THALASSEMIA AND SICKLE CELL SOCIETY

TSCS
STRIVE FOR PREVENTION

ANNUAL REPORT 2019

Kamala Hospital & Research Centre

Vuppala Venkaiah Memorial Blood Bank

Vuppala Krishna Rao & Chandrakala Diagnostic Services

B Narayana Das Shyam Sunder Loya Cure Thalassemia Welfare Trust

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Cover Page Story

Ms Ratnavali Vice President of TSCS was invited to Rashtrapati Bhavan to interact with Hon'ble President Shri Ram Nath Kovind ji on 03rd January, 2020 for her significant work on Thalassemia and Sickle Cell Anemia. Dr Suman Jain, Secretary also joined her for the interactive session with Hon'ble President.

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Mr Naresh Rathi
Chief Patron

Mr Shyam Loyaji
Chief Patron

Mr Chandrakant Agarwal
President

Mr Pradeep Uppala
Chief Patron

Dr Suman Jain
Secretary & CEO

Mrs K Ratnavali
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Dr D Venkata Ramana
Executive Member
(Ex President)

Mrs Rama Vuppala
Treasurer

Dr J Rajeshwar
Advisory Member

Dr Shirisha Rani
Advisory Member

President's Message

Chandrakant Agrawal
President

With so much of what we can do to improve stability, peace, and prosperity in some of the most fragile family affected with thalassemia? What can we do to ensure that such a traumatic situation do not arise due to ignorance. These are the vital questions that TSCS brings in their daily activity. But we know the answer: Educating our society and awareness.

In the core of our heart we believe thalassemia can be eradicated. Investing in thalassemia patients and spreading awareness is an investment that returns huge dividends in letting many know and ultimately eradicating thalassemia from the face of Telangana. Therefore our philosophy is to improve the health care of thalassemia affected children, govern, educate and spread awareness for a long-term peace and prosperity.

We are committed group of people with a vision to reach out with one call and one voice "Thalassemia Free Telangana".

Achieving this vision will require a strong and effective engagement from each one of us, "Join the call".

Secretary's Message

Dr. Suman Jain
CEO, C.M.R.O &
Secretary

I feel distinctly privileged and honored to be associated with the society. Our focus is simple: Patient care comes first, quality is always assured.

TSCS's vision of growth and progress in leading thalassemia affected with a holistic health care provision year after year, we strive to assure a strong foundation with likeminded philanthropist, collaborators, partners, medical professional, staff and supporters through their constant contribution and concern for the future of thalassemia patients. In accomplishing this we will live up to our motto of 'Leading to a Healthy Future'

That is not all, as we strive to give the best possible care, we are also equipping ourselves to give more advanced treatment through partnership across the world. This is not possible as long as we have many like you joining our call. We must act now, and act together.

Thalassemia and Sickle Cell Society (TSCS) is a registered Non-Profit Organisation with registration number 5359 striving towards the better treatment and management of the patients affected with Thalassemia and Sickle Cell Anemia. It is the only place in the state of Telangana and Andhra Pradesh with all the facilities including Blood Bank, Transfusion Centre, Diagnostic centre and Research Lab under one roof catering to the management requirements of more than 2600 patients. TSCS was established in the year 1998 by patient's parents, doctors, and well – wishers, with the motto to provide comprehensive care, cure and counselling to people suffering with Thalassemia and Sickle Cell Anemia. TSCS has recently collaborated with Sankalp India Foundation, Bangalore to bless the thalassemia children with a permanent cure through Bone Marrow Transplantation.

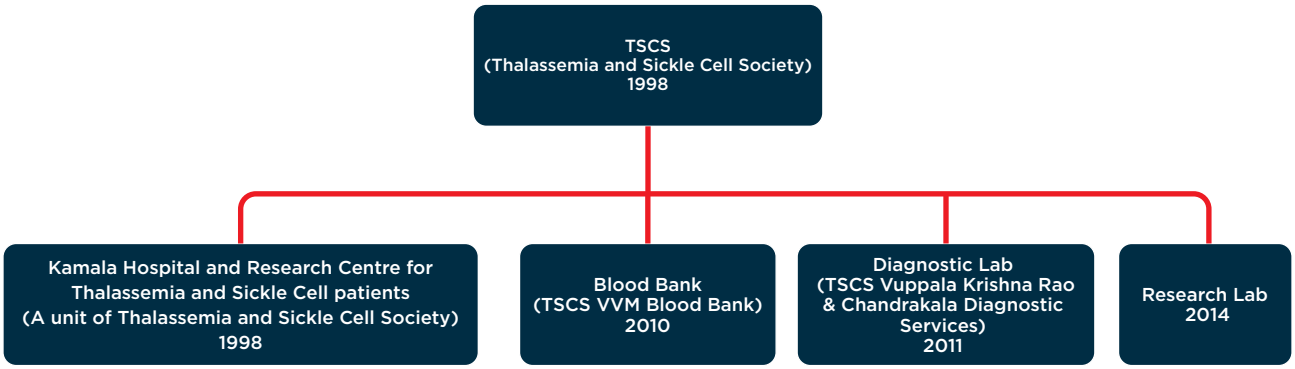
Mission

Thalassemia and Sickle Cell Society is dedicated to ensuring the best treatment and quality of life possible for patients suffering with Thalassemia and Sickle Cell Anemia. Based in Hyderabad, it has been serving those afflicted for the last 21 years.

Aim

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

Organogram of Society



Ethical Committee Members

Name	Designation
Dr. Vijayalakshmi Valluri	Chairperson
Dr. Hannah Anandaraj	Social Scientist
Shri. VSR. Moorty	Theologian
Dr. Veerender	Physician
Mr. Deepak Bhattacharjee	Senior Advocate
Dr. Suman Jain	Secretary

Advisory Board

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

Bankers and Auditor

Canara Bank Pattargatti Branch, Hyderabad	**NVS Murty& Co Secunderabad, Telangana**

Patron Doctors

Name	Designation
Dr. Sirisha Rani	Pediatric Hemato - Oncologist
Dr. Amarnath Kulakarni	Pediatric and Adolescent Endocrinologist
Dr. Sreenivas Namineni	Pediatric Dental Surgeon
Dr. Anuradha Kulkarni	Opthalmologist
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	Haemo Pathologist
Dr. A Narendra Kumar	Professor of Pediatric Surgery
Dr. Ravi Mehrotra	Endocrinologist
Dr. Chandra Prakash Jain	ENT Consultant
Dr. Parinitha Gutha	Pediatric Hemato - Oncologist

Research Advisory Committee

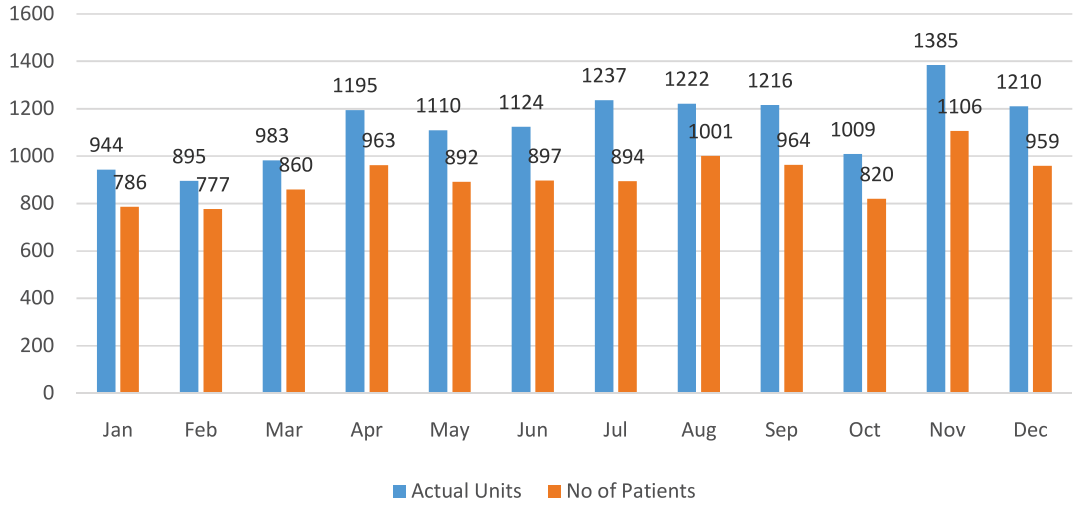
Sl. No	Name	Designation
1	Dr. M.P.J.S. Anandaraj	Emeritus Scientist
2	Dr. Q. Annie Hasan	Professor & Head of Dept. of Genetics & Molecular Medicine Senior Scientific Officer
3	Dr. Kaiser Jamil	Emeritus Research Scientist and Head, Genetics Dept
4	Dr. K. V. Radhakrishna	Scientist “D”
5	Dr. Lavanya M Suneetha	Head- Research & Training Infectious Disease Research Laboratory,
6	Dr. Ashwin Dalal	Head, Diagnostic Division,
7	Dr. Shailesh R. Singi	Consultant Hematologist and BMT Physician
8	Dr. S. Sirisha Rani	Consultant, Paediatric Hemato - Oncologist
9	Dr. Suman Jain	Chief Medical Research Officer & Secretary

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

TSCS is the only transfusion centre in India with more than 2695 Thalassemia and Sickle Cell Anemia patients with age group ranging from anywhere 3 months to around 40 years, as on December 2019. As children affected with Thalassemia need blood transfusions throughout their life, the programme provides free blood and transfusion facilities to the children registered. The programme seeks to increase the lifespan of marginalised and poor families affected by Thalassemia and SCA as they are unable to afford the treatment. This is also helping them improve the health of Thalassemia and SCA affected children and prolonging their life. We strive to give these children full support and strength in painful crisis. We also encourage and counsel to develop confidence in affected children to lead a normal life as any other human being.

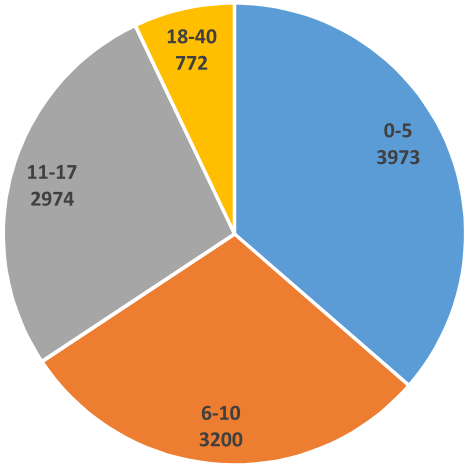
No of Patients vs Transfusion Units

Actual total no of patients visit are 10,919 and actual number of units given for patients are 13,530 during the year.



Transfusion for different age groups

No of transfusions patients at different age groups during the year



Kamala Hospital & Research Centre for Thalassemia and Sickle cell Society

Society has been actively supporting research activities for improving patient's treatment and in identification of mutations status/genetic variation.
Research Objectives:

- Prevention of Thalassemia by Carrier screening and counselling. Presently about 3600 cases have been screened for carrier status and counselled.
- Population Screening among Ethnic Groups in and around twin city of Hyderabad.
- Importance of iron chelators in non-transfusion dependent thalassemia (Thal intermedia)
- Beneficial effects of Combination Chelation Study on quality of life: Desferal and Asunra Thalassemia Longitudinal Cohort (TLC) in Thalassemia major
- Reproductive health in Thalassemia patients- Fertility Study
- Effect on Iron overload on thalassemia patients
- Impact of repeated blood transfusions on quality of life of thalassemia patients
- Effect of Nutrition on Thalassemia patients
- Reproductive health in adolescent thalassemia patients
- Stem-Cell research and gene therapy.

Paper Publications

Thalassemia and Sickle Cell Society has published 11 papers in National and International Journals. The following papers are published during the year:

- Bhargava Nupur, Jaitly Shashank, GoswamiSangam, Jain Suman, Chakraborty, Debojyoti, RamalingamSivaprakash. Generation and characterization of induced pluripotent stem cell line (IGIBi001-A) from a sickle cell anemia patient with homozygous -globin mutation. Stem Cell Research 2019 39. 101484. Doi: 10.1016/j.scr.2019.101484.

- Sundaram Acharya, Arpit Mishra, Deepanjan Paul, Asgar Hussain Ansari, Mohd. Azhar, Manoj Kumar, Riya Rauthan, Namrata Sharma, MeghaliAich, Dipanjali Sinha, Saumya Sharma, Shivani Jain, Arjun Ray, Suman Jain, SivaprakashRamalingam, SouvikMaiti, Debojyoti Chakraborty Francisellanovicida Cas9 interrogates genomic DNA with very high specificity and can be used for mammalian genome editing Proceedings of the National Academy of Sciences Oct 2019, 116 (42) 20959-20968; DOI: 10.1073/pnas.1818461116.

- Agarwal RK, Sedai A, Ankita K, Parmar L, Dhanya R, Dhimal S, Sriniwas R, Gowda A, Gujjal P, H P, Jain S, Ramaiah JD, Jali S, Tallur NR, Ramprakash S, Faulkner L. Information Technology-Assisted Treatment Planning and Performance Assessment for Severe Thalassemia Care in Low- and Middle-Income Countries: Observational Study. JMIR Med Inform. 2019 Jan 23; 7(1):e9291. doi: 10.2196/medinform.9291.

- Gayatri RangarajanIyer, Aruna Priya Kamireddy, Saroja Kondaveeti, Suman Jain, Qurratulain Hasan Establishing Mutational Spectrum of Beta Thalassemia by Molecular Screening in a Low Resource Setting – Implications in Counseling and Prevention. International Journal of Public Health and Health Systems 2019; 4(2): 36-43.

Vuppala Venkaiah Memorial Blood Bank

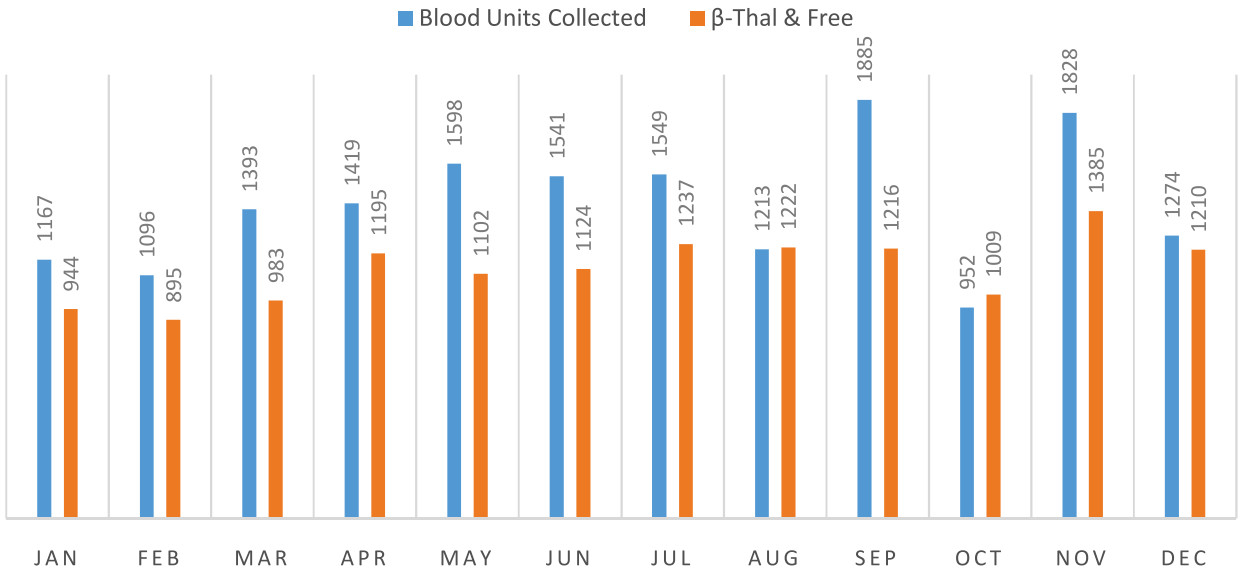
Vuppala Venkaiah Memorial Blood Bank started in 2010, keeping in mind the need for safe Blood for our own Thalassemia and Sickle Cell patients. This is one of the major effort to keep the children away from any issues/adverse reactions arising of unsafe blood transfusion. We are counted/ranked among the best NGO - run blood banks. We have a better number of voluntary donations from various organizations in and around Hyderabad. Our prompt and proactive actions ensure blood safety and maintain better quality of components. TSCS Blood Bank supports almost 1300 in house Thalassemia infected kids and also caters to the needs of nearby hospital on daily basis.

Blood Bank has successfully completing 10 years of service. Since beginning we have collected 1, 60,721 units of blood from 2015 voluntary blood donation camps in and around Hyderabad. Out of which 1, 00,091 (62.27%) units of blood was given to Thalassemia and Sickle Cell patients at free of cost and 55,688 (34.65%) units of blood given to Government Hospitals and General Issues. During the year Blood Bank has actively participated different programmes like World AIDS Day, World Blood Donors Day conducted by TSACS, MNC's etc. Our Blood Bank was awarded as the **Best Performer - for organizing 100% voluntary blood donation camps during the year 2019** by TSACS.

Blood bank activities during 2019

Sensitisation Programmes	Donation Camps	Blood Units Collected	Discard of Blood Units	Issues	
				β-Thal& Free	Govt. Hospital
258	201	16915	269	13522	836

Collection of Blood units Vs Free issues to Thalassemia patients



Vuppala Krishna Rao Chandrakala Diagnostic Centre

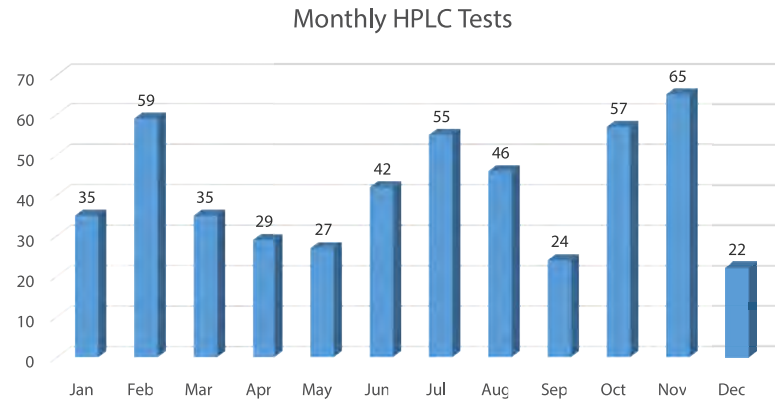
Thalassemia and Sickle Cell Society Vuppala Krishna Rao & Chandrakala Diagnostic Services established in September, 2011 offers facilities for carrying out Laboratory investigations with the advanced technology in the diagnostic field.

We have wide range of laboratory testing services in Biochemistry, Clinical Pathology, Hormonal assay, Microbiology, Haematology, Histopathology, ECG, Clotting Factors & HPLC for estimating hemoglobin levels. The Lab has high quality precision equipment's that provide qualitative and quantitative method of analysis of biological fluids such as blood, serum, tissue etc.

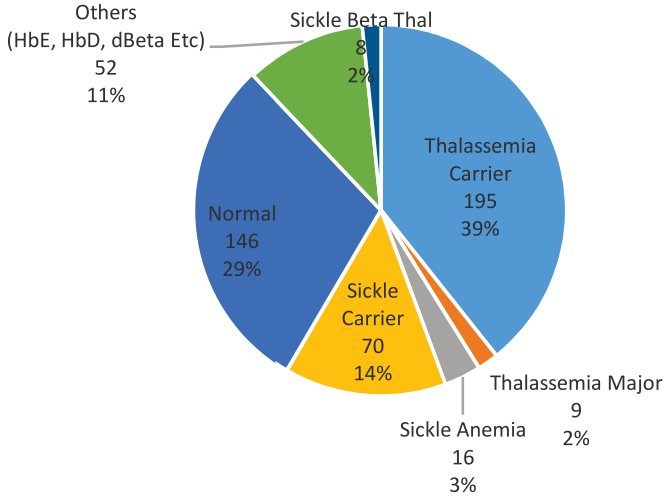
Thalassemia & Sickle Cell Society is committed to provide affordable laboratory testing services to all members of the communities.

HPLC Tests

New Registered Cases	HPLC Tests	CVS Referred to Nims &Cdfd	Splenectomy	HLA Typing	Screening Camp
159	496	25	4	454	608



During the year 496 HPLC tests were done for patient's siblings, parents and their relatives at free of cost. Out of which 39%, 14% of them were Thalassemia and Sickle Cell carriers respectively



⌘ Total DNA samples screened for mutations - 130

Casing every Obstacle alongside Thalassemia.

Thalassemia is still a less known fact to many people from all walks of life, this gets even shocking when unknowingly it sneaks into your family without sign. At the time of diagnoses the word thalassemia is a hard pill to swallow for any family. Today after 21 Years of life the perspective has shifted for Sai Srujana and her family she was just 3 months when doctors from AIIMS, Delhi brokeout the news to her parents.

The journey since then has been an incredible one, full of emotions, ups and downs, but ultimately, it has taught many things ranging from all time low to a time of big achievements. It is sheer blessings to have those right people and the family support and above all the right choice to express in the limitation, thalassemia challenges to people like us.

Srujana has embraced the right lifestyle while making sure that she retains the cultural values and traditions. Over the years, she has made great friends in school and in college (currently) however, it is the support system she had for the past 21 years from family, school teachers, professors, and most importantly, the nursing and doctoring staff, that has been so inspiring. The love and care with which TSCS treats their patients make every prick from the transfusions and chelation medicines seem so insignificant. The constant mode of encouragement and compassionate care received from the committed staff inspires anyone.

Living with thalassemia has been a humbling experience. Beyond the hardships, it provides a different perspective and perhaps a deeper respect for life. Even though with moments of low energy which makes it difficult to sit and stand when hemoglobin count goes less, seeing things beyond pain and momentary suffering, gives hope & assurance to strive for a better tomorrow.

Today Srujana excels as a painter, as a dancer a great pal to be with her MBA classmates. Her life speaks volume about her dedication and passion in spite of many stumbling block in her path. We take good things for granted and blow up the problems. As a consequence, we tend to fall prey to the petty concerns and annoyances in our lives, letting them determine our well-being. It's often when we lose what we have, that we start to appreciate it.

As a consequence, our stress levels increase and we are not as happy as we could be. How can we capitalize on the gift of life instead of letting negative experiences overshadow our well-being?

By embracing, rather than resisting, the challenges, greater the challenge the higher is the opportunities to excel, that is what Srujana could sum her positivity to life.

Paintings of Sai Srujana

Achievements – 2019

- We have computerised data of 2695 patients which can be utilised for scientific research.
- Around 1000-1200 children are given free blood transfusion every month.
- Since establishment of blood bank (2010), issued 1,00,091 units free blood to thalassemia children.
- Free periodic medical check-up were conducted with multi-speciality doctors on alternate months basis. Around 5 screening camps were organized catering 350 patients.
- Around 496 people including the parents, siblings, relatives of thalassemia patients were screened by HbA2 test for thalassemia at free of cost.
- Research collaboration have been established with institute of genetics, CSIR - Institute of Genomics & Integrative Biology (IGIB), CDFD, Kamineni Hospital - Genetic Department, Genetic Department of Osmania University and Sankalp India Foundation, Bangalore.
- Bone Marrow Transplantation(BMT) of our children has been initiated in collaboration with Sankalp India Foundation. Three children are under medical observation to undergo BMT in Jan/Feb 2020.
- 480 patients are enrolled under Aarogyasri Scheme (Telangana).
- Government of Andhra Pradesh has empanelled our hospital to avail YSR Aarogyasri scheme for patients from Andhra Pradesh. Around 70 patients are availing services under the scheme.
- TSCS has collaborated with Clinical Genetics of CDFD in NIMS and Molecular testing at CDFD centre, Uppal, to carry out prenatal diagnosis.
- Blood Bank received award of excellence from TSACS for working towards 100% voluntary blood donation on 1st December 2019.
- Our new premises at Shivrampally is equipped with Transfusion centre, Blood bank and Diagnostic services under one roof. Separate Research wing will be operational from March 2020.
- Creating awareness is key point in prevention of Thalassemia and Sickle Cell disease. Awareness programmes have been conducted in and around Hyderabad on regular basis.
- During the year four papers have been published in national and international journals and two are under communication.

Patient Profile

Classifications of Disease	
Type of Disease	**No of patients (%)**
Thalassemia Major	1831 (67.94%)
Thalassemia Intermedia	98 (3.63%)
Sickle Beta Thalassemia	159 (5.90%)
Sickle Cell Anemia	496 (18.40%)
E- Beta Thalassemia	49 (1.81%)
Others	62 (2.30%)
Grand Total	**2695**

- 65% of cases are Thalassemia major.

Patient's registration from Telangana, Andhra Pradesh and Other States

Telangana District	No. of Patients		Andhra Pradesh District	No. of Patients
Adilabad	146		Ananthapur	55
Bhadradri Kothagudem	24		Chittoor	21
Hyderabad	676		Cuddupah	34
Jangaon	8		East Godavari	104
JayashankerBhupalpally	11		Guntur	81
Jogulamba	3		Krishna	66
Kamareddy	6		Kurnool	78
Karimnagar	103		Nellore	7
Khammam	165		Ongole	12
Kumarambheem	12		Prakasham	19
Mahabubabad	5		Srikakulam	12
Mahabubnagar	98		Vishakhapatnam	55
Manchirial	26		Vizianagaram	12
Medak	75		West Godavari	80
Medchal	16		**Sub Total**	**636**
Nagarkurnool	18			
Nalgonda	148		**Other States**	**No. of Patients**
Nirmal	9		Assam	4
Nizamabad	74		Bihar	4
Peddapalli	3		Chhattisgarh	3
Ranga Reddy	134		Karnataka	51
Sangareddy	23		Madhya Pradesh	6
Siddipet	9		Maharashtra	21
Suryapet	12		Odisha	7
Vikarabad	14		Rajasthan	1
Wanaparthy	10		Uttar Pradesh	4
Warangal Rural	63		West Bengal	3
Warangal Urban	45		Others	19
Sub Total	**1936**		**Sub Total**	**123**
Total Number of Patients				**2695**

'Prevention is better than Cure', keeping this in mind TSCS is taking necessary steps to create more awareness in the public through various programmes.

Counselling: Regular counselling is being done to all patient's parents and relatives who visit to society for transfusion by Medical Officers and dedicated Counsellor on daily basis.

12 Jan – 28 Feb 2019

A Stall was setup at All India Industrial Exhibition, Nampally, Hyderabad to create awareness on Thalassemia and Sickle Cell Anemia among the public. Around 20,000 people interacted with the staff out of which 1150 got registered and 61 suspected cases were referred for HbA2 test at TSCS.

05 May 2019

Bike-rally: On the occasion of World Thalassemia Day (8thMay) a Bike Rally was organized by TSCS on 5th May, 2019 in association with Wanderers: The Royal Enfield Bullet Club of Hyderabad. Nearly 100 bikers traveled around the city spreading awareness on Thalassemia with banners and flags.

14 June 2019

On the occasion of World Blood Donors Day, Thalassemia and Sickle Cell Society actively participated in the rally organised by TSACS, Hyderabad.

30 Nov 2019

An awareness talk on Thalassemia was delivered to the staff at Shrinath Rotopack Pvt Ltd, Maheshwaram by Ms Ratnavali, Vice President, TSCS.





24 Jan 2019

An interactive season was organized for HLA matched patients to educate them on and their parents, on different aspects of Bone Marrow Transplantation with Dr Lawrence Falkner who is BMT specialist.

08 Mar 2019

Dr Suman Jain given lecture at Kamineni Hospitals.

09 Mar 2019

Dr Suman Jain was Chief Guest for Marvadi Samaj Meeting on Women's Day.

17 Dec 2019

An awareness talk on Thalassemia was delivered by Ms Ratnavali, Vice President, TSCS to 200 community workers from 11 districts at Telangana State Institute for Rural Development, Hyderabad.

02 & 03 Nov 2019

Free HLA typing camp was organised by Thalassemia and Sickle Cell Society in association with "Lets Help Some 1", Hyderabad on 2nd and 3rd November 2019. A total of 406 buccal swabs were collected including patients (189) their siblings or mothers (217). Thanks to the team of "Lets Help Some 1" for their support. Special thanks to "DKMS" Germany, for sponsoring the test.

05 Nov 2019

Thalassemia and Sickle Cell Society entered into Memorandum of Understanding with Sankalp India Foundation, Bangalore for carrying out Bone Marrow Transplantation (BMT) of in-house patients at Peoples Tree Hospital, Bangalore.

In this context an Orientation programme was conducted by TSCS with Sankalp India Foundation, Bangalore to discuss on the various aspects of BMT. Families of 37 HLA matched patients had an opportunity to interact with Dr Stalin, BMT Specialist and Mr Rakesh, CEO, Sankalp India Foundation and clarify their doubts on BMT.

10 Nov 2019

On the occasion of Milad-Un-Nabi, blood donation camps were conducted by TSCS at Central Library, Afzalgunj and Balamrai, Secunderabad which was supported by Milad Committee - Hyderabad, Lions Club of Jeedimetla and HDFC Bank.

Dr K Laxman, BJP state president and Board Members and VIPs of Milad Committee visited the camp. Special thanks to Mr Aleem Baig, Jt. Secretary, TSCS, for organising the camp successfully.












14 Mar – 16 Mar 2019

Dr Suman Jain Visited UK to attend Sickle Cell Disease Advocacy Advisory Board meeting in London.

31 Mar – 10 Apr 2019

Dr Suman Jain and Dr Padma participated in Genomics programme which included interaction and hands-on training in different aspects of next generation sequencing conducted by CSIR Institute of Genomics and Integrative Biology (IGIB), New Delhi.

27 Apr 2019

Mr Chandrakat Agarwal and Dr Suman Jain attended the 7th Thalassemia Lunch-on symposium organised by Mumbai Hemotology group, Goregaon Medical Association and A Ward Medical Associationat Mumbai.

07 July 2019

Dr Suman Jain, Mr Aleem Baig and Dr Saroja attended a seminar on “Improving quality of life: Thalassemia” at Little Stars Children Hospital, Panjagutta, Hyderabad organised by Dr Ramana Dandamudi.

28 Aug 2019

Dr Suman Jain and Dr Padma attended the Bio-Rad's South Asia Symposium on Hemoglobin Update on 28 Aug 2019 at Mumbai.

19 Sept 2019

An awareness talk was delivered on Thalassemia, Sickle Cell Anemia importance of voluntary blood donation to 200 students by Dr Saroja, Medical Officer, TSCS at Vision 40, IIT Academy, Hyderabad organised by Lions Club of Secunderabad, Vivekanandapuram.

23-24 Sept 2019

Dr Suman Jain and Mr Ravi Kumar participated in the 2 days Thal Care training organised by Sankalp India Foundation, Bangalore to strengthen the team's understanding and have more focused inputs from Sankalp panel of hematologists including Dr Lawrence Faulkner, in Bangalore to all NGO's working in Thalassemia and Sickle Cell disease control programme.

12 Oct 2019

Mr Chandrakant Agarwal, Dr Suman Jain and Dr Saroja attended the 8th Thalassemia Lunch-on symposium, organised by Mumbai Hemotology group, Goregaon Medical Association and A Ward Medical Association at Bombay Hospital, Mumbai.

14 Oct 2019

Dr Suman Jain attended the workshop organised by Sankalp India Foundation, Bangalore on 14th October 2019. Dr Sklar from MSKCC, New York, a world renowned paediatric endocrinologist and expert in physical development issues in children and late effects of chemotherapy was the key speaker. He focussed on the late effects of chemotherapy, endocrine issues and fertility stimulation in children post BMT.

23 Oct 2019

"NGO Day"was organised by Microsoft India at Microsoft campus, Gachibowli to showcase the activities of different NGO's to the staff. TSCS had an opportunity to create awareness about Thalassemia and Sickle Cell Anemia among the staff and encourage them to go for HPLC testing to know the carrier status. Thanks to Microsoft for organising it very well and the staff for their enthusiasm to know about the activities of different NGO's.

08 Mar 2019

On the occasion of World Women's Day, an orientation programme was organised by TSCS to educate the parents on disability certificate for Thalassemia patients.

8 May 2019

On the Occasion of World Thalassemia Day, a drawing competition was organised by TSCS for thalassemia children. All the children participated with great pomp and enthusisam. Gifts and cash prize were given to the three best performers.

An awareness talk was delivered by Ms Ratnavali, Vice President, TSCS at Institute of Genetics, Osmania University, Hyderabad on the occasion of World Thalassemia Day.

10 June 2019

On the occasion of World Thalassemia Day (08th May) one of our well-wisher Shri Surendra Agarwal ji sponsored a day out to Wonderla Amusement Park for thalassemia and sickle cell anemia children. Around 180 Thalassemia and Sickle Cell children, their parents and staff had a great day at wonderla.

19 June 2019

On the occasion of World Sickle Cell Anemia day, a cultural event was organised by TSCS for Sickle cell anemia patients. It was a very successful event with children and their parents participating in different entertainment and competitive activities. Gifts were distributed for the best performers in dance and games by Ms Ratnavali, Vice President, TSCS and Dr Saroja, Medical Officer, TSCS.

20 July 2019

A felicitation programme was organised by TSCS to acknowledge and thank the selfless voluntary groups, associations, societies, individuals, who with missionary zeal have organised blood donation camps braving all odds and have been saving countless, most precious lives of our Thalassemia patients.







09 Aug 2019

Thalassemia and Sickle Cell Society (TSCS) is the world's largest NGO dedicated to the prevention and eradication of the disease. On it's way to expansion to serve patients with best quality services under one roof, constructed a new building in Raghavendra Colony, Shivarampally with support from well-wishers and philanthropists.

On the occasion of its inaugural function, Honorable Health Minister, Telangana State Shri. Etela Rajender Garu was the Chief Guest, Honourable MP–Chevella Dr Gaddam Ranjit Reddy Garu, Honourable MLA, Rajendranagar, Shri T Prakash Goud Garu, Retd., Additional Director General of Police, Maharastra, Shri VV Laxminarayana Garu, Entrepreneur Shri Shyam Sunder Loya Ji, Chairman, Vasudha Foundation-Shri Mathena Venkata Ramaraju Garu, Spiritual Scientist Shri VSR Murthy Garu, Proprietor, Sri Krishna Jewellery Mart Shri Uppala Pradeep Garu were the guest of honour.

15 Aug 2019

On the occasion of 73rd Independence Day, flag was hoisted at the premises of Thalassemia and Sickle Cell Societyby Mr Chandrakant Agarwal, President,TSCS. Mrs Ratnavali, Vice President; Dr Suman Jain, Secretary and CEO; Mr AleemBaig, Jt Secretary, Mr Naresh Rathi, Chief Patron; Mr Ameen, Mr Rajesh Jain, Mr RitishDevda, Mr D Srinivas, Executive members, Staff, Patients and Parents participated in the celebrations.
JAI HIND!

24 Nov 2019

An event was organized by Sun Pharma Laboratories Limited for thalassemia and sickle cell anemia patients to celebrate children's day on 24th November, 2019 at Thalassemia and Sickle Cell Society. Dancing, Singing, Elocution and Games competitions were conducted to motivate the children to show their hidden talents and to make them feel that they are no less than normal children. Children participated in the competitions with great enthusiasm and zeal. The event was a grand success and thanks to Sun Pharma Laboratories Limited for organizing the event.








31 Aug 2019

Shri Ratnavali Kottapalliji has been appointed as Gandhi Peace Ambassador International for Hyderabad, India.

14 Sept 2019

Dr. Suman Jain and Mrs Ratnavali were felicitated by SevaBharathi Organisation for their selfless service to thalassemia and sickle cell anemia children.

01 Dec 2019

On the occasion of World Aids Day, a rally was organized by TSACS in association with Thalassemia and Sickle Cell Society and others on 1st December 2019. Blood Bank of TSCS was awarded as the Best Performer.

20December 2019

Mrs Ratnavali was honoured withVisitaSevaPuraskar and Marri Chennareddy award 2019 on the eve of Centenary celebrations of Marri Chennareddyby Brahma Kumari, a Shanti sarovar.

04 Jan 2019

Dr.Yazdi Italia, Chairman, Indian Society Of Blood Transfusion & Immunohematology - West Zone; Hon. Secretary, ValsadRaktdan Kendra, Valsad visited the society and shared his valuable thoughts for raising the funds for screening the population of Telangana for Sickle Cell disease.

09 Jan 2019

Dr.Minniti, Professor of Clinical Medicine and Paediatrics at Einstein College of Medicine visited the society on 9th January, 2019. She is also the Director of Sickle Cell Centre for Adults at Montefiore Medical Centre, whose mission is to provide exceptional, seamless, comprehensive, compassionate and individualized care, education, counselling, and research for people living with sickle cell disease (SCD).

08 April 2019

Dr M B Agarwal, Eminent Hematologist visited our center on 8 April 2019 and given valuable suggestion to further improve our services.

24 Apr 2019

Novartis team visited our society – Mr Amitabh Dube, Ms Rajni Abijit, Mr Geo Yohannan and Mr Sagar Manepally, they suggested to use the platform of social media to enhance our activity and visibility.

हैमेटोलॉजिस्ट डॉ. एम.बी. अग्रवाल ने किया कमला अस्पताल का दौरा

हैदराबाद, 7 अप्रैल-(मिलाप ब्यूरो)

शिवरामपल्ली स्थित थैलीसीमिया एंड सिकल सेल सोसाइटी द्वारा संचालित कमला अस्पताल व अनुसंधान केन्द्र का आज प्रसिद्ध हैमेटोलॉजिस्ट डॉ. एम.बी. अग्रवाल ने दौरा किया।

आज यहाँ जारी प्रेस विज्ञप्ति के अनुसार, डॉ. एम.बी. अग्रवाल मुंबई में बॉम्बे हॉस्पिटल, लीलावती अस्पताल, ब्रीच कैंडी अस्पताल व अन्य अस्पतालों में सलाहकार हैमेटोलॉजिस्ट के रूप में कार्यरत हैं। अवसर पर सोसाइटी के अध्यक्ष चंद्रकांत अग्रवाल एवं नरेश राठी ने उन्हें अस्पताल में उपलब्ध सभी नवीनतम सुविधाओं की जानकारी दी। उन्हें केंद्र में आरंभ होने वाली बोन मैरो ट्रांसप्लांट एवं रीसर्च लैब सुविधा के बारे में जानकारी दी। अवसर पर डॉ. अग्रवाल ने थैलीसीमिक से ग्रस्त बच्चों की सेवा के लिए कार्यरत संस्था का मार्गदर्शन व सहयोग करने का आश्वासन दिया।

21 June 2019

Dr A K Kundra, Maj Gen R S Chhatwal and his team from Autism Ashram visited our society to know about the services rendered to Thalassemia patients. They expressed our services as “Wonderful Experience Beautiful Centre with great staff”.

10 July 2019

Dr. Mahesh Joshi, Emergency Chief (Casualty) Head of Apollo hospital, has visited the society on 10th July, 2019. He was overwhelmed with the services of the society and assured full support.

16 Aug 2019

Mr Ajay Kalhan, Runner in Airtel Hyderabad Marathon 2018 and 2019 had visited the society. He has raised an amount of more than 1.30 lakhs in the year 2018 and 1.07 lakhs on 19 Aug 2019 through campaigning on behalf of Thalassemia and Sickle Cell Society.

11 Oct 2019

A team of three members from Dr. YSR Aarogyasri Health Care Trust, Government of Andhra Pradesh have visited the Society for inspection.

14 Nov 2019

Mr Surendra Agarwal had donated Swaraj Mazda 13 seater vehicle for conducting blood donation camps.


Van donated by
Mr Surendra Agarwal

Aarogyasri (Telangana)/ YSR Aarogyasri (Andhra Pradesh)

Aarogyasri 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".

Ms Sania

Aadab! I am mother of 9 year old Sania, who was diagnosed with Thalassemia Major at an age of 5 months. My husband is a tailor and I assist him in his work. I lost 2 children with Thalassemia as we could not afford to taken them for regular blood transfusions and buy Iron chelators. Thanks to TSCS and Telangana government for enrolling us under Aarogyasri scheme under which we are able to get the medicines and investigations done free of cost. I am now able to take proper care of my daughter and provide her with good education.

Master Harikrishna

Namaste! I am maternal grandfather of Harikrishna who is suffering with Thalassemia Major. I work as a watchman. Harikrishna's parents stay in Srikakulam. They are daily wage workers and hence could not support their child. I took the responsibility of looking after him and got him to TSCS. Due to non-availability of facilities under Aarogyasri scheme for patients of Andhra Pradesh in Telangana for last three years, it was very difficult for me to manage with his medical expenses. But now thanks to Andhra Pradesh Chief Minister for allowing us to avail Aarogyasri services in Telangana under which my grandson is able to get free transfusion and medication free of cost. I will now be able to support my grandchild for a better education and bright future.

TSCS organises periodical medical check-up for all patients on bi-monthly basis at free of cost. We have conducted five screening camps during the year 2019. Around 600 patients were screened for Dental, 2D Echo, General check-up & ENT.

Name	Designation
Dr. Shirisha Rani	Pediatric Hemato-oncologist
Dr. Amarnath Kulkarni	Pediatric and Adolescent Endocrinologist
Dr. Srinivasa Namineni	Dentist
Dr. Anuradha	Opthalmogist
Dr. Nageshwar Rao	Pediatric Cardiologist
Dr. Jain	ENT Specialist
Dr. K Nagarjuna	Pediatric Surgeon
Dr. A Nagender	Pediatric Surgeon
Dr. Mounika	Pediatric Dentist






Academic/Professional Achievements 2019:

ClassX	Inter	Degree	Professional	Working
Amrita Agarwal	Saleh	Manisha	Ramya - Aero	Sushma- Google
D Sandeep	Md Sufiyan	Noorunissa Begum	Hari Krishna - MBA	Shirisha - Med. Transcription
E Hari	Samin Ali	Hema Rupani	Ameena - MBA	Usha Shri Beniya - LVP Eye Hospital
Atteqa Shaik	Jahanavi	Bharat Rupani	VishwaTeja - M.Tech	Soi Aditya - Namasthe Telangana
Abdul Mannan	Saina	Sai Srujana	Ankita - B.Tech	B Shiva Kumar - TSCS
Jayaram	Rashmi	Nikunj Patel	Prashanth - Diploma	G Srikanth - Oracle
	Divya	Madhusudhan	Sai Krishna-Polytechnic	Rishab - Wipro
	Ch Santhoshi	MsSwathi	VishwaTeja - B.Arch	Ashwini - Physiotheraphy
	Naresh	Arsheen Fathima	Vikram - Dip Civil Eng	Tagore Naik- BSC Nursing
	Azra Ahmed	Ranjeeth	Rahul - Diploma EEE	Osman Pasha - Video Mixing
	Taniya	Sumaira Fathima	Sewtha - MPHW	SoiVara Prasad - Genpact
	Yogitha	Neelima	Elisha - Catering	M Priyanka - TSCS
	B Praveen	Sajida Begum	Yeshu Paul - Cattering	Krishna chaitanya - Animation
	Abhishek	Jahnnavi	Arsheen Baig- BSc	Souvik Bose - Wipro
	Poornima	Tajdar	Shivani - Tally(Accounts)	Raghavendra - Tech Mahendra
	Nehru	Venkat Karthik	Manirathgoud - B.Tech	Khaza Nadeemuddin - Own Restaurent
	Muthahuruddin	Sherly	Ravinder -Tribal Welfare	Mukhram Ali - Activa Show room
	Edukondalu	Zahda Mahavin	Swathi - B.Tech	Chanakya Reddy - Own Business
	Naveen Kumar	Mohsina Thabsum	Neelima– Lab Technician	Nooruddin - Own business
	Jagadeesh	Ravi	Sai Srujana– MBA	Bharat Roopani - Cardiac Capital, Delhi
	Omer	Afroz	B PremSagar–B.Tech 2nd	Dr. Azra Fatima - Researcher at Learn
	Naveen Kumar	Amisha Patel	J Ravi –B.Tech 3rd Year	Raghav - Own Business
	Sai Chaitra	Rashmi	SourabhMisra -MBBS 1st	Harshith – Infosys
	Paneshwari	Harish Kumar		Krishnam Raju – Own Laboratory
		B Pentaiah		Manisha – Honda Showroom
				Jyothi – GNM Nurse at General Hospital
				Swathi - Google
				Sonal Shivani – Delhi Public School




#	Name of Donor		#	Name of Donor
1	Blend Colours Pvt Ltd		34	Mr SattaluriSriram Gopal
2	Mr Srikanth Gullapalli		35	Mr Md Ahamed
3	Ambika Iron & Steel		36	Meenakshi Jewellers
4	Smt Banarsai Bai		37	Ms Padmaja V S Kothapally
5	A S Iron & Steel		38	Lions Club of Hyderabad, Jeedimetla
6	Aims Asia		39	Mr Iva Mukherjee
7	Mr V Balveeeraih Sons		40	Global Conferance Organiser
8	Mr C Shashider Reddy		41	Ms Sudha Prashanth
8	NavDurga Textiles Pvt Ltd		42	Mr S Shyam Sunder
10	Dr C Anupama Reddy		43	Ms Geetha Pandey
11	S P P Poly Pack Pvt Ltd		44	Srimathrutre Charitable Trust
12	Global Steels		45	Mr Anuj Agrawal
13	Shrinath Rotopack Pvt Ltd		46	R V Sai Prasad Therapiva Pvt Ltd
14	Hari Om Pipe Industries Ltd		47	Mr B B Prasad
15	Mr Murali K Siripurapu		48	Mr SitaramManthriPragada
16	Kumar Enetrprises		49	Mr J Santhosh
17	Mr Aravind Kumar Gupta		50	Institute of Genetics
18	Mr Amir Ali Dharani		51	Lord Sri Krishna Charitable Trust
19	Deccan Switch Gears		52	Sai Saran Enterprises
20	Sreyas Holistic Remedies Pvt Ltd		53	Mr S K Riyaz
21	Manna Trust		54	Ms Trisha
22	Sri Krishna Jewellary Mart		55	Baby Abhigna
23	Mr Chandrakant Agarwal		56	Sea Sky Freight Systems India Pvt Ltd
24	Mr Munish Agarwal		57	Ms Lakshmi Kumari
25	Supreme Agencies		58	Mr Amitabh Bose
26	Timing Technologies		59	K-allah
27	Giving Foundation		60	Mr Ananda Mohan
27	Nasscom Foundation		61	VNRVJIET
29	Mr Chetan Sharma		62	Master Aharhan
30	Mr Paresh Vora		63	Swetha Developers
31	Suman Dhurvalia		64	Shree Jewellers Eximp Pvt Ltd
32	Prof. V Raghavendra Rao		65	Sri Navdurga Billets Pvt, Ltd.
33	Mr Atul			

Thank you
for your continuous support

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		**Building 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 for	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 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

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

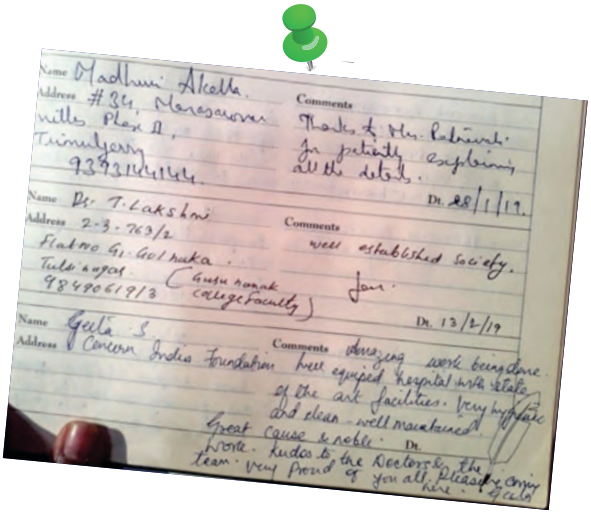
LIABILITIES	AMOUNT		ASSETS	AMOUNT	
Capital Account			**Fixed Assets**		
Capital Fund	2368216		Airconditioner	142500	
Less Excess of expenditure over income	-3792544				
Donations Towards Corpus Fund	17810099		Ambulance	1261898	
Life Members Ship	2459500	18845271	CAR	260000	
			Biometric Attendence System	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 Society
SECRETARY

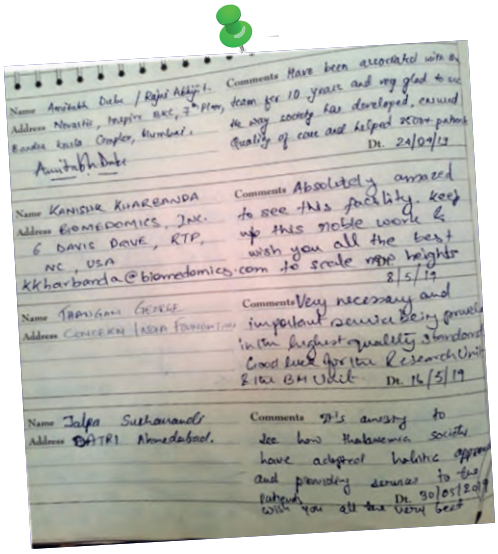
THALASSEMIA & SICKLE CELL SOCIETY R.R.-52 040-29885458 040-29885658



Name Madhuri Akella
Address #34, Manasaroovar Villas Phase II, Trimulgherry 9393144144
Comments Thanks to Mr. Pabbisetti for patiently explaining all the details.
Dt. 28/1/19

Name Dr. T. Lakshmi
Address 2-3-763/2 Flat no G1 Gothuka, Tilak nagar 9849061913 (Guru nanak college faculty)
Comments well established society. Jai.
Dt. 13/2/19

Name Geeta S
Address Concern India Foundation
Comments Amazing work being done. Well equipped hospital with state of the art facilities. Very hygienic and clean - well maintained. Great cause & noble work. Kudos to the Doctors, the team. Very proud of you all. Please carry on. Geeta
Dt.

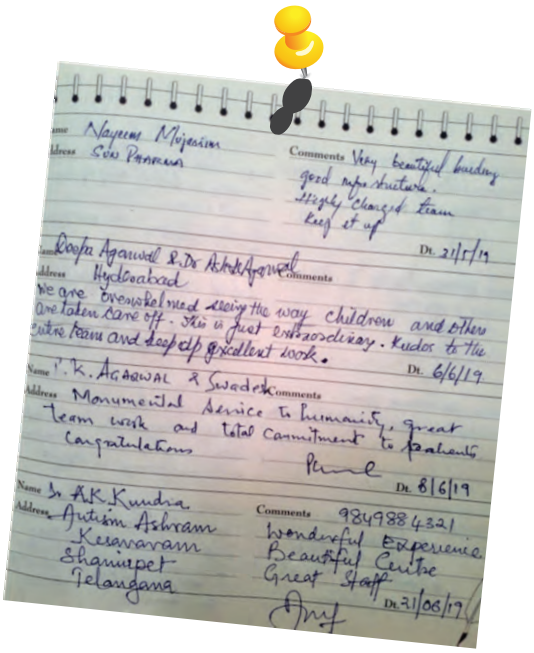


Name Amitabh Dube / Rajni Abhyankar
Address Novartis, Inspire BKC, 7th Floor, Bandra Kurla Complex, Mumbai.
Amitabh Dube
Comments Have been associated with the team for 10 years and very glad to see the way society has developed, ensured quality of care and helped 25000+ patients
Dt. 24/04/19

Name KANISHK KHARBANDA
Address BIOMEDOMICS, INC. 6 DAVIS DRIVE, RTP, NC, USA
kkharbanda@biomedomics.com
Comments Absolutely amazed to see this facility. Keep up this noble work & wish you all the best to scale new heights
8/5/19

Name TRAVIGAM GEORGE
Address CONCERN INDIA FOUNDATION
Comments Very necessary and important service. Being provided in the highest quality standards. Good luck for the Research Unit & the BM Unit
Dt. 14/5/19

Name Jalpa Suthawandi
Address DATRI Ahmedabad.
Comments It's amazing to see how Thalassemia society have adopted holistic approach and providing services to the patients. With you all the very best
Dt. 30/05/2019



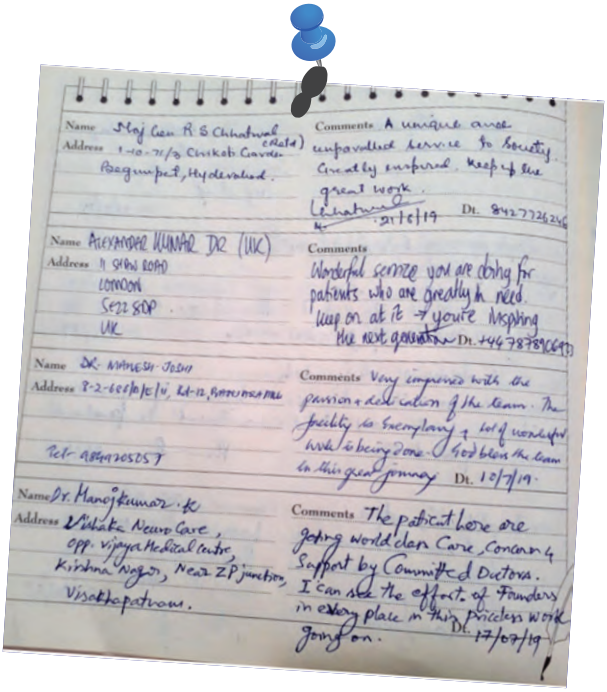
Name Nayeem Mujeeb
Address Sri Lanka
Comments Very beautiful building good infrastructure. Highly charged team. Keep it up
Dt. 21/5/19

Name Roopa Agarwal & Dr Ashok Agarwal
Address Hyderabad
Comments We are overwhelmed seeing the way children and other are taken care off. This is just extraordinary. Kudos to the entire team and keep up the excellent work.
Dt. 6/6/19

Name T.K. AGARWAL & Swadesh
Address Monumental Service to humanity, great team work and total commitment to patients. Congratulations
Dt. 8/6/19

Name Sri AK Kundra
Address Autism Ashram Keesaravam Shamirpet Telangana
Comments 9849884321 Wonderful Experience. Beautiful Centre. Great Staff
Dt. 21/06/19

Visitors Feedback

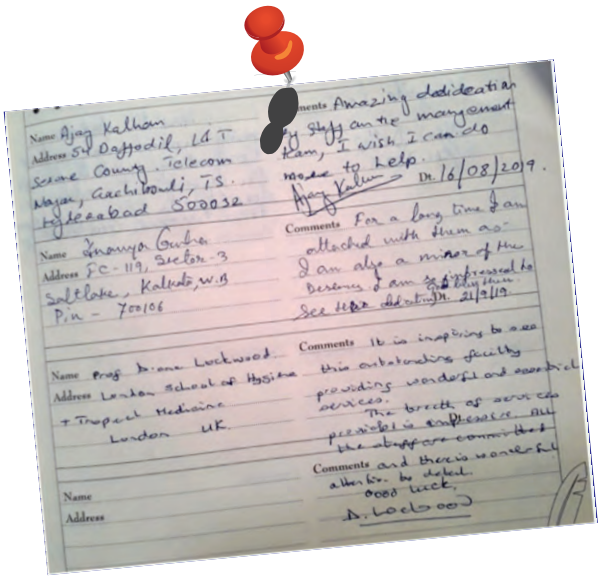


Name Maj Gen R S Chhatwal (Retd)
Address 1-10-71/3 Cricket Garden Begumpet, Hyderabad.
Comments A unique and unparalleled service to humanity. Greatly inspired. Keep up the great work.
Dt. 21/6/19

Name ALEXANDER KUMAR DR (UK)
Address 11 SHAW ROAD LONDON SE22 8DP UK
Comments Wonderful service you are doing for patients who are greatly in need. Keep on at it & you're inspiring the next generation
Dt. 44 7878 06493

Name DR. MAHESH JOSHI
Address 8-2-608/B/E/11, RK-12, RAMNASKAMPALLY
Tel- 9849705257
Comments Very impressed with the passion + dedication of the team. The facility is exemplary & lot of wonderful work is being done. God bless the team in this great journey
Dt. 10/7/19

Name Dr. Manojkumar K
Address Vikalpa Neuro Care, opp. Vijaya Medical Centre, Krishna Nagar, Near ZP junction, Visakhapatnam.
Comments The patient here are getting world class Care, Concern & Support by Committed Doctors. I can see the effort of Founders in every place in this Priceless work. Keep on.
Dt. 17/07/19



Name Ajay Kalhan
Address S/o Daffodil, L&T Service County, Telecom Nagar, Gachibowli, T.S. Hyderabad 500032
Comments Amazing dedication by staff on the management team, I wish I can do more to help.
Dt. 16/08/2019.

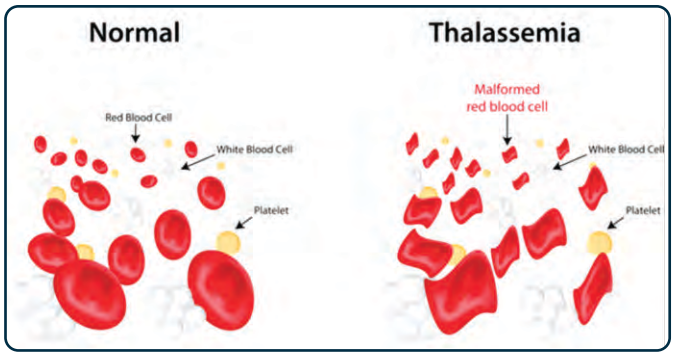
Name Sowmya Guha
Address EC-119, Sector-3 Saltlake, Kolkata, W.B. P.N - 700106
Comments For a long time I am attached with them as I am also a minor of the persons. I am so impressed to see their dedication.
Dt. 21/9/19

Name Prof Diane Lockwood
Address London School of Hygiene + Tropical Medicine London UK.
Comments It is inspiring to see this outstanding facility providing wonderful and essential services. The breadth of services provided is impressive. All the staff are committed and their work is wonderful. Good luck.
Dr. Lockwood

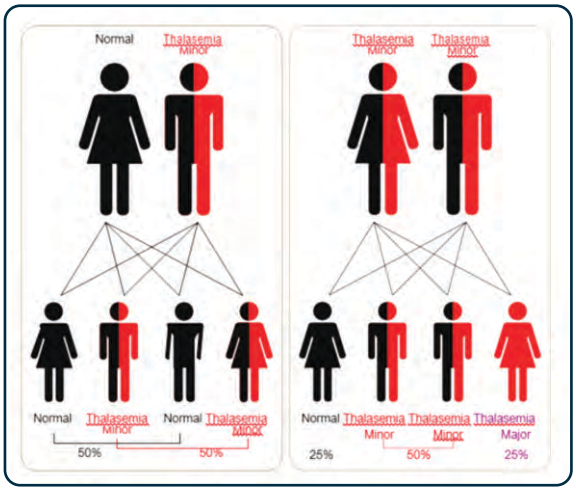
Name
Address

Dedicated staff of TSCS

Thalassemia



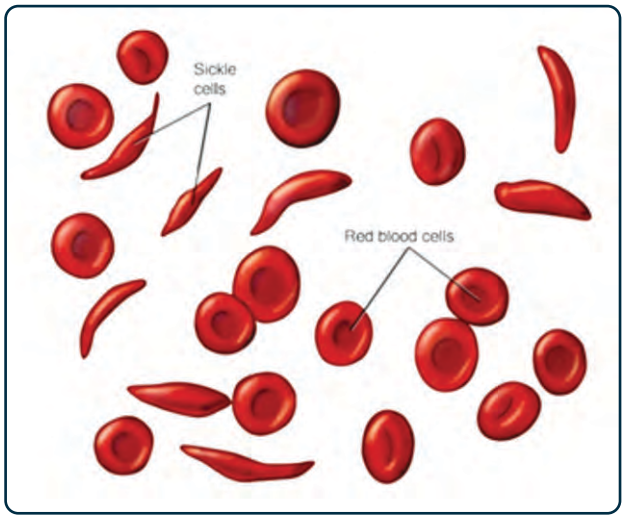
Thalassemia is an inherited blood disorder characterized by inadequate synthesis of red blood cell protein known as hemoglobin that carries oxygen to the tissues. This results in the destruction of large numbers of red blood cells thus causing anemia. Thalassemia can be of several types depending on the variations in the genes coding for globin chains of hemoglobin and severity of the condition. Depending on the genes involved it can be alpha thalassemia, beta thalassemia or delta thalassemia. The severity of thalassemia (minor, major, intermedia) is in turn reflected by the number of mutated genes involved and the age at which the symptoms are expressed. The most severe form of thalassemia is -thalassemia major also known as Cooley's anemia which requires regular blood transfusions and extensive medical care. It represents a significant health problem worldwide due to its frequency and severity. The patients become pale, have poor appetite and have retarded growth. Without treatment, their spleen and liver become enlarged and are prone to infections and heart failure which are the leading cause of death among children with -thalassemia major. Another major complication in patients with thalassemia is iron overload which results due to regular blood transfusions given to patients to maintain the hemoglobin levels in order to sustain their life. Iron overload is so common in patients that it has been referred to as “second disease” during the treatment of first and results in a number of other diseases and serious clinical complications like cardiomyopathy, arrhythmias and liver cirrhosis dueto iron deposits in the organs.



Thalassemia affects >400,000 new-born every year worldwide. It is estimated that about 10000-15000 babies with Thalassemia Major (TM) are born every year in India, - Thalassemia is most prevalent across the country with an average carrier frequency of 3-4%.

Treatment of thalassemia depends upon the level of severity. For milder forms of the condition, advice and counseling are often all that are necessary. For more severe forms, treatment consistsof blood transfusion and chelation therapy to reverse iron overload. Bone Marrow Transplantation(BMT) is the only cure available for thalassemia provided Human Leukocyte Antigen(HLA) matched donor is present. Removal of the spleen (splenectomy) could help to reduce theneed for blood transfusions in people with thalassaemia major or intermedia but there is currentlyno reliable evidence from clinical trials about its effects. Population screening for carriersfollowed by genetic counseling could reduce the incidence of the condition in the population.

Sickle Cell Disease



Sickle cell anemia (sickle cell disease; SCA or SCD) is a genetic blood disorder caused by abnormal hemoglobin, the molecule in red blood cells that carries oxygen to all parts of the body. People with this disorder have atypical hemoglobin molecules called hemoglobin S, which distorts the red blood cells into a sickle, or crescent, shape. Characteristic features of this disorder include a low number of red blood cells (anemia), repeated infections, joint pains, stomach pain, spleen enlargement, gall bladder stones, jaundice, liver enlargement etc.,

SCA is inherited in autosomal recessive pattern which means two copies of the gene in each cell have mutations. It is caused by substitution of the glutamic amino acid for valine at position 6 of the beta globin gene of hemoglobin. A person with a mutation in one copy of the gene is referred to as Sickle Cell Trait or Sickle Cell Carrier and does not always show the symptoms of the disease except that there are traces of sickle shaped RBC's in the blood. However, there is a possibility that his children inherit Sickle Cell Anemia if he happens to marry a Sickle Cell Carrier or Sickle Cell Disease patient.

SCA is highly prevalent in sub-Saharan Africa, tribal regions of India, and the Middle East. In India, the sickle gene is prevalent in the tribal populations and in some non-tribal population groups like the scheduled castes and other backward classes belonging to a low socioeconomic status with carrier frequencies ranging from 1-40%. Significant prevalence has been noted in certain communities like Lambada, Madiga, Mala, Mudiraj, Muslims (Sunni), Hindu Dhodhia, Kukna, Varli, Bheel, Kolcha, Gaameet, Chowdhary etc.

Treatment for sickle cell anemia is usually aimed at avoiding crises, relieving symptoms and preventing complications. It includes medications to reduce pain and prevent complications, and blood transfusions. Medications include antibiotics, pain killers and hydroxyurea which stimulate the production of fetal hemoglobin- a type of hemoglobin found in newborns.

SCA can be managed properly by establishing the correct diagnosis early in life, ideally during the newborn period. The identification of affected infants by neonatal screening programs allows early initiation of prophylactic penicillin and pneumococcal immunizations, which helps prevent overwhelming sepsis. Ongoing education of families promotes the early recognition of disease-released complications, which allows prompt and appropriate medical evaluation and therapeutic intervention. The burden of sickle cell anemia in the population can be reduced by initiating awareness and screening programmes. Carriers can be identified in the population by reliable blood testing followed by genetic counseling (premarital and prenatal) in order to reduce the incidence of the condition in the population.

Bone Marrow Transplantation (BMT):

BMT is the only cure available for Thalassemia patients. To undergo BMT procedure patients should have fully matched Human Leukocyte Antigen(HLA) sibling/parent. The treatment is an expensive and an unaffordable procedure for patients. Setting up BMT centre is very expensive and complex affair. Hence TSCS entered into MoU with Sankalp India Foundation (SIF) for BMT procedure.

Sankalp India Foundation

Sankalp India Foundation is a Bangalore-based non-government organisation. It is a youth organisation working for Blood donation, Thalassemia, Bone Marrow Transplantation and Disaster relief. Sankalp Program for Thalassemia Cure offers Bone Marrow Transplant - the permanent curative option to the children suffering from Thalassemia.

SIF have partnerships that enable reliable BMT on a non-profit basis bringing down the cost of the transplants substantially. The organisation seeks to identify the most suitable candidates and offer them the option of BMT. At the cost equivalent to 4-5 years of thalassemia management, the organisation offers complete cure from the disease.

SIF team has vast expertise with BMT for thalassemia. The selection of patients for transplants is being done scientifically and judiciously to ensure that the patients who are most likely to benefit from the transplant are offered the same, keeping aside their financial limitations. They have established a program which will ensure systematic preparation of the chosen kids for transplant and their long-term follow-up – further enhancing the outcome and reducing the cost.

Dr Lawrence Faulkner Medical Director Cure2Children Foundation-Italy and Program Director Sankalp, People Tree Centre for Paediatric BMT Bangalore-India.After working for almost 20 years in affluent countries as a pediatrician specialized in blood disorders such as thalassemia and Sickle Cell disease. Dr Faulkner is also an inspector for JACIE (Joint Accreditation Committee ISCT-EBMT).

Dr Lawrence Faulkner's team has already achieved overall survival rate of 94% in patients with full matched-related sibling/parent donor, below 15 years of age, and we are confident that in collaboration with this highly successful team we too will achieve amazing results in curing thalassemia.

Memorandum of Understanding (MoU) with SIF:

Based on their success rate and dedication towards BMT, TSCS entered into MoU with SIF, for BMT treatment at Peoples Tree Hospital. Under guidance of Dr Lawrence Faulkner for at the cheapest cost possible less than 10 lakhs (otherwise it costs up to 50 lakhs) with one year pre and post-transplant treatment with highest degree of professional competence.

TSCS and SIF made MoU in Oct 2019 to send the patients whose HLA matched with their sibling(s) or parents to undergo BMT. SIF achieved 98% of success rate in BMT. So far five patients have undergone the BMT successfully from our society. As on Oct 2019 there are around 40 patients from TSCS whose HLA is matched and ready to undergo BMT provided they mobilise the funds for treatment.





BMT Success Children

INAUGURATION OF NEW PREMISES OF TSCS












































Donations

Your valuable 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) act of Income Tax Act 1961

Our TSCS Society is awarded section IT 35 1 (ii) by Govt of India, a very rarest award. Donations given by you for research purpose will benefit you by deduction of 150% in Income Tax on donated amount

DONATE GENEROUSLY

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	1181101023165
Account Name:	THALASSEMIA AND SICKLE CELL SOCIETY	
Bank Name:	Canara Bank	
Branch:	Pathergatti Branch, Hyderabad	
IFSC Code:	CNRB0000608 (11 digits)	
Swift/BIC Code:	CNRBINBBHFD	
Currency:	Indian Rupees (INR) -	

"Donate your blood for a reason, let the reason be life"

Thalassemia FREE Telangana

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. Hyderabad, Telangana – 500052

Website: www.tscsindia.org | E Mail: tscs@tscsindia.org | Ph: 040 – 29885658/29880731/29885458

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