



● JULY 2021

Thalassemia & Sickle Cell Society

“ It is just another obstacle which becomes the part of life” *report*



mindful patients and parents gave a big relief. Frequent counseling that thalassemia is a treatable blood disorder that can be well-managed with blood transfusions (the process of receiving blood or blood products into one's veins to replace lost components of the blood) and Chelation therapy (medicine to remove excess iron from the body) and also the key influence of TSCS that has guided them through the difficulties of living with this rare disease has helped to overcome many emotional and physiological problems.



People usually think that marriages with-in relation can be a cause of thalassemia, but in this case it was not so. Non consanguineous marriage is also likely to inherit thalassemia. This is about a marriage in the year 2002 in Hyderabad, this couple was blessed with a daughter the following year. Until 6 months she was all well, later the kid started getting vomiting's, fever, parents got her admitted in the hospital, the diagnosis was a surprise to everyone. Genetic tests showed each of the parents were carrier of the thalassemia trait and the daughter had inherited two defective genes, one from each of the parents. Doctors from Niloufer hospital directed them to TSCS for better Thalassemia management

Going to TSCS was now part of the living, parents had a lot of anxiety around it but with frequent interaction with like-

Of course [thalassemia] comes with symptoms and it comes with limitations. But at the same time, it is just another obstacle which becomes the part of life. One should not look at it as a bad thing. One should not see this condition as a disability, but pave a path within the limitations.

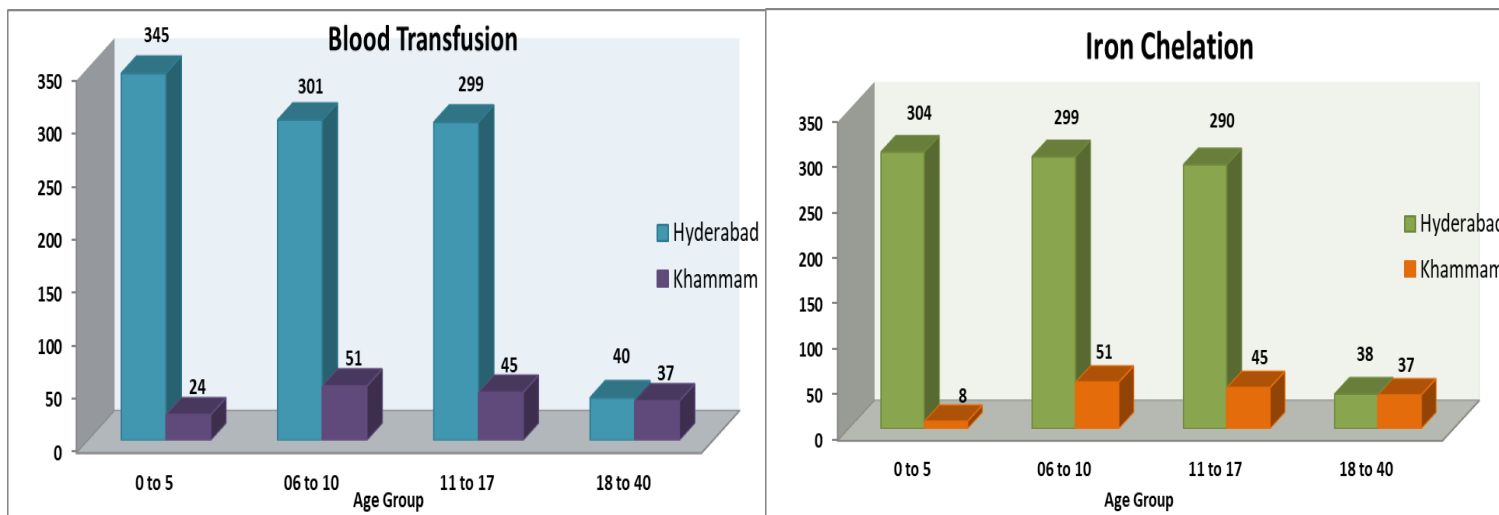
TSCS reinforces how crucial it is to stay on track with transfusions and other treatments for thalassemia in order to stay healthy.

Parents credit this consistent, outstanding care by the society in making a vital difference in their daughter's life.

“There's something different about people who are confronted with challenges, such as thalassemia.



Transfusion Details



Total number of patients for the month of **July 2021** including all patients group were **1142** some patients were given 2 units of blood, the total units provided where **1552** this include **275** units provided in **Khammam**.

HPLC at Society Couples/siblings	CVS referred to CDFD	New registrations	Splenectomy
181	8	17 (6 – Khammam)	Nil

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Tips for supporting children to learn from home

Plan a routine together

Try to establish a routine that factors in age-appropriate education programmes that can be followed online. Also, factor in play time and time for reading. Use everyday activities as learning opportunities for your children. And don't forget to come up with these plans together where possible. Although establishing a routine and structure is critically important for children and young people, in these times you may notice your children need some level of flexibility. Switch up your activities. Do not forget that planning and doing house chores together safely is great for development of fine and gross motor functions.



Have open conversations

Encourage your children to ask questions and express their feelings with you. Remember that your child may have different reactions to stress, so be patient and understanding. Start by inviting your child to talk about the issue. Find out how much they already know and follow their lead. Discuss good hygiene practices. Make sure you are in a safe environment and allow your child to talk freely. Drawing, stories and other activities may help to open a discussion.

Take your time

Start with shorter learning sessions and make them progressively longer. If the goal is to have a 30- or 45-minute session, start with 10 minutes and build up from there. Within a session, combine online or screen time with offline activities or exercises.

Protect children online

Digital platforms provide an opportunity for children to keep learning, take part in play and keep in touch with their friends. But increased access online brings heightened risks for children's safety, protection and privacy. Discuss the internet with your children so that they know how it works, what they need to be aware of, and what appropriate behavior looks like on the platforms they use, such as video calls.



Thalassaemia & Sickle Cell Society

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Particulars	Units
SENSITISATION PROGRAMMES ORGANISED	12
BLOOD DONATION CAMPS	10
OPENING STOCK	179
COLLECTED UNITS OF BLOOD	2218
DISCARD OF BLOOD UNITS	83
UNITS PROVIDED TO THALASSEMIA + GENERAL FREE ISSUES (<i>Khammam 275Units</i>) / Government	1798
GENERAL PAID ISSUES	97