



WORK WEEKEND 2019

Toronto, Canada

Spring 2019 Work Weekend Agenda
 April 12-14, 2019
 Peter Gilgan Centre for Research & Learning
 686 Bay Street, Toronto, M5G 0A4

FRIDAY APRIL 12, 2019 (Room 11-9701)

Time (EST)	Session Title	Speaker / Lead / Discussants	Goals / Objectives
7:45-8:15	Reception, Registration, Continental Breakfast, Welcome	William DeCampi (CHSS, Arnold Palmer Hospital for Children) William G. Williams (CHSS Data Center)	Objectives for Friday's meeting: Data Review
8:15-9:00	Session 1 – Kirklin-Ashburn Fellow Update	Paul Devlin (CHSS Data Center)	<ol style="list-style-type: none"> 1. Review of work completed by Fellow 2. Overview of current cohorts
9:00-10:30	Session 2 – Pulmonary Conduit Cohort Update	Paul Devlin (CHSS Data Center) Nabi Aghaei (CHSS Data Center)	<ol style="list-style-type: none"> 3. Gore Grant Discussion 4. Freedom from conduit interventions 5. Impact of Melody Valves
10:30-10:45	Coffee Break		
10:45-12:00	Session 3 – Tricuspid Atresia and Critical Left Heart Obstruction	Paul Devlin (CHSS Data Center) Kate Pearson (CHSS Data Center)	<ol style="list-style-type: none"> 1. Review of Past Projects 2. Data Overview 3. Discuss ideas for future projects 4. Fontan data
12:00-13:00	LUNCH		



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13:00-14:30	Session 4 – AAOCA Cohort	Anusha Jegatheeswaran (CHSS Data Center) Michael Jiang (Cleveland Clinic)	<ol style="list-style-type: none">1. Surgical Outcomes Project Overview2. Cohort Numbers3. Discuss ideas for future projects4. Cleveland Clinic Adult AAOCA Database
14:30-14:45	Coffee Break		
14:45-15:45	Session 5 – Statistics Overview	Paul Devlin (CHSS Data Center) Eugene Blackstone (Cleveland Clinic)	<ol style="list-style-type: none">1. Understanding Competing Risks
15:45-17:00	Session 6 –AVSD Cohort	Paul Devlin (CHSS Data Center) Tharini Paramanathan (CHSS Data Center)	<ol style="list-style-type: none">1. PAB in AVSD Project Overview2. AATS Presentation Run #13. Cohort Numbers/Abstraction4. Discuss ideas for future projects
17:00-17:45	Session 7 – Ebstein’s Overview	Tharini Paramanathan (CHSS Data Center) Leaders of the Ebstein’s Cohort	<ol style="list-style-type: none">1. Outline anticipated questions2. Define project timelines/plan3. Preparing the stage with an upcoming cohort for Saturday’s discussion
18:30	Dinner	LOCATION: AdegA	



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SATURDAY APRIL 13, 2019 (Room 11-9701)

Time (EST)	Session Title	Speaker / Lead / Discussants	Goals / Objectives
7:45-8:15	Reception, Registration, Continental Breakfast, Welcome	William DeCampli (CHSS & Arnold Palmer Hospital for Children) William G. Williams (CHSS Data Center)	
8:15-9:15	Session 1 – Quality Improvement Project vs Research Registry	Sunita O’Shea (CHSS Data Center) Linda Lambert (Primary Children’s Hospital, Utah)	<ol style="list-style-type: none"> 1. Proposed frameworks for moving forward 2. Central IRB vs Single IRB Models 3. Fee structures 4. Common Rule Change
9:15-10:30	Session 2 – Engaging CHSS Members	William DeCampli (Arnold Palmer Hospital for Children) Anusha Jegatheeswaran (CHSS Data Center) John Spertus (University of Missouri, Kansas City)	<ol style="list-style-type: none"> 1. How can the CHSSDC engage members? 2. Do CHSS members care about research? 3. How can the CHSSDC help you navigate the infrastructure you have at your institutions? 4. Making CHSS studies a priority from a resource standpoint 5. How can we improve funding for research studies?
10:30-10:45	Coffee Break		



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<p>10:45-12:00 Session 3 – Engaging Cardiologists</p>	<p>Anusha Jegatheeswaran (CHSS Data Center) Julie Brothers (Children’s Hospital of Philadelphia) Craig Fleishman (Arnold Palmer Children’s Hospital) Craig Broberg (AARCC, Oregon Health Sciences University) Natalie Jayaram (Children’s Mercy, Kansas City)</p>	<ol style="list-style-type: none"> 1. The importance of engaging cardiologists in the CHSS to increase enrollment and long-term follow-up 2. Engagement of other organizations (AARCC, ISACHD)
<p>12:00-12:30 Session 4 – Imaging Core Lab</p>	<p>Luc Mertens (Hospital for Sick Children) Craig Fleishman (Arnold Palmer Children’s Hospital) Richard Lorber (Children’s Hospital of San Antonio)</p>	<ol style="list-style-type: none"> 1. Current Status of virtual core lab 2. Road blocks in establishing remote reading capabilities?
<p>12:30-13:30 LUNCH</p>		
<p>13:30-14:30 Session 5 – Engaging Subjects</p>	<p>Paul Devlin (CHSS Data Center) Arti Singh (CHSS Data Center) Anna Wasiak (CHSS Data Center)</p> <p>Stacey Lihn (Sisters by Heart) Melissa McQueen (Transplant Families) Jessica Lindberg (Ethan Lindberg Foundation) David Kasnic (PCHA) Amy Basken (PCHA)</p>	<ol style="list-style-type: none"> 1. Follow-up engagement numbers 2. How we currently conduct follow-up 3. How can we streamline the follow up process? 4. How can we continue to follow lost to follow up, moving, aging, and patients who are seen primarily at non-CHSS institutions (2nd-opinion)? 5. How can we engage patient advocacy groups (PCHA, Sisters by Heart, Transplant Families)? 6. Can we become a patient advocacy group?



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<p>14:30-15:30</p>	<p>Session 6 – Data Abstraction Process</p>	<p>Eugene Blackstone (CHSS & Cleveland Clinic) Paul Devlin (CHSS Data Center) Kate Pearson (CHSS Data Center) Tharini Paramanathan (CHSS Data Center) Nabi Aghaei (CHSS Data Center)</p>	<ol style="list-style-type: none"> 1. Current process of data abstraction 2. Can we incorporate remote data abstraction? 3. Is there such a thing as too much data? 4. When has a cohort enrolled enough patients? 5. How can we determine the denominator? 6. How can we ensure data quality? 7. How can we streamline this process? 8. Engaging other organizations that collect similar data? (AARCC, NDI, patient advocacy groups, INTERMACS, PEDIMACS, ACTION network, Pediatric Heart Transplant Society)
<p>15:30-15:45</p>	<p>Coffee Break</p>		
<p>15:45-16:45</p>	<p>Session 7 – CHSS-AHA Grant Opportunity</p>	<p>Tara Karamlou (Cleveland Clinic)</p>	<ol style="list-style-type: none"> 1. Review of grant opportunity



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SUNDAY APRIL 14, 2019 (Room 11-9701)

Time (EST)	Session Title	Speaker / Lead / Discussants	Goals / Objectives
7:45-8:15	Reception, Registration, Continental Breakfast, Welcome	William DeCampi (Arnold Palmer Hospital for Children) and William G. Williams (CHSS Data Center)	Objectives for Sunday's meeting: Towards a brighter future
8:15-9:00	Session 1 – Presentation Run	Paul Devlin (CHSS Data Center)	1. PAB in AVSD Run #2
9:00-12:00	Session 2 – Summary of Saturday's Discussion	William DeCampi (Arnold Palmer Hospital for Children) Paul Devlin (CHSS Data Center) Sunita O'Shea (CHSS Data Center)	1. Summary of proposed action items and timelines