

The Journey of One Woman's Heart

One mother's experience with epilepsy and how it shaped her family's life.

By Lisa Boylan, Managing Editor, *EpilepsyUSA*

Mary Lou Connelly begins each chapter of her book, *Missing Michael: A Mother's Story of Love, Epilepsy and Perseverance*, with a quote—a pearl of wisdom here, a shard of truth there—but the most compelling one, by Elizabeth Stone, accents the first chapter of the book and sets the tone for subsequent chapters: “Making the decision to have a child—it’s momentous. It is to decide forever to have your heart go walking around outside of your body.”

The metaphor effectively nails the pride, the fierce protectiveness and the helplessness inherent in parenthood. If having a child is exposing an integral part of yourself to the world, however, writing a book about that child—who has epilepsy—is a further leap into vulnerable terrain.

As she writes in her acknowledgements, “I have exposed a part of my family’s soul, the place where we live.” Clearly, it was a story that she needed to tell and the subject of the book, her son Michael, was her biggest champion in getting it done. She says, “He really started getting on me about it. He was pretty convinced he wanted this story to be told.”

Mary Lou’s son Michael was diagnosed with epilepsy when he was 5 years old. Over the years she kept a journal of her family’s struggles, accomplishments and setbacks and finally decided to write a book. As a nurse she had done a lot of professional health writing, she enjoyed the process and—most importantly—found it therapeutic.

The Connelly’s unintended journey with epilepsy began with a febrile seizure when Michael was 2 and led to a point where Michael was having 24 seizures before noon. The family—Mary Lou, husband Barry, Michael and big sister Meaghan—

navigated a labyrinthine course of medications (Phenobarbital, Keppra, Klonapen, Topamax), schools, recreational activities and basic life-coping skills in a quest to find the right balance for Michael and themselves.

Michael began experiencing the first stings of his peers’ rejection in third grade. His medication dulled his senses, making it difficult to respond to questions quickly. Mary Lou said, “He felt stupid. He wasn’t as alert because

of the medication. So, while his seizures were controlled in third grade, the side effects of the medication were troubling in terms of school work and coordination.” Boys who had been his best friends started picking him last for games. Mary Lou said he “became more isolated and he definitely recognized that he was no longer a part of the particular group that he had been a part of.”

Mary Lou observed her child—her heart—being mistreated on the often cruel topography of the playground. She says, “Of course you want everything to work out well for your children. You want them to feel that they belong, but there’s very little that you can do about it when that occurs except to make them feel secured and loved at home.”

Because of her experience in the health care field she knew only too well how vulnerable they were as a family. She says, “I think for parents who have children with a chronic illness it can either make you grow stronger and create a better union or it can, in many instances, be so stressful that it can dissolve families.” She continued, “For us, it’s just been something that brought us closer together.”

The Connelly’s met each challenge—and there were many—with a solution. Mary Lou recognized early on that they would need to set aside special time for themselves—as a family—so they started taking vacations when Michael was about 10. She says the vacations were “a sense of salvation of sorts—a chance to regroup and chill out and come back and face whatever had to be faced.”

There is no one-size-fits-all category when it comes to epilepsy treatment. Nor is there one prescriptive way for a family to cope with a child's epilepsy diagnosis.



Michael, at 2, wearing his grandfather's fire chief hat.



Michael, his father Barry, and Mary Lou on a summer trip off the coast of Maine.

The family rallied and supported one another, but they made a conscious effort to keep their struggle mostly to themselves. Because they lived in California, they felt the need to shield their family—3,000 miles away on the East Coast—and limited their discussion of Michael’s epilepsy from co-workers and friends.

In one of the more moving passages in the book, Mary Lou recounts a rare time when she did call on one of her parents for help. Michael was having breakthrough seizures and her parents were visiting for the holidays. She writes:

Early one morning, during my parents' stay, he had a tonic-clonic seizure. Barry had already left for work. My father was in the bathroom close to Michael's room. I called, "Daddy." He came in and saw Michael in the final stages. I am so very sorry even to his day that I called out to him. I vividly remember catching a glance of my sweet father's face reflected later in the bathroom mirror.

She says, "He was a fire chief; he was a very strong man. I think he just felt kind of powerless that he couldn't do anything to help and he was looking at his 10-year-old grandchild having a seizure and he couldn't do anything. I think my regret is that it caused him too much pain." She adds, "On the surface he seemed very calm and controlled and so I think it caused him pain, it hurt him in a way that I hadn't seen him hurt before. I still regret it."

Their decision to shield family and friends, she now reflects, was not healthy. She says, "We did hold a lot in when we probably should have shared and could have gotten more support from people when we were in a time of need. I think that the book, in a sense, has been pretty liberating for all of us because it just puts it out there." She adds, "Denial is definitely a coping mechanism, but it may not be the most healthy one."

The family continued to strategize, trying new medications and choosing different schools. Michael attended a small private school for 7th and 8th grades that they hoped would be a good fit because of the reduced student-to-teacher ratio. But Michael began having breakthrough seizures during the day that, once again, caused his peers to shun him. During his first week of school he was hospitalized.

The purpose of writing the book was to "help increase awareness about epilepsy and how it can impact lives." She says, "It was very liberating."

The most challenging times were in his junior and senior years of high school because, until then, he had never had a tonic-clonic seizure in a school setting. He was on the ketogenic diet and the family was optimistic that he was weaning himself off drugs and steadily becoming more alert—more like himself.

Then, starting in May of his junior year and continuing to December of his senior year, he had a full blown tonic-clonic seizure every 3 weeks—six of which occurred on campus. The paramedics came; he was hospitalized—the routine was exhausting for everyone. His neurologist recommended going back on a drug he had been on

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An exclusive excerpt from *Missing Michael: A Mother's Story of Love, Epilepsy and Perseverance* by Mary Lou Connolly

Stolen Slumber

Lying in the dark, listening to the silence, it's sometimes impossible to push the bad thoughts away. Day-to-day worries are replaced by anxiety that is caused by envisioning a series of unthinkable scenarios. In the stillness, I tense up, toss my body about, and shake my head trying to free myself from images of a seizure in the shower, a lengthy tonic-clonic seizure we do not hear at night, a fall down the stairs. Then...deep breaths as I try to imagine waves lapping onto the seashore, saying over and over to quiet my racing mind, "Be still, be still, be still."

I hear a rustling of sheets. What's going on? I should check. I walk down the hall and peek in Michael's room. He's still. I make my way back to bed next to Barry, trying not to disturb his sleep as I restlessly tuck in again. I chide myself of course. This is what I used to do when the kids were babies...tiptoe into their rooms to assure myself they were breathing. Later, I hear a groan. Was that a movement? This time I pick up my pace down the hall. Michael's breathing is heavy now. He's noisily snoring. He must have had a brief tonic seizure. Satisfied it's over, I retrace my steps and attempt to quietly re-enter my own bed.

As morning approaches, I hear a familiar and unwelcome sound that I liken to an old man crying out in agony. It must be 4:00 or 5:00 a.m. Barry joins me in the hallway run for these; the more lengthy and severe tonic

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seizures. Sometimes, they last a minute or two and sometimes longer. We can go back to our bed after the five to fifteen second tonic seizures now. We can even manage to close our eyes—sleep after them—most times. But the aftermath of the longer-lasting tonic seizures is a different story. First, there is the pure visceral fear of seeing your child's body writhing, eyes rolling back, lips turning blue. When will he take a breath? How long will this last? How long is TOO long? We watch...count...cradle him in our arms. Then there is the relief; it's over. But it's not really over. His body is exhausted, the mind spent. Sleep, baby, sleep. I will stay by you till your heart stops racing and you are peaceful in your post-seizure state.

How many seizures are too many in a night? What does this do to the brain? How will they impact Michael's function tomorrow, next week, next year? Will there ever be a treatment these seizures respond to? What if we don't hear a seizure? What if we're not here? What if they never become controlled? What if...

Oh, yes, nighttime...in addition to the chronic worry and anxiety, it's also the perfect environ for second guessing. Barry has said many times we shouldn't second guess our decisions. After all, they're over and done and we cannot reverse course. He does well with this mode of action. However, my nature as a "bogtrotter" (Barry's description of my pessimist side) will not allow me to peacefully accept our past choices. Thus, I lay there and fret over school choices, medication regimens, the timing of the diet, the surgery, the decision to take a year off after high school, and so on and on and on.

And, in the silence of the night, I grieve. I grieve Michael's losses: friendships and moments, days, weeks, even months of childhood and adolescence because he can't remember them. I grieve because he is not experiencing the joys of gaining independence—the ability to drive, to go away to college, to experience a first love. All that so far has been denied him, missed. Then, finally, on some nights, sleep comes—and the spirit is refreshed to awaken to the daytime world, whatever it may bring.

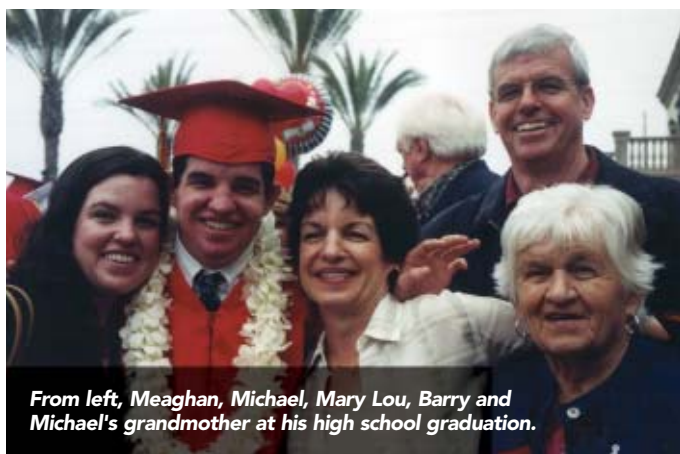
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previously and Mary Lou put her foot down, saying, “No, there just has to be something else, we can’t go backwards!” She began seriously investigating the Vagus Nerve Stimulator (VNS).

Michael had the VNS implanted in 2002 when he was a senior in high school. It took a little time to adjust the settings, but then he enjoyed a year-and-a-half seizure-free. There have been subsequent episodes where his seizures have not been under control but nothing, Mary Lou says, like it was prior to the implant. She states, “It’s made a real difference in terms of quality of life.”

Mary Lou explains that the purpose of writing the book was to “help increase awareness about epilepsy and how it can impact lives.” She says, “It was very liberating.”



From left, Meaghan, Michael, Mary Lou, Barry and Michael's grandmother at his high school graduation.

Mary Lou never expected to be an integral part of the epilepsy community; however she speaks with great admiration of her experience with the Epilepsy Foundation in San Diego, where she serves as a board member: “I have met some phenomenal individuals. Kathy West, the executive director, has an incredible ability to maximize this little epilepsy foundation office.” She adds, “Her enthusiasm and ability to raise funds has been something I am in awe of.” She adds, “I don’t know what kind of charitable foundation I may have become involved in if it weren’t for epilepsy, but I know that for me the experience of working with the foundation in a volunteer role has been very satisfying.”

She is also delighted with the reception her book has received, mainly because it has spoken to individuals who, she says, “were dealing with their situation and they felt isolated and now they know that they have a place to go—they have a support system that’s available—so that’s really gratifying.”

Michael graduated from high school in a ceremony that was emotional for the whole family. Mary Lou writes in her book:

The pictures afterward captured a handsome young man with an enormous grin and hugs for anyone close by, including a couple of very pretty graduates who singled him out and told him “I’ll miss you.” The camera captured a mosaic of relief, accomplishment, finality, and pride in all our faces.

After high school Michael took a year off because school had been a constant struggle for him in terms of medications, side effects, hospitalizations, slowed responses and the reactions of his peers. He’s now taking classes at a local community college. Mary Lou observes, “For the first time in his life he actually enjoys going to classes and is getting a lot of satisfaction from learning. She adds, “The combination of drugs and the Vagus Nerve Stimulator has really changed his life.”

Philosophically, Mary Lou notes that “All in all obviously if I could go backwards and change things, I would have Michael’s life not be complicated by having epilepsy.” However she says she has “a lot of hope that during Michael’s lifetime there is going to be a discovery of either a new medication or a new technology that will make his life even better.” She emphasizes, “I am really hopeful for the future.”

Order *Missing Michael: A Mother's Story of Love, Epilepsy, and Perseverance* by Mary Lou Connolly in the Marketplace at www.epilepsyfoundation.org

A mother's story that celebrates the bond of family and the power of love and hope. **\$13.99**



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