

Pediatric Heart Transplant Study

NEWSLETTER

JANUARY 2018

MESSAGE FROM THE DCC

PHTS continues to grow each year now with **55** hospitals in **4** countries and over **400** members. There are over **8500** listings and over **6500** transplants entered in the database. PHTS investigators published **10** manuscripts in 2017, presented **8** abstracts, and accepted **8** new research proposals. After a large effort over the past several years, for the first time in five years, all active centers were included in the Quality Assurance (QA) and Benchmarking reports. The first semi-annual QA reports were distributed in December. All PHTS leadership committees are changing over and updated committee member lists will be available on the PHTS website as committees are finalized. Major enhancements have been made to the web based data entry system and will continue to be made through 2018. 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.

KEY DATES

January 11-12, 2018

- Leadership Visit in Birmingham, Alabama

January 31, 2018

- Data submission deadline for all events through December 31, 2017

February 1, 2018:

- Spring Call for Proposals opens

February 28, 2018:

- Spring Call for Proposals closes

CONGRATULATIONS

Jennifer Conway, MD

University of Alberta
Stollery Children's Hospital
Elected as Vice President of PHTS for the
November 2017 - November 2019 term

Rachel Ryan, BSN, RN

Children's Hospital of Philadelphia
Elected as Non-Physician Representative for the
Steering and Database Committee
November 2017-November 2019 term

Annual Meeting Recap

In November 2017, PHTS had the annual fall membership meeting in Anaheim, California. With over 80 members in attendance, there was representation from almost all centers in PHTS.

Each committee provided an update on the activities of the committee. There was discussion of timelines from proposals getting accepted to the publication of the manuscript. Dr. Everitt led a discussion on the progression of elections where it was proposed that the Vice-Chair of the PHTS Foundation is elected in a separate cycle from the PHTS Study Group elections as opposed to the current model of PHTS President serving as vice-president and progressing through to become Chair of the Foundation. And lastly, the newly elected PHTS Vice-President and Non Physician Representative was announced.

Slides from the meeting are available here: <http://www.uab.edu/medicine/phts/meetings/fall-2017-anaheim>

Thank you again to our sponsors, Loma Linda University and UCLA Mattel Children's Hospital.

Upcoming membership meetings



CHICAGO, IL
NOVEMBER 2018
Annual Fall Meeting

ORLANDO, FL
APRIL 2019
25th Anniversary
Gala



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

Newly Accepted Proposals

Congratulations to the submitting authors of our newly accepted PHTS proposals. These proposals will be submitted as abstracts to AHA 2018 in June 2018.

♥ **Retransplantation: Underutilized or One heart per child?**

First Author: Dr. Maria del Carmen Vazquez Alvarez (Hospital for Sick Children)

Senior Author: Dr. Anne Dipchand (Hospital for Sick Children)

♥ **Predictors of Grade Level Placement and Use of Special Education Services in Pediatric Heart Transplant Recipients**

First Author: Dr. Micah Brosbe (Johns Hopkins Hospital)

Second Author: Dr. Lydia Wright (Children's Healthcare of Atlanta)

Senior Author: Dr. Shri Deshpande (Children's Healthcare of Atlanta)

Recent Publications

- ♥ ***Cancer Recurrence and Mortality after Pediatric Heart Transplantation for Anthracycline Cardiomyopathy: A Report from the Pediatric Heart Transplant Study (PHTS) Group***
Bock M, Pruitt E, Pahl E, Rusconi P, Boyle GJ, Parent JJ, Twist C, Kirklin JK, Bernstein D. *Pediatric Transplantation*. 2017 Aug, 21 (5) e12923.
- ♥ ***Post-transplant outcomes in pediatric VAD patients: A Pedimacs-Pediatric Heart Transplant Study linkage analysis***
David Sutcliffe, Elizabeth Pruitt, Ryan Cantor, Justin Godown, John Lane, Mark Turrentine, Sabrina Law, Jodie Lantz, James Kirklin, Dan Bernstein, Elizabeth Blume, *J Heart Lung Transplant*. 2017 (In Press)

ISHLT 2018 Accepted Abstracts

- ♥ **Practice variation in the diagnosis of acute rejection among pediatric heart transplant centers: An analysis of the Pediatric Heart Transplant Study (PHTS) Database**
J. Godown, E. Pruitt, J. Vo, D. A. Dodd, I. Lytrivi, G. J. Boyle, D. Sutcliffe, J. A. Kleinmahon, R. Shih, S. Urschel, B. Das, W. F. Carlo, W. A. Zuckerman, S. West, M. A. McCulloch, M. D. Zinn, K. Simpson, S. J. Kindel, J. R. Szmuszkovicz, M. Chrisant, S. R. Auerbach, M. P. Carboni, D. T. Hsu
- ♥ **Failure to Improve Renal Function Following VAD Placement Predicts Renal Injury and Chronic Kidney Disease Following Cardiac Transplant**
S. A. Hollander, E. Pruitt, S. M. Sutherland, R. S. Cantor, J. Kirklin, W. J. Ravekes, R. Ameduri, M. Chrisant, T. Hoffman, I. Lytrivi, J. Conway
- ♥ **The Effect of Infectious Complications During Ventricular Assist Device Use on Outcomes of Pediatric Heart Transplantation**
S. R. Auerbach, E. Pruitt, T. T. Bradford, M. J. Bock, E. R. Skipper, R. S. Cantor, D. A. Koehl, K. Butler, J. C. Alejos, R. E. Edens, J. K. Kirklin
- ♥ **Worse Survival after Heart Transplantation in Children with Heterotaxy Syndrome**
A. Khan, E. Pahl, E. Pruitt, J. Kirklin, E. Azeka, P. Rusconi, S. Guan, A. Barnes, S. Blendsdorf, M. Everitt
- ♥ **Practice Variation in Detection of Coronary Allograft Vasculopathy (CAV) in Children: A Pediatric Heart Transplant Study**
E. Pahl, D. Nandi, J. Vo, K. Schumacher, M. Fenton, R. Singh, K. Lin, J. Conway, E. Pruitt, S. Dahl, J. M. Lamour, J. Kirklin, C. Chin
- ♥ **Earlier Cardiac Allograft Vasculopathy and Graft Failure in Pediatric Heart Transplant Recipients after Rejection with Severe Hemodynamic Compromise**
J. A. Kleinmahon, J. Gralla, S. R. Auerbach, G. A. Wallis, K. Ramakrishnan, R. Singh, R. L. Caldwell, R. Kirk, A. J. Savage, H. T. Henderson, M. D. Everitt

Nov. 2017-Nov. 2019 Steering Committee

Marc Richmond, MD, MS Columbia University-Morgan Stanley Children's Hospital of New York Presbyterian	President
Jennifer Conway, MD, FRCPC University of Alberta	Vice President
Melanie Everitt, MD Children's Hospital Colorado Heart Institute	Past President
Elfi Pahl, MD (2016-2018) Ann & Robert H. Lurie Children's Hospital of Chicago	Scientific Committee. Liaison
Rachel Ryan, RN, BSN The Children's Hospital of Philadelphia	Non Physician Representative
Timothy Hoffman, MD UNC Children's Hospital	Member at Large
Clifford Chin, MD Cincinnati Children's Hospital Medical Center	Member at Large
Juan Carlos Alejos, MD Mattel Children's Hospital	Member at Large
James Kirklin, MD University of Alabama at Birmingham	UAB Representative

Nov. 2017-Nov. 2019 Database Committee

Jennifer Conway, MD University of Alberta	Chair
Heather Tinling, BSN, RN Johns Hopkins All Children's Hospital	Non Physician Representative
Rachel Ryan, BSN, RN The Children's Hospital of Philadelphia	Non Physician Representative
Kurt Schumacher, MD, MS University of Michigan, CS Mott Children's Hospital	Member at Large
William Jeff Dreyer, MD Texas Children's Hospital	Member at Large
Jacob Simmonds, MD Great Ormond Street Hospital for Children	Member at Large
Aamir Jeewa, MD Hospital for Sick Children	Member at Large

Spring 2018 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. In the form manual, a year is listed next to each question so you can see how long that specific data point has been collected. Members interested in submitting proposals are encouraged to submit a feasibility request through the PHTS website. Feasibility requests can be completed through the PHTS website: <http://www.uab.edu/medicine/phts/research/request-form-data>

Call for proposals opens
February 1 - February 28

Quality Of Life Committee

The PHTS leadership has been tasked with reviewing the possibility of adding a Quality of Life (QoL) form to the PHTS data collection. This has been discussed among the Steering Committee and it has been decided that an ad-hoc QoL committee will be assembled.

This committee will be responsible for reviewing the different tools available for QoL data collection and selecting the best one for PHTS. They will then be responsible for testing the QoL tool with their center to provide feedback to the Steering Committee on the difficulty or burdens of collecting this information at their center as well as the additional data entry burden of adding this form to the data collection. The committee will also make a recommendation for the interval at which this information should be collected. More information will be included in future newsletters as the work of this committee progresses.

Committee Members Include:

Karen Uzark, PhD (Committee Chair)
University of Michigan, CS Mott Children's
Hospital

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

Beth Kaufman, MD
Lucile Packard Children's Hospital at Stanford

Kathy Grady, PhD
Northwestern University

Kim Lin, MD
The Children's Hospital of Philadelphia

Jo Wray, MD
Great Ormond Street Hospital for Children

Connie White-Williams, PhD
University of Alabama at Birmingham

Jennifer Conway, MD
University of Alberta

James Kirklin, MD
University of Alabama at Birmingham

Elizabeth Pruitt, MSPH
University of Alabama at Birmingham

Kathleen Van't Hof
Ann & Robert H. Lurie Children's Hospital of Chicago

Mariah Strickland, MSN, CRNP, CCTC
Children's of Alabama

Nancy McDonald, CPNP
Lucile Packard Children's Hospital at Stanford

Barb Roessner, PA-C, CCTC
Children's Hospital and Medical Center

Amy Rothkopf, MPH, MS, CPNP
Columbia University-Morgan Stanley Children's Hospital
of New York Presbyterian

Coordinator's Corner

Web Based Data Entry System (WBDE) and Data Submission

Version 1.1.4 (Released November 21, 2017)

The latest release of the web based data entry system included a number of changes. A complete list of changes included in this release is available here: <http://www.uab.edu/medicine/phts/wbde>. The biggest change in this release is the revision of the infection organism data entry, which was previously a free text field, into a series of check boxes. This will improve the quality of the data and help streamline data submission.

Upcoming Releases

- Additional form descriptions on patient summary underneath each form
- 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
- Past due form indicators in the "Pending and In Progress" grid of forms on the site dashboard
- Listing and transplant reconciliation tracking within WBDE application
- Data download
- Clinical Summary Report
- Site Analytics and Cohort Comparisons

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

Heart Ornament Sale

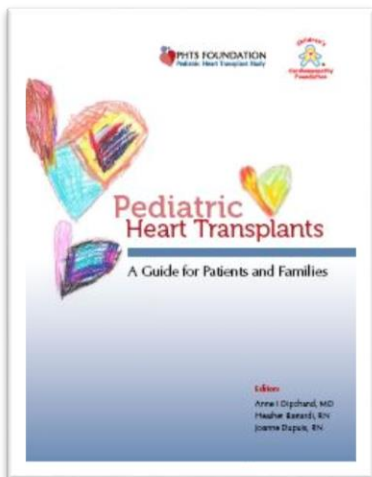


Every holiday season, a new PHTS Foundation ornament is released and available to purchase to help raise money for this important cause. Thank you to everyone who has participated in this year's Heart Ornament Sale!

The PHTS Foundation receives 50% of each ornament sale and we are happy to share with you that as of December 31, 2017, 269 ornaments have been sold, raising \$1614 for our mission!

THANK YOU to everyone for their support.

PHTS Foundation Patient Guidebooks



Pediatric Heart Transplant: A Guide for Patients and Families

Guidebooks are still available for purchase! This valuable, educational resource is offered as a paperback booklet to PHTS participating centers for just \$10/booklet.

To order: <http://www.phtsfoundation.org/index.php/guidebook>

Donate to PHTS

Become a Monthly Donor:
Click the 'subscribe' button below to sign up to give monthly

Friend : \$25.00 USD - monthly ▼

Subscribe



Donate by Check
PHTS Foundation
P.O. Box 55904
Birmingham, AL 35255

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

Donate

