

● OCTOBER 2020

Thalassemia & Sickle Cell Society

report

“ We are constantly in a bigger fight for livelihood ”



Sheik Mohammed Musa

Sheik Rahim earns out a living by selling things as street vendor in Hyderabad. He has to sustain three children who live with him in a small rented home. And he is not sure when he would be able to save enough to secure their future.

Among his 3 kids his 2 year old son, Sheik Mohammed Musa, who was diagnosed with thalassemia when he was 6 months old and since then we are part of TSCS. “Life is full of worries, when you have thalassemic children, the problems also multiplied”, he said.

Thalassemia is the most common chronic hereditary disease that is seen in almost all races globally and is transmitted from parents to children. Approximately 240 million of the world's population are carriers of beta-thalassemia.

It's a daily fight for survival working outside as street vendors exposed to strong sun, heavy

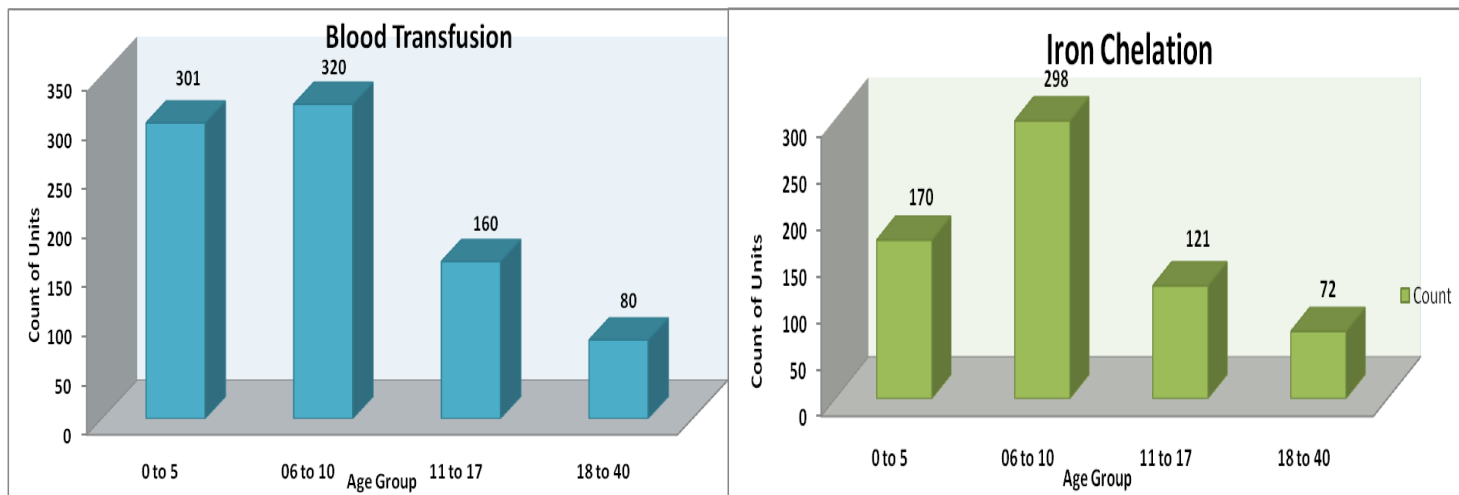
rains and extreme heat or cold and other routine occupational hazards. Poverty collides with health every day and in the midst of all this managing thalassemia child is a challenge. Praise to TSCS, it makes it possible for people like us to raise their kids. We are constantly in a bigger fight for livelihood as street vendors, we live in constant fear of what might happen, some days we are roughed up and sometimes our stalls are pushed or damaged, or we are asked to move without any notice. The going is very tough.

Being a parent of a thalassemia child we experience a wide range of problems, such as physical, emotional, mental, social and economic situations. I can't think very much of the future of my son because it scares me a lot. Rearing a child with thalassaemia entails suffering from different forms of challenges, they need more attention as compared to healthy children. Psychological distress, social isolation, worries, and fear of the disease and its future consequences keeps on running in my mind.

I have two daughters who are found to be carriers. The doctors at TSCS counselled us on premarital screening and advised to take preventive measures before getting them married. My son's HLA matched with his sister and I am looking forward for his recovery through Bone Marrow Transplantation.



Transfusion Details



Total number of patients for the month of **October 2020** including all patients group were **861** some patients were given 2 units of blood, the total units provided where **1027**.

HPLC at Society Couples/siblings	CVS referred to CDFD	New registrations	Splenectomy
37	6	8	Nil

MONTHLY DONORS FOR OCTOBER 2020

1	MURALI K SIRIPURAPU	13	DR ANUPAMA SRIKANTH TALLURI
2	SHRINATH ROTOPACK PVT LTD	14	HARIOM PIPE INDUSTRIES LTD
3	MUNNA TRUST	15	SRI KRISHNA JEWELLERY MART
4	PRASANTHA	16	SPP POLY PACK PVT LTD
5	SUPREME AGENCIES	17	GLOBAL STEELS
6	SRIKANTH GULLAPALLI	18	SMT BANARSAI BAI
7	PROF. V. R. RAO	19	AMIR ALI DHARANI
8	DECCAN SWITCH GEARS	20	CHANDRAKANT AGARWAL
9	DR. C. ANUPAMA REDDY	21	RAJINIKANTH AGARWAL
10	C. SHASHIDAR REDDY	22	A S IRON & STEEL
11	V BALVEERAIAH SONS	23	AIMS ASIA
12	SRAYAS HOLISTIC REMEDIES PVT LTD	24	ALPHA SHAH

COVID-19 PARENTING Structure Up

COVID-19 has interrupted our daily work, home and school routines.
This is hard for children, teenagers and for you. Making new routines can help.

Create a flexible but consistent daily routine.

- > Make a schedule for you and your children that has time for structured activities as well as free time. This can help children feel more secure and better behaved.
- > Children or teenagers can help plan the routine for the day – like making a school timetable. Children will follow this better if they help to make it.

You are a model for your child's behavior.

- > If you practice keeping safe distances and hygiene yourself, and treat others with compassion, especially those who are sick or vulnerable – your children and teenagers will learn from you.

Teach your child about keeping safe distances

- > If it is OK in your country, get children outside.
- > You can also write letters and draw pictures to share with people. Put them up outside your home for others to see!
- > You can reassure your child by talking about how you are keeping safe. Listen to their suggestions and take them seriously.

Make handwashing and hygiene fun

- ▼ Make a 20-second song for washing hands. Add actions! Give children points and praise for regular handwashing.
- ▼ Make a game to see how few times we can touch our faces with a reward for the least number of touches (you can count for each other).

Particulars	Units
SENSITISATION PROGRAMMES ORGANISED	22
BLOOD DONATION CAMPS	17
COLLECTED UNITS OF BLOOD	2027
CLOSING STOCK	934
UNITS PROVIDED TO THALASSEMIA + GENERAL FREE ISSUES	1027
GENERAL PAID ISSUES	87
FFP ISSUES	43



Thalassemia & Sickle Cell Society

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