The Polio Post

Ohio Polio Network Newsletter

Spring 2013 Issue

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BOB WALKER 1928 - 2012

by Lorain County Post Polio Group

It is with much sadness that the Lorain County Post Polio Group tells of the loss of Bob Walker. He passed away Dec. 20 at Parkvue in Sandusky, OH. Bob's wife Betty is still at Parkvue and we all want her to know that she has our deepest sympathy and sincere condolences.

It has been a real delight to know Bob and Betty. They were the backbone of our group. They attended almost every meeting with Bob driving his latest car (he was a car guy) and Betty handling his wheelchair. They were a wonderful, caring couple. Bob always mailed out the meeting reminder postcards and put together our member list each year.

Bob was born in Lorain, Ohio on May 18, 1928. He was raised in Amherst graduating from Amherst Central High. He proudly served in the United States Army during the Korean War where before returning home he contracted Polio. He was employed at the Ohio Bureau of Employment Services in Sandusky for twenty-seven years retiring in 1987 as office manager. He was a member of St. Peter United Church of Christ in Amherst and active with the church council serving as the secretary. He also taught Sunday school. Bob was an active member of the Amherst Jaycees serving as President, Vice President and Secretary. He was also a member and Vice President of the North West OBES, the Disabled American Veterans of Lorain and the Amherst American Legion Post #118.

All we can say is you will go a long way before you find a better man than Bob Walker, he will be missed.

Mid-Ohio Valley Post-Polio Support Group Celebrates 25th Anniversary by Warren and Judy Peascoe

The Mid-Ohio Valley Post-Polio Support Group (MOVPPSG), sponsored by the Wood County Society is planning its 25th anniversary celebration for June 17, 2013.

A membership list, in the year 2000, contained about 60 active and inactive members--either individuals and families. There are now fewer than 20 members. To celebrate the anniversary the members hope to compile a book of the history of the Support Group. Brief polio stories, biographies and photos are needed. Please contact Warren Peascoe using the email address movppsgcontact at suddenlink dot net or phoning 304-295-4233 to submit information for the memory book or to attend the anniversary lunch.

Articles should be submitted by May 1. More information will be posted as plans become definite.



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Post-Polio Contact Information

Editor: Alice Sporar

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Post-Polio Support Group holds Thanksgiving and Christmas Party

by Warren and Judith Peascoe

Approximately 12 members of the Wood County Society's Mid Ohio Valley Post-Polio Support Group



Deby King, server at the Golden Corral, receives a thank you card on behalf of management and staff from Larry Young of the Mid-Ohio Valley Post-Polio Support Group

Photo by Warren Peascoe

MAKING YOUR HOME ACCESSIBLE

The Accessible Home: Designing for All Ages and Disabilities by Deborah Pierce is a book with photos and stories about making your present home or designing a new home to fit your present and future needs. It's published by Taunton Press and is available from www.tauntonstore.com and www.amazon.com or in electronic form from iTunes book section.

NEW MOBILITY MAGAZINE

New Mobility is a magazine full of articles on all subjects of interest to people with disabilities. It's published by the United Spinal Association, 714 Market Street Suite 100, Philadelphia, PA 19106. Phone 800-404-2898 ext. 7260. You can also order it at www.newmobility.com

Correction: In The Polio Post Winter 2012 Issue page 5, article "The Dangers of Benzodiazepines" by Anneliese Feddersen, it should state: Since October 15, 2010, (not 2012) I am free of this drug and back to my old self again.

MY EXPERIENCE WITH YANKIE BIONICS BRACING

by Harriette "Holly" F. King

September 29th, 2012, I attended a yearly Ohio Polio Conference in New Philadelphia. One of the speakers there was Roger Marzano of YANKIE BIONICS who had been working with physically challenged people since a teenager - clearly 20+ years. He was able to tell us how we functioned mentally and physically with our handicaps - things I hadn't recognized or been aware of in myself. He also brought numerous braces and designs of braces for different needs. I was drawn to the braces that were seen on contestants that were in the 2012 London Olympic Games. It was explained to us that these braces had been available to veterans for quite awhile and were now being made available to the civilian population. We were told that the price could be a problem depending on insurance.

In November, my local polio group, COPN, introduced Marie O'Neal from YANKIE BIONICS who was locally situated. After her talk, I asked her to evaluate my left knee which had been operated on 6 times; (1 & 2) stunting the growth of the left leg procedure, (3) torn ligaments and cartilage surgery, (4) lump under knee cap removal and (5 & 6) knee replacements. The replaced knee wouldn't stay in place. Marie got down on her knees to observe the action of the knee and having been told of the burning sensation I felt when bending and unbending the knee, she applied pressure on the knee cap toward the inner part of my leg and at the same time applied the pulling of my calf toward her and asked for me to bend and unbend the knee. It responded effortlessly and painlessly AND NO CRUNCHING AND GRINDING! I didn't hesitate; "What prescription should I request from my doctor for the left knee and right polio leg."

Fast forward to January 7th, 2013. On the way to my YANKIE BIONICS appointment with Marie, I told Fred, my significant other, "Marie may put me back into the hard plastic brace.", because that was the impression I was getting from her on a previous appointment. I said, "If she does, I would respect her opinion, because I trusted her." She is the type of person who when seeing someone struggle, wants to help them. We patients say we want a concerned doctor to help us. In Marie's case, she wants the right kind of patient, one with an open mind, and she will do wonders for them. My whole experience with YANKIE BIONICS were with people who cared.

For the last 17 years, I had been wearing a hard plastic form fitting brace that went from the arch in the bottom of my foot, under and around the ankle to finish up the back of the leg to the knee. A problem with the old inflexible hard plastic brace, was when dealing with rolling terrains. When going up hill, the brace would want to force my leg backwards or going down hill, the brace would slam me in the back of the leg causing my leg to buckle. The brace definitely wasn't ideal, but I liked it because I could 'speed walk' - keep up with my peers. Marie had observed my old brace in November and she was prepared to plaster my leg for the same old brace, but first, she wanted me to try one of the new concept in braces that were available. She had experienced the mind set of some disabled brace wearing individuals; "If it works, don't mess with it!" Well, she soon learned, I was there specifically for the new brace. I trusted her because of her evaluation and correction of my left knee. (Neither my family doctor nor my knee replacement doctor took the time to consider what my problem was with my knee.) So she left the room to come back with the brace. In putting on the brace which was already in my shoe, she explained that I had to have my knee forward and my foot placed back 110 - 120% to strap my leg. Unlike all previous fixed non-giving braces for the past 66 years, the brace went from the bottom of the flexible foot plate, with a flexible support system going up the outside of my foot to a fixed front form fitting panel. So after tying my shoe laces I stood up and took a couple of steps. I was aware that Fred and Marie were talking and asking questions, but, I was in my own little 'single world', when it was so necessary for a disabled person to analyze their environment for their safety sake? (Continued on page 4)

MY EXPERIENCE WITH YANKIE BIONICS BRACING (Continued from page 3)

I wasn't familiar with nor totally comfortable with what I was feeling - it was "weird" and I said so. I was trying to figure out what this new feeling meant to me. But, then without thinking, I needed to see myself walk. What would taking stairs or a ramp be like? WHAT A DIFFERENCE! I walked without a limp. I could take shallow steps without a stair bar. And the ramp, well it was like level ground, effortless. I had gone there to see if my life could be easier, if I would benefit from the new advances in bracing. Normal people walk without thought, whereas disabled people have to psych themselves up, get some adrenaline going. The first thing I noticed was the tireless way of walking - I had push off power. Instead of swing-ing my leg forward at the hip, I was using toe power supplied by the flexible foot plate. It was immediate, and was the reason for Fred insisting, that I wasn't limping. At the time, it seemed like the brace was returning energy, but it must have been residual adrenaline, because it hasn't occurred since.

On my next appointment, Marie braced my left knee. Now when walking, I am free - not concentrating on how my legs are reacting to a given location or time of day. I am enjoying what everyone else is enjoying, company, surroundings, situations.

Until the initial conference of September 2012, I had no idea of the life-changing technology that could be provided for me. After six decades of disability with no hope for any change, I have achieved near-normal mobility. I went from being an actual polio poster child to a person who can now enjoy life at full speed with those I love and those who love me.



TWIN PROBLEM. Beverly Jackson, 3 helps adjust the brace on her twin sister, Harriet, a Franklin County (Columbus), Ohio, Chapter patient stricken with polio in 1946. They live with their parents in a trailer at Blacklick, just outside Columbus.

Harriette "Holly" F. (Jackson) King and her twin sister Beverly

National Foundation News Published by: The National Foundation for Infantile Paralysis Volume 7 June 1948 Number 6

ANTIBIOTICS CAN GIVE RISE TO AN INFECTION

Dear Dr. Donohue: A little more than a month ago, I was hospitalized for pneumonia. I spent a full week in the hospital, taking antibiotics. I was still taking them when I went home. That's when I developed diarrhea. My doctor told me to stop the antibiotics, and I did. The diarrhea continued, and I had to be readmitted to the hospital. They put me on a different antibiotic.

I think I'm okay now, but I wonder about all of this. What exactly went wrong?

D.P.

Answer: You had antibiotic-associated colitis, the cause of which is a bacterium by the name of C. difficile. It happens like this: People take an antibiotic for an infection like your pneumonia. The antibiotic is somewhat indiscriminate in killing off bacteria. In this instance, it kills off the good bacteria in the colon, the ones that keep the digestive tract in balance. Then the C. difficile bacterium, often found in the hospital environment, takes over the vacuum left by the death of the good bacteria. Soon it becomes the predominant bacterium. Any antibiotic is capable of spawning the proliferation of C. difficile, but at the top of the list are clindamycin, ampicillin, cephalosporins, and fluoroquinolones.

C. difficile makes toxins that produce diarrhea. In the United States, estimates indicate that there are as many as 750,000 infections with the bacterium every year. Invariably, the person is on or has been taking antibiotics.

Stopping the antibiotic puts an end to diarrhea in seven out of ten cases. That still leaves a significant number of people with diarrhea so severe that it can be life-threatening. Metronidazole and vancomycin are two antibiotics that usually can eradicate C. difficile.

The Food and Drug Administration has approved a new drug for antibiotic-associated colitis. It's fidaxomicin (Dificid). It gives doctors additional ammunition to treat this illness should other remedies fail.

Write to Dr. Donohue at PO Box 536475, Orlando, FL 32853-6475.

Reprinted from Sun Sentinel, FL, September 14, 2011.

Contributed by Jane McMillen, member, Second Time Around, January 2013- Publication of Boca Area Post Polio Group, Boca Raton, FL.

Editors Note: Whenever I take an antibiotic, I also eat a couple spoonfuls of plain yogurt or more, depending on how many doses of antibiotic, two hours after the antibiotic dose. Check with your doctor or pharmacist first, because sometimes yogurt shouldn't be taken with certain antibiotics. I have found that yogurt keeps the bacteria in balance.

HAWAII CONFERENCE

The 29th Annual Pacific Rim International Conference on Disability and Diversity will be held April 29-30 at the Hawaii Convention Center in Honolulu. Their website is www.pacrim.hawaii.edu. Contact person is Charmaine Crocket. For more information email prinfo@hawaii.edu or call 808-956-7539.

IS HEAT INTOLERANCE ALSO A POST-POLIO PROBLEM?

by Richard Bruno, PhD

Q: In the Polio Paradox and on polio survivors' websites I read about "cold intolerance," that polio survivors are always cold. My feet are always cold in the winter, but I have the most trouble in summer. I get exhausted in the heat, especially when it's humid. Is heat intolerance also a post-polio problem?

A: You bet. In our 1985 National Post-Polio Survey, cold caused muscle weakness in 62 percent of polio survivors, muscle pain in 60 percent, and fatigue in 39 percent. But that survey also found that 39 percent of polio survivors have fatigue when it's hot.

Whether it's cold or hot, polio survivors have three strikes against them when it comes to controlling their body temperatures. First, the poliovirus damaged the hypothalamus, the part of the brain that serves as the body's thermostat. Second, the poliovirus killed neurons in the spinal cord that make the veins in you skin become smaller or larger as the temperature changes. Basically, polio survivor's veins are always too big. When it's cold outside, warm blood pools in those big veins near the surface of the skin, causing heat in the blood to radiate into the air, the skin to get very cold and to look purple or even blue. When it's hot outside, or when polio survivors take a long hot bath or spend time in a steaming Jacuzzi, the skin becomes lobster red as the veins and arteries open wide and hot blood rushes to the skin. When polio survivors stand up, gravity pulls blood into the open veins in their legs and blood pressure can drop, causing fatigue, lightheadedness or even a faint. And here's the third strike: polio survivors who have smaller leg muscles due to polio motor neuron damage causing atrophy have more blood pool in the legs, since muscle contractions help to pump blood back toward the heart.

So, since your body can't regulate its own temperature, you have to do it. Our 1983 study found that polio survivors' nerves function as if it's 20 degrees colder than the temperature of their skin. In the winter, polio survivors should dress as if it's 20 degrees colder than the outside temperature. You need to dress in layers so that you can regulate your body temperature by changing the amount of insulating clothing covering your body.

But the trick is to stay warm from the get-go. You should dress right after showering when your skin is warm and red. Try wearing heat retaining sock liners or even long johns made of the woven, breathable plastic fiber polypropylene. Then put on warm socks, battery-powered heated socks or ski-boot insoles, and put on the layers. (If you ever need surgery, remember to remind the doctors and nurses that you get cold easily so they can provide a heated, water filled blanket in the recovery room.)

When it's hot, stay out of the sun, move more slowly, and take more frequent rest breaks with your feet elevated to make it easier for blood to flow back to our heart so that you can prevent foot swelling and keep your blood pressure up. It's especially important to have smaller amounts of food for lunch, have cool foods and cold drinks, and to take a feet-up break after eating, since midday is when polio survivors have the most trouble with dropping blood pressure and fatigue (see January 2002 PPS Forum). It's also a good idea to take cooler baths or showers in summer and to keep the air conditioning turned up. It is also smart to cool down the car before getting in during the summer as it is heating the car up in the winter. But be careful. Whether you're being chilled by a Northeast wind in November or by excessive air conditioning in August, always cover your upper body, especially your neck to prevent muscle spasms and headaches caused by cold air blowing on your muscles.

IS HEAT INTOLERANCE ALSO A POST-POLIO PROBLEM? (Continued from page 6)

Many polio survivors don't realize that they can have as many symptoms and some even more, during change of seasons, when the temperature goes up and down from day to night and from day to day. Fall and spring bring increases in symptoms, especially muscle pain and headaches, as polio survivors' temperature-challenged bodies can't decide if they should sweat to stay cool or shiver to stay warm. Layering of clothing is especially important when the world is as thermally confused as polio survivors, unable to decide what temperature it wants to be.

Reprinted from Polio Post News, Sept-Oct 2012, newsletter of Central Florida Post-Polio Support Group.

WHAT IS THE ROLE OF EXERCISE IN THE TREATMENT OF PPS?

The symptoms of pain, weakness, and fatigue can result from the overuse of muscles and joints. These same symptoms can also result from disuse of muscles and joints. This fact has caused a misunderstanding about whether to encourage or discourage exercise for polio survivors or individuals who already have PPS.

Exercise is safe and effective when carefully prescribed and monitored by experienced health professionals. Exercise is more likely to benefit those muscle groups that were least affected by polio. Cardiopulmonary endurance training is usually more effective than strengthening exercises, especially when coupled with the pacing of activities to allow for frequent breaks and strategies to conserve energy. Heavy or intense resistive exercise and weight-lifting using polio-affected muscles may be counterproductive because they can further weaken rather than strengthen these muscles.

Exercise prescriptions should include:

- * the specific muscle groups to be included
- * the specific muscle groups to be excluded
- * the type of exercise, together with frequency and duration

Exercise should be reduced or discontinued if it is associated with additional weakness, excessive fatigue, or unduly prolonged recovery time that is noted by either the individual with PPS or the professional monitoring the exercise. As a general safe rule, no muscle should be exercised to the point of causing ache, fatigue, or weakness.

Reprinted from August 2012 Publication of Post Polio Alliance of South Florida, Inc. From US National Institute of Health website - Post Polio Fact Sheet at http://www.ninds.nih.gov/disorders/post_polio/detail_post_polio.htm#17896317%202



".....and that's part of doctoring, too!"

by Ernest W. Johnson, MD

Some one once threw out, as a shocker, an estimate that over one-half of the patients knocking on the physician's door are people with "functional problems"...using this phrase in the best sense (some would say – ceramic sense). This is probably low. Add to that total the chronically ill, the elderly with organic largely unalterable conditions who need psychosomatic "shoring-up" to keep going, and there is a major and rapidly growing group of doctor-seeking people with problems. There are problems which likely do not have a chromosomal, enzymatic or biochemical solution.

One Saturday evening a few weeks ago, a Western program took me away from the JAMA "Ole Doc Adams" of Gunsmoke was fighting scurvy in a widow and her grown son. Because of a drouth, there were no fresh vegetables or fruits, food which he knew were effective in the prevention and treatment of scurvy. The elderly lady became progressively worse as she fed her meager rations to her son, until she was on her death bed.

One night Doc Adams told his preceptee he was on his way to make a house call on this dying woman. When confronted with the preceptee's question: "Why are you going, there's nothing you can do," Ole Doc Adams responded: "I'm going to sit with her and comfort her, son – y'know – *that's part of doctoring too*!"

There is a lesson in this for all physicians. Somehow, many of us get mired in the notion that all of human ills will vanish with the arrival of the computer, a miracle drug or a touch of a sharp scalpel. This naive approach is nurtured by representing the patient as a collection of organs, one of which has an enzymatic misfire.

We tend to view modern medicine as a complete electronic marvel analyzing more and more of the patient's excretions and secretions with greater and greater precision.

An obvious advantage of this mechanistic approximation of the patient is protection of the physician from the difficult and often frustrating interpersonal relationships emanating from the reality of psychosocial disruption of health. This is the state of non-health which often results from family, job, friendship disequilibrium.

To neglect the effects of these sustattive influences in a patient's management is to subvert his convalescence.

Listening, empathy, comfort, support, kindness, understanding are all a part of doctoring.

Our new curriculum will provide opportunity by electives for this kind of leavening of the student. A committee is at work now to transform the physical diagnosis course into comprehensive evaluation of the patient.

It seems to me that the really tough problems of medicine in the future, and now, reside in a seething psyche rather than a suffering soma.

.....that's part of doctoring, too.

Ernest W Johnson, MD

Editor

Summer 1965

THE POLIO POST

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