

Thalassemia & Sickle Cell Society

report

"Difficulties in Dealing with the Feeling."



Afzal Khan has two kids his daughter Khaswa is 8 years and son Faizal is 5 years. Coming from a Muslim background , they have been giving their sons & daughters for marriage in relation for generation. Afzal also got married in relation. Suddenly his son Faizal started getting fever and vomiting , doctor advised for a blood test and discovered that their son was suffering with thalassemia.

Thalassemia results in frequent hospitalization of patients because its management requires regular blood transfusion. Faizal is coming to TSCS since 5 years. Parents bring their son all the way from Nizamabad boarding train at 2:00 am midnight for blood transfusion each month spending a whole day at TSCS. They have to

take care of their sick child and perform other responsibilities for their professional, social and family roles simultaneously.

Thalassemia affected the psychological status of parents causing fear, despair, and helplessness. Parents who care for such children tolerate a great burden. Understanding these sufferings seems necessary in order to provide appropriate care. Emotional distress, fear of death and difficulties in dealing with feelings are some of the common concerns.

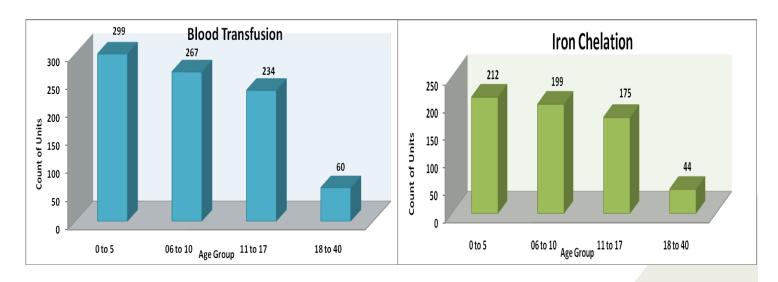
When Faizal's parents were directed to visit TSCS to know and get counseled over thalassemia that's when they got to learn about compressive treatment and lifelong condition. Father lives in a constant fear. Hence the families of patients with Thalassemia are taught how to deal with frequent hospital visits, resulting in a psychosocial burden. Psychological support for the caregivers is therefore particularly important and is a vital part of comprehensive medical treatment in TSCS.

Financial issues is another major concern that parents expressed. High expenses of treatments and Transportation besides the living cost imposed a heavy burden on the families. Thalassemia at present is considered as one of the most challenging disorder with no permanent cure





Transfusion Details



Total number of patients for the month of March 2019 including all patients group were 860 some patients were given 2 units of blood, the total units provided where 983

HPLC at Society Couples/siblings	CVS referred to CDFD	New registrations	Splenectomy
34	2	18	2

MONTHLY DONORS FOR MARCH 2019						
1	MUNNA TRUST	21	SWETHA DEVELOPERS	41	BLEND COLOURS PVT LTD	
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10	HARIOM PIPE INDUSTRIES LTD	30	A S IRON & STEEL	50		
11	S P P POLYPACK PVT LTD	31	NAV DURGA TEXTILES PVT LTD	51		



Why is it important to give blood?

Facts about blood needs

- Every year our nation requires about 4 Crore units of blood, out of which only a meager 40 Lakh units of blood are available.
- The gift of blood is the gift of life. There is no substitute for human blood.
- Every two seconds someone needs blood.
- More than 38,000 blood donations are needed every day.

Particulars	Units
Sensitisation programmes organised	17
Blood donation camps	12
Opening Stock	176
Collected units of blood	1393
Discard of blood units	18
Closing Stock	365
Units provided to thalassemia + general free issues	983
30% Govt Hospital free issues	0
General paid issues	203
FFP ISSUES	1440



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