



Pediatric Heart Transplant Society
NEWSLETTER

WINTER 2019/2020

MESSAGE FROM THE DCC

PHTS continues to grow each year now with **56** hospitals in **4** countries and over **450** members. There are over **10,000** listings and over **7,300** transplants entered in the database. PHTS investigators published **5** manuscripts in 2019, presented **6** abstracts, and accepted **5** new research proposals. All PHTS leadership committees are changing over and updated committee member lists will be available on the PHTS website as committees are finalized. The PHTS Web Based Data Entry system has undergone several enhancements throughout 2019 including the addition of the Form Download, the Patient Summary, and the Quality of Life Data Collection. Enhancements will continue to be made to the web based data entry system through 2020. PHTS would like to extend a big 'Thank You' to all the members of the database for continued efforts to support PHTS and our mission.

CONGRATULATIONS

Scott Auerbach, MD

Medical Director, VAD Program
Children's Hospital Colorado Heart
Institute

Vice President of PHTS and Chair of
the Database Committee

Nov. 2019 – Nov. 2021 term

Donna Lee, RN, CPNP

Pediatric Heart Transplant
Coordinator/ Nurse Practitioner
Lucile Packard Children's Hospital
Stanford

Non-Physician Representative for the
Steering and Database Committee

Nov. 2019 – Nov. 2021 term



Pediatric Heart Transplant Society



SAVE THE DATE

PHTS Annual Spring Meeting

Evening of
Wednesday, April 22, 2020
Montreal, Canada

Hotel information coming soon

ISHLT 2020 Accepted Abstracts

♥ Obesity Leads to Increased Mortality in Pediatric Heart Transplant Recipients – A Pediatric Heart Transplant Society Study

Carmel Bogle, MD; Ryan Cantor, PhD; Devin Koehl; Jillien Lochridge, CPNP; James Kirklin, MD; Aliessa Barnes, MD, Gonzalo Wallis, MD; Shah Nawaz Amdani, MD; Rebecca Ameduri, MD; Elfriede Pahl, MD; Kathleen Simpson, MD; Elizabeth D. Blume, MD

♥ Heart Transplant Outcomes in Children with Fontan-Associated Plastic Bronchitis: A Pediatric Heart Transplant Society Analysis

David W. Bearl, MD, MA, Ryan Cantor, PhD, Devin Koehl, MS, Jeffrey G. Gossett, MD, Matthew Bock, MD, Nancy Halnon, MD, Lauren Glass, MD, Vernat Exil, MD, MBA, Courtney Musselwhite, RN, James Kirklin, MD, Justin Godown, MD, Chitra Ravishankar, MD

Spring 2020 Call for Proposals

Interested in submitting a research proposal? On the PHTS website, you can find a complete list of abstracts and publications that have been recently presented or published. For reference, you can also find the current data collection forms to help guide your proposal. Members interested in submitting proposals are encouraged to submit a feasibility request through the PHTS website. All feasibility request must be submitted at least 5 business days prior to the proposal submission deadline to allow sufficient time for the DCC staff to process these requests. Feasibility requests can be completed through the link below:

<http://www.uab.edu/medicine/phts/research/request-form-data>

February 1-28

Call for proposals open

March 1-30

Proposals reviewed by Scientific Committee

April 1-30

Submitting authors will be notified of decision

Enduring Hearts-PHTS Proposal Applications

Enduring Hearts is now co-funding one proposal from each cycle. To be considered for this award, please complete the separate Enduring Hearts proposal application. Enduring Hearts is looking specifically for proposals on the following topics:

- Accurate, early identification of the onset of cellular and antibody-mediated rejection and cardiac allograft vasculopathy (CAV)
- Develop better non-invasive methods to accurately detect early heart rejection
- Develop evidence-based standardization of post-transplant protocols
- Development of innovative technologies or applications thereof to improve the care of transplant patients and thereby impact outcomes
- Develop novel and effective immunotherapies, identify of novel targets for immunosuppression, reduce the side effects of immunosuppressive agents as well as better monitoring and measurement of the level of immunosuppression
- Develop effective strategies to improve medication compliance, especially in adolescent patients and young adults
- Develop improved organ utilization, matching strategies and other innovations that would allow better organ matching, preservation, utilization and allocation

Terms of Award:

- For the primary investigator, \$1,000 – \$1,500 for travel to Birmingham, Alabama to meet with the Data Coordinating Center statisticians, to develop a statistical analysis plan for the approved project and to review the data at the study's conclusion
- \$1,500 to support the investigator's attendance to either the ISHLT or AHA meetings provided that the investigator has an abstract accepted for oral or poster presentation
- Statistical Support provided by the PHTS DCC

NOTE: Only applications submitted on the Enduring Hearts Application and that fall into the categories listed above will be considered for this award.

Coordinator's Corner

Web Based Data Entry System (WBDE) and Data Submission

Version 1.1.11 (January 3, 2020)

There are a number of changes included in the next release of the web based data entry system.

The biggest changes included are:

1. Addition of Quality of Life and Family Impact Scale data collection forms
2. Patient Summary Reports

Web Based Data Entry System Training

? Have questions about the web based data entry system? A number of training guides are now available on the PHTS website (<http://www.uab.edu/medicine/phts/forms-and-manuals/training-guides>).

Form Submission Deadlines

Event Occurrence	Months	Absolute Submission Deadline
1st Quarter	January February March	April 30
2nd Quarter	April May June	July 31
3rd Quarter	July August September	October 31
4th Quarter	October November December	January 31

QA Reports

The next QA reports will be available in January 2020. These reports will contain events occurring through June 2019. Sites must be 90% compliant with their data submission for all data to be included in the report. To check your site compliance, log into the web based data entry system and click "Reports" in the top gray header, select the first link titled "Follow-up Compliance" and from here, users can view their overall compliance scores (first tab) as well as their quarterly compliance scores (third tab).

Once the reports are complete, they will be available to all users of the web based data entry system. Reports will be accessible through the "Files" tab in the top gray header of the data entry site.

Nov. 2019-Nov. 2021 Steering Committee

Jennifer Conway, MD, FRCPC University of Alberta	President
Marc Richmond, MD, MS Columbia University-Morgan Stanley Children's Hospital of New York Presbyterian	Past President
Scott Auerbach, MD Children's Hospital Colorado	Vice President
Donna Lee, RN, CPNP Lucile Packard Children's Hospital at Stanford	Non Physician Representative
Deip Nandi, MD Nationwide Children's Hospital	Member at Large
Heather Henderson, MD Medical University of South Carolina	Member at Large
William (Bill) Ravekes, MD Johns Hopkins Hospital	Member at Large
TBD	Vice Chair and Steering/Scientific Committee Liaison
James Kirklin, MD University of Alabama at Birmingham	UAB Representative

Nov. 2019-Nov. 2021 Database Committee

Chair

Scott Auerbach, MD
Children's Hospital Colorado

Non Physician Representatives

Donna Lee, RN, CPNP
Lucile Packard Children's Hospital at
Stanford

Rachel Ryan, BSN, RN
The Children's Hospital of Philadelphia
Nov.2017-Nov.2020

Members at Large

Aamir Jeewa, MD (Nov.2017-Nov.2020)
Hospital for Sick Children

Jake Kleinmahon, MD
Ochsner Hospital for Children

Matt Bock, MD
Loma Linda University Children's Hospital

Shriprasad Deshpande, MD
Children's National Health System

Jennifer Su, MD
Children's Hospital of Los Angeles

Daphne Hsu, MD
Children's Hospital at Montefiore



Pediatric Heart Transplant Society Foundation

2020 Foundation Board of Directors

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Marc Richmond, MD, MS
Columbia University - Morgan Stanley Children's Hospital of
New York Presbyterian

Vice Chairman/Secretary

Elfi Pahl, MD
Ann & Robert H. Lurie Children's Hospital of Chicago

PHTS President

Jennifer Conway, MD
Stollery Children's Hospital

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PHTS Foundation

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Children's of Alabama

Past Chairman

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Children's Hospital Colorado Heart Institute

At-Large Members:

James Kirklin, MD (Ex-Officio)
University of Alabama at Birmingham

Rebecca Ameduri, MD
University of Minnesota Masonic Children's Hospital

Maryanne Chrisant, MD
Joe DiMaggio Children's Hospital

Micheal Kuhn, MD
Loma Linda University Children's Hospital

William (Jeff) Dreyer, MD
Texas Children's Hospital

Jay Fricker, MD
University of Florida, Shands Hospital

Mike Paseornek
Parent Representative

Sponsorship / Exhibitor Opportunities Available 2020 SPRING ANNUAL MEETING



The 2020 PHTS Spring Annual Meeting is being planned for Wednesday, April 22, 2020 in Montreal, Quebec, Canada.

Sponsorship / Exhibitor opportunities are now available:

Featured Sponsor - \$10,000

Supporting Sponsor - \$7,500

Dinner Sponsor - \$5,000

Exhibitor - \$2,500

Contact DeAnna Archer at deannabeckham@uabmc.edu for more details.

Amazon Smile



Support the PHTS Foundation when you shop online at Amazon!

Amazon Smile is the same great Amazon you have come to know and love – same products, same Amazon Prime benefits, and the same convenience.

But when you shop through Amazon Smile, your shopping experience can help our mission to raise and administer funds to support the science and treatment of children listed for and following heart transplantation. Amazon will donate a 0.5% of your total to the PHTS Foundation! Every penny adds up!

1. Click on the link: <https://smile.amazon.com/ch/27-4436351>
2. Sign in using your Amazon account
3. You shop, and Amazon gives!

HOUGEN FOUNDATION QUALITY OF LIFE INITIATIVE

The Hougen Foundation Quality of Life Initiative is now live as of January 3, 2020. The Hougen QOL Initiative will be completely voluntary. The purpose of the initiative will help PHTS learn more about the quality of life of children undergoing a heart transplant by using the PedsQL quality of life assessment tool.

Pediatric Heart Transplants: A guide for patients and families

The newly updated “Pediatric Heart Transplants: A guide for patients and families” is now available for purchase. Please visit <http://www.phtsfoundation.org/index.php/guidebook> if you wish to place an order.

The advertisement features a book cover on the left and a blue background on the right. The book cover is titled "Pediatric Heart Transplants: A guide for patients and families" and includes logos for the Pediatric Heart Transplant Society Foundation and the Children's Cardiomyopathy Foundation. The editor is Heather Dastak, cPNS, CCTC. On the right, the text "PHTS Guidebook" is displayed in large white font, followed by "A Guide for Patients and Families" in a smaller white font. A prominent red button with the text "Order Here" in white is located at the bottom right of the advertisement.

NEW PHTS Brochures Available

PHTS brochures are now available for centers to use when consenting their patients or for general informational purposes. Please contact Craig Collum at phtsfexecutivedirector@gmail.com if you wish to receive your very own.



Get Involved!

This year, we have a goal to raise \$75,000! Help support our fundraising efforts by making a tax-deductible donation today! There are many ways to support PHTS! Your financial support, at any amount, is appreciated and is important to improving the outcomes for children who need a heart transplant.

To get involved, visit us at www.phtsfoundation.org or simply click on the link below:

[Donate](#)



Here are some ways to Support:

1. Make a one-time donation
2. Monthly Giving
3. Honor a Loved One
4. Make a Memorial Gift
5. Start a Fundraiser
6. Planned Giving