



Doctor's Speak

Liver transplantation remain the ONLY lifesaving treatment for endstage liver disease in children. Though large adult programs have been operational in India since the last 3 decades, pediatric liver transplantation has been a relatively recent phenomenon. This cause for this delay is twofold – one, lack of awareness and two, a singular lack of organized funding.



Though liver diseases in children are not as common as in adults, the large population in our country translates into a large disease burden. Estimates suggest that while 4000 children need liver transplants annually in India, only about 150-200 children are receiving transplantation. A very large gap exists between the demand and the supply.

The common indications for liver transplantation in children are:

1. Biliary atresia. This is an obliterative disease of the bile ducts seen in neonates and infants. The tiny tubes that carry bile from the liver to the intestine are progressively obliterated. This results in bile stasis in the liver, progressive liver damage and ultimately liver failure.

2. Metabolic liver diseases. These are a group of inherited disorders, wherein certain chemicals or enzymes are lacking, resulting in altered metabolism and deteriorating health. Wilson's Disease, where in a critical enzyme that is needed by the body to process copper is missing, is a classic example. This results in excessive copper deposition all over the body organs, liver failure and death if untreated.

3. Acute liver injury as a result of infections such as with hepatitis A virus and drug induced liver failure- paracetamol being the commonest culprit.

4. Liver cancers in children such as advanced hepatoblastoma

Liver Transplantation is expensive. Even after a successful transplantation, children require a lifelong immunosuppression and medical care. Also, most children needing liver transplantation come from young families which do not have the resources to fund their child's care. As a result, treatment is often delayed or not offered at all. Secondly, even when transplantation is offered, the

costs to these young families are catastrophic. The only way they can raise funds is by selling away precious assets such as land and home- often at throwaway prices due to the urgency of their child's medical needs. In such instances, even after a successful transplantation, the family never recovers from the financially and continues to remain in long term debt. Adverse consequences of this financial burden such as nutritional and social deprivation of other family members/siblings and broken homes are, unfortunately, far too common. As governmental funding for maternal and child health is focused on infectious diseases and nutrition, complex procedures such as transplantation are not funded.

It is in this situation and light that the activities of TPAF must be seen.

1. Organised funding:

TPAF has actively engaged stakeholders in liver transplantation for children – medical professionals, hospitals, other funding agencies and social workers, to evolve a system of need-based funding for children requiring liver transplantation. In majority of instances, such funding facilitates the child receiving the required transplantation. In addition, the family avoids 'catastrophic medical expenses' – resulting, hopefully, in better long-term financial security and a better social outcome. The plan to further scale up operations based on lessons learned and continued engagement of stakeholders will only spread the benefits of this model to more needy children.

2. Education and awareness campaigns:

Liver transplantation for children is now widely available in the Country. Most families will have access to this treatment in their own state and vicinity. Outcomes too, with some standardization of care, have steadily improved. Children can now look forward to long term survival and a good quality of life. This message needs to be disseminated to the community and community level health care workers.

Disease prevention by early detection and treatment is an efficient and proven way to reduce the burden of liver transplantation in the community. This is an ideal goal, and it is a prudent move on the part of TPAF to allocate resources for this. Various strategies to educate lay public, primary health care workers, community level doctors and pediatricians on early detection and referral of liver disease in children are a pressing need and should be actively pursued.

The PAF has rightly focused upon the core aspects of stakeholder engagement, funding and education. As more medical institutions and personnel, more effected patients and families and other relevant agencies come on board, a strong foundation is being laid for a future where any needy child will have access to a lifesaving liver transplantation.

Dr.Sanjay Rao
Senior Consultant and Head,
Department of Pediatric Surgery
Narayana Health Hospitals,
Bangalore.
Sanjay.rao.dr@narayanahealth.org

Affordable Liver Transplant Conclave 2019



The Affordable Liver Transplant Conclave 2019 held at Mumbai was an assembly of India's best liver transplant specialists, healthcare professionals and crowd-funding partners who addressed the core challenges faced in conducting successful liver transplant surgery in the country. Numerous innovative solutions were proposed during the conclave by the biggest brains associated with biliary sciences in India. The most remarkable outcome of this event was that it revealed all the potential barriers experienced by patients and physicians alike.

The theme of 'Affordable Liver Transplant Conclave 2019' was to make quality liver care available to all. There were three-panel discussions altogether, where each panel addressed a wide range of problems associated with liver transplant surgery.

Panel 1 (1:30 PM to 3:00 PM) discussed the **parameters for increasing the success rate of liver transplant surgery**. As pediatric liver transplantation surgery is highly complex in nature, even the subtlest of factors have a major say in its success rate. The importance of raising awareness about the liver

donation to the masses was also stressed, as this leads to an increase in donors.

Brief Outline Of Discussions In Panel 1

- Different factors that increase the success rate of liver transplant surgery.
- Constructing a pre- and post-transplant care network
- Improving the overall infrastructure set up and expertise of physicians

In Panel 2 (3:00 to 4:00 PM), the subject of discussion was '**the earlier detection of liver diseases to prevent liver transplant surgery in infants**'. This panel was the highlight of the whole conclave as renowned doctors in India presented new methods and techniques to diagnose the liver diseases at the earliest. Several insights on boosting the efficiency of physicians to detect the need for pediatric liver transplant surgery were reviewed.

Brief Outline Of Discussions In Panel 2

- Techniques and methods for earlier detection and prevention intervention of liver diseases.
- Boosting the efficiency of physicians to detect the need for liver transplantation quickly.
- Entrusting and empowering the mothers for earlier detection of Biliary Atresia by making them aware of stool charts

In Panel 3 (4:00 to 5:00 PM), the emphasis was on **enhancing the post-surgery of care of children and also to establish a firm relationship between the families of liver donors and recipients**. The importance of having long term rehabilitation centres for complete recovery was also thoroughly discussed.

In India, many families of child patients are complaining about a lack of liberty in following up with different liver transplantation centres. This is the most prominent reason for lack of accessibility to liver surgery in the country. The steps required to resolve this issue was also debated in this panel.

Brief Outline Of Discussions In Panel 3

- Improving the nature of fund support for facilitating successful liver transplant.
- Establishing nodal patient networks through peer-support groups in different cities to share success stories and to seek medical as well as non-medical support.
- Capability building of doctors, especially pediatricians for the micro-management of infections.



#ALTC2019

Conclave Mission

TPAF's mission is to enable the provision of high-quality liver care for everyone and the conclave brought out best practices to improve the outcomes of paediatric liver transplants and set benchmarks in the Indian context. The need to shift focus to meaningful survival of patients including all aspects, from their physical to mental well-being resonates with our core values. The discussion on early detection and prevention of disease where panellists deliberated the dissemination of stool charts at scale. The prospect of deployment through primary healthcare workers and leveraging artificial intelligence for this is very exciting. The reiteration of public-private partnerships amongst the liver transplant teams to build the capability of government facilities to facilitate pre- and post-transplant care is important for the ecosystem.



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Panelist Speak

"Mere survival is not enough, we need to focus on meaningful survival" – Dr. Ashish Dhawan

"It is a myth that Biliary Atresia is diagnosed by doctors. In reality, it is the mother that already plays or in some cases should play a key role in diagnosing the disease" – Dr. Priya Ramachandran

"Patient compliance is an issue in India and aftercare is lacking; there is need to build a network of local centres with paediatricians and doctors" – Dr. Naresh Shanmugam

"Its not only about detecting a rare disease but guiding the family regarding the next steps" – Dr. Shailendra Hegde

"Doctors are primarily worried about discharging the patient within the first month of the transplant as this is the period wherein the maximum number of complications arise"

– Dr. Neelam Mohan

“It is the family that gets exhausted and collapses at stages through the transplant journey”

– Prassana Kumar Shirol

Beneficiary Speak



**A Young Boy Shares His Experience
Along His Transplantation Journey**

Blogs

A study by Lancet Oncology journal has shown that there are almost 4,00,000 new cases of childhood cancer annually across the world.

This figure is alarming as barely half the number of children mentioned above are logged in national health registries. One such childhood cancer which is not so known to the masses is pediatric liver cancer.

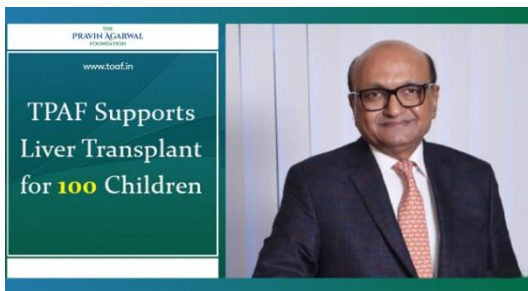
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Current Updates



TPAF collaborates with the Indian Academy of Paediatricians at their Bengaluru and Mumbai Chapter (EMBICON).



TPAF (The Pravin Agarwal Foundation), a social impact foundation, focused on helping children impacted with liver disease has completed 100 successful liver transplants. [Read more »](#)

Apply for Financial Assistance

children up to the age of 18 years can avail financial assistance for liver transplant by filling out the form on our website and or call us on 7768853030

+91-7768853030

info@tpaf.in

www.tpaf.in
