



THALASSEMIA AND SICKLE CELL SOCIETY

*Honoured to meet the
Governor of Telangana*



ANNUAL REPORT 2021



*Inauguration of Antenatal
screening project – Mahabubnagar PHC*



- 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 •

2021 – Initiatives

Screening of Antenatal Women at MGMH, Petlaburj – February 2021



TSCS Blood Transfusion Centre at Khammam – March 2021



Initiation of Antenatal Screening Programme at Rajapur & Balanagar PHCs- October 2021



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Management Committee



Mr Naresh Rathi
Chief Patron



Mr Chandrakant Agrawal
President



Mr Shyam Sunder Loya Ji
Chief Patron



Mrs Ratnavali K
Vice-President



Mr Pradeep Uppala
Chief Patron



Dr Suman Jain
Chief Medical Research Officer & Secretary



Dr D Venkataramana
Executive Member (Ex-President)



Mr M A Aleem Baig
Joint Secretary



Dr Sirisha Rani
Advisory Member



Mr Manoj Rupani
Treasurer



Dr D Rajeshwar
Advisory Member



Mrs Rama Vuppala
Treasurer

President's Message

We are absolutely thrilled by the fact that the TSCS program has brought a miraculous change in the lives, health and well being of patients and their families. Years of selfless, dedicated services are now making their mark being felt by everyone concerned. Decades and decades of toiling is now bearing fruits of health, happiness and joy in the lives of thalassemia children and their families. Building collaborations, enhancing our capabilities and ever-growing services by our Society, have definitely brought a better quality of life to the thalassemia affected and is being universally applauded.

And the beauty of this all is the fact that we are not resting on our laurels, we are not stopping here; as it is just a good beginning for us. Our aim, our mission, our goal, is to serve, serve with more vigour, with more vitality, with more enthusiasm, just to alleviate the suffering of our beloved thalassemia children, and this noble mission shall always achieve the hallmark of sustainability, quality, through optimum use of resources, through education, awareness, information and through unstinted support. With the cooperation of one and all, we have started a new centre in Khammam to serve nearly 200 thalassemia affected children from tribal families, who had no access to medical care till then. Now, the smile on their faces, is the biggest reward one can aspire for.

As you all know, we have embarked on a mission to make our beautiful Telangana – Thalassemia Free forever. Sincerely we hope, and fervently we pray, to all concerned, to please, join our noble mission, please come, be a part of it in whichever way you can. We request all our people to help us make Telangana Thalassemia free by 2025. We earnestly need your enduring commitment and continued support, for transforming ideas into action.

Ceaselessly we are striving for a G.O. by the Government of Telangana, making screening for Thalassemia mandatory. A National Conference by the medical fraternity under the auspices of our society has already been planned to create awareness on the preventive measures. You will be delighted to know that T2 MRI has been made free for all our thalassemia patients. Our Society is also providing weekly screening services through a renowned endocrinologist, Cardiologist, Haematologist, Radiologist & Ophthalmologist.

You will be thrilled to hear that, our thalassemia children are getting cured through bone marrow transplant, that too, almost free of cost. We have aligned with Sankalp Foundation for this life-saving purpose, the cost of BMT being Rs.8.5 Lakhs, the lowest in the world and M/s. Bajaj Electronics Ltd. is funding the same for all the registered TSCS Patients till 2025.

Whatever little, that has started and achieved is nothing but the result of dedicated help received from our donors, volunteers, supporters, staff, colleagues, friends, patients, parents, patrons, office bearers, blood donors & organisers, NGOs, and all concerned. What you have done, can never be captured in words, it can only be felt, we all are totally filled with gratitude for what you have done for the society in the service of thalassemia child. Your unending support has made us what we are, and we shall continue to strive to give our best in the service of society.

Our Staff, Volunteers & medical professionals are really doing amazing work year after year. I honour them. Please accept my heartiest thanks. Thank you one and all.



Mr Chandrakant Agrawal
President

Secretary's Message

We have entered the year 2022, yet our objective remains the same "Save future lives". We want to keep our core values to the utmost importance in fulfilling of our services to Thalassemia Society. We are dedicated to serve the thalassemia affected to the fullest with promise to enhance the physical and emotional wellness of the children, teens & adults.

Due to unawareness among the masses, India has turned up as the Thalassemia capital of the world. Preventive healthcare diagnosis can diminish the risk of transmitting the mutated gene from the parent to the offspring, thereby potentially reducing the number of children born with Thalassemia.

I strongly believe that it's our duty and our responsibility toward thalassemia affected children, therefore, we are courageously marching on to take new challenges and advance in our treatment. We envision research in a holistic perspective, starting from its conception through execution till application or publication phases.

However, it also marks a year of adapting and pushing through many challenges during COVID era and learned how to move forward and manage thalassemia and sickle cell children. We are so fortunate & thankful to have a community of dedicated caregivers who work hard with compassion and respect during these unprecedented time. As we've pushed through the uncertainty, we have met countless opportunities to reflect, refine, realign and revisit what we are doing and move forward with a renewed sense of purpose, hope and gratitude.

We have partnered with International Sickle Cell World Assessment Survey (SWAY) project to know the incidence of VOCs, symptoms and treatment in Sickle cell anemia and have been credited with 3 research papers. I am the committee member for Global Alliance of Sickle Cell Disease Organizations (GASCDO) to give a global outlook to the treatment of sickle cell patients.

I would like to express my heartfelt gratitude toward our donors and supporters for their commitment and dedication towards our Society, who are always there to back us with all possible support.

I look at the employees, Volunteers & the medical professionals and see that all of us are doing this amazing work year after year. I honour you, I am in awe of you, and I am thankful to you.



Dr Suman Jain
Chief Medical Research Officer
and Secretary

About TSCS

Thalassaemia and Sickle Cell Society (**TSCS**) is a registered (Reg. No. 5359) non-profit, non-governmental organisation founded in 1998 represented 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. Since the time we started two decades ago, our priority has always been to provide good services in accordance with latest developments in treatment, management and prevention of the same.

With an objective to provide best facilities to 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 3000 registered patients.

In a day 40-60 patients visit TSCS for consultation, blood transfusion and counselling. We have eminent specialists like hemato-oncologist, paediatric endocrinologist, cardiologist, paediatrician, pathologists, ophthalmologist, dentist, radiologists and research scientists associated with us to provide the best **comprehensive care and cure** for our patients. All the facilities at the centre are **free** which includes consultation, saline washed RBC (SWRBC), blood transfusion, counselling, medicines, investigations, food etc.

TSCS is not just dedicated to make **Telangana Thalassemia free** but also those affected free from thalassemia by getting their **Bone Marrow Transplantation (BMT) done**.

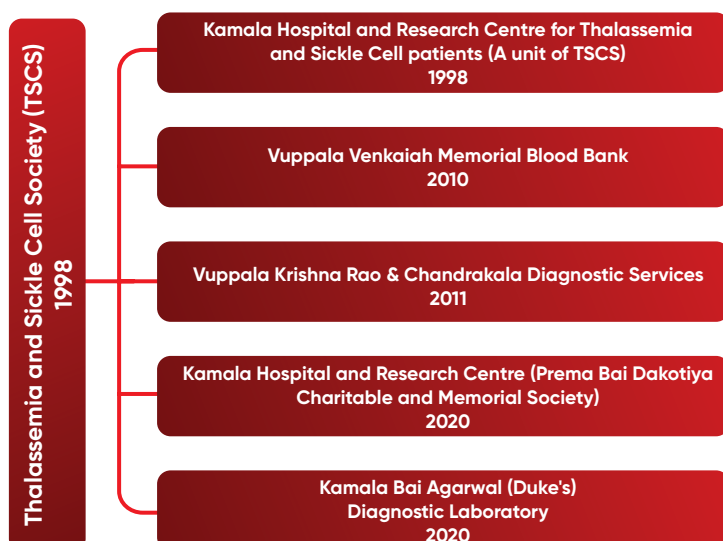
Mission:

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

Aim:

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

Organogram of Society



Ethical Committee Members

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

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 Aejaaz Habeeb	Gastroenterologist
Dr K Gayatri	Pathologist
Dr A Narendra Kumar	Professor of Pediatric Surgery
Dr Chandra Prakash Jain	ENT Consultant

Advisory Members

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

Auditor

NVS Murty & Co.
Secunderabad
Telangana

Banker

Canara Bank
Pathargatti Branch
Hyderabad

Eminent Doctors Working with TSCS

Sl. No	Name of Doctor and Qualification
1	Dr. SUMAN JAIN, MBBS, DCH, Paediatrician, Chief Medical Research Officer
2	Dr. SUJAI SUNEETHA, MBBS, DCP, PhD, 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, PhD, Genetic Epidemiologist (Population)
15	Dr. G PADMA, M.Sc, PhD 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, PhD, Bio-Chemistry
20	Dr. SUDHEER ALURU, PhD Human Genetics, Scientist
21	Dr. MAMATHA, PhD Genetics, Scientist
22	Dr. KURAPATI PRADEEP KUMAR, MBBS, MD (Paediatrician), Khammam
23	Dr. RUDRA GOUTHAM NARESH, MBBS, MD (General Medicine), Khammam
24	Dr. M HARSHAVARDHAN RAO, MBBS, Medical Officer, Khammam
25	Dr. MOHD JULFAKAR ALI, MBBS, Medical Officer, Khammam
26	Dr. R VENUGOPAL, MBBS, MD (Radiologist), Khammam
27	Dr. CHARITHA SRANVANTHI BATTU, MBBS, DNB (Pathology), Khammam

Research Advisory Board

#	Name	Designation	Internal/ External	Organization
1	Dr. M.P.J.S. Anandaraj	Scientist	External	Ex-Director, Institute of Genetics and Hospital for Genetic Diseases, Osmania University, Hyderabad
2	Dr. Q. Annie Hasan	Professor & Head, Dept. of Genetics & Molecular Medicine Senior Scientific Officer	External	Kamineni Institute of Medical Sciences, Hyderabad, Telangana Vasavi Medical Research Center, Telangana, Hyderabad
3	Dr. Kaiser Jamil	Emeritus Research Scientist and Head, Genetics Dept.	External	Bhagwan Mahavir Medical Research Centre, Hyderabad, Telangana
4	Dr. K. V. Radhakrishna	Scientist "D"	External	National Institute of Nutrition, Hyderabad, Telangana
5	Dr. Lavanya M Suneetha	Head- Research & Training Infectious Disease Research Lab	External	CODEWEL Nireekshana, Hyderabad, Telangana
6	Dr. Ashwin Dalal	Head, Diagnostic Division	External	Center for DNA Fingerprinting and Diagnostics, Hyderabad
7	Dr. Shailesh R. Singi	Consultant Hematologist and BMT Physician	External	Century Hospital, Hyderabad, Telangana
8	Dr. S. Sirisha Rani	Consultant, Paediatric Hemato Oncologist	External	Rainbow Hospital for Women and Children, Hyderabad, Telangana
9	Dr. Suman Jain	Chief Medical Research Officer & Secretary,	Internal	Thalassemia and Sickle Cell Society, Hyderabad, Telangana

Achievements – 2021

- ♦ A Major initiative to prevent the birth of Thalassemia and Sickle Cell Anemia children was started by TSCS in February 2021 to screen antenatal women visiting Modern Government Maternity Hospital, Petlaburj, Hyderabad.
- ♦ Another feather in the cap of TSCS... 13 bedded new transfusion centre was started in Khammam for easy access of treatment for patients residing in Khammam and the surrounding districts on 5th March 2021.
- ♦ Having Digital and manual data of 3031 patients
- ♦ 1200-1400 patients are given free blood transfusion every month
- ♦ 19,557 units of blood was collected from 201 voluntary blood donation camps organised with help of donors, politicians, philanthropists, police personnel etc.
- ♦ 1941 HbA2 tests were done for parents, siblings, extended family members of patients and antenatal women. All the tests were done free of cost.
- ♦ TSCS has collaborated with NOVARTIS in a project entitled "Burden of Vaso-Occlusive pain crisis: A Cross-sectional observation of study among patients with sickle cell disease in India (B-VOCAL SCD) to know the burden of pain events in sickle cell disease the medication used for the treatment to study complication and to know the cost of the pain events. 23 centres from all over India have participated in this study.
- ♦ Eleven Thalassemia patients underwent Bone Marrow Transplantation (BMT) in collaboration with Sankalp India Foundation, Bangalore.
- ♦ 3 Mega Blood Donation Camps for Thalassemia and Sickle Cell Anemia patients were organised by Mr Maganti Gopinath garu M L A, Jubilee Hills on occasion of Shri Kalvakuntla Taraka Rama Rao Ji's Birthday at Kotla Vijay Bhaskar Reddy Indoor Stadium, Yusufguda on 24 July 2021, Milad Blood Donation Camp – Focuss and Bajrang Foundation Camp at Guntur
- ♦ Research collaboration with Institute of Genetics, CSIR-Institute of Genomics & Integrative Biology (IGIB), New Delhi, 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)
- ♦ On occasion of Bhagwan Birsa Munda Birth Anniversary, Dr Suman Jain organised SCD virtual workshop between 19th Nov – 23rd Nov 2021, under Ministry of Tribal Affairs, an initiative to bring to the notice of Honourable Prime Minister current scenario of Sickle Cell Disease in following 4 states of India (1st phase) Gujarat, Jharkhand, Andhra Pradesh and Rajasthan
- ♦ With the aim to reduce/prevent Thalassemia births, Screening of Antenatal women was initiated in PHC's (Balanagar & Rajapur) of Mahabubnagar District with the support of District Collector and DMHO on 22 October 2021.
- ♦ Every month 625 Thalassemia and Sickle Cell Anemia children in Telangana and 120 children in Andhra Pradesh received services through Aarogyasri health scheme
- ♦ "Prevention of Hemoglobinopathies through antenatal screening" a prevention project was initiated by Sankalp India Foundation at Bangalore under our able guidance.
- ♦ National Thalassemia Day and Children's Day were celebrated on 15th November with the support of SUN PHARMA Ltd.
- ♦ During the year Three papers have been published in various national and international journals and two are under review
- ♦ ISO 9001:2015 Certificate which is valid for the Scope: Providing services for Thalassemia and Sickle cell anemia in the area of "Diagnostic services, Prevention, Treatment and Cure, Blood Bank, Blood Transfusion and Research and Development.

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 3031 Thalassemia and Sickle Cell Anemia registered patients with age group ranging from 3 months to 50 years, as on December 2021. As children affected with Thalassemia need regular blood transfusions and management throughout their life, all the registered patients receive free services. The programme seeks to increase the lifespan and improve the quality of life of marginalised and poor families affected by Thalassemia and Sickle Cell Anemia. As the treatment and management is expensive many families are unable to afford the treatment. We are striving to give these children full support and strength in painful crisis. We also wish to develop confidence in Thalassemia and Sickle Cell Anemia children to lead a near normal life.

The details of 3031 patients registered in the society since the inception in 1998 are given below.

Demographic Details

Diagnosis	Telangana	Andhra Pradesh	Other States	Total (India)
Thalassemia Major	1432	535	68	2035
SC - Sickle Cell Anemia	179	31	7	217
SBT - Sickle Beta Thalassemia	466	94	1	561
Thalassemia Intermedia	52	8	2	62
E Beta Thalassemia	71	20	9	100
PRCA - Pure Red Cell Aplasia	33	17	1	51
Others	2	0	3	5
TOTAL	2235	705	91	3031

Consanguinity

YES	1489
NO	1542
TOTAL	3031

Total New Registrations (Khammam)	HPLC tests (Antenatal)	CVS Referred to NIMS & CDFD	HLA Typing with DKMS	Splenectomy
229 (44)	1941 (1028)	43	550	5

Age Group wise Patients

Age	No. of Pts
0-5 Yrs	342
6-10 Yrs	593
11-15 Yrs	804
16-20 Yrs	531
21-15 Yrs	396
26-30 Yrs	188
Above 31 Yrs	177
TOTAL	3031

Classifications of Disease - 2021

Type of Disease	No
Thalassemia Major	135
SC - Sickle CellAnemia	45
SBT - Sickle Beta Thalassemia	31
EBT - E-Beta Thalassemia	12
Thalassemia Intermedia	3
HDT - HbD Thalassemia	2
HS - HSpherocytosis	1
TOTAL	229



By continuous and aggressive counselling and follow-ups 43 parents went for Prenatal Diagnosis (PND), out of which 12(28%) foetus were found to be affected. In 11(91.6%) of these cases parents followed the protocol. Thus, saved children affected with Thalassemia from taking birth.



Blood Bank

Blood Transfusion Service is a vital part of the health care service. Increasing advancement in the field of Transfusion Medicine and Technology has necessitated enforcing measures to ensure quality of Blood and its products. In order to improve the standards of Blood Bank and the Blood Transfusion services, well-equipped blood centre with adequate infrastructure and trained manpower is an essential requirement.

Blood bank means, a centre within an organization or an institution for collection, grouping, cross-matching, storage, processing and distribution of whole human blood or human blood products from selected human donors.

Thalassemia and Sickle Cell Society Vuppala Venkaiah Memorial Blood Bank (TSCS-VVMBB) was started 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 have 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 kids and also caters to the needs of nearby hospitals in a month.

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

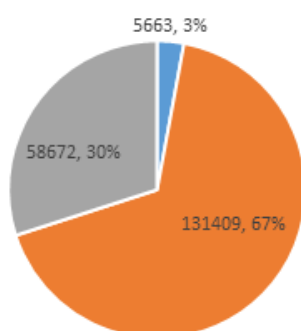
We are very much indebted to all our organisers and donors who supported us during this COVID-19 crisis and came forward to save the lives of hundreds of our patients. The following are few of our Major and Regular Blood Donation Camp Organisers:

1. **Milad Blood Donation – Focuss, Afzal Gunj**
2. **Hyderabad, Cyberabad and Rachakonda Police Commissionerate**
3. **Mr Maganti Gopinath garu M L A, Jubilee Hills**
4. **Bajrang Foundation at Guntur**
5. **Zindagi Foundation, Shamshabad and many more voluntary organisations/individuals.**

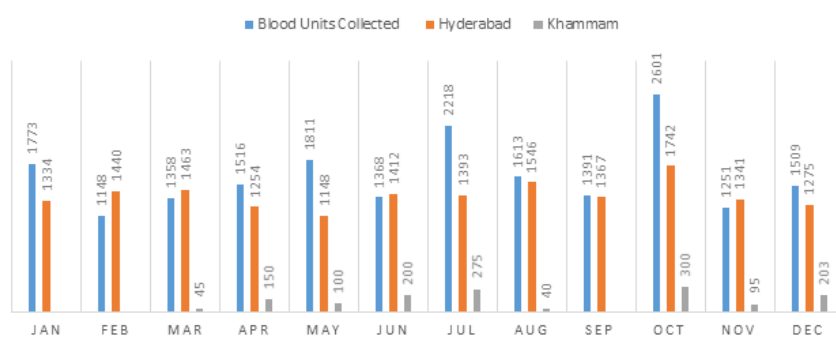
The following are few achievements of our Blood Bank:

- ♦ **Total number of blood units collected: 1,95,744**
- ♦ **1,31,409 (67%) units of blood given to Thalassemia children**
- ♦ **2411 Voluntary Blood Donation camps were organised till Dec 2021**

Blood Bank Details - 2010 to 2021



BLOOD UNITS ISSUED TO THALASSEMIA PATIENTS 2021



■ Discarded ■ Thalassemia patients ■ Govt and General issues

VUPPALA KRISHNARAO CHANDRAKALA DIAGNOSTIC 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 this year 1941 people were screened for Thalassemia and Sickle Cell Anemia (HPLC test), the details of which are as follows:

Type of Disease	No of Persons
Normal	1362
Thalassemia Trait	394
Sickle Carrier	113
Sickle Cell Anemia	18
HbD	17
Sickle Beta Thalassemia	12
Thalassemia Major	11
Delta Beta Thalassemia Trait	8
E Thalassemia carrier	2
E Beta Thalassemia	2
Thalassemia Intermedia	2
Grand Total	1941

Sl.No	Test Name	No of Tests
1	Complete Blood Picture (CBP)	20,200
2	Ferritin	3,200
3	Ft4	900
4	T3	140
5	T4	140
6	TSH	1,000
7	CUE	80
8	LFT	2,400
9	LIPID Profile	220
10	Blood Urea	500
11	Sr. Creatinine	3500
12	Sr. Uric Acid	270
13	Glucose	1400
14	Sr. Calcium	1200
15	CRP	240
16	HbSAg	1500
17	HIV	1500
18	HCV	1500
19	Malaria	200
20	Dengue NS1	200
21	Vitamin D3	900
22	Widal	350
23	Blood Grouping	150



Research Laboratory

Thalassemia and Sickle Cell Society has established a well-equipped Molecular Research Laboratory viz., Kamala Hospital and Research laboratory (supported by Prema Bai Dakotiya Charitable and Memorial Society) to carry out different research activities pertaining to the diagnosis and improvement of the quality of life of the patients affected with thalassemia and sickle cell anaemia.

Studies carried out at molecular research lab

- ♦ Various molecular techniques have been developed to screen for alpha, beta, delta genes to detect mutations causing beta thalassemia, sickle cell anemia, alpha thalassemia and delta beta thalassemia. So far, we have detected the causative mutations in around **500 patients** with some showing a rare phenomenon of **pseudodominance** in the inheritance of the disease.
- ♦ Collaborated with ChroGene Aarogyam Biotech Private Limited to develop **a non-invasive device for detecting sickle cell anemia**.
- ♦ Collaborated with CSIR Institute of Genomics and Integrative Biology, New Delhi and are working on **studies related to stem cells**.
- ♦ Participated in the **Sickle Cell Assessment Survey** conducted by Novartis to evaluate the impact of the disease on patients suffering with sickle cell anemia.

Screening of Antenatal Women for Thalassemia and Sickle Cell Anemia as a step towards prevention:

Initiated an **antenatal screening program for thalassemia and sickle cell anemia at government maternity hospitals in Hyderabad and Mahabubnagar** to screen for carriers among antenatal women who are in the 1st trimester of pregnancy. In case of carrier women husbands will be screened for thalassemia and sickle cell anemia. If both the couple are found to be carriers they will be counselled to go for prenatal diagnosis and if the fetus is found to be affected then the parents are advised to follow the protocol. This would help in preventing the birth of affected children which would reduce the incidence of the condition in the population.

Details of Antenatal women screened and carriers detected:

Carriers Detected	Modern Government Maternity Hospital, Petlaburj	Primary Health Care Center Rajapur, Mahabubnagar Dist.	Primary Health Care Center Balanagar Mahabubnagar Dist.	Total
Total no. of Antenatal Women	836	76	89	1028
Thalassemia	25 (2.99)	2 (2.63)	2 (2.24)	29 (2.82)
Sickle cell anaemia	7 (0.83)	3 (3.9)	-	10 (0.97)
Sickle Beta Thalassemia	1 (0.11)	-	-	1 (0.09)
HbD (Punjab)	2 (0.23)	-	1 (1.1)	3 (0.29)
Delta Beta Thalassemia	1 (0.11)	-	-	1 (0.09)

- ♦ Of the 1028 antenatal mothers screened for thalassemia, a carrier frequency of around 2.8% has been found for Thalassemia. This program has helped us to create more awareness among the antenatal mothers about thalassemia and sickle cell anemia which is a preventable genetic disorder.
- ♦ Iron overload is one of the major complications in thalassemia leading to cardiac and liver problems. However, in some patients the iron overload is more as compared to others inspite of less number of transfusions. In order to account for this variability, we are now working on the genes involved in iron metabolism

Ongoing Research Projects: 3

Projects Submitted for Funding and Under Review: 3

Research Papers Published (Thalassemia and Sickle Cell Anemia): 16

Papers under Communication: 1



Advance Diagnostic Laboratory

Kamala Bai Agarwal (Duke's) Diagnostic Laboratory was setup in 2020 to provide advanced services to our Thalassemia and Sickle Cell Anemia patients under one roof. The laboratory is equipped with modern instruments including **Digital X-Ray, ECG, T2 MRI, Ultra-Sound and 2D-ECHO cardiogram offering free testing to all our patients.** As Thalassemia and Sickle Cell patients are prone to iron overload and painful crisis respectively, they have to be screened regularly to monitor their growth and organ functions. Availability of these facilities under the same roof aids in offering better treatment for our patients.

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

Doctor/Centre Name	Tests	No. of Patients
Dr Swetha, Consultant	Radiology	542
Dr Raghavendra Goud, Consultant	Cardiology	435
Dr Sandhya & Dr Varshini, Consultant	Haematology	377
Dr Anuradha Kulkarni, Consultant	Ophthalmology	224
Dr Amarnath Kulkarni, Consultant	Endocrinology	195
Dr. Vijay Bhaskar Noori, Vista Diagnostics	T2 MRI	120
Dr Sampath Reddy, Rohini Foundation	Dental	850

THALASSEMIA AND SICKLE CELL SOCIETY – KHAMMAM

With a vision to extend its services to all the patients Thalassemia and sickle Cell Society has a moved a step forward to spread its centres across Telangana and Andhra Pradesh. As an initial step it has opened a new centre with 10 beds at Khammam, to support the patients coming from the surrounding districts. TSCS has collaborated with Vijayasri Blood Bank, Khammam to provide safe blood to thalassemia patients at free of cost. Our Khammam centre got empanelment under Telangana Aarogyasri Health scheme to avail free services for our patients.



Counselling Report

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

1. Genetic counselling

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

2. Planned pregnancy

Parents of Thalassemia children are made aware of prenatal diagnosis to prevent the birth of affected children. As a part of it, they are advised to get the DNA of the patient done. Following the results of CVS (Chorionic villus sampling) test or amniocentesis (arranged in association with NIMS hospital), parents are counselled about the possible options of continuing or discontinuing the pregnancy. In 2021, a total of 43 PNDs were arranged of which 12 foetus were found to be affected and 31 unaffected. Of the 12 affected, 11 did not want to continue the pregnancy and they followed the protocol while one continued with the pregnancy in spite of repeated counselling about the risk of bearing a thalassemia child.

3. Extended family screening

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

4. Maintenance of patient health

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

5. Quality of Life

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

6. Counselling for BMT

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



Donor List

#	Donor Name
1	A S Iron & Steel
2	Abdul Rahman
3	Adv Chemical Pvt. Ltd.
4	Aim Asia
5	Alpha Shah
6	Aman Sonia
7	Amir Ali Dharani
8	Anish Goyal
9	Anjum Hudda
10	Ashoka Beera
11	Bharat Bhushan Agarwal
12	Bharath Chadalavada
13	Bimal Behari Prasad
14	Blend Colours Pvt.Ltd.
15	C. Vanthabhanu
16	Ch. V. S. R. Krishna
17	Ch. Shashidhar Reddy
18	Ch. VSR Krishna
19	Chandrakant Agarwal
20	Chrogene Aarogyam Biotech Pvt. Ltd.
21	Debabrata Saharay
22	Deccan Switch Gears
23	Dr. Anupama Srikanth Alluri
24	Dr. C. Anupama Reddy
25	Dr. Sahitya Koneru
26	Dukes Products India Ltd.
27	Faequa Syed
28	G. Sai Srujana
29	Gemini Prakash Kollipara
30	Give Foundation
31	Give India
32	Giving Foundation
33	Global Steels
34	Hari Om Pipe Industries Ltd.
35	Harsh Jain
36	J. N M Rao
37	J. Santhosh Kumar
38	J. Santosh Kumar
39	K. Srinivasa Rao
40	Kabir Hudda
41	Kadiyala Srinivasa Rao
42	Kumar Enterprises
43	Lions Club of Hyderabad Jeddimetla
44	M. Abhigna
45	M. Narsimhulu
46	Madhuri Chinta
47	Md. Khaja Mohiuddin
48	Mediseti Durga Latha
49	Mitesh Ahuja
50	Munna Trust
51	Murali K Siripurapu
52	N. Usha Rohini
53	Naresh Pothula
54	Naresh Rathi
55	Narsimulu Arigala
56	Narsinga Rao
57	Nasscom Foundation
58	New Life Foundation

#	Donor Name
59	Novartis Healath Care Pvt. Ltd.
60	Pallavi Jain
61	Parag H Shah
62	Parag H Shah
63	Prabhmeet Singh Bhatia
64	Prasanth
65	Prema Bai Dakoia Charitable and Memorial Society
66	Prof Rajkumar
67	Prof. V. R. Rao
68	Mahesh Kumar Agarwal
69	Rajnaveen Rajendran
70	Ram Chander
71	Ramesh Ellanti
72	Ramesh Govindula
73	Rathod Ram
74	Richa Tripathi
75	Rishi Saket
76	Rozina Jiwani
77	Ruthwik & Kushal
78	Saiteja Nangunoori
79	Sameer Agrawal
80	Sangeeta Jain & Virendra Jain
81	Sangeeta Modi
82	Sarfaraz Banatwala
83	Seema Dharani
84	Shrinath Rotopack Pvt. Ltd.
85	Siva Kumar Gorantla
86	Smt Banarsai Bai
87	SPP Poly Pack Pvt. Ltd.
88	Sree Krishna Automotive Pvt. Ltd.
89	Sreekanth Katar
90	Sreyas Holistics Remedies Pvt. Ltd.
91	Sri Babulal Jain (Sanklecha)
92	Sri Krishna Jewellery Mart
93	Sri Nav Durga Textile Processors Pvt. Ltd.
94	Sri Navadurga Billets Pvt. Ltd.
95	Srikanth Gullapalli
96	Srinath Rotopack Pvt. Ltd.
97	Sriram Gopal
98	Sudha Prashant Medha
99	Sujeet's Cricket Academy
100	Suman Dhawal
101	Sunkari Shyam Sunder
102	Sunkari Shyam Sunder
103	Supreme Agencies
104	Suyeb Alam
105	Swarnangsu Acharyya
106	Teradata
107	V. Balaveerah & Sons
108	Venkat Reddy
109	Venkatadri Divvala
110	Venkatarama Vegesna
111	Vipul Chawla
112	Y. Vijay Kumar
113	Yerram Remesh
114	Yuva Vega Nova
115	Zoi Health Pvt. Ltd.

ACADEMIC/PROFESSIONAL ACHIEVEMENTS 2021:

Professional Degree	Working	
Ramya - Aeronautical Engg.	Harshith – Infosys	Sushma- Google
Md Sufiyan, B.Tech 3rd Year	Krishnam Raju – Own Laboratory	Shirisha – Med. Transcription
Ameena - MBA	Manisha – Honda Showroom	Usha Shri Beniya - LVP Eye Hospital
Vishwa Teja - M.Tech	Jyothi – GNM Nurse at General Hospital	Sai Aditya – Namasthe Telangana
Ankita - B.Tech	Swathi - Google	B Shiva Kumar - TSCS
Prashanth - Diploma Elect	Sai Srujana - Genpact	G Srikanth - Oracle
Sai Krishna - Polytechnic	Hori Krishna MBA – Part time	Rahul
Amisha Patel – MBA 2nd year	Dr. Azra Fatima - Researcher at Learn Maximum PC polyclinics	Khaza Nadeemuddin - 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,	Osman Pasha - Video Mixing
Sumaira Fathima, MBA	Suvarsha - Panchayat Secretary	Md Rahemuddin – Private Job
Nikunj Patel – MBA 1st year	Ms Swathi - Private Job	M Priyanka - TSCS
Arsheen Baig- BSc Nutrition	Aditya – Computer Operator, District Civil Supply	Krishna Chaitanya - Animation
Saroj Kumar Samal, B.Tech	Elisha - AGS Co.	Souvik Bose - Wipro
Manirath goud B.Tech	Yesupaul – Wipro	Raghavendra - Tech Mahendra
Bargav – Diploma 3rd Year (Mechanical Engineer)	Raghav, Own Business	Mukhram Ali - Activa Show room
SK Riyaz – B.Tech 2nd Year	Nooruddin - Own Business	Chanakya Reddy – Own Business
Yogita - BBA	Krishna Chaitanya - Business	Tagore Naik – Electricity Dept., Paleru
Noorunnisa – M.Com	Swamy – Newspaper Business	Mubeena – HSBC
B Prem Sagar – B.Tech 3rd Year	Lovely-Fashion	Ramakrishna Tandra – Indusind Bank Ltd. as Branch Credit Manager
J Ravi – B.Tech	Rishab - Wipro	Arsheen Fathima - Clinical Nutrition & Dietetics
Sourabh Misra, MBBS 2nd Year	Shivani Mundada- Tally(IT Filing)	Soujanya, MSC Biotechnology
Rafiya Sultana – MBBS 1st Year	N. Venkateswarlu – Auto Driver	Ravinder, Tribal Welfare Association – Gurukul
V. Sravya Teja – M.Tech	Asfaq Koundinya - Business	Pavan – Business
Shaik Omer – BBA	Pharameshwari – Business	Kiran – Accenture
Shaik Omer – BBA	Nithya – Sankalp India Foundation	Neelima – Lab Technician

Thalassemia and Sickle Cell children studying at various levels

SSC - 20	Intermediate –20	Graduation – 48
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All India Payam E Insaniyat Forum(AIPIF) East Zone – Hyderabad

◆ Krushi Foundation

◆ Aaradya Physiotherapy Clinic



◆ Commissioner Police Anjani Kumar IPS

◆ MS Education Academy, Masab Tank

◆ Quli Qutub sha Polytechnic College



◆ Smt. Gadwal Vijayalaxmi Mayor Greater Hyderabad(GHMC)

◆ Mr Maganti Gopinath garu M L A, Jubilee Hills





- ◆ Sri. Anil Kumar, IPS.,
- ◆ Sri. L. S.Chowhan, IPS.
- ◆ Masjid -e- Raheem Khan, Karwan
- ◆ YSR Telangana Party
- ◆ Mahakali Temple, Uppuguda
- ◆ Forum for Cultural Upgradation & Social Service (FOCUSS)
- ◆ Milad Blood Donation Committee
- ◆ Telangana Meeseva Federation
- ◆ Karma Team





◆ Bajrang Foundation, Guntur

◆ Insaan Foundation

◆ Sunni United Forum of India

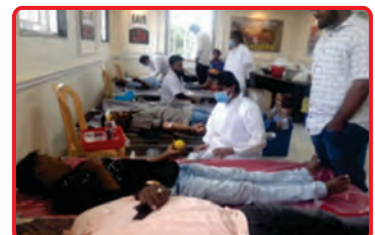
◆ Production House

◆ All India Payam E Insaniyat Forum

◆ All India Marwadi Yuva Manch

◆ Aarya Kshtriya Samajam, Patancheru

◆ Azad Studio





◆ Team Ganashraya

◆ Rajendranagar Police Department

◆ R R Charitable Trust

◆ Hyderabad Traffic Police Department

◆ Varun Motors, Begumpet

◆ Vijaya Nursing Home (Dr Uma Maheswara Rao)

◆ Somavamshi Arya Kshatriya Samaj

◆ Rane Engine Valve Limited, Azil Nagar, Plant - 4, Hyderabad

◆ Paravasthu Foundation

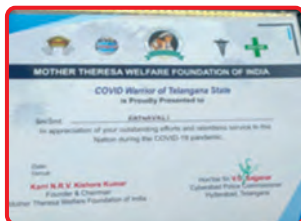
◆ Ramky Foundation



News And Events

07th March 2021

Mrs Ratnavali, Vice President, TSCS was felicitated by Commissioner of Police Sri Sajjanar with Covid Warrior Award on 07th March 2021



21st January 2021

Mr. R. Sanjay Kumar IPS Officer was welcomed by our President Chandrakant ji on 21 January 2021



23rd January 2021

Our President Sri. Chandrakant Agarwal ji was felicitated with NETAJI SAMAJ RATNA award for his best services towards Thalassemia children in Telangana by Hon'ble Health Minister Sri Etela Rajendra garu on 23 Jan 2021



7th February 2021

Thalassemia and Sickle Cell Society team Mr Chandrakant Agarwal, President; Shri. V.S.R. Murthy, Advisor; Dr Suman Jain, Secretary and Mrs Ratnavali K, Vice President had an opportunity to meet Honorable Governor Shri Dr Tamilisai Soundararajan on 07 Feb 2021 to brief about activities of our Society and discussed about reducing the burden of Thalassemia and Sickle Cell Anemia in Telangana State and work towards achieving the goal of "Thalassemia Free Telangana"



18th March 2021

Dr Suman Jain participated in the webinar on 'Integrating newer therapies in SCD' as panelist on 18 Mar, 2021 and briefed about 'Vaso-occlusive crisis of SCD'

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Dr Suman Jain participated in the webinar on 'Integrating newer therapies in SCD' as panelist on 18 Mar, 2021 and briefed about 'Vaso-occlusive crisis of SCD'

8th May 2021

Interactive session of Dr Suman Jain and Dr Saroja K with Thalassemia patients as part of webinar organised by Sun Pharma Pvt Ltd. on occasion of World Thalassemia Day

22nd May 2021

Dr Suman Jain participated in "GASCDO 2021 Annual General Meeting" organised by Global SCD. Dr Suman Jain from TSCS is one of the member in the Organising Committee

23rd May 2021

President Chandrakant Agarwal ji and Secretary Dr Suman Jain participated in the pre-launch webinar on "S01E53 - SICKLE CELL DISEASE NEWER THERAPIES", under the aegis of Mumbai Hematology Group (MHG)

23rd May 2021

Dr Suman Jain and Dr Saroja K participated in the webinar on "CHALLENGES IN THE DAY TO DAY MANAGEMENT OF THALASSEMIA", Organized by Thalassemics India & Thalassemia Patients Advocacy Group.

10th June 2021

Visit by Mrs Poornashanthi from Sri Sai Shanthi Sahaya Seva Samithi who helps physically challenged people and widows. She distributed groceries worth Rs.35,000/- to our patients on 10 June 2021 along with Dr Saroja K. A great relief to the families whose income was affected due to COVID pandemic.



16th June 2021

Dr. Suman Jain was the Program Director for the webinar: How We Treat- Sickle Cell Disease – Regional Recommendations on VOC prevention which was organized NOVARTIS.

18th June 2021

Dr Suman Jain and Dr Saroja K participated in the Webinar on Reimagining SCD in India: Expert Conclave – on eve of WSCD 2021 organised by National Cancer Society and Manage Health Foundation..

19th June 2021

♦ Dr Suman Jain participated in Second National Conclave webinar on 'Sickle Cell Disease in India' on 19th June 2021 to mark the World Sickle Cell Day organised by FICCI under the guidance of Ministry of Tribal Affairs (MOTA) and in partnership with members of the National SCD Council. The event was inaugurated by the Honourable Union Ministry, MOTA, Shri Arjun Munda Ji, who also released the Economist report on India SCD scenario and launched the Ministry's SCD portal.

♦ On occasion of World Sickle Cell Anemia Day 2021 – Mrs Rathnavali K was live on 101.9 FM Radio

10th July 2021

Visit by Sri Maganti Gopinath garu, MLA, Jubilee Hills and his team on 10th July 2021 to discuss the arrangements of Mega Blood Donation Camp organized on the occasion of TRS Party Executive President, Minister Sri KTR's Birthday



14th July 2021



Awareness and counselling given to Thalassemia patient's parents/volunteers who came from Kurnool, Andhra Pradesh.



31st July 2021

FREE HPLC testing camp organised by TSCS on 31 July 2021 for Extended family members of Thalassemia patients at Kurnool in the process of achieving Thalassemia Free India by creating awareness and initiating prevention program.



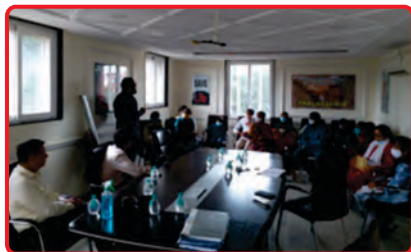
15th August 2021

TSCS celebrated independence day with gusts, board members, staff, patients and their parents.



19th August 2021

Visit by Mr Abhijit and Mr Santhosh of Sankalp India Foundation to interact with patients who are ready for BMT.



29th August 2021

Visit by a team from Mahbubnagar Collectorate on 31 Aug 2021 to see the facilities provided to thalassemia patients at TSCS and discuss on the initiation of antenatal project at PHCs in Mahabubnagar district.



4th September 2021

Donation given by Sri Narsing Rao garu and Smt. Padma garu from Manikonda on 4 Sept 2021 for the welfare of Thalassemia children.



22nd September 2021

Inauguration of new premises of Sankalp India Foundation at Bangalore being attended by President Mr Chandarakant Agarwal.



25th September 2021

Dr Suman Jain participated in the webinar on " β -Thalassaemia & Myelodysplastic Syndrome(MDS) : Medical Advisory Board". She is the member of Medical Advisory Board". For the launch of the drug Luspatercept of Bristol Myers Squibb for Thalassemia treatment.

The highlights of the meeting were:

1. To take insights on disease epidemiology of β -Thalassaemia & MDS.
2. To take insights on safety and efficacy data of Luspatercept in β -Thalassaemia & MDS based on BELIEVE & MEDALIST trial.
3. To understand appropriate Patients who will benefit the most with Luspatercept in β - Thalassaemia & MDS
4. To take insights on the educational unmet need of Haematologists/ physicians regarding education on Luspatercept in β -Thalassaemia & MDS

25th September 2021

Review meeting conducted for Extended family members at Kurnool by TSCS team for patient's parents as a part of Thalassemia Prevention.



15th November 2021

Drawing competition organised by SunPharma for our patients on occasion of Children's Day on 15th Nov 2021 and distribution of gifts



16th November 2021

Visit by Mr. Ambati Murali Krishna Garu of Bajrang Foundation, Guntur to our Society on 16 November 2021.



17th-21st November 2021

Dr Suman Jain was given opportunity to co-ordinate with 4 state coordinators in organizing the SCD workshops on the occasion of Bhagwan Birsa Munda Birth Anniversary week by Ministry of Tribal Affairs, to work together towards creating awareness about SCD which is being neglected.

#	State	Coordinator	Date
1	Jharkhand	Dr. Anupa Prasad	19th November 2021
2	Andhra Pradesh	Dr. Chaitanya Kumar	20th November 2021
3	Gujarat	Dr. Umang Mishra	22nd November 2021
4	Rajasthan	Dr. Pradeep Dwivedi	23rd November 2021

19 November 2021

Shri Aleem Baig, Joint Secretary, TSCS felicitated with "Seva Ratna Legendary Award" by Sri Dr. SK Joshi Garu former Chief Secretary Telangana and Sri Justice G Chandra, State Human Rights Commissioner and other dignitaries. His services to Thalassemia patients were recognized and praised.



30th November 2021

Shri Aleem Baig, Joint Secretary, TSCS felicitated with "Seva Ratna Legendary Award" by Sri Dr. SK Joshi Garu former Chief Secretary Telangana and Sri Justice G Chandra, State Human Rights Commissioner and other dignitaries. His services to Thalassemia patients were recognized and praised.





TSCS Blood Warriors



AAROgyasRI



**Aarogyasri Health care Trust
Government of Telangana**

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



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

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



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

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



TSCS has 625 patients from Telangana state and 120 from Andhra Pradesh who are availing this facility since last 8 years.

All the health care services under Aarogyasri scheme are cashless.



Case Study



Md Khalid is one among those unfortunate boys who is diagnosed with thalassemia at 8 months of age. His parents sought medical attention when their lively, happy baby experienced a drop in energy level and looked pale. His parents were shocked by the diagnosis, and initially thought the doctors made a mistake. They couldn't understand how their son ended up with thalassemia, a genetic blood disorder they never heard of or even aware of it in any of their extended family members.

In some of the Indian societies people still do not have any idea about thalassemia, they always blame mothers for such birth, and try to search for all possible issues in the mother. Something similar happened in Khalid's case.

Thalassemia patients and children go through the painful process of blood transfusions for several years in their life impacting their upbringing both physically and physiologically. Considering the cases of thalassemia in India, the disease burden is significant and requires lot of attention. A Hematopoietic stem cell transplant (Bone Marrow transplant BMT) is the only curative intervention available for a transfusion-free status with a normal life span for Thalassemia patients.

The challenge of living with thalassemia is something Khalid and his parents know and hence they have a better understanding. Since the age of



8 months, he has spent much of his life in TSCS receiving transfusion therapy. Khalid's mother expressed "if possible I would take the disorder from my son without hesitation – I would take it all in his place – but I have to accept that this is his disorder. I can be his source of support and guidance, and when appropriate I can be an advocate for him. Mostly however, I have let him deal with it and hope that he will be one to prevail."

Khalid is 17 years now getting trained in Mee-Seva to provide financial support to his parents, on a longer run he would like to be a builder. He is different from the rest of his family members quite silent from his other brothers & sister.

This is what Khalid has to say, "I would never have been able to handle all of the challenges associated with thalassemia had I not had a family that was willing to reach TSCS, and this society provides all the medical care that we needed to deal with such a demanding disorder. And they have always been willing to give up a lot of their time to make sure I can stay healthy."

Khalid is extremely grateful to TSCS for the expert care they give out of the rich experience and knowledge the doctors have, that enables many thalassemia kids lead a healthy and fulfilling lives.

Visitors

Name	Hbsh Ibrahim	Comments	A very good, well organized, well equipped and excellent centre. Commendable work!
Address	Macedpally Secunderabad		
		Dr.	
Name	Moud Usseem	Comments	Moud Usseem, Very good center, well equipped, good staff, good doctors, good work.
Address	Maddurpet Kalyandurg		
		Dr.	
Name	Ruksana Sultan (consultant)	Comments	A wonderful hospitality. Organised work well. Good staff and organization. Working forward to the work.
Address	Eva care clinic (frangipani)		
		Dr.	
Name		Comments	One, thankful to my friend for giving this opportunity for visiting the society.
Address			
		Dr.	

[illegible]

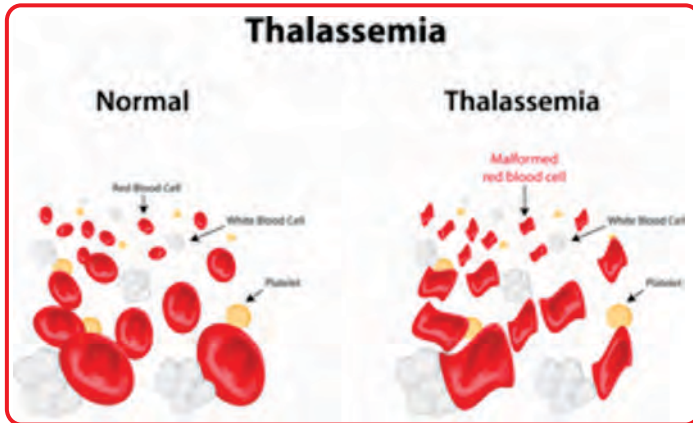
Name	Dr. G. Santosa	Comments	Very impressed with facility and and in particular research lab.
Address	Mamata Academy of Medical Sciences, Bhatnagpally.		
			Dr.
Name	DR. P. MURALI DHAR SUPRAN	Comments	Very developed
Address	MAMATA RING HOSPITAL 9848039174		Work in the line of Sick cell - d also Research Little - in College - 25/3/24
Name	Dr. Sai Shanti (M.B.B.S)	Comments	
Address	C/O Anuradha Padmanathan FOOT, Acute Windchimes Ph - 7415 682703		Very well managed centre - noble cause
			Dr.
Name	E. Poorneshanthi	Comments	Sri Sai Shanti
Address	8-6-706/15/19 East Highline Plaza S-ges Road - Sec020		Sabaya Seva Samithi 99666 55388 "Extant Success"
			Dr.

Name	SANJAY KUMAR . R	Comments	I never seen this type of decision any where. God has created some people with deformity. Some are God has created you with great heart and helping hands. I decided I will be witness in future of this thing.
Address	ACP RAGENDRANAGAR.		Dr. 21/1/21
Name	Dr. I. C. K. Radhika	Comments	
Address	Minolepale Corachapara Hyderabad.		Highly impressed with the facility of construction of this project of the organization. After thinking here, I strongly
Name		Comments	like that. That's all. I like this idea. It is not very far. Do it. Raising two years. Pishori.
Address			Dr.
Name	Prasanna Roy	Comments	
Address	Bisnampur Chatterjee		We support Societies Vision of eradicating Thalassemia by 2031.
	NOVARTIS		Happy to be Rose Diology

Thalassemia

Thalassemia is preventable inherited blood disorder characterised by less oxygen-carrying protein (haemoglobin) and fewer red blood cells in the body than normal.

Patients may experience: Anaemia, fatigue, or weakness, failure to thrive, iron overload, pallor, shortness of breath, or yellow skin and eyes, bone deformities etc.



It is estimated that about 1.5% of the global population are beta thalassemia carriers, with about 60,000 symptomatic individuals born annually. India has the largest number of thalassemia children in the world with about 1 to 1.5 lakhs and 10,000 - 15,000 babies born every year with thalassemia.

Some babies show signs and symptoms of thalassemia at birth; others develop them during the first two years of life. The disorder is diagnosed by CBP, HPLC (Hb electrophoresis).

Thalassemia is caused by mutations in the DNA of cells that make hemoglobin. The mutations associated with thalassemia are passed from parents to children. Hemoglobin molecules are made of chains called alpha and beta chains that can be affected by mutations. In thalassemia, the production of either the alpha or beta chains are reduced, resulting in either alpha-thalassemia or beta-thalassemia.

Treatment includes Vitamin supplements, blood transfusion and iron chelation

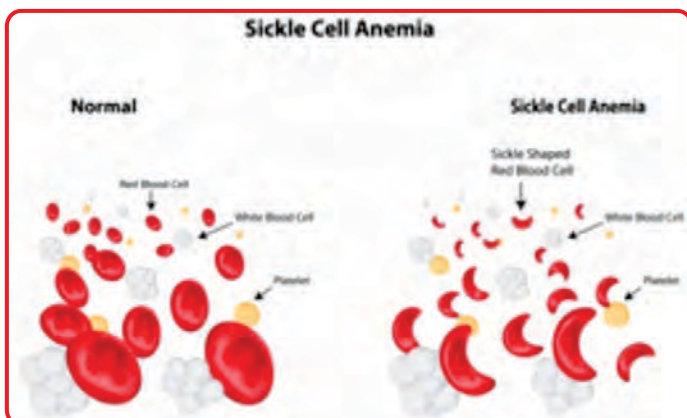
Cure is Bone Marrow Transplantation

Sickle Cell Anaemia

Sickle cell disease, an inherited group of disorders, red blood cells contort into a sickle shape. The cells die early, leaving a shortage of healthy red blood cells (sickle cell anaemia) and can block blood flow causing pain (sickle cell crisis).

Infections, pain and fatigue, yellow skin and eyes, pallor, shortness of breath are symptoms of sickle cell disease.

Treatments include medication, oral fluids, vaccination, blood transfusions and rarely a bone-marrow transplant.



Sickle cell anemia is highly prevalent in Middle east, Mediterranean regions, Southeast Asia and Sub Saharean African, India, it is prevalent in the tribal and non tribal groups like the scheduled castes and other backward classes belonging to low socio economic status with carrier frequencies ranging from 1-40%.

Bone Marrow Transplantation (BMT)

A bone marrow transplant is a medical treatment that replaces defective bone marrow with healthy cells. The replacement cells can either come from your one's body or from a donor.

A bone marrow transplant is also called a stem cell transplant or, more specifically, a hematopoietic stem cell transplant. Transplantation can be used to treat certain types of cancer, such as leukemia, myeloma, lymphoma, Thalassemia, Sickle Cell Anemia and other blood and immune system diseases that affect the bone marrow.

What is bone marrow?

Bone marrow is a soft, spongy tissue in the body that contains hematopoietic stem cells. It is found in the centre of most bones. Hematopoietic stem cells are also found in the blood that is moving throughout one's body.

When hematopoietic stem cells are damaged, they may not become red blood cells, white blood cells, and platelets. These blood cells are very important and each one has a different job:

Red blood cells carry oxygen throughout the body. They also take carbon dioxide to lungs so that it can be exhaled.

White blood cells are a part of the immune system. They fight pathogens, which are the viruses and bacteria that can make a person sick.

Platelets form clots to stop bleeding.

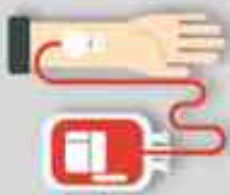
A bone marrow/stem cell transplant is a medical procedure by which healthy stem cells are transplanted into one's bone marrow or blood. This restores the body's ability to create the red blood cells, white blood cells, and platelets it needs.

Allogeneic Bone Marrow Transplant

is done by using another person's stem cells
whose bone marrow matches the patient.

1

Collection
from Donor



2

Processing



3

Chemotherapy



4

Reinfusion
into Patient



09 June 2021

Sangi Harini registered with Thalassemia and Sickle Cell Society (TSCS) become the first child to be transplanted and discharged at Sankalp India Foundation, Bangalore in 2021. With an unwavering determination of Team TSCS to enable cure for each child, several months of effort by both teams had paid off. The new centre at Bhagwan Mahaveer Jain Hospital - BMJH has been made possible, thanks to the immense support from DKMS Germany. The journey of cure that we started with Cure2Children Foundation has another milestone. We wish the little one good health and well-being. Cheers! for each one who worked and contributed towards making this possible. The journey to give life a better chance gathers more energy.



So far 11 children successfully underwent BMT and are free from Thalassemia leading a transfusion free life. Many more are awaiting. Thanks to the entire team of TSCS and Sankalp India Foundation for their selfless efforts to give a new life to these children.



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

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

All donations to Thalassemia and Sickle Cell Society are exempted under section 80G and 35(1)ii (Research only) act of Income Tax Act 1961

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

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

Bank Account Details

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	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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