

**Montreal, May 3 – 5, 2018**  
**ME/CFS Canadian Collaborative Team Conference**  
*Advancing an International Research Agenda to Address ME/CFS Research Priorities: From Basic Research to Clinical Practice*

**DAY 1 - Healthcare community**

**May 3, 2018 Pre-Conference Medical Education Symposium on ME/CFS**

7:00-7:55 Registration & Continental Breakfast

7:55-8:00 Welcome Address  
**Morris Duhaime, MD**, Conference Chair

**Session 1 ME/CFS: Spectrum of a Complex and Chronic Disease**

[Amphitheatre 250]

8:00-08:40 *Review of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome for Clinicians*  
**Alison C. Bested, MD, FRCP(C)**, Clinical Director, Institute for Neuro-Immune Medicine, Nova Southeastern University, Fort Lauderdale, Florida, USA

8:40-9:20 *Brain Imaging and How to Examine a Prospective ME/CFS Patient*  
**Byron Hyde, MD**, Nightingale Research Foundation, Ottawa, ON, Canada

9:20-10:00 *Orthostatic Intolerance in ME/CFS*  
**Peter C. Rowe, MD**, Director, Children's Center Chronic Fatigue Clinic, John-Hopkins University, Baltimore, MD, USA

10:00-10:15 Break

10:15-10:55 *ME/CFS: Central Sensitivity Syndromes and the Complex Chronic Diseases Program at BC Women's Hospital*  
**Ric Arseneau, MD, FRCPC, MA(Ed), MBA, FACP, CGP**, Clinical Associate Professor Division of General Internal Medicine St. Paul's Hospital, Women's Hospital University of British Columbia, BC, Canada

10:55-11:35 *Objective Diagnosis of ME/CFS*  
**Lucinda Bateman, MD**, Founder and Medical Director, Bateman Horne Center Salt Lake City, UT, USA

11:35-12:15 *Peripheral and Central Mechanisms of Chronic Fatigue Syndrome*  
**Roland Staud, MD**, Professor of Medicine, University of Florida, FL, USA

12:15-13:15 Lunch (*Meditation session available from 12:45 to 13:10 in the Conference room*)

**Session 2 How to Differentiate and Manage ME/CFS**

[Amphitheatre 250]

13:15-13:55 *Differentiating ME/CFS from Psychiatric Disorders*  
**Eleanor Stein, MD, FRCP(C)**, Calgary, AB, Canada

13:55-14:35 *Management of Pediatric ME/CFS*  
**Peter C. Rowe, MD**, Director, Children's Center Chronic Fatigue Clinic, John-Hopkins University, Baltimore, MD, USA

14:35-15:15 *What do we Learn About ME/CFS From a Cardiopulmonary Exercise Test?*  
**Betsy Keller, PhD**, Professor, Department of Exercise and Sport Sciences, Ithaca College, Ithaca, NY, USA

15:15-15:30 Break

15:30-16:10 *Diagnostic Dilemmas: Etiology and Treatment of the Fatigued Patient*  
**Riina I. Bray, BSc, MSc, MD, FCFP, MHSc**, Medical Director, Environmental Health Clinic, Women's College Hospital, Toronto, ON, Canada

16:10-16:50 *ME/CFS Pharmacotherapies and Drug Interactions*  
**Kevin Mejo, BPharm**, Montreal, QC, Canada

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- 16:50-17:00 Closing Remarks  
**Alain Moreau, PhD**, Chair, Scientific Committee, Professor, Université de Montréal, QC, Canada
- 17:00-19:00 Cocktail [Atrium]

**Session 2B 13:15 – 17:00 [Amphitheatre 125]**  
**Pre-Conference Workshop on Meeting Unmet Needs**  
Organized by the National ME/FM Action Network  
*Participation in the Workshop is open to anyone interested in discussing how services could be delivered to people with ME/CFS and related illnesses in the years to come.*

**DAY 2 – Healthcare community and patients**

**May 4, 2018 ME/CFS Canadian Collaborative Team Conference: From Basic Research to Clinical Practice**

- 7:00-8:00 Registration & Continental Breakfast
- 8:00-8:30 **Opening Remarks**  
[Amphitheatre 250]
- 8:30-9:00 **Plenary Lecture 1: A Short History of ME and CFS**  
**Byron Hyde, MD**, Nightingale Research Foundation, Ottawa, ON, Canada  
[Amphitheatre 250]
- 9:00-9:30 **Plenary Lecture 2: The Future of ME/CFS Research in the Multi-omic and Big Data Era**  
**Ronald Davis, PhD**, Director Stanford Genome Centre, Stanford University, Palo Alto, CA, USA  
[Amphitheatre 250]
- 9:30-9:45 Breakout to reach concurrent sessions:
- Session A for researchers in Amphitheatre 125
  - Session B for ME/CFS patients in Amphitheatre 250

**Session 1A Genetics, Genomics and Epigenetics**

[Amphitheatre 125]

- 09:45-10:05 *The Epigenetic Landscape of ME/CFS: Deciphering Complex Phenotypes*  
**Patrick O. McGowan, PhD**, University of Toronto, ON, Canada
- 10:05-10:25 *An Integrative, Molecular, Data and Technology-Driven Approach to ME/CFS*  
**Ronald Davis, PhD**, Director, Stanford Genome Center, Stanford University, Palo Alto, CA, USA
- 10:25-10:45 *Genetic and Nutriepigenetic Regulation of Plasma Homocysteine Levels in ME/CFS*  
**Alain Moreau, PhD**, Université de Montréal, QC, Canada
- 10:45-11:05 *Cultivating Change: Leveraging Epigenetics via Lifestyle Modification: An Integrative Multidisciplinary Treatment Model in ME/CFS*  
**Alexis Goth, MD, and Tara Sampalli, PhD**, Integrated Chronic Care Service in Primary Health Care at the Nova Scotia Health Authority, NS, Canada
- 11:05-11:20 Break

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<b>Session 2A</b>	<b>Biochemistry, Metabolomics and Proteomics</b>
	[Amphitheatre 125]
11:20-11:40	<i>Metabolism in ME/CFS</i> <b>Maureen Hanson, MD</b> , Cornell University, NY, USA
11:40-12:00	<i>The Biochemistry to Support the Evidence of Neuroinflammatory Involvement in ME/CFS</i> <b>Jonas Bergquist, MD, PhD</b> , Uppsala University, Sweden
12:00-12:20	<i>Cellular Bioenergetics is Impaired in Patients with ME/CFS</i> <b>Cara Tomas, PhD candidate</b> , Institute of Cellular Medicine, Newcastle University, Newcastle upon Tyne, UK
12:20-12:40	<i>Connective Tissue Laxity and Adverse Neural Tension in ME/CFS</i> <b>Peter C. Rowe, MD</b> , Director, Children's Center Chronic Fatigue Clinic, Johns Hopkins University, Baltimore, MD, USA
12:40-13:40	Lunch ( <i>Meditation session available from 13:05 to 13:35 in the Conference room</i> )
<b>Session 3A</b>	<b>Infection, Immunity and Clinical Research</b>
	[Amphitheatre 125]
13:40-14:00	<i>Diagnosis of ME/CFS: Can Immune Modulators Play a Role?</i> <b>Amir Landi, MD, PhD</b> , University of Alberta, Edmonton, AB, Canada
14:00-14:20	<i>Epidemiological and Clinical Research in ME/CFS: How can they Support Hypothesis Generation and Testing?</i> <b>Luis Nacul, MD, PhD</b> , Faculty of Infectious and Tropical Diseases, CURE-ME Team, London School of Hygiene and Tropical Medicine Disability and Eye Health Group, UK
14:20-14:40	<i>Clinical Trial on Immunoabsorption in ME/CFS</i> <b>Carmen Scheibenbogen, MD</b> , Professor and Deputy Chair, Institute of Medical Immunology, Charité – Universitätsmedizin, Berlin, Germany
14:40-15:00	<i>Fine-tuned interaction between human immune system and gut microbiota: potential impact on ME/CFS</i> <b>Derya Unutmaz, MD</b> , The Jackson Laboratory, Farmington, CT, USA
15:00-15:15	Break
<b>Session 4A</b>	<b>Biomarkers, Biobanking, and Clinical Trials – Part 1</b>
	[Amphitheatre 125]
15:15-15:35	<i>The EUROMENE Biomarker Project</i> <b>Carmen Scheibenbogen, MD</b> , Professor and Deputy Chair, Institute of Medical Immunology, Charité – Universitätsmedizin, Berlin, Germany
15:35-15:55	<i>Cerebral Blood Flow and Functional Connectivity in ME/CFS</i> <b>Roland Staud, MD</b> , Professor of Medicine, University of Florida, FL, USA
15:55-16:15	<i>UK ME/CFS Biobank: A Resource for International Research</i> <b>Luis Nacul, MD, PhD</b> , Faculty of Infectious and Tropical Diseases, CURE-ME Team, London School of Hygiene and Tropical Medicine Disability and Eye Health Group, UK

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<b>Session 4A Biomarkers, Biobanking, and Clinical Trials – Part 2</b>	
	[Amphitheatre 250]
16:15-16:35	<i>Australian ME/CFS Databases and Biobanks: The Down Under Experience</i> <b>Chris Armstrong, BSc</b> , Researcher, University of Melbourne, Bio21 Molecular Science and Biotechnology Institute, Department of Biochemistry and Molecular Biology, Melbourne, Australia
16:35-16:55	<i>From Biomarkers and modeling to implemented targeted clinical trials: Comparison between Gulf War Illness and ME/CFS</i> <b>Nancy Klimas, MD</b> , Director, Institute for Neuro-Immune Medicine, Dr Kiran C Patel College of Osteopathic Medicine, Nova Southeastern University and Director of Environmental Medicine, Miami VA Medical Center, FL, USA
16:55-17:15	<i>The Future of Research on ME/CFS</i> <b>Vicky Holets Whittemore, PhD</b> , National Institute of Neurological Disorders and Stroke, National Institute of Health, Bethesda, MD, USA
17:15-17:35	<i>Open Collaboration and Patient Engagement, a Must</i> <b>Linda Tannenbaum, CEO/President</b> , Open Medicine Foundation, Los Angeles, CA, USA
17:35-19:35	Cocktail [Atrium]

**Day 2 – Healthcare community and patients**

**May 4, 2018 Addressing Unmet Needs of the ME/CFS Community**

<b>Session 1B What We Know and Still Don't Know About ME/CFS Etiology and Pathomechanism</b>	
	[Amphitheatre 250]
9:45-10:05	<i>Pathophysiological Mechanisms in ME/CFS</i> <b>Alison C. Bested, MD, FRCP(C)</b> , Clinical Director, Institute for Neuro-Immune Medicine, Nova Southeastern University, Fort Lauderdale, Florida, USA
10:05-10:25	<i>Objective Diagnosis of ME/CFS</i> <b>Lucinda Bateman, MD</b> , Founder and Medical Director, Bateman Horne Center Salt Lake City, UT, USA
10:25-10:45	<i>ME/CFS: Could Neuroplasticity Play a Role?</i> <b>Eleanor Stein, MD, FRCP(C)</b> , Calgary, AB, Canada
10:45-11:05	Panel Discussion
11:05-11:20	Break

**Session 2B Advancing ME/CFS Research and Treatments**

	[Amphitheatre 250]
11:20-11:40	<i>ME/CFS Research Landscape in Canada: How can Science/Innovation Address Unmet Needs?</i> <b>Margaret Parlor</b> , President of the National ME/FM Action Network, Ottawa, ON, Canada
11:40-12:00	<i>Is Heart Rate a Valid Exertional Index in ME/CFS?</i> <b>Betsy Keller, PhD</b> , Professor, Department of Exercise and Sport Sciences at Ithaca College, Ithaca, NY, USA

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12:00-12:20	<i>Alberta Healthy Living Program: The Role of ME/CFS Education</i> <b>Eleanor Stein, MD, FRCP(C)</b> , Calgary, AB, Canada, <b>Judy-Anne Wilson</b> , representative of Edmonton ME Society and <b>Alison Rae</b> , Board Chair and CEO, Action CIND, ON, Canada
12:20-12:40	Panel Discussion
12:40-13:40	Lunch
<b>Session 2B</b>	<b>Panel Discussion: Meet the Experts</b>
	[Amphitheatre 250] <b>Moderator: Raeka Aiyar, PhD</b> , Stanford University and Open Medicine Foundation, Palo Alto, CA, USA
13:40-14:00	<i>Medication and ME</i> <b>Kevin Mejo, BPharm</b> , Montreal, QC, Canada
14:00-14:20	<i>Nutrition and ME</i> <b>Speaker TBA</b>
14:20-14:40	<i>Genetics and ME</i> <b>Speaker TBA</b>
14:40-15:00	Discussion Period
15:00-15:15	Break
<b>15:15-16:15</b>	<b>Panel Discussion: Creating a Transformative Research Agenda for ME/CFS</b>
	[Amphitheatre 250]  <b>Moderator: Raeka Aiyar, PhD</b> , Stanford University and Open Medicine Foundation, Palo Alto, CA, USA  Panelists: <ul style="list-style-type: none"><li>• <b>Diane Ching</b>, President, M.E. Society of Edmonton</li><li>• <b>Kati Debelic</b>, Board member, ME/FM Myalgic Encephalomyelitis and Fibromyalgia Society of BC, Canada</li><li>• <b>Barbara Fifield</b>, Board member, Millions Missing Canada</li><li>• <b>Bev Friesen</b>, Chairperson of the Board, Manitoba ME/CFS Support Group, MA, Canada</li><li>• <b>Gloria Gray</b>, President, M.E. Victoria Association, BC, Canada</li><li>• <b>Carol Head</b>, President and CEO of Solve ME/CFS Initiative</li><li>• <b>Kimberly Hicks</b>, Board Member and Treasurer, Open Medicine Foundation, Los Angeles, CA, USA</li><li>• <b>Valérie Miller</b>, General Coordinator, Association Québécoise pour l'Encéphalomyélite Myalgique (AQEM), QC, Canada</li><li>• <b>Margaret Parlor</b>, President, The National ME/FM Action Network, ON, Canada</li><li>• <b>Alison Rae</b>, Board Chair and CEO, Action CIND, ON, Canada</li><li>• <b>Elizabeth Sanchez</b>, President, ME/FM Myalgic Encephalomyelitis and Fibromyalgia Society of BC, Canada</li><li>• <b>Linda Tannenbaum, CEO/President</b>, Open Medicine Foundation, Los Angeles, CA, USA</li></ul> <p><i>Panelists will share their thoughts on how innovation is transforming the ME/CFS research landscape in Canada and abroad for five minutes. Special attention will be given to developing a collaborative, sustainable, and transformative ME/CFS research agenda.</i></p> <p><i>Participants will have the opportunity to interact with panelists to discuss research priorities and the role of patients and advocacy groups in the ME/CFS research ecosystem.</i></p>
17:35-19:35	Cocktail [Atrium]

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**Day 3 – Healthcare community**

**May 5, 2018 Advancing an International ME/CFS Research Agenda**

[Amphitheatre 250]

7:00-08:00 Registration & Continental Breakfast

8:00-08:15 Introduction and Objectives, **Alain Moreau, PhD**, Université de Montréal, QC, Canada  
[BMO Conference Center]

Context:

- Where have we been – where are we going?
- Creating a shared vision for the future
- Sustaining collaborative research in a competitive landscape
- Attracting world-class researchers from other disciplines
- Mentoring the next-generation of ME/CFS researchers and clinicians

**Session 1 Developing ME/CFS Networks and International Collaboration**

[Amphitheatre 250]

**Moderator: Raeka Aiyar, PhD**, Stanford University and Open Medicine Foundation, Palo Alto, CA, USA

8:15-8:30 *Report from the ME/CFS Patient Community about Creating a Transformative Agenda for ME/CFS*

**Margaret Parlor**, President of the National ME/FM Action Network, Ottawa, ON, Canada

8:30-9:00 *The Common Data Element Challenge in Establishing ME/CFS Research Consortia*

**Becky McNeil, PhD**, Biostatistics and Epidemiology Division, RTI International, Research Triangle Park, NC, USA

9:00-10:30 **Roundtable 1**

**Moderator: Raeka Aiyar, PhD**, Stanford University and Open Medicine Foundation, Palo Alto, CA, USA

*Participants will discuss the creation of a sustainable, collaborative, and transformative ME/CFS research agenda and the strategies to attract more funding through national and international research initiatives as well as to sustain talent development to prepare the next-generation of researchers in this field*

10:30-10:45 Break

**Session 2 Development of International Working Groups on ME/CFS**

[Amphitheatre 250]

10:45- 12:20 **Roundtable 2**

**Moderator: Alain Moreau, PhD**, Chair Scientific Committee, Professor, Université de Montréal, QC, Canada

*Participants will discuss the creation of virtual working groups to further develop international research collaboration and interdisciplinary teams.*

12:20-12:30 Closing Remarks

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**Alain Moreau, PhD**, Université de Montréal, QC, Canada