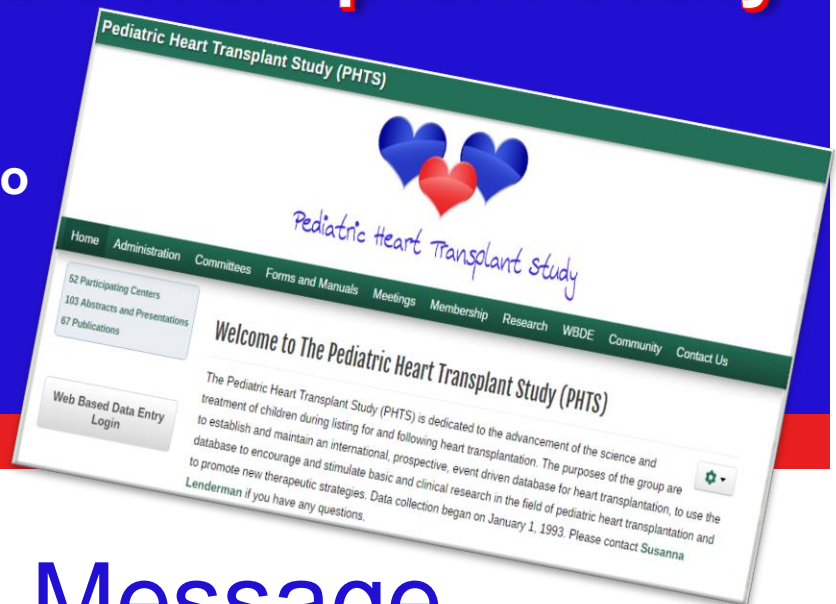


Pediatric Heart Transplant Study

Check out the
PHTS website for up to
date information!

www.uab.edu/phts

December 2016



Key Dates

- Jan. 23rd – 24th: Leadership Visit
- Jan. 31st: All 2016 Data Due
- February: Spring Meeting
Registration Opens
- February: Call for Proposals Opens
- March: Call for proposal Closes

Save the Date:

PHTS Annual Spring Meeting
Wednesday, April 5, 2017
San Diego, CA

Inside This Issue

1. Message from the DCC & PHTS Leadership Visit
2. 2016 Annual Fall Meeting Recap & 2017 Annual Spring Meeting-Save the Date
3. 2017 ISHLT Accepted Abstracts for Presentation
4. Welcome New Committee Members & Message for Outgoing Committee Members
5. 2016 PHTS Publications
6. PHTS Foundation Social Media & A Guide for Patients and Families
7. Angel Ornaments & Happy Holidays from the PHTS Foundation

Message from the DCC

Greetings,

The PHTS DCC generates hospital specific Quality Assurance Reports each year. The 2016 reports have now been completed and were sent to the PI of each hospital on December 22, 2016. These reports contain graphs on data entered through July 2016 for events that occurred through December 31, 2015. For questions or comments regarding these reports, contact Elizabeth Pruitt at elizabethpruitt@uabmc.edu.

-Data Coordinating Center

PHTS Leadership Visit

On January 23rd – 24th, 2017, PHTS will hold the second annual PHTS Leadership Visit at UAB. Those who will attend include, Dr. Melanie Everitt, Dr. Marc Richmond, Dr. Rob Gajarski, Dr. Elfi Pahl, Dr. Simon Urschel, Dr. Anne Dipchand, and the PHTS DCC. If you have any topics you wish to have discussed during this time, please submit them to Dr. Melanie Everitt at melanie.everitt@childrenscolorado.org or Susanna Lenderman at susannalenderman@uabmc.edu.

2016 Annual Fall Meeting Recap

On November 13th, PHTS had a great turn out at the Annual Fall Meeting in New Orleans, Louisiana. A total of 59 people attended from 33 institutions. A number of important topics were discussed with the membership including updates from all of the committees, the PHTS Foundation, the Scientific Committee workshops leaders and Pedimacs. Dr. James Kirklin provided an update from the DCC. Dr. David Naftel discussed the Web Based Data Entry System and future plans for the system. Dr. Marc Richmond discussed any future revisions that are planned from the Database Committee. Dr. Rob Gajarski, Craig Collum, and Brittney Wilk provided an update on the PHTS Foundation. And Dr. Daphne Hsu discussed the Scientific Committee's interest in prospective studies and the future directions of PHTS research.

The meetings slides are now available on the PHTS website.

Click [here](#) for the meeting slides.

2017 Annual Spring Meeting

SAVE THE DATE

PHTS Annual Spring Meeting
San Diego, CA

Hotel information coming soon!

Tuesday April 4, 2017

Practice Variation Workshops
6:00pm – 8:00pm



Group 1:
Immunosuppression
Protocols

Group 2:
Diagnoses of Cellular
Rejection and Surveillance

Group 3:
Diagnosis and Treatment
of Graft Atherosclerosis



Wednesday April 5, 2017

Annual Spring Meeting
6:30pm

Coordinators Meeting

Date and Time coming soon!

Meeting sponsored by:



2017 ISHLT Accepted Abstracts for Presentation

We are very pleased that the PHTS submitted 6 abstracts to the ISHLT for the 2017 meeting and that all 6 have been accepted for presentation. Four of these were analyzed at the PHTS DCC and two were the result of analyses by researchers who received the de-identified PHTS data. We greatly appreciate the efforts and collaborations of the lead investigator for these projects.

Analyzed by the PHTS DCC

- ♥ **Mechanical Circulatory Support (MCS) in Infants with Congenital Heart Disease listed for heart transplant-A PHTS Multicenter Experience.**
Jennifer Conway, MD; Elizabeth Pruitt, MSPH; James Kirklin, MD; Dean Eulrich, MD; Robert Spicer, MD; Dipankar Gupta, MD; Michael McCulloch, MD; Alfred Asante-Korang, MD; and Elfi Pahl, MD
- ♥ **Post-Transplant Outcomes in Pediatric VAD Patients: A Pedimacs-PHTS Linkage Study.**
David Sutcliffe, MD; Elizabeth Pruitt, MSPH; Ryan Cantor, MSPH; Justin Godown, MD; John Lane, MD; Mark Turrentine, MD; Sabrina Law, MD; Jodie Lantz, MSN, RN, PCNS-BC; David Naftel, PhD; James Kirklin, MD; Dan Bernstein, MD; and Betsy Blume, MD.
- ♥ **The long-term outcomes of patients supported with the Berlin Heart EXCOR as a bridge to transplantation: A multi-institutional study.**
Aamir Jeewa, MD; Margaret Tresler, MPH; Michiaki Imamura, MD; Charles Canter, MD; Rob Niebler, MD; Christina VanderPluym, MD; David Rosenthal, MD; James Kirklin, MD; Mike McMullan, MD; Victor Morell, MD; Mark Turrentine, MD; Rebecca Ameduri, MD; Knahn Nguyen, MD; Kirk Kanter, MD; Jennifer Conway, MD; Robert Gajarski, MD; and Charles Fraser, MD.
- ♥ **Association of Insurance Coverage on the Development of Coronary Allograft Vasculopathy after Pediatric Heart Transplant.**
Elizabeth Pruitt, MSPH; Simon Urschel, MD; Melanie Everitt, MD; David Naftel, PhD; and James Kirklin, MD.

Analyzed by Researchers who received de-identified PHTS Data

- ♥ **Hemodynamics of the Pediatric Failing Fontan.**
John Dykes, MD; Doff McElhinney, MD; Dan Bernstein, MD; Spenser Chen, MSPH; Maryanne Chrisant, MD; Rebecca Ameduri, MD; Ken Knecht, MD; Marc Richmond, MD; Kimberly Lin, MD; Simon Urschel, MD; Jacob Simmonds, MD; Katie Simpson, MD; Chris Almond, MD; and Sharon Chen, MD.
- ♥ **HLA Eplet Mismatching Is Associated with Increased Risk of Graft Loss in Pediatric Heart Transplant Recipients.**
Erin Albers, MD; Neal Jorgensen, MS; Joshua Friedland-Little, MD; Borah Hong, MD; Mariska Kemna, MD; Paul Warner, PhD; and Yuk Law, MD.

Welcome New Committee Members

2017 Scientific Committee

Anne Dipchand, MD (new)	Chair
Simon Urschel, MD	Co-Chair
Elfi Pahl, MD	Vice-Chair
TBD	Committee Liaison
James Kirklin, MD	DCC Representative

Members at Large:

Scott Auerbach, MD (new)	Jacque Lamour, MD (new)
Dan Bernstein, MD	Janet Scheel, MD
Charlie Canter, MD	Bob Shaddy, MD (new)
Jennifer Conway, MD (new)	Rocky Singh, MD
Matthew Fenton, MD	Steve Webber, MD (new)
Ashwin Lal, MD (new)	

2017 Steering Committee

Melanie Everitt, MD	President
Rob Gajarski, MD	Past President
Marc Richmond, MD	Vice-President
TBD	Committee Liaison
Nancy McDonald, NP	Non-Physician Rep
James Kirklin, MD	DCC Representative
Alfred Asante-Korang, MD	Member at Large
Gerard Boyle, MD	Member at Large
Kimberly Lin, MD	Member at Large

Message for Outgoing Committee Members

As 2017 begins, it marks the end for some of our outstanding committee members. It is the PHTS DCC's pleasure to thank everyone for their extraordinary work, leadership skills, and dedication and the great job each have accomplished. Over the last two years, the stewardship to PHTS has been characterized by innovative ideas, strategic thinking, and tireless efforts.

Thank you:

**Dr. Linda Addonizio, Dr. Ryan Butts, Dr. Daphne Hsu,
Dr. Steve Kindel, Dr. Ken Knecht, Dr. Yuk Law, and Dr. Bob Morrow.**

2016 PHTS Publications

- ♥ **Outcomes of heart transplantation in children with hypoplastic left heart syndrome previously palliated with the Norwood procedure.**
 Alsoufi B, Mahle WT, Manlihot C, Deshpande S, Kogon B, McCrindle B, Kanter K and the Pediatric Heart Transplant Study Investigators. The Journal of Thoracic and Cardiovascular Surgery, 2016-01-01, Volume 151, Issue 1, Pages 167-175.e2
- ♥ **Impact of initial Norwood shunt type on young hypoplastic left heart syndrome patients listed for heart transplant: A multi-institutional study**
 Carlo W, West S, McCulloch M, Naftel D, Pruitt E, Kirklin JK, Hubbard M, Molina K, Gajarski R, and the Pediatric Heart Transplant Study Investigators. J Heart Lung Transplant 2016: March 35 (3): 301-305.
- ♥ **Statin therapy is not associated with improved outcomes after heart transplantation in children and adolescents.**
 Greenway SC, Butts R, Naftel DC, Pruitt E, Kirklin JK, Urschel S, Knecht K, Law Y, and the Pediatric Heart Transplant Study Investigators. J Heart Lung Transplant. 2016 Apr; 35 (4):457-65.
- ♥ **Left ventricular non-compaction cardiomyopathy in children listed for heart transplant: Analysis from the Pediatric Heart Transplant Study Group**
 Lal A, Pruitt E, Hong B, Lin K, Feingold B, and the Pediatric Heart Transplant Study Investigators. J Heart Lung Transplant. 2016 Apr; 35 (4):540-542.
- ♥ **A multi-institutional evaluation of antibody-mediated rejection utilizing the Pediatric Heart Transplant Study database: Incidence, therapies and outcomes**
 Thrush PT, Pahl E, Naftel DC, Pruitt E, Everitt MD, Missler H, Zangwill S, Burch M, Hoffman TM, Butts R, and Mahle WT. 2016 Dec, 35 (12): 1497-1504.
- ♥ **Fontan Patient Survival After Pediatric Heart Transplant Has Improved in the Current Era**
 Simpson K, Pruitt E, Naftel D, Kirklin J, Singh R, Barnes A, Edens E, and Canter C. The Annals of Thoracic Surgery. 2016. Article in Press.
- ♥ **Use of sirlomus in pediatric heart transplant patients: A multi-institutional study from the Pediatric Heart Transplant Study Group**
 Rosanno JW, Jefferies JL, Pahl E, Naftel DC, Pruitt E, Lupton K, Dreyer WJ, Chinnock R, Boyle G, Mahle WT, on behalf of the Pediatric Heart Transplant Study Investigators. J Heart Lung Transplant. 2016. Article in Press



PHTS Foundation Social Media

Stay Connected!

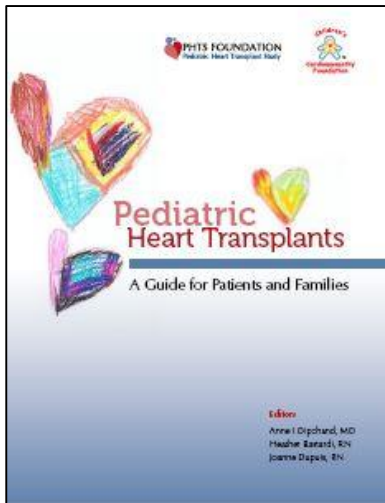
PHTS Foundation is on social media!
Connect with us on Facebook & Twitter. 'Like' and 'Follow' us to stay up to date on all the latest news, information, and events.

We want to hear from you! Send in photos, videos, and stories to be shared on our website and social media!



You can submit any news, stories and pictures to Brittney Wilk at brittneywilk@uabmc.edu

A Guide for Patients and Families



Pediatric Heart Transplant: A Guide for Patients and Families

is a manual designed to provide information about heart transplantation in children for parents and family members.

Sections include:

- ♥ Before the Transplant
- ♥ The Transplant
- ♥ After the Transplant
- ♥ Additional Resources

This valuable, educational resource is now being offered as a paperback booklet to PHTS participating centers for **\$10!** All proceeds support the PHTS Foundation and our mission to improve outcomes for children in need of heart transplants.

Contact Brittney at BrittneyWilk@uabmc.edu if you are interested in placing an order, or you can find the order form here: <http://www.phtsfoundation.org/index.php/guidebook>.

Thank you to KIRSO for the printing of this guidebook.



Kirklin Institute for Research
in Surgical Outcomes

Angel Ornaments

Thank you to everyone who has participated in and made this year's ornament sale a big success! The Pediatric Heart Transplant Study Foundation received 50% of each sale and happy to share that PHTS had wonderful involvement from so many people. We will be sharing the final numbers soon.

Each holiday season, we will release a new exclusive PHTS Foundation keepsake ornament. If you haven't ordered this year's Angel Heart ornament, it's not too late! You have until midnight on December 31ST to get your order in.

Order here: <http://www.phtsfoundation.org/index.php/events/angel-ornaments>



- ♥ Unique Lace Imprint
- ♥ 4 vibrant colors
- ♥ 5" tall and 4.5" wide

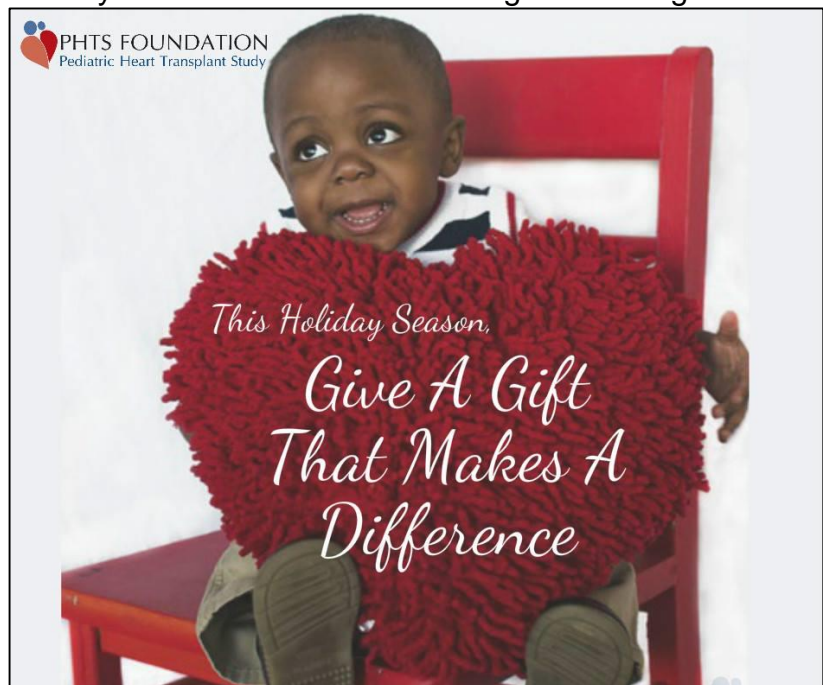
Happy Holidays from the PHTS Foundation

We hope you are enjoying a wonderful holiday season with your loved ones. 2016 will soon be over and we will be welcoming in a new year. Please consider making one more gift before the year end.

Give a gift that makes a difference by donating to the Pediatric Heart Transplant Study Foundation to support research to help continue to improve outcomes for children in need of a heart transplant. The PHTS Foundation is a 501c3 non-profit organization and your donation is tax-deductible. Remember to donate by midnight on December 31st in order to be able to claim deductions for your charitable giving in 2016.

Make a one-time or monthly re-occurring donation, or consider

making a Tribute Donation in someone's honor or memory. We will send a card to the individual and/or their family letting them know of the gift.



Click [here](#) to Donate!

