

POST-POLIO HEALTH

FORMERLY POLIO NETWORK NEWS

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To Brace or Not to Brace? Improving Function

Holly H. Wise, PT, PhD, and Jenny Adams, CPO, Coastal Post-Polio Clinic, Charleston, South Carolina

Many polio survivors wear braces (orthoses) or have had braces recommended to them. Frequently, the question is raised, "Does the use of a brace accelerate the weakening of the braced muscles?"

To Brace?

Braces are typically recommended to polio survivors to provide stability to a joint(s) and can improve function, decrease pain, and enhance energy conservation. In addition, bracing may allow individuals to increase their levels of physical activity by improving overall muscular strength and cardiovascular endurance, which are both important for health and wellness.

Some persons with a spinal cord injury or reversible peripheral neuropathy, who have increased activity as the result of bracing to immobilize one or more joints, have noted an improvement in strength. This observation demonstrates that bracing does not prevent a muscle from being able to contract. Increasing strength may not be possible with muscles that have lost *functional* strength due to prior polio. The case study below illustrates the benefits of bracing for a polio survivor.

Polio Survivor Case Study

SJ is a 53-year-old male who works fulltime in a large corporation. SJ acquired polio at age 2 with involvement in his right lower leg. He participated in sports in high school despite a mild limp. He exercised on a regular basis until several years ago when he developed right hip pain when walking long distances and putting on his shoes. He was evaluated at the Coastal Post-Polio Clinic and reported the following:

- Right ankle and hip pain,
- Difficulty with balance when climbing a ladder at work,
- Fatigue after a full day of work, and
- Difficulty sleeping with muscle twitching in the right calf at night.

SJ's right calf muscle was significantly smaller than the left. His right lower leg was shorter and his foot was one size smaller. In addition, SJ had limited flexibility in his right ankle. A muscle test revealed that he had significant weakness in the right ankle dorsiflexors and plantarflexors.

The dorsiflexors are ankle muscles that lift up the foot as one swings the leg forward when walking. Individuals who report tripping or stumbling when walking have dorsiflexors that are weak.

The plantarflexors are the calf muscles that help push off on the toes when walking forward. When these muscles are weak, individuals report difficulty

Wise and Adams are team members of the Coastal Post-Polio Clinic, along with Kerri A. Kolehna, MS, MD. Adams (jencpo@hotmail.com) is a Certified Prosthetist/Orthotist with Hanger Prosthetics and Orthotics in Charleston. Wise (wisehh@musc.edu) is currently an Assistant Professor in the Physical Therapy Educational Program, Department of Rehabilitation Sciences, College of Health Professions, Medical University of South Carolina.

continued on page 2

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walking on their toes. Both groups of muscles are important for maintaining balance and when either group of muscles is weakened, safety can be a concern.

The assessment of SJ's walking, or gait pattern, revealed that he walks with a "steppage gait" – he picks his knee up higher than normal. Individuals expend additional energy when picking their legs up higher than normal, but they avoid tripping over their feet. This difficulty in lifting the toes and ankle up is due to muscle weakness.

Due to the tightness in his right heel cord, SJ had excessive backward bending of his knee whenever he put full weight on his leg. Excessive backward bending, also known as hyperextension, leads to abnormal biomechanical stresses at the hip and trunk.

A modified Fatigue Severity Scale (FSS) was administered, and SJ received a score of 33/36, indicating a high level of fatigue with his activities.

The team recommended a plastic ankle-foot orthosis (AFO). SJ was evaluated by the team orthotist and was fitted with a custom AFO. He was instructed to gradually increase his wearing time as he adjusted to the AFO.

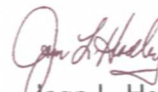
From the Editor ...

Thank you for the many positive comments about the organizational changes we've announced. And, please continue to send your comments about the content of *Post-Polio Health*.

Several support group leaders appreciated the article about Neurontin, because they were concerned about its promotion as the solution for post-polio problems. The alert support group in the Nashville, Tennessee area, led by Nickie Lancaster, had reported to Pfizer, in late 2001, that several members had observed worrisome side effects from Neurontin.

Our lead article addresses "The Question" about bracing that so many of you have asked. Once again, as with exercise, there is no cookie-cutter answer. But, armed with information coupled with an honest assessment of our abilities, each of us can make the right decision.

A summary of the US Social Security Administration's new ruling on "post-polio sequelae" is on pages 6-7. Polio survivors whose condition prevents them from working have benefited from this program. However, this document is not intended to alert employers of pending problems of employees who had polio, for many polio survivors are able to work. Instead, its purpose is to identify all of the possible medical evidence that will be considered when applying for disability.



Joan L. Headley, MS, Executive Director
Post-Polio Health International

An ankle-foot orthosis (AFO) is designed to protect, support, and prevent or correct deformity of the foot, ankle, and lower leg complex. AFOs are commonly used to provide support for footdrop or for ankle instability.

SJ was seen *3 months later* and reported the following:

- Decreased ankle pain, but hip pain was unchanged due to arthritis and SJ was placed on Celebrex,
- Decreased knee hyperextension when walking,
- Decreased muscle cramping at night due to a decrease in overuse of his calf muscles affected by polio, and
- Decreased fatigue – his new FSS score was 23/36.

SJ was seen *one year later* being fitted with the AFO.

- He has not lost any strength in the muscles supported by the brace.
- His wife can no longer recognize him at a distance because he no longer walks with a noticeable limp and does not land as hard on his left leg when walking.

Not to Brace?

Many polio survivors are fearful that they will lose functional strength when wearing a brace and choose not to even explore the benefits. *It is important to understand that bracing is not recommended if the survivor has functional strength.* Rather, a brace is recommended when the muscle has deteriorated to less than a functional level resulting in joint instability and overuse of uninvolved muscles and joints.

All muscles show a slow decline in strength with aging. With a normal decline in strength due to natural aging, the decline in function is more dramatic for a muscle affected by polio. This is due to the fact that a muscle affected by polio does not have the same number of nerves and muscle fibers as an unaffected muscle. A muscle affected by polio may appear to have full strength, but it has overcompensated for years.

In theory, immobilization of a joint with bracing may result in a decline in strength in the specific muscles around that joint. But, *a decline in strength also occurs with the aging process.* Using a brace with a mechanical joint that allows some limited movement may prevent the weakness associated with immobilization. A careful discussion of the components of a brace with a Certified Orthotist (CO) is necessary to develop the most functional design.

“The Question”

To brace or not to brace? There is no one correct answer. It can be found within each individual and with recommendations from trusted health professionals knowledgeable about polio and post-polio syndrome. Each polio survivor must examine his/her goals for mobility and participation in activities of daily living and his/her health and wellness. The goals must reflect individual concerns and be cost-effective. Discussion about the pros and cons of bracing is a hallmark of a good team approach when managing post-polio syndrome. ●

Related Readings

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- Halstead, L.S., & Grimby, G. (1995). *Post-Polio Syndrome*. Philadelphia, PA: Hanley & Belfus, Inc.
- Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*. Rev. Ed. (1999). Saint Louis, MO: Gazette International Networking Institute (now Post-Polio Health International).
- March of Dimes International Conference on Post-Polio Syndrome: Identifying Best Practices in Diagnosis & Care*. (2001). White Plains, NY: March of Dimes.
- Silver, J.K. (2001). *Post-Polio: A Guide for Polio Survivors & Their Families*. New Haven, CT: Yale University Press.
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The West Nile Virus Infection: Like and Unlike the Poliovirus Infection

K. Ming Chan, MD, FRCPC, and Zoe W.M. Doyle, Division of Physical Medicine & Rehabilitation, Center for Neuroscience, University of Alberta, Edmonton, Canada (ming.chan@ualberta.ca)

Although human infections by the West Nile Virus (WNV) were first reported in Africa over 60 years ago, it is a new disease in North America. The first human case occurred in New York City in 1999. Within three years, the number has skyrocketed from 149 cases in 1999-2001 to over 3,000 cases in 2002 – a 20-fold increase. The virus now affects humans in more than 40 states in the US and almost every province in Canada.

Avoid mosquito bites to avoid infection.

1. Apply insect repellent containing DEET (look for N,N-diethyl-metatoluamide) to exposed skin when you go outdoors. Even a short time being outdoors can be long enough to get a mosquito bite. -Centers for Disease Control and Prevention

Related Readings

Brinton, M.A. (2002). The molecular biology of West Nile virus: A new invader of the western hemisphere. *Annual Review of Microbiology*, 56, 371-402.

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Campbell, G.L., Marfin, A.A., Lanciotti, R.S., & Gubler, D.J. *West Nile virus*. [Review] [90 refs]. *The Lancet Infectious Diseases* 2002, 2, 519-529.

Marfin, A.A., & Gubler, D.J. (2001). West Nile encephalitis: An emerging disease in the United States. [Review] [44 refs]. *Clin Infect Dis*, 33, 1713-1719.

Not widely appreciated until recently, some of the insults due to WNV infection have an uncanny resemblance to that of poliomyelitis. This eerie resemblance poses a troubling specter: is it possible that a new wave of epidemics is coming?

The number of new cases of WNV infection will likely continue to climb steeply. The western states and provinces are still 'virgin' territories for the virus. Perhaps more worrisome is that the WNV has been more virulent in cases seen in North America. Besides infecting a far larger number of individuals than those epidemics reported in Africa, Europe, and Asia, the WNV also seems to cause more severe symptoms, more debilitating long-term consequences, and greater numbers of fatalities in North America. Whether this is due to a change in the behavior of

the virus in a new ecological milieu or simply an increase in our awareness of the possible complications of WNV infection is not yet clear. However, the former possibility would not be surprising since the virus is not indigenous to the North American continent and there has been little time for native species to develop vigorous immunity to resist the infection.

Comparing poliovirus and West Nile Virus

To understand the potential implications of the WNV epidemic, it is useful to first briefly review several important features of the virus. *Unlike the poliovirus* that is a member of the picornavirus family, the WNV belongs to the family of flaviviruses. Also, unlike the poliovirus, for whom the human is the only natural host, mosquitoes are highly effective carriers of the WNV. Furthermore, mosquitoes along with several species of birds and mammals, such as horses, also help to harbor and multiply the WNV in large number, effectively acting as a reservoir to cause a greater number of human infections.

Like the poliovirus, the WNV also has a particular affinity for the central nervous system, especially the brain. Although most infected individuals may develop no more than a high fever and flu-like symptoms, some will go on to develop full-blown symptoms of encephalitis (infection of the brain) and even die. It is increasingly recognized that the WNV is also capable of causing severe paralysis by destroying motoneurons in the spinal cord – a role that is often associated with the poliovirus.

2. Clothing can help reduce mosquito bites. When possible, wear long sleeves, long pants, and socks when outdoors. Mosquitoes may bite through thin clothing, so spraying clothes with repellent containing permethrin or DEET will give extra protection. Don't apply repellents containing permethrin directly to skin. Do not spray repellent containing DEET on the skin under your clothing. -Centers for Disease Control and Prevention

What does the future hold?

Can we expect to see a flood of acute paralysis cases as a result of WNV infection in the coming years? Although nobody has a crystal ball, we believe that catastrophes, such as those seen during the polio epidemics in the 1950s, are probably unlikely to occur for two reasons. First, while the majority of individuals affected by the poliovirus were infants and young adults, those who become severely ill from contracting the WNV are mostly older individuals with co-existing illnesses, i.e., the vulnerable population is smaller. Second, science has come a long way since the 1950s and we are now in a better position to stem the spread of the infection. For example, a vaccine against the WNV has already been developed and the first field trials in susceptible animals have begun.

There are risks that this optimum scenario may not play out as expected. To minimize this possibility, two things will need to happen. First, considerable resources and coordinated efforts will be needed from all levels of government and health authorities to minimize the risks of exposure by vigorously controlling carriers and amplifying hosts, such as mosquitoes.

Second, as in the case of polio, the availability of an effective and safe vaccine will be a pivotal point. The delivery of a vaccine for human use from the time of development can be very lengthy. Since there is still no effective treatment once an individual has contracted the disease, this is not a luxury that we can afford.

Learning from the past

Lessons we have learned about post-polio syndrome over the past two decades may be instructive and applicable to some WNV survivors as well. The symptoms in post-polio syndrome, such as renewed muscle weakness, are related to over-fatiguing muscles affected by motor nerve loss from the poliovirus.

The same may also apply to WNV survivors and have important implications when setting rehabilitation goals and tailoring exercise programs for these individuals as they recover from the acute infection. Equally important is long-term advice regarding the appropriate types and intensity of physical exercise after the initial period of recovery. Based on observations made on many post-polio survivors, high intensity strength exercise is potentially damaging and should be avoided. In contrast, lower intensity but regular strengthening exercise programs are much more likely to be helpful. This is particularly true if the program incorporates cardiovascular fitness training as well.

Although WNV infection has many differences compared to poliomyelitis, there are also some striking similarities. Experience that has been gained from polio survivors could well be instructive when treating WNV. Prospectively following the long-term functional outcomes of the WNV survivors may yield further insights into the relationship of nerve and muscle function during physical activities and exercise training in persons with past viral infections. ●

3. Be aware of peak mosquito hours. The hours from dusk to dawn are peak mosquito biting times for many species of mosquitoes. Take extra care to use repellent and protective clothing during evening and early morning - or consider avoiding outdoor activities during these times.

-Centers for Disease Control and Prevention

Generally, products with about 30% DEET have proven the most effective in the long run.

-Consumer Reports

"This ruling sends the message that polio can result in a variety of manifestations in later life that can adversely affect an individual's ability to function and we (SSA) need to be aware of the cumulative and interactive effects of all of these."

—Sandra Salan, MD, SSA

New SSA Ruling for Polio Survivors with "Post-Polio Sequelae"

Joan L. Headley, MS, Executive Director, Post-Polio Health International (editor@post-polio.org)

The Social Security Administration (SSA) has issued a new ruling (SSR 03-1p) for evaluating disability claims for polio survivors in the United States seeking Title II SSDI (Social Security Disability Insurance) benefits or Title XVI SSI (Supplemental Security Income) payments.

The new ruling became effective July 2, 2003 upon its publication in the Federal Register. The POMS (Program Operations Manual System), to be released this month, is the document that applies to everyone within the SSA and contains a description of the medical and other evidence that documents the presence of a disabling impairment. SSA will educate the appropriate decision-makers within their system concerning the new POMS.

The new ruling defines post-polio sequelae as the "documented residuals of acute infection as well as all other documented clinical conditions that have an etiological link to either the acute infection or to its residual deficits."

Motor weakness, usually with muscle atrophy and reduced peripheral reflexes, is listed as the most common residual. Other residuals include post-polio syndrome, degenerative musculoskeletal disorders, early advanced degenerative arthritis, chronic pain disorders, sleep disorders, respiratory insufficiency, and a variety of mental disorders.

Officials at the SSA state that the mental disorders refer to the cognitive limitations some polio survivors have due to revived traumatic psychological experiences associated with acute polio infection, as well as the possibility of a significant psychological effect of

perceiving the onset of further weakness, fatigue, respiratory dysfunction, or joint pain, many years following the acute infection. Signs and symptoms of anxiety and depression may produce further deterioration in function.

The ruling comments that some polio survivors report the onset of problems with attention, concentration, cognition, or behavior. Some researchers have suggested that certain cognitive and behavioral deficits are the result of the prior polio infection that involved the brain, although others do not agree with that concept.

SSA will depend on documentation provided by an individual's treating physicians and psychologists (including a report of the medical history, physical examination, and available laboratory findings) to establish the presence of post-polio sequelae as a medically determinable impairment.

Other notable facts:

- ◆ Electromyographic (EMG) studies may be used, but are not needed. Typically, SSA will not order or purchase EMG studies.
- ◆ Respiratory insufficiency should be documented by abnormal pulmonary function studies. SSA generally will not purchase a polysomnogram (also called a PSG, sleep study, or sleep test).
- ◆ The careful development of post-polio sequelae should include descriptions of the past acute illness (old records are not required), as well as a report of the current findings on physical examination. The examination report should also include the severity of any residual weakness, as well as

The complete text of the POMS, along with the official identification number, will be on Post-Polio Health International's website (www.post-polio.org), as soon as possible.

Members without access to the Internet can contact Justine Craig-Meyer (314-543-0475) for a copy.

the onset, pattern, and severity of any new physical or mental deficits.

- ◆ The medical evidence should readily support an expected duration of at least 12 or more months.

- ◆ A disability onset date is based on the individual's allegations, his or her work history, and the medical and other evidence concerning impairment severity. Generally, the new problems associated with post-polio sequelae are gradual and non-traumatic, but acute injuries or events may be markers for establishing a disability onset date.

Post-Polio Health International's Medical Advisory Committee assisted SSA in reviewing the proposed document at various stages during the process. The Committee expressed its wish that the medical evidence be inclusive of all of the consequences of having had polio. It also expressed concern about the "mental disorders" terminology. SSA reports that the term does not mean that polio survivors have a mental "impairment" as a result of having had polio and they are not saying "it is all in your head." Nevertheless, they wish to acknowledge that *some* survivors may experience cognitive deficits that result in significant functional limitations even if the cause is unclear.

Lastly, the informal discussions with the SSA staff included the fact that individuals vary in their responses to illnesses and to treatments, and that various treatments used to relieve symptoms can adversely impact an individual's physical and mental functioning, for example, adverse side effects from medications. ●

"The generosity of the participants, and their interest in and appreciation for our work is so important to us – really, it breathes life into all of those numbers."

Claire Kalpakjian, PhD, University of Michigan Medical Center, Ann Arbor

Update on Research Funded by The Research Fund of Post-Polio Health International

(formerly The GINI Research Fund)

Claire Kalpakjian, PhD, University of Michigan Medical Center, reports that 1,200 polio survivors have completed the surveys for the research project – "Women with Polio: Menopause, Late Effects, Life Satisfaction, and Emotional Distress."

The primary objective of the study is to explore the relationship between menopause and late effects for women with a history of polio. Similarly, little is known about the interaction of physical disability and menopause. In an effort to highlight the unique contribution of menopause, men with a history of polio serve as a control group.

Study Finesses Standardized Scale: A standardized scale was developed for a pilot study conducted in the summer of 2002 called the *Late Effects Problems Profile (LEPP)*. This is a scale of 12 commonly reported late effects problems. For each problem, the respondent indicates whether or not this is a current problem (yes/no). If it is, they go on to rate the severity of the problem on a scale of 1 ("slight") to 5 ("extreme"). The total score is the sum of all the severity ratings. In order to evaluate the usefulness of this scale, particularly because it is new and therefore untested, several statistical tests were performed and they suggest that this is a reliable instrument.

Of the 792 participants whose data have been analyzed, their most frequently reported problems from the LEPP were muscle weakness in involved muscles and fatigue (90% and over). Cold intolerance, muscle atrophy, muscle weakness in uninvolved muscles, and muscle pain each were reported in the 70-89% range. Joint pain, sleep problems, contractures, and breathing problems were reported in the 50-69% range.

Kalpakjian (UM-Polio-Research@med.umich.edu) reports that a website dedicated to the project will be established in August.

All study participants will be notified of the website address via a post card. Post-Polio Health International's site – www.post-polio.org – will link to the study site. ●

Foods that Shutdown STRESS

Janice Knight Hartman, Baltimore, Maryland (jann@comcast.net)



Polio survivor Jann Hartman, who has a degree in Home Economics and Nutrition, has written and lectured on nutrition for the past 20 years. She has been living with post-polio syndrome since 1989.

Jann is the mother of three boys, all presently serving in the Navy. She and John, her husband and fellow traveler of 32 years, have two granddaughters.

Did you realize that the foods you eat can help you deal with stress?

First, you need to know that salty foods, sugary foods (candy and desserts), high fat foods, caffeinated coffee, soft drinks, and alcoholic beverages can add to your stress levels. So what should you eat? Here are a few ideas.

Caffeine-Free Beverages: 100% pure juices (a natural source of soothing fruit sugars) and herbal teas will provide necessary trace minerals, such as zinc and selenium.

Idea! Drinking hot or iced herbal tea or juice (like grape, orange, or papaya) can be tranquilizing due to tryptophan, a necessary amino acid.

Raw Vegetables: Eating foods high in fiber can help lower cholesterol, and even lower blood pressure and tension. Vegetables contain nerve-soothing potassium and are naturally low in sodium. Plus, you get vitamins A and D, and folic acid.

Idea! Try adding some dark greens like parsley, watercress, or even dandelion greens to a tossed salad.

Whole Grains and Nuts: Grains are a great source of vitamin E, potassium, and pantothenic acid (an anti-stress B vitamin). These are nutrients often missing from fast foods such as French fries or a sweet roll. Magnesium (nature's tranquilizer) is abundant in nuts. Try them unsalted.

Idea! Look for sugar-free bran muffins, oatmeal, wheat germ cereal, and salt-free nuts and seeds for snacks.

Yogurt: Rich in vitamins A, D, and B-complex, yogurt is a great lowfat source of protein. It is high in calcium, which eases the stress of insomnia and migraine headaches. Yogurt is digested 50% faster than regular milk, so it is very easy on your digestive system.

Idea! Have a breakfast sundae. Alternate layers of plain yogurt and freshly sliced berries. Top with toasted wheat germ.

Sea Vegetables: Kelp, dulse, and spirulina are 12% sodium, but also provide protein, calcium, fiber, and vitamin A.

Idea! Make a super salad packed with vitamins A and C by adding sprouts, greens, and a dash of dulse flakes.

Soybeans: Try bringing home the tofu instead of bringing home the bacon. Soy foods are a great source of calcium, magnesium, B-complex vitamins, protein, and tryptophan.

Idea! Add cubes of tofu to tuna salad. Make a tofu shake or buy "soy nuts" for a tasty protein snack.

Next time you're stressing out, reach for a food or drink that can help your body by shutting down stress! ●

Adapted from "The Foods That Shut Down Stress" by Harold Rosenberg in the *Philadelphia Inquirer* (June 29, 1986) and "Power Nutrition for Your Chronic Illness" by Kristine Napier, MPH, RD.

Idea! Take a stress-reducing dish and recipe to your next support group meeting.

STRESS

Stress is a normal part of life. In small quantities, stress is good – it motivates people and can help them be more productive. However, too much stress can actually harm the brain and body. Persistent and unrelenting stress often leads to anxiety.

It's widely believed that most illnesses are related to unrelieved or unmanaged stress. Eating well and relaxation techniques are two things readily accomplished without much time and effort.

If you find that your stress won't go away regardless what you do, beware!

This may be a sign of a hidden illness, such as:

- ♦ Thyroid disease (low or low normal)
- ♦ Calcium imbalance (high or low)
- ♦ Anemia (low iron)
- ♦ Diabetes (too much sugar, not enough insulin)
- ♦ Manic depression (Bi-polar disorder)
- ♦ Liver disease
- ♦ Kidney malfunction
- ♦ Vitamin deficiency
- ♦ Hormone deficiency

If your symptoms and stresses are not getting better, be sure to see your doctor for a complete physical examination, including blood and urine tests.

- National Institutes of Health (NIH)

Mozo Shoes: Easy on the Sole

Debbie Hardy, Volunteer Editor,* Whittier, California
(dhardy828@earthlink.net)

Shoe shopping can be a major headache for polio survivors with different size feet, not to mention that it can be a major expense. Jim Agnew, founder of Mozo Shoes, is willing to give you some relief by eliminating the expense of buying two pair of shoes to get one pair that fits. The shoes offer stylish, all-leather uppers with cushioned soles that can be ordered in any size for any foot. Polio survivors can order separate sizes at no additional cost, or purchase a single shoe.

After an auto accident in 1972, Agnew was unable to walk on one of his feet for many months. In an effort to help solve his orthopedic dilemma, Agnew, an experienced shoemaker, invented his own self-molding silicon footwear. He made and sold his footwear for years, but eventually returned to work for a major company where he created athletic shoes. He became disillusioned and branched out on his own again. He knew that people who work on their feet all day are just as important as athletes; yet no one was addressing their specific needs.

The production of Mozo shoes began in 1998 with the goal of making a shoe that helped the foot to function properly. Agnew states, "When we decided to make Mozo Shoes, our one rule was that all design and materials serve the purpose of supporting the foot, absorbing shock, and helping the foot work properly. If it doesn't do that, we don't have it." His major challenge has been in educating people on how the feet should work properly in shoes.

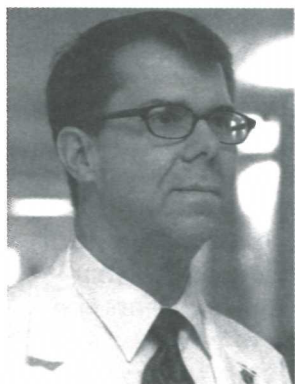
The shoes are built on a last that is shaped like a human foot providing extra room for toes and metatarsal movement. Each shoe comes with a fully molded leather-lined orthotic that can be modified or replaced easily with a prescription one. The company will also "customize modularize" a product, meaning they can assemble each shoe for the particular needs of the foot. "Fit plates" can be sent to help people create a customized fit.

After making shoes for a polio survivor in Taos, he decided to offer his footwear to people with special size needs. Visit Mozoshoes.com or call 877-834-6696.

Mozo will accommodate people who have limited resources. Please contact *Post-Polio Health* at 314-534-0475 or info@post-polio.org for more details. ●

**From Debbie: "I found a doctor who was interested in post-polio and after many months of treatment, he insisted that what would help me most would be a change in lifestyle, i.e., retirement. I hate to admit it, but I do feel so much better now. I have cut the medication I was taking to one-fourth. All of a sudden, I have tons of free time, and I would like to use the time to give something back and do something that is meaningful to me."*

Advocate Retires



Stanley K. Yarnell, MD, Medical Director, Physical Medicine and Rehabilitation, St. Mary's Medical Center, San Francisco, California, retired at the end of June. Dr. Yarnell and 300 guests were read a tribute from Joan L. Headley, Executive Director, Post-Polio Health International, on behalf of polio survivors and the organization.

"For those of you who don't know the history of the late effects of polio aka post-polio syndrome aka post-polio sequelae, Stan was one of the very first physicians who really listened to his polio patients, led by Renah Shnaider, and followed that up with action – a meeting for polio survivors in November of 1981. He has been a tireless advocate for polio survivors for the last 23 years. Stan did not seek recognition for this work. He just DID it."

With Gratitude

We thank our donors for their contributions in memory of the following special individuals.

To the Gini Laurie Endowment Fund

Ruth Peacock Cambon	Anne Gawne, MD	Raymond Webster
Mary Ann Farrington	Phillip Kagan	
June Fortezzo	Mr. Krieger	

To The Research Fund

Evelyn Alberts	Sylvia Fisher	Georgene McGown
Marie Connelly	Rod Headley	Krauser

We thank the following support groups for their support of the work of Post-Polio Health International.

Long Island Post-Polio Support Group
Polio Epic, Inc., Southern Arizona
Polio Heroes of Tennessee/Nashville Area
Polio Outreach of Connecticut
UCLA/Westside Post-Polio Support Group

The Board of Directors of Post-Polio Health International

is pleased to welcome the following individuals to its **Medical Advisory Committee**. For a complete listing, visit www.post-polio.org/brd.html.

Nancy L. Caverly, OTR/L, Cedar Ridge Wellness Center, Bland, Missouri

Diana Guth, BA, RRT, Home Respiratory Care, Los Angeles, California

Lauro S. Halstead, MD, National Rehabilitation Hospital, Washington, DC

Robbie B. Leonard, MS, PT, Anmed HealthSouth Rehabilitation Hospital, Anderson, South Carolina

Mary Westbrook, PhD, The University of Sydney (ret.), Chatswood, New South Wales, Australia

Readers Requests

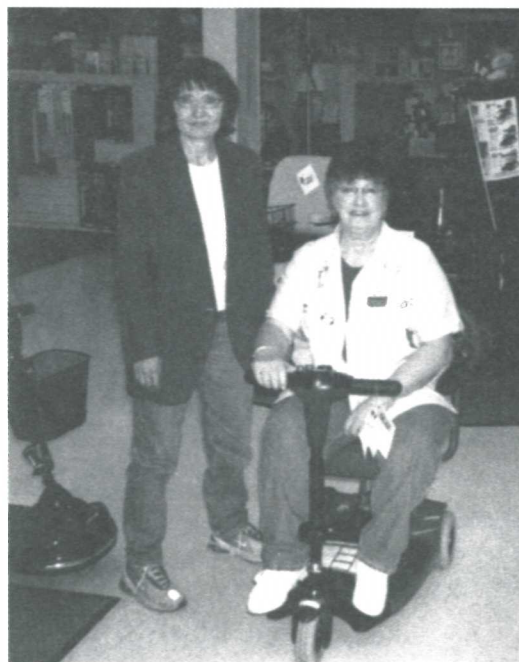
"I have slept in an iron lung for years and now use it during the day. I would like to call and speak with others who use the lung." -Bill Brown

(Contact Post-Polio Health International.)

"I had carpal tunnel surgery and deQuervain's tendonitis surgery on both arms – November 6 and December 11. My right hand was in a cast for 14 days; my left hand, 10 days. I wear splints when using the keyboard and support my forearms on pillows at night. I still use prescription ibuprofen and still have inflammation. It appears that my wrists are getting smaller and I fear I am losing muscle. Does anyone have any suggestions as to what I should do or not do?"

(Contact Post-Polio Health International.)

Scooters Purchased



Wilma Hood, Missouri, and Joan L. Headley, Executive Director, Post-Polio Health International (PHI), with the new scooter purchased with assistance from PHI. Assistance was also given to survivors from Thailand, Florida, and Nebraska. Please contact Justine Craig-Meyer at PHI to receive an application to apply for the two remaining \$500 awards towards the purchase of a scooter.

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314-534-5070 fax

THE MISSION OF POST-POLIO HEALTH INTERNATIONAL, including International Ventilator Users Network ... is to enhance the lives and independence of polio survivors and home mechanical ventilator users by promoting education, networking, and advocacy among these individuals and healthcare providers.

HOW TO CONTACT US ...

Post-Polio Health International Including International Ventilator Users Network

4207 Lindell Boulevard, #110
Saint Louis, MO 63108-2915 USA
www.post-polio.org, info@post-polio.org
314-534-0475, 314-534-5070 fax

Emerging Horizons, a travel magazine for people with disabilities, is offering a discount to members of Post-Polio Health International. The cost of this quarterly publication has been reduced from \$14.95 to \$12.95. The offer is good until September 30, 2003 and in the US only. Call 209-599-9409 or log on to www.EmergingHorizons.com with your PHI membership ID number that can be found directly above your name on the mailing label. If you have questions, contact Justine Craig-Meyer at PHI.

Post-Polio Health International thanks Obata Design (www.obatadesign.com), Saint Louis, Missouri, for contributing to the design of our new name, and Lexmark International for the printer.

THE SUMMER 2003 ISSUE OF **POST-POLIO HEALTH** FEATURES ...

**To Brace or To Not Brace? Improving Function ... The West Nile Virus:
Like and Unlike the Poliovirus Infection ... New SSA Ruling ... and more.**

POST-POLIO HEALTH
INTERNATIONAL

POST-POLIO HEALTH INTERNATIONAL
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