

TOP STORY EDITOR'S PICK TOPICAL

Jim and Jill Kelly have devoted their lives to saving others from the pain of losing a child. Their work paid off

Tim O'Shei
Feb 4, 2024



Camryn Kelly, Parker Bean, Erin Kelly-Bean and Jill Kelly at the Hunter's Hope Family Symposium at the Holiday Valley Resort in Ellicottville, N.Y. The family is celebrating a vote that added Krabbe disease to a national list of recommended newborn screening tests.

Joseph Cooke, Buffalo News

Tim O'Shei

Jill Kelly and her two daughters were getting in the car when the text arrived:

“It passed! 10 to 3”

This was 2:28 Tuesday afternoon. Jill and her older daughter, Erin Kelly-Bean, had just finished recording the mid-February edition of their podcast, “Light Your Heart With Hope.” The episode coincided with the birthday of their husband and dad, legendary Buffalo Bills quarterback Jim Kelly, and their son and brother, Hunter, who like his father, was born on Valentine’s Day.

Hunter died nearly 20 years ago, at age 8, and was vividly on the minds of Jill, Erin and the Kellys’ younger daughter, Camryn, who was home from college that day and accompanied her mom and sister to the recording. The podcast episode marked what would have been his 27th birthday, if Krabbe disease had not taken him.

“It passed! 10 to 3”

People are also reading...

- 1 Underground AM&A's vault deterioration prompts closure of sidewalk – again**
 - 2 Buffalo State, Brockport officials will address security after fight following basketball doubleheader**
 - 3 Alan Pergament: Future of WBEN, WGR and all local Audacy stations up in the air**
 - 4 Ten Lives Club will put 'every penny' of \$377,000 raised for Bills kicker Tyler Bass toward caring for cats**
-

Now sitting in the car, Jill allowed the message on her phone to sink in. The text had come from her mother, Jacque Waggoner, who added a trio of praise-hand emojis, as if to say, *Thank God, our prayers have been answered.*

Jill absorbed the message. She thought about her two grown daughters, who were here with her today. She thought about Hunter, who never had that chance. She must have thought about Jim, her Hall of Famer husband, who lost the son he always wanted, and whose own health battles have been fought publicly over the last decade, and outmatched in intensity only by the Kelly family’s fight for kids like Hunter.

Those kids. Those babies. Those families who find out, as the Kellys did in 1997, that their child has the rare disorder called Krabbe disease, which impairs the brain’s ability to send signals to the rest of the body. For Hunter, Krabbe disease was fatal. But for children now, it doesn’t need to be.

Because of this 10-to-3 vote by a panel of doctors on a federal advisory committee, Krabbe disease is now going to be added to a national list of recommended newborn screening tests. That means children today who have Krabbe disease will also have the chance to get something Hunter never could: lifesaving treatment.

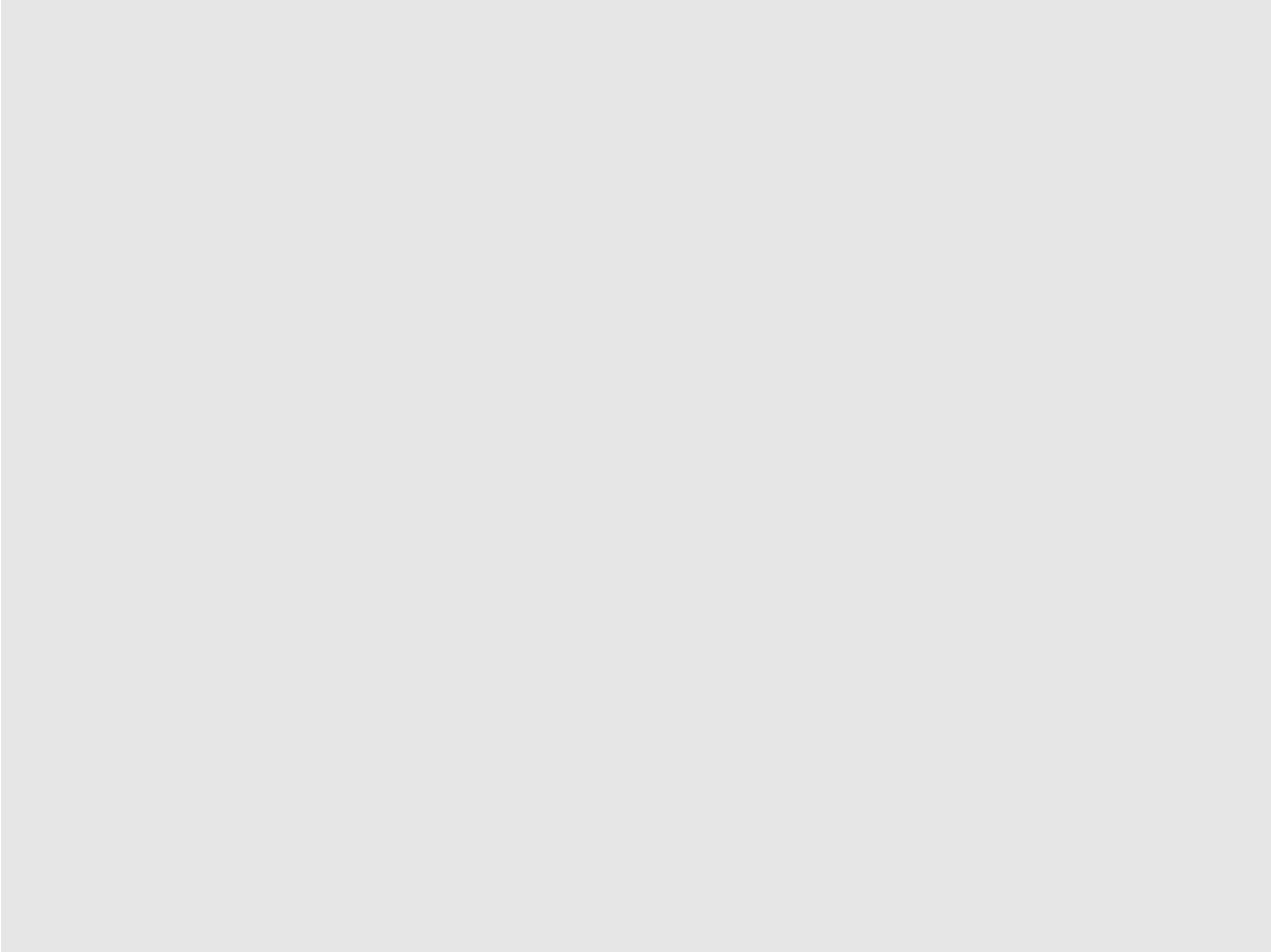
It took nearly two decades of work, incalculable heartbreak and endless faith to reach this point. Now, it means that Hunter's death may help save children in all 50 states.

As those thoughts flooded Jill's heart, she burst into tears.

* * *

What happened Tuesday was either bureaucracy in action, or the end of bureaucracy inaction. Either way, the Kelly family and their allies got what they wanted.

The nonprofit organization Hunter's Hope was formed in 1997 – the first year of Hunter's life – to support research and awareness of Krabbe disease and other leukodystrophies, which are a series of rare, inherited disorders that affect the brain and central nervous system. The Kellys spread word, raised money and built a network of support for families. Jim's celebrity pried many doors open, and almost certainly helped get Krabbe on some states' lists of newborn screening tests.



Back left to right, Jill Kelly, Camryn Kelly, Erin Kelly-Bean and Parker Bean show emotion during the Hunter’s Hope Family Symposium at the Holiday Valley Resort in Ellicottville on July 21, 2023. The event honors children who lost their life to leukodystrophy. Jill's son and Camyrn and Erin's brother, Hunter, passed away from the disease on Aug. 5, 2005.

Joseph Cooke/Buffalo News

“It’s huge,” said Dr. Barbara Burton, a professor of pediatrics at Northwestern University who specializes in disorders diagnosed through newborn screening. “I think we probably would not have Krabbe newborn screening in any state right now if it weren’t for them.”

In 2005, New York was the first state to add Krabbe. Then-Gov. George Pataki welcomed Kelly to the State of the State address. “Hunter’s dad is with us today,” Pataki said. “Whether throwing touchdowns for the Buffalo Bills or for this great cause, he’s always been a New York hero and a true champion. Jim Kelly, thank you. Today’s victory belongs to you.”

Pataki then added, “Newborn screening can help ensure that children are given an opportunity to grow into healthy, vital adults. But let’s not stop there.”

That last sentence was meant to be transitional (Pataki was moving to the next item on his health care agenda: childhood obesity). But in truth, that point was, and remains, transformational. If Krabbe disease is detected at birth, it can be treated through a stem cell transplant. While it's not a cure – children who receive the transplant can still develop physical disabilities – it can be a lifesaving procedure.

Knowing that, the Kellys and their Hunter's Hope staff and consultants have worked for the last 20 years to get Krabbe on newborn screening lists across the country. It's been a state-by-state effort, with 11 signing on so far, and a 12th (Minnesota) potentially adding Krabbe later this month.

But there is an all-in-one option to likely land Krabbe on every state's screening list, and it's one that runs through the alphabet soup of the federal bureaucracy.

The HRSA (Health & Resources Services Administration), which is an agency within the HHS (U.S. Department of Health & Human Services), relies on a committee of doctors and scientists to recommend newborn screening tests. This group, called the ACHDNC (Advisory Committee on Heritable Disorders in Newborns and Children), reviews and votes on conditions. If a condition receives enough votes, it is added to a list called the RUSP (Recommended Uniform Screening Panel), so long as the secretary of health approves.

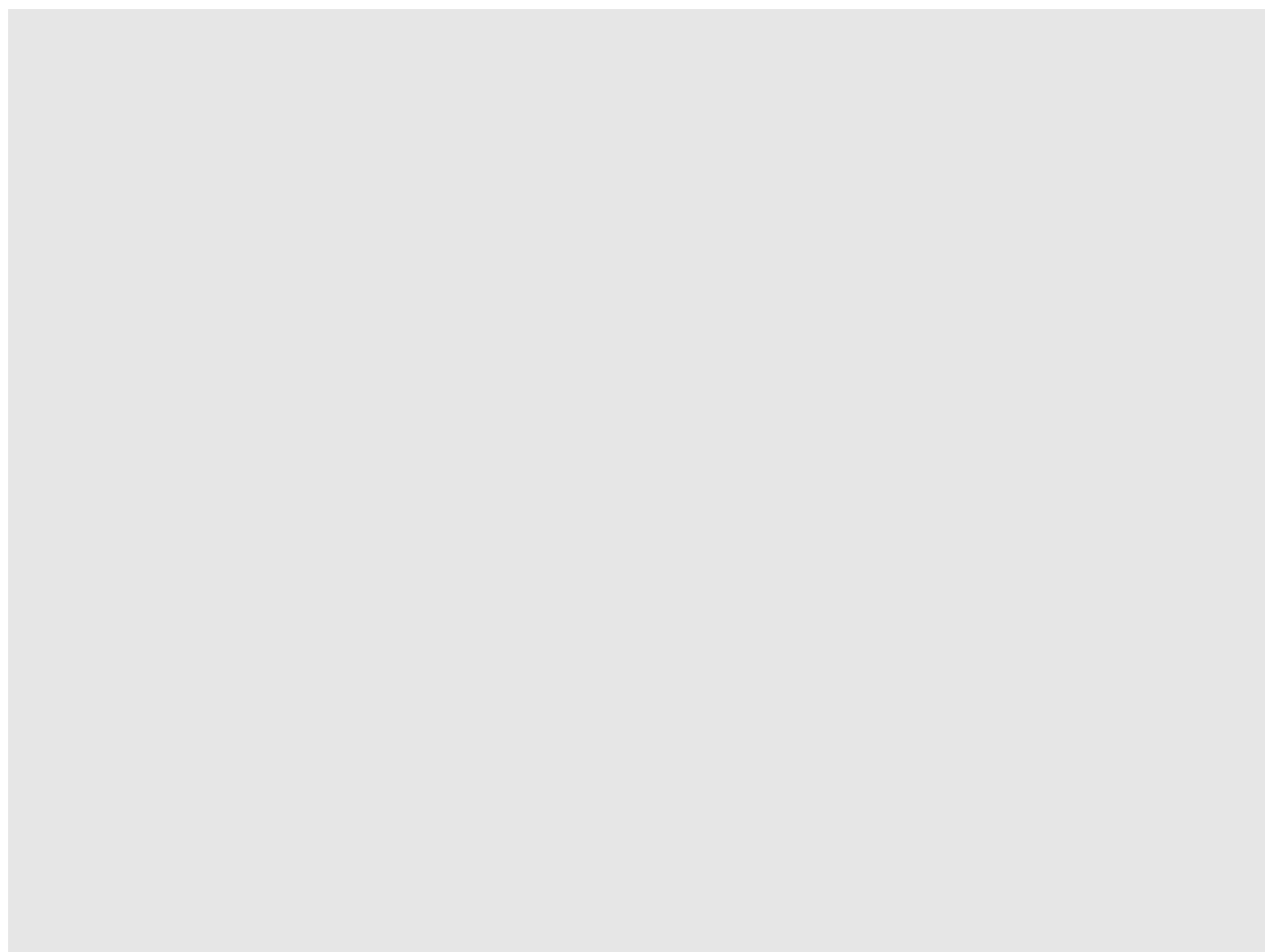
If that process sounds laborious, it's nothing compared to the actual task of landing a disease on the testing list. Hunter's Hope has been trying, and getting rejected, for more than a decade. The early turn-downs came in part because the Krabbe test also flagged infants who did not develop Krabbe symptoms, or wouldn't develop them until later in life, thus causing deep anxiety in some families, and in part because the available treatment isn't an actual cure. In recent years, the testing procedure has been "tuned up" for high reliability, Burton said, and the question of whether a treatment should be a cure is more of an ethical than a medical one.

"I think that families should be able to choose to make those decisions (whether to pursue a transplant) themselves," said Burton, who has supported Hunter's Hope's efforts to land Krabbe on the RUSP. "You explain to them what is the treatment, what is the expected outcome. They have the choice. They can choose not to go with treatment and let the disease run its natural course, or choose the treatment."

One year ago, those doctors convened to consider Krabbe, and the vote was tied – a near-miss that was yet another rejection. That ignited a public campaign by the Kellys and Hunter’s Hope to convince the committee to reconsider.

“It’s sad because we’re talking about newborns and you want to give them the best chance at life, regardless of what they’re born with,” Jill Kelly told The News in an interview in June in the Orchard Park office of Hunter’s Hope. “To not be able to give every child the opportunity to have the best life possible is just a disregard for life itself.”

Jim, sitting next to her, added, “I was able to dream as a kid. My dream was to play football. I want kids to be able to do that, to be able to dream. I want parents to be able to see their kids grow up and be able to fulfill their dreams.”



Jim Kelly, with his wife, Jill, son, Hunter, and daughters Erin and Camryn, on Nov. 18, 2001, the day Jim was placed on the Bills Wall of Fame. Hunter died nearly 20 years ago at age 8 from Krabbe leukodystrophy, a degenerative neurological disease.

Buffalo News file photo

When the Kellys started Hunter's Hope, they knew the research and breakthroughs they sought wouldn't help their son – it was too late. But they believed then, and now, that Hunter's story, his legacy, can save many lives.

“God is opening these doors,” Jill said. “I mean, we never imagined that we would have an opportunity through newborn screening to touch the life of every child born in our country.”

For that, they needed faith, funding and hope.

And votes.

* * *

The advisory committee agreed to expedite a new review of the Krabbe application, and the doctors and scientists working with Hunter's Hope tightened the testing parameters to ensure the most accuracy possible. The vote was scheduled for Jan. 30 in the HRSA's Maryland offices.

Two Hunter's Hope officials attended in person: Executive Director Melissa Jablonski and Anna Grantham, the foundation's director for newborn screening and the Leukodystrophy Care Network. For Grantham, who has led the foundation's efforts to land Krabbe on the RUSP, the vote was deeply personal: She joined Hunter's Hope in 2011, a couple of years after her friend's 4-month-old daughter was diagnosed with Krabbe disease.

“When her daughter was diagnosed, they were told she would probably die by her first birthday,” said Grantham, who lived then – and still now – in Alabama. “Then we learned that if she had been born in New York, she would have had the chance for early diagnosis and treatment. That's when I got really angry.

“If she had just been born in a different state, she could have lived and could have been spared so much suffering.”

As the meeting happened, Hunter's grandmother Jacque Waggoner, who is still the foundation's CEO, watched a livestream from her winter home in Florida. When the vote happened, Waggoner texted her daughter, and soon the family group chat was blowing up with good news.

While this was happening, Jim Kelly was on a plane home from baseball Hall of Famer Reggie Jackson's golf tournament in Florida. When Jim landed, he saw the notifications on his phone and, rather than reading every message, reached out to Jill.

“What’s going on? What’s going on?” he asked.

The news was gratifying, but the enormity didn't hit Jim until the next day, when he saw coverage on TV, including footage of his son, and started crying. “We've all been really sad, actually,” Jill said. “Sad and so filled with gratitude and joy. It's been bittersweet.”

They're not nearly done: Krabbe isn't on the RUSP officially until HHS Secretary Xavier Becerra signs off – though that's just a formality. Even then, each state has the option of whether to include it. Hunter's Hope is also advocating for research, testing and treatment for other diseases that affect the central nervous system.

“Is this a huge victory? Yes, but there's so much more to be done,” Jill said, acknowledging that the mixed surge of emotions has been “a little bit shocking to us ... You've climbed this mountain for so long, and when you finally get to the top, part of you is overcome with the fact that you got there, and what it took to get there...”

“And at the same time, immediately I'm thinking about Hunter.”

Follow Tim O'Shei on Twitter [@timoshei](#).

By Tim O'Shei
Enterprise Reporter
