In the Spotlight: Jennifer Marshall

Are you interested in participating in the CHSS studies but do not know where to start? Do the legal and ethical (ERB or IRB) requirements discourage you from getting your patients to join the CHSS studies? Help is here in the form of experienced and enthusiastic support from Jennifer Marshall, RN, RRT, CCRC from Children’s Mercy Hospitals and Clinics in Kansas City, MO.

Jenny is the Manager of Cardiovascular Surgery Clinical Research and Development at Children’s Mercy Hospitals and Clinics. Jenny works with Dr. Gary Lofland and her services to the CHSS community are fully funded by Children’s Mercy. Her role with CHSS includes assisting member sites with initiation of CHSS studies such as facilitating the legal paperwork between the site and Toronto, as well as aiding in the IRB process for the site. Jenny is also able to assist with data collection at sites if needed once patients have been enrolled in studies. Due to her involvement with many centers across the US, she is able to share what has worked best for other sites in terms of process implementation, as well as legal and ethics documentation.

She is more than willing to assist sites over email communication, through phone consults, or by direct site visits. She has made numerous site visits throughout the US and helped establish the CHSS studies at many member institutions. Part of Jenny’s role at Children’s Mercy is to enroll local patients in CHSS studies and to subsequently follow them on an annual basis. She has made numerous presentations and publications on regulatory and ethical aspects of clinical research at Children’s Mercy and other venues.

On a personal note, Jenny became Mrs. Marshall last July, and many of you may remember her by her former name of Jenny Swihart. She and her husband Tim live in Lenexa, Kansas (a suburb of Kansas City). She is currently working on her Master’s in Public Health and hopes to finish in December 2011. She enjoys the study of all areas of healthcare and truly likes to help people. In 2007, she participated in a medical mission trip to Sudan, East Africa where she saw the desperate need for improved healthcare in other parts of the world. Jenny has kindly offered her services to all CHSS member sites to assist them with participation in CHSS research studies. Contact Jennifer Marshall at jamarshall@cmh.edu to learn more about how you can benefit from an incredible resource at your service.

Concluded Work: Interrupted Aortic Arch

Our analysis focusing on repeated events and mortality within the Interrupted Aortic Arch culminated in an oral presentation on May 3rd, 2010 at the 90th annual meeting of the American Association of Thoracic Surgery, held in Toronto.

This presentation, given by our current Kirklin/Ashburn fellow, Dr. Anusha Jegatheeswaran was extremely well received and highlighted the main conclusions from our complex analysis.

The main purpose of this study was to investigate patterns and factors associated with both subsequent procedures and mortality using the statistical techniques of modulated renewal (a type of repeated events analysis) and competing risks.

New Initiative: Monthly Conference Calls for Research Coordinators

Many researchers working with the CHSS Data Center have had questions about our research studies, ethical or legal issues or patient screening and enrollment. Some of you asked those questions, some did not. At the Data Center, we always strive to make participation in a CHSS study easy for a member center. We recognize the need to be more proactive and seek out any unsolved questions and provide answers. Dialogue will become even more efficient when your peers ask the same question that you had in your mind.

In order to achieve these goals, we have initiated a series of monthly conference calls from this summer. We aim to update you about the activities at the CHSS Data Center and invite your questions and comments through this call. We encourage research managers, nurses and coordinators to attend our monthly Conference Calls. Our first Conference Call on 23rd June was highly successful in attracting important questions. The next call is scheduled on July 28, 2010 at 2:00 PM Eastern Time. Contact us at chss.dc@sickkids.ca to participate and benefit from this initiative.
Work in Progress: AAOCA Study Update

The Anomalous Aortic Origin of a Coronary Artery with Interarterial, Intraconal or Intramural Course (AAOCA) is our latest CHSS study. Many CHSS centers have already joined and many more are in the process of being a part of the AAOCA. Your CHSS Data Center is ready to enroll your patients in this latest endeavor that already has 19 institutions and approaching 100 patients.

The CHSS AAOCA Cohort will likely be the largest cohort of this rare anomaly ever assembled. We hope it will provide a clear direction in the quest to discover the best treatment protocol for individual patients who may have any one pattern among the wide variety of AAOCA. Your participation will help chart future course of clinical care of your patients.

Please contact Maulik Baxi, the CHSS Data Center Research Program Manager, at maulik.baxi@sickkids.ca to enroll your patients in the study.

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

We sought to determine the time dependent risk for subsequent procedures (1st, 2nd, 3rd, etc.), the inter-relationships and factors associated with subsequent procedures and the inter-relationships of subsequent procedures and factors associated with mortality.

We found that our 447 patients, from 33 CHSS member institutions, underwent 436 subsequent procedures. This included 158 arch, 100 left ventricular outflow tract, and 192 “other” procedures. Our principle findings from this study were that following IAA repair:

1. Subsequent procedures are common
2. The risk of subsequent arch procedures DECREASED with each further procedure, while the risk of subsequent LVOT procedures INCREASED with each further procedure
3. Factors associated with subsequent arch procedures WERE related to the type and timing of previous subsequent procedures, but this was not the case for subsequent LVOT procedures
4. Mortality was adversely impacted by the type and timing of subsequent procedures

Coming down to the wire with such a large study “challenged our mettle”, said William DeCampli, senior author, “but I recalled an old Norman Shumway quip, 'Nothing's so bad that it couldn't be worse', and we got the work done with great teamwork and lots of midnight oil.”

Work Weekend Topic: Pulmonary Conduit

One focus during our next work weekend will be on the pulmonary conduit cohort. We are currently in the process of completing data entry of the patients who have been enrolled, and are getting ready to close the data set and prepare to clean and analyze the data.

For those of you who have been present at recent work weekends, we have presented some preliminary summaries of the data, and will be preparing a formal analysis plan shortly.

Fall Work Weekend is here: Nov 19-21, 2010

We invite you to attend our Fall 2010 Work Weekend at the CHSS Data Center, Toronto from November 19 to 21 this year.

We are planning to cover a number of different cohorts in the discussion including:

- Pulmonary Conduit
- PAIVS exercise test cohort
- Left Ventricular Outflow Tract Obstruction
- Tricuspid Atresia
- Anomalous Aortic Origin of a Coronary Artery study update