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 disease. 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).

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...
Hunter's Hope

A Father's Heartache and Newfound Joy

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 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.

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.

The 2002 inductee into the Pro Football Hall of Fame

heart is what it’s all about,” said heart is what it’s all about,” said

as the years went by, I learned to accept and respect the way God was going to provide for her. I was able to see that she was stronger than I could ever be, and that was an asset to me.

I’ve learned that you can’t stay down. You have to keep moving forward and believe that God will provide for you. I’ve also learned that you can’t be afraid to ask for help when you need it. I’ve seen how God has provided for me in the past, and I know that He will continue to do so in the future.

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I want to see

eventually made that choice.

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

“I came to the realization that I wanted to see my son

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 foot-

ball 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,

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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 physi-

cally 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 for all that we needed with two

hours of sleep, and three hours of sleep sometimes. He abso-

utely 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 be-

lieve, because in the midst of our pain there was incredible joy that
could have only come from God. It’s impossible without Him.

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

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 al-

lowed 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

his life. I hope we have the

opportunity to see him grow into

that calling. We’ll never forget
Hunter’s Hope

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 anything, 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 every day 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 — 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 — Jill 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 with 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 with words, to give them to God as He 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, and 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-mail your comments to pe@ag.org.