



A *Light* IN THE DARKNESS

By Peg Carmack Short

A fairytale romance and the seemingly charmed life of NFL Buffalo Bills superstar, Jim Kelly, and his beautiful wife, Jill, turned into a story of tragedy when their only son was diagnosed with a fatal illness. How they found light, even in the shadow of death, can bring hope to others.



Upper Left: Jill Kelly found her hope in Jesus

Left: Hunter, shortly after he was born

Above: Jill and Jim Kelly



There were many exciting moments in the life of Hall of Fame, NFL quarterback Jim Kelly—many involved football: four superbowl appearances, four AFC Championships, six AFC East Championships, and five Pro Bowl invitations. Still, what could compare to the excitement and pride Jim felt when, on February 14, 1997—his 37th birthday—his wife, Jill, gave birth to a son: Hunter James Kelly. With the doctor's announcement, "It's a boy!" Jim was soon out the door to tell everyone the joyous news. Jill described Jim's reaction to the birth of his son in her New York Times bestseller *Without a Word*, saying, "Hunter's future was set in stone and the playbook for his life was written. He would play football. He would go hunting. He and his daddy would do all the things that fathers and sons do together. . . the two would be inseparable. This was going to be the relationship that every boy would long to have with his father."

While Jim was out telling everyone the good news, Jill was blissfully examining their perfect newborn.

His body seemed strong and healthy, and she relished his beautiful features. Like her husband, her dreams were already forming for their precious child. She could hardly wait to show him off to his 2-year-old sister, Erin.

Jill recalls that everything seemed just as it should be. During their two-day hospital stay, Hunter was peaceful and content. Jill says, "When he started nursing and he passed all his [newborn] screens, we were oblivious to any problems." But very quickly Jill began to have concerns about Hunter. She says, "In the first weeks and month of his life, he became very irritable."

At first, the Kellys thought Hunter was just colicky. Jill wondered if perhaps there were problems with her nursing Hunter—even though this was her second child, and she was an experienced nursing mother.



Above: Buffalo Bills Fans: Camryn, Jill, Hunter, Erin

Right: Jill and Jim working with Hunter. She sensed something was awry.

After sharing her concerns with their pediatrician, he suggested Jill stop nursing and switch to formula feeding. But despite trying almost every formula on the market, along with a variety of different bottles and nipples, nothing seemed to help.

Jill became more alarmed as Hunter failed to meet any of the normal milestones. By three months, most of Hunter's waking hours were spent screaming. About this time, his arms and legs began to stiffen. The doctor then misdiagnosed Hunter, saying he must have cerebral palsy. While this news was upsetting, the Kellys thought they could still do everything to give Hunter the best opportunities. Intervention programs were put in place to give Hunter the therapies they thought he would need.

However, despite all the Kellys' and their doctor's best efforts, Hunter continued to decline. In addition to his body becoming more rigid, it was obvious that he was having difficulty swallowing, and then he started having seizures. The Kellys took their son to a child neurologist, Dr. Duffner, who told them that, along with other things, she would be testing Hunter for leukodystrophies. "Coming from healthy families," Jill says, "we had no idea what this word even meant."

Jill and Jim later learned that leukodystrophies are a group of genetic diseases that affect the white matter in the brain. "The white matter," Jill explains, "controls sight, hearing, swallowing, and movement [of the] the limbs."



In children with various types of leukodystrophy, a defect in the gene causes myelin loss, a change in brain cells, and neurological damage. But at the time Jill and Jim took Hunter for his initial diagnosis, leukodystrophies and their devastating effects were unknown to them.

Hoping the best for their son, Jill and Jim waited anxiously for the results of the tests. The news they received was more terrible than they could comprehend. Dr. Duffner told them, "Your son has been diagnosed with a fatal genetic disease called 'Krabbe Leukodystrophy.' There is no treatment and no cure. I will do everything I can to help your son. But the disease has already progressed so fast that I don't think he will live to see his second birthday."

Jill recalls her feelings that day, saying, "It is really almost beyond description. I was in shock. I remember thinking that this can't be true—there had to be something, some way to help Hunter."

As they drove home from that visit, Jill was still in denial. Because of Jim's fame and resources, Jill was thinking, We will do something; we will pay for it; we will go and travel; we will find something. But

what the Kellys found was that, because of its rarity, little was being done to research or help with the disease—even experimentally.

Like Jill, Jim was in shock and couldn't believe this was happening to his son. His first response was anger. "I was ticked off at everything and everybody—especially God. He [Hunter] was dying and there was nothing I could do to help him. Nothing."

Jill and Jim also had no way to help themselves. They had gone to church when they were growing up, but neither really had a deep understanding of God or a personal relationship with Him. Consequently, they had no spiritual resources to draw from. So for the first year of Hunter's life, Jill says she and Jim were simply in "survival mode." But as she searched for help and answers for Hunter, Jill found herself desperately seeking to know God. "At first," she says, "I wanted to know Him for selfish reasons." She especially wanted to know about Heaven. She wondered, Is it real? What does it take to get there? "I just wanted Heaven so badly," she says, "that I was seeking after God with everything in me."

As she searched for help and wondered who would rescue them, there were people who came into her life and home and began to talk with her about the things of God. They read His Word and offered a sense of hope that the world couldn't offer. It was Jill's Uncle Mark, however, who eventually shared the salvation story with her. He explained how all are sinners and need the Savior.



Costumes On. Clockwise from bottom left: Camryn, Erin, Jim, Jill and Hunter

He described how God, through the birth, death, and resurrection of His son, Jesus, provided forgiveness and a way to have eternal life through Him. After spending a lot of time talking with Mark and reading and studying the book of Job, Jill eventually came to understand God's great love.

From this point on, Jill began to understand and accept that God had different plans for Hunter and their family. That's also when she changed her attitude and started seeing and treating Hunter in a different way. "I started to treat him as someone who was living and not dying," she says, "because he was."

Despite this change of attitude, Hunter's disease continued to worsen, and, over the course of years, more and more equipment and interventions were required to sustain Hunter's needs and his life. Yet, Jill says, "Regardless of his daily struggle, Hunter's inner joy continued to radiate and penetrate the hearts of all who met him."

A big breakthrough for Hunter came when he was three years old. One of the Kelly's nannies, Reggie, taught Hunter how to communicate with his eyes. She taught him to blink once to indicate "yes." In this way, Hunter's friends and family were better able to meet his needs.

Although Jill was initially uncomfortable with the lack of privacy caused by all the caregivers in her home, she quickly came to see how much everyone loved Hunter and how they pulled together to help him. She affectionately named all those who worked so hard to aid her son "Team Hunter." But while so many people were pulling together to help Hunter, Jill and Jim were drifting further and further apart.



SAVING THE CHILDREN

What Are Leukodystrophies?

Leukodystrophies are inherited, progressive disorders that affect the brain, spinal cord, and peripheral nerves. Specifically, the diseases affect the myelin sheath, the material that surrounds and protects nerve cells. As in Hunter's case, these diseases usually appear during infancy or childhood. They can be hard to detect early because children seem healthy at first. However, symptoms gradually get worse over time. Sadly, once children are showing symptoms and the disease is advancing, it is already too late to help. That is why Jill and Jim Kelly and their foundation, Hunter's Hope, are striving to get laws passed in each state to conduct Universal Newborn Screening, a state-based public health system that is essential for preventing the devastating consequences of a number of medical conditions not clinically recognizable at birth.

What you can do to help?

While Hunter's Hope is helping families in many ways, Jill suggests a few things you can do to help.

- Pray for children like Hunter and their families.
- Tell your family and friends who are expecting a baby to find out what diseases their baby will be screened for at birth. And, if their state is not screening for the maximum number of diseases possible, tell them about the availability of Supplemental Newborn Screening.
- Donate money for research for cure and treatment and to help families whose children have leukodystrophies.

To find additional ways to help a child or families in need, visit www.huntershope.org and click on "Get Involved."



By the time of Hunter's diagnosis, Jim was retired from the NFL, but he was working as a color analyst for NBC and later ESPN. Consequently, he was still traveling frequently. Jill expected, though, that because of Hunter's illness, Jim would try to be with them as much as possible. "When he didn't," Jill says, "my resentment grew."

In time, Jill would understand that Jim couldn't possibly fill her needs, only God could. Still, she continued to draw away from Jim. Every time Jim traveled, Jill wondered what he was doing. She knew that in his bachelor days Jim had led a partying, celebrity lifestyle. So she was understandably unsure and worried when he was away. Also, because she was consumed with taking care of Hunter and his needs while simultaneously juggling Erin's (and eventually their third child, Camryn's) needs, she was physically and emotionally drained. Jill and Jim's fairytale life was disintegrating, and their life as a couple was unraveling.

But there was one thing that Jill and Jim were united on: their love for Hunter and their determination not to give up on him and to provide him with as many normal experiences as they could. However, despite the joy and wonderful experiences the family provided, Hunter's suffering seemed to have no end. Frequent bouts of pneumonia and other health issues often landed Hunter in the hospital. Still, the courageous little boy fought on. Jill says, "Though outwardly it appeared that Hunter was wasting away, his inward spirit continued to shine as he battled seizures and all sorts of serious physical complications."

All these struggles drove Jill to her knees and to God. However, Jim's anger at everyone—even God—continued to make him pull away. It was only after Hunter succumbed to his illness at age 8, that Jim finally accepted Christ as his Savior. It was Jill's mother who confronted Jim about his behavior. Jim says, "I wanted to see Hunter again." Jim knew that if he was to reunite with his son in Heaven, he would need to give his life to Christ. This realization made him confess his sin and ask for forgiveness—first to God and then to Jill. Jim admitted to Jill that he hadn't been faithful to her and asked forgiveness. Finding God and asking for Jill's forgiveness, too, made all the difference in their marriage. A healing began, and today the Kellys have a solid marriage and work together in the foundation they started, Hunter's Hope, to bring help to other families and children who suffer with leukodystrophies. While the foundation helps in many ways, Hunter's Hope is actively involved in pushing for states to adopt Universal Newborn Screening.

Children with diseases like Hunter's and many other leukodystrophies can be helped if the disease is diagnosed early. By screening every baby at birth, many serious mental or physical disabilities can be helped. By getting universal screening in every state, many children will be saved and not have to suffer unnecessarily. And that is Jill and Jim's hope—Hunter's Hope.

Today, Jill still marvels at how Hunter's unspoken love changed everything for their family. Though he wasn't healed here on earth, Jill sees the many miracles that came through Hunter's life. "But the most profound miracle of all," she says, "was having my son's suffering lead me, Jim, and our two girls to the greatest act of suffering that changed, and continues to change, everything—the Cross of Christ. In understanding His sacrifice and suffering, we have found meaning and beauty in Hunter's suffering."

Although they lost their son, Jill and Jim are able to reflect that God gave them His Son. Jill says, "God is real. He loves you like crazy. God rescued our family, and he can rescue others, too." †

For more information about the book Without a Word and to find out more about how to help children like Hunter, visit www.huntershope.org.



Jill with their daughters, Erin and Camryn

Soup's On

By Pat Baker

Each fall as I watch the maple leaves turn from green to brilliant shades of orange and red, I know it won't be long until the meteorologist will predict the first forecast of snow. This is my signal to pull out my tantalizing, good-to-the-last-drop soup recipes, throw the ingredients together and give them all the time they need to simmer. The aroma that fills my home tells me that winter isn't such a bad boy after all!

I invite more dinner guests into our home in winter than during any other season. It's hosting at its simplest and best. Set the soup pot in the middle of the kitchen table, accompanied by a basket of assorted crackers and let the serving begin. A hostess couldn't ask for happier, more satisfied customers. We finish up the meal with dessert and hot, steaming cups of coffee.

Whether you are delivering soups to people who are sick, or inviting neighbors and friends into your home to enjoy a soup supper with you, each of these recipes comes with a guarantee to take the edge off freezing temperatures and chilling winds. Also, hot soups often are credited for chasing away the blues that may accompany long, dreary, cold days and nights..

By trial and error I have discovered that each of these soup recipes is freezer-friendly. So when the temperature plummets without warning, this can be your cue to thaw, heat and enjoy these stored soups.

