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Living | Arts

A tragic bond

Three women whose children suffered severe brain injuries took on seat belt laws in the '80s. Now they're eyeing youth sports.

By Don Aucoin
GLOBE STAFF

WESTBOROUGH — For all of them, there was that stomach-dropping moment when they got the phone call every parent dreads. The one that told them their child had been in a car crash. The one that changed their lives forever.

That was more than 25 years ago. Since then, Arlene Korab, Inta Hall, and Marilyn Spivack have counted on one another during the tough times, and there have been plenty of those. But their friendship has also been an alliance. From the ashes of personal devastation, these leaders of the Brain Injury Association of Massachusetts created a force to combat what Spivack calls the “silent epidemic” of traumatic brain injury.

Now they are trying to mobilize that force to bring about change in the world of youth sports. They refuse to let policymakers forget that the kind of injury that permanently impaired their children happens to 1.4 million people a year — and that many of the injuries are preventable.

They live with that knowledge every day, because their children were not wearing seat belts when they were injured in separate accidents. So Korab, Hall, and Spivack joined the fight on Beacon Hill in the 1980s for the state’s mandatory seat belt law. “They knew me as the crazy seat belt lady,” Hall, of Hingham, says with a wry smile. “And some of them still know me as such.” The late Jerry Williams, a talk show host who vociferously opposed the seat belt law, “did a job on me personally,” recalls Hall. “Called me names.”

According to the National Center for Injury Prevention and Control, 50,000 people die each year because of traumatic brain injury, while 235,000 are hospitalized and 1.1 million are treated and released from hospi-

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Trio found friendship as well as a mutual cause

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tal emergency rooms. Roughly 40,000 people each year suffer traumatic brain injuries in Massachusetts. It is usually caused by a severe blow to the head during a car crash, a fall, or another event that disrupts the brain's normal functions. Because damage to the brain is not as visible as a broken leg, coaches sometimes send players back onto the field who have suffered concussions, with lifelong consequences.

Hoping to spotlight the often-overlooked danger of brain injury to participants in youth sports, the Brain Injury Association of Massachusetts today will convene a conference on sports injuries in Marlborough that will bring together coaches, doctors, nurses, and parents for training on how to prevent, diagnose, and treat sports-related brain injuries.

The conference will be another step toward ensuring that other families don't feel as isolated and helpless as they once did. "I didn't know another soul, literally another soul, who had ever gone through this," recalls Korah, of Westborough, the association's executive director. "I thought we were the only family going through this."

All three know better now. It is estimated that more than 5 million people in the United States live with a disability stemming from a traumatic brain injury. But

when it comes to something as life-altering as traumatic brain injury, the numbers don't begin to tell the whole story.

Tragedy strikes

In September 1980, Korah's son Kevin was an 18-year-old freshman at Northeastern University. He was not wearing a seat belt when a friend lost control of the car in which he was a passenger. Kevin's brain stem was crushed. He was in a coma for six months. When he emerged, he was paralyzed on his right side, his speech was severely affected, and he suffered from a Parkinson's-like disease that causes severe tremors. To this day, he is in a wheelchair, and

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INTA HALL, who fought for the seat belt law in Massachusetts

when the driver lost control of the car and crashed into a tree. "I got a call from the emergency room that said, 'Come and identify,'" recalls Hall, the association's public policy consultant.

Greg was alive, but he spent seven weeks in an intensive care unit and 10 months in a rehabilitation facility. He had to learn how to walk, talk, and feed himself all over again, and his memory was

reliant on around-the-clock care in the professionally staffed home where he lives.

Hall's son Greg was 16 and had just finished his junior year at Hingham High School in the summer of 1980

when he was injured. He, too, was a passenger in a car; he, too, was not wearing a seat belt

when the driver lost control of the car and crashed into a tree. "I got a call from the emergency room that said, 'Come and identify,'" recalls Hall, the association's public policy consultant.

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MICHELE McDONALD/GLOBE STAFF

Arlene Korah of Westborough, whose son Kevin was injured in 1980, heads the Brain Injury Association of Massachusetts.

impaired. "He couldn't accept that he was not what he had been," says Hall. "We didn't know how to deal with it. He'd be in his room and he'd come out swinging; he'd be mad because he couldn't read. He'd read a paragraph and two seconds later he couldn't remember." Today, he works as a mail-room clerk, but he still has to be on medication to prevent seizures.

When their children were injured, Hall and Korah had entered a grim community that Spivack had joined five years earlier. Her daughter, Deborah, was a 15-year-old high school sophomore in 1975 when she was riding in the back seat of a van returning from a ski trip with eight other teenagers. None of them were wearing seat belts when the driver lost control of the van. "Your daughter is dying," the voice on the phone told Spivack. "You'd better hurry up and get here, because she may not survive."

Deborah lived, but she was in a coma for five months, and was hospitalized for a year and a half. Today, she remains severely disabled, and lives in a supported-living home. She was recently hospitalized for several months with a major seizure disorder.

Back in 1980, as Spivack began to explore the options available to her child, she was stunned by how few resources there were to treat and rehabilitate traumatic brain injury victims, and how few public advocates they had. So in 1980, she and her husband, Dr. Martin Spivack, along with other families and specialists, founded the National Head Injury Foundation, later renamed the Brain Injury Association of America. By late 1981, the Massachusetts chapter was starting to take shape.

When the three women met, they recognized one another as kindred spirits. A year and a half after Hall's son was injured, her

oldest son, Bill, was killed in a car crash at age 22. Spivack had also lost a child, a son, Jon, 20, in a motorcycle accident, in 1976. 15 months to the day after Deborah was injured. The women developed a bond that was both emotional and pragmatic: when Korah learned that her son Kevin had to undergo surgery recently, she immediately contacted Spivack for advice.

"I have no hesitancy, and neither does Inta or Arlene, in calling each other and talking about anything," says Spivack, of Framingham, who sits on the association's board and is a neurotrauma outreach coordinator at Spaulding Rehabilitation Hospital.

Nor do they have any hesitancy about reaching out to other families whose loved ones have suffered traumatic brain injury. "Healing comes through helping," says Spivack. "The more you help others, the more you absorb." Their combined efforts helped lead to the development of the Statewide Head Injury Program, which provides services to enable people with brain injuries to live and work independently.

They have thrown themselves into efforts to require airbags in cars and to stiffen drunk-driving laws; they have gone into schools to advocate the wearing of bicycle helmets. Next: youth sports.

It could make them unpopular in some circles, but they're not fazed.

"We're not finished yet," says Korah. "There's a lot more work to do."

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