June 4, 2007 (No. 11)

Helping Each Other Help Others

LEADERSHIP

Nancy Baldwin Carter, Omaha, Nebraska

Q: My physician seems to have little knowledge of potential 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 shrinks for what he thought were our imaginary ailments. Today’s medical community is aware of post-polio syndrome. 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.

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—let these few simple samples serve as inspiration:

● DO write a list of personal concerns and take it to discuss with the doc.
● 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 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 polio issues. Be sure to provide everyone with reliable material pertaining to the subject at hand ahead of time. Thus we spare the doctor 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:*


5. Post-Polio Health International website: [www.post-polio.org](http://www.post-polio.org)

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**Modafinil Study Conclusion**

A study in the May issue of *Neurology* [*Neurology*. 2007 May 15;68(20):1680-6] concluded that “based on the utilized measures of outcome, modafinil was not superior to placebo in alleviating fatigue or improving quality of life in the studied post-polio syndrome population.”

The abstract can be found at PubMed – [www.pubmed.gov](http://www.pubmed.gov).

Pubmed is a service of the [U.S. National Library of Medicine](http://www.nlm.nih.gov) that includes over 17 million citations from MEDLINE and other life science journals for biomedical articles back to the 1950s. PubMed includes links to full text articles and other related resources.

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**Road to Freedom Tour**
The Road To Freedom bus has been on the road since last November. The tour coordinated by ADA Watch/National Coalition for Disability Rights. The Road to Freedom is a yearlong, 50-State bus tour and photographic exhibit chronicling the history of the grassroots "people's movement" leading to passage of the Americans with Disabilities Act (ADA). More information and a list of the cities where the bus will stop is available at

http://roadtofreedom.org/cs/the_tour/tour_map_schedule

Corrected Links:

In the last PHI Communiqué (No. 10), the links below did not connect properly. Try these!

It’s Picnic Time!

- Don’t forget to wear protection from mosquito bites. Check out the latest…CDC: West Nile Virus - Updated Insect Repellent
- Don’t forget to wear protection from the sun. Check out the latest…EPA SunWise: Sun Safety Action Steps

And, here is a new one! Barbecue Basics: Tips to Prevent Foodborne Illness

Notes from a Association Members

The members of the Post-Polio Support Group of Lehigh Valley report that one of their founding members, Beverly Solomon, 81 of Allentown, Pennsylvania, passed away on Saturday, June 2, 2007 in the Inpatient Hospice Unit of the Lehigh Valley Hospital. She and I had many discussions over the years about the challenging, but rewarding, undertaking of coordinating a group. I will miss her, as will her family and group.

Joan Toone, President, Post-Polio Awareness and Support Society of British Columbia, wrote an excellent letter reminding people about post-polio to http://www.50plus.com/ that published an article discussing the success of the polio vaccines in quelling...
the polio epidemics.

Joan L. Headley, Executive Director