



When Does a Seizure Become Epilepsy?

When is a seizure more than a seizure? When does it become epilepsy?

Recently, the International League Against Epilepsy (ILAE) released a proposal looking at the definition of epilepsy. This may seem simple enough at first glance, but when you look closer, you learn that epilepsy is so diverse that identification and diagnosis can sometimes be difficult.

Epilepsy was defined as:

A disorder of the brain characterized by an ongoing predisposition to epileptic seizures.

In practical terms, if someone had two unprovoked seizures more than 24 hours apart, it was considered epilepsy.

An unprovoked seizure is one that has no immediate cause, unlike seizures that occur as a direct result of the impact of things such as low blood glucose, exposure to toxins, alcohol withdrawal, immediate effect of a trauma, or fever in young children.

The ILAE commissioned a task force to consider altering the definition. The task force proposes that epilepsy be considered to be a disease of the brain defined by any of the following conditions;

1. At least two unprovoked seizures occurring more than 24 hours apart;
2. One unprovoked seizure and a probability of further seizures similar to the general recurrence risk after two unprovoked seizures (75% or more);
3. At least two seizures in a setting of reflex epilepsy, (Reflex epilepsy is when seizures are set off by specific stimuli. For example - flashing lights, flickering computer monitor, sudden noises, bold patterns, etc.).

Epilepsy is considered to be no longer present for individuals who:

- had an age -dependent epilepsy syndrome but are now past the applicable age,
- or those who have remained seizure-free for at least 10 years off anti-seizure medicines, provided that there are no known risk factors associated with a high probability (75%) of future seizures.

But even though the seizures are no longer present, this is not necessarily identical to the conventional view of "cure."

This revised definition of epilepsy brings the term in line with the common use by most epileptologists.

If you would like to learn more, please ask your neurologist or physician, or contact the Epilepsy NL Office.



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Epilepsy NL Scholarships

*The purpose of learning is growth, and our minds, unlike our bodies,
can continue growing as long as we live.
~ Mortimer Adler*

School is expensive! But did you know about ENL's scholarships especially for post-secondary students with epilepsy?

Each year, Epilepsy Newfoundland and Labrador is proud to award two scholarships, each valued at \$1000, to deserving students with epilepsy, for tuition, books, or any of the other many necessities that come along with school.



The Zach Rowe Memorial Scholarship

- ➔ For students who have just graduated from high school and are moving into their first year of post-secondary studies.

The Jim Hierlihy Memorial Scholarship

- ➔ For students who are beyond their first year, or who have decided to return to school after a period of being in the workforce.

Deadline for both is November 1st

For full scholarship information, or an application form, visit our website at www.epilepsynl.com, or call the office at 1-866-EPILEPSY.

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.

Taking Centre-stage in Fight Against Epilepsy

The first of two feature articles from the IEC Congress Report, July 2013, as prepared by Helen Leask PhD

The International Epilepsy Congress (IEC) was held in Montreal last month, the first time this huge global gathering of epilepsy researchers and advocates has been held in North America. The big themes were: technical advances in diagnosis, medicine and surgery; new ways to organize the healthcare system; psychological and social issues; and the fight against stigma.

Not just seizures: Other factors can dramatically affect quality of life in epilepsy

Everyone involved in epilepsy is trying to improve quality of life for people with epilepsy. So what, exactly, determines quality of life for people with seizures? It is logical to think that controlling the seizures is all that's needed to improve quality of life in someone with epilepsy but this is not always the case, said scientists at the IEC. "Remission [stopping seizures] is not necessarily related to quality of life," said Dr Elizabeth Donner from the Hospital for Sick Children in Toronto.

For this article, we polled epilepsy experts who attended the conference and asked them two questions:

1. What, in your opinion, is the biggest determinant of quality of life in epilepsy?
2. What is the ONE thing you would do right now to improve quality of life for people with epilepsy in your country?

Their answers are below.

Dr Athanasios Covanis from Greece, incoming president of the International Bureau of Epilepsy:

[Question 1] "Seizures, side effects and stigma"

[Question 2] "Direct access to a specialized epilepsy center and free health care"

Dr Emilio Perucca from Italy, incoming president of the International League Against Epilepsy:

[Question 1] "Complete seizure control without undue side effects is by far the greatest determinant of good quality of life in epilepsy. Simply reducing the frequency of seizures is not enough, although for highly disabling seizures such as drop attacks reducing the number of seizures can have an important impact...If seizures cannot be fully controlled, the most important determinants of quality of life are the adverse effects of medications and the presence of comorbidities, most notably depressed mood."

[Question 2] "We need more, and better, specialized services to improve the clinical care of people with epilepsy."

Dr W. McIntyre Burnham, President of Epilepsy Canada:

[Question 1] "For question #1, I would have to say uncontrolled seizures, which lead to unemployment and the loss of drivers' licenses. If I could have two answers, I would say uncontrolled seizures and the co-morbidities like memory problems, anxiety and depression. The co-morbidities are under-treated."

[Question 2] "For question #2, what I would do 'right now' is to increase the number of people that get seizure surgery. I believe that seizure surgery is our greatest underused resource. We now have a program in Ontario designed to implement more seizure surgery."

Gail Dempsey, President of the Canadian Epilepsy Alliance:

[Question 1] "Since quality of life is really a value judgment of a person's own life, my opinion really doesn't matter all that much. I am however, happy to pass along the opinion of 671 Canadians living with epilepsy. In 2012 The Canadian Epilepsy Alliance/Alliance canadienne de L'epilepsie (CEA/ACE) partnered in a survey entitled *The Impact of Epilepsy on Canadians*. That research showed that the five biggest challenges respondents reported were: a lack of independence (56%); impacts to their social life (38%); stigma/discrimination (38%); maintaining employment (31%); maintaining relationships (25%)."

[Question 2] "Since people with epilepsy have told us that their biggest challenges are non-medical, including stigma and discrimination, if I could only do ONE thing, it would be to continue and improve community programs, from coast to coast in Canada, to help promote independence, educate employers and the general public, and help people with epilepsy to build and maintain healthy social relationships to improve the burden of the disorder and help remove the barriers that people with epilepsy face on a day-to-day basis."

In the Winter Epilepsy News, watch for the second feature article entitled: **Needs of families: Research shines rare spotlight on fear, depression and clinical chaos**



Back to School with Epilepsy

Now that school is beginning again, it is important for parents of children with epilepsy to ensure that teachers are aware of the disorder, and know the effects that can come with it.

If your child has epilepsy, pass this page along to your child's teacher. If they would like further information, feel free to have them contact us here at the office and we can send them a full copy of our **Teacher's Guide**.

Students with epilepsy have the same range of intelligence as other students, and often epilepsy itself has no effect on intelligence or ability. However, students with epilepsy may have a higher rate of difficulty in school as well as a lower level of achievement.



A student with seizures may experience the world as an unpredictable and scary place. Concerns of parents and teachers regarding safety may lead to overprotecting the student and consequently, they may become dependent and feel helpless and unworthy.

Many students with epilepsy feel embarrassed when a seizure occurs in public. Feeling isolated or different from other children is also common. This often leads to low self-esteem and feelings of low self-worth.

Students who are having a difficult time adjusting to their seizures may exhibit hyperactivity, anxiety, aggression, and acting out

behaviours. This may serve to further distance them from their peers.

In a school setting, teachers may often perceive a student with epilepsy as being unmotivated, not realizing that seizures can have a profound cognitive impact on a child. This misunderstanding can lead to a lot of frustration for the student, their family, as well as the teacher.

The challenges can be great. But there are things that every teacher can do to make things much better. What follows are some of the most prevalent challenges to learning and behaviour for the student with epilepsy, as well as suggestion on what you can do to minimize or overcome them.

Medication - Seizure medication can affect learning and have a wide range of side effects, including hyperactivity, memory loss, fatigue, headache, behavioral changes, nausea, blurred vision, dizziness, or depression.

Teachers can ease the negative side effects caused by anti-seizure drugs through providing additional assistance, a buddy system for notes, ensuring that medications are taken correctly, and by providing valuable feedback to parents,.

Anxiety - The unpredictability of seizures, and overprotective relationships can result in anxiety and insecurity in a student. This may affect initiative and independence in the classroom.

If a teacher is calm and straightforward in dealing with seizures in an understanding manner, this may help to alleviate some of the anxiety. Enabling understanding by other students and staff as well, can help to create a supportive learning and social environment.

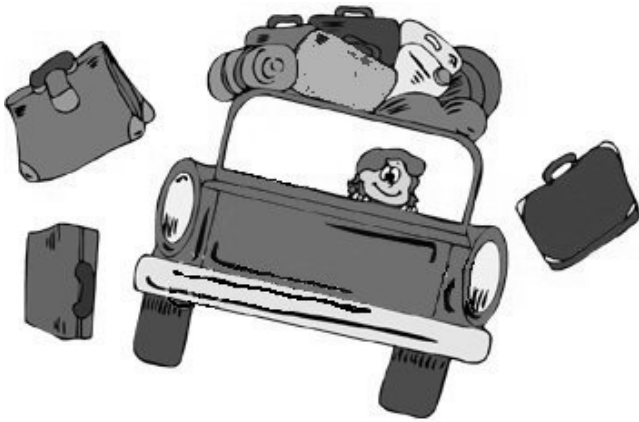
Seizures - The actual process of having a seizure may affect learning significantly. Students experiencing absence seizures throughout the day will have their learning experience continually disrupted. Memory can also be affected following complex partial seizures or tonic clonic seizures resulting in further learning challenges. Nocturnal seizures also can result in tiredness at school.

Assigning a buddy to the student who can answer questions and explain what was missed will provide both emotional and academic support to the student. Providing visual and written instructions and/or repeating verbal instructions can also be used to assist the student.

Attitudes - Some teachers assume that a student with epilepsy will have less ability and lower potential than other students. This often becomes a self-fulfilling prophecy especially if the student is struggling. Teachers are one of the primary role models and influences for each and every child as they grow up. The impact teachers have is enormous and their attitude will be conveyed to other teachers and students.

With a little understanding and accommodation, students with epilepsy can achieve just as much as any other student. If teachers' attitudes are negative, educate them. Or contact us. We provide cost-free in-service sessions specially designed for educators.

Fall Excursion to Central



September has arrived, and with it our annual Fall Excursion. For a week each year, I pack up and set out to an area of the province we don't usually get much chance to visit. I will spend the week talking with students, groups, organizations and individuals about seizure awareness and first-aid.

I love the fall, and getting to meet so many people and share their stories is one of the highlights of my year.

This time around I am first heading west to Deer Lake, then visiting here and there in Central NL, including the Baie Verte Peninsula and the Springdale area.

My week will look something like this:

Monday, September 23rd - Deer Lake
 Tuesday, September 24th - Pollard's Point & Hampden
 Wednesday, September 25th - La Scie
 Thursday, September 26th - Baie Verte & Springdale
 Friday, September 27th - Buchans & Badger

Some of the groups that I will be talking with include:

- K-12 Schools - Both students and teachers
- Community and church groups
- RCMP
- Daycares
- Government Agencies
- General public

If you, or someone you know, is at any of my stops, I would love to talk with you. We can meet over tea, or you are welcome to sit in on any of the sessions that I will be doing throughout the week.

I will be checking in with the office and checking my email along the way, so even if I have already left, you can still reach me.

Volunteer with Epilepsy NL

Interested in volunteering with Epilepsy Newfoundland and Labrador? No matter where you are in the province, there are lots of ways to help!

Just get in touch with us if you have some time to spare for any of the following great volunteer opportunities

- **Helping in the Epilepsy NL Office** - photocopying, stuffing envelopes, organizing resource information, updating contact lists, etc. (Greater St. John's area only)
- **Helping at Previously Loved, the Epilepsy NL Thrift store** - helping in the warehouse, tidying the store displays, helping as needed (Greater St. John's area only)

- **Helping in the community** - Distributing epilepsy resources and pamphlets to businesses, schools, or organizations in your hometown, or helping out with epilepsy presentations (Anywhere in NL)
- **Helping with Fundraisers and Special Events** - Purple Day fundraisers or awareness projects, Door-to-Door Campaign volunteer in your hometown (Anywhere in NL)
- **Helping Online** - Upgrade or update the epilepsynl.com website, Help with posting interesting, epilepsy-related information on our facebook page at facebook.com/epilepsynl. (Anywhere in NL)

There's an App for That!

For patients and caregivers, comprehensive epilepsy information never has to be out of reach. Introducing **E-Action® Info**, a fun and educational mobile epilepsy resource now available in the Apple App Store for iPhone, iPod Touch and iPad.

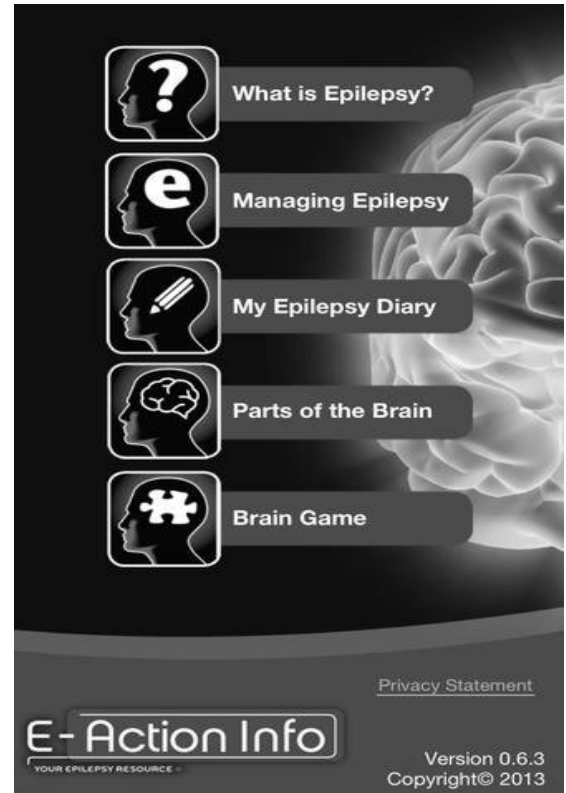
This **FREE** app is designed to teach you more about epilepsy in a fun and informative way. Some of the features of the app include:

- Epilepsy education and management information for both patients and caregivers
- The “brain game” where you match structures of the brain with their appropriate name. See how your brain stacks up!
- Lifestyle tips
- Links to Canadian epilepsy associations
- Seizure diary access, to help you keep an accurate record of when you have seizures

To download for **FREE**:

Access the Apple App Store with your Apple device and search “E-Action Info” or go to:

<https://itunes.apple.com/ca/app/e-action-info-your-epilepsy/id616614882?ls=1&mt=8>



Free
Magazine &
SUBSCRIPTION

Join a community of people
who are living well with epilepsy



E-Action is an online community and resource for anyone living with epilepsy and seizures. The magazine is filled with great stories, and lots of epilepsy related news and information.

E-Action will:

- provide you with information on important epilepsy-related issues
- introduce you to people with epilepsy who are facing life's challenges with perseverance and courage
- relate stories to reassure, empower, and inspire you
- help answer your questions

Best of all, it is FREE!

Simply register online or by postal mail and you will receive the bi-yearly E-Action Magazine, completely free of charge.

Don't miss this opportunity to learn more about epilepsy, and read stories from people all over the country who are not letting their seizures stop them from living a full and productive life. Just head to www.e-action.ca/ to register.

Don't have the internet at home? No problem. Just call Pam at Epilepsy NL and she can help you register over the phone.

No Child Without - Free MedicAlert® for Kids

Now that school is starting up again, it is so important that every child with seizures **owns** and **wears** a medical alert bracelet or pendant. In an emergency, it can make an enormous difference.

During the school day, kids will interact with many different individuals, many of whom will know little to nothing about your child and their medical needs. It could be at recess, at lunch, in the classroom or after school at a friend's house or at a sports activity.



A MedicAlert® bracelet or pendant can ensure that important medical information about your child is readily available no matter where they go, and can be easily and accurately communicated in the case of an emergency.

The Canadian MedicAlert® Foundation is a charitable organization and the leading provider of emergency medical information services linked to customized medical bracelets and necklaces.

Cost-free MedicAlert® memberships are available to students age 4 to 14 through the No Child Without® program in select schools.

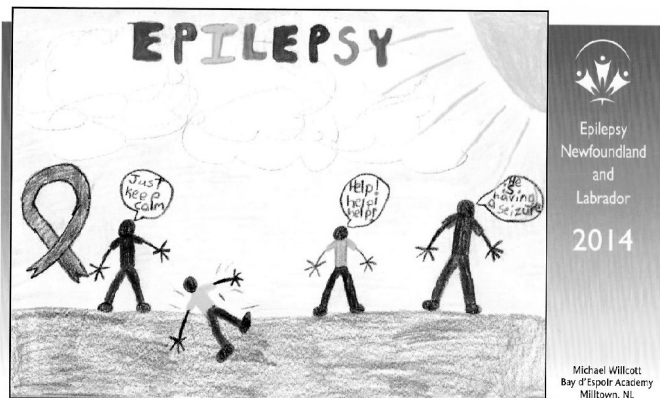
The financial support of the Government of Canada and Lions Clubs allows students to receive the MedicAlert® membership for FREE.

Many of this province's schools are already covered!

Find out more information by visiting:

<http://www.nochildwithout.ca> or call 1-866-679-3220

2014 Epilepsy NL Pocket Calendars are Here!



2014 Pocket Calendars are now available. Get yours before they're gone!

Call 1-866-EPILEPSY

Our Calendar Campaign is underway! For each donation of \$20 or more to Epilepsy Newfoundland and Labrador, we are proud to send you a copy of our 2014 Pocket Calendar with artwork by Grade 4 children from all over our province.

Students featured in the 2014 calendar are:

- Michael Wilcott, Bay d'Espoir Academy, Milltown
- Bethany Lambert, Holy Name of Mary Academy, Lawn
- Hannah Doyle, Harbour Grace Primary, Harbour Grace
- Chloe Caroline Fudge, Bay d'Espoir Academy, Milltown
- Lisamarie Slavwhite, Bishop White School, Port Rexton
- Adailia Earle, Harbour Grace Primary, Harbour Grace
- Clare Molloy, Goulds Elementary, Goulds
- Chloe Osborne, Fortune Bay Academy, St. Bernard's
- Noah Durnford, St. Simon & St. Joseph Academy, Francois
- Hailey O'Connell, St. Peter's Academy, Benoit's Cove
- Ashley Cuff, Bishop White School, Port Rexton
- Teresa Finn, Goulds Elementary, Goulds
- Shawna Edwards, Holy Name of Mary Academy, Lawn

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Off The News Wire

Exercise Reduces Epilepsy Risk for Men

Young male adults who exercise vigorously could reduce their risk of developing epilepsy later in life, according to a study published online in the journal *Neurology*.

Researchers from Sweden analyzed the fitness of 1.17 million Swedish military servicemen, who were required to carry out cycle tests that measured their cardiovascular fitness when they enlisted for service at the age of 18. The participants were then assessed for the prevalence of epilepsy for an average of 25 years. During this period, 6,796 men were diagnosed with the condition.

The findings of this study revealed that young men who had a high level of fitness were 79% less likely to develop epilepsy later in life, compared with young men with low fitness levels.

Additionally, compared with young men who had medium fitness levels, the high-fitness-level group was 36% less likely to develop epilepsy.

The results were broken down, according to fitness levels, showing the proportion of men who developed epilepsy:

- Of men with high fitness levels, 0.48% (2,381 out of 496,973) developed epilepsy
- Of men with medium fitness levels, 0.62% (3,913 out of 629,876) developed epilepsy
- Of men with low fitness levels, 1.09% (502 of 46,230) developed epilepsy.

The researchers say that when other factors were taken into consideration, such as history of traumatic brain injury, stroke, diabetes or genetic factors, the results only lessened by a fraction.

Elinor Ben-Menachem, of the University of Gothenburg in Sweden and an associate member of the American Academy of Neurology, says:

"There are a host of ways exercise has been shown to benefit the brain and reduce the risk of brain diseases. This is the first study in humans to show that exercise may also reduce the risk of epilepsy, which can be disabling and life-threatening. Exercise may affect epilepsy risk in two ways. It may protect the brain and create stronger brain reserve, or it may simply be that people who are fit early in life tend to also be fit later in life, which in turn affects disease risk."

A study from Princeton University suggests that exercise reorganizes the human brain to become more resilient to stress.

Medical News Today, September 6th, 2013

Epilepsy in a Dish

A new stem cell-based approach to studying epilepsy has yielded a surprising discovery about what causes one form of the disease, and may help in the search for better medicines to treat all kinds of seizure disorders. U-M scientists created these neurons (brain cells) from stem cells that they had made out of skin cells from a patient with Dravet syndrome, a genetic form of epilepsy. The technique allows them to study epilepsy at the cell level.

The findings, reported by a team of scientists from the University of Michigan Medical School and colleagues, use a technique that could be called "epilepsy in a dish". By turning skin cells of epilepsy patients into stem cells, and then turning those stem cells into neurons, or brain nerve cells, the team created a miniature testing ground for epilepsy. They could even measure the signals that the cells were sending to one another, through tiny portals called sodium channels.

In neurons derived from the cells of children who have a severe, rare genetic form of epilepsy called Dravet syndrome, the researchers report abnormally high levels of sodium current activity. They saw spontaneous bursts of communication and "hyperexcitability" that could potentially set off seizures. Neurons made from the skin cells of people without epilepsy showed none of this abnormal activity.

The new findings differs from what other scientists have seen in mice -- demonstrating the importance of studying cells made from human epilepsy patients.

"With this technique, we can study cells that closely resemble the patient's own brain cells, without doing a brain biopsy," says senior author and team leader Jack M. Parent, M.D., professor of neurology at U-M and a researcher at the VA Ann Arbor Healthcare System. These patient-specific induced neurons hold great promise for modeling seizure disorders, and potentially screening medications."

Meanwhile, patients with other genetically based neurological diseases can also help U-M scientists discover more about their conditions, by taking part in other efforts to create induced neurons from skin cells. Parent and his team have worked with several other U-M faculty to create stem cell lines from skin cells provided by patients with other diseases including forms of ataxia and lysosomal storage disease.

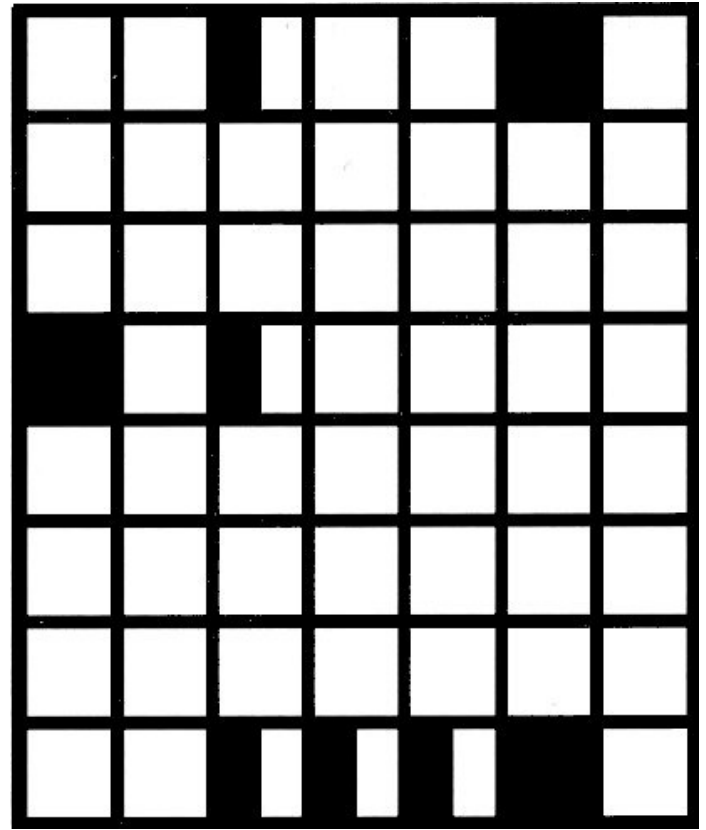
University of Michigan Health, July 25th, 2013
<http://www.uofmhealth.org/news/archive/201307/epilepsy-dish-stem-cell-research-reveals-clues-diseases>

A Little Time Out

How much do you know about your brain?



- The weight of the human brain is about 3 lbs.
- Your skin weighs twice as much as your brain.
- The brain is made up of about 75% water.
- There are no pain receptors in the brain, so it is unable to feel pain.
- While an elephant's brain is physically larger than a human brain, the human brain is 2% of total body weight (compared to 0.15% of an elephant's brain), meaning humans have the largest brain to body size.
- There are 100,000 miles of blood vessels in the brain.
- At birth, your brain was almost the same size as an adult brain and contained most of the brain cells for your whole life.
- Your brain uses 20% of the total oxygen in your body and 20% of the blood circulating in your body.
- While awake, your brain generates between 10 and 23 watts of power—or enough energy to power a light bulb.
- The old story of humans only using 10% of their brain is not true. Every part of the brain has a known function.
- You can't tickle yourself because your brain distinguished between unexpected external touch and your own touch.
- Every time you recall a memory or have a new thought, you are creating a new connection in your brain.
- The average number of thoughts that humans are believed to experience each day is 70,000.



Can you figure out the hidden message in the grid above?
(Hint: It might help to tilt the page)



Email or Postal Mail?

Help us, and help the environment too! Here at ENL, one of the greatest expenses we have is postage. Because of this, and in the interests of being as environmentally friendly as possible, we want to offer our members the option of receiving newsletters and notices by email instead of postal mail.

Privacy is not a concern. Nobody else will see your email address. And we would never make our email or mailing lists available to anyone else.



If you wish to sign up for e-mail communication from us, just drop us a line at info@epilepsynl.com. If you ever want to change back, just let us know and we will be happy to do so.

If you don't have e-mail, or don't want to receive email newsletters and notifications from us, you don't need to do a thing. We will continue to send you your information through postal mail like always. Have questions? Call us at 1-866-EPILEPSY.

Social & Support Group

In St. John's and the surrounding area?

Interested in meeting with other people who face seizures in their daily lives?

Epilepsy Newfoundland & Labrador will be holding two Support Groups this fall:

- one for parents of children with epilepsy
- one for adults with epilepsy

If you would be interested in attending either of these, please call Pam at the Epilepsy NL office 722-0502 or 1-866-EPILEPSY.

I Would Like To Help in the Fight Against Epilepsy

- I am enclosing a donation of \$ _____
- I would like to become a member of Epilepsy NL. I am enclosing my \$5.00 membership fee.
- I would like to become a volunteer. (We can use volunteers from right across the province)

Name:	Email:
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Address:

Phone:	Would you prefer mail-outs by email or postal mail?:
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If you would prefer to pay by credit card, please complete the following:

Account #	Type of card:	Expiry:
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Clip and mail this form to Epilepsy Newfoundland and Labrador - 351 Kenmount Road, St. John's, NL A1B 3P9