

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

## CONTENTS

A Multi-Staged Surgical Approach to Treating Tuberous Sclerosis Complex.....	1
Brett Mayerson .....	2
The Chores-for-Charity Program .....	2
The Child with Epilepsy and Disabilities .....	3
FACES Gala .....	5
Research Update.....	6
Evening Epilepsy Lecture Series .....	6
Using Artificial Neural Networks to Study Neural Networks in the Brain.....	7
The Sleep/Epilepsy Correlation, Part II.....	8
The "E" Word .....	9
Donations.....	11
Upcoming Events .....	12
NYU Comprehensive Epilepsy Center.....	12

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



SCHOOL OF MEDICINE  
NEW YORK UNIVERSITY

## A Multi-Staged Surgical Approach to Treating Tuberous Sclerosis Complex

By Chad Carlson, M.D.

Tuberous sclerosis complex (TSC) is a genetic disease associated with developmental delays as well as seizures. Many children with TSC have medically refractory seizures which persist despite trials of multiple antiepileptic medications. These difficult-to-treat seizures can have a negative impact not only on the quality of life for the child and family, but also on the child's continued development.

As in many patients with refractory epilepsy, surgical treatment strategies have been employed for the treatment of epilepsy in TSC. This treatment strategy in TSC was described by the Montreal Neurologic Institute in 1966. Subsequent studies over the past several decades have largely focused on patients with a single, large tuber as the presumed site of seizure onset.

Howard Weiner, M.D., Associate Professor of Neurosurgery and Pediatrics at the New York University (NYU) School of Medicine, along with epileptologists from the NYU Comprehensive Epilepsy Center, recently reported on an innovative surgical treatment approach to refractory epilepsy in patients with TSC. This study, published in the journal *Pediatrics* in 2006 and recently presented at the American Academy of Neurology meeting in San Diego,

reviews the surgical strategy and outcomes in a series of patients over six years.

Dr. Weiner and colleagues noted that, although surgical strategies for the treatment of epilepsy in TSC have been reported as effective in older children with a single seizure focus, this traditional approach does not include the patients that have multiple tubers detected by neuroimaging (e.g. brain scans such as MRI). Dr. Weiner utilized a multi-staged surgical approach to the treatment of these cases.

The first stage is the implantation of electrodes to record brain activity directly from the brain surface (referred to as subdural or intracranial electrodes). After capturing seizures and identifying the target region or regions, the NYU surgical team executes a second surgical stage involving removal of the seizure onset zone. Following resection, electrodes are replaced on the brain surface in some patients. This strategy allows for the identification of remaining seizure onset regions either near or remote from the initial zone. Following another period of data review from the electrodes, the third and final stage of surgery is performed in which the electrodes are removed along with any additional seizure onset regions identified.

*continued on page 4*

## Chair

Orrin Devinsky, M.D.

## Research Coordinator

Melissa Murphy, MSW

## Education Coordinator

Mark Farley

Jeffrey Benowitz

Lori and Paul Billyard

Laurie Block

Jennifer Purdy and Brendan Byrne

Donna Emma & Larry Davis

Judy Ebner

Irina and Roger Erickson

Claudia and Harry Falk

Anna and Jim Fantaci

Colleen and Matthew Farrell

Christine Flaherty

Lisa Garman

Jane and Richard Gilbert

Loretta Glucksman

Kathy and Peter Gogolak

Elaine and Robert Grosinger

Kathyann and Perry Gruss

Peggy Guinnesssey, CTRS

Anne Metcalf and John Hunt

Elizabeth Jarvis

Lynn and Noel Jeffrey

Ruben Kuzniecky, MD

Kathy and Warren Lammert

Randi and Jeffrey Levine

I.D. Luckower

Jean-Anne and Bill Madden

Leila and Richard Mansouri

Amy and Seth Markowitz

Karen and Jeff Mayerson

Daniel Miles, MD

Elizabeth Millstein

Amy and Sasha Moritz

Gigi Mortimer

Nancy and Paul Novograd

Gaye and Lawrence Pecker

Sharon Perhac

Kate Cooney-Picco and Gianni Picco

Leanne Raesener

Joan Regan

Jill and David Robbins

Ulises and Jaimee Sabato

Victor & Mame Kennedy Schragar

Richard Shane

Remi Silverman

Leslie and Phillip Smith

Candice and Steven Stark

Amy Steinman-Cohen

David and Susan Swinghamer

Alice Thorpe

Jen and Bill Townsend

Blanca Vazquez, MD

Leah and Michael Weisberg

Stacey and Neil Weiss

Richard Wheelless

*Donations to FACES support epilepsy research and programs for all persons affected by epilepsy. All donations are tax-deductible. Please e-mail your questions about FACES to [FACESinfo@nyumc.org](mailto:FACESinfo@nyumc.org).*

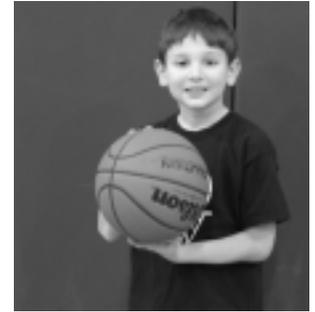
## Brett Mayerson *By Karen and Jeff Mayerson*

Brett Mayerson is an 8 year old who just celebrated his 3-year anniversary of being off all seizure medication and he has been seizure free for 5 years. Today Brett still has some irregular brain waves and suffers with sleeping. Brett currently sees an occupational therapist and speech pathologist to help him with his learning and other school related issues. We are extremely optimistic about Brett's continued success.

Brett currently plays in the 1st & 2nd grade Basketball league at the JCC of Central NJ located in Scotch Plains. After scoring one basket in each of

his first two games he decided it was time to show the world what he can do. In an amaz-

ing performance, he poured in 8 baskets, scoring 16 points in a game. Basketball is helping Brett gain some confidence, which will surely carry through in life. We are so proud of how far Brett has come and felt compelled to share this story with our friends at **FACES**. ❖



*Brett Mayerson*

## The Chores for Charity Program

Chores-For-Charity (CFC) is an exceptional program that allows young people and adults to turn some of the time worked on their part-time, summer or odd job into "time volunteered" by donating a portion of their earnings to **FACES**. The CFC program was begun by Ilana Rothbein in honor of her brother, who suffers from epilepsy, as a way to raise money for epilepsy research.

Many high schools require students to earn community service credits before graduating. The CFC program satisfies these community service credits for most schools so students are able to earn these credits while donating to epilepsy research at the same time.

With the help of participants, corporate sponsors and in-kind donors, the CFC program has raised more than \$20,000 for epilepsy research at **FACES** since its inception. The program has also received attention from notable individuals such as Tony Coelho, primary author of the Americans with Disabilities Act (ADA) and current New Jersey Governor Jon Corzine. Ilana has also won several awards, including the New Jersey Prudential Spirit of Community Award and the President's Volunteer Service Award.

For information on how to participate in the program, visit [www.choresforcharity.com](http://www.choresforcharity.com).

# The Child with Epilepsy and Disabilities

## Effects on Family *By Melissa Murphy, MSW*

The news of a pregnancy is an exciting time for a family. Preparation begins immediately and extends through the nine months. The diagnosis of pediatric epilepsy or a chronic illness affects the entire family. Parents are forced to reevaluate their roles and often feel besieged. It is difficult to know where to turn first. Fortunately, today with the internet, resources and information are available instantaneously. Not only can parents research their child's prognosis, but are able to identify support networks in their area.

Doctor visits, medication, EEGs, and MRIs begin to penetrate the daily activities of the family and the focus lies on the child with epilepsy. The severity of the disorder dictates the time that is taken away from the home and those who reside in it. The first few months after diagnosis can prove to be the most difficult. With a variety of antiepileptic drugs (AEDs), neurologists search for the best medication or combination with the least side effects. During this process, children can experience anything from behavior issues to cognitive challenges. Primarily, the transformation from "child" to "child with epilepsy" can have a significant effect on self image and identity.

Children with epilepsy desire the freedoms other children have. One of the frequent and principle parental concerns is the unpredictability of epilepsy. Parents find themselves being overprotective, which can stifle autonomy. Many children grow to resent this aspect of epilepsy more than anything else. In order to promote healthy growth and self esteem it is helpful if children are encouraged to interact with their peers as much as possible. Although parental concerns are valid, allowing a child to be expressive both physically and emotionally is important.

The transition for parents can be challenging, which is exemplified by the high divorce rate, particularly in the

United States. According to the US Census Bureau 57% of all marriages will end in divorce. There is more marital distress among families with special needs children; therefore the divorce rate for these families is significantly higher. Weighed down with antagonizing emotion in conjunction with an increase in financial stress, anger and frustration are commonly displaced. A relationship is compromised by the lack of time and energy needed to foster a healthy bond. As tension builds, communication suffers and parents find themselves unable to repair the damage that has been done.

Sibling relationships make up a child's first social network. The relationship between siblings sets the stage for future interactions. The unaffected siblings may experience mixed emotions towards their sister or brother. Parents that put emphasis on communication can alleviate potential animosity and fear. Siblings may feel isolated when parents and physicians do not share information about their brothers' or sisters' condition. A small child who witnesses a tonic-clonic seizure can be frightened if they are unsure of what is transpiring. Siblings need information to answer their own questions as well as the questions raised by others. Education can be the catalyst to decrease anxiety and encourage empowerment.

Parents can be proactive by utilizing available information, asking pertinent questions while visiting their neurologist and maximizing the use of local support groups and foundations. Parents getting involved in the community can create a positive network for the family as a whole. Sharing stories enables families to compare notes of what has worked for their child, what hasn't and most importantly, a place to express their fears and concerns. This is not only beneficial for parents, but also for siblings and, of course, the child with epilepsy. ❖

---

*Education can be the catalyst to decrease anxiety and encourage empowerment.*

---

Dr. Weiner and colleagues utilized this approach to first identify the seizure onset zone in patients in whom no clear, single seizure onset zone or tuber could be identified pre-operatively. A total of 25 patients were included in the study with an average age of 4.4 years at the time of surgery. Following surgery, 17 of the 25 children (68%) were seizure free. Six of the 25 (24%) had a 90% or greater reduction in seizures and the remaining 2 children (8%) had a 50%-90% reduction in seizures following surgery. In addition to significant improvements in seizure control, Charles Zaroff, Ph.D., Attending Neuropsychologist at the NYU Comprehensive Epilepsy Center, reported evidence of developmental progress in a group of six patients included in this study. Dr. Zaroff and colleagues recently published this work in *Epileptic Disorders* in 2005.

These studies highlight the continued advances in surgical treatment strategies for patients with refractory seizures TSC. Further investigations to advance analysis of electroencephalographic (EEG or brain wave) data involving quantitative computational techniques are currently underway involving collaboration between physicians at the Columbia Comprehensive Epilepsy Center and the NYU Comprehensive Epilepsy Center. These mathematically based techniques aim to further enhance the ability of physicians to identify the region or regions of the brain contributing to seizure onsets. Ultimately, these and other techniques may further increase the number of patients that are seizure free following epilepsy surgery in TSC and other conditions. ❖

## 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](mailto:FACESinfo@nyumc.org).

### FACES Game Day

Join us on Sunday, October 15th, 2006 from 1:00pm to 4:00pm for a free, fun-filled time for the whole family at the Field House at Chelsea Piers in New York City. Parents, children with epilepsy and their siblings will have exclusive use of the facility including a soccer field, two basketball courts, four batting cages, trampolines, foam pits, rock climbing walls, a toddler gym, games and more. There will also be face painting, balloon animals, and a magic show! Food and drinks will be served. To register, visit <http://FACES.kintera.org/GameDay06>.

### FACES Apartments 'face lift'

The FACES Apartments are free, furnished apartments adjacent to NYU Medical Center for out-of-town families in financial need accompanying a loved one undergoing testing or surgery for epilepsy. Each year we create a wish list of items needed for the apartments that can be purchased by generous friends of FACES. If you would like to browse the list and make a purchase for the apartments, please follow these simple steps:

1. Go to [www.walmart.com](http://www.walmart.com)
2. Click on "Wish List" in the upper right hand corner of the page
3. Under "Find a Wish List" type in "NYU" under first name and "FACES" under last name then click "Find".

Thank you for your support!

The **FACES** Gala 2006 proved another tremendous success, raising more than \$3 million for epilepsy research, clinical programs and events. **FACES** would like to extend their warmest thanks to Gala co-chairs Kate and Gianni Picco and Claudia and Harry Heller Falk for their outstanding vision, Leah and Michael Weisberg and Randi and Jeff Levine for chairing the auctions and event journals and to all attendees, auction donors, contributors and, of course, our wonderful volunteers for their support throughout the event. Special thanks to Stephen Colbert, US Women's Olympic Ice Hockey Team goalie Chanda Gunn, Stone Phillips, Hugh Hildesley, and Andrew Cook for taking part in the evening's ceremonies. Preparations are already underway to make next year's event an even bigger success!

Auction items are currently being accepted for the 2007 event. Please contact Mark Farley at [facesauction@yahoo.com](mailto:facesauction@yahoo.com) for details. ❖



*Hugh Hildesley*



*Art category*



*Stone Phillips receives award*



*Stephen Colbert*



*Special guest Chanda Gunn*

## Research Update *by Ruben Kuzniecky, M.D., Research Director*

As our supporters know, **FACES** directly supports a large number of epilepsy research projects. Some projects are known to our **FACES** family while new projects are beginning. Below is a short update on a few noteworthy projects.

### **Metabolic Neuro Protection with Creatine**

NYU and Yale began a National Institutes of Health (NIH)-sponsored study to look at the effects of creatine, a nutritional supplement, on seizures and metabolism in the brain. Creatine, which is in use by weight lifters for increased muscle strength, has a beneficial effect on muscle and brain metabolism. Preliminary studies show that it may improve brain energy reserves in humans. This might translate into improved seizure control. This trial is open and actively recruiting patients who have temporal lobe epilepsy and continue to experience seizures despite adequate treatment with medications.

Please contact Mary Miceli R.N. at the NYU Epilepsy Center for more information.

### **EPGP: Phenotype/Genotype Analysis of Intractable Epilepsy**

The EPGP (Epilepsy Phenome/Genome Project) consortium has re-submitted a \$30 million grant to NIH to support the largest study to date defining the genome/phenome (genetics and clinical features) correlations in a large number of patients with epilepsy. We have just completed a preliminary recruitment study which shows that the consortium will be able to recruit the needed patients for the study. We are expecting the NIH to review our grant application in the coming months. **FACES** has supported the planning portion for the past three years.

### **The Effects of Keppra on Brain GABA Activity**

We've initiated a new investigation on the effects of Keppra (Levetiracetam) on GABA levels in the brain. Keppra is a well-known anti-convulsant drug that has few side effects and has a complex mechanism of action. Many anti-convulsant drugs can affect brain neurotransmitters but it is unknown whether Keppra has any effects on the function of GABA, the brain's main inhibitory neurotransmitter. This study involves normal volunteers and patients with epilepsy using a

powerful MRI machine to determine Keppra's effect on GABA levels.

If you are interested in this study please send an e-mail to: [epilepsyresearch@med.nyu.edu](mailto:epilepsyresearch@med.nyu.edu)

### **Hybrid Neural Prosthesis For Treatment of Focal Epilepsy**

Good progress is being made on the HNP project. A recent paper by Dr. Ludvig clearly shows that local microinjections of anti-convulsant drugs can stop seizures in animals. This important development shows that a number of drugs can be used to stop seizures by directly infusing them into the brain. Ongoing studies with other drugs and compounds are presently underway. In addition, the first human studies began this spring. The human studies are carried out during epilepsy surgery by placing small amounts of local anesthetics directly into the brain. Anesthetics have similar actions to anti-convulsant drugs and preliminary results of this study show that they have an effect on epileptic activity in the brain.

### **Localized Brain Cooling For Treatment of Epilepsy**

A new translational project employs brain cooling to treat seizures. Focal cooling reduces neuronal firing and may reduce seizure spread. Animal studies have shown that it is possible to abolish and, in other cases, stop seizures with brain cooling. Parallel to this, we have also begun studies of brain temperature measurement using specialized probes in patients that are undergoing surgery. This is an exciting area of research and we hope to produce preliminary data in the next six months.

### **Convolutional Neural Network Analysis to Predict Seizure Propagation**

Dr. Deepak Madhavan and Dr. Ruben Kuzniecky have received a grant from the Epilepsy Foundation of America towards Dr. Madhavan's fellowship this year to develop a new method of EEG analysis. Using highly sophisticated computerized neural network analysis, they plan to apply this to intracranial EEG. This sophisticated analysis may be able to predict when a seizure will occur, leading to improved understanding and development of preventive therapies to stop seizures (see page 7). ❖

# Using Artificial Neural Networks to Study Neural Networks in the Brain

By Deepak Madhavan, M.D.

The greatest challenges of epilepsy surgery are deciding what region of the brain is most responsible for the start of a seizure and the brain areas to which a seizure spreads. Epileptologists use the electroencephalogram (EEG) to find these areas by looking at brain waves. This is initially done with a scalp EEG, and later with direct recordings of the brain surface (intracranial EEG, or iEEG). With these direct brain recordings, we can get an exquisitely sensitive picture of normal and epileptic brain function. In the setting of a seizure, the goal is to identify the portion of iEEG that displays abnormal brain waves at the seizure's start to identify the area(s) of brain tissue that provide the "spark" for the event.

However, this can sometimes be a daunting task, due to the architecture of the brain. To generate coordinated thoughts and actions, the brain must utilize its vast, interconnected system of electrical circuits to do so. In a typical brain, these connections form specialized networks of activity to perform specific functions, such as speech, vision, or motor activities. In a brain affected by epilepsy, however, abnormal connections can form between brain cells, resulting in networks that cause seizure activity. Some of these networks can be widespread, which can be difficult to characterize even with iEEG. When looking at the iEEG of such a brain, many areas appear to "spark" at the same time, giving the appearance that there are several areas of the brain responsible for seizure generation. Further complicating this problem is the fact that some of these areas are known as "eloquent" brain tissue, or areas of the brain essential for language, vision, or movements. As the goal of epilepsy surgery is to remove brain tissue with abnormal connections while preserving these eloquent areas, accuracy in localizing the area of the seizure generation is of utmost importance. However, widespread activation on iEEG, can pose significant challenges.

To address this problem, we have begun a collaborative research effort with Prof. Yann LeCun, head of the Computational and Biological Learning Lab in the Department of Computer Science at NYU, and a world-renowned researcher in the field of Machine Learning. With Prof. LeCun's assistance, we are currently researching an exciting computational technique he invented that will aid us in the interpretation of iEEGs. This technique is called a convolutional neural network, or CNN.

CNNs, and more generally Artificial Neural Networks (ANN), are mathematical tools inspired by "real" neural networks such as the human brain. Just like their biological counterpart, they consist of a highly complex network of interconnected processing units ("neurons") that each performs simple mathematical operations: integrating inputs and create an output. This output is then propagated to other connected neurons in the network. ANNs aim at trying to reproduce the brain's amazing learning skills, utilizing the observation that humans and animals learn by examples and through trial and error. ANNs learn by using sophisticated mathematical calculations to adjust the connections between the neurons until the patterns are correctly recognized. As of today, most envelopes and bank checks in the U.S. and Europe are reliably read by computerized systems based on ANNs. CNNs, a recent invention of Prof. LeCun, have a specific architecture that enables them to process data such as images or speech by both focusing on small details and integrating all the information in a general picture, enabling this technique to be applied to very difficult problems.

The aim of our research is to design a CNN that correctly analyzes the brain activity of a patient as measured on iEEG, and can also predict the effects of neurosurgery on the propagation of epileptic seizures by "learning" the functional relationships of different areas of the iEEG. This technique would be an additional diagnostic tool that could aid the epileptologist in understanding the complex mechanisms underlying a patient's seizures.

We are currently in the preliminary stages of research in this area, but we have already achieved some encouraging results. In the future, we plan to further enhance the predictive power of the network by incorporating other features of the iEEG into the system, thereby giving it more information through which to characterize particular seizures. We also are planning to "road test" the system in a few months, by having this network learn the iEEGs of patients that have already undergone seizure surgery, to see if the area the CNN predicted to be the zone of seizure onset was successfully removed during surgery. We believe that the CNN's role in seizure analysis has the potential to be used with other techniques in addition to resective surgery to stop seizures, such as the emerging fields of

*continued on page 10*

# The Sleep/Epilepsy Correlation, Part II

By Alcibiades Rodriguez, M.D.

## NREM parasomnias

Paroxysmal nocturnal events include epileptic and non-epileptic behaviors. Parasomnias are undesirable physical events or experiences that occur during entry to sleep, within sleep and during arousals from sleep. The word derives from the Greek prefix *para*, meaning alongside of, combined with the Latin *somnus* for sleep.

Parasomnias are divided into Non-Rapid Eye Movement (NREM) parasomnias (confusional arousals, night terrors and sleepwalking), Rapid Eye Movement (REM) parasomnias (REM sleep behavior disorder, recurrent sleep paralysis and nightmare disorder) and non-state dependent parasomnias (rhythmic movement disorder, bruxism and enuresis).

NREM parasomnias occur more frequently during the first third of the night (NREM sleep is more common during this time). During this period, the patient is unresponsive to external stimuli and may be confused if awakened. *Sleepwalking* involves complex, coordinated motor behaviors, including standing and walking. *Sleep terrors* are characterized by autonomic, motor and vocal manifestations of intense fear. *Confusional arousals* involve disorientation without the complex motor behaviors of sleepwalking or the intense fear of sleep terrors. These Parasomnias may be very difficult to distinguish from nocturnal seizures, therefore video EEG-Polysomnography is required at times (see table 1).

Parasomnias are of genetic origin. As a general rule, NREM parasomnias are more common during childhood. However, up to 20% of children who sleepwalk may continue to do so during adult years.

NREM parasomnias are exacerbated by sleep deprivation, unusual sleep-wake cycles, some short acting sedatives, stress, anxiety, or any sleep disturbance that affects sleep quality or quantity.

These disorders may co-exist with epilepsy in the same patient. If this is the case, nocturnal seizures may worsen Parasomnias and the Parasomnias may worsen

	NREM Parasomnias	Nocturnal Seizures
Time	First 1/3 of the night	Any time of the night
Frequency	Not every night	May occur nightly
Stereotypical behavior	No	Yes
Memory of the event	None	None
Age of Onset	Usually childhood	Any age
Duration	Usually minutes	Seconds to minutes
Family History	Strong	Variable
EEG	Normal	Abnormal or Normal

Table 1. NREM Parasomnias vs. Nocturnal seizures

seizure control. Up to 34% of patients with nocturnal frontal lobe epilepsy (a form of epilepsy yielding nocturnal seizures exclusively) may have a history of probable parasomnia while 39% have a first degree relative with this problem. Recent surveys have shown, however, that epilepsy patients do not have a higher frequency of Parasomnias compared to control subjects.

It is important to recognize Parasomnias in patients with epilepsy as these sleep disorders are medically treated differently than epilepsy. In the same way, nocturnal seizures may be misdiagnosed as parasomnias when the reality may be the first manifestation of epilepsy in a child. It may be difficult for individuals to recognize the differences and thus, it is important to consult a specialist in sleep medicine and/or epilepsy to help with the diagnosis.

In future newsletter editions we will review REM and non-state dependent parasomnias and their differences to epilepsy. ❖

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



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

## The “E” Word *by Marie A. Pepe*

When I was younger, I never told anyone that I had the “e” word (epilepsy) for fear that I would be an outcast wherever I went. I was convinced that the least amount of people who knew, the better off I would be. Back then, we called it “blacking out” and as I grew into my teens it had graduated into a “seizure disorder”.

Each time I did fall ill, almost poker faced, it mortified those around me. I remember people sticking all sorts of utensils in my mouth so I wouldn’t swallow my tongue (as if that were even possible). The end result was always the same with the so-called Good Samaritan remaining with bruised fingers for weeks. I thought that person should have kept their fingers out of my mouth to begin with!

The internet also serves people by providing doctors a quick medium to exchange ideas as well as a quick source for epilepsy sufferers to learn of medical updates. I have found chat groups very encouraging as well as I am able to talk to other people with epilepsy and share thoughts with them.

I have realized that a person with epilepsy is able to have the same dignified quality of life as the person sitting next to them on the bus or train. The ingredients of self-education, support, and the proper medical attention, form a recipe resulting in a fundamentally resilient person with epilepsy. We no longer have to be the “sick kid on the block.”

At puberty my seizures disappeared but returned during my adult years. Now in my forties, my seizures have just about “left town”. One must be tolerant of the varying stages of epilepsy. Plenty of research and proper medical attention enlightened both my family and I to the forces that drive this illness.

For years, as a single mom, I was told by all that the reasons for my seizures were stress-related. This made no sense, as I was so very happy. Although physically I was feeling worse with each day so I changed doctors and investigated further.

Now, I realize that millions of people have epilepsy. Some people suffer more than others with forms of epilepsy that are not under control. Fortunately, many people become seizure-free with surgery, never having to swallow another AED (anti-epileptic drug) again. Unlike other illnesses, epilepsy is not always curable and can remain constant.

I attend lectures on behalf of **FACES** and other epilepsy organizations. The audience is filled with people craving knowledge about epilepsy. I think years ago many people had this illness but did not know how to recognize it or, like myself, did not wish to speak of it.

About seven years ago I met Dr. Vahid Ghiasian (Dr. G). After he prescribed and observed my video monitoring, he suggested that my meds be altered and changes be made to my daily lifestyle. Dr. G. convinced me that epilepsy was not one of the worst illnesses. Over the years he has shown me that I can get the most out of life by not letting epilepsy control me and taking charge of my life.

Through my family, friends, colleagues and my first-rate doctor, I have learned to deal with the curves this illness pitches. Now, I have reached the plateau where-

by I am no longer ashamed but proud that I was able to come this far and accomplish so much. I wear an emergency medical alert necklace and even my “THINK POSITIVE” bracelet to support the Epilepsy Foundation. I no longer hide the fact that I have epilepsy. I have been rushed to the hospital enough times because people did not know my condition or what to do for me. I realized that I was only fooling myself by not letting

others know. My childhood hypothesis of epilepsy was so warped and misconceived.

Presently I take over 11 pills each day. Professionally I work in the field of Corporate Finance. I am fortunate as I now have a caring husband and a compassionate daughter who have supported me over the years. My parents and some friends have also helped me through the rougher years when I was so ill and lost faith. Now my confidence level peaks at 100%. I have also been fortunate as my brain remains clever regardless of all the seizures I have had in the past.

It is important to put your trust in a good doctor as that is half your ticket to health. The other half is your own perseverance.

Do not be afraid or ashamed of having epilepsy as it is a condition you can work into your life without missing out on the many opportunities life has to offer. More importantly, concentrate on another “e” word that will increase life’s value and that is your *enthusiasm* for it. ❖

---

*I am no longer  
ashamed but proud  
that I was able to  
come this far and  
accomplish so much.*

---



Special thanks to the student government body at the Walter Kassenbrock Elementary School - PS 185 in Brooklyn for choosing FACES among four other charities to donate the proceeds of their Common Cents Penny Harvest project toward FACES Game Day. The children put on a wonderful check ceremony organized by school guidance counselor Dana Warren and parent coordinator Mary Maguire.

### Now Donating to FACES won't cost you a cent!

You can help generate funds for FACES at no cost to you by utilizing GoodSearch. FACES is now a member of GoodSearch, a new internet search engine that donates half of its advertising revenue to member charities. Every time you use GoodSearch to search the internet and designate FACES as your charity of choice, GoodSearch donates a portion of the advertising revenue earned from the search to FACES.

Getting started is easy.

1. Go to [www.goodsearch.com](http://www.goodsearch.com)
2. Specify FACES as your charity by typing "Seizures" in the "I'm Supporting" field and clicking the Verify button.
3. After FACES appears perform your internet search in the field above.

After doing this once, every time you come back to the GoodSearch page, FACES is automatically listed as your charity of choice, making donating to FACES easy! Make [www.goodsearch.com](http://www.goodsearch.com) your browser's home page or bookmark it to make the process even more seamless.

It is estimated that each search will raise approximately \$0.01 for FACES. If 1,000 people search the internet twice a day using GoodSearch and choose FACES as their charity of choice, FACES will receive \$7,300 annually! Please help spread the word to as many family members and friends as possible to help our cause. The more people searching, the more FACES benefits. Try it now!

## Evening Epilepsy Lecture Series

The Evening Epilepsy Lecture Series has been extremely successful thus far. On February 27th, Dr. Daniel Miles lectured on when epilepsy surgery might be appropriate for children. Our March 27th lecture, featuring Dr. Arthur Grant, drew the largest attendance ever. Dr. Grant's topic focused on the effects of epilepsy on memory and thinking. June 12th saw the debut of our live webcast for the lecture series with Dr. Josiane LaJoie lecturing on choosing the right anti-epileptic drug for children. To view the lecture, please visit [www.nyufaces.org](http://www.nyufaces.org) and click on the Downloads page. The upcoming lecture schedule is as follows:

MONDAY, AUGUST 28, 2006

"ANTIEPILEPTIC DRUG BENEFITS AND SIDE EFFECTS"

KATHERINE MORTATI, MD

MONDAY, NOVEMBER 13, 2006

"SLEEP AND EPILEPSY"

ALCIBIADES RODRIGUEZ, MD

To register for any remaining lectures, visit:

<http://FACES.kintera.org/EveLecture2006>

## *Using Artificial Neural Networks to Study Neural Networks in the Brain*

*continued from page 7*

direct drug delivery to the brain surface, and electrical stimulators.

Deepak Madhavan, M.D.

Piotr Mirowski, MSc.

Ruben Kuzniecky, M.D.

This study is supported by the Epilepsy Foundation of America and FACES.

# DONATIONS

January 2006 – June 2006

## The following individuals donated to FACES in honor of Rhoda and William Kellman's 50th Wedding Anniversary:

George Birnbaum  
Judith and Murray Garber  
Veronica and Sam Isaacson  
Sally and Melvin Klein  
Toby and Sidney Perris

Rosalind and Marvin Samuels  
Minnie and Cyrus Shavrick  
Peggy and Jeff Shupp  
Gail Weinberger

### In memory of Edna Sharp:

Emrick Artz  
Auten Road Intermediate School Sunshine Club  
Jean Biggio  
Sue and William Bolan  
Staff at Cambridge Elementary School  
Maureen and William Canonico

Hillsborough Education Association  
Maul Electric, Inc.  
Patricia Morgan  
Carolyn and Jacob Peternel  
Mary and John Ross  
Dorothy Canonico and Illona Schoifet  
Laurel Sickler

## The following employees of Waldner's Business Environments would like to honor Rachael Rose:

Ruth and William Berne  
John Conkling  
Martina Doshan  
Wendy and Jeffrey Fatum  
Judith and Raymond Ferri  
Karen Harris  
Deborah Hopewell  
Cynthia and Peter Kelly

Michelle and Mark Krumenacker  
Karen and Robert Rose  
Vivienne Smith  
Audrey and Hank Sussman  
Rachel Tyrrell  
Holly Cooper and Scott Weintraub

### In memory of Christine Billyard:

Kevin Cofsky  
Dolores and John Dearborn  
Evercore Partners Services East, LLC

Mary and Kenneth Klim  
Timothy LaLonde  
E. Monahan  
Nancy Roberts

## Thank you to all of our contributors!

### \$5,000+

URSA Development Group

### \$2,000+

Richard Shane

Williams Trading, LLC

### \$1,500+

Stacey and Andrew Feller

MediVia

### \$1,000+

Ronald Millman, OD "In honor of Dr. Vazquez and her help with our daughter Lisa"

Barbara Paca, PhD "In gratitude to Dr. Devinsky for his remarkable talents"

Ginny Spiegel

### \$500+

Giacomo Picco "In the name of Liam and Kate"

Wendy and Neil Sandler

Laurie Simon

Linda Last Spellun "In honor of ID Luckower's 70th Birthday"

### \$200+

P.S. 185 / Common Cents  
New York, Inc.

Ethel and Julian Decter

Stephanie and Thomas Duane

Rosann and Albert Gaetani  
"In honor of Dr. Devinsky"

HR Industries

Philip Herschenfeld

Virgina Schaaf and Daniel Lowenstein

Joey Morer

Ellen and Allan Spellman  
"Many thanks to Dr. Devinsky"

Gary Sowers

Union County Epilepsy Support Group "In memory of Cheryl Collins"

# UPCOMING EVENTS

Stay tuned to [www.nyufaces.org](http://www.nyufaces.org) for information on our upcoming events!

**MONDAY, AUGUST 28, 2006**

## Evening Lecture Series

### Antiepileptic Drug Benefits and Side Effects

See page 10 for more information

**SUNDAY, OCTOBER 15, 2006**

## FACES Game Day at Chelsea Piers

See page 4 for more information

**SUNDAY, NOVEMBER 5, 2006**

## Epilepsy Conference

Details to follow

**MONDAY, NOVEMBER 13, 2006**

## Evening Lecture Series

### Sleep and Epilepsy

See page 10 for more information

**faces**

FINDING A CURE FOR EPILEPSY & SEIZURES

724 Second Avenue • New York, NY 10016  
212.871.0245 (phone) • 212.871.1823 (fax)

[www.nyufaces.org](http://www.nyufaces.org)

Email: [FACESinfo@nyumc.org](mailto:FACESinfo@nyumc.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
Macy Carobene, RN	212.263.8354
Barbara Clayton, RN	212.263.8871
Werner Doyle, M.D.	212.263.8873
Mark Farley	212.871.0245
John Figueroa, CSW	212.263.8871
Vahid Ghisian, M.D.	718.683.3766
Arthur Grant, M.D., Ph.D.	212.263.8327
Peggy Guinnesssey, 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
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
Melissa Murphy, MSW	212.871.0245
Siddartha Nadkarni, M.D.	212.263.8870
Southel 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
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, M.D.	212.263.8876
Bonnie Wang, MHSA	212.263.8358
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