children with epilepsy, all ranging in age from 7 years old to 18 years old; 39% had dogs in the family for at least one year. The parents reported seizure-related behaviours regarding their family dog and their children. Specifically:

- 42% of families reported seizure-specific reactions from their dogs.
- About 40% of these dogs showed these behaviours in anticipation of the seizure.

It's a remarkable ability that may develop spontaneously in some dogs and has recently been documented in dogs living with epileptic adults -- but not in children, writes researcher Adam Kirton, MD, a paediatric neurologist with Alberta Children's Hospital at the University of Calgary in Alberta.

These seizure-alerting dogs may reduce frequency of epileptic seizures, improving the families' quality of life, he explains.

Kirton got his information from telephone interviews with 45 families, all having children with epilepsy, all ranging in age from 7 years old to 18 years old; 39% had dogs in the family for at least one year. The parents reported seizure-related behaviours regarding their family dog and their children.

Specifically:
- 42% of families reported seizure-specific reactions from their dogs.
- About 40% of these dogs showed these behaviours in anticipation of the seizure.

The family dog can often sense when a child has an impending epileptic seizure, a study shows.

One dog may sit on toddler before an attack. Another dog might push a young girl away from stairs just minutes before her seizure. Yet another dog wakes up in the night 20 minutes before a child's seizure.
Breed with this ability included Golden Retriever, Standard Poodle, German Shepherd, Akita, Rough Collie, Rottweiler, Cairn Terrier, Great Pyrenees, and one mixed breed dog.

Dogs acquired this ability after about one month with the family -- generally with the first seizure the dog witnessed.

The typical response was licking the child's face, protecting the child, and whimpering; the dogs were never aggressive or harmed the child.

Also, the dogs were rarely wrong, Kirton reports. Sometimes the seizure alert behaviour was just 10 seconds before the epileptic seizure; in other cases, the alert came up to five hours before.

Parents' Stories
One parent reported that her Sheltie-Spitz dog would "forcibly sit on her toddler and not allow her to stand prior to a drop attack," writes Kirton.

An Akita pushed a young girl away from the stairs just 15 minutes before a convolution. One Golden Retriever could anticipate night time seizures up to 20 minutes before they occurred.

One Rottweiler would lick a toddler's feet or forcibly position himself on either side of the child before a drop attack.

One Great Pyrenees would attach itself to a 3-year-old -- not eating, drinking, or being with anyone else -- during the hours before a generalized convolution. The same dog would forcefully lie on the child's 8-year-old sister 10 minutes before she had a partial seizure.

Families with these sensitive animals had better quality of life than the other families did, he says.

Dogs may pick up on subtle early symptoms of epileptic seizures, writes Kirton. For dogs, developing such a skill offers a significant survival advantage, which is perpetuated through natural selection, he says. The skill gets reinforced when seizures occur repeatedly, he explains.

Kirton says research is exploring the abilities of animals to sense human brain activity. Future efforts to validate these behaviors and establish training programs will help uncover the mechanism by which detection of seizures occur, this will also benefit those with epilepsy.

New definition for epilepsy

An expert task force has created a new definition for epilepsy that refines the scope of patients diagnosed with this brain disease.

The study published in Epilepsia, a journal published by Wiley on behalf of the International League Against Epilepsy (ILAE), provides a greater level of detail to diagnose epilepsy by including individuals with two unprovoked seizures, and those with one unprovoked seizure and other factors that increase risk of seizure recurrence.

The 2005 report by the ILAE task force defined an epileptic seizure as “a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain” and epilepsy as “a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures, and by the neurobiologic, cognitive, psychological, and social consequences of this condition. The definition of epilepsy requires the occurrence of at least one epileptic seizure.”

"Why change the definition of epilepsy?" asks task force lead author Dr. Robert Fisher from Stanford University School of Medicine. "The 2005 definition does not allow a patient to outgrow epilepsy, nor does it take into account some clinicians’ views that epilepsy is present after a first unprovoked seizure when there is a high risk for another. The task force recommendation resolves these issues with the new, more practical, definition of epilepsy that is aimed at clinicians. However, some researchers might use criteria similar to those of the old definition to facilitate comparison with prior studies."

The task force suggests that epilepsy is a disease of the brain defined as:

- At least two unprovoked (or reflex) seizures occurring more than 24 hours apart; or
- One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years; or
- Diagnosis of an epilepsy syndrome.

"The burden of determining recurrence risk does not fall on the clinician. If information is not available on recurrence risk after a first seizure, then the definition defaults to the old definition," adds Dr. Fisher. According to the article epilepsy is "resolved" in individuals who are past the applicable age of an age-dependent epilepsy syndrome, or those that have been free of seizures for the last 10 years and off anti-epileptic drugs (AEDs) for 5 years or more. The authors note that, the meaning of "resolved" is not identical to that of "remission" or "cure."

"The published definitions were supported with factual data, but in some cases medical evidence did not exist and the task force used a "consensus" approach for these definitions," explains Drs. Gary Mathern and Astrid Nehlig, Editors-in-Chief of Epilepsia. In these instances, the editors are asking readers' opinions adding, "We encourage you to go to http://surveys.verticalresponse.com/a/show/1539433/ea840f4206/0 to share your feedback regarding the new definition of epilepsy."
The 2nd African Epilepsy Congress (AEC) took place in Cape Town, South Africa, on 22-24 May 2014.

This congress was built on the foundations established through the 1st African Epilepsy Congress, held in Nairobi, June 2012.

The 2nd AEC is a significant scientific event for the epilepsy community in Africa and farther afield. The programme comprised of plenary sessions, topical lectures and interactive sessions. Sessions of particular interest to people with epilepsy, their families and carers took place during the Epilepsy and Society Day Seminar, on Saturday 24th May.

Selected speaker presentations are available on the AEC website: http://www.epilepsycapetown2014.org/

Robert Cole, IBE Treasurer and CEO of The Epilepsy Centre, South Australia & the Northern Territory delivered “Men’s Issues – sexual problems”.

This session focussed on Sexual issues that men face, Assisting men to talk more freely about epilepsy & sex with their partners & doctors, Epilepsy and relationships, Sexual dysfunctions and problems, Medications & its effects and Getting help.

During the AEC, the International Bureau for Epilepsy African Regional Executive Committee met to build networks and to assist all IBE African member associations to improve the quality of life for people and their families living with epilepsy. African IBE Regional Executive Committee Chair, Mr Youssouf Noormamode chaired the meeting.

Pictured Above: Robert Cole, IBE Treasurer, Kenneth Ninying Nsom from Cameroon, Sari Tervonen, IBE Secretary General and Mbusomuni Mahalela, National Director of the Swaziland Epilepsy Organisation.
1. What is genetics?

Genetics is the study of genes and inheritance. It studies how parents pass on to their children different characteristics or traits. Every person inherits half of their genes from the mother and the other half from the father. Still, everyone is unique in a variety of traits, such as height, eye color, health or disease. Therefore, children are in many ways similar but not identical to their parents or their siblings. Most of our traits are determined by a combination of genes and environment (e.g., body weight is caused by genetics and lifestyle).

2. What is the basis of my genetic make up?

Human cells contain structures called chromosomes (see Figure 1A). Chromosomes are thread-like structures that package our genetic information. The genes are lined up on the chromosomes, like beads on a string. Each person has 23 pairs of chromosomes. One member of each pair comes from the mother and the other from the father. In Figure 1, pink bars represent chromosomes that are inherited from the mother and blue bars represent chromosomes inherited from the father. One of the 23 chromosome pairs is special because it determines sex – males have an X and a Y chromosome, and females have two X chromosomes. In Figure 1B, pink and blue bars represent sex chromosomes X and Y. Males inherit an X chromosome from their mother and a Y chromosome from their father. Females inherit an X chromosome from their mother and another X chromosome from their father. The most important component of chromosomes is DNA (deoxyribonucleic acid), a long molecule shaped like a twisted ladder, or double-helix (Fig.1A). The DNA molecule is made up of substances (“bases”) called G, C, T, and A. The order (or “sequence”) of these bases (GCT, GAT, TTT, etc.) makes up our genetic code, which provides the information needed to make proteins,
large molecules that are important for proper structure and function of a human body. Proteins are made up of amino acids, and each 3-base unit of DNA determines the specific amino acid that will be included in the protein. A gene is a unit containing a blueprint for making a specific protein. There are about 20,000 genes packed in each parental chromosome set (23 pairs of chromosomes).

3. What is a genetic mutation?

A gene mutation is a permanent change in the DNA sequence of a gene that leads to problems with the gene’s protein product. There are many different kinds of mutations, ranging from a change in a single base (A, T, C, or G) or a few bases (Fig. 3A), to much larger changes involving extra or missing pieces of genetic material that could include several genes or even a whole chromosome (Fig. 3B). Gene mutations occur in two ways: they can be inherited from a parent (hereditary mutations) or occur for the first time in a person (de novo mutations).

4. Is epilepsy a genetic disorder?

Genetics is believed to play a role in most forms of epilepsy. However, perhaps surprisingly, most people with epilepsy do not have any affected relatives. Current scientific evidence suggests that the role of genetics in epilepsy is complex – many genes with a small or modest effect on risk are likely involved – so that it is difficult to predict which people are at high risk. In some unusual families, however, many people develop epilepsy, consistent with an effect of a mutation in a single gene with a strong effect on risk in the family. Studies of these rare families have been very informative for identifying genes that cause epilepsy.

5. I am pregnant and I have epilepsy. Is my child going to have seizures, too?

Certain epilepsy types do seem to run in families. However, for most people with epilepsy, the amount of increased risk appears to be modest. The risk of epilepsy in the close relatives (parents, offspring, and brothers and sisters) of people with epilepsy is about two to four times higher than that of people in the general population, depending on the type of epilepsy. Studies suggest that, except in some unusual cases, the chance is less than 1 in 10 that a child of a person with epilepsy will also develop epilepsy.
6. How can I find out about the risk of epilepsy for myself or my children?

Genetic testing is available for several known epilepsy genes. Genetic counseling is an important part of the testing process. Talk to your neurologist or an epilepsy specialist about a referral to a genetic counselor. You will meet with a specially trained health care professional who will review in detail your medical and family history. He or she may recommend additional laboratory and/or genetic testing and will calculate the risk of developing epilepsy within your family.

7. How can I participate in a research study on epilepsy?

Genes play an important role in epilepsy. Still, in the majority of patients, the exact genetic mechanisms or causes have not been identified. Participation in research studies on genetic mechanisms of epilepsy is critical for improving our knowledge and ability to diagnose disease, predict who will or will not develop epilepsy, and develop better treatments.

There are many studies in epilepsy genetics or epilepsy mechanisms conducted locally, nationally, and internationally. There are several ways to get involved:

You may talk to your physician or contact your local academic center. You will either be able to participate locally or you will be referred to a research center.

In the US, you may visit the following sites:

- Epilepsy Foundation, who might be able to refer you to a research site.
- The Epilepsy Foundation also has a web site that lists some ongoing studies: [http://www.epilepsyfoundation.org/research/participateinresearch/current-open-studies.cfm](http://www.epilepsyfoundation.org/research/participateinresearch/current-open-studies.cfm).


Search through the national research funding agencies, such as The National Institutes of Health: [http://www.clinicaltrials.gov/ct2/results?cond=Epilepsy](http://www.clinicaltrials.gov/ct2/results?cond=Epilepsy)

Browse the internet since many universities post links to their research studies.

Resources:

To learn more about genetics, visit:

To learn more about epilepsy, visit:
- The Epilepsy Centre [http://www.epilepsycentre.org.au](http://www.epilepsycentre.org.au)

This article is provided as a public educational service by the Genetics Commission of the International League Against Epilepsy, 2013

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### Family Planning & Epilepsy

If you are a woman who has epilepsy, there are some important things you should know before using birth control or planning a pregnancy. Any birth control that is safe for women, in general, is safe for women with epilepsy. However, having epilepsy -- and some treatments for the condition -- can make some forms of birth control less effective. Also, because anti-seizure medications for epilepsy can increase the risk of birth defects, it's important to plan pregnancy carefully.

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#### Birth Control and Anti-seizure Medication

If you have epilepsy and take anti-seizure medication, your birth control options could include hormones such as birth control pills or Depo-Provera injections, barrier methods like condoms or a diaphragm, or an intrauterine device (IUD). Natural family planning such as the rhythm method -- abstaining on your fertile days -- can also be used, although this method may not be as reliable as others. All of these methods are safe for you.

If you are taking anti-seizure medications, some of these drugs can interact with some hormonal types of birth control and make them less effective. (cont. P10)
There are certain people in our lives who just make the world a better place. They give us hope and raise our spirits simply by being the kind of people they are. Some people stand up and champion a cause, or provide the spark, or defy the odds, or do the right thing simply because it’s right. They don’t really worry about fame or acclaim, they just think about being good friends, good neighbours, good people. We don’t say it often enough, but we are grateful to have these people in our midst. Thank you for being you.

The Epilepsy Centre work tirelessly raising money for children in need of Seizure Monitors for nocturnal seizures. With everyone’s help over the last year, we have been able to raise enough funding to purchase 23 seizure monitors for all of these children in need and they are eternally grateful as are their families. Warmed and touched by the kindness of complete strangers coming together to contribute to a family who are struggling.

These Seizure Monitors, costing $900 each, are specifically designed for people living with epilepsy. They activate a loud alarm if a child has a seizure in their sleep. This alerts the family that a seizure is occurring and is life-saving. More importantly it allows the children to sleep in their own beds whilst providing peace of mind and a more restful sleep for parents.

The generosity of the general public to date has overwhelmed all of these children’s families as we are able to surprise them with the gift of a Seizure Monitor from the donations received.

Did you know that The Epilepsy Centre does not receive any Government funding for the assistance that we provide to many of the families who live with Epilepsy? South Australia is the only state in Australia which does provide Government funding for the approx. 48,000 people living with Epilepsy.

Additionally Epilepsy is not even recognised as a disability in this State making it even tougher for people to receive support and services in South Australia and the Northern Territory, unlike every other state in Australia.

Every week we have a child who is in need of a Seizure Monitor. The team here at The Epilepsy Centre are determined to make a difference.

Jet, 8 years old, Henley Beach  Bree, 12 years old, Mount Barker
Isabella, 11 years old, Cowandilla  Alex, 10 years old, Millicent
William, 4 years old, Daw Park  Chantel, 9 years old, Alice Springs
Stephanie-Louise, 2 years old, Yorketown  Hannah, 2 years old, Darwin
Joel, 11 years old, Hope Valley  Benjamin, 13 years old, Craigmore
Danny, 2 years old, Daw Park  Charlotte, 7 years old, Daw Park
Spencer, 4 years old, Banksia Park  Brodie, 5 years old, Huntfield Heights
Mikayla, 6 years old, Alice Springs  Imogen, 7 years old, Goolwa
Abigail, 4 years old, Basket Range  Blake, 6 years old, Craigmore
Jerome, 8 years old, Morphettville  Ella, 10 years old, Morphett Vale
Izla, 4 years old, Exeter  Chloe, 10 years old, West Lakes
The Epilepsy Centre’s innovative youth programs

YES is The Epilepsy Centre’s youth employment program. Launched as a grant-funded pilot program at the beginning of the year, it has received an enormous response from the young people as well as from employment service agencies and employers themselves. YES, for Youth Employment Skills, describes the program’s principle aim to see young people with epilepsy learn how to develop strong epilepsy self-management skills, to understand how Australian State and Federal Law impacts on them and to understand both their own and potential employers’ responsibilities.

It is a multifaceted program that caters to the need of the individual. It also provides workplace epilepsy training specific to the individual, client specific workplace risk assessments, a workplace emergency care plan, as well as ongoing epilepsy support for the employer. The program has seen young people grow in knowledge and confidence with each one leaving the program with a firm understanding of their own epilepsy and a strong understanding of when and how to disclose their epilepsy in a way that conveys a positive message to potential employers.

YES YouthEmploymentSkills

The Epilepsy Centre’s youth program has been designed to realise its vision to see young people thrive in life despite living with epilepsy. The overall program has a broad focus comprising numerous individual programs that are founded on extensive research and together aim to meet a range of epilepsy-related physical, emotional, psychological and social needs. Two of the programs that are seeing particular success at present are the employment program and the leadership program.

Young Epilepsy Leaders of South Australia (YELSA) is The Epilepsy Centre’s new leadership program. Designed to help young people with epilepsy realise their own potential, participants learn how to overcome personal challenges, particularly those relating to epilepsy. The program’s plan over the coming year will see young people attend workshops and personal development events designed to provide individual learning and development opportunities. The year will culminate in SUMMIT1625, a leadership summit offered to young epilepsy leaders between the ages of 16 and 25. These summits will occur annually in different locations, the first two of which have already been selected.

The Epilepsy Centre is very excited about the first SUMMIT1625 scheduled for March 2015 in Rotorua, New Zealand. Young people with epilepsy from South Australia, the Northern Territory and New Zealand will join together in a shared growth experience. This initial summit provides a wonderful opportunity for The Epilepsy Centre of South Australia and the Northern Territory to partner with Epilepsy New Zealand. This partnership has involved trips between the two countries to plan activities, with a final trip to New Zealand in March this year ensuring that all accommodation, venues and activities both compliment our program and convey the overall standard of excellence we are striving for. The summit program will see our young people engage in a range of workshops and will enable them to enjoy many of New Zealand’s natural, cultural and fun tourist experiences. Our belief is that the entire experience will be a great learning and growth experience for all our youth.
If you understand these interactions, most of the time you can use the pill and other kinds of hormonal birth control effectively. Different types of anti-seizure medications interact with hormonal birth control in different ways:

- One group of anti-seizure drugs is known as "liver enzyme-inducing" drugs. They increase the rate at which the liver breaks down the contraceptive hormones that you get from birth control. This means that the contraception medication will leave your body faster. Liver enzyme-inducing drugs include carbamazepine (Tegretol, Carbatrol), oxcarbazepine (Trileptal), phenytoin (Dilantin), phenobarbital (Luminal), primidone (Mysoline), and topiramate (Topamax). If you are taking one of these drugs, it can make your hormonal birth control less effective.

- Two drugs -- valproate (Depakote) and felbamate (Felbatol) -- can even increase hormonal levels. If you are on one of these drugs, your doctor may need to adjust the dosage of your birth control so that you don't have too much of the contraceptive in your body.

- Finally, there are "neutral" drugs which don't have any effect on hormone breakdown. Gabapentin (Neurontin), lamotrigine (Lamictal), levetiracetam (Keppra), clobazam, clonazepam, ethosuximide, Lyrica, sodium valproate, Zonegran, and tiagabine (Gabitril) will not interfere with your birth control.

Reliable Birth Control When You Have Epilepsy

If you are taking a liver enzyme-inducing drug, and you want to use hormonal birth control, you should talk to your neurologist and your gynaecologist. It is a good idea to use a second method of birth control as a backup. Barrier methods, like condoms, diaphragms, and new-generation IUDs, are good options. In the past, doctors have sometimes prescribed higher-dose birth control pills to make up for the rapid breakdown of the contraceptive drug. That may work, but there is no clear research to tell us one way or the other. "Doctors used to say that increasing the amount of the estrogen in the pill took care of this problem," says Jacqueline French, MD, professor of neurology at New York University's Langone Medical Center and co-director of Epilepsy Research and Epilepsy Clinical Trials at the NYU Comprehensive Epilepsy Center. "But we have no data to confirm that."

Reliable Birth Control When You Have Epilepsy continued...

In one case, hormonal birth control might make your anti-seizure drug less effective. That can happen if you are taking lamotrigine (Lamictal). The body's levels of Lamictal appear to be reduced when a woman takes hormonal birth control. "This is the only anti-seizure drug we know of that acts like that," says Mark Yerby, MD, MPH, founder of North Pacific Epilepsy Research in Portland, Oregon. "If Lamictal is controlling a woman's seizures very well, and she begins to take the pill, sometimes the seizure control is not as good." (Lamictal and other seizure medications can also become less effective when a woman is pregnant.) What if you want to use natural family planning to prevent pregnancy? There are a number of natural family planning methods. In general, they work by tracking your menstrual cycle, and that's why you probably want to reconsider using this method. If you have epilepsy, there is more of a chance that your cycles are irregular. That would make natural family planning very unreliable for you.

Epilepsy and Planning Ahead for Pregnancy

If you have epilepsy, keep in mind how important it is for you to plan ahead for a pregnancy. As part of that planning, be sure to start taking folic acid supplements before getting pregnant. It's a good idea for women with epilepsy who are of childbearing age to start taking 0.4 milligrams a day of folic acid just in case they get pregnant. This helps prevent birth defects of the spinal cord and brain. And as you think about what kind of birth control is right for you and do your planning, it's important to talk with your neurologist and your gynaecologist. Both of these doctors should be very involved in your care. Each of them needs to know about the drugs or treatments that the other prescribes.
Networking

Here for YOU
Need Help, or just want to find out more?
Please “like us” so that others know we’re here for them too!

Visit, www.epilepsycentre.org.au
or Call 1300 850 081

THE EPILEPSY CENTRE

Networking

In Memory

Saturday 7th June was a day to remember, as The Epilepsy Centre proudly presented Sandy’s Big Day Out, in loving memory of Sandy who sadly lost his life to epilepsy. This day was dedicated to his memory and to those affected by epilepsy.

It doesn’t matter how much time goes by, you never forget losing someone that you love. For so many of the families that we assist, it’s something that they are forced to think about every day. The loved ones they have lost, the possibility of one day losing someone that they love to epilepsy.

Children and families of The Epilepsy Centre attended The Beach House at Glenelg. Refreshments were provided, and a fabulous light lunch was held where we all took an opportunity to contemplate upon Sandy’s memory and those no longer with us.

On behalf of The Epilepsy Centre, we wish to thank Sandy’s family for turning this dream into a reality. You have become a touchstone to so many parents affected by epilepsy. Through our vision of Sandy’s Safari, it is an opportunity to honour Sandy’s memory as well as all those affected by epilepsy.
About 10% of the population will have epilepsy at some stage of their life. Most diagnoses are in children and older people. Whether your school knows of a student with epilepsy or not, there is a high chance within the school community that epilepsy could be part of the life of parents, staff, grandparents or friends. Being Epilepsy Aware is important and relevant for all schools.

An Epilepsy Aware school is one that understands epilepsy and puts in place inclusive practices to support a student with epilepsy to achieve their academic potential and develop positive social relationships. It takes a whole school approach working with the student with epilepsy, other students, teachers, staff, parents and the school community. Broadly, there are three key goals for schools to strive to achieve:

- All students with epilepsy have a current Epilepsy Management Plan and policies and procedures are in place to ensure inclusive and safe practices
- School staff understand the possible impact of epilepsy on students – attend training from The Epilepsy Centre (and emergency medication administration when indicated)
- Educate students about epilepsy

To find out exactly how your school can be an Epilepsy Aware School, or to update your training, contact The Epilepsy Centre on 1300 850 081

Look after your family first

Then, remember The Epilepsy Centre in your Will and estate plans or make a donation and help transform lives.

Call 1300 850 081 and leave your mark on the future