



**Saturday, November 7, 2020**

**9:00am – 4:30pm (EST)**

## **PAIN - SHEDDING LIGHT ON INEQUITIES OF HEALTH**

Ehlers-Danlos Syndromes and Related Disorders, as well as Spontaneous Intracranial Hypotension Caused by a Spinal Cerebrospinal Fluid Leak



## Pain

### *Shedding Light on Inequities of Health*

Ehlers-Danlos Syndromes and Related Disorders, as well as Spontaneous Intracranial Hypotension Caused by a Spinal Cerebrospinal Fluid Leak

## WELCOME

The ILC Charitable Foundation (“**The ILC**”) is excited to be co-hosting its eighth-annual conference with Spinal Cerebrospinal Fluid Leak Canada (“**Spinal CSF Leak Canada**”). This conference will expand the understanding and resources on Ehlers-Danlos Syndromes (“**EDS**”) and the related conditions of heritable connective tissue disorders, as well as Spontaneous Intracranial Hypotension (“**SIH**”) caused by spinal cerebrospinal fluid (“**CSF**”) leaks. Educational focus will be on current best evidence from leading Canadian and international specialists while providing healthcare professionals and patients resources to manage symptoms and improve quality of life.

While last year's in-person format provided great opportunities for networking between professional peers and individuals alike, we have no doubt that this year's remote web-conferencing format will allow people to connect and learn in equally meaningful ways.

The ILC and Spinal CSF Leak Canada would like to extend a heartfelt thank you to all participants, speakers, academic program leaders, vendors, sponsors and volunteers for their help in organizing this event. Your dedication and support are helping to inform policy and give hope.

## Message from The ILC

The ILC mission is to help individuals overcome the challenges of living with EDS and other chronic pain diseases through knowledge sharing resources, awareness, education, peer support and research to find cures.

2020 has brought so many challenges to people across our country and the globe. From wild-fires to COVID-19, our resilience has been tested beyond the daily pain that our members already face. For The ILC, as a charity in its 10<sup>th</sup> year of developing programs that have helped to make a difference, we have been devastated by the loss of our Founding Ambassador of Hope, Brooklyn Mills. Brooklyn passed away suddenly on Sunday, August 16<sup>th</sup> due to complications of EDS. Her presence is felt every day by those of us that were lucky enough to know her. The energy that she brought to people with the constant message of “*never give up*” resonates and we continue to carry her torch and remain committed in the promise to not give up. Please see the tribute page in recognition of the impact she has made.

In these challenging times, we embrace new technology to help us come together for this important learning event. We are going to miss connecting in person with each of you, but we are grateful to know that you are with us, and we hope that this educational experience will prove impactful.

**The ILC**  
Sandy Smeenk



Brooklyn (right) with Olivia speaking  
at the 2017 conference  
Forever in our hearts and never forgotten

## Message from Spinal CSF Leak Canada

Spinal CSF Leak Canada is a not-for-profit national health organization that is run entirely by volunteers. Our vision is to improve the health and lives of individuals suffering from SIH caused by spinal CSF leaks, and to help equip the Canadian medical community to combat this condition.

Despite the challenging times imposed upon us by the current pandemic, we continue in our efforts to move forward. This conference marks the first SIH conference in Canada and is a true milestone for our organization. We are pleased to be joining The ILC and taking part in shedding light on SIH.

We are extremely grateful to our medical advisory team for their efforts in advancing the SIH cause in Canada. Historically, knowledge of public awareness of SIH was virtually non-existent, and today knowledge of the condition within the medical community remains sparse. In fact, under-diagnosis and/or misdiagnosis is extremely common, and treatment options are limited for most individuals suffering from the condition.

We hope that through our educational initiatives and the raising of awareness that comes with those initiatives, patients will in time have better access to diagnostic testing, treatment, and care. To those suffering from SIH and related disorders, to those healing from it, and to those that have “survived” it, remember that you are not alone. Together we will conquer SIH.

**Spinal CSF Leak Canada**  
Bahareh N. Cloutier

[www.spinalcsfleakcanada.ca](http://www.spinalcsfleakcanada.ca)

[Visitez notre site en Français](#)

## OVERVIEW

The ILC is excited to have created a platform of participation through which multidisciplinary clinicians and researchers, patient groups and non-profits can expand the types of resources provided to members. This year's conference will build upon the momentum achieved in 2019. The 2019 ILC Annual Conference provided valuable resources highlighted by organizational attendees such as Spinal CSF Leak Canada, Dysautonomia Canada,

Mastocytosis Society of Canada and Solutions for Kids in Pain. Each year, we work to bring world renowned multidisciplinary speakers to present on their respective areas of expertise. Healthcare professionals, individuals and caregivers attend with a genuine interest to improve the level of understanding, care and support services that can be provided through knowledge sharing.



## TARGET AUDIENCE

Target Audience: Patients, Caregivers, Youth, Multidisciplinary Healthcare Professionals including:

- Anesthesiologists
- Cardiologists
- Emergency Physicians
- Family Physicians
- Pediatricians
- Geneticists
- Hematologists
- Immunologists & Allergists
- Internal Medicine
- Kinesiologists
- Neurologists
- Neuroradiologists
- Neurosurgeons
- Nurses
- Occupational Therapists
- Orthopedics
- Physiotherapists
- Psychiatrists
- Psychologists
- Rheumatologists
- Social Workers
- General & Orthopedic Surgeons

## CONTINUING PROFESSIONAL DEVELOPMENT

This conference has been awarded Continuing Professional Development credits which are summarized as follows:

- College of Family Physicians of Canada = Mainpro+: 1 credit/1hour & Group Learning: 6.0 credits/6 hours
- Royal College Maintenance of Certification Section 1 = 6.0 credits/6 hours



## LEARNING OBJECTIVES

Participants will be able to describe the best-evidence informed approach for management of multi-systemic manifestations in EDS and other Heritable Disorders of Connective Tissue.

- Participants will be provided with tools to help express compassion and empathy in healthcare delivery to develop patient/physician partnerships
- Participants will construct a practical approach for office-based screening of individuals with EDS and HCTD with co-existent spinal CSF leaks, SIH, and mast cell disorders.
- Participants will receive an update on SIH including current imaging protocol
- Participants will obtain resources regarding treatment and tools to manage symptoms and pain to improve quality of life.
- In patients with SIH caused by a spinal CSF Leak, understanding and expanding knowledge about diagnostic criteria and treatment of SIH caused by a cerebrospinal fluid leak in the spine, and the predisposing factors linked with a spinal CSF leak including connective tissue disorders such as EDS type II.

## PLANNING COMMITTEE

*(listed alphabetically)*

### The ILC

**Nimish Mittal**, MD, Assistant Professor, Department of Medicine, Anesthesiology, University of Toronto

**Maxim Rachinsky**, MD, Family Physician

**Jacqueline Raposo**, Director, The ILC

**Sandy Smeenk**, Director & Co-Founder of The ILC

### Spinal CSF Leak Canada

**Farnaz Amoozegar**, MD, MSc, FRCPC, Clinical Associate Professor, Dept Clinical Neurosciences, Cumming School of Medicine, University of Calgary and Hotchkiss Brain Institute

**Bahareh N. Cloutier**, Chair & Co-Founder of Spinal CSF Leak Canada

**Azadeh N. Lavictoire**, President of Spinal CSF Leak Canada

**Philip Peng**, MD, MBBS, FRCPC, Founder (Pain Medicine), Professor, Department of Anesthesiology and Pain Management, UHN, Sinai Health Network, Women's College Hospital, University of Toronto

**Rosann Seviour**, MD, MSc Epi, FRCPC, Family Physician, St. John's Newfoundland & Labrador

## PRESENTERS & MODERATORS

**Farnaz Amoozegar, MD, MSc, FRCPC**, Clinical Associate Professor, Dept Clinical Neurosciences, Cumming School of Medicine, University of Calgary and Hotchkiss Brain Institute



### **SPONTANEOUS INTRACRANIAL HYPOTENSION: A FOCUS ON CLINICAL CHARACTERISTICS**

Dr. Farnaz Amoozegar is a neurologist and clinical associate professor at the University of Calgary. She completed undergraduate studies and her medical training at the University of Calgary, followed by a neurology residency at the University of Ottawa. She then returned to Calgary and completed subspecialty training in the area of Headache and Facial pain with Dr. Werner Becker. Over the next few years, her interest in clinical research led her to complete a Master's degree in Clinical Epidemiology. Currently, Dr. Amoozegar practices as a neurologist and headache specialist at the University of Calgary and the Calgary Headache Assessment and Management Program. In addition to clinical practice, she is heavily involved in clinical research, including investigator-initiated and industry-sponsored clinical trials, cohort studies, and a registry for Spontaneous Intracranial Hypotension. She is also involved in teaching of fellows, residents and medical students in various settings. Dr. Amoozegar is a member of the Medical Advisory Team of Spinal CSF Leak Canada.

**Ian Carroll, MD**, Anesthesiology, Associate Professor of Anesthesiology, Perioperative and Pain Medicine (Adult Pain) at the Stanford University Medical Center



### **THE PROBLEM OF THE CHRONIC POST-DURAL PUNCTURE HEADACHE- THE ROLE PHYSICIANS PLAY IN CREATING INTRACRANIAL HYPOTENSION, AND WHAT TO DO ABOUT IT.**

In 2015 Dr. Ian Carroll collaborated With Stanford's Neuroradiology and Neurology Headache divisions to create the Stanford CSF Leak Headache Program after his daughter suffered through an initially undiagnosed CSF leak. This experience left him with a passion for helping patients experiencing CSF leaks around the world. He is board-certified in four different specialties: Headache Medicine by the United Council for Neurologic Subspecialties; Addiction Medicine by the American Board of Addiction Medicine; Pain Medicine by the American Board of Anesthesiology; and Anesthesiology by the American Board of Anesthesiology. His primary focus is on spinal cerebrospinal fluid (CSF) leaks. He has spoken at numerous national meetings on CSF leaks, management of the pain from nerve injuries, and factors influencing opioid cessation. He has conducted visiting professorships at Johns Hopkins University, Vanderbilt University, Yale University, University of California at Davis Medical Center, and others.



Dr. Carroll graduated summa cum laude and Phi Beta Kappa from Columbia University, and then graduated with an M.D. from Columbia University. He was a Research Fellow at the Experimental Immunology Branch at the National Cancer Institute at the National Institutes of Health in Bethesda Maryland. He completed his internship in Internal Medicine, residency in Anesthesiology, fellowship in Pain Medicine, and was elected Chief Resident of Anesthesiology from 2001-2002 at Stanford University Medical Center. He joined Stanford's Department of Anesthesiology as a primary teaching and research faculty in the Pain Management clinic in 2004.

Dr. Carroll completed Stanford's two-year Clinical Research training program earning a M.S. degree in clinical epidemiology from Stanford in 2006. He has published over 50 original articles including research funded by the Foundation for Anesthesia Education and Research (FAER); the National Institute for Drug Abuse (NIDA); and the Stanford Institute for Neuro-Innovation & Translational Neurosciences (SINTN).

In addition to his clinical and research responsibilities, Dr. Carroll helps select and train Stanford Anesthesia residents, Pain Management Fellows and Neurology Headache Fellows. Dr. Carroll is a member of the Medical Advisory Team of Spinal CSF Leak Canada.

## **Clair Francomano, MD, Medical & Molecular Genetics, University of Indiana**



### **DIAGNOSING HEREDITARY DISORDERS OF CONNECTIVE TISSUE, WITH A FOCUS ON DIFFERENT TYPES OF EHLERS-DANLOS SYNDROMES, AS WELL AS WHEN TO THINK ABOUT CSF LEAKS IN THIS POPULATION**

Dr. Clair Francomano received her undergraduate degree at Yale University and her medical degree from The Johns Hopkins University School of Medicine. She trained in internal medicine and medical genetics at Johns Hopkins and joined the full-time Hopkins faculty in 1984. From 1994-2005, she served in the Intramural Research Program of the National Institutes of Health. She joined Greater Baltimore Medical Center's Harvey Institute of Human Genetics in 2005 and was Director of Adult Genetics from 2005 – 2019. In 2019 she moved to Indiana University School of Medicine as Professor of Medical and Molecular Genetics. Dr. Francomano is board-certified in internal medicine, clinical genetics and clinical molecular genetics. She is a member of the American College of Physicians, the American Society of Human Genetics and the American Society for Clinical Investigation and is a founding fellow of the American College of Medical Genetics. Her clinical and research interests include the hereditary disorders of connective tissue, with an emphasis on the Ehlers-Danlos Syndromes and Hypermobility Spectrum Disorders. She received EDNF's Shining Star award in 2012 and the Lifetime Achievement Award from the Ehlers-Danlos Society in 2019 for her dedication to people with EDS. As a Medical Advisor to The ILC, she values the opportunity to interact with the Canadian patient population and providers caring for patients with EDS and Hypermobility Spectrum Disorders.

**Linda Gray-Leithe, MD, Neuroradiology, Duke University, Associate Professor of Radiology at Duke University Medical Center Durham, NC**



### **SPONTANEOUS INTRACRANIAL HYPOTENSION: AVOIDING MISDIAGNOSIS**

Dr Linda Leith-Gray (also known as Dr. Gray) began her career at Duke Medical Center in neuroradiology and has been on faculty at Duke in Neuroradiology for 33 years. Initially her career was occupied with running the residency-training program for a dozen years. In 2002 when CT fluoroscopy came to fruition, she initiated CT fluoroscopic guided pain management and pioneered CT interventions along the spinal axis including central cervical epidurals extending from C1-2 and throughout the cervical, thoracic and lumbar spine. In 2006, she initiated a program in CT fluoroscopic guided interventions for the treatment of spontaneous intracranial hypotension. She has mentored at least 15 neuroradiologists and 8 institutions throughout the United States in the performance of these procedures and has initiated the concept of cerebrospinal fluid (CSF) pressure problems as a secondary cause of migraine headaches throughout the headache community. She is now an invited speaker on the subject, giving multiple lectures throughout the year.

In the field of Spontaneous Intracranial Hypotension Dr Gray pioneered targeted percutaneous fibrin glue and bloodpatching and has now mentored and trained 3 neuroradiologists at Duke who are now part of the “spine team” treating and diagnosing patients with spontaneous intracranial hypotension. A CT scanner equipped with CT fluoroscopy is dedicated to the diagnosis and treatment of these individuals. A visiting fellowship program has developed to train physicians and headache specialists from other institutions. There is now funding for a 6 month – 1 year dedicated CT spine intervention fellowship program which will train young physicians in the techniques of CT guided interventions. Recently she initiated a multidisciplinary CSF leak conference in the Triangle to educate more physicians and midlevel providers in considering and recognizing CSF pressure as a possible cause of headache when other treatment modalities fail. Additionally, Dr Gray was the first to recognize and describe rebound high pressure as a consequence of bloodpatching. The spine team at Duke consists of 4 neuroradiologists, 2 physician assistants, 2 nurses and 4 support staff comprised of primarily CT technologists and a research coordinator who assist our patients in scheduling and treatment. We treat patients from all over the world and are dedicated to the diagnosis and treatment of patients with CSF pressure disorders as a secondary cause of headache. We now see over 400 patients per year for the diagnosis and treatment of possible CSF pressure disorders. Dr. Gray is a member of the Medical Advisory Team of Spinal CSF Leak Canada.



**Nimish Mittal**, MD, Assistant Professor, Department of Medicine, Division of PM&R, Department of Anesthesiology and Pain Medicine (cross), Department of Kinesiology and Physical Education (cross) University of Toronto, Academic Program Director



#### **MODERATOR**

Dr. Nimish Mittal is the Medical Lead of the Ehlers-Danlos Syndrome Program. He is a physiatrist at the University of Toronto with subspecialty fellowship training in chronic pain management. His expertise involves management of complex connective tissue disorders and comprehensive multimodal pain management including USG and fluoroscopy guided interventions. He is a committee member of the Pain Working Group of the International Consortium of the Ehlers-Danlos Syndrome and the newsletter liaison of the regenerative pain medicine special interest group of the American Society of Regional Anesthesia and Pain Medicine. He is also pursuing a Master of Science in Health Research Methodology at McMaster University.

**Philip Peng**, MD, MBBS, FRCPC, Founder (Pain Medicine), Professor, Department of Anesthesiology and Pain Management, UHN, Sinai Health Network, Women's College Hospital, University of Toronto



#### **SPONTANEOUS INTRACRANIAL HYPOTENSION: CHALLENGES IN MANAGING SIH PATIENTS – A CANADIAN PERSPECTIVE**

Dr. Philip Peng is the professor in the Department of Anesthesiology of University of Toronto. He is a leader, researcher, educator and pioneer in the application of ultrasound for pain medicine. His innovative research led to different new procedures in pain intervention. He received numerous educational awards including the John J Bonica award from ASRA and ESRA-Spain Distinguished Service Award.

He also has a special interest in managing spontaneous intracranial hypotension. Dr. Peng is a member of the medical advisory board of Spinal CSF Leak Canada.

He has delivered more than 350 lectures and workshops nationally and internationally. He has edited 8 books and published more than 200 peer-reviewed publications and book chapters.

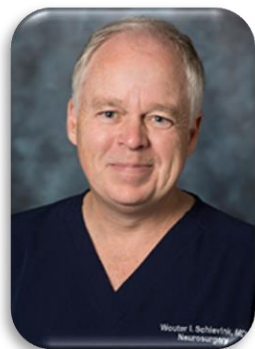
**Max Rachinsky, MD, Family Physician, Chronic Pain Management, University of Toronto**



#### **MODERATION**

Following graduation from the University of Toronto Family Medicine Residency Program, Dr. Maxim Rachinsky completed a Fellowship in Chronic Pain Management and connective tissue disorder at Toronto General Hospital. As a family physician in the GoodHope Ehlers-Danlos Syndrome Clinic, his current roles include initial patient assessment and follow-up, as well as advice and strategies on pain management.

**Wouter I. Schievink, MD, Professor, Neurosurgery, Director, Microvascular Neurosurgery Program, Cedars-Sinai, Los Angeles, CA**



#### **SPONTANEOUS INTRACRANIAL HYPOTENSION: FROM GENE TO SURGERY**

Dr. Wouter Schievink was born and raised in Amsterdam. After finishing medical school, he immigrated to the United States where he went to the Mayo Clinic for neurosurgical training. He has been at Cedar Sinai in Los Angeles since 1998. Dr. Wouter Schievink is a member of the Medical Advisory Team of Spinal CSF Leak Canada.

**Rosann Seviour, MD, MSc Epi, FRCPC, Family Physician, St. John's Newfoundland & Labrador**



**SPONTANEOUS INTRACRANIAL HYPOTENSION: A SURVIVOR GUIDE FOR PATIENTS AND PRIMARY HEALTH CARE PROVIDERS**

Dr. Rosann Seviour graduated from Memorial University Medical School in 1987. She interned in Montreal and then lived and practiced as a family doctor in various provinces, New Zealand and Germany. She returned to study Community Medicine at the University of Ottawa where she also completed her Masters in Epidemiology. She has worked as a Medical Officer of Health and as a family physician until her recent return to full time work as a Medical Officer of Health during the COVID-19 pandemic. Dr. Rosann Seviour is a member of the Medical Advisory Team of Spinal CSF Leak Canada.

**Peter Vadas, MD, PhD, Allergist & Clinical Immunologist, University of Toronto**



**ADVANCES IN OUR UNDERSTANDING OF MAST CELL ACTIVATION SYNDROME**

Dr. Peter Vadas is Head of the Division of Allergy and Clinical Immunology at St. Michael's Hospital, Medical Director of the Regional Anaphylaxis Clinic at St. Michael's Hospital, and Associate Professor of Medicine at the University of Toronto. He is Past President of the Anaphylaxis Foundation of Canada, Past Chair of the Anaphylaxis Committee of the American Academy of Allergy, Asthma and Immunology and Past Head, Section of Anaphylaxis and Adverse Reactions of the CSACI.

# **PAIN - Shedding Light on Inequities of Health**

Ehlers-Danlos Syndromes and Related Disorders, as well as Spontaneous Intracranial Hypotension Caused by a Spinal Cerebrospinal Fluid Leak

## **MULTIDISCIPLINARY PHYSICIAN & PATIENT LEARNING CONFERENCE**

November 7<sup>th</sup>, 2020

### **CONFERENCE ACADEMIC PROGRAM DIRECTOR AND MODERATORS**

Dr. Farnaz Amoozegar, MD, MSc, FRCPC, Neurology, University of Calgary, Clinical Professor of Neurology

Dr. Nimish Mittal, Assistant Professor, Department of Medicine, Division of PM&R, Department of Anesthesiology and Pain Medicine (cross), Department of Kinesiology and Physical Education (cross)  
University of Toronto, Academic Program Director

Dr. Max Rachinsky, Family Physician, Chronic Pain Management, University of Toronto

### **MORNING SESSION**

**EACH PRESENTATION IS 30 MINUTES FOLLOWED BY 15 MINUTES OF Q & A VIA "CHAT"**

- |          |                                                                                                                                                                                                                                                             |
|----------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 9:00 am  | <b>Welcome and Opening Addresses</b><br>Sandy Smeenk, Director & Founder of The ILC Foundation<br>Bahareh Nourbakhsh Cloutier, Chair & Founder of Spinal CSF Leak Canada<br>Dr. Nimish Mittal, University of Toronto, Academic Program Director             |
| 9:05 am  | <b>Farnaz Amoozegar, MD</b> <ul style="list-style-type: none"><li>▪ Spontaneous Intracranial Hypotension: A Focus on Clinical Characteristics</li></ul>                                                                                                     |
| 9:45 am  | <b>Philip Peng, MD</b> <ul style="list-style-type: none"><li>▪ Challenges in Managing SIH Patients - A Canadian Perspective</li></ul>                                                                                                                       |
| 10:30 am | <b>Clair Francomano, MD</b> <ul style="list-style-type: none"><li>▪ Diagnosing Hereditary Disorders of Connective Tissue, with a Focus on Different Types of Ehlers-Danlos Syndromes, as well as When to Think About CSF Leaks in This Population</li></ul> |
| 11:15 am | <b>Linda Gray-Leith, MD</b> <ul style="list-style-type: none"><li>▪ Spontaneous Intracranial Hypotension: Avoiding Misdiagnosis</li></ul>                                                                                                                   |
| 12:00 pm | <b>Interactive Speakers Panel with Morning Presenters</b> <ul style="list-style-type: none"><li>▪ Ask Your Questions Live and Interact with the Panel</li></ul>                                                                                             |

## AFTERNOON SESSION

EACH PRESENTATION IS 30 MINUTES FOLLOWED BY 15 MINUTES OF Q & A VIA “CHAT”

- |         |                                                                                                                                                                                                                          |
|---------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1:00 pm | <b>Rosann Seviour, MD</b> <ul style="list-style-type: none"><li>▪ Spontaneous Intracranial Hypotension: A Survival Guide for Patients and Primary Health Care Providers</li></ul>                                        |
| 1:45 pm | <b>Peter Vadas, MD</b> <ul style="list-style-type: none"><li>▪ Advances in Our Understanding of Mast Cell Activation Syndrome</li></ul>                                                                                  |
| 2:30 pm | <b>Ian Carroll, MD</b> <ul style="list-style-type: none"><li>▪ The Problem of the Chronic Post-Dural Puncture Headache- The Role Physicians Play in Creating Intracranial Hypotension, and What to do About it</li></ul> |
| 3:15 pm | <b>Wouter Schievink, MD</b> <ul style="list-style-type: none"><li>▪ Spontaneous Intracranial Hypotension: From Gene to Surgery</li></ul>                                                                                 |
| 4:00 pm | <b>Interactive Speakers Panel with Afternoon Presenters</b> <ul style="list-style-type: none"><li>▪ Ask Your Questions Live and Interact with the Panel</li></ul>                                                        |
| 4:30 pm | Closing Remarks                                                                                                                                                                                                          |

**THANK YOU**

## INFORMATION & RESOURCES

### THE ILC RESOURCES

[Canadian Pain Task Force – Working towards a National Pain Strategy](#)

[COVID-19 - Stay safe – Be calm – We're all in this together](#)

[Emergency and Anesthetic Precautions for EDS](#)

[What is Chronic Pain?](#)

[Toronto EDS Clinics - Adult and Children/Youth](#)

### SPINAL CSF LEAK CANADA RESOURCES

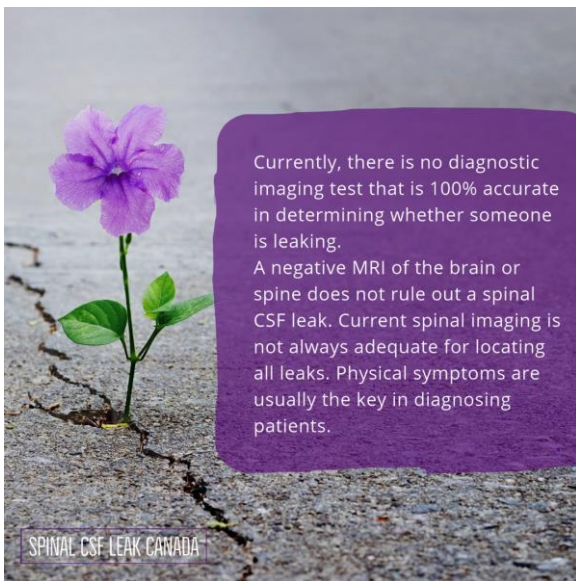
[Spontaneous Intracranial Hypotension](#)

[Intercranial Hypotension Fact Sheet](#)

[Rebound Intracranial Hypertension](#)

[Fuite Spinale LCS Canada \(En français\)](#)

[Spontaneous Intracranial Hypotension - VIDEOS](#)



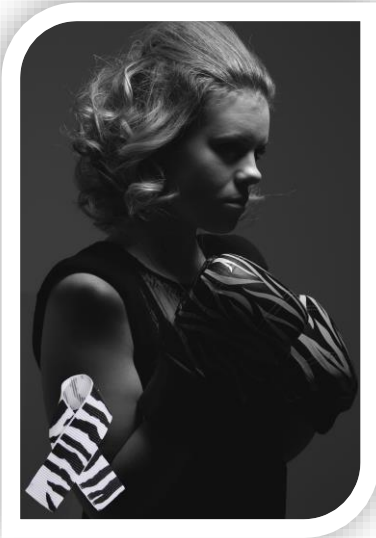
Currently, there is no diagnostic imaging test that is 100% accurate in determining whether someone is leaking. A negative MRI of the brain or spine does not rule out a spinal CSF leak. Current spinal imaging is not always adequate for locating all leaks. Physical symptoms are usually the key in diagnosing patients.

SPINAL CSF LEAK CANADA



## PATIENT STORIES

THE **ILC** FOUNDATION  
Chronic Pain 🍁 Ehlers Danlos 🍁 HCTD

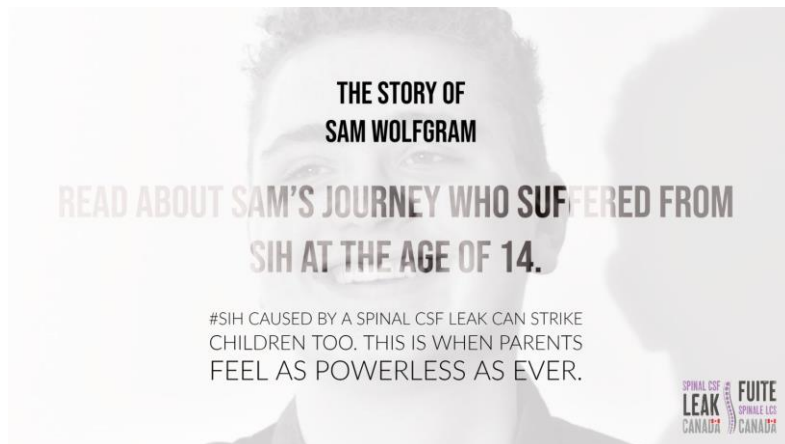


Help raise awareness by sharing your patient story  
[Read about the journeys of patients affected by EDS](#)  
Submit your story [here](#).

**Canadian Healthcare Professional Self Register Directory**  
To be included in The ILC Canadian directory, please register [here](#).



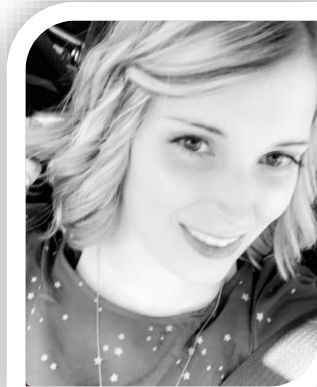
Help raise awareness by sharing your patient story  
[Read about the journeys of Canadians affected by SIH caused by a Spinal CSF Leak](#)  
Submit your story [here](#).



## Tribute to Brooklyn Mills



Video: Presenting at the 2017 Conference



Brooklyn Mills  
Never Forgotten  
Forever in our Hearts



Video: Advocating for access to EDS neurosurgical care to the Legislative Assembly of Ontario



Raising awareness at fundraising event



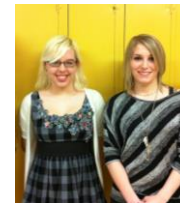
Friendships through Peer Support



Informing research priorities at SickKids



Video: Patients and Parents Speak



Speaking at High School about EDS & invisibilities of Chronic Pain




We think of that very first video shoot that was created with hopes of having a dedicated centre of excellence for people with EDS. Families that became members of The ILC came together to meet our Ambassador of Hope, Brooklyn Mills. She spoke genuinely about the importance of peer support as she learned herself in that experience that she was not alone. Over the years as she was able, Brooklyn spoke publicly where she bravely and stoically imprinted on the hearts of everyone she met in profound ways. Whether at a school, conference, a government relations presentation or a fundraising event, Brooklyn would have men and women alike in tears as she used her voice to share the journeys of so many.

We want to express our gratitude to Brooklyn and her family for wanting to see better care for all. This kind of pain and loss, it cracks us open. But we are going to hold on to the magic and resilience of Brooklyn, with angel wings on our shoulders.

## CONFERENCE IT SPONSOR

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Please sign on to the afternoon session at 12:55 to learn more about how *Finchloom* has become an impassioned sponsor in providing their expertise!

## CONFERENCE SUPPORTERS




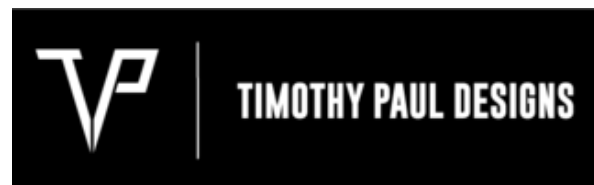
**Digisplint Inc**



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We make custom finger splints to keep your fingers from hyperextending and dislocating so that everyday activities no longer cause pain or fatigue.





**THANK YOU!**

Your attendance is helping to improve access to care  
through awareness and education!



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e-Visit us: [www.spinalcsfleakcanada.ca](http://www.spinalcsfleakcanada.ca)