

talking with { Marc Palmieri }

Chronicling a medical nightmare

BY BARBARA SCHULER
Special to Newsday

From November 2006 to June 2018, Marc Palmieri didn't get much sleep. The playwright, who grew up in Melville, spent most nights on the wood floor next to the bed of his daughter, Anna, sleeping lightly at best so he would know if she was having an epileptic seizure.

In "She Danced With Lightning" (Post Hill Press, \$18), Palmieri outlines — in often excruciating detail — the way Anna's illness governed every aspect of his family's life. "We had ended up in the wrong play," he writes, "hoping every day that the curtain would come down on it."

Palmieri, 51, an assistant professor in the communications studies program at Mercy College in Dobbs Ferry, discovered his love of theater when he saw "The Night of the Iguana." He also wrote the screenplay for "Telling You," starring Jennifer Love Hewitt as well as a trilogy of plays about growing up on Long Island.

In a phone conversation from his home in Bayside, Palmieri, who will speak at Barnes and Noble in East Northport on Oct. 16, talked about surviving this medical nightmare.

After spending most of the night reading your book, my first question has to be, "How is Anna?"

Anna is doing very well. She continues to dance competitively and she's starting her junior year in high school, playing varsity soccer. We're moving on 3½ years with no seizures, so it's a very different

existence. It seems the surgery worked. As I say at the end of the book, even after seizure control is established, either through medicine or something more radical like surgery, you never really know. The brain continues to grow and change, growth spurts happen. But in this case, it's such a radical difference, going from thousands of seizures to zero.

From the first diagnosis, when she was 5 months old, you and your wife, Kristen, were forced down the rabbit hole of medical bureaucracy. What was the most frustrating?

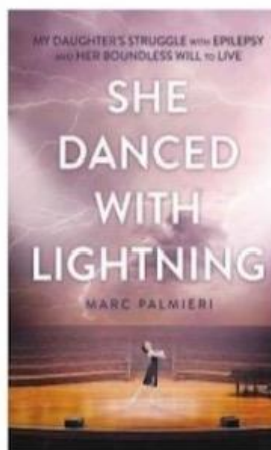
It was frustrating that each medicine at best would only work temporarily. The majority of epilepsy patients are able to control their seizures with one or two medications. But that other 25% . . . are not able to be controlled completely with medication. . . . Over the years, Anna was mostly on one drug at a time. We'd try one, it would work for a while, then seizures would pop through and we'd start another one. We were up to six or seven medications when things took a bad turn.

The decision to proceed with potentially lifesaving brain surgery had to be so terrifying.

We had never thought of surgery, she was living a mainstream life during the day. Night was very challenging, but by morning she was ready to go. Making the decision to go ahead with the surgery was the ultimate terror. . . . Anna's case was very difficult and challenging. That desperate few months really forced our hand. We



Marc Palmieri, who grew up in Melville, writes about his daughter's epilepsy in "She Danced With Lightning."



Many of your family arguments centered on Anna's love for dance and her insistence on performing in the recital. Do you still have regrets about not wanting her to perform — and of being overruled by your wife?

I'm gratified that I learned so much from that conflict. I'm happy that I lost, but it looked to me like an irrational choice. . . . I was trying to protect her. I just wanted her to survive the surgery and told her she'd have to wait until next year. She believed she might not be here next year. My wife sided with Anna and she danced. It was the one day in three months that she didn't have a seizure.

When 10-year-old Gregg LaPenna, who also had epilepsy, died during a Little League game in Lido Beach in April, you wrote in an essay that his parents were heroes. Do you feel heroic?

No, not at all, I feel very lucky and grateful. The LaPennas lived through the other side of the story. I hoped they could see that he was on the field, that they provided him the life he wanted and deserved. There are many heroes in everyone's life — in this story, the surgeons, our parents, Anna, of course. I never really dared to imagine this was something we could fix. And it got fixed.

WHAT Marc Palmieri will discuss his book "She Danced With Lightning"
WHEN | WHERE 2 p.m. Oct. 16, Barnes & Noble, 4000 Jericho Tpk., East Northport
INFO 631-462-0208, barnesandnoble.com

never thought we would get to that point; we did have hopes that it would go away. There are many cases where epilepsy is only in childhood. Things got so dire that the unthinkable choice was really not a choice at all.