



Pediatric Heart Transplant Society
NEWSLETTER

FALL 2019

MESSAGE FROM THE DCC

As we close out the third quarter, many exciting activities are going on in PHTS.

- During the month of October centers will vote on the new Vice President who will progress to the role of President in November 2021. This member will also serve as chair of the Database Committee.
- Two abstracts from the registry are planned for submission to ISHLT in October.
- Two abstracts were accepted for presentation at the upcoming AHA meeting in Philadelphia, Pennsylvania in November.
- PHTS will hold its bi-annual membership meeting at Children's Hospital of Philadelphia on Sunday, November 17th.
- The fall call for proposals will open in October. Details on submitting a proposal are included on page 3.
- Don't forget those third quarter forms! All forms for events that occurred through September 30, 2019 are **due by October 31**.
- The annual leadership visit will be held at the University of Alabama at Birmingham on January 9-10, 2020.



Pediatric Heart Transplant Society



REGISTRATION NOW OPEN

PHTS Annual Fall Meeting

The Evening of Sunday, November 17, 2019

Registration: 7:15pm

Meeting: 7:45pm

Room: Abramson 123

[Click Here to Register](#)

Registration Fee: \$100

Registration Closes Sunday, November 3, 2019

Both Events Hosted By and Held at The Children's Hospital of Philadelphia



Children's Hospital
of Philadelphia
Cardiac Center

Upcoming Membership Meetings

- ♥ **Montreal, Canada**
April 22, 2020
ISHLT 2020
- ♥ **Dallas, Texas**
November 15, 2020
AHA 2020

2019 Elections

Voting is now open for PHTS **Vice President**. Nominees are:

- ♥ Scott Auerbach, MD
 - Children's Hospital of Colorado Heart Institute
- ♥ Matthew Bock, MD
 - Loma Linda University Children's Hospital
- ♥ Shriprasad Deshpande, MBBS, MS
 - Children's National Heart Institute
- ♥ Katie Simpson, MD
 - St. Louis Children's Hospital

One member was nominated for Non-Physician Representative so there will not be any voting for this position.

To cast your vote for Vice President, please consult with the members of your center and email the DCC your center's choice for Vice President. Voting will be open until **Thursday, October 31**. The results will be announced at the PHTS Annual Meeting in Philadelphia, Pennsylvania on the evening of Sunday, November 17th.

Vice President (*The member who is elected vice president will also serve the following roles*)

November 2019-November 2021: Steering Committee Vice President and Chair of the Database Committee

November 2021-November 2023: Steering Committee President and Liaison to the PHTS Foundation

November 2023-November 2025: Steering Committee Past President

Non-Physician Representative

The member who is elected Non Physician Representative for the Steering Committee will also serve in this position on the Database Committee. This term is November 2019-November 2021.

PHTS AHA 2019 Abstract Presentations

- ♥ **Prolonged Hospital Length Of Stay After Pediatric Heart Transplantation And Its Impact On Outcomes: A PHTS Database Analysis**
Dipankar Gupta, Ryan Cantor, Devin Koehl, Neha Bansal, Chesney Castleberry, Allison Kimbro, Stephen Pophal, Kenneth O Schowengerdt Jr, Alfred Asante-Korang, Paolo Rusconi, James Kirklin, David Sutcliffe
 - **Poster Session:** CH.APS.16 - Pediatric Heart Failure and Transplant
 - **When:** Monday, November 18, 2019 from 11:30am-12:00pm
 - **Location:** Zone 4, Science and Technology Hall
- ♥ **The Fontan Immunophenotype and Post-Transplant Outcomes in Children: A Multi-Institutional Study**
Benjamin Mantell, Estela Azeka, Ryan Cantor, Waldemar F. Carlo, Maryanne Chrisant, John Dykes, Timothy Hoffman, James Kirklin, Devin Koehl, Thomas J. L'Ecuyer, Jennie M. McAllister, Adriana C. Prada-Ruiz, Marc Richmond
 - **Poster Session:** CH.APS.16 - Pediatric Heart Failure and Transplant
 - **When:** Monday, November 18, 2019 from 11:30am-12:00pm
 - **Location:** Zone 4 of Science and Technology Hall

Fall 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. Feasibility requests can be completed through the link below:

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

October 1-31

Call for proposals open

November 1-30

Proposals reviewed by
Scientific Committee

December 1-31

Submitting authors will be
notified of decision

Coordinator's Corner

Web Based Data Entry System (WBDE) and Data Submission

Version 1.1.10 (Coming Soon)

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

The biggest changes included are:

1. Range checks added to hemodynamic questions on Listing Form, Relisting Form, Transplant Form, and Post Transplant Annual Follow-up Form.
2. Malignancy Form: Added an 'Other, specify' field to question 6c, Clonal Analysis Results.
3. Added search field for medications on post transplant annual follow-up form.
4. Faster loading time on site dashboard.

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



Pediatric Heart Transplant Society Foundation

2019 Foundation Board of Directors

Chairman

Melanie Everitt, MD
Children's Hospital Colorado Heart Institute

Vice Chairman/Secretary

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

Society/Foundation Liaison

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

Executive Director (Ex-Officio)

Craig Collum, MPH
PHTS Foundation

Non-Physician Representative

Mariah Strickland, BSN, RN, CPN
Children's of Alabama

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

Mike Paseornek
Parent Representative

Jay Fricker, MD
University of Florida, Shands Hospital

Sponsorship / Exhibitor Opportunities Available FALL ANNUAL MEETING



This year's PHTS Fall Annual Meeting will take place on Sunday, November 17, 2019 at the Children's Hospital of Philadelphia in Philadelphia, Pennsylvania.

We still have sponsorship/exhibitor opportunities available:

Featured Sponsor - \$10,000

Supporting Sponsor - \$7,500

Dinner Sponsor - \$5,000

Exhibitor - \$1,500

Please click on the following link below if interested:

<https://www.uab.edu/medicine/phts/meetings>

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!

ENDURING HEARTS-PHTS INVESTIGATOR AWARD

We are now accepting applications for the Enduring Hearts-PHTS Investigator Award beginning October 1, 2019. If you would like to be considered for this award please complete an application

<https://www.uab.edu/medicine/phts/research/new-study-proposal>

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

Funding decisions will be based on scientific merit and alignment with the areas of scientific interest relevant to improving heart transplant recipient longevity as follows:

- 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.

Additional weight will be given to research that has a high likelihood of being translated into clinical practice within five years.

HOUGEN FOUNDATION QUALITY OF LIFE INITIATIVE

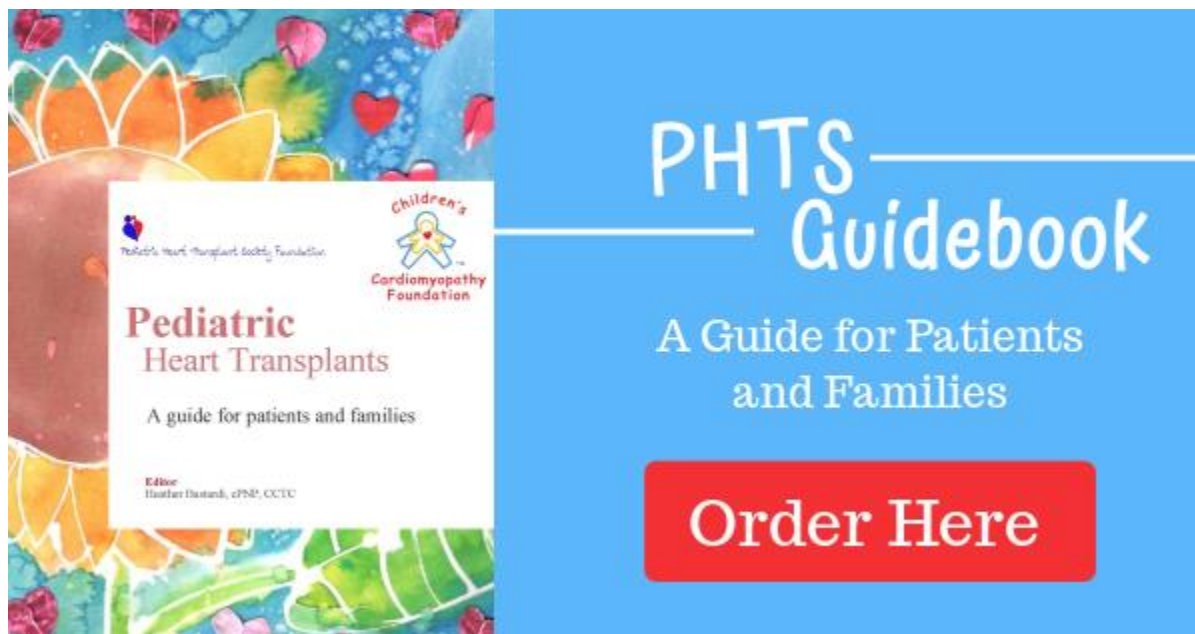
The Hougen Foundation Quality of Life Initiative is set for release on January 1, 2020. The Hougen QOL Initiative will be completely voluntary. The purpose of the initiative will help PHTS learn more about the quality of life of children undergoing a heart transplant by using the PedsQL quality of life assessment tool.

Angel Ornaments

The PHTS Foundation's exclusive 2019 ornament will be available for purchase this fall! We are so excited to be partnering again with Prodigal Pottery this holiday season to bring you one of a kind precious heart ornaments! Each ornament is handmade at King's Home in Chelsea, Alabama, by women who have fled domestic abuse.

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 graphic is split into two main sections. The left section shows the front cover of the book "Pediatric Heart Transplants: A guide for patients and families". The cover has a white background with a colorful, abstract illustration of hearts and leaves in shades of orange, yellow, green, and blue. Logos for the Pediatric Heart Transplant Society Foundation and the Children's Cardiomyopathy Foundation are visible. The editor's name, Heather Hutson, is also listed. The right section is a blue banner with white text. It reads "PHTS Guidebook" in a large font, followed by "A Guide for Patients and Families" in a smaller font. At the bottom of the banner is a red button with the text "Order Here" in white.

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