

● JUNE 2019

Thalassemia & Sickle Cell Society

report

“Poverty and Illiteracy can struck harder than any other possible hit,



Mahadevi- 7 Yrs

This is a story of a mother explaining her plight or rather a difficult situation of her unfortunate encounter with thalassemia. To top this up, condition of poverty and illiteracy struck harder than any other possible hit. Laxmi was married to a person from a nearby village. Being a daily wage worker, loading bricks on a truck can hardly fetch enough to run a family, this is what both the couple could do to run their life. As days passed she gave birth to her first daughter Mahadevi.

Life turned its course when Mahadevi turned to 1.5 years, she falll sick and after series of examination and tests it was discovered that the kid has thalassemia and needed blood transfusion whole her life. By then Laxmi was already pregnant with her second kid and soon gave birth to her second daughter Vashnavi.

For the parents there was another blow when Vashnavi would often fall sick and by the age of one she was also diagnosed thalassemic. Hard days for

parent's to keep the two infant alive at a very tender age. Poverty impacts children, families and individuals in a variety of different ways some of them this family is stuck with are Malnutrition, education & proper shelter. The disease is manageable with regular blood transfusions and iron chelation drugs, but affordability is the question, when asked how do you manage your kids, it was told that they are not going to school as of now, when it is hard to meet two ends meal for a laborer, forget about schooling or even good or new clothes in their birthday, having a full stomach sumptuous meal at home is more than enough that too is hard to do mission.

To top it all the family had the third daughter, with the understanding that since the first two kids are thalassemic the 3rd kid will be normal, when asked why do you have just an understanding, mother pointed to her counseling and her interpretation “I was not given the right counseling. I was told that one child will be thalassemia and other child will be normal”. Being almost illiterate it becomes hard to put the analogy together unless it is explained well in a layman's perspective. After coming to TSCS she understands what does a probability of 50% means. Right counseling and proper knowledge could have been the key to avoid many unforeseen circumstances that this family is going through.

Today parents bring all the 3 kids month after month to TSCS and they are supported with Free Blood and Medication. Since we have a large number of these children in our city, TSCS thought it is appropriate to give them daycare. So these children can stay in a comfortable environment get the blood collected, cross match and transfusions and then go home by

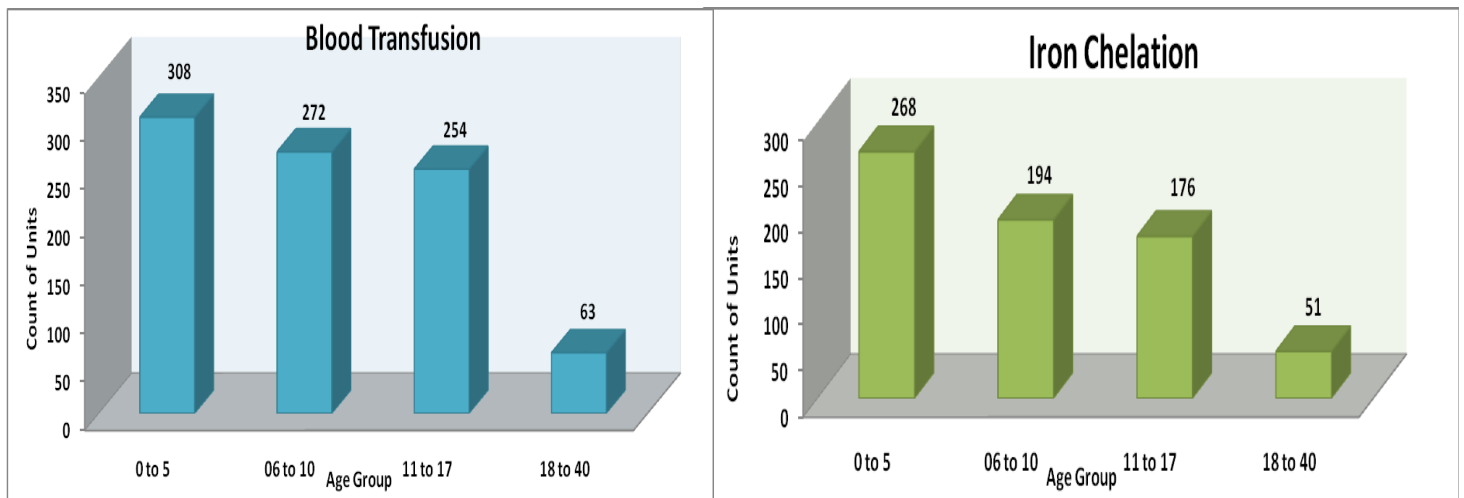


Vashnavi-5 Yrs



Swapna-3 Yrs

Transfusion Details



Total number of patients for the month of **June 2019** including all patients group were **897** some patients were given 2 units of blood, the total units provided where **1124**

HPLC at Society Couples/siblings	CVS referred to CDFD	New registrations	Splenectomy
40	NIL	14	0

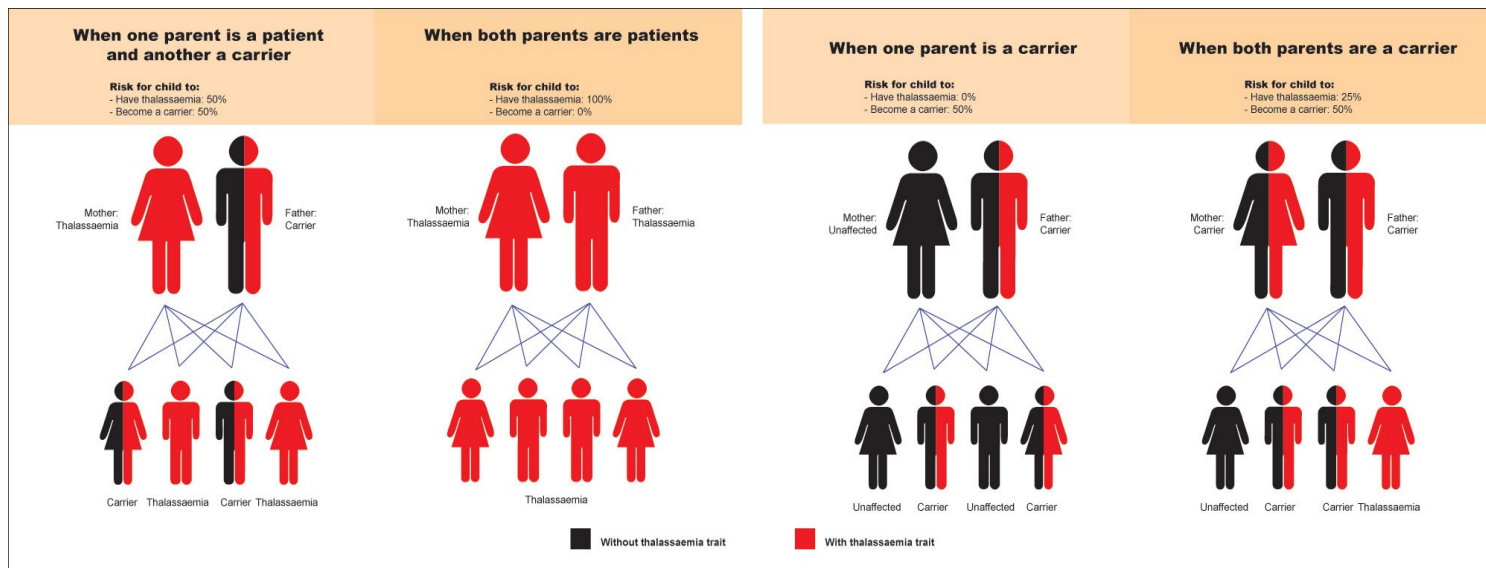
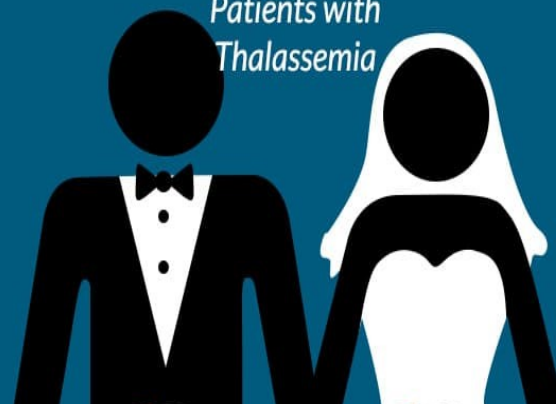
MONTHLY DONORS FOR JUNE-2019

1	SHREE JEWELLERS EXIMP PVT LTD	11	DR C ANUPAMA REDDY	21	AIMS ASIA
2	MURALI K SIRIPURAPU	12	MR SHASHIDER REDDY	22	GLOBAL STEELS
3	PADMAJA V S KOTHAPALLY	13	HARI OM PIPE INDUSTRIES LTD	23	MR SRIKANTH GULLAPALLI
4	MUNNA TRUST	14	SATTALURI SRIRAM GOPAL	24	SMT BANARSAI BAI
5	TIMING TECHNOLOGIES	15	SRI KRISHNA JEWELLARY MART	25	MR CHANDRAKANT AGARWAL
6	SUPREME AGENCIES	16	AMIR ALI DHARANI	26	DECCAN SWITCH GEARS
7	SHRINATH ROTOPACK PVT LTD	17	PARESH VORA	27	A S IRON & STEEL
8	BLEND COLOURSPVT LTD	18	S K RIYAZ	28	NAV DURGA TEXTILES PVT LTD
9	S P P POLYPACK PVT LTD	19	KUMAR ENTERPRISES	29	AMBIKA IRON & STEEL
10	V BALVEERAIHAH SONS	20	ATUL	30	MR ARAVIND KUMAR GUPTA

Can Thalassemia Patients Marry?

It is generally advised that the parents who are the carrier of thalassemia should not plan a child as there is 75% chance of passing off this disease to the next generation and the baby being either a carrier or sufferer of thalassemia.

Patients with Thalassemia



Particulars	Units
Sensitisation programmes organised	22
Blood donation camps	19
Opening Stock	364
Collected units of blood	1541
Discard of blood units	33
Closing Stock	463
Units provided to thalassemia + general free issues	1124
General paid issues	285
FFP ISSUES	2058



Thalassemia & Sickle Cell Society

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