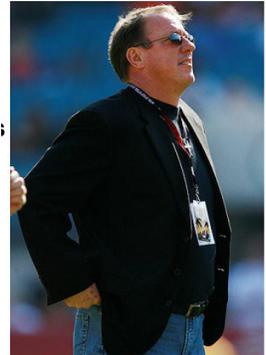


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Good Guy of the Week

Jim Kelly, retired quarterback, Buffalo.

Kelly, who never could get the Bills over the Super Bowl hump in his Hall of Fame career, has a new mission these days -- to get every state to test for 54 potentially fatal diseases that could be diagnosed at birth. Only one state, Minnesota, tests for that many today.

He's on this mission because of the death of his son, **Hunter**, in 2005, from a rare brain disease called Krabbe Leukodystrophy. The disease (leukodystrophies afflict one of every 100,000 American births) could have been diagnosed at birth, but New York State did not test for the illness when Hunter was born in 1997.

"The tragedy for Hunter, and for so many children born with fatal illnesses, is that they're simply born in the wrong state," Kelly said the other night. "If you don't think that's something that just tears at your heart every day ..."

I've known Kelly for a long time, and I've always found him to be one of the biggest life-of-the-party guys I've covered. He was a prolific pre-curfew beer man in his Bills training-camp years, when the Buffalo players were as tight as a team could be. But when I saw him the other day, I saw he'd changed. There was a grimness to a once-carefree guy, with more lines on his face than I remembered. The grimness is not from giving up; it's a grim determination.

He's already seen governors of three states -- New York, Pennsylvania and Kansas -- and gotten each to increase dramatically the number of diseases tested for at birth. When babies are born, their heels are pricked and a blood sample taken to test for diseases. With Kelly's lobbying, New York has increased from 11 to 44 diseases tested for, Pennsylvania from 11 to 29, and Kansas from four to 29.

Parents can buy a kit to screen their children for the maximum number of diseases for less than \$100, but Kelly, and his foundation, want the tests to be done for every child as a matter of course. Considering that the costs of caring for children with one of many known leukodystrophies can run from between \$500,000 and \$1 million per year, it seems like early-testing money would be well spent.

"I never won a Super Bowl," said Kelly, "and for a long time that really bothered me, obviously. But this is real. This is life. My Super Bowl victory will be to get every state to adopt universal newborn screening so we can save lives that are now being lost needlessly. When that day comes, that victory will be 10 times better than any Super Bowl."

Because New York now tests for Krabbe, Kelly met a perfectly healthy boy, now a year and half old, who was diagnosed at birth and successfully treated. "Little Elmer," he said with a grin. Now his goal is to meet a lot more Elmers. If you'd like to help, or learn more about Kelly's mission, you can go to www.huntershope.org.