In the Spotlight: Dr. Peter Gruber

Dr. Peter Gruber is the Chief of the Division of Pediatric Cardiothoracic Surgery at Primary Children’s Medical Center, Salt Lake City, Utah. Dr. Gruber attended Medical School at the University of Pennsylvania, followed by training in General and Thoracic Surgery at Johns Hopkins and associated hospitals. He performed a pediatric cardiothoracic fellowship at The Children’s Hospital of Philadelphia, with a visiting 6-month fellowship at Hôpital Necker-Enfants Malades in Paris, France. Dr. Gruber also spent 2 additional years during residency as a cardiac development research fellow at the American Heart Association Bugher Foundation for Molecular Biology in San Diego.

Dr. Gruber also spent 2 additional years during residency as a cardiac development research fellow at the American Heart Association Bugher Foundation for Molecular Biology in San Diego. Dr. Gruber is an internationally recognized expert in cardiac development and more specifically in the genetic abnormalities associated with congenital heart disease.

Dr. Gruber recently became a member of the Congenital Heart Surgeons’ Society. He attended the recently concluded Work Weekend at the CHSS Data Center and presented the concept of collecting genomic data by using Biobanks. Biobank programs may contain various materials such as DNA, RNA, protein, tissue, serum, and processed data from the previous or other materials.

In an effort to foster broad, collaborative opportunities, the CHSS is considering creating a Biobank registry, essentially a “registry of registries.” Initially, member groups would submit non-PHI data to track biological samples obtained from each member institution in a diagnosis-specific fashion. The idea is for each member institution to maintain their own physical samples, data, and confidentiality. However, individual Biobanks would provide a list of de-identified samples by diagnosis to the CHSS to maintain a registry of ALL samples in ALL CHSS member institutions. The de-identified information would be available to member sites. In addition, links would be provided such that an investigator could easily identify others with samples of interest thus fostering a new collaborative opportunity.

We have recently sent out surveys to establish the membership’s access to biobanks. We hope you have received it in mail. If you have not had a chance to complete the surveys, you can take a minute to complete it online by clicking here.

AAOCA Cohort: Interim review of data

Dr. Jeff Poynter, the current Kirklin-Ashburn Fellow at the CHSS Data Center lead an interim review of the Anomalous Aortic Origin of a Coronary Artery (AAOCA) cohort. The AAOCA cohort, which began enrollment in 2009, has enrolled over 200 patients by now at the Data Center from member 23 institutions. This cohort is already the largest ever prospective cohort study for this rare congenital anomaly and is rapidly growing and has the potential of shaping the future course of the AAOCA management. Using the data calculations performed by Dr. Poynter, this cohort has enough statistical power already to detect a 10% mortality difference in the follow-up within the patients with anomalous right coronary artery (ARCA). Because of the overall lower prevalence of the Left coronary anomalies, we still need to enroll more patients to confidently report negative findings.

The results of the interim analysis were discussed with many CHSS members at the recently concluded Work Weekend. This followed a wider call for participation as well as a conference call and further refined abstract was submitted to this year’s American Heart Association meeting.

We continue to invite future participation from the entire membership. If you have not yet been able to participate in this prospective observational cohort but would like to contribute your patients’ data, please contact us at chss.dc@sickkids.ca at any time.

The Kirklin-Ashburn Fellowship Applications

Your CHSS Data Center is inviting applications for the next John W. Kirklin – David Ashburn Fellowship. The focus of the fellowship is outcomes research, primarily of the many multi-institutional prospective cohort studies of the Congenital Heart Surgeons’ Society. The Fellow will become expert in database management and in all aspects of biostatistics and epidemiology. Particular emphasis is placed on the research methods, presentation at national meetings, and manuscript preparation and publication. Previous fellows have made important contributions to the field, including high profile international presentations and publication on behalf of the CHSS.

The next Fellowship will begin in July of 2013. The selection process will include the requirement for completed applications and letters of recommendation to have been received by September 1, 2012. To see the full announcement, including application information, please visit the Data Center website by clicking here.
Work in Progress: REDCap application for Technical Performance Score Data Collection

Your CHSS Data Center has access to the Research Electronic Data Capture (REDCap) software through The Hospital for Sick Children Research IT. The REDCap is a secure web application for building and managing online surveys and databases. According to the REDCap website, this software is currently in production use or development build-status for more than 38500 projects and has almost 52000 users.

The data collection tool we are creating will be online and accessible to all participating member institutions. Your Data Center team is internally pilot testing the Technical Performance Score (TPS) project forms, created during the Work Weekend now. Once the internal pilot is completed, the form will be rolled out to member institutions.

AAOCA Working Group Meeting

The next AAOCA working group meeting is just around the corner.

Location: The Children’s Hospital of Philadelphia
Date: June 28th, 2012
Time: 9:30 AM - 3:30 PM

The working group, instrumental since the study initiation in 2009 also welcomes participation from other members who have enrolled patients in the cohort. For those who cannot make it to Philadelphia, but would like to participate remotely, please let us know by writing at chss.dc@sickkids.ca and we will forward webinar details to you.

Research Coordinators’ Meeting at CHSS Data Center

Your CHSS Data Center would like to thank member institutions, surgeons and research coordinators for a very successful Research Coordinators’ Meeting recently held at Toronto. It was a fantastic day and a half of learning and sharing on the importance of the CHSS studies. Linda Lambert gave a wonderful talk on the history of the CHSS, providing many of us with a new perspective on why it was started and how it differ from other research studies. Dr Williams gave a pathology lesson on AVSD, an important and timely lesson, as we launch our new study on this cohort.

To the Coordinators who visited Toronto and participated via webinar/teleconference:

Your Data Center team really enjoyed meeting everyone and we all learned a great deal from each one of you. Your hard work, dedication and eagerness to learn about the CHSS studies were very evident during this visit. We at the data center really appreciated this effort.

To all the Member surgeons:
A BIG thank you for supporting your coordinators to attend this meeting. We appreciate your financial support and allowing them to travel here for face to face meetings.

We will strive to encourage better engagement from all member institutions and their research team members. We all share the same goal to improve care for our patients with combined experience building. A meeting like this provides the much sought after venue to share these experiences and takes our research collaboration up a notch. We are looking forward to any comments you have on how the day and a half went as well as any suggestions for future meeting for the coordinators.