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Is the Post-Polio Syndrome Associated with Chronic Poliovirus Infection?

Angelo Genoni, PhD, Konstantin Chumakov, PhD, Antonio Toniolo, MD, University of Insubria, Varese, Italy and Food and Drug Administration, Silver Spring, Maryland, USA

The central message of our study is that post-polio syndrome might be associated with a chronic low-level poliovirus infection caused by the virus type that – at the time of the initial event – had infected each patient. That is, the possibility exists that poliovirus remains in a “quiescent state” in the body for a long period of time.

The conclusion is derived from the study of a cohort of Italian PPS patients (112) and their family members (51), together with non-polio controls (71), and aged polio survivors with “stable polio” (18). Nearly three quarters of PPS patients appear to harbor “poliovirus remnants” (in other words polioviral genomes and low-level virus activity), while survivors with stable polio very rarely harbor poliovirus.

The identity of the poliovirus remnants is being clarified by genome sequencing using novel techniques in collaboration with Konstantin Chumakov, one of the best poliovirus experts of the U.S. Food and Drug Administration. It is believed, but not completely proven yet, that the poliovirus forms persisting in polio survivors represent “mutated” (that is, genetically changed) derivatives of the virulent polioviruses that were infecting the patients at the time of the acute polio.

It is thought that slow virus infection of the nervous and muscular cells may be responsible for the slowly progressive loss of neural and muscular cells and chronic inflammation. A further conclusion of the

study is that poliovirus remnants are not transmitted from PPS patients to their family members. Thus, these poliovirus remnants are not dangerous to the population, nor represent a possible form of reinfection for poliomyelitis.

Finally, the possible infectious etiology of PPS calls for an “effective cure and prevention.” So far, in fact, anti-inflammatory drugs and other treatments have failed in this field. A possible remedy is seen in the administration of intravenous human immunoglobulins (i.e., antibodies derived from blood donors; a form of “passive” immunotherapy). These antibody preparations also contain anti-poliovirus antibodies.

Our work brings the attention of clinicians and the pharmaceutical industry to the need of antiviral agents for treating PPS. New antiviral compounds are being developed for picornaviruses (the virus family that comprises polioviruses), some of them having activity against polioviruses. These novel antivirals might be tested in PPS patients, provided that the pharmaceutical industry is willing to design and finance clinical trials.

Quantitative methods for evaluating the possible efficacy of these drugs are already available at a number of clinical centers worldwide. Investigations in this field could lead to significant progress as seen over the last few years in the successful therapy of cases with chronic liver infection due to hepatitis C virus. ■

This study, “Poliovirus Genome in Patients with Post-Polio Syndrome,” was funded by The Research Fund of Post-Polio Health International. Toniolo and his team also received PHI funds for the initial work on the project in 2009.

For more information: Mid-Study Report: Summary of Poliovirus Genome in Patients with Post-Polio Syndrome, *Post-Polio Health*, Volume 31, Number 3, Summer 2015 (<http://www.post-polio.org/edu/pphnews/PPH31-3sum15p6-7.pdf>).

Baj A, Colombo M, Headley J, McFarlane J, Liethof M-a, Toniolo A. Post-poliomyelitis syndrome as a possible viral disease. *Int J Infect Dis*. 2015;35:107-116. (<https://www.ncbi.nlm.nih.gov/pubmed/25939306>).

WE'RE STILL HERE!

October 9-15, 2016
www.post-polio.org

Family Life!

WE'RE STILL HERE! 2016 Photo Contest

PHOTO CONTEST WINNER!

Bruce Lessard

I can't train and race bikes like I used to, having had to cut back on the training intensity to avoid right leg pain that started occurring in my 50s, which was a suggestion from Dr. Maynard of Post-Polio Health International. That doesn't mean I need to quit. Instead, I'm

making adjustments. I've learned two things: (1) too much exercise causes right leg pain, and may contribute to more serious problems down the road; and (2) inactivity actually leads to pain in my right leg, but a low to modest amount of exercise actually helps to keep my right leg pain-free. So I can still enjoy activities with my family, like mountain biking with my granddaughter, Maggie. I realize I'm pretty lucky compared to many people with post-polio syndrome.



FIRST RUNNER-UP

Bob Andersch

This picture was taken on July 17, 2015 at my daughter's wedding reception at Rock Island Lake Club, Sparta, New Jersey. There wasn't a dry eye in the room. I primarily use a scooter, but I walked to the dance floor with my forearm crutches to dance a father-daughter dance. We danced to Tim McGraw's "My Little Girl."

POST-POLIO HEALTH

Fall 2016

Vol. 32, No. 4

ISSN 1066-5331

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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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and new addresses.

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SECOND RUNNER-UP

Barbara Mayberry

This photo of myself and husband David was taken on August 17, 2013, along the shoreline of Lake Michigan, north of Holland, Michigan. David and I have been riding motorcycles since 1983. We get many second looks as we ride along with my crutch tied onto the side of the motorcycle. Most people assume the crutch is from a motorcycle accident, but if I get a chance to talk to people about it, I always tell them the crutch and left leg brace are the result of polio that I had in 1952 as a five-year-old child.

Some younger people may have never heard of polio, but many who are old enough to remember are surprised that I ride a motorcycle. I like to remind them that my disability has not kept me from doing whatever I decided I wanted to do. Our travels on the bike have taken us to all 48 contiguous states and Canada. We still ride as often as we can.



THIRD RUNNER-UP

Britta Westhausen

As a polio survivor, since 1950, I am still lucky to be able to enjoy all aspects of a family life. My two sons and I do a lot together. We travel, dine together, visit art exhibitions and museums, and share a lot of funny and interesting things when we have the time.

As a visual artist, I have to travel. Last year, I was in Beijing and my eldest son was my “bodyguard;” otherwise it would not be possible. My family are and have always been totally relaxed about my condition.

This photo was taken at the National Aquarium Denmark on September 18, 2016.

FOURTH RUNNER-UP

Mary Ellen Hemby

The below photo shows me with my three-year-old grandson, Bo, in January, 2009. We found a bicycle trailer that easily connected to my power wheelchair!



WE'RE STILL HERE! was established in 2007 by Post-Polio Health International (PHI) as an annual campaign to educate the health care community and the public that there are survivors of polio still in need of healthcare and still making the world a better place for all people with disabilities.

Thank you for your participation in this year's contest! Do you have ideas for next year?

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Joan L. Headley, Post-Polio Health International, St. Louis, Missouri

Post-Polio Health International established its Research Fund in 1995 with a bequest from Thomas Wallace Rogers, a polio survivor and ventilator user from Moline, Illinois. PHI has funded 11 grants over the years. Summaries of the all of the studies, many of which have been published in *Post-Polio Health* and *Ventilator-Assisted Living*, are posted at www.post-polio.org/res/index.html#awa.

The front page article of this issue is a report from the 2014-2015 recipients, represented by lead researcher Antonio Toniolo, MD, Italy. Other recipients reported to PHI recently.

2016-2017

The study currently underway with a completion date of late 2017 is entitled, “CoughAssist: use education needs, health service utilization and outcomes.”

Research coordinators, Louise Rose, RN, MN, PhD, Associate Professor, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, and Mika Nonoyama, PhD, RRT, FCSRT, Assistant Professor at the University of Ontario Institute of Technology and a lecturer in the Department of Physical Therapy at the University of Toronto, Canada, are working with the publically-funded Provincial (Ontario) CoughAssist Program that makes the device and associated equipment available free of charge to ventilator-assisted individuals living at home.

They report that the project is identifying user needs for initial and ongoing education and support for use of the CoughAssist (Philips Respironics) device at home; examining the impact of the Provincial CoughAssist Program on health service utilization, costs and patient-reported outcomes; and exploring user compliance with CoughAssist device prescription.

Nonoyama states, “We have completed interviews for four new users, four new caregivers, five established users and four established caregivers of the CoughAssist device.”

The group is also following new users of the CoughAssist for a nine-month period to collect data on healthcare utilization and costs, patient-reported outcomes and usage. The research coordinator for the project moved to another position, so there has been a delay in recruitment for this part of the study until the job is filled.

2013

“Effects of Whole Body Vibration on People with Post-Polio Syndrome,” a study led by Carolyn Da Silva, PT, DSc, Board Certified Neurologic Clinical Specialist, Texas Woman’s University in Houston, Texas, was completed and reported in *Post-Polio Health* (Volume 31, Number 3) Summer 2015.

Fifteen participants (14 with post-polio syndrome, one polio survivor with no PPS) completed a randomized cross-over experimental design study investigating whole body vibration. Each survivor participated in eight sessions within a four-

week period of a low-intensity protocol and eight sessions of a high-intensity protocol, with the order randomized.

Overall, the participants reported significantly less pain severity. The group that started with the higher intensity protocol also walked significantly faster. No significant changes were found in measured leg muscle strength, walking endurance, or self-reported muscle cramping, fatigue, sleep quality or pain interference.

Dissemination of the results included a published abstract with poster presentation at the American Physical Therapy Association Combined Sections Meeting, February 2016 in Anaheim, California. The manuscript is currently under scientific peer review by one journal and has been submitted to another.

Da Silva used this pilot study to help justify a larger federally-funded grant. This study, if approved, will be a home-based whole body vibration study (randomized control trial) of post-menopausal women who are polio or stroke survivors, looking at their bone mineral density, activity levels, pain, etc.

Da Silva adds, “I have also presented the results when training entry-level Doctor of Physical Therapy students, post-professional neurologic clinical physical therapist residents, and physical and occupational therapy staff at local out-patient clinics.”

2011

“The Role of Glutathione in Health Outcomes Among Persons with the Late Effects of Poliomyelitis” was completed by a team at the University of Michigan led by Claire Kalpakjian, PhD.

“Essentially, the glutathione intervention had no effect on anything. We concluded that given the high sedentary behavior of survivors in the study efforts may be best served by interventions to increase physical activity,” says Kalpakjian.

The glutathione study has been a challenge for them to publish. It has been rejected twice based on too small a sample and null findings. Twenty people is fine for a pilot study, but there is “not much to take away.”

Kalpakjian reports, “We are trying a third journal, because it is a well-designed little study.” One word of caution from the research team: “We were rejected by one journal because we had published a summary in *Post-Polio Health*.”

Kalpakjian also received PHI funds in 2003 for “Women with Polio: Menopause, Late Effects, Life Satisfaction and Emotional Distress.” That study resulted in two publications: “Quality of Life and Menopause in Women with Physical Disabilities” by Kalpakjian, C., Lequerica, A. in *Journal of Women’s Health*, 2006:15(9):1014-27 and “Hormone replacement therapy and health behavior in postmenopausal polio survivors” by Kalpakjian, C., Riley, B., Quint, E., Tate, D. in *Maturitas*, 2004: 48(4): 398-410.

Next call for proposals

PHI is scheduled to award its next grant at the end of 2017 for work done in 2018. The deadline to submit a proposal is October 3, 2017. The guidelines and requirements are posted at www.post-polio.org/res/rfcall.html.

Status of The Research Fund

Funds donated to The Research Fund are sequestered and invested in an account overseen by the Board of Directors of Post-Polio Health International.

As of October 10, 2016, the fund contains \$713,000 of which \$84,000 is committed to projects through the end of 2017.

Donations appreciated and accepted

Many of the donations come from family members and friends of polio survivors as a tribute to them upon their death. PHI is honored to receive the gifts given out of love and respect for lives well lived.

Donations may be given online at <http://shop.post-polio.org>, a secure area. Gifts may also be mailed to Post-Polio Health International, 4207 Lindell Boulevard, #110, Saint Louis, MO 63108. Please write “Research Fund” on the memo line of the check.

Final thoughts

I attended the *Australasian-Pacific Post-Polio Conference – Polio: Life Stage Matters*, in Sydney September 20-22. One of my presentations was called “Post-Polio Research: Why and What?” The PowerPoint is online at www.post-polio.org. (If you do not have internet access and would like a copy, contact 314-534-0475.)

The abstracts from the Australasian Post-Polio Conference are in the *Journal of Rehabilitation Medicine* as a PDF and also accessible at www.post-polio.org.

Brian Tiburzi, Post-Polio Health International, also attended and filmed several presentations, including the above-mentioned one, Dr. Toniolo’s update on his team’s research and the presentation, “IVIg as a treatment for post-polio syndrome: trial results,” by Prof. Frans Nollet, MD, PhD, University of Amsterdam, Academic Medical Centre.

They will be posted on www.polioplace.org and shared with Polio Australia for their site, which is scheduled to post the PowerPoints of those presenting who gave their permission. ■

It Is Complicated and Important: Payment for Vents

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

Post-Polio Health International does parallel work as International Ventilator Users Network (IVUN). It publishes *Ventilator-Assisted Living*, a bimonthly e-newsletter, the *Resource Directory for Ventilator-Assisted Living*, and compiles www.ventnews.org and www.ventusers.org.

We have been following and reporting in *Ventilator-Assisted Living* the unending battle with the Centers for Medicare and Medicaid Services (CMS) to assure that they pay for the correct breathing devices needed in the home by people who are beneficiaries of Medicare and Medicaid. In the case of polio survivors, it is the correct device needed to support their breathing due to respiratory muscle weakness.

Historically, polio survivors used negative pressure ventilators (e.g., iron lungs and chest cuirasses) powered by electric motors. Next came the basic volume ventilators (e.g., PLV-100, 102), which replaced the older machines and were used noninvasively by polio survivors experiencing new breathing muscle weakness. With the development of bi-level devices such as the “BiPAP,” offering an inspiratory assist (breath) and a lower pressure assist while breathing out, it was prescribed to many for night-time use. It has not been approved by the FDA for life support or for use with a tracheostomy.

Consequently, the machine is less expensive. When deciding payment to home healthcare companies, the CMS logically decided on a lower rate and to not confuse them with a “true vent” that

was for life support and more costly, they called them respiratory assist devices (RADs). RADs is a term that is not used by the FDA when approving devices nor a term used by researchers when studying the benefits of the devices. Simply, respiratory assist devices is a term used by CMS and not recognized in the clinical literature.

What happened next: Manufacturers continued to develop more complex machines that could “do everything.” Health professionals in Europe wanted one machine that could be used during the duration of a person’s illness. When the multi-mode devices (e.g.

Trilogy, LTV Series, Newport) were approved for payment, the payment code assigned was the one that paid the most because the machine could be used as life support.

What happened in reality is that many of the machines were prescribed for conditions that used the CPAP or bi-level mode, which the machine could provide. (The CPAP mode is approved for treatment of obstructive sleep apnea while the bi-level modes are for distinctly different, more problematic scenarios.) Even set at the other modes, the home healthcare companies received the higher payment as if it were for life support.

Another factor in the increase in the use of the code was that it was much easier to medically qualify for the “Cadillac” device than the more appropriate “Chevy/bi-level device.” Additionally, many receiving the devices were diagnosed with COPD, shifting from

In the case of polio survivors, it is the correct device needed to support their breathing due to respiratory muscle weakness.

used mostly by individuals with neuromuscular conditions to those with respiratory conditions.

The payment for the E0464 code and combined expenditures *skyrocketed* 89-fold from 2009-2015 (\$3.8 million to \$340 million).

CMS noticed.

Their first act, starting January 1, 2016, was to simplify the codes from five to just two. They are E0465

– home ventilator, any type, used with invasive interface, (e.g., tracheostomy tube) and E0466 – home ventilator, any type, used with non-invasive interface, (e.g., mask, chest shell). They lowered

the monthly payment to home healthcare companies by about 33%. (A side benefit for ventilator users is that their 20% co-pay is also lowered.) I have not seen data as to the results of this move.

Meanwhile, Phil Porte, Executive Director of National Association for Medical Direction of Respiratory Care (NAMDRC) reported in the March 2016 *CHEST Physician* that it continues to work with Centers of Medicare and Medicaid (CMS) and interested parties to address issues related to home mechanical ventilation (HMV) and bilevel/RADs (respiratory assist devices).

As NAMDRC explains, Medicare home mechanical ventilation policies are outdated and do not reflect the state-of-the-art standard of care. For example, the Medicare policies have not incorporated the latest thinking (backed by research) on the use of a ventilator using noninvasive ventilation rather than always requiring ventilator use with a tracheostomy.

Additionally, many times they incorrectly interpret the guidelines to mean that a ventilator is only for those in danger of death, aka as the “imminent death requirement.”

For more than two years NAMDRC, with additional help from the American Association of Respiratory Care and the American College of Chest Physicians, has attempted to work with CMS and submitted a reconsideration of the

current Medicare National Coverage Determination for home ventilators, including bi-level devices, to CMS. The group presented rationale and documentation and waited and waited.

NAMDRC and others have attempted to work with CMS ... The only recourse is to go to Congress and change the law. That will be a difficult task but necessary.

Just this month, CMS responded saying it will not move forward on the request saying, “As stated in the FR Notice, in the event that we have a large volume of NCD requests for simultaneous review, we prioritize these requests based on the magnitude of the potential impact on the Medicare program and its beneficiaries and staffing resources.”

The only recourse is to go to Congress and change the law. That will be a difficult task but necessary. Work has begun.

Grassroots assistance will be needed.

To be involved, connect with IVUN at info@ventusers.org and www.ventusers.org or www.ventnews.org. ■

QUESTION: *As I get older with polio, my friends and family get older and have new ailments. They see me as just another person with a cane, but I think of it differently. I feel isolated and misunderstood. What are your thoughts?*

Response from Rhoda Olkin, PhD:

I hear you! It can be frustrating when our contemporaries see us as just another aging person with typical aches and pains and mobility issues. But there is a difference between having a disability and then aging, and aging then acquiring a new impairment.

Some of those differences are positive: we are used to coping, we have developed compensatory mechanisms, we are more likely to be open to using assistive technology, and we have insider knowledge about accessibility and assistive devices. Many of us have joined support groups, and taken steps in the home for fall prevention.

But some of those differences are not so positive: we are starting the aging process with weakness and fatigue already in effect, our incomes might be less due to retiring earlier or cutting down work hours, our expenses might be more from housing modifications and assistive device purchases and upkeep, and additional impairments compound existing limitations.

For polio survivors in particular, we have the issue of diminishing numbers, and less familiarity with polio on the part of the public. And we may feel less sympathetic with our peers who have new ailments (“You’ve lived with this for all of five minutes, quit whining!”).

They didn’t experience childhood with a disability, adolescence with a disability, dating, partnering and parenting with a disability. They don’t have early medical experiences, some of which were traumatic. They haven’t faced the daily

microaggressions people with disabilities experience. And when someone asks them “What happened to you?” the answer garners sympathy, not the quizzical or frozen looks that we get when we say “I had polio.”

But all of this leaves you feeling isolated and misunderstood. Truthfully, it is very hard for those without disabilities to really understand what the experience is like. The ones with new ailments may think they get it, but inside you know they really don’t, and this alienates you.

There are no easy answers to this, but there are ways to cope. First, don’t expect friends to get it. They won’t; they can’t. This is why there are support groups for polio survivors, this newsletter and PHI.

Second, take time to admire in yourself the strengths you have built from surviving polio. Are you more resilient? Better able to cope with pain? Do you have more knowledge about managing fatigue?

Third, remember that socialization is a part of living well longer. Friends may not be able to supply the kind of understanding we think we need, but stay social. Have different groups for different activities – the one you talk to when you are blue, the one you go to movies with, the one who will get you a few things at the farmer’s market, the one who asks how you are.

Fourth, volunteer to help others. Studies suggest that altruism is one of the traits associated with happiness. For example, in one study people were given money, and those who spent it on someone else had reduced heart rates, compared to those who spent the money on themselves.



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.

Fifth, consider getting a kitten! Despite their reputation for aloofness, they like to snuggle, give you unconditional positive regard, and are fairly low maintenance.

Response from Stephanie T. Machell, PsyD:

Because the outward appearance of your post-polio syndrome and their normal aging is similar, your family and friends may be doing what everyone does – assume we know based on our own experience how another person feels. When it works it allows us to feel we understand and support others and are in turn understood and supported. It works best if our experiences really are the same.

Of course, no two people have the exact same experiences. If the differences are small, setting them aside is easy. As the differences grow, so does the possibility that what was meant to be reassurance that you are part of the community of your (aging) peers ends up with you feeling the other person not only doesn't have a clue but is dismissing your experience – and you.

Your family member or friend may also be threatened by the changes he or she sees in you, especially if those changes affect your relationship. For example, the spouse who enjoyed physical activities with you wants to believe that the exercise will be equally good for both, rather than facing the possibility that afterwards you'll need a week to recover. The friend who now uses a cane but can still shop for hours wants to believe you can do the same. Either or both might believe that telling you about their experience of aches and pains will act as encouragement for you to try harder and to act and feel more "normal."

Instead it, like the empathic mismatch, leaves you feeling isolated and misunderstood. When their well-meaning efforts fail to provide comfort and support, or to cajole you into engaging in your previous activities, your family member or friend may feel confused and frustrated, maybe even angry. Unaddressed, the feelings grow on both sides and may jeopardize the relationship.

Once you've been misunderstood you may be reluctant to try to share more about your experiences. But doing this is key to overcoming your isolation and to maintaining the relationships. Because you are likely to feel even more vulnerable now, it's even more important to be mindful of remaining nondefensive and using "I" statements to explain the ways your experiences differ from the assumptions your significant others are making.

But even if you are able to communicate clearly and calmly, not everyone in your life will be equally willing or able to listen. Some may never get it, and you may have to decide how or if you can have a relationship with someone who is unwilling or unable to understand your experience.

If that person is someone whose understanding is critical, like a spouse, you can try bringing him or her to appointments. Hearing a medical provider or therapist explain the ways PPS differs from normal aging can be easier and less threatening than hearing it from you. Reading the same information from an objective source like PHI's *Post-Polio Health* and websites might give your family member time to metabolize and integrate it into their worldview. ■

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: *After several weeks when my polio-affected right leg began to swell, beginning at the foot and now up into the knee, a vascular physician diagnosed the condition as lymphedema and referred me to physical therapy. The swelling decreases only slightly after sleeping all night, even with my legs elevated. My ability to exercise (walk) is not practical having great instability and imbalance. I also have symptoms of neuropathy in both feet contributing to lack of balance. I do use a cane.*

In 1949, my right ankle underwent a triple arthrodesis with a tendon transfer, which really was a great help although I have had to go to a supportive in-shoe ankle/foot brace to avoid tripping.

My question becomes, is the diagnosis of lymphedema something to be expected and what treatment or medication protocol would be appropriate?

A: Lymphedema is a fairly common complication in a paralyzed lower limb, particularly as people age, if there are any open sores on the feet/ankles from minor/major traumas, and/or there is dependent swelling from at least some degree of venous insufficiency.

It is important to treat lymphedema vigorously after it is first diagnosed, because further complications can occur and the longer it is present, the harder it is to treat and sometimes resolve.

Vigorous treatment involves “elevation with specific message” as a one-to-three times per day regimen that can be taught by a “lymphedema therapist specialist” (usually a PT or OT) to a family member or friend.

Additionally, the limb must be wrapped with specialized materials between treatments. Sometimes the therapists must also utilize Jobst pumping sleeves as a specific frequent treatment until the limb circumferences measurements stabilize. Then, one must order custom-sized compression garments that are worn when one will be sitting up with legs dependent.

The vigorous treatment regimens can be time consuming and expensive but are worth it in the long run, and usually aren’t too intrusive of time after one-to-three months. Feel free to share these thoughts with your doctors or therapists.

Question: *I am 66, had polio in 1951 or ‘52, and to my knowledge the only part of my body impacted was my left leg with paralysis in the quadriceps. I have always been physically active. Even now, I exercise four to five days a week and play golf when weather permits.*

I wore a brace – KFO – in high school to straighten out my left knee, and until about ten years ago, basically used the brace only to play golf, as it locked the knee and permitted me to follow through on my golf swing and to walk golf courses. Without the brace, I probably could walk about a quarter of a mile before extreme fatigue set in.

With the advent of hip issues in the past, my physical therapist suggested I use the brace more frequently as it gave me better posture/alignment and it took pressure off of my good (right) leg.

Eleven years ago I had hip replacement surgery on my right side, and my recovery was excellent. Since using the brace I have noticed an improvement in my back pain – practically non-existent – all of which is great. BUT, I can’t walk without the brace without having to hold in my knee to keep





it from buckling. (I seem to be able to ride the exercise bike as well as before the hip surgery and walking distances with the brace is still not a problem.)

Here is the question: Is the increased inability to walk without the brace due to a dependence on the brace or simply due to increased age and post-polio issues?

Pain isn't an issue – never really has been (other than my good hip before the surgery). Most muscle pain that I have is usually resolved through exercise, and I seldom take anything other than an occasional ibuprofen.

If it is due to increased dependence on the brace, is there something I can do to retrain myself so that I can walk some without the brace? I miss the freedom of not having to wear the brace all the time.

A: Your question brings up several recurring issues for aging active polio survivors. It is common that arthritis develops in a polio survivor's stronger leg. You were wise to take your therapist's advice and use the KFO regularly during and after your recovery from the hip surgery.

If you now have a safe, pain-free and functional walking ability, albeit with the KFO, your primary goals have been met.

Your concern that your ability to walk without the KFO is now worse is understandable, but probably can't be significantly altered (at least not without a lot of time and effort and with questionable results, particularly lasting results).

What has most likely happened is that your "post-polio syndrome" weakness in the right quadriceps (the muscle most involved from your original polio infection) has worsened, both as a result of time and age as well as by several months of only walking with the brace which led to less vigorous regular contractions of that muscle.

Once a chronically weak post-polio muscle, particularly the quadriceps reaches the point that it cannot stabilize the knee joint, it cannot regain sufficient strength to do this function again, at least not without assistance, such as pushing on the thigh with your hand during stance on that leg.

My advice would be to "count your blessings" and go on with your life using the KFO and having it become part of you and being sure it is well-maintained and modified as needed to be maximally comfortable and minimally intrusive. ■

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