2013 Annual Report

“I just want to learn.”

--Danny Stanton on his first day of preschool
“Tell me and I forget. Teach me and I remember. Involve me and I learn.”

--Benjamin Franklin
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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 sixsome 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 7:15AM.

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 that last line of Danny’s obituary caught the attention of many people, including a writer from the Associated Press, who penned an article that started like this:

“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. Horribly, 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. Further, not once was information presented regarding 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 were Danny’s body had grown cold atop of ours as we laid with him and prolonged letting the Medical Examiner’s office take him to the morgue-- 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 advance awareness of epilepsy in general and of Sudden Unexpected Death in Epilepsy in particular. Thank you for your participation in that success, 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 behind; the impact that you’ve had on your family, your friends; your business; the sum of good that you have done. Danny has and continues to grow his legacy through the families helped by the Danny Did Foundation. And in 2013, he added one more piece to the way he is remembered in the world: a new law aimed at collecting data on Sudden Unexpected Death in Epilepsy (SUDEP).

In August 2013, months of effort culminated with the passage of the “Danny Stanton SUDEP Act,” an Illinois state law that mandates 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 toward understanding the scope of its impact, and toward securing funding for the research required to pinpoint why it happens and how to prevent it.

While this legislation immortalizes Danny into the law books, of course it doesn’t do what his family would like best: to bring him back. This year Danny would have celebrated his 8th birthday. He would have entered the third grade, a safe and nurturing place where his curiosity, talents and friendships would have grown with the passing of another school year. Epilepsy 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.

A highlight to 2013 was the culminating weekend of our partnership with Northwestern University: a 30-hour dance marathon event attended by a record-number of Northwestern students. Why did more students take part and raise more money than in any other year in the event’s 39-year history? We like to think it was Danny’s smile, his energy, and the passion of the foundation that bears his name. We will forever be thankful to the Northwestern University Dance Marathon and the student leaders who embraced us as its 2013 charity partner.

In April, Carrie McAteer, a person living with epilepsy, bolstered our foundation by joining our Board of Directors. Carrie has quickly become a strong and active advocate in sharing her story and advancing our cause. A final highlight to 2013 came when Danny Did was a partner to the first ever Epilepsy Awareness Day at Disneyland Resort. This event drew nearly 1,000 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 43 states, Canada, Luxembourg and Brazil. We appreciate your friendship for a little boy whose legacy continues to grow. - 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 is dedicated to advancing public awareness of epilepsy and Sudden Unexpected Death in Epilepsy (SUDEP), enhancing the SUDEP communication model between medical professionals and families impacted by seizures, and gaining mainstream acceptance and use of seizure detection and prediction devices that may assist in preventing seizure-related deaths.

We view these devices as complimentary to medicinal, surgical and dietary measures that are used to treat seizures. Epilepsy impacts nearly three million people in the United States and 65 million people worldwide. One in 26 Americans will develop epilepsy over their lifetime. Seizures can sometimes be fatal from a range of causes; more people die as a result of seizures than from fires and sudden infant death syndrome (SIDS) combined. Thousands of deaths occur annually from SUDEP, status epilepticus (prolonged seizures), and other seizure-related causes such as drowning and other accidents.

To achieve our goals, the DDF engages physicians and researchers in the fields of neurology and epileptology; we collaborate with medical technology companies; we consult with epilepsy organizations, and we interact with all those affected by Danny's story. We ask doctors to talk about SUDEP, and we offer ourselves as an outlet to which doctors can steer patients. We create informational pieces about safety in epilepsy in general and SUDEP in particular. We pursue the latest seizure detection and seizure prediction technologies, and once identified as viable and worthwhile instruments, we work to get these products approved by the United States Food and Drug Administration and then covered by insurance companies.

Like Danny, we want to learn. We want to know why a worldwide medical condition is so widely misunderstood by the general public and how it has remained such a riddle to the global medical community. And because epilepsy has taken Danny from us, we will not stop questioning until we know the answer. To this end, the DDF recognizes epilepsy as the monster that it is: a thief of livelihoods, a robber of wellbeing, and a weighted cloud that stamps out a sunny day.

From grammar school students to nationally recognized epilepsy experts, Danny Did Foundation believes that a global problem such as epilepsy deserves the attention of all of the globe’s inhabitants. 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.

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.
The Object of Our Objective: Epilepsy

Q: What is epilepsy?
A: If a person has two or more unprovoked seizures, that’s epilepsy.

A seizure is caused by abnormal electrical activity in the brain that results in a sudden episode of transient neurologic symptoms such as involuntary muscle movements, sensory disturbances, and altered consciousness. Epilepsy is a disorder of the nervous system characterized by recurring seizures that result in sudden, brief changes in the way the brain works. Epilepsy is not a mental illness, and it is not contagious.

Most people living with epilepsy go about their daily routines just like those who are not affected by epilepsy. However, they also live with the knowledge that at any moment they could have a seizure and that the quality of their lives will be affected by the frequency and severity of their seizures. Three million people in the United States suffer from epilepsy, which is equal to the number of people with cerebral palsy, multiple sclerosis, and Parkinson’s disease combined. People die from epilepsy, too: tens of thousands of lives are lost annually in the United States to the effects of seizures, and an estimated 20-25 percent of those deaths are SUDEPs. That’s what got Danny.

And so, even though we were treating Danny for what was termed a ‘seizure disorder,’ what we know now is that Danny had epilepsy. And because that proper medical diagnosis was never presented to us, we were kept in the dark with regard to the two critical facts that would have altered aspects of our treatment for Danny: 1) if a person has two or more unprovoked seizures, that’s epilepsy, and 2) a person can die from epilepsy.

The simplicity of these two facts is clear; the presentation of these two facts by medical professionals should be effortless; the withholding of these two facts has proved to be devastating. Had we been informed of epilepsy and the full range of its effects and possible consequences, Danny still may have died. We accept this. What we do not accept is the knowledge not shared with us by the medical professionals who treated Danny, and what opportunities that knowledge would have presented to us in our care for and treatment of Danny. We were after all, the guardians of Danny’s welfare. And what we have come to know is that a lack of communication regarding epilepsy and its full range of effects and consequences is an experience too common to remain unaddressed. The condition of depression and the illness of breast cancer were once woefully overlooked, as well, until someone, or some organization, had enough.

So again, we ask: What is epilepsy? What is this object of the Danny Did Foundation’s objective? Epilepsy is the medical diagnosis that was never mentioned to us, epilepsy is the neurological condition that affects nearly three million people in the United States, and epilepsy is the scourge that dwells in the shadow of popular culture to the detriment of the advancement of awareness of epilepsy, of funding for epilepsy research, and of saving the life of another little boy like Danny. The Danny Did Foundation’s objective is to present epilepsy to the world, and in doing so to help prevent another death caused by a seizure.
Danny Did Foundation
Staff

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, Chief Operating Officer

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.

Danny Did Foundation 2013 Intern
Angel Reyes

DePaul University
Scott Verhey, President

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 coaches boys basketball at Queen of All Saints School in Sauganash and 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 began his term as DDF Board President in April 2012.
Molly House, Vice President

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. Molly began her term as DDF board of directors Vice President in April 2012.
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, Secretary

Carrie McAteer has worked at DePaul University for 11 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 who 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 eighth 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 secretary of the DDF board of directors in April 2013.
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.
Danny Did Foundation Board of Directors

Nick Feinberg

Nick Feinberg attended the University of St Andrews in Scotland on a combination golf scholarship/Clark Academic Scholarship. He graduated with a degree in Economics and Philosophy then went on to Northwestern University to complete a post-baccalaureate in preparation for medical school. Nick became involved with the Danny Did Foundation as a golf instructor to Danny’s siblings, Johnny and Mary Grace, through the First Tee of Chicago, a Chicago Park District Youth Program.

Nick’s efforts at the Foundation include researching FDA regulations for medical device clinical trials and helping neurologists to facilitate and advance such trials. Nick also leads the Bake For Danny initiative – a national fundraising and awareness program centered on community bake sales hosted by Danny Did supporters.

Nick is currently attending medical school and looks forward to spreading the message of Danny Did to medical educators and the next generation of doctors.
Senator Dan Kotowski

Illinois State Senator Dan Kotowski Dan 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.
Pete Lazzara

Pete Lazzara is a decorated Chicago Fire Department Ambulance Commander and a longtime neighbor of the Stantons in Edgebrook.

A Chicago native, Pete graduated from Northeastern Illinois University in 1979 with a degree in education, and began teaching and coaching at Gordon Technical High School, then the largest all-boys Catholic High School in the country. While teaching, Pete completed Loyola University Medical Center’s Paramedic program and the following fall, accepted a position with Paramedic Services of Illinois as a Firefighter/Paramedic and began serving in that role for several area Fire Departments. In 1990, Pete accepted a position with the Chicago Fire Department as a Fire Paramedic, rising to his current rank of Ambulance Commander.

While working for the Chicago Fire Department, Pete has been awarded several department commendations and in 1997 was awarded the West Suburban Hospital’s “Paramedic of the Year” award. Pete has also worked at the Loyola University Medical Center as an EMS instructor and received further training to serve as a Flight Medic with their air medical helicopter program “LifeStar.” Pete was hired in 1997 to be the first Emergency Medical Services Coordinator at Children’s Memorial Hospital where he received the Illinois Department of Public Health’s Ron W. Lee, MD Memorial Award for “Excellence in Pediatric Care”, as well as the Illinois Department of Child and Family Service’s “Program Excellence Award.”

Pete has worked with city officials to develop the Midwest’s first state-of-the-art Fire/EMS training simulation laboratory to enhance emergency response skills of current and new paramedics. In addition, Pete is the founder and President of EMSed, an educational company specializing in Emergency Medical Services educational concepts. He is a nationally recognized EMS speaker and annually presents at EMS conferences nationwide.

Pete and his wife have two kids and have been married for over 30 years. Pete is committed to helping the Danny Did Foundation reach its goals.
Danny Did Foundation Board of Directors

Sean Murphy

Sean works as an S&P 500 options trader for Quiet Light Trading. His passion for the financial world has lead to a special interest in fundraising for the Danny Did Foundation. In addition to his friendship with the Stantons, Sean also has another personal interest in being a part of building the Danny Did Foundation as his nephew suffers from a seizure disorder. Sean currently lives on the northwest side of Chicago with his wife and two children.

Danny Did Foundation Board of Directors

Susan Nicholl

Susan is the President of Dillon Productions, Inc., an event management/marketing company that she founded 18 years ago.

Susan also serves as the Executive Director of Special Children's Charities, a financial supporter of Special Olympics Chicago programs since 1969.

Susan has extensive experience in major fundraising events and not-for-profit marketing and is one of the most respected figures in the Chicago non-profit community.

Born and raised in Chicago, Susan is a graduate of Loyola University in Chicago and is dedicated in bringing success to the Danny Did Foundation.
Mariann Stanton

Danny’s mom Mariann has been an educator in numerous school systems for over 20 years. She is currently a Chicago Public School High School English teacher.

Mariann received a bachelor’s degree in English from Loyola University in Chicago, which she attended on a four-year basketball scholarship. Mariann also earned a Master’s degree in Education from DePaul University.

Mariann and her husband Mike have four kids – Mary Grace, Johnny, Danny, and Tommy – and live on the northwest side of Chicago.
Danny Did Foundation Medical Advisory Board

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.

Danny Did Foundation Medical Advisory Board

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 Foundation Ambassador Group

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.

Dana Alfassa,
Illinois

A former intern for the Danny Did Foundation, Dana now spreads the word of our foundation via her university community in Montreal and her networks in her hometown of Chicago.

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.

Danny Did Foundation Ambassador Group

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.
Danny Did Foundation Ambassador Group

Misty and Stephen Phillips
Oxford, Mississippi

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 Oxford, Mississippi couple are also running several local races to raise awareness and work to grow Team Danny in their home state.

Danny Did Foundation Ambassador Group

Cindy Mitchell & Family
California

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

Tom and Mary Nugent  
*Northern Illinois*

Tom and Mary Nugent have three sons, Jack, Will and Quinn. The younger of their two 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.

Danny Did Foundation Year in Review

“Our 15 month-old son has epilepsy and has been having seizures since he was 4 months old. Our doctors told us there was not a monitor to detect seizures and did not initially tell us about SUDEP. My sister found your foundation and through that we learned of the Emfit monitor. We have had the Emfit monitor on his crib since last May and it recently alerted us to his first night time seizure at 3:30 am. His seizures have never stopped on their own, and this one was so bad he ultimately was put on a ventilator and airlifted to Children’s of Alabama. He is doing good now and is back at home. My husband and I feel forever indebted to your foundation because we know it helped save our son’s life. The work you all are doing is impacting lives, including that of my son and we will be supporting your foundation now and in the future. – Jacy, Alabama
In 2013, the Danny Did Foundation continued its growth, helped families across North America and beyond, and accomplished meaningful and measurable successes. Some highlights include:

• Continued a game-changing partnership with the Northwestern University Dance Marathon, one of the largest college-run philanthropic organizations in the United States. As the charity partner of their 39th annual campaign, we spent the 2012-2013 school year raising awareness and education of epilepsy and seizures on Northwestern’s campus in Evanston, Illinois. This partnership culminated with a 30-hour dance marathon the weekend of March 8-10, 2013, which raised a record $1.2 million.

• Funded a grant at Boston Children’s Hospital in Massachusetts to study biomarkers that could signal heightened risks for SUDEP. This project can help researchers better understand the mechanisms of SUDEP and the potential monitoring benchmarks that are critical for parents and caretakers to be alerted to. We also funded a research grant at Northwestern Memorial Hospital in Chicago, where a newly created infrastructure

• We have updated and distributed thousands of Seizure Safety and SUDEP Information brochures to families, hospitals, doctors, and epilepsy organizations across North America. Hundreds of people have told us that this type of literature is as appreciated as it is necessary, and just as many have let us know that information like this has never before been presented to them.

• In August, after months of effort, we achieved passage of the “Danny Stanton SUDEP Act,” an Illinois law that mandates 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.

• 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 about epilepsy and changing the stigmas and obstacles that have impeded progress for the epilepsy movement for generations.

• In 2013 we subsidized seizure alarm monitors for 91 families nationwide, up from 67 in 2012. We have now provided financial assistance to families across 43 states. We believe seizure detection and prevention devices and other forms of technology can and should compliment medicines, surgical procedures, and diet to combat seizures and to help keep people alive while doctors search for a cure.

• 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 Danny Did Foundation’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.
will enable promising devices and technologies to be tested in a uniform clinical setting that multiple epilepsy centers have access to.

•We continued to expand awareness in the world of social media, with more than 17,000 fans on Facebook and active followings on Twitter and LinkedIn.

Danny Did Foundation Year in Review: 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, in partnership with the Epilepsy Foundation of Chicago, created a **Seizure Safety/SUDEP Information Brochures**.

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, pediatrician’s offices, neurologists’ offices, hospitals, and epilepsy centers heightens awareness of epilepsy and contributes to improving treatment and response to seizures that occur in public. People who don’t know how to react to a seizure now know how. It’s a tangible and important change.

In addition to our Seizure Safety brochures, we build awareness through utilizing many platforms. We understand that for people to care about epilepsy, they have to be aware of it. Therefore, there is the Danny Did billboard in downtown Chicago...
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, include a radio campaign on ESPN 1000 AM to promote National Epilepsy Awareness Month**
- Social media presence, including Facebook (over 17,000 fans), LinkedIn, Twitter, YouTube, and Vimeo
- **Our frequently updated website at http://www.dannydid.org.**

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.
Danny Did Foundation Year in Review: Trials and Grants

In 2013 the Danny Did Foundation Funded a grant at Boston Children’s Hospital in Massachusetts to study biomarkers that could serve as height risks for SUDEP. This trial can help researchers better understand the mechanisms of SUDEP and the potential monitoring benchmarks that are critical for parents and caretakers to be alerted to.

We also funded a research grant at Northwestern Memorial Hospital in Chicago, where a newly created infrastructure will enable devices and technologies to be tested in a uniform clinical setting that multiple epilepsy centers have access to.
Danny Did Foundation Year in Review: 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 them device to families nationwide so that they can investigate its potential usefulness for their loved one. And while many have gone on to purchase one, 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 43 states, the District of Columbia, and Canada, Luxembourg and Brazil. Feedback from parents tells us that these monitors are having a practical impact and providing peace of mind.
Thank you for enabling such an amazing product that has potentially saved so many lives. Because of the Danny Did Foundation providing my son with the Emfit monitor we have been alerted to many seizures we may not have ever caught before. My little one no longer expresses being fearful of going to sleep and I am able to have a better feeling of security throughout the night.
- Heather, Glastonbury, CT

Danny Did Foundation Year in Review: Events

4th 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, Gordon Tech College Prep, and Benet Academy.

4th Annual Hearts and Hugs Gala Over 300 Danny Did Foundation supporters joined the DDF at its 4th Annual Evening of Hearts and Hugs at the Jean Marie Ryan Center on the North Side of Chicago.

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

4th 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 2013. Merging fitness and fundraising while raising awareness for our foundation, our supporters
to prevent deaths caused by seizures.

Awards were presented to outstanding epilepsy advocates, and we also awarded the 3rd annual Danny Did Foundation High School Scholarship Award.

Team Danny Did participated in walks, runs, bike rides, and triathlons nationwide. Team Danny Did continues as a growing platform for the DDF.

Above: Team Danny in the 2013 Chicago Marathon
Danny Did Foundation Year in Review: Sample Media Coverage

Chicago Tribune

April 24, 2013

Kotowski’s Proposal Creates National Model to Prevent SUDEP

Springfield - A measure to improve awareness and gather research concerning sudden unexpected deaths in epilepsy (SUDEP) passed the Senate on Tuesday.

State Senator Dan Kotowski (D-Park Ridge) worked with Tom Stanton, the executive director of the Danny Did Foundation, to put together this proposal. Mr. Stanton’s 4 year-old nephew, Danny, lived with epilepsy before dying from SUDEP following a seizure that occurred during his sleep. His family was never made aware of the possibility of SUDEP, a seizure-related risk that is not often discussed between doctors and patients.

“Coroners and medical examiners can play a key role in recording instances of SUDEP, and this data will help to educate the public on its causes and signs,” Kotowski said.

The definition of ‘Sudden Unexpected Death in Epilepsy’ (SUDEP) is accepted as an unexpected death in a person with epilepsy, with no clear causes for death. It is a baffling condition that brings sorrow and bereavement to many families every year. Little is known about the precise causes of SUDEP, although it is now accepted that it is likely to be triggered by a seizure as, almost invariably, SUDEP seems to happen in the aftermath of a seizure. SUDEP is the most common cause of death in epilepsy and accounts for an estimated 20,000 of deaths in people with epilepsy every year.

“This legislation will create a national model to further SUDEP research,” Kotowski continued. “It will help save lives by providing accurate data that furthers research and hopefully one day can prevent sudden death for those with epilepsy.”

“Providing data to a national SUDEP registry is a key factor in discovering the causes behind this devastating occurrence,” said Stanton. “It is critical that an autopsy includes inquiries about a history of seizures and epilepsy and that the process includes the opportunity for a bereaved family to further epilepsy research. This bill will make Illinois a national leader in fighting SUDEP.”

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Northwestern University Dance Marathon Raises Over $1.2 Million for Charity

Justin Barbin / March 13, 2013

There were a lot of amazing events this past weekend throughout the Chicagoland area, but there was only one of me and only one philanthropic event I would not have missed for anything in all of Chicago.

Northwestern University held its 39th annual Dance Marathon (NUDM) from March 8-10 with over 1,000 college students participating and raising over $1.2 million dollars. $1,214,632 to be exact.

I donated my photography services for this incredible weekend-long experience -- an incredible enough experience that Illinois Governor Pat Quinn honored NUDM with an official proclamation for March 8-10, 2013 to be "Northwestern University Dance Marathon Weekend" in the state of Illinois. The organization's impact on the surrounding community, The Danny Did Foundation, and every sponsor and participant is immeasurable. The dancing may last 30 hours, but the true effect of NUDM really lasts for years to come. The donations they provide each year to a specially chosen charity helps in funding research endeavors, covering any needs the organization may have, and developing programs to enrich communities among other benefits. Past charities NUDM has supported include Andrew McDonough B+ Foundation for childhood cancer, The Children's Heart Foundation, Bear Necessities, and CURE (Citizens United for Research in Epilepsy). This year NUDM supported The Danny Did Foundation along with the Evanston Community Foundation. Founded in January 2010 by Chicagoans Mike and Mariann Stanton after the sudden unexpected death in epilepsy (SUDEP) of their 4-year-old son Danny, The Danny Did Foundation is dedicated in its mission to prevent deaths caused by seizures. The issue of aggressively addressing SUDEP is as urgent as it is logical with nearly three million people facing the challenges of epilepsy in the U.S. and 50 million people affected by epilepsy worldwide.

What exactly goes down during 30 hours of dancing?

For starters, participants do get some time off their feet in between 10 dancing periods of time (called blocks). Each block lasts for three hours and dancers get 10 minutes for resting. During each block, a pre-determined theme (this year's standout themes: Thrift Shop, Let's Get Weird, and Space Jam) influences the music played and the costumes worn by the dancers. Snacks are periodically delivered to the dance floor via well-orchestrated food committee parades that weave through the hundreds of participants, as well as three designated breaks for breakfast, lunch, and dinner.

Special performances and visitors take the stage to cheer on the dancers and lift their spirits throughout the marathon which this year included Illinois State Senator Dan Kotowski, Football coach Pat Fitzgerald and the Northwestern football team along with speakers from The Danny Did Foundation who provided personal stories to share how important the dancers' participation was to so many people. The cast of Modern Family, Jonah Hill, Adam Sandler, Olympian and NU alum Matt Grevers, activist Erin Brokovich, and director David O. Russell among a slew of other celebrities shared their support for NUDM via video
messages that were broadcast on the tent's two jumbo screens.

The energy inside the DM tent is indescribable. If I plotted the alertness level of the crowd throughout the 30 hours it would look like a V (the first two blocks obviously having the most energy and then the final two blocks culminating with the big reveal of how much NUDM has raised). The marathon begins at 7 p.m. on Friday with all the dancers giving it their all on the dance floor. By sunrise, exhaustion is inescapable, but the annual song series of "Here Comes the Sun," "Piano Man," and "Seasons of Love" with yellow balloons dropping from the ceiling lift tired spirits (this is my favorite moment of DM). Breakfast at 7 a.m. is the lowest point of energy for the large majority of dancers. They finally get to sit down and eat their first meal while student groups perform in hopes of giving the dancers some energy to get through the 18 hours left. Not even the NU drumline succeeded in keeping everyone awake. Once breakfast is over, things can only look up.

Contests, organized games on stage, a choreographed routine that is taught to all the dancers, and more speakers and videos guide the participants through the remaining hours of dancing to the most important moment of the marathon -- the big reveal of how much NUDM raised.

Block 10 is when everyone forgets about how tired they are. The final three hours are filled with the happiest dancers you'll ever see -- happy for the end of the marathon but mainly for how much they've done in support of The Danny Did Foundation.

As 12:30 a.m. Sunday morning approaches, a large board is brought on stage (not unlike one you'd find on The Price is Right) and the executive committee that organized the event led by Northwestern seniors Matt Larsen and Katie Amys sits on stage hugging each other with bated breath for the final total.

This year, the reveal of the record-breaking $1,214,632 brought the greatest cheers as last year's amount is trumped by over $100,000. The immense amount of love and tears that spreads throughout the tent is indescribable. There is finally a moment of stillness as Collin McLoughlin's acoustic cover of "Save the World Tonight" plays and the entire crowd (most of them -- and me -- in tears) takes the moment in.

Together, they have raised over $1.2 million. Together they have danced for 30 hours. Together they have made a difference.

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