



The Starzl Spotlight

September 2023



Upcoming Meetings

- 2023 Starzl Network In-Person Meeting, Sunday, October 15, from 8:00 am - 12:00 pm ET at Hotel Bonaventure in Montreal, Canada for those who plan to attend the SPLIT meeting. Please plan on arriving in time for the Starzl Network meeting before SPLIT. We will cover your hotel room on Saturday night.
 - Register Here: <https://www.surveymonkey.com/r/2023StarzlMontreal>
- 2023 Fall Virtual Meeting, Sunday, October 22, from 10:00 am - 12:00 pm ET hosted on Zoom. This meeting is open to all members of the Starzl Network. We plan to provide updates on current projects and next steps for the Network.
 - Register Here: <https://www.surveymonkey.com/r/StarzlFallVirtual2023>
- Save the Date! 2024 Starzl Network Annual Meeting, February 15-16, in Orlando, FL co-hosted with AdventHealth for Children. We look forward to returning to an in person annual meeting with everyone. Registration information coming soon!

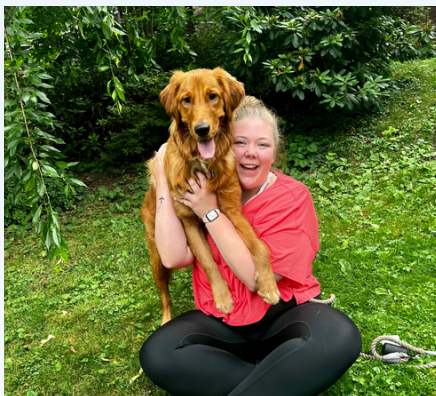
Staff Update

Meet our new Project Coordinator, Lauren Bodi!

"I am so excited to be joining the Starzl Network team. I previously worked in a drug and alcohol rehabilitation setting focusing in case management. I am excited to apply my skills and passions to the Starzl Network team and work together to reach our goals.

When I am not working, you can find me reading or hanging out with my golden retriever, Auggie!"

Lauren can be reached at bodil@upmc.edu.



Collaborator Highlights

Eric Pahl, OmniLife Health

The Transplantation Society Travel Award to attend the 27th Annual Meeting of SPLIT

Presentation "Prediction of offer acceptance and graft type selection in deceased donor pediatric liver transplantation"

Oral Presentation on Tuesday, October 17 at 10:30-11:10 am

Nehal Swami, RealTime Clinic

PRO Collection & Analysis Solution of the Year 2023: RealTime Clinic

Realtime Clinic has been awarded in the sixth year of the Fitness and Nutrition Awards 2023. "We are delighted to once again offer recognition to those raising the bar across the fitness, nutrition, health and sport sectors internationally."

Research Coordinator Resources

Starzl Network research coordinators expressed a need for additional resources to enter data into the data mart.

As a result:

- We have hosted multiple meetings led by coordinators to review data points and discuss the data entry process.
- We have created a Basecamp page with resources just for research coordinators.
- We plan to have ongoing conversations with the coordinators to maximize data entry!



If you or a member of your team would like to be added to Basecamp and attend calls, please contact C.J., cj.confair@starzlnetwork.org

Starzl Data Mart Updates

- Do you need access to the Data Mart?
 - Send login requests to [C.J. Confair](#)
- Deidentified data file is available via a request to the DUPC – Contact [Jim Squires](#) & [Rene Romero](#)
- Basecamp group for data mart resources and to ask questions – Contact [C.J. Confair](#)
- Starzl Network Data Mart Access
 - <https://starzlnetwork.org/data-mart/>

Manuscript Updates

Immunosuppression Team, in submission: Impact of early immunosuppression on pediatric liver transplant outcomes within one year: a parallel analysis of the United Network for Organ Sharing and the Society for Pediatric Liver Transplant Registry

PARTNER (PCORI), submitted to American Journal of Transplantation: Patient-centered research in pediatric transplant: Engaging families and recipients

Mental Health Testimonial - Parent of a 2x Liver Recipient

My daughter has had two transplants in the past 8.5 months old and 4 years old, respectively, due to Maple Syrup Urine Disease. Before her transplant, we received some invaluable advice that has stuck with us to this day. We were told that as parents, we would always be faced with life-altering decisions. Our child was not old enough to understand and would look to us for how to feel about the situation. If we showed her it was going to be okay, she trusted that. We were encouraged to try and make the whole experience a positive one by acknowledging the trauma and emotions that come with it. By doing this, we were able to be more open to those feelings and learned how to approach them with more grace and understanding. We also recognized that these triggers were going to be a part of our lives going forward, and that we needed to learn how to deal with them accordingly. We were encouraged to see our child as more than just their medical history - to look beyond their diagnosis and see the child underneath. This is a concept that we continue to practice in our daily lives and will remain with us forever. Therapy has been a huge help in working with processing the trauma. What has surprised me the most is how many people want to help and support us. Complete strangers and our community rallied around our family and provided so much support. The process helped me find my voice for advocacy and volunteer work. I love giving back to the transplant community.