

# Epilepsy battle inspires father's memoir

By Kris DiLorenzo

As part of Dobbs Ferry Public Library's "Meet the Author" series, award-winning author, playwright, actor, screenwriter, director, dramatist, and teacher Marc Palmieri will read from his book, released in August, "She Danced with Lightning: My Daughter's Struggle with Epilepsy and Her Boundless Will to Live," on Thursday, Nov. 10 at 7 p.m.

Palmieri, an assistant professor of communications in the School of Liberal Arts at Mercy College, tells the story of his daughter, Anna, now 16, diagnosed with epilepsy at 5 months old, and his experience throughout her childhood as she declined and then, at 12, underwent lifesaving brain surgery. Described as "part family memoir, part medical mystery," the book chronicles the progression of Anna's illness and its effect on him, his wife, Kristen, and Anna's sister, Nora, now 14 — and Anna's determination to pursue her passion, dancing.

In a conversation with the Enterprise on Nov. 7, Palmieri discussed his book and what he has learned from his daughter's persistence. "The book is completely nonfictional, but the story has the qualities of a medical mystery," he explained. "The book is really a parenting memoir... While the medical narrative is certainly the action, really the book is about my beholding and being inspired by the incredible courage



Marc Palmieri and the cover of "She Danced with Lightning"

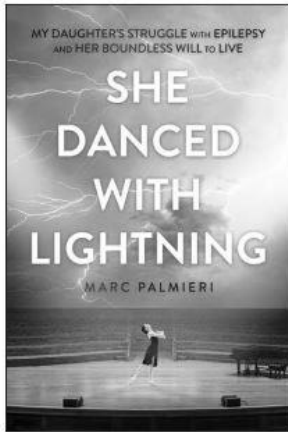


PHOTO OF MARC PALMIERI BY JOHN PAIYZ

she showed."

Anna had received three different diagnoses; the original one by doctors at New York-Presbyterian/Weill Cornell Medical Center proved correct. This kind of puzzle is not atypical for epilepsy patients, Palmieri stated.

"What's common is that someone with epilepsy has a hard time pinpointing what the cause is as well as what treatment is most effective. For most, it's just a constant search for something

that works better."

For the Palmieris, that included seven different medications, diets, alternative treatment, medical marijuana, and CBD.

At first, Anna's seizures were all nocturnal. Her parents took turns sleeping on the floor next to her bed; when she was little, someone slept in the bed with her. Because his wife had to leave early

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for her job as a fourth-grade teacher in Commack, Long Island, that parent was most often Marc Palmieri. When he was working in theater, he'd come home late from shows and take his wife's place.

Anna's life during the day appeared normal; she did what a child ordinarily does, but was on various medications, had to go to hospitals for routine tests, and was exhausted. She also had a paraprofessional watching her at school. Anna was hospitalized numerous times, including scheduled overnights. Sporadic emergency situations arose when the medications were no longer working.

Despite her situation, Anna continued to dance. Both girls had been taking lessons since age 2, starting with "Mommy and Me" ballet classes. (Nora now attends the Professional Performing Arts School in Manhattan.) Anna performed in recitals at Annmarie's Studio of Performing Arts (ASPA) in Queens, near the family's home in Bayside, as well as regional competitions.

As Anna approached her 12th birthday, the pattern of seizures began changing from nocturnal to randomly during the day. They increased in frequency, spiraling within two months from a handful of small episodes during the day to near "status epilepticus," a virtually unceasing state of seizure that usually is fatal. By 2018, she was having daily seizures.

Since Anna was first diagnosed, Palmieri said, he and Kristen had feared SUDEP (sudden unexpected death in epilepsy), which usually occurs during sleep. Brain surgery was the only option left.

"She had many thousands of seizures before her brain surgery," Palmieri related. "Surgery had to be proposed because she was dying, essentially."

Surgeons at Weill Cornell removed a lesion in Anna's front left lobe, with no damage to her brain. After that, Palmieri noted, "Every day was a mystery... did it work? Is there a seizure coming? Eventually over time you realize this was a success."

Palmieri, 51, has kept a journal for 30 years. "That helped in going back, and helped me recall details, times, places, and people, but also there's so much documentation: reports, emails, medical records. I started writing it in early 2020, when Anna was 14."

"I always think a good story has to be about two things at once," he continued. "When I realized that this was not only about what happened, but also who she was through it, and that commitment to living her life fully even as her faculties were collapsing, is really why I wrote it." He added, "A big part of the book is the relationship between a parent who has perfect health and a child who has this kind of extreme challenge."

Before her surgery, Anna coped with limitations: she couldn't go on sleepovers with her friends, for example. Though her parents wanted her and Nora to understand this factor, they also encouraged Anna to live her life fully.

She wanted to perform in the dance school's spring recital, held before an audience of 400, but her father wanted her to sit this one out, telling her she'd have a chance to do it next year. "She just said, 'You're not like me. You don't understand me, you never will. I have to do this because I don't know if I'll be here next year.'"

Palmieri wouldn't attend the first show, but after a call from his wife about how well Anna had done, he came to the second performance, "still terrified," he admits, worrying about Anna falling and hitting her head on the floor. She shocked him.

"For that 5-hour span, she did not have a seizure; she executed her dance perfectly," Palmieri recalled. "I'm sure science can explain it, but I learned I was wrong. She performed a duo tap piece where she had to do a cartwheel. I couldn't believe my eyes... This kid I had picked up off the floor the day before, facing this enormously risky surgery... This was my recognition scene, reckoning with my wrongness. After the show she was standing there smiling, holding flowers, just like everyone else — and then a few hours later, back to the nightmare. She ended up having six seizures that evening. That's when I realized I had a story to tell."

Since the surgery, Anna has been seizure-free for three years. Now a junior, she plays on the varsity soccer team at Holy Cross High School in Flushing, but dancing is still her passion.