THALASSEMIA AND SICKLE CELL SOCIETY

ANNUAL REPORT 2020

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

www.tscsindia.org | tscs@tscsindia.org | Follow us : /tscs1998

COVID 19

The outbreak of COVID-19 pandemic has led to sudden shift in the dynamics of life. In every crisis, doubt or confusion, TSCS has taken the higher path - the path of compassion, courage, understanding and love to continue our services to Thalassemia and Sickle Cell affected.

No pandemic is powerful enough to uproot our zeal to manage Thalassemia and Sickle Cell patients.

Thalassemia and Sickle Cell Society during the COVID-19 pandemic has followed all the COVID-19 prevention guidelines.

- Cleaning our hands often using soap and water, or an alcohol-based hand rub
- Maintaining a safe distance from anyone who is coughing or sneezing
- Wearing a face mask, face shield and disposable apron
- Maintaining physical distancing
- Not touching eyes, nose or mouth
- Covering nose and mouth with bent elbow or a tissue while coughing or sneezing
- Staying at home if unwell
- Seeking medical help in case of fever, cough and difficulty in breathing

TSCS started taking necessary precautions at the onset of pandemic before the lockdown by sending SMS to our patients to avoid social and religious gatherings, personal care and hygiene, avoiding use of public transport. During the period of lockdown necessary documents such as transport pass, ID cards, transport to the patients and staff was arranged. Utmost priority was given for smooth functioning of the society and safety of patients and staff.

Index

Management Committee

Mr Naresh Rathi
Chief Patron

Mr Shyam Sunder Loya Ji
Chief Patron

Mr Pradeep Uppala
Chief Patron

Mr Chandrakant Agrawal
President

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
Treasurer

Dr D Rajeshwar
Advisory Member

Dr Sirisha Rani
Advisory Member

Message from President

Mr Chandrakant Agrawal
President

At the very outset, please accept my best and warm wishes for a great year ahead. Together we have faced, fought and survived the pandemic Covid-19. This pandemic has taught us new lessons in survival, sustainability and our vision of life.

It gives me immense pleasure to meet all of you through this annual report. Whatever we are, and whatever we will be, because of each one of you who is reading these lines. From the core of my heart please accept my heartiest thanks for the kind and sustained support for this noble cause of serving our beloved thalassemic children.

Progress, development and achievement are not a game of chance, they are the result of herculean efforts, dedication, commitment and never say die – attitude. I am truly proud of our team at the society, who have worked in the most adverse of circumstances during pandemic and served the most neglected section of society – the the thalassemic child.The world around us is rapidly changing, things which we never imagined are now becoming new normal, in such times, we have to adopt to the new normal and shall move ahead for achieving our cherished goal by constantly innovating, embracing the new and ever! technology, focusing on research and thereby making a difference in the life of children under our care. This spirit of "Yes, We Can " which resonates in every layer of our organization, which is getting embedded in DNA of our team will work towards the miracle of a thalassemia free Telangana.

It is the passion and dedication of our team members that has enabled us to progress so far and will be a key constituent to the success in our future endeavours. I would like to thank each and every one for your constant commitment and support. I would we failing in my duty, if I do not recognize the great team we have as Board of our Society, the Board of the society deserve, all appreciation and thanks for the stellar work done during the year under this report. I also convey my heartfelt appreciation for all our Donors, Patrons, Doctors, Associates and our Government who have continued to collaborate with and support our society over the years. We deeply value the overwhelming faith maintained by all our members and patrons over the years. We sincerely look forward to your continued support as we move towards our worthy goal of thalassemia free Telangana.

With Warmest Regards,

Message from Secretary

Dr Suman Jain
Chief Medical Research Officer
and Secretary

At TSCS, our mission is to provide the highest quality service to every thalassemia and sickle cell anemia affected person. We strive to continually grow and direct our efforts to shaping the future of thalassemic children. We believe this is a place where every thalassemia child is given the right to live.

A great example of our commitment to our mission was our handling of the COVID-19 pandemic. We quickly adapted to the pandemic ensuring the health and safety of our staff and children and choose to provide the best services possible without any disruption.

Our aim is to bring into light the inherited and preventive nature of Thalassemia and Sickle Cell Anemia through extensive awareness, screening and counselling. This awareness will then help reduce new thalassemic cases. To ensure better quality of life for our patients, we use the most advanced equipments in our Diagnostic Centre & Blood Bank. Efforts were put in to establish Research Laboratory with a hope for a better tomorrow for every thalassemia and sickle cell anemia affected. Here we carry out molecular screening, collaborate and respond through paper publications and identification of risk groups and many more avenues to unfold in years to come.

Our sincere Thanks to all our supporters and well-wishers who stand by our side in every situation and help us carry out our mission of serving the needy.

Best wishes

About TSCS

Thalassaemia and Sickle Cell Society (TSCS) is a registered (Reg No. 5359) non-profit, non-governmental organisation founded in 1998 representing mainly by a small group of patient's parents, doctors, well-wishers, philanthropists etc. to provide best treatment and management to patients suffering with Thalassemia and Sickle Cell Anemia. Ever since we started, our priority has always been to improve our services provided to patients in accordance with latest developments in treatment, management and prevention of the same.

With the objective of helping all of our Thalassemia and Sickle Cell Anemia affected children, TSCS has established, **well maintained transfusion centre, high quality blood bank, modern diagnostic laboratory and advanced research centre** under one roof to support more than 2800 registered patients for the past 22 years.

TSCS provides free consultation, free blood and transfusion facilities, counselling, investigations and food for around 45-50 patients daily. We are proud to have eminent doctors, specialists, hemato-oncologist, paediatric endocrinologist, cardiologist, paediatrician, pathologists, ophthalmologist, dentist, radiologists and research scientists associated with us in helping to provide best **comprehensive care and cure** for our patients.

TSCS is putting its heart and soul in getting BMT (Bone Marrow Transplantation is the only cure for Thalassemia) done for the patients by doing free HLA typing, counselling them for BMT and helping them financially. Which is a great social, mental and emotional support and relief to the family.

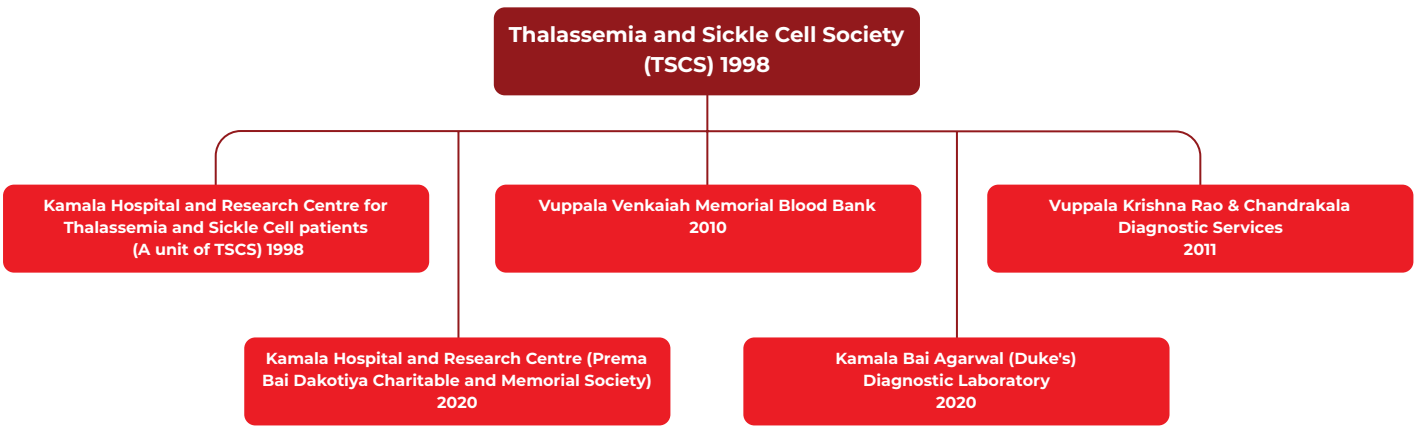
Mission:

Thalassemia and Sickle Cell Society is dedicated to ensuring the best quality treatment and quality of life possible for Indians suffering with Thalassemia and Sickle Cell Anemia and move towards our worthy goal of Thalassemia free Telangana.

Aims :

- To provide appropriate treatment to improve the quality of life of 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 for pre- and post- Bone Marrow Transplantation (BMT) management

Organogram of Society



Ethical Committee Members

Name	Designation
Dr Vijayalakshmi Valluri	Chairperson
Dr Hannah Anandaraj	Social Scientist
Shri V S R Moorty	Theologian
Late Dr Veerender	Physician
Mr Deepak Bhattacharjee	Senior Advocate
Dr Suman Jain	Secretary

Advisory Board

Advisory Board
Mr R Srinivasan
Mr Vaman Rao
Dr Geeta Kolar
Dr Ashwin Dalal

Banker	Auditor
Canara Bank Pathargatti Branch Hyderabad	NVS Murty & Co. Secunderabad Telangana

Patron Doctors

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

Eminent Doctors Working with TSCS

Sl. No	Contents
1	Dr. SUMAN JAIN, MBBS, DCH, Paediatrician
2	Dr. SUJAI SUNEETHA, MBBS, DCP, Ph.D, Pathologist & Leprologist
3	Dr. K SAROJA, BHMS, DHHM, Medical Officer
4	Dr. MOHD IQBAL MOINUDDIN, MBBS, Medical Officer
5	Dr. SARASWATHI SUSARLA, MBBS, MD (General Medicine)
6	Dr. AMARNATH KULKARNI, MBBS, DCH, DNB, Paed. Endocrinologist
7	Dr. SIRISHA RANI , MBBS, MD, MRCPCH (Paed. Hemato Oncologist)
8	Dr. PARINITHA, MBBS, MD, MRCPCH, CCT (Paed. Hemato Oncologist)
9	Dr. RAMANA DANDAMUDI, MBBS, DCH, MRCP (Paed. Hemato Oncologist)
10	Dr. D M NAIK, MBBS, MD, Pathology (Pathologist)
11	Dr. A RAGHAVENDER GOUD, MBBS, MD, FSCAI (Cardiologist)
12	Dr. B SWETHA, MBBS, MDRD (Radiologist)
13	Dr. ANURADHA KULKARNI, MBBS, MS, Ophthal (Ophthalmologist)
14	Prof. V R RAO, M.Sc, Ph.D, Genetic Epidemiologist (Population)
15	Dr. G PADMA, M.Sc, Ph.D Genetics, Sr. Research Scientist
16	Dr. V SANDHYA, MBBS, MD, FNB (Paediatric Hemato Oncologist)
17	Dr. B VARSHINI, MBBS, DNB, FNB (Paediatric Hemato Oncologist)
18	Dr. CH SAMPATH REDDY, MDS, FDS, RCPS, MFDS, RCS (Dentist)
19	Dr. PRADEEP NAIK, M.Sc, Ph.D, Bio-Chemistry

Achievements – 2020

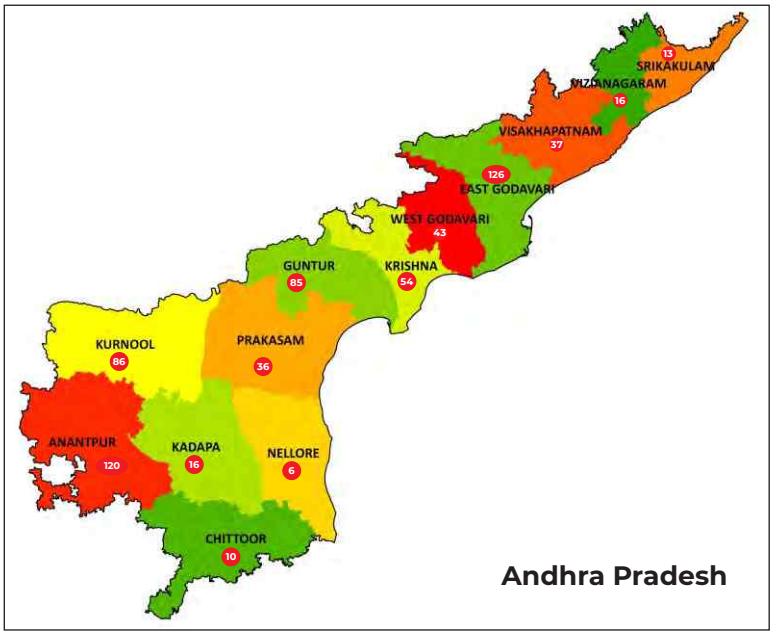
1. Ms Ratnavali Kothapalli, Vice President, TSCS was felicitated by Shri Ram Nath Kovind ji, President of India for her services towards Thalassemia and Sickle Cell patients on 3rd Jan 2020.
2. During the year in spite of COVID-19 pandemic with support from police personnel, voluntary blood donation organisers and voluntary donors we could collect 15,466 units of blood
3. We have computerised data of 2800 patients which can be utilised for scientific research· Around 1000-1200 children are given free blood transfusion every month
4. Every month 450 Thalassemia and Sickle Cell Anemia children from Telangana and 50 children from Andhra Pradesh received services through Aarogyasri health scheme
5. Around 287 HbA2 tests were conducted for all the parents, siblings, relatives of the extended families of our Thalassemia patients free of cost
6. Two children had successful Bone Marrow Transplantation (BMT) in collaboration with Sankalp India Foundation, Bangalore. Due to COVID-19 pandemic others couldn't undergo BMT.
7. TSCS participated in Sickle Cell World Assessment Survey (SWAY), the survey conducted by Novartis to evaluate the impact of the disease on patients' daily lives, treatment/management of SCD and patient satisfaction.
8. Research collaboration 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)
9. During the year 2020 Research Laboratory and Modern Diagnostic Laboratory were established to provide better services to our patients.· Creating awareness is the key in prevention of Thalassemia and Sickle Cell disease. We have been regularly conducting awareness programmes in and around Hyderabad·
10. "Prevention of Hemoglobinopathies through Antenatal screening" a prevention project initiated by Sankalp India Foundation at Bangalore under our able guidance.
11. Our proposal "Screening of Antenatal Pregnant women for Thalassemia and Sickle cell Anemia as a step towards awareness and prevention" to prevent the birth of thalassemia patients is approved and is schedule to start in collaboration with the Modern Government Hospital, Petlaburj,Hyderabad
12. During the year Four papers have been published in various national and international journals and two are under review

Kamala Hospital and Research Centre for Thalassemia and Sickle Cell Patients (A unit of Thalassemia Sickle Cell Society):

TSCS is the only transfusion centre in India with more than 2800 Thalassemia and Sickle Cell Anemia registered patients with age group ranging from 3 months to 40 years, as on December 2020. 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. Treatment and management is very 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.

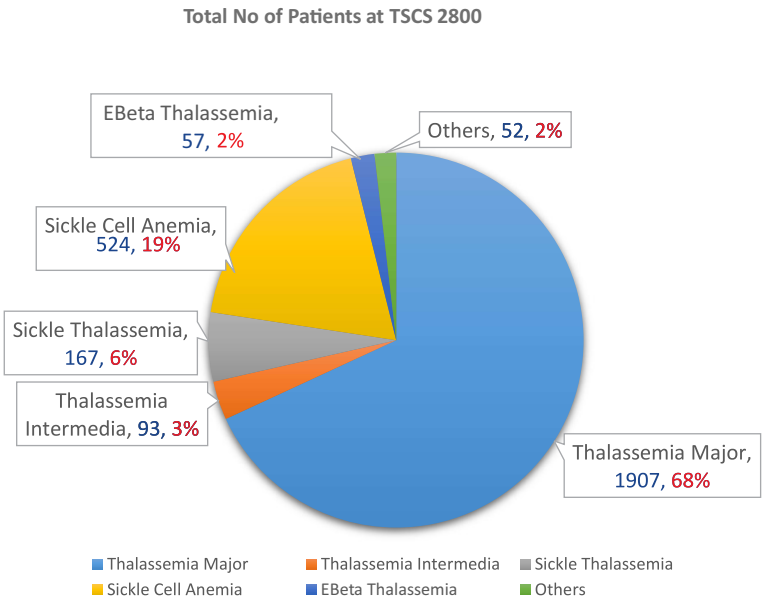
Demographic Details

The details of 2800 patients registered in the society since the inception in 1998 are given below:



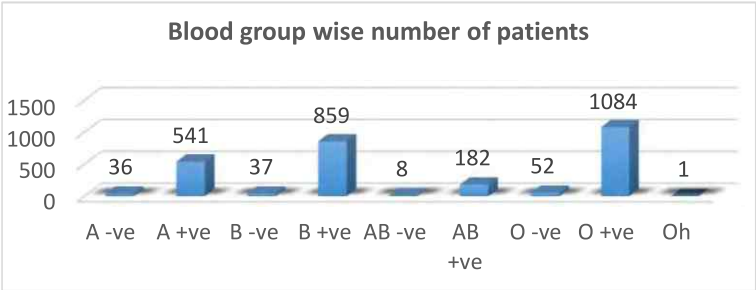
Demographic Details

STATES	Nos
TELANGANA	2069
ANDHRA PRADESH	648
OTHERS	83
TOTAL	2800



Age and Sex wise Details			
Age group	Sex		
	Female	Male	Total
00-02	38	50	88
03-04	47	83	130
05-06	77	84	161
07-08	100	130	233
09-10	128	182	310
11-15	291	417	708
16-20	195	284	480
21-25	130	192	322
26-30	53	89	143
30-40	46	81	127
>40	10	18	28
Not Available	29	42	71
Total Patients			2800

Consanguinity Details		
Consanguinity	No.	%
Present	1511	53.97
Not present	1289	46.03
Total	2800	100



Classifications of Disease - 2020	
Type of Disease	No.
Thalassemia Major	74
Thalassemia Intermedia	2
Sickle Thalassemia	4
Sickle Cell Anemia	22
E-Beta Thalassemia	2
Total	104

New Registered cases	HPLC tests	CVS Referred to NIMS & CDFD	HLA Typing	Splenectomy	Screening Camps
104	287	27	10	2	1

By continuous and aggressive counselling and follow-ups 27 parents agreed to go for Prenatal Diagnosis (PND), out of which 7 foetus were found to be affected of which 6 followed the protocol. Thus we could prevent the birth of Thalassemia children.

TSCS Daily Activities














Vuppala Venkaiah Memorial Blood Bank

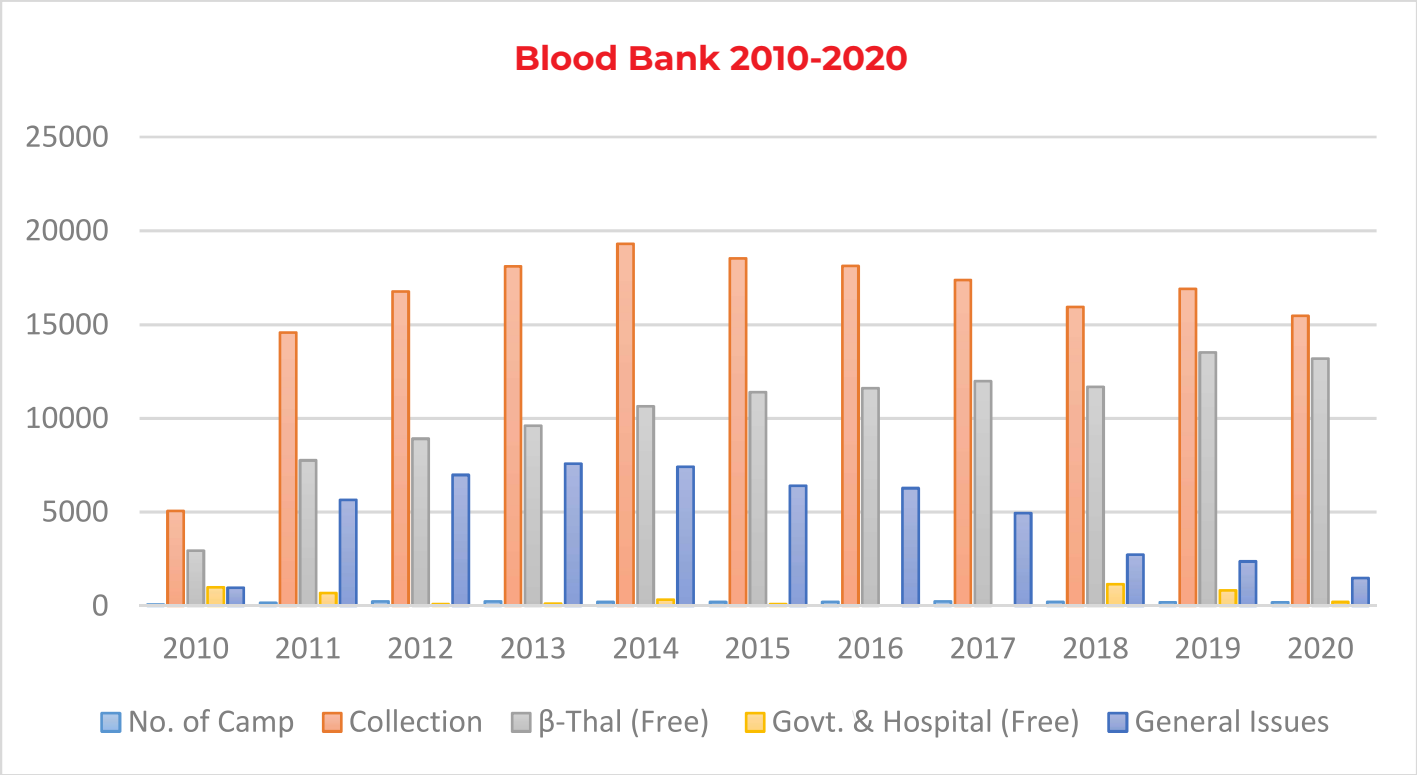
Thalassemia and Sickle Cell Society Vuppala Venkaiah Memorial Blood Bank (TSCS-VVMBB) was launched in March 2010 keeping in mind the need for safe Blood for Thalassemia and Sickle Cell Anemia patients. This is one of the major effort to keep the children away from any issues/adverse reactions arising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

We are counted/ranked among the best NGO-run blood banks. 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 better quality of blood components.

TSCS Blood Bank supports almost 1300 in-house Thalassemia and Sickle Cell Anemia patients and also caters to the needs of nearby hospitals in a month.

During blood donation camps 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 .

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.



Blood Bank Activities 2020	
Sensitisation Programmes	247
Donation Camps	196
Blood Units Collected	15466
Discard of Blood Units	249
β-Thal & Free - Issues	13401
General Issues	1495

We gave nearly 90% of the Blood collected free to our Thalassemia and Sickle Cell Anemia patients

Vuppala Krishnarao Chandrakala Dagnostic Centre

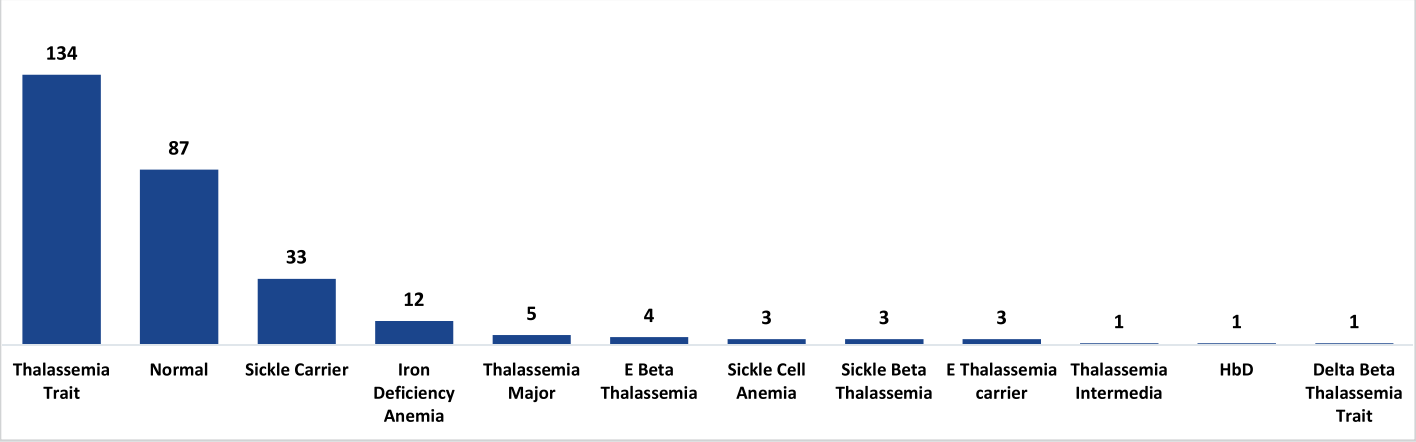
Thalassemia & Sickle Cell Society Vuppala Krishna Rao & Chandrakala Diagnostic Services established in September, 2011 is equipped with latest methods and technologies to carry out investigations for the benefit of the affected.

The diagnostic centre has high quality precision equipments 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 & High Performance Liquid Chromatography (HPLC: for screening HbA2 levels).

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

During the year 287 people were screened free for Thalassemia and Sickle Cell Anemia (HPLC test), the details of which are as follows:

Details of 287 HbA2 test



Research Laboratory

Kamala Hospital and Research laboratory was established (supported by **Prema Bai Dakotiya Charitable and Memorial Society)** with an aim to screen the patients for various mutations in alpha, beta, gamma genes causing thalassemia. The main objective of the research is to conduct various studies to improve the quality of life of the patient and to formulate better treatment strategies.

Aims of Molecular Research Lab

- To maintain a demographic, clinical database of all the patients which would help in formulating better treatment profiles
- To extract DNA from the patients and maintain a DNA databank. The DNA would be screened for mutations in different hemoglobin genes to confirm their diagnosis.
- To develop rapid screening methods for screening different haemoglobinopathies
- To study the impact of repeated blood transfusions on quality of life of thalassemia patients
- To study the effect of modifier genes on the severity of thalassemia

National and International Collaborations

- Institute of Genomics and Integrated Biology (IGIB), New Delhi for working on gene therapy for Thalassemia and Sickle Cell Anemia
- Centre for DNA Fingerprinting and Diagnostics for prenatal diagnosis
- Aurelia Maggio, Dept of Hematology and Rare Diseases, Palermo, Italy to be a part of "Health Repository Data for developing an International Prognostic Scoring System for Thalassemia"
- Chrogene Aarogyam Biotech Private Limited for developing Noninvasive device for detecting Sickle Cell Anemia
- VNR Vignana Jyothi Institute of Engineering and Technology, Hyderabad for Identification of Sickle Cell Anemia using Deep Neural Networks through Artificial Intelligence
- Collaborated with Novartis in SWAY SURVEY and contributed data on 123 sickle Cell patients reflecting the Indian scenario at the international level.

- **Ongoing Research Projects: 7**
- **Projects Submitted for Funding and Under Review: 1 and 1 project is shortlisted by DBT**
- **Research Papers Published: 14**

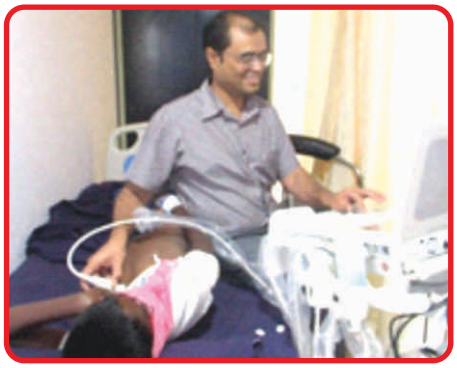
Advanced Diagnostic Laboratory - Eminent Specialists

Kamala Bai Agarwal (Duke's) Diagnostic Laboratory was setup in 2020 to provide specialized 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 regularly screened to monitor their growth and organ functions. Availability of these facilities under the same roof aids in offering better treatment .

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





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.

Board Members

TSCS Dedicated Staff

Donors List

Sl. No	Donor Name
1	A S Iron & Steel
2	AIM ASIA
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4	Ambika Iron & Steel
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9	Chandrakant Agarwal
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12	Dr. C. Anupama Reddy
13	Geetha Pandey
14	Give Foundation
15	Global Steels
16	Golden Royal Warehouse Pvt Ltd
17	Guru Foundation
18	Guru Technologies Ventures
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Sl. No	Donor Name
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55	Srimathrutre Charitable Trust
56	St Ann's Degree College For Women
57	Suman Dhuwalia
58	Supreme Agencies
59	Teradata India Pvt Ltd
60	V Balveeraiah Sons
61	Virendra Jain
62	Yerram Remesh
63	Yuva, Vega, Nora
64	Zoi Health Pvt Ltd

Financial Report

THALASSEMIA SICKLE CELL SOCIETY
Door No: 22-8-496 to 501 ; Purani Haveli; Chatta Bazar,
Opp: City Civil Courts Purani Haveli, Hyderabad - 500 002
STATEMENT OF AFFAIRS AS ON 31ST MARCH 2019

LIABILITIES	AMOUNT		ASSETS	AMOUNT	
Capital Account			**Fixed Assets**		
Capital Fund	2368216		Airconditioner	142500	
Less Excess of expenditure over income	-3792544				
Donations Towards Corpus Fund	17810099		Ambulance	1261898	
Life Members Ship	2459500	18845271	CAR	260000	
			Biometric Attendence System	12000	
			Centrifuge Machine for Lab	32957	
Amount accumulated for	61309828		Computers	897158	
construction of Hospital and			Electrical Transformer	251696	
Research block			Four Channel Coagultion Analyzer	147500	
less amount utilised for construction					
during the financial year	-30342506	**30967322**			
current liabilities			Furniturs & Fixtures	1674451	
			HPLC Machine	3339000	
Sundry Payables		15010	Honda Activa	77067	
ESI Payable		39770	Machinery	405365	
PF Payable		63378	Medical Equipments	6435226	
Professional Tax		5800	Office Equipments	846323	
			Pasaari Electronics	254060	
			Printer	51250	
			Refregirator	92040	
			UPS	95000	
			Xerox Meachine	80540	**16356031**
			Current Assets		
			Closing Stock Regular		1744108
			Closing Stock Research		116918
			Deposits (Asset)		18000000
			Tax deducted at source		10138508
			Rent advance		120000
			Other Advances		1932000
			Bank balances		
			society Regular		1463504
			Research wing		65482
Total		**49936551**	**Total**		**49936551**

For NVS MURTY & CO.
Chartered Accountants
CA NVS MURTY
(Proprietor)
M.No.022727

NVS MURTY & CO. Sec'bad M.No. 022727 Chartered Accountants

For Thalassemia & Sickle Cell Soci

SECRETARY

THALASSEMIA & SICKLE CELL SOCIETY R.R-52

Financial Report

THALASSEMIA SICKLE CELL SOCIETY
Door No: 22-8-496 to 501 ; Purani Haveli; Chatta Bazar,
Opp: City Civil Courts Purani Haveli, Hyderabad - 500 002
INCOME AND EXPENDITURE FOR THE PERIOD ENDED WITH 31ST MARCH 2019

PARTICULARS	AMOUNT		PARTICULARS	AMOUNT	
Opening Stock		3299813			
			Aarogyasri Claims	59466863	
Purchase Accounts			Contribution From General Patients for B	10624054	
Purchase Group	34815934		Contribution From Patients for Laborator	937895	
Purchases For scientific Research	116918	34932852	Contribution From Patients for Medicines	1521370	
Indirect Expenses			Contribution From Patients Maintanance	436400	72986582
Bulilding construction expences	22260744				
Salaries & Wages	14267062				
Salaries from scientific Research	167600				
Audit Fees	99715				
Bank Charges	13502				
Camp & Awareness Expenses	997330				
Consultation Charges	395950		Donations Regular	3365165	
Convayance	627435		Donations FCRA	797368	
Electricial Items	8210		Donations Recd for scientific Research	350000	
Electricity Expences	868773		Interest FCRA	13151	
Esi Late Fee	722		Interest Received	1645783	6171467
Fuel Charges	643600				
House Keeping	335985				
HLA Testing	536100		Closing Stock Regular		1744108
Insurance	25903				
Nutrision	814717				
Office Expences	1270380		Closing Stock Research		116918
Postage & Courier Exp	3183				
Printing & Stationery	738733		Excess of income over expenditure		3792544
Rent	427000				
Repairs & Renovations	633020				
Service Charges	114766				
TDS Deduction	123474				
Tds Penalty	23170				
Telephone Expenses	180730				
Transportation	1001150	46578954			
Total		84811619	**Total**		84811619

For NVS MURTY & CO.
Chartered Accountants
CA NVS MURTY
(Proprietor)
M.No.022727

NVS MURTY & CO. Sec'bad M.No. 022727 Chartered Accountants

For Thalassemia & Sickle Cell Society
SECRETARY

THALASSEMIA & SICKLE CELL SOCIETY 040-29885458 040-29885658 R.R-52

Financial Report

THALASSEMIA SICKLE CELL SOCIETY

Door No: 22-8-496 to 501 ; Purani Haveli; Chatta Bazar,
Opp: City Civil Courts Purani Haveli, Hyderabad - 500 002

RECEIPTS AND PAYMENTS FOR THE YEAR ENDED WITH 31ST MARCH 2019

RECEIPTS	AMOUNT		PAYMENTS	AMOUNT	
Opening Balance					
Bank Accounts			**Indirect Expenses**		
Andhra bank	5475		**Bulilding construction expences**	22260744	
Canara Bank	724797		Salaries & Wages	14267062	
Canara Bank-1181101023165	1001		Salaries from scientific Research	167600	
Cash-in-hand	1000	**732272**	Audit Fees	99715	
			Bank Charges	13502	
			Camp & Awareness Expenses	997330	
Capital Account			Consultation Charges	395950	
Life Members Ship		**382900**	Convayance	627435	
			Electricial Items	8210	
			Electricity Expences	868773	
Current Assets			Esi Late Fee	722	
Deposits (Asset)			Fuel Charges	643600	
Fixed Deposit			House Keeping	335985	
			HLA Testing	536100	
Income			Insurance	25903	
Aarogyasri Claims	59466863		Nutrision	814717	
Contribution From General Patients fo	10624054		Office Expences	1270380	
Contribution From Patients for Laborat	937895		Postage & Courier Exp	3186	
Contribution From Patients for Medicir	1521370		Printing & Stationery	738733	
Contribution From Patients Maintanan	436400	**72986582**	Rent	427000	
			Repairs & Renovations	633020	
Indirect Incomes			Service Charges	114766	
Donations Regular	3365165		TDS Deduction	123474	
Donations FCRA	797368		Tds Penalty	23170	
Donations Recd for scientific Research	350000		Telephone Expenses	180730	
Interest FCRA	13151		Transportation	1001150	**46578957**
Interest Received	1645783	6171467			
			Addition to Fixed Assest		1665187
			Purchases Regular		34815934
Fixed Deposit with drawn		10000000	Purchases Research		116918
			Advances for Building Construction		4000000
Increase CapitalFund		2108239			
			Pyments Made to Outstanding Liabilities		518114
			Tax Deducted At Sources		3157364
			Closing Balance		
			Bank Accounts		
			Bank Accounts		1463504
			Bank Account Research		65482
Total		**92381460**	**Total**		**92381460**

For NVS MURTY & CO.
Chartered Accountants
CA NVS MURTY
(Proprietor)
M.No.022727

NVS MURTY & CO. Sec'bad M.No. 022727 Chartered Accountants

For Thalassemia & Sickle Cell Society

SECRETARY

THALASSEMIA & SICKLE CELL SOCIETY 040-29885458 040-29885658 R.R-52

Thalassemia

Thalassemia is an inherited blood disorder characterized by decreased haemoglobin production. Haemoglobin is a protein in the red blood cells that carries oxygen to all parts of the body. This leads to excessive destruction of red blood cells, which causes anaemia.

Thalassemia is caused by either a genetic mutation or a deletion of certain key gene fragments. It is of different types viz., alpha thalassemia, beta thalassemia or delta thalassemia based on the genes involved. The most severe form of thalassemia is beta thalassemia major also known as Cooley's anaemia which requires regular blood transfusions and extensive medical care. If untreated their spleen and liver become enlarged due to iron overload and are prone to infections and heart failure which are the leading cause of death among children with beta thalassemia major.

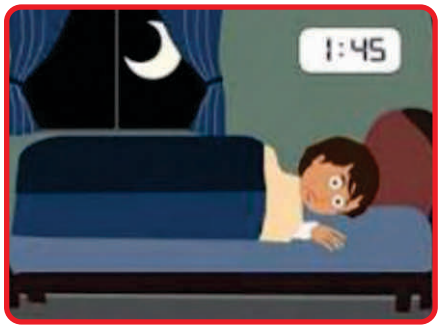
Thalassemia represents a significant health problem worldwide due to its frequency and severity. It affects >400,000 new-born every year worldwide. In India it is estimated that about 10000-15000 babies with beta thalassemia major (TM) are born every year. Beta thalassemia is most prevalent across the country with an average carrier frequency of 3-4%. A higher frequency has been observed in certain communities, such as Lambadas, Malas, Madiga, Mudiraj, Sunni, Sindhis, Punjabis, Gujaratis, Bengalis, Mahars, Kolis, Saraswats, Lohanas and Gaurs.

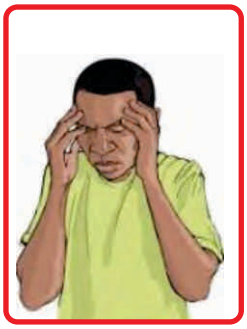
Thalassemia is inherited in autosomal recessive manner. It develops when both the parents carry the genes for the disorder (either carriers or affected). When both the parents are carriers for thalassemia then there is 25% chance at every conception that the child might be affected.

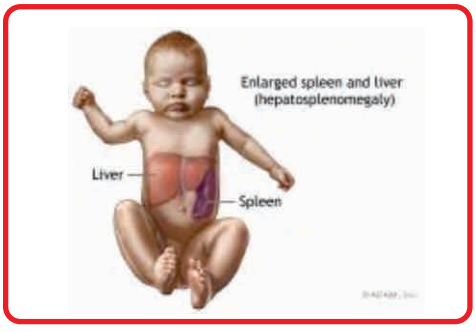
This disease can be prevented by a simple blood test for HbA2 levels which can be done before marriage or during pregnancy. Bone Marrow transplantation offers a cure for thalassemia but it is costly and requires a Human Leucocyte Antigen (HLA) matched donor. Hence as the adage says “Prevention is better than cure” thalassemia can be prevented by doing a simple blood test for HbA2 levels and reduce the incidence of affected births in the population.

Signs and symptoms of Thalassemia

- **Normal at birth**
- **Between ages of 6 week to 2 years**
- Become pale
- Restless
- Do not sleep well
- Have poor appetite
- Often have big spleen
- Fatigue
- Headache
- Weakness







Sickle Cell Anemia

Sickle cell anaemia, (SCA), Sickle cell anemia is the most common blood disorder in India, next to beta thalassemia that requires lifelong management and contributes to infant and childhood morbidity and mortality. It is a genetic disease of the red blood cells (RBCs). Normally, RBCs are shaped like discs, which gives them the flexibility to travel through even the smallest blood vessels. However, in SCA, the RBCs have an abnormal crescent shape resembling a sickle which makes them sticky and rigid and prone to getting trapped in small vessels thereby blocking the blood from reaching different parts of the body. This causes painful crisis in the patients.

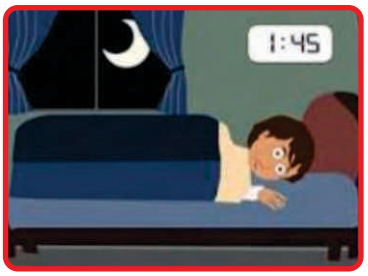
It is caused by substitution of valine for glutamic acid in position 6 of the globin chain (GAG to GTG) and is inherited in an autosomal recessive manner. Patients having only SCA are unaware of the disease as they are asymptomatic and can tolerate Hb levels of 7 or 8g/dl. The key difficulty arises only when the damaged sickle erythrocytes occlude the microcirculation blocking the blood vessels and cause episodes of severe pain. It may also be co-inherited with beta thalassemia, causing a condition known as Sickle Beta Thalassemia.

SCA affects millions of people worldwide and is particularly common among those whose ancestors came from sub-Saharan Africa, South America, the Caribbean and Central America, Saudi Arabia, India, and Mediterranean countries like Turkey, Greece and Italy. An estimate of about 250,000 children are born annually with SCA worldwide. It is highly prevalent in the tribal populations of Southern, Central and Western states reaching as high as 48% in some communities. In Telangana SCA is most prevalent in Mandamarri Mandal, Adilabad district and tribal areas of Warangal and Khammam districts.

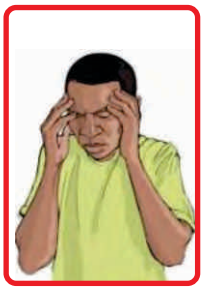
Signs and symptoms of Sickle Cell Disease

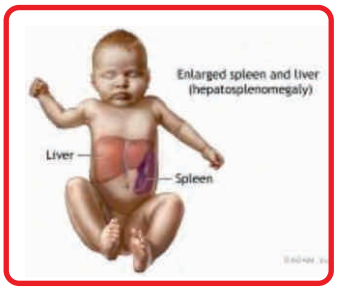
- **Asymptomatic as they are able to tolerate Hb levels of 7 or 8g/dl**
- **Difficulty arises only when red blood cells block the blood vessels**

- Yellowish discolouration of junctiva (Jaundice)
- Joint pains
- Become pale
- Restless
- Frequently fall sick
- Have poor appetite
- Fatigue
- Headache
- Weakness







Academic/Professional Achievements 2020 of our Patients

SSC - 20
Intermediate – 25
Graduation - 27

Professional Degree	Working	
Ramya - Aeronautical Engg.	Harshith – Infosys	Arsheen Fathima - Clinical Nutrition & Dietetics
N Divya DEI Ed	Krishnam Raju–Own Laboratory	Dr. Azra Fatima - Researcher at Learn Maximum PC polyclinics
Ameena - MBA	Manisha– Honda Showroom	Shirisha - Med. Transcription
Vishwa Teja - M.Tech	Jyothi – GNM Nurse at General Hospital	Usha Shri Beniya - LVP Eye Hospital
Ankita - B.Tech	Swathi - Google	Raghavendra - Tech Mahindra
Prashanth - Diploma Elect	Sonal Shivani – Delhi Public School – Teacher	G Srikanth - Oracle
Sai Krishna - Polytechnic	Swathi - Cognizant	Rahul - Wells Fargo
Vishwa Teja - B.Arch	Y Premsagar (Process Quality Analyst (CYIENT)	Khaza Nadeem Uddin - Own Restaurant and Charitable Trust
Vikram - Dip Civil Eng	Sai Srujana – Genpact	Ashwini - Physiotherapy
Rahul - Diploma EEE	Neelima – Lab Technician, Warangal	K Karthik – Axis Bank
Saleh - Polytechnic	Bharat Rupani - Dexter Capital, Bangalore	Souvik Bose - Wipro
Sumaira Fathima-MBA	Suvarsha - Panchayat Secretary	B Shiva Kumar - TSCS
Soujanya Msc Bio-Tech.	Yesupaul – Wipro	M Priyanka - TSCS
A Yashwanth – B Tech 1st Year	Aditya – Computer Operator, District Civil Supply	Mukhram Ali - Activa Show room
Saroj Kumar Samal, B.Tech	Elisha - AGS Co.	Chanakya Reddy - Own Business
Manirath Goud B.Tech	Rishab - Wipro	Tagore Naik – Electricity Dept., Paleru
Ravinder, Tribal Welfare Association - Gurukul	Raghav, Own Business	Mubeena – HSBC
Sourabh Misra, MBBS 2nd Yr	Nooruddin - Own business	Ramakrishna Tandra – Indus Ind Bank Branch Credit Manager
Neelima – Lab Technician	Krishna Chaitanya - Business	Shahul Hameed - TSCS
Mohd Omer – BBA 1st year	Swamy – Newspaper Business	Sushma- Google
J Ravi – B.Tech Final Year	Shivani Mundada- Tally (IT Filing)	Osman Pasha - Video Mixing
Rafiya Sultana – MBBS 1st Year	N. Venkateswarlu – Auto Driver	K Karthik Axis Bank (AM)
V. Sravya Teja – M.Tech	Hari Krishna – Axis Bank	
M Harish MBA HR		
S Arun Kumar B.Tech		
Md Sufiyan – Msc. Food Science and Technology		









News and Events

03 Jan 2020

Mrs Ratnavali Kottapalli and Dr Suman Jain with Honourable President of India Shri Ramnath Kovind ji on occasion of President interaction with social service activists on 3rd Jan 2020 at Rashrapati Bhavan, New Delhi. Mrs Ratnavali Kottapalli was invited to attend the programme for her services to Thalassemia and Sickle Cell Anemia patients.

07 Jan 2020

Mrs Ratnavali, Vice President TSCS, gave an awareness talk on prevalence and prevention of Thalassemia in Telangana at National Institute of Rural Development Rajendranagar,

26 Jan 2020

71st Republic Day celebrated at TSCS premises with patients, parents, staff and Board Members

27 Feb 2020

Awareness talk on #Thalassemia# at IACG Multimedia College, Dilsukhnagar Main Road, Hyderabad for around 200 students by Mrs Ratnavali Kothapalli, Vice President, TSCS

28 Feb 2020

42nd Healthcare Innovation Summit by Elets Health at Park Hayatt, Banjaara Hills. Dr Saroja K was panellist, Mrs Ratnavali Kothapalli, Dr Padma, Ravi Kumar and Bhargava also attended the summit

8 Mar 2020

Mrs Ratnavali was felicitated on the eve of international women's day by IMC India Media Council, Hyderabad and Mallareddy Engineering college for women where she also delivered an awareness talk.

09 Mar 2020

International renowned BMT specialist Dr Lawrence Faulkner, Dr Paula Tacla from Brazil, Mr Rakesh Dhanya the team of Sankalp visited TSCS to evaluate HLA matched patients for BMT, counselled the patients and gave their valuable suggestions for further management




13 April 2020

It's was our honor to receive Honorable Justice Shri Challa Kodanda Ram, High Court, Hyderabad during his visit at our society, and it was a kind gesture on his part to donate blood during lock-down and also provide packed lunch for our children, parents and staff during that period. He appreciated the dedicated services to Thalassemia and Sickle Cell children.

14 April 2020

Dr Lavanya NJP, ADCP Admin, Cyberabad along with Dr K Saritha, Unit Doctor, CTC, Cyberabad visited TSCS to see our services during COVID-19 Lockdown.

2020

Chandra kant Agrawal awarded Neta ji Samaj Ratna & “Best THALASSEMIA service provider in TELANGANA” by the honourable Health minister of TELANGANA.

12 May 2020

Ms Chandrakala, RDO, Rajendranagar along with Dasari Srinivas Retd. IAS (Special Chief Secretary) visited our society and were impressed by our services and commitment for upliftment of thalassemia patients.

13 Aug 2020

Pooja was conducted on auspicious day of 13th August 2020 to start the work in research lab.

15 Oct 2020

A webinar on “Breakthrough in Sickle Cell Disease: A Review” was organised and moderated by Dr M B Agarwal attended by 600 delegates.Dr Suman Jain gave a presentation on “Other Infections in Sickle Cell Diseases”.

22 Oct 2020

A Webinar on “Sickle Cell Disease: Recent Advances and Future” was organised by TSCS and sponsored by Novartis attended by 172 delegates. Programme Director was Dr Suman Jain, International Sickle Cell Specialist, Dr Baba Inusa, spoke on “Thinking beyond sickling and Does only severe VOC matters” & “Unsolved puzzling SCD”. Dr Radhika Shetti talked on “SCD in India: A Collage from Treatment Centre”. SCD in clinic a case based discussion was moderated by Dr Ganesh S Jaishetwar and panellists were Dr Sirisha Rani, Dr Parinitha Gutha, Dr A Bhagyalakshmi, Dr Nanadakumar Menon and Dr Praveen Varma.

29 November 2020

A webinar was organised by Kinnera Memorial Trust on “Managing Blood Disorders during COVID-19” attended by around 200 delegates. Dr Suman Jain, Dr Ramana Dandamudi and Mrs Ratnavali K from TSCS gave presentation. Moderator of the programme was Mr Ramprasad Ravi Senior Journalist. Various queries and doubts of the parents were answered.

03-04 December 2020

Dr Suman Jain, Mrs Ratnavali, Dr Padma, Ravi Kumar the team from TSCS and Mr David from Tribal Welfare Department, Government of Telangana visited Utnoor to give them suggestions for starting Care and Control centre for Thalassemia and Sickle Cell Anemia patients

7 Dec 2020

Mrs Ratnavali met Shri K Kavitha, Ex-MP , Nizamabad seeking her support in getting disability certificate for thalassemia and sickle cell anemia patients and brief about our aim and efforts for achieving Thalassemia Free Telangana.

Shyam Loya

15 Dec 2020

We are very grateful to Mr Abu Md Aimal Akram of Azad Khidmat for providing free lunch every day to our thalassemia children and parents. Maulana Jafar Pasha Hussami Sahab visited our society and was moved by plight of our children taking blood transfusion and announced that he would arrange two to three blood donation camps every month. He also inaugurated free food services on the same day

Blood Donation Camps

Due to COVID 19 pandemic organising blood donation camps was a big challenge and herculean task for our Blood Bank. There was scarcity of blood for our Thalassemia and Sickle Cell Anemia patients during the year, due to sudden lockdown and closure of IT industry. Blood donation camps were severely affected as there were COVID-19 pandemic restrictions. During this crisis Mr Aleen Baig, Joint Secretary TSCS, Mr Srinivas Rao, Board Member TSCS and our entire blood bank team worked hard to organise smaller blood donation camps keeping in mind COVID-19 restrictions and following all COVID protocol. People were encouraged for blood donation to donate at the society (in-house). All the necessary precaution and safety measures were taken during in-house donations. We are very much grateful to them for enabling continuous availability of blood to our patients during the crisis.

Our special thanks to Mr V C Sajjanar, IPS, Commissioner of Police, Cyberabad, Mr Sanjay Kumar, Assistant Commissioner of Police, Rajendranagar, Police team Rajendranagar Division and volunteers like Mahesh Talari and other organisations like Focuss, Tanzeem Irshaad ul Muslimeen and Insaan Foundation, Lions Club of Jeedimetla etc. for supporting and organising blood donation camps for our children during the pandemic.

We also like to thank each and every donor for their courage and gratitude during this COVID 19 pandemic who had come to our society voluntarily to donate blood.

3 September 2020

Blood donation camp was organized by Dr Uma Maheshwar Rao garu, Vijaya Nursing Home, Chandanagar, Hyderabad on 3rd September 2020. Thalassemia and Sickle Cell Society appreciate your support in organising the blood donation camp when we were facing acute shortage of blood due to COVID-19 pandemic

6 September 2020

Mrs Ratnavali, on the eve of Late Master K Rohit's birthday organised Blood donation camp and distributed gifts to the patients in his memory

25 October 2020

TSCS thanks Sunni United Forum of India and Mr Aleem Baig for organizing Quadri chaman Blood donation camp for Thalassemia patients at Falaknuma, Hyderabad.

30 October 2020

11th Milad Blood donation camp for Thalassemia patients at Central Library, Afzalgunj Hyderabad was organised by Focuss and Tanzeem Irshaad ul Muslimeen under the guidance of Mr Aleem Baig, Joint Secretary, TSCS.

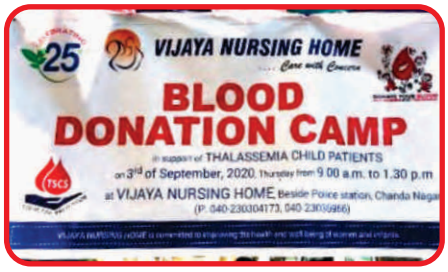
Special thanks to Insaan Foundation for organizing Milad Blood donation camp for Thalassemia patients at Prime Function Hall, New Mallepally, Hyderabad.

21 December 2020

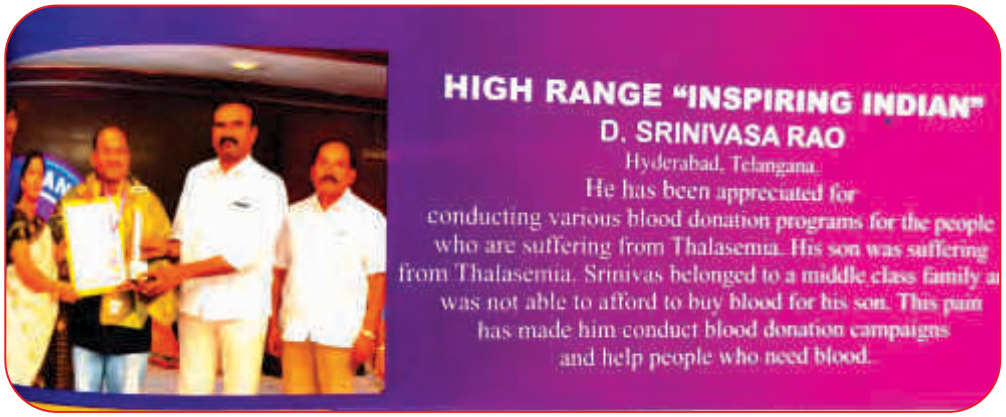
On occasion of Shri Y S Jagan Mohan Reddy's and Chief Minister of AP and Birthday Blood donation camp was organised by Dr. C Prapulla Reddy in Yusafguda, Hyderabad

27 December 2020

Shri Mandadi Srinivas Rao also helped us in arranging blood donation camp at KPHB, Kukatpally for Thalassemia patients.




BLOOD DONATION CAMP
DONATE BLOOD SAVE LIVES
SHIRDI NAGAR RESIDENTS WELFARE ASSOCIATION
DATE : 06 / SEPTEMBER / 2020 - SUNDAY
TIME : 10 AM TO 3 PM
LOCATION : SHIRDI NAGAR COMMUNITY HALL
FOR
THALASSEMIA CHILDREN

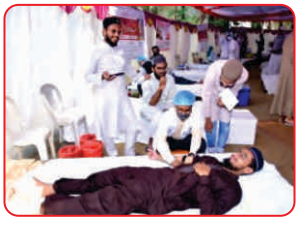

HIGH RANGE "INSPIRING INDIAN"
D. SRINIVASA RAO
Hyderabad, Telangana
He has been appreciated for conducting various blood donation programs for the people who are suffering from Thalasemia. His son was suffering from Thalasemia. Srinivas belonged to a middle class family a was not able to afford to buy blood for his son. This pain has made him conduct blood donation campaigns and help people who need blood.


BLOOD DONATION CAMP
Thalassemia
RNA
Cont: 77995 40044

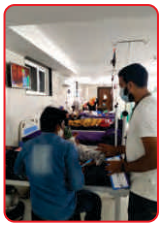

11th MILAD BLOOD DONATION CAMP
DONATE BLOOD
SAVE LIFE
ALL ARE INVITED


मिलाद के उपलक्ष्य में किया गया रक्तदान


గౌ॥ శ్రీ వై.యస్. జగన్‌మోహన్ రెడ్డి గారి
జన్మదిన సందర్భంగా
రక్తదాన శిభిరం
తేది: 21 - 12 - 2020




థలస్సీమియా వ్యాధితో బాధపడుతున్న పిల్లలకోసం
రక్తదాన శిభిరం
Hartly Welcome
మందాడి శ్రీనివాస్‌రావు గారు
థలస్సీమియా అండ్ సికిల్ సెల్ సొసైటీ
సెల్ నెం. 9000516017

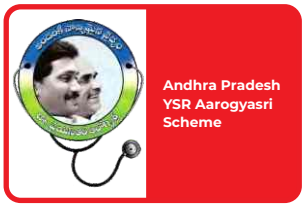


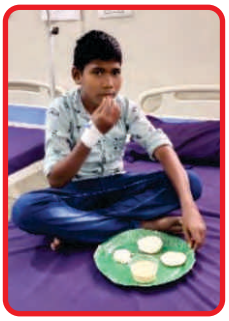

I'MA
DONOR
Saving Lives


BLOOD

Aarogyasri

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".





Aarogyasri Case Studies

I am Mr Naresh Chavan, my child Manoj Chavan (8 years) has been suffering from Thalassemia. He is on blood transfusion since the age of 6 months. Initially as we were not aware of the society were taking treatment at private hospital in Mahabubnagar.

Since last 6 years I'm coming to TSCS which has been great help to me and my child. I am a private cab driver with meagre income which is not even enough to make ends meet. With the burden of Thalassemia and COVID -19 pandemic it was all the more difficult, the only solace of hope was Aarogyasri at TSCS. Due to Aarogyasri at TSCS inspite of the pandemic treatment of my child was unaffected. I am very thankful an indebted to Aarogyasri Health Scheme and Government of Telangana.

G Maddiletty F/o 5 year old Uma Devi who was diagnosed with Thalassemia at the age of 3 months. Till February 2020, we have been taking blood transfusion and treatment at various hospitals in Kurnool, which was very expensive for us as I am a small time tailor with lot of economic constrain. I am very thankful to TSCS where I got my daughter registered in Feb 2020 when it was getting difficult anywhere to get blood during COVID-19 pandemic TSCS was only place where I got immense support and reduced my financial burden by enrolling in Dr YSR Aarogyasree scheme. I am also very thankful to Government of Andhra Pradesh for providing pension to Thalassemia affected which has been an huge relief for my family

Case Study

Suhani is 17 years old, hailing from the state of Maharashtra but now her parents are settled in Laldarwaja Hyderabad. Father Balasaheb Kashid works as manager in a Jewellery shop, while mother Shobha is a homemaker. Suhani was 9 months baby when she first started to show the symptoms of Thalassemia. She used to vomit after every feed along with severe loose motions which made her go weak day after day. Parents unaware of the cause took her to the Pediatrician who then directed them to a private hospital. It is here she was given symptomatic treatment and after investigation they confirmed the diagnosis as Thalassemia Major and started her 1st blood transfusion. The family was directed to TSCS by the private hospital and from 2005 they are associated with TSCS.

The parents were devastated to know about this disorder and the very thought of transfusion that has to go for lifelong increased their worries related to education, job and life. The family's dreams got scattered. Study reveals that those families with thalassemia, kids face numerous range of problemm in different aspects, such as physical, emotional mental, social, economic and psychological. There is no go then to accept the fact that life is full of worries and the problems are multiplied with a thalassemia kid. As children grow, the worries grow with the expectation thrown by the society such as ours, like need for job, marriage & settlement. Life was not easy as Suhani had to be brought to hospital every 15-20 days. The family could not see ray of hope of having a happy family as they had multiple miscarriages, one particular incident that mother recalls with teary eyes is when she is when she narrated the miscarriage of a six month foetus who was found to be normal after the prenatal screening suggested by TSCS. Oh how she wished to have a normal child. The family had a history of consanguineous marriages from three generations.

They wish Suhani had a sibling/s who could have been a support to their daughter. Suhani feels blessed to have been surrounded by supportive people especially her parents from whom she draws strength to face each day. She feels she is no less than other children and loves to play badminton and listen to music. She is pursuing her 10th now and wants to study further and become a school teacher, she wants to be independent as long as life let her live.

TSCS helps not only in blood transfusion but helps to minimize emotional suffering of thalassemic children, to identify relevant psychosocial factors; improve mother/child communication to foster a positive relationship, to help patient and mother to cope with events occurring in the family, and to realize that erroneous beliefs could cause emotional distress.The entire clan has decided to put a

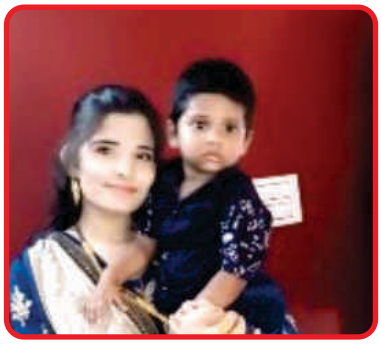
Thalassemia is not a Hindrance for Marriage

Marriage is not just about love. It's more than that a commitment, giving, taking, communicating and understanding. The fact that you want to spend your entire life with someone and be part of everyday life means that you are ready to share everything, compromise somewhere and trust your partner.

The above sentence stands so true to our Thalassemia affected patients. It takes lot of commitment and patience to being married to Thalassemia affected as they have to get them for blood transfusion regularly and see that they are taking their medicines on time.

Staff at the society counselled the patient and their family to get their partner's HbA2 test before marriage so that they are spared of having a Thalassemia child and lead a near normal life.

It gives us immense pleasure to share some of our married couples and their children photos



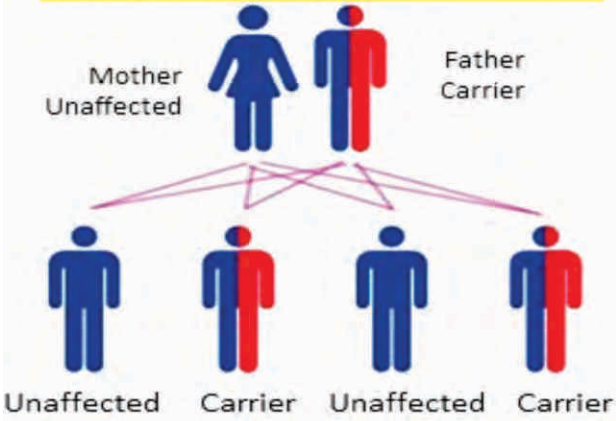
Marriage stands the test of times when both you and your spouse work towards making things better.

Pregnancy is never easy. Moms had to go lot of experience and changes emotionally physically and mentally with some journeys being tougher than others. It is all the more tougher for thalassemia patients but with proper management and care even they can have healthy children.

How can we get Thalassemia / Sickle Cell Anemia?

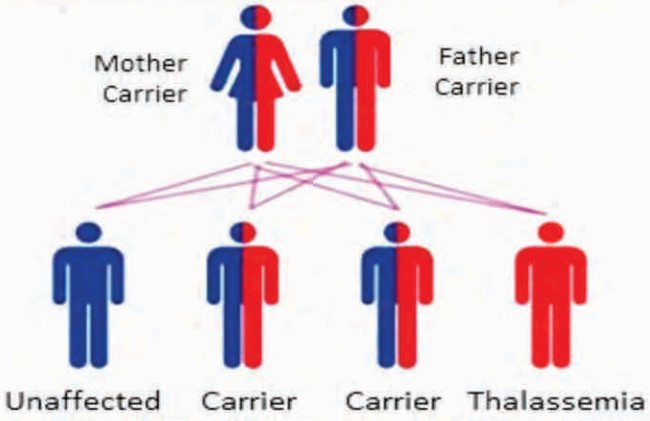
When one parent is carrier

Risk for child to:
> Become a carrier:50%
> Normal: 50%



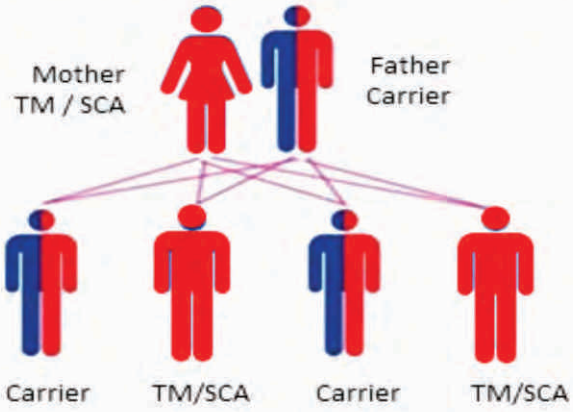
When both parents are carrier

Risk for child to:
> Have TM/SCA: 25%
> Become a carrier: 50%



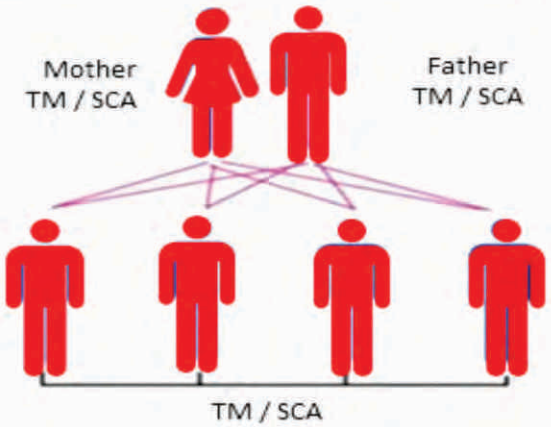
When one parent is a patient and another a carrier

Risk for child to:
> Have TM/SCA: 50%
> Become a carrier: 50%



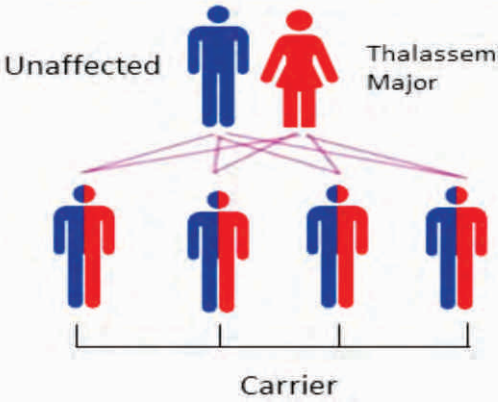
When both parents are patients

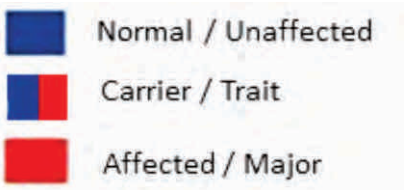
Risk for child to: 25% Normal
> Have TM/SCA: 100%



When one parent is a patient and another is normal/unaffected

All the children will be carriers





TM - Thalassemia Major
SCA - Sickle Cell Anemia

A Word From Visitors

Name: Manjula Soni.
Address: New Delhi.
16 Jan 2020.
Comments: Had the fortune of going around your hospital. Congratulations to the team for the magnificent & noble work done. Karma Shares. Good karma come around. God bless.

Name: Chandrakala
Address: RDO- Rajendranagar RR dist
9649904207.
Comments: Great initiative and great humanity. Good atmosphere.
Chandrakala
Dt. 6/5/2020

Name: Aby Sam John
Address: Regional Head Operations DATRI Blood Stem Cell Donors Registry, Cochin, Kerala
7397772455
Comments: Really impressed and moved by the services offered for Thalassemia patients. Keep doing the wonderful work.
Dt.

Name: Dr. DASARI. SRINIVAS, I.A.S.
Address: Raghavendra Nagar
8885670055
Special Chief Secretary to AP & Telangana.
Comments: A great facility. Committee management supported by devoted doctors and a team of supporting staff. Wish good luck
Dt. 12-05-2020

Name: Dr. Lavanya NJP.
Address: ADCP Admn Cyb.
Visit was during "LOCK DOWN"
Comments: Had a good opportunity to visit TSCS @ Shivrampalli and am impressed by the way such a great work with such humbleness & simplicity. I wish them all the very best.
Dt. 14-04-2020.
Lavanya

Name: MIRZA FEROZ BAIG
Address: Banjara Hills, Hyd.
Comments: Never seen such dedication from individuals for a cause. Congrats to the whole team.
Dt. 9/10/20

Name: Dr. K Saritha
Address: Unit Doctor CTC, Cyberabad
Comments: This is Really great opportunity to visit this place and I appreciate all the members for their hard work and efforts. All the best for your future.
K. Saritha 4/2/2020

Name: Lion [illegible]
Address: District Cabinet [illegible]
9949093338
Comments: This is godly service. I wish and pray if I could be of some help. I have made my mind. I will surely contribute. my [illegible].

Thalassemia

Thalassemia is an inherited blood disorder characterized by decreased haemoglobin production. Haemoglobin is a protein in the red blood cells that carries oxygen to all parts of the body. This leads to excessive destruction of red blood cells, which causes anaemia.

Thalassemia is caused by either a genetic mutation or a deletion of certain key gene fragments. It is of different types viz., alpha thalassemia, beta thalassemia or delta thalassemia based on the genes involved. The most severe form of thalassemia is beta thalassemia major also known as Cooley's anaemia which requires regular blood transfusions and extensive medical care. If untreated their spleen and liver become enlarged due to iron overload and are prone to infections and heart failure which are the leading cause of death among children with beta thalassemia major.

Thalassemia represents a significant health problem worldwide due to its frequency and severity. It affects >400,000 new-born every year worldwide. In India it is estimated that about 10000-15000 babies with beta thalassemia major (TM) are born every year. Beta thalassemia is most prevalent across the country with an average carrier frequency of 3-4%. A higher frequency has been observed in certain communities, such as Lambadas, Malas, Madiga, Mudiraj, Sunni, Sindhis, Punjabis, Gujaratis, Bengalis, Mahars, Kolis, Saraswats, Lohanas and Gaurs.

Thalassemia is inherited in autosomal recessive manner. It develops when both the parents carry the genes for the disorder (either carriers or affected). When both the parents are carriers for thalassemia then there is 25% chance at every conception that the child might be affected.

This disease can be prevented by a simple blood test for HbA2 levels which can be done before marriage or during pregnancy. Bone Marrow transplantation offers a cure for thalassemia but it is costly and requires a Human Leucocyte Antigen (HLA) matched donor. Hence as the adage says “Prevention is better than cure” thalassemia can be prevented by doing a simple blood test for HbA2 levels and reduce the incidence of affected births in the population.

Sickle Cell Anemia

Sickle cell anaemia, (SCA), Sickle cell anemia is the most common blood disorder in India, next to beta thalassemia that requires lifelong management and contributes to infant and childhood morbidity and mortality. It is a genetic disease of the red blood cells (RBCs). Normally, RBCs are shaped like discs, which gives them the flexibility to travel through even the smallest blood vessels. However, in SCA, the RBCs have an abnormal crescent shape resembling a sickle which makes them sticky and rigid and prone to getting trapped in small vessels thereby blocking the blood from reaching different parts of the body. This causes painful crisis in the patients.

It is caused by substitution of valine for glutamic acid in position 6 of the globin chain (GAG to GTG) and is inherited in an autosomal recessive manner. Patients having only SCA are unaware of the disease as they are asymptomatic and can tolerate Hb levels of 7 or 8g/dl. The key difficulty arises only when the damaged sickle erythrocytes occlude the microcirculation blocking the blood vessels and cause episodes of severe pain. It may also be co-inherited with beta thalassemia, causing a condition known as Sickle Beta Thalassemia.

SCA affects millions of people worldwide and is particularly common among those whose ancestors came from sub-Saharan Africa, South America, the Caribbean and Central America, Saudi Arabia, India, and Mediterranean countries like Turkey, Greece and Italy. An estimate of about 250,000 children are born annually with SCA worldwide. It is highly prevalent in the tribal populations of Southern, Central and Western states reaching as high as 48% in some communities. In Telangana SCA is most prevalent in Mandamarri Mandal, Adilabad district and tribal areas of Warangal and Khammam districts.

Bone Marrow Transplantation (BMT)

Chavan Rishi
(left) with HLA matched sibling (Kujitha Priya)

Bone marrow transplantation is a medical treatment that replaces defective bone marrow with healthy bone marrow stem cells donor. The donor is the person who is a Human-Leukocyte Antigen (HLA) match with the patient. BMT is the only permanent cure available for thalassemia patients provided HLA matched donor is present. It is performed in assistance with high-dose chemotherapy to eradicate thalassemia-producing cells in the bone marrow, those of which are then replaced with healthy donor cells. It is the most effective treatment and is shown to have a success of 70-90% in case of matched sibling donor and 36-65% with unrelated donors. The younger the patient, the better the success rate would be.

Harish
(left) with HLA matched sibling (Vishwa Teja)

After successful transplant of these two kids are now free from painful blood transfusions every 3rd week.

BMT team at Sankalp
With Chavan Rishi post transplant

At TSCS, bone marrow transplantation is carried out at a very low cost in collaboration with Sankalp India Foundation, Bangalore, a boon to our patients suffering with lifelong transfusions and complications arising due to iron overload and organ damage.

DONATIONS

Your contribution will help us to provide treatment and management for Thalassemia and Sickle Cell Anemia patients.

All donations to Thalassemia and Sickle Cell Society are exempted under section 80G and 35(1)ii (Research only) 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	40020811564
Account Name:	THALASSEMIA AND SICKLE CELL SOCIETY	THALASSEMIA AND SICKLE CELL SOCIETY
Bank Name:	Canara Bank	State Bank of India
Branch:	Pathergatti Branch, Hyderabad	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

In Continuation to our drive for eradicating THALASSEMIA

FREE HbA2 TEST FOR THALASSEMIA

— For the first time in Telangana—

Please avail the opportunity and Live a Thalassemia Free Life

Thalassemia and Sickle Cell Society

Door No. 8-13-95/1/C, Opp Late to National Police Academy, Raghavendra Colony, Shivaramplally, Rajendra Nagar, Ragareddy Dist. Hyderabad, Telangana – 500052

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