



ANNUAL REPORT | 2019  
March 3<sup>rd</sup>, 2020

epilepsy  
durham region



## TABLE OF CONTENTS

EXECUTIVE MESSAGE .....	4
OUR MISSION, VISION AND VALUES .....	5
BOARD OF DIRECTORS .....	5
A YEAR IN REVIEW   2019 IN A GLANCE .....	6
VOLUNTEER ACKNOWLEDGEMENTS .....	8
VOLUNTEER AWARDS .....	9
CANNABIS AND EPILEPSY .....	10
THE CHALLENGE IS EPIC .....	11
STATEMENT OF OPERATIONS .....	12
FINANCIAL STATEMENT .....	13
NOTES .....	14
AGENCY INFORMATION .....	15



## EXECUTIVE MESSAGE

### Empower | Engage | Influence

On behalf of the Board of Directors, I wish to express my gratitude to the volunteers, associate members, and staff of Epilepsy Durham Region (EDR) whose dedication to this agency's mission and values is commendable. Many members of our community have contributed to the successful effort to build a sustainable, compassionate and knowledgeable agency that serves the families touched by epilepsy in Durham Region.

Epilepsy Durham Region has been an influential voice at regional, provincial, and national levels, advocating for the establishment of consistent and appropriate standards of care, and protecting students with prevalent medical conditions in school. They continue to address the critical drug shortages that people with epilepsy face, and help to build much needed awareness through public education and outreach. This year placed a significant emphasis on recognizing and coping with the isolation that often impacts those with epilepsy – EDR is continuing their effort to maintain and grow their peer-to-peer program, connecting families so that they never feel alone.

Most notably, EDR celebrated a significant milestone in 2019 – the first anniversary of our local Clinic to Community Epilepsy Clinic. With a 200% increase in request for service in its first month of practice, EDR successfully engaged a second Epileptologist in 2019, continuing to positively influence how, when, and where people in Durham Region living with epilepsy receive specialized care.

Epilepsy Durham Region continues to be community focused and responsive to the needs of families, and strives to have its clients' voices heard. Much of what is accomplished year to year is a direct result of the feedback received from our stakeholders in the communities we service. We look forward to continuing to work alongside families, and fostering new partnerships in our community to establish innovative ways to enhance delivery of programs and services. Thank you for engaging with Epilepsy Durham Region and one another to influence opportunities for unified support in Durham Region.

*Cris Douglas – President*

It's  
Because  
of You!

## OUR MISSION

*We are committed to promoting independence and optimal quality of life for individuals living with epilepsy and their families through support, advocacy, and public education.*

————— be kind ♥

## OUR VISION AND VALUES

Creating a world where not another moment is lost to a seizure.

These serve as guidelines for our conduct and behaviour as we work towards our mission:

- Caring and empathic
- Integrity and honesty
- Accountability
- Efficient and cost effective management

I wish  
people  
understood

You're  
NOT  
Broken

You  
are more  
than what  
people say  
- stay strong

We are  
Stronger  
together  
#SCNBA strong

## OUR BOARD OF DIRECTORS

Cris Douglas	President
Cindy MacEwen	Vice President
Joseph Mauceri	Treasurer
Marla Labriola	Secretary
Debra Fraser	Director
Tracey German	Director
Randy Farmer	Director

### **NATIONAL | CANADIAN EPILEPSY ALLIANCE INITIATIVES**

Epilepsy Durham Region works collaboratively with epilepsy agencies coast to coast to implement initiatives of the Canadian Epilepsy Alliance (CEA). In 2019, the James Lind Alliance (JLA) assisted with the development of a Priority Setting Partnership amongst the JLA, the Ontario Brain Institute and EpLink, which includes patients, physicians, and community epilepsy agency representatives. The goal of this partnership is to identify the top ten unanswered questions about epilepsy in order to guide future epilepsy research. The CEA has made it a priority to ensure that physicians and families touched by epilepsy nationwide have their voice heard through this survey.

Additionally, Epilepsy Durham Region CEO, Dianne McKenzie, represents the CEA for the Best Medicines Coalition; this organization is currently dedicating their efforts to protect the Canadian drug supply from proposed changes to US legislation which could result in an increase in drug shortage issues in Canada.

Epilepsy Durham Region is honoured to continue to represent the voice of epilepsy in our community at a national level.

### **PROVINCIAL | GOVERNMENT RELATIONS TASK FORCE**

Epilepsy Durham Region is working collaboratively with representatives from Epilepsy South Central Ontario, Epilepsy Toronto, and Epilepsy Ontario as the Government Relations Task Force for Epilepsy. In 2019, the Task Force completed a pre-budget submission to the Ontario government which highlighted the current government healthcare costs associated with living with epilepsy, as well as how these costs could be reduced by investing in Community Epilepsy Agencies, specifically a community Epilepsy Educator. We worked tirelessly to have as many Ontarians sign our provincial petition to be included in the 2019 government budget, with good results. While our submission was received favourably, funding for Community Epilepsy Agencies was not fulfilled in the 2019 budget. After our Task Force was invited to resubmit our application for the 2020 budget, EDR CEO, Dianne McKenzie, and an Epilepsy Ontario representative met with the Deputy Premier, Christine Elliott, in early 2020 to discuss the submission further. We will continue to work alongside our fellow Community Epilepsy Agencies to advocate for funding to ensure province-wide consistent and appropriate epilepsy care.

## A YEAR IN REVIEW | 2019 IN A GLANCE

### REGIONAL | EPILEPSY CARE IN DURHAM REGION

In November of 2019, EDR celebrated the first anniversary of our local Clinic to Community (C2C) Epilepsy Clinic, located at the Oshawa Clinic. Prior to its launch, there was no specialized care to treat people living with epilepsy or a seizure disorder available in our community. Clinic to Community Epilepsy Clinic plays a critical role in the safety and well being of people with epilepsy. Embodied in the Epilepsy Clinic the comprehensive C2C referral program consists of information, support and training tools to help navigate the different aspects of an epilepsy diagnosis; connecting individuals with a network of support services and advocates for increased availability of mental health resources and social supports. Clinic to Community also aims to reduce unnecessary emergency department visits related to seizures and epilepsy. Families and individuals can participate in the C2C program with referral by doctor or by self-referral. Epilepsy Durham Region was excited to welcome Dr. Carlos M. Florez in 2019 to our C2C Epilepsy Clinic, dedicated every Tuesday of his practice to epilepsy patients; this means that our C2C Epilepsy Clinic now has two Epileptologists, a full-time EEG technician, and a satellite office for our Community Epilepsy Educator.

### REGIONAL | GRADE 5 PROGRAM ENDORSED BOARD WIDE

In October 2019, EDR was invited to present our Grade 5 *Thinking About Epilepsy* Education Program to members of the Durham District School Board (DDSB). After meeting with the DDSB Superintendent of Safe Schools and Mental Health & Well-Being, as well as the DDSB Operations Officer, we are happy to announce that our comprehensive and adaptive Epilepsy Education Program has been endorsed by the DDSB and has been circulated among the 133 schools in Durham Region. Our evidence-based program is associated with significant increase in epilepsy knowledge and positive attitudes, helping to ensure that children living with epilepsy in our community will reach their full academic potential, and feel safe and understood while attending school.



#### SCHEDULE A PRESENTATION

Complete our in service presentation request located on our website [www.epilepsydurham.com](http://www.epilepsydurham.com)

#### TALK ABOUT EPILEPSY

National Epilepsy Awareness Month is in March - ask us how you can become involved

#### SUPPORT 1 IN 100 STUDENTS WITH EPILEPSY

Build an accurate knowledge of what epilepsy is and teach students what they can do to help an individual living with seizures in the school community

## GETTING STARTED

There are three steps to getting started

- Step 1 - Raise awareness of epilepsy
- Step 2 - Complete Thinking About Epilepsy program
- Step 3 - Ensure students with epilepsy have a current Epilepsy Management Plan and Plan of Care (PMH ICI)

Thinking About Epilepsy

## VOLUNTEER ACKNOWLEDGEMENTS

Our volunteers embody the heart and spirit of champions. Every act of kindness has made a significant impact. All of our accomplishments and successes are made possible by the critical work of our volunteers.

Thank you to all of you who continue to make a difference in the lives of so many.

### EPIC CHALLENGE TEAM

C. Douglas  
T. Johnson

R. Farmer  
J. Mauceri

P. McVean  
R. Ling

### MULTIPLE INITIATIVES

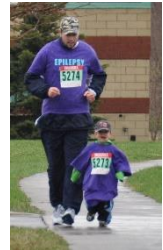
A. Clarke  
G. & M. Souter  
J. Boss  
J. Mauceri  
M. Ceylan-Leamen & Family  
R. Farmer & Family  
S. Bei der Wellen-Banach

Bloschinsky Family  
H. Haslett  
J. Kilgannon  
L. Hogg  
M. Beach  
R. Ling  
T. German

C. MacEwen & Family  
H. Rogin  
Johns Family  
M. Labriola  
R. & B. Carr  
R. Pregent  
W. & A. Coats-Latour

*be kind.*

## MAKING IMPACT IN ALL FORMS





## VOLUNTEER AWARDS

### MARK F. SEETNER VOLUNTEER AWARD OF EXCELLENCE

Epilepsy Durham Region provides care, services, and support for many and are successful with the help of our dedicated volunteers. It is only with the contribution of our volunteers that we are able to stretch our resources and ensure that we are making maximum impact in our community. We are proud to celebrate the value and importance of two volunteers who have dedicated 18 years to our cause.

Miriam joined EDR and put her knowledge and skillset of being a retired operating room nurse to practice. She has been an important facet in our outreach programs, providing education to thousands throughout her years with our organization. She is quick to lend a helping hand, volunteering every month at the Oshawa Clinic, and joining us for our signature events. Her knowledge is only matched by her kindness and incredibly big heart. When you meet Miriam, you are sure to be met with a warm smile, the voice of reason, and a calming story to guide you on the right path. We are forever indebted to her passion and kindness.



The second recipient of our volunteer award is Arnold – a volunteer who inspires us to work hard every day and be happy for what we have. Living with epilepsy himself, Arnold has been an inspiration to many of those that have connected with EDR. Arnold's volunteer work doesn't just stop at our events; over his 18-year involvement, Arnold has developed his own volunteering and fundraising initiatives including his own coin canister campaign throughout the

region as well as walking an additional 400 – 1200km each year to raise awareness and funds for our Walk for Epilepsy. The amazing thing about Arnold is that his passion for volunteering is driven by his want to heighten awareness about epilepsy in our community to help others like him. For his many years of dedicated services, we thank Arnold from the bottom of our hearts.

## CANNABIS AND EPILEPSY

### Dr. Evan Cole Lewis

MD, FRCPC, CSCN EEG Diplomate



Dr. Evan Cole Lewis is a Pediatric Neurologist and Clinical Neurophysiologist with expertise in epilepsy, epilepsy surgery, (EEG), teleneurology and medical cannabis for the treatment of neurologic disorders. Dr. Lewis is the director of the Neurology Centre of Toronto (NCT) which he established in January 2017. At NCT, Dr. Lewis treats children with a variety of neurological disorders and he also treats adults for concussion, headache and epilepsy.

Dr. Lewis' interest in medical cannabis began in 2013 while training at Miami Children's Hospital – one of the major sites for the Epidiolex trials. He has significant clinical experience with medical cannabis in adults and children and is a member of the Canadian Consortium for the Investigation of Cannabinoids (CCIC), Canadian Childhood Cannabinoid Clinical Trials (C4T), and the Cannabinoid Research Initiative of Saskatchewan (CRIS).

Dr. Lewis attained his MD from the University of Ottawa, and trained as a Pediatric Neurologist at the Children's Hospital of Eastern Ontario (CHEO). He completed fellowships in both clinical neurophysiology and epilepsy at Nicklaus Children's Hospital (formerly known as Miami Children's Hospital) and the Hospital for Sick Children. Dr. Lewis was a staff neurologist, clinical neurophysiologist and the Director of the Epilepsy Fellowship Training Program at the Hospital for Sick Children between 2015 and 2016. He also held a staff position as the primary neurologist for the Early Care Concussion Clinic at Holland Bloorview Kids Rehabilitation Hospital from 2016 – 2018.

## PURCHASE WITH A PURPOSE

EDR's gift shop, Pebble Stone & Co., offers a dynamic gift line which not only provides an opportunity to purchase something beautiful for yourself or a loved one, but also is the gift that gives twice – all proceeds support our programs and services.

Browse online at: [www.epilepsydurham.com/gift-shop](http://www.epilepsydurham.com/gift-shop)

## THE CHALLENGE IS EPIC

### THE EPIC CHALLENGE CONTINUES Reaching an Overwhelming Milestone

Throughout the years of the Epic Golf Challenge, one very special thing remained consistent – it brings together individuals in our community, most of whom have no connection to epilepsy, that pledge to raise awareness and funds to ensure that families in Durham Region have access to the support they need. Year after year, as our Epic Golf Challenge family grew, we were introduced to amazing civic minded individuals that represent kindness in its truest form.

2019 marked our 5<sup>th</sup> anniversary of the Epic Golf Challenge, and with that milestone our Task Force presented an equally EPIC goal – to raise \$500,000 by the end of our 5<sup>th</sup> year of this event. When the goal was presented to our golfers, it was met with open arms as they offered their knowledge, skillsets, support and fundraising efforts in order to create lasting positive impact for people with epilepsy.

It is only with the help of these dedicated individuals that we are able to continue the success of our local Clinic to Community Epilepsy Clinic, improving access to quality and specialized care in our community. Each year we are overwhelmed with the generosity and kindness that this group demonstrate, and we are humbled to announce that their passion and hard work paid off; Epilepsy Durham Region wrapped up 2019 by surpassing the Task Force goal, and raising a grand total of \$512,720.62! There are not enough words to truly express the gratitude that we feel, but on behalf of Epilepsy Durham Region and all of those that are impacted by epilepsy in our community...

**THANK YOU**



## STATEMENT OF OPERATIONS | DECEMBER 31, 2019

### Revenues

Fundraising	114,823	
Bingo and Nevada	76,219	
Donations   Government Grants	62,436	
Interests & Miscellaneous	<u>8,921</u>	
		<u>262,399</u>

### Expenses

Administrative Salaries & MERCs	133,225	
Fundraising	34,799	
Occupancy	17,818	
Office	3,309	
Insurance	3,527	
Telephone	2,253	
Professional Fees	2,895	
Programs   Education   Advocacy	8,435	
Other	<u>1,978</u>	
		<u>208,239</u>

Net Operating Surplus	<u>54,160</u>
Opening Net Assets	<u>419,793</u>
Closing Net Assets	<u>473,953</u>

### Expenditure Breakdown

Charitable Activities	145,282	
Management and Administration	21,127	
Fundraising	34,799	
Other Expenditures	7,031	
		<u>208,239</u>

Joseph Mauceri, CPA, CMA, BCompSc  
*Treasurer*

## STATEMENT OF FINANCIAL POSITION | DECEMBER 31, 2019

### Assets

Cash and Investments	461,929
Amounts Receivable	8,280
Inventory	4,974
Prepaid Expenses	630
Due from government	<u>4,669</u>

**480,482**

### Liabilities

Accounts Payable	<u>6,529</u>
	<b><u>6,529</u></b>

### Equity

Unrestricted Net Assets	<b><u>473,953</u></b>
-------------------------	-----------------------

**480,482**

Joseph Mauceri, CPA, CMA, BCompSc

## THE IMPACT OF YOUR DONATION WITH HEARTFELT THANKS

Epilepsy Durham Region relies on the generosity of its volunteers and donors to continue its work. We thank you for your generous gifts.

### PROGRAMS AND SERVICES MADE POSSIBLE BY:

100 Men of Oshawa	OPG   Darlington Nuclear
Ajax Lions Club	OPG Corporate Citizenship Program
AWC Credit Union	Optimist Club of Ajax
BoSs'S Business Network	Oshawa West Lions Club
Burns Family	Police Services Board   DRPS
Canada Summer Jobs   Gov. of Canada	Ranfar Steel Ltd.
Cargill Deicing Technology	Rotary Club of Courtice
Corporation of the Town of Whitby	Rotary Club of Oshawa Parkwood
CRCS-DKI	SCN Industrials Inc.
Deer Creek Cares Charitable Fdn.	Sunovion Pharmaceuticals Canada Inc.
Deighton Associates Limited	Symcor Inc.
Durham Community Foundation	The Royal Canadian Legion
Eisai Limited	Town of Ajax Corporation
Lifelabs	Unifor Auxiliary no. 27
Mississaugas of Scugog Island	Uxbridge District Lions Club
Mount Lawn Funeral Home & Cemetery	William F. Hayball Foundation
Municipality of Clarington	



## HOW YOU CAN HELP MAKE AN IMPACT

Your time is critical to the success of helping people living with epilepsy in our community. Can we count on you to volunteer with epilepsy Durham Region in 2020? Pick up your volunteer application form at our information table, or connect with EDR staff tonight. Thank you!

## CONTACT

### EPILEPSY DURHAM REGION

[www.epilepsydurham.com](http://www.epilepsydurham.com)  
[support@epilepsydurham.com](mailto:support@epilepsydurham.com)

310 BYRON STREET SOUTH, SUITE 3  
WHITBY ON L1N 4P8  
(T) 905-430-3090 | (F) 905-430-3080



### DIANNE MCKENZIE

CEO

[dmckenzie@epilepsydurham.com](mailto:dmckenzie@epilepsydurham.com)

### CHELSEA KERSTENS

Community Outreach Associate

[clientservices@epilepsydurham.com](mailto:clientservices@epilepsydurham.com)

**epilepsy**  
durham region

*Working together to improve epilepsy care in Durham Region*

Every effort has been made to recognize volunteers, individuals, foundations and corporations who have generously supported Epilepsy Durham Region and its mission in 2019. Please accept our apologies should any errors or omissions have occurred and notify us at (905) 430-3090.

CHARITABLE REGISTRATION NO. 89670-5399-RR0001

## CAN WE COUNT ON YOUR SUPPORT?

Yes! I want to help people in my community that are impacted by Epilepsy. I would like to contribute to ensure that people with epilepsy know that they are not alone – Epilepsy Durham Region is here to help.

Please accept my monthly gift of \$: \_\_\_\_\_

Please accept my one-time gift of \$: \_\_\_\_\_

Name:

Address:

City/Town:

Postal Code:

Telephone:

Email:

\*Your information is required for Epilepsy Durham Region to issue a tax receipt

\*We do not share your personal information

\*Please make cheques payable to **Epilepsy Durham Region** or make an online donation at: [www.epilepsydurham.com](http://www.epilepsydurham.com)

**epilepsy**  
durham region

Thank you for your support – making lasting impact and changing the lives of so many in our community touched by epilepsy

CHARITABLE REGISTRATION NO. 89670-5399-RR0001

