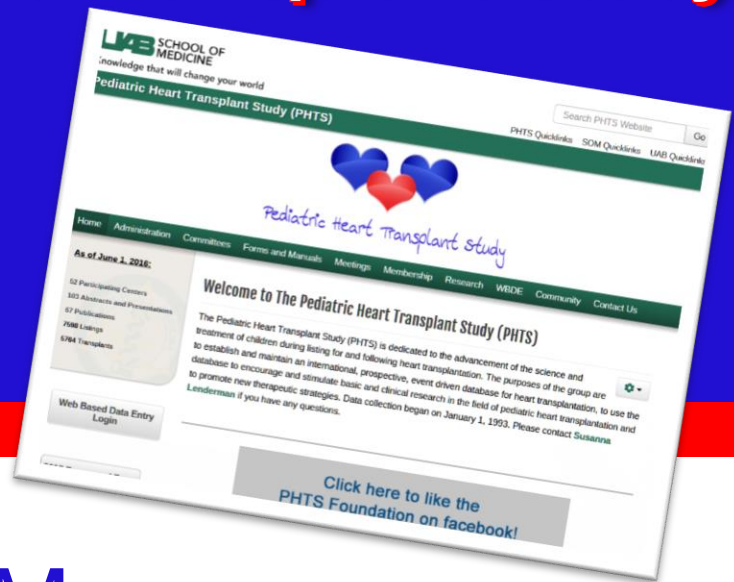


Pediatric Heart Transplant Study

Check out the
PHTS website for up to
date information!

www.uab.edu/phts



June 2016

Key Dates

- July 15th: The 2015 Research Data Deadline
- July 31st: The 2016 2nd Quarter Data Entry Deadline
- Sept 29th: PHTS Foundation Event: Hearts After Dark

Save the Date:

PHTS Annual Fall Meeting
November 13, 2016
New Orleans, LA

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Message from the DCC

Greetings,

In 2016, the PHTS DCC have strived to improve and broaden the PHTS website. We are pleased to announce that the PHTS website now offers a section to share Community Posts. Check out the PHTS website for current and upcoming events. If you would like to have an event posted, please email Susanna Lenderman at susannalenderman@uabmc.edu.

-Data Coordinating Center

AHA 2016 Submissions

New-onset Diabetes after Pediatric Heart Transplantation. — Joshua Sparks, MD

Writing Group: Elizabeth Pruitt, MSPH, Tricia Brown, NP, James Kirklin, MD, Michael Carboni, MD, William Dreyer, MD, Steven Kindel, MD, Thomas Ryan, MD, and Bob Morrow, MD.

Pediatric Heart Transplantation in Pre-Sensitized Recipients: A Current Perspective.

— Bibhuti Das, MD

Writing Group: Elizabeth Pruitt, MSPH, Leah Knox, BSN, RN, James Kirklin, MD, William Ravekes, MD, Scott Auerbach, MD, Andrew Savage, MD, Kimberly Molina, MD, and Daphne Hsu, MD.

Data Submission

- **July 15, 2016** is the **absolute** deadline for any outstanding 2015 data.
 - If you are unsure what your center is missing for 2015, please contact [Susanna Lenderman](#).
- **July 30, 2016** is the data entry deadline for events that occurred between January 1, 2016, and June 30, 2016.

The DCC wants to remind everyone the importance of your center's data being entered before the deadline of July 15, 2016. Anything entered after the deadline will not be included in the research datasets until the following year. In order for each center to be included in the PHTS research dataset, we require that each center be at least 90% complete with all form submissions (listings, transplants, annual follow-ups, events, etc.). This is very important for your own center's report. It is also important for other center's reports, as each report compares the individual hospital to the aggregate PHTS data.

The DCC has done a detailed review of submitted and missing forms at each center for events that happened in 2015 as we get ready to finalize the 2015 research datasets. Once the datasets are finalized, we will be producing the annual Quality Assurance reports which will contain data through December 31, 2015. We will also use the updated data for the newly accepted proposals that will be submitted to ISHLT in November.

WBDE Update

Do You Know?

- Each page in the web based data entry system has a unique URL. This URL does not contain any PHI. You can copy & paste this URL into a non-secure email and email it along with your questions to your colleagues. Once your colleague clicks on the URL, they will be prompted to log in and then it will take them to the exact page on which you were.
- Once a user submits a Screening Log for a patient, a Demographics Form will automatically generate so the user will not have to add the form manually.
- For each patient, pre & post-transplant annual follow-up forms will automatically generate at the time of the patients listing/transplant anniversary. These forms will also appear in the site dashboard under "In Progress Forms."

Coming Soon!
Version 1.1.0

ISHLT 2016 Annual Meeting Summary

Tuesday, April 26, 2016

It was so nice to meet and see many of you at the ISHLT 2016 Annual Meeting.

- ✓ Attendees from 48 of the 52 participating centers.
- ✓ Meeting slides available online [here](#).



Heart Institute

Part of the Children's National Health System

***A big thank you to Children's National for sponsoring the Annual Spring Meeting at ISHLT 2016.**



Practice Variation Workshop Summary



Group Title	Leader
Immunosuppression Protocols	Dr. Marc Richmond
Diagnoses of Cellular Rejections & Surveillance	Dr. Daphne Hsu
Diagnoses & Treatment of Graft Atherosclerosis	Dr. Elfi Pahl

At the PHTS Annual Spring Meeting in April, a number of members convened to discuss the variation in practice among their centers. Together they will create suggested protocols for each topic. Once complete, these protocols will be available on the PHTS website.

New Group Members: It's not too late! If you are interested in joining on of our practice variation groups to work on standardized protocols, please contact [R. Lauren Turner](#).

Existing Group Members: The DCC will be reaching out soon to schedule conference calls to discuss next steps.

Recent Publication

THE JOURNAL OF
**THORACIC AND
CARDIOVASCULAR SURGERY**

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

PHTS & Football



Please double check your local IRB approvals and informed consent to ensure they have the correct **University** listed. At the DCC, we have noticed that often times the IRB approvals and the informed consents state that the centers are sending data to the **University of Alabama**. Please take note that your data are actually sent to the **University of Alabama at Birmingham**.

Interesting Facts:



The **University of Alabama**, located in Tuscaloosa, AL, has won a total of 16 National Championships since they began playing in 1892.



The **University of Alabama at Birmingham** began playing football in 1991 and was obligated to end their football program in 2015. After much protest from the city of Birmingham, AL the football program will return in the fall of 2017.



Hearts After Dark

PHTS Foundation is busy planning and gearing up for our big fundraising party! **Hearts After Dark** will take place on September 29th from 6:30pm-9:30pm at Iron City in Birmingham, Alabama. Guests will enjoy a beer and wine open bar, delicious heavy hors d'oeuvres by Iron City Grill, and opportunities to bid on exciting items in both live and silent auctions, while enjoying the music and entertainment of a live band. All funds raised will support our mission in advancing the science and treatment of children waiting for and after a heart transplant.

Tickets go on sale July 20, 2016 but Sponsorship Opportunities are available now.

Please consider supporting this event.

Contact Brittney at brittneywilk@uabmc.edu for questions or additional information.

Past Fundraisers

♥ On May 11th, we partnered with 10 California Pizza Kitchen (CPK) locations across the country for Pizza with a Purpose. Thank you to all your help in promoting and participating.



Be sure to check the PHTS Foundation website and the PHTS Foundation Social Networks for the upcoming announcement of which center's CPK was the highest grossing restaurant.

We truly appreciate your efforts and your commitment to the cause!

The next CPK fundraiser will be in **November 2016**. If you have a CPK near you and are interested in your city participating, please contact [Brittney Wilk](#).



♥ On Friday, June 27th, the Kendra Scott store in Birmingham, AL, hosted a Give Back Night for the PHTS Foundation. We enjoyed small bites, bubbly, and benefiting from 20% of all sales. Thank you to everyone who came to shop in store or called in their orders!

Thank you to Dr. Chad Mao and his wife from Children's Healthcare of Atlanta for joining us for this event.



Brittney Wilk Craig Collum Susanna Lenderman Dr. Chad Mao and wife