



STARZL NETWORK

for Excellence in Pediatric Transplantation



CITRONE
POWERED BY: **thirty** / **three**

UPMC | **CHILDREN'S**
HOSPITAL OF PITTSBURGH

HOW WE STARTED

STARZL NETWORK FOR EXCELLENCE IN PEDIATRIC TRANSPLANTATION

Vision

A network of pediatric transplant institutions committed to continuous improvement until every child can achieve a long and healthy life.

History of the Network

The Starzl Network aims to improve lifelong outcomes for children in need of organ transplantation. The Network was launched in 2017 with a leadership gift from Cindy and Rob Citrone, founders of Citrone 33, during the *Play It Forward Pittsburgh* campaign, an initiative which continues to amplify the need for transplant organ donation at a national level by seeking to register organ donors, raise awareness about organ donation and transplantation, raise funds to improve pediatric transplant outcomes, and encourage relevant policy updates.

Citrone 33

Citrone 33 was founded by Rob and Cindy Citrone to provide hope and happiness to people in their time of need. The organization is committed to improving quality of life by performing everyday miracles. Other signature initiatives of the foundation include *EMBRACE Pittsburgh* and *Protect the Cups*. As champions for children, the Citrones understand the lifesaving value of organ transplantation. Our deepest thanks to the Citrone family and Citrone 33 for giving kids the chance to attain miracles of their own through transplant.

Thomas E. Starzl, MD, PhD

Dr. Thomas Starzl, the “father of transplantation,” was a groundbreaking surgeon and researcher. Globally recognized as a medical and scientific leader in organ transplant, he performed the world’s first successful liver transplant and greatly advanced medications that have improved quality of life following transplantation. A faculty member at the University of Pittsburgh and clinician at the UPMC Children’s Hospital of Pittsburgh, Dr. Starzl led the largest and busiest transplantation program in the world.

Dr. Starzl transformed thousands of lives through advances in organ transplant that many thought weren’t possible. He was a genius and a pioneer, but it was his passion for saving lives through transplant that defined him. The Network was named in his honor, seeking to continue his legacy of innovation, care, and collaboration in support of a brighter future for pediatric transplant patients.

George V. Mazariegos, MD, FACS

Dr. George Mazariegos is the director of Pediatric Transplantation at UPMC Children’s Hospital of Pittsburgh and the Thomas E. Starzl Transplantation Institute, as well as a professor of surgery at the University of Pittsburgh. Dr. Mazariegos and his colleagues, through the generous support of Citrone 33, founded the Starzl Network for Excellence in Pediatric Transplantation to honor the vision and legacy of their friend, mentor, and colleague, Dr. Thomas Starzl. Dr. Mazariegos serves as the Chairman of the Starzl Network and leads and directs the Network’s overall efforts.

WHY WE STARTED

What is a Learning Health System?

In 2006, the Institute of Medicine (IOM) convened a Roundtable on Evidence-Based Medicine to explore innovative strategies for improving health care. IOM's guiding principle was that medical decision-making and health care systems should be "grounded on a reliable evidence base," "account for individual variation in patient needs," and facilitate "the generation of new insights on clinical effectiveness."¹ To realize these goals, the IOM experts envisioned implementing learning health systems (LHS), which would be built to enable "continuous improvement and innovation, with best practices seamlessly embedded in the delivery process and new knowledge captured as an integral byproduct of the delivery experience."² LHS aim to integrate research, improvement, management, and patient care such that every patient receives "the right care at the right time...every time."³ Critical to a successful LHS is the integration of all stakeholders that utilize and interact with the system, in its construction and implementation. This includes patients, families, medical providers, administrators, representatives from supporting industries, and policymakers.

Accelerating Patient Care

The Starzl Network is a Learning Health System designed to transform transplantation by combining transparency, best practices, and patient reported outcomes with innovative technology.

Key components include engaging patients and families as partners in the design of network priorities, database design, and tools to disseminate learning, implement knowledge, and improve practice.

REFERENCES:

1. Institute of Medicine. *The learning healthcare system: Workshop summary*. Washington, DC: National Academies Press: 2007.
2. Institute of Medicine. *Roundtable on value & science-driven health care*. Washington, DC: National Academies Press: 2006.
3. Forrest CB, Margolis P, Seid M, Colletti RB. PEDSnet: How a prototype pediatric learning health system is being expanded into a national network. *Health Aff. (Millwood)*. 2014; 33(7):1171-1177.

Gaps this Learning Health System Addresses

Challenges

- Pediatric transplantation is a rare disease
- Variation in practice
 - Geographically
 - Age
 - Center
- Time to implementation and dissemination of knowledge is too long
- Lack of evidence-based practice

Approaches

- Collaboration
- Learning from other disciplines
- Include patient voice
- Integration of industry and tech partners
- Use improvement and research strategies

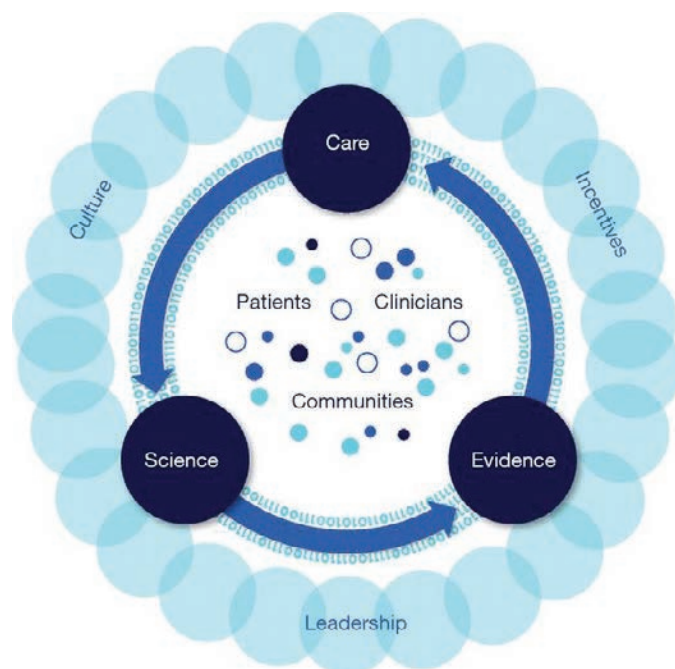


Figure: Peng, D, Rosenthal, D, Zafar F, et al. Collaboration and new data in ACTION: a learning health care system to improve pediatric heart failure and ventricular assist device outcomes. *Translational Pediatrics*, 2019 Oct; 8(4): 349-355.

WHO WE ARE

Mission

To unite big data, technology, patient advocacy, and transplant thought leaders to deliver the best possible care and develop new, scalable solutions to pediatric transplantation's most challenging problems.

Goals

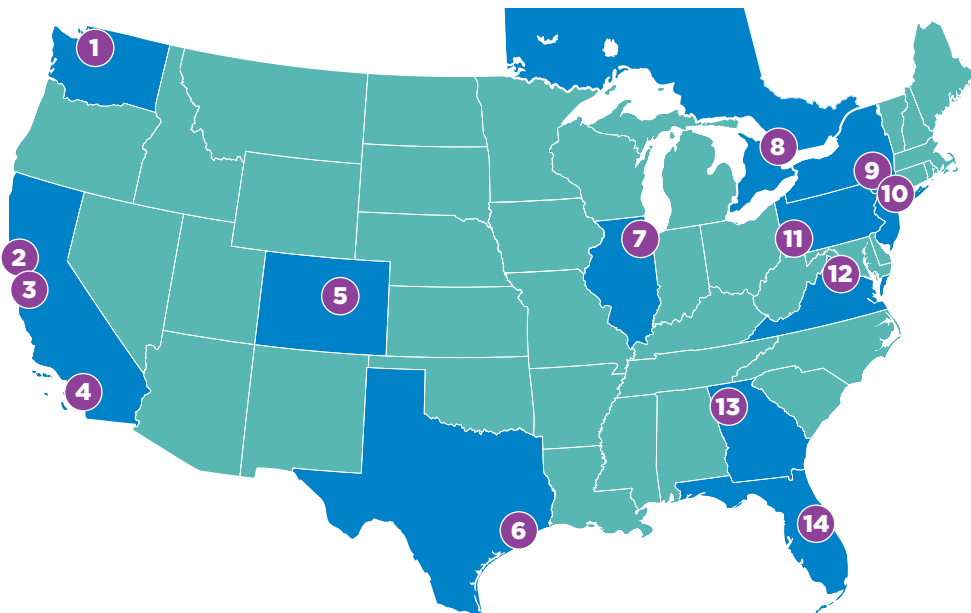
- Collectively determine gaps in transplant outcomes, beginning with liver transplant, to plan network projects.
- Standardize and transparently share data for better outcomes in pediatric transplantation.
- Initiate transplant technology competitions to encourage and foster innovation.

Benefits for Patients and Families

- Increase awareness of complications and outcomes following transplantation for patients and families.
- Access cutting-edge, patient-centered technology and use it to advance the field.
- Strengthen the voices of pediatric patients and their families.
- Utilize feedback to shape research and improvement priorities.

Guiding Principles

- **Collaboration:** A desire among members to forgo individual gains in lieu of collective efforts.
- **Urgency:** A shared sense of determination to quickly and dramatically improve patient care and outcomes.
- **Transparency:** A willingness among members to freely and openly share data within and beyond the Network.
- **Innovation:** A determination to identify and use leading approaches and technologies to advance our goals.
- **Excellence:** A commitment to engage leaders across multiple fields and combine their expertise.
- **Synergy:** A drive to build off existing systems (e.g., SPLIT) or provide expertise to regulatory bodies (e.g., UNOS) who are advocating for improvement in outcomes for children.



Network Members



WHAT WE DO

Priority Areas

- Optimizing Immunosuppression
- Anticoagulation Best Practices
- Adoption of Pediatric Liver Transplant Quality of Life (PeLTQL) Survey
- Understanding Variations in Transition of Care Resources and Practices

Teach Higher for the Starz(l): Next Gen Online Resources for Child Liver Transplant Patients and Their Families

Goal: With American Legion Child Welfare Foundation support, the Starzl Network will develop more educational content and make widely available educational resources for thousands of children and parents.

Surgeons Working Group

Goal: Serve as a resource to the transplant community by collaborating with all liver transplant stakeholders to advocate and disseminate surgical best practice in the care of children with liver disease, with the goal of improving outcomes in pediatric liver transplantation for all children regardless of race, ethnicity, or socioeconomic status.

Listserv

Goal: Serve as a quick response resource for physicians and surgeons to ask questions and provide comments on complex cases.

Patient & Family Voice

Goal: Bring the knowledge and expertise of patients and families to the Starzl Network's goals of creating and implementing innovative projects and research to improve outcomes and unite the pediatric transplant community.

Network Accomplishments

2019

Priority Project Retrospective Data Collection

2020

American Legion Child Welfare Foundation Grant

2021

Pitt Innovation Challenge Award

2021

Launched Data Mart with UNOS

2021-2023

Patient-Centered Outcomes Research Institute Award

2022-2024

Henry L. Hillman Foundation Grant

2021-2024

Agency for Healthcare Research & Quality Grant

2022

American Legion Child Welfare Foundation Grant

SUPPORT LEVELS



Disruptor

\$250,000 & up/year



Visionary

\$100,000/year



Innovator

\$50,000/year



Catalyst

\$25,000/year



Collaborator

\$10,000/year

Your contributions to the Network help support:

- Expand the reach of the Network
- Increase center participation
- Starzl Network Database
 - Data Collection & Analysis
- Impact Projects
 - Optimizing Immunosuppression
 - Anticoagulation Best Practices
 - Transition of Care
 - Quality of Life
- Patient & Family Voice Engagement
- Annual Meeting
- Teach for the Starzl(l) Resource Updates
- Surgeons Working Group and Listserv
- New Innovative Projects






FOR MORE INFORMATION OR TO CUSTOMIZE A SUPPORT PACKAGE, PLEASE CONTACT:

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SUPPORT LEVELS

					
Benefits	Disruptor \$250,000+	Visionary \$100,000	Innovator \$50,000	Catalyst \$25,000	Collaborator \$10,000
Recognition on Starzl Network Website	✓	✓	✓	✓	✓
Exhibit at Annual Meeting	✓	✓	✓	✓	✓
Invitations to Annual Meeting	5	4	3	2	1
Named Project Annual Sponsorship	✓	✓	✓		
Reception/Dinner Invitation at Annual Meeting	3	2	1		
Email Blast to All Network Members	✓	✓			
Vendor Presentation During Network Call	✓				
Meet and Greet with Network Representatives at Annual Meeting	✓				
Social Media Package*	✓				

*Social Media Package – tailored opportunity on YouTube, Instagram, Facebook, Twitter can be discussed.