



Hunter's Hope

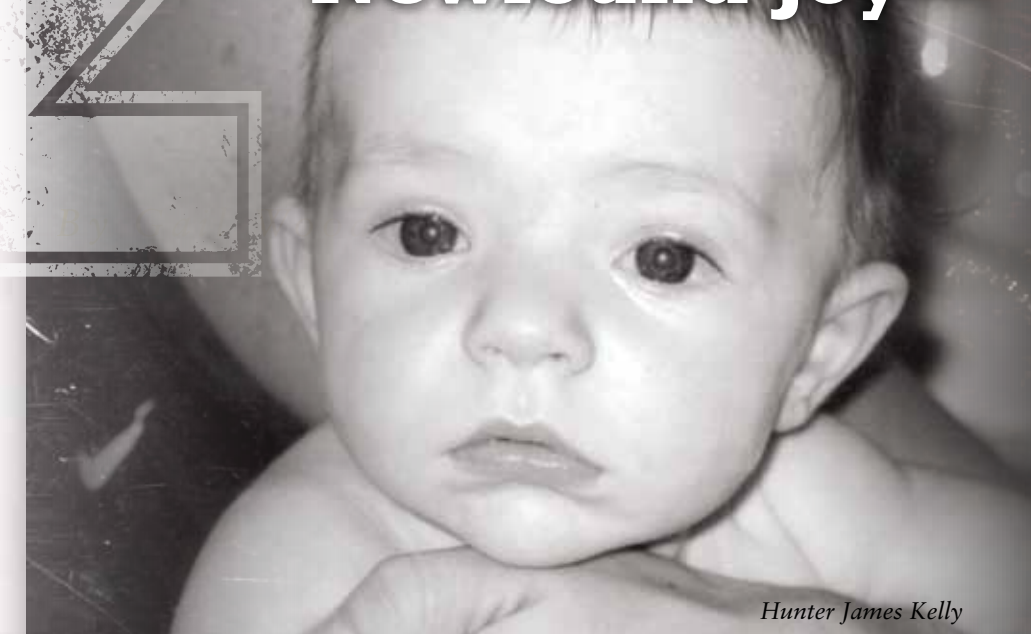
Jim and Jill Kelly never imagined the pain they would share with their son, or the immeasurable joy he would bring into their home.

Pro Football Hall of Famer Jim Kelly and his wife, Jill, were catapulted from a seemingly fairy-tale life of celebrity into a world of private struggle and medical uncertainty when their infant son, Hunter, was diagnosed with Krabbe (pronounced crab-A) leukodystrophy. Krabbe disease is a rare, inherited degenerative disorder of the central and peripheral nervous systems that impairs the growth or development of the myelin sheath, the fatty covering that acts as an insulator

around nerve fibers. Severe deterioration of mental and motor skills results. There is no cure for Krabbe disease, and Hunter's life expectancy was only two years. Though he would never walk or speak, Hunter lived until he was 8. During his very challenging but miraculous extended lifetime, he proved to be the key to Jill, and then Jim, discovering the boundless comfort and guidance of a faith in Jesus Christ. In September 2010, Jill Kelly released her memoir of Hunter's life, Without a Word: How a Boy's Unspoken Love Changed Everything. She spoke with Scott Harrup, managing editor, about their family's journey with Hunter. More information on Krabbe disease and about the Kellys' commitment to helping families impacted by it is available through Hunter's Hope Foundation (huntershope.org).

The interview begins on page 14.

Jim Kelly A Father's Heartache and Newfound Joy



Hunter James Kelly

When his infant son, Hunter James Kelly, was diagnosed with Krabbe leukodystrophy, former Buffalo Bills quarterback Jim Kelly blamed everybody. Including God.

"I was mad at everyone who came up and told me I was a chosen father," Kelly said during a Sunday morning service last September at his home church, The Chapel, in Getzville, N.Y. "Where I ran and blamed God, Jill ran to seek God."

While his wife, Jill, along with members of her family and Hunter's care team, would be praying for his son, Kelly "would go and do my thing." That all changed when Hunter passed away on Aug. 5, 2005, at the age of 8.

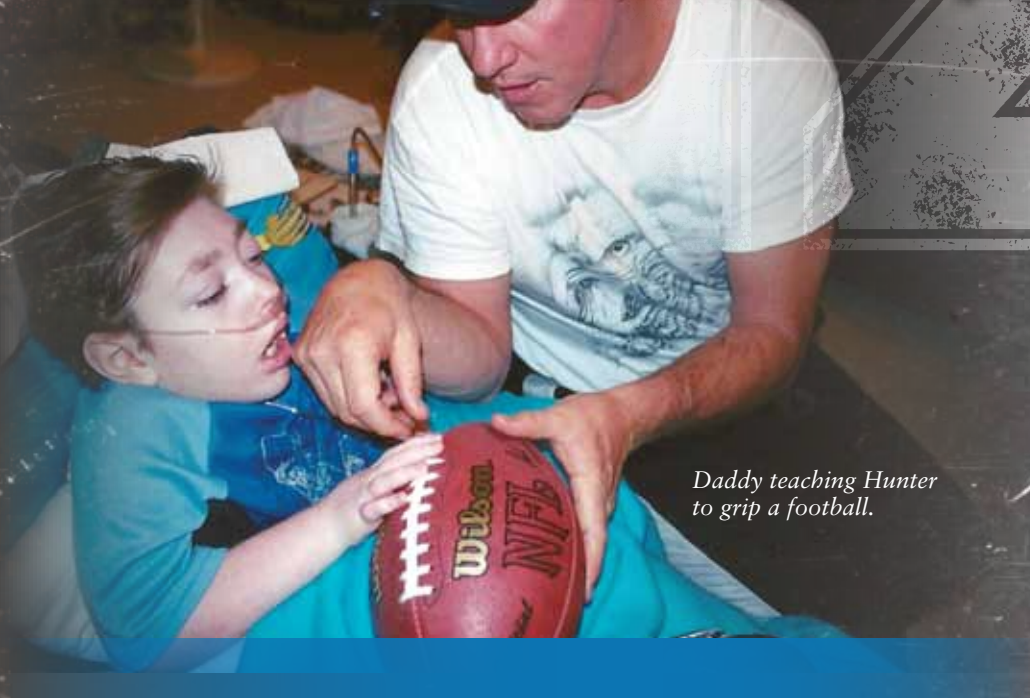
"I wasn't sure what was going on," Kelly recalled. "I knew if I didn't change my ways, I would never see my son again. I made



Family photos courtesy of Jill Kelly

Jill and Jim Kelly with children (from left) Camryn, Erin and Hunter walk onto the Buffalo Bills' field in 2002 for Jim's Wall of Fame ceremony.

Jim Kelly A Father's Heartache and Newfound Joy



Daddy teaching Hunter to grip a football.

a lot of mistakes in my life. I needed to ask the Good Lord for forgiveness.”

The 2002 inductee into the Pro Football Hall of Fame eventually made that choice.

“I came to the realization that I wanted to see my son again,” said Kelly, the only NFL quarterback to lead his team to four consecutive Super Bowls. “I want to see Hunter do all the things he couldn’t do here.

“Things will go wrong in everybody’s life — but it’s what you do about them that count. I did something about it. I never gave up; I never quit. The day I gave myself to the Good Lord is a day I look back on and wish I had done that a long time ago.

“I am not where I want to be,” Kelly added. “I am a work in progress.

“Just because I played football doesn’t mean anything, because what I have inside my heart is what it’s all about,” said the 1983 first-round draft pick out of the University of Miami, who concluded with succinct advice he directed toward the men in the congregation. “Don’t run away from Him; run to Him.”

— Ron Kopczick



evangel: Any special reflections or memories crossing your mind today?

Jill: This is the first opportunity I’ve had in many days to respond to messages through my website of people’s struggles and their hopes and fears, and I’ve been crying most of the morning. But it’s a good cry just knowing that God is able and He is in it all. His sovereignty and His goodness overwhelm me. I’m in awe of what He’s done thus far.

evangel: One of the many powerful themes in *Without a Word* is Hunter’s influence on your marriage and family. Could you talk about his impact on you and Jim and Erin and Camryn?

Jill: Really, the story is Jesus, fully and in every way, and how He used Hunter as a beacon of light in our home. We continue to reflect on Hunter’s courage in the midst of suffering and that he was such a light even though he struggled daily. Our girls are reminded of that, probably on a daily basis, and some days in a more profound way because of their own struggles and their friends who are dealing with issues. Jim and I, because we’re in this season of sharing our memoirs through *Without a Word*, are reminded of Hunter’s influence daily. There’s not a day that goes by that we are not thinking about Hunter. God continues to remind us of the goodness and grace that He showed us in the midst of Hunter’s life.

evangel: Few people, even after reading your book, can comprehend the level of care Hunter needed. Could you summarize your daily schedule?

Jill: It was 24-hour care. On a daily basis, depending on how

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Hunter felt, he needed chest therapy every four hours around the clock. That part of his care had to be consistent because his lungs were always at risk. He couldn’t swallow, so he would aspirate. Hunter needed suctioning around the clock in order to keep his lungs as clear as possible. His chest therapy regimen usually took an hour and a half

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to two hours depending on how his lungs sounded at the time and what he needed. Every day, he had physical therapy and occupational therapy for an hour. In the midst of all those necessary elements, we tried to incorporate activities where he could still have fun.

evangel: You could never think in terms of a full night of sleep.

Jill: Oh no, no, no. I slept with Hunter. On the days I wasn’t

with him, my mother shared that experience with me and she slept with him. But even those nights when I wasn’t with him physically in the room, I was still with him in a sense. My mother and I look back and reflect, and we see how God sustained us and how He completely provided all that we needed with two hours of sleep, and three hours of sleep sometimes. He absolutely sustained us. Yes, we were exhausted, and there were times when I just fell apart. Thank God, my mom was there to help take care of Hunter.

But we experienced so much blessing as well. After Christ intervened, we had so much joy even in the midst of our pain. That’s why love endures, I believe, because in the midst of our pain there was incredible joy that could have only come from God. It’s impossible without Him.

evangel: Hunter had a treasured friendship with a boy named Robert. How is Robert doing? What’s going on in his life?

Jill: Robert is getting big. He’s getting really tall, and he loves football. He plays for the Hunter James Kelly Football Association here in Orchard Park, N.Y., so he is playing for his namesake, his best buddy’s team. The last time that we saw Robert he did an audio version of what he wrote for *Without a Word*, so I got to spend an entire day with him and his mom.

I’m so amazed at how God allowed that friendship to be, and that Hunter went to heaven on Robert’s birthday. I believe God wanted to remind Robert of the influence Hunter had on his life, and I believe God has a call on Robert’s life. I hope we have the opportunity to see him grow into that calling. We’ll never forget





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Jim and Jill Kelly renewed their wedding vows on Sept. 19, 2008.



The Kellys at the 2009 Hunter's Hope Candlelight Ball

Robert; every Aug. 5 we also remember Robert.

evangel: *You described Hunter's powerful connection with God. What were some ways you observed that relationship day to day?*

Jill: Hunter wasn't able to communicate with words. But he had the Word of God read over him almost every single day. He was fully cognitive, and we were very particular about everything that we allowed Hunter to hear and see. "The peace that surpasses understanding" that radiated from his countenance to me was evidence of his relationship with the Lord.

He would pray with us. In fact, Camryn would remind me during family prayers, "Mom, it's Hunter's turn to pray." We would all be silent, and Hunter would blink when he was done praying.

I won't fully grasp what his relationship with Jesus was like until I see him again in heaven. But I know that the relationship Hunter had was real because it radiated from him. I think of the story of Moses when he spent time on the mountain with God and had to shield his face because of the glory of God radiating from him. God's glory was evident to me in Hunter, and there was a peace about him all the time, even though he was struggling so much.

evangel: *Childhood pain, childhood illness and early death create some of the most pressing questions about the goodness of God. How did you deal with those questions?*

Jill: I wrestled with God through journaling and praying and crying out to Him. The Book of Job really helped me to

see I might not get the answers that I want or that I'm seeking — and that God might actually be silent — but that God is eventually going to reveal more of himself in the midst of my pain. That's the beauty of what I feel God continued to do as I wrestled with Hunter's suffering.

If God told me why Hunter had Krabbe and He explained it, the pain would still be there.

He made me, He made Hunter, and He knows the details of all that's going on. So, rather than getting answers, I got more of Jesus. And that's really the answer.

And if He explained Hunter's death, just the darkness of that time of grief, the pain would still be there. But rather than answer my prayers with *Jill, this is why* ... God gave me more of himself. He deepened my relationship with Him. He allowed me to, in a sense, recognize His grief over sin and to share our story more boldly with hope and faith

and to press on in the midst of all that we were going through. We could not do that apart from Him.

Jesus said, "You can do nothing apart from Me." I felt that God definitely gave me the freedom to be honest and real with Him rather than trying to pretend that I was going to be OK because of my great faith. I felt, in the midst of asking, that He said it was OK to ask. God is big enough for all that I'm wrestling with because He made me, He made Hunter, and He knows the details of all that's going on. So, rather than getting answers, I got more of Jesus. And that's really the answer — Jesus is the ultimate Yes, He's the ultimate Amen in all of this.

evangel: *What are some themes that are close to your heart as you travel in ministry?*

Jill: Joy in the midst of sorrow and the sovereignty of God. That He is able. But I don't have a set theme by any means. I just go and allow the Holy Spirit to speak through me. God has shown me, *Girl, you can be prepared, but don't go setting your own agenda, because I have one.* And that's really liberating. That frees me to allow Him to have His way. When I've over-prepared, God is quick to remind me.

It's vital that we trust Jesus in every circumstance of our lives. As God continues to give us the blessing of sharing our testimony — Jim has been a Christian now for three years — we find that people still want something more than Jesus, or they think that it's "Jesus plus something" when it comes to meeting their needs. Really, Jesus provides us everything we need in our relationship with God. And God continues to

remind me of that. *It's just Me. Fix your eyes on Me.*

When I try to figure my life out, my focus moves from the core of what I need in Christ to all the surface issues or circumstances at hand. So I look for every opportunity to share Jesus. But I also speak about suffering and the beauty of how God uses suffering to accomplish wonderful things in spite of those circumstances.

evangel: *What are some current projects or milestones for the Hunter's Hope Foundation?*

Jill: Our advocacy for newborn screening continues to be a main priority for us. We will continue to press for testing for the maximum number of treatable diseases to prepare families for what they might face.

After a nearly three-year search, we've hired a director for the Hunter James Kelly Research Institute based in Buffalo. He and his wife are from Milan, Italy, and are highly respected. They will be doing myelin research and repair, which affects all sorts of diseases, not just Krabbe.

Our ultimate goal is to bring hope to families who are struggling. Having our story in print is huge. It's another way for us to advocate for the foundation, but more than that to share Jesus. My hope through *Without a Word* is that a family suffering from their child being diagnosed with a terminal illness — or even a football fan who wants to know more about Jim's life — would find Jesus more than anything else in the pages of our book.

evangel: *Is there a specific theme from the book you'd like to comment on beyond Hunter's life and faith?*

Jill: I tried to communicate the beauty of our daughters' lives and their spiritual walk and how God has formed and shaped them as a result of their brother being sick and then going to heaven. Erin and Camryn are so heavenly minded and have developed such compassion that God's given them through watching a disabled boy grow and then go to heaven. That has been incredibly profound. The words they share in the book are just a tiny portion of their hearts.

I'm just thankful to be blessed with two girls, and I could never have taught them what they've learned. It's completely been the work of the Holy Spirit in their lives. Camryn was 6 when she wrote those little vignettes at the back of the book. I'd like to close with a quote from "I Am Free to Run," one of her first journal entries after losing Hunter.

We are free to run.

We are free to run with God today.

When we get to heaven we will run free.

And horses run free forever in heaven.

I am free to run, God.

I am free!

We are free in You, Lord.

God will let us go free.

That, to me, is the Holy Spirit. It has nothing to do with Camryn. God just used her little hands to write those words on paper. **e**

E-mail your comments to pe@ag.org.