2011 Annual Report

“I just want to learn.”

--Danny Stanton on his first day of preschool
“Learn from yesterday, live for today, hope for tomorrow. The important thing is not to stop questioning.”

--Albert Einstein
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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 7:15AM.

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 was an epileptic. 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. 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 is a measurement in the medical world called “Years of Potential Life Lost”, or YPLL. As the name suggests, it is an estimate of the average years a person would have lived if he or she had not died prematurely. It is, therefore, a measure of premature mortality. As a method, it is an alternative to death rates that gives more weight to deaths that occur among younger people.

To calculate the years of potential life lost, you have to set an upper reference age. In the United States, this is age is commonly set at 75. So for my nephew Danny, who died shortly before his fifth birthday, his YPLL is roughly 70 years. To imagine losing 6 months or a year and even a few years of your life is troubling. But to lose 70 years, that is nearly impossible to comprehend.

According to Dr. David Thurman of the Centers For Disease Control and Prevention, SUDEP falls second behind only stroke as a cause of YPLL among neurological disorders. Among all of the alarming statistics surrounding epilepsy and seizures, that to me ranks near the top.

And so what can we as the Danny Did Foundation do? Little things, for now, that are starting to add up. In 2011 we provided monitoring devices to families across the United States to give them the chance to be present when a seizure occurs, and we continued distribution of our Seizure Safety/SUDEP Information brochures, in both English and Spanish, to families, doctors and hospitals around the country. We developed our educational outreach programs for grammar school, high school, and college students, and expanded our Danny Did Ambassador Program to states spanning from West Virginia to California. We partnered with medical professionals in reaching the Foundation’s goals, and with peer advocacy organizations in nationwide Epilepsy-related conferences and events.

All of those efforts we took on because of a little boy who liked to have fun, who loved his family, who took time to help people. And he would have done those things for about 70 more years if he had the chance. So for as long as we’re able, we’ll do all those things that Danny did. We greatly appreciate your support.

Tom Stanton
Danny Did Foundation Mission Statement and Purpose

Founded by Chicagoans Mike and Mariann Stanton in January 2010 after their four-year old son Danny died from a seizure while he was sleeping, the Danny Did Foundation (DDF) is dedicated in its mission to prevent deaths caused by seizures.

To achieve this mission, the DDF focuses on two main goals: (1) advancing awareness of Sudden Unexpected Death in Epilepsy (SUDEP) via enhancing the SUDEP communication model between medical professionals and those afflicted by seizures, and (2) the mainstreaeming of seizure detection and seizure prediction devices that may assist in preventing deaths caused by seizures.

With three million people in the United States and 50 million people globally afflicted by the neurological disorder of epilepsy, the DDF’s mission to prevent deaths caused by seizures through the direct advancement of information regarding safety issues in epilepsy to both medical professionals and to those who suffer from seizures is as necessary as it is logical. And with an estimated 50,000 annual deaths in the United States alone attributed to the effects of seizures, the DDF’s contribution to the discovery, the development, and the distribution of commercially available seizure detection and seizure prediction devices is critical to reducing a death-rate that is greater than that of those who suffer from breast cancer.

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 well-being, and a weighted cloud that stamps out a sunny day. And to this end as well, the DDF engages all --from grammar school kids to nationally recognized epilepsy experts-- in our effort to prevent another death caused by a seizure.

*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 disease, it 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 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 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.
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 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 to is dedicated to work to help others in Danny’s name.
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 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 will begin his term as Board President in April 2012.
Danny Did Foundation 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. Molly will begin her term as 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

Kathleen Malone, Secretary

Kathleen Malone is a realtor with @properties, where she works with buyers and sellers throughout the greater Chicago area and specializes in new construction luxury sales. Kathleen is the Director of Residential sales for The Elysian Private Residences and also a member of the sales team at Six North Michigan Residences. Kathleen has been featured in The New York Times, The Wall Street Journal, and the Chicago Tribune for her work.

Upon her graduation from Marquette University, Kathleen moved to Boston as a full-time volunteer with the Jesuit Volunteer Corp. There, Kathleen served as the Director of the Children’s Program at Sojourner House, a transitional housing facility in Roxbury, MA for women and children. As its director, Kathleen collaborated with the Boston College PULSE program and provided the children of Sojourner House a cluster of education, health care, recreational, and child care services while leading fundraising efforts for the program. Kathleen returned to Chicago and spent the next two years working as finance director for a United States Senate campaign before entering the real estate profession.

Kathleen resides in Chicago with her husband, who has lived with epilepsy for the last 17 years, and their son. Kathleen is committed to improving the lives of those who suffer from epilepsy and is committed to doing so through her association with the Danny Did Foundation. Kathleen began her service as DDF Secretary in 2011.
Danny Did Foundation Board of Directors

Doug Bruno

A pioneer and crusader for women’s basketball at all levels, Doug Bruno completed his 26th season as DePaul University’s head coach in 2011-12. Whether it is coaching hundreds of eight-year olds at the Doug Bruno Basketball Camp during the summer, or ending every press conference during the season with “Thank you for supporting women’s basketball,” Doug is always promoting and growing the game. Danny’s mother Mariann is one of the thousands of former campers upon whom Coach Bruno had a positive impact, and their friendship has remained strong to this day.

In addition to working with youngsters at his camps, Coach Bruno also works with the sport at the highest levels with USA Basketball and the WNBA. In September of 2009, Bruno was named an assistant coach for the USA Women’s National Team, who will compete at the 2012 Summer Olympics in London. During the Summer of 2006, he served as head coach of the U.S. U18 National Team and led the USA squad to the Gold Medal at the FIBA Americas U18 Championship. He also assists the WNBA’s newest team, the Chicago Sky, as a consultant to the professional franchise.

Over the last seven seasons, Coach Bruno has led his team to seven straight NCAA Tournament appearances and the programs’ first Sweet Sixteen showing in 2006. Overall, Coach Bruno has led the women’s basketball program to 18 postseason appearances in the last 21 years.

Doug and his wife have six children and five grandchildren. Doug and his family reside on the north side of Chicago and is proud to serve the Danny Did Foundation.
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.
Danny Did Foundation Board of Directors

Senator Dan Kotowski

Illinois State Senator Dan Kotowski Dan advocates for Danny Did Foundation first as a person who has 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 second term on January 14, 2009.

In his time serving the people of the 33rd 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 to represent the 33rd district 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

Peter 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.”

In his current assignment for the Chicago Fire Department, 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 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 17 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 the past 20 years. She is currently a Chicago Public 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.

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**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 and Montreal, Canada

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.

Danny Did Foundation Ambassador Group

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 five-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

Cindy Mitchell & Family
California

Cindy and her husband Tom have a son 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.

Danny Did Foundation Ambassador Group

Kendal and Andrew O'Lenick
Georgia

Kendal and Andrew have a 3 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 Year in Review

“WOW...I just found this site [www.dannydid.org] through our local Epilepsy Foundation page and it is overwhelming. As a mom of a 9 year old who has had seizures since he was 3 months I am shocked and angered at the neurologists who have kept this information from us. I specifically remember our first neurologist telling us that “a seizure won’t kill him.” God bless you and your family in your quest to make SUDEP known to the community. I pray that your work will bring you peace in the months and years ahead. Thank you!” - Kristen, Colorado

In 2011, the Danny Did Foundation continued its growth, helped families across North America, and accomplished meaningful and measurable successes. Some highlights include:

• Together with the Epilepsy Foundation of Greater Chicago, we played the lead role in initiating a three-hospital clinical trial (Children’s Memorial Hospital, Northwestern Memorial Hospital, and Rush University Medical Center) of a seizure detection device called the Emfit Movement Monitor. This study is the first of its kind in the United States and is providing valuable data that doctors are using to make informed recommendations to their epilepsy patients. Data from these trials were presented at the annual meeting of the American Epilepsy Society (AES) in December 2011 and have led to further testing of the device at a hospital in Tennessee.

• We have updated and distributed 20,000 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 made available to them. In collaboration with the Epilepsy Foundation of Los Angeles and Dr. Reyna Duron in Honduras, we have also had this brochure translated and printed in Spanish.

• In 2011 we have subsidized seizure alarm monitors for 56 families nationwide, up from 19 in 2010. We have now provided financial assistance to families across 35 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 for
epilepsy. The inquiries we receive from both families and doctors about the monitor indicate that our awareness efforts for this resource are making a practical difference.

• To enhance our accessibility to people all over the globe, in 2011 we redesigned and relaunched our website, www.dannydid.org, and continued to grow our presence in the world of social with more than 13,000 fans on Facebook and active followings on Twitter and LinkedIn.

• Our “Danny At Your School” educational program has continued to develop and grow, and included DDF presentations to elementary schools, high schools, and colleges throughout 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.

• We created the Danny Did Ambassadors program, designed to further integrate our cause and mission into communities and networks across the United States.

I truly believe that without the Stanton’s the awareness of SUDEP would still be in the infancy stage. Only two years ago when I was researching, I could not find any news on SUDEP. How sad that we have to lose someone we love to get to this point. –Kari, Minnesota
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, have 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 20,000 of these informational brochures to date. This brochure is now in homes nationwide, and in many medical settings, including: Children’s Hospital in Boston, MA; Riley Children’s Hospital in Indianapolis, IN; Yokosuka Navy Base in Yokosuka, Japan; Cleveland Clinic Hospital in Amhurst, OH; Swedish Covenant Family Practice Clinic in Chicago, IL; and Wellspan Pediatric Neurology in York, PA.

Having this brochure available in schools, pediatrician’s 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. People who don’t know how to react to a seizure will now know how. 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**
- Social media presence, including Facebook (over 13,000 fans), LinkedIn, Twitter, YouTube, and Vimeo
- **Our frequently updated website at** [http://www.dannydid.org](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.

“Thank you for your website, we have found your information regarding epilepsy and SUDEP quite helpful. We have a 10 year-old daughter who was diagnosed with Rolanic Benign Seizure disorder 2 years ago (seizures that occur as she is falling asleep). We have visited your website several times, it was the first one we went to after her last seizure. We have taken some of your suggestions and incorporated them into monitoring her sleep. We have learned quite a bit from your website that we didn’t hear from the “Experts.” You could have let someone else step up to the plate when it came to educating the world regarding epilepsy. Thank you for educating us.” - Mike and Gigi, Illinois
Danny Did Foundation Year in Review: Trials and Grants

In 2011 the Danny Did Foundation played the lead role in initiating a three-hospital clinical trial (Children’s Memorial Hospital, Northwestern Memorial Hospital, and Rush University Medical Center) of a seizure detection device called the Emfit Movement Monitor. This study is the first of its kind in the U.S. and is providing valuable data that doctors can use to make informed recommendations to their patients about an in-home seizure detection/alarming system. Data from these trials was presented at the annual meeting of the American Epilepsy Society in December 2011 and has led to further testing of the device at a hospital in Tennessee.

Another device we’ve researched is the California-based Smart Monitor’s SmartWatch, which is a wireless wristwatch device that continuously monitors, detects, and alerts upon the onset of movements that are similar to those caused by seizures. In an effort to further clinical trials and bring SmartWatch to the general public, Danny Did awarded a grant in August 2011 to help fund several clinical trials of the device at leading medical institutions, including Stanford University. The device is expected to become available for sale 2012 and, as we do with the Emfit Movement Monitor, we will subsidize the cost of the SmartWatch for families who are unable to afford one.

The Danny Did Foundation has really come a long way. You are doing a phenomenal job in raising SUDEP awareness and helping families. As parents of two boys with epilepsy, there is nothing more important to us than finding ways to keep our boys safe. It’s something we deal with everyday and that is why we became involved with the Foundation. We need to find more support, funding, research and commitment to find solutions. I know the momentum you are building will continue to grow and for this we are so thankful!
– Tom, Illinois
Danny Did Foundation Year in Review: Monitor Subsidies

In the process of discovering the Emfit Movement Monitor as one that we wish we had known about ourselves, the Danny Did Foundation has introduced this 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 35 states, the District of Columbia, and Canada. Feedback from parents tells us that these monitors are having a practical impact and providing peace of mind.

*I just wanted to you to know that this monitor has been a true blessing to my family and me. I feel like it will give me peace of mind that I haven’t had in what feels like forever. No words can describe our appreciation, but as soon as we are able, we will begin planning a fundraiser to show our support.* - Mollie, Alabama

*I wanted to let you know that my daughter’s movement monitor went off an hour ago and woke me up. This time I really do wonder if it saved her life because she had turned and had her face pressed up against her pillow when I found her. Had I not heard the alarm on her monitor I honestly can’t say what would have happened, because her seizure continued on for a few minutes more after I moved her face away to clear her airway. My heart is still racing. Thank you Danny Did Foundation.* – Renee, Ontario, Canada

*Went to the pediatrician today. The doc noticed my [Danny Did] bracelet and the one I put on the baby’s car seat (I figure when people stop to see the new baby, they will see Danny too :) The doctor had never heard of the monitor and was very impressed when I told her where it was being tested. She wrote it all down (the foundation name/site and the Emfit) in my son’s chart! Our Duke appt is on Monday and we will talk about you guys there too : ) We love what you guys are doing! Keep it up Danny!* – Meghann, North Carolina
Danny Did Foundation Year in Review: Events

2nd Annual Buzz Cuts: Chicago, IL, Orland Park, IL and Tunkannock, PA Hundreds of boys and men received Danny’s favorite cut as they got ready for summer and gave a nod of their heads to a little boy who knew how to live his life in style.

The girls and the ladies got into the game as well this year as they sported purple hair extensions representative of the color of Epilepsy awareness.

Entire baseball and softball teams showed up in Chicago for buzz cuts and extensions in support of Epilepsy. SUDEP, and the Danny Did Foundation.

2nd 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!

Countless volunteers, coaches, umpires, face painters, and parents made the day a big success for Epilepsy and SUDEP Awareness.

2nd Annual Hearts and Hugs Gala Over 300 Danny Did Foundation supporters joined the DDF at its 2nd Annual Evening of Hearts and Hugs at Misericordia on the North Side of Chicago.

From senators 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 medical professionals and other epilepsy advocates, and we also awarded the first annual Danny Did Foundation High School Scholarship Award.
**Epilepsy Awareness Month: November Online Campaign** In conjunction with Epilepsy Awareness Month, our supporters nationwide and around the world to take part in the Danny Did Foundation’s Epilepsy Awareness Month Campaign, which ran throughout November 2011 and during which we received donations from supporters in 20 states, Canada, and Switzerland. Watch our video at http://www.vimeo.com/30753232.

**Bake For Danny Sales** A new initiative that blends fundraising and awareness with old fashioned community spirit. The program consists of Danny Did Foundation supporters nationwide hosting a local bake sale in any location. Proceeds from each bake sale are donated to Danny Did. Along with their baked goods, hosts distribute information on Danny Did’s mission to prevent deaths caused by seizures.

**Team Danny Did** Team Danny Did members represented and raised money for the DDF in races across the country in 2011. Merging fitness and fundraising while raising awareness for our foundation as supporters participate in a walks, runs, bike rides, triathlons or any type of athletic event, Team Danny Did is a growing platform for the DDF.

**Fly Danny Fly: Book Launch for Children’s Book** A new children’s book, *Fly Danny, Fly*, written by authors Chip Gilbertson and Gina Restivo, who were inspired to complete the project thanks to the way that Danny lived his life. The Danny Did Foundation will receive partial proceeds from the sale of *Fly Danny, Fly*, which is now available for purchase at http://www.pigupstation.com.
Family: Danny making a real difference for others

By Tamara L. O'Shaughnessy
Wednesday, November 23, 2011

It's been 23 long months for one Chicago family, but this Thanksgiving, the Stantons will pause and reflect on what they've accomplished in their little boy's name.

Danny Stanton was 4 when he died in his sleep Dec. 12, 2009, during a seizure, a possibility his family never imagined or were warned could happen. It is called SUDEP--Sudden Unexplained Death in Epilepsy--and his family has worked hard to make sure what happened to their family doesn't happen to others.

The statistics are scary: 50 million people suffer from seizures, with 45,000 children diagnosed in the U.S. every year. Fifty thousand people die from seizure-related deaths annually. While other organizations raise money for treatment and a cure, the Stantons decided to focus their efforts on making a practical difference, or as Danny's uncle and foundation Executive Director Tom Stanton says, to help a family get to the next day.

So far, the Danny Did Foundation has provided 67 Emfit seizure alarm monitors to families who can't afford them in 30 states and facilitated clinical trials on the monitor at three Chicago hospitals, with the hope that it one day lead to FDA approval and insurance coverage. It also has provided a grant to support clinical trials of a SmartWatch wristwatch device at Stanford University, which alerts caregivers via smartphone of a seizure.

The foundation also created and distributed 20,000 seizure safety brochures to families, hospitals, doctors and epilepsy organizations. As the Stantons found, this information was not readily available to families.
"It makes you take a step back and you think not only how many lives he has changed, people with and without epilepsy, but how many lives has he saved already," Danny's mom Mariann Stanton says about the accomplishments so far. "... He's changing people's entire lives, the way they live and he's 4 and a half years old."

From the start, Mariann Stanton says she has tried to keep life as normal as possible for their other children - Johnny, Mary Grace and Tommy. They talk about Danny a lot, she says, and they are involved in all of the activities for the foundation. It's still hard, she says.

As for her? "A part of him is forever a part of me... I am just walking slowly through life, I'm just trying to walk forward and not backwards right now."

**How to help**

The Danny Did Foundation is hosting a November Awareness Month Campaign, [http://vimeo.com/30753232](http://vimeo.com/30753232). The goal: to reach 15,000 Facebook fans to spread the word about SUDEP and for 1,000 people to donate $25 each to help provide seizure alarm monitors to people who need them but can't afford them. To contribute, visit events.org/november.

Kids can get involved through the Bake for Danny Did initiative. Supporters host a local bake sale, with the proceeds donated to the Danny Did Foundation to continue to raise awareness of SUDEP.

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loved sports; he was already a switch hitter and could ride a two-wheel bike at four years old. Danny's preschool teacher told his parents that the first thing Danny said to her on his first day of school was, "I just want to learn."

"He was just the most engaging, athletic, inquisitive kid you'd ever meet," his father, Mike Stanton, a police officer in Chicago, told HuffPost. "In every way in his life, he was unique."

But when he was only two years old, Danny experienced his first night seizure -- his eyes rolled back into his head and he started to shake violently. Mike and his wife, Mariann, didn't know what was happening to their son, but they rushed him to the hospital. After a round of tests, the doctors weren't able to determine what caused Danny's seizure. But they assured the Stantons that Danny would be OK; children often outgrow their seizures, doctors said, and they shouldn't worry.

"It was horrifying to wake up to that," Mike said. "But we were given this sense of comfort, that everything would be fine."

Danny experienced a few more seizures in the years that followed. Neurologists and other doctors met with him consistently, but none ever gave the indication that Danny's seizures could eventually be fatal. Danny was put on daily medication, but otherwise, he lived a normal life.

"But then, here we are now," Mike said.

Just over two years after Danny's first seizure, on a December morning in 2009, Mike and Mariann entered Danny's room to find him lifeless. Five EMT personnel attempted to revive him in their home, and he was again rushed to the hospital, but Danny could not be saved. He was a victim of SUDEP: Sudden Unexplained Death in Epilepsy.

Mike remembers getting home from the hospital that day. "My wife and I were up in our room looking at each other, asking: how could this happen? How could we not know that something like this could happen? We were so involved in his life, in his health, how did we not know this was a possible outcome?"

Rather than turn inward, Mike and his family made the decision to take action. They enlisted Mike's brother, Tom, who had a history of working with non-profits and legal organizations, and together, they formed the Danny Did Foundation -- its name a take on the words Mike wrote at the end of Danny's death notice: “Please go and enjoy your life. Danny did.”

"When we started, we didn't have a real framework for how it should work," said Tom Stanton, who is now the executive director of the foundation. "But we just posted a little Facebook page, and Mike just started posting pictures of Danny, with captions -- very personal thoughts about his son. And then, all of a sudden, we had 3,000 fans within 48 hours."
Things grew from there. Initially, the foundation was just focused on drumming up awareness for SUDEP, but soon they began promoting prevention methods, purchasing seizure detection and prevention devices for families with children in need (such a device might have saved Danny’s life) and sharing their findings with doctors and hospitals nationwide. The site currently features a slew of emphatic testimonials from families who have been helped by the foundation.

Mary Duffy, who is now the chief operating officer for the foundation, told Mike early on that they’d need to "start big and stay big" if they wanted to have an impact, and Mike has taken that mantra to heart. He and his family continue to work tirelessly for their cause, despite his own full-time job as a Chicago cop.

"The most important thing I want to communicate, through all of this, is Danny himself," Mike said. "It's Danny that drives us every day, without question."

Of course, Mike wishes someone else had started a similar foundation before Danny died. Their desire to raise awareness for SUDEP and epilepsy in general is mixed with the anger they feel about how little information they were given about Danny's condition.

"We certainly wonder sometimes why we had to do this," he said. "Why didn't somebody else do it first? If we had known what was possible, we might have treated it differently. The term epilepsy had never been raised to us. There was a real failure on the doctors' part to provide this information."

Currently, epilepsy claims the lives of 50,000 people each year; more than breast cancer. The Danny Did Foundation is "urgently committed" to getting the right information to doctors across the country -- to let them know that these seizures can be fatal, but with enough detection and care, there are ways to prevent fatalities. And they're here to help.

"We want a meaningful, measurable, and immediate impact," Mike said. "We don't want to wait around."

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