

Destination Barcelona ... or Not

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The 12th International Conference on Home Mechanical Ventilation, sponsored Journées Internationales de Ventilation à Domicile (JIVD), was held in Barcelona on March 27 and 28, 2009. I was excited to present my poster among the 96 accepted at the meeting.

In 1991, I sustained a complete C3-4 lesion with paralysis and loss of sensation below my neck and today use a trach. The previous HMV conference I attended in 2005 had opened up a wide range of contacts with people in other countries who face similar challenges in independent living.

Planning a visit to Spain presented something of a challenge. Our initial enquiries about rail transport were with Rail Europe, which had a problem understanding my basic requirements. They were unaware that the overnight direct rail connection between Paris

and Barcelona does not accommodate wheelchair passengers who are unable to leave their chairs. An alternative route via Montpellier is similarly unavailable to wheelchair users. However, the JIVD Secretariat offered to arrange vehicle transfer from Perpignon, France, to Barcelona.

Two of my carers and the poster had gone ahead and arrived safely in Barcelona three days earlier. My own journey with two carers began well and uneventfully. We left Stirling at 10:30, reaching London at 15:58. The onward arrangements were to collect our Eurostar tickets at St. Pancras (successful) and the Rail Europe tickets, which were to be left for collection at the Eurostar office. They had not been left.

The person who had dealt with these plans had gone off duty, but another person assured us that these arrangements were NEVER made. Since we had the reference numbers for our journey from Lille and had arranged to stay overnight there, we concentrated on enjoying Eurostar and the 50% reduction on first class travel for wheelchair users.

Once in Lille, we found that our Eurostar-booked apartment/hotel, which we understood was about a three-minute walk from the station, was three stops away on the Metro. No taxis would transport me and my wheelchair! The travel information centre at Lille Europe did everything that was possible to help, and even gave us a coloured print-out of the

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Liz at home with attendant.

Vent Users Denied Flight from Milwaukee to Las Vegas

Michael Luber (msl21@wi.rr.com)

My brother and I both use the PLV-100 (Philips Respironics), and I have taken more than 90 flights using my vent.

We planned a trip to Las Vegas on Wednesday, May 6th, but it was canceled the Friday before by Airtran Airlines. The airlines would not let us use our ventilators during takeoff and landing, because the vents are considered electronic devices and had not been approved by the Federal Aviation Administration (FAA).

I am aware of the new Air Carriers Access Act (ACAA) regulations that started May 13, which requires our ventilators to have a sticker.

It was suggested that we sue for inconsistent practice because we flew on Airtran twice before. But, an attorney told us that there is not much we can do and that the damage is minimal. We disagree since we lost our vacation to visit our brother and niece. It helps to have some direction from others who have fought this battle before. I am requesting that those who have experience with filing complaints or suing airlines to contact me.

IVUN Issues a Call for Action

The Department of Transportation (DOT) final rule "Nondiscrimination on the Basis of Disability in Air Travel" became effective May 13, 2009. The rule contains many improvements for people with disabilities, and the major changes that affect ventilator users are described on pages 4 and 5.

The May 13th deadline has passed, and the FAA admits that "very few POCs and no other respiratory devices such as ventilators, respirators and CPAP machines display labels." Without the appropriate stickers on their equipment future travelers will face the same consequences as the Luber brothers.

Ventilator Users and Their Advocates Are Asked to Contact

■ Nancy Lauck Claussen, FAA, at nancy.l.claussen@faa.gov, to expedite the approval of ventilators for flying and/or delay the implementation of the specific regulation requiring a sticker until the FAA and the manufacturers complete the process. Claussen acknowledged that the FAA stickers are not readily available but the DOT decided to go ahead with the ruling because of its many other improved initiatives for people with disabilities. So for now, it is "up to the carriers."

■ Providers of ventilators (home health companies) to ask them to contact manufacturers about the urgency of approving their vents for flying.

■ The customer service departments of the manufacturers asking them to make expedite the process of issuing stickers for their equipment and/or negotiate a change in the date of implementation with the FAA.

This is the status of the situation at press time. Watch www.ventusers.org for updates and to find email addresses and phone numbers of people to contact.

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 and IVUN, set your spam filters to allow messages from info@post-polio.org and info@ventusers.org.

area, identifying the 20-minute walk between the Metro exit for our hotel. While these details were being clarified, we joined the queue to find our tickets.

It proved impossible for SNCF, the French National Railway Service, to confirm these reservations and therefore to give us tickets. The reference numbers provided by Rail Europe did not correlate with SNCF data, nor did a search using our names.

Our train departure to Perpignan was for 11:57 the next day, and there were no wheelchair spaces available to us. We chose the only option that seemed available: a wheelchair space on the train to Perpignan departing at 08:47, for which we purchased tickets.

As we left the Metro to walk to our accommodation, we got trapped in the closing doors. It was then after 23:00. The concierge had departed and entry was by telephone instructions. After giving your name, a series of numbers (in French) were provided. These were pinged into a keyboard to open the door. Once inside there was another system to open a box in which were keys to the rooms.

There was no way we could get to the station to catch the early train to Perpignan the following morning. We appreciated the efforts of two ambulance drivers to attempt to lift me and my chair into their vehicle, but they found it impossible. We set off again on foot to the Metro to hopefully find our lost tickets at the Rail Europe office.

Once back at Lille Europe, we presented the correct reference for our reservations from Rail Europe. SNCF confirmed that these were still incorrect, and we bravely watched the Perpignon train depart without us. We ate in the Irish Pub at the station, explained to the Secretariat that we would not be able to join them, and purchased Eurostar tickets for our return to Scotland.

It was very disappointing not to meet other delegates and discuss my poster.

The important aspects of life for me include freedom of choice, being able to enjoy my life as much as possible for as long as possible, and minimizing avoidable complications.

I have plans to visit my sister in Holland soon, using ScotRail, which has experience of my wheelchair travels. They provide me a corner to share with the bicycle space, and it comfortably accommodates me, my wheelchair and two companions.

By using only overseas rail travel carriers that accept wheelchair users, I am confident in extending my journeys. ▲



Liz uses the BREAS PV 501 at night and has a Laerdal resuscitator attached to her chair with her portable suction device and bag of back-up bits.

New Regulations Affect Ventilator Users Who Fly

IVUN recommends reading the complete list of new regulations as explained by Brennan at www.southwestada.org/html/publications/ebulletins/legal/2009/may2009.html.

New Regulations Affect Ventilator Users Who Fly

Regulations for the updated Air Carriers Access Act (ACAA) became effective May 13, 2009, and some of the new requirements impact users of home mechanical ventilation. The following sections were extracted from Legal E-Bulletin – May 2009 by Jacquie Brennan from the Houston-based DBTAC (Disability and Business Technical Assistance Centers) Southwest ADA Center and interspersed with “Answers to Frequently Asked Questions Concerning Air Travel of People with Disabilities Under the Amended Air Carrier Access Act Regulation” from the Department of Transportation (DOT).

Electronic Devices that Assist with Respiration

Carriers, except for on-demand air taxi operators, who conduct passenger services must allow, on all aircraft with a capacity of more than 19 seats, any passenger with a disability to use a ventilator, respirator, CPAP machine or an FAA-approved portable oxygen concentrator (POC), unless either the device does not meet FAA requirements for medical portable electronic devices and does not display a manufacturer’s label that indicates the device meets those FAA requirements or the device cannot be stowed and used in the passenger cabin consistent with TSA, FAA and PHMSA (Pipeline and Hazardous Materials Safety Administration) regulations.

Are ventilators, respirators, continuous positive airway pressure machines (CPAP) or FAA-approved POCs labeled by the manufacturers as meeting applicable FAA requirements for medical portable electronic devices?

Few, if any, such devices have been labeled as meeting applicable FAA

requirements for medical portable electronic devices as of the date this document was issued. (May 13, 2009)

May a carrier refuse to allow a passenger to use on the aircraft any respirator, ventilator, CPAP machine or FAA-approved POC that does not have a manufacturer’s label indicating compliance with the standards of RTCA/DO-160 (current edition) or other applicable FAA or foreign government requirements for medical portable electronic devices?

Yes. Carriers may refuse to allow a passenger to use a respirator, ventilator, CPAP machine or FAA-approved POC onboard the aircraft if the proper manufacturer’s labeling is not present on the device. However, DOT would encourage carriers to voluntarily conduct the necessary tests on a particular respirator, ventilator or CPAP machine model that is not labeled, in order to determine its compliance with the applicable safety standards and allow passengers to use those devices found to be safe on its aircraft.

Advance Notice

An air carrier may require that a passenger with a disability ... give up ... to 48 hours advance notice and check in one hour before the check-in time for the general public is required to use a ventilator, respirator, continuous positive airway pressure (CPAP) machine or portable oxygen container (POC).

Also, an air carrier does not have to provide a hook-up for a respirator, ventilator, CPAP machine or POC to the aircraft electrical power supply, but if it chooses to do so, it can require 48 hours advance notice and check in one hour before the check-in time for the general public.

How Often Should Tracheostomy Tubes Be Changed?

Jerry Hammersley, RCP, RRT, Simi Valley, California, jhammer@newstarthc.com

As the general manager of a DME company that specializes in tracheostomy (invasive) positive pressure ventilation, I have noticed an increase over the past two to three years in requests to perform tracheostomy tube changes in ventilator users' homes. It seems that there are fewer and fewer providers who are willing to perform this procedure that can be risky and potentially life-threatening. For those who are willing to brave this endeavor, here are a few practical guidelines.

Unfortunately the healthcare industry has not established clear-cut guidelines for how often, if at all, routine trach changes should occur, especially in the homecare setting. One should not base the practice purely upon tradition, e.g., "Our hospital always changes the trach tube every month," but upon evidence. Regrettably the evidence for this practice is lacking.

However, the industry has provided several recommendations regarding the process of changing the trach. These recommendations include the following:

1. The initial tracheostomy tube change (outer cannula) should always be performed in the acute care setting and preferably by the surgeon or ENT, continued, page 8

Services on the Aircraft

Air carrier personnel must provide the following assistance, when requested, for a person with a disability ... assistance in stowing and retrieving carry-on items, including mobility aids and other assistive devices stowed in the cabin. Carriers must permit passengers with a disability to bring the following ... for stowage or use within the cabin ... POCs, ventilators and respirators that use non-spillable batteries, as long as they comply with applicable safety, security and hazardous materials rules.

May a carrier refuse to allow a passenger to stow on the aircraft any respirator, ventilator, CPAP machine or FAA-approved POC that does not have a manufacturer's label indicating compliance with the standards of RTCA/DO-160 (current edition) or other applicable FAA or non-U.S. government requirements for medical portable electronic devices?

No. Carriers must allow passengers to *carry* a respirator, ventilator, CPAP machine or FAA-approved POC on-board aircraft, subject to applicable safety requirements, even if the device may not be *used* onboard the aircraft.

When the required manufacturer's label is not present on a ventilator, respirator, CPAP machine or FAA-approved POC, what safety requirements apply to the stowage of the device on the aircraft?

To be accepted for stowage on an aircraft, a ventilator, respirator, CPAP machine or FAA-approved POC that does not have the required manufacturer's label on the device must comply with FAA size and weight limits and have the battery removed, packaged and protected from short circuit and physical damage in accordance with the FAA's Special Federal Aviation Regulation (SFAR) 106, Section 3 (b)(6). ▲

From Around the Network

Judith R. Fischer, IVUN Information Specialist, info@ventusers.org



Puritan Bennett 540™

New Products

Puritan Bennett 540™ ventilator recently released in the U.S. by Covidien Ltd. Is small and lightweight (under 10 lbs.) The 540 ventilator can deliver both pressure and volume ventilation, and be used with either a single- or double-limb breathing circuit. Its internal lithium-ion battery is designed to provide up to 11 hours of power; an external battery is also available. Accessories include a small cart to transport the ventilator inside the home, a backpack-like carrying bag for the ventilator that can hang on a wheelchair, a car charger and remote alarm capabilities.

www.puritanbennett.com



Trilogy100

Trilogy100 ventilator, recently released by Philips Respironics, is compactly designed, weighing 11 lbs. Capable of delivering both pressure and volume control, it can be set for both day and night use. It also provides interchangeable active and passive exhalation ports. There is a three-hour lithium-ion internal battery as well as a three-hour detachable external battery. DirectView software downloads data directly to health professionals.

<http://trilogy100.respironics.com>



Falco 101

Falco 101 is a multi-mode ventilator manufactured in Italy by Siare Engineering International Group, s.r.l. The Falco offers many ventilation modes and can be used with a single- or double-limb breathing circuit. The NiMH (nickel-metal hybrid) internal battery life is two and a half hours; the external battery provides up to 10 hours of power. Small and compact, the Falco weighs 3.9 Kg. The Falco has many alarm features and can store usage data for 72 hours. It is available in Europe and other international markets, but has not been FDA-approved for use in the U.S.

www.siare.it



Hayek RTX

Hayek RTX is a biphasic cuirass ventilation system, from United Hayek Medical, that controls both the inspiratory and expiratory phases of respiration (unlike the old negative pressure ventilators) and provides higher tidal volumes and higher frequencies. Developed in the U.K., it is now FDA-approved in the U.S. Eleven cuirass sizes (four adult, seven pediatric) are available. It can also be used to assist cough and clear secretions. Weight is 9 Kg.

www.unitedhayek.com

SleepWeaver™ ADVANCE all-cloth nasal mask is new on the U.S. market. Made of the same material as ski clothing, the mask can be cleaned by hand or machine washing and put in the dryer. The life of the mask is about six months. It has been successfully tested at pressures up to 20 cm H₂O. Very small holes serve as exhalation ports. Reading and watching TV are possible when wearing the mask.
www.sleepweaver.com



SleepWeaver™ ADVANCE

Books

Families of SMA Care Booklets. Two new booklets are available. *Breathing Basics: Respiratory Care for Children with SMA* by Mary Schroth, MD, University of Wisconsin, includes topics such as respiratory care management in SMA, breathing exercises, coughing practices for airway clearance, breathing support options, care during a respiratory infection, and special needs of children with SMA Types I, II and III. *Caring Choices* is for parents of infants newly diagnosed with SMA Type I. Sections include information on noninvasive respiratory care, invasive respiratory care, palliative care, and support and guidance. To request copies, email FSMA (info@FSMA.org) or call 800-886-1762.

Pediatric Tracheostomy Home Care Guide by Cynthia Bissell, RN, is now available as a handy pocket guide for \$22.95. Bissell's son Aaron was the inspiration for both the book and Aaron's Tracheostomy Page on the Internet. The book can be ordered online at www.tracheostomy.com. Congratulations to Bissell who was recently presented with the Mother of the Year Award.

Barcelona HMV Conference

The 12th International Conference on Home Mechanical Ventilation (HMV), held March 27-28, 2009, in Barcelona, attracted 1,500 attendees.

Audio recordings and slides from more than 42 sessions are available on DVD for 105€ from OneScience (www.e-onescience.org). Contact Brigitte Hautier, JIVD, brigitte.hautier@free.fr; www.jivd-france.org.

Reports

One Degree of Separation: Paralysis and Spinal Cord Injury in the United States, a report released by the Christopher and Dana Reeve Foundation, presents new information about the prevalence and demographics of paralysis and SCI. The researchers conducted a survey of more than 33,000 households and learned that paralysis is approximately 1.9% of the U.S. population or 5,596,000. Paralysis is broadly defined "... as a central nervous system disorder resulting in difficulty or inability to move the upper or lower extremities." There are recommendations for improving quality of life and finding a cure. www.visualwebcaster.com/Reeve-Foundation-Prevalence-Study ▲

and it should occur between three to seven days after the initial surgery. Once the initial change has occurred, the homecare provider can take over the changes in the home.

2. Tracheostomy tube changes should be performed by a qualified individual who is well-trained, experienced and prepared for untoward circumstances that may occur during the change, such as malplacement of the tube (false channel), a blown cuff, bleeding and patient decompensation, to list a few.

3. The individual changing the tube should always have a back-up trach tube that is one size smaller than the tube being replaced.¹ A functional and tested resuscitation bag with mask should be present at the bedside, and supplemental oxygen would be ideal.

The bottom line for trach changes is don't change them too often if there is no evidence of infection, bleeding and the trach tube cuff (if present) is intact; it's not encrusted; and there is no stenosis (narrowing) or tracheomalacia (flaccidness). And, don't change them too infrequently, particularly if there is a cuffed tube involved, because there is nothing worse and more painful for a ventilator user than having to remove a cuffed trach tube that has not been changed for an extended period. Caregivers should discuss with the user and the physician the possibility of extending a trach change from every month to every two months, as long as there are no issues; they have effectively decreased trach changes by 50%.

Complications of Long-Term Tracheostomy

My company cares for many patients who have used tracheostomy ventila-

tion for years, some more than 20. Generally, there are few complications associated with long-term tracheostomy, but they do sometimes occur.

Infection is of course a risk factor. According to some sources, 75% of trached patients are colonized with *Pseudomonas aeruginosa* within 10 days of the procedure.² *P. aeruginosa* is an opportunistic pathogen that will manifest itself when an individual's immune defenses are low. The keys to resisting *P. aeruginosa* and other staph infections are maintaining hygienic trach care practices (caregivers must learn to religiously *wash their hands!*) and suction techniques, and notifying one's physician when secretion color changes.

Another complication is granuloma, a lump or nodule of granulation tissue, that can result from abrasion by the trach tube at the stoma. If large enough, a granuloma may cause airway obstruction.

Tracheomalacia is a significant risk for patients who have a cuffed trach tube. It is imperative that the cuff not be overinflated. We see it all too often — caregivers or family members overfill the cuff and inevitably the ventilator user ends up with a distended trachea, esophageal fistula or other complications. The best practice is to use minimal leak technique for cuff inflation — just enough air injected into the cuff in order to allow only a slight leak at peak inspiration from the ventilator.

Although the healthcare industry may not have clear-cut guidelines regarding trach changes, it is heading in the right direction.

References

1. AARC Clinical Practice Guideline: Long-Term Invasive Mechanical Ventilation in the Home — 2007 Revision & Update, 10.1.10.

2. Private communication, December 1, 1994, Michael W. Sicard, MD, Bobby R. Alford Department of Otolaryngology-Head and Neck Surgery, Baylor College of Medicine, Houston, Texas.

How Often Should Ventilator Circuits Be Changed?

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

As a nurse, care for my patients was guided by evidence-based research. When I became a ventilator user due to ALS, I expected to use the same principles to guide my home care. But I quickly discovered that no research-based standards or guidelines exist for the routine basic care we require. I searched for an answer to a question I thought was especially important: How often should I change my ventilator circuits?

According to the American Association for Respiratory Care *Clinical Practice Guideline: Long-Term Invasive Mechanical Ventilation in the Home – 2007 Revision & Update*, “Evidence is lacking to support an optimal plan for changing and processing ventilator circuits and ancillary equipment in the home.” However the guideline states that circuits need not be changed more often than once a week.

Next, I looked for direction from the Centers for Disease Control and Prevention (CDC). Based on research data from acute care hospitals, the CDC guidance on ventilator circuits states, “Do not change routinely on the basis of duration of use. Change the circuit when visibly soiled.” This guidance seems inadequate for home users.

Finally, I searched for best practices and trends from ventilator users themselves. I asked an online ventilator user discussion group, “How often do you change your ventilator circuits?” I received 20 responses – 16 from those using invasive ventilation and four from those using noninvasive ventilation.

One respondent with limb-girdle muscular dystrophy who has used a ventilator since 1994 changes the circuits once a month. Another respondent with spinal muscle atrophy changes the heated circuits once a month and the “chair circuits” twice a month.

A young man with nemaline myopathy used to change his circuits every three days but now changes them once a week. A respondent with a C2-3 SCI since 1985 changes the circuits three times a week. A man with Pompe disease who has used a ventilator for 12 years used to change his circuits every three days but now changes them once a week.

A man with spinal muscle atrophy who has used a ventilator since 1982 changes his circuits twice a week though he’s “heard one time per week is OK.” A post-polio respondent from New Zealand changes her circuits only when soiled. A man with a C2-3 SCI for 24 years changes his circuits three times a week, but two other individuals with SCI change their circuits once a week. A man with ALS who has used a ventilator since 1993 changes his circuits once a month. And I change mine once a month.

Two parents of young children using invasive ventilation responded differently. One changes the circuits once a month for her son who has Duchenne muscular dystrophy, the other parent whose son has cerebral palsy changes his circuits once a week or “when he coughs in it.”

Of the four noninvasive ventilation respondents, three were polio survivors. One changes his circuits every

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How Often Should Ventilator Circuits Be Changed?

continued from page 9

two months, another every month, and the third never changes her circuits, although she does wash her mask every second day and the mouthpiece only occasionally. Another respondent who has congenital myopathy cleans her circuits every six weeks.

Of the 20 responses, four people clean their circuits instead of disposing of them. The cleaning techniques also vary. One person washes them in warm soapy water, rinses, then soaks in Control III solution for ten minutes, rinses again, and hangs to dry. Another respondent soaks her circuits with a 1:4 ratio of vinegar and hot water, and after she has had a cold, she soaks them overnight in a 1:1 vinegar/water solution. A third respondent washes them with dish soap, rinses, then soaks in Control III solution for 15 minutes, rinses again, and hangs to dry. The fourth respondent uses Control III solution for 10 minutes.

I also asked the discussion group who instructed them on how often they should change the circuits since their practices were so diverse. Their responses were as different as their practices: no instruction given – 4, DME rep – 3, RT – 3, homecare

agency/nurse – 2, Medicare – 1, unknown – 7.

Considering that no standards or guidelines exist for home-based circuit changes, I wasn't surprised that practice varies so dramatically. But two trends did emerge from this informal search for answers. The first is that most invasive ventilator users change their circuits either once a week or once a month. And the second is that noninvasive users change their circuits less often than invasive users. Until a formal research study can be conducted to answer this important question, we ventilator users have to answer it ourselves. ▲

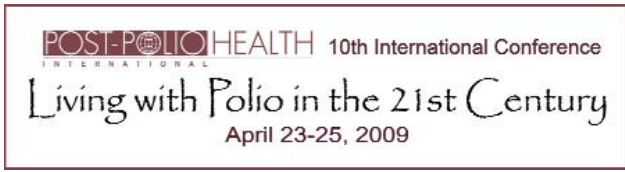
Summary: How often do you change your ventilator circuits?

	Via Trach	Noninvasive
3 times a week	2	
2 times a week	2	
Every week	5	
Every 3 weeks	1	
Once a month	5	1
Every 6 weeks		1
Every 2 months		1
Only when soiled	1	
Never		1

The Butcher's Daughter: The story of an Army nurse with ALS

by Sandra Lesher Stuban, RN, has been published. Stuban, a ventilator user for 12 years (four years using noninvasive ventilation before converting to tracheostomy ventilator for the last eight years), is a frequent contributor to *Ventilator-Assisted Living*.

The book is 190 pages and available in paperback for \$13.95, plus shipping and handling, through virtualbookworm.com, Amazon.com, and Barnes & Noble. www.stubanbooks.com



“The Spirit of Warm Springs” was evident as the staff at Roosevelt Warm Springs Institute for Rehabilitation (RWSIR) in Warm Springs, Georgia, welcomed 436 registrants during the three-day meeting. In attendance were survivors, family members and health professionals from 11 countries (46 individuals) and 39 states and the District of Columbia.

“The opportunity to see and learn about equipment with which I was unfamiliar was timely. I recently had begun to notice how tired my chest was just from breathing and how forgetful I was getting. I realized I was not breathing sufficiently, and ‘Bingo!’ I saw how the need for a volume ventilator and CoughAssist® was staring me and my trach in the face.” *Marie Latta, Georgia*

“As a user of night-time ventilation only, I’m naïve about tracheostomy ventilation, but I realize that I might sometime need an emergency tracheotomy, even if it is only temporary. Seeing firsthand a Passy-Muir tracheostomy speaking valve in use and how it works, I was amazed by its elegant and simple design, almost a miniaturized version of the positive pressure flap on an iron lung!” *Larry Becker, Virginia*

“After I explained some of my trach problems, I was shown a model whose internal cuff totally flattens when deflated. Since I need a cuffed trach, this one will allow more air to flow around my trach, enabling me to breathe and talk easier during the day when I am off my vent.” *Linda Bieniek, LaGrange, Illinois*

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Daily program booklets (Thursday–60 pgs; Friday–98 pgs; Saturday–70 pgs) from PHI’s 10th International Conference: *Living with Polio in the 21st Century* are now available.

In PDF format on a single CD, the files contain abstracts and handouts. Cost to US Members: \$15 postpaid; US Nonmembers: \$22 postpaid; Cost to International Members: \$18 postpaid; International Nonmembers: \$25 postpaid. Orders should be sent to the address on page 2. ▲

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Trilogy100

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