

THE PRAVIN AGARWAL FOUNDATION

Enabling Liver care for Children

Newsletter February 2021

*New Year, New Promises
TPAF pledges to be on your side*



The year 2021 is our year of hope. Many positive things are happening around us – COVID-19 vaccination drive, normalcy settling in, and moving ahead into the future with enthusiasm while complying with new rules and safety measures.

The year 2020 has taught us the importance of health and hygiene – the two parameters of a good life that we have often ignored and overlooked in the past.

At The Pravin Agarwal Foundation (TPAF), we urge one and all to be on guard and safe. Follow the necessary precautions and keep diseases and infections at bay. We wish you a very healthy and fitter year ahead!

At TPAF, our mission has been to make paediatric liver transplants affordable and accessible to every child in need irrespective of his/her socio-economic background. When the pandemic forced everything to come to a standstill, we strived our best to keep up with our promise. Fundraising for our cause didn't halt because diseases (like liver diseases) didn't stop deteriorating its victims' health. We remained accessible and approachable to our beneficiaries. We functioned in coordination with our partner hospitals, partner funders, doctors / hepatologists, and support groups to ensure that help was meted out to those who reached out to us.

Founder speaks

*Mr. Pravin Agarwal, the founder of The Pravin Agarwal Foundation,
Chairman, Sterlite Power Transmission Limited
Vice Chairman, Sterlite Technologies Limited*



“As we march into the year 2021, I wish each one of you good health, happiness and well-being. The year 2020, has been a year of learning for all of us and I hope we take with us the morals of the lessons we learnt and apply them in our lives.

“I have always believed that health is not just wealth but a culmination of all that you are. Your health quotient tells a lot about who you are and what you are. If you are ignorant about your health, it reflects on everything that you do. That's why I firmly believe that commitment starts with self. If you are attentive to your health, you will show the same dedication in your work and beyond. So, stay safe and take good care of yourself.

“It gives me immense pleasure to mention that in the year 2020, despite the obstacles we faced due to the pandemic, we didn't cease our functions. We tried and helped our beneficiaries in every way possible to make their experience a soothing one. We also supported our 200th liver transplant just before the close of calendar year 2020, a milestone, since the inception of TPAF in 2016. We wish to touch many more innocent lives as we move forward.”

The journey so far: 200 in 2020 for TPAF



When we reached 200, in other words, helped the 200th patient get a transplant done, the number seemed astounding. In 2016, we just started taking small steps to help families of paediatric liver transplant patients. The journey ever since has not only been thrilling but a very fulfilling one.

200 is not just a number or an achievement or a milestone. It is also our emotional quotient (the higher, the better). It is a motivation for us to stay committed towards our cause. Our happiness lies in the smiles of those little ones whose paths we crossed on our journey. Hope we keep adding more zeros at the end of 200.

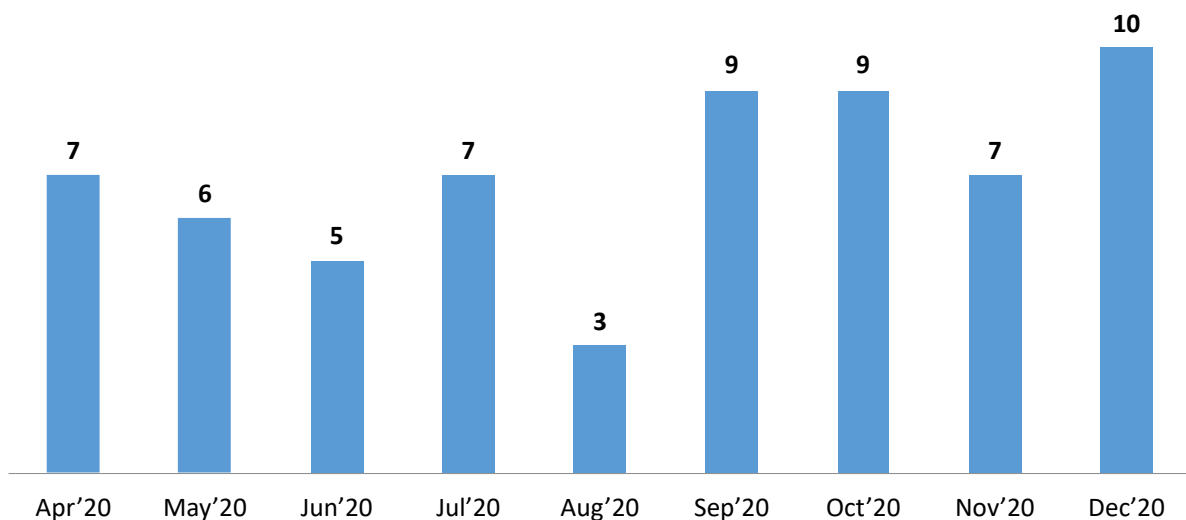
The year that was



Even as the pandemic hit us and had thrown our lives off track, at TPAF, it was work as usual.

Between April 2020 and December 2020, TPAF supported 63 beneficiaries for liver transplants during the nationwide lockdown, the highest during any previous nine-month duration. And we are on track to support 100 liver transplants by the end of this financial year.

Month-wise Liver transplants supported by TPAF



In coordination with our partner hospitals **Aster Bangalore & Kochi; Apollo, Delhi; Global, Mumbai; Apollo, Mumbai; Lakeshore, Kochi; ILBS, Delhi; Narayana, Bangalore; Apollo, Hyderabad; Amrita Institute, Kochi; Medanta, Gurgaon**, and other eminent establishments, we served the beneficiaries with the best care and support.

Stories of some of the lives touched on the way



KUSHAL AMBEDKAR: A transplant in time restores a childhood at nine

Kaushal who is just nine years old underwent a liver transplant in November 2020 at Aster RV Hospital, Bengaluru, one of our partner hospitals to get rid of the diseased organ and get a new lease of life. Kaushal, was born a healthy bony baby and showed no signs of ill health in the first three years of his life. But when he was four years old, his parents started to notice certain changes in his body. The tiny child showed some physical disproportionality. His stomach looked distended.

His parents rushed him to the doctor for a check-up. His family hailed from Jharkhand and had limited access to specialty healthcare services. Doctors who checked on him, said he had an enlarged spleen.



An enlarged spleen can be caused by infections, cirrhosis and other liver diseases, blood diseases characterized by abnormal blood cells, problems with the lymph system, or other conditions. He was first given medication to treat the problem. But when there was no symptomatic relief with medications, doctors advised a splenectomy (removal of spleen). In fact, a biopsy was done to ascertain the diagnosis. This took a turn for the worse at the operation table, **when the doctors realised that the problem was not his spleen but liver. Kaushal, suffered from paediatric liver cirrhosis.** In very young children, cirrhosis is most often caused by a genetic (inherited) liver problem such as biliary atresia. Only a liver transplant could save Kaushal.

In November 2020, Kaushal got a liver transplant done with funds and support extended to him by TPAF and its partners. We hope the cuts and scars heal soon and his health restores back to normalcy again. The good news is he is doing fine with proper care and medication now.

SAMARTHYA GUPTA: Light at the end of the tunnel

Samarthya Gupta was 56 days old when he had to go under the knife to undergo a Kasai procedure. It is the classic operation for the condition of congenital biliary atresia. When Samarthya was born, his bile reading was too high and doctors suggested the procedure to save the liver from getting infected.

Globally, it is seen that biliary atresia is one of the common causes of liver failure in children. A Kasai procedure, when done in infants has a success rate of 60 to 80 per cent.

Samarthya's parents with a heavy heart agreed to let their infant go under the knife to save him from the clutches of paediatric liver disease. But the Kasai didn't help much in Samarthya's case. His bilirubin readings always stayed high and never came down to the normal range. Samarthya suffered from the usual symptoms – yellowing of the eyes and skin. A



raised bilirubin is also a sign of liver problems. It also means that the liver isn't able to function well to remove bile from the bloodstream.

His parents' worst fears came true when the doctors said that a liver transplant was the only way to save their child. **Samarthya is one of the many beneficiaries who reached out to us on TPAF helpline** and we are proud that we could be of help. In December 2020, at the age of 3 years, Samarthya underwent the transplant at Sir Ganga Ram Hospital. He is recovering well. We wish him good health and speedy recovery.

KAVYA RAUT: We share our joys and shed our worries with our support buddies

We want to share the story of little **Kavya Raut, one of our support group members** who is just three years old and her smile can melt your heart in seconds.

She has faced the harshness and sting of the scalpel very early in life. When Kavya was two months old, her mother noticed something amiss with her stool colour. Unlike the usual colour, she passed a white coloured stool.

When she was nine months old, she started showing other problematic signs – breathing problems. One such episode was so severe that she had to be admitted to the hospital immediately. Doctors suspected chest infection, but slow weight gain, stool complains made them do an in-depth investigation of her health.

It was then that the doctors found out she suffered from biliary atresia a disease of the bile ducts that affects only infants. She underwent a liver transplant in 2018. Today she is all smiles, living a carefree and healthy life.



New endeavors for better outcomes

There is a famous saying by **Helen Keller** – **“Alone we can do so little; together we can do so much.”** At TPAF, we believe in working in conjunction with other thought leaders, organisations, and establishments with a similar vision and a relatable mission. While we are striving to create an ecosystem that will benefit the patient community, some help is always welcoming and encouraging.

We have recently partnered with three like-minded organisations for better outreach and engagement. We will be closely working with – **Rotary Club of Bombay Peninsula** and **Rotary Club of Delhi South Central, Sonu Sood Charity** Foundation.

These new partnerships will help us impact the liver ecosystem to be beneficial for the patients and improve quality of care and provide faster assistance.

We have also joined hands with renowned liver transplant centres such as, **Sir Ganga Ram Hospital Delhi, Amrita Institute of Medical Sciences Kochi** and **SRCC Hospital Mumbai** to help beneficiaries get the best hospital care during their surgery.

Staying connected and concerned



Our beneficiaries are not just a name or a number to us. They are much more than that – our extended family, they leave imprints of memories on our path that we cherish. That is why at TPAF, we don't just part ways with our beneficiaries once the surgery is done and the patient is discharged; we stay connected through our various patient engagement programs. Recently, **we launched our patient support groups on WhatsApp for North and West Zone**. Technology has made aftercare support a clickable entity and we aren't complaining. 😊

Affordable Liver Transplant Conclave 2020 (ALTC 2020): TPAF organized Asia's biggest Webinar on Paediatric Liver Transplant



In its 3rd edition, the conclave was streamed as a webinar to discuss and strategize ways to make liver transplants in children affordable and accessible amidst the Covid-19 pandemic. The theme for the year 2020 was Paediatric Liver Transplants and Covid-19.

Celebrated Bollywood actor Sonu Sood applauded globally for his humanitarian actions and awarded the prestigious 'SDG Special Humanitarian Action Award' by the United Nations Development Programme for his humanitarian works during Covid-19 was the Guest of Honour at the conclave.

The conclave had doctors, knowledge experts and speakers from multiple countries to share their perspective on paediatric liver transplants. It is the first time that a webinar at such a large scale was organized within the fraternity.

Watch the entire webinar here: <https://www.youtube.com/watch?v=ceLIYAbdbnA>

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.

Order No. ITBA/EXM/S/80G/2020-21/1030260053(1) Date 01.02.2021 PAN- AADTT5065D

Join the cause. Connect with us.

info@tpaf.in | +91-7768853030

