Congenital Heart Surgeons' Society Data Center
Our Research Saves Lives™
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CHSS President's Message

Dr Erle Austin
President, CHSS

I am privileged to add a message to the recently introduced newsletter of the CHSS Data Center. Indeed, the Data Center is an integral and vital part of our society having been conceived and implemented by John Kirklin and Gene Blackstone in the mid 1980s when the CHSS was more of a club than a professional medical organization. The CHSS now claims over 100 active members associated with over 65 institutions. Still small by comparison to other societies, the CHSS is unique by virtue of the CHSS Datacenter. Now ably directed by Bill Williams and Chris Caldarone at The Hospital for Sick Children in Toronto, the Data Center is responsible for keeping track of the patients entered into our study cohorts.

Since its inception the Data Center has enrolled over 5600 patients and is currently following almost 4000 patients annually. This continued follow-up permits assessment of more than operative mortality. Thanks to the work of the Data Center we are learning from large multicenter-derived cohorts that surviving an operation does not necessarily mean living happily ever after. The follow-up of our interrupted aortic arch cohort, for instance, has allowed us to determine that this condition is a chronic one with multiple interventions required after the initial repair. We are now using this cohort and our oldest cohort, the Transposition group, to learn about how the survivors are transitioning into adulthood in terms of both health and psychosocial development. Nine other diagnostic groups are also being followed. Tracking and keeping up with all of these patients requires an immense amount of hard work by our Data Center staff.

On behalf of the members of the CHSS, I would like to express our sincere appreciation to each staff member. This includes Maulik Baxi, Sally Cai, Carol Chan, Amandeep Malhie, Susan McIntyre, and Olga Levesque. This cordial and dedicated team is primarily responsible for the significant productivity of the Data Center. With their continued efforts, the leadership of Drs. Williams, Caldarone, Blackstone, and Marshall Jacobs, and the significant involvement of many of our active members, we can be confident that the CHSS and its Data Center will continue to positively impact the care we provide our patients.

Work in Progress: Functional Health Status and Transition to Adult Care

As mortality related to congenital heart disease declines, the focus of clinical care has shifted to morbidity and quality of life. Health status has multiple domains, related to both physical functioning and psychosocial aspects. It can be affected by numerous factors including medical history, current medical morbidity, perceptions, reactions and adaptations to health-related problems, available health resources, and opportunity to deal with those problems, as well as the patient's psychosocial milieu and support systems.

Patients who have undergone Interrupted Aortic Arch (IAA) repair are often subject to numerous subsequent procedures as we have learned from our most recent CHSS analysis. As such children post IAA repair are subjected to complex and prolonged medical care, and often including frequent re-interventions. Therefore investigation of functional health status (FHS) is an important outcome parameter. There have been no previous studies of FHS in patients post IAA repair. Similar to the project involving the IAA cohort, we have collected two questionnaires from our TGA patients. Although there have been some studies of Functional Health Status in this population, including our previous paper, this will be the first study to assess FHS for a second time in such an old cohort.

We have proposed some questions for CHSS member surgeons in our annual report. We invite your participation in the work weekend where we will analyze the dataset to find the answers.

Revised CHSS Data Work Weekend Dates: January 14-16, 2011

Due to an unexpected problem, we are forced to postpone the work weekend and would like to reschedule it for the weekend of January 14th-16th 2011. We realize that your time is valuable and it is hard to set aside free time to travel to Toronto and, therefore, wish to assure you that we do not take this issue lightly. We hope you will understand the unusual circumstances associated with this postponement and will look forward to hosting the work weekend in January.

Members Say for Unbalanced AVSD paper

Fantastic Anusha, Dave, Meryl and all. It is important to recognize and acknowledge that this represented an intense cardiologic-surgical collaboration. *-Dr. Eugene Blackstone, Cleveland Clinic*

Excellent study. We are already using the data from this study clinically. *-Dr. Suvro Sett, New York Medical College*

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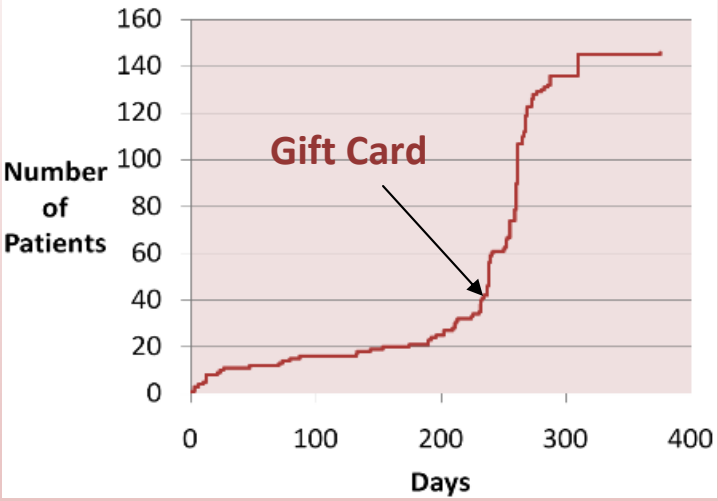
Behind the scene: Patient Follow-up

Interacting with patients at regular intervals is essential component of any prospective cohort study. Most of CHSS Studies are of this type, and hence keeping in touch with your patients is of paramount importance for our success. We get equally warm response from the patients who happily provide us with their health information. As these patients become older and move away from their homes for higher education, it can become difficult to stay in touch with some of them. In the last newsletter we had mentioned our experiment with one such cohort of Interrupted Aortic Arch (IAA) patients. Any patient who completed this year's follow up and all the questionnaires with them were to receive a $ 20 gift card.



Effect of monetary incentive on follow-up completion

We analyzed the result of response rate before and after the experiment to find a startling difference. It has been shown that a monetary incentive helps in improving the response rate. Although at this point we do not have any plans to replicate the results for any other cohort, it appears that the incentive has helped us in achieving a higher follow up completion rate.

For CHSS Surgeons: Data Center Report

All CHSS members who attended the Annual Meeting in Chicago have received the CHSS Data Center Annual Report. The report highlights the quantum of work done at the Data Center as well as the studies being analyzed currently. The Data Center has sent the annual report to all the members who could not attend the meeting by email as a PDF copy. If you do not receive your PDF copy, please contact us at chss.dc@sickkids.ca.

Members Say… *(Continued from page 1)*

Congratulations to you, Anusha, and to Dave and the other authors on what should become a landmark article. This kind of work makes me proud to be a CHSS member.

-Dr. Erle Austin, Kosair Children's Hospital

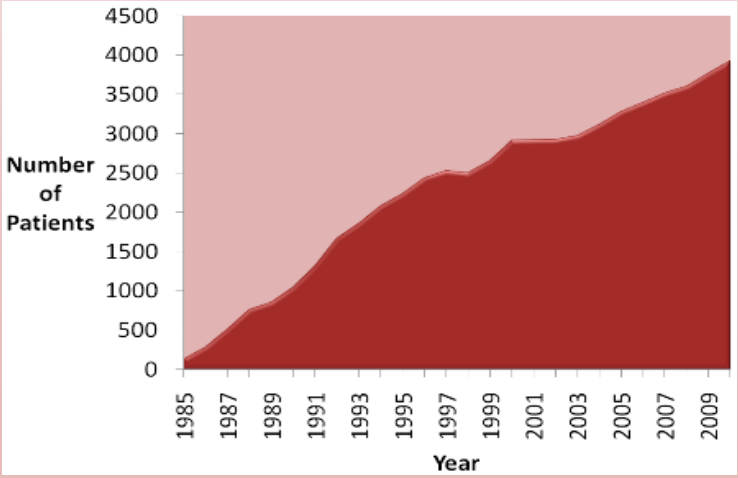
How to track difficult to find patients?

In a recent email communication with the Data Center, Dr Henry Walters and his research team provided some insight into the method they employ for locating patients who are difficult to track. These are the steps in their strategy:

1. Call all contact numbers in office chart
2. Call all contact numbers in electronic chart of the hospital
3. Look up the patients in an internet phone book
4. Look for valid contact information from outside referring cardiologist office if the patient is not followed at the hospital
5. Try to call between 7-8 AM and between 5-6 PM

We are sure every surgeon and researcher goes through this difficulty at some point, and everyone attempts to solve it their way. It also forms the very core of research tasks for the Data Center for which we have a well designed process chart for patient follow up. We believe that by sharing practical examples like these, we help one another obtain higher quality data. Improved data quality translates into better study results and helps every surgeon make better treatment decisions about their patients.

Do you have your own examples of your follow-up process to share? Write to us at chss.dc@sickkids.ca to share your experience!



Growth in the Number of Patients followed every year by the CHSS Data Center since the inception of Cohorts

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