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Grieving parents work to save other kids

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BY SUE ONTIVEROS Sun-Times Columnist

Maybe you remember hearing about Danny Stanton.

It was right before Christmas. A sweet, smiling 4-year-old boy died during the night of Dec. 12. Seizure disorder, the stories said.

In the obituary staff writer Maureen O'Donnell wrote for the Sun-Times, she described his love of sports and zest for life. An affectionate little guy who would climb up into Daddy's lap and tuck his arms in so he could be hugged.

If after that unspeakable loss Danny's parents, Mike and Mariann Stanton, decided to hole up in their Edgebrook home with their three surviving children, Mary Grace, John and Tommy, who could blame them? But they haven't, even though their grief is obvious.

Instead, with the help of family and friends, they have started a foundation, Danny Did, www.danny.did.org.

Now you might be asking yourself, aren't there already organizations that deal with Danny's problem? Are there really things not being done to help those who have a seizure disorder and in the case of children, their parents?

Oh brother, are there.

For one thing, no one ever said to the couple: Your child might die from this.

"Doctors don't want to alarm you," Mariann Stanton said in an interview last week.

How the Stantons wish someone had alarmed them.

Sure, they knew the seizures, which occurred only while he slept, were serious. (Many parents of epileptics have since told them they thought sleep time was the one time their child was safe from seizures.) As a precaution after Danny's first seizure at age 2, his parents had him sleep in their bed for six months.

Since starting the foundation, they have met with top doctors in Chicago who specialize in epilepsy and seizure disorders. One told them that he alerts parents during the second visit of the possibility of death.

"My heart started racing, because there might not be a second visit," Mariann said.

So, part of their mission is to let others know about Sudden Unexplained Death in Epilepsy, which is the professional term for what happened to Danny. This takes the lives of 50,000 people a year in the United States. And yes, a seizure can occur while a person is sleeping.

If you know a person is having a seizure, there are steps you can take, so the Stantons set out to find a device that alerts parents or caregivers to a seizure.

Sadly, not long after Danny's death, they found one that's made in Finland, the Emfit Movement Monitor. The thin device, tucked between the mattress and box spring, sounds an alarm when a seizure occurs. The Stantons brought the Emfit to the attention of doctors here. Two local hospitals are awaiting shipments to put the monitors through their own tests.

Here's what the Stantons would like to see happen when a family finds out their child has a seizure disorder:

In that very first doctor visit, they would be told of all the possibilities, including Sudden Unexplained Death in Epilepsy, and they would walk out with an alerting monitor, possibly the Emfit. This is similar to parents of children with allergies getting EpiPens and those whose baby is in danger of Sudden Infant Death Syndrome getting heart-rate monitors.

Some day, the Stantons say, they'd like to see seizure monitors in day care centers, schools, any place kids nap. And why not? At one time defibrillators were rare, but now they're everywhere. And why? Because they save lives.

Heavy though their hearts may be, the Stantons aren't stopping at Chicago. Once they get the word out here, they say, it's on to other

Midwest cities and beyond.

"Danny's going to have an impact long past his last breath," Mike said. "It's hard to say, but it's true."

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