Launch of Unbalanced Atrioventricular Septal Defect Inception Cohort

We had announced the launch of Unbalanced Atrioventricular Septal Defect (AVSD) Inception Cohort in our April 2011 newsletter. We are glad to share with you more details and extend our invitation to participate in the cohort.

Our prime objective is to improve survival among patients with AVSD by further characterizing that portion of the disease spectrum customarily referred to as unbalanced atrioventricular septal defect (uAVSD) and evaluating the relationships between patient and procedural factors and outcomes.

Proper selection of treatment strategies for uAVSD is particularly difficult. Consensus regarding a standard definition of “unbalance” is lacking, and there are few evidence based guidelines for selection of treatment strategies. The overall high degree of mortality observed in patients with uAVSD is likely to reflect suboptimal choices of treatment strategy. Thus, overall survival might be better if the relationships between morphologic and physiologic aspects of the disease and the outcomes of various surgical treatment strategies were more fully understood. Treatment choices are relatively clear at the extreme ends of the anatomic spectrum of disease. When the AVSD is severely unbalanced, the smaller ventricle is incapable of supporting adequate cardiac output and functionally univentricular repair is required. In contrast, a biventricular repair strategy is uniformly appropriate for balanced AVSD. Between these extremes, the choice of repair strategy is confounded by gaps in present knowledge of the relationship between patient factors, anatomy, repair strategy, and outcome. (Continued on page 2)
Data Center welcomes new staff!
Your CHSS Data Center welcomes two new colleagues who have joined us since early July!

Annette Flynn joined the CHSS Data Center in July 2011 as Clinical Research Project Assistant. Annette is a 20-plus year veteran of The Hospital for Sick Children, Toronto. Her interest in congenital heart disease began in the early nineties when she transferred positions to the outpatient cardiac care clinic. Annette has four children and eight grandchildren.

Veena Sivarajan joined the CHSS Data Center in July 2011 as Clinical Research Nurse Coordinator. Veena completed her Bachelor of Science in Nursing at McMaster University in 2001. Prior to starting at the Data Center, Veena worked in the Cardiac Critical Care Unit at The Hospital for Sick Children, Toronto, for the last 5 years and previously worked on the Cardiology inpatient unit as well as the Respiratory Medicine unit. Veena recently had the opportunity to present her abstract at the Cardiology Conference in Arizona.

Launching uAVSD (continued from page 1)

Participation in this cohort is voluntary for member institutions and surgeons. In an effort to encourage consistent enrollment of study patients by member institutions, foster active surgeon involvement, and ensure imaging studies of sufficient quality for analysis, each participating center will expected to support the following initiatives:

Echocardiography Training: Echocardiograms must be of sufficient quality and completeness that all study measurements may be performed by the echo core lab personnel. To ensure this quality and completeness, each participating center will send at least one lead sonographer and one echocardiographer (M.D.) to a one day educational seminar hosted by the echo core lab team. The number and location of these seminars is to be determined, but will most likely be held at the Data Center or in conjunction with national pediatric cardiology meetings. These seminars will be recurring to facilitate accrual of additional participating sites, and their cost to the participating site covered under the study budget.

Member Participation: It is expected that a surgeon representative of the participating center will attend a minimum of one project related working session, either at a CHSS Data Center “work weekend” or at a national meeting where work on the study is being conducted.

Please contact us any time by email at chss.dc@sickkids.ca to learn more about the study.

Thank you for your participation!

Below is a graph showing number of institutions actively enrolling new patients in different cohort studies. We are greatly encouraged by your sustained and ever-increasing contributions and hope this would inspire more participation. Please let us know how we can assist you better by writing to us at chss.dc@sickkids.ca. We look forward to hear from you.

We will create a group of children with complete AVSD at participating CHSS member institutions. The CHSS Data Center, located at The Hospital for Sick Children in Toronto, will collect and interpret clinical information received from participating institutions.

We will also contact these patients once a year to learn more about their health. We will study details like the type of operation, early and late survival as well as how their heart, lungs and the body fight with the illness over a period of time.

uAVSD: Background for patients and families

Atrioventricular Septal Defect is a type of disease where the valves that separate the upper and lower chambers of the heart and the tissue surrounding these valves are not developed properly. When the flow between these chambers is unequal due to difference in type and shape of this defect, it is called “Unbalanced Atrioventricular Septal Defect” (uAVSD). Gaps in present knowledge of the relationship between patient factors, structure of the heart, type of operations, and results makes selecting one versus another type of operation difficult.

We will create a group of children with complete AVSD at participating CHSS member institutions. The CHSS Data Center, located at The Hospital for Sick Children in Toronto, will collect and interpret clinical information received from participating institutions.

We will also contact these patients once a year to learn more about their health. We will study details like the type of operation, early and late survival as well as how their heart, lungs and the body fight with the illness over a period of time.