❖ Winter 2005/2006 ❖
Volume 17
www.nyufaces.org

faces

FINDING A **CURE** FOR EPILEPSY & SEIZURES

The mission of FACES is to improve the quality of life for all people affected by epilepsy through research, education, awareness, and community-building events.

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The FACES newsletter is edited by Mark Farley and Melissa Murphy with support from Daniel Miles, M.D. and Ruben Kuzniecky, M.D.

NYU Medical Center

School of Medicine
New York University

The S.E.E. Program at NYU Medical Center

By Dr. Robert J. Mittan

Here is a question you need to ask yourself. Why should I spend my whole weekend listening to some funny looking doctor talk about epilepsy?

If you are a person with epilepsy, a family member, or parent of a child with epilepsy, listening to that funny looking doctor could change your life and the life of your family. On March 18-19, 2006 FACES and the New York University Comprehensive Epilepsy Program will be presenting Robert J. Mittan, Ph.D. and the Seizures and Epilepsy Education (S.E.E.) program. S.E.E. is an award-winning seminar of help and hope for anyone affected by epilepsy.

What can listening do for you? Many people are waiting for a cure – but what if that cure already exists? For many patients and families, what they don't know about epilepsy is responsible for uncontrolled seizures. The following is a true story.

Robin and Wayne lived in the far northwest corner of North Dakota. Their four-year-old daughter Ashley was having up to 40 convulsive seizures a day. After a time, the neurologist treating Ashley told Robin to get used to the seizures because this was how Ashley's life was going to be. (Have you ever been told something similar?)

Robin heard through a family member about the S.E.E. program. Robin and Wayne had been struggling with seizures for years, so they thought they knew everything there was to know about epilepsy. Out of sheer desperation, they decided to come to the S.E.E. program anyway.

Attending the program wasn't easy. They had to find someone willing to baby sit a four-year-old having 40 seizures a day for four days. Most parents would have given up right there, but not Robin and Wayne. They needed the sitter for four days because the nearest S.E.E. program was a 12-hour drive from their home. They needed an extra day for travel each way.

The S.E.E. program surprised them. Within minutes they were astonished to find how little they actually knew despite years of medical treatments. They learned about the many kinds of epilepsy, the latest diagnostic procedures, and about a whole range of treatments. They learned about medications and about controlling side effects. Most of all they discovered there were things they could do right now to help Ashley.

On the long drive home they worked out a plan. Now that they understood how com-

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Dr. Mittan presenting the S.E.E. program.

Recent Epilepsy News

Epilepsy Surgery Helps Ease Depression and Anxiety, According to Study

Epilepsy surgery can significantly improve the depression and anxiety that are common among people whose epilepsy can't be controlled by medication, a new study finds. The study of 360 people at seven epilepsy centers in the United States found that rates of anxiety and depression disorders declined more than 50 percent after up to two years following epilepsy surgery. Patients who were seizure-free after surgery were most likely to no longer experience anxiety and depression. Researchers aren't sure why depression and anxiety improve following epilepsy surgery. "Removing dysfunctional areas of the brain may be critical," study author Dr. Orrin Devinsky stated. "Whether the benefit comes from reducing or eliminating seizures or other effects is not clear. People may also be benefiting from an improved sense of self-control, less fear of seizures, higher activity levels and a lessened burden from medications." Study findings appear in the December 13th edition of *Neurology.*

Trileptal FDA Approved for Adjunctive Therapy in Younger Children

The FDA has approved an expanded indication for oxcarbazepine (Trileptal tablets and oral solution, made by Novartis Pharmaceuticals), allowing its use as adjunctive therapy for partial seizures in children with epilepsy aged 2 to 4 years. The approval was based on data from a multicenter study in 238 pediatric patients, showing that the addition of high-dose oxcarbazepine (60 mg/kg/d) to 1 or 2 antiepileptic drugs (AEDs) significantly reduced partial seizures compared with use of a lower dose (10 mg/kg/d). Oxcarbazepine was previously approved for use as monotherapy or adjunctive therapy for partial seizures in epileptic adults and children aged 4 years and older.

Studies Reveal Ketogenic Diet Methods

Although the high-fat, calorie-restricted ketogenic diet (KD) has long been used to prevent childhood epileptic seizures that are unresponsive to drugs, physicians have not really understood exactly why the diet works. New studies by a research team at Emory University School of Medicine show that the diet alters genes involved in energy metabolism in the brain, which in turn helps stabilize the function of neurons exposed to the challenges of epileptic seizures. This knowledge could help scientists identify specific molecular or genetic targets and lead to more effective drug treatments for epilepsy and brain damage.

Women With Epilepsy Not Informed on Health Issues

A new poll conducted among women with epilepsy found that women aren't receiving enough information about epilepsy and its effects on key issues regarded as being important to women. The online poll, found at www.iVillage.com/epilepsy, surveyed 440 women age 18 or over who indicated taking antiepileptic drugs (AEDs). The poll also showed that education is needed regarding these medications and how they affect women's lives. Other surprising results showed that 82 percent of women thought themselves to be "less than knowledgeable" about a broad range of health issues related to epilepsy and AEDs. FACES' own Dr. Blanca Vazquez served as epilepsy expert for this poll.❖

Epilepsy & Autism

By Josiane LaJoie, M.D.

The autistic spectrum disorders (ASD) include conditions such as Autistic Disorder, Asperger's Syndrome, Pervasive Developmental Disorder, and Sensory Integration Disorder. Individuals affected by these conditions have impairments in language and communication skills, sociability, and behavioral flexibility. These patients may also exhibit repetitive behaviors. Both autism and epilepsy are both neurological conditions at their root. Seizures occur when there is excessive firing of brain cells that lead to a clinical change in an individual. Epilepsy is defined as two or more unprovoked seizures separated by at least 24 hours. There are common mechanisms involving neuroanatomical and neurochemical systems that can account for both disorders.

There are numerous causes for both conditions. In many cases, an exact cause for the individual's symptoms cannot be determined. Frequently, a diagnosable condition can be the cause of both epilepsy and autism (for example, Tuberous Sclerosis). Genetics do play a role, with usually more than one gene involved. Genetic patterns of both conditions are complex in the way these genes are inherited and expressed; thus they often do not follow typical inheritance patterns. These factors make it more difficult for researchers to identify the exact genes responsible for these disorders.

Previous research has shown that there is an increased risk of seizures in people with autism. Epilepsy occurs in 30% of patients with autism. Some studies report that individuals with autism and severe cognitive impairments and/or motor difficulties are at a higher risk. This increased risk can also be present in autistic children with significant receptive and expressive language disabilities as opposed to those children whose language is less affected.

Electroencephalogram (EEG) abnormalities can also be seen in approximately 30% of autistic individuals. These abnormalities tend to be focal in nature, but generalized changes can also occur. Abnormal EEGs are more likely to occur in individuals with symptoms suggestive of seizures (e.g. staring, convulsions, language regression). All seizure types can be associated with autism. Initial presentation of seizures can begin at any age but are most likely to first occur either before the age of 5 or after 10 years of age. In the latter group, hormonal changes associated with puberty may be an important factor. This phenomenon can also be seen in patients with epilepsy who do not have autism.

One third of parents report a regression of language in children with autism. This typically occurs between 18-24 months of age. The cause of this regression is unknown and controversial. This regression can sometimes be associated with electroencephalographic abnormalities during sleep known as electrical status epilepticus of sleep (ESES). In these children prolonged Video EEG can be diagnostic. For those patients whose EEG abnormalities are seen diffusely, magnetoencephalography (MEG) can sometimes be helpful in localizing the epileptic focus.

The treatment of seizures in patients with autism does not differ from the treatment of patients without autism. The goal is to eliminate seizures without side effects. In patients with autism, it is also important to attempt to improve behavioral impairments which can be difficult. In patients with ESES, an additional goal is to reduce or eliminate the epileptiform activity with the hope of improving the patient's language skills. Treatment of seizures primarily involves the use of anti-seizure medications. All available medications have been used in the treatment of seizures, but there have been few controlled trials using these medications in the autistic population. In addition, Valproic acid and Lamotrigine have been shown to improve the behavioral aspects of autism due to their mood-stabilizing properties. Thus, the use of these medications not only may lead to improved seizure control but may also have positive effects on the neuronal systems that have an impact on seizures and behavior. In some instances, antiepileptic medication can cause behavioral problems. Treatment must be individualized based on the type and frequency of seizures, taking into account the patient's baseline behavior. For refractory seizures and ESES, additional treatment options include steroids, immune globulin, and in some cases surgery. Vagus Nerve Stimulation (VNS) has also been used in certain individuals.

Patients with autism are at risk for epilepsy. The genetics of both conditions are quite complex. The use of investigative techniques such as EEG with careful clinical evaluation and should be considered in these patients. MEG can also be used in more difficult cases. Treatment usually involves the use of antiepileptic medications, but there are additional options for patients. More studies are needed regarding genetics and the effects of various treatment options. Studies such as these will help enhance diagnostic methods as well as treatment options.❖

The S.E.E. Program at NYU Medical Center… *continued from page 1*

plex epilepsy could be, they knew they needed to take Ashley to an epileptologist. But the solution wasn't just in seeing a specialist; it was in understanding what needed to be done for Ashley with the specialist.

The effort was difficult. Once a week, Robin had to drive 12 hours to bring the seizing Ashley to the epilepsy center. Each appointment required an overnight stay. For the first time Robin and Wayne felt confident making decisions regarding Ashley's care. They knew how to actively participate in Ashley's treatment. Slowly the seizures started to improve. The appointments moved to every two weeks, then every month. Finally, after a little more than a year, Ashley became seizure free.

Last year Ashley graduated as valedictorian of her high school class. Robin still shudders when she thinks about what would have happened to Ashley if she had accepted the original prognosis and if she and Wayne had not attended the S.E.E. program. The cure was already available. The barrier to Ashley's future was not medical, but was what Robin and Wayne did not know about epilepsy. Two days of listening changed all of their lives.

The S.E.E. program is a two-day-long seminar with a unique goal: To make your life better now – starting the moment you walk into the program. S.E.E. answers the questions you have had for years, and provides you with the comprehensive information you must have to get the best seizure control possible with the fewest side effects from treatment. S.E.E. opens the door to new treatments, to new diagnostic procedures, and to new things you can do in your daily life to take control of seizures. Not everyone will become seizure free like Ashley, but don't you deserve the chance?

For many, beating the seizures is only a part of the problem. Epilepsy breeds fear. Fear is what makes life so hard day by day. Fear of when the next seizure might occur, fear that the seizures could cause brain damage – or worse. When you think about it, most people with epilepsy spend 99% of their time not having seizures. So why is epilepsy such an exhausting emotional challenge? Fear is the 800 lb. gorilla sitting on your kitchen table, staring you in the face every day.

The S.E.E. program takes that fear head on. You will learn how realistic those fears are. More important, you learn how to put that gorilla back in its cage and live a life free from crippling fear. That is not something you get in an ordinary epilepsy program.

I know people affected by epilepsy often feel they are a failure for not coping better. I know because I talk with thousands of families every year. The problem is not that you are somehow inadequate; the problem is epilepsy does not come with an owner's manual. And kids with epilepsy don't come with parenting manuals. Coping with epilepsy or raising a child with epilepsy requires knowledge and certain key skills.

It turns out the knowledge and skills needed to cope with epilepsy are surprisingly easy to learn. All you need is a teacher. That is what the S.E.E. program is – a teacher to show you how to master the medical, emotional, family, and social challenges of epilepsy. You'll find it is like riding a bike. Once you have it, coping and moving past epilepsy becomes easy to do.

This is the first time in 20 years that the S.E.E. program will be presented at NYU. Don't miss it. To learn more about S.E.E., go to www.theseeprogram.com. While you are there, you can also find out why Dr. Mittan is that funny looking doctor. You can also check out what past participants say about S.E.E.❖

Seizures and Epilepsy Education (S.E.E.) program

S.E.E. was created for people with epilepsy, their family members, and for parents of children with epilepsy. S.E.E. is for people who want to take control over seizures, their treatment, and their day-to-day lives. S.E.E. is for people who want answers. It is a two-day seminar that includes video, demonstrations, graphics and animations, and stories of how real-life people overcame seizures.

When: March 18 & 19, 2006 from 8:30AM to 6PM each day.

Where: NYU Medical Center, Farkas Auditorium, 550 First Avenue (at 32nd Street), NYC.

Costs are $40 per person and $75 for a family of up to 4 persons.

To register, visit http://FACES.kintera.org/SEE or call the FACES office at 212.871.0245.

Had a look at our website lately?

The FACES website has been newly redesigned and it's the best way to keep your finger on the pulse of what's going on at FACES. Take a look at www.nyufaces.org today and let us know what you think.

NYU Medical Center Comprehensive EpilepsyCenter & faces
FINDING A CURE FOR EPILEPSY & SEIZURES

are proud to sponsor the second annual

Evening Epilepsy Lecture Series for Parents & Adults

Doctors at NYU will personally conduct the lectures and take time to answer questions following each presentation.

Monday, February 27th

Daniel Miles, MD

Topic: When is Epilepsy Surgery Appropriate for Children?

Monday, March 27th

Arthur Grant, MD

Topic: The Impact of Epilepsy on Memory and Thinking

Monday, June 12th

Josiane LaJoie, MD

Topic: Choosing the Right AED for Your Child

Monday, August 28th

Katherine Mortati, MD

Topic: AED Benefits and Side Effects

Monday, November 13th

Alcibiades Rodriguez, MD

Topic: Sleep and Epilepsy

Each lecture will be audiotaped and available on the FACES website. There is no charge to attend the Evening Epilepsy Lecture Series, but you must register to attend by visiting http://FACES.kintera.org/EveLecture2006 or call the FACES office at 212.871.0245.

Sleep Case Studies

By Alcibiades J. Rodriguez, M.D.

Adequate amounts and quality of sleep are essential components in the treatment of patients with epilepsy. Sleep deprivation is known to increase epileptogenic activity and provoke seizures. If the quality of sleep is disrupted due to a sleep disorder, then seizure control may worsen. Studies have shown that treatment of Obstructive Sleep Apnea (OSA), a condition in which there is a transient obstruction of the upper airway during sleep, improves seizure control. Other sleep disorders in patients with epilepsy have not been studied extensively.

Three cases in which the treatment of a sleep disorder may improve quality of life in patients with epilepsy will be presented.

Case 1

A six year-old boy with a history of epilepsy presented with complaints of very restless sleep. He had a history of moving frequently and kicking his legs during sleep as well as sleeping with the mouth open and sweating at night. Approximately two times per week he had episodes of waking up in the middle of the night scared with an increased heart rate. These episodes occurred during the first part of the night. In the morning it was difficult to wake him up and he became very hyperactive as the day progressed. The parents were concerned that the patient was having seizures at night. He was taking several medications, including topiramate, valproate, phenobarbital and clonidine.

A Polysomnogram (PSG), which is a sleep exam that measures multiple variables, including Electroencephalogram (EEG), respiratory effort, leg movements, oxygen saturation in the blood and heart rate was ordered. During this study it was confirmed that the patient was very restless at night mostly related to leg kicking or the disorder, Periodic Legs Movements of Sleep (PLMS). The patient had no evidence of respiratory problems and was not having nocturnal seizures. PLMS is strongly related to low serum Ferritin levels. Ferritin is a protein related to total body iron stores. The patient had a mildly decreased Ferritin level and iron supplementation loss began.

After three months of iron replacement his Ferritin level increased and he is sleeping quietly and through the night. He no longer experiences episodes of night terrors (where he woke up scared with increased heart rate). He is not hyperactive at school and seizures are under control.

Case 2

Fifty six year-old woman with epilepsy reported difficulty falling asleep for approximately 4 years. The next day she would feel tired and frequently experience morning headaches. Her seizures were under relatively good control. She was concerned that her lack of sleep could precipitate a seizure. It used to take her up to 2 hours to fall asleep. She mentioned an "urge" to move her legs at night or when sitting quietly. Moving her legs made her feel better. He husband also mentioned that she was "kicking" her legs frequently at night. She tried several medications in order to help her sleep, but with no success. She was taking Lamotrigine for her epilepsy. Lamotrigine may cause difficulties in falling asleep, however she needed this medication to control her seizures. A diagnostic PSG showed evidence of very frequent Periodic Legs Movements of Sleep (PLMS). She was diagnosed with Restless Legs Syndrome (RLS) and PLMS. These two problems are a type of movement disorder related to sleep. She was placed on a dopamine agonist medication, which is the current treatment of choice for Restless Legs Syndrome (RLS) and Periodic Legs Movements of Sleep (PLMS). Since the treatment was initiated she has had no problems falling asleep and both her daytime tiredness and morning headaches have been resolved.

Case 3

A twenty seven year-old woman with Down's syndrome and epilepsy arrived for evaluation of excessive daytime sleepiness. The patient snored loudly and slept restlessly. She slept with the mouth open and her upper airway was very narrow. Her weight increased over the last few months before her visit. Her seizures were under control, but most occurred at night. A diagnostic PSG revealed evidence of Obstructive Sleep Apnea (OSA). We recommended the use of a CPAP (continuous positive airway pressure) device in order to correct this problem. This machine acts as a pneumatic splint in order to open her upper airway at night. She now sleeps better and feels more alert during the day.

These three cases illustrate how little changes can make huge differences in the lives of patients. It should not be assumed that sleep problems are related to seizures or medications. Patients with epilepsy have the same sleep problems as patients without epilepsy. A careful and thorough evaluation should be obtained from a qualified Sleep Medicine specialist.❖

Alcibiades J. Rodriguez, M.D.
Diplomate, American Board of Sleep Medicine
New York Sleep Institute
NYU Comprehensive Epilepsy Center
Assistant Professor of Neurology
New York University School of Medicine

NEW YORK
SLEEP INSTITUTE
724 Second Avenue • New York, NY 10016
Telephone: 212.871.0227 • Fax: 212.871.1827
www.nysleepinstitute.com

FACES FALL EVENTS

FACES Game Day

On Sunday, October 2nd families enjoyed a fun-filled time at the Field House at Chelsea Piers. Guests enjoyed carnival games, soccer, basketball, arts and crafts, batting cages, gymnastics, rock climbing and remote controlled race cars. There was also face painting and a magic show! Many thanks to Sharon Perhac, Michelle Aguas, Sylvia Rothbein and all volunteers who helped make the event a wonderful success.

Kids enjoyed the opportunity to paint mini pumpkins in the arts and crafts area.

Kids were up to the challenge of the rock climbing walls.

Looney Lenny dazzled everyone with his outstanding magic show.

2005 Epilepsy Symposium

FACES and the NYU Comprehensive Epilepsy Center held their annual conference on Saturday, September 17th at NYU Medical Center in NYC. This free conference featured three simultaneous programs (Adult, Pediatric and Spanish) covering topics of great interest to the epilepsy community. Special thanks to all of our volunteers! All programs were audiotaped and are available for download on the Downloads page of the FACES website at: **www.nyufaces.org**.

2005 NYC Marathon Fundraiser

CEC Director Dr. Orrin Devinsky and pediatric neurosurgeon Dr. Howard Weiner ran and completed the 2005 NYC Marathon on November 6th. Both doctors finished in outstanding times with Dr. Devinsky finishing in a personal best 3 hours, 42 minutes and Dr. Weiner completing the race in 4 hours, 25 minutes. FACES Steering Committee Members organized a fundraiser that yielded more than 60 pledges and raised over $18,000 for FACES research and programs.

Chita Rivera FALL Fundraiser

On Tuesday, November 22nd at 3pm, supporters of FACES were treated to a truly unique Broadway experience at the Schoenfeld Theatre. They enjoyed a final dress rehearsal for Broadway legend Chita Rivera's latest show, "Chita Rivera: The Dancer's Life." The two-time Tony Award winner put on a dazzling display of her life as a dancer and the many exciting circumstances she met along the way. FACES would like to thank Freddie Gershon, Jim Brandeberry and Alan Wasser Associates for donating tickets to this one-of-a-kind event.

faces
FINDING A CURE FOR EPILEPSY & SEIZURES

Gala 2006

Funds raised by the FACES Gala will support Epilepsy Research, FACES Events, Education Programs & enhance the clinical care of epilepsy patients.

What

Silent Auction, Dinner & Live Auction to benefit
Finding a CURE for Epilepsy & Seizures at the NYU Comprehensive Epilepsy Center

Where

Pier Sixty at Chelsea Piers

When

Monday, March 13, 2006
6:30 pm Cocktails & Silent Auction • 8:00 pm Dinner & Live Auction

Emcee: Stephen Colbert
of Comedy Central's *The Daily Show & The Colbert Report*

Honoree: Stone Phillips

Special Guest: Chanda Gunn, goalie for the 2006 US Olympic Ice Hockey Team

Attire: Business

Ticket & Table Prices:

$100,000	Vice Chairmen includes a table of 10 & a Platinum journal page
$50,000	Leadership Table includes a table of 10 & a Gold journal page
$25,000	Benefactor Table includes a table of 10 & a Silver journal page
$15,000	Patron Table includes a table of 10 & a Bronze journal page
$10,000	Sponsor Table includes a table of 10 & a Black & White journal page
$2,500	Benefactor Ticket (each)
$1,000	Patron Ticket (each)
$750	Sponsor Ticket (each)

We need your help!

Volunteers are needed to:

- Sell tickets, tables and journal ads.
- Solicit auction items (*dinner gift certificates, sports memorabilia, theatre & sports tickets, wine, jewelry, etc.*)
- Make phone calls to prior donors and supporters.
- Help set up the auction on March 13th.
- And much, much more!

For further information, contact the FACES office at 212.871.0245 or email FACESinfo@nyumc.org.

Teamwork is of the Essence *By Mark Farley*

When you think of electroencephalography (EEG) testing, you don't always take time to consider all that goes on behind the actual test. If you could embark on a journey behind closed doors, you would see that there is a great deal of teamwork that ties things together. Webster's dictionary defines teamwork as "work done by several associates with each doing a part but all subordinating personal prominence to the efficiency of the whole." Sounds like an EEG technician's job description.

An EEG machine records electrical activity in the brain through wires connected to electrodes placed on the patient's scalp. The EEG is the most common neurological tool for finding disturbances in the brain. So it's not surprising that the EEG department is one of the busiest units in all of NYU Medical Center. There are four individual labs that make up the EEG Department: the 12th Floor of the Arnold and Marie Schwartz Health Care Center (HCC-12), the 9th Floor of the Tisch Building, the 17th Floor of the Tisch Building and on the 4th Floor of the Rivergate facility at 403 East 34th Street. There are also four portable EEG machines used by the unit to perform EEG testing anytime, anywhere.

EEG techs are responsible for administering EEGs to all epilepsy patients with whom they come into contact. The information collected from this monitoring is vital to the care of the patient. EEG data is one of the most crucial forms of data analyzed by a patient's care team and will help determine the direction of care for the individual. It is because of this that extreme care must be given in the administration of an EEG according to an HCC-12 technician. "It is most important that electrode integrity is maintained during an EEG exam. This data helps determine a person's seizure focus so you want to make sure all electrodes are kept clean and give you the best possible readings."

The Neurodiagnostic lab at NYU is a 24 hour a day, 7 day a week operation. There are a total of 16 employees, including a project assistant in the department split across three shifts. After each shift reports for work, they must take report from the outgoing shift. Then they begin the process of closing and re-opening the individual patient files on the server to save the data collected during the previous shift to minimize the risk of losing long periods of data in the unlikely event of a server crash. Of course, electrodes must be inspected and adjusted if necessary. Any events entered by the nursing staff on a patient's event sheet or data chosen by a physician following his or her review of

the patient's readings for the previous 24 hours must be recorded and archived to CD. At all points during the day, EEG technicians must be ready to administer an EEG test to incoming patients or to those whose referring physicians have requested a test for. Techs interact with patients and their families a great deal and over the years develop nice working relationships with them, which is a welcome part of the job according to another technician. "It feels good to know we're helping our patients. Getting to know them over time they become like part of the family."

An EEG tech's responsibilities are not just limited to epilepsy care. These EEG technicians are on call to all of NYU Medical Center from general neurologists and other physicians who might require a routine EEG or video monitoring, including trips to the operating room for EEG monitoring during different types of brain surgery. So technicians must not only work well with the Epilepsy nursing unit but other units as well. All this interaction with different departments and personalities would certainly lead one to consider EEG technicians the ultimate team players. NYU agreed. The Recognition Program at NYU bestowed its very own Team Award on the EEG Department this past October. The program was established in 1995 to celebrate employees of NYU Medical Center and School of Medicine who have made outstanding contributions to the mission of the Medical Center and demonstrate exceptional performance of hospital service standards.

The EEG team was awarded at a ceremony and reception at NYU Medical Center on December 2nd. Congratulations to the EEG team on their award and outstanding display of teamwork.❖

Pregabalin: A New Drug for Epilepsy

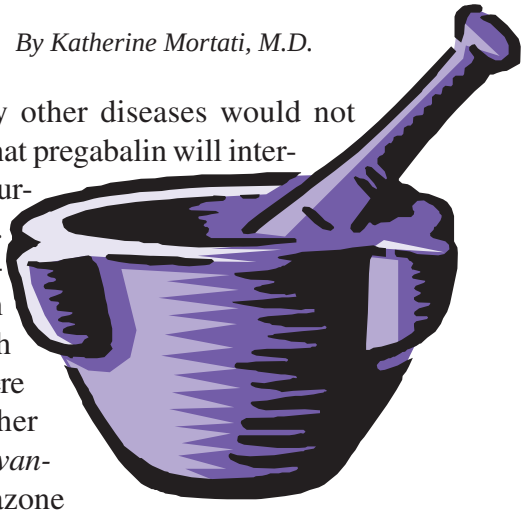
By Katherine Mortati, M.D.

Approved by the Federal Drug Administration (FDA) last year for the treatment of neuropathic pain, pregabalin (*Lyrica*) was just approved by the FDA this past September for add-on therapy in epilepsy. Although many new anti-epileptic drugs (AEDs) have been introduced since 1990, there has been a need for an AED which not only abolishes or reduces seizures, but also is well tolerated by the patient, does not interact with other medications, and is easy to use. Pregabalin might be such a drug.

Pregabalin is a structural analog of the major inhibitory neurotransmitter in the brain, gamma-amino butyric acid or GABA. Like gabapentin (*Neurontin*), another GABA-analog AED, pregabalin does not appear to mimic the action of GABA and the exact mechanism by which it works is poorly understood. Studies have shown that pregabalin binds to calcium channels in the brain, reducing the release of several excitatory neurotransmitters, probably decreasing overall brain excitability and thus contributing to its anti-seizure properties. Also, although direct comparison studies have not been done, pregabalin has been more potent than gabapentin in animal studies, and one would expect similar potency differences in humans. This is important because it suggests that we might be able to use lower doses of pregabalin for similar seizure control, thereby avoiding the side effects associated with elevated doses.

That said, pregabalin has a rather benign side effect profile. As with all drugs that target the brain, dizziness, fatigue, unsteadiness, and headache have been reported, however in less than 10% of patients each. Fewer than 5% of patients have experienced double or blurred vision, tremor, difficulty thinking or weight gain. Most of these symptoms were reported as mild to moderate and usually resolved within the first few weeks of treatment. On another note, pregabalin has been associated with a feeling of euphoria, or a "high." For this reason, it is currently designated as a controlled substance.

Another benefit of pregabalin is its lack of interactions with other drugs, and vice versa. That is to say, pregabalin has not been shown to affect the way other drugs act, and doesn't seem to be acted upon by other drugs. This is especially important in patients with epilepsy, who are often taking multiple drugs, AEDs and non-anticonvulsant drugs alike. Younger women taking oral contraceptives, older women taking hormone replacement therapy, men or women taking medication for blood pressure, high cholesterol, depression, and many other diseases would not have to worry that pregabalin will interfere with their current therapies. However, studies have shown that patients with diabetes who were also taking either rosiglitazone (*Avandia*) or pioglitazone (*Actos*) have experienced a higher incidence of weight gain or swelling compared with those who were not taking these drugs. So make sure to tell your doctor if you or your loved one are taking one of these drugs.



Pregabalin is easy to use! It comes in many dosage capsules (25 mg, 50 mg, 75 mg, 100 mg, 150 mg, 200 mg, 225 mg and 300 mg), allowing one to take as few pills as possible. It can be taken two or three times a day, and starts taking effect in most patients by the second day of treatment. The typical starting dose is 150 mg total per day with a goal dose of 150 mg to 600 mg daily. In patients with renal impairment, these dosages should be lowered, depending on the degree of impairment. Also, if you undergo hemodialysis for kidney disease, you should take a small dose of pregabalin right after you've had dialysis, to replace what dialysis has removed. Your doctor can work with you to find the right daily dose and any supplemental dose you might need, but you should make sure to inform him or her of any kidney conditions you have.

Finally, pregabalin is useful in other conditions. As mentioned above, it is being used in the treatment of neuropathic pain (in particular, in the settings of diabetic peripheral neuropathy or post herpetic neuralgia) with good success. Although it has yet to receive FDA approval for generalized anxiety disorder, studies have shown good success of pregabalin in reducing anxiety. Because patients with epilepsy often have concurrent conditions, including anxiety and pain, pregabalin could be a truly helpful add-on treatment option in these patients for multiple reasons.

If you or your loved one is experiencing difficult to control seizures, whether multiple AEDs have been tried or not, ask your doctor now whether pregabalin could be right for you.❖

DONATIONS

September 2005 - December 2005

Thank you to all of our contributors!

$20,000+
James T. Lee Foundation

$10,000+
George Shields Foundation, Inc

$5,000+
Orrin Devinsky, MD

Patrick Mahon "In honor of Meghan Byrne"

$3,000+
Kim Herbert "To the team of Drs. Devinsky & Doyle"

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$500+
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$300+
Carol & William Gander "In memory of Cheryl Collins"

$200+
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Sea Breeze Graphics

Richard Shane

Janice and Robert Shane "In honor of Sheila & Harvey's 50th Anniversary"

James Zenda

FACES would like to extend a very special thank you to all those who contributed to our NYC Marathon and Fall Fundraisers. Your outpouring of generosity is extremely heart-warming.

Many thanks

for your continued support of FACES.

Some corporations will match your donation!
Check with your company to see if your contribution to FACES can be matched!

Although every donation to FACES is appreciated and important, we regret that in order to keep our newsletter costs to a minimum, we can only acknowledge donations of $200 or more.

UPCOMING EVENTS

Stay tuned to www.nyufaces.org for information on our upcoming events!

Monday, February 27, 2006
Evening Lecture Series:
When is Epilepsy Surgery Appropriate for Children?
see page 5 for more information

Monday, March 13, 2006
FACES Gala 2006
at Chelsea Piers - Pier Sixty
see page 8 for more information

Saturday & Sunday, March 18-19, 2006
S.E.E. Conference
see page 4 for more information

Monday, March 27, 2006
Evening Lecture Series:
The Impact of Epilepsy on Memory & Thinking
see page 5 for more information

E-Newsletter & Alerts

Want to receive an electronic version of our newsletter instead of a paper copy? Send us your name, postal and e-mail addresses and we'll set you up. You also become part of our e-mail announcement list. Along with our website, it's a great way to find out how to register for spontaneous events that don't have time to make it into the newsletter. Send all information to FACESinfo@nyumc.org.

Suggestion Box:

If there are events, programs, newsletter articles, or conference topics you would like FACES to work on, please contact us at FACESinfo@nyumc.org.

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FINDING A CURE FOR EPILEPSY & SEIZURES
724 Second Avenue • New York, NY 10016
212.871.0245 (phone) • 212.871.1823 (fax)
www.nyufaces.org

NYU Comprehensive Epilepsy Center

403 East 34th Street, 4th Floor
212.263.8870 (phone) 212.263.8341 (fax)

Orrin Devinsky, M.D.	212.263.8871
Kenneth Alper, M.D.	212.263.8854
William Barr, Ph.D.	212.263.8317
Meeta Bhatt, M.D.	212.871.0227
Barbara Clayton, RN	212.263.8871
Werner Doyle, M.D.	212.263.8873
John Figueroa, CSW	212.263.8871
Vahid Ghisian, M.D.	718.683.3766
Arthur Grant, M.D., Ph.D.	212.263.8327
Peggy Guinnessey, CTRS	212.263.2644
Eric Halgren, Ph.D.	617.726.5464
Maria Hopkins, RN	212.263.8359
Ruben Kuzniecky, M.D.	212.263.8870
Josiane LaJoie, M.D.	212.263.8318
Daniel Luciano, M.D.	212.263.8853
Nandor Ludvig, M.D., Ph.D.	212.263.2168
Roseanne Mercandetti, RN	212.263.8321
Erica Metzger-Hare, MBA	212.263.8358
Mary Miceli, RN	212.263.8359
Daniel Miles, M.D.	212.263.8318
Chris Morrisson, Ph.D.	212.263.8317
Katherine Mortati, M.D.	212.263.8327
Siddartha Nadkarni, M.D.	212.263.8870
Souhel Najjar, M.D.	212.263.8872
Steven Pacia, M.D.	212.263.8875
Kim Parker, RN, NP	212.263.8871
Alcibiades Rodriguez, M.D.	212.871.0227
Catherine Schevon, M.D., Ph.D.	212.263.8870
Alyson Silverberg, RN, NP	212.263.8873
Anuradha Singh, M.D.	212.263.8311
Rolando Sousa, M.D.	212.604.4206
Pat Traut, RN	212.263.8871
Blanca Vazquez-Santana, M.D.	212.263.8876
Chunmao Wang, Ph.D.	212.263.2257
Howard Weiner, M.D.	212.263.6419
John Wells, M.D.	212.772.6683
Charles Zaroff, Ph.D.	212.263.8317
Melissa Murphy	212.871.0245
Mark Farley	212.871.0245