



Pediatric Heart Transplant Society

NEWSLETTER

MARCH 2018

MESSAGE FROM THE DCC

This year has started with a big change to the PHTS organization. After a vote from the membership, the name has officially changed to the 'Pediatric Heart Transplant Society'. Likewise, the database will be known as the Registry of the Pediatric Heart Transplant Society. As we move forward with the transition from a 'Study' to a 'Society', we would like to design a new logo for the society. Currently the Registry and the Foundation have two separate logos. This new logo will represent both the Registry and the Foundation as it will be for the Society itself. PHTS will be holding a contest for the new Society logo. Logo designs may be submitted to the DCC electronically or mailed to the PHTS Foundation. The deadline for logo submissions is Monday, May 14, 2018. Once the submission deadline has passed, a vote will be held among the membership to select the new logo. Additional details will be coming soon.

In parallel to this Society logo re-design, the PHTS Foundation is in the process of updating the Patient Guidebook. The PHTS Foundation will be accepting submissions for patient artwork to be used on the cover of the guidebook and throughout the book. Additional details are available on page 5 of this newsletter and will be distributed to the membership in the coming weeks.

While PHTS will not be holding a membership meeting at ISHLT this year in Nice, France, there will be **SIX** PHTS presentations during the conference. Page 3 of this newsletter has all the presentation details. If you will be attending the conference, be sure to check out these presentations!

Lastly, the PHTS DCC is in the process of finalizing the 2017 data to create the 2017 Annual Quality Assurance Reports. If your center has any remaining forms to enter or corrections to make, these should be made in the web based system as soon as possible. Reports will be distributed to all site PIs in June 2018.

KEY DATES

Early April

- Announcement of Accepted Proposals

April 11-14, 2018

- ISHLT (Nice, France)

April 30, 2018:

- Second Quarter Forms Due

June 30, 2018

- 2017 QA Reports Distributed

Welcome New Members



Jeffrey Gossett, MD
Peter Kouretas, MD
Caron Burch, RN, MSN, FNP, CCTC
Megan Keating, MSN, PMP
MaryAlice Gowen, RN, BSN

Upcoming Membership Meetings



CHICAGO, IL
NOVEMBER 11, 2018
Annual Fall Meeting

ORLANDO, FL
APRIL 3, 2019
25th Anniversary Gala



Important: Please note that PHTS will not have a membership meeting at ISHLT April 2018 in Nice, France.

PHTS and the AHA HBCU Scholars Program



To promote the advancement of minority scientists and medical professionals trained to understand the impact of cardiovascular disease in their communities, the American Heart Association (AHA) has launched the AHA HBCU Scholars Program. This program is designed for outstanding students enrolled at Historically Black Colleges and Universities (HBCU), with the goal to support the development of minority scientists and physicians trained to impact the understanding and treatment of cardiovascular disease.

Through KIRSO, PHTS has partnered with the AHA HBCU Scholars Program to host Keila Lawrence and Jelicia Daily from Miles College. Since September of 2017, these undergraduate students have been learning

about outcomes research in the setting of PHTS research. In April, both students will present what they have learned methodologically and share a few of the preliminary findings that resulted from the application of their training.

Recent Publications

- ♥ **The impact of flow PRA on outcome in pediatric heart recipients in modern era: An analysis of the Pediatric Heart Transplant Study database**
Bibhuti Das, Elizabeth Pruitt, Kimberly Molina, William Ravekes, Scott Auerbach, Andrew Savage, Leah Knox, James Kirklin, David Naftel, Daphne Hsu. *Pediatr Transplant*. 2018 Feb, 22(1).
- ♥ **Development and Validation of a Major Adverse Transplant Event (MATE) Score to Predict Late Graft Loss in Pediatric Heart Transplantation**
Christopher Almond, Helena Hoen, Joseph Rossano, Chesney Castleberry, Scott Auerbach, Lingyao Yang, Ashwin Lal, Melanie Everitt, Matthew Fenton, Seth Hollander, Elfriede Pahl, Elizabeth Pruitt, David Rosenthal, Doff McElhinney, Kevin Daly, Manisha Desai. *J Heart Lung Transplant* 2018 Apr, 37 (4) 441-450
- ♥ **Impact of Routine surveillance Biopsy Intensity on the Diagnosis of Moderate to Severe Cellular Rejection and Survival after Pediatric Heart Transplantation**
Matthew Zinn, Michael Wallendorf, Kathleen Simpson, Ashley Osborne, James Kirklin, Charles Canter. *Pediatr Transplant*. 2018;e13131.

ISHLT 2018 Presentations

Abstract Title	First Author	Type	Time & Location
DCC Analyses			
The Effect of Infectious Complications During Ventricular Assist Device Use on Outcomes of Pediatric Heart Transplantation	Scott Auerbach Children's Hospital Colorado Heart Institute	MINI ORAL	<u>Hermes Room</u> Wednesday, April 11 6:15pm - 7:15pm (6:50pm)
Worse Survival after Heart Transplantation in Children with Heterotaxy Syndrome	Asma Khan Ann & Robert H. Lurie Children's Hospital of Chicago	MINI ORAL	<u>Hermes Room</u> Wednesday, April 11 6:15pm - 7:15pm (6:25pm)
Failure to Improve Renal Function Following VAD Placement Predicts Renal Injury and Chronic Kidney Disease Following Cardiac Transplant	Seth Hollander Lucile Packard Children's Hospital at Stanford	MINI ORAL	<u>Uranie/Calliope</u> Thursday, April 12 6:15pm - 7:15pm (7:05pm)
Practice Variation in Detection of Coronary Allograft Vasculopathy (CAV) in Children: A Pediatric Heart Transplant Study	Elfi Pahl Ann & Robert H. Lurie Children's Hospital of Chicago	POSTER #1009	<u>Agora 3</u> Thursday, April 12 6:15pm - 7:15pm
Practice variation in the diagnosis of acute rejection among pediatric heart transplant centers: An analysis of the Pediatric Heart Transplant Study (PHTS) Database	Justin Godown Monroe Carell Jr. Children's Hospital at Vanderbilt	ORAL	<u>Mediterranee 6</u> Saturday, April 14 8:15am – 9:45am (8:30am)
Limited Datasets			
Earlier Cardiac Allograft Vasculopathy and Graft Failure in Pediatric Heart Transplant Recipients after Rejection with Severe Hemodynamic Compromise	Jake Kleinmahon Children's Hospital Colorado Heart Institute	ORAL	<u>Mediterranee 6</u> Saturday, April 14 8:15am – 9:45am (9:00am)

Coordinator's Corner

Web Based Data Entry System (WBDE) and Data Submission

Version 1.1.5 (Released February 28, 2018)

The latest release of the web based data entry system included a number of changes. A complete list of changes included in this release can be found here: <http://www.uab.edu/medicine/phts/wbde>.

The biggest changes included are:

1. Past Due Form Rules: The due date for each form will now display on the 'Pending & In Progress Forms' grid on the Site Dashboard. Past due forms will be highlighted in red.
2. MCSD for SV Patients: The MCSD Form (Form 15) now has a new option added to VAD type. This option says "Systemic VAD (for single ventricle patients only)".
3. Patient Summary Descriptions: The patient summary page for each patient now has additional descriptions under each form pulling data entered on each form to display at the summary level.

Upcoming Releases

- Additional data entry fields on lab values for centers outside of the US to enter in different units
- Ranges added to all lab values and hemodynamics
- Listing and transplant reconciliation tracking within WBDE application
- Data download
- Clinical Summary Report
- Site Analytics and Cohort Comparisons

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 30th
2nd Quarter	April May June	July 31st
3rd Quarter	July August September	October 31st
4th Quarter	October November December	January 31st

PHTS Foundation Patient Guidebooks

Our current guidebook, *Pediatric Heart Transplants: A Guide for Patients and Families*, is being updated. We have about **100** printed guidebooks remaining and will not be reprinting any more guidebooks until the updated version is complete. With a limited amount remaining, if you are in need of guidebooks, we encourage you to place an order soon. This valuable, educational resource is offered as a paperback booklet to PHTS participating centers for just \$10/booklet. To order, click the “order” button below.



Limited number available



**Pediatric Heart Transplant:
A Guide for Patients and Families**

Now Available!



Order Here

Help us design a new cover!



ART CONTEST



HELP US DESIGN A
NEW COVER!

YOUR CHILD'S ART
COULD GO HERE!

For contest rules & eligibility, visit
www.phtsfoundation.org



PHTS FOUNDATION
Pediatric Heart Transplant Study

The PHTS Foundation will be holding an art contest for the cover of the revised guidebook. Information about the contest will go LIVE on the PHTS Foundation website and social media pages on April 2, 2018. On the PHTS website, you will find printable contest flyers with general contest information and guidelines. We would love for you to encourage your patients and families to participate!

Contact Brittney at (205) 934-1916 or at BrittneyWilk@uabmc.edu with contest questions or concerns.

More information is available at:
www.phtsfoundation.org

PHTS 25th Anniversary Gala



Mark your calendars NOW for PHTS's **25th Anniversary Gala!** The celebration will take place on Wednesday evening, **April 3, 2019** at **Howl At The Moon** in **Orlando, Florida**.

More information coming soon!

PHTS Foundation Fundraising

This year, we have a goal to raise \$30,000! Help kick off our fundraising efforts by making a tax-deductible donation today! There are many ways to support PHTS – make a one-time donation using a credit card or PayPal, sign up to be a monthly donor, make a Tribute donation in honor of someone special, or send a check to the mailing address below. Your financial support, at any amount, is appreciated and is important to improving the outcomes for children who need a heart transplant.

Donate online

Click the 'donate' button below to make a one-time donation via PayPal



Donate by Check

PHTS Foundation
P.O. Box 55904
Birmingham, AL 35255

