

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.

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*The faces newsletter
is edited by
Valerie Lusczek and
Alethea Morris,
with support from
Daniel Miles, M.D. and
Ruben Kuzniecky, M.D.*



SCHOOL OF MEDICINE
NEW YORK UNIVERSITY

Does Epilepsy Affect The Brain In Between Seizures?

We all know that seizures are the defining feature of epilepsy, but does the brain function completely normally in between seizures, in the “interictal” state? Until recently, both physicians and patients were taught that while brain function was clearly disrupted during a seizure and perhaps for several minutes afterwards, during the “post-ictal” state, at all other times brain function was entirely normal. However, thanks to patients with epilepsy speaking up about their problems with memory, language and other cognitive abilities, we are learning that some types of epilepsy can affect certain aspects of thinking, or cognition, even in between seizures. At the NYU Comprehensive Epilepsy Center, Dr. Arthur Grant, MD, PhD has a National Institutes of Health (NIH) grant to study the effect of temporal lobe epilepsy (TLE) on perception. Specifically, he is investigating vision, hearing and touch perception in patients with TLE. The research study has two parts. First, Dr. Grant and his colleagues are comparing perception in people with TLE to that of control subjects who do not have epilepsy. All of the subjects undergo a battery of visual, auditory and somatosensory (touch) tasks, each of which assesses a different aspect of perceptual acuity or sensitivi-

ty. In the second part of the project, Dr. Grant is comparing how well patients do on these tests of perception before and after surgical treatment of their epilepsy with temporal lobectomy. In this procedure, reserved for those patients whose seizures can not be controlled with medication, an epilepsy neurosurgeon removes part of the temporal lobe of the brain, including the part that generates the seizures, the “seizure focus”. While you might think that removing a part of the brain would necessarily result in deficits of brain function, it is also possible that removing “nociferous cortex”, such as the abnormal brain tissue that generates seizures, could allow the rest of the brain to behave normally.

Although the research is ongoing and patients are still being recruited, some preliminary results are becoming available. Patients with TLE do show minor but significant impairments in some of the touch and hearing tasks, but not on any of the visual tasks. This finding is not surprising when one considers that the visual part of the brain, the occipital lobe, is both anatomically and functionally very distinct from the regions of the temporal lobe where seizures usually originate. On the other hand, sound and touch information is processed by parts

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Donations to faces support epilepsy research and programs for all persons affected by epilepsy. All donations are tax-deductible. For more information please contact faces at FACESinfo@nyumc.org.

Faces Has Some New Faces

Spring represents new beginnings, new opportunities and a refreshing outlook - a time to look back at the past, celebrate previous accomplishments, and set a fresh course for the future. To help with this new vision - a new team.

Please welcome Valerie Luszczek, Executive Director for **faces**. Valerie comes to us from Memorial Sloan-Kettering Cancer Center where she was previously Director of Donor Relations in the Department of Development. In her spare time, she devotes her time and talents to a local organic farm-based non-profit organization called the Poughkeepsie Farm Project, for which she is the incoming Chairman of the Board. Several years ago, Valerie made a purposeful career change into the not-for-profit sector to fulfill her passion to directly impact a positive change in the world.



Valerie Luszczek

She brings with her an expertise in development, fundraising, and special events as well as general operations.

We are also privileged to have Alethea Morris, **faces** Coordinator, join our team. Alethea is no stranger to NYU; she was part of the Department of Development for 16



Alethea Morris

years in various roles, most recently in the Special Events division, where last year she helped implement the highly successful 2006 **faces** Gala. Alethea enjoys swimming, handball and running, and annually volunteers her time to manage the Colgate Women's Games – the world's largest amateur track meet. Alethea is a welcome addition to the **faces** team.

As our two new staff members are settling in, please feel free to reach out to them to introduce yourself, offer your suggestions, or stop in to say hello. **Faces** is here to serve individuals and families who are affected by epilepsy, and Valerie and Alethea are committed to this mission, and to furthering the good work that has been the foundation of this organization since its inception.

We look forward to reinventing ourselves, strengthening the services we have, and identifying others we need. The common denominator in this vision is you. Through your ideas, volunteerism, and generous philanthropy, together we are one step closer to Finding A Cure for Epilepsy and Seizures. ❖

Even though I'm only 32, I've suffered from epilepsy for about 15 years. When I was 14 years old I was injured on my head, and as a result I suffered from complex-partial, secondary-generalized and grand mal seizures. At first I didn't know what was going on. I would wake up and not remember lying down to fall asleep or my tongue would be bitten to the point where I could hardly speak. It started feeling a little too weird so I told my mother and she took me to the hospital. They told me I was having seizures. My mother supervised me until she saw me have one; she said I would stare without blinking while shaking my right hand or sometimes lose my balance and fall to the floor.



Andrea Edwards

From that moment on I was embarrassed of myself and didn't want to be around friends that didn't know about my injury. I tried to hide it from them.

Unfortunately that was difficult since I was having three different kinds of seizures – over a dozen times a week. I was taking three antiepileptic drugs (AEDs) twice a day and felt like my life was already over at 17. Instead of going out and shopping with friends, I was constantly in clinics, hospitals and seeing therapists.

Over the years I've had just about every AED for epilepsy and have been to countless hospitals. Unfortunately it seemed that the doctors only continued to increase my dosage even though I complained about side effects and how my seizures were getting worse. The side effects of the AEDs were too much and too strong for me to handle, especially bad mood swings, loss of appetite, memory loss, and the worse feeling anyone can have - suicidal thoughts. I really felt as if I was going crazy and that my life should end. Once my mother found out about this she would stay up at night so she could sit awake outside my bedroom to watch and supervise anything and everything I did. I

realized I was in need of help so I visited the Epilepsy Institute and they introduced me to the International Center for the Disabled (ICD) program. At ICD I met people who had epilepsy and other disabilities. Meeting others made me open up, stop being embarrassed of myself and always thinking when I was outside that all eyes were on me.

In August 2005 I was hospitalized at NYU, the best hospital for epilepsy. Dr. Siddhartha Nadkarni, the first doctor I ever had in my life that really listened to my complaints, took note about my seizures, medications and the terrible side effects. He grabbed my hand and said "Andrea trust me, you're at the right hospital! We will be very happy to give you the help you are asking for and need."

*Today I am on
KEPPRA, and
tolerating it very well.*

I was monitored at NYU Medical Center and hospitalized for 5 days. I was shocked to finally be hospitalized in a great hospital with a kind and caring staff. When I walked out of NYUMC on August 13th, 2005, I

never knew it felt so good to be happy!! This was my first smile since the day before my injury in 1989. I've been to many different hospitals and seen so many physicians but unfortunately none of them worked as partners with me in my care. My AED regimens persistently had very difficult side effects which were affecting my quality of life - yet even though I was constantly complaining and communicating, it seemed as if no one was listening. After working with the team at NYU it was apparent my medications were not working in conjunction with my lifestyle. Dr. Nadkarni listened attentively, discussed it with me, and changed my medication based on my feedback. Today I am on KEPPRA, and tolerating it very well. Because of the professionals at NYU, I am very happy with my new and improved life.

I've been seizure free since August 2005. My appetite is back, and my everyday frown has turned into an everyday smile! Now I am able to focus much better

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Research Update

The EPGP Study Had Been Funded and Is Underway!

The Epilepsy Phenome Genome Project is the largest epilepsy study to date. Thanks to **faces** which provided \$400,000 in seed money, the study is now funded by the National Institutes of Health (NIH) for \$22.5 million dollars. It involves 14 epilepsy treatment sites, of which NYU and University of California, San Francisco are the coordinating centers. Dr. Kuzniecky is one of two lead investigators for the overall project. Dr. Devinsky is the principal investigator for the phenome portion of the study. This project will help create the largest database of epilepsy cases to better understand how genetic factors contribute to causing epilepsy, influence why some patients respond and others do not to antiepileptic drugs, and why some genes interact to produce “benign” and “refractory” forms of epilepsy. Our hope is that this information will lead to a major advance in our understanding of epilepsy syndromes, their genetic basis, and their treatment.

Direct Brain Antiepileptic Delivery System

Work continues on the development of a novel medical implant that can monitor the electrical activity of the brain and deliver antiepileptic compounds “on demand”, directly onto the cerebral cortical epileptic focus to prevent or stop seizures. The team, made up of Dr. Ludvig, Dr. Kuzniecky, Dr. Devinsky, Dr. Doyle,

Dr. Sheffield, Mr. Baptiste, Mr. von Gizycki and Ms. John, recently proved in animal experiments that it is sufficient to deliver these antiepileptic compounds, such as pentobarbital or GABA, into the cerebrospinal fluid just above the epileptic focus to achieve a seizure-controlling effect. Importantly, this delivery method leaves the normal brain tissue intact, while it can be used to treat epileptogenic regions both resistant to conventional drug therapy and unsuitable for surgical resections. These findings were recently published in the journal *Epilepsia*, with a second related paper soon appearing in *Epilepsy Research*.

While this research has proved the therapeutic viability of this envisioned medical implant, the actual construction of the entire device has yet to be completed. On this front, the group has achieved two promising results. With our engineering colleagues, Geza Medveczky, Laszlo Kando and Lorant Kovacs, we have shown that several prototypes of miniature, implantable pumps are suitable for delivering antiepileptic compounds onto the cortical seizure focus, while also allowing the simple, periodic refilling of the implanted pumps through the skin. Second, in collaboration with Mr. Rick Rizzolo at DocXS Biomedical, Dr. Ludvig designed a multi-port silicone catheter that works with these minipumps and can dispense antiepileptic compounds over the cortical epileptogenic zone.

continued on next page

Does epilepsy affect the brain in between seizures? continued from page 1

of the temporal lobe itself, as well as the neighboring parietal lobe. It is still too early to tell how performance on these tests changes after temporal lobectomy surgery. However, if performance improves after surgery, it would be strong evidence that this type of epilepsy surgery may do more than stop seizures, it may actually allow other parts of the brain to begin functioning normally again.

Many questions are still unanswered. For instance, what causes impaired interictal cognition, whether in the form

of memory, language, or perception difficulties? Can these cognitive problems be treated without epilepsy surgery, for instance with specific remedial training, or medications? Would epilepsy surgery be a consideration in someone whose seizures are reasonably well-controlled with medication, but who suffers from significant interictal cognitive problems? Hopefully these questions and others will be answered as research into TLE and perception continues at the NYU CEC. ❖

Research Update *continued*

These animal and engineering studies have laid down the groundwork for a pilot clinical study to answer the fundamental question of whether localized cortical drug deliveries can prevent epileptiform EEG spikes and seizures in the human epileptic focus. The team will soon test, using the newly developed multi-port catheter, whether localized applications of GABA and other compounds (e.g., lidocaine) onto the seizure focus, just prior to its neurosurgical removal of the seizure focus, can eliminate the focal epileptiform EEG spikes in epilepsy patients. ❖

Childhood Absence Epilepsy (CAE) National Multi-Center Trial

The NYU Comprehensive Epilepsy Center is currently participating in a national multi-center trial for children diagnosed with childhood absence epilepsy (CAE) but not yet treated. The study is supported by a grant from The National Institute of Neurological Disorders and Stroke (NINDS). Approximately 439 children at over 30 medical centers across the United States will enroll in this study over a three year period. Dr. Tracy Glauser from Cincinnati Children's Hospital is the study chair and Dr. Daniel Miles is the Principal Investigator at our center.

Children between the ages of 2-1/2 to 13 years of age are being asked to participate. Patients with CAE experience brief staring spell seizures that occur suddenly,

unpredictably, and frequently throughout the day. This is a randomized, double blind comparative trial of ethosuximide, lamotrigine, and valproic acid as initial monotherapy. While there are many medications to choose from to treat epilepsy these three are usually used as the first treatment for children with CAE. Ethosuximide and valproic acid have been approved by the Food and Drug Administration (FDA) for the treatment of children with CAE. Lamotrigine, which has been studied before in children with CAE and is the third most commonly prescribed medicine for this type of epilepsy, has been approved by the FDA only for the treatment of children with other types of seizures, and its use for children with CAE is still considered investigational. Although each of these medicines may help, not all medicines work for all children, and each has certain side effects. We do not know which of these three medicines is the best first choice for children who have just been diagnosed with CAE, nor do we know why one medicine and not others control some children's seizures. The purpose of this study is (1) to find the best medicine to use first to treat children with CAE, (2) to learn more about how these medicines effect children, and (3) to find out if there are tests that in the future could be used to help pick the best medicine for each individual child diagnosed with CAE.

If you are interested in having your child participate in this research study please contact the NYU Comprehensive Epilepsy Center at (212) 263-8359. ❖

My Story *continued from page 3*

which helps and guides me to accomplish my goals. I am living the life which I never thought was possible before I met the professionals at NYUMC!! I give thanks to all the neurologists especially Dr. Deepak Madhavan and the wonderful Dr. Siddhartha Nadkarni, as well as the therapists and the supportive staff at NYU. I extend special thanks to friends and loved ones, including my loving mother, who stands there beside me regardless of the situation. Trust me, even

though we're the ones that are diagnosed with epilepsy and taking AEDs, they are suffering much more by watching us go through it and not being able to stop it.

To all people with disabilities, don't be ashamed to speak out about yourself. Share your thoughts and feelings more often. The more we speak about it, the more we learn about it. The more we learn about it, the more we can help each other!! ❖

Faces Gala 2007

A paramount success, the **faces** 2007 Gala raised a record amount for epilepsy research, clinical programs and community-building events. Held on Monday, March 5th at Pier Sixty at Chelsea Piers, over \$4.3 million was raised at this annual event!

We extend our warmest appreciation to all those who have made this possible, especially our extraordinary Gala Chairs Lannie and Howie Lipson, our dedicated and tireless Auction Chair Kathyann Gruss, and Anna and Jim Fantaci for generously underwriting the event. We also thank Leah Weisberg and Randi Levine for their continued commitment and dedication.

The memorable evening opened with Hugh Hildesley as Master of Ceremonies and Auctioneer who reminded us all of the reasons that we work together to make this event a success, "...we come here because we want to make a difference, and to make further progress in the incredible job that's being done, not only in the treatment of epilepsy but in educating the world around us..." We were all honored to have Tiki Barber join us, making the event very special. Dr. Orrin Devinsky, Director, NYU Comprehensive Epilepsy Center, shared highlights of the work that has been accomplished over the past year, many of the initiatives which are highlighted in this newsletter. The room was touched by both individuals who were honored - Warren Lammert and Howard Weiner, M.D. - each an incredible champion for advancing epilepsy treatment, education and awareness, and most importantly making the world a distinctly better place for those living with epilepsy.

Our sincere congratulations to the honorees, and thanks to the many, many people who've been wonderfully generous, including: Katie and Todd Boehly, Harry Falk, Anna and Jim Fantaci, Loretta Brennan Glucksman, Kathy and Warren Lammert, Lannie and Howie Lipson, Andrea and Anthony Melchiorre, Mary Q. Pedersen and Alice Thorpe. There are so many people who gave generously, both in time, talents and resources - we are grateful to the Benefit Committee, volunteers, professional staff, donors and friends. With your help, our **faces** family is stronger, and together we are one step closer to Finding A Cure for Epilepsy and Seizures. ❖



Tiki Barber and Orrin Devinsky, MD



*Dr. Jacqueline French, Warren Lammert,
Dr. Ruben Kuzniecky*



*Tom Lindsey presents Dr. Howard Weiner
with an award*



Gala Chairs, Howie and Lannie Lipson

*For a copy of the Gala 2007 journal, which lists all of our incredible supporters, please contact the **faces** office.*

Faces Apartments

Furnished apartments are available free of charge for the parents and families of patients seeking epilepsy treatment at NYU Medical Center. Offered to those who are traveling from far distances and are unable to afford a lengthy New York City hotel stay, the apartments are available at no fee due to donations which help defray the cost.

With treatments lasting anywhere from several days to several weeks, the **faces** apartments have a constant waiting list. And, we know from people who have had the chance to stay in a **faces** apartment, what an amazing difference it makes...

“We would like to express our gratitude regarding our stay at the faces apartment next to the NYU Medical Center. We are from San Francisco and our 4-year-old daughter Julia had epilepsy surgery at NYU. We were in New York for 4 weeks for her surgery and recovery. The last week of Julia’s stay, we stayed right next door to the hospital in the faces apartment... The amenities were everything we needed and did not have to venture out too far away from our daughter.”

– Janine & John Steenman

“Our son, Cesare, is 10 years old and was diagnosed with intractable epilepsy in 2003. After three long years of suffering with epilepsy, we found Dr. Howard Weiner and the NYU Comprehensive Epilepsy Center. We have accompanied our son Cesare to NYU for surgery on three different occasions thus far. On only one of those occasions, the longest stay in January 2007, did we have the great gift of having a FACES apartment. The psychological stress that parents experience when

their child is going through brain surgery is immense. Having a place where we could go, away from the sickness, the IV alarms and the constant flow of medical staff helped us to cope with our son’s ordeal. Equally important, having the FACES apartment kept our family together during that very difficult time. Cesare has a twin whom he is very close to. His brother, Griffin, suffered during Cesare’s first course of surgery in September 2006 when there was no apartment to bring him to. Being separated from his twin and from his parents exacerbated Griffin’s stress- impacting his school performance. This past January, when Cesare was in the hospital for more than three weeks, having his brother by his side each day gave Cesare enormous comfort, and calmed Griffin’s anxiety.

We cannot thank FACES enough for this rarest of gifts. We only wish there were apartments available for every family who needs one. ”

– Amy Silvestro and Tom Richardson

Realizing the need to obtain an additional space to alleviate our long waiting lists, we appealed to the big-hearted folks who attended the 2007 **faces** Gala. The excitement of the live auction concluded with an appeal for children’s services and a commitment for a third **faces** apartment.

Grateful for the extraordinary generosity and support, and with almost \$300,000 pledged that evening, **faces** has now secured an additional apartment! Thank you to everyone who stood behind this effort at the Gala, and all year long with donations directed to supporting this initiative. ❖

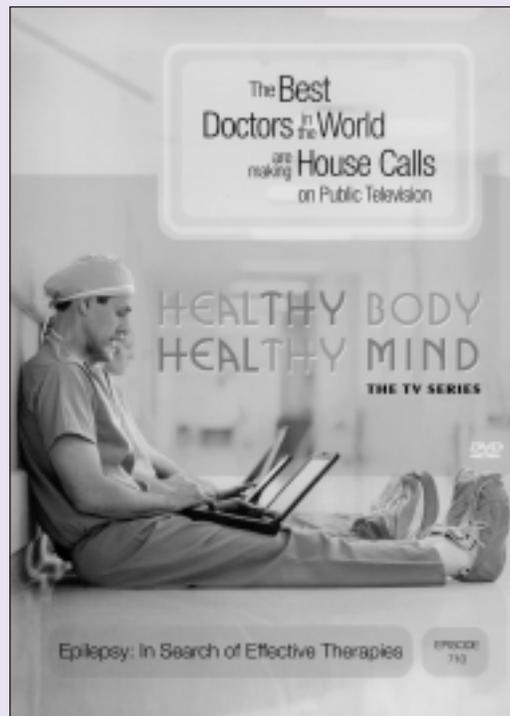


Amy Silvestro, Griffin, Cesare, Tom Richardson



Cesare and Griffin

PBS Documentary



Faces is an advocate for finding new therapies and works closely with the Epilepsy Therapy Development Project, Co-founded by Warren Lammert, Chairman. **Faces** co-hosted an event at The Xchange where the new documentary entitled “Epilepsy: In Search of Effective Therapies” was debuted. One of the first educational films of its kind, it highlights the challenge of 1/3 of the population affected by epilepsy, approximately 1 million people, whose seizures are uncontrolled. This important documentary simultaneously raises awareness through patients and families sharing their stories and encourages the discovery of novel AEDs and additional research, both of which are vitally needed. To learn more or to view the documentary visit www.epilepsy.com.

Evening Epilepsy Lecture Series

The 2007 Evening Epilepsy Lecture Series is underway. Led by NYU Comprehensive Epilepsy Center physicians, the lectures offer a topic of interest followed by a question and answer session. The first lecture took place on Monday, March 26th where Arthur Grant, MD, PhD presented information on “Memory and Epilepsy.” Our April 23rd lecture, featuring Dr. Katherine Mortati, focused on “Epilepsy-Understanding Your Condition.” Each lecture is recorded and posted on our website. If you missed these events, please visit www.nyufaces.org and click on the Downloads page.

Upcoming lectures include:

Monday, June 25, 2007
“Epilepsy, Diet and Nutrition”
Josiane LaJoie, MD

Monday, September 24, 2007
“Women’s Issues and Epilepsy”
Blanca Vazquez, MD

The lectures are open to all and are free of charge. Food and beverages are served prior to each event, and are held at NYU Medical Center, 550 First Avenue, New York City. To register for the lectures please email us at facesinfo@nyumc.org or contact Alethea Morris at 212.871.0245 x113. We look forward to seeing you there!

Faces GAME DAY

Save the Date! Join us on Saturday, September 29, 2007 for the annual **faces** Game Day, held at the Field House at Chelsea Piers in New York City. This free event will be filled with fun activities for children of all ages including carnival games, rock climbing wall, gymnastics center, basketball courts, soccer fields, batting cages, clowns and more! Stay tuned for more details...

faces

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YOUNG ADULTS INSPIRE

The **faces** family is made up of many bighearted people, whose time, talents and generosity shape this organization, and help advance the work we do in a positive way. Samantha Weiss, 12, and Ryan Garske, 16, are two young adults who happily surprised and inspired **faces**, and all those in our community. In their own ways each has made a difference in many people's lives, and we are deeply grateful. ❖

Ryan Garske's Generosity Touches Many Children

Ryan, a sophomore at Chaminade High School in Long Island, was recently inspired to improve the quality of life for kids at NYU hospital. Ryan was in the hospital with his brother, Chris, who has epilepsy and was being monitored for a few days. The Garske family is no stranger to hospitals - Chris had been admitted four times in the past and many times to a different hospital in Long Island. Chris's family usually accompanies him, so Ryan knows how long it can seem when you are waiting for your loved ones to get better, or when you are lying around yourself and waiting to recover.



During their visits the boys often play with the Playstation game consoles provided by Child Life Services, which have helped make the time go by more quickly. Recently, when Chris was in the hospital, the two brothers were playing on the Playstation. The game consoles are shared with the other kids on the floor, and Ryan realized that there were many kids in the hospital who would love to be able to play, but they couldn't all use it at once. He had an idea...

Ryan had been saving his own hard-earned money to buy the newly released Playstation 3 for many months. However, after realizing how much the children in the hospital enjoyed using the Playstation and how important it was for them, he changed his mind. Instead he purchased two Playstation 2s with the money he had saved, and he donated one to the hospital - this way more people could play at the same time! Ryan didn't stop there; he also collected many games from his friends and brought them all to the hospital as well.

His parents were happily surprised to learn of his sudden inspiration. Pleased that their 16 year old

chose to share his earnings with children that were ill and he didn't even know, than to get the latest games for himself. Ryan and Chris are enjoying their new playstation2, as are the kids in the hospital!

The entire staff of the NYU Comprehensive Epilepsy Center and the Pediatrics unit greatly appreciates Ryan's thoughtfulness and generosity. Ryan has inspired us all, and has touched many lives in the process. Thank you, Ryan, for your kindness. ❖

Samantha Weiss' Unending Generosity

Samantha Weiss, known to her family and friends as Sammi, is a very special young lady. She recently celebrated a rite of passage, her Bat Mitzvah. This celebration is a milestone and usually remembered fondly for many, many



years – and in this case it will not just be Sammi and her family and friends who recall this event, but also **faces**.

Sammi has selflessly asked her friends and family for her Bat Mitzvah to direct contributions to **faces** in lieu of gifts. An incredible donation has been presented by Sammi to her doctor, the Director of NYU Comprehensive Epilepsy Center, Orrin Devinsky MD - a check worth almost \$40,000!

We thank the Weiss family for all that they have done and continue to do for **faces**, and we thank Sammi for being exceptionally generous and wonderful. On behalf of all those that will be touched by this superb donation...thank you! ❖

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January 2007 – April 2007

Thank you to all of our contributors!

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UPCOMING EVENTS

Please visit our website, www.nyufaces.org for additional information on our upcoming events!

Evening Lecture Series

MONDAY, JUNE 25, 2007

Topic: Epilepsy, Diet and Nutrition

MONDAY, SEPTEMBER 24, 2007

Topic: Women's Issues and Epilepsy

See page 8 for more information

Faces Game Day at Chelsea Piers

SATURDAY, SEPTEMBER 29, 2007

See page 9 for more information

Faces Epilepsy Conference

SATURDAY, OCTOBER 27, 2007

More details to follow soon!



SUGGESTION BOX:

We always welcome suggestions for our newsletter. If there are ideas you would like to share, please email us at facesinfo@nyumc.org or (212) 871.0245

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