

The Kelly family,  
photo taken in  
July 2004



# A Foundation of Hope

*Football great Jim Kelly leads a valiant battle against deadly Krabbe disease*

by Norm Zeigler

**W**hen Hall of Fame quarterback Jim Kelly and his wife, Jill, were told in 1997 that their four-month-old son Hunter had Krabbe disease, the news was devastating. The inherited neurodegenerative disorder, their physician told them, was a deadly killer and Hunter would likely not see his second birthday. But the Kellys were not ready to give up without a fight. They became determined to battle for him and for other families affected by this terrible disease.

Krabbe (pronounced crab-A) disease—the medical term is Globoid Cell Leukodystrophy—is caused by the absence of an enzyme that helps protect nerve cells. According to the brochure for the Hunter's Hope Foundation, "Progression of the disorder is rapid and death occurs in early childhood."

In the United States, approximately 50 babies each year are born with Krabbe disease (about one out of 100,000). Because in many states there is no general neonatal testing program for the illness, many children are misdi-

agnosed, or diagnosed only after it has progressed to a dangerous stage. In its early stages, Krabbe disease can mimic colic, food allergies, and cerebral palsy.

The Kellys founded the Hunter's Hope Foundation in 1997 to pursue a number of goals: providing support for victims and their families, raising public awareness, making testing at birth standard practice, and funding research. But it is the latter goal that best exemplifies the "hope" aspect of the organization's name.

In an interview for this article, Kelly

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# World Class Care Here at Home

told of the family's torment and heartache as they faced a relentless foe. He especially expressed his love and gratefulness for Jill's strength and determination. After learning that Hunter had a fatal disease, he said, "I wanted to crawl into my own little shell... If it wasn't for her faith we might not have gotten through this." Jill is a devout born-again Christian.

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"He was my hero," Kelly said... "He went eight years, but finally he said, 'It's time for me to go to heaven now.'"

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"My wife was the one who opened my eyes," he said. Together they vowed not to give up but to fight with all their energy for Hunter and against the implacable disease, despite the lack of any effective therapies. "At that time there was pretty much nothing available," Kelly said. "Going on nine, 10 years later, there are treatments available."

In recent years, a new type of therapy—umbilical cord stem cell transplant—has presented an exciting opportunity for progress to combat this killer disease. This revolutionary procedure offers a true treatment option where formerly there was none.

According to the National Institutes of Health (NIH), prior to umbilical cord stem cell transplant the only options were palliative, unable to provide any real weapons against Krabbe's inevitable and deadly progression. Physical therapy was one. Though it has not yet become the standard treatment option, umbilical cord stem cell transplant seems to offer the potential miracle cure that the Krabbe commu-



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**Jim and Hunter Kelly**

nity has long dreamed of. Newborns who have undergone the treatment soon after neonatal testing “prior to symptom onset developed with little or no neurological impairment,” the NIH reports. In other words, it stopped the killer in its tracks.

Unlike bone marrow transplants, which require matching donors, embryonic cord stem cell transplants are both more efficacious in treating Krabbe disease and much more easily obtained. The key to the new therapy is early diagnosis, and the Kellys and their foundation are tireless in their efforts toward making testing universally available. Unfortunately, Kelly said, the number of diseases newborns are tested for varies widely from state to state. But Hunter’s Hope is determined to change that. “We just want to make sure every state does the maximum [testing],” Kelly said.

Their message is getting through. One example is New York’s expansion of its Newborn Screening Program from eleven to forty conditions in August 2006. A key to the change was Kelly’s personal appeal to New York Governor George Pataki. Kelly has also recruited New York Senator Hillary Rodham Clinton for his “team.” Last year Clinton secured \$500,000 in feder-

al funds for the Hunter’s Hope Foundation. The money is designated for the study of Krabbe disease and related conditions at the Hunter James Kelly Research Institute at the University at Buffalo’s Center for Excellence in Bioinformatics and Life Sciences.

Kelly would like to see more effort on the part of the federal government. In October 2006 Senator Clinton co-introduced a bill in the United States Senate titled the Screening for Health of Infants and Newborns, or SHINE, Act, to expand newborn testing.

During the interview, Kelly talked openly and with heartfelt emotion about his love for his son and finally accepting his own role as a “chosen father.” Part of that role, he said, was the logistics of the family’s own personal battle for their little boy’s life, which included twenty-four-hour-a-day care and therapy. Kelly has unending love and admiration for Jill and her mother, Jacque Waggoner, who “totally dedicated their lives to him,” Kelly said.

But though he proved the doctors wrong, surviving far beyond their dire prognoses, Hunter, the little boy who showed unending courage in the face of suffering and the threat of death, and who inspired an organization to help





other victims of this vicious disease, died August 5, 2005.

“He was my hero,” Kelly said. “He went eight years, but finally he said, ‘It’s time for me to go to heaven now.’”

The Hunter’s Hope Foundation holds a number of fundraising events each year. One of the most successful is the Drive Fore Hope Celebrity Golf Challenge, held annually at the Lely Golf Resort in Naples, Florida. This year’s event will take place April 13 and 14. Among this year’s participants will be football legends Bruce Smith, Thurman Thomas, “Shooter” McGavin, Marv Levy, Quinn Early, Andre Reed, Dwight Clark, Randy LaJoie, and Ed McCabe.

As of December 2006 the foundation had raised nearly \$14 million for research on Krabbe and other degenerative nerve disorders. It has awarded more than \$4 million for research.

For more information on the Drive Fore Hope Celebrity Golf Challenge, visit [www.DriveForeHope.net](http://www.DriveForeHope.net)

*For more information on Krabbe disease and the Hunter’s Hope Foundation, contact Hunter’s Hope, P.O. Box 643, Orchard Park, NY 14127, 877-984-HOPE, [www.HuntersHope.org](http://www.HuntersHope.org); National Organization of Rare Diseases (NORD), [www.rarediseases.org](http://www.rarediseases.org); International Rare Disease Support Network (IRSDN), [www.raredisorders.com](http://www.raredisorders.com); National Newborn Screening and Genetic Resource Center, <http://genes-r-us.uthsca.edu>*

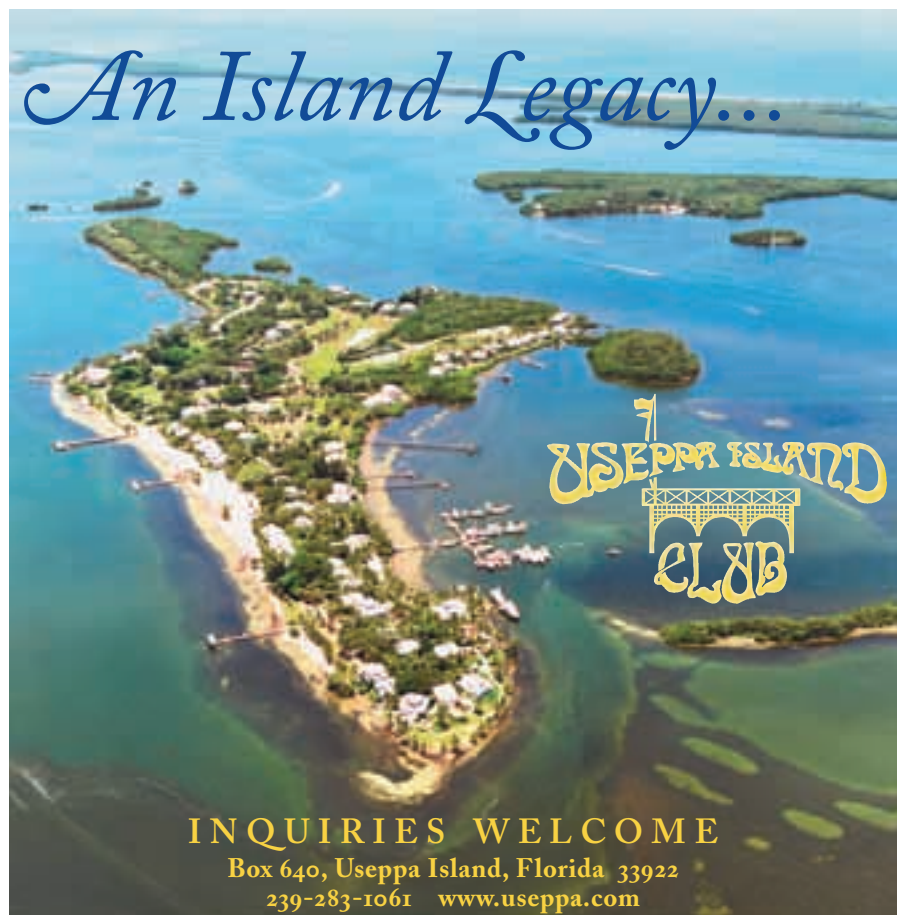
*Norm Zeigler is a local author and freelance writer for Times of the Islands.*

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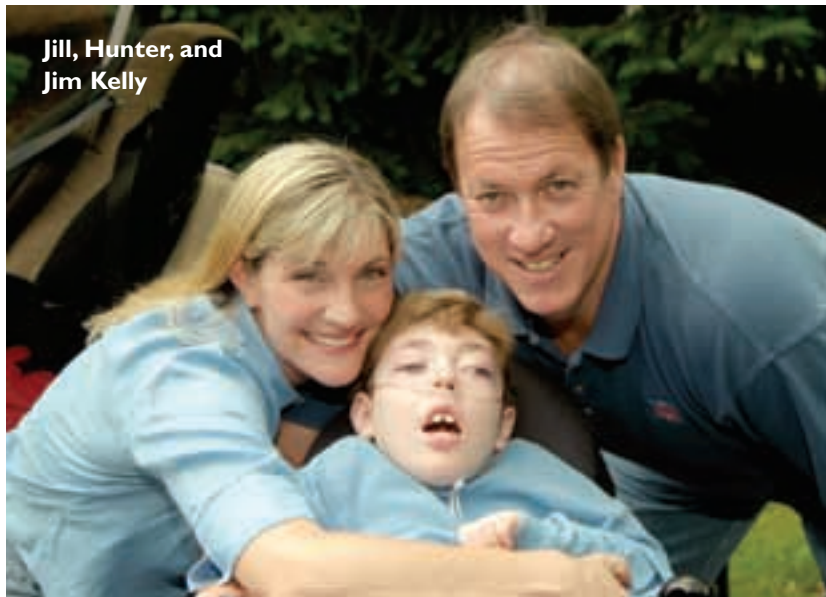


*An Island Legacy...*



# A Lifetime of Perseverance

*The Jim Kelly story—family and football*



Jill, Hunter, and Jim Kelly

by Norm Zeigler

Jim Kelly has had many challenges and accomplishments throughout his life. Growing up in Pittsburgh during the 1960s and '70s set the pattern for the two main themes of his life: family and football. In his 2002 Pro Football Hall of Fame acceptance speech he joked that “growing up with five brothers you learn at an early age that you need to be tough to survive—not only on the field, but at the Kelly dinner table.”

Later, at the University of Miami, he faced an even more daunting challenge. After seriously injuring his shoulder during his senior year, he was told by medical experts that his football career was over. But with the encouragement of the Miami trainer and his college roommate, Mark Rush, Kelly followed a rigorous rehab program, proving the

doctors wrong and going on to become one of pro football’s greatest quarterbacks. In eleven seasons with the National Football League he took the Buffalo Bills to the playoffs eight times.

Kelly’s NFL career statistics are stunning: 35,467 total passing yards; five Pro Bowl selections, including the MVP Award in 1990; the sixth highest career passing rating in NFL history (84.4); named AFC Offensive Player of the Week ten times; and the only player in NFL history to quarterback his team to four consecutive Super Bowl appearances. At Kelly’s 2002 Hall of Fame induction, longtime Buffalo Bills coach Marv Levy praised him as “the ultimate competitor, the ultimate team player.” During his acceptance speech, Kelly thanked his family, especially his wife, Jill, and his daughters, Erin and

Camryn, former teammates, coaches, and others. But he saved special recognition for Hunter. “It has been written throughout my career that toughness is my trademark. Well, the toughest person I’ve ever met in my life is my hero, my soldier, my son.”

In an interview for this story, Kelly emphasized his dedication to his new team: the Hunter’s Hope Foundation. Victory for this team, he said, would “give these kids a chance for a quality of life; give them a chance to dream... If they can get diagnosed at birth, they can get treatment right away. Then they can have a chance at life.”

*Norm Zeigler is a local author and freelance writer for Times of the Islands.*



## Health Tip

### Focus on Relieving Stress

Stress is the most common health problem in our society. It affects everyday performance and accounts for 70 percent of all visits to family doctors. Finding a way to relieve it is essential.

“Any type of focused activity can relieve stress,” says Jack Barone, a certified personal trainer and fitness supervisor at Sanibel Harbour Resort & Spa. He suggests finding an activity that serves as a form of meditation. “Yoga can do that,” he says, “as can running and lifting weights.”

With proper instruction and focus, exercise, weight training, yoga, and pilates can create a relaxed state of mind and cause a release of stress and tension for the body. “Yoga’s focused postural alignments and stretching, as well as consistent, natural breathing, can create a sense of well-being and a release of stress from your body,” says Barone.

For those who don’t enjoy or have time for exercise, Barone suggests trying it by allotting some time for it on a regular basis and starting with some basic exercises. “Once you get into a routine, you realize it feels good, and that you feel better at the end of the day. The self-fulfilling aspect and the strength that it gives your body are the rewards that will hopefully last a lifetime.”

And for those who can’t exercise, Barone says that not all stress relieving activities require athletic ability. Instead, you should focus on the meditation aspect. For example, even gardening can relax people by allowing them to focus on the plants and working outside.

—by Cristina Barone

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