Letter From The Founders

Dear Friends,

In December 2009, our lives changed forever. In a flash, the world became an unbearable place because Daniel George Stanton was no longer in it. We were crushed and alone, left barren and wasted, void of desire and stripped of belief.

We've searched for answers in every conceivable way. Why did this happen? How could this happen? Could we have prevented this? What we've found is that there are no answers, and there are no words. Joseph Kennedy, who too experienced the death of a child, expressed this exact sentiment in a letter to a grieving friend whose son had died:

“There are no words to dispel your feelings at this time, and there is no time that will ever dispel them. I cannot share your grief, because no one could share mine. When one of your children goes out of your life, you think of what he might have done with a few more years, and you wonder what you are going to do with the rest of yours. Then one day, because there is a world to be lived in, you find yourself a part of it again, trying to accomplish something—something perhaps he didn't have enough time to do. And, perhaps, that is the reason for it all. I hope so.”

Today, as we strive to find strength, we rely mightily on the power that is a single moment of hope. Such moments are elusive, yet we recognize their transformative ability if only we can string enough of them together. You all have given us those moments through your friendship.

Together, we are accomplishing something, and together, we are all allowing ourselves to accept an answer to this tragedy in the form of a reason: the creation of the Danny Did Foundation. For the rest of our years we will pick up where Danny left off, giving our hearts and our hugs to those in the world who need our help. Each of you is a champion for our cause, and, more than anything else, each of you is a champion for Danny.

Thank you for joining us on our mission, thank you for this moment of hope, and thank you for your continued support.

Warmest Regards,

Mariann and Mike
Mission Statement

Founded in January 2010 by Mike and Mariann Stanton after the Sudden Unexplained Death in Epilepsy (SUDEP) of their four-year-old son Danny, the Danny Did Foundation is dedicated in its mission to prevent deaths caused by seizures. With more than three million people facing the challenges of epilepsy in the U.S. — and more than 50 million people affected by epilepsy worldwide — the issue of aggressively addressing SUDEP is as urgent as it is logical.

The mission of the Foundation is to prevent deaths caused by seizures. This mission — which is ultimately the mission to cure epilepsy — will one day be achieved via medicinal, surgical, or other technologies. Until then, the Danny Did Foundation holds as its main goals (1) advancing awareness of Sudden Unexplained Death in Epilepsy (SUDEP) and enhancing the SUDEP communication model between medical professionals and those afflicted by seizures, and (2) the mainstreaming of seizure detection and prediction devices as well as other technologies that may assist in preventing deaths caused by seizures.

We will pursue these goals with the aim of keeping people alive until the ultimate mission is accomplished.

To achieve our goals, the Danny Did Foundation is engaging physicians and researchers in the fields of neurology and epileptology; we are meeting with medical technology companies; we are consulting with epilepsy organizations; we are talking to our friends, our neighbors, and all those affected by Danny's story. We are asking doctors to talk about SUDEP, and we are offering ourselves as an outlet to which doctors can steer patients. We are creating informational pieces about safety in epilepsy in general and SUDEP in particular. We are pursuing sensor technology. We are asking why technology for home-use that measures and monitors vital statistics specific to seizure activity doesn’t exist, and we are finding that maybe it does, in one form or another. We are asking why such tools aren’t consistently — and as a matter of protocol — presented as options to parents and loved ones of those afflicted by seizures. We are cutting through the barriers that prevent those who do or should know of these types of technologies and instruments from talking about them to those of us who need to know about such devices. Finally, once identified as viable and worthwhile instruments, we will work to get these products FDA approved and covered by insurance companies.

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.*
Board Of Directors

Mike Stanton, Co-Founder and President
Mike grew up in Chicago’s Rogers Park neighborhood, where he attended St. Margaret Mary grammar school. Loyola Academy was next followed by a few years off then working his way through night school at Northwestern. Mike is currently an Evanston police officer. Previously, Mike worked as an Investigator for the Cook County State’s Attorney’s office. Mike and his wife Mariann have four kids and live on the northwest side of Chicago.

Mariann Stanton, Co-Founder and Vice President
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 and her husband Mike have four kids and live on the northwest side of Chicago.

Doug Bruno, DePaul University Women’s Basketball Coach
A pioneer and crusader for women’s basketball at all levels, Doug Bruno completed his 23rd season as DePaul University’s head coach in 2008-09. 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,” he 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 2010 Women’s World Championships in the Czech Republic. 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 the Blue Demons 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, Patty, are the parents of six sons, Bryan, Kevin, David, Brendan, Patrick and Bradley and are the proud grandparents of five. Bryan and his wife, former DePaul women’s basketball player Stacy Krumrei, are the parents of Jackson, Morgan and Owen. Kevin and his wife Sarah have two children, Brendan and Nora. Kevin, David (married to wife Bethany) and Brendan are graduates of St. Ignatius High School. David played on the DePaul men’s team for four seasons while Bryan, Kevin and Brendan played at junior college power Tallahassee Community College for two seasons. After playing two years of college basketball, Bradley is currently a student at DePaul. Patrick played high school basketball at Mt. Carmel under DePaul graduate Mike Curta before transferring to St. Benedict’s where he played for Dereck Rubino. Bradley played at St. Patrick’s high school under DePaul grad Mike Bailey.

The Bruno’s call the Rogers Park neighborhood on Chicago’s north side home. Doug, Patty and their sons have been long time friends to the Murtaugh and Stanton families, and the Danny Did Foundation is most grateful for Coach Bruno’s support.

Dan Kotowski, Illinois State Senator
State Senator Dan Kotowski 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 progressive 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. Dan has successfully led the fight in the following areas:

• Funding for veterans with post traumatic stress disorder
• Requiring insurance coverage for women at risk of breast cancer
• Protecting our children from predators on the internet
• Preventing people who are a danger to themselves and the community from purchasing a firearm
• Protecting taxpayers through transparent, on-line postings of all government contracts
• During his first term in office, Dan was the chief sponsor of 15 bills and co-sponsor of 69 more that were enacted into law by the State Legislature.

Dan currently serves on five committees in the Illinois Senate including his role as chairman of the Commerce Committee. He also serves on the Committee on Human Services, the Committee on Appropriations II, the Criminal Law Committee, and continues to serve as the vice-chair of the Financial Institutions Committee.
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’s role provided him with the ability to move easily between: the legislature in Springfield; the executive suites at many of Illinois’ largest corporations; as well as the living rooms of local families to achieve a unifying goal of building a better environment for children and families in Illinois.

Dan is the son of Casimir and Mary (Jinx) Kotowski. Having both studied for religious vocations, his parents set a wonderful, faith-based example for Dan to follow. One of five siblings (three brothers, one sister), Dan attended Daniel Boone Elementary School and then Loyola Academy in Wilmette. He graduated from the University of Illinois, Champaign-Urbana with a degree in English and Communications, and recently received a Masters of Arts Degree from DePaul University, graduating with distinction.

**Pete Lazzara, Chicago Fire Department Ambulance Commander**

Peter Lazzara is a decorated Chicago Fire Department Paramedic and a long time neighbor of the Stanton family. He was the first emergency responder on the morning of December 12, 2009, and the Stanton family will be forever grateful for his valiant and unrelenting efforts to assist Danny that day, and many days prior.

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 has been married to his wife Betty for 29 years and has two children, Katie (22) and Patrick (19). Amidst all of his activity and accomplishments, Pete found the time to be a tremendous friend to Danny, and he does the same with Danny’s siblings Mary Grace, Johnny and Tommy. Pete found great joy in spending time with Danny, playing baseball, kickball and simply hanging out with him on his swing set any day of the week. The feeling was mutual. Danny enjoyed helping Pete wash his car and plant flowers in his garden. As Pete says, “Everything was right with the world when you were hanging with Danny.”

Kathleen Malone, Realtor
Kathleen Malone is a realtor with @properties, where she has worked for the last six years. 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 grew up in the Beverly area of Chicago and attended Mother McAuley High School and Marquette University. Upon graduation, 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 Roscoe Village with her husband Brendan Malone, who has lived with Epilepsy for the last 17 years. They are close friends of the Stanton family and are committed to improving the lives of those who suffer from Epilepsy.

Sean Murphy, S&P 500 Options Trader
Sean Murphy grew up in Rogers Park the youngest of eleven children. He has been friends with Mike, and the entire Stanton family, since their young summer days spent together at Leone Beach. Years later, Sean went on to become a staff member of the Chicago Park District junior lifeguard program where he worked with hundreds of children including all of the Stanton kids.
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 Stanton, Sean has another very personal interest in being a part of building this foundation from the ground up, as his nephew was recently diagnosed with a form of seizure disorder.

Sean currently lives in Lincoln Park with his wife, Courtney, and daughter Elizabeth (4) and son Henry (2). In his spare time, Sean loves to golf, run, travel and spend time outside with his kids.

Susan Nicholl, Executive Director of Special Olympics Chicago
Susan is the President of Dillon Productions, Inc., an event management/marketing company that she founded 16 years ago. She serves as the Executive Director of Special Children’s Charities, financial supporters 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 non-profit community. The Danny Did Foundation is grateful for the guidance that Susan will provide in focusing on an annual large-scale fundraising event.

Born and raised in Chicago and graduate of St. Scholastica and Loyola University, Susan is married to Austin Nicholl, a life-long friend of the Stanton Family from the parish of St. Margaret Mary's. The loving aunt of numerous nieces and nephews, Susan lives with the same generosity, kindness and love for life that Danny Did.

JoAnne Pepper
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, Bryan have three children, Liam, Tia and Dylan. JoAnne loves being with her family and watching her children experience new things as they grow. She also enjoys reading and is looking forward to running the Chicago Marathon as a member of the Danny Did Team. JoAnne has known Danny’s mom Mariann for many years and is extremely proud to be working with the Danny Did Foundation.

Scott Verhey, Esq.
Scott Verhey is an attorney practicing law in Chicago at his firm founded in 1995. Born and raised in the suburbs of Chicago and a graduate of William Fremd High School in Palatine, Scott and his wife Margaret are long-time friends of Mike and Mariann Stanton, neighbors for many years.
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.

Scott began private practice in 1991 concentrating his practice 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.

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.

In his free time, Scott enjoys cooking, reading, making his family laugh and traveling to Milwaukee to attend Marquette Basketball games. His greatest accomplishments are and always will be his children, Megan and Matthew, who make him proud every day. Scott is grateful for the opportunity to help the Danny Did Foundation reach its main goal to prevent deaths caused by seizures.
Danny Did Foundation Medical Advisory Board

The Danny Did Foundation Medical Advisory Board is a select group of medical professionals with a specific interest in confronting and solving the riddle that is Sudden Unexplained Death in Epilepsy (SUDEP). Members of the DDF Medical Advisory Board act as medical experts and representatives of the DDF who share our vision of openly addressing SUDEP and who believe in our ultimate goal of preventing deaths caused by seizures.

Marvin A. Rossi M.D., Ph.D.
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.synaptic.com); American Medical Association; Illinois State Medical Society; Chicago Medical Society; IEEE Computer Society; New York Academy of Sciences; International Brain Research Organization (IBRO); and the Society for Neuroscience.

Danny Did extends a special note of recognition to additional doctors who have taken the time to assist our cause: Dr. Elson So of the Mayo Clinic in Rochester, MN; Dr. Doug Nordli of Children’s Memorial Hospital in Chicago; Dr. Stephan Schuele of Northwestern University Hospital in Chicago; Dr. Jorge Ascanope of Loyola University Medical Center in Maywood, IL; and Dr. Angela Black of the IDEA League.
Danny Did Foundation Development Committee

Second only to Danny, fundraising and development are the most critical components to sustaining our cause and our mission to prevent deaths caused by seizures. As the first component of our Partnership Program, the role of Danny Did Development Committee members is to personally contribute or otherwise raise a minimum of $5,000 for the Danny Did Foundation. Ideally this contribution occurs on an annual basis. Arriving at the $5,000 figure is left to the discretion and creativity of each member. Examples include a lump-sum personal contribution; the collection of smaller lump sums; or the hosting of a fundraising event such as a coffee or dinner party. Members are encouraged to act independently, but with the knowledge that Danny Did is available to support them with information and resources to assist their successful efforts.

The secondary role for members of the Development Committee is to shape and nurture relationships with additional donors and corporations on behalf of Danny Did. Members are also encouraged to instigate ideas regarding specific fundraising campaigns (e.g., a year-end letter writing campaign). Lastly, we encourage our Development Committee members to share their affiliation with our organization with their personal and business networks. Danny Did gains great value from that.

The Danny Did Foundation is grateful for the following individuals who form the Development Committee:

Kevin Clancy  
Linda Dewald  
Scot Gillespie  
Bill Gillespie  
Gene Heidkamp  
Julie Fowler Kelley  
Patti Lussa  
Anne Mannix  
Charles Martell  
Sean and Courtney Murphy  
Ashley Paige Olsen  
Mike Stanton  
John Wrenn
Danny Did Foundation Affiliate Group

As the second component of our Partnership Program, DDF Affiliate Group members provide recurring contributions to the Danny Did Foundation. Contributions are delivered through various strategies, including set-dollar-amount monthly donations, percentage-of-sales donations, and set-dollar-amount from individual-sales donations. Danny Did is grateful to the following Affiliate Group members:

Verizon Wireless/Mobile Generation donates $10 to the DDF for every mobile phone/device purchased by DDF supporters. This program also includes a donation to the DDF for new activations and upgrades. Please note that accessory-only purchases do not qualify. View offer and participating store locations here.

Contact Info:
Jerome Kohne
Account Executive – Non Profit
Verizon Wireless – Mobile Generation
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Jen Evola, owner of Mobile Health and Wellness, Inc., donates a set-dollar amount of $100.00 of Mobile Health and Wellness Inc.’s income per month to the Danny Did Foundation.

Jen is a Licensed Registered Dietitian, a Licensed Massage Therapist, and a Certified Golf Fitness Instructor. She is also certified in Massage Therapy and Hot Stone and Pre/Post Natal massage. Jen addresses a wide variety of issues including diabetes, adult/childhood obesity, cardiovascular disease, osteoporosis, GI disorders, women’s health issues, eating disorders, and sports nutrition. Jen’s current clients include professional, college, and high school athletes as well as physical rehabilitation patients.

Contact Info:
Jen Evola
Mobile Health and Wellness, Inc.
www.mobilehealthandwellness.com
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(773) 563-3863
**Emfit Corporation** donates 10% of each sale of its Emfit Movement Monitor to buyers who express an affiliation with the Danny Did Foundation.

Founded in Kuopio, Finland in 1990, Emfit is the creator of the Emfit Movement Monitor, a technology for monitoring an individual who, during sleep, may experience certain types of movements which a caregiver or family member should be alerted to.

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**Chicago-based musician Gareth Woods** donates $1.00 to the Danny Did Foundation from the sale of each copy of his latest CD, ‘Made of Love,’ available online at CDbaby.com.

A native of Ireland, Gareth landed in Chicago 15 years ago and gave his first performances in the city’s subways before becoming a regular on Chicago’s music circuit. In addition to his solo efforts, Gareth is also a member of the band Sugarbeat. Read the Irish American News’ review of Gareth’s ‘Made of Love.’

Contact Info:
Gareth Woods
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www.garethwoods.com
2010 Year In Review

In our first year, the Danny Did Foundation has had some wonderful and meaningful successes.

• Together with the Epilepsy Foundation of Greater Chicago, we have played the lead role in initiating an upcoming **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 will provide valuable data that doctors can use to make informed recommendations to their patients. We are very proud to be a part of spearheading this significant effort.

• On the awareness front – and also in collaboration with the Epilepsy Foundation of Greater Chicago -- we have created and distributed over **8,000 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. [Update: We are now at 20,000 brochures.]

• In 2010 we subsidized seizure alarm monitors for **21 families across 14 states**, coast to coast. 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 help to keep people alive while doctors search for a cure for epilepsy. [Update: We are now at 30 monitors.]

• Because we want to connect with and be accessible to people all over the globe, we’ve built a first-class multimedia website – [www.dannydid.org](http://www.dannydid.org) - and created a strong presence in the world of social media, including more than **10,000 fans on Facebook**. [Update: We are now at 12,000 fans.]

• We’ve also utilized more traditional outreach, because we know it still works. Our letter-writing campaign to Governor Quinn helped to restore more than $1 million in services for the 130,000 people in Illinois who suffer from seizures.
The very first place I turned was the Danny Did Foundation. It is all I know about epilepsy. Danny Did help me get through the first few hours of a diagnosis no Mommy ever wants to hear!" – Katie, Illinois

More than 3 million people in the U.S. and 50 million people worldwide have epilepsy, defined by the occurrence of 2 or more seizures.

Danny Did addresses SUDEP by advocating for open doctor-patient communication, promoting sleep supervision, and assisting the development and mainstream use of seizure detection and prevention devices and technologies.

Three year-old Lily, one of more than 20 Danny Did sleep monitor recipients

“Thank you from the bottom of my heart for all you’ve done to bring awareness to SUDEP. You are a blessing and inspiration to all of us parents navigating this world of seizures.” – Leah, Calgary, Alberta

A Danny Did supporter takes Danny’s spirit along to the summit of Mt. Rainier in Washington State. Danny Did bracelets have made their way around the world in support of our mission to prevent deaths caused by seizures.

“All seizure patients should be made aware of the risks so they can put steps in place to prevent death.” – Diane, Shetland, England

Looking Ahead to 2011, our ambitious plans include:

- Expand our events and development committees to regions nationwide
- Expand our network of doctors and our Corporate Partnership Program
- Expand our seizure device subsidy program to reach more families

“We have been living with epilepsy for so many years, but didn’t know about this tragic possibility. Without the Danny Did Foundation, we still wouldn’t know.”

– Morgan, Illinois
At our Buzz Cuts For Danny event in April, 320 boys and men received Danny’s favorite haircut – a buzz cut – to raise money and awareness for epilepsy and SUDPE. In 2011, this event will take place nationwide.

Danny’s parents Mike and Mariann at our First Annual Hearts & Hugs fundraiser at Misericordia. This cocktail party raised nearly $50,000 and included more than 300 guests and a live auction that funded the purchase of 5 seizure detection monitors for families in need.

Team Danny Did at the Chicago Half Marathon in May. More than 45 runners joined efforts to raise nearly $50,000. Another Team Danny Did participated in the Bank of America Chicago Marathon in October.

In July we held our 1st Annual Danny Stanton Kickball Tournament. This free event drew over 300 kids from throughout Chicagoland to play Danny’s favorite sport and to spread awareness about epilepsy.

Other 2010 events included a Bike Ride Around Lake Michigan in July, an August Golf Outing, and a National Epilepsy Awareness Month Campaign in November that brought in donations from 30 states and 5 countries.

Happy Holidays from the Danny Did Foundation.
My name is Kevin, and I’m a social media addict.

Yes, there, I’ve said it. And I’m not afraid to admit it. I love social media, and I’m probably one of those people you hear about. I’m constantly tweeting and chatting with others on Twitter. I update my Facebook status religiously. I switch back and forth between the Facebook and Twitter apps on my iPhone, lamenting the fact that I have such boring friends because there’s nothing new in the five seconds since I last checked.

Lately, instead of reading before falling asleep at night, I’ve even taken to catching up on my Twitter stream.

Yet, even for me, there are days when social media is too, well, social. The trouble with throwing yourself into interacting with countless people online is that you’re interacting with countless people online. And people don’t always behave as you’d like them to. They can be irritating and annoying. They can say rude things. They can disappoint.

And then, just as I’m about to delete all of my accounts, retire to a cave and start communicating via homing pigeons and smoke signals, something reminds me about the true power of social media: a connection to humanity.
This happened for me just recently. I’d become grumpy and cranky and was generally pessimistic about the state of things, both online and offline. Everything seemed highly annoying and a general waste of time, until I logged into Facebook and saw a status update from a work colleague who’d just recently left the company. It said, simply: “Danny’s generous spirit always found those who needed him most. Please get to know a child who could use your love.”

Danny was the four-year-old nephew of my former colleague Tom. He had passed away suddenly in his sleep from a seizure. I was immediately saddened by the loss of a child, and could not imagine what Tom and his family must be going through. But it was only later that I truly came to realize what we all had lost.

Over the next several days other notes about Danny started to appear on Tom’s Facebook page. There was his obituary, which described him as an amazing child, with a love of baseball and who started every day with a hug. It ended with “Please go out and enjoy your life. Danny did.” Then an article from the Chicago Sun-Times appeared, prompted by Danny’s obituary. A week later his story went national in a piece on ABCNews.com.

These articles described a fearless child who took life on, literally going to bat for every challenge. At just four, he joined a championship baseball game when a team of seven year olds were down a player. He raced onto the field in a jersey that went to his ankles, hitting and fielding balls like a kid twice his age. Danny sought out both adults and children who felt isolated and shy, pulling them into his world with a tug and a smile. He helped a neighbor carry in her groceries, always taking the heaviest items. His first words at preschool were “I just want to learn.”

Everyone who knew Danny, it seems, had a story to tell about how he had helped them.

I never had the privilege of knowing Danny during his too-short life, but I have had the joy of coming to know him through social media. A few years ago, I would have probably lost contact with Tom shortly after he left the company, and it’s unlikely I would have heard about Danny. I certainly would not have come to know this boy, and learn from him, as I have. He has inspired all who read about him, and brought joy to everyone who has seen his smiling photo on Tom’s Facebook page.
It’s in letting the world know about people like Danny, one connection at a time, that social media shows its true potential. It’s not a business tool, or a method of virtual social climbing. It’s not a game to be played like an endless popularity contest. Social media connects us in ways we are just learning to appreciate.

As such, we must be careful. For in the digital howl of tweets, status updates and comment wars, we might miss one small child and his powerful message: Please go out and enjoy your life.

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*Postscript:* Danny’s family have started a foundation aimed at raising awareness about seizure disorders in children. For more information, please visit [http://www.dannydid.org](http://www.dannydid.org).

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Grieving parents work to save other kids

March 21, 2010

BY SUE ONTIVEROS Staff Reporter

Maybe you remember hearing about Danny Stanton.

It was right before Christmas. A sweet, smiling 4-year-old boy died during the night of Dec. 12. Seizure disorder, the stories said.

In the obituary staff writer Maureen O'Donnell wrote for the Sun-Times, she described his love of sports and zest for life. An affectionate little guy who would climb up into Daddy's lap and tuck his arms in so he could be hugged.

If after that unspeakable loss Danny's parents, Mike and Mariann Stanton, decided to hole up in their Edgebrook home with their three surviving children, Mary Grace, John and Tommy, who could blame them? But they haven't, even though their grief is obvious.

Instead, with the help of family and friends, they have started a foundation, Danny Did, www.danny.did.org.

Now you might be asking yourself, aren't there already organizations that deal with Danny's problem? Are there really things not being done to help those who have a seizure disorder and in the case of children, their parents?

Oh brother, are there.

For one thing, no one ever said to the couple: Your child might die from this.

“Doctors don’t want to alarm you,” Mariann Stanton said in an interview last week.

How the Stantons wish someone had alarmed them.

Sure, they knew the seizures, which occurred only while he slept, were serious. (Many parents of epileptics have since told them they thought sleep time was the one time their child was safe from seizures.) As a precaution after Danny’s first seizure at age 2, his parents had him sleep in their bed for six months.

Since starting the foundation, they have met with top doctors in Chicago who
specialize in epilepsy and seizure disorders. One told them that he alerts parents during the second visit of the possibility of death.

“My heart started racing, because there might not be a second visit,” Mariann said.

So, part of their mission is to let others know about Sudden Unexplained Death in Epilepsy, which is the professional term for what happened to Danny. This takes the lives of 50,000 people a year in the United States. And yes, a seizure can occur while a person is sleeping.

If you know a person is having a seizure, there are steps you can take, so the Stantons set out to find a device that alerts parents or caregivers to a seizure.

Sadly, not long after Danny’s death, they found one that’s made in Finland, the Emfit Movement Monitor. The thin device, tucked between the mattress and box spring, sounds an alarm when a seizure occurs. The Stantons brought the Emfit to the attention of doctors here. Two local hospitals are awaiting shipments to put the monitors through their own tests.

Here’s what the Stantons would like to see happen when a family finds out their child has a seizure disorder:

In that very first doctor visit, they would be told of all the possibilities, including Sudden Unexplained Death in Epilepsy, and they would walk out with an alerting monitor, possibly the Emfit. This is similar to parents of children with allergies getting EpiPens and those whose baby is in danger of Sudden Infant Death Syndrome getting heart-rate monitors.

Some day, the Stantons say, they’d like to see seizure monitors in day care centers, schools, any place kids nap. And why not? At one time defibrillators were rare, but now they’re everywhere. And why? Because they save lives.

Heavy though their hearts may be, the Stantons aren’t stopping at Chicago. Once they get the word out here, they say, it’s on to other Midwest cities and beyond.

“Danny’s going to have an impact long past his last breath,” Mike said. “It’s hard to say, but it’s true.”

Danny Stanton was just 4 when he died from a seizure he suffered in his sleep in December. Now his parents are trying to alert other parents to the risk of Sudden Unexplained Death in Epilepsy. (Sun-Times Media)
BY TAMARA L. O’SHAUGHNESSY

If they had only known.
That thought lingers through the busy mornings getting the kids out the door to the quiet nights and all the hours in between for Mike and Mariann Stanton, who are doing their best to survive the unthinkable.
The death of a child.

If they had only known, Mike says, to ask doctors about the worst possible outcome for 4-year-old Danny, who had the first of four known nighttime seizures when he was just 2. If only they had known about seizure alarm devices. If they had only known about sudden unexplained death in epilepsy.

“If we had known that deaths could occur, we would have operated a lot differently. The things we are doing now, we would have done then,” Mike says.

But they did not know.
Until it was too late.
Now the Stantons want to make sure other parents have the information in time to save the next child.

A life full of children
Mike, a Chicago Northsider, and Mariann, a Chicago Southsider, created a home together filled with love, laughter and the boundless energy of children.
Mary Grace.
Johnny.
Danny.
Tommy.

Each unique in their own way. But it was Danny who possessed what his dad calls a “specialness about him.” Intelligent, affectionate, athletic, compassionate, with big bright eyes that mirrored his mom’s, Danny liked to hug, especially those who needed his hugs the most.

“He truly did enjoy his life. He really did. Every day. With such gusto, he did. Just a robust kid, he took it all in and he gave it all out, too,” Mike says.

“Danny really was special in that way.”

Life took a terrible turn on Sept. 20, 2007. With Danny snuggled sleeping between his parents, his body clenched and shook, his eyes rolling up.
Parents, friends pour love for a little boy into helping others keep their kids alive

“It was terrifying. It was absolutely terrifying to see it occur,” Mike says.

Swooping him up, they rushed next door to friend Pete Lazzara, a Chicago Fire Department paramedic.

Lazzara knew immediately the boy he adored was having a seizure. At the hospital, an alphabet of tests—CAT scans, EEGs, EKGs and MRIs—filled the night. Though Danny’s EEG showed abnormalities, Mike and Mariann remember doctors telling them children sometimes have a seizure, then never again.

Yet, that night changed her forever, Mariann admits.

Dread filled the bedtime routine. “I didn’t want nighttime to come every day,” she says softly.

In the many nights that followed, with Danny sleeping between them, Mike and Mariann didn’t sleep, alert for even the slightest movement. “The thing is, we were right there. We could protect him. We had medicine ready,” Mike says.

A second seizure struck a month later, just before Halloween, again as Danny slept. After the third, Mike and Mariann faced a major decision: Putting Danny on seizure medication. It was a two-year commitment with big potential for complications. But the medication worked, not slowing Danny down one bit. “He was a champ all along,” Mike says.

When Danny moved back into his room with big brother Johnny, Mike and Mariann still found themselves creeping into the boys’ room hundreds of times to peer closely into Danny’s sleeping face in the bottom bunk bed.

Just to make sure.

Nearly 22 happy, busy months passed.

No seizures.

Hope, then a nightmare

On Dec. 8, 2009, Mike and Mariann met with doctors about Danny’s latest EEG. The abnormalities, Danny’s doctor told them, looked a little better. “We walked out of there very heartened,” Mike says.

Four days later, Dec. 12, they awoke to find Danny’s sweet mouth ringed in blue.

As Mariann ran to get Lazzara, Mike lugged their little boy to the big family room and began CPR.

In his heart Mike believes Lazzara knew their Danny was gone, but he worked to revive him, as did the Fire Department crew, who also knew the family. “They worked on him and worked on him and worked on him,” Mike says, reliving the horror as their Mike says. “Nobody wanted to let him go.”

But they all knew. Danny was gone.

continued on page 48

Dr. Aaron Donnell and Dr. Kelly Newhall
2551 N Clark St, Suite 201, Chicago, IL 60614
773-388-2322
www.chicagofamilyasthma.com

Spring Coughing, Wheezing, Itching, Sneezing, Sniffling, Snorting

We’re so happy when sun and warmth return to Chicago in the spring! But for some of us, this means the return of seasonal allergies, which means trouble. Mold spores and spring pollens from trees and grasses return to the air in April and May to irritate the noses, lungs, eyes, and skin of millions of allergy sufferers.

Suffering from allergies is more than just a nuisance. The tolls of asthma, eczema, and nasal and eye allergies are costly: physically, emotionally, and financially. Why are allergic diseases so serious? Although many symptoms are uncomfortably obvious, untreated allergies may also lead to:

• Fatigue (from poor sleep quality and reduced daytime wakefulness)
• Difficulty focusing on daily tasks (imagine having a constant cold)
• Poor school performance
• Hyperactivity

Hay fever, or seasonal allergic rhinitis and conjunctivitis, affects as many as 30 percent of adults and up to 40 percent of children. Common symptoms include:

• Stuffy nose (often with snoring!)
• Runny nose or sore throat
• Sneezing
• Itchy or watery eyes

Patients with allergic asthma can become exhausted, constantly ill, or even have a life-threatening attack with:

• Coughing, especially at night or with exercise
• Difficulty breathing or shortness of breath
• Wheezing
• A tight feeling in the chest

The best treatment for your allergies is avoidance. Here are some tips:

• Keep windows closed during pollen season, especially during the day.
• Take a shower, wash hair, and change clothing after working or playing outdoors.
• Visit an Allergist to review your allergies and to be proactive about surviving the season.

Chicago Family Asthma & Allergy wants to work with you to find out what allergies are affecting your family’s life and how to help you feel better. Knowing your allergies helps you know when to use your medications and if allergy shots can benefit you. These shots slowly introduce a little bit of what you are allergic to, so your body learns to tolerate it, rather than reacting with sneezing, coughing, wheezing, a stuffy nose or itchy eyes. Our goal is to maximize your quality of life by preventing allergies from affecting school, sleep, sports, and life in general.

Chicago Family Asthma & Allergy provides the full spectrum of allergy disease diagnosis and management for children and adults. Dr. Newhall and Dr. Donnell are board-certified Allergists who completed training at Children’s Memorial Hospital and Northwestern Memorial Hospital. Our goal is to provide a friendly and accessible expert environment to care for your family’s total allergy and asthma needs.
Danny
continued from page 47

Tucking Danny’s tiny hands into his chest, Mike and Mariann laid down on the hospital bed and simply hugged their boy.

Nearly an hour passed. “He just got colder and colder. We just kind of took him in,” Mike says.

Strength to hold on
On the day Danny died, or maybe the next day, Mike remembers talking with Mariann about how this could tear them apart.

“But we have three other kids. What kind of life are they going to have if we can’t work through this somehow? We both know the answer to that. That’s not something we’re willing to take a chance on. That’s what kept us together,” he says, sliding his foot to stroke Mariann’s.

They began his obituary, ending it with a poignant reminder that would come to define the hard days that followed: “Please go and enjoy your life. Danny did.”

WEB EXTRA
Watch an audio slideshow of the Stanton family and read more about SUDEP.
ChicagoParent.com/multimedia
The funeral came and went. Life’s activities began again. Christmas came and went. Tommy’s second birthday needed celebrating. Lunches needed to be made for school every morning. Spelling words needed to be drilled. Diapers needed changing.

Waking up every day continues to be difficult, they admit. Mike yearns for nights he hopes are filled with dreams of Danny. “I hope I get that,” he says. They cry in front of the kids. “We tell them we’re OK, that they’re OK,” Mariann says. Grief clearly etched on her pretty face even as she smiles with her kids. It’s not always going to be like this, she tells them.

Focus on others now

Mere weeks after Danny’s death, something amazing began to grow out of their grief. A non-profit, the Danny Did Foundation, began. In no time, nearly 7,000 people signed on as fans of its Facebook page, seeing daily photos of Danny living life to its fullest and his parents’ heart-tugging thoughts and memories.

The foundation’s focus: To save other parents from such pain. Mariann says they were never told and didn’t ask, “What’s the worst possible outcome for Danny?”

The foundation is working with neurologists, medical tech companies, researchers, government agencies and organizations to make sure parents have the information the Stantons never received. Mike and Mariann want parents to know about SUDEP, sudden unexpected death from epilepsy, even though it’s rare and doctors are hesitant to bring it up to already scared parents.

“Our goal is for doctors to present the broad range of outcomes that can happen and let the family base their decisions on having the complete picture,” Mike says.

Family friend Mary Duffy located a seizure alert device, manufactured by a small company in Finland, something the Stantons wish they had learned about before Dec. 12. Whether it’s this device or something else developed by experts, the foundation is working to get a device approved by the FDA that could be as easily prescribed by doctors after a child’s first seizure and covered by insurance as a nebulizer is for people with asthma.

“We hope this foundation grows and makes a difference in the world, makes the world a better place, like Danny would have, like he is,” Mike says.

It’s one parent, one doctor at a time. Mariann checks her grief to answer other moms’ questions. Even on Valentine’s Day morning, she opened her home to a stranger, a mother just starting the journey with her daughter. What should I do, the mom wanted to know.

“That’s what this is all about. That’s why we’re doing it,” Mariann says. “We find the strength in those moments to make sure we are being as clear as possible and trying to give the most information we can, to help.”

They are also trying to keep Danny’s memory alive, from sharing with the world the 7,000 photos they have of him enjoying life to helping 2-year-old Tommy, who is looking more like Danny every day, remember him. “Tommy, where’s Danny?” they ask him quietly.

“In my heart,” Tommy says, tugging his shirt.

Tamara L. O’Shaughnessy is Chicago Parent’s editor and a mom of three, Marty, Arlee and Zoe.

Getting to the Heart of What Really Matters

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BY THE NUMBERS

Epilepsy: More common than you think
- Epilepsy and seizures affect over 3 million Americans of all ages, at an estimated annual cost of $12.5 billion in direct and indirect costs. In Chicago and the surrounding region, there are as many as 125,000 individuals with epilepsy. Between 5,000 and 7,000 new cases occur annually in the Chicago area.
- 200,000 new cases of epilepsy are diagnosed each year. In the Chicago area, that translates to between 6,000 and 8,000 new diagnosed cases annually.
- 326,000 school children through age 15 have epilepsy. In Chicago, that number is between 9,780 and 13,040 children.

Sudden Unexplained Death in Epilepsy (SUDEP)
- Among people with epilepsy in the United States, up to 50,000 deaths occur annually from SUDEP, prolonged seizures and other seizure-related causes.
- The incidence of SUDEP is about 1 in 1,000 people with epilepsy per year. This is at least 10 times the sudden death rate found in the general population.

Source: Epilepsy Foundation of Greater Chicago
Dad runs to save other families' kids

BY SUE ONTIVEROS Sun-Times Columnist

It wasn't enough that Mike Stanton decided five weeks out that he'd be participating in the Chicago Marathon.

Really, you'd think that would be an ample challenge. A marathon is no walk in the park. It's 26.2 hard miles, a daunting endeavor even for the most seasoned runner. And Stanton is aware of what he's in for; he ran the marathon in 1999 and remembers how grueling it was.

Mike Stanton is running in the Chicago Marathon on Oct. 10 to raise money for his son's Danny Did Foundation to help kids like Danny, who died last December from a seizure disorder.

For months now, runners have been building up their endurance for the Oct. 10 race. Go online and you'll see 18-week and 20-week training guidelines. There are no five-week training plans, which is why Stanton had to devise his own. (He said he received online comments such as, "Don't even try to do it.")

He ran 16 miles last weekend; 18 is the goal for this weekend. Still, he realizes race day is oh-so-soon.

"I'm counting on a lot of support and adrenaline to get me through," he told me last week.

Just running the marathon could have been sufficient. Instead, the Edgebrook man has attached an incredible fund-raising goal. Stanton has started a campaign to raise $1 million for each mile of the marathon by race day. Yep, that's right, his goal is $26 million, money that will go toward the nonprofit his family and some friends created last winter, the Danny Did Foundation.

The foundation is named for Stanton's sweet-faced 4-year-old boy who died in his sleep of a seizure disorder, Sudden Unexplained Death in Epilepsy, on Dec. 12, 2009. Last spring, I wrote about the foundation, which wants to educate others about the disorder -- which many are unaware of -- and the Emfit Movement Monitor, which warns of a seizure.

Stanton and his wife, Mariann, and family and friends have done an incredible amount of groundwork already.

They're making sure doctors and parents realize the dangers. A brochure on the disorder co-created by the Danny Did Foundation and the Epilepsy Foundation of Greater Chicago has been placed in hospitals here and across the country.
September 19, 2010

*Dad runs to save other families’ kids*

They've subsidized monitors that have been placed with families in 12 states. If you check out the foundation's website, www.dannydid.org, you'll be amazed at how far-reaching their efforts have been.

Or, check out the foundation's page on Facebook and you can read how Danny and the foundation's work have touched so many.

People profusely thank Mike and Mariann for spreading the word, and the Stantons know that Danny and their efforts have touched so many.

Yet, in quiet, reflective times, Danny's dad and mom say to one another: If only someone had done this before us.

"We would have proceeded differently," Stanton said with a wistful sigh.

Now, Stanton's got his sights set on the marathon and this fund-raising effort to put the foundation and its mission in the spotlight.

A heartfelt letter he wrote about his effort has been making the rounds on the Internet.

Stanton knows that raising $26 million in four weeks sounds difficult to others. But here's what's really hard: Getting up every day knowing you're not going to see your little boy again in this lifetime.

A 26.2-mile run?

Trying to raise millions of dollars?

That's a piece of cake in comparison.

In the midst of this incredible family tragedy, they have been lifted and so grateful for the efforts of others in the name of the Danny Did Foundation. So while right now they may have raised just $3,200, stay tuned.

"You never know," Stanton said. "Mariann and I don't rule anything out."

*To make a donation, go to www.dannydid.org.*
Area players give back via basketball clinic

By Scott Powers

NILES, Ill. -- Benet’s David Sobolewski bounced one basketball with his left hand, one with his right hand, kept his eyes up and continued speaking.

A Northwestern recruit, Sobolewski had no trouble with the basic drill, as expected.

When the half dozen kindergarten through fourth grade kids surrounding Sobolewski attempted the same feat, it proved much more difficult and comical. Some stared down and focused as hard as they ever had in their young lives attempting to get both balls to bounce simultaneously. They would dribble once with their left hand, then once with their right and eventually the two balls would end up scattering in different directions across the gym.

As the kids chased down the basketballs, Sobolewski smiled and kept on dribbling. He was enjoying himself, plus it beat practice.

Sobolewski, along with Benet coach Gene Heidkamp, Loyola coach Tom Livatino, Notre Dame coach Kevin Clancy and players from their teams, took time away from their own programs on Thursday to spend the afternoon running a basketball clinic for 300 kids to raise money for the Danny Did Foundation, which aims to create awareness for the condition of Sudden Unexplained Death in Epilepsy.

The Danny Did Foundation was created by Mike and Mariann Stanton after their four-year-old son, Danny, died in December of 2009 from a seizure while he was sleeping. In the last year, the foundation has published and distributed flyers that are handed out at hospitals around the country, raised around $300,000 and convinced three Chicago-area hospitals to begin clinically testing a Finnish-made device that detects seizures.

“Right after the day Danny died, my wife Mariann and I, amongst the many things we said to each other was, ‘Why didn’t we know this could happen?’” Mike said.

“Subsequently, we found out that doctors do know that this result does occur with a condition like Danny’s. Right away, we decided we’re going to start something to let other people know.

“The name Danny Did came from the last line of his obituary, which I wrote. It’s, ‘Please go and enjoy your life. Danny did.’”
Benet became involved with Thursday’s basketball clinic through Heidkamp’s lifelong relationship with the Stanton family. He grew up three doors down from the Stantons in the Edgewater neighborhood and has remained friends with Mike and his brother Tom Stanton. Tom was previously an assistant for Heidkamp at Nazareth and is currently an assistant at Loyola.

Heidkamp helped set up the clinic and cancelled his team’s Thursday practice to allowing his players to participate in it.

“The foundation is something that’s important to a lot of people,” Heidkamp said. “Our team was very excited to be asked. I just took volunteers. I asked if anybody would be interested in coming out. As you can see, we had a nice turnout. This is their first day off from school. For them to come out on their first day, the first day they can probably sleep in, and want to be a part of it, means a lot to me, and I think it shows a little bit about these kids. When I explained what the cause was for and why we were doing it, these guys all got on board.”

Sobolewski didn’t hesitate at volunteering.

“It’s a great way for our whole team to give back to the community,” Sobolewski said. “Obviously, it was a tragic event that happened. We were all really excited to help out today. It’s awesome interacting with the kids. They’re all fans of basketball, and they’re willing to learn from you and listen to you. It’s been really nice to coach them up and teach them a few things.”

For the Stanton family members, such events are always bittersweet. They look at the hundreds of kids running around with smiles on their faces, and it places a smile on their own faces, but it also reminds them of Danny.

“It’s very emotional for me,” Mike said. “The reason we have something like this is because Danny would have loved to have something like this. To come out here and walk in and see the line out the door with all these kids, it’s extremely emotional. It’s hard, but it’s like, ‘I’ll take it.’

“One thing I always say is, ‘Danny continues to have an impact in this world’, and I believe that.”

While it’s often difficult, it also drives them to push forward with the foundation.

“We’ve been really aggressive in our outreach, and we’ll keep doing that because we feel it needs to be done, and people need to know about SUDEP,” Tom said. “They need to know you can die of a seizure, and 50,000 people die because of seizures every year in the U.S. People hear that, and they’re surprised, and that’s not right. It’s a message that needs to get out.”

For more information on the foundation and SUDEP, go to www.dannydid.org.
Tragedy turns parents into successful activists
Associated Press
By Lindsey Tanner

December 24, 2010

CHICAGO (AP) — Epilepsy takes as many as 50,000 lives each year — grim statistics Mike and Mariann Stanton hadn't heard of until their 4-year-old son, Danny, became one of them.

Somehow, that horrible tragedy a year ago transformed a blissfully ordinary Chicago family into extraordinary activists. With zero experience but fueled by wrenching grief, their passionate advocacy has brought widespread attention to a rare, little-understood medical condition called Sudden Unexplained Death in Epilepsy, or SUDEP.

The Stantons want other families to know what they'd never been told — that epileptic seizures can be deadly.

They've put up billboards, created more than 8,000 informational SUDEP brochures for doctors' offices, hospitals and families; held fundraising events to boost awareness and research dollars; and created a foundation that has garnered more than 10,000 Facebook followers. But their biggest coup is getting researchers at three major medical institutions in Chicago to launch the first-ever rigorous study of a monitoring device for detecting dangerous seizures during sleep, ideally before they turn deadly.

The study launches early next year. Even if it shows the device doesn't work, Mike Stanton says their work won't be done until epileptic seizures can be wiped out for good.

Dr. Doug Nordli of Children's Memorial Hospital, who agreed to participate, called it "extraordinary" that a major study would be prompted by a family's advocacy.

"You put yourself in the position of a parent who has lost a child, and I think you're naturally sympathetic and want to help in whatever way you can," Nordli said.

Before the tragedy, the Stantons were a family that inspired admiration and envy, with four adorable young children, dozens of devoted relatives and friends, and full lives punctuated by kickball games, pizza with neighbors and other kid-oriented things.

When Danny died in his sleep from a seizure two weeks before Christmas, their lives could have been shattered. Their second-youngest was an irrepressible boy known throughout their close-knit neighborhood for his exuberant zest for life. Danny's mere presence made people smile; the shock of his absence still shows in his parents' sad eyes.
In January, they created the Danny Did Foundation, after the poignant final words Mike wrote in Danny's death notice: "Please go and enjoy your life. Danny did." Mike's younger brother, Tom Stanton, who has a background in public relations and volunteer work, serves as the nonprofit's executive director. Both 40, these parents seem in awe of what they have created.

"Sometimes, I step back and I look at what we've done in 11 months with this," said Mike Stanton, an investigator for the Cook County State's Attorney's Office. "What is it about this little boy that has created this enormous presence? He definitely keeps giving."

More than 3 million Americans have epilepsy, recurrent seizures caused by electrical disturbances in the brain. About 40 percent have seizures hard to control with medicine. They face the highest SUDEP risk, although anyone with epilepsy is at risk.

SUDEP claims a reported 3,000 lives each year nationwide, but the actual toll is likely higher, said Dr. Elson So, a Mayo Clinic neurologist and leading SUDEP expert. He learned about the upcoming research on a seizure-detector from Chicago colleagues and has offered to take part.

"Even if the impact of this device on the SUDEP risk is small, there should be other advantages from a device that detects seizures, in terms of knowing how frequently a patient is having seizures and also preventing injuries, if not death," So said.

The Stantons learned about the device, used in Europe, after Danny died. It's designed to sound an alarm if seizures are detected during sleep. That theoretically would give parents time to reposition their child to prevent choking, administer medicine and get help if needed.

Made by Emfit Ltd. of Finland, it features a plastic sensor sheet placed under a mattress, and a bedside monitoring device that together are designed to detect unusual movement that could indicate a seizure.
The $600 Emfit device is not approved by the U.S. Food and Drug Administration, but the Stantons initially wanted doctors to recommend it anyway, based on anecdotal yet unscientific reports that it works.

With help from the local Epilepsy Foundation chapter, they contacted several epilepsy experts including Dr. Marvin Rossi, a neurologist at Rush University Medical Center. He was hesitant but found the Stantons knowledgeable and committed — and they understood his skepticism.

"You may as well be promoting snake oil until we understand it better," Rossi said.

"What the Danny Did Foundation clearly helped me see is that there's such a huge gap in the field that it's worth setting up an initiative like this."

With some of the nearly $300,000 they've raised, the Stantons bought and distributed Emfit monitors to more than 20 families unable to afford them. Emfit now gives the foundation $60 when people ordering monitors mention the Stantons — but all the money goes into foundation operations, Mike Stanton said. The foundation's Facebook followers include a Chicago taxi driver who was touched by Danny's story and staged a 1,000-mile fundraising bike ride around Lake Michigan.

Danny Stanton only had a handful of seizures, at night and always terrifying. For a long time, his parents had him sleep in their bed. They gave him recommended medicine, had him undergo brain wave tests, and were told he'd likely outgrow the problem.

Whether families of epilepsy patients should be told about SUDEP is a topic of "huge discussion" among doctors, said Dr. Stephan Schuele, a Northwestern University who also is participating in the research. The reason some don't mention SUDEP is because it's rare, and patients with well-controlled seizures are thought to face little risk. Also, Schuele noted, some people would prefer not to know every worst-case scenario.

Stanton knows his son might have died even with a monitor. But he feels he could have done so much more if he'd known death was a possibility, and that overwhelming sense of powerlessness eats away at him.

"We didn't know what we were facing," Stanton said in a tearful speech at last month at an Epilepsy Foundation of Chicago meeting. "That is difficult to accept and it is maddening."

*On the Net:*

The Danny Did Foundation: [http://www.dannydid.org](http://www.dannydid.org)
Epilepsy Foundation: [http://www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)

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Fundraising Campaign Letter

Greetings,

My name is Mike Stanton and, along with my wife Mariann, I am the co-founder of the Danny Did Foundation, an organization established in January of this year shortly after the December 2009 death of our four-year old son Daniel George Stanton, who died of an epileptic seizure while he was sleeping in our Edgebrook home on the north side of Chicago.

I am writing to introduce you to Danny and to the Danny Did Foundation, and to appeal to your support. Danny was an engaging, athletic, affectionate, and intelligent little boy---the third of our four children--who had his first seizure less than two years before his last seizure killed him.

One of the first thoughts that occurred to Mariann and me after Danny died was that there must have been something we could have done to possibly prevent this tragedy. The answer to that thought is the Danny Did Foundation. The mission of the Danny Did Foundation is to prevent deaths caused by seizures, and this mission is achieved by focusing on two main goals: (1) advancing awareness of Sudden Unexplained Death in Epilepsy (SUDEP) and enhancing the SUDEP communication model between medical professionals and those afflicted by seizures, and (2) through the mainstreaming of seizure detection and seizure prediction devices ---as well as other technologies--- that may assist in preventing deaths caused by seizures.

Our commitment to our success is driven by a desire to prevent our devastation from becoming that of another family. To that end we have assembled an active Board of Directors, which includes state senator Dan Kotowski and DePaul University's women's basketball coach Doug Bruno. Of equal importance is our Medical Advisory Board, which includes Dr. Marvin A. Rossi, a highly respected epileptologist at the Rush Epilepsy Center in Chicago. We have also raised $250,000 to date and have achieved immediate and impacting successes in our use of these funds.

The origin of the foundation’s name is the last line of Danny’s obituary, which reads, “Please go and enjoy your life. Danny Did.” I remember writing those words, and I remember the accompanying thoughts: Danny Did engage others in his life; Danny Did take his time in life; and, more than anything else, Danny Did enjoy his life. I see no end to what we can accomplish in Danny’s name, and I appreciate the support you can give via a tax-deductible donation that will ensure our reach is as expansive as possible. For your convenience, a return envelop is enclosed, as is our annual newsletter to lend more background. Thank you, and always remember: Danny Did enjoy his life. Please go and enjoy your life too.

Warmest Regards,

Mike Stanton
President and Co-Founder / Danny Did Foundation