# Annual Report 2017-18



Let's give life a better chance

# Sankalp India Foundation®

94800-44444 | www.sankalpindia.net | sankalp.admin@gmail.com #460, "GOKULA", 8th Main, 4th Block, Koramangala, Bangalore 560034, India

# Rakta Kranti - Unique Features

#### END TO END CAMP MANAGEMENT

Publicity and awareness creation, donor motivation, blood bank selection, drive execution, feedback and review.



Ad

STRONG PUBLICITY CAMPAIGN Multi-pronged approach - mailers, posters, brochures, floor talk, banners; use in house volunteers wherever possible

#### FOCUS ON QUALITY

Emphasis on adherence to national & international guidelines; Non compliance is measured, debated and acted upon.

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CAREFUL PLANNING 150 units per blood bank; Need based distribution

#### PERSONNEL TRAINING

Drive managed by trained SIF personnel; Investment on Blood bank staff training done





**TECHNOLOGY BACKBONE** Data for each drive is in electronic means; Collection, complication, deferral, compliance is measured and analyzed.

#### POLICY MAKING

Standards on complication prevention, management created. Standards for donor selection and deferrals now available.



# **Emergency Team and Blood Helpline**



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Multi-pronged, technology driven strategy for making blood available

Specialized handling of extremely rare blood groups by subject experts

Bombaybloodgroup.org - the first integrated platform for management of rare groups

Electronic documentation of blood requests for analysis and strategic improvement

**Pioneered voluntary single** platelet apheresis donation in **Bangalore** 

**Promoting alternatives like** autologus donation, blood salvaging etc



Nationwide networking for blood 🗼 🖤 🚊 management in emergencies.



# **Building Internal Strength**



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

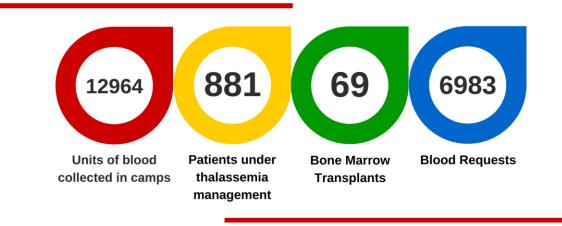
Our numbers do show progress - we had about 13,000 units of blood collected, trained about 2000 children on voluntary blood donation, had nearly 900 children receiving systematic management of thalassemia, completed 69 bone marrow transplants, addressed nearly 7000 blood requests with about 150 of them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

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



2017-18 performance at a glance

### YEAR 2017-18



Each blood donor that walks into our drives to donate, each patient that calls on our helpline seeking blood, each child that comes into our thalassemia day care or BMT centers and every donor who contributes for the projects deserves nothing short of the best. Sankalp exists because of the trust these people have in us. They are and will continue to be the ones who will help us grow.



The work and strength built over the last year has brought in more potential collaborations with different institutions to expand our boundaries of work. We feel humbled but poised to take flight to embrace these opportunities to fulfill our mission of 100% Voluntary Blood Donation and Thalassemia Free India.

Lalith Parmar President Sankalp India Foundation



# RAKTA KRANTI

#### **VISION:** We seek to achieve 100% voluntary blood donation in Karnataka.

Rakta Kranti is an initiative by Sankalp India Foundation to bring in 100% voluntary blood donation in Bangalore and thereby ensure continuous availability of safe blood. This is done by organizing efficient and well-managed blood donation drives with standards that are comparable to the best in the world. We bring to the donor all the information related to blood donation that makes him/her absolutely comfortable and confident about the process.



Blood Donors who have kept the Spirit of Voluntary Blood Donation Alive for 1000+ Sankalp Drives

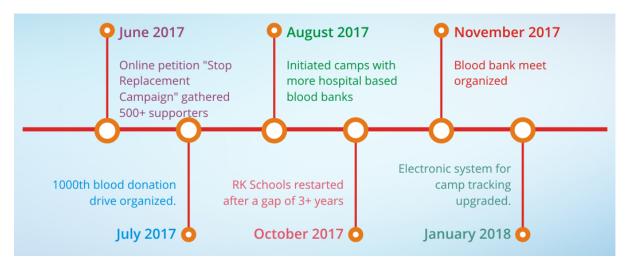
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Rakta Kranti in 2017-18 focussed on having greater number of drives planned in periods of extreme requirement, build a campaign to fight against the practice of replacement donations and build future voluntary blood donors through educational sessions in schools in the other portions of the year. All the three fronts saw sustained progress over the year. Here are some key things achieved over the year

- **Blood when required:** In the months of critical blood shortage in Bangalore (i.e. from April-July and Nov-Jan) 9500+ units were collected leading to better availability of safe blood
- Improving Quality: The instances of non compliance by blood banks in drives was on an average less than 1.0 per camp showing increased focus on quality. Complications fell by .2%



- **Technology Adoption:** Significant improvements made in use of technology. Donor registration, feedback from stakeholders, capturing drive information all moved on to TeamRed platform thereby reducing time and errors.
- Small drop in replacement trend: 15 replacement based blood banks were approached to start doing voluntary blood donation drives. 4 of them agreed and have started small drives thereby bringing marginal drop in replacement donations
- Young minds being nurtured: Through a host of children specific educational methods including games, quizzes and sessions, young minds were exposed to the idea and need of voluntary blood donation.
- **Improve donor connect:** Through publicity campaigns that are donor centric rather than just being drive centric, direct engagement with donors is being improved. Rapid use of SMS, mailers and social media platforms started in last quarter.



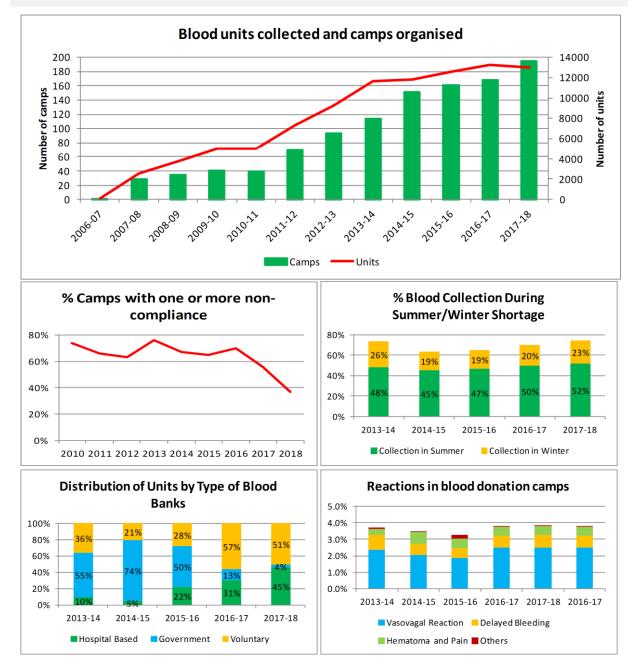




Sankalp India Foundation 5 Annual Report 2017-18

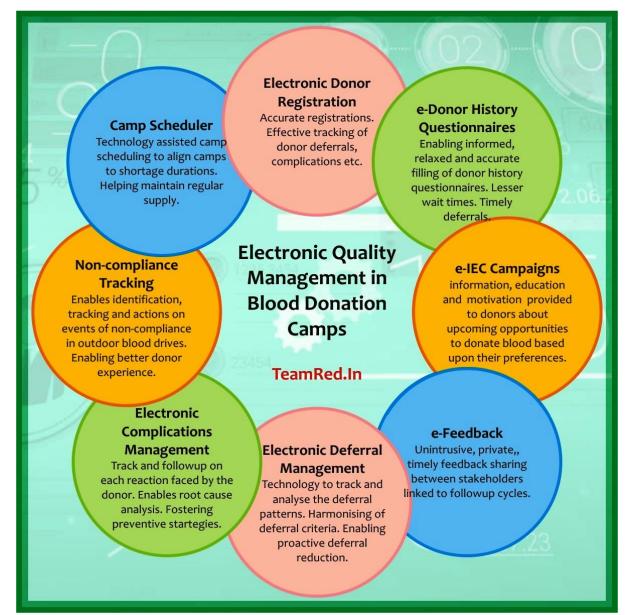


#### **PERFORMANCE AT A GLANCE**





Our Projec	t Partners
Rashtrotthana Blood Bank, Bangalore	Narayana Hrudayalaya Hospital Blood Bank, Bangalore
Vydehi Hospital Blood Bank, Bangalore	Fortis Hospital Blood Bank, Bangalore
Bowring Hospital Blood Bank, Bangalore	Nimhans Blood Bank, Bangalore
St John's Hospital Blood Bank, Bangalore	Indira Gandhi Institute of Child Health, Bangalore



Sankalp uses technology extensively for quality management in blood donation camps. The above graphic shares the various segments.



#### **ROLL OF HONOUR**

#### Our partners who supported us in our blood donation drive.

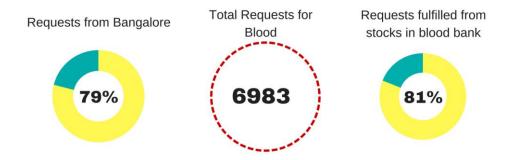
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1MG- Lido Mall	Epsilon	National Law School of India University, Bangalore
Aegis Limited	Faurecia Emissions Control Technologies India Pvt Ltd	Novo Nordisk India
AIG	FedEX	OLA Cabs
Alcon Laboratories	FELDER Bangalore	PayPal India
AMD	General Motors	Prateek Apparels Pvt Ltd
ANAROCK Property Consultants	Grant Thornton India	Qualcomm
Applied Materials	HDFC Sales Pvt Ltd	Rainbow Residency
Aramex India Pvt Ltd	Helping Hands	Rambus
Artech Infosystems Pvt Ltd	Hilton Hotels and Resorts	RBL Bank Ltd
Ascendas-Singbridge	Hindustan Field Services	Redington India Limited
Awfis	Huawei Technologies	Riya Tours and Travels
Axio Biosolutions Pvt Ltd	ICON Clinical Research	Robert Bosch Limited
Azim Premji University	Idea Cellular Limited	Samsung Research and Development
Bangalore University	Indecomm Global Services	Sankalp Semiconductor Pvt Ltd
Bhartiya City	Indegene	Schneider Electric
Biocon	Indus Towers Limited	Seagate Technology
Blue Dart Express Ltd	Infosys BPO	SmartERP Consulting India Private Limited
Blueocean Market Intelligence and Borderless Access	Inteva Products	Societe Generale Group
Burger King	Jawaharlal Nehru Centre for Advanced Scientific Research	Softtek
CAE Simulation Technologies Pvt Ltd	KMV Red Hills High School	St. Theresa's Church
Campus Students Communities Pvt Ltd	Knolskape	Stanley Black & Decker
Cargill Business Services	Li and Fung India Pvt Ltd	Star Bazaar
CGI Group	Mahaveer Kings Place Bangalore	Suncity Gloria Apartments
Cholamandalam Investment and Finance Company Limited	Mantri Espana	Sutherland Global Services Inc
Conduent Labs India	MathWorks	Swiggy
Continental AG	McDonald's	TATA Power SED
COVIAM	Medi Assist	Treebo Hotels
Cox and Kings Limited	Microchip Technology	Trelleborg Sealing Solutions India Pvt Ltd
CPG Consultants India Pvt Ltd	Microland	Uttishta Bharata
Deutsche Bank Group	Microsoft Corporation	Vanguard Business School
Directi	Moody's Analytics Knowledge Services	VIBGYOR High School
ECI Telecom	Mphasis	Volunteer For Cause
Emtec Inc	National Centre for Biological Sciences	Wipro
Envoy Mortgage India Pvt Ltd	National Instruments	WNS Global Services



# **EMERGENCY TEAM AND BLOOD HELPLINE**

#### **VISION:** We seek to ensure that nobody suffers because of shortage of blood.

Sankalp's blood helpline – Disha is the first point of contact for blood emergencies. Disha gets blood stock information from 65 blood banks across Karnataka every day and guides people to the nearest blood bank. The blood requests which are not handled with the existing blood stocks in blood banks are escalated to the volunteers who form the emergency team. The team takes up blood requests for extremely rare blood groups, unusual blood products and other corner cases of blood banking. The team prepares and trains itself to handle the difficult situations as and when they come. The Emergency Team also maintains www.bombaybloodgroup.org an initiative for wholesome management of Bombay blood group – an extremely rare blood type.



The year 2017-18 saw a steep rise in the number of rare blood group requests and single donor platelets requests, though the number of calls for regular blood groups did not change significantly. The team aimed at strengthening the internal capacity to handle calls round the clock. With one Bombay blood group request every 62 hours, that too from all over the country and abroad, the ongoing process of strengthening the network continued to happen. A major step forward this year was that the increase in the competency of the staff which receives the calls to be able to help in extremely difficult scenarios without direct involvement of the senior volunteers. The following were the key achievements for the year gone by:

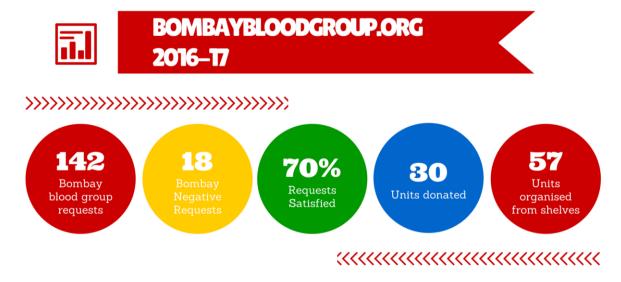
- **More calls on the helpline:** Number of blood requests on the helpline reached 6983 which is an increase of 10% over previous year.
- **Greater participation from blood banks:** 73% more Bombay blood group units were reported this year taking the total number to 57.
- **Increased reach:** Number of Bombay blood group requests nearly doubled from one request every 4 days to one request every 62 hours (2.5 days)
- **Rarest of rare requests:** 18 Bombay negative requests were received an increase of 80% from the 10 requests from the last year.



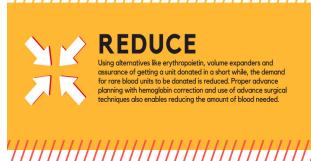
- Strengthening rational use of rare blood units: Emergency team could guide the treating doctors to use erythropoietin (growth factor) in 6 requests while in 10 others counselling led to identification of another person with Bombay blood group within the family. Atleast four of the family donors eventually donated for the patient, while in 5 others requests even when use of erythropoietin was an option it was not used.
- Wide reach: Bombay blood group requests were received from 15 states and 1 from outside the country.



Some of the regular Bombay blood group donors – people who we bank upon to come forward and rescue the situation – especially in exceptionally trying circumstances.



# 3Rs for Rational Blood Use



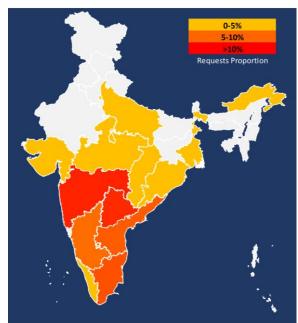
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**REUSE** Using alternatives like erythropoietin, volume expanders and assurance of getting a unit donated in a short while, the demand for rare blood units to be donated is reduced. Proper advance planning with hemoglobin correction and use of advance surgical techniques also enables reducing the amount of blood needed.

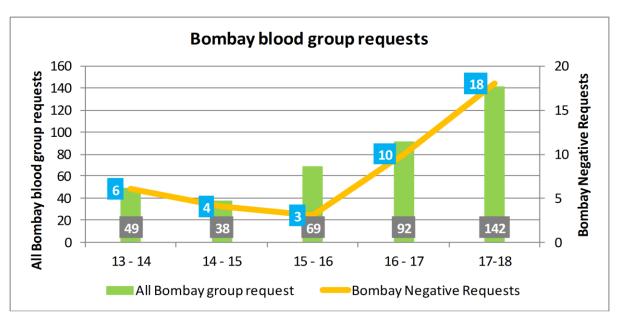


#### RECYCLE For planned surgeries it is recommended for the patient to donate blood for themselves – autologous donation. It is also possible to collect the blood lost during surgery and process it to be transfused back to the patient. Minimum exposure to other person's blood is best.

The emergency team uses 3 Rs to ensure that each patient with a rare blood group get's blood on time even as the ratio of donors to requests is disproportionate.



The map shows the states from where the team received requests for extremely rare blood groups



Steady increase in the demand for Bombay blood group units has been a result of sustained attempts to sensitise blood banks about this rare blood groups. With the number of requests we receive, it is clear that the blood group may not be as rare as it is thought to be.

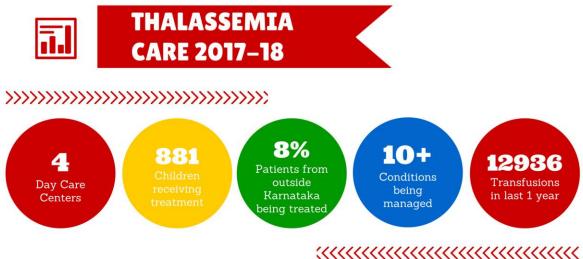


# **PROGRAM FOR THALASSEMIA MANAGEMENT**

**VISION:** We seek to ensure that each thalassemia patient should receive appropriate and adequate care and management irrespective of their financial status with the goal of restoring normalcy in their life.

Thalassemia is a genetic blood disorder where the individuals suffering from this cannot produce healthy blood cells. They depend on blood transfusions throughout their life which as a side effect causes multiple complications. With proper care and treatment, the patients can live a near normal life.

Over 2017-18, the focus for thalassemia management program was towards consolidation of care across day care centers. Efforts were put in place to regularly assess the children who are not doing well with standard care and bring in specific treatment regimens. With a total of more than 15 haematological conditions being managed at the 4 Sankalp centers, the organisation is headed in the direction of being the pioneer in Karnataka in management of hemoglobinopathies in children.



# Due to the setup of a new center at Wenlock Hospital, Mangalore, the total new registrations for the year into the program was more than 200, pushing the total number of children being managed to nearly 900 with a male to female ratio of 3:2. Sustained efforts put in place to strengthen routine management for this entire set

resulted in the following for the year

- **Median pre transfusion Hb** Improved across centers with 3 of them hitting 9 or above. The total number of transfusions also went up quite significantly with nearly 13,000 units over the year
- **Median ferritin levels** Despite new enrolments that generally are not too well managed, median ferritin was below 3000 in 3 centers. No of children on



support was increased. Towards the second half of the year secondary chelators were used for several children with addition of several new Deferoxamine pumps

- **Median stay** The median duration of stay in the hospital was about 7 hours despite increase in load
- **Mortality** With increased focus on early detection and management of complications, the mortality rate dropped to below 0.1%
- **Quality of Blood** The median age of blood was 4.4 days across all centers with 3 of them giving blood less than 5 days old
- **Effective Down staging** Down staging clinics have been initiated in 3 centers and children are being systematically prepared for BMT

In 2018-19 the program is poised for growth with the addition of new centers outside Karnataka. The challenges are going to be new and plenty to standardize care across the new and old ones. Therefore, plans have been put in place to centralize care



The Independence Day 2017 brought the gift of the first ever comprehensive day care center for management of blood disorders in coastal Karnataka





#### **PERFORMANCE AT A GLANCE**

#### Quality Management in Thalassemia Care

HERE IS WHAT WE DO TO ENSURE TOP QUALITY IN CARE



#### 1.) TECHNOLOGY DRIVEN

Assistance in delivering child specific treatment

#### 2.) TRENDS

Reports indicating trends for most crucial parameters – to assess and improve



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3). SKILL BUILDING

Annual training for clinicians and staff

#### 4.) LOWEST TTI RATES

Less than 0.7% with appropriate and safe blood with median age of 4–5



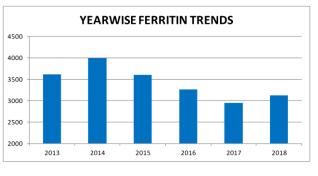
5.) MINIMAL DISRUPTION

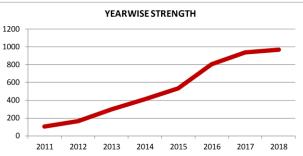
Median stay of 7-8 hours ensuring holistic care over a single day

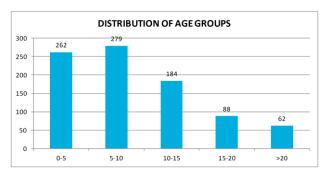
#### 6.) EQUITY

Equity of care despite change in education levels, distance from center, gender distribution and economic status of families

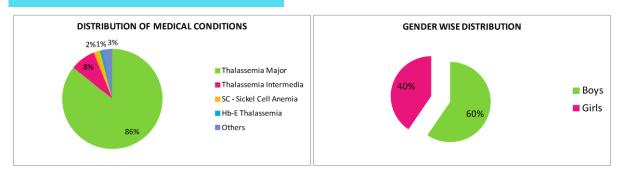












\*The average ferritin levels have fallen in-spite of the fact that we continue to have more children enrolled.





ThalMeet 2017 was organised on 14-15 July 2017 at Bangalore. The two day scientific event had participation from 14 different centers



A CME was organised by Rural Development Trust Ananthpur together with Sankalp in December 2017 to strengthen the prevention and care for thalassemia in nearby districts of Andhra Pradesh.



#### **OUR CENTERS**



Project Samraksha - Rashtrotthana Parishat, Bangalore



Jai Shivshakti Center for Thalassemia Management at KLES Hospital and JNMC, Belgaum



Indira Gandhi Institute of Child Health, Bangalore and DayCare Center for Haematological Disorders, Wenlock Hospital, Mangalore

# **OUR SCIENTIFIC**

**Biology of Blood and Marrow Transplantation** 

The Official Journal of the American Society for Blood and Marrow Transplantation

The Case for High Resolution Extended 6-Loci HLA Typing for Identifying Related Donors in the Indian Subcontinent

opnature publishing group n



Bone Marrow Transplantation (2017) **52**, 1585–1586

#### LETTER TO THE EDITOR

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

**REGULAR ARTICLE** 

blood advances

ATG vs thiotepa with busulfan and cyclophosphamide in matched-related bone marrow transplantation for thalassemia

Downloaded from jamia.bmj.com on April 12, 2014 - Published by group.bmj.com

Case report



A prospective international cooperative information technology platform built using open-source tools for improving the access to and safety of bone marrow transplantation in low- and middle-income countries

Pediatric Hematology Oncology Journal 2 (2017) 107-113



Pediatric Hematology Oncology Journal journal homepage: https://www.elsevier.com/journals/pediatrichematology-oncology-journal/

Contents lists available at ScienceDirect



Low-cost matched sibling bone marrow transplant for standard-risk thalassemia in a limited-resource setting



# PUBLICATIONS



Home Current issue Instructions Submit article

Asian J Transfus Sci. 2016 Jan-Jun; 10(1): 53–58. doi: 10.4103/0973-6247.165840 PMCID: PMC4782495 PMID: 27011671

Complications related to blood donation: A multicenter study of the prevalence and influencing factors in voluntary blood donation camps in Karnataka, India

> Asian Journal of Transfusion Science

<u>Asian J Transfus Sci</u>. 2015 Jan-Jun; 9(1): 23–28. doi: <u>10.4103/0973-6247.150942</u> PMCID: PMC4339926 PMID: 25722568

A study of the noncompliance of blood banks on safety and quality parameters in blood donation camps in Bengaluru



Blood Transfus. 2016 Jan; 14(1): 89–90. Prepublished online 2014 Jul 16. doi: 10.2450/2015.0072-15 PMCID: PMC4731344 PMID: 26192784

Managing rare blood group requests - Bombay Oh phenotype: our experience with <u>www.bombaybloodgroup.org</u>

Thalassemia Care





Can inequity in healthcare be bridged in LMICs – Multicentre experience from thalassemia day care centres in India



Pediatric Hematology Oncology Journal 2 (2017) 74-78



Contents lists available at ScienceDirect

Pediatric Hematology Oncology Journal journal homepage: https://www.elsevier.com/journals/pediatrichematology-oncology-journal/



Multi-institutional, retrospective review of blood transfusion practices and outcomes in a large cohort of thalassemia patients in South India



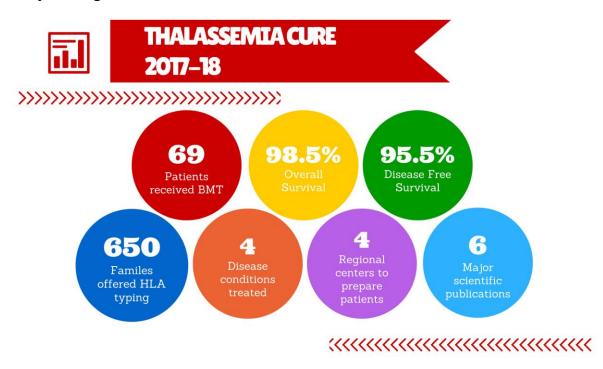
# **PROGRAM FOR THALASSEMIA CURE**



Several families who had a bone marrow transplant at our Bangalore center came together to participate in the celebration of completion of 50<sup>th</sup> transplantation.

**VISION:** We seek to provide high quality patient focused curative option to children suffering from Thalassemia irrespective of financial background with focus on technology and transparency.

Bone Marrow Transplant is currently the only fully established procedure offering a chance of cure from thalassemia. Sankalp's foray in this domain started in 2012 with the HLA typing of a few kids from its own day care centers. Since there was no facility of its own, Sankalp sent the children to a center overseen by Cure2Children in Jaipur. When all 3 of them were cured, the dream to establish an affordable, quality conscious cure facility at Bangalore took birth.



Through partnerships with People Tree Hospitals, Bangalore in 2015 and Care Institute of Medical Sciences, Ahmedabad in 2017 Sankalp has setup 2 BMT centers and is operating them on not for profit basis. A combination of clinical, scientific, administrative and nursing expertise have ensured an overall survival of nearly 94% and disease free survival of 86% over the 100+ transplants performed.

In 2017-18, the program reached new heights. With 65+ transplants for thalassemia alone, we are today perhaps the biggest entity in the world doing these many transplants for thalassemia. Following are the key highlights in the last year

 Ahmedabad operational: Sankalp's second center in Ahmedabad fully operational with 30 transplants having excellent results [29 successful and 1 rejection]



- **Bangalore improves quality & efficiency:** The Bangalore facility completed 1.5 times more transplants over the past year with results that were much better.
- **Consultation & Training:** Nursing and clinical teams from MY Hospital Indore and Ghana were trained to setup and run their own BMT centers



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- Stronger Data Analytics: Special focus on setting up in house and efficient data analytics resulted in constant assessment and review of results leading to more publications
- **Strengthening peripheral centers:** Efforts to push pre and post transplant care to peripheral regions taking shape with OPDs in 4 new cities



• **Knowledge enhancement & sharing:** Our clinical team has attended and presented our results in International BMT meetings with several universities and individuals keen on partnering for knowledge enhancement and sharing.



Sankalp-Cure2Children Network Meeting at Ahmedabad in September 20







In January 2018 a delegation from DKMS visited our center. The two day meeting concluded with the organisations finding synergy in the common mission to cure as many children as possible. Besides this Dr. Thomas Klingebiel, Paediatric Haematologist, University of Frankfurt and Dr. Fulvio Porta, BMT Specialist, Italy also visited the BMT unit and expressed their happiness with the functioning of the BMT Unit in terms of Quality and Outcomes.

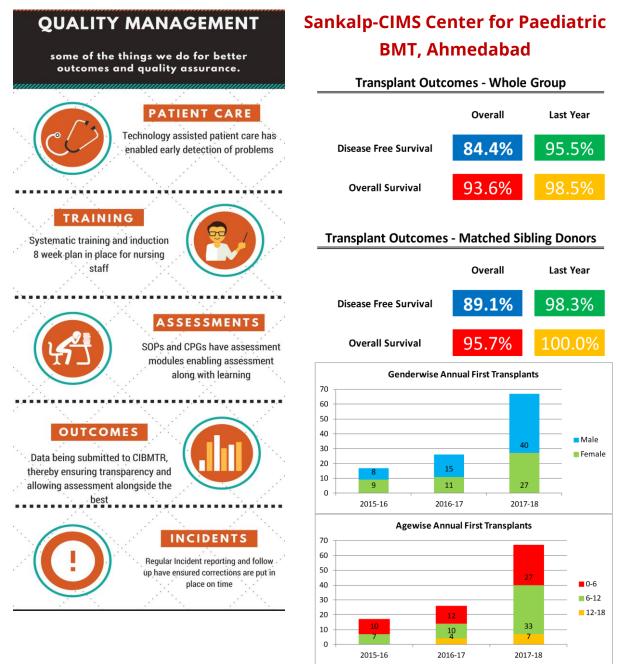
#### **OUR CENTERS**

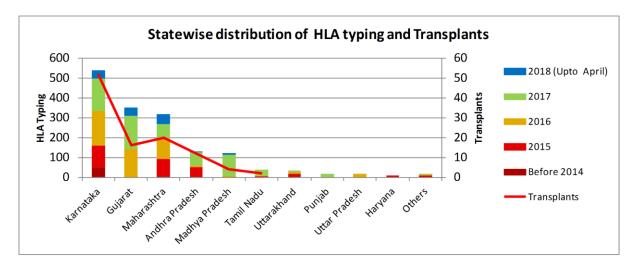


Sankalp-People Tree Center for Paediatric BMT, Bangalore





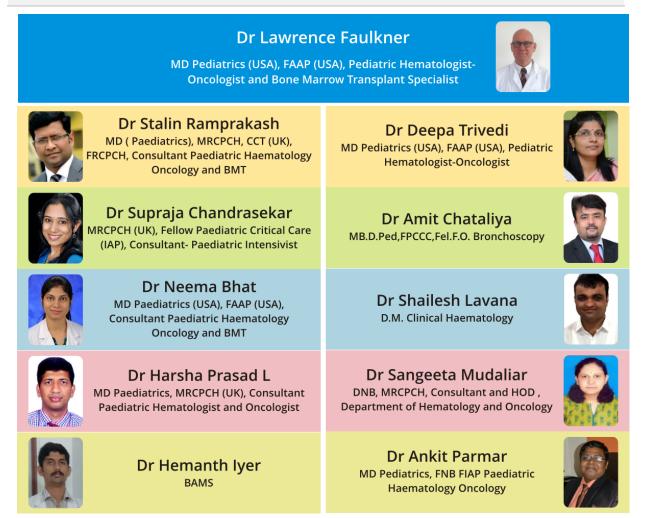






Our Projec	ct Partners
Cure2Children, Italy	DKMS, Germany
People Tree Hospitals, Bangalore	Care Institute Of Medical Sciences, Ahmedabad
Rashtrotthana Parishat, Bangalore	Rural Development Trust, Ananthpur
KLES Hospital, Belgaum	Bai Jerabai Wadia Children's Hospital, Mumbai
Supratech Labs, Ahmedabad	Indira Gandhi Institute of Child Health, Bangalore
Jeevan Blood Bank, Chennai	We Care Trust, Mumbai
Anand Labs, Bangalore	Jagriti InnoHealth Platforms, Bangalore

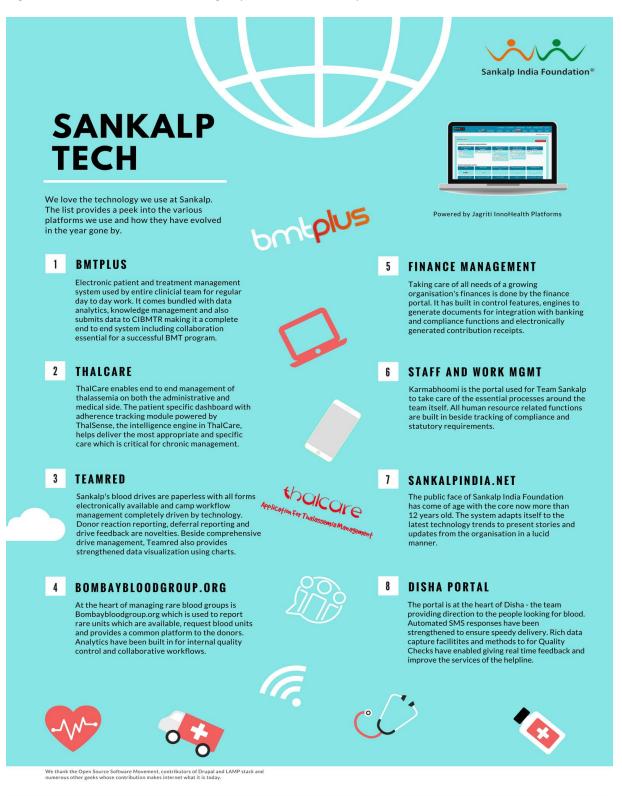
# **OUR MEDICAL TEAM**





# **TECHNOLOGY AT SANKALP**

Quality and measurability is at the heart of what we do at Sankalp. In order to achieve this, we have our own technology platforms each one of which is meant to support a unique functional area within the organisation. The Sankalp Tech Team ensures that the knowledge management within the organisation is at its best. Here is a glimpse of the various systems and how we use them.





# A WORD OF THANKS

We express our heartfelt gratitude to our partners, associates, contributors, donors, patients, friends, families, suppliers, teachers, critics and all others who have placed their trust in the work that we choose to undertake. It is only when the numerous little efforts by so many people finds synergy that some little progress is made. We have challenges which look insurmountable at times, but thanks to the persistent support and contribution of so many people in their own very unique and very special capacities, no task looks too hard to accomplish.

When a person receives blood on time, when a child gets treatment and care, when a donor feels cared for, when medical teams feel supported and when numerous individuals who Sankalp India Foundation is able to touch in different ways experience some relief, regain their smile – it's all thanks to the thousands of men and women who are part of the extended Sankalp family.

The volunteers of Sankalp India Foundation are extremely privileged, honoured and grateful to be receiving the trust, faith and support and be chosen as instrument of delivery in the mission to 'give life a better chance'.

All what was done in the previous year would not have been possible without the support of several individuals and organisations. We are sincerely grateful to the partner organisations for their continued commitment to stand with us to Help Give Life a Better Chance.



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#### FINANCIAL CONTRIBUTIONS 2017-18

Organisational / Corporate Donors		
TATA Trusts	Cipla Foundation	Kalpataru Trust
Jai Shivshakti Health & Educational Foundation	Rural Development Trust	Didwania(Ratanlal) Charitable Trust
DBOI Global Services Private Limited	Amit Iyer Memorial Foundation	We Care Trust
Ranka Charitable Trust	DKMS, Germany	Cure2Children Foundation
Sharada Health & Educational Foundation	Suvarna Arogya Suraksha Trust	Erase Poverty
Bhanushali Samaj	Thyrocare via PATUT	Ghelani Charitable Trust
TransAsia Bio-Medicals via PATUT	Shri Odhavram Arogya Nidhi Trust	Medicos Educational Society

	Individual Contributors	
Bharat B Shah	Vikramjit Singh Kanwar	Harish Rangwala
Leela S Iyer	S V lyer	Kamal Balkrishna Trivedi And Shraddha K Amal Trivedi
Dharmendra Hariyani	Silky Rout	Himanshu Ashwin Popat
S G Chaturvedi/Bharti Srinivas Poojaman Sarinivas	Shirish Belapure	Prabha Puttegowda
Afsar Jamal Sharif	Jatinder Pal	Dr Anil Shah
Pc Mohan M.P	Pravinbhai Balubhai Shah / Chandraben Pravinbhai Shah	Saood Ahmed Shariff
Sudha Y S Bhat	Siddharth Shah	Velganesh S
Aniket Deshpande	Dr. Krishan Kumar Narani & Janak Narani	Nithya Sree
Pavithra P	Sayeed Ahamad Khan	Mythili S R / Srinivasan S
Nikhil Satyarthi	Harshad Nanubhai R	Manju Kedarnath
Prakash M Mahale	Jaya Ramakrishnan Iyer	Deepak Bhanushali
Karsanbhai Dama	Khiyashi Parpeya	Shankarlal Deviji Nakhua
Kunal Chourasia	Mahesh Vanigota	Sameer Nitin Thakkar
Renu Chellani	Rohit Agarwal	Surya Tibrewala



#### **TRANSPARENCY DISCLOSURES**

- Rakesh Dhanya, the General Secretary was appointed as the CEO on a remunerative basis. No remuneration, sitting fees or any other form of compensation was paid to any other board member or volunteers.
- We have 12 salaried employees. We have a CEO, 2 work for Thalassemia Day Care - IGICH, 1 works for Thalassemia Center at Wenlock Hospital, 3 work for Rakta Kranti, 1 for Disha and one employee each at our Bangalore, Mumbai (clinic) and Ahmedabad BMT centers. 1 person works for finance.
- Kumari Ankita and Rajat Kumar Agarwal are board members who are married to each other. Vibha H G and Rakesh Dhanya are board members who are married to each other.
- Dr Lawrence Faulkner is the Medical Director of the organisation in a remunerative basis as well as the member of the Advisory board in a non-remunerative basis.

#### **THE BOARD**

Name	Designation	Gender	Employment	Contact
Lalith Parmar	President	Male	Business Development Professional, Jagriti InnoHealth Platforms	
Amit Sedai	Vice President	Male	Software Professional, Jagriti InnoHealth Platforms	amit@sankalpindia.net
Rakesh Dhanya	General Secretary	Male	Sankalp India Foundation	rakesh@sankalpindia.net
Prabha P	Joint Secretary	Female	Software Professional, LAM Research	prabha@sankalpindia.net
Kumari Ankita	Treasurer	Female	Software Professional, Jagriti InnoHealth Platforms	ankita@sankalpindia.net
Rajat Kumar Agarwal	Executive Member	Male	CEO, Jagriti InnoHealth Platforms	rajat@sankalpindia.net
Vibha H G	Executive Member	Female	Software Professional, Cerner	vibha@sankalpindia.net
Venugopal B	Executive Member	Male	Official @ Indian Postal Department	venu@sankalpindia.net





Standing on the shoulder of the giants - we the Advisory Board - May 2017

#### **ADVISORY BOARD**

Name	Designation
Dr Lawrence Faulkner	Program Director, Sankalp – People Tree Hospitals Bone Marrow Transplant unit & Medical Coordinator, Cure2Children, Italy
Mr J M Maheshwari	Head, Jai Shiv Shakti Health & Education Foundation, Maangalya Group
Dr Nandakishore	Blood Bank Medical Officer, M S Ramaiah Hospital
Dr S.K. Shankar	Former Emeritus Professor and Head of Brain Bank, NIMHANS, Bangalore
Dr Sundar P	Professor, Department of Transfusion Medicine & Blood Bank Medical Officer, NIMHANS, Bangalore
Mr Sundaresan V Iyer	Former Senior H R Consultant and Head, Cipla Ltd, Mumbai

#### **FINANCIAL DISCLOSURES**

#### Name and address of Bankers:

- Punjab National Bank, Jayanagar, Bangalore
- HDFC Bank, Banerghatta Road, Bangalore
- Allahabad Bank of India, HSR Layout, Bangalore

#### AUDITORS

Sneha Bhavesh Shah, Vanivilas Road, V V Puram, Bangalore



#### Income and Expenditure for the year ending on 31<sup>st</sup> March 2017

25,212.00 20,440.00 5,695.56 1,30,833.00 25,059.70 1,085.00 1,10,543.67 9,40,050.20	By General Contribution By Bank Interest By Contribution towards Thalassemia Care By Contribution towards Thalassemia BMT	39,84,867.00
5,695.56 1,30,833.00 25,059.70 1,085.00 1,10,543.67 9,40,050.20	By Contribution towards Thalassemia Care	
1,30,833.00 25,059.70 1,085.00 1,10,543.67 9,40,050.20		39,84,867.00 1,90,22,694.90
25,059.70 1,085.00 1,10,543.67 9,40,050.20	By Contribution towards Thalassemia BMT	1,90,22,694.90
1,085.00 1,10,543.67 9,40,050.20		
1,10,543.67 9,40,050.20		
9,40,050.20		
1000		
1,52,208.00		
28,42,906.94		
1,87,29,121.77		
1,840.00		
8,000.00		
10 <b>,00</b> ,335.60		
	1,87,29,121.77 1,840.00 8,000.00	1,87,29,121.77 1,840.00 8,000.00

#### Balance Sheet

	R	ALANCE SHEET AS	AT 31st MARCH, 2017		
	100	alance sitter as	AT JISCHARCE, 1917		
LIABILITIES		AMOUNT	ASSETS		AMOUNT
CORPUS FUND			CAPITAL ASSETS		
Opening Balance			As per Schedule "I"		42,58,882.0
as on 01.04.2008		43,760.00			
			CURRENT ASSETS		
Surplus {being excess			Cash in Hand	4,951.00	
of income over expenditure)	10,00,335.60		Balance With Bank	32,79,029.86	
Add : Surplus (being excess			IT Refund of Previous Years	30,600.00	
of income over expenditure)			IT Refund AY 2017-18	1,000.00	
from previous years)	26,93,745.50	36,94,081.10	Security Deposit	1,90,000.00	
			Prepaid Expenses	12,500.00	35,18,060.8
FIXED ASSETS CAPITAL FUND		24,16,736.00			
			INVESTMENTS		*
DISASTER RELEIF FUND		20,803.25	FD for Disaster Releif Fund		20,803.2
CURRENT LIABILITIES					
Expenses Payable	8,86,073.76				
Creditors for Capital Expenditure	6,59,424.00				
TDS Payable	76,888.00	16,22,385.76			
Total	-	77,97,766.11	Total		77,97,766.1

Since the annual report is prepared in May while the audited accounts are available only in October, we share the previous year's accounts. In October, the online version of the annual report will be updated with the latest accounts and made available on www.sankalpindia.net.

# **OVERALL ACHIEVEMENTS OF SANKALP**

It has been close to 15 years since the organization took its first steps in the direction of giving life a better chance. The following are the major achievements on the organization:

- a. Sankalp's 'Rakta Kranti team' has collected more than **94,000 units of blood in 1100+ blood donation drives.**
- b. Sankalp's State wide Helpline for Blood has received more than 87,000 calls for blood and handles
  100+ extremely critical blood requests per month. The organization has specialization in extremely rare blood groups (Bombay blood group) and organizes for this blood unit internationally
- c. Sankalp runs 4 thalassemia care center where **more than 900 children receive blood transfusions**, **medicines and tests**
- d. Sankalp offers **Bone Marrow Transplants with high quality and optimized cost for thalassemia** at associated centers in Bangalore and Ahmedabad. **More than 100 transplants have been completed**.
- e. Sankalp has organized **nation and state wide workshops for training and education of medical staff** for betterment of transfusion services and nursing care in transplants.
- f. Sankalp has **published and presented papers on quality in Blood Donation Drives, Thalassemia Management, HLA Typing, and Bone Marrow Transplants.**
- g. Sankalp has **participated in disaster relief activities** Tsunami in Nagapattinum in 2004, Kashmir Earthquake 2005, Flood Relief in Tanjavur in 2005, Bihar Floods of 2007, Terror attacks by arranging for blood, Karnataka Floods 2010, Sikkim Earthquake 2011 and Assam floods 2012

# **AWARDS & RECOGNITIONS RECEIVED**

#### Some awards and recognitions given to Sankalp

- **Recognised by the Government of Karnataka** for contribution to the field of Voluntary blood donation in 2012 and again in 2013
- Awarded the '**Spirit of Humanity**' award by Americares Foundation in 2011, 2014 and 2016 for work in different spheres emergency and blood transfusion services, voluntary blood donation, thalassemia management and bone marrow transplants.
- Awarded winner of 'e-NGO Challenge 2014' for achieving organisational efficiency by using information technology.
- Awarded the 'Gillette Blade of Honour Award' by CNN IBN
- Awarded second place in **technical paper presentation** by Indian Society of Blood Transfusion and Immunohematology Conference in 2011. (Only non-doctor to get this award at a medical conference)
- Winner of Manthan Award Asia Pacific-2013 for "ThalCare", a Thalassemia Management tool.



# **FORTHCOMING PLANS: WHERE ARE WE HEADED IN 2018-19**

The National Blood Transfusion Council has set 2020 as the year by which voluntary blood donation must be 100% in our country. In Karnataka, we are far away from the goal as the practice of replacement donations is still rampant. While we will still plan plenty of voluntary blood donation drives, we also intend to tackle the problem of replacement through efforts involving administrators and decision makers to take strong steps to root out replacement blood donations.

On the Thalassemia front, we are exploring partnerships with a host of hospitals and other social organisations to set up more day care facilities in several different cities across the country. While Sankalp will be involved in the operations of some, the role will be that of a consultant in a few others. We believe that if we are able to propagate the model followed in our current day care centers in Karnataka in each of these units, the quality of care for regular thalassemics will begin to improve drastically. We could be looking at 1600-2000 children by the end of the year.

Efforts are on to increase the capacity to perform 50-70% more transplants over the year that went by. Haploidentical transplants and transplant for other related haematological disorders are being lined up. Knowledge enhancement of existing staff and addition of new qualified resources is already underway.

The backbone of our work had been technology. User friendly enhancements, advanced features, security upgrades and new age methods for data analysis are in the pipeline. This coupled with clear separation of clinical and administrative duties with trained people on both fronts will hopefully get us where we dream to reach this year.

# Jai Hind!







*Glimpses from the blood donation camps - where numerous faceless heroes roll up their sleeves and donate to help someone who they may never meet.* 

# **Thalassemia Management - Methodology**



SAMRAKSHA - REFERRAL CENTRE Any complicated cases which need aggressive management and care are eferred to Samraksha

#### LEARNING AND NETWORKING

We are providing several centres an opportunity to learn from each other and enhance patient care.



COHORT BASED MANAGEMENT Patients with similar conditions are identified, grouped together and managed for their specific needs. HIGH END DIAGNOSTICS Availability of sophisticated lab investigations at doorsteps on highly discounted prices.



THAL REPORT CARD Weekly/monthly automatic performace assessment reports. Periodic review meetings with each centre. SUNDAY MEETINGS

On opportunity for all parents and stakeholders to interact, share, learn and make progress.





PROFESSIONAL DEVELOPMENT Knowledge sharing and participation in national and international scientific forums. ACCESS TO INTERNATIONAL EXPERTS Enabling consultation with international subject experts wherever needed



# **Thalassemia Cure - Methodology**

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Aggressive downstaging an preparing child for transplant Access to transplant irrespective of financial status

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High grade HLA typing: Internationally accredited lab State of the art technology for realtime monitoring and management

Step down facility and long term followup

Complete coverage from transplant associated costs.



Internationally comparable outcome.

Open collaborative approach adding to transplant safety.



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