**In the Spotlight: Dr. Eugene Blackstone, MD**

In 1985 Drs. John Kirklin and Eugene Blackstone proposed that the CHSS surgeons pool their experience in managing infants with rare congenital anomalies of the heart and this concept lead to the establishment of the CHSS Data Center.

Dr. Blackstone has continued to have a major, central role in operations, not only of statistical analysis, but of study conceptualization, design, and eventual abstract and manuscript production. He has continually enhanced the quality of CHSS investigations, introducing cutting edge analytic tools, and applied these to CHSS data sets. His contribution to the overall quality and impact of CHSS multi-institutional outcome studies is enormous, as is his contribution to the training of many member surgeons as clinical investigators.

Currently, Dr. Blackstone resides in Cleveland and is full-time head of Clinical Investigations at the Sydell and Arnold Miller Family Heart & Vascular Institute at Cleveland Clinic, and staff member of the Department of Thoracic and Cardiovascular Surgery, Quantitative Health Sciences and Transplant Center.

**Background**
- University of Chicago (BS 1962, MD 1966)
- University of Alabama (Internship 1968-69)
- Army Research & Development Command (1969-72)
- University of Alabama at Birmingham (1972-97)
- Cleveland Clinic, Ohio (1997- Present)

**Interests**
- Research in cardiothoracic surgery
- Mathematical models of time-related events
- Modeling of dynamic systems
- Digital signal processing
- Use of clinical information
- Computerized patient records

**Work in Progress: Interrupted Aortic Arch**

At the Spring 2010 Work Weekend, the surgeons visiting the CHSS Data Center had an opportunity to participate in an impressive analysis that is just coming to a conclusion.

Our current Kirklin/Ashburn fellow, Dr. Anusha Jegatheeswaran, has been completing an analysis on the interrupted aortic arch cohort, with a focus on repeated events and mortality. Numerous CHSS member surgeons have visited the Data Center and participated in the Work Weekends and the analysis. Dr. Jega has been supported by Dr Bill DeCampli on this project and mentored by Drs Eugene Blackstone and Brian McCrindle.

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**Announcing the 6th Kirklin/Ashburn Fellow**

Dr. Jeff Poynter will be the 6th John W. Kirklin/David A. Ashburn Fellow of the CHSS Data Center. Jeff completed his B.S. in Cell and Molecular Biology at the University of Michigan in 2005. He went on to complete his medical education at the University of Michigan, graduating in 2007.

Currently a 3rd year General Surgery resident at Indiana University, Jeff has obtained NIH support for myocardial ischemia research in the laboratory of Dr. Daniel Meldrum. Jeff has been sponsored for this position by Drs Henry Walters, John Brown and Richard Ohye.

Jeff has been pursuing a career in congenital heart surgery since his first exposure in high school. Since that time, he has contributed to multiple publications and presentations. Jeff will earn a Master’s of Science in Clinical Epidemiology during his Fellowship. His wife, Liz and their two dogs will accompany him to Toronto. After completing his training, Jeff intends to remain committed to research throughout his career in congenital heart surgery.

**News You Can Use: Data Sharing Agreements**

Data Sharing Agreements (aka Data Transfer Agreement or Data Use Agreement) are legal contracts for sharing research information between two participating institutions in multi-institutional research studies. Learn what they are, why we need them and what we are doing for you on the next page...
Data Sharing Agreements (...Continue from Page 1)

With the passage of HITECH Act, 2009, the Data Sharing Agreements have become a legal requirement in order to participate in multicenter studies. We are aware that this can significantly increase the workload on part of the member center, and seriously hamper data collection carried out by your Data Center.

The following graphic illustrates the case of AAOCA study. Out of 39 centers interested in participating in our newest study, only 9 centers have been able to fully complete all the documentation including their IRB and DSAs.

![Status of DSAs for AAOCA](image)

Interrupted Aortic Arch (...Continue from Page 1)

As a follow up to the work weekend (March 26-28, 2010), Dr. Jegatheeswaran has been working hard to refine the statistical analysis in preparation for our presentation at the AATS and for submission of the manuscript to JTCVS. In addition we have had several conference calls (one of which was 3.5 hours long!) to discuss the interpretation of results and polish the manuscript. The complexity of this analysis is secondary to the statistical technique used, modulated renewal, which has never been used before in pediatric cardiac surgery. Essentially what we sought to determine was whether a subsequent repair of the aortic arch or left ventricular outflow tract left a patient the ‘same as new’, ‘better than new’ or ‘worse than new’.

Our main conclusions center on our findings that IAA is a chronic disease whereby patients often undergo multiple subsequent procedures with persistent risk. These risks are related to the nature and timing of prior procedures, as well as factors related to morphology and the details of the index procedure.

If you would like to hear more about this ground breaking analysis make sure you come to our AATS presentation on Monday, 3rd May.

Study Update: Critical Left Ventricular Outflow Tract Obstruction (LVOTO)

The LVOTO cohort is currently in its fifth year of enrollment. We have been able to enroll 465 patients by now from 16 institutions. Our aim is to enroll at least 500 patients by fall 2010 and perform interim analysis of this cohort. The LVOTO study has enrolled patients faster than any other enrolling CHSS studies in last decade.

This cohort differs substantially from the recent SVR trial. This cohort includes patients who were treated with transplantation, hybrid procedures as well as the patients who were not surgical candidates.

These wider entry criteria will help us to compare these different palliative strategies.

To participate in the study, simply designate a research coordinator and send us an email at chss.dc@sickkids.ca!

Check out our website: www.chssdc.org

Your CHSS Data Center has recently launched an updated website. Check out the website, your YouTube videos and invite your patients to visit it too!

LVOTO Enrollment in last 6 years

![LVOTO Enrollment in last 6 years](image)