Pediatric Heart Transplant Society

PEDIATRIC HEART TRANSPLANTATION TODAY

PHTS NEWSLETTER

April 2023

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

PHTS GROWTH*

11,676	patients enrolled
12,144	total listings/ relistings entered
8,920	transplants/ retransplants entered
488	listings for 2022
395	transplants for 2022
59	listings for 2023
49	transplant for 2023

*as of April 1, 2023

A MESSAGE FROM THE CHAIR OF RACIAL DISPARITY TASKFORCE

The PHTS Healthcare Disparities Taskforce was formed in July, 2020 on the heels of the overwhelming public response and call to action following the brutal killing of George Floyd. We aim to use evidence-based data-driven methodology to understand and mitigate the impact of social determinants of health, clinician biases and community risk factors on pediatric heart transplant outcomes. The 28-member taskforce is subdivided into 3 groups, namely: 1. Social status/Transplant access and outcomes Group: 2. Racial Bias Study Group: 3. Patient/Family Survey Group.

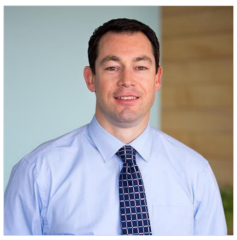
The HD Taskforce has conducted 4 studies that have all shown disparate outcomes for Blacks and low socio-economic patients. The studies include: a) Racial and Socioeconomic Bias Amongst Pediatric Heart Transplant Care Teams. b) Impact of race and health coverage on listing and waitlist mortality in pediatric cardiac transplantation. c) Impact of community risk factors on outcomes for children following heart transplantation and d) Impact of Insurance and Social Construct Race on Pediatric Heart Transplant Outcomes-

We have had several presentations including webinars by known experts from the AAP Health Equity council and other institutions, and are in the process of designing actionable programs to benefit our patients and society members in our quest to eliminate racial and other health disparities in pediatric heart transplantation.



Alfred

Alfred Asante-Korang, MD
Chair of Racial Disparity Taskforce



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



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Unintended consequences? - Policy changes and equity in pediatric heart transplantation

Lydia Wright, MD

In recent years, there has been a growing recognition of the importance of health equity. Achieving health equity, defined by the Centers for Disease Control and Prevention as the state in which everyone has a fair and just opportunity to attain their highest level of health, requires focused efforts on multiple levels, from individual behavior and attitudes to national and international policy changes. Identification of health disparities (particular types of health differences closely linked with economic, social, or environmental disadvantages that adversely affect certain groups), is the first step towards achieving health equity for a given population (1).

Racial and socioeconomic disparities have been found in outcomes for children in need of advanced cardiac therapies at all levels of care, with worse outcomes seen for minority and lower income children from presentation in heart failure, through transplant listing, and after transplant. With targeted support from PHTS, our understanding of the ways in which race, ethnicity, insurance status, and socioeconomic status affects these outcomes in children both before and after heart transplant continues to increase (2, 3).

For children living in the U.S., OPTN policy can have significant effects on outcomes both while on the waitlist and after transplant. With any change in policy, it is important to evaluate effects on health equity to ensure that benefit is seen for all children and there are no unintended worsening of outcomes or widening of health disparities. The 2016 OPTN Pediatric Heart Allocation Policy change, which aimed to reduce unacceptably high waitlist mortality for children awaiting transplant, significantly altered listing criteria and tightened the requirement for status 1A listing.

Our group used PHTS data to evaluate waitlist mortality before and after this policy change with a focus on racial disparities (4). Previous work had shown potential improvements in waitlist mortality for minority children; with this policy would these improvements continue and lead to equivalent outcomes for listed children regardless of race, or would outcomes again diverge and lead to worsening disparities? Unfortunately, we found that the latter seemed to be true. Among those listed under the old allocation system from 2012 to March 2016, white children and non-white children had very similar waitlist mortality (around 12% at 12-months), with no difference seen when controlling for other clinical factors. Under the new allocation system, waitlist mortality went down to 10% for white children while it rose slightly for non-white children to 13.4%. Risk of waitlist mortality was more than 30% higher for non-white children when controlling for other factors, including OPTN region. It was surprising that these differences were seen both in children with congenital heart disease as well as those with cardiomyopathy. We had hypothesized that we would see worse outcomes in the cardiomyopathy group due to the policy change resulting in their being downgraded to 1B. This group was more likely to be non white than in the patients with congenital heart disease. This had been a major driver of this change. The mechanisms of these widening disparities remain unclear and are likely multifactorial. How much of the change can be directly attributable to the policy change and its effects on listing criteria and how much is due to unrelated changes in care during the same period? Further understanding of contributing factors is essential for targeted interventions.

The policy change may be contributing to the unequitable waitlist outcome due to the increased use of status exceptions. Status exceptions, particularly in the period studied, are much more subjective in nature than the standard criteria. They have been shown to be unequally applied in several different organ groups. This occurs in several different factors including geographical and other patient characteristics such as race and socioeconomic status. In follow-up work using OPTN data, our group evaluated the contribution of status exceptions and their potential differential use with interesting findings. We found significant increases in status 1A exceptions amongst patients regardless of race or neighborhood socioeconomic status, but 1B exception increases were seen predominantly in high-income and non-Hispanic white children. We additionally saw worse waitlist outcomes in non-Hispanic Black children listed at lower statuses (1B or 2) compared to white children. Listing with a status exception also provided a survival advantage. It may be that status 1B exceptions, by increasing competition for donor organs in the 1B group, may be disadvantaging those listed 1B without an exception, and contributing to our failure to rescue these children before dying or becoming too ill for transplant. Clearly the decision making in these scenarios are complex, but

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more standardization in exception criteria to improve access across institutions for those who would benefit most may help improve some of these disparities. Guidelines were released in 2021 by OPTN with exactly this goal; follow-up studies will be needed to ensure that increased standardization does improve access.

As is often the case, we may be able to learn from our adult colleagues. The large number of adults needing transplant makes detecting subtle trends in relatively short periods of time a priority. This allows for rapid evaluation of policy changes that are more challenging in pediatrics and may help us gain insight into potential interventions. The OPTN adult heart allocation policy also underwent a recent change; taking place in 2018, this policy change established more status levels with more strict criteria at each level. Interestingly, despite the very different policy change, a similar effect was seen. In their recent study, Cogswell and colleagues found both measured rate of transplant and rate of delisting for death or clinical deterioration have worsened for Black waitlist candidates since the 2018 policy change (5). This remained true when controlling for co-morbidities, education and job status, as well as community-level social determinants of health. The authors note that disparities were expected to narrow with more objective criteria in the updated policy, and the fact that this was not realized may point to "the extent to which subconscious or implicit bias is embedded in clinical decision making."

It can often feel daunting to tackle these issues and push for more equitable outcomes for our patients. Many of these injustices underpinning disparities are long-standing and deep-rooted in our systems and our society in ways that can seem beyond the reach of us as healthcare providers. Any policies that we enact are subject to the society in which they are enacted. This makes it even more important for us to understand the ways in which policy changes may have unintended consequences, either by adversely affecting one population or having outsized benefits in another. The same is true for development of new medications and devices. It is imperative that we continue to collect data that will help ensure that our care delivery and outcomes are as equitable as possible for all children needing advanced cardiac therapy.

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Bias in Pediatric Cardiac Transplantation

Authors: Shahnawaz Amdani MD, Alfred Asante-Korang MD

Pediatric Heart Transplant Society (PHTS) has advanced the science for children listed and those undergoing heart transplantation for three decades 1. These progresses are due to the collaborative and multi-disciplinary engagement by a variety of pediatric heart transplant (HT) clinicians nationally and internationally. As a community, we are now increasingly listing recipients at higher risk for post-HT mortality and yet demonstrating improved post- transplant outcomes for this cohort 1-3. As the PHTS community looks forward to the future, one critical issue to evaluate and address is improving access for children in need of HT.

The HT listing practices are variable across institutions, but most typically have input by a team of clinicians, namely the transplant physician, surgeon, infectious disease specialist, pharmacist, nutritionist, social worker and, hepatologist to name a few. The ultimate decision to list a child for HT is based on the collective review of this team's medical opinion as to the suitability for transplant. In such circumstances, it is possible for each individual's implicit (unconscious) bias, if any, to affect their review and decision-making process, and this can hence affect who gets listed for HT.

It is well known that racial/ethnic and socioeconomic disparities exist in pediatric HT 4-6. It is also known among a variety of healthcare disciplines that there is an implicit bias against racial/ethnic minorities and against individuals from lower socioeconomic neighborhoods 7, 8. The PHTS Healthcare Disparities Taskforce was formed in 2020 and aims to understand the impact of clinician bias and social determinants of health on pediatric heart transplant outcomes scientifically, and ultimately provide the society with education and tools to reduce and eliminate healthcare disparities. A recent project that members of the PHTS healthcare disparity taskforce conducted was to evaluate the degree of implicit racial and socioeconomic bias among pediatric HT clinicians 9.

A cross-sectional survey was conducted between June to August 2021, and survey respondents were asked to fill out demographic questions followed by explicit and validated implicit race and socio-economic questionnaires (Implicit Association Tests, IAT). Of 500 invitations sent, 91 (18%) responded for the race test, 70 (14%) for the socioeconomic status test and 44 (8%) for both tests. Given that data was incompletely filled by a few respondents, the final analysis cohort included 78 responses for the race and 52 for the socioeconomic status test. Most of the study respondents were physicians, aged 40-50 years, female and White.

Main study findings:

There was moderate implicit preference for White over African American individuals.
There was strong implicit preference for people from higher socioeconomic status to those from lower socioeconomic status.
There was strong explicit education bias for people with higher education.

Implications and next steps

As heart transplant clinicians, the first step is to be aware that we all harbor unconscious biases that may be very different from our egalitarian explicit beliefs. As we have shown, there was lack of correlation between our implicit and explicit biases. This work is an important first step in raising awareness around the issue. A good exercise for all pediatric heart transplant programs may be to ask all clinicians involved in decision making to take the implicit tests on a routine basis. These results do not have to be publicly reported but will allow for self-reflection. Also, it has been shown that merely taking the implicit test leads to a wider acceptance of under-represented minorities 10. Since the publication of this study, a variety of webinars have been provided by experts studying bias mitigation strategies to help all of us in the community. Subsequent work should focus on how our implicit preferences ultimately affect our decision-making regarding allocation of advanced heart failure therapies, our interaction with our families and patient's adherence to our recommendations.

Bias in Pediatric Cardiac Transplantation

Authors: Shahnawaz Amdani MD, Alfred Asante-Korang MD

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PHTS Research

Pediatric Heart Transplant Society

Enduring Hearts
HEALTHY KIDS • STRONGER HEARTS • LONGER LIVES



Congratulations!

Newly Accepted Proposal for the 2022 Fall Enduring Hearts-PHTS Investigator Award

Chronic corticosteroid immunosuppression in African American pediatric heart transplant recipients: risk without reward

Natalie Shwaish, MD

Pediatric Heart Transplant Society



Congratulations!

Manuscript accepted for publication in Journal of Heart and Lung Transplantation!

Single-Drug Immunosuppression is Associated with Non-Inferior Medium-Term Survival in Pediatric Heart Transplant Recipients

PHTS at ISHLT 2023

Pediatric Heart Transplant Society



Abstract Presentation at ISHLT 2023

Oral Presentation

Impact of Anti-HLA Antibody Desensitization Strategies in Pediatric Heart Transplant Recipients: A PHTS-PHIS Linkage Analysis

Deipanjan Nandi, MD, MSc

Thursday, April 20, 2023 2:15pm - 2:25pm MT

Session title: Current Challenges in Pediatric Heart Transplant Selection and Outcomes



Enduring Hearts

Abstract Presentation at ISHLT 2023

Oral Presentation

Statin Use in Pediatric Heart Transplantation Recipients in the Current Era

Madeleine Townsend, MD

Saturday, April 22, 8:00-9:00am 8:45-8:55am

Session title: Medications and Machines: Which Ones Improve a Pediatric Heart Transplant Outcomes?

Join PHTS in Denver, Colorado

Pediatric Heart Transplant Society

PHTS Meetings at ISHLT

Wednesday, April 19, 2023

Hyatt Regency Denver at Colorado Convention Center - Mineral Hall

Visit www.PHTSociety.org to register

11:15am - 12:15pm	**Grants Meeting** Room: Mineral Hall D-E Mandatory Registration Required - Maximum 50 participants before Monday, April 17, 2023 to receive a box lunch. Register at www.PHTSociety.org
12:15pm - 1:00pm	**Junior Faculty Meeting** Room: Mineral Hall D-E
12:15pm - 1:00pm	**Prospective Research Meeting** Room: Mineral Hall A
12:15pm - 1:00pm	**Nursing and Allied Health Committee Meeting** Room: Mineral Hall B
12:15pm - 1:00pm	**Standardizing Care/QI Committee Meeting** Room: Mineral Hall C

Visit the PHTS Booth at ISHLT 2023

Make sure to stop by the PHTS Booth at ISHLT 2023 - Booth #602







Join PHTS in Denver, Colorado

PHTS 30th Anniversary Gala

Please join us in celebrating 30 years of the Pediatric Heart Transplant Society on Thursday, April 20, 2023 at the Denver Art Museum in Denver, Colorado. The celebration will include a reception, silent auction, hors d'oeuvres, and entertainment.

All proceeds from the Gala will be used to support the mission of the Pediatric Heart Transplant Society. The PHTS Foundation is a 501 c.3 non-profit organization whose mission is to raise and administer funds to support the advancement of the science and treatment of children through the journey of heart transplantation.

If you are interested in becoming a sponsor, visit www.PHTSociety.org



Information Corner

Job Postings

Duke Children's Hospital Pediatric Advanced Heart Failure/Transplant Cardiologist: New Position

Duke Pediatric Cardiology and Duke University School of Medicine are seeking an early to mid-career pediatric cardiac transplant/heart failure physician to join our transplant/heart failure team. Candidates should be academically motivated, BE/BC in pediatric cardiology and have advanced training and/or experience in pediatric transplant and heart failure. This position will focus on care in both the in-patient and outpatient settings for the cardiology transplant/heart failure service. The ideal candidate would be motivated to work within a high functioning transplant/heart failure service seeking to provide innovative care to a rapidly expanding patient population. Applicants with research interests/funding are also invited to apply.

Interested candidates should submit CV and Letter of Interest via https://pdc.dukehealth.org/physician-jobs

Dell Children's Medical Center/University of Texas Dell Medical School in Austin

The Texas Center for Pediatric and Congenital Heart Disease at Dell Children's Medical Center is seeking qualified candidates to apply for a Heart Failure and Transplant Position.

Dell Children's Medical Center in Central Texas received UNOS approval in 2020 and has performed 19 transplants to date. We also have an active MCS/VAD program and have placed HeartWare, HeartMate III, and Berlin Hearts. We are a growing program with over 25 pediatric cardiologists and a dedicated Cardiac Care Unit. Applicants will be hired through the University of Texas Dell Medical School at Austin with full faculty benefits.

Interested appicants can upload their CV on the UT Dell Medical School website at:
https://faculty.utexas.edu/career/72860

I'm also available for any questions or to discuss details of the position at:
chesney.castleberry@austin.utexas.edu

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

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