

THE
PRAVIN AGARWAL
FOUNDATION

Enabling Liver care for Children

Newsletter May 2021

"Tough times never last, but tough people do."

Robert H. Schuller



This quote seems to be apt for the times that we are living in. While the year started with hope and jubilation - the much awaited vaccination drives - as the entire nation was grappling under a pandemic, our happiness was short lived. We saw a surge in the numbers of corona victims and the nation collapsed to the vengeance of the second wave of Covid-19.

Amid tears shed, unsaid goodbyes, living amidst fear and anxiety, we realised that the only two things that can help us move ahead and triumph over these excruciatingly painful situations are - kindness and compassion. Heroes of our times have emerged from unknown dark quarters - the stories of common men who came forward to help in whatever way they could are aplenty. We take this opportunity to salute the unsung heroes.

Founder speaks



By Mr. Pravin Agarwal,
Founder, The Pravin Agarwal Foundation
Chairman, Sterlite Power Transmission Limited
Vice Chairman, Sterlite Technologies Limited



“Words are less to express the grief that the world is holding on to at the moment. The air is heavy with shattered dreams and untimely goodbyes. In such times the only thing we can cling on to is hope. This too shall pass and we will come out stronger. Let’s promise to be there for each other in times of need and shed our greed. Humankind has a better scope to thrive and revive if we leave the bitterness behind and move ahead.

“At TPAF, we will continue to function and care for the families who reach out to us. With an aim to help little kids overcome liver diseases and lead a healthy life ahead, we will continue to function for your well-being and deliver the promises we made.”

Doctor speaks



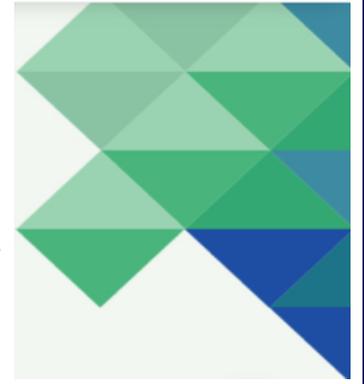
A perspective: Understanding paediatric liver diseases, low rates of Paediatric Liver Transplantation and busting few myths around the same

By Dr Anurag Shrimal

Senior Consultant-HPB, Liver & Pancreas Transplant Surgery

Lead – Pediatric and Pancreas Transplant Program

Global Hospitals, Mumbai



Pediatric Liver Transplantation is a niche specialty in our country. Though we are one of the world leaders in living donor adult liver transplantation, a lot of work is indeed needed in the emerging field of Pediatric Liver Transplantation.

Liver disease in kids is much different and hence are the indications for liver transplantation. Some of the common indications for Pediatric Liver Transplantation are as follows:

Biliary Atresia: BA affects approximately 1 of 8000 to 12000 live births, affecting girl children more often. This disease is characterized by progressive fibro-inflammatory processes affecting intra and extra hepatic bile ducts. This obliteration of bile ducts progress to cirrhosis before the age of 2 years. The stool colour card is a simple, efficient, and applicable mass screening method for early diagnosis of BA. A timely Kasai Portoenterostomy (KPE) is the surgery of initial choice. However, more than chronological age (<90 days), presence of synthetic liver dysfunction (hypo-albuminemia, coagulopathy), ascites, portal hypertension and failure to thrive should make a case for primary liver transplantation. Liver transplantation (LT) may still be required in 70% of children despite the timely performance of KPE. Certain intra-operative challenges in this set of patients include presence of portal hypertension, vascularised adhesions, associated atretic portal vein with poor flow and sometimes large for size liver allograft making abdominal closure difficult and the entire surgery more challenging. Malnutrition and associated metabolic abnormalities needs to be addressed in the post-operative period. With comprehensive care 90% of these kids can have long healthy lives.

Hepatoblastoma: Primary cancer of liver is rare accounting for only 1% of all malignancies in the paediatric age-group. More than two thirds of these are hepatoblastoma, rest being hepato-cellular carcinoma and embryonal sarcoma of liver. Prematurity and low birth weight (<1500g) are known risk factors. The good thing about these tumours is that they are highly chemo sensitive. Around 20% of kids suffering from hepatoblastoma (multifocal, bi-lobar, otherwise unresectable, without extrahepatic extension of the tumour, that responds to chemotherapy) may require liver transplantation as a curative surgery. With advancement of chemotherapy and surgery more than 75% 5-year survival is achieved.

Metabolic Liver Disease: While we wait for gene therapy to evolve, a lot of inborn errors of metabolism can be cured with liver transplantation. Auxiliary Partial Orthotopic Liver Transplantation (APOLT) a new surgical technique allows to preserve part of the native liver, with the transplanted liver being the source of required enzymes to correct the metabolic defect.

Wilson's disease is far more common in some subsets of our population. The traditional practice of consanguineous marriages needs to be discontinued to reduce the incidence of Wilson's disease. Though medical therapy is available, some of these kids present late with liver transplantation being the only curative treatment left.

Acute Liver Failure: Paediatric acute liver failure is a rare, complex, rapidly progressing, and life-threatening illness. The aetiology is most of the time unknown and varies according to the age. In infants metabolic and infectious aetiology are common, whereas in adolescents drug induced liver injury and autoimmune hepatitis are more common. In our country Hepatitis A & E, and anti-tubercular drugs related to ALF are far more common. To ensure good outcomes in these extremely sick children, they should be treated at specialised centres in close collaboration between paediatric hepatologist, intensivist, neurologist, nephrologist, metabolic disease specialists and transplant surgeons. Some of these kids improve with medical management and some need a timely liver transplant. With advanced multi-disciplinary care more than 70% of these kids have a good outcome.

Congenital Vascular Malformation: Though extremely rare some of the kids suffering from Abernethy malformation and giant haemangioma may require liver transplantation as the last resort.

Pediatric Liver Transplantation being an emerging field brings in its own new set of challenges

Lack of awareness

There is a lack of awareness not only in the parents but also in the physician community involved in treatment. Most often jaundice in children is thought to be just innocuous and never evaluated in detail. Simple measures like the stools color cards can be used to screen children with biliary atresia. Early encephalopathy is often missed. A great majority of kids never reach a transplant center due to lack of awareness.

In our country organ donation rates post brain death are extremely poor. More than 70% of these are from elderly population with a lot of comorbidity. Such organs are not acceptable for splitting and for using them for pediatric liver transplant.

Poor Organ Donation Rates

Lack of specialized pediatric liver care & transplantation

There is a lack of trained pediatric hepatologist and pediatric liver transplant surgeons across the country. Also, this specialty is almost non-existent in major public hospitals.

Pediatric liver transplantation is out of reach of most average Indian families. Most often the parents are young and themselves trying to settle in their own profession.

High cost of Treatment

Myths Surrounding pediatric liver diseases and transplantation

M Y T H S	Kids cannot lead a normal life after liver transplant	F A C T S	Any jaundice that persists beyond a few weeks needs to be investigated.
	Most often jaundice improves		Post-transplant after 3 to 6 months these kids develop as any other kid. They just have to take their daily medicines. They grow up, go to parks, schools and achieve everything in life.
	Liver donation possesses a significant risk to life		Liver donor surgery is extremely safe. Also as the liver regenerates, there are no long term medication or consequences.

The lives we touched



Master Abdul Hannan: A little life blooms, fighting all the odds that once loomed



When he was four months old, Master Abdul Hannan came to Global Hospitals, Mumbai with a complaint of persistent jaundice. He had been suffering from the same since his birth. Further investigations revealed that he was suffering from Biliary Atresia, a medical condition that affects the bile ducts. He was post 90 days from birth, and had already developed decompensated chronic liver disease. The only available treatment option was a timely liver transplant surgery.

His father Mr. Shahnawaz Pathan had just returned from Saudi Arabia after losing his job due to the COVID pandemic. The family, being residents of Lanja Village in Ratnagiri, had no other source of income.

Adequate funds for him were raised through crowdfunding, TPAF and other funders for evaluation of donor and recipient, hospitalization in the wait period, transplant surgery and even post-transplant medication.

His mother, Mrs Tarannum Pathan came forward to donate a part of her liver. The transplant surgery was done on November 04, 2020. It was a successful operation and post op recovery was smooth and consistent.

Abdul is now well, reaching all his developmental milestones and celebrated his first birthday with doctors who gave him a lease of life.

Master Tanush Sain: A mighty fighter, a happy baby, a courageous soul

If resilience had a face, it would be of Master Tanush Sain. It pains us to see how many times this little soul had gone under the knife and come out brave with a smile lingering on his lips. When he was one-year-old this boy from Shri Ganganagar district of Rajasthan suffered from Wilms tumor of the left kidney. He received chemotherapy and underwent left Nephrectomy (removal of left kidney). He defeated his cancer at a very young age.



At the age of 3 years, Tanush developed a rare side effect of chemotherapy – Veno-occlusive disease of Liver. His disease progressed and he developed Hepato-Pulmonary Syndrome (HPS). HPS is a very rare complication of Cirrhosis of liver. In this condition blood is shunted through the lung without getting Oxygen. The only possible treatment of this condition is a timely liver transplant.

Tanush underwent a successful living donor liver transplant at Global Hospital, Mumbai where his mother was the donor.

Due to very severe HPS his post-operative recovery was very challenging. He required Tracheotomy, inhaled NO₂, ventilator support and prolonged stay at ICU. He was admitted at Global Hospital for 60 days till he could be weaned off completely from oxygen support and weaned off tracheostomy.

All the hospital equipment (stethoscope, syringes etc.) became his toys. He defeated his Cancer, Veno-Occlusive disease of liver and very severe HPS and came out as a real hero.

If this little boy doesn't move you to get up and get going in life, we don't know what will.

Master Owais Shaikh: Little miracles happen everywhere



Master Owais Sheikh, 3-year-old, otherwise healthy boy was born in a family of doctors. Due to his continuous tantrums initially, family thought him to be very moody and irritable child. These were ignored by the family members at first but latter further investigations led to the diagnosis of vascular malformation in liver, *Abernethy malformation*.

In this disorder blood flows directly from intestine to heart bypassing the liver. Hence the toxic metabolites are not filtered in the liver. These metabolites reach the brain and cause hepatic encephalopathy. If the treatment is delayed, these children develop permanent damage to their brain. The only available treatment option for this disease is a timely liver transplant.

Though the parents were willing for organ donation for their son but none of them were suitable match. In such a situation he underwent a *swap liver transplant*. (A swap liver transplant involves exchange of donated liver between two families where the family member can't donate to their own family member but can donate to the second family and vice versa)

Owais is completely cured of his disease and is growing is a happy and a lively child.

Awards & Honors



We are happy to share that our founder, Mr Pravin Agarwal, received the prestigious Dr. Prathap C Reddy Philanthropy Award, for his contribution to the society in making paediatric liver transplants affordable and accessible to all at the The Global Association of Physicians of Indian Origin 2021 in February'21.

Advisory Board



- Dr. Sonal Asthana- Advisor, HPB and Liver Transplantation
- Mr. Prashant Mandke- Advisor, Social Impact and Rural Marketing
- Mr. Anil Agarwal- Advisor, Partnership and Strategy

Medical Expert Panel



- Dr. Ashley DCruz
- Dr. Neelam Mohan
- Dr. Sanjay Rao
- Dr. Bipin Vibhute

Looking into the future

We are striving to enable resources to support another 100 patients and we look forward partnering with mission aligned corporates and individuals.

All contributions are exempt under section 80-G of Income Tax Act 1961.

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Join the cause. Connect with us.

info@tpaf.in | +91-7768853030

