Alyssa Jung: Hunter: An Unexpected Hero Page 1 of 2

February 4, 2010



Contributing Writer at www.chicksinthehuddle.com

Posted: January 29, 2010 04:32 PM

Hunter: An Unexpected Hero

This is the first in a series of posts. These posts are just as important, actually even more, as the ones I love to write and y'all love to read during the season. Not only is the off season a time for us fans to recuperate and rev up our delusional expectations for next season, it's a time to focus on the bigger picture -- the people and organizations that are all tangled up in the world of professional football. The things that give the NFL its true value, which goes far beyond supplying superstar careers and weekly entertainment. This first post will introduce you to a little boy who made a ginormous footprint on the world and snuck his way into the hearts of everyone he came across during his eight years on this earth. And who inspired the organization "Hunter's Hope."

Hunter. His name is Hunter. Hunter James Kelly. From the day he was born, Valentine's Day 1997, he was far from an ordinary boy. His father was HOF QB Jim Kelly, but that's not what made him so special. What made him special was his gift; what he was able to teach his family and everyone around him. He taught them about hope, acceptance, forgiveness, the true meaning of life and what it's like to experience a miracle.

He liked to play the keyboard, swim, read and watch movies. He was an artist and got to go to Disney World. He loved his parents, his sisters, his teachers and caretakers. He had a special friend, Bambi the horse, and he liked to snuggle with his dogs, Butterscotch and Buddy. He was a regular kid.

Hunter also had Krabbe Disease, a degenerative neurological disorder that made him unable to talk or laugh like we do; instead, his parents said he did this with his eyes and eyebrows. He ate through a feeding tube and had an extremely difficult time breathing, hospitalized dozens of times for pneumonia complications and not expected to live past 14 months. That's where the miracle began. Like his father, Hunter was a fighter and with the odds stacked against him, he pushed on and helped his family push on. As each year passed, they no longer lived their life fearing when he would go, they lived it appreciating each second, minute, hour and day they had with him. They took what would have broken so many families down and turned it into a chance to change the world.

They started Hunter's Hope Foundation, a charitable organization aimed at raising awareness about Krabbe disease and other devastating diseases that go undetected in newborns, far too often.

It provides a support network for families around the country who are enduring the same struggle Jim and Jill Kelly did. It's mission is also to institute Universal Newborn Screening (UNBS) for 54 such diseases, nationwide. With a simple heel prick, the thousands of infants that die or are permanently disabled by treatable diseases could be decreased drastically. In Hunter's case, had UNBS been performed and Krabbe Disease been detected before he was about four-months-old, his life could have been saved.

Hunter's Hope funds research for these diseases with the Hunter James Kelly Research Institute, a partnership with the University at Buffalo that conducts research that could lead to the development of effective treatment strategies and correction of the genetic defect. This research does even more, discovering ways to help patients with conditions that destroy white matter in the brain (Multiple Schlerosis and stroke).

Above all, Hunter's Hope is about loving, celebrating and appreciating children. It provides resources, an equipment exchange program, a Family and Medical Symposium and Hunter's Homes (housing for families to utilize while their children receive treatment). The foundation hosts events throughout the year to foster this love and raise money for its mission. Stay tuned for next week's post about one such event, Hunter's Day of Hope for Children.

Now you know Hunter. Do you love him? I do. There's no way to touch on everything this courageous young boy did nor do justice to the impact he had and continues to have. Visit Hunter's Hope Web site to read about his life, his family and everything his foundation does. You might be inspired--I am. You may cry--I did. You should feel an urge to spread the message--I do.

Please check back next week for my next post! This series is enlightening for me to write and I hope it's eye-opening for you to read. There are some powerful messages current and former Bills players support and this is the place to learn about them. **As always, GO BILLS!!!**

Follow Alyssa Jung on Twitter: www.twitter.com/Lysssie