

## **CHSS Work Weekend Report**

**April 7-9, 2017**

“Unabridged” Notes from the sessions

### **Opening Talk**

**“Statistics 101”**

**Bill DeCampli**

“Man is not good at reasoning with uncertainty.” Using cardiac surgical publications as examples, Bill spoke on the facts and fallacies we encounter when trying to reason with uncertainty, bringing into the discussion very simple probability and statistical concepts such as truth inflation, the base rate fallacy, “prisoner’s dilemma”, and Simpson’s paradox.

**AVSD: Baseline Echo Descriptive Analysis: Results**

**Jim Meza**

See slide deck at: <https://chssdatacenter.app.box.com/s/imx70wp7pf24c4xmkn6pju1ffo04ad5>

Please contact [chss.dc@sickkids.ca](mailto:chss.dc@sickkids.ca) for the password. The link will be active until May 31, 2017.

Conclusions:   1. Lots of data with very little correlation of the usual measures of unbalance.  
                  2. May benefit form more sophisticated analysis, such as cluster analysis

### **Invited Talk**

**Clinical Research in the Era of Big Data**

**Mjaye Mazawi, MD, Sickkids**

See slide deck at: <https://chssdatacenter.app.box.com/s/imx70wp7pf24c4xmkn6pju1ffo04ad5>

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**Neonatal Coarctation Repair: Long-term Follow-up.**  
**Nancy Poirier**

Background: 975 neonates enrolled from 27 institutions between 1986-90  
Neonates with complex CHD (the subject of the subsequent LVOTO cohort) were eliminated, leaving approximately 500 neonates to follow.

Potential Research Questions

1. Are 1994 published CHSS results for survival verifiable now?
2. What care are these patients receiving now as young adults?
3. Could we identify risk factors now that would affect their current care as adults?
4. What is the (? Time-related) incidence of HTN, what associated morbidity has occurred?

Decision is to attempt question 2 by a patient-based questionnaire

- Challenges are to re-initiate follow-up after a 20+-year hiatus (options: social media, advocacy group appeal, IRB/REB submission, etc.)
- Needs a draft questionnaire constructed including further surgery, further cath intervention, current medical practitioner, medication (Y/N), high blood pressure (Y/N), functional health, employment, education level attained, etc.
- Peter Gruber suggested collecting saliva for a genetics arm of the study to develop a genetic profile to determine whether CoAo patients with hypertension have a similar or different genetic markers for hypertension that the know results for the general population.

Conclusion: Construct a plan for using social media and develop a questionnaire  
Develop cost estimate and funding plan

**Longitudinal Modeling – Dynamic Risk Profiles**  
**Jim Meza**

Using the timing of stage II data from the LVOTO cohort, Dr. Meza presented a 4-part seminar on the development of dynamic risk profile analysis, a technique that, while not entirely novel, is being applied increasingly to “big data” sets to provide predictive power to observations. The intent is to demonstrate the ever-changing risk stratification for patients post Norwood & prior to Stage II as events occur (or not) that may increase or decrease risk as time progresses.

Features of the analysis are that mixed effects models allow random input in time with each event considered as a separate but continuously changing risk of death. Additional extensive data were obtained for this analysis, such as all recorded intervening “events”, O2 saturations, etc....

(DC Issue: We need to incorporate Tina’s data (currently in Excel) into the DC Access db). This work is part of the “Stage II Timing” ongoing study but is open to additional working group membership.

Subsequently, the group worked on an abstract, “Maximizing Survival through 3-stage UVH Palliation: Developing a Risk Score for Inter-stage Mortality” to be submitted for the fall 2017 AHA Scientific Sessions.

**AVSD: Baseline Echo Analysis: Poster Presentation Discussion**  
**Jim Meza**

The AATS poster presentation was discussed and edits suggested.

**Featured Talk**

**Sausage Making: From Raw Information to Analyzable Data**  
**Eugene H. Blackstone**

Using vivid, if not graphic imagery from the sausage-making industry, Dr. Blackstone once again “blew the audience away” with an insightful perspective on the challenges of acquiring, transporting, and processing raw data so it is finally fit for analysis.

**Arch obstruction in LVOTO – Update and Next Steps**  
**Tara Karamlou (by webinar)**

The proposal was previously discussed at the prior Work Weekend and is in revision for submission to the Research Committee. Among the 534 patients, data about re-intervention has been reviewed in 128. The first priority is to review the remaining 406 charts for every echo report, cath report & OR note.

To do this the DC needs the data fields from the initial review and develop an Access (or Redcap) database to record standard data fields that can be merged with the DC legacy LVOTO Access files. This preliminary analysis, together with a financial support plan, will support evidence of feasibility for the study for RC resubmission.

Tara will canvas the membership & others to form a working group.

**AAOCA: Discussion of AAOCA Ischemia Study, Focus on Study Design**  
**Anusha Jegatheeswaran (& Julie Brothers by webinar)**

We have finally worked out that the ischemia group is currently 39 patients.

In the entire cohort to December 31, 2016 (& their data entered before Jan 1, 2017) there are 560 patients in the AAOCA cohort.

Among these Initial testing for ischemia (any one or more of 3 tests and baseline ECG) were done in 261 patients and were positive in 45, negative in 216. The 216 would be 'controls' for the 39 ischemia patients (Among the later 39, 23 tested positive, 2 negative and 14 not tested for ischemia)

Conclusions:

1. Study design: The clinical paper will focus on the 39 ischemia patients and compare them to the 216 who tested negative
2. A comparison of those tested vs. not tested was rejected as the study design
3. Anusha & Julie need to determine their analysis plan (statistical methods)
4. Anusha needs to tell us what data they need
5. The imagers need to review the additional echos for 10 patients not previously reviewed
6. The imagers need to review the CT/MRIs among the 39 ischemia patients.
7. The imagers need to decide whether to conduct a review of the 216 'controls'

**TGA Late Follow Up Proposal**  
**Ram Subramanyan** (by webinar)

Not all PIs of this proposal were not available for Work Weekend participation. The group had a general discussion of the nature of the cohort and the follow up challenges. The DC has consented 107 TGA patients to provide us with follow-up data. That leaves **329 TGA patients** who are not known to have died but for whom we have not attempted follow-up since the 2014 annual cross-sectional follow-up.

DC Issues:

1. We need to send out the follow-up forms to the 107 already consented (& to new consents as they are obtained)
2. Beth Stephenson, MD, REB Chair is in accord with our efforts, and Dr. Williams will arrange a further meeting with her to discuss regulatory issues.
3. Brenda & Arti to send out TGA follow-up forms to the 107 we have permission to contact. Any further contacts Arti makes should be followed by sending out the follow-up as she contacts them.
4. Inshan (Legal Counsel, SickKids) to ask for his input on a TGA letter that asks 2 things: 1) can we use their data for analyses? 2) Would they give us signed permission to retrieve their heart-related reports from medical sources? The RI follow-up templates that Inshan suggested do not appear to be applicable to our needs. We need to pursue this plan with Beth to find the missing 400 TGA patients. Of course the problem of obtaining valid contact information will plague us given > 300 were contacted in 2014.

**Miscellaneous Discussion:**

DC Issues:

1. The handouts of AAOCA are being updated for Marshall who will present the data (prior to any analysis) at the upcoming invited lecture at AATS.
2. We need to develop more efficient means of extracting preliminary data of our cohorts from Access for summaries & date integrity checks.

3. We should consider targeting 2, 3 or 4 studies for our next Kirklin/Ashburn Fellow, Paul Devlin, to present to the membership at the annual meeting to inform them (& interest them) of data we have for potential analyses.

### Appendix – List of Attendees

#### *In Person Attendees*

Amine Mazine  
Annette Flynn  
Anusha Jegatheeswaran  
Arti Singh  
Brenda Chow  
Brian McCrindle  
Cheryl Fackoury  
Christopher Caldarone  
Clauden Louis  
Eugene Blackstone  
Igor Bondarenko  
James Meza  
Kamal Pourmoghadam  
Kathryn Coulter  
Kristina Kovach  
Linda Lambert  
Luc Mertens  
Michael-Alice Moga  
Mjaye Mazwi  
Nancy Poirier  
Osami Honjo  
Paul Devlin  
Peter Gruber  
Sally Cai  
Susan McIntrye  
William DeCampli  
William Williams

#### *Webinar Attendees*

Ali Dodge-Khatami  
Craig Fleishman  
David Blitzer  
John Karamichalis  
Julie Brothers  
Marshall Jacobs  
Phillip Burch  
Rajesh Krishnamurthy  
Ram Subramanyan  
Richard Lorber  
Shubhika Srivastava  
Tara Karamlou