



EPILEPSY YORK REGION

We care...We can help!



EYR has new email addresses!

praymond@epilepsy york.org

dharper@

epilepsy york.org

info@

epilepsy york.org

2009 GIFT WRAPPING CAMPAIGN



Article on

Pg. 4



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The Chairman's Article - Derwyn Miller

On behalf of the Board of Directors, I would like to extend season's greetings and wish you all a happy, prosperous new year.

Unfortunately, the Board has recently lost two very valuable board members due to health and time constraints. Elisa McFarlane, our former secretary, was instrumental in developing the Bylaws which were passed several years ago. She had served as secretary for several years and her experience with several boards of directors in addition to our own will be greatly missed. Her input was invaluable in developing our current strategic plan and we all very much enjoyed her sense of humor and personal commitment to EYR. Robin John was chair of the program development committee and worked with Paul Raymond to develop support programs for parents of children diagnosed with epilepsy. Her medical expertise will be greatly missed.

On the plus side, I would like to welcome Joyce Grandy to the board. Her experience as a Chartered Accountant and her corporate connections will be a great asset to the board.

There have been quite a few exciting developments over the last year. During the year, the board participated in a United Way workshop enabling us to develop a strategic plan we are currently implementing. Paul, David and numerous volunteers have enabled us to educate the Farsi, Hindi and Urdu speaking communities and we are currently working with volunteers to extend our speaking about epilepsy into the Mandarin and Cantonese speaking communities. The number of presentations and number of people being educated about epilepsy have both greatly increased this year due to the efforts of the many multilingual volunteers we have. We have, of course, continued to offer educational presentations to students and staff of numerous schools and service clubs. I would like to thank the volunteers who developed our new website which is now active. If you would like to check it out, it is available at www.epilepsyork.org.

Another exciting program that has been developed is a program to make it easier for those having epilepsy to travel on the VIVA and the YRT transit system. The drivers will be given training about the signs and symptoms of epilepsy and how to react to someone having a seizure. An identity card has been developed to show to drivers when boarding the system to make them aware that you may have a seizure so that they can act appropriately. If you wish to have a card, contact the office at 905-508-5404 or 1-866-374-5377. I would like to thank those volunteers who developed and organized workshops for members on how to use the VIVA and YRT system.

As you can see, there have been many initiatives developed involving many volunteers over the last year to help you, our members. What we now need is **your** active support. You can help in many ways including giving us feedback on programs we are offering, suggesting new programs we should offer to help you, renewing your membership, referring new members to our organization, signing up as a volunteer on our website or making a donation to enable us to carry on our work. Feel free to contact us either through the phone numbers above or through the website.

On a personal note, this is my last newsletter as chair. I would like to thank the board members past and current for their support, Paul and David for the tremendous job they have been doing over the last few years and the numerous volunteers who have given freely of their time to help make our organization better.



Coming Out of the Shadows: Stigma of Epilepsy

Written By: Aliza Panjwani

For most of the general public, it may come as a surprise that epilepsy is one of the oldest conditions known to man. In fact, the earliest mention of epilepsy dates back to fifth millennium B.C. Mesopotamia (even more ancient than your grandmother's knitted blue scarf!). Given epilepsy's perpetual existence, one would imagine that the stigma surrounding it decreased through the ages. Unfortunately, it seems as if the reverse has happened. Many people that can serve as advocates and supporters of epilepsy are not open about having it because they are wary of negative treatment.

Celebrities and other public figures are often in the position to serve as role models. I can think of many an affliction represented by well-known media personalities. Take Michael J. Fox as an example, he is an active role model for the people that suffer from Parkinson's disease. We know of many public figures that have served as spokespersons of breast cancer (Sheryl Crowe, Nancy Reagan, and Christina Applegate). Diabetes has been well-represented by famous media figures such as Larry King, Halle Berry, and Mary Tyler Moore. There are countless such examples. Now, try thinking of current public figures that serve as ambassadors of epilepsy. How many come to mind? One or two? Perhaps none?

Fortunately, we can find our inspiration from shining personalities in history (blasts from the past, if you will) that not only lived with epilepsy, but accomplished unforgettable things during the course of their lives. Consider Aristotle, the gifted philosopher you grew up hearing about. His metaphysical treatises and deductive logic may have escaped some of us. But, we can at least give him our vote as a highly intelligent man who contributed immense knowledge to the fields of science and philosophy. What you may have not learned in philosophy class is that Aristotle had epilepsy. What did having epilepsy take away from his intelligence? Nothing.

If you enjoy reading, but intricate philosophical writings are not really your preference, well...you are not the only soul in *that* imaginary room. You may, however, have heard of Charles Dickens or Lord Byron. The name Edgar Allan Poe may result in a resounding head nod, but I'll even accept a noncommittal mutter. Who remembers the young and adventurous storybook character Alice? You know, the one that explored wonderland (now, I'm getting lots of nods, I'm sure). Lewis Carroll, the author, is known to have had epilepsy. In fact, several examples of epilepsy symptoms can be found in his writings. For example, Alice begins her wondrous journey in wonderland when she falls into a hole. Interestingly, many people experience a similar "falling into a hole" feeling during their seizures. These literary 'prophets' were exceptional poets and storytellers, and guess what? They also had epilepsy.

Brilliant world leaders are also known to have had epilepsy. We are all familiar with Napoleon Bonaparte, Alexander the Great, and Julius Caesar. They are extraordinary exemplars of generals that led armies to victory, built empires, and innovated change even in the most tumultuous times. Though they had epilepsy, it did not prevent them from accomplishing remarkable feats that are still discussed today. Can you honestly imagine coming out the victor in a chess game with any one of these guys? However, the accomplishments of these infamous personalities are not really most relevant here. It is the fact that these historical figures embraced their ability to be great.

Given that epilepsy dates back to the time of such thinkers and doers, the amount of myths surrounding it are especially surprising. Although some people may think otherwise, epilepsy does *not* affect intelligence. Having epilepsy does *not* mean that one cannot work or handle responsibility. Most people with epilepsy are *not* physically limited. Although research is still ongoing, current treatment options are beneficial to many. However, most of the general public is either unaware of epilepsy, is only aware of its misconceptions, or thinks that epilepsy is extremely rare and affects few and far in between.

That may be the biggest misconception of all. In fact, as I sit here in the York region Epilepsy office, my eyes are privy to a poster that reads the following: 300,000 Canadians have epilepsy and are coming out of the shadows. That number is an estimation, and is probably even larger than we think. Contrary to the poster, it is evident that the stigma surrounding epilepsy is so great that people are reluctant to emerge out of its shadows. As a result, currently there are not many public role models that have epilepsy, which is why looking to a few historical personalities as a source of inspiration seemed fitting. While we wait for the future public role models of epilepsy to take a stand (and they will), we should remind ourselves that by being active in our own communities, we can help reduce the stigma, making their journey easier. Begin today. If you do not know a lot about epilepsy, you should start learning. And, if you already know about it, then you should start sharing. Educate yourself, and then *Pass It On*.

Gift Wrap

2009



It's that time of year again!

The “shop ‘till you drop” time of year!

**Stop by the EYR Gift Wrapping booth
at the Hillcrest Mall and we'll help you
get all of those gifts wrapped in time
for Christmas!**

All proceeds go towards EYR.

We wish to thank all the volunteers and members who sold Glads to their friends and families. Sharron Rowan-Toy was the winner of the most bunches sold by an individual. Great job Sharron! (Picture of Sharron Rowan-Toy and David Harper)



The Executive Director's Article

By: Paul Raymond



As I sit at my desk to write this piece, on a grey dreary November day - I simply cannot believe that we are on the eve of another year!!! Time here at Epilepsy York Region seems to be flying by....which must indicate that we are having fun.

2009 has been an awesome year, we have had so many successes and the occasional failure, but overall we have come a long way. As Executive Director, I am extremely proud of the work done here. Everyday all of our actions are driven by our mission to support people with epilepsy in York Region. We have initiated new member events, recruited new members and networked with many other organizations. None of this could have been done without the support and dedication of the MANY volunteers.

I am always afraid to mention volunteers by name, for fear of omitting someone, so let me start by thanking everyone who has contributed an hour, a day or a week over the last year.

I do want to thank the members of the Board for their leadership, direction and guidance over the past year. Special thanks to Derwyn for his leadership and commitment to the position of Chair over the past 4 years.

I also need to thank the many office volunteers who come in hour after hour, day after day, week after week. A special mention must be given to David Harper, the organizations' "right hand man". EYR would not be able to accomplish a sliver of what we have accomplished if David did not volunteer here.

I owe a tremendous amount of thanks to Cindy Baird our Membership Coordinator. I know that it is Wednesday as soon as I walk into the office and get a big warm smile from Cindy. Thanks to Jessica Coates, who has fearlessly agreed to take on more and more with EYR. I appreciate her willingness to do more and her ability to generate new ideas and definitely David and I on our toes!!! Thanks to Josie who relentlessly comes in on Tuesdays and gets straight to work entering data for us. I wish to thank Karen Smith for returning to EYR. She has helped us with those very difficult and complicated patient inquiries. Her calm and professional demeanour really helps us in the office to stay grounded and focused. This is only a short list of those to thank: there are many, many more people including our 2009 summer students - Cathy and Jennifer, our placement students Aina and Shirin, all of our donors and our corporate sponsors.

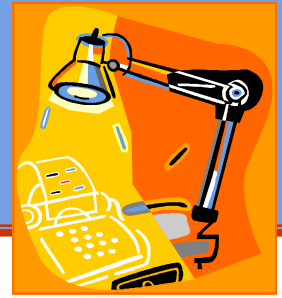
Last but definitely not least, I would be remiss if it didn't thank the members and their families. This is YOUR organization and you are always welcome to drop into the office or picking up the phone just to say hi...!

As I look forward to another wonderful year ahead, I would like to close by wishing you all a very MERRY CHRISTMAS and I look forward to working with all of you in 2010...

All the Best
Paul

The Volunteer manager's Article

By: David Harper



With the year drawing to a close I thought I would mention some of the projects that our volunteer team at Epilepsy York Region has accomplished in 2009.

March Awareness: We put displays in the libraries in Georgina during March. We were represented at the Lavender Tea put on by the Richmond Hill Heritage Society.

We did school presentations on epilepsy at elementary schools.

Glad Days Fundraiser: Our volunteers sold Glads at various locations in York Region as well as selling Glads at the TTC Subway at Finch and Yonge.

Christmas Gift Wrap: we are in the midst of our gift wrap at Hillcrest Mall. Volunteers will have filled 350 shifts during the month of December. A wonderful way of raising funds to further the work of Epilepsy York Region.

Website: Our new website is up and running. Again volunteers played a major part in the design and implementation of the site. Volunteers will be keeping the site up to date.

Transit Program. We have been offering assistance to individuals with epilepsy in riding the YRT/VIVA Transit in York Region. This, of course, is an ongoing project.

Presentations: Our volunteers have given over 25 presentations to teachers, pupils, health care workers, and service clubs during 2009.

Our monthly Members' Update and the Quarterly Epigram are produced by a volunteer.

Our Board of Directors, who are responsible for the governance of EYR, are, of course all volunteers.

When you add ongoing office projects such as maintaining records, entering material into the database, publicity, and other duties you can see how valuable our volunteers are to Epilepsy York Region.

Our volunteers are consistently giving their time, talent, and treasure to a cause in which they believe and trust me we value their help. It's not based on "what can I get out of it", it's based on giving with a caring heart. I would like to extend a huge thank you to all the volunteers of Epilepsy York Region. You help make EYR the great organization it is today.



Thank you and all the best for 2010.

Did You Know?



- We estimate that the volunteers of EYR will have contributed 6,300 hrs during the year of 2009!
- Volunteer support helps to keep EYR helping those with epilepsy! In the year of 2009 we had over 250 volunteers!
- We have new email addresses!
Paul Raymond –praymond@epilepsyork.org
David Harper –dharper@epilepsyork.org
General Information –info@epilepsyork.org



Epilepsy York Region Board of Directors

Chairman-Derwyn Miller

Treasurer-Vinita Savani

Directors- Gillian Yeung, Adriana Morrison, Jim Steen,

Raymond Leung, Roshni Patel, Joyce Grandy

Confidentiality: *All information regarding Epilepsy York Region clients, including members, volunteers, sponsors and donors; it is private and confidential, and is not disclosed to anyone!*

Epilepsy York Region

11181 Yonge Street, Richmond Hill, L4S 1L2



Tel: 905-508-5404 ~ Fax:905-508-0920

Email: info@epilepsyork.org ~ Website: www.epilepsyork.org

Editor: Jessica Coates