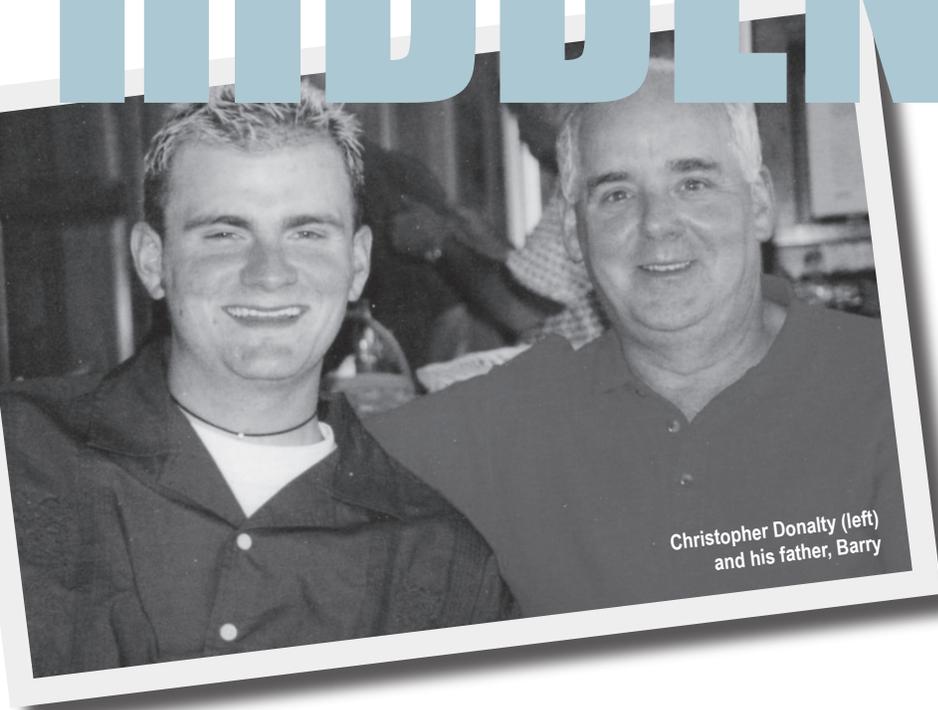


EPILEPSY'S HIDDEN TOLL



Christopher Donalty (left)
and his father, Barry

By Morgan Murphy

Communications Coordinator

On February 21, 2002, Christopher Donalty wasn't feeling well. The Stetson University senior decided to take his books and go study at his girlfriend's apartment. She was not due back for several hours, so Christopher would have some time alone.

When his girlfriend came home, she walked in to find Christopher, eyes closed, still surrounded by his textbooks. At first she thought he had fallen asleep. Then she realized he wasn't breathing.

She tried to revive him, and then called 911. But it was too late: Christopher Donalty was dead.

Sudden Unexplained Death in Epilepsy (SUDEP) was determined to be the cause of Christopher's death. The 21-year-old had been diagnosed with epilepsy nearly four years earlier, yet when his mother was told the cause of his death, she was taken aback. She had never even *heard* of SUDEP.

"I don't know why it happened," Jeanne Donalty, his mother, explains. "I do know that Christopher didn't want to die."

When Christopher was in fourth grade, Jeanne rushed to his school after receiving a call that Christopher had "an episode" in the cafeteria and that an ambulance was on its way. At the hospital, tests were done, and everything came back normal. It was be-

lieved that Christopher had fainted.

Four years later, on Christopher's first day of eighth grade, the same thing happened, and again, the doctors "couldn't find anything."

The summer before his senior year in high school, Christopher was working on the playground and another ambulance had to be called. This time, however, after the tests were completed, Christopher was referred to a neurologist and an MRI was performed.

"The doctor looked at Christopher and said, 'You're strong, you can take what I have to tell you,'" Jeanne remembers.

The doctor told Christopher that he had epilepsy, but he stressed that he would be able to live a full and normal life.

"As a parent, that's what you want to hear," Jeanne says, "and we thought it could have been worse."

Christopher was put on medication and continued to live his life. He wasn't happy with adjustments that had to be made—he couldn't drive anymore, plus, he began having upset stomachs, a side effect of the medication—but that wasn't going to deter him from graduating from high school and going to college in Florida, where he could play baseball.

In November of his freshman year, Christopher called his parents to tell them that he'd had a seizure. Then, that summer, Christopher had two more sei-

zures—this time, at home. The second one was just a couple days before he started his sophomore year and his doctor decided to change his medication.

"He went back to school, but had a terrible first semester," Jeanne says. "He had problems with the meds, and then he hurt his pitching arm. He was so depressed, but he just wanted to stick it out."

His medication was adjusted one more time, and although he had felt depressed, he wanted to start his junior year. Christopher was back in school, and it seemed like the medication was working. In December of Christopher's senior year, he came home for Christmas. Jeanne remembers how much happier he had become. They talked about the fact that he had been seizure free for two years, and he was excited to go back to Florida to celebrate New Year's Eve. It wasn't until after he died nearly three months later, that his parents learned that Christopher had been having seizures regularly.

"We never thought this could have happened," Jeanne says. "We didn't know that you could die from epilepsy. Our 21-year-old son was ripped away from us and the 'what if' feeling is something no parent should have to go through."

Jeanne feels that they should have been told about SUDEP when Christopher was diagnosed; the message he and his family heard was that "you can have a normal life with epilepsy." Death was not something they were told to take into consideration; SUDEP was never discussed.

"For a long time, we did not realize that seizure can cause severe injury and death not only through trauma and drowning," notes Dr. Stephan Schuele, director of the Comprehensive Epilepsy Center at Northwestern Memorial Hospital, "but also seemingly unexplained. It is estimated that every one in one thousand adults with epilepsy dies from SUDEP."

Research shows that SUDEP is most common while an individual is sleeping and is alone, has uncontrolled generalized tonic clonic seizures, is on more than one anti-epileptic drug, and is an adult male. The cause of SUDEP is not exactly known, however, possible factors have been determined. According to Schuele, SUDEP can most commonly be attributed to three "mechanisms" that can occur while a person is having a seizure:

- Central Apnea - breathing stops and does not

resume once the seizure is over.

- Cardiac Arrhythmia - the heart stops beating or beats irregularly, resulting in diminished blood flow to the brain.

- Neurologic Pulmonary Edema – fluid flushes the lungs because of a sudden surge in the autonomic nervous system during a seizure, making it impossible to breathe.

It is difficult to treat these causes directly, therefore, Schuele believes that optimized seizure control and general measures are currently the best way to lessen the risk of SUDEP occurring.

“Patient and physician should strive for complete control of their seizures,” Schuele says. “In about two-thirds of patients, medicine can keep you seizure free. No seizures means no SUDEP. A person has to be willing and able to realize that in order to get the best treatment and to stay on the medication, day by day.”

In Christopher’s case, Jeanne says she doesn’t know why Christopher didn’t want his family to know he was having seizures.

“I try to put myself in his mind. Maybe he tried to rationalize why something like this couldn’t happen. At that age, you don’t think anything can happen to you.” However, she believes that if he knew the risks of SUDEP, things would be different today.

“I do know with complete certainty that Christopher would not have gone somewhere by himself if he knew that he was putting himself at risk by being alone.”

After Christopher’s death, Jeanne began her own research and quickly learned that her son’s doctor is not the only one that doesn’t inform their patients about the risk of SUDEP.

“I found that doctors are uncomfortable with telling their patients about SUDEP,” Jeanne says. “They don’t know how to tell someone there is a chance they could die when there is little that can be done to prevent it from happening.”

Schuele recognizes that many doctors “do not want to be the messenger of a bad message if there is nothing directly to be done. It is easier to warn the

patient of a risk they can avoid, e.g. not to swim alone or drive while still having seizures.” However, Schuele also believes that addressing all of the facts and the routes a person can take in order to reduce their risk of death, is a significant factor in the care of a patient.

“You don’t want to make someone’s fears worse. However, having uncontrolled seizures can have huge consequences,” Schuele says. “If a person can realize the importance of complete control of their seizures, then they are motivated to get the best treatment. Having two or three seizures a year is not good enough—not for driving and also not for preventing SUDEP.”

Today, Jeanne works to raise funding for epilepsy research through the non-profit organization Citizens United for Research in Epilepsy (CURE), and is an active advocate for increasing awareness about SUDEP. She shares her family’s experience in order to educate the public and is fighting for a U.S. policy that would require doctor’s to tell their patients about SUDEP.

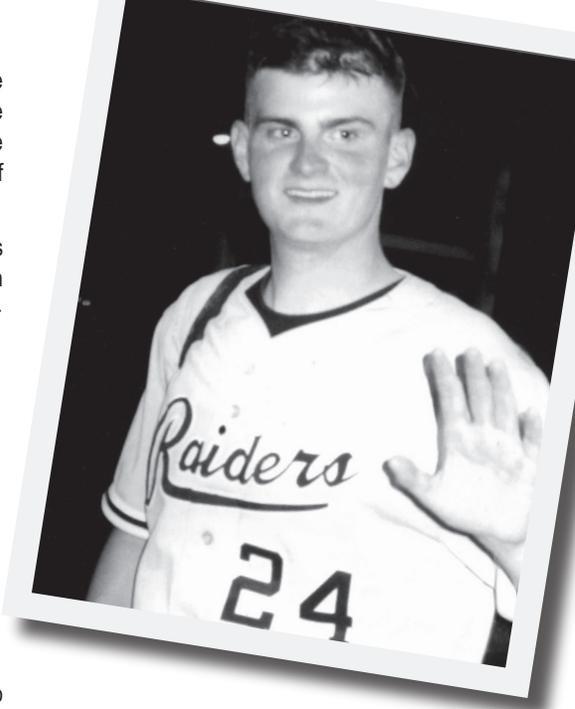
“Knowledge is power,” Jeanne says. “I understand that no doctor wants their patient to die and it’s difficult to address, but to know shouldn’t be looked at as something bad.”

The interest and amount of research dedicated toward SUDEP has greatly increased over the last twenty years,

“There is a higher sense of awareness amongst neurologists and epileptologists and there is a much more open debate about discussing SUDEP with patients,” Schuele notes. “However there still is a lot of research to be done and more support is needed from other members of the medical community.”

For Schuele, the experience of losing a patient to SUDEP was enough to make him change the ways he approached many of these issues.

“After seeing a patient only once, two days before her follow-up visit she was found dead,” Schuele recalls. “It was SUDEP. And you have to think ‘what could have happened if I had been able to see her one more time?’ You don’t forget that. I do many things differently now.”



Today, Schuele is very involved in its research and considers himself much more outspoken about SUDEP and proactive with his patients and colleagues.

He is not fearful of informing his patients about SUDEP, especially the ones who are most at risk. In fact, he’s discovered that their reactions are relatively positive: they are receptive and want to learn more.

“It is one way to acknowledge and share concerns my patients already have and not to leave them alone with it,” Schuele says. “Particularly patients who have experienced generalized convulsive seizures already have a sense that they could die from epilepsy. And they are the ones at highest risk for SUDEP.”

Jeanne will continue to fight for increased awareness about SUDEP. She doesn’t want other families to have to experience what their family has gone through and believes any parent who has been in her shoes would do the same.

“I could not let Christopher’s death be the end of his story,” she says. “He is our son and we lost him. The burden of thinking ‘if I had only known,’ is so cruel. We are fighting for him.”

In Brief: SUDEP

CAUSES:

Current research indicates that changes to breathing and heartbeat during seizures are the most likely causes of SUDEP. For example, sometimes people stop breathing during a tonic-clonic seizure. Usually the breathing returns as the seizure ends, but it seems that in some cases this natural recovery may not happen.

Alternatively, during a seizure, part of the brain which controls the heartbeat may be affected. It is

possible that this could cause an abnormal heart rhythm to develop and in some cases this could possibly cause the heart to stop beating.

RISK FACTORS:

Research to date has not managed to identify the exact cause of SUDEP. What has come to light is that there are certain common factors that link many of the cases. These include:

- Forgetting to take some dosages or not taking the medication at all.
- Taking more than one type of anti-epileptic drug.
- Having frequent changes of AED dosage .

- Having poor seizure control .
- Having seizures during sleep.
- Being alone at the time of the seizure.
- Experiencing tonic-clonic seizures.
- Having brain damage.
- Being a young adult, particularly male.

When considering the risk factors, remember that just because some or more of these may apply it does not mean that someone will die from SUDEP. It is clear that further research into SUDEP is needed.

(Source: Epilepsy Action, epilepsy.org.uk)