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Diary of a Birth

SEATTLE, Washington August 25 1997

By Pramila Jayapal

Once in a rare while, we experience something that tests the core of our emotional fiber. It challenges us to question our sacred beliefs. It tears down the elaborate screens we erect to hide our human failings. It forces us to find stability in places we had not looked before, to learn to breathe calmly when we feel we are gasping for air. It teaches us the long-lost ability of living day by day.

On February 27, 1997, our son, Janak Jayapal Preston, was born in Bombay, India. At the time of his birth, he had been in utero for only 27 weeks, just two-thirds of the time that a full-term baby has before she or he has to face the outside world. Janak weighed one pound 14 ounces (850 grams) at birth, and measured 13.5 inches long.

It is ironic that our son was born in India. India, my partner — sometimes hidden, always alive in my mind. India, whose role in my life I had returned to reconcile. India that brought me back to who I am — as an Indian and, ultimately, as an American. Perhaps he wanted to be born in India, as many of my friends said when they heard of his early birth. Perhaps he will go through his own struggles of identity with this strange, marvelous country, as I have done.

In a way, Janak's birth cut my fellowship short. Without a goodbye to Varanasi, where we had lived for six months, to Northern India, which we had explored for two years, to our friends to whom we had given our hearts through our travels, we left. We left for Bombay, a city we had never wanted to be in. Now, in our time of need, we embraced its relative modernity and access to technology. We existed in Bombay, noticing very little around us — a complete departure from the way we had immersed ourselves in India for the previous two years.

And yet the whole experience of Janak's birth and the months that followed was the ultimate fellowship experience, the ultimate "immersion" in India. We would never choose to go through such an experience again. But then perhaps the greatest lessons are learned through experiences that happen only once — and not out of choice.

This newsletter is my recollection of the whole experience of Janak's birth and the time after. In some ways, I feel selfish writing a lengthy newsletter about this personal and emotional experience. It is my purging of the experience, tales that I told to people in bits and pieces but that were too difficult to relate fully at the time. It will also be Janak's remembrance one day of how he came into this world. Ultimately, I decided to write this newsletter because Janak's birth was my last and one of my most important fellowship experiences.

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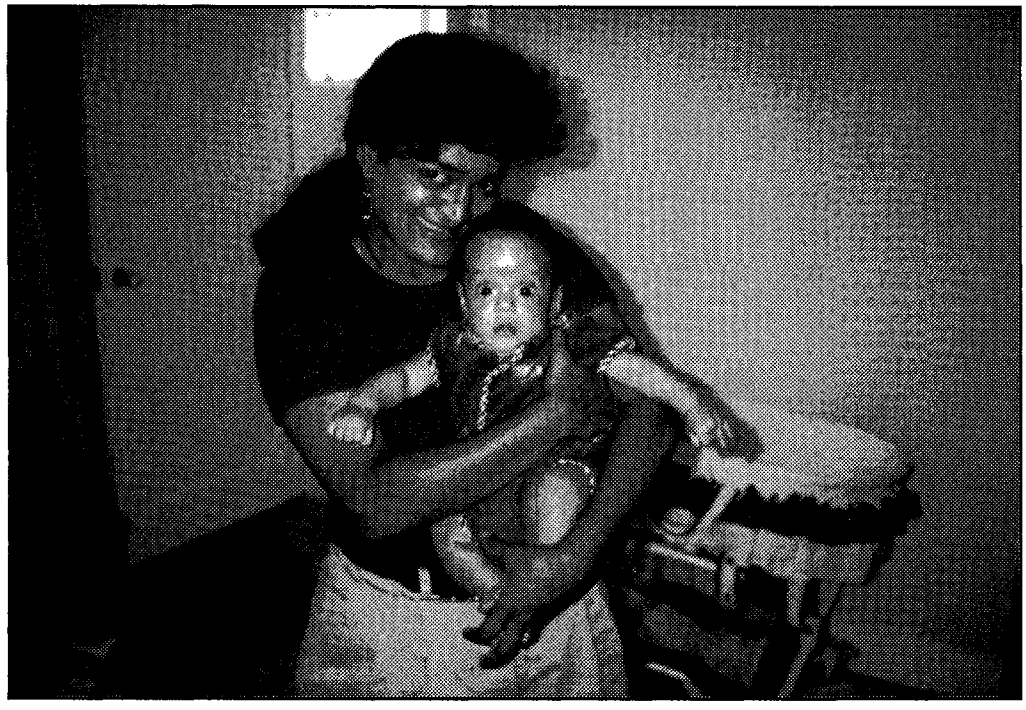

I always found it difficult to tell people in India that I was pregnant. People looked somewhat embarrassed, as if in mentioning the word "pregnant" I had crossed the line of decency. It seemed strange in a country that had a population of one billion people. Perhaps it is because childbirth is such an accepted part of marriage, life and relationships. Or perhaps it is because talking about being pregnant underlines the fact that a sexual act had to have occurred first, and Indian society is often not comfortable speaking about sex in any form.

My first clue to this discomfort was when I told my Hindi teacher I was pregnant. I used the Hindi phrase that literally means, "I am pregnant." He looked embarrassed and then awkwardly told me that I should not use this phrase, but rather a more indirect phrase that means, "I am with stomach."

I was careful during my pregnancy, but still often did things that my concerned Indian friends (and strangers that I met) felt I should not do. I was not supposed to carry even one bag of groceries home. Rickshaws were not advised. Exercise was out, though I could go for very slow walks if necessary. The advice was never-ending, and I ignored most of it. I had in my mind pictures of my American friends who went running, carried on jobs and lived life with little difference than before their pregnancy. I felt confident that I was strong and my pregnancy would be easy. My last three months, we had decided, we would spend in America — just to be sure that we were prepared.

Underlying my desire to not fuss over my pregnancy was the difference I saw in how pregnant middle- or upper-class women were treated, and how pregnant lower-class women were treated. The former often went into complete bed rest during pregnancy, moving in with their mothers who could ensure that they controlled their diets (which often meant eating as much *ghee* as possible), did as little work as possible and received daily oil massages to keep them supple and relaxed. For the less fortunate, economically poorer women, pregnancy is just one more addition to their tasks. Their work — be it sweeping and cleaning, or working in the fields — is never disrupted. In the train station, I saw a pregnant sweeper woman lifting a heavy pail of water and then sinking to her knees to scrub the bathroom floors. She was huge; her belly seemed to almost touch the floor as she scrubbed. "The baby's due in a few weeks," she told me proudly. Obviously, no one was looking after her to ensure her health. She was expected to continue her back-breaking work regardless.

I never got over the fact that many village women, when they deliver their children, are made to go out into the fields with the animals so that they do not contaminate their houses. Births are quick and businesslike, nothing like the long, laboring, carefully designed processes one sees in America. Thinking about these women, it always made me feel uncomfortable to worry too much about my pregnancy and myself. Like so many things in India, it did not seem very fair.

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In PJ-17, I had written about my troubles finding a gynecologist. After months of searching, I did find an ab-

solutely wonderful person — interestingly, a man. He had been recommended to me before, but I had studiously avoided him, feeling more comfortable with women. After sweeping through several women gynecologists with great disappointment, I finally turned to him.

Dr. Prakash was sensitive, knowledgeable, caring and gentle. He explained every step to Alan and me in great detail, and allowed us to pelt him with questions. Dr. Prakash's training was from the U.K., and he continued to practice there three months of the year. As a result, he was informed and up-to-date on issues of quality of care by physicians, and completely supported women's right to know and decide.

How lucky that I found Dr. Prakash when I did. My first visit to him was in mid-January, when I was already five and a half months pregnant. I told him that I planned to return to America after the sixth month and deliver the baby there. In his hands, I finally felt comfortable and began to relax.

I had had two routine visits with Dr. Prakash by mid-February. My pregnancy was progressing well. Alan and I began planning for our return to America, packing boxes and making last-minute arrangements to say our farewells to our wonderful friends and India.

On February 18, at 5 a.m., I awoke to find my bed wet. When I got out of bed to go to the bathroom, I found I was continuing to drip fluid. It occurred to me briefly, thanks to the many pregnancy books I had read, that my waters had broken but I brushed aside the thought quickly. I was only twenty-five and a half weeks pregnant. I was certain that it was just a weakened bladder.

By 9 a.m., the leaking had not stopped and I was worried. We did not have a phone in our apartment, so Alan and I walked five minutes to the nearest phone booth to call Dr. Prakash. "For some reason, my bladder seems to have weakened," I told him. "I am leaking urine." "Are you sure it is urine?" he asked. "Or is it amniotic fluid?" I told him I did not know. He advised us to take a sample and drop it off at a nearby lab to test the fluid. "Take complete bed rest, and if it continues, or if you develop any labor pains, call me immediately," he finished.

Unfortunately, the lab did not have any of the test in stock, and there was no other lab nearby that could perform the test. Hoping that the leaking would stop on its own, I stayed indoors, using a bedpan and taking sponge baths given to me by my sister-in-law, who was visiting from America. I was having no contractions, and continued to be in denial that this could be amniotic fluid that was leaking. I was still planning our return to America and our activities for the remaining two weeks. I approached my bed rest with frustration and impatience, as something that perhaps was not really necessary, a big fuss over nothing.

After several days of leaking, Dr. Prakash made the first of many home visits to check on me. He concluded that I must have developed a leak in my amniotic sac. "Many times, these leaks will just seal off," he said. "Even if it does not completely seal off, you could go on leaking for weeks without necessarily putting the baby at risk. The longer the baby can stay inside, the better its chances of survival. In a worst-case scenario, the leaking will continue and will actually stimulate labor. Let's hope that does not happen. You are only 26 weeks pregnant, and, quite frankly, a baby born at this gestation stands little chance of survival."

That was the prelude to a week that would crescendo into our own personal terror. It was now looking as if we would not be able to travel to America as planned on March 9. In my denial, however, I was still unable to believe that we would be delayed by more than a few weeks. Alan, who was more realistic, tried to tell me we would probably have to spend the next few months in India and that we should think about where we would deliver the baby. I could not bring myself to enter into that discussion, but I did agree that I should ask my mother to fly to Varanasi from Bangalore in case my bed rest continued.

"In our worry, we did what our American background had taught us to do — we tried to get information and gain some semblance of control."

The flat that we lived in was a simple two-room apartment on the second floor of a house. Our bathroom was a concrete structure off the kitchen that had a squatter toilet. We had no shower and no hot water. To heat water, we would carry a bucket of water into the bedroom, and stick an "immersion rod" into it — essentially an electric-rod heater. When the water was hot (and it would get hot only if there was electricity, which was not always), we would carry the bucket of water back into the bathroom and take a quick shower, gasping as the cold February air hit our chests between mugfuls of hot water. As I mentioned, we had no telephone. If our landlady was home, we could receive incoming calls on her phone. For outgoing calls, we had to go to our local phone booth five minutes away. We loved our apartment, but the conditions were far from ideal for a pregnant woman in fear of going into early labor.

On February 21, my mother flew to Varanasi from Bangalore. As I continued to leak, we became more certain that this leak might not seal itself. In our worry, we did what our American background had taught us to do — we tried to get information and gain some semblance of control. What did this mean for the baby? Should we be trying to fly back to the States or at least to another major Indian city? What was the possibility that I would deliver soon? Dr. Prakash answered these and many other

questions to the best of his ability. I do not think we would have received different answers from a physician in America, but in America we would have had several people to consult for second and third opinions. In Varanasi, we felt crippled by not having anyone else to talk to or consult with.

On February 23, Alan finally decided to call my mother's gynecologist in Bangalore, who is the retired Director of the OBGYN department at a well-known hospital in Bangalore. Perhaps like any doctor who is consulted from afar would be, he was extremely conservative about the possibilities of survival of the fetus, and very concerned about my health. "Once there is a leak in the sac," he said, "infection can go in and out. After several days of leaking, it is highly likely that the fetus is infected and that the mother is also infected." He asked Alan if Dr. Prakash had started me on a course of antibiotics and steroids. The first was to control the infection; the second was to mature the lungs of the baby in case of early delivery. Alan's reply that Dr. Prakash had done neither met with silence. "Have you at least had an ultrasound done?" he asked. Another no.

Alan returned from the phone call in a panic. He was beginning to doubt Dr. Prakash, the one person we needed desperately to trust at that point. The lack of information, conflicting information, and the realization that this nightmare was actually reality was beginning to hit. We felt helpless on many counts, not knowing what to do or what the outcome would be. Furthermore, logistics were extremely difficult. The fact that we had no phone meant that, in an emergency, we would have to rely on using our landlady's phone (*if* she happened to be home) or run to the nearest phone booth. Second, we had no car, and there was no call-in taxi service in Varanasi. If we had to go to the hospital, we would have to search for someone with a vehicle to take us. Third, I was not being continuously monitored, so there was no certainty about the baby's or my continued health. In America, if a woman begins leaking, she is immediately taken to the hospital and put on monitors to ensure that the fetus does not go into respiratory distress, and that the mother is safe. In Varanasi, there were no such facilities. Finally, we knew (though we tried to forget) that if the baby happened to be born in Varanasi, the chances of survival were next to zero. In Dr. Prakash's words, "saving a 26-week-old baby anywhere in the world is difficult. Here in Varanasi, we just do not have the equipment to do so." Dr. Prakash's strategy, therefore, had been to keep the baby in for as long as possible; every day made a difference.

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We passed a tense day, waiting for Dr. Prakash. He had been called in for a delivery that day, and ended up being able to visit us only late at night. Our discussion was difficult, but open about our concerns. He had been planning, he said, to give antibiotics that day. He had been hesitant about administering steroids to me, for fear that they would stimulate contractions. Ultimately, however, he prescribed both steroids and antibiotics for me. In retrospect, the steroids played a key part in saving Janak's life.

Dr. Prakash also agreed that we should have an ultrasound done the next morning to determine the amount of water lost and the weight of the baby. He had resisted doing this earlier, he said, because the ultrasound clinic was half an hour away on bumpy roads, and he did not want to exacerbate the leak. In addition, Dr. Prakash was uncertain how the information would change his decisions. If, for example, we found out that half the water was gone or my cervix had begun to efface [become thin], what would he do? "My dilemma is this," he said honestly. "I could do a c-section and hand you a live baby, but then the chances of survival are poor. Or, I can do nothing, hoping to buy a couple of extra weeks, even days. If I am inclined to do the latter anyway, what is the point of the ultrasound?" Watching Dr. Prakash expose himself and his thought process in a way that doctors rarely do was both comforting and terrifying. Comforting, because we understood his thinking and his dilemma. Terrifying, because even our expert seemed to be unsure of what to do. Ultimately, Dr. Prakash's decision to do the ultrasound came down to a desperate need to know and assess the situation.

To administer the antibiotic and steroid injections, we had to find a trained nurse or physician who would come to our house at the odd hours of 5 a.m. and 10 p.m. (the timings had to be strictly followed), since I was not allowed to move. Alan and a friend of ours walked around to several clinics nearby to find someone, but had no luck. Finally, our friend found a man who was the neighborhood "compounder" — equivalent of a physician's assistant. We approached this man with a degree of fear because, according to our landlady, he was "not very clean." Alan watched him like a hawk to ensure he washed his hands, and then we provided him with clean, disposable syringes and needles. For Rs. 70 (about U.S.$2), he agreed to come over for two days in the early morning and late night. In the mornings, he would arrive looking as if he had just rolled out of bed, clothed in a bathrobe over a pair of white cotton pajamas and his hair sticking up on end. He was in his 50's, and thrilled to be performing this service in a foreigner's house. After the injections, he asked Alan very seriously if he could ask some questions. It turned out that he was extremely interested in Alan's food habits in America! Smothering his laughter, Alan would conscientiously recite what he ate for breakfast, lunch and dinner when in America.

On the morning of February 24, I got out of bed for

the first time in six days, climbed down the stairs and into a friend's van to go to the ultrasound clinic. There were no ambulance services in Varanasi, and my friend's van was rusted and old. I could feel every pothole in the road slamming into my back. The ultrasound showed that, although my cervix had not started to efface and my bag of waters had not actually broken, 50 percent of the fluid in my sac had leaked out. It also predicted a weight of 1.1 kilograms (about 2.4 pounds) for the baby, above the minimum threshold of one kilo. Although Dr. Prakash felt it was unlikely that the baby would stay inside to term, he continued to hope we could buy another couple of weeks. However, he warned us that the possibility of an early delivery was high. If fluid continued to leak out, it was also possible that the baby could go into respiratory distress.

It was as if a firecracker had landed in front of us and was about to explode. We could not think straight. What should we do? Where should we go? Whom should we see? We considered trying to make it back to the States, but Dr. Prakash advised against this in case the baby was born in the air. Should we fly to another Indian city, then? He thought about this longer, and in the end, agreed that this might be a good idea. If we could make it to Delhi or Bombay, and the baby was born before 32 weeks, it would stand a decent chance of living. We did not know any doctors in these places, and although we could have found one through a network of family friends, this would take time. Would I make it through the stress of flying? Dr. Prakash could not guarantee anything, but felt it was worth the risk.

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Together we sat and made quick decisions. It would be Bombay, because Dr. Prakash knew of a colleague that he had met at some conferences who was supposed to be very good. He was not sure what hospital this Doctor Soonawalla was connected with in Bombay, but he gave Alan his fax and phone number and advised us to call immediately. He warned us that many gynecologists would refuse to take a case where the baby was of this gestational age, because chances of survival were not high and they would want to keep their record clean. And, Dr. Prakash warned, this gynecologist traveled a great deal so he might not even be in Bombay. If he were away, we would have to go back to the drawing board.

Alan faxed the clinic immediately, and followed up with a phone call. Dr. Soonawalla happened to be in Bombay at the time, and agreed to take me. "Fly to Bombay immediately," his secretary told us, "and check into a hospital." "Which one?" Alan asked in confusion. The assistant gave him a few choices, and Alan took the one called Breach Candy that was described as "plush." This was not a time for scrimping.

The next 24 hours, we operated on sheer adrenalin. Alan called a friend in Bombay to arrange for an ambulance to meet us at the airport. After much maneuvering, our friend called to tell us he had arranged it. We made reservations for the next day on the one daily flight from Varanasi to Bombay that left at 2:30 p.m. and arrived at 6 p.m. In order to travel, Dr. Prakash would have to do an internal exam and write a statement to the airline that I would not go into labor on the plane. He agreed to come to our flat the next morning before we left.

Fear had begun to set in. I would be trusting myself and our baby to a gynecologist I did not know and had never met, but the alternative of delivering the baby in Varanasi where it would be certain to die was worse. Dr. Prakash vouched for Dr. Soonawalla's competence, but said we should prepare ourselves for the possibility that he would not have much time for us, given his busy schedule.

Many times in those days, I thanked the forces that be for Dr. Prakash. He visited us at home at least three times in that week (often as late as 10 p.m.), and fielded dozens of phone calls. He gave unstintingly of his time and advice, at the same time listening and responding to our concerns. His encouragement to fly to Bombay was another critical factor in saving Janak's life. His calm demeanor kept my stress level down, and almost certainly helped prevent me from having stress-induced contractions. Perhaps the greatest testament to my faith in him is that if he lived in America, I would use him again, in spite of all the choices of excellent men and women doctors here.

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The next day, the day of our proposed departure from Varanasi, was exactly one week from the day I had begun leaking. We planned to just lock up our house and come back at some point to pack up. For the trip to Bombay, we readied small backpacks that we could take as carry-on luggage, so that we would not have to wait at the Bombay airport to get our bags. We planned to leave for the airport at noon, giving us plenty of time to make a 2:30 flight. At 11:30, Dr. Prakash arrived at our house to give me an internal exam. According to him, my cervix remained completely undilated and long, so it was extremely unlikely that I would go into labor. Just to be sure, however, he gave me an injection of a labor suppressant that would last for about five hours.

By 11:45, neither our tickets (which were being delivered) nor the friend who was taking us to the airport had arrived. Alan paced up and down our terrace, and then up and down our lane, waiting. Finally, at 12:25, both arrived. Vidhu, our friend, was late because the students

of Benaras Hindu University were rioting, burning cars and creating roadblocks. He had gone back to his house to get a black scarf that he could wave out the window to show solidarity. The tickets, on the other hand, were late just because they were late.

As I stepped out of the house, I felt the blood rush from my head. I steadied myself on my mother's arm. I made it to the terrace, before muttering to her that I was about to faint. She shouted immediately for Alan, who came running up from the car and made it just in time to catch me before I slumped over in a faint.

I came to on the sofa in the flat to a sea of worried faces. It was 12:40. Alan had called Dr. Prakash, who said that the fainting was probably due to the labor suppressant, which also lowers blood pressure. Though still slightly dizzy, I was anxious to try and make the plane. Dr. Prakash agreed that we could still go, but asked that we stop by his house so that he could check me one last time and make sure I was okay. We reached Dr. Prakash's house at 12:55. He was waiting outside for us, with his doctor's bag. He checked me quickly, and blessed us as we left. It was 1 p.m.

I was stretched out in the middle seat of this old, lime-green mini-van. Every bounce shot up through my spine, and I could feel liquid continue to trickle out. It was boiling hot, and sweat had gathered on my upper lip and forehead. Alan was crouched on the floor of the van in front of my seat, his head stuck between our friend who was driving, and his wife.

"I knew when I saw Alan's face that we had missed the flight. The airline staff had told Alan that the plane was on time, the doors had been closed and the engines had been started."

Under normal circumstances, we would have had plenty of time to make it to the airport. That day, however, riots had blocked all city streets. Vidhu, waving his black scarf out the window, cursed as he swerved the wheel left and right, trying to make it through the crowds but eventually getting stuck in traffic jams for tens of precious minutes. The back of his shirt was drenched with sweat.

The tension mounted to unbearable levels in the car. Vidhu and his wife argued about which route we should take, and Alan and Vidhu argued over whether they should pull over to a phone and try and call the airline to ask them to hold the plane. Ultimately, we just went as quickly as possible to the airport without stopping. We pulled up to the gates of the airport terminal at 1:20 p.m.

Airline flights in India rarely, if ever, take off on time. In our two years in India, I think I had been on one flight that took off on time. We hoped that either the flight had been delayed, or that the crew would hold it for us. Alan and Vidhu ran inside, while my mother helped me into a wheel chair. I was wheeled to the seats in front of the check-in counter. I could hear shouting, but could not make out what was happening. I could feel that I was continuing to leak more and more fluid. To distract myself, I joked with one of the airport boys that I recognized from previous trips.

I knew when I saw Alan's face that we had missed the flight. The airline staff had told Alan that the plane was on time, the doors had been closed and the engines had been started. According to government regulations, they said, once the engines were started, they could not bring the plane back. Alan and I have often wondered, since then, why regulations — which are hardly ever adhered to — were adhered to so stubbornly that day. Alan, Vidhu and my mother alternately pleaded and screamed. Alan even told the crew he would buy every empty seat on the plane if they would bring it back (he later told me that he had no idea what he would do if they had agreed, but he was desperate to make them understand the severity of the issue!). It was to no avail.

We had two choices. One was to try and get on a flight to Delhi leaving in about an hour. From there, we could try to catch the last connecting flight to Bombay, which would arrive in Bombay at about 11 p.m. The other option was to take the same flight the next day that we had just missed. Alan called Dr. Prakash, who urged us to wait till the next day. He was afraid that the continued stress would only make the leaking worse and possibly trigger contractions.

On the edge of tears, we packed ourselves back into the rickety van. The air was filled with a tremendous sense of demoralization. I felt we had lost the baby's only chance, and I was hanging on to sanity by a very thin thread.

We could not face the thought of another long journey through rioting crowds back to Varanasi city. Instead, we checked into a hotel about half an hour from the airport. That night my leaking was non-stop. I hardly slept, worrying that we had missed our opportunity to leave Varanasi. The next morning, Dr. Prakash, bless his soul, made the long journey to the hotel to do another internal (the airline required a new certificate dated on the day of travel). He said he could feel my cervix just beginning to open a little, but I should have no problem making it to Bombay. We decided against the labor suppressant this time, but Alan insisted that Dr. Prakash show him how to catch the baby, should it arrive unannounced on the plane!

The staff at the check-in counter remembered us and seemed more sympathetic this time. They assured us three seats where I could lie down. I was exhausted, as were my mother and Alan. I could no longer feel the baby moving; the amniotic sac had shrunk so much that the baby had no room to kick. More frightening, my stom-

ach had become almost completely flat with the loss of so much fluid. Completely unconsciously, though, I was delving into every reserve of strength I had. I knew intuitively that my composure was essential to our making it to the hospital.

We passed time by playing cards and singing Hindi bhajans. The flight had one stop in Lucknow. Just after taking off from Lucknow, I went to the bathroom and found that I had started bleeding. All the control I had imposed on myself began to crumble. I thought at that minute that I had lost the baby. I toyed with the idea of not telling Alan for fear that he too would crumble, but eventually decided I needed his support to help me think. He talked to the pilot and the airline stewardess, who assured him that they would get an airport ambulance to meet us on landing, and that we would be the first ones off the flight. They also made an announcement for a doctor on board, but there was none.

The crew never made the announcement to other passengers to stay in their seats and let us through. As is typical on all Indian flights, people leapt up as soon as the wheels touched the runway, and began putting together their bags and standing in the aisles. Alan pushed his way through only to find there was no ambulance waiting. By the time I made it to the front with my mother, I could see Alan from the top of the stairs, screaming at the crew to get an ambulance. I knew that all of us were dangerously close to collapse and breakdown. If I could just make it to the hospital, I kept telling myself, things would be fine.

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Alan ended up wheeling my chair to the terminal, and eventually found the ambulance ordered for us by our Bombay friend. It was a small minivan with a bench on either side in the back — very different from American ambulances, but at that moment, the most wonderful thing I could have laid my eyes on. I lay down on a bench, and grabbed a handrail for stability.

It was rush hour in Bombay, a city where traffic rivals the worst in the world. The ambulance turned on a flashing red light, which helped a little. The ride has stayed a complete blur for me, but Alan told me later that police had waved the car through when possible and some cars did move to the side to let us pass. I could hear the siren, and I remember at one point Alan and my mother exclaiming because we were going down a street on the wrong side of the road, but that is the extent of my memory.

At the hospital, I was carried in on a stretcher, and put down in the middle of the reception area (there was no emergency room). People walked around me looking down curiously until eventually, I was taken up one floor to the labor and maternity ward. My room was cream yellow, air-conditioned and clean. I could feel my heartbeat beginning to come down, my whole body beginning to relax as the realization set in that I was finally close to medical help. Nurses in white, starched uniforms and caps surrounded me and began taking all my vital signs. Where was the doctor, Dr. Soonawalla? I asked. He will come soon, the head nurse replied.

An hour later, Dr. Soonawalla had still not arrived. Instead, his son, a thirty-something who practices with him, arrived to tell me that Dr. Soonawalla Sr. had been unexpectedly called out of town to Delhi! I tried to stay calm, as I listened to him tell me that he and another senior doctor in the practice would be taking care of me until his father returned the next night from Delhi. "Rest tonight," he urged me. "Tomorrow, we will do the tests and see what is happening."

Surprisingly, I slept well. I was exhausted, and for the first night in many, felt that I was as safe as I could be. My room had no monitoring equipment, but during the night nurses came in every three hours or so to check the baby's heart rate and to take my vital signs, all of which seemed to be fine.

The next morning, as I ate my breakfast and looked out at the ocean through the open french doors in my room, I began to once again believe that this was just a bad dream. Soon I would be out and on the next plane to America. Just then, the head nurse came in and informed me that they were ready to do the ultrasound. It was a portable machine, the first I had seen in India. The technician expertly greased my stomach, and began tapping away at the computer. I could see images from the side, but nothing that helped me determine what was happening to my baby. "There is almost no fluid left in your sac," she said, looking at her screen. I tried to ask her more questions, but she shook her head. "You'll have to talk to your doctor."

Dr. Soonawalla's partner, Dr. Nagarwalla, came in shortly after. "It looks like we will have to terminate the pregnancy," she said to me bluntly. My head was spinning. I thought she meant terminate the baby's life, when in fact, she meant bring the baby out and end the pregnancy itself. Tears welled up in my eyes. It was completely real now, and yet unreal. This could not be happening to me! "What are the chances of survival?" I asked, trying desperately to hold back my tears. "Well, the culture we did on the fluid that is leaking from your sac shows that there is an infection inside. It is almost certain, given how long you have been leaking, that the baby is infected. Given the infection, the gestational age and the weight, the chances of survival are about 40 percent," she said. "The good news is that the ultrasound predicts a weight of 1.5 kg (about 3.5 pounds), which is a good

weight for a 27-week-old baby." I thought of my niece who had been born at 6.5 pounds. This was just half of that! Dr. Nagarwalla was talking again, telling me that Dr. Soonawalla would be returning from Delhi that evening. Unless I went into labor or the baby became distressed, she said, we would wait for him to decide what to do.

The day was endless. For the first time since I had started leaking, I cried. I cried because I was convinced that our baby would not live. I cried for failing this tiny being, for somehow forcing him out too early, for the lost life he would not get to live. My mother and husband tried to comfort me, and I tried to comfort them by being as strong as I could. We were tied together that day more closely than ever before, by pain, fear, sorrow and love. I could not sleep, so Alan and I sang bhajans to my mother, looking out at the water, thinking of our lives in Varanasi, wondering if this was due to something we had done.

No one knew what time Dr. Soonawalla would arrive. He finally showed up at 9:45 p.m. He had come straight from the airport, and had been briefed on my case. He repeated some details of my situation to me to assure me that he knew what was going on. He was an older man, about 70 years old but looked not a day older than 60. I found out later that we were exceedingly lucky to have found him in India at all, since he is often called to attend to patients around the world.

After his internal examination, Dr. Soonawalla confirmed that the baby would have to come out immediately. "There is hardly any fluid left in your sac, as you know. You have two choices for how the baby should come out. You can try to have a normal delivery, or you can have a cesarean section. If you have a normal delivery, your labor will probably be long and dry, because your cervix remains completely undilated and there is no fluid left to support the process. The baby could be in danger in this case. If you have a cesarean, the baby will have about a five-to-ten-percent better chance of survival than in a vaginal delivery. Obviously, this is surgery, which is never desirable. It is your choice."

We had come to Bombay to give the baby the best possible chance of survival, so the decision was not difficult. At 10:15 p.m., we told Dr. Soonawalla that we had decided to have the C-section. He went immediately to prepare for the operation, and asked the nurses to prepare me for surgery, scheduled for 10:45 p.m. As he left the room, it seemed ironic that I had had such grandiose ideas about interviewing and choosing a gynecologist. Now, here I was trusting myself to a man who I had never even met until half an hour before — and feeling absolutely lucky that I even had somebody to whom to trust myself.

I was cleaned and prepared for surgery, a green cloth draped over me, and moved to a stretcher. Alan had decided, after some thought, to watch the surgery. He walked with me to the operating theatre, and then left to gown himself for the surgery. I was hooked to an ECG monitor, and a catheter was inserted into my bladder. The anesthesiologist came and introduced himself to me and asked if I was ready for the anesthesia to be administered. Because of a missing disc in my lower back, I had to be given general anesthesia instead of a spinal epidural. The anesthesiologist began to administer the anesthesia. It was as if little pieces of ice were being inserted into my vein; as they melted, they flooded my whole body with cold. I did not have my contact lenses on; I could see only distant blurs. I thought I saw Alan's eyes smiling at me over his mouth mask from where he was standing about three feet past my feet. That was the last memory I had.

I awoke at about 5 a.m. My lower back felt like it was tied to a wooden plank. I tried to move and winced in pain. I had an IV in one arm, and I could feel the needle in my skin as I attempted to change positions. I must have been moaning, because Alan came to my side immediately from the chair he had been sitting in.

"I could not wait, nor could I understand how they could think I would want to wait. I wanted to see Janak immediately."

"The baby?" I croaked, my voice hoarse from the anesthesia. "The baby's okay," he said, stroking my head. "Boy or girl?" I asked. "Boy," he replied tenderly. And then, tentatively, "He is a little lighter than they thought he would be. He's 850 grams." I could not comprehend what he was saying. All I knew was that the baby was alive.

It was only later when I was fully awake that Alan told me about the operation. He dealt with it, he said, by not looking at my face, by pretending that it was someone else being cut up on the table. It took only fifteen minutes or so to bring the baby out, and double that time to stitch me up. There was so little fluid left in the sac that the doctor had to actually scrape the baby off the membrane. Janak was immediately rushed to the Neonatal Intensive Care Unit (NICU), which was down the hall from the operating theatre. He was put on a ventilator, and antibiotics were started immediately. Many days after Janak's birth, Alan told me he would never watch a C-section again, but he was glad he had been there. I, too, was glad. It provided a link between the end of my pregnancy and Janak's birth that would otherwise have been missing. To hear Alan talk about how Janak was born made it that much more real for me.

I was still groggy when I finally woke up some hours later. I was to be shifted from my labor room to a maternity room. "When can I see the baby?" I asked. They told me I could go any time, but perhaps I wanted to wait that evening when I felt a little stronger. I could not wait, nor could I understand how they could think I would

want to wait. I wanted to see Janak immediately. They agreed to wheel me to the NICU.

At the outside door, I left the wheelchair and my shoes and, leaning heavily on one of the nurses, walked through the small entry room. It had a sink, a refrigerator, a two-burner stove with a big sterilization pot and a big wooden closet. Underneath the closet were several pairs of rubber slippers. I put on a pair, and walked through a door with a small window that led to the main room of the NICU. At the instruction of the nurses, I washed my hands in the sink near the door and put on a sterile gown.

Janak was being kept in a smaller room just off the big room. He was lying in one of two infant warmers in the room. The warmer was a small plastic rectangular box crib with no cover, about two feet wide and three feet long. A couple of feet above the box was a radiant heater, electric rods that let off ambient heat. Janak was on a thin mattress in the middle of the crib.

I expected the worst. Alan had prepared me that Janak's skin would be shriveled and that he would be tiny. Perhaps it is the essence of parenthood that his ugliness seemed beautiful to us. I had never imagined that he would be as tiny as he seemed. His length was only about one and half of my hands. He was very fair, just bones with skin loosely laid over it. One arm was weighted down with an IV and a heavy splint so that he could not move it. He had a test tube attached to his penis, so that they could measure the amount of urine he was passing. His head looked huge compared to the rest of his body. His knees were bony protrusions in the middle of sticks. I could not think of much except that he was alive, and, though tiny, all his organs seemed perfectly developed. Over his head, he had a plastic oxygen hood that looked like a cake cover. It went down to his neck, and had a small hole in the top where a tube was inserted that piped in supplemental oxygen. He had three ECG pads on his chest, which were so big they covered his entire bony chest. A feeding tube that led to his stomach was inserted into his nose.

"Perhaps it is the essence of parenthood that his ugliness seemed beautiful to us. I had never imagined that he would be as tiny as he seemed."

I could not stay for more than five minutes. My stomach was screaming in pain, and I felt my whole body choked with emotion. This was my baby. I had not touched him yet, but I had seen him and he was alive.

I was in the hospital for five days. My new room was smaller than my old one, with no view, but just as clean. My hospital bed was adjustable, and there was an armchair on the side for visitors. I had an attached bathroom that was as big as my room, with yellow tiled walls. It was one of the cleanest bathrooms I had ever seen in India. Every day, Janak's pediatrician and my gynecologist visited me. Parents of NICU babies were allowed to spend as much time as we wanted in the NICU, but entry of anyone else was strictly prohibited to minimize the risk of infection to these tiny babies.

Throughout Janak's stay in the hospital, we were in the NICU entire days, with breaks only to eat, sleep, and do short errands. We slowly became used to the NICU environment, where alarms constantly sounded and monitors beeped. Perhaps the most terrifying moments in those early days were when Janak, like most premature babies, would have apnea spells where he would stop breathing for more than 20 seconds. The alarms would sound loudly, the ECG monitors showed flat lines, and we would see him go completely limp. The nurses would rush in to bring him back to consciousness by flicking his toes or palpating his chest. According to our doctor, the apnea spells were (simplistically put) because Janak's brain and lungs were not fully developed, and the brain would forget to send messages for the lungs to breathe. We learned to watch for these spells, and sometimes even palpated Janak ourselves.

We steeled ourselves to watch as nurses pricked him with needles, clamped devices on to his arms and legs to measure blood pressure and blood oxygen levels, and stuck ECG leads on his chest. We learned to ask during that first month only how he was doing at that moment, because we knew it could change from minute to minute.

Janak was born with a severe infection that sent his white blood cell count soaring as his immune system tried to combat the infection. We took some heart in the fact that his immune system was functioning at all. The infection raged on for two weeks, stubbornly refusing to respond to over seven different antibiotics. Finally, on March 10, Janak's white blood cell counts began to come down in response to a new anti-fungal drug.

During those first few weeks, we did not know if Janak would live or die. The doctors could offer little consolation. Our daily thought was simply that he would make it to the next day. Once his infection was controlled, our attention turned to his feeding and weight. Janak's digestive organs remained undeveloped, unable to digest food. For the first few days after birth, he was fed only glucose. About five days after birth, he was given 2 cc of milk (about 30 drops). Two hours after giving the milk, the nurses would aspirate his stomach, which meant putting a syringe to one end of his nose tube through which he was being fed, and pulling up the plunger. If the milk remained undigested in his stomach, it would appear in the tube. Aspirations meant that he would not be given milk again for another day. Janak was unable to tolerate any feeds for two weeks. His weight dropped quickly to just over one pound. Once he was able to tolerate one cc of milk, the doc-

tors increased this amount by one cc per day.

Janak was in the hospital for two and a half months. After the first month, we knew he would live. Then it became a matter of time, and a question of what other effects he might suffer due to his prematurity. We struggled now with issues not of Janak's mortality, but of his morbidity. In retrospect, Janak did unbelievably well given the possibilities premature babies of his age often have to face. However, we never relaxed. Just as we thought he had turned the corner, he would develop new problems. Whether due to a sky-rocketing eosinophil [a form of white cells] count or symptoms that seemed to indicate toxoplasmosis or cytomegalovirus, Janak's condition was far from stable. His weight also caused us great anxiety. It took him two and a half weeks to regain his birthweight, and then another 1.5 months to gain another two pounds. Janak was weighed once a day at 5 a.m. Our first question upon arrival at the NICU was, "What is his weight?" Every gram counted; to talk of weight gain in terms of pounds or kilograms seemed sadly unthinkable.

While we worried about whether or not Janak would live, no other worries seemed important. Perhaps it is human nature to narrow down one's focus during a crisis, just to make it through. Once we knew Janak would live, it was inevitable that other smaller frustrations and stress factors would begin to affect us. We were thankful for his life, but still ached to hold him, to be his primary caregivers, to enjoy and love him without caution. We watched as full-term babies came in and out of the NICU, or as nurses and glowing mothers carried their healthy babies outside in the maternity wards.

"Every gram counted; to talk of weight gain in terms of pounds or kilograms seemed sadly unthinkable."

There were no support services at the hospital. I was going through guilt about Janak's early arrival into the world, and wished that I had a qualified counselor to speak with. The mother of the other premature baby in the unit, Seema, was going through similar feelings, I found out. But she was convinced that it was definitely her fault, and not something she should talk about. This was consistent with the Indian cultural norms that frown on people who discuss their problems openly. I also wished, on a practical level, that I had a lactation counselor. The hospital had no electric breast pump, so critical to helping mothers of prematures establish and maintain a healthy milk supply. With the pediatrician's support, I initiated manual pumping every two to three hours as soon as Janak was born. The nurses actually encouraged me *not* to pump, since I was getting so little milk, but I knew from my books that if I did not, my supply would never increase. The nurses often made unintentionally disparaging remarks about the small quantity of milk that I was producing which, on the emotionally shaky ground I was treading, toppled me over the brink of sensibility.

It was a full two months before I could even try nursing Janak. Even then, he had a very weak suck and was unable to get much milk. The nurses insisted that I hold him in a certain position, which made it very difficult for him to reach the nipple. Finally, after reading some of my books, I found that all the books recommended a different hold during nursing for premature babies. The NICU nurses were not very happy when I changed the hold, but it worked much better.

One of the most stressful issues we faced was that we did not trust the nursing staff. Janak's two pediatricians could hold their own against American physicians in terms of knowledge (if not practical experience). The nurses, however, were little more than competent assistants, able to keep the unit clean, to change the babies, and possessing some basic knowledge of emergency care. Our distrust was fostered by the fact that we often came into the unit and found the nurses ignoring some of the doctors' specific instructions. For example, it is well known that an excess of supplemental oxygen can cause retinopathy of prematurity (ROP). To protect against this, supplemental oxygen should be closely monitored so that the baby's blood oxygen level does not rise above 95 percent. Although we had heard the doctors instruct the nurses often on the importance of this, we often found the monitors showing 99 percent blood oxygen levels.

We had also been reading dozens of articles sent to us by a close friend in Seattle who works at Children's Hospital. Many of these articles discussed new findings that showed how handling of babies and their hospital environment can have long-term developmental effects.

American NICUs today focus heavily on ancillary behaviors that can affect later development of premature babies. Limiting noise, creating a warm and secure sleeping environment, speaking softly and handling babies gently are all standard practices in America. In India, however, the NICUs are too new and the nurses untrained as yet to incorporate these practices. The focus has been on mortality, rather than on looking down the road at developmental issues.

Having read these articles and new research findings, we were horrified to see the nurses try to wake up Janak by clapping their hands in front of his face or ears, flicking his feet to make him cry, or holding him directly up to sunlight. They felt that he should learn to take milk through his mouth instead of using the naso-gastric tube for feeding (in America, many premature babies are often released with the tubes still in), so they would hold open his mouth and pour the milk in as he screamed. The discrepancy in how the nurses treated Janak and how

our articles talked about treating babies was often too much for us to bear. We constantly weighed our discomfort with leaving him in the nurses' care with the risk of taking him out of the hospital too early. Our lack of trust in the nurses, combined with our high stress level, often meant that we micro-managed the nurses, which could not have been much fun for them either.

Our pediatrician himself recognized the gaps in "soft" care. "We now have the hard equipment," he once told us. "Now we need to work on the nursing skills. In America, nurses are equals to doctors, with their own areas of specialty and training. They interact on the same level, discussing issues and care. Here, nurses are generally afraid of the doctors, and are merely following orders."

There were other stresses too. Janak often needed medication that was too expensive or rare for the hospital to stock. The hospital policy was that the parents were responsible for getting the medicines. The nurses would call us at odd hours of the day and night to tell us that they urgently needed a certain medication or a particular size of neonatal catheter. This involved our taking taxis around the city of Bombay (which we did not know) to dozens of pharmacies to find one that was open and stocked the particular item. According to Seema, this was standard practice for most hospitals. In fact, she and her husband told us, Breach Candy was much better than most. Most would not even stock standard items like needles and gauze!

"The nurses would call us at odd hours of the day and night to tell us that they urgently needed a certain medication or a particular size of neonatal catheter."

Compounding all the medical issues was our unstable living situation. It was essential that we live close to the hospital, which was located in a very upscale part of Bombay. The first week I was in the hospital, my mother and Alan had stayed with a friend in their small apartment. The arrangement was far from ideal, however. Our friend and her husband lived with their son and daughter-in-law in a two-bedroom apartment. Although they insisted that we could stay as long as we needed, adding three more bodies was not realistic.

Two years ago, Bombay rents were the highest in the world; today, they remain in the top three. We tried desperately to find an apartment to rent without success. No one was willing to rent for just a few months, and even if they had been, they would have required a deposit worth *the value of the apartment itself*! For apartments in Breach Candy, this could mean the equivalent of U.S.$300,000 and up. The deposit policy was to protect owners against tenants who moved in and decided never to leave. Indian laws favor the occupants of an apartment rather than the owners, and there have been thousands of cases of renters refusing to leave an apartment.

We ended up moving from our friend's house to a small club for a few weeks, and then renting a room in someone's house. This system, called "paying guest accommodation" is very popular, but still not cheap. For our one bedroom and attached bathroom, we paid almost U.S.$500 a month. When Janak finally was ready to leave the hospital, we moved to another house that belonged to friends of Alan's parents. They were in Europe at the time, and generously agreed to let us share the house with their 25-year-old son.

Financially, although we had backing of the Institute of Current World Affairs, it was complicated to get sufficient funds from America into India to meet our medical expenses. The hospital did not accept credit cards or checks. We had to pay our bills with Indian-rupee cash. We did not have a bank account in India, and the amount of foreign exchange one is allowed to bring in is limited. We were constantly maneuvering to get sufficient cash. In addition, we had to prepay up to 5-7 days of care (the hospital had no customer-credit billing at all).

To add insult to injury, as a U.S. permanent resident, I was supposed to return to the States at least once a year. My year would officially expire on April 20. We had planned our return in March partly because of this issue. If I failed to return by April 20, I would lose my green card, and not be allowed back into the U.S. Alan went to the U.S. consulate, armed with letters from our doctor explaining that Janak was in critical condition and would be unable to leave the hospital by April 20. Alan spoke with several U.S. embassy officials, who were sympathetic but firm. According to them, we had only two options: 1) allow the green card to expire and apply for a new one, which could take anywhere from six months to a year to get; 2) fly to American soil before April 20, touch down and fly back to Bombay immediately. Alan tried to explain that we could not, under any circumstances, leave the baby but it was to no avail.

Dozens of phone calls, letters, and visits to the embassy later, it was an ICWA trustee, Kitty Hempstone, who finally rescued us. Kitty's pleas to the State Department (reinforced by the fact that her ICWA-Fellow husband had been a U.S. Ambassador) allowed the U.S. Embassy in Bombay to expedite an application for a special visa that would allow me back into the States, after which time I would have to apply for a new green card. We thought our trouble was over, but it continued. After filling out numerous forms, paying hundreds of dollars and submitting myself to a complete physical examination (including x-rays and an AIDS test), I was told that my self-reported complaint of a missing disc in my spine (which I have always had and always disclosed on the medical forms) could be a symptom of tuberculosis. I would now have to undergo a series of tests to determine if I had T.B. "Ridiculous!" I said indignantly. I had

had a T.B. test in the States and it was negative, but the doctor was adamant. "I am the one who has to certify that you will not get T.B. If you land up in the States and are diagnosed with T.B., they will come after me." I screamed and cried, but in the end had to submit myself to more x-rays, which eventually turned out negative.

When I was handed my visa almost two months later, I decided that I would finally take the plunge that I have always resisted: upon returning to the U.S., I would apply for U.S. citizenship. My loyalty to India was great, but I had been beaten down by the only bureaucracy that easily rivals Indian bureaucracy: the United States Immigration and Naturalization Service.

In the end, we made it through those two and a half months because we had to. As long as Janak was alive, we wanted to appreciate this baby, who was more special than anything we could ever imagine. His life, almost taken away and then given back to us, was priceless.

Many of my friends in America have asked me about the medical care we received in India. Especially given my newsletter, PJ-14 "America: Looking Back," where I wistfully remembered the medical care available in America that seemed to be completely unavailable in India, people worried that our experience with Janak's care would be as bad. Interestingly, many of my friends indicated that perhaps I did not remember American medical care properly. They told me stories about incompetence and lack of caring in the U.S. health system that rivaled my tales of health care in India.

I do not say, for a minute, that health care is perfect in America. In fact, my experiences with Janak's medical care showed me that medicine has two sides to it: technology, and heart. It is far easier to find the former in America, and the latter in India. And yet, when the chips are down, would any of us actually *choose* to be in India for a medical emergency? There is something to be said for America's reputation as a leader in medical technology, information, and knowledge. Much of the information and knowledge has yet to filter back to India; and many of the latest procedures and drugs cannot filter back, by virtue of the simple fact that they are far too expensive for the majority of Indians.

Perhaps the most relevant statement I can make about Janak's medical care is that he lived. This, above anything else, speaks volumes. At the same time, I must admit that Alan and I wished often that we had made it back to America before Janak's birth. The terror that we experienced in Varanasi at being cut off from information, from medical help, from *technology* itself is unforgettable. We in America take for granted luxuries like ambulances, phones, and mobile equipment. Even in big Indian cities like Bombay and Delhi, these often do not exist. Subtler is the gap in care when it comes to some of the longer-term developmental issues of premature babies. Much of this gap was due to the level and skill of the nurses, and the relatively short time that the Breach Candy NICU had been operating.

In describing our experience with Janak's birth, I am also acutely aware of how completely unrepresentative it is of the care available to the general Indian public. Dr. Soonawalla's assistant had described Breach Candy Hospital as "plush," and although it might not seem that way compared to an American hospital, it earned its description compared to other Indian hospitals I have seen. As a private hospital and one of the best in the country, Breach Candy charges about U.S.$70 a night for a bed in a private room with attached bath. To give more perspective, the total bill for two and a half months of Janak's care (including bed charges, doctors' visits and medicines) was U.S.$5,600. For my five days in the hospital, including operation and doctors fees, we paid U.S.$1,800. And all this for some of the finest doctors and facilities in all of India. While this sounds outrageously cheap for Westerners, the average Indian earning U.S.$5-8,000 per year is necessarily excluded.

"I thought many times about the thousands — maybe millions — of women who need but never get access to the medical care that we had."

After striving to live a Fellow's life that did not take full advantage of the privileged situation we knew we were in, Alan and I felt uncomfortable to suddenly be catapulted into a situation where we were taking advantage of something available only to the rich. I thought many times about the thousands — maybe millions — of women who need but never get access to the medical care that we had. The difference is in the results: Janak lived and thrived. Their babies are just a fraction of the tens of millions of infant deaths that occur in India even today in the modern 20th century. It, among many other things, was just one more in a series of issues that I struggled with constantly during my two years in India.

The Breach Candy NICU had only five beds. Two were considered "critical" beds, and were in the small room adjoining the main room. A modern Hewlett-Packard monitor was attached to one bed, with capabilities for blood-pressure and heart-rate monitoring. Between the beds was another, very new and modern ventilator. Another ventilator was housed in the Intensive Care Unit upstairs in the hospital, and was brought downstairs when needed. At the time of Janak's birth, there was another extremely premature baby in the NICU who was on a ventilator so the second ventilator was brought down for Janak. Each NICU bed was connected to a three-lead ECG monitor, and there were two stand-alone pulse oximeters (to measure blood oxygen) in the unit. Interestingly (particularly for someone like me who

used to sell defibrillators), there was no defibrillator located in the unit. Unlike most hospitals across India, Breach Candy also had facilities for portable ultrasounds and x-rays.

The sanitation practices in the hospital, contrary to what many might think, were excellent. Partly because of Breach Candy's reputation and partly because the doctor-in-charge (our pediatrician) was well aware of the need for sterility in an NICU setting, we found people fairly scrupulous about cleanliness. Cleaning men came through the general wards and the NICU several times a day to sweep and mop the floors. The nurses in the NICU carried out a thorough cleaning of all the surfaces in the unit twice a day. All utensils were sterilized in a huge pot of boiling water for over ten minutes. Doctors and nurses always carefully washed their hands thoroughly (there were detailed instructions on hand washing above the sink), and used sterilium and other liquid disinfectants before touching the babies.

Our pediatrician, Dr. Mahesh Balsekar, had started the Breach Candy NICU just three years ago. He was trained in India and had also done some observation internships in London and in America. Coming from a wealthy family and with a wife (a gynecologist) who is half English, Mahesh had traveled abroad many times. He often spoke to us with wonderment about his three months at Johns Hopkins University, about the enormous size of the NICU there, and the technology. Although his knowledge of the field was excellent, Mahesh was not trained as a neo-natologist. His colleague, Dr. Cyrus Contractor, had worked in an NICU in Australia for several years, but was also not a neonatologist.

"During our whole experience and even today, I am most thankful for the relationship we had with our doctor."

In the beginning, this scared us. However, we realized that our choices in neonatologists were non-existent. Neonatology is a new field in India. The first NICUs opened in the early 90s, but remained quite sparsely equipped. It is no surprise, then, that medical colleges do not offer specialized training in the field. Mahesh and Cyrus, though not officially trained in the field, did know a tremendous amount from their reading and, more in Cyrus' case, from their training abroad.

During our whole experience and even today, I am most thankful for the relationship we had with our doctor. Dr. Balsekar, from the beginning, treated Janak, Alan and me as his patients. That means he felt he was responsible for our well being, as well as Janak's. He forged a personal relationship with us in the early days, talking to us about America and his visits here and asking about our lives.

Dr. Balsekar was available to us day and night. On our first meeting, he gave us his home number and his cellular phone number so that we could call him at any time. Especially in the beginning, when Janak's condition was critical, he would visit the NICU a minimum of twice a day, often calling in between to get updates on his status. He worked at Breach Candy part time so that he could also work at a public hospital in Bombay, where many of his patients could not afford to pay for care.

Dr. Balsekar often went well beyond the call of duty. One incident stands out. Janak's need for frequent blood transfusions created tremendous stress for us, because we did not want to use the hospital blood bank but also did not know enough people in Bombay to line up a slew of donors. Because of my C-section, my hemoglobin levels were too low to give blood. Alan had been on anti-malarial prophylactics and therefore was also not able to donate his blood. One family friend turned out to be Janak's blood type, and she managed to give enough blood for three transfusions. When she was no longer allowed to give, we did not know what we would do. At the time of Janak's fourth transfusion, we were desperate enough to decide that I would have to give blood. Dr. Balsekar would try and convince the hospital blood bank to accept the blood in spite of the low counts. The morning that I was to give the blood, I came in to the hospital to find Janak's blood transfusion in progress. "Whose blood is this?" I asked, puzzled. To my amazement, I was told that Dr. Balsekar had decided to donate blood for Janak. When I tried to thank Dr. Balsekar, he shrugged it off, saying lightly, "We often do this," a statement I knew to be false from the NICU residents and nurses.

Dr. Balsekar took it upon himself to be not just Janak's doctor, but the guardian of our fragile psychological stability. A few days after Janak's birth, we were in the NICU when Janak's IV needle became dislodged. At his weight of just over a pound at the time, every drop of blood was critical. We watched anxiously as blood trickled out of his tiny veins. The nurses took off his splint to re-enter the IV, but as they peeled the plaster from his arm, his tender skin also peeled off leaving raw flesh underneath. Janak, who could not even cry for many months after birth, gave a guttural, strangled scream that sounded more like a baby lamb bleating before slaughter. When I heard this and saw him draw his legs up to his chest in pain, the weeks of suppressed tension and accumulated stress exploded. I left the room crying uncontrollably, just as Dr. Balsekar was entering. He asked me what was happening, and I just shook my head, unable to answer.

Before leaving the NICU that day, Dr. Balsekar asked Alan and me to sit down with him. Gently, he discussed with us the need for us to do things that would relieve our stress. "This will be a long process. We have to take

Janak's health one day at a time. Typically what happens is that one's adrenalin kicks in for the first week, and you are able to continue. But long-term, it is the low-grade stress that persists and will gradually build up and explode if it is not addressed. What kinds of things do you like to do?" he asked. Within minutes, he had arranged for us to swim at the beautiful club next to the hospital of which he was a member, and to accompany him to a classical Indian music concert that weekend. "Don't worry," he said, guessing that we would be nervous to leave Janak's side for several hours, "you will be with me, and I will have my pager so we'll know immediately if anything is going on."

Over the course of the several months that we were in Bombay, Mahesh and his wife Sheila took care of us in a way that I doubt modern physicians take care of people in America. They invited us to their house for dinner, helped us to find places to live in Bombay, and put up with all our questioning on medical topic. Mahesh encouraged us to call him at any time of the day or night if we had questions or concerns (we only did this a few times, because our Western attitudes to disturbing people unnecessarily were ingrained). He was used to this, he said, because Indian patients considered it a right. One night when we were at his house for dinner, the phone rang non-stop, with many of the calls being for small things that could have easily waited until morning. When Janak was ready to leave the hospital, it was Mahesh who drove us home. A few days after coming home from the hospital, Mahesh and Sheila made a house call on their way back from a dinner engagement to relieve our worry about a problem Janak was having.

Mahesh's genuine interest in us, the long amount of time he was willing to spend with us discussing Janak's health or even just in social conversation, and the little things he and his wife did for us made us wonder if this was what the "family physician" of old (or perhaps the family doctor that still exists in rural America) was like: providing medical care based on relationships, rather than on money and schedules. We felt extremely fortunate to have had Mahesh as our doctor, in spite of his lack of practical experience with certain issues in neonatology.

On June 4, we returned with Janak to America. He was just under six pounds at the time, over three times his birth weight. Two days after we arrived in Seattle, we took him to the neurosurgery department of Children's Hospital. His head was growing much faster than normal, and Dr. Balsekar had advised us to see a neurosurgeon immediately upon our return to America. Thanks to a good friend who worked at Children's, we had been squeezed in to the schedule; otherwise, we would have had to wait — possibly weeks — for an appointment.

Walking into Children's Hospital, we experienced our first (and perhaps greatest) culture shock. The walls were brightly painted with cartoon figures in primary colors. Fish tanks and giant Mickey Mouse wooden figures decorated the hallways. Corridors, sections of the hospital and elevators were named for animals and decorated accordingly. We checked in at a desk, where we filled out forms, provided our insurance card so that the company could be billed directly, and then were given a small plastic blue card for Janak that we could show every time we visited.

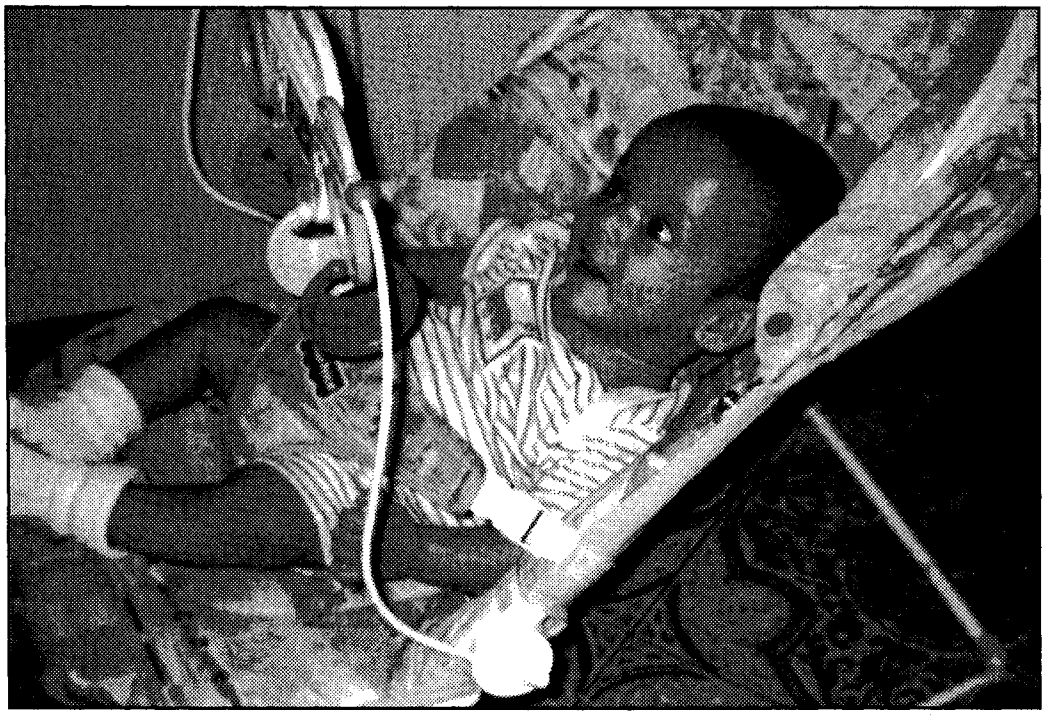
In the waiting room, children played video games, watched movies and careened about on mini-playground furniture. Toys and books littered the room.

When the neurosurgeon came to see Janak, he did a ten-minute examination. "There is something going on in his head," he said, referring to Janak's large head size. "I'd like to have a brain CT scan done on him now." We were ushered downstairs to a sophisticated room, where they strapped Janak into an infant CT scan tunnel. Within ten minutes, we had found out that although there was a little extra fluid above one of the ventricles in Janak's brain, there was no need for any immediate surgery or other action. When our bill arrived some weeks later, it was for approximately $1,500 plus another $750 consultation fee for the neurosurgeon.

"On June 4, we returned with Janak to America. He was just under six pounds at the time, over three times his birth weight."

What would have it been like in a similar situation in India? After seeing Children's, even Breach Candy — one of the best hospitals in India — seemed tattered and old. Breach Candy's plain yellow walls, which had seemed so friendly at the time, suddenly appeared peeling in retrospect. What we had thought was modern then now belonged in the Stone Ages. Breach Candy did not have a neurosurgery department or a CT scan. A neurosurgeon would have had to have been found and then called to the hospital for consultation (or Dr. Balsekar would have done the diagnosis). We would have had to take Janak to another clinic for the scan. The neurosurgeon and/or Dr. Balsekar would have spent a good hour discussing the situation with us. If we had to go to a different clinic, Dr. Balsekar or one of the senior resident doctors would have accompanied us there. Results would take the rest of the day to obtain. Our bill would have been, at most, Rs. 3,000 (less than $100) for the neurosurgeon, and perhaps another Rs. 5,000 for the CT scan.

So, in the end, would I rather have the extra time with my doctor friend (who is not necessarily trained and experienced in the field of diagnosis), or ten minutes with a trained but arms-length neurosurgeon? Let's face it, I can't have my cake and eat it too. In returning to a very



technologically competent environment with highly trained professionals, I have realized that I have to give up my desires for a doctor who is available to us day and night by pager and cellular phone, whose home number is one of the first things he gives to patients, who is willing to spend hours on end discussing our questions.

We have found a wonderful pediatrician in Seattle. She cares about us and about Janak, but she still works within the American medical system. That means our appointments with her are generally 15-20 minutes. If Janak is having problems, I call the clinic and am connected with a nurse who tries to answer my questions. She will check with the doctor, and convey messages to me. If I need to schedule an appointment, I sometimes have to wait four to six weeks, unless it's an emergency.

If we could paint the perfect scenario, it would be to have a doctor like Dr. Balsekar with access to the specialists and technology of America. That doesn't seem realistic now, but I can still dream about a day when everyone has access to medical care that has not just the expertise and technology of America, but the heart of India.

Janak has been alive for six months now and weighs a hefty 13 pounds. In medical terms, he is three months old, corrected age. To arrive at his corrected age, we subtract the number of months he was premature (three) from the total number of months he has been alive (six). His corrected age is what we should look at for developmental milestones. And I must say, it is easier to say he is three months old when people ask, so that I don't have to go into long explanations of why he is so small for six months.

Janak is enrolled in a high-risk follow-up program at the University of Washington. He will be watched and tested at various points along the way, to determine what — if any — effects his early birth have had on his development. We know the road ahead is still long, but we feel that he and we are incredibly lucky. There have already been several scares, but they have miraculously resolved themselves. The neurosurgeon at Children's Hospital told us we were one of the luckiest families he had ever seen.

The name Janak is the name of the King of all Kings, father of Sita, from the famous Indian epic "The Ramayana." We had chosen it on a lark, when we went to a wedding in Rajasthan and the groom-to-be was named Janak. Alan and I looked at each other, raised our eyebrows and found that we had finally found an Indian boy's name that we both liked. And it is not as if we had much time to decide at the end.

No matter what happens later, Janak is our miracle boy, King of all Kings in our mind, here on this earth because he persevered, and because somewhere in the plans of this Universe, he was granted a space. ❑