Annual Report 2010-11

THALASSEMIA & SICKLE CELL SOCIETY

Mission

To promote the provision of appropriate treatment and to achieve a good quality of life for every patient with Haemoglobinopathies, and to encourage prevention policies with the aim of reducing the number of newly affected births

Aim

To offer comprehensive treatment to treat thalassemia patients, provide safe blood, medical assistance, counsel & educate thalassemics and their families on the management of the disease, campaign for blood collection, and disseminate information for control of thalassemia to general population

Contents

Dear Friends,

The year 2010 is to be remembered as the year of Blood Bank dedicated to thalassemic families. It has been an ambitious year of various programmes and activities, while working within the constraints of conservative budget. For the last 13 years, TSCS has continued to strive with one aim: to provide a good quality of life for every child with thalassemia/ sickle cell anaemia.

I appreciate the tireless efforts and dedication of our staff in the pursuit of supporting the families with thalassemia and sickle cell anaemia all these years. We conducted several awareness programmes in remote areas where thalassemia is the most prevalent.

I would like to take this opportunity to say a very special “Thank you” to the donors who have contributed for the establishment of Blood Bank and Thalassemia Society. I am pleased to observe that more and more individuals are coming forward to support our work.

I am grateful to all our Board members for their active participation. Without the hard work of our employees – doctors, technical staff and the administrative staff, present position would not have been reached; I appreciate and thank them for their valuable contributions.

I would like to thank you for your support of our initiatives during this year and hope you will be pleased with our accomplishments outlined in the Annual Report.

Dr. Ramana Dandamudi
President

Dear Friends,

The year under review 2010 -11 was a qualitative year for the Society. We are happy to report that we have improved upon over the years. It is also a proud moment for us to inform you that society has started its own Blood Bank in March, 2010. Inspite of the constraints of limited funds and staff, the Society carried its work and there is optimistic feeling about our performance.

In terms of services TSCS continued to provide comprehensive treatment, provision of safe blood for thalassemia patients. It focused on prevention of thalassemia and sickle cell anemia, as a result we have been able to prevent births of thalassemia children. Improved survival of patients with thalassemia has given new importance to dealing problems with adults.

The year also saw, collaborative effort with Narayana Hrudayalaya in the establishment of Bone marrow transplantation unit in the year 2011 in their hospital. TSCS is ready to move ahead in the process of adding a diagnostic centre to our existing building.

We would like to thank Andhra Pradesh AIDS Control society for their guidance and cooperation in the establishment of Blood bank. We also thank MBS Jewellears, State Bank of Hyderabad, State Bank of India, NMDC, LIC Golden Jubilee Foundation, Nimmagadda Foundation, Kinnera Memorial Trust, Sree Krishna Jewellary Mart & Cognizant Foundation for their support to provide equipments for blood bank. We thank the blood donors for saving lives of thalassemia patients.

I thank board members for their timely advice and unstinted cooperation is greatly appreciated. I look forward to their support as together we can take our Society to the next level of growth.

We are grateful to philanthropists and well wishers whose trust in us and continued cooperation give us the confidence to tide over the problems and achieve our mission.

Our sincere thanks to our team – our staff - their hard work and dedication throughout the past years are greatly appreciated.

As we move into yet another year, we look forward to continued relationships with all, as well as to the continued success and growth of the Society.

Dr. Suman Jain

Secretary

The Beginning

Health and lifestyle issues which affected the existence and well-being of thalassemia patients motivated few parents and doctors to embark on a drive to start a centre to treat thalassemia patients. Thalassemia & Sickle Cell Society (TSCS) was started in 1998 and registered as a Society (Registration No. 5359 dated 22.10.1998) with an elected governing body of two physicians, two social workers, a civil servant and a businessman, three of them being fathers of thalassemia children. Hence with a humble beginning TSCS started functioning with 20 patients at its office at Banjara Hills, Hyderabad. As the patients increased, the place was insufficient to accommodate all of them. In 2009, TSCS shifted to the present facility at rented double storied building at Chatta Bazar, Purani Haveli, Hyderabad.

A 20-bed Transfusion centre provides the latest diagnostic and treatment facilities to thalassemics people free of cost. The society also provides medicines at subsidised price, regular growth monitoring of children, free medical consultation and genetic counseling, periodical medical checkup of patients by specialist doctors etc

From 2005.onwards the society's interest in prevention of thalassemia focused on public-health education activities in reaching parents and the general community and educational institutions in Hyderabad, Ranga Reddy, Kurnool, Nalgonda, Adilabad, Khammam, Vijaywada, West Godavari, Warangal, Karimnagar, Tirupati, Mahaboobnagar districts of Andhra Pradesh.

The society added feather in its cap of achievements, as it started a full fledged Blood Bank named "Thalassemia & Sickle Society Vuppala Venkaiah Memorial Blood Bank" which was inaugurated on 20th March, 2010. The society has proved itself in enhancing its mission of providing safe blood and quality services to thalassemia patients as well to others requiring blood transfusion.

It is through the support and strength of kind-hearted philanthropists, Trusts and Foundations, Banks, parents of thalassemia children etc. that TSCS could successfully scale through the initial difficulties of securing financial support and getting resource persons. With persistent determination, the society was able to achieve what it stands today the only Transfusion centre in Andhra Pradesh providing quality treatment for over 1364 .patients with thalassemia and sickle cell anemia.

Governing Body:

President:	Dr Dandamudi Ramana
Vice President :	Mr Manoj Rupani, Mrs K.Ratnavali
Secretary:	Dr.Suman Jain
Jt. Secretary:	Mr Aleem Baig
Treasurer:	Mr J Rajeshwar
Jt. Treasurer:	Mrs Rama Vuppala
Executive Members :	
	Mr Shiv Rathan Agarwal
	Mr Mohammed Amin
	Mr Surender Agarwal
	Mr Chandrakant Agarwal

Transfusion centre functions as day care centre & has facilities:

- Two air-conditioned halls has 10 beds each to monitor the patients during transfusion.
- Emergency drugs and oxygen cylinder for the patient needs.
- Van for blood donation camps and transporting patients in case of emergency.
- A well stocked medicines like iron chelation drugs, leukocyte filters and emergency drugs to cater to the patient needs
- A team comprising a doctors and well trained nurses have specific knowledge of thalassemia, work together in the management of thalassemia and sickle cell anemia

Every year 10,000 to 15,000 children affected with Thalassemia major are born in Andhra Pradesh

During the year, the patients were provided the following services :

- Saline washed blood to thalassemia patients
- Inpatient transfusion services
- Regular checkup for thalassemics to maintain the hemoglobin level above 9-10g/dl.
- Iron chelation after 10 – 15 transfusions
- Multi organ screening camp every quarter held in January, May, September
- Community awareness on the control of thalassemia

- Genetic Counseling for couples at risk. Counseled pregnant women and their partners in order to identify couples who are at risk of having a child with any of these genetic conditions,

Raising Public Awareness and Education

The important part of the Centre's role is to raise public awareness through community publicity campaigns, education in schools, colleges and universities, business houses about proper care and management of people with these conditions. TSCS produced a varied number of health promotion leaflets, to help educate the general public.

Mr. Kasarla. Srinivas, Coordinator for Adilabad district is an active parent. He is responsible for initiating blood bank at Mancherial which has helped thalassemia children from Adilabad region for blood transfusion.

Statistical data of activities

Transfusion				Age group	Iron chelation therapy				
0 - 5	5 - 10	11-15	18-20	**Total**	0 - 5	5 - 10	11-15	18-20	**Total**
2124	1699	931	356	**5110**	815	1109	567	236	**2727**

New cases registered	HPLC at Society Couples/siblings	CVS referred to Fernandez Hospital & CDFD	Splenectomy	Patients examined during the multi-organ screening camp
234	260	4	5	220

Raghavendra

Outstanding performance by thalassemia children

Raghavendra, 14 years secured 86% and

Ramya, 14 years secured 92%

in the SSC examination held in March, 2011.

Shiva Prasad secured 61% in B.Com (computers) held in April, 2011.

Shiva Prasad

BMT unit in Hyderabad city for Thalassemia patients

"Bone Marrow Transplantation Unit" was established in July, 2011 at Narayana Hrudayalaya Hyderabad under the name "Cure Thalassemia". The unit is promoted by Dr. Guido Lucarell amd Dr.Pietro Sodani, renowned transplant physicians from Italy.

Mr. Chandrakant Agarwal, an Industrialist is the key person in this joint venture. TSCS motivated and counseled parents for undergoing bone marrow transplantation. It helped patients in getting HLA typing done at Global Hospitals at nominal cost.

Periodic Medical Checkup

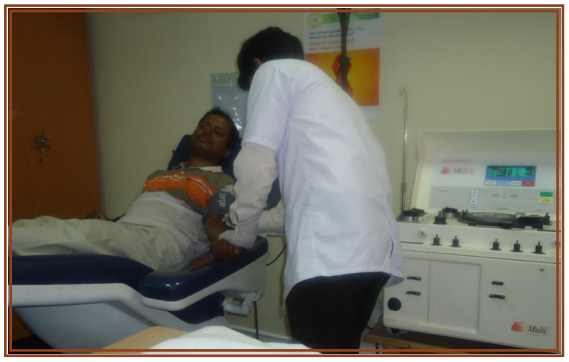
Thalassemia & Sickle Cell Society Vuppala Venkaiah Memorial Blood Bank

Before the establishment of TSCS blood bank, the families of the patients had to arrange blood from other blood banks or find their own blood donors. There were several cases wherein the transfusion had to be delayed due to non-availability of blood. It has affected the patient's health due to decrease in hemoglobin levels. To mitigate these concerns, TSCS established its own blood bank to offer comprehensive thalassemia treatment with all its operations under one roof.

The Blood Bank is located in a busy area, close to City Civil Court, 2 kms from Afzalgunj and 3 kms from Charminar and is easily approachable for patients. The two-storied building with an in-built area of 2500 sq.ft. is designed to suit the needs of a blood bank.

The Blood Bank has modern highly sophisticated equipments namely programmable Cryo centrifuge, ELISA washer & reader, Freezers -20^{0}C, -80^{0}C, Platelet agitator, cold room which ensure safety for the process of collecting, testing, processing and storing blood. Well trained and qualified technicians and the management do their utmost to ensure properly grouped and cross matched blood.

Round the clock Blood Banking Services:



Aphereses Room

Activities

- Sensitisation programmes : 225
- Blood donation camps : 124
- Collected units of blood : 8767
- Units provided to thalassemia : 4285
- Units provided to government hospitals: : 1814

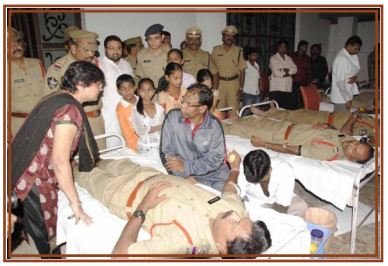
Cryocentrifuge

Services Provided

- Round the clock services to cater to the demands of blood and blood components for the treatment of thalassemia and other emergency needs.
- Facilities for the issue of whole blood, packed red cells, fresh frozen plasma, platelet concentrates and cryoprecipitate.

Component Storage Room

Sensitizing programmes on thalassemia and its management were organised at colleges/corporates as a part of voluntary blood donation drives. Voluntary pre-marriage screening shall continue to be encouraged through public awareness campaigns.



Serology Lab & Cold Room

Demographic details of patients

District	Total	District	Total
ADILABAD	131	MEDAK	37
ANANTHAPUR	13	NALGONDA	79
CUDDUPAH	16	NELLORE	3
CHITOOR	9	NIZAMABAD	31
EAST GODA-VARI	36	PRAKASHAM	27
GUNTUR	40	RANGA REDDY	56
HYDERABAD	397	VISHAKHA-PATNAM	18
KARIMNAGAR	76	WARANGAL	67
KAKINADA	5	WEST GODA-VARI	42
KHAMMAM	92	KARNATAKA	18
MAHABOOB-NAGAR	39	MAHARASTRA	10
KRISHNA	27	ONGOLE	7
KURNOOL	28	VIJAYAWADA	4
VIJAYANA-GARAM	7	NOT AVILABLE	42
SRIKAKULAM	7	GRAND TOTAL	1364

Dedicated Support Team

Transfusion Centre

Blood Bank

More about thalassemia

- **Thalassemia & Sickle Cell Disease** is a serious inherited blood disorder.
- An estimated 4.5% population in India are either Thalassemia or Sickle Cell 'carriers'
- Over 10,000 Thalassemia major patients are born every year , all of whom may require blood transfusion as they become anemic due to RBC destruction
- There are over 300,000 or more Sickle Cell Disease patients in India
- Survival of Thalassemia patients depends upon repeated life long blood transfusions and iron chelation due to iron overload from blood transfusion, whilst those with sickle cell disease would need the same less frequently
- More than 400,000 Patients with Haemoglobinopathy require some form of treatment
- The disease can be prevented by creating awareness, genetic counseling and screening at pre-nuptial or pre-conceptual stage followed by antenatal diagnosis.

What is Thalassemia?

Thalassemia is a group of inherited blood disorders characterised by mild to severe anaemia caused by haemoglobin deficiency in the red blood cells. In individuals with thalassemia, the production of the oxygen-carrying blood pigment haemoglobin is abnormally low.

There are two main types of thalassemia: alpha thalassemia and beta thalassemia. In each variant a different part of the haemoglobin protein is defective. Individuals with mild thalassemia may be practically symptom-free throughout their lives. Intermediate to severe cases are associated with a variety of symptoms, such as anaemia, enlarged liver and spleen, increased susceptibility to infection, slow growth, thin and brittle bones, and heart failure.

Treatment

Thalassemia major should be diagnosed as early as possible in order to prevent growth restriction, frail bones and infections in the first year of life. The infant's haemoglobin levels and development should therefore be monitored closely. If Hb is lower than 70 or the child shows signs of poor growth and development, regular transfusion is the treatment of choice. According to the WHO, the aim of this treatment is to retain a median haemoglobin value of 115-120g /l. This can usually be achieved by carrying out transfusions of concentrated red blood cells at intervals of every three to four weeks.

Only cure

Today thalassemia major can be cured by stem cell transplantation. A prerequisite is usually that the affected individual who has siblings with identical tissue type (HLA type) a transplantation of blood stem cells referred to as a "bone marrow transplant", can be carried out.

Thank you blood donors

TSCS on behalf of patients/parents of thalassemia children thank the blood donors for they have helped to save young lives.

Acknowledgements

We are grateful for the generous donations. We greatly appreciate our partnerships with donors who have come alongside us to increase our services to people living with thalassemia & sickle cell anemia.

M/s LIC Golden Jubilee Foundation
M/s MBS Jewellers
M/s Nimmagadda Foundation
M/s State Bank of Hyderabad
M/s State Bank of India
M/s Kinnera Memorial Trust
M/s NMDC
M/s Cognizant Foundation
Mrs G Ragini, GMR
M/s Volkart Foundation
Mr Surender Agarwal
Sri Ram Charitable Trust
Shri Ketan Vora
Shri Vasanth Vora
Ms Revathi
M/s Terumo Penpol ltd.
Mr. C Shashider Reddy
Dr C Anupama Reddy
Shri Sanfdas Murali Rupani
M/s Sri Krishna Jewellery Mart
Smt Banarasi bai
Mrs Marni Devika rani
M/s Hi-Tech Engineers
Shri M A Radha Krishan
Mr Atluri Nageshwar Rao
Mr Charadar
M/s Novartis
Shri P R Chaudary
Mr V L V Sudheer
Mr Arief Abdul Sattar
Dr Suman Jain
Mr Vaman Rao
Mr Kiran Kumar
Ms Soundarya Lahari
Jaya Chabey
Ms Sudha
Mrs. Savitha Rathi
Mrs Anand Durga
Mr Danial Sunder Singh
Mr Venkata Ramana
Shri Siddamma
Shri B Anasuyamma
Mr Yeshwanth Kumar I V A
Shri Sumera Fathima
M/s Deccan Switch Gear
Dr Annie Hassan

M/s SBI Ladies Club
Mr Md Amin
Shri Naresh Bansal
Mr Chinanal Single
M/s Boorgu Gems & Pearls
Shri V V Krishna Rao/V M Radha
M/s Grand Lodge of Mark
Mr Rajgopal
M/s New life Society
Shri Ritesh & Friends
Shri R K Sharma
Mrs Sudha Vora
Mr Ayub Khan
Mr Chandrakant Agrawal
Mr Amin Bhimani
M/s Sri Krishna Jewellers
M/s Union Bank of India
M/s Gurukaruna, Srichakra Foundation
Mr K Srinivas
M/s Polypack pvt ltd
M/s Shrinath Potopack ltd
M/s Madhushree Enterprices
Mr Rajender Kaur
Mr Pramod Kumar Jain
Mast. Aryan Jain
Mr A Shoban Reddy
Mr Srinivas
Shir Surender Agarwal
Shri Suman Agarwal
Shri Val & Terry
Mr Rajesh Jain
M/s Sunflower School
Shri Rani Siddaram kashekar
HBL Power Systems
Mr Madhusudhan Boddu
M/s Blend Colours pvt. Ltd
Shri Hassan
Mrs Soma ranjani
Mrs S Advait
Mrs Sheshamani
Shri D Rohit Bhargav Varma
Mr Vamshi
M/s IRSLA
Shri B B Prasad

Financial Audit Report

THALASSEMIA AND SICKLE CELL SOCIETY
DOOR NO 22-8-496 TO 501 CHATTA BAZAR, NEAR CITY CIVIL COURTS
PURANA HAVELI , HYDERABAD -500 002
RECEIPTS & PAYMENTS FOR THE PERIOD ENDING WITH 31ST MARCH 2010

RECEIPTS	AMOUNT	PAYMENTS	AMOUNT
OPENING BALANCE		MEDICINE PURCHASES	1,511,809
CASH	3,342	MEDICAL CONSUMABLES	185,203
BANK	236,398	MEDICAL DISPOSABLES	253,055
		SALARIES	1,021,432
DONATIONS TOWARDS CORPUS FUND	9,197,866	AUDIT FEES	11,030
		CONVEYANCE	12,150
LIFE MEMBERSHIP FEE	70,700	OFFICE EXPENCES	68,960
MEDICINE SALES	1,398,600	NUTRITION EXPENSES	70,973
DONATIONS RECEIVED	2,552,909	TRAVELLING EXPENSES	99,125
INTEREST RECEIVED	109,026	TELEPHONE EXPENSES	37,811
FIXED DEPOSIT RETIRED	1,262,442	RENT	262,000
		ELECTRICITY CHARGES	28,497
		HOUSE KEEPING EXP	36,857
		INSURANCE	5,774
		TDS ON RENT	30,000
		ADVERTISEMENT	96,020
		POSTAGE & STAMPS	4,415
		REPAIRS & RENOVATIONS	140,134
		PRINTING & STATIONERY	234,286
		BANK CHARGES	2,081
		ADDITIONS TO FIXED ASSETS	8,560,611
		CLOSING BALANCE	
		CASH	18,622
		BANK	2,140,438
TOTAL	14,831,283		14,831,283

For N. V. S. MURTY & Co.
CHARTERED ACCOUNTANTS
N. V. S. MURTY
PROPRIETOR

For Thalassemia & Sickle Cell Society

PRESIDENT SECRETARY

THALASSEMIA AND SICKLE CELL SOCIETY
DOOR NO 22-8-496 TO 501 CHATTA BAZAR, NEAR CITY CIVIL COURTS
PURANA HAVELI , HYDERABAD -500 002
INCOME & EXPENDITURE FOR THE PERIOD ENDING WITH 31ST MARCH 2010

EXPENDITURE	AMOUNT	INCOME	AMOUNT
MEDICINE PURCHASES	1,511,809	MEDICINE SALES	1,398,600
MEDICAL CONSUMABLES	185,203	DONATIONS RECEIVED	2,552,909
MEDICAL DISPOSABLES	253,055	INTEREST RECEIVED	109,027
SALARIES	1,021,432	EXCESS OF EXPENDITURE	
AUDIT FEES	11,030	OVER INCOME	1004054
CONVEYANCE	12,150		
OFFICE EXPENCES	68,960		
NUTRITION EXPENSES	70,973		
TRAVELLING EXPENSES	99,125		
TELEPHONE EXPENSES	37,811		
RENT	262,000		
ELECTRICITY CHARGES	28,497		
HOUSE KEEPING EXP	36,857		
INSURANCE	5,774		
TDS ON RENT	30000		
ADVERTISEMENT	96,020		
POSTAGE & STAMPS	4,415		
REPAIRS & RENOVATIONS	140,134		
PRINTING & STATIONERY	234,286		
BANK CHARGES	2,081		
DEPRECIATION	952,978.00		
TOTAL	5,064,590		5,064,590

For N. V. S. MURTY & Co.
CHARTERED ACCOUNTANTS
N.V.S. MURTY
PROPRIETOR

N.V.S. MURTY & Co. Chartered Accountants SECUNDERABAD

For Thalassemia & Sickle Cell Society

DU Ramana — PRESIDENT

Suraj Jain — SECRETARY

THALASSEMIA AND SICKLE CELL SOCIETY
DOOR NO 22-8-496 TO 501 CHATTA BAZAR, NEAR CITY CIVIL COURTS
PURANA HAVELI , HYDERABAD -500 002

STATEMENT OF AFFAIRS AS AT 31ST MARCH 2010

LIBILITIES	AMOUNT		AMOUNT
CAPITAL	2,362,958	FIXED ASSETS	
LESS EXCESS OF EXPENDITURE OVER INCOME	(1,004,054)	FURNITURE & FIXTURES	1,714,015.00
		COMPUTERS	362,542.00
DONATIONS TOWARDS CORPUS FUND	9,197,866	MEDICAL EQUIPMENTS	4,965,866.00
		MACHINARY	660,069.00
LIFE MEMBERSHIP FEE	70,700	TAX DEDUCTED AT SOURCE	9,685.00
		FIXED DEPOSITS	636,233.00
		RENT ADVANCE	120,000.00
		CASH ON HAND	18,622.00
		CASH AT BANK	2,140,438
TOTAL	10,627,470		10,627,470

For N. V. S. MURTY & Co.
CHARTERED ACCOUNTANTS
N. V. S. MURTY
PROPRIETOR

N.V.S. MURTY & CO. Chartered Accountants SECUNDERABAD

For Thalassemia & Sickle Cell Society

PRESIDENT SECRETARY

Appeal

We seek your support to help more children suffering from thalassemia. Join us in our efforts in the prevention of thalassemia and sickle cell anemia.

The Medical cost of each child is:

1. To support a thalassemic child towards treatment Rs. 8,000/- to 10,000/- per month (annual rs. 1,20,000)
2. Leucodepletion filters for safe blood transfusion to avoid reaction. Each filter Rs. 515/- (Requirement is two filters per month. Annual Rs. 12,360/- per child)
3. **Prevention is better than cure:** Sponsoring Awareness programme along with screening aimed at propagating relevant and appropriate information required to progressively diminish the burden of inherited and preventable blood disorder. Rs. 50,000/-(each camp). Screening for estimation of HbA2 level to know the carrier status by HPLC which cost Rs. 40,000/- for 100 people
4. Sponsor Blood Donation Camp: Rs. 5,000/- within the city & Rs. 10,000/- outside Hyderabad.
5. Donate to Corpus Fund to support the activities of the Society.

All Donation to Thalassemia & Sickle Cell Society are exempted u/s 80G of Income Tax Act.

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 the Bank Account No. 1181101023165

TSCS has achieved much, but much more need to be done. We always strive for quality treatment to thalassemia patients. Our 'hands-on' approach to treatment coupled with proper guidance has achieved good results in the well being of thalassemics.

Thalassemia & Sickle Cell Society
(Regd. 5359/98)
Door No. 22-8-496 to 501,Chatta Bazar
Near City Civil Courts, Purani Haveli, Hyderabad - 500 002
Ph:040- 24560011, 64610610, 24403783, 24520159
Email: tscsap@gmail.com
Website: www.tscs.in