Danny's legacy raises epilepsy awareness

COMMENTARY | Father reflects on son's death from epilepsy; works to raise awareness of the disease

Comments

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BY MIKE STANTON

Eleven months ago, on a magnificently sunny and frigidly cold Chicago morning, I awoke to my terror-stricken wife screaming these words:

"Mike! Mike! Oh my God, Mike! He's blue! He's blue, Mike!!!! He's not breathing! Mike! Mike! Mike!"

Our 4-year-old son Danny was dead. Three months shy of his fifth birthday, Daniel George Stanton had died of a seizure while sleeping.

The Cook County Medical Examiner's office determined Danny's cause of death as "seizure disorder." I am looking at the death certificate now as I write these words, and -- believe me -- for a parent there is no greater disconnect from a rational comprehension of your life and its place in this world than the experience of reading on a piece of paper that your child is deceased.

We were fully aware that Danny had seizures while he slept (he had a total of five that we knew of, including the last one) and we were treating this condition by following the guidelines set forth by a pediatric neurologist. Since Danny was not otherwise sick and since the cause of his seizures was unknown, he was diagnosed with "childhood seizure disorder." A two-year treatment program of medication and occasional EEGs, the doctor told us. It sounded so simple.

What the doctor didn't tell us, though, is this: Your son can die from a seizure. The doctor also didn't mention Sudden Unexplained Death in Epilepsy, or SUDEP. For that matter, the doctor never even mentioned the word epilepsy. Looking back, this is mind-boggling -- and maddening.

Today, though, we are trying to look forward. And in the wake of October and of the extraordinary and warranted awareness that that month brings to the disease of breast cancer, does anyone know that November is National Epilepsy Awareness Month? Well, it is. And this should be a big deal. Why? Because three million people in the United States have epilepsy, that's one in every 100 Americans.

In the 11 months since Danny died, I've learned much about epilepsy. Simply put, epilepsy is a disorder of the nervous system characterized by either loss of attention or by convulsions, i.e., seizures. I've learned that "seizure disorder" and "epilepsy" are interchangeable descriptions of a single condition.

Epilepsy affects 50 million people globally. I've learned that 45,000 cases of epilepsy are diagnosed each year in children under 15 years of age in the United States. I've even learned that epilepsy is referred to in the Bible.

The kicker is that I've learned this staggering fact: close to 50,000 people die from epilepsy-related causes -- including SUDEP -- each year in the United States. That's more than are lost annually to breast cancer.

The issue of aggressively advancing awareness among the general public regarding the existence and the effects of epilepsy is as critical as it is urgent, as it is logical. So much about this age-old and often mysterious condition with roots deep inside the brain still is extremely elusive. But lack of specific knowledge should not result in lack of general awareness.

The last line of Danny's obituary reads: Please go and enjoy your life. Danny Did. Those are words to live by.

And help raise awareness and research dollars for finding a cure for epilepsy. After all, it's November, National Epilepsy Awareness Month.

Mike and Mariann Stanton reside in Edgebrook with their three children. They established the Danny Did Foundation, (www.dannydid.org.) *to advance awareness of epilepsy.*

Dealing With Epilepsy
From Healthy Lifestyle Blogzine

Feline Epilepsy
From For Your Cat - Cat Health Care Blog

The views expressed in these blog posts are those of the author and not of the Chicago Sun-Times.

curley wrote:

Danny Did backs backs up their talk with action. They have provided Emfit seizure monitoring devices to several families who couldn't otherwise afford one. They are saving lives! Support them now and you can too.

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scott v wrote:

Help support the Danny Did Foundation and November's campaign to help raise awareness of Epilepsy and SUDEP....follow the link below to contribute today:http://www.events.org/november/cpage.aspx?e=31489

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