



### In the Spotlight: Dr John Hawkins



Dr Hawkins receiving the Dugan Award from the Western Thoracic Surgical Association

Dr John Hawkins is Professor of Surgery at University of Utah and a senior CHSS Member. Dr Hawkins and his team at Primary Children's Medical Center, Salt Lake City, have been one of the leading contributors to our research studies. The other members of his research team include Drs Aditya Kaza and Phil Burch as well as Linda Lambert, MSN-cFNP. Over the last 5 years, Dr Hawkins and his team have contributed almost 20% of the total CHSS studies enrollment!

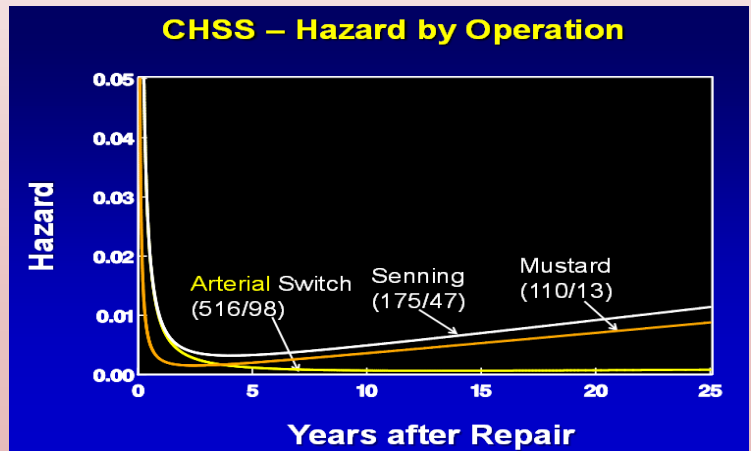
Dr Hawkins has not only been a major patient contributor but also has been instrumental in initiation and success of the Pulmonary Conduit study, including funding this CHSS cohort. He recently received the David J. Dugan award from the Western Thoracic Surgical Association, presented to members of the Association in recognition of distinguished achievement and outstanding contributions to the field of thoracic surgery in the areas of science or leadership over a sustained period of time.

Along with contributing to the CHSS Data Center studies, Dr Hawkins is also involved with development and expansion of cardiovascular surgery database at Primary Children's Hospital, Utah. Dr Hawkins' personal interests include playing and making electronic Guitars as well as traveling. Dr Hawkins presents a wonderful example of dedication and commitment to patients and research for all CHSS member surgeons.

### Work in Progress: CHSS TGA Cohort

In the early 1980' the established management of an atrial repair technique (Senning or Mustard) for babies with complete transposition (TGA) was confounded by Jatene's successful report of the arterial switch operation. Drs. John Kirklin and Eugene Blackstone saw opportunity in the dilemma and challenged the CHSS membership to pool their individual experience into a common database.

Within 4 ½ years (1985-1989), 895 newborns with TGA admitted to any of the CHSS institutions and < age 2 weeks enrolled and had a repair by either an atrial (n=285) or the newer arterial switch (n=516). Survivors have been followed annually by your Data Center. The survivors are now all adults > age 18 years. The cohort have been the subject of 9 CHSS publications that are available though our website (<http://www.chssdc.org/content/publications>).



Of concern now is the increasing late risk to the atrial repair patients, as illustrated in the Hazard Analysis for 2010 follow-

### University of Nebraska achieves 100% completion of the PAIVS Exercise Test Study!

University of Nebraska Medical Center (UNMC) has become the first CHSS center to achieve 100% completion rate for its patients enrolled in the Exercise Test study in the PAIVS cohort.

This study involves a graduated exercise test protocol and questionnaires. The study is currently in the stage of completing follow up and data collection.

Congratulations to Dr Kim Duncan and Christy Woell, Pediatric Clinical Nurse Specialist at UNMC!



### CHSS Data Center IAA Manuscript Accepted!

Your Data Center is proud to announce that the manuscript on the Interrupted Aortic Arch was accepted by the Journal of Thoracic and Cardiovascular Surgery **without any revisions!**

Dr Anusha Jegatheeswaran, the current Kirklin Ashburn Fellow, is primary author of this manuscript and Dr Bill DeCampli is the senior author. Other authors included Drs Brian McCrindle, Eugene Blackstone, Marshall Jacobs, Gary Lofland, Earl Austin, Tom Yeh, Victor Morell, Jeff Jacobs, Richard Jonas, Marco Ricci, Bill Williams as well as Jeevanantham Rajeswaran, MSc and Sally Cai, MSc.





## Behind the scene: Interrupted Aortic Arch

The Interrupted Aortic Arch (IAA) study is just finishing its annual follow up. This year we had administered functional health assessment as well as a questionnaire to assess the transition of care and a questionnaire to assess the prevalence of DiGeorge syndrome. The follow-up was a team effort spearheaded by our new research assistants, Carol Chan and Amandeep Malhie. We encountered significant challenges in completing this follow up. Some of the difficulties included reluctance on part of the patients and parents to complete the questionnaire which they felt were very long.

In order to address these difficulties the CHSS Data Center included an incentive of \$ 20 gift card to assess if this benefit would improve the response rate. As the monetary incentive in form of a gift card was an area of patient follow-up that the CHSS Data Center has not attempted before, we are currently tracking its response rates. This was a shift from our traditional approach and we do not have any plan to offer similar incentive for any other study.

We are writing about this behind the scene endeavor to highlight the evolution of a CHSS Cohort. It is an effort to express that we value our patient relationship. It also stresses the need to stay in touch with our patients & sustained input by member centers in all the CHSS research studies.



## Please RSVP for Fall Work Weekend 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. Many of our cohorts have successfully completed the follow up for this year and are ready for the data analysis.



We hope you will attend the work weekend. Please let us know of your plans by writing to [chss.dc@sickkids.ca](mailto:chss.dc@sickkids.ca). We recommend Hotel Delta Chelsea (Reservations 416.595.1975) for your stay, which is conveniently located across the street from The Hospital for Sick Children. We look forward to see you in Toronto!

## Work in Progress: TGA (...Continue from Page 1)

Survival 25 years after repair is excellent with little difference among the repair techniques (Senning 70%, Mustard 84% and Arterial 81%). But this was an era when the arterial switch operation had 17% in-hospital mortality. Kirklin et al, in their 1992 paper identified risk factors for the arterial switch cohort that predicted early survival could be 97% to age 5 years. It became clear that the arterial switch operation was the procedure of choice.

The late hazard (instantaneous risk of death) is a very low constant rate for the arterial switch group but shows an alarming increase for the atrial repair patients. These folks need increased surveillance.

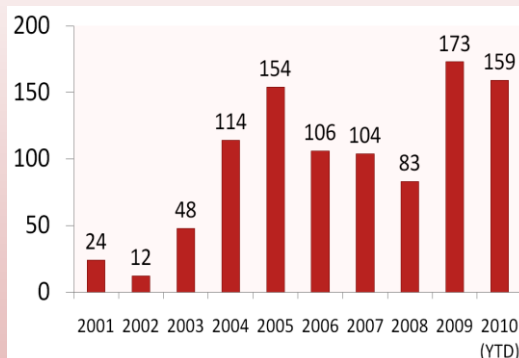
The 2010 follow-up also included an assessment of the CHSS patient's transition to adult care and a functional assessment questionnaire (SF-36). The latter may be compared to the functional assessment we performed 10 years earlier.

TGA will be a focus of the November 19 Data Center Work Weekend. We are still trying to improve the 2010 follow-up and appreciate any help the institutions can provide in contacting your patients.

## Be a part of your CHSS Data Center's Progress!

Your CHSS Data Center has been relentless in recruiting patients to help you generate new knowledge and test the validity of current practices. A major component of this process is increasing and sustaining new patient enrollment from all the CHSS member centers. This graph shows total number of patients enrolled in the first nine months over last decade.

This is just an illustration that explains the work behind published results. We hope that your support will sustain the future growth. To join these studies, simply send an email at [chss.dc@sickkids.ca](mailto:chss.dc@sickkids.ca)!



Number of patients enrolled in the First Nine Months in a year over last decade