

EPILEPSY DURHAM REGION

It's a Milestone

2016

EPILEPSY
DURHAM REGION

EMPOWER | ADVOCATE | ENGAGE

where you're never alone

30th
ANNIVERSARY

CHANGING LIVES AND
MAKING LASTING IMPACT

Annual Report

May 30th, 2017

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EXECUTIVE MESSAGE

Empower • Advocate • Engage – words to live by.

On behalf of the Board of Directors, we wish to express our gratitude to the volunteers, clients and staff of Epilepsy Durham Region. Many have contributed so much to the successful effort to build a sustainable, compassionate and knowledgeable agency to serve the approximately 1 in 100 residents of Durham Region who live with Epilepsy.

The work at Epilepsy Durham Region (EDR) has always been a team effort, first to build a vision and then to find a way to achieve and sustain the vision. The EDR team has needed a leader and we are all lucky to have Epilepsy Durham Region Executive Director, Dianne McKenzie fill that role. Dianne has a unique knack for letting everyone contribute to the best of their ability and the results have been nothing less than remarkable.

As a member of the board, it has been gratifying to work with so many talented people past and present. The path from a few volunteers in a church basement to being on the threshold of the opening of a dedicated centre here in Durham Region has been a remarkable voyage.

Epilepsy Durham Region has been an influential voice at the table at the provincial and national level advocating for the establishment of standards of care, protection of students living with Epilepsy, resolving drug shortages, and helping to build awareness through public education, and the promotion of National Epilepsy Awareness Day each March.

With the history of success EDR has realized in their first 30 years it will be amazing to see the accomplishments EDR works toward in the next 30 years. While we may not be able to predict any one of these achievements in the next 30 years, we do know that they will continue to be community focused and responsive to the needs of those living with Epilepsy and their families.

Every year 6,000 Ontarians learn they have Epilepsy and our voice engages more members of the public thanks to you. Together, we have to increase the volume. Together we will make it happen. Together, we will help one more person feel less alone!

Will Thurber – Acting President

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.

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



OUR BOARD OF DIRECTORS

Will Thurber	Acting President
Howard Smith	Secretary/Treasurer
Debra Fraser	Director
Ros Whitby	Director
Vanessa Heembrock	Director

A YEAR IN REVIEW | 2016 IN A GLANCE

CANADIAN EPILEPSY ALLIANCE

The Canadian Epilepsy Alliance (CEA) addresses issues of national importance to people living with Epilepsy. One of the key priorities for the CEA for several years has been to focus on the very critical shortage of Epilepsy medication across the country. Additionally, the CEA has recently experienced a notable increase in requests for information concerning the use of cannabis in the management of Epilepsy. *“Little is actually known; this drug has not yet undergone the same sort of investigative rigors as other anti-epilepsy medications in the marketplace and experts are ill-positioned to offer advice,”* says CEA president, D. Floyd. The CEA is working to understand the use of cannabis by building consumer dialogue, supporting research, and advocating within the industry.

TAKING ACTION AGAINST DRUG SHORTAGES

As an active member of the Canadian Epilepsy Alliance, EDR is proud to be a part of a national body whose steadfast commitment ensured that drug shortages are legally required to be reported across Canada; at its most critical apex, 74% of all Epilepsy medication was in shortage in 2016. This national crisis inevitably impacted many local individuals who reached out to EDR for assistance. With valiant efforts, EDR has assisted in obtaining medication in the most dire of times, in some cases our reach has been outside of province. EDR's work with drug shortage issues does not stop there. While we have worked hard to develop a strategic action plan and partnerships to assist with the navigation of this issue, there is still ongoing critical advocacy that must to be addressed.

EPILEPSY ACTION DAY AT QUEENS PARK

In collaboration with Epilepsy Ontario and 13 agencies across the province EDR continues to address the safety and well-being of students with Epilepsy requiring emergency rescue medications in school with Members of Provincial Parliament. While the commitment was made by provincial government in 2015 to develop an overarching Policy and Program Memorandum on the management of prevalent medical conditions, the collaboration is ongoing. EDR, alongside Epilepsy partners, persistently advocate on this matter with the expectation that a comprehensive policy on the management of prevalent medical conditions will provide equitable protection across the province to students with Epilepsy, Diabetes, Asthma, and Anaphylaxis, including the administration of rescue medication. EDR continues to keep the safety of our children in school at the forefront with our local MPPs.

GUIDELINES FOR STRATEGY OF CARE FOR EPILEPSY

Ontario has been acknowledged as an international leader in recognizing and beginning to address the burden of Epilepsy. The Epilepsy Implementation Task Force (EITF), a team that was established to maximize value from the system of Epilepsy care in Ontario, released six documents in 2016 outlining the strategies and guidelines for care of people living with Epilepsy. These guidelines aim to improve access to coordinated care, establish standardized diagnostic and surgical protocols, and develop support for primary care providers. The guidelines are critical for frontline healthcare to understand the need for referral and treatment to Epilepsy Health Centres in Ontario. The EITF have created a document for community neurologists that will be distributed by medical science liaisons. Dissemination to family physicians will be the next phase of this initiative.

ANNUAL EPILEPSY EDUCATION FORUM

EDR brought together experts from different fields to discuss what is new in our understanding of Epilepsy and how the brain works, all with the goal of improving the lives of people with Epilepsy. Epileptologists Dr. Daryoush Gharghi and Dr. Eduard Bercovici, as well as Dr. MacIntyre Burnham, helped families to understand the complexities of Epilepsy and how it can affect woman in particular, the new standards of Epilepsy care in Ontario, and how medical cannabis (CBD oil), may help those affected by Epilepsy.

LOCAL EPILEPSY CENTRE ON THE HORIZON

EDR and community partners continue with their vision of a community Epilepsy Centre in Durham Region. Many can attest to the challenges associated with the lack of specialized care in our region. EDR has worked steadfastly to coordinate a task force to ensure that appropriate care can be received in our community. We are proud to announce that an Epileptologist is now accepting referrals through EDR and working to support families locally. Our next steps include the investigation of a dedicated Epilepsy Care Centre to be developed in Durham Region.

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 GOLF CHALLENGE TEAM:

Cris Douglas
Neil Smith

Kyle Douglas
Terry Johnston

Matt Douglas

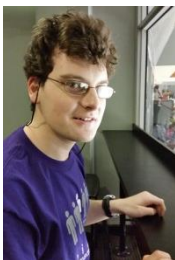
MULTIPLE INITIATIVES:

Alex Shiels & Family
Chris Poynter
Howard Haslett
Mary Gammon
Miriam Beach
Randy Ling
Tracey Strong & Family

Arnold Clarke
Deloitte ID Volunteers
Howard Smith
Melike Ceylan-Leaman & Family
Oogled Marketing
Ros Whitby
Vanessa Heembrock

Brenda Paterson
Grant & Mary Souter
Jacqueline Bos
Melissa Bradford
Ralph & Barbara Carr
Sandra Saava & Family
Will Thurber

MAKING IMPACT IN ALL FORMS



VOLUNTEER COMMUNITY PARTNER AWARDS

CORPORATE CHAMPION – RANFAR STEEL LTD.

The support of local community businesses is critical to our organization to ensure that we are able to connect with families, and provide support, education, advocacy and awareness. As a small grassroots agency, we rely on the kindness and partnership to help us to overcome our roadblocks; with every ask, and without hesitation, Ranfar Steel Ltd. owner, Randy Farmer, and his staff and family are always up to the challenge.

We were first introduced to Mr. Farmer two years ago, and it is safe to say that when thinking of a sense of community, in this instance it is incredibly simple – to know Mr. Farmer is to know what a kind, giving, compassionate man he is. Whether he is rallying the troops to raise much needed funds, stopping by the office, sending a quick email to check in, or opening the doors of his business to treat EDR like family, Mr. Farmer is quick to stand up to help us make a difference.

For his friendliness, empathy, and generosity, Ranfar Steel Ltd. is recognized for demonstrating the true depiction of what it means to be a community partner. It is our duty to *make it so* and extend a special thank you to Randy.



MARK F. SEETNER VOLUNTEER AWARD OF EXCELLENCE

We are profoundly grateful to all of our gracious volunteers who lend their expertise, time, encouragement and spirit to our organization. We would like to recognize Lorraine Hogg with the Mark F. Seetner Volunteer Award of Excellence for her commitment to EDR for more than a decade.

Lorraine has been an ambassador for those living with Epilepsy, always willing to share her story with others, create a connection, and offer a shoulder to lean on. She is one of the first to respond to any call to action, her passion and dedication fuels our commitment to work hard to ensure not another moment is lost to a seizure.



On behalf of EDR, thank you Lorraine for your kindness!

NAMASTE | THE IMPORTANCE OF WELL-BEING

The impact of Epilepsy on both physical and emotional well-being can be significant. Managing stress is a key component to managing both seizures and overall health.

Clarington's Wellness Path provides a single location that can meet all holistic health care needs. Their mission is to assist in achieving greater health and wellness by making a wide range of natural health options available along with providing personalized guidance to develop the ideal path to wellness.

Owner and Clinical Director of Clarington's Wellness Path, Nancy Metcalf's goal is to offer a centre that provides natural solutions and support for any health concern and a wide range of natural health solutions that absolutely help to achieve health and happiness. She is passionate about bringing in specialists who care not only for physical ailments, but also for the mind and soul. She is pleased to say that Clarington's Wellness Path is now home to over twenty practitioners, from acupuncture to yoga and almost everything in between.

Stress is one of the most important factors determining our quality of life and overall health, and for some can trigger seizures. Ms. Metcalf will help to understand the importance of finding balance in our lives; whether we're looking to focus on self-discovery, wellness, or personal growth, Ms. Metcalf and her wonderful staff is here to help.



Wellness Path
Natural Solutions for Health & Happiness

THE POWER OF A COMMUNITY

72 people, unknown to one another, unknown to our world of living with seizures – what was the common denominator?

Kindness and overwhelming generosity

In September, 2015 the EPIC Challenge was launched; five community leaders heard our plight, were moved by our challenges, and took charge; they wanted to help. They set a goal of not only raising awareness, but also of communicating the message to so many living with Epilepsy that they are not alone.

The group of five quickly became the ‘Power of 72’ who made a promise to help Epilepsy Durham Region with their mission of establishing an Epilepsy Centre in Durham Region. These efforts have mobilized our community and have had a cascading effect to date and will continue for years to come.

“First off, this is the most fun golf event I’ve ever attended. And I’ve been to A LOT. I highly recommend Epilepsy’s EPIC Challenge for anyone thinking of putting something back into the community. I knew NOTHING about Epilepsy until I attended this event and I think it’s criminal that in a community as affluent and large as Durham Region does not have our own specialist to help the kids, men and women with Epilepsy.” - Jay, Third year participant

The EPIC Challenge continues to be a force to be reckoned with, we are confident that as each day passes we are getting closer to our vision. THANK YOU.



STATEMENT OF OPERATIONS | DECEMBER 31, 2016

Revenues

Fundraising	120,838
Bingo and Nevada	28,262
Donations	71,844
Other	<u>10,709</u>
	<u>231,653</u>

Expenses

Payroll & Mandatory Costs	111,592
Fundraising	18,544
Occupancy	12,345
Office	3,647
Insurance	2,638
Telephone	2,747
Professional Fees	3,473
Advertising & Promotion	3,059
Other	<u>3,562</u>
	<u>161,607</u>

Net Operating Surplus	70,046
Opening Net Assets	<u>187,119</u>
Closing Net Assets	<u>257,165</u>

Howard Smith, FCPA, FCA
Treasurer/Secretary

STATEMENT OF FINANCIAL POSITION | DECEMBER 31, 2016

Assets

Cash and Investments	259,820
Amounts Receivable	9,173
Inventory	13,497
Prepaid Expenses	<u>2,661</u>

285,151

Liabilities

Accounts Payable	3,066
Deferred Revenue	<u>24,920</u>
	<u>27,986</u>

Equity

Unrestricted Net Assets	<u>257,165</u>
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285,151

Howard Smith, FCPA, FCA
Treasurer/Secretary

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:

100 Men of Clarington, Oshawa, & Scugog	Knights of Columbus Council #8951
100 Women of Clarington	OPG Darlington Nuclear
Baagwating Community Association	OPG Employees & Pensioners Fund
Canada Summer Jobs Gov. of Canada	Optimist Club of Ajax
Cargill Deicing Inc.	Rotary Club of Ajax
Corporation of the Town of Whitby	Rotary Club of Port Perry
Corrigan Insurance & Benefits Planning Inc.	Rotary Club of Whitby Sunrise
CRCS-DKI	UCB Canada Inc.
Durham Community Foundation	Veridian Connections Inc.
Insurance Brokers Assoc. of Durham Region	William F. Hayball Foundation
Knights of Columbus Council #10098	

NOTES

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AGENCY INFORMATION

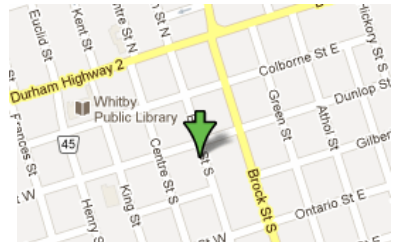
Epilepsy Durham Region enhances the lives of people who are affected by Epilepsy and seizure disorders by providing a network of services that educate, support, and build community awareness.

CONTACT

EPILEPSY DURHAM REGION

www.epilepsydurham.com
support@epilepsydurham.com

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



DIANNE MCKENZIE

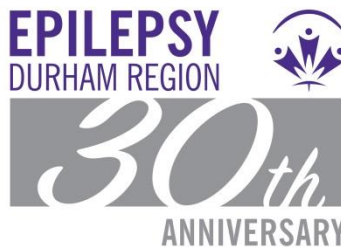
Executive Director

dmckenzie@epilepsydurham.com

CHELSEA KERSTENS

Community Outreach Associate

clientservices@epilepsydurham.com



CHANGING LIVES AND MAKING LASTING IMPACT

Every effort has been made to recognize volunteers, individuals, foundations and corporations who have generously supported Epilepsy Durham Region and its mission in 2016. Please accept our apologies should any errors or omissions have occurred and notify us at (905) 430-3090.

CHARITABLE REGISTRATION NO. 89670-5399-RR001

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 one-time gift of \$: _____

Name: _____

Address: _____

City/Town: _____

Postal Code: _____

Telephone: _____

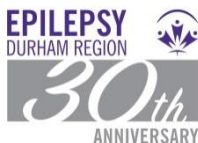
Email: _____



*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**



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

Charitable Registration No.: 8967-5399-RR0001