

PARTNER: PATient-centered Research in TransplAnt-Engaging families+Recipients



Background: For thousands of children with liver disease, transplantation is lifesaving. But at every point in the journey towards, through, and for a lifetime after transplant, many decisions must be made about medical care. These decisions always aim to achieve the best possible long-term outcomes for children and their families, and to balance risks with benefits. Ideally families and transplant providers are lifelong partners in these care decisions, working together from a patient's earliest transplant experiences through adulthood.

Proposed Solution: In PARTNER, we seek to build on the established bonds between providers and patient partners, within the Starzl Network for Excellence in Pediatric Transplantation (SNEPT) and Transplant Families (TF). We aim to build a larger partnership with shared priorities, knowledge, and capacity to do collaborative patient-centered outcomes research.

Objectives: Our long-term goal is sustainable, equitable health and wellness for pediatric transplant patients. PARTNER will help us do this by preparing people and our network to do patient-centered outcomes research—projects that families and providers develop in partnership and that focus on the priorities of patients and families.

We need you! We are currently seeking PARTNER Advisory Board members

Time commitment: 1.5-2 hours, once every 3 months

Term: 2 years

Reimbursement: \$30 gift card per training module/feedback survey, \$60 gift card per Advisory Board meeting

What will PARTNER Advisory Board Members do?

- Participate in self-guided training modules and feedback surveys, on your phone, tablet or computer (30 minutes, 3 times per year)
 - Attend and actively participate in Advisory Board meetings (Video/Audio conference calls), to share your perspective on the training, surveys, and future direction of PARTNER projects (1 hour, 3 times per year)
 - Read and respond to PARTNER project email communications
 - Assist with outreach to other transplant families at your center or that you know, to expand PARTNER participation
 - Attend Starzl Center Annual Meeting (may be Zoom or in-person; 3-4 hours, 1 time per year)
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PARTNER Advisory Board Members need to be:

- ✓ Parent, guardian, or family member of a current patient at a PARTNER care center OR received a liver transplant as a child and is now 18 years of age or older
 - ✓ Willing to learn about PARTNER strategy and goals
 - ✓ Willing to learn about patient-centered outcomes research.
 - **You do NOT need prior experience in research or this kind of work—we will be learning together!**
 - **Your lived experience with liver transplant is the important expertise for this role!!**
 - ✓ Able to regularly attend Advisory Board meetings, and participate in the learning curriculum/feedback survey every 3 months (to the best of your ability)
 - ✓ Interested in sharing your opinions and viewpoint on life after pediatric liver transplant
 - ✓ Willing to listen to the viewpoints of others, and participate in shared decision-making with the team
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We would love to have you be a PARTNER Advisory Board member!

**If you are interested, or if you are not sure and have more questions about it,
please contact C.J. Confair, partner@starzlnetwork.org,
or visit starzlnetwork.org/partner.**

Thank you for considering! We look forward to hearing from you!