

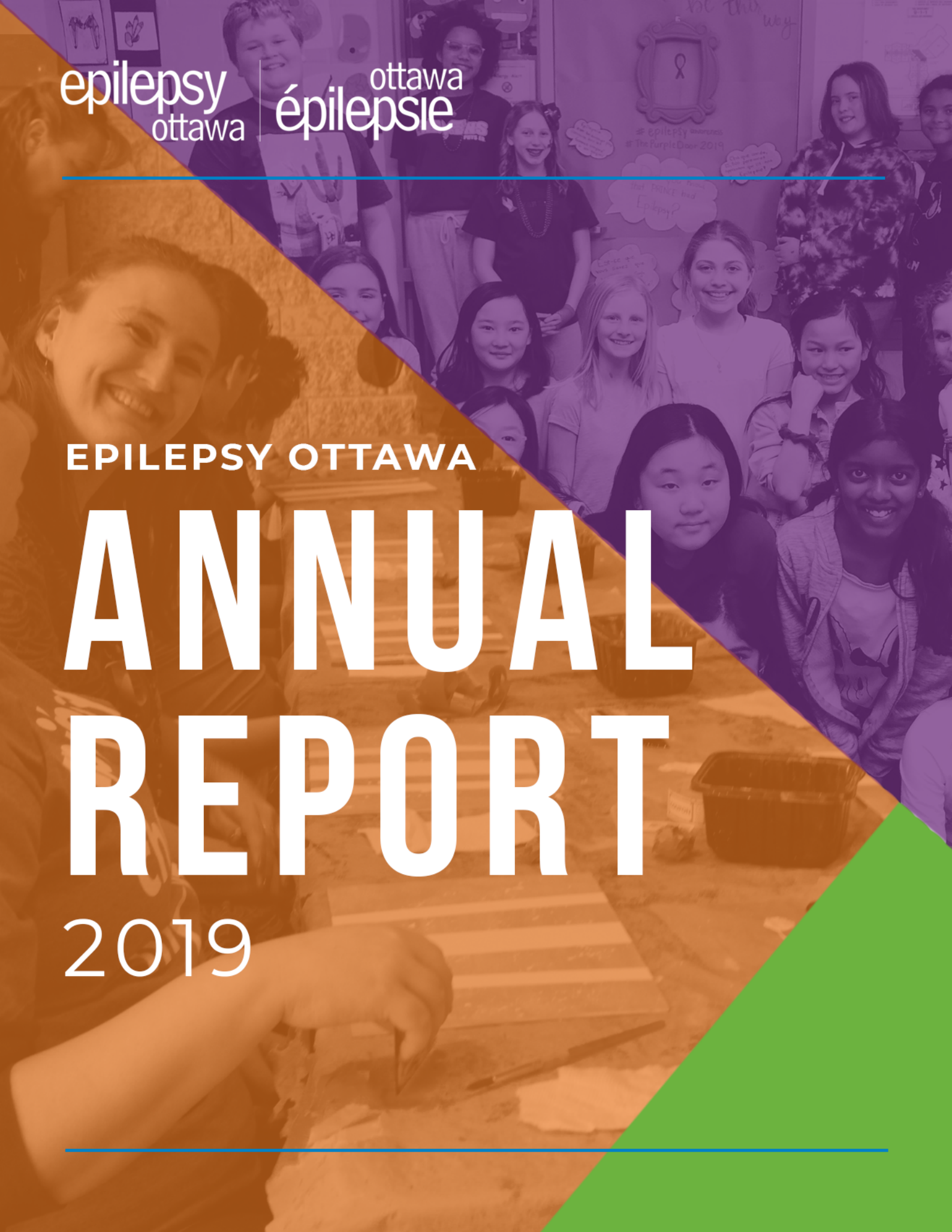
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EPILEPSY OTTAWA

ANNUAL REPORT

2019



LETTER FROM THE EXECUTIVE DIRECTOR

Dear friends,

2019 was a year of great strides! With a multi-year grant from Ontario Trillium Foundation, we expanded our team and provided support to more people with epilepsy than ever before. We've seen significantly more doctor referrals compared to previous years and expanded into additional office space to meet the increased demand.

We continued to provide our most popular programs and enthusiastically introduced some new ones. Epilepsy Ottawa expanded Clinic to Community, the number of participating teams in our annual Ottawa Fire Truck Pull at Landsdowne Park almost doubled, and Seizure Smart continued to increase the public's awareness on how to help someone having a seizure. New programs included Epilepsy Perspectives Image Club (E.P.I.C.) which brought our younger members together to gain story-telling and photography skills while sharing their experience of living with epilepsy. During Epilepsy Awareness Month, the newly launched Purple Door Campaign was a major hit where schools and businesses decorated their doors to increase epilepsy awareness.

As much as these programs provide our epilepsy community with much-needed support, we always look forward Purple Day in March when we get to join together as one big group. Seeing the diversity of our members and their families together for a day of fun brings us so much joy. Creating a comfortable environment where people with seizure disorders can meet others and share their experiences helps build connections and reduce social isolation. This year's community events resulted in long-lasting friendships and even more smiles.

As we move into a new decade, Epilepsy Ottawa is committed to working even harder to improve the lives of the 10 000 individuals living with epilepsy in Ottawa and the surrounding regions. I would like to thank our Board of Directors, our staff, and our many dedicated volunteers. Epilepsy Ottawa will continue to work on providing the best quality services to our wonderful clients.

Cheers to 2019! I hope to see many of you in the new year.



Nikki Porter, PhD
Executive Director

“We expanded our team and provided support to more people with epilepsy than ever before.”

EDUCATION

Living with epilepsy can be overwhelming, scary, and lonely. Clinic to Community provides families with a safe environment to discuss their concerns, and connects them to other families struggling with similar challenges.



CLINIC TO COMMUNITY

This year, Epilepsy Ottawa was thrilled to expand our Clinic to Community program to include families with children or teenagers with epilepsy in addition to the newly diagnosed adults we support with this program. With a multi-year Grow Grant from the Ontario Trillium Foundation, Clinic to Community branched out to help children and their families at any stage of their epilepsy journey.

Meeting with a trained Epilepsy Educator, Clinic to Community allows families to obtain useful information unique to their loved one's own experience with epilepsy. They can rest assured that they're receiving accurate information in an evidence-based program. The trained Educators supply helpful emotional support, information, tools, and materials to help people with epilepsy and their families better manage life with epilepsy.

AWARENESS

#THEPURPLEDOOR2019

**OLD
WAYS
WON'T OPEN
NEW DOORS**



March is Epilepsy Awareness Month!

This year, we're excited to launch #THEPURPLEDOOR2019 campaign!

Submit a photo of your decorated classroom door between March 1st 2019 and March 31st 2019 and be entered to win a PURPLE DOOR PARTY for your class.

For more information visit:
www.epilepsyottawa.ca/thepurpledoor

Campaign courtesy of
Epilepsy Southwestern
Ontario

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PURPLE DOOR CAMPAIGN

Epilepsy awareness is a priority of our core mission. We are always looking for new and innovative ways to get the community involved. To this end, Epilepsy Ottawa was pleased to launch The Purple Door Campaign as part of Epilepsy Awareness Month 2019. Schools and workplaces decorated their doors purple and submitted photos of their finished designs for a chance to win a prize.

Often, people living with epilepsy don't open up about their experiences to their peers due to stigma. The Purple Door Campaign was designed as a fun, creative, and collaborative experience to help normalize the conversation around epilepsy awareness.

We received 16 door submissions from schools and businesses for this campaign's first year. Thank you to all who participated!

Supporting Epilepsy

Purple Day - March 26
www.purpleday.org

Around The World!

COMMUNITY

PURPLE DAY

On **March 26**, people around the world celebrated with friends and family what it means to live with epilepsy. At home in Ottawa, it was no different. With our Epilepsy Ottawa flag waving high and proud in front of City Hall, our employees, volunteers, and most importantly our clients and their friends and families came together for an afternoon of celebration. Handcrafted midway games created and donated by Ottawa City Woodshop, a beginner ukulele lesson, and Pop Up Painting were enjoyed by all. We had a great list of guest speakers, including Deputy Mayor Laura Dudas, MPP Jeremy Roberts, Andrea Porter from Ontario Trillium Foundation, and Dr. Asif Doja of Children's Hospital of Eastern Ontario.

We would like to thank Épilepsie Outaouais for helping us create a space where both French and English families could comfortably participate. Thank you to our giving sponsors UCB Pharmaceutical and Eisai Limited. We are grateful to Costco Wholesale Gloucester, Via Rail, and Ingenium-Canada's Museums of Science and Innovation for their generous prize donations. Lastly, thank you to all our amazing volunteers.

This was a Purple Day to remember. It was a joy to see all who joined in on the celebration to empower those living with epilepsy.

“There was a time once when I didn’t let my mom tell anyone I had epilepsy, and now it is an integral part of my politics, my activism, and how I move through the world. It has shaped me.”

SPOTLIGHT: ELLA LAKE

Those who have epilepsy can be our friends, our families, our peers, and also our community leaders. Ella Lake, a 15-year-old with absence seizures is a leader. She lives with epilepsy but also works to make sure young voices are heard around environmentalism and disability justice.

Ella and her family have been familiar with seizures for quite some time. She first had seizures at age three that eventually stopped at age four. At age 12 however, the seizures began again and have since been a part of her life.

Absence seizures differ from what most people think of when unfamiliar with epilepsy. Absence seizures usually last 5-15 seconds, can happen dozens of times a day, and have subtle symptoms. Often when Ella has a seizure she looks like she is staring or daydreaming and she can forget what she was talking about just before one occurs.

Ella wants people to know that her seizures do not stop her from pursuing passions.

“There was a time once when I didn’t let my mom tell anyone I had epilepsy, and now it is an integral part of my politics, my activism, and how I move through the world. It has shaped me,” says Ella.

With some of her friends, Ella has since created an activist group in her town just outside of Ottawa.

“After having a flareup of my illnesses I wasn’t able to go to school. I started joining in with some old friends in my area who are homeschooled to maintain a level of interesting things in my life while still being lower energy,” Ella explains. “We started a group called Chelsea Youth. We created a group to represent the youth in the municipality”.

As Ella has not always been confident dealing with her epilepsy, at a meeting she attended with her family to prepare for Epilepsy Ottawa’s annual Ottawa Fire Truck Pull, she asked us if there were any youth groups she could join. At the time there were none specific to young people with epilepsy but that soon changed with our Epilepsy Perspectives Image Club (E.P.I.C.).

Without E.P.I.C. Ella says, “I wouldn’t have found other kids with similar experiences that empowered and boosted my self-confidence to do all the things that I love doing now”.



We were very pleased to have our second annual Ottawa Fire Truck Pull at Lansdowne Park, building on the success of the previous year. We raised \$34 000 dollars – up more than \$10 000 dollars from last year!

Once again, teams worked together to compete against each other, not only to see who could pull the fire truck the fastest, but who had the best team spirit, who could raise the most money and who was the overall best team. Newly added this year was the Shawn Mathieson First Responder Challenge which commemorated the Ottawa Firefighter who passed away in 2016.

Congratulations to all teams. Every team was able to get the fire truck moving, contributed to such a fun atmosphere, and raised money that will help the 10,000 people with epilepsy in our community.

Special shoutout to Ottawa Police Service for winning the Fastest Pull and the Shawn Mathieson First Responder Challenge. Shoutout to Team Shrek for winning the Most Charitable Team title. Lastly, shoutout to Station 53 and Friends for winning Best Team Spirit and Overall Best Team.

Thank you to all the amazing teams, dedicated staff and volunteers, Ottawa Fire Services, and our generous sponsors. Thank you to TekSavvy Solutions, Ontario Brain Institute, Eisai Limited, Turner Moore LLP, UCB Canada Inc., Tulmar Safety System Inc., Craft Beer Market, and Quest Awards.

OTTAWA FIRE TRUCK PULL

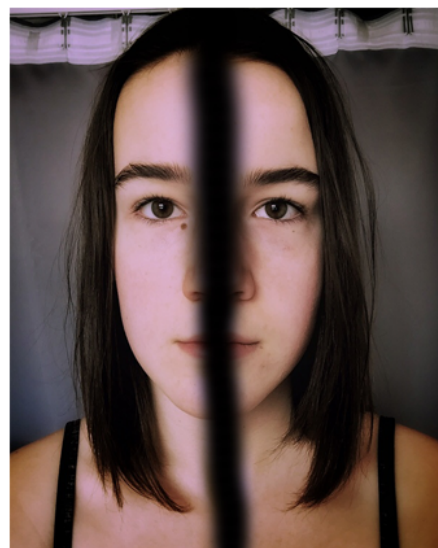
SUPPORT



E.P.I.C: EPILEPSY PERSPECTIVE IMAGES CLUB

This January we launched the pilot project Epilepsy Perspective Images Club (E.P.I.C.) for youth aged 12 to 25 with epilepsy. E.P.I.C. was created as an opportunity for our younger members to join together and take part in photography, storytelling, and vlogging workshops to learn how to artistically express their own experiences living with epilepsy. The program was also designed to help participants gain self-esteem, confidence, social strength, emotional strength, and meaningful connections amongst their peers.

E.P.I.C: EPILEPSY PERSPECTIVE IMAGES CLUB



In September, after lots of hard work, our E.P.I.C. members, their friends and family, our own Epilepsy Ottawa team, and the general public came together for an evening to showcase the outstanding final pieces. The young club members were very brave and inspirational for sharing such personal stories. We are all proud of their hard work and in awe of their photography, vlogging, and story-telling talents.

We'd like to thank MPP Joel Harden and program funder Ontario Trillium Foundation representative Fareeha Sagheir for joining us to celebrate and conclude our successful pilot project.

Visit epilepsyottawa.ca/epic to see the photos, stories, and vlogs created by E.P.I.C. participants.

Top photograph by Ella Lake:
Absence, 2019

Bottom photograph by Samantha Gauthier:
Small Things Matter, 2019

“I think if my classmates and teachers knew I had seizures, and seizure first aid, they might have known what to do when I had my seizure.”

~ Ashley, 17 years old

436

members of
epilepsy
community
attended our
community
events and
activities

37

volunteers
dedicated

452

volunteer
hours

taught

973

how to
be Seizure
Smart

supported

325

people by
phone, email, or
face-to-face
meetings

MEET THE TEAM



Nikki Porter, PhD
Executive Director



Jamie Everitt, RSW
Epilepsy Educator



Stephanie Youngdale
Program Coordinator

BOARD MEMBERS

Peter Andrews
President

Sherisse Al Sabeh

Jeffrey McCully

Allen Wright

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Via Rail

SPECIAL THANKS

GRANTS & FOUNDATIONS

Canada Summer Jobs Program

Ontario Brain Institute

Ontario Trillium Foundation

Ottawa Community Foundation

COMUNITY PARTNERS

City of Ottawa, Lansdowne Park

Children's Hospital of Eastern
Ontario, Epilepsy Program

Épilepsie Outaouais

Epilepsy Southwestern Ontario

Hybrid Pharm

LivaNova

Ottawa Fire Services

The Ottawa Hospital, Civic Campus,
Epilepsy Program

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OUR VISION

Creating a community where persons affected by epilepsy or seizure disorders are empowered and supported to live life to the fullest, free of stigma and barriers.

OUR MISSION

Epilepsy Ottawa is a not-for-profit, charitable agency dedicated to improving the quality of life for those living with epilepsy or seizure disorders and those closest to them through support services, education, advocacy, and on-going public awareness.

Epilepsy Ottawa provides services to those affected by epilepsy in the Ottawa region, including the wider rural communities (Lanark County, Renfrew County, Prescott-Russell County, and Stormont Dundas & Glengarry Counties).

About 10,000 people in this area have been diagnosed with epilepsy. The effect of an epilepsy diagnosis goes beyond the individual; it impacts the entire family.

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