OCTOBER 2019

Thalassemia & Sickle Cell Society *report*

Make life simpler then the spirit within will be liberated from heavy burdens”

Arshad Ali

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Arshad Ali is 18 year old. Reflecting on his life journey back when he was just 5 years, that is when he started to comprehend the difference between good & bad, and then came a whole set of realization, why this treatment to me, why I am put on blood transfusion every month, why I have to go through the pain of this prick , why not all are like me, in-fact why I am not like them carefree in all that they do. Journey just began with comparison in every area of life. Slowly it started settling down the cause and the answers are too big for little brain to process, acceptance is the only way because there is no other way, then to get the blood transfusion. Any sort or confrontation was not working with the parents

This is a known fact in the family because Arshad’s paternal uncle also has a son suffering with Thalassemia. Now the question is why this extended family is suffering with so called genetical disorder and the paternal uncle family dint disclosed the child suffering from thalassemia and did not advice HbA2 testing before marriage.

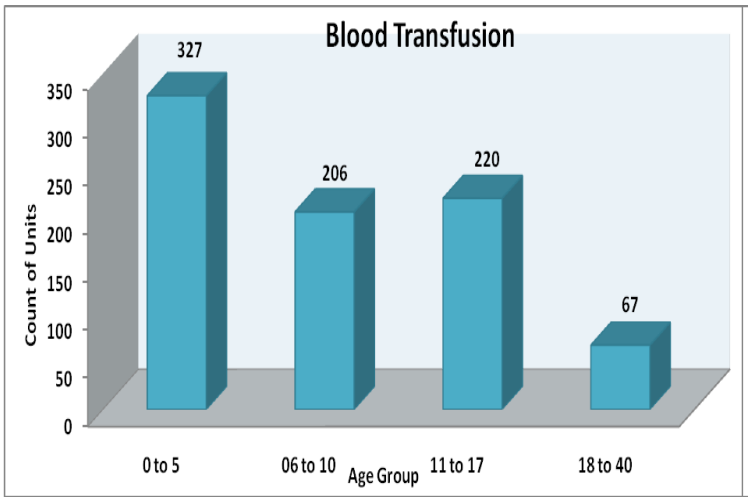
Today after accepting Thalassemia as it is, it makes life simpler and the spirit within is much liberated from heavy burdens. Maintaining the treatment routine is the top priority. It can be challenging at times.

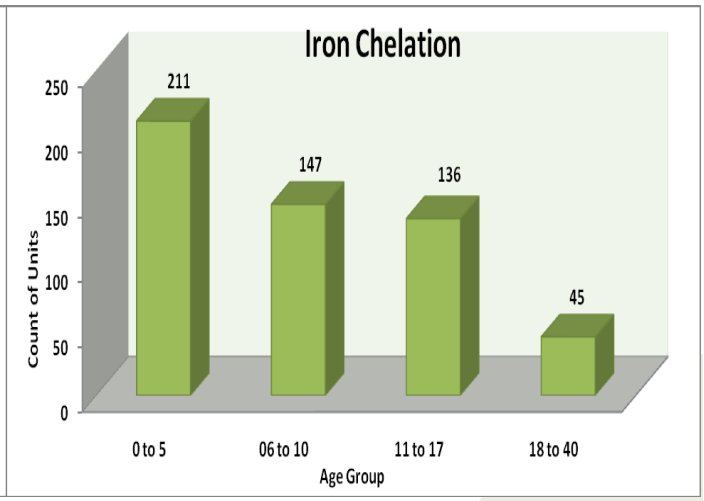
TSCS is committed to give the right treatment and counseling with its vast experience of managing kids at various stages ranging from young to adult to almost 2800 registered patients.

TSCS offer a one-stop solution for thalassemia patients with complex situations, saving them valuable time, effort in educating them, counseling them, empowering them to reach their ultimate motive of reducing thalassemia birth in the state of Telangana.

TSCS
STRIVE FOR PREVENTION

Transfusion Details





*Total number of patients for the month of **October 2019** including all patients group were* **820** *some patients were given 2 units of blood, the total units provided where* **1009**

HPLC at Society Couples/siblings	CVS referred to CDFD	New registrations	Splenectomy
62	NIL	21	NIL

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Gene Therapy For Beta-Thalassemia: Updated Perspectives

Stem cell transplantation was until very recently, the only permanent cure option available for patients suffering from transfusion-dependent beta thalassemia. Gene therapy, by autologous transplantation of genetically modified hematopoietic stem cells, currently represents a novel therapeutic promise, after many years of extensive preclinical research.

Indeed, genetic treatment of beta-thalassemia has been very early singled out as one of the most promising areas for future gene therapies by the American Society of Gene and Cell Therapy

Particulars	Units
Sensitisation programmes organised	22
Blood donation camps	16
Collected units of blood	952
Units provided to thalassemia + general free issues	1009
GENERAL PAID ISSUES	134
PRP ISSUES	223
FFP ISSUES	731

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