



the epilepsy experience

In history books, seizures are disputed as one of two things: a curse or a celestial power. Today, epilepsy is as common as breast cancer, but receives a third of the funding. And for many of us, that's personal.

STORY: **BRITTANY BATSEL** PHOTO: **RICHARD ROSSETTO**



This is how it begins: “I feel funny,” he says. I make him sit down and I inadvertently start holding my breath.

Then, his eyes start to flutter, color drains from his face, and his complexion assumes a pasty shade of white. His expression goes blank and he looks at me like a stranger. Parts of his body will twitch and I start to say a prayer, my heart pounding as I try to barter with this thing that we can't control. A familiar fight or flight instinct tells me to take a breath, rub his arm, keep him safe. The next moments pass slowly. Time has a way of appearing idle when you just want something to end. The “funny feeling” is an aura, or a warning. A preface some people with seizures are fortunate enough to experience. He has a sense of humor so he has labeled this sensation as feeling “seizure-ific.” When the 60-or-so-seconds pass he will make eye contact and I will tell him what day it is. I will get him an Advil because his head hurts. As the color slowly comes back to his face and his absent stare has passed, I begin to explain simple pleasantries like what he had for lunch and who won golf on Saturday. Then, we wait for the memories to return. I will remind myself that this was a good one. This was a “partial” seizure — and I am encouraged by the relative simplicity of the term.

My husband, Rob, had his first seizure in the batting cage when he was 12 years old.

“It is impossible to explain the fear and emotion that overwhelms a parent when that ambulance you hear in the distance is on its way to get your child,” says his mother, Paula.

After months of testing and praying the results arrived: there was no detectable reason for Rob's seizures. Recounting the initial news from Rob's neurologist, Paula explains how her frustration quickly turned into appreciation.

“Dr. Carney told me that he spends many days telling parents that their children have inoperable brain tumors and cancer and that I should be grateful that my child's tests were normal. And I very much was.”

To this day, despite yearly testing, the mystery source, the lesion, remains unidentified. After experimenting with medications and lifestyle adjustments Rob was fortunate enough to find normalcy. Today, he is able to regulate his seizures with lifestyle routines — medications, sleeping habits and limited alcohol consumption. In the event that an episode does occur, he has fair warning by way of auras. Both auras and seizures are infrequent and under control now, which places him in a category of epilepsy patients with controlled seizures.

when it subsides

Half an hour after Rob first feels “seizure-ific” we will resume whatever routine was interrupted. Seizures have been a staple in my marriage since day one, a fixture in Rob's life for 15 years, and have long established their disregard for time or place. Like our honeymoon flight to Italy when a game of Sudoku was interrupted with those haunting words: “I feel funny.”

Or when he was swimming in Crystal River and a Sunday afternoon ended with admission into Seven Rivers Intensive Care Unit, 17 days in a coma and a recovery that would make any skeptic reconsider.

His only memories of that day are from the scars on his torso that tell of the trachea and chest tubes that kept him alive. When the story is recounted to him years later his eyes still widen in disbelief: a seizure under water, an ambulance speeding through a sleepy town, two collapsed lungs, pancreatitis, acute respiratory distress syndrome (ARDS), a coma.

“One moment, a dream come true,” Paula recalls. “A new house on Crystal River, surrounded by family and friends and the next moment, a nightmare. Nothing but water for miles and our son is under there, somewhere.”

Days of prayers, the amazing strength and fight of a 19-year-old boy, the incredible doctors and

no question, God, she says, are the reasons that today there is a living, breathing Rob.

When he opened his eyes, 30 pounds lighter, his short-term memory was slightly repressed, but his determination was not.

“After my accident, I woke up in a number of ways. There are people out there incapable of enjoying their lives,” Rob says. “Uncontrolled seizures have taken away their ability to think clearly or operate, and in some cases, lives have been lost. And I have been given a second chance to do something to help.”

So it goes, that adversity breeds opportunity. Having achieved seizure management, Rob is not one to dismiss his good fortune. Instead, he is using his success story as a philanthropic platform.

“Rob has never sought pity or made excuses for himself,” Paula says. “It is no surprise to me that he aspires to help other people. He has accepted his situation, managed his condition, and is such an example to others.”

looking back

Evidence of seizures has been recorded as early as the ancient Babylonians and Greeks. The source of epilepsy has long wavered between diabolical sources and clairvoyant abilities. The Ancient Romans professed that epilepsy came from demons and was highly contagious. Years later, dubbed “the sacred disease” there was a strong belief that those with seizures

were possibly touched by the gods. When leaders like Alexander the Great and Julius Caesar began experiencing seizures the latter theory was often denoted and the demonic label turned into a prophetic one. But it was not until the end of the 19th century, that English neurologists began the modern medical era of epilepsy research.

Medically speaking, epilepsy is the disorder and a seizure is the event. When one experiences a singular seizure it does not qualify him or her as an epileptic. One is epileptic when seizures are recurrent and the central nervous system experiences an imbalance in the brain's electrical activity.

Dr. Paul Carney, Professor and Chief of Pediatric Neurology at the University of Florida College of Medicine and Wilder Chair for Epilepsy Research, explains that epilepsy is a chronic disorder.

"Seizures, on the other hand are repeated events that people with epilepsy have," Carney says, explaining

that it is estimated that one in nine people will have a seizure at some point in their lives, 25 percent will go on to develop epilepsy.

seizures in society

Today, approximately three million Americans are affected by epilepsy and seizures; one third of which do not respond to treatment. Epilepsy impacts the same number of people as breast cancer and affects more people than Parkinson's disease, multiple sclerosis (MS) and cerebral palsy combined. Funding for epilepsy research is less than \$4 per patient, a tough contrast to the \$50 per patient spent for the likes of Parkinson's disease and MS. Why the disparity?

"Funding of any disorder is highly dependent on society and individuals to organize," Carney says. "Some of the observations are that epilepsy funding is just not as organized."

Carney says that one argument is that epilepsy tends to have its

greatest impact on people in a lower socioeconomic class.

by the numbers

epilepsy+seizures

Epilepsy and seizures affect almost **three million people** in the U.S. alone.

The estimated annual direct and indirect costs are **\$15.5 billion.**

200,000 new cases of epilepsy are diagnosed each year (approximately).

10 percent of the American population will experience a seizure in their lifetime.

Three percent will develop epilepsy by age 75.

Incidence is highest under the age of **two and over 65.**

45,000 children under the age of 15 develop epilepsy each year.

In 70 percent of new epilepsy cases, no cause is apparent.

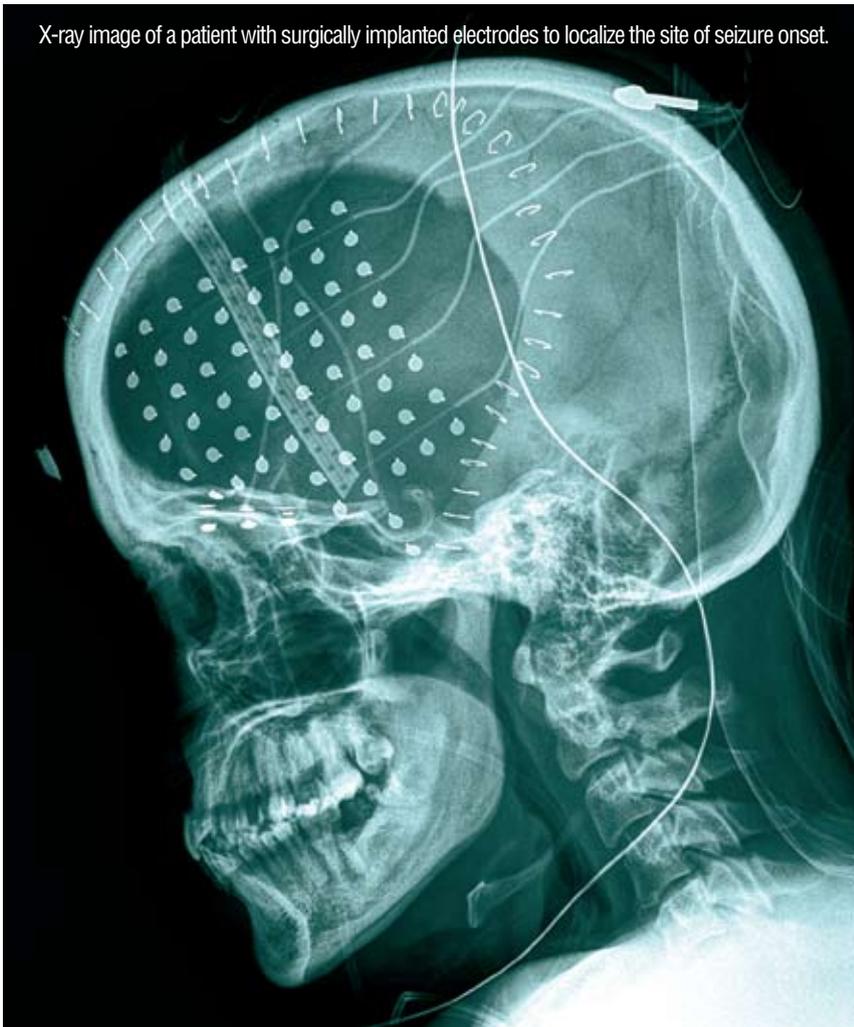
50 percent of people with new cases of epilepsy will have generalized onset seizures.

Generalized seizures are more common in children under **the age of 10,** afterwards more than half of all new cases of epilepsy will have partial seizures.



SOURCE:

X-ray image of a patient with surgically implanted electrodes to localize the site of seizure onset.



"Because of the disease, many people with epilepsy cannot work or drive and employers don't want to hire them because of the risks involved," Carney says.

In addition, unlike other diseases epilepsy commonly surfaces in younger age groups.

"Parkinson's impacts people later in life, allowing people to be productive in terms of their careers or learning capacity up until the time they develop the disease," Carney says. "People with epilepsy, on the other hand, may not have had the opportunity to be as productive."

Rob is fortunate enough to live a normal, productive life with seizures. Sure he has to sacrifice things like scuba diving and donating blood, but his forfeits are so minute in comparison to the countless patients who live lives of dependency because of sudden grand mal seizures.

"I owe it to the people still trying to

fight the good fight to do my part to find an answer," Rob says. "So, we're going to raise money to encourage the best and brightest to gain interest and find a cure."

This is how it begins: you file articles of incorporation with the State of Florida. Months later, the paperwork arrives, and an idea is made tangible with personalized bylaws and a board of directors. Influenced greatly by Dr. Carney's initiatives, Rob has formed his own brainchild in response to the epilepsy need. Society Overcoming Seizures — The S.O.S Foundation — was born in 2010 with a mission to provide funding for epilepsy therapy research. Armed with his personal experience and an ambition for facilitating change, Rob's intentions with S.O.S are dually focused on Dr. Carney's research team and increasing epilepsy advocacy in and around the community.

"This is an issue that the average person simply doesn't understand. So, the general goal is to raise awareness," Rob explains. "I am confident that once people realize what is on the table the fundraising effort will be successful. There is a huge need for funding to help researchers provide solutions for families whose lives are in complete disarray because of a child or family member with uncontrolled epilepsy."

Historically, epilepsy may be a condition regarded as ambiguous, but the brand is transforming into one better suited for modern times. With voices beginning to speak louder on behalf of epilepsy, the change may be gradual, but it is imminent. For now we can start small, with a local voice — one that is doing his part to turn curiosity and necessity into invention. One who is not only acquainted with the condition, but who is alive to tell about it. 0

I have been given a second chance to do

radical research

Just up the street, at the University of Florida, scientists and physicians are paving the way for some of the most cutting-edge medical research to date. At UF's Biomedical Sciences Building inventive minds are merging to stimulate multi-disciplinary research and create progressive medical movements. It is here, that Dr. Carney's Epilepsy Research Laboratory is located and that partnerships and active research collaborate as physicians and scientists work closely to understand neurological diseases and translate things that happen in the laboratory to the bedside. Recognizing the importance of taking basic science and engineering a better therapy, Carney's team is working to understand the mechanics of epilepsy by bringing together the various elements within the University. This creates an alliance between the colleges of Medicine, Engineering, Public Health and Health Professions, designed to pioneer therapies and techniques by merging disciplines. Since epilepsy is a multifaceted disorder, the facility allows for dialogue between scientists and physicians which Carney says is important in moving epilepsy research forward.

Thanks to a generous gift from B.J. and Eve Wilder, the Wilder Research Endowment, Carney and his team are currently operating under dedicated dollars, specifically allocated for researching new epilepsy therapies and cures.

For more information visit <http://www.neurology.peds.ufl.edu/carneylab/>

A photograph of a man with dark hair, wearing a light blue button-down shirt, looking off to the side. A hand with a ring is resting on his shoulder. The scene is lit with vibrant, overlapping colors of red, orange, and green, creating a dramatic and emotional atmosphere. The background is blurred, showing another person's face.

something to help.

— Rob Batsel