Coordinator Newsletter

4th Annual Coordinator Meeting

The Data Center would like to thank all of the coordinators who recently attended the 4th Annual Coordinator Meeting in Chicago.
Alongside study and follow-up updates from the Data Center staff, we had a couple of guest speakers including: Linda Lambert ‘Research & the Coordinator’s Role’, Dr. William DeCampli ‘Unique Nature of Studies conducted by the CHSS Data Center’ & Dr. James Meza (current KA Fellow) who spoke on ‘Echocardiography and the ECHO Core Lab: Role in Research’ (substituted for Dr. Luc Mertens). Kathryn Coulter, our resident regulatory expert, gave a talk on ‘IRB/REB, Data Use Agreement & Regulations’ which stirred up important discussion amongst the group.

Drs. M. Jacobs and W. Williams also dropped by to thank the group and reinforce the importance of the coordinator’s role in CHSS studies.

Our last session gave the group an opportunity to openly discuss issues of enrollment and follow-up strategies as well as administrative hurdles. We hope that in the future, coordinator meetings will include an open forum set-up as well as lecture style presentations. We want to encourage collaboration and networking amongst you all, as we are all working towards the same goal.

For those of you that could attend, we hope you found this year’s meeting informative and educational. For coordinators who weren’t able to attend, you will be able to find the Data Center Report and all corresponding Coordinator Meeting presentations on the website shortly. The Data Center staff wants to notify the coordinator group that we will be taking your suggestions into serious consideration and that going forward; we hope to create a manual of operations for not only new sites/coordinators but for each of the individual studies as well.

Please be on the lookout for a SurveyMonkey questionnaire requesting your feedback and opinions on the Coordinator Meeting in general.

**Quarterly Conference Call: Postponed**

We’ve taken your suggestions into consideration, thus we will be rescheduling the December Quarterly Conference Call to the New Year. We would like to focus on the needs of the coordinators. Please let us know what you would like to see covered on the quarterly call, i.e., comprehensive training sessions/webinars, etc. in January. Please contact us with suggestions chss.dc@sickkids.ca We will notify the group of the calls dates and details in the near future.
To our surprise, the AVSD cohort has not had the enrollment that we had anticipated thus far. Considering it is a relatively common congenital heart defect, we would expect the rate of enrollment to be more rapid three years after inception. We encourage you to speak with your member surgeon to see if they are interested in participating in this cohort. If you have any questions, please do not hesitate to contact us at 1-866-477-2477 or chss.dc@sickkids.ca.


Title 45 Public Welfare  
Subtitle A – Department of Health and Human Services  
Subchapter A – General Administration  
**Part 46 – Protection of Human Subjects**  
[Revised January 15, 2009; Effective July 14, 2009]

Title 45 Public Welfare  
Subtitle A – Department of Health and Human Services  
Subchapter C – Administrative Data Standards and Related Requirements  
**Part 160 – General Administrative Requirements** [last revised: June 7, 2013]  
**Part 164 – Security and Privacy** [last revised: June 7, 2013]

**Health Information Privacy**

**HIPAA = Health Insurance Portability and Accountability Act (1996)**

Children and Research  
**Ethical Conduct of Clinical Research Involving Children (2004)**


**CANADA**


Health Information Privacy  
**PHIPA = Personal Health Information Protection Act**  
**Personal Health Information Protection Act, 2004, S.O. 2004, Chapter 3, Schedule A**  
[Last amendment: 2010, c .11, s. 128]

**Ontario Regulation (O. Reg.) 329/04, General**  
[Last amendment: O. Reg. 331/11 (as am. by O. Reg. 367/13 and O. Reg. 269/14)]

**Information and Privacy Commissioner of Ontario**
Fall Work Weekend

Join us for the CHSS Data Center's Fall Work Weekend on November 20-22, 2015 in Toronto. We hope that you can attend this meeting alongside your member surgeon. For more details, please click here.

Data Center & CHSS Websites Merging

We are excited to announce that the Data Center and CHSS websites will be merging into one. The merger will allow researchers and parents to gain access to their respective information sites of interest. It will also help parents in identifying and
recognizing that the CHSS, and the Data Center, are a cohesive entity. We have big plans for this merger and hope to incorporate interactive and educational elements into the site. This is a vast undertaking and will be a work in progress, so we do appreciate your patience. Stay tuned for more details and updates on the anticipated merger!