AVSD: ECHO TRAINING WEBINARS

AVSD Echo Training Webinars are schedule to be held on **July 27, at 4 p.m. EST** and **July 30, at 2 p.m. EST**. The purpose of the webinar is to update sites on the current status of the AVSD project, as well as review the current echo protocol (required measurements/images) to ensure quality and completeness of echocardiograms for both baseline, and post-operative imaging. This will also be an opportunity to address any questions or concerns.

We encourage your echo staff to participate in one of the webinars listed above. If you plan on attending the webinar or have any questions, please contact [veena.sivarajan@sickkids.ca](mailto:veena.sivarajan@sickkids.ca)

REGULATORY CONNECTION

Study Documentation Request to Participating Sites/Institutions

If you have not already done so, please provide a copy of the following to the CHSS Data Center for each CHSS research study in which your institution/site is participating (and the CHSS Data Center is the Coordinating Site for the study):

1. **Institutional Review Board (IRB)/Research Ethics Board (REB)/Privacy Board**
   (a) Initial IRB/REB approval of the study
   (b) IRB/REB approval of any amendments subsequent to the initial IRB/REB approval of the study
   (c) Any Privacy Board Approvals/Re-Approvals, as applicable [US sites only]
   (d) Current IRB/REB-approved Consent Forms/Assent Forms, and for US sites only: any separate HIPAA Authorization used for the study (as applicable)
   (e) Each IRB/REB re-approval/continuing approval of the study, subsequent to the initial IRB/REB approval of the study

2. **Contract – Data Transfer Agreement (DTA)**
   Please ensure that you have a fully executed DTA to cover all CHSS research studies in which your
institution/site is participating (and CHSS Data Center is the Coordinating Site).
A copy of the fully executed DTA needs to be on file at your institution/site, as well as at the CHSS Data Center.
*For your convenience, the current DTA templates are located on our website: www.chssdc.org – these are general DTA templates (one template for US institutions; one template for Canadian institutions), set up to cover all CHSS Data Center research studies you are/may be participating in.

If you are not sure if your institution/site has provided the above-requested documents/ if you need to submit the requested documents/ if you have any questions regarding this, please contact: kathryn.coulter@sickkids.ca.

Please Note: There is no need to re-submit any documents that have already been submitted to the CHSS Data Center.

SAVE THE DATE: ANNUAL COORDINATOR MEETING

We are in the process of planning the **CHSS Annual Coordinator Meeting on October 25-26, 2015** in Chicago, IL. We would love to have each member surgeon represented by his/her coordinator! For the coordinators that have joined us in previous years and asked that we provide **CEU credits**, we are working on providing them this year, without an increase to the registration fee. This is in thanks to the executive committee who has agreed to cover this cost.

The agenda is not quite finalized so if there are topics that you would like to see presented, please let us know. A preliminary agenda should be ready for your review by **August 1**, on the CHSS website. As you know, a key part of research is the collection and submission of data by the coordinators. We view coordinator attendance at this meeting as a step towards our goal of engaging coordinators and stressing the vital role that coordinators play in the success of CHSS studies. We encourage surgeon members to speak with their coordinators and support them in attending this annual meeting.

FOLLOW UP: PROGRESS REPORT

We are in the middle of follow up calls for **LVOTO** and have sent out a data update request to those institutions involved in the study. Currently, follow up is open for **LVOTO, IAA and TA**. If you have any **current demographic** or **clinical** updates on patients in any of these cohorts, please feel free to send us their information via Secure File Transfer, mail or fax.
ACTIVELY ENROLLING COHORTS

AAOCA (435pts) – patients ≤ 30 years of age, diagnosed from Jan. 21, 2009
Tricuspid Atresia Type 1 (352pts) – patients < 3 months of age, diagnosed after Jan. 1, 1999
LVOTO (812pts) – neonate patient ≤ 30 days of age with critical LVOTO
uAVSD (196pts) – patients with complete AVSD, age ≤ 1 year of age, surgery after Jan. 1, 2012

†Please check website for more detailed information regarding inclusion criteria

TECHNICAL ASSESSMENT PROJECT

We are pleased to announce that the web-based TAP modules are now functional. The TPS ‘measures’ specific components of an operation (for example VSD closure and relief of RVOTO for Tetralogy of Fallot). The premise is that, by scoring different elements of the repair, an individual surgeon will gain insight into those parts of an operation they do very well, but might be able to improve on others. Please discuss this project with your member surgeon. The Data Center has received QI approval as well as approval from its legal department of the data sharing agreement. However, your institution may still require IRB approval or waiver before you can begin entering data. If this is the case, you will need the CHSS approval letter/protocol and the data sharing agreement located on the CHSS website: www.chssdc.org/content/technical-assessment-project

Again, please inquire with your IRB what will be required prior to beginning participation.

¿HABLAS USTED INGLES?

When conducting annual follow up calls, we run into a common language barrier. Certain Spanish-speaking families have trouble completing their annual follow-up over the phone. We would like to ensure that this population is able to participate, therefore, we are asking coordinators if it is at all possible when enrolling Spanish-speaking families to find out if they have an English-speaking relative or representative that they would like to designate in order to help complete the participants’ annual follow-up. The Spanish-speaking families that we have been in correspondence with normally have a designated individual for us to call in order to obtain follow up.

We would like to maintain contact with the Spanish-speaking population through this method in the future and hope that you can help us!
We are reaching out to our institutional coordinators to see if we can compile a comprehensive list of support groups within each state/province. We plan to post this list to the CHSS website so that we can direct patients who are interested in connecting with other families, and peers, for additional support throughout their journey. Please send all support group information to ilina.ristevska@sickkids.ca if you haven’t done so already.

We have planned out the coordinator webinar conference calls for the next year. We will schedule two consecutive calls each quarter; however, you only need to participate in one of these calls.

- We have set agendas for the calls but we are always open to discuss any issues you have
- Webinar and call in details and the agenda will be emailed out one week prior to the calls

Please mark these dates in your calendar:

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<th>Quarter 3</th>
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<th>Quarter 4</th>
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If you have any questions/suggestion regarding the coordinator calls, please contact susan.mcintyre@sickkids.ca

**FALL WORK WEEKEND**

The Fall Work Weekend has been finalized and is scheduled for the weekend of **November 20 – 22nd, 2015.**

**SAVE THE DATE!** Details to follow as the date nears.