Pediatric Heart Transplant Society

PEDIATRIC HEART TRANSPLANTATION TODAY

PHTS NEWSLETTER

July 2023

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

PHTS GROWTH*

11,876	patients enrolled
12,334	total listings/ relistings entered
9,045	transplants/ retransplants entered
522	listings for 2022
412	transplants for 2022
178	listings for 2023
135	transplant for 2023

*as of July 1, 2023

A MESSAGE FROM FELLOWS AND JUNIOR FACULTY MENTORSHIP GROUP

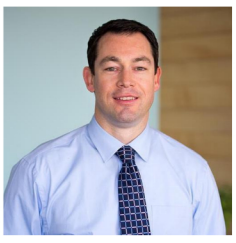
With the support of the PHTS Steering Committee, the "Fellows and Junior Faculty Mentorship Group" was officially launched in 2022 to help create productive connections between fellows, APPs, and junior faculty members with mid to late career PHTS members. We envisioned that this group could foster mentorship in career development, program building, clinical practice, and research endeavors.

Our first task was to organize one-on-one pairing of senior mentors with junior mentees. We asked that each pair meet virtually at a minimum every 3 months, and they are free to discuss anything that they deem as important to them. As of this month, we have over 30 pairings and have received feedback that these sessions are incredibly helpful and fun! We recently held a break out session at the PHTS meeting during ISHLT in Denver in April where 4 senior members spoke on various mentorship topics such as leadership, business of academic medicine, interpersonal skill development, and research tips (see pics). Our group also sponsored a junior faculty survey led by Dr. Manu Varma that was presented at ISHLT and will be submitted as a manuscript soon. Other opportunities include helping more junior members to get involved with "PHTS Live!" and the "ACTION Donor Decision Forum", along with putting together the newsletter this month.

If you are interested in participating in this group either as a junior or senior member, please reach out to Claire Covington (claire.covington@kirso.net).

Arene Butto, MD (Junior Faculty Leader)
Assistant Professor of Pediatrics
Emory University School of Medicine

Rakesh (Rocky) Singh, MD, MS (Senior Faculty Leader)
Haugland Family Associate Professor of Pediatric Cardiology NYU Grossman School of Medicine
Medical Director, Pediatric Heart Failure and Transplantation Program
Hassenfeld Children's Hospital at NYU Langone



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

Thoughts from Incoming Fourth Year Fellows

Majid Husain, MD; Ashish Garg, MD; Elizabeth Kalb, MD

As we stand on the threshold of starting our advanced fellowship in pediatric heart failure and transplant, we would like to share our thoughts, motivations, and hopes in pursuing this path. While we come from different institutions and backgrounds, we share a common passion to make a meaningful difference in the lives of pediatric patients battling life-threatening cardiac conditions and to contribute to this field in an impactful way.

In order to do so, we recognize that we must appreciate the rich origin of the field, its inspiring history, current challenges and promising future, the pioneering clinicians of the past and present, along with the courageous patients and their families that have paved the way. On that note, the first successful human heart transplant was performed in 1967 by Dr. Christiaan Barnard in South Africa. However, it was not until the 1980s that pediatric heart transplantation gained traction. Since then, in less than 50 years, the field of pediatric heart failure and heart transplant has advanced significantly, most notably with regards to immunotherapy, rejection surveillance, and mechanical circulatory support. Today, there are almost 500 pediatric heart transplants performed in the United States annually - with 490 pediatric heart transplants in 2021, a 36% increase from just 10 years ago. (1) Along with this increase in volume, there has been an increase in overall survival after transplantation, with patients living longer in the modern era. (2)

Despite the advances in clinical medicine and technology that have led to these improved outcomes in our patient population, we recognize that there is still more work to be done. Specifically, the scarcity of organs continues to be a major problem, the waitlist mortality remains unacceptably high, and the long-time side effects of transplant immunosuppression are a perpetual challenge. Nonetheless, we are optimistic. In the past 3 years of our pediatric cardiology fellowship alone, we have seen incredible progress in the field of xenotransplantation, including transplantation of a genetically modified porcine graft into an adult with nonischemic cardiomyopathy, (3) to provide potential alternatives for selective patients. The expanded use of ABO-incompatible hearts and donation after cardiac death has further increased the donor pool, and optimization of organ transportation perfusion devices (4) continues to reduce the deleterious effects of ischemic time. Furthermore, the field of pediatric mechanical circulatory support has also grown significantly, both in terms of patient volume and innovative strategies to support even the most complex patients. We have also witnessed advances in rejection surveillance, such as the use of donor-derived cell-free DNA technology, (5) that will afford an individualized approach to immunosuppression that may allow for lower but adequate doses of medications and reduce the need for invasive procedures. Collectively, these incremental changes are moving the needle toward improved organ preservation, expanding transplant options, and decreasing waitlist mortality to ensure our patients thrive after heart transplant with minimal complications.

By embarking on this additional fellowship, we seek to acquire knowledge and expertise in providing comprehensive care to our pediatric patients with heart failure. We understand this involves learning the intricacies of disease progression, implementation of effective treatment strategies, and facilitation of timely access to heart transplantation when necessary. In addition to building our foundational knowledge, we aim to conduct research projects aimed at better understanding the patients we treat, the treatments we prescribe, and risks we tolerate. We find inspiration in studies such as the TEAMMATE Trial, the first multicenter randomized clinical trial in pediatric heart transplant aimed at evaluating the safety and efficacy of everolimus and low-dose tacrolimus compared to standard-dose tacrolimus and mycophenolate mofetil. (6) We are looking forward to its clinical findings but also lessons learned in designing and conducting future trials in pediatric heart transplant. We aspire to partake in such projects to develop personalized treatment plans and roadmaps - slowly parting ways from protocolized "one size fits all" strategies. Simultaneously, we will strive to ensure that pediatric patients, regardless of socioeconomic status, have equal access to all available therapies. And, as many more of our transplanted patients are reaching adulthood, we will collaborate with our adult colleagues to ensure that transition programs become standardized and refined.

Thoughts from Incoming Fourth Year Fellows

Majid Husain, MD; Ashish Garg, MD; Elizabeth Kalb, MD

In the immediate future, we also expect to play an active role in improving the short-term and long-term outcomes of our patients with an emphasis on neurodevelopmental measures and quality of life - especially the unique population of Fontan patients and sensitized recipients. We will work on developing guidelines specific to pediatric patients for the management of heart failure and advocating for development of ventricular assist devices made specifically for young children. To aid in this endeavor, we are looking forward to joining PHTS and the ACTION network. In the long-term, we dream that in our careers as transplant clinicians, xenotransplantation or bioengineered hearts becomes routine, where a heart is readily available for whoever needs it and whenever. It may sound far-fetched and something out of a science fiction movie but patients with complex congenital heart disease would no longer have to endure staged palliative surgeries and numerous catheter-based interventions - there would be a personalized heart that could be ordered or taken "off the shelf". We hope waitlist mortality becomes a thing of the past or at least significantly reduced.

Moreover, it's no surprise that the field of pediatric heart failure and transplant thrives on collaboration and the synergy of a multidisciplinary team consisting of pediatric cardiologists, surgeons, advanced practice providers, nurses, transplant coordinators, social workers, pharmacists, psychologists and most importantly the patients we serve and their families. This alliance ensures a holistic and individualized approach that encompasses key aspects of medical, emotional, and psychosocial support for each patient and their families throughout their journey. By capitalizing on this multidisciplinary teamwork, institutional partnerships, precision research, and empathic efforts, we aim to make a lasting impact on the lives of children with heart failure and their families, continually striving for improved outcomes and brighter futures for these young patients.

Lastly, as we begin preparing for the next step in our professional career, we recognize we would not be here without the tremendous guidance from our mentors. Thank you. We are grateful to those who have paved the way for us and feel incredibly humbled to join this field. Additionally, we are excited to become each other's colleagues and look forward to collaborating with each other on future projects.

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New Academic Year, New Chapter

Carmel Bogle, MD

Shortly after finishing college, I remember meeting my mentor's daughter. She was the sweetest little girl, the first of my friends to have a child. My mentor mentioned though she loved to play, she often got easily winded and had to start taking medicine. Meeting her for the first time, she smiled during the nebulizer treatment that she took to help her breathing. Though our encounter was brief, she remained on my heart as such a sweet young girl.

I followed several months later as the family learned that she in fact did not have asthma, but something called "dilated cardiomyopathy". Her heart was too big and not working well enough and she would need a heart transplant. Reading their journey online, I was captivated as they traveled from one hospital to another to go through numerous tests to decide if she'd be eligible to be listed for a heart transplant. There was only a brief reprise when she was able to be listed and then came the arduous, uncertainty that comes from waiting. There was lots of travel back and forth and split time during a time when they would want nothing more than to soak up all the family time together. One family member waited in the hospital while the other navigating work, bills, etc. another state away. It seemed too much. However, several months later, they shared a picture shortly after her transplant of her precious body sitting up asleep with her sternal dressing, followed by a second picture of her playing. They noted how much energy she had now, and it seemed to make the onerous journey for them more worthwhile. Those pictures remained etched in my mind. Though our lives had drifted apart, I was overwhelmed with joy to see graduation pictures shared several weeks ago and see her bright smile. It has been such a gift to see the remarkable young woman she has grown to be teeming with compassion, creativity and intellect.

Much like her graduation, there is a group of physicians that will also graduate from a long and demanding journey. Whether it is the final graduation of completing their 4th year where they will now embark on this much anticipated journey of being a pediatric heart transplant physician or the final chapter to their training of entering 4th year heart failure/transplant fellowship, it should be one met with immense pride for both themselves and the countless mentors, family members and patients that helped them to get to this stage.

What motivates us to continue another year of training? It's hard to explain it to those that haven't seen the look of hope in a child and their family's eyes when they receive the news that a heart is available. Or the wonder (and scariness) of watching a heart barely squeeze and then watch that same young child bounce away playfully while a parent races after them with their Berlin device a short while later. Those experiences that engrave into your core memory and the privilege to do that as part of your everyday job is a wonder.

To my mentors: I truly thank you. Thank you for answering my endless questions and calls in the middle of the night to make sure I made the right call on a patient. Thank you for sharing stories of your patients' vacations, weddings and future graduations and being an example of how to see the patient beyond the hospital gown. Thank you also for seeing me beyond just a trainee but as one with potential and providing opportunities both clinically and research related. Thank you for expanding my circle so that the pool of mentors and colleagues I could call in a pinch or to just run an idea by only continues to grow. I am truly forever grateful that you took a chance on me.

To the incoming 4th years: Welcome! Some might be starting bright eyed to FINALLY practice their passion, while some might be weary from the past 6 years of intense post-graduate training. Perhaps, most likely, a combination of both. Studies have noted that burnout can be high for our pediatric cardiology fellows, especially in high-pressure clinical settings (1). Many trainees can struggle with imposter syndrome, fear of failure, and feel the heavy weight of clinical responsibility (2). During these times of struggle, I encourage you to press into your inner drive that brought you here. Fourth year provides the opportunity for individualized education that addresses not only learning gaps and ensuring competence, but also ensures goals for your

New Academic Year, New Chapter

Carmel Bogle, MD

specific career path and autonomy (3). The days might seem long, but the year overall will go fast at lightning speed. Therefore, ensure you expose yourself to take up every opportunity that comes your way. Don't be afraid to ask "dumb" questions of your attendings because in 365 days from now, it will be harder to ask and the question will inevitably come at three in the morning. You never know when that experience will come in handy down the road. Studies have noted that as trainees we can often be so focused on the "what": the task at hand, that we can often lose sight of the long-term outcomes and care for the patients (4). Therefore, despite the many checkboxes that you will have on your list, I encourage you to take the extra time to really get to know your patients and their families. Play that extra round of Uno or take the extra lap around the unit for you never know the impact it can have on that patient or their family. It will make the long calls more worth it. Also know that you are not alone but have joined a village of experts and colleagues that are cheering you on.

To the patients and families: thank you for allowing us to be part of such a delicate season in your life. Thank you for the extra grace of allowing the new face of a 4th year to be part of your lives even for just a little while. Though the time may be brief, their experience with you will stay with them and empower them to deliver better and more effective care to families in the future.

As heart transplant providers, we are in an exciting time where the testing, treatment and devices are continuously changing to allow more patients to see graduations, weddings and perhaps even one day – grandchildren. The mentorship and community we have built thus far will only grow as we grow stronger moving forward together as one community. I am so grateful for my mentors that formed my foundation in pediatric transplantation and gave me the wings to fly. Their passion to deliver the highest level of patient care with compassion, hands on mentorship and clinically relevant research have made the fabric of my clinical DNA. Their words of wisdom echo in my mind while I discuss hard news to a patient or discuss therapies for patients. Though I still have much to learn, it has inspired me to continue that pattern of mentorship for the trainees that come after me. Therefore, may the beginning of this academic year help remind us all why we joined this exclusive club. Studies have shown that we do hard work! Burn out rates can be high (5). So why do we stay? Why do we show up and do what we do everyday? The professional fulfillment of impacting a child and their families' lives can't be beat and is worth it's journey to get there. Happy July!

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PHTS Research

Pediatric Heart Transplant Society

Enduring Hearts
HEALTHY KIDS • STRONGER HEARTS • LONGER LIVES



Congratulations!

Recipient of the
2023 Pediatrics Professional Community
Award for Excellence

Statin Use in Pediatric Heart Transplantation
Recipients in the Current Era

Madeleine Townsend, MD

Pediatric Heart Transplant Society



Congratulations!

Manuscript accepted for publication in
Journal of American College of Cardiology:
Heart Failure

Assessing donor-recipient size mismatch in pediatric heart transplantation: Lessons learned from over 7500 transplants

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

Pediatric Heart Transplant Society

PHTS Release 1.1.25 is now live

Release 1.1.25 includes changes to the following forms:

- Form 1T (Transplant)
- Form 4 (Coronary Evaulation)
- COVID-19 Enrollment and COVID-19 Infection Forms
- Form 6 (Infection)
- Form 7 (Malignancy/Lymphoproliferative Disease)
- Form 8 (Post-Transplant Follow-up)
- Form 12 (Pre-Transplant Follow-up)
- Form 18 (Donor Derived Cell Free DNA form)

Updated forms and form manual can be found at
PHTSociety.org under Forms/Training.

Coming Up in PHTS

Registration for all upcoming events can be found at www.PHTSociety.org

Pediatric Heart Transplant Society

PATIENT AND FAMILY COUNCIL

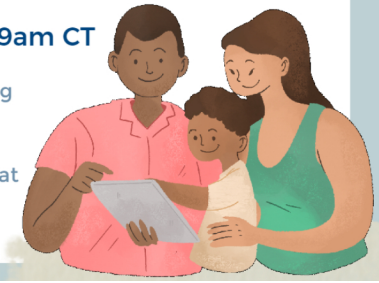
PATIENTS, FAMILIES, AND CAREGIVERS

Please join us!

PHTS will be hosting another Patient and Family Council meeting to discuss the formation of the council.

Next Meeting:
Thursday, August 3rd at 9am CT

If you are interested in joining the call, please register at www.PHTSociety.org or reach out to DeAnna Archer at deanna.archer@kirso.net



Pediatric Heart Transplant Society

PHTS Webinar

Donor Derived Cell Free DNA Form
with Dr. Melanie Everitt

August 10, 2023
2:00-3:00pm CT

Register at www.PHTSociety.org



Pediatric Heart Transplant Society

PHTS Webinar

Standardizing Care Project:
Just how many biopsies do we need the first year after transplant?

Thursday, August 17, 2023
3:00pm CT

Register at
www.PHTSociety.org



Pediatric Heart Transplant Society

SAVE THE DATE

PHTS Virtual Fall Business Meeting

Tuesday, October 24, 2023
3:00pm - 5:00pm CT

Registration information coming soon



Join PHTS In Person

PHTS Booth at World Congress of Pediatric Cardiology and Cardiac Surgery

Washington D.C. August 28 - 31, 2023



PHTS Fall Annual Meeting in Philadelphia



Information Corner

Job Postings

Transplant Nurse Practitioner Job Opportunity - Cincinnati Children's Hospital Medical Center

The Cincinnati Children's Hospital Medical Center (CCHMC) is seeking a Nurse Practitioner to join our team in a full-time position working within the Advanced Cardiomyopathy Program. Currently we have 6 physicians, 2 nurse practitioners, 6 nurse coordinators, 2 social workers, and a dedicated pharmacist. The nurse practitioner position will include primarily inpatient but some outpatient responsibilities providing care before and after transplantation. Additional responsibilities will include consulting throughout the hospital for cardiomyopathy, cardio-oncology, and other advanced cardiomyopathy program patients.

Interested candidates should submit a CV addressed to Dr. Clifford Chin at clifford.chin@cchmc.org.

Job Opportunity for Additional Advanced Practice Provider at Seattle Children's Hospital

The Heart Center at Seattle Children's Hospital is seeking a motivated, detail oriented Advanced Practice Provider (NP or PA) to join our Heart Failure and Transplant team. The position is focused on providing medical management and continuity for the complex needs of our transplanted population. The role is primarily ambulatory focused. This is a great opportunity to join our team that is a Center of Excellence in pediatric heart transplant, with some of the best post-transplant 1-year and 3-year survival rates in the nation.

For more information, contact Molly Richter at Molly.Richter@seattlechildrens.org

Medical Director, Heart Failure and Heart Transplant Program - The Congenital Heart Center UT Health San Antonio/University Health System

The Congenital Heart Center UT Health San Antonio/University Health System is building a congenital cardiac transplant and heart failure program. We are looking for a full-time medical director of pediatric heart failure, transplant and mechanical circulatory support to develop a pediatric heart failure and heart transplant program.

Please send curriculum vitae and letters of recommendation to: Ginnie Abarbanell, MD - Professor of Pediatrics Chief, Division of Pediatric Cardiology University of Texas Health - San Antonio E-mail: abarbanell@uthscsa.edu

Faculty Opportunity: Pediatric Heart Failure & Transplantation Utah

This is an outstanding opportunity to join a vibrant and collegial academic environment and work in a children's hospital ranked as one of the best in the U.S. The Division of Pediatric Cardiology at the Spencer Fox Eccles School of Medicine is seeking a Pediatric Cardiologist with expertise in heart failure, mechanical circulatory support, pre- and post-transplant and ventricular assistant devise (VAD) patients, cardiac transplantation, and extracorporeal membrane oxygenation (ECMO).

For additional information about the position, please contact Antonio Cabrera, M.D., Division Chief of Pediatric Cardiology, at antonio.cabrera@hsc.utah.edu

Faculty Opportunity: Pediatric Heart Failure & Transplantation Utah

The Congenital Heart Center at C.S. Mott Children's Hospital, in conjunction with the University of Michigan School of Medicine, is pleased to offer a new philanthropically funded position for a fourth year of advanced training in advanced heart failure, cardiac transplantation, and mechanical circulatory support with a specialized focus in single ventricle heart disease and Fontan circulatory failure.

Interested candidates should send a curriculum vitae, at least three letters of recommendation, and a personal statement to Amanda McCormick (acdelong@med.umich.edu) by August 18th, 2023.

Information Corner

Job Postings

Section Chief Opportunity: Pediatric Heart Failure & Transplantation Utah

This is an outstanding opportunity to join a vibrant and collegial academic environment and work in a children's hospital ranked as one of the best in the U.S. The Division of Pediatric Cardiology at the Spencer Fox Eccles School of Medicine is seeking a Pediatric Cardiologist with expertise in heart failure, mechanical circulatory support, pre- and post-transplant and ventricular assistant devise (VAD) patients, cardiac transplantation, and extracorporeal membrane oxygenation (ECMO) to serve as the Section Chief of Advanced Cardiac Therapies and Transplantation.

For additional information about the position, please contact Antonio Cabrera, M.D., Division Chief of Pediatric Cardiology, at antonio.cabrera@hsc.utah.edu

Section Chief Opportunity: Pediatric Heart Failure & Transplantation Utah

We are now seeking a Medical Director, for this program who is BE/BC in Pediatric Cardiology and meets UNOS criteria for Pediatric Heart Transplantation to lead the initiation of these programs. Candidates of any tenure will be considered, and they will be supported by our award-winning and collegial team of physicians at the Cohen Children's Heart Center. The role will also offer the opportunity for research, advocacy and education of medical students, residents, and fellows. Faculty appointment will be with the Donald and Barbara Zucker School of Medicine at Hofstra/Northwell, and clinical rank will be commensurate with experience. The successful candidate will oversee the growth and development of these programs and will have strong support and partnership from our Division Director who has extensive transplant and program building experience.

For further details and opportunities, please contact: Jeffrey Gossett, MD; Vice President and System Chief, Pediatric Cardiology, jgossett1@northwell.edu or Lindsay Appelman, Senior Physician Recruiter, Northwell Health, lappelman@northwell.edu.

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

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