“I just want to learn.”

--Danny Stanton on his first day of preschool
“Live as if you were to die tomorrow. Learn as if you were to live forever.”

--Mahatma Gandhi
Table of Contents

MEET THE DANNY DID FOUNDATION

MEET DANNY ................................................................................................................................. 4
LETTER FROM THE CO-FOUNDERS ............................................................................................. 7
LETTER FROM THE EXECUTIVE DIRECTOR ................................................................................. 8
MISSION STATEMENT AND PURPOSE ......................................................................................... 9
THE OBJECT OF OUR OBJECTIVE: EPILEPSY ........................................................................ 10
DDF STAFF ..................................................................................................................................... 11
BOARD OF DIRECTORS .............................................................................................................. 13
MEDICAL ADVISORY BOARD ..................................................................................................... 23
DANNY DID AMBASSADOR GROUP ............................................................................................ 24

DANNY DID FOUNDATION YEAR-IN-REVIEW

YEAR IN REVIEW .......................................................................................................................... 27
ADVANCING AWARENESS ........................................................................................................... 29
TRIALS AND GRANTS .................................................................................................................. 31
MONITOR SUBSIDIES .................................................................................................................. 32
EVENTS ........................................................................................................................................ 33
SAMPLE MEDIA COVERAGE ........................................................................................................ 35
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

According to a 2012 report from the Institute of Medicine – an independent, nonprofit organization that works outside of government to provide unbiased advice to decision makers and the public - approximately 1 in 26 Americans will develop epilepsy during their lifetime. Beyond that, roughly 150,000 new cases of epilepsy are diagnosed in the United States each year. The report also concluded that epilepsy ranks fourth among the most common neurological disorders. These staggering numbers detail the depth of epilepsy’s impact. One of the world’s oldest known disorders – documented back to biblical times – is still developed by 1 in 26 people over the span of a lifetime.

But of course, numbers don’t tell the whole story. This year Daniel George Stanton would have celebrated his 7th birthday on March 2nd. He would have entered the second grade and he would have done what he did best: learn, make new friends, and make people happy. No study or report can capture the loss of Danny’s heart, smile, or hugs. His story and the stories of millions of other families who are impacted by seizures are what continue to drive Danny’s foundation ahead.

There were several exciting efforts to support the Danny Did Foundation this year, including the “100 Miles For Danny” ice skating campaign by 8 year-old Chicago boy Nick Curley, who, as third grader, raised more funds for our cause than any other person to date. Jon Duresky, a grandfather and pilot from Warner Robins, Georgia, completed a 72-mile hike along the Appalachian Trial in Tennessee’s Great Smoky Mountains to raise awareness for epilepsy in honor of his two grandsons, Connor and Asher, who suffer from seizures.

Our foundation has continued to grow with the creation of the “Bake For Danny” program, and the launch of the “Danny’s Girls” fitness program, led by Danny’s mom Mariann. We’ve also added some great new people. Kendal O’Lenick and her husband Andrew joined our team as our Danny Did Ambassadors in Atlanta, and Brendan Malone, a longtime advocate and a person living with epilepsy, joined our Board of Directors.

In the summer of 2012, we were proud to be an affiliate of the Partners Against Mortality in Epilepsy (PAME) Conference in Evanston, IL, the first conference in North America to focus on Sudden Unexpected Death in Epilepsy (SUDEP). Medical professionals, advocates and families joined to raise awareness, advance understanding, and push for more solutions as part of the quest to find a cure for seizures and SUDEP.

Our supporters enabled us to spread awareness nationwide and to lend financial assistance to families across 38 states and Canada in Danny’s name in 2012. We appreciate your friendship for a boy who continues to make a difference.

Tom Stanton
Danny Did Foundation Mission Statement and Purpose

Founded by Chicagoans Mike and Mariann Stanton in January 2010 after the death of their four-year-old son Danny, the Danny Did Foundation works toward its mission to prevent deaths caused by seizures with these main goals in mind: advancing awareness of Sudden Unexpected Death in Epilepsy (SUDEP) and enhancing the SUDEP communication model between medical professionals and those afflicted by seizures, and the mainstreaming of seizure detection and prediction devices that may assist in preventing deaths caused by seizures.

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 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.
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.
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, 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 evaluations 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.
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

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.
Danny Did Foundation Board of Directors

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 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 Stanton's 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 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.
Dr. Marvin Rossi M.D., PhD

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

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

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

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

Dr. Marcuccilli’s professional memberships include the American Epilepsy Society, the American Academy of Neurology, and the American Academy of Pediatrics. Dr. Marcuccilli is also a member of the board of directors for First Steps Foundation.
Danny Did 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.

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

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 will run the 2012 Chicago Marathon as part of Team Danny Did. The Oxford, MS 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 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

“I just wanted to say thank you for all that you do. My son is 7 years old and just recently spent three weeks in the hospital with uncontrolled seizures. I had happened upon your site when researching SUDEP. No coincidences, I then contacted Emfit and received our first monitor within the last few months. That monitor saved his life on July 4th at 1 am when it alarmed and we found him turning blue after a grand mal. I thank you for all that you continue to do and I am forever grateful for finding the Danny Did Foundation. – Tom, New York
In 2012, the Danny Did Foundation continued its growth, helped families across North America, and accomplished meaningful and measureable successes. Some highlights include:

• Began a 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 fall of 2012 raising awareness and education of epilepsy and seizures on Northwestern’s campus in Evanston, Illinois. This was an incredible opportunity to engage talented, service-oriented college students into the greater cause of epilepsy.

• Funded a grant at Rush University Medical Center in Chicago to advance clinical trials for seizure alarm devices. These trials provide data that doctors need to make an educated recommendation to their patients.

• We continued to expand awareness in the world of social media, with more than 15,000 fans on Facebook and active followings on Twitter and LinkedIn.

• 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 June, we served as a partner and lead sponsor for the inaugural Partners Against Mortality in Epilepsy (PAME) Conference, the first meeting in North American solely dedicated to advance progress against SUDEP.

• 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 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.

• In 2012 we have subsidized seizure alarm monitors for 67 families nationwide, up from 56 in 2011. We have now provided financial assistance to families across 38 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.

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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 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 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 15,000 fans), LinkedIn, Twitter, YouTube, and Vimeo
- **Our frequently updated website at http://www.dannydid.org.**

![Danny Did billboard in downtown Chicago](image-url)
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’s story touched a worried part of me. My son has had seizures for most of his life. One night I woke up to him turning blue and stiff. I thought I was too late. I have asked, several times since then, if I could lose him and they tell me no, it’s not likely. They weren’t with me when I picked him up knowing he wasn’t there and the pain that tore through me. Or the worried joy I felt when I heard him breathe again. Thank you for fighting for kids like mine. Danny is still making a mark on the world.”

- Tammy, Michigan
Danny Did Foundation Year in Review: Trials and Grants

In 2012 the Danny Did Foundation funded a clinical trial at Rush University Medical Center in Chicago that set out to test the efficacy of a new iteration of the Emfit Movement monitor, as well as a wireless EEG telemetry helmet (Emotiv). The sensitivity of the bed mattress monitor will be measured and compared during the awake and sleep states for time of detection for seizure-related heart rate changes with time of detection of seizure-related brain wave changes as measured by the EEG telemetry unit. As 2012 ended this studied continued.

Trials and studies for the Emfit Movement Monitor and the SmartWatch from Smart-Monitor that were instigated in 2011 continued in 2012.

It is amazing the impact this little boy has had on the world. In his short life he has inspired so many to act, to help and to selflessly put other people first. He has opened my eyes to all that is good. I tell my kids how much I love them, I tell my friends how important they are to me and I approach every day with optimism. I am a 51 year-old man and my life has taken on a new purpose and a renewed passion. All because I became sick and learned of an amazing organization that has transformed a tragedy into tremendous acts of charity, hope and support. I am inspired by your family and your organization. I am a better man because of a little boy I never met. – Brian, Chicago
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 38 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.

*Our son is four and, despite having a complicated medical history, remains sweet and smiling. He has autism, and a connective tissue disorder called Ehlers-Danlos Syndrome. Words can’t express how grateful our family is to be receiving this monitor. It is an unbelievable gift that eases our minds and warms our hearts. – Burrows family, Virginia*

*Thanks to your advice, my husband and I can sleep at night. After two seizures during sleep, at least the two that we know of, we didn’t dare to leave our son sleep by himself. We live in South America and EMFIT is not known here, we can now sleep quiet at night. Thank you very much for the job you do, your help goes further that you can imagine. - Silvina, Montevideo, Uruguay*

*Since Danny Did generously provided us with an Emfit Movement Monitor for our daughter, it is so much easier to relax a bit at night. This is quite a sophisticated piece of technology with an impressive sensitivity setting. Luckily, we have had a very limited amount of times that we have had to react to it but we know that it is going to be there for us when it is truly important to be alerted. We can’t thank you enough for what you have done for us and what you do everyday for families everywhere. We continue to get the word out about Danny and the Danny Did Foundation. – Doug, Farmingville, NY*
Danny Did Foundation Year in Review: Events

**3rd Annual Buzz Cuts** Hundreds of boys and men received Danny’s favorite cut as they got ready for summer and shed their locks for 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.

**3rd 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.

**3rd Annual Hearts and Hugs Gala** Over 300 Danny Did Foundation supporters joined the DDF at its 3rd 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 2nd 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 2012 and during which we received donations from supporters in 20 states, Canada, and Europe.

**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 to combat seizures in races across the country in 2012. Merging fitness and fundraising while raising awareness for our foundation, our supporters participated in walks, runs, bike rides, and triathlons nationwide. Team Danny Did is a growing platform for the DDF.
8-year-old's 100-mile journey on skates ends Sunday at Wolves game

Curley raises money to help fight Sudden Unexpected Death in Epilepsy

By Chris Kuc / October 28, 2012

With only 5 miles remaining in a 100-mile journey that began in July, 8-year-old Nick Curley has begun pondering how he will feel once he reaches the finish.

"Great," the third grader from Norwood Park said. "And relieved."

And then there will be the sense of accomplishment and pride that will come along with doing something special to honor a little boy he never met while at the same time helping families avoid tragedies like the one that took the life of 4-year-old Danny Stanton in 2009.

During the first intermission of the Wolves game Sunday afternoon at Allstate Arena, Curley will skate the final mile of his "100 Miles For Danny" campaign that is raising money to help fight Sudden Unexpected Death in Epilepsy, or SUDEP. Through donations, Curley has raised more than $15,000 toward his goal of $25,000.

The money will go to the "Danny Did Foundation," with the intent to purchase monitoring devices for families impacted by epilepsy. The monitors help detect dangerous seizures like the one that claimed the life of Stanton while he slept. The name "Danny Did Foundation" is derived from the last sentence of Danny's obituary written by his father, Mike Stanton, that read: Please Go and Enjoy Life. Danny Did.
Mike Stanton grew up in Rogers Park with Nick Curley's dad, Brian, and when then 4-year-old Nick heard about the boy who passed away at his same age, he wanted to do something — especially since the cause of the tragedy hit home. Nick's 9-year-old cousin, Jenny, has epilepsy and has also suffered night seizures.

"I wanted to help somebody and do something fun at the same time," Nick Curley said. "And because my cousin had the same disease that Danny had."

Eventually, "100 Miles For Danny" was launched and Curley has been skating ever since. He has skated 5-mile increments in Chicago-area rinks heading into Sunday's final leg, and has been helped along the way by hockey players and dignitaries, including Blackhawks legend Denis Savard and Illinois Congressman Mike Quigley.

Curley will skate Miles 96-99 before Sunday's Wolves game, and during the first intermission will be joined for the final mile by former NHL goaltender and current Wolves general manager Wendell Young, who has spent some time getting to know the youngster.

"It's an honor for our team, our organization and a huge honor for me personally to be skating the last mile with Nick," Young said. "He's doing something extraordinary, taking a bad situation and making something out of it.

"I don't think he knows the magnitude of what he's really doing. For a person who's that young and wants to do something like this it speaks volumes of his parents and the child

As if skating 100 miles isn't difficult enough, Curley is doing many of them backward ("because I'm a defenseman") and at the end will have skated 68 of the 100 that way.

"At the beginning it was very hard," said Curley, who plays for the Glenview Stars Mite team. "After a while you get used to it and it's not so hard."

For more information or to donate, go to dannydid.org.

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Twitter @ChrisKuc

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Jon Duresky, On the Trail of a Cure

By Chris Deighan
April 22, 2012

Even the best conditioned among us have soft spots. For Jon Duresky, it’s his family. In the midst of a light discussion detailing the ways sponsors have contributed to his campaign, Duresky grows suddenly silent. Eyes brimming with tears, he strains against the emotion.

Yes, he’s touched by their generosity. Beyond that, however, the conversation again reminds him of the challenges faced by his daughter’s family. Conner, her 3-year-old son and Duresky’s grandson, is epileptic. Each new day offers only uncertainty.

“You can’t ever let your guard down,” Duresky’s daughter Kendal O’Lenick said. Thankfully, Conner’s condition is relatively well-managed despite the rarity of his particular brand of epilepsy. His first seizure came when he was 10 months old. He’ll turn 4 in July. O’Lenick and her husband, Andrew, have spent a lot of the last three years learning -- then teaching others -- about epilepsy.

They formed “Seize the Day” as a charitable organization to increase epilepsy awareness. In time, they joined forces with a larger foundation, dannydid.org, that has a similar mission. (Danny Stanton was an epileptic who suffered Sudden Unexpected Death in Epilepsy. The charity was formed in his honor.)

Awestruck by his daughter’s determination, Duresky sought a way to help.

“We all have limitations,” he said. “I don’t have unlimited money, so I can’t fund all the research. I don’t have unlimited brains so I can’t contribute brilliant reseah.”

He does have sustainable energy, however. And, especially at age 51, impressive physical conditioning. After hiking a section of the 2,100-mile Appalachian Trail two years ago with family members, Duresky hit on an idea: accept pledge donations for a hike of his own. In May of 2011, he did just that. He’ll tackle another section beginning May 21 in his second annual Hiking for a Cure.
Duresky comes across as a good candidate for the endeavor. A retired U.S. Air Force pilot who now flies for AirTran (soon to be Southwest), Duresky was a three-year wrestling letterman at the Air Force Academy. He officiates high school wrestling to this day.

In addition, Duresky counts “personal trainer” among his varied interests. One of his T-shirts reads, “There is no off-season.” He and wife, Brenda, converted a spare bedroom of their Warner Robins home into a well-appointed mini-gym. Physical training for the hike has included hours climbing the home’s stairs while wearing a weighted pack.

“I told Brenda I’d probably wear out the carpet,” Duresky said. “She said, ‘Good. That means I can replace it.’ ”

The O’Lenicks live in Dacula, so Duresky doesn’t see them as much as he’d like. But they’re never far from his thoughts; especially about 8 a.m. and 8 p.m. That’s when Conner must take his medication.

“Life revolves around the eights,” Duresky said.

He marks the time by performing “extra credit” workout maneuvers in Conner’s honor. Considering what his grandson endures, Duresky figures it’s the least he can do.

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