



Lunch 'n Learn 4: Unveiling the Power of Registries: Enhancing Care for Spinal Muscular Atrophy (SMA) and Rare Diseases

Tuesday, June 10, 2025 - 12:15 PM – 1:45 PM Eastern

Rogers Centre Ottawa, Level 2, Room 207

Faculty: Hanns Lochmuller • Megan Crone • Kathryn Selby

Description:

This session will raise awareness about the evolving role of registries in optimizing care in SMA in Canada and internationally. Disease registries are increasingly recognized as important repositories for real world evidence that can inform the management of patients – particularly those with rare diseases such as spinal muscular atrophy. This course will provide an overview of how registries have played an instrumental role in informing new clinical standards in other areas and explore opportunities for implementation in Canada.

Learning Objectives:

- Identify why registries are used to inform the management of spinal muscular atrophy and other rare diseases
- Describe how learnings from international registries can be applied in Canadian clinical practice
- Apply the learnings from registries and real-world evidence to ameliorate management of patients with rare disease

Audience: Adult Neurologist, Child Neurologist, Neurosurgeon, Neuroradiologist, Neurophysiologist, Resident, Fellow, Nurses with interest in topic

Learning Level: Intermediate (Practicing Physician), Advanced (Special Interest, Higher Level Discussion)

Learning Format: Audience response system, Case studies, Demonstration, Forum/panels, Lecture/plenary method

CanMEDS: Medical Expert, Scholar, Communicator, Collaborator, Leader, Health Advocate, Professional

Time	Presentation Title	Name of Speaker
12:15 PM ET	Data from key registries and their influence upon patient care and management	Hanns Lochmuller
12:35 PM ET	SMA care: questions from patients that can be answered by registries	Megan Crone
12:55 PM ET	Case Studies in SMA	Kathryn Selby
1:15 PM ET	Interactive Panel Discussion with Polls and audience engagement	Hanns Lochmuller, Megan Crone, Kathryn Selby
1:30 PM ET	Q&A	Hanns Lochmuller
1:40 PM ET	Wrap up & Specific Course Evaluation	

This program was developed by the CNSF and Novartis Pharmaceuticals Canada and was planned to achieve scientific integrity, objectivity and balance. It is an unaccredited learning activity and not eligible for MOC credits.