



THALASSEMIA AND SICKLE CELL SOCIETY

KAMALA HOSPITAL AND RESEARCH CENTRE, HYDERABAD, INDIA

SCAN TO KNOW MORE



Board Meeting



Successful 50 in-house PND



SBI Support

2025

ANNUAL REPORT



Invitation to Health Minister

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



✉ tscs@tscsindia.org

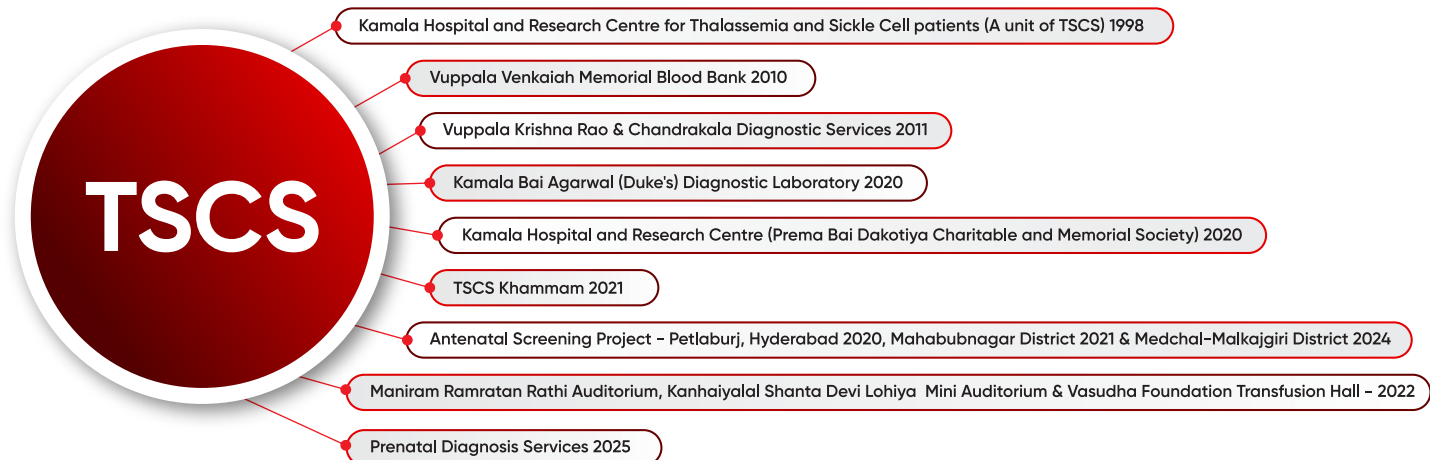
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Milestones

- Thalassemia and Sickle Cell Society (TSCS) formed on **9th August 1998** with 20 Thalassemia parents.
- Registered as an NGO **22nd October 1998** and under Societies Act with **Registration No. 5359** for Free blood Transfusion centre and Medical consultation.
- **2002** – Initiation of prenatal diagnosis in collaboration with Fernandez Hospital, CDFD, CCMB and Institute of Genetics.
- **2009** – Research collaboration with Institute of Genetics on Biochemical & Genetic aspects.
- **2010** – Establishment of in-house **Vuappala Venkaiah Memorial Blood Centre**.
- **2011** – Establishment of Biochemical and Clinical Pathology Laboratory.
 - National AIDS Control Organisation (**NACO**) recognition for **Blood Centre**.
- **2014** – Recognition by **Scientific and Industrial Research Organisation (SIRO)** for Kamala Hospital and Research Centre.
- **2015** – Kamala Hospital and Research Centre for Thalassemia and Sickle Cell patients, a unit of TSCS empaneled under state government **Aarogyasri Health Scheme**.
- **2017** – Inclusion of Thalassemia as a chapter in the High School Science curriculum.
- **2018** – Establishment of **comprehensive health care centre** with state of art facilities at Raghavendra Colony, Shivarampally, Rangareddy District, Hyderabad.
- **2020** – Mrs. Ratnavali invited to **Rashtrapati Bhavan by Hon'ble President of India Mr. Ramnath Kovind ji**.
 - Establishment of **Prema Bai Dakotiaya Charitable and Memorial Society Research Laboratory & Kamala Bai Agarwal (Duke's) Advanced Diagnostic Laboratory**.
 - Initiated Free Bone Marrow Transplantation (BMT) for thalassemia patients at Sankalp India Foundation, Narayana Hrudayalaya, Bangalore with financial support from Electronic Mart India Limited (EMIL). Later Rainbow Children's Hospital, Hyderabad.
- **2021** – Branch of TSCS – **Day Care Centre at Khammam**.
 - Initiation of **Antenatal Screening Project** at Modern Government Maternity Hospital, Petlaburj, Hyderabad.
- **2022** – Antenatal Screening Project at all PHC's of **Mahabubnagar district**.
 - 1st National Conference on **"Prevention of Thalassemia and Sickle Cell Anemia"**.
 - Member of Global Alliance of Sickle Cell Disease Organizations (**GASCDO**).
 - Inauguration of Maniram Ramratan Rathi Auditorium, Kanhaiyalal Shanta Devi Lohiya Auditorium and Vasudha Foundation Transfusion Hall II by Hon'ble Mr. M. Venkaiah Naidu, Vice President of India.
- **2021 - 2023** – A Continuing Medical Education (**CME**) programs for Obstetricians and Gynecologists (OB-GYN)
- **2024** – 2nd National Conference on **"Combatting Thalassemia: Aware, Share, Care and Cure"** and **Silver Jubilee Celebrations**.
 - **Antenatal Screening Project** at all PHCs of **Medchal-Malkajgiri District**.
 - Member of Global Action Network for Sickle Cell & Other Inherited Blood Disorders (**GANSID**).
- **2025** – Recognition as **Thalassemia International Federation (TIF) Collaborating Centre in India**, fostering global partnerships to enhance research and improve care for Thalassemia and Sickle Cell Disease.
 - Establishment of **Prenatal Diagnosis Centre** in collaboration with Fernandez Hospital to detect the status of foetus.

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Mr. Shyam Sunder Loya
Patron



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Mrs. Rama Vuppala
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Mr. V. S. R. Moorthy
Advisory Member



Mr. Harsha Bhogle
Brand Ambassador

President's Message

It is with great pride and gratitude that I present this year's Annual Report of the Thalassemia & Sickle Cell Society (TSCS), Hyderabad. For more than two decades, TSCS has stood as a beacon of hope for families affected by Thalassemia and Sickle Cell Anemia. What began as a small initiative by determined parents has grown into one of the largest comprehensive care centers for inherited blood disorders, serving thousands of patients with compassion and commitment.

During the past year, the Society has continued to strengthen its patient-centric services by providing safe blood transfusions, advanced diagnostic support, multidisciplinary medical care, and psychosocial counseling. Our voluntary blood donation movement remains a lifeline for patients, and I extend my heartfelt appreciation to the countless donors and organizers who make this noble service possible.

Prevention continues to be our highest priority. Through antenatal screening, carrier detection, genetic counselling and prenatal diagnosis, TSCS is helping families make informed decisions and reducing the burden of these preventable disorders. Our expanding outreach across districts is creating awareness and building a healthier future generation.

I sincerely thank our dedicated doctors, staff, donors, volunteers, government partners, and well-wishers whose unwavering support sustains our mission. Together, we move forward with renewed determination towards our shared vision – a society free from Thalassemia and Sickle Cell Anemia.

Mr. Chandrakant Agarwal
President



General Secretary's Message

It is my privilege to share the progress and achievements of the Thalassemia & Sickle Cell Society (TSCS) over the past year. TSCS continues to evolve as a comprehensive centre of excellence providing integrated care, prevention services, and research initiatives for Thalassemia and Sickle Cell disorders.

Our holistic care model ensures that patients receive regular transfusion support, essential medications, advanced diagnostics, specialist consultations, and continuous counselling under one roof. The Society now supports thousands of registered patients, ensuring continuity of care and improved quality of life through a multidisciplinary approach.

A major focus of our work remains prevention. Large scale antenatal screening programmes, carrier detection, genetic counselling, and the establishment of in-house prenatal diagnostic services have strengthened early detection and prevention strategies. These efforts are crucial in reducing disease incidence and supporting informed reproductive choices.

We are proud of our growing contributions to research, professional training, and national and international collaborations. Recognition as a Thalassemia International Federation Collaborating Centre marks an important milestone and reinforces our commitment to global standards of care and knowledge sharing.

I express sincere gratitude to our medical teams, partners, donors, volunteers, and supporters for their continued trust and cooperation. With collective effort and shared responsibility, we remain committed to improving lives today while working toward a thalassemia-free tomorrow.

Dr. Suman Jain
General Secretary



About Thalassemia Sickle Cell Society (TSCS)

Mission and Objectives

Thalassemia and Sickle Cell Society (TSCS), Hyderabad, established in 1998 is a premier non-governmental organization dedicated to the comprehensive care, management, and prevention of Thalassemia Major and Sickle Cell Anemia. For the past 27 years, the Society has been relentlessly working to improve the quality of life of affected children and adults, while simultaneously striving to prevent the birth of new cases through systematic screening and awareness programs. Formed by 20 parents of thalassemic children with the support of dedicated doctors and philanthropists, TSCS has today grown into the largest society in the world serving patients with inherited blood disorders.

Mission

The mission of TSCS is to ensure that every child and adult affected by Thalassemia and Sickle Cell Anemia receives high-quality, affordable, and comprehensive medical care, while simultaneously striving to eliminate these disorders through effective prevention strategies. The Society is committed to:

- Providing safe and regular blood transfusion services, advanced diagnostics, and modern treatment facilities under one roof.
- Promoting preventive programs such as antenatal screening, carrier detection, genetic counseling, and prenatal diagnosis.
- Creating awareness among the public, medical fraternity, and policymakers about the preventable nature of these genetic disorders.
- Supporting research, training, and capacity building to improve standards of care.
- Advocating for policy support and government involvement to make prevention and treatment accessible to all sections of society.

Objectives

1. Comprehensive Patient Care:

To deliver integrated medical services including transfusion support, chelation therapy, bone marrow transplantation facilitation, diagnostics, pharmacy, and specialized hospital care, thereby improving survival and quality of life of Thalassemia and Sickle Cell patients.

2. Prevention Programs:

To reduce the incidence of Thalassemia and Sickle Cell Anemia through large-scale awareness programs, premarital and antenatal screening, carrier detection, genetic counseling, and in-house prenatal diagnostic services.

3. Voluntary Blood Donation:

Organize promote 100% voluntary non-remunerated blood donation camps to ensure a safe and adequate supply of blood.

4. Awareness and Education:

To conduct community outreach programs, school and college awareness sessions, Continuing Medical Education (CME) and observance of World Thalassemia Day and World Sickle Cell Day to disseminate knowledge about prevention and management.

5. Research and Training:

To promote clinical and laboratory research in hemoglobinopathies and to serve as a training and knowledge hub for healthcare professionals through collaborations and at national and international conferences.

6. Advocacy and Collaboration:

To work in close coordination with government departments, national and international organizations, and funding agencies to strengthen policies, mobilize resources, and expand access to curative options such as Bone Marrow Transplantation.

Through its mission and objectives, TSCS envisions a future where no child is born with Thalassemia or Sickle Cell Anemia, and where every affected patient leads a healthy, dignified, and productive life.

Ethical Committee

#	Name	Designation
1	Dr. Lakshman Rao RL MD Community Medicine; Vice Principal - Osmania Medical College	Chairman & Medical Scientist
2	Dr. Mamatha M PhD Human Genetics, Scientist - TSCS	Member Secretary
3	Dr. Sirisha Rani Siddaiahgari MD& DNB Paediatrics - Rainbow Children Hospital	Clinician
4	Dr. Mohammed Iqbal Moinuddin MBBS-TSCS	Clinician
5	Dr. Vijaya Lakshmi Valluri PhD Immunogenetics , Scientist & Head- Immunology Molecular Biology Dept. - Bhagwan Mahaveir Medical Research Centre.	Scientific Member
6	Dr. Padma G PhD Human Genetics, Scientist - TSCS	Scientific Member
7	Mr. Moorthy VSR Spiritual Scientist	Member
8	Dr. Hannah Anandaraj PhD Social Science	Social Scientist
9	Mr. Deepak Bhattacharjee LLM	Legal Expert
10	Mr. Lakshmanaswamy MCA	Lay Person

Research Advisory Board

#	Name	Designation	Internal/ External	Organisation
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 Centre, 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	Centre 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

#	Name of the Doctor and Qualification	#	Name of the Doctor and Qualification
1	Dr. SUMAN JAIN MBBS, DCH, Paediatrician, Chief Medical Research Officer	15	Prof. V. R. RAO M.Sc., PhD, Genetic Epidemiologist (Population)
2	Dr. SUJAI SUNEETHA MBBS, DCP, PhD, Pathologist & Leprologist	16	Dr. G. PADMA M.Sc., PhD Genetics, Sr. Research Scientist
3	Dr. K. SAROJA BHMS, DHHM, Medical Officer	17	Dr. V. SANDHYA MBBS, MD, FNB (Paediatric Hemato Oncologist)
4	Dr. MOHD. IQBAL MOINUDDIN MBBS, Medical Officer	18	Dr. B. VARSHINI MBBS, DNB, FNB (Paediatric Hemato Oncologist)
5	Dr. SARASWATHI SUSARLA MBBS, MD (General Medicine)	09	Dr. M. MAMATHA PhD Genetics, Research Scientist
6	Dr. SIRISHA RANI MBBS, MD, MRCPCH (Paed. Hemato Oncologist)	20	Dr. PRADEEP NAIK M.Sc., PhD, Bio-Chemistry
7	Dr. SIRISHA KUSUMA MBBS, MD Pediatrics, FRCPC, (Ped Endocrinologist)	21	Dr. KURAPATI PRADEEP KUMAR MBBS, MD (Paediatrician), Khammam
8	Dr. RAMANA DANDAMUDI MBBS, DCH, MRCP (Paed. Hemato Oncologist)	22	Dr. RUDRA GOUTHAM NARESH MBBS, MD (General Medicine), Khammam
9	Dr. D. M. NAIK MBBS, MD, Pathology (Pathologist)	23	Dr. RAJAKUMAR YADAV MBBS, Medical Officer, Khammam
10	Dr. A. RAGHAVENDER GOUD MBBS, MD, FSCAI (Cardiologist)	24	Dr. SANAULLA MBBS, Medical Officer, Khammam
11	Dr. B. SWETHA MBBS, MORD (Radiologist)	25	Dr. R. VENUGOPAL MBBS, MD (Radiologist) Khammam
12	Dr. ANURADHA KULKARNI MBBS, MS, Ophthal (Ophthalmologist)	26	Dr. CHARITHA SRANVANTHI BATTU MBBS, MD (Radiologist) Khammam
13	Dr. R. SRIKANTH MBBS, MD, PGDCC (APOLLO), (Cardiologist)	27	Dr. GEETA KOLAR MBBS, MD (OBG), DNB (OBG, DGO) Gynaecologist
14	Dr. KARTHIK ADIRAJU MBBS, MDRD, (FIFI & FICI), (Radiologist)	28	Dr. LEENATHA REDDY J MBBS, MRCPCH (CCT), Pediatric Adolescent Endocrinologist

Patron Doctors

#	Name	Designation
1	Dr. Sreenivas Namineni	Pediatric Dental Surgeon
2	Dr. Ashwin Dalal	Head Diagnostic Division, CDFD
3	Dr. K Nageshwar Rao	Cardiologist
4	Dr. K Nagarjuna	General Surgeon
5	Dr. Md Aejaz Habeeb	Gastroenterologist
6	Dr. K Gayatri	Pathologist
7	Dr. A Narendra Kumar	Professor of Pediatric Surgery
8	Dr. Chandra Prakash Jain	ENT Consultant
9	Dr. Partha Pal	Gastroenterologist
10	Dr. Geeta Kolar	Gynecologist

Research Advisory Members	Dr. Dipty Jain, Dr. Satwinder Sahota and Prof. Kalpna Gupta
Auditors	NVS Murty & Co., Secunderabad, Telangana
Bankers	Canara Bank, Pathargatti Branch, Hyderabad State Bank of India, New Delhi (FCRA)

Advisory Members



Mr. Satish Chandra, I.A.S. (Retd.)
Chairman, Public Service Commission,
Union territory of Jammu and Kashmir



Mr. Vinod K. Agrawal, I.A.S. (Retd.)
Formerly Special Chief Secretary,
Government of Telangana

Special thanks to Mr. Satish Chandra, IAS (Retd.) and Mr. Vinod K. Agarwal, IAS (Retd.) for graciously accepting their roles as Advisory Members of TSCS and for their active involvement and valuable contributions to the Society's initiatives.

Papers Published – International and National Journals

1. HPLC first approach in detecting thalassemia and other common hemoglobinopathies is more cost and time effective. *Frontiers in Hematology*. 2025 Section Red Cells, Iron and Erythropoiesis, 4, 1461498
2. Burden of vaso-occlusive crisis, its management and impact on quality of life of Indian sickle cell disease patients. *British Journal of Haematology*. 2024;00:1-14
3. Development of pathophysiologically relevant models of sickle cell disease and thalassemia for therapeutic studies. *Nat Com mun*. 2024 Feb 27;15(1): 1794
4. Scalable-nan-invasive amplicon-based precision sequencing (SNAPseq) for genetic diagnosis and screening of thalassemia and sickle cell disease using a next-generation sequencing platform. *Frontiers in Mol Biosciences*. 2023;10
5. Identification of a novel variant c.163delG in HBB gene resulting in a beta null phenotype in a proband with Thalassemia Intermedia, *Hemoglobin*, 2024;48(1):1-3
6. Serum ferritin levels in comparison with MRI in the clinical management of Beta thalassemia major. *Int J Current Flesch arch*. 2023;15(4):24225-24229
7. Rare Phenomenon of Pseudodominance Causing Phenotypic Heterogeneity in the Expression of Delta Beta Thalassemia when Co-Inherited with Beta Mutation. *Ann Med Health Sci Res*. 2023;13:420-424
8. Prevalence of thalassemia and sickle cell anemia carrier frequency among antenatal women-A first study from Telangana. *Population Indian Journal of Obstetrics and Gynaecology Research*, 2023;10(1):32-35
9. Highly stratified population sickle cell frequencies and prevention in India. *Human Biology Re view*. 2023;12(1):13-21
10. A Simple, Cost Effective, and Extraction-Free Molecular Diagnostic Test for Sickle Cell Disease Using a Non-Invasive Buccal Swab Specimen for a Limited-Resource Setting. *Diagnostics*. 2022, 12:1765
11. Impact of sickle cell disease on patients' daily lives, symptoms reported, and disease management strategies: Results from the international Sickle Cell World Assessment Survey (SWAY), *Am J Hematol*, 2021; 96(4): 404-417.
12. Establishment and characterization of induced pluripotent stem cell line [IGIB002-A] from a thalassemia patient with IVSI-5 mutation by non-integrating reprogramming approach. *Stem Cell Res arch*. 2021; 50-102124
13. Identification and Development of a High-Risk District Model in the Prevention of Thalassemia in Telangana State, India, *Hemoglobin*, 2020; 44(5):371-375
14. A comprehensive resource of genetic variants from over 1000 Indian genomes. *Nucleic Acids Res arch*. 2021;49(D1): D1225-01232
15. Management Strategies and Satisfaction Levels in Patients with Sickle Cell Disease: Interim Results from the International Sickle Cell World Assessment Survey (SWAY), *Blood*. 2019, 134(Supplement-1):1017
16. Generation and characterization of induced pluripotent stem cell line (IGIB1001-A) from a sickle cell anemia patient with homozygous-globin mutation. *Stem Cell Research*, 2019, 39:101484.
17. Francisella novicida Cas9 interrogates genomic DNA with very high specificity and can be used for mammalian genome editing. *Proceedings of the National Academy of Sciences*. 2019; 116(42):20959-20968
18. Information Technology-Assisted Treatment Planning and Performance Assessment for Severe Thalassemia Care in Low and Middle-Income Countries: Observational Study. *JMIR Med Inform*, 2019, 7(1): e9291.
19. Establishing Mutational Spectrum of Beta Thalassemia by Molecular Screening in a Low Resource Setting-Implications in Counselling and Prevention. *International Journal of Public Health and Health Systems* 2019; 4(2): 36-43
20. Caninequity in healthcare be bridged in LMICs Multicentre experience from thalassemia day care centres in India. *Paediatric Haematology Oncology Journal*. 2017; 2:88-95
21. Multi-institutional, retrospective review of blood transfusion practices and outcomes in a large cohort of thalassemia patients in South India, *Paediatric Haematology Oncology Journal*. 2017; 2(4): 74-78.
22. Association of BCLA genetic variant (rs11886868) with severity in beta thalassaemia major & sickle cell anaemia. *Indian. Med Res*. 2016; 143(41):449-54

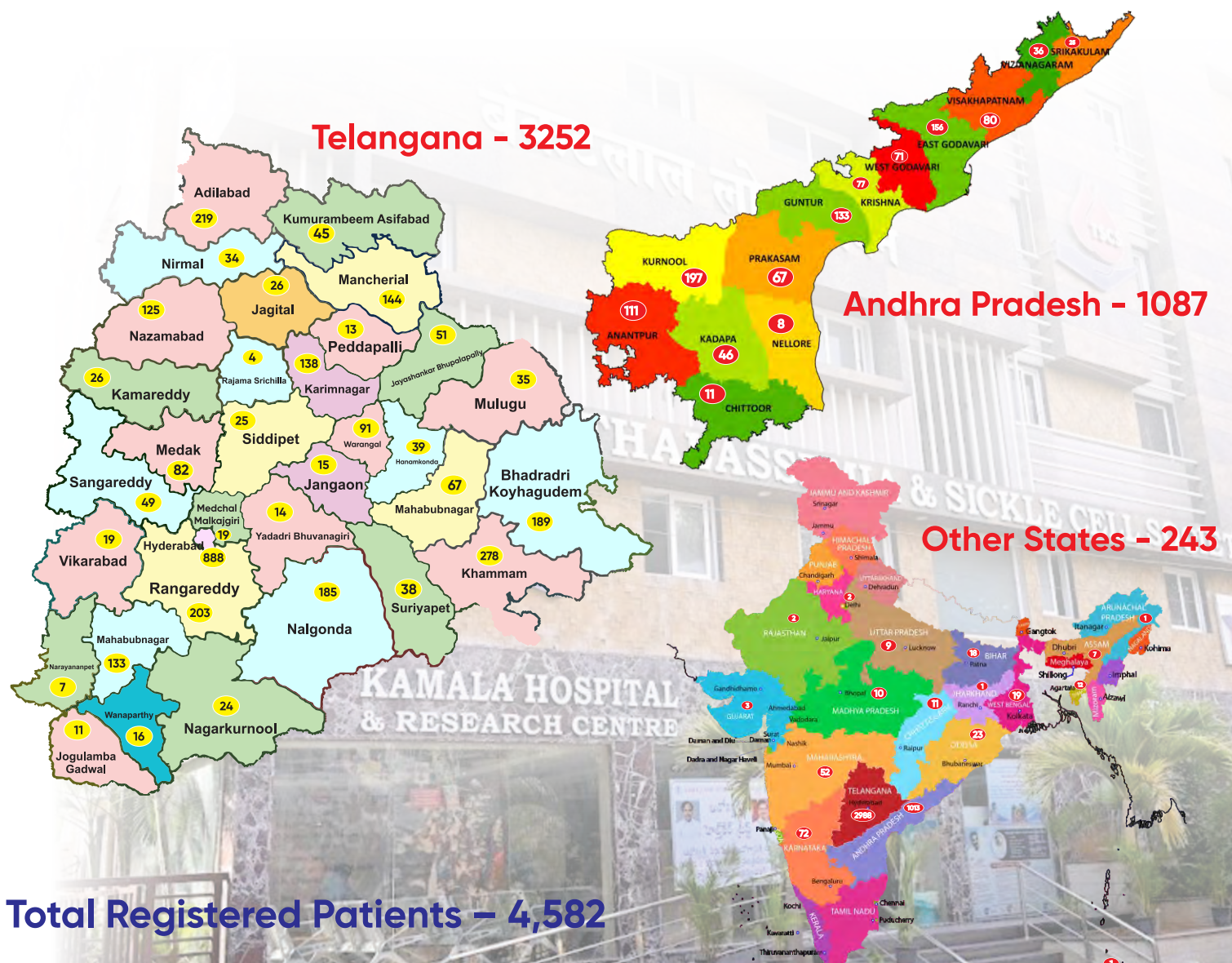
Transfusion Unit

The Transfusion Unit of the Thalassemia & Sickle Cell Society (TSCS), Hyderabad, serves as the backbone of patient care providing safe regular and life sustaining blood transfusion services to Thalassemia Major and Sickle Cell Anemia patients. Furthermore, TSCS extends day-care support for patients at its Khammam Unit, enabling them to receive transfusions, medical monitoring, and supportive care in a comfortable and child-friendly environment. As of 31st December 2025, a total of **4,582** patients are registered with TSCS and are supported through this unit with lifelong transfusion care. Approximately 50–70 patients receive blood transfusions on a daily basis.

The unit functions with stringent quality and safety standards, ensuring the availability of properly screened and cross-matched blood through internal services and a strong network of voluntary blood donation camps. On every visit, patients receive free consultation from qualified doctors, along with free essential diagnostic services to monitor their clinical condition and treatment requirements.

Patients also undergo regular free health assessments by a multidisciplinary team of specialists, including haematologists, paediatricians, cardiologists, endocrinologists, ophthalmologists and other allied experts, ensuring holistic care and early detection of complications. In addition to transfusion support, TSCS provides free iron-chelating drugs to manage iron overload, a major complication of repeated blood transfusions.

Through safe transfusions, free consultations, diagnostics, multidisciplinary care, iron chelation, and day-care support, the TSCS Transfusion Unit significantly improves the survival and quality of life of children and adults with Thalassemia and Sickle Cell Anemia.



Blood Centre

Thalassemia and Sickle Cell Society – Vuppala Venkaiah Memorial Blood Centre (TSCS-VVMBC)

Established in March 2010, the TSCS-VVMBC Blood Centre has emerged as a vital support system for patients living with Thalassemia and Sickle Cell Anemia. Guided by the commitment to ensure the availability of safe, high-quality blood, the centre plays a crucial role in safeguarding children and adults from the risks associated with inadequate or unsafe transfusion practices.

A Pillar of Comprehensive Transfusion Care

Blood transfusion remains the backbone of treatment for individuals with hemoglobinopathies. With continuous advancements in transfusion medicine and stringent quality requirements, TSCS-VVMBC functions with modern infrastructure, advanced technology, and a team of well-trained professionals to maintain the highest standards of safety and efficiency.

The Centre undertakes all essential services including blood collection, grouping, cross-matching, component preparation, storage, and timely distribution. In addition to meeting the needs of TSCS patients, the facility also extends support to surrounding hospitals and the larger community, strengthening the regional blood supply network.

Reach and Services

At present, the Blood Centre caters to nearly 1,500 Thalassemia and Sickle Cell Anemia patients every month, ensuring uninterrupted access to lifesaving transfusions. Alongside clinical services, TSCS-VVMBC actively promotes voluntary blood donation through regular camps and awareness programs, sensitizing the public on Thalassemia prevention and the indispensable role of voluntary donors in saving lives.

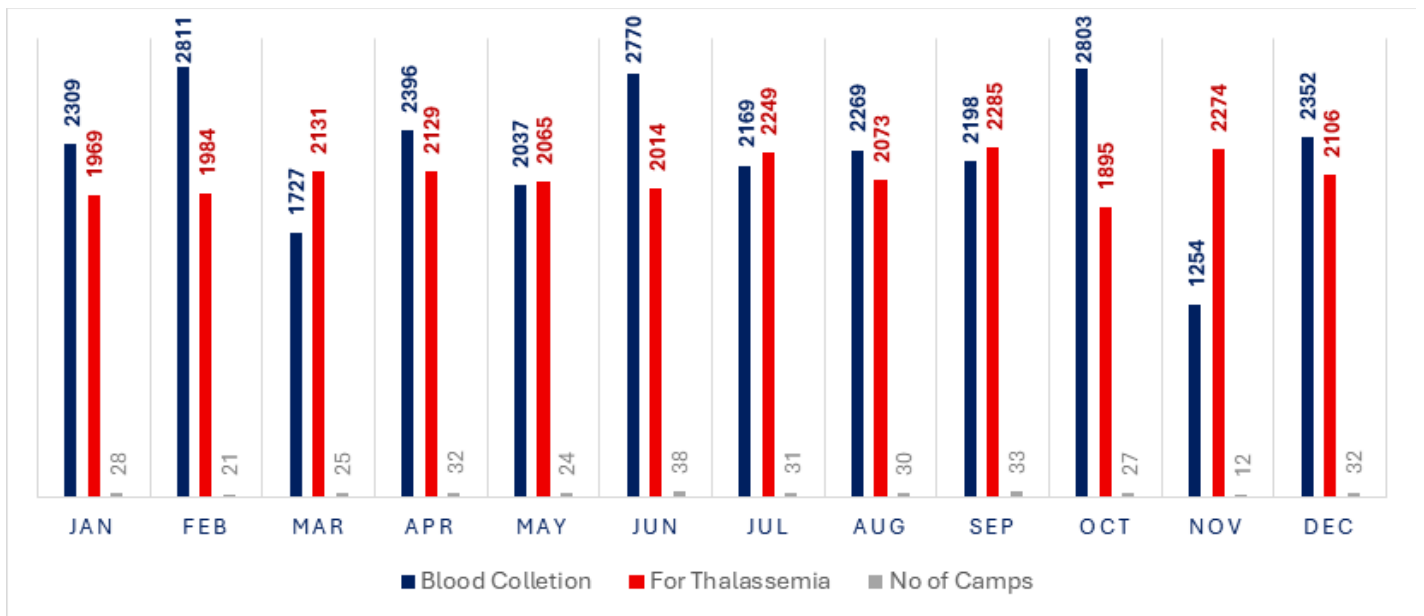
Achievements

- 1. Total Blood units collected (2010 – 2025) : 298004
- 2. Blood units for Thalassemia patients: 283103 (95%)
- 3. Voluntary Blood Donation Camps: 3722



Blood Centre Team

Monthly chart - 2025



During the year, total number of Blood Collection 27095 units, Transfusions 25174 units and Camps 333

Diagnostic Services: Vuppala Krishna Rao Chandrakala Diagnostic Centre

Vuppala Krishna Rao & Chandrakala Diagnostic Centre of the Thalassemia and Sickle Cell Society (TSCS) established in September 2011, has evolved into a centre of excellence in diagnostic services. Equipped with advanced, state-of-the-art technology, the laboratory plays a pivotal role in supporting the diagnosis, monitoring, and management of patients with Thalassemia and Sickle Cell Anemia through accurate and timely investigations.

Comprehensive Diagnostic Capabilities

The Diagnostic Centre is designed to perform high-precision qualitative and quantitative analysis of biological samples including blood, serum, and tissues. A wide spectrum of investigations is offered through well-established departments, including:

- Biochemistry
- Clinical Pathology
- Haematology
- Hormonal Assays
- High-Performance Liquid Chromatography (HPLC) for HbA2 screening

These advanced facilities ensure reliable results that are essential for early detection, appropriate clinical decision-making, and effective long-term care of patients.

Ensuring Affordable and Accessible Services

In line with TSCS's mission, the Diagnostic Centre is committed to providing cost-effective and easily accessible testing to all sections of society, with special emphasis on investigations critical for the diagnosis, treatment, and follow-up of Thalassemia and Sickle Cell Anemia patients.

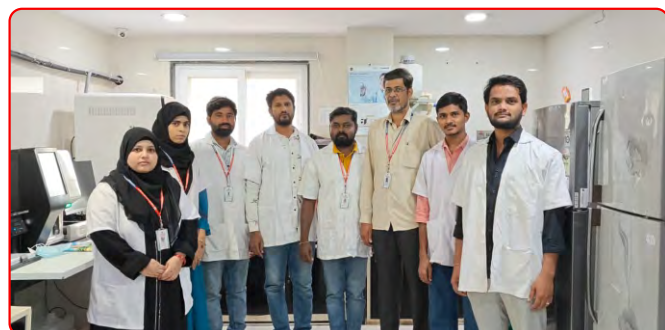
Key Achievements

In collaboration with Sankalp India Foundation, DKMS, and DATRI (HistoGenetics), a total of 1353 thalassemia major patients were collected for HLA typing with their sibling and parents. Among them, 248 patients were found to have undergone successful Bone Marrow Transplantation (BMT).

Till 31st Dec 2025, a total of 56,126 were screened using HPLC to identify thalassemia and sickle cell carrier status, significantly contributing to carrier detection and prevention of affected births.

#	Description	Mahabubnagar	Petlaburz	Medchal-Malkajgiri	Extended Family	Other Hospitals	Private
	Total	20972	11864	10269	474	2792	1812
1	Normal	20453	11474	9896	351	2723	1759
2	Thalassemia Carriers	383	258	202	113	68	39
3	Sickle Carriers	70	72	113	8	20	8
4	Sickle Beta Thal	1					
5	Thal Intermedia		1				
6	Others	65	59	58 (3 HbE Thal*)		11	6

*Three cases were identified as Homozygous E Thalassemia



Kamala Hospital and Research Centre for thalassemia and sickle cell patients –A unit of Thalassemia and Sickle Cell Society

Established in 2020, Kamala Hospital and Research Centre has emerged as a dedicated center for the diagnosis, screening, and research of hemoglobinopathies. The Centre is committed to improving patient care, advancing molecular diagnostics, and contributing to translational research in inherited blood disorders.

The Centre provides molecular diagnostic services for a spectrum of hemoglobinopathies, including beta thalassemia, alpha thalassemia, delta beta thalassemia, sickle cell anemia, and sickle beta thalassemia. Diagnosis is performed using standardized Polymerase Chain Reaction (PCR) techniques and Sanger sequencing, ensuring high accuracy and reliability in mutation detection. Since its inception, the Centre has successfully provided confirmatory molecular diagnosis to more than 2,000 individuals, significantly strengthening early detection and clinical management.

A major focus area of the Centre is preventive screening. It has implemented antenatal and cascade screening programs to reduce the burden of hemoglobinopathies. These initiatives have played a crucial role in genetic counseling and informed reproductive decision-making. The Centre is also preparing to introduce genetic testing of the fetus as a part of its prenatal diagnosis centre, which will further enhance preventive strategies and reduce disease incidence in high-risk populations.

In addition to clinical services, the Centre has made meaningful research contributions. **Three novel genetic** variants have been identified through its molecular investigations, adding valuable knowledge to the existing mutation spectrum of hemoglobinopathies. Research studies have included demographic profiling of patients registered with TSCS, providing insights into disease distribution and population characteristics. Comparative studies evaluating serum ferritin levels with MRI findings have helped refine iron overload assessment protocols. The Centre has also undertaken validation studies of point-of-care diagnostic devices, including non-invasive technologies, and has participated in clinical trials aimed at improving therapeutic outcomes.

Further molecular research has explored haplotype heterogeneity among patients, particularly those homozygous for the common c.92+5G>C mutation, highlighting genetic diversity within seemingly uniform mutation groups. These findings contribute to a better understanding of genotype-phenotype correlations and disease variability.

Looking ahead, the Centre's future research will focus on identifying genetic and molecular markers that contribute to intrafamilial variation in phenotypic expression. By investigating the modifiers influencing disease severity among individuals with similar genotypes, the Centre aims to enhance personalized management strategies and improve prognostic prediction.

Overall, since its establishment, Kamala Hospital and Research Centre has demonstrated a strong commitment to excellence in diagnostics, prevention, and research, making significant contributions toward the control and understanding of thalassemia and sickle cell disorders.



Antenatal Screening Project

The Thalassemia and Sickle Cell Society (TSCS) has been implementing an antenatal screening programme across Telangana to identify carriers of **Thalassemia and Sickle Cell Anaemia (SCA)** and prevent the birth of affected children through timely **genetic counselling and prenatal diagnosis (PND)**. The initiative began in **March 2021** at the **Modern Government Maternity Hospital, Petlaburj**, expanded to all **PHCs of Mahbubnagar** (2023), and later to all **PHCs in Medchal–Malkajgiri** (2024).

Objectives

- Screen antenatal women <18 weeks for Thalassemia/SCA carrier status.
- Test husbands when antenatal women are carriers.
- Provide counselling and offer PND to carrier couples.

Implementation

TSCS got approvals from District health authorities, Ethical Committees for implementation of the project. Medical officers, lab technicians, and ASHA workers received training on inheritance, diagnosis, and prevention. Awareness materials (pamphlets/posters) were displayed to motivate pregnant women.

Blood samples (3 ml EDTA) were collected at PHCs/hospitals and transported to TSCS for:

- **CBP** for haematological indices
- **HPLC** to measure HbA2 (>3.5% for Thalassemia carriers) and HbS (30–40% for SCA carriers)



When both the partners are identified as carrier they were given detailed genetic counselling and suggested for prenatal diagnosis.

Key Results

	Antenatal Women Screened	Carriers Detected	Husbands Screened	Couple Carriers	Couples Underwent PND	Affected Fetuses Identified
Petlaburj	11864	390	365	14	10	0
Mahbubnagar	20972	519	513	22	15	4
Medchal Malkajgiri	10269	373	299	24	9	4
Private Hospitals	4411	111	86	6	4	1
Total	47516	1393 (2.9%)	1263	66 (5.2%)	38	9 (30%)

Note: Out of 1,393 carrier pregnant women, 1,263 husbands were screened, resulting in a screening coverage of 90.6%. However, among the 66 carrier couples identified, only 58% underwent Prenatal Diagnosis (PND). This gap highlights the critical need for increased community awareness, counseling, and education, which are essential to improve acceptance of PND and move closer to the goal of achieving a thalassemia-free India.

Key Observations

- Carrier prevalence is consistently high (2.65–3.70%), justifying universal antenatal screening.
- Medchal–Malkajgiri shows the highest carrier rate.
- PND uptake is good, with minimal refusals.
- Early detection prevents lifelong transfusion dependency and reduces future healthcare burden.

Conclusion

TSCS's antenatal screening initiative demonstrates a scalable, cost-effective strategy to prevent Thalassemia and Sickle Cell Disease in Telangana. Strengthening district-wide implementation, enhancing awareness, and ensuring accessible genetic counselling and PND can significantly reduce the incidence of these genetic disorders and support the goal of a Thalassemia-free Telangana.



Prenatal Diagnosis Centre – Thalassemia and Sickle Cell Society

Adding one more feather to the services of TSCS, it gives us immense pleasure to announce the establishment of a **Prenatal Diagnosis (PND) Centre**, which is a major milestone in the effort to prevent the birth of affected children. The centre was set up with the aim of providing prenatal diagnostic services for hemoglobinopathies, ensuring that carrier couples receive seamless screening, counselling, sampling, and timely diagnostic reports under a single integrated unit. This has significantly strengthened informed decision-making and improved turnaround times for families at risk of having a child affected by thalassemia or sickle cell disease.

Since its inception, May 2025 the centre has successfully conducted 50 prenatal diagnostic procedures, including both chorionic villus sampling (CVS) and amniotic fluid analysis. Early detection and efficient reporting have enabled prevention in more than 80% of the cases, contributing substantially to reducing the burden of hemoglobinopathies in Telangana and supporting the goal of a thalassemia-free future.

The Society extends sincere gratitude to Fernandez Hospital, particularly Dr. Geeta Kolar, for their invaluable collaboration in sampling. Their consistent support in performing CVS and amniotic fluid collections has played a crucial role in the successful functioning of this pioneering PND centre.

TSCS stands as the only NGO globally to offer exclusive in-house Prenatal Diagnosis (PND) services for early detection of Thalassemia and Sickle Cell status in the fetus, reinforcing its commitment to prevention.

Around 411 parents of children with thalassemia have so far undergone prenatal diagnosis (PND) to determine the status of the fetus, reflecting a growing awareness and proactive approach toward preventing the birth of affected children.



Successful completion of 50 in-house prenatal diagnosis within just seven months.



Regular commitment of the medical team – the driving force behind our services.



Admin Department

Kamala Bai Agarwal (Duke's) Advanced Diagnostic Laboratory

Established to strengthen Patient management and monitoring, the **Kamala Bai Agarwal (Duke's) Diagnostic Laboratory** serves as a cornerstone in delivering advanced diagnostic services to Thalassemia and Sickle Cell Anemia patients under one roof. The laboratory is supported by state-of-the-art infrastructure, including **Digital X-Ray, ECG, Ultrasonography, and 2D-Echocardiography**, with all investigations provided free of cost to registered patients.

Given the high risk of **iron overload in Thalassemia** and **recurrent painful crisis in Sickle Cell Anemia**, regular monitoring of growth parameters and organ function is essential. The availability of advanced diagnostic facilities within the Society ensures timely evaluation, early detection of complications, and more effective clinical management.

To further enhance patient outcomes, the laboratory works in close coordination with a multidisciplinary team of visiting specialists, including **Endocrinologists, Cardiologists, Paediatric Hemato-Oncologists, Ophthalmologists, Dentists, Radiologists, Pathologists, and Orthopaedicians**, who periodically assess and guide the long-term care of patients, ensuring a holistic and integrated approach to treatment and support.

As part of comprehensive care, patients at risk of iron overload are referred for T2* MRI screening at no cost, ensuring early detection and timely management.



We express our sincere gratitude to all our specialists for their continued support and cooperation in this noble mission, enabling us to provide better treatment outcomes for our patients.

Doctor Name	Specialization	No. Of Patients Consulted				
		2021	2022	2023	2024	2025
Dr. Swetha, Consultant Dr. Karthik, Consultant	Radiology	542	474	234	310	790
Dr. Raghavendra Goud, Consultant Dr. Srikanth, Consultant	Cardiology	432	334	236	414	610
Dr. Ramana Dandamudi, Dr. Sirisha Rani, Dr. Anurag Reddy Dr. Sandhya & Dr. Varshini, Consultants	Haematooncology	377	292	409	520	890
Dr. Anuradha Kulkarni, Consultant	Ophthalmology	224	240	301	290	310
Dr. Leenatha Reddy, Consultant Dr. Rohini Kasturi, Consultant Dr. Sirisha Kusuma, Consultant	Endocrinology	195	201	212	540	630
Dr. Vijay Bhaskar Noori, Consultant	Radiology (T2* MRI)	120	195	328	235	222

Counselling Services at Thalassemia and Sickle Cell Society (TSCS), Hyderabad

The Thalassemia and Sickle Cell Society (TSCS), Hyderabad, provides extensive and continuous counselling services as an integral part of holistic care for patients affected by Thalassemia and Sickle Cell Anemia, their parents, and extended family members. Counselling at TSCS aims not only to support medical management but also to address the psychological, social, and preventive aspects associated with hereditary blood disorders.

Counselling for Patients

Patients with Thalassemia and Sickle Cell Anemia require lifelong care and regular medical interventions. TSCS offers age-appropriate counselling to help patients understand their condition, the importance of regular blood transfusions, chelation therapy, medication adherence, and follow-up care. Adolescents and young adults are counselled on coping with chronic illness, self-care, education, career planning, and transition from paediatric to adult care. Emotional support is provided to help patients manage stress, anxiety, and social challenges, thereby improving treatment compliance and quality of life.

Genetic and Preventive Counselling

Genetic counselling is a key component of TSCS services. Carrier parents and family members are counselled on inheritance patterns, risks of having affected children, and the importance of carrier screening. Couples are guided on premarital screening, antenatal screening, and available prenatal diagnostic options to prevent the birth of affected children. Counselling is provided in a culturally sensitive and non-directive manner, enabling informed decision-making.

Counselling for Extended Family Members

Recognizing the hereditary nature of hemoglobinopathies, TSCS extends counselling services to siblings, relatives, and extended family members. Family counselling sessions emphasize awareness, voluntary screening, early detection of carriers, and prevention strategies. This family-centric approach helps reduce stigma, promotes shared responsibility, and strengthens preventive efforts at the community level.

Psychosocial Support and Long-Term Impact

TSCS counselling services adopt a multidisciplinary approach involving doctors, counsellors, social workers, and trained staff. Continuous counselling helps build resilience, encourages treatment adherence, improves psychosocial well-being, and empowers families to actively participate in care and prevention. By integrating counselling with clinical services, TSCS ensures comprehensive support that enhances the overall quality of life of patients and contributes significantly to the long-term goal of reducing the burden of Thalassemia and Sickle Cell Anemia.



CME for Government Nurses and Lab Technicians on occasion of International Nurses Day

Aarogyasree



GOVERNMENT OF TELANGANA
Rajiv Aarogyasri Health Care Trust
AYUSHMAN BHARAT PRADHAN MANTRI JAN AROGYA YOJANA



GOVERNMENT OF ANDHRA PRADESH
Dr. Nandamuri Taraka Rama Rao Vaidya Seva Trust
AYUSHMAN BHARAT PRADHA MANTRI JAN AROGYA YOJANA

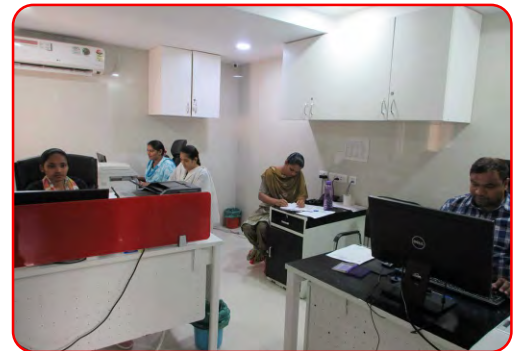


Kamala Hospital & Research Centre, a unit of the **Thalassemia & Sickle Cell Society (TSCS)**, plays a pivotal role in ensuring that Thalassemia patients fully benefit from various government-supported health schemes. The Centre actively facilitates access to **free blood transfusions, essential medications, and advanced medical interventions**, thereby strengthening continuity of care for economically vulnerable families.

TSCS works in close coordination with major government health programs such as the **Rajiv Aarogyasri Healthcare Trust / Dr. Nandamuri Taraka Rama Rao Vaidya Seva** and the **Ayushman Bharat – Pradhan Mantri Jan Arogya Yojana (PMJAY)**, implemented across **Telangana and Andhra Pradesh**. These schemes offer significant financial protection to **Below Poverty Line (BPL)** families, providing coverage of up to **₹10 Lakhs (Telangana) & ₹25 Lakhs (Andhra Pradesh)** per annum for the treatment of serious illnesses requiring hospitalization, surgeries, and high-end procedures.

The primary objective of these initiatives is to enhance access to quality healthcare for BPL families through a recognized network of healthcare providers, ensuring timely treatment for identified diseases that require specialized care.

Through sustained collaboration with government authorities over the past decade, **TSCS has enabled 850 patients from Telangana and 306 patients from Andhra Pradesh** to avail themselves of these benefits, substantially reducing the financial burden on families and contributing to an improved quality of life for Thalassemia patients.



Agasthya's Journey of Strength and Resilience



Born on **21 August 2002 to D. Venkateshwarlu**, Agasthya grew up like any other child, surrounded by the hopes and dreams of her family. Today, at 23 years of age, she is a confident and accomplished young woman who has completed her **M.Sc. in Nutrition and Dietetics** and remains deeply committed to leading a healthy lifestyle. Her journey, however, has been shaped by early health challenges that tested her strength and determination.

Her health concerns began in 2007 when she developed persistent jaundice that did not improve despite medication. Doctors at Bellampalli Area Hospital conducted further investigations and discovered gallstones – an uncommon finding in a child of her age. This unusual diagnosis prompted additional blood tests, which revealed sickle-shaped red blood cells, indicating a possible hemoglobin disorder. Recognizing the seriousness of her condition, she was referred to the Thalassemia and Sickle Cell Society (TSCS), Hyderabad, a specialized center dedicated to the care and management of hemoglobin disorders.

At TSCS, Agasthya underwent confirmatory testing, including High Performance Liquid Chromatography (HPLC). In August 2009, she was diagnosed with **Sickle Cell Anemia**. While the diagnosis was emotionally challenging for the family, timely medical intervention and expert guidance provided a clear path toward effective

management.

Following diagnosis, TSCS initiated structured medical care and regular monitoring. Between 2009 and 2011, Agasthya required three blood transfusions, with the last transfusion administered on **5 September 2011**. Since then, her condition has been successfully managed through periodic health checkups, prescribed medications, proper hydration, and adherence to a balanced and nutritious diet. With consistent care and disciplined self-management, she has remained stable and transfusion-free for more than a decade.

Rather than allowing her condition to limit her ambitions, Agasthya **transformed her experience into motivation**. Understanding the vital role of nutrition in maintaining health and preventing complications, she pursued **higher education in Nutrition and Dietetics**. Today, she leads a healthy, active, and productive life, demonstrating the power of awareness, lifestyle management, and resilience.

Agasthya's journey highlights the **importance of early diagnosis, specialized care, and continuous follow-up in managing sickle cell anemia**. Her story serves as an inspiration to patients and families, reinforcing that with timely medical support, informed lifestyle choices, and personal determination, individuals with hemoglobin disorders can lead fulfilling and successful lives.



Donor List

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Thank you for helping us through your kind donation!

The remarkable journey and progress of our Thalassaemia and Sickle Cell warriors toward healthier, empowered lives.



Jagadish Prasad
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Harshit
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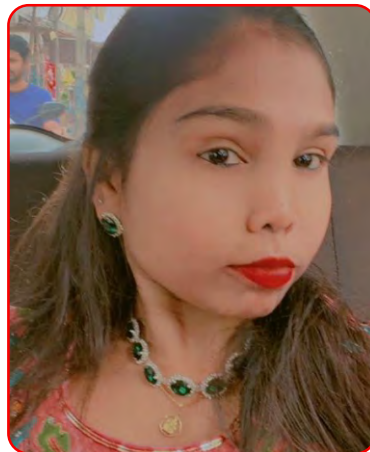
Vikram
Marketing Executive



Harish Kumar
Global Logic



Arsheen Fatima
(Msc Nutrition, RD) – Consultant Dietitian



Tejaswini
Depth Care

Working

Harshith – Infosys
Krishnam Raju – Own Laboratory
Manisha – Honda Showroom
Jyothi-GNM Nurse at General Hospital
Swathi – Google
Sai Srujana – Genpact
Hari Krishna – Amazon
Dr. Azra Fatima- (M.A, Psy.D)Clinical Psychologist RCI licensed
Sai Srujana – Genpact
GB Ashwini -Teacher
Bharat Rupani-Base layer Technology
Suvarsha – Panchayat Secretary
Ms Swathi – Private Job
Arsheen Fatima (MSc Nutrition, RD) – Consultant Dietitian, Zoi Hospitals
Aditya – Computer Operator, District Civil Supply
Elisha – AGS Co.
Yesupaul – Wipro
Kranthi -Accenture Senior software
Nooruddin – Business
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Samia-HDFC Bank
Asfaq Koundinya – Business
Pharameshwari – Business
Ayesha Azmath - HR generalist, Aionsi India private limited
Nithya-Sankalp India Foundation
Naresh – Data Entry Operator, Cooperative Society
Naveen-Medha Servo Drives Pvt Ltd
Rana Banjare – ITS Govt
Sufiyan Shaikh – Field Appl.Executive, BioMerieux India Pvt Ltd
Samuel – Own School
Tejaswini-Depth Care
Parusu Ramudu – Lab Technician
Shaikh Omer- Garment Business
Saleh – Business
Manirath Goud – ADP



Dr. Azra Fatima
 (M.A, Psy.D)
 Clinical Psychologist RCI licensed



Jai Ram
 Govt. High School Teacher



Sonal Shivani
 Delhi Public School, Teacher



Ankitha
 Deloitte



Lovely
 Mac Cosmetic Beauty Adviser



Ayesha Azmath
 HR Generalist in a Private Limited Company

Working

Sushma - Google
Shirisha - Med. Transcription
N. Rahul - Ministry of Defense, Bangalore
T. Divya - IIT
Amisha Patel - DuPont
G. Srikanth - Oracle
Vikram - Marketing Executive, Hero Showroom
Khaza Nadeem Uddin - Own Restaurant and Charitable Trust
Ashwini - Physiotherapist
K. Karthik - Axis Bank
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Omkar - Dhana Laxmi Bank Officer
Ramakrishna Tandra - Branch Credit Manager, IndusInd Bank Ltd.
Souvik Bose - Wipro
Raghavendra - Tech Mahindra
Chanakya Reddy - Own Business
Tagore Naik - Electricity Dept., Paleru
Mahaveen - Nykaa Cosmetic Beauty Advisor
Soujanya, MSc Biotechnology - Dr. Reddy's Lab
Jai Ram - Govt. High School Teacher
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J. Ravi - OU Assistant Professor
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Sonal Shivani - Teacher, Delhi Public School
B. Sushmitha Bindu, M.Tech - TCS
B. Shashidhar - Tele Caller, VSR Nature Care
Yugendher - Prathima Institute of Medical Science (Dialysis Technician)
K. Arun Kumar - Civil Engineering
G. Vamshi - Govt Employee
Shivani - Depth Care
Bala Narsimha - Depth Care
Pedda Babu - Lab Technician
Abdullah - Own Business



Sufiyan Shaikh
 BioMerieux India Pvt Ltd
 Field Appl. Executive



Sai Manognya
 Thala Hunt Winner



Yugendher
 Prathima Institute of Medical
 Science (Dialysis Technician)



Mahveen Fathima
 Makeup Artist

Professional Degree

Vaishnavi - MBBS 3rd Year
Sai Kiran - MBA
Ameena - MBA
Danush - B.Tech 4th Year (MEC)
Prashanth - Diploma in Electronics
Sai Krishna - Polytechnic
Rahul - Diploma EEE
Sumaira Fathima - M.Com
Nikunj Patel - MBA 3rd Year
Saroj Kumar Samal - B.Tech
Md Hussain Abdulla - MBA
Bargav - Diploma Mechanical
SK Riyaz - B.Tech
Yogita - BBA
Noorunnisa - M.Com
Nehru - CA
Sourabh Misra - MBBS 4th Year
Rafiya Sultana - MBBS 4th Year
V. Sravya Teja - M.Tech
Rahul - MBBS 1st Year
Vindhya Sree - MBA 1st Year
Yashwanth - B.Tech
T. Divya - IIIT
N. Bai Jaiyanthi - MA Political Science
Ganesh - B.Pharm
T. Sandhya - MA, B.Ed
Satish Naik - M.Sc
Gunadarapu Navya - B.Tech 3rd Year

Graduation – 58 Intermediate – 45 SSC – 50

Ms. Jyothi Shirisha, a Sickle Beta Thalassemia Warrior from Bhadradri Kothagudem, Achieves Group-I Success; Appointment Letter Presented by Hon'ble Chief Minister Shri A. Revanth Reddy garu and Felicited by Hon'ble Deputy Chief Minister Shri Bhatti Vikramarka garu.



Asian Thalassaemia Conclave 2026 (ATC 2026)

The **Asian Thalassaemia Conclave 2026 (ATC 2026)** is scheduled to be held on 10th and 11th January 2026, with the objective of fostering knowledge exchange and strengthening collaboration among Asian countries in the field of Thalassaemia and Sickle Cell Anemia.

The conclave has received an encouraging response, with around **55 distinguished faculty members from across the globe** confirming their participation to share their expertise. As of 31st December 2025, more than **105 NGOs, societies, institutions, and organizations** have confirmed their participation, along with over **290 delegates** from across India and the Asian region.

Through this prestigious event, TSCS aims to create a significant impact by engaging with both the Government of India and State Governments, advocating for stronger initiatives toward the prevention of these blood disorders. The collective voice and collaboration of participants are expected to contribute meaningfully toward policy influence and the advancement of preventive strategies in the region.

THALASSEMIA AND SICKLE CELL SOCIETY
 KAMALA HOSPITAL AND RESEARCH CENTRE, HYDERABAD, INDIA

THALASSAEMIA INTERNATIONAL FEDERATION | **ISNHD**
 INDIAN SUB-CONTINENT NETWORK FOR HAEMOGLOBIN DISORDERS

ATC
ASIAN THALASSEMIA CONCLAVE 2026

10 & 11 January 2026
 "Mission Thalassaemia Free India – 2035"

Organised by: Thalassaemia and Sickle Cell Society (TSCS), Hyderabad, Telangana
 Collaborators: Thalassaemia International Federation (TIF), Cyprus.
 Indian Sub-Continent Network for Haemoglobin Disorders (ISNHD)

Supporters: EMI, Narayana Health, DKMSB, Fernandez, etc.
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CHIEF GUEST

Shri Damodar Raja Narsimha garu
 Hon'ble Minister for Health, Government of Telangana
 Hyderabad, Telangana

GUEST OF HONOUR

Dr. Androulla Eleftheriou
 Executive Director, Thalassaemia International Federation, Cyprus

Mrs. Vinita Srivastava
 National Health Authority under the Ministry of Health & Family Welfare, Govt. of India

Mr. P. Uday Kumar, IAS
 Chief Executive Officer, Raju Anjaneyulu Health Care Trust, Government of Telangana, Hyderabad

Mrs. Lanre Tunji-Ajayi, M.S.M
 Chief Executive Officer, Global Action Network for Sickle Cell & Other Inherited Blood Disorders (GANSID)

SPECIAL GUESTS

Mr. Satish Chandra, I.A.S. (Retd.)
 Chairman, Public Service Commission, Union territory of Jammu and Kashmir

Mr. Vinod K. Agrawal, I.A.S. (Retd.)
 Formerly Special Chief Secretary, Government of Telangana

TSCS looks forward to making ATC 2026 a grand success through the support of its esteemed international and national collaborators, partners, and sponsors. We are especially grateful to the distinguished global and national faculty who have consented to be part of this event, bringing with them rich expertise and invaluable insights in the treatment and management of Thalassaemia and Sickle Cell Anemia.

Awareness and Advocacy

Awareness and advocacy form the cornerstone of the Thalassemia and Sickle Cell Society (TSCS), Hyderabad's mission to improve the quality of life of affected individuals and prevent the birth of children with Thalassemia and Sickle Cell Anemia. Recognizing that these hereditary blood disorders are largely preventable through education and early screening, TSCS has consistently focused on community awareness, stakeholder engagement, and policy advocacy as key strategic priorities.

Community Awareness Programs

TSCS conducts regular awareness programs targeting schools, colleges, industrial establishments, healthcare institutions, and community groups. These programs focus on educating the public about the genetic nature of Thalassemia and Sickle Cell Anemia, modes of inheritance, the importance of carrier screening, and available preventive options. Awareness sessions are designed to be culturally sensitive and age-appropriate, using interactive discussions, visual aids, and real-life experiences to enhance understanding and acceptance.

Observance of National and International Days

TSCS actively organizes and participates in awareness rallies, public meetings, seminars, and media outreach activities on key occasions such as World Thalassemia Day, World Sickle Cell Day, Voluntary Blood Donors Day, Inherited Blood Disorder Day and other relevant health observances. These events help amplify public messaging, mobilize voluntary blood donors, and reinforce the importance of prevention, early diagnosis, and sustained care.

TSCS actively participates in initiatives organized by TIF and GANSID, contributing to global awareness efforts on International Thalassemia Day and World Sickle Cell Day.

Advocacy with Government and Policy Makers

Advocacy is a critical component of TSCS's efforts to bring systemic and sustainable change. TSCS regularly engages with government departments, public health authorities, and policymakers at state and national levels to advocate for inclusion of Thalassemia and Sickle Cell Anemia in public health programs. The Society has actively contributed to discussions on antenatal screening, carrier detection, blood transfusion safety, and access to essential medicines, aiming to influence policy frameworks that support prevention and patient care.

Capacity Building and Professional Engagement

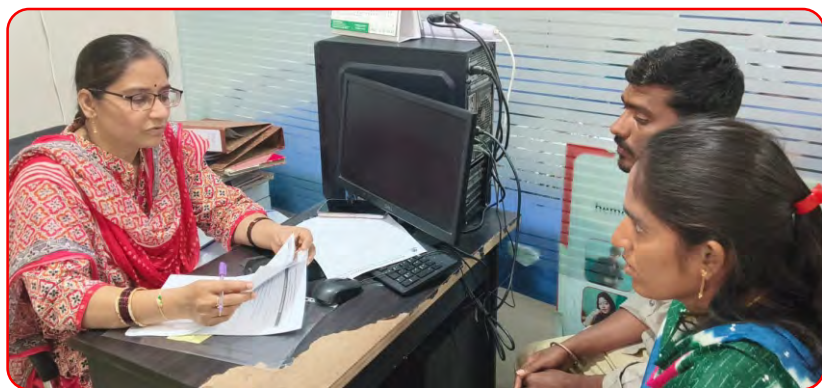
TSCS conducts Continuing Medical Education (CME) programs, workshops, and training sessions for doctors, nurses, laboratory personnel, and counsellors to strengthen knowledge and skills related to diagnosis, management, and prevention of hemoglobinopathies. By engaging healthcare professionals & Paramedical Staff, TSCS ensures that awareness translates into improved clinical practices and standardized care.

Media and Public Outreach

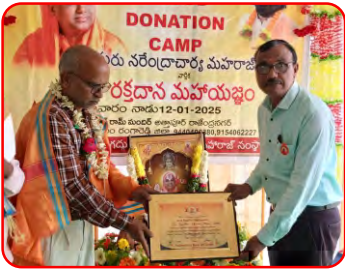
The Society leverages print, electronic, and social media platforms to disseminate accurate information, share patient stories, and promote positive messaging around prevention and voluntary blood donation. Media advocacy helps reduce stigma, correct misconceptions, and create an enabling environment for informed decision-making among families and communities.

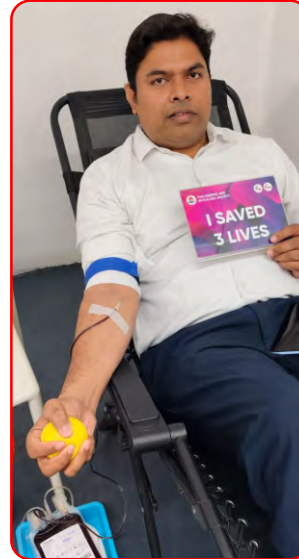
Long-Term Impact

Through sustained awareness and advocacy efforts, TSCS has contributed significantly to increased screening uptake, improved public understanding of hemoglobinopathies, and stronger policy attention to Thalassemia and Sickle Cell Anemia. These initiatives support TSCS's long-term vision of reducing disease burden and working towards a future where preventable hereditary blood disorders are effectively controlled.



Blood Donation Camps





Donation



Rotary Club of Lake District Moinabad support to our proposal, "Towards a Thalassemia-Free Generation: Sponsorship of Prenatal Diagnosis in Carrier Couples."



Donation for research by Mrs. Dantuluri Sarojini Garu & Mr. D Srinivasa Raju

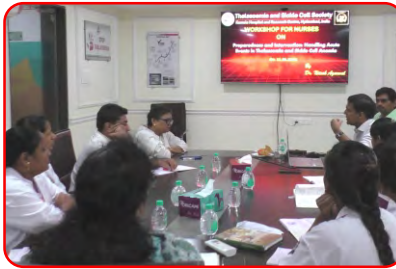


On the occasion of Shri K. T. Rama Rao's birthday support of 3 Lakhs towards Thalassemia patient support



Under its CSR initiative, Shri Challa Sreenivasulu Setty, Chairman of State Bank of India extended support worth ₹30 lakhs to TSCS. The support includes a Force Ambulance Van, 50 blood donation beds, and 50 blood donation chairs, significantly enhancing TSCS's capacity to conduct voluntary blood donation camps and provide timely services to patients.

Training



Dr Nitesh Kumar Agarwal MD(Paed) FIMA-AMS organised workshop for Nurses at TSCS on Handling Accute events in Thalassemia and SCA.



Dr. Suman Jain and Dr. Sujai Suneetha were invited as resource faculty by the Nepal Leprosy Trust, Lalgadh, Nepal, from January 15-18, 2025, to train staff on the use of High-Resolution Ultrasound (HRUS) for early detection of Leprosy.



Through the Dr. Reddy's Foundation training program, Thalassemia and Sickle Cell patients gained skills and job support, helping several beneficiaries secure employment and become financially independent.



Dr. Suman Jain successfully completed The TIF Renzo Galanello Fellowship Programme 2025 at London



Blood Bank procedure training given by Dr. Suman Jain to the staff

Partnership



The Atha Welfare Foundation from Afghanistan, team visited the Thalassemia & Sickle Cell Society (TSCS) to collaborate and share technical expertise in the care and management of thalassemia.

Awareness



Meetings



Celebrations



CME For Nurses and Lab Technicians on Occasion of International Nurses Day.



New Year Celebrations



Children's Day Celebrations



Women's Day Celebrations



Diwali Celebrations



BHARTIYA FEDERATION OF THALASSEMIA SOCIETIES (Reg. No. 1 of 2026)

The **Bhartiya Federation of Thalassemia Societies (BFTS)** is a national non-governmental federation established to bring together Thalassemia societies across India under a unified platform. The Federation aims to represent the collective interests of its member organizations, strengthen national advocacy efforts, and promote uniform standards

in prevention, care, and management of Thalassemia and other haemoglobinopathies.

BFTS focuses on coordinating awareness programmes, providing policy support, enhancing capacity building, fostering research collaboration, and facilitating knowledge sharing among member organizations. The Federation envisions a long-term goal of making India Thalassemia-free through effective prevention strategies and comprehensive patient care.

Aims and Objectives

- To represent the collective interests of member societies at national and international platforms.
- To bring together all Thalassemia societies across India for coordinated advocacy, awareness, and policy initiatives.
- To promote uniform standards of care, prevention, treatment, and support for patients with Thalassemia and related disorders.
- To organize conferences, meetings, training programmes, and capacity-building activities.
- To facilitate exchange of knowledge, data, and collaborative research among member societies.
- To work towards the long-term goal of making India Thalassemia-free through effective prevention strategies.

Background

The **Bhartiya Federation of Thalassemia Societies (BFTS)** was registered under the **Telangana Societies Registration Act, 2001**, with the Registrar of Societies, Ranga Reddy District, on **1st January 2026**.

The Federation was formally announced during the **Asian Thalassemia Conclave 2026**, held on **10th January 2026**, where approximately **115 societies, institutions, and organizations** from across India participated and appreciated this landmark initiative. On the same day, **22 organizations enrolled as founding members of BFTS**.

An increasing number of organizations have shown strong interest and are expected to join as BFTS members shortly.

Name Anil Kumar Yadav, M.D. R.S. Comments I am really touch by the service done here. We all believe in God and God has selected you for this cause in his service. I will support Dr. 11/01/25

Name Clavate Comments We are very pleased for having a service here. The work they are doing is really commendable. We will try our best to help in the way we can. 11/01/25

Name Dr. A. Vijayagurun Comments Visited Kamala Hospital and Research centre for Thalassemia and Sickle cell. Under PC-PNBT special drive started on 10th March. Found all documents related to Hospital. Doctor & Scan machine are correct. Hospital registered and Genetic Council centre, verified lab also, all are found. 11/01/25

Name T. Narayana, M.D. Comments 11/01/25

Name Salva Fatima (Pilot) Comments I am seriously into words on seeing the condition of patients, you people are doing an extraordinary work for another. Dr. 11/01/25

Name Shehan (Qu-2n Neurologist) Comments It is an enlightening experience to see the patients & interact with the side battling this disease. This experience has described me to reduce this with changing the thalassemia service as per the best of our ability. 11/01/25

Name Alisha Fatima (JTB - Hyd) Comments I appreciate the Estem cause from bottom of my heart and my interaction with patients enlightens me for how impacted this area to be addressed and how hope to contribute for this cause. Thank you. Dr. 11/01/25

Name Dr. Sai Chaitanya Comments I am very much touched and filled with emotional & motivational thoughts for this noble cause. I will definitely be a part of this noble cause & do my part. Thank U. 11/01/2025

Name Anand Kumar Comments I am really touch by the service done here. We all believe in God and God has selected you for this cause in his service. I will support Dr. 11/01/25

Name Dr. A. Vijayagurun Comments Visited Kamala Hospital and Research centre for Thalassemia and Sickle cell. Under PC-PNBT special drive started on 10th March. Found all documents related to Hospital. Doctor & Scan machine are correct. Hospital registered and Genetic Council centre, verified lab also, all are found. 11/01/25

Name T. Narayana, M.D. Comments 11/01/25

Name J.D.M. PILLAI Comments I am really touch by the service done here. We all believe in God and God has selected you for this cause in his service. I will support Dr. 11/01/25

Name MURTHY PRAKASH Comments God bless T.S.S. Society. Every work done by the society will be successful. I will be glad to help in the way we can. 11/01/25

Name Srinivas Reddy Comments I am really touch by the service done here. We all believe in God and God has selected you for this cause in his service. I will support Dr. 11/01/25

Name Satish Chandra (ASB) Comments I am really touch by the service done here. We all believe in God and God has selected you for this cause in his service. I will support Dr. 11/01/25

Name Anand Kumar Comments I am really touch by the service done here. We all believe in God and God has selected you for this cause in his service. I will support Dr. 11/01/25

Name Dr. Gayatri Patel Comments Amazing work done by the society. I will be glad to help in the way we can. 11/01/25

Name M. Arjun Kumar Comments I am really touch by the service done here. We all believe in God and God has selected you for this cause in his service. I will support Dr. 11/01/25

Visitors to Society



Thalassemia and Sickle Cell Anemia: A Worldwide Overview

Thalassemia and Sickle Cell Anemia are inherited hemoglobin disorders affecting millions globally. Both conditions impact hemoglobin—the oxygen-carrying protein in red blood cells—and lead to chronic anemia, serious health complications, and significant morbidity if not properly managed.

Thalassemia

Thalassemias result from genetic mutations that reduce or eliminate the production of one of the globin chains that make up hemoglobin. There are two major forms:

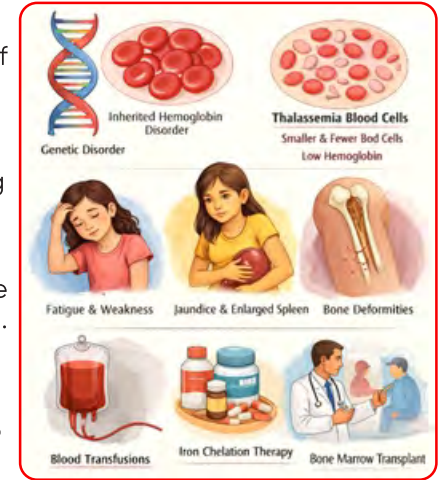
- **Alpha-thalassemia** – more severe when all four genes are affected.
- **Beta-thalassemia** – includes Thalassemia major (severe, requiring lifelong transfusions) and Thalassemia intermedia (moderate severity).

Global Distribution:

Thalassemia is most prevalent in the Mediterranean region (e.g., Italy, Greece), the Middle East, South Asia (India, Pakistan, Bangladesh), Southeast Asia, and parts of Africa. Migration has led to rising prevalence across Europe, North America, and other regions.

Impact:

Severe thalassemia requires regular blood transfusions and iron chelation therapy to prevent iron overload. Without treatment, patients face growth failure, bone deformities, organ damage, and premature death.



Sickle Cell Anemia

Sickle Cell Disease (SCD) is caused by a single nucleotide mutation in the β -globin gene, resulting in production of abnormal hemoglobin S. Red blood cells become rigid and sickle-shaped, causing blockages in blood vessels, pain crises, anemia, and organ damage.

Global Distribution: Sickle Cell Disease is most common among people of African descent, but is also prevalent in the Middle East, India, the Mediterranean, and parts of Central and South America. Global migration has increased recognition of SCD in Europe and North America.

Impact: Clinical complications include pain crises (vaso-occlusive episodes), acute chest syndrome, stroke, infections, and chronic organ damage. Lifelong comprehensive care improves survival and quality of life.



Epidemiology & Burden

Together, thalassemia and SCD represent significant global health burdens:

- **Millions of carriers worldwide** – carriers are often asymptomatic but can pass the trait to offspring.
- Over **300,000 affected infants born annually** with severe hemoglobinopathies, especially in low- and middle-income countries.
- Many affected individuals lack access to early diagnosis and specialized care.

Prevention and Control

Both disorders are genetically inherited, making prevention strategies critical:

- **Carrier Screening:** Enables identification of at-risk couples.
- **Genetic Counselling:** Educates families on inheritance, reproductive options, and risks.
- **Prenatal Diagnosis:** Detects affected pregnancies early.
- **Newborn Screening:** Improves early detection and care initiation, especially in SCD.

Countries like Cyprus, Greece, and Italy have reduced births of affected children through sustained screening and counselling programs. Newborn screening for SCD in the U.S. and parts of Europe has transformed outcomes.

Management and Care

Optimal care requires a multidisciplinary approach:

- Regular **transfusions and chelation** for thalassemia major.
- **Hydroxyurea, pain management, vaccinations, and infection prophylaxis** for SCD.
- **Bone marrow transplantation** can be curative in selected cases.
- Advancements in **gene therapy** show promise for both disorders.

Global Initiatives

International bodies and NGOs (e.g., World Health Organization, Thalassemia International Federation) advocate:

- Inclusion of hemoglobinopathies in national health agendas.
- Universal newborn screening.
- Equitable access to diagnostics and therapeutics.
- Enhanced community awareness to reduce stigma.

Conclusion

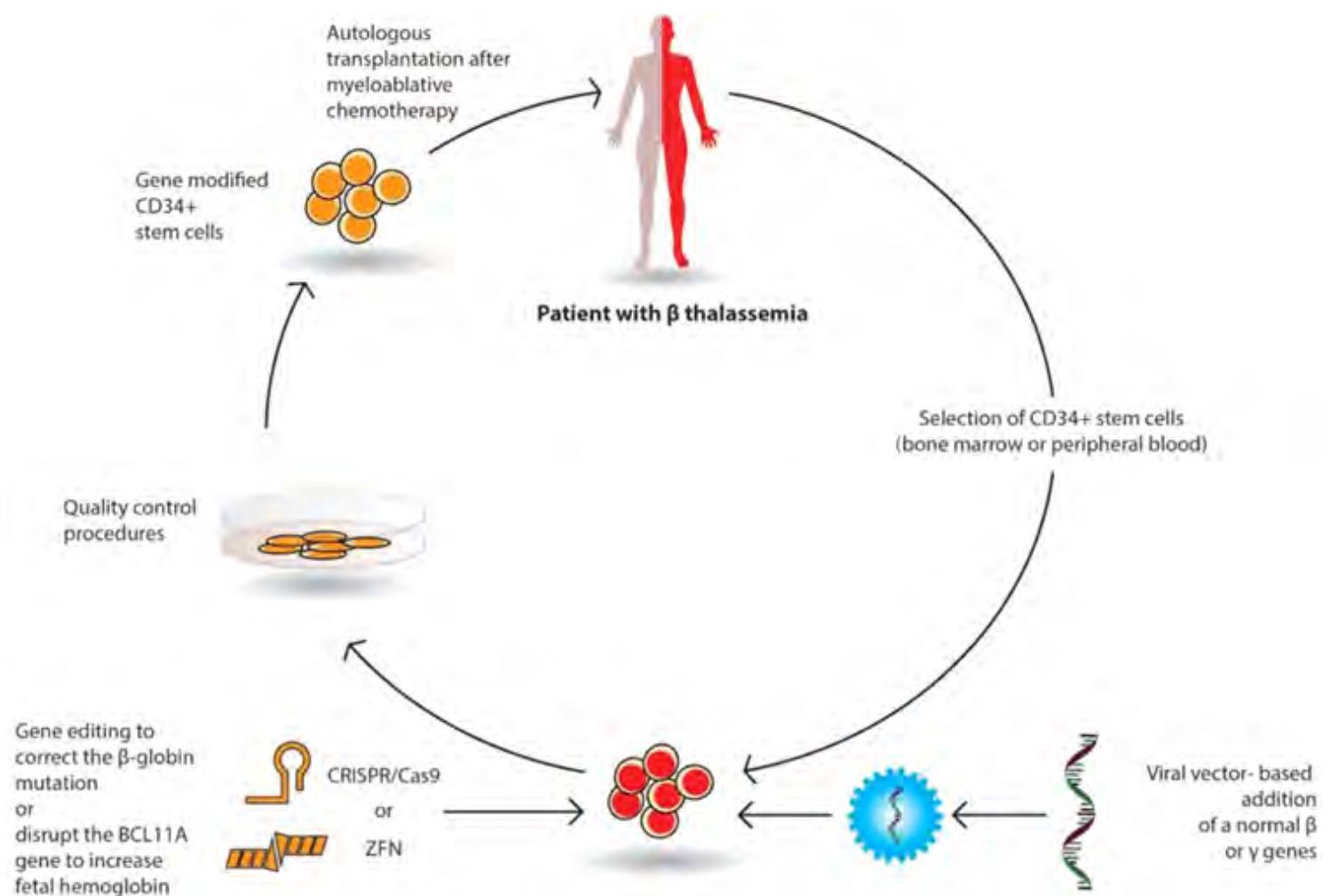
Thalassemia and Sickle Cell Anemia remain major hereditary blood disorders with significant global impact. While effective clinical care has transformed outcomes in many regions, prevention through screening, awareness, and policy action remains essential—especially in high-prevalence countries. Collaborative global efforts are crucial to improve quality of life for patients and advance equitable health care access worldwide.

Gene Therapy for Thalassemia Patients

Gene therapy is an advanced treatment that aims to correct the genetic defect responsible for Beta Thalassemia. Instead of managing the disease with lifelong blood transfusions, gene therapy attempts to provide a long-term or potentially curative solution.

In this procedure, the patient's stem cells are collected and edited in the laboratory by inserting a healthy beta-globin gene. The corrected cells are then infused back into the patient so they can produce normal hemoglobin. This therapy has the potential to significantly reduce or eliminate the need for lifelong blood transfusions. Although promising, gene therapy is currently expensive and available only in specialized medical centers

Gene therapy is considered one of the most promising curative approaches for thalassemia, alongside bone marrow transplantation, and ongoing research is improving its safety and accessibility.



Bone Marrow Transplantation (BMT)

BMT is the only established curative treatment besides Gene Therapy for Thalassemia Major and selected cases of Sickle Cell Disease. It involves replacing the patient's diseased bone marrow with healthy stem cells from a compatible donor, preferably an HLA-matched sibling. When performed early and at specialized centres, BMT offers high cure rates. However, careful patient selection, donor availability, and expert follow-up are essential due to potential risks and complications.

TSCS collaborated with **Sankalp India Foundation**, **Narayana Hrudayalaya**, and **Rainbow Children's Hospital** to facilitate Bone Marrow Transplantation (BMT) for patients. We are deeply grateful to **Electronics Mart India Limited** for extending financial support to several patients during the year.

Some of our patients (less than 12 years of age) have undergone BMT with support from **Coal India Limited** under its CSR initiative, **Thalassemia Bal Sewa Yojana**, which provides financial assistance of up to ₹10 lakhs per child for BMT procedures. In partnership with the **Union Health Ministry**, this program supports eligible, low-income patients at 18+ empanelled hospitals across India.



2025 Successful BMT Patients

Full Matched BMT (22 patients)




Haplo BMT (11 Patients)



BMT Patients Evaluation by Narayana Hrudayalaya & Sankalp India Foundation





“Even the smallest donation to Thalassemia and Sickle Cell patients can make a huge impact on their family”

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

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

Bank Account Details

Local Account (Donations within India)		FCRA Account (Foreign Donations)
Account Number:	0608101049513 0608101055132 (Research)	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

📍 Door No. 8-13-95/1/C, Opp Lane to National Police Academy, Raghavendra Colony, Shivarampally, Rajendra Nagar, Rangareddy Dist – 500052, Telangana

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