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1. 2019 FACES GALA RAISES OVER $5.4 MILLION

Thanks to the incredible generosity of the guests, sponsors, and donors of the 2019 FACES Gala, FACES was able to raise over $5.4 million towards epilepsy research and FACES programs. Look out for a full recap in the 2019 annual edition of Insight!
2. FACES FORMING LIFELONG FRIENDSHIPS
BY TILLY PECKER

Two strong women have undergone two different journeys in their plight to fight epilepsy. Both Dana Pirolli and Ali Nicklas knew that their epilepsy stories would be a major part of their lives, but what they didn’t know is that their stories would intertwine.

Dana was diagnosed with epilepsy at the age of 11. After experiencing five years of seizure-freedom, she developed an “out of sight, out of mind” outlook on life in regard to her disorder. This worked in the short term, but when her seizures came back in a more persistent way after graduating college, Dana wanted to engage herself in a community that understood the challenges she was facing. After years of searching for the right outlet in her hometown of Philadelphia, Dana was feeling helpless. However, in February of 2015, she came across FACES and found a lot of meaning in volunteer work at her first FACES Gala. Moved by the connections between doctors and patients at the event, Dana continued volunteering and started seeing Dr. Blanca Vazquez. In the fall of 2017, Dana was invited to be the patient speaker at FreshFACES, where she first met Ali.

“Ali and FACES are so important to me because I found them when I was going through such a hard time trying to manage my epilepsy… I was looking for something stable because my life at the time was anything but.”

A patient of Dr. Devinsky and passionate FACES volunteer, Ali was touched by how Dana’s powerful words and inspiring story shined through in her speech, and she related to many of the feelings that Dana shared. Ali, who started seeing Dr. Devinsky in 2010 and began volunteer work with FACES in 2014, launched her own non-profit called Different & Able, an organization that provides resources, support and role models to empower people with differences to reach their fullest potential. Hearing Dana’s eloquent and uplifting speech motivated Ali to reach out and ask her to write an
article for *Different & Able*. Dana ended up writing two articles for Ali from her home in Philadelphia and they kept in touch with one another via email.

It is so profound that a remote working task for an acquaintance’s non-profit would soon develop into a meaningful relationship founded on the commonality of a mutual battle. This year at FreshFACES, Ali was the patient speaker and conveyed how she perseveres through living with epilepsy, difficulties with fine motor skills and the anxiety that surrounds it. Following this speech, Ali and Dana reunited in person at the event for the first time since meeting at FreshFACES in 2015. Seeing one another again and hearing more about each other’s journeys made Ali and Dana realize that their bond may go deeper than being epilepsy patients loosely associated through the same organization.

“Going through this journey with someone who understands and someone who I can confide in is so important to me. Whether it be about epilepsy or our personal lives, it is such a special kind of support.” Ali expressed her excitement about this newfound friendship with Dana - someone who she has formed connections with on so many levels in such a short period of time. Recognizing that epilepsy would be a part of Ali’s life was a very anxiety ridden realization and she did not know what her future held. Dana helped her become more accepting of her disease and together, they realized that they can live life to the fullest.

They visit one another in their respective home cities, exchange Christmas gifts, attend FACES events together, and most importantly, have become great friends who have each other’s backs through thick and thin. Today, both women check-in with one another on a regular basis, whether it has to do with their physical and mental stability or just enjoying small talk about their daily lives. While this friendship has gone beyond meeting at volunteer events, Ali and Dana are grateful that FACES brought them together.

“FACES means that I have a community and support network that goes beyond my treatment at NYU Langone.” Ali is so thankful that FACES not only
provided her with a caring doctor and web of compassionate people, but also a best friend.

Dana emphasizes the importance of being in a properly balanced mental state in order to live a gratifying life, and she credits FACES for helping her develop this mindset. “I look back and think about how I used to sit home with cabin fever and watch my friends move along. I never pictured my life where it is out now and I have FACES to thank for how incredibly grateful I am.”

The FACES family is overjoyed to play a role in creating this beautiful friendship and looks forward to watching it grow.

3. 2019 FACES EPILEPSY CONFERENCE

The 2019 FACES Epilepsy Conference was a huge success with over 200 patients, caregivers, exhibitors, volunteers, and medical professionals who share FACES’ goal of advancing epilepsy education and awareness. A full recap will be offered in the 2019 Annual Newsletter. Thank you to all who were able to attend!
4. SAMMI RUBENSTEIN’S 17TH BIRTHDAY PARTY FUNDRAISER
I am so proud that my most recent FACES fundraiser brought in more than $3,500! My friends and I had a great time dancing our FACES off for this amazing foundation which has brought so much hope and support to my ten year old brother, Mac!

5. DEVELOPING PRECISION MEDICINE THERAPIES FOR EPILEPSY BY DR. SASHA DEVORE
The past two decades have witnessed an explosion in advanced genome sequencing technologies that have enabled the identification of precise mutations associated with a wide range of neurodevelopmental disorders including epilepsy. To date, more than 80 epilepsy-related genes have been identified including mutations in the *HNRNPU* and *DHPS* genes, discovered by investigators at the Comprehensive Epilepsy Center (CEC), in collaboration with the Institute for Genomic Medicine at Columbia University. Although the scientific and medical communities still lack an understanding of how many of these mutations give rise to epilepsy and seizures, gene therapies hold the promise of permanently correcting these devastating genetic conditions. The CEC is actively collaborating with
scientific partners at NYU and globally to develop precision genetic-based treatments for epilepsy.

**Dr. Chengzu Long** (Depts of Medicine, Neurology & Neuroscience, NYU School of Medicine) has established a ‘Neuroediting’ approach to correcting epilepsy-causing mutations in the genome. Dr. Long’s lab creates novel CRISPR-based gene-editing tools to permanently correct mutations present in individual epilepsy patients’ cells. Within a few short months of launching a collaboration with the CEC, Dr. Long and his colleagues have corrected diverse mutations in the *SCN1A* gene in stem cells from patients with Dravet syndrome. The Long lab is now working on tools to correct other genes including *DHPS*, as well as showing that they can make functional corrections in neurons.

In addition to correcting mutations in individual cells, the ability to deliver functional genes directly into the brain is also emerging as a potential therapy for neurodevelopmental disorders. The CEC is working with **Dr Chae-Ok Yun** (Hanyang University) to develop safe methods for delivery of whole genes (including *HNRNP* and *DHPS*) using an intranasal approach. The ultimate goal of these collaborations is to develop safe and effective precision genetic therapies that restore function to neurons in defined groups of epileptic patients.

This research is generously supported by Lauri and Michael Herman, Marlene and Michael Perlmutter Research Fund, Colleen and Tagar Olson, Amy and Lee Pressler, and Jill and David Robbins.
When we adopted Frankie at 5 years old we had so many hopes and dreams for him. When Frankie was diagnosed with epilepsy, we felt like our world was crumbling. We didn’t know what to do next. Shortly after, we were told by a school professional of all of the things Frankie would never be able to do, and we were devastated. To this day I remember how I felt sitting in the small conference room being told that Frankie will never be able to tie his shoes. Unable to hold back tears, I walked out of the meeting and left the school without the meeting being formally over. That afternoon I picked Frankie up from the bus stop and we went to the shoe store to buy sneakers with laces – no more Velcro! That day we decided we will never give up on Frankie and we would support him in every way we possibly could.

Shortly after diagnosis we knew we needed to find doctors who we felt were specialized and experienced enough to treat Frankie. That is when we found Dr. Miles. At our first visit we were overwhelmed to learn about all of the potential
treatment options for epilepsy and brain surgery was mentioned. As the visit progressed we realized how experienced Dr. Miles was, but most of all, he listened to our every concern. He didn’t dismiss our concerns that day or any other day since. Since our first appointment he has never given up trying to help Frankie, and for that we are so grateful. Over the years Frankie has tried many medications, the ketogenic diet, subdural EEG (yes, even brain surgery), and has a Vagal Nerve Stimulator. We found the care we had hoped for at NYU. And a doctor who was just like us – not willing to give up on Frankie.

We have tried over the years to create a life for Frankie that would be as typical as possible. We wanted him to have the same experiences as any other typical child would have. Frankie wanted to play sports and initially soccer, hockey and tee-ball were fine until the sports became too competitive. It was difficult for Frankie because he could no longer keep up with the speed of the games. Then there were the other parents who felt that their 10 year olds were playing in the MLB, MLS, or NHL. Imagine being Frankie or his parents and having grown adults criticize you when you are trying your hardest to just to be a part of the team. He just wanted to play sports, but most of all, he just wanted to be with the other kids.

Frankie loved music and at 11 years old it was time to pick an instrument. Frankie always dreamed of playing in the marching band in high school. How could we make this be successful? How could he do this? Frankie struggles reading books and in every aspect of school. Will the school even give him a chance? As always we were determined to help support him. We had the music department choose an instrument. We assumed they would have him play the triangle or maybe even deny him the opportunity to play. When the teacher called and said he chose the
trombone for Frankie we laughed and were very skeptical. On that same day, we rented a trombone, scheduled private lessons, and started on a quest to take on this dream. We found a trombone tutor who didn’t judge Frankie based on test scores, but instead he set his expectations high. He taught Frankie how to read music before he could read a book. Frankie had to practice a lot and at times he needed to relearn his music after having seizures but, he never gave up. Frankie was first chair in the middle school band full of typical students.

Now, Frankie is playing his trombone in his high school marching band.

Frankie still wanted to play sports. He played in several different teams for athletes with disabilities, but we couldn’t find any that were competitive enough for him. Too competitive, not competitive enough – we couldn’t win! Frankie still had fun but, he wanted more, so at 13 years old he started working out in a gym. He has personal trainers who help guide him and help empower him to work hard. When Frankie was 14 he asked to go running, so we went to the high school track. Frankie could barely make it around the track once. He never gave up and insisted on visiting the track almost every day. Frankie said running and working out made him “stronger than his seizures”. One day Frankie said he wanted to run a race, so we found a fun run for him to participate in. We had no idea it was a fun run to benefit a special needs running club. That changed everything for Frankie.

Frankie ran 4 to 5 times a week and after 3 months he ran his first half marathon. We faced many hurdles as parents when it came to running. What happens if he has a seizure while running? What happens if he gets lost? Is it too much activity for him? Then, there are the various side effects of the medications that affect him at times too. The most difficult challenge was having him join the school team. The school had a lot of concerns and prevented Frankie from joining the team when he first tried. By now you would think the school would know us and know we wouldn’t let them exclude him. With the help of all of his doctors, nurses, FACES, and the Epilepsy Foundation, Frankie joined the next season of
track. At his first track meet Frankie had a seizure during his race. Although he was embarrassed and upset he never gave up and returned the next day. Currently, Frankie is on the high school varsity track team and is very successfully included.

Since Frankie’s first half marathon, he has competed in the past two years at the National Junior Paralympics resulting in several gold medals and silver medals. Frankie has also run in several local 5k, 10k, and four other half marathons. Frankie’s most recent half marathon was the 2019 United Airlines NYC Half Marathon. For the past two years Frankie wanted to run in this race. Why did he want to run in this race? Was it because it is an iconic race? Nope! Was it because it would be fun? Nope! Frankie wanted to run past NYU Langone Health to show all of his doctors and other patients with epilepsy how strong he really is! Frankie trained very hard for this half marathon all winter long. He followed a training schedule from a virtual coach, Scott Brinen from The Badger Track Club in Wisconsin. Frankie ran the marathon proudly representing the national team, Athletes Without Limits. Like the other athletes on the team Frankie says he has “no limits!” Frankie states he has no limits because he can do anything he works at, and he is right! Frankie ran this race with his music teacher Michel Nadeau. Michel is the first teacher that not only taught Frankie how to play an instrument but, taught him the most valuable lesson in life, that if you work hard your possibilities are endless.

We are fortunate that Team Frankie consists of Dr. Miles, the nurses and staff at the Comprehensive Epilepsy Center of NYU Langone Health, coaches, a music teacher, personal trainers, friends, and family who believe in him and never give up on supporting him. Epilepsy may try to limit Frankie, but you cannot limit someone who has no limits!

On March 17, 2019, Frankie tied his running shoes himself and ran the United Airlines NYC Half Marathon with his music teacher by his side. Frankie
ran past NYU Langone Health setting a new personal record! He ended the race with a sense of pride and is looking forward to showing Dr. Miles his medal.

7. NYU COLLEGE OF DENTISTRY’S ORAL HEALTH CENTER OPENS
Individuals with physical, cognitive, and developmental disabilities now have a dedicated treatment center in New York City for dental care: NYU College of Dentistry’s Oral Health Center for People with Disabilities. The 8,000-square-foot center, located in the NYU College of Dentistry’s Weissman Building at 1st Avenue and 24th Street, provides much-needed comprehensive care for patients whose disabilities or medical conditions prevent them from receiving care in a conventional dental setting.

Dr. Orrin Devinsky and FACES board member Kate Picco were invited to speak at the center’s opening on February 11th, 2019. As the parent of a child with special needs, Kate explained the devastating cognitive and physical disruptions caused by taking her son to the dentist. She also identified 5 factors that helped her and her son during his dental visits:

1. Provide a calm environment that is not over-crowded—opening the office early or having later hours is helpful.
2. Talk through any alternatives and work as a team with the parent and the dentist to make decisions.
3. Take a collaborative approach to your child’s overall care. It should be a seamless process—dentist talks to the pediatrician and the neurologist—etc.
4. Find a dentist who has a hopeful bedside manner
5. Find a non-judgmental office—kindness and respect from the front desk to the exam room is critical.

Dr. Devinsky then took the podium and explained that there is nothing more important than treating children with special needs as people—despite the fact that many are non-verbal. He explained that medical providers have to assume that they can understand more than we realize and they should prepare the patient by minimizing auditory/visual stimuli, invite behavioral support to attend and potentially utilize anxiety medication prior to the office visit. In 2009, only 14% of children with special needs had annual preventative dental visits. Many of the barriers for patients to receive care include communication, sensory, psychological and, physical and emotional issues. There are also barriers on the side of the caregiver—including health literacy, language, geography, financial/insurance issues, transportation, physical demands and an incomplete knowledge of the patient’s medical history. NYU Dentistry took the lead nationally to address this population by building this state-of-the-art facility.

“The NYU Dentistry Oral Health Center for People with Disabilities addresses a major public health challenge by providing comprehensive,
compassionate dental care for people with a full range of disabilities who experience significant barriers to accessing care,” said Charles N. Bertolami, DDS, DMedSc, the Herman Robert Fox Dean of the NYU College of Dentistry.

In New York City alone, an estimated 950,000 people—in a city of 8.5 million—have some form of disability, including 99,000 who use wheelchairs. Research shows that people with disabilities have worse oral health than the general population and are less likely to have access to dental care services. People with disabilities face many barriers to receiving dental care, including physically accessing dentists’ offices, which may not be able to accommodate wheelchairs or other assistive devices. In addition, some dentists lack confidence in their ability to meet the needs of people with disabilities, so may not be prepared or willing to welcome disabled patients.

As a result, patients with disabilities are often referred to hospitals for dental care because of the need for sedation and may wait as long as six months to get an appointment to be seen in an operating room. These visits are often one-off emergencies without follow-up or continuous preventive care, which can trigger a cycle of recurring dental problems.

“Numerous studies have shown generally poor access to vital health services for both children and adults with disabilities,” said Marco Damiani, chief executive officer of AHRC New York City, one of the largest nonprofits supporting people with disabilities in New York State. “The NYU Dentistry Oral Health Center for People with Disabilities will promote greatly improved access, but it exceeds basic expectations by enabling access to a welcoming state-of-the-art facility, dental treatment services from highly experienced and engaged faculty, and a service vision that underscores dignity, respect, and coordination of care.”

NYU Dentistry’s Oral Health Center for People with Disabilities features nine spacious patient treatment rooms, including one with a reclining wheelchair
platform that allows patients to be treated in their wheelchair instead of being transferred to a dental chair. © NYU Photo Bureau: Roemer

**Designed for patients with disabilities**

The new Oral Health Center for People with Disabilities was designed to meet the unique and diverse needs of people with a range of disabilities. The center was completed through a $12 million renovation by Henningson, Durham & Richardson Architecture and Engineering, P.C. (HDR).

The center features nine spacious patient treatment rooms. In addition, there are two fully equipped sedation suites to provide both inhaled and intravenous sedation administered under the supervision of anesthesiologists.

“Our on-site sedation options eliminate the need for most patients to be referred to hospitals,” said Ronald Kosinski, DMD, clinical director of the Oral Health Center for People with Disabilities and clinical associate professor at NYU College of Dentistry. “In cases where general anesthesia is required, patients can be treated by specially trained NYU Dentistry faculty at one of our hospital affiliates—NYU Langone Health or Bellevue Hospital Center—but remain patients of record at the NYU College of Dentistry.”

The center has two fully equipped sedation suites to provide both inhaled and intravenous sedation administered under the supervision of anesthesiologists, eliminating the need for most patients to be referred to hospitals. © NYU Photo Bureau: Roemer

A multisensory room, located off of the waiting area, will soon offer patients an immersive environment to reduce their anxiety, help them relax, and engage their senses. The room is being developed in partnership with the **NYU Ability Project**, an interdisciplinary team of health specialists, engineers, and artists working at the intersection of disability and technology.

Led by Kosinski—a pediatric dentist and specialist in dental anesthesia—the center is staffed by multidisciplinary faculty, a nurse practitioner, a nurse, a social worker,
three patient-service representatives, a clinic manager, and a patient care coordinator. Patients are cared for by faculty at NYU College of Dentistry with particular interest and expertise in treating people with disabilities. Senior dental students provide basic dental care not requiring sedation.

**Training the next generation of dentists specializing in treating people with disabilities**

The center builds upon NYU’s long history of educating dental students to care for patients with special needs. NYU College of Dentistry was one of 11 schools funded by the Robert Project, a collaboration of the Tandon School of Engineering; the Steinhardt School of Culture, Education, and Human Development; and the Tisch School of the Arts.

“The Oral Health Center for People with Disabilities not only offers much-needed clinical services to patients, but also a unique training opportunity for our students. Our goal is to create the next generation of dentists who will practice with competence, confidence, and compassion in providing quality dental care for people with disabilities,” said Bertolami.

**At a Glance: NYU Dentistry Oral Health Center for People with Disabilities**

*Address:* 345 E. 24th Street at First Avenue
*Phone number:* 212-998-9988
*Web site:* https://dental.nyu.edu/patientcare/ohcpd.html
Congratulations TeamFACES! On Sunday, March 17, 2019, five FACES athletes participated in the United Airlines NYC Half Marathon, raising more than $35,000. Thank you Derek Birkenhauer, Shawna Camilleri, Kristen Fusco, Tim Marshall and Matt Reynolds for your dedication and support of our incredible mission.
9. DIFFERENT AND ABLE LAUNCH BY ALI NICKLAS

Different & Able is an online support platform that provides free access to an inclusive online community, to empower the vulnerable; to inspire the hopeless. They address a wide range of physical, learning, speech, emotional and medical differences. The community offers dynamic self-help, as well as professional resources from leading doctors and researchers. They gather personal stories from the people who are on their journey with differences and who have sought out resources to live different and able lives. Given free access to this type of support network and knowledge of various resources, they hope to change the word of disability. Follow them on Instagram @differentandable and Facebook, visit their website: www.differentandable.org to become part of our database!

ABOUT THE FOUNDER:

As a child, I envisioned becoming a doctor or psychologist one day. I had limitations though that would interfere with my physical, cognitive and medical functioning. I had fine and gross motor skills on the right side of my body, reading and executive functioning problems as well as epilepsy. Growing up, I spent my time outside of school doing daily therapy to compensate and overcome my challenges. Was I really able to become a doctor or psychologist? However, given the determined and courageous individual that I am, I worked hard in hopes to achieve what I wanted in life.

To do so, I had weekly occupational and physical therapy as well as cognitive remediation. In occupational and physical therapy, I learned ways to navigate physical activities such as tying my shoe laces, cutting with scissors and typing on a computer. Cognitive remediation focused on skills to comprehend different reading materials and ways to stay organized and focused. When I was diagnosed with epilepsy, Dr. Devinsky found a medication to adequately control my seizures. Over time, I learned how to be successful. I became a role model to others with similar differences, showing them that with support, success in overcoming obstacles is possible!

I graduated from the Hewitt School. In college, I took courses in psychology, anatomy and physiology as well as biology. These courses were difficult and it was at this moment in time, I realized becoming a doctor or psychologist was not going to be possible. My interest then shifted to Speech-Language Pathology. I received
my B.A. in Speech-Language Pathology from Marymount Manhattan College and did some years in the Speech-Language Pathology master’s program at CUNY Lehman College. But, Speech-Language Pathology turned out to be too difficult for me too.

At the age of 27, I was now searching for a career that was medically oriented but did not require graduate school. This was the moment I decided to start something based on my success in overcoming my differences in an effort to pay it forward and help others. I founded the Different & Able Foundation in 2017 to share and help others with differences in their journeys, whether dealing with epilepsy or other physical, emotional and learning differences.

While the hope of becoming a doctor or psychologist did not work out, I can say that things turned out pretty good. I am leading a successful and happy life as well as giving back to others. I couldn’t imagine my life any other way.

10. **MAEVE MAKES A DIFFERENCE**

Faces friend, Maeve Reynolds made a surprise delivery, with dozens of boxes of Girl Scout cookies for the doctors and nurses at NYU Langone Health. The yummy donation is so appreciated!
11. JOIN TEAM FACES

CALLING ALL MARATHON RUNNERS: Only a few spots left on FACES’ NYC Marathon team! Join TeamFACES on November 3rd, and help us as we race to find a cure for epilepsy and seizures. Contact Amy Savage, Manager of Special Events, at amy.savage@nyulangone.org.
Berries and Cream Mini Popsicles – Recipe from The Charlie Foundation

Berries and Cream Mini Popsicles are the perfect small snack for a summer day. The recipe here uses 40% heavy cream, however you may also dilute the cream for lower ratios or even use full fat, unsweetened coconut milk for a dairy free option.

Ingredients:

5g fresh blueberries
5g fresh raspberries
15g 40% heavy cream
Optional: Liquid Stevia drops
Water if needed to fill the popsicle molds

Directions:

1. Place the berries in the popsicle molds
2. Add the heavy cream and liquid stevia to the berries. Add water to the molds to fill to the top
3. Note: the ring pop molds are slightly different sizes. Start with the smallest mold and adjust your snack calculation to fit your specific needs, making sure the ingredients fit the mold. For larger molds, dilute the cream with water to fill the remaining headspace.

6g fat | 1g protein | 1g net carbs | ~60 calories | 3.7:1 ratio

Please contact your dietitian to adjust the recipe for you or your child’s ketogenic diet.
13. NOTEWORTHY NEWS

1. Does CBD Actually Work?
2. Scientists Unravel Brain Mysteries
3. ‘He Was Cold as Ice’: Hundreds of Children Die Each Year with No Explanation. Their Parents Are Pushing for Answers.
4. Engage Therapeutics to Present Phase 2b Open Label Run-In Data from StATES Trial of Staccato Alprazolam at 2019 American Academy of Neurology Annual Meeting
5. Scientists Find First Evidence for Necessary Role of the Human Hippocampus in Planning
6. Surviving Daylight Saving Time
7. What Do We Actually Know About CBD? (Hint: Not Much.)
8. An Introduction to Columbia Care: A World-Class Medical Cannabis Business
9. What Scientists Are Saying About the CBD Boom
10. Can CBD Help Your Child?
11. CBD Is Everywhere, But Scientists Still Don’t Know Much About It