1. PEACE OF MIND RECAP – TIPS ON LIFESTYLE MODIFICATIONS AFTER AN EPILEPSY DIAGNOSIS

By: Santoshi Billakota

I had the pleasure of speaking with patients about the importance of lifestyle in the management of epilepsy at the Peace of Mind Lecture on January 8th. Often times, the focus is on pharmacological management of epilepsy, but we now know that other psycho-social factors also play an important role in seizure control. In this lecture, I highlighted the importance of self-management, as part of your epilepsy management. Self-management includes management of seizure triggers, medication management, focusing on your personal mental health and wellness. Other things I have seen play a key role in management of epilepsy has been the importance of sleep, diet, fitness and overall stress management. I think, with an increased focus on self-management, most patients will be able to exercise a more holistic and complete approach to epilepsy care, which may lead to better seizure control.

To see the video recording of this lecture and all others, visit: http://faces.med.nyu.edu/events-programs/peace-mind-lecture-series
2. FUDGERAISER 2020

In November, Noelle D’Amato, James Pugliese and Jonathan Cocca held the annual FUDGERAISER for FACES in which they make, sell and deliver fudge to raise money for the organization. This year, the Fudgeraiser, in its ninth year, raised $2,100. In total, the FUDGERAISER has donated over $22,000 to FACES!

The kids dedicate their efforts in loving memory of Eric Berninger and will continue to raise money for all those who deal with the effects of epilepsy.
3. TEAM FACES – RUNNING FOR A CAUSE

On Sunday, March 15 2020, Courtney Lipson, Corey Deutsch and Brett Deutsch will be running the United Airlines Half Marathon for FACES (Finding A Cure for Epilepsy and Seizures).

From Courtney:
Epilepsy has had a very profound effect on each of our lives, whether through direct experience with epilepsy (Brett and Jared) or watching our loved ones suffer from this awful disorder (Courtney and Corey). It is hard to put into words what it is like to watch from the sidelines as a loved one is having a seizure, knowing that there is next to nothing you can do in the moment. What many people don't realize is that the actual seizure is only half the battle for people with this disorder, as not only do individuals suffer from the direct consequences of epilepsy (seizures, medications, EEG scans, etc.), but there are indirect implications that individuals such as Brett and Jared have to face including being stripped of daily pleasures that many of us take for granted such as the ability to drive a car, swim in a pool or even just live independently without constant oversight.

March 14th, the day before the run will be the 4 year anniversary of Courtney's twin brother, Jared, unexpectedly passing away from SUDEP (Sudden Unexpected Death in Epilepsy). FACES recognizes the severity of SUDEP and is striving to make this something that can be avoided for future epileptics, as FACES allocates a portion of donated dollars towards research of SUDEP (you can read more about it here: http://faces.med.nyu.edu/research-education/aan-and-aes-issue-public-recommendations-for-sudep).

The three of us are beyond proud to be running in this half-marathon for such an incredible cause.

To support Team FACES and our runners: visit https://nyulangone.org/give/fundraise/unitedhalf

Jared and Courtney

Brett, Garret and Corey
4. DON’T FORGET!

Save the Date!
2020 FACES Epilepsy Conference

April 26, 2020

Speakers and Moderators (More TBA)

William Barr, PhD
Orrin Devinsky, MD
Sasha Devore, PhD
Jacqueline French, MD
Peggy Guinnessey, CTRS
Josiane LaJoie, MD
Jennifer Rosenberg, MD
5. SLEEP AND EPILEPSY
By Sloka Iyengar, PhD, PMP

Title of study: Sleep quality and related clinical features in patients with epilepsy: A preliminary report.

Journal and citation: Epilepsy Behav. 2020 Jan; 102:106661.
Authors: Çilliler AE, Güven B

Purpose
- Sleep and epilepsy have a complex relationship; poor sleep in people with epilepsy may be due to the effect of seizures; effect of anti-epileptic drugs; or comorbidities such as depression, which itself can be associated with poor sleep quality.
- These sleep issues in people with epilepsy can be related to a decrease in quality of life.
- The purpose of the current study was to explore sleep quality, daytime sleepiness, fatigue, and symptoms of depression in people with epilepsy.

Description of the study
- This was a survey done on people with at least two unprovoked seizures in the past two years.
- In order to gain understanding of how seizures affect sleep, following patients were excluded from the study:
  o These included people working at nights, those taking medications that might affect sleep, and those with other additional conditions that may affect sleep independent of seizures.
- Sleep quality, excessive daytime sleepiness, fatigue, and symptoms of depression were evaluated using questionnaires.
- Seizure frequency was examined to investigate if seizures and sleep deprivation were corelated.

Summary of findings
- More than half of the patients surveyed had fatigue and symptoms of depression.
- Less than half of the patients in the survey reported as having poor sleep quality and excessive daytime sleepiness.
- An association between the quality of sleep and seizure frequency was found i.e. the seizure frequency and worsening sleep quality were correlated.

What do the results mean?
- Poor sleep has a significant impact on quality of life of people with epilepsy.
- As one of the first studies in its field, this paper shows that sleep, fatigue, depression, and epilepsy are closely related.
  o More research is needed to figure out the effect of anti-epileptic drugs on sleep.
• Sleep can be thought of as a period of hyper-synchronization of neuronal circuits (i.e. many neurons firing at the same time and in the same relative frequency), which may overlap with mechanisms of seizures.
  o In line with this, the effect of nighttime seizures on sleep also needs to be examined.

Sloka Iyengar, PhD, PMP
Sloka’s graduate and postdoctoral work focused on mechanisms of epilepsies. She then worked as a clinical research coordinator and was involved in clinical trials in adults and children with refractory epilepsies. Currently, Sloka works as an Associate Medical Director at Phase Five Communications. She has lobbied for neuroscience funding on Capitol Hill, and teaches evolution and neuroscience to educators at the American Museum of Natural History. She is also a professional dancer, performing and teaching in the New York City area. You can find more about her and contact her at www.slokaiyengar.net.

6. NICOLE APPEL ARTWORK

NICOLE APPEL is a professional artist with an impressive track record of successful exhibitions and sales that would be the envy of most artists. Her work is represented in important collections internationally. At only 29 years old, Nicole is already a rising star in the art world. She also has autism and epilepsy. Thanks to the superlative care, compassion, and dedication of Dr. Devinsky, Director of the NYU Comprehensive Epilepsy Center, Nicole has been able to pursue her artistic career unimpaired and seizure free for over a year, and looks forward to a bright future. As an expression of her heartfelt gratitude she is donating 5 signed, numbered, limited edition, museum quality giclees (fine art prints) from her recent, very successful exhibition, at the 2020 Outsider Art Fair, to the 2020 FACES Gala silent auction. One of the drawings in the exhibition was recently purchased for the Martin Eisenberg collection, one of the major collections of contemporary artwork in the United States.

ABOUT NICOLE APPEL’S WORK: “Simply put, conventional portraits have traditionally represented people using their faces. Alternatively, Nicole Appel’s “Patchwork Portraits” are non-traditional portraits that represent people as a collection or ‘Patchwork’ of the things that they like or care about.”

TO PREVIEW THE CATALOGUE for Nicole’s 5 giclees and to learn more about the amazing backstories associated with them, please go to the following link:
https://www.shelternyc.com/projects-appel

“Jerry Saltz loves Nicole’s work!” Jerry Saltz, Pulitzer Prize winning art critic, at the 2020 Outsider Art Fair with Nicole Appel’s “Patchwork Portraits.”
7. LESS THAN A MONTH AWAY!

TICKETS ON SALE NOW
Visit: nyulangone.org/give/events/faces-gala

BE NOTIFIED WHEN THE FACES GALA AUCTION GOES LIVE!
Click here to be added to our mailing list:
faces.med.nyu.edu/mailing-list
8. FACES 2020 COLLEGE SCHOLARSHIP IS NOW OPEN!

The below is a statement from Lauren Trebour, 2019 FACES College Scholarship recipient.

“I have epilepsy.” Those are the three words that I never thought I would be saying out loud. In fact, I had no knowledge of what it actually meant until I was diagnosed with focal epilepsy in 2013. At first, I didn’t want to accept that I had this medical condition. For some reason, I felt that the word epilepsy was a scary term. I kept telling myself that I had a seizure disorder and that I would outgrow it. Little did I know, epilepsy was going to be a part of my life and it was here to stay. In fact, I would soon learn so much about it that it inspired me to become involved in the medical field.

My focal seizures all began in middle school while I was on the basketball team. It was then that I had my first seizure. My friends, family and coach didn’t know what was happening to me. I was quickly rushed to the hospital and then all the testing began. I have been through a tremendous amount of testing from blood work, EEGs, CT scans, and MRIs. I’ve seen many doctors and specialists from Boston to New York City. After seeing neurologists and being misdiagnosed, the final conclusion was that I was someone living with epilepsy. I needed to accept this in order to educate myself about it and start living my life without fear. For a middle school student, this was difficult especially since my friends didn’t know much about epilepsy. They started to exclude me from overnight sleep overs and hangouts in fear that my seizures may occur at their homes.

With the help from my supportive family and twin brother, I continued to live my life just as I normally should. I became very involved in school, and community service activities. I volunteered weekly at a community hospital, participated in cancer awareness and fundraising activities, volunteered at a camp for children who were grieving the loss of a parent, and working with local Veterans. I always had the desire to help those less fortunate than me. I even worked everyday in high school as the Athletic Trainer’s Assistant so that I could help injured athletes.

Throughout high school, my seizures were controlled with medication. Therefore, I was able to function well and study hard. I am proud to say that my GPA was a 3.7 in high school and I was accepted into a nursing school not too far from home. However, during my freshman year at college, my breakthrough seizures returned and were occurring more frequently. I began to have trouble in my classes and missed a great
deal of school due to testing and hospital stays. My GPA dropped to 2.7 and I began to feel devastated. I lost my college scholarship due to a low GPA. I was a high achiever and although I tried my best under these circumstances, I was not producing the work that I knew I was capable of before the frequent seizures.

In the fall of 2019, I decided to get a partial temporal lobe resection. In doing so, that would mean that I would need to take the whole fall semester off for the surgery and recovery period. Again, I needed to go through many tests and have a two-part surgery. One surgery was to implant electrodes on my brain so it could be used for brain mapping. The second was to do the resection. I was in the hospital for three long weeks.

During this time in the hospital, I agreed to take part in a research study. The study was entitled, “Neurophysiology of Human Epilepsy and Cognition.” I knew this research was important to increase future knowledge about epilepsy and epilepsy related conditions such as Tuberous Sclerosis Complex and Focal Cortical Dysplasia. Giving back to the epilepsy community was important for me. This study wouldn’t benefit me at the time, but it would definitely affect future epileptic patients. In addition, I volunteered to speak to other patients who may be going through similar experiences.

I have now been readmitted to Fairfield University so that I can continue my nursing studies. Being a caring, compassionate, knowledgeable nurse is my goal. I will continue to share my experiences so that others can also realize that epilepsy shouldn’t define who they are or stop them from achieving their goals.

The 2020 FACES College Scholarship application is now ONLINE. Eligibility requirements and application can be found here: http://faces.med.nyu.edu/application. For questions, please contact Brielle Cummings at facesscholarship@nyulangone.org. Your email will be returned within 48 hours. Good luck to all applicants!
Dr. Blanca Vazquez Summer Camp Scholarship program is now OPEN.

All applications are due by **Friday, May 8th**.

To see eligibility requirements and complete an application, visit: [http://faces.med.nyu.edu/events-programs/dr-blanca-vazquez-summer-camp-scholarship](http://faces.med.nyu.edu/events-programs/dr-blanca-vazquez-summer-camp-scholarship)

For questions, contact Brielle Cummings, Scholarship Coordinator at 646-558-0820 or [facesscholarship@nyulangone.org](mailto:facesscholarship@nyulangone.org)

Good luck to all applicants!
9. PURPLE SPOON

Chocolate Truffles – recipe adapted from the Charlie Foundation
Yields: 24 truffles
Ratio: 2.5:1
Serving size: 1 truffle
Nutrition facts per serving: 36 calories, 3.38g fat, 0.5g protein, 0.87g carbs

Ingredients:
• 100g (1/3 cup + 1.5 Tablespoon) Coconut Milk, Original
• 56g (4 Tablespoons) butter
• 80g (1, 2.8oz bar) Lily’s 70% Dark Chocolate Sea Salt
• 15g (2.5 Tablespoons) Cacao powder

Instructions:
1) Combine the coconut milk, butter and dark chocolate in a microwave safe bowl. Heat the mixture in 30 second intervals until melted, stirring between each cycle. You may also melt the chocolate by setting up a double boiler. Avoid overheating the chocolate, as it will separate and not reset properly.
2) Once the ingredients are thoroughly warmed, stir very well until smooth and the chocolate has melted completely. If you’d like to use silicone molds to make pretty shapes, pour the melted mixture into the molds and refrigerate overnight.
3) If you plan on rolling the mixture into spheres, cover the bowl tightly with plastic wrap and refrigerate overnight.
4) After the truffles have cooled, roll into spheres, or remove from the silicone molds, and coat them with the cacao powder. To do this, place the cacao powder in a small plastic bag and add the truffles, one at a time, and shake to coat.
5) Place the truffles in a single layer in a storage container and enjoy when desired!

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

1. Epilepsy Foundation Files Criminal Complaint and Requests Investigation in Response to Attacks on Twitter Feed
2. People with Epilepsy Could Benefit from a Seizure Monitoring Device
3. Exactly How Dangerous Is Football?
4. Should Doctors at This Age Be Tested for Competency?
5. 40% of Americans Say They’re Sleep-Deprived After the Super Bowl