

## NAKDR - Montreal Meeting Saturday March 17, 2018 (Agenda)

Time (EST)	Session Title	Speaker/Lead	Goals/Objectives
8:15-8:30	Reception, Registration, Welcome	Brian McCrindle (Hospital for Sick Children) and Nagib Dahdah (Centre Hospitalier Universitaire Sainte-Justine)	.
8:30-8:50	Session 1 – The NAKDR collaborative effort 4 years after inception	Brian McCrindle (Hospital for Sick Children) and Nagib Dahdah (Centre Hospitalier Universitaire Sainte-Justine)	1. Review current status of the registry and recap progress to date
8:50-9:15	Session 2 – Report on the Data Coordinating Centre (DCC)	Mathew Mathew (Hospital for Sick Children) Cedric Manlhiot (Hospital for Sick Children)	1. Update from the DCC: data holding and quality, review data management and cleaning procedures, review process for statistical analysis requests and scientific requirements for new proposal
9:15-10:15	Session 3 – International Kawasaki Disease Symposium (IKDS) 2018 Update	<ol style="list-style-type: none"> <li><b>Kevin Friedman (Boston Children’s Hospital)</b> - Comparative Effectiveness Study: Acute Treatment of KD Patients with CAA</li> <li><b>Audrey Dionne (Boston Children’s Hospital)/Nagib Dahdah (Centre Hospitalier Universitaire Sainte-Justine)</b> - Coronary artery intervention in children after Kawasaki disease</li> <li><b>Jonathon Osborne (Hospital for Sick Children)</b> - Practice concordance with guidelines on long-term management of Kawasaki Disease patients</li> </ol>	<ol style="list-style-type: none"> <li>Working session, for each project submitted to IKDS 2018</li> <li>Review preliminary analysis prepared for abstract submitted to IKDS 2018</li> <li>Group feedback, DCC analytics staff to answer questions</li> <li>Plan for revisions/additional analyses to be done before IKDS 2018</li> </ol>
10:15-10:30	Break		
10:30-12:00	Session 3 - continued	<ol style="list-style-type: none"> <li><b>Mathew Mathew (Hospital for Sick Children)</b> - Structural factors of coronary arteries associated with normalization of luminal diameter in patients with coronary artery aneurysms following Kawasaki Disease.</li> <li><b>Seda Tierney (Stanford University)</b> - Variations in Pharmacological Management of Children with CAA after KD</li> <li><b>Cedric Manlhiot (Hospital for Sick Children)</b> - Thrombosis and thromboprophylaxis for patients with giant CAA after KD</li> <li><b>Brian McCrindle (Hospital for Sick Children)</b> - Medium-term outcomes of CAA after KD</li> </ol>	As above

<b>12:00-12:45</b>	<b>LUNCH</b>		
<b>12:45-14:00</b>	Session 4 – NAKDR operations	To Be Determined	<ol style="list-style-type: none"> <li>1. Feedback from sites about the process for annual updates of the NAKDR data</li> <li>2. Proposed changes to REDCap data collection forms (format/organization)</li> <li>3. Proposed changes to data elements to be collected for new patients and as part of follow-up</li> <li>4. Requirements to maintain REB approvals and submit evidence to DCC</li> <li>5. Consenting of future patients for future contact?</li> </ol>
<b>14:00-15:00</b>	Session 5 –NAKDR strategic planning	To Be Determined	<ol style="list-style-type: none"> <li>1. Determine whether NAKDR inclusion criteria should be expanded to other cohorts (e.g. &lt;1999, non-CAA acute, adults, etc.) or whether some patients should be excluded from future updates (e.g. small CAA)?</li> <li>2. Determine whether we should expand NAKDR to other international sites? <ul style="list-style-type: none"> <li>&gt; If yes, should we have a booth/session at IKDS?</li> <li>&gt; If yes, should the registry change name?</li> </ul> </li> <li>3. NAKDR activities/presences at IKDS</li> <li>4. Strategize regarding organizational logistics and operations</li> <li>5. Strategize funding and resources allocation</li> <li>6. Planning of moving the data collection to a prospective registry with stakeholder involvement</li> </ol>
<b>15:00-15:15</b>	<b>BREAK</b>		
<b>15:15-16:15</b>	Session 6 – NAKDR governance	To Be Determined	<ol style="list-style-type: none"> <li>1. Review proposed leadership/organization</li> <li>2. Plans for annual meetings</li> <li>3. Review/amend draft governance documents</li> </ol>
<b>16:15-16:30</b>	Session 7 – Voting and wrap up	Round table discussion	<ol style="list-style-type: none"> <li>1. Voting on governance documents and ratification of charter</li> <li>2. Election of NAKDR leadership</li> <li>3. Any other items requiring votes</li> <li>4. Plan for next meeting at IKDS</li> <li>5. Wrap up</li> </ol>