Thalassemia & Sickle Cell Society

Managing Thalassemia is hard but not Impossible"



Nahia-6-Yrs

This is yet another family with two of their kids suffering with thalassemia. A very brutal truth faced by the family, very hard to get this term thalassemia sink in the mind and understand that this is genetically transferred from parents cause they had a marriage within close cousins. A hard price to pay bringing 2 kids on borrowed blood every 2-3 weeks, see the pain of transfusion, vulnerable to all sorts of diseases and cannot leave them carefree like any other normal kids. Above all high cost of managing this disease combined with time consumed makes it even more difficult. What an 'Odd deal'

Today knowing of this mother's pain in bringing Nahia (6) and Mukram (4) both suffering with this dreadful condition of thalassemia, she expressed "Our only cry to God Almighty is to bring

up a permanent cure to Thalassemia before these kids grow up". Giving daughters & son within relation in marriage is very customary in their religion and there are many cousins in such marriage, but none of their kids have been diagnosed with thalassemia.

This brings a huge shock and even a biggest eye opener that kids can suffer because of the ignorance of the parents. When the first kid Nahia at the age of 2 was diagnosed with thalassemia, parents felt this is a disease that will be treated, transfusion is the means of treating and soon Nahia will be all set for life without any issues. Little did they know that their little daughter of 2 Yrs is tied to blood transfusion for life!, by then Nahia's mother delivered another son Mukram, unfortunately he was also diagnosed thalassemic.

Maintaining the treatment routine is the top priority. It can be challenging at times.

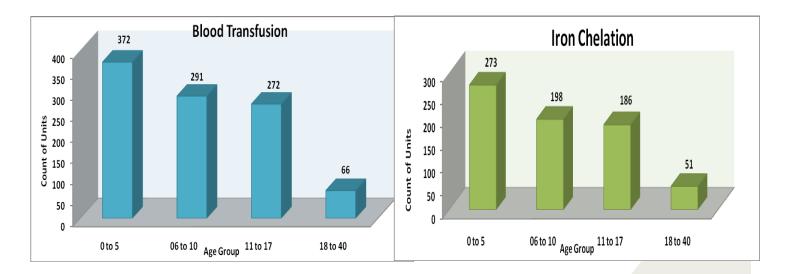
It is hard to handle all of the challenges associated with thalassemia had it been TSCS not in palace willing to provide all that is needed and the medical care that they give to deal with such a demanding disorder.



report



Transfusion Details



Total number of patients for the month of August 2019 including all patients group were 956 some patients were given 2 units of blood, the total units provided where 1222

| HPLC at Society Couples/siblings | CVS referred to CDFD | New registrations | Splenectomy |
|----------------------------------|----------------------|-------------------|-------------|
| 44 | NIL | 10 | 1 |

| MONTHLY DONORS FOR AUGUST 2019 | | | | | | | |
|--------------------------------|----------------------------------|----|--------------------------------|----|------------------------|--|--|
| 1 | MURALI K SIRIPURAPU | 11 | DR C ANUPAMA REDDY | 21 | AMBIKA IRON & STEEL | | |
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| 10 | DR C ANUPAMA REDDY | 20 | NAV DURGA TEXTILES PVT LTD | | | | |



Despite medical and technological advances, blood cannot currently be made. The only way of getting hold of it is via blood donations from people who give blood. Common Questions people have abut blood donation

1. "I'm afraid."

A lot of people are scared the first time, but after you make one donation, you'll wonder why you ever hesitated. There's really nothing to it!

2. "How many people donate blood?"

Only 5% of the population donates blood. If only 10% of the population would donate, it would possibly eliminate all blood shortages.

3. "Do you need my type of blood?"
We need regular donations of ALL blood types. The rarest blood is the type which is not available when it's needed.

| Particulars | Units |
|---|-------|
| Sensitisation programmes organised | 22 |
| Blood donation camps | 19 |
| Units provided to thalassemia + general free issues | 1222 |
| 30% Govt Hospital free issues | 146 |
| General paid issues | 174 |
| FFP ISSUES | 1000 |
| SDP | 1 |



Thalassemia & Sickle Cell Society

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