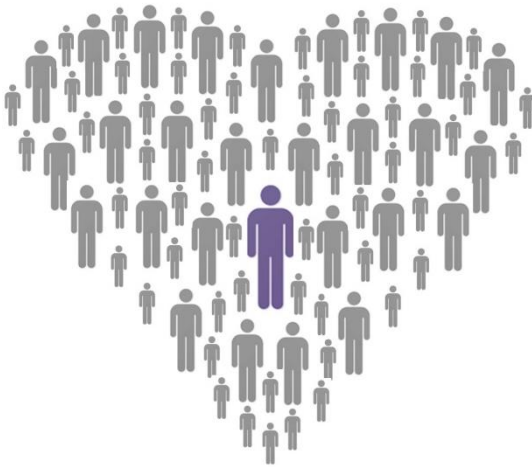


EPILEPSY DURHAM REGION

Annual Report

2015



CHANGING LIVES AND
MAKING LASTING IMPACT

March 7th, 2016

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EXECUTIVE MESSAGE

Empower • Advocate • Engage – words to live by.

2015 will long be seen as a turning point in Epilepsy Durham Region's history, as we launched our plan to develop a first of its kind – an Epilepsy clinic. With your support, we significantly *empowered* those living with Epilepsy, transforming Epilepsy treatment in Durham Region.

On behalf of Epilepsy Durham Region, thank you for making 2015 extraordinary. Your commitment strengthened and motivated us, and helped us to produce some remarkable achievements.

Our 'year of transformation' campaign helped us to influence a group of individuals to come together in an epic fashion, raising funds but more importantly inspiring individuals to learn more about Epilepsy and to champion our agency.

Our message *engaged* more than 34,000 people to reach out to us in 2015 for assistance and donating their time to reduce the fears for families touched by this neurological disease. There is an undeniable drive amongst our partners to nurture change and 'do something' about the resources available in our community.

This heightened awareness also drove record-breaking fundraising, championed by the people who tirelessly drive our mission forward — people like you, our volunteers, donors, corporate partners, and ambassadors. This support allowed us to continue our resolve to *advocate* and ensure that not another day is lost to a seizure and every child has an opportunity to make life-long happy memories. Your investments have energized and empowered us and our volunteers. Our Queen's Park Epilepsy Action Days are improving government's understanding and resulting in additional hospital beds, increased research funding dollars, and a pilot project of a Community to Clinic model.

Every day 38 Canadians 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

Dianne McKenzie
Executive Director

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 | 2015 IN A GLANCE

BRAINFEST – Jan.

EDR was invited to be a part of the Ontario Brain Association's BRAINFest exhibition at the Ontario Science Centre, standing alongside other prominent organizations representing a multitude of neurological conditions.

PANCAKE DAY | KICK OFF FOR EPILEPSY AWARENESS MONTH

In partnership with the Clarington Older Adult Association, and the Rotary Club of Bowmanville, EDR hosted our annual pancake eating competition. It was an exciting day had by all, and especially moving to have our local heroes, firefighters, police officers, military, and politicians around the table.

COURTICE MENTAL HEALTH AWARENESS DAY – April

Organizations across our community stood strong together to educate staff and students of Courtice Secondary School about mental health issues.

RACING AGAINST DRUGS DURHAM – May

This year marked EDR's 10 year anniversary with RADD. With a week-long event, EDR was able to educate over 7,000 grade five students and teachers from Durham Region about seizure recognition and seizure first aid.

EPIC GOLF CHALLENGE – May

The day our world began to change. Please turn to page 11 to see how the 'Power of 36' has made lasting impact in our community.

EPILEPSY ONTARIO CONFERENCE – June

EDR joined 14 Epilepsy agencies from across the province, working together to develop the best practices to support the nearly 90,000 people in Ontario living with Epilepsy.

WORLD BRAIN DAY – July

Alongside Chevy Nurse Cadillac Ltd. and Grillin' Like a Villian, EDR celebrated World Brain Day by educating people about Epilepsy and the importance of 'knowing your brain'. With test-drives, bean bag tosses, and delicious food, the day was a great success.

A YEAR IN REVIEW | 2015 IN A GLANCE

CLARINGTON FAMILY SAFETY DAY/ FIRETRUCK *PULL* – Sept.

A platform for EDR to educate members of the public and our local first responders to become seizure smart. Family Safety Day is capped off with our annual Fire Truck *PULL*, where teams of ten *PULL* together to move a fire truck for those living with Epilepsy – a challenge synonymous with living with Epilepsy.

QUEEN'S PARK EPILEPSY ACTION DAY – Oct.

Epilepsy agencies from Ontario assemble at Queens Park, meeting with MPP's to express the need for support for people living with Epilepsy – working hard to express the importance of local community agencies, consistent health care across the province, and the development of provincial wide legislation to ensure children with Epilepsy are safe in school.

GIVING TUESDAY – Dec.

EDR is a proud supporter of the National Giving Tuesday Campaign. We rallied our community through a social media campaign to encourage people to give to a cause that is close to their heart, and express the importance of giving. #WhyIGive

CHRISTMAS IN THE NEIGHBOURHOOD BASH – Dec.

With the kindness of local residents, EDR invited those who attended the Whitby Santa Claus Parade to join us to warm their hands and their hearts with some hot chocolate, hot cider, cupcakes, and a side of Epilepsy Awareness.

HEADSUP! DURHAM STEERING COMMITTEE MEMBERS

EDR is happy to sit on the steering committee of a new local initiative, HeadsUp! Durham, providing brain injury awareness and prevention education to Durham Region.

THE POWER OF TWO MINUTES

In two very busy days, EDR worked alongside volunteers and Grand Design Films to film three very powerful videos to highlight the isolation and stigma associated with living with Epilepsy, and the vital role that a local community agency can play in advocacy in combatting these challenges. We are very proud to unveil the videos during Epilepsy Awareness Month.

View videos at: www.youtube.com/user/DurhamEpilepsy

IN THE WORDS OF A MOM

So who doesn't love summer, sports and just having fun? Our son Aydin was that boy until three years ago.

At the age of four, what began as a small tick quickly became myoclonic, absence, and tonic-clonic seizures. With medical attention, we were hopeful as his 100 plus seizures a day began to decrease, however medications resulted in intensified tonic-clonic seizures. After extensive testing, our family received the news that we feared most; **Aydin's seizures are intractable**, meaning they do not respond to medication and he is not a candidate for brain surgery. Aydin has withdrawn from the sports he used to love and is faced with the everyday challenges of medication side-effects, nightly myoclonic seizures, and the isolation and stigma associated with Epilepsy.

We are a close, united family, supporting each other and rallying to support Aydin, but with no two days alike, Epilepsy always rears its ugly head. Aydin is only one of over 50 million people living with this disease. Becoming an advocate for him is the only way of helping to improve his quality of life. We try every day to remain positive with the support of Epilepsy Durham Region – they help us to understand, and hear our concerns and give Aydin a way to express his feelings both creatively and vocally, and for that we are thankful.

My husband Jim and I encourage you to share your stories, and connect with other parents. Being an expert in your child's health and being an advocate for them can seem like a lonely journey, but it doesn't need to be.

– Melike, Jim, and Dilara



VOLUNTEER COMMUNITY PARTNER AWARDS

CORPORATE – MANUFACTURING & TECHNOLOGY CENTRE

The very mention of the name of this company in Durham Region is synonymous with the words 'giving, caring, and empathy'. You might wonder why we associate these adjectives with a technology and manufacturing centre. Let us share a short story with you.

Several years ago, we had the honour of meeting a gentleman at a dinner celebrating businesses who championed employing individuals with a disability. We talked of how strong our community was in terms of leadership and recognized the value and dignity all individuals' possess regardless of their *ability*. Later that evening we learned that we had been sitting beside the President of MTC, Mr. Howard Humphry who was being honoured for his contributions and support to our community.

Over the years our paths crossed intermittently, Mr. Humphry supported a number of initiatives within EDR and was genuinely interested in our work. When Mr. Humphry heard of the troubles our children are faced with he didn't miss a beat, just said, "For the kids... what do you want me to do?" He and his company stepped in immediately; the very core of this leading company is one of generosity and empathy. It is our pleasure to salute Howard and MTC for their help.

MARK F. SEETNER VOLUNTEER AWARD OF EXCELLENCE

Every day we have passionate, committed individuals lend their time, expertise, and kind words of comfort and encouragement to help drive our organization forward. Our volunteers' dedication is contagious and emboldens our commitment to work hard to make a positive lasting impact on the lives of people living with Epilepsy.

We would like to recognize Benito Suppa – local resident, business owner of both Durham Escape Rooms and Grillin' Like a Villain, and a dear friend. Benito's commitment to the community of Durham Region is anything but villainous as his professional namesake implies. His desire to take action and change lives is equally matched by his big heart and vivacious personality, helping to bring together community partners to rally and support a cause. On behalf of Epilepsy Durham Region, we present the Mark F. Seetner Volunteer Award of Excellence to Benito Suppa for his continued efforts with our organization, enabling us to help people with Epilepsy when they need it most.

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
Ros Whitby
Vanessa Heembrock

Arnold Clarke
Deloitte ID Volunteers
Howard Smith
Melike Ceylan-Leaman & Family
Oogled Marketing
Sandra Saava & Family
Vicki Sheehan & Family

Bev Ball
Grant & Mary Souter
Jacqueline Bos
Melissa Bradford
Ralph & Barbara Carr
Tracey Strong & Family
Will Thurber

MAKING IMPACT IN ALL FORMS



THE POWER OF A COMMUNITY

36 people, unknown to one another, unknown to our world of living with seizures, and what was the common denominator? Kindness.

In September, 2014, five people decided to take charge; they heard our plight, were moved by our challenges, and wanted to help. They set a goal of not only raising awareness, but also of communicating the message to so many children living with Epilepsy that they are not alone. This group of five reached out to their friends, family, and their business networks and asked them to join the cause – our EPIC challenge.

The group of five quickly became the ‘Power of 36’. On May 14th, 2015, the Power of 36 made a promise to help Epilepsy Durham Region help children living with Epilepsy in our community. Often living with Epilepsy you do so in isolation, but this group of people made us know that we are not alone. They made it their mission to understand a mother’s cry for help, a child being asked to leave school, and limited access to specialized healthcare in Durham Region. The exquisite aspect of what took place was watching the Power of 36 not only commit to one day in the month of May, but rather several months of rallying towards an unprecedented goal in support of our Pediatric Management Program. These efforts have mobilized our community and have had a cascading effect to date and will so for years to come.

The most meaningful impact of their generosity is their ability to help EDR build a sound foundation for specialized medical care for people with Epilepsy in their own community, Durham Region. We wish that we could describe what the face of relief looks like when we say ‘We can help you fix that.’ – this is the direct result of the Power of 36. There are very few words to convey how humble we feel, but we will start with *THANK YOU*.



STATEMENT OF OPERATIONS | DECEMBER 31, 2015

Revenues

Fundraising	18,849
Bingo and Nevada	32,796
Grants	6,771
Donations	120,195
Other	3,460
	<u>182,071</u>

Expenses

Payroll & Mandatory Costs	113,456
Fundraising	18,275
Occupancy	13,239
Office	3,195
Insurance	2,469
Telephone	2,381
Professional Fees	2,607
Education & Promotion	5,297
Other	2,003
	<u>162,922</u>

Net Operating Surplus	19,149
Opening Net Assets	<u>167,970</u>
Closing Net Assets	<u>187,119</u>

Howard Smith, FCPA, FA
Treasurer/Secretary

STATEMENT OF FINANCIAL POSITION | DECEMBER 31, 2015

Assets

Cash and Investments	203,398
Amounts Receivable	510
Inventory	11,515
Prepaid Expenses	<u>2,563</u>
	<u>217,986</u>

Liabilities

Accounts Payable	4,413
Due to Government Agencies	1,493
Deferred Revenue	<u>24,961</u>
	<u>30,867</u>

Equity

Unrestricted Net Assets	<u>187,119</u>
	<u>217,986</u>

Howard Smith, FCPA, FA
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.

GRANTS MADE POSSIBLE BY:

Baagwating Community Association
Cargill Deicing Inc.
Durham Community Foundation
EISAI
Knights of Columbus Council #8951
Nurse Chevrolet Cadillac Ltd.
Ontario Power Generation
Oshawa Golf & Curling Club

Rotary Club of Bowmanville
Rotary Club of Whitby Classic
Rotary Club of Whitby Sunrise
SCN Industrial
UCB Canada Inc.
Veridian Connections
William F. Hayball Foundation

NOTES

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AGENCY INFORMATION

Epilepsy Durham Region is a not-for-profit, non-governmental health organization dedicated to promoting independence and optimal quality of life for those living with Epilepsy and seizure disorders through information, awareness, support, advocacy, and research. Epilepsy Durham Region is committed to the elimination of stigma and to dispelling the myths surrounding this disease.

CONTACT

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CHELSEA KERSTENS

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CHARITABLE REGISTRATION NO. 89670-5399-RR001

Every effort has been made to recognize volunteers, individuals, foundations and corporations who have generously supported Epilepsy Durham Region and its mission in 2015. Please accept our apologies should any errors or omissions have occurred and notify us at (905) 430-3090.

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

