A BRIEF RECAP OF
2018

NATIONAL WALK FOR EPILEPSY
We joined thousands of families in Washington, D.C. at the 12th annual National Walk for Epilepsy. Danny Did sponsored a Remembrance Wall at this event, to honor the lives lost to epilepsy.

2018 EPILEPSY PIPELINE CONFERENCE
The American Academy of Neurology and the American Epilepsy Society jointly released the first ever practice guideline on SUDEP, recommending that all neurologists inform all patients about the risk of Sudden Death. Danny Did had advocated for this benchmark change for nearly six years.

DANNY STANTON KICKBALL TOURNAMENT
More than 300 kids took part in this sold-out event in Chicago. Each player learns about seizure safety and wears a #19 t-shirt in honor of Danny.

PARTNERS IN MORTALITY AGAINST EPILEPSY CONFERENCE
DDF executive director Tom Stanton served as Co-Chair for this multi-stakeholder, international collaboration. PAME is designed to advance progress related to education, awareness, and research around SUDEP and all forms of mortality in epilepsy.

AMERICAN ACADEMY OF PEDIATRICS CONFERENCE
Danny Did participated in the 2019 Illinois AAP conference, providing education and resources for providers who work in a range of settings, including schools and hospitals. Danny Did also partnered with AAP on its National Coordinating Center for Epilepsy project, fostering strategic approaches to Improving Quality of Care for Children and Youth with Epilepsy.

EPILEPSY AWARENESS DAY AT DISNEYLAND
Nearly 2,000 parents and children attended this free educational expo and awareness initiative at Disneyland. Danny Did is a co-founding partner to this annual event.

TEAM DANNY DID
Athletes from across the U.S. participated in events to raise awareness of epilepsy. Team Danny Did raised more than $100,000 in 2018, a new high.

DEVICE SUBSIDY PROGRAM
We reached our 50th state in providing funding support to families in need of seizure monitoring and alerting systems, devices which increase safety for patients and provide caregivers peace of mind.
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Meet Danny

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

A wonderfully normal two years of 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. 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. Soon, Danny was 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 without 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 Unexplained Death in Epilepsy, of course, crossed no lips and fell upon no ears. 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. 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 Unexplained 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 has epilepsy, and along with this diagnosis comes a plethora of safety issues that you need to become aware of…”

Danny’s daily behavior was completely normal. He continued to be athletic, inquisitive, engaging, social, and, more than anything, affectionate. 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. We caught him twice more having a seizure in his sleep. We informed our doctors of every event.
We continued to trust and believe that we were doing all that we could. 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.

After a year of no known seizures, Danny returned again to his own bed. And then as he turned four 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.’ 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. He had a one-hour EEG done while sleeping, and we met with his doctor afterward. There was still abnormal activity showing up, but maybe a lesser amount than the previous EEG showed. We increased Danny’s dosage that day to accommodate a slight weight gain since his last visit.

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

How many seizures did Danny have that we did not catch? We will never know. 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.

Now life continues—in many respects—albeit without the soft bounce of one little boy’s feet upon the dirt of the Earth. 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.
Letter from the Co-Founders

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

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

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

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

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

Mariann and Mike Stanton
Letter from the Executive Director

I’m pleased to report that 2018 was a year of continuity, growth and progress. Jeanine McShea, the mother of two adult children with epilepsy, continued as President of our Board of Directors. We also continued a partnership with the Cause Marketing Initiative at Northwestern University, through which we enhanced the way we share our story. During National Epilepsy Awareness Month, Danny Did returned as a co-host of the 5th Annual Epilepsy Awareness Day at Disneyland. We welcomed more than 2,200 attendees, all wearing purple to raise awareness of epilepsy at one of the world’s most iconic venues.

This year, the Centers for Disease Control and Prevention revealed that 3.4 million Americans have epilepsy, more than ever before. Each person impacted by seizures has a family that needs resources, information, champions and most of all, a reason to restore hope.

In 2018, Danny would have entered the 7th grade, a safe and nurturing place where his curiosity, talents and friendships would have grown with the passing of another school year. Epilepsy impacts 1 in 26 Americans, and is second only to stroke among neurological disorders in Years of Potential Life Lost (YPLL). Each family who has lost a loved one to epilepsy knows how painful those lost years can be. The communication between medical professionals and their patients about risk of SUDEP is still unacceptably low.

In July, I served as Co-Chair of the Partners Against Mortality in Epilepsy conference in Virginia, where all stakeholders affected by mortality in epilepsy joined to discuss challenges and solutions. Danny Did’s support for families in need extended to all 50 states and 11 countries, resources that many have described as life altering. As we grow to help more people, we encourage and appreciate your partnership. We are excited for what is to come, and anxious for more progress.

Tom Stanton
**Mission:**
To advance epilepsy and Sudden Unexpected Death in Epilepsy (SUDEP) awareness, protect people with epilepsy, and prevent deaths caused by seizures.

**Vision:**
To create a reality in which healthcare providers discuss SUDEP and all mortality related risks associated with seizures with their patients. To elevate awareness of, and access to, technologies that provide early intervention and added safety when a seizure occurs.
ABOUT EPILEPSY

A seizure is a sudden behavioral change resulting from excessive electrical activity in the brain. Seizures may be provoked (also known as acute symptomatic; for example, a fever in a young child, drug intoxication or withdrawal, electrolyte imbalance) or unprovoked, resulting from a genetic, developmental, acquired (for example, head trauma, tumor, stroke), or an unknown cause.

When a person has two or more unprovoked seizures, they have epilepsy. An estimated 3.4 million Americans have active epilepsy, with up to 200,000 new cases diagnosed in the United States each year. Approximately 1 in 26 people will develop epilepsy at some point in their lives, and the onset of epilepsy is highest in children and older adults. Epilepsy impacts 65 million people worldwide and is a spectrum that spans more than 40 syndromes. Despite all available treatments, 30 to 40 percent of people with epilepsy continue to experience uncontrolled seizures. In two-thirds of patients diagnosed with epilepsy, the cause is unknown.

A report from the Centers for Disease Control and Prevention (CDC) indicates that the number of Americans with epilepsy is higher than ever. Epilepsy affects more people than multiple sclerosis, cerebral palsy, muscular dystrophy and Parkinson’s combined – yet receives fewer federal dollars per patient than each of these. According to advocate group Citizens United for Research in Epilepsy, epilepsy costs the United States approximately $15.5 billion each year. The indirect costs associated with uncontrolled seizures are seven times higher than that of the average for all chronic diseases.
ABOUT SUDEP

Seizures can sometimes be fatal from a range of causes, and no matter how the death is defined, every time it is a huge loss. There are numerous ways that a person can die stemming from seizure activity – drowning, an accident, head trauma, suicide, or status epilepticus. Another category of epilepsy mortality is Sudden Unexpected Death in Epilepsy, or SUDEP. SUDEP is the most common category of death in epilepsy. SUDEP is just that: sudden and unexpected. The most recent research shows that a case of SUDEP occurs in 1 in 1,000 people with controlled epilepsy, and for 1 out of 150 people with uncontrolled epilepsy.

The Danny Did Foundation pledges to shine a light on SUDEP for as long as is necessary to achieve major progress in awareness and in the advancement of preventative measures.

WHAT DEFINES A CASE OF SUDEP?

SUDEP is not a cause of death but rather a category of death. A death is referred to as SUDEP when a seemingly healthy person with epilepsy dies unexpectedly and no clear reason for the death can be determined. In most cases, an autopsy is required to rule out other causes of death. The most common criteria used to determine whether a death is due to SUDEP are:

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

OUTDOOR BILLBOARDS

PARTNERS AGAINST MORTALITY IN EPILEPSY CONFERENCE

CAUSE MARKETING INITIATIVE, NORTHWESTERN UNIVERSITY

PSA RADIO CAMPAIGNS

O’HARE AIRPORT AWARENESS CAMPAIGN

For a collective reach of more than 5 million people!
Our practical impact is to enable access to seizure alert devices for families in need. These systems provide added safety for patients, and enhanced peace of mind for caregivers.
Baynon Family, North Carolina

“I am very grateful for what Danny Did has done for epilepsy families. Recently our support group had a doctor from one of the larger neurology practices speak on the subject of SUDEP. Over the past few years I have also noticed that the doctors at Duke are not only addressing it with families, but are sending it home within the discharge paperwork. It’s a far cry from 2010 when they didn’t tell you or were dismissive about it. Thank you for all of your work. Danny is still doing. :-) ”

Turner Family, Chicago

"We cannot begin to express our appreciation for granting us the monitor. As we lay our son down at the end of the day, sleep is not something we get very much of, since we sleep with one eye open in fear of SUDEP. Thank you for making a difference in our little boys’ life, as well as so many others living with this beast they call Epilepsy. I cry tears as this organization is absolutely amazing."
I am a doctor who attended the SUDEP symposium that Danny Did Foundation was a partner to with the Child Neurology Foundation. Listening to the speakers there completely changed the way that I talk with my patients about the risk of sudden death, and I now understand the importance of having the conversation with EVERY family. Since adjusting my communication on this topic, I have noticed an unexpected benefit: my patients are more compliant with their medications and more open about breakthrough seizures. I wish I had thought of this sooner! I have been using the materials provided at the symposium, and I will be ordering more soon.

Pediatric Neurologist, New Jersey
Education

School Presentations in 2018

Visiting with student leaders at DePaul College Prep

With Young Leaders at Highland Park HS

A huge assembly at Meadow Ridge School
HUSTLE & HEART BASKETBALL CLINIC
Chicago Area high school teams volunteered, and 300+ kids enjoyed a day of hoops and epilepsy education.

LinkedIn HAPPY HOUR
Nearly 100 employees at the New York City office of LinkedIn attended a company happy hour to raise funds for Danny Did.

SMOW TURKEY TROT
Danny Did returned as a charity partner to the St. Mary of the Woods Turkey Trot, where nearly 500 runners took part for epilepsy awareness.

4TH ANNUAL STAND UP FOR DANNY COMEDY NIGHT
Hosted by the DDF Young Professionals Board, this annual event drew a large crowd of Twenty-somethings.

9TH ANNUAL EVENING OF HEARTS & HUGS
A record crowd of 650 people attended our Chicago gala, which took place at Theater on the Lake in the Lincoln Park neighborhood.
“One family in Chicago is determined to make a difference for families across the country.”
— NBC5

“My desire to do something to help my siblings — and others who dream of a seizure-free future — kept me going.”
— Loyola Magazine

“1 in 26 people in the United States will develop epilepsy.”
— Joe Girardi, YES Network
OUR PEOPLE

Danny Did Foundation
CO-FOUNDERS

Mike grew up in a family of 10 in Chicago’s Rogers Park neighborhood. After graduating from Loyola Academy, he earned his college degree from Northwestern University. He has worked in law enforcement for more than 20 years, and is also a Realtor for Baird & Warner. He and his family live on the northwest side of Chicago.

Mike Stanton, Co-Founder

Mariann grew up near Chicago’s south side in Oak Lawn, where she attended St. Catherine grammar school. Mariann then attended Mother McCauley high school where she was a star basketball player before going on to Loyola University as a four-year basketball scholarship player. Mariann earned a degree in English from Loyola and then went on to earn a Master’s degree in Education from DePaul University. Mariann is a high school teacher in Chicago.

Mariann Stanton, Co-Founder
Tom Stanton
Executive Director

Tom became Danny Did’s founding executive director in 2010. He remembers many endless summer days and nights playing with Danny and his siblings on Leona Avenue. Tom leads the communications and fundraising efforts for Danny Did, and works to expand their collaborations and impact in the larger epilepsy community. Tom holds a journalism degree from the University of Dayton, and a master’s degree in Public Policy from DePaul University. More than anything, Tom gained happiness from the love Danny gave by way of lots of hugs. He is thankful to have the chance to keep Danny’s spirit alive through service to Danny Did.

Mary Duffy
Assistant Executive Director

Mary has been a part of the DDF staff since 2010. However, her relationship with Danny’s family began when her young sons, Brenden and Charlie, spent years playing sports with the Stanton children. Mary leads Danny Did’s efforts with family support, event planning, and volunteer coordination. She earned her Bachelor’s of Science at Northern Illinois University and her Master’s in Human Resources at Loyola University in Chicago. Mary considers it an honor to serve at Danny Did, and the Stanton family is most grateful not only for her friendship, but also for the wonderful buddy that Charlie was to Danny.

Cathy Rockey
Program Support

Cathy is the newest member to the DDF staff. Her diverse duties including leading interactions with the thousands of families that reach out to Danny Did annually. She has a long history as a small business owner and family advocate.
Julie Dix

Julie is a media sales executive and her career path has featured sustained success at some Chicago's largest radio stations. She is currently an executive at Prime Time Media, where she utilizes her experience and relationships to connect the Danny Did Foundation with a variety of awareness platforms and opportunities. Julie is a graduate of Purdue University, and lives in Wilmette, IL with her husband and their children.

Lynn Hanley

Lynn is an attorney specializing in commercial real estate development, land use and zoning. Lynn has also taught real estate and zoning classes at the University of Richmond Law School and the Loyola University of Chicago Law School. She holds a BA from Miami University, an MA from Xavier University and a JD from Loyola University of Chicago. She and her family live in Winnetka, IL.

Tracy Jablonski

When the eldest daughter of Tracy and Brian Jablonski was diagnosed with epilepsy and a brain tumor in 2015, they learned about the Danny Did Foundation. She has since become an advocate to spread awareness about epilepsy, SUDEP, and the technologies available. Tracy is a graduate of St. Francis University. She and her family live in LaGrange, IL.

Dan Kotowski

Dan advocates as a person who has epilepsy himself. A former Illinois state senator, he has devoted his adult life to public service. While in office, Dan steered passage of the "Danny Stanton SUDEP Act", to mandate reporting of SUDEP cases to a national registry. He now serves as the CEO of ChildServ, a nonprofit that helps at-risk children build better lives. Dan graduated from the University of Illinois and received a Masters of Arts Degree from DePaul University. He and his family live in Park Ridge, IL.

Jerry Luo

Jerry is a medical student at the University of Illinois College of Medicine at Chicago. He first started working with Danny Did as an executive board member of Northwestern University's Dance Marathon, where he successfully managed an effort that raised $1,214,632. Jerry holds a B.A. from Northwestern and an M.S. in from Georgetown. He is a native of Buffalo Grove, IL.
CAROLINE MCATEER

Caroline has worked at DePaul University for over 14 years and manages employer relations for the Career Center. Caroline was diagnosed with epilepsy when she was a teenager. Her personal experience has led to her desire to raise awareness of epilepsy. She holds a BA from the University of Dayton and an MS from DePaul University. She and her family live in Chicago, IL.

MARGARET STOREY

Margaret Storey is Professor at DePaul University and a parent advocate for children with medical complexity. She comes to epilepsy advocacy as the parent of daughter with Aicardi Syndrome, a rare and debilitating condition that causes early-onset, intractable seizures. She received her PhD from Emory University, and has written for The Guardian online, the Motherlode Blog at The New York Times, and The Chicago Tribune. She and her family live in Evanston, IL.

JEANINE MCSHEA

Jeanine has spent 25 years in the real estate industry, both as a broker and an executive. With her daughter Erin McShea, she oversees the McShea Group at @properties. Jeanine is mother to two adult children with epilepsy, both who serve on the Danny Did Young Professionals board. She holds a bachelor's degree from Winona State University, and lives in Chicago with her family.

COURTNEY MURPHY

Courtney leads the consumer and national promotions practice for dynamic retail marketing agency, TPN. Courtney has several personal connections to epilepsy and utilizes her marketing experience to advocate for Danny Did. She holds a BS from the University of Illinois, and an MBA from the University of Illinois at Chicago.

MARY EILEEN MURTAUGH

Mary Eileen is a teacher in the Chicago Public School system. As Danny's aunt, she knew and loved him since the day he has born, and now she is proud to play a part in keeping his presence alive in the world through his foundation. She holds a BA from the University of Dayton and a MA from Northeastern Illinois University. Mary Eileen and her family live in LaGrange, IL.

SCOTT VERHEY

One of the Danny Did's longest serving board members, Scott is an attorney in Chicago at his firm founded in 1995. 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 holds a degree from Marquette University and a law degree from The John Marshall Law School. He lives in Chicago.

Danny Did Foundation
Diane Garvey
Diane works in alumni relations at Regina Dominican High School in Wilmette, ILL. She has hosted several fundraising events for Danny Did, with several featuring her role as a zumba dance instructor.

John Wrenn
John owns and operates several Chicago area businesses, including Theater on the Lake, a premier dining and event space located on Chicago’s lakefront in Lincoln Park. He is active in all forms of philanthropy and specializes in fundraising and development.

Josh Gabby
Josh is an analyst for JPMorgan Chase. His support for Danny Did includes strategy planning, marketing and support of the DDF treasurer.
DANNY DID FAMILY AMBASSADORS

- Tom and Mary Nugent
  Northern Illinois

- Misty & Stephen Phillips
  North Carolina

- Michelle Filip
  Western Michigan

- Mylissa & Jeff Daniels
  West Virginia

- Scott and Lana Frey
  Indiana

- Kari and Dennis Knapp
  Twin Cities, Minnesota

- Stefanie and Marc Mingle
  South Florida

- Cindy Mitchell & Family
  Southern California
We Can't Do it Without You!

DONATE TO DANNY DID
1. Make a Tax Deductible Donation at Dannydid.org
2. Shop on AmazonSmile to Benefit Danny Did
3. Donate Auction Items
4. Employee Matching Plan

ADVOCATE WITH DANNY DID
1. Volunteer at a DDF Event
2. Apply for a Danny Did Internship
3. Share the Seizure Safety Quiz at your School
4. Lead a “fan raising” Social Media Campaign

HOLD AN EVENT WITH DANNY DID
1. Organize and Host your Own Fundraising Event
2. Sponsor a Danny Did Event
3. Coordinate an Epilepsy and Seizure Safety Presentation at Your School
5. Plan a Danny Did kickball Tournament

PARTNER WITH DANNY DID
1. Medical Professionals: Help Us Talk About SUDEP
2. Families: Assist Danny Did’s Outreach to Doctors

Find out more at www.dannydid.org/get-involved
THANK YOU
For Your Support!
Protecting Kids with Epilepsy

Visit us at Dannydid.org  DannyDid  @DannyDidOrg  danny_did.foundation

CONTACT US

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info@dannydid.org