

## My Journey through the Basics of Post-Polio Breathing Problems

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Breathing was becoming problematic. For years I'd used a ceiling fan to stir the air in my room and give it a semblance of freshness, which made it easier to breathe. But sometimes I'd wake in the night with a start, feeling for a second that I couldn't get a breath, and this worried me. I'd seen the list of signs and symptoms that indicate it's time to consult a pulmonologist (preferably one who understands neuromuscular disorders) about getting an evaluation. Several of those signs were all too familiar. I made an appointment.

"You know, Nancy, you may need to use a ventilator to help you breathe one of these days," the pulmonologist said. His very words made it hard to take a breath. The thought of having to depend on a machine to breathe terrified me. My imagination ran wild – suddenly I felt vulnerable; a heavy weight closed around me. "I could never do that," I replied. "You'll change your mind when the time comes," he said.

### Signs and Symptoms of Underventilation

The presence of any one of these can alert polio survivors to the possibility of breathing difficulties:

- Weakness and fatigue, low energy, daytime sleepiness
- Air in the room seems somehow stale, claustrophobic
- Difficulty concentrating, impaired memory
- Irritability or anxiety or depression
- Morning headaches
- Waking in the night short of breath or with choking sensation
- Feeling unrefreshed upon waking in the morning
- Shortness of breath during the day
- Difficulty breathing when lying flat

### Underventilation

All pulmonary doctors treat lung disease. However, polio breathing difficulties (such as *underventilation* – also known as hypoventilation) are not caused by lung disease, but rather by problems outside the lungs that limit the amount of air entering the lungs with each breath – they do not get enough air to become fully inflated. Without proper ventilation to bring in oxygen-containing air and carry out the carbon dioxide made in the body, a buildup of carbon dioxide and a decrease in oxygen levels can occur. This is underventilation. Underventilation difficulties most often relate to *respiratory muscle weakness* or *scoliosis* or *sleep-disordered breathing*. Telling a pulmonologist about a history of polio is imperative.

**Respiratory muscle weakness** refers to muscles disabled by polio, such as the diaphragm or chest muscles, that affect breathing by causing smaller-than-normal breaths. If the breathing muscles of certain polio survivors were weakened by the initial virus, these individuals may have used an

continued, page 3

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

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## *Inside this Issue ...*

Pages 1-6

### **My Journey through the Basics of Post-Polio Breathing Problems**

is a further attempt at explaining the subject from a polio survivor's perspective. Some of you may ask, "Why? Why again?" We are motivated by calls and letters we continue to receive from survivors and their families. The story told by Ann O'Meara on page six is an example that is still too common.

If you have questions or need more detailed information after reading Nancy Baldwin Carter's journey, check out [www.ventusers.org](http://www.ventusers.org), the new website of International Ventilator Users Network, an affiliate of PHI. Past articles about breathing problems can be accessed at [www.post-polio.org](http://www.post-polio.org), too.

Page 7

### **Books, etc.**

Once again, we list and describe new books related to polio and post-polio. Your messages have told us this is a very popular service. More and more information is only available on the Internet. Members of PHI who do not have Internet access are invited to contact us and we will access the information for you.

Pages 8-10

Letters we receive: **Keeping America Sick** arrived via email containing a very compelling message on many levels. Reji Mathew, now in New York City, had polio in India. She clearly sets out the problems many of us with a chronic condition face when accessing the health care system. Her commentary is a nice fit for PHI's WE'RE STILL HERE campaign, which appears to be a success. As we go to press, the week is not over; letters are still being written. Check out the back page for photos of just a few of the activities, and our website, [www.post-polio.org](http://www.post-polio.org).

Page 11

Don't miss the announcement of **PHI'S "Call for Proposals"** for its fifth award of \$25,000 to be given in 2009. Spread the word among bright, innovative researchers in your area.

If you are a Member of PHI and know others who are not, please pass the Membership form on to them. We financially depend on your Memberships, and your thank yous, comments and suggestions encourage and advise us. For this, we thank you.

—Joan L. Headley, Executive Director of PHI

iron lung. They should be on the lookout for possible underventilation and seek treatment to avoid respiratory failure. Since even survivors who did not initially need an iron lung can develop underventilation, they, too, should be aware of troublesome signs and symptoms.

**Scoliosis** refers to a curvature of the spine that alters the space in the chest and compromises breathing or coughing.

**Sleep disordered breathing**, in this discussion, refers to *apnea* plus hypopnea (slow, shallow breathing.) *Apnea* is a Greek word meaning “without breath.” In sleep apnea, individuals literally stop breathing for as long as a minute or so during sleep, and possibly do this hundreds of times in a night. There are three types:

1. *Obstructive sleep apnea* happens when the airway becomes blocked, as when the soft tissue collapses at the back of the throat. It is possible for polio-weakened throat and neck muscles also to close off the airway during sleep.
2. *Central sleep apnea* happens when the brain “forgets” to tell the muscles to breathe.
3. *Mixed sleep apnea* is a combination of the other two.

In my case, bulbar polio affected the bulbar nerves and left me with weakness of the throat and neck muscles. Over the years it’s been increasingly difficult to get the necessary “lift” to keep the airway and throat open for breathing and swallowing. Finally my cousin made a “chin crutch” for me from the leg of a tripod (so its length can be adjusted) with a small rubber ball on the bottom (to anchor it com-

fortably) and a sheepskin-padded block on top that tucks under my chin. It’s always in place when I sleep and rest, and frequently during the day when I feel my throat closing, I grab the crutch.

### Incidence of Sleep Apnea

More than 12 million individuals in the United States general population have sleep apnea. It occurs more often in men, in those over forty, and in those who are obese, though anyone at any age can be susceptible. Polio survivors can have sleep apnea, too, sometimes along with any variety of other sleep difficulties pertaining to their polio conditions. Their polio histories should always be considered to ensure that polio-related symptoms are not mistaken for something else.

These sleep problems can be subtle, perhaps going unnoticed for too long. They can be life-threatening and therefore must be taken seriously.

### Diagnosis

All polio survivors might be better off having at least a *baseline pulmonary function test* to see if further investigation is warranted.

### Baseline pulmonary function tests

consist of several easily accomplished elements:

■ **Vital capacity (VC)** is usually measured by inhaling deeply and then blowing (one big, long breath to empty the air from the lungs) into a tube to see how much air is exhaled and how much remains in the lungs. When done as quickly as possible, this is called Forced Vital Capacity (FVC). VC should be measured in sitting, lying and other positions, as each of these may yield

Carter used many resources in writing this article. The Resource List is available at [www.post-polio.org/edu/pphnews/pph23-4res.pdf](http://www.post-polio.org/edu/pphnews/pph23-4res.pdf) or by calling 314-534-0475.

continued, page 4

significantly different results if respiratory muscles are weak.

■ **Maximum Inspiratory Pressure (MIP) and Maximum Expiratory Pressure (MEP) tests** measure diaphragm muscle power by breathing forcefully in and out into a mouth tube.

■ **Peak cough flow** is measured to test the effectiveness of a cough. Weak respiratory muscles can mean a weak cough impeding secretion removal, and can lead to respiratory infections and pneumonia.

I was told that people who did not have polio sometimes improve their VC scores with repeated tries at forceful breathing. Not so for polio survivors like me with respiratory muscle weakness, as I learned the first time I was tested. I may have reached my peak in the initial attempt, and after that not only were my efforts less productive, my excessive huffing and puffing caused me to seriously overwork those muscles, leaving me, by that night, in pain and with difficulty breathing. I should have known enough to stop after the first several breaths.

■ **Sleep studies** may be suggested when a pulmonologist determines that additional tests are needed. These studies are usually done overnight in a specially equipped laboratory and include ECG (electrocardiogram), EEG (brain wave), eye movements, snoring, and measurements of airflow, apnea and shallow breathing events, and blood oxygen saturation, among other tests. Polio survivors may want to ask if a lab uses an end-tidal CO<sub>2</sub> monitor, since this device is meant to detect underventilation. In some cases a breathing machine, such as a BiPAP®, may be tried for a few hours in order to analyze its effectiveness.

■ **An Arterial Blood Gas (ABG)** is done by drawing blood from the artery on the underside of the wrist, testing levels of oxygen, carbon dioxide and pH in the blood and evaluating pulmonary gas exchange. Since in underventilation carbon dioxide increases, pushing out oxygen in the blood, an ABG can be a good diagnostic tool. Pulse oximetry is a noninvasive measurement of oxygen saturation in the blood, but it is less precise than an ABG.

### Assisted Breathing

Because underventilation results from too little oxygen and too much carbon dioxide in the blood, some polio survivors (and perhaps even a few in the medical community) may make the mistake of believing that oxygen is the way to treat the problem. It is not. Mechanical ventilation is essential. Polio survivors with respiratory muscle weakness who are developing progressive respiratory failure risk death if their underventilation is not treated with proper ventilation.

Depending on the breathing difficulty, pulmonologists will recommend the breathing machine best suited to a survivor's needs. These can be used in the home:

■ **CPAP (Continuous Positive Airway Pressure)** – Air flows continuously through a breathing mask into the airway. It is used mainly to treat obstructive sleep apnea because of its ability to use positive air pressure to keep airway open. Some units work automatically to provide the right level of pressure. CPAP delivers a single preset level of pressure in both the inspiratory and expiratory phases. A CPAP is not a ventilator.

### For more about ventilator-assisted living –

International Ventilator Users Network (IVUN) is the premier source of information about living independently with a ventilator. An affiliate of PHI, IVUN has its own website ([www.ventusers.org](http://www.ventusers.org)), quarterly newsletter (*Ventilator-Assisted Living*), and its *Resource Directory for Ventilator-Assisted Living*. IVUN's Home Ventilator Guide ([www.ventusers.org/edu/HomeVentGuide.pdf](http://www.ventusers.org/edu/HomeVentGuide.pdf)) provides details about the numerous breathing machines.

■ **Bi-level Positive Airway Pressure** – Air flows continuously through a breathing mask into the airway, but the inspiratory and expiratory pressures can be adjusted separately. It is used mainly to treat sleep apnea and under-ventilation that occur simultaneously. Certain bilevel devices function similar to a ventilator because they have a backup rate.

■ **Volume Ventilator** – A device that delivers more air (measured by volume) and thus deeper breaths through a breathing mask into the airway. Air does not flow continuously, but rather is delivered in the right amount with each breath, with the correct breathing rate and the exact inspiratory flow speed. This ventilatory support is sometimes necessary for those with respiratory muscle weakness and under-ventilation when a bilevel device cannot deliver sufficient pressure.

■ Newest on the scene are **multi-mode ventilators** that provide volume control, pressure support and control, and bilevel device and CPAP modes. They are smaller, weigh about 13-20 pounds, and cost more than other breathing machines.

■ **Negative pressure devices** are still used by the occasional polio survivor. Vacuum-like intermittent negative pressure devices used on the chest and abdomen include iron lung, chest shell and body jacket, though they are considered less effective than positive pressure machines.

■ **Rocking beds** exist but have given way to more effective solutions.

■ **Tracheostomy** is a surgical opening into the trachea for creation of artificial airway. This invasive method is sometimes indicated and in certain cases may not be avoided. It provides

#### **PRACTICAL SUGGESTIONS:**

- Adopt a healthy lifestyle, avoiding that which makes breathing more difficult, such as obesity, smoking, alcohol intake.
- Be aware – avoid unnecessary oxygen therapy, sedatives, humidity, extremes of temperature and excessive fatigue.
- Get flu and pneumonia vaccinations at the right time and stay away from people with respiratory tract infections.
- Plan well before surgery, especially anesthesia use, avoiding general anesthesia whenever possible in favor of local or regional anesthesia. Avoid unnecessary surgery.
- Carry out chest or lung expansion and assisted coughing exercises and other therapies recommended by the doctor.
- Use small, home devices for monitoring, such as a peak flow meter or an incentive spirometer or a portable oximeter to assess stability, especially during respiratory infection, if your doctor agrees.

direct access to the airway for ventilation and secretion management. Because of its potentially serious complications, many patients prefer to avoid or delay tracheostomy in favor of noninvasive methods, unless it is a matter of life or death.

#### **Interfaces**

All breathing machines deliver air through tubes going from the machine to the person using them. These tubes connect to an individual by an interface such as a face mask or nose mask or nasal pillows or mouthpiece. Numerous styles of interfaces exist. Through trying several of them, a comfortable one that doesn't leak can be found (or can even be custom-made).

Getting my ventilator and mask took some experimenting. At first I was sent home with a BiPAP® machine and a Respiratory Therapist (RT) to get me started. She adjusted the controls according to the doctor's orders, placed the mask over my nose, and turned on the machine. I was immediately hit with a blast of air the likes of which I hadn't felt since I stuck my head out of the car window as a kid when my dad was driving down the highway. There was no way I could take a breath with all that air coming at me. It was frightening not to be able to inhale – especially when I was using a machine designed to help me

continued, page 6

#### **Reminder:**

It's flu season ...  
*be sure to get your  
flu shot.*

### Excerpts from a Letter to Post-Polio Health International

*Ann O'Meara, New Jersey, called one day to talk about her brother and his recent death. She is committed to telling his story to encourage family members of other polio survivors to be alert. The excerpt below is only part of the story. The full story can be found at [www.post-polio.org/edu/pphnews/pph23-4ann.pdf](http://www.post-polio.org/edu/pphnews/pph23-4ann.pdf)*

My brother John was stricken with polio at seven years of age. He spent nine months in the hospital in an iron lung and lost the use of his right arm.

Over the past few years, John had recurring bouts of bronchitis. He often had trouble sleeping and would get out of bed and sit in a chair to finish the night. We thought the interrupted sleep was causing his fatigue. He began to fall asleep more and more during the day. Then his speaking became softer and slower, as if he didn't have enough air. His incredibly sharp mind and even quicker wit sometimes drifted into randomness during conversations.

John was under the care of a cardiologist who asked him to wear a 24-hour EKG, which he did. Eleven days later, the cardiologist's office called and told him to "go to the emergency room." There John experienced an "event" in which he stopped breathing. He was moved to Intensive Care, placed on a respirator, and later given a pacemaker.

During the hospital stay John realized how sick he had been. He came to understand our concern. I was hopeful that he would be a stronger advocate for himself. I contacted Post-Polio Health International and ordered the *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors* so that I could learn more.

John returned home and seemed well for a week or so. Then, again, I began to notice the slowing of his responses. He was bereft of energy. He returned to sleeping in the chair. It was in the chair that he died in the early hours of an April morning. I received the *Handbook* I'd ordered. As I read, through my tears, I was stunned to see the symptoms that were exactly John's experience.

## My Journey through the Basics of Post-Polio Breathing Problems

continued from page 5

breathe. I asked the RT to change the settings. She said she could not. Clearly my breathing problems were not meant to be solved by BiPAP® at those settings.

Later I was given a PLV®-100 volume ventilator to try. With settings determined by my pulmonologist, this gentle machine gives me the predetermined amount of air I need at the predetermined moment when I need it. In a sense, it breathes for me. It's easy to care for: every morning I rinse the nose pillows and mask tubing in delicately soapy water, and once a week I soak them in a vinegar and distilled water solution. I also change the longer disposable tubing and filter weekly.

Since my weak neck muscles have trouble handling any weight at all above the shoulders, and I cannot tolerate a band around the back of my head, I decided to adapt a nose pillow mask to my needs. I simply discarded all the paraphernalia holding the mask onto the head and attached the front

mask piece to a light plastic dime store headband with duct tape. No leaks, only a couple of ounces of weight – AND my pulmonologist approves.

### A Final Word

What was I thinking all those years ago when I was resisting mechanical ventilation? I was so afraid to let go. I thought if I could just hang tight to my life the way it was and not allow anything more to slip away from me, not cave in to another limitation, everything would be fine. I fought for this. I did not want the risk of change. It seemed impossible that the hideous green machine now residing in my bedroom could bring me freedom – but it has.

While I sleep, my polio-weakened muscles get to rest, and I awaken refreshed, free to go about my day feeling more energetic and alive. I've found a serenity in all of this that I never dreamed of.

There's great value in acceptance. ▲

***Polio Voices: An Oral History from the American Polio Epidemics and Worldwide Eradication Efforts*** by Julie Silver and Daniel J. Wilson was released in early September 2007 by Praeger Publishers, Westport, Connecticut. The hardcover (ISBN 0-275-99492-9), 192-page book sells for \$39.95 and is available online. Incorporating many rare photographs – most never made public before – from the family albums of survivors who tell their stories, the book includes testimonies from people who worked in polio wards and those involved in the worldwide eradication efforts. The book also addresses the emergence of the disability rights movement, the challenges of post-polio syndrome, and the state of developments today.

Carol Poore, who had polio in 1952, is a professor of German Studies at Brown University in Providence, Rhode Island, and author of ***Disability in Twentieth-Century German Culture*** (Ann Arbor: University of Michigan Press, 2007). The book is the first comprehensive exploration of disability in Germany during this tumultuous century. It features a section comparing images of Franklin D. Roosevelt to the disabled German politician Wolfgang Schäuble and includes a memoir about the author's experiences in Germany as a person with a visible disability. The book is available from bookstores, the University of Michigan Press ([www.press.umich.edu](http://www.press.umich.edu)), or [amazon.com](http://amazon.com).

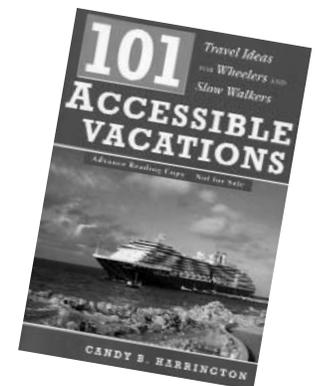
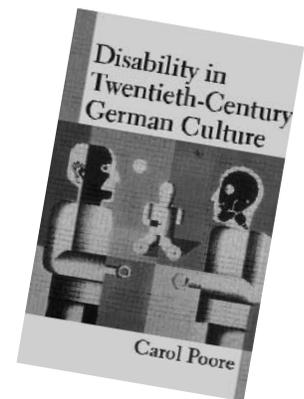
Candy B. Harrington's latest contribution is ***101 Accessible Vacations: Travel Ideas for Wheelers and Slow Walkers*** (ISBN 1932603433) published by Demos Medical Publishing (New York, 2008). Selling for \$24.95 and available online, the 352-page, softcover book contains destination information about over 101 cities in the US. Unlike other guidebooks that are organized geographically, *101 Accessible Vacations* includes sections ranging from Road Trips and The Great Outdoors to Historic Haunts and Cruisin'. Details can be found at <http://101accessiblevacations.com/>

### **New Internet Domain Targeting Volunteers**

The Foundation To Encourage The Potential Of Disabled Persons based in Thailand recently published its eighth book title, ***A Volunteer Handbook – Getting It Right***, which is now available for downloading from [www.volunteer.infothai.com](http://www.volunteer.infothai.com). The book provides broad volunteer guidelines as well as hands-on practical information for individuals, NGOs and government agencies.

### **My Polio Life Available on Internet**

A 16-page “patient questionnaire providing baseline information and comparison charts on the life of a polio survivor” has been developed by the Lincolnshire Post-Polio Network (UK). The questionnaire is to help polio survivors provide pertinent information to health professionals. It can be downloaded from [www.lincolnshirepostpolio.org.uk/downloads/extra/mypoliolife.pdf](http://www.lincolnshirepostpolio.org.uk/downloads/extra/mypoliolife.pdf). The survey is for your personal use, but you can also send a photocopy to Lincolnshire Post-Polio Network, PO Box 954, Lincoln, Lincolnshire, LN5 5ER UK, so it can be compiled with the responses of others. ▲



## Keeping America Sick

Reji Mathew, PhD, New York University, New York, Rqm3463@nyu.edu

At 38, the life I knew and expected for myself ended. In the span of two weeks, I suffered five falls, resulting in bloodied knees, a bruised hip, a bruised wrist and a fractured ankle, leaving me homebound and crawling, unable to bear weight on either leg. Up until this point in time, I managed on my own, living a physically limited but functional life, but now I could no longer ward off the progressive muscle weakening effects of post-polio syndrome. I arrived at a frightening turning point in my life – I was unable to control my gait without assistance.

With dread, I sought help. What generated a greater sense of powerlessness than coming to grips with dead and weakening muscles was the helpless position of being a patient in our health care system.

In my initial consultation, the doctor hesitantly took my history, telling me of a friend she knew who had little luck with this condition. “Well, um ... but ... umm ... we don’t really treat post-polio patients at this office, but we’ll see how far we get.” I did not understand what this meant.

My next call was to a doctor to inquire about a leg brace consultation to stabilize my mobility difficulties. “In this day and age we don’t brace post-polio patients,” he stated. I was confused.

The real shocker came during an initial physical therapy visit, “You’re the typical type A polio patient; you want to do everything!” She misread my anxiety. Crawling was a low point I did not want to go back to. I was starting to imagine my forties as a markedly disabled person. I was simply scared.

Without warning, I was forced to revisit my illness after years of managing on my own. I kept thinking to myself, “I am motivated, insured and informed; someone should be able to

take an interest in working with me.” I was wrong. I cycled through several doctors who were under-ambitious, and I learned quickly that my illness had a reputation, bringing with it a transparent bumper sticker plastered to my forehead:

**CHRONIC – NO IMPROVEMENT  
EXPECTED – LOW REIMBURSEMENT**

Looking back, I don’t think these health care professionals were incompetent, but rather influenced by a phenomenon I call *insurance conditioning*. Current health care reimbursement structures in this country have created a paradoxical situation, dictating its own guidelines, often inconsistent with the principles of health management. As a result, most health care settings operate like factories. Acute care gets reimbursement, while chronic care is often ignored or minimized.

As I started doing my own research on reimbursement for chronic conditions, I learned that fellow patients within paralytic spectrum disorders such as stroke, spinal cord injury, multiple sclerosis and cerebral palsy struggle to get reimbursement for illness management treatment options – physical therapy, speech therapy, occupational therapy and updated mobility equipment.

In my case, after persistent searching, I eventually found a caring team of doctors. I took a partial medical leave from my job and started the difficult process of adapting to my new mobility limitations. I entered outpatient rehabilitation and got fitted for leg braces and assistive devices. I underwent gait training and learned muscle preservation exercises. I also learned lifestyle strategies to ration out my muscle strength throughout the day to minimize the risk of further disability. Most importantly, I gained access to current technology, aiding me in remaining an independent person. I am learning how to drive with my hands and type with my voice. Learning how to get up and sit down is the most invaluable intervention; it keeps me independent for daily activities like using the bathroom.

The interventions I received are specific to my mobility impairments, but interestingly, my treatment parallels what I know about counseling chronically ill individuals in my role as a cognitive behavioral therapist. Disease management training, which most chronic conditions require, is an ongoing learning curve over the life span. In reimbursement language, this is known as *preventive* or *maintenance* care. The acute care reimbursement model does not allow for intermittent intervention for the long term treatment needs of the chronically ill – neither do the ambiguous promises of universal health care.

Having access to active rehabilitative care has offered me more than the polarizing choices of health care economics – show up when you have an acute need, or stay home and collect disability. The point is, from a cost/benefit perspective, intermittent inter-

vention keeps me out of the hospital and allows me to continue to be a contributing member of society.

As a health care professional, I know the challenges of managing difficult patient loads, providing emotional comfort session after session. What the economic discourse in this country does not account for are the intangible ingredients of health maintenance and recovery: human regard and imparting the capacity for self care. Self care is a skill most often learned when modeled by another. Patients cannot do it alone.

I have medically stabilized, but I am left with a mix of hope and fear. The questions I grapple with feel like the beginning of an end. How long will I be independent? How long will my muscles last? What kind of care will I need as an aging person with a disability? Will I find a disability policy that will not penalize me for my pre-existing condition? In addition, I am also faced with the enormous challenge of allotting most of my adult income towards planning for health care costs.

The late John Belluso, a playwright who himself suffered from a chronic illness, once commented on disability status: “It is the one minority class in which anyone can become a member of at any time.” Every American inevitably faces the chasm between an active mind and a failing body. For chronic conditions, narrow media portrayals of individual heroics are such a disservice. A more accurate picture is success due to individual will, community support and access to lifetime care. It is estimated that close to 48 million Americans live

continued, page 10

**Reji Mathew, PhD** is a senior counselor at the Counseling & Behavioral Health Division of the New York University Student Health Center, Assistant Adjunct Professor at the NYU School of Social Work, and author of an upcoming book, *Evolving Traditions in America: South Asians and Arranged Marriage*.

She contracted polio in India at 9 months.

with some form of disability. With growing populations of need around the USA – aging baby boomers, returning veterans and the elderly – these issues will not subside.

This coming election year will be full of health care rhetoric. As long as the health care system continues to be hijacked by a treatment-restrictive economic structure, chronically ill individuals will continue through the vicious cycle from acute need, to band-aid care, to the next acute need. For many chronically ill Americans,

managing an illness is a full time job with no endpoint. And if money is the bottom line, does the acute care treatment framework actually cut costs?

I may have to transition to a wheelchair someday, but for the moment, having had access to skillful rehabilitation, illness-specific education, assistive devices and community resources has led me to a restorative realization.

My illness may be my fate, but it need not be my story. ▲

### *Letter to the Editor from Jeanne M. Carlock*

After reading the recent article about assistance dogs by Dr. Mary Lee Nitschke, I'd like to relate some of my own experiences. In 2006, I investigated getting a dog through an agency that trains service dogs. Some agencies offered to train and place a dog and to train the recipient at no cost. Others required the recipient to help in fundraising. However, with all of them, there was quite a waiting list, from two to four years or more.

Fortunately, I have a wonderful friend, experienced in the training of guide dogs for blind people, who offered to train a dog for me. With her expert guidance, I purchased a golden retriever puppy. Choosing a puppy that was neither too passive nor too aggressive was a challenge, even among those of this breed who are known for being excellent assistance dogs. My dog, Lucy, is now one year old. She has lived most of her time at my friend's home, gradually spending several days at a time at my house. We have training sessions once or twice a week. This will go on for most of the next year.

The article by Dr. Nitschke implies that training an assistance dog is easy for the person with a disability. After watching my friend work with Lucy, I know I could never train a dog. It is very physically demanding. Also, for me there were several questions to be answered: Can I commit time daily to reinforce dog training? Will my husband take on extra duties like "poop scooping" and playing with a large dog? Can I afford all the expenses of owning a dog? And, can we adapt to the lifestyle changes in our home?

I do not think that every breed of dog can become a service dog as was stated in the article. Dogs must like to work, want to please people, be fairly strong, and enjoy retrieving things. For these reasons, Labrador and golden retrievers are often used. ▲

## Call for Proposals: PHI's Fifth Research Grant

Are you a researcher? Do you have an innovative idea for investigating the late effects of polio or neuromuscular respiratory disease?

Guidelines for applying are available:  
[www.post-polio.org/res/rfcall.html](http://www.post-polio.org/res/rfcall.html)

### Dates to Remember:

**Monday, March 3, 2008**

Deadline for Phase 1 application

**Monday, April 14, 2008**

Invitation to submit Phase 2

**Monday, June 16, 2008**

Deadline for Phase 2 application (if invited by PHI)

**Monday, November 10, 2008**

Announcement of recipient

**Thursday, January 15, 2009**

Receipt of \$15,000

**Wednesday, July 15, 2009**

Receipt of \$10,000

### Special Thanks to Our Supporters

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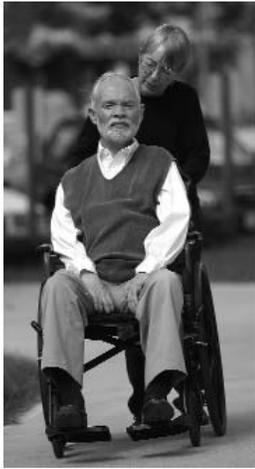
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**Polio History – WE'RE STILL HERE!**



Charlotte and Larry Becker

Photo credit: Sam Dean/  
The Roanoke Times

**PHI's WE'RE STILL HERE! campaign** began Sunday, October 14, with an article in *The Roanoke Times*, Roanoke, Virginia, featuring **Larry Becker, PhD**, PHI's Board President. To learn more about the Becker's philosophical approach to life and polio, go to [www.roanoke.com/news/roanoke/wb/135733](http://www.roanoke.com/news/roanoke/wb/135733)

**Daniel J. Wilson, PhD**, PHI Board member, was the guest speaker at the WE'RE STILL HERE activities in Johnstown, Pennsylvania, October 15th. Wilson, co-author of the new book, *Polio Voices* (See page 7.) discussed polio's impact on American history, including the important role of polio survivors in securing the rights of individuals with disabilities.

**The John P. Murtha Neuroscience and Pain Institute**, Johnstown, Pennsylvania, launched a new online registry of polio survivors to promote research. The web address is <http://postpolio.conemaugh.org>



Daniel J. Wilson

**Members of the European Polio Union (EPU) paraded in the centre of Brussels on October 16, 2007** to bring more attention to the needs of people with polio in Europe. Member states of the EPU are Belgium, Denmark, England, France, Germany, Hungary, Ireland, Italy, The Netherlands, Spain, and Switzerland. Prior to the rally, the groups gathered the signatures of 75 Members of the European Parliament (MEP) in support of the cause.



From left to right: **Thomas M. Kurtz, MBA**, Vice President of Governmental Affairs & Business Development, Conemaugh Memorial Medical Center; **Barbara J. Duryea, MSN, RN, CPHQ**, Director Research and Development, John P. Murtha Neuroscience and Pain and Institute (JPMNPI); **Steven E. Tucker**, President, Conemaugh Memorial Medical Center; **William DeMayo, MD**, Medical Director and Principal Investigator, Polio Program, JPMNPI.

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