Channeling Grief Into Policy Change

Survivor
Advocacy
for Injury
Prevention

Introduction Survivor

Into many lives, terror and grief resulting from trauma come in an instant, without warning. It then takes a lifetime to come to grips with the ensuing loss. The loss can be the life of a child, partner, parent, family member or dear friend. Or someone survives a terrifying experience, and is left with scars, either physical or psychological.

"If it can't be done, don't interrupt the person who is doing it."

Anonymous

A small number of survivors channel the force of their grief or shock into preventive action—so that no one else has to go through "this" again. Among the most persistent and effective advocates are parents who have lived through the death or disabling injury of a son or daughter. This is certainly not to imply that grandparents, spouses, children, or trauma victims are not powerful advocates. However, survivoradvocates who are parents have been central to some of the major advances in the prevention of injury.

In 1975, Pete Shields became a spokesperson for the newly formed Handgun Control, Inc. after his 23 year old son was fatally shot in San Francisco. Candy

Lightner founded Mothers Against Drunk Driving (MADD) in 1980 after one of her 13 year old twin daughters was killed by a drunk driver. Marilyn Spivak founded the National Head Injury Foundation (now the Brain Injury Association) in 1980, five years after her 15 year old daughter sustained a disabling brain injury. In the past several years, parents of children killed by guns have begun to mobilize survivor-led, grassroots public support for rational gun policy.

To this list should be added those survivor-advocates profiled here. All but one lost a child. We tell their stories because we want to celebrate their successes, while appreciating full well that these have come at the ultimate price—the death of a child. Their efforts will never bring back their child. However, they work unselfishly to protect other parents from similar excruciating grief.

Grief is a powerful emotion for those who grieve and for those who support them. It is comforting to know that expressions of grief can take as many forms as there are those who grieve. Advocacy is only one of many ways that people work through grief. The www.tf.org website provides links to educational resources about grief.

We want to encourage injury prevention professionals to assist survivor-advocates in their work, as survivor advocates assist professionals in achieving their prevention goals. These stories reveal opportunities for collaboration, and some factors which can strain such partnerships. Every story is unique, yet common threads weave through them.

The power of the partnership between survivor advocates and injury prevention professionals far exceeds the power of either working alone.

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ADVOCACY

Top: Martha and bottom: Liz McLoughlin

Remembrance: The loved one is always at the very core of the survivor advocates' work. Each one honors her or his child's brief life and strives to give meaning to the child's apparently senseless death. The struggle for prevention is an act of remembering. The joy and energy which each child had brought to the parent during life now fuels the drive to prevent death.

Passion: Survivor advocates' work is personal and passionate. These are the qualities that make their message attractive to the media, persuasive to some policymakers, puzzling to many professionals, and aggravating to their opponents.

"One person with a belief is equal to the force of 99 who have only an interest."

John Stuart Mill

Singular responsibility: These survivor advocates had an immediate and urgent need to do something to prevent future tragedies. "If I don't do it, it's not going to get done." The sense of singular personal responsibility lingered even after they joined forces with others working on the same issue. Others might move on to other issues, but survivor advocates usually stay focused on their own issue.

Colleagues: At first many survivor advocates felt like "lone rangers", finding little interest or help for their work. They did

not find in others the burning intensity they felt within themselves. However, most were not the first, nor in fact, the only ones working to prevent "this". These profiles highlight solely the work done by the survivor advocates. The contributions of countless other workers must be left for other accounts.

Fast learning curve: Learning by doing, they quickly became experts in the problem and its potential solutions. They figured out the politics of the issue. None had been trained to be advocates; none had any background in public health, although several had advanced educational degrees. All were smart and resourceful. They often became more knowledgeable about their particular issue than the professionals, but were in danger of being dismissed or barely tolerated as "overly emotional, zealot safety moms" (even if they were dads).

Money and the lack thereof: They used personal savings to fund their prevention work, and this often threatened their families' financial stability. Lobbying and advocacy is extremely time and money consuming. There are out-of-pocket expenses for travel, telephone, postage, on-line computer searches, and office supplies. Particularly discouraging to some was the realization that they often were the only ones serving on committees or attending meetings who were not being paid to work on the issue.

At all costs: The passion for prevention was stressful in many families. Soon everything took second place. Spouses and surviving children suffered; some marriages fell apart. Being totally over-tired became the norm; every spare moment went to advance the cause. But nothing seemed to matter more than the next step to be taken toward the prevention goal.

Every day, every pre-mature death, every disabling injury, creates potential survivor advocates among the dozens of family members and friends who grieve. We hope that the stories presented here will encourage survivors and health professionals to join together to achieve their common goals.

Liz and Martha McLoughlin were fourteen months apart in age. Martha was 18, and had just finished her first year in college. On June 11, 1960, Martha, her roommate and their dates were heading to a dance in Long Island City. The four stepped off the curb to cross the street when a car, hoping to make the light, sped around the corner and hit the two young women. Martha sustained massive head and internal injuries, and died three hours later; her roommate was seriously injured but recovered. Forty years later, Liz, a co-author of this newsletter, considers herself firmly in both categories: survivor advocate and injury prevention professional.

the Danny Founda

Danny's Strangulation

When John and Rose Lineweaver were married in 1981, their merged family had 11 adopted children. When Danny was born in 1982, he made it an even dozen. On July 14, 1984, just before his 2nd birthday, he fussed when put into his crib for a nap. Soon, the room became quiet. When the Lineweavers went to check on him, they found him hanging outside his crib, his shirt caught on the corner post extension of his crib. Strangled, he suffered permanent brain damage and severe disability. Danny died peacefully at age eleven from complications of a respiratory illness.

Through Grief To Advocacy

At first, the Lineweavers thought that what had happened to Danny was a unique "freak accident". But they soon learned that 40 children had died in similar circumstances between 1973-1985. They knew that there could be many more incidents that they had not heard about, and death was only part of the tragedy. How many little ones like Danny had survived, only to live very restricted and care-intensive lives?

They hired a law firm to determine what, if anything, they could do. They sued the crib manufacturer and the retail outlet that sold them Danny's crib. A settlement from the lawsuit permitted them to create and provide initial funding for The Danny Foundation in 1986.

The Danny Foundation's mission is to educate the public about crib dangers and to eliminate the millions of unsafe cribs currently in use or in storage. Cribs are the only juvenile product manufactured for the express purpose of leaving a child unattended. Therefore, we must take extraordinary care to ensure that a crib is the safest possible environ-

ment. The Danny Foundation provides citizen leadership in the development of regulatory standards for safe nursery products.

The Lineweavers were appalled to learn that there was only one mandatory standard for crib safety, dating back to the 1970s, which addressed slat spacing. It set the widest allowable distance between crib slats at 2 3/8 inches. Wider spaces had permitted children to slide their bodies but not their heads through the openings. The weight of their bodies outside the crib would cause strangulation.

But Danny had dangled by his shirt caught on the crib's corner post. The Lineweavers wanted to pass a law about crib corner posts, but discovered they could only get a voluntary standard. They agreed to work with the American Society for Testing and Materials (ASTM), a century-old, not-for-profit voluntary standards setting organization.

Rose & Danny Lineweaver



TON JOHN & ROSE LINEWEAVER

In 1986, the allowable height for a crib's corner post was reduced from 2-3 inches to 5/8 inch. Then Temple University conducted a study and found this height was just as lethal. ASTM dropped the standard to an allowable height of 1/16 inch.

But the Lineweavers also discovered another terrible reality. CPSC and ASTM standards applied only to new cribs. They estimated that there were 20-30 million cribs in storage or in use at that time. They petitioned CPSC to recall all unsafe cribs, but the petition was denied.

Attempts at recalls have been dismal because manufacturers are responsible for administrating them. Because of the threat of liability, manufacturers have never supported these efforts. John Lineweaver notes that "common sense would tell you that crib manufacturers could sell more cribs if all the dangerous ones were destroyed, but the liability issue is so threatening that they have never really supported recalls."

Manufacturers identify each crib by model number. The Danny Foundation believes that manufacturers and model numbers are almost irrelevant for older cribs. If you explain to people what to look for in a dangerous crib, people are smart enough to know if they have one. A new petition was

filed on March 20, 2000 with the CPSC requesting a total recall of unsafe cribs.

Public education is essential. The public thinks that "if their crib hasn't been recalled, it's safe". The Danny Foundation would like a quarterly education campaign for the next three years, and wants injury prevention professionals to help. A wide variety of programs are needed, such as a toll free 800# in English and Spanish, hospital and prenatal programs, and a website.

To destroy dangerous cribs, "reception stations" could be set up by, for example, Goodwill Industries and the Salvation Army. Currently these organizations refuse to accept cribs, even as a donation. Waste management companies could make a real contribution. They could pick up and destroy any cribs left at "reception sta-



Rose Lineweaver, John Lineweaver and Guy Greco, Fremont Bank. John Lineweaver is presenting the 'Presidents Award' to Guy Greco.

tions". The Danny Foundation supports giving people tax credits for donating dangerous cribs.

In 1994, at the urging of the Danny Foundation and partners, California was the first state to make it illegal to use an "unsafe crib" for any commercial purpose. "Unsafe" was defined as not conforming to current standards. The law applied to resale, hotels, leasing, daycare and childcare centers and hospitals, etc. There is similar legislation in Washington, Arizona, Colorado, Pennsylvania and Illinois where *The Danny Foundation* worked with *Kids In Danger*. A federal bill is pending, but has no appropriations to enforce its provisions.

CPSC reports that there were about 200 crib-related deaths in 1973. Now, about 50 infants and toddlers die each year in crib-related tragedies. The Danny Foundation wants to cut that number to zero. Danny's mother, Rose, observes that "The Danny Foundation is the only good that has resulted from my son's tragic and needless death."

"Common sense would tell you that crib manufacturers could sell more cribs if all the dangerous ones were destroyed, but the liability issue is so threatening that they have never really supported recalls."

Ways to Contact/Contribute

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Kids In Danger

Danny's Death

Danny Keysar was 16 months old, the second son of Linda Ginzel and Boaz Keysar, both University of Chicago professors. On May 12th, 1998, Linda left Danny at his childcare home with his beloved caregiver, Anna. Danny took his nap in Anna's Travel-Lite portable, foldable crib. But when Anna checked on him, the crib had collapsed. Danny was trapped by the neck and not breathing. Unaware, Linda arrived to pick up Danny. Instead, police drove her to the hospital. A doctor told Linda and Boaz that they had done everything they could for their son, but that Danny was dead.

Through Grief To Advocacy

The day after Danny's funeral, Linda learned that the crib that killed Danny had been recalled by the U.S. Consumer Product Safety Commission (CPSC) five years before. Linda and Boaz were stunned. Why didn't people who owned those cribs know that? For seven days after the funeral, Linda and Boaz and their son, Ely, sat Shiva for Danny. They were surrounded by family, friends, and colleagues from the University of Chicago Business School where Linda is director of its corporate education program.

Colleagues began to explore the facts and implications of Danny's death in terms they used every day: profit and loss, business ethics, marketing, and product design. Why didn't the recall succeed in getting that crib out of that childcare center? How many such cribs were still out there? The more they talked, the more it came clear to Linda that something had to change. She asked them: "What can Boaz and I do—without any money, without anything, just us?" (1)

Research and education were familiar tools. Immediately, Danny's parents began to concentrate



on recalled cribs. Finding sleep difficult, they spent nighttime hours at the computer researching recalls and learning why they failed. They found that CPSC conducts about 250-300 recalls per year. Of these, approximately 100 involve children's products, with an estimated 38 million units recalled in 1998 alone (not including car seats). CPSC says that they get unsafe products off store shelves. However, they cannot get currently used items out of homes and childcare centers.

Linda and Boaz searched for ways to get life-saving information to the people who needed it most—all parents of babies and owners of defective cribs. "If the government can't do this, and the manufacturers don't," she says, "then we will. We'll tell everyone we know to tell everyone they know, and we'll get word to the level of the users." (2)

Linda Ginzel, President Clinton, Boaz Keysar

Within 11 days of Danny's death, Linda and Boaz sent an email to 5,000 people, describing Danny's death, warning about the Travel-Lite portable crib, and about other recalled portable cribs known to be defective. On the subject line, they wrote: Prevent death of next child. They asked each recipient to forward the message to everyone s/he knew. The message generated 300 responses, some from users of the defective cribs.

A few weeks later, using \$20,000 in personal savings, they established a new non-profit, *Kids In Danger*, with its own website (www.kidsindanger.org). It took off. Linda and Boaz used their network of friends to contact the American Academy of Pediatrics, the Ambulatory Pediatric Association, and the Illinois Department of Children and Family Services, which licenses childcare centers. They contacted the AARP to alert grandparents. The Chicago Commissioner of Consumer Services printed the crib warning on the pay stub of every city employee. A journalist friend wrote an article for a parenting magazine. A marketer friend helped with a brochure entitled: *Minefields: How recalled products put your children at risk and what you can do about it*.

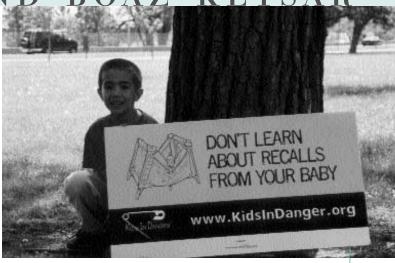
But information alone was not enough. They had found that days before Danny's death, state inspectors had paid a routine inspection visit to Sweet Tots (Danny's childcare center), but they had not checked for recalled products, because they weren't required to. So Linda and Boaz championed an Illinois bill—the Children's Product Safety Act, which makes it illegal to sell or lease an unsafe or recalled children's product. It also requires that licensed child-care facilities be inspected for unsafe products and prohibits any business from selling or leasing them. On May 13, 1999, one year after Danny's death, this bill passed unanimously in the state senate. The governor signed it in August 1999. In July 2000, Michigan passed legislation modeled after the Illinois law.

In September, 1998, Linda Ginzel was named to the American Society for Testing and Materials (ASTM), representing the interests of parents and consumers in the development of voluntary safety standards for children's products.

In November 1999, US Congressman Rod Blagojevich introduced a federal bill that would amend the Consumer Product Safety Act in order to make a number of improvements in the way that CPSC handles recalls of defective children's products and make information about these recalls more accessible to the public. The bill's title is the Daniel Keysar Memorial and Children's Consumer Product Safety Act of 1999 (HR 3208).

President Clinton presented Linda Ginzel and Boaz Keysar with the 2000 President's Service Award, the most prestigious national recognition for volunteer service directed at solving critical social problems.

For the present, Kids In Danger wants to raise awareness and put the issue of children's product safety on the national agenda. Ultimately, they want to prevent dangerous products from reaching the market in the first place. "Unlike poverty and world hunger, this is a very solvable problem."



Ely Keysar, Danny's older brother

"Unlike poverty and world hunger, this is a very solvable problem."

ways το Contact/Contribute

Kids In Danger

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Drowning Preventic



Samira's Death and JJ's Near-drowning

Samira Riggsbee was two; her brother JJ a year younger. On July 14, 1978, the Riggsbees left their children with a teen-aged babysitter, to share a quiet dinner alone. Later, the babysitter felt ill and went to the bathroom, leaving Samira and JJ alone in the family room. She returned in fifteen minutes; the sliding glass door was open. Both children were floating face down

in the pool. A neighbor heard her scream, called 911 and summoned the Riggsbees. When they arrived at the hospital, a nurse and firefighter wouldn't make eye contact. Samira had died. JJ was in critical condition.

Through Grief To Advocacy

JJ's brain was severely injured. Nadina stayed at the hospital for four months, unable to go home to an empty house. It became clear that JJ would be severely disabled. After seven months, she looked unsuccessfully for a "place" for him. In June, 1979, she decided to take him home, the youngest child ever to go home with that level of disability.

JJ had a tracheal tube, quadriplegia, severe brain damage, and needed around the clock care. Nadina's time was consumed by JJ and her newborn son Eric. She bore two more children in quick succession. As JJ grew older, she fought every step of the way for him to be in school. Since 1979, Nadina's advocacy skills have been finely honed by working with hospital, health care and school bureaucracies on JJ's behalf. JJ is now 24.

Drowning prevention became her other passion. In 1980 Nadina began to study the problem. She discovered that drowning was the leading cause of all deaths for California's children ages 1-4 years. When she asked a doctor why no one did anything about drownings, she was told, "nobody has bothered".

She "bothered". She advocated for environmental protection, primarily mandatory four-sided fencing of residential swimming pools. In 1982, she attended a luncheon, where the guest speaker was a member of the Board of Supervisors for Contra Costa County. She moved the seating cards at his table so that she could sit next to him, to educate him about pool fencing.

She organized families of drowning victims to testify at Board of Supervisors meetings. For a full year, the pool industry lobbyists fought hard in opposition to fencing requirements. Before a key

Nadina & JJ Riggsbee

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1 Foundation RIGGSBEE

vote, a local newspaper ran a story about drowning and the problem of 'negligent parents'. But she and her co-workers prevailed.

In 1983, the swimming pool ordinance was passed, effective November 1984. Contra Costa County was the first jurisdiction to pass a residential swimming pool ordinance, setting national precedence. However, it covered only the unincorporated areas of the county.

In 1985 she created the Drowning Prevention Foundation, a non-profit agency which works to create awareness and advocate for policy change to prevent childhood drowning. That year, she met with a commissioner of the Consumer Product Safety Commission in Washington, DC, who at first argued that a pool was not a 'product.' Since then, CPSC has been a valuable part-

Nadina Riggsbee

ner in advocating 4-sided fencing for residential swimming pools.

Her foundation was a sponsor of California's 1996 Swimming Pool Act, which requires that all home swimming pools built in or after 1998 comply with safety standards for swimming pool enclosures, safety pool covers, or exit alarms. The

"or" bothers her. She is a "fence lady", believing that alarms are ineffective, but an easy way to satisfy the building code.

Nadina also educates the public. She has produced educational brochures for pediatricians' offices, preschools, and libraries. Every year, California's governor names May as Drowning Prevention Month. For the past 13 years, Safeway grocery stores nationally have put drowning prevention messages on their paper bags for that month.

Nadina's advocacy goes beyond pool drownings. Children love to play in water. Drownings happen in spas, bathtubs, barrels, and 5-gallon pails—any place where water can cover a child's nose and mouth. She is concerned about the use of bath-

tub ring devices for young children. The bottom suction cups can come loose, children push up, fall forward and drown. She knows of at least 85 drowning deaths due to the use of bathtub rings. In July, 2000 her foundation submitted a petition to CPSC to get these devices off the market.

Nadina has been frustrated by lack of funding for 20 years. She had a small contract with the Contra Costa County health department to work with other cities on pool fencing ordinances. The State Farm Insurance and Pacific Life Insurance funded the brochures. But she was unsuccessful competing against health departments for a grant. They want her help—but they "contact", not "contract". She questions why most money for prevention goes to county health departments for programs or to scientists

for research, not to the important advocacy work of nonprofit organizations.

Nadina knows the profound burden imposed by childhood drownings. Her marriage ended in divorce, as do many marriages when there is a death or brain damage of a child. But she continues her care of JJ and drowning prevention. She has testified as an expert witness in cases involving drownings. She serves on many committees, and is the Chair of the Drowning Prevention Committee of California's Children's Health and Safety Coalitions. Upon request, she assists other jurisdictions as an advocate for fencing ordinances, meeting with building code officials, and helping to implement local educational programs. She is now running for the Danville Town Council.



Ways to Contact/Contribute

Drowning Prevention Foundation

P. O. Box 202 Alamo, CA 94507 T: 925-820-SAVE F: 925-820-7152 www.drownprevention.com E:dpf@pair.com

Stop for Kid's Safe

Dan Dan's Death

Dan Dan was 8 years old, loved video games and bike riding. July 14, 1992 was a nice sunny day, so Dan Dan and his brother convinced Marie, their mother, to let them play outside. At about 3 pm she called for the kids to come inside, but they did not answer. Her oldest, Pierre, came running inside and said, "Mom, come and help me."



Dan Dan and his bike were lying in the street, hit by a car while its driver was talking on a cell phone. He was unconscious and died later that day in the hospital.

Through Grief To Advocacy

Marie's heart was broken. Her pain was so intense, it felt like it was squeezing her heart out. Her husband was strong during the funeral for both of them. Four to five months after the incident, she shared her pain with the director of the Whitney Young Child Development Center, who said, "Let's do something together. Let's do something that will help you deal with your pain."

Marie's therapy was to do something to prevent others from feeling this pain. She had lived in the neighborhood for 20 years. She decided to bring people together on the streets to tell San Francisco that pedestrian deaths and injuries should not happen. She decided to walk from Hunters Point to downtown San Francisco. In 1992, the first year, five people walked together. The SF Fire Department Chief and two police officers on bikes were with them.

The walk became an annual affair—growing in numbers each year. In 1993, 30 people walked; that number doubled in 1994. In 1995, the walkers included eight supervisors and two members of the mayor's staff. By 1997, there were 300, including Marie, who had given birth to a new baby the day before. By 1999, 500 people walked. In 2000, they sent out 12,000 flyers; unfortunately, rain kept the crowd to about 800. At first, Marie paid for everything herself. After 4 years, she received some financial help for the walk.

Marie supports laws and regulations for pedestrian safety, like traffic calming. She wanted speed bumps to be installed on her street, but found, unfortunately, that they were no longer allowed. Cars going too fast over speed bumps caused serious shaking which damaged city streets and people's houses.

She wants to slow traffic down by increasing the number of speed limit signs posted and the enforcement of speed limits. She works with various groups to stop red-light running by installing photo-enforcement cameras on dangerous intersections. She wants more education for drivers about the risks of speeding.

She wants to ban the use of cell phones by drivers while they are driving. The man who killed her son was talking on a cell phone. Police said it was just an "accident", and the man never took any responsibility for her son's death.

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MARIE WILLIAMS

"I want a Pedestrian Bill of Rights, and extended sidewalks, and safe routes to school."

She wants a pedestrian's "bill of rights". On pedestrian issues, she works with BayPeds, the Senior Health Network, the Pedestrian Task Force, Walk SF, Neighborhood Safety Partnership, Emergency Medical Services (EMS), various SF advocates, supervisors, a city task force, and private citizens.

She works on bicycle safety issues, to honor her son who was biking when he was

killed. The SF Bicycle Coalition's president comes to her walks. In 1997, she received a Golden Wheel award from the Coalition for her work. She insists upon action as well. She wanted a

She insists upon action as well. She wanted a stop sign on her street so she contacted the new Mayor, Willie Brown. The former mayor's staff had promised to take care of it. She was literally on the phone with Brown's office, when her husband told her they were putting up the stop sign. She says to pressure officials at election time, because that is when they are most anxious to please voters.

Marie assumed that most people would want to work on prevention after enduring a family tragedy. Given how many people are hit in San Francisco, she figured that there should be hundreds of survivor advocates. When the news media had a story about a pedestrian dying, she tried to contact family mem-

bers. But she found that people grieve differently. The intense pain and need for privacy led many to choose not to join public efforts to prevent pedestrian deaths and injuries.

In 1996, her 14 year old son Pierre was hit and injured at a school crossing. Pierre has completely recovered, but these

things happen again, and again, and again. Marie and her husband want to protect all children, especially their own eight, four teenagers and four "little ones".

She wants people to see her pain, a pain no one should have to endure. She wants others to see through her eyes and those of her family and her community. Hundreds of people are affected by every death of a child. This is her power and the power of her program.

Marie believes there is a God who tests one's faith, and that God took her son for a reason. She works on prevention to make sure Dan Dan's life means something. There is nothing else she can do for him, except work very hard to prevent people from being hit by cars. In return, Dan Dan gives her the extra energy it takes to get up every morning.





Stop sign near Maria's SF home.

Ways to Contact/Contribute

Stop For Kids Safety

2055 Falcon Dr.
Fairfield, CA 94533
T: 707-435-0378
F: 707-435-0379

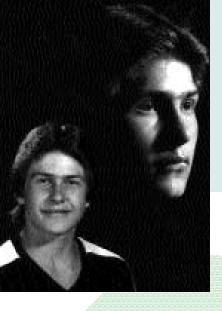
VM: 415 207-2409

Website: Under construction

E:Ozniesha@aol.com



Marie Williams. Necklace's "stop sign" pendant says: "We'll never stop loving you."



Californians for

Jimmy's Death

Jimmy, Jonny and Joel Holquin are brothers. Jimmy was 18 and a motorcyclist. On Friday, September 6, 1985, Jimmy left for school, leaving his helmet behind. On the way, Jimmy swerved when a car made an unexpected u-turn in front of him. He hit the car, flew over its top, and landed on his head. Jonny called his mother, Mary, at work, saying a friend had just seen Jimmy bleeding on the street. Throughout the weekend, Mary, Jonny and Joel watched helplessly at the hospital as doctors tried in vain to treat the massive brain injury. Jimmy died on Monday morning.

Through Grief To Advocacy

One week after Jimmy's funeral, Mary was the first person on the scene of another motorcycle crash. She went over to help the helmeted driver, a young man about Jimmy's age. He was crying—his leg hurt. His helmet had scratches on it, but the young man was talking. He would live.

Mary "saw" her son's face in that helmet. She was convinced that if Jimmy had worn a helmet, he would have lived. She was determined to get a law in California that required every motorcyclist to wear a helmet.

She had no experience in politics or advocacy, but she was not to be deterred.



Mary Price and her son, Joel Holquin

She called the Secretary of State to find out how to pass a law. She was told she would need to provide 375,000 signatures or find a legislator to carry the bill. She started collecting signatures and contacting legislators.

Assemblyman Dick Floyd (D-Gardena) had carried a helmet bill in 1980, but it never got out of committee. Floyd agreed to meet with her. He showed up at the restaurant in jeans and a belt buckle that said, "Born to Ride." He told her if she did all the lobbying, he would carry the bill.

AB (Assembly Bill) 36 was introduced in December, 1986. The bill had many hurdles: Transportation and Ways and Means Committees in both the Assembly and Senate, floor votes in both chambers, and the governor's signature.

Mary was a single mom, working in a factory. She re-scheduled her job to work nights—6pm-6am—so she could lobby all day. Life was hard. Her mother had just been diagnosed with Alzheimer's disease.

For two years, she was the sole lobbyist—unpaid. Assemblyman Floyd offered to help her set up a nonprofit organization and find funding. She set up Californians for Safe Motorcycling, but was unable to find any funding, until just before the bill became law. "Everyone at organizing and

Safe Motorcycling

committee meetings had a salary, except me." But, then "I did not owe anybody anything", which she thinks might be one reason she was so effective.

The issue become intensely partisan. The Republican Caucus urged members to defeat the bill. However, many Republicans were sympathetic and helped pass the bill. Her most vocal non-elected opponents were the Hells Angels and members of ABATE (American Brotherhood Against Totalitarian Enactments). They would all ride their motorcycles and surround the capitol on hearing days. They argued: "Let those who ride, decide! Get government off our backs. We are adults and free to choose." Whose freedom of choice? "Jimmy left me no freedom of choice but to bury him", says Mary. She and her allies countered: "Let those who pay have the final say!"

During each session, Mary counted votes. She visited every legislator before each vote, so she would know where each stood. A refusal to say where they stood usually signaled opposition. She became an avid observer of power politics and horse-trading. For example, one assemblyman who had previously supported the bill said that if Dick Floyd did not support his gun control bill, he would not vote for the helmet law.

AB36 made it through all of the committees in two years, but Governor Deukmejian vetoed it in 1988. Dick Floyd reintroduced it as AB8 in December of that year. It passed the legislature, but again the governor vetoed it in 1989.

Mary's work at the capitol was all-consuming. She was exhausted most of the time. Having no financial support for advocacy, she had money troubles. She was portrayed as an over-protective, over-reactive mom, even as someone trading sexual favors for votes! She received death threats in telephone calls. She had time and energy for nothing else, including her other sons, whom she feels she "lost" as well. She felt she had no choice. It was up to her to get a helmet law passed. Jonny

and Joel urged her to continue.

Floyd reintroduced the bill again in 1991 as AB7. California had a new governor who let it be known that he was open to considering a helmet law. For a third time, the legislature passed the bill, and it became the very first bill Governor Pete Wilson signed into law. Researchers have reported significant decreases in deaths and severe head injuries among motorcyclists since the law took effect in 1992.

Mary has just about recovered from her exhaustion. Life is easier. She is happily married, and has moved out of California. She even has taken up motorcycling with her husband who is an avid rider. She goes to rallies, mixes with other riders, keeps her fingers on the pulse of motorcycle helmet politics, and monitors annual attempts to repeal "her law" in California.



Assemblyman Dick Floyd, Governor Wilson, and Mary Price

"Making a choice not to wear a helmet doesn't affect just that rider. It affects us all."

Ways to Contact/Contribute

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Mary Price and Representative Jim Cooper, D-Tennessee

Save A Life Fo



Christina's Death

Christina Spizzirri was 18, about to start college and working at a restaurant. She decided not to accompany her mother, two sisters and friends on a Labor Day weekend trip to Florida. On Labor Day night, September 7, 1992, Christina left work. On the way home, she was involved in a car crash that caused severe injuries and bleeding. The first people to arrive at the scene were local police officers, who waited for emergency medical service personnel to administer first aid. Christina bled to death before they arrived.

Through Grief To Advocacy

Carol Spizzirri, Christina's mother, acknowledges that no one knows whether first aid or CPR could have saved Christina's life. However, she wanted her to have had a chance.

Carol's passion to assure first aid training and certification for public servants began almost immediately after Christina's death, in response to an "inner voice" urging her to do so. "Christina's death was a negative that I had to turn into a positive. This is what she would have wanted me to do."

Carol read the Coroners' Inquest, and found out exactly how and why the police officers acted as they did when they arrived on the scene of Christina's crash. She identified major flaws in the training and certification of public servants. Illinois law did not require that police and fire personnel be trained in first aid or cardio-pulmonary resuscitation (CPR), although many did so voluntarily. They were not required to have up to date first aid and CPR certification.



Carol Spizzirri

Police departments, wary of law suits, discouraged their officers from rendering first aid.

Just two months after Christina's death, Carol formed the Save A Life Foundation, and began her mission. She went to the state capital and recruited Representative Chuck Hartke to sponsor legislation. She wanted to mandate first aid, CPR training and regular re-certification for all front-line professionals, such as firefighters, 911 dispatchers, school teachers, nurses and coaches. At the first hearing she attended, they did not even call the bill. Undaunted, she prevailed in having a task force established to study the issue.

"No one was there to teach me how to lobby. I'm just a mother on a mission from God. Like the Blues Brothers." The second time she got smarter. She decided to address only police and firefighters. Senator Bob Raica got involved. She worked the halls, with Chrissy's picture and fierce determination.

She contacted corporate presidents, union leaders, police and fire chiefs, and television stars to support her legislation. She got endorsements from the National Safety Council, the American

undation carol spizzirri



Medical Association, several insurance companies, and the National Highway Traffic Safety Administration. Opponents argued that training would cost too much.

She was persistent. State Representative Chuck Hartke has said: "I don't think [Spizzirri] totally understands that not everyone has that as their No. 1 priority. Her persistence and her almost unbelievable simplistic approach is what is surprising." "I had to convince every politician individually. I kept going back to every office because they would say: "Oh yeah, I agree", but then do nothing." 3

In September, 1994, the Governor signed the law mandating that police officers and firefighters be trained in first aid and CPR before graduating from their academies. But she learned early on that you cannot mandate unless you have the money. So she

went to Washington, DC. She convinced then Illinois Representative Dick Durbin to draft language

to permit all states to use grant money from the National Highway Traffic Safety Administration (NHTSA) to fund CPR and first aid training.

In 1995, the Save A Life Foundation collaborated with EMS departments in the Chicago area to develop two programs: Save A Life For Kids® for students ages 4 to 12; and Bystander Basics® for high school students. The Foundation supplies the materials and EMS/medical professionals teach the children. The Chicago Board of Education passed a resolution to include these programs in their school curriculum. Their content was used in developing the Basic Emergency Lifesaving Skills (BELS) Guidelines (DHHS/MCHB).

The accomplishments have exacted a high price. Her mission has drained about \$67,000 from her personal savings. At one point, she was at risk of losing her home. She lost her accounting job at the district school. She worked out of her home office 7 days a week, it seemed 24 hours a day. She lost friendships with

her neighbors, who she said grew weary of her relentless crusading. Finally, in 1994, her marriage dissolved when she and her husband realized that they had to handle their grief in separate ways.

Her accomplishments are real. As the result of legislation which Carol Spizzirri initiated, all Illinois police officers and firefighters are mandated to receive a 18 hour first aid and CPR course prior to graduation from their academies. Illinois firefighters are now required to keep their skills current, although unfortunately, police are still not required to do so.

To offset this neglect of re-certification for police, she has developed the "Blue Angels" program. Local EMS providers have already trained thousands of police officers statewide in basic lifesaving emergency skills.

Carol continues to lead the Save A Life Foundation, and assists advocates in other states who want to have their public safety professionals and their children trained in basic lifesaving emergency skills.

1. Chicago Tribune, March 8, 1993

2,3. Chicago Tribune, January 16, 1995.



Left and upper left: Training photos

"No one was

there to teach

me how to lobby.

I'm just a mother

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Trunk Releases Urger

The Fennell's Kidnaping

Greig, Janette and infant Alexander Fennell returned home around midnight in October 1995. A masked man rolled under their descending garage door. He and an accomplice forced the adults at gunpoint into the trunk of their car, drove to a remote area, robbed them, and left. Cramped and frantic, they tore apart the trunk's interior. Finally, they found the release cable. Freeing themselves, they found that

San Francisco Chronicle

Baby Survives Pacific Heights Carjacking

Parents locked in trunk, boy left on porch

And the first f

Alexander was no longer in the back seat. They located a phone booth and called the police. Returning home, they saw a policeman holding Alexander, who had been left outside their home.



Through Trauma To Advocacy

The Fennell kidnaping was front-page news and journalists wanted the story. The Fennells agreed to collaborate, as long as the focus was on prevention. The police had said: "It usually doesn't end this way" after they learned Alexander was unharmed. Janette decided to find out what usually does happen. But no one could tell her. Highway safety data, criminal justice statistics, health data—no one collected data on trunk entrapment. So she developed her own database. She used newspaper accounts, court records, Internet sites, Lexis/Nexis, and word of mouth to develop a database. As of May 2000, she has uncovered documentation on 931 incidents of trunk entrapment involving 1,082 victims in the United States in the last quarter century (1976–2000).

Janette was absolutely determined to make car trunks escapable. She knew that regulation and product redesign had prevented children from dying when trapped in discarded refrigerators. She felt strongly: "Any manufacturer who produces a product that can trap people inside should be obliged to provide a means of escape."

Janette founded the organization TRUNC (Trunk Releases Urgently Needed Coalition) in 1996 and created its website in mid-1997 (www.netkitchen.com/trunc). This became a powerful tool for providing information for survivors, consumers, journalists, and policymakers.

Media coverage kept the issue alive. Fellow advocates from Florida encouraged the Fennells to be the spokespeople on a nationally syndicated TV talk show in January 1997. They urged viewers to advocate for making interior trunk releases a standard feature on all vehicles. In December 1997, a prime time investigatory program ran a feature segment about the trunk entrapment issue. *Good Housekeeping* covered the story in November 1997.

tly Needed Coalition

The Fennells naively thought that carmakers would fix the problem if they knew about it. They wrote a letter to all carmakers in February 1997 and again in November 1997. These letters were virtually ignored. The carmakers' trade association did respond in January 1998, after a prime time TV investigatory program indicated that automakers were unresponsive.

A series of introductions led Janette to a sympathetic policy-maker. A nurse in a Wisconsin hospital led her to a children's organization, who led her to a police chief interested in abductions, who introduced her to a former highway patrolman, Congressman Bart Stupak. Stupak also wanted cars to have interior trunk releases. He introduced a bill in the Congress, but Congress was unwilling to regulate trunk releases. However, in June 1998, in its omnibus transportation bill, Congress included Stupak's amendment requiring NHTSA to conduct a study about trunk entrapment.

Then in July/August of 1998, 11 young children died of hyperthermia after being trapped in trunks in three separate incidents in New Mexico, Pennsylvania and Utah. Janette led a *USA Today* journalist to link the stories. This linkage re-framed the story from an isolated "freak accident" to a significant safety problem and a front-page national story. Janette's database and experience permitted her to influence coverage of these unwelcome but newsworthy tragedies. She argued for trunk releases through various popular print and electronic channels and thus reached diverse segments of the population. Media features included *LA Times* (3/30/99), *People* magazine (5/24/99), Oprah (6/4/99), *Washington Post* (6/19/99), Readers Digest (10/99) and *Redbook* (2/00).

In November 1998, NHTSA asked the National SAFE KIDS Campaign to convene the trunk entrapment panel. They formed the Expert Panel on Trunk Entrapment, which included experts from psychiatry, law enforcement, health and medicine, safety advocacy (including Janette) and the automotive and toy industries. The panel concluded in June 1999 that NHTSA should issue a standard requiring vehicles to be equipped with interior trunk release mechanisms.

In December 1999, NHTSA issued for public comment a proposed rulemaking to mandate that release mechanisms be installed by Jan.1, 2001in all vehicles with a trunk. NHTSA allows automakers to choose what type of handle or device to use. Some manufacturers have already begun to install trunk releases as standard equipment.

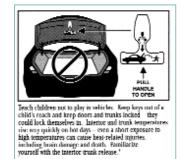
For five years, Janette's life has been consumed with the campaign to make car trunks escapable, in combination with grieving the death of her mother in 1997, caring for Alexander and giving birth to her second son Noah in 1998. Time for sleep has been in very short supply. In addition, the Fennells financed all their advocacy work



Greig, Alexander, Janette and Noah Fennell

out of personal savings, receiving no outside financial support.

Now that NHTSA has begun the process of rulemaking to require internal trunk releases, Janette has taken on another cause—to prevent deaths and injuries resulting from children being left unattended in and around vehicles. She has founded a new organization, KIDS 'N CARS, with two survivor advocates, Michele and Terrill Struttmann, whose toddler son Harrison was killed by a van put into drive by two toddlers who had been left alone in the van.



Ford's new car information card.

Ways to Contact/Contribute

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FOR SURVIVOR ADVOCATES

- Is there a field of "injury prevention & control"? Yes. There have been safety experts working in industry for a long time. In the 1960s, Congress created many regulatory agencies to work on safety (for example, U.S. Consumer Product Safety Commission [CPSC]; National Highway Traffic Safety Administration [NHTSA], Food and Drug Administration [FDA]). In the 1970s, an "injury science" emerged as a distinct interdisciplinary field of research and practice within the public health arena.
- Are people paid full time to work on injury prevention? There are three major employers of people working in the injury prevention field: governments, universities, and non-profit agencies. These employers pay people to work on specific types of injury, depending on the governmental mandate for their department, grants or contracts to explore specific research questions or programs, or mission statements of the non-profit agencies.
- How can I find out who is working on my issue? The Trauma Foundation's www.tf.org is a good place to start. Click on "advocates" which will lead you to several resources. The survivor advocacy bulletin board permits you to post your questions to others interested in injury prevention. The site provides links to the major injury prevention websites at the federal government, universities, injury centers, and non-profit organizations. You may also post a memorial to honor your loved one and call for preventive action. This way, others who care about your issue can find you, and you can find them.
- What help can injury prevention professionals give me? These professionals can share their knowledge, expertise, information, and contacts with you. They can help you find and interpret data, brainstorm about strategies to pursue, answer questions about the science and practice of injury control. They can also introduce you to their key contacts who might be interested in helping you, and partner with you in advocating for common goals.
- Where can I get money to support my work? This is a very tough question, because money is always tight. You can start your own non-profit agency, so you can accept (but don't expect) tax-free donations from people or philanthropic foundations. This entails lots of work. It is wise to find an advisor knowledgeable about the pluses and minuses of doing this. You might find an existing non-profit agency or "umbrella organization" willing to serve as your fiscal agent and advisor for your grants. It may be possible for agencies to contract with you for some specific work, but this is not com-

mon. The budgets for most agencies and departments are already committed to existing staff and programs. They may be able to assist by offering you the use of an office copier, telephone, fax machine, email and Internet access. Many injury professionals are skilled grant writers (they have to be), and they may share this expertise with you.

Is it easy to work with injury prevention professionals? It is impossible to generalize. Most are likely be supportive. However, most have too many projects on their desks and "to-do" lists already. They may not feel able to devote time or energy on your project, even if your issue and their responsibilities appear to match. Find some enthusiastic partners, and figure out ways to collaborate most efficiently and productively.



FOR PREVENTION PROFESSIONALS

Who are survivor advocates? Both words are crucial. A "survivor" is someone who has sustained a personal and traumatic loss. The loss can be the premature death of a family member or close friend. The loss might be a disabling injury, sustained by oneself or a loved one. The "loss" might be of one's sense of safety or well-being, caused by a traumatic event. An "advocate" is someone who actively argues for a cause. For our purposes, survivor advocates work to prevent any repetition of whatever caused their pain.

Is every survivor an advocate? No. In fact, it is most likely that only a few people suffering profound losses will channel their grief into advocacy. As is clear from the stories told here, some survivors are self-initiating advocates, and these tend to be the most effective.

Is it possible to recruit survivors to get involved in injury prevention? Often journalists ask medical or injury prevention profes-

sionals to "find me a victim" to personalize a story. It is possible to invite survivors to participate in injury prevention, but it requires exquisite sensitivity. Each person works through grief and heals in her or his own way and time. Depending upon the circumstances of the incident, survivors deal with guilt, remorse, or anger as well as grief. The best invitations for collaboration 1) are offered by someone already known to the survivor; 2) are very specific as to what actions are requested; and 3) are very easy to decline with-

"The role of advocate does not come easily to many scientists. Yet often it is only by taking on this role that we can turn our special knowledge about the causes of injury into public policies that will prevent injury."

Susan Baker, The Charles S. Dana Award for Pioneering Achievement in Health.

out bad feelings. There are differences between survivors who are willing to tell their story to the media and those who become true advocates. Survivor advocates are extremely knowledgeable about the problem, and go beyond personal experience to argue passionately for solutions.

What can injury prevention professionals do for survivor advocates? Survivor

advocates are catapulted into this work without training about goals, objectives, or methods of injury control, although many are skilled in other areas. They tend to have few institutional supports. Money is always a problem. Here are some ways to assist:

- share expertise in goals and methods of injury control;
- share personal networks, help make contact with key experts;
- share "fund-finding" expertise (finding sympathetic foundations, publicizing government grant opportunities; sharing nuts and bolts of grant writing);
- create consultancies and small contracts, if goals are shared and money is available;
- let them use office machines (copy, fax, scan, telephone, etc.) and if possible, office space.

Is it easy to work with survivor advocates? It is impossible to generalize. The advantages are numerous. The partnership creates a powerful alliance of authenticity with expertise. However, working with the passion and intensity of many survivor advocates can be time and energy consuming. Good working relationships become more personal than is common in professional collaboration. You may wish to learn more about the process of grieving, so that you can give support while pursuing shared goals.

www.tf.org

Create Partnerships Through Our Survivor Advocacy Website

Come to www.tf.org, and click on Advocates.

The Trauma Foundation has developed this organizing tool on our website to make it easier for survivor advocates and injury prevention professionals to find and help each other. The hard work of network building can be a little easier through memorials and a survivor advocacy bulletin board.

Survivors: Introduce the person you love who was killed or injured through a memorial: a brief biography and a photo.

Survivor advocates: In addition to your memorial, share your advocacy story, your struggles, your strategies, your successes—so that others can be inspired, or find ways to help.

Injury prevention professionals: Ask your tough questions, state your needs, advertise for survivor partners who are interested in working on specific prevention programs and policy objectives.

Survivors & professionals: Grief is a powerful emotion. Use this website to link to resources for those who grieve and for those who support them.

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