	Disease Free Survival
People Tree, Bangalore	162	87%	74%
CIMS, Ahmedabad	103	98%	95%
Other Centres	11	91%	82%
Total	276	92%	82%

Rakta Kranti - The Blood Revolution

	Blood Donation Camps	Total Donors	Total Units Collected	Rate of Post Donation Complications	Rate of Donor Deferral
				<2%: Good 2-4%: Average >4%: Bad	<10%: Good 10-15%: Average >15%: Bad
Last two months	37	3935	3273	🚩 3.4%	🚩 16.8%
2019-20	182	14964	12476	🚩 3.8%	🚩 16.6%
2018-19	216	17627	14869	🚩 3.5%	🚩 15.6%

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

Altisource
Bhartiya City
Blue Ocean
Bosch
Brigade Metropolis
CGI
Conduent Labs
Coviam
Deutsche Bank

DSR
Finastra
Golden Metro
IQVIA
Mahaveer's Place
Manipal
Mantri Espana
Masjid E Mamoor
National Law School

Philips
Swiggy
Synamedia
Trelleborg
Uttishta Bharatha
Wipro
Yokogawa
Zyme

ThalMeet 2019 – Half yearly meeting of Thalassemia Day Care Centers organized in Bangalore



23-24 September 2019, Bangalore.

Annual Thalassemia meet 2019, was organized by Sankalp India Foundation on 23rd and 24th September 2019 for all day care coordinators, nursing staff and doctors. This is an ongoing event which is held twice a year. This event involves brainstorming with the participants in an attempt to understand as well as enhance their knowledge with regard to Thalassemia management, decoding lab investigations and interpreting reports. The event also involves providing intense training to coordinators and nurses to handle day to day clinical issues, new technologies and facilities available in ThalCare (a comprehensive thalassemia management software platform). This event helps to create and build a strong network of coordinators and nurses which go a long way in strengthening thalassemia care as a whole.

The event saw active engagement of participants in several sessions. Dr. Lawrence Faulkner, Pediatric Hemato Oncologist and lead Medical coordinator of

Cure2Children and Sankalp India Foundation spoke about Sankalp's experience in Bone Marrow Transplantation. He highlighted that the care in the day care centers has been very focused and patients were very well managed. He also shared his knowledge and experience on haplo transplant which was a good learning / knowledge sharing for the team. The session helped improve the understanding of the day care team's role in curing the children, the importance of following the Thalassemia Management Protocols of the network, understanding of the complications of hematological disorders.

Dr. Stalin Ramprakash, Pediatric Hemato Oncologist and Program Director of the Sankalp People Tree Center for Pediatric Bone Marrow Transplant spoke about effective transfusion practice, management of iron overload, and how to ensure quality in transfusion management. Dr Raghuram, Consultant Pediatric Hemato Oncologist at Sankalp People Tree Center for Pediatric Bone Marrow Transplant spoke about the

"A person can achieve everything by being simple and humble"

- Rig Veda

usage of Hydroxyurea for different conditions, management of splenomegaly, prevention and management of transfusion transmitted infections.

Dr. Suman Jain, CEO Thalassemia Sickle Cell Society, Hyderabad shared her experience in prevention of new Thalassemia birth in centers and also she educated the team on how to interpret the HPLC report and confirm the diagnosis. Mr Rakesh Dhanya, CEO Sankalp India Foundation spoke about lab investigation frequencies and Sankalp's aim at finding more partners and reach out to many more kids with systematic, reliable and holistic care and management

Beside the core skills, in this meeting we also focussed on improving the life skills of the team. We were very fortunate to have Mr R N Prasad, our mentor, take a session on how to grow in our career. He educated the team using various videos, examples and stories. The session was interesting and motivated the participants to learn and grow.

Dr Jayaranganath M, Pediatric Cardiologist from Sri Jayadeva Institute of Cardiology, Bangalore spoke about prevention and management of cardiac complications. He also briefly explained about reading the cardiac screening report, interpretation and necessary actions to be taken. Mr Santhosh Hegde, the Project Manager of Sankalp Program for Thalassemia Management, enlightened the team about the new changes in the ThalCare, retrieving data and report generation in the system. The last session was wrapped up by Mr. Lalith Parmar from Sankalp group who shared the progress, the vision and future plans of Sankalp India Foundation.

We would like to take this opportunity to thank Sun



Pharma who supported the program.

Overall, the 2-day sessions involved holistic knowledge sharing sessions with meaningful queries and interactions. The participants went with new learnings and clear lines of action for improving the quality of Thalassemia care in their day care centers.

Coordinators, nurses and doctors from the following Thalassemia Day care center were present.

- 1) Indira Gandhi Institute of Child Health, Bangalore
- 2) Project Samraksha, Bangalore
- 3) Jai Shiv Shakti Centre for Thalassemia Management, Jawaharlal Nehru Medical College and KLE Hospital, Belgaum
- 4) District Wenlock Hospital, Mangalore
- 5) Thalassemia Society of Central India, Rughwani Hospital, Nagpur
- 6) Indian Red Cross Society, Rajkot
- 7) Rural Development Trust, Ananthpur
- 8) Samarpan, Mumbai
- 9) Jalaram Daycare Center, Ahmedabad
- 10) Indian Red Cross Society, Nellore
- 11) Indian Red Cross Society, Elluru
- 12) Sickle Cell Society, Hyderabad
- 13) Vishwa Bharti Thal Daycare Center, Kurnool
- 14) Mamtha Foundation, Vijayawada.

Little Karmaraj Got A New Life!

Nani Vavdi is a very small village near the Morbi city in the western part of Gujarat. The village has a limited number of populations. Bhaudeepsing and Varshaba got married a few years ago and started a "Happy Married Life". Bhaudeep was a school auto rickshaw driver, who was earning very less but that was quite sufficient to survive in a small village.

After one year of marriage their lives bloomed, because of having a birth of a little princess named Dhara. They all were living happily in a joint family. Again after 2-3 years Varshaba gave birth to a small prince named Kamaraj.

After six months something went wrong, Kamaraj started looking pale. Bhaudeep took him to the primary health care center but the doctor advised them to take him to Morbi Civil Hospital as there was no sufficient medical facility for the treatment. At Civil hospital doctor advised them for a few blood tests. After seeing the reports, the doctor was shocked to see that the child was suffering from a life threatening disorder called Thalassemia. It means now Kamaraj needed blood transfusion every month for life.

Many of their relatives advised them not to go for further treatment and plan for another healthy child! But the family was against it and had decided to fight the disease till the end and to save their prince.

Every 25-30 days they used to go to Morbi Civil Hospital for blood transfusions, as it was working out to be costly in a private hospital. Kamaraj was also on iron chelation treatment to avoid overload of iron. This treatment became a part of life for the family. In spite of free treatment, it was very tedious for the family.



They were looking for a permanent solution for this disease.

They came to know about free HLA matching camp at Rajkot which was organized by Sankalp India Foundation. They came to know about the Bone Marrow Transplantation, which is the only permanent cure for thalassemia disease. They underwent an HLA test at the camp. Few months later the test reports revealed that Kamaraj has a fully matched donor, his sister. The family found it difficult as the treatment was going to be very expensive and they would never be able to afford it. But with regular interaction with Sankalp medical team and coordinators assurance for the financial support, the family gained hope and confidence to proceed for the Bone Marrow Transplantation.

The family raised some funds and the balance was raised by the Sankalp India Foundation. Karmaraj underwent BMT at CIMS hospital, Ahmedabad. He has been discharged and is under post transplant care. The family is happy to see the child, a new life without blood transfusion and slowly recovering and getting into a normal life. Sankalp team wishes Karmaraj a speedy recovery!

"Learn from the mistakes of others. You can't live long enough to make them all yourselves!"

- Chanakya

Thank you ISBTI and Sri Jayadeva Institute of Cardiovascular Science!



Sankalp India Foundation was awarded for Excellence in Voluntary Blood Donation at the Transcon 2019 - the 44th Annual Conference of Indian Society of Blood Transfusion & Immunohaematology on 3rd November 2019 at Jalandhar Punjab. We thank ISBTI for the honour. We also take this opportunity to congratulate and thank colleagues at ISBTI Karnataka who have been very active in strengthening voluntary blood donation movement.

Sri Jayadeva Institute of Cardiovascular Science and Research confers Humanitarian Award upon Team Sankalp on Mahatma Gandhi's 150th Anniversary. Celebrating the 150th birth anniversary of Mahatma Gandhi on 2nd October 2019 by recognising the contribution of 4 individuals and 4 organisations to greater good by conferring upon them the Humanitarian Awards. In recognition of contribution to

voluntary blood donation movement, thalassemia and for the work done in bone marrow transplantation, Sankalp was honoured to be among the organisations which were selected to be the recipient of this honour. We thank Team Jayadeva for the continued collaboration, support and encouragement.



"The great are strongest when they stand alone, A God-given might of being is their force."

– Sri Aurobindo

CME on late effects of chemotherapy organised



Since Dr. Sklar was in Bangalore to spend time with us we thought it would be a great opportunity to share his experience not only with us but also with other Hemato Oncologists. So, we had organized an event where the doctors from all over south India had come to witness his session. He shared his views, experiences and ideologies on the treatment of childhood cancers, how to reduce the toxicity, late effects of radiation, very high risk factors of cardio and

pulmonary issues and death due to recurrence. The session was also briefed by Dr. Lawrence Faulkner on Thalassemia management and late effects of Thalassemia. He also highlighted that 50% of patients die before Transplantation in India and also, he stressed that the chemotherapy is more damaging on the fertility related issues which is a big concern and how we can try and control the issue. We thank Sanofi for supporting the program.

Monthly long term followup clinic. BMT team celebrating cure with the little ones



It's never too late to start over. If you weren't happy with yesterday, try something different today.
Don't stay stuck. Do better.

Five abstracts presented at the ASH Annual Meeting



We are happy to share that 5 abstracts by the Sankalp-Cure2Children Network were selected to be presented at the 61st Annual Meeting of the American Society of Haematology held in Orlando-USA in November 2019. Dr Lawrence Faulkner, our Medical Director and Dr Pallavi Mehta represented our team at ASH this year.

pool of knowledge available to cure patients suffering from serious blood disorders, especially in the context of low- and middle-income countries. Our findings have been addressing issues which are peculiar to limited-resource settings and thereby contributing to personalised medical practice. The abstracts which were selected were on the following subjects.

We are happy to be making active contributions to the

Peripheral Blood to Marrow Collection White Cell Count Ratio As an Indicator of Harvest Quality and Transplant Outcomes in G-CSF-Primed Marrow Grafts

Incidence, Risk Factors and Outcomes of Venous Occlusive Disease / Sinusoidal Obstruction Syndrome (VOD/SOS) in Children with Severe Thalassemia (ST) Conditioned with Busulfan- Cyclophosphamide (Bu-Cy) Based Regimen

Information and Communication Technology Applied to Continuing Quality Improvement for the Care and Cure of Childhood Severe Hematological Disorders in India

Assessment of Mortality and Its Associated Risk Factors in Patients with Transfusion Dependent Thalassemia in India

In-Vivo Adsorption of Iso-Haemagglutinin (IHA) Antibodies By Donor Type Red Cell Transfusion during Conditioning Is a Safe and Effective Method to Overcome Major ABO Incompatibility-Related Acute Hemolytic Reactions in Stem Cell Transplant Using Bone Marrow As Stem Cell Graft Source

"Some goals are so worthy, it's glorious even to fail"

- Capt. Manoj Kumar Pandey, PVC



Glimpses from our blood donation drives

From:

Call: 9480044444 | Visit: www.sankalpindia.net

Mail: contact@sankalpindia.net

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Koramangala, Bangalore - 560034

To: