What’s New in Antiepileptic Drugs?
by Dr. Jacqueline French

This article will provide a recap of the emerging antiepileptic drugs (AEDs) and the clinical advances we saw in 2008. In the last two decades, a dozen new AEDs have been introduced to the market. However, since 2003, a year when Levetiracetam (Keppra™), Zonisamide (Zonegram™) and Oxcarbazepine (Trileptal™) were all approved, only a single additional AED, pregabalin (Lyrica™) joined their ranks. In contrast, this has been a banner year for AED progress. There are many promising drugs in the pipeline, and we have three new AED approvals. All the newly approved drugs were already available in Europe, Rufinamide (Banzel™) for the last 6 months, Vigabatrin (Sabril™) for the last decade, and Lacosamide (Vimpat™) only for the last few months.

This is good news, as it means we know more about the effects of the drugs in a broader population. Rufinamide, marketed by Eisai Pharmaceuticals, is approved for use with children and adults with the Lennox-Gastaut Syndrome, but it was also effective with partial seizures in clinical trials. Common side effects are headache, dizziness, fatigue, somnolence, unsteadiness, double vision, and nausea, but these tended to be mild, and few people discontinued due to side effects in the trials that led to drug approval. No safety issues have been identified with the drug. Some interactions with other AEDs may occur. Vigabatrin, marketed by Ovation Pharmaceuticals, will be approved for use in infantile spasms, a type of seizures occurring in...
Greetings from faces. It has been quite some time, but we are pleased to present the Spring issue of the faces newsletter. faces has experienced a number of changes over the past year—we have a new home, a new website and new members of the team. What remains the same is our commitment and dedication to our community and to funding innovative and cutting edge research that will someday lead to a cure.

By the time you receive this newsletter, you may already have seen the April 20th issue of Newsweek with its cover story: “The Mystery of Epilepsy: Why We Must Find A Cure.” Our own Dr. Devinsky is featured in this very timely issue, which speaks of how epilepsy in America is widely misunderstood and how research has been grossly underfunded for far too long. The article makes note of the incredible team at the Comprehensive Epilepsy Center with attention paid to faces for its work in promoting research and supporting new treatments. It is an incredible first step but we all know we must do more to advance our mission.

The faces team plans to use the summer to prepare for the upcoming year. We are already working closely with our Parents Network and have scheduled Game Day and our Annual Conference. We also look forward to trips to minor league baseball games and even kick off the first ever faces Lemonade Stand challenge. There are many ways to get involved and we welcome your ideas and support. When you visit the Center, please stop by the faces office and say hello!

The Epilepsy Phenome/Genome Project is the largest study ever created to identify genes that influence the development of epilepsy and genes that affect the response to treatment. The study is looking for two types of people: 1) people who have been diagnosed with epilepsy and who also have a brother or sister with epilepsy; 2) people who have epilepsy due to infantile spasms, Lennox-Gastaut Syndrome, polymicrogyria, or periventricular nodular heterotopia. To learn more please visit http://www.epgp.org.
infants, as well as for partial seizures. However, the FDA will require people taking this drug to be monitored closely. While it can be very effective for seizure control, it is associated with the occurrence of visual field restrictions that, once they occur, are irreversible. Since monitoring cannot necessarily avoid these problems, the potential benefits of using the drug must outweigh the risks. UCB Pharmaceuticals will market Lacosamide. It will be approved for use in partial seizures only. Common side effects are double vision, dizziness, headache and nausea, which are more common as the dose is increased. No interactions with other AEDs are foreseen. These three drugs will provide new opportunities for patients whose seizures have not been controlled with any of the previously available AEDs. In addition, many other AEDs are currently undergoing testing in clinical trials at the Comprehensive Epilepsy Center. Anyone who would like to find out more about clinical trials should feel free to contact the Clinical Trials Team or to ask their physician at the Center.

Dr. Jacqueline French is the Director of the Clinical Trials Consortium at the Comprehensive Epilepsy Center at NYU Langone Medical Center and is the recipient of the 2005 American Epilepsy Society Service Award. She is head of the Scientific Advisory Board for the Epilepsy Therapy Project and is the current Director of the epilepsy course for the American Academy of Neurology.

"Fun in the Sun"

At the faces Gala, held on March 10th, we announced that “In recognition of her unparalleled compassion and dedication on behalf of her patients, we establish, in her honor, the Blanca Vazquez Summer Camp Scholarship Program.” To learn more information about some of the camps we sponsor, you may call the faces office at (646) 558-0900.

Sean is 9 years old and suffers from daily seizures. He is unable to speak. I am his sister so I will tell his story.

Sean and I attend camp together. He is in the Comet Moon group. Sean’s favorite activity of the entire day is swimming. He loves to kick and swim around on his own. Running around in the yard or indoor gym is also lots of fun for him. He is quite fast and usually hard to catch! In Arts & Crafts he will color and during movies, Sean prefers to nap. At camp we have a DJ that plays all the coolest music and Sean loves to dance. He sways to the beat and hums the tunes. Several of Sean’s classmates attend camp also so they have their group of friends. Sean cannot speak and most of his friends can so they take on a protective role with him. Everyone in camp knows that the cute little redhead is named Sean and he loves to sit on your lap and cuddle. Although camp is in no way as structured as school is, a daily schedule is followed. Campers are given choices to whether they prefer some activities to others. Sean, through listening and signing, has learned to indicate his preferences to his counselors. And if all else fails, they come to get me to help translate! Every summer that Sean attends camp increases his independence and he has a great time. Thank you for helping give Sean this opportunity.

Sincerely,
Shannon Quirk, Age 10
A key component of the faces mission is to promote awareness and the need for a cure for epilepsy and seizures. Read these inspiring stories of people whose lives have been touched by this condition.

Regarding epilepsy, what I find helps me to deal with it best is my outlook. Sure, medication, support and a good doctor are imperative, but if my attitude were different it would be much more difficult to tackle the many setbacks that come along with having this illness. When I was younger it was difficult to understand why this was happening “to me”. I felt alone in a crowd. Now I am grateful that my seizures are controlled through medication. I feel confident amongst my peers. There are many ill-effects and side-effects that come along with this affliction no matter what stage you are regarding any short term or long term recovery. However, working hard to feel good gives me the strength and incentive to commute to work in NYC, to spend time with my family, to enjoy vacationing and so many other activities. To achieve the finest quality of life has always been a goal for me. Life simply has too many opportunities to pass by. Most importantly, I refuse to let epilepsy win this battle as I continually stare it in the face and show it my courage. One prescription that I would dispense and recommend – determination, all day, every day.

In my ten years of working as a recreation therapist at the HCC-12 Epilepsy Unit, I have had the fortunate experience of working with many patients and families and exploring the ways to enhance how they spend their free time.

One of the main things that I have learned is no matter the severity of one’s seizure; there is always a place for one to engage in recreation. Whether it is art, music, video games, sports or computers, patients need to have the experience of and the independence to do something they absolutely love. For example, I remember one particular patient who was in high school and unable to participate in his high school sports program due to his seizures. The patient, his mother, and I all discussed at length how he could still be part of a team; enjoy spending time with friends and socializing in a team setting without suiting up to play. The result was assisting the coach of the high school football team. In this role he was at every practice and on the field with the team at every Saturday game.

Though having epilepsy may create boundaries in one’s life, there are ways to adapt one’s leisure interests to help promote self-esteem and enhance one’s quality of life.
Brain Imaging Research at the NYU Comprehensive Epilepsy Center
by Thomas Thesen, PhD

Chronic epilepsy can have profound influences on the cognitive performance of patients across their lifespan. The Cognitive Neurophysiology Research Group at the NYU Comprehensive Epilepsy Center studies sensation and cognition in the human brain in health and disease using novel and sophisticated neuroimaging techniques. The young and active research team is headed by Thomas Thesen, Ph.D. and Chad Carlson, M.D., both Assistant Professors in the Department of Neurology, and collaborates directly with many other members of the Epilepsy Center. The goal of the research group is to investigate how the healthy brain processes sensory and cognitive information, such as language, memory and decision-making amongst others, and to understand what happens when these functions break down in patients with epilepsy. The group, consisting of basic scientists and clinical practitioners, has a special emphasis on translational research: moving state-of-the-art brain imaging techniques from the laboratory into the clinical practice, and at the same time using the clinical environment to generate novel hypotheses about brain function that can be tested in the laboratory. A major goal of the research group is to advance the understanding of cognition in epilepsy in order to help patients preserve and regain their cognitive abilities to enable them to live rich and fulfilling lives.

MRI Brain Morphometry

To study the relationship between brain structure and cognition, the researchers are using high-resolution MRI scans from healthy controls and epilepsy patients. These scans are analyzed with a novel and automated 3D whole-brain segmentation procedure for obtaining delineations of different neuroanatomical structures, including hippocampus, amygdala, thalamus, cerebellum, caudate, putamen, and globus pallidus and ventricles. This technique also measures the thickness of the cortical mantle at every point in the cerebral cortex, a metric which is especially relevant to seizures originating outside the mesial temporal lobes.

The MRIs of individual patients can thus be compared to a group of healthy individuals to detect small, but significant, changes in brain anatomy related to the patient’s epilepsy. These malformations can often cause seizures, but once detected and localized, they prove to be formidable targets for surgery because their removal carries a high chance of achieving seizure freedom. Current routine clinical MRIs rely on visual inspection and are not able to detect subtle malformations. This new method, developed with support from faces, allows for exact quantification and comparison of brain anatomy and has already shown to be more sensitive and reliable to detect disease-related changes in brain structure than conventional approaches. A better diagnosis leads to better treatment.

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There was a great buzz during the cocktail reception as guests of the 2009 faces Gala mingled and enjoyed their time bidding on the wonderful silent auction items on view. Over 620 guests attended this annual event, held at Chelsea Piers on Tuesday, March 10th, making it the largest fundraising activity that faces organizes.

The festivities began with the silent auction in which many of our faces volunteers were involved – from soliciting gifts, organizing the displays and encouraging guests to participate in the fun. The program then kicked-off with sports star, Tiki Barber, leading the many congratulations to Gala Chair, Mary Pedersen, and Auction Chair, KathyAnn Gruss. Next followed Dean Robert Grossman of NYU Langone Medical Center who, with Dr. Orrin Devinsky, offered their thanks to the gala leadership and the many contributors for their support.

The evening’s honoree, the Comprehensive Epilepsy Center’s
own Dr. Blanca Vazquez, in recognition of her unparalleled compassion and dedication in the field, was then awarded with the establishment of the Blanca Vazquez Summer Camp Scholarship Program. Dr. Vazquez’ heartfelt thanks to the doctors, researchers, staff and patients, who work tirelessly to eliminate the effects of epilepsy, was a moving highlight of the evening.

After dinner, Sotheby’s auctioneer extraordinaire, Hugh Hildesley, created a lively and fun atmosphere as he enticed the audience to bid on the exceptional live auction prizes. With the evening’s silent and live auctions, the dinner tables and tickets sold, the Gala Journal and the many contributions made by generous donors, this wonderful event raised over $2.9 million for faces and for the many research and community projects it supports. And finally, even before the dust has settled on the 2009 event, plans are happily underway for next year’s 10th Anniversary Gala.
Mapping of brain function for presurgical evaluation

For patients with medically intractable epilepsy, surgery is often the last hope for obtaining seizure freedom. A comprehensive evaluation prior to surgery, including mapping of brain functions are often essential for success. We are using non-invasive functional MRI and Magnetoencephalography (MEG) along with task paradigms that conform to the current standards in cognitive neuroimaging to study and localize areas in the brain that are associated with language, memory, movement and touch. These assessments help the clinical and neurosurgical team to better ensure that the surgical procedure will only target epileptogenic regions without having an impact on the patient’s sensory and cognitive functions.

Intracranial EEG

Candidates for epilepsy surgery often undergo intracranial EEG monitoring where electrodes are placed inside the skull and directly on the brain. Many of the patients agree to participate in cognitive studies during their hospital stay, a decision which does not influence their clinical care and is conducted in strict accordance with the ethical guidelines of the University Medical Center. The NYU Comprehensive Epilepsy Center has the highest volume of epilepsy surgeries in the country. Studying the human brain with intracranial EEG allows for the detection of brain activity with an unparalleled degree of spatial and temporal resolution. Over the past years we have assembled a consortium of high-profile collaborators from departments within NYU and other institutions, such as the University of California, San Diego and Harvard. Intracranial EEG studies conducted to date investigate a broad array of topics, such as memory, language, multisensory integration, face-perception and decision-making. We recently started work on brain computer interfaces, whereby a computer reads brain activity recorded from implanted electrodes and learns to interpret the signal. With this mechanism, a computer cursors or artificial limbs can be controlled through mere ‘thinking’. Such a neural prosthetic device may help patients with paraplegia or locked-in syndrome in the future. The research team is very grateful to all patient volunteers who have devoted their time to help us understand more about the brain and epilepsy! Without them, none of this exciting research would be possible.

Thomas Thesen is head of the Cognitive Neurophysiology Research Group and Assistant Professor of Neurology at the NYU School of Medicine. More information on the Cognitive Neurophysiology Research Group can be found at http://www.med.nyu.edu/thesenlab.
After successfully recovering from back surgery in 2002, I began a slow and steady decline in physical activity. Then one day in January 2007, while on a cruise with my family, I saw a picture of a rather fat bald man and my daughter. It took a few moments for me to realize that the person was actually me. It was only a matter of minutes until I was on the treadmill on the cruise ship! Two months and a gym membership later, a friend told me that no person should go through life without completing a triathlon. So off I went to train (and learn how to really swim). At the end of the summer, and after many months of training, I finally found an event: a half Ironman. About 11 miles into the run, I came to the realization that all of the effort I was putting forth should actually benefit someone, besides my massage therapist. So, during the spring of 2008, I decided to participate in 2 events to raise funds for charity.

Our 8-year-old daughter, Sloane, was diagnosed with a seizure disorder as a newborn. In my quest to "swim, bike and run" for charity, our family decided that faces was aligned with our needs and values as a family. We approached the faces team and explained our desire to raise funds for the organization. The staff could not have been more grateful and helpful. Within a couple of weeks faces had set up a website and people were making donations. By the time I completed the 2nd event I had raised $6,000 for faces. Overwhelmed by people’s generosity I felt the need to repay people the only way I knew how...more effort. In their honor, by the end of the year, I successfully completed my 2nd half Ironman and then the Philadelphia marathon several weeks later. Next year I plan to continue the effort (for faces of course) by completing several more triathlons. If you have any interest in sponsoring my efforts, please visit us on the web at: http://faces.kintera.org/GStriathlon.

As a special note of thanks, in addition to faces and Dr. Goldberg, I would like to thank my wife, Aimee, and kids for being so tolerant of my training schedule (sometimes I think my training is harder on them than me).

What a Mench!
by Eric Byrne-Oberman

“For my Bar Mitzvah, I held a fundraiser for my friends and family and used the proceeds to buy toys for the children being assisted by faces. I also donated a portion of the Bar Mitzvah money I received to faces. NYU faces helped a family member of mine and it was the least I could do to pay them back.”

You too can Fundraise for faces!

We can promote your faces fundraising efforts! For more information, please contact the faces office at (646) 558-0900 or email us at facesinfo@nyumc.org.
My whole life I’ve played the typical older sister role. But my role has involved another aspect that is not so typical: the responsibility of spreading awareness about epilepsy to people my age. Drew Blake, my younger brother, is in eleventh grade and has had epilepsy his entire life. He is on medication to control his seizures so, overlooking the daily pills and frequent doctor visits, he is able to live a relatively normal life. I feel obligated to inform our classmates about Drew’s condition so that they don’t get uncomfortable when he mentions his daily pill dosage or frustrated when he zones out temporarily. Drew is extremely comfortable with his epilepsy and makes no attempt to hide it; an attitude that I was inspired to adopt in order to attempt to eliminate the ignorance surrounding this disease, primarily at our school, but hopefully beyond it as well.

I began by looking for ways to actively get involved with faces. It turned out there was a need for gift bags that would be given to the children when they visited their doctor at the Comprehensive Epilepsy Center. Drew and I, along with a few of my friends from school, went to Liam’s house, a young boy with epilepsy who wanted to help, to fill the 500 bags with the goodies we purchased. Liam could not have been sweeter to all of us, but he took a special liking to Drew, possibly because of their shared illness. He insisted that Drew play the drums with him and watch a movie with him, the whole time grabbing Drew by the hand and leading him to their next destination. After seeing first-hand the almost brotherly relationship that was formed between the two boys in a matter of hours, as a result of the condition they share, I have developed a much more emotional connection to placing emphasis on the part of the organization that deals with such personal interactions. Even though fund-raising is always important, I believe that active involvement in hands-on activities like this one bring benefits to both the organization and to those participating. A result of this experience, a deeper sense of commitment to the success of the faces organization was fostered in myself and my friends. Drew and Liam developed a bond that will continue to grow. For others looking to help faces, there is always a need so don’t hesitate to actively get involved!

THE GIFT BAG
by Caroline Blake

CLINICAL TRIALS
by Kimberly Parker – Menzer, RN, NP and Mary Miceli, RN, NP

The Comprehensive Epilepsy Center at NYU Langone Medical Center has been actively participating in clinical research trials for over 15 years. Any antiepileptic medication that you may be taking was likely studied in these trials before making it into your pill box! Recruitment for these studies is difficult due to the inability to reach all individuals who may be appropriate study candidates or to the hesitancy of these potential candidates because of lack of information. What follows is a brief summary about clinical research and why you should consider getting involved.

Clinical Epilepsy Trials are medical investigations that test new treatments and therapies with the hope of uncovering better ways to treat, diagnose, and understand epilepsy. Research studies are carefully designed to safeguard participants’ health while answering specific research questions. Individuals must willingly volunteer to participate. Through a process called “informed consent”, participants are provided with the key information about the study in which they will take part. For example, participants learn the purpose, potential risks, benefits, and procedures involved in the study as well as what is expected from them for the duration of the study. There are many benefits to becoming a research participant that include helping other epilepsy patients by contributing to medical research, playing an active role in health care, potentially gaining access to new treatments before they become widely available and receiving regular and careful medical attention from a research team that includes doctors and nurses.

For more information about how you can be involved in clinical trials at the Comprehensive Epilepsy Center, please speak to your healthcare provider or contact the Clinical Trials Department at 646-558-0842.
My son had his first seizure when he was 11 months old. At the time they thought it was febrile and although a scary incident, I thought it was something we could deal with without medication. Within five months, he had a 20-minute, partial seizure, and our lives changed. He started the first of what would be eight different medications, most with little success. From his first seizure until he was five years old he had 135 tonic colonic (or “grand mal”) seizures, the longest being one hour. He is diagnosed with Generalized Epilepsy-Febrile Seizures Plus. Liam’s seizures changed our lives in a way that is hard to describe to most people with the exception of other parents who have children with epilepsy. The uncertainty and panic was ever present, but the isolation of the diagnosis was potentially the most challenging. Our family had no experience with seizures and no one in our group of friends had dealt with epilepsy (although when I start talking about my son’s condition, I’m always surprised by how many people have some connection to epilepsy). As with other life challenges, we thought we could handle it on our own and move on. We were wrong.

Thankfully, I had received a flyer about the faces annual conference and attended the daylong event in October 2004. It was the best thing I did to help not only our son, but also myself. For the first time, I was with a community of people who “got it”. My involvement with faces saved me from the isolation that is often hard to escape. The people I met at the conference and since then have helped me immeasurably. We are traveling a similar path. We finish each other’s sentences. We commiserate at the low points and celebrate the high points. We are a lifeline for each other when we need it the most.

When Peggy Guinnessey approached me about being part of a the faces Parents Network, I jumped at the opportunity. We are attempting to expand on the success of faces informal network and build a larger community of parents who can support each other. We are meeting with families who have newly diagnosed children and connecting them with parents who have been in a similar situation. In the past few months, I am sure I have gained more from my interaction with these families than I have given. I am continually amazed and comforted by the strength and resiliency of these amazing parents.

Thanks to the fine work of NYU’s Epilepsy Center, Liam has enjoyed a healthy 2009. I thought when we had reached this point there would be little I didn’t know about how to manage life with epilepsy, but the challenges continue...schooling, therapies, peer relationships. Thankfully, I have an incredible community of parents to turn to - their advice and compassion continue to change our lives.

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The parent networking program is designed to connect parents with parent mentors that have experienced similar issues when dealing with a child who suffers from a chronic illness. Whether it’s the hospitalization process, educational services or social support resources, the added benefit of speaking to another parent that has lived through this experience can be quite valuable. If you would like more information please contact Peggy Guinnessey through the faces office at (646) 558-0900.
A Call for Ideas and Articles

Do you love to write? Do you have great ideas for our newsletter? If so, please let us know! We are currently starting to think about the summer/fall issue of our newsletter. Please contact us if you have an idea for a story.

SAVE THE DATES:
Upcoming faces events!

Evening Lecture Series, Spring 2009
NYU Langone Medical Center
Smilow Seminar Room, 1st Floor
550 First Avenue
June 16th, 2009
Herbal Treatment of Epilepsy
Daniel Luciano, M.D.

October 10th, 2009
Game Day
Chelsea Piers

October 25th, 2009
Epilepsy Conference
NYU Langone Medical Center
Schwartz Lecture Hall

Ways to Help
If you would like to further faces mission, you can do so by becoming a volunteer or making a donation. For more information, visit www.nyufaces.org or call (646) 558-0900.