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## **UNITED FOR AN EX-TEAMMATE'S STRUGGLE**

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Photo © Boston Globe

### LOWELL

Jason Hilton was never a big guy, as football players go. But he was athletic and aggressive, and he played with heart. As starting center for the Merrimack, N.H., High School team, he would call everyone together for a play. "Huddle up!" he'd shout, and the team would gather round, waiting for quarterback Dan O'Neil's direction.

It was a tight team. Most of them had grown up playing Pop Warner football together. They chose "**United We Stand**" for their motto, and went on to win the New Hampshire state football championship in 1987 the only one in the school's history. On a freezing November day in Concord, N.H., the Merrimack Tomahawks beat the Londonderry Lancers by a score of 27 to 13. Jason Hilton made the last tackle of the game.

Today, Hilton is still at the center of the action, even though he's in a wheelchair and lives at a Lowell nursing home. His teammates who are now lawyers, accountants, and businessmen have started a nonprofit called **United We Stand for Jason**. Its motto: "Huddle Up for Huntington's Disease."

Hilton, 36, was diagnosed with the devastating neurological disease four years ago. Though some patients regress slowly, his descent has been swift. He can no longer walk, his ability to speak has all but disappeared, and his food must be mashed or ground up, because he has trouble swallowing. Huntington's disease is genetic; there's a 50 percent chance an offspring of an afflicted parent will contract it. Hilton's father died of it in 1995, and it killed his paternal grandmother.

No one noticed when Hilton started having a little trouble with his legs his senior year in high school no one except his mother. "I saw signs, the different way his legs were moving. I put it down to a nervous twitch," says Gail Sprague. His parents had divorced years earlier, before his father was diagnosed, so the family had never experienced Huntington's disease firsthand.

Hilton went off to Plymouth State College, where he was a star football player and wrestler. His high school teammates had scattered to various colleges. They graduated and started careers; Jason worked in computers. Some married and had children. The guys would run into one another at a wedding or at the annual Thanksgiving Day football game at their high school.

Hilton wasn't at the 2003 game. Someone mentioned he was sick, but no one had details. His teammates called his mother and got the news: He had Huntington's disease, a progressive condition that robs victims of movement, speech, and intellect and eventually their lives. Symptoms usually begin appearing between ages 30 and 50, and most people live 10 to 20 years after the disease's onset. There is no cure.

"This was a shock to me, because I didn't know anything about Huntington's disease," says O'Neil. He researched it and began to organize trips by former teammates to the Lowell nursing home where their star center now lived. They learned that he had had symptoms but didn't want to tell anyone; when he was diagnosed, he told no one but family. "This disease befuddles me," says O'Neil, an accountant who is an investigator for the Massachusetts inspector general's office. "People take it as a shameful thing. They cloister themselves. They don't want anyone to know. The families get isolated. People don't visit."

But members of the championship Tomahawks did. At first, they just dropped by. Then they saw that Jason needed things: a television, maybe a DVD player, which they bought. But what else could they do that would make a real difference for him, and the others at the Lowell Health Care Center also suffering from Huntington's?

### **A broad mission**

Last October, O'Neil and a couple of the teammates, now lawyers, started **United We Stand for Jason**. It benefits more than just Hilton; the mission is to raise money for education and awareness of the disease, and to improve the quality of life of Hilton and the others in Lowell. Of the original 22 teammates, 15 live in the area and are active in the charity. Others come for the events.

Their first event, a golf tournament, raised \$12,000. They took Jason and the other patients in Lowell and their family members to a hockey game, the circus, and "A Christmas Carol" at the Merrimack Repertory Theatre. Last Thursday they went to a Lowell Spinners baseball game. At every event, they hand out literature about Huntington's disease. They plan to buy helmets for those at the nursing home, since uncontrollable head-jerking can cause injuries.

"The fact that he still has his friends . . . Those guys have done more for him mentally and even physically than a doctor could," says Hilton's mother, who works in an electronics factory. "They were one of the closest teams I've ever seen. They stood up for each other. They backed each other. There wasn't anything they wouldn't do for each other, and it's obviously still like that. I can't say enough about these guys."

Joe Raycraft coached the Merrimack Tomahawks for 27 years, but he remembers the 1987 team the best, and not just because of their trophy. "They were a different group in that they hung around with each other, even after graduation," he says. "They were really, really close. There was no bickering. They were very athletic, but they also had a real concern for each other. It's a special thing that comes along once in a lifetime."

As for Hilton, Raycraft recalls a hard-working boy who wanted to play defense but wasn't allowed. "We didn't want him to get hurt. He was too valuable for us on offense. It was very difficult to find a kid to snap the ball, to remember the snap count and be able to block, and he did all of those things exceptionally well."

Raycraft, who participates in the events for Hilton, says he isn't at all surprised by what his former players are doing. "I think it's a great tribute to this team."

## The look of winners still

On a recent night, several teammates who sit on the board show up for a meeting, held monthly at the Lowell center. The room seems dwarfed by some of the big men, who though they are in their mid-30s look like they could still go out and win another game. Hilton sits in his wheelchair, beaming as one after another slaps him on the shoulder or teases him about his paunch and balding head. There's Steve Krasinski, captain of the team; Dean Emerson, running back; Dennis Goodridge, linebacker; Pat Richard, tackle; Dan Gilmore, tight end; Greg Townsend, lineman, and O'Neil, the quarterback who is the board treasurer. Gilmore serves as president. Rob Perreault and Steve Poulin, neighbors who didn't play football, are also on the board, as is classmate Jenn Cyr. Laura Gannon, a CPA and classmate, advises them on tax matters. Also at the table is John Hilton, Jason's older brother, an Army reservist who has elected not to be tested to determine whether he has the Huntington's gene.

Krasinski pats Hilton's stomach. "You've been eating too many Krispy Kremes," he says. Hilton laughs. He understands everything that is said, according to his mother, and attends support groups at the nursing home. "Mentally he's still with it," she says. "He's fully aware of what's going on and what's to come. They don't hide anything from any of them."

Board members discuss sending Hilton to a camp in upstate New York for people with the disease. They table a motion to create a scholarship and then discuss upcoming events. They're running a raffle for tickets to a Red Sox- Tigers game; of the 50 raffle tickets sold, O'Neil bought 40. "Hopefully we can win and take Jay," he says.

Krasinski puts a bottle with a straw to Hilton's lips. After he sips, Krasinski wipes his mouth with a napkin. It's a natural moment; no one at the table misses a beat. Hilton laughs at jokes, and looks as if he wants to speak, but his mouth doesn't cooperate. Some of the men recently took him out for lunch simply picked up his wheelchair and walked through the front door. "It was fun, and we kidded Jason about gaining so much weight and having our backs give out," O'Neil says. Teammates sat on both

"Jay," says O'Neil, "was the smallest guy out of the whole line, but he played with the biggest heart and most determination of any athlete I've ever played with."

In the fall, there will be a pancake breakfast to benefit Hilton, and there will be some sort of team reunion around Thanks giving. It's been 19 years since Jason Hilton made that last tackle, sealing the state championship for the team with the motto **"United We Stand."**

"And here we are, all these years later," says Krasinski, the team captain, "still living that