

● FEBRUARY 2019

Thalassemia & Sickle Cell Society *report*

Raising a Child with Thalassemia



Lakshmi Kanth

Raising a child with thalassemia is difficult specially when you have no idea about the disease and more so when your income is below middle class. By having a child with thalassemia, you have to deal with many difficult situations, both financially and mentally.

Our 14 year old son Lakshmi Kanth, (Chintu) who was born with thalassemia, is a brave boy and studies in 8th Standard. We were told that Chintu's life would be reliant on blood transfusions and the only cure was bone marrow transplant. It was our first time hearing the word thalassemia, we had no other option but to wait helplessly while he was transfused.

Like every other parent, we tried every possible treatment, options to save our son. Since we learned that the only option to cure

the disease was bone marrow transplant and it was out of our reach, we went on with Blood transfusion only.

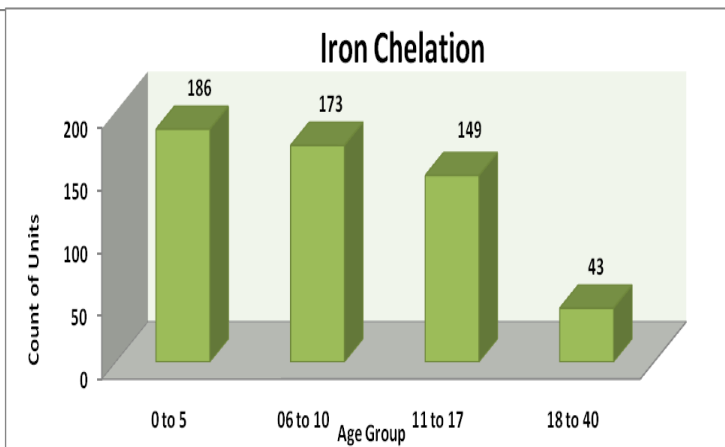
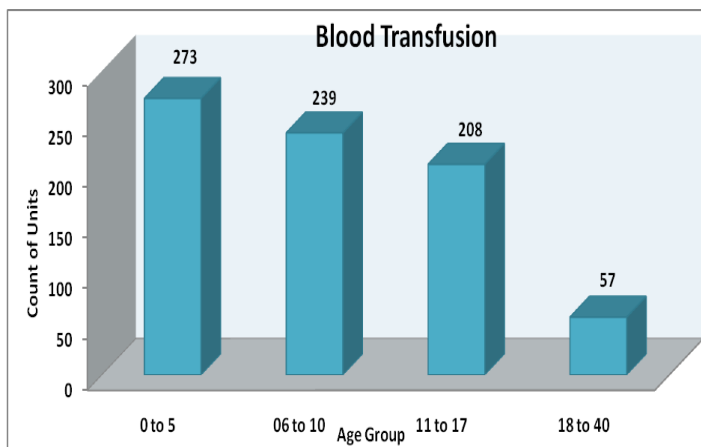
The disease is manageable with regular blood transfusions and iron chelation, but I was not able to afford the Iron chelating drug as they were very expensive. Working as a sales person in a footwear shop, did not provide enough income for me to treat my son. This got adverse effect on his health for life. Recently my son has gone through spleen removal operation due to high iron deposit and severe pain in his stomach. Thanks to TSCS for stepping in at the right time to save my son.

I have confidence that Chintu would be able to live a long life, like many other patients. The disease is manageable with regular blood transfusions and iron chelation. After operation he is much better and through the Aarogyashree scheme he is getting the medication which has now improved his health.

Life looks locative & hunky-dory from distance but if you have to really check deep in my heart it's a pain that a father goes through whenever I see my son, I get my strength from many other parents who are going through the same situation. I have not lost hope, but pressing against all such situation to bring the best in my son. I have no complaints why almighty has to bring this on my family, but I am running my race with the best foot forward.



Transfusion Details



Total number of patients for the month of February 2019 including all patients group were 777 some patients were given 2 units of blood, the total units provided where 895.

MONTHLY DONORS FOR FEBRUARY 2019

1	MURALI K SIRIPURAPU	10	SRI KRISHNA JEWELLERY MART	19	S P P POLYPACK PVT LTD
2	GEETHA PANDEY	11	KUMAR ENTERPRISES	20	BLEND COLOURS PVT LTD
3	V BALVEERAIAH SONS	12	AIMS ASIA	21	HARI OM PIPE INDUSTRIES LTD
4	MUNNA TRUST	13	AMIR ALI DHARANI	22	CHETAN SHARMA
5	SHRINATH ROTOPACK PVT LTD	14	GLOBAL STEELS	23	SREYAS HOLISTIC REMEDIES PVT LTD
6	DECCAN SWITCH GEARS	15	MR SRIKANTH GULLAPALLI	24	A S IRON & STEEL
7	DR C ANUPAMA REDDY	16	SMT BANARSAI BAI	25	NAV DURGA TEXTILES PVT LTD
8	MR C SHASHIDER REDDY	17	MR CHANDRAKANT AGARWAL	26	AMBIKA IRON & STEEL
9	T ANANDA MOHAN	18	MR MUNISH AGARWAL	27	MR ARAVIND KUMAR GUPTA

GENETIC COUNSELLING

Genetic counseling is the most complex aspect of prevention. Genetic counseling is inseparable from genetic diagnosis, aiming to replace misunderstandings about the causes of genetic disease with correct information, and to increase people's control of their own and their family's health by informing them of the resources available for diagnosis, treatment and prevention.

Genetic counseling has been defined as: "The process by which patients or relatives at risk of a disorder that may be hereditary are advised of the consequences of the disorder, and the probability of developing and transmitting it and the ways in which this may be prevented or ameliorated"

Why couples should do HbA2 test before Marriage

Marriage is a complex social phenomenon in India. Life partners today are selected on the basis of age-old parameters like 'Janam Kundlis' (astrological chart as per Hindu calendar). However, the prime criteria for choosing a bride or groom should also be a thalassemia test.

Awareness plays a major role in thalassemia. Owing to ignorance, patients often do not opt for diagnosis and end up transferring faulty genes to their children. Compared to the awareness of most commonly discussed diseases like cancer, diabetes, heart diseases, AIDS, etc, most average Indians haven't even heard about Thalassemia. According to estimates, more than 10,000 children in India are born with thalassemia every year due to the sheer lack of awareness among couples, preparing to get hitched. This ignorance is further leading to a rise in the number of deaths among thalassemic patients, most being in the rural areas.

It is time, we upped the ante and encourage couples to get HbA2 tested for thalassemia at an accredited medical diagnostics laboratory. Though it runs in families with history of thalassemia, it is beneficial for everybody to know their thalassemia status.

<i>HPLC at Society Couples/siblings</i>	<i>CVS referred to CDFD</i>	<i>New registrations</i>	<i>Splenectomy</i>
57	Nil	16	Nil

Particulars	Units
Sensitisation programmes organised	21
Blood donation camps	17
Units provided to thalassemia + general free issues	895
General paid issues	157
FFP Issues	892



Thalassemia & Sickle Cell Society
Door No. 22-8-496, Chatta Bazar
City Civil Court, Purani Haveli
Hyderabad Ph: 040-24560011

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