

FACES

FINDING A **CURE** FOR EPILEPSY & SEIZURES

ANNUAL NEWSLETTER 2015

FEATURING

- » *FACES Gala 2015*
- » *Shining a Light: SUDC*
- » *freshFACES Cocktail Party*
- » *A Prom For Everyone*

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TABLE OF CONTENTS

- 1 Welcome
- 2-3 Recognizing FACES
- 4 Blurbs From the Board
- 4 Attitude of Gratitude
- 5 Epilepsy Conference
- 6-7 Gala 2015
- 8 *fresh*FACES
- 9 Fundraising Corner
- 10 TeamFACES Marathon Success
- 11-12 FACES Research Projects
- 12 Teen Day
- 13 Meet the Neuropsychologists
- 14-15 Shining a Light on the Unknown: SUDC
- 16 Antiepileptic Drugs and Device
Trial Meeting XIII
- 17 The Purple Spoon
- 18-19 FACES Apartments: A Place That
Feels Like Home
- 20 Dr. Blanca Vazquez Summer Camp
Scholarship Story: Meet Joshua
- 21 Houston's College Scholarship Story
- 22 A Prom For Everyone
- 23 A Parent Perspective
- 24 The Magic Pill For My Epilepsy

THE MISSION OF FACES

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.

WELCOME

LETTERS FROM LEADERSHIP

FACES is all about the people we care for. Our community of doctors, nurses, neuropsychologists, technicians, and administrators at NYU Langone and our wider community of collaborators in epilepsy care around the world.

Our research program is robust and exciting. We are exploring new genetic therapies for epilepsy, novel compounds that work 'outside the box' of usual epilepsy medications - targeting immunological mechanisms underlying epilepsy and novel neuronal systems. Our pioneering research on the safety and efficacy of pure cannabidiol (CBD) in children and young adults with treatment resistant epilepsy has garnered national attention and we are now leading the first scientifically controlled trials of CBD in Dravet Syndrome and Lennox Gastaut Syndrome. Our surgical teams are developing novel methods to treat epilepsy and are attracting a larger and wider referral base of the most difficult-to-treat cases. Through the North American Sudden Death in Epilepsy Registry (SUDEP) collaboration with the NIH Center for SUDEP Research, and a new international program to study risk factors for SUDEP, we are intensely focused on reducing epilepsy-related mortality. Our collaboration with the Center For Healthful Behavior Change at NYU has led to work with the Centers for Disease Control to reduce disparities in epilepsy care for those who have less financial resources. There are so many new projects, like, improving memory through transcranial magnetic stimulation to unraveling the genetics of epilepsy and studying devices to detect seizures and alarm caregivers. Collaborations within the NYU Langone and Downtown campuses and with international colleagues have allowed us to focus deeply on specific projects while diversifying our research efforts.

We are also proud of our FACES program. The Annual Epilepsy Conference is one of the largest in the world. The annual newsletter and monthly e-newsletter are read by more than 12,000 people. Game Day at Chelsea Piers brings families together for fun and our Camp Scholarships bring the joy of friendship for campers and respite for parents. The College Scholarship program awards much needed funds to students with epilepsy. This is thanks to the incredible support we have received.

It is always worthwhile to reflect and look back. Reflecting fills me with a sense of honor to be part of this amazing community, and it fills me with a hunger to do more, since our goal of significant progress towards a cure for epilepsy remains far too elusive.

Orrin Devinsky, MD

Founder

FACES supports the tremendous work of the medical team here at the Comprehensive Epilepsy Center at NYU Langone Medical Center.

On Monday, March 2, 2015, FACES celebrated our annual Gala at Chelsea Piers in Manhattan. Over \$4.9M was raised to provide for life-enhancing programs in cutting-edge research, clinical care, education and awareness programs, and community building events.

TeamFACES continued its athletic streak with 7 runners raising \$118,000 - \$51,000 more than last year - for the NYC Marathon. In March, 5 runners raised just over \$25,000 for the NYC Half Marathon and we already have 12 runners registered for the 2015 marathon! Two runners ran the Boston Marathon, raising just over \$20,000. We are so proud of all of our FACES athletes and are thrilled with the popularity of this new program. The arrival of spring also brought the Epilepsy Conference on Sunday, April 26, 2015 at NYU Langone Medical Center. Over 400 patients, caregivers, parents and medical professionals attended to learn about the latest developments in the epilepsy field.

Our FACES Apartments provided lodging for 73 families from 24 states and 2 countries. The length of stay per family ranged from 1 day to 8 weeks and a total of 567 room nights were provided throughout the calendar year.

FACES is happy to extend an opportunity for children to attend summer camp and college through the Dr. Blanca Vazquez Scholarship and our College Scholarship programs. This year 40 children were awarded a total of \$26,000 in camp scholarship dollars and last year 15 students were awarded a total of \$25,000 in college scholarships. The 2015 college scholarship program application deadline is July 15th. FACES kicked off their 3rd annual Teen Program on June 6th with a movie, tour and lunch at The American Museum of Natural History in Times Square. Don't forget to hold the date for Game Day, which will take place on Saturday, October 24, 2015. The fall will bring a new set of Peace of Mind lectures - and we would love to hear the topics that interest you the most.

Finally - SAVE THE DATE for our second annual freshFACES event on Thursday, October 8, 2015. This fundraiser and cocktail party will be held at espace in Manhattan and is sure to be the talk of the town.

The FACES team is always here to be of assistance. Please do not hesitate to contact us.

Pamela Mohr
Executive Director

RECOGNIZING FACES

By: Robin Dunn Fixell

It has been two decades since the inception of FACES at the NYU Langone Comprehensive Epilepsy Center and, in light of the fact that it has done so much for so many during the past 20 years, there's no better time to illuminate its history and future potential. Dr. Orrin Devinsky, Director of the NYU Langone Comprehensive Epilepsy Center, recently sat down and discussed the past, present and future of this remarkable organization.

Created in 1995, FACES originally referred to the "Fight Against Childhood Epilepsy and Seizures." Through the years, as FACES grew more ambitious and broadened its efforts to serve the community, foster fundraising and pursue research, the acronym came to stand for "Finding a Cure for Epilepsy and Seizures."

"FACES really came out of the collective questions and desires of people we cared for in the Epilepsy Center to do more," explained Dr. Devinsky. "And they suggested we organize a meeting to look at ways to increase the advocacy, education, research and clinical programs of the NYU Langone Comprehensive Epilepsy Center."

Today, at least half of the 20 or so individuals who attended the first meeting that gave rise to FACES remain active supporters. Steven Spiegel, for example, is currently a board member; and Hugh Hildesley, of Sotheby's, was not only instrumental in retaining this prestigious institution for FACES' first fundraiser, but continues to serve as auctioneer at FACES' galas and remains a dedicated supporter. Stone Phillips, first fundraiser host and MC, has returned numerous times in that capacity; he and his wife are active supporters.

According to Dr. Devinsky, "There was no specific plan" when it came to envisioning FACES' growth. "After our first fundraiser raised about \$200,000, we were ecstatic and I was not sure we would ever repeat the event and success. When, in 2000, Robin Williams came and we had our event at the Puck Building, and we finally hit the \$1,000,000 mark, I was absolutely convinced...that we would never reach that number again. Luckily, I was wrong."

The results of so much support have been evident in so many areas. "FACES has grown far beyond anything I could have imagined," remarked Dr. Devinsky, "and has allowed us, as an epilepsy center, to broaden its scope, and to recruit remarkable people like Dr. Ruben Kuzniecky and Dr. Jackie French, and many others on the clinical side; and many like Thomas Thesen, Karen Blackmon, Heath Pardoe and others on the basic science side. And, we've been able to support collaborations

with outstanding scientists, both at NYU Neuroscience Center and NYU Downtown."

Today, education remains a top priority for FACES. "We have multiple individual conferences and, perhaps, one of the world's largest lay conferences for people with epilepsy," stated Dr. Devinsky, as well as "a newsletter which disseminates a lot of epilepsy-related information." In addition, he pointed out that there has been a great deal of support for community groups—adolescents, summer campers and college students.

"Clinical care and research probably remain the two centerpieces of what FACES supports," said Dr. Devinsky. "We pay for a dietitian and the full dietary program we have here, but it also supports people in many other states and countries who are seeking epilepsy dietary care." Just one of the many programs offered by FACES includes providing apartments to out-of-town families visiting NYU for surgery, specialized treatments or evaluations.

"Most importantly," emphasized Dr. Devinsky, "FACES supports a very wide portfolio of basic and clinical research efforts that are geared in epilepsy and they are especially targeted on finding discoveries that we hope will impact people's lives in the near future."

But what makes FACES unique as an epilepsy and seizure organization, Dr. Devinsky explained, is that while "it is primarily focused on patient education, care and research programs here at the NYU Langone School of Medicine, FACES also has very active collaborations with more than 30 epilepsy centers throughout the world, and has supported large initiatives that unite many groups, individuals and centers throughout the country and the world."

One example of FACES' far-reaching effect, continued Dr. Devinsky, has been providing "substantial seed money to projects at the Epilepsy Phenome/Genome Study." This major research project combined the efforts of more than 35 epilepsy centers and research institutions worldwide, and received more than \$20,000,000 of support from NIH, and \$10,000,000 additional support through the Epi-4K grant to analyze the genetics of that study.

Other initiatives that have been the focus of collaborations have included: The North American SUDEP Registry, which fosters connections between many medical examiners and epilepsy centers; The

Epilepsy Monitoring Unit Retrospective Study on SUDEP, which will see more than 30 epilepsy centers throughout the world collaborating to identify biomarkers and understand SUDEP; and The Human Epilepsy Project, led by Dr. Jackie French and Dr. Ruben Kuzniecky, which has incorporated more than 25 centers around the United States.

“I think we’ve been able to take a very active lead in research projects that are able to involve large-scale collaborations,” said Dr. Devinsky. “And the concept of team science is emerging as one of the most important ones to help get answers that no individual center or group of centers can do in isolation.”

Striving to make significant and far-reaching changes in

the world of epilepsy and seizures, FACES owes much of its success to fundraisers and donations.

“Certainly, our greatest contribution to FACES’ programs has been through our annual gala, and this has remained our strongest source of support,” said Dr. Devinsky.

“However,” he concluded, “we have recently been able to work with individual donors and families that have been very focused on targeted programs and targeted areas of research, and I think this certainly remains one of the great opportunities for the future.”

Thanks to the many opportunities made possible by FACES, it’s a future that’s brighter.

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 person *who gets it, or who has been there.*

Joining The Parent Network gives you the opportunity to:

- connect with a support parent
- become a support parent

The Parent Network gives many families much-needed information on a variety of topics ranging from:

- Educational Services
- Hospitalization
- Social Support Resources

To learn more about getting involved in The Parent Network, please contact Peggy Guinnesssey at (212) 263-2644, or peggy.guinnessey@nyumc.org

BLURBS FROM THE BOARD



I have been involved with FACES since 2003 when my youngest daughter had a seizure. From the moment I met Dr. Orrin Devinsky and the FACES team, the outpouring of love, support and of course amazing medical care began. My daughter has happily been seizure free for 10 years, is off meds and doing great. We will always support FACES as a thank you for helping us through such a difficult time.

The Gala is my favorite event! The first year I was involved myself, Leah and Nancy actually pushed a car in and out of the elevator! The Gala brings all the branches of the FACES family together - patients, docs, pharma, friends and family all working toward the same goal - a cure. The love in the room is palpable.

-Randi Levine



I first became involved in FACES as a patient in 1981. My parents joined FACES to support me and all the other patients that suffer from seizures and epilepsy. My mother was on the board for years and helped with many of the fundraising and research projects. When my mother stepped down a few years ago I

took her place. Being on the board has been one of the most amazing experiences in my life.

My favorite FACES event has to be the Gala. I remember the first one which was at the Puck building with Robin Williams as the MC. It has been an incredible journey watching this event change and grow every year. I am honored to be on the board at FACES surrounded by smart and incredibly motivated people on a mission to find a cure.

-Amy Moritz



I became involved with FACES when I was desperate to connect with people walking a similar path. When my son was diagnosed - 12 years ago - I knew no one else dealing with epilepsy. I found FACES and connected with a community of people who "got it". I stayed involved because I continue to meet neat,

amazing people who help me at every turn. The people I have met through this group are my lifetime heroes.

I don't know what I'd do without them and FACES.

I love every FACES event! I don't care if it's a Steering Committee meeting, the Epilepsy Conference or the Gala. I am lucky to gather with this community and learn, learn, learn. Right now, I'm a bit partial to our newer events...anything with the Parent Network has me engaged! I'm also a proud supporter of freshFACES. Last year was a laid back fun event - so rare to get out for an easy night. I'm lucky to be involved with this uniquely great group.

-Kate Picco

ATTITUDE OF GRATITUDE

Thank you all so much. I know you have heard many times how helpful it is to stay in a FACES apartment during a long hospital stay and I just wanted to thank you for everything you do. You make a difference in a family's life at a time when everything is turned upside-down and even people with strong support networks struggle to stay on top of everything.

This will be Evan's second brain surgery and our second stay at a FACES apartment. Preparing for a second surgery has been harder for us because we already know we will enter into an experience that will come with unforeseen challenges and test us in unexpected ways. We will walk

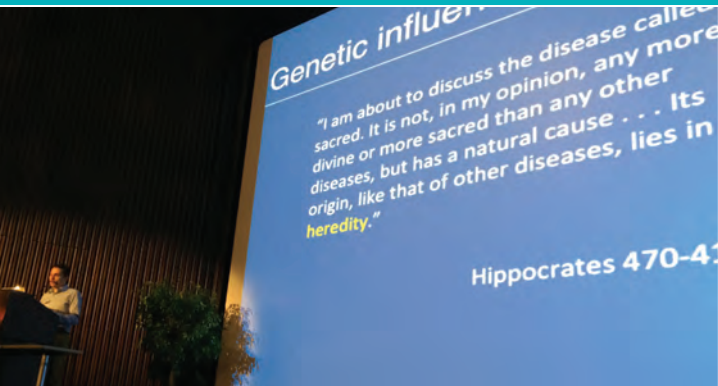
through the revolving doors at NYU and check our lives at the door. And we will put our son's future in Dr. Weiner's gifted hands, again.

Evan's first surgery was successful but TSC is relentless. Moving forward, we are filled with hope for Evan and are so grateful for everyone at both FACES and NYU Langone Comprehensive Epilepsy Center. There is nowhere we would rather spend the month of August and we are looking forward to a new beginning.

- Lisa

EPILEPSY CONFERENCE RECAP

By: Dana Pirolli



On April 26th, FACES hosted their annual epilepsy conference. The day was full of support from those associated with epilepsy and professionals working on finding a cure. With back to back sessions of treatment options, personal stories, therapeutic studies, progression in prevention, and much more; the day was genuinely filled with hope. People from all walks of life were there to learn and network with one another. With various sessions; I was fortunate enough to observe a few. Each and every one was worth every moment spent.

DEEP BREATHING & EPILEPSY

Wellness Coach and founder of “Beyond the Bridge: An Integrative Wellness Consultancy”, Linda Shields, works with NYU Langone Medical Center to help individuals who are diagnosed with epilepsy. She works with patients through a process using deep breathing and meditation, providing the patient with knowledge and self awareness to calm themselves down if any trigger towards a seizure should arise. This can teach those how to relax the body and have a rhythmic breathing pattern to get blood flowing to and from the brain. These different breathing exercises and meditation skills were a great alternative to learn. Many others who joined in on this session found it to be very positive and insightful. Much of the audience shared specific details as to how deep breathing has improved their lifestyle or the life of people they know with epilepsy.

PARENT PANEL

FACES has created a program called “The Parent Network” that offers support for those who live with and care for loved ones with epilepsy. Three speakers presented their stories; there was not a dry eye in the entire audience. The level of suffering and compassion truly blended together, by expressing how looking after someone with epilepsy truly impacts their everyday life and changes their idea of reality; not just by adjusting

to the struggle, but also by fostering an appreciation of those who have a chronic illness.

A sister of an individual who suffers from epilepsy, described how it has shaped her and how she wants to help others in the future. She plans to attend nursing school and believes that by witnessing the experiences of her brother, she now has discovered her career goal. A father of a little boy, who was recently diagnosed, described how difficult it has been to come to terms with his son's diagnosis. He and his wife are still on the path to exploring different options for their son and FACES has truly given them much hope. And a mother of a nineteen year old told her story. Even though it was very stressful to figure out what would work for their son, it only made her and her husband persevere more on educating themselves to design a perfect plan for him. Courageously revealing their thoughts behind every personal situation gave many people a perspective on the family members' emotions and aspects towards the condition itself.

CANNABIDIOL, SUDEP, & DEVICES

Dr. Orrin Devinsky, founder of FACES, was last to speak at the conference. His lecture at the end seemed to be what many people were anxious to hear. He delivered the progress of the studies that researchers are working on to better understand epilepsy and search for a cure. Dr. Devinsky discussed the pros and cons of medicinal cannabis, SUDEP, and other inquiries within the epilepsy community. He continued to discuss how significant it is for individuals to voice awareness and wisdom. The more people that share their experiences, the more professionals can provide better information to other patients who are diagnosed with epilepsy.

The words that were spoken throughout the day were truly inspiring and brilliant. Individuals left with positive energies and hopeful minds. Everyone who attended felt vigorous ambition towards the future and finding a cure.





FACES GALA 2015

FACES Gala 2015 held on Monday, March 2nd at Pier Sixty at Chelsea Piers honored distinguished members of the FACES community - Mary Quick, FACES advisory board member, for her long-standing dedication and philanthropic commitment, and the NYU Langone Comprehensive Epilepsy Center's Jacqueline French, MD for her remarkable endeavors in science and medicine that have influenced the development of new epilepsy therapies.

The evening's program commenced with Dr. Robert I. Grossman, Dean and CEO of NYU Langone Medical Center, delivering the welcome remarks. Gala chairs Angela and Matt Stone followed with their message and introduction of Mike Myers (multi-talented film and television personality of SNL, Wayne's World, Austin Powers, Dr. Evil and Shrek fame) who lent his inimitable talent as emcee.

Before proceeding with the award presentation, Dr. Orrin Devinsky extended grateful appreciation on behalf of FACES and the NYU Langone Comprehensive Epilepsy Center to gala chairs Angela and Matt Stone, auction chair Barbara Walsh, auctioneer C. Hugh Hildesley, underwriters Leah and Michael Weisberg, all gala sponsors and guests, and the FACES community at large.

Dr. Devinsky shared significant on-going and future initiatives, lauding the Epilepsy Center's extraordinary team of nurses, nurse practitioners, research scientists, EEG technicians, administrators, and doctors. Margaret Pedersen, daughter of Mary Quick, stepped up as the voice of grateful patients, courageously sharing her journey from the time of her diagnosis in 2005, and how she conquered her fear of living with epilepsy.

Photo Credits: Jay Brady and Ann Watt

BOTTOM ROW FROM THE LEFT: Mary Quick, Leah Weisberg, Jeffrey Levine, Randi Levine, Ben Fraimow, Dr. Jacqueline French, Mike Myers.



PIER SIXTY AT CHELSEA PIERS MONDAY, MARCH 2, 2015

“Here I am 10 years later and I have finally gotten to the other side of fear. I appreciate all that I am able to do with my life while suffering from epilepsy. I stop and marvel at what other children with far worse afflictions than I suffer from. Their strength inspires me.”

- Margaret Pedersen

Additional highlights of the gala included transitioning from the traditional printed souvenir journal into a digital format, where journal ads were looped onscreen throughout the evening, and opening the “online” silent auction a week before the gala.

Bidding was feverish for the unique and exclusive auction packages that went on the block for the live auction, and the same was true for the online auction.

The FACES Gala is the major source of funds that provide for mission delivery programs and services, which include cutting-edge research, education, and community-building initiatives. This year’s event has raised over \$4.9 million to date.

Photo Credits: Jay Brady and Ann Watt

TOP ROW FROM THE LEFT: Kelly Myers, Mike Myers, Matt Stone, Angela Stone, Lorri Shackelford, Pamela Mohr, Veronica Mainetti, David Fishel, Mike Myers.

BOTTOM ROW FROM THE LEFT: Amy Pollner Moritz, Alice Thorpe, Wendy Belzberg, Dr Orrin Devinsky, Esther Fine, Deborah Devinsky, Todd Boehly, Katie Boehly.

FRESH FACES

LAUNCH EVENT FRESHFACES COCKTAIL PARTY RAISES \$100,000 AND EPILEPSY AWARENESS



The first-ever *freshFACES* Cocktail Party took place on Thursday, September 18, 2014 at espace in Manhattan, raising \$100,000 for FACES!

The evening was a tremendous success with nearly 250 guests in attendance. Keynote speaker, Dr. Orrin Devinsky explained the importance of the FACES mission, and why it's crucial to raise funds for research, programs and services.

Throughout the night, attendees took to social media tweeting and posting pictures of the event under the #ShowUsYourFACES hashtag. Attendees had a fantastic time participating in the "freshExperience Stations" such as hand massages, wine and olive oil tastings, caricatures

SECOND ANNUAL
freshFACES COCKTAIL PARTY
Thursday, October 8, 2015



and palm readings.

An auction run by CK Swett elicited feverish bidding on vacations to destinations like Jamaica and Las Vegas. The event culminated with a set by DJ Andrew Gangi that brought guests to the dance floor.

We hope to double our attendees for this year's event with some new experiences for guests to enjoy. Tickets for *freshFACES* 2015, which will take place at espace on Thursday, October 8th, are on sale now. Visit: giving.nyumc.org/freshfaces to purchase today!

Photo Credit: Ann Watt

FUNDRAISING CORNER: HOPE 5K

By: Dr. Marc Greenstein

On May 3, 2015 over 800 people crowded Livingston High School for the Third Annual Strides for HOPE 5K and Family Fun Walk. Our family started the Greenstein H.O.P.E. (Help Overcome Pediatric Epilepsy) Fund five years ago.

Supporters gathered to celebrate the strength, courage and bravery of the children and their families fighting with epilepsy.

We had a beautiful and warm spring day. Children enjoyed face painting, balloon animals, snacks, picture with Elsa from the Disney movie Frozen and pictures with Stormtroopers from Star Wars.



Over 200 runners competed in the 5K while hundreds of families walked the one mile course. Children 12 and under competed in fun races. The event raised over \$100,000 to support the pediatric epilepsy program at Saint Barnabas Medical Center in Livingston, New Jersey.

AFTERNOON TEA



At the age of seven months, our beautiful daughter Skylar was diagnosed with mild cerebral palsy complicated with a seizure disorder. My husband Steven and I searched and prayed to find a doctor who could help Skylar and stop her frequent and debilitating seizures. Our days, once carefree, became days filled with anxiety and sadness.

So much of what we had once taken for granted were now moments spent holding our breath fearful for the havoc that 50 to 100 seizures a day would do to our baby. Watching how this affected Skylar, and feeling helpless were the worst moments that Steven and I had experienced. We were driven to find answers.

At the lowest point of our despair, our prayers were answered the day we met Dr. Orrin Devinsky at the NYU Langone Comprehensive Epilepsy Center. Dr. Devinsky brilliantly found the ideal combination of medication

By: Candice Stark

to control Skylar's seizures. Now, at the age of twenty-six our precious Skylar lives practically seizure-free and has close to the quality of life that we as parents all want for our children.

With Skylar serving as inspiration, I decided to host a tea in my apartment on October 29, 2014 to benefit FACES. It was a beautiful, fun and inspiring afternoon for everyone present, listening to heartwarming remarks made by Skylar, followed by Dr. Orrin Devinsky's insightful address relating to cutting-edge research initiatives that he and his team of extraordinary medical professionals are currently investigating. Guests enjoyed sweet and savory treats and, more importantly, an afternoon of delightful shopping.

Because of everyone's generosity, over \$70,000 was raised. Participating boutiques such as Carolyn Rowan, Dorie Friedrich, Adrienne Landau, Jodi Rose and Sherry Miller donated 15% of their sales and Jill Haber and Roni Blanshay donated 100% of their proceeds.

Raising epilepsy awareness is an important priority of mine, and of Skylar's. We hope to continue to host this event, which will serve to raise funds and educate the community on epilepsy and seizure disorder.



TEAMFACES MARATHON SUCCESS

\$230,000+ RAISED | 78.6 MILES | 22 RUNNERS

With 4 incredible New York City races complete, TeamFACES has grown bigger and stronger over the past 2 years than ever expected. When the program started in 2013 we ran the NYC Marathon with 5 runners, raising over \$60,000. One year later - FACES completed the 2014 NYC Marathon with 7 runners, raising over \$118,000 and this November we will race the NYC Marathon again, with 12 runners!

Each and every year the enthusiasm around our program stretches beyond those physically training for the race. TeamFACES allows families and friends of those affected by epilepsy to join in our mission. Through individual donations to a runner, creative fundraising events, support while training, cheering from the side lines, or celebrations after a successful race, FACES has seen communities both local and far rally together to spread epilepsy awareness.

Not only has TeamFACES filled the streets of New York during the full marathon, but we've also successfully completed the 2014 and 2015 NYC Half Marathons. In addition to New York, two past TeamFACES runners participated in the 2015 Boston Marathon this spring - each raising over \$10,000 individually, on top of contributions already received during their previous races!

The drive, motivation and spirit behind each runner is truly unique to FACES and we cannot thank each and every person enough for their dedication and commitment. In the future, FACES hopes to see more purple fill the streets, both in New York and elsewhere, as we continue to run and continue to spread epilepsy awareness!

As a result of our continued success, we have decided to create a training program for our athletes. Elizabeth Azze from Mountain Peak Fitness will be the coach for TeamFACES. Her company specializes in online coaching, consulting, and working with clients & athletes in one on one and group session formats. They design strength & conditioning and sports specific training plans from the beginner level, to the elite athlete. We feel confident that through Elizabeth's leadership, TeamFACES will reach the next level.

FACES is currently a charity partner of New York Road Runners and participates in the New York City Marathon in November as well as the New York City Half Marathon in March. If you receive an entry (not affiliated with another charity) to an endurance event elsewhere and would like to use that as an opportunity to fundraise for FACES, please contact us! FACES can provide you with a personal fundraising page, your own TeamFACES athletic shirt, signage for your race day and additional support.

FACES RESEARCH PROJECTS FY'15

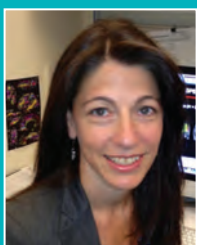


Disruption and Restoration of Memory Consolidation During Sleep in Epilepsy Patients

Anli Liu, MD

Strong converging evidence reveals the importance of sleep for learning and memory. Patients with temporal lobe epilepsy (TLE) can have

abnormal electrical activity, called interictal epileptiform discharges (IEDs), during sleep. By disrupting brain activity which transfers memories into long-term storage, IEDs may contribute to memory dysfunction in epilepsy patients. Understanding how these patterns may disrupt the stabilization of memories during sleep may help clinicians better manage this important issue which affects quality of life in many epilepsy patients.



Hyperfamiliarity: The Development of a Scale

Karen Blackmon, PhD

Hyperfamiliarity is a type of paramnesia characterized by strong feelings of familiarity for unfamiliar people or faces. It has primarily been observed in populations

with frontal and temporal lobe pathology, specifically populations with temporal lobe epilepsy (TLE). Typically, hyperfamiliarity is observed in the post-ictal stages of tonic-clonic seizures and, in rare cases during simple-partial seizures.

Unlike other paramnesia's such as Capgras syndrome (the delusion that a close family member, friend or spouse has been taken over by an imposter), or Fregoli syndrome (the delusion that different people are in fact a single person in different disguise or with an altered appearance), hyperfamiliarity is not a symptom of delusion but instead the result of a 'mismatch' between the neural systems underlying emotion and facial recognition.

The purpose of the current study is to investigate the reliability and validity of a newly developed scale designed to capture symptoms of hyperfamiliarity in epilepsy patients. To establish scale validity, we will examine the relationship between self-reported symptoms and objective performance on facial recognition and memory tasks. The study further aims to investigate the prevalence of hyperfamiliarity symptoms in the normal population and to establish a clinical cut off score for diagnosis.



The Interaction Between Autism Spectrum Disorders and Epilepsy

Alejandro Salah, MD, PhD

Autism spectrum disorders (ASD's) are developmental disorders characterized by social and emotional deficits often associated

with epilepsy. I will use the Timothy syndrome mouse model (TS2-neo mice), an established mouse model for autism developed in Dr. Richard Tsien's Lab, through an L-type calcium channel mutation (CaV1.2) to investigate their seizure tendency compared to normal animals using long-term video-EEG. These mice develop an autism phenotype prior to 3 months of age, but the time course of abnormal electrical brain activity is not known. These experiments are critical for a better understanding of the relationship between autism and epilepsy. Preliminary reports from the first part of the study show that these animals preseting autism have more spontaneous epileptiform activity in the form of interictal spikes compared to normal animals.



AED Adherence, Depression and Quality of Life in Chinese Patients with Epilepsy

Tanya Spruill, PhD

Epilepsy self-management has been identified as a priority research area by a number of clinical and public health organizations. We

have established a multidisciplinary collaboration between NYU Langone's Departments of Neurology and Population Health to develop and evaluate a set of innovative, technology supported tools to improve antiepileptic drug (AED) adherence and depression, and in turn, quality of life (QOL) and clinical outcomes. A major focus of this work to date has been the translation and cultural tailoring of these tools for African American and Hispanic patients.

However, Chinese patients comprise approximately 13% of the Bellevue epilepsy clinic population from which our study participants are recruited; these patients are currently unable to participate in and potentially benefit from this research. Little is known about the factors that contribute to AED non adherence and depression among Chinese patients with epilepsy, particularly in the United States. Identifying the most important predictors will inform the selection of intervention targets and the development of tailored self-management tools to

improve outcomes in these patients. In collaboration with the NYU Center for the Study of Asian American Health (CSAAH), the proposed study will examine a broad range of potential predictors of AED adherence, depression, and QOL in Chinese epilepsy patients living in NYC and will use this data to adapt the set of self-management tools we have developed

the brain that causes seizures is important information used by physicians to plan a treatment strategy for the individual patient. One of the primary challenges for the project is to ensure that epilepsy-causing brain regions are identified without misidentifying healthy brain tissue.

We have used MRI scans from individuals who have undergone successful epilepsy surgery in the past to improve our ability to localize epilepsy-causing brain regions in new patients. The novel approach developed in this study addresses an important challenge in providing useful patient-specific brain maps for planning epilepsy surgery.



Focal cortical dysplasia detection using multi-site clinical MRI

Heath Pardoe, PhD

Most people with epilepsy will receive an MRI scan at some point during their treatment. The aim of this project is to use an MRI scan, in combination with advanced computational methods, to locate brain regions that cause seizures. The location in

TEEN DAY



The 3rd Annual FACES Teen Event, held on Saturday, June 6th at the **American Museum of Natural History**, was a day of adventure!

Upon arrival, teens were able to mingle with one another before watching a movie titled, *Tiny Giants*. The 40-minute film followed the titanic challenges that small animals face as they make their way in a much bigger world.

After the movie, a friendly tour guide took the FACES teens around on an exhilarating *Night at the Museum* themed tour. From a statue of Theodore Roosevelt, models of woolly mammoths,

elephants, lions and zebras to a fossil skeleton of Tyrannosaurus Rex, the FACES teens enjoyed a real treat!

The event ended with a delicious lunch in the museum's cafeteria.

Although none of the exhibits came to life on our tour, all who attended were thrilled with the experience. FACES was able to bring a great group of teens together, and as a result many friendships were made. Take a look at these photos of our smiling faces!

MEET THE NEUROPSYCHOLOGISTS

The neuropsychology group at the NYU Langone Comprehensive Epilepsy Center provides neuropsychological assessment services to patients experiencing difficulties with memory, concentration, and other cognitive functions secondary to epilepsy. The team provides more extensive testing for those patients undergoing surgical treatment, including special procedures such as the Wada Test and Presurgical Language Mapping. Neuropsychology faculty members also provide assessment services for patients with other neurological conditions, including concussion, Parkinson's disease, stroke, and geriatric memory disorders. The group has an active training program with two postdoctoral fellows, interns, and a number of pre-doctoral students from local universities. Ongoing research ranges from studies of memory disorders in epilepsy to studies on quality of life.



William B. Barr, Ph.D., ABPP

Dr. Barr is the Director of the Neuropsychology Division and an Associate Professor of Neurology and Psychiatry at the NYU School of Medicine. He has over 25 years of experience in clinical practice, training, and research in the field of

neuropsychology with specialties in epilepsy and mild brain injury. Dr. Barr received his doctorate at the New School for Social Research and completed his internship training at the Boston VA Medical Center. Research interests include neuropsychological assessment of epilepsy and sports concussion.



William MacAllister, Ph.D.

Dr. MacAllister joined NYU Langone Comprehensive Epilepsy Center in 2007 where he is a Pediatric Neuropsychologist and is also a Clinical Assistant Professor for the Department of Neurology at NYU Langone Medical Center. He

received his doctorate from the Pacific Graduate School of Psychology at Palo Alto University in 2001 before completing a fellowship in clinical neuropsychology at SUNY Stony Brook from 2001-2003, where he specialized in pediatrics. Thereafter, he was on the faculty at SUNY Stony Brook in the department of neurology, serving as the

director of pediatric MS research before coming to NYU Langone Medical Center. Clinical and research interests include the ecological validity of neuropsychological testing in children with epilepsy as well as learning disabilities and attentional disorders in childhood seizure disorders.



Chris Morrison, Ph.D.

Dr. Morrison is a board certified Clinical Neuropsychologist at the NYU Langone Comprehensive Epilepsy Center. She received her Ph.D. from the City University of New York Graduate School at Queens College. After completing her internship at Long Island

Jewish Medical Center, she received grant funding for a post-doctoral fellowship at Mount Sinai Medical Center (specializing in movement disorders) and then went on to complete a second fellowship at the NYU Langone Comprehensive Epilepsy Center. In her current faculty position at the center, she is involved with clinical, training, and research activities. Her research interests include the cognitive, behavioral, and affective sequelae of neurological diseases and their treatments, with a specific focus on epilepsy and movement disorders.



Linnea Vaurio, Ph.D.

Linnea earned her doctoral degree in clinical psychology, with a concentration in neuropsychology, from the SDSU/UCSD Joint Doctoral Program. She completed her internship with a focus in neuropsychology at the UCLA

Predocutorial Internship Program and then completed a two-year post-doctoral fellowship in clinical neuropsychology at the NYU Langone Comprehensive Epilepsy Center. Currently, she is a Clinical Neuropsychologist here at the epilepsy center and a Clinical Assistant Professor in the department of neurology. Her research efforts have focused on fetal alcohol spectrum disorders, attention-deficit/hyperactivity disorder, epilepsy, and issues related to aging. She has published in these areas. More recently, her research has focused on developing interventions for children and adolescents with epilepsy to improve quality of life and mood.

SHINING A LIGHT ON THE UNKNOWN: SUDC

By: Laura Crandall

When I meet someone for the first time, it usually goes something like this..

“What do you do for a living?”

Me: “I research sudden unexplained death in children- SUDC”

“You mean SIDS?”

Me: “No, SUDC. It is an unexplained death in a child after their first birthday- not young babies”

“Oh...Oh my goodness, I never even knew that could even happen!!!”

Me: “Me too.”

The last 17 years of my life have been filled with the most wonderful memories and also the most painful ones of my life. I still think of my life as two parts- the time before Maria died and the time after. The former of which included that blissfully ignorant phase of my life that was free of any real pain or suffering.

Maria was my first born child and she made me love motherhood more than I could have ever imagined. At the age of 15 months, she was a happy, bubbly little girl who loved everything and everyone she met. And at the age of 15 months and 9 days, as I walked around the house doing chores with the sound monitor on my hip while she napped, she quietly and inexplicably left this world. What followed stills feel like a dream- calling 911, police, ambulances, a too quiet emergency room... and so many questions.

The professionals had many for me and I asked just as many, if not more, right back to them. What happened to her? Could I have prevented it? Did she suffer? How often does this happen? She is too old for SIDS! Will this happen again if I have any other children? What does the medical research say? Who is researching this?? Does anyone know anything????



Answers to my questions never came, and a full autopsy never provided a reason as to why Maria didn't wake up that beautiful day. I was encouraged to accept that sometimes we just don't understand and to move on and to believe that Maria was a rare tragedy and not a public health issue. Years later, the first recognition of SUDC as a specific category of death was developed and that progress continues today.

“Sudden Unexplained Death In Childhood (SUDC) is the sudden and unexpected death of a child over the age of 12 months, which remains unexplained after a thorough case investigation is conducted.” (Krous et al. 2005)

We have made progress in answering some of those early questions- with full credit going to the hard work of many families who refused to give up and the amazing efforts of pathologists and SUDC researchers who dedicated themselves to our children.

According to the CDC, Sudden Unexplained Death in Childhood (SUDC) accounted for 388 deaths in the United States in 2013. Among 1-4 year olds, 224 died from SUDC; one of the top five causes of death for that age group. Sudden Infant Death Syndrome (SIDS) is fourfold more common (1575 deaths in 2013) than SUDC and is far better understood, with a >100-fold difference in published research and funding.

There has been little progress in understanding the causes of SUDC and no progress in prevention. Despite reductions in SIDS and other causes of mortality in childhood, according to some reports the rate of SUDC has increased during the past two decades.



My connection with Dr. Orrin Devinsky and FACES may still seem unclear, but our meeting may just result in the most positive shift in SUDC efforts to date. First published in 2005, SUDC research identified some children with a history of febrile seizures and our latest reports show a ten-fold elevation of febrile seizures prevalence in SUDC cases reported to the SUDC Foundation.

Today, I am the Co-Founder of the SUDC Foundation and also a Research Scientist at NYU helping to direct the newly created SUDC Registry and Research Collaborative (SUDCRRC). Both provide me avenues to help those in need after the devastating loss of a child as well as push forward our scientific understanding to aide in finally reaching the future that is free of these mysterious tragedies.

The SUDCRRC is a multisite collaboration between NYU Langone Medical Center, Columbia University, Mayo Clinic and pathologists around the country working together to improve our understanding of SUDC. The SUDC Registry and Research Collaborative analyzes these cases to understand risk factors and causes, and develop preventative measures. By bringing together these rare cases, we hope to support grieving families with a greater understanding of their child's death and support medical research efforts into all causes of Sudden Unexplained Death in Childhood. The SUDC Foundation is a non-profit 501c3 that provides a centralized resource for information, advocacy, support and research into SUDC. It includes a community of over 650 affected families from all around the world and all services are provided at no cost to its recipients. It also provides services to professionals investigating SUDC and those caring for families of SUDC.

Advocating for the many needs of SUDC is complex. Whether it is advocating for a particular family as they navigate a lengthy death investigation that often spans many months, or educating professionals at medical conferences or coordinating efforts in our nation's capital.

I doubt that anyone could have convinced me 17 years ago that my journey after Maria's death would lead me to meeting the President of the United States on December 18, 2014, let alone watching, as he signed into law an act which is the first acknowledgment that SUDC actually exists in our country.

Specifically, the act will build upon existing activities at the Center for Disease Control and Prevention (CDC) to improve the quality and consistency of data collected during investigations to better inform prevention and intervention efforts related to stillbirths, Sudden Unexpected Infant Deaths (SUID) and Sudden Unexplained Death In Childhood (SUDC). This will enable doctors and researchers to better track, research and prevent these tragic losses.



At the beginning of this article, I shared a frequent conversation in my life that highlights the lack of awareness of SUDC. It is not my goal that everyone know of SUDC or that it become a household name. My goal is to understand it and prevent it- so that no one ever has a need to know about it ever again. I am so grateful for SUDC's partnership with FACES and Dr. Devinsky in this effort which is so close to my heart. SUDC has found the most wonderful home in my alma mater - NYU.

To learn more about the SUDC Foundation and the SUDC registry and Research Collaborative, go to: www.sudc.org

ANTIEPILEPTIC DRUG AND DEVICE TRIALS XIII MEETING

By: Jacqueline French, MD and Sarah Zubkov, MD

On May 13-15, the 13th biennial Antiepileptic Drug and Device Trials meeting was held in Turnberry Isle Miami Hotel, Aventura, Florida.

The conference, orchestrated by Dr. Jacqueline French, was sponsored by the Epilepsy Study Consortium in collaboration with the Epilepsy Foundation. It focused on drug and device development from preclinical through clinical evaluations and identified challenges in bringing new treatments to market. Participants included representatives from academic medicine, National Institute of Health (NIH), Food and Drug Administration (FDA), as well as from pharmaceutical and device companies.

The meeting began with a look at how drugs are developed through laboratory (preclinical) research, an essential step before drugs are tested in the clinic. New animal models were discussed, and a debate was held over whether more rigorous animal studies would increase a drug's likelihood of success in human trials. The need for therapies modifying disease processes (i.e., anti-epilepsy drugs) rather than symptoms (i.e., anti-seizure drugs) was identified.

The conference shifted focus to the drug approval and regulation process. Both academic physicians and FDA representatives discussed current trial designs and how they could be improved in the future. Emphasis was placed on finding trial designs that are patient friendly and safe.



Dr. Jacqueline French (Co-Director of Epilepsy Research & Epilepsy Clinical Trials, NYU Langone Comprehensive Epilepsy Center), Dr. Russell Katz (former FDA neuropharmacology division director), Mary Ann Brodie (Executive Director, Epilepsy Study Consortium) and Marc Dichter MD (professor, University of Pennsylvania, symposium co-director) together in 1992, the first year the course was held, and in 2015.

The second day started with a review of requirements for performing trials and approving drugs for children. This is critically important, since many types of epilepsy occur



only in children. On the other hand, some types of epilepsy occur both in adults and children, and the representatives from the FDA discussed an initiative that would allow children to have access to drugs based on adult trials. This effort would allow children faster access to new drugs, when appropriate. Dr. Daniel Friedman from NYU Langone Medical Center highlighted new devices for seizure counting, including SmartWatch, Epi-care Free, Brain Sentinel, Embrace, and implantable EEG systems.

The second day wrapped up with a “shark tank” competition, sponsored by the Epilepsy Foundation. Six pre-selected finalists pitched their novel ideas to improve the lives of those with epilepsy, and compete for up to \$200,000. Three sharks voted to award \$75,000 to Empatica, a company marketing a smartwatch that uses a combination of accelerometry, heart rate, and galvanic skin response to detect seizures and notify loved ones. The remaining two sharks, along with the audience, awarded \$125,000 to Mark Cook for his sub-scalp seizure monitor for diagnosis of epilepsy. Both devices are in development, and should be available to patients in the near future.

The third day included the “Pipeline” presentations. These presentations, given by companies and academics, highlight new drugs and devices that are being developed for the diagnosis and treatment of epilepsy. Many exciting new treatments were presented, including some therapies being developed specifically for childhood epilepsies such as Dravet syndrome, Lennox-Gastaut syndrome, and some genetic epilepsies. Some are still in the laboratory and some are in clinical trials, while others are very close to approval for patients.

For more information on this conference, including the agenda, please visit www.epilepsy.com

The Purple Spoon

This summer ceviche is a crisp, light recipe that is perfect as a side dish for any summer BBQ or outdoor event. You can serve this as a side dish or even spoon it out into small plastic cups and serve as single serve appetizers (garnish with a parsley leaf or a lime wedge). The avocado and olive oil provide much needed heart healthy fats in a low calorie alternative to typical high fat appetizers or side dishes. Trade this salad for a typical potato salad and save more than 150 calories. Avocado is a super food – it is high in healthy fats and high in fiber. In fact 1 whole avocado has 17g of carbohydrates, of which 14 grams are fiber! That is a fantastic carbohydrate to fiber ratio. Avocados provide an excellent source of healthy fats and also offer 20 different vitamins and minerals making this recipe not only low calorie, but nutrient dense.

COOKED SUMMER CEVICHE

INGREDIENTS

- 2lbs cooked shrimp chopped
- Cilantro chopped
- Parsley chopped
- 4 Tomatoes chopped
- 1 Red onion chopped
- 1 Avocado cut into chunks
- ¼ Cup red wine vinegar
- Juice of 1 Lemon or lime (your preference)
- ½ Cup olive oil
- 2 Cloves chopped garlic
- Salt/pepper to taste



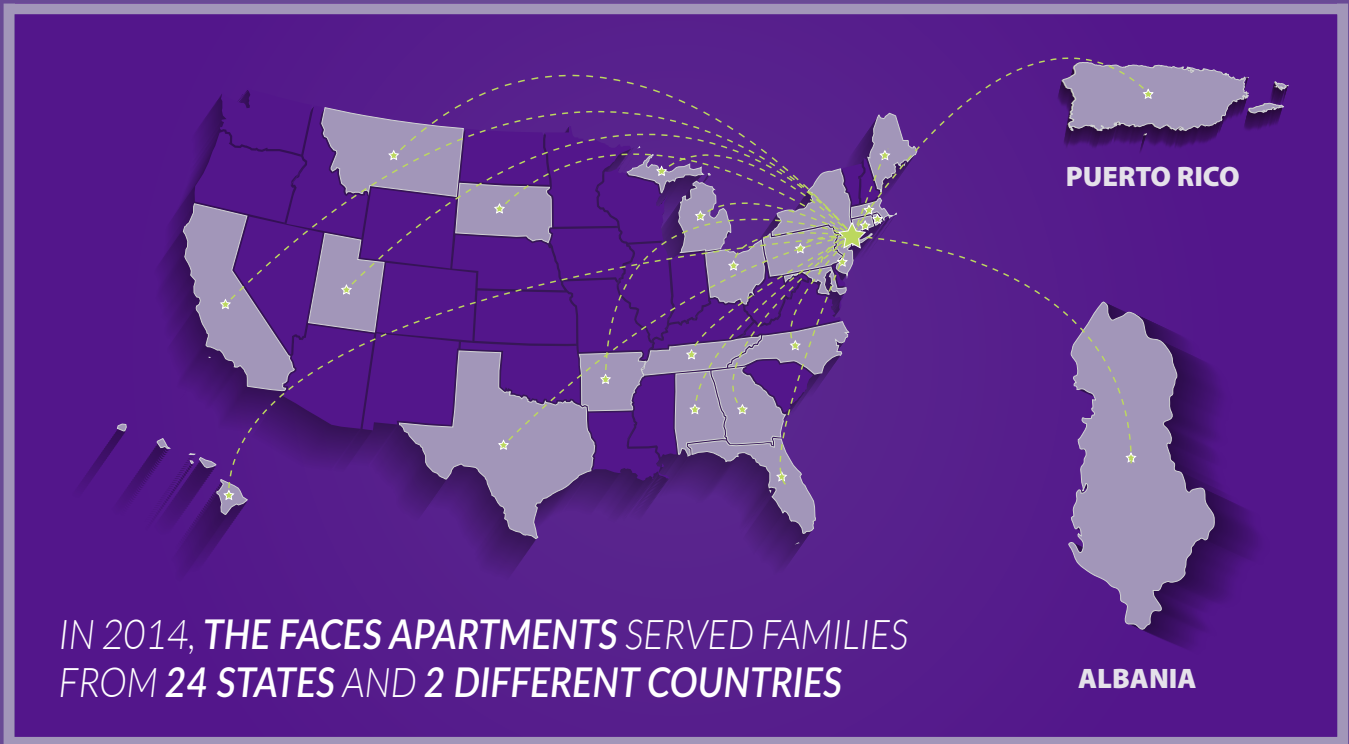
DIRECTIONS

Mix the oil, vinegar, garlic and lemon juice together and pour this over the shrimp. Let it marinate for at least an hour. Add the other ingredients and toss together. Serve cold.

Makes: 12 servings

(Nutrition Analysis per serving): 192 calories, 12.5g fat, 4.5g carbohydrate, 1.8g fiber, 17g protein)

FACES APARTMENTS: A PLACE THAT FEELS LIKE HOME



Grateful is the word that comes to my mind when I think of FACES and what it means to me and my family.

In July of 2014, my husband, who has had epilepsy for over twenty years, had undergone a battery of tests and was found to be a suitable candidate for the RNS implant. This was an answer to prayer, as his seizures were not controlled. On August 5, 2014, he underwent brain surgery at NYU Langone Medical Center. The procedure involved placing several electrodes directly on his brain. His medication was slowly weaned until he produced enough seizures to determine where to place the RNS device. He remained connected to the electrodes for one week, and then the surgery to implant the device was scheduled the following week.

With everything looking successful with the surgery, my husband came out of ICU shortly and was subsequently discharged from the hospital. We had to remain in New York City for another week to ensure that my husband was doing well. I stayed with my husband at the hospital from the time of his initial surgery and my mother-in-law was able to join us for the second surgery. With limited accommodations for family members at the hospital, staying at a nearby hotel was the only option where my

mother-in-law could stay, as we live in Tennessee and know very few people in the city outside of the hospital staff.

Our entire stay in New York City during this process would have posed a considerable financial burden to our family. We were so thrilled that prayers had been answered when we were informed after he came out of ICU that a FACES apartment became available for our use. It was a true blessing to have a place to rest and shower for me and my mother-in-law, and my husband after he was discharged from the hospital. It was great comfort to be able to focus solely on his recovery. Knowing we had a nice, cost-free place to stay was amazing! The hotel staff were all very friendly and they went out of their way to take care of my husband. We could not have asked for better care.

Soon after we returned home, I started noticing changes on my husband's word recall ability and other strange behaviors. After a few days, my husband's incision began to drain and a CT scan confirmed that he had developed a brain infection along with brain swelling and fluid build-up. My father-in-law, my husband, and I immediately flew back to New York on September 4, 2014 and he had surgery the following day to remove the infection, the

RNS device, and the fluid. The surgery was successful, but he became extremely ill, developing blood clots and the infection caused his cognitive functioning to deteriorate.

Once again, FACES came through for us, and we were able to stay close to the hospital. My mother-in-law was able to join us, and all three of us supported each other through this crisis. We remained in New York for a few weeks as my husband recovered enough to go home. My husband remained ill for quite some time, but through God's grace, he has recovered quite well.

As a result from the infection, part of his skull was eaten away. We returned to New York in April 2015, to have a prosthesis implanted in his head. My husband received "a clean bill of health."

We are continuing to monitor his seizure activity, and are hopeful for the future. Once again, the FACES apartment was available for our use, which was another blessing!!

We would like to take this opportunity to thank Dr. Werner Doyle, Dr. Orrin Devinsky, Alyson Silverberg, Mary Micelli, the FACES staff, and all the other numerous hospital staff that invested their knowledge, care, and concern for our family. The FACES apartment provided comfort and peace of mind, and we know that there are no words to express what a blessing it was for us.

The FACES apartments are provided cost-free to families traveling to NYU Langone Medical Center for inpatient epilepsy treatment or evaluation. Accommodations at a hotel within walking distance to the hospital are provided on a first-come-first-serve basis for families coming from far distances.



A DR. BLANCA VAZQUEZ SUMMER CAMP SCHOLARSHIP STORY: MEET JOSHUA

By: Sandra Edwards

Where do I begin? It is difficult at times to know what and how much to say. I will start at the beginning with Joshua. He is my only child, who happens to be adopted (we'd always talked about having both adopted and birth children). What we did not know in the beginning was that he had a seizure disorder, ADHD, and a speech language delay. From the beginning of his school experience Joshua has had an IEP (individual education plan) and this has followed him throughout his school years.

What I did not know was that shortly after my son turned 5-years old I would be parenting him pretty much on my own. His father helps financially through child support however, any extracurricular activities, or for that matter anything extra. I was on my own then, and still am now.

Not only did my son start out life with some health challenges that he would have to learn to cope with, but he also had some emotional pain he would have to manage at some level for the rest of his life.

Not wanting to leave him floundering, I got support from my church and counseling, got him involved in gymnastics, football, then martial arts, and helped him through his challenges as best I could with my love and support, and from others in our lives.

Joshua has always been successful in school, in martial arts, and his other sports endeavors, but he was also reserved, shy, and held himself back from getting too involved or close to others. He was shy and reserved at birthday parties, and would be a little sad seeing his friends sit with their mommy and daddy at school programs, parties, and daycare events. He was unsure and lacked the confidence in himself or his abilities. Occasionally, he still needs the reassurance that he's doing a good job or the right thing.

Attending a number of workshops related to his seizure disorder (absence seizures) allowed me to meet the wonderful people at Children's National Medical Center who run The Brainy Camps Association. They have a number of camps every summer for kids with medical conditions such as Camp Great Rock for children with epilepsy, which Joshua attends.



It was through Brainy Camp's Dr. Susan Mehlman that I became aware of the Dr. Blanca Vazquez Summer Camp Scholarship Program of FACES. Dr. Mehlman forwarded an application for a camp scholarship to me. I know you all don't go to camp with him or council him, and he may not remember the name "FACES" (until I remind him of the scholarship). FACES gave him the chance to attend camp for his particular seizure disorder.

The scholarship opened the door for a formerly scared, shy boy to grow into a confident, self-assured young man with goals and dreams. The camp gave him a safe environment and allowed him to grow emotionally, physically, and mentally.

Joshua is now in 11th grade and is in an STI (science and technology) high school, in a program that he had to apply for and get accepted to. He aspires to go to college and eventually open his own auto repair shop! I do not believe that he would have been able to have these dreams - going to college and owning his own shop - if it were not for the chance to attend Camp Great Rock over the years.

You all, the faces behind FACES, have generously provided my son with opportunities, that without your help, I could not have provided on my own. You are truly a blessing in our lives! We are so very thankful for the scholarships that you have granted Joshua over the years!

HOUSTON'S COLLEGE SCHOLARSHIP STORY

By: Sherri Williams



We are on the downhill slide of Houston's freshman year! His first year in college has been a roller coaster of emotions, but experiences of this past year have been invaluable.

Houston is not different from many college students who need to adjust to a new phase in their lives. Balancing college and personal lives, especially for someone like him with medical issues such as epilepsy, is not a small task. Strong-willed, Houston stubbornly refused any special treatment. His medical condition has not stood in the way of his love for athletics. The first time he showed up for practice, the trainer and coach were caught off guard because that morning he had a seizure and it was recommended he stay in to rest. He loves the mound as you can see from the photo taken during his first "college" game.

In his freshman year, he qualified for the junior varsity... and the varsity teams. The coach has him pitching on the junior varsity to get the experience and prepare him to eventually step on the mound with varsity. Hopefully, by the end of the season he will have the opportunity. Oh by the way, his first "college pitch" was a strike!

The path has not always been smooth for Houston. He is struggling with some of his studies, but he has remained obstinate in getting through the hurdle. He receives tutoring and meets with an academic counselor. Dr. Kass, his college advisor, said that kids with medical problems try to do everything on their own, like Houston. Houston has reached out this semester and realized everyone needs assistance. I think this was a good experience.

Epilepsy has made Houston strong. He has overcome many obstacles, making him resilient and headstrong with a vision of the future as a coach. His experiences will connect him with students who, like him, need to muster the courage to overcome their own obstacles!!

We are very grateful that Houston was among the recipients of the FACES College Scholarship Program. We are glad he could be the first in the South to get it... covering a large area by living in Arkansas, graduating in Texas, and going to an Oklahoma college! Everyday... despite the challenges he has to encounter, it is a blessing that he is up and ready to take the mound.

SEEKING EPILEPSY PATIENTS FOR THE STUDY

"MECHANISMS AND ENHANCEMENT OF LEARNING DURING SLEEP" (S14-00609)

We are currently seeking epilepsy patients to participate in a sleep and learning study. Subjects will be asked to sleep at the NY Sleep Institute, located at 724 E. 2nd Ave (between 38th and 39th Streets). Subjects will complete several questionnaires, participate in behavioral testing and undergo an EEG.

We are seeking epilepsy patients with a diagnosis of well-controlled partial epilepsy who are between the ages of 18-35 years old, and fluent in English. Subjects may not have ongoing night time seizures or generalized epilepsy, a sleep disorder, or current use of a psychoactive medication (such as an anti-depressant or a stimulant).

Subjects must not have travelled across time zones or engaged in night-shift work for 1 month prior to participation. Subjects will be compensated \$15 per hour for participation.

For more information, please contact:

Anli A. Liu MD MA,

anli.liu@nyumc.org or

Sarah Barnard at

sarah.barnard@nyumc.org

(ph) 646-558-0876



A PROM FOR EVERYONE

MADISON SQUARE GARDEN - GARDEN OF DREAMS

By: Marianne Hauck

In the spring, flowers start to bloom, days get longer and lots and lots of teenagers look forward to a major rite of passage... Prom! But, for some teens who live with circumstances that put them at a "disadvantage", Prom might not be possible. Many kids in our area struggle with limitations ranging from financial to a wide range of health concerns.

Insert - Garden of Dreams Foundation! This Madison Square Garden (MSG) organization invited 100 teens from the New York City area to attend their Prom on April 14 at Madison Square Garden. Katie Hauck, 14, is a patient of Dr. Orrin Devinsky. Katie has been living with epilepsy, which is managed by medication, since she was four years old and she was thrilled to be invited to participate in the Prom as a member of FACES, Finding A Cure for Epilepsy and Seizures.

MSG invited all the young men and women to a few events in advance of the Prom, so they could mingle, become acquainted with each other and learn more about each other's struggles and successes. Must have been tough meeting and hanging out at the Maroon 5 concert at MSG! Next, all were invited to have private fittings for the long gowns and suits at Macy's in midtown. The girls were given complimentary jewelry, evening bags and high heels to complete their Prom ensemble. The guys looked dapper in their suit and tie and shiny shoes.

To prepare the young ladies for the "Red Carpet" (literally...there was an actual red carpet with media interviews and photo ops, etc...), Supermodel Damaris Lewis and several of her other model friends and

volunteers worked with the girls as they practiced walking smoothly, but "with attitude" and knowing the exact time to stop and pose. The models were so generous and supportive; they seemed to bring out the joy and beauty in each and every girl...whether they were tall or short, shy or sassy, or simply dealing with their everyday struggles.

On the big day, everyone met early at the Affinia Hotel across the street from MSG to have their hair styled by Bumble and Bumble, make-up done by professional MAC make-up artists and have help getting into the dresses and suits.

By 4:00, everyone was ready to start the night of their dreams...a tour around New York City, walking the red carpet with their assigned date, and being interviewed by supermodels, and then, dancing the night away to music. And, there was food, of course!

Katie met so many interesting people from all over the area. The Prom was a great experience to show that living with epilepsy or any other health issue is something that can be managed with the help and support of a great medical community and organizations like FACES and the Garden of Dreams Foundation. And, that most people just want to experience the "normal" things in life. Having epilepsy is just one aspect of who Katie is. Dancing all night and making new friends is another aspect!

THE PARENT PERSPECTIVE

By: Kelly Spier

If I would have started sharing my story with you a few months ago, I think it would have been a little bit different. Unfortunately, Summer, my five year old daughter, just recently had a sudden relapse of her seizures which were under control for over a year. This has put me in a very bad place, as it reminds me of what happened two years ago and how my life and my family's lives were changed forever. Summer had her first seizure at 18 months of age, during a high fever, which we hoped was the main cause and several more over the next 18 months all of which were also associated with high fevers. Our neurologist at the time chose not to give her medication and she continued to do wonderfully. Prior to her 3rd birthday, Summer had her first really bad seizure and started her first medication. A few weeks later, she developed a new type of seizure - they were quick, lasting from a few seconds to a minute or so. Within days, she was having hundreds to thousands of these seizures a day. She was hospitalized and given medication which seemed to work, however the day we were discharged she started to have them all over again.

After 9 months of hospital intensive care visits and 9 failed medications, Summer was still having thousands of seizures a day and drastically regressed in all aspects of her life. It was then that we decided to try a modified ketogenic diet, which has been a miracle for her. Two days after starting the diet we saw a clear improvement in her seizures. Nine days into the diet, Summer went from having thousands and thousands of seizures a day, to having zero!

When we started the diet, it was a daunting task. How were we to keep her on such a restricted diet with three other daughters (now four other daughters) eating anything they wanted? In the beginning, we both cried out of frustration and the restrictions of the diet. The first few weeks were so very difficult, but to our surprise, Summer became amazing with the diet. She knows what she is allowed to eat and drink and has no issue with what her sisters and friends are eating. She will get them cake and cookies and never try to take a bite or cheat on her diet. She is a remarkable young girl. I don't know any other girl her age who's been through what she has, and still smiles and laughs like she does.

During the first year on the diet, we played "catch up," and watched her regain her lost abilities such as talking, walking and being social with

her peers. Words started flowing from her mouth once again! I still have "Summer's Big Word Chart" hanging in my kitchen that we used to record her progress. The diet had given our daughter back to us and allowed her to flourish. We are so very thankful for Dr. Devinsky and Courtney Glick for their guidance through her transition on the diet.

With 5 daughters ranging between 5 months - 8 years of age, it's easy to keep yourself distracted. Unfortunately, now that the seizures returned, I find myself back to asking questions and repeatedly calling her name - "Summer, Summer...are you ok?"; "How are you feeling?"; "Can you answer mommy?"; "Can you lift your left hand, squeeze my hand?"; "What did you do at school today?"; "Today is Tuesday, what do we have after school today, do you remember?" I think, "There, she made eye contact... I think she is ok." For our 5 year old Summer, it is most likely perceived as an annoying, nagging mommy.

For me, it's for my own reassurance, to keep my anxiety in check, and to hear her actually say she is "ok". If I see her staring out in space, I will ask these questions as if getting her to answer me would somehow ward off a seizure. If it can only be that easy! As a parent, I am in need of constant reassurance that my epileptic child is safe. This is how this disease makes you think: try and do everything in your power to make sure your child doesn't have another seizure, knowing that they will and it's unpredictable. You can give medication on time, carefully prepare her ketogenic meals and make sure she gets enough rest, but too often Summer may still have an "off day".

The reality is our home life is stressful and challenging. With 5 kids and four dogs, there is not enough time in the day to meet everybody's attentional needs. When you add a child

with special medical needs to the mix, well, that can tip you over the edge. Medication may be given 10 minutes late because I was feeding the baby, a keto meal may be prepared to perfection but she just doesn't want it all, and restful sleep is hard in a busy, active home.

Over the past few months, some of her jerking seizures on her left arm and hand have resurfaced. Maybe it was due to a growth spurt, maybe her diet needs adjusting, maybe her medication needs to be increased. I feel saddened and defeated, like we are back to square one. We were doing so well for a while, but then someone yanked the



carpet out from under us and brought us back underwater.

Whether her seizures are under control or not, I still feel the anxiety every day for her well-being, quality of life, or future. When she is at school, every time the phone rings, during the night or when my husband travels for business, I'm afraid that something will happen and I may not handle it properly. I actually feel like I am afraid of her. What an awful feeling as a parent. I am permanently scarred from the negative thoughts, stress and nightmares about those long months of seizures. There is no worse pain than seeing your child suffer while you are powerless.

I have to remind myself to look differently at the situation. She is doing amazing and has come far in her epileptic journey. Summer runs around with friends, mimics her peer, makes her own decisions, walks on her own, and can play in a room

with her sisters without an adult watching. She will be back at a regular camp this summer and will make the huge milestone of attending kindergarten this fall, on a regular bus with all her friends!

As I write this, Summer had a perfect evening - no seizures, laughing and dancing with her sisters. Hopefully the changes we made were what she needed. The anxiety will continue as I will keep watching her every move, ask her if she is "ok" a dozen times, stare watching for a jerk, battle my own thoughts (negative and positive), fear a seizure and question myself. I will continue to spend hours creating new keto meals and her 4 sisters will learn to understand in time why she may get more attention from mommy and daddy. I will forever be thankful for the transfer to NYU Langone Medical Center and the ketogenic diet, which have given us our daughter back.

THE MAGIC PILL FOR MY EPILEPSY

By: Alexandra Nicklas

Epilepsy does not have to take over your life. However, finding the right treatment takes time. I was seizure free for 19 years. I had my first seizure the night of orientation freshman year. I was in the cafeteria eating dinner with my new friends when I choked on a piece of pizza. My right arm immediately became numb and I called for help as I started to lose consciousness. I thought I was dying. I was rushed in an ambulance to the hospital. The doctors told me that I had a seizure and this was most likely the beginning of epilepsy.

My life instantly was shattered. How was I going to be able to have a normal life with heightened anxiety and possible seizures at anytime? I certainly did not know. During the proceeding weeks, I was scared, tossed and turned in my sleep and felt uneasy about my future. When I came to the Comprehensive Epilepsy Center, I met Dr. Devinsky. At my initial meeting with him, tears were streaming down my face with extreme fright and the biggest plea for help. Dr. Devinsky's comforting words made me know that I was going to be okay. Routine EEG's and seizure management became a part of my life. I tested many different seizure medications in which I experienced intolerable side effects from. After two more seizures and a year and a half later, Dr. Devinsky found the right medication. This was a breakthrough and my medication would now also be known as my magic pill to living seizure free. I could now accomplish my goals and desires: graduate college and get my masters in Speech Language Pathology.

Taking medication has changed my life. Since I started taking the pill in October 2012, I am not scared, heightened with anxiety and can go about my daily routines knowing that I am protected. This is not to mention that I cannot have a seizure in the future, however, the chances of a seizure are significantly low. I am a member of the FACES steering committee, I graduated college from Marymount Manhattan last year and just completed my first year of graduate school for my masters. I also have many friends, go out to parties and events, I am dating and I drive. The normal life that I have comes to a shock to others when I say I have epilepsy. It is an invisible condition and I make it invisible to others. I wake up every morning, take my medication and run off to do what is important to me. Nothing can stop me and any minimal anxiety I can encounter at times, I push away.

I count my blessings everyday for the amazing life I have, the people, family and the doctors that support me. Dr. Devinsky is a vital person who has changed my life indefinitely. His positive nature, comforting words and encouragement to live my dreams despite my epilepsy keeps me going everyday even on days that can be hard and frustrating. I know not everyone has the good fortune as me with their epilepsy, but there can be solutions to live and get the most out of life that one can get. For me that was my magic pill, however for others it may be different.





Does your child have epilepsy? Is your family interested in forming a lasting and healing relationship with a pet?



If so, your family might be eligible to participate in a study at the New York University Comprehensive Epilepsy Center examining possible benefits of pet companionship on mood and quality of life.

We are looking to include families with children **ages 8-18** with a confirmed **diagnosis of epilepsy** who would be interested in adopting a pet.

If you are interested or would like more information on the **FACES Pet Relationship Project***, please contact:

Linnea Vaurio, Ph.D. or William Barr, Ph.D. at (646) 558-0809



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