

# AFFORDABLE LIVER TRANSPLANTS CONCLAVE 2018

**DATE: 12<sup>th</sup> AUGUST 2018**

**VENUE: THE ORCHID HOTEL, MUMBAI**

## CONTEXT

The **Pravin Agarwal Foundation (TPAF)** is a philanthropic organisation pioneered by Mr. Pravin Agarwal, Chairman of Sterlite Power and Director of Sterlite Tech. TPAF is committed to make paediatric liver transplants more accessible in India and supports children threatened by liver disease by providing access to quality liver care and enabling liver transplants. Mr. Agarwal started by supporting 15 liver transplants in 2017 and has supported about 51 paediatric liver transplants across India to date. The aim is to enable 100 liver transplants by 2019.

On the eve of World Organ Donation Day, The Pravin Agarwal Foundation invited experts and luminaries in the paediatric liver transplant space to discuss ways to improve the accessibility and affordability of paediatric liver transplants in India. The panel discussion with liver transplant specialists, healthcare professionals, philanthropists, foundations, and crowd funding partners from all over India was envisioned to be a platform to initiate and shape the discourse around paediatric liver transplants in India. Furthering the UN Sustainable Development Goal to ensure healthy lives and promote well-being for all at all ages, the ***Affordable Liver Transplants Conclave 2018*** was a milestone step towards the development of the liver transplant ecosystem in India.

## SUMMARY OF PANEL DISCUSSIONS

### ***Panel 1: Improving Access To Paediatric Liver Transplants In India: How To Reach Children In Need?***

Panellists	Key points
Dr. Sonal Asthana (Moderator)	<ul style="list-style-type: none"> <li>● It can be estimated that about two thousand children need a liver transplant in India, and approximately a hundred and fifty children get access to it</li> <li>● The main barriers to referrals are               <ul style="list-style-type: none"> <li>○ Cost of the surgery</li> </ul> </li> </ul>

Dr. Aabha Nagral	<ul style="list-style-type: none"> <li>○ Reluctance of paediatricians to refer patients as a result of information bias regarding the high success rate</li> <li>○ Lack of awareness amongst doctors and patients regarding available financial assistance</li> <li>○ Mindset of the patients' family and aversion to surgery due to costs involved (for transplant surgery and post-surgical medical costs), health of the liver donor, and option of having more children</li> <li>● The outreach of paediatric liver transplants in India can be improved by           <ul style="list-style-type: none"> <li>○ Popularising paediatric liver transplant surgery by creating a network of healthcare professionals</li> <li>○ Establishing a platform for capacity building of the entire ecosystem with a focus on academia and research</li> </ul> </li> </ul>
Dr. Senthil Kumar	
Dr. Tom Cherian	

***Panel 2: Making Paediatric Liver Transplants Affordable: How To Optimise Costs?***

Panellists	Key points
Dr. Sunil Shroff (Moderator)	<ul style="list-style-type: none"> <li>● The overall cost of any transplant depends upon the           <ul style="list-style-type: none"> <li>○ Type of establishment</li> <li>○ Type of the transplant</li> <li>○ Length of stay in the hospital.</li> </ul> </li> <li>● The cost of a liver transplant           <ul style="list-style-type: none"> <li>○ Government hospital is between 6 to 10 lakhs</li> <li>○ Non-profit is 12 to 15 lakhs</li> <li>○ Private hospital is 18 to 25 lakhs</li> </ul> </li> <li>● This comprises of capital expenditure and cost of the equipment, salaries of the staff and consumables</li> </ul>
Dr. Sujoy Pal	

Dr. Megha Khobragade	<ul style="list-style-type: none"> <li>● Cost reduction is highly dependent upon the willingness of the senior leadership and hospitals.</li> <li>● In certain states Government schemes like Chief Minister’s scheme in Tamil Nadu and National Rural Health Mission in Assam subsidise costs of liver transplants for patients and can be replicated in other states in India.</li> <li>● A common platform with information regarding schemes pertaining to liver transplant needs to be established for potential patients and healthcare workers to utilise the support available</li> </ul>
Dr. S K Mathur	

***Panel 3: Financing And Grants For Paediatric Liver Transplants: How To Increase Funding For Transplants?***

Panellists	Key points
Mr. Srikrishna Sridhar Murthy (moderator)	<ul style="list-style-type: none"> <li>● Milaap has hosted 15,000 healthcare campaigns</li> <li>● About 70% of Ketto’s campaigns are focused on healthcare</li> <li>● Crowd funding platforms demonstrate that the wisdom of the crowd is stronger than the wisdom of an individual and it has the potential to tap the online market of \$400-500 million</li> <li>● The importance of due diligence and ‘template’-isation of requirements for grants to patients rises with the involvement of different types of donors.</li> <li>● There is a need to establish a single window concept for different financing sources to streamline the process of funding</li> </ul>
Mr. C. Yogendra Pal	
Mr. Varun Sheth	
Mr. Anoj Viswanath	
Ms. Suja Nair	

	<ul style="list-style-type: none"><li>• Creative approaches and strategic marketing need to be developed to bring different stakeholders like CSRs into the game to raise the overall pool of funds</li></ul>
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### **KEY DISCUSSION NOTES**

#### ***Panel 1: Improving access to Paediatric Liver Transplants in India: How to reach children in need?***

- Approximately seventy percent of children who need a liver transplant suffer from Biliary Atresia. The global incidence of the disease is one in nine thousand while the incidence in India is estimated at one in seven thousand. The numbers are arguably underestimated. However, focusing on Biliary Atresia was identified as a good option to reach children in need of a liver transplant
- While it is estimated that there is a demand of approximately two thousand paediatric liver transplants in India annually, only 150-200 paediatric liver transplants are conducted, indicative of the demand and supply gap
- It is estimated that there are only about fifteen trained paediatric liver transplants surgeons in India
- Paediatric Liver Transplant is not suggested as an option by doctors for patients who belong to a weak economic background due to the high costs associated with it. Some families after learning about the costs have preferred to have another baby
- A study conducted in an eye care hospital providing free services in southern part of India showed that even though the treatment provided was free, the patients were not availing this treatment. This was because fifty percent patients did not know that the treatment was free of cost. This showcases the need for widespread dissemination of information
- Out of every hundred patients referred to tertiary care, about thirty percent disappeared and could not be contacted thereafter. Seventy percent in need of treatment fell off the radar. In a study conducted in Zimbabwe it was observed that the attitude of the healthcare workers also influences the patients' clinic attendance as the patients may feel unwelcome if not inducted with sensitivity.
- From the patients' perspective the following were identified as reasons for not availing treatment:
  - They were not aware about the exact cost of the surgery, financial aid available and the outcome of the surgery
  - Family resistance and their cultural background influencing their mindset regarding surgical procedures

- Fear of leading an unhealthy life post the surgery which would alter their capacity to work
- From the healthcare professional's perspective, the following were identified as factors limiting the outreach of paediatric liver transplants:
  - Primary liver diseases in children are treated by paediatricians. They might not know when to refer and where to refer. A hepatologist's perspective of liver disease is different from a paediatrician's. The former is relatively more aware regarding the diagnosis that could lead to a transplant
  - Misperception about terminology, intent and scope of tertiary care amongst doctors at primary and secondary hospitals are all barriers to referral
  - Doctors are afraid about the complications associated with the surgery and hence are reluctant to refer their patients due to information gap as they do not want to compromise on their patient's well-being
  - Lack of awareness regarding all sources of funding available to make the paediatric liver transplant more affordable
- To overcome the outreach challenges and reach children in need, the following ideas were agreed upon:
  - Popularise the paediatric liver transplant surgery by building a network of doctors led by pioneers of the surgery in India
  - Establish a certified body for paediatric liver transplants which would be responsible for performing the following functions:
    - Providing a platform for discussions and knowledge exchange through meetings, conferences and newsletters
    - Focusing on research and publishing journals related to various aspects of the transplant
    - Building a database of all the stakeholders of the liver care ecosystem including but not limited to hospitals, doctors, sources of funding and past patients
  - Capacity building at the grassroots with respect to primary interventions like stool chart to enable linkages between village level institutions like ASHA, ANM and Anganwadi and tertiary care hospitals.
- The panel concluded with the belief that with increased collaboration and information exchange, the outreach of paediatric liver transplants in India will improve significantly

***Panel 2: Making Paediatric Liver Transplants Affordable: How To Optimise Costs?***

- The organ donation rate has multiplied by four times in the last five years. There were 1,005 Live Donor Liver Transplant and 650 Deceased Donor Liver Transplants in India in 2016.
- The overall cost of a transplant depends upon
  - Hospital type

- Type of the transplant
- Length of stay in the hospital
- Complications associated with the surgery like
  - Re-exploration or repeat liver transplant surgery during the same hospitalisation
  - Co-morbidities like sepsis, pneumonia, wound disruption and stroke
- The cost of a liver transplant
  - Government hospital is between 6 to 10 lakhs
  - Non-profit is 12 to 15 lakhs
  - Private hospital is 18 to 25 lakhs
- This comprises of capital expenditure and cost of the equipment, salaries of the staff and consumables used for patients like blood and blood products
- The cost of the transplant is low in government hospitals because the patients pay one fourth of the maximum retail price. The cost of consumables and salaries is borne by the government along with the cost of any complications along the surgery. The capital expenditure is low as well as most of it is already covered by the government
- Christian Medical College Vellore was able to conduct the surgery for 6 to 10 lakhs
- Institute of Liver and Biliary Sciences has a package of 11.5 lakhs inclusive of 30 days of Intensive Care Unit for the patient and donor costs for two weeks
- All charitable hospitals are non-profits as there are costs paid by the institution which are not recovered from the patient
- The cost of the liver transplant is highest in private hospitals as they have to account for capital expenditure especially for hospitals in the starting phase and a profit margin. The accepted profit margin varies from hospital to hospitals. Procurement cost for hospitals varies depending upon the size of the procurement they are making
- For private hospitals which were provided subsidised land, 10% of their services are supposed to be rendered free. Apart from this, 2% of profits are to be spent for CSR
- Private hospitals charge a higher fee as they are worried about complications with the procedure and not as a means to make money. The will of the senior leadership of a hospital becomes a deciding factor on whether to take on certain procedures or not
- On a cost per dose basis, antibody induction immunotherapy is the most expensive component of the immunosuppressive regimen. They comprise of one third of the cost of the initial transplant admission
- National Organ and Tissue Transplant Organisation (NOTTO) runs organ donation programs through its network of State Organ and Tissue Transplant Organisation (SOTTO) and Regional Organ and Tissue Transplant Organisation (ROTO). NOTTO will be preparing a list of all sources of government support available in different states for easy access. It has schemes which provide financial assistance to hospitals for infrastructural development as well

- The Zonal Transplant Coordination Centre (ZTCC) observed that there are patients who are given an organ and denied at the later point as they cannot afford the cost of transportation of the organ. The hospitals are also not able to fund the cost of transport and hence, organ goes to the richer patient. At times the cost of transportation can go up to about Rs. 15 lakhs.
- In Telangana, the Aarogyashri scheme funds 10.5 lakhs for a deceased donor liver transplant and 14.5 lakhs for a living donor liver transplant
- In Assam, Paediatric transplants are funded through the National Rural Health Mission
- There is a need to get the state government schemes together, their learnings and best practices and are applicable pan-India
- To optimise the cost of the liver transplant surgeries, the government, private and non-profit hospitals have to work together. A network of hospitals needs to be established which has 1-2 model hospitals in every city which have agreed upon a baseline cost for the liver transplant through partnerships, cost to cost surgery and bulk procurement.

***Panel 3: Financing And Grants For Paediatric Liver Transplants: How To Increase Funding For Transplants?***

- Crowd funding platforms like *Milaap* and *Ketto* are excited to raise the money that is needed to fund paediatric liver transplants
- Crowd funding has played an instrumental role in providing financial assistance to children in need of a liver transplant as clear visuals and stories of children pre- and post-surgery are accessible on these platforms. Since funders have seen that the child has gone on to do well, they have the assurance that their money has had the greatest impact
- India has the highest out of pocket expenses on healthcare. People come up with these expenses from their personal savings, borrowings and about 6% comes from informal networks and philanthropy which comprises of eight to ten thousand crores. This is the market that needs to be tapped into
- Out of the 2000 campaigns for transplants initiated by *Milaap*, 650 have been for Bone Marrow, 500 for Liver Transplants, 300 hundred for Paediatric Liver Transplant, more than 600 for Kidney and about 100 for heart and lung indicating that there is a lot more money in the transplants space which people are not aware about
- As a part of gifting for birthday parties and weddings, live retail donation counters are set up at events. They are also surveyed whether they would want to be an organ donor in the future and are signed up for the same
- The payment gateways need to be optimised as the success rate of gateways is 70% without dedicated tech support
- About 25% of international donors make up 40% of the total amount generated as online donations

- Tata Trusts supports paediatric liver transplants in Mumbai at Jaslok Hospital. In certain exceptional cases, they have processed requests in one day for transplants at a partner hospital. The paper work for Non-Mumbai hospitals is quite long and complicated. Tata Trusts has a rigorous due diligence process which includes home visits which is hard to do for patients outside Mumbai
- Chronic Liver Diseases do not require immediate surgery and there is substantial leeway for multiple stakeholders from the funding agency are able to study the patient, their family background to conduct the due diligence effectively
- Formal collaboration with crowd funding agency is an effective means to ensure funding options for the surgery. *Milaap* has a network of 150 hospitals wherein they are able to assess the existence of the patient, his or her disease and the need of the funds smoothly
- As of March 2017, Joint Endeavor for Enhancing Transplants (JEET Initiative) was set up for helping the poor with transplants by the following means:
  - Providing them financial assistance
  - Assisting them in the process of organ donation
- Social media can be used as a means of raising funds through urgent campaigns, WhatsApp broadcasts and through advertisements
- Creative ways of involving corporates as funders need to be developed. Corporates through CSR may not be comfortable funding individual patients and might prefer to opt for funding hospital infrastructure instead
- A single window approach through ‘template’-isation needs to be followed to streamline the funding available from different sources and direct it to the patients in need of financial assistance by building stronger partnerships with hospitals and fraternity