Launch of New CHSS Inception Cohort: Unbalanced Atrioventricular Septal Defect

The CHSS is excited to announce that we will be launching a new inception cohort study of patients diagnosed with complete atrioventricular septal defect. The principle aims of the study are to refine the diagnostic criteria used to identify patients with unbalanced AVSD and to improve surgical outcomes for these patients through improved matching of anatomy and therapy.

Using the findings from our the Unbalanced AVSD Lookback Study, championed by Dr. David Overman, we have successfully obtained funding from the Saving tiny Hearts Society for this new study. We will be inviting participation in this project on the part of CHSS member institutions in the coming months. As with the launch of the Anomalous Aortic Origin of a Coronary Artery Study, you will be receiving a series of emails, each email will direct you as to how to get your center involved in this new initiative.

The emails will request your response to the following queries:

1. Would you like to get your center involved in the AVSD study?
2. Please provide us with the name and email of the research coordinator at your center who will be responsible for liaising with us on this project.
3. Please provide us with the name of one lead sonographer and one echocardiographer (M.D.) who will be involved in this project and will attend a one day training seminar hosted by the echo core lab team.

In addition, we will be sending out all the template documents that your center will need in order to complete the REB/IRB submissions. Of course, we will be available throughout this process to help you in any way needed. If you have any further questions about getting involved, please feel free to contact our Kirklin-Ashburn Research fellow Dr. Anusha Jegatheeswaran at (416) 813-5184 or anusha.jega@sickkids.ca.

Member Spotlight: Dr. David Overman

Dr. Overman joined the Congenital Heart Surgeons’ Society in 2004. He has been an active participant in various CHSS events including the annual meeting and work weekends as well as a number of research projects. Apart from his personal time and efforts, Dr. Overman and his research team regularly screen and enroll patients in various CHSS cohorts.

Apart from the CHSS, Dr. Overman is a member of the Society of Thoracic Surgeons, Midwest Pediatric Cardiology Society, Twin Cities Thoracic and Cardiovascular Surgical Society, Minneapolis Surgical Society, University of Toronto Surgical Alumni Society, Rush Surgical Society, and the Hitchcock Surgical Society. He is a fellow of the American Academy of Pediatrics.

Dr. Overman most recently received a grant from Saving tiny Hearts Society to launch a CHSS Inception Cohort on Unbalanced Atrioventricular Septal Defect. We have included more details and contact information for this cohort in the newsletter.

Dr. Overman, his wife Kristine, and their four children live in Minneapolis.
TGA: Functional Health Status and Transition to Adult Care Projects

In the past, outcomes for children with TGA have been measured in terms of morbidity and mortality. However, as patients with TGA now have excellent long-term survival after repair, two areas have become increasingly important and require further elucidation. These are functional health status and medical care for these patients as adults. At our recent work weekend and the CHSS Annual Meeting, we discussed late functional health status (FHS) of patients from our TGA cohort, as they have transitioned to adulthood. We received a very positive response to our formal invitation to participate in an evaluation of functional health status and transition to adulthood among survivors after TGA repair. As written in our invitation, we will be analyzing this data with the intention of putting together an abstract and manuscript through a series of conference calls and a ‘Writing Day’ on May 19th at the CHSS Data Center in Toronto.

AAOCA Update: Age distribution

The AAOCA Cohort continues to acquire more patients thanks to enthusiastic participation from many member institutions. Our thanks go to all participating surgeons, cardiologists and everyone else in the research team. We also thank all the patients who consent to participate in the study to help us find the best possible solution to this condition.

The AAOCA study is currently in the first year of its follow-up. We have enrolled over 125 patients by the end of March 2011. A brief age distribution of the patients can be graphically described as below. As you would notice we do not have many adult patients. We encourage every participating institution to continue screening and enroll adult patients whenever possible.

CHSS Data Center update: Dr. Maulik Baxi

The CHSS Data Center Research Program Manager Dr. Maulik Baxi was recently appointed to the Minority Affairs Committee of the American College of Epidemiology for a three year term. Maulik holds a medical degree from Medical College, Baroda, India and Master of Public Health from the Columbia University in New York. Maulik is Board Certified in Public Health and has been working with the Data Center since August 2008.

Thank you: Retiring research team members!

We would like to thank Terri McLees-Palinkas, MS, CCRC who recently retired as the Research Coordinator at the Heart Institute, Rady Children’s Hospital-San Diego. Terri worked with the research team of Dr. John Lamberti on the CHSS studies. She helped navigate and launch new studies at San Diego, updated enrollment and follow-up for our patients. San Diego program became one of the top contributors in the last couple of years under the able leadership of Terri and Dr. Lamberti. Research coordinator like Terri can provide inspiration to all other CHSS institutions. Our gratitude and best wishes to Terri on behalf of the society and our patients who will benefit from these studies!