Work Weekend Update

Your CHSS Data Center is happy to report the updates from a successful Spring 2013 Work Weekend. The weekend had a full agenda and included broad participation from the membership. At the start of the Work Weekend, Brian McCrindle presented the successful grant proposal on Functional Health Status and Exercise testing in critical Aortic Stenosis patients. Via webinar, Jeff Jacobs presented an update on the CHSS-STS data link study. After the initial presentations, Jeff Poynter, the CHSS Kirklin-Ashburn Fellow, presented the current status of the Tricuspid Atresia cohort to the membership and invited their inputs to refine the data analysis. This discussion was followed by another presentation from Jeff Poynter on the AAOCA cohort.

The membership also discussed updates in Technical Performance Scores (John Karamichalis), Biobank Registry of Registries (Peter Gruber) and Atrioventricular Septal Defect Inception Cohort (David Overman, Via Webinar). Among the new topics for discussion was the Ebstein Anomaly project jointly proposed by Joseph Dearani, Christian Pizarro and Christopher Knott-Craig. A presentation by Gene Blackstone on statistical methodology called enrichment technique was the learning highlight of this work weekend. We hope that this summary will be of your interest and will invite your participation in the upcoming work weekend and other Data Center events.

Work In Progress: Tricuspid Atresia

Attendees of the Work Weekend this spring have identified the following research questions for our analysis of the Tricuspid Atresia cohort: 1) Do the presence and type of accessory pulmonary blood flow and age at first systemic-pulmonary artery shunt (SPS) influence mortality after initial palliation of tricuspid atresia with a SPS? 2) Which factors influence ongoing mortality after cavopulmonary anastomosis among children with tricuspid atresia who were initially palliated with a SPS?

The long-term mortality rate for children initially managed with a SPS is 36%. This is much greater than the mortality rate of children initially managed with cavopulmonary anastomosis (4%) or pulmonary artery banding (5%). Interestingly, there appears to be an ongoing, persistent mortality risk amongst children managed with an initial SPS. The figure illustrates survival amongst children with TA who were initially managed with a SPS; mortality is greatest between SPS and cavopulmonary shunt (red line).

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CHSS Kirklin-Ashburn Fellowship

The CHSS Data Center would like to take this opportunity to thank the membership for their continued support of the Kirklin-Ashburn Fellowship. The fellowship, started in 2001, has emerged as one of the most prestigious research fellowships in the field of congenital heart surgery. All the members and all the researchers who have contributed their resources, time and efforts share this success. The Data Center has been the home and the learning ground of this fellowship, has strived to nurture and promote young surgeons in training to solve critical issues in congenital heart surgery using the collective experience and wisdom of the CHSS membership.

The CHSS Data Center, located at the Hospital for Sick Children in Toronto, plays a crucial role in recording, analyzing and tracking the data of many patients with congenital heart disease. Moreover, the Research Fellow is critical to furthering the goals of both the CHSS and the Data Center while providing an outstanding research experience for a young trainee. In order to recruit the very best talent available, we must ensure that the John W. Kirklin/David Ashburn Fellowship Fund is fully supported.

To make your tax deductible donation towards the John W. Kirklin/David Ashburn Fellowship Endowment Fund, please visit the link here.

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**CHSS Kirklin-Ashburn Fellowship**  
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David Ashburn was the first CHSS fellow from 2001 to 2003. David earned his Master’s degree from the Institute of Medical Science at the University of Toronto.

Tara Karamlou was the second Fellow from July 2004 to June 2006. She completed her congenital surgery fellowship at Seattle Children’s Hospital and is now on faculty at the University of California at San Francisco.

Edward Hickey, the 3rd John W. Kirklin Fellow began his tenure in the CHSS Data Centre July 2006. He later joined University of Toronto Cardiac Surgery program and continues as staff surgeon at The Hospital for Sick Children, Toronto.

Anusha Jegatheeswaran began her tenure in July 2008. She is pursuing her PhD in Clinical Epidemiology at University of Toronto. She is intending to complete her training with a fellowship in congenital heart surgery.

Jeffrey Poynter began his tenure with in July 2011 and will be completing the fellowship this month. He intends to complete his Masters in Statistics from University of Toronto and return to Indiana to complete his surgical residency.

**Work In Progress: Tricuspid Atresia**  
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intermediate between cavopulmonary shunt and Fontan (blue line), and least, but still persistent, after achievement of Fontan (black line). We suspect the ongoing mortality in children with a history of prior SPS may be due in part to an ongoing decrement in ventricular function arising as a consequence of a period of volume loading while palliated with a SPS.

![Graph showing survival rates](image)

We are very excited to see what new information this analysis may generate. Currently, we are adding indices of ventricular contractile function from echocardiograms into the dataset. Once this expansion of the dataset is completed, we will be ready to continue refinement of the analysis.

**Dr. Eugene Blackstone presented AATS Scientific Achievement award**

We are proud to let our membership know that Dr. Eugene Blackstone was presented the prestigious AATS Scientific Award at the 2013 AATS Annual Meeting on Monday, 6th May 2013 at Minneapolis, MN. Considered the highest recognition by the AATS, the Award serves to honor individuals who have achieved scientific contributions in the field of thoracic surgery. Dr. Blackstone is being honored for his pioneering work in the cardiothoracic surgery field both clinically and in mathematical research and analysis. Dr. Blackstone is the 10th recipient of this prestigious award that was established in 1994.

**Dr. Christo Tchervenkov sponsors a research student visit to abstract LVOTO Data**

The LVOTO cohort is now the largest cohort actively enrolling new patients with over 700 registered patients and has the largest volume of data to be abstracted. David Drullinsky, a research student with Dr. Christo Tchervenkov, recently visited the Data Center to assist with data abstraction on three separate occasions. He abstracted baseline echo and second stage surgical intervention data. Dr. Tchervenkov himself also spent two days at the Data Center for the LVOTO cohort in March 2013. We would like to take this opportunity to express our sincere gratitude to Dr. Tchervenkov and David Drullinsky.