



The Polio Post

Ohio Polio Network Newsletter

Editor: Alice Sporar

Winter 2011 Issue



MERRY CHRISTMAS

&

HAPPY NEW YEAR



(Clockwise) Nancy Murphy, Kay Eichmiller, Judy Hickman, Randall and Lois Vannoy, Edwin and Shelba Boso, Pauline Monfreda, and Judy Peascoe. Photographer: Warren Peascoe

News from the Mid-Ohio Valley Post Polio Support Group

by Warren and Judy Peascoe

Warren and Judy Peascoe went to a West Virginian conference on the handicapped. One lady mentioned that their local group met at various restaurants. If they were treated well and the restaurant was set up to be handicap friendly, they presented the restaurant manager with an award and submitted an article to the local newspaper.

The Mid-Ohio Valley Post Polio Support Group (MOVPPSG) has been regularly having Dutch-treat luncheon meetings at the Parkersburg Golden Corral for several years.

So in early November the MOVPPSG met at the Golden Corral. We were allowed to rearrange the tables in the semi private room and decorate it. Once seated we gorged ourselves at the buffet, exchanged news, wrote cards to absent members, and exchanged gifts. We also presented the manager of the Golden Corral with a certificate of appreciation and then submitted an article to the local newspaper.

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News from the Mid-Ohio Valley Post Polio Support Group

by Warren and Judy Peascoe

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The Group plans on meeting at the Golden Corral at 11:30 on the second or third Monday of the month in January, February, March and April. The group takes advantage of the Wood County, West Virginia school closings to cancel the luncheon in the event of inclement weather. Meetings are planned for Jan. 9, Feb. 13, March 19, and April 16. Plans for talks and DVDs for May and June are in the works.

Mid-Ohio Valley Post Polio Support Group (MOVPPSG) Celebrates Thanksgiving and Christmas at Parkersburg Golden Corral

by Warren and Judy Peascoe



Michael Kelly (left), Manager of the Parkersburg Golden Corral receives a Certificate of Appreciation from Warren Peascoe, Assistant Group Leader of MOVPPSG

At their combined Thanksgiving and Christmas celebration members of the Mid-Ohio Valley Post Polio Support Group (MOVPPSG) presented the Parkersburg Golden Corral with a Certificate of Appreciation for being handicap friendly. Warren Peascoe, Assistant Leader of the group explained that the Golden Corral hosts the monthly Dutch-treat luncheon meetings in one of their semi-private rooms. The restaurant permits the furniture to be rearranged so that those in wheel chairs can circulate among the other members. In addition the staff cheerfully provide assistance with service when needed, provide frequent drink refills, and keep the table clear.

Peascoe explained that the MOVPPSG is open to people experiencing the symptoms of post-polio syndrome (PPS) and related conditions, their family members and friends. The group seeks to provide education about PPS and strategies for coping with handicaps. It provides members with social and emotional support. The Wood County Society sponsors the educational mission of MOVPPSG. Anyone interested in the group should phone 304-295-4233 and leave a message.

Post-Polio Thoughts

by Nancy Baldwin Carter, BA, M Ed Psych,
Omaha, Nebraska, (n.carter@cox.net)

WHAT'S A PATIENT TO DO?

Let's say we're doctor-shopping. Maybe we've moved to a new city or our long-time doc is retiring—for whatever reason, we need a different doctor. Question is—where to start? How to choose?

We all want the best. Someone who knows what he's doing, who can get the diagnosis right. Someone reliable, respectful, trustworthy. We want more than a good listener—we want a doc who understands, who acknowledges that our concern is real. We realize not all physicians have special post-polio expertise—still, the best are curious, interested. They don't miss a beat. They ask all the right questions, answer every one of ours as fully as possible—and they keep searching. How do we find this special person?

Top of the list? Check qualifications. Here's some great advice: Start with Board Certification.

This one's important. While being **licensed** to practice medicine assures that a doctor holds certain minimum requirements, **board certification** goes way beyond this. Doctors who choose to be board certified do so voluntarily to demonstrate skill in their particular area of practice. While every specialty and subspecialty has its own certification, some boards may not be very exacting. Clearly, some are better than others. What we must look for, then, is board certification that has been approved by the **American Board of Medical Specialties (ABMS)**.

The ABMS carries out a rigorous standard of testing and evaluation. In addition to strict initial certification, doctors must go through a recertification process every six to 10 years. They must also keep their certification current with the ABMS **Maintenance of Certification (MOC)** program, which requires more testing and proof of continuing education and experience throughout their period of certification.

How can we learn that a doctor is board certified with ABMS approval? One place is www.healthgrades.com. It's easy. Go there. Enter your doc's name. Details pop up before your eyes. His specialties are listed, and if he's board certified, a mark following each of these indicates ABMS approval. (If your doctor is not specified here, try CertificationMatters.org.)

Beyond certification, notice the state where the doc is licensed; details concerning his education; and a background check that shows any malpractice, sanction history, and board action history in the past five years. General guides. This is good stuff.



Post-Polio Thoughts by Nancy Baldwin Carter, BA, M Ed Psych

WHAT'S A PATIENT TO DO?

(Continued from page 3)

Maybe not so reliable are patient evaluations. While the criteria rated can be of interest, this may be biased, bearing no resemblance to accuracy. It's merely one patient's word.

Other things can make a difference, too. Ever notice the initials after doctors' names? Does it matter whether the amorphous "Dr." Mary Smith diagnoses my underventilation, or whether this is left to Mary Smith, M.D.? Better yet, could I feel even more secure if my pulmonary problem were in the hands of Mary Smith, M.D., FCCP? Education, staying current, searching for excellence, earning the best credentials—all of this matters. Even so, looking good on paper isn't all there is. What else counts?

Our interaction with the doctor, for one thing. If we've done our part—handed her the list of our meds, our allergies, and a complete history, discussed every issue we meant to, asked every question and open-mindedly heard every response—we can begin to assess the situation. Are the two of us developing a healthy rapport? Are we becoming partners in pursuit of wellness?

These days we expect doctors to believe us when we say we have a problem. We expect them to search in every direction for answers, to keep at it until we find relief.

If this doesn't happen, we move on. No need to pull out the voodoo doll. Simply get a second opinion, find another doctor. Ask around for referrals—and then begin, again, by checking qualifications. Remember—we deserve the best.

Nancy Baldwin Carter, B.A., M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.

Source: Post-Polio Health International (www.post-polio.org)



Post-Polio Thoughts

by Nancy Baldwin Carter, BA, M Ed Psych,
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CLOSE ENCOUNTERS OF THE POST-POLIO KIND

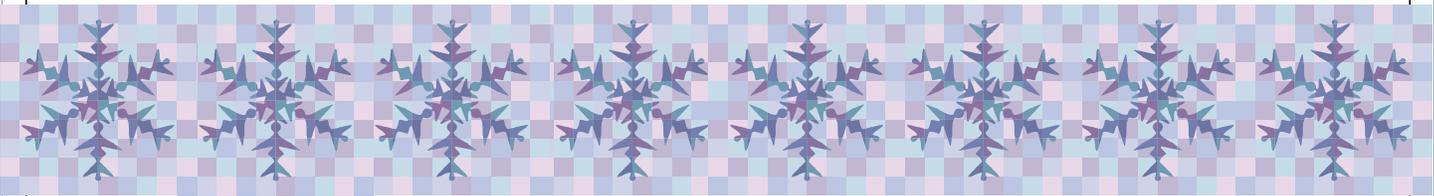
It's not as if we polio survivors never run into a glitch or two in a day. Let's face it—dealing with the unexpected has become part of everyone's routine. Developing the finesse to do that smoothly and successfully—well, that may be a different matter.

Consider Alice, a former nurse with serious arm weakness. Alice just returned home from two weeks at a rehab center where she was evaluated by a PT, an OT, and her personal physician, all of whom concluded that she needs a power chair.

Congestive heart failure and weakness in her legs make it difficult for Alice to walk around the house, and she finds it impossible to be independent when it comes to such things as getting to the bathroom. She needs the power chair.

So the rehab center folks contact a power chair supplier and arrange for them to meet with Alice to work out the details for finding the right chair.

Meantime, Alice (now home and renting a power chair) engages a home health agency to provide the PT her doctor orders. And herein lies the problem.



The PT, seeing Alice only once, decides he will be a miracle worker, says he'll have her up and walking in no time, and puts the kibosh on the power chair. Without consulting anyone, he calls the power chair outlet, switches them to his own questionable evaluation of Alice's condition, and declares that only a manual chair is indicated for our weak-armed Alice. Trouble ensues.

Time for Alice to jump into action.

We all have options. We do not have to sit passively and watch others take over our lives. This doesn't require shouting angrily in indignation, loudly stirring the pot with wild demands or accusations. A calm, quiet, "I'm in charge here," will do.

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Post-Polio Thoughts by Nancy Baldwin Carter, BA, M Ed Psych

CLOSE ENCOUNTERS OF THE POST-POLIO KIND

(Continued from page 5)

Alice could:

1. Start by firing the PT (if not the home health agency) and hire one that will honor the perfectly acceptable existing evaluations already attained. Check the qualifications of workers sent by any agency and be clear on job descriptions. Everyone must understand that our health care decisions are up to us—we do not casually hand over our authority to every individual who stumbles into the picture.
2. Speak up. If we have already been through a certain process and have no intention of doing it again, we have merely to say so. If someone insists on our participation when we know this to be wrong for us, we refuse. The word “NO” comes to mind. And if this is more than we can handle, then we’d best find ourselves a “NO-man” to carry along with us to utter the word.
3. Work with experts. For instance, see an assistive technology professional to get exactly the fit and the kind of chair needed. Don’t settle for anything less. Discover what works for us.

Don’t allow a salesman with extra scooters in his inventory to decide that would make a better purchase than the chair we want. Who knows our bodies better than we do?

Of course it isn’t just Alice. Lots of people need to realize it’s OK to act on the courage of their convictions. You know how it is. Jack makes an appointment with his doctor. When he arrives at the office, he learns he will be seen by a nurse only. Fine, if that’s what he wants. If not, he needs to say so. Firmly, but calmly, he must insist a pinch-hitter is not acceptable. Next time he can avoid this situation by confirming this when calling to get on the schedule. Nothin’ to it.

Easy enough—no whining or complaining. We simply gather up our polio pluck and make our lives work for us. What could be better than that!

Nancy Baldwin Carter, B.A, M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.

Source: Post-Polio Health International (www.post-polio.org)

ABLE TO TRAVEL

"Able to Travel" is a full-service travel agency specializing in the needs of individuals with disabilities. Call for pricing and itinerary details. 888-211-3635 or www.abletotravel.org.

Editor's note: This information was taken from "Life in Action," the membership publication of the National Spinal Cord Injury Association, a program of United Spinal Association. I do not have first hand experience with "Able to Travel."

**(EVERYDAY ADVOCACY)
MEDICAL ACCESS:
NEW GUIDELINES**

By Michael Collins

Q. I've been battling with a nearby medical clinic that refuses to install a wheelchair accessible scale and exam tables. It's a new, multidisciplinary clinic that cost more than \$50 million to build, and I'm sure they spent millions more equipping it with diagnostic devices and machines. Since I have coronary artery disease, I went to the old facility and now the new one, and I asked for these things before the new building was completed and have asked multiple times since then.

Whenever a non disabled person goes to a cardiologist or even their general practitioner, they get weighed. But not me, even though my condition warrants it. When you can't find a scale that's usable, you can gain a lot of pounds and not know it. Ten or twenty pounds can make a significant difference in blood pressure and stress on the heart, as well as the kidneys and other organs.

Now that there are new ADA regulations that cover medical equipment, as well as doctors' offices, is it possible to force these changes to be made? If they continue to refuse, what are my rights?

Chad

A. Chad, it continues to amaze me that there are still inaccessible medical offices despite a requirement that they were to become accessible in 1992, when the ADA went into effect. Section 504 of the Rehabilitation Act required that same level of accessibility prior to the passage of the ADA, for any medical practitioner who received federal assistance (including Medicare or Medicaid payments). At first, some medical providers protested that accessible medical equipment was not available, yet other hospitals and doctors offices managed to procure such equipment. Because of those requirements, ADA lawsuits have been filed against some medical offices and hospitals, which has resulted in remodeling and establishment of policies that improved access to medical care.

The United States Architectural and Transportation Barriers Compliance Board (Access Board) developed specific guidelines for these facilities that went into effect March 15, 2011. They also reaffirmed the requirement that medical providers must provide accessible medical equipment, such as, examination tables and scales. The new Access Board regulations do not change the initial requirements that medical practitioners be accessible, as first stated in the Rehab Act or the ADA, so any person who feels they have been discriminated against while trying to receive health care could, thus, still file a complaint or a lawsuit under the original laws.

If you choose to take preliminary steps to gain access to the new medical clinic, I would recommend a couple simple actions. The Department of Justice recently published a new booklet, "Access To Medical Care For Individuals With Mobility Disabilities," which can be printed from the DOJ website or ordered by phone. (See Resource below). A copy could be printed out and personally handed to the management staff of the clinic or hospital where you prefer to receive medical treatment. Following that up with another copy of the booklet attached to a letter, perhaps with a copy to an attorney, should make it clear that there are no excuses for inaccessible medical treatment or facilities and that immediate changes should occur.

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(EVERYDAY ADVOCACY) MEDICAL ACCESS: NEW GUIDELINES**by Michael Collins****(Continued from page 7)**

I would recommend that anyone with a mobility impairment obtain a copy of this publication. It contains multiple diagrams that detail how best to create accessibility in existing examination rooms, as well as where to locate accessible exam tables, lifts, and wheelchair scales. The booklet also clarifies that it is up to the provider to transfer individuals who need to receive treatment on an exam table, if they cannot transfer themselves. Some larger facilities may need to have multiple accessible examination rooms and exam tables, in order to accommodate the needs of those they serve.

Finally, know that you are not alone. As a power wheelchair user, I have not found anyone to determine my accurate weight in almost twenty-two years, and have never been on an accessible exam table. My own physician will be receiving a copy of the DOJ booklet during my next visit. I hope you have great success in advocating for your needs, and that providing the clinic with the updated information will get you the access you require and are entitled to.

Michael Collins is the former Executive Director of the National Council on Disability and of the California State Independent Living Council. Send questions to tgilmer@newmobility.com.

Resource: DOJ booklet on medical access requirements: 800-514-0301 or www.ADA.gov

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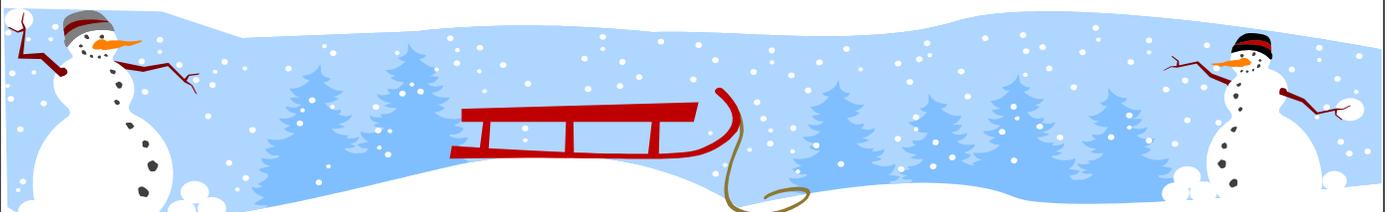
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