



Difficult to Diagnose Diseases: Ehlers-Danlos Syndrome

2nd Annual Canadian Medical Conference

November 1st – 2nd, 2014

Toronto Airport Marriott Hotel
901 Dixon Rd, Toronto, ON

Doctors now believe the prevalence of this connective tissue disorder is 1 in 100. Join us in learning how to best identify and treat this multi-systemic heritable condition that causes chronic pain, fatigue and so much more. Through education and collaboration we can improve the quality of life for these patients.

TARGET AUDIENCE:

- Family Physicians
- Internists
- Cardiologists
- Pain Specialists
- Neurologists
- Neurosurgeons
- Neuroradiologists
- Gastroenterologists
- Geneticists
- Hematologists
- Urologists
- Immunologists
- Allergists
- Chiropractors
- Orthopedics
- Nurses
- Allied Health Professionals
- Students & Residents

*Patients and families are welcome to attend but are asked not to participate during the question periods.

OBJECTIVES:

- To review the current evidence in the diagnosis and management of Ehlers-Danlos Syndrome (EDS)
- To recognize the implications, indications and interpretation of diagnostic tools for EDS such as specific blood work, genetic testing, imaging, cardiac and neurological tests, etc.
- To incorporate a practical approach for the comprehensive management and follow up of patients with EDS in the family physician's and specialist's practices
- To consolidate a network of physicians and allied professionals with an interest in difficult to diagnosis diseases including EDS

TO REGISTER GO TO: <https://2014edscanadianconference.eventbrite.com>



For More Information Contact:

Sandy Smeenk, Event Coordinator

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Website: www.theilcfoundation.org

AGENDA NOVEMBER 1ST

All Registrants

8:00 - 8:45	REGISTRATION/BREAKFAST/NETWORKING	
8:45 - 9:00	Welcome: Affirming the importance of guideline development with EDS as a model of optimal care	Dr. Norm Buckley
9:00 - 9:30	Outcomes from the 2013 Scientific Workshop: Clinical Experience in EDS EDS Heterogeneity - A Foray into the Diagnostic Dilemma	Dr. Allan Gordon Dr. Howard Meng
9:30 - 10:00	Clinical Genetics Presentation of EDS and 2014 Update	Dr. Clair Francomano
10:00 - 10:30	Molecular Genetics Presentation of EDS and 2014 Update	Dr. Roberto Mendoza
10:30 - 10:45	BREAK	
10:45 - 11:15	Chronic fatigue in EDS and its impact on quality of life	Dr. Peter Rowe
11:15 - 11:45	Postural Orthostatic Tachycardia Syndrome (POTS)/ Dysautonomia in EDS	Dr. Juan Guzman
11:45 - 12:15	Mast cell in EDS and its impact on quality of life	Dr. Peter Vadas
12:15 - 1:15	LUNCH/NETWORKING	
1:15 - 1:45	Tethered cord in EDS	Dr. Petra Klinge
1:45 - 2:15	Neurosurgical management of EDS	Dr. Fraser Henderson
2:15 - 2:45	Neuroradiology and Measurements in EDS	Dr. Myles Kobay
2:45 - 3:00	BREAK	

Academic Registrants Only

3:00 - 3:30	Panel Discussion and Q&A	Moderator: Dr. Kristianna Martiniuk
3:30 - 4:00	Planning for the short, medium and long term	Break out groups
4:00 - 4:30	Networking / Evaluate the process of working within a multidisciplinary collaborative/perceived value	Break out groups
4:30 - 5:00	Looking forward	Sandy Smeenck

Patient/Family Registrants

3:00 - 3:30	Guided Meditation	Elfreda Pretorius
3:30 - 4:00	Healthy Lifestyle: Psychology and Nutrition	Dr. Kim Daniel
4:00 - 4:30	Moving forward with best practices through a communication strategy	Marli Brown
4:30 - 5:00	Looking forward	Susan Hawkins

AGENDA NOVEMBER 2ND

Academic Registrations Only

9:00 - 11:00	Exploring What Needs to be Known for Changing Practices- Patient and Physician Round Table. (A small, representative group of EDS patients has been invited.)	Moderator: Dr. Allen Finley
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ALL PRESENTATIONS ARE 25 MINUTES WITH A 5 MINUTE QUESTION PERIOD. PROGRAM SUBJECT TO CHANGE.

Comments received after the 2013 Conference...

"Following the scientific workshop in 2013, we revisited patient files and confirmed diagnosis of Ehlers-Danlos Syndrome in 40 additional patients proving a 200% increase in this patient population. Today, we are diagnosing approximately 5 patients a week with Ehlers-Danlos Syndrome."

Dr. Allan Gordon

"Your outstanding effort will lead to a change in culture from the individual to the multidisciplinary medical approach as well as it will impact patients and families. Well done!"

Dr. Juan Guzman

"I have been most impressed by the rapid progress made by the ILC charitable foundation over the last three years. The ILC has accomplished a small miracle in bringing together a group of committed physicians and non medical individuals to broaden the understanding of Ehlers-Danlos Syndrome."

Dr. Fraser Henderson

"Without the ILC, I would be a Canadian living with EDS with no hope of ever having surgery with an expert to give me back a quality of life. Now I know there's a team of people, who are working to make this possible for me and people like me, here in Canada. We don't need to feel alone anymore."

Danette Hillier-McVeety

Northern Ontario

"The ILC's Scientific Workshop in 2013 helped identify the importance of diagnosis in chronic pain, to ensure that harm is not done by doing too much of the wrong thing and not enough of the right thing in this patient population."

Dr. Norm Buckley

Presenters:

Norman Buckley, MD, FRCPC

Professor of Anaesthesia
McMaster University

Marli Brown, BSW, RSW

Kim Daniel, PhD Psychology

Clair Francomano, MD

Clinical Genetics
Greater Baltimore Medical Center
Baltimore, MD, USA

Allan Gordon, MD

Neurology
Director, Wasser Pain Management Center
Mount Sinai Hospital, University of
Toronto
Toronto, ON

Juan Guzman, MD, MSc, FRCPC

Internal Medicine, Cardiology, POTS &
Dysautonomia
McMaster University
Hamilton, ON

Fraser Henderson, MD

Director of Neurosurgery
Doctors Community Hospital
Lanham, MD USA

Petra Klinge, MD, PhD

Neurosurgery
The Warren Alpert Medical School of
Brown University
Providence, RI, USA

Myles Koby, MD

Diagnostic Radiology and Neuroradiology

Roberto Mendoza-Londono, MD

Paediatrics and Molecular Genetics
Hospital for Sick Children
University of Toronto
Toronto, ON.

Dr. Howard Meng

Anesthesia Resident
Mount Sinai Hospital

Elfreda Pretorius

Author and Motivational Speaker

Peter Rowe, MD

Adolescent Health
Johns Hopkins Hospital
Baltimore, MD, USA

Peter Vadas, MD

Allergy and Immunology
St. Michaels Hospital, University of Toronto
Toronto, ON

Planning Committee:

Norman Buckley, MD, FRCPC

Professor of Anaesthesia
McMaster University

Juan Guzman, MD, MSc, FRCPC

Assistant Professor of Medicine
McMaster University

Kristianna Martiniuk, MD, FCFP

Family Medicine

Christina Pridmore

Registered Kinesiologist, Osteopathy

Sandy Smeenk

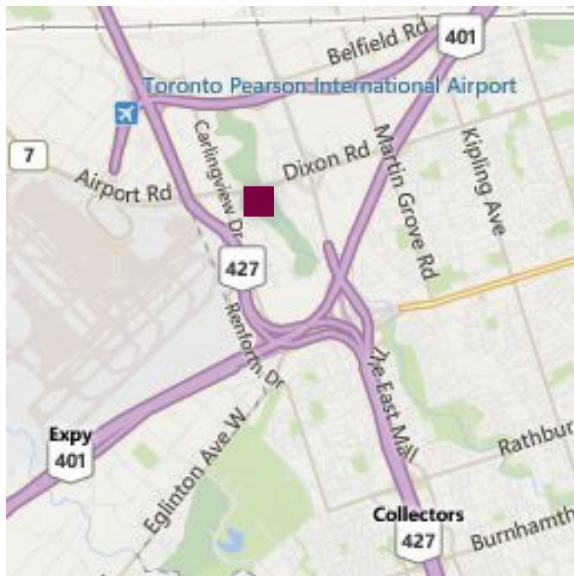
Founder and Executive Director
The ILC Charitable Foundation

Conference Location:

Toronto Airport Marriott Hotel 901 Dixon Rd, Toronto, ON M9W 1J5

The hotel is located on the Southeast corner of Dixon Road and Carlingview Drive 5 minutes from the airport and easily accessible from Toronto's major roadways.

Hotel Accommodation Group Rate: \$106/night
Rate is guaranteed until October 10th. Bookings should be made through this link:
<https://resweb.passkey.com/go/ILCFoundation>



Conference Packages

Conference package includes a hot breakfast, coffee breaks, and a hot lunch.

Cancellation Policy

Cancellations received before October 29 will be refunded. No refunds will be made after this date.

Liability

The ILC Foundation hereby assumes no liability for any claims, personal injury, or damage:

- To any individual attending this conference.
- That may result from the use of technologies, program, products and/or services at this conference.
- That may arise out of, or during this conference.

Freedom of Information & Protection of Privacy Act

The information will be used for administrative purposes, including: your registration in the course; preparation of course materials for your use and to notify you of other courses or pertinent information. Financial information will be used to process applicable fees and will be retained for future reference. This information is protected and is being collected pursuant to section 39(2) and section 42 of the Freedom of Information and Protection of Privacy Act of Ontario (RSO 1990).

Registration Fees

Saturday, November 1st Session

Physicians.....	\$125
Other Health Professionals.....	\$100
Resident/Student & Patient Population*.....	\$60

Sunday, November 2st Session

Physicians only	\$ 0
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* Children are not permitted in the conference setting as it distracts from the learners.

Accreditation Statements

McMaster University, Continuing Health Sciences Education Program (CHSE) is fully accredited by the Committee on Accreditation of Continuing Medical Education (CACME) to provide CFPC Mainpro and RCPSC Maintenance of Certification (MOC) study credits for Continuing Medical Education.

This program meets the accreditation criteria of The College of Family Physicians of Canada and has been accredited by McMaster University, Continuing Health Sciences Education Program for up to 8.25 Mainpro-M1 credits.

This activity is an Accredited Group Learning Activity (Section 1) as defined by the Maintenance of Certification program of The Royal College of Physicians and Surgeons of Canada and approved by McMaster University, Continuing Health Sciences Education Program for up to 8.25 MOC Section 1 credits. Through an agreement between the Royal College of Physicians and Surgeons of Canada and the American Medical Association, physicians may convert Royal College MOC credits to AMA PRA Category 1 Credits™.

Information on the process to convert Royal College MOC credit to AMA credit can be found at:
www.ama-assn.org/go/internationalcme.

Each healthcare provider should claim only those hours of credit that he/she actually spent in the educational activity. Participants that receive a Certificate of Attendance and need to report their participation to their own regulatory bodies, should attach a copy of the program brochure ensuring the accreditation statement is visible with a copy of their Certificate of Attendance.

Disclosure of Potential Conflicts of Interest

In keeping with accreditation guidelines, McMaster University; Continuing Health Sciences Education requires all speakers and planning committee members participating in this event to disclose any involvement with industry or other organizations that may potentially influence the presentation of the educational materials or program being offered.

Disclosure must be done verbally and using a slide prior to the speaker's presentation.