

# THE PRAVIN AGARWAL FOUNDATION

## Newsletter January-2025

### A New Year of Hope and Awareness

As we welcome the year 2025, The Pravin Agarwal Foundation (TPAF) reaffirms its commitment to improving lives and spreading awareness about pediatric liver transplants. Each year, we step closer to making healthcare accessible for children in need, and this year will be no different. Together with hospitals, doctors and our supporters, we strive to ensure timely medical intervention, provide financial support, and empower families with the right knowledge.

### Improving Understanding of Pediatric Liver Transplants through our Patient Outreach Program

Since 2016, TPAF has been collecting information from the partner hospitals to understand the landscape of and critical challenges surrounding pediatric liver transplants in India. Recently TPAF also connected telephonically with parents of children who were financially supported by TPAF for their liver transplant. The findings of these initiatives have been put forward in the form of a "Patient Insight Report"; key objectives of the which are as below:

- Understand demographics of the children who undergo a liver transplant
- Understand societal awareness and perception about liver transplant
- Understand quality of life and challenges to follow up care after a liver transplant

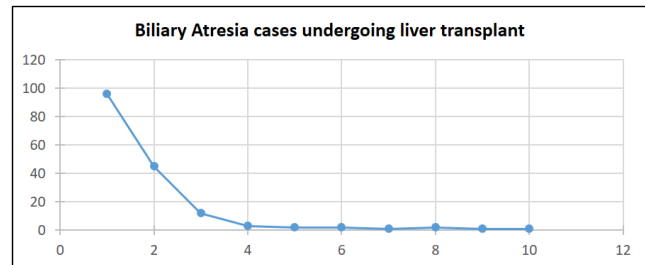
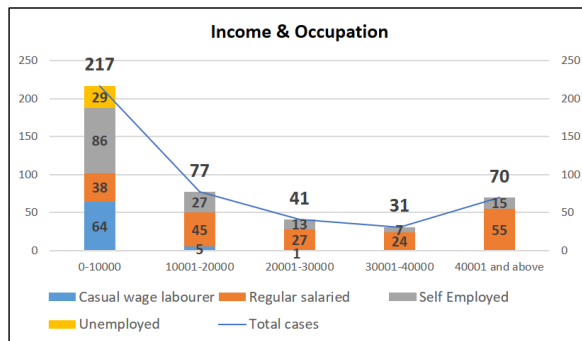
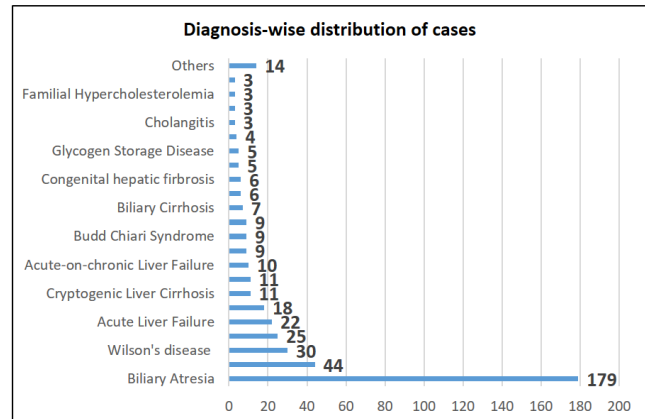
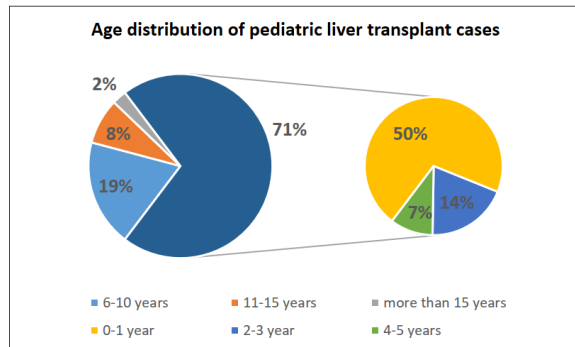
### Demographics of the children who undergo a liver transplant

The findings of the report are on the basis of a group of 436 children supported by TPAF since 2016.

Out of the total 436 children 62% were male and remaining were females. 71% of children undergoing transplant were under the age of 5 years. Further, 50% of them were under the age of 1 year. This highlights the complex and unique nature of this

treatment while reinforcing the need for special training and expertise to care for these children.

Biliary Atresia with 41% topped the list of indicators for liver transplant among the study group followed by Progressive Familial Intrahepatic Cholestasis (10%), Wilson's disease (7%) and Hepatoblastoma (6%). A staggering 58% of children suffering from Biliary Atresia underwent transplant in the first year of life and another 27% in the second. Only 15% of the children reached beyond 2 years without transplant.



While looking into the economic background of the families, it was found that half of the families had income less than INR 10,000/- per month, making them highly vulnerable to financial stress for expensive treatment like a liver transplant. A majority of the cases the earning members were regular salaried (43%) while another majority were self-employed (34%).

82% of children supported by TPAF were Indian nationals, 13% were from the Philippines and a small proportion from neighboring countries like Bangladesh and Nepal.

TPAF collaborates with Hospital partners across India as a part of this initiative, this helped us gauge the median actual cost of a transplant which stood at 18.65L. Geographical distribution of the transplant centre is a known contributor to the inaccessibility to this type of care and it was further reinforced by our finding that 46% of families had to seek transplant care outside of their state of origin. These families

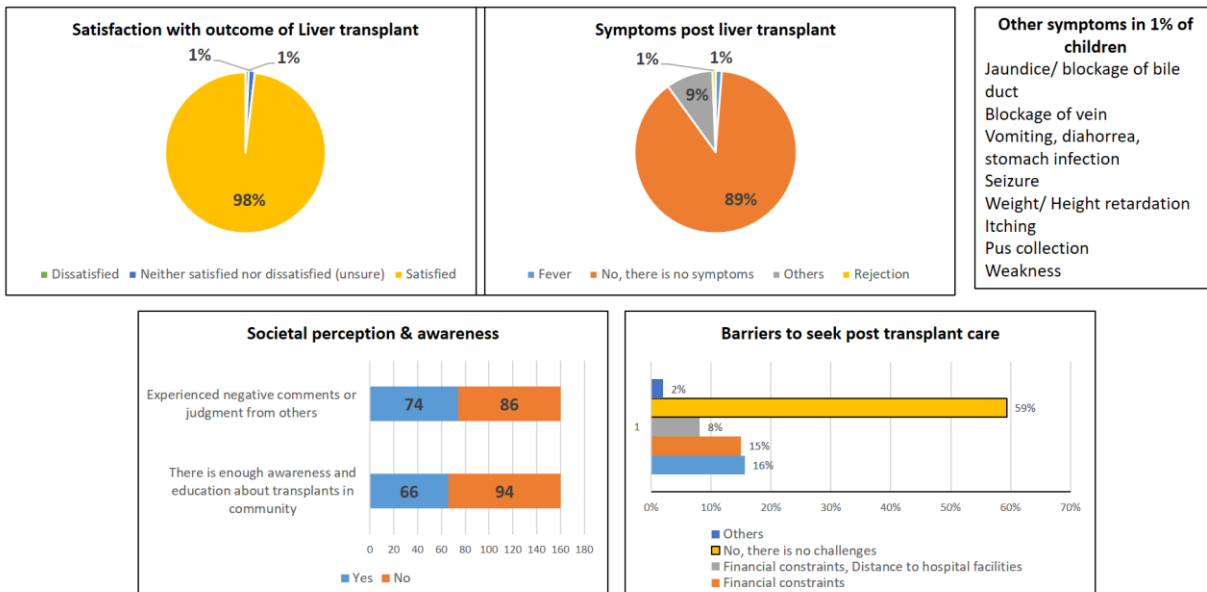
sought care in states like Delhi, Tamil Nadu, Karnataka, Maharashtra, Telangana which are also known to have state of the art transplant care centres.

## Societal awareness and perception about liver transplant

The report also attempted to understand the parent's perception of their community's understanding of the liver disease and transplantation from their firsthand experience. Over 59% of parents agreed that there is not enough awareness and education about transplants within their communities. Nearly 15% of parents were also advised against the procedure due to societal myths and misinformation. This highlights a significant gap in understanding, where families are often left confused or misinformed, while delaying life-saving decisions for their children.

## Quality of life and challenges to follow up care after a liver transplant

Over 98% parents were satisfied with their child's health post-transplant, which demonstrates the transformative impact of this unique medical intervention. An increase in child's physical activity after the transplant was reported by 79% of parents, of which 74% shared that their child engaged in any form of physical activity on a daily basis.



While a vast majority (88%) of children led a healthy life after their liver transplant, a small number of children did suffer from symptoms ranging from frequent bouts of fever to those like rejection of transplanted liver and biliary obstruction. This once again suggests that a liver transplant has an overall positive impact on the life of the child and his family, while at the same time underlining the importance of continuous post-operative care and clinical monitoring.

A child who has undergone a liver transplant requires lifelong care and follow up with the healthcare provider to maintain a healthy self. This indicated the need to delve further into any challenges that the families might be facing during the post-transplant period. Distance from the Hospital and financial constraints emerged as top barriers for seeking timely post-operative care.

Overall, the insights point to a clear need for awareness campaigns in the community, financial support systems and bringing follow-up care closer to the patient. By addressing these challenges, we can empower families with the knowledge and resources they need to make informed decisions and improve outcomes for children requiring liver transplants.

### **The lives we touched....**



**Anish Mithbavkar**

Anish, a 2 month old baby, was diagnosed with Biliary Atresia. His parents faced immense challenges in ensuring timely medical care of their son. On July 23, 2024, Anish underwent the Kasai surgery at Bai Jerbai Wadia Children's Hospital, Mumbai, and a critical procedure to manage his condition.

Amidst their financial struggles, TPAF stepped in to support the family, providing essential financial assistance during this difficult time. Today, Anish is thriving because of his parent's love and timely medical intervention.



**Dipto Mondol**

A 3 month old Dipto Mondol was diagnosed with Biliary Atresia after initially experiencing Jaundice. His parents travelled all the way from Bangladesh to Rela Hospital, Chennai to seek lifesaving treatment for their baby. On May 17, 2024, Dipto underwent a liver transplant, a critical step towards his recovery.

TPAF extended financial assistance to the family, easing their burden during this challenging time and ensuring Dipto received the care he needed.

Let's step into 2025 with a promise to spread awareness and bring new hope to families in need.

We wish you all a Happy New Year filled with good health, hope, and togetherness.  
Let's continue to make a difference, one child at a time.

## **Support us by Volunteering, Donating or Spreading the message**

### **Amplify**

We warmly invite you to join us in strengthening and amplifying our efforts.

[www.tpaf.in](http://www.tpaf.in)

### **Assistance**

If you have any query, need any support or would simply like to have a conversation, reach out to us on

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