IVUN News

International Ventilator Users Network
Saint Louis, Missouri USA

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Breathing and Pregnancy

Amy Marquez (ames24@aol.com)

Danielle, Amy, and Steve Marquez

When I was in my early 20s (I am now 31), I asked my doctor, a general practitioner, about the possibility of having a child because of my diagnosis of SMA (spinal muscular atrophy) Type I, later questionable as to which type. Though surprised by the question, he responded very optimistically, reasoning that my scoliosis was not severe enough and there was enough abdominal space in which a fetus could grow. He recommended consulting a genetic counselor because SMA is a genetic condition. There was no mention of breathing difficulties that might arise.

Several years later I began to meet people outside of my social circle through the Internet, a tool that allowed people to get to know who I was as a person before they ever learned that I was disabled and used a wheelchair.

Early in 1997, I was introduced to Steve, a friend of a friend who was from Chicago, my home, but living in Maine. We began to get to know one another over the Internet, sometimes "talking" for six hours straight. In October, Steve moved back to Chicago, and soon we moved into our own apartment together. A year later, on October 17, 1998, Steve and I married and began discussing having a family.

In December 1998, we received the news that I was pregnant and would be expecting our first baby towards the end of August 1999. Although the pregnancy was unplanned, we were elated, but, due to my physical condition, concerned about what carrying a baby to term meant for both our unborn child and me. Our family doctor recommended that we seek prenatal care from a high-risk pregnancy team at a Chicago hospital.

In the days before our initial appointment, my husband and I had several in-depth and intense conversations covering all possible scenarios. We both wanted a family, we both wanted this baby, and we were both willing to make extreme "sacrifices" to ensure our baby was born healthy. We agreed abortion would *only* be an option if the doctors were 110% certain both the baby and I would not survive the pregnancy. If there was even the slightest chance our baby would make it, we were willing to try and needed the same commitment from the doctors involved.

The high-risk team did not offer us much encouragement. We were immediately advised to abort the fetus since there was no known record of a woman diagnosed with SMA Type I carrying a child to term. They predicted that the fetus would be born either stillborn or too premature to breathe independently and, therefore, survive. I was also warned that I would suffer severe strain and trauma to my lungs and would need to use a ventilator well before the second trimester. Furthermore, the odds of my ever being weaned from the ventilator were nearly impossible.

We decided to seek a second opinion and to find a doctor with experience in delivering babies of women with disabilities and willing to work with us. We found Eileen Murphy, MD, obstetrician/gynecologist at Northwestern Memorial Hospital and the Rehabilitation Institute of Chicago (RIC).

Although our initial conversation with Dr. Murphy was at times painfully honest in discussing compromised breathing, bed restriction, and the possibility of death for our baby and me, it was a hopeful one. We were convinced that having a successful pregnancy was a definite, but not easy, possibility. Dr. Murphy recommended that I undergo an ultrasound, and we saw our baby girl for the first time.

In early January 1999, physiatrist Kristy Kirschner, MD, pulmonol-

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Managing Noninvasive Ventilation: A Portuguese Experience

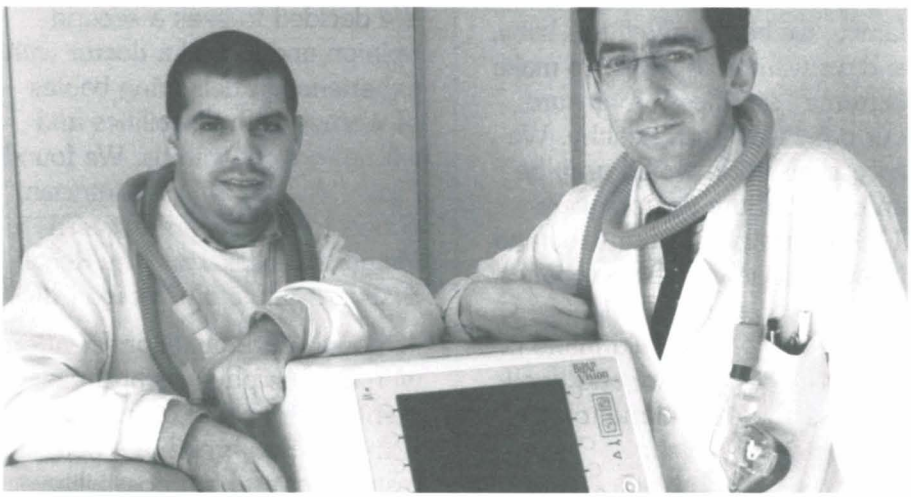
João Carlos Winck, MD, and Miguel Gonçalves, PhT, Rehabilitation and Lung Function Unit, Pneumology Department, Hospital São João, Faculdade de Medicina-Porto, Portugal (jwinck@hsjoao.min-saude.pt, fisiomiguel@hotmail.com)

Noninvasive ventilation (NIV) is becoming an evidence-based management approach to patients with acute or chronic respiratory failure. The past decade has seen a increase in the use of NIV, largely due to the development of nasal ventilation for greater convenience, comfort, safety, and less cost than invasive ventilation.

S. João Hospital is a university institution, the largest hospital in the city of Porto, in northern Portugal, drawing from an area of approximately 3 million inhabitants. In 2001, our department followed 43 patients using NIV at home. The Portuguese government pays for bilevel positive pressure units; volume ventilators are hard to obtain. Unfortunately home care is not organized and is mainly operated by private equipment providers. Caregivers are family members, with primary physicians and nurses visiting at home.

We manage chronic respiratory failure (CRF) patients in the Sleep Laboratory, part of the pulmonary function unit of the Pneumology Department, performing a wide variety of pulmonary function tests, arterial blood gas analysis, and sleep studies. Most of the patients evaluated in this unit have obstructive sleep apnea (OSA) syndrome, obesity hypoventilation syndrome, or CRF due to obstructive or restrictive syndromes. Our sleep service includes two beds for full polysomnography and up to four for simplified sleep studies. Multiple sleep latency tests are also performed regularly.

COPD patients with CRF are evaluated for long-term oxygen therapy. In case of symptomatic hypercapnia (high CO_2) with nocturnal hypoventilation and recurrent exacerbations with hospital admissions, a trial of NIV may be started.



Miguel Gonçalves, PhT, and João Carlos Winck, MD, in the sleep laboratory of the Pneumology Department, Hospital São João.

The individuals with CRF and restrictive syndromes are mostly people with neuromuscular disorders (ALS, myotonic dystrophy, Duchenne and other muscular dystrophies). Our four-step management approach includes evaluation of respiratory involvement, adaptation to NIV, follow-up, and respiratory muscle aids. Each step is done on an outpatient basis.

In evaluating respiratory involvement, we conduct pulmonary function tests (including inspiratory and expiratory muscle strength), home pulse oximetry, and arterial blood gas analysis. We also evaluate unassisted and assisted peak cough expiratory flows and maximum insufflation capacity. A formal sleep study may be also performed, especially if sleep apnea is suspected.

In initiating NIV, we connect the patient to a ventilator with a display (BiPAP® Vision, www.respironics.com), monitor leaks and titrate ventilatory parameters using plethysmography (Respitrace Plus, www.viasyscriticalcare.com), and pulse oximetry for SpO_2 and transcutaneous CO_2. Based on these physiological responses and patient tolerance, we choose the proper settings and the most efficient and comfortable interface. Finally we teach how to manage the ventilator and interface at home. A second pulse oximetry is conducted to ensure adequate settings.

After analysing the results of the first step, we evaluate the patient's adaptation to NIV and compliance. Difficulties with managing NIV at home are discussed with patient and caregiver: the interface is one of the primary concerns. Again based on physiologic data, a decision on changing settings, ventilatory mode, or interface is made, in order to improve comfort and success of home NIV.

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My Experience with Noninvasive Ventilation

Steve White (sjaw@attbi.com)

I have ALS, also known as Lou Gehrig's disease. I am totally paralyzed and dependent on a ventilator to breathe, but I have survived more than seven years due in large part to my decision to utilize noninvasive ventilation.

I believe in starting to use noninvasive ventilation early. It helps ensure a good night's sleep, so that you have more strength and energy during the day. I believe it also slows down the respiratory decline. As with everything, it takes time to obtain the equipment and supplies, find the best interface and supplies, and learn how everything works. I began using noninvasive ventilation during the night when my forced vital capacity dropped to 75% of normal.

My initial experience was not positive. The home care dealer delivered a Respironics BiPAP® S/T (www.respironics.com) and a nasal mask. The inspiratory pressure (IPAP) was set at 15 and the expiratory pressure (EPAP) at 5. When I asked how to adjust the settings, I was told the unit required a special gauge and could only be changed by a respiratory therapist after getting a revised prescription from my pulmonologist. I was never able to tolerate the setup for more than 20 to 30 minutes. The mask was uncomfortable and leaked no matter what I did, but the high pressures seemed to be the main problem.

Frustrated, I decided to learn more. From the alt.support.sleep-disorder newsgroup on the Internet, I learned about a large variety of masks and that I should try several until I found one that worked for me. In one of Dr. John Bach's books, I read that people with ALS rarely need supplemental oxygen. I also read that higher than necessary EPAP settings are often prescribed because this is a common setting for sleep apnea patients who need pressure while exhaling to keep the airway open. And, I read that suggested settings for IPAP range from a low of 6 to a high of 18, with people usually starting at the low end of this range and gradually increasing the pressure.

After discussing the problems with my pulmonologist, I learned that he had prescribed titrating the IPAP setting, slowly increasing it over time to a maximum pressure of 15. He was not surprised that I could not tolerate that high a setting. He contacted the home health dealer and requested a BiPAP unit I could adjust and several other masks to try. He also prescribed an EPAP setting of 2-3 and an IPAP setting to be adjusted to patient comfort.

The BiPAP® S/T was swapped for a Healthdyne Quantum PSV (since discontinued) which had front panel controls and readouts for adjusting settings. I gradually increased IPAP from an initial setting of 7 to a setting of 17. The respiratory therapist also brought 8 to 10 different masks for me to try. I found ResMed's Mirage® nasal mask (www.resmed.com) and Puritan Bennett's ADAM™ system with nasal pillows (www.puritanbennett.com) to leak the least and to be the most comfortable. I used the Mirage at night with a chinstrap to keep my mouth closed. When I needed to use the bilevel unit during the day, I used the nasal pillows because I could wear my glasses. (ResMed has since introduced the Ultra Mirage® that I currently use. I also currently use the nasal pillows with the Breeze™ SleepGear™.)

The bilevel unit worked well until my breathing became weaker, at which point I had some problems inhaling with enough force without consciously triggering the unit. It still worked but was much less comfortable. While it was

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Body Brace

Julie Levine (jmlpooks@sbcglobal.net)

Since June 1994, following the removal of a brain stem tumor, I have been an incomplete quadriplegic. I use BiPAP® at night, but breathe sufficiently without assistance during the day. I have tried several different masks, but always return to the Monarch™ Mini mask (no longer manufactured by Respironics). It provides me with the best ventilation, least leaks, and minimal amount of pressure on my face.

Over a period of time after my surgery, it became increasingly difficult to hold up my head. By 2000, my condition became chronic, and I developed swan neck syndrome; the cervical spine in the C-3 to C-5 region was curving in the shape of a swan's neck. After several surgical consults, I found a surgeon I felt confident could fuse my neck and, on November 6, 2000, after 10 hours of surgery, Duncan McBride, MD, of UCLA Medical Center, successfully fused my neck.

Upon awakening after the surgery, I discovered that my breathing was greatly improved and not labored. This was an unexpected plus. It seems the surgery relieved pressure on a nerve that affected my breathing.

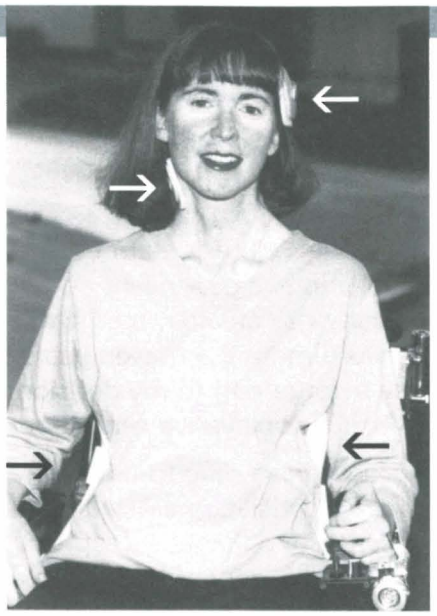
I wore a brace on my torso and neck for three months after the surgery, to guarantee a solid and successful fusion. However, after the removal of the brace, it became apparent that my head was turned to the right and tilted left. My spine was fused perfectly straight yet I was tilting. I was thrilled with the unexpected improvement in my breathing, but perplexed with the tilting of my head. The cause of the tilting was attributed to extreme atrophy of the sternacleidomastoid area on the right side of my neck. I remained this way for the next two years hoping my head would straighten out over time.

Then I began to search for an orthotics specialist. I met with many orthotists but none was able to correct the problem. Several suggested surgery to weaken the muscle on the other side or to fuse my head to my neck, neither of which choices appealed to me. Eventually I decided to search for Jan Krzeminski, CO, who had made a torso and leg brace for me five years ago.

I found Jan at Johnson's Orthopedics (7254 Magnolia Avenue, Riverside, CA 92405, 909-785-4411). After meeting with Jan and his associate, Michael Moncovich, CPO, my condition was diagnosed as torticollis, a contracted state of the cervical muscles with torsion of the neck. Generally this condition is found in children and is difficult to correct. When torticollis occurs in an adult, the correction is more challenging. Jan and Michael created a design that kept my torso stable with an attachment to straighten my neck. Their main concern was to correct the head alignment without creating discomfort or breakdown to my skin.

I have worn the brace (made of a thermoplastic composite) for several months. It is hard to believe that I struggled for so long without it. When I take the brace off, my head remains straight for a while. The brace has also helped improve the strength and mobility of my upper arms.

Another exciting event in the last year was the award of two grants for an enclosed vertical lift in my home. For the past eight years, I have slept in a family room off the kitchen and taken sponge baths for lack of a downstairs shower. I live with my widowed mother who is my sole support, and we could not afford moving or renovating.



I searched the Internet for grant opportunities and, with the help of my social worker Peggy Vivirito, I applied for and was awarded grants from The Change of Life Foundation and the California Spinal Cord Injury Fund. My synagogue also donated funds.

Obtaining approval of the lift was not easy. I applied for and received a permit from the city of Irvine, California. The biggest obstacle was the approval from the townhome association. After a three-month battle and a signed petition from 250 neighbors, permission was finally granted. I now have my vertical wheelchair lift. The lift has interlocking doors, enclosed in a shaft that is painted with blue and white clouds like the sky, and takes me from the downstairs directly into my upstairs bedroom. I am truly in heaven. ■

Interfaces, Ventilators, and Supplies

Mirage® Vista™ is the latest nasal mask available from ResMed Inc. (www.resmed.com). It features a unique "one snap elbow" and "set and forget headgear" that helps to position and fit the mask, eliminating the need for disassembly and readjustment after each use.

Pre-Owned Ventilators. HealthCare Dynamics, Inc., of Lawrenceville, Georgia, buys pre-owned ventilators and bi-level units that are no longer needed, and then sells them to home health care agencies. They do not sell to individuals directly. Check their site: www.healthcaredynamicsusa.com or contact them toll-free, 888-241-1663.

Reusable rubber suction catheters. Many people who use tracheostomy positive pressure ventilation prefer reusable red rubber tracheal suction catheters (Bard Medical Division of C.R. Bard, Inc., www.bardmedical.com) instead of disposable plastic catheters because they cause less irritation and are less expensive. E.A.Oppenheimer, MD, advises on cleaning them with soap and water after each use. "Soaking in hydrogen peroxide can be used if there is stubborn mucus sticking to the inside of the catheter. Some people use a diluted vinegar solution to decontaminate the catheter, similar to the method used for ventilator circuits. After washing and rinsing well, the catheter is air dried, and then kept covered with a dry clean towel. This is called the 'clean technique' rather than the sterile technique. In my experience, this works well and lower respiratory infections do not occur often." Ask your local home health dealer for these reusable catheters.

Pulse Oximeters. In order to monitor oxygen saturations and be alert to hypoventilation, especially during upper respiratory tract infections, it might be advisable for ventilator users to invest in a finger pulse oximeter. There are many on the market, but the Onyx® 9500, manufactured by Nonin, Inc., is popular. The Onyx costs about $400 and is available through Aeromedix (888-362-7123, www.aeromedixrx.com) and home health care dealers. A doctor's prescription must accompany the order.

Nasal-Aire®, manufactured by InnoMed Technologies,Inc. (800-200-9842, www.innomedinc.com) and distributed by Medical Industries America, Inc. (800-759-3038, www.medindustries.com) is a low-profile interface for bilevel and CPAP use, available in five sizes. ■

Ron Mills, who has ALS, wearing the Nasal-Aire®.

Managing Noninvasive Ventilation

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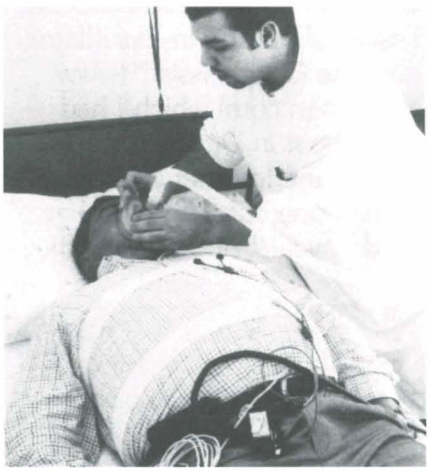
Neuromuscular patients have very low vital capacity and their thoracic cages are very stiff. Mobilization of the lungs to prevent chest wall contractures and lung restriction is achieved by providing regular deep volumes of air (insufflations) or deep breaths with NIV. We teach the patient to "air stack" with a manual resuscitator and to practice several times at home. The objectives are: increasing their cough flows and maximum insufflation capacity, maintaining or improving lung elasticity, and preventing or eliminating atelectasis (incomplete expansion of the lungs). We also teach our patients to "air stack" with glossopharyngeal or frog breathing.



Patient using the CoughAssist™ via facial mask.

Most of these patients have inefficient cough due to muscle weakness, and we teach the family manually assisted coughing techniques. If the patient cannot achieve good cough flows with manual techniques, the next approach uses mechanically assisted cough (CoughAssist™, www.jhemerson.com) to help clear airway secretions.

The CoughAssist is not commercially available in our country yet, but we are using one unit in our department in a clinical study of the efficacy of the device. Our preliminary results confirm good tolerance and physiologic improvement in patients with either restrictive or obstructive disorders, and the usefulness of the CoughAssist as a complement to NIV. ■

in for repairs, I was loaned a Puritan Bennett KnightStar™ 335 with an adjustable sensitivity feature that determines how strongly you need to inhale to trigger the unit. This unit was much more comfortable to use.

I started investigating a volume ventilator because I was using the bilevel almost fulltime in what amounted to life support, and my ALS had progressed so that I was almost totally paralyzed. I needed a unit with alarms. After considerable research, I selected the LTV1000® from Pulmonetic Systems, Inc. (www.pulmonetic.com) and attended an in-service training session before trying a demonstration unit.

My insurance carrier initially rejected coverage for the LTV, considering it a backup for the bilevel, but I immediately contacted my employer, my case manager, and my pulmonologist to clarify that I needed a ventilator that was approved for life support. The alternative was a tracheostomy, which would be much more costly. The insurance company quickly approved the LTV. (I now have a pair of LTV950® ventilators.)

The LTV was mounted on the seatback of my power wheelchair using a slide bracket to allow easy transfer between my wheelchair and a bedside stand. A battery box containing a U1 gel battery was also mounted on the back of my wheelchair. This MK battery (www.mkbattery.com), that we charge nightly, will power the LTV for about eight hours. I use the LTV in pressure mode, more comfortable for me than the volume mode, with essentially the same settings that I used for the bilevel.

About six months after I obtained the LTV, I caught a chest cold and was hospitalized. Several doctors, including my pulmonologist, said it was time to get a tracheostomy. I refused. They tried various techniques to clear my lungs including deep suctioning, nebulizer treatments, quad cough, and a percussion vest – with only modest success. I asked about the In-Exsufflator, now the CoughAssist™ (www.jhemerson.com) which I had read about in Dr. Bach's book and on the Internet. The hospital had one but it had not been used in years, and claimed they were no longer certified to use it. After several days of antibiotics and repeated attempts by the respiratory therapists to remove secretions from my lungs, I asked to go home even though I was still quite weak.

Once home, the home health dealer brought the CoughAssist for me to try. It worked superbly, and I coughed up large amounts of secretions in about 45 minutes. I used it several times over the next few days and rapidly recovered my strength. Within a week of leaving the hospital, I was back to feeling normal and returned to work. My insurance company purchased the CoughAssist that I use as needed to clear secretions or aspirated food or drinks and to expand my lungs.

I do not plan on a tracheostomy until my swallowing worsens to the point that I cannot manage my saliva. Then I will get one primarily to protect my airway. I hope that is still a couple of years away. Until then, I firmly believe noninvasive ventilation is the answer. ■

Noninvasive Ventilation Alternatives in Neuromuscular Disease Conference, San Diego, California, November 2002

Some of the speakers, ventilator industry reps, and conference planners. (L to R): Angela King, RRT, Pulmonetic Systems, Inc.; Rich Clingman, NIVnetwork.com; Judith Fischer, IVUN; Barbara Rogers, Respiratory Resources, Inc.; John R. Bach, MD; Judy Whitman, RRT, and Mary Marchand, Advanced Respiratory.

Editor's Note: Steve lives in Oregon with his wife, Janis, who is his primary caregiver, and their teenage daughter Alissa. He uses augmentative communication, currently a TrackIR head mouse (www.naturalpoint.com) and Skeleton Key onscreen keyboard (www.catalaw.com/sk) with a sophisticated audio/video control setup. He has written articles on the subject available online (www.alsa-or.org/adaptive/adaptive).

ogists Chris Winslow, MD, and John Parsons, MD, completed the team of RIC doctors to assist throughout the pregnancy. Every member of the RIC team was willing to listen, to work with us, and to take whatever risks were necessary to help bring our baby into this world alive and healthy.

During the first trimester, I endured serious morning sickness, but when the second trimester arrived, it was as if a switch had been flipped, and the nausea and vomiting abruptly stopped. I soon felt healthy and strong.

The team decided to take advantage of my health to prepare for occasions during the remainder of the pregnancy when I might not feel so strong.

I had undergone a tracheotomy for secretion removal when I was 5 years old due to my limited ability to cough and numerous bouts of pneumonia. My neck size did not grow "normally" as a result of SMA, and my tracheostomy tube size and style remained the same since age 5.

I never required the assistance of a ventilator prior to being pregnant, but on the assumption that I would need ventilatory assistance in the later stages, I worked with a variety of different tracheostomy tubes and ventilators to get used to having a machine breathe for me, and finally became comfortable using a BiPAP unit whenever necessary.

During the second trimester, I experienced difficulty breathing only after I consumed a full meal. Dr. Winslow monitored this and found that my oxygen saturation levels dropped significantly, so a BiPAP unit was delivered to our home, and I used it whenever I experienced any difficulty breathing. It was recommended that I eat continually throughout the day, rather than two or three full meals, thus avoiding overcrowding. Such simple advice proved to be vital in easing my breathing difficulties.

CHRISTOPHER WINSLOW, MD, Amy's pulmonologist states, "When Amy presented to me 10 weeks pregnant, her lung function was 80% lower than the previously reported lowest value in the medical literature for a pregnant woman with SMA. After our initial meeting, I discussed her case with a dozen pulmonologists in my group, and all (including me) predicted that she would require full-time use of a ventilator by her 20th week. The fact that her body was able to carry this pregnancy with minimal support from assisted ventilation, i.e., BiPAP®, is truly remarkable. It should prompt physicians to rethink conventional wisdom that is based on nondisabled women during pregnancy. The body seems to have a capacity to adapt that is under-appreciated. The case study of Amy's pregnancy will be published in early 2003 in the *American Journal of Physical Medicine and Rehabilitation.* Women with SMA who are considering pregnancy may wish to discuss this article and others with their physicians."

Somewhere beyond the fifth month, I began to experience physical discomfort and pain, initially mild and alleviated by a small pillow, stretching, and/or the use of a hot/cold pack. Nevertheless, the pain grew more severe, and I went into labor over the Independence Day holiday. I went into the hospital, was monitored over the span of seven hours, did not dilate at all, and was released. I later developed body shakes and an overall restlessness, regardless of my surroundings.

On July 6, 1999, Steve and I met with Drs. Kirschner and Murphy and together determined that the best solution would be to admit me to Northwestern Memorial Hospital so that the team could assist with my pain management up until the birth. As anticipated, my pain and discomfort intensified as our baby increased in size, taking up more and more of my internal space. By mid-July, the restlessness and pain became unbearable. No amount of therapy, repositioning, or pain medication would help. Finally, Dr. Murphy agreed to deliver our baby on July 19, 1999.

I hoped my body would accept an epidural and that I could be awake to welcome our child into the world. However, the epidural would not take due to my scoliosis, and all involved agreed to move ahead with complete anesthesia. I was connected to a hospital ventilator and awakened hours later by Dr. Murphy and a beautiful bundle sleeping on my chest.

Steve and I were able to spend a few moments with our new daughter, Danielle Coral (born at 34½ weeks gestation, 17 inches long, weighing 4 pounds, 10 ounces) before I was taken to the surgical ICU, where I remained for overnight monitoring. I continued to use the ventilator for several hours after surgery, and finally had it disconnected on the condition I would use it should I experience any trouble breathing. I never did.

Steve and I look at Danielle, today a happy 3½-year-old, and are thankful that we sought a second opinion. We could not have managed without the constant professionalism, compassion, and support of the RIC team. We are seriously considering another child, but only if we can have the same team of doctors by our side. ■

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Children Who Are Medically Fragile or Technology Dependent: Building Relationships, Respecting Diversity. Loews Philadelphia Hotel, Philadelphia, Pennsylvania. Contact Ken-Crest Services, 215-844-4620, www.kencrest.org/medfrag/conf.html.

APRIL 10-12

FOCUS on Respiratory Care Annual Conference. Opryland Hotel, Nashville, Tennessee. Contact Focus, 800-661-5690, www.foocus.com.

JUNE 20-22

Families of SMA Conference. Hyatt Regency-Capitol Hill, Washington, DC. Contact Families of SMA, 800-886-1762, www.fsma.org.

JUNE 26-28

CCHS Family Network Conference. Caribe Royale Resort Suites, Orlando, Florida. Contact Mary Vanderlaan, 607-432-8872, www.cchsnetwork.org.

JULY 10-13

Parent Project Muscular Dystrophy Conference. Omni Netherland Hilton, Cincinnati, Ohio. Contact Parent Project, 800-714-KIDS, www.parentprojectmd.com.

OCTOBER 23-26

Ninth International Conference on Home Ventilation. "Noninvasive Ventilation: From the ICU to Home." Caribe Royale Resort Suites, Orlando, Florida. Contact IVUN, 314-534-0475, www.post-polio.org/ivun OR the American College of Chest Physicians, 847-498-1400, www.chestnet.org.

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