

# e community bulletin

Epilepsy Toronto's publication of community news and events

## PURPLE DAY FOR EPILEPSY



### inside

New Faces at Epilepsy Toronto..... ②

Purple Day..... ④

Courage on Canvas..... ③

Annual Conference..... ⑦

# New Faces at Epilepsy Toronto

Epilepsy Toronto would like to welcome 2 new members of our staff team. Here are a few words from them.

## Rachael-Lea Rickards-Director of Public Education and Outreach

Hi, I'm Rachael-Lea, Director of Public Education and Outreach. Being a Jamaican born Canadian citizen, I certainly understand the challenges of racially diverse communities. Recognizing the importance of epilepsy awareness, my goal is to ensure that all communities have a firm grasp on what to do and how to support those living with epilepsy.

I come with a background of Training and Development as well as a Social Service worker diploma. My passion is also in the arts. Being an actor, playwright and published author, I bring creativity to my position and look forward to sharing my strengths so that Epilepsy Toronto continues to thrive and touch lives. If you have any questions in regards to community awareness, diversity and/or inclusion, please do not hesitate to contact me.



## Oliver Stamp-Recreation Group Coordinator

I am the Recreation Group Coordinator responsible for recreation activities that take place every Friday afternoon from 1-4pm. This group caters to adults with epilepsy who have a desire to have fun and excitement and isn't a counseling or mentoring group. My role is to support each member's individuality by encouraging activities that challenge and motivate interests such as Art Therapy, sports, movies, and music that bring about mental, social, intellectual, spiritual and emotional wellbeing.



I also encourage members to forward new ideas for activities they are interested in participating in.



### Staff

**Geoff Bobb**  
executive director

**Brandon Fairley**  
director, development

**Alexandra Keay**  
employment manager

**Katie Lundy**  
director, children & youth services

**Pam McDonald**  
office manager

**Pia Marin**  
financial services manager

**Mackenzie Muldoon**  
marketing & entertainment  
director, Scotiabank  
BuskerFest

**Nicole Nelson**  
director, development

**Tim Nourse**  
co-ordinator, enabling change  
project

**Rachael-Lea Rickards**  
director, public education and  
outreach

**Rosalee (Rosie) Smith**  
director, adult services

**Kirsten Sixt & Rindy  
Bradshaw**  
teaching awareness through  
puppetry

**Oliver Stamp**  
coordinator, recreation group

**Bonnie Taylor**  
festival director, Scotiabank  
BuskerFest

**Drew Woodley**  
director, communications

### Board of Directors

**Daryl Yeo**  
president

**Tracy Day**

**David Caplan**

**Irene Elliott**

**Jim Feyerer**

**Brad Freelan**

**Jonathan Lipszyc**

**Mark McAllister**

**Barry Pickford**

**Wende Rapson**

**Natasha Stoddart**

**Dr. Peter Tai**

**Caroline Tapp-McDougall**

**Dr. Taufik A. Valiante**

## Thank You

- To outgoing board member Andris Pone for leading a year-long brand foundation development for Epilepsy Toronto. We are excited to have new mission, vision, and value statements for ET and a new tagline, *See the Person*, all of which are being incorporated into our materials and communications.
- To ET members Michael Kennedy, Dan Madge, and Tannys Williams for contributing their time and talents in writing articles for this edition of the Bulletin.



*Prepared by Michael Kennedy, ET Member*

Just in time for Epilepsy Awareness Month, Epilepsy Toronto is the first Canadian epilepsy support centre to offer an art therapy program. The new project will provide children and youth with a safe and welcoming environment to artistically express emotions about their condition that may be too difficult to explain in words. The children in this group represent a handful of the 15,000 Canadians who will be diagnosed with epilepsy in 2014.

We have learned that people living with epilepsy greatly benefit from an outlet to express their emotions and increase feelings of self-worth and confidence. The Courage on Canvas program at Epilepsy Toronto aims to act as a vehicle to provide participants this opportunity and strengthen their voices.

Each session focuses on different life experiences unique to children with epilepsy. These brave youth live with uncommon hopes and fears that are often ignored or taken for granted. The Courage on Canvas program focuses on the unique hopes, fears and “superpowers” children develop while living with epilepsy. The final week concludes with a celebration of the work and progress achieved throughout the six-week period.



The Courage on Canvas program is designed to give group-members an opportunity to better understand themselves and their disorder. Participants are able to make new and lasting connections and friendships in an environment that fosters social and safe-care skills.

Sessions are administered by Sarah Hughes, a clinical art therapy student currently attending the Toronto Art Therapy Institute. Hughes has extensive experience working with children at the Delisle Youth Services and Ronald McDonald House Toronto. The experience she gained from both opportunities has provided her with the tools required to support the needs of children and families experiencing challenges associated with long-term medical diagnoses such as epilepsy.

*The first program of Courage on Canvas runs for six weeks from February to April.*



# PURPLE DAY FOR EPILEPSY

Across the country on March 26<sup>th</sup>, individuals and groups will be participating in Purple Day to raise public awareness about epilepsy.

*Prepared by Dan Madge, ET Member*

Purple Day is upon us, and Epilepsy Toronto will be an active participant again this year. But it is our members who are help making it our most successful Purple Day yet!

If you are looking for a great way to get involved in Purple Day and want to educate your friends, family or colleagues about epilepsy, you should consider joining our Ambassador Program.

The Ambassador Program was designed to ensure that we spread the word all across the city with the help of our members. We want you to go out into your community and influence the people you live, work or play with. We need to educate Torontonians about epilepsy and help build better awareness and acceptance.

Our goal is to have 100 events across the city on March 26<sup>th</sup> and to reach a total of 10,000 people with our message about epilepsy. That is where our members come in – we need volunteers to sign up as Ambassadors and to organize events in your workplace, school or community.



What type of Purple Day event you organize is completely up to you. The event can be as ambitious or as modest as you feel comfortable with. There are many more ways that you can get involved as a Purple Day Ambassador – just ask us and we'll be able to identify an event that makes sense for you. Becoming an Ambassador is easy and we're here to help with every step along the way.

With your support we can build awareness of epilepsy throughout the community, breakdown barriers and stigmas and raise funds to allow Epilepsy Toronto to continue to support people living with epilepsy.

There is still time to sign up. For more information on Purple Day and the Ambassador Program, and how to become involved, please contact Brandon Fairley, Director of Development at [brandon@epilepsytoronto.org](mailto:brandon@epilepsytoronto.org).

# WEAR PURPLE

## MARCH 26<sup>TH</sup>

### What Can I Do For Purple Day?



There are dozens of different ideas that you can adopt for your event – but in case you’re having a tough time coming up with one that you’re comfortable with, here are a few options for consideration.

#### Do you work in an office?

Send an email around for a “purple-themed” lunch where you discuss epilepsy with your peers and collect donations to go towards Purple Day.

#### Are you involved with your church?

Arrange a post-service tea party where information about epilepsy is available and donations are collected for Epilepsy Toronto.

#### Do you want to do something simple to educate your neighbours?

Pass out purple buttons in your lobby and tell them about your experience with epilepsy.

### This Purple Day Watch For:

- A Purple flag flying at City Hall
- A Purple CN Tower
- Members of the Downtown Yonge BIA with Purple Day displays in their stores and restaurants



# Diversity Outreach: What's Happening at ET

Prepared by Tannys Williams, ET Member

Many people think that epilepsy is most common in children under the age of 2; but with an aging population, children are now sharing that status with seniors over age 65. This is one of the little-known facts that Epilepsy Toronto is trying to showcase with their new outreach programs to reach diverse groups such as newcomers to Canada, women, seniors, and the disadvantaged. Two of the outreach programs are already underway, with very positive results.

## South Asian Health Promotion Working Group

The South Asian Health Promotion Working Group project involves many different Canadian foundations, such as Epilepsy Toronto, the Heart & Stroke Foundation, the Canadian Lung Association, the Alzheimer's Society of Canada, and others. Each of these foundations gave a presentation at the Malvern Family Resource Centre in August/September in an attempt to reach out to South Asian communities, which represent the largest percentage of newcomers to Toronto.

The intent was to ensure all were aware of programs in Toronto that can improve their health or quality of life, and how to access those programs. The development of the initiative is a result of several issues: different cultures may feel a stigma or shame in the seeking of health services; they may, for linguistic or cultural reasons, be unaware of such programs; or they may feel they don't qualify or have no way to attend.



So far, the South Asian Health Promotion Working Group has received great feedback for their presentations and intends to continue by searching for volunteer trainers who speak at least one South Asian language. They will be coached and then will give the presentations in other diverse communities.

## Focus Group for Seniors

The Focus Group for Seniors is an exciting program funded through a New Horizons for Seniors grant given by the federal Employment and Social Development Department. It started as a focus group consisting of seniors (those over age 55) with epilepsy. ET had designed the program in order to gain information about the experience of an older adult with epilepsy, the services that are needed by seniors, and how ET can best offer those services.

After only three meetings, the focus group has transformed into a type of support system, allowing those with common needs and difficulties to share their issues. A new goal of the program volunteers has become the spreading of information to others, by leaving materials in doctors' offices, seniors' homes, and other such locations.

Anyone who would like more information or is interested in participating in one of these programs can contact Epilepsy Toronto at [info@epilepsytoronto.org](mailto:info@epilepsytoronto.org).

# 2014 Annual Meeting and Conference

May 10th 2014 • 8:30am – 4:00pm

Metro Hall, John Street, Toronto

Epilepsy Toronto's 2014 Annual Meeting & Conference is just around the corner and you don't want to miss out. This year's conference promises to be interesting and informative with excellent presentations on a variety of topics including treatment options and living with epilepsy.

## Keynote Speaker: Dr Brien J Smith

We are excited to announce that Dr Brien J Smith, Chief Neurologist at Spectrum Health Medical Group in Michigan will be our keynote speaker. His address, *Epilepsy, A physician's firsthand account*, will focus on his experience with epilepsy and brain surgery, how it impacted his life and practice as a neurologist, and suggestions for people with epilepsy on how to 'live well' with such a challenging condition.

Dr. Smith is well-respected in the medical community as a top neurologist and his personal experience with epilepsy has fueled his passion to serve others. He has had a strong advocacy presence in Washington and has advocated for more funding to promote a wide range of epilepsy research toward better treatment options, a greater understanding of seizures, and a cure for epilepsy.



You won't want to miss this year's conference, so mark the date and register your interest by calling or sending an email to [info@epilepsytoronto.org](mailto:info@epilepsytoronto.org). Space is limited. Registration forms will be available soon.



# Family Retreat

Fifteen families came together for a weekend of fun and discussion at this year's enormously successful Family Retreat at Geneva Park near Orillia. With the theme of "Go For Gold", both adults and kids had the chance to take part in an Olympic-themed scavenger hunt, floor hockey, and got out-of-doors to cross-country ski, ice-skate, and snowshoe in the lovely winter weather.

While adults had an opportunity to meet and discuss issues with physicians in group sessions, the kids developed their talents in art and dance. Saturday night was capped-off with s'mores around the campfire.

Thank you to our presenters, Dr. Eduard Bercovici, Sarah Hughes, Ryan Lee, and Dr. Ljubica Zotovic for making this an incredible weekend and a huge thank you to Mackenzie Financial for making it all possible.

*"Thank you all from the bottom of my heart for allowing me and my family to join your family. I just wanted to let you know what it meant for me to let my guard down for once. As a Parent we are always over protective over our kids, especially when something happens that you are not familiar with. I learned this weekend to let go a bit and that Epilepsy does not define who you are... We have made such great memories and will never forget this weekend."*

-Joanna, Family Retreat Parent

