

Epilepsia

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Dear Epilife Readers,

Earlier this fall, those of you on the agency's mailing list received announcements and pledge cards in the mail promoting ESNI's annual fundraising event. I wish to extend my most sincere appreciation to those of you who have already responded. Some of you may have put the pledge aside with the intention of giving later. I would like to take this time to encourage you to support this endeavor now.

ESNI is a small organization, highly dependent upon the generosity of our clientele and readers. This year your contribution is especially important to us. Earlier this year, ESNI received notice that our program would no longer receive funding from a long-standing United Way source. I can't tell you how stunned we were upon hearing this! It is important to note the cessation of funding was in no way a reflection of the services we deliver at ESNI, nor was ESNI singled out. Several community providers who were similarly affected have difficult decisions to make in the coming months.

ESNI's Board of Directors passed a deficit budget as a result of this decision. There will be no decrease in personnel or service delivery. We already operate on a very tight budget.

ESNI needs your help to overcome this fiscal obstacle. Please support the marathon event. Yes, you will receive ESNI's annual solicitation in December requesting support for EPILIFE publishing expenses, but marathon support is specifically designated for programs and services to those affected by epilepsy in north suburban Cook and Lake counties.

ESNI is a one of a kind place. We are the ONLY agency in Chicagoland offering psychotherapy for those with a primary diagnosis of epilepsy. ESNI's program is accredited, state-supported and unique.

Please help us maintain the quality of service to which you are accustomed.

Thank you!



Maureen Galassie
Executive Director, ESNI

GENES & SEIZURES: A Complicated Interaction

By Beryl Lieff Benderly
EpilepsyUSA, 2006

At least as far back as Hippocrates, observers have suggested epilepsy is inherited. About 400 B.C., the Greek physician who is said to have founded Western medicine wrote that epilepsy's "origin is hereditary."

In recent years, modern genetic research has proven that his basic conclusion about heredity was right, at least for several types of epilepsy. Researchers have also begun mapping out a molecular basis for understanding how some epilepsies are transmitted and how they may some day be treated.

A specific epileptic syndrome was first mapped to a chromosome location in 1989. About a dozen genes known to relate to epilepsy have been found. But scientists have long known numerous forms of epilepsy appear to run in

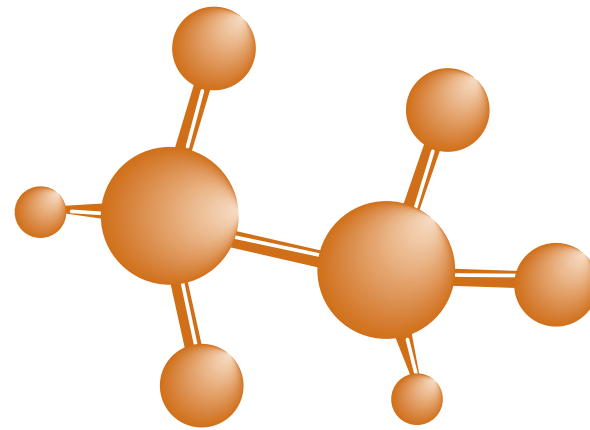
families, strongly suggesting genetic influence.

As research advances, the picture of the relationship between genes and epilepsy is becoming more complex because epilepsy is not one condition but an array of different disorders of the brain with a variety of causes. Genetic research has already produced major insights into the processes underlying some kinds of seizures, as well as promising new approaches in treatment that could lead to important advances.



Origins of Risk

Genetics cannot explain all types of epilepsy. Experts classify about 25% of cases as symptomatic, or resulting from known damage to the brain. Common causes include traumatic accidents, mishaps during pregnancy or birth, infectious diseases (such as



meningitis), abnormal blood sugar levels (such as hypoglycemia), tumors, strokes, and certain types of brain malformations. Although the effects of some infectious diseases can include seizures, epilepsy is not, in itself, contagious.

A number of symptomatic epilepsies occur as a result of disorders that cause widespread abnormalities of the brain. Seizures are only symptoms of these larger syndromes affecting many aspects of the individual's cognitive or neurological functions.

Gene abnormalities already identified, though very important scientifically, account for under 1% of epilepsy cases. The causes of the remaining

3/4 of cases remain unknown, but experts believe genetics play a role in many of them.

Some experts divide these undetermined cases into two categories: idiopathic, or resulting from an unknown cause, often thought to be genetic; and cryptogenic, or resulting from a hidden cause, often thought to be related to some underlying condition. Other authorities reject this distinction as being of little use.

The risk to an affected person's family members varies markedly depending on the epilepsy's cause. Relatives of those with symptomatic epilepsies caused by known trauma, such as an accident or stroke, are no more likely to develop epilepsy than are members of the general population, who face a risk of only about 1%-2%.

When the cause of a primary epilepsy cannot be pinned down to a particular injury, the risk of relatives developing epilepsy is higher than that of the general public. Still, in more than 90% of such cases,

no one in the family has the disorder; in this case, the epilepsy is called sporadic. When multiple family members have epilepsy, it is called familial. The risk to relatives is generally higher in familial rather than sporadic epilepsies.

Children of parents with epilepsy generally have a 10%-12% risk of developing epilepsy; the risk is higher when the affected parent is the mother. Siblings of persons with epilepsy of unknown origin run a 4%-8% risk, except for identical twins, whose risks are much higher. The more closely related the family members with epilepsy are, the greater the risk that other close relatives will develop it, too.

Relatives face a much lower risk if the onset of the seizures occurs after age 35 than in childhood or adolescence. If the seizures are generalized, immediate family members run a higher risk than if the seizures are partial or focal.



Understanding Genetics

Several factors further com-

plicate the genetic picture. Epilepsy is not a single disorder, but a collection of syndromes and conditions that involve seizures of various types and doubtlessly arise from a number of different causes. One expert, Ruth Ottman, Ph.D., a professor of epidemiology at Columbia University (NY) and a member of the Epilepsy Foundation's professional advisory board, described a seizure as "a very general manifestation...like sneezing." Just as sneezes can result from allergies, air pollution, a mild cold or a grave disease, "a lot of things could cause you to have a seizure." In the great majority of cases thought to result at least in part from inheritance, researchers have not yet found the specific gene or genes responsible.

A second complication is that among the genes found, the effects on various individuals can vary considerably. Epilepsies of the same type may be more or less severe. Nor is the correspondence between genetics and symptoms necessarily exact.

People with the same genetic abnormality may have different types of seizures. People with the same form of epilepsy may have different genetics.

The two major categories of apparently genetic epilepsy correspond to different patterns of inheritance. The 1% associated with currently known genes generally follow a pattern called simple or Mendelian inheritance. An abnormality in a single gene is responsible for a disorder passed by either parent to some or all of their children in a clearly discernible way. The other category follows a pattern known as complex inheritance. The disorder results from abnormalities in a number of genes from either parent, as well as environmental forces. The patterns are often obscure.

A third category of genetic disorders results from defects in genes contained in structures within the cells called mitochondria. Individuals inherit mitochondrial genes from their mothers only. Disorders can also result from changes that affect the chromosomes,

the cellular structures that contain the genes. Types of epilepsy can also occur from genetic changes that take place on their own (de novo) within affected individuals themselves.

Epilepsies caused by chromosomal abnormalities are generally parts of larger syndromes, such as Down syndrome and Wolf-Hirshhorn syndrome. An epilepsy type caused by a de novo single mutation occurring in the individual is severe myoclonic epilepsy of infancy, a rare and grave syndrome.



Future Directions

The epilepsy genes thus far identified have a special significance to science. Funding the functions they serve in the brain has provided new insights into mechanisms that can produce seizures. Some of the known genes affect the ability of cells to migrate to the proper locations during early brain development. Others affect the form of structures known as ion channels that act as gates and

have a vital role in passing signals among the cells of the brain. Each known ion channel mutation creates a particular defect in a specific type of channel without harming the structure of the rest of the cell. Abnormal functioning of these molecular portals is therefore fundamental to certain epilepsies. Genes have been identified relating to sodium, calcium and potassium channels in the brain.

Other cellular abnormalities such as errors in breaking down certain proteins and carbohydrates, have also been related to certain epilepsies through identification of the particular gene mutations that cause them.

In addition to increasing researchers' understanding of the processes that produce seizures, genetics may lead to better treatments by revealing defects that are promising targets for new or improved treatments. More than 2,000 years after Hippocrates, the hope of understanding the various types of epilepsy is beginning to come true!

Epilepsy Surgery Yields Long-Term Successes

Mayo Clinic, Summer, 2006

In one of the largest epilepsy surgery studies ever conducted, Mayo Clinic researchers have found that 81% of patients with intractable epilepsy become totally or nearly seizure-free six months following epilepsy surgery. Ten years later, 72% remained totally or nearly seizure-free. The findings are published in the *Journal of Neurosurgery*.

“I think this is very exciting because the surgery not only can stop the seizures following the operation, but it can stop them for the long term,” says Gregory Cascino, M.D., Mayo Clinic neurologist and study investigator. Aaron Cohen, M.D., lead study investigator, agrees. “This shows us seizure surgery is durable—it remains effective and safe over time.” Dr. Cohen is a former Mayo Clinic neurosurgical resident who is now a neurosurgical

fellow at the University of Arkansas for Medical Sciences.

Of the over 2.7 million Americans with epilepsy, 30%-40% have intractable epilepsy, i.e. medications alone do not control the seizures, and the seizures have a disabling effect on quality of life. “All other forms of treatment, specifically maximum anticonvulsant treatment, have failed for these patients,” says Fredric Meyer, M.D., chair of Mayo Clinic Department of Neurologic Surgery and study investigator. “Often these patients are on two to three anticonvulsants and are still suffering from intractable epilepsy prior to surgery.”


To conduct this study, the researchers analyzed the cases of 399 consecutive patients who underwent epilepsy surgery to remove the focal region of their diseases in the brain at Mayo Clinic between



1988 and 1996.

There were 214 females and 185 males, and the average age at surgery was 30. Prior to surgery, quality of life is poor for these patients, the Mayo Clinic researchers explain.

“These patients typically can’t drive or use dangerous machinery, have difficulties with employment or can’t work at all or can’t complete their education,” says Dr. Cascino. “They usually would have several seizures per month and may be prone to having spells with loss of consciousness. They can injure themselves from seizures, drown, or have sudden unexpected death due to epilepsy.”



Quality of life typically improves dramatically after surgery, says Dr. Meyer. “If these patients have improved seizure control after surgery, which most of them do, then there is an incredible paradigm shift toward a better quality of life,” he says. “These patients break out from the stigmata of epilepsy and find employment, often drive, and lead a productive life.”

Though epilepsy surgery is not risk free, Dr. Cascino notes that patients with intractable epilepsy are continually at risk

already before surgery. “This is a big operation for a big medical problem,” he says. “These patients are medically, physically and socially affected by their epilepsy.” Dr. Cascino says that it is cost-effective for society when surgery can stop a patient’s seizures, due to the significant number of epilepsy patients who are unemployed or underemployed because of their seizures.

An appropriate candidate for epilepsy surgery is in good health, with the exception of epilepsy, is not responding to

seizure medications; the region of the brain affected by the disease can be pinpointed; and the affected regions of the brain can be safely extracted without damaging the surrounding area. For those who are not surgical candidates, other treatment options are available, says Dr. Cascino. “Patients suffering from epilepsy should seek an evaluation at an epilepsy center and not give up hope,” says Dr. Meyer. “There may be excellent options to help them.”

Studies Offer Clues to Non-Epileptic Seizures

EpilepsyUSA, August 2006

The results of new studies published in the June edition of the journal, *Neurology*, reveal data about psychologically-based seizures that may help clinicians to better treat and diagnose patients.

One study showed that nearly 30% of individuals diagnosed with epilepsy actually have “psychogenic” seizures that are a result not of abnormal electrical activity in the brain, but are rather of psychological origin. One differentiating characteristic is that, where people experiencing psychogenic seizures almost always close their eyes, those with epileptic

seizures do not. People who do not have epilepsy tend not to respond to medications.

Researchers also found that seniors (55 and over) tended to have psychogenic seizures as a result of health-related traumatic experiences related to aging, whereas younger people with psychogenic seizures were more likely to have experienced sexual abuse.

The results of these studies may help physicians and people with seizures to better determine whether the seizures are psychogenic or epilepsy-related, and subsequently guide treatment decisions.

Epilepsy Drug May be Linked to Birth Defect

The epilepsy drug, Lamictal, may increase the chances of having a baby with a cleft lip or palate when taken during the first trimester of pregnancy, U.S. regulators warn. "More research is needed to be sure about this possibly increased chance of cleft lip or palate in babies born to mothers who take Lamictal," the FDA said in an alert posted on its Web site.

Woman who are pregnant or thinking of becoming pregnant should not stop taking Lamictal without talking to a doctor, the FDA said. The drug's generic name is lamotrigine. "Lamictal is used to control seizures or bipolar disorder, serious conditions that need treatment even during pregnancy," the FDA added.

After discussions with Health Canada in August, GlaxoSmithKline (the drug's maker) said the cleft palate

deformity was detected at "an elevated rate" in infants whose mothers took the drug during the first three months of pregnancy, compared with others who were not exposed to the drug.

A spokesman for Glaxo in London said the safety and efficacy profile of Lamictal was well established but, as with all medicines, doctors had to make decisions about prescribing based on the risk/benefit profile of individual patients. "We have been in discussions with FDA for several months on this matter. It is clear that more data is required, as the FDA have said in their advisory" he added.

Lamictal sales totaled \$1.59 billion worldwide last year, with \$1 billion generated in the United States.

Earlier, the drug was approved by the FDA to treat one of the most serious forms of epilepsy, know as tonic-clonic or grand mal seizures in children aged 2 and older as well as for adults.

Lamictal is already approved as an additional therapy to treat partial seizures and seizures associated with Lennox-Gastaut syndrome. It is also approved as a maintenance therapy for adults with bipolar disorder, or manic depression.





Young Adults with Disabilities Can Exercise Voting Rights

By Marcia Kelly
Pacer Center, Minneapolis

For years, your child with a disability has been affected by the government's funding and policy decisions concerning special education, transition programs and more. This fall, if your child is 18 or older, s/he may have the opportunity to influence those decisions by voting in the general election. With more than 200 seats to fill in state and national offices, this election offers all citizens the chance to have an important impact on issues that matter most to them.

As a group, people with disabilities have the same right to vote as other Americans, yet they are 20% less likely to go to the polls than other adults, according to Mai Thor, voting outreach advocate with the Minnesota Disability Law

Center. Part of that reason may be that parents are unaware that their young adult is eligible to participate in elections.

Like all other Americans, your young adult with disabilities may vote if s/he:

- ✓ is a U.S. citizen
- ✓ is 18 or older
- ✓ has lived in the state at least 90 days before the election
- ✓ is not under guardianship that denies the right to vote
- ✓ is not legally incompetent
- ✓ is not a convicted felon deprived of his or her civil rights

"Standards aren't more difficult for people with disabilities than for any other voter," Thor explains. "It's important for people nearing 18 and others who have not voted before to think about registering and not let their disability stop them from voting."

New Drug May Prove Safer

EpilepsyUSA, August, 2006

A potentially new and safe drug treatment for epilepsy has been developed by researchers at the Hebrew University of Jerusalem School of Pharmacy. The new drug is a potential alternative to valproic acid (VPA), which has been a treatment of epilepsy since 1967. VPA, however, has difficult side effects for some patients. Professors Meir Bialer and Boris Yagen have developed the drug, called propylisopropyl acetamide (PID), which demonstrates antiepilepsy activities without the side effects common to VPA.

Bill of Rights for People Living with Epilepsy

EpilepsyUSA, August, 2006

1 People with epilepsy have the right to be treated fairly and with respect

People with epilepsy should be able to live without facing stigma, in a society that understands epilepsy as a medical condition. To correct the lack of knowledge and prevent discrimination, members of the epilepsy community should seek to raise the public dialogue about the condition to educate as wide an audience as possible.

People with epilepsy should be treated fairly, with compassion and understanding by law enforcement officers and other first responders (e.g., emergency medical technicians, firefighters, public transit workers and school

personnel, etc.). First responders should be trained to know the difference between a person who is confused or disoriented because of a seizure or their medications, and a person who is intoxicated. First responders should also be trained to properly administer first aid to a person who is having a seizure and should be able to recognize most types of seizures.

2 People living with epilepsy have the right to receive comprehensive, understandable information about epilepsy and its treatment.

People living with epilepsy and their families should receive easy to understand and up-to-date information about the condition, including

information about treatment options related to their specific seizure type and current research. This information should be given at the initial diagnosis and during the treatment process.

People living with epilepsy are encouraged to ask their doctor to review, explain and interpret their medical tests (e.g., MRI, blood tests, EEG, etc.) with them so they will become more informed about their condition.

Non-English speaking people living with epilepsy are encouraged to ask for information from their health-care provider in their native language.



3

People living with epilepsy have the right and responsibility to be active members of their health-care team.

Many people living with epilepsy work with a healthcare team to treat their condition. They should feel comfortable asking for the qualifications of the people taking care of them.

The healthcare team may include (but is not limited to) primary care doctors, neurologists, epileptologists, nurses, physician's assistants, speech and language pathologists, physical and occupational therapists, social workers, pharmacists and emergency personnel.

People living with epilepsy are encouraged to share their treatment and quality of life goals with their health care team and ask for these to be considered and incorporated into their healthcare plan. They are also encouraged to

ask for accurate information about their condition on an ongoing basis.

People living with epilepsy have the right to seek a second opinion from another doctor and to ask for a copy of their medical records to provide to the new doctor. However, insurance policies vary, so a visit to a new doctor may not be covered for certain individuals.

People living with epilepsy can ask their healthcare providers and insurance company about the financial costs of medical tests and treatments.

4

People living with epilepsy have the right to know and understand all of the treatment options that are available to them.

People living with epilepsy are encouraged to work with their healthcare team so they can make informed decisions about their own care.

People living with epilepsy have the right to ask for information about which medications are appropriate for treatment of their condition and which have been approved by regulatory agencies.

People living with epilepsy have the right to ask for information about any medication prescribed to them, whether it's for day-to-day use or in a hospital setting.

People living with epilepsy can ask if a doctor has changed or a pharmacist has substituted a prescription for a brand name drug with a generic drug.

People living with epilepsy have the right to ask their doctor whether their epilepsy can be treated with a single medication.

People living with epilepsy have the right to ask for information about other available treatments, such as surgical options and diet.

FAMILY ISSUES

People living with epilepsy can access publicly available information about the availability of and eligibility criteria for clinical trials with investigational drugs and other interventions. People interested in clinical trials should talk to their doctors and/or visit www.clinicaltrials.gov.

5 **Special populations of people with epilepsy (e.g., children, adolescents, women of child-bearing age, people with developmental disabilities, the elderly, etc.) have the right to ask about treatment and information appropriate to their specific needs.**

Woman living with epilepsy have the right to ask about the effects of seizures and AEDs on contraception, fertility, family planning, pregnancy, breast feeding and menopause.

Parents have the right to ask which medications and other treatments are appropriate

for use in children with epilepsy.

People living with epilepsy who are taking medications for other conditions (e.g., people with developmental disabilities and the elderly) are encouraged to ask which AEDs are appropriate to take in combination with those medications.

6 **People living with epilepsy have the right to understand all of the options and legal protections for accessing healthcare benefit coverage available to them.**

People living with epilepsy are encouraged to seek easy-to-understand, timely information regarding health plan benefits, exclusions, appeal and appeal denial procedures and to advocate for an appropriate resolution.

People living with epilepsy have the right to ask about the specific rules governing insurance policies and other

health systems (e.g., Medicaid, Veterans Administration, etc.) for the state where they live.

People living with epilepsy have the right to know that in certain situations the Health Insurance Portability and Accountability Act of 1996 (HIPAA) may provide certain protections in regards to pre-existing conditions. For more information visit www.cms.hhs.gov/hipaa.

7 **People with epilepsy have the right to know that healthcare providers will hold personal and medical information confidential.**

Maintaining patient confidentiality is a basic responsibility and ethical obligation of healthcare providers. Patients are entitled to communicate in confidence with their healthcare providers.





8 Children with epilepsy may have the right to receive special education and related services at school; parents have the right to advocate for such services.

Parents of children with epilepsy need to know that there are laws in place designed to protect the rights of children with disabilities in school. Epilepsy may or may not be classified as a disability, depending on a number of factors that vary among individuals.

Adult students in post-secondary education programs that receive federal funding may also be entitled to accommodations.

People living with epilepsy and parents of young children with epilepsy are encouraged to alert teachers and other staff to their condition and any medications they may be taking. Both epilepsy and AEDs can have a pronounced

effect on a person's cognitive abilities, thus affecting performance in school. Additionally, schools should be encouraged to offer training to their staff on how to properly administer first aid to a person who is having a seizure and properly respond to other issues associated with epilepsy. (If you believe your child could benefit from such a service, please contact Maureen or Jill at ESNI to arrange an in-service at your child's school.)

9 People with epilepsy have the right to know that there are federal and state laws that may provide them with protections in the workplace.

People with epilepsy need to know that there are many federal and state laws in place that may provide them with protections in the workplace, such as the Americans with Disabilities Act (ADA). To learn more about these laws, contact your state Equal

Employment Opportunity Commission or visit www.eeoc.gov.

10 People with epilepsy have the right to access help and support that will assist them in making informed decisions about living with epilepsy.

Epilepsy support agencies have up-to-date educational materials on epilepsy and are poised to help patients, family members and others concerned about epilepsy to understand the condition, its treatment options, and its effect on quality of life.

Epilepsy support agencies provide information on local comprehensive epilepsy centers and social support services to help each person and family living with epilepsy access the best care and support available.





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Epilepsy can be a difficult road to travel...

...It need not be traveled alone

Counseling

ESNI offers psychological counseling to all persons whose lives are touched by epilepsy. ESNI clients come to understand that epilepsy is not a disease, but rather a brain disorder. They learn why seizures occur, how medical treatment acts to control them, and to what extent this disorder will affect their lives.

All ESNI counselors are cross-trained in standard counseling techniques and are skilled in addressing the special psychosocial problems associated with epilepsy.

Support & Discussion Groups

Shared experiences are a great source of strength and encouragement. In peer, parent support and discussion groups led by ESNI counselors, the participants come to understand that the prejudices and other epilepsy-related problems they encounter in everyday life are neither new nor unique to them alone. They learn that, for thousands of years, these same problems have been experienced by countless others with epilepsy. More importantly, they learn how to cope and successfully resolve them.

Information & Referral

A directory is available to persons seeking the services of an area neurologist. The directory is available without charge and is updated every year.

Many problems that persons with epilepsy face are unique. ESNI counsels and guides clients in areas as diverse as special housing, employment programs, and procurement of insurance. A counselor/client relationship is carefully built and zealously maintained for as long as a need exists.

Community Education

ESNI provides a full range of informational and educational literature on epilepsy. It is available, without charge, to individuals, school nurses, teachers, libraries, or any interested person.

ESNI maintains pamphlet files on epilepsy at all public libraries in its service area.

Community education programs featuring neurologists speaking on medical aspects of epilepsy are presented to the public without charge at area hospitals. Professional in-services on epilepsy are provided to school staffs, teachers, employers

and staff of other human services agencies by skilled ESNI counselors. ESNI serves as an exhibitor at health fairs and similar events.

Vocational Assistance

Persons with epilepsy often encounter unexpected obstacles in the job market. ESNI provides counseling and, when necessary, referral to special community resources such as sheltered workshops, the Department of Rehabilitation Services, the Private Industry Council, etc. Through ongoing support, clients are able to maximize their potential, and achieve realistic employment goals.

Advocacy

ESNI is prepared to vigorously intercede on behalf of clients whenever and wherever needed. This includes employers, HMO organizations, schools, insurance providers, as well as national, state, county and community government agencies.

**Call ESNI at
847-433-8960**



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