Pediatric Heart Transplant Society

NEWSLETTER

JUNE 2018

MESSAGE FROM THE DCC

As the second quarter of 2018 comes to a close, we have already had an eventful first half of the year and are looking forward to continuing that momentum through the second half.

- The 2018 Quality Assurance Reports (containing data through December 31, 2017) will be available by the end of July. Previously, reports have been sent to the PI of each center through NeoCertified. Now, all reports will be uploaded into the web based data entry system and available for download.
- Membership list update: at the time of the quality assurance reports each year, we like to check with each site to make sure we have the most up to date information on all the members at each site. Each site will be receiving an email in July to confirm membership information.
- Don't forget those second quarter forms! As today closes out the end of the second quarter, all forms for events that occurred in April, May, or June are due by July 31.
- Lastly, we hope to see all of you at the PHTS Annual Fall Meeting on Sunday, November 11. The meeting will be held at and sponsored by Ann & Robert H. Lurie Children's Hospital of Chicago.

KEY DATES

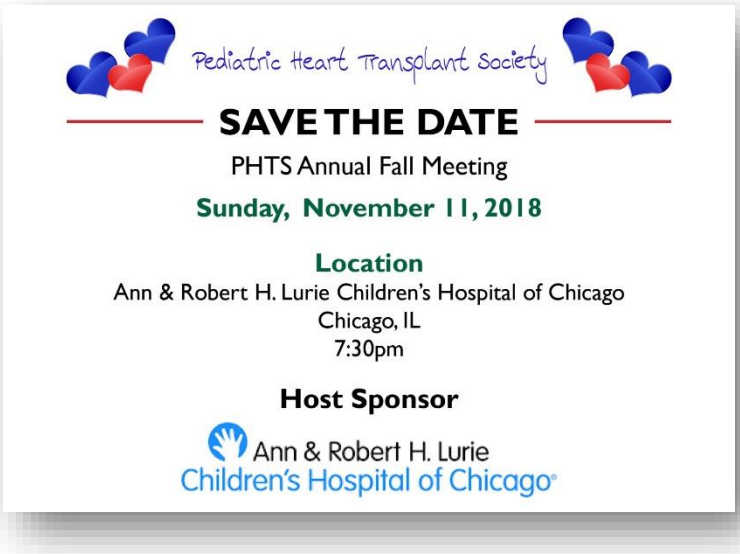
July 31, 2018
- Second Quarter Forms Due

July 2018
- 2017 QA Reports Distributed

September 2018
- Annual Meeting Registration opens

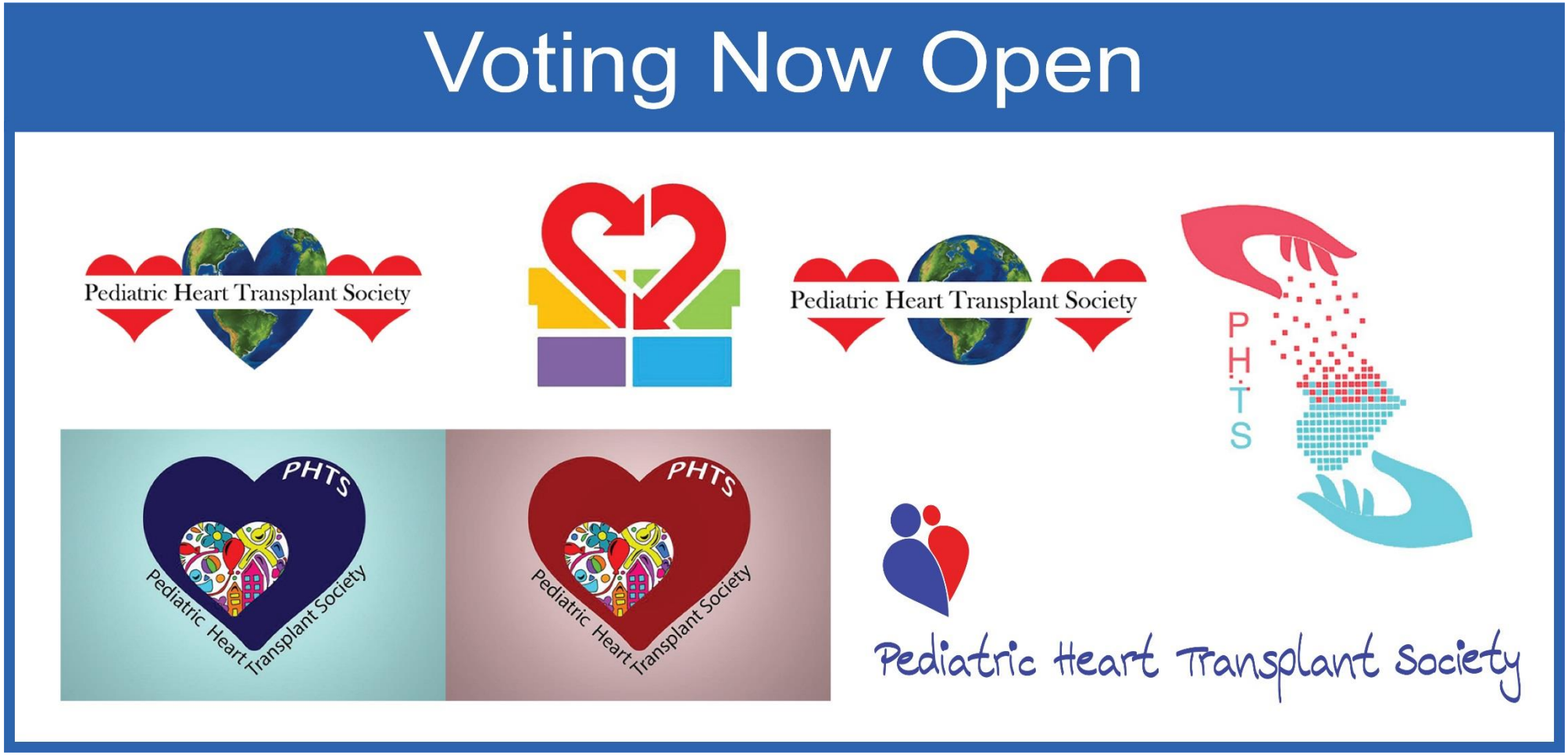
September 14, 2018
- Proposal Submission Opens

October 12, 2018
- Proposal Submission closes



PHTS New Logo Contest

As you know, the membership voted earlier this year to change our name from the Pediatric Heart Transplant Study to the Pediatric Heart Transplant Society. We have been accepting new logo submissions throughout the summer and now it is time to vote! Voting is at a **member level** rather than a center level and every member of PHTS is welcome to vote. To cast your vote, visit http://www.uab.edu/medicine/phts/logo-contest and enter your information. Voting will be open through July 31 and the new logo will be announced shortly thereafter. Thank you for everyone who participated in in submitting his or her logo ideas.



Upcoming Membership Meetings



Orlando, FL
April 3, 2019
25th Anniversary Gala

Philadelphia, PA
November 17, 2019
AHA 2019



Recent Publications

- **Risk stratification to determine the impact of induction therapy on survival, rejection, and adverse events after Pediatric Heart Transplant: A multi-institutional study**

  Castleberry CD, Pruitt E, Ameduri R, Schowengerdt K, Edens E, Hagin N, Kirklin JK, Naftel D, Urschel S, J Heart Lung Transplant 2018 Apr, 37(4) 458-466

- **Post-transplant outcomes in pediatric VAD patients: A Pedimacs-Pediatric Heart Transplant Study linkage analysis**

  Sutcliffe DL, Pruitt E, Cantor RS, Godown J, Lane J, Turrentine MW, Law SP, Lantz JL, Kirklin JK, Bernstein D, Blume ED, J Heart Lung Transplant. 2018 June, 37 (6) 715-722

AHA Submitted Abstracts

- **Educational and Learning Morbidity in Pediatric Heart Transplant Recipients: A Pediatric Heart Transplant Society Study**

  Micah S Brosbe, Lydia Wright, Elizabeth Pruitt, William J Dreyer, Sonya Kirmani, Margaret Knight, Stephanie Nakano, Steven J Kindel, Thomas D Ryan, James K Kirklin, Shriprasad R Deshpande

Fall 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. Members interested in submitting proposals are encouraged to submit a feasibility request through the PHTS website. Feasibility requests can be completed through the link below:

http://www.uab.edu/medicine/phts/research/request-form-data

September 14 - October 12
Call for proposals opens

October/November
Proposals reviewed by Scientific Committee

December
Submitting authors will be notified of decision

Coordinator's Corner

Web Based Data Entry System (WBDE) and Data Submission

Version 1.1.6 (June 22, 2018)

There are a number of exciting changes included in this release of the web based data entry system. 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. Site Dashboard: There is now a link to the form manual available on the site dashboard to assist with searching for additional information on specific questions.
2. Previously, if an edit was made to a form already in a 'complete' status, all fields added to that forms since the event occurred were required to be completed. With this release, a single field may be edited without answering additional questions if the form is already in a 'complete' status.
3. Listing, Relisting, Transplant, Annual Follow-up, and Dialysis Forms: lab ranges have been added for all lab values to these forms. Additionally, individual units may be selected for each lab rather than the site converting the labs to the unit collected by PHTS.

Upcoming Releases

- 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

Give Back Events

PHTS Foundation has been partnering with merchants to help raise money and awareness for the PHTS Foundation and our mission. So far, we have raised over $600! We would like to thank Mooyah, Blaze Pizza, Sky Castle, and Kendra Scott for their partnership and support!









(Interested in partnering with a restaurant or shop in your community for a Give Back event, contact the PHTS Foundation Development Director, Brittney Wilk at brittneywilk@uabmc.edu for assistance getting started.)

Guidebook Cover Contest

Thank you to everyone who helped encourage participation in our recent Guidebook Cover Art Contest! We received artwork submissions from 4 talented young artists from Nebraska, England, Iowa, and California! We asked the public to help us select the winning artwork for the cover of our guidebooks, *Pediatric Heart Transplants: A Guide for Patients and Families*, and voting closed on June 15th.



We are excited to announce the winner – **Kennedy, age 10**, from **Carroll, Iowa**! She received a heart transplant in 2008 at St. Louis Children's Hospital!

Updated guidebooks with the new cover are due to be printed later this year. Other artwork submissions may be used in other parts of the guidebook.

PHTS Foundation Patient Guidebooks

There are about 100 printed guidebooks remaining. Guidebooks are $10/book. Click the button below to order:



PHTS 25th Anniversary Gala

Mark your calendars NOW for the PHTS 25th Anniversary Gala!



Sponsorship opportunities are available now!

Please see *Sponsorship Packet* attached to this email for more information.

Should you have any questions or suggestions in regards to the Gala, please contact Brittney at phtsfdevelopmentdirector@gmail.com or at (205) 934-1916.

PHTS Foundation Fundraising

This year, we have a goal to raise $30,000! Help support 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

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

amazon smile