



**THALASSEMIA AND  
SICKLE CELL SOCIETY**  
Hyderabad, Khammam & Kurnool



# ANNUAL REPORT 2022



- Kamala Hospital and Research Centre
- B Narayan Das Shyam Sunder Loya Cure Thalassemia Welfare Trust
- Vuppala Venkaiah Memorial Blood Centre
- Vuppala Krishna Rao & Chandrakala Diagnostic Services
- Prema Bai Dakotiya Charitable and Memorial Society
- Kamala Bal Agarwal (Duke's) Diagnostic Laboratory

## Services at TSCS

1. **FREE consultation** with specialised Doctors on every visit for blood transfusion

2. 3 tyre counselling to Patient, Parents/Guardians and also to Extended family members

3. **FREE BLOOD** and Blood Transfusion for all Thalassemia and Sickle Cell patients

4. **FREE Chelating** and all other medication for patients not eligible for Aarogyasri Health Care Scheme.

5. **FREE periodic Medical check-up/consultation** for all patients with: Hematologist, Cardiologist, Endocrinologist, Pathologist, Ophthalmologist, Dentist and Radiologist

6. **FREE Investigations** (T2 MRI, 2D-Echo, X-Ray, Ultra sound Sonography, Scanning and Eye Testing)

7. **FREE HPLC testing** for all to identify the carrier status

8. **FREE HLA typing** for patients' siblings and parents.

9. **FREE Bone Marrow Transplantation** (BMT) for eligible (HLA fully matched) patients at Sankalp India Foundation, Bangalore. Electronics India Mart Ltd extended their support for our patients to undergo BMT procedure under their CSR Activity.

10. Financial support for Haplo-matched patients for BMT at Narayana Hrudayalaya, Bangalore

11. TSCS initiated programmes to prevent the birth of Thalassemia children through screening of pregnant women for carrier status at government maternity hospitals.

12. **FREE DNA Test** of patients for Beta Thalassemia, Delta Thalassemia, E-thalassemia, Alpha Thalassemia and Sickle Cell Anemia.

13. **FREE Prenatal counselling** to Thalassemia carrier parents and guidance for CVS sampling and amniocentesis in collaboration with NIMS Hospital.

14. **FREE Breakfast and Lunch** to all patients and attendants coming for transfusion.

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## Management Committee



**Mr Naresh Rathi**  
Chief Patron



**Mr Shyam Sunder Loya**  
Patron



**Mr Chandrakant Agarwal**  
President



**Mr Pradeep Uppala**  
Patron



**Dr Suman Jain**  
Chief Medical Research Officer  
and Secretary



**Mrs Ratnavali K**  
Vice-President



**Mr Manoj Rupani**  
Treasurer



**Mr M A Aleem Baig**  
Joint Secretary



**Dr D Venkataramana**  
Executive Member (Ex-President)



**Mrs Rama Vuppala**  
Joint Treasurer



**Dr D Rajeshwar**  
Advisory Member



**Dr Shirisha Rani**  
Advisory Member



## President's Message



### Chandrakant Agarwal

President

As rear view mirror is essential for a safe journey, I feel reviewing our past performance, we can learn a lot and improve our performance and when look at our past, there is immense scope for innovation, improvement and initiative in many areas of our activities, we must never rest on our laurels, but strive hard with determination and dedication for realizing our dream of "Thalassemia Free Telangana".

"One step and another, longest walk is ended ", and every step we take here at TSCS shall lead to eradication of this disease forever and which is clearly is in the realm of possibility.

National level conference on prevention of Thalassemia, Training Medical Officers for prevention of Thalassemia, opening of our new centers at Khammam and Kurnool, visits of eminent Doctors, Scientists, Scholars, at our centers, Mega Blood Donation Camp, 2,25,000 Transfusions, 80 BMTs, 330 PND, 350 T2\*MRI, 68 new registrations in Jan Feb 2023, 3500+ Total Registrations, 2800+ Blood Donation Camps, 11202 HbA2 Tests, the list may go on.

These achievements, spurs us to move higher and higher in achieving our cherished goal of thalassemia free Telangana.

In all these, we are immensely grateful to TELANGANA Govt & outstanding community of people dedicated to service above self, with hope on the horizon, thank you very much for a incredible year of service.

To survive, we must continuously innovate and strive for excellence and single mindedly focus on our priorities. Kindness, grace and compassion of all our Donors, Doctors, Medical Officers, Media, Officials, well wishers, stakeholders, patients, parents, guests, our most dedicated staff and all concerned persons, who have helped us in this trying times, is being acknowledged with a grateful heart, please accept our sincere and heartfelt thanks. Thank you very much.

**Wishing you all that is best and warmest of regards,**

**-Chandrakant Agrawal.**

## Secretary's message



### Dr Suman Jain

Chief Medical Research Officer  
and Secretary

As we have entered into the 25th year of our services to thalassemia and sickle cell anemia children, it gives me immense pleasure to share that the year 2022 has seen a tremendous milestone in the development of Thalassemia and Sickle Cell Society with the inauguration of our second transfusion hall, research laboratory and auditorium by Our honorable Former Vice President of India, Shri. M Venkaiah Naidu Garu. It was a great honor to have Sir with us which was

a true inspiration to us to move towards achieving our goals further.

Our main aim from the beginning was to prevent the birth of affected children, as due to the lack of awareness among the masses, India has turned out to be the Thalassemia Capital of the World. Preventive antenatal screening program initiated by us at Govt. Maternity Hospital, Petlaburz, Hyderabad bore fruitful results with screening of over 3000 antenatal women. This motivated us to extend the program to Primary health care centers in Mahbubnagar district. I am looking forward to a day when we can proudly say that we have achieved "Thalassemia Free Telangana." I know that my vision is broad but with hard efforts and dedication I strongly believe that this wouldn't be impossible.

With the advent of new drugs in the treatment of thalassemia and sickle cell children, we are courageously marching on to take up new challenges and advances in our treatment protocols. Our goal is to serve the thalassemia and sickle cell anemia children to the fullest with a promise to boost their physical and emotional wellness.

I extend my heartfelt thanks to all our donors and well-wishers for their continuous support and commitment towards our society which is driving us to serving our children in great heights.

Lastly, I would like to thank all my employees and medical professionals who are working with us and without whose team spirit and efforts this wouldn't have been possible.

**Wishing all the best with your endeavour,**

**-Dr Suman Jain.**

## About TSCS

Thalassaemia and Sickle Cell Society (TSCS) is a registered (Reg. No. 5359) non-profit, non-governmental organisation established in 1998 (celebrating its SILVER JUBILEE YEAR) by a small group of patient's parents, doctors, well-wishers, philanthropists etc. with an aim to provide the best treatment and management possible, to the patients suffering with Thalassemia and Sickle Cell Anemia. Ever since the time of its inception, its priority has always been towards serving its patients with better services in accordance with the latest developments in treatment, management and prevention of the same.

This year as Thalassaemia and Sickle Cell Society (TSCS) enters into 25 years of selfless services we are happy to share our journey from 20 patients to 3400 registered patients availing our FREE services. It was a small beginning under the able guidance of Dr A N Krishna Kumari garu who was the driving force behind starting an NGO for Thalassemia and Sickle Cell affected. Those days we were given a space at ITMR for blood transfusions. It was run with minimal staff with just one consultant, Nurse and an ayamma with a lot of difficulties in initial stage. The journey of 5-7 transfusions in a day at ITMR has led to 60-80 transfusions a day at one of the Largest State of Art Thalassemia Center with well-maintained Transfusion center, modern Blood center and Diagnostic Laboratory and an Advanced Research center under one roof a feat appreciated by all.

TSCS has eminent specialists like hemato-oncologist, paediatric endocrinologist, cardiologist, paediatrician, pathologists, ophthalmologist, dentist, radiologists and research scientists associated with it to provide the best comprehensive care and cure for the patients. All the facilities at the centre are provided at free of cost including consultation, saline-washed RBC (SWRBC), blood transfusion, counselling, medicines, investigations, food etc.

TSCS has also opened a centre at Khammam in 2022 to cater to the needs of the patients residing in Khammam and surrounding districts making ease their travel and spreading more awareness about these disorders. TSCS has also initiated to open a centre in Kurnool on the request of the registered patients to provide a transfusion centre at Kurnool.

TSCS is fast spreading its wings to serve as many patients as possible and working towards achieving Thalassemia Free Telangana through its prevention programs like antenatal screening, cascade screening and educating the patients parents to go for prenatal diagnosis at their subsequent conceptions.

TSCS is not just dedicated to making Telangana Thalassemia free but also getting their patients cured from thalassemia through Bone Marrow Transplantation (BMT).

TSCS has recently entered into its 25th (SILVER JUBILEE) YEAR of selfless service to patients affected with thalassemia and sickle cell anaemia and its only dream is to achieve Thalassemia free Telangana and Thalassemia Free India by appealing to the government to pass a G.O making HbA2 test mandatory during the first trimester of pregnancy and save thousands of children from being born with the dreadful genetic disorder, thalassemia.

## Mission:

Thalassemia and Sickle Cell Society is dedicated to ensuring the best treatment and quality of life for patients suffering with Thalassemia and Sickle Cell Anemia. Moving ahead to reach our goal of Thalassemia free Telangana.

## AIM:

- » To provide appropriate treatment to improve the quality of life to patients.
- » To promote prevention policies to reduce the number of newly affected births.
- » To promote research activities for bringing about latest and affordable treatment
- » To reach/assist the under-privileged communities with free blood transfusion, medication and counselling
- » To provide safe/good quality blood to the patients
- » To create platform for counselling and pre- and post- Bone Marrow Transplantation (BMT) management
- » To encourage for BMT and make patients Thalassemia Free

## Organogram of Society



## Ethical Committee Members

Name	Designation
<b>Dr Lakshman Rao RL,</b> MD Community Medicine; Vice Principal – Osmania Medical College	<b>Chairman &amp; Medical Scientist</b>
<b>Dr Sudheer Aluru,</b> PhD Human Genetics, Scientist – TSCS	<b>Member Secretary</b>
<b>Dr Sirisha Rani Siddaiahgari,</b> MD& DNB Paediatrics – Rainbow Children Hospital	<b>Clinician</b>
<b>Dr Mohammed Iqbal,</b> MBBS – TSCS	<b>Clinician</b>
<b>Dr Vijaya Lakshmi Valluri,</b> PhD Immunogenetics, Scientist & Head– Immunology Molecular Biology Dept. – Bhagwan Mahavir Medical Research Centre.	<b>Scientific Member</b>
<b>Dr Padma G</b> PhD Human Genetics, Scientist – TSCS	<b>Scientific Member</b>
<b>Mr Moorthy VSR,</b> Spiritual Scientist	<b>Member</b>
<b>Dr Hannah Anandaraj,</b> PhD Social Sciences	<b>Social Scientist</b>
<b>Mr Deepak Bhattacharjee,</b> LLM	<b>Legal Expert</b>
<b>Mr Lakshmanaswamy,</b> MCA	<b>Lay Person</b>

## Patron Doctors

Name	Designation
<b>Dr Sreenivas Namineni</b>	<b>Pediatric Dental Surgeon</b>
<b>Dr Ashwin Dalal</b>	<b>MD in Pediatrics DM in Genetics</b>
<b>Dr K Nageshwar Rao</b>	<b>Cardiologist</b>
<b>Dr K Nagarjuna</b>	<b>MBBS MS M.ch</b>
<b>Dr Md Aejaaz Habeeb</b>	<b>Gastroenterologist</b>
<b>Dr K Gayatri</b>	<b>Pathologist</b>
<b>Dr A Narendra Kumar</b>	<b>Professor of Pediatric Surgery</b>
<b>Dr Chandra Prakash Jain</b>	<b>ENT Consultant</b>

### Advisory Members

<b>Mr R Srinivasan</b>
<b>Mr Vaman Rao</b>
<b>Dr Geeta Kolar</b>
<b>Dr Ashwin Dalal</b>

### Auditor

<b>NVS Murty &amp; Co.</b>
<b>Secunderabad</b>
<b>Telangana</b>

### Banker

<b>Canara Bank</b>
<b>Pathargatti Branch</b>
<b>Hyderabad</b>

## Research Advisory Board

Sl. No.	Name	Designaton	Internal/ External	Organization
1	Dr. M.P.J.S Anandaraj	Scientist	External	Ex-Director, Institute of Genetics and Hospital for Genetic Diseases, Osmania University, Hyderabad
2	Dr. Q. Annie Hason	Professor & Head, Dept. of Genetics & Molecular Medicine Senior Scientific Officer	External	Kamineni Institute of Medical Sciences, Hyderabad, Telangana Vasavi Medical Research Center, Telangana, Hyderabad
3	Dr. Kaiser Jamil	Emeritus Research Scientist and Head, Genetics Dept.	External	Bhagwan Mahavir Medical Research Centre, Hyderabad, Telangana
4	Dr. K. V. Radhakrishna	Scientist "D"	External	National Institute of Nutrition, Hyderabad, Telangana
5	Dr. Lavanya M Suneetha	Head- Research & Training Infectious Disease Research Lab	External	CODEWEL Nireekshana, Hyderabad, Telangana
6	Dr. Ashwin Dalal	Head, Diagnostic Division	External	Center for DNA Fingerprinting and Diagnostics, Hyderabad
7	Dr. Shailesh R. Singi	Consultant Hematologist and BMT Physician	External	Century Hospital, Hyderabad, Telangana
8	Dr. S. Sirisha Rani	Consultant, Paediatric Hemato Oncologist	External	Rainbow Hospital for Women and Children, Hyderabad, Telangana
9	Dr. Suman Jain	Chief Medical Research Officer & Secretary,	Internal	Thalassemia and Sickle Cell Society, Hyderabad, Telangana

## Eminent Doctors Working with TSCS

Sl. No	Name of Doctor and Qualification	Sl.	Name of Doctor and Qualification
1	Dr. SUMAN JAIN, MBBS, DCH, Paediatrician, Chief Medical Research Officer	16	Dr. V SANDHYA, MBBS, MD, FNB (Paediatric Hemato Oncologist)
2	Dr. SUJAI SUNEETHA, MBBS, DCP, PhD, Pathologist & Leprologist	17	Dr. B VARSHINI, MBBS, DNB, FNB (Paediatric Hemato Oncologist)
3	Dr. K SAROJA, BHMS, DHMM, Medical Officer	18	Dr. CH SAMPATH REDDY, MDS, FDS, RCPS, MFDS, RCS (Dentist)
4	Dr. MOHD IQBAL MOINUDDIN, MBBS, Medical Officer	19	Dr. PRADEEP NAIK, M.Sc, PhD, Bio-Chemistry
5	Dr. SARASWATHI SUSARLA, MBBS, MD (General Medicine)	20	Dr. MAMATHA, PhD Genetics, Scientist
6	Dr. AMARNATH KULKARNI, MBBS, DCH, DNB, Paed. Endocrinologist	21	Dr. KURAPATI PRADEEP KUMAR, MBBS, MD (Paediatrician), Khammam
7	Dr. SIRISHA RANI, MBBS, MD, MRCPCH (Paed. Hemato Oncologist)	22	Dr. RUDRA GOUTHAM NARESH, MBBS, MD (General Medicine), Khammam
8	Dr. PARINITHA, MBBS, MD, MRCPCH, CCT (Paed. Hemato Oncologist)	23	Dr. M HARSHAVARDHAN RAO, MBBS, Medical Officer, Khammam
9	Dr. RAMANA DANDAMUDI, MBBS, DCH, MRCP (Paed. Hemato Oncologist)	24	Dr. MOHD JULFAKAR ALI, MBBS, Medical Officer, Khammam
10	Dr. D M NAIK, MBBS, MD, Pathology (Pathologist)	25	Dr. R VENUGOPAL, MBBS, MD (Radiologist), Khammam
11	Dr. A RAGHAVENDER GOUD, MBBS, MD, FSCAI (Cardiologist)	26	Dr. CHARITHA SRANVANTHI BATTU, MBBS, DNB (Pathology), Khammam
12	Dr. B SWETHA, MBBS, MDRD (Radiologist)	27	Dr Lakkireddy Chandan Obul Reddy, Kurnool
13	Dr. ANURADHA KULKARNI, MBBS, MS, Ophthal (Ophthalmologist)	28	Dr S Mohd. Ashwaq Hussain, Kurnool
14	Prof. V R RAO, M.Sc, PhD, Genetic Epidemiologist (Population)	29	Dr. Raj Kumar Yadav, Khammam
15	Dr. G PADMA, M.Sc, PhD Genetics, Sr. Research Scientist		



## Achievements – 2022

- » Thalassemia and Sickle Cell Society (TSCS) organised a First-of-its-kind **National Level Conference on Prevention of Thalassemia and Sickle Cell Anemia** with an aim of “Thalassemia Free India” on 30th April and 01st May 2022. Shri T. Harish Rao Garu, Minister for Finance, Health, Medical & Family Welfare, Government of Telangana inaugurated the conference.
- » **Shri M. Venkaiah Naidu Garu**, Hon'ble Vice President of India visited TSCS to Inaugurate 2nd Blood Transfusion unit, Research Laboratory, Advanced Diagnostic Laboratory and two Auditoriums at our centre on 14th June 2022.
- » Our blood got centre recognized and Awarded by the government of telangana and TSACS for giving best services to thalassemia patients and collecting blood only from **Voluntary Blood Donors** on 14th June 2022. Received this award from Dr Harish Rao, Honble Health Minister, Telangana State.
- » Kamala Hospital and Research Centre for Thalassemia and Sickle Cell patients was awarded **Certificate of Appreciation** for exemplary performance under Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (AB PM-JAY) – Aarogyasri in the state of Telangana by Smt. P. Sabitha Indra Reddy, Hon'ble Education Minister, Telangana Government on 15 Aug 2022.
- » Another feather in the cap of TSCS... 10 bedded new **Transfusion Centre was started in Khammam** for easy access of treatment to patients residing in Khammam and the surrounding districts on 14th March 2022.
- » Dr Padma received the **Best paper presentation award** at Care, Cure and Curb, Pune conference on 13th November 2022
- » We have digital and manual data of 3388 patients.
- » **1800-2000** patients are given **Free blood transfusions every month**.
- » **23,365** units of blood were collected from **332** voluntary blood donation camps organised with help of donors, politicians, philanthropists, police personnel etc.
- » **1066 HbA2 tests** were done for parents, siblings, extended family members of patients and antenatal women. All the tests were done free of cost.
- » TSCS has collaborated with NOVARTIS in a project entitled “Burden of Vaso-Occlusive pain crisis: A Cross-sectional observation of study among patients with sickle cell disease in India (B-VOCAL SCD) to know the burden of pain events in sickle cell disease the medication used for the treatment to study complication and to know the cost of the pain events. In this study 23 centres from all over India had participated.
- » **Twenty five Thalassemia patients** under went **Bone Marrow Transplantation (BMT)** in collaboration with Sankalp India Foundation, Bangalore during the year .
- » Research collaboration established with Institute of Genetics, CSIR-Institute of Genomics & Integrative Biology (IGIB), Centre for DNA Fingerprinting and Diagnostics (CDFD), Kamineni Hospital - Genetic Department, Genome Foundation, Sankalp India Foundation, Bangalore, Department of Hematology and Rare Diseases, Italy and Novartis Sickle Cell World Assessment Survey (SWAY).
- » With the aim to reduce/prevent Thalassemia births, **2366 Antenatal women were screened** in Government Maternity Hospital, Petlaburj, Hyderabad and PHC's (Balanagar & Rajapur) of Mahabubnagar District.
- » Every month around **750** Thalassemia and Sickle Cell Anemia children in Telangana and **150** children in Andhra Pradesh received services through **Aarogyasri Health Scheme**.
- » “Prevention of Hemoglobinopathies through antenatal screening” a prevention project was initiated by Sankalp India Foundation at Bangalore under our able guidance.
- » National Thalassemia Day on 8th may 2022 and Children's Day were celebrated on 20th November with the support of SUN PHARMA Ltd.
- » During the year Three papers have been published in various national and international journals and two are under review.
- » **ISO 9001:2015** Certificate is valid for the Scope: Providing services for Thalassemia and Sickle cell anemia in the area of “Diagnostic services, Prevention, Treatment and Cure, Blood Bank, Blood Transfusion and Research and Development.

TSCS is the only transfusion centre in India with more than 3388 Thalassemia and Sickle Cell Anemia registered patients with age group ranging from 3 months to 50 years, as on December 2022. As children affected with Thalassemia need regular blood transfusions and management throughout their life, all the registered patients receive free services. The programme seeks to increase the lifespan and improve the quality of life of marginalised and poor families affected by Thalassemia and Sickle Cell Anemia. As the treatment and management is expensive many families are unable to afford the treatment. We are striving to give these children full support and strength in painful crisis. We also wish to develop confidence in Thalassemia and Sickle Cell Anemia children to lead a near normal life.

The details of 3388 patients registered in the society since the inception in 1998 are given below.

Diagnosis	Telangana	Andhra Pradesh	Other States	Total
Thalassemia Major	1540	591	96	2227
SC - Sickle Cell Anemia	558	109	11	678
SBT - Sickle Beta Thalassemia	211	32	1	561
Thalassemia Intermedia	71	21	2	94
E Beta Thalassemia	61	8	14	83
PRCA - Pure Red Cell Aplasia	1	3	1	5
Others	36	15	6	57
<b>TOTAL</b>	<b>2478</b>	<b>779</b>	<b>131</b>	<b>3388</b>

## Consanguinity

YES	1380
NO	2008
<b>TOTAL</b>	<b>3388</b>

## Age Group wise Patients

Age	No. of
0-5 Yrs	437
6-10 Yrs	583
11-15 Yrs	868
16-20 Yrs	604
21-25 Yrs	450
26-30 Yrs	214
Above 31 Yrs	232

## New Registration - 2022

Type of Disease	No
Thalassemia Major	190
SC - Sickle Cell Anemia	110
SBT - Sickle Beta Thalassemia	31
EBT - E-Beta Thalassemia	14
OT - Others	6
<b>TOTAL</b>	<b>351</b>



Total New Registrations (Khammam)	HPLC tests (Antenatal)	CVS Referred to NIMS & CDFD	HLA Typing with DKMS	Splenectomy
351 (55)	3348(2282)	63	613	11

By continuous and aggressive counselling and follow-ups 63 parents went for Prenatal Diagnosis (PND), so far out of which 14(22%) foetus were found to be affected. All 14 followed the protocol. We could prevent 14 affected births.







## Blood Centre

A Blood Centre is a place where blood is collected from Voluntary blood donors tested and different components are prepared and stored. Whenever the need arises for patients, the blood centre supplies the required group of blood and blood components after cross-matching.

Blood Transfusion service is a vital part of the health care service. Blood transfusion is a medical operation where a patient requires blood or blood product as a life-saving measure. Increasing advanced treatment in the field of transfusion Medicine and technology is necessary to ensure the quality of blood and its products. In order to improve the standards of blood centre and blood transfusion services, well-equipped blood centre with adequate infrastructure and trained manpower is an essential requirement. The main objective of a quality assurance program within the blood Centre setting is to minimize the risk to safety and quantity by ensuring that the blood centre processes will reliably deliver safe efficacious blood and blood components that are collected and manufactured in a manner that causes no harm to donors and recipients.

**Thalassemia and Sickle Cell Society Vuppala Venkaiah Memorial Blood Centre (TSCS-VVMBC)** was launched in March 2010 keeping in mind the need for safe Blood for Thalassemia and Sickle Cell Anemia patients. This is one of the major efforts to keep the children away from any issues/adverse reactions arising from unsafe blood.

We are counted/ranked among the best NGO-run blood Centres. We are tied up with various organizations for voluntary blood donations in and around Hyderabad. Our prompt and proactive actions ensure blood safety and maintain a better quality of blood components.

TSCS Blood Centre supports almost 1500 in-house Thalassemia and Sickle Cell Anemia kids and also caters to the needs of nearby hospitals in a month.

We also organise programmes to create awareness among the public/blood donors about Thalassemia its prevention and the need for blood to sustain their life during blood donation camps.

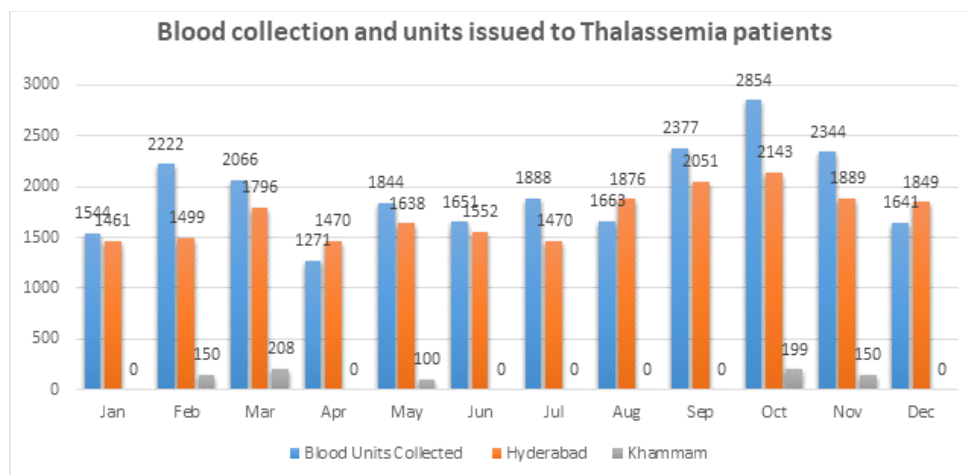
We are very much indebted to all our organisers and donors who supported us during this COVID-19 crisis and came forward to save the lives of hundreds of our patients. The following are few of our Major and Regular Blood Donation Camp Organisers:

1. Azad Reporter – Md Akram Ali Abu Aimal
2. Milad Camp – Focuss Foundation (Moulana Ahsan Al Hamoomi Sahab)
3. AIPIF – Malakpet – Qutubuddin Nadvi Sahab
4. Karma Foundation – Rahul
5. Nampally Shahi Masjid - Moulana Ahsan Al Hamoomi Sahab



### The following are few achievements of our Blood Bank:

- ›› Total number of blood units collected: 2,19,109
- ›› 1,52,702 (69%) units of blood given to Thalassemia children
- ›› 2743 Voluntary Blood Donation camps were organised till Dec 2022





## Vuppala Krishnarao Chandrakala Diagnostic Centre:

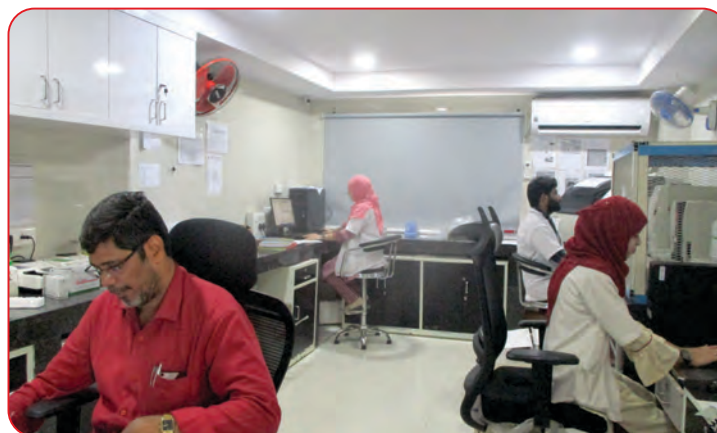
Thalassemia and Sickle Cell Society Vuppala Krishna Rao & Chandrakala Diagnostic Services established in September, 2011 is equipped with latest methods and technologies to carry out investigations for the benefit of the affected.

The diagnostic centre has high quality precision equipment that provide qualitative and quantitative methods of analysis of biological fluids such as blood, serum, tissue etc. We have wide range of testing services in Biochemistry, Clinical Pathology, Haematology, Hormonal assay and High Performance Liquid Chromatography (HPLC: for screening HbA2 levels).

Thalassemia and Sickle Cell Society is committed to provide affordable laboratory testing to all members of the communities.

During the year 1066 people were screened for Thalassemia and Sickle Cell Anemia (HPLC test), the details of which are as follows:

HbA2 test details		2022		2017-2022	
Sl. No.	Description	Total No.	Percentage	Total No.	Percentage
1	Normal	358	33.58	1372	34.22
2	Thalassemia carriers	400	37.52	1567	39.09
3	Thalassemia major	7	0.66	41	1.02
4	Sickle carrier	141	13.23	473	11.80
5	Sickle cell disease	16	1.50	45	1.12
6	Sickle Beta thalassemia	5	0.47	20	0.50
7	Thal Intermedia	0	00	6	0.15
8	Others	139	13.04	485	12.10
Total HPLC		1066	100.00	4009	100.00



## Research Laboratory

Molecular Research Laboratory of TSCS (supported by Prema Bai Dakotiya Memorial and Charitable Society) was established to offer accurate and precise diagnosis of the patients and carry out different research projects pertaining to better understanding of the disorders at the molecular level and develop strategies to improve the quality of life of the patients affected with thalassemia and sickle cell anaemia. The lab activities are also oriented in the line of creating awareness and preventing the recurrence of the condition in the future generations.

### Studies carried out at molecular research lab

- » Molecular diagnosis has been standardized for beta thalassemia, alpha thalassemia, delta beta thalassemia and Sickle cell anemia. So far, molecular diagnosis has been carried out for over 900 patients with some showing peculiar mode of inheritance patterns.
- » Collaborated with various organizations to develop a non-invasive device for detecting sickle cell anemia, generate hematopoietic stem cells for gene therapy, evaluate the impact of SCA on the patients etc.,
- » Initiated an antenatal screening program for thalassemia and sickle cell anemia at government maternity hospitals in Hyderabad, Mahbubnagar and Bangalore (in collaboration with Sankalp India Foundation) as a measure to create awareness and prevent the birth of affected children through genetic counselling and prenatal diagnosis.

### Carrier Frequency of different types of thalassemia among antenatal women screened during the year 2022

Carriers	MGMH (N=1811)	Balanagar (N=301)	Rajapur (N=254)
Thalassemia	29 (1.60%)	8 (2.65%)	9 (3.54%)
Sickle Cell Anemia	10 (0.55%)	3 (0.99%)	-
Delta Beta Thalassemia	-	-	-
HbD Punjab	8 (0.44%)	1 (0.33%)	-
HbE Carriers	3 (0.16%)	1 (0.33%)	-
<b>Total</b>	<b>50 (2.76%)</b>	<b>13 (4.31%)</b>	<b>9 (3.54%)</b>



Of the 2366 antenatal mothers screened for thalassemia, a carrier frequency of around 2.8% has been found. This program has helped us to create more awareness among the antenatal mothers about thalassemia which is a preventable genetic disorder.

A similar antenatal screening is being carried out in Bangalore in collaboration with Sankalp India Foundation wherein a total of 6072 antenatal women have been screened and a carrier frequency of about 3.7% (224/6072) has been detected for different types of hemoglobinopathies.

So far, around 15 couples went for prenatal diagnosis out of which 10 fetuses were found to be normal, one affected and four reports are awaited.

- » Extended family screening of our patients is also undertaken to identify the carriers and offer pre and post marital screening to prevent the birth of affected children.
- » Various scientific research projects are being pursued to understand the clinical manifestation of the disease and its complications, to identify the genes ameliorating the condition and develop new insights into the treatment and management of the condition.

**Ongoing Research Projects: 7**

**Projects Submitted for Funding and Under Review: 1**

**Research Papers Published (Thalassemia and Sickle Cell Anemia): 20**

**Papers under Communication: 2**





## Advance Diagnostic Laboratory

Kamala Bai Agarwal (Duke's) Diagnostic Laboratory was setup in 2020 to provide advanced services to our Thalassemia and Sickle Cell Anemia patients under one roof. The laboratory is equipped with modern instruments including Digital X-Ray, ECG, Ultra-Sound and 2D-ECHO cardiogram offering free testing to all our patients. As Thalassemia and Sickle Cell patients are prone to iron overload and painful crisis respectively, they have to be screened regularly to monitor their growth and organ functions. Availability of these facilities under the same roof aids in offering better treatment for our patients.

A team of specialists including Endocrinologist, Cardiologist, Paediatric Hemato Oncologist, Ophthalmologist, Dentist, Radiologist, and Pathologist visit our society to evaluate the patients.



We are thankful to all our specialist for supporting and cooperating with us in this noble cause of serving our patients and facilitating better treatment for them.

Doctor/Centre Name	Tests	No. of Patients	
		2021	2022
Dr Swetha, Consultant	Radiology	542	474
Dr Raghavendra Goud, Consultant	Cardiology	435	334
Dr Sirisha Rani, Dr Sandhya & Dr Varshini, Consultant	Haematooncology	377	192
Dr Anuradha Kulkarni, Consultant	Ophthalmology	224	240
Dr Amarnath Kulkarni, Consultant	Endocrinology	195	201
Dr. Vijay Bhaskar Noori, Vista Diagnostics	MRI	120	195
Dr Sampath Reddy, Rohini Foundation	Dental	850	-

## Thalassemia And Sickle Cell Society – Khammam

With a vision to extend its services to all patients Thalassemia and Sickle Cell Society has moved a step forward to spread its centres across Telangana and Andhra Pradesh. As an initial step, it has opened a new centre with 10 beds at Khammam, to support the patients coming from the surrounding districts. TSCS has collaborated with Vijayasri Blood Bank, Khammam to provide safe blood to thalassemia patients at free of cost. Our Khammam centre got empanelment under Telangana Aarogyasri Health scheme to avail free services for our patients. Official inauguration of the centre was initiated by Shri V P Goutham, IAS, Collector, Khammam Dist. on 14 March 2022.

During the year 2,266 blood transfusions were given to Thalassemia and Sickle Cell anemia patients. 55 new patient registrations were done at the centre. 211 free extended family screenings for HbA2 test were conducted. 450 units of blood were collected from local blood donation camps.





## Counselling Report

Genetic counselling plays an important role in creating awareness among the public about the inheritance pattern management and prevention of the disease. As a part of family and child counselling, the following tasks are regularly performed at the society:

### 1. Genetic counselling

Every patient and their family are counselled as to what is Thalassemia major, how it is caused and the treatment protocol.

### 2. Planned pregnancy

Parents of Thalassemia children are made aware of prenatal diagnosis to prevent the birth of affected children. As a part of it, they are advised to get the DNA of the patient. Following the results of CVS (Chorionic villus sampling) test or amniocentesis (arranged in association with NIMS hospital), parents are counselled about the possible options of continuing or discontinuing the pregnancy. In 2022, a total of 63 PND's were arranged of which 49 were found to be unaffected and 14 affected. All the 14 affected did not want to continue the pregnancy and they followed the protocol.

### 3. Extended family screening

Families are counselled to get their extended family members' screening to rule out their thalassemia and sickle cell carrier status. Special attention is given to relatives planning their marriage or starting a family and advised to go for the HbA2 test so they can avoid further birth of thalassemia children in their family.

### 4. Maintenance of patient health

A holistic management of Thalassemia patient's health requires constant motivation of families especially if they come from economically disadvantaged backgrounds. Everyday sessions with families are carried out to encourage maintenance of hemoglobin, ferritin levels, medicine compliance, and regular checkups with consultant doctors at the society.

### 5. Quality of Life

Patients are encouraged to maintain or enhance their quality of life by following proper diet, doing regular exercise and getting vaccinations. Wherever possible, moral support is provided in striving for better opportunities, be it in their education or professional life, and handling social and mental pressure. New patients' families are given supportive counselling to accept the reality of the condition.

### 6. Counselling for BMT

Making effective use of the bone marrow transplant and HLA typing being arranged by the society, patients are identified, supported and counselled for the process of getting cured. Treatment options are disclosed with utmost care to make sure that parents are aware and know what to expect from the procedure. Children are motivated to maintain overall good health before they go for BMT.





## Vice President's Visit

Visit of Shri M. Venkaiah Naidu Garu, Hon'ble Vice President of India to TSCS for inauguration of 2nd Blood Transfusion unit, Research Laboratory, Advanced Diagnostic Laboratory and two Auditoriums at our centre on 14th June 2022.

**As a token of appreciation for the support and encouragement towards providing facilities for thalassemia children making Thalassemia Free India the following donors were felicitated**

01	Shri Jawaharlal Rathi (Maniram Ramratan Rathi)	04	Shri Ramesh Kumar Agarwal Duke's Products India Ltd.
02	Shri Kanhaiyalal Shanta Devi Lohiya		
03	Shri Mantena Venkara Rama Raju Chairman, Vasudha Foundation	05	Shri Vinod Kuma Dakotiya Prema Bai Dakotiya Charitable & Memorial Society









## National Conference

Thalassemia and Sickle Cell Society (TSCS) organised a First-of-its-kind **National Level Conference on Prevention of Thalassemia and Sickle Cell Anemia** with an aim of "Thalassemia Free India" on 30th April and 01st May 2022. Shri T. Harish Rao Garu, Minister for Finance, Health, Medical & Family Welfare, Government of Telangana inaugurated the conference.









## Executive Members



## Dedicated Staffs





## Donor List

#	Donor Name
1	A S Iron & Steel
2	Abdul Rahman
3	Adama India pvt ltd
4	Aim Asia
5	Ambica Iron and Steel
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40	Mevadevi Ramchander Nagori Charitable Trust
41	Munish Kumurr Signodia
42	Munna Trust
43	Murali K Siripurapu
44	Naresh Rathi
45	Narsimulu Arigala

#	Donor Name
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47	New Life Foundation
48	Novartis Healath Care Pvt. Ltd.
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53	Prof. V. R. Rao
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68	Smt Banarsai Bai
69	SPP Poly Pack Pvt. Ltd.
70	Sree Krishna Automative Pvt. Ltd.
71	Sreyas Holistics Remedies Pvt. Ltd.
72	Sri Krishna Jewellery Mart
73	Sri Navdurga Textile Processors Pvt. Ltd.
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76	Sriram Gopal
77	Sudha Prashant Medha
78	Sujeet's Cricket Academy
79	Sunkari Shyam Sunder
80	Sunkari Shyam Sunder
81	SunPharma laboratories ltd
82	Supreme Agencies
83	T.Radhika
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85	V. Balaveerah & Sons
86	Venkatadri Divvala
87	Sri MahaLaxmi Jewellers
88	Maniram Ramratan Rathi
89	Shri Kanhaiyalal Shanta Devi Lohiya
90	Premabai Dakotiya Charitable & Memorial Society



TSCS thanks for the support by TANA Foundation for management of thalassemia and sickle cell anemia patients.

## Academic/Professional Achievements 2022:

### Thalassemia and Sickle Cell children studying at various levels

SSC - 25	Intermediate -30	Graduation - 40
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Professional Degree	Working	
Vaishnavi- MBBS 1st Year.	Harshith – Infosys	Sushma- Google
Md Sufiyan – MSC Computers	Krishnam Raju – Own Laboratory	Shirisha – Med. Transcription
Ameena – MBA	Manisha – Honda Showroom	N.Rahul- Ministry of Defense Bangalore
Vishwa Teja – M.Tech	Jyothi – GNM Nurse at General Hospital	Sai Aditya – Namasthe Telangana
Samia MBA 1ST Year	Swathi – Google	B Shiva Kumar – TSCS
Prashanth – Diploma Elect	Sai Srujana – Genpact	G Srikanth – Oracle
Sai Krishna – Polytechnic	Hori Krishna – Google	Ashwini – Physiotherapy
Amisha Patel – MBA 3rd year	Dr. Azra Fatima – Researcher at Learn Maximum PC polyclinics	Khaza Nadeemuddin – Own Restaurent and Charittable Trust
Vikram – Dip Civil Eng	Neelima – Lab Technician, Warangal	K Karthik – Axis Bank
Rahul – Diploma EEE	Bharat Rupani –Base layer Technology	Ankitha- Deloitte
Saleh – Polytechnic	Suvarsha – Panchayat Secretary	Md Rahemuddin – Private Job
Sumaira Fathima, MBA	Ms Swathi - Private Job	M Priyanka - TSCS
Nikunj Patel – MBA 2st year	Aditya – Computer Operator, District Civil Supply	Krishna Chaitanya – Animation
Arsheen Baig- BSc Nutrition	Elisha – AGS Co.	Souvik Bose – Wipro
Saroj Kumar Samal, B.Tech	Yesupaul – Wipro	Raghavendra – Tech Mahendra
Manirath goud B.Tech	Raghav, Own Business	Kranthi –Accenture Senior software
Bargav – Diploma 3rd Year (Mechanical Engineer)	Nooruddin - Own Business	Ramakrishna Tandra – Indusind Bank Ltd. as Branch Credit Manager
SK Riyaz – B.Tech 3rd Year	Krishna Chaitanya - Business	Tagore Naik – Electricity Dept., Paleru
Yogita - BBA	Swamy – Newspaper Business	Mubeena – HSBC
Noorunnisa – M.Com	Lovely-Fashion	Arsheen Fathima – Clinical Nutrition & Dietetics
B Prem Sagar – B.Tech 4rd Year	Rishab - Wipro	Chanakya Reddy - Own Business
J Ravi – MBA 1st Year	Shivani Mundada- Tally(IT Filing)	Soujanya, MSC Biotechnology
Sourabh Misra, MBBS 3nd Year	Sai ramya- Diebold nixdorf	Ravinder, Tribal Welfare Association - Gurukul
Rafiya Sultana – MBBS 2st Year	Asfaq Koundinya - Business	Pavan – Business
V. Sravya Teja – M.Tech	Pharameshwari – Business	Kiran – Accenture
Shaik Omer – BBA-3rd Year	Nithya – Sankalp India Foundation	
Sonal Shivani – M.Sc 2st Year	Neelima – Lab Technician	



**R Sai Aditya**  
PERSONAL SECRETARY  
(Collector Yalddri  
Bhuvanagiri District)



**Sai Ramya**  
Supply chain coordinator  
at Diebold Nixdorf



**Shaik Sufiyan**  
Research Associate



**Rahul**  
Working as LDC in the  
Ministry of Defence



**H Omkar**  
Junior Officer at  
DANA LAKSHMI BANK



**J. Sonal Shivani**  
Teacher at Delhi Public School



## Aarogyasri



**Aarogyasri Health care Trust  
Government of Telangana**

**Aarogyasri (Telangana)/ YSR Aarogyasri (Andhra Pradesh)** is the flagship of all health initiatives of the State Governments with a mission to provide quality healthcare to the poor. The aim of the government is to achieve "Health for All".



TSCS patients are indebted and immensely thankful to the Government of Telangana and Andhra Pradesh for empanelling our Hospital under Aarogyasri Health Care Scheme.

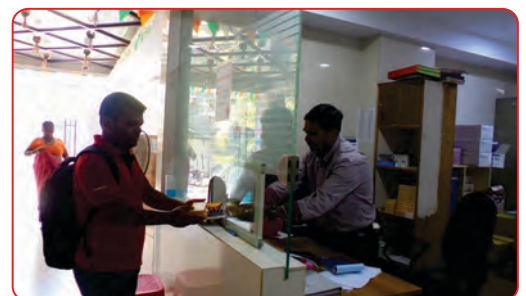
Treatment for Thalassemia is a huge economic burden to the families. People for whom providing basic necessities to the family is difficult, managing the thalassemia patient is a financial nightmare for them.

Aarogyasri Health Care Scheme has been a blessing for all those non-affordable patients due to which they are now able to provide best possible treatment to their children without worrying about the expenses of the treatment.

This has played a major role in improving their quality of life with timely and easily availability of medicines.

TSCS has 750 patients from Telangana state and 150 from Andhra Pradesh who are availing this facility since last 8 years.

All the health care services under Aarogyasri scheme are cashless.

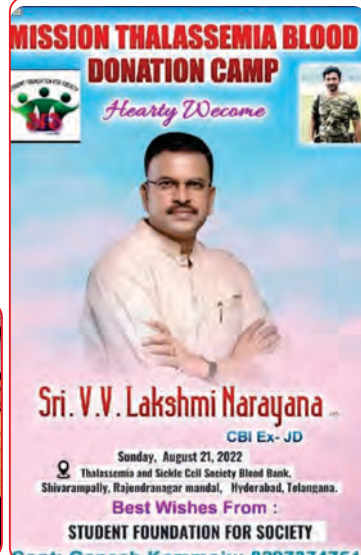
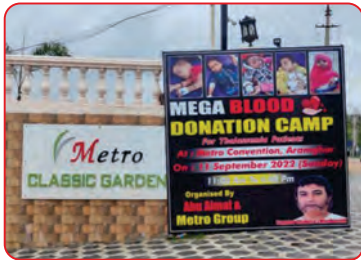




1. Abu Aimal – Azad Reporter
2. CGI- Kavitha Natrajan
3. Team Care And Share Foundation- Suresh
4. Google – Rohit
5. Karma Foundation – Rahul
6. IBM – Anil
7. Blood 4 India – Srikanth
8. Service Now India – Roja Puppala
9. Swecha Vedika Society – Raju
10. Zindagi Foundation – Prem
11. Amma Social Welfare Association – Sreenivasa Prasad Rao. S
12. HSBC -Naresh Goli
13. Optum – Trupti
14. Infosys- Padmaja Ramani
15. Dhathrutha Foundation – Karthik
16. Broadridge Ind Pvt Ltd -Vamsi
17. Focuss Foundation- Milaad Camp
18. Lions Club 320 – B – Kamal Agarwal
19. Wipro – Geeta Sadhu
20. Team Ganashraya – Murali







Cont: Ganesh Kommoju: 8297374754



**01 Jan 2022:** Visit by Shri Anumula Revanth Reddy, MP, Malkajgiri & President of Telangana Pradesh Congress Committee along with his supporters to donate blood to our Thalassemia patients. Mr Chandrakant Agarwal, President, TSCS and Board Members presented a memento to Shri A Revanth Reddy Garu.



**10 Jan 2022:** Distribution of Bags and drawing items sponsored by SDIF to our thalassemia patients by President, Vice President, Secretary, Joint Secretary, Dr Saroja, Mrs. Durga, Mrs Anita Upadhyaya, Mr. Jaleel and Mrs. Priyadarshini of TSCS. Special thanks to Mr. Azam khan and Mr. Feroz Baig.

**12 Jan 2022:** Blood Donation Camp organised by Ministry of External affairs, Branch Secretariat, Hyderabad in association with Regional Passport Office, Protector of Emigrants and ICCR a part of MEA'S SWACHHATA PAKHWADA 2022.



**26 Jan 2022:** Republic day celebrations at TSCS. Flag hoisting by Mr Chandrakant Agarwal, President, TSCS and Board members.

**24 Mar 2022:** Awareness talk by Mrs K Ratnavali, Vice President, .TSCS at BNI topaz meeting @hotel lemon tree.



**08 May 2022:** World Thalassemia Day celebrations at TSCS. Magic show and Zumba dance was organised for thalassemia children and gifts were sponsored by Business Network International (BNI). Shri Vuppala Srinivas Gupta Garu, Chairman, Tourism was our Chief guest.

At Khammam, Blood donation camp was organised as a part of World Thalassemia Day celebrations in collaboration with Vijayasri Blood Bank.

**11 Jun 2022:** A meeting with Hon'able Shri M Venkaiah Naidu Garu, Former Vice President of India, requesting him visit the society, witness the activities and motivate our children with his gracious presence.



**14 Jun 2022:** BEST BLOOD BANK IN TELANGANA AWARD to TSCS VVM Blood Bank, Hyderabad, from the Hon'ble Health Minister Shri Harish Rao Garu. TSCS would like to thank Telangana Govt. for recognizing our efforts and services to thalassemia patients.

**01 July 2022:** Certificate of recognition awarded to Dr Suman Jain on the occasion of National Doctor 's day for exemplary contribution under Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (AB PM - JAY) - Arogyasri by treating the beneficiaries of the scheme in the State of Telangana and thereby supporting India's journey towards ensuring equitable access to quality health care service to all. Shri S.A.M. RIZVI, CEO, AHCT presented the certificate.



**08 July 2022:** Organised a workshop on "antenatal screening for thalassemia and sickle cell anemia" for healthcare workers of Rajapur and Balanagar PHCs Mahabubnagar district as a part of creating awareness about antenatal screening at TSCS premises. A total of 82 participants including medical doctors, health educators, supervisors, ASHA workers and Anganwadi workers had attended the workshop.



**02 Aug 2022 :** Issue of HPLC reports and counselling to all the family members (38) of four families enrolled in cascade screening project by Dr Suman Jain, Dr Padma & Mrs. Anita at Balanagar PHC, Mahbubnagar district. Carrier adolescents were counselled for premarital screening and carrier couples were suggested prenatal diagnosis at every pregnancy.

**15 Aug 2022 Award:** Kamala Hospital and Research Centre for Thalassemia and sickle Cell patients received Certificate of Appreciation for exemplary performance from Smt. P. Sabitha Indra Reddy, Hon'ble Education Minister, Telangana Government and Shri Amoy Kumar, IAS, Collector, Rangareddy District under Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (AB PM-JAY) – Aarogyasri in the state of Telangana







**14 Sept 2022:** A meeting with Hon'able Minister for Health Shri. T. Harish Rao Garu by Mrs.K Ratnavali, Vice President, TSCS along with thalassemia children giving representation for disability certificate for Thalassemia and Sickle Cell Anemia children. Thanks to Shri Harish Rao Garu for his positive response.

**20 Sept 2022:** Felicitation of Mrs.K Ratnavali, Vice President, TSCS by Indian Red Cross Society at Kama eddy by Shri. Srinivas Gupta Garu, Minister, Tourism for her selfless services to Thalassemia and Sickle Cell children.



**26 Sept 2022:** Felicitation of Mr Chandrakant Agarwal, President TSCS by Hon'ble Governor of Haryana Shri Dattatreya Garu, National President of All India Vaishya Federation Shri Gireesh Sanghi Garu & others for his noble services to thalassemia and Sickle cell children.

**22 Oct 2022:** Visit by a medical team of Narayana Hrudayalaya, Bengaluru, led by Dr. Sunil Bhatt, to TSCS, for the review and selection of Haplo matched & fully matched thalassemia patients for Bone Marrow Transplantation (BMT). They selected around 40 patients to be eligible for BMT.



**29 Oct 2022:** Sickle cell day organised by TSCS every month to evaluate the health condition of sickle cell anemia patients motivating them to come for regular follow ups. Around 53 patients attended the program.

**07 Nov 2022:** Visit by a team of Novartis from abroad and India to evaluate the services and infrastructure rendered by TSCS to recognise it as a Nodal center for Sickle Cell Anemia treatment



**20 Nov 2022:** Children's Day celebrations sponsored by Sun Pharma at TSCS. Different activities and games were organised for the children by adult patients. Around 150 children participated in the program.

**01 Dec 2022:** "H.D. Shourie Memorial National Award" presented to Mr Chandrakant Agarwal, President, TSCS at the 'Har Ghar Raktdata' a national CME workshop on voluntary blood donation, held at the National Institute of Biologicals, Noida by Federation of Blood Donor Organisations of India. The award was in recognition of Society's services such as running a blood bank, blood transfusion centre, research lab and diagnostic centre. In the year 2022 alone, TSCS reached a milestone of 25,000 blood transfusions.



**02 Dec 2022:** Round table meeting on Safe Blood Transfusion focussing on Thalassemia organised by TIF Delhi, Dr Suman Jain was participated.

**04 Dec 2022:** Dr Suman Jain was invited to participate During the camp Mega health camp organized by the Ministry of Tribal Affairs (Mrs Vinita Srivastava) at Sariakela, Jaharkhand. During the camp more than 45,000 people utilized the services Congratulations Mrs Vinita Srivastava ma'am.

**21 Dec 2022:** Issue of reports and canceling of extended family members of our patients as a part of Cascade Screening Program at Balanagar PHC, Mahabubnagar.



**24 Dec 2022:** "Yuva Ratna – 2022" award presented to Mr Chandrakant Agrawal, President, TSCS at 14th International Conference by All India Marwari Yuva Manch.



## Case Study

Zaima Ameen is a 14-year-old cute looking girl who was diagnosed with thalassemia at the age of 4 months. Her parents, Md Abdul Ameen Asif works at Air Arabia and mother Zeenath Jana is a teacher. They got married in relation (Consanguineous Marriage) unaware of the fact that they both were carrying the gene for a rare blood disorder which could lead to the birth of an affected child in their family.

In most of the Indian societies, people are unaware of the prevalence of genetic diseases and go for consanguineous marriages which might increase the risk of inheriting these disorders. The same holds true with Zaima's Parents who ended up in giving birth to a thalassemia child.

They were overwhelmed with joy when Zaima was born but that did not last long as she started falling ill at the age of 4 months. They took her to Apoorva Hospital, Mehdipatnam who referred them to a hematologist. The parents approached Dr Ramana Dandamudi, where the doctor suggested to go for complete blood test and variant analysis of the parents. After seeing the reports, the doctors counselled the parents about thalassemia and the need for taking blood transfusions throughout their daughter's life. The parents were taken aback by the doctor's diagnosis and went back

home without going for blood transfusion due to lack of awareness about the disorder and the thought that everyone was normal in their family.

Ignorance about genetic disorders leads to delayed treatment and worsening of the symptoms. The same happened with Zaima whose hemoglobin levels dropped down further and needed medical attention. The parents went back to the hematologist who suggested them to visit Thalassemia and Sickle cell society (TSCS), Hyderabad.

Zaima's father visited the society where he was explained about thalassemia in detail regarding about its inheritance, symptoms, treatment and medications. He was counselled about the complications of not maintaining hemoglobin levels and the need to go for blood transfusions regularly. He brought his daughter for blood transfusions regularly and followed the advice of the doctor's

promptly. Zaima is now maintaining her hemoglobin levels at optimum and taking chelation medicines on time due to which her serum ferritin levels are in normal range.

The parents went for prenatal diagnosis at their subsequent conceptions and are now blessed with two normal children. The parents now accept that a simple blood test for thalassemia could have saved their child from lifelong suffering. However, if Zaima follows the treatment regularly then she can overcome the complications of thalassemia and lead a happy and cheerful life like her siblings.

Zaima is doing well in her studies and is excelling in extracurricular activities. She has won first prize in hand writing competition. Zaima and her parents are extremely thankful to TSCS for their expert care and support that is giving a ray of hope to many thalassemia children to overcome their health issues and lead a happy and fulfilling lives.



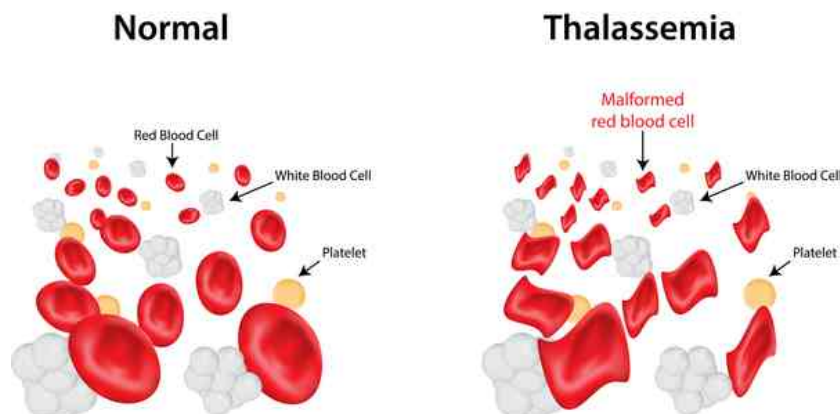


Name	Hibah Ibrahim	Comments	A very good, well organised, well equipped and excellent centre (commendable work)
Address	Marredpally Secunderabad		

## Thalassemia

Thalassemia is an inherited blood disorder that results due to lack of synthesis of haemoglobin molecules or defective haemoglobin respectively. There are different types of thalassemia of which beta thalassemia is the most severe form also known as "cooley's anemia". It causes devastating impact on the health of the patients and finances of their families as the patients require lifelong blood transfusions and extensive medical care. Without treatment, their spleen and liver become enlarged and are prone to infections and heart failure which are the leading cause of death among children. Another major complication in these patients is iron overload which results due to regular blood transfusions given to maintain the hemoglobin levels in order to sustain their life.

### Thalassemia

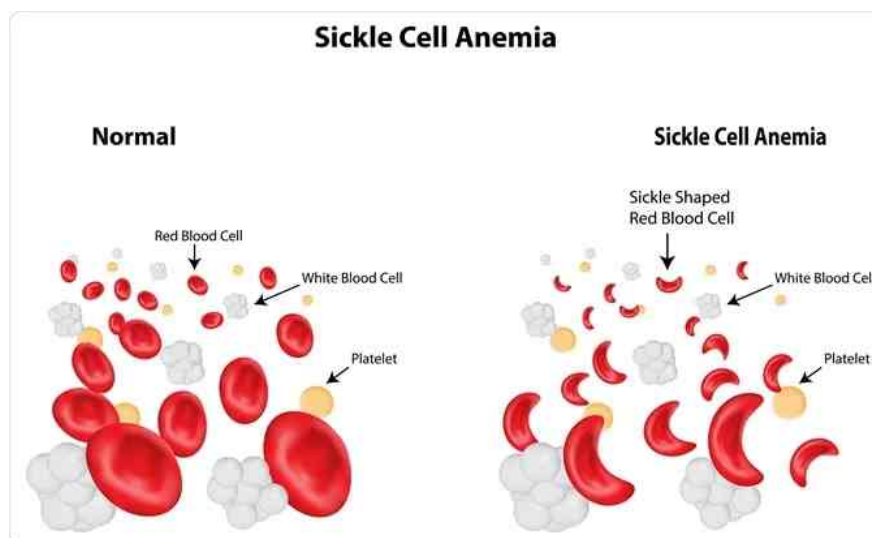


It affects >400,000 new-borns every year worldwide. In India it is estimated that about 10000-15000 are born every year with thalassemia. It is most prevalent across the country with an average carrier frequency of 3-4%. In fact, India is considered to be the capital of thalassemia. It is predicted that in the next 20 years, about 900,000 patients with thalassemia will be born in the world, with 95% of them being in Asia especially in India and Middle East.

## Sickle Cell Anaemia

Sickle cell anemia is an inherited disease that affects the shape of red blood cells, which carry oxygen to all parts of the body. Red blood cells are usually round and flexible and move easily through the blood vessels. But in sickle cell anemia, the cells are sickle or crescent moon shaped that become rigid and sticky and block the blood flow. It is caused by a single base-pair point mutation in the  $\beta$ -globin gene resulting in the substitution of the amino acid valine for glutamic acid in the  $\beta$ -globin chain.

It is now recognized as a major public health problem in India with an increasing burden on the health care system. SCD was mainly believed to affect the tribal population of Central India, however non-tribal persons are also affected in many states such as Odisha, Chhattisgarh, Gujarat, Maharashtra Madhya Pradesh and Telangana have a significant burden of disease with a carrier frequency in the range of 1 to 44 %.





## Bone Marrow Transplantation (BMT) – A Cure for thalassemia

Bone Marrow Transplantation (BMT) is the only potential cure available for thalassemia patients. The rationale for BMT is to eliminate thalassemia producing cells in the marrow and replace them with healthy donor cells. For this, a donor is required whose Human Leukocyte antigen (HLA) matches with that of the patient, usually a sibling or a parent.

### Types of BMT donors:

- » Matched Sibling Donor or Optimal Donors (MSD): usually a sibling or a parent. This is the best option with the highest success rate.
- » Matched unrelated donor (MUD) or Alternative donors: HLA matched but an unrelated person is the donor.
- » Haploidentical: These donors have a 50% HLA tissue match with the patient such as biological parents

### Criteria for the patient to be a candidate for BMT:

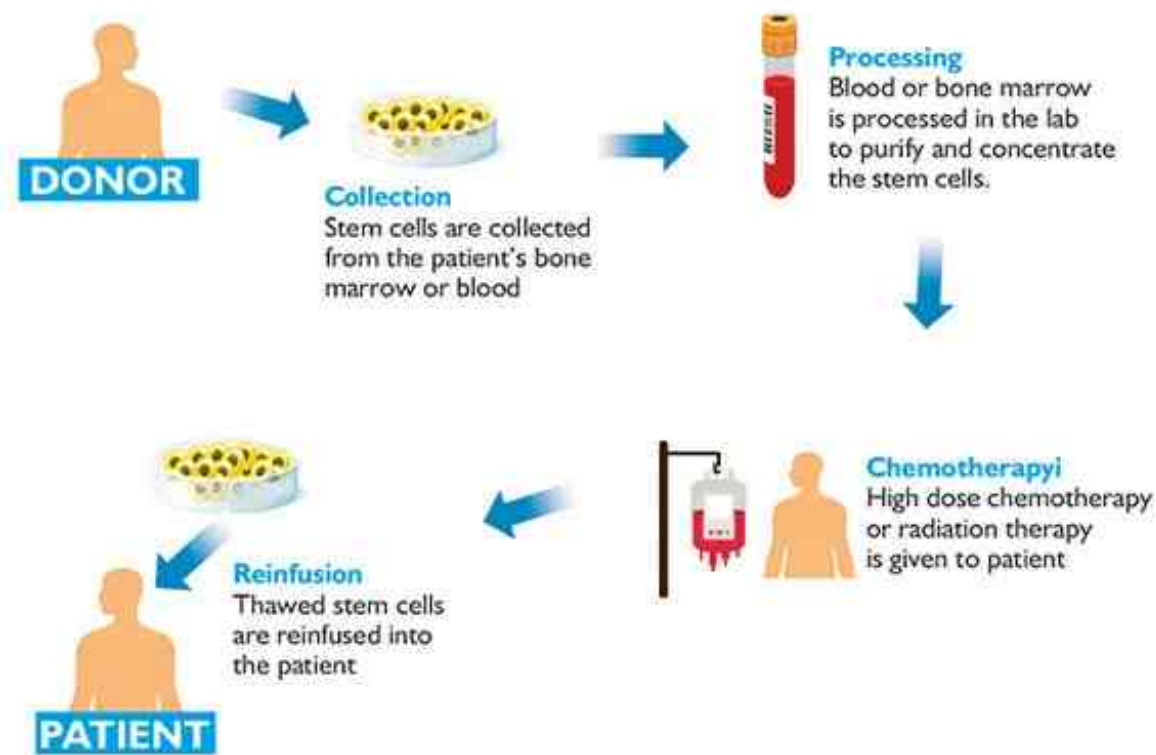
- » Should be 16 years or younger
- » Have a healthy liver
- » Have low body iron content (minimal excess iron)

Older patients with pre-existing conditions face more risks of developing complications post BMT in spite of having fully HLA matched donor.

### Success Rate:

The overall thalassemia-free survival of low-risk, HLA-matched sibling stem cell transplantation patients is found to be 85 to 90 percent, with a 95 percent overall survival.

## ALLOGENEIC BONE MARROW TRANSPLANT



TSCS has collaborated with Sankalp India Foundation, Bangalore and Narayana Hrudayalaya, Bangalore for Bone marrow transplantation (BMT) so as to provide a Thalassemia free life to its patients. This is offered to the patients at free of cost and is being sponsored by Electronics Mart India Ltd. So far around 48 patients went for BMT of which 41 underwent successful transplantation and are transfusion free. Thanks to the entire team for their selfless service to thalassemia children who are blessed to lead a normal transfusion free life.



Inauguration of new premises of BMJH-Sankalp Center for Paediatric Hematology Oncology and BMT Center at Bangalore was attended by Dr Suman Jain and Dr Saroja which was preceded by an interactive session on Haplo identical BMT by Dr Lawrence Faulkner.





## World Thalassemia Day Celebrations on 08 May 2022



## World Sickle Cell Anemia Day Celebrations on 19 June 2022





***"Even the smallest donation to Thalassemia and Sickle Cell patients can make a huge impact on their family" One month expenditure to manage thalassemia patient is around ₹ 10,000 - ₹ 20,000/-***

Your generous contribution will help us to provide better treatment and management for these patients.

**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**

Under 35 1(ii), the donor will receive 100% weighted deduction on the amount donated for Scientific purpose.


**You may contribute to the cause by Cheque/DD as follows:**



#### **Bank Account Details**

<b>Local Account (Donations within India)</b>		<b>FCRA Account (Foreign Donations)</b>
Account Number:	0608101049513	40020811564
Account Name:	THALASSEMIA AND SICKLE CELL SOCIETY	THALASSEMIA AND SICKLE CELL SOCIETY
Bank Name:	Canara Bank	State Bank of India
Branch:	Pathergatti	Sansad Marg
Bank Address:	# 22-7-110, 2nd Floor, SYJ Shopping Mall, Opp Madina Building, Pathergatti, Hyderabad, Telangana, India - 500002	11 Sansad Marg, New Delhi - 110001
IFSC Code:	CNRB0000608	SBIN0000691
Swift/BIC Code:	CNRBINBBHFD	SBININBB104



## **THALASSEMIA AND SICKLE CELL SOCIETY**

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