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 EPILEPSY PHENOME/GENOME PROJECT:
A LOOK INTO THE FUTURE

by Ruben Kuzniecky, M.D.

When a person is diagnosed with epilepsy, many questions arise: Why did this happen to me or my child? Which treatment (or no treatment) is best for me? How long will the epilepsy last? Will any of my children or relatives be affected with seizures? Unfortunately, and despite major advances in medicine over the past decade, many of these questions remain without a clear answer.

In the spring of 2002, Dr. Dan Lowenstein from UCSF and I had a conversation focusing on the major questions daunting the diagnosis and treatment of seizures. What became clear from the onset was that to answer these questions, we would need to collect and study in detail a large number of patients. After many meetings and years of planning, the Epilepsy Phenome/Genome Project (EPPG) came to fruition.

EPPG is the largest study ever created to understand how genetics influences epilepsy type, outcome and response to treatment. This study is funded by the National Institutes of Health/National Institute of Neurological Disorders and Stroke. Researchers from 21 major epilepsy centers around the United States, Canada, Australia and Argentina will collect blood samples and detailed seizure histories on a group of people with specific types of epilepsy. This information will be used to identify genes that contribute to a person developing epilepsy and the response to seizure medications. The hope is that this information will reveal new insights, improve diagnosis and treatment, and answer the troubling questions described above.

(continued on page 3)
Greetings from the faces team. The first half of 2010 has been extraordinarily successful. Our research agenda continues to thrive highlighted by the incredibly generous $1 million gift from the Shaw Family. This has enabled us to, among other things, recruit talented new leaders and scientists who will advance research initiatives in inflammation. We enjoyed our first Parent’s Network social event, launched faces-Forward - a new online giving campaign - and in March we launched our 10th Anniversary Gala where we raised almost $3.6 million. Large and small, our programs strive to support our community.

And, as summer approaches, it is good to reflect upon the important moments from the past six months. Thanks to our Steering Committee, Teen Bowling was introduced and will now become an important initiative for this population. Not only were we met by a group of enthusiastic teenagers who were ready to bowl and have some fun, but it also provided a forum for parents to meet and chat about their shared experiences. Most importantly, new friendships were forged with each high five after a strike or spare. Sometimes, when we are working on the bigger events and conferences, we forget to take a step back and realize that faces is about individual moments - one person, one family and one story at a time. Each is unique and always inspires.

In the summer issue of the faces Newsletter, I’m pleased to introduce you to some extraordinary people who are making a difference and helping to advance the faces mission. We meet children and adults, doctors and volunteers who all make up the fabric of faces. Every story should be celebrated as each accomplishment makes our work possible.

Over the next few months, I ask you to devote a few moments to faces - reach out to us, send us an email, share your story, let us know how we can better involve you with our efforts. Tell us about your successes and challenges and we will do what we can to help: we are a part of a shared community and our goal is to be the best. This information would help guide doctors in choosing medications that are more effective and cause fewer, if any, side effects. If you would like more information, please visit our website: www.epgp.org, or contact EPGP at: 1-888-279-3747, e-mail: info@epgp.org or contact Dr. Kuzniecky at 646-558-0802.

I wish you a happy and healthy summer filled with new adventures and lots of quality family time.

LISA MILLMAN, EXECUTIVE DIRECTOR OF faces

NYU faces
223 East 34th Street
New York, NY 10016
(646) 558-0900
facesinfo@nyumc.org
www.nyufaces.org

Founder:
Dr. Orrin Devinsky
Executive Director:
Lisa K. Millman
Assistant Director of Special Events and Communications:
Linda Azarian
Program Coordinator:
Ari Hershey
Sr. Recreational Therapist:
Peggy Guinesssey

COVER STORY CONTINUED:

To understand the complex genetics of epilepsy, EPGP seeks to enroll 3,000 people who have epilepsy who also have a brother, sister, parent, or child with epilepsy. The study is also enrolling 750 participants who have seizures due to infantile spasms, Lennox-Gastaut Syndrome, polymicrogyria, or periventricular heterotopia. For this second group of people, both biological parents (without epilepsy) are required to participate. We focus on siblings and parents because the genetics of epilepsy are complex and likely to be regulated by many genes and not single gene mutations. It is also the clinical and genetic differences between siblings or parent/children that will be able to tell us much about why epilepsy may be mild or severe in some cases. Although the results of the study will apply to many different people with epilepsy, focusing this research effort on very specific types of epilepsy will allow the genetic analysis to be completed faster.

Participating in the study involves blood draw and interviews. Numerous safeguards are in place to protect the privacy of participants, and the researchers will not share personal identifying information with anyone outside of their study center. Participation does not require travel to one of the study centers, and participants may receive small compensation for their time.

EPGP is starting its fourth year this spring. It has recruited over 2,000 patients so far and we hope to be able to add new centers and patients to complete the study. EPGP will help shape the future of clinical care of people with epilepsy. For the project to be successful, it needs to be a strong collaboration among all of the people with epilepsy in our country.

Our dream is that, in the not-too-distant future, we will be able to do a blood test to test genes so we can tell the patient what type of seizures he has, which drug is likely to be the best. This information would help guide doctors in choosing medications that are more effective and cause fewer, if any, side effects.

faces is turning a new leaf! In an effort to dedicate more of our resources towards funding faces programs, we are moving to an electronic newsletter...and a greener planet! From now on, we will be sending an email newsletter to all current subscribers with an email address in our system. If you haven’t provided us with your email address you’ll still receive our newsletters via mail; however, there are plenty of good reasons to opt into our e-newsletter! For every electronic newsletter conversion or sign-up, faces is able to put $2 back towards our mission.

By swapping mailbox for inbox, you are helping to support faces research, education, advocacy, and community outreach. We’ve already been able to return thousands of dollars back to the programs that matter. Plus, email newsletters allow us to keep you up-to-date on all important faces news and events. You can do your part to support our environmentally-friendly communications efforts by subscribing to our email newsletter online at http://faces.med.nyu.edu/webform/faces-contact-form or by sending your email address to facesinfo@nyumc.org.
I n some cultures to become a healer, one must meet rigorous spiritual benchmarks and be chosen by a higher power. Often, training of Shaman runs two or more decades before one is allowed to practice unsupervised. Medical education in the United States models earlier systems of apprenticeship. Many interns today may use the word indiure. It is a process of graduated supervisions and acquisitions of technical and knowledge as well as increasing autonomy and responsibility. To become a “fellow” in epilepsy, one has to have graduated with an accredited undergraduate degree (four years generally), matriculated in and graduated from an accredited medical school (four years), and completed an accredited neurology residency (four additional years generally, five for pediatric neurologists). The tally comes to 16 years of training after high school. At this point the person applies for fellowships in subspecialty areas in neurology. One of which is clinical neurophysiology, which encompasses epilepsy, neuromuscular disorders, and sleep medicine. It is a time in the fellow’s life to hone skills in a particular area within neurology with the end in mind of becoming a specialist in that field. Fellows tend to be the brightest among the bright as they are selected from a very high level of training to begin with and there are many more applications than there are fellowship positions. We have been blessed with excellent fellows. Currently, we have a clinical neurophysiology fellowship at NYU with two tracks, an epilepsy/EEG track and a neuromuscular/electromyography track. We have four first year fellows in the epilepsy track and two in the neuromuscular track. We usually also have one second year research fellow in the epilepsy track as well. Fellows are integral to the life of our Center and are our colleagues and collaborators. The teaching flow in both directions and all of us learn from each other. They are often the ones patients have contact with in the evenings or on weekends. They see patients with the attendings in clinic as well as in the hospital on various services including intracranial Video EEG monitoring, Adult and Pediatric EEG monitoring, and the epilepsy consult service. They learn how to evaluate these patients, write EEG reports, and read EEG’s. Usually one of the four epilepsy fellows goes on to stay in academia and the others go on to private practices specializing in epilepsy and Clinical Neurophysiology.

There are many young men and women who raise money for faces as part of a community service project, which is both charitable and generous. I’ve recently had a chance to talk to some families whose children are soon having either a Bar or Bat Mitzvah and are doing a service project in honor of their special occasions, with some even asking friends and family to give to faces in lieu of receiving gifts. The Fortgangs, Arnolds and Mayersons are three families whose children have chosen to celebrate this important rite of passage by giving to others.

Thanks to Skyler Fortgang, his family and music teachers, a concert titled Rhythm for a Cure will be held on June 18th. Skyler is a witness to the effects of epilepsy as it relates to a member of his family. For his Bar Mitzvah, he has arranged a concert as a community service effort to help faces combat epilepsy. He started organizing the project one year ago by taking care of public relations, managing the performers and even securing the concert hall in Verona, New Jersey. All ticket sales and donations will benefit faces. More information on this concert can be found on http://rhythmforcure.people-stories.com.

Ashley Arnold is a budding entrepreneur and has made eye-catching note cards as a Bat Mitzvah project to also raise funds for faces. She not only designed the floral cards, but packaged them and sold them at her temple and on-line. She has raised over $2,000 and an additional $200 in direct donations for her efforts on behalf of faces. If you haven’t been to her site yet, please visit http://faces.kintera.org/Ashley to see what you can purchase.

Brett Mayerson is another successful entrepreneur as he has personally designed bracelets to raise money for the Dr. Blanca Vazquez Summer Camp Scholarship Fund. As his Bar Mitzvah project, he designed and sold these great looking bracelets on-line for $5 each, which has already generated $1,000 for faces. If you want to learn more about Brett’s project, you can visit http://BrettBarMitzvah.kintera.org/Project. It’s wonderful to know that there are people like Skyler, Ashley and Brett. Thanks to all of you!
The 2010 Gala on March 9th was a dual commemoration for faces. It was the 10th anniversary celebration of this event as well as a recognition of more than 15 years of service that the organization has given the epilepsy community.

The actual day of the gala began at 7:00 a.m. with 15 faces volunteers arriving at Pier Sixty at Chelsea Piers to set up the amazing 350 silent auction displays. After a break and time to change clothes, the volunteers returned to manage their auction areas—now joined by 30 additional volunteers—just before guests arrived to have cocktails and do a little shopping, all for a good cause. In total, 635 people attended the gala, with some coming from Pennsylvania, Massachusetts and Maine.

The program began with master of ceremonies, Stone Phillips, who welcomed the audience and introduced Dean Robert Grossman of NYU Langone Medical Center. Dean Grossman thanked those who played a major role in organizing the event: Gala Chair, Melissa Mathison; Auction Chairs, Susan and David Swinghamer and Gala Underwriters, Leah and Michael Weisberg.

Dr. Orrin Devinsky took the stage after dinner and spoke about the collaborative effort it takes among different researchers and organizations to approach the problems of epilepsy care. No one could have exemplified this shared purpose more than the evening’s honoree, Susan Axelrod, as Co-Founder and President of CURE (Citizens United for Research in Epilepsy) spoke of the great strides we’ve made as a community, how far we still have to go and how we need to continue to collaborate with other epilepsy organizations. A highlight of the evening was the introduction of two young people who spoke of their progress and personal hopes as patients of the NYU Comprehensive Epilepsy Center.

It was a great night and many people participated to make it a success: one didn’t only need to buy dinner tickets for the event—ads were also bought for the Gala Journal, many wrote note cards to friends and colleagues asking them to make contributions, people either solicited auction prizes, donated or purchased them (or did all three!) and people contributed through the Forward campaign which reached out to the full community through our website. All these individual efforts raised close to $3.6 million for faces. To all of our gala friends, we offer our heartfelt thanks.
SHARON SHANDLER

This past month, I had the pleasure of meeting Sharon Shandler, another member of the faces community. We met for lunch in NYC and the conversation was as bright as that spring day.

I found out that Sharon became involved with faces through her neurologist, Dr. Orrin Devinsky. She plays a role on the Steering Committee where she helps as a solicitor, donor and a volunteer for the silent auction at the annual faces Gala. Sharon became involved with faces because she was concerned that epilepsy affects so many people’s lives and there are still those who do not seek help or even speak about it publicly. She hopes that through the type of support that faces offers its community, “some day people will speak more freely about this condition and its complexities”. Supporting faces has helped Sharon find strength even as she manages her own personal health issues.

In her spare time Sharon designs jewelry and even helps other organizations in need. She also speaks very highly of her own personal support groups, her friends and family. Sharon is committed to helping faces achieve its goals and is there whenever she is needed.

RACING FOR faces

by Robin Dunn Fixell

There are motivated individuals who push themselves to reach their personal goals and there are those who reach out to help others. One former Olympic athlete has managed to do both.

In a unique, physically wrenching, mentally-challenging adventure called, “Racing the Planet,” Gabriel “Gab” Szerda tested his physical and emotional endurance while raising funds for two charities: faces and ReserveAid (providing financial assistance to families of military reservists).

Racing the Planet—a seven-day, six-stage, 155-mile foot race run in remote desert locations throughout the world—is an endurance event that appealed to Gab who, now 32, represented Australia in wrestling at the 2000 Olympic games. Today a trader in New York City for Macquarie Bank (headquartered in his native Australia), Gab considers himself a “weekend warrior” who’ll “never shy away from a challenge.”

Living in the United States for nearly 12 years and attending college here, Gab resides in Manhattan with his wife, Julia Valente, currently an NYU medical student who is also a patient of Dr. Devinsky’s. According to Gab, they’re “wanted to get a little more active in helping out” those in need.

Gab entered the race this April to raise money for ReserveAid and faces. The Macquarie Group Foundation provided matching gifts for Gab’s pledges. Including the match, says Gab, the total raised for both charities will hopefully come close to $125,000.

Running in 110-degree heat and 85% humidity through the remote Kimberley Region in northwestern Australia, Gab traversed treacherous terrain that included canyons, water hazards, rocks and salt flats—while carrying his 20-pound backpack.

“The conditions were so hard that many times you wanted to quit,” said Gab. “Then you...think about the support you’re getting, the money you’re raising and it just kept me moving.” He was “ecstatic” to come in seventh out of 188 runners from over 35 countries. Next year he hopes to run in Nepal. According to Gab, “In the Olympics I was motivated by my own goals and ambitions in a hope of representing my country - however this race was more about helping others first and satisfying my own ambitions second.”

A PATIENT’S PERSPECTIVE ON ADULT-ONSET EPILEPSY

by Cathie Golden

Although epilepsy is often thought of as a childhood disease, anyone at any age can develop it. While it is most often seen in the very young (two years of age and younger) and the senior population (older than 65 years of age), over 2.6 million of the more than three million people in the United States with epilepsy are patients older than 15 years of age.

Of the 200,000 new cases of epilepsy diagnosed every year, 155,000 are over the age of 15, with the majority of those over 65 years of age.

Developing epilepsy as an adult can be confusing, scary, and difficult to come to terms with. Most feel a loss of independence and a fear of the unknown. The good news is that one really can live a happy, productive life. Here’s a story about one patient who did.

Sherry, NYC, 59 years of age

Sherry grew up in New York City and was accustomed to the hustle-and-bustle of a city that never sleeps. As an adult she thought nothing of overseeing a staff of 100 at a very prestigious law firm. It was all just a part of everyday life—until her first seizure.

Sherry was at home one evening when a strange sensation overcame her and she fell to the floor unconscious. When she awoke, she called a family member for help and immediately went to the hospital. Because no one had witnessed what had happened, the only clues were the few details Sherry remembered. She was admitted to the hospital and after countless tests, Sherry was released with a clean bill of health and told it was probably a one-time event.

Sherry continued living her busy life until a similar event occurred eight months later in a retail store. This time, thankfully, customers in the store witnessed the event and called the EMS workers who told Sherry that she had experienced a grand mal seizure. Sherry was diagnosed with epilepsy and put on an anti-epileptic drug to help control the seizures.

Sherry was shocked and unaware that she could develop epilepsy at her age. She was also very unfamiliar with the disease and didn’t know where to turn. She began to experience panic attacks whenever she left the house. She stopped going out alone, stopped seeing friends, and even retired from her job. She thought life was over.

Wanting to gain control of her life again she began to educate herself about the condition. She worked with her doctor to find the right medication and even started seeing a neuro-psychologist to overcome her fears. Sherry took her first bike ride in Central Park a few months later. She started making plans with friends and even found time to be a volunteer for faces and started driving out to the beach as she did before.

There are many ways to manage life with epilepsy, as Sherry found out. Finding the right medication, seeking counseling, enjoying support from family and friends, and maintaining a positive outlook can lead you back to your life.

1. http://www.epilepsyfoundation.org/about/factsfigures.cfm

FOLLOW faces ON FACEBOOK AND TWITTER!
I experienced staring episodes in class and missed vital information that we would be tested on later. Thankfully, the first week and remember to remind all of my teachers two days before each test that I would be taking the exam. I was the only one of my friends with epilepsy and, at the start of college, I was very aware of it. However, the new, loving faces I made were interested in learning more about the disorder and their questions reassured me that I had established a close group of friends who cared about each other. I will always cherish the lifelong friends I have made.

LESSON THREE: Take advantage of every opportunity and make the most of it

There will be moments in college you wish you could forget or avoid. However, an important part about going to college is learning how to overcome uncomfortable situations and gain the confidence and maturity that will turn you into the adult you want to be. Therefore, it is important to challenge yourself, to try new activities, and overcome your fears. Most likely, during the process you will meet new people, learn new skills, discover unknown talents, and possibly find something that really interests you.

LESSON FOUR: Help others

I was fortunate enough to work for faces over my summer and winter breaks. The faces team taught me that everyone can and deserves to lead his or her own best life, and that it is important to assist as many people as possible to achieve this.

Everyone has different experiences in college, but I can guarantee that all students will learn that those who reach out to help others in need will not only make a difference in the world, but will lead happier, more fulfilled lives.

When Scott met Jodi on a blind date, he knew then and there that a new life was in store for him with the woman he fell in love with that evening. Little did he know that he was gaining another family... the faces family. Over the years, Scott has become a leading volunteer for faces, helping it raise much needed revenue during the gala season.

Scott Schubert is M.I.S. Director at Man-Dell Foods Stores on Long Island and his company owns several Key Food supermarkets in the city, primarily in Queens and Brooklyn. Man-Dell is also part of the 110-store Key Food Co-Operative, one of the largest food retailers in the New York City area. Scott’s numerous ties throughout the food industry nationwide have come in handy when reaching out to colleagues to help a cause that is near and dear to the Schubert family. Scott’s new family began soon after that first date. He married Jodi and became a parent to her two beautiful children, Lindsay and Nicole. Nicole is a teenager patient of Dr. Orrin Devinsky at the NYU Comprehensive Epilepsy Center and is very popular when she visits the office. Her energy and good will are infectious. She is also extremely well liked by the staff, suppliers and vendors of Man-Dell Foods who know her through her visits to the stores with Scott, or through letters and emails that Scott sends in January of each year. With the tireless support of Roseann Marabello, Man-Dell’s Advertising and Shipping Coordinator, a series of emails are sent to vendors throughout the United States asking them to give to a cause that helps Nicole and the Schubert family deal with the challenges of her condition. Help comes in abundance through advertisements in the gala journal or gifts donated to the gala’s silent auction. This year’s Journal contains ads from Pepsi Cola, S.K.I. Beer Corp, BRdata, Brad’s Organic products, Key Foods, Man-Dell Foods and practically every member of the Schubert family. This incredible outpouring of affection and love shows the family that friends and colleagues share their hopes for a seizure-free life for Nicole and a cure for epilepsy.

Providing money for cutting-edge research which will help people like Nicole is an extraordinary testament to faces and the Epilepsy Center. Thank you Scott and Roseann for all your hard work on behalf of the Schubert family and so many other families in our faces community.
A Call for Ideas and Articles
Do you love to write? Do you have great ideas for our newsletter? If so, please let us know! We are currently starting to think about the fall issue of our newsletter. Please contact us if you have an idea for a story.

SAVE THE DATES!

**Game Day**
September 25, 2010

**faces Epilepsy Conference**
October 17, 2010

**S.I. Yankee’s Game Outing**
July 26, 2010

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