CHSS Fall 2012 Work Weekend Update

Thanks to your enthusiasm, support and hard work, your CHSS Data Center held another successful work weekend in November 2012. Twenty one guests attended the work weekend in person and ten guests participated via webinar and conference calls.

Spearheading the data analysis for a current CHSS cohort, **Jeff Poynter** summarized the data of the infants under the age of two years with Tricuspid Atresia enrolled between January 1999 and the present. **David Morales** initiated the weekend with an excellent summary of his clinical and experimental work with a synthetic membrane made by CorMatrix. **Peter Gruber** dialed into the Webinar to explain the rationale of creating a CHSS Registry of Biobanks – a concept of stimulating multicenter research by identifying a critical mass of banked material. **Rich Lorber** presented a review of diagnostic imaging of AAOCA and discussed variations in morphology and how these variations could best be imaged.

**Constantine Mavroudis** led a data extraction group through a complete review of all 106 AAOCA operative notes. **Eugene Blackstone** gave an update of his American Academy of Pediatrics 2012 Founder’s lecture a presentation concerning important issues related to clinical research. **Jeff Jacobs** updated progress with linking the 5 active CHSS cohorts with STS database users to allow us to determine the denominator in our cohorts. Taking the next step of progress in the Technical Performance Score lead by **Emile Bacha**, Sally Cai demonstrated the REDCap program and the group then entered 117 echos to test the program. They identified important issues that are being corrected before going live.

We are very grateful for the support of a large group of Work Weekend volunteers. The above summary does not do justice to the amount of work the group achieved in a short time. We have uploaded a more detailed summary prepared by Dr. Bill Williams on the Data Center website which can be found click here.

Tricuspid Atresia Study Update

During the recently concluded Fall 2012 Work Weekend, the group asked the question “To reduce mortality for children with Type I Tricuspid Atresia who require initial palliation with a systemic-pulmonary artery shunt, should you ligate or not ligate the main pulmonary artery and/or ductus arteriosus?”

The group performed an extensive chart review of patient deaths. They also clarified how the ductus arteriosus and main pulmonary artery were managed at the time of palliation with a systemic-pulmonary artery shunt. Our parametric model of mortality for this cohort was expanded to allow for consideration of all relevant demographic, morphologic and procedural variables. We have constructed a time-dependent variable to reflect the presence of competing pulmonary blood flow over time. Our next step is to incorporate this variable into our parametric modeling to examine the effect of competing pulmonary blood flow on mortality and to identify other associated factors.

CHSS Presentations in 2012

Your CHSS Data Center is happy to present the productivity and research output summary for 2012 for your quick reference:

**PAIVS: Functional Health Status Study**

**Anomalous Aortic Origin of a Coronary Artery Cohort**
Symptoms and Coronary Anatomy are associated with Management Decisions in Children and Young Adults with Anomalous Aortic Origin of a Coronary Artery: A Congenital Heart Surgeons’ Society Study. Presented at the American Heart Association Scientific Sessions. 2012, Los Angeles [Link]

**Pulmonary Conduit Cohort**
Effect of Conduit Type and Size on Right Ventricle-Pulmonary Artery Conduit Durability in Infants Less Than Two Years of Age: A Congenital Heart Surgeons’ Society Study. The Society of Thoracic Surgeons 2013 Annual Meeting

(Accepted as the J. Maxwell Chamberlaine Paper)
Spring Work Weekend: April 12-14, 2013

The CHSS Data Center Spring 2013 Work Weekend will be held in Toronto from 12th to 14th April, 2013. We will circulate a draft agenda close to the work weekend. If you are planning to attend, please RSVP at chss.dc@sickkids.ca. We look forward to see you in Toronto!

Work Weekend Spring 2013
Date: April 12-14, 2013
Venue: CHSS Data Center
The Hospital for Sick Children
555 University Avenue
Toronto, ON, M5G 1X8, Canada

Enrollment in CHSS Studies

We would like to take this opportunity to update our patients and parents, member institutions and contributing researcher coordinators and data managers as well as all the research leaders who contribute to the Data Center research of our five prospective observational cohort studies that have been enrolling new patients.

Thanks to your supports, these cohorts continue to enroll new patients and acquire new data that will help generate new knowledge and improve care for our patients. In 2012, 26 institutions have enrolled new patients in YOUR CHSS studies.

A note of gratitude to our donors

As the year of 2011 nears the end, we would like to express our gratitude to all the donors who have made our research endeavors possible. We would especially like to express our sincere thanks to:

- Congenital Heart Surgeons’ Society Surgeons & Institutions
- The Hospital for Sick Children, Toronto
- The Children’s Heart Foundation
- Saving tiny Hearts Society
- The Children’s Heart Clinic (Dr David Overman)
- Primary Children’s Medical Center (Dr John Hawkins)
- The Children’s Hospital of Philadelphia (Dr Julie Brothers)
- CryoLife, Inc.
- CorMatrix Cardiovascular Inc.

We would also like to express our gratitude to Nonin Medical Inc who has committed a generous amount of unrestricted funds to the CHSS Data Center. Nonin Medical invented finger pulse oximetry and specializes in the design and manufacturing of noninvasive physiological monitoring solutions, including its EQUANOX™ Regional Oximetry System for cerebral and somatic monitoring of tissue oxygen saturation. Nonin distributes its pulse and regional oximeters, capnography systems, sensors and software to health professional and consumers in more than 125 countries and has more than 100 OEM partners worldwide.

For donors from the United States:
www.chssdc.org/donate

For donors from Canada:
www.sickkidsfoundation.com/donate/

Number of CHSS institutions enrolling new patients in a year

The currently enrolling cohorts are:
1/ Tricuspid Atresia (TA)
2/ Pulmonary Conduit (PC)
3/ Critical Left Ventricular Outflow Tract Obstruction (LVOTO)
4/ Anomalous Aortic Origin of a Coronary Artery (AAOCA)
5/ Atrioventricular Septal Defect (AVSD)

We invite you to participate in one or all of the above cohorts and send us your patients’ data. Should you have any questions about your participation, please contact us at chss.dc@sickkids.ca at any time and we will be glad to be of assistance to you.

Number of patients enrolled in currently enrolling CHSS cohorts since their inception from all participating cohorts

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