

PHI's mission is supported by its Membership.

Effects of Whole Body Vibration on People with Post-Polio Syndrome

Carolyn P. Da Silva, PT, DSc, NCS, Texas Woman's University, Houston, Texas, and Yi-Wen Michelle Pu, MD, Baylor College of Medicine, Houston, Texas

Introduction

People with post-polio syndrome (PPS) frequently have difficulty finding ways to exercise without worsening symptoms or over-exerting muscles. Whole body vibration (WBV) is a way to exercise that causes muscle contractions through stimulation of reflexes. The purpose of this study was to determine the feasibility of WBV as a means of weight-bearing exercise in people with PPS by assessing its effects on walking speed and endurance (measured by 10-meter walk test and two-minute walk test, respectively), pain severity and interference (measured by the Brief Pain Inventory), sleep quality (measured by the Pittsburg Sleep Quality Index), fatigue (measured by the Fatigue Severity Scale), leg muscle strength (measured by manual muscle testing and hand-held dynamometry), and muscle cramping (through patient reported written logs).



Carolyn P. Da Silva

The Participants

The study was approved by the human subjects Internal Review Boards of Baylor College of Medicine and Texas Woman's University in Houston, Texas. Twenty-one individuals were recruited from the TIRR-Memorial Hermann Rehabilitation and Research outpatient post-polio clinic, Texas Polio Survivors' Association and Post-Polio Health International. Each

person provided medical clearance from their personal or TIRR physician.

Fifteen completed the study, with withdrawals due to non-study related reasons. Average age of the participants was 63.53 years, with average age at onset of polio 3.55 years. Nine females and six males completed the study. Eleven walked full-time, three part-time and one did not walk. Three people used one or both AFOs (short braces), two people used one or both KAFOs (long braces). Three people used one straight cane or walking stick, one used two straight canes and one used two Lofstrand crutches. Five people continued to work full-time during the study, two worked part-time and eight had retired prior to the study.

The Activity

Each person participated in eight sessions of WBV over four weeks on two different WBV machines. Each person was asked to stand on the machine's vibrating platform with knees slightly bent and weight as even between the two legs, as possible. They did not wear their braces/orthoses during vibration sessions, to avoid possible loosening of hardware or friction between the device and person's skin. They wore socks only on their feet to best feel the vibration. If the person was unable to stand, then he or she sat in a wheelchair or chair with seat elevated, leaning forward onto knees with feet on the platform. (See the photos for equipment used and sitting and standing positions.)

continued on page 4

**WE'RE
STILL
HERE!**

October 11-17, 2015
www.post-polio.org

WE'RE STILL HERE! 2015 Photo Contest Show Me Accessibility!

*What activities do you now enjoy that were previously impossible to access?
What places have you now visited that were previously inaccessible?
Send us a photo that illustrates the ability to access the activity or location.*

Help us document that people who had polio are still here, active and involved thanks to laws such as the Americans with Disabilities Act or the UN Convention on the Rights of Persons with Disabilities.

Post-Polio Health International will select a grand prize winner (\$150 USD) and four runners-up (free PHI Membership for two years).

The runners-up will be announced October 12-15 with the announcement for grand prize to follow on October 16.

Contest Rules:

- Print or digital (JPEG with a minimum of 300 dpi) photographs will be accepted. Print photographs will not be returned.
- Color or black and white photographs will be accepted.
- Identify the location and date of the photograph and include an explanation of how accessibility laws made the picture possible. Submitting a caption is optional.
- Each person is limited to submitting two photographs.

NOTE: By submitting the photograph to PHI you are confirming that the photograph is your property/work. You are agreeing to its limited use by PHI. PHI will state with the winning photos the following: Photo by (Name). Permission to use must be obtained through PHI. Decision of the judges is final.

***Deadline to submit a photograph to info@post-polio.org
is 12:00 pm CST on October 1, 2015.***

POST-POLIO HEALTH

Summer 2015

Vol. 31, No. 3

ISSN 1066-5331

Editor: Gayla Hoffman
editor@post-polio.org

Designer: Sheryl R. Rudy
webmaster@post-polio.org

©2015 Post-Polio Health International (PHI).
Permission to reprint must be
obtained from Post-Polio Health
International (PHI).

*PHI's mission is to enhance the lives and independence of polio survivors
and home mechanical ventilator users through education, advocacy,
research and networking.*

How to contact PHI

Executive Director
Joan L. Headley, MS
director@post-polio.org

4207 Lindell Blvd., #110
Saint Louis, MO 63108-2930 USA
Phone: 314-534-0475
Fax: 314-534-5070
info@post-polio.org
www.post-polio.org
www.polioplac.org

*PHI sends PHI Membership Memos via email.
Be sure to set your spam filter to receive emails
from info@post-polio.org.*

Moving? Change of address?

Notify PHI before you move by calling 314-534-0475
or email info@post-polio.org, and tell us your old
and new addresses.

Away temporarily?

Send us your second address and dates you will be there
and we'll do our best to send your newsletter.

Multicenter, Multi-country Study Underway

Joan L. Headley, Executive Director, PHI

Typical of most studies, the name of the most recently announced study related to post-polio syndrome is long but exactly descriptive: A Multicenter, Prospective, Randomized, Placebo-controlled, Double-blind, Parallel-Group Clinical Trial to Assess the Efficacy and Safety of Immune Globulin Intravenous (Human) Flebogamma® 5% DIF in Patients with Post-Polio Syndrome.

The main purpose of the study is to select a dose of Flebogamma® 5% DIF and confirm the efficacy of the selected Flebogamma® 5% DIF dose by assessing physical performance, as measured by 2 Minutes Walk Distance (2MWD) test.

Breaking it down, the study uses the March of Dimes clinical criteria for the diagnosis of post-polio syndrome. Other criteria to be included in the study are walking unassisted or using a cane and/or other assistive devices or orthotics (braces), age range of 18-75, BMI less than 35 kg/m², negative test for pregnancy and meet the requirements about newly weakened muscle groups.

The list of exclusion criteria is long and related to other conditions a person may have, other treatments, allergies, intolerances and more.

Participants will be randomized into groups receiving either 2g/kg Flebogamma® 5% DIF or 1g/kg Flebogamma® 5% DIF or placebo (normal saline solution) every four weeks over two days for 52 weeks. Flebogamma® 5% DIF is the trade name for Immune Globulin Intravenous (Human) manufactured by Grifols Biologicals, Inc. (Instituto Grifols, SA) headquartered in Barcelona, Spain.

Centers in the following cities are involved in the study. USA: Los Angeles, St. Louis, Syracuse, Philadelphia; Canada: Toronto, Montreal; Denmark: Aarhus, Copenhagen; Germany: Berlin, Hannover, Jena, Münster; Italy: Verona; Netherlands: Amsterdam; Poland: Lublin, Poznan, Warsaw; Romania: Bucharest; Spain: Barcelona; Sweden: Göteborg, Lund, Orebro, Stockholm.

Principal investigator Dr. Marinos Dalakas, Professor of Neurology at Thomas Jefferson University Hospital, Philadelphia, states: “This is the most promising study ever conducted in PPS because it uses a multi-potent drug that works in many different ways to safely modify the immune system, as has been successfully applied in many different autoimmune neuromuscular diseases. Even though PPS is not technically an immune disease, a number of immune factors seem to play a role. Further, this is the only study ever conducted in PPS that examines the long-term effect of such a drug.”

Dr. Kristian Borg, Professor and Chair, Division of Rehabilitation Medicine, Karolinska Institute, Stockholm, adds, “We have conducted several studies on IVIg treatment in PPS and we have recently been able to characterize subgroups of responders to the drug. It will be of great interest to be able to verify our findings in a broader multinational and multicenter study.”

Eleven of the 23 centers are currently recruiting participants. To learn more about the study, the specific centers and principal investigators in each city, visit <https://clinicaltrials.gov/ct2/show/study/NCT02176863#contacts>. Members of PHI who do not have internet access may call the PHI office (314-534-0475) to learn how to participate.

The study is approved by the United States Food and Drug Administration and Health Canada. ■

Select articles about use of intravenous immunoglobulin (IVIg) in polio survivors in chronological order.

Prior poliomyelitis – Ivlg treatment reduces inflammatory cytokine production, Gonzalez, H., Khademi, M., Andersson, M., Wallström, E., Borg, K., Olsson, T., *Journal of Neuroimmunology*, May 2004: 150(1): 139-44.

Intravenous immunoglobulin in post-polio syndrome, Farbu, E., Rekan, T., Gilhus, N., Strøm, V., Opheim, A., Stanghelle, J., Aarli, J., *Tidsskr Nor Laegeforen*, Sept 2004: 124(18): 2357-58.

Effect of Intravenous Immunoglobulin in Patients with Post-Polio Syndrome – An Uncontrolled Pilot Study, Kaponides, G., Gonzalez, H., Olsson, T., Borg, K., *Journal of Rehabilitation Medicine*, 2006: 38(2): 138-140.

Intravenous immunoglobulin for post-polio syndrome: a randomized controlled trial, Gonzalez, H., Stibrant, S., Sjöberg, I., Kaponides, G., Olsson, T., Borg, K., *Lancet Neurology*, 2006: 5(6): 493-500.

Post-polio syndrome patients treated with intravenous immunoglobulin: a double-blinded randomized controlled pilot study, Farbu, E., Rekan, T., Vik-Mo, E., Lygren, H., Gilhus, N., Aarli, J., *European Journal of Neurology*, Jan 2007: 14(1): 60-65.

IVIg in other autoimmune neurological disorders: current status and future prospects, Dalakas, M., *Journal of Neurology*, Jul 2008: 255(Supple 3): 12-6.

Effect of intravenous immunoglobulin on pain in patients with post-polio syndrome, Werhagen, L., Borg, K., *Journal of Rehabilitation Medicine*, November, 2011: 43(11),1038-40.

IVIg treatment in post-polio patients: evaluation of responders, Ostlund, G., Broman, L., Werhagen, L., Borg, K., *Journal of Neurology*, May 2012.

Intravenous immunoglobulin treatment of the post-polio syndrome: sustained effects on quality of life variables and cytokine expression after one year follow up, Gonzalez, H., Khademi, M., Borg, K., Olsson, T., *Journal of Neuroinflammation*, 2012: 9(1): 167.

Intravenous immunoglobulin for postpolio syndrome: a systematic review and meta-analysis, Huang, Y.H., *BMC Neurology*, 2015 Mar 22;15:39.

continued from page 1

Each person started with one minute standing with vibration on, one minute sitting down with no vibration, repeating this sequence 10 times for a total of 10 minutes of vibration time per session. Time was gradually increased to 10 times of two minutes of vibration for total of 20 minutes per session. Each person was able to increase to the goal of 20 minutes without difficulty. Blood pressure and heart rate were measured before and after each vibration session. Rating of perceived exertion was measured after each session.

All participated in eight sessions on the Soloflex unit at its lowest setting of “acceleration-load” 0.3 g and eight sessions on the Power Plate Pro5 at settings of 35 vibrations per second, low amplitude (vibration height). The Power Plate settings were more intense than the ones on the Soloflex. When measured with a separate accelerometer, the total amplitude of the Power Plate was 8.82 millimeters and the Soloflex was 4.53 millimeters. The g forces were 2.76 on the Power Plate and 2.21 on the Soloflex. The people were randomized into which machine/settings were used for the first eight and second eight sessions.

Testing

A physical therapist (PT) who did not know which vibration machine was being used by each person performed all the testing. Testing of outcome measures occurred before and after each four weeks of eight sessions per machine and two weeks following the last testing session. There were two weeks scheduled off in between the two four-week vibration interventions. Each person completed muscle cramping logs two weeks prior to start



of any testing and vibration and continued throughout entire study period (approximately three months).

Rationale

I first became interested in WBV when a patient from our post-polio clinic asked me if it was safe for him to do, as he had been advised by

a physician to start a vibration program because of his recent diagnosis of osteopenia (bone density loss, prior to osteoporosis). I had to tell him that I did not know, would look some things up, and get back with him. As I studied WBV, I became more and more interested in it to see if it could be an addition to a person’s exercise routine or used as an exercise substitute. Frequently,

people with PPS have difficulty finding safe ways to exercise without worsening their symptoms of muscle weakness, pain, sleep disturbances, fatigue and/or muscle cramping.

Studies have shown WBV to improve leg strength, balance, flexibility, health-related quality of life and bone mineral density in healthy and elderly populations. There have also been small studies of WBV used with adults with stroke, Parkinson’s disease, multiple sclerosis and cerebral palsy that have inconsistently shown improvements in leg strength, balance and walking. One previous study of people with PPS was discontinued after no changes were found in leg strength or walking performance.

Concerns

My first concern in designing the current study was that I did not want to cause any of my patients and other polio survivors to have more problems than they already had. This concern was why we used a low intensity protocol on the Soloflex and a higher intensity one on the Power Plate. No one reported any increasing PPS symptoms, even handling fatigue although some of the people commuted more than one hour each direction to participate. Additionally, one person had her work demands approximately double and another babysat her two very young grandchildren for two weeks full-time during the course of the study, with both situations potentially greatly impacting fatigue levels. A few of the participants reported feeling quite energized after sessions.

Of the people who completed the study, one person who was unable to walk and stand used the sitting protocol. One other person who was able to walk and work full-time chose to sit through most of the higher intensity protocol due to it being “too intense.” Most of the people who first participated in the higher intensity protocol asked if the low intensity of the Soloflex could be “turned up,” because they felt like they were “not getting enough.” Some reported the testing sessions to be more strenuous than the vibration sessions.

Results

There were no study-related adverse events. The people who first started with the higher intensity protocol on the Power Plate significantly improved in their walking speed ($p = 0.017$). However, when combining the people who started with either intensity of intervention, their improvement was not significant ($p = 0.087$). Pain severity significantly improved ($p = 0.049$) and pain interference came close to significant improvement ($p = 0.055$) as measured by the Brief Pain Inventory after the more intense Power Plate vibration intervention, regardless if they had the Power Plate vibration sessions in the first intervention block or not.

No significant changes were found after the gentler Soloflex intervention. There were no significant changes in walking endurance, sleep quality, fatigue, leg strength or muscle cramping. There were also no significant changes in blood pressure and heart rate after each session. The changes seen in walking speed and pain severity and interference were temporary and not maintained during follow-up testing.

The Limitations

The biggest study limitation was of recruitment. Many people expressed interest by email or when approached in the clinic. However, the biggest reason given for choosing not to participate was due to the time, expense and energy involved with commuting into the huge Texas Medical Center in Houston, Texas twice a week for the testing and vibration sessions. The most common reason for a person to be excluded from the study was due to metal implants, particularly joint replacements or internal bone fixations due to scoliosis or previous fractures.

Because of the small number of people who were able to participate and complete this study, the results of improved gait speed and pain must be interpreted cautiously, and I do not have an explanation for why the one group of people walked faster than the other after the Power Plate intervention, as both groups' baseline walking speeds were not statis-

tically different. Obviously, the 15 people who completed this study cannot represent the wide spectrum of types of people who have survived polio, with or without PPS. Also, the improvements that were found did not last until the follow-up testing that occurred two weeks later, indicating that a person may need to continue with WBV to maintain the effects.

The Strengths

Strengths of the study included having two PTs administer all the tests, with significant effort made for each PT to follow the assigned participant throughout the study duration, as much as possible. Each PT worked full- or part-time at TIRR Memorial Hermann and was skilled in the testing protocols. They were "blinded" to which machine each participant was using and to previous testing forms to maximize their objectivity and minimize bias. The primary investigator, who has worked with polio survivors at TIRR since 1998, was present during almost all of the vibration sessions and able to verbally or physically assist with participants accessing the vibration platforms, body positioning and education regarding the protocols.

Conclusions

In conclusion, WBV appears to be a safe, tolerable, and feasible type of weight bearing exercise for people with PPS. Further research needs to be done to study long-term use in people with PPS and other neurological conditions, particularly in reducing barriers to participation to promote the physical aspects of health and wellness.

Dissemination Plans

Preliminary data and results were presented at the Texas Physical Therapy Association meeting in Galveston, Texas in October, 2014. Final study results have been submitted as abstracts for presentations at the American Physical Therapy Association Combined Sections Meeting and American Congress of Rehabilitation Medicine and will be submitted as a manuscript for Archives of Physical Medicine and Rehabilitation. ■

Acknowledgments

We wish to acknowledge the following people for their assistance in this study: Dr. Carlos Vallbona for sharing his wealth of knowledge about PPS and general support; Dr. Elaine Magat for continuing the PPS clinic at TIRR; Natasha deSa, PT, DPT, and Lauren Szot, PT, DPT, NCS for testing; Arianne Stoker, PT, DPT, Kelly Hodges, DPT, Mariana Sanjuan, SPT, and Maggie Strange, SPT who were/are entry-level PT students who helped provide vibration sessions and data collection; Amanda Smith, MS, Zoheb Allam, MS, and Rene Paulson, PhD who provided statistical assistance. We also wish to thank Joan Headley and the research committee of Post-Polio Health International who believed in this project and financially supported it 2013 to 2014.

References

Bautmans I, Hees EV, Lemper J, Mets T. The feasibility of whole body vibration in institutionalized elderly persons and its influence on muscle performance, balance and mobility: a randomized controlled trial. *BMC Geriatrics*. 2005; 5:17.

continued on page 7

Mid-Study Report to PHI

Summary of Poliovirus Genome in Patients with Post-Polio Syndrome

Joan L. Headley, Executive Director, PHI

In late 2013, Post-Polio Health International awarded \$100,000 to the team of Antonio Toniolo, MD; Andreina Baj, MD; Martina Colombo, PhD – Laboratory of Medical Microbiology and Virology, Department of Biotechnology and Life Sciences, University of Insubria Medical Center, Varese, Italy, to expand its search for poliovirus genome in various populations. The team’s work is enhanced by the expertise of Konstantin

Chumakov, PhD, Associate Director for Research, Office of Vaccines Research and Review, FDA Center for Biologics Evaluation and Research, Silver Spring, Maryland.

The goals are: 1) to complete the systematic search of poliovirus genomes in the Italian cohort of post-polio syndrome cases, and 2) to verify if poliovirus genomes are also present in aging polio survivors with “stable polio” (i.e., those aged >60 years that have not developed post-polio syndrome).

The team will compare virus prevalence of point 1 versus point 2 with the aim of establishing whether the presence of persisting polioviruses may have a pathogenic role in post-polio syndrome and of defining the peculiarities of genomic sequences of polioviruses detected in cases with post-polio syndrome as opposed to the genomic sequences of wild-type polioviruses.

Why look for poliovirus genome?

For many, the origin of post-polio syndrome is still poorly understood. Some do not question its origin, but attribute its consequences to living active lives with

bodies that have fewer nerves and fewer muscles. Time and age takes its toll. But, looking for an additional explanation makes sense.

Persistent poliovirus (PV) infection has been reported in individuals with B lymphocyte deficiency (and low or absent serum immunoglobulins; Li et al., 2014). Some evidence suggests that persistent PV infection could be associated with post-polio syndrome (Leon-Monzon et al., 1995; Baj et al., 2015).

Inflammatory changes in meninges, spinal cord and muscles have been reported (Ikemoto et al., 1996; Semino-Mora & Dalakas, 1998) and may suggest: persistent PV infection, autoimmune attack to central nervous system (CNS) targets, increased vulnerability of CNS to further infections.

What has been accomplished?

Polio patients have been seen by neurologists and appropriately diagnosed with post-polio syndrome (PPS) (or other forms of polio) using current diagnostic criteria (Farbu et al., 2011). Participants in the study have included PPS cases, stable polio cases, polio-free family members of PPS patients, non-polio neurologic controls and healthy blood donors.

What are some preliminary results?

Low-level genomes and infectivity *related to any one of the three PV types* have been detected at high frequency in PPS patients decades after the acute attack.

An additional conclusion of relevance to the field of public health (and also important for family members and co-workers of PPS cases) is that PV infection is not being transmitted from PPS patients to their family members.

Since effective treatments for PPS are still missing (Koopman et al., 2011),

“For many, the origin of post-polio syndrome is still poorly understood. Some do not question its origin, but attribute its consequences to living active lives with bodies that have fewer nerves and fewer muscles. Time and age takes its toll. But, looking for an additional explanation makes sense.”

Left to right: Drs. Takashi Onodera, Konstantin Chumakov and Antonio Toniolo at National Institutes of Health discussing how to apply novel sequencing methods for examining poliovirus isolates of PPS cases.

identification of chronic PV carriers might indicate the need of treatment with human IgG or antiviral drugs/antibodies that are under development (McKinlay et al., 2015). Some treatments (Hu immunoglobulins) are currently under clinical trial in a multicenter international study.

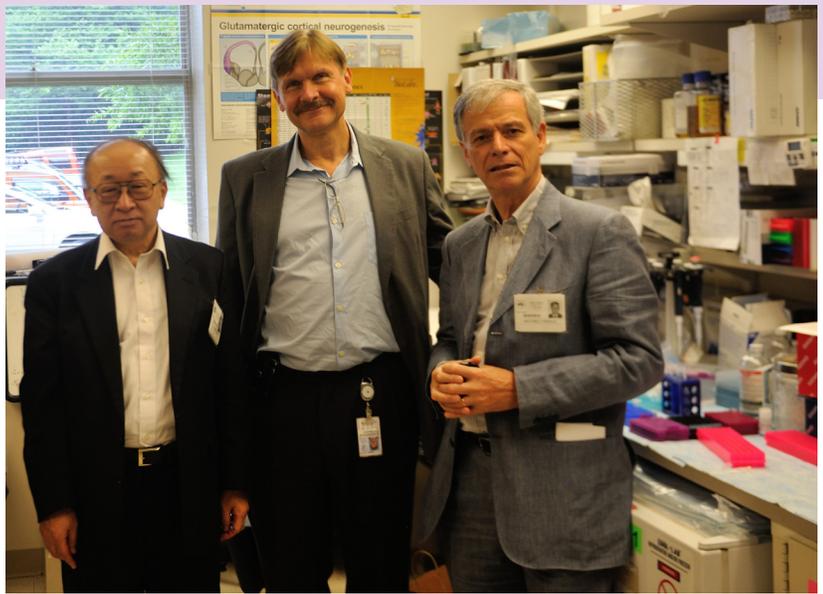
What are the team's next steps?

Select viruses isolated from PPS cases are being examined at the FDA in order to define the peculiarities of genomic sequences of polioviruses present in PPS cases versus those of wild-type polioviruses.

The recruitment of polio survivors with “stable polio” is continuing to extend the observations from the current to at least 30-40 cases.

The team will evaluate if anti-poliovirus antibodies may be effective in blocking the infectivity of poliovirus strains derived from PPS patients.

If positive, the results of the above tests will allow the team to propose “specific serotherapy” for treating PPS. In the meantime, they want to understand the possible role of poliovirus antibodies in the current therapy that is mainly based on the infusion of human immunoglobulins. ■



References

- Baj A, Colombo M, Headley J, McFarlane J, Liethof M-a, Toniolo A. Post-polio myelitis syndrome as a possible viral disease. *Int J Infect Dis.* 2015;35:107-116.
- Farbu E, Gilhus NE, Barnes MP, Borg K, de Visser M, Howard R, Nollet F, Opara J, Stalberg E. Post -polio syndrome. In: *European Handbook of Neurological Management.* Volume 1, 2nd Edition. NE Gilhus, MP Barnes, M Brainin (Eds.). Blackwell Publishing, Oxford, 2011; pp. 311-9.
- Ikemoto A, Hirano A. Immunohistochemical studies on clustered pericapillary bodies in the spinal cord of post-polio myelitis patients. *Acta Neuropathol.* 1996;92:164-9.
- Koopman FS, Uegaki K, Gilhus NE, Beelen A, de Visser M, Nollet F (2011). Treatment for postpolio syndrome. *Cochrane Database Syst Rev.* (2):CD007818.
- Leon-Monzon ME, Dalakas MC. Detection of poliovirus antibodies and poliovirus genome in patients with the post-polio syndrome. *Ann N Y Acad Sci.* 1995;753: 208-18.
- McKinlay MA, Collett MS, Hincks JR, Oberste MS, Pallansch MA, Okayasu H, Sutter RW, Modlin JF, Dowdle WR. Progress in the development of poliovirus antiviral agents and their essential role in reducing risks that threaten eradication. *J Infect Dis.* 2014;210:S447-53.
- Semino-Mora C, Dalakas MC. Rimmed vacuoles with beta-amyloid and ubiquitinated filamentous deposits in the muscles of patients with long-standing denervation (postpolio myelitis muscular atrophy): similarities with inclusion body myositis. *Hum Pathol.* 1998;29:1128-33.

Effects of Whole Body Vibration on People with PPS continued from page 5

- Brogårdh C, Flansbjerg U-B, Lexell J. No effects of whole body vibration training on muscle strength and gait performance in people with late effects of polio: a pilot study. *Arch Phys Med Rehabil.* 2010; 91:1474-1477.
- del Pozo-Cruz B, Adsuar JC, Parraca JA, del Pozo-Cruz J, Olivares PR, Gusi N. Using whole body vibration training in patients affected with common neurological diseases: a systematic literature review. *J Altern Complement Med.* 2012;18:29-41.
- del Pozo-Cruz B, Hernández Mocholí MA, Adsuar JC, Parraca JA, Muro I, Gusi N. Effects of whole body vibration therapy on main outcome measures for chronic non-specific low back pain: a single-blind randomized controlled trial. *J Rehabil Med.* 2011;43:689-694.
- Marin PJ, Rhea MR. Effects of vibration training on muscle strength: a meta-analysis. *J Strength Cond Res.* 2010;24:548-556.
- Rittweger J, Karsten J, Kautzsch K, Reeg P, Felsenberg D. Treatment of chronic low back pain with lumbar extension and whole body vibration exercise. *Spine.* 2002;27:1829-1834.
- von Stengel S, Kemmler W, Engelke K, Kalender WA. Effects of whole body vibration on bone mineral density and falls: results of the randomized controlled ELVIS study with postmenopausal women. *Osteoporos Int.* 2011;22:317-325.

QUESTION: *I worked so hard to walk again after acute polio. I have extreme pain in my hip in my weaker leg and since I had a knee replaced, my back pain when standing is also extreme. I use a cane sometimes and I know I should use a scooter or a wheelchair, but I just can't overcome that horrible feeling of being a failure if I do. Besides that I have gained weight and if I don't move some, I will gain even more. Help!*

Response from Rhoda Olkin, PhD:

Ohhhh, been there! I have pain in my knee area, my back hurts, I can't stand for more than a minute, and I spent my formative years doing everything possible to remain ambulatory. Now I use a wheelchair or scooter 90% of the time, crutches the remaining 10%, starting about 10 years ago. My weight gain has been alarming, and I no longer see in the mirror the person I think I am from the inside (who seems to be much younger, cuter, thinner and with great hair!). But I do not see a failure, only flaws that I can address. The flaws do not include the fact that I use a wheelchair, because doing so got me my life back. Pain and limited ambulation were forcing a reduction in activities that narrowed my world.

We get so many messages from everywhere about how walking is good and how the need for any sort of assistive devices is bad. Consider the language often used: "Wheelchair bound" (with the emphasis on the inability to get out of the wheelchair), "non-ambulatory" (not able to walk), "suffers from polio" (as if that's all you are). What if we said "uses a wheelchair" and "fully mobile" (by whatever means!) instead? A wheelchair is not a failure, but a window into a wider world of options. Imagine you lived in a poor country with no access to wheelchairs. In such circumstances people devise their own sets of wheels, and getting a real wheelchair would not represent failure, but wings to fly.

Try an experiment. Go to a big store that has a scooter for customers to use. Do not use it. Go up and down each aisle. Note your level of fatigue and pain. Now go on another day and use the scooter, again going up and down each aisle, and again noting your level of fatigue and pain. What do the results tell you?

Okay, I'm not going to gloss over the significance of using a wheelchair. First, using a wheelchair often means less overall body movement, which can lead to secondary conditions (weight gain, decubitus ulcers, lassitude of some muscles). You have to be careful to avoid these. Since you can walk, do so a bit, or get on the floor and move/exercise, or do chair exercises. (Once a day I walk with crutches from my office to the bathroom and back, a total of 100 steps. I notice I feel better when I do this.) Second, it's a change in body image. People everywhere start reacting to you differently, and that feedback forces some recalibration of the self. Third, it can be harder to maintain or lose weight. Make sure you don't have another condition (hypothyroid, sleep apnea) and then find a balance in intake and output that you can live with. And when you do, write me, so I can use it as well!

Do not let anyone – family, friends, doctors, rehabilitation specialists, physical therapists – lead you to believe using a wheelchair represents failure. It is an alternate means of mobility and does not change the fundamental you.



Dr. Rhoda Olkin is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology.

She is a polio survivor and single mother of two grown children.

QUESTION: *Sixty years later I still live daily with anxiety stemming from hospital treatment, not abusive but certainly traumatic for a child. Do you have suggestions on how I can reduce the stress of this anxiety?*

Response from Stephanie T. Machell, PsyD:

So many of my clients struggle with this! The hospital experience was indeed traumatic. You had a serious life-threatening disease that in its acute phase included severe pain, a high fever and the inability to move and/or breathe on your own. Your family was absent and often unable to visit even briefly. And the treatments themselves could be painful and at times humiliating.

And no one was explaining why any of this was happening or letting you express your fears. If you tried, you were told to be brave, that big girls and boys don't cry, or something similar. At that time pediatric professionals believed that children didn't experience depression or anxiety and that only disturbed children would suffer long-term emotional effects from polio.

Of course that wasn't true. And because what isn't addressed cannot heal, you like so many others still suffer the aftereffects.

Anxiety can manifest as panic, worry, ruminations, obsessions, compulsions, frightening intrusive memories or nightmares, phobias, fears, a sense that something terrible might happen, avoidance of places or experiences (for example, medical care or wearing heavy clothing). Most likely you have more than one of these symptoms.

There are many self-help techniques for reducing anxiety. Mind-body techniques such as meditation, relaxation, guided imagery, gentle yoga, or tai chi "reset" an overactive autonomic nervous system.

Grounding techniques interrupt panic or flashbacks. For example: Open your eyes.

Feel your feet on the floor and/or your butt in the chair. Breathe steadily. Look at something that reminds you you're safe.

Worriers can set a worry time of 15 minutes at the same time every day. For the other 23 hours and 45 minutes, when you catch yourself worrying, stop and say, "I need to save this for worry time." When worry time comes you MUST worry for 15 minutes. When the time is up, you MUST stop worrying until the next worry time.

Writing can be helpful. Part of what makes trauma traumatic is that it is unspoken and unshared. Putting your experience into words, even if just for yourself in a journal, helps you process and make meaning of your experiences. Others have used art in this way.

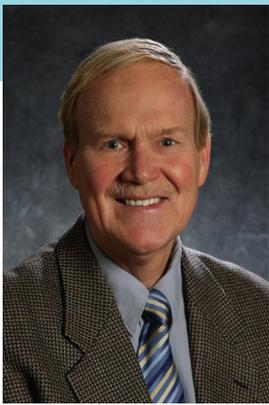
Reading about the trauma of polio helps some and overwhelms others, so use your judgment. Along with the many memoirs there are some useful articles about trauma and the polio survivor. The best one, "Bridges to Wellness" by Linda Bieniek, is on the PHI website. The Lincolnshire Post-Polio Library contains some excellent articles. Though not specific to polio there are also workbooks and self-help books for reducing anxiety and other aftereffects of trauma.

Have you seen a psychotherapist? If no one in your area works specifically with polio survivors, look for someone who deals with trauma and/or disability. Many of my clients have found that once they dealt with their trauma, they had a reduction in their PPS symptoms, especially fatigue and cognitive difficulties. Finding a therapist and going through therapy isn't easy. But healing is worth it. ■

Dr. Stephanie T. Machell is a psychologist in independent practice in the Greater Boston area and consultant to the International Rehabilitation Center for Polio, Spaulding-Framingham Outpatient Center, Framingham, Massachusetts.

Her father was a polio survivor.





Frederick M. Maynard, MD

Ask Dr. Maynard

Send your questions for Dr. Maynard to info@post-polio.org.

See other questions at www.post-polio.org/edu/askdrmay.html.

Question: *Why does no one ever address the problems that polio caused to the digestive system? I had polio when I was 6 years old and have had problems with my digestive system ever since. Has there been any research on the effects polio had on the digestive system?*

A: While there are many polio survivors who complain of heartburn and GERD symptoms, there is no evidence to support the idea that these problems are more common than among people of the same age without a history of polio. You are the first polio survivor that I know of that has experienced “stomach digestive problems” ever since their original polio. You don’t indicate how severely affected by polio you were or if your breathing muscles were affected greatly or if you have scoliosis.

Some of the secondary complications of more severe polio paralysis can contribute to digestive problems because of inactivity/immobility and/or weakness of abdominal wall vs. diaphragm muscles. There is no evidence that the poliovirus had a direct damaging effect on the digestive system organs, and symptoms or problems would need to be managed in the same way that they would in anyone, with the exception of any need to modify treatments because of significant disability.

Research on the subject isn’t being done because of the absence of plausible hypotheses for why polio would have directly affected the GI system.

Question: *I had polio at age 5 in 1968 apparently contracted from the oral polio vaccine. The acute illness lasted about a month, then a slow recovery ensued (upper and lower right limb involvement) that took about a year. Is there any difference between PPS symptoms in patients who have contracted the disease through vaccine and those who contracted it naturally?*

After many years with mysterious health problems, I have been diagnosed with PPS by my family doctor, but neurologists who we have consulted are confused by some of my most prominent symptoms. They say that they are not familiar with PPS causing anything more than difficulty swallowing (which I have). However, I also have severe reflux, intermittent gastroparesis, slow GI motility, constipation and right upper quadrant pain after fat-containing meals. Are these added GI problems in line with what could be caused by PPS?

A: In answer to your first question, there are no known differences between the late effects of polio that develop in people with a history of vaccine-related polio vs. wild polio. The way you describe your recovery after polio also sounds typical for recovery from wild polio illness/paralysis, and there is a wide variation in the speed of recoveries that is primarily due to the severity and extent of nerve damage/nerve loss, not immunological issues.

Regarding your second question about gastrointestinal problems beyond swallowing difficulties related to throat muscle weakness, I would have to say that there is no convincing scientific evidence or study that shows they are directly related to having had polio. There are reports that suggest aging polio survivors MAY have a higher incidence of gastrointestinal motility disorders, as you describe them, but the evidence is weak and not widely accepted as “real” compared to chance occurrence because these problems are common in many older populations. The treatment would also be the same in any case.





Question: *What are the symptoms in patients with post-polio syndrome with facial involvement? I am a PT with facial nerve involvement due to polio.*

A: Regarding facial nerve involvement after poliomyelitis: It is not common but also not rare. I have seen well over a dozen patients with significant one-sided facial weakness secondary to polio. I have not seen anyone who reported facial weakness early on after acute polio who then had complete resolution of facial weakness and who then found the facial weakness returned during the typical post-polio syndrome years (20-40 years later).

Among the post-polio survivors with chronic facial weakness whom I have known for more than 20 years as a doctor, none have had appreciable or significant worsening of the facial weakness or any new complications from it. Some minor concerns that have occurred include increased drooping of the face and appearance change, some tendency to slur words more and/or work harder on clear articulation, and some increase of minor drooling from the mouth, particularly if there are also new swallowing difficulties at the throat.

If any of these problems were to become significant, I would suggest a consultation and evaluation by a PhD speech and language pathologist who sees patients with dysphagia (swallowing problems) and/or an Ear, Nose, Throat (ENT) surgeon.

Question: *I had non-paralytic polio in 1949 when I was 2. I now wear two leg braces; one on my polio leg for drop foot and the other one on my left leg because I started dragging that foot. My right leg is always very cold to the touch even though it never feels cold to me unless I touch it. Is there any therapy or anything else I can do to get this atrophied leg warm? I wear compression knee socks and sometimes two pairs of regular knee socks and these do not solve the problem. Thank you for all you do to help polio survivors.*

A: You are doing the only helpful thing for cold polio-atrophied legs by wearing layers of warm socks in cooler weather. Try to put the socks on when the leg is at its warmest, like after a hot bath or first thing in the morning before getting out of a warm bed. I would reassure you that the persistent coldness will not lead to other problems, nor is it likely a sign of other problems. I know you stay active and that may be helpful also. ■

Not yet a Member?

Join PHI for just \$30 a year (Subscriber Membership) and receive your own copy of *Post-Polio Health* four times a year (February, May, August, November), plus eight *PHI Membership Memos* via email. For \$55 (Subscriber Plus Membership), join PHI and IVUN and also receive *Ventilator-Assisted Living* via email six times a year (February, April, June, August, October, December) and six *IVUN Membership Memos*.

You can join online at <http://shop.post-polio.org> or send (or fax, 314-534-5070) this form to: Post-Polio Health International, 4207 Lindell Blvd, #110, Saint Louis, MO 63108-2930 USA. Questions? 314-534-0475 .

\$30 Subscriber

Post-Polio Health (quarterly)

\$55 Subscriber Plus

Both *Post-Polio Health* (quarterly) AND *Ventilator-Assisted Living* (bi-monthly)

Name _____

Affiliation _____

Address _____

City _____ State/Province _____

Country _____ Zip/Postal Code _____

email _____

Phone (include area/country code) _____

I am enclosing a check for \$ _____ made payable to "Post-Polio Health International." (USD only)

Please charge \$ _____ to this credit card:

VISA MasterCard Discover

Card No. _____ Exp. Date _____

Name on Card _____

Signature _____

POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

4207 Lindell Boulevard, #110
Saint Louis, MO 63108-2930 USA

Call for Proposals

The Research Fund of Post-Polio Health International is looking for researchers interested in studying post-polio myelitis or neuromuscular respiratory insufficiency.

The call for funds to be dispensed in 2016 is broad. The Research Committee is asking for proposals to study the cause(s), treatment and management of the late effects of polio or neuromuscular respiratory insufficiency or to explore historical, social, psychological and independent living aspects of living with polio or with long-term mechanical ventilation.

The research must have the potential to improve the lives of polio survivors or ventilator users. Preference will be given to innovative or original research, which leads to new interventions, products, methods or applications.

The maximum amount of the award for one year is \$50,000. PHI will accept proposals that require two years to complete for a maximum of \$100,000.

Inside *Post-Polio Health*

Vol. 31, No. 3, Summer 2015

Effects of Whole Body Vibration on People with Post-Polio Syndrome ... 1

Multicenter, Multi-country Study Underway ... 3

Study of Poliovirus Genome in Patients with Post-Polio Syndrome ... 6

Promoting Positive Solutions ... 8

The “Request for Proposals Guidelines” can be downloaded from PHI’s homepage, www.post-polio.org, or from the “Research” area at www.post-polio.org/res/rfcall.html. The “Applicant Information,” required when submitting a proposal, is also available for download.

The deadline for submitting proposals is October 1, 2015.