Thalassemia and Sickle Cell Society

Awareness about Thalassemia

Carrier testing during pregnancy can prevent the birth of affected children

By Priyadarshini B & Dr. Padma G

Manoj is a Thalassemia Major child born to Suresh, a farmer and Muniratna, a two-wheeler trainer. The parents had a non-consanguineous marriage but still ended up in giving birth to a thalassemia child emphasizing the importance of getting tested for a rare genetic disorder like thalassemia before marriage or in the first trimester of pregnancy.

The mother had an abortion at her first conception and the second child Manoj was hail and healthy till the 4th month. In the fifth month, Muniratna noticed that her child was turning pale and took him for a check up to a nearby hospital in Anantapur. The doctor advised for a Complete blood picture to rule out the cause for his paleness. They were shocked to find the child's haemoglobin levels very low around 5gms/dl and advised the parents to take the child immediately to St Ann's hospital in Bangalore. They admitted the child for a week and transfused him 1 unit of blood. Meanwhile they suggested for HPLC analysis of the parents but the father refused to go for the test as he felt that he was normal and not the reason for his child's condition. However, the mother agreed to get tested and turned out to be a carrier for thalassemia.

Muniratna is a strong lady who teaches two-wheeler driving to ladies. She got reminded of a thalassemia major child Ayesha, to whose mother she taught driving. She immediately consulted Ayesha's mother and approached Thalassemia and Sickle Cell Society, Hyderabad where Ayesha was undergoing treatment for Thalassemia. The doctors counselled about the symptoms, inheritance and treatment for thalassemia and got them registered. They convinced the father to go for HbA2 testing to diagnose thalassemia and he also turned out to be a carrier. However, he is adamant and refuses to accept the fact that he is a carrier and his child inherited the disorder from his parents.

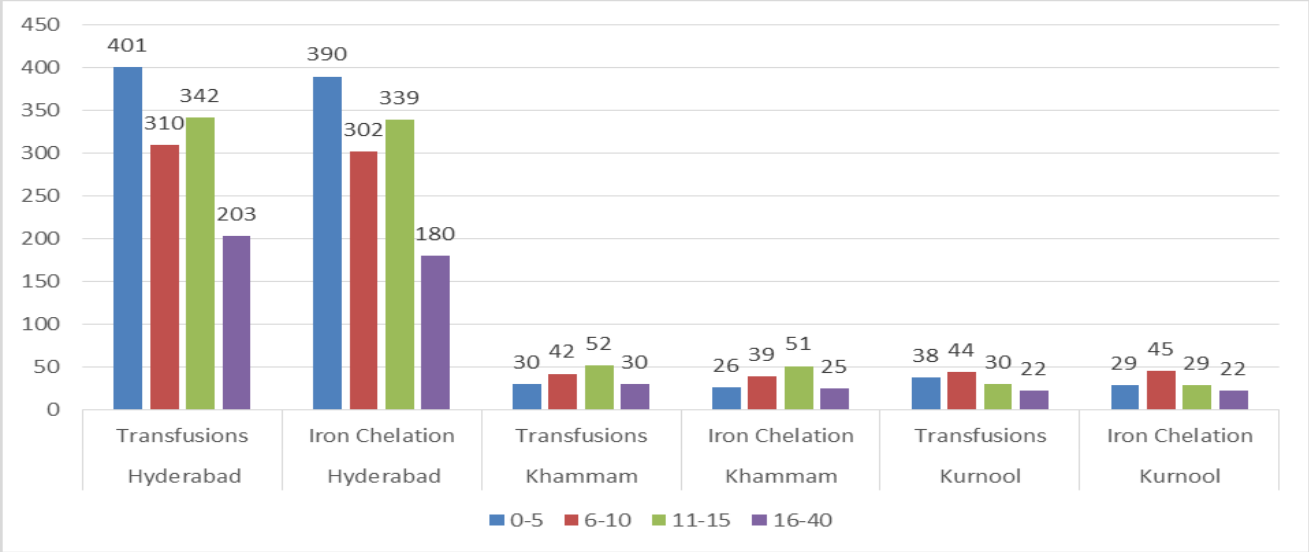
But Muniratna is bold enough to accept the truth and continues Manoj's treatment at TSCS. She takes a very good care of him and brings him for regular transfusions to TSCS in Hyderabad all the way from Anantapur. It is pathetic that most of the men still hold the women responsible for their child's unhealthy condition and refuses to accept that they may also be equally responsible for contributing a defective gene to their progeny. Its high time that people are made aware about genetic diseases and the fact that if both the parents are carriers then there is 25% chance that the child my be affected at every conception/pregnancy. A simple blood test like HbA2 during first trimester of pregnancy can prevent the birth of such affected children and save them from lifelong suffering.

Muniratna decided not to have any more children as the father is still not accepting that he is a carrier. She wants to take good care of Manoj with timely blood transfusions and medications. Manoj is now studying in 5th class in a Montessori school and wants to become a doctor. He is very talented and likes painting and playing chess. May all his dreams be fulfilled.!!!

Thalassemia FREE Telangana

Donate blood and be the reason of smile to many faces.!

Transfusion Details



Total number of Blood Transfusions for the month of **April 2023** including all patients group were **1256** & a total of **1661** units blood provided to patients in **Hyderabad.** Transfusions at **Khammam** 30 and **Kurnool** 38

HPLC at Society	CVS referred to CDFD	New registrations	Splenectomy
285	03	24 (18 @ Hyderabad, & 06 @ Kurnool)	NIL

185 Antenatal women were screened for Thalassemia and Sickle cell anemia carrier status from Government Maternity Hospital, Petlaburj (145) , Balanagar PHC (18) and Rajapur PHC (22) of which 04 were found to be Thal carriers, 01 AS, 02 HbD, 01 HbE, 01 DT and 02 HbE carriers but husbands are normal.

BLOOD BANK

S.No	Particulars	Units
1	Sensitization Programmers Organized	25
2	Total No of Blood Donation Camps	22
3	Blood Units Collection at Camps	1344
4	Blood Collection Camps and In-house	1516
5	Discard Bags	34
6	Thalassemic & General Free Issues	1671

Donations

Monthly Donors For November 2022			
1	Murali K Siripurapu	14	Giving Foundation
2	Shrinath Rotopack Pvt Ltd	15	Sri Mahalaxmi Jewellers
3	Manna Trust	16	Aim Asia
4	Prasanth	17	Sri Nava Durga Billets Pvt Ltd
5	Supreme Agencies	18	Blend Colours Pvt Ltd
6	Srikanth Gullapalli	19	SPP Poly Pack Pvt Ltd
7	Prof. V. R. Rao	20	Sri Krishna Jewellery Mart
8	Deccan Switch Gears	21	Smt Banarsai Bai
9	Dr. C. Anupama Reddy	22	A S Iron & Steel
10	Ch. Shashidar Reddy	23	Dilip
11	V Balveeraiah & Sons	24	Dr Anupama Srikanth Alluri
12	Sreyas Holistic Remedies Pvt Ltd	25	Devendra Gupta
13	Hariom Pipe Industries Ltd		

NEWS & EVENTS

TSCS team requested & reminded Mr. Asaduddin Owaisi MP, regarding prevention & eradication of Thalassemia in Telangana.

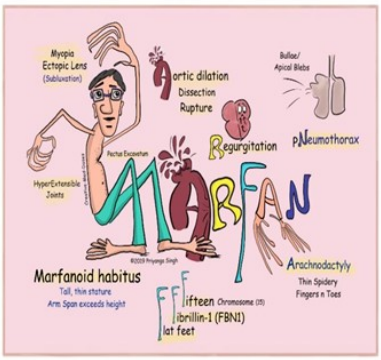
Dr Chandrakant Agrawal - Recognised and honoured with the PhD Title in social service, by the Euro Asian University ESTONIA

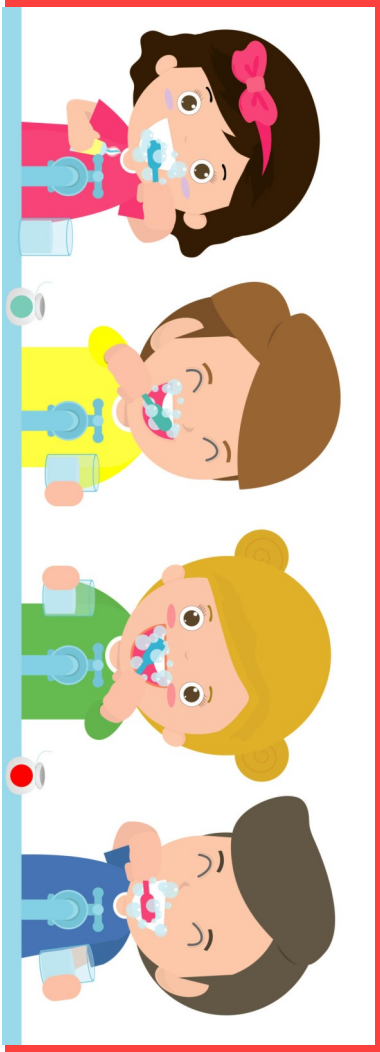
TSCS organized a special programme "Celebration of Life" which marks the completion of successful 97 Bone Marrow Transplantations (free of cost) at the society. The society has expressed their special gratitude towards Govt. of Telangana, Sankalp India Foundation & Electronic Mart India Limited which has been helping TSCS with all the necessary funds towards the procedures and other necessities for Bone Marrow Transplantation.

Cystic fibrosis

By Rishitha, Project Assistant TSCS

Marfan syndrome is a dominant inherited genetic disorder that changes the protein which make a healthy connective tissue. Mutation occurs in chromosome 15 of FBN1 gene, changes a fibrilin-1 protein which makes elastic fibres in the connective tissue. There is an increased production of TGF-β (transforming growth factor beta) due to abnormality in fibrilin protein. In this case there is a problem with the development of connective tissues. It can be mild to severe. It can affect different areas of the body including, eyes, heart and blood vessels, skin, lungs etc. Affected person looks thin and elongated body, fingers etc.





Symptoms may vary from person to person because the connective tissue is present throughout the body and also based on which part of the body is affected. Common symptoms include: abdominal pain, flat feet, headache, loose joints, back pain, numbness in legs, vision changes, heartbeat fluttering etc.

Mitral valve prolapse
(Medial necrosis of Aorta)
Aortic aneurysm
Retinal detachment
Fibrillin defect
(FBN1 gene mutation on Ch. Fifteen)
Arachnodactyly
Negative Nitroprusside test
(+ve in Homocystinuria)
Subluxated lense

Treatment also varies based on which part of the body is affected, and vary from person tom person.

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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