

MARCH-APRIL 2020



FOCUS ON EPILEPSY



THE NEWSLETTER OF THE EDMONTON EPILEPSY ASSOCIATION

The Epilepsy Association of Northern Alberta - Our 60th Year of Service

(This Newsletter can be viewed in full colour on our website: www.edmontonepilepsy.org)

Member Outings & Activities

March & April

**No Activities Planned
Due To Coronavirus
Situation**

2020 Diary & Seizure Record Book

We have recently received
our stock of
2020 Diary & Seizure
Record Books, which can be
picked
up at the EEA Office
or mailed to you on request.

Adult Support Group Schedule

(Group meets from 10:00 - 1200 p.m. in the
EEA office.)

**Please call the Office to advise if you will
be attending**

**Cancelled Until
Further Notice**

EEA Reponse to COVID-19/ Coronavirus Concerns

Our office remains open at this time. However, we have placed a short-term freeze on all in-person events that are routinely offered by us.

We will continue to follow the recommendations of the Federal, Provincial and Municipal Governments which are evolving.

The well-being of our members, employees, friends and families is of the deepest concern to us.

We will continue to keep you updated on our status through emails, Facebook, Twitter and for our members without electronic means of communication, Direct Mail.

We can always be contacted by phone (780-488-9600) or email.

INFORMATION ON COVID-19 BY THE AMERICAN EPILEPSY SOCIETY

The American Epilepsy Society (AES) urges its members and their patients to be aware and cautious while keeping the coronavirus disease 2019 (COVID-19) situation in perspective. In addition to monitoring [US Centers for Disease Control and Prevention \(CDC\) statements and directives](https://www.cdc.gov/media/releases/2020/s0501-covid-19-practice.html), healthcare providers (HCPs) should closely monitor statements and actions of state and local health departments.

Patients should be instructed to work with their HCP's office and pharmacy to initiate prescription refills at least one week before they anticipate running out of medications for 30-day prescriptions and at least two weeks in advance for 90-day prescriptions. While not always possible under payer practices, where feasible and warranted by individual patient situations, HCPs may wish to consider writing 90-day rather than 30-day supplies of medications to ensure that patients have a sufficient quantity of medications on hand.

In a reminder of usual best practice, providers should encourage patients to work with their pharmacists to synchronize prescription refills of all medications, not just antiseizure medications. In addition, patients should be advised to discuss home delivery options with their pharmacy. These measures can minimize public exposure, in the event that public health authorities limit travel or public activities. Epilepsy centers and HCPs should also consider readiness for utilizing remote care options, if possible; i.e., telephone, telehealth, and electronic health record (EHR) messaging.

Viral illnesses may be a trigger for seizures for some, and patients should have an up-to-date plan for managing breakthrough seizures. If medications are involved in this plan, patients should ensure that they have a supply of these medications on hand, with expiration dates at least six months away.

Additional advice for patients with epilepsy and their families is provided on the Epilepsy Foundation web page, [Concerns about Coronavirus](https://www.epilepsy.com/coronavirus).





Edmonton Epilepsy Association

The Epilepsy Association of Northern Alberta



Focus on Epilepsy is published 6 times annually by the **Edmonton Epilepsy Association**. Articles appearing in **Focus on Epilepsy** do not necessarily reflect the opinions of the Association.

We welcome your contributions:

Do you have a poem or maybe a short story (1/2 page) that you would like to share with others. Or maybe you have read a book from our library and want to share a review with others. If you would like to share your wisdom, please submit your items to Sharon at our office or e-mail her at info@edmontonepilepsy.org

BOARD OF DIRECTORS

President...Colleen Matvichuk
Vice President...Cameron Reid
Treasurer...Terry Mahon
Secretary...Katrina Breau
Executive Director...Gary Sampley
Directors-at-Large:

Guy Doucette	Alex Law
Joe Scalzo	Anne Starreveld
Dr. Elout Starreveld	Irene Szkambara

STAFF

Gary Sampley... Executive Director & Chief Operating Officer
gary@edmontonepilepsy.org

Sharon Otto... Program Manager & Education Coordinator
sharon@edmontonepilepsy.org

Dr. Sunny Kim... Counsellor
sunny@edmontonepilepsy.org

Cam Reid... Volunteer Coordinator
cam@edmontonepilepsy.org

Edmonton Epilepsy Association **The Epilepsy Association of Northern Alberta**

11215 Groat Road NW
Edmonton, AB T5M 3K2



(780) 488-9600
(780) 447-5486 fax
1-866-EPILEPSY

info@edmontonepilepsy.org
www.edmontonepilepsy.org



Canadian
epilepsy
Alliance

Alliance
canadienne de
l'épilepsie



Link to E-Action's On-line
Epilepsy Resource and
Community

Edmonton Epilepsy Association

EEA Employabilities Programs

- ⇒ Employment Counselling
 - ⇒ Assistance with Resumes
 - ⇒ In-office Skills Training
 - ⇒ Referrals to Select EEA Partners In Employability
- For Further Information contact EEA Executive Director,
Gary Sampley, 488-9600 or gary@edmontonepilepsy.org

Bus Tickets Available for Members in Reduced Circumstances

Our 2019 allotment of Donate-A-Ride bus tickets is now depleted. However, Alberta Blue Cross has very kindly donated a number of adult ticket packs to us to hopefully get us through till next April. These can be accessed by MEMBERS with limited financial resources who need help getting to medical appointments, EEA events, food shopping, etc., and who do not qualify for an ETS low-cost bus pass.



Now you can Donate to the EEA online!

If you would like to make either a lump sum Donation or a monthly donation contribution to the Association by credit card, please visit our website, www.edmontonepilepsy.org, and click on the [Canada Helps](#) Logo. This donation program gives you the ability to instantly print off a donation receipt.



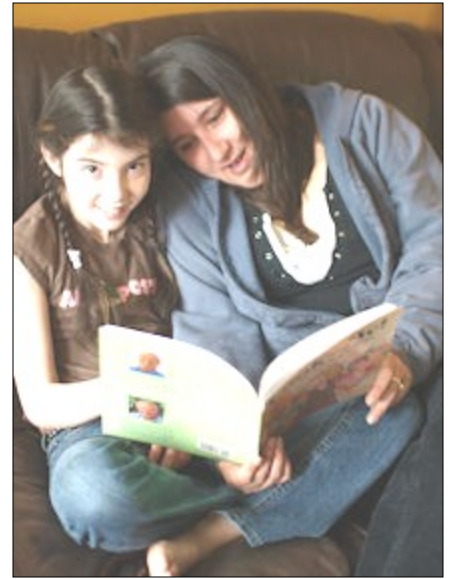


Purple Day Beginnings

Cassidy Megan created the idea of Purple Day in 2008, motivated by her own struggles with epilepsy. Cassidy's goal is to get people talking about epilepsy in an effort to dispel myths and inform those with seizures that they are not alone. The Epilepsy Association of Nova Scotia came on board in 2008 to help develop Cassidy's idea which is now known as the Purple Day for epilepsy campaign.

Epilepsy Association of Nova Scotia and The Anita Kaufmann Foundation

In 2009, the New York-based Anita Kaufmann Foundation and Epilepsy Association of Nova Scotia joined forces to launch Purple Day internationally. As the global sponsors of Purple Day, both organizations are committed to partnering with individuals and organizations around the world to promote epilepsy awareness. The combined efforts of The Kaufmann Foundation and Epilepsy Nova Scotia have led to the involvement of numerous organizations, schools, businesses, politicians and celebrities around the world. On March 26, 2009, over 100,000 students, 95 workplaces and 116 politicians participated in Purple Day.



Cassidy Megan with mom, Angela

Purple Day - March 26

For more information on how you can get involved, click [Join the Campaign](#). Please wear purple on March 26 to promote epilepsy awareness world-wide. Have a suggestion or question? Email us at partners@purpleday.org.



Gala News

Due to the ongoing situation with Covid-19, the EEA Gala scheduled for June 11th, 2020 has been cancelled. It will be rescheduled for the Fall.



Sunrise Bakery Donates \$10,000 To EEA For Future Programs For Families

Hank Renzenbrink of Sunrise Bakery is seen presenting the Donation to a very grateful EEA Executive Director Gary Sampley.



Still Wanted: Volunteer Casino Workers

The EEA is still recruiting experienced Casino Worker Volunteers for our 2020 Casino. Our scheduled dates, April 10 & 11th were cancelled due to the Coronavirus.

However, we expect to be rescheduled once the Casinos re-open. If you have previous casino experience and are interested in helping us, please contact the EEA Office.



2020 EEA Continuing Education Scholarship Awards

The Edmonton Epilepsy Association will fund two \$1000 Scholarships in 2020, for the purpose of assisting students to advance to or continue with College or University studies. Application for these Scholarships is open to Greater-Edmonton area students aged 17-29 years of age who are currently under a Canadian physician's care for epilepsy and are Canadian Citizens or who have permanent resident status.



Visa students are not eligible for this award.

Deadline for applications extended to May 1st, 2020

To download an application, visit our website: www.edmontonepilepsy.org, or call our Office at 780-488-9600 if you wish to receive one by mail.



Life Enhancement Scholarship Program For Youths



The **Brittany Hughes Memorial Life Enhancement Scholarships for Youth**, to a maximum of \$500 each, are available for Youths of any age, up to the age of 18, to assist them in participating in Arts, Music, Dance and/or Ethnic Identity Cultural Programs that will enhance their development as individuals.

Scholarship criteria, eligibility details and the current Application Form can be downloaded from www.edmontonepilepsy.org, or a hard-copy Application can be mailed to you on request to the EEA Office, 780-488-9600.

Does Your Child or Teen Have Upcoming Sports or Recreational Activities Costs?



The **Garry Hannigan Memorial Life Enhancement Scholarships for Youth**, to a maximum of \$500 each, are available for Youths of any age, up to the age of 18, to assist them in participating in Sports or Recreational Activities that will enhance their development as individuals.

Scholarship criteria, eligibility details and the current Application Form can be downloaded from www.edmontonepilepsy.org, or a hard-copy Application can be mailed to you on request to the EEA Office, 780-488-9600.



Barb Bolstad is EEA 2019 Achiever Of The Year!

Barb receives her award as EEA's Achiever of the Year from EEA Executive Director Gary Sampley and President Colleen Matvichuk.

The Achiever of the Year Award is presented annually to an individual living with epilepsy who has achieved significant success in life, inspiring others in the process.

Retiring EEA Board Members

Retiring Board Member Craig Heyland receives his Plaque of Appreciation from EEA Executive Director Gary Sampley and President Colleen Matvichuk.

Also retiring from the Board is Cheryl Renzenbrink. Cheryl was out of the country and will be recognized on her return.

Both Craig and Cheryl served a total of six years on the EEA Board.



Donations from Jewel Rebekah Lodge #25 and Maple Leaf Rebekah Lodge #2

Thank you to Kay Wannamaker who was instrumental in obtaining two Rebekah donations for the EEA. Jewel Rebekah Lodge #25, of which Kay is a member, generously donated \$5,000.00 and Maple Leaf Rebekah Lodge #2 donated \$1000.00

Pictured is Kay presenting the cheques to EEA Executive Director Gary Sampley.





DECLARATION

WHEREAS: Epilepsy is a neurological condition marked by recurring seizures,

AND WHEREAS: Onset of this disorder can occur in childhood or in later years, and can have a significant impact on individuals' physical and psychological wellbeing,

AND WHEREAS: The Government of Alberta is working to provide access to the highly specialized treatment and support Albertans with epilepsy need through centres offering care from a team of health providers,

AND WHEREAS: The Epilepsy Association of Calgary and the Edmonton Epilepsy Association are working on behalf of Albertans with this condition to address their needs and concerns,

THEREFORE: THE HONOURABLE TYLER SHANDRO IS PROUD TO DECLARE MARCH 26, 2020 PURPLE DAY FOR EPILEPSY IN ALBERTA.

The Honourable Tyler Shandro,
Minister of Health





PROCLAMATION

WHEREAS, epilepsy is a chronic disorder marked by recurrent, unprovoked seizures;

AND WHEREAS, epilepsy is one of the most common neurological disorders, affecting approximately 15,000 people in Edmonton and Northern Alberta;

AND WHEREAS, symptoms and severity of epileptic seizures may vary, with possible effects including sensory disturbances, convulsions and/or loss of consciousness;

AND WHEREAS, although there is no known cure for epilepsy, the majority of those living with this disorder can be effectively treated with long-term medication;

AND WHEREAS, the City of Edmonton is proud to join communities around the world in promoting epilepsy awareness by participating in Purple Day on March 26;

THEREFORE I, MAYOR DON IVESON, DO HEREBY PROCLAIM MARCH 2020
"EPILEPSY AWARENESS MONTH" IN EDMONTON, ALBERTA'S CAPITAL CITY.

Dated this 1st day of March, 2020

Don Iveson
Mayor of the City of Edmonton



Could The Ancient Remedy Of Magnolia Bark Treat Drug-Resistant Epilepsy?

Researchers have published a paper which suggests the ancient Chinese remedy of magnolia bark could help treat drug-resistant epilepsy. Researchers have published a paper in the journal *ACS Chemical Neuroscience* that states they have found a potential new treatment for drug-resistant epilepsy by turning to the traditional Chinese medicine of *Magnolia officinalis*.

Tests of 14 extracts from plants used in ancient remedies led the team to one compound – magnolol – derived from the ancient magnolia tree, that successfully stopped drug-resistant seizures in both fish and mice.

Developing new drug-resistant epilepsy medications

Epilepsy is one of the most common neurological diseases worldwide, and the [World Health Organization](#) estimates that about 50 million people have the disorder. Medications are available, but they don't help everyone. Research suggests that about 70% of patients with [epilepsy](#) can control it well with medication, leaving many patients without effective treatment.

However, even when the medicines do work, they can cause a range of side effects from dizziness to mood disruptions. To look for new drug leads that could help even those patients who don't respond to conventional anti-seizure medications, Peter de Witte and colleagues set their sights on plants used in traditional Chinese medicine.

The team collected 14 plants used in traditional Chinese medicine anti-seizure remedies then tested the plants' extracts in two types of zebrafish with epileptic-like seizures. One of these could respond to conventional [anti-seizure drugs](#), whereas the other type could not.

The tests showed that only extracts from the bark of *Magnolia officinalis*, a tree native to China, reduced seizure-like behaviour in both types of fish.

In tests with mice, the researchers found that the magnolia bark's most potent anti-seizure compound, magnolol, reduced the rodents' otherwise drug-resistant seizures.

According to the researchers magnolol and similar compounds in magnolia bark could provide a starting point for the development of treatments for resistant epilepsy.

Stephanie Price

March 12th, 2020

<https://www.healtheuropa.eu/could-the-ancient-remedy-of-magnolia-bark-treat-drug-resistant-epilepsy/98527/>

Epilepsy Awareness: Epilepsy Between The Sheets

Just about all aspects of a person's life can be impacted by a diagnosis of epilepsy, including working, driving and family life. But the effects of epilepsy can reach into the bedroom as well, causing sexual dysfunction and disrupting intimate relationships.

"Patients often think about the things they can't do on a larger scale, but a lot of them don't think about how it's affecting them in the bedroom," says epileptologist Eddie Chengo. "Sexual function can also be part of epilepsy, and if it's affecting a patient's quality of life, they need to bring it to their doctor's attention."

While the exact reasons aren't entirely understood, epilepsy may impact your sex life in the following ways:

- Decreased interest in sex
- Difficulty becoming aroused
- Pain during intercourse for women
- Trouble sustaining erections
- Seizures during or after sex

Tips to a better sex life with epilepsy

Though strenuous physical activity and powerful emotions can trigger seizures in some people, there's no concrete evidence that sex itself causes seizures.

If you have epilepsy, there are many things you can do to enjoy sex despite your seizure disorder:

- Talk to your doctor

Don't be embarrassed or shy. Together, you can get to the bottom of what's causing problems in your sex life. There may be a simple, and highly treatable, explanation for your difficulties. It could be other medical conditions such as diabetes, high blood pressure, or thyroid problems to blame and not your epilepsy. If you don't talk about it and fail to do some investigating, you'll never know what the problem is or how to fix it.

Get seizures under control

People whose seizures are well-controlled may experience less anxiety about sex, and hence have fewer sexual problems.

- Try other medications

Work with an endocrinologist (a hormone specialist), along with your neurologist, to balance good seizure control with a suitable level of sex hormones. Changing medications, or using the same medication at a different dose, may control your seizures without compromising your sex life.

• Consider medications to improve sex

If you are a woman who experiences vaginal dryness, your doctor can prescribe a special lubricant or cream to alleviate pain during sex. Effective medications can also be prescribed for men who experience difficulty with erections.

- Consider sex therapy

A sex therapist can help you deal with anxiety about having seizures during sex and may also help treat any underlying depression that could be affecting your feelings about sex.

You can enjoy sex despite epilepsy. Work closely with your doctors to find the right combinations of medications and seek out additional advice and support if necessary so you can have the healthy, happy sex life you deserve.

Fredrick Beuchi Mboya

March 11, 2020

<https://www.standardmedia.co.ke/evewoman/article/2001363770/epilepsyawareness-epilepsy-between-the-sheets>





Advancements in Neurosurgery - Atlantic Health System Neuroscience at Overlook Medical Center



Garwood resident Lucille Bonfanti will never forget February 13, 2017. That's the morning she experienced an endovascular stroke. "I got out of bed at 4 am, and when I got back to bed I said to my husband, 'My eye is killing me,'" she recalled. "The pain was horrendous." Rich, her husband, asked her if she wanted to go to the hospital, but she refused. A moment later, she agreed. Then she passed out. Lucille doesn't remember her time spent in the neuro-intensive care unit at Atlantic Health System's Overlook Medical Center in Summit, NJ, but she knows she was given 50-50 odds of survival. Arriving at the hospital at 5 am, she had a CT scan that revealed a bleed in her left parietal lobe. Fortunately, Atlantic Health System neurosurgeon Paul Saphier, MD was available, quickly performing a procedure on Lucille using the Apollo System. The Apollo System is a surgical tool inserted via a small incision that suction blood and clots out of the brain, preventing further damage without the need to shave the head and open up the skull. Atlantic Health System is one of the few healthcare systems in the region trained and experienced with this advanced aspiration technology. Lucille's procedure with the Apollo System took several hours, according to Rich--and although successful, she was not out of the woods yet. "She was paralyzed on her right side," Rich said. Lucille suffered a seizure after surgery, and in the days afterward, she was not herself. "She didn't know who I was," Rich said. "She didn't even know who she was." After 10 days in Overlook's neuro-intensive care unit, Lucille was transferred to rehabilitation. After nearly five weeks, she was discharged to continue her recovery at home.

Two and a half years later, 70-year-old Lucille is almost fully recovered. She enjoys time spent with Rich and walking in her neighborhood, weather permitting. "My balance is not 100 percent," she said. "My peripheral vision is off and I choose not to drive anymore. But I can do basically anything I want." She cherishes the trips she's taken since her ordeal, including an extended family vacation to Walt Disney World in Orlando with her daughters and grandchildren, as well as a jaunt to Kentucky with a group of friends. "I have in the back of my head that I'd love to go back to Europe," she adds, explaining that she'd like to delve into her family history in Sicily, although she's a little hesitant to travel so far because of her imperfect vision. Sometimes, though, she can't believe she even has the luxury of contemplating travel at all. "It's mind boggling to me how sick I was," she said. "It's hard for me to comprehend because of my amazing recovery." She credits her recovery to her three granddaughters as well as to Dr. Saphier. "Whatever Dr. Saphier did was fabulous and wonderful," she said. "He's such a responsive, kind doctor, and a down-to-earth guy. He just makes you feel confident, and I owe him my life."

First Surgery with ROSA Brain Robot for Epilepsy

Conventional neurosurgery for epilepsy requires a craniotomy, which is the surgical removal of part of the bone from the skull to expose the brain, so that electrodes can be placed to detect and record seizure activity. Due to the complexity of epilepsy surgery, only the most technically skilled neurosurgeons are trained to use the ROSA Brain robot which does not require opening the skull, or even shaving the head. Overlook Medical Center's first surgery using the ROSA Brain robot was performed by Ronald Benitez, MD, chief of endovascular neurosurgery for Overlook Medical Center, Atlantic Health System, and neurosurgeon with Atlantic Neurosurgical Specialists. This groundbreaking technology is the latest advancement available to patients at Overlook Medical Center's Level 4 Epilepsy Center - yet again placing Overlook at the forefront of epilepsy care in New Jersey.

"We're truly excited to be the first in New Jersey to use the ROSA Brain robot during brain surgery," said Dr. Benitez. "Seizures can be a daily occurrence for epilepsy patients and approximately 30 percent of these patients don't respond to medication. Using a tool like the ROSA robot is a far less invasive surgery and adds new surgical options that can drastically improve the quality of life for patients with seizures." Using the ROSA Brain robot, surgeons make tiny holes in the skull through which they insert the electrodes. The electrodes record brain activity and help pinpoint exactly which part of the brain is responsible for seizures. The robot also can assist in deep brain stimulation, trans-nasal and ventricular endoscopy, and brain biopsies.

Deep Brain Stimulation Treats Parkinson's Disease

Christine Treger's journey with Parkinson's Disease began more than eight years ago, when she noticed her pinkie finger was twitching a lot. Christine was under the care of a Parkinson's Disease specialist at Overlook Medical Center's Atlantic Neuroscience Institute and was doing well. But after several years, Christine found herself having to take larger doses of medication and at more frequent intervals, and still she experienced tremors. Her neurologist, Marcie Rabin, MD, told her that she was a good candidate for deep brain stimulation (DBS), as she had been on medication for several years and wasn't getting relief, but Christine didn't pursue that avenue. Several more years passed, and Christine's tremors worsened. She was working full time as the director of faith formation at the Presbyterian Church of Westfield, and she was totally exhausted. Finally, in 2018, she had done enough thinking about DBS to bring it up again with Dr. Rabin. "I was ready," she recalled. Dr. Rabin connected her with Paul Gigante, MD, a neurosurgeon at Overlook Medical Center who specializes in non-invasive DBS surgery for Parkinson's Disease sufferers, and her procedure was scheduled.

In DBS, thin wire leads with four electrodes at the tips are implanted into a targeted area of the brain. While anesthesia is briefly paused, the neurosurgeon and neurological team speak to the patient and assess motor function at the same time they're stimulating specific areas of the brain so as to determine the optimum locations for the electrodes. In a follow-up procedure, a battery-operated device is planted just under the skin, near the chest. This device is connected to the electrodes on the brain and delivers electrical stimulation that helps reset abnormal circuits that cause Parkinson's Disease symptoms. Christine doesn't remember much about the procedures, but most incredible to her was what happened when she returned to Overlook Medical Center a week after her surgeries so Dr. Rabin could activate the battery-powered device: "She turned it on and my symptoms went totally away. Immediately. It was like a miracle. I had arrived in a wheelchair, and I walked out. I felt totally normal." "I'm feeling great," she said. "I can do anything I want to do." Asked if she had any advice for other Parkinson's Disease patients who might be on the fence about DBS, Christine didn't hesitate. "I would tell anybody who's a candidate to go for it," she said. "Dr. Gigante is a miracle worker. He's wonderful. He's always upbeat, he's always smiling, and he's very smart, too."

March 16th, 2020, <https://abc7ny.com/advancements-in-neurosurgery---atlantic-health-system-neuroscience-at-overlook-medical-center/6010401/>





Hold The Phone: Smartphone Video Makes It Easier To Diagnose Epilepsy And Psychogenic Seizures

It's difficult to describe something so that others can truly visualize it. Think of a time when you experienced something extraordinary, be it beautiful or disturbing or emotionally intense. It can be frustrating trying to recount the experience to others; the verbal description pales in comparison to the actual experience.

Witness descriptions of seizure events are incorporated as part of the diagnostic cascade, but as with any secondhand accounts, they are necessarily imprecise. This may contribute to misdiagnosis, particularly for people with psychogenic seizures.

In current clinical practice, between 20% and 50% of people who undergo video EEG—the gold standard for diagnosing or ruling out epilepsy—are found to have psychogenic seizures. Most have spent years living with a misdiagnosis of epilepsy, receiving treatment for a disease they don't have while not getting the treatment they need.

What if a tool could help with faster, more accurate diagnosis of both psychogenic seizures and epilepsy? And what if this tool was simpler and less expensive than video EEG, and easy to access almost anywhere?

The tool already exists, and billions of people use it every day.

It's smartphone video.

Videos improve diagnostic accuracy

A recent multicenter trial found that physician review of a high-quality smartphone seizure video, in addition to medical history and physical exam, resulted in diagnostic accuracy of epilepsy and psychogenic seizures 95.2% of the time—far more accurate than utilizing only medical history and physical exam (78.6%). Clinicians also had more confidence in a diagnosis if it included a smartphone video.

"It's a common saying that a picture is worth a thousand words – in this case, a video is worth a thousand words," said William O. Tatum, first author of the study, [which was published online January 21 in JAMA Neurology](#). Tatum is director of the Comprehensive Epilepsy Center and Epilepsy Monitoring Unit at Mayo Clinic Hospital, Jacksonville, Fla.

The results add to the literature supporting the utility of smartphone video as a tool in diagnosis, noted Sándor Beniczky, head of clinical neurophysiology at the Danish Epilepsy Centre and professor of neurophysiology at Aarhus University. In 2012, Beniczky and others published [results from a single-center study](#) showing that analysis of seizure videos resulted in 85% diagnostic accuracy, compared with 54% accuracy using standard clinical practice (witness descriptions).

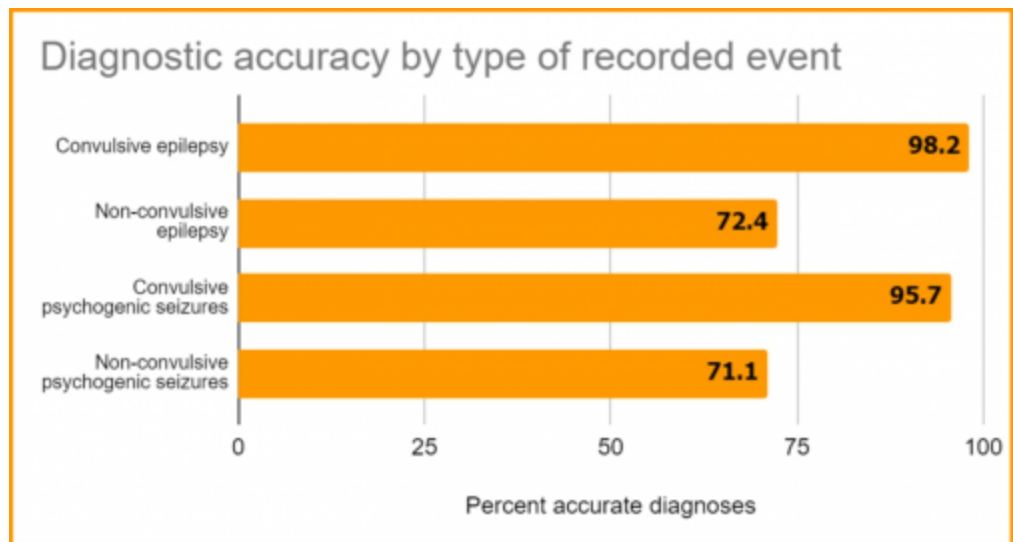
The takeaway is that a good smartphone video can improve diagnosis, particularly for people with psychogenic seizures, said Tatum.

Using videos to triage

"As more patients become more technologically involved, we're all going to see smartphone videos from patients," Tatum said. "This study shows that we may be able to use them, in conjunction with a medical history and physical exam, to triage people to the next step that makes the most sense for them, whether that's the epilepsy monitoring unit for surgery evaluation, or cognitive behavioral therapy for psychogenic attacks."

In many lower-income countries, smartphone videos could play an even larger role, Tatum said. "Some regions may not have a routine EEG, let alone video EEG—but almost everyone has a phone. In those places, by using a smartphone in association with a history, you can maybe get to the bottom line with greater efficiency."

The study included 44 people; each submitted one video, which was reviewed by anywhere from 2 to 17 reviewers. Reviewers included epilepsy experts and senior neurology residents, who served as a comparator group. (The residents had no plans for epilepsy or sleep medicine fellowship.)





Diagnoses using video review were compared with video EEG results to determine accuracy. Smartphone video analysis resulted in a correct diagnosis 89.1% of the time (95% confidence interval 84.2%-92.9%) and correctly ruled out a condition 93.3% of the time (88.3%-96.6%).

The study also found that neurology residents were less accurate than experts (see graph) but were more confident in their diagnoses. "I was pleasantly surprised and intrigued by the difference in accuracy," said Tatum. "We've always thought that experts would be more accurate, but there's been little actual evidence."

Improving psychogenic seizure diagnosis

Nearly three-fourths of the videos came from patients with psychogenic seizures. Tatum said this trend may be partly because psychogenic seizures can be difficult to diagnose. If someone believes they've been misdiagnosed with epilepsy, he said, they may be more likely to want to provide video evidence of their seizures.

Of the videos that generated 100% accuracy in diagnoses among reviewers, all were of patients with psychogenic seizures. "We were hoping that video could really add value for people with psychogenic attacks," said Tatum. "And that's the group for which video seemed to have a very high yield. It looks like a perfect fit."

The next step, said Tatum, is a prospective multicenter study. It will focus on the effects of early diagnosis of psychogenic seizures (using patient-supplied video) on treatment-seeking behavior and outcomes. Currently, up to half of people diagnosed with psychogenic seizures do not pursue treatment. Smartphone videos may help to change this, he said.

"When people talk to you about their seizures, and then you tell them they have psychogenic attacks, they wonder how you can say that, because you haven't seen what happens to them," said Tatum. "But if they show you a video and you review it, and *then* tell them that they have psychogenic attacks—now you've seen what they go through, and maybe they're more apt to believe the diagnosis."

Seizure videos on social media

If it sounds cold or exploitative to record someone having a seizure, consider this: There are more than 12 million seizure-related videos on YouTube. Some are professional educational pieces about epilepsy or psychogenic seizures, but many are personal home videos of people having seizures.

The videos are of toddlers, of young people, of men and women. Some include a warning that the content may be distressing. They are watched millions of times and receive thousands of comments, almost all supportive.

One young woman in Canada is raising awareness of epilepsy by chronicling her experience; she's posted dozens of videos of her seizures, and others depicting her daily life. They've been viewed more than 22 million times, and her YouTube channel has more than 175,000 subscribers.

People are not afraid to show their seizures. But when someone has a seizure, it can be difficult for a family member or friend to switch from caregiver to recording a video, noted Markus Reuber, professor of clinical neurology at the University of Sheffield, UK.

"We need to learn how to encourage more patients (or their families) to produce high-quality seizure videos," he said. "This study has demonstrated that it is worth providing such support."

Aspects of a high-quality video

The videos submitted to the study investigators ranged from 9 seconds to 9 minutes in length. About 75% were of high enough quality to contribute to a diagnosis. Study participants received instruction on what makes for a useful seizure video:

- Record the entire event, or as much as possible
- Include the person's whole body
- Make sure there is adequate lighting
- Include audio
- Include interactions of a bystander with the person during the event, to demonstrate presence or absence of awareness

While high-quality smartphone videos clearly add value, said Tatum, they aren't meant to be used as a standalone diagnostic tool.

"No test should be used in isolation," he said. "You need expert diagnostic skills, along with a medical history, physical exam and all the rest. Without all of that, it's just a video."

International League Against Epilepsy

March 4th, 2020

<https://www.newswise.com/articles/hold-the-phone-smartphone-video-makes-it-easier-to-diagnose-epilepsy-and-psychogenic-seizures>





Our Programs and Services



- ◆ Free “Kids on the Block” puppet presentations that educate children (and their teachers, administrators, caregivers, and group leaders) about kids with Epilepsy in an entertaining manner;
- ◆ Free specially-tailored In-services about Epilepsy to schools, businesses, group homes, Public Service bodies, Colleges, etc. (includes annual training for NAIT EMT students and ETS Supervisors and Security Personnel, and on-line information about Epilepsy on the EPS Training System)
- ◆ Annual Epilepsy Educational Forums, both of interest to Health Care Professionals as well as the General Public;
- ◆ Free provision of our series of 12 Epilepsy Education Information booklets to Members, Hospitals, Clinics, Neurologists’ Offices and Pharmacies;
- ◆ Website, print and video information about Epilepsy, and a free lending library for members;
- ◆ Bi-monthly newsletter for Members that includes the latest current medical information available about Epilepsy, as well as current news about the Association and our services and events;
- ◆ Scholarship Program for Post-secondary Students with Epilepsy (minimum two scholarships a year);
- ◆ Garry Hannigan Memorial Life Enhancement Scholarships for Youth, to assist young people (up to the age of 18) to participate in sports, arts, cultural or recreational activities that will enhance their development as individuals;
- ◆ No-cost Counselling on Epilepsy-related problems for people with Epilepsy and families of people with Epilepsy, with referrals to other supporting Agencies as needed;
- ◆ Monthly group sessions geared toward Adults with Epilepsy and concerned family members;
- ◆ Information and support for Parents/Caregivers of Children with Epilepsy;
- ◆ No-cost provision of assistance/advice on diverse matters, including, but not limited to, finding employment, driving and Epilepsy, potential side-effects of medication, and dealing with the complexities of Government forms and applications (AISH, Disability, housing subsidy, etc);
- ◆ No-cost advocacy on behalf of people with Epilepsy experiencing discrimination or other problems;
- ◆ No-cost social and recreational activities for Members that help reduce social isolation, free ETS Bus Training, and free “Donate-a-Ride” Program bus tickets for Members in need;
- ◆ An annual no-cost in-house Collective Kitchen Cooking Training Program, An Annual Collective Gardening Program and an annual in-house Computer Training Program for Members;
- ◆ Ongoing recruitment and screening of quality Volunteers, annual recognition of all Volunteers, and annual award of Member-nominated Volunteer-, Achiever-, and Employer-of-the-Year Awards.


Edmonton Epilepsy Association

Edmonton Epilepsy Association
11215 Groat Road NW
Edmonton, AB T5M 3K2

Place address label here

*If you are planning to move in the near future please inform our office
so that we can continue to ensure that you get your newsletter...*