INTRODUCING: LINDA LAMBERT, MSN-CFNP

We are delighted to announce Linda Lambert, from Primary Children’s Hospital, Utah, has accepted the newly created role: Director of Institutional Data Coordinators for the CHSS Data Center.

Linda is involved with many institutional and international research studies including the PHN, and CHSS Data Center studies. She has helped develop study protocols, with both the CHSS and the PHN, and has presented posters, as well as oral presentations, at many national and international meetings. Thus, she is well qualified to help us in this newly evolving role. With over 70 data center coordinators, and institutions, we saw a need to establish this role and thought immediately of Linda. Our vision is to help improve enrollment, increase the success of our annual follow-up, as well as maintain, and improve, the quality of data sent to the Data Center.

CHSS SPRING WORK WEEKEND

The CHSS Data Center Spring Work Weekend will be held in Toronto on April 10th to 12th, 2015. We will circulate an agenda as soon as it is formalized. Make your reservations now at the Eaton Chelsea, and the hotel will give you an institutional room rate if you inform them that you are meeting at SickKids Hospital. The meeting will begin at 7:30 a.m. Friday at the Data Center. For those members and researchers unable to attend we plan to have a webinar and conference calls open during sessions of interest.

ACTIVELY ENROLLING COHORTS†

AAOCA (400pts) – patients ≤ 30 years of age, diagnosed from Jan. 21, 2009
Tricuspid Atresia Type 1 (338pts) – patients < 3 months of age, diagnosed after Jan. 1, 1999
LVOTO (775pts) – neonate patient < 30 days of age with critical LVOTO
uAVSD (177pts) – patients with complete AVSD, age ≤ 1 year of age, surgery after Jan. 1, 2012

†Please check website for more detailed information regarding inclusion criteria

CURRENT STUDIES‡

<table>
<thead>
<tr>
<th>Study Name</th>
<th>P.I.</th>
<th>Start Date</th>
<th>Status</th>
<th>Working Group</th>
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</thead>
</table>
### LVOTO a) Hybrid and Norwood survival comparison

**C. Pizarro**  
**Apr. 2014**  
Abstract accepted and presented at 2014 AHA. Final draft in review.  

### LVOTO b) Propensity matched comparison of survival, RV function and AVVR in Norwood BT and Norwood-RVPA

**A. Phillips**  
**Jun. 2014**  
Abstract accepted for presentation at 2015 AATS, currently writing first draft.  

### LVOTO c) Trends in RV dysfunction and TR in children with HLHS

**TBD**  
**Jun. 2014**  
Abstract accepted for presentation at 2015 ACC, currently working on intro and results sections.  

### LVOTO – Baseline Echo characteristics analysis

**L. Mertens**  
**Jul. 2014**  
In progress  
L. Mertens, M. Slieker

### AAOCA – BMI in weight restricted patients

**J. Brothers**  
**Sep. 2014**  
In progress  
M. Elias

‡We would like to encourage the membership to contact the Data Center if they wish to join a future working group

## MANUSCRIPTS

<table>
<thead>
<tr>
<th>Title</th>
<th>PI</th>
<th>Deadline</th>
<th>Target Date</th>
<th>Status</th>
<th>Working Group</th>
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### Late survival and right ventricular performance in 332 matched children: Norwood-BT shunt versus Norwood-Sano modification

A. Phillips  
Apr. 28, 2015  
Mar. 9, 2015  
First draft in progress  

### Trends in Right Ventricular Dysfunction and Tricuspid Regurgitation after Single Ventricle Palliation of Hypoplastic Left Heart Syndrome and their Differential Impact on Survival

TBD  
TBA  
Mar. 2015  
Currently working on intro and results sections  

### PRESENTATIONS

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<tr>
<th>Meeting</th>
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<td>ACC</td>
<td>Mar. 14-16</td>
<td>San Diego, CA</td>
<td>Hybrid and Norwood survival comparison</td>
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<tr>
<td>AATS</td>
<td>Apr. 25-29</td>
<td>Seattle, WA</td>
<td>Propensity matched comparison of survival, RV function and AVVR in Norwood BT and Norwood-RVPA</td>
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### PROJECTS

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<tr>
<td>Technical Assessment Project</td>
<td>Web program for members use</td>
<td>Pending approval</td>
<td>G. Cohen</td>
<td>J. Karamichalis, T. Karamlou, M. Nathan, A. Grady</td>
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<td>Registry of Biobanks</td>
<td>Registry of Registries</td>
<td>Active data collection from 9 CHSS institutions</td>
<td>P. Gruber</td>
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<tr>
<td>Genomics</td>
<td>Grant Prep</td>
<td>Pending application</td>
<td>P. Gruber/Rick Kim</td>
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<tr>
<td>Ebsteins Cohort</td>
<td>Proposal to Research Committee</td>
<td>Awaiting submission</td>
<td>Dearani/Pizarro/ Knott-Craig</td>
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<tr>
<td>Imaging Core Lab</td>
<td>AAOCA/AVSD/LVOTO</td>
<td>Active</td>
<td>L. Mertens</td>
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GRANTS

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<th>End Date</th>
<th>P.I.</th>
<th>Status</th>
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<tr>
<td>Children’s Heart Foundation</td>
<td>2012</td>
<td>Extended to 2015</td>
<td>B. McCrindle</td>
<td>Ongoing</td>
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<td>Michael H. Ludwig Foundation</td>
<td>2012</td>
<td>Renewed in 2014</td>
<td>J. Brothers</td>
<td>Ongoing</td>
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COORDINATORS SECTION

A LOOK AHEAD: 2015 FOLLOW UP

We have closed follow up on AVSD 2014 at 87%, and are currently following up on PAIVS and AAOCA cohorts. We plan to mail out LVOTO for 2015, mid-March. If you have any current demographic or clinical updates on patients in any of these cohorts, please feel free to send us their information via Secure File Transfer, mail or fax.

AVSD: WHAT YOU NEED AND HOW TO MOVE FORWARD

This prospective study aims to establish the echocardiographic indices, as well as patient anatomic and physiologic factors that favor BVR and those that favor UVR. Thus, this study requires copies of the ECHO images to be sent to the Data Center at the following 3 time points:*

1. **Baseline** – most complete diagnostic study prior to surgery
2. **Discharge** – may be completed pre-discharge or within 30 days post-op, whichever is first
   - Must be **post initial** index surgery (i.e. PA band/Norwood/Complete AVC repair)
   - Echo’s should also be sent for any reintervention within the same admission (i.e. valve repair, residual VSD etc.) even if outside of the 30 day window
3. **One year post surgery** (ideally between a range of 9 to 15 months)

*The baseline and discharge ECHO’s should be sent at the time of enrollment. The one year ECHO can be sent with annual follow up.

HOW:

- ECHO’s should be **complete** echo’s to include all images required for study measurement (refer to CHSS website at [www.chssdc.org/studies](http://www.chssdc.org/studies) and review AVSD baseline echo review webinar)
- ECHO’s should be **transthoracic (TTE)** ECHO’s DO **NOT** send transesophageal (TEE) ECHOS’s
- Must be sent in **DICOM** format
- Centers participating should have an identified echocardiographer (cardiologist) champion. For this project to be successful, you must designate **ONE** cardiologist. If one has not been identified, this must be done now. Please send their name and contact information to the DC
- ECHO’s can be copied by study coordinator, cardiologist, or sonographer to disc for shipment to DC