CHSS WORK WEEKEND – RECORD ATTENDANCE!

Thank you to everyone who attended the CHSS Spring Work Weekend! This Work Weekend was attended – either in person or by webinar – by a total of 53 people, which is the greatest attendance to date. If you would like to be acquainted with the details of the weekends’ presentations & sessions, please visit the CHSS website and follow the ‘Work Weekend’ link to review a summary report. CHSS members also received a link to a ‘virtual binder’, which included all of the content found in the hard copy binders handed out at the meeting, as a reference. We hope those who were unable to attend this meeting will join us for our Fall Work Weekend.

TECHNICAL ASSESSMENT PROJECT: AN UPDATE

The Technical Assessment Project was officially launched on April 23rd, 2015. All members should have received an email with instructions on how to participate in the project. Along with the email, members should have received copies of the Data Collection Forms and regulatory documents (QI approval from The Hospital for Sick Children, as well as a DSA). We hope that you will be able to take part in this very exciting initiative.

ACTIVELY ENROLLING COHORTS†

AAOCA (428pts) – patients ≤ 30 years of age, diagnosed from Jan. 21, 2009
Tricuspid Atresia Type 1 (348pts) – patients < 3 months of age, diagnosed after Jan. 1, 1999
LVOTO (802pts) – neonate patient < 30 days of age with critical LVOTO
uAVSD (192pts) – 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>
</tr>
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</table>
LVOTO b) Propensity matched comparison of survival, RV function and AVVR in Norwood BT and Norwood-RVPA

LVOTO c) Trends in RV dysfunction and TR in children with HLHS
TBD  Jun. 2014  Abstract accepted and presented at 2015 ACC, 1st draft being finalized.

LVOTO – Baseline Echo characteristics analysis
L. Mertens  Jul. 2014  In progress
L. Mertens, M. Slieker

AAOCA – BMI in weight restricted patients
M. Elias

†We would like to encourage CHSS members to contact the Data Center if they wish to join a future working group

MANUSCRIPTS

Title | PI | Target Journal & Submission Date | Status | Working Group
--- | --- | --- | --- | ---


Late survival and right ventricular performance for matched children with critical left ventricular outflow tract obstruction: Norwood with modified Blalock-Taussig shunt versus Norwood with right ventricle to pulmonary artery conduit  

A. Phillips  

Submitted to JTCVS, Apr. 14 2015  

Submitted  


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

TBD  

JACC, early May 2015  

Author revisions in progress  


Health-Related Quality of Life and Healthcare Responsibility in Adolescents with Aortic Valve Atresia  

In progress  

Stackhouse, K.

Aortic Valve Atresia: Neonatal Transplantation or Palliative Reconstruction? Insights from Long-Term Survival and Beyond  

In progress  

Stackhouse, K.

PROJECTS

<table>
<thead>
<tr>
<th>Project</th>
<th>Summary</th>
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<tbody>
<tr>
<td>Technical Assessment Project</td>
<td>Web program for members use</td>
<td>Launched Apr. 23 , 2015</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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<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>J. Dearani</td>
<td>--</td>
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<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>
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<th>Status</th>
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<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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<tr>
<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 for PAIVS 2015 at 62%. We are currently following up on AAOCA, LVOTO and IAA cohorts. We plan to mail out TA for 2015, in May. 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.

REQUIRED REGULATORY DOCUMENTS

Before a site can begin enrollment in one of the CHSS cohorts, the following documents must be on file with the Data Center:

- Data Use Agreement or Data Transfer Agreement (fully executed)
- IRB approval
- Study Team contact information (PI, study coordinator, others)

If you have any questions about regulatory documents, please contact us!

KEEPING CONNECTED: CONFERENCE CALLS

A reminder to our coordinators of our upcoming quarterly coordinator call! We are aiming to set up a conference call on May 20th at 2:00 PM EST, and May 21st at 11:00 AM EST. Please check your calendars and be sure to join us on one of those days! If you have any topics or suggestions for the call, please don’t hesitate to contact us. We are here to assist and provide you with answers to any of your questions, or concerns, regarding studies, enrollment and follow up.

CHILDREN & YOUNG ADULTS WITH CHD – SUPPORT GROUPS IN YOUR AREA!

We are reaching out to our institutional coordinators to see if we can compile a comprehensive list of support groups within each state. We plan to post this list to the CHSS website so that we can direct patients who are interested in connecting with other families, and peers, for additional support throughout their journey.