Thalassemia and Sickle Cell Society

Awareness about Thalassemia

Harmony Amidst Thalassemia: Ghousiya's Journey

By Dr G Padma, Research Scientist, TSCS

Ghousiya's journey through her battle with thalassemia was a challenging one, but with the support of her family and the care provided by TSCS in Hyderabad, she found hope and a path to better health.

In the heart of Andhra Pradesh, Ghousiya's family lived a simple life. Her parents had never heard of genetic blood disorders like thalassemia until their precious daughter was diagnosed at the tender age of one. Her two brothers were fortunate to be born without the condition, but Ghousiya's life was about to take a different path.

Early on, Ghousiya frequently suffered from unexplained fevers. Her parents grew increasingly concerned for her well-being, and their journey to find answers began. They sought medical help, visiting several hospitals in their hometown. At one point, Ghousiya was diagnosed with malaria, and her parents breathed a sigh of relief when she recovered after treatment.

However, the relief was short-lived. A subsequent fever sent them back to Kadapa RIMS Hospital, where a blood test revealed something more ominous—a blood infection. They were referred to hospitals in Kurnool and Tirupati, leaving Ghousiya's parents anxious and confused.

Determined to find the best care for their daughter, they eventually made their way to Niloufer Hospital in Hyderabad. Here, the medical team recommended an HPLC test to uncover the underlying cause of Ghousiya's persistent weakness. The results were devastating—she had thalassemia major, a condition that her parents had never heard of before.

Returning to Kadapa RIMS Hospital, Ghousiya began receiving transfusions to manage her condition. However, her health deteriorated rapidly, and the hospital lacked the resources to provide comprehensive care. In this dire situation, a ray of hope emerged in the form of Ghousiya's uncle, a doctor, who suggested they turn to TSCS in Hyderabad.

TSCS, a center dedicated to caring for thalassemic children, offered not only free treatment but also invaluable support and guidance. Ghousiya and her family made their way back to Hyderabad, where they registered with TSCS. Here, they received counseling about the disease, the importance of maintaining hemoglobin levels, and the significance of genetic testing before marriage or during the first trimester of pregnancy to prevent the birth of affected children.

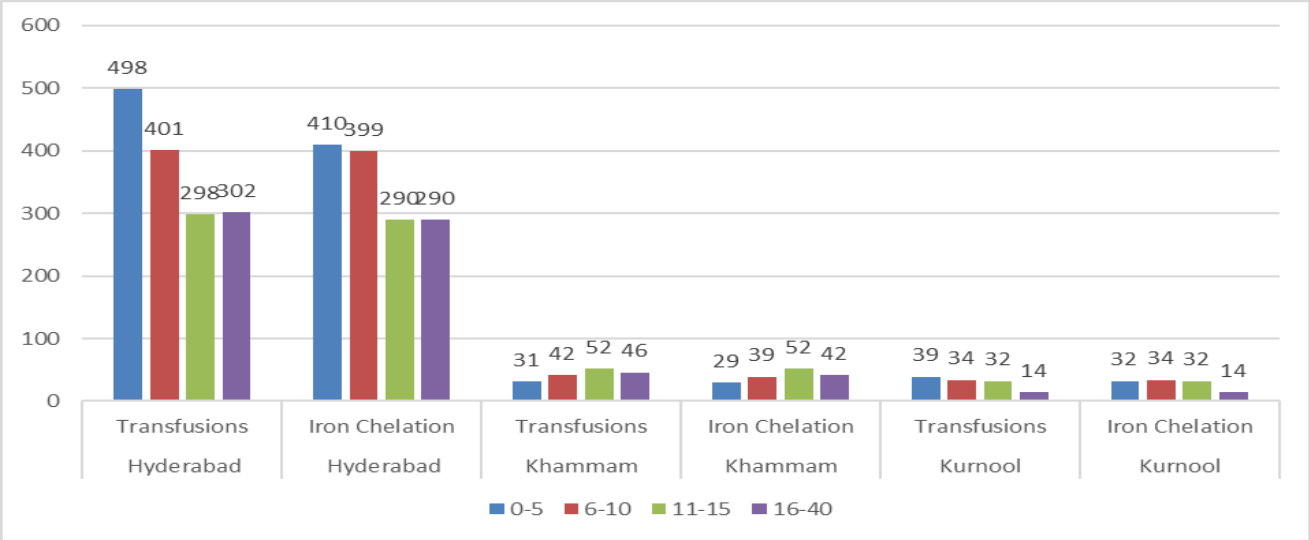
Under the care of the dedicated medical professionals at TSCS, Ghousiya's health began to improve. Regular transfusions and chelation medicines became a part of her life, helping her manage the challenges of thalassemia. Despite the hurdles she faced, Ghousiya remained resilient and maintained her dreams and ambitions.

One of her passions was singing, and she aspired to become a talented singer. Through the support of her family and the care provided by TSCS, Ghousiya was not only able to manage her condition but also pursue her dreams. Her story serves as a testament to the importance of awareness, early detection, and proper care in managing genetic blood disorders like thalassemia, and it demonstrates the power of hope and determination in the face of adversity.

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 **August 2023** including all patients group were **1499 (Hyderabad), 171 (Khammam) and 119 (Kurnool)** & a total of **1792, 189** and **137** units of blood provided to patients in respective centres

HPLC at Society	CVS referred to CDFD	New registrations	Splenectomy
1036	05	45 (38 @ Hyderabad, 06 @ Khammam & 01 @ Kurnool)	01

696 Antenatal women were screened for Thalassemia and Sickle cell anemia carrier status from Government Maternity Hospital, Petlaburj (280) , Mahabubnagar PHCs(416) of which 14 were found to be Thal carriers, 04 - AS, 01 - HbE and 02 - HbD carriers out of all 01 husband AS.

BLOOD BANK

S. No	Particulars	Units
1	Sensitization Programmers Organized	38
2	Total No of Blood Donation Camps	32
3	Blood Units Collection at Camps	1649
4	Blood Collection Camps and In-house	1783
5	Thalassemic & General Free Issues	1798

Donations

Monthly Donors For August 2023			
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	Shyam Ji
11	V Balveeraiah & Sons	24	Sudha Prasanth
12	Sreyas Holistic Remedies Pvt Ltd	25	Maqubool Ahmed
13	Hariom Pipe Industries Ltd	26	Dilipe

NEWS & EVENTS

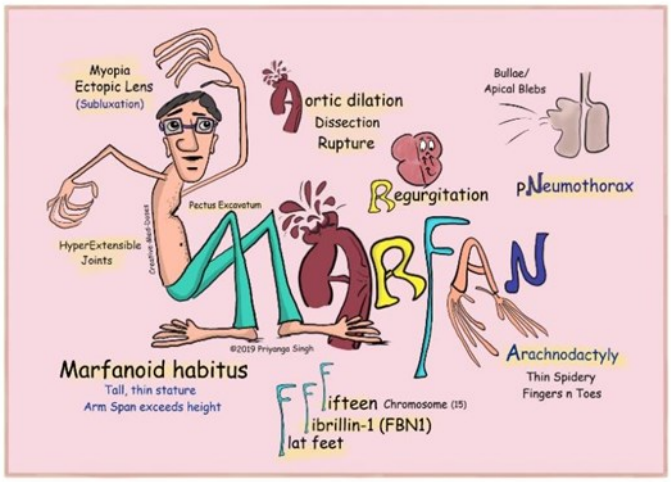
Ramky Foundation Blood Donation Camp 18 Aug'23

Blood donation camp

Successfully conducted awareness programmes in one of the remote villages in Mahabubnagar (Ganded, Mohamadabad and Hanwada PHC's)

Marfan syndrome

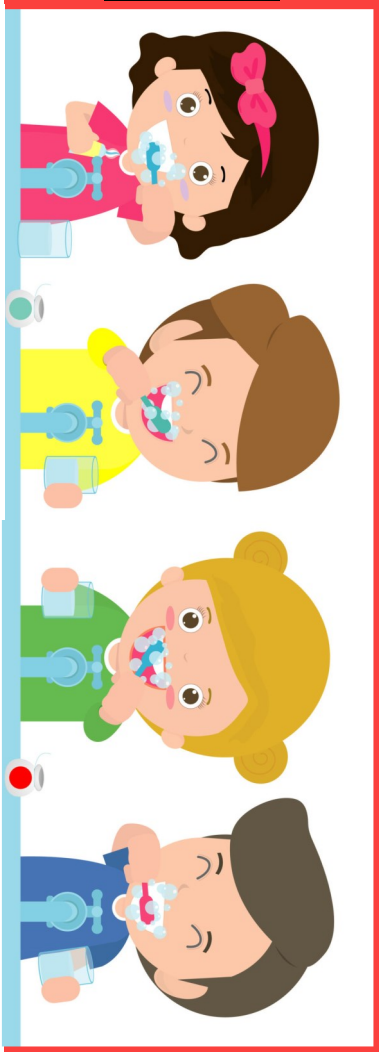
By Dr Rishitha, Research Scientist, TSCS



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.

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. Symptoms may be mild to severe based on the person's condition. Common symptoms include: abdominal pain, flat feet, headache, loose joints, back pain, numbness in legs, vision changes, heartbeat fluttering etc.

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

Door No. 8-13-95/1/C,
Opp. lane to National Police Academy,
Raghavendra Colony, Shivarampally,
Rajendra Nagar, Rangareddy District – 500052
Hyderabad, Telangana
Ph. 040-29885658 / 29880731 / 29885458
Website: www.tscsindia.org
E-mail: tscs@tscsindia.org / tscsap@gmail.com

Thalassemia FREE India