

Epilepsy News

The Quarterly Newsletter of Epilepsy Newfoundland and Labrador

Fall 2003

Keppra Now Available in Canada

"Despite the availability of many anti-epileptic drugs in Canada, one in three people living with epilepsy don't respond to conventional drug therapies"

On July 31, 2003 Lundbeck Canada Inc. announced in Montreal that KEPPRA® (levetiracetam), a novel second generation anti-epileptic drug (AED), is now available in Canada. KEPPRA®, which is chemically unrelated to other AEDs, has been approved by Health Canada's Therapeutic Products Directorate as adjunctive therapy in the management of patients with epilepsy who are not satisfactorily controlled by conventional therapy.



"Despite the availability of current treatment options, about 30 per cent of patients suffering from epilepsy are still refractory to treatment," said Dr. Joseph Dooley, Pediatric Neurologist at the IWK Health Centre and Professor of Pediatrics at Dalhousie University in Halifax. "KEPPRA® represents a promising new treatment option for Canadian physicians and their patients, and may allow some of them to achieve seizure freedom."

"People with epilepsy have to deal with unpredictable episodic seizures which means a loss of control in their lives," said Denise Crépin, National Executive Director, Epilepsy Canada. "We welcome this new treatment which provides physicians with another potential to further reduce the population of uncontrolled seizure patients."

KEPPRA® seems to work in a novel way. Evidence has suggested that its anti-epileptic effect may occur because it is believed to prevent calcium entry into brain cells, thus reducing neuronal activity which helps in preventing seizures. KEPPRA® is the only anti-epileptic drug that seems to counter the effect of zinc and beta-carbolines, compounds that alter the excitability of brain cells.

"With KEPPRA® it is easy to initiate treatment rapidly and then to quickly see its impact on seizure control. The lack of drug interactions make it simple to maintain KEPPRA® at a therapeutic dose."

KEPPRA® is absorbed rapidly and almost completely. A starting dose of levetiracetam 1000 mg per day (500 mg twice daily) is often a fully effective dose for seizure reduction and results in a high responder rate as demonstrated by the randomized, double-blind, placebo-controlled phase III clinical trials conducted in 904 patients with refractory (i.e., not responding to therapy) partial epilepsy.

KEPPRA® is not known to interact with other drugs in any clinically meaningful way, nor have other drugs been found to interact with KEPPRA. This is an important feature given that KEPPRA® will be used in combination with other medications.

In clinical studies, levetiracetam was generally well tolerated by patients. The use of levetiracetam is associated with the occurrence of central nervous system adverse use events classified as somnolence and fatigue, coordination difficulties and behavioural abnormalities. In controlled studies, when levetiracetam was given with other AEDs, the most frequently reported adverse events were somnolence, asthenia (fatigue), infection and dizziness. Adverse events were usually mild to moderate in intensity.

KEPPRA® - is a registered trademark of UCB SA. Distributed by Lundbeck Canada Inc.

(Mood Disorder Society of Canada, July 2003)

In old Ireland, epilepsy was known as "St. Paul's Disease". The apostle discreetly mentioned his epilepsy on several occasions. In the 2nd. letter to Corinthians (2, 7) he says "...to keep me from being puffed up with pride...I was given a painful physical ailment...to beat me and keep me from being proud." He again mentioned his ailment in Galatians 4, 13-14.

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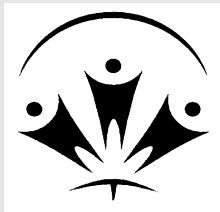
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Notes from Pam

Greetings all! For those who haven't met me yet, my name is Pam Anstey, I'm the new Information Officer here at Epilepsy Newfoundland and Labrador. One of my tasks as your Information Officer is to develop an interesting and informative newsletter every quarter. We've gone with a new look this time, and a new format. I hope you like it. If there is anything you would like to see added or changed, by all means let me know and I will do my very best.

My last few months here at ENL have been busy ones. I've been working very hard to learn as much as I can about epilepsy, both the medical and social aspects. I am amazed that even though epilepsy is the second most common neurological problem (headaches are the first) so little information and statistics has ever been gathered. It's definitely time to bring epilepsy out of the shadows once and for all.

One of the main things I have been working on so far is a brand new website. It's now up and running and we're very proud of it. It has a wealth of information on ENL and what we can do for you. As well, it is loaded with epilepsy information on topics such as medications, treatments, and living well with epilepsy. You can check it out at www.nfld.net/epilepsy.

In the next while I'll be hitting the pavement to do as many presentations and public information sessions as I can. If you know of a group, class, or organization that might be interested in learning about epilepsy, have them call me. We do presentations for all ages - from kids to seniors, and I would welcome the opportunity to spread epilepsy education and awareness to even more people. For folks outside of the Avalon, we can arrange to have someone in your area come and do the presentation on our behalf.

So if you have any questions, need some help with an epilepsy related issue, or just want to say hello, give me a call. You can reach me by phone at 709-722-0502 or long distance at 1-866-epilepsy (374-5377), or by email at epilepsy@nf.aibn.com. Have a safe and happy fall!

Pam
Information Officer/Editor

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.

We can't help everyone, but everyone can help someone.

- Dr. Loretta Scott

Canadian Government To Sell Marijuana To Patients

The Canadian Minister of Health has announced a new policy of supplying marijuana to users who are authorized to own the drug for medical purposes.

The policy comes after certain aspects of the Marijuana Medical Access Regulations (MMAR) were declared unconstitutional by the Ontario Supreme Court earlier this year. The court ruled that the regulations did not guarantee a legal distribution system for the supply of the drug to those with a wide range of conditions, including epilepsy, who had been authorized to use marijuana to help alleviate their conditions.

Pending clarification by the courts of the government's roles and responsibilities with respect to the provision of marijuana for medical purposes, the government have announced they will: make marijuana seeds available to persons authorized to produce marijuana for medical purposes and who do not currently have

plants at any stage of production; and, provide a legal source and supply of dried marijuana to individuals authorized to use marijuana for medical purposes who are unable to produce it themselves or find a person who can produce on their behalf.

The Minister, Anne McLellan, said: "As Minister of Health, my first obligation is to ensure the safety and efficacy of this product. Marijuana is not a proven therapeutic product. Therefore, I remain committed to the Government of Canada's medical marijuana research program, which promotes research on the medical value of marijuana while taking a compassionate approach to Canadians who suffer from serious medical conditions".

There is scientific evidence to suggest that cannabis may be beneficial in treating a number of conditions, including epilepsy.



(Epilepsy Action News, July 2003)

New Gene Identified: Involved in Both Intellectual Disability and Epilepsy

Intellectual disability and epilepsy often occur together and frequently have genetic causes. Now, for the first time, researchers from the Women's and Children's Hospital, Adelaide have identified a major gene that is responsible for both conditions.

Senior hospital scientist Dr Jozef Gecz from the Dept of Cytogenetics and Molecular Genetics says, "This gene is found on the X-chromosome and is one of probably 100 genes on that chromosome, which when mutated, can cause intellectual disability."

"The really novel aspect to this gene is its involvement in epilepsy as well as in intellectual disability". Previously nine other epilepsy-causing genes have been identified and these belong predominantly to a specific group called 'ion channels' and they have nothing to do with intellectual disability.

"Our new gene is different, being more of a master gene, controlling how, where and when other genes work and thus contributing to the normal cognitive function of human brain".

"It will be very interesting to know the identity of these genes, that are under control of this master gene as they may potentially be involved in either epilepsy, intellectual disability, or both", says Dr Gecz, who led the team of 17 researchers from six countries collaborating on this project.

Dr Gecz and his team are puzzled by their finding that the same mutation in this gene can give rise to very different clinical outcomes.

"We studied genetic material from nine families worldwide and found the same mutations in the gene gave rise to epilepsy including infantile seizures (early childhood epilepsy) and other types of seizures, dystonia (disorder of muscle tone causing muscle contraction) as well as intellectual disability. We have no answers for why this occurs, but it is something we are keen to study further".

"Our findings of mutations in this gene in the set of nine families with various clinical presentations including West syndrome, Partington syndrome, myoclonic epilepsy, syndromic and non-specific intellectual disability is quite unexpected," Dr Gecz says.

Dr Gecz says the immediate benefit of this discovery is that we can now provide feedback to the affected families and thus assist them in making informed reproductive decisions.

It is estimated that up to 2% of the population suffer from intellectual disability and 2% from epilepsy.

(Nature Genetics, 2002)

Seizures and School

Having seizures at school can be socially damaging to a child and frightening to others. However, it doesn't have to be.

A well-informed, confident teacher and a supportive school staff and school administration can make all the difference in the world. There are several steps parents can take to create a more accepting school environment for a child.

Meeting The Teacher

First, take time to meet with your child's teacher before the beginning of each school year to discuss how epilepsy affects your child, what type of seizures he or she has, and how you would like the teacher to handle the seizures when they occur.

As seizures are a common problem, many teachers will have had other students with epilepsy. If your child's teacher is unfamiliar with seizures and needs information, contact Epilepsy Newfoundland and Labrador.

Videos, pamphlets and first aid presentations available from ENL have a basic message: that students with seizures belong in school and are in no way a kind of threat to other children. With information, reassurance, and plenty of opportunities to ask questions, other children can also learn to take seizures in stride and continue to accept the child who has them.

But gaining acceptance is not the only challenge for children with seizures.

Aiding Achievement

While many children with epilepsy test within the same range as other children, their achievement at school may be lower.

There may be several reasons for this, including side effects from the medication, days spent out of school for tests or doctor visits, and anxiety about having seizures at school. Memory or attention may also be affected.

One boy told his mother, "Mom, I study and I know the words and I know it all and then, suddenly, it all goes away and I can't remember any of it. I try to hold on to it, but it goes away."

After a seizure a child may be unable to remember anything that happened the previous day or immediately afterwards. Testing for learning disabilities may reveal specific difficulties related to where the seizures are occurring in the child's brain.

(Adapted from an Epilepsy Foundation of America article)

New Child Disability Benefit

The Government of Canada has introduced an income benefit to help **children with severe and prolonged disabilities** living in low- and modest-income families. The first payment of the Child Disability Benefit (CDB) supplement will be issued with the March 2004 Canada Child Tax Benefit (CCTB) payment and will include a retroactive amount from July 2003 to March 2004 inclusive.

What is the Child Disability Benefit?

The Child Disability Benefit (CDB) is a tax-free benefit of up to \$1,600 per year for low- and modest-income families caring for children under the age of 18 who have a severe and prolonged mental or physical impairment.

When will the Child Disability Benefit be paid?

The CDB will be paid monthly, as a supplement to CCTB payments. The first payment will be issued to eligible families in March 2004. The March 2004 payment will include a retroactive amount for the period from July 2003 to March 2004.

How to apply



If you receive the CCTB for your child and you or your current or former spouse or common-law partner has already submitted an approved Form T2201 for that child, you do not need to contact the Canada Customs and Revenue Agency (CCRA) or send in any other forms. Your CDB will be calculated automatically and included in the March 2004 CCTB payment.

If you receive the CCTB, but you or your current or former spouse or common-law partner have **not** filed Form T2201 for a child who may be eligible, please obtain one, have it completed and signed by a qualified person, and send it to your tax centre which will determine whether or not you are eligible to receive the CDB.

More information

For more information about the CDB, call 1-800-387-1193. Information is also available on the CCRA's *Child and Family Benefits* Web page at www.ccra.gc.ca/benefits.

(From the Canada Customs and Revenue Agency website)

It goes without saying that you should never have more children than you have car windows.

- Erma Bombeck

A Helmet for Michael

The following is a true account of how many different people came together to assist one young boy with epilepsy. It is also an account of my first introduction to the challenges and frustrations that kids with epilepsy, and their families must face on a regular basis.

It was my first day on the job, and like anyone would be, I was nervous. Wanting to do everything just right, afraid I would mess up. I knew very little about epilepsy, but I was determined to learn, and determined to help in any way I could.

As I sat down at my desk I noticed a message waiting for me. It was from a mom who had a son with Lennox Gastaut Syndrome and was looking for some information. Taking a deep breath I called her up.

She told me about her son Michael, who has had myoclonic or 'drop' seizures for some time. Michael was required to wear a helmet to protect his head when he fell. But the hockey helmet he had been wearing just wasn't working well enough. Michael's mom said that Dr. Buckley, the Pediatric neurologist had told her about something called a 'seizure helmet', specially designed for kids like Michael, and if she could find one, that would be best.

But where to find one? She didn't know. But like any mom would, she was determined to do all she could to protect her children from harm and injury. And so she had called us to ask for our help.

After our conversation, I sat with Gail, our Executive Director here at the office met and talked about Michael's case for a while. We had never heard of a seizure helmet either, but if there was one to be found, we were determined to find it.

We started our search by sending word out across Canada to all members of the Canadian Epilepsy Alliance, to see if anyone had heard of a seizure helmet. One group wrote back that Bloorview Hospital in Ontario had a program to make such helmets. A lead! We contacted Bloorview, who advised us to talk with the folks here at the Orthotics Department at the Janeway, which we did right away.

It was here that we met two great people, Cy Power and Carol Cantwell. They then took it on themselves to contact Bloorview to find out about their program. What they found out was that Bloorview custom made all their helmets, but to be fitted, the person would have to be there in person. A dead end!

So we went back to the drawing boards. For days we researched, looking for a company that could make Michael's helmet. Time was of the essence because school would be starting soon and without his helmet, Michael couldn't join his classmates back at school.

And then a breakthrough! A company in the states made exactly what we were looking for. But how could we get one fitted? Although they had never fitted a seizure helmet before, Cy and Carol said they would take care of it.

And so it was that not three days later, Michael, along with his mom arrived in St. John's to be measured for his very special helmet.

As of the time of this newsletter printing, Michael's helmet is currently mailing it's way from the United States. When it arrives, Michael's mom will be able to breathe a little easier knowing her son will be just a little safer each day as he faces the challenges of his epilepsy.

And me? Well I learned a lot over the days and weeks of searching to help find a helmet for Michael. But I think the most important thing was that no one has to face epilepsy alone. People are here to help, and eager to help if asked. Together we can help to make living with epilepsy a little easier, and a little less lonely.

Do you have a problem or an issue relating to epilepsy that we might be able to help you with? Let us know. We will do our very best to find the solution or offer some direction. That's what we are here for - to serve our members to the very best of our ability and bring epilepsy out of the shadows for good.

*Pam Anstey
Information Officer
September 17, 2003*

*No act of kindness, no matter how small, is ever wasted.
- Aesop*

Asked and Answered

Q I'm going for a job interview soon and I was wondering what they are allowed to ask me during the interview about any medical conditions. Also, if I get the job, when should I tell my employer I have epilepsy?

A It is illegal for an employer to ask medical questions on an application form. Should such a question appear on an application anyway (likely due to employer ignorance), you can refuse to answer it.

The employer may, however, ask you questions during the interview to determine your ability to perform the particular job. A sample appropriate question would be, "Do you have any medical condition which would interfere with your ability to perform this job?" It is illegal to ask, "Do you have any medical problems?" In other words, a medical question in the job interview must be tied to ability to do the job, not just to gather information. A work-related medical examination may only be requested after a written offer of employment.

After you begin a new job, you can disclose your condition at any time or not at all, depending on your comfort level and how active your seizures are. There is no right time for everyone; it is an individual decision. Whatever time you choose, including never, will have both advantages and disadvantages. Many people who have active seizures think the best time to disclose is after the job offer is made, so as not to run the risk of clouding the hiring decision. But some say this introduces an element of jeopardy into the probation period before you are permanently on staff.

An equally important issue is how to disclose. It is essential, above all, for you to have a thorough knowledge of your own epilepsy. Relevant information about what others can expect to witness and how they can best respond to your needs should be communicated clearly, calmly and concisely. Your employer will be guided to react appropriately by your knowledgeable, reassuring manner. This approach promotes understanding and flexibility in the workplace.

It is important to remember that disclosing to your manager or human resources department does not confer permission to tell your co-workers. This information is confidential. If safety issues are a factor, the employer may want your immediate co-workers to know, so that appropriate measures can be taken when or just before you have a seizure. The employer should, however, discuss the matter with you first. It is generally better for you to disclose to your co-workers yourself so that you can present the information firsthand in the way that seems best to you.

Q I have had epilepsy for many years. I got married recently and my husband and I want to start a family but I'm concerned about passing my epilepsy on to my children. What are the chances this will happen? Is it even possible?

A Some forms of epilepsy have now been linked to specific genes. In addition, scientists believe that everyone inherits a seizure threshold which determines how susceptible a person is to seizures, but whether or not they ever develop epilepsy is another story. In fact, in most cases epilepsy develops without any family history of the condition.

If a parent has seizures, the likelihood of passing epilepsy on to their child is estimated to be about 6%, compared to a 1% or 2% risk of epilepsy in the general population. Basically, unless both parents have a strong family history of epilepsy, the chances that any of their children will inherit the tendency to have seizures are quite low.

Q Can a person with epilepsy drink alcohol?

A It has been assumed that alcohol is bad for everyone with epilepsy. However, there is no clear evidence that infrequent use of small amounts of alcohol would be harmful to people with well-controlled epilepsy. **However, in persons with uncontrolled epilepsy, even a small amount of alcohol may aggravate seizures and cause problems.** Seizures can also be caused by missing medications when you drink, or by missing a lot of sleep. If you wish to drink, you should talk to your doctor first.

Do you have a question for our *Asked and Answered* column? Write, phone or email us at

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Announcements and Appreciations

Annual General Meeting - The AGM of Epilepsy Newfoundland and Labrador will be held on November 13, 2003 at 7:30 pm. All members are invited to attend. Out of town members can attend via teleconference from anywhere in the province. For more details see the full page insert in this newsletter.



Scholarships - Each year ENL offers two scholarships for students in Newfoundland and Labrador - The Jim Hierlihy Memorial Scholarship and the Mature Student Scholarship. Each scholarship is valued at \$1,000.00 and is open only to members of Epilepsy Newfoundland and Labrador who have been diagnosed with epilepsy or seizure disorder. For more information on the two scholarships, contact our office.



Honour Someone Special Today - We're changing the name of our Mature Student Scholarship to honour someone who has made a contribution towards living with epilepsy. This can be someone who has epilepsy, a volunteer who has helped raise awareness or supported persons with epilepsy, or anyone else who you think has made a difference. To submit a name for this award, please send up by mail or email your name, the person you are nominating, and why you think they are deserving of this award. Application deadline is November 1, 2003. For more information contact us at (709) 722-0502 or toll free at 1-866-epilepsy.



Did you know? - Epilepsy Newfoundland and Labrador is 20 years old this year! We're very proud to have been able to help promote epilepsy information and support for so long, and look forward to the next 20 years promoting epilepsy awareness.

Calendar Campaign - Special thanks to everyone who volunteered, or donated to this year's Calendar Campaign. Thanks to your help with projects such as this, we can continue to provide epilepsy support and educational services to the people of Newfoundland and Labrador.



Winner!! - All donations to our recent Calendar Campaign who sent in their pledge within the two-week early bird date will be entered into a draw for a fabulous art print by Carl Beam, one of Canada's foremost native artists. The piece is appraised at \$1000 and comes with an appraisal certificate. The lucky winner will be announced in our next newsletter.



Nursing Students Project - Here at ENL we welcome two students from the Centre for Nursing Studies. Krista Brown and Natasha Power will be working with us through to December as the community portion of their fourth year studies in Nursing. Krista and Natasha will be working on a plan to incorporate epilepsy education more substantially into the Nursing program.



Don't Forget Your Membership - Just a little reminder to the members who have still not sent in their membership renewal form this year to get them in soon. Without your renewal, we don't know if you still want to be here from us, and may discontinue sending out information and newsletters. So don't delay, renew today!



Epilepsy Is Far More Common Than Most of Us Realize

About 300,000 Canadians (1% of the population) are affected by this seizure disorder.

Each year, 1 in 2000 is diagnosed with epilepsy.

Each day in Canada, an average of 38 people learn that they have epilepsy.

In one year, an average of 14,000 people learn that they have epilepsy.

60% of new patients are young children or senior citizens.

Among seniors epilepsy is the third most common neurological disorder, after dementia and stroke.

The prevalence of epilepsy in persons over the age of 65 is approximately 7%: 1 in 14 seniors.

Just for Kids

CRAYON SCRATCHINGS

Create rainbow coloured scratch drawings.

What You Need

- Crayons of various colors, one must be black
- White paper
- Paper clip, used up pen, or something else to scratch with.

How To Make It

Color patches of colour on the white paper with various colours of crayons. Color darkly.

After the page is completely covered with color, color over the whole thing with black crayon. Press down hard so all of the other colors are covered by the black.

Use the paper clip or pen to scratch out the picture that you want. Where you scratch your picture, the colours underneath will show through creating a rainbow effect.

Q What happened when the cat ate a ball of wool?

A *She had mittens!*

Q A man and a dog were going down the street. The man rode, yet walked. What was the dog's name?

A *Yet.*

Father: How do you like going to school?

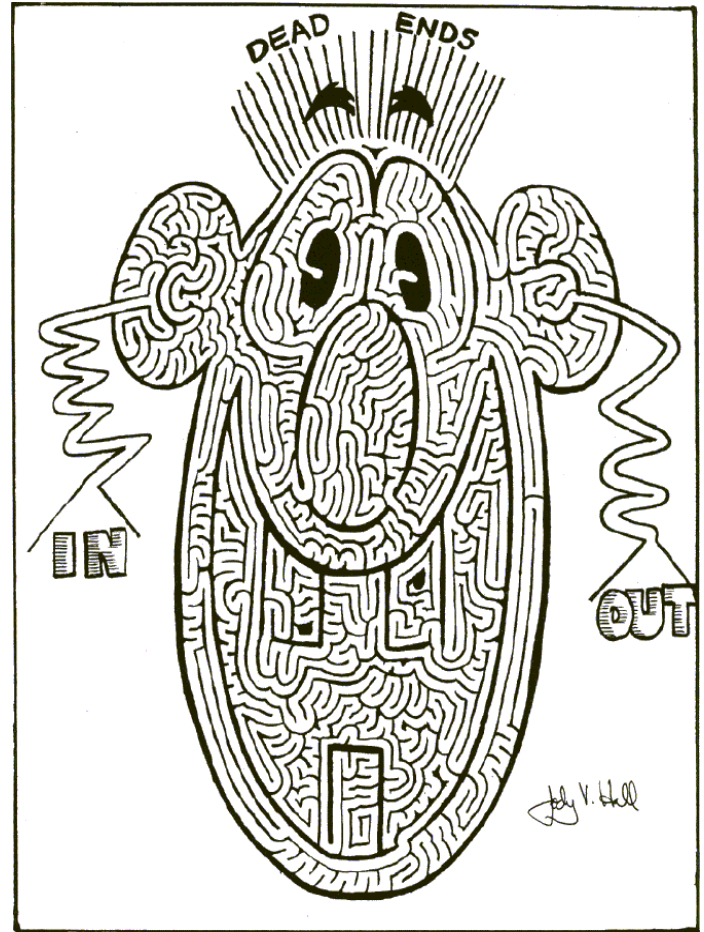
Son: *The going bit is fine, so is the coming home bit too, but I'm not too happy about the time in-between!*

Q What do cats eat for breakfast?

A *Mice Crispies*

Q What did the banana do when the monkey chased it?

A *The banana split*



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BALLOONS BALLOONS!

Can you figure it out?

There are four friends (Adam, Elizabeth, Peter, Sally) and each has a balloon.

The kids are aged 5, 6, 7 and 8 and one of them has a blue balloon.

1. The six year old girl has a green balloon.
2. Adam has a red balloon and is older than Peter.
3. Elizabeth is 5 years old but her balloon isn't yellow.

From the clues above can you match each of them with their age and balloon?

Tickle Your Funny Bone, Tease Your Brain

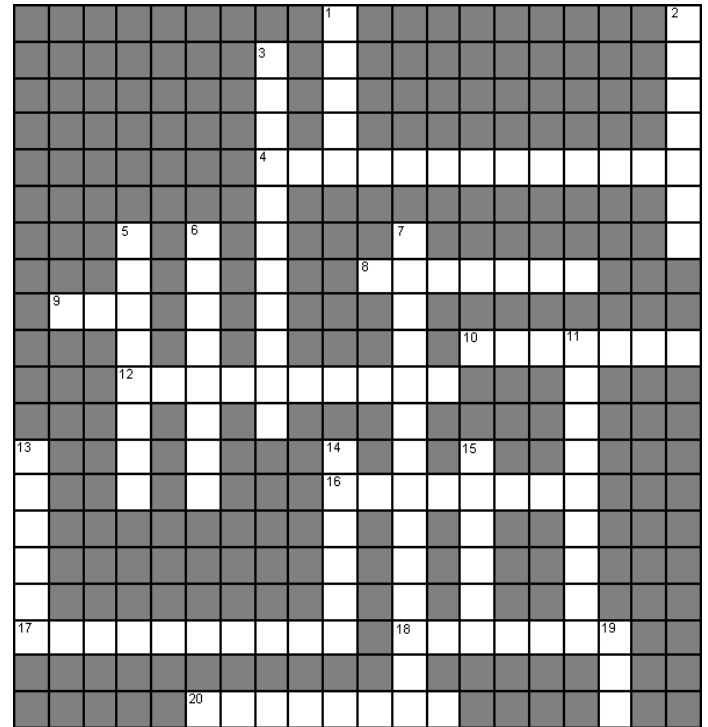


While working for an organization that delivers lunches to elderly shut-ins, I used to take my four-year-old daughter on my afternoon rounds. She was unfailingly intrigued by the various appliances of old age, particularly the canes, walkers and wheelchairs.

One day I found her staring at a pair of false teeth soaking in a glass. As I braced myself for the inevitable barrage of questions, she merely turned and whispered, "The tooth fairy will never believe this!"

*Humor is laughing at what you haven't got
when you ought to have it.*

The first (on record in Canada) neurosurgical electrical stimulation procedure, as treatment for recurrent seizures was performed in 1909 in St. Anthony, Newfoundland, by Dr. John Mason Little. Dr. Little came to the Labrador coast from Massachusetts General Hospital in the summer of 1907. He worked out of St. Anthony until 1915. These procedures were usually performed at major medical centres.



Across Clues

- 4. Antiepileptic drug
- 8. Ictus
- 9. Number of primary generalized seizure types
- 10. A very early AED
- 12. Motor seizure
- 16. Antiepileptic drug
- 17. Used in diagnostic recording
- 18. Petit mal
- 20. Antiepileptic drug

Down Clues

- 1. What one shouldn't do
- 2. Implies altered consciousness
- 3. Common site of seizure origin
- 5. What one shouldn't reach
- 6. Antiepileptic drug
- 7. Multiple seizure types and retardation
- 11. Single muscle extension
- 13. Implies normal consciousness
- 14. Enduring state
- 15. What one doesn't need
- 19. Diagnostic test

Choose from:

- absence
- bromide
- complex
- convulsion
- depakote
- dilantin
- drive
- EEG
- electrodes
- hippocampus
- lennox-gastaut
- levels
- myoclonic
- phenobarbital
- seizure
- simple
- six
- status
- tegetrol

Answers on page 10

