

Pursuing the true purpose of life...

Aby Sam John was an ambitious young man who was pursuing a high profile job in Histogenetics, Chennai. He had solid dreams about reaching the higher rungs of his career after his M.Tech in Biotechnology. But the play of chance made him the savior of a life and harbinger of a lifesaving organization – Datri to Kerala.

Aby belongs to Venmony in Chengannur District. His mother, Susamma John, runs a home appliance business after his father passed away unexpectedly following a heart attack. His sister is working as a clinical specialist after her Pharm. D. Aby's wife, Jaya Mary Jacob, is working in St. Thomas College of Engineering, Kozhuvalloor after her Ph. D in Chemical Engineering.

Aby started working after his M.Tech. His first job was in US based Histogenetics who do HLA typing in Chennai. Histogenetics is the pioneer in HLA typing. He worked as the Genetic Research Analyst there for almost two years. He is the Kerala coordinator for Datri for the past two years.

Before Datri in Chennai, Indian registries were very rare but now have 4 blood stem cell registries in India. At present, there are around 2 lakh donors from all these registries and the largest donorship is registered in Datri with more than 1, 50,000 donors.

One day Aby, who was afraid of injections and blood donation, attended a Datri blood stem cell donation awareness session. After the session, though with apprehensions in mind, he too registered. Three months after registration, he got a call from Raghu Rajagopal, the co-founder of Datri informing him that he was a match for a patient.

He had mixed feelings. He went to Histogenetics and shared the news with his friends who congratulated him. He still had a wavering mind as he was not completely sure of the after effects of blood stem cell donation. Then Datri coordinator Jaya met him and explained the whole scenario. He was convinced but was not quite happy about the whole affair. His father expired around that time and the whole family was still in shock.

His mother upon knowing this asked him to take his decision and some relatives shared their fears thinking of his future. Finally, he took his decision to donate his blood stem cells in the nearest donation centre, Apollo, Chennai. The coordinator was with him throughout and he was taken for a counselling



Aby Sam John

in Apollo with Dr. Jose Easow. Raghu Rajagopal also accompanied him to give him more courage. Aby asked all his doubts and the doctor convinced him that the process is quite safe. On March 27, 2013, he donated his blood stem cells. He had to go through the procedure with 5 days of injections and the donation was on the 5th day, which took around three to four hours.

Bone marrow is the production centre of blood cell. It can be harvested either directly from the hip bone (iliac crest) or collected from the peripheral blood. Now, 80 % blood stem cells donation is Peripheral Blood Stem Cell (PBSC) donation. GCSF injections will be administered to stimulate and mobilize the blood stem cells. For the first 4 days, the donor gets injections and the 5th day the donor donates the blood stem cells. Less than 10% donors have experienced a temporary, slight back discomfort or flu-like symptoms which can be alleviated with Paracetamol. Aby didn't have such effects.

After the first donation, he reflected on the purpose of his life and realized this life saving venture to be the real purpose of his life. As he was convinced that the procedure was safe, he became confident and motivated.

The donor gets all kinds of comforts during the donation. He was given a TV and watched 2 cricket matches during the procedure. He felt slight giddiness for 5 minutes which was cleared after he had his lunch. He was very contented that he could do something to save a precious life.

After this, Aby became more close to Raghu and had great respect for him. At this time, there were a few donor registrations in Kerala also. One day, Jaya called up and told him that there was a person working in Cochin Shipyard and his cells are match to a patient. Aby was asked to help Datri to counsel the person by explaining the process and also about his personal experience as a donor. He talked to the person over phone and he donated henceforth and the patient was saved. Aby considers this as a valuable achievement.

He started volunteering with Datri after this. At this time, there was a patient request to do awareness campaigns in Kerala, both in Trivandrum and Kottayam. Raghu spoke to Aby about giving awareness camps in Kerala as such activities were rare in Kerala at that time. Aby's first camp was in the Marthoma seminary in Kottayam. After the camp, 150 of them registered as donors. Next session was in Trivandrum for the same patient. Later, Aby started to volunteer for Datri on weekends.

Six months later, a request from Sachin Sijoy, an angelic infant of 7 months from Kerala came up. The child didn't get a match and was affected by SCID. His parents' samples didn't match. Sachin's uncle came to Aby and requested to help them but Aby had only



Aby with Mayur Bargaje

weekends to spare as he was working with Histogenetics then. During this time, Raghu called him and asked his opinion about joining Datri.

Realizing his true purpose of life, he finally decided to join Datri realizing him to be the selected medium by god to save lives. He joined Datri as the Kerala Coordinator in March 2014 after resigning the prospective job in Histogenetics. That was the time of struggle for blood stem cell organizations because of lack of awareness.

Initially, he joined Datri's Palaghat camp for Sachin. After the camp, there were 1800 registrations for him. This stands as a record. Then there was another camp in Calicut. Though the week was tough and he spent sleepless nights, he got a surprise birthday celebration arranged by Sachin's relatives, which he treats as a memorable gift.

Though they got around 10,000 registrations for Sachin, but unfortunately, the child passed away without getting a proper match. Aby was really disappointed by this as he had worked hard for him. But these camps benefited another 10 patients as they got proper match from the registrations. Recently Sachin's parents called him and Aby consoled them telling him that though they couldn't save him, he became the triggering agent for blood stem cell awareness campaigns in Kerala which in turn breathed life to almost 10 people.

He has managed 20 donations till time. Aby states that majority of requests are for children below 10 years. "Datri has the most registrations and Kerala has a major contribution with more than 30,000 registrations. We found 197 matches and 20 are from Kerala".

Aby acts as a one man army in Datri's Kerala sector. He gives counseling to donors at their homes, gets doctor's appointments, arranges the tests relating to the procedure, man-

Success Story | Aby Sam John

ages the conveyance and accommodation of the donor, transports the samples, be with the donor throughout the procedure - he has done all these. Now, Aby has a colleague, Deepu, who helps him out in office administration.

Blood Stem cell donation helps patients with blood related disorders - many types of leukemia, thalassemia, SCID, aplastic anaemia etc. The bone marrow of these patients will be defective. The patients will be given a set of chemo and their defective cells will be removed. The healthy blood stem cells from donor will be transfused to the patient and these cells will be recognized as their own cells as they have genetic resemblance.

These donor blood stem cells produce new, healthy blood cells inside the patient. In most case, the patient's blood group will change to the donor's blood group in few weeks. Aby's blood group is A+ve and the recipient's blood group was B+ve, which later changed to A+ve. The success rate of the transfusion depends on the disease, stage, the condition of the patient and the availability of proper match.

All recognized blood stem cell registries follow the guidelines of World Marrow Donor Association (WMDA). The donor and patient details are to be kept confidential for upto one year of transplant. After one year, if both the parties are willing, they can meet. One year after his donation, in 2014, Raghu called up and asked him whether he wanted to meet the recipient, who was a blood cancer survivor now. He was thrilled to see Mayur Bargaje, a 27-year old software professional who was diagnosed with cancer in 2010. In 2013, his cancer relapsed and the only option was a blood stem cell transplant. He was a very active person and had die-hard friends. One of them gave a 56-hour boxing event where he made continuous punching, which made a Guinness record, in order to raise funds for Mayur's treatment.

Aby went to Pune to meet Mayur. They had organized a surprise event to celebrate the meeting of the two. The family was overwhelmed seeing him and Mayur embraced him with great affection, who was their single child. He thanked him from his heart and called him his blood brother. At that moment, he felt that what he did was worthwhile. He thought that he had achieved something in life.

Aby is the 25th donor from Datri and the first donor from Kerala for an unrelated patient. He treats his work as 'little efforts to make big achievement in saving lives'. His wife is very understanding and gives him maximum freedom to work for Datri. HLA typing is usually very expensive. It comes to around Rs. 14000 for a test and is done by very few hospitals. As Datri is a not-for-profit organization, Histogenetics offers the typing at a subsidized rate of Rs. 1800. Datri takes care of the donor completely and even meets the whole expense of the donor. "If



Aby collecting samples during registration

the donor is not ready for travel, we go to his place and will be with him for 5 days. There will be a routine follow up after 7 days, one month and after one year to ensure that he is safe. All these will be managed by Datri", Aby comments.

As the procedure is done in a fully sterilized environment, in BMT unit for cancer patients, it leaves no chance for infection. There will be initial medicines and eventually, there won't be any lifelong medications. Datri has apheresis centers like Amrita Institute of Medical Sciences in Kerala; Apollo in Chennai, Narayana Healthin Bangalore etc. The samples have to be transported in 2-8 degree Celsius by air to other states without getting them x-rayed. The blood stem cells could be destroyed if they go through x-ray check. Aby takes care of all the procedures from registration to product transport if the donor is from Kerala.

He has no intention of leaving this job. "The awareness is increasing. My aim is to increase awareness and the donor ratio in Kerala", he adds. Recently there was a donor-recipient meet in Cochin between donor, a Gujarati and the patient from Calicut, Shivarama Krishnan. Cochin range IG S. Sreejith IPS came for the meet as the recipient was his friend. He requested for awareness programs to be conducted in Kerala and registered as a donor.

"We target colleges and large corporates. Though we have many young volunteers, the donations usually don't materialize because the families can't be convinced", comments Aby. Datri does health check up of the donor for his safety and also patient safety. "If the donor has any health issue, it might affect the patient also as they lack immunity. We absolutely ensure both the parties are in good health. Donors with high BP, cardiologic issues, chronic asthma etc. are usually excluded", adds Aby.

The main challenge, according to him is the unfounded fear about the donation. "If you voluntarily feel that you should register as a donor, you should take it seriously. Be completely informed and convinced of the procedures. And if there is a match, please don't back out from this because killing hope is just as cruel as a killing the patient", Aby puts this words forward as a message to the prospective donors. ■

Raghu Rajagopal

The Man with a Mission

Raghu Rajagopal has kindled a spark named Datri which has fanned all over India saving many lives. An engineer who passed out from the prestigious BITS Pilani, he started thinking differently after his entrepreneurial endeavours including an e-business, a product company and a BPO venture in the US. Thus, the not-for-profit organization, Datri came to life in Chennai.



He got associated with blood stem cell registries in the US as a friend of his had to undergo a blood stem cell transplant. He had actively partaken in donor drives in the US. On his return to India, he realized that the concept had not yet reached the people here. Raghu who knew about the potential of blood stem cell transplant, formed Datri joining hands with the founders of Histogenetics, Dr. Nezh Cereb and Dr. Soo Young Yang. Histogenetics are the pioneers in HLA typing to find a match for the patients. Thus, Datri started as the first functional blood stem cell registry in India.

Datri is associated with World Marrow Donor Association (WMDA) and a member of Bone Marrow Donor Worldwide (BMDW). Just like every new venture, Datri's challenge was the lack of awareness about this initiative of gifting lives. Indians consider the concept as life threatening or disabling. Raghu states that peripheral stem cell donation is a very safe procedure which can save lives without any hassles. The chance of finding a match within the family is just 25% and hence others have to search for a genetic match outside the family. In this scenario, the unrelated donor gains significance. "The probability of a genetic match for an Indian is high within India and is higher if we search within the same community or religion as it is mostly happening in the same criteria", Raghu comments.

Datri has 1,50,000 donors registered across India since 2010 and has facilitated 197 donations, including a 19 donations for international patients. The real challenge is finding a perfect match. From finding a match to transporting the product, the entire process requires high precision. In many cases, Raghu himself has transported the blood stem cells to the recipients at various destinations.

The biggest challenge that Datri faces is the lack of awareness of the Indian community about blood stem cell donation. Even educated people are unaware of this life-saving initiative.

"The first step to save a life is to register with us. We have many young volunteers now who have registered with us. Once you attend the camp and register, you start feeling that you are part of a huge system that can save a precious life. That itself is rewarding". Raghu states that at present, because of the increased awareness through camps and media, many companies have come forward to fund this mission. He hopes that more corporates will join hands with him to make this drive a huge success.

As the Co-founder & CEO of Datri, Raghu is optimistic about the future of 'Datri', the Sanskrit meaning of the word being 'Donor'. He anticipates the rate of donors will rise even more in the coming years making it easier to find more matches. "After all, if you can save a life, that gives you strength to move on forward confidently with a smile, no matter whatever personal adversities are", Raghu states with a gleam of satisfaction in his eyes. ■



Raghu Rajagopal