

My story

The devastating news

EARLY ONE MORNING AFTER MY HUSBAND had gone to work, I heard my baby Joseph crying for me. A mother knows her baby's cry, and this cry was one I had never heard before. I ran to his room. Fear gripped me when I saw him. His whole mouth, lips, feet and fingers were completely blue. It looked as though someone had smashed them in a door. I was so frightened I was speechless. My mind begged for an answer. What was happening to my baby? I reached for him and the terror spread through me like a wave. Why was his little body cold and clammy? I was overcome by fear. Was he dying?

In an instant my mind flashed back to my wedding day. It was a hot summer day in Florida when Joe and I were married. We were young and in love. Our dream was to marry and have two healthy children. That dream did not become a reality for eleven long years.

On June 22, 1988, God blessed us with our daughter, Jennifer. She was perfect in every way. Two years later, another baby was on the way. Our family would be complete, just the way I always imagined. Our son Joseph was born on December 6, 1990. He was a happy and healthy baby until the nightmare began.

In February of 1992, both of the children were ill. They started vomiting profusely. Within eight hours they became so dehydrated that they had to be admitted into the hospital. The diagnosis was rotavirus, a common contagious gastrointestinal virus. Joseph had an IV in his foot for 24 hours to receive intravenous fluids. Still, he was able to return home the next day. Not Jennifer; she was getting worse. She had to be rushed to Shands Hospital at the University of Florida in Gainesville. Finally, after one week, Jennifer was well enough to return home.

Our children stayed healthy for seven months. On August 30, 1992, when Joseph was only 21 months old, his appetite started diminishing rapidly. I felt that was quite odd, because Joseph loved to eat. So, by the end of the day when he had not eaten much of anything, I called his doctor.

The doctor asked, "Is he drinking and urinating?"

"Yes," I replied.

The doctor said, "He probably has a stomach virus that's going around. As long as he's drinking, he'll be fine."

"Okay," I said.

Two days went by without Joseph eating. I called the doctor again. The doctor reiterated his message: if Joseph had no fever or vomiting and was drinking well and urinating, we were not to worry.

Four days now had elapsed and still there were no signs of improvement in Joseph. Something was wrong with my baby, but what? That night, Joseph was extremely thirsty. He urinated constantly. He would not just wet his diaper now, but also his clothes and the bedding.

His bed had puddles of urine in it. I used a box of diapers and six sheets throughout the night. In the early morning, Joseph was tired and began crying again. I ran to his room and, as I looked down at him, his whole mouth, lips, fingers and feet were completely blue again. His body was cold and clammy as I held him close to me. I was so frightened and overcome with fear. Joe had already gone to work. Who would I get to help me now?

I called my friend Lois to help me. Joseph was shaking severely. We quickly wrapped him in a blanket and a jacket. His little fin-

gers, toes and lips were still blue. Joseph asked for some juice. He had an extreme thirst, consuming 38 ounces within a few minutes.

Ten minutes passed and the blue color began to fade. Lois and I felt relieved to see him looking like his normal self again.

Still, I knew something was very wrong. I called the doctor, who told me to bring him in. He said it sounded like a lack of oxygen. We hurried to the doctor's office.

The doctor came in and examined him. He said, "He looks fine. He just has the flu."

I looked at the doctor as though he were crazy. "I'm sorry, but this is not the flu," I insisted. "He drinks like he has never drunk before in his life. He urinates a flood and you say nothing is wrong with him? Come on!"

His expression changed quickly. "Oh, God," he said, "it sounds like sugar. Just wait here."

Two minutes became an eternity as I waited. I held Joseph in my arms.

The doctor returned to prick Joseph's finger. "I need to check his blood," he said. He pricked my son's finger, then handed the blood strip to a nurse to insert into a meter.

Next I heard the doctor yelling at the nurse. "Don't you know how to operate this machine!"

What was wrong?

The doctor, still in a loud voice, said, "I'll test my own blood sugar level." His blood sugar read 73 mg/dl; the meter could only go as high as 400 mg/dl. Apparently Joseph's had gone to the top. The doctor rushed back into the examining room.

"There might be something wrong with your son's sugar level. We must take some vials of blood from him so we can send them to the hospital immediately," he said. The doctor seemed urgent now, ordering us to go home. "Gather his clothes," he said. "If I'm right, Joseph will need to be admitted to the hospital at once. Just go home and wait for my call."

I felt numb and confused. Why was the doctor talking so fast? My eyes filled with tears; my heart shattered. Why my baby? "No. No. Please, God, let him be wrong," I prayed.

I rushed to the phone. I needed to talk to my husband. When I heard his voice, I broke down and began crying so hard that he could not understand me.

I drove home frightened and alone. What was going to happen to my baby? I could not control my pain; the tears would not stop.

It took me a long 20-minute drive before I got home. There was something peaceful about coming into our yard. I breathed a sigh of relief. They were wrong. When the doctor calls he will tell us they have made a mistake. Joseph is fine. Again I drew deep breaths. Joseph is fine, I thought.

I sat in the rocker cradling Joseph until my husband came home. He wrapped his arms around us, as only a husband could do. We were in this embrace when the phone rang.

Now my confidence left me. I was terrified to answer the phone. It rang several times. Then I picked the receiver up.

“Hello, Mrs. Peurrung, I have some bad news,” the doctor said gravely. My ears were ringing. I thought I would faint. “Joseph’s sugar reading is over 800, and he is in great danger. He is very ill. You must get him to the hospital now. I am sending an ambulance to your home.”

“Wait. Wait!” I screamed. “What does all this mean? His sugar is high? What does that mean?”

“Mrs. Peurrung, your son must get to the hospital at once; your son has juvenile diabetes. We’ll answer your questions there. An ambulance is on the way.”

“An ambulance!” I cried.

My husband took the phone from me. He told the doctor we would drive Joseph ourselves. We lived way out in the country and by the time an ambulance would arrive, we could be halfway there.

The hospital was fifty miles away. We left immediately. It was a long hour. My husband drove fast, yet carefully. We both felt that Joseph looked fine. We agreed that he did not have juvenile diabetes. No one in our families had diabetes. Most likely the flu had caused his sugar level to rise. We both began to relax with our false hope.

When we arrived at the hospital emergency room, there was a room waiting for Joseph. When the nurses put him in a crib, I cringed. It looked like a cage. We sat there for about five minutes before half a dozen doctors came in.

One doctor was a pediatric endocrinologist; the others were in various stages of training. They wanted to draw blood. It was difficult because they couldn't find his veins. Joseph screamed and cried. My poor baby finally fell into an exhausted sleep.

Joe and I were sitting in the back of the room when the doctor decided to acknowledge us and explain the problem. "Joseph has juvenile diabetes. He is a very sick little boy. His glucose count is 869 mg/dl and he has an extremely large amount of ketones."

"What is juvenile diabetes?" I asked. "I don't even know anyone who has juvenile diabetes. No one in our family has this. Why does he have it?"

The doctor explained to us that one out of 300 children is diagnosed with juvenile diabetes. The medical profession still does not know exactly what triggers this disease. He told us that we must accept it and start learning how to take care of him. The doctor was generous with his time and spent about an hour explaining things to us.

When they left us alone Joe said, "I don't believe them. They could be wrong." This gave us a little hope.

Maybe Joe was right and the doctors were wrong. Maybe after a week or so our baby would be fine. My prayer was that the doctor had given us the wrong diagnosis; but, in my heart, I knew it wasn't just the flu.

I spent the night with my baby. I held his hands all night. Why Joseph? I kept asking myself. He is such an innocent child to be so sick. How will I be able to care for him? I don't know what to do, how to give an injection. I know absolutely nothing about diabetes. The night went by extremely slowly. The morning finally came and I thought things might have changed, but they had not. Joseph had juvenile diabetes, period.

A diabetes nurse educator came in later that morning when the doctors arrived. She tried to explain all about diabetes. It was overwhelming.

“How will I be able to understand all this in just a few days?” I asked.

Clinically cool, she said, “Oh, you will.”

Easy for you to say, I thought. Numbly, I reached out as she handed me some papers and a book. There was no way I could do all this. I was afraid and angry. What if I could not care for Joseph properly? I knew that my husband, Joe, couldn't handle this disease. Joe didn't even want to look at a single paper about diabetes. He didn't want to help at all, because he was afraid. He couldn't come to terms with the fact that his young son had diabetes. Without Joe, I was totally alone, isolated and afraid.

At long last, my sister Donna walked into the hospital room. She grabbed me and held me. I dissolved into tears, realizing I wasn't alone. It felt so good to see her. No one else in my family had come. Why are families so detached when you need them the most?

Donna was filled with encouragement. She was very uplifting, but my grief was beyond words. Donna stayed cheerful and tried to make me laugh.

Then the nurse came in. She told me I would have to give Joseph a shot in his leg. “I can't do it,” I said.

“Yes, you can,” she replied.

My heart dropped and I began to shake. The nurse filled the syringe. She handed it to me.

“Pinch up the skin, insert the needle, push down, then pull out,” she replied.

Oh! How can I do this? Didn't nurses go to school first? Do they just expect me to start stabbing my baby with this sharp needle?

I inhaled and prayed, Lord, please help me. It took two nurses and my sister to hold him down. I pinched his thigh and inserted the syringe. The needle dangled there until I yelled, “I can't. I just can't do this.” The needle fell from his leg.

The nurse was calm but firm. “You must try again,” she said.

Joseph was screaming and screaming. I was crying and crying. "I can't do it!"

"Yes, you can."

I tried again. This time I only pushed the syringe in halfway, pulled it out and threw it on the floor. "Forget it; I just cannot do this."

I ran out of the room crying. In the hallway I tried to compose myself, but it took about twenty minutes before I could return to the room. The nurse took pity on me. She said I could try again tomorrow. Little did she know that I had decided not to even try again. I could not do this alone; I would not do this. Joe was going to have to help me!

I could not stop crying. Every time I looked at Joseph the tears poured from my broken heart. Why my baby?

The room was closing in on me. I asked my sister to watch him. I had to go for a walk. I had to get out of that room.

Walking calmed me. I noticed a young woman standing alone in the hallway. She was crying. I wiped my own tears away. "Are you all right?" I asked.

She looked at me with hopelessness in her eyes. She said, "I don't know what is going to happen to my life next."

"What do you mean?" I asked.

"Well, see my little baby in there? She is only eighteen months old, and this is her second open-heart surgery. But now they have diagnosed her with terminal cancer. She won't see her second birthday. Her father left us because he couldn't take the pressure."

I embraced her. Her plight was so sad. My heart ached for her. She turned and left when the doctor called her name.

My attitude started to change then. I felt fortunate that Joseph only had diabetes.

I continued my walk and came upon a room with children playing. There were at least ten children in the room.

A nurse was in there, as well as some parents. Looking around, I noticed that some children had no hair, some had little hair, and some had baseball caps on their heads. I asked the nurse what was

wrong with these children, and she said, "They all have cancer." It was heartbreaking. The emotions I felt for these children were so overwhelming. I ran out of the room and down the hall where there was a room I entered. I was all alone in this small dark room. I started beating the wall yelling. "Why? Why? Why are all these little children so sick and dying?" My back hit the wall and I slid down and sat on the floor weeping and weeping. As I was sitting there, I felt somehow relieved. I started feeling how lucky I was that my baby was going to live a happy life and that I would be able to be part of his life. I knew that God gave me the two children I asked for, and that he would give me the strength I needed to raise these children. I felt so much better. Seeing those other sick children made me realize how fortunate I was. I was coming to terms with the situation: Joseph did have diabetes. I knew if I did not take care of him, he would die. I had no choice but to face it and do the best I could do.

When I got back to the room, my sister and the nurse were there. I told the nurse that I was ready to learn all I needed to know about giving an injection. So she suggested that I practice on Donna. It took Donna and me about an hour to get up enough nerve to prick our own fingers. Once we got past the finger-pricking stage, it was time to advance to giving an injection. We laughed at each other, because we had never realized how chicken we really were. When Donna finally let me give her an injection, she told me to hurry up and get it over with, but what she did not know was that I had already given it to her. This helped me to overcome the fear that I had of hurting my son.

After seven days in the hospital, Joseph finally got to leave. We were glad to be home!

Still, I felt as though I didn't know much of anything about diabetes. I was scared and lost. We had to call the doctor all the time about everything for four weeks. My husband would not prick Joseph's finger or give him an injection. I would get so upset at him because I had to sit in a chair and put Joseph's legs between mine, holding his chest so he wouldn't move, and give him his injection. Joseph would scream and scream. He made me feel so awful. It

would just make me cry. I hated to do it, but I had no choice. No one else would help me—and I mean no one.

Joe and I would argue because he would not do anything that had to do with diabetes. He would not read about it, go to the clinic with me, prick Joseph's finger, or give him an injection. Joe was just too afraid. But I felt that if I could do it, he could also. The excuse Joe would use is that he was too tired because "he had worked all day." I felt trapped, alone, and very depressed. The future certainly did not look like a very happy one.

When I went grocery shopping it took me 3½ hours. I had to read labels to know the ingredients in everything. It was a chore just to find the right foods that we could eat. Almost everything had too much sugar in it. But after a while, I began to feel that our family would be much healthier by eating more nutritious foods.



OUR DAUGHTER JENNIFER, who was terrified of needles, felt bad that her brother had to have his finger pricked five or more times a day and had to receive two injections a day. When I would take Jennifer to the doctor's office for a shot, she would cry for twenty minutes. I always said how blessed I was that Jennifer didn't have diabetes.

Ever since my daughter was born, she had always been easy to please and quite patient. She was not a demanding child at all. If she wanted something and I was busy at the time, she would just wait until I could get it for her.

Then in January of 1994, 5½-year-old Jennifer came down with the chicken pox. It lasted for about a week, and then Jennifer started to feel poorly again. That night she did not want to eat dinner and wanted to go to bed at six p.m. I thought, Great, now she has the flu. Around ten that night, Jennifer called for me and asked me for some milk. That was quite odd, I thought, because she doesn't like milk. So I gave her an 8-ounce glassful, and she said she wanted more. I gave her more.

"Are you feeling all right?" I asked her.

She replied, "I feel okay." She did not have a fever and looked all right. I went back to bed. At around 11:30, Jennifer called me again. She wanted more milk, so I gave her another glass. At one, again she asked for something to drink. By this time I was getting a little upset. I told her, "It's time to go to sleep, and if you keep drinking like this you will wet the bed."

"I'm just thirsty, mommy," she replied.

This went on every hour until four. Then, as I lay in the bed, I felt that I should check her blood sugar level. I fought with myself for about 30 minutes saying, "No! No! It just can't be. She couldn't have diabetes." I was terrified of the thought of her having diabetes. I didn't want to get up and check her sugar level, but I finally did get up, got the meter, and walked into her room. I didn't even wake her, but I grabbed one of her fingers and pricked it.

She woke up crying. She asked, "Mommy, what are you doing?"

"It's okay, honey, go back to sleep," I said. The count of forty-five seconds seemed like five hours. Then the meter beeped and her blood glucose level indicated 559 mg/dl. My hands turned numb; my heart started beating so fast that I thought that I wouldn't even make it across the room. I ran into our bedroom and yelled, "Oh, my God, Joe!"

Joe woke up from a sound sleep. He said, "What happened? What happened?" I couldn't even talk.

He held me and I said, "It's Jennifer—she has it, too."

"Has what, honey?" he asked, very frightened.

"Diabetes! She has diabetes. It's happening all over again."

Joe said, "No, it's got to be wrong." We both just held each other and cried. We were in such a state of shock. We had feelings of such hopelessness. Why both of our little children? Why?

On the way to the hospital, I held Jennifer and was afraid of how this would affect her now and later in her young life. Even though we were all together in the car, I felt alone again. I knew that our lives would become even more difficult. It was extremely stressful to have one child with diabetes, and now both of my children have it.

The diagnosis was what we thought – Jennifer did have dia-

betes. The doctor told us that our second child had a 5-percent chance of developing diabetes. But this was not told to us until Jennifer was diagnosed with the disease.... Well, maybe it was, and I blocked it.

Jennifer reacted remarkably well to her diagnosis. The injections were difficult for about two months, and then they got a little easier. By 2½ months, Jennifer started checking her own blood sugars. We were so very proud of her! We never forced her—she did it all on her own.

The night Jennifer was diagnosed with diabetes was the time when Joe truly came to terms within himself about the disease. He finally started helping me give injections and checking the children's sugar levels. Joe's support and love have helped our family come through these hard times.



ONCE THE SHOCK of the diagnosis had worn off, the reality of the everyday task began. In our case it happened twice; we got a double dose of reality. I am not going to tell you that it was or is easy, because it is not. It takes a lot of time, patience, understanding and love to raise two small children with diabetes. There have been times when I just wanted to quit.

What made me want to quit was that I knew I was doing everything within my power to keep them healthy and still their sugar levels were either too high or too low.

With time and the doctors' help, the children's blood sugar levels became a little more consistent.

It was extremely hard for me to determine why the children were acting up. Was it because their blood sugars were too high or too low? Or was this just another challenging but normal toddler behavior?

Keeping a balance was my greatest challenge. With juvenile diabetes the usual rules do not apply, as Joe and I learned one morning.

Both of the children were at the breakfast table eating their morning snacks. I was with them in the kitchen so I could see

them. They were happy, both eating and laughing. This made me happy, too.

Then Jennifer spilled her drink everywhere. She stopped laughing and sat on the floor.

I went to her, asking, "What's the matter?"

"I don't know." Her tone was hateful.

Joe overheard her nasty remark. He told Jennifer to go to her room. She stood and went into the living room instead.

Joe was baffled. Why was she acting like this? It was not like Jennifer to be disobedient. He went to her and, in a stern voice, he insisted that she go to her room.

Jennifer ran to her room.

Joe followed her. She was sitting on her bed crying. He tried to talk with her to encourage her to tell him what was wrong. She would not listen. Then Joe lost his cool. "Jennifer, stop crying!" he yelled.

In an instant he yelled for me. "Vicki, hurry. Hurry up! Something is wrong with Jennifer. She is looking right through me." I grabbed the glucose meter and some juice and rushed to them. I took her sugar level; it was very low. I had to coax her to drink some juice and eat some crackers. It took about 35 minutes for her to recover completely.

When the crisis passed we talked with Jennifer about what had happened. She was shocked. She could not believe what had happened, nor did she remember spilling her drink, yelling at us or any of the events. To this day, Jennifer insists those things never happened.

This crisis taught us a lot. At the time of the incident Jennifer was incoherent. She was very close to being unconscious or having a seizure. Joe felt bad about scolding her and not being able to see what was happening to her. We both felt guilty. It took us days to get over this incident and to learn from it.

From that day on, we always ask ourselves: Are the children acting up because they have a blood sugar problem or because they are just kids? If we are not sure what is going on with them, we check their blood sugar first and deal with them accordingly.

It is one thing to deal with normal childhood behavior, but

blood sugar swings are stressful for all of us. This situation is difficult to handle. One minute the children can be laughing, having a great time, and the next minute, a sugar fluctuation occurs and things can be almost out of control.

As the Boy Scout motto recommends, I've learned always to be prepared.

I remember one afternoon in particular when I took the children horseback riding. It was just after lunch, and Jennifer's blood sugar tested at 325 mg/dl. I gave her an injection, with one unit of regular insulin. The fact that she had eaten only half of her lunch concerned me. I could not get her to eat more, but she had plenty to drink so I felt she would be fine until snack time.

We rode the horse around the house. We had been outside for about an hour. Jennifer said that her legs were shaking as she was sitting on the grass. I did not think her blood sugar level was low because at lunch it was so high.

Since we were just a short distance from the house, I was not too concerned that I had not brought any glucose or sugar foods with us. I would soon learn another valuable lesson about managing juvenile diabetes.

Jennifer started to cry. Quickly I put her on the horse with her brother, then guided them straight to the house. Jennifer jumped from the horse and fell to the ground. I ran inside the house for some juice and the meter.

By the time I returned to her, she could hardly drink her juice. She kept crying, "I can't, I can't." Immediately I checked her blood sugar level; it was very low; 32 mg/dl. As she drank, she slowly returned to normal.

Now I never leave the house without some glucose tablets or a juice drink. It is just too dangerous to go anywhere without an emergency kit of food.

Coping with juvenile diabetes is an ongoing education. Just an ordinary experience such as taking the children and their friends to the country club pool for an afternoon of splashing and fun can change dramatically in a moment.

In the back of my mind I was always afraid of their having a

seizure, and I kept the glucagon kit close whenever we were away from the house, always hoping that I would never have to use it.

But one sunny day at the pool turned frightening immediately after our picnic lunch.

I put sun block lotion on the children. When it was Jennifer's turn for me to apply the lotion, she shrugged me away.

At first I thought she was just being contrary. Still, I took a mental inventory. She had eaten a snack at 11 a.m. and her blood sugar level tested 144 prior to leaving the house. She was just now eating lunch and had not been in the pool yet, so everything should be okay. Yet each time I tried to touch her with the lotion, she fidgeted away.

She did the opposite of everything I told her to do. I told her that we needed to check her sugar level. I asked her to come down by the porch where there were fewer children. Instead of doing what I asked of her, she went into the pool. I ordered her from the pool. She staggered toward me. It was like watching a movie of a drunk person trying to act sober. She crashed into the chairs, she tripped over her own feet, and there was a blank stare in her eyes.

I yelled for her to sit down. At that point my worst fears surfaced. I dropped the emergency kit and grabbed her. She tried to push me away. We were both on the ground. I struggled with the emergency kit, trying to get some glucose tablets. I couldn't unzip the kit and hold her down, too. I was shaking with fright. How could I do this by myself? No one at the pool offered to help.

Finally I opened the kit and the tablets spilled all over the place. I grabbed one and tried to get Jennifer to eat the tablet. She tried, but it dribbled down her chin. She could not swallow. This is common during a seizure. I tried other things; still she could not swallow. I knew that I had to use the thing I feared the most, and that was the glucagon emergency kit.

It is frightening to learn on the scene, with your child in trouble. It was difficult to work with one hand as I had to hold Jennifer down with the other hand. To administer the glucagon I would need to unseal the bottle, inject the syringe fluid into the glucagon, remove the syringe, shake the bottle, then reinsert the

syringe for a dose of medicine. In my panic all I could withdraw was air. I simply could not get any fluid. I started to cry. My child was kicking and screaming. The other people at the pool were staring at us. Still, no one tried to help. I thought, There is no way I can do this alone.

Then I looked at my daughter and knew I had to make the glucagon work. At that point I wrapped my legs around her to lock her down and free both my hands. I stuck the syringe back into the glucagon solution and was able to get only a quarter of solution and a lot of air. With the needle pointed up I removed the air, reinserted the needle and withdrew a proper amount of medicine.

Next I injected Jennifer with the medicine. She screamed and pulled away. All I could do then was hold her and comfort her. We had to wait for the medicine to work.

I tried to be brave, but I could not hold back my tears. I held her and spoke softly until I could tell she was reviving.

What I learned from this terrifying incident was to practice these emergency procedures frequently so that I would be better able to cope.

Sometimes diabetes gets overwhelming, but we count our blessings because we have each other for love and support. I know that our children will be able to run, laugh and do anything that other children can do. They just need to monitor their blood sugar levels, take their insulin, exercise and eat a well-balanced diet. Our entire family has begun to lead a healthier lifestyle.

I know in my heart that I am doing my best to educate my children about diabetes, letting them know that they can control their disease. Diabetes does not have to control them. Life can be wonderful, even after the devastating news.

I know there are times when you think you won't be able to get through the day, but somehow you do. You should be proud of yourself because caring for a child or children with diabetes is not easy. You are not alone. We are all going through basically the same difficulties. Try to find a support group near you or, if you can, find a family member who would be willing to help you through the tougher days.

Don't give up because the child has diabetes. As hard as this may be to believe, you will find that you will become much closer to the child. You will know this child so well. My husband and I cherish every new day that we have to share with our children. Our lives are much richer because of what we have been through and have handled together. I am truly blessed with such wonderful children.

My husband and my children are my greatest loves. We need to give our children a lot of love, patience and positive encouragement. You will feel wonderful when you see your children lovingly enjoying life in spite of their diabetes. Remember, with the right management of their diabetes, children can do anything they strive for. Nothing should stand in their way.

My life is now devoted to my children and family. They come first in every aspect of my life. To me, there is not a job on earth that is more important than raising children. What greater gift in life is there than giving children all the opportunities that life offers! Through the support of a loving, attentive family, success in life will not be diminished by diabetes.

God bless you. You are the reason I wrote this book. I pray this book will help and encourage you as a family to live each day to its fullest. Life has many beautiful things to offer and children have many things to share.

Treasure life.