ISSN: 2455 – 409X

sankalp patrika

A monthly newsletter by Sankalp India Foundation
Volume 7 | Issue 04 | April 2017

Let's give life a better chance

We step into our 15th year

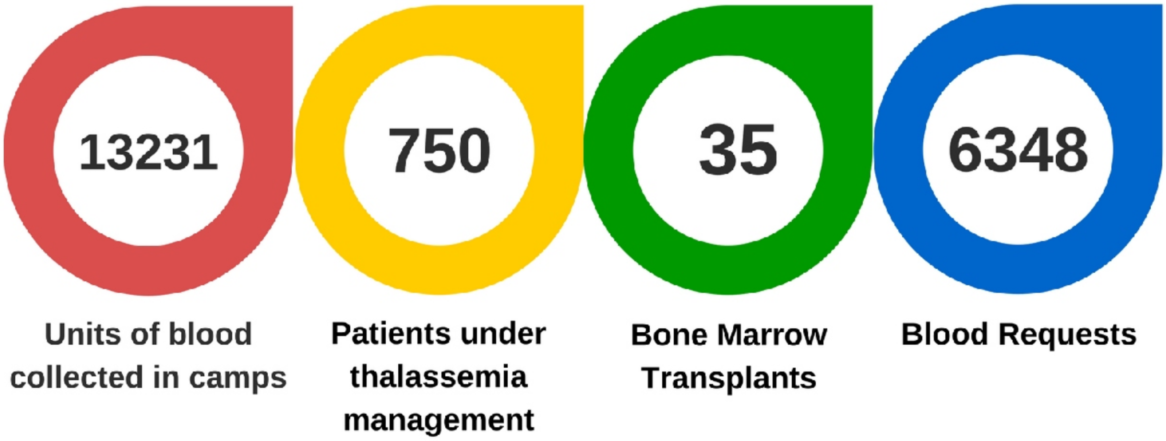
Time has flown by and we have entered the 15th year of operations. When we started off in 2003, little did we know what distance we would have walked. Sankalp has progressed from a truly voluntary organisation to something that today employs nearly a dozen people in powerful change making roles. With the purpose of 'Giving Life A Better Chance' Sankalp we wanted to fight the limitations of the current healthcare delivery systems involved in blood donation and thalassemia by building systems which promise to make the problems associated with these domains a thing of the past.

It is indeed a matter of great honor to be today counted as one among the select organisations in the country who specialize in blood donation services, emergency blood management, thalassemia and bone marrow transplants. With the growth numbers showing up year on year, we believe we are on the right track to ensure that world class health care in the field of thalassemia and blood transfusion services be made available to the needy irrespective of their social and economic status.

The financial year of 2016-17 has been the busiest in our history. Like every year, each project made significant progress. While our 3 thalassemia day care centres were busy and bustling nearly 750 registered patients coming for regular treatment, 30 children were taken through the process of BMT to be completely cured of the burden. Rakta Kranti added 13231 units of blood into the city through the 168 blood donation drives organised and as many as 50 emergency and rare group requests were served along with the nearly 8000 regular blood requests on the helpline. We had a new BMT centre in Ahmedabad also come up in the year. Through publications in international journals and paper presentations on a variety of topics both in India and abroad our work was put before the scientific community and was well appreciated.

We thank all our financial contributors, blood donors, partner organisations, friends and well wishers for all the support. We hope that 2017-18 will be even bigger and better!

YEAR 2016-17



"Instead of complaining about your circumstances, get busy and create some new ones."

Proud Achievements in Science & Technology

Sankalp uses it's own custom technology platforms for all it's projects. As a natural consequence, all project related data is captured digitally on a day to day basis. This gives the teams an opportunity to not just view retrospective data from time to time, but also the power to analyze data and consequently bring in regular improvements in the work. Contribution to the field of transfusion medicine, thalassemia and bone marrow transplants is also something that Sankalp regularly offers through such systems.

Although the journey of going for hard scientific analysis, review and eventually publishing the learnings started in 2013-14, it is only in the last 1 year that this is done as a matter of standard practice.

We are extremely happy and proud to share that through our association with our technology partner, Jagriti Inno-Health Platforms, the algorithms, techniques and standard practices for data analytics, reporting and presentation have been automated into most of our platforms. This practice has brought in agility and sustained focus on following the right practices. A large pool of professionals are already part of the Sankalp ecosystem and bring in their expertise and knowledge in ensuring that the papers and presentations have a high degree of scientific relevance.

In this regard, we are happy to share that www.bloodadvances.org the official journal of American Society of Hematology (ASH) has accepted Sankalp-Cure2Children BMT Network's work on using ATG versus Thiotepa for immunospuression for publication. The tile of the publication is "**ATG vs. thiotepa with Busulfan and Cyclophosphamide in matched-related bone marrow transplantation for thalassemia**" We cannot wait for the process to complete and the article to be available online. We will keep it open access and available for all to read, thanks to Cure2Children. Dr Lawrence Faulker from Cure2Children, Italy who medical director of the Sankalp People Tree Bone Marrow Transplant Unit is the main author. A sincere thanks to all the partner organisations and co-authors (from People Tree Hospitals, Bangalore, India; South East Asia Institute for Thalassemia, Jaipur, India; Children's Hospital Pakistan Institute of Medical Sciences, Islamabad, Pakistan; Asiri Central Hospital, Colombo, Sri Lanka; Nawaloka Hospital, Colombo, Sri Lanka) for working with us on this publication.

AMERICAN SOCIETY OF HEMATOLOGY ® blood advances™

"Whether you think you're ready or not, just start right now. There is magic in action"

Another significant breakthrough was achieved in the last month. We are proud to have started submitting our transplant data to the Center for International Blood and Marrow Transplant Research (CIBMTR).

bmtplus

CIBMTR®
CENTER FOR INTERNATIONAL BLOOD
& MARROW TRANSPLANT RESEARCH

The CIBMTR® (Center for International Blood and Marrow Transplant Research®) is a research collaboration between the National Marrow Donor Program® (NMDP)/Be The Match® and the Medical College of Wisconsin (MCW). The CIBMTR collaborates with the global scientific community to advance hematopoietic cell transplantation (HCT) and cellular therapy worldwide to increase survival and enrich quality of life for patients. The CIBMTR facilitates critical observational and interventional research through scientific and statistical expertise, a large network of transplant centers, and a unique and extensive clinical outcomes database.

This sets the bar of transparency, accountability and quality higher. The data from our transplant centers will be submitted electronically to international registries (through BMTPlus); thereby enabling benchmarking of transplant outcomes with the best centers in the world. We believe that this is an important step in the direction of making transplants safer, more accessible in our country.

We are confident that with the addition of more knowledgeable professionals into our network (which is already happening on several fronts), the brining on board of a Clinical Research Associate and the formation of an Institutional Ethics Committee Sankalp will be able to facilitate the studies on various topics of relevance in the field of thalassemia, Bone Marrow Transplants, blood donation and transfusion medicine.

"There is pleasure in the pathless woods, there is rapture in the lonely shore, there is society where none intrudes, by the deep sea, and music in its roar; I love not Man the less, but Nature more."

The special relationship we share with our blood donors at Rakta Kranti

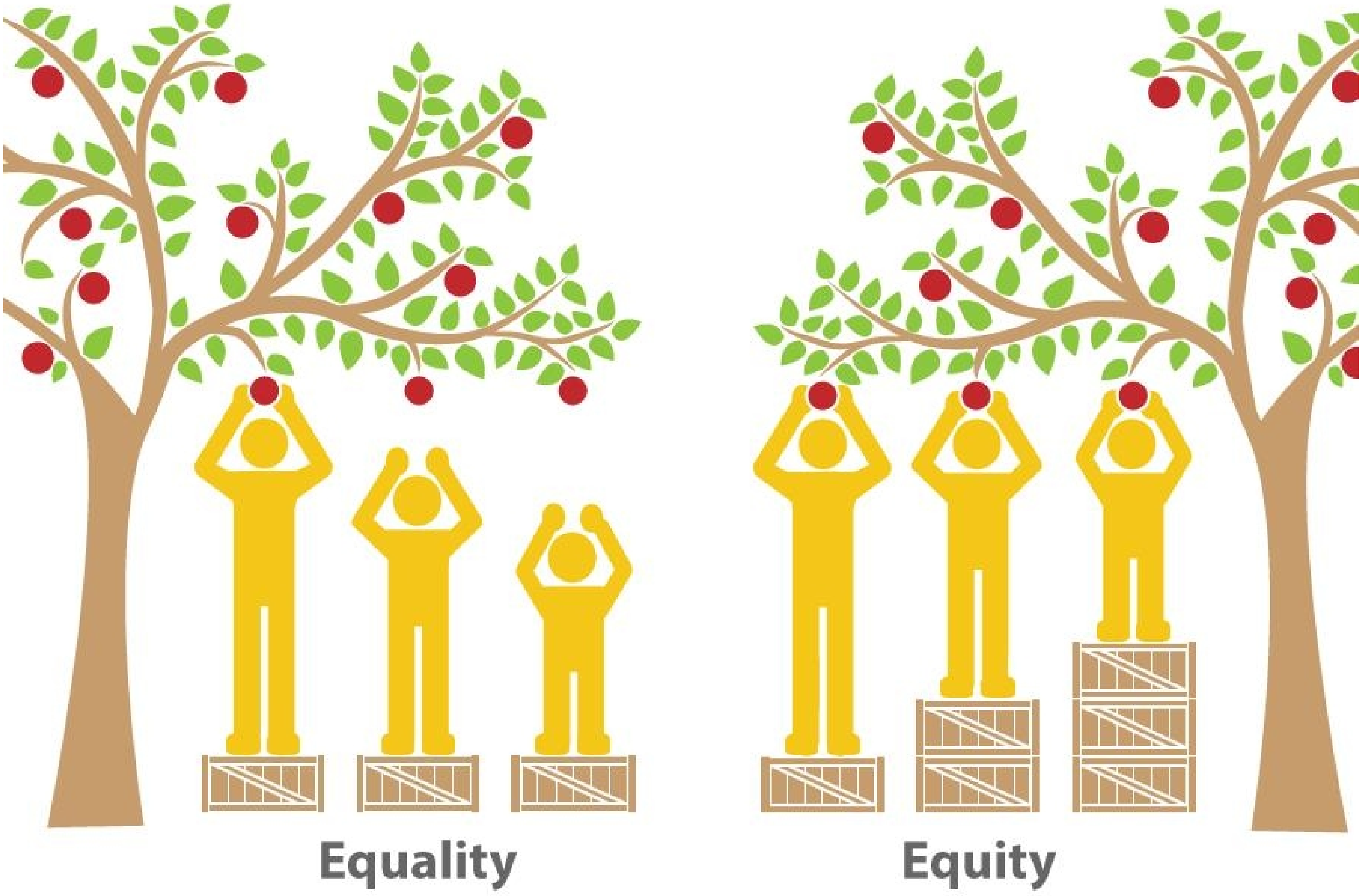
Sankalp India Foundation's programs have often been designed with focus on maximizing benefit to the end recipient. Our Rakta Kranti program however is a little different. Here the focus is the donor the selfless, heroic blood donor. Through the nearly 950 blood donation drives and approximately 83000 units of blood collected, we have focused only on quality in drive execution with maximum compliance to standards.

This thought process has borne fruits. We have built a unique relationship with our blood donors. Testimony to that is our blood donation drives at ITPB. Sankalp has been doing drives at ITPB for the last 10 years. Several donors have donated. Some of them have been donating very regularly drive after drive. These donors are not confined to a single organization. Hence the messaging and connect is not very directly driven by the HR of their respective organization but is strongly managed by Sankalp. Now, several donors walking across the multipurpose hall in ITPB for their post lunch stroll recognize a Sankalp volunteer in a Sankalp T shirt from far away. The next moment they are heading towards the drive, rolling up their sleeves and queuing up to donate. Even with donors confined to messaging from their organization's HR, the story is changing. From the last few months, Sankalp has started sending in SMS invites to donors (only the ones who have expressed their consent to receive updates from Sankalp) for the next drive at their organization. Many have expressed their excitement and gratitude for this invite. The stickers and certificate provided to donors have decorated their vehicles, their desktops and laptops. They feel important and connected to our story.

It is for us the people in the blood banking community to realize that these donors are our people. They are our real gems who when given a good ambience to contribute will come with smiling faces to help Give Life A Better Chance.

"People will believe if you believe in yourself"

Equity of care at our Thalassemia Day Care Centers



The World Health Organization (WHO) has been planning and adopting several measures to ensure that equity of care is never compromised or ignored in the delivery of healthcare.

WHO defines equity of care as (source WHO website page on Equity in Health Systems) "Equity is the absence of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically. Health inequities therefore involve more than inequality with respect to health determinants, access to the resources needed to improve and maintain health or health outcomes. They also entail a failure to avoid or overcome inequalities that infringe on fairness and human rights norms. Reducing health inequities is important because health is a fundamental human right and its progressive realization will eliminate inequalities that result from differences in health status (such as disease or disability) in the opportunity to enjoy life and pursue one's life plans"

It must be noted that equity of care does not necessarily simply mean giving everybody equal opportunity .Equity is about promoting fairness. The

"Strive not to be a success, but rather to be of value." –Albert Einstein

aim of equity is to achieve equality in outcome not in the method to achieve it. In health promotion equity revolves around the achievement of a good level of health for all, which means that each person is given the same amount of control over their own health in order to achieve good health.

Attaining equity of care in a resource constrained and overburdened healthcare system in India is extremely challenging. At most places there seems to be a complete lack of sensitization on the part of healthcare professionals towards such equity measures. This is especially true in the pubic healthcare systems. Whenever the government or enforcement authorities have taken steps to act on this, it has either been that the model is not sustainable or not wholesome and therefore lacking in quality. Individuals with access to good financial resources will always approach the private establishments, while the poor will continue to struggle. Consequently, the availability of better care and cure opportunities is directly dependent upon the social, economical status of the patient. A bigger disadvantage and problem is that the equity of health is mostly not quantifiable due to lack of consistent and reliable methods of recording patient related profile or clinical information.

When Sankalp's first thalassemia day care unit was established it was at a government institute. The economic status of many families was very bad and they came from several remote areas of the state. Therefore, right from 2011 we have aimed at creating a model where all steps required to ensure that the child is doing well medically is put in place.

Our thalassemia day care centres are powered by ThalCare. Capturing intense level of patient profile and clinical information is done as a matter of standard routine for all patients. Every visit is recorded and each test done, blood products transfused, medicines prescribed are all recorded for each patient. This makes it possible for us to investigate if there is any mismatch in the equity of care being provided.

We believe that this possibility to regularly view and analyze retrospective data has implicitly empowered the staff at the centres to achive equity in delivery. It ofcourse also does involve external factors like support, counseling etc. If we were to take chelation as an example, we follow multiple strategies - full support , partial support , support through public healthcare schemes based on eligibility or encourage the family to bear the costs if it is financially viable for them. The baseline goal is to ensure that there is no iron overload to the degree that it can cause damage. Irrespective of how chelation is made available, we constantly review the ferritin levels of all patients to check if there are any trends indicating more intervention. The moment we realize that in successive determinations the child seems to be having disturbing levels of iron overload in the body, we initiate the next level of action. For several of them it could to start them on desferal therapy. This is done without creating any additional financial burden on the family. So here while the review, analysis, intervention techniques are all powered by ThalCare, strategies for support, making additional resources available are all external factors.

We embarked upon an exercise to assess the equity of care at 5 centres powered by ThalCare. All these centres are treating a minimum of 100 patients, and have nearly complete adoption of ThalCare for all patients in their centres .In total the assessment

"Life is what happens to you while you're busy making other plans." – John Lennon

PERFORMANCE REPORT

Sankalp Program For Thalassemia Management

Centers	Total Patient Visits (patients)	Number of units of blood transfused (units)	How many day old blood units were transfused (days)	Time taken to process blood components (hours)	Pre-transfusion Hemoglobin (g/dl)	Share of blood units from attached blood bank (%)
			<7: Good 7-10: Average >10: Bad	<2: Good 2-3: Average >3: Bad	>9: Good 8-9: Average <8: Bad	>95%: Good 90-95%: Average <90%: Bad
Indira Gandhi Institute of Child Health	325	411	🟥 11	🟩 1.8	🟩 9.8	🟩 98%
Project Samraksha	317	381	🟩 3	🟥 3.0	🟩 9.0	🟩 100%
KLE Belgaum	240	235	🟩 2	🟥 3.5	🟩 9.1	🟩 100%

Sankalp Program For Thalassemia Cure

	Total HLA typings	Total number of children offered Bone Marrow Transplantation	Total number of children cured of Thalassemia by Bone Marrow Transplantation
This year	910	28	22
Total	2742	48	38

Bombay blood group network

	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	456	18%	23%
This year (cumulative)	5765	16%	26%
Last year	8392	89%	23%

March 2017

Rakta Kranti - The Blood Revolution

	Blood Donation Camps	Total Donors	Total Units Collected	Rate of Post Donation Complications	Rate of Donor Deferral
				<2%: Good 2-4%: Average >4%: Bad	<10%: Good 10-15%: Average >15%: Bad
This month	7	576	499	🚩 4.0%	⚑ 13.2%
This year	149	13895	11870	🚩 3.6%	🚩 15.2%

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

Blue Ocean
DHL
Robert Bosch

Silvan Innovation Labs
Tata Power

Volunteer for a Cause
Yaskawa

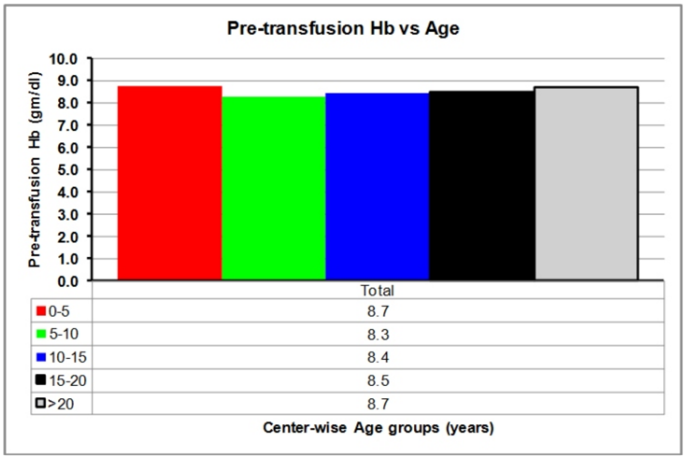
Disha Statewide Blood Helpline - 9480044444

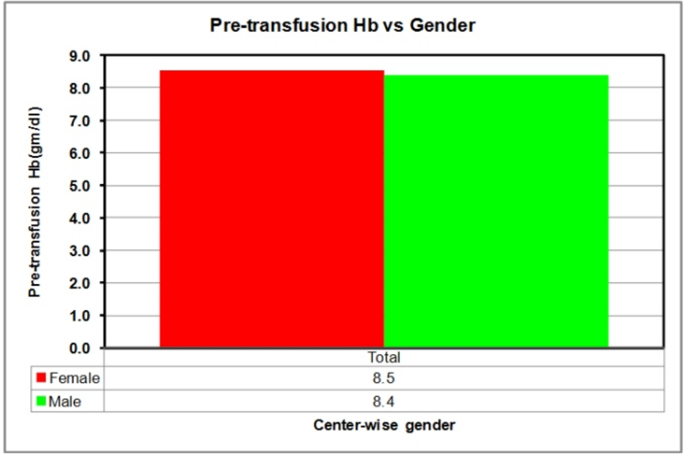
	Total bombay blood group requests	Number of units organised off the shelf	Number of units donated
Last month	8	6	3
This year (cumulative)	56	17	18
Last year	68	30	50

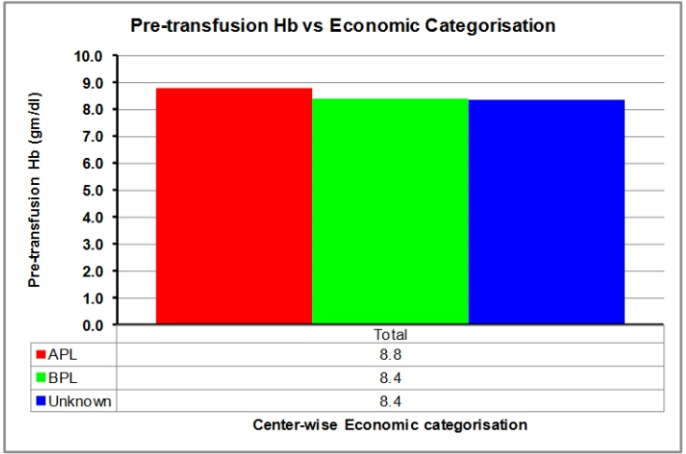
For any queries or suggestions, please write to sankalp.admin@gmail.com involved nearly 2500 patients. It must also be noted that this assessment is from the time the centre was operational. Therefore for some centres it has data for nearly 5 years and for the more recently opened ones data is available atleast for the last one year

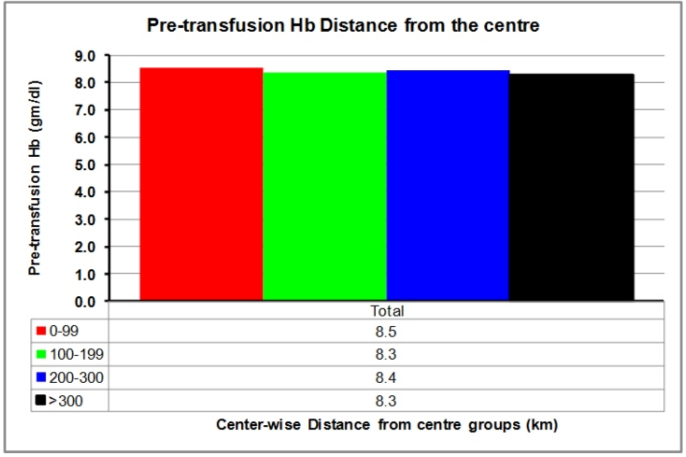
There was no clinically significant difference observed in the equity of care as measured by average pre-transfusion haemoglobin levels between the two gender, the distance of the patient's house from the centre, the age of the patients and the economic categorization of the patients. Girls outperformed the boys in most centres and patients managed to maintain haemoglobin levels across age groups in-spite of the increased blood requirements and frequent visits. Children coming from economically weaker families had marginally lower haemoglobin levels.

All centres saw a steadily dropping rate of mortality, which got limited to about 1% in last year. There was no significant difference in mortality based upon gender(p=0.48) ,distance the patient had to travel to reach the point of care (p=0.46) and whether or not splenectomy was done(p=0.35). The survival of patients from the families below poverty line was better than those above poverty line (p=0.036).









"The most common way people give up their power is by thinking they don't have any. "

This may party be explained by the fact that poorer families almost always had free chelators given by the centre and thus had full compliance while those above the poverty line unlike the patients above poverty many of which were expected to party pay for their chelation therapy.

The mortality varied very significantly with the age of enrolment at the centre (p=0.003).37 patients were cured of ST with BMT while 4(10.8%) suffered from transplant related mortality. We are in the process of summarising this outcome in a peer reviewed publication shortly.

A key challenge in the delivery of healthcare is maintaining equity across gender, religion, age, economic status and distance from the point. Post enrolment, there were no clinically significant differences observed in the access to care, which is in stark contrast to the prevalent situation in the country.

While the gender ratio was highly skewed at enrolment, during the course of treatment the girls received care at par with the boys. In some centers, girls marginally outperformed the boys. We also noted that the difference in enrolment of girls and boys increased from metros, to tier to cities and was most striking for patients from smaller towns. There still remains a marginal difference between those below and above the poverty line. Loss of salary of the guardian for the day on which they bring the child for treatment may be contributing to this

While the results make us excited and helped us ascertain that equity of care is being addressed on most parameters, it also helped us identify gaps in our own centres.

We are happy that more centres are displaying an intent to adopt ThalCare for their operations. This gives us the confidence that in a few years time, the equity of care achieved in thalassemia management through ThalCare will be looked upon as a benchmark reference across the Indian healthcare domain.

"Your time is limited, so don't waste it living someone else's life." – Steve Jobs

Remembering the victims of the Jaliianwalah Bagh

The Jallianwala Bagh massacre, also known as the Amritsar massacre, took place on 13 April 1919 when a crowd of nonviolent protesters, along with Baishakhi pilgrims, who had gathered in Jallianwala Bagh, Amritsar, Punjab, were fired upon by troops of the British Indian Army under the command of Colonel Reginald Dyer.

The civilians had assembled to participate in the annual Baisakhi celebrations, a religious and cultural festival for Punjabi people.

Official British Indian sources gave a figure of 379 identified dead, with approximately 1,100 wounded. The casualty number estimated by the Indian National Congress was more than 1,500, with approximately 1,000 dead.

A memorial was built on the site and inaugurated by President of India Rajendra Prasad on 13 April 1961. The central 30-ft high pylon, is built with 300 slabs with Ashoka Chakra, the national emblem, carsed on them. On all four sides of the pylon the words, "In memory of martyrs, 13 April 1919", has been inscribed in Hindi, Punjabi, Urdu and English.

"The two most important days in your life are the day you are born and the day you find out why." – Mark Twain

Upendranath Brahmachari -He saved millions of lives

Rai Bahadur Sir Upendranath Brahmachari was a renowned Indian scientist and a prominent medical practitioner of his era. He had a remarkable personality and his most outstanding research contribution was the discovery of Urea Stibamine, an organic antimonial compound, which played a vital role in the treatment of Kala-azar (a Hindi term for black fever), a protozoal infection. His "Treatise on Kala-azar" is a premier work on the subject .

Kala-azar is an infectious disease of South Asian and Mediterranean countries.The disease is transmitted by sand flies and it is characterised by an enlarged spleen and liver, irregular fever, anemia etc. Though various forms of treatment were in vogue but they did not help to reduce the death rate. Doctors across the world invented methods to treat this disease. Prominent among them was the intra-venous administration of tartar emetic (potassium salt of antimonyl tartrate) Brahmachari decided to improve the results by use of alternative strategies so that the disadvantages could be nullified. He tried many techniques only to realize over time that all of them had significant disadvantages as well. Towards the end of 1919 Brahmachari received a grant from the Indian Research Fund Association for conducting further research into the treatment of the disease. He carried out his research work in a small ill-equipped room in the Campbell Hospital with limited resources available at his disposal. Working under such adverse conditions Brahmachari discovered a potent agent against Kala-azar, which he named Urea Stibamine.

Urea Stibamine was a great success in treating Kalaazar. In 1932, Col. H. E. Short, Director, Kala-azar Commission, appointed by the Government of India stated: "We found Urea Stibamine an eminently safe and reliable drug and in seven years we treated some thousands of cases of Kala-azar and saw thousands more treated in treatment centers. The acute fulminating type characteristic of the peak period of an epidemic responds to treatment extraordinarily promptly and with an almost dramatic cessation of fever, diminution in the size of spleen and return to normal condition of health." Today the incidence of Kala-azar has drastically reduced in India and other parts of the world. There are occasional or sporadic cases here and there. Today Kalaazar persists only in very poor and remote areas.

"Life shrinks or expands in proportion to one's courage." – Anais Nin

His discovery led to the saving of millions of lives in India, particularly in the erstwhile province of Assam, where several villages were completely depopulated by the devastating disease. The achievement of Brahmachari was a milestone in successful application of science in medical treatment in the years before arrival of antibiotics, when there were few specific drugs, except quinine for malaria, iron for anaemia, digitalis for heart diseases and arsenic for syphilis. All other ailments were treated symptomatically by palliative methods. Urea Stibamine was thus a significant addition to the arsenal of specific medicines

Brahmachari started his career as a doctor under Sir Gerald Bomford (1851-1915) in Calcutta. Bomford recognised Brahmachari's talent and offered the then 27 year old Brahmachari a teaching position in Physiology in Dacca Medical School in November 1901. In 1923, he joined as Additional Physician in the Medical College Hospital. He retired from the Government service as a Physician in 1927. After retirement from the Government service Brahmachari joined the Carmichael Medical College as Professor of Tropical Diseases.

He also served the National Medical Institute as In-charge of its Tropical Disease Wing. He was also the Head of the Department of Biochemistry and Honorary Professor of Biochemistry at the University College of Science, Calcutta.

During the years of his service and even after retirement, he remained actively connected to various spheres in the University of Kolkata. He was associated with almost all the known scientific and literary organizations at Kolkata and took a keen interest in humanitarian and cultural activities.

> *'As a matter of the most vital concern in nation-building, the problem of nutrition demands very careful consideration by statesmen and scientists alike, more so due to the fact, as has been recently observed, that a great part of the world's population is not consuming the necessary food stuff. An eminent Swiss authority predicts the decay of civilization unless there is a fundamental revision of the people's diet.'*
>
> *- Upendra Nath Brahmachari in his General Presidential address to the Indian Science Congress (1936).*

He also played a significant role in the formation of the world's second Blood Bank at Kolkata. Designated as the Chairman of the Blood Transfusion Service of Bengal, he was the Vice President of the St. John Ambulance Association of the Bengal branch and also it's President. He was the first Indian to become the Chairman of the Managing Body of the Indian Red Cross Society of the Bengal Branch. He generously contributed to the High School in Purbasthali (in Bardhaman district) near his ancestral house. He was the founder of Brahmachari Research Institute which became successful in the fields of both research and manufacture of medicine.

Brahmachari died on February 06, 1946. The Kolkata Municipal Corporation renamed Loudon Street as Dr. U.N. Brahmachari Street.

"I wouldn't ask anyone to do anything I wouldn't do myself." Indra Nooyi

PLAN NOW

TO AVOID SUMMER SHORTAGE

This alarm is being sounded for all in blood banking. It is being sounded to the authorities, the blood banks and to all the organisations involved in promotion of voluntary blood donation.

It's the right time to draw up a comprehensive plan to ensure that regular blood donation drives are organised starting May right through till July, traditionally the period of shortage of blood.

This summer - let us ensure that there is no shortage of blood!

ALL THE BEST!

SAY **NO** TO BLOOD SHORTAGE

YOU too can make a difference.

Plan to organize a blood donation drive.

Call 9480044444
to know more.

We are offering free 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.

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. 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.

"By our stumbling the world is perfected"

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 propogate the message of blood donation
- Volunteer in our blood donation camps

Thalassemia Prevention

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

Thalassemia Management

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

Thalassemia Cure

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

Contribute

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

From:

Call: 9480044444 |Visit: www.sankalpindia.net
Mail: contact@sankalpindia.net
Address: #460, "GOKULA", 8th Main, 4th Block,
Koramangala, Bangalore - 560034

To:

Registered RNP / KA / BGS / 2179 / 2015-17 | Cost of single copy Re. 1/- | Published on 15th and posted on 17th of every month at Bangalore-PSO, Bangalore - 560026. RNI No: KARENG/2010/35892 | Total Pages: 16
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.