

# Annual Report

2020-21



Lets Give Life A Better Chance




**Sankalp India Foundation®**

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## The Year Gone By

In 2020-21	OUR JOURNEY	Since 2011
290	👤 THALASSEMIA CARE ENROLMENT	2,703
20	✋ TRANSPLANTATIONS	315
6,393	☎ BLOOD REQUESTS	56,605
656	🩸 UNITS COLLECTED	1,26,566



## The Covid-19 Pandemic Year

### Blood

- Voluntary blood donation came to a sudden standstill
- Willing blood donors faced difficulty reaching blood centres
- Blood centres were not sure about continuing outdoor collection
- Stocks quickly ran out and provisioning became a herculean task.

### Transplantations and intense care

- Admissions were halted all over - continue to remain affected
- Uncertainty of the medical management in the wake of Covid-19
- Transplant volumes reduced to a fraction even after a year

### Access to care

- Transplantation spaces were reassigned to Covid-19 capacity
- One thalassemia centres was designated as a Covid-19 hospital
- Clinics to continue transfusions / follow-up became a challenge
- Travel restrictions made it difficult for families to reach centres

### Supplies

- Public supported critical medicines ran out.
- Lockdowns made critical medicines harder to access
- Consumable shortages and inflation went through the roof

### Labs





- Covid-19 focus impacted lab services for other patients
- Option to utilise lab services outside the city attenuated.

### Personnel

- Challenges balancing work with safety of frontline workers
- Separations from families necessitated for some staff to limit exposure

# Thalassemia Care and 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.*

In 2020-21	OUR JOURNEY	Since 2011
290	 NEW ENROLMENT	2,703
28,182	 VISITS	1,12,801
1,23,210	 BLOOD TRANSFUSIONS	1,23,210
37,285	 LAB INVESTIGATIONS	1,75,870

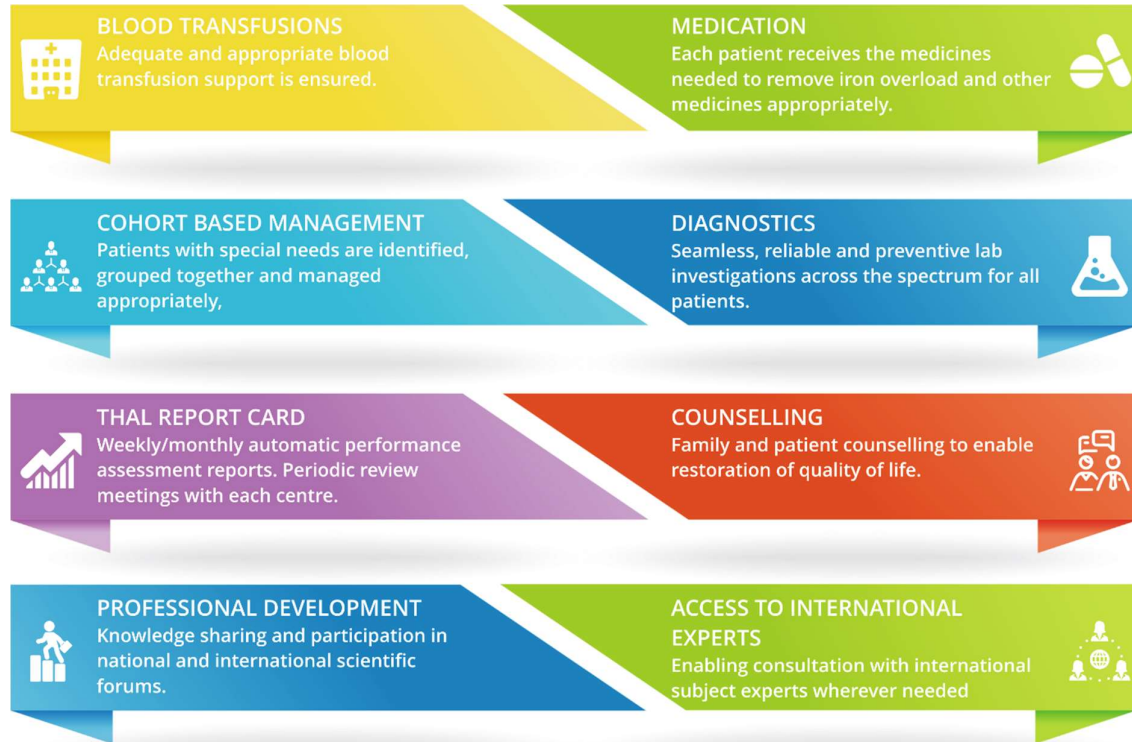
## WHAT WE DO?

Thalassemia is a genetic blood disorder the individuals suffering from which do not produce blood. They depend on blood transfusions throughout their life. With proper care and treatment, the patients can live a near-normal life.

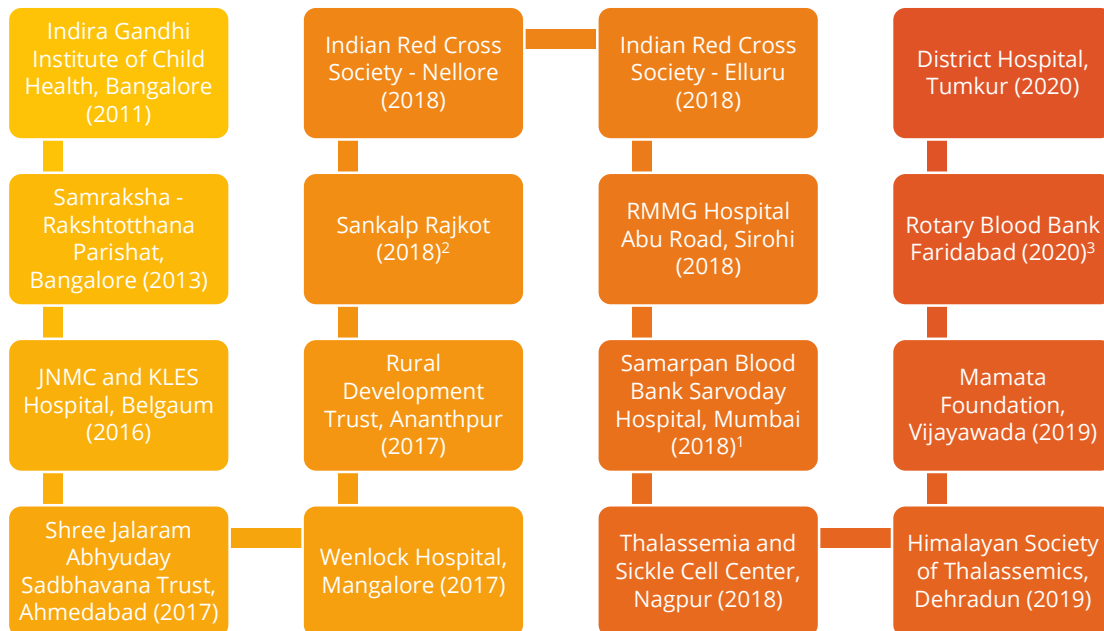
However, most individuals suffering from thalassemia die before celebrating their 18th birthday. There are more than 1,00,000 individuals with thalassemia major in India and 10,000 new births each year. Cost on the management of thalassemia in private setup is estimated upwards from Rs 1,50,000/- per year in India. Because of high costs of management, inadequate care and management, lack of focus on treatment, and inappropriate treatment, these children lose the battle against the disease at an early age.

Sankalp Program for Thalassemia Management offers end-to-end management of thalassemia to each child in need. We have woven a network of centers across the country for this purpose.

### KEY FEATURES



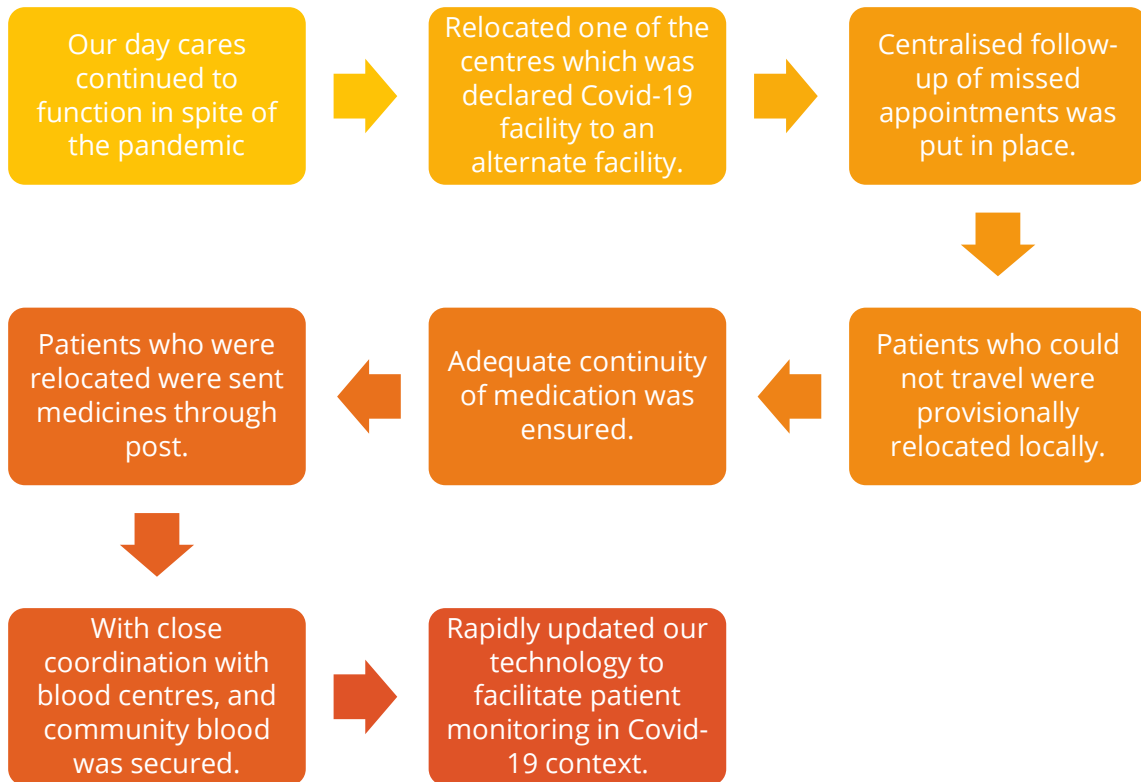
### OUR CENTERS

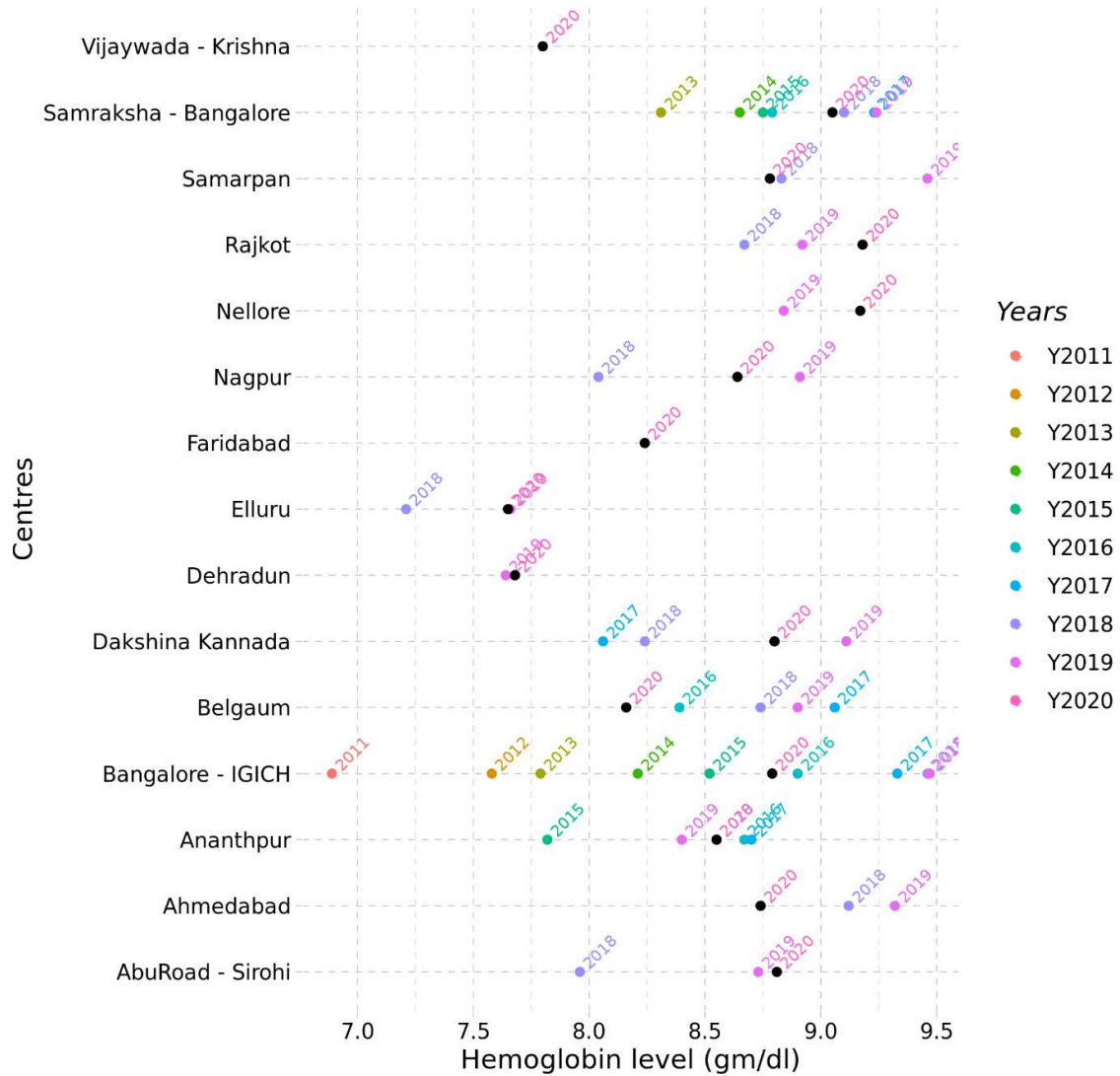


1. One of the centres which we previously supported was dropped.

2. In Rajkot, Sankalp switched to a Sankalp operated centre together with SJAST, Ahmedabad
3. We welcome Rotary Faridabad to our network of thalassemia centres.

### THE YEAR'S HIGHLIGHTS





*Years of gains made in correcting baseline hemoglobin have reversed in 2020-21. In spite of the best efforts, at several places, not enough blood could be secured through the blood centres which the day-cares rely upon in many places. This experience has triggered a chain of actions which are aimed at mitigating such a situation in future.*





*"As pandemic set in, the limited funds available for care and management were used up quickly. We reached out to our donors, friends and family. An unprecedented effort on their part followed to help tide over the crisis. Gradually, resources came in and we could continue care! A special word of gratitude for those faceless souls who strengthened our hands and joined in during the most challenging times."*

## Sankalp Program for Thalassemia Cure

*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.*

In 2020-21	THE CURE JOURNEY	Since 2015
20	👉 FIRST TRANSPLANTS	315
913	📅 HLA TYPING	9,938
86%	SURVIVAL AFTER TRANSPLANT	88%
86%	TRANSPLANTATION SUCCESS	79%
81%	COMPLETE RETURN TO NORMALCY	77%

### WHAT WE DO?

Sankalp Program for Thalassemia Cure offers Bone Marrow Transplant - the permanent curative option to the children suffering from Thalassemia and other non-malignant blood disorders.

Sankalp India Foundation enables reliable transplants on a non-profit basis. The organisation offers the option of cure to the most appropriate candidates irrespective of their financial status. At the cost equivalent to 4-5 years of thalassemia management, the organisation offers a complete cure.

The organisation has brought together experts who have vast experience with BMT for thalassemia, and health care set-ups that are willing to offer transplants on a not-for-profit basis. Sankalp has established a program that ensures systematic preparation of the chosen kids for transplant and their long-term follow-up – further enhancing the outcome.



SANKALP-PEOPLE TREE CENTRE FOR BMT, BANGALORE  
(2015-2020)

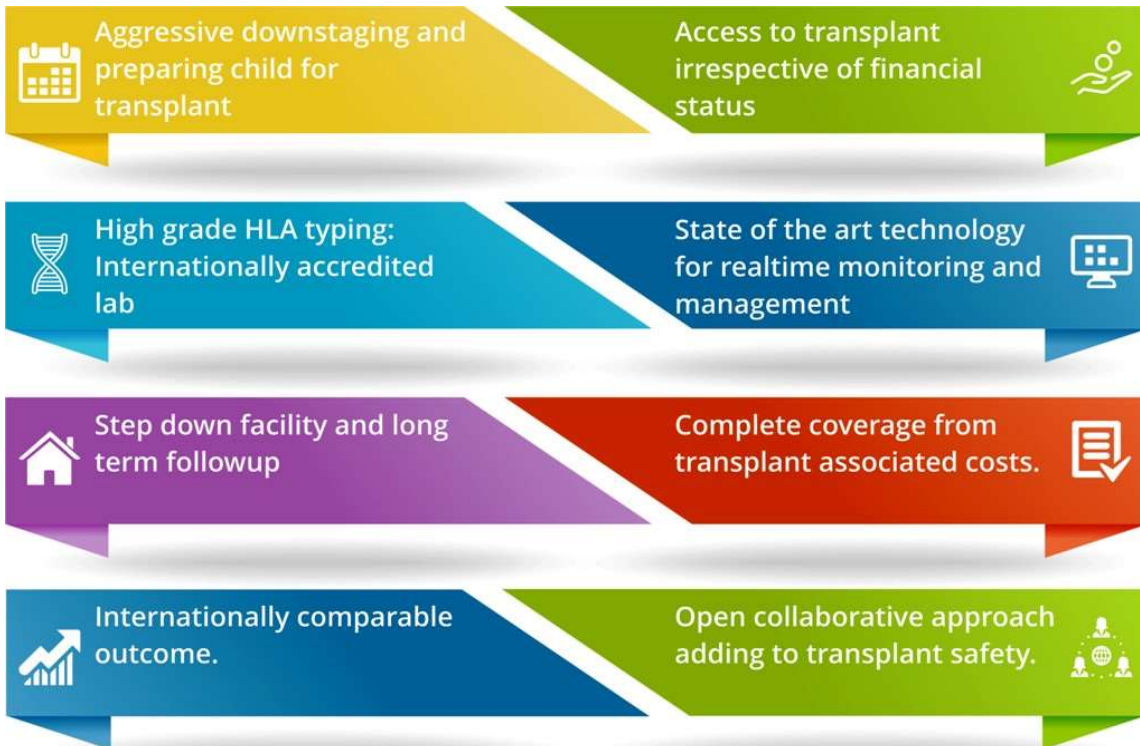


SANKALP-CIMS CENTRE FOR PEDIATRIC BMT, AHMEDABAD  
(2017)

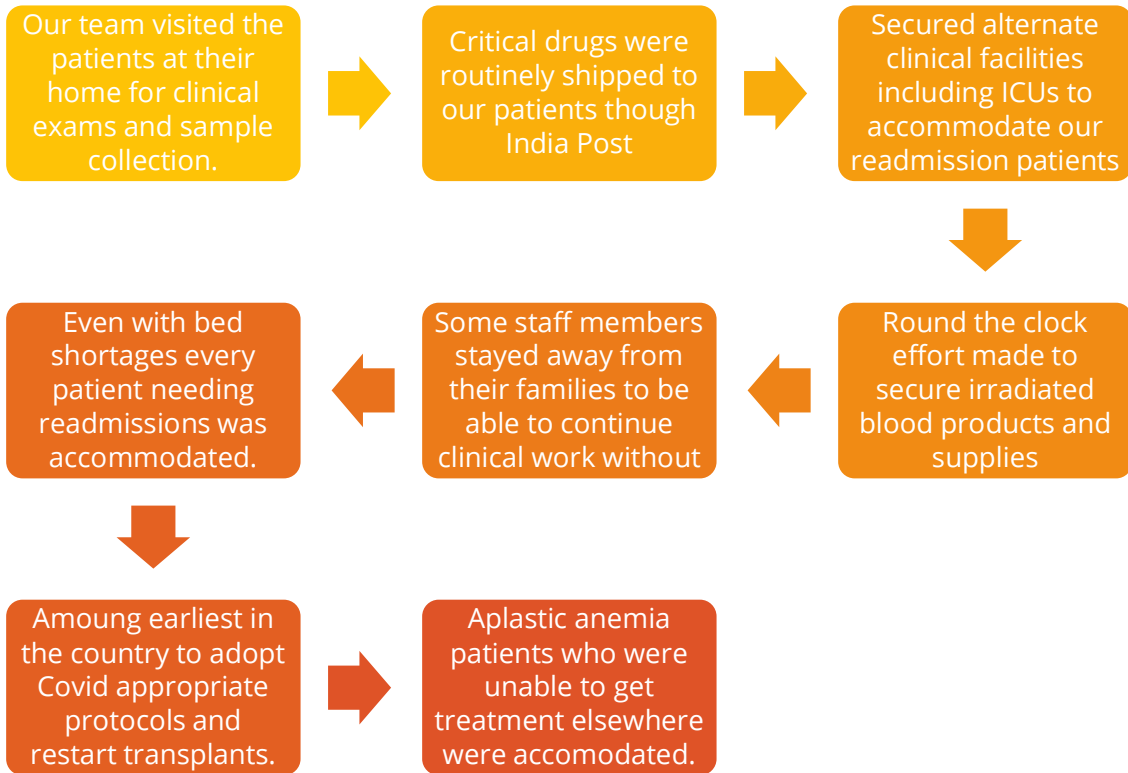


SANKALP-BMJH CENTRE FOR PEDIATRIC HEMATOLOGY ONCOLOGY AND BMT, BANGALORE  
(2021)

### KEY FEATURES



## THE YEAR'S HIGHLIGHTS



## KEY PARTNERS



Cure2Children  
Foundation, Italy



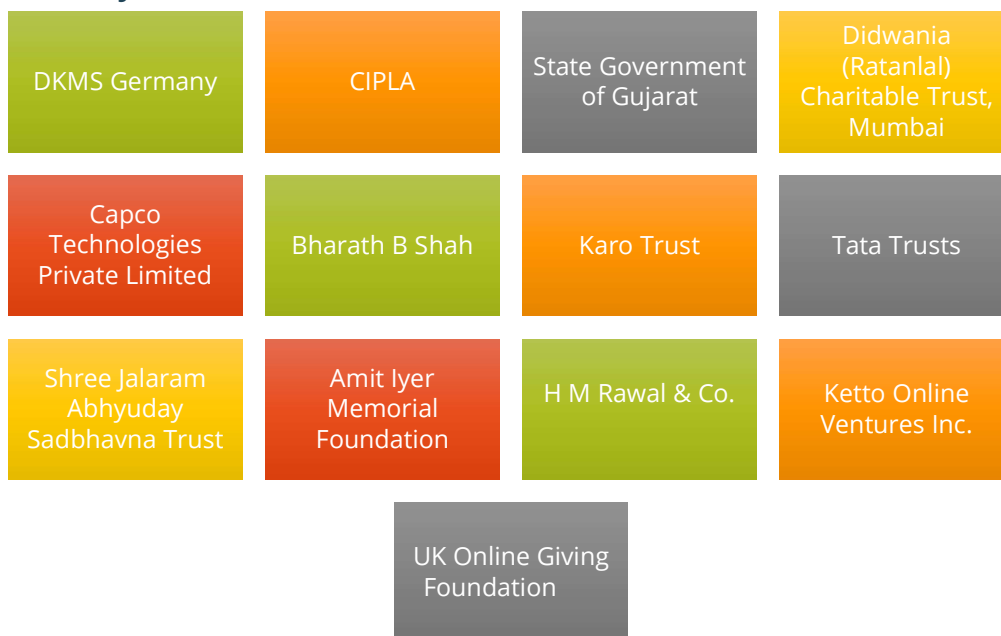
Rural Development  
Trust, Ananthpur



Thalassemia and Sickle  
Cell Society,  
Hyderabad



## JOINING HANDS TO MAKE THE IMPOSSIBLE POSSIBLE ARE



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On 14th March 2021 the Paediatric Diseases Working Party (PDWP) of the eBMT announced "Middle-Income Countries Pediatric Advanced Care Training (EMPACT) 2021-2022" - a pilot educational program by the Outreach Subcommittee, Paediatric Diseases Working Party - EBMT, supported by DKMS and Cure2Children and consisting of a two-year haematopoietic cell transplantation training course for nurses from Middle-Income Countries (MICS). We are happy to be the first centre which was selected to host this fellowship program.

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# Sankalp Program for Thalassemia Prevention


*VISION: Thalassemia Free India.*

In 2020-21

**OUR JOURNEY**

Since 2011

273  COUPLES SCREENED

24  CVS OFFERED

130

7  CONFIRMED POSITIVE

30

## WHAT WE DO

For years Sankalp was actively encouraging prevention of blood disorders by offering antenatal screening to the at-risk couples in the extended family of the thalassemia patients. Starting December 2020, together with Thalassemia and Sickle Cell Society, Hyderabad – India, we are strengthening the program for thalassemia prevention. We have established 2 centres in hospitals which have high load of early pregnancy visits. Here we provide counselling and screening to pregnant women who seek antenatal care within the first trimesters.

## OUR CENTERS

Lady Goschen  
Hospital,  
Mangalore

District  
Hospital,  
Tumkur



## Rakta Kranti

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

**In 2020-21**

**OUR JOURNEY**

**Since 2005**

35



BLOOD DRIVES

1,577

656



UNITS COLLECTED

1,26,566

### WHAT WE DO?

In spite of the advances made, our country continues to struggle to maintain stocks of voluntarily donated blood. The practice of replacement blood donation is highly prevalent. Not only does it impose immense pressure on the relatives of the patients, it is also a proven threat to blood safety.

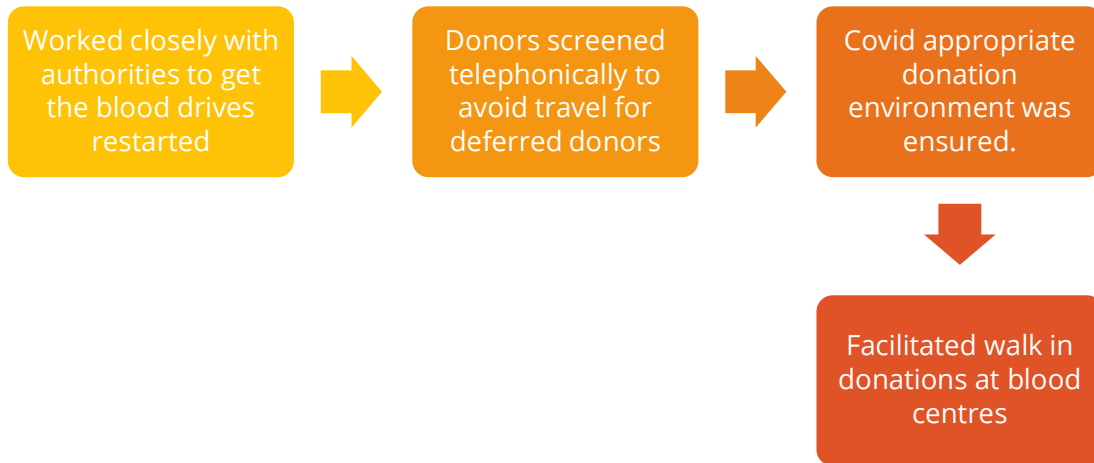
Rakta Kranti aims at organizing efficient and well-organized blood donation drives with standards that are comparable to the best in the world. We bring to the donor all the information relating to blood donation that makes him/her comfortable and confident about the process.

At Rakta Kranti, Sankalp has a very dedicated and self-motivated team, which is constantly working hard to reach out to people and disseminate knowledge and goodness of voluntary blood donation.

## KEY FEATURES



## THE YEAR'S HIGHLIGHTS



Aratt Vivera Apartments	Cattleya Projects Sriven Nest	Chamundi Emerald	Citizens Welfare Association Langford
Dada Amar Charitable Trust	Divyasree Developers Pvt Ltd	Healing Touch	ID Fresh Food (India) Pvt Ltd
KMV Projects Ltd	Karnataka Marwari Youth Federation	Rebuild Humanity	Shilpitha Splendour Apartments
Sankalp India Foundation	Akhil Bhartiya Terapanth Yuvak Parishad	Uttishta Bharata	Varthur Malayalee Association
Volunteers For a Cause	VRR Nest Apartments	Wipro Infrastructure Engineering-Aerospace	Yuva Bangalore

## When the going gets tough (EW)

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

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**In 2020-21**

**OUR JOURNEY**

**Since 2011**

6393



BLOOD REQUESTS

56,605

126



BOMBAY BLOOD  
GROUP REQUESTS

802

Switch to confirmation  
before sharing the  
contacts



Continued support to  
rare blood requirements  
by moving units around  
the country even with the  
restrictions



Assistend in securing  
donation slots and passes  
for walkin donors

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*What if there is at-least one blood centre ensuring that blood units of all types were available on the shelf all the time, we may never have to struggle to find blood in an emergency.*

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## Resilience

- financial crisis
- CIPLA supported the Covid specific services and supported Thal Management
- Individuals and organisations rose to the occasion and padded us up
- Sankalp let go of it's office. - Investments and capacity building to keep the organisation online paid off.

## Antifragility

### New start

The BMT Centre which Sankalp started in 2015 at People Tree Hospitals desperately needed more space. The organisation was looking for opportunities to expand capacity for a while. The lockdowns and the pandemic halted fresh admissions. Turning adversity into opportunity the organisation embarked upon a mission to establish a new facility which is more aligned to the needs of the organisation. The effort resulted in the coming together of the organisation with DKMS-Germany, Bhagwan Mahaveer Jain Hospital - Bangalore and Cure2Children Foundation - Italy. In memory of Mechtild Harf, the inspiration behind DKMS, we initiated work on the BMJH-Sankalp Centre for Pediatric Hematology-Oncology and BMT. This unit is planned to have 10 transplant rooms, separate day care, readmission rooms, ICU and all other spaces needed for a world class transplant centre. Even as work was ongoing, a portion of the facility was activated and 2 patients had already come in in March 2021.

### Sankalp labs

The laboratory services which are cornerstone to transplantations as well as regular thalassemia care experienced unprecedented obstruction. The organisation for long had feel facing challenges in ensuring availability of high quality diagnostics from labs which have specific capabilities to cater to the needs of children with blood disorders. Responding to the challenge the organisation decided to take a major step towards vertical integration of services by initiating the Sankalp Labs. The lab which commenced early operations in March 2021, has state of the art facility on for both pathology and molecular departments. It is providing timely, high quality and reliable solution for both the medical and research needs of the organisation. This major step forward was made possible with the very kind support of DKMS, Germany, Amit Iyer Memorial Foundation, Mumbai and Didwania (Ratanlal) Charitable Trust, Mumbai.

### Sankalp Pharmacy

Another major step forward towards vertical integration and cost effectiveness taken this year was the commencement of Sankalp Pharmacy. The pharmacy has been setup at the BMJH-Sankalp Centre goes beyond the traditional role of stocking and supplying medicines. Headed by a clinical pharmacologist and setup to safely and appropriately prepare chemotherapy, the facility in intended to contribute towards better quality of the services.

## Major Publications

Our study "Pre-transplant donor-type red cell transfusion is a safe and effective strategy to reduce isohemagglutinin titers and prevent donor marrow infusion reactions in major ABO-mismatched transplants" was published in the Annals of Hematology.

Annals of Hematology (2021) 100:2071–2078  
<https://doi.org/10.1007/s00277-021-04571-3>

ORIGINAL ARTICLE



### Pre-transplant donor-type red cell transfusion is a safe and effective strategy to reduce isohemagglutinin titers and prevent donor marrow infusion reactions in major ABO-mismatched transplants

Pallavi Mehta<sup>1,2</sup> · Stalin Ramprakash<sup>1</sup> · C P Raghuram<sup>1</sup> · Deepa Trivedi<sup>3</sup> · Rakesh Dhanya<sup>4</sup> · Rajat Kumar Agarwal<sup>4</sup> · Lawrence Faulkner<sup>5</sup>

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We are happy to have contributed to the position paper by the Pediatric Diseases Working Party of the European Blood and Marrow Transplantation Group on "Setting up and sustaining blood and marrow transplant services for children in middle-income economies: an experience-driven position paper on behalf of the EBMT PDWP". Our experience with our transplantation program has contributed significant ideas to this major publication.

Bone Marrow Transplantation (2021) 56:536–543  
<https://doi.org/10.1038/s41409-020-0983-5>



PERSPECTIVE



### Setting up and sustaining blood and marrow transplant services for children in middle-income economies: an experience-driven position paper on behalf of the EBMT PDWP

Lawrence Faulkner<sup>1,2</sup> · Marta Verna<sup>3</sup> · Attilio Rovelli<sup>3</sup> · Rajat Kumar Agarwal<sup>4</sup> · Rakesh Dhanya<sup>2</sup> · Lalith Parmar<sup>2</sup> · Amit Sedai<sup>2</sup> · Ankita Kumari<sup>2</sup> · Stalin Ramprakash<sup>4</sup> · C. P. Raghuram<sup>4</sup> · Pallavi Mehta<sup>4</sup> · Sandeep Elizabeth<sup>2</sup> · Sadaf Khalid<sup>1,5</sup> · Aliya Batool<sup>5</sup> · Sarah Khan Ghilani<sup>5</sup> · Itrat Fatima<sup>6</sup> · Tatheer Zara<sup>6</sup> · Priya Marwah<sup>7</sup> · Rajpreet Soni<sup>7</sup> · Deepa Trivedi<sup>8</sup> · Valentino Conter<sup>3</sup> · Marta Canesi<sup>3</sup> · Dosti Othman<sup>9</sup> · Vian Faeq<sup>9</sup> · Katharina Kleinschmidt<sup>10</sup> · Akif Yesillipek<sup>11</sup> · Catherine G. Lam<sup>12</sup> · Scott C. Howard<sup>13</sup> · Selim Corbacioglu<sup>10</sup> · the Pediatric Diseases Working Party of the European Blood and Marrow Transplantation Group

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## Conclusion

In fond memory of ...

Wish we could do more ...

The show must go on ...

