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
• Chiropodists
• Orthopedics
• Nurses
• Allied Health Professionals
• Students & Residents

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

For More Information Contact:
Sandy Smeenk, Event Coordinator
Phone: 416-822-3494
Email: Sandy@theilcfoundation.org
Website: www.theilcfoundation.org

TO REGISTER GO TO: https://2014edscanadianconference.eventbrite.com
## All Registrants

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Presenter</th>
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<tbody>
<tr>
<td>8:00 - 8:45</td>
<td><strong>REGISTRATION/BREAKFAST/NETWORKING</strong></td>
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<tr>
<td>8:45 - 9:00</td>
<td>Welcome: Affirming the importance of guideline development with EDS as a model of optimal care</td>
<td>Dr. Norm Buckley</td>
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<tr>
<td>9:00 - 9:30</td>
<td>Outcomes from the 2013 Scientific Workshop: Clinical Experience in EDS</td>
<td>Dr. Allan Gordon &amp; Howard Meng</td>
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<tr>
<td>9:30 - 10:00</td>
<td>Clinical Genetics Presentation of EDS and 2014 Update</td>
<td>Dr. Clair Francomano</td>
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<tr>
<td>10:00 - 10:30</td>
<td>Molecular Genetics Presentation of EDS and 2014 Update</td>
<td>Dr. Roberto Mendoza</td>
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<tr>
<td>10:30 - 10:45</td>
<td><strong>BREAK</strong></td>
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<tr>
<td>10:45 - 11:15</td>
<td>Chronic fatigue in EDS and its impact on quality of life</td>
<td>Dr. Peter Rowe</td>
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<tr>
<td>11:15 - 11:45</td>
<td>Postural Orthostatic Tachycardia Syndrome (POTS)/Dysautonomia in EDS</td>
<td>Dr. Juan Guzman</td>
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<tr>
<td>11:45 - 12:15</td>
<td>Mast cell in EDS and its impact on quality of life</td>
<td>Dr. Peter Vadas</td>
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<td>12:15 - 1:15</td>
<td><strong>LUNCH/NETWORKING</strong></td>
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<td>1:15 - 1:45</td>
<td>Tethered cord in EDS</td>
<td>Dr. Petra Klinge</td>
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<td>1:45 - 2:15</td>
<td>Neurosurgical management of EDS</td>
<td>Dr. Fraser Henderson</td>
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<td>2:15 - 2:45</td>
<td>Neuroradiology and Measurements in EDS</td>
<td>TBA</td>
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<td>2:45 - 3:00</td>
<td><strong>BREAK</strong></td>
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<tr>
<td>3:00 - 3:30</td>
<td>Panel Discussion and Q&amp;A</td>
<td>Moderator: Dr. Kristianna Martiniuk</td>
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<td>3:30 - 4:00</td>
<td>Planning for the short, medium and long term</td>
<td>Break out groups</td>
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<tr>
<td>4:00 - 4:30</td>
<td>Networking / Evaluate the process of working within a multidisciplinary collaborative/perceived value</td>
<td>Break out groups</td>
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<td>4:30 - 5:00</td>
<td>Looking forward</td>
<td>Sandy Smeenk</td>
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## Academic Registrants Only

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<td>Guided Meditation</td>
<td>Elfreda Pretorius</td>
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<tr>
<td>3:30 - 4:00</td>
<td>Healthy Lifestyle: Psychology and Nutrition</td>
<td>Dr. Kim Daniel</td>
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<tr>
<td>4:30 - 5:00</td>
<td>Looking forward</td>
<td>Susan Hawkins</td>
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## Patient/Family Registrants

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<td>9:00 - 11:00</td>
<td>Exploring What Needs to be Known for Changing Practices-Patient and Physician Round Table. (A small, representative group of EDS patients has been invited.)</td>
<td>Moderator: Dr. Allen Finley</td>
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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

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Presenters:

**Norman Buckley, MD, FRCPC**
Professor of Anaesthesia
McMaster University

**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

**Roberto Mendoza-Londono, MD**
Paediatrics and Molecular Genetics
Hospital for Sick Children
University of Toronto
Toronto, ON

**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

Registration Fees

Saturday, November 1st Session
Physicians..................................................$125
Other Health Professionals...........................$100
Resident/Student & Patient Population*...........$60

Sunday, November 2nd Session
Physicians only .....................................................$ 0

* Children are not permitted in the conference setting as it distracts from the learners.

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.

Conference Packages

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

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).