

Rebecca Claire Fakier

April 29, 1995-July 18, 2003

Rebecca was born on April 29, 1995. She was a very welcome addition to her two brothers, Edward and Mark. Everything about Rebecca's first six years was completely normal. She attended St. Bernadette School and was an excellent student. She loved learning and she loved making A's! I can still remember how indignant she would get when we would open her test folder on Tuesdays and find a B in it! In the first week of March of 2002 she had a viral illness, fever, sore throat, usual stuff. We never even went to the doctor. However, because of the fever she was unable to go to school for three straight days. Very unusual for her and for anyone that has dealt with makeup school work; you know that you work really hard to get them back to class as soon as possible. Finally, she was able to return, though I must say that she enjoyed her time at home with me very much. We were very close. On Saturday she attended the birthday party of one of her good friends but later that night she began to complain of her neck hurting. I asked if maybe she landed funny on it in the space walk that was at the party, but she said she didn't think so. Monday morning came and though I thought that she felt warm, she got up with no complaints and so because she had missed three days the week before, I sent her off to school with her brothers. I figured that if she started feeling poorly or her fever got any higher that the school would call me. I heard nothing from the school all day and picked her and her brothers up as usual just before three. I pulled her hair up into a high pony tail, it was quite long at the time, and she changed for soccer practice. She participated in practice with no problems and then we went directly to piano lessons. When we got home that night she complained about her neck again but she wasn't acting as though she felt unwell. She was piddling around in her dad's office and made the same complaint to him. He pulled her close and then came immediately out of his office alarmed by what he saw. Even though I had pulled her hair up into a pony tail, there was no evidence earlier of large glands on the back of her neck. When they walked into the kitchen, suddenly they were obvious from several steps away. He showed me Rebecca's neck and asked if I had noticed these earlier. We quickly talked about the illness from the previous week, the slight fever that morning and David, being a physician, began

to think that she had developed abscesses in the glands on the back of her neck. He called the CT suite to see if they were busy and off they went to get a CT of her neck. I stayed at home and worried about the need to be in the hospital on IV antibiotics for an abscess and yet more missed school time. I put the boys to bed. Even more time passed and I began to get more and more worried as it seemed to be taking way too long.

I remember calling our friend and Rebecca's doctor, Mark Walker and talking to him about what he thought she might have. Then the finally came home. David kissed Rebecca tenderly, thanked her for being so good, and asked me to put her to bed. As I was doing that I overheard him place a call to another friend who is a physician, Raul Doria. I thought that that was truly not good but could not imagine what was happening. When I came downstairs, David asked me to sit down. He showed me the CT pictures of the huge mass in her chest and said that he didn't know what our baby had but that it was not good.

By the next morning after a series of frantic phone calls and an almost sleepless night, we were on our way to Oschner to see Dr. Raphael Ducos of the pediatric oncology department. Right away he was concerned about a cancer called neuroblastoma. We did some scans and preliminary workups but knew that it was a bone marrow exam that was needed to give us a more definitive answer. There was initially cause for hope as her bone marrow came back negative. A pediatric surgeon came to see us and was quite sure that the large tumor in her chest was actually a benign tumor called ganglioneuroma. One day later, we had our answer. It was unfortunately, the very malignant neuroblastoma. This is where things began to get really hard, a dark tunnel, with almost constant worry on our part and constant pain on Rebecca's part. We stayed in New Orleans for almost three weeks with no end in sight to the surgical complication that Rebecca developed called a Chylothorax. This is common in chest surgeries, absolutely no fault of the surgeon and whereas many recover on their own with this, Rebecca was not going to do so. She was losing 1200 ccs of fluid per day from now two chest tubes and in horrific pain from the medications that caused pancreatitis. We were desperate to find a solution to the problem and that came in the form of a friend suggesting that we call a friend of theirs that was an adult oncologist in NYC at

Sloan-Kettering Hospital. We kindly explained that we needed to solve the surgical issue before we could even think about the issue of her cancer, but the friend was insistent. David called the man and they began to talk about Rebecca's case. He strongly recommended a surgeon at Sloan, Michael LaQualgia, who does nothing but pediatric cancer resection. We contacted them, filled them in on the status of her case and within two days were boarding a med-evac flight to NYC. The thought of the surgeons having to go back in to do the repair was very difficult but it was the only way to move forward and even begin to address the issue of her cancer. Rebecca actually had her surgery on Good Friday. I thought at the time that it was the perfect day because I told Jesus that I felt as though I was in the tomb with him and that it was very dark. I could not imagine what we would do if this surgery was not successful. Just three weeks before I had a normal family and now I was looking at the possibility of losing one of my children. It was terrifying and incomprehensible to me. That night as I watched the pleura-vac fill with fluid again, I remember saying to Jesus that I never before knew what people meant when they said to turn a problem over to you but I was so incapable of thinking of what the future held that I gladly put the outcome in His hands. That night I slept well and was able to face the next day. When David came in and saw the amount of fluid, he also began to worry. I asked him not to talk to me about it and I explained that I had put it all in Jesus' hands and that whatever happened I knew He was in control. It was not until 4pm on Saturday that the surgeon came in and told us that he was delighted with how things turned out. He explained that the fluid we were seeing was mostly the antibiotics that he had poured into her chest cavity! What a relief that was and for the first time in what seemed like forever, we could begin to move forward with treatment for Rebecca. At that point I was filled with hope and very grateful for Jesus' presence on that very dark Good Friday.

But that was me, Rebecca was not so filled with hope, she was just angry. As she recovered from her surgery and we moved to the Ronald McDonald House, it became more and more apparent. She would actually huff and puff whenever we went to Mass and actually turn her back on the altar. One Sunday, David and I talked to her about her anger. I asked her if she was angry at God. Her reply was swift. "YES"! I asked her why specifically and she told us that she had asked God after

she was sick the week before her diagnosis if she could stay home with me. She then said, "Is this what He thinks I meant!!!???? Why did he do this to ME?????" I was blown away by her clarity as well as her anger. She never considered as so many adults do that there might not be a god, because how could a loving god do this to a child. No, she was certain about the presence of God but very angry that he had chosen her to suffer so. She felt all alone, as though she was the only one made to suffer so. I asked her to look around. She was not alone in her battle with cancer. In fact, there at Sloan/Ronald McDonald House, she was surrounded by children from all over the world that were going through the same thing as her. That seemed to open her eyes. I won't say that her anger evaporated on the spot and that she didn't struggle with the reason for her suffering but it was the beginning of her choosing to rely on God rather than be angry at him.

There were so many good days in those 16 months and so many, many blessings that only the reality of cancer can bring. When Rebecca felt good there was no limit to her energy, walking with us all over the city, a wonderful city that provided so many distractions from treatment. Each week a new friend or family member of mine would journey up to NYC to stay with us when David couldn't be there. Rebecca, when she felt well, loved nothing better than to show the city off to people who had never been there. She so much appreciated all those visitors. It made the dark times so much easier.

It would take a book to detail the entire journey, but it was evident as her treatment continued that nothing we were doing was slowing down the disease by more than a few months. There were many events and people that sustained Rebecca and us during those days. One song in particular became her theme song, a beautiful song from the animated movie, "Joseph, King of Dreams". Here is the link to the you tube video from the movie.

<http://www.youtube.com/watch?v=8oL6HlzQZLo>

Better than I

**I thought I knew what's right, I thought I had the answers
I thought I'd chose the surest road, but that road brought me
here.**

**So I put up a fight and told you how to help me
Now, just when I have given up, the truth is coming clear
You know better than I, you know the way
I've let go the need know why**

**For you know better than I - If this has been a test - I cannot
see the reason But maybe knowing I don't know is part of
getting through, I try to do what's best**

**And faith has made it easy to see the best thing I can do is put
my trust in you For you know better than I, you know the way
I've let go the need to know why for you know better than I**

**I saw one cloud and thought it was the sky, I saw a bird and
thought that I could follow But it was you who taught that
bird to fly If I let you reach me, will you teach me, For you
know better than I....**

**Rebecca always had a wonderful sense of herself and her
abilities. She loved to learn and she loved to sing. She spent a
lot of time singing in her days in NYC and even spent an entire
day recording "Better than I" with the woman who came to
Sloan to help kids with their school work. When we were told
that all that could be done had been done and that we should
take Rebecca home, she performed this song for the entire
school at the final mass of what would have been her second
grade year. I know that Rebecca internalized and lived out the
words to that song.**

**I had several conversations with her in her last few days.
Two stand out vividly and speak so highly of her complete faith.
For the first story I have to backtrack a little. When we were
in the hospital once for about three weeks, her roommate was
a boy of about 4 named Matthew Hendry. We both loved
Matthew and his mother, Nadia, and enjoyed our time together.
When Matthew felt bad, which was often, Nadia would have to
lie in bed with him for hours on end while he twirled her hair
between his little fingers. When he would finally fall asleep,**

Nadia would try to sneak out of the bed, just to get a break. Sometimes she was successful in this attempt and sometimes she wasn't. When she was, however, she would whisper for Rebecca and me to tell Matthew that she just went to get a coke and that she would be right back. Over the course of those long weeks we helped her with this several times. It was not unusual for Matthew to cry a little and then ask a few worried questions about when she would return and then he would usually settle right down. Well, little Matthew died in March of 2003 and it was not long after that Rebecca asked me a question which blew me away. She said, "I don't get heaven!" I asked her what she meant. She told me that she didn't see how Matthew could possibly be happy in heaven because Nadia was that not there with him. After all she pointed out that he didn't even really like to let her out of the bed to even get a coke! I always felt like the Holy Spirit was with me because the reply I gave her seemed to satisfy her completely. I told her that if a man lived to be 100 years old on earth, we considered him to be a really old man and that he had lived a very long life. I then asked her to imagine how long that must seem like to God. I asked her to remember that God had created the world many, many years before and that to God a human life, even a very long life, was like a second. So for Matthew, it will be just like when he used to fall asleep and when he woke up, she and I would tell him that Nadia would be back in a second and then he would be happy. She accepted that and asked no more questions. When we were in our last few days, one night she said to me, "I'm scared." I started to say to her, "Remember how we talked about when Matthew died that to Matthew it would just seem like a second...." Well, she cut me right off and said, "Yeah, yeah, I know about that second thing but that is not what I'm scared about". I asked what she was scared about and she said that she was worried that something would happen to David or me. I was so taken aback by that statement that all I could do was assure her that her dad and I were fine and that we would not be going anywhere. That relieved all fears and questions. I later realized that it was her way of saying that she would rather be the one going. She could imagine her leaving but she could not imagine living her life if either David or I were to die. And in the end, in her last conversation with me, she asked if she was going to die. I told her that only God knew that and I was sure praying that He would leave her here with us. Her reply amazes me to this day. She said, "Oh, I hope I get to stay. I still have so much I want

to do. I want to be a singer and a veterinarian and an actress". No comment or thought at all about heaven - what it would be like. No thought as to if it actually existed or if she had been good enough in her life to go. It was clear that she accepted the reality of where she would be when she left; she just wasn't ready yet to go. Her last days make faith easy for me. I want to be where she is.

There are just so many stories, so much which could be said. We know that Rebecca is alive and still has an impact on so many lives. One classmate of Rebecca's was Hannah Hornsby. When Rebecca first got sick Hannah would pray that she would get well and come back to school. When Hannah saw her and realized just how sick Rebecca was she changed her prayer to asking that Rebecca not hurt and not be sick anymore. On the morning that Rebecca died, Hannah had an eye doctors appointment. They received the news in a phone call about her passing and Hannah, with a big smile realizes that Rebecca is in heaven and said, "she is not hurting anymore". They go off to the appointment and for the first time ever, Hannah tells her mother that she doesn't want to wear glasses anymore. Her mother thought this unusual as she has worn them since she was three (her prescription was +8) and they had never bothered her. Hannah's mother jokingly said that she didn't think that Rebecca had been in heaven long enough to pull off that miracle. Well the doctor walked in and began to examine her. Long story short - Hannah walked out of the office having been told that she no longer had to wear glasses. Hannah asked to come to Rebecca's wake. She presented flowers and her glasses to David and me. To this day she still does not wear glasses.

Rebecca knew how to put her trust in God. We have learned many lessons from her, even after her death. I will leave you with an excerpt from a diary that she had. The entry was just before her last major surgery and she knew exactly what she was going to face in pain and recovery. She wrote, "I'm scared about my next surgery and I just want you to help me, God. If I promise to try my best, will you help me? I believe in you, it is hard to believe but I still do". In her time with us, she was such a blessing and we thank God daily for having been fortunate enough to have had her for the time that we did.