Escaping Hurricanes Katrina and Rita

Jon Steven Leslie, Jr., formerly of New Orleans, Louisiana, bordcountry921@yahoo.com

I am 23 years old and have spinal muscular atrophy. When I was five years old, I had a bad case of pneumonia and was trached. I now use an LP6 (Puritan Bennett).

Before Hurricane Katrina, I had my own van and motorized wheelchair and was living on my own in an apartment supplied by House of Choice. It was the agency that also supplied my personal care attendants, who had been taking care of me around the clock.

Just before Katrina hit, I had a new aide named Willie Lee Cargo; she started working for me the month before.

At first, House of Choice was considering not evacuating, but I managed to convince them to evacuate me to my dad's house in Winnie, Texas, located between Houston and Port Arthur. Willie, her daughter and I left the next day, driving from 9 a.m. that Sunday to 2 a.m. Monday morning. My ventilator was powered by an external battery and an electric generator, enough for the long drive.

(It was a good thing that we left, because my apartment in New Orleans was completely flooded and is uninhabitable.)

We all stayed at my dad's now very crowded house. A week went by, and Willie did not have any time off from her attendant duties for me.

If I hadn't been able to talk, I would have been in a lot of trouble, because Ms. Willie was still learning how to take care of a ventilator user.

She eventually found a house in Texas, and let me move in with her.

When Hurricane Rita hit, we had to evacuate again—this time to Kerrville, Texas. We had to stay about three weeks. When we returned, we were relieved that there was no damage to Willie's house.

In all this time, Willie has not been paid for anything she has done or been given any kind of help with me. She says she doesn't want to ever go back to Louisiana, but that we will definitely keep in touch with each other.

I am moving into my own apartment in St. Rose, near Kenner, Louisiana, in the next month. An agency called AAA Your Choice will provide my new attendants.

I hope life gets back to normal.
Medicare Changes Payment for RADs

Who is affected?
Medicare beneficiaries who use bilevel ventilatory equipment (called respiratory assist devices or RADs) with backup rates, e.g., users of Respiration’s BiPAP® S/T and BiPAP® Synchrony; ResMed’s VPAP® III ST and VPAP® III ST-A; or Puritan Bennett’s KnightStar® 330.

The Changes:
Respiratory assist devices (RADs) with backup rates are no longer considered durable medical equipment (DME) requiring frequent and substantial servicing (FSS). The new classification is best described as “rent-to-own.” Title to the equipment will pass from the DME supplier to you. Medicare payments will end after 13 months, and you will own your RAD with backup rate. Medicare is slated to pay for maintenance and servicing but the rules have not been decided by CMS, and CMS has discretion on how/when payment for maintenance and servicing will be made.

There will be a transition period for devices which are currently being rented to Medicare beneficiaries and paid for under the FSS rate. Your rental months paid prior to April 1, 2006, will not count toward the rental payment cap.

CMS reports that your coinsurance amount may decrease, beginning with the fourth month of rental. For example, if you had been paying up to $128 per month, your coinsurance decreases to around $96 per month.

What is the back story?
In looking for ways to save Medicare dollars, CMS determined that these devices were in the wrong payment category. An inspection of the equipment and home health suppliers by the Office of the Inspector General (begun in 1999 with a final report in 2001) revealed that some durable medical equipment suppliers were not fulfilling the responsibilities required of them when receiving the higher payment for frequent and substantial servicing.

Unfortunately, CMS does not consider the cost of respiratory care services that are needed to help you use your RAD. Reimbursement for these services has been bundled together with the reimbursement for the equipment. It is predicted that this cut in payment from Medicare may result in lesser respiratory care service from the RTs that work for the suppliers/home health care company.

IVUN and other concerned groups, both respiratory health professional organizations and organizations for people with neuromuscular conditions, have repeatedly written to CMS (starting in 1999) emphasizing that many individuals who use these devices depend on the backup rate feature to initiate a breath when they cannot initiate breaths on their own. To assure patient safety, the devices require frequent and substantial servicing. Unfortunately, CMS ruled otherwise. ▲

The advocacy efforts continue, and we will report any changes in status of this decision in the next issue of Ventilator-Assisted Living or on www.post-polio.org/ivun.
To: Members of International Ventilator Users Network  
Fr: Virginia (Ginny) Brickley

I want to keep you informed, through the spring, summer and fall editions of this newsletter, on the progress of the VUME Project—funded by the Christopher Reeve Foundation (CRF)—in which I am privileged to be engaged.

**The Motivation:** I write this memo with sadness but also with hope. The grant from the CRF was a “Quality of Life” grant, a program conceived by Dana Reeve, who died at age 44 on March 6. May we all exert an extra measure of determination to make this health promotion project a resounding success in her honor.

**Project Goal:** The project goal is to educate all parties who may be involved in medical emergencies experienced by ventilator users to perform their respective roles with fewer complications, increased confidence and more successful outcomes. “Parties” are users of home mechanical ventilation, their support person(s) and any health care professional they may encounter.

**Project Plan:** The project's major steps are to develop a questionnaire for each of the three groups about their emergency experiences; to analyze the responses; and to use the information gleaned to develop specific guidelines for each group.

**Questionnaire Development:** On February 28, five Chicago-area members shared their medical emergency experiences and lessons learned in a two-hour brainstorming session. The group created a powerful list of issues to use in drafting the three questionnaires. In so doing, Linda Bieniek, Mary Ann and Bill Buckingham, and Valerie and Rick Brew-Parrish also gained a reputation as "the liveliest group we've had around here in a while," according to the director of the Southwest Community Center which hosted us.

**Your Turn:** By the time this newsletter goes to press, the questionnaires will have been sent to IVUN's Consumer and Medical Advisory Boards for critique. The VUME Questionnaires will be distributed in early April. But please don't wait until then to start making note of your experiences. The more thought out and in depth your responses to the questionnaires, the more powerful will be the end product. So we invite you to pick up pen or mouse right away.

While these are certainly not the only questions, the first and most comprehensive questions on each questionnaire are:

- What **bad** experiences have you had during medical emergencies?
- What could have mitigated or eliminated the problem(s)?
- What **good** experiences have you had?
- What contributed to the positive outcome(s)?

Questions?
IVUN's VUME Project  
c/o Virginia Brickley,  
Project Leader  
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Elmhurst, IL 60126  
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False Security: The Old Plan

I have no use of my arms and use a Bi-PAP® for sleep. Charlotte has been my caregiver since we married in 1967. She is almost supernaturally healthy and we have rarely faced the need to “outsource” my care—even as we aged, and even as I have increasing problems with balance and weakness in my legs due to post-polio.

Beginning in the mid-'80s, I began to hire assistants to help with some routine tasks at work (e.g., around lunchtime; in running errands). In 1989, I started to do all my professional travel with a male companion who could manage the increasing number of strength moves required to get me in and out of cars, airplanes and hotel rooms. In the late '90s, by a fortunate fluke, I was able to get a long-term health care policy through my employer.

And the final big piece of the plan (or so we thought) came about when we discovered, also in the late '90s, that it was going to be difficult to get me into an assisted living facility if I needed one, given my need for nighttime ventilation. In Virginia, and many other places in the US, the label “ventilator-dependent” excludes you from anything but a skilled care facility.

Our response to this, in 2001, was to use the money we had saved for buying into a retirement community to finance a major addition to our modest bungalow—one that nearly doubled its size by adding a large master bedroom with roll-in shower and a suite of rooms with a separate deck and private entrance that could be used by a live-in caregiver.

We were, and continue to be, very pleased with this addition. It will work well if we have to go to a permanent arrangement with a full-time caregiver.

The Rude Awakening: Gap in the Plan

In early December of 2005, however, we suddenly found ourselves in the emergency room of a local hospital late at night. Charlotte had what turned out to be a ruptured appendix. She was very ill for several days and had to be quite careful with the recovery for six weeks afterwards.

My doctor had assured me some years ago that in an emergency like this, he would admit me to the hospital for a couple of days while I worked out other arrangements. So we thought we had a workable emergency plan.

We were wrong.

What happened was this:

1. Charlotte was the one with the medical emergency, and we all needed to focus on her problems, so the ER staff and I took steps to make it look as though the backup plan for
me was working brilliantly. That is, we lied to her. Because insurance rules and hospital practices have changed, the old plan no longer worked.

2. The ER physician couldn’t get me admitted, but worked out a temporary arrangement to get me hooked up to my Bi-PAP® for a few hours in Charlotte’s room until the next morning (Monday), when the hospital social workers would be on duty. This depended on the good will of the nurses caring for Charlotte, and my willingness to ask for very little from them.

3. My internist was away at a medical conference. The physician making rounds for him on Monday morning decided that the only solution was to force the hospital to admit me. He went all-out to get this done, while I did what I could to stay with Charlotte immediately before and after her emergency surgery.

4. I was in fact admitted to the hospital later in the day on Monday, but in order to accomplish that, the physician wrote orders without my knowledge indicating that he thought I had “chronic respiratory failure” requiring the use of a “ventilator” for substantial portions of the day (for rest) and night (for sleep).

5. Then the comedy began. The hospital—a large, regional medical center and teaching institution—reacted by focusing on the words “respiratory failure” and “ventilator.” I was whisked away from Charlotte’s room, where she was awaiting the call for surgery, and taken to the spiffy unit where patients are evaluated for placement in various versions of intensive care. The staff there decided to admit me to a “monitored” bed.

6. From my fancy monitored bed, I was dependent on the hospital social workers for help in working out alternatives and on the nursing staff for sneaking me off the ward to visit Charlotte. When the social workers started calling around town using the term “ventilator-dependent,” my alternatives quickly got limited to three: staying in the hospital indefinitely (Plan A); around-the-clock care at home with a licensed nurse (prohibitively expensive for me); or admission to a skilled care nursing facility. The only nursing homes willing to take me on such short notice were locked-ward private pay dementia units that did not accept Medicare. (I am not making this up.)

7. So, by Wednesday afternoon the social workers had more or less decided on Plan A with a twist. I would stay in the hospital until after Charlotte was discharged and had spent a few days at home recuperating and setting up an affordable homecare arrangement. When consulted, Charlotte firmly rejected that plan in favor of her own, which was, “When I go home, he goes home.” (The social worker escaped without injury, and there was only minor damage to the hospital room.) Back to square one.

8. Later Wednesday afternoon, three other things happened. Mercifully, they occurred outside Charlotte’s hearing. The first was that Medicare retroactively denied my admission to the hospital, and my secondary insurance followed suit.

The second was that the hospital decided to treat the first three days of my stay as free of charge, opening continued, page 6
the money drain only after the denial by Medicare.

The third was that the hospital decided I didn't need a monitored bed after all and could be moved to a much less expensive room.

9. In that room, I finally managed to focus on my own situation and set up Plan B. It was a combination of unskilled homecare, several days of help from my out-of-town brother, visits from housekeepers, and various other bits and pieces related to my work. Charlotte and I went home together on Friday.

We were greeted by my brother and, moments later, by homecare workers. By the end of the weekend, my brother and I had figured out how to reduce my care (in the house, at least) to zero strength moves. The need for homecare workers evaporated by Monday, and the need for housekeepers diminished steeply over the next two weeks. Charlotte's activities were limited for another month after that.

We were lucky, overall, but it's best not to rely on luck. We needed a better plan for emergencies. Here's what we came up with.

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Useful Facts about Respite Rooms

An increasing number of full-service retirement communities—as well as some smaller, assisted living facilities—set aside a few rooms for “respite care.” They are typically used by families that need to place cognitively disabled relatives in temporary care while the family travels or just takes a break.

These respite facilities can respond to emergencies best if they are dealing with people who have already gone through a “prior approval” screening process. That involves touring the facility with its marketing director to find an appropriate unit; having a personal interview with the nurse in charge of the unit during which the details of your care can be discussed frankly; filling out a variety of forms asking for financial, medical, daily care and “social” information; and having your primary care physician give you a routine physical examination in order to describe your current medical needs directly to the facility, as well as to certify that you are free of TB and other infectious diseases.

On that prior approval basis, you can get on the assisted living facility's active list for respite admissions. Then if there is an emergency that disables your primary caregiver or defeats your other backup arrangements, and if the facility has an available room, they will take you, no questions asked.

For obvious reasons, it's best to be on the active list at several assisted living facilities, just to be sure at least one of them will have a room when you need it.

Staying on these active lists requires a recertification from your primary care physician every six months, and that means an office visit. One of the best facilities in my area also requires people on their active list to make at least one overnight stay within 30 days of the first physician certification. This is, I suppose, a good test run for both sides.

Cost: Make up your mind that it's going to be private pay.

If you have been living at home, your dependence on a caregiver will not qualify you for admission to a
hospital when that caregiver becomes disabled. At least this is true for Medicare, and probably for many private insurance plans. You would probably be qualified in those circumstances for admission to a skilled care unit, but that’s no help if the insurance rules require an approved hospital admission prior to transfer to skilled care. Catch-22.

The good news is that these respite rooms are reasonably priced, and they don’t seem to vary much according to the level of care needed by the client. I need quite a lot of help in the early morning and the late evening, a little help around mealtimes and with transfers. Prices by the day, for the level of care I need, range from $85 to $130 in my area.

**But Will They Take Us?**

Most of the places I called were very receptive to considering me for prior approval and were not at all concerned about my use of a Bi-PAP® as long as nobody said the word “ventilator-dependent.”

I went to visit four places that were willing to let me go through the admission process in advance. One turned me down because I answered “no” to the question, “Can feed self?” Another rented respite rooms only by the month and rarely had one available. The other two, however, were fine. Making these visits was psychologically demanding. Depressing, even. But I’m glad I did all of them.

**My New Plan for Emergencies**

**Step One:** Getting a respite room. I’m now on the active list at two large retirement communities, at least one of which will almost certainly have a room for me in an emergency (or be able to make one available). That will take care of the first few days.

**Step Two:** Setting up homecare. One of these retirement communities also has a large homecare operation, and I filled out the forms necessary to get on their active list of clients as well. (This involved having the nurse manager visit our house to take a tour and to assess my physical abilities.) Once in the respite room, I am assured it will be an easy matter to interview homecare workers and agree upon—and test—a reliable schedule.

**Step Three:** Working on financing. I’m trying to get an exception made to my secondary health insurance policy so that emergency respite care and homecare would be covered, at least partially. In lieu of that, I will do what I can to set aside enough to cover the costs for the three months of respite or homecare it will take for my long-term health care insurance to take over.

I think it’s basically sound, as plans go. If anyone sees any flaws, other than the fact that even the best laid plans sometimes fail, let me know!

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"At home, I use the new BiPAP® S/T System with Encore® Pro Smart Card® with integrated humidifier. When I first got this machine I was unpleasantly surprised to find that there was no pure “timed” option but a timed backup rate that required some getting used to.

"For travel, I use a 10-year-old BiPAP® S/T®, set to the timed option.

"In the hospital, I used the old machine, and that was a good thing, since that helped convince them it wasn’t a “ventilator.” The new machine has a fancy set-up screen which apparently persuades the nursing staff to call in respiratory technicians. My old machine simply has an on-off switch, with other controls hidden behind a panel on the back.”

-Lawrence C. Becker
An Alternative to a Trach Tube
Dan Vachon, Somersworth, New Hampshire, drv@unh.edu

I started using ventilation for sleeping in 1962, after polio, using negative pressure with a cuirass (chest shell). I used that until 1979 when I developed difficulty in breathing at night. The cuirass was not providing me with enough ventilation. My physician suggested a trach as the only alternative. I tried it for a year and found the routine most disagreeable.

In searching for another alternative, I discovered the work of Augusta S. Alba, MD, New York City. At that time, she had been a promoter of noninvasive positive ventilation by mouth for many years. I wrote to her, and she suggested trying the Bennett Lipseal. One of my new physicians agreed.

In 1980, I started using my first Bennett Lipseal. It was such a relief to be rid of the trach and all the care it involved (suctioning, stoma care, cleaning, maintaining sterility, etc.)

It took me only two nights to become accustomed to the Lipseal. However, I did make a major adjustment to the apparatus. It comes equipped with a very flimsy strap that, in my opinion, isn't strong enough and only lasts a few days before breaking.

So I had a head harness made using the clip that came with the Lipseal and some 1-inch nylon webbing. The harness consists of two straps—one connects to the Lipseal and goes behind my neck with Velcro on it so I can adjust the tension; the other strap goes over the top of my head and connects to the first strap near my ears. These two straps are tied together by a third strap that goes from the center of the neck strap to the center of the head strap. (See photograph.)

To care for the Lipseal, I disassemble it every morning and rinse it under running warm water and set it aside to dry. The nylon strap is tossed in the laundry once a week.

I started using the Bennett Lipseal with the old Bantam vents. Now I am using the Newport HT50®. For humidification, I use the HC150 (Fisher & Paykel Healthcare), although in my opinion, it is not as good as the now discontinued Cascade from Puritan Bennett. ▲
ComfortLite™ 2 Nasal Mask (www.Respironics.com)

The new mask offers three cushion options.

- Pillows Cushion (see photo), that inserts slightly in the nose; available in four sizes.
- Simple Cushion™, that rests on the tip of the nose; available in four sizes.
- Direct Seal™, that fits just outside the nostrils for people who want a pillow-like cushion without any insertion in the nostrils; available in sizes one through six.

The headgear design eliminates facial pressure points. Stability of the fit relies on the headgear not the nostrils.

DC to DC Power Source for Pulmonetic Systems Ventilators

The PowerTech Vent Power Center safely converts energy from your wheelchair’s batteries and powers any of the LTV® series ventilators from Pulmonetic Systems, a division of VIASYS Healthcare (www.pulmonetic.com).

The small compact device measures 5” x 6” x 1.” Attach to your power wheelchair or carry in the LTV’s backpack and operate the LTV directly from the wheelchair’s 24-volt batteries. Use with the LTV mounted directly to your chair back. Goodbye trays, and big, bulky, portable vent batteries.


Vaccine News

Booster shot for whooping cough

Whooping cough (pertussis) cases are on the rise in both adolescents and adults. People immunized during childhood were thought to have life-long protection, but it is now apparent that the immunity provided by the vaccine is only good for about 10 years.

Although whooping cough is more severe in infants, it causes a prolonged cough in adolescents and adults and may last from two or three months to sometimes eight or nine months. A highly contagious disease, pertussis can be easily transmitted by coughing and sneezing.

A new combined vaccine booster for tetanus-diptheria-pertussis for adults, recently approved by the FDA, is now available. Check with your physician and/or pulmonologist for advice about receiving the shot.

Influenza vaccine advised for children with neuromuscular conditions

A recent study by researchers at the Children’s Hospital of Philadelphia (CHOP) found that children with neurological and neuromuscular conditions were at highest risk of respiratory failure due to influenza. The Advisory Committee on Immunization Practices added these conditions to the list of chronic conditions warranting an annual flu vaccination.

Ron Keren, MD, MPH, CHOP pediatrician, says, “Children with neurological and neuromuscular disease often have diminished pulmonary function and ability to handle secretions at baseline, and therefore are more vulnerable to respiratory complications of influenza.” The same statement can apply to adults with these conditions who are also advised to obtain an annual influenza vaccination.
2006 Camps for Ventilator-Assisted Children


JUNE 25-29. Pennsylvania Vent Camp. Camp Victory, Millville, Pennsylvania. Contact Lois Marshall, Pediatric Critical Care Department, Penn State Children’s Hospital, 717-531-5337, lmarshall@psu.edu.

JULY 2-7. Camp Inspiration. Rocky Mountain Village, Empire, Colorado. Contact Monte Leidholm, RRT, The Children’s Hospital, 303-837-2502, leidholm.monte@tchden.org.


Calendar 2006


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VL 20/1
THE RESEARCH FUND PROPOSAL DEADLINE EXTENDED

What? Call for Proposals for The Research Fund

Who should apply? Researchers investigating the late effects of poliomyelitis and/or neuromuscular respiratory disease. The Fund's priorities are to provide funds to initiate new research; to continue notable projects; to combine with other resources to complete research into post-poliomyelitis and neuromuscular respiratory research.

How much? $25,000 for 2007

Deadline for Phase 1: August 1, 2006 (Applicants will be notified by September 1, 2006, if accepted for Phase 2.)

Deadline for Phase 2: November 1, 2006