

December 10 – 13, 2020
Virtual Conference Agenda
Important **All times are in EST

Thursday, December 10

9:00 – 10:30

Grief counselor English – Coping with the loss of a child

11:00 – 11:45

Les soins respiratoires dans l'amyotrophie spinale

Thanh Diem Nguyen, MD, M.Sc., FRCP(C)

Thanh Diem Nguyen, MD, M.Sc., FRCP(C), Pneumologue pédiatre, Service de pneumologie, CHU Sainte-Justine, Professeure adjointe de clinique, Université de Montréal

12:00 – 12:45

Mise à jour sur le Risdiplam.

Maryam Oskoui, MD, MSc, FRCPC, FAAN

Director, Division of Pediatric Neurology, Associate Professor, Departments of Pediatrics and Neurosciences, McGill University, Associate Member, Department of Epidemiology Biostatistics and Occupational Health, McGill University, Evidence-Based Methodologist, American Academy of Neurology

1:00 – 2:00

Nutrition Matters! Nutrition and SMA

Rebecca Hurst Davis MS, RD, CSP, CD, CNSC

Clinical Nutrition Manager
Primary Children's Hospital, Salt Lake City, Utah

2:15 – 3:00

Nusinersen treatment update for adults with SMA

Erin K. O'Ferrall, MD, MSc, FRCPC

Neuromuscular Neurology, Assistant Professor, Clinical
McGill University, Department of Neurology, Neurosurgery and Pathology

4:00 – 4:45

Mise à jour sur le traitement avec nusinersen pour les adultes atteints d'amyotrophie spinale

Erin K. O'Ferrall, MD, MSc, FRCPC

Neurologue Neuromusculaire, Professeure Adjointe,
Université de McGill, Département de Neurologie, Neurochirurgie et Pathologie

5:00 – 5:45

Care for the Caregiver

Rhonda Teichrob, Social Worker, Paediatric Neuromuscular Clinic Thames Valley Children's Centre London Ontario and
Kaylie MacDonald, RN Cerebral Palsy Clinic & Neuromuscular Clinic, Thames Valley Children's Centre

6:00 – 6:45

Spinraza - mise à jour pédiatrique

Nicolas Chrestian MD, FRCPC

Neurologue pour enfant/ Child neurologist, Spécialisé en maladies neuromusculaires/Subspeciality paediatric neuromuscular disorders, Centre hospitalier Mère-Enfant-Soleil Université Laval

7:00 – 7:45

Zolgensma - mise à jour

Nicolas Chrestian MD, FRCPC

Neurologue pour enfant/ Child neurologist, Spécialisé en maladies neuromusculaires/Subspeciality paediatric neuromuscular disorders, Centre hospitalier Mère-Enfant-Soleil Université Laval

Friday, December 11

9:00am– 9:45am

Pediatric update on Spinraza

Hernan D. Gonorazky M.D. CSCN Diplomate (EMG) Assistant Professor, Faculty of Medicine University of Toronto Division of Neurology, Department of Paediatrics, Director, Neuromuscular Fellowship Program, The Hospital for Sick Children

11:00am – 11:45

Ortho Care – Caring for the back and bones

Dr. Chris Reilly, MD, FRCSC, Investigator, BC Children's Hospital
Head, Department of Pediatric Orthopedics, BC Children's Hospital Head, Division of Pediatric Orthopedics, Department of Orthopedics, University of British Columbia

12:00 – 12:45

Risdiplam update

Maryam Oskoui, MD, MSc, FRCPC, FAAN Director, Division of Pediatric Neurology, Associate Professor, Departments of Pediatrics and Neurosciences, McGill University, Associate Member, Department of Epidemiology Biostatistics and Occupational Health, McGill University, Evidence-Based Methodologist, American Academy of Neurology

1:00 – 2:00

Peripheral pathology in SMA: Implications for clinical care
(What goes wrong in SMA and how to fix it - lessons learned from recent studies)

Dr. Rashmi Kothary Deputy Scientific Director and Senior Scientist at the Ottawa Hospital Research Institute (OHRI).

Biomarkers for SMA

Dr. Robin Parks Senior Scientist in the Regenerative Medicine OHRI, Full Professor in the Department of Medicine and the Department of Biochemistry, Microbiology and Immunology at the University of Ottawa.

2:30 – 3:30

À la recherche du rôle d'SMN dans les neurones et muscles : une stratégie pour l'identification de nouvelles cibles thérapeutiques pour l'Amyotrophie Spinale Infantile.

Dr. Jocelyn Côté Full Professor Cellular and Molecular Medicine, Faculty of Medicine, University of Ottawa

4:30 – 5:15

Entraînement en milieu aquatique pour les personnes atteintes d'amyotrophie spinale

Monique Émond pht, M.Sc, Programme des maladies neuromusculaires
Centre de réadaptation Marie Enfant, CHU Ste-Justine

5:30 – 6:30

La vie suite à la perte d'un enfant

Niky Panayotopoulos , Travailleuse sociale, Deuil-Jeunesse

10:00am – 10:30am

Teens/adult transition and the importance of multidisciplinary care

Dr. Aaron Izenberg – Staff neurologist, Sunnybrook Health Sciences Centre
Assistant professor, Department of Medicine, Division of Neurology, University of Toronto

11:30am – 12:30pm

The Changing Landscape of Respiratory Care for SMA

Reshma Amin MD, FRCPC, MSc, Staff Respiriologist & Sleep Physician
Div. of Resp. Med., Hospital for Sick Children, Associate Professor, University of Toronto, Senior Associate Scientist, Child Health and Evaluative Sciences, Research Inst.

1:00 – 1:45

Covid Isolation – Navigating anxiety, depression and more

Brooklyn Marx – Therapist in training, SMA type 2 adult, Masters in Councelling Psychology,
Bachelor of Science in Biomedical Sciences

2:00 – 3:00

Designing a pan-Canadian Rare Drug Program to Optimize Access to SMA Therapies

Durhane Wong-Rieger President & CEO of CORD, Canadian Organization for Rare Diseases

4:00pm – 4:45

SMA Newborn Screening in Canada; Current status and Path Forward

Dr. Alex Mackenzie – Pediatric neurologist and researcher, CHEO Research institute, UOttawa

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5:00 – 5:30

SMA Family Camp – Fun Family Support

Holli Vander Wyk –SMA Camp Director

What is SMA camp, memories that will last a lifetime!

10:00am – 10:45am

Zolgensma update

Hugh McMillan, MD, MSc, FRCPC, FAAN

Assistant Professor, University of Ottawa, Pediatric Neurology, Children's Hospital of Eastern Ontario
Program Director, Pediatric Neurology Residency Training Program

12:00 – 1:00

Sexual Health for adult women affected by SMA

Micaela Evans, Paije Gorham, Sasha Kirkland, Rachel Stewart

Closed group for women only - teens 16 + to adult - affected by SMA

Must be pre registered to receive access code.

2:00 – 3:00

“Is there someone out there for me” Navigating the obstacles of dating and relationship Patient group panelists, sharing stories and ideas, interactive.

Julia & Gregory Wees, Desiree & Scott Parisien, Tonya Cass, Micaela Evans & Anthony Skou

3:30 – 4:30

Covid 19 - Déjouer l'isolement et l'incertitude en temps de pandémie... Comment faire?

Annie Perreault, M. A. Psychologue,

Professeure de clinique affiliée au DMFMU, Faculté de médecine U. Laval

5:00 – 6:00

Naviguer entre l'espoir et l'épuisement: discussion et conseils pour les proches aidants.

Annie Perreault, M. A. Psychologue,

Professeure de clinique affiliée au DMFMU, Faculté de médecine U. Laval

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