ANNUAL REPORT 2018

TSCS

STRIVE FOR PREVENTION

Thalassemia and Sickle Cell Society

THE BIGGEST SOCIETY IN THE WORLD

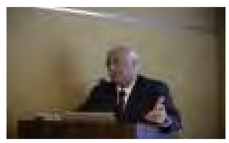
Kamala Hospital & Research Centre

B Narayana Das Shyam Sunder Loya Cure
Thalassemia Welfare Trust
Vuppala Venkaiah Memorial Blood Bank
Vuppala Krishna Rao & Chandrakala Diagnostic Services




World Blood Donor Day -2018



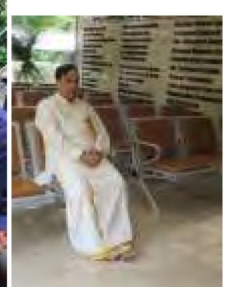



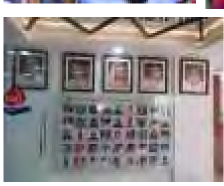




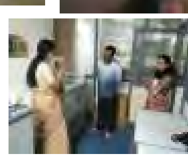
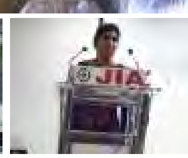


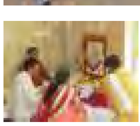
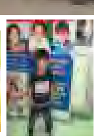
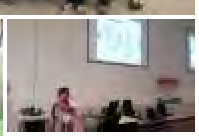






World AIDS Day
Know
your Status!


JIA

Thalassemia and Sickle Cell Society (TSCS) is a registered Non-Profit Organisation with registration number 5359 established in 1998 by patients parents, doctors, and well wishers,to give comprehensive care, cure and counselling to people suffering with Thalassemia and Sickle Cell Disease. TSCS is the only place in the state of Telangana & Andhra Pradesh, wherein a transfusion centre with attached Blood Bank, is Managing the Treatment of Thalassemia, Sickle Cell Anemia and other blood disorders in Hyderabad.

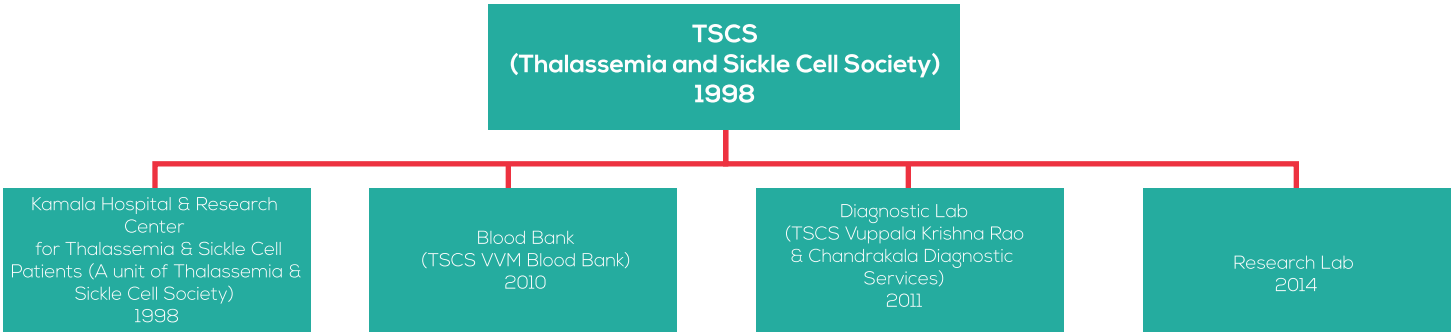
Mission:

Thalassemia and Sickle Cell Society is dedicated to ensuring the best treatment and quality of life possible for Indians suffering from Hemoglobinopathies. Based in Hyderabad, weve been serving those afflicted with Thalassemia and Sickle Cell Anemia for the past 20 years.

AIM:

- To provide appropriate treatment to improve and provide quality 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 the under-privileged communities with free blood transfusion, medication and counselling
- To provide good quality blood to the patients
- To create platform for counselling pre and post Bone Marrow Transplantation (BMT)

Organogram of Society:



President's Message:

We at TSCS are carrying our dreams soon to turn into reality in the lives of every Thalassemia impacted family. We are commencing comprehensive treatment with Prevention Awareness & Cure (PAAC) all under one roof with an effort to knock out Thalassemia once and for all. TSCS with its new state of Art facilities is giving a new lease of life to all the patients under one roof. Under able guidance of Dr. Lawrence Faulkner a world renowned Hematologist, TSCS is also setting up an International standard Born Marrow Transplant Center.

As part of TSCS movement, the success and the true sense of making a difference lie in our belief that it takes only an honest thrive by few honest people like you to make a considerable amount of difference.

Come join us in making Telangana a Thalassemia Free State. Let every citizen of India resound his/her awareness and take the new generation out of the clutches of thalassemia.

Mr Chandrakant Agarwal
President - TSCS

Secretary's Message:

I am very grateful to all our well wishers who have partnered with us for 20 long years in a struggle for freedom from thalassemia. In this endeavor, we at TSCS have moved on from just facilitating blood transfusion to providing free blood through our own Blood Bank. It breaks our heart to know that there are still kids born with this disease because parents do not know about thalassemia. Society need awareness and awakening, our constant effort at TSCS is to keep the nation aware that Thalassemia is a preventable Blood disorder.

Our heart goes out to the suffering children, in the pursuit of providing permanent cure, TSCS is on its way to establish a fully fledged Born Marrow Transplant Center at affordable cost. We are not just stopping here our Research department is putting a persistent effort every day to study and know more about thalassemia, so that one day it can make life easy for Thalassemia affected.

Let our voice rise up to form the voice of this nation to make India THALASSEMIA FREE and it all begins with you. .AND THEN OUR JOY WILL BE COMPLETE..

Dr Suman Jain
CMRO & Secretary - TSCS

The Management Committee (MC) of TSCS comprises of 15 members enriched with skills and experiences in various fields. MC governs the activities of the organisation.

- During the year 2018, five Management Committee meetings were held at TSCS
- Members of Management Committee play a vital role in ensuring organisations compliance to the laws and regulations and take appropriate decisions on various activities.
- Members of Management Committee are not paid any remuneration, they work on honorary basis

Mr Naresh Rathi
Chief Patron
I Believe: Very little is needed to make a happy life; it is all within yourself, in your way of thinking.

Mr Pradeep Uppala
Chief Patron
I Believe: We are constituted so that simple acts of kindness, such as giving to charity or expressing gratitude, have a positive effect on our long-term on all the patients, have a positive effect on all the patients

Mr Chandrakant Agarwal
President
I Believe: We must value life and treasure each breath we take. We must also value each person and touch others lives every day.

Mrs K Ratnavali
Vice-President
I Believe: A little thought and a little kindness are often worth more than a great deal of money

Dr Suman Jain
Secretary
I Believe: If we all take care of one another and go the extra mile to help and work together, we all gain, each one of us is lifted up

Mr M A Aleem Baig
Joint Secretary
I Believe: Goodness is about character integrity, honesty, kindness, generosity, moral courage, and the like. More than anything else, it is about an act of care for other people.

Mr Manoj Rupani
Treasurer
I Believe: My religion is very simple. It is all about kindness & care.

Mrs Rama Vuppala
Treasurer
I Believe: what you do for others make more impact on your life than what you do for yourself.

Dr D Venkata Ramana
Executive Member (Ex President)
The best and most beautiful things in the world cannot be seen or even touched they must be felt with the heart.

Dr Shailesh Singi
Executive Member
In the end, its not the years in your life that count. Its the life in your years what you did to make a difference in others life

Dr J Rajeshwar
Advisory Member
I Believe: Here are the values that I stand for: kindness, compassion, treating people the way you want to be treated and helping those in need.

Dr Sirisha Rani
Advisory Member
I Believe: Lifes most important question is: What are we doing for the society?

ADVISORY BOARD

R. Srinivasan
Shika Management Services Innova Childrens Heart Hospital

Mr. Vaman Rao
IPS officer (Retired)

Dr. Geeta Kolar
Head of Foetal Medicine Fernandez Maternity Hospital

Dr. Ashwin Dalal
MD in Pediatrics, DM in Head of Medical Genetics

PATRON DOCTORS

Dr. Sirisha Rani
Pediatric Hematologist

Dr. Amarnath Kulkarni
Pediatric and Adolescent Endocrinologist

Dr. Sreenivas Namineni
Pediatric Dental Surgeon

Dr. Anuradha Kulkarni
Ophthalmologist

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

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

Banker and Auditor

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

Research Advisory Board:

#	Name	Designation
1	Dr. M.P.J.S. Anandaraj	Emeritus Scientist
2	Dr. Q. Annie Hasan	Professor & Head, Dept. of Genetics & Molecular Medicine, Senior Scientific Officer, KIMS and Vasavi Medical Research Center
3	Dr. Kaiser Jamil	Emeritus Research Scientist and Head, Genetics Dept., BhagwanMahavir Medical Research Centre
4	Dr. K. V. Radhakrishna	Scientist D, National Institute of Nutrition
5	Dr.Lavanya M Suneetha	Head- Research & Training Infectious Disease Research Laboratory, CODEWEL Nireekshana
6	Dr. Ashwin Dalal	Head, Diagnostic Division, CDFD
7	Dr.Shailesh R Singi	Consultant Hematologist and BMT Physician, Century Hospital
8	Dr. S. Sirisha Rani	Consultant, PaediatricHemato Oncologist, Rainbow Hospital for Women and Children
9	Dr. Suman Jain	Chief Medical Research Officer & Secretary, TSCS

Achievements:

- Society started in 1998 with 20 children and reached to 2536 in Dec 2018. Comprehensive database of patients is maintained for research purpose
- Around 1300 children are given free blood transfusion every month
- Establishment of our own blood bank in 2010 enabled free blood to all the children. So far 98,201 (December 2018) units of blood issued to Thalassemia children
- Free periodic medical check-up with multi-specialty doctors
- Research Collaboration with Institute of Genetics-Hyderabad, Centre for DNA Fingerprinting and Diagnosis-Hyderabad, Genetic Department of Kamineni Hospitals - Hyderabad, Genome Foundation Hyderabad, CSIR Institute of Genomics and Integrative Biology (IGIB) - New Delhi and Sankalp Foundation -Bangalore
- Bone Marrow Transplantation(BMT) of our children in collaboration with Sankalp Foundation
- Enrolment in Aarogyasri scheme to give free medicines, Iron-chelating drugs, investigations and transport to around 450 Thalassemia children
- To facilitate for establishing prenatal diagnosis centre in Hyderabad with the help of Fernandez Hospital and CDFD
- Received awards of excellence from NTBC and NACO for working towards 100% voluntary blood donation on 14 June 2016 and also from TSACS in 2015
- With support from well-wishers, new building constructed at Shivarampally, Rajendranagar, Rangareddy district with modern facilities at Blood Bank and Transfusion Centre
- Research Centre Recognized by Department of Scientific and Industrial Research (DSIR) and under section 35(1)ii (Reseach only) act of Income Tax Department, 1961
- Credited with seven papers published in various national and international journals and two are under review

Patient Profile:

In the society 2536 patients are registered since the inception in 1998 the details of the patients are given in the following tables.

- During the year 2018, 131 patients were registered with our society
- 77% of the cases are Thalassemia major and remaining 23% are associated with Sickle Cell Anemia, Sickle Thal, E beta Thal & Thal Intermedia

Demographic Details:

Telangana	Total	Andhra Pradesh	Total	Other	Total
Adilabad	225	Ananthapur	25	Karnataka	19
Hyderabad	632	Cuddupah	34		
Karimnagar	124	Chitoor	14	Maharashtra	13
Khammam	183	East Godavari	85		
Mahaboobnagar	119	Guntur	78	Others	72
Medak	88	Kakinada	12		
Nalgonda	140	Krishna	55		
Nizamabad	75	Kurnool	75		
Rangareddy	119	Nellore	6		
Warangal	134	Prakasham	55		
		Srikakulam	14		
		Vijayanagaram	10		
		Vishakhapatnam	52		
		West Godavari	78		
Sub Total	1839		593		104
GRAND TOTAL					2536

Classification of Disease	
Type of Disease	No.
Thalassemia Major	1733
Thalassemia Intermedia	91
Sickle Beta Thalassemia	137
Sickle Cell Anemia	461
E Beta Thalassemia	40
Others	74
Grand Total	2536

Blood Group Details	
Blood Group	No.
A ve	24
A +ve	474
B ve	45
B +ve	744
AB-ve	09
AB+ve	158
O ve	48
O +ve	1033
Oh (Bombay Phenotype)	1
Total	2536

About TSCS

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 Telangana with more than 2536 Thalassemia and Sickle cell anemia patients with age group ranging from 3 months to above 20 years, as on December 2018. We strive to give these children full support and strength in painful crisis. We also strive to develop confidence in thalassemia children to lead a normal life as any other human being.

Kamala Hospital & Research Centre:

Society has been actively supporting research activities for improving patients treatment and in identification of mutations status/genetic variation.

Research Objectives:

- Prevention of Thalassemia by Carrier screening and counselling. Presently about 2500 cases have been screened for carrier status and counselled..
- Population Screening among Ethnic Groups in and around twin city of Hyderabad.
- Importance of Deferasirox (Asunra) treatment in non-transfusion-dependent thalas semia (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 of 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.

Thalassemia & Sickle Cell Society Vuppala Venkaiah Memorial Blood Bank:

TSCS blood bank was launched in March 2010 keeping in mind the need for safe Blood for our very own Thalassemia kids. This is one of the major effort to keep the children away from any adverse reactions arising of unsafe blood transfusion.
We are 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 affected kids and also caters to the needs of nearby hospital on daily basis.

Vuppala Krishnarao Chandrakala Diagnostic Centre:

Thalassemia & Sickle Cell Society Vuppala Krishna Rao & Chandrakala Diagnostic Services established in September 2011 offers facilities for carrying out Laboratory investigations with 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 screening HbA2 levels. The Lab has high quality precision equipments that provide qualitative and quantitative methods of analysis of biological fluids such as blood, serum, tissue, urine, stool etc.
Thalassemia & Sickle Cell Society is committed to provide affordable laboratory testing services to all members of the communities.

Activities of TSCS

Jan - Dec 2018	12,171 blood units were given to thalassemia patients out of 15,930 blood units collected from blood donors during this year
Jan - Dec 2018	Multi Organ Screening camps were conducted in January, March, July, September and December for Thalassemia and Sickle Cell patients
26th Jan 2018	Flag Hoisting on Republic Day at Society with Thalassemia children, staff and Board Members

21st Feb 2018	Connect 2018: Regional Partners Meet for Greater Synergy & Pgoramme Impact by Charity Aid Foundation, Manasarovar The Fern, Hyderabad attended by Dr Saroja and Mr Anil Reddy. Main objective of the programme - How to use social media to improve our societys image and generate funds

23rd Mar 2018	Symposium on Hemoglopinopathies: Clinical Insights and Basic Science on Friday, 23 rd March, 2018 at IGIB, New Delhi. Dr Suman Jain and Dr Renuka Raju participated in the Symposium
24th Mar 2018	"Awareness on Thalassemia Prevention and Parents Perspective of Thalassemia" was conducted by Council of EHS Professional at Jeedimetla. Mrs Ratnavali and Dr Saroja spoke on the importance of Blood Donation and HBA2 Test
6th May 2018	On the eve of "Thalassemia Day" Mr.Surendra Agarwal sponsored a Picnic to Mount Opera. Around 120 Thalassemia & Sickle cell anemia children, their parents and staff had good time.

7-13th May 2018	Hands on traning on "Transfusion techniques and Management of Thalaseemia and Sickle Cell Anemia" was provided to Government Hospital staff (including 3 doctors and 3 nurses) of Mahabubnagar
18th & 19th May 2018	Sankalp provided digitalisation of Thalasemia patient records and Blood bank management software. They organised meeting for sharing the experiences and betterment of the services with all their customers and partners at Bangalore attended by Dr Suman Jain, Dr Saroja, Mr Ravi, Mr Bhargav and Ms Sonal Lakhani

2nd June 2018	Inauguration of Transfusion center in Government Hospital of Mahabubnagar attended by Dr Suman Jain

14th June 2018

On Eve of Blood Donor's Day, TSCS participated in the walk organised by Telagana State Aids Control Society (TSACS). A Skit based on Thalassemia and its prevention was performed by Thalassemia Children of our society at Ravindra Bharati, Hydreabad.

18th July 2018

Symposium - Growth Puberty, Bone Health in Thalassemia - Chilhood to Adulthood" was jointly organised by ESI Medical college Dept. of Pediatrics & Medicine, Sanath Nagar and TSCS, Hydreabad in assocation with Hyderabad Pediatric & Adolescent Endocrine Group. Nearly 50 Pediatrician, Hematologist, Pedriatric Endocrinologist attended the Symposium

11th Aug 2018

An Educational seminar was organised by Lets Help Someone where in Dr MB Agarwal a renowned and respected Hemato-Oncologist gave a lecture to thalassemia patients and parents on the management of Thalassemia

16th Aug 2018

A training programme was organised by Wishing Factory at Red Cross, Warangal to Thalassemia patients and parents on the importance of Iron-chelation and usage of infusion pump attended by Dr Suman jain and Mrs Ratnavali

26th Aug 2018

Letzchange helped us to get connected with Airtel Hyderabad Marathon 2018 runners Mr Ajay Kalhan and Praveen Velmury. They opted to raise funds for the cause and welfare of Thalassemia children

12th Sep 2018

Pooja was performed at B Narayandas Shyam Sunder Loya Cure Thalassemia Welfare Trust - Our New Premises at Shivarampally to commemmorate the opening

25-28th Oct 2018

Shifting of Blood Bank to the new premises at Shivarampally

14th NOV 2018

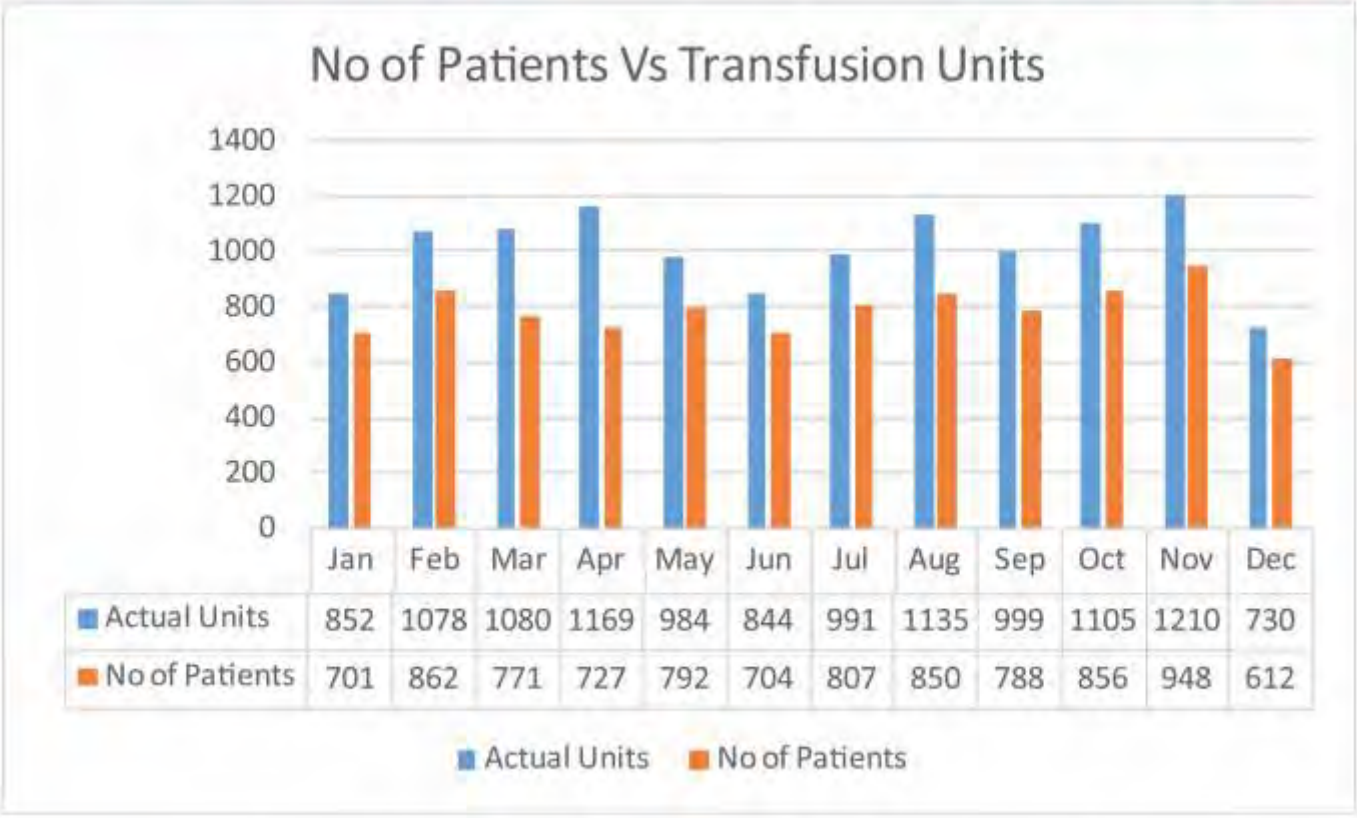
Children's Day & World Diabetes day was celebrated at Lotus Hospital, Lakdikapool by Thalassemia patients with diabetes to exhibit their talents. Dr Amarnath Kulkarni had organized this fun packed programme to encourage the children. Dr Suman Jain was the Cheif Guest

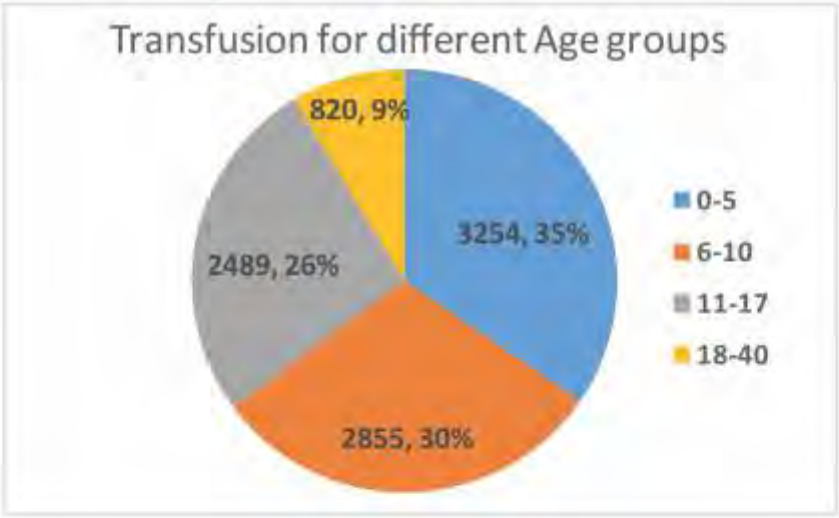
17-18th Nov 2018

"6th Thalassemia Lunch-On Symposium Both meetings are open to Medicos and patients / parents / social groups; Main speakers were Dr Baba Inusa and Dr YeþimAydinok. This symposium was organised by Dr M B Agarwal, Mumbai Haemotology group at Bombay Hospital. This scientific meeting was attended by Dr Suman Jain and Dr Saroja"

1st Dec 2018

On occasion of World Aid's Day Thalassemia and Sickle cell Society had put up a stall and actively participated in the 2k run organized by TSACS at Peoples plaza, Hyderabad



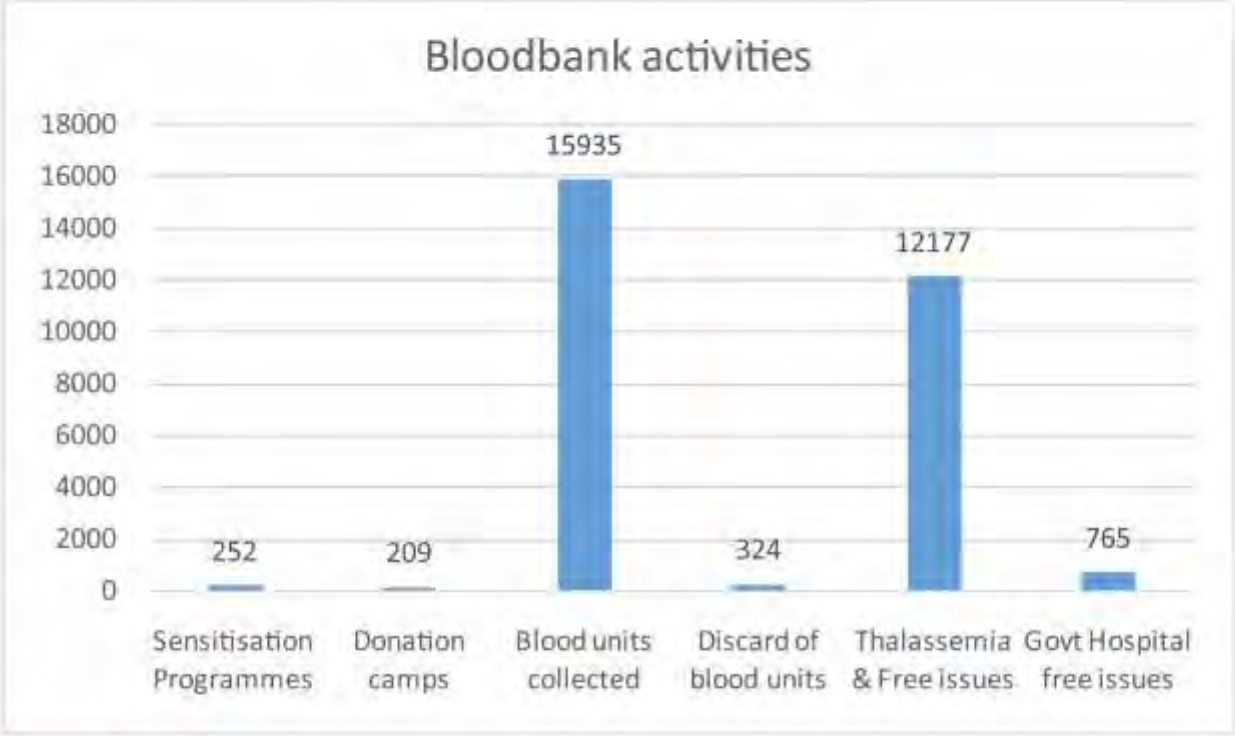


HPLC tests:

New cases Registered	HPLC at Society Couples/Siblings	CVS referred to NIMS Hospital & CDFD	Splenectomy	HLA Typing	Patients examined during the multi-organ screening camp
131	743 (445 free)	9	4	57 (46 free)	530

Blood Bank:

- Blood bank is shifted to new spacious premises with ultra-modern facilities at Shivarampally, Rajendranagar, Rangareddy District
- The important part of the organisation's role is to raise public awareness through community publicity campaigns, education in schools, colleges, universities, business houses about proper care and management of people with these conditions. TSCS produced a varied number of health promotion leaflets, to educate the general public. During the year we have conducted 252 sensitisation programmes in and around Hyderabad
- 76.42% of free blood units were given to Thalassemia and Sickle Cell patients



Research:

#	Project Title	Sponsoring Agency/ Collaboration
1	β -Thalassemia Disease Burden and Mutation Micro Profiling in Populations of Telangana	Telangana State Council of Science andTechnology (TCOST) under Assistance for Development of State S&T Councils Programme of DST (GOI) - Prof V R Rao
2	Reactivating fetal haemoglobin in patient-derived human stem cells through miR-96 knockout using CRISPR/Cas9: An approach for treating β-hemoglobinopathies	IGIB (Institute of Genomics and Integrative Biology, Council of Scientific and Industrial Research, New Delhi, India) - Dr NeelamLahani
3	Precise gene correction of the haemophilia B and beta-thalassemia disease mutations in human induced pluripotent stem cells (hiPSCs) using gene-editing nucleases for cell-based therapy	IGIB - Dr Sivaprakash Ramalingam
4	Generation of naturally occurring beneficial HPFH mutations using CRISPR-Cas9 based targeted genome editing to reactivate fetal haemoglobin: As strategy for treating β-hemoglobin disorders	IGIB - Dr Sivaprakash Ramalingam
5	Genomic approaches for Rare Genetic Disease Diagnosis (Rare Gen)"	IGIB- Dr. Chetana Sachidanandan

Aarogyasri

Aarogyasri Scheme is a unique Community Health Insurance Scheme being implemented in TSCS. Aarogyasri is the flagship scheme of all health initiatives of the State Government with a mission to provide quality healthcare to the poor.

The scheme provides financial protection to families living below poverty line with white card up to Rs. 2 lakhs in a year for the treatment of Thalassemia affected children. The objective of the scheme is to improve access of below poverty line families to quality medical care for treatment of Thalassemia disease involving hospitalization, surgeries and therapies at Kamala Hospital & Research Center (KHRC) a Unit of TSCS.

This Scheme is an effective model to enable the poor families to avail quality medical treatment in a cashless manner. Till now we have 451 families who are benefitted in our society. Under this scheme all transactions are cashless for covered procedures.

Free Breakfast, Lunch and Transportation consultation, counseling, investigation, blood transfusion and medication

Testimony of Aarogysri Scheme Beneficiary

Working as a Post Master, it was very difficult for me to manage two Thalassemia Sons (Yugendher 12 yrs, Tirupathi 11 yrs). I couldnt afford to buy all the prescribed medicines or get the investigation done.

Since last two years under aarogyasri scheme at TSCS, I am getting medicines as well as investigations done free. This has reduced my financial burden and I am now able to provide better education to my children.

Father - Kishan

AAROGYASRI
Health Care Trust

Periodic Medical Check-up:

Dr Sirisha Rani, Pediatric Hemato-oncologist

Dr Anuradha, Opthalmogist

Dr Jain, ENT Specialist

Dr A Narender, Paediatric Surgeon

Dr Srinivas Namineni, Dentist

Dr Nageshwar Rao, Paediatric Cardiologist

Dr K Nagarajuna, Paediatric Surgeon

Dr. Amarnath Kulkarni, Pediatric and Adolescent Endocrinologist

Special thanks to our dedicated team of doctors for rendering their free services to our Thalassemia & Sickle Cell Anemia patients

Academic/Professional Achievements:

Class X	Inter	Degree	Professional Degree	Working
Poornima	Saleh	Manisha	Ramya - Aeronatical Eng	Sushma- Google
Nehru	Md Sufiyan	Noorunissa Begum	Hari Krishna MBA	Shirisha - Med. Transcription
Muthahuruddin	Samin Ali	Hema Rupani	Ameena - MBA	Usha Shri Beniya - LVP Eye Hospital
Edukondalu	Jahanavi	Bharat Rupani	Vishwa Teja - M.Tech	Sai Aditya - Namasthe Telangana
Naveen Kumar	Saina	Sai Srujana	Ankita - B.Tech	B Shiva Kumar TSCS
	Rashmi	Nikunj Patel	Prashanth - Diploma Elect	G Srikanth Oracle
	Divya	Madhusudhan	Sai Krishna - Polytechnic	Rahul - Wells Fargo
	Ch Santhoshi	Ms Swathi	Vishwa Teja - B.Arch	Rishab - Wipro
	Naresh	Arsheen Fathima	Vikram - Dip Civil Eng	Ashwini - Physiotheraphy
	Afra Ahmed	Ranjeeth	Rahul - Diploma EEE	Durga - BSC Nursing
	Taniya	Sumaira Fathima	Sewtha - MPHW	Osman Pasha - Video Mixing
	Yogitha	Neelima	Elisha Catering	Sai Vara Prasad Genpact
	B Praveen	Sajida Begum	Yeshu Paul Cattering	M Priyanka TSCS
	Abhishek	Jahnnavi	Arsheen Baig- BSc Nutrition	Krishna chaitanya Animation
		Tajdar	Shivani - Tally(Accounts)	Souvik Bose - Wipro
		Venkat Karthik	Manirath goud B.Tech	Raghavenra - Tech Mahendra
		Sherly	Ravinder, Tribal Welfare Association - Gurukul	Khaza Nadeemuddin - Own Restaurent and Charittable Trust (Vice-President)
		Zahda Mahavin	Swathi - B.Tech	Mukhram Ali - Activa Show room
		Mohsina Thabsum		Chanakya Reddy - Own Business
		Ravi		Nooruddin - Own business
		Afroz		Bharat Roopani - Cardiac Capital, Delhi
				Dr. Azra Fatima - Researcher at Learn Maximum PC polyclinics
				Raghav, Own Business
				Harshith - Infosys

Let your action make a difference There is Hope.

My name is Rashmi , and I was born with thalassemia, a blood disorder which requires transfusions every other week to keep me healthy and alive. There are a lot of complications associated with thalassemia, especially transfusion-related iron overload which requires a daily drug treatment, and sometimes it can be scary knowing that excess iron will damage my heart and liver if I cant get it out. But thanks to the expert care I receive from experienced and knowledgeable doctors at TSCS

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 take me to TSCS and seek the medical care that we receive from expert Doctors to deal with such a demanding disorder. Parents have always been willing to give up a lot of their time to make sure I can stay healthy. I dont remember when I was diagnosed, but they say I was around one year old.

My parents had a marriage within relation that is why thalassemia came as a genetic disorder. It got deep itched in my mind that blood transfusion is part of my life, there is no comparison there is no questions.

Though I always wanted to excel in all that I do including sport, just that my parents bring their concerns because of my sickness. But I am a good dancer and have partici pated and won many awards, representing my school in different levels. My parents are the motivating factor behind my ability to stand strong in different circumstances, be it dancing or my studies, my mother stands with me to give that extra boost to my imagination and competitive spirit.

Thalassemia is daunting, but that is not the end of life, there is life beyond and I would like to say that there is joy and joy in celebrating every moment with friends & family. It is simple to lead a healthy life by taking few precaution blood transfusion and regular medication. A positive thoughts can bring in better results and higher quality of life, do not limit yourself in petty thinking and feeling sad for yourself in any circumstances. I also feel society at large needs to accept and assimilate people like me in the mainstream. We all have to understand that people like me are not sick or feeble or unintelligent just because I am a thalassemia patient.

Destiny has bigger role to play in my life and I am living every day looking forward and pressing on to my goal. Every day throws a new challenge but I am geared to overcome it with positive attitude.

Donor List:

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79	Komaravolu Prasantha
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95	Molly Anirban Pathak
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111	P Radhika
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133	Rajesh Jain
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156	Shashikant Agarwal

157	Sher Ali Hajiyani
158	Shree Jewellers
159	Shivrathan Agarwal
160	Shri Pankaj Agarwal
161	Shrinath Rotopack Pvt Ltd
162	Shrutika Murthy
163	Shweta Developers
164	Shwetha Srivasthava
165	Sitaram Manthri Pragada
166	Spp Poly Pack Pvt Ltd
167	Sreyas Holistic Remedies Pvt Ltd
168	Sri N V Rao
169	Sri Krishna Jewellery Mart
170	Sri P S Rao
171	Sri Ramgopal
172	Sri Sathya Sai Nigamagamam
173	Sri Tirumala Steel Traders
174	Sridevi
175	Srikanth Gullapalli
176	Srilatha
177	Srinivas Chaitanya
178	Srinivas Kolla
179	Sriram Srinivas
180	Sriram Srinivas
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183	Sunil Trading Company
184	Sunpharma Labortories Limited
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186	Suraiya Hajiyani
187	Suryakala
188	Sutrave Keerthana
189	Tourism Department Of Telangana
190	Tulja Bhavani Devi
191	Uma Nambiar
192	Uma Nambiar
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197	Vasudha Pharma Chem Ltd
198	Veeturi Bramalinga Swamy
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201	Venkata Giridhar Nallaparaju
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203	Venkata Ramani
204	Vijaya Saradhi
205	Vijayalakshmi
206	Vinod & Neela Malani
207	Yasoo Dharani
208	Yuva & Vega

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 2018

RECEIPTS	AMOUNT		PAYMENTS	AMOUNT	
Opening Balance			**Capital expences**		
Bank Accounts			Air condsioner: Air Comfort System	40000	
ANDHRA BANK	5412		Refrigerater: Bajaj Electronics	23500	
Canara Bank	231047		UPS: Cyber Power Solutions	95000	
Canara Bank-118110102316S	4515		Ambulance: Jasper Industries Pvt Ltd	1061800	
Cash-in-hand	10016	251589	HPLC Machine: Bhee Agencies	3371957	
			Printers: Spectrum Corporation Sales	51250	
			Xerox: Teja Copier Sales Services	80540	
			Computers	129280	5006997
Capital Account					
Life Members Ship		392400	**Building Construction Expences**		
			Al Jamar Floor Ceiling Expenses	200000	
			Civil consultancy: C-Con Consultants	218000	
Current Assets			Cement for New Building	92530	
Deposits (Asset)			Chemicals for New Building	116026	
Fixed Deposit		9000000	Cold Room Expenses for New Building	294700	
			Electrical Fittings for New Building	241138	
Income			Electrical Transformer for New Building	177349	
Aarogyasri Claims	5181410		Electronic Goods (Pleasen Electronic) New Building	1177757	
Contribution From General Patients for Blood Testin	12381153		Fire Safety Expenses	1165820	
Contribution From Patients for Laboratory Testing	1097090		Flooring & Innovation Expenses	421190	
Contribution From Patients for Medicines	2187485		Hardware items for New Building	9448	
Contribution From Patients Maintenance	474200	67934009	Iron and Steel for New Building	8196	
			Iron Steps and Door Expenses	193822	
Indirect Incomes			Plumbing expences: Monad Ishaq	110000	
Donations Recd	8727994		Tiles work expences: Mohd Aslam	40000	
Interest FDRs	9572		Office Maintenance Charges for New Building	12790	
Interest Received	1924229	10661795	Granite work expenses: Osman	234899	
TDS payable		21800	Security Service Charges for New Building	47200	
			Shoket Abbas Electrician for New Building	175000	
			Thrinaina Electronic Security Systems for CC Camera	45000	
			Tiles for New Building	1261507	
			Transport Charges, Amalies,Labour Charges Etc	74430	
			Water Proof and Seal Exp: New Building	125946	6442503
			Revenue Expences		
			Purchase of Medicines	38870639	
			ESI Payable	243908	
			Outstanding Liabilty	9998357	
			PF Payable	486080	
			Professional Tax	34900	
			TDS paid	80800	
			Audit Fees	59000	
			Bank Charges	14136	
			BMT Expenceses	453000	
			Camp & Awareness Expenses	1115431	
			Consultation Charges	182700	
			Conveyance	442460	
			Electrical Items	53550	
			Electricity Expences	1063856	
			Fuel Charges	860150	
			House Keeping	238264	
			Insurance	259000	
			Nutrition	748089	
			Office Expenses	2083663	
			Postage & Courier Exp	4454	
			Printing & Stationary	868086	
			Rent	481000	
			Repairs & Renovations	583472	
			Service Charges	93078	
			TDS Deduction	164655	
			Tds Penalty	17080	
			Telephone Expenses	155824	
			Transportation	990360	
			Travelling Exp	23284	
			Dubes & Taxes	30900	52661989
			Other Payments		
			Payments to Medical Creditors		612492
			Innovative Financial Advisors Pvt Ltd		1932000
			Fixed Deposit		9000000

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

Financial Report:

			B Narayana Das Shyam Sundar		10900000
			Closing Balance		
			Bank Accounts		
			ANDHRA BANK	5475	
			Canara Bank	724797	
			Canara Bank-1181101023165	1001	
			Cash-in-hand	1000	
			Tax Deduction At Source	2108240	2840512
Total		88251593	Total		88251593

For Thalassemia & Sickle Cell Soc...
SECRETARY

THALASSEMIA & SICKLE CELL SOCIETY
Phone: 040-24560911 040-64610910

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

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

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

SO DONATE GENEROUSLY

Financial Report:

THALASSEMIA SICKLE CELL SOCIETY
Door No: 22-8-496 to 501 ; Purani Haveli; Chatta Bazar,
Opp: City Civil Courts Purani Haveli, Hyderabad - 500 002
INCOME AND EXPENDITURE FOR THE PERIOD ENDED WITH 31ST MARCH 2018

PARTICULARS	AMOUNT		PARTICULARS	AMOUNT	
Opening Stock		1350475	Income		
			Aarogyasri Claims	51814101	
Purchase Accounts			Contribution From General Patients for Blood Testin	12361153	
Purchase of Medicines		30870639	Contribution From Patients for Laboratory Testing	1097090	
Indirect Expenses			Contribution From Patients for Medicines	2187465	
			Contribution From Patients Maintanance	474200	67934009
Salaries & Wages	10656482				
Audit Fees	59000				
Bank Charges	14138				
BMT Expencess	450000		Indirect Incomes		
Camp & Awareness Expenses	1115431		Donations Recd	8727994	
Consultation Charges	162700		Interest FCRA	9572	
Convayance	442460		Interest Received	1924229	10661795
Electricial Items	53550				
Electricity Expences	1063856		Closing Stock		3299813
Fuel Charges	850150				
House Keeping Expences	236284				
Insurance	259000				
Nutrtion Expences	746069				
Office Expences	2093063				
Postage & Courier Exp	4493				
Printing & Stationery	988096				
Rent	461000				
Repairs & Renovations	663472				
Service Charges	93078				
TDS Deduction	164995				
Tds Penalty	17080				
Telephone Expenses	155824				
Transportation	990300				
Travelling Exp	23284				
Duties & Taxes	30000	21793805			
Excess of Income over expenditure		27910698			
Total		81895617	Total		81895617

For Thalassemia & Sickle Cell Society
SECRETARY

THALASSEMIA & SICKLE CELL SOCIETY
Phone: 040-24560011 040-64610610

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

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

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
BALANCE SHEET AS ON 31ST MARCH 2018

LIABILITIES	AMOUNT		ASSETS	AMOUNT	
Capital Account			**Fixed Assets**		
Capital Fund	35767346		Airconditioner	49000	
Add Excess of income over expenditur	27910698	63678044	Ambulance	1261898	
			CAR	260000	
Donations Towards Corpus Fund	17810099		Centrifuge Machine for Lab	32957	
Life Members Ship	2076600	**19886699**	Computers	746158	
			Electrical Transformer	251696	
			Furniturs & Fixtures	1674451	
Current Liabilities			HPLC Machine	3339000	
			Machinery	405365	
Sundry Payables		557506	Medical Equipments	5573706	
ESI Payable		32775	Office Equipments	846323	
PF Payable		48291	Printer	51250	
Professional Tax		3500	Refregirator	23500	
			UPS	95000	
			Xerox Machine	80540	**14690844**
			Building work in progress		**26342503**
			Current Assets		
			Closing Stock		3299813
			Deposits (Asset)		28000000
			Rental Advance		120000
			Cash-in-hand		1000
			Bank Accounts		731272
			Tax Deduction at Source		9089384
			Receivables		
			Innovative financial advisors		1932000
Total		84206815	Total		84206816

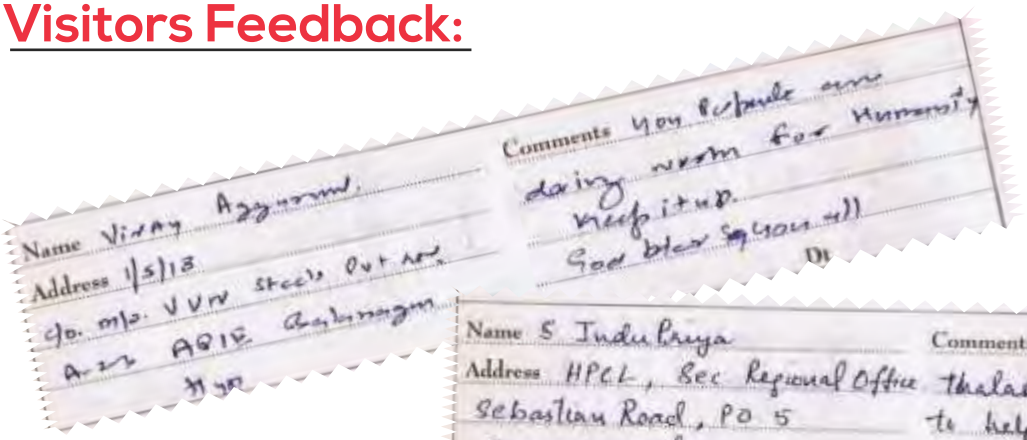
For Thalassemia & Sickle Cell Society
SECRETARY

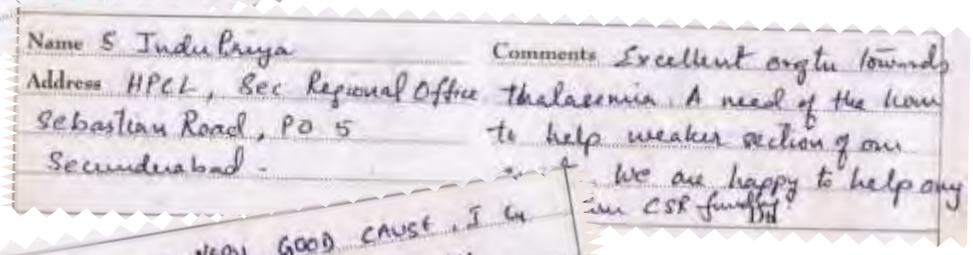
THALASSEMIA & SICKLE CELL SOCIETY Phone: 040-24736011 040-64610810 HYD-2.

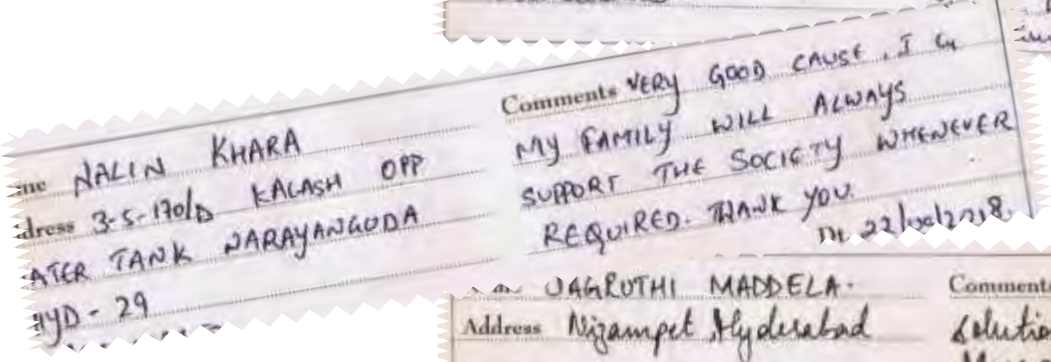
NVS MURTY & CO. Sec'bad M.No. 022727 Chartered Accountants

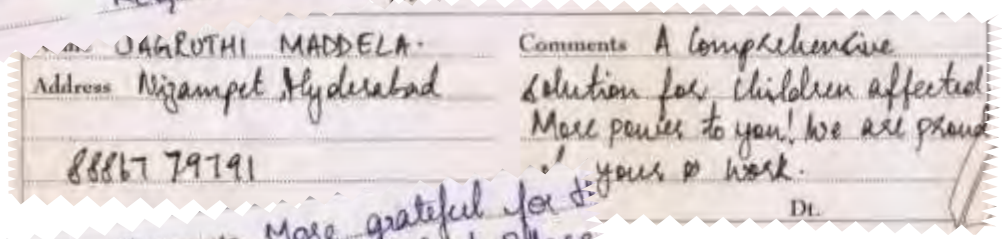
For NVS MURTY & CO.
Chartered Accountants
CA NVS MURTY
(Proprietor)
M.No.022727

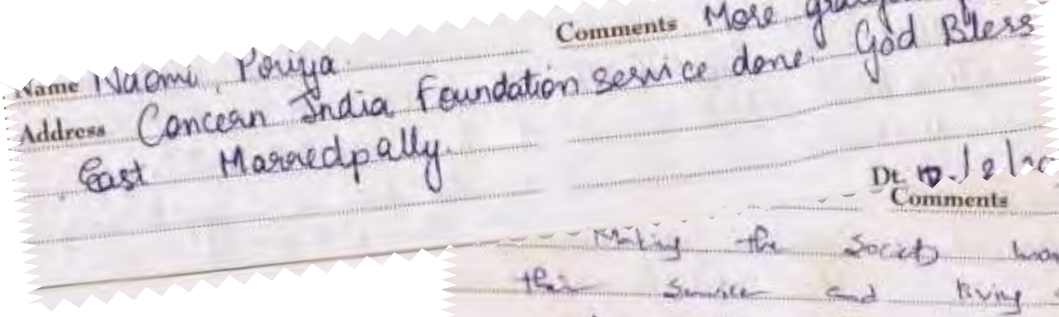
Visitors Feedback:

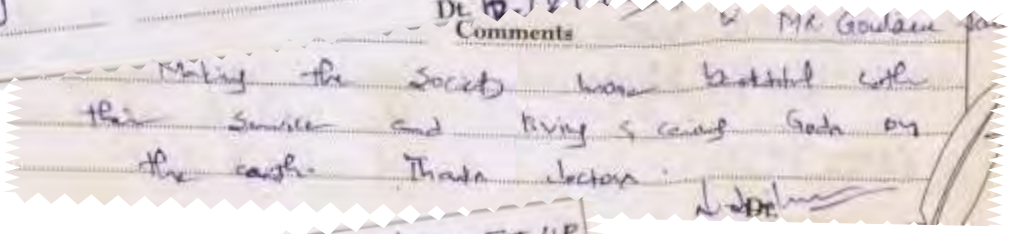

Name Vinay Agarwal
Address 1/5/13
c/o. m/s. VVM Steels, Pvt Ltd.
A-23 APIE Balanagar
Hyd
Comments You people are doing warm for Humanity keep it up.
God bless you all
Dt

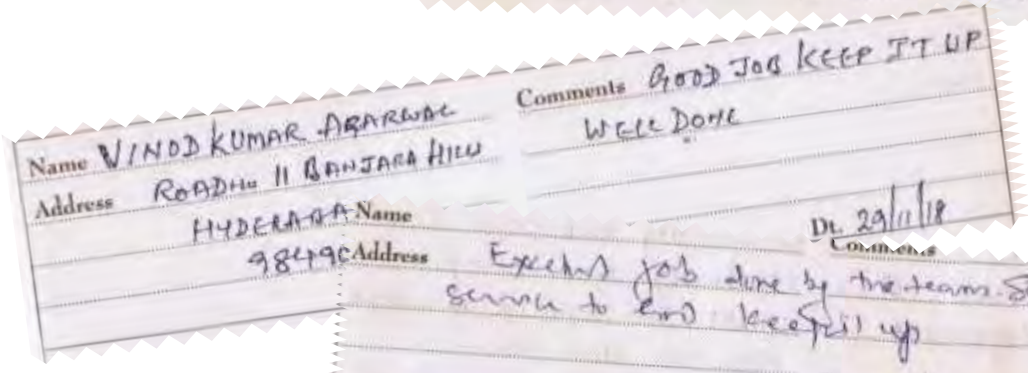

Name S Indu Priya
Address HPCL, Sec Regional Office
Sebastian Road, PO 5
Secunderabad.
Comments Excellent orgtn towards thalassemia. A need of the hour to help weaker section of our ... we are happy to help any ... CSR fund
Dt

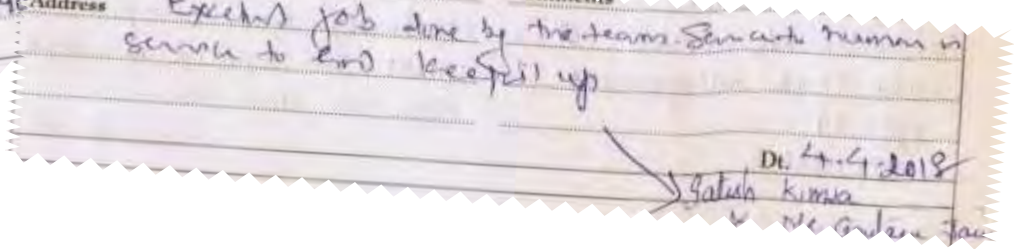

me NALIN KHARA
dress 3-5-170/D KALASH OPP
ATER TANK NARAYANGUDA
YD - 29
Comments VERY GOOD CAUSE. I & MY FAMILY WILL ALWAYS SUPPORT THE SOCIETY WHENEVER REQUIRED. THANK YOU.
Dt 22/12/2018


JAGRUTHI MADDELA.
Address Nizampet Hyderabad
88867 79791
Comments A comprehensive solution for children affected. More power to you! We are proud of your work.
Dt.


Name Naomi Poriya
Address Concern India Foundation
East Maredpally
Comments More grateful for the service done. God Bless
Dt 19/12/18


Comments Making the Society happy with their Service and living & caring Gods by the earth. Thanks doctors
Dt


Name VINOD KUMAR AGARWAL
Address ROAD No 11 BANJARA HILL
HYDERABAD Name
9849 Address
Comments GOOD JOB KEEP IT UP
WELL DONE
Dt. 29/11/18
Comments


Excellent job done by the teams. Sincere requests to ... keep it up
Dt. 4.4.2018
Satish Kumar
We ... for


TSCS
STRIVE FOR PREVENTION

Epidemiology of Thalassemia:

Hemoglobinopathies are inherited disorders of red blood cells. Being an important cause of morbidity and mortality, they impose a heavy burden on families and the health sector in our country. India has the largest number of children with Thalassemia major in the world about 1 to 1.5 lakhs and almost 42 million carriers of ß (beta) thalassemia trait. About 10,000 -15,000 babies with thalassemia major are born every year. Sickle Cell Disease affects many communities in certain regions, such as central India and States of Gujarat, Maharashtra and Kerala. The carrier frequency of the Sickle cell gene varies from 1 to 35 % and hence there are a huge number of people with Sickle cell disease.

Burden of Hemoglobinopathies in India

In India, β-Thalassemia is prevalent across the country, with an average frequency of carriers being 3-4%. A higher frequency has been observed in certain communities, such as Sindhis, Punjabis, Gujaratis, Bengalis, Mahars, Kolis, Saraswats, Lohanas, Lambada, Sunni, Mudiraj, Madiga and Gaurs. HbS is highly prevalent in the tribal populations of Southern, Central and Western states reaching as high as 48% in some communities. HbE is common in the North Eastern states, and has a carrier frequency as high as 50%, in some areas. HbD is present in about 2% of people in Punjab. It is estimated that about 10,000-15,000 babies with Thalassemia Major (TM) are born every year.

Thalassemia & Sickle Cell Disorders

HAEMOGLOBINOPTHIES (Thalassemia & sickle cell disorders) are a group of inherited disorders in which the production of normal hemoglobin is partly or completely suppressed because of the defective synthesis of one or more of its component globin chains.

Thalassemia & its inheritance:

- Thalassemia is an inherited disorder of the red blood cells. These cells contain the hemoglobin molecule, which is responsible for binding oxygen from the air we breathe and carrying it to the tissues where energy is released.
- In Thalassemia one of the components of the hemoglobin molecule is inadequately produced or not produced at all. If there is lack of α- chain production then the resulting disease is known as α-thalassemia. If the component that is lacking is the β-chain, then the resulting condition is β- thalassemia.
- The reason for the inadequate or non- production of these components is a change in the genetic code (mutation), in that part of the DNA, which is the template for the production of the protein. The mutation or altered gene cannot initiate the process, which hamper the production of necessary amount of protein.
- Genes, sections of DNA responsible for a protein, are carried on chromosomes and each individual has a pair: one chromosome from each parent.
- A mutation may exist on one chromosome of a pair, but not on the other. The protein produced by the one, healthy chromosome is enough to keep the individual well, even though his/her red cells are smaller than normal. Such an individual is known as a carrier (or heterozygote) that can only be detected by special blood tests (HPLC and HbA2). A carrier may give his/her offspring either the healthy chromosome or the one bearing the mutation.
- Severe thalassemia (Thalassemia Major) will result if a child inherits the abnormal (mutation bearing) chromosome from both parents. In other words both parents must be carriers if a major Thalassemia disorder is present in the child. This situation is known as homozygous thalassemia.

Signs & Symptoms for thalassemia:

Normal at birth. Signs and symptoms appear at the age of 6 weeks to 2 years, paleness of face, restlessness and fussy, loss of appetite, lack of sleep, enlarged spleen. If undiagnosed could lead to complications such as chronic anemia, growth failure, enlarged spleen & liver, abnormal stools, leg ulcers, deformed bones, skin bronzing, repeated infections etc. As age progresses the other complications would be iron overload, heart failure, infectious myocarditis, hypothyroidism, hypoparathyroidism, hypopituitarism, delayed puberty, infertility along with diabetes mellitus

Diagnosis:

Patients haematological parameters such as complete blood picture (CBP), haematocrit (PCV, MCV, MCH, MCHC), RDW (red cell density width) and HbA2 and HbF levels by electrophoresis and HPLC would help in the diagnosis of thalassemia. Further DNA mutational analysis confirms the diagnosis.

Treatment & management of Thalassemia

- Saline washed packed red cell blood transfusions every 3 4 weeks to maintain haemoglobin above 9-10 gm/dl.
- Iron Chelation therapy after 15 blood transfusions (One child requires Rs. 3,000 to 15,000 per month for their iron chelators).
- Periodic medical check-up for serum ferritin level, liver function test & screening for hepatitis B and C, HIV, renal function tests, serum calcium & phosphorus level, dental check-up, cardiac check-up and endocrine analysis.
- Bone Marrow Transplantation(BMT) can cure the disease. For BMT one should have HLA matched donor. However the possibility of getting Histocompatibility Linked Antigen (HLA) matched sibling donor is only 30%

Sickle Cell Anemia

Every human being has red blood cells (RBCs) present in a round and flexible form moving easily through our blood vessels. When these round and flexible cells pass through a very narrow blood vessel they assume an elongated form and regain their round shape once they are passed out in to a regular blood vessel. These red blood cells acquire red colour due to the presence of haemoglobin in the blood. Usually in a healthy person the haemoglobin is stable and normal, but when there is any abnormality in the haemoglobin, the shape of the red blood cells changes from round and flexible form to a sickle or crescent moon like structure called as sickle cell that is rigid and sticky. These irregularly shaped sickle cells can get stuck in narrow blood vessels blocking or slowing down the flow of blood and oxygen to other parts of the body.

It has been noted that the disease (Sickle Cell) has significant prevalence in the following communities viz., Lambada, Madiga, Mala,Mudiraj, Muslims (Sunni), Hindu Dhodhia, Kukna, Varli, Bheel, Kolcha, Gaameet, Chowdhary etc. Hence, it is most imperative to have awareness on What is Sickle Cell Anemia, Who is Sickle Cell Patient and Who is a Sickle Cell Carrier. This has to be made known to the common man and spread awareness of the same among the population.

Sickle Cell Anemia is of two types

1. Sickle Cell Trait:

- A person with Sickle Cell Trait is referred to as Sickle Cell Carrier (S.C.C).
- The patient is considered as Sickle Cell Carrier when abnormal haemoglobinHb-S is less than 50% and normal haemoglobin Hb-A is more than 50%.
- A person with Sickle Cell Trait is referred to as a carrier and does not always show the symptoms of the disease except that there are traces of sickle shaped RBCs in the blood. However, there is a possibility that his children inherit the Sickle Cell Disease if he happens to marry a Sickle Cell Carrier or Sickle Cell Disease patient.

2. Sickle Cell Disease

- A patient with Sickle Cell Anemia is referred to as Sickle Cell Disease (S.C.D).
- The patient is considered as affected with Sickle Cell Disease, when abnormal haemoglobinHb-S is around 80% and normal haemoglobin is absent.
- A Sickle Cell Disease person carries certain symptoms which can be easily inherited by his children hinder the growth and development of the child

How does this disease get inherited by the child?

- When both the parents (father and mother) have normal haemoglobin and are neither Sickle Cell Carriers nor Sickle Cell Disease, then their children would be absolutely normal with normal haemoglobin
- If any one of the parents (either father or mother) has Sickle Cell Trait (or is a Sickle Cell Carrier), then there is a chance that 50% of their children would be Sickle Cell Carriers and 50% would be normal
- If both the parents are having Sickle Cell Trait (or are Sickle Cell Carriers) then 25% of their children would be normal, 50% would be Sickle Cell Carriers and 25% would be Sickle Cell Disease
- When amongst both the parents if any one parent, either mother or father is affected with Sickle Cell Disease then all their children (100%) would be Sickle Cell Carriers
- When amongst both the parents, if one parent is Sickle Cell Disease and other parent is Sickle Cell Carrier, then 50% of their children would be Sickle Cell Carriers and remaining 50% would be Sickle Cell Disease
- If both the parents (mother & father) are affected with Sickle Cell Disease, then all their children (100%) would be affected with Sickle Cell Disease

Symptoms of a patient with Sickle Cell Disease (SCD)

Symptoms include joint pains, stomach pain, spleen enlargement, gall bladder stones, anemia, jaundice, liver enlargement etc., would all hinder the growth of the child leading to two things.

One - The child is left with poor energy levels and

Two - If the diagnosis of the child is not done at proper time, then he/she may die due to improper treatment in early childhood only.

Treatment

- There is no remedy to prevent the onset of Sickle Cell Disease as it is purely inherited by the child from his/her parent. However, a timely and appropriate treatment can allow the patient to lead a comfortable and long life.
- Whenever there are joint pains, it is advisable to take painkillers or antibiotics in appropriate dosage as prescribed by the doctor.
- Whenever the patient is serious, he/she should be admitted in the hospital for proper care and treatment.
- One tablet of folic acid can be taken daily, as recommended by the doctor. Consuming one tablet each day will enhance the formation of red blood cells in the body
- Do not treat the pain of the patient as the pain of arthritis






Pooja was performed on 12 Sept 2018 by Mr & Mrs Chandrakant Agarwal and Board members at our new building located at Shivarampally, Hyderabad which is a four storied building with an area of 22,500 sft. The land was given on lease by Mr Shyamsunder Loya. Blood bank has been shifted to the new premises. Kamala Hospital and Diagnostic Laboratory will also be shifted shortly.





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

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

Cheque/DD to be drawn in favour of THALASSEMIA AND SICKLE CELL SOCIETY, Hyderabad or directly in the Bank Account No. 0608101049513, Canara Bank.

We accept foreign contribution to our FCRA Bank Account No. 1181101023165

Follow us on:

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