In the digital age of social media, we are constantly overwhelmed with updated statuses, tweets and pictures detailing the day-to-day life of others who lead seemingly perfect, sunny, blissful, satisfying lives. What we often fail to realize is you don’t see the hard days that may occur between these photos and updates. However, those are the days that count and help shape our individuality, push our beliefs and help us to make a difference in our world today. The birth of a child is normally one of the happy photos; the start of a lifetime of love, happiness and possibility. Life can throw us curveballs and the unexpected may occur at anytime. Our reactions to these curveballs can empower and educate us while imprinting a lasting, positive impact on our children, our friends or perhaps to a perfect stranger who may be experiencing similar adversity.

...an excerpt from Erin Conway’s article, page 10
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.

THE FACES FAMILY

BOARDS OF DIRECTORS
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Cynthia Wartanian
Senior Program & Events Specialist
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Project Associate
Heather Wall
Coordinator of Faces Apartment & Summer Camp Scholarship Programs
Peggy Guinnessey
The Parent Network Coordinator

WEB PAGE: www.nyufaces.org

WELCOME
A LETTER FROM OUR FOUNDER

The first half of 2012 has been a remarkable time for the epilepsy movement and for FACES. The Institute of Medicine (IOM) released its much-anticipated report—Epilepsy Across the Spectrum: Promoting Health and Understanding (I). FACES helped sponsor the report that identified important areas. These include prevention; access to care; educating people with epilepsy, their families and health care professionals; community resources; and increasing public awareness. The report has stimulated the epilepsy community into action and will hopefully lead to more funding for epilepsy care, education, and research. Many of the IOM’s recommendations are mission central to FACES. Our annual educational symposia on epilepsy (II) for patients and families is one of the largest in the country available on our website at www.nyufaces.org. Our community resources like Game Day increase support, awareness and connections. Our team educates health care workers through academic publications and lectures throughout the world.

The first Partners Against Mortality in Epilepsy (PAME) (III) was held in late June and summarized by Dan Friedman in this newsletter. In addition to co-sponsoring this meeting, FACES is the main sponsor for the North American SUDEP Registry, which will collect clinical information, DNA and tissue for research by international researchers. FACES is also launching several prospective studies of outcomes in severe childhood epilepsies such as Dravet syndrome, to better understand risk factors and identify preventive strategies.

Our 2012 Gala (IV) set a new record while honoring three people who lie at the core of FACES: Loretta Glucksman and Leah and Michael Weisberg. It was a special night of caring and passion. Jon Stewart was spectacular, not only for his brilliant wit, but for his compassion and friendship. Amy Moritz, our Gala Chair, helped us reach further than we ever have before. Dean Robert Grossman introduced Dick Tuin, the inaugural director of the new NYU Neuroscience Institute. We look forward to collaborations with Dick and our incoming Neurology Chair, Steve Galetti. We also introduced three new members of the NYU Epilepsy and FACES team—Jim Rivello, the Director of Pediatric Neurology and a world-renowned epileptologist, Erin Conway our pediatric epilepsy nurse practitioner, and Courtney Schnabel, our epilepsy dietitian.

The 2011 fall launch of Insight (V), our monthly e-newsletter, and the “new” FACES logo were precursors to exciting transformations and upgrade in content, layout and design. Focus on Facebook (VI) and Twitter (VII) pages were fortified and thus far, our pace on the social media road has continued to accelerate, with each month reflecting a steady and substantial increase in traffic.

As we look ahead, there are incredible opportunities to improve the lives of people and families with epilepsy through clinical care, education, and research. Our vision is for FACES to focus on high impact areas where we can make a difference. We are blessed to have a dedicated team comprised of nurses, EEG technologists, social workers, dieticians, doctors, scientists, and administrators that form the core of our center. We are equally fortunate to have collaborators throughout the United States and the world to share ideas and work towards our goal of improving lives. But most of all, FACES is a community of people with epilepsy and their families who make everything we do possible. Hugs thanks to all.

FACES is all about involvement—there are many ways to be involved with FACES—from giving us feedback about your needs to volunteering to helping support summer camp scholarships or research. Please reach out to Luis Valero, Cynthia Wartanian or me for more information.

Orrin Devinsky, MD
Founder

The PARENT NETWORK

The Parent Network provides opportunities to connect with parents on the many issues surrounding care for a child with epilepsy. Sometimes parents just want to talk to another parent who knows what it’s like to have a child with epilepsy.

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WORLD-WIDE OUTREACH
FACES ONLINE
WWW.NYUFACES.ORG GOT A FACELIFT IN 2012!
As we strive to make the FACES website the cornerstone for information on epilepsy and seizures—with an emphasis on research initiatives, as well as fundraising and awareness campaigns—we urge you to visit our website regularly to obtain the most current educational updates in the epilepsy community.

FACEBOOK.COM/FACESFRIENDS
Our Facebook page, NYU FACES has over 900 Likes, but we want more! Visit Facebook.com/FACESfriends today and “Like” our page so you too can receive the most current news and updates not only at FACES, but all news pertaining to epilepsy and seizures.

FACES FAMILY

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.
MOTHER & DAUGHTER

By Stephanie Ledford, mother

A lthough epilepsy is a disease that affects the brain, it is so much more to me and my family. It is the disease that has defined my daughter's life, but it has also brought our family closer together. Epilepsy has been a part of our lives for as long as I can remember. I was diagnosed with epilepsy as a child, and I vividly remember being treated by Dr. Devinsky, who is a world-renowned neurologist. He has been a constant presence in our lives, and I often write to him for advice and support.

Growing up with epilepsy certainly made for some interesting times growing up. My older brother and I, along with my parents, were constantly monitoring my health and trying to keep me safe. We would take long walks in the park and play board games, but we always had a plan in case things went wrong. We even had a special system in place to alert the neighbors in case of an emergency. It was a way of life.

My epilepsy has been under control now for about two years and I live a normal life. I have a job, I have a life, and I am happy. I am grateful for every day that I have had and I am grateful for the doctors and nurses who have helped me so much. I am grateful for the support of my family and friends, and I am grateful for the support of the Epilepsy Foundation, which has helped me so much.

We are all unique in our own way, and I am no different. I have had my struggles and my successes. I have had my ups and downs, but I am always learning and always growing. I am grateful for the opportunity to share my story, and I hope that it will help others who may be going through similar experiences.

By Hillary Ledford, daughter

G rowing up with epilepsy certainly made for some interesting times growing up. My older brother and I, along with my parents, were constantly monitoring my health and trying to keep me safe. We would take long walks in the park and play board games, but we always had a plan in case things went wrong. We even had a special system in place to alert the neighbors in case of an emergency. It was a way of life.

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BY BEN SILVA
Are you a woman with epilepsy who’s considering pregnancy? You may have many questions that you want to ask your doctors to have the best possible outcome for themselves and, in the future, women with epilepsy will be better able to participate in research projects, these issues can be better understood and, in turn, improved. It is unknown whether epilepsy causes a decreased fertility rate or if the decreased fertility rate is related to other factors. There are many different explanations that could account for this difference, and a team of researchers in three different hospitals, including NYU Comprehensive Epilepsy Center, is currently exploring the reasons for this disparity. The study involves keeping track of seizures and other information using a daily electronic log as well as a few blood draws. Suzie enrolled in the study in January, was pregnant by April and had a beautiful, healthy baby boy the following January. When asked about her experience in the study, Suzie said that the tracking device was “very easy to use” and “made [her] feel safe... so if anything were to happen, it was easier to get in touch with someone.” When asked about the blood draws, she said that they were “not a big deal at all. I don’t live in the city so the coordinator came to me — it was very convenient.”

There are many questions that women with epilepsy face when considering pregnancy. With more than one million women and girls in the US having a seizure disorder, many women throughout the country will have to encounter these issues. When asked why she joined the study, Suzie explained, “I feel like I never give back to the epilepsy community, so this is my way of giving back to others and helping the epilepsy cause. I felt it was time to give back.” The hope is that this research will improve the lives of women with epilepsy everywhere. It is unknown whether epilepsy causes a decreased fertility rate or how seizure frequency changes during the stages of pregnancy. By participating in research projects, these issues can be better understood and, in the future, women with epilepsy will be better able to work with their doctors to have the best possible outcome for themselves and their children.

Are you a woman with epilepsy who’s considering pregnancy? You may be eligible to participate in this research study on fertility in women with epilepsy. For more information, please contact Joseph Lee, NYU CEC research coordinator, at Joseph.Lee2@nyumc.org or Dr. Jacqueline French at Jacqueline.French@nyumc.org.

THE DEPARTMENT OF CLINICAL TRIALS

The NYU Comprehensive Epilepsy Center Clinical Trials Department has been participating in clinical drug trials sponsored by various pharmaceutical companies for over 14 years. Dr. Blanca Vazquez, Director of Clinical Trials and Co-Director Dr. Jacqueline French have participated in over 100 multi-center protocols for both partial and generalized epilepsy. We offer patients who qualify, voluntary participation in clinical trials to gain access to new, anti-epileptic drugs (AEDs) before they are marketed still being studied in clinical trials. Studies for both adults and children with epilepsy are conducted. Patients are screened for eligibility according to each trial's criteria by the physician along with the Nurse Research Coordinators, Maria Hopkins, R.N., and Kim Phelpes, R.N. and if appropriate and willing are enrolled into the trial. Clinical Trials patients are seen regularly by the Research Staff to assess safety and efficacy of the drug or treatment being studied. If you or a loved one have uncontrolled seizures, are between the ages of 12-80 and are interested in participating in a clinical trial, please speak to your doctor or call the Department of Clinical Trials at (648) 655-0842 to see if you are eligible for any of our ongoing trials.

THE AUCTION

The Auction is a signature part of the FACES Gala generating $700,000 for the event annually. With over 300 items in the Silent Auction, and another 10 in the Live Auction, the FACES Auction is one of the largest charity auctions in Manhattan.

Our goal for the 2013 FACES Gala is to raise $1 million in the auction, and we need your help.

Auction items are featured in a wide range of categories including, but not limited to:

• Art
• Beauty & Fashion
• Children & Family
• Dining (gift certificates to fine restaurants and gift baskets)
• Electronics
• Jewelry
• Premier Experiences
• Sports
• Theatre & Entertainment
• Travel
• Wine

Please contact Cynthia Wartanian in the FACES office if you are interested to procure auction donations, and make a gift in-kind to support the event.

Visit faces.med.nyu.edu for more information.

WITH EMMA DAVIS

After attending the FACES Gala this past March I can say without a doubt that, above anything else, FACES celebrates people. There was something I already knew, it was a true gift to see how a mutual cause brought so many types of people together. The evening was truly a party for all involved whatever with the auction, good food, music, many friends and Jon Stewart it was such a happening time. However, the most astonishing part of being there, the part I didn’t expect, was how much I was overwhelmed with both gratitude and pride.

For so many years, I carried these feelings of shame with me in my back pocket everywhere I went. Maybe my maturity finally kicked in or maybe it was just enjoying myself, but all those eyes that always seemed fixated on me because I was “special”, they weren’t judgmental at all. They were full of congratulations and tears of joy. Throughout the evening I felt that all eyes were on me but instead of with daggers, with olive branches.

Everywhere I bounced to and fro that night there was someone with their own connection to FACES; their own story. When I was able to share a moment with any given person, I knew we were there for the same reason. Smiles and laughter and giggles twinkled about the space. But underneath it all, I felt a wave of acceptance wash over me. I am finally content with my past.

Sitting at my table was where I felt my pride the most. It wasn’t that I was proud I had epilepsy. Not at all, although I am proud I got through it. I was overwhelmed that I had the power to draw a whole table full of people to help me raise money for epilepsy, to support FACES, and to support me. The idea that there was some part of me that people wanted to help, to share, and to discover along with me was a true pleasure.

Of course, the Gala was an uplifting event and these subtleties were in my own little world. But I have a hunch that everyone else in the room was feeling that exact same feeling of “thank you”. Thank you for my health. Thank you for my happiness. Thank you for FACES. Thank you for me.

The Auction, and another 10 in the Live Auction, the FACES Auction is one of the largest charity auctions in Manhattan.

Visit faces.med.nyu.edu for more information.

7
ACES Gala 2012 at Pier Sixty at Chelsea Piers was the place to be on the evening of Tuesday, March 6th. All of the over 800 guests from the FACES community could not have wished for a more gorgeous evening to hold the event and raise funds for a very special mission - Finding A Cure for Epilepsy and Seizures. The evening was a record-breaking success with more than $5.3 million being raised to support research and community projects at the Comprehensive Epilepsy Center at NYU Langone Medical Center.

Gala chair Amy Pollner Moritz and Dr. Orrin Devinsky, FACES Founder and Director of NYU Comprehensive Epilepsy Center, led the charge in honoring esteemed members of the FACES community: Loretta Brennan Glucksman and Leah and Michael Weisberg. Joining them in saluting the gala’s honorees were members of the FACES Board of Directors, an elite corps of NYU Langone Medical Center’s medical professionals, headed by Dr. Robert I. Grossman, Dean and CEO of NYU Langone Medical Center.

Guests arrived to a welcoming site of greeters and instant excitement at the sight of an abundance of silent auction prizes that lined the entrance hall and stretched all the way to the cocktail reception area. Silent Auction participants had a better opportunity and convenience to select multiple items they wished to go after, without having to circle the room hurriedly. Yes…silent bidding through Apple iTouches were the novel, state-of-the-art gadgets that replaced pens and bid sheets of auctions past. Guests vied for coveted art pieces, jewelry, wines and spirits, sporting event tickets and memorabilia, “must have” designer merchandise, and a wide range of gifts and certificates while enjoying the company of friends. All in all, there were over 300 items but not nearly enough to satiate everyone. An enormous note of gratitude goes to Lenore Cheeseman for chairing the Silent and Live Auctions as well as to members of the Board and the Benefit Committee responsible for securing all the items.

The ballroom was a sight to behold. Votive candles lined the glass panels, illuminating the view of the Hudson River and the night sky. The floral centerpieces of white roses brightened the room and exuded a warm welcome as guests sat at their tables. The dinner program started promptly with welcome remarks delivered by Dean Grossman, immediately followed by his introduction of the evening’s Master of Ceremonies, TV and media personality and award-winning host of The Daily Show, Jon Stewart. Mr. Stewart’s incredible charisma and unique wit raised the energy and excitement in the ballroom. He introduced Dr. Orrin Devinsky who succinctly shared exciting news and information vital to the FACES community then proceeded with the order of the program by calling to the podium individually, the gala chair and honorees. Each person spoke separately, but expressed the same sentiment of genuine gratitude because “their lives were changed,” thanks to the extraordinary work and dedication of Dr. Devinsky, the Comprehensive Epilepsy Center and FACES. Echoes of affirmation reverberated in the ballroom from end to end.

The energy in the room soared further when auctioneer Courtney Booth of Sotheby’s stepped up to start the live auction. Bidding was feverish for the exquisite items put on the block that ranged from enchanting and “uber” exclusive European vacation destinations, Epicurean feasts, and invaluable items for connoisseurs of wines, arts, and entertainment. The live auction’s special highlight was a campaign for funding of research initiatives, particularly a series of studies on SUDEP (Sudden Unexpected Death in Epilepsy) to learn more about the disorder and develop strategies to prevent it. As one may have guessed…the response was outstanding!

The excitement about FACES Gala 2012 did not end when the evening ended and guests prepared to leave. Conversations about inspiring speeches and seamless flow of the event, as well as shrieks of excitement by winning bidders, was audible from different corners. On their way out, a sweet ending awaited…a cup of hot cocoa “to go” and a FACES sugar cookie!

March 6th was a truly special and memorable evening, thanks to the inspiring loyalty and generosity of everyone in the FACES community.
I am neither a doctor, nor a researcher, I like many of you, am simply someone diagnosed with epilepsy with something to say. We all have our own embarrassing experiences living with epilepsy, and I am here to say that you are not alone and hopefully my article, in which I share some of my embarrassing epilepsy stories, will help you realize that.

Have you ever had an episode in school? I was diagnosed with epilepsy when I was fifteen years old, just two years after I transferred to a new school. Before I was diagnosed I remember having “space outs,” but I never knew what was happening. In my class, I learned these episodes were actually petit-mal seizures. One afternoon while in chemistry class, I passed out, remembering nothing, and then nothing. I came out of my episode and heard myself stating a chemical name of some type. It was a scary experience for me, and I remember being so embarrassed. It took me a little while to get my question out, but by that time the room was full of students. I didn’t know what to do or what to say. I was scared and didn’t want to make jokes about what I was saying! I was “silly and felt sick.”

We cannot control the timing of our seizures or what happens when they do occur. All we can do is accept what happens and try our best to take care of ourselves in advance.

BY MARIE BRADDOCK

Dr. L.R. Harper

I look around you. Stigmas exist everywhere in our lives. The natural tendency for most people is to jump to fear and preconceived notions of things they are not familiar with, whether it be someone else’s religion, where they are from, how they look or act, what they do, a sickness or condition they have–the list goes on and on.

I have had temporal lobe epilepsy for twenty-plus years and have a hard time dealing with my family, doctors, and the rest of the people I deal with every day. I don’t want to think about the episodes that I have had over the years. Fortunately my seizures have been well controlled with medication, although there have been episodes every once in a while. I also regularly see my excellent doctors for check-ups and testing, as it is very important to be compliant and responsible. So, how do we do that? We have to step up to the plate and take care of ourselves so that perhaps the world will take notice in a more kind and gentle way. In fact, my husband always tells me that epilepsy is a sweet part of who I am and never looks at it as something scary and wrong.

BY BRYN CONWAY

CERTIFIED PEDIATRIC NURSE PRACTITIONER

BY MARNE BRADDOCK

The worst thing we can do is do nothing. The world is in dire need for support and it’s important to know that you too can make a difference in the lives of others. Therefore, my final request is that you reach out to others. It is surprising to me how many people still know about it. When people have epilepsy they are usually completely surprised. Several have told me a story about someone they know that used to have “fits” and suffered from that type of “mental illness.” The misconceptions and stigmas remain, and this is where the opportunity for education begins, case by case, to enlighten and raise public awareness and understanding of my condition and millions of others’ condition. Take the risk to talk openly about epilepsy and little by little understanding will follow and the stigma will fade.

BY L.R. HARPER

In the not-so-distant past, people did not talk openly about cancer, mental illness, addictions, HIV/AIDS, diabetes, autism, prostate issues and mental illness, openly. They lived in fear, prejudice and discrimination.

But today we are part of the common vernacular: in the media, at home, dinner conversations, everywhere. And, the drugs used to treat these conditions and the research that led to those drugs, epilepsy should be invited to the party and have a place at the table, too.

People are all different and we should embrace rather than fear our differences, as this is what makes each of us special and unique.

I recognize that some suffer much more than others and have dealt a much more difficult hand than I have, and whatever the degree, we should never shoulder the burden alone. There is support, people who care and understand, friends, family, strangers and our FACES family because really, we are all of like kind.

It wasn’t until the end of high school that I felt comfortable talking about epilepsy. In that time I attended practically every FACES lecture and the Epilepsy Conferences with my mom to learn more about the disorder and found that I slowly became more accepting of my condition. As I began to open up about my epilepsy with my friends and family, I realized that they were actually much more supportive than I thought.

FACES has helped me realize that just because I take medication daily does not mean I am strange or different and that I am just as capable of living a healthy, “normal” life as anyone else. I have my high school party and founded a club, had a great group of friends, took five classes a semester and even held a job my senior year. You can do ANYTHING you set your mind to and it is important to prove that to yourself, as well as others.

We can start to combat the stigma attached to our disorder by educating ourselves and everyone around us about the reality of the condition that they are not alone. Therefore, my final request is that you talk openly about epilepsy with your friends and loved ones. The best way we can do this is by doing nothing.
A diet plan. Whether it be medication related weight gain or weight loss, general weight loss or gain
working with many of the doctors and nurses to get nutrition education to those who wish to begin
with the oil to coat.

Line a baking sheet with a piece of
Peel the turnips, and cut into
French fry-sized sticks, about
1/3 by 4 inches.

2 pounds turnip, raw
1 teaspoon onion powder
1/3 cup parmesan cheese

RECIPE:

1/4 teaspoon paprika
1/2 teaspoon black pepper

Serving (6-8oz): 128 calories, 5g

2 cups turnip, raw
3/4 cup extra virgin olive oil
1 teaspoon garlic salt
1 teaspoon onion powder

INGREDIENTS:

DIRECTIONS:

of calories, 22 grams of
and 45g carbohydrate) 6oz) at 450 calories, 22 grams of

30 minutes.

of controlling their seizures and even more must live with seizures and/or
biologics, devices and other treatments over the past decade since its formation.
The Epilepsy Therapy Project (ETP) launched a new and comprehensive
Late-Stage Development

seizure detection devices are limited by the availability of a nearby caregiver
the United Kingdom but have never been tested and remain unproven. Finally,
electrodermal skin response, heart rate, and respiratory rate (e.g., MIT-Boston
detectors, and include accelerometers (e.g., SmartWatch*, EpiLert (watch),
and their role in preventing SUDEP remains unproven. Although EEG based
alarm caregivers could potentially prevent SUDEP. A variety of seizure detection

Evidence from epidemiological studies, cases of SUDEP witnessed in the
countries, epilepsy itself is associated with increased mortality. Epilepsy-
trials were short-term and cannot be generalized to routine clinical care, they
found no increased risk with lamotrigine. A meta-analysis of randomized AED
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AED drug polytherapy and alcohol abuse. Although lamotrigine is a risk factor
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Evidence from epidemiological studies, cases of SUDEP witnessed in the
community and recorded on video SEG all suggest that seizures, most often
GTCS, are more likely to occur when the patient is underweight or overweight at
an increase in the number of deaths in those individuals. In fact, the current
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Visit the Alicia & Friends webpage: faces.kintera.org/aliciaandfriends

With the help of FACES ambassadors and special friends who have spearheaded their own fundraisers at home, you have helped raise an additional $300,000 for FACES this year!

If you are interested in organizing a fundraiser of your own, please email Cynthia at Cynthia.Wartanian@nyumc.org to set up a time to discuss your idea and help you plan your fundraising. We can provide you with a custom website (like the samples on the next page), and offer you guidance and support in creating a successful fundraiser. Do you already have a planned event? Do you own a business? Cynthia can also help advise on how to donate a portion of your proceeds back to FACES.

The Allison & Andrew Whiner Fund for Brain Tumor Research has already raised well over $18,000 this year alone in its incredible fundraising efforts to raise money specifically for Brain Tumor Research!

To keep things interesting, with each attempt I have made so far, but I’m now more of an adventurer and to date I have run 5 marathons and 6 50Ks. I am an ultra runner and I have completed a half Ironman and a half Ironman. I have also run several half marathons and dozens of 10k races.

The Adventure this year will be a two-fer. I will compete in the Great Chesapeake Bay Run in Annapolis, Maryland (yes, | finally got it) in the Great Chesapeake Bay Run in Annapolis, Maryland (yes, | finally got it). This is an event that has already raised over $181,000 for the axial spondyloarthropathies foundation (ASAF). The annual event, which started in 1987, only allows 600 swimmers, starts just before daybreak, and ends after 16 hours at a small sandy beach on Kent Island.

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UPCOMING EVENTS:

GAME DAY
SATURDAY, SEPTEMBER 22ND

GALA
TUESDAY, MARCH 5TH

This Annual Newsletter is also available in digital form on our website at www.nyufaces.org, along with updates in research, education, events and patient resources.

STAY CONNECTED WITH FACES YEAR-ROUND ON FACEBOOK AND TWITTER!
REGISTER AT WWW.NYUFACES.ORG TO RECEIVE EMAIL UPDATES.