

Friday Aug. 19	Cure SMA Canada - National SMA Conference - Montreal Agenda	
5:00 – 6:00 pm Drummond Room	Meet and Greet Sponsored by Novartis Canada	
6:00 – 6:30 pm Drummond Room	Dr. Hugh McMillan	Newborn screening for spinal muscular atrophy in Canada
6:00 – 7:00 pm Salon 6,7 Room	Dr. Xavier Rodrigue	Study results – Adult patient - Spinraza and Risdiplam
6:30 – 7:15 pm Drummond Room	Dr. Hugh McMillan	Zolgensma - Onasemnogene abeparvovec : final results from SPR1NT
7:00 – 8:00 pm Salon 6,7 Room	Dr. Xavier Rodrigue	Adult patient - Importance of awareness of personal health Q & A
7:15 – 8:00 pm Drummond Room	Dr. David Zielinsky	Respiratory care
8:00pm	Montreal Tower & CN Tower Lighting at 8:00/SMA awareness month recognition moment	
Saturday Aug. 20		
8:00 – 9:00 am Drummond Room	Breakfast	
9:00 – 10:00am Drummond Room	Catherine Desautels , O.T. / Ergothérapeute Sarah Turgeon Desilet P.T. / physiothérapie	Pediatric OT, PT
9:00 – 10:00 am Salon 6,7 Room	Speaker panel – Taylor Danielson, Natalie MacDonald, Desiree Parisien, Brooklyn Marx, Paije Gorham, Susi Vander Wyk CSMAC	Canadian Adult access gaps – Personal stories and looking forward.

10:00 – 10:15am	Break	
10:15 – 11:00 am Drummond Room	Speaker panel – Aniello & Rosa Cavallaro, Janik & Suzanne Dionne, Jenna & Eddie Stewart, Claudia McNeil	Working on a healthy marriage/relationship when we raise a child with SMA
10:15 – 11:00am Salon 6,7 Room	Speaker panel – Desiree & Scott Parisien, Paije and Kolt Gorham, Ken Kramer	Working on a healthy marriage/relationship when one of us has SMA
11:05 – 12:00pm Drummond Room	Dr. Jean Ouellette	Orthopedic - prevention and care of a healthy spine
12:00 – 1:00pm Drummond Room	Lunch Sponsored by Biogen Canada	
1:00 – 1:30 pm	Dr. Maryam Oskoui	Risdiplam update
1:30 – 2:00pm	Dr. Maryam Oskoui	Spinraza update
2:00 – 3:00 pm	Speaker panel - Taylor Danielson, Jonah Monaghan	Assistive Technology – Taylor Danielson – Kinova/Intro into assistive Robotics, Taylor Danielson - Technology for living Jonah Monaghan – Painted Waters Video game, Overjoyed/playability initiative
3:00 - 3:15 pm	Break	
3:15 - 4:00 pm	Brent Fraser – VP Pharmaceutical reviews CADTH	CADTH Reimbursement review process and the use of Real World Evidence (RWE)
4:00 – 5:00 pm	Durhane Wong-Rieger	The role and importance of RWE in our proposed drug pathways and the Rare disease centres of excellence

Sunday Aug. 21		
8:00 – 9:00 am	Breakfast	
9:00 – 10:00 am	Real Talk Panel – Holli Vander Wyk, Ben Flosman, Desiree Parisien, Rachel O’Hagan Hosted by Roche Canada and Cure SMA Canada	Canadians living with SMA and one caregiver speak about important topics within the SMA community.
10:00 – 10:30 am	Isabelle Boudreault/Air Canada	Air Travel Tips
10:30am – 10:45am	Break	
10:45 – 11:15am	Gail Ouellette	RQMO – Quebec Access gaps, path forward
11:15 – 11:45am	Speaker Panel - Brooklyn Marx, Julianna Cavallaro	Mental health - talking about awareness and coping mechanisms
11:45 – 12:15 pm	Speaker panel – Susi Vander Wyk (Canada) Amy Loignon/Isabelle Boudreault (Quebec)	Advocacy Efforts done and looking forward – addressing the gaps

Thank you!!

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