

Epilepsy News

Serving the people of Newfoundland and Labrador for 25 years!

THE QUARTERLY NEWSLETTER OF EPILEPSY NEWFOUNDLAND AND LABRADOR

SPRING 2009

Purple Day 2009 - Positively Phenomenal!

t was a sea of purple on March 26th, 2009 - Purple Day for Epilepsy. Not just here in Newfoundland and Labrador, but across the country and around the world.

People of all countries coming together to bring epilepsy out of the shadows. From the UK, Philippines, South Africa, Israel, Australia, Argentina, the US, Canada, and many others, wearing their purple proudly to let everyone who lives with seizures know that they are not alone. Actors, celebrities, politicians, models, musicians, and thousands of people young and old. It was inspiring, emotional, and simply beautiful. Purple Day; a global event that began from the idea of one nine year old girl.

We were thrilled to be a part of it all here in Newfoundland and Labrador. Organizations, businesses, students, and individuals all over the province joined in and wore purple on March 26th. Some as part of an event or fundraiser, and some just because it was important to them.

Epilepsy NL organized two different events for Purple Day. The first was our 'Ask the Doctors' Question and Answer Session which you can read all about on page 5 of this newsletter. The second was our Provincial Purple Preschool Bunny Hop. Preschools all over Newfoundland and Labrador were hopping for epilepsy awareness with the first ever Purple Preschool Bunny Hop. Kids and educational staff alike dressing up their centres in purple, learning about epilepsy, and hopping for seizure awareness because, as we all know <code>AnyBUNNY</code> <code>Can have EpilepSy</code>.

We would like to thank the following for their participation in Purple Day 2009. You have made a difference.

Metrobus Transit Drivers Department of Business, Gov. NL Investors Group Special Education Faculty, MUN Rainbow Daycare Creative Learning Daycare Dr. David Buckley Merry Care Daycare Confederation Bldg Daycare Reach for the Stars Daycare Newijik Wij'sik/Four Winds On Your Mark Daycare Building Blocks Child Care Dr. Abayomi Ogunyemi



Investors Group - Proudly Purple for Purple Day



On Your Mark Daycare Hungry Bunnies!



Previously Purple Tea Break - Tetley tea with a message.



Creative Learning Daycare - We Hop for Epilepsy

Epilepsy News is printed quarterly by:

Epilepsy Newfoundland & Labrador

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On My Mind

while back, a popular online epilepsy support message board run by the Epilepsy Association of America was infiltrated by people intent on having a little 'fun.' The hackers used code and flashing computer animation to trigger migraine headaches and seizures in some users.

The incident, "possibly the first computer attack to inflict physical harm on the victims, used a script to post hundreds of messages embedded with flashing animated graphics. The attackers then turned to using software that redirected users' computers to a page with a more complex image designed to trigger seizures in both photosensitive and pattern-sensitive epileptics."

I read about this story with a mixture of shock and disgust. Who would ever think that provoking seizures in unsuspecting people using an epilepsy support website was fun!? Arrrghhl! What is the matter with these people? Sometimes I swear common sense is an all too rare quality.

It does highlight the fact though, that sometimes people can be cruel. And no matter how much education and awareness that we do, there will still be people intent on having a little 'fun'. It's unfortunate. And as much as I want to shake the people who did this, I know I can't.

But what I can do is make sure people see the good, as well as the bad. We have just come from a month that saw thousands of people all over the globe united to support epilepsy awareness, we have seen businesses and schools and individuals go out of their way to help and promote understanding, we have seen more and more people stand up and say "yes, I have epilepsy, but it doesn't have me!"

Against a force like that, computer troublemakers don't even stand a chance.

Pam

Pamela Anstey Information Officer

Disclaimer

The materials contained in the Epilepsy Newfoundland and Labrador newsletter are to provide general information about epilepsy to the public. The information presented is not intended as medical or legal advice. Epilepsy Newfoundland and Labrador, its employees, board members, medical advisors, volunteers, agents and sponsors do not assume responsibility for inaccuracies or omissions or for the consequences from the use of the information obtained in this newsletter. Epilepsy Newfoundland and Labrador is not liable for any outcome or damages resulting from information in either a direct or indirect form. We recognize that each individual's experience of epilepsy is different. Consult your physician and/or neurologist with any questions you have.

People with epilepsy should never discontinue anti-epileptic medications or make changes in activities unless specifically advised to do so by an attending physician.

Ask the Doctors - A Q&A Forum

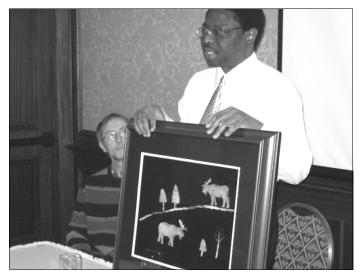
ur signature event of Epilepsy Awareness month has always been the 'Ask the Doctors' Question and Answer Forum. This year, we were pleased to have attendees both in person, and connecting from around the province via teleconference.

We were also honoured once again to be joined by both Dr. Abayomi Ogunyemi, and Dr. David Buckley, two of the provinces foremost neurologists.

Questions ranged from the personal and specific to the more general, and like every single year, new things were learned. Even the doctors were stumped at a couple of the questions but assured us they would find out the answers and let us know. Some of the questions that were asked included:

- Can someone have signs of a coming seizure days in advance?
- How do migraines relate to seizures?
- Can invitro-fertilization cause epilepsy?
- Do different seizures look differently on an EEG?
- When should adults/children wean off meds?
- Is melatonin a safe and effective way to assist in getting adequate sleep, and thereby helping to prevent seizures?

This year marked Dr. Ogunyemi's twentieth year participating in the event. As a show of our gratitude, he was presented with a framed traditional tufting picture - a 3-d artwork made entirely of animal hair, primarily moose and caribou, by artisan Derrick Hewitt.

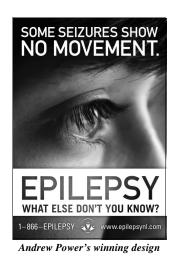


Dr. Buckley and Dr. Ogunyemi at the 'Ask the Doctors' Session as Dr. Ogunyemi accepts a gift from ENL for being a part of this event for 20 years.

In this time of turmoil within the province's medical system, we are truly fortunate to have specialists who are willing to give of their time freely and willingly every year.

Thank you as well to everyone who attended, told your story, and asked questions.

Advertising With Meaning

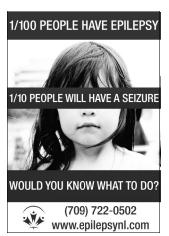


ach year during March EpilepsyNL works especially hard in order to try to educate, inform, and hopefully help people to gain a better understanding about epilepsy and seizures.

Again this year we challenged the students in the Graphic Design program at the College of the North Atlantic to develop a bus shelter ad that would convey the type of messages we want people to know.

It was an excellent opportunity for the students to work on a real-life business project, and a chance for us to tap into some amazing talent.

The two winners for 2009: Andrew Power and Tyler Saunders. The graphics you see here really can't do justice to the designs. Both ads are now on display at two very prominent bus shelters here in the city.



Tyler Saunders' winning design

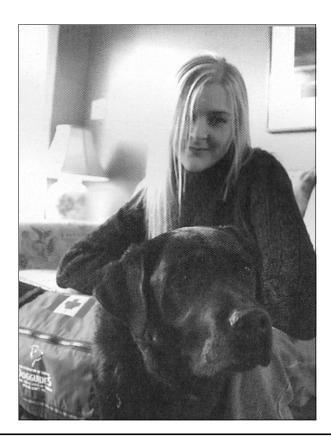
Moving Mountains

ENL is pleased to welcome Lesleigh Hiscock as a contributor to our newsletter. Lesleigh, and her seizure response dog Ashton, are well acquainted with epilepsy. Here, Lesleigh talks of her life with Ashton, and the difference he has made.

escribing the impact that Ashton has upon my life is like describing the importance of my very next heartbeat or breath; yet Ashton, my seizure response dog from Dog Guides Canada, has only been in my life for two short years.

My need for such an extremely talented, spectacularly well-trained, devastatingly handsome (forgive the gushing ©) black Labrador Retriever hasn't been very long. Now 41 years old, I only began having seizures around six years ago. Then, as now, I have never had any type of warning before one occurs.

Anybody having experienced a seizure knows all too well that the journey it takes you on, from upright to horizontal, is seldom one of those 'delicate lady-like faints' onto an awaiting mountain of fluffy down-filled pillows. It was a shocking lack of delicate faints and fluffy pillows being present during my seizures that had a great deal to do with this four-legged blessing being at my side.



And what a blessing Ashton truly is. Beyond being a seizure response dog, he became able to anticipate oncoming seizures. When he alerts me, I immediately lie down, and for the first time since this whole adventure began six years ago, I am usually able to avoid the serious injuries I had become so accustomed to getting. For those who have never been through it, the ground is: A) very hard, and B) a very long way down, especially if you're tall like me.

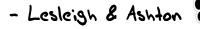
This hasn't been a strictly physical experience. Without Ashton by my side these past two years it would have been a journey down a VERY rocky road; one I am uncertain I would have had the strength - physically or emotionally - to have continued.

But Ashton, by his steadfast presence and abiding love alone has helped me in ways I never dreamed possible. His sweet spirit continues to work its magic within me every day.

Add to that the reclaimed and newfound glory in feelings of security, freedom, and pure joy, and I guess you could say I do have a pretty big mountain of those fluffy downfilled pillows in Ashton, who is right now stretched out next to me, playfully demanding yet another belly rub.

I would urge anyone who has epilepsy to consider the difference having a seizure response dog could make in your life. For more information, get in touch with Marilyn at the Lions Foundation of Canada Dog Guides Centre at 1-800-768-3030 or email info@dogguides.com.

All their dogs, along with all training services are free.





Please note: Seizure response dogs are not trained to detect seizures in advance. In fact, no one knows why or how some dogs (and not just seizure response dogs) are able to tell when a seizure is coming. Seizure response dogs are specifically and intensively trained to alert and assist during and after a seizure. So while finding a seizure response dog that can detect oncoming seizures may be rare, thanks to Dog Guides Canada and Lions Clubs all over the country, finding one that will profoundly impact and forever change your life is a given. My advice, go for it!

Together for Life - Mary Beth and Patti Thistle

hirteen-year-old Mary Beth Thistle loves bubbles, "Barney," "Blue's Clues," and "Bear in the Big Blue House." Her friends call her Biffy. "When she was born, her brother Benjamin was two years old and he called her Mary Biffy. So the Biffy stuck," says Mary Beth's mother, Patti Thistle.

Mary Beth sits on the living room floor in front of her mother. It's difficult to say if she understands any of the conversation about her health.

"I always thought Mary Beth was at about the level of a four-year-old. But when Christopher came along, when he was about 18 months, they were playing really well together. And by the time he was 24 months, he'd begun to pass her, socially," Patti says of Mary Beth's younger brother, who is now three.

Diagnosed with Dravet syndrome (also known as severe myoclonic epilepsy of infancy), Mary Beth began having seizures at the age of 5 $\frac{1}{2}$ months.

"She had a half-hour grand mal on the left side of her body. Within weeks, she had another one involving the other side of her body. Since then, she has been in epileptic status more times than I can count," her mother says. "She has died in my arms four times."

On one occasion, Patti says, Mary Beth's lungs stopped working for more than four minutes.

"We couldn't get any air into her. Her lungs did not relax until she died and we brought her back to life. She lost many skills that day. At age four she really regressed mentally."

Patti describes her daughter's seizures as "catastrophic epilepsy." Over the years, Mary Beth has had at least 13 different kinds of seizure, her mother says.

For the past seven years, they've been sharing the same bed. Patti needs to be there for Mary Beth when the seizures strike.

"Normal seizures don't hurt you unless you fall down or bite your tongue, but catastrophic seizures steal skills from you," she explained. "And Mary Beth's seizures stole everything from her.

"All she could remember (at age five) was her brother Benjamin. She forgot blankie. She forgot how to walk and talk and eat. She even forgot me. She didn't have a clue who I was."

Mary Beth is a challenging needs student at Macdonald Drive Junior High School in St. John's. She has a student assistant with her at all times as well as one-on-one after-school care.

Her typical week includes about three grand mal seizures every second night.

Patti says Epilepsy NL has been



extremely helpful in providing her with information, particularly when Mary Beth was first diagnosed.

"Gail was my rock," Patti says of Epilepsy Newfoundland and Labrador founder and executive director Gail Dempsey. "She gave me the confidence I needed to go ask the questions I needed to ask."

Mary Beth may be unable to make an X or an O, or to put together simple jigsaw puzzles, but she still has the ability to warm hearts. "When she smiles at you, your world lights up," Patti says, watching as her daughter picks up puzzle pieces and drops them on the hardwood floor.

Mary Beth loves conversation, but often repeats the same phrase. "It's all she can think of to say," her mom said. Patti says several words, encouraging her daughter to repeat them. After several moments, Mary Beth glances up. Rather than repeat one of the words her mother has said, she finds her own. "Mommy," she says slowly, smiling at Patti before returning to her puzzle pieces.

Patti reaches out to stroke her daughter's cheek.

(Continued next page)

Together for Life cont.

(continued from previous page)

"What else do you love, Biffy?" Patti asks, then goes on to answer for her daughter. "Oh, she loves phoning people. And she loves visiting and picking things up and passing them to you. And she can pick out the Pepsi and Mary Brown's logos. And sometimes she can pick out M.B.T. for her initials."

"Grammy," Mary Beth says, as her mother explains that her grandmother is one of the people Mary Beth loves phoning. Patti is excited that her daughter has spoken.

"P-I-Z-Z-A," Patti sings, spelling out the letters. She is rewarded with another big smile and the word "pizza" from her daughter. "Yes, pizza, that's right," Patti said, smiling at the victory.

Mary Beth requires full-time, around-the clock care, but Patti says the entire family has learned many valuable lessons from her. "People are always telling me what a fine young man Benjamin is," she said.

"He's 15 years old and very respectful of people, their feelings and needs. ... Christopher, the three-year-old, is much better at sharing than he ever would have been if he didn't have to share everybody's time and energy with Mary Beth. He is well on the way to being as empathetic and helpful as Benjamin."

Patti has learned her own lessons from her daughter. "You never know what you can do until you have to do it," she said.

While she admits it's impossible not to worry about what the future holds for Mary Beth, one thing is certain. "We're together for life," she said.

Asked & Answered

I have been having seizures for almost ten years but this past six months they have gotten much worse, so the doctor put me on a new medication to try and help bring things under control again. Ever since, I seem to have lost patience with everything. I'm angry, upset, and moody, like everything is out to aggravate me. Is this from the increase in my seizures, or from the new medication? Or am I totally losing it completely?

Chances are you're not losing it completely. It may very well be either the increase in seizures or the medication but only your doctor would be able to say for sure. You need to be seen by your neurologist or GP to get your blood levels tested, and talk about these changes.

Most people who take anti-convulsant medication do not experience serious or intolerable side effects from it. In some cases, however, the side effects from taking medication may affect behaviour and/or emotions. This can include an impairment of drive, mood, sociability, alertness, or concentration.

If you are taking more than one kind of anti-convulsant medication, it may be that the side effects of one medication are compounded by the side effects of another. If these effects are not well-tolerated, changes in behaviour and mood can occur. However, if the amount of medication is reduced, these changes can be reversed.

The place in the brain where seizures originate may also

have an effect on emotions and behaviour. Seizures with temporal lobe involvement, complex partial or focal seizures are most commonly associated with behavioural changes and can include rapid fluctuations in mood, or over-attention to detail.

So, bottom line - see your neurologist. Only then will you be able to gain some direction as to the cause, and even more importantly, how to help make it better.



Off The News Wire

Common Anti-Seizure Medications May Increase Risk Of Cardiovascular Problems

An important clinical repercussion in the treatment of epilepsy has been discovered by a research team at Jefferson Medical College of Thomas Jefferson University. The team has determined that two of the most commonly prescribed anti-seizure medications may lead to significantly increased levels of cholesterol, C-reactive protein and other markers of cardiovascular disease risk. The finding may help doctors manage the care of patients with seizures more effectively by prescribing different anti-seizure medications that will not adversely affect cardiovascular health.

The study involved two of the most widely-prescribed anticonvulsants - phenytoin (Dilantin) and carbamazepine (Tegretol, Carbatrol) - which have potent effects on many enzymes in the body involved in different areas of metabolism. The researchers recruited 34 epilepsy patients taking either one of those two drugs who were being switched over to one of two newer anti-seizure drugs which do not widely affect enzymes - lamotrigine (Lamictal) or levetiracetam (Keppra). The goal was to determine if the change affected the patients' cholesterol levels and other key markers of cardiovascular disease.

Just 6 weeks after the patients' drugs were switched, there were significant declines in total cholesterol, non-high-density lipoprotein (commonly referred to as 'bad') cholesterol, triglycerides and C-reactive protein, suggesting the older, commonly-used drugs might substantially increase the risk of cardiovascular disease.

"The epilepsy patients in this study saw a rapid and clinically significant improvement in several markers related to cardiovascular disease, including a decrease in total cholesterol that averaged 26 points. This is almost certainly not due to some positive effect from the new drugs. It's a consequence of being taken off the older ones, which were causing the cholesterol and other markers to be elevated in the first place," said Dr. Mintzer. "While more investigation is needed, these results may help physicians better understand the risks of these drugs and choose the most appropriate treatment for their epilepsy patients, especially those who are already at risk for cardiovascular disease or have a family history of it."

Thomas Jefferson University, March 2009

Nothing in life is so hard that you can't make it easier by the way you take it. - Ellen Glasgow

Brain Injury Raises Epilepsy Risk for Years

A severe brain injury puts people at risk of epilepsy for more than a decade after they are first hurt, a finding that suggests there may be a window to prevent the condition. A Danish team found that the odds of epilepsy more than doubled after mild brain injury or skull fracture and was seven times more likely in patients with serious brain injury. The risk remained even 10 years on, more so in people older than 15.

"Traumatic brain injury is a significant risk indicator for epilepsy many years after the injury," they wrote. "Drug treatment after brain injury with the aim of preventing post-traumatic epilepsy has been discouraging, but our data suggest a long time interval for potential, preventive treatment of high-risk patients." Reuters, February 2009

Surgery for Babies and Toddlers Is Relatively Safe and Is Effective in Controlling Seizures

A new study published in Epilepsia reveals surgery for babies and toddlers suffering from epilepsy is relatively safe and is effective in controlling seizures. The findings also show that early surgery may have a positive impact on babies' brain development.

The children in the study generally underwent major brain operations, including removal of or disconnection of half of the brain. Despite such large operations, there were few complications and only one death. At the time of surgery, children were having an average of 21 seizures per day, with one child having as many as 600 seizures per day. One year after surgery, 67.3 percent were seizure free, 14 percent had a greater than 90 percent improvement in seizures. Only 7.5 percent did not benefit from surgery. Development improved in 55.3 percent of the children after surgery.

"The results of this study lead us to conclude that epilepsy surgery in children under three years is relatively safe and is effective in controlling seizures," says Dr. Paul Steinbok of British Columbia's Children's Hospital and the University of British Columbia, lead author of the study. "Thus, very young age is not a contraindication to surgery in children with epilepsy that is difficult to control with medications."

The results of this study argue that surgery may be a better option than continuing drug management and should be considered earlier in the treatment process than is typically done. *Epilepsia, March 2009*

Student Employment

If you are a post secondary student with a disability looking for a summer job, the Office of Employment Equity for Persons with Disabilities may be able to assist you in your job search.

The Office's Student Summer Employment Program provides post-secondary students with disabilities career related work experience within provincial government offices. These employment opportunities will provide

students with practical skills and

knowledge to prepare them for their future entry into the labour market. Summer placements are generally 10 weeks in duration and run between June and September.

To be eligible for this program, students must be:

- currently attending a post-secondary school
- returning to school in September
- registered with the Office of Employment Equity for Persons with Disabilities.

The deadline for applications is May 1, 2009.

For further information on this program or to request an application, please contact the Office at (709) 729-5881, TTY (709) 729-5441, Toll free in NL 1-800-950-4414,

e-mail at openingdoors@gov.nl.ca

Caregiver Expo

The Atlantic Canada Caregivers Expo June 13th & 14th, 2009 Mount Pearl Arena

he Atlantic Caregiver Expo is the largest event of its kind in Atlantic Canada. This event will bring together family and professional caregivers for a two days of learning, networking, sharing, support and relaxation.

Participants will explore a variety of resources, products, and services in one place all aimed at providing direction and support to care givers. Information will be offered that can assist the care giver and improve the quality of life of those being cared for.

These include information regarding home care, assisted living issues, nutrition, communications, transportation, personal fitness, security, rehabilitation, financial and health concerns, governmental support systems, life-long learning and current health related products.

Epilepsy Newfoundland and Labrador will be doing one of the workshops at the Expo. We will be offering a session on **Seizure Awareness and response for Caregivers**.

If you would like more information on the Expo, feel free to get in touch with us here at ENL. By phone it's 722-0502 or toll-free 1-866-EPILEPSY. Or you can contact the Expo organizers directly at (902) 406-7344, or visit their website: www.atlanticcaregiver.com.

Previously Loved Clothes and Things

Where you'll find hundreds of treasures with experience!

id you know that ENL operates a thrift store - Previously Loved Clothes and Things? Our selection includes:

- clothes, outerwear, and footwear for everyone
- household items & small appliances
- bedding, curtains, & furniture of all descriptions
- toys & sporting equipment
- vintage glassware & unique collectibles

At Previously Loved Clothes and Things you never pay sales tax! Because we are a charity, 100% of the proceeds from the sales at our store stay right here in the province and go directly back into the community through the programs and services of Epilepsy NL.

Want to help support ENL but don't have the time to volunteer or do door-to-door canvassing? No problem!

- Donate your unwanted clothes and household items to us for sale in our store. You can drop donations off at the store located at 26 O'Leary Avenue, or, if you live in the metro area, we can often arrange to pick them up for free. Just call 722-5571 to arrange a pick-up time.
- Shop at our store. Open 7 days a week and always tax-free! Come in and browse around. You'll never know what treasures you might find. Plus, you'll feel good knowing that you have helped people with epilepsy right here in NL.

A Little Time Out



"What a school day! The computers broke down and we had to LISTEN!"

A guy was in a supermarket when he noticed an old lady following him around. Whenever he stopped, she stopped, and she also kept staring at him. She finally overtook him just before the checkout where she turned to him and said: I hope I haven't made you feel uncomfortable — it's just that you look so much like my late son."

"Oh, that's ok," he said.

"I know it's silly," she continued, "but if you called out 'Goodbye, Mother' as I leave, it would make me ever so happy."

The old lady proceeded through the checkout and as she left the supermarket, the man called out "Goodbye Mother." The old lady waved back, and kindly smiled. Pleased he had brought a bit of sunshine to someone's day the man went to pay for his groceries.

"That'll be 105 dollars 35," said the clerk.

"How come?" inquired the man. "I've only bought a few things!"

"Yeah, but your mother said you'd pay for her..."

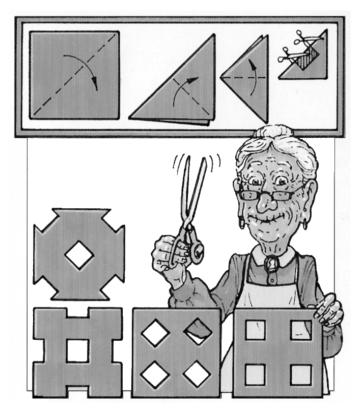
The back specialist, who was known for extraordinary treatment of arthritis, had a waiting room full of people when a little old lady, almost bent over in half, shuffled in slowly, leaning on her cane.

When her turn came, she went into the doctor's office, and, amazingly, emerged within 5 minutes walking completely erect with her head held high.



A woman in the waiting room who had seen all this rushed up to the little old lady and said, "It's a miracle! You walked in bent in half and now you're walking erect. What did that doctor do?"

"He gave me a longer cane," she said.



Blanche runs a quilting class. She has asked her students to fold and cut a square of fabric, following the patters shown on the chart above. The results are in. Which of the four students' squares is the correct fold and cut as indicated by the chart? (answer on page 10)

Brain Links

President's Chaice. Children's charity Making difficult lives a little easier.



President's Choice Children's Charity is dedicated to helping children who are physically/developmentally challenged. Their aim is to remove some of the obstacles that make everyday living extremely difficult and make it a little easier for the child or family to cope with the disability. They provide direct financial assistance in the purchase of expensive mobility equipment, environmental modifications, physical therapy and more.

Do you have a child with a physical or developmental disability? Are they 18 years of age or under? Do they need help with mobility equipment, an environmental modification or therapy?

Find out more information and how to apply by visiting:

http://www.presidentschoice.ca/ChildrensCharity/ or call 1.877.525.4762

Bulletin Board

nother successful March Door to Door Campaign has just passed us by. It could never have been the success it was without the help of our dedicated team of volunteers from right across the entire province.

We have received a great many of our kits back so far, but there are a still a number outstanding. If you have one of the outstanding kits, please get it back to us as soon as you can so we can get our project completed for another year.

The winners of our Door to Door draws for 2009 were: **Zone Captain** - Dave Ball, Grand Falls-Windsor **Over \$100 Collector** - Patricia Hatch, Corner Brook **Canvasser** - Robert Gale - South Branch

We would like to take this opportunity to thank every canvasser and zone captain who so willingly gave of their time and efforts to make this campaign a success, as well as a thank you to everyone who donated even a little. Your efforts will go a long way towards the promotion of epilepsy support and awareness in NL.



The correct quilt square should look like this:

I Would Like To Help in the Fight Against Epilepsy

		orador. I am enclosing my \$5.00 membership fee. ht across the province)
Name: Email:		mail:
Address:		Phone:
If you would prefer to use your credit	card, please complete the following:	
Type of card:	Account #:	Expiry Date:
Signature:	Date:	

Clip and mail this form to Epilepsy Newfoundland and Labrador - 26 O'Leary Avenue, St. John's, NL A1B 2C7