“I just want to learn.”

— Danny Stanton on his first day of preschool
“I am always doing that which I cannot do, in order that I may learn how to do it.”

— Pablo Picasso
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Meet Daniel George Stanton

Danny Stanton was born on March 2, 2005. Danny Stanton died on December 12, 2009.

A wonderfully normal two years of growth and development followed his birth as Danny joined his sister Mary Grace and his brother Johnny and took his place as kid number three in the Stanton family. He was, as his grandma Murtaugh dubbed him, the “little toughie” of the family. The kid was a scrapper who held his own as he established his place within his family and, although the youngest child, Danny’s levels of affection, compassion, intelligence, and athleticism evened the score on all fronts as he experienced the day-in and day-out of life’s situations. Even at two years of age, he had established himself somehow, and in many ways—as an equal not only in terms of experiencing life, but also as one who brought experience to the lives of everyone in his family. Danny was, though, soon enough no longer the youngest Stanton as his brother Tommy came along when Danny was two.

It was at age two when Danny had his first seizure. His eyes rolled back and he shook. We did not know what was happening. We dialed 911 then rushed him to our next-door neighbor, who is a paramedic. Danny seized for almost 10 minutes. On that night, we had a battery of tests done at Children’s Memorial Hospital in Chicago. There was no known reason or cause found for Danny’s seizure. No injury, no trigger. We were told that sometimes seizures in children have no known cause and that kids often outgrow them. The experience was terrifying.

We left the hospital that night sans any written information about seizures or seizure disorders, sans any mention of epilepsy or epilepsy organizations, and sans anything short of the feeling that we had fallen into a hole that had no bottom. Sudden Unexpected Death in Epilepsy, of course, crossed no lips and fell upon no ears. And of course, as well, this made sense to those who made sense of such matters as we—as adults and as parents—were not prepared, in others’ estimations, nor entitled to such privy information. It was just too early. Too early for prevention? Danny began sleeping in bed with us after that first seizure.

Danny had a second seizure while sleeping just over a month later. After this second seizure, he had an MRI. Again, no underlying cause was found for his seizures. Danny was then put on a variety of medicines to control the seizures, and regular electroencephalograms (EEGs) were scheduled and
performed. At this time his neurologist determined that Danny had childhood seizure disorder. Still no mention of epilepsy, still no suggestion of outreach to epilepsy organizations, and still, of course, no mention of Sudden Unexpected Death in Epilepsy. What we were told was this: he’ll outgrow it, many kids experience this, we don’t know why it happens, maybe it’s “his normal.” How might life be different had a sophisticated and tough-minded doctor sat us down and said “let me tell you something that will shock you but that I am mandated both by my profession and by my personal sense of duty to inform you of . . . your son is epileptic, and along with this diagnosis comes a plethora of safety issues that you need to become aware of . . .”

Danny’s day-in and day-out behavior was completely normal. He continued to be athletic, inquisitive, engaging, social, and, more than anything, affectionate. Vacations to the water park, trips to Target, outings to baseball games . . . he was a part of it all. As we continued meeting with Danny’s neurologist for regular check-ups, we became more and more comfortable with the idea that we were doing all we could for Danny and that we were on a clear and well-defined path. We were told that a slightly abnormal EEG might just be Danny’s ‘normal.’

After sleeping with us for a half a year, Danny began to return to his own bed. On hundreds of occasions we left our bed to check on him, and we frequently just brought him back to bed with us. We caught him twice more having a seizure in his sleep. We informed our doctors of every event.

We continued to trust and to believe that we were doing all that we could. We continued, as well, to roll as a six-some through the city of Chicago in our blue minivan, in our strollers and buggies, and on foot. Downtown, the parks, the beach, baseball games, the pool, pizza parties with the neighbors, school plays, kickball in the front yard, catch in the alley, hoops at the Y, around the block on scooters and bikes and Big Wheels, walks to Happy Foods for doughnuts . . . the package was complete. Birthdays, holidays, block parties . . . each month brought more punch to us as a family, and each day brought hugs from Danny: he’d tuck his arms into his own chest and then wait for you to surround his body with yours. He’d then nestle his head under your chin, take a deep breath, and let his exhale say that he had found the spot. It was Danny’s hug that inspired the DDF logo.

After a year of no known seizures, Danny returned again to his own bed. And then as he turned four (and started pre school) and had gone without a known seizure for 18 months, we thought that our course of action had been successful and that his neurologist was right: Danny would, through medicine and time, outgrow his ‘seizure disorder.’ We were optimistic and giddy. It was like a rebirth for us and for Danny.

On Tuesday, December 8, 2009, we took Danny for a scheduled appointment with his neurologist.
That day, Danny had a one-hour EEG done while sleeping. We met with his doctor after the EEG and went over the results. There was still abnormal activity showing up, but maybe a lesser amount than the previous EEG showed? Maybe, we were told. A little progress, we were told. The medicine was working, we were told. We increased Danny’s dosage that day to accommodate a slight weight gain since his last visit. How we looked at each other and at Daniel as we left the hospital that day. And how Danny looked back at us: cool as a cucumber, as usual, and ready to get some lunch and back to playing with Tommy.

Four days later, on December 12, 2009, we found Danny’s lifeless body in his bed at 7:15 AM.

How many seizures did Danny have that we did not catch? We will never know. We wonder what Danny knew. We wonder what our little, middle boy knew. One thing we do know are the last words to ever fall upon that little toughie’s ears. They are the words whispered by his mom to Danny each and every night as she put him to bed: “I love you, sweet boy.” These words were always followed by three kisses: one to the forehead, one to the nose, and one to the lips. I love you, sweet boy.

And now life continues – in many respects – albeit without the soft bounce of one little boy’s feet upon the dirt of the Earth, and the family that was is now the family that is. Our Danny boy has entered a new phase, part of which is in the form of his organization, the Danny Did Foundation, which derives from the last line of Danny’s obituary: Please go and enjoy your life. Danny did.

Turns out that the last line of Danny’s obituary caught the attention of many people, including a writer from the Associated Press, who wrote in an article:

“The disarming smile of a 4-year-old boy with a buzz cut brightens an otherwise drab newspaper page, where whole lives are summed up in three inches of tiny newsprint. Danny Stanton’s death notice first makes you wonder how he died. But the eight haunting, final words make you want to know how he lived: ‘Please go and enjoy your life. Danny did.’”

Danny Did enjoy his life. Danny Did engage others in his life. Danny Did take his time in life. Please Go And Enjoy Your Life. Danny Did.
Letter from the Co-Founders

Imperfectly, our son Danny had epilepsy. Tragically, our son Danny died from epilepsy. Specifically, Danny died from Sudden Unexpected Death in Epilepsy, also known as SUDEP. Graphically, Mariann found Danny dead in his bed one cold December morning two weeks before Christmas in 2009. Horrifically, I tried to resuscitate Danny that morning in front of his sister Mary Grace and his two brothers, Johnny and Tommy. Distressingly, we believed that we had been doing everything possible to care for Danny.

Through two years of treatment by medical professionals, we were never informed that Danny had epilepsy, and even though Danny suffered from seizures we were never informed that Danny could die from one of his seizures. We were never told about SUDEP. We were never given information about organizations that could educate and support us as we swirled through Danny’s seizure episodes.

And so when Danny died, we knew that he and that we had been robbed of the opportunities of a lifetime. An actual lifetime. And we were furious. And we asked each other in our bedroom on that morning in December – after we had returned home from the hospital where Danny’s body had grown cold atop of ours as we laid with him - we asked ourselves, “how could this happen?”

Part of our answer to that question has been the formation of the Danny Did Foundation, which we are nurturing and developing as if it were part of Danny himself, and together with so many other individuals and organizations, we are changing the perception of epilepsy and the outlook for those afflicted by epilepsy.

And so as one year closes and another begins, we look forward to new partnerships and to new alliances as we continue our work to enable access to seizure monitoring and detecting devices for families who cannot afford them, and to advance awareness of epilepsy and the risks that accompany it, including Sudden Unexpected Death in Epilepsy. Thank you for your participation and for helping to prevent another death caused by a seizure.

Mariann and Mike Stanton
Letter from the Executive Director

There are a lot of ways that a person can leave a legacy: the impact that you’ve had on your family, your friends; your business; the sum of good that you have done. Danny Stanton continues to grow his legacy through the families helped by the Danny Did Foundation. In 2014 he added one more piece to the way he is remembered: a new law aimed at collecting data on Sudden Unexpected Death in Epilepsy (SUDEP).

In January 2014, months of effort culminated when the “Danny Stanton SUDEP Act” became Illinois law, mandating that coroners and medical examiners in Illinois must report cases of SUDEP to a national registry. This law was sponsored by Danny Did Foundation board member Senator Dan Kotowski and is only the second of its kind in the United States. Recording every SUDEP case is critical for understanding the scope of its impact, and essential to securing funding for research into why and how it happens.

While this legislation immortalizes Danny in the law books, of course it doesn’t do what we would like best: to bring him back. In March 2015, Danny would have celebrated his 10th birthday. He would have entered the fourth grade, a safe and nurturing place where his curiosity, talents and friendships would have grown with the passing of another school year. Epilepsy impacts 1 in 26 Americans, and is second only to stroke among neurological disorders in Years of Potential Life Lost (YPLL). Every family who has lost a loved one to epilepsy knows how painful those lost years can be.

This year, Caroline McAteer, a person living with epilepsy, continues to serve as President of our Board of Directors. Caroline leads as a strong and active advocate in sharing her story and advancing our cause. We’ve also continued a partnership with the Young Irish Fellowship of Club of Chicago, through which we’ll raise more funds and awareness. During November National Epilepsy Awareness Month, Danny Did was a co-host of the 3rd Annual Epilepsy Awareness Day at Disneyland Resort. We welcomed more than 1,500 attendees, all wearing purple to raise awareness of epilepsy at one of the world’s most iconic venues.

To date, our supporters have enabled us to provide financial assistance to families spanning 48 states, Canada, Luxembourg, Brazil, South Africa, Kenya and the Philippines. Your generosity enables us to reach and grow, along with the legacy of a little boy who started it. - Tom Stanton
Danny Did Foundation Mission Statement and Purpose

Founded by Chicagoans Mike and Mariann Stanton in January 2010 after the sudden death of their four-year-old son Danny, the Danny Did Foundation’s primary mission is to prevent deaths caused by seizures. The Foundation advances public awareness of epilepsy and Sudden Unexpected Death in Epilepsy (SUDEP), strives to improve communication about SUDEP between medical professionals and families impacted by seizures, and advocates for the mainstream acceptance and use of seizure detection and prediction devices that may assist in preventing seizure-related deaths.

Epilepsy impacts 65 million people worldwide, and nearly three million people in the United States alone. One in 26 Americans will develop epilepsy over their lifetime. But what few people understand, including many people impacted by the disorder, is that seizures can be fatal. Amazingly, more people die as a result of seizures than from fires and sudden infant death syndrome (SIDS) combined. The causes of death can vary and include drowning, other accidents and status epilepticus (prolonged seizures). In addition, thousands of deaths occur annually from SUDEP, a fact that is little known and too rarely addressed in public and in medical circles.

It is DDF’s urgent priority to change the conversation about SUDEP. We have a two-pronged strategy to accomplish our goal. First, DDF engages physicians and in the fields of neurology and epileptology and asks them talk and write about SUDEP. We help to educate doctors about how to approach this difficult topic with their patients and families, and we create educational materials about SUDEP for physicians to share at clinic visits. We also partner with other epilepsy organizations to raise awareness of SUDEP and the need for better education on the risks faced by people with epilepsy.

Our second strategy is to collaborate with medical technology companies and researchers who are working on the latest in scientific understanding of SUDEP and how to prevent it. We pursue the latest seizure detection and seizure prediction technologies, and once identified as viable and worthwhile instruments, we advocate for these products to be approved by the United States Food and Drug Administration and then covered by insurance companies. We view these devices as complementary to the vast array of medical, surgical and dietary measures currently used to treat seizures. But we also view them as equally important to those traditional treatments, because researchers have shown that seizure monitoring, especially at night, seems to notably lower the incidence of SUDEP. To that end, DDF also helps patients and their families purchase such devices if they are unable to afford them.

Danny Did Foundation believes that SUDEP deserves the attention of all of the globe’s inhabitants, from grammar school students to internationally recognized epilepsy experts. We believe that one life lost to SUDEP is one too many, and we strive to make living with epilepsy safer and happier for the millions of people who struggle with this disease every day.

Danny Did is a non-profit corporation organized in Illinois and recognized by the IRS as a 501(c)(3) tax-exempt organization. Learn more at www.dannydid.org, www.facebook.com/DannyDid and www.twitter.com/dannydidorg. Please go and enjoy your life. Danny Did®
SUDEP: Sudden Unexpected Death in Epilepsy

An important component of safety in epilepsy is the knowledge seizures can sometimes be fatal. One way a person can die due to a seizure is Sudden Unexpected Death in Epilepsy, or SUDEP. SUDEP is one of the least talked about aspects of epilepsy, yet because of its tragic consequences, it is the one aspect of epilepsy about which people have the most questions. Remember, good seizure control and the use of safety measures can reduce the risk of seizure-related death.

**Q: Can people die from epilepsy?**

A: Yes. Most people with epilepsy live a full life span. However, there are potential factors associated with living with epilepsy and seizures that may increase the risk of early death:

- Accidents such as drowning, burning, choking, or falling can occur during a seizure, and may result in injuries that are serious or life threatening.
- Very long seizures, or seizures that happen quickly and one after another (called status epilepticus), can be life-threatening. Ask your doctor about the scenarios under which status epilepticus could occur.
- People with epilepsy are more prone to experience depression and anxiety. In extreme cases, this can increase the risk for suicide.
- Some people with epilepsy may die suddenly and without explanation. This is SUDEP. The precise cause or causes behind SUDEP are not currently known, although research is underway that attempts to define or better understand them.

**Q: What is SUDEP?**

A: A death is referred to as SUDEP when a seemingly healthy person with epilepsy dies unexpectedly and no clear reason for the death can be determined. In most cases, an autopsy is required to rule out other causes of death. The most common criteria used to determine whether a death is due to SUDEP are:

- The person has epilepsy, which is defined as recurrent unprovoked seizures.
- The person died unexpectedly while in a reasonable state of health.
- The death occurred suddenly and during normal activity (often during sleep).
- An obvious medical cause of death could not be determined at autopsy.
- The death was not the direct result of status epilepticus.

**Q: How often does SUDEP occur?**

A: The incidence of SUDEP differs greatly depending upon the population studied. One challenge in pinpointing the numbers behind SUDEP is that information from county and state mortality registries is sometimes incomplete. Some physicians are unfamiliar with SUDEP, and do not list SUDEP on a death certificate. While the statistics on SUDEP are fluid, the fact that SUDEP exists is constant. Persons with absence or myoclonic seizures are not known to have increased risk for SUDEP, while the risk of sudden death increases among people with convulsive seizures. Talk with your neurologist or epileptologist and gauge the risks factors as they relate to you or your loved one.
Q: What causes SUDEP?
A: At this time, it is not known exactly what causes SUDEP. Most theories about SUDEP focus on breathing (respiration), heart rhythms and brain function, or some combination of those three factors. What role seizures play in SUDEP is currently being studied.

Q: What are the risk factors for SUDEP?
A: SUDEP can happen to anyone with epilepsy. Some people are at higher risk than others, and you should discuss your individual risks with your doctor. Risk factors that are most consistently associated with SUDEP are:
- Seizures that can’t be controlled
- A higher number of anticonvulsant medications, at high doses
- Long-standing chronic epilepsy
- Generalized tonic-clonic (grand mal) seizures
- Seizures that happen during sleep
- Not taking anticonvulsant medicine as prescribed
- Stopping the use of anticonvulsant medicine abruptly
- Developmental delays
- Onset of epilepsy at a young age

Q: What can I do to reduce the risk of SUDEP?
A: The full understanding of SUDEP is still unfolding, but there are measures that people with epilepsy and their families can take in effort to minimize their risk:
- Patients People with epilepsy should make sure to take the medications as prescribed for them to maximize seizure control.
- If medicines are not effective, research and consider alternative therapies such as surgical options, dietary options, or devices/technologies that may help to enable early intervention when seizure activity occurs.
- Consider supervision during sleep hours to monitor for nocturnal seizure activity.
- Lead a healthy lifestyle and keep stress to a minimum whenever possible. Patients should visit with their doctor regularly, especially if convulsive seizures are not completely controlled.
- Ensure that family members and caretakers have knowledge of seizure first aid and of emergency resuscitation measures including CPR and defibrillator use.

Q: What should I know about seizure detection devices and resources?
A: A variety of options exist, from sleep monitors to seizure dogs to seizure-alerting wristwatches. Many of these options undergo clinical trials testing to provide data on their efficacy. Some of them are listed at our website: www.dannydid.org. Danny Did does not recommend any one device, but simply that you investigate your options and see which one could be a fit for you and your loved one. Please note that to date, no commercially available seizure detection/monitoring devices have been proven to predict or prevent SUDEP. If you find a device that seems like a fit for your needs, ask the manufacturer if they can provide data that supports its usefulness, and consult your doctor for their feedback.
Q: How do I talk with my doctor about SUDEP?
A: If your doctor has not spoken with you about the health risks associated with epilepsy, including SUDEP, schedule an appointment to meet with them. Remember, no one can or will advocate for your loved one better than you.

More research and studies are needed to answer the many questions that remain about SUDEP. The topics listed above address some of the basic and frequently asked questions related to SUDEP. For information related to your individual situation, consult with your doctor. Education and advice from a medical professional that knows your specific case background is the best source.

We will lead this fight until the fight is finished, and we are leading the fight with this mantra in mind: Example is not the main thing influencing those around you, it is the only thing.

Please Go And Enjoy Your Life. Danny Did.
Tom Stanton, Executive Director

As Danny’s uncle, Tom knows just what Danny Did, day in and day out, and is eager to spread the word about the way that Danny lived his life and to work with the Danny Did Foundation to help individuals and families who are facing a similar scenario.

Tom has more than 10 years of experience working with non-profits in various capacities, from volunteer work and mentoring, to public relations, events management and sitting on boards of directors. Tom has spent his career primarily working in the communications field, including several years as a spokesman for former Cook County State’s Attorney Dick Devine. He has earned excellent standing among Chicago and national media outlets through his work as a media relations professional for various private and public sector organizations. He has also served as a spokesperson during the winning political campaigns of several elected public officials, including Cook County Sheriff Tom Dart and former Congressman Rahm Emanuel. He began his career as staff writer for a national magazine.

His pursuits outside the workplace are rooted in community service and volunteerism, centered on 15 years spent as a youth sports coach and mentor. He is a board member for Special Children’s Charities, the fundraising arm of Special Olympics Chicago, a 42-year-old organization that serves the needs of more than 5,000 special needs athletes. He has also volunteered as a mentor through the Uhlich Academy on Chicago’s North side.

Tom holds a journalism degree from the University of Dayton, and a master’s degree in Public Policy from DePaul University.

Tom is thankful to have the chance to keep Danny’s spirit alive through service to the Danny Did Foundation.
Danny Did Foundation Staff

Mary Duffy, Assistant Executive Director

Mary earned her Bachelor's of Science at Northern Illinois University and her Master's in Human Resources and Industrial Relations at Loyola University in Chicago. Mary has 15 years of experience in Human Resources for large, international companies and was most recently employed at Pearson VUE, a leading provider of computer-based testing solutions.

Extremely active in community service, Mary is dedicated to the fundraising efforts for Edgebrook Elementary, where her children attend school. She is a Chairperson for the school's annual Spring Fling event, which raises more than $90,000 each year. Mary also lends her time as a Class Room Mom, and she volunteers for the Posse Foundation and for JumpStart’s Read For The Record program.

Mary considers it an honor to serve the Danny Did Foundation and is dedicated to work to help others in Danny’s name.

Diamanta Panford
Northwestern University

Danny Did Foundation 2015 Interns
Abby Reed and RJ Curington
DePaul University
Scott Verhey

Scott Verhey is an attorney practicing law in Chicago at his firm founded in 1995. Scott began private practice in 1991 concentrating on select commercial litigation and civil trial work. In 1996, he was appointed as a Special Assistant Attorney General of the State of Illinois to represent the Illinois Department of Transportation in the prosecution of condemnation proceedings and related matters. Since 1998, Scott has served as “Of Counsel” for Amari & Locallo, representing and consulting with the law firm in various areas of interest including real estate taxation issues and complex real estate transaction. During his career, Scott has tried cases and argued appeals in the Circuit Courts of Illinois and the U.S. District Court. In 2001 he was sworn in and licensed to appear before the United States Supreme Court. Scott has served on various boards for the Illinois State Bar Association and currently is a member of The John Marshall Law School Board of Trustees Litigation Committee.

Scott graduated from Marquette University in 1988 with degrees in Political Science and Philosophy. Following the recommendation from a philosophy professor, Scott attended law school at The John Marshall Law School in Chicago. While attending, Scott served on the editorial board of its Law Review.

In addition to his work for the Danny Did Foundation, Scott volunteers for Marquette University representing the school and meeting with prospective college students and their families at college fair events at Chicago area high schools.

Scott is grateful for the opportunity to help the Danny Did Foundation reach its main goal to prevent deaths caused by seizures. Scott is a Past President of the DDF board of directors.
Molly House

Molly House is a vice president in the large lines commercial property and casualty division of Mesirow Financial. Molly evaluates existing insurance programs and works closely with contacts in the insurance market to develop more efficient and comprehensive coverages that suit her clients’ needs. Since starting in the insurance industry in 1993, Molly has become well versed in various facets of risk management ranging from large, commercial accounts to smaller, specialty accounts. Prior to joining Mesirow Financial, Molly spent eight years at Near North Insurance Brokerage, where she served in the Real Estate and Healthcare Practices.

Molly holds a degree in political science and public administration from Miami University of Ohio, where she ran Track and Field and Cross-country. She and her husband Ken have two children and are very involved with their parish, Saint Andrew, in Chicago’s Lakeview neighborhood. Much of her time is spent driving her kids to and from hockey rinks, one offshoot of being married to a Canadian husband. Molly is honored to be a part of the Danny Did Foundation, and is a big believer in its mission and the people who are behind it.
Danny Did Foundation Board of Directors

JoAnne Pepper, Treasurer

JoAnne Pepper graduated from the University of Wisconsin – LaCrosse with a degree in finance and attended law school at DePaul University. After an accomplished career in the insurance industry and as a risk manager, she left the business world to spend more time raising her children. JoAnne has served on the parent board at her children’s school and continues to be an active volunteer at their schools. She also volunteers on the local park district’s Advisory Council.

JoAnne and her husband live in Chicago and have three children. JoAnne ran the 2011 Chicago Marathon as a member of the Danny Did Team and is extremely proud to be working with the Danny Did Foundation. JoAnne began her term as DDF board treasurer in 2011.
Danny Did Foundation Board of Directors

Carrie McAteer, President

Carrie McAteer has worked at DePaul University for 13 years and currently manages a university-wide internship program in the Career Center. In this role, she is responsible for building and maintaining relationships with businesses and nonprofit organizations that are interested in hiring DePaul interns. Her previous experience includes working as a recruiter at a staffing firm and outside sales in the telecommunications industry.

Carrie was diagnosed with epilepsy when she was a teenager. Her personal experience with this often-misunderstood disease has led to her desire to raise awareness of epilepsy, and she is thrilled to do so through the Danny Did Foundation.

In addition to her work with the Danny Did Foundation, Carrie is serving her ninth year on the board of directors for the Lincoln Park Chamber of Commerce and is the Vice President of External Affairs for the executive committee. She is also a board member of Personal PAC and the State of Illinois Comprehensive Health Insurance Plan (ICHIP). She was recently chosen as a delegate of the Illinois Women’s Institute for Leadership, a program that trains women to become effective leaders in Illinois government and politics.

She holds a BA in public relations from the University of Dayton and an MS in public service administration from DePaul University.

Carrie is honored to advocate on behalf of the epilepsy community in this role for the Danny Did Foundation. She lives with her husband and their young daughter Norah, who is her pride and joy, in Chicago. She began her term as president of the DDF board of directors in April 2014.
Danny Did Foundation Board of Directors

Brendan Malone

Brendan Malone is a senior associate as part of the senior living team at Ziegler, a specialty investment bank. As a person living with epilepsy, Brendan has effectively served in a variety of advocacy roles and knows the impact of seizures first hand. Prior to joining Ziegler, Brendan had been a history teacher at Saint Ignatius College Prep.

He earned a B.A. in political science from Northwestern University in Evanston, IL.
Courtney Murphy, Secretary

Courtney Murphy leads the consumer and national promotions practice for dynamic retail marketing agency, TPN. Her extensive knowledge of the retail landscape extends across all channels and media, providing TPN's brand and retailer clients with basket-building solutions and action-oriented campaigns to drive the point of purchase.

Throughout her 17-year career, Courtney has helped re-imagine the retail experience for leading brands such as Tropicana, Gatorade, Propel, Quaker, Mike’s Hard Lemonade, Barilla and Arch Chemicals. Her unique skills and talent were instrumental in growing TPN’s Gatorade business 300 percent and in helping Tropicana to execute their largest loyalty promotion to date.

Courtney has several personal connections to epilepsy and has become a highly effective advocate.
Senator Dan Kotowski

Illinois State Senator Dan Kotowski advocates for Danny Did Foundation first as a person living epilepsy himself. Dan has devoted his adult life to public service and to his family. Since taking the oath of office in January of 2007, Dan has quickly become an independent voice for the 33rd Senate district ushering in a new era of leadership for Illinois. He was sworn-in for his third term on January 2013.

In his time serving the people of the 28th district Dan has produced results and helped shape the debate on important issues such as healthcare, property taxes, veteran affairs and public safety.

Prior to being elected in 2006, Dan served as the vice president of development and public affairs for UCAN, a human service agency that serves 5,000 children and families every year.

Dan graduated from the University of Illinois, Champaign-Urbana with a degree in English and Communications and received a Masters of Arts Degree from DePaul University.
Danny Did Foundation Board of Directors

Jeanine McShea (Secretary)

In the Chicago real estate market, Jeanine McShea is renowned among colleagues and clients alike for her integrity, loyalty and expertise. With over 25 years in the industry, both as a broker and an executive for prominent Chicagoland brokerages, Jeanine brings a level of professionalism and a network of connections to each partnership that she establishes with her clients, giving them a solid edge when buying or selling a home in the city.

With a career in the real estate industry spanning from broker, managing broker, to vice president, Jeanine’s wealth of real estate knowledge and experience allows her to provide expert professional and business development support, as well as sound guidance throughout the transaction process. Jeanine is a broker that has been a part of every process (both macro and micro) that goes into buying or selling a home, and her results reflect that.

Partnering with @properties, the No. 1 real estate brokerage firm in the Chicago, has allowed Jeanine to once again assist clients interested in either purchasing or selling their first time home to transitioning to a downtown residence. Together, with her daughter Erin McShea, Jeanine oversees the McShea Group, which was founded on the premise of providing clients with the utmost expert counsel throughout the home buying or selling experience.

Jeanine’s Achievements & Accolades:

Chicago Association of REALTORS®, Board of Directors
Danny Did Foundation, Board of Directors

Jeanine holds a bachelor’s degree from Winona State University, and was named 2008 Distinguished Alumni of the year for Winona State. Jeanine currently lives in Chicago with her husband. She has three adult children, who also reside in Chicago. Jeanine is a passionate Chicago Blackhawks fan, aspiring artist, and a passionate advocate for people with epilepsy as a board member for the Danny Did Foundation.
Margaret Storey

Margaret Storey is an Associate Professor in the History Department at DePaul University in Chicago and a parent advocate for children with medical complexity and disability. She received her PhD in United States History from Emory University in 1999 and is the author of numerous historical publications as well as opinion pieces about medical marijuana, special education, and disability rights for The Guardian online, the Motherlode Blog at The New York Times, and The Chicago Tribune. She comes to epilepsy advocacy as the parent of daughter with Aicardi Syndrome, a rare and debilitating condition that causes early-onset, intractable seizures as well as a range of developmental and physical disabilities. She is the past president of the Family Advisory Board and current member of the Public Policy Committee at The Ann and Robert H. Lurie Children’s Hospital of Chicago. She worked closely with The Epilepsy Foundation of Greater Chicago and The Danny Did Foundation to advocate for the legalization of medical marijuana for children with epilepsy in Illinois.
Danny’s dad Mike has worked in law enforcement for over 20 years.

Mike received a bachelor’s degree from Northwestern University.

Mike and his wife Mariann have four kids –Mary Grace, Johnny, Danny, and Tommy– and live on the northwest side of Chicago.
Dr. Marvin Rossi M.D., PhD

Dr. Rossi is an Assistant Professor and Attending Physician at the Rush Epilepsy Center of Rush University Medical Center in Chicago. As a teacher and physician, Dr. Rossi is dedicated to seeking out and providing the most up-to-date information and treatments to his students and patients. As a researcher, Dr. Rossi is most interested in the development and implementation of new detection and control technologies that stabilize dysfunctional neural pathways.

Dr. Rossi’s professional memberships include: American Epilepsy Society, full member; American Academy of Neurology; President and founder of SynaptiCOM (http://www.synapticom.net); American Medical Association; Illinois State Medical Society; Chicago Medical Society; IEEE Computer Society; New York Academy of Sciences; International Brain Research Organization (IBRO); and the Society for Neuroscience.

Dr. Charles J. Marcuccilli M.D., PhD

Dr. Charles Marcuccilli is an Associate Professor of Pediatrics in the Section of Pediatric Neurology at The University of Chicago. Dr. Marcuccilli attended medical school at the University of Chicago’s Pritzker School of Medicine and trained at the University of Chicago's Children’s Hospital in the departments of Neurology and Pediatrics. In addition to being a teacher, a researcher, and a clinician, Dr. Marcuccilli is also a skilled lecturer who was listed in 2010 as one of the “Best Doctors in America.”

Dr. Marcuccilli’s professional memberships include the American Epilepsy Society, the American Academy of Neurology, and the American Academy of Pediatrics. Dr. Marcuccilli is also a member of the board of directors for First Steps Foundation.
Danny Did Ambassadors are extraordinary volunteers who choose to serve the Danny Did Foundation at elevated levels of engagement and responsibility. Each Ambassador shares their personal story to further the Danny Did Foundation’s mission to prevent deaths caused by seizures. With the support and backing of the DDF, Ambassadors work independently and proactively as official representatives of the Foundation to help Danny Did integrate into networks and communities across the United States.

Allison Austin,
Northern Virginia

Allison is the mother of two young boys and lost her husband Jeff to SUDEP on February 26, 2012. Jeff died from SUDEP after experiencing only his second known seizure, at the age of 42, and his family was never informed that seizures could be fatal. Allison now advocates in her husband’s name through fundraising events and media awareness around SUDEP. Her efforts have helped numerous families in her community.

Mylissa and Jeff Daniels
West Virginia

Mylissa and her husband Jeff lost their 5 year-old son Dallas to SUDEP in January 2011. They have held several fund raisers to benefit Danny Did, including a 5K walk and a T-shirt sale. Mylissa has spoken before the Institute of Medicine to represent both her personal experience and our shared cause.
Danny Did Foundation Ambassador Group

Scott and Lana Frey
Indiana

Scott and Lana Frey have a six-year-old daughter who faces the challenges of both Cerebral Palsy and Epilepsy. A dentist, Scott utilizes his professional networks to raise awareness and funds for our cause. The Freys also serve as our liaisons to the Indiana Chapter of the Epilepsy Foundation.

Kari and Dennis Knapp
Minnesota

Kari and her husband Dennis lost their 22-year-old son Jake to SUDEP in March 2009. They serve as our liaison to the Minnesota Chapter of the Epilepsy Foundation. Each summer the Knapp family hosts a Socks & Sandals Golf Outing fund raiser, aptly named because Jake always wore socks with his sandals. Portions of the proceeds are used to purchase seizure detection devices for families who cannot afford them.
Misty Phillips became an epilepsy advocate after her son Lucas began having seizures on Christmas Eve 2009 at age 11. An avid runner, Misty and her husband Stephen ran the 2012 Chicago Marathon as part of Team Danny Did. The couple is also running several local races to raise awareness and work to grow Team Danny in their home state.

Cindy and her husband Tom have a son adult Robert who has epilepsy. The Mitchells have represented the Danny Did Foundation at several epilepsy conferences, meetings, and expos in California, and serve as our liaisons to the Los Angeles Chapter of the Epilepsy Foundation. Robert is a proud member of Team Danny Did.
Danny Did Foundation Ambassador Group

Kendal and Andrew O'Lenick
Georgia

Kendal and Andrew have a 4 year-old son, Conner, who has epilepsy. A personal trainer, Kendal is helping to bring participation and fundraising for Team Danny Did to the Atlanta area. Her dad Jon conducts an annual hike of the Appalachian Trial to benefit epilepsy awareness. Says Kendal, “As a mom, not a day goes by that I don't worry about SUDEP. I want other parents to have an outlet and know that we are not alone with our battle against epilepsy.”

Danny Did Foundation Ambassador Group

Sherri and Brad Newman
Virginia

Sherri and her husband Brad lost their 12 year-old son Joshua to SUDEP in November 2010. Following the suggestion of their daughters, they registered Team “Joshua’s Smile” in the 2011, 2012 and 2013 National Walk for Epilepsy. Though they had originally planned to walk as a family of five, following Joshua’s unexpected death, their team grew to 160 friends and family who raised over $18,000. As a new tradition, each November they host the Joshua A. Newman Memorial 5K Run/Walk to advance epilepsy awareness and to support the Danny Did Foundation in purchasing seizure detection devices for families unable to afford them.
Danny Did Foundation Ambassador Group

Stefanie and Marc Mingle
*South Florida*

Stefanie and Marc lost their daughter Emmy to SUDEP in July 2013, a few months before her second birthday. These brave parents now advocate for epilepsy and SUDEP awareness in Emmy’s honor, and work to advance understanding of seizures in their South Florida community.

Danny Did Foundation Ambassador Group

Tom and Mary Nugent
*Northern Illinois*

Tom and Mary Nugent have three sons, Jack, Will and Quinn. Their two youngest boys have epilepsy. The Nugents represent the Danny Did Foundation at numerous conferences and meetings throughout the Chicago area and serve as mentors to many parents who care for multiple children with epilepsy. Tom and Jack Nugent are also alumni of Team Danny Did.
Year In Review: Achievements At A Glance

In 2015, the Danny Did Foundation continued its growth, helped families across North America and beyond, and accomplished meaningful and measureable successes. Some highlights include:

• The DDF continued as a partner member to the North American SUDEP Registry (sudep-registry.org), and our executive director began serving on the NASR Advisory Committee. This registry collects critical data that will accurately track the number of SUDEP cases in the United States and Canada. This data will form the basis for funding of research into the cause of SUDEP.

• We have updated our Seizure Safety and SUDEP Information brochures and distributed thousands to families, hospitals, doctors, and epilepsy organizations across North America. Feedback has been overwhelmingly positive and people have applauded our brochures as providing necessary information. Even more importantly, they have let us know that the brochure is the first such information they have ever received. We are filling a crucial gap in educating people with epilepsy and their families about SUDEP.

• In 2015 we subsidized seizure alarm monitors for 180 families nationwide, up from 116 in 2014, an increase of 35 percent. We have now provided financial assistance to families across 48 states. We believe seizure detection and prevention devices and other forms of technology should compliment medicines, surgical procedures, and diet to combat seizures and to help keep people alive while doctors search for a cure.

“I read your article in our local paper yesterday and couldn’t wait to tell my daughter about it. My 3 year-old grandson has suffered from seizures since he was 6 months old and each time was sent home with the “I don’t know” diagnosis. Finally, last year right before Christmas my daughter insisted the doctors admit him to the hospital because he was having up to 8 grand mal seizures a day. They diagnosed him with epilepsy and he’s been taking Keppra and has been seizure free since. I worry daily about him as they did find in the hospital that he was having seizures in his sleep. His neurologists have assured my daughter that he will never die from this! How can they make that assumption? Thank you so much for giving us knowledge and for keeping the fight. I ordered four DDF shirts last night and can’t wait to wear them proudly for Danny! – Michelle, Pennsylvania
Danny Did was a sponsor of the 2015 Epilepsy Shark Tank Contest, a financially-incentivized competition that seeks to find and advance new technologies and devices that work to alert to, predict, or even prevent seizure activity. Early intervention when a seizure occurs is critical toward preventing death.

We continued to expand awareness in the world of social media, with more than 21,000 fans on Facebook and active followings on Twitter and LinkedIn.

The Danny Did Foundation continued as a partner member to the Partners Against Mortality in Epilepsy Conference (PAME), a 3-day educational event that brings together families, medical experts, advocates and researchers from around the world to discuss mortality in epilepsy, and ways to combat it. This event is unique in the epilepsy community for gathering all invested parties to the same forum.

Our “Danny At Your School” educational program has continued to develop and grow, and included DDF presentations to the Chicago area. This program is aimed at educating kids and teachers about epilepsy in an effort to erase the stigma associated with seizures that has impeded progress for the epilepsy movement for generations.

We grew the Danny Did Ambassadors program, designed to further integrate our cause and mission into communities and networks across the United States. Danny Did Ambassadors are extraordinary volunteers who choose to serve the Danny Did Foundation at elevated levels of engagement and responsibility. Each Ambassador shares their personal story to further DDF’s mission to prevent deaths caused by seizures. With the support and backing of Danny Did, ambassadors work independently and proactively as official representatives of the foundation to help Danny Did integrate into networks and communities across the United States.

The DDF was a co-sponsor of the SUDEP Memorial Wall at the 2015 National Walk for Epilepsy in Washington, D.C. This display is a dedicated space at the country’s largest epilepsy walk, a place where families and spectators can take time to honor the men, women, and children who have been lost to epilepsy.
Progress On Our Initiatives: Advancing Awareness

Danny’s parents were not provided with literature or pamphlets when they brought Danny to various doctors and hospitals. To address this shortcoming, the DDF created a Seizure Safety/SUDEP Information Brochure.

In our efforts to advance awareness of Sudden Unexpected Death in Epilepsy among both patients and doctors, we have researched, developed, printed, and distributed thousands of these informational brochures to date. This brochure is now in homes nationwide, and in many medical settings from coast to coast and around the world.

Having this brochure available in schools, pediatricians’ offices, neurologists’ offices, hospitals, and epilepsy centers heightens awareness of epilepsy and contributes to improve the treatment of and response to seizures that occur in public. The brochures teach seizure first aid to those who don’t know it. It’s a tangible and important change.

In addition to our Seizure Safety brochures, we build and grow our awareness program by utilizing many platforms. We understand that for people to care about epilepsy, they have to be aware of the scope of the problem. Our awareness outreach includes:

- **Presentations at epilepsy conferences**
- Sponsorships of SUDEP discussion panels
- **Presentations at schools nationwide**
- Media exposure across television, print, and Internet
- **Advertisements across magazine, radio, and billboard platforms, including a radio campaign on 101.9 FM The Mix to promote National Epilepsy Awareness Month**
- Social media presence, including Facebook (over 21,000 fans), LinkedIn, Twitter, YouTube, and Vimeo
- **Our frequently updated website at http://www.dannydid.org.**

Danny Did billboard in downtown Chicago
Social media, traditional media, and grass roots promotions all serve as a means to raise the stature of our cause and to enable us to serve as an outlet to which doctors can steer patients for more information about epilepsy and SUDEP. Our goal is to multiply and expand these efforts locally, nationally, and globally.
Progress On Our Initiatives: Trials and Grants

In 2015 the Danny Did Foundation continued funding support towards a research grant at Northwestern Memorial Hospital in Chicago, where a newly created infrastructure will enable data on SUDEP to be shared and accessed by multiple epilepsy centers. Led by Dr. Stephan Schuele, the funding for this project was made possible by proceeds from the 2013 Northwestern University Dance Marathon. The DDF is also funding a four-center trial of the SmartWatch monitoring device, which is taking place at the University of Virginia, Stanford University, Boston Children’s Hospital and New York University.
Progress On Our Initiatives: Monitor Subsidies

In the process of discovering the seizure detection alarms as resources that we wish we had known about ourselves, the Danny Did Foundation has introduced monitoring device options to families nationwide so that they can investigate their potential usefulness for their loved one. And while many have gone on to purchase a device, many too have discovered that such a valuable seizure-detection device is cost prohibitive.

To make this technology available for those who can’t afford it, the Danny Did Foundation has purchased movement monitors for families in need across 48 states, the District of Columbia, and Canada, Luxembourg, Brazil, Philippines, South Africa and Kenya. Feedback from parents tells us that these monitors are having a practical impact and providing peace of mind.

Thank you once again for this wonderful opportunity to gift our son a Smart Monitor watch. You can only imagine the sense of gratitude and relief that my husband and I now feel knowing that Josh will now have the freedom to live a more normal life. He will be able to play with his friends outside without his 5 year-old brother tagging along in case of a seizure to call for help. With Grateful hearts to the Danny Did Foundation. - Lieutenant Colonel Jeff Howell & Mrs. Caitlin Howell, Wahiawa, Hawaii
Progress On Our Initiatives: Events

6th Annual Basketball Clinic 320-plus boys and girls enjoyed a fun day of basketball with friends, and were educated on seizure safety and the power they have to shut down the stigma often shown against young people who have epilepsy.

This event was run by volunteer high school players and coaches and Loyola Academy, Notre Dame College Prep, DePaul College Prep, Regina Dominican and Benet Academy.

6th Annual Hearts and Hugs Gala Over 450 Danny Did Foundation supporters joined the DDF at its Annual Evening of Hearts and Hugs at The Montgomery Club in Chicago's River North neighborhood.

From elected officials to world-class doctors to supporters from across the country, all had a great time and raised money to carry on in our mission to prevent deaths caused by seizures.

Awards were presented to outstanding epilepsy advocates, and we also awarded our annual Danny Did Foundation High School Scholarship Award.

6th Annual Danny Stanton Kickball Tournament Over 300 kids, 30 games, 24 teams. Kids in 1st grade through 8th grade kicked it all day in one of Danny's favorite parks, and they were all wearing his favorite number, 19! Scores of volunteers, coaches, umpires, face painters, and parents made the day a big success for Epilepsy and SUDEP Awareness.

Team Danny Did Team Danny Did members represented and raised money to combat seizures in races across the country in 2015. Merging fitness and fundraising while raising awareness for our foundation, our supporters participated in walks, runs, bike rides, and triathlons nationwide. Team Danny Did continues as a growing platform for the DDF.
DDF In The News: Sample Media Coverage

The Jackson Sun

June 16, 2015

“He Has Epilepsy, It Doesn’t Have Him”

One in every 26 Americans will develop epilepsy at some point in their lives, according to the Danny Did Foundation, a nonprofit organization dedicated to raising awareness about the disease.

The Bezold family of Jackson is one family affected by epilepsy. Julie Bezold said her son Nick first began showing signs of the disease in second grade.

"He would just zone out," she said. "I would be like, 'Why aren't you looking at me? I'm talking to you.'"

Julie said a pediatrician recognized the zoning out as seizures and a possible sign of epilepsy and sent Nick to Vanderbilt for tests. He was placed on high doses of medication that altered his behavior and personality.

Julie said that was a struggle for her.

"(The drugs) had an effect on him cognitively and emotionally," she said. "The doctors want to stop the seizures, but I still want my child to have quality of life."

She said she tried to find support groups, but could not find anything in the area. Soon, she decided to start raising awareness so people at least knew what the disease was.

"That's when people started coming out of the woodwork," Julie said.

She began organizing the Purple Way 5K each year to raise awareness and funds, and each year more people participated.

Julie said she wants people to know that people with epilepsy are not contagious, they are courageous. She said there is a lot of fear that comes with epilepsy because it can be unpredictable.

She used to be afraid to leave Nick alone because he might have a seizure. She said Nick taught her not to think like that.

"When he was 13, he told me, 'I don't have to worry because God's got me,'" Julie said. "If he can think
like that at age 13, I need to let go of that, too."

Julie said Nick has always loved sports, and he continues to play — and play well. He is a starter on the Madison Academic Magnet High School soccer team that advanced to the state quarterfinals this spring.

Julie said epilepsy prevents Nick from being able to drive and do other things that kids his age do, but it does not prevent him from being himself.

"He has epilepsy," she said. "It doesn't have him."

Julie said her family has learned to manage the seizures. Nick has an alarm under his mattress that will alert them if he has a seizure in the night, and they know how to deal with them.

She said viruses and sleep deprivation tend to be triggers for Nick, and keeping a good routine, resting and staying hydrated help prevent episodes.

"We take it one day at a time," Julie said.

She said it's important to remain calm when someone is having a seizure. Move things away from them and protect their head, but do not try to restrain them, she said.

"There are tons of resources out there," she said. "No one should ever feel alone."

The Bezolds are now ambassadors for the Danny Did Foundation, and they share their story around Tennessee to raise awareness and funds for the organization.

Tom Stanton, Danny Did Foundation executive director, said the Bezolds are making an impact through their efforts.

"Nick has tremendous athletic talent, and his family utilizes sports to elevate awareness of a disease that needs more attention and more progress," Stanton said in a news release. "They are an inspiration to our cause and to many families."

For more information on epilepsy and the Danny Did Foundation, visit www.dannydid.org.

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R.J. Curington never imagined how the life of a disarming 4-year-old boy with a buzz cut and hugs for everyone could turn a summer internship into a cherished life lesson.

What the junior guard on DePaul's basketball team discovered working a summer internship at the Danny Did Foundation is the heart and soul of a passionate advocacy spreading awareness about a particularly frightening medical condition known as Sudden Unexplained Death in Epilepsy (SUDEP).

The life and times of Danny Stanton is both heartwarming and tragic, and his story added so much meaning to Curington, teammates Frederick Scott and Develle Phillips and staff members Kevin Edwards and Edwind McGhee spending time in late July at the Danny Did Foundation's basketball camp for kids with epilepsy at Proviso East.

A sports-crazy, affectionately scrappy kid nicknamed "Little Toughie" by his grandmother, Danny had his first seizure at the age of two.

"His eyes rolled back and he shook," wrote his father, Mike Stanton, in a memorial to his son. "We did not know what was happening. We dialed 911 then rushed him to our next-door neighbor, who is a paramedic. Danny seized for almost 10 minutes.

"On that night, we had a battery of tests done at Children's Memorial Hospital. There was no known reason or cause found for Danny's seizure. No injury, no trigger. We were told that sometimes seizures in children have no known cause and that kids often outgrow them. The experience was terrifying."

Almost as frightening was the terror of the unknown. This was 2007 and Mike and Mariann Stanton left the hospital that night without any information about SUDEP. A second seizure a month later resulted in another battery of tests along with medication.

Mike wrote that the neurologist's diagnosis was childhood seizure disorder and there was still no mention of epilepsy or SUDEP.

"We were told he'll outgrow it, many kids experience this, we don't know why it happens, maybe it's 'his normal.'"

Other than the times he slept in his parents' bed so they could monitor his condition---and they caught two more seizures---Danny remained true to his shining personality.

"Danny and Johnny were best friends, and Danny got into sports because of his older brother Johnny,"
said Danny's uncle Tom Stanton, the Danny Did Foundation executive director. "He was the little brother who was always hanging around and playing ball with the older kids. He was a dynamic, outgoing kid running up and down the block.

"He was the mayor of Edgewood and brought a lot of life to the block on the Northwest Side. He would high-five a 60-year-old man as easily as playing a game with a kid his own age."

Curington began to appreciate Danny's unique qualities during the internship.

"It seems like he was such a special kid," Curington said. "Even though he was so young, he showed you how much love and affection could come from someone.

"People who were uncomfortable showing their affection wouldn't hesitate to give Danny a hug. He had a special impact on everyone from kids his own age to older people.

"Tom Stanton and Mary Duffy, a close friend of Danny's family, talk about Danny all the time—-the kind of kid he was and how the family was always with him."

Here's an excerpt from an Associated Press story:

"Danny was buddies with Mary's son, Charlie, the same age but extremely shy. During one of the regular kickball games outside the Stanton home, Danny noticed Charlie on the sidelines, grabbed him by the hand and brought him into the house.

"Danny thought, 'Well, he doesn't want to play sports, here's all my action figures,' and laid them all out in front of him," Duffy recalled. "Danny created that environment for him. Danny figured it out."

"His charity didn't end once he left the ball field, or a neighbor's yard. He seemed to sense when people around him needed a hand, even the grown-ups. Danny loved to help next-door neighbor Betty Lazzara carry in her groceries."

"I'd always try to give him a light bag," Betty said, "but Danny would say, 'I can carry that gallon of milk' and would lug it into her house. He knew a treat from Lazzara's snack drawer would be waiting---fruit roll-ups or Gushers were his favorites---and Danny always asked to take home enough for his brothers and older sister, too."

A seizure on Dec. 12, 2009 took Danny's life---a life that ended with a hug.

"That's just how he expressed his life, and how he gave it," Mike Stanton told the AP. "How he just let you in was so beautiful."

The AP story continued: "So when Danny died of a seizure 14 days before Christmas---after frantic attempts by his parents, neighbors, paramedics and doctors to revive him, after all the medical tubes were disconnected---Danny's dad lay down on the hospital bed. And he tightly hugged his little boy in
return, as his body grew colder and colder.

"I kind of lost track of time," Stanton said. "I could have laid there with him forever."

The foundation was created a month later and gets its name from the final words of an obituary written by his dad: "Please go and enjoy your life. Danny did."

Curington has been caught up in the foundation's work which in its first year put up billboards, created more than 8,000 SUDEP pamphlets for hospitals, doctors' offices and families, held fundraising events and drew a large following on Facebook. DePaul women's basketball coach Doug Bruno is a member of the foundation's board of directors.

"Every fundraising event at the foundation has been fun and exciting," Curington said. "When I applied for the internship, I had no clue what this entailed. I help set up for events and come up with different plans for future events. I learned a lot about all the preparation that goes into a big fundraiser.

"The foundation is an ideal setting for a nonprofit organization. With all the fundraising, an excellent website, the SUDEP monitoring devices and all the other clothing and accessories, they really hook it up. You would think this is some kind of global foundation."

Tom Stanton said Danny Did's fundraising helps families across 48 states and seven countries gain access to devices and technology that can monitor seizure activity, especially when someone is asleep.

"Most of the time, people who have died are found the next morning in bed," Tom Stanton said. "My brother Mike and and his wife Mariann had never heard of monitoring devices, and they hadn't been informed that these resources can help complement other forms of treatment. When we started the foundation, awareness among parents of kids with epilepsy about the risk of SUDEP was extremely low."

It was Curington who suggested adding a little flair to the annual Bounce Out the Stigma Basketball Camp run in conjunction with the Epilepsy Foundation of Greater Chicago.

"I talked to Tom about the annual event and said why not bring in some of my teammates and members of our staff in to pump up the camp?" Curington said. "He was really excited. He is a big fan of DePaul and even played noonball a couple of times."

Stanton said the camp demonstrates that someone with epilepsy is just like any other kid participating in sports, clubs or other activities and no one has to be defined by epilepsy. The camp seeks to break down the stigma and educate kids and their parents about how to respond when there is a seizure. He said if a seizure occurs during the camp, there's a nurse on hand to take care of it, and the camp moves on.

"R.J. brought his teammates and the campers really loved it and looked up to them," Tom Stanton said. "You could tell by the looks on their faces, the kids were in awe from the moment they walked in. It was their size, and they had an aura about them."
"The DePaul players jumped right in and never hesitated interacting with the kids. R.J. is such a great role model and so personable---he makes the kids feel comfortable. I heard from so many parents about how the players represented themselves so well. That really made it a special day for the kids.

"There was this girl Gabby who was too little to shoot a basketball. Develle Phillips lifted her up and she put it in the basket. Our kids will remember this day for a long time. DePaul made a bunch of new basketball fans among parents and children---no doubt about that."

And Curington developed some newfound respect for his fellow Blue Demons.

"I talked to some of my teammates, and they were surprised and happy to work with the kids," Curington said. "When we first walked into the gym, the kids were really excited. They thought we were superstars or something. We showed them how to do stuff on the court.

"When I started hitting a bunch of three-pointers, there were all these `ooohs' and' aaahs' from the kids. It was funny. It was like we were NBA players to them.

"The guys had no idea what would happen. We talked about the experience afterwards. They were describing each kid and their characteristics, and you couldn't tell they had epilepsy. They were just regular kids and part of the camp.

"What my teammates did---these guys are awesome. They really cared about it, and it made me proud to be their teammate."