

## To Have Surgery or Not to Have Surgery – That Is the Question!

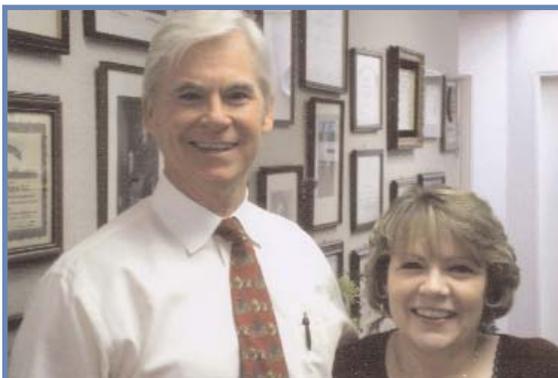
Debbie Hardy, Whittier, California, dhardy828@earthlink.net

**M**ention to someone that you need to have surgery and anyone within earshot of the conversation feels free to join in and tell you a horror story about a relative, friend, acquaintance or any combination of the above who had disastrous results with the same surgery that you are having.

The decision to have surgery is a difficult one for anybody, but for those of us who have chronic ongoing health problems, it is especially challenging. In addition to the typical worries one associates with having surgery, we have the added fear of aggravating our current condition and ending up in even more pain or with more limitations than we already have. Another big concern is recovery time – will it take longer than usual because of our current health issues, and how long will we be experiencing more pain than we normally do on a daily basis?

In March of 2005, my orthopedic surgeon ordered an MRI because of a pain in my lower back that was running down my right leg and into my foot. The MRI showed I had moderate spinal stenosis. Spinal stenosis is a

narrowing of the spinal canal caused by the growth of bone or tissue or both that reduces the size of the openings in the spinal bones and causes pressure and constriction on the nerves and/or spinal cord.



Dr. Mayo and Debbie Hardy

My physician advised that eventually I would need to have surgery for this condition and said I should think about that possibility. In the back of

my mind, I started replaying all of those horror stories you hear about people having back surgery. I thought I would have the surgery the 12th of never or when I couldn't walk at all – whichever came first.

Occasionally, over the course of the next two years, I would seek medical help when I physically over-extended myself in some way and was in such pain I could barely get around. Sometimes, I even let the idea of surgery roll around in my head for a few days, but eventually the steroids, pain pills and rest would significantly relieve the pain, and I would dismiss the thought of surgery and get busy with the process of living life.

While recovering from a serious fall in June, I found myself unable to move my right leg from the knee

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.*

## **Post-Polio Health** Winter 2008, Vol. 24, No. 1

ISSN 1066-5331

Editor: Joan L. Headley, MS  
editor@post-polio.org

Designer: Sheryl R. Rudy  
webmaster@post-polio.org

*Special thanks ...*

Nancy Baldwin Carter  
Maria J. Gray

©2008 Post-Polio Health International (PHI).  
Permission to reprint must be obtained from  
Post-Polio Health International (PHI).

### **How to contact PHI** Post-Polio Health International (PHI)

Including International Ventilator Users Network

4207 Lindell Blvd., #110  
Saint Louis, MO 63108-2930 USA  
314-534-0475, 314-534-5070 fax  
info@post-polio.org  
[www.post-polio.org](http://www.post-polio.org)

*To be sure you receive email updates from PHI, set your spam filters to allow messages from [info@post-polio.org](mailto:info@post-polio.org).*

## *Inside this Issue ...*

Pages 1-4

### **To Have Surgery or Not to Have Surgery – That Is the Question!**

Debbie Hardy found her answer to this question, but not without consultation and contemplation amid the pain. Success can also be attributed to her physicians, and PHI is seeking the names of other experienced orthopedic surgeons.

Pages 5-7

To assist struggling support groups, Post-Polio Health International instituted an Association Membership in 2006, with a benefit of an e-newsletter called *PHI Association Communiqué*.

Nancy Baldwin Carter explains in **PHI's "Leadership" Column Comes to the Website** the history of her column featured in the e-newsletter. If your support group would like to become an Association Member, contact [info@post-polio.org](mailto:info@post-polio.org).

Pages 8 and 12

Many of you express concern about polio survivors in other countries with the hope that what we have learned will help them. **Change of Perspective Benefits Survivors in Northern Nigeria** is a sampling of successful programs. The book on page 12 is excellent and would be a welcome gift to individuals/groups in many countries.

Page 9

Clara Reiss' **Letter to the Editor** seemed to require a photograph, which didn't happen but not for the lack of trying. I can attest to the fact that getting up from a chair the wrong way resulted in pain in my "polio arm" shoulder. Let us hear from you, as we heard from Peggy Whitcomb, whose message about exercise is a positive one.

Page 10-11

Be sure to check out Post-Polio Health International's activities and visit our website – [www.post-polio.org](http://www.post-polio.org) (Don't forget the hyphen.).

Until May,  
Joan L. Headley,  
Executive Director of PHI



down. This was a particularly devastating problem for me. Polio had partially paralyzed my left leg, so I use a long leg brace and crutches to ambulate. But my right leg has always been extremely strong, and without it in proper working order I knew I could not get around at all on my own feet.

My first thought was I had injured my quadriceps muscle in the fall. When I saw my physician, he assured me my quadriceps muscle was intact. He ordered an MRI of my back, saying he thought it was causing the problem with my leg. He also sent me to a neurologist to assess the problem and to test for nerve damage.

The nerve conduction studies completed by the neurologist showed there was nerve damage in the right thigh above the knee. However, he said the nerve damage was “old,” probably from polio, and that a combination of overuse of the leg and injury from the fall had stunned the damaged nerves. He thought that once the nerves had healed a bit, I would once again regain full use of the leg.

Unfortunately, the MRI showed that the spinal stenosis had progressed from moderate to very severe and was almost completely compressing the spinal cord at L-4 and L-5. I was advised the problem was severe enough to cause loss of bladder and bowel function in the near future. That was enough for me to make my decision. Pain and difficulty walking was one thing, but the thought of losing control of my bowels and bladder was unfathomable – I would have the surgery.

After thoroughly explaining the procedure used to do the surgery and

advising that this would take care of the leg pain only and not the lower back pain I had due to another condition, my orthopedic surgeon advised me to get a second opinion. He also suggested I access the Internet to read everything I could about my condition, as well as the surgery, and to ask as many questions as I needed to make myself comfortable with my decision.

In September of 2007, I had a decompression lumbar laminectomy. Through an open incision in my lower back, the bone and soft tissues of the spine that were compressing the spinal cord and nerves were removed and enlarged to relieve the pressure on my spine.

Even though my surgery took longer than expected and was particularly difficult because I had waited until things deteriorated to a severe level, when I awoke the first thing I noticed was that the pain that had run from my lower back down into my foot was no longer there. Also, I wasn't in as much pain from the surgery as I expected. After spending two nights in the hospital, I came home. Within a week, I was cooking and doing light housework.

When I mentioned to my orthopedic surgeon, Dr. Joseph G. Mayo III of Placentia, California, that I was going to write this article, he told me he was glad somebody was going to shed a positive light on this surgery because back surgery is still associated with such negative connotations.

I asked him what advice he would give to people contemplating surgery, and he offered the following:

continued, page 4

### Having surgery?

Check out the [Summary of Anesthesia Issues for Post-Polio Patients](http://www.post-polio.org/edu/hpros/sum-anes.html) at [www.post-polio.org/edu/hpros/sum-anes.html](http://www.post-polio.org/edu/hpros/sum-anes.html) prepared by Selma H. Calmes, MD, (retired), Chairman and Professor, Anesthesiology Department, Olive View–UCLA Medical Center, Sylmar, California.

## Recommend an Orthopedic Surgeon

### Have you had successful surgery during the last three years?

Post-Polio Health International wants to expand its list of orthopedic surgeons who have performed surgery on polio survivors. If you feel that your surgeon did an exemplary job and should be included on our list, we ask that you please mail the following information to the email or address listed on page 2:

- Your physician's name and degrees
- his/her specialties
- business address
- phone, fax, and website (if applicable)



### It is time to update *Post-Polio Directory* for 2008.

Published since July 1985, *Post-Polio Directory* is an international listing of post-polio clinics and health professionals who are committed to staying abreast of the developments in post-polio syndrome and aging with a disability. The *Directory* also includes post-polio organizations and supports groups worldwide.

If you have been in past editions, watch your email for the request to update your entry. If you are not listed and would like to be, contact the PHI office.

The *Post-Polio Directory 2008* will be ready March 1 and is a benefit of Contributor and Sustainer Memberships. Others may contact the PHI office for a print copy (\$12 USA; \$14 Canada and Mexico; \$16 Overseas air, USD only).

## To Have Surgery or Not to Have Surgery – That Is the Question!

continued from page 3

- ◆ It is important for patients to get a correct diagnosis.
- ◆ Patients need to be treated properly to see if the condition can be resolved medically before surgery.
- ◆ Patients need to understand their condition and treatment plan and be comfortable with it – ask questions.
- ◆ The surgeon and patient need to work together as a team – it is a joint effort.

As a patient, I think it is most important not only to find a good surgeon, but also to find one who treats you with dignity and respect and one you trust and with whom you can com-

municate. I did and I feel it made a huge difference in my outcome. Am I happy I made the decision to have surgery? Yes! Even though I have post-polio syndrome and limited mobility, I didn't have any more problems recovering from this surgery than anyone without these pre-existing conditions. In fact, this was the least painful surgery I've ever had, and the recovery was the quickest.

But, I am sorry I waited so long and suffered needlessly because of my own fears about what could happen. I wish I had realized sooner that back surgery, just like everything else in the field of medicine, keeps improving all the time. ▲

## PHI's "Leadership" Column Comes to the Website

Nancy Baldwin Carter, Omaha, Nebraska, n.carter@cox.net

**G**ermination of an idea, 2005: Dr. Lauro Halstead from the National Rehabilitation Hospital in Washington, DC, telephoned. He was putting together a new book with an emphasis on aging well with our disabilities – *Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio*. He wondered if I wanted to participate. If I did, he suggested I put in a call to Joan L. Headley, PHI's Executive Director, and see if she'd take me on as co-author of a chapter on keeping support groups active and useful.

As the two of us worked through the chapter, Joan and I discussed the growing pains we knew post-polio groups had encountered over the years. Now things were changing drastically in many directions. As polio survivors aged, more and more of us also experienced increasing post-polio differences. Groups themselves were taking a look at their own survival, searching for the right adjustments to serve their metamorphosing membership. Certain long-established leaders felt inclined to let someone else take over. It was a time for radical innovation.

Not all groups were prepared for such transformations. Some had no idea how to proceed. A number of once-vibrant, healthy teams faced the possibility of dissolving into nothing more than social clubs; others closed down altogether. Suddenly post-polio support groups that, in the beginning had been considered the model for other groups, were struggling, limping along from meeting to meeting. Needs were no longer being met.

Maybe post-polio support groups are an unusual breed. Maybe because of the special abilities of our members, our meetings have invariably provided unique insights and much-appreciated camaraderie not always found elsewhere. Many of us realized that support groups need to be an inside

job. Now the question involved how to retain our level of quality in groups where founding polio survivors were burning out, ready to move to the back of the room.

The situation often became surprisingly more complicated when former leaders began to hand over the reins. Post-polio support groups have always continued to attract newcomers – every day more survivors discover their need for help. Unfortunately, this fresh blood didn't necessarily infuse the life it might have into meetings. Sometimes new members were not being groomed to take over. Survivors were not rotating from one job to the next; little effort was made to include newcomers and old-timers alike in full participation. As a result, most members had no idea of the structure of the group or how to maintain a dynamic operation. After a time, then, certain meetings began to feel stale, new leaders did not step into the spotlight, and paralysis set in.

More than ever, PHI was receiving calls and e-mails from group leaders and members asking for help: How can we keep our group alive? What should we do to actively involve members? Our meeting has done every program imaginable – what's left? Where can we find accurate polio information? We don't have knowl-

continued, page 6

edgeable post-polio doctors around here – now what? We don't really want outsiders running our group – what can we do? Some of our members are too loud and pushy – or – our leaders are too loud and pushy – or – nobody around here is loud enough and pushy enough. Some of our wonderful groups were in crisis.

In the midst of this surge in group difficulties, PHI created a new e-newsletter called the *Association Members Communiqué* – the perfect outlet to respond to these concerns. The polio community can't afford to lose its internal support, always such an essential element of genuine assistance for polio survivors. Post-polio support groups run by polio survivors for polio survivors play a leading role in this scenario.

And so emerged the "Leadership" column, a monthly *Communiqué* feature meant to suggest ways to stir leaders and members into action and point toward different avenues to take to improve a given situation. Leaders and members contact PHI with questions and comments – the Q&A "Leadership" column then kicks into gear, hoping to find a few solutions for our end of the dialogue.

Sometimes all it takes is to jog the memory: Why are we here? We come together for the emotional support we get from fellow survivors, for the encouragement and comfort new information provides, and for the strength to face what lies ahead as the late effects of polio and aging meet to change our lives yet again.

Sometimes it takes ideas for exciting projects, for ways to interact with each other or the medical community, or for beneficial discussion topics for

members to explore. What will help our members want to spring to life?

The "Leadership" column is a resource. How can our leaders, our members, our groups meet the challenges each new day brings? We're here to talk about it.

Now PHI has gathered these columns together in their own "Leadership" spot on the website – [www.post-polio.org/net/leadcol.html](http://www.post-polio.org/net/leadcol.html). Here's a sample of what you'll find there:

**Q:** *My physician seems to have little knowledge of potential post-polio problems. Should I be worried? What are my options?*

**A:** The good news is that we are way beyond the days when polio survivors took their complaints to a puzzled doctor who felt his only recourse was to refer us to a psychiatrist. Today's medical community is aware of post-polio syndrome (PPS). Most doctors now see PPS as a legitimate medical problem. That's one hurdle behind us.

Are all physicians prepared to treat the many manifestations and nuances of this condition? Of course not – no more so than they were when polio came our way in the first place. There's nothing new about the fact that medical science seems woefully inadequate to individuals who pose perplexing challenges beyond a doctor's knowledge. I'll bet it seems that way to doctors, as well. There's plenty of frustration to go around.

Post-polio support groups can help.

Why not start by working together to figure out sensible ways to think about the situation? We have all known survivors who, amazingly, seem devoted to whining about yesterday rather than considering today's possibilities.

Dynamic groups discuss healthy ways to bring issues into focus. Seeking solutions is always better than dwelling endlessly on the problem.

Groups can explore creating better partnerships with doctors. For our part, we must give up expecting the quick fix of a pill for every malady. We must learn to work together with our doctors. If physicians and patients, together, approach this alliance with open minds and the willingness to listen, we will both learn new things. It's not a matter of magic – if we expect answers beyond what we now receive, then we must participate in the search for our wellness.

Herein lies the opportunity for a most productive meeting. Members might talk their way to truly helpful revelations. They could also devise an “office visit list” – some DOs and DON'Ts to propel individuals way beyond the usual. Perceptive groups will come up with lists much keener than the short one below.

- Do write a list of personal concerns and take it to discuss with the doctor.
- Do present issues succinctly and clearly.
- Do ask pertinent questions.
- Don't be shrill and demanding – or a wilted petunia, either.
- Don't waste the doctor's time.
- Don't assume patients know nothing (or everything) – and doctors know everything (or nothing).

Another good activity – groups can answer these questions, as well:

- How can we successfully vie for the attention of a physician who is overscheduled and underinformed?
- How can we improve our own behavior as patient/physician partners?

- How should we judge our expectations – is what we expect reasonable?
- How do we ready ourselves factually to carry the post-polio message?
- How do members respond to the statement, “If we want better doctors, we must become better patients”?
- How accurate is it to believe that younger doctors know little about polio, whereas older ones are well-informed?
- How do we encourage members to tell doctors that they had polio and to be persistent in asking if their difficulties could be connected to PPS?

Interactive meetings provide a further step in the right direction. Our groups can be outstanding liaisons between doctors and survivors. We help educate physicians and members alike when we invite doctors to speak at our meetings on specific post-polio issues. Be sure to provide everyone with reliable material pertaining to the subject at hand ahead of time. We spare the doctors hours of research, and members are more able to ask relevant questions during the after-speech Q&A session.\*

What all of this leads to is exactly what support groups do best: working together to produce beneficial results. Let us hear more voices, breathe new ideas into our discussions. Active groups are always on the lookout for new members, and we'll find them, since many individuals are only now experiencing the signs of PPS. Voila! There is much yet to do in our mission to make life easier for polio survivors, and infusing our groups with “fresh blood” is sure to build enthusiasm for the task. Why not go for it? ▲

#### \*A few excellent sources for material:

1. Jubelt, Burk, M.D. and James C. Agre, MD, “Characteristics and Management of Postpolio Syndrome,” July 26, 2000, *JAMA* copyright 2000, American Medical Association.
2. Halstead, Lauro S., MD, *Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome*, NRH Press, copyright 1998 by Lauro S. Halstead, MD.
3. Halstead, Lauro S., MD, *Managing Post-Polio, A Guide to Living and Aging Well with Post-Polio Syndrome*, Second Edition, NRH Press, copyright 2006 by NRH Press.
4. Maynard, Frederick M., MD, and Joan Headley, MS, *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*, copyright 1999 by Gazette International Networking Institute (now PHI).
5. Post-Polio Health International website: [www.post-polio.org](http://www.post-polio.org)

## Change of Perspective Benefits Survivors in Northern Nigeria

Elisha P. Renne, PhD, University of Michigan, Ann Arbor, Michigan, erenne@umich.edu



Babangida riding to school.

Until three years ago, Babangida Al-Laban lived with his parents in a small village east of Zaria in Kaduna State in Northern Nigeria. Although Babangida did not attend school, he learned to read Hausa and knew some arithmetic. It was clear to those who knew him that Babangida was a very bright child.

However, this boy could not walk and his main means of mobility was crawling, wearing pads to protect his knees. His future held little promise.

Then the Al-Laban family moved to Zaria City and Babangida got lucky. A neighboring family (whose son is a polio survivor) arranged for him to take an entrance examination for a nearby junior high school. One year later, Babangida was first in his class. As for mobility, the neighbor's son, Musa Muhammed, located a hand-operated tricycle, and Babangida was on his way.

When he graduates from this school in 2008, Babangida will apply for entrance to one of four secondary schools in Kaduna State that are part of the “Integrating Schools Program,” a special education effort begun in 1998. Here, students receive free room, board, books and travel expenses, all provided through the Kaduna State Ministry of Education.

In the past, people in Northern Nigeria with disabilities, people like Babangida, were left to beg for a living. Now, through a huge shift in perspective, the Nigerian Government, international agencies such as USAID (United States Agency for International Development), and the Kano State and Kaduna State Governments are supporting education and training programs that lead to employment for those with disabilities.

Mallam Mohammed Abbas Aliyu, headmaster of Al Huda Huda School, the secondary school Babangida hopes to attend, says, “More recently the disabled are starting to feel that everyone should be treated as a member of society, who should have the right to go to school.” He explains that making it possible for those with disabilities to attend school may encourage parents to give their children an alternative to begging. These children must complete primary school to the sixth grade in order to qualify for the new program.

“Their ability to attend and complete Primary 6 is a major accomplishment — so that instead of leaving the child to beg, the government says the child should go to school,” says Mr. Ayuba Amwe, Acting Director of Special Education at the Kaduna State Ministry of Education.

Even more opportunities exist today for polio survivors in Northern Nigeria. One of them is the organization of the Kano Polio Victims Trust Association (KPVTA), which offers employment and education for those with disabilities in Kano. Others are Kano’s newly formed business groups, such as the National Disabled Business Association (NDBA), which supports activities such as selling phone cards, mobile phones and accessories.

This group has received a microcredit loan to start poultry and fish farms in addition to the phone operations. A USAID program known as COMPASS (Community Participation for Action in the Social Sector) has provided vocational training and literary classes. The future is changing in Northern Nigeria for many like Babangida. ▲

**Renne** is an associate professor in the Department of Anthropology and the Center for Afroamerican and African Studies at the University of Michigan. Her research on polio in Northern Nigeria has been published in *Social Science & Medicine* and in the *Journal of the International Institute*; a chapter in the edited volume, *Anthropology and Public Health*, is forthcoming.

Post-polio has resulted in quadriceps weakness that makes me have to use my arms to get up from a chair or toilet. Last winter my shoulders became quite painful, which I assumed was arthritis.

... from Clara Reiss

In mid-winter, I was referred to the Rusk Vestibular Clinic for balance retraining. Two physical therapists came to get me in the waiting room. They saw me getting up with my hands placed on the chair arms so that my fingers pointed toward my body, my elbows out away from my torso. They screamed together, "Don't do that!" and said that it could lead to my rotator cuffs being torn. They then instructed me to place my hands on chair arms in the opposite way, with my fingers pointing out, away from my body, leaving my elbows close to my torso. Within a month, the shoulder pain was gone.

Holly Wise, PT, PhD, Medical University of South Carolina comments, "The position of the individual's shoulders during the original chair push-up (fingers pointed in towards body) was one of internal rotation and promoted rounded shoulders which can impinge the rotator cuff causing pain, etc. By switching the position of the hands, the shoulders became externally rotated opening up the chest and improving posture, apparently eliminating the biomechanical impingement of the rotator cuff."

Robbie Leonard, PT, Leonard Physical Therapy, Inc, South Carolina, comments, "The way Clara describes is the better way of getting out of a chair, and she has the muscle strength to do so. Some folks who use unusual positioning for performing functional techniques do so because they are using the muscles that they have."

After being diagnosed with post-polio syndrome, I went online to discover what it was and everything I read seemed to warn sternly against exercising. I quit my daily swims and home exercise routine, and finally retired. Several years later I was overweight and depressed and felt totally desperate. I read Dr. Julie Silver's heartening article "Polio Myths and Half-Truths" (*Post-Polio Health*, Vol. 18, No. 2), and decided to start exercising again. It took all my strength just to get down on the floor to do one sit-up and then get up again. Then I did one bend-over. And that's all per day for a month. Then I could do two each day, then twice a day. Immediately I felt better.

... from Margaret  
(Peggy) Whitcomb

By the end of three years I was "really" exercising and 1000% better, physically and emotionally. Amazingly, my endurance keeps increasing and some strength as well. Through it all, however, other survivors have predicted terrible collapse.

I also began to study my nutritional needs, deciding on high protein with carbs provided in fresh vegetables, some fruit, berries and nuts. I eat small meals several times a day, as well as taking vitamins and various supplements. Within four years I lost the fifty pounds I had put on, and that is a huge relief.

It seems to me that not every motor neuron in my body was polio damaged. I've depended on the unaffected muscles for over 60 years to support me. I've come to view myself as a whole, with some areas weakened by disease but all of my body and mind and spirit working together to stay as healthy as possible. I discipline myself and compensate where necessary. I pace myself every day in all activities including exercise. That is, as Dr. Silver noted, the key. Well, the first key was accepting post-polio syndrome. ▲

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

Help spread the word to researchers who have innovative ideas for investigating the late effects of polio or neuromuscular respiratory disease that the guidelines for applying are available at [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

### History of The Research Fund

Polio survivor and iron lung user Thomas Wallace Rogers bequeathed the initial funds for The Research Fund established in 1995. Grant awards are distributed from the interest gained on the corpus of the special segregated fund. Today, the fund's assets exceed \$600,000.

### Past Recipients of The Research Grant

**2007:** *Pilot Study to Identify PPS Biomarker* by a team of researchers from the University of Arkansas for Medical Sciences (UAMS), Little Rock.

**2005:** *Timing of Noninvasive Ventilation for Patients with Amyotrophic Lateral Sclerosis* by a team of researchers from Johns Hopkins University, Baltimore, Maryland.

**2003:** *Women with Polio: Menopause, Late Effects, Life Satisfaction and Emotional Distress* by a team from the University of Michigan, Ann Arbor.

**2001:** *Ventilator Users' Perspectives on the Important Elements of Health-Related Quality of Life* by a team from the University of Toronto.

The final reports of the 2001, 2003 and 2005 grants are online at [www.post-polio.org/res/index.html#awa](http://www.post-polio.org/res/index.html#awa). A summary of the final report from the *Pilot Study to Identify PPS Biomarker* (2007) will be published in the next issue of *Post-Polio Health* (Vol. 24, No. 2).

### Increasing The Research Fund

Contributions to The Research Fund may be mailed to PHI, 4207 Lindell Blvd, #110, Saint Louis, MO 63108-2930, or contributions may be made on our secure site at [www.post-polio.org/donForm.html](http://www.post-polio.org/donForm.html).

If you have any questions, please call Joan L. Headley at 314-534-0475.

### Physicians Join PHI Board of Directors



**Brenda Jo Butka, MD**, is a pulmonologist at Vanderbilt Stallworth Rehabilitation Hospital in Nashville, Tennessee. In this position, Dr. Butka treats individuals with neuromuscular conditions, many of whom who use home mechanical ventilation.

**John R. Fisk, MD**, is recently retired from the Southern Illinois University School of Medicine where he served as a professor of surgery in the Division of Orthopaedics and Rehabilitation and medical director of the Motion Analysis Laboratory. Dr. Fisk has provided a polio course to orthotists in several developing countries.

The complete list of PHI Board of Directors is online at [www.post-polio.org/about/board.html#boa](http://www.post-polio.org/about/board.html#boa)



## Special Thanks to Our Supporters

Post-Polio Health International thanks all of its Members for their financial support and for their helpful suggestions. We want to confirm that we do not sell your name and give your name to others only with your permission.

PHI's most recent annual report is online:  
[www.post-polio.org/about/AnnRep0506P.pdf](http://www.post-polio.org/about/AnnRep0506P.pdf)

### Recent contributions to The Research Fund ...

#### In Honor of

Julia Bidus Debra Hansen  
Joanne Flickinger

#### In Memory of

Carl E. Badgley, MD John Kearney, Jr.  
Barry Goldberg, MD Charles Ross  
Shirley Herried Bertie Rutledge

### Recent contributions to PHI's educational, advocacy and networking activities ...

#### In Honor of

Ida Elliott Jack & Elaine  
Jim & Judy Headley Memishian

#### In Memory of

Geraldine Asprey John Kearney, Jr.  
Carl E. Badgley, MD Mary Ann McLain  
A. David Bertoncin Mary Anne McLean  
Preston Covey, Jr. Louise E. Price  
Bea Denenholz Doris Sterret  
Cleo Marie Cash Ruby M. Wagner  
Fowler

### The Gilbert Goldenhersh Memorial Tribute Fund ...

#### In Memory of

Florence Kottle Goldenhersh

### Take Charge, Not Chances Available Online



The most recent issue of *Ventilator-Assisted Living* (Vol. 21, No. 4), mailed to Members of International Ventilator Users Network (IVUN), was a special 20-page issue containing the "product" of the grant received from the Christopher and Dana Reeve Foundation.

**Take Charge, Not Chances** is a portfolio of four documents designed to assist users of home mechanical ventilation to be better prepared for a hospital stay, specifically in an emergency.

All of the documents can be downloaded from IVUN's website - [www.ventusers.org](http://www.ventusers.org) - by clicking on the Take Charge, Not Chances logo. A limited number of print copies are available. Send your request to [info@post-polio.org](mailto:info@post-polio.org).

Not already a Member?  
**Join PHI!**

Support Post-Polio Health International's educational, research, advocacy and networking mission.

Rates Effective July 2007

PHI membership levels make it easy to start taking advantage of timely and important news and activities relating to the late effects of polio. Select your level below and return it with your check or credit card information. Or join PHI online at [www.post-polio.org](http://www.post-polio.org). Memberships are 100 percent tax-deductible.

#### \$30 Subscriber

Quarterly newsletter of your choice:

Post-Polio Health OR  Ventilator-Assisted Living

#### \$55 Subscriber Plus

Both quarterly newsletters:

Post-Polio Health AND Ventilator-Assisted Living

#### \$100 Contributor

ALL the benefits of Subscriber Plus AND

Post-Polio Directory AND

Resource Directory for Ventilator-Assisted Living;

discounts on special publications

and meetings sponsored by PHI

#### \$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 PHI

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

\$250 **Bronze Level Sustainer**

\$500 **Silver Level Sustainer**

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

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

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

Name \_\_\_\_\_

Affiliation \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State/Province \_\_\_\_\_

Country \_\_\_\_\_ Zip/Postal Code \_\_\_\_\_

email \_\_\_\_\_

Phone (include area/country code) \_\_\_\_\_

Fax (include area/country code) \_\_\_\_\_

I am enclosing a check for \$ \_\_\_\_\_ made payable to "Post-Polio Health International." (USD only)

Please charge \$ \_\_\_\_\_ to this credit card:

VISA  MasterCard  Discover

Card No. \_\_\_\_\_

Exp. Date \_\_\_\_\_ Card Verification # (3 digits on back of card) \_\_\_\_\_

Name on Card \_\_\_\_\_

Signature \_\_\_\_\_

Send this form to: Post-Polio Health International  
4207 Lindell Blvd, #110  
Saint Louis, MO 63108-2930 USA  
314-534-0475 314-534-5070 fax

### A Health Handbook for Women with Disabilities

The Hesperian Foundation is a non-profit publisher of books and educational materials that help people take the lead in their own health care and organize to improve health conditions in their communities. Their books are simply written, heavily illustrated and developed in collaboration with groups around the world.

For more information, email [bookorders@hesperian.org](mailto:bookorders@hesperian.org) or call tollfree in the US: 888-729-1796. The book may be ordered online ([www.hesperian.org](http://www.hesperian.org)) for \$20 plus shipping.

