IN Inside:

Epilepsy and Driving
Two Sides of the Story

Dr. Vazquez on Burns & Epilepsy
What Everyone Must Know

Featuring:

Emma Davis’
“The Teen Scene”

My Sister’s Incredible Journey

Growing up in a home being one of four kids made for a lot of fun times and of course, frequent battles. From a very young age I remember my sister Kim, the youngest of the quartet, being very physically strong. She would even have the strength and courage to take on our older brother when his taunts got the best of one of his three sisters. This strength has proven to be an amazing gift in my sister’s life.

...article by Sharon Perhac continued on page 11
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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Parent’s Network Program

The Parent’s Network Program offers support for parents with the many challenges surrounding care for a child with epilepsy.

The Parent’s Network gives families much-needed information on:

- Educational Services
- Hospitalization
- Social Support Resources

Would you like to be a part of our Parent’s Network Program?
Would you like to get in contact with a support parent?
Interested in becoming a support parent?

For more information, please contact the faces office at (646) 558-0900 or facesinfo@nyumc.org
A LETTER FROM OUR EXECUTIVE DIRECTOR

COMMITMENT – that is the word I use to summarize faces and the NYU Comprehensive Epilepsy Center. My first day as the new Executive Director of faces began on February 1, 2011. It was an awful day outside with severe freezing rain that later turned to snow. However, indoors the energy, focus and commitment of the doctors, nurses, and administration was palpable. To be part of an organization where the bottom line goal is to find a cure for epilepsy and seizures is remarkable. I have been deeply impressed by everyone who takes part in improving the quality of life for all those affected by epilepsy and seizures. I have recently had the privilege of observing a brain surgery at the invitation of Dr. Werner Doyle earlier this spring. This remarkable experience in the OR demonstrated to me just how complicated, yet possible, it is to cure epilepsy.

As an ongoing commitment - faces has a top priority in making sure the information that you need is available. There will be a greater focus on our online development as we work through this summer. Our goal is to provide you with a revitalized faces website, featuring a blog, a LinkedIn page, a Facebook page, and a Twitter page to offer a forum for our community, while maintaining our standard as a primary resource for research, content, events, and all things related to epilepsy and seizures.

Enjoy the enclosed articles that reflect the work and commitment of so many these past few months. Also, I hope you enjoy the new format and presentation of the faces Newsletter.

faces would not be the organization it is without your unwavering and ongoing commitment! Thank you for all your support in numerous ways. Wishing everyone a safe and wonderful summer season, I remain,

Sincerely yours,

Brian G. Bachand

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THE EPILEPSY CONFERENCE

BY WENDY ABRAMOWITZ

On May 15, 2011, faces held their annual Epilepsy Conference which was very well received. The conference got started with volunteers setting up breakfast, signing people in and steering attendees in the right direction for their conference sessions. faces is very grateful for the help from the 35 volunteers who kept the conference on track.

Thanks to an overwhelming response to the invitation, there were over 300 attendees throughout the wide variety of presentations that were given. All of these presentations were based on research being done at the NYU Comprehensive Epilepsy Center as well as other medical facilities around the world.

Dr. Orrin Devinsky kicked off the conference with the morning keynote speech on Mistakes in Epilepsy Care. This was followed by two morning sessions where attendees had a choice of three different topics for each session. Topics in the morning ranged from Tuberous Sclerosis, Epilepsy Surgery, Pediatric Epilepsy, Depression and Anxiety in People with Epilepsy, New Developments in Diagnosis and Treatment, and Attention and Working Memory Challenges in Kids with Epilepsy. A great selection of topics to please all types of people attending the conference. The audience included patients and caregivers, along with medical students and the press. It was clear that much of the audience were quite knowledgeable as we all listened to the questions being asked after doctors completed their presentations. Indeed, there were so many questions that doctors continued their Q&A sessions in other rooms after their presentation times expired!

FINDING HER VOICE: ANN CARLETTA TELLS HER STORY

BY ROBIN DUNN FIXELL

“Every time I’m getting older, I’m really happy about it,” says Ann Carletta, an upbeat redhead who lives in Edgewater, New Jersey, and who turns 50 in a few weeks. In December 2005, after 36 years of suffering from seizures, she opted to undergo a left temporal lobectomy.

Ann believes that a head injury caused by a swinging baseball bat was the start of her epilepsy and so she began taking medication at the age of eight. Two of Ann’s sisters had seizures for a period of time, but it wasn’t until her thirties that Ann (oldest of nine siblings) really believed that she herself, had epilepsy. She always thought that a person diagnosed with the disease would drop to the ground and exhibit the signs of a grande mal seizure; and, although she did have a few seizures in which she lost consciousness, hers were mostly simple and complex partial seizures.

While Ann worked in the field of advertising for many years, she now pursues a career in acting. The irony of an actress losing her ability to speak became painfully apparent to her during an unfortunate incident on stage. Several years ago while performing in a play, Ann had a seizure on stage and though able to remember her part and walk to her designated place on stage, she was unable to speak her character’s lines. Although Ann felt that theater was never her true calling, she decided at that moment that she would never again take to the stage. She continues to act in television and movies, however, and currently has a role in “Men in Black III.”

“The seizures never motivated me to consider surgery,” says Ann, “but the cognitive problems did. I’m meds-free for a year now and seeing a huge difference in my cognitive ability. I called for pizza today and I knew the phone number! That is a new thing for me.”

It was after her surgery and speaking to other patients that Ann was inspired to go to medical school. Having always been fascinated by the field of medicine, Ann came to the realization that, as wonderful as her doctors have been, there is still a gap between patient and doctor in
At lunch time there were a variety of organizations providing information for attendees. These included resources like seizuretracker.com, a very helpful website that lets people with epilepsy keep track of their seizures online. The Epilepsy Foundation of Metropolitan New York was busy with participants, as were organizations discussing lesser-known syndromes such as Lennox-Gastaut, Tuberous Sclerosis and Dravet. Two drug manufacturers, Lundbeck and UCB both discussed particular drugs under development.

A third session took place in the afternoon where topics of discussion included New Technologies for Improving Memory, Seizure Safety and Risk, SUDEP, and Women’s Issues in Epilepsy. Finally, an afternoon keynote was given by Dr. Jacqueline French where she reviewed New Drugs on the Horizon and Generic Substitution.

But it was obvious from all of these presentations that there is much more happening in the epilepsy world than treatments through medication and/or surgery. As we know, Vagus Nerve Stimulation (VNS) has a certain success rate. But now, Responsive Nerve Stimulation (RNS) is under development and is going through the FDA approval process currently. RNA was discussed at two of the presentations. As well, questions asked by patients and caregivers were quite revealing as far as how certain generic medications may not control seizures to the extent that the original medications did. So in all, this conference proved worthwhile for attendees.

"...discussion included New Technologies for Improving Memory, Seizure Safety & Risk, SUDEP, and Women’s Issues in Epilepsy"

Other than the two keynote speakers, faces is grateful to the following doctors for their presentations: Drs. William Barr, Werner Doyle, Daniel Freidman, Scott Hirsch, Ruben Kuzniecky, William McAllister, Daniel Miles, Blanca Vazquez.

For those unable to attend, presentations from the 2011 Epilepsy Conference are available on the faces web site at http://faces.med.nyu.edu/epilepsyconference.

understanding how it really feels to have a seizure. Ann believes that by becoming a doctor herself, she can treat a patient and truly understand what that person has experienced.

Ann’s appreciation of life and the people who surround her is readily seen in her desire to give back through volunteering at faces. In addition to volunteering at the faces annual gala this year (as she’s done in the past), Ann wanted to do something to contribute to the evening whose honoree was her neurosurgeon, Dr. Werner Doyle. Ann decided to produce a tribute video along with several other former patients to honor the much-loved doctor by expressing their deep appreciation to Dr. Doyle for giving them back their lives.

"He doesn’t even know that we’re still talking about him," says Ann, who put the video on YouTube in March 2011. "If there’s any way I could ever properly say ‘Thank You’ to Dr. Doyle and Dr. [Orrin] Devinsky...still, to this day, I call Dr. Doyle my fairy god mother."

"Ann came to the realization that... there is still a gap between patient and doctor in understanding how it really feels to have a seizure."

And how has faces made a difference in Ann’s life? "It’s just an amazing group," says Ann. "I still talk to the friends I made before having my surgery," she says, referring to the bond shared by many of the patients she met through faces.

"The best example: I’ve worked at Game Day, where kids come with their families and every year, some parent approaches me and says, ‘My kid feels normal when he’s here.’“ Speaking with great enthusiasm, Ann continues: “I feel great supporting faces events as they raise money to find a cure for the disease—which is fantastic! And you’re around people like yourself!”
How did you find faces and how did you become connected to it?

My son was having increasing seizures when he was two years old and we were researching hospitals and doctors. The whole approach of everyone we spoke to at faces was more positive—very reassuring. Andrew responded very quickly to the medication. We donated some money. We went to the faces Gala and, little by little, we became more involved. I later joined the Steering Committee.

What kind of epilepsy does Andrew have?

Well, right now he has no seizures. He was on Depakote for about two and a half years and he was seizure-free during the whole time. We weaned him off the medication about eight months ago and so far he’s been seizure-free. He was having just petit, no grande mal; he would jerk and space out.

As a member of the Steering Committee, what has been your function?

Whatever I can do to help. Since joining the committee, we’ve [The JAR Group] offered our help pro bono to help identify and drive strategy for faces: how to use the website, how to drive additional exposure for the Gala. faces-Forward was something we suggested and then helped launch two years ago...not only to raise money, but to save [faces] money on the mailings and increase engagement. We’re looking for ways to engage a broader online community. There are very active communities around epilepsy online: there are discussion forums, social media, Facebook groups, etc. That’s where we’re hoping to try to continue moving faces--into broader engagement.

Since its inception in 2010, facesForward has raised over $130,000 for faces through its simple campaign run through emails and social media. Visit: bit.ly/facesforward2011 for details

Would faces be a warehouse of information and a forum for sharing ideas?

Yes, one of the areas we’re looking at now is the Epilepsy Conference faces puts on once a year. It’s amazing because it’s free and geared to the general public (not medical professionals)—and it’s a truly wide and deep breadth of what’s currently going on. What we’re working on are innovative and useful ways to put that online so people who don’t live in New York or people who don’t even know faces exists can do research. There is a great desire for information out there.

All presentations from this year’s Epilepsy Conference are available on www.slideshare.net/nyufaces

What is your approach on coping with your son’s epilepsy?

My wife has a bachelor’s in public health and MBA in health care administration, so following the rules and tracking things is pretty much second nature to her, whereas I’m more impulsive. With our son, my wife made sure we tracked everything—his medication, his reactions. We fought—not fought [A.J. chuckles]—as couples often do on how much do you protect and how much do you let the child be. We were told early on that: “Whether he goes out and lives his life as able as he is, or if he’s cautious—that’s going to come from you.” Children get that you’re worried about things. It’s very hard to protect your child, yet also teach them the idea of thinking for themselves.

What advice would you give to other parents whose children have epilepsy?

It’s always easy when you have people to talk to. No matter what your child’s experience, there’s someone who’s either lived it, or is going through it. It certainly helps to meet others who are going through a parallel circumstance and finding there’s a new perspective. That’s the best advice I can give.

By joining the faces community and attending faces events, patients, caregivers and friends can belong to a greater community who are affected by seizures and epilepsy and are all working towards a future without.
Home is a place where most people feel safe, but for a person living with epilepsy it’s a place full of hidden dangers. It is known that people with epilepsy have a higher rate of fatal car accidents than patients with other medical conditions. What is not so widely realized by patients and families is that home is the most common place for seizure-related accidents and in many instances is preventable. Home safety is a challenge for the whole family. As part of the comprehensive epilepsy care, patients and caregivers should have a discussion about home safety. It is crucial to anticipate potential accident scenarios in areas of the home such as the bathroom, stairs, fireplace, rooms with space heaters, and the kitchen, where domestic accidents are more likely to occur. Seizure events in any of these areas are dangerous and of more concern when a patient is alone. Adjustments needed to maintain safety are very much based on the frequency of seizures and the seizure type.

This article will explore some of the factors that may affect a patient’s safety in the bathroom and ways to lessen the risks of burns in the shower.

A FEW FACTS ABOUT THE RISK OF BURNS IN PATIENTS WITH EPILEPSY

- Patients with epilepsy are a high-risk population prone to severe burns as a consequence of seizures while showering.
- Epilepsy was three times more likely to be associated with burn injuries, with women being five times more likely to be burned.
- In a burn unit series, 7% of domestic burns were due to epilepsy.
- In some reports, up to 74.5% of the burns in patients with epilepsy were classified as third and fourth degree burns.
- Household water heaters supply water at about 65-75°Celsius. Yet, around 40° will provide a comfortable shower.
- The time taken to produce a full thickness scald burn injury in adults is ten minutes at 49°C, one minute at 53°C, five seconds at 60°C.
- Patients with epilepsy may sustain serious burns, affecting the trunk, legs, arms, and buttocks, when a seizure occurs while showering.

SOME RECOMMENDATIONS

- Individuals with epilepsy should use showers designed with pirouetting taps, rather than levers, to regulate water temperature.
- Patients should have safety devices installed in their water heaters that limit maximum water temperature.
- Set the temperature of the water heater low (120°F / 48.9°C) so that it won’t scald a person who loses consciousness.
- Turning on the cold tap first in the shower or basin and lowering the temperature of the hot water are good safety hints for any home.
- Keep all electrical appliances away from the sink or bathtub.
- A precautionary measure is to take medication first thing in the morning, 20-30 minutes before taking a shower.
- Hand held showers may be a good option for people with epilepsy since the water will not be directed to the body in case of seizures.

During the many years I have cared for patients with epilepsy, I have seen a significant number of patients fall victim to domestic accidents during a seizure or in the immediate period after an event. I have been very conscious of overall seizure safety, but am especially concerned with patient safety in the home environment. I worry that I can’t always protect patients from harm while they are having seizures, but in many instances can help identify potentially dangerous areas that allow for implementing safety measures to prevent serious injuries. We need to anticipate what will happen next, in order to protect patients from injuries. As every home is different, my recommendation is to take a walk around the home and make your own assessment of potential dangerous zones to help with the implementation of a safety or action plan. Safety and independence at home is the ultimate goal.

The Epilepsy Burn Prevention Campaign is an effort to create awareness about the need to take steps to prevent burns and other domestic accidents and to make the home a safe place for patients with epilepsy. The NYU Comprehensive Epilepsy Center in collaboration with faces has put together a task force of patients, physicians, nurses and makers of temperature control devices to work on this initiative. For more information please contact the faces office.
Eight hundred friends of the faces community gathered at Pier Sixty on the evening of March 8th to raise funds for the mission – Finding A Cure for Epilepsy and Seizures. This annual event raised $4.2 million for faces, in which the money raised supports research and community projects at NYU Langone’s Comprehensive Epilepsy Center.

The event graciously honored the laudable Dr. Werner Doyle, along with Melissa Morgan Hildesley. faces would like to especially thank Ginny and Steven Spiegel, and Barbara and Joseph Walsh III, who served with distinction as co-chairs of the Gala.

An alluring entrance lined with important and unique art – such as original Chagall drawings and a painted horse named “Trigger” – led guests down to the ballroom where beautiful florals and countless candles opened the doors to the Silent Auction: a much-anticipated part of the evening. With many thanks to Veronica Mainetti for chairing this year’s Auction, both the Silent and Live arenas met prestige by offering an array of exclusive items, including a Valentino gown from one of Valentino Garavani’s last personal designs of his collection, as well as limited-edition wines and personal experiences ranging from time spent with Oliver Sacks to a meet-and-greet with the American Idol tour. With over 300 items available for auction, the dining, wines and travel sections managed to contain high traffic, yet again.
It was a regular Monday... I woke up and did my normal routine to get ready for work. While in the shower, I went to make the water temperature a little warmer. At that moment, I ended up having a seizure and fell with my hand on the hot water faucet which turned it all the way up.

I eventually woke up in pain, turned off the water but not quite sure what had happened. [It wasn’t until a friend arrived at my house later and asked him to look at my back because I was in pain that he saw how burnt I was and] he called 911 where the ambulance took me to The New York Presbyterian burn unit. I was there for 5 weeks.

All together, 20% of my body was scalded that day. In addition to having three surgeries and two procedures, I had months of physical therapy… three times a week, as well as every day at home with my father, so I could regain full range of motion in my left arm and be able to bend over to tie my shoes.

This incident was the most painful experience of my life, both physically and emotionally. I always thought that if, God forbid, I had a seizure in the shower I would bump my head or slip or fall. I would never have imagined this. Now, in both bathrooms in my home anti-scald showerheads have been installed. I urge everyone to take this precaution as I hope nothing like this ever happens to anyone else.

The dinner program began with a comedic introduction by Emmy-nominated John Oliver who set the stage for Emmy award winner Katie Couric, the Master of Ceremonies for the evening. In her highly regarded manner, Ms. Couric shed light on the importance of the evening with her illuminating style and wit as she welcomed to the podium Dr. Orrin Devinsky, Founder and Director of faces, and Robert Grossman, Dean and CEO of NYULMC. Soon after, Dr. Doyle approached the stage and eyes filled throughout the room for his work within the epilepsy community has rejuvenated so many people’s lives. Ms. Hildesley shared her own personal experience and, as she and her family have been friends of faces for so many years. The excitement of the event fully set in as C. Hugh Hildesley of Sotheby’s, M. Morgan’s father, set to stage for yet another faces Live Auction. Mr. Hildesley didn’t have to work too hard as the items available included a glamorous travel and stay to Bordeaux’s Chateau de Mirambeau in France, a private dinner at Danny Meyer and Union Square Hospitality Group’s Gramercy Tavern, and premier seating and travel to the 2012 Super Bowl.

This special evening could not have been the success it continues to be without the generosity of Leah & Michael Weisberg who graciously underwrote the affair.

**Gala Financials**

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For many, driving is a vital function of everyday life. However, if you experience seizures that involve alteration in or loss of consciousness or body control, your legal right to drive may be restricted. The good news is that having had a seizure in one’s lifetime is not a permanent obstacle to driving.

It is important to understand that the state that issued your driver’s license determines the criteria for operating a motor vehicle with a history of seizures. A general fact common to all state Department of Motor Vehicles (DMV) is the restriction for an individual having active seizures involving alteration in or loss of consciousness. The required “seizure free” period before a license is reinstated varies from state to state, however many average six months. Individuals with epilepsy must notify the licensing state of their medical history when applying for a driver’s license, as well as when renewing. Your provider can review the state law with you in regards to your specific condition, and will instruct you not to drive according to the state law if applicable. Furthermore, mandatory physician reporting is required in some, but not all states. This means that in some states either the emergency room physician treating you after a seizure or your neurologist is required by law to report your seizure to the DMV. While other states may not have this requirement, providers, as well as anyone, can report seizures to the DMV on a case by case basis if there is concern that someone who is experiencing active seizures is continuing to drive. As a licensed driver, you are legally responsible for following the rules of the body that has authorized you to drive. Via “medical review forms” provided by your state DMV, your practitioner is able to make recommendations to the DMV as to when he/she believes you are cleared to drive, however the final determination is made by the DMV.

Unfortunately, there have been many cases when an individual with epilepsy has driven against medical and DMV recommendations, or during a time when they are at high risk for seizures (after missing meds, consuming alcohol the night prior, with sleep deprivation) and accidents have occurred. Many such accidents have resulted in injury or death to the driver or innocent others on the road. Individuals with epilepsy should use common sense when they have been cleared to drive by the DMV and avoid driving after missing meds, while sleep deprived, and the day after consuming more than two alcoholic beverages—as these are times when they are more apt to experience a seizure. Driving under the aforementioned circumstances is taking a chance not only with one’s life, but with all others that share the road. At the minimum, there are legal ramifications of any accident, and the worst case scenarios can shatter lives. While all who live with or treat individuals with epilepsy advocate for life without restrictions, DMV laws regarding driving with epilepsy are to protect all on the road.. including YOUR loved ones.. and should be abided by.

For more information regarding the DMV laws in your state, or to access medical review forms, please look on your state DMV website.
THE DRIVE THAT CHANGED MY LIFE

BY ENZA SALLUSTIO

For most of my life, epilepsy was a foreign concept. I had no idea what it was, nor did it relate to me or any one else in my life. In my early twenties, I loved driving and I loved cars, but after 2006 my love for freedom and driving was disrupted. Epilepsy made sure I knew it existed and my freedom became scarce.

June 11, 2006 marked the day I became aware of how fast life could change. I found myself waking up from a coma in St. Vincent’s Hospital while my sister and our friend recovered from surgery at Bellevue Hospital. We had been involved in a major cab accident concerning an epileptic cab driver who took himself off anti-seizure medication. As a result he drove us, his passengers, into a building off the West Side Highway at speeds high enough to cause broken femur bones and my brain injury. His seizure not only caused horrific injuries, but killed my friend at age nineteen.

"The feelings of inadequacy, dependence, and separation from those my own age is undeniable.

The rehab for brain injuries is ongoing. My past neurologist recommended Topamax for headaches and seizure precaution. Two seizure-free years later, I was taken off Topamax and continued driving, working, and ignoring how different I secretly felt. However, last year I had the privilege of being introduced to my first Grand Mal seizure, which occurred minutes before I entered my car to drive. Five seizures later, my diagnosis was, and still is, Grand Mal seizures related to the brain injury I suffered five years ago. My freedom has slowly been taken away in the form of car keys and the need to have someone with me at all times. The feelings of inadequacy, dependence, and separation from those my own age is undeniable. Love interests become frustrated with my dependence and are scared off by the idea of epilepsy. My younger sisters have become responsible for being my personal chauffeurs. Besides them, I cannot get around without walking or public transportation. In turn, my life is very different from my pre-accident years.

Despite these frustrations, and unlike my cab driver, I prefer to take my seizure medication and stay off the road until further notice. I know the reason I have seizures is because of a man who decided to be irresponsible about his medical condition. And because of that irresponsibility, he subjected others to injuries, death and pain. One year with seizures has taught me that you can still love cars without driving them, and it is possible to love life’s small freedoms with epilepsy without hurting others.
Do you ever feel completely alone? Do you ever think that no one has your back? And that if you were to fall off the face of this Earth that no one would miss you? Do you ever think that despite all that you are blessed with in this world that you have absolutely no one to share it with? And without those special someones all that you achieve means absolutely nothing? I know I do.

I remember as a kid in preschool, I would sit in my cubby all day. Completely alone. The teachers would ask me to join in for story-time or games but I wouldn’t budge. I sat there every day with my arms crossed over my chest and a puss face. As I got older and I had to deal with people, I wasn’t exactly sure what the rules were and I ended up on the sidelines. Completely misunderstood and alone, I looked at what everyone else had and I was jealous. I was always the last picked for the teams in P.E., never invited to sleepovers or parties, the one who was constantly teased but no matter how terrible it all got, I never strayed from my moral principles. As I built up my confidence over time, in a way, I became my own friend. However, when people suddenly realized how exuberant and kind I was, something I knew about myself all along, I didn’t know how to react. I had already been hurt so much and I didn’t know if I could take much more.

As a child, I was used to having to protect myself due to constant rejection. I built a brick wall around myself and as I’ve grown older, though its been a struggle to break it down brick by brick- I’ve done it. I’ve realized that just because you’ve had your guard up in the past doesn’t mean that you have to continue on that path. Don’t be afraid to let people in, they might surprise you. I have and I am blessed to have some pretty amazing people in my life. All different and all have a special place in my heart. And I know that I have one in theirs.

Samantha
Age 11

I have epilepsy. I had my first seizure when I was around one year old. Since it started at the age of one, my mom and dad were not sure if I was born with it. I had about forty seizures from the age of one until about the age of five. I had my last seizure four days before my fifth birthday.

The types of seizures that I had are called Generalized Tonic-Clonic Seizures (aka “Grand Mal”). They happened every time I had a fever. I would get very high fevers sometimes. My mom told me that I used to say I had a tickle in my throat right before I had a seizure. I don’t really remember any of them. A couple of years ago, I started having dreams about a few of my seizures and I would ask my mom if they were similar to the ones that actually happened. Sometimes she would say “yes” but sometimes she would say “no.” I don’t have Epilepsy anymore and I don’t have seizures anymore. I grew out of my epilepsy seven years ago.

When I was little, my old doctor never told my mom about EEGs. (I call it an “Egg”). Then, a wonderful and amazing family friend, Dr. Kazmir, told us about Dr. Devinsky. He introduced us and now Dr. Devinsky is the doctor for my brother, Leo, and me. That was when we started getting EEGs. He has been sooo good to us. He makes sure that everything gets done, and he makes sure that everyone is well taken care of.

My brother also had Epilepsy. He had a different kind of Epilepsy than mine. The type of seizure that he had was called Complex Partial Status Epilepticus. He only had one seizure which happened when he was one year old. My mom gave him medication every day to prevent him from having any more seizures. He had epilepsy much longer than me. He had it from the age of one until the age of eight. He is nine years old now, and he doesn’t have epilepsy anymore.

See, you are not the only one that has epilepsy or other types of brain problems. Many people do. I hope this article has inspired you to have faith and hope, and I do hope that you help faces just like me and my wonderful family.
Epilepsy first entered our family when I was eight years old. My older siblings and I came home from school one fall afternoon to find my dad home from work. Kim, who was just six at the time, hadn’t gone to school that day because she wasn’t feeling well. He explained to us in the gentlest way possible that Kim was in the hospital because she had a “dizzy spell”. I will never forget the panic I felt nor comprehend what my parents must have been going through. This would be the first of many, (more than a thousand), seizures my sister was about to face in her life.

Over the next twenty years, my parents sought out the best possible medical care with neurologists in our area. Unfortunately, like many families experience, nothing was really working and my sister’s seizures were actually getting worse. As an adult myself, I knew I also needed to help my sister search for a cure. So, I became very active doing volunteer work for epilepsy organizations in New York City hoping to gain as much knowledge as possible about the best doctors and the best treatments for epilepsy.

The turning point in my family’s quest for the best medical care for Kim came when we watched Dr. Orrin Devinsky being interviewed on the TV news show “20/20”, discussing a breakthrough treatment for epilepsy, which at the time it was – brain surgery. Through my volunteer work shortly thereafter, I had the privilege of meeting Dr. Devinsky and knew right away that my sister’s best chance of living the fullest life possible would be under his care and the care of his staff at the Comprehensive Epilepsy Center at NYU Langone Medical Center.

I was right. Fifteen years later, Kim is thriving and doing well; even though her seizures are not yet controlled, there is no one in the world that I am more proud of. The strength and determination I witnessed in her as a child continue to grow to this day. Even though she’s been through a tremendous amount over the past years from brain surgery to multiple VNS implant surgeries, she tackles each challenge head-on and never lets epilepsy get in the way of her life, her ambitions, or her dreams. I am also so proud of her willingness to help others with epilepsy. She has been part of several clinical trials for new medicines for epilepsy, never knowing for certain if they are going to help her but might someday help others. She frequently volunteers at the faces office and at many of the faces events and conferences.

Her favorite pastime though is karate. She is a brown belt, (soon to become a black belt), and competes in tournaments throughout the Northeast, winning trophy after trophy. I always feel safe walking with her in New York City! A few years ago she started her own business called, “Hand Knits by Kim”, where she designs and creates beautiful handcrafted clothing for children and adults. Kim also loves to travel – even if it means the occasional trip to an emergency room in a foreign country. The list goes on and on.

As any family personally affected by epilepsy knows, this disease affects the entire family in one way or another. By getting involved with an organization like faces and utilizing the tremendous resources they have to offer, it’s incredible to see that these opportunities made all the difference in the world for the quality of life my sister Kim now has.
$100,000 AND COUNTING!

With the help of faces ambassadors and special friends who have spearheaded their own fundraisers at home, you have helped raise an additional $100,000 this year for faces!

As we hit the mid-year mark for 2011, we look forward to supporting you in the more fundraising initiatives some of you plan to take on, as well as help work with others who have an idea but need a little help getting it underway.

That’s why we’re here! If you’re interested in organizing a fundraiser of your own, please email Cynthia at Cynthia.Adarian@nyumc.org to setup a time to discuss your ideas and chat about the best plan to move forward.

We can provide you with a custom website along with other guidance and support on putting on a successful fundraiser. Do you already have a fundraiser setup? You can also call Cynthia to arrange a portion of your proceeds to be donated back to faces. Basically, we can customize it to your needs, so call on Cynthia today and see how you can support faces without necessarily digging into your own pocket…

Run For Julianna
Jason Goldstein raised over $10,000 in his daughter’s honor while running a marathon last fall

Run For Dominic
Courtney Carter raised funds for faces in her first 5k run to honor her brother

Fudgeraiser
3rd Grader Noelle D’Amato advertised, promoted on email, baked and packed fudge to sell and send proceeds to faces. Each package, in her 5 year old cousin’s honor, was sealed with a knife and a personalized message: “fudge makes faces smile.”

faces’ own young Julia was again the face… but now of her own campaign: Jewels For Juju
Designer friends held a jewelry sale in Juju’s honor, and though impromptu, raised a considerable amount for faces.

Alicia & Friends III held its third annual fundraiser that raised another $10,000 for faces!
12 year old Alicia was accompanied by her closest theater friends, young and old, to put on a time-stopping musical performance for an audience of hundreds, paid homage to Broadway’s best, and was hosted by Tory Ryden.

A new friend to faces, 15 year old Chandler has setup an eBay site where 10% of all sales proceeds come to faces in honor of his sister
This is just the start of the many ideas he has, in addition to a new website launch and more this summer.

One of best things about New York?
The food, of course! A fabulous restaurant Txikito
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HOW CONNECTED ARE YOU TO faces?

Today, more than 50 million people around the world are affected by epilepsy. In the general population, one in every 10 people will have a seizure in their lifetime.

WHY DOES THIS MATTER TO YOU?

In an age where three major social media networks have over 900 million members altogether, you can see how important it is for faces to have a presence in these arenas. faces is putting a major emphasis on expanding its exposure among these networks and come fall 2011, we will re-launch our Facebook, Twitter, and LinkedIn sites.

HOW CAN YOU HELP?

If you are already part of the faces community and we have your email on file, you will receive an exclusive invitation to be part of the founding members for our new social media sites! Upon the launch, be sure to share our links with all your family, friends, colleagues and classmates so they too can join faces and learn about updates in research and news about events supporting epilepsy and seizures.

WHAT WILL YOU LEARN FROM THESE NEW SITES?

Through these new sites, faces will be presenting:

- News around the epilepsy and seizure community
- Blogs with fresh information and new insights from the staff, volunteers, researchers and doctors
- Research updates and announcements
- Exclusive invitations to events
- Fundraisers around the world and ideas to start your own
- Easy links to share and raise funds for faces in support of yourself, a loved one, or even your doctor

WHEN WILL THE NEW LAUNCH TAKE PLACE?

Be on the lookout for an email from faces later this season. In the meantime, have a wonderful summer!
SAVE THE DATE

FACEBOOK LAUNCH  LATE SUMMER
2011 GAME DAY  SATURDAY, SEPTEMBER 24TH
PARENT NETWORK EVENT  TUESDAY, OCTOBER 4TH
2012 FACES GALA  TUESDAY, MARCH 6TH

NEW FACEBOOK, TWITTER, LINKEDIN PAGES COMING SOON!
REGISTER YOUR EMAIL AT WWW.NYUFACESS.ORG