

Safety Issue Generates Practical Solutions

Sandra Stuban, RN, Fairfax, Virginia, stubanrn@aol.com

Accidents happen. But when you are a ventilator user, they can have deadly consequences. Because most of us ventilator users have limited use of our arms, and in some cases no use at all, we must rely on others to reconnect tubes that pop off and to respond to ventilator alarms in the middle of the night in a timely manner. In this sense we are dependent on others for our safety and our very existence. However, fatal accidents are unnecessary and preventable.



Sandy Stuban, RN, using her computer via a sensor next to her check, with son, Nick.

Prompted by the news of the accidental death of a ventilator user caused when the ventilator tube popped off his trach at night and the caregiver slept through the alarm, I asked an online ventilator discussion group, “How can we keep ourselves safer, especially at night?” The responses were swift, imaginative, practical, high-tech, low-tech and no-tech – a creative outpouring of ideas from vent users, and some respiratory therapists, to benefit other vent users.

Preventing disconnects. Silas and Dave use rubber bands, or ponytail holders, to prevent pop-offs. One end is threaded through the opening on the trach flange where the trach collar is attached; the other end goes up over the tube holding it firmly in place. Cathy uses a similar technique but with a strip of elastic gauze tied around her neck. Many commercial trach-securing, or anti-disconnect, devices are also available. Check IVUN’s Resource Directory for Ventilator-Assisted Living, www.post-polio.org/ivun/d.html.

Airway Pressure Monitors. These pressure monitors can be attached to bilevel or CPAP units or volume ventilators. Marcelo, who uses a BiPAP®, relies on this monitor to alarm when low pressure is detected, such as during disconnects or pop-offs. From her experience with this same system, Cathy says that its alarm is much louder than her ventilator alarm. Cyndy, a respiratory therapist working for a large ventilator manufacturer, also recommends a secondary alarm system because the system alarms when the ventilator alarms during pop-offs, providing twice the volume. Angela, also a respiratory therapist, while recommending this system, warns that occasionally a bilevel unit or an inline heat moisture exchanger (HME) can “fool” the low pressure alarm so it should be tested carefully first. Example: www.msdistributors.com/biomed/meh/BIPARHTM.

Baby Monitors. Many ventilator users say they rely on baby monitors at night to enhance and direct the alarm sound. The stationary component is placed beside the alarm output and the mobile unit stays close to the caregiver, preferably near their ear.

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International Ventilator Users Network's mission is to enhance the lives and independence of home mechanical ventilator users and polio survivors through education, advocacy, research and networking.

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Special thanks ...

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To be sure you receive email updates from PHI, set your spam filters to allow messages from info@post-polio.org and news@post-polio.org.

Inside this Issue ...

Pages 1 and 3

Safety Issue Generates Practical Solutions

Sandra Stuban, a registered nurse and retired lieutenant colonel in the Army Nurse Corps, challenged vent users on Jim Lubin's online discussion list to "help make us safer." Stuban, a certified ICU nurse, compiled the information she received to benefit our readers. Diagnosed with ALS in 1995, Sandra used a BiPAP® around the clock for four years but has used the LP10 ventilator 24/7 since 2001.

Pages 4 and 5

Social and Ethical Implications of Long-term Ventilation for Men with Muscular Dystrophy

Researcher Barbara E. Gibson, PhD, PT, explored the lives of adult vent users with Duchenne muscular dystrophy (DMD). Their candid responses resulted in recommendations that would benefit not only men with DMD, but all vent users.

Pages 6 and 7

Polio survivors Rick Van Der Linden and Deborah Cunningham present their solutions for addressing muscle respiratory weakness due to prior polio. Cunningham, a vent user for decades, is thrilled with her new custom mask, and Van Der Linden relates his transformation of attitude and of equipment.

Pages 8-10

IVUN Information Specialist, Judith R. Fischer, and I review disability and industry press releases, online discussion groups, email list serves and your messages to ventinfo@post-polio.org to keep you up-to-date on products and resources. Know something we should pass along in "From Around the Network"? Send it to us.

Pages 11 and 12

Thanks to those of you who completed our recent readers' survey. Check out page 11 for a few things we learned; additional suggestions will be evident in future issues.

Our work is supported by your Memberships and on page 11, we list our new Membership levels and fees effective July 1, 2007, representing our first increase in four years. Costs of creating and printing information have slowly crept upwards. Postage rates, as you know, have increased once again.

Our sponsors' contributions are crucial to our work. This issue we welcome a new sponsor – Kindred Healthcare (www.kindredhealthcare.com).

–Joan L. Headley, Executive Director

Cell Phones and Pagers. Several vent users have their home phone number in memory dial in a cell phone kept in bed with them. When they need assistance, the home number rings for a caregiver sleeping in another room. Andrea and her son, who uses a bilevel unit, like this method because a ringing phone always wakes her up. Cynthia uses a pager at night to wake a sleeping caregiver.

Doorbells and Plug-in Flashlights. Blane has a buzzer, made from parts bought at RadioShack®, that he sleeps with at night. Andrea's son bought a wireless doorbell system. When her son pushes the button, it rings in his parents' bedroom.

Dan uses a doorbell as a call button as well but also uses plug-in flashlights as a backup during power outages. They are permanently plugged into an electrical outlet where they are constantly being charged. When the power goes out, the flashlights automatically turn on. Dan plugs his flashlights into extension cords so he can move the flashlight beam anywhere, not just up and down, and directly into the face of his sleeping caregiver.

Oximeters. Angela, the respiratory therapist, suggests using an oximeter with an alarm. The oximeter, placed on a finger or earlobe, monitors the percentage of hemoglobin saturated with oxygen in the blood. When this level falls, as occurs during pop-offs and hypoxia, the alarm sounds.

Panic Buttons. Marcelo recommends a one-touch alarm button that when activated sounds a screeching siren and flashes lights. *Example:* www.x10.com/security/pa5800_s.html.

Service Dogs. Joanne, the parent of two young adult vent users, has two extremely well-trained medical alert service dogs. In her experience, the dogs respond quicker, are persistent until a responsible person resolves the alarm, and on occasion sense a problem before the alarm even goes off. "When the vent alarms, both dogs start moving with the initial sound," says Joanne. Her dogs are from East Coast Assistance Dogs (www.ecad1.org), though not all service dog companies work with ventilator users.

Vibration Alarms. Carrie relies on two sensory alarms, sound and vibration, to wake one of her sleeping caregivers who is deaf. When the unit receives a signal from a transmitter, such as an alarm or baby monitor, it vibrates. Though it is designed to be worn close to the body, Carrie places hers under her caregiver's mattress.

Example: www.adcohearing.com/not_silent_call.html.

Walkie-Talkies. Dan says walkie-talkies can not only alert a caregiver at night but also have the benefit of working during power outages. Jeff added that some can be purchased with a VOX feature, meaning they are voice-activated so no buttons need to be pushed.

X10 Unit. John uses an X10 unit to flash the bedroom lights at night when the response to alarms is slow. Bonita also uses this unit to activate chimes, but her setup is different. As a C2 quadriplegic ventilator user, she uses her lips to trigger the switch which is positioned on a microphone stand with a flexible gooseneck near her bed. *Example:* www.interactplus.com/x10_technology. ▲

If you are interested in joining this online ventilator discussion group, send an email to vent-users-request@eskimo.com and type "subscribe" in the subject line.

Social and Ethical Implications of Long-Term Ventilation for Men with Muscular Dystrophy

Barbara E. Gibson, PhD, PT, Assistant Professor, Department of Physical Therapy, University of Toronto, Canada, barbara.gibson@utoronto.ca

PURPOSE OF THE RESEARCH

The purpose of the research was to explore the lives and identities of men living with Duchenne muscular dystrophy (DMD) who use ventilators. Ventilation represents a relatively new life-extending treatment for young men with DMD and very little is known about their experiences as adults. In total, ten men living in an urban community setting participated in the study. Each participated in an initial face-to-face interview, created a personal video “diary” and then participated in a second interview.

KEY FINDINGS

“Going Out” as a Central Activity

Day-to-day activities tended to revolve around three areas: care and maintenance of the body; solitary pursuits such as watching television, listening to music or playing video games; and excursions into the community. Getting “up and out” was of central importance to most participants, yet they spoke about how this was often difficult to accomplish. Going out required considerable planning and effort that included arranging public transport, coordinating excursions with toileting needs, dressing for the weather, and packing suctioning equipment.

It was also unsafe to go out alone because of the risk of ventilator disconnection or mucus plugging. The lack of funding for support workers to accompany ventilator users limited how far away from home some participants would venture. Two participants rarely left their homes except for medical appointments; others went out one to seven times per week on average, but far fewer times in the winter because of the cold weather.

“I don’t go out as much as I want to. Or when I go out, I have a great time, then I come back and I feel you know, blah, again. The next day I want to go out again, but I can’t. There’s no one to go with me.”

Medical Technologies

Participants spoke about positive and negative aspects of using technologies and assistive devices. Almost all of the men spoke about how they have “gotten used to” having a tracheostomy and/or using a ventilator. Fast and light wheelchairs were often a source of pride, and three participants included segments in their videos that highlighted wheelchair speed and maneuverability.

Technologies could also be the source of problems by limiting accessibility and social interaction. A number of participants spoke about the stares of strangers and/or how people “tend to see the chair first.”

“People on the street kind of freak out when they see the (ventilator) hose.”

Housing

Three participants lived in supportive housing units, five with parents, and two in a long-term care facility. Housing was a major concern. Limitations to housing options included both extensive waiting times for supportive housing and limited choice of neighbourhood and region where one resided. This had resulted in some participants having to move a significant distance away from loved ones and/or into neighbourhoods where they did not always feel safe.

“I’m very comfortable here, so it’s hard to pull away. But I think I need to pull away to truly be, like, an adult.”

Attendant Care Support

The amount of publicly funded nursing and attendant care provided to study participants living with parents ranged substantially from 7.5 hours of attendant care/week to 45 hours of nursing care/week. The reasons for this discrepancy are not clear but were not related to degree of assistance needed. Since the amount of service provided is negotiated on a case-by-case basis, the discrepancy suggests that some families may be better at navigating the system to obtain all the available services.

Living Day-to-Day

All participants, particularly those over the age of 30, tended to focus on living day-to-day with very limited reference to the future. When hopes for the future were expressed, they tended to focus on three areas: being healthy, moving out on one's own (for those who had not) and being in a committed intimate relationship.

"I don't have a plan. I just live as I go, really. I don't think too far ahead 'cause I don't know what's going to happen. If I'm still around, I'm sure I'll be all right."

Healthcare Services

Many participants discussed how healthcare services are limited for men with DMD compared with children and that existing services often did not address specific adult needs including sexual health, mental health and gastrointestinal issues. All of the men who lived on their own reported avoiding the healthcare system because of the ordeal of traveling and waiting.

"They expect us all to be gone but we're still around and we need services ... There's nothing for DMD for people my age out there really."

TEAM:

Barbara E. Gibson, PhD, PT, University of Toronto; Patricia McKeever, PhD, Bloorview Kids Rehab and University of Toronto, Ross E.G. Upshur, BA (Hons), MA, MD, MSc, Sunnybrook Health Sciences Centre and University of Toronto Joint Centre for Bioethics; Nancy L. Young, PhD, Laurentian University and Hospital for Sick Children.

The research was conducted between 2002-2005 in partial fulfillment of Dr. Gibson's PhD program requirements at the University of Toronto and was funded through a grant from the Canadian Nursing Foundation/Canadian Health Services Research Foundation Nursing Care Partnership. Dr. Gibson was supported by fellowships from the Canadian Institutes of Health Research, the Health Care Technology and Place Strategic Training Program, and the Ontario Respiratory Care Society.

Publications resulting from the research include:

Gibson B.E., Young N.L., Upshur, R.E.G, McKeever, P. (in press) Men on the margin: A Bourdieusian examination of living into adulthood with muscular dystrophy, *Social Science and Medicine*.

Gibson B.E., Upshur, R.E.G, Young N.L., McKeever, P. (2007). Disability, technology and place: Social and ethical implications of long-term dependency on medical devices, *Ethics, Place & Environment*. 10(1): 7-28.

Dr. Gibson is currently an Assistant Professor in the Department of Physical Therapy where she conducts research on the social and ethical dimensions of disability and rehabilitation.

RECOMMENDATIONS

The research supports a need for the following:

- ❖ Accessible multidisciplinary healthcare services.
- ❖ Research and capacity building regarding the unique healthcare needs of men with DMD.
- ❖ Engineering and design alternatives for cold weather (e.g. clothing, wheelchair design).
- ❖ Publicly-funded recreation programs.
- ❖ Equitable and appropriate amounts of attendant care services across jurisdictions.
- ❖ Expanding job descriptions of attendant care workers to include accompanying ventilator users to school or social pursuits.
- ❖ Increased availability of accessible housing options across jurisdictions.
- ❖ Accessible post-secondary education through flexible options and/or improved accommodations.
- ❖ Increased profile of men with DMD on muscular dystrophy association websites and other educational and promotional materials.
- ❖ Future-oriented care for boys with DMD. ▲

Bilevel Ventilation

Rick Van Der Linden, Editor, *The Southern California PPS Manager Newsletter*,
ppsman@aol.com

A polio survivor from the class of 1953 at age five, I was diagnosed with bulbar polio. The doctor advised my mother that she should not be surprised to find me in an iron lung some day, but I never was put in the “can.” The most apparent effect of the disease shows in my pectoral muscles.

I started experiencing the late effects of polio – mainly pain, weakness and fatigue – during the late ‘80s. That prompted an all-out effort to rebuild strength. My weapon of choice was long-distance bicycling. Within a few years, I was able to ride 75 to 100 miles per week and rode the occasional century (100 or more miles in one day) while training to ride from California to Virginia.

During months of preparation I noticed that, in spite of strict attention to diet and a carefully planned training schedule, I was dropping behind my older training partner. The first hint of breathing weakness came when I discovered that I could reduce burning in my leg muscles by using my abdominal muscles to increase ventilation. Then I noticed reduced performance at elevations over 3,000 feet.

One day, on a casual ride near my home, I came across a lady walking slowly along the roadside. As soon as I saw the braces on her legs, something clicked, so I stopped to talk. Yes, she had had polio and worn braces as a child, but then had forgotten all about it – until now. They were new braces. I concluded I had better watch out for polio’s late effects. The bicycling phase of my life soon tapered off.

For the next few years, I experienced breathing and sleep problems that included sleepless nights, waking up in a sweat, “drowning” dreams, memory and concentration problems, poor judgment, high blood pressure and chronic fluid in my lungs. (Asthma runs in my family, I have allergies, and I smoked for 10 years.) I was

unaware that breathing assistance could solve my problems.

I sold my business, signed up for Social Security Disability Insurance, started using leg and back braces, and moved to a lower elevation. Later, after pulmonary function tests (PFTs), Jacquelin Perry, MD, Rancho’s famous polio doctor, brought up the idea of using a machine to help me breathe. That scared me, so I put it out of my mind for a while.

I had three more PFTs, two home sleep studies, and two overnight lab sleep studies over a period of two or three years. A pulmonologist who does not believe in post-polio syndrome determined that I was not significantly impaired and that the findings were “borderline.” He prescribed a CPAP unit and then a basic bilevel unit – both of which I struggled with using over the next year.

Finding the appropriate ventilator has been a lengthy learning experience for me. By the time I got a basic bilevel unit (S – spontaneous – mode means you can initiate your own breaths), I was so bad off that I needed to recover some physical and, most importantly, mental function before I could start to

recognize the individual reasons for my underventilation and mixed sleep apnea problems. It was then that I realized that the spontaneous mode didn't address all my problems.

When I explained my need for a bilevel machine with a backup rate (ST – spontaneous and/or timed – mode means if you can't initiate a breath on your own, the machine can be set to do it for you), my doctor agreed but said I would be in for a long battle with my HMO.

I made the decision to switch to Medicare Direct, found a durable medical equipment company experienced in neuromuscular breathing/sleep problems and noninvasive ventilation (they tested my vital capacity in the supine position), and obtained a VPAP® III ST.

Even though my self-initiated breaths have increased, I will always need the timed function to start a breath for me. Reason: If I overdo during the day, I go to bed too tired to start each breath. Over time I get into a deficit situation, and it begins to snowball. Without a backup rate, recovery can take days or weeks depending on my general life situation at the time. With the timed feature, I can recover quickly.

I've been using VPAP® III ST with built-in humidifier for more than a year with an Ultra Mirage® II nasal mask (both from ResMed; www.resmed.com). The VPAP is so quiet that I forget I am using it.

I'm fortunate to be able to set the machine myself. The smaller IPAP (inspiratory positive airway pressure) and EPAP (expiratory positive airway pressure) increments of .2 taught me that my polio-weakened diaphragm

and intercostals are more sensitive to the pressure setting than I previously thought. Since I don't have the classic obstructive sleep apnea problem in which the upper airway needs to be kept open, I prefer 3 or even 2 (lowest EPAP setting on VPAP III is 4).

A lower EPAP setting also makes it easier to start a breath, increasing the percentage of self-initiated breaths.

Understanding the way the machine settings need to balance has helped me visualize my exact breathing needs and make corrections accordingly for a greatly improved quality of life. ▲

Custom masks.

Matt Singer of Silicone Ocular & Singer Prosthetics in Memphis, Tennessee, specializes in maxillofacial prosthetics. He has recently made a unique custom facial mask (retained by dental appliances) for respiratory polio survivor Deborah Cunningham (Deborah@mcil.org). The mask design is similar to Deborah's old mask made by Sue Sortor and her team at Dallas Rehabilitation Hospital many years ago.



Singer's masks are made of vacuform plastic with a removable silicone gasket, either soft or firm. Total cost is \$2,800 (covered by most insurance carriers) with a turn-around time of two days. Masks are estimated to last

for several years, providing the person does not lose or gain a significant amount of weight and the person's teeth remain essentially the same.

To contact Matt Singer, phone 901-405-4440 or email msinger@flexiglasseye.com.

From Around the Network

Judith R. Fischer, IVUN Information Specialist, ventinfo@post-polio.org

VENTILATORS

LP10 Vent Users: In response to the news that Puritan Bennett will be phasing out support of the LP10 ventilator by 2011, Jerry Daniel says, "We can keep the ones in use running a long time, by servicing them and scrapping a few for certain parts. I service the LP6s and LP10s, and they come out fine." Contact Jerry Daniel at his company, VENTEK, 360-883-4857 or jerry.daniel@comcast.net.

Carina™ home, a multi-mode ventilator from Draeger Medical Inc. is now available in the USA. Compact (15.2"L x 6.9"W x 10.8"H) and weighing 10.8 lbs., the Carina is advertised as quiet (< 29 dBA). Two-hour internal battery and 10-hour external battery. www.draeger.com

Negavent DA3-Plus Pegaso from Dima Italia, S.r.l., an Italian ventilator manufacturer, is a negative pressure ventilator that can be used also as a cough assist unit and chest percussor. It is only available in Europe. www.dimaitalia.com

MASKS

The FlexiFit™ 432 is the new model of Fisher & Paykel Healthcare's Full Face Mask that features a soft foam cushion with contoured silicone seal. Check with your home health care company. www.fphcare.com

Mirage® Swift II™ is the newest nasal pillows model from ResMed Corp. Able to be used with glasses. www.resmed.com

SNAPP X is the latest nasal pillows model from VIASYS Healthcare Inc. www.viasyshealthcare.com

Discontinued. The following masks manufactured by Respirationics, Inc. will no longer be available after June 30, 2007: ComfortLite® 1, Soft Series®, GoldSeal® and Spectrum®. Parts for these products will be available through June 2008. www.respirationics.com

RECALLS

ResMed Corp. is voluntarily recalling its **S8 CPAP units**, due to the potential for the devices to short circuit in the power supply connector. The units involved in this recall were manufactured between July 2004 and May 15, 2006. Part numbers include 33007 (S8 Escape™); 33021 (S8 Elite™); 33030 (S8 Compact™); and 33112 (S8 AutoSet Vantage™). www.resmed.com

REMstar® heated humidifiers manufactured between December 2001 and April 2003 are being voluntarily recalled by Respirationics. Models affected include 1005792, U1005792, R1005792, S1005792, AC1005792, and 1007861. Contact the home health dealer from whom you obtained the humidifier. www.respirationics.com

ACQUISITIONS

Respirationics Inc. acquired the J.H. Emerson Co., manufacturer of the CoughAssist®, the noninvasive alternative to secretion removal, in April. Respirationics had previously been the major distributor of the CoughAssist®. www.respirationics.com

Iceland Offers Attendant Care and Home Ventilators

Gudjon Sigurdsson reports that the Icelandic government will offer home ventilator service in a two-year trial to people with ALS. Similar to the Danish “helpers system,” it enables people with ALS/MND to take an active part in life, rather than force them into living in an institution. If successful, the program will be expanded to all those who need help to live at home.

Sigurdsson, who uses bilevel ventilation at night, writes, “Being with ALS myself for three years now does make me realize that we all die from respiratory failure. No one in Iceland (with ALS) has chosen to go on a respirator until this day. I started looking into it and found out that we had a choice between death and living with a respirator at hospital. To go on respirator at a hospital is not a real choice, so people before me have chosen death. To have home respirator service, we need 24/7 care at home. Government pays for all costs.

“My fight has been education of the professionals to learn about the equipment and the work around it; adoption of the Danish helpers system of five to six individuals/attendants especially trained for this job; and adoption of the Living Will as a legal document in Iceland.”

Contact Gudjon Sigurdsson: gudjon@mnd.is. ▲

Travel with Oxygen

The EverGo™ portable oxygen concentrator from Respironics, Inc. is the latest addition to the oxygen travel market. Weighing less than 10 lbs and with an eight-hour battery life, it has been approved by the FDA and ten commercial airlines. www.respironics.com

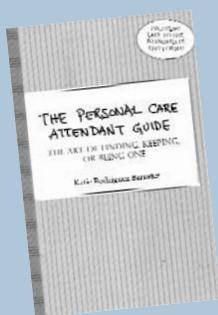
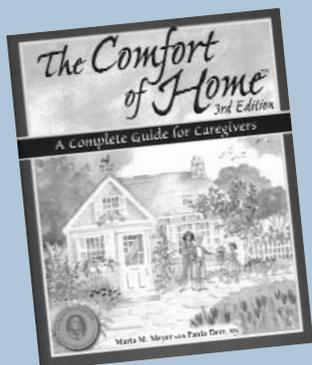
Other portable oxygen concentrators approved for inflight use include SeQual's Equalizer™ (www.sequal.com/Travel_connection.asp); Inogen's One (www.inogen.net/faa); and Airsep's LifeStyle™ (www.airsep.com/medical/airline.html). ▲

New from Christopher and Dana Reeve Foundation

The Paralysis Community The Paralysis Resource Center (PRC), a program of the Christopher and Dana Reeve Foundation (CDRF), created The Paralysis Community – an international online health and wellness community for people living with all forms of paralysis and their caregivers. Located at www.paralysis.org, the Community allows registered members to take part in moderated discussion groups and post personal blogs, enabling them to support one another.

New Website in Spanish A study by the PRC revealed that more than 37% of Hispanics know or have known someone who lives with paralysis, yet almost 56% were not aware of information and resources available to their community. In response, the CDRF unveiled a new comprehensive online resource in Spanish. Check out www.paralisis.org or dial 800-539-7309 and ask to speak with an Information Specialist – available in English or Spanish. ▲

BOOKS



The Comfort of Home,™ A Complete Guide for Caregivers, 3rd Edition (2007)

Maria M. Meyer with Paula Derr, RN
CareTrust Publications (800-565-1533, www.comfortofhome.com)

Maria Meyer, a speaker and workshop leader on caregiver topics, founded CareTrust Publications to provide high-quality, user-friendly information to those with the responsibilities of caring for friends, family or clients.

Paula Derr is a clinical educator for three hospital emergency departments in Portland, Oregon.

Now in its third edition, this fully updated guide continues to provide caregivers with reliable, simple and practical information.

Topics include preparing the home, purchasing equipment and assistive devices, helping with activities of daily living, ensuring proper nutrition. Readers will benefit from the checklists, free or low-cost resources, and tips sprinkled throughout the book.

The 400-page paperback with index, glossary and resources (ISBN 10: 0-9664767-9-4; ISBN 13: 978-0-9664767-9-8) is available in bookstores nationwide, amazon.com and BarnesandNoble.com for \$24.95.

The Personal Care Attendant Guide: The Art of Finding, Keeping or Being One (2006)

Katie Rodriguez Banister
Demos Medical Publishing, New York (800-532-8663, www.demosmedpub.com)

Katie Rodriguez Banister survived an auto accident in 1990 that left her a quadriplegic, paralyzed from the chest down. She has lived independently since 1992.

The book teaches readers how to find a competent caregiver and also gives current and prospective attendants the vital information they need to succeed in this demanding work environment. It will equip people with disabilities, as well as their caregivers, with the skills to successfully find, interview, hire, train and supervise their personal attendants.

This 145-page paperback lists for \$16.95 and is available through amazon.com, BarnesandNoble.com and all major bookstores.▲

2007 Conferences

JUNE 21-23. FSMA Families and Professionals Conference. Hyatt Regency Woodfield, Schaumburg, Illinois. www.fsma.org

JUNE 22-24. Noninvasive and Home Mechanical Ventilation: ICU and Beyond. Le Centre Sheraton, Montreal, Quebec, Canada. www.chestnet.org/education/courses/NMHV07/registration.php. See *details on page 10*.

JULY 12-15. Parent Project for Muscular Dystrophy. Lowe's Hotel, Philadelphia, Pennsylvania. www.parentprojectmd.org

SEPTEMBER 15-19. European Respiratory Society Annual Congress. Stockholm, Sweden. www.ersnet.org

OCTOBER 4-6. ALS/MND Nursing Symposium. Radisson Hotel, Chicago, Illinois. www.lesturnerals.org/educationalactivities.htm#nursing

OCTOBER 20-25. CHEST 2007. American College of Chest Physicians, Chicago, Illinois. www.chestnet.org

DECEMBER 1-4. 53rd International Respiratory Congress of the American Association for Respiratory Care. Orlando, Florida. www.aarc.org

IVUN Member Survey Observations

Many thanks to those of you who returned the IVUN Member survey. It revealed that health professionals find IVUN's educational, networking and advocacy mission valuable. So do our to our core Members – the users of home mechanical ventilation. While many of our readers use a vent due to polio, many report using a vent due to other conditions, which supports our goal of making IVUN an organization that is cross-disability.

Members want product announcements, product reviews, information about assistive devices and research updates. They want to see more information on research, pharmaceuticals and symptom management. Those (almost one-third) who acknowledged our advocacy work were enthusiastic in asking us to do more.

What was surprising was the high number who had never visited the IVUN website! It appears that the mass email messages sent to Members are what attract most people to the site. Currently, the IVUN site (www.post-polio.org/IVUN) is accessed through Post-Polio Health International's site, but that will change this summer. Watch for the email announcement of the new IVUN site – www.ventusers.org.

VUME Project

Ginny Brickley, Project Leader for the Ventilator Users' Medical Emergency (VUME) Project, reports that the health professional medical advisors are finessing the final documents in response to concerns raised by ventilator users. Everyone involved in the project is convinced that the resulting advice, worksheets and checklists will meet the goal of "improving the often traumatic outcome of medical emergencies experienced by individuals with a neuromuscular disease who use home mechanical ventilation."

The VUME Project is funded by the Christopher and Dana Reeve Foundation. ▲

IVUN membership levels make it easy to start taking advantage of timely and important news and activities relating to home mechanical ventilation. Select your level below and return it with your check or credit card information. Or join IVUN online at www.post-polio.org/ivun. Memberships are 100 percent tax-deductible.

\$30 Subscriber

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Ventilator-Assisted Living OR Post-Polio Health

\$55 Subscriber Plus

Both quarterly newsletters:

Ventilator-Assisted Living AND Post-Polio Health

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ALL the benefits of Subscriber Plus AND

Resource Directory for Ventilator-Assisted Living

and Post-Polio Directory; discounts on special publications and IVUN's sponsored meetings

\$150 Sustainer

ALL the benefits of Contributor AND

One additional complimentary gift membership to:

Person of your choice (include name and address) or

Person who has expressed financial need to IVUN

Membership at the following levels includes ALL benefits PLUS special recognition in IVUN publications:

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\$500 **Silver Level Sustainer**

\$1,000 **Gold Level Sustainer**

\$5,000 **Platinum Level Sustainer**

\$10,000 **Gini Laurie Advocate**

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