



Hunter at Seven

I figured it was as good a time as ever to start telling you about myself instead of having my mother do all the talking. Well, yes of course she is the one typing all this good stuff into the computer for all of you to read and she sure knows me better than anyone else on this earth but I know me the most – so I will be telling you about me this time. There is so much to tell you; so many good things and a few not so good things to share with you about my life over the past year and a half. I am a busy kid. In fact, I bet my daily schedule is busier than most adult schedules. Most of the time I really enjoy being busy and actively involved in my daily routine. But, guess what, if I am too tired, I just snooze away. It's pretty funny actually because as much as everybody wants me to be awake for whatever reason, I just tune it all out and rest whenever I please. A growing boy needs his rest, especially a growing boy like me. I need all the energy I can get to accomplish my daily activities, in addition to my school responsibilities and the many other fun things I do.

For the most part my routine has not changed too much except for a few new exciting things I will tell you about a little bit later. Every week my physical therapist, Ms. Elizabeth comes for five hours – five days a week for an hour each day. She is grrreat, like so great. She has helped me to move my body into positions that are really crazy. Even my mommy comes in the playroom sometimes while we are having therapy and she says, "Are you sure he is o.k. like that Elizabeth." It feels so good to move my body. The more movement the better for this kid. Ms. Kathy, my occupational therapist comes over for five hours too – five days a week for an hour each day. Sometimes she and Ms. Elizabeth team up and I am movin' and groovin'. I just love them. And I trust them to be very careful and move my body into special positions I need to go in. They can tell when I am directing them to move me a certain way because they know me and my body. Ms. Kristin, my speech therapist visits me for three hours a week – three days for an hour each day. We really have a blast together. She is very creative and we spend a lot of time learning and creating things for me to show off. My family loves the cool things I create. I get to turn my learning into crafty things for my mommy to hang up all around the house. Ms. Kristin helps me to communicate. As you may know, I use my eyes to talk. I blink once for yes, and I don't blink at all for no. I can make choices and I understand



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concepts and associations. Those are big words, basically, I can put two and two together and I comprehend what Ms. Kristin teaches me. I even write book reports. I have been using my head and my mouth to communicate too. Sometimes I blink and move my mouth at the same time to say yes. It feels so good to move my head and my mouth, even though it takes some concentration to do it. I am a go getter, and I will never give up trying. Because I am now in second grade I have a new teacher. My new teacher is Ms. Bonnie. I like her. Ms. Bonnie comes over to teach for three hours every week – two days a week for an hour and a half each session. I want her to come over for school more often. Hmmm, I'll have to talk to my mother about that. So far, Ms. Bonnie is a good fit for me. She listens to me and has a soft voice and a gentle touch. I like the cool things she is teaching me. We just finished learning about the different kinds of seasons, and all the different kinds of leaves. Because our summer in Buffalo pretty much started in late September, I have been going outside a lot for school. When you are home schooled like me you get to do some really cool stuff.

To help me communicate even more I now have a vision therapist. Ms. Tory is her name and she comes to see me once a week for an hour. She brings all these interesting gadgets that have bright lights and different shapes. Ms. Tory is discovering what size letters and shapes I can see the best and at what distance away from me things are in focus. It is all new for me and I like it all so far. So as you can see, I am busy everyday. On top of all my therapies I am still using the Therapy Vest for my lungs every four hours. In between all my fun learning and activities I must care for my lungs and body. The Vest is very helpful. It helps me to clear out any fluid in my lungs so that I can breathe better. Sometimes, unfortunately, when I use my vest, the inside of my belly gets irritated near my feeding tube sight, and I bleed. We have had the doctor look at it a few times with a scope and with an x-ray but they don't have a clear solution. So what we do is stop using the vest for a little while and instead do the old fashioned chest physical therapy with the percussor. Either way, my lungs are taken care of. The last time I was in the hospital, on a respirator, because of my breathing was right before Christmas last year (2003), so I have been much healthier for a long time. My medicines have not really changed that much except a few additions and a few deletions. I now get a strawberry milkshake through my



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feeding tube (which is a GJ tube – where food and some meds go directly into my intestines and only a few medicines go into my stomach) everyday in the morning and two new vitamins – Calcium and Magnesium. The milkshake is actually Neutra-Phos, a sodium and potassium phosphate dietary supplement. There we go with those big, adult words again. I take all of these to strengthen my bones so that they do not break. And so far, they are really helping me a lot. One good thing is that I don't really need Tylenol and Motrin that much anymore. I still take them both if I need to, but I haven't really needed to take them as much. So that is a good change for me. I also used to take antibiotics for various reasons but I have not needed one in a long time and that is a good thing too.

While I was in the hospital before Christmas last year, a special eye doctor looked at my eyes. I have gorgeous green eyes, just in case you didn't know that (smile). The doctor said that I had some very bad scaring on my eyes because I do not blink my eyes enough. They told my mommy to make sure that we put eye gel in my eyes every hour or as needed to make sure that my eyes stay moist all the time. If we do not care for my eyes, the scar tissue will grow over my pupil and that would cause me not to see very well. I even tried contacts. That idea didn't really go over too good but it was fun to try them. The contacts were to help the dryness and scaring in my eyes, they were not to see well, like a pair of glasses. My Grandma came up with a great idea to help my eyes. At bedtime, I wear a headband around my head with tissue folded over my eyes so that my eyes stay closed and so I can sleep. Sometimes, I try to peek so that I don't miss anything. But for the most part, I like my headband so that I can rest my eyes. It all works out. Hey, I almost forgot to tell you, I grew out of my Kid-Kart and now I am cruising around in a Quickie Iris Wheelchair. I am growing so fast these days and my new ride is much more comfortable. Speaking of new rides, my mom and dad are going to buy a special van for me to drive around in. When ever we go anywhere right now my mom or grandma usually hold me and that really is not very safe anymore – but I like it. I love to be held, especially by my two favorite girls.



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In addition to my school activities I have done some pretty cool stuff over the past year. I went snowmobiling! Can you even believe it? During the winter my family goes to Ellicottville and there is a lot of snow there. So my mommy and grandma thought I should go snowmobiling and I did. It was crazy and cold. But we did it – oxygen, suction and all. When the weather was much warmer I went fishing in our pond in Ellicottville, and I caught four fish. Erin, my big sister caught one. We just threw them back in after we caught them, it was so much fun. We have a pool table at our lodge too and I learned how to play pool. I think I'll leave that game for the big boys. Oh, and one more thing, I built my first fort ever in our bunk beds. It was dark in our fort and very adventurous.

Horses are still my favorite animal. Our dog Butterscotch has a new friend, Buddy, our new black lab puppy. He is so cute. Swimming in Grammie's pool is still my favorite summertime fun. I can even stand in the shallow end now, which is really cool. Every chance I get I go squirrel hunting too. Those critters are so fast. I also enjoy movie time with my two sisters, Erin and Camryn. We usually watch Rescue Heroes Animal Planet Videos or Stuart Little Cartoons. My sisters are really snuggly, they sometimes give me a kiss attack – where they keep kissing me and don't stop. My heart smiles when they do that. I just love those girls. My Daddy and I like to watch football games together. The Buffalo Bills are not as good as when my Dad played for them. I wish I could watch my Dad play football. He has taught me a lot about the game and it is very exciting. Oh, and so I don't forget to tell you, I lost ten teeth so far and my new teeth are all coming in nice and big and straight. Out of all the fun things I get to do, spending time with my best friend Robert is my most favorite. Robert is the same age as me, seven. His mother is my physical therapist. Robert loves me for me and I love Robert. We have some things in common that are cool, like I like football and Robert does too. I went to one of his football games and it was so much fun. Robert introduced me to Spiderman and now every time I turn around my mother is buying me something with Spiderman on it. Robert also likes to read and almost every time he comes to see me he reads me a book. We read all kinds of books like Nate the Great and Henry and Mudge. I like when Robert comes over. He is fun to be with and such a special person. I thank God for giving me a friend like Robert.



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There are some other important people in my life that help me so much every day - my nurses. Dodie, Ellen, Lisa and Tammy are very helpful to me and my mom. They take very good care of me and make my days extra special.

I really could go on and on about my life. There is so much to say. I am so thankful for so many reasons. God is so good to me and I love Him for loving me so much. I love to read the bible. God has taught me so much through reading His Word. In fact, I have completed over ten bibles studies so far. My sisters and I know three Psalms by heart (Psalm 23, Psalm 121, Psalm 63 and Isaiah 40:28-31). The bible encourages me and gives me hope. Heaven is my real home and until I go there, God has a very important job for me down here on earth. My job is to live with overflowing joy and peace in the midst of all my struggles. My job is to love people unconditionally and spread hope to the hopeless. My ultimate job is to shine for Jesus! I have been blessed with the courage and strength of mighty warriors. I am not afraid of what tomorrow holds for me, because the Lord has promised that He is always with me no matter what. Thank you for learning more about me and for praying for me. I love you!