Pediatric Heart Transplant Society

NEWSLETTER

JUNE 2019

MESSAGE FROM THE DCC

PHTS would like to extend a big 'THANK YOU' to every member of the community for the continued dedication and support of the Society. A few general announcements are below.

- The semi-annual QA reports, based off events through December 31, 2018, have now been uploaded into the web based data entry system for review and download. The next reports based off events through June 2019 will be available in December 2019.
- Interested in submitting a research proposal? The next proposal cycle will open in the fall of 2019. Keep an eye out for an email to the community with exact dates.
- Don't forget those second quarter forms! All forms for events that occurred through June 2019 are **due by July 31**. This is an extremely important deadline as the data team will begin working on checking and processing the data for the first half of 2019 in preparation for the next QA reports. Centers that are not at least 90% compliant with form submission will not be able to have their data included in these reports.
- The Form Download is now available in the web based data entry system. This feature will allow users to download the data entered by their site into Excel spreadsheets. This is available by clicking the 'reports' tab in the top gray header of the data entry site and then selecting 'Form Download'. User's can download their data by individual forms or download all forms at once.
- The PHTS DCC Data Team has been working through a rigorous review of all variables in the web based data entry system and how data has been collected across form revision for each question. Only variables that have completed this review process are currently available in the Form Download. New variables will be added regularly as they complete the review process by the data team.



Upcoming Membership Meetings

- **Montreal, Canada**
  April 22, 2020
  ISHLT 2020

- **Dallas, Texas**
  November 15, 2020
  AHA 2020

Recent Publications

- **Cardiac allograft vasculopathy and graft failure in pediatric heart transplant recipients after rejection with severe hemodynamic compromise**
  Jake Kleinmahon, Jane Gralla, Richard Kirk, Scott Auerbach, Heather Henderson, Gonzalo Wallis, Karthik Ramakrishnan, Rakesh Singh, Randall Caldwell, Andrew Savage, and Melanie Everitt. J Heart Lung Transplant. 2019 Mar;38(3):277-284.

- **Characteristics, risks, and outcomes of post-transplant lymphoproliferative disease >3 years after pediatric heart transplant: A multicenter analysis**
  Shawn West, Josh Friedland-Little, Kenneth Schowengerdt, David Naftel, Elizabeth Pruitt Freeze, Kelli Smith, Simon Urschel, Marian Michaels, James Kirklin, Brian Feingold. Clin Transplant. 2019 May;33(5)

- **Renal injury and recovery in pediatric patients after ventricular assist device implantation and cardiac transplant.**
  Seth Hollander, Ryan Cantor, Scott Sutherland, Devin Koehl, Elizabeth Pruitt, Nancy McDonald, James Kirklin, William Ravekes, Rebecca Ameduri, Maryanne Chrisant, Timothy Hoffman, Irene Lytrivi, Jennifer Conway. Pediatr Transplant 2019 May 24

- **New-onset diabetes after pediatric heart transplantation: A review of the Pediatric Heart Transplant Study**
  Joshua Sparks, Ryan Cantor, Elizabeth Pruitt, James Kirklin, Michael Carboni, William Dreyer, Steven Kindel, Thomas Ryan, Robert Morrow. Pediatr Transplant 2019 May 24

Recently Accepted Proposals

CONGRATULATIONS to the investigators below on the acceptance of their proposal during the spring proposal cycle. These projects will be submitted to ISHLT 2020.

- **The Trend of Obesity and Dyslipidemia in the Pediatric Transplant Population and its Associated Outcomes**
  Dr. Carmon Bogle, Ann & Robert H. Lurie Children's Hospital of Chicago

- **Outcomes of heart transplantation for patients with plastic bronchitis**
  Dr. David Bearl and Dr. Justin Godown, Monroe Carell Jr. Children's Hospital at Vanderbilt

AHA 2019 Submitted Abstracts

- **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

- **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

Coordinator's Corner

Web Based Data Entry System (WBDE) and Data Submission

Version 1.1.9 (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. Updated logo throughout data entry system
2. Form 2 (Donor) Question 18 (Inotropes at time of 'harvest'): Changed the word 'harvest' to 'procurement'
3. Form 5 (Rejection): revised wording on form so that 'Episode' refers to the overall 'Episode' of rejection – the entire form, and the 'Evaluation' refers to the biopsies or echos within the rejection episode
4. Form 6 (Infection) Question 7 (Intervention): the free text of surgical therapy has been changed to a dropdown list of options
5. Form 8 (Post Tx Annual F/up): Medication free text has been changed to a 'check all that apply' and existing free text entries have been mapped to the appropriate checkboxes
6. Form 8 (Post Tx Annual F/up): An additional question has been added asking if patient has hypertension and treatment for hypertension
7. Form 10 (Death Form): Cause of death free text entries have been mapped to existing answer options and a few new answer options have been added

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

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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

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PHTS Foundation

Nurse 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
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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

25th Anniversary Gala – HUGE SUCCESS!



The PHTS 25th Anniversary Gala was held on Wednesday, April 3rd, 2019 at Howl at the Moon in Orlando, Florida. Over 200 people turned out to participate in helping us celebrate 25 years of PHTS. We would like to thank all of those who attended and to our gracious host and event and table sponsors for a wonderful evening. The Gala grossed over $50,000 for the Foundation and the response from those who attended were outstanding.

PHTS Foundation is already making plans for the 30th Anniversary Gala on April 27, 2022 in Boston, Massachusetts.

PHTS and ENDURING HEARTS DEVELOP PARTNERSHIP

The Pediatric Heart Transplant Society Foundation (PHTS) and Enduring Hearts (EH), Inc. (Marietta, GA) have signed a five (5) year agreement to develop a partnership to further the scientific understanding of the determinants of longevity of transplanted pediatric recipients and their transplanted heart to improve the quality and duration of life.

Terms of the Collaboration:

- EH and PHTS agree to disseminate information about research funding opportunities as well as research-related news and progress reports.
- EH and PHTS agree to collaborate and share each organization newsletters within their respective networks.
- EH and PHTS agree to sponsor two annual "Enduring Hearts/PHTS Investigator Awards" to recognize either an early or established investigator in the field of pediatric heart transplantation. The first award will aim for eventual presentation at the Annual ISHLT Scientific Meetings and Sessions along with publication in the Journal for Heart and Lung Transplantation. A second award will aim for eventual presentation at the Annual AHA Scientific Sessions along with publication in one of the American Heart Association Journals.
- As part of the award EH agrees to co-fund with the following:
  - Up to $2,500 to co-fund statistical support and access to PHTS Data Coordinating Center for the mutually approved project.
  - 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.

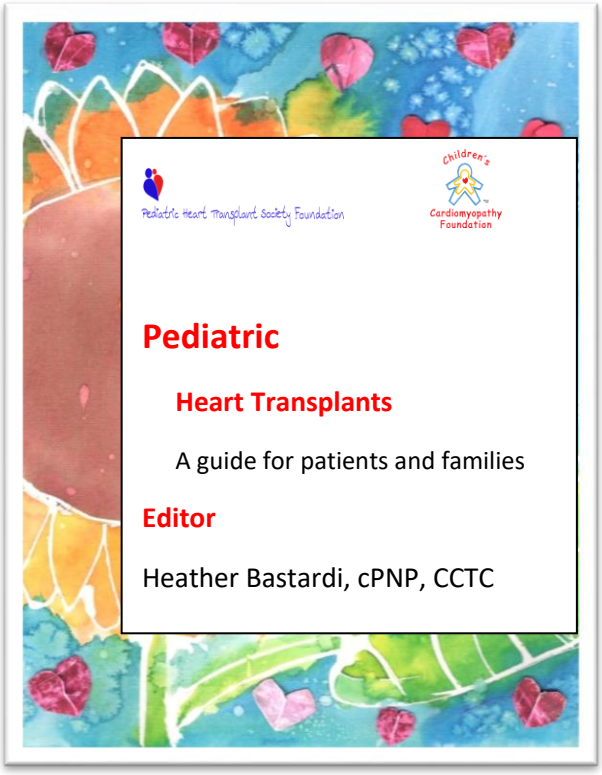
  As part of the award, PHTS agrees to co-fund with the following:
  - Up to $2,500 to co-fund statistical support from the PHTS Data Coordinating Center.

HOUGEN FOUNDATION QUALITY OF LIFE INITIATIVE

The Hougen Foundation (Michigan) has agreed to sponsor a PHTS Quality of Life Initiative that is being planned for late 2019/early 2020. Mr. Randall Hougen, President for the Hougen Foundation has graciously agreed to pay for the license fee for access to the PedsQL and Family Impact modules for PHTS. The DCC is in the early stages of developing a timeline for the modules to be programmed into the web based data entry system. 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.

Pediatric Heart Transplants: A guide for patients and families

The newly updated “Pediatric Heart Transplants: A guide for patients and families” will be available for purchase in late July. Please contact Craig Collum at phtsfexecutivedirector@gmail.com if you wish to place and order.



NEW PHTS Brochures Available

PHTS has created new brochures that are 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 them.

