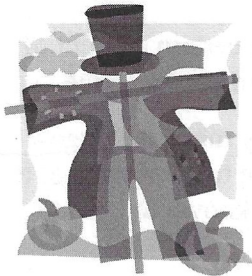


# The Polio Post

Ohio Polio Network Newsletter

Editor: Alice Sporar

Fall 2009 Issue



## Pat Kelly's Message

Congratulations to the winner of the Name the Newsletter contest, Brenda Ferguson. The new name of the newsletter – as you've probably already guessed – is "The Polio Post". It has been observed that this is a good title since it flips the words in the term "post-polio," but keeps the same meaning for us. A number of post-polio newsletters from around the world have names and now we have joined them.

With this newsletter, I will be leaving my post as temporary editor and Alice Sporar is now the sole Editor of "The Polio Post." I want to thank Alice very-much for volunteering to continue as Editor.

We would like to thank Melanie Hogan and Linking Employment, Abilities and Potential (LEAP) of Cleveland, Ohio, for volunteering to assist us by assembling, printing, and mailing the newsletter. This will be a tremendous help to us. For more information about LEAP, please visit [leapinfo.org](http://leapinfo.org).

LEAP also has an article and photo about Joyce Metheny on their Web site. The link is [leapinfo.org/News.asp](http://leapinfo.org/News.asp). Joyce was very active in many other organizations, including LEAP.

Our Treasurer, Ruth McCort will still receive dues from the members and update the expiration date for each member and print the labels (which also contain the expiration date) for the newsletter.

Please send articles or letters for the news letter to Alice Sporar using the return address of this newsletter.

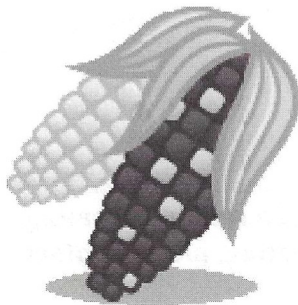
For those who have not seen it, I would like to invite you to go online to our Web site, [OhioPolioNetwork.org](http://OhioPolioNetwork.org). If you have a question or comment, you can reach us there as well. Just enter your comment or question in the form found under the menu item "Contact Us/Request". These are checked frequently and we will get back with you.

If you are interested in helping us, consider volunteering to be on the Ohio Polio Network Board. The Board meets quarterly. For more information, please contact me or a Board member. You can also use the Contact Us form on the Web site.

Our next OPN Board meeting is scheduled for November 7, 2009 at the Westerville Ohio Library from 12 p.m. – 3 p.m.

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# It's always an adventure

by Joanne R. Sage, Lorain County Chapter

What am I talking about? Mountain climbing, sky diving? No—it's using a public rest room when you are disabled.

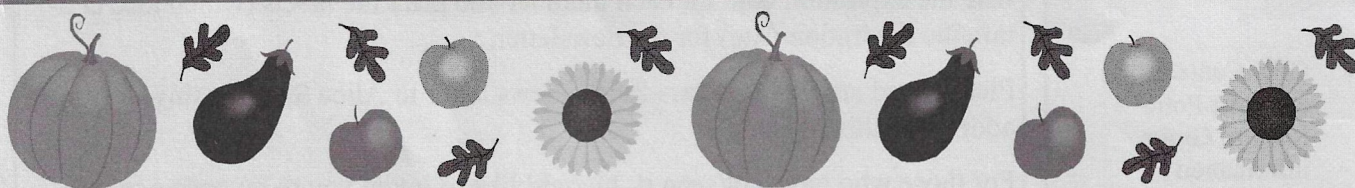
My husband and I have it worked out that if I use a bathroom in a restaurant he waits a certain amount of time before he sends in a waitress to rescue me and believe me I've had to be rescued more than once.

Just because the ADA has specifications that should be followed it does not necessarily mean they know what they are doing. For instance they may have installed two grab bars but you'd have to have arms of a gorilla to use them. I especially like the towel dispenser too high to reach. I have been known to use my skirt many a time.

I have found, much to my amazement, that some of the worst bathrooms are in medical facilities. Once we went to visit a relative at Elyria Memorial Hospital and I got stuck by the door and could just open the door a crack to watch for someone passing by in the hall and yell for help. I was not near the pull cord by the way since I hadn't even gotten that far.

Then there is the "Landerhaven Saga". We were invited by the March of Dimes to be the table of "Token Polios" at their annual meeting. I had been asked by Alice Sporar to bring a tape measure to make sure their toilets were the correct height. During the dinner Dolores Herron and I went to the ladies' room and I didn't even need to measure since once we sat down we realized we were not going to be able to get up. We started laughing (which doesn't help by the way) because it was apparent we were going to have to be creative. We had to take off our shoes and nylons so we could get traction on the slippery floor. Meanwhile Teddie Gideon had come in and joined in the fun. She even had to hold the heavy door open for us once we were ready to leave. Of course this had all taken so long we missed hearing the speaker.

Just another chapter in the life of a disabled person using a public rest room!!



**OPN Board Meeting**  
**Saturday, November 7, 2009**  
**Westerville, OH Library**  
**Noon - 3 PM**

**OPN members are welcome to attend. OPN is always looking for members interested in becoming Board Members. If you are interested or have agenda items for the Board Meeting, please contact Patrick Kelly, [pkelly03@sprynet.com](mailto:pkelly03@sprynet.com)**



# Are you suffering from swelling?

Living with swelling is inconvenient. Swelling in the arm or hand can affect your ability to write or use the involved arm for daily activities. Leg or ankle swelling can limit your ability to wear shoes or clothes, challenge your balance, and impair your walking. In more severe cases swelling can cause cellulitis/infection or open wounds.

It can limit your daily function or cause pain and stiffness. Facial swelling can affect your ability to eat and swallow.

There are two common causes of swelling:

- **Venous Insufficiency:** Ankle or leg swelling that gets worse as the day progresses because of poor circulation. This type of swelling is commonly treated with diuretics. A diuretic is a water pill prescribed by a physician that helps to reduce swelling. A diuretic is effective with minimal to moderate swelling; however, as the swelling becomes more severe, it is less effective.
- **Lymphedema:** A collection of protein rich fluid in the tissue space generally as a result of cancer related surgery/treatment, trauma, poor circulation, congestive heart failure, or congenital (born with swelling due to a malformation in the lymphatic system).

It is wise to let your physician assess the swelling and determine the cause.

Treatment is available for those battling this condition. Unfortunately, in many cases, the swelling can only be controlled, not cured.

The treatment of choice by specialists who treat this condition is Complex Decongestive Physiotherapy, which consists of:

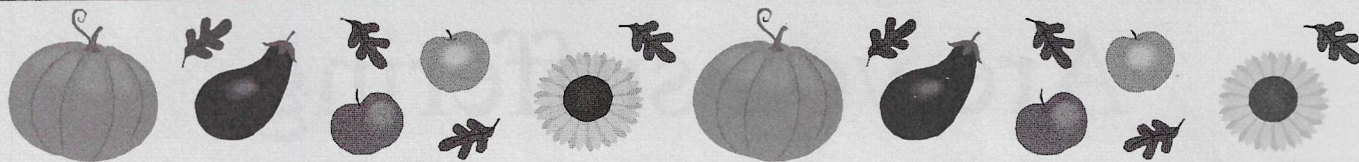
- Manual lymph drainage (specialized massage)
- Compression bandaging for swelling reduction
- Meticulous skin care
- Therapeutic exercise
- Education

Once the swelling is reduced, the limb is fit for a compression garment that is worn thereafter on a daily basis to maintain the reduction.

Controlling swelling can improve your quality of life! What are you waiting for? Talk to your physician to determine if this type of treatment would be beneficial for you.

*Reprinted from USA Weekend, June 14-17, 2007, HealthSmart Column by Dr. Tedd Mitchell and from East Coast Post-Polio Support Group, Ormond Beach, Fla., Jan-Feb. 2009.*

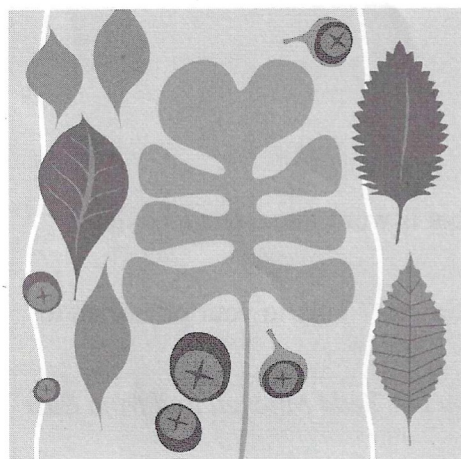




## News & Notes

- **New Disability Web site**  
For information on federal programs that serve people with disabilities, go to [Disability.gov](http://Disability.gov). This Web site replaces the former [DisabilityInfo.gov](http://DisabilityInfo.gov).
- **Post-Polio Information**  
For information on post-polio Issues, join Post-Polio Health International. Memberships run from \$30 to \$150 per year, depending on what level you choose. For more information, contact Post-Polio Health International at 314-534-0475, 4207 Lindell Blvd. #110, St. Louis, MO 63108, or [www.post-polio.org](http://www.post-polio.org)

Educating ourselves about the effects of post-polio syndrome is important and may save our lives.



# No more excuses

A power chair (not manual) or scooter is not an instrument of torture (although a manual chair can be!) Using a power chair or scooter will not make you look stupid at least not as much as pretending you don't need one while taking pain meds and stumbling around, falling down, requiring surgery on hands, elbows, shoulders, knees, etc.

Using a power chair or scooter will give you more energy because you won't be using all your energy in trying to accomplish the impossible (i.e. looking like you don't need one). Using a power chair or scooter will actually be more freeing. You will have the freedom to go wherever you want, without having to have someone chained to you to push you here and there – and then go off to look at something else that interests them and leave you stranded. (Been there, done that!)

Using a power chair or scooter will relieve the strain on overtaxed shoulder muscles and joints that were never meant to be walked on in the first place, thereby eliminating much of the unnecessary surgeries which, by the way, will not last unless you change the way you do things. You may also find that you don't need as much or any of the pain meds.

Using a power chair or scooter will show that you are winning the battle! But you need to define your battles. You already had polio. No way to change that. You are having post-polio sequelae. Another done deal. These are battles people frequently think that they need to fight against, but there is no way to win here. It's happening. Live with it. But the battle you can win is the battle for independence! You can be your own person again. It has been said, "Fight only the battles you can win". Living life on your own terms is possible only if you have the stamina, the balance, and the heart for it. We all have the heart for it...we are polio survivors! What we don't have are the balance and the stamina. A power chair or scooter can help.

Do you always walk to the grocery store 5 miles away? Do you walk to work? To church? Of course not! You use the technology available to you – a car or public transportation. Do you mix your cake batter with a spoon? Or do you use an electric mixer? These

*Continued, See CHAIR on Page 6*



# Little White House tour and other sight seeing

by Warren and Judith Peascoe

We had time to tour the Little White House in Warm Springs early Sunday afternoon before we checked into the retreat. Roosevelt built this house while he was Governor of New York and used it during his visits to Warm Springs. Now there is a modern museum, fairly large grounds, a gift shop and of course the house and associated buildings.

There had been sprinkles all morning so we decided to do the White House and Grounds first and then do the museum. Leaving the museum, we saw a circular landscaped area with a fountain. To the left and going up a hill to the old museum is a wide walkway with a parade of flags and stones, one from each state in alphabetic order. Straight ahead were two white guard houses and a large gate set so the path was open but which could be rotated on its center pivot to block the road. To the right and before the White House was a garage with servant quarters on top. The rooms were small, and the ceiling so slanted and so low that I could barely stand up in places. The garage underneath had one of Roosevelt's cars in it. Ahead was a house not much larger than a Habitat for Humanity house. People on foot entered at the right end using a wooden bridge. People in wheelchairs and scooters entered through the main doors as the bridge was not strong enough to support the chairs. The walk ended in a porch with a huge icebox and a door leading to the kitchen and pantry. All the old fixtures and appliances were preserved. I went into the dining room and then entered the living room with fire place. Large doors led to a concrete deck that looked out on the woods. The deck was at least a story above the ground. The white secret service building and some of the green telephone-booth sized marine guard houses were visible. To the right was Missy's bedroom and bath. You could see in as the walls had been replaced by Lexan but you could not enter. Roosevelt's bedroom was entered from the left end of the deck. He had a bathroom which contained a toilet raised on a block and a bathtub. I walked directly into Eleanor's bedroom, which shared the same bathroom. This was really a guest bedroom with two twin beds as Eleanor was rarely there. I walked through this room to get to the main entrance. The house had no central hall. I don't remember whether it was doorless or whether the doors had been removed. At the door was a statue of a Scotty, in remembrance of Falla. Ranger Nancy told us that if you were a child who didn't reach her chest and held hands with the adult, who brought you, all the time you were in the building, you could pet the Scotty as you left.

The museum contained a number of displays concerning Roosevelt's life including one of his hand-controlled cars. Many of the canes he had been given were displayed in a wall of cases about 12 feet long. There was also a twenty minute show on Roosevelt's life and the history of Warm Springs. On the way to the exit, the unfinished portrait of Roosevelt and the one completed after his death were on display.

On Saturday after the conference closed we had the time to tour the traveling Smithsonian Exhibit on polio which documented the history of polio, its treatment and eradication in the States. We took the self guided tour of the quadrangle and buildings close including the Roosevelt Chapel. The quadrangle was modeled after the University of Virginia quadrangle which was designed by Thomas Jefferson. The first building in the quadrangle was Georgia Hall in which the conference had been centered. The quadrangle also included Roosevelt Hall, which had a large handicap accessible auditorium, and a polio hall of fame on

*Continued, see SIGHT SEEING on Page 6*



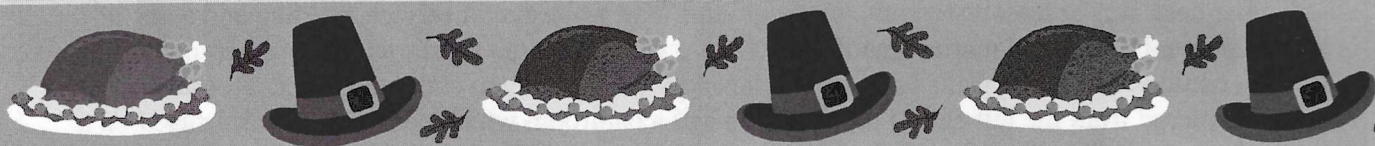
## SIGHT SEEING continued from page 5...

which there were 12 heads of people most influential in treating and conquering the disease. There was also an indoor pool, now drained, which had rehabilitation equipment. An outdoor exercise area was at the far end of the quad from Georgia Hall. Most of the buildings were connected by covered walkways. These would be convenient in inclement weather but even on mild spring days were very nice as the sun was hot.

Sunday we toured the historic pools. The tour guide was an alumna who now used a walker. She was represented in the movie *Warm Springs*, by the character Daisy. Apparently in the thirties the pools were filled every morning and drained every night. The pool foundation can not take the daily change in weight without collapsing, so the pool is now only filled on the Labor Day Weekend. Admission for swimming is charged to raise funds. The three pools are now without roofs but in Roosevelt's time, one pool had been glassed in and two sunrooms existed. We were able to go down into the middle pool, called the play pool, using a long ramp. At the bottom was a bathtub-sized pool with water from the warm springs. We could put our hands into the water to feel how warm it was. When our hands dried off, they were very slippery from the residual minerals left by the evaporating water.

Seeing the disused pools, both on the quadrangle and the historic pools and the apparently underutilized facilities, made me feel that the place was haunted--just waiting for the return of Roosevelt and the generations of polio patients with their hi-jinks, plays, parties, and romances.

Roosevelt had a favorite picnic spot about 20 miles from Warm Springs called Dowdell's Knob. He sat on a stone formation that overlooked a beautiful valley. The formation was not easy to get to. This area is now a state park. There is a statue of Roosevelt, wearing his braces outside his trousers. The statue is in a much more handicap accessible area than the original stone seat is. It is constructed so that a tourist can sit beside the President. Of course we had ourselves photographed with Roosevelt.



## CHAIR continued from page 4...

are devices that help to make our lives easier. So are power chairs and scooters. You are not giving in... you're stepping up to an easier way of doing things. And boy, are they ever fun!

If you are thinking about it, it is probably past time to do it. And the sooner you start using a power mobility aide, the longer you might retain the ability to walk and the easier it will be on your arms and shoulders in the long run. I wish you well.

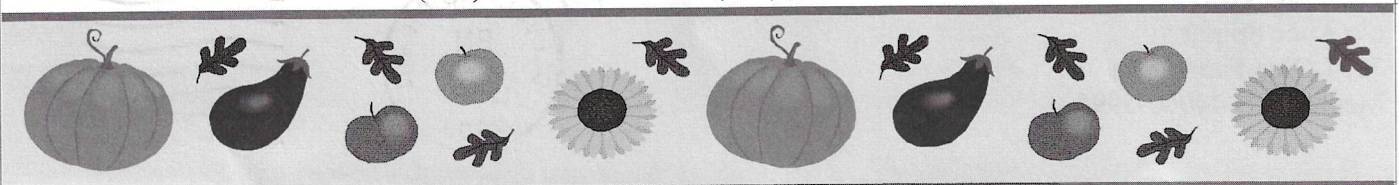
FECPPSG Editor's note: - As most of you know, I use a scooter – in fact, I'm on my third Electric Mobility Rascal. Whenever I see a polio (or other mobility impaired individual) who should be in a power chair or scooter I cringe. If I question them as to why they're not using a power chair or scooter, their answer is usually that they don't need it – they aren't that bad. Hopefully, this article will help some realize that using such an aid will open many doors that have been closed to them – such as going to the mall, going to theme parks, taking a "walk" with the grandchildren....Please, if you need a power chair or scooter, look into getting one.

*Reprinted from Florida East Coast Post-Polio Support Group, Ormond Beach, FL, Jan./Feb. 2009.*

*Reprinted from FECPPSG newsletter of November/December 2005. Reprinted from Polio Heroes of*



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