



## Hunter at Six

Webster's New World Dictionary defines a *miracle* : 1. *an event or action that apparently contradicts known scientific laws and is hence thought to be due to supernatural causes, esp. to an act of God* 2. *a remarkable event or thing; marvel* 3. *a wonderful example*. The Kelly Family would like to define the word miracle too - MIRACLE-1. HUNTER JAMES KELLY. If we were to prove this claim on the basis of the world's standards, or Webster's definition, Hunter's life would undoubtedly be considered a miracle. His life totally "*contradicts known scientific laws*" - when Hunter was diagnosed with Krabbe Leukodystrophy at four months of age his doctors told us that he would not live to celebrate his 2nd birthday - he's six. "*Hence, thought to be due to supernatural causes, esp. to an act of God*" - you better believe it - God created Hunter to open our eyes and hearts to His amazing love and power. We have finally learned what prayer is all about. "*A remarkable event or thing; marvel*" - Hunter is more than remarkable, what an understatement, he continues to prove to us all what true humility, courage, trust and strength are. He is absolutely marvelous!! "*A wonderful example*" - Hunter Kelly is the best example of everything that is important in life. He is also the best teacher. He continues to teach all of us the great value in hardships and suffering and the treasures found through trials and tribulations

It really seems like just yesterday, Hunter turned five and now he's six. Unbelievable! He is so relentless and resilient. He presses on with every ounce of strength in him day in and day out. While his challenges are many, his heart of determination continues to rise above his troubles. When his struggles are great and the outcome looks hopeless, Hunter never gives up - never. When we feel discouraged and fearful, he does something amazing and totally gives us renewed hope. Each and every moment of Hunter Kelly's life is a miracle. We are so fortunate to witness it first hand, what a blessing.

So, what's new with this six-year-old dude? Well, where should I start? Hunter's communication skills continue to improve with the help of his speech therapist, caregivers, Grammie and of course, his sisters. Hunter has school time (kindergarten/first grade) and speech therapy twice a week for an hour each session. Encouragement and excitement seem to be the name of the game - when Hunter blinks once for "yes" and



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three times for "I love you", we get excited. He actually completed his first book report - his therapist asked him specific questions and he answered them correctly and she wrote down his answers in book report format. We continue to give Hunter as many opportunities to learn as possible and he continues to amaze us with his knowledge.

Physically, Hunter still has major issues, especially with his hips - both of them are dislocated and cause him pain at times. But, despite his hip situation, Hunter is still able to use his tri-stander (which he grew out of by the way, and we had to get a bigger one!) and his kid-kart for school time as well as play time. He spends at least 2 - 4 hours in his kid-kart a day and we try to get him in his stander daily as well. The most exciting development for Hunter over the past year has been his ability to do his own exercises. Depending on his mood and health status, Hunter will move his arms up and down and turn his head from left to right and back again. In the past, Hunter has always needed our assistance to move his body, but now he is actually doing some movement on his own. It's so cool to watch him because he gets so excited (so do we). He is also very determined to show us that he can do it on his own.

Hunter's respiratory status remains a roller coaster ride with more highs than lows lately. We administer chest therapy using The Vest Airway Clearance System five times a day. Depending on Hunter's lung situation we increase his therapy amount. A vital part of Hunter's chest therapy regimen, which we implemented in March of this year, is his new Cough Assist. The Cough Assist basically helps Hunter cough because he is unable to do so on his own. Air is forced into and out of Hunter's lungs - therefore acting like a "cough." We are very impressed with the Cough Assist so far because it appears to be helping Hunter by clearing his secretions and expanding his lungs. Hunter continues to receive physical and occupational therapy five times a week for an hour each session. Water therapy - or "jacuzzi time" continues to be an important part of Hunter's daily routine. He loves the water!

Hunter is very interested in arts and crafts and board games as well as musical instruments too. He loves to get paint all over his hands and he is quite an artist. As soon



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as he hears the word "paint" his eyebrows go up and his hands start moving. It's so much fun to watch him get excited. His favorite board game right now is Herd Your Horses, of course, because Hunter loves horses. And believe it, or not, Hunter wins every time - no kidding. Musically, Hunter is actually a member of a small Christian band (no name yet) that consists of three, sometimes four members - uncle Justin plays guitar and vocals, Hunter plays either bells or percussion, cousin Jaden plays keyboards and if we're really jamming, sisters Erin and Camryn join in the vocals area. He really gets into it.

All Hunter's therapists are amazed by Hunter's tireless drive and tenacious spirit. He just never gives up - never. He wants so badly to be involved in everything that is going on around him and he wants to have fun. Typical little kid - right? We don't ever give up on Hunter. We are constantly trying to improve all aspects of his care as well as his playtime. And as always we continue to pray and hope for a miracle. Hey, you never know - but you can always HOPE!