


FAMILY PERSPECTIVES ON PREMATURITY



Editor's Note: Perhaps the most meaningful perspectives on prematurity are those offered by the families of premature babies. Their perspectives vary, one from another, and shift over time, depending on each family's circumstances and the baby's developmental course. The family members who tell their stories here responded to an invitation to Zero to Three readers or were referred to us by their friends. We welcome additional family stories for publication in Zero to Three or posting on the ZERO TO THREE Web site.

Little Man

Nicole Conn and Gwendolyn Baba

March 15, 2002. After an emergency C-section at 25 1/2 weeks, our son, Nicholas James, is born. He is the size of a portable phone, with the heft of a bottle of Coke: 10 1/2 inches; 475 g.

The delivering doctor from the neonatal intensive care unit (NICU) forewarns us that in all her years, she can count on one hand how many babies his size have made it. He's known as an "under 500-grammer." She tells us, "There is no book on your baby. No research. No data." There are so few who survive that the government does not recognize them statistically.

Four surgeries. Two "codes." Chest compressions. Collapsed lungs. Six different ventilators. Oscillators. Hundreds of suction from the lungs. Needles in every conceivable vein. Heel sticks until the foot looks like swollen strawberries. Excreting feces from the stomach. Eight centimeters cut from the bowel. Thirty blood transfusions. Four kidney failures. A spinal tap. This is our son's first month of life.

In the NICU, a respiratory therapist whispers eerily, "We call it baby hell"—her intonation implying, "where nothing is impossible and everything is surreal." This is the world where one can count on nothing. Within hours of Nicholas's initiation into this strange habitat, he is strung up to so many wires, needles, monitor leads, and a huge endotracheal (ET) tube that I can barely see his monkey-bird body. The tears stream down our faces.

Who are these insane and gracious creatures called nurses? These woman and men who are primary caregivers, who become your best friend, your therapist and partner? They tend to these splayed-out fetuses, triage the preemies' continuous medical emergencies, and still see the humanity beneath the gelatinous glaze of their skin. These people, like no others, feel our son and immediately accept and embrace him.

Nicole: An irony of huge proportions: One day I joked with my partner that I was too impatient for the entire gestational process. "Wouldn't it be cool if babies were born like after 20 weeks and you could just hold them in your palm? Put on little play diapers?" But God has topped even my freakish imagination. Destiny has played a twisted joke, granting my desire at 25 weeks.

Before my introduction to the NICU, I would change the channels as fast as I could if I saw a preemie on TV. I'm ashamed to say that they gave me the willies. Now, I hear the whispers behind my back. Friends have actually backed away upon seeing the curled-up fetus for the first time—that's what he is. No matter how many times they see the pictures of our son, visitors blanch when they see what no eye is prepared to see. But to me, he is beautiful. They say I see him with a mother's eyes, for I find Nicholas nothing less than exquisite, with his silky cashew feet, 2-centimeter-sized heart, and plum-sized head laced with the crinkly wrinkles of a sage tribal elder.

At Nicholas's 6-week assessment, we ask our attending physician if we're hallucinating that our son hasn't grown in all this time. We are not. Because he has barely finished one crisis before he starts another, Nicholas has never even had what is called maintenance calories. This same doctor tells us sadly that in Nicholas's first multi-doctor conference, the physicians concluded very quickly that Nicholas "would never make it." But it is now weeks later, and Nicholas is still fighting the good fight.

On Nicholas's 87th day of life, he codes for 12 minutes. Has cardiac arrest done irreparable damage?

Nicole: I almost step in three different times to stop the dedicated staff during the agonizing effort to resuscitate Nicholas. But I stop myself each time as his heart rate recovers. A nurse says

he's coming out of it. And, indeed, after 12 minutes of unconsciousness, his eyes meet mine.

Of the more than 4 million babies born in 2001, 1,200 of them weighed less than 500 g. Only 15% of these infants survive. In 2002, Nicholas is the smallest surviving patient born at Cedars Sinai in Los Angeles.

After 5 ½ months, Nicholas goes home from the hospital. At 15 months, he weighs only 13 pounds—a 13-fold increase during his life. He still deals daily with the continuation of multiple monitors, but every day he continues to grow.

Nicole: *I'm currently in post-production on **little man**, a documentary chronicling the struggles (before and after) the birth of our son. His story—our family's story—remains like so many who experience the NICU—largely untold. The production has unprecedented access. No cameras are allowed in an intensive care unit.*

little man is more than just a story of our son's survival. It is the story of a family's destruction and reclamation, of Gwen's terror upon knowing I will have this child at all costs and against every doctor's admonitions. It is a story of catharsis, a journey filled with questions that haunt in the night: What price life? When does caring become cruelty? Where is the fine line between medicine and miracle?

She Is a Wonder

David Shoob

There are times I feel as if I am married to one of those 1850 Old West pioneer women.

Kerstin, my wife, and I were at an ice cream parlor in Phoenix on November 3, 2001, discussing the odd cramps she was experiencing. Alana, our then 3-year-old daughter, was amusing herself by pouring salt on her ice cream and the table. Our second child, gender unknown, was to arrive on January 13, 2002.

The day was a long, painful one for Kerstin. We called the on-call OB from our physician's office, who spoke of the very normal symptoms of pregnancy my wife was experiencing. Kerstin lay down for the bulk of the day and, though quite



PHOTO: DAVID SHOOB

uncomfortable, avoided taking any type of pain reliever, as she is *au naturel* while pregnant. We talked about going to the hospital but decided to call the OB again. He reiterated the no-sweat outlook.

That night at 1:00 a.m., Kerstin took it upon herself to drive 14 miles to the neonatal specialty facility in Phoenix. Within 20 minutes of arriving, she gave birth to a 3-pound girl. The delivery team said that our daughter virtually fell out. Kerstin called and left me a message (I slept through the ringing) telling me this. I awoke in the early morning, heard the message, and responded with "what? What?! WHAT??!"

We already had names chosen. Natasha Elle Shoob is our early bird's name. She arrived 10 weeks premature but required oxygen for only 4 hours, as her lungs were remarkably well developed. She remained hospitalized for the next 5 weeks, 3 in the NICU and then 2 weeks at a hospital near our home. For the first 10 days, Natasha had jaundice, which was relieved by sun lamps placed around her crib. (She looked like a skinny rotisserie chicken.)

Kerstin recovered from the delivery quickly but was, obviously, quite concerned about Natasha's health. She would drop Alana off at preschool in the morning and go to the hospital for 3 to 4 hours. When I arrived home from work, Kerstin, Alana, and I would drive to the hospital to spend a couple of hours in the evening with Natasha. It was killing us that our little girl couldn't be at home with us. Of course we knew how fortunate we were: Here was our baby, born 10 weeks early and, by all outward appearances, healthy.

Thankfully, Natasha continued to do well. Week after week she gleefully took to her mother's breast and gained weight steadily. Hearing, vision, and awareness were all right on target. I felt as if we had won the lottery. She was so minute and fragile that I was almost hesitant to embrace her. Kerstin and Alana were not so apprehensive.

Five long, taxing weeks passed. On December 15, Natasha was at last cleared to go home. An odd, wonderful adjustment period followed. Our little peanut was sleeping in our room, rather than across town. Developmentally, Natasha continued to demonstrate fantastic improvement. Physicians and other medical professionals offered positive comment after positive comment regarding her status. In addition, everyone we knew seemed to have some story about a preemie in their family. I found it amusing that most of these preemies were now described as 6 feet 4 inches tall and weighing 240 pounds—regardless of gender.

Natasha is now a shade over 20 months. She began walking at about 15 months and running at 15 ½ months. She has a superb sense of humor and is an extremely loving little girl, particularly toward her sister (who is quite loving in return). Her language is developing well, her favorite word being either "Mama" or "candy."

I suppose Kerstin and I view Natasha as slightly fragile, but she would disagree. She is very bright and is the owner of a smile that would bring peace to the Middle East. (See the photograph at left).

We had a tumultuous ride those first few days and months of Natasha's life. Fortunately, Kerstin and I are both pretty relaxed people who, for the most part, anticipate good things happening in life. Owning those feelings made a potentially unbearable situation a bit more manageable. Natasha entirely reinforced that outlook. She is a wonder.

Lisa

Vicky Youcha—Lisa's mother

Twenty-three years later she moved to Florida without me. I didn't have a good feeling about this. Getting organized was always hard for her. Her spatial perceptions were poor; she could never see how things fit together. Many tasks took her a long time. If she felt rushed she just got more disorganized. She had never moved without incident, or without me. She'd missed planes, left belongings behind, and generally been stressed each time.

I knew why—she was a preemie.

Born 10 1/2 weeks early, weighing just over 2 1/2 pounds she looked like a scrawny Cornish game hen. My connection and guilt were immediate. The chart on the wall of the NICU reported a 50–50 chance of survival. I ran an early intervention program and she was my nightmare come true. I didn't want my daughter to look anything like the squashed-face portraits of the successful NICU graduates. I knew everything that could go wrong.

Lisa came home just before her due date. She weighed 4 pounds, 12 ounces. At 1 year she weighed slightly less than 15 pounds. Her tongue stuck out of her mouth and she was bald. When she walked, at 18 months, she dragged one leg. She wore a brace and she drooled. She got frequent stomach bugs and could get dehydrated in half a day. When she took swimming lessons she was purple in less than 5 minutes.

Later she spent 4 hours each night doing third-grade homework. In high school it finally dawned on her that she spent way more time studying than any of her friends. When she learned to drive she had no idea how to tell where the car was in relationship to the road. She couldn't read a map.

I knew why—she was premature.

The connection and the guilt have continued. I always needed to be there with a towel to warm her up, hot chocolate for late-night studying, and boxes and tape to move in and out of dorm rooms. This time I wouldn't be there. It didn't matter that she was 23 years old and a Phi Beta Kappa college graduate. It didn't matter that she had lived and worked independently for a year since college. It only mattered that she was born early.

So, she moved to Florida. She couldn't fit everything in the car and had to delay her departure so she could ship more boxes (and had to spend a night in a motel so she could ship *more* boxes). She was angry that she had to move alone. But she drove from Pennsylvania to Florida, found an apartment, and started her job as a newspaper reporter on time. Maybe, I thought, she will be OK after all.



PHOTO: VICKY YOUCHA

So I told her I was writing about having a premature baby, and I asked if she would like to write something.

She said she really had nothing to say.

She said she would never have known she was premature if I hadn't told her.

Lisa's Sister

Sarah Rab

My sister was early. I don't want to sound like I'm complaining, but, well, I am. We weren't expecting her so soon. It was less than 2 weeks before my third birthday, and the party plans were in motion. The baby wasn't supposed to be born until the end of March, and it was only January.

And suddenly, one night, out came Lisa. I'm sure it wasn't quite so sudden for my mother, I'm sure the delivery gave her some time to prepare—but as far as I was concerned, BOOM, there she was. All 2 pounds of her, a little baby birdlike thing, born 8 days before my birthday. Talk about unfair! The party was cancelled, and as a consolation prize I got a box of Mike & Ikes from the hospital vending machine. My parents were busy at the hospital for several months to come.

And that's pretty much how I've viewed Lisa for the last 20 years—BOOM. She was early, for the first and only time in her life. She was thin and small, a figure she got to keep while I grew curvy and gained weight. She had the elements of surprise and danger on her side—she was a precious, delicate thing that the family was grateful to have and afraid of losing. And I was just a normal baby, 2 days late in fact, maybe even a bit overweight.

Talk about premature! I wasn't ready for a little sister, let alone a "special" one. I know parents are always concerned about a sibling's reaction to a new infant, but good luck preparing a toddler for the introduction of a preemie into the family. I wasn't prepared, I never coped, and now I'm 26 (and the firstborn!), trying to tell you that to me, she's still a preemie—and I'm still not ready.

The Crucible of the NICU

Catherine Thomas (with gratitude to Marjorie Gellhorn Sa'adah)

When I was in a graduate program on infant development, my class took a field trip to visit a NICU. A cavalier first time visitor, I was stunned by the technology required to care for such tiny babies. I saw an infant with translucent skin, hands the size of dimes, and I fainted.

Now I see tiny babies every day. For the last 7 years, I have worked as a developmental specialist in the Follow Up Program at a level III NICU. On a typical day I see 3 children for extensive developmental evaluations. Parents and I discuss their concerns and questions, and I make referrals for early intervention and therapies.

This work sounds straightforward, but it often feels like witnessing a profound shift. In the hospital, parents are confronted with an unfamiliar culture, and each moment can become concentrated, even as the days stretch into months. Out of the spotlight and acute medical crises of the NICU, families are faced with a different challenge entirely. They are making meaning of their hospital experience, integrating it into the stories of their lives, and living out their transformed histories.

When I'm asked to present the Follow Up program to my colleagues, people want to know the facts about how premature babies fare developmentally, 2 years postdischarge. Medical staff are particularly interested in statistics, but I always bring a video excerpt of a 2-year-old doing the test, to give life to the numbers. While discussions about data can inform clinical practice, the deeper questions generated by this work are much more subtle and intangible.

Here are the questions that tug at me:

- How do parents come to comprehend medical events that seem random and incomprehensible?
- Which NICU moments will become salient, pulled from the chaos and set down into story?
- How do parents reclaim power by articulating "This is what happened to my child, to me, during our time in the hospital"?
- How can NICU staff hold memory, bear witness, and keep company with families?

I would be remiss in writing of my experience with ex-preemies if I did not mention that I had 3 miscarriages while working in Follow Up. My grief was huge, heavy, and baffling. Without knowing my situation, mothers of NICU graduates told stories that sustained me. One woman, whose son had been recently diagnosed with cerebral palsy said, "What I thought would be impossible has become the everyday." And another, in describing the process of persevering through her child's liver transplant, "Not everyone gets the chance to step up to the plate and show her best self in the face of crisis. It's a privilege for me." A parent of twins revealed, "Now that the

kids are 2 and I have a sense of what the future holds, I can finally relax a little, but I'm falling apart. I'm wondering if I have post-traumatic stress syndrome." Their courage in the crucible of the NICU experience and its aftermath spoke to my own despair and offered gentle guidance.

Because I've come to value the impact of story to illuminate a life and alter its direction, I try to ask questions of families that will spark emotional memory and generate authentic discussion. How did the first few days and weeks at home with your baby flow? How does a typical Saturday unfold at your house? How will you talk to your child about her time in the NICU? What are the questions about your child that weigh on you?

But there are other questions, the ones I yearn to ask and don't, because they seem too penetrating. What if I asked, "Tell me about the baby you imagined. How is this child different? How do the image and the actuality intersect?" What if I asked, "What is it that you truly need, that your heart desires, that is your unspeakable yearning as a parent?" What if I asked, "Would it help if I revealed more of myself, if I shared with you other parents' stories that will leave an imprint on your own?"

Families have graciously shared with me their stories of alchemy, where the history of early hospitalization becomes a seminal, guiding myth for parents and child. Where trauma and despair are reconstituted, sometimes years later, into a tale of wonder and endurance. The media barrages us with images of NICU "miracles," tiny survivors who are growing up despite the odds. Let us remember that there are deeper, more plentiful—but never common—miracles.

A Tale of Two Preemies

Regina Obey

"As big and healthy as you and your husband are, I don't know why you can't have a full-term healthy baby." The doctor was frustrated. He predicted that this time my pregnancy would be different—different from my experience with my premature firstborn.

We all understood why Nichole came early. When I conceived her, I already had a fibroid tumor the size of a 2-month fetus. Each month, the tumor grew more aggressive, feeding off of the blood supply and space that should have been reserved for the baby. The doctor suggested that we not buy anything in advance of the baby's birth. He just wasn't sure if she could survive the tumor. He didn't suggest we take Lamaze classes, because he was certain that the baby would have to be delivered by C-section. There was no way she could naturally get past the tumor, which at 7 months had grown to 10 pounds.

But the doctor was wrong! On May 24, 1983, at 4:40 am, my husband, Nat, rushed me to the hospital. The doctor thought we had time, and asked the intern to call him to confirm that I was in labor. The intern did call, extremely upset, because I was already 6 centimeters dilated. The delivering

doctor finally rushed in, checked on me, and then made one more wrong assumption. He thought he had about 10 minutes to get a cup of coffee. One last scream/push, however, and Nichole slipped out on her own and lay breathless on the delivery table. Nat screamed for help and they whisked the baby away. What happened to that picture-perfect moment, reserved for new mothers, when their baby is laid upon their breast for the first time? It doesn't happen when you have a preemie. Other things take priority. You have barely seen your baby's face when suddenly the moment is replaced with fast-moving doctors, nurses, monitors, hospital jargon, tubes, respirators, and a period of paralyzing uncertainty.

It was about an hour later that the doctor came to my room and gave us the good news. Nichole was doing fine. She was 4 pounds, 10 ounces and after about an hour was able to breathe on her own. We were able to take her home, but I had to return in a few weeks to have the 10-pound tumor removed.



PHOTO: REGINA OBEY

Well after Nichole's delivery, I still looked pregnant.

Now, 5 years later, I was at Howard University Hospital with the same doctor. He is a wonderful gynecologist who is passionate about babies and who worked diligently with me through the process of infertility. We had been trying to have a second child for 3 years. The last year I had been placed on double-dose Clomid. I had finally conceived, and my doctor was certain that I would carry a huge baby. He did at least two sonograms and joked about how big the baby "boy" would be.

One month before my due date, on December 5, 1987, I lay across my bed and began to feel a very unusual sensation. I looked at my clock and, oddly enough, every 4 minutes the flap on the digital clock would drop, and I would feel that strange flutter. There was no pain, just the same sensation exactly every 4 minutes. I called my doctor. This time he was extremely responsive. He insisted that I come to the hospital immediately. (Since I had had the tumor removed in a C-section-like procedure, it was not wise to risk having my second child vaginally; the incision could burst.) So once

again, we rushed to the hospital. I was immediately placed on a monitor, and staff confirmed that I was in labor. Although 5 years had passed, the doctor remembered his miscalculation with my first childbirth and declared that he would not be fooled again. I was prepped for a C-section delivery. Nat was in place with the video camera, and the doctor was ready to deliver a huge baby boy.

Instead, Natalyn was born. She weighed 5 pounds and was in extreme distress, unable to breathe on her own. The flurry of staff activity began once again. Something was very wrong with either Natalyn's lungs or her heart. They weren't sure. (They later discovered that one of her lungs was not fully developed.) Again my baby and I had had no bonding moment, but this time there was no clear explanation why. There had been no tumor; she was only 1 month early. A neonatologist came to my room often and gave me updates regarding their consultation with Children's Hospital. He even stopped in once at midnight. But he never said that Natalyn might not live, and I never understood that her survival was in question. Why didn't I realize the severity of the situation? I think it was because I already had a preemie. Nichole was now 5 years old—vibrant, healthy, and with no signs of long-term complications. She was, in fact, both tall and large for her age.

So I would waltz down to the NICU and marvel at Natalyn, my little miracle. Some of the other babies in the NICU were one-third her size. After I visited with another mother who literally held her baby in the palm of her hand, I became even more confident that Natalyn's problems weren't too severe. Three days after her birth however, the neonatologist entered my room and announced, "We think your baby's going to live." I was in shock—what was he talking about? He saw my surprise and said that he had been wondering why I had been visiting the NICU with so little worry. I didn't *know* to worry. I had learned that babies are extremely resilient. Doctors do the best they can, but there is uncertainty and individuality with every baby and with every birth. When it was time for me to be discharged, it was hard to leave Natalyn in the hospital. It did help that we were able to bring Nichole to the NICU to visit her baby sister. We would joke that Natalyn was still in the oven cooking because she had been placed in an incubator under a bright light for jaundice treatment.

On December 17, after much prayer, we were able to take Natalyn home. She was the best Christmas present ever—a little sister for Nichole. Nichole's biggest concern: "I hope she's going to stop crying soon; we're sharing that room!"

Every Question is Important in the NICU—Lessons Learned by a Grandparent/Neonatologist

Alan R. Spitzer, MD

Recently, after 25 years of academic practice in the field of neonatology, or newborn medicine, I found myself on the

other side of the NICU experience. My daughter-in-law, Jennifer, suddenly and unexpectedly delivered 10 weeks early after a completely uneventful pregnancy up to that time. Jacob, my first grandchild, rapidly developed severe respiratory distress syndrome (RDS) and became very ill. He required mechanical ventilation for more than a week and later developed bronchopulmonary dysplasia, remaining oxygen dependent for the first 7 weeks of his life. In addition, he suffered an intraventricular hemorrhage, or bleed in the brain, provoking serious concerns about his long-term future.

As the grandparent of that particular 30-week baby, I had the opportunity to learn a great deal about what it is like on “the other side” of the NICU experience. It was one of the most challenging periods of my life—hoping each day that my grandson would recover, while watching my son, my daughter-in-law, and my wife try to cope with a life experience for which one can never truly prepare. Furthermore, it made me aware that it is even more difficult to experience an illness in your grandchild than to have your own child as a patient. When your own child is ill, you are forced to directly confront the circumstances; but when your grandchild is ill, you not only experience the pain of the baby’s illness, but you must cope with the sadness and anguish of your children as well. Grandparents therefore have a unique position when their grandchild is a NICU patient. In my own case, the circumstances were even more unusual, since I had the combined responsibility of being both a grandparent and a neonatologist, the daily role in which I oversee the care of critically ill newborn infants.

In this instance, though I did not treat my grandson directly, everyone in the family seemed, at times, to hang on my every word or gesture to a disconcerting degree. If I did so much as frown when I received some news about Jacob, my wife would get teary, my son would become anxious, and my daughter-in-law would begin accumulating a series of questions to ask me when the time was right. The psychological support that I needed to offer them, as well as to our extended family, was considerable and more than I would ever have anticipated.

In addition to the emotional issues that affected my family, I gained a great deal of insight into many of the daily stresses that I never fully appreciated from the perspective of a neonatologist. When I was able to gather my courage to call the NICU to learn about the Jacob’s condition, for example, and a clerk accidentally disconnected me four times in a row, it seemed as if my phone call was trivial and unimportant. If the nursing staff either avoided me because of their nervousness about my background or answered one of my questions with a series of irrelevant, meaningless observations, it raised concerns for me about the confidence of the staff and the quality of care that my grandson was receiving. Even if the care were excellent, this level of thoughtlessness only served to undermine our faith in the staff’s abilities and made us wonder if he was in the right hospital.

Ultimately, Jacob began to deteriorate clinically, and his oxygen requirement progressively increased each day. Until that time, I had tried to avoid directly questioning his physicians about his care, preferring to remain a grandfather and not a neonatologist. At that point, however, I felt compelled to call his attending physician to gain some insight as to what she thought was happening and what his chest X-ray showed, since my son was so distraught by this change in the baby’s condition. When the attending physician angrily and incomprehensibly dismissed my concerns and curtly hung up on me, I finally realized that I had to make some critical decisions on behalf of my son and my daughter-in-law, but, most importantly, for Jacob’s future.

Finding myself in this situation was not easy, and my objectivity was greatly tested. I knew that I could not unilaterally make such a decision because of my obvious emotional involvement. I therefore decided that the best approach was to gather a group of my neonatology colleagues and senior members of the nursing staff and present the situation to them with one primary question: Should I transfer Jacob to our NICU at Stony Brook? After a brief, but emotional discussion among everyone present, the Director of Maternal–Infant Nursing looked at me very directly and said, “If you don’t transfer the baby, each time that you look at him for the rest of your life, you will hate yourself.” This compassionate, insightful response was exactly what I needed, and we sent the transport team for him that same day. Although his recovery felt excruciatingly slow, my colleagues and the nursing staff did a superb job of both caring for him and helping my children begin their lives as parents of a beautiful child. Today, at 11 months of age, Jacob is thriving, hitting normal developmental milestones, and he has become a joyous focal point of our lives.

I will never know what might have happened if I had not intervened and moved him to Stony Brook. Even today, as glad as I am that I made the decision to transfer him, I find myself dismayed that I had ever needed to take that step. All that I wanted was to remain in the background and support my family during a very difficult time, while allowing his doctors and nurses to do their work. But when relatively simple questions are trivialized, or when unwarranted anger is directed at a concerned parent or grandparent, it becomes impossible to maintain confidence in the care that a child is receiving, no matter how superb the care is.

Our work in the NICU demands that we address the needs of the family as much as we provide medical treatment of the baby. To do anything less is unacceptable. From a parent’s perspective, there is never such a thing as an unimportant question. To lose sight of the obligation to respond to parents demeans the medical profession as a whole. Although my grandson is only 11 months old, he has already managed to teach me a great deal about our responsibilities in medicine—especially toward families and what they require from us. These are lessons I will never forget.

Advocating for Yourself

Amy Nicholls-Swanson

When I found out I was pregnant, I had no idea that my experience as a child and family advocate would come in so handy. I learned, however, that the tools of advocacy work not only in the legislature, but also in the hallways of hospitals and other medical facilities.

When my water broke early in April, I was surprised. Doctors had closed my cervix (cerclage) at about 24 weeks, so even though I was expecting my son to come a few weeks early when they removed the stitches, I certainly wasn't expecting him to arrive 6 weeks early! Getting pregnant was a challenge for me, after suffering for years with endometriosis. However, due to the excellent efforts of my OBGYN, and with a little help from Mother Nature, I was pregnant. Then the real worrying began. In 2000, I had miscarried at 15 weeks, so my husband and I were extra-cautious—but still optimistic.

My first trimester was a breeze, but my during my 15th week I received positive results for my tri-screen for spina bifida. The next week I started to bleed, so my doctors scheduled a high-risk, targeted ultrasound. Thankfully, the news was good. The baby didn't have any problems and was progressing nicely. I, on the other hand had an "incompetent cervix" and was likely to have this baby really early if they didn't do something to stop it. So, a cerclage was "installed" during my 24th week of pregnancy. Painful, but necessary to keep the cervix closed and our baby boy "baking." Cerclage stitches are generally removed during the 36th week, so I was confident that I would carry at least until then. I breathed a sigh of relief.

But the relief was short-lived. Several weeks later, I flunked my glucose test. And, while I had expected a borderline result due to family history and the number of M&Ms I was consuming, I hadn't expected to fail the test flat! So began my weekly stress tests. Which actually were a rewarding—20 minutes of being in a quiet, dark room listening to my baby's heartbeat. You really can't beat that. But on one of my test mornings, I knew that something wasn't right. Now I know that what I experienced was my water beginning to break. At the end of my visit, the doctor told me that everything was a false alarm. But 20 minutes later, standing in our driveway, my husband and I realized that what was happening was no false alarm—it was a true emergency. I was on my way to the hospital.

At that moment I did not realize how valuable the lessons that child and family advocates learn would be to me and my family, nor how important organizations that advocate for infants would be to me. So, instead of sharing all of the details of Holden's birth and my experience, let me offer mothers on bed rest and parents of premature babies some tips from the front line. (As a side note, these tips also work when dealing with elected officials!)

- Introduce yourself to your caregivers. Treat hospital staff as part of your extended family. Believe me, after



PHOTO: AMY NICHOLLS-SWANSON

a few weeks when your "charm" has worn off and your real family members find you not so amusing anymore (or the hospital parking frustrating) you need the support of these people.

- Ask questions. When in doubt, don't hesitate to ask. There is an old saying: "The body is a temple." Whether or not it is a temple, it is your body and, you should know what is going in it. Remember, the nurses and doctors are taking care of hundreds of patients. It is better that you ask now, or forever hold your peace. Speak up, ladies and gents (yes, that includes spouses too)!
- Read and reflect. You receive a tremendous amount of paperwork and literature on premature babies, you should read it, put it down, and reflect on it. Don't hesitate to ask your caregivers for additional information, or to share stories of situations that they have seen over time. Sometimes the information in these materials is a little scary, so don't absorb it all immediately, you've got time, so take it and reflect! In my opinion, the March of Dimes produces the best materials—read these first!
- Communicate what you need and want. Don't assume that people know how things make you feel, or what you want. This includes things like: cart showers and having your hair washed; popsicles during delivery (they cost \$10 each, but they are the best \$10 you'll spend your whole pregnancy); a portable toilet instead of a bed pan (believe me this sounds strange, but you all know what I'm talking about here); and snacks.
- Thank everyone. Send thank-you notes with pictures of the baby. In the hospital, you'll end up with more flowers and treats than you'll know what to do with. Leave some there when you go home. Believe me, about a week later, when you're picking petals off your kitchen floor, you'll wish you had left more flowers behind for everyone to enjoy! 💡