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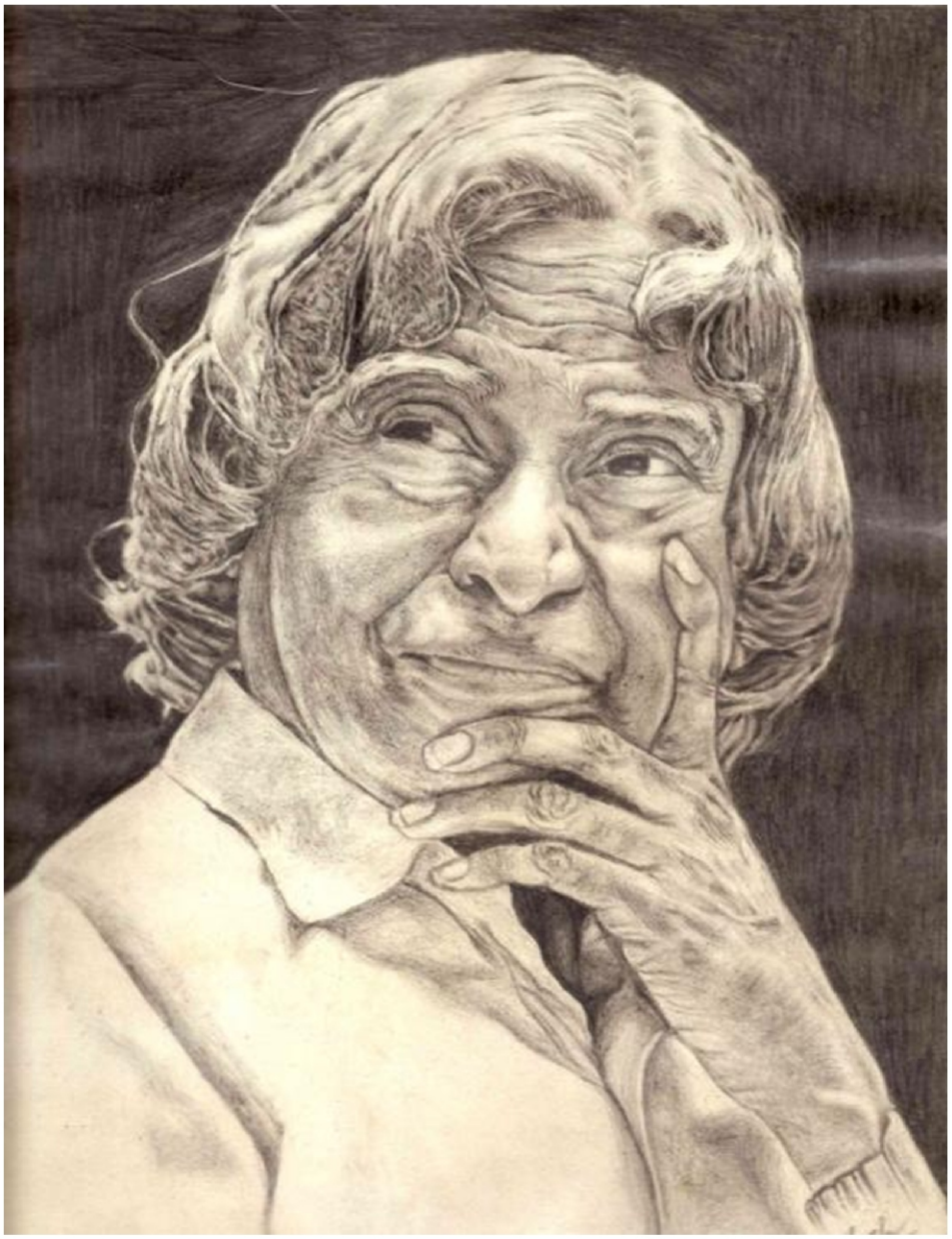

Dream is not that which you see while sleeping.

It is something that does not let you sleep.

- Dr A P J Abdul Kalam

(October 15, 1931 — July 27, 2015)

The Dream That Persists – Possibly Forever

November 14 2011 saw the birth of a new commitment for volunteers at Sankalp. From a bunch of volunteers taking up emergency blood requests and organizing a few blood donation drives, we took up something more serious and potentially game changing. On that day, first Thalassemia day care centre supported by Sankalp was inaugurated at Indira Gandhi Institute of Child Health. The fact that close to 90% of thalassemiacs in India do not receive proper care and management (As per the results of a study published by WHO) was too hard to be taken lightly. That day the dream was to make life better for each child with thalassemia. A challenge was taken up to deliver the best for each child and yet not pass on the burden of finances to families of the patients. There was excitement mixed with apprehension as to how far we will go.

For the first 18 months, volunteers believed in streamlining processes and protocols in order to deliver systematic care and management. In collaboration with our technology partner Jagriti innovations a technology platform named ThalCare was built. We forged relationships with several other organizations, vendors etc in order to ensure that treatment plans are never affected. By August 2013 things had improved with number of patients at our center crossing 200 (it was 66 on day 1).

Owing to the growing list of patients and the limited capacity at the first centre, things fell in place for the start of the second centre – Samraksha along with Rashtrotthana Parishat. Several patients came here too. Scheduled appointments, procedural treatment routines including documentation and updates on ThalCare (ex. Pre transfusion Hb, growth parameters of the child, hb at the time of discharge) became a norm. Day care coordinators ensured compliance and adherence to treatment plans.

During this journey we were lucky to have known and forged a relationship with an

"Look at the sky. We are not alone. The whole universe is friendly to us and conspires only to give the best to those who dream and work." - Dr. A P J Abdul Kalam

organization named Cure2Children, Italy, who are doing a massive amount of work in addressing the problem of thalassemia in several developing nations. With support and guidance from Dr Lawrence Faulkner, we learnt that there could be more to do. Biochemistry, serology, cardiac, endocrine, dexa scan and other tests were introduced. Every effort was being put in to determine the possibility of complications and address them. ThalCare matured into the most powerful system in the whole world for thalassemia management. Several national and international organizations applauded the ease with which it worked. ThalCare was extended to a few more centres in India.

But then, if you think that all is done and sit back you fail to see how much more can be done. That is when Bone Marrow Transplant (BMT) was being discussed at Sankalp. Although some initial ground work had been done, no substantial progress was made on lines of identifying children and taking through the process of transplant. Since June 2014 time and energy was spent on identifying the right candidates, preparing them medically and most importantly making BMT affordable for our children. Be it HLA typing for families, Hydroxyurea as a new treatment routine for eligible patients or working on the socio economic factors of a transplant along with the families – everything was done. We knew that this was more serious. We knew that we are taking up the responsibility of saving a life. With the help of several philanthropic individuals, 3 children successfully underwent BMT at South East Asia Institute of Thalassemia, Jaipur. The costs have been optimized so drastically that the total cost of the transplant is 50% or less compared to any other transplant centre in the country. Yet, the success rates are among the best in the world and definitely the best in the country by a good distance. The fruits of hard labor is

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out. Finally we have children dropping out of our centre – because they are CURED!

The levels of hope and energy in our daycares is at an all-time high. While the children receive transfusions, the parents sit and chit chat about the road ahead – towards cure – wherever possible. The young children, even in the most dejected and deprived families, are being seen in a new light – the light which promises a bright future. Even those who do not have an option for cure immediately, know that science is catching up and they must maintain themselves well because sooner or later – they too may have the option of cure. The joy which the parents, the children, the families, the doctors, the care givers and the volunteers feel extends further.

These transplants have been made possible because of exceptionally generous men and women who contributed towards these transplants. While Sankalp strived to ensure that each transplant is done in the most judicious and non-profit manner, the friends and well-wishers made sure that cost does not form the barrier between the little children fighting thalassemia and a cure for a lifetime. Hats off to all the donors!

In the meanwhile we wondered if there is a possibility to have the pain and suffering reduced further for the families. We dreamt of a similar transplant centre in Karnataka. After more than 6 months of efforts, we are close to realizing that as well! Sankalp India Foundation is on the verge of inaugurating a Bone Marrow Transplant Centre in Bangalore. The official inauguration is due on 27th August 2015. More than 20 children have been identified as potential candidates for transplant. Should the final pieces of the puzzle fall in place soon, we will have several children undergo transplants and be completely cured over the next year. Plans are being put in place to offer HLA typing for patients at other centres and offer those patients too a chance to be freed of the burden of dealing with thalassemia forever. We will reach out to several centres over the coming months to be able to make this a reality.

We know that we are not done yet. For us the dream is on. We will possibly continue to dream forever. At every milestone, we are motivated to dream further of the endless ways in which we may be able to give these young lives a better chance at life. For example, should these transplants go as planned and the children recover fully, the question of how do we cure other children (for whom transplant from a sibling is not possible for several reasons) will come back to haunt us. Is haplo transplants the way forward? Or is there something else being discovered and worked upon that can make a difference?

You could also refer a child suffering from thalassemia to explore how Sankalp India Foundation can help them explore the option of cure. Please ask the families to call +91-9480044444 for appointments.

"Life is a difficult game. You can win it only by retaining your birthright to be a person."
- Dr. A P J Abdul Kalam

A Step Towards Safer Blood Donation Drives

It is said that if you stop learning, you stop creating history and become history. At Sankalp a practice of striving to improve continuously is imbibed in all volunteers. Hence training and knowledge sharing sessions form an important aspect of projects.

In the last 2 financial years, Sankalp has organized 300+ blood donation drives. In this financial year more than 70 have been organized in 4 months' time. We have blood bank teams from 7 institutions coming in for drives, close to 200 staff including technicians, doctors, volunteers manage the show. It is a challenge to maintain consistency in delivery in each and every event, especially with so many members as part of the team. The only way out is to come together and keep learning the essentials.

Hence a training program on "Procedures and Practices in Voluntary Blood Donation Drives" was organized on the 27th of July 2015 at Bangalore Medical College. Teams from Victoria and Bowring Hospital – the 2 hospitals under BMC that have blood banks were part of the training program. More than 30 students who will be a part of blood donation drives in the future also attended the training. In total there were 55 attendees. Dr Sundar P, Professor, Transfusion Medicine from NIMHANS was present as a guest trainer.

The training started off by giving an overview of the way Sankalp Rakta Kranti unit works, the roles and responsibilities taken up by the team in organizing blood donation drives and expectations from blood banks to deliver what is promised. Senior Sankalp volunteers stressed on the need for maintaining professionalism in blood donation drives by working on all areas of compliance as laid down in standards set forth by NACO or DCI. Emphasis was also laid on having a professional attitude and maintaining time, hygiene in the drive.

Crucial time was also spent on upgrading the soft skills of team members. It has been proved beyond doubt by various studies all over the world that if a blood donor has a pleasant experience he/she is very likely to come back to donate again and again in successive drives. This helps in converting the donor to a regular voluntary blood donor for life and also retain the confidence and trust of organizers to give us an opportunity to conduct a drive in their premises. Instances of how poor treatment has had bad consequences were put forward.

Modules relevant to the role of an individual was also a part of the program. Sankalp has drafted together a protocol on assessing donor suitability for donation – something that is crucial in deciding whether a person must be accepted for or deferred from donation. An end to end discussion was held on the same in the presence of Dr Sundar, Dr Sreelatha – HOD Transfusion Medicine, Bangalore Medical College, Dr Dheemanth & Dr Prasanna – Associate Professors at the Transfusion Medicine Department, Dr Zaheer – blood bank medical officer at Bowring Hospital and a few PG graduates. The doctors agreed on using the document as a guideline for selecting/deferring donors in blood donation drives.

While this discussion and debate was on, modules on Hb estimation, pre-donation tests, phlebotomy techniques were held for the technical and nursing staff. Materials that included high quality videos, well designed and informative booklets were used. Every aspect of Hb estimation – including need, the right tools and methods, proper way of doing things, maintaining hygiene and sanitation were discussed in detail. The training on phlebotomy techniques covered preparing the site of phlebotomy, selection of vein, maintaining right pressure, the correct method of pricking and handling donors. Mr Jagadish, a senior technician and one with a rich experience of having led teams in more than 200 drives shared some valuable practical tips and techniques. He too emphasized the need for doing things right at phlebotomy with sheer regard to professionalism, careful consideration of the specifics related to the donor. He brought out instances from his rich experience where incorrect treatment meted out to donors has had a negative effect. The reason and need for good pre donation hydration was discussed in detail. The students too asked several questions and jotted down notes throughout the session. The technicians and students were also given a walkthrough of the donor questionnaire form and the importance of each field in the same.

"One of the very important characteristics of a student is to question. Let the students ask questions." - Dr. A P J Abdul Kalam

Following a short break, the session convened again with all doctors, technicians and nursing staff to learn about identification and management of complications in blood donation drives. Dr Sundar walked the attendees through the various complications as listed in the complications manual adopted by Sankalp and participating blood banks in November 2013. Every complication, its symptoms, interventions required to manage the donor were discussed. The trainees were also given an overview of emergency drugs, the triggers for their administration. Finally the session touched upon the role each individual needs to play when there are complications and how by better coordination and team work every situation can be well managed.

The trainees were very happy with the half a day program and several students expressed satisfaction and gratitude for having taken them through various practical aspects. "Such programs are useful for both newcomers and experienced staff members. For the newcomers it is an opportunity to get first hand access to valuable information before they attend regular blood donation drives. For the ones who are already part of teams, these sessions help make our basics stronger, enable us to think about the mistakes made and look at corrective measures we need to adopt in blood donation drives. I am happy and glad to have been a part of this" said Jagadish. The entire team of Bangalore Medical College expressed satisfaction on the conduct of the event.

The Rakta Kranti team is hoping that future blood donation drives involving teams from BMC will have greater compliance to standards, have better quality and most importantly give every donor a memorable experience.

Bringing in a Consensus on Donor Deferrals The Emergence of a Protocol

Since voluntary blood donation drives are the cornerstone of a continuous supply of safe blood in India, organizing a voluntary blood donation drive is not just making necessary arrangements but also creating awareness and educating potential regular donors. Ensuring that a donor becomes permanent is the greatest challenge the blood banking fraternity faces today.

Across Sankalp's 500 blood donation drives and 55,000 units of blood collected, statistics indicate that deferrals can get as high as 45-50%. In 2014, 15,200 donors in 151 blood donation drives volunteered to donate blood. Of this, only 11,700 were deemed eligible to donate. The remaining 23% were deferred for different reasons. Unnecessary deferrals negatively impact the overall collection of blood. More pronounced damage than immediate loss of blood units is the fact that deferral has been linked with lower donor return rates both in first time and repeat donors. A donor deferred without solid grounds can lead to a unit lost every few months for the rest of his/her life.

Studies across the world suggest that the deferral rate of blood donors stands between 5-25%. Most of the studies go on to emphasize the fact that strategies to minimize deferral are needed to ensure an adequate and safe blood supply. Studies have also shown that donor deferral rates can be reduced without compromising donor's safety. Sankalp India Foundation has measured deferrals in outdoor voluntary blood donation drives with a good mixture of donors of both gender, first-time and repeat donors, and of various age groups.

Challenges faced with donor deferrals in blood donation drives

Several key factors which have implications on the donor deferral procedure and rates have been reported and observed:

- For some blood banks, the medical officer coming in for donor screening has had little or no exposure to voluntary blood donation drives.
- Medical officers (whether from the same or different blood bank) practice different standards many of which did not have enough medical evidence.
- In cases where the medical officer had a doubt about a medical condition, the easier and presumably safer option was taken to defer the donor. Yet no attempt was made to arrive at a clear and definitive criteria for that medical condition.
- Medical officers tend to take the decision

on deferral based upon untested-hypothesis and tradition. This aspect is further pronounced when less experienced medical officers attend the camps.

✎The references which are available for medical officers for donor selection are ambiguous. While the guidelines applicable within India list the broad criteria to look for, they do not explicitly state the conditions for acceptance or deferral. The guidelines available in India also have overlooked the interpretations for some commonly seen problems – eg. smoking, alcohol consumption etc.

✎A uniform donor selection criteria adopted from the criteria available from WHO and adjusted to the local law and demography has not been developed.

✎Several donors who have donated multiple times have expressed dissatisfaction over the different criteria followed by various blood banks. At times donor who has been donating blood regularly get's deferred without any change in his medical conditions.

✎Donors dissatisfied with deferral criteria followed by blood banks have not just got disappointed, but have gone further to imparts a negative message about blood donation to the potential donor community, particularly if deferral is made on grounds that seem frivolous.

✎There have been situations when medical officers have deferred donors purely based upon their gender. This has led to the propagation of message of the blood bank unduly discriminating with donors and questions have been raised about the whole public education and awareness program being organized at a local as well as national level.

✎Sometimes the medical officers have chosen to defer donors on criteria which is clearly indicated within the limits of eligibility for donation in the IEC material provided to the donors. The lack of consistency between donor education/motivations and the eventual process of blood donation is unacceptable to organizers.

✎Sankalp's statistics indicate that some blood banks consistently have higher donor deferral rate compared to the others. Higher deferrals do not correlate decisively with the rate of complications. Therefore, either some blood banks are selecting donors who should be deferred or some others are deferring donors who were eligible to donate.

✎None of the blood banks have a clearly written protocol for donor selection which includes the criteria and associated reasons for acceptance or deferral.

A Protocol on Assessing Donor Suitability

The best interest of voluntary blood donation and donor retention demands that steps be taken to streamline and standardize the donor deferral criteria. WHO has laid out several guidelines for the same. However in India, the two major guidelines/regulations which are being used are "Regulatory Requirements of Blood and/or its Components Including blood Products" by the Central Drugs Standard and Control Organization (CDSCO) and

"Voluntary Blood Donation Program - An Operations Guide" from National AIDS Control Organization (NACO).

Both these documents fall short of addressing the details of the donor selection criteria. While they do suggest the criteria to be used but there is limited information on the conditions of acceptance and deferral for each criterion. A review of the donor selection criteria as indicated in these two guidelines seems to suggest that there are inconsistencies and they leave wide scope for interpretation. Thus, in our country, the problems associated with unscientific and unmethodical donor selection continue to persist.

Blood banks in India collect 9.9 million units each year against the estimated demand for 12 million units. In the absence of a uniform criteria and consequently the significant variation in donor selection, a lot of individuals who should not be donating blood in the best interest of both donor and recipient are being selected for blood donation while there are a lot of those who are being deferred unnecessarily. Both the implications of inaccurate donor screening would have serious impact on the intention to provide safe blood from voluntary blood donors to one and all - as mandated by the National Blood Policy, 2007 and the Action Plan for Blood Safety, 2007.

The need for consensus and the evolution of this protocol is imminent. Sankalp India Foundation has put together a document for the benefit of the blood banking community to make donor acceptance and deferrals more standardized in voluntary blood donation drives. It has been reviewed and accepted by senior transfusion experts in Karnataka. Should you need a copy, please drop an email to Sankalp.admin@gmail.com.

"Let us sacrifice our today so that our children can have a better tomorrow." - Dr. A P J Abdul Kalam

News and Updates from July 2015

Rakta Kranti

Dengue continued to be the biggest challenge to deal with for all teams at Sankalp. For Rakta Kranti, it was to maintain a steady supply of blood in the city. The plan was to have atleast 15-20 blood donation drives in this period. However, in total 13 blood donation drives were organized by the team leading to a collection of 1078 units of blood.

The month began with a host of small blood donation drives - HDFC Ergo, a new partner organized a drive leading to a collection of 34 units, Bethel Marthoma Church organized a drive where 9 donors donated blood, an apartment complex in Whitefield (Mahaveer Palace) had a drive with 30 blood donor heroes coming in to donate. Good time and energy was spent on motivating and educating donors. The small drives helped maintain the stocks for 1/2 days at a time.

Among the regular organizations who support the cause of blood we had Xentrix Studios organise another series of blood donation drives at their offices. Enthusiastic donors came in good numbers at their Bagmane campus and patiently waited for their turn to donate as the venue was a little small. 48 units were collected. At their other location, the timing was not too right and hence only 16 people could donate. At the blood donation drive in Continental 221 units of blood were collected. With a new facility having more than 1000 people, the team put in tremendous efforts to publicize the event and close to 300 people walked in. The team are enthusiastic and hopeful to improve the numbers further in the next drive! This is clearly an example how a team red within the organization can make a big difference.

We also had our next series of blood donation drives at ITPB campus. With publicity using mails, SMS and brochure distribution on site 226 units were collected in a 2 day drive. As always, the support from Ascendas and Applied Materials was instrumental in having a smooth event. National Instruments as usual bailed us out of trouble with a blood donation drive on very short notice. This time the team planned for a blood donation drive involving the entire tech park thereby giving a chance for a greater number of units to be collected.

he event saw 70+ donors walking in and 55 units of blood being collected.

2 other organizations where an excellent publicity campaigns made a difference were Sankalp Semiconductors and Xerox. Both organizations are small in terms of number of employees working there. However, they have gone out of their way to invite people from several other organizations in the campus and ensure that patients do not suffer due to lack of blood. 100+ donors walked in to the drive at Sankalp Semiconductors and a massive 200+ at the Xerox drive (In fact at this place the drive stopped because we ran out of resources!). Such organizations are an example of how simple and meaningful steps by corporates can build a culture of regular blood donation for the employees.

This month also saw us roping in a new organization on board - the Indian Institute Of Management (IIM), Bangalore. The blood donation drive at the sprawling campus saw 150+ students come forward to donate and 118 units were collected. Here too good publicity ensured a steady flow of blood donors throughout the day. Sankalp would like to thank all these organizations and the blood donor heroes at each of them for Giving Life A Better Chance. With a non compliance of 1.5 per camp, 2.69% adverse reactions and 13.8% deferrals the numbers looked promising and progressive on all fronts. Teams from Victoria, Bowring, Nimhans, Rashtrothana, Sanjay Gandhi, Narayana hrudayalaya participated in the drives.

Emergency Wing

For the emergency team, the sleepless days and nights continued. Huge demand for platelets and regular requests for SDP meant that throughout the month the number of cases to deal with was quite high. The team got in touch with several donors through the course of the month and enabled many SDP donations across Bangalore city. The team also coordinated with patients and blood banks in making effective use of RDP units. The average number of calls on the helpline through the month was >50 per day.

Sankalp Tech

Receipt generation has been fully automated for Sankalp Finance. Gone are the days for manually creating receipts for our donors. The new feature created by Sankalp Tech team tracks receipts, provides a beautiful printable receipt and acknowledgement, reaches back to our donors through mails and provides them with the 80G receipts for their contributions on time. Sankalp Finance is now end-to-end tech driven!

Thalassemia Management

We had a total of 266 patient visits and 343 blood transfusions at Indira Gandhi Institute of Child Health in July 2015. While the median pre-transfusion hemoglobin of 8.7gm/dl looked pretty, the hospitalisation duration of 8.8 hours was not that impressive. The highlight for the month was the starting of the annual cardiac screening schedule. Every year Sri Jayadeva Institute of Cardio Vascular Sciences helps us screen all the children above 10 years for any cardiac complications. This leads to early identification of complications and timely interventions ensure that the problem is nipped in the bud. The periodic labs are going on smoothly and so is the chelation therapy. With an increase in the number of children seeking transfusions, it has become difficult to schedule patient visits and soon we will need to expand the capacity of the unit.

At Project Samraksha, the month was buzzing with the 189 patient visits which clocked 242 transfusions. The median pre-transfusion hemoglobin was an impressive 9.1 and the average duration of stay was 8 hours. The team at Samraksha was also kept busy preparing the kids who have been selected for transplants both medically and otherwise. Hyroxyurea has shown excellent results at Samraksha with several children maintaining spontaneous hemoglobin above 10 for months together with the therapy. However, strict monitoring and evaluation for all kids who are under hydroxyurea therapy is ongoing process at Samraksha which ensures that if there is an impact - it's only a positive one. The dosage of chelators was revised for several children in this month leading to substantial increase in the costs associated with chelation therapy support.

We had a very difficult situation with one of the families needing antenatal screening having to suffer undue delays and mental agony. With all the attempts we have made so far, we have not been able to streamline the antenatal screening and the genetic workup. The facilities available in other institutions in Bangalore tend to have shown serious limitations and difficulty. Sooner or later we will need a more tightly integrated and predictable screening process for the families who are carrying a foetus who may be affected from thalassemia.

Emphasis on endocrine complication management is increasing in our centres. When we started, most of the children who came to us have never received any chelation before. This led to a situation that we had children with ferritin levels upwards from 5000. Last year, when we tried to tackle the endocrine complications, the paediatric endocrinologist suggested that we bring the ferritin levels under control first and then explore other aspects of management. With her advice, we set out to correct the ferritin levels aggressively. We still have not received the ideal situation, but all kids are on chelation and most are showing improvement. With this, the spotlight is back on endocrine issues which we hope to address in next few months.

How some people make a difference

When people go beyond their zone of comfort and honestly work hard towards something, the results are always good. The actions of such individuals inspire people around. This story is of one such individual. An individual who is a blood donor hero by himself.

Sankalp has been organizing blood donation drives at ITPL since 2007. Thanks to the support from Ascendas and Applied Materials, the drive at ITPB campus is held regularly once in 4 months. ITPB has more than 15,000 people walking into their campus on any given day. Hence, a crucial aspect when planning blood donation drives there is to invest time and effort in publicity. Usually, one volunteer of Sankalp takes up the task of distributing brochures and inviting people to the drive. But ITPL has always helped us meet some very fine individuals. One man came to donate after hearing about the drive. He donated, but was wanting to do more. When the Sankalp volunteer at the drive told him that he can go back to his office, motivate more people and help collect more blood, he had a task at hand. He asked for a publicity mailer on the basis of which he will pull in more people. The volunteer at the camp site informed one other volunteer to send a publicity email. Unfortunately there was a delay. Although this man was interested. Perhaps he wanted a backup which could prove his claim that blood was required in good numbers during the dengue period. He came back to the came back to the camp venue demanding for the mail to be sent. However, there was a little more delay and the mail only reached him by the end of the first day – He still had the 2nd day as it was a 2 day blood donation drive.

The information that Sankalp puts forth in publicity mailers is short, inspiring and to the point. He used this mail and his personal aura to great effect. After the drive started off on day 2, he came and ensured everything was ready. He then spent a substantial amount of time making a noise about the blood donation drive. He caught the attention of several people in his office. He convinced them and perhaps narrated to them his own good experience at the drive on the previous day.

Towards the mid of day 2, he walked in again – this time not alone but with several donors trooping behind him. Of the 105 units collected on that day, 8-10 were from his side – close to 10% of donations for the day! Now, this is a man whom we had never known, yet his commitment to the cause of blood made him a temporary volunteer of Sankalp. He could have just donated and gone back, or maybe not come back after the publicity mail reached him late despite a second reminder. He chose not to give up. Such donors are for us the face of voluntary blood donation in India. It is through their selfless and timely actions that safe blood is available on the shelves of blood banks.

We are offering HLA Typing

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

There is good news. Currently, we are offering free HLA typing to those children with thalassemia who have a healthy sibling donor in association with Cure2Children Foundation, Italy. So far this facility was available for the children taking transfusion at centres supported by Sankalp. We are happy invite the families to make use of this opportunity. Please spread the word about the availability of this option for the families. The families can call our central help-line number 9480044444 for further information and appointment. Due to limited supply, we, however, might consider the eligibility of the family to avail free HLA typing before it is provided.

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