



Thalassemia and Sickle Cell Society

Lack of awareness -A curse on the family

By Priyadarshini B & Dr. Padma G

This is the story of a family where lack of awareness about blood disorders like thalassemia and sickle cell anemia lead to the birth of two affected children in the extended family. It is a pathetic situation wherein though the number of thalassemia births are increasing and India is considered to be capital of thalassemia, people are still ignorant about the disorder. They are landing up in complications due to inaccurate diagnosis, lack of proper treatment, medication and counselling from the healthcare front. Due to social stigma, the parents don't reveal about the condition of their child in their family, and as a consequence, more number of affected children are born in the extended family. It is need of the hour that extensive awareness programs should be conducted to educate the population about these disorders so that early diagnosis and treatment can reduce the mortality rate among the affected and preventive measures can be adopted to reduce the incidence of these conditions and save millions of children from life long suffering.



Varun Naik is a resident of Yerragondapalem, Prakasam district born to Ram babu Naik, a farmer and Revathi Bai, a homemaker. They have four children, Varun Naik being the third child. Their first daughter is normal, second daughter died in her childhood without diagnosis and youngest son is normal. Varun Naik was taken to RIMS hospital in Cuddapah when he started falling sick and was diagnosed with thalassemia major. They were just advised to go for blood transfusion lifelong. No other counselling was given regarding its inheritance, management or prevention due to which the parents went for fourth conception and luckily the child turned out to be normal. The parents were unaware of prenatal diagnosis to detect the affected status of the fetus. They were also not counselled about the need for extended family screening which led to the birth of another affected child Anand Naik in their family.

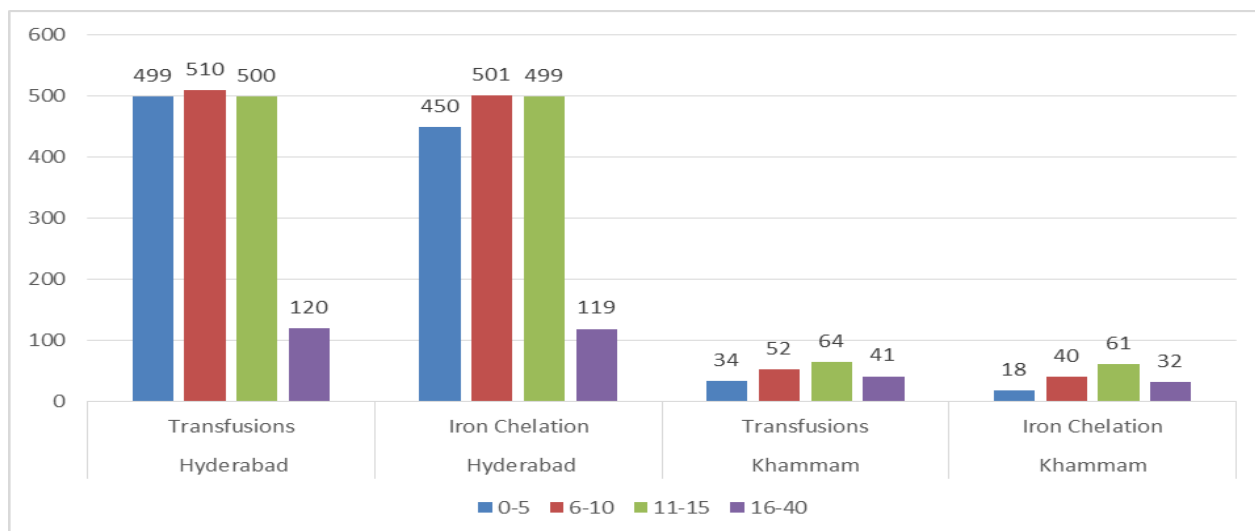
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Anand Naik is the maternal cousin of Varun Naik born to Naresh Naik, daily wage labour and Rameshwari Bai, a house maker. He is their second child and was taken to RIMS, Cuddapah where he was diagnosed with thalassemia major. They were also not given proper counselling except for that the child should be given blood transfusion whenever the hemoglobin falls below 5gms/dl.

Then they came to know about TSCS through one of their relative and approached the society. Here, they were made aware about the different aspects of the disorder and the need to take medications on time to reduce the iron overload and the complications associated with it. They were enrolled under Aarogyasri to avail medications and investigations at free of cost. They were counselled about prenatal diagnosis at every conception to prevent the birth of an affected child. They are very happy to have been registered with the society and advising their family members to get tested for these disorders to protect their future generations.

Awareness about these disorders among the public and healthcare system is very much important to provide timely treatment and reduce the complications and also to prevent the recurrence of the conditions in the population.

Transfusion Details



Total number of Blood Transfusions for the month of **November 2022** including all patients group were **1629** & a total of **1879** units blood provided to patients and in Khammam 191 transfusions were given

HPLC at Society	CVS referred to CDFD	New registrations	Splenectomy
330	03	32 (02 @ Khammam)	01

236 Antenatal women were screened for Thalassemia and Sick cell anemia carrier status from Government Maternity Hospital, Petlaburj (167) , Balanagar PHC (41) and Rajapur PHC (28) of which 06 were found to be Thal carriers, 02 HbD, 01 AS and 01 HbE carrier but husbands are normal.

BLOOD BANK

S.No	Particulars	Units
1	Sensitization Programmers Organized	29
2	Total No of Blood Donation Camps	27
3	Blood Collection at Camps and In-house—104	2344
4	Thalassemic & General Free Issues (Khammam –199 units)	2039

Novartis Global team visit to TSCS on 07 Nov 2022



National C3 Thalassemia Conference at Pune on 13 Nov 2022



Donations



Monthly Donors For November 2022

1	Murali K Siripurapu	15	Sri Mahalaxmi Jewellers
2	Shrinath Rotopack Pvt Ltd	16	Aim Asia
3	Manna Trust	17	Sri Nava Durga Billets Pvt Ltd
4	Prasanth	18	Blend Colours Pvt Ltd
5	Supreme Agencies	19	SPP Poly Pack Pvt Ltd
6	Srikanth Gullapalli	20	Sri Krishna Jewellery Mart
7	Prof. V. R. Rao	21	Smt Banarsai Bai
8	Deccan Switch Gears	22	A S Iron & Steel
9	Dr. C. Anupama Reddy	23	Dilip
10	Ch. Shashidar Reddy	24	Dr Anupama Srikanth Alluri
11	V Balveeraiah & Sons	25	Life Line Foundation Trust
12	Sreyas Holistic Remedies Pvt Ltd	26	Timing Technologies India Pvt Ltd
13	Hariom Pipe Industries Ltd	27	Shahenaj Hajayani
14	Giving Foundation		

NEWS & EVENTS

Children's Day celebrations at TSCS. Programme was sponsored by SUN Pharma. Activities like dance, indoor games, cultural programmes were conducted prizes given to winners and gifts for all participants



Healthy Eating habits for Children

By Rishitha,
Research Scientist, TSCS

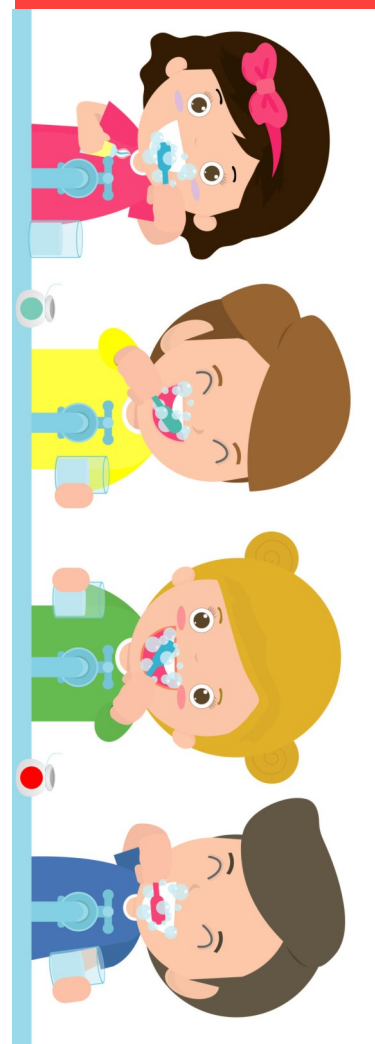
Health is wealth. A healthy eating improves child's overall growth and development. It reduces the chances of developing health problems as they get older.

Children should enjoy a wide variety of foods from these 5 food groups:

- fruits
- vegetables, legumes and beans
- cereals (including breads, rice, pasta and noodles), preferably wholegrain
- lean meat, fish, poultry and/or alternatives
- milks, yoghurts, cheeses and/or alternatives (children under 2 should have full-fat milk, but older children and adolescents can have reduced-fat varieties)



Children should limit their intake of foods that contain saturated fat, added salt or added sugar. They should drink plenty of water and exercise regularly.



Reach us to extend your Help

All donations to Thalassemia and Sickle Cell Society are exempted under section 80G and 35(1)ii (Research only) act of Income Tax Act 1961



THALASSEMIA AND SICKLE CELL SOCIETY

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