



2020 SMA Conference Agenda

Hyatt Regency Toronto – 370 King St. , Toronto

Thursday, February 27 – Group Sessions

5:00pm – 6:30pm

Pre Conference - Dinner Speaker/presentation:

A BIOGEN EVENT

The Facilitation of Care and the Patient Journey

Patients, caregivers and physicians: experience navigating the health care system

7:00pm – 9:00pm

Newly Diagnosed Informational Session (Room 1)

Dr. Selby and Dr. McMillan – Treatment decisions, practical applications

Cure SMA Canada – Who we are, what we do

Open Discussion

7:00pm – 9:00pm

SMA Adult Patient and Caregiver Informational Session (Room 2)

Dr. Izenberg – Treatment decisions , practical applications

Cure SMA Canada – Where are we going next for adult patient advocacy.

Round table discussion, experiences, hopes collaboration

Open discussion

Friday, February 28 – Informational session

8:30am – 4:00pm	Child Care/ Activities Room Open (Volunteer child care)
8:00am – 9:00am	Breakfast provided
8:45am – 9:00am	Susi Vander Wyk - General welcome, opening comments
9:00am – 9:45am	Dr. Mackenzie, Dr. Selby - SMA Newborn Screening in Canada; Current status and Path Forward
9:45am - 10:15am	Drug Approval Process in Canada - Explanation
10:15am – 10:30am	Break – Refreshments Provided
10:30am – 12:00pm	<u>Medical Treatment Information, Treatment access, Clinical trial</u> Speaker Panel; Dr. Kathy Selby – Approved Intrathecal treatment presentation Dr. Hugh McMillan – Investigational Gene therapy treatment presentation Dr. Craig Campbell – Investigational Oral treatment presentation
12:00pm – 1:00pm	Lunch Provided
1:00pm – 2:00pm	<u>Canadian Research Projects & The global benefit of Canadian research</u> Speaker Panel; Dr. Rashmi Kothary - The changing landscape of spinal muscular atrophy: multi-system features of the disease” Dr. Jocelyn Côté - SMN & Friends: What We Can Learn From Identifying SMN Interacting Partners in Motor Neurons and Muscles Dr. Robin Parks - A new approach to monitor disease progression and response to therapy.
2:00pm – 2:15pm	Break – refreshments provided
2:15pm – 3:00pm	Durhane Wong-Rieger - President & CEO of CORD Access to Rare Disease Drugs: Critical Role of Patient Organizations
3:00pm – 3:30pm	Susi Vander Wyk - Cure SMA - Why continue research – funding even though “we have treatment” Guest speaker
3:30pm – 4:00pm	Cure SMA Canada – Past, Present, Future

Saturday, February 29 – Family Support Session

8:30am – 4:00pm	Child Care/ Activities Room Open (Volunteer child care)
8:00am – 9:00am	Breakfast provided
8:45am – 9:00am	Susi Vander Wyk – Cure SMA Canada - Opening comments
9:00am – 9:30am	Holli Vander Wyk, Nicole Lamont – SMA Family Camp – Fun Family Support
9:30am – 10:15am	Ken Kramer QC, KMK Law – Estate and Trust Planning – Protecting our families.
10:15am – 10:30am	Break – refreshments provided
10:30am – 12:00pm	Medical Professional Speaker Panel – Respiriologist, Dr. Reshma Amin , Social Worker - Zoe Schwartz , Neuromuscular Clinic Nurse – Cindy Balayewich , Physiotherapist – Melissa Dermody
12:00pm – 1:00pm	Lunch provided
1:00pm – 1:45pm	Speaker Panel – The emotional roller coaster of a progressive disease; Jenna Stewart, Julia Lamb, Kira Palmer, Leah Sidora, Stella Palikarova
1:45pm – 2:30pm	Speaker Panel – Life with Treatment – Sharing experiences; Desiree Parisien, Yan Défossés, Nicole Lamont, Shailynn Taylor, Angie Durant, Paul Sanguinet
2:30pm – 2:45pm	Break – refreshments provided
2:45pm – 3:15pm	Speaker Panel – Keeping Positive – “Every day is a Good Day” Ken Kramer, Holli Vander Wyk, Sammy Cavallaro, Sarah Bartlett
3:15pm – 3:30pm	Susi Vander Wyk - Closing statements

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