

Spenser's Story

By

Gretchen Miller



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Today is July 13, 2001. Spenser would have been three months old today. Although he's been gone for three months, his due date isn't for another three weeks. We should be putting the final touches on his nursery and installing his car seat for the ride home from the hospital. We should be looking forward to midnight feedings and dirty diapers. We put our heart and soul into preparing for his birth. Instead of washing his clothes and cleaning his bottles, we are dusting his memorial and urn. I still ask, and will always ask, how could this happen? How could this happen to *us*?

When we decided to have a second child, we did our homework. Our first pregnancy was difficult, going into preterm labor at 29 weeks. My doctor told us that there wasn't any reason she could think of for my preterm labor, sometimes it just happened that way. I was in and out of the hospital, on total bedrest, and on every medication my doctor could think to put me on. I followed all the rules, not cheating on my bedrest even once. I took all the medications, even though it made my heart race to the point that talking on the phone, one of the few things you can do on bedrest, was difficult. We went to the hospital when my doctor told us to, even if it was in the middle of the night. We did everything right and we were rewarded with a beautiful baby boy. He was born at 37 weeks, and was almost nine pounds. Perfectly healthy. So, when we begin to entertain thoughts of a second child, we talked to our doctor before we made a final decision. As hard as bedrest and everything else was without any other children, we knew it



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would be twice as hard with a three year old. My doctor told us that there was a 40% chance that preterm labor would happen again. With those odds, we decided to go to see a specialist in high-risk pregnancies. She told us that because I carried our first son to term (37 weeks), I should be all right with the second pregnancy, as long as I took it easy at 20 weeks. We decided that we could do it. We could alter our lives for four months, if it meant that we would come out of it with another beautiful baby. I became pregnant right away. When we discovered we were having a boy, we decided to name him Spenser, after my husband Jeff's favorite literary character from the Spenser detective stories by Robert B. Parker.

Everything went just as expected. We knew that we were not going to have the customary 40 weeks to get everything in order, so we had everything ready by 20 weeks. The nursery was painted, furniture bought and put together, and clothes washed and folded neatly in the dresser. We even had diapers out and ready to go on the changing table. Then, on the day 20 weeks arrived, I began to "take it easy". We moved everything to the middle level of our home and worked it out so I would not have to go up and down the stairs more than two or three times a day. I spent most of the day on the couch, even playing with my three-year-old from the couch. Only three days into my 20th week, I began to have contractions. I went into the doctor's office and it was discovered that my cervix was changing. I was devastated. I was hooked up to the uterine monitor and was showing heavy



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contractions every four minutes. I was given a shot of Terbutaline and the contractions stopped. Again, my doctor could not tell me why this was happening, or why it was happening so much earlier than with my first pregnancy, which scared me. I knew that going into labor so early was very bad, and having a premature birth before 30 weeks was very risky. I was given oral Terbutaline to take every four hours and sent home. I was told I didn't need total bed rest, but I shouldn't drive anymore and should remain as stationary as possible. Jeff altered his work schedule so he could be home in the morning to get our son ready for school and my friends took turns bringing my son home for me.

This worked for about a week. I began to experience contractions again and went back to the doctor's office. I was given another exam and told that my cervix had changed even more and I was dilated to about one centimeter. I was given another shot of Terbutaline and put on total bed rest. I was told that bed rest was necessary to alleviate the pressure on the pelvis. I was also kept on the oral Terbutaline and given an antibiotic just in case it was an infection. Needless to say, I was beyond devastated. I was prepared for six weeks of bedrest. I was not prepared for four months of bedrest, and neither was Jeff. With this pregnancy it wasn't just Jeff and I being affected – we had our son to consider. Before I went on bedrest there was never a day when either Jeff or I didn't take him to school. I was always there to pick him up and we spent much of our time together. Once



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bedrest started I couldn't take him to school or pick him up. I couldn't have him at home with me after school so he went to friends' houses everyday. He was confused and missed me very much. Jeff had to change his work hours so he could drop our son off at various friends' houses each morning. When Jeff got home at night, he never sat down. He had to get everything ready for the next day. He made me a lunch and snacks, which he put in a cooler. He got our son a bath and set his clothes out for the day. He fed all of our pets and did the dishes and laundry. He became a single parent with two children to care for.

After being on bedrest for about one week, I went to the doctor's office for a regular checkup. They performed a vaginal ultrasound and detected what is called funneling. This is when the cervix begins to open and the amniotic fluid sack begins to "funnel" into the cervix. I was sent to the labor and delivery ward at the hospital. I was in the middle of my 21st week. Before all this happened I told my doctor that if I had to go to the hospital I was going to freak out – and I did. I had never been apart from my son for more than one night a year – and that was when Jeff and I went away for our anniversary. Now I was being told that I needed to stay at the hospital for an undetermined length of time. It broke my heart. Jeff brought our son to visit me and he would ask when I was coming home, and why couldn't he sleep at the hospital with me. He was confused and scared, as was I. Along with the agony of being separated from my son, I was dealing with the fear of losing Spenser. I was put in a bed that was tilting back,



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given Indocin to reduce the amniotic fluid, thus reducing the funneling (supposedly), and told to relax and drink water and hope for the contractions to stop. There just wasn't much the doctors could do. They didn't know why I was contracting, so they were hard pressed to find a way to help me. There was some talk of inserting a cerclage (stitching the cervix closed), but I was too far along and was contracting too much. A cerclage only keeps the cervix from opening for so long – eventually the contractions will rip it open. So they gave me more shots of Terbutaline and we waited for the contractions to stop. After the first day I was having only about one an hour, so I was moved up to the maternity ward to be kept on observation for another day. This turned out to be torture. I was put in a room with a woman who had given birth the night before and had her entire family parading in and out of the room all day. She received numerous congratulatory calls and had the baby in the room often. It was awful to be so afraid for the future of Spenser while at the same time being witness to someone else's total joy. All I did was cry all day.

After two and half days in the hospital I was sent home. While in the hospital I was given a Terbutaline subcutaneous pump. This was nothing new to me as I had had one with my first pregnancy. The pump is a machine that pumps Terbutaline through a tube and into your leg 24 hours a day. The pump (with the constant dose of Terbutaline) was the thing that made my heart race. I was jittery and jumpy and couldn't keep my voice from shaking when I talked. I went home,



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back to total bedrest, and waited. I was told to lay completely flat all day. Even to eat as flat as possible. I could only get up to go to the bathroom and take a shower once a day. I decided that I would only get up to take a shower every two or three days. I made it this way for exactly two weeks. One morning I began to feel contractions again. I called Jeff home from work and went to see the doctor. I knew it was bad. The contractions were every 4-5 minutes and were getting stronger. The doctor examined me and told me I was dilated to about four centimeters and my water sack was bulging. She tilted the exam table back and called an ambulance to take me to the hospital. I was 23 weeks, 3 days. I was petrified. I kept thinking that we had done everything we were told to do. I was told to take it easy, I took it easy. I was told to take Terbutaline, I took it. I was told to go on bedrest, I did it. I was told I needed to give up control of my son for four months, I was doing it. Jeff was told that he needed to alter his work schedule, he did it. He was told to take care of me and our son, he did. We did it all, and *this* is what happened?

I got to the hospital and everything began to get worse. My contractions worsened to the point that they were happening every minute or two and were lasting for 30 to 60 seconds. I was dilating to five centimeters. I was given the steroid shot that is supposed to help Spenser's lung development. I was put on Magnesium Sulfate. I also had Magnesium with my first pregnancy and I held no fond memories of it. They started the drip at 2g an hour. That didn't do anything,



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the contractions were still happening. The NICU sent a doctor over to talk to us to tell us what to expect. The doctor was very nice and factual. She said that Spenser had about a 10% chance of making it out of the delivery room. All I could do was look at her and ask her that if Spenser died, could I hold him? She said that I would be able to. The Magnesium dose was upped to 3g, then 4g, then 5g. Finally at 5g the contractions became controlled, but they didn't stop. Through the night I dilated to seven centimeters. The Magnesium was doing damage to me as well. I couldn't move, had triple vision and was very nauseous. Jeff stayed in the room with me all night. In the morning my doctor and Jeff decided that not only was the Magnesium not working, it was hurting me. We decided to turn off all the medication and let nature take its course. It was a very hard decision. I felt like we were giving up on Spenser. But, it was obvious at this point that nothing was going to work. For whatever unknown reason, my body could not hold this baby inside. Also, we had our three year old to consider. He needed his Mommy back, and he needed his parent's home. He needed some normalcy to return. The medicine was stopped and the NICU came in to prepare the room for the delivery of our second son.

The doctor told me that because my water sack was bulging so much, that all I would have to do is sit up and my water would break and Spenser would come. So, after the Magnesium began to wear off, they sat me up. Nothing happened. In fact, the contractions, that had been going on for 24 hours and couldn't be



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stopped by medication, were stopped by doing the one thing they told me not to do; sit up. After sitting up for a couple of hours it became apparent that Spenser wasn't going to come, so they finally let me eat. I hadn't eaten since breakfast the day before. The horrible Jell-O never tasted so good. Jeff stayed with me all the time, except to go to the cafeteria twice a day. They said Spenser could come at any time, so he couldn't leave. Our son was with relatives and we called to check on him many times a day. I missed him terribly. For the entire day, I stayed dilated to nine centimeters, medication free. Every doctor and nurse in labor and delivery said they had never seen anything like it. The joke going around was that all I needed to do was sneeze and my water would break. We were told that as long as my water didn't break and I showed no signs of infection, Spenser could stay put. My temperature was taken every hour and I was given an ultrasound. Spenser was measuring big for his age, which was 23 weeks, 4 days. That worked in his favor. Also, by this time, we had had 24 hours with the steroids to help his lungs. But that was all he had going for him. All that day we waited. By nightfall, we were exhausted. I had been sleeping in an uncomfortable hospital bed with tubes coming out of everywhere, and Jeff had been sleeping in an easy chair that rocked every time he moved. We had been on an emotional roller coaster for a month now. We had resigned ourselves to the fact that Spenser coming the day before, but now we were waiting indefinitely. Although in my heart I knew that every hour helped Spenser's chances, I just wanted it to be over. I had nothing left. Neither Jeff nor I had seen our son for 36 hours, with no



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end in sight. I just didn't want to be scared anymore. I didn't see how one or two days could really make a difference and it was very clear that we weren't going to get any more time out of this pregnancy than that.

The next day, still no change. In the morning I was still at nine centimeters, with no contractions. Jeff and I just sat around all day waiting for something. That night, it happened. My contractions just started up again – for no apparent reason. Very quickly the contractions were right on top of each other. I told my doctor that I didn't want any drugs. I thought I may only get one chance to see Spenser, and I didn't want to be all drugged up. The NICU people came in and we got started. It didn't take all that long, about 30 minutes. I remember on the last push, I cried because I thought I had just killed my Spenser. My doctor told me that it was O.K. She said Spenser was trying to cry and that was a good sign. The Neonatologist put the breathing tube down his throat and took some quick vital signs. She even let me kiss Spenser before she took him away to the NICU. As Spenser left the room, I felt strangely calm. I had told myself that if he beat the odds and made it out of the room, he would be fine. I looked at the time; it was 11:31pm, Friday the 13th. I just leaned back in the bed and took a deep breath. It was over. At least I thought it was over. In reality, it was just beginning.

About an hour later the NICU nurse came to tell us that Spenser had been stabilized for the moment. Jeff went to see him. I couldn't go yet because I



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couldn't stand up. I had been in bed for a month and had just given birth, so I needed a little more time. He came back and said that it was very hard to see him hooked up to half a dozen machines and that he looked really small – but he was beautiful. After a couple of hours, I went to see him on my way up to the maternity ward. He was the smallest thing I had ever seen, only twelve inches long. I just wanted to scoop him up and give him a big hug and let him know that his Mommy was there with him. I wanted to stay with him all night and just stare at him, but I was physically ill and dizzy and exhausted. I looked at him in his little warming tray, with his breathing tube and IV's coming out of his umbilical cord and monitors hooked up to him and my only thought was how good it was going to feel to take him home. They took me to my room and my nurse came in to talk to me. All I wanted to do was sleep. Jeff left to go home and sleep – for the first time in three days. I felt at peace.

I woke up around four in the morning and called the NICU. The nurse assigned to Spenser told me that he was doing well and said they were going to run all kinds of tests on him during the day. I knew that later the Neonatologist would be up to talk to me. I went back to sleep for a few more hours. I called Jeff around 8:00 and woke him up to come back to the hospital. I also called Jeff's aunt, who had been watching our son, and told her to bring him by as soon as she could. That morning, I had none of the anxiety that would plague my life in the coming days. I had just given birth to a beautiful baby boy, my older son was coming to see me,



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and I was going to get a shower for the first time in seven days. I was really happy. I called the NICU again and they said Spenser was doing fine. Jeff got there and we just sat and stared at each other. It was hard to believe that Spenser was already here. When our son walked into the room, I almost jumped out of the bed. After seeing my tiny baby, my three-year-old looked huge. He came in and looked all around the room asking where Spenser was. We told him that Spenser had to stay down in a special area because he was so small and needed special doctor's to take care of him. He really wanted to see Spenser, as did I, so we all went down to see him.

It was a shock. I was still feeling queasy and weak from giving birth less than twelve hours before so I had to go in a wheel chair. Our son rode in my lap, and it felt really good to be able to give him big squeezes without worrying about him hitting my stomach. Jeff wheeled me right up to the edge of Spenser's tray and picked our son up to look at him. It was so hard not to pick Spenser up. He was hooked up to a machine to help him breathe, a machine to give him a blood transfusion, a machine to measure the oxygen in his blood, a machine to give him nutrients, a machine to give him different medicines, and he had four photo lamps shining on his little body. He looked so tiny. The eyeshades covering his eyes were bigger than his entire head. The nurses had given Spenser a bunny rabbit toy for his tray and said we could bring other small toys for Spenser. I never would have thought of that, but it was very comforting. Our oldest son



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wanted to go out and get a toy for Spenser right away. We stayed for a few minutes while the doctors and nurses told us a million things – procedures to follow, tests that would be done, what all the monitors meant, and what Spenser’s particular problems were. Although I paid attention at the time and could recite almost verbatim what I was told about my son, I remember very little medical stuff now. What I remember now is what he looked like and how he moved. His eyes were still fused shut. He was all skin and bones because his muscle mass had not developed. He had the most feathery blonde hair. His fingers were so small I could see the blood vessels through the skin. His feet looked huge compared to the rest of him. He moved a lot. He did before he was born, too. He was kicking his little legs and moving his hands, and he always sucked on his breathing tube. When it was time to go, our son freaked out. He wanted to take Spenser home and didn’t understand why Spenser had to stay at the hospital. It was Jeff and my first glimpse at how hard this situation was going to be for our son to cope with.

Something I had not thought of hit me the day after Spenser was born. I was going to have to breast feed him. I always planned to formula feed Spenser. We had formula fed our first son and that arrangement worked well for us so we decided to go with it for Spenser. But, now that breast milk would make such a difference for Spenser, I decided that I would use a breast pump and store my milk until Spenser needed it. Jeff bought an extra freezer to put in our basement



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because we were told that there would be so much milk, we would need the space. I asked to have someone come and show me how to use the breast pump and I rented one from the hospital. I had to pump every four hours or so. I didn't like it, but it was one of the few things that I could do for Spenser, so I did it. I had to spend one more retched night in the hospital, and then I got to go home. It was Easter Sunday. I couldn't get out of the hospital fast enough. I almost left before the nurse could give me the final physical examination. I had very few post delivery symptoms. Spenser was so small that I didn't have any tearing, hardly even any swelling. I didn't bleed that much and really didn't have any pain, other than the occasional cramp from my uterus shrinking back to normal size. When we left the hospital, I still believed that everything would be fine. I had that post delivery high, when all is right with the world.

We weren't home more than a few hours when the hospital called. They said that Spenser had had a problem and that we should come over. We immediately gathered up our son and went back to the hospital. Luckily for us the hospital was less than five minutes from our house. We got there and the doctor told us that Spenser had had some kind of brain bleed. We were told that two of the most common problems for micro preemies like Spenser was pulmonary bleeding and brain bleeding. We were trying to juggle our son and listen to the doctor, but our son was not cooperating, so we left. We called a friend and dropped off our son, then went right back to the hospital. The doctor said that



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they wouldn't know how bad it was until they were able to get an ultrasound of Spenser's brain and that wouldn't happen until the next day. Spenser had appeared to stabilize though, so we were optimistic. We stayed with him and talked to him for a long time. We were able to hold his fingers and touch his feet. I remember crying the entire time. I just felt so helpless. I couldn't make it better for him and that is a mother's worst nightmare. The next day we went back and were given very bad news. We were told that Spenser had a grade four intraventricular hemorrhage, the worst type of brain bleed. The doctor explained what that was, but all I understood was that it was bad and would get worse. It was the first time that I grasped Spenser's fragile state. The doctor wanted to forward x-rays of Spenser to a doctor at Johns Hopkins in Baltimore. This doctor was supposed to be the leading neuroneonatologist in the country. We were told that Spenser would most likely be moved to Hopkins the next day, but we would have to wait and see. All that day was horrible.

The next day we called in the morning to check on Spenser (we called every few hours every day). Hopkins was coming at eleven, so we needed to be there then. Jeff came down with the stomach flu that morning, so I had to take our son and go to a relative's house to stay. I couldn't take the risk of becoming sick too. One of us needed to be there to sign consent to have Spenser moved. Our son wanted to know if it was Daddy's turn to go to the hospital now. I was falling apart. Jeff was sick, my son was so confused, and my baby was very sick. I took



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our son to a friend's house and I went to the hospital to wait for the transportation team. I was there for two hours. The transportation team finally called and said they couldn't come. Looking back on it, it was the best time I had with Spenser. I sat there all alone and just talked to him and told him stories. It was just he and I – the best. When I left the hospital, Spenser was fine. He needed less and less oxygen every day and was responding well to every medicine. The next day I called over and was told that the doctor at Hopkins wanted to try some medicine to reduce the swelling that the bleeding had caused. At first there was some talk of an operation, but Spenser was too small to operate on, so the medicine was one of the only choices. It was great news for us. It meant that Spenser would not go to Hopkins in Baltimore.

The medicine was given to Spenser, but it didn't work. From Tuesday to Friday we followed the same routine. We called the NICU every few hours, went to see Spenser three times a day, and waited for him to get better, for the medicine to work. On Friday we found out that Spenser was going to be moved to Hopkins on Saturday morning. They wanted him there for closer observation. Baltimore was only twenty minutes away, but it would mean not seeing Spenser as much as we wanted. Saturday morning came, and Spenser was moved to Hopkins. We were at the hospital to see them pack up all of his things. Over the week he had accumulated little stuffed animals (one of them given to him by his big brother). I took the little baggie of his things and told Spenser we would be to see him as



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soon as possible. They told us not to come for a couple of hours because it would take some time to get him settled. My mother-in-law was staying with us for a few days, so we left our son with her and went to see Spenser in his new home. I hated the new place at once. At the first hospital, he was nestled in a little bumper and he liked to put his feet up on it. He had a blanket and always looked really comfortable. When we got to the new NICU, he was just laying in a warming tray with nothing. He looked so lonely. I brought his animals and put them around his tray and asked them to give him back his bumper. They said they were still getting him settled but would as soon as possible. We talked to the new doctors and nurses for a little while, but I don't remember anything other than the fact that these new people seemed to think that Spenser was in a worse state than the other doctors did. His heart rate was up, but they said it was just because he had been moved.

We were home for an hour before we got the call. The doctor said Spenser appeared to have a very bad infection. I immediately knew that this was it. From the beginning the doctors kept telling us that the worst thing that could happen to a preemie was an infection. The doctor said to come back to the hospital. Jeff and I rode all the way there stunned. When we got there, it was awful. Spenser, who had always looked healthy and pink, looked dark and his stomach was blue. His heart rate was way up and his breathing was more labored. I knew it was over. It was about 8:00pm. The doctors told us he had a NEC infection (a bowel



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infection) and there was nothing they could do except give him antibiotics and see what happened. We decided that we couldn't leave the hospital. The NICU had rooms with bunk beds for parents in our situation. We stayed by Spenser's side and just talked to him. After about 3 hours, I needed to sleep. I was so exhausted. Jeff and I talked about it and decided that as long as Spenser was not in pain, we would let him fight. I woke up at two in the morning. Jeff had been by Spenser's side the whole time. When I looked at Spenser, he looked worse. His blue stomach had spread to his abdomen. I persuaded Jeff to come take a rest. We both slept until about 6:00am. Even though I knew the end was near, I still had visions of going to Spenser's bedside and seeing him miraculously recovered. However, when I looked at him, I began to sob. The blue had spread to his chest. We asked the doctors if anything was imminent, or if we had time to go home. We decided to go home and shower and see our older son. We stayed long enough to have a little breakfast and shower and hug our son, then we went back to the hospital. Jeff and I had not talked about what we wanted to do. I knew Spenser was dying, but Jeff couldn't see it yet.

When we got back to the hospital and saw that Spenser was on medication for pain, I went numb. I walked over to Spenser and told him that he should do whatever he needed to. If he couldn't fight anymore, that was ok. I told him that I loved him and that I was sorry. Jeff still refused to believe that Spenser was beyond help. We talked to Spenser some more and to the doctors. After another



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ultrasound revealed that his brain bleed was worse and his breathing became so labored that every time his head was moved he crashed, the doctor called us back to a conference room. Jeff told me that whatever I decided was what we would do, he couldn't make any decisions. That walk down the hallway to the conference room was the hardest walk I had ever taken. The doctors told us that there was no chance that Spenser would recover. They said he might hold on for a couple of days, but that was it. I told them that we wanted to hold him and then they could disconnect the machines; his little body had been through enough. We went back to Spenser's bedside and the nurse had everything ready. She had set up a screen so we could have some privacy and she had gotten out a little outfit for Spenser to wear. She let me change his diaper. I was crying so much that I could barely do it. I knew that it was the first and only time I would change him and it broke my heart. I helped to get Spenser dressed. They had a beautiful white long shirt that had ribbon and little buttons on it. His little body felt so warm. They disconnected as many machines as possible and brought in a rocking chair. They wrapped Spenser in a blanket and asked me to sit down. When they handed him to me I fell apart. He weighed almost nothing, just a pound and a half. He moved his head and opened his eyes and looked at me. It was as if he was seeing me and telling me that it was all right, that he was going to be better off where he was going than he was while he was here. I just talked to him. The nurse took my picture holding him and I rocked him for a while. When I passed him to Jeff, I felt a part of myself go with him. I always loved to see Jeff holding



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and playing with our first son, he is such a wonderful father. At that moment I realized what was happening. All the memories we would not have flashed before me - all the things Spenser would not be there for. He never even got to see the sun. The nurse took Jeff's picture holding Spenser also. When it was time to disconnect the breathing tube and let Spenser go, I held him again. Jeff knew I would need to be the one who held him in the end. They took out the tube, and I finally got to see my baby's face. He was so beautiful. I remember telling Jeff that this was too hard, that I could feel my heart breaking. I kissed Spenser on the forehead and the nurse came over and listened for a heartbeat. There wasn't one. I wanted to stay there forever holding him. I wanted to run out of there and take him with me. But, I knew that the longer I sat there with him, the harder it would be to let him go. I gave him to Jeff, and we put him back in his tray. The nurse had gotten all of his things together for us and we kissed our baby one last time and left the hospital. When we got home, we had to tell our son that his brother had died. It was the first time our son ever shed a tear.

The next few days were a blur. We had to make final arrangements for Spenser. We decided to have him cremated and bring him home. He belonged with us. We didn't want a service; we just wanted to let him be. We purchased a wall cabinet with lots of windows and put him in there with all the animals from his tray, his bumper, his hospital bands, and the pictures of Jeff and I holding him. We hung it in our living room so he could be in the sun all day. We were lucky enough for the



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hospital to have taken a picture of Spenser after he died. It is the only picture we have of him without any tubes. We framed one of these pictures and hung it next to his cabinet. We had relatives coming in, friends bringing dinner, and people calling all the time. It was a great outpouring of support and love. Jeff and I would go up to Spenser's room, where his crib waited for him and his clothes remained in the dresser, and we would just hold each other and cry. We would cry those deep, long, wailing cries. Sometimes we would take out the clothes Spenser was wearing when he died and hold them. Through all of this, I was still recovering from giving birth. I was still cramping and my emotions were going crazy. I was also recovering from not using the breast pump anymore, which was extremely painful.

In the months since Spenser has died every day has been a struggle, but there are some things that have been particularly unbearable. Two of my close friends have given birth. It was awful to see them with their babies for the first time. I am fortunate to have wonderful friends who understand how painful it is for me, but it is excruciating. We were supposed to hold our babies together. My son was supposed to be a big brother with his friends. Whenever I see their babies, it will remind me of how old Spenser would have been. However, every time I see the new babies it gets easier to tolerate. It will always be painful and sad, but it is no longer devastating. I don't go to playgroups anymore. It is just too hard to see every one of my friends with a baby or a toddler



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My postpartum check-up was an ordeal. After only six weeks I had to go back to my doctor's office and sit in a waiting room with a million happy pregnant women. When the nurse finally called my name the first thing she asked me was "where is the baby?" I wanted to punch her in the face. I told her that my baby had died and she looked like she wanted a hole to open up and swallow her. All she needed to do was look at my chart and she could have saved us both an awful memory. My doctor told me that having more children would not be a good idea. Even though I knew that having more children would not be a good idea, being faced with it was not what I needed. Now that my due date is near I'm getting samples of formula in the mail, catalogs for birth announcements, and congratulations on your new arrival things. It is a slap in the face every time I get the mail.

Jeff and I thought we were going to have a lifetime with Spenser. We thought we were going to see our two sons grow up together. We couldn't understand why this had happened. There had to be a reason for Spenser's life. After we hung up Spenser's cabinet and sent out his birth announcement, we couldn't let it be over. There had to be something more we could do for Spenser. That is how Spenser's Hope was born. The more we thought about it, the more outraged we became that nothing could be done for us. The doctors threw everything they had at me and I contracted through it all. No one, not even the specialists that came to see me in the hospital, could tell me why. There were so many things that they could



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do for Spenser after he was born. But they couldn't give him the one thing he needed- more time. When we began to look into what is known about preterm labor, and labor in general, we found pathetically little. It is too late for our little Spenser. But maybe his life can teach everyone that more needs to be done. A solution needs to be found.



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Today is January 9, 2002. I have had almost ten months to get used to the idea of Spenser being gone forever, and the one thing that has become clear is that I will need a lifetime more. I have done a lot of research, and soul searching, and have come to the realization that I will never get over this. I will add it to who I am, I will learn from it, I will incorporate it into my life – but I will never get over it. I have written that I felt my heart break the day Spenser died, and it will never be whole again. This does not mean that I am not happy. It does not mean that I do not laugh and feel joy and play with my son. What it means is that there will always be a hole in my life where Spenser should be. That is a tough realization – to know that everyday for the rest of my life will be a fight. Some days I can think about Spenser and smile and remember how beautiful he was and how lucky I am to have had even a brief time with him. Other days I can't imagine how I am going to go on without him. It's my son, and Jeff, who keep me going on those days.

When I think back to who I was before Spenser was born, I have a hard time remembering it. So much has changed. I have lost friends I thought I would have forever and found ones I didn't know were there. I have come to depend on the support of others, whereas before I always tried to do everything myself. I have become somewhat of a workaholic, just trying to keep busy. All the energy I was going to pour into Spenser has to go somewhere. I have taken up acupuncture to help me relax and see more clearly. I now know what a problem



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is instead of obsessing over the trivialities of life. I cry openly in public without shame. Strangely, I have gained a sense of empowerment because I have faced my worst fear and come through it. It is cliché to say that my life changed forever the day Spenser died, but it is true. My life, my personality, my priorities, my future, everything is different now.

There have been many hurdles to overcome in the short months since I last wrote about my Spenser. Things that I knew would be hard have been – and things I thought would be easy have been awful. I took some time off from my friends, and their babies, and tried to let things relax. When I decided it was time to get back into things, I found out that I could see my friends, even those with newborns, one on one, but to see them in groups was too hard. My son would see all of his friends with their little siblings and his face would fall. I would go to friend's houses and see all their baby equipment and try not to look at it, try not to imagine Spenser in it. I felt like babies were repellent, and tried to ignore them. This didn't work for long. I soon realized that I was going to have to be able to tolerate babies if I wanted to see my friends. I called a friend of mine who had a baby in June and told her that I was coming over to hold her baby. I expected it to be horrible. But it was wonderful. I looked at her baby, a little boy, and saw her baby – not Spenser. I smiled at him and fed him and discovered that I could take joy in a baby. It was a wonderful experience. It was a big hurdle



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to jump. I still don't hold babies that often and never in front of anyone but my closest friends, but it is nice to know that I can without having a breakdown.

The pain my son is in is something I was not prepared for. I knew he would be sad. We had done a great job of prepping him for Spenser's arrival. Never having had a sibling, I didn't think he would feel a great sense of loss; only sadness and confusion. The day after Spenser died, our son started coming up with ways to get Spenser back. Being only four, the concept of death was new to him. He thought about getting a really big ladder to climb up to heaven to bring him back, or asking a super hero to fly up and get him, or flying an airplane up to him. He invented an entire species of people that are giants and can reach their heads up to heaven and talk to Spenser. He even dressed as one for Halloween. He draws pictures for him and collects leaves and flowers to give him. When he makes paintings at school, he makes one for Spenser. Every day he'll go through the same thing, almost like a script. "It's not fair that Spenser died", he'll say. "He was a cutie"; "He'll always be in my heart". It just rips my heart out every time I hear him talk about the things he wanted to show Spenser. He asked me once if I could get us another baby. I told him that I didn't think so. He has taken to singing "Spenser songs". He sings very softly about how he loves his little brother and will always remember him. Sometimes I have to tell him that I can't listen to a song because it makes me too sad. He told me a few weeks ago that he needs a baby break. He said that seeing his friends with their



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babies made him sad, so I've started having his friends over alone. I was so preoccupied with the fact that babies reinforced my sense of loss that it never occurred to me that my son would be feeling the same thing.

I knew that when my son started school again it would be an ordeal. It was, but not for the reason I thought it would be. There are 14 children in my son's class. Only three of us don't have babies 2 or younger. I thought it would be hard to go to school and see 11 women with their babies or toddlers and feel left out. It was hard to do this, but I had thought about it so much that it was almost anti-climactic. The problem turned out to be that I had envisioned taking

Spenser to school with me. I had envisioned my friends saying things to me like "he's so cute", "he's grown so much over the summer", "how is your older one handling it". Instead I watched the scene I had imagined with Spenser and I playing the leading roles, being played out by other women with their healthy babies. I had also envisioned that when my older son went back to school it would be Spenser's time to have his mommy all to himself. Instead I went home to a lonely and quiet house. I had never felt more alone. My son has been back at school for almost five months and I still find it hard to come home while he's in school. Sometimes it is just too depressing. I see visions of myself with him everywhere in this house. I see us playing on the living room floor; me bouncing him on the sofa; changing his diaper in his crib; folding his little laundry; carrying



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him until he finally stops crying; singing him lullabies in his room; warming bottles in the kitchen. Thoughts of him are everywhere.

The holidays weren't all that bad. Like the beginning of school, I had prepared myself for them. The worst part was all the before meal prayers when family would say how fortunate that everyone could be with us and that we were all healthy, and that we all made it through the year together. What were they talking about?! Had they already forgotten that Spenser didn't make it through the year, and wasn't able to be with us? That really hurt. It felt as though he was already in the past – forgotten. Other than that, we got through them all right. We didn't do a lot of celebrating or spend a lot of family time. We mostly spent time together, the three of us. The part that really surprised me was how difficult it was to start the New Year without Spenser. Jeff and I had spent the entire year saying how glad we would be to see 2001 go. However, when it came down to it, it was so hard to imagine starting the rest of our lives without such a big part of us. I cried for days. I went to Spenser's room and talked to him. I talked to my four year old when he slept to let him know that everything was fine and things would get better. After I had cried myself out, I realized that I hadn't really cried since Thanksgiving. I had been holding everything in, just trying to get through the holidays. It felt so good to finally release it all.



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Lately, I find myself asking – what's next? I had my entire life planned out and now I don't know where I'm going. It's time to move on, but to where? The first step is to decide what to do with Spenser's room. It's been sitting up there awaiting his arrival for almost a year. The clothes are still in the drawers, crib still made. We need to do something. It will be a slow process. Pack up the clothes one day. Wait a few weeks. Disassemble the crib. Wait a few weeks. It will go like that until we are done. The room is now like a tomb, and I don't want that for our Spenser. I want to celebrate his life, not shut it away in a lifeless nursery.

Sometimes I get so angry that people don't want to talk about him any more. No, that's not right. I get so angry because they don't want to talk about my grief anymore. I'm sad – very sad. I am envious of every woman I see with a baby. I still want to have a baby in my life very much and the fact that I can't have one hurts to the core. I put on a strong face when I take my son to school, or when pregnant friends talk about how happy they are that they will have a new baby soon. But when I get home and am all alone, I just scream. And no matter how much I scream, I can't feel better. And that is what I need to realize, and everyone else close to me needs to realize. I will always want to scream. I will always miss him. No matter what direction my life takes, I will always be sad. I will always need to talk about how much I miss him. I feel like there are times when all I do is talk about how miserable I am. And when I feel that way, I pick certain friends to talk to. Those really good friends who will let you do whatever



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you need to do to feel better. Those are the friends that are special – and the ones I will never lose.

I am not looking forward to the coming months. Our older son will graduate from preschool, and move on to Kindergarten. Spenser's birthday will come and go. Friends will have babies and bring them to school to show them off. It will be very tough. But I know that. I know that until I get used to this life I have, until I get used to my son being in Kindergarten and me being home alone, it will be a fight. I will get through it. My son will get through it. My husband will get through it. We will all get through it together.



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Today is November 8, 2004. It has been a long time since I have written anything about my family. I finally feel like it is time to put pen to paper again and tell my story. This journey has been long and strange and horrible and has led me to the most rewarding thing I have ever done. I have grown. I have learned the true meaning of the word "Mom".

So much has happened since I last wrote that I don't know where to begin so I will begin with the biggest thing – we have another child. Our journey for a third child began about a year after Spenser died. I realized that all the reasons we wanted Spenser in our life were still there. I wanted my eldest son to have a sibling and I wanted to be a Mommy again. My husband and I talked and decided that we were not willing to give pregnancy another try. The thought of putting another child through what Spenser went through was just too much. Not to mention the thought of holding another child of mine as they took their final breath. I couldn't do it again. My thoughts turned to adoption. After some research and discussion we decided to adopt from Korea. The process was long (14 months) and in so many ways more grueling than a pregnancy. But in the end we welcomed home a beautiful baby boy who was born on February 15, 2003. He was only 4 months old when he came home and the first time I held him I could feel the love flow out of me. All of the Mommy feelings I had been forced to bury deep inside for almost 2 years came pouring out. Our family was finally complete.



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I don't mean to say that our third son has taken the place of our second son, Spenser. It is really the opposite. I very much feel as if I have three children. When people ask why I waited so long to have another child I tell them that my middle child passed away. When you ask my eldest son how many brothers he has he will tell you 2 – one who is alive and one who is dead. Spenser is still very much a part of our lives and will forever be. What I mean by saying our family is complete is that I am no longer aching for another child. I no longer feel the deep need to hold a baby. We no longer wonder what it would be like to watch our children play together. Our lives are healed and we are ready to move on. I don't think I would have ever been able to truly move forward if we had not had another child. I will forever be grateful to our third son for making our lives happy and full again. When he is old enough he will learn about his "other" big brother.

I still think about Spenser every day. I don't cry for him as often, but I still do. I talk to him and imagine what he would be doing now that he would be 3 ½ years old. The day we brought our new son home I missed Spenser so much. Spenser was a big brother too and it was something else he was missing out on. It was a very bittersweet time. Spenser's absence has been brought to the surface in so many strange ways. Sometimes, when we are doing very mundane things, like shopping or running to the library, I'll get a flash of him there with us. When my sister-in-law got married I missed him terribly. Everyone was having



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such a great time – I knew he would have loved it too. Then there are times, for no reason at all, I will just start weeping for him. Maybe it's a smell, or a random thought, or even a commercial on TV, that makes me miss him. I suspect that for the rest of my life I will be missing him. What parent wouldn't miss their child?

Since beginning Spenser's Hope I have come into contact with all sorts of people I never would have met before. Some are looking for help for their newly premature child/grandchild/niece/nephew. Some are looking for answers as to why their baby died, and realizing that those answers may never be found. Some are just looking for a connection to someone else who understands. I have cherished each and every one of these connections, and become very good friends with some of them. There are those who think that we, and other parents like us, are holding on to our children too long, but we can't deny that our children were here and that they were and will always be our babies. My husband and I are doing what any parents would do for their child – everything we possibly can. It is so important for every parent to know – to truly understand – that their child is special and worthy of love. No matter how long their child was here, or whether their child was here at all. Spenser's Hope began to help those experiencing preterm labor and premature birth, but it has grown into so much more. I will forever marvel at the paths life sends us down. I never would have chosen to walk this path, but am doing the best I can to walk it with my head held high. And if I stumble, I know my little Spenser will be there to pick me up and



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show me how important it is to take this path. Most of all, he will be there to remind me how important it is never to forget the path he was sent on.



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Today is December 21st, 2010. How have so many years gone by without me writing about my Spenser? He's been on my mind every day. Every time I see my other two boys smiling I see the shadow of his face. Whenever I see a happy mom, or even a haggard one, holding their baby I see myself holding Spenser. I thought that these feelings would have lessened by now, but if anything they have gotten stronger. Perhaps that's why I haven't written about him in so long. I've tried very hard to move on and make a happy life for myself. At first I tried to do that by constantly talking about Spenser, hoping that by doing that he would somehow still be with us. Then I tried to work diligently to make people see how much of a problem preterm labor was and why it needed to be researched and eradicated. But no one wanted to hear about a dead baby and after a while I stopped fighting. Then I tried to act like I had gotten my life together and the pain of losing Spenser was simply a faint memory. That hasn't worked either. So now I find myself writing again trying to sort through life without my son.

First of all I should say that I am happy. My life is wonderful. My husband and I are one of those rare couples that are truly in love. Our two boys are great. Our eldest is 13 and very imaginative and brilliant. Our younger one is almost 8, equally brilliant and showers me with love and hugs every day. I homeschool both of them and have been very grateful for the time I've been able to share with them. We started taking vacations to Disney World a few years ago and loved them so much that we're moving to Florida so we can go to Disney every day.



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That's a pretty good life. There's just the one thing. Spenser's not here to share it with us. Almost every happy memory I have since Spenser died has been tainted by Spenser's loss. No matter how happy I am, there's always that twinge, sometimes small and sometimes large, that reminds me how much better it could be. When I was first introduced to my niece (who was 5 months old at the time) it was wonderful to see her. But I cried so much that I couldn't enjoy it. I couldn't even hold her because I was such a wreck. I'm still not able to hold new babies and send all my new baby congratulations cards through email. Life is good, except for this one part.

I've been thinking more and more about Spenser over the last year while at the same time talking about him less and less. This has been a hard time. I've been watching my boys get older and older, needing me less and less every day. Soon they'll be going to high school and then moving away to college. In the blink of an eye I'll be the person they make their obligatory weekend phone call to. For the last 14 years I've done nothing but be a mother. Now the time when my kids need me the most is nearly gone. That's why I feel Spenser's loss more now than ever. Now that I'll never have babies again, the baby I lost calls out to me louder than ever. Would I still feel the sting of my children growing up so strongly if Spenser hadn't died? I'll never know. I'm not your normal, average, everyday mom. I'm damaged. Some days I feel as if all that's holding me together is the sheer force of my will not to fall apart.



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Should it still be this hard after nearly 10 years? Of course it should. I held my baby in my arms and watched him die. How does someone get over that? The simple answer is - they don't. I wrote once that life changed forever the day Spenser died and I don't think I've ever written anything more true than that. I often wonder what my life would be like if I had never gotten pregnant with Spenser at all. My older son wouldn't have had to go through the horror of losing his brother - something that still haunts him. My husband and I wouldn't have had to go through the pain of losing our son. Most importantly, Spenser wouldn't have had to go through the pain of life. But I know that this life, the one that I'm living now with the knowledge of Spenser's death, is the better one. I had a glorious week with my Spenser. I got to kiss him and hold him and tell him how much I loved him. Some parents don't get that chance with their babies. My eldest son learned the value of life and knows that even after something tragic happens, life goes on. I like to think that Spenser felt our love; that he knew we were there for him; that we would have given anything to make him well.

The lesson I wish I could teach everyone, myself included, is to cherish every moment. It can always be worse. Not getting pregnant with Spenser, although so tempting with its ease of emotion, would have been worse. When I hear parents, especially mothers, complaining about how tired they are and how they wish they could just have a minute to themselves, I want to tell them that it could be worse. I have very little sympathy for mothers who tell me how hard it is to



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have more than one child under four or five years of age. They have no idea how hard it could really be. When my boys are being particularly challenging, I try to tell myself at least they're here with me.

Over the years we haven't forgotten Spenser for a moment. We celebrate his birthday every year. We have cake and try to think of something a boy his age would enjoy doing and have a great day as a family. Whenever we go on vacation we buy Spenser a tiny something to go in his cabinet. We keep him with us where ever we are. When we first began Spenser's Hope, we wanted to make a difference. We wanted to help find a cure for preterm labor and premature birth. We quickly learned that, although we wanted it very much, it wasn't going to happen. The key organizations leading the way in preterm labor research didn't want to promote dead children. They wanted to promote "miracle babies". It made me feel as if my Spenser wasn't a miracle. How cruel. Just because my baby died doesn't make him any less of a miracle than any other baby. So Spenser's Hope changed into more of a support and recognition website. I think that's even better. There are so many babies that die each year and so many of them are forgotten. Maybe it's too painful to remember. I can understand that. But it's only through remembering that we can make peace with our pain. The pain will never go away. Sometimes I think it will swallow me. But to forget all about Spenser would be pain I couldn't stand.



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I really miss my middle son. I've been trying to hide that, or run from it, for the last couple of years. How foolish that's been. Yes, my son died. Yes, it hurts. Yes, it will always hurt. But I love him. And a mother's love is stronger than anything. If I run from the pain of his loss, I'm also running from my love for him. Even now, all these years later, I can still feel how soft his skin was. If I close my eyes I can remember what it was like to look into his tiny, newly opened eyes and clearly see the deep blue of them. Those are things I don't ever want to forget. I know the pain -know it very well. It will always be there. I can only hope that the joy of remembering Spenser never goes away.

Gretchen Miller, Spenser's Mommy



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