Pediatric Heart Transplant Society

# PEDIATRIC HEART TRANSPLANTATION TODAY

**PHTS NEWSLETTER**

*October 2022*

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

## PHTS GROWTH*

| | |
|---|---|
| 11,356 | patients enrolled |
| 11,818 | total listings/ relistings entered |
| 8,692 | transplants/ retransplants entered |
| 546 | listings for 2021 |
| 443 | transplants for 2021 |
| 260 | listings for 2022 |
| 237 | transplant for 2022 |

*as of October 1, 2022

## A MESSAGE FROM THE PHTS PRESIDENT

Watching our society make progress over the past year has been invigorating and you should all be proud of what you have accomplished. We continue to lead the field of pediatric heart transplant research. PHTS already has 8 abstracts accepted (including 4 to be presented at the upcoming AHA Scientific Sessions) and 9 manuscripts accepted or published in 2022. We are grateful for the hard work of not only our investigators, but also our scientific committee and data coordinating center.

Our research committee has made great progress on laying the foundation for future prospective research through PHTS by navigating the regulatory environment, developing resources for grant writing, and developing a framework for potential prospective studies (Kevin Daly, Ashwin Lal, and Daphne Hsu).

Our Standardizing Care Committee is nearly ready to unveil standardized approaches to rejection surveillance that will give centers options for rejection surveillance that match their philosophical approach (Defne Magnetta, Ryan Butts, and Jacque Lamour).

The Quality Improvement committee is nearly ready to begin its project aiming to improve utilization of oral contraceptives in adolescent and teenage heart transplant recipients (Deipanjan Nandi, Neha Bansal, and Robert Gajarski).

The database committee has updated multiple PHTS data collection forms, which are being implemented in a phased approach (Shri Deshpande).

Our Health Disparities Taskforce has given us a deeper understanding of how social determinants of health and implicit bias impact our patients' outcomes through both research and educational webinars. One manuscript has already been published and at least 3 more are on the way (Alfred Asante-Korang).

Our Nursing and Allied Health professionals are developing best practice resources for transition from pediatric to adult transplant care. It is exciting to see the interest in this project from our Nursing and Allied Health members (Heather Missler and Kristin Anton).

We now have a junior faculty and fellows group designed to improve mentorship and the junior faculty experience across PHTS. A junior faculty "meet and greet" during ISHLT in Boston got them started and the first group of mentors and mentees have been paired (Rakesh Singh and Arene Butto).

PHTS experts in the field of noninvasive rejection surveillance have partnered with the scientific and database committees to develop a voluntary form to collect data on donor derived cell free DNA. This project should give the field of pediatric heart transplant a better understanding of how to use this new marker of graft injury.

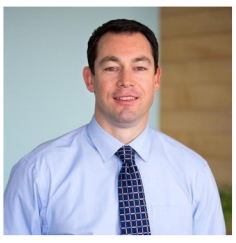
PHTS live continues to educate us about important topics in our field using a webinar-based format and has developed a global audience (Shri Deshpande).

We have developed important collaborations with other organizations like Enduring Hearts, Transplant Families, ACTION, and Heart University, just to name a few. These partnerships have enhanced the research, advocacy, and educational mission of PHTS and will continue to benefit the field for years to come (Jennifer Conway).

The outstanding work you are doing fills me with optimism for the future of PHTS and pediatric heart transplant as a field. While we always need to be looking toward the future, we would be remiss not to celebrate our rich past. I hope you will all join us for the PHTS 30th Anniversary Gala at the Denver Art Museum on April 20th (during ISHLT 2023).

*Scott*

Scott Auerbach, MD
PHTS President



**PHTS President**
Scott Auerbach, MD
Children's Hospital Colorado
Denver, Colorado



**PHTS Vice President**
Shriprasad Deshpande, MD
Children's National Health System

Visit our website to learn more:
**www.PHTSociety.org**

# Creating a Culture of "Yes" in Pediatric Heart Donation

*Seth Hollander, MD - Department of Pediatrics (Cardiology), Stanford University*

*Waitlist mortality for pediatric heart transplant candidates continues to remain unacceptably high, ranging from 17-30%.[1] Whereas it would be natural to assume that the solution to improving waitlist survival hinges on increasing organ donation rates, studies show that nearly 50% of pediatric hearts offered for transplantation are not utilized. Although some of these refused organs are of inferior quality and should not be used for transplantation, our understanding of what makes a donor heart "acceptable" is still evolving. An historic lack of consensus on what donor features are relevant to post-transplant outcomes coupled with entrenched institutional beliefs likely contributes to an important proportion of these hearts inappropriately refused based on "risk factors" not supported by the extant medical literature.[2,3] With an increasing number of pediatric patients being listed for heart transplantation and a relatively steady donor pool, increased utilization of appropriate donor organs remains a critical area in which we can improve waitlist outcomes.[4]*

*The pursuit to better understand acceptable donor heart characteristics is relatively new. In 2013, using the Pediatric Heart Transplant Study (PHTS) database, Conway et al. published the first multi-center study focused on donor characteristics and post-transplant outcomes for pediatric patients, demonstrating that donor cause of death, need for inotropes and donor cardiopulmonary resuscitation (CPR) did not affect post-transplant survival despite a traditional belief that these features defined a "marginal donor".[5] The authors note that the lack of studies guiding physicians available at that time likely contributed to the mischaracterization of appropriate donor hearts as unacceptable, concluding that parameters for accepting a donor heart could be expanded with a better understanding of donor factors.*

*Since then, the last decade has seen a flurry of literature aimed to shed light on the impact of specific donor characteristics traditionally believed to impact post-transplant outcomes, culminating in 2020 with an International Society for Heart & Lung Transplantation (ISHLT) consensus statement on donor acceptability in pediatric heart transplantation.[1] This paper, which aimed to "ensure that no usable donor heart is discarded, waitlist mortality is reduced, and post-transplant survival is not negatively impacted" cited nearly 40 papers published in the last decade covering a wide range of topics dispelling many long-held beliefs about donor characteristics previously believed to impact donor quality and post-transplant outcomes.[1] With so many studies characterizing both relevant and irrelevant donor features published during this time, one would expect that this shared knowledge would favorably impact donor acceptance practices with increased allocation of organs previously believed unacceptable. Although measuring this kind of change is difficult, there is little evidence to suggest that our donor acceptance practices have changed much over time. This is not surprising when one considers that what influences an individual physician's decision to accept or reject a donor offer goes beyond their knowledge of the medical literature. Decisions are influenced equally, if not principally by behavioral motivators, including fatigue when donor decisions are made the middle of the night, or regulatory incentives, including the desire to avoid societal scrutiny or medical-legal risk. Similarly, the decision to accept or reject a donor offer may be motivated by the desire to protect one's program's reputation, as donor declines are not tracked as a quality measure, but post-transplant survival statistics are available publicly. Lastly, and probably most importantly, despite our best intentions, we are personally motivated to be overly conservative when it comes to donor offers as post-transplant mortality is often internalized by providers as an individual failure whereas waitlist mortalities are more easily attributed to non-personal factors, like the inadequate donor supply, natural progression of pediatric heart disease, or a dysfunctional organ allocation system.*

*Yet, improving our utilization of truly appropriate donor heart offers remains difficult; barriers to learning from our collective experience abound. Firstly, the acceptance criteria employed by many centers are too strict, making it impossible to know where the boundaries of acceptable donor quality lie. This is particularly true for low-volume transplant programs whose survival statistics suffer disproportionately from individual patient mortalities, fostering more risk-averse donor acceptance practices, often to their own detriment, as this approach has been shown to result in longer wait list times and worse post-transplant survival. Secondly, donor heart acceptance practices vary greatly between centers, driven by institutional culture as much if not*

# Creating a Culture of “Yes” in Pediatric Heart Donation

*Seth Hollander, MD - Department of Pediatrics (Cardiology), Stanford University*

*more than by evidence-based practice, preventing our community from learning through shared experience. The end-result of all of this is that, despite our desire to get as many children as possible to transplant, when it comes to donor offers, we as a transplant community have created a culture of “no”. Regardless of what we want for our patients or our fidelity to following the medical literature, ultimately, the incentives pushing one to decline a donor offer overpower those pushing one to accept. Even worse, we appear to be stuck in a cycle where our practices serve to reinforce our existing beliefs rather than encouraging us to grow.*

*So, how do we change? If individualism is the problem, then community is the solution, whereby working together to create a culture of “yes”. Community discussion groups, like the Advanced Cardiac Therapies Improving Outcomes Network (ACTION)-PHTS Donor Decision Forum allow for real-time sharing of ideas and collaborative learning without the delays and drawbacks of using the medical literature, an often-inefficient vehicle for change. We must also advocate for improvements in the way the United Network for Organ Sharing (UNOS) donor offer platform presents information such that relevant data is presented clearly and in context while less relevant information (like CPR duration) is de-emphasized or omitted altogether. Lastly, we must continue to push for better characterization of donor declines through more descriptive refusal codes and easier ways for centers to study the fate of organs they refused. With these, and other interventions, together we can create the culture of “yes” that will best serve our patients.*

*Acknowledgements*

*Dr. Hollander would like to thank Dr. Aamir Jeewa for editing this article.*

*References*

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2. *Rizwan R, Zafar F, Bryant R, 3rd, et al. The Number of Refusals for Donor Organ Quality Does Not Impact Heart Transplant Outcomes in Children. Ann Thorac Surg. 2018;105(4):1223-1230.*
3. *Riggs KW, Kroslowitz BJ, Chin C, Zafar F, Morales DLS. Pondering Higher-Risk Pediatric Heart Donors: Can We Use More? Ann Thorac Surg. 2020;110(1):198-205.*
4. *Colvin M, Smith JM, Hadley N, et al. OPTN/SRTR 2016 Annual Data Report: Heart. Am J Transplant. 2018;18 Suppl 1:291-362.*
5. *Conway J, Chin C, Kemna M, et al. Donors' characteristics and impact on outcomes in pediatric heart transplant recipients Pediatr Transplant. 2013;17(8):774-781.*

# PHTS at AHA 2022

## PHTS Presentations



**Manu Varma, MD**

Time course and predictors of decline in renal function after pediatric heart transplantation

Saturday, November 5th
11:00 AM - 12:00 PM CT

Poster Presentation

Session Title:
Heart Failure and Transplant - Pediatric Cardiology



**Irene Lytrivi, MD**

Contemporary outcomes and management strategies of pediatric cardiac transplantation with a positive retrospective HLA Crossmatch

Sunday, November 6th
11:00 AM - 12:00 PM CT

Poster Presentation

Session Title:
Risk Stratification in Congenital Heart Disease and Pediatric Cardiology

Enduring Hearts



**Shahnawaz Amdani M.D., F.A.C.C.**

The Influence Of Social Determinants Of Health And Race On Pediatric Heart Transplant Outcomes

Sunday, November 6th
3:20 PM - 4:10 PM CT

Rapid Fire Oral Session

Session Title:
The Groundwater in Health Inequities: Structural Determinants of Health



**Humera Ahmed, MD**

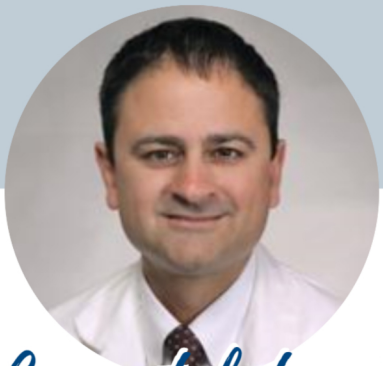
Post-operative Dialysis In Failing Fontan Patients Undergoing Heart Transplant: How Well Does The Pre-transplant Creatinine Clearance Risk-stratify Patients?

Sunday, November 6th
3:45 PM - 4:45 PM CT

Poster Presentation

Session Title:
Fetal and Single Ventricle - Pediatric Cardiology

# Published Abstracts



*Congratulations!*

**Manuscript accepted for publication in JHLT!**

Racial and Socioeconomic Disparities in Pediatric Heart Transplant Outcomes in the Era of Anti-Thymocyte Globulin Induction

Waldemar A. Carlo, MD



*Congratulations!*

**Manuscript accepted for publication in Pediatric Transplantation!**

The effect of the 2016 United States pediatric heart allocation policy change on racial disparities in waitlist outcomes for children awaiting heart transplantation

Lydia Wright, MD

# PHTS Awards




Linda J Addonizio, MD
2022 PHTS Lifetime Achievement Award




Whitney Kaslow, DNP
PHTS Excellence Award for Allied Health Professionals




Diane Long, DNP
PHTS Excellence Award for Transplant Coordinators

# PHTS Foundation

Pediatric Heart Transplant Society



Congratulations!

**Heather Henderson, MD**
**New PHTS Foundation Chair**

Pediatric Heart Transplant Society



Congratulations!

**Jeff Gossett, MD**
**New PHTS Foundation Vice Chair**

Pediatric Heart Transplant Society

Beachwood Street

## PHTS is partnering with Beachwood Street again this year!

Beachwood Street provides beautiful eco-friendly handmade pottery. Proceeds from sales will go towards benefiting the PHTS Foundation.

More information will be available soon!



# Coming up in PHTS

## PHTS Fall Proposal Review Schedule

### October 1 - 31, 2022

Investigators who are planning to submit a proposal are strongly encouraged to reach out to the DCC to obtain specific data frequencies to ensure the feasibility of their proposal. To make a data request, complete the Data Request Form on the PHTS website, https://pediatricheartransplantsociety.org/new-study-proposal/

- **October 1-31** Proposal Submission
- **November 1-30** Proposal Review by DCC and Scientific Committee
- **December 1-31** Notification to investigators
- **January 1-31** Enduring Hearts Award Proposal Review

## PHTS 30th Anniversary Gala



# Information Corner

## Job Postings

### Pediatric Heart Failure/Transplant Position – Arkansas Children's Hospital

The University of Arkansas for Medical Sciences and Arkansas Children's are seeking a junior or mid-level heart transplant/heart failure cardiologist to join our established and growing program. This is a full-time academic position with the full range of opportunities. Please see notice in Basecamp for full details of this opportunity.

Contact: Paul Seib, MD - SeibPaulM@uams.edu

### Phoenix Children's Heart Failure/Heart Transplant Physician

The Cardiology Division of Phoenix Children's Hospital is looking for a pediatric cardiologist to join their Heart Failure, Heart Transplantation, and Mechanical Circulatory Support Program. We are in search of a full time physician to join our team that currently includes two dedicated heart transplant cardiologists, three cardiac surgeons, three nurse practitioners and a nurse (VAD) coordinator.

Contact: Dr. Steven Zangwill - szangwill@phoenixchildrens.com

### LE BONHEUR Childrens Hospital Heart Failure Transplant

The Heart Institute at Le Bonheur Children's Hospital and the University of Tennessee Health Science Center in Memphis seeks to recruit a Pediatric Heart Failure and Transplant Cardiologist to join their existing four Pediatric Cardiomyopathy, Heart Failure, Mechanical Circulatory Support/Ventricular Assist Device (VAD), and Transplant Cardiology faculty.

Contact: Jeffrey A. Towbin, M.D. - jtowbin1@uthsc.edu

### Ochsner Hospital For Children HF/Tx APP Position

Ochsner Hospital for Children is looking for an Advanced Practice Practitioner (APP) to join our growing advanced cardiac therapies and heart transplant team. This position will be primarily inpatient based providing inpatient and occasional outpatient coverage to the pediatric heart transplant, heart failure, ventricular assist device, and pulmonary hypertension program.

Contact: Jake Kleinmahon, MD - jake.kleinmahon@ochsner.org

### Heart Failure & Transplant Cardiologist Position in Seattle

The Department of Pediatrics at the University of Washington is seeking an open rank faculty position as full-time Assistant Professor (without tenure by reason of funding), Associate Professor (without tenure by reason of funding) or Full Professor (without tenure) on the Clinician Scholar pathway to join the Division of Cardiology. Academic rank at the time of appointment is commensurate with experience and qualifications. Anticipated start date is Winter 2023

Contact: Yuk Law, MD - yuk.law@seattlechildrens.org

**More information about each job posting can be found on PHTS Basecamp under Resources for Job Opportunities**

# Information Corner

## Job Postings

### Transplant Coordinator/NP Position - Rady Children's Hospital San Diego

Rady Children's Hospital San Diego is seeking a full-time Pediatric Heart Transplant/Heart Failure Nurse Practitioner Coordinator. Responsibilities span all phases of the transplant process from initial referral through outpatient follow up.

Contact: Matthew Bock - mbock@rchsd.org

### Pediatric Heart Failure/Transplant Cardiologist Position at Hassenfeld Children's Hospital - NYU (New York, NY)

We are seeking a pediatric heart failure/transplant cardiologist for a full-time academic faculty position in the Department of Pediatrics at NYU Grossman School of Medicine and Hassenfeld Children's Hospital at NYU Langone Health. The successful candidate will be joining our growing Pediatric Heart Failure and Transplant Program and be responsible for providing comprehensive clinical services, education, research and programmatic development in conjunction with the current Medical Director and transplant nurse practitioner coordinator.

Contact: Jahayra Negron (jahayra.negron@nyulangone.org) and Rakesh Singh, MD, MS, (rakesh.singh@nyulangone.org)

### Pediatric Heart Failure/Transplant - Kansas City

The Ward Family Heart Center at Children's Mercy, Kansas City is seeking a Pediatric heart failure and transplantation physician. Applicants should have formal 4th year fellowship training in Pediatric heart failure, cardiomyopathy, transplantation, and mechanical circulatory support and must be board certified/eligible in Pediatric Cardiology. Current trainees are welcome to apply.

Contact: Aliessa Barnes MD - physicianjobs@cmh.edu

### Pediatric heart failure and transplantation physician - UCLA Mattel Children's Hospital

UCLA Mattel Children's Hospital Division of Pediatric Cardiology is seeking a Pediatric heart failure and transplantation physician. Applicants should have completed a formal 4th year fellowship in Pediatric heart failure, cardiomyopathy, transplantation, and mechanical circulatory support and must be board certified/eligible in Pediatric Cardiology. Current trainees are welcome to apply.

Contact: Juan Alejos MD - jalejos@mednet.ucla.edu

**More information about each job posting can be found on PHTS Basecamp under Resources for Job Opportunities**


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