

2013 Annual Report



~ Purple Pancakes for Epilepsy Awareness ~

The Epilepsy & Seizure Disorder Resource Centre is a non-profit charitable association dedicated to improving the quality of life for those affected by epilepsy and seizure disorders. The mission of the association is to provide support, education and advocacy services for those affected by epilepsy and seizure disorders.

Message from the President

When I addressed the AGM last year, it was to report progress coming out of a very difficult time. I am pleased to say that our organization can proudly announce that we are no longer an organization experiencing difficulties. In the past year, we have moved beyond the struggles that beset us and can now speak to the solid foundation that has been laid for the organization as we move into the future. Just the fact that we can speak to the future instead of having to reflect on the current situation and the past is a tremendous accomplishment for the board and staff of this organization. The feedback that we have received from our funding bodies has been nothing but positive, and we no longer worry about our funding being at risk. We can now look forward to a time when we can go to funders and say that we have excelled in what we do, and can offer more to the community if they are able to assist us with financial resources. In a recent strategic planning session we were able to look ahead to the day when we hope to be fully staffed, with at least six staff providing multiple levels of service. We also look forward to the day when we can provide comprehensive services to the rural areas of our community, and move towards providing services in the Quinte area once again.

As a board, we are proud of the services that our staff provides, and we recognize the great progress that our staff has made in re-establishing our credibility within the professional community. We look forward to even greater progress in this area, and as a board, we hope to be able to reinforce and support our staff in continued growth and development as they provide service to the community.

I am not providing a list of specific accomplishments, as I believe the greatest indication of our accomplishments are those that our executive director will be identifying as enhancements in service delivery, which have now taken a priority over survival.

It continues to be a pleasure to attend board meetings and work with people who are committed to seeing this organization grow and flourish. One of the greatest challenges for a board is to develop to the point that we have a full complement of board members and the ability to use the board effectively in the area of fundraising and community relations.

A few notable events for the board:

- **Bingo Fundraising**

Volunteering at a bingo is now elevated to a more professional level and board members must take a course prior to embarking on a session of volunteering at the bingo hall. This year, board members have been volunteering as ambassadors of the Epilepsy Resource Centre at Community Spirit Bingo. As a result, we are receiving regular financial payments through the Ontario Lottery and Gaming Corporation.

- **Garage Sale**

Board members organized a garage sale that was held in the parking lot of the Kingston Community Credit Union. This experience demonstrated to us that it was probably not the greatest fundraising activity, as the amount of time and energy needed to stage and host the event was far greater than the yield in actual dollars. On the other hand, it was a positive event in bringing board members together and demonstrating how effectively we can work in the face of great diversity.

In the past year it has also been a pleasure to attend Board meetings in which we continue to look to the future without having to worry about the very question of our existence. We can now focus on where we want to go and how we can achieve this. In particular, we hope that members joining our board can do so with the sense that they are contributing to an organization that has a strong future and a place in bettering the lives of the people for whom we exist to serve.

Last year in closing I quoted St. Francis of Assisi:

“Start by doing what's necessary; then do what's possible; and suddenly you are doing the impossible.”

In reaching the place we are today, we have achieved what was thought to be impossible in the minds of some observers three years ago. In closing my statement for this year, I would like to again look to a quote to carry us through the next year from one of my favorite philosophers and social activists, Noam Chomsky.

“Optimism is a strategy for making a better future. Because unless you believe that the future can be better, you are unlikely to step up and take responsibility for making it so.”

Thank You

Jim Docherty
Board Chair

Message from the Executive Director

What a difference a year makes. As I reflect on the position of the Epilepsy Resource Centre one year ago compared to now, I am amazed at the change and positive growth that has occurred. It has been a delight this year to shift our focus from stabilization of the organization to that of service delivery. We have been providing increasing levels of support to our clients, and have been working diligently to increase the profile of the Epilepsy Resource Centre in the communities we serve. We continue to grow, expanding on our existing programs and events, and introducing some exciting new initiatives.

This year we have seen our mission come to life, as we have dedicated our energies to providing support, education and advocacy services for those affected by epilepsy and seizure disorders. We have provided information and support to those in our community who are struggling with the far-ranging impact of epilepsy, and have expanded the range of services we are able to offer, including peer support and support groups. We have recently launched a parent support group, and hope to expand our support group offerings in the coming year. Demand for these individual services continues to grow.

We continue to note that awareness of our organization by those who need us most remains low. Increasing this awareness was a strong focus in the past year, which included hiring an outreach assistant and a Queen's work study student to proactively contact community groups and schools, while also ensuring that our materials are on display in relevant medical settings. As a result of these efforts, community awareness of the Epilepsy Resource Centre is slowly improving. Additionally, we continue to build upon relationships in the medical community to increase referrals to our organization. As is reflected in our strategic plan, continuing to develop these relationships is a primary focus in the coming year. We have also increased our presence in the local media (for which we thank our many media supporters!).

In addition to our enhanced client support and increased initiatives to raise awareness of our organization, several highlights of our successes in the past year include:

Speaker Nights

- New in 2012 was a series of Speaker Nights, which were held in both Kingston and Brockville, to offer information about epilepsy, treatment options, and coping strategies to both those affected by epilepsy, and the general community. These events provided an opportunity to raise awareness about epilepsy to a broad range of people, while also creating opportunities for our clients to connect. Thank you to Dr. Athen MacDonald and Dr. Allison Spiller for providing presentations for our series. We look forward to continuing our Speaker Nights with a new series of topics in the fall of 2013.

Epilepsy Awareness Month and Purple Day

- Our community celebration of Purple Day for Epilepsy Awareness in March grew exponentially this year. We hosted two Purple Pancake breakfasts to raise awareness of epilepsy, held in Gananoque and Kingston, which were a huge hit.
- On Purple Day itself, we directly supported nine schools in celebrating Purple Day in the Kingston, Frontenac, Lennox and Addington and Leeds and Grenville communities, while other schools also participated without our direct support. Over 5000 students were exposed to Purple Day in their schools this year in our area.
- New this year was the participation of several local businesses in Purple Day, whose staff worked tirelessly to promote epilepsy awareness and raise funds for the resource centre. We thank them for their generosity!
- 2012 also saw the passing of the Purple Day Act, establishing March 26th as a legally recognized day for epilepsy awareness in Canada. This year, I proudly represented the Epilepsy Resource Centre and the Canadian Epilepsy Alliance at a reception for the first official Purple Day on parliament hill. It's an exciting time as support for epilepsy research, treatment, support and awareness grows locally, provincially, and nationally.

Fundraising














- We once again ran a successful Glad Days campaign last summer, raising \$5000 and spreading epilepsy awareness. This year, however, we are embarking upon a new major fundraiser in place of Glad Days: the *Pull Together for Epilepsy* fire truck pull.
- As part of our strategic plan we will be working to broaden our funding base through both pursuing grant opportunities and developing a comprehensive fundraising plan.

I am thrilled with where our organization now stands, which is the result of the hard work of our board, staff, volunteers, and our many community supporters. I extend a heartfelt thank you to everyone who has supported us, and I look forward to the coming year with expectations of the Epilepsy Resource Centre continuing to flourish as we provide support to those affected by epilepsy in our community.













Thank you

Susan Harrison
Executive Director

The Epilepsy & Seizure Disorder Resource Centre by the numbers! June 2012 to 2013

-  Number of people living with epilepsy in our area (approx.): 3000
-  Number of clients who received supportive counselling: 77
-  Number of education presentations: 18
-  Number of people who learned about epilepsy at our presentations: 286
-  Number of Speaker Nights: 5
-  Number of community displays: 18
-  Number of people who attended our displays and learned about epilepsy: 782
-  Number of booklets stickered: 3000
-  Number of purple ribbons pinned: 750
-  Number of gladiola stems sold during Glad Days 2012: 2700
-  Number of amazing volunteers: 32
-  Number of staff: 5 (2 Permanent, 3 Contract)
-  Number of placement students: 2

Presentation Locations:

-  St Lawrence College – Kingston and Brockville Campuses
-  Kingston General Hospital
-  Trenton Military Family Resource Centre Day Care
-  La Garderie Croque Soleil
-  Community Living Kingston
-  Brockville YMCA
-  Central Public School, Kingston
-  Girl Guides of Kingston
-  Vanier Public School, Brockville
-  Camp Awakening
-  Gananoque Lions Club
-  Pathways to Education, Kingston Community Health Centre

Display Locations:

-  FCMHAS Community Services Fair, Kingston
-  11th Annual Connect Youth Fair – South Grenville District High School, Prescott
-  Queen's University Sidewalk Sale
-  Garrison Expo and Leisure Show, Kingston
-  Local Corrections Institutions
-  HMCS Cataraqui, CFB Kingston
-  StarTek, Kingston
-  KCHC Community Health Fair
-  Brockville General Hospital
-  Kingston General Hospital
-  St. Mary's of the Lake Hospital
-  Loblaws Princess Street Market, Kingston
-  Food Basics, Kingston
-  ValuMart, Brockville
-  DuPont Health and Wellness Fair

Board of Directors 2012-2013

President:

James N. Docherty

Vice-President:

Jason Field

Secretary:

Kim McFarlane

Directors:

Frances Berry

Saozinha Connor

Peggy Davidson

Jessica Gies

Karen Labbett

Dr. Athen MacDonald

Epilepsy Resource Centre Staff

Executive Director

Susan Harrison

Youth and Administrative Coordinator

Hanna Kitchingman

2012 Special Events Coordinator

Kalla Tonus-Burman

Education Coordinator

Mary Tao

Outreach Assistant

Zack Bell

2013 Special Events Coordinator

Laura Casselman

Our volunteers are the heart of this agency. We thank you for everything you do to assist in bringing epilepsy out of the shadows.


Our Thanks To You!

The Epilepsy Resource Centre gratefully acknowledges its donors and supporters for their generous assistance in the past year. It is thanks to their generosity that the Epilepsy Resource Centre is able to continue to deliver and provide support to the thousands in our community affected by epilepsy and seizure disorders.

A Special Thank You to

United Way of Kingston, Frontenac, Lennox and Addington
United Way of Leeds & Grenville
UCB - The Epilepsy Company
Service Canada - Canada Summer Jobs
Community Spirit Bingo Association
Kelvin Chan

Glad Days 2012

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|  Food Basics, Barrack St. Kingston |  The Ostermans for coordinating sales in Amherstview |
|  Foodland, Amherstview |  Klaas Van Der Meer– Green Acres Greenhouse |
|  St. Mary's of the Lake Hospital |  McMahan's Flower Shop |
|  Kingston General Hospital |  Tim Hortons, Kingston |
|  Metro, Gananoque |  Queen's Hospitality Services and Sodexo |
|  Valumart, Brockville |  Digigraphics |
|  Loblaws Princess Street Market, Kingston |  Discount Car and Van Rentals |
|  Rideaucrest | |
|  Royal Canadian Legion, Kingston | |
|  Ontario Public Service Employees Union | |

Purple Day 2013

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|---|--|
|  Loblaws Princess Street Market, Kingston |  QECVI |
|  St. Andrew's Presbyterian Church, Gananoque |  Front of Yonge Public School |
|  Jordan Bell with Arbonne Cosmetics |  Frontenac S.S. |
|  DuPont Kingston |  Napanee District H.S. |
|  Kingston Community Credit Union |  Gananoque S.S. |
|  Wal-Mart, Kingston |  Lord Strathcona P.S. |
|  StarTek |  Catarqui Woods E.S. |
|  Avanta Spa |  North Hastings S.S. |
|  Baldree's No Frill, Gananoque |  Vanier P.S. |
|  Metro, Gananoque |  MyFM 99.9 Gananoque |
|  Mega Dollar, Gananoque |  St. Lawrence EMC |
|  Tim Hortons, Gananoque |  Snap Kingston |
|  Gord and Kim's No Frills, Kingston |  Snap Brockville |
|  KCVI | |

The Epilepsy and Seizure Disorder Resource Centre is a proud member of the Canadian Epilepsy Alliance and is pleased to be an affiliate agency of Epilepsy Ontario.