Pediatric Heart Transplant Society

PEDIATRIC HEART TRANSPLANTATION TODAY

PHTS Newsletter

Dr. Juan "Chuck" Alejos, Senior Editor
Dr. Neha Bansal, Junior Editor

May 2025



We had a great time in Boston this spring—welcomed by beautiful weather, incredible food, and the warmest of people. The ISHLT conference brought a fantastic mix of old friends and new connections, making it a memorable gathering for all.

We're especially proud of Dr. Lydia Wright and Dr. Waldemar Carlo for their fantastic oral presentations at the ISHLT conference, representing PHTS with excellence and insight.

A special highlight of the week was the PHTS Lifetime Achievement Reception honoring the remarkable Dr. Daphne Hsu, featuring an inspiring speech by Dr. James Kirklin at our Spring Annual Meeting. We also enjoyed the PHTS and Enduring Hearts Mix and Mingle, and the always productive Mentor and Mentee Luncheon.

Thank you to everyone who joined us and contributed to such a rich and rewarding few days. We can't wait to see you all again in November as we come together to celebrate a historic milestone, 10,000 transplants in PHTS!

Neha and Chuck



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PHTS GROWTH*

13,081 → Patients Enrolled Total
13,469 → Listings/relisting entered
9939 → Transplants entered
474 → Listings for 2024
372 → Transplants for 2024
101 → Listings for 2025
79 → Transplants for 2025

*as of May 1, 2025

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Madeleine Townsend, MD
Cleveland Clinic

Statin Use for CAV Prevention in Pediatric Heart Transplant Recipients: Helpful or Harmful?

As highlighted by Dr. D'Addese in her review of aspirin use to prevent cardiac allograft vasculopathy (CAV) in the latest PHTS Newsletter, CAV remains the major Achilles heel to long-term graft survival after heart transplantation, with no proven strategies identified to prevent CAV development in children. With their greater patient numbers and resources for large-scale research, studies of adult heart transplant recipients (HTRs) remain a primary source of information from which we extrapolate management and treatment options for our pediatric HTRs. The adult data on statin use is compelling, with a recent meta-analysis of statin use in adult HTRs demonstrating decreased all-cause mortality, rejection, and CAV.[1] However, as we all well know, children are not just tiny adults, and so adult strategies for CAV prevention may or may not be truly applicable to our patient population. With this background in mind, we felt a contemporary evaluation of the PHTS registry could help us better understand the prevalence and efficacy of statin use in pediatric HTRs.[2]

Background

Statins (HMG-CoA reductase inhibitors), through their effective treatment of hyperlipidemia, are commonly utilized for primary and secondary prevention of traditional atherosclerotic cardiovascular disease in adults. They have been hypothesized to attenuate the ischemia-reperfusion injury inherent to cold storage of donor hearts as well as have immune modulatory effects, and early initiation in the first few months post-transplant have demonstrated the greatest benefit to adult HTRs.[3] The International Society for Heart and Lung Transplantation (ISHLT) guidelines for the care of HTRs recommend consideration of statin therapy in all HTR (pediatric and adult).[4]

However, considerations unique to our pediatric population have limited uptake of statin usage, including concerns about safety during childhood growth and puberty, lack of Federal Drug Administration labelling for some statin medications in children, lack of liquid medication formulations, and conflicting data on the true efficacy of statins in the absence of the more metabolically driven risk factors for coronary atherosclerotic disease in adult HTRs. Moreover, the pediatric literature on statin use in pediatric HTRs is largely limited to single center series with mixed results, and the previous study of the PHTS database by Dr. Greenway and colleagues found no association between statin use in the first-year post-transplant and post-transplant survival or CAV development, and in fact raised concern for risk of earlier rejection.[5] The authors identified important limitations of their study, including the distinct possibility that the patients receiving statins represented a higher-risk cohort, with numerous unidentified confounding factors, leaving interpretation and extrapolation of the results to standard-risk pediatric HTRs challenging.

The last two decades have brought long-term safety and efficacy data on statin use in the pediatric familial hyperlipidemia population. Moreover, given the limited options to prevent or treat early CAV and extent graft survival in pediatric HTRs, statins continue to be commonly prescribed by many pediatric heart transplant practitioners. The goal of our recent study was thus to evaluate the contemporary prevalence and trends of statin use in pediatric HTRs and the association between statin use and CAV incidence as well as graft survival.

Study Design

Pediatric patients (<17 years at primary heart-only transplant) were identified from the PHTS database between January 2001 through December 2018, with three years of follow up data available. Our analysis specifically sought to evaluate the use of statins as a primary prevention therapy (i.e., prior to the development of endpoints such as CAV that would prompt treatment) and thus evaluated the use of statin therapy in the first 3 years post-transplant (Figure 1). As statins have a more established safety profile in children ≥10 years of age, a sub-analysis was undertaken for patients who were ≥10 years old at the time of transplant.

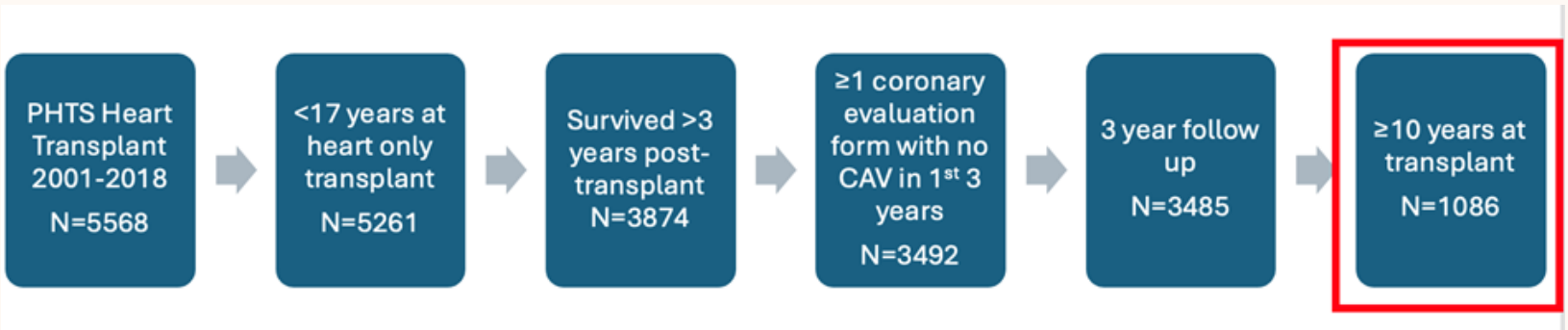


Figure 1. Study cohort flowchart.

Statin use was identified on the annual post-heart transplant follow up forms and classified as:

1. Consecutive (present on all 3 forms)
2. Intermediate (1-2 forms)
3. None (0 forms).

Statin utilization patterns were evaluated. The primary endpoints evaluated were graft survival and freedom from CAV diagnosis. A secondary analysis was performed looking at center practice variation, which compared patients not on statins at low (0-25%) statin use centers to those on statins at high (76-100%) statin use centers in an attempt to compare standard risk pediatric HTRs receiving, or not receiving, protocol-driven statin preventative therapy.

Key Results

Of the 3485 pediatric HTRs who met inclusion criteria, 17% received consecutive statin therapy, 19% intermediate use, and 65% no statin in the first 3-years post-transplant, while in the ≥10-year-old cohort (n=1086), 29% received consecutive statin therapy, 32% intermediate use, and 39% no statin (Figure 2). Patients not on statins represented a different patient population (younger, congenital heart disease, higher cardiopulmonary support). However, in the older cohort, the patients on consecutive vs intermediate vs no statin use were largely similar. Therefore, in conjunction with increased statin usage in this group, the outcome analyses focused on this group.

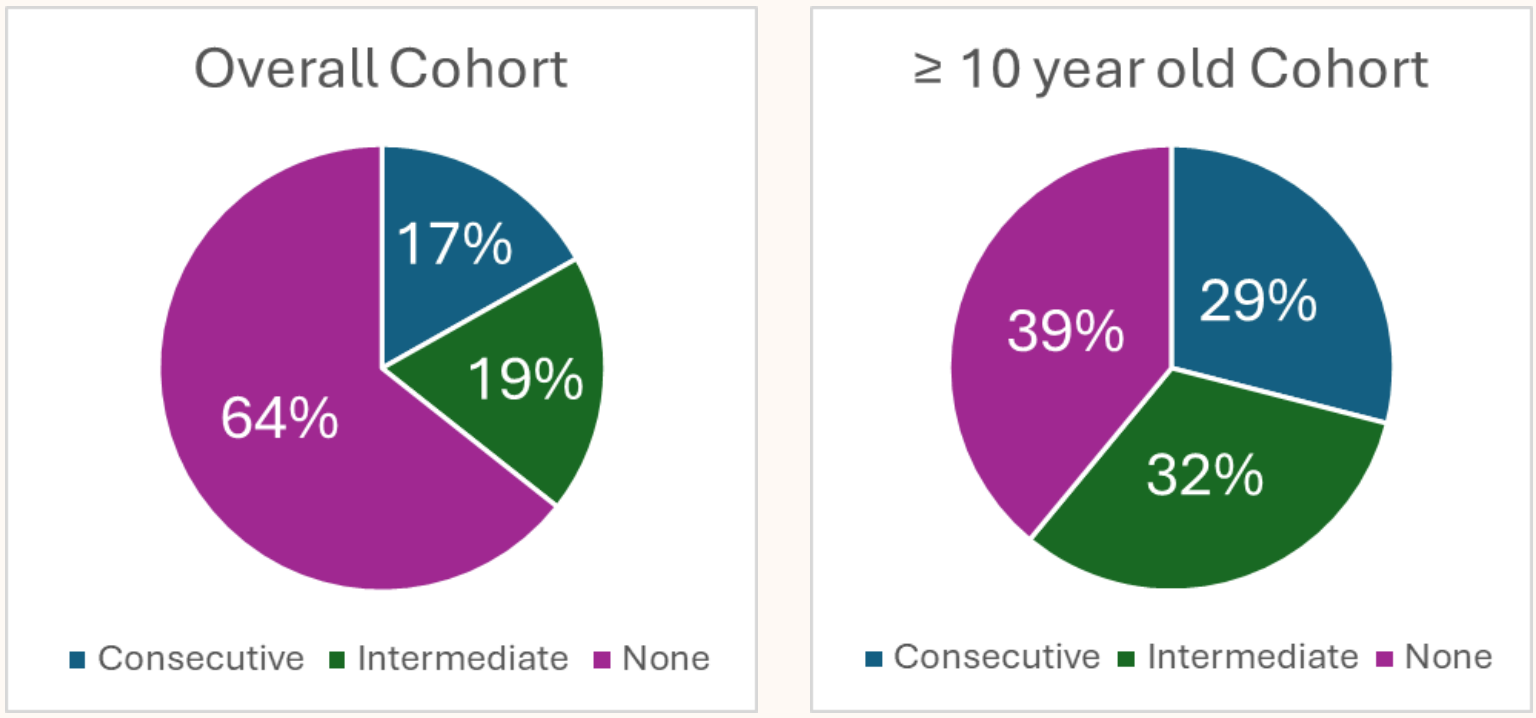


Figure 2. Statin usage in the first 3-years post-transplant in the overall and ≥10-year-old cohorts.

Statin use was highly variable across the 54 PHTS centers, with 20 sites having 0-25% of their patients in the overall cohort on statins, 23 sites 25-50% of patients, 8 sites 50-75% of patients, and 3 sites 75-100% of their patients on statins across the first three annual follow up visits (Figure 3).

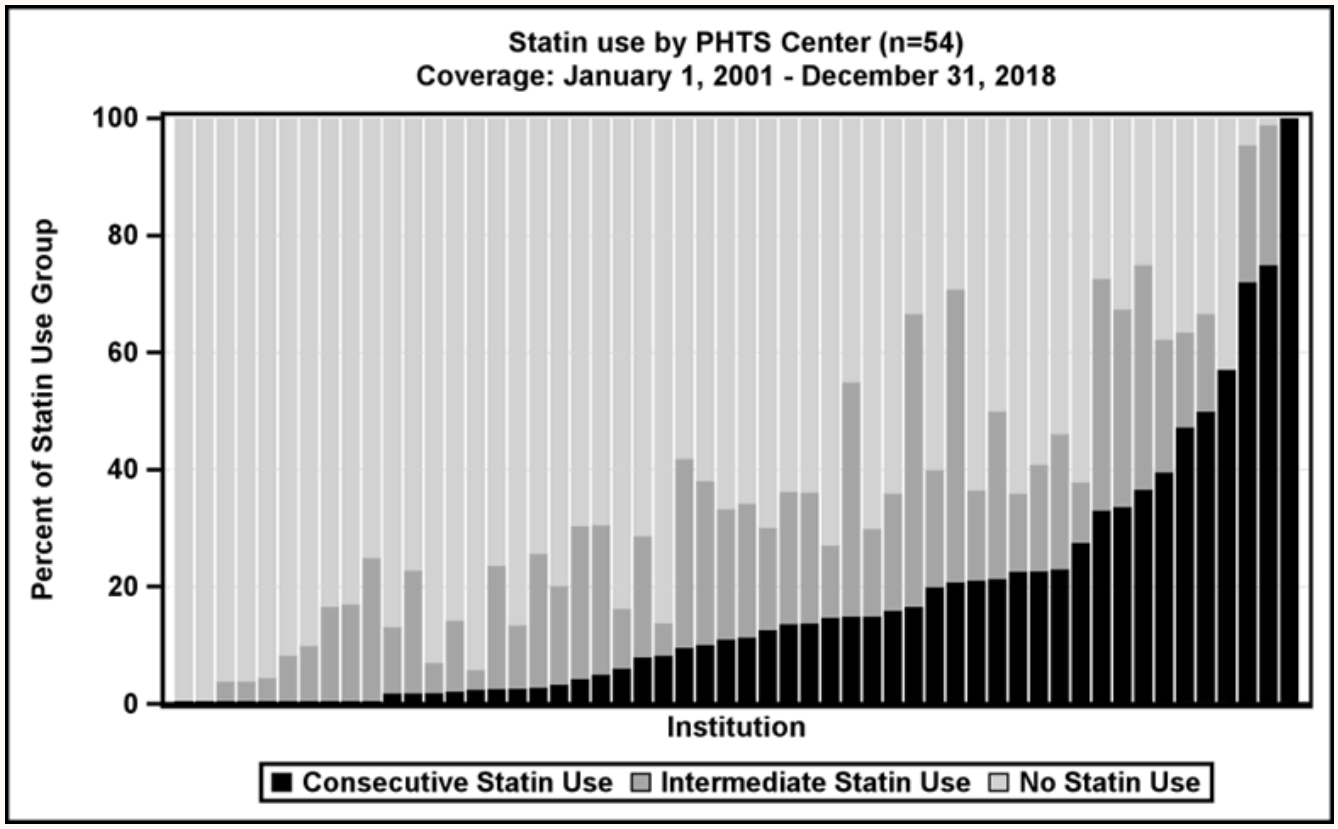


Figure 3. Statin use by PHTS center in the overall cohort.

Statin use:

- Increased with increasing patient age
- Was more likely to be initiated by the 1-year visit in ≥10-year-olds (42%) vs 3-years (8%) or 5-years (3%) post-transplant
- Overall and consecutive statin usage increased over time in the ≥10-year-olds, but not in the overall cohort
- Was not associated with improved graft survival or decreased incidence of CAV in multivariate or propensity score matched analysis, or in the comparison of center practice variation

Implications, Limitations and Future Directions

This contemporary PHTS study of statin use in children did not demonstrate statins to be protective in terms of graft survival or prevention of CAV. However, there are important limitations inherent to the registry data, which begin with the need to define early statin use at the 1-year post-transplant follow up form, which is beyond the timeframe of highest statin benefit post-transplant seen in the adult data. Statin medication type and dosing is not collected. CAV is diagnoses on coronary angiography, which is likely a late identifier of disease. Finaly, adolescents may age out of receiving care at PHTS centers, which limits long-term outcomes data. This study does seem to put to rest any clearly identified harm from statins in children, at least from a graft survival standpoint, and so we turn back to the adult data, which continues to compel us to further study the potential benefits of early statin use in children. A prospective study of early statin use in pediatric HTRs that utilizes imaging techniques that can provide early diagnosis of CAV, and that supports collection of long-term follow up data, is likely the only way we will be able to identify with certainty whether statins are truly helpful in our pediatric patients. Given the equipoise in the literature, the safety data on statin use from other pediatric populations, and the practice variation seen between PHTS centers, a prospective trial that evaluated statin and aspirin use for the prevention of CAV and improvement in long-term graft survival in pediatric HTRs is needed.

References

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PHTS Live!

June 18, 2025

"Decision making in transplantation: the interplay between science and bias"

Valerie Chepp PhD. - Lerner Research Institute Cleveland Clinic

July 2025 - Date coming soon

"SRTR Survival Calculator"

Speakers announced soon

Host



Juan Alejos, MD



Manu Varma, D.O.



Lynsey Barkoff, CPNP



SAVE THE DATE

PHTS Fall Annual Meeting

Sunday, November 9, 2025

Join us in New Orleans this November as we honor a remarkable milestone, 10,000 pediatric heart transplants recorded in the PHTS registry.

PHTS Leadership Nominations Opening This Fall

PHTS will be accepting nominations this coming fall for two important leadership positions: **Vice President and Allied Health and Nursing Representative**.

We encourage all members to begin considering colleagues who would be strong candidates for these roles. Nominations will officially open in the fall, and the elected individuals will be announced during the PHTS Annual Business Meeting in October.

Vice President

The elected Vice President will serve a multi-year leadership progression on the PHTS Steering Committee:

- November 2025 – November 2027: Vice President and Chair of the Database Committee
- November 2027 – November 2029: President and Liaison to the PHTS Foundation
- November 2029 – November 2031: Past President and Chair of the Liaison Committee

Allied Health and Nursing Representative

The elected Allied Health and Nursing Representative will serve on both the Steering Committee and the Database Committee:
Term: November 2027 – November 2029

Member Spotlight

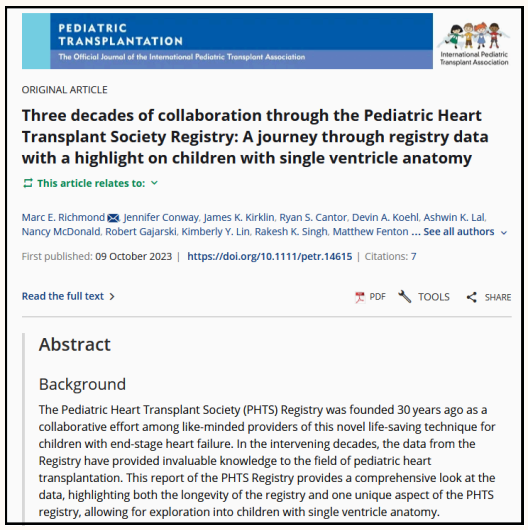


Humera Ahmed, MD

Manuscript accepted for publication in Pediatric Transplantation

Post-operative Dialysis in Fontan Patients Undergoing Heart Transplant: How Predictive is the Pre-Transplant Serum Creatinine?

TOP 10



PEDIATRIC TRANSPLANTATION
The Official Journal of the International Pediatric Transplant Association

ORIGINAL ARTICLE

Three decades of collaboration through the Pediatric Heart Transplant Society Registry: A journey through registry data with a highlight on children with single ventricle anatomy

This article relates to:

Marc E. Richmond, Jennifer Conway, James K. Kirklin, Ryan S. Cantor, Devin A. Koehl, Ashwin K. Lal, Nancy McDonald, Robert Gajarski, Kimberly Y. Lin, Rakesh K. Singh, Matthew Fenton ... See all authors

First published: 09 October 2023 | https://doi.org/10.1111/petr.14615 | Citations: 7

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Abstract

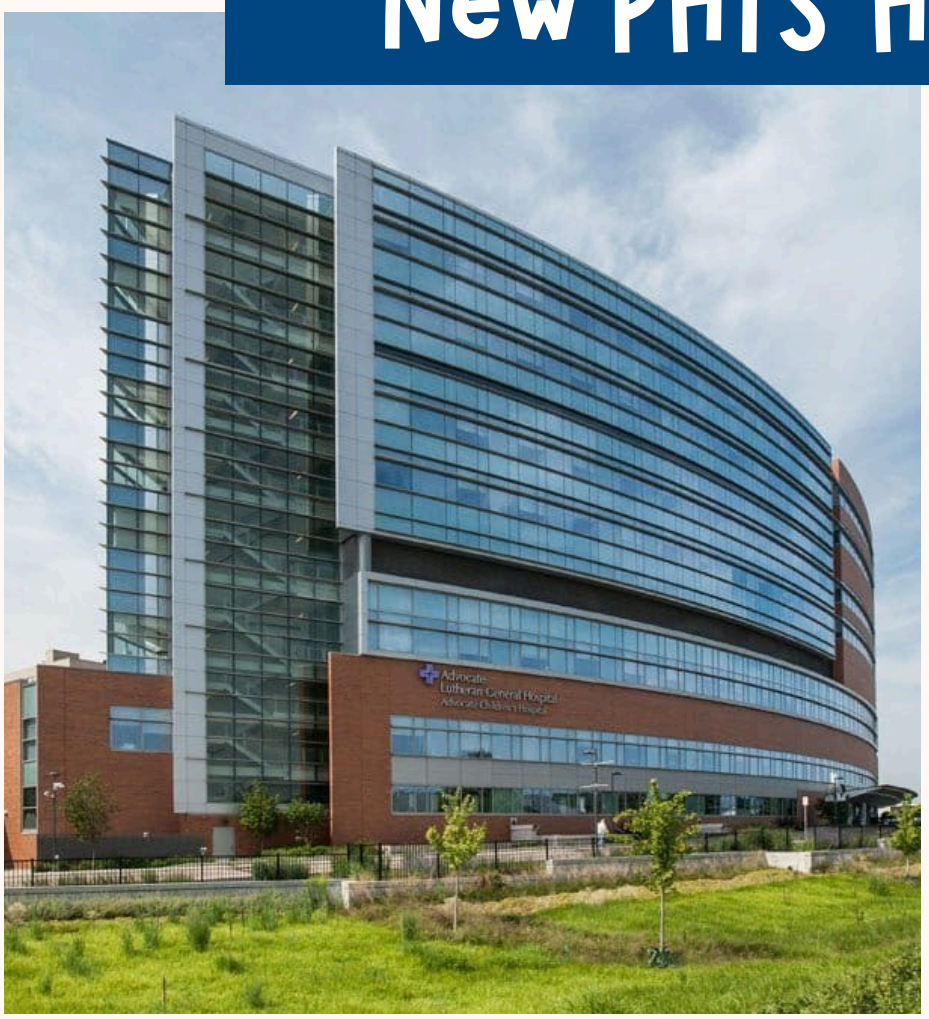
Background

The Pediatric Heart Transplant Society (PHTS) Registry was founded 30 years ago as a collaborative effort among like-minded providers of this novel life-saving technique for children with end-stage heart failure. In the intervening decades, the data from the Registry have provided invaluable knowledge to the field of pediatric heart transplantation. This report of the PHTS Registry provides a comprehensive look at the data, highlighting both the longevity of the registry and one unique aspect of the PHTS registry, allowing for exploration into children with single ventricle anatomy.

One of the top 10 most-cited papers published in Pediatric Transplantation in 2023

Three Decades of Collaboration Through the Pediatric Heart Transplant Society Registry: A Journey Through Registry Data with a Highlight on Children with Single Ventricle Anatomy

New PHTS Hospital



Welcome!

Advocate Aurora Research Institute

Oak Lawn, Illinois

PHTS at ISHLT 2025





PHTS Lifetime Achievement Reception honoring

Dr. Daphne Hsu





PHTS Spring Annual Meeting

Guest Speaker:

Dr. James Kirklin





PHTS at ISHLT 2025

PHTS Mentor and Mentee Luncheon





lead by
Alicia Kamsheh

PHTS and Enduring Hearts Mix and Mingle

Enduring Hearts
HEALTHY KIDS • STRONGER HEARTS • LONGER LIVES







PHTS Booth

Job Postings

Pediatric Heart Failure and Transplant Position - Joe DiMaggio Children's Hospital

he Heart Institute at Joe DiMaggio Children's Hospital (JDCH) is seeking a full-time pediatric transplant cardiologist to join an established team of specialists. The Heart Transplant Program started in 2010 and has become the second busiest program in the state of Florida.

Contact: Please reach out directly with any questions - sshugh@mhs.net

4th Year Fellowship Opportunity at UPMC Children's Hospital

The Heart Institute at UPMC Children's Hospital is pleased to offer a 4th year of advanced training in heart failure, heart transplantation, and mechanical circulatory support. Qualified candidates will have completed a fellowship in pediatric cardiology at an ACGME-accredited program and will be board eligible by the start of the advanced training year on 1 July 2026.

Contact: Susan Fancsali, MBA, MS (fancsalisk@upmc.edu)

Medical Director of Pediatric Heart Failure and Transplant at Rady Children's Hospital in San Diego

The Division of Cardiology in the Department of Pediatrics at UC San Diego and Rady Children's Hospital San Diego is seeking a Medical Director of Heart Failure and Cardiac Transplantation. The University of California, San Diego (http://www.pediatrics.ucsd.edu) is committed to academic excellence among its faculty, staff, and student body.

Contact: Caitlin Carter, MD cecarter@health.ucsd.edu

Stanford 4th Year Fellowship in Advanced Heart Failure & Transplant

Lucile Packard Children's Hospital/Stanford University School of Medicine is now accepting applications for advanced fellowship training in pediatric heart failure, transplant and mechanical circulatory support (MCS) for the 2025-2026 academic year. Applicants must have completed their general pediatric cardiology fellowship prior to the start date of July 2026, to be eligible.

Call for Applications: Cincinnati Children's 4th Year Fellowship in Cardiomyopathy, Heart Failure, Transplant and Mechanical Circulatory Support

We are thrilled to announce that Cincinnati Children's Hospital Medical Center is now accepting applications for our 4th year advanced fellowship in Pediatric Cardiomyopathy, Heart Failure, and Transplant for the 2026-2027 academic year. Eligible candidates will have completed a categorical pediatric cardiology fellowship in time for a start date of July 2026.

Contact: Cindy Pottorf, hi.fellowship@cchmc.org, or 4th year fellowship director, Dr. Ben Mantell, at Benjamin.Mantell@cchmc.org

Job Postings

Texas Children's Hospital 4th Year Fellowship in Pediatric Heart Failure & Transplantation

Texas Children's Hospital / Baylor College of Medicine is now accepting applications for an advanced fellowship in pediatric heart failure, cardiomyopathy, mechanical circulatory support, and transplantation for the 2026-2027 academic year. Applicants must have completed their general pediatric cardiology fellowship prior to July 1st, 2026 to be eligible.

Contact: Dr. Kyle Hope (kyle.hope@bcm.edu) and cc Jose Soto (jrsoto@texaschildrens.org)

Advanced Fellowship in Pediatric Heart Failure & Transplantation at Lurie Children's Hospital

Lurie Children's Hospital of Chicago is now accepting applications for advanced fellowship training in pediatric heart failure/transplantation/MCS for the 2026-2027 academic year.

Contact: Defne Magnetta, MD (dmagnetta@luriechildrens.org) and Brittany Dixon (bdixon@luriechildrens.org) by August 1, 2025.

If you have a job posting that you would like to share with the PHTS Membership, visit the PHTS Basecamp board called Resources for Job Opportunities to add your job posting.