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IMPACT REPORT

2021

CREATING CONNECTIONS, BUILDING COMMUNITY

You are a vital member of our community. Any reduction in depression, social isolation, fear, and anxiety our clients experience is, in part, a result of our generous donors, dedicated and caring staff and volunteers, and support from our partners. You helped lighten the load for the 1,230 people affected by epilepsy that Epilepsy Ottawa reached in 2021.

Improving the quality of life of those with epilepsy or seizures and their loved ones is Epilepsy Ottawa's mission, the driving force behind everything we do. This has remained our North Star throughout the last two difficult years of the pandemic.

As challenging a time as it's been, Epilepsy Ottawa's programming and our reach have grown since 2020. Video conferencing has made it easier for clients in the rural communities surrounding Ottawa to join our support and social groups. We've seen more people at our Parents Support Group – possibly because they no longer need to get childcare, rush through dinner, and then travel to downtown Ottawa to join us.

Clinic to Community has expanded our client base, and now we can tailor some meetings for smaller segments of our community. We've always had programs for adults with epilepsy, parents whose children have epilepsy, and families with epilepsy. In 2021, we added a social group for children and teens with epilepsy, a sibling support group, and a support group for people with Psychogenic Non-Epileptic Seizures (aka Functional Seizures).

These are a few of the ways Epilepsy Ottawa's mission has made an impact in 2021. In the coming pages, clients, volunteers, and staff will share their stories.

OUR YEAR BY THE NUMBERS

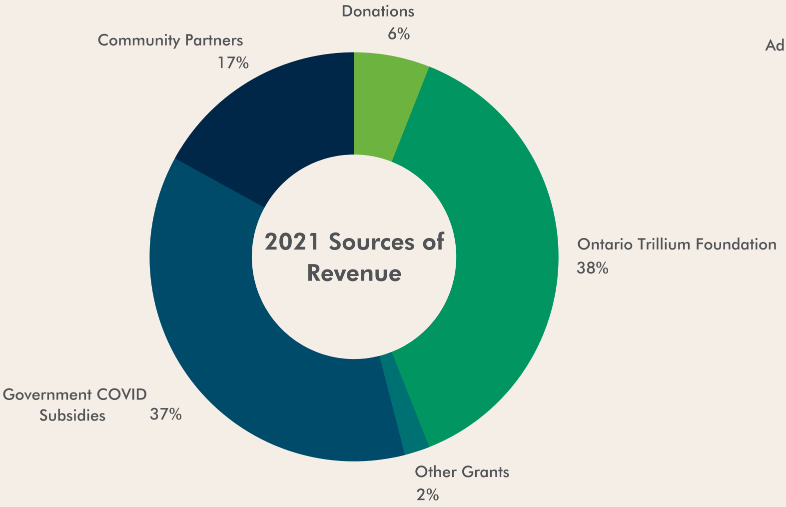
220 teachers **284** students received epilepsy education

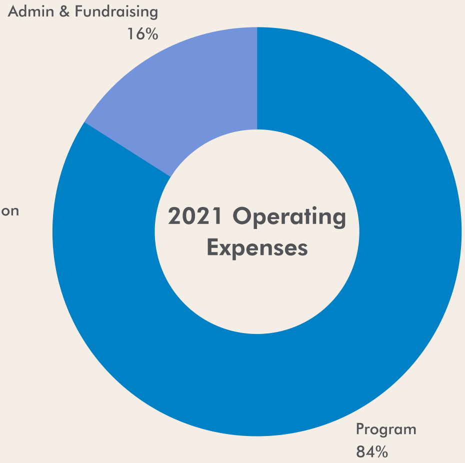
55 people participated in UPLIFT

245 people attended our social and support groups

Clinic to Community Reached **101** people

325 accessed other Client Support Services





JAMIE EVERITT:

A BRIDGE IN THE JOURNEY FROM CLINIC TO COMMUNITY

C2C

Clinic To Community

When Jamie Everitt started working at Epilepsy Ottawa, she had no idea the stories she'd hear and the impact she'd have on the epilepsy community in the Ottawa area. Five years and a pandemic later, she's more committed than ever before.

Since Jamie joined the Epilepsy Ottawa team, she's seen first-hand how early intervention programs like Clinic to Community can improve someone's experience of the first year after they're diagnosed with epilepsy.

When people are newly diagnosed, they are often overwhelmed by information, questions they have about epilepsy, and what it means to live with epilepsy now and when planning their future. "A lot of our clients come to us feeling very lost, like they're floating in the unknown," Jamie explains.

Clinic to Community provides the foundational knowledge and confidence they need to advocate for themselves at work or school and with their doctors. Jamie is known for spending as much time with people in a Clinic to Community meeting as they need until all their questions are answered and their concerns are addressed – even if it takes hours.

It's not only people who are newly diagnosed that Jamie helps in Clinic to Community, but those who have lived with epilepsy for years. "This program is completely eye opening for those who may have been having lesser-known seizure types without realizing it." It's not unusual for someone with Tonic Clonic seizures to learn in a Clinic to Community meeting that they're having other types of seizures as well. Then they can speak with their doctor about further treatment options. It can be life changing.

What Jamie loves the most about Clinic to Community is that "we get to know our clients so much deeper than a phone call allows. We learn a lot about their story and can address their needs by providing or creating programming that is impactful for the entire community."

LOUISE: UPLIFTING

Louise Blanchet knows first-hand that when people are diagnosed with epilepsy, depression soon follows: “For me, it was denial, fear of the future, and that just spirals and brings you down.” There was such a stigma around epilepsy, that she didn’t talk about it when she was first diagnosed 30 years ago. She felt like she was hiding.

Louise started volunteering as an UPLIFT co-facilitator so she could offer people the support she needed early in her epilepsy journey. UPLIFT is an 8-week mindfulness-based cognitive behavioural therapy program for people with epilepsy and depression or anxiety.* It is co-facilitated by a Registered Social Worker and a person with lived experience.

As a co-facilitator, Louise loves seeing the impact this program has on participants over 8 weeks. “I see them opening up more. I see in some of them, the anger subsides or diminishes.” Louise gets it when participants tell her that sometimes they start using the UPLIFT techniques without even realizing it – because it’s happened to her, too! She uses some of the mindfulness techniques to reduce anxiety and stay present.

Another benefit of the program, Louise notes, is that it offers people with epilepsy a place to share their stories with others who understand how they feel and have gone through the same things. “You can talk to friends, you can talk to family, you can talk to your doctor, but nobody really understands.” In UPLIFT, things are different, “there’s that connection from session one.” This connection is one of the reasons that Louise has returned time and again to co-facilitate more UPLIFT groups.

**UPLIFT is also available to those with depression or anxiety who are parents and caregivers of people with epilepsy.*

ROBERT:

A FAMILIAR FACE

Robert Desautels has been part of our community for at least a dozen years. He attends just about every activity and event he can. He enjoys meeting different people and getting to know them. He's made some good friends through the Social Group. Making these connections has helped Robert think positively and he's learned that "you shouldn't let epilepsy get you down."

Like many people in our community, Robert is looking forward to the return of in-person social activities where conversation is easier and you get to know people better. We look forward to that, too.

Community is as important at Epilepsy Ottawa as education and mental health programs. Social groups, support groups, and community events bring people with epilepsy together to connect with others who understand their experiences in a fundamental way. For some, this is the only place they spend time with other people living with epilepsy.

VÉRONIQUE:

GIFTS BEYOND MEASURE

> *Talking about my story was a way of letting people know that these things happen: A lot of people can suffer from epilepsy. You can see someone walking down the street and that person can suffer from epilepsy, but you wouldn't know it. It's kind of an invisible illness.*

In 2020, Véronique Sylvain celebrated her 20-year seizure-free anniversary with a Facebook fundraiser for Epilepsy Ottawa. She shared her epilepsy story and promised to shave her head if she met her goal. She not only reached her goal, but she more than doubled it!

Véronique was grateful for the generosity of her friends, family, and Facebook acquaintances she barely knew!

She's also pleased that her efforts raised epilepsy awareness. "Talking about my story was a way of letting people know that these things happen: A lot of people can suffer from epilepsy. You can see someone walking down the street and that person can suffer from epilepsy, but you wouldn't know it. It can also be an invisible illness."

When Véronique shaved off her hair, at first, she was a bit insecure about showing the scar on her head from her epilepsy surgery. That soon changed when people saw it and asked her questions about it. "I think it was part of my recovery just to tell my story, but also to show that life can continue after an illness."

Strangers even shared their epilepsy stories with her. For some of them, it was the first time they talked about it with anyone outside their own family.

Véronique's first Facebook fundraiser helped Epilepsy Ottawa provide UPLIFT - a mindfulness based cognitive behavioural therapy program for people with epilepsy and depression or anxiety. The techniques used in the program reduce stress, which can, in turn, reduce seizures.

"What's heart warming for me is when I was suffering from epilepsy, my mom subscribed me to some mindfulness classes. Mindfulness is part of my daily routine now. So I'm glad that the money I raised supports people with epilepsy to raise awareness but also to learn about mindfulness."

The Facebook fundraiser was such a success, that it's become an annual event for Véronique. It's an easy way to support people with epilepsy and continue raising epilepsy awareness.

TATYANNA:
#Iam1in10

> *Even if you don't have epilepsy, you can learn more about it.*

13-year-old Tatyanna is proud of herself for being the face of the #Iam1in100 campaign. When she participated a few years ago, she told the world "I have epilepsy and I'm a fighter and a singer." Her sign would look a little different now that she spends less time singing and more time on her favourite hobbies: reading, baking, and dancing. Tatyanna wants to clarify that when she wrote that she's a fighter, she didn't mean she's combative but that she stands up for herself.

Tatyanna found it fun to participate in an epilepsy awareness campaign and she knows it's important for others to see, too: "Even if you don't have epilepsy, you can learn more about it." She thinks it can lead to people without epilepsy helping and supporting people who do have it.

Tatyanna also believes that it's important for people with epilepsy to see epilepsy awareness campaigns, because it may lead them to resources like Epilepsy Ottawa's programs. "If they don't know there's this group they can join, they can hear about it and be like 'oh I'm going to go to this next meeting'" It's scary when you feel like you're alone and you have no one to talk to. Epilepsy awareness campaigns can help people realize they aren't alone.

LOOKING FORWARD

Epilepsy Ottawa is about to face a seismic shift. Over the last few years, much of Epilepsy Ottawa's revenue was from Ontario Trillium Foundation in support of Clinic to Community. This funding provided us with the resources to expand our staff, reach many new people with epilepsy and their families, and expand our programming in support of our growing client base. As this funding comes to an end, Epilepsy Ottawa will look elsewhere to sustain the programs and services our community needs and deserves.

This fall will see a relaunch of the Ottawa Fire Truck Pull. We are diversifying our grant applications to ensure schools receive Seizure Smart to support students with epilepsy, UPLIFT will be available to those with epilepsy and depression, and people dealing with a new epilepsy diagnosis will have access to Clinic to Community. As our community grows, we trust that community support will grow along with it.

The evolution of these revenue streams will ensure that our team continues to provide support and social programs for kids and youth with epilepsy, as well as their siblings. Parents of children with epilepsy will continue to connect in our parent support group. People with functional/psychogenic non-epileptic seizures will find community. And we'll continue to address emerging community needs.

There is a lot of work to do to sustain this agency and continue providing a wide array of programs and services to improve the quality of life for people with epilepsy and their families. The Epilepsy Ottawa team is emboldened by the community response so far, and we look forward to continue in the future.

> ***It's crucial to have organizations like this to say 'Hey, you don't have to carry all of this by yourself.' It's vital. It's so vital!***
>
> –Sean Bufton, client and volunteer

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