

CONTENTS

Great Fortune..... 1

From the Program
Coordinator..... 2

Sleep Center Opening..... 2

Sleep & Epilepsy..... 3

Announcements..... 5

Level Four..... 5

FACES Gala..... 6

Developing A Hybrid
Neuroprosthesis For
Epilepsy Treatment: A
Status Report..... 7

Can You Eat Your Way To
Seizure Control?
The Ketogenic And Atkins
Diet For Epilepsy..... 8

John Durrue's Story..... 10

Evening Epilepsy Lecture
Series..... 10

Donations..... 11

NYU Comprehensive
Epilepsy Center..... 12

The **FACES** newsletter is edited by
*Christine Toes and
Melissa Murphy*
with support from
*Josianne LaJoie, M.D.,
Daniel Miles, M.D. and
Ruben Kuzniecky, M.D.*



SCHOOL OF MEDICINE
NEW YORK UNIVERSITY

Great Fortune *by Richard Shane*



Richard Shand, ten months after surgery, on top of Aspen Mountain with niece Tatum Shane and brother Steven Shane.

I used to have complex partial seizures approximately every two weeks, never more than 3 weeks seizure-free. With the inspiration, guidance and confidence instilled in making the right decision offered to me by Dr. Devinsky and then the incredible compassion and obvious brilliance of the remarkable Dr. Doyle, I am able to share with you this life changing experience.

What is the value of improving your health to the best it's been in 22 years? Priceless. Then discovering how to help others with what you've learned? Additional wealth.

Thank you Dr. Devinsky, Dr. Doyle and the team of professionals at NYU. Furthermore, thank you to everyone who accompanied me on my journey in search of an answer to controlling my seizures.

continued on page 4

STEERING COMMITTEE

Chair

Orrin Devinsky, M.D.

Program Coordinator

Christine A. Toes

Research Coordinator

Melissa Murphy

Jeff Benowitz

Brendan Byrne

Margot Chvatal

Kate Cooney Picco

Larry Davis & Donna Emma

Sharon & Peter Donovan

Judy Ebner

Harry Falk

Anna Fantaci

Colleen Farrell

Jane Gilbert

Peter & Kathy Gogolak

Elizabeth Jarvis

Lynn & Noel Jeffrey

Ruben Kuzniecky, M.D.

Warren & Kathy Lammert

Leonard & Marilyn Lehrer

Randi & Jeff Levine

I.D. Luckower

Leila Mansouri

Amy & Seth Markowitz

Karen & Jeff Mayerson

Anne Metcalf

Mary Miceli, RN

Daniel Miles, M.D.

Elizabeth Millstein

Nancy Novograd

Lawrence & Gaye Pecker

Sharon Perhac

Jaimee Sabato

Mame Kennedy Schragger

Richard Shane

Remi Silverman

Leslie Smith

Stevie Solomon

Candice Stark

Amy Steinman Cohen

David Swinghamer

Blanca Vazquez, M.D.

Leah & Michael Weisberg

Neil & Stacey 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 NYUfaces@yahoo.com.

From the Program Coordinator

What an incredible few months it has been at FACES! The FACES Gala raised over \$2.7 Million for epilepsy research and programs. Read more about the event on page 6.

The FACES Steering Committee reviewed and approved two Public Service Announcements (PSAs) that were developed by the Canadian Epilepsy Alliance. The PSAs have been revised at no cost to FACES through a strategic partnership with the Anita Kaufmann Foundation to include the FACES logo and 800 number. If you have any connections in television that might help us to get these aired pro bono, please let us know.

The Young Professionals (ages 20-32) met for brunch on 2/26. Several members asked if they could help put together a Young Professionals Event that would be priced at \$100-150 a ticket. If you are interested in serving on a committee to work on this event, please let us know. The event would take place in the fall or winter of 2005.

Three new faculty members will be joining the Epilepsy Center in the next few months. Arthur Grant, M.D., Ph.D. from Univ. of California - Irvine, is an NIH grant recipient who will be working on research into cognitive functioning in epilepsy; Katherine Mortati, M.D. who has just completed a two year fellowship in epilepsy and neurophysiology at Harvard Medical School; and Alcibiades Rodriguez, M.D. who has completed epilepsy and sleep fellowships at the Mayo Clinic. We are thrilled to welcome them to NYU.

Finally, my last day at FACES is May 5th! It has been wonderful working with everyone for the past five years. Thank you so much for your generosity and support of FACES. Melissa Murphy, the FACES Research Coordinator, has been promoted, and we will be hiring a new Education Coordinator in the next few weeks. I would love to stay in touch, so please update your address books with my new email address: ChristineToes@gmail.com.

Christine Toes, M.P.A.



Sleep Center Opening

The NYU Comprehensive Epilepsy Center is pleased to announce the opening of the New York Sleep Center, at 724 Second Avenue in Manhattan. More than 40 million people in the United States suffer from sleep-related disorders such as snoring, fragmented sleep and sleep apnea. However, only about five percent have been diagnosed and treated according to the National Sleep Disorders Research Center. Since sleep deprivation can trigger seizures in people affected by epilepsy, we are pleased to offer this important service to our patients. For more information, please visit <http://www.nysleepinstitute.com> or call 212.871.0227.

Sleep & Epilepsy

By Meeta Bhatt, M.D., Ph.D.

A relationship between sleep and epilepsy has been long recognized. In 1929, Langdon-Down and Brain classified seizures with respect to their relationship to sleep as diurnal (daytime), nocturnal (night time), and diffuse (day + night). In 1962, Janz introduced the term, “awakening epilepsy.” Further, it was realized that seizure patterns have a tendency to remain stable with respect to sleep-wake cycle. For example, Juvenile Myoclonic Epilepsy (JME) occurs shortly after awakening in the morning or at night, or at sleep onset. This helps researchers and physicians analyze the etiology, prognosis, and plan treatment.

To understand the relationship between sleep and epilepsy, one needs to understand the mechanism of each. **Epilepsy** is dependent on genetic and acquired factors that increase excitatory brain cell activity. This increased brain cell activity in turn helps to transform an interictal discharge (subclinical seizure activity) into an ictal state (clinical seizure). **Sleep** consists of two distinct stages in humans: non-rapid eye movement (NREM) and rapid eye movement (REM) sleep. NREM sleep accounts for 75-80% total sleep time and REM sleep accounts for 20-25% total sleep. NREM sleep is further divided into 4 stages ranging from light to deep sleep time. The NREM and REM sleep stages recur in a cyclic manner throughout the night. During NREM sleep the brain cells discharge at the same time which facilitates the spread of seizure discharges. In contrast, during REM sleep the brain cells do not discharge at the same time, hindering the spread of seizure discharges. In addition, the muscle tone is preserved during NREM sleep which permits seizure associated movements (e.g. jerking) to occur, while the muscle tone is reduced in REM sleep preventing seizure related motor movements.

Thus, understandably so, seizure discharges are more frequent in NREM sleep, increase gradually with deepening level of NREM sleep and have a greater tendency to spread in the brain during NREM sleep. On the other hand, factors that lead to REM sleep deprivation exacerbate epilepsy.

Now looking at the reverse aspect, how does epilepsy affect sleep? Researchers have shown that sleep fragmentation is noted in all epilepsy types even on seizure-free nights. This results in excessive daytime sleepiness or fatigue, more on days after nocturnal seizures as compared with seizure-free nights. Further, sleep deficits are noted to correlate with severity of seizures. Additionally, antiepileptic



drugs (AEDs) produce a variety of alterations in sleep architecture and varying degrees of daytime sleepiness.

Further, several authors have reported a high incidence of primary sleep disorders in the epileptic population, most notably obstructive sleep apnea syndrome (OSAS), periodic limb movements in sleep (PLMS), and narcolepsy or idiopathic hypersomnia. Individuals with epilepsy may be predisposed to OSAS due to the adverse effects of AEDs, particularly sedation and weight gain. It has been shown that treatment of the primary sleep disorder frequently leads to improvement in seizure control and in daytime sleepiness in these patients.

Thus, sleep and epilepsy are reciprocally related. Improvement of nocturnal sleep and appropriate treatment of co-existent sleep disorders may be associated with a reduction in seizure frequency and a substantial improvement in quality of life.

Meeta Bhatt, M.D., Ph.D.

Director, New York Sleep Institute
Assistant Professor, Neurology (Clinical)
Department of Neurology
New York University and Medical Center
E-Mail: Meeta.Bhatt@med.nyu.edu



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

I learned and now cling to the belief that all things can happen to all kinds of people. As a result, it is necessary to maximize every day to its fullest. We owe it to ourselves and to the less fortunate who would trade anything to be in our position.

As for me, I was 22 years old when I started “spacing out” about once every three weeks. I’d make a moaning sound, rest on my shirt collar, and after a few seconds “be back” but it would take a minute or so to realize the day, time and location. I was convinced that all I had to do was go back to the gym and work it out of me. This was not the first time I was wrong about my seizures.

After many years of taking virtually every AED (anti-epileptic drug) available and investigating what I thought was every protocol, I accepted that seizures would be part of my life, but not my entire life. I stopped driving but it this was okay as living in NYC made it possible to get around easily.

Ten years ago, following ten years of failed drug treatments, the doctors at Columbia Presbyterian suggested that I investigate surgery. It took a year for the doctors there to realize that it was pointless to continue to bring up the subject as I was firm in my reluctance. I was steadfast that no one was going to take out a portion of my brain.

I remember meeting with Dr. Devinsky for the third time to discuss the surgery. I asked the same questions over and over again. Yet still, I didn’t want to look back in ten years, sorry that I didn’t have the surgery which could have vastly improved my quality of life.

I had to face the truth that my seizures could get worse, damage my brain,

and make my memory even worse. I was still hesitant, but Dr. Devinsky said, “Richard, if you’re worried about a little white scar on the side of your head...” He made me realize that the seizures were affecting my ability to think things through.

When I met Dr. Doyle, I soon realized that if I was going to have my life in someone’s hands, I wanted it to be Dr. Doyle’s. He is both brilliant and compassionate. He answered every question my family and I had. He has touched my life more than anyone else ever has.

*Appreciate what you have
and remember although
seizures may be part of
your life they do not have
to take control of your
entire life.*

While in the hospital bed after the first of my two surgeries, I asked myself, quite annoyed, “why did God choose me?”

Rather than appreciating the fact that I was one of the fortunate 10% qualified to be a candidate for this type of surgery, I wanted the answer as to why, at 44 years old, I was in this helpless position with wires coming out of my head.

One week later, through the video monitoring, I gave the doctors the “hoped for” seizure that would better determine the location of my seizures. Within a few hours, I was back in the

OR. I remember being wheeled in and seeing Dr. Doyle and holding his hand. I didn’t want to let go. “Please Dr. Doyle, take good care of me,” I said. I knew he would.

I also knew my parents and two brothers were at my side this entire time. They traveled from Florida, Texas and Colorado to be with me in New York for as long as I needed them to be there. A support group is critical during a time like this.

My two surgeries resulted in a two week hospital stay. After that, more weeks at home recuperating. Thereafter I would return to my Manhattan office to work part time. After two months I would be working almost full time again.

Frankly, the most difficult part of this entire process was facing depression. As a result of the surgery, the chemicals which seem to cause depression were unleashed resulting in yet another challenge. About three major crying experiences plagued me over a month’s period. This was controlled and phased out through therapy and medication. While not welcomed, the upside of being seizure-free is worth the trade-off for a few weeks of depression.

March 23, 2004 was the date of the second surgery and I have not had a seizure since. I now have my driver’s license back after a 22 year hiatus. I have a newfound appreciation for what is important and to value it every day. How much of this is because I no longer have seizures affecting my brain? I do not know, but I no longer have to worry that seizures are damaging who I am or how I think. Surgery has successfully improved my quality of life.

ANNOUNCEMENTS

The NYU CEC would like to welcome the following new physicians to our staff:

Chunmao Wang, Ph.D., Associate Research Scientist

Eric Halgren, Ph.D., Adjunct Professor Neurology

Arthur Grant, M.D., Ph.D., from the University of California at Irvine

In July, we will be joined by:

Katherine Mortati, M.D., from Brigham Hospital at Harvard

Alcibiades Rodriguez, M.D., from the Mayo Clinic

Accolades!

Dr. Catherine Schevon was awarded a 5-year NIH K-08 grant. This is the Epilepsy Center's first "K" award, a grant given to young investigators.

Best Wishes

We are saddened to announce the departure of Christine Toes from FACES as of May 6th. The Comprehensive Epilepsy Center at NYU and FACES would like to express our gratitude to Christine for her hard work over the last 5 years. Since joining our staff, Christine has contributed many great ideas and programs. We wish Christine much success in her future endeavors!



Level Four

The NYU Comprehensive Epilepsy Center has been designated a Level Four epilepsy center by the National Association of Epilepsy Centers. Level Four centers are national referral facilities, providing the most complex forms of intensive monitoring, more extensive neuropsychological and psychosocial services, and neurosurgical services for epilepsy treatment. Level Four centers are the most comprehensive epilepsy centers in the country. For more information, please visit <http://www.naecepilepsy.org>.



Great Fortune... *continued from page 4*

I have since promised myself to help others with the unique education I received as a result of the expertise, guidance and compassion of Dr. Devinsky, Dr. Doyle and the entire staff who have gone through this with me.

I have been fortunate as I have gained a lesson of what truly is important. I no longer have seizures and feel physically and mentally the best I have ever felt. Thank you to all who have made this possible.

Now at 44 years of age, the best lesson I have since learned and I would like to pass on is:

Appreciate what you have and remember that although seizures may be part of your life, they do not have to take control of your entire life.

This is the Great Fortune I have well found. ❖

Edited by Maire Pepe

The **FACES** Gala raised over \$2.7 Million for epilepsy research and programs! The Gala, held on Monday, April 4, 2005, at Pier Sixty featured Jon Stewart as our emcee and New Jersey Governor Richard Codey as our special guest. Tony Coelho, former Majority Whip of the House of Representatives and Founder of the Americans with Disabilities Act, presented Mike Milken, our honoree, with his award. 800 people attended the event, which featured a 400 item silent and 11 item live auction.

Special thanks to Randi and Jeff Levine and Deborah and Orrin Devinsky, MD for co-chairing the event, and to Margot Chvatal for chairing the auction. **FACES** would also like to thank Emily Taub and her staff in the NYU Office of Special Events for coordinating the event. Christine Toes, Melissa Murphy, and temp Mark Farley did a terrific job coordinating the silent and live auctions.

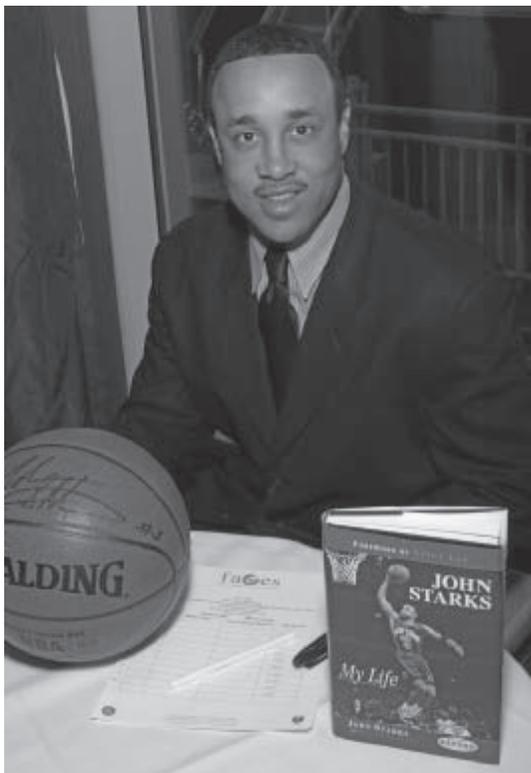
Thank you to everyone who made a donation to the event or purchased tickets, tables, or journal ads. **FACES** would also like to thank our auction donors and winning bidders! Due to the event's overwhelming success, we will continue to hold the event every year.



Special guest, New Jersey Governor Richard Codey and Gala emcee Jon Stewart



Orrin Devinsky, MD, Michael Milken, and Tony Coelho



*John Starks autographs basketballs at the **FACES** auction.*



Randi and Jeff Levine

Developing A Hybrid Neuroprosthesis For Epilepsy Treatment: A Status Report

By Nandor Ludvig, M.D.

As announced in our 2004 Summer newsletter, the NYU Comprehensive Epilepsy Center had initiated an ambitious program to develop a novel intracranial therapeutic device for the treatment of epilepsies that are both drug-resistant and unsuited for surgery. The device, US Patent No. 6,497,699, is named as “Hybrid Neuroprosthesis,” or HNP. The name implies that the invention is a hybrid of electrophysiological and pharmacological components. It serves to correct abnormal neural functions, and, like other prostheses, it is fully implanted in the body.

The basic idea behind the development of the HNP is that since many forms of epileptic seizures originate in well-defined epileptogenic zones in the brain, the optimal way to treat these seizures is to get access to the very sites of these epileptogenic zones and treat them locally. This strategy makes surgical tissue removal unnecessary, yet allows the exposure of the epileptogenic zones to appropriately high concentrations of antiepileptic drugs without inducing side-effects. The HNP aims to translate this strategy into a medical implant, which records EEG activity in the epileptogenic zones, recognizes abnormal EEG signals prior to an imminent clinical seizure, and prevents the development of this seizure by delivering antiepileptic drugs into the epileptogenic zones.

Since the announcement of this research program last year, our research team has made significant progress in the preclinical work that should precede the actual clinical trials.

First, we refined the animal model that serves to test the function of the HNP before the clinical trials. Some key data was published in 2004, in the journal *Epilepsia* (vol. 45; Suppl.7; pages 212-213). This animal model, employing monkeys, is necessary as neither computer models nor tissue cultures are able to simulate the complex interactions between an epileptogenic zone and an implanted HNP.

Second, to extract as much information as possible from these demanding animal experiments, we collected new

Since the announcement of this research program last year, our research team has made significant progress in the preclinical work that should precede the actual clinical trials.

data for demonstrating that localized antiepileptic drug deliveries in the primate brain do produce antiepileptic effects, and that the intracranial catheters for such drug deliveries cause no apparent behavioral abnormalities or harmful tissue damage.

Third, we modified our original HNP software, named “SeizureGuard,” to recognize abnormal, epileptiform EEG signals specifically in the mentioned

monkey model of epilepsy. This will allow us to test in this model the ability of the HNP to deliver antiepileptic drugs in response to the signs of an imminent seizure. In fact, we have made progress in developing a second version of this software which can recognize abnormal epileptiform EEG signals in epileptic patients prior to clinical seizures. This software development effort uses electrophysiological data collected with our EEG systems at Tisch Hospital. A unique feature of the SeizureGuard software is that it uses relatively simple calculations and, as a consequence, it can run on processors that do not consume much electricity. For fully implanted devices, such as the HNP, this will be an important advantage.

Fourth, our collaboration with Lenox Laser (Glen Arm, Maryland) led to a \$132,000 grant from the National Institutes of Health (NIH). While the primary aim of this project is to develop a method for delivering and sampling proteins in brain, it has also helped us to improve the drug delivery catheter of the HNP. This improved catheter will allow the delivery of antiepileptic drugs via laser-made, microscopic perforations, filtering out the surrounding brain cells and thus eliminating the possibility of catheter-clogging.

Fifth, a milestone was reached by completing the development of the first prototype of the minipump that will mediate the drug deliveries into the epileptogenic zones. This cylindrical minipump, weighing less than 15 grams and having a diameter of as small as 15mm, can be periodically

continued on page 9

Can You Eat Your Way To Seizure Control?

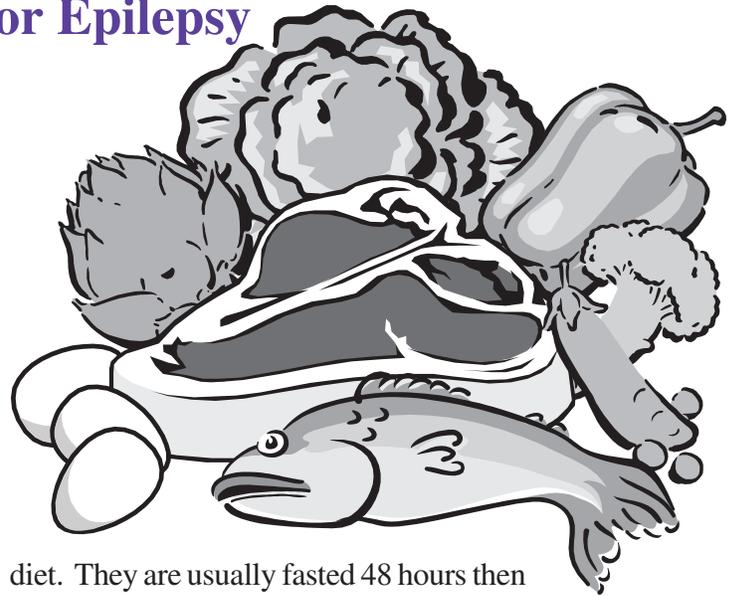
The Ketogenic And Atkins Diet For Epilepsy

By Eric H. Kossoff, M.D.

Despite a doubling of anticonvulsants available for the treatment of epilepsy over the past decade, there has been a growing recognition that if two or three drugs don't work, the odds of finding a successful medicine for seizures is nearly zero. Many children, adolescents, and adults look for another answer. For those that are fortunate, surgery can not only help but cure. However, there is a large group of people with epilepsy that medicines haven't helped and surgery either is not an option or failed as well. When this happens, epilepsy experts consider other approaches, namely dietary therapies and vagus nerve stimulation (VNS). Both work in very different ways from drugs, and probably have a milder side effect profile. Many people wonder, with good reason, why these approaches are not used earlier in the course of epilepsy.

The ketogenic diet has been around for the past 80 years, perhaps even dating back to references in the Bible (Mark 9: 14-29) of Jesus curing patients with epilepsy by fasting. In the early part of the century, a water diet was used to mimic starvation. In 1921, the first true "ketogenic" diet was created at the Mayo Clinic by using a very high fat, low protein, extremely low carbohydrate diet. When medications such as Dilantin became popular in the 1940s and 1950s, the ketogenic diet fell out of popularity. Things changed in 1994, when a young child named Charlie was treated at our institution after failing many medications. His remarkable success prompted his father, Jim Abrahams, a Hollywood movie producer, to create the Charlie Foundation (www.charliefoundation.org), which has dramatically increased the use of the ketogenic diet in this country. The diet is also now available in nearly 80 countries worldwide and can be done for vegetarians, those with milk allergies, and those with religious food restrictions (e.g. kosher, Hindu).

Despite the widespread use of the ketogenic diet, how and why it works remains a mystery. We know that ketosis (measured in both blood and urine) is likely very important, but may not be the only reason why the diet works to suppress seizures. The diet consists of foods such as eggs, heavy whipping cream, meats, oils, mayonnaise, green vegetables, and fish. Foods are carefully weighed and measured; all medicines are checked carefully to make sure they contain no carbohydrates. At Johns Hopkins Hospital, we admit children in groups of 3 or 4 once a month for the



diet. They are usually fasted 48 hours then an egg-nog liquid diet is slowly advanced over several days. Most of the admission is spent in classes learning how to use the diet at home.

Does it work? About half of children will have half of their seizures reduced; one quarter will have a 90% or better response. Only about 10% become seizure-free. Although most children remain on medications, several drugs can be either lowered or stopped completely in a large number of children. For children with feeding tubes or infants on formula-only, ketogenic diet is not only effective but easy to provide. The ketogenic diet is not all-natural, holistic, or free of side effects. Children can form kidney stones, have an increase in their cholesterol, become constipated, lose weight, and occasionally, they will experience slower than average growth. Our patients stay on the diet usually two years if it is helpful, although sometimes for much longer if necessary.

Other than side effects, does the ketogenic diet have any drawbacks? Definitely. For one, it is restrictive outside the house. Dinners at restaurants can be nearly impossible for families to plan. Second, it is hard (but not impossible) for teens and adults to stick to measured and weighed foods. Third, not every epilepsy center in the U.S. offers the ketogenic diet. Many of our families travel great distances to start the diet. Fourth, most centers, including ours, still fast children and admit them for a week, which requires their parents to take time off from work.

Enter the Atkins diet. Why would this be of any value? We know that the Atkins diet is similar in terms of foods, and seems to be able to make the liver form ketones just

like the ketogenic diet. However, it is very different in other ways. Foods do not need to be weighed, calories are not restricted, and the protein percentage is much higher. No admission or fast is necessary, low-carbohydrate foods can be carefully used and are available many places, and interestingly, adults seem able to stick to it as well.

In 2002, we began treating some children and adults with a modified Atkins diet; restricting carbohydrates initially to 10 grams per day, providing a multivitamin and calcium, checking labs and weight regularly, and leaving medications constant. We reported our early success with six patients in the journal *Neurology* in December 2003. Now, a year and a half later, we have enrolled more than 20 children with epilepsy into a formal research study on the Atkins diet. This study was generously supported by the Atkins Foundation in New York City. Although no formal results are published yet, results have been very encouraging and side effects minimal.

Our second pediatric study has recently begun at Hopkins. We have enrolled children ages 3-18 with daily seizures that have failed 2 or more medications. Prior exposure to the ketogenic diet is allowed. The 6-month study will randomly choose 10 or 20 grams of carbohydrates per day for an individual child to help find out which is the ideal starting point. Although clinic visits at this time are not covered, we hope to secure outside funding soon to help pay for family expenses as we did for our first study.

We are also very excited about a current study looking at a modified Atkins diet for adults 18 and over with 2 or more seizures per week that have failed 2 drugs. This 6-month study covers all expenses (excluding travel to Baltimore) through a grant from the NIH. If you are interested in this study, or our next pediatric study, please contact our center at the address listed. Our website is <http://www.neuro.jhmi.edu/Epilepsy/Peds>. ❖

Eric H. Kossoff, M.D.
Assistant Professor, Pediatrics and Neurology
Co-Director, Ketogenic Diet Program
The John M. Freeman Pediatric Epilepsy Center
at Johns Hopkins Hospital
Jefferson 128
600 North Wolfe Street
Baltimore, MD 21287-1000
Phone: (410) 614-6054
Email: ekossoff@jhmi.edu

The NYU Comprehensive Epilepsy Center also provides the ketogenic and Atkins diets for patients who are good candidates for dietary treatment. For more information, please call 212.263.8871.

Developing a hybrid...

continued from page 7

refilled through the skin. Importantly, the design of this minipump also allows its continuous control by the SeizureGuard software. As a consequence, the minipump will be able to deliver drugs into the brain only when necessary: for the duration of abnormal, epileptiform EEG signals.

The main task that is now ahead of us is to integrate all the existing components into a single, flawlessly operating, implantable device, equipped with a power supply module that is harmlessly rechargeable through the skin, and completed with a periodically active radiotelemetry system so the physician can occasionally check the status of the implant. For this work, we applied for a \$ 2.7 million grant to the National Institutes of Health (NIH). This fund will also be vital for establishing a laboratory for intracranial therapeutic device development at NYU.

The main participants of this project from the Epilepsy Center are: Nandor Ludvig, M.D., Ph.D, who is the Principal Investigator, and Co-Investigators Orrin Devinsky, M.D., Ruben I. Kuzniecky, M.D. and Werner K. Doyle, M.D. The bioengineers involved in the studies are: Lorant Kovacs, M.S., from ESCO (software development), Geza Medveczky, M.S., from G-tech (minipump development), and Frank Bihari from Apollo Microsurgicals and Walter Blumenfeld, M.S., from Lenox Laser (HNP electrode and catheter development). We also receive consultation from EEG expert Solomon L. Moshe, M.D. (Albert Einstein College of Medicine), neuropathologist Marc Del Bigio, M.D., Ph.D (University of Manitoba) and anesthesiologist Jean Charchafieh, M.D. (SUNY Downstate Medical Center). The progress we have made so far hopefully conveys to the reader that each and every member of this team gives his utmost effort to one day make the vision of the HNP a clinical reality. ❖

John Durrua's Story *By Michelle Murphy*

John's seizures began at the age of one. His parents recall his first seizure as one of the most frightening days of their lives. It was 1967 and John, who had just recently learned how to walk, was experiencing his first grand mal seizure. His parents immediately took him for a medical evaluation. The seizure lasted over an hour and he was paralyzed on his right side after coming out of it.



Although medical treatment in 1967 was not what it is today, doctors were able to diagnose John and educate his family. The early detection of John's epilepsy taught him to deal with it from the beginning stages of his life. He feels that the impact of epilepsy on his life has been minimal due to the fact that he has lived with it all his life and is thus "used to it." "My epilepsy is not so bad to deal with," John says, "because it's under control."

John experiences a grand mal seizure about once every four years, with complex partial seizures occurring at random. When asked what a seizure feels like and how he knows one is coming, John laughs and says: "That is the thousand dollar question!" Starting with a feeling of jittery nerves and a tingling sensation in his body, the seizure takes effect. John describes it as being similar to the feeling he gets when coming out of a seizure – that's how he feels when he is going into one.

Determined to play outdoors with his three kids again, John went in for epilepsy surgery on September 16, 2004. His seven year old son told friends at school: "My daddy is going to have the seizures taken out of his head." As for the surgery itself, John said it was "Fantastic!"

"I went into it optimistic and without a care in the world. Ever since the surgery, there have been noticeable differences in my life." John owns a canoe and kayak shop in New Jersey, and he can now go paddling twice a week. He is also able to drive again – something he hasn't done in four years. John is thankful for all of his wife's support because he believes it is harder to live with people with epilepsy than it is to live with epilepsy.

John has had an incredible experience with the NYU Epilepsy Center. He holds Dr. Devinsky and Dr. Doyle in the highest respect, claiming that they made him feel as though he was their only patient. John believes that in order to prevail, you need to have faith in your doctors. His advice: "Become your own doctor. Do your research, do your homework. Most of all, be grateful about finding the right people."❖

Edited by Maire Pepe

Evening Epilepsy Lecture Series

On March 7th we began our First Annual Evening Epilepsy Lecture Series for Parents and Adults with Dr. Blanca Vazquez lecturing on Women's Issues and Epilepsy. Dr. Vazquez discussed hormones, puberty, the menstrual cycle, planning for pregnancy and menopause in women with epilepsy. Dr. Vazquez highlighted why epilepsy is different in women due to constant hormonal changes.

On May 2nd, Dr. Daniel Luciano spoke on New Medications and Treatments. Dr. Luciano highlighted the characteristics of new AEDs and treatments including the pros and cons of each.

Both lectures were audiotaped and will soon be available at www.nyufaces.org.

Evening Epilepsy Lecture Series will take place at:

NYU Medical Center
550 First Avenue, NYC
Skirball 3rd Floor Seminar Room
6:00pm-7:00pm

Please arrive promptly. Food will be served.

UPCOMING LECTURES FOR 2005

MONDAY, JULY 11, 2005

TOPIC: MENTAL HEALTH ISSUES

SPEAKER: SIDDARTHA NADKARNI, MD

MONDAY, SEPTEMBER 12, 2005

TOPIC: EPILEPSY SURGERY

SPEAKER: RUBEN KUZNIECKY, MD

Each lecture will be audiotaped and available on the [FACES](http://www.faces.kintera.org/eveninglecture) website. There is no charge to attend the Evening Epilepsy Lecture Series, but you must register to attend by visiting www.faces.kintera.org/eveninglecture. Please contact Melissa at 212.871.0245 with any questions.

DONATIONS

November 2004 - April 2005

Thank you to all of our contributors!

\$15,000+

Levine Builders

\$9,000+

Tuberous Sclerosis Alliance

\$5,000+

The Epilepsy Project

Sylvia & Howard Rothbein

\$3,000+

Lorraine & Randy Smith

\$1,000+

Altria Group, Inc.

Lauren & Kenneth Meyer

Rosenson Family Foundation

Richard Shane & Treasure
Chest

\$500+

Alice & Daniel Cunningham

Anne & Thomas Deutsch

Nancy Eng & Deutsche Bank

\$200+

Cheryl & Max Batzer

In honor of Michael
Weisberg's birthday

Katherine Cooney

In honor of Christine Toes

Laura & Kenneth Lund

In honor of Dr. LaJoie

Sharon Perhac

In honor of Christine Toes

Dr. & Mrs. Joshua Shuchatowitz

The Shulist Family

In honor of Dr. Devinksy,
Dr. Miles, Dr. LaJoie & "the
guy with the magic hands,"
Dr. Weiner

Phyllis & Lester Smith

In honor of Michael
Weisberg's birthday

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!

TUESDAY, JULY 5, 2005
yankees game

MONDAY, JULY 11, 2005
**evening epilepsy lecture series:
mental health issues**

MONDAY, SEPTEMBER 12, 2005
**evening epilepsy lecture series:
epilepsy surgery**

SATURDAY, SEPTEMBER 17, 2005
**epilepsy conference:
2005 epilepsy symposium**

TO BE ANNOUNCED

**the faces of epilepsy at
the school of visual arts**

Please note our new address:
724 Second Avenue, New York, NY 10016

Suggestion Box:

If there are events, programs, newsletter articles, or
conference topics you would like **FACES** to work on,
please contact us at NYUfaces@yahoo.com.

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

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
Peggy Guinnesssey, CTRS	212.263.8782
Eric Halgren, Ph.D.	617.726.5464
Maria Hopkins, RN	212.263.8359
Ruben Kuzniecky, M.D.	212.263.8870
Josianne 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 (Manager CEC)	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
Siddhartha Nadkarni, M.D.	212.263.8870
Souhel Najjar, M.D.	212.263.8872
Steven Pacia, M.D.	212.263.8875
Kim Parker, RN	212.263.8871
Catherine Schevon, M.D., Ph.D.	212.263.8870
Melanie Shulman, M.D.	212.263.8856
Alyson Silverberg, RNNP	212.263.8873
Anuradha Singh, M.D.	212.263.8311
Rolando Sousa, M.D.	212.604.4206
Ravi Tikoo, M.D.	212.263.8318
Pat Traut, RN	212.263.8871
Blanca Vazquez, 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