



Just Causes

Legacy of Hope

A former quarterback takes on an opponent unlike any he faced during his storied NFL career: the disease that claimed his son.

By Brion O'Connor

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In hindsight, no one would blame Jim Kelly if, in 2005, he had walked away from the fight, retreated to his acreage in western New York and immersed himself in his favorite pastime, hunting. The rugged Buffalo Bills quarterback had just lost his only son, 8 ½-year-old Hunter, to a devastating neurological disease—a blow far more painful than any sustained during his 13-year Pro Football Hall of Fame career.



But Kelly's competitive spirit, and the enduring memory of his young son, simply wouldn't let that happen. Instead, Kelly and his wife, Jill, continued to devote their efforts to the Hunter's Hope Foundation, which they established in 1997, shortly after they learned their son was afflicted with Krabbe leukodystrophy, a degenerative neurological disorder.

"When Hunter was first diagnosed, I didn't want to hear that my son was here for a reason. I didn't want to hear that I was a chosen father," says Jim Kelly today. "But now, and I've known this for a while, I realize my son was a chosen little boy, and that I am a chosen father, because through Hunter's Hope we are going to make a difference for thousands and thousands of kids."

The motto for Hunter's Hope today is straightforward and powerful: "Every Child. Every Time. Everywhere." The maxim captures the essence of universal newborn screening, the Kellys' stated goal for the foundation. Mandatory universal screening would require all 50 U.S. states to test for the 54 diseases currently recommended by the American College of Medical Genetics (ACMG)—including cystic fibrosis, sickle-cell anemia and the human immunodeficiency virus (HIV)—as well as any diseases ACMG adds to its list in the future. In the United States, newborn screening is a state-based initiative, meaning each state determines which diseases are

tested for and whether the tests are mandatory. Not surprisingly, the number of diseases targeted for testing varies dramatically by state. According to Hunter's Hope and the National Newborn Screening and Genetics Resource Center, West Virginia mandates testing for only 14, and New Jersey mandates testing for 25, while Minnesota screens for 54. In general, though, states are screening for more and more diseases.

The screening procedure is quite simple; a single heel stick taken shortly after birth provides enough blood to test for all 54 illnesses. Yet many parents aren't aware which diseases their state tests for. The results can be grim.

"Thousands of babies die every year, and thousands more become permanently disabled, because they're born in the wrong state," says Jim Kelly. "This has been going on for years and years and years."

Some diseases on the ACMG list, such as digestive disorders, can be managed by diet. Others have no cure, but early detection and treatment can add years to a child's life, and greatly enhance the quality of life. Even Krabbe disease can now be treated with a cord blood transplant, if the procedure is performed prior to the onset of symptoms. Early detection and treatment could also save insurance companies, caregivers and taxpayers billions of dollars annually in medical costs.

"It cost in excess of \$700,000 a year for Hunter's direct care, over eight years," says Jacque Waggoner, the CEO of Hunter's Hope (she's also Jill's mother and Hunter's grandmother). "That's one child. Now multiply that by 10,000 who become permanently disabled and [whose diseases] could have been prevented, and you're talking about seven billion dollars a year [in medical costs]." And the cost of losing the 3,000 children who die each year cannot be measured.

Ironically, the list of diseases for universal screening currently endorsed by Hunter's Hope doesn't include Krabbe leukodystrophy, though the foundation has submitted the disease for inclusion, which would bump the total to 55. The fact that Hunter's Hope promotes the current list anyway reflects the foundation's broad appeal, and the Kellys' ability to see the big picture.

"What made me focus on more than just Krabbe disease is that so many of these kids are suffering and they're not getting a chance," says Jim. "When I was a little boy, I dreamt of being a professional quarterback. These kids can't say a word, they can't voice their opinions. I'm the voice for all those little boys and girls, and their parents."

In addition to its lobbying activities, through Hunter's Hope more than \$15 million has gone to research related to leukodystrophy and other neurological diseases. The foundation has also partnered with the University at Buffalo to establish the Hunter James Kelly Research Institute, has opened three residences—Hunter's Homes—near the Duke University Medical Center in North Carolina for families with children undergoing leukodystrophy treatment, and hosts the annual Hunter's Hope Foundation Family and Medical Symposium each summer in New York.

Supporting Hope

For more information on the Hunter's Hope Foundation and universal newborn screening—including opportunities to donate and volunteer—visit huntershope.org.

Born on his father's birthday, Valentine's Day, in 1997, Hunter James Kelly was diagnosed four months later with Krabbe leukodystrophy—one of 38 known leukodystrophies—a disorder that disables the myelin sheath, the protective membrane around the body's nerve fibers. Newborns who inherit infantile Krabbe disease exhibit symptoms within the first six months, and have an average life expectancy of only 13 months. Despite staggering odds, and daily struggles simply to breathe, Hunter lived to be 8, and saw his father inducted into the Pro Football Hall of Fame in 2002.

Though he passed away in August 2005, Hunter—"The toughest little boy I've ever met in my life," says his father—is still a driving force for his parents. "His life, day in and day out, continues to leave a huge impression on me," says Jill Kelly, who is the chairwoman of the Hunter's Hope board and mom to the Kellys' two daughters, Erin and Camryn. "His life, every breath he took, every move he made, was a huge feat for him. That will forever inspire me and encourage me to continue to persevere in my own journey."



"I want the pressure all on my back," says Jim Kelly. "That's how I thrive. I'm driven by challenges."

Hunter's Hope, without question, plays a vital role in that journey. When Hunter was born, New York screened for fewer than a dozen treatable diseases. That number is now 50, and includes Krabbe disease. "Hunter's suffering is paying off because it's helping other kids out there," says Jim Kelly. "I didn't want to believe that in the beginning. I didn't want to hear it. I wanted him to be healthy. But now that I'm removed from that, I understand, and I accept it.

"If I wouldn't have accepted it," Kelly continues, "not only would it have torn me apart, it would have torn my family apart. Our marriage would not be here today without our faith, and without understanding the whole perspective of why Hunter had to suffer."

He also understands the role of celebrity in this campaign. But the man who guided the Buffalo Bills to four straight Super Bowls isn't fazed by the added responsibility. "It's how I played football," he says. "We ran the no-huddle offense. I called all the plays. I want the pressure all on my back. That's how I thrive. I'm driven by challenges."

And on or off the field, Kelly is not about to accept a losing season. "To be honest with you, if I didn't do this, it will still probably happen, but it might not happen for 10, 15, 20 years," he says. "Until it gets corrected, there's going to be a lot of suffering that could have been prevented."

"What really makes my blood pressure spike is that people can't see this. But trust me, they will."

Clearly, Kelly's comfortable with the ball in his hands, the clock ticking down and the goal line in his cross hairs. As an example, he points to his home state of Pennsylvania, which last summer passed legislation, at the urging of Hunter's Hope and the March of Dimes, to increase the number of diseases tested for from nine to 29.

"But we're not stopping until we get to 54. Twenty-nine is a good step, but it's not where we want to be," says Kelly, employing a few football metaphors (naturally) as he continues his thought. "They're in the red zone, but they haven't gotten in the end zone. A touchdown for us will be when every state tests for 54."

"For me, that's going to be my Super Bowl victory."

Boston-based writer Brion O'Connor is a frequent contributor to Sky, and has written for Sports Illustrated, Men's Journal and ESPN the Magazine.

Photos courtesy of Hunter's Hope Foundation
