

1. Doctor's Speak:

First Impressions of Outreach Clinics in partnership with local paediatricians in the northeast

Liver disorders in children are usually present since birth or genetic. Unlike in adults, these do not arise from lifestyle related issues and consequences are different in all aspects of diagnosis and management. The perspective of a paediatric hepatologist when seeing a young child is to maintain an adequate liver function for the expected longevity, which would in real sense translate to 60-70 years. This is in stark contrast to the outlook of an adult hepatologist who seeks a couple of decades in the distant vision. The cumulative effect of medications and illness, emotional and social impact on a young developing mind and soul are unique aspects, inherent to the practice of a paediatric hepatologist.

The sub-speciality of pediatric hepatology in India is in its infancy with very few qualified doctors available across the country. On my return to India, I started seeing children in my practice coming from as far as 1000Km away for a consultation and follow up. Each family coming from far has a story to narrate of the difficulties faced in getting the liver-specific care. It's a niche speciality and cannot be expected from paediatricians or adult gastroenterologists. In contrast, children from Delhi and around were finding it easier to reach me and hence being diagnosed with their conditions earlier and as a result fewer needed transplants. The double impact of delayed diagnosis, delayed treatment was resulting in more hardship and higher expenses for children coming from far from Delhi. This scenario started a thought process of partnering with paediatricians in the community, to manage more such children in their own regions.

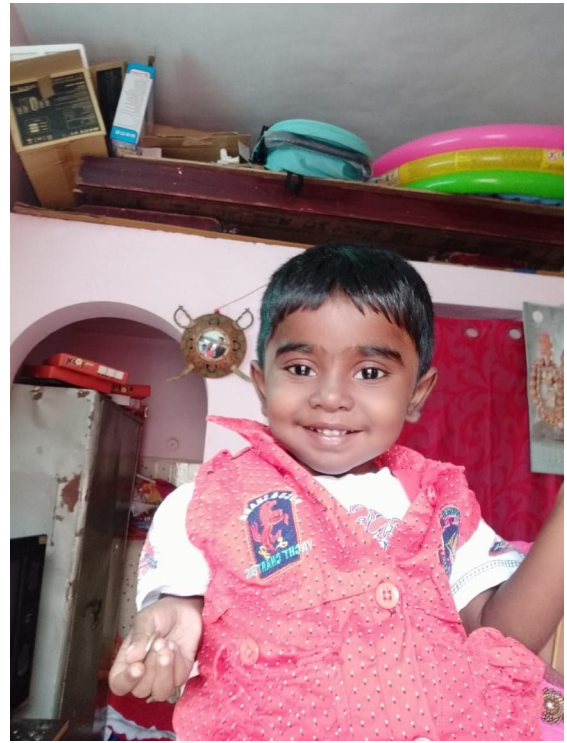
By definition, an outreach clinic is a need-based model, wherein clinical services are provided to an underserved region. The main aspects to establish a successful program are to have a local partner who is interested in establishing a new service in their unit, has adequate infrastructure to support your new expertise and shares your vision. Working on this principle, I started with a pilot project in Gauhati. Dr Prakitish Bora is a well-known paediatrician in Gauhati, a specialist in paediatric intensive care and having a flourishing practice at Excelcare hospital. We started to have monthly clinics and the first lesson we learnt was to establish a definite schedule, a certain day of each month. Gauhati being 3 hours from Delhi, the clinic involved a full days commitment. Leaving my practice in Delhi for an additional day, that is not a holiday but additionally tiring and expensive is a struggle, even now 18 months later. It takes a strong commitment and a long term vision to persist with the regular schedules. On many occasions we think, if its worth! But soon enough when we see children benefiting from a service they would not have access otherwise, it's deeply satisfying. To share your knowledge with eager local paediatricians, to

teach best practices to the paramedical staff, to provide the perspective of multi-disciplinary management is all professionally gratifying.

This outreach clinic experience has enriched me professionally, personally, given me a

great friend in Dr Bora who is ready to struggle for the same vision. In this friendship, I find the strength to persist as it needs reinforcement, support and encouragement. Its not easy to establish the outreach clinics but when done after due diligence, they immensely benefit the community and are emotionally gratifying.

2. Beneficiary Case Study:



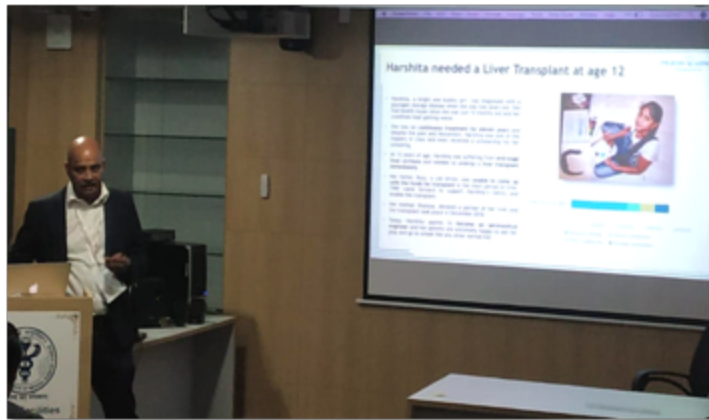
Sooraj* was 8 months old when his parents realised that his illness was not a minor one. His abdomen was enlarged and a boy who was lively and cheerful would never stop crying now. Residing in a small town in the district of Chittoor, Andhra Pradesh and earning a meagre income Sooraj's parents ensured that they are able to give him the best healthcare available. They did several visits to the district hospital, meeting various doctors but could not diagnose the illness he is suffering from. Sooraj's eyes were consistently yellow and along with him, his parents were also in pain as they did not know what would improve Sooraj's condition. It was only when they visited a super-speciality hospital in the nearest city they were told that Sooraj would need liver transplantation. The family was not in a position to arrange funds for the surgery but wanted to do everything they possibly could to ensure a better life for their child. This was when they approached The Pravin Agarwal Foundation to raise money for their child's treatment. They received an overwhelming amount of support from donors on the crowdfunding platform and Sooraj successfully underwent a liver transplantation on 24th July 2017. It has been more than 18 months since Sooraj received a piece of the liver from his mother. In conversations with his parents, it was found that Sooraj is a healthy

and happy child, always finding ways to enjoy himself through different fun activities. His mother is grateful that Sooraj underwent a liver transplantation as that gave him and his family a new lease of life. All tears have now turned into endless moments of Joy!

*Name changed to protect identity

3. Updates (please pick one image, note that the image quality will be better in mailchimp)

- a. TPAF's presence at the first Annual Conference of Liver Transplant Society of India 2018 (15 - 17th November, 2018, New Delhi)



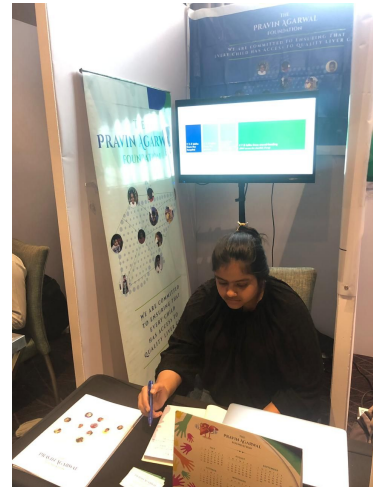
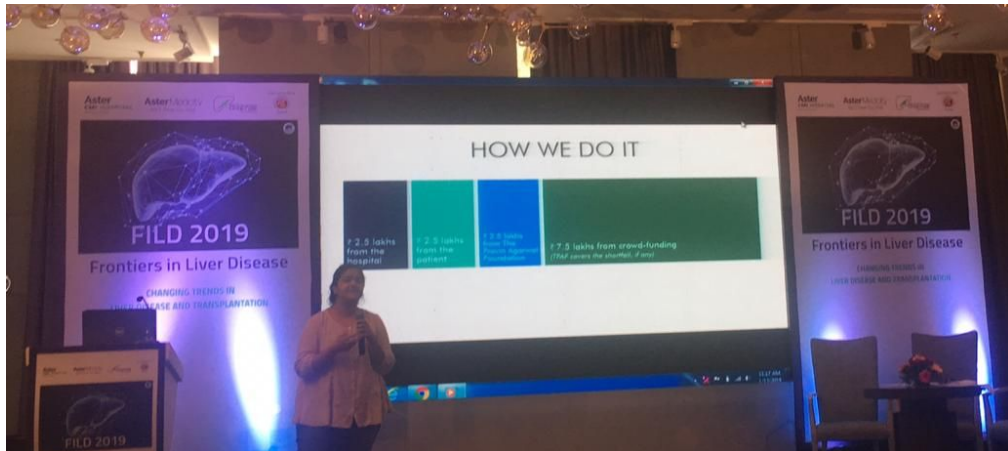
Dr. Sonal Asthana along with TPAF led a talk on ***'Making Paediatric Liver Transplants Affordable'*** at a session which hosted several Paediatric Liver Transplant surgeons in India.

The TPAF stall piqued the interest of doctors from across India and they signed up for TPAF updates



- b. TPAF partnered with the Frontier's in Liver Disease Conference in Bengaluru on 12th and 13th January, to

share our vision, mission and journey so far.



Please suggest which picture should be used. In case you have better pictures of the stall please do share.

4. Upcoming Events: (please suggest any more content that can be placed here, can we use the IAP logo?)

- a. The Pravin Agarwal Foundation collaborates with the Indian Academy of Paediatricians



5. Children up to the age of 18 years can avail financial assistance for liver transplantation by filling out a simple Patient Application Form (download here) and send it to us on info@tpaf.in

