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PHI Awards \$100,000 Research Grant to Team from Academic Medical Center, University of Amsterdam

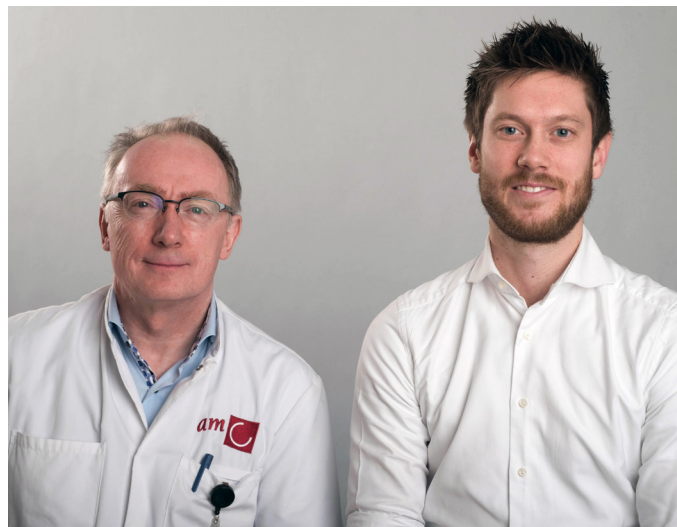
The Research Fund of Post-Polio Health International (PHI) has awarded its tenth grant to a team of researchers from Academic Medical Center Amsterdam in the Netherlands. The two-year, multicenter study will be led by Eric L. Voorn, PhD, and Frans Nollet, MD, PhD. Dr. Voorn is a Postdoctoral Researcher in the Department of Rehabilitation. Dr. Nollet is head of the Department of Rehabilitation and Amsterdam Movement Sciences.

The study, entitled “B-FIT! A guideline to individualized exercise in post-polio syndrome,” will evaluate the effectiveness of a personally tailored aerobic training program according to the B-FIT training guideline on physical fitness, physical functioning and quality of life of individuals with PPS in the United States and the Netherlands, as well as evaluate patient and healthcare professional satisfaction with the use of the training guideline. B-FIT includes a training program that is highly personalized in that it is adapted to the individual's needs and capacities.

B-FIT was successfully applied in a pilot study in rehabilitation centers in the Netherlands, demonstrating its potential for clinical practice. However, a more comprehensive study was needed in order to determine the effectiveness of the B-FIT training program to improve physical fitness in those with PPS and determine its usability on a larger international scale.

The training program attempts to identify the optimal approach to exercise, finding a balance between improving physical fitness and preventing the overburdening of polio-affected muscles. If proven effective, the researchers hope the B-FIT training program will be able to assist healthcare professionals in the prescription of a personalized exercise program resulting in improved rehabilitation care for polio survivors.

Collaborating partners in the study include Burk Jubelt, MD, SUNY Upstate Medical University, Syracuse, New York; Susan Perlman, MD, University of California, Los Angeles; and Marinos Dalakas, MD, Thomas Jefferson University, Philadelphia, Pennsylvania. The study is expected to be concluded by the end of 2019.



Frans Nollet, MD, PhD, (left) and Eric L. Voorn, PhD

“We consider it a great honor to receive the PHI grant,” said Dr. Nollet. “It will mean an important boost to continue and expand our PPS research.”

Previous Research Fund Grants

Beginning with its first grant in 2001, PHI's Research Fund has awarded nearly half a million dollars for research dedicated to the management of neuromuscular respiratory insufficiency or the late effects of polio or to exploring historical, social, psychological and independent living aspects of long-term home mechanical ventilation or living with polio.

Opportunity to Participate in Research

Are you (or someone you know) an older adult with a long-term mobility impairment?

Researchers at the University of Illinois are conducting an interview study that explores the everyday challenges older adults with long-term mobility impairment experience as they age, and how they manage those challenges. Their goal is to design interventions and technologies to help older adults age in place.

This is a one-time study that consists of two parts:

1) Questionnaires

and

2) An interview.

Each part will take roughly an hour to complete. All aspects of this study can be done remotely: the questionnaires can be completed online and the interview remotely via phone call or video call. Participants will be compensated \$30 in the form of a credit on Amazon for their time.

Participants must:

- Be between the ages of 70-79 years.
- Self-identify as being mobility impaired: Using a mobility aid (i.e., cane, crutches, wheelchair, walker or scooter) and having serious difficulty walking or climbing stairs (or unable to walk or climb stairs).
- Have had the mobility impairment prior to the age of 50.
- Be fluent in English.
- Live in the United States.

If you are interested in participating, contact the project coordinator:

Lyndsie Koon, PhD

HFA-Lab@illinois.edu, 217-300-5445

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Editor: Brian Tiburzi, MA
editor@post-polio.org

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

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

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Executive Director
Brian Tiburzi, MA
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
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Away temporarily?

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

The Ninth Award (2016)

“Cough Assist: use education needs, health service utilization and outcomes”

Louise Rose, RN, MN, PhD, Associate Professor, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, Ontario, Canada, and Mika Nonoyama, RRT, PhD, Assistant Professor at the University of Ontario Institute of Technology

The Eighth Award (2014)

“Poliovirus genome in patients with post-polio syndrome (PPS):

Defining virus mutations by novel genome sequencing methods and investigating possible treatments with antiviral antibodies and drugs”

Antonio Toniolo, MD, FAMH, University of Insubria, Varese, Italy

The Seventh Award (2013)

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

Carolyn Da Silva, PT, DSc, NCS, Texas Woman’s University, Houston, Texas

The Sixth Awards (2011)

“Characteristics of poliomyelitis and post-polio patients among Jews and Arabs in Jerusalem”

Zeev Meiner, MD, and Isabella Schwartz, MD, Hadassah Medical Center, Jerusalem, Israel

“The Role of Oral Glutathione in Improvement of Health Outcomes among Persons with Late Effects of Poliomyelitis”

Claire Z. Kalpakjian, PhD, MS, University of Michigan, Ann Arbor

The Fifth Award (2009)

“Persisting Noninfectious Fragments of Poliovirus in PPS Patients: Virus Detection and Susceptibility to Antiviral Drugs”

Antonio Toniolo, MD, FAMH, University of Insubria, Varese, Italy

The Fourth Award (2007)

“Regulatory T Cells as a Biomarker of Post-Polio Syndrome”

Rahnuma Wahid, PhD, University of Arkansas for Medical Sciences, Little Rock, Arkansas

The Third Award (2005)

“Timing of Noninvasive Ventilation for Patients with Amyotrophic Lateral Sclerosis”

Noah Lechtzin, MD, MHS, Johns Hopkins University, Baltimore, Maryland

The Second Award (2003)

“Women with Polio: Menopause, Late Effects, Life Satisfaction and Emotional Distress”

Claire Z. Kalpakjian, PhD, MS, University of Michigan, Ann Arbor

The First Award (2001)

“Ventilator Users’ Perspectives on the Important Elements of Health-Related Quality of Life”

Mark Tonack, MA, Dina Brooks, PhD, Roger Goldstein, MD, West Park Health Care Centre, Toronto, Canada;

Audrey King, MA, The Center for Independent Living in Toronto

*More information about each grant can be found at
www.polioplace.org/phi-funded-research*

2017 Bay Cliff Post-Polio Wellness Retreat Generates Renewal of Mind, Body and Spirit

Sunny Roller, MA, Ann Arbor, Michigan

On a deep-frozen wintery day in Michigan, it's revitalizing to rekindle warm memories of our Bay Cliff Post-Polio Wellness Retreat last September. Post-polio wellness retreats have been held for the past 11 years at the Bay Cliff Health Camp in Michigan's Upper Peninsula. Each has been a week-long holistic wellness program that focuses on the health and well-being of polio survivors. The exceptional feature of this wellness retreat's format is that it has been specifically designed to zero in on the unique and little-known needs of people who had polio and who are now growing older with polio's late effects.

Located 28 miles northwest of Marquette, Bay Cliff's woodland getaway is not only beautifully situated on the shores of Lake Superior, it is completely wheelchair accessible. This retreat's venue and program design intentionally foster a safe haven for open exchange, where everyone is encouraged to feel like part of a supportive family of friends, ready to learn and have fun.

This past year, over 40 polio survivors, along with friends and spouses, participated in the retreat's full range of daily programs that were designed to address wellness of mind, body and spirit. Everyone received individualized attention from a blend of volunteer retreat facilitators—post-polio physicians, counselors, nurses; physical, occupational and recreational therapists; members of the clergy, and those from a wide range of other helping vocations.

As my winter reverie brings our Bay Cliff experience into even clearer focus, I realize that we were indeed having smart fun. First, we had intelligently chosen to learn even more about living with a post-polio disability. We were shrewd seekers of good health—reaching out to discover how to incorporate new positive health behaviors into our lives. Every day we attended educational programs. Topics

ranged from detailed information about post-polio syndrome, to exercise, to meditation, to tapping into our spiritual strength. People learned all kinds of things and came to practical and often profound new realizations.

Here's practical information that Mark discovered:

"Powered chairs and crutches are much more effective in the camp environment than manual wheelchairs. There is too much stress put on the shoulders with the manual lightweight chairs, especially when traversing the inclines around the camp."

Perhaps as powerful, was the support and information that post-polio participants exchanged with each other. We openly shared life experiences and many of our well-earned secrets for living a successful life with a disability.

Bonnie revealed:

"I find as I am held captive more and more by my advancing disability, more adjustments have to be made, and sometimes I am not sure how or what to do. Or sometimes, I am not aware that adjustments even need to be made because I am in denial or just have not come to the conclusion that things have changed. At some points, I find I am owned by regret rather than taking action (or maybe less action in the case of PPS).

"Being at Bay Cliff is so freeing ... no pretenses, and I am informed by my own regret rather than being owned by it. Sometimes, it takes being with others who share your issues to realize they need confronting, and I learn lessons on how to confront them in a safe, healthy way."



As people shared many of their personal challenges and concerns, deeper friendships were nurtured.

Frederick Maynard, MD (who routinely offers expert advice on the late effects of polio in these very pages) continues to be one of our best friends. He not only was a primary founder of the program in 2006, he has also led the program curriculum development and attended each year, providing medical direction and generously answering each person's particular questions.

Throughout the course of each day, he could be seen freely helping retreat participants with medical advice and counsel, whether it was during a planned group educational session or in a spontaneous one-on-one encounter.

As one camper disclosed, "Words cannot express the level of devotion and commitment that Dr. Maynard has for the polio population. I have grown to love and respect him for his efforts, knowledge

and deep understanding of what we are going through. You can see it in his eyes."

We were not only ready to learn; we were also ready to have fun as we gained new knowledge. This often meant taking part in experiential learning opportunities, which were set up to be both engaging and enjoyable. With excellent food served at every meal and recreational activities adapted just for us, for one short week we had become pampered campers and smiling sunrise watchers.

We fished, swam, danced, sang and went on nature hikes. We had lively fun in the beautiful warm weather as we learned important tips on how to stay healthy. Even though most of us are in our sixties and seventies, many of us had first-ever recreational experiences—like learning how to dye silk scarves or discovering how to use a bow and arrow.

continued on page 6

**Cathleen conveyed:**

"I'd never heard of the NuStep and really enjoyed trying and learning it. I thrilled to the recumbent hand-cycling with Don as we flew down a country road incline. He adjusted and fixed a bike to fit me. Dr. Maynard kindly helped me walk into Lake Superior, however briefly!

"There were so many fabulous experiences that I can't list them all. I'd never been fishing before and thoroughly enjoyed that sunny and relaxing afternoon in the pontoon boat on Lake Independence with Max, the expert fisherman.

"I loved the warm pool and helpful lifeguard. I remember the wonderful picnic in the sunny orchard and picking plums afterwards ..."

Others described their retreat experience as:

"... a homecoming ... mellow ... warm ... grounding ... humorous ... enlightening ... expanding ... reflective ... challenging ... flirty ..."

And I am here to report that the positive impact of Bay Cliff can also be long-lasting. Simply rekindling the warm-hearted memories of our retreat has revitalized my own feelings of inspired renewal and loving regeneration. That's a wonderful gift. It's a big bear hug on this very cold winter day. Or, perhaps better said ... it's a big Bay Cliff hug. ■

To learn more about the next Bay Cliff Post-Polio Wellness Retreat go to the Bay Cliff Health Camp website at www.baycliff.org/bay-cliffs-post-polio-wellness-retreat or call the Bay Cliff office at 906-345-9314.

A similar post-polio wellness retreat will be held this year high in the beautiful Colorado Rockies. It will be sponsored by Colorado Post-Polio and Easter Seals Colorado and is titled Colorado Post-Polio 2018 Rocky Mountain Getaway. It will take place from Sunday, August 19 thru Thursday, August 23, 2018 at the Rocky Mountain Village Camp in Empire, Colorado. To get on the mailing list and for more information contact Nancy Hanson, Easter Seals Colorado, 303-233-1666 ext 237, nhanson@eastersealscolorado.org.

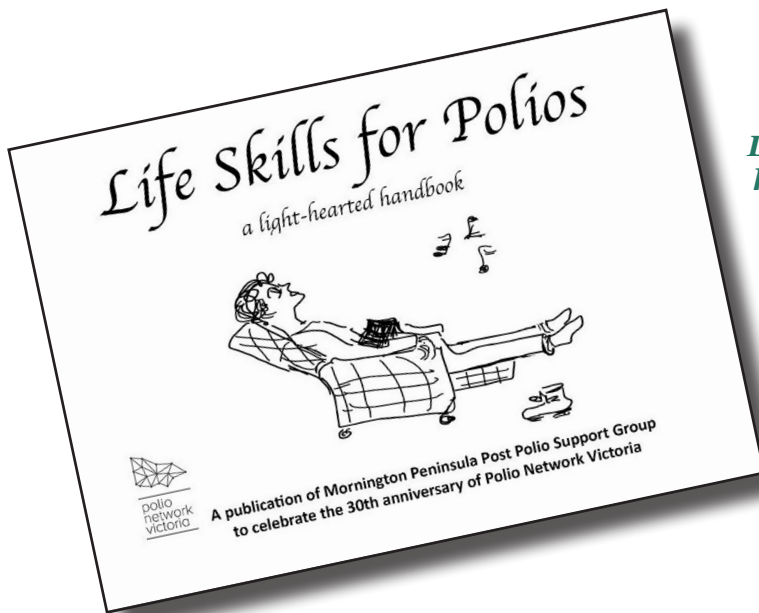
To see additional online articles about past post-polio wellness retreats, check out:

Nourishing Mind, Body and Spirit: People, Pictures and Pasties at

www.sunnyrollerblog.com/nourishing-the-body-mind-and-spirit-the-people-the-pictures-and-the-pasties
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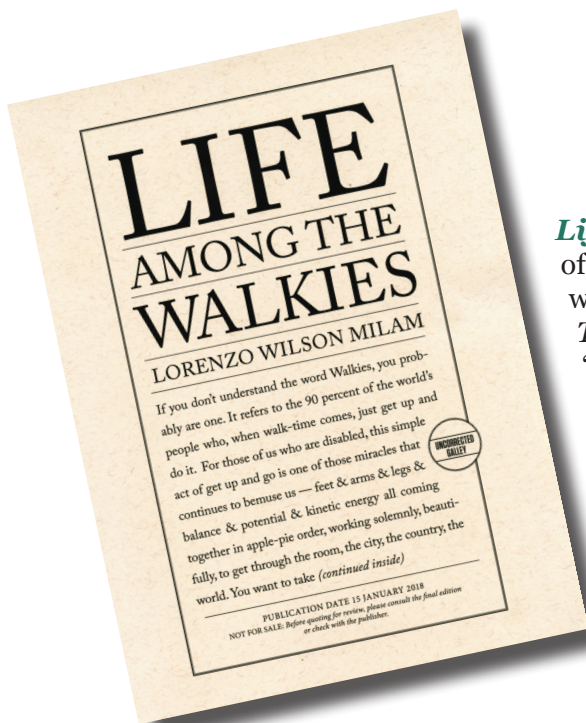
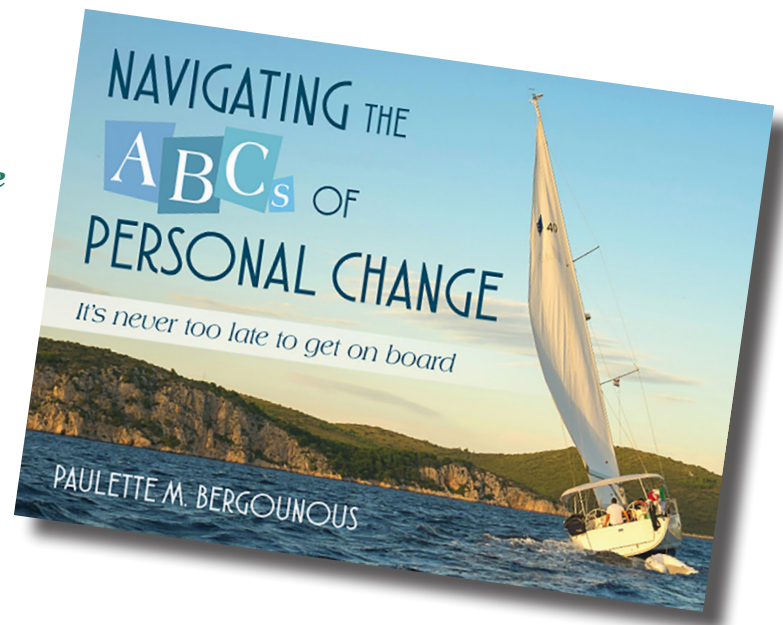
The Colorado Post-Polio Wellness Retreat: Grasping Sweet Thorns in the Rockies at

www.sunnyrollerblog.com/the-colorado-post-polio-wellness-retreat-grasping-sweet-thorns-in-the-rockies.



Life Skills for Polio—a light-hearted handbook by retired Australian journalist, author and polio survivor Fran Henke, explores the themes of Home, Body and Mind—covering downsizing, tips for the kitchen and laundry, plus the big topics of pain, fatigue, exercise and coping with past treatment in the face of the new symptoms. Find out more at www.franhenke.com/untitled. Also listen to a radio interview with Fran on the home page.

Navigating the ABCs of Personal Change by polio survivor Paulette M. Bergounous. According to the author, “[The] book is a way for me to tell my story but also to share the lessons I learned. It is meant not just for polio survivors but anyone dealing with change at any age.” Find out more or purchase the book at <http://navigatingpersonalchange.com>.



Life Among the Walkies by Lorenzo Wilson Milam is a collection of nearly forty essays drawn from his humorous, often-irreverent writings in *The Sun*, *RALPH*, *salon.com*, *New Mobility*, and *The Los Angeles Times*. Milam, a polio survivor, seeks to dispel “this cruel silence,” concerning the subject of suicide and disability and, at the same time, “offer some ways out of the dilemma representing mind and body in deep, often agonizing, conflict.” ■

QUESTION: *Recently, I've noticed that both my polio leg and my "good" leg have been getting weaker. It's getting harder and harder to go even short distances (from room to room in my house, for example). I've used a cane in the past and, more recently, a walker. My doctor wants me to use a motorized wheelchair, and my children agree this would be a good idea. There is no way I'll agree to this! I feel like this is a point-of-no-return. I feel like if I choose to go into a chair, I'll be embarking on the beginning of the end. I just picture all those movies and TV shows where these sad, old people are parked in front of the TV and essentially forgotten. I know this sounds silly. I've heard all the arguments about how it will be safer for me and give me more mobility, but I just can't get past my aversion to wheelchairs. I worked hard to recover from polio, and it feels like I'm admitting defeat.*

Response from Rhoda Olkin, PhD:

Of course you don't want to use a wheelchair. You spent all your life trying not to use a wheelchair. A wheelchair seems like a mark of a serious decline, many more of which will follow. No one can tell you to use a wheelchair, not even your kids.

But you need to use a wheelchair.

So now that we got that out of the way, let me explain. Most importantly, using a wheelchair is not the beginning of the end, but the beginning of a new beginning. This would be a beginning where you could go from room to room without having to think about it; where you could be less fatigued and do more; where you could go to movies and museums and big box stores, even on rainy, slippery, days; where you could cook and do laundry and other quotidian chores without that being your entire energy allotment for the day.

Are there disadvantages to using a wheelchair? Oh, let me count the ways! Insurance is likely to pay for a portion of the wheelchair but not for any means of transporting it. You may need some modifications in the house. You may get patted on the head. Some people may talk down to you. Someone younger than

you will call you "honey" or "sweetie." The wheelchair needs upkeep and repairs, as does any lift on the car.

I know you are averse to what I am saying. I really do get it. Let me suggest a way to try it out. Rent a small electric wheelchair or scooter for a month and use it in the house, out of sight of any witnesses. (A week is not long enough; you will fight it the whole first week.) See what it feels like, notice what you can and cannot do. You don't have to tell anyone—this is only for you. Maybe keep notes each day, so that you are not so swamped with negative emotions that you do not notice the behavioral aspects.

Go by yourself to a grocery store or a big box store that has a scooter, and use it in the store. Again, note what the experience is like both emotionally and physically. (Be sure not to buy more than you can handle when you get home—it is easy to load up a scooter basket, but my guess is you won't have wheelchair access from your car to the kitchen.) I am trying to move you from comparative values (wheelchairs are less valuable than legs for ambulation) to intrinsic values (wheelchairs allow mobility).



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.

Probably right now every fiber of your being is resisting what I am saying. Just know that I am saying all this as someone who went from being ambulatory unaided, to using crutches, to a scooter, to a wheelchair for distance, to a wheelchair in and outside the house, i.e., everywhere. Please seek a knowledgeable professional therapist who can help you make this tough transition.

Response from Stephanie T. Machell, PsyD:

This column is directed to your children, but I hope you'll appreciate it too.

At the age of 87, my dad finally agreed to have a power wheelchair evaluation. Of course, he qualified. The next time I visited, there was no wheelchair. Why not? "It will make me look old," he replied. Because I got my sense of humor from him he laughed when I replied, "Dad, that ship has sailed."

He kept walking and falling for the next two years, until a few weeks before he died. Had he not cancelled it, the wheelchair would have become a place to hang jackets. Or he might have donated it to charity as he did with his braces.

Your dad sounds a lot like mine, and every other polio survivor I've ever known who was told he or she should be using a power wheelchair. All of them feared what this implied, because for them victory over polio meant walking. This made sense in the inaccessible world they were being rehabbed into, where a wheelchair was more than a symbol of dependence and defeat.

Their hard-won ability to walk became part of their identity. It's difficult for someone whose sense of self turns on "Use it or lose it" to accept the need to

"Conserve it to preserve it." But it's not impossible.

Every polio survivor I've known who decided to use a power chair has told me they wish they'd done it sooner, because the benefits they gained were substantial. So, what were these benefits, and how might you use them to help your dad replace his belief that he would be "confined to a wheelchair" with the more accurate "confined without a wheelchair?"

Power chairs extend the user's range, allowing trips to places your dad may have avoided as well as making it easier to navigate his own home. Rather than keeping him from walking, the rest it provides for overused muscles may well improve his ability to walk when he wants or needs to do so. Walking less reduces overuse pain and fatigue, greatly improving quality of life, as does reducing the risk of falling and breaking a polio limb.

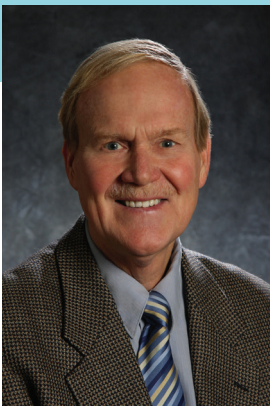
Legs and walking may seem to be what independence is all about. In reality, well-functioning arms and shoulders are more important in daily life. Though walkers are easier on arms than canes or crutches, using a power chair can offer better protection from overuse.

Tell him all this, including how much you worry about his well-being. But most likely he gave you this column and has already read it himself. So give him a kiss and/or hug and say, "It's your decision, Dad. Now that I've read the column, I know it's a big one, but I trust you to make the right one for yourself."

He may still refuse. Or get the chair and use it as a coat rack. Remember, reinventing yourself takes time. ■

Dr. Stephanie T. Machell is a psychologist in independent practice in the Greater Boston (MA) area. She specializes in working with those affected by polio and other physical disabilities. 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: *Recently, my hyperextended leg started going numb. It started with my foot and worked its way up to my knee. When it got so numb that I couldn't walk, I got scared and immediately called my doctor. The doctor said that because my hyperextended leg has gotten worse, any brace I wore would put pressure on a nerve that is on the outside of my knee and causes numbness. I have three braces that I switch between. Whenever I try to wear one, my leg numbs up, and it takes hours to get back to normal. I don't know what I'm supposed to do. I can walk without a brace, but tire much more easily and miss the support it gives my leg. Have you ever heard of this?*

Answer: Your description of numbness progressing up from the foot when you wear a long leg brace to control knee hyperextension is a fairly common occurrence. Your primary doctor is correct that it is due to excessive pressure on the peroneal nerve (also known as the fibular nerve), usually as it goes around the fibular head, which is the bony prominence just below the outside of the knee joint. The first thing to do is report this problem to the orthotist who made the brace. He/she will need to modify it, perhaps with some special padding above and below the bone, to eliminate the excessive pressure on the nerve that builds up when you wear it for very long. This problem is important to solve in order to prevent permanent damage to the nerve; and it sounds like you do need the additional support that the larger brace provides when you are going to be walking very much. Hopefully it can be resolved promptly by the padding or by minor modifications of the brace to make it fit snugger, since some further shrinkage in size of a braced polio leg is common after the first few years of wearing a new brace and/or wearing it more often.

Sometimes the resolution of this problem of excessive pressure on the nerve will require a change in design of the brace; and if this is the opinion of the orthotist, then you should also get an opinion from the doctor who prescribed the brace, who hopefully is experienced and knowledgeable about bracing weak polio legs. Otherwise, you would have to seek out an "expert" on this subject. You might also want to learn more about new bracing options that avoid this problem. A wonderful resource for this is available at www.humangaitinstitute.org where an educational reading is available, entitled "Exploring Leg Bracing Options."

Question: *What is the current thinking on the use of the drug lamotrigine for the stabilization of PPS? Is there data to show it is effective without significant side effects? It has been ordered for me by my neurologist at 100 mg twice daily. I am 81 and reluctant to start this drug as the side effects are very scary, and it is being ordered off-label. Are there any drugs that have been proven effective for post-polio fatigue or muscle weakness?*

Answer: There are no studies that clearly demonstrate a benefit from taking lamotrigine for polio survivors with PPS. There are some reports that it may provide some modest relief of severe fatigue, but it has not been of proven benefit. There are no "placebo-controlled" studies showing a benefit for people with PPS from any drug at this time. At age 81, I would agree with your decision to forego the risk of side-effects for an unestablished modest benefit of symptoms. ■

Thank you for recognizing your friends and loved ones with contributions to the activities of PHI and IVUN and for your generous Membership contributions.

Please contact us if we made an error.

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Inside *Post-Polio Health*

Vol. 34, No. 1, Winter 2018

PHI Awards \$100,000 Research Grant ... 1
2017 Bay Cliff Post-Polio Wellness Retreat ... 4
Promoting Positive Solutions ... 8
Ask Dr. Maynard ... 10

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