



FINDING A **CURE** FOR EPILEPSY & SEIZURES
at NYU Langone Medical Center



SHINING A **LIGHT**...



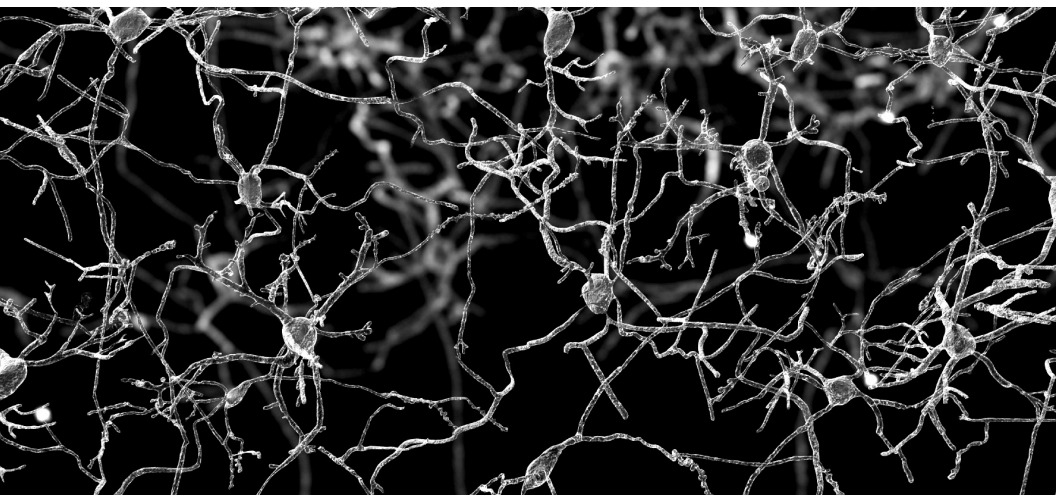
BUILDING **COMMUNITY**
PROVIDING **CARE**
FINDING A **CURE**



FACES FUNDS:

- RESEARCH TO IMPROVE EPILEPSY CARE
- ADVANCEMENT OF NEW THERAPIES
- A SUPPORTIVE COMMUNITY FOR CHILDREN, ADULTS, FAMILIES, AND CAREGIVERS WHO LIVE WITH THE CHALLENGES OF EPILEPSY

WE'RE LIGHTING THE WAY
TO A BETTER DAY BY WORKING
TO FIND A CURE



Welcome to FACES!

Finding A Cure For Epilepsy and Seizures (FACES) is an organization dedicated to helping people and families living with epilepsy, through research, education, and clinical and community support programs. We are very proud of what we have accomplished and remain ambitious about plans for the future.

The heart of FACES is our community of doctors, nurses, neuropsychologists, technicians, and administrators, and – most importantly – the people and families we care for along with friends and our wider community of collaborators in epilepsy care around the world.

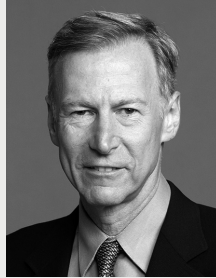
Our research program has never been as robust or exciting as now. Currently, we are exploring the immunological mechanisms underlying epilepsy, researching the safety and efficacy of pure cannabidiol (CBD) in children and young adults with treatment-resistant epilepsy, developing novel methods to surgically treat epilepsy, undertaking studies to understand the risk factors and mechanisms underlying sudden death in epilepsy (SUDEP), advocating for individuals who suffer from healthcare disparities, developing new strategies to treat depression in people with epilepsy, and more than a dozen other ongoing studies with collaborators around the world.

Our 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.

All this is thanks to the incredible support we have received.

Once again, welcome!

ORRIN DEVINSKY, MD



RESEARCH

FACES SUPPORTS THE TREMENDOUS WORK OF THE MEDICAL TEAM HERE AT THE COMPREHENSIVE EPILEPSY CENTER AT NYU LANGONE. ONGOING RESEARCH INITIATIVES, CLINICAL TRIALS AND PATIENT SUPPORT ARE PAVING THE WAY TO A CURE.

Epilepsy Phenome Genome Project (EPGP) and EPI4K

Using seed money from FACES, New York University and the University of California San Francisco organized The Epilepsy Phenome/Genome Project (EPGP). More than 25 major epilepsy centers and over 100 investigators and colleagues throughout the United States, Canada and Australia collaborated to create a powerful database on epilepsy. EPGP has recruited over 4,100 epilepsy patients, family members, and control individuals to study the relationship between clinical and genetic data.

The Human Epilepsy Project (HEP)

The Human Epilepsy Project (HEP) is a large, 5-year prospective study with the goal of identifying biomarkers that predict epilepsy outcome, progression and treatment response in patients with recently diagnosed focal epilepsy. HEP is a partnership between 26 academic centers, foundations, and industries, led by the Comprehensive Epilepsy Center at NYU Langone. HEP will collect high resolution MRI, EEG, and blood samples on 500 patients. This project will create an open data repository of clinical information and biologic samples for future studies.



2 million+

Epilepsy affects over 2 million Americans and 65 million people worldwide.*

150,000

Each year over 150,000 people are newly diagnosed with epilepsy. 30% of them are children.*

2x

In America, epilepsy is twice as common as breast cancer and takes as many lives.*

1 in 26

Approximately 1 in 26 people in the United States will develop epilepsy at some point in their lifetime.*

* source: www.epilepsy.com

RESEARCH

Epilepsy Study Consortium

The Epilepsy Study Consortium is a group of scientific investigators from academic medical research centers across the United States and Europe. The cooperation of these expert trial centers will improve clinical trial research methodology and enhance the likelihood that the best drugs are brought to market for the people who need them.

Neurophysiology of Epilepsy and Cognition in Patients Implanted with Intracranial Electrodes

Candidates for epilepsy surgery often undergo intracranial EEG monitoring, in which electrodes are placed directly on the surface of the brain. These studies can detect brain activity with an unparalleled degree of spatial and temporal resolution. The neuroscience team at NYU Langone has assembled a consortium of high-profile collaborators from the University of California, San Diego, Princeton, and Harvard. Our intracranial EEG studies have investigated a broad array of topics, such as memory, language, multisensory integration, face perception, and decision making. Recent findings have been published in high-impact scientific journals, such as *Science*, *Nature Communications* and *Neuron*, and highlighted on CBS News.

Cannabidiol (CBD)

The initial goal of this research program is to test the safety and tolerability of pure cannabidiol (CBD) at different doses in children and young adults with treatment-resistant epilepsy. This research program includes randomized controlled trials of CBD to treat intractable seizures. Results will have an important impact on treatment options for individuals with some of the most severe forms of epilepsy.

Sleep and The Ketogenic Diet

We prospectively assess the sleep habits of children on the classic ketogenic diet. Improved sleep patterns can improve pediatric epilepsy and overall quality of life. Exploring the ketogenic diet's effect on sleep patterns will provide the patient and clinician with a more comprehensive care plan. We hope that these comparisons will help provide insight into the diet's effect on sleep, and improve treatment of sleep disorders in patients undergoing ketogenic diet therapy.

RESEARCH

Tuberous Sclerosis Complex

FACES supports cutting-edge research investigating the causes of Tuberous Sclerosis Complex (TSC) and identifying new therapies through collaborations between basic science, neuroimaging, and clinical research teams. Molecular, cellular, and functional abnormalities in brain tissue removed at surgery are associated with signal abnormalities on MRI scans and ultimately with clinical symptoms, such as intellectual disability. Research on the electrophysiology of the TSC brain utilizes specialized electrodes and novel endoscopic neurosurgical techniques to perform minimally invasive removal of brain tumors in TSC. We are working to unravel how mTOR inhibitors reverse the underlying problems—including brain tumor formation—in patients with TSC.

Anti-Inflammatory Therapy as a Treatment for Epilepsy

There is increasing evidence—from animal models of epilepsy as well as from surgical tissue removed from patients with uncontrolled seizures—that inflammation can cause epilepsy that persists despite treatment with antiepileptic drugs. This process may be a target for novel anti-epilepsy therapy. NYU investigators and international collaborators are translating these important findings to accelerate new therapies and potentially improve the complex neurological deficits in these patients.

Autism and Epilepsy Initiative

A quarter of all patients with autism have epilepsy. In individuals with autism, epilepsy is often difficult to control and severely affects their quality of life. FACES has supported the creation of a clinical and genetic data repository of people with autism and epilepsy, with the aim of identifying biomarkers for drug responsiveness. Epilepsy in autism is associated with lower cognitive ability and more severe behavioral symptoms. Research has identified quantitative MRI abnormalities in the brains of people with autism that are potential biomarkers for seizure risk and responsiveness to medications.

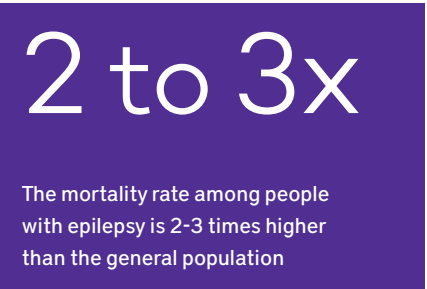
RESEARCH

Sudden Unexplained Death in Epilepsy (SUDEP)

SUDEP is the most common cause of death among individuals with epilepsy. For older adolescents and adults whose tonic-clonic seizures are not fully controlled by antiepileptic drugs, the risk of SUDEP can exceed 10% over a decade. The Comprehensive Epilepsy Center at NYU Langone is spearheading a series of studies on SUDEP to learn more about the disorder and develop strategies to prevent it. FACES support has led to the creation of the North American SUDEP Registry (NASR), a detailed repository of clinical data and biospecimens from SUDEP cases.

Additional Projects Funded By FACES

- Establishment of a Dravet Center for research and clinical care to help children and adults with this disorder
- Identifying how the Modified Atkins Diet results in a decrease in seizure activity by studying changes in the human brain
- Exploring risks of adverse outcomes in pregnant women (e.g., seizures, change in medications, depression, c-sections) and adverse outcomes in their children (e.g., lower birth weight, thinking or behavioral problems), through the Maternal Outcomes and Neurodevelopmental Effects of Antiepileptic Drugs (MONEAD) study, funded by FACES and the National Institute of Health
- Identifying risk factors for anxiety and depression following epilepsy surgery
- Assessing the therapeutic role of oxygen during and after seizures
- Development of the first epilepsy surgery prognostic scale
- Development of home seizure detection devices



EDUCATION

FACES HOSTS A VARIETY OF COMMUNITY BUILDING EVENTS AND EDUCATION PROGRAMS THROUGHOUT THE YEAR. WE WELCOME ALL PEOPLE IMPACTED BY EPILEPSY INCLUDING PATIENTS, SIBLINGS, PARENTS AND CAREGIVERS.

Peace of Mind Lecture Series

This series of cost-free lectures is open to the public to help educate patient and family members. Lectures are given by doctors and other professionals affiliated with the Comprehensive Epilepsy Center at NYU Langone.

Annual Epilepsy Conference

This annual one-day conference brings together world-renowned doctors and researchers to present pioneering information on the treatment of epilepsy and seizures to patients and their caregivers.

FACES School Club

The School Club Starter Kit is for students who are interested in uniting together to volunteer for FACES, sharing the common goal of raising funds and awareness of epilepsy and seizures at school.

You Can Do This DVD

An instructional DVD on first aid for seizures and related topics that is provided cost-free to individuals, schools and organizations.

FACES Newsletters

Our newsletter covers FACES programs and activities and features articles by patients caregivers and staff of the Comprehensive Epilepsy Center at NYU Langone.

Epilepsy.com

This domain name was initially purchased and developed by FACES and continues to serve as a central resource for families that are seeking up-to-date information about epilepsy and relevant research trials. It is the #1 online resource and community (blogs, forums, chats) for people and families living with epilepsy.



“The Annual Epilepsy Conference is a valuable resource where I can learn about the latest advances in the epilepsy field from world-renowned experts. It also provides me with a unique opportunity to meet and network with others who have had the experience of living a life with seizures.”

RICHARD SHANE

We also inform and connect through:

www.nyufaces.org

 facebook.com/facesfriends

 [@NYUFACES](https://twitter.com/NYUFACES)

SUPPORT

IMPROVING QUALITY OF LIFE IS AN ESSENTIAL PART OF THE FACES MISSION. WE STRIVE TO PROVIDE YOU WITH THE TOOLS AND RESOURCES TO HELP GUIDE YOU AND YOUR CAREGIVERS THROUGH THIS JOURNEY.

Dr. Blanca Vazquez Summer Camp Scholarship Program

Awards financial need-based scholarships to children with epilepsy and seizure disorders each year to a summer camp of their choice.

College Scholarship Program

Awards financial need-based scholarships to incoming freshmen or those presently enrolled in college, who meet specific requirements and are affected by epilepsy and seizure disorders.

FACES Apartments

Provides cost-free accommodations to families traveling to NYU Langone Medical Center for inpatient epilepsy treatment or evaluation. Hotel rooms are available on a first-come-first-serve basis for families coming from far distances.

The Parent Network

Connects parents with parent mentors who have experienced dealing with issues surrounding care for a child with epilepsy, such as the hospitalization process, educational services or social support resources. Trained parent mentors actively provide support through e-mail, telephone, events and hospital bedside visits.

Epilepsy Diet & Nutrition Program

FACES funds the nutrition/dietetics program at the Comprehensive Epilepsy Center at NYU Langone. Since starting in 2012 we have provided modified Atkins and ketogenic diet therapy to over 300 patients. Courtney Glick is the Registered Dietitian Coordinator who oversees this program.

Lodging provided to patients and families from **21 states** and **4 countries**



“Since we live 2 hours away, commuting back and forth to the city would be a tremendous hardship on our family. The FACES apartment is our home away from home that has allowed me to stay with my son and get some much-needed rest.”

SUSAN TUCCI

PHILANTHROPY & EVENTS

THE GENEROSITY OF OUR COMMUNITY IS VITAL TO THE SUCCESS OF FACES. THERE ARE MANY WAYS ONE CAN GIVE BACK FROM FINANCIAL DONATIONS TO HOSTING FUNDRAISERS TO SIMPLY RAISING AWARENESS.

FACES Gala

A memorable and inspiring evening that offers an opportunity for members of our community to celebrate and raise funds for our mission.

FACES Gala Auction

Support FACES by bidding on over hundreds of packages online or by donating items to be used in the auction.

FreshFACES

A social fundraising event that brings together supporters for an evening of food, beverage, entertainment, and awareness.

FACESforward

An online fundraising program designed to raise awareness and funds. Our community is encouraged to donate and share the link with friends and family as part of our spring campaign. Visit www.nyufaces.org/facesforward for more information.



“A spirit engulfs the FACES Gala unlike any fundraising event I have ever attended. It is a magical evening where warmth, generosity and togetherness is in abundance. Remarkable life-changing victories over epilepsy are celebrated. Progressive medical discoveries by expert doctors are enthusiastically applauded. You cannot escape the feeling you are part of something very important and special.”

DAVID SWINGHAMER



“Since Game Day’s inception 15 years ago, it is now host to over 400 members of the FACES community. The afternoon is full of fun activities which include face painters, carnival games, inflatable slides, and the all-time favorite – the Lollipop Game! The day is all about saying ‘Yes. Yes, you can climb the rock wall. Yes, you can jump on the trampoline. Yes, you can do it even though you have epilepsy!’”

**SHARON PERHAC AND
MICHELE AGUAS**



PHILANTHROPY & EVENTS

Endurance Events

Team FACES encourages athletes to participate in endurance events, such as the NYC Marathon and Half Marathon, to raise funds and spread epilepsy awareness.

Game Day

A fun-filled afternoon of carnival games and activities at the Field House at Chelsea Piers. We welcome children with epilepsy and seizures, their siblings, family, and friends.

Teen Event

An event for teens with epilepsy and their siblings, aged 13-18. Venues include an arcade, bowling, and museums.

Personal Fundraising Pages

FACES provides a custom website and offers assistance with your personal fundraising goal. From triathlons to lemonade sales, mitzvah projects to dance parties, our community has found creative ways to garner support from friends and family.



“Running the New York City Marathon was an experience of a lifetime; racing on behalf of FACES added meaning far beyond the 26.2 miles. It awarded me the opportunity to bring awareness and to give back to a cause close to my heart, larger than my own self.”

ULRIKA CITRON

JOIN

Become a member of our FACES Steering Committee and help us plan our events and programs.

VOLUNTEER

Help us at our events like Game Day and Gala.

CREATE

Start your own fundraising page to raise awareness and money for FACES.

VISIT

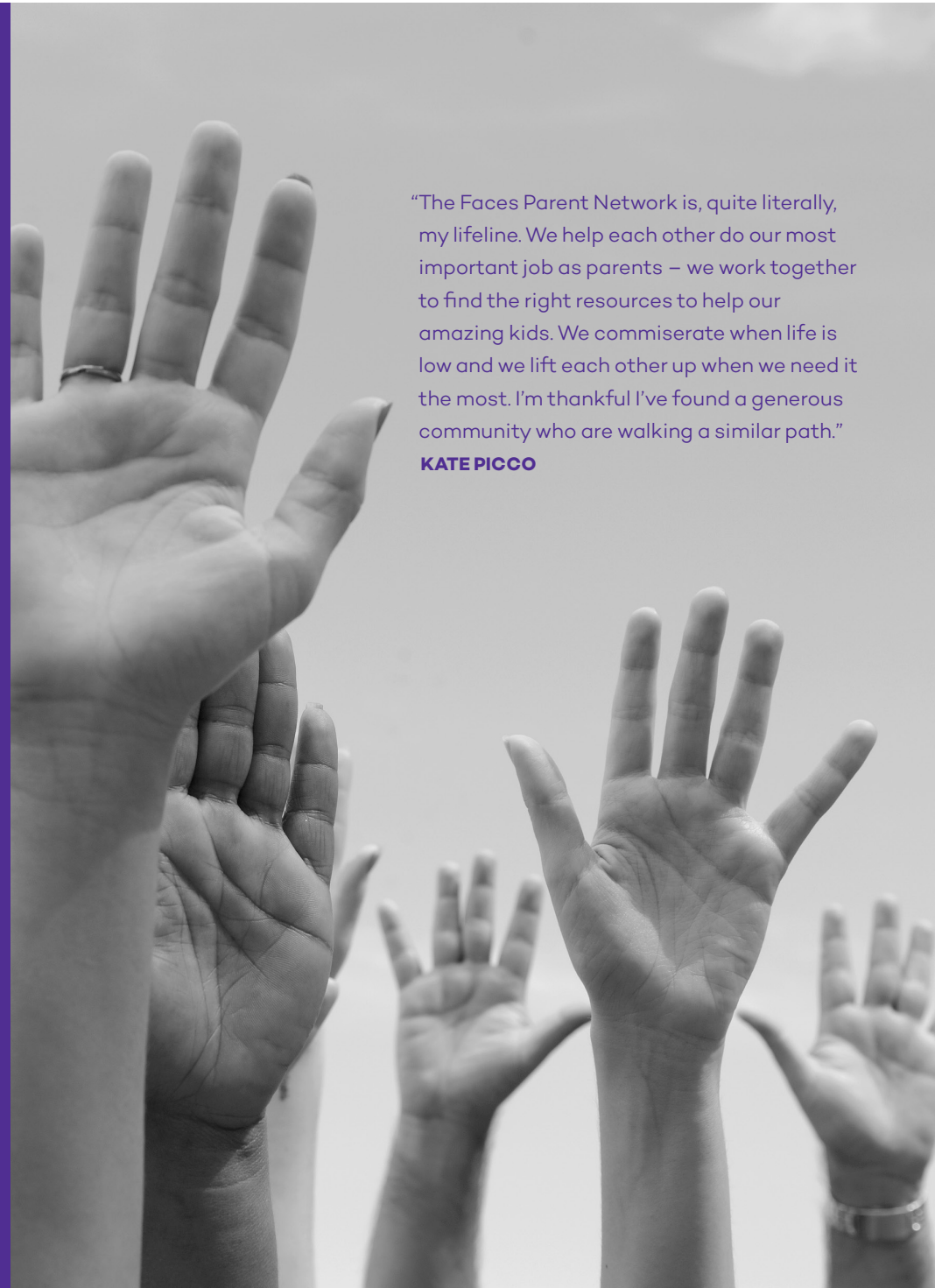
✉ facesinfo@nyumc.org

📘 www.facebook.com/facesfriends

🐦 @NYUFACES

☎ 646-558-0900

223 East 34th Street
(between 2nd and 3rd Avenues)
New York, NY 10016



“The Faces Parent Network is, quite literally, my lifeline. We help each other do our most important job as parents – we work together to find the right resources to help our amazing kids. We commiserate when life is low and we lift each other up when we need it the most. I’m thankful I’ve found a generous community who are walking a similar path.”

KATE PICCO

