



it's _____
Because

You *of*

EMPOWER | ENGAGE | EDUCATE

ANNUAL REPORT | 2018
March 5th, 2019

epilepsy
durham region

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EXECUTIVE MESSAGE

Empower | Engage | Educate – It's Because of You

I would like to begin by thanking our volunteers, our associate members and staff of Epilepsy Durham Region who tirelessly and generously give their time to support Epilepsy Durham Region in realizing its mission. With the support of our community 2018 represented a significant milestone year for those living with Epilepsy in Durham Region. Together we have influenced how, when, and where people living with epilepsy receive care.

The foundational work we have invested in over the past few years has been instrumental and has led us to building a strong and sustainable future for people living with epilepsy. We have had the privilege of engaging an epileptologist and developing an Epilepsy Clinic in Durham Region with the support of both internal and external stakeholders whose insights have helped us realize our dream of appropriate care in our community.

Our clients' voices have never been stronger as we introduced more ways for you to reach out to us. These include social media channels, one-on-one intake referrals, and in-service sessions within our school and work place environments. New initiatives like province wide ministry of education *Supporting Children and Students with Prevalent Medical Conditions in School*, including epilepsy, and bringing experts and clients together through our Lecture Series and annual forums for the ideal education opportunities. Much of what we accomplished this year came as the result of timely feedback received from you, our stakeholders, and from all of the communities we service; we are on track and will continue to enhance our delivery of service, fostering new partnerships and creating more opportunities for unified support.

Powered by our vision of improved quality of life for those living with epilepsy – we look forward to continuing to work with you and your families to help shape our services.

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.

Education + Knowledge + Support

EMPOWERMENT

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 |

A YEAR IN REVIEW | 2018 IN A GLANCE

NATIONAL | BEST MEDICINES COALITION

Representing the Canadian Epilepsy Alliance, CEO Dianne McKenzie sits on the Best Medicines Coalition (BMC).

The BMC is a national alliance of 24 patient organizations with a shared goal of equitable and consistent access for all Canadians to safe and effective medicines to improve patient outcomes. As an important aspect of its work, the BMC strives to ensure that Canadian patients have a voice and are meaningful participants in health policy development, specifically regarding pharmaceutical care.

Throughout 2018 BMC directors from coast to coast, focused on national pharmacare implementation, with a submission report for '*Equitable & Comprehensive Pharmacare For All*' to the Advisory Council. They also invested in input regarding proposed amendments to the patented medicines regulations, ensuring the patient voice is heard regarding pricing of medication being aimed at sustaining the life, health and wellbeing of patients, medication availability, and timely access.

EDR is honoured to continue to be a part of this national coalition supporting those living with epilepsy nationwide.

PROVINCIAL | SCHOOL SAFETY LEGISLATION

Safety and the well-being of students with epilepsy in schools has always been a top priority for EDR. Working in collaboration with Epilepsy Ontario and fellow Community Epilepsy Agencies, EDR played an integral role in the development and approval of the Ontario government's 2017 policy, *Supporting Children and Students with Prevalent Medical Conditions*. This new policy, officially launched across the province in 2018, improves the safety of children living with prevalent medical conditions like epilepsy by requiring school boards to provide an individual plan of care, which outlines contacts and procedures tailored to meet the daily medical needs of the student. EDR has actively been a part of insisting this policy is adhered to for students in Durham Region. Please inquire with your school/school board if you have not partnered with your school administration to complete your child's plan of care.

Education + Knowledge + Support = EMPOWERMENT

A YEAR IN REVIEW | 2018 IN A GLANCE

PROVINCIAL | GOVERNMENT RELATIONS TASK FORCE

Queen's Park – Epilepsy Action Day

Community Epilepsy Agencies across the province have a unique vantage point in that we provide information and support to persons with epilepsy across the continuum of the lifespan. We understand the fear after the first seizure and the misconceptions that newly diagnosed people share. Living with epilepsy is extremely difficult, which leads to disturbing rates of depression, unemployment, and suicide. With the burden that epilepsy has on the families affected by it, the healthcare system, and the economy, EDR is working collaboratively Epilepsy South Central Ontario, Epilepsy Toronto, and Epilepsy Ontario and has developed a Government Relations Task Force. In 2018, this task force completed a pre-budget submission to the Ontario government outlining the current costs associated with emergency room visits and how costs could be reduced by investing in epilepsy educators. The submission was received favourably, reviewed and returned for clarification. We are happy to announce we have been invited to resubmit for 2019 our application. We continue with our Queen's Park Action initiatives to advocate for funding with our local MPPs and work collectively to ensure epilepsy and its provincial wide consistent care remain on the forefront for funding and budget allocation.

REGIONAL | EPILEPSY CARE IN DURHAM REGION

Community Epilepsy Agencies, like EDR, are on the front line working to support children, youth, parents, adults, and seniors living with epilepsy. As front line workers, we often see individuals and families seeking information and support during a crisis, after the loss of a job, or after the injury or death of a loved one. Our message is very clear – we need to be proactive to provide newly diagnosed individuals with epilepsy with information and support before they are in crisis. With that, in November of 2018, EDR launched its first day our local Epilepsy Clinic, which sees a local Epileptologist, with a full time EEG capacity, and EDR's Clinic to Community (C2C) Education Centre. C2C helps the entire family to develop health management skills and combines health information with patient education, highlighting our hallmark that **EDUCATION** combined with **KNOWLEDGE** and **SUPPORT** equals **EMPOWERMENT**.



VOLUNTEER ACKNOWLEDGEMENTS

All of our accomplishments and successes are made possible by the critical work of our volunteers. Our volunteers help us to find strength in numbers, enabling our ability to provide support, education, advocacy, and empowerment to those touched by epilepsy.

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
C. MacEwen & Family
H. Rogin
J. Mauceri
M. Ceylan-Leamen & Family
R. Farmer & Family
T. German & Family

BOAA
G. & M. Souter
J. Boss
L. Hogg
M. Beach
R. Ling
W. Coats-Latour

B. Paterson
H. Haslett
J. Kilgannon
M. Labriola
R. & B. Carr
S. Bei der Wellen-Banach
Wimpy's Diner Oshawa

Education + Knowledge + Support = EMPOWERMENT

MAKING IMPACT IN ALL FORMS



VOLUNTEER AWARDS

MARK F. SEETNER VOLUNTEER AWARD OF EXCELLENCE

Every so often you meet someone who can brighten your spirit and remind you of what really matters.

Two years ago we had the pleasure of meeting Wanda Coates-Latour and her daughter Abigail. We must say none of us have looked back since.

Wanda and Abi both are a driving force for many of our projects, working tirelessly, and often behind the scenes, inspiring others living with epilepsy. Some of you may have seen the beautiful artwork Abi has produced; at an event in October one of her paintings sold for \$1000. Or you may have purchased one of your Abi-Beads bracelets, all in support of programs dedicated to helping people with epilepsy. Wanda has been managing our Bingo events, ensuring funds are available for EDR to deliver our education programming and is quick to lend a helping hand, not only at signature events, but for day to day assistance.

Volunteers and non-profit organizations, like EDR, deliver services, provide care, support, and generally improve the lives of people living with epilepsy. We are proud to celebrate the value and importance of the contribution both Abi and Wanda have made to our community. EDR strongly believes that those living with epilepsy need access to education, knowledge and community engagement to feel empowered. *It's Because* of volunteers like Wanda and Abi that allow us to stretch our resources and make maximum impact. We are indebted to both of you. – Thank You Wanda and Abi!



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

OUR JOURNEY WITH EPILEPSY

Cassidy Sankey



I had my first seizure when I was 10 years old. I was conscious while having tonic-clonic seizures. After being 12 years seizure free and taken off medication, I had a seizure in 2016. It changed my life and I found out that I should not have come off medication with my type of seizures that were discovered within those 12 years.

Melike Ceylan-Leamen

Our journey began eight years ago, when our beloved son was two. At age five Aydin was diagnosed with epilepsy, experiencing more than 100 seizures a day. Despite countless medication trials and consultations with medical experts, including multiple tests and school board meetings, Aydin does not have controlled seizures nor a medical plan of care in place. The journey has been challenging for our family, but we have hope.



Andy Ayotte



At the age of 4 months our daughter Stephanie was diagnosed with West Syndrome and more recently, with Lennox-Gastaut Syndrome. It was a grave prognosis for Stephanie and our family, living with intractable seizures and severe mental challenges. On the other hand, Stephanie brings joy to all of those around her – being non-judgmental and finding happiness in the simplest things in life.

THE CHALLENGE IS EPIC

THE EPIC CHALLENGE CONTINUES

40 individuals | 10 teams | Overwhelming Kindness & Generosity

What began 5 years ago as 36 individuals, unknown to one another, pledging to raise funds and awareness for epilepsy, has now transformed into something much bigger than anyone could have foreseen. In 2018, 40 individuals, who have now become an extension of our EDR family, continued in their quest to not only raise awareness, but ensure that our dreams of a local Epilepsy Clinic became a reality.

While we wrapped up our fourth annual **Epic Golf Challenge**, we not only saw a total of \$357,743.12 raised over its four year run, but we were also witness to an amazing group of community, civic minded individuals who are so passionately dedicated to improve the care of epilepsy in Durham Region. Here in lies the phenomenon of the Epic Golf Challenge; what began as a fundraising sporting event, now is host to a group of individuals on a mission, working together, offering their knowledge and expertise to our agency to help create positive, lasting change for people with epilepsy.

While we work towards our fifth annual Epic Golf Challenge in 2019, we are reminded of the common denominator that we see year after year – overwhelming kindness and generosity. There are very few words to convey how humbly indebted we are to this group of individuals, but we will start with...

THANK YOU



STATEMENT OF OPERATIONS | DECEMBER 31, 2018

Revenues

| | | |
|-------------------------------|--------------|----------------|
| Fundraising | 105,695 | |
| Bingo and Nevada | 33,273 | |
| Donations Government Grants | 146,367 | |
| Interests & Miscellaneous | <u>7,542</u> | |
| | | <u>292,877</u> |

Expenses

| | | |
|------------------------------------|--------------|----------------|
| Administrative Salaries & Benefits | 110,363 | |
| Fundraising | 13,701 | |
| Occupancy | 21,623 | |
| Office | 2,485 | |
| Insurance | 3,036 | |
| Telephone | 1,632 | |
| Professional Fees | 4,849 | |
| Programs Education Advocacy | 18,556 | |
| Other | <u>7,913</u> | |
| | | <u>184,158</u> |

| | |
|-----------------------|----------------|
| Net Operating Surplus | <u>108,719</u> |
| Opening Net Assets | <u>311,074</u> |
| Closing Net Assets | <u>419,793</u> |

Joseph Mauceri, CPA, CMA, BCompSc
Treasurer

Education + Knowledge + Support

EMPOWERMENT

STATEMENT OF FINANCIAL POSITION | DECEMBER 31, 2018

Assets

| | |
|----------------------|-----------------------|
| Cash and Investments | 400,461 |
| Amounts Receivable | 4,518 |
| Inventory | 15,678 |
| Prepaid Expenses | <u>1,365</u> |
| | <u>422,022</u> |

Liabilities

| | |
|------------------|---------------------|
| Accounts Payable | <u>2,229</u> |
| | <u>2,229</u> |

Equity

| | |
|-------------------------|-----------------------|
| Unrestricted Net Assets | <u>419,793</u> |
| | <u>422,022</u> |

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 are proof that every penny does count and many hands truly help to master the stigma associated with Epilepsy. We thank you for your generous gifts.

PROGRAMS AND SERVICES MADE POSSIBLE BY:

| | |
|-------------------------------------|---------------------------------|
| BOSs'S Business Network | OPG Darlington Nuclear |
| Canada Summer Jobs Gov. of Canada | OPG Employees & Pensioners Fund |
| Cargill Limited | Optimist Club of Ajax |
| Corporation of the Town of Whitby | Rotary Club of Bowmanville |
| CRCS-DKI | Rotary Club of Port Perry |
| Deighton Associates Limited | Rotary Club of Whitby |
| Durham Community Foundation | Rotary Club of Whitby Sunrise |
| Eisai Limited | St. Joseph's Council #6361 |
| Gay Company | UCB Canada Inc. |
| Knights of Columbus Council #8309 | Veridian Connections Inc. |
| Mount Lawn Funeral Home & Cemetery | William F. Hayball Foundation |

Education + Knowledge + Support = EMPOWERMENT

NOTES

*It's because
of
YOU!!*

AGENCY INFORMATION

Epilepsy Durham Region enhances the lives of people who are affected by Epilepsy and seizure disorders by providing a network of services that educate, support, and build community awareness in the areas of Ajax, Pickering, Whitby, Oshawa, Clarington, Scugog, Brock and Uxbridge.

CONTACT

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DIANNE MCKENZIE

CEO

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CHELSEA KERSTENS

Community Outreach Associate

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 2018. 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

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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

