

Chicago Boy Lost to Epilepsy Still Making An Impact

Advocacy: Danny Stanton's parents didn't know about the risk of Sudden Death in Epilepsy. Now they educate others.

December 12, 2009 was a cold, clear Saturday in Chicago. As the Stanton home lay quiet that morning, 4 year-old Danny – the third of four siblings - was suddenly lifeless in his bottom bunk bed.

A flurry to rescue him ensued. Danny's dad rushed into the room and attempted CPR. The family's neighbor – a Chicago Fireman who was called – did the same. Soon paramedics arrived and tried to revive Danny in route to the hospital. Despite all efforts, the vivacious boy was gone.

Danny's type of death, a case of Sudden Unexpected Death in Epilepsy -- or SUDEP -- is described by the National Institutes of Health as the most common form of epilepsy-related death. Danny's parents had never learned about the risk of SUDEP from his doctor in the two years Danny was treated for a childhood seizure disorder.

"A parent's role is to ensure the safety of their child," said Mike Stanton, Danny's dad. "We didn't know the full range of risks that Danny's epilepsy presented. We faced a serious blind spot."



Danny Stanton (second from left) died following a seizure in 2009. The foundation started in his name has helped families in all 50 states.

Giving Other Parents A Chance

In 2010, Danny's parents founded the Danny Did Foundation. The name originates from the last sentence of Danny's obituary, written by his dad, which read: "Please go and enjoy your life. Danny did."

The foundation's mission is to prevent deaths caused by seizures, and a central goal is to enhance communication between doctors and caregivers about the risk of SUDEP. The Stanton's foundation also shares information about monitoring devices that enable early intervention when seizures occur. Danny Did has provided grants to families across all 50 states and eight countries to allow them to purchase monitors.

"We see the foundation as an extension of Danny's place in the world," Mike says. "He continues to help others and spread happiness, like he would if he were here today."