

On Losing A Polio Mom

Audrey King, MA, Toronto, Ontario, Canada, king.aj@me.com

When you are a child you think like a child, like the 9-year-old I was.

Boxed in an iron lung – trapped in a bed, the horror of food at mealtimes, resolving not to cry during therapy, saying goodbye yet again to those who mattered most. Those were the day-to-day dramas that filled my head. There were also joys: getting up first time in a wheelchair, a picnic with parents, floating to that sweet spot in the therapy pool where staff couldn't reach me – such a powerful surge of pleasure, a momentary autonomy.

I didn't think about survival or walking again, about the weight of lost dreams, life-long responsibility and dependence. I was but a child.

I had no idea of such things until I grew older, eventually discovering my mother's diary of those early polio years (life threatening illnesses, her fight to get me

in school, battling authorities, acceptance) and, many, many decades later, finding my own self in the place she once was as a parent. It hadn't been easy for her, a mother of four with an often absent father and no community supports at the time. It wouldn't be easy for me.

The role reversal was gradual. My mother lost her energy and abilities slowly. The changes were so subtle others could not see them, and at times I wondered if the problems I saw were imagined. At first I was puzzled, frustrated, even angry at her illogical, independent behavior. I had no knowledge of aging or early dementia. Once I began to understand and to recognize some of my own tenacious traits, to see myself in her, many situations became humorous rather than helpless and much more manageable.

As adults, our mother-daughter relationship had always been one of autonomy and respect for each other. We lived together with separate lives, friends and interests. We had no difficulty encouraging and supporting each other's interests in traveling and exploring new ventures. I was the wage-earner who went out to work each day. She was the homemaker. In many ways, we were the best of friends.

We discussed major decisions, including what she wanted to do as she got older. I needed to know her choices so that I could honor them, but she could not, would not, broach the subject. I did not want to take over or make decisions for her. Lurking in my own past was the awful knowledge of what it feels like to lose autonomy and control over your own life and circumstances, to have others assume what they think is best for you.

If my mother wanted to move to a retirement residence or ultimately a nursing home, we could begin the process together, but she could not, would not, decide and the months and years ticked by. We finally



Maisie Jean (Ramsay) King, mother of Audrey King.



Joan L. Headley,
Executive Director, PHI

Save the Date for Promoting Healthy Ideas: PHI's 11th International Conference

Saturday, May 31, 2014 – Tuesday, June 3, 2014

PHI and International Ventilator Users Network (IVUN) look forward to greeting old and new friends in St. Louis, Missouri, in late spring of 2014. For the 11th time since 1981, we are gathering the survivors of polio and users of home mechanical ventilation, their families, health professionals, researchers, service providers and related organizations to collectively assist polio survivors worldwide to live a better life by **Promoting Healthy Ideas**.

Health in its broadest definition includes not only the physical, but also the emotional, social, psychological and spiritual. Featuring “health” in our name when we changed it in 2003 was deliberate. People who had polio are much more than their untypical body, and “to enhance life and independence” we need to pay attention to all aspects of health.

First things first: To build a program with a theme of “Promoting Healthy Ideas,” we need to know specific issues you want addressed. For example, are you aging solo? Have special concerns as you age alone? Special issues related to using home mechanical ventilation? Did you have polio in another country, but now live in the United States? Are there cultural issues to discuss? Have you found a healthy solution that you want others to know about and try? Are you a health professional with expertise to share with your colleagues and polio survivors?

We will offer sessions that are educational, interactive, exploratory and fun. You are invited to send your ideas for the program to director@post-polio.org (or via the mail) for consideration by the Planning Committee. We will use all the ideas that we can because we want you help us be *relevant to you* as a Member.

Others ways to help: We welcome partners to support **Promoting Healthy Ideas: PHI's 11th International Conference**. Do you manufacture products that contribute to the health and independence of survivors and vent users? Can you host a lunch, exhibit your products or sponsor the attendance of a polio survivor? Could you donate printing or videotaping services so PHI can distribute the information to our Members and to the larger post-polio community? Do you have others ways you can help? Give me a call.

I am guessing that you have learned over the years that if you don't educate yourself and make your own decisions, someone will make them for you.

Here is your chance. Help us decide what topics are the most pertinent, so we can gather or create the information.

Our International Conferences are always described as a life-changing experience. So mark your 2014 calendar and plan to attend! ■

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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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Away temporarily?

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

Navigating the Seating and Mobility World with Post-Polio

Sara Kraft, PT, DPT, NCS, ATP, Assistant Professor, Medical University of South Carolina, Division of Physical Therapy, College of Health Professions, kraftsv@musc.edu

Navigating the seating and mobility world can be daunting for many with post-polio syndrome. Issues with scoliosis, back pain and even pressure problems can be quite serious for the person living with post-polio. If using a wheelchair, the solutions can be manageable and more easily rectified by customizing seat cushions or wheelchair backrests.

For those who are still walking, the solutions may not be so clear-cut. Walking is an activity that many take for granted but is a vital component to both quality of life and health. When problems such as scoliosis, back pain or pressure problems arise many people with post-polio are left with few choices that do not involve wheeled mobility. There are, however, options for these problems which may allow people to keep walking while avoiding secondary complications.

Pressure Problems

Let's start with the pressure problems. The same cushions that are used in wheelchairs can often be used in regular chairs. These cushions can more evenly distribute pressure as well as provide pelvic support. Cushions come in a variety of materials including air, gel, fluid, foam or any combination of materials and have properties that are more effective at reducing pressure or providing pelvic support. A trained seating and mobility specialist can assist with the selection of the most appropriate cushion depending on the specific needs of that individual.

The Backrest Dilemma

The backrest dilemma is a more difficult one to address. Upright sitting is important for many reasons ranging from social to medical. Scoliosis can lead to problems with swallowing and breathing if left unchecked. Backrests designed for wheelchairs have many options for

providing lateral trunk support to help maintain the most upright and midline posture possible. Unfortunately, unlike wheelchair cushions, fitting these backrests onto everyday chairs is not easy due to the hardware and mounting requirements. Commercial lumbar supports do not provide adequate lateral trunk support although they can be helpful to prevent or reduce low back pain, and they can be attached to any chair.

continued on page 7

Don't Ignore Pressure Sores

Mary Ann Buckingham, Worth, Illinois, 708-448-7237

Mary Ann Buckingham had polio when she was 12 and walked using braces and crutches. Now 73, she started using a wheelchair about 20 years ago when her arms became too weak to use crutches.

As a polio support group leader for 10 years, she was well aware of the danger of pressure sores and took preventive measures to avoid them such as rotating her weight every 15 minutes and never scooting out of the chair. And, until recently, she was successful.

"I never had one," she said, "and after getting a new cushion, I noticed a tingling and self-medicated with zinc oxide, which had no healing effect." She went to her family doctor who sent her to a wound clinic where she was diagnosed with a Stage 2 wound (the topmost layers of skin are severed with some drainage).

"They prescribed two different types of medicated patches and said the sore would heal in two weeks. I couldn't believe it, but it did" she said. "The first patch was ConvaTec DuoDerm® that I changed every days and the second was 3M TEGadern, a thin cellophane-like patch."

Both are hydrocolloid adhesive dressings coated with substances that promote wound healing without causing softening and breaking of tissue.

Her advice: Don't delay seeing a doctor if you think a pressure sore is developing and follow guidelines for prevention and treatment. See a seating and mobility specialist for evaluation and recommendations for proper cushions.

Mary Ann has an appointment for a seating evaluation in March.

See "Pressure Sores Are Painful, but Preventable" at www.post-polio.org/edu/pphnews/PPH27-4fall11p1etc.pdf.

applied to a number of nursing homes, but my mother rejected all of them one by one when a bed was offered. The time never seemed right.

I increasingly took on the homemaking role through hired help. I assumed responsibility for her medical needs and appointments. A major merger was threatening my employment situation at the time and post-polio challenges were emerging. My tenacious will had always been able to overrule any physical limitations. But my body, it seemed, no longer listened. I had no choice but to give up work.

While I was hospitalized yet again with serious pneumonia and on life support, family members placed my mother temporarily in a nearby nursing home. I visited her on the way home from hospital discharge. She was miserable, desperate to come home. I could not leave her there.

I knew all too well the fear, the feeling of abandonment, the helplessness of nobody listening or understanding. My own memories were too powerful, too imprinted on my brain to resist. During those early polio years many people, including knowledgeable healthcare practitioners, had encouraged my mother to place me in lovely homes that existed for people like me. She had refused and by doing so, provided me with a rich family life and profound opportunities to achieve in both education and career.

As the months and years went by my mother's dementia and physical needs

increased. I brought in more and more daily help. Often her brilliant wit and reasoning shone through. She didn't want a bath today. She didn't want to eat – why should she? Why were we pushing her around like a child? It was a challenge trying to understand, interpret and balance competency versus choice.

Giving a person choice, enabling them to be who they want to be, assisting them in doing what they are driven to do – that's what genuine support is about when it comes to persons with physical disability. How and why is it different for someone whose thinking and reality is altered? For someone whose competence is variable?

Many times she insisted on going to the basement to her car, driving back home to Saskatchewan, getting up and cooking for her long gone kids. We tried to humor her, inevitably frustrating everyone and often increasing the distress.

“I learned how to fight, to charm, to write, to advocate effectively.”

My mother wasn't the burden. She just happened to be the bearer of physical and cognitive deficiencies that made her dependent on bureaucracies providing support. It was the system that I had to battle constantly to get more caregiver hours, to manage healthcare specialists who contributed nothing but greater challenges, not to mention the wasted expense of society's health care dollars. It was dealing with the multitude of unhappy caregivers who left my mother in a mess for the next caregiver to clean up.

I was constantly in the middle. It was like running a business with employees who expected you to solve problems but would not take direction because they were not accountable to you. (The exceptions were the ones I hired who also bore the brunt and burden of incompetent government-funded caregivers.)

I learned how to fight, to charm, to write letters, to advocate effectively.

Audrey King contracted polio in 1952. A rehabilitation psychologist for 30 years, she is an author who writes and speaks to international audiences, teaches at a university and is a consultant on ventilator issues. She was involved in founding the first supportive housing, outreach attendant services and direct funding programs in Ontario and chaired the first Ontario March of Dimes Post-Polio conference after attending PHI's first conference in 1981. Her mother, Maisie King, died in June 2012, six weeks shy of her 101st birthday.

I discovered the shock value and unimagined “power-up” potential of being a quadriplegic caregiver.

At the worst of times I periodically wavered in my decision to keep my mother in her home with me. Each time I inevitably decided it was easier for me to keep an eye on her care, intervening and advocating as needed if she stayed.

Aside from the transportation challenges of visiting a nursing home on a regular basis, I would have no influence and little awareness of what was happening to her when I was not there. I already had equipment at home she could use – a Hoyer lift, an extra wheelchair, a commode, a ceiling track lift over the bathtub. As an experienced user myself, a healthcare professional and a certified teacher of Ontario’s personal support worker curriculum, I could supervise and teach others in their proper use.

My 30-year career as a psychologist in a rehabilitation setting gave me knowledge of systems, budgets, negotiating skills and human resource techniques. How could I not put these skills to use for someone who had invested so much of herself in enabling me to grow and develop and become the person I was?

I learned much from my once proud, independent mother throughout her inevitable decline. I saw grace and humor in the face of the humiliation and embarrassment that her failing body caused her. I marveled at her wit and charm, at her ability to appreciate what caregivers did for her, even in the face of pain and suffering. Her tenacity and determination carried her through to the end.

She wanted to leave this world. She felt her job was done and she didn’t want to be a burden. She said it so many times and in so many ways. But we, myself in particular, would not listen. We mounted a continuous concerted effort to get her to eat, to get her dressed and out of bed each day. It was clearly painful and exhausting. All she wanted to do was sleep.



Maisie King with daughter Audrey King (center) and granddaughters, Carole-Anne and Lynda King.

I felt relief when she finally left us – both for her and for myself. I felt incredible lightness and freedom. The burden was gone. I felt guilt for my lack of grief until I realized I had lost her long before, and my grief and sorrow had been stretched over many years through the heart-wrenching ups and downs of each day. I had already grieved the loss of the marvelous mother she had once been.

My guilt then shifted to a guilt about keeping her alive, in spite of her strong wishes. Was I selfish in not wanting to lose her? Whose life was it anyway? I still ask myself.

When I get old and decrepit enough to consider life not worth living, will those more able than I, those responsible for my care, listen to me? Will they hear what I am really asking through my confusion? Inevitably, it isn’t as simple as having a living will. When you realize that someone loved you so immensely and completely that they invested their life in removing the massive early boulders blocking your way, forging your life’s path that enabled you to “walk” in her footsteps, it’s not easy to let go. ■

Research Update

Joan L. Headley, Executive Director, Post-Polio Health International, St. Louis, Missouri, director@post-polio.org

PHI Announces 2013 Research Award Recipient

Post-Polio Health International (PHI) awarded a \$25,000 grant to study the effects of using an innovative machine that has shown early promising results with frail elders and people with various neurologic conditions in pain reduction, strengthening and bone density improvement.

The study – Effects of Whole Body Vibration on People with Post-Polio Syndrome – will be led by Carolyn Kelley, PT, DSc, NCS, from Texas Woman's University, Houston, Texas. Carlos Vallbona, MD, TIRR-Memorial Hermann Rehabilitation & Research, is part of the research team.

The team will study the possible negative, as well as positive, effects of two innovative machines (Power Plate® pro5™ and Soloflex), machines with a platform that a person can stand or sit on, that vibrates the entire body. “Whole body vibration” is being used in fitness clubs, people's homes, and nursing homes to either enhance exercise protocols or as an exercise substitute.

The study will recruit 40 people who have post-polio syndrome. Participants who qualify will use each of the machines for a month, with the order randomly assigned. People who walk full-time, part-time, and not at all can qualify.

Kelley explains that because this is an interventional study, people will need to either reside in the Houston metropolitan area or be able to stay in Houston for about three months.

For more information about the project and inclusion/exclusion criteria, contact Carolyn Kelley, PT, DSc, NCS at ckelley@twu.edu or 713-794-2087.

(See page 12.)



Power Plate® pro5™

Updates from 2011 Recipients

■ **Isabella Schwartz, MD**, Head of Physical Medicine & Rehabilitation, Gait Laboratory and Post-Polio Medical Center, Hadassah-Hebrew University Medical Centers, Jerusalem, reports analysis of the data collected from about 195 polio patients is continuing. The team presented, “The Clinical and Demographic Parameters Associated with Developing Post-Polio Syndrome Among Polio Survivors in Jerusalem” at the Ninth Mediterranean Congress of Physical and Rehabilitation Medicine, Sorrento, Italy, October 2012, and at the recent Israeli Annual Physical Medicine and Rehabilitation Congress.

■ **Claire Z. Kalpakjian, PhD, MS**, Principal Investigator; Mark J. Ziadeh, MD, Co-Investigator, University of Michigan, Department of Physical Medicine and Rehabilitation, Ann Arbor, Michigan, report on their study, “The Role of Oral Glutathione in Improvement of Health Outcomes among Persons with Late Effects of Poliomyelitis.” The team successfully enrolled 20 polio survivors. Participants took glutathione supplement by mouth for three months after an initial medical visit, blood draw and physical exam.

The study design included four time points during three months. Subjects filled out surveys and recorded food intake and sleep times in diaries for seven days. They wore a Sensewear monitor that records physical activity, body temperature and other measures for seven days. After the fourth time point they returned to the medical center for another physical exam and blood draw. A final report will be ready by the end of March 2013.

■ **Daria A. Trojan, MD**, Montreal Neurological Institute and Hospital, McGill University, Montreal, Quebec, Canada, presented an abstract at the November 15–18, 2012 AAPM&R meeting held in Atlanta, Georgia.

Entitled “*Post-Poliomyelitis Syndrome Is Not Associated with Brain Atrophy*,” the cross-sectional study was designed to determine if post-poliomyelitis syndrome (PPS) patients have smaller brain volumes than normal control subjects.

A 1.5 T Siemens Sonata machine was used for magnetic resonance imaging (MRI) of the brain of the following participants: 49 ambulatory PPS patients, 28 normal controls, and 53 ambulatory multiple sclerosis (MS) patients.

Normalized brain volume (NBV) was assessed using the automated program SIENAx. This method does not assess the brainstem.

Technically adequate NBV’s were available for 42 PPS patients (mean age 60.88 ± 7.62 years, mean \pm SD), 27 normal controls (mean age 46.96 ± 14.56) and 49 MS patients (mean age 46.18 ± 9.45).

As previously reported, in a multi-variable regression analysis adjusted for age, NBV was significantly lower in MS patients than controls ($p=0.0054$). However, for PPS patients, in a multi-variable model adjusted for age, NBV was not significantly different from normal controls ($p=0.28$).

The authors stated that based on previous studies, acute paralytic poliomyelitis is associated with encephalitis in essentially all cases, and that it is possible that this early brain involvement can produce permanent neuronal injury with brain atrophy. Encephalitis due to other viruses (such as Herpes I and II) in children has been reported to produce permanent parenchymal abnormalities.

To date (2012), there have been no studies of brain volume in PPS patients. This study, conducted at the Montreal Neurological Institute and Hospital, McGill University, includes a relatively large number of PPS subjects as well as a control group of MS subjects who are known to have brain atrophy.

In this study, Trojan and team confirm the presence of brain atrophy in MS, but do not find a significant loss of brain volume in PPS subjects. Because the method used to assess brain volume excluded the

brainstem, it is possible that brainstem atrophy was not noted in this study.

From PHI’s Medical Advisory Committee

A few studies have been published regarding the use of IVIg for treatment of post-polio problems. (See Spring 2012, *Post-Polio Health*, Vol. 28, No. 2, page 9). PHI’s Medical Advisory Committee states that as clinicians they are not ready to use it, or promote its use, based on the current evidence. The group enthusiastically supports a Randomized Placebo-Controlled (RPC) U.S. clinical trial of IVIg for post-polio syndrome. ■

Navigating the Seating and Mobility World with Post-Polio

continued from page 3

Funding and Access

Funding and access must also be considered. Unfortunately, neither cushions nor backrests are covered by insurance unless they are being ordered for a wheelchair. The average cost of cushions ranges from \$300 to \$500 and backrests from \$300 to \$600. The cost can be self-limiting depending on the person’s resources.

Access, however, in the form of an evaluation by a seating and mobility specialist is covered by insurance. People who are having postural or pressure difficulties should seek the help of a seating and mobility specialist to problem solve their unique case. This may entail modifying their everyday seating systems including office chairs, home chairs, etc., or recommending customized cushions that will help with their issues.

Both physical and occupational therapists can be trained as seating and mobility specialists. The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) tests and certifies health professionals as assistive technology professionals (ATP). Seeking such qualified and certified health professionals is an important first step in determining solutions to the seating and mobility conundrum faced by people living with post-polio. ■

PROMOTING POSITIVE SOLUTIONS

QUESTION: *I am a 72-year-old widowed male. I read in the September issue about the reader whose parents didn't tell her about having polio and only discovering it as an adult. I had a similar experience and have always felt my parents were ashamed of my polio, not just wanting to protect me, and this had a scarring effect on my self-esteem growing up. I have let this issue go, but I cannot forgive them. I feel the "they did the best they could do" explanation I have read in self-help books pushes me to forgive, which does not feel doable for me. I have been able to forget, but not forgive. Is this healthy?*

Response from Rhoda Olkin, PhD:

In a word, no, it's not healthy. It is actually in your own best interest to come to a place of forgiveness. Numerous studies indicate the benefits of forgiveness. Let's keep two things in mind as we consider this.

First, what exactly do you need to forgive? Is it the withholding of the information that you had polio, or is it the shock of how you found out, or it is the idea (not necessarily the reality!) that they were ashamed of you as a person with polio, or all of these? Becoming clear on what you need to forgive might help you – it's not a blanket "I forgive you (parents) of any and all wrong doing" but rather a more specific "I forgive you for not knowing that telling me as a child was better for me" (for example).



Rhoda Olkin, PhD

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.

And second, forgiveness is not the same as saying "I would have done it the same way you did if I had been in your position" – forgiveness is not the same as agreeing. It is more akin to understanding – "I understand why you did it, given what you knew, what you thought was best, that there was no one to ask, that you did not mean for it to hurt me further." You do not say if your parents are still alive; given your age, I am guessing they might not be. It is easier to forgive a real person than an abstraction.

I always encourage my clients to make peace with their parents before they lose the parents, not so much for the parents' sakes, but for the adult clients' sakes. Sometimes what is important is saying something to someone who has wounded you, even if you do not believe they will genuinely hear it. This is a milestone of sorts, i.e., giving up the fantasy that your parents will get it right if you just give them one more chance, and recognizing that you need to say something anyway, that the *saying* is the important part.

Notice that I did not start by defending your parents or trying to explain why they might have withheld your polio from you. I take it on faith that they would not have knowingly done something that would be so hurtful to you if they had all the information available to them about options and probable consequences.

You already know about the absence of any role models, a history of shamefulness about disability, the scary views of eugenics circulating around the time of World War II, and the culture at the time of not talking about many things we are now more open about (e.g., about a child being adopted). These have not helped you. I hope this will – you will feel better, more comfortable, more at ease, more open, if you can bring yourself to forgive them. You may still feel the hurt of not having known until you were an adult, but separate that hurt from the reason you didn't know, i.e., that your parents didn't tell you.

QUESTION: *I am a 49-year-old female with PPS. I am divorced and finally feel ready to date again. I find that some potential partners want to be intimate first before developing an emotional bond. This causes me a lot of anxiety. I haven't had sex since being diagnosed with PPS and feel anxious about how to bring this issue up. I am not as spontaneous physically as I used to be and also have back and hip pain now. If I do choose to be intimate, how can I talk about my fears with a partner make sure it is the kind of experience I want it to be?*

Response from Stephanie T. Machell, PsyD:

However you raise the issues, the most important thing to remember is that when and whether to be intimate is as much your choice as it is your potential partner's. Doing something that goes against your own values and beliefs won't lead to good sex or to a good relationship.

Once you've made the decision to be intimate, being able to talk openly and honestly about sex with potential partners is part of the brave new world of dating. Discussing issues of disease, contraception, preferences and physical limitations ideally should happen before any sexual encounter.

Notice I said "ideally." Given the expectations most of us have that sex – especially sex with someone we don't know well – should be something that happens spontaneously, talking about the practicalities involved can feel wrong.

But this discussion will make sex better for both of you. Remember that if your partner is around your age or older, his physical condition and ability to perform may not be what they once were either. Bad backs and knees are common. Older men may have difficulty with erections and need more time to become aroused. It may be easier for them to perform in the morning than later in the day.

In other words, even if your potential partner seems eager for sex, you can't assume you will be the only one who might have difficulties. But because of the expectation that men should always be ready for sex, he might find it even harder to discuss it – and might appreciate it if you did.

How are your dates letting you know they want intimacy? If they are asking how you feel about it, then the topic is out there. If you are interested in that person, you could simply let him know that you are and go from there. If you are comfortable with it, humor can make awkward moments easier. For example, you could say something about having told your children that if they were mature enough for sex, they had to be able to talk to their prospective partner about it first and that having never been a hypocrite, you have to do the same. Then you could raise your concerns and ask about his.

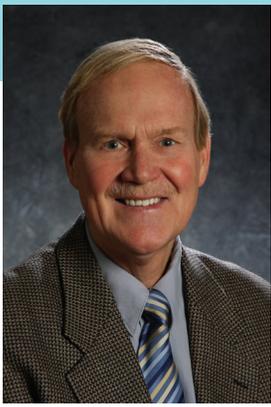
Or you could just be straightforward and tell him you would be happy to be intimate with him but that you have problems with back and hip pain and therefore there may be certain positions or activities that wouldn't work for you. You could let him know you need to plan ahead so that you won't be too fatigued to enjoy the experience. And if you are so inclined, you could suggest that exploring ways to make the experience the best it can be might be a lovely way to get to know each other better. ■



Stephanie T. Machell, PsyD

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: I had polio in both legs at age 10 in 1953 and was unable to walk for a year. With therapy and exercise, I pretty well recovered in one leg and can walk without help. How does fatigue affect people who have had polio? I'm constantly tired. A sleep study shows some sleep apnea and some restless leg syndrome waking me up. My good leg is having knee problems, and I will eventually need knee replacement. I've had one gel shot last year and will get another one soon. Does the bad leg make me tired all the time or could it just be the sleep apnea? Also, having the good knee replaced will put more pressure on the weaker leg. How does that work out for people in my situation?

A: A weak post-polio leg does require more energy for walking, compared to energy spent walking by people without leg weakness. However, I would expect that your fatigue severity would then correlate with how much walking you did. If the fatigue is more or less constant and unrelated to your activity levels, then sleep apnea would be a much more likely primary cause for it. With effective treatment of sleep apnea, many people have remarkably improved energy levels, occasionally described as a "new lease on life." It is definitely worth treating if it is confirmed you have it.

Regarding a knee replacement putting more pressure on a weaker leg, I would assume the opposite to be true. After recovery from a successful knee replacement, you can again rely on the stronger leg and reduce stress on the weaker leg. During the first few weeks, and sometimes the first few months, after a knee replacement, you may need to rely more than usual on the weaker leg, but there are many ways to minimize this from being a problem.

The most common way is to use a walker during the post-operative period when the affected knee is healing and regaining its strength. If you continue to use the walker, or one or two canes/crutches, until the affected leg is again stronger than the weaker one – and is without pain – you should do well and meet my expectation that the operation will help reduce stress on the chronically weaker leg. A thorough gait assessment (careful analysis of your walking pattern) would also be helpful; and if a brace would help improve your walking pattern efficiency, it would be wise to do this before the knee replacement.

I presume by gel shot you mean an injection of hyaluronan (brand names Synvisc® and Orthovisc®). If these injections are helpful, they can be repeated every six months indefinitely, and they are a good way to postpone or avoid the need for knee replacement surgery.

Question: I contracted polio in 1984, when I was 3 years old. In 2009, I discovered that I had very high blood pressure with figures ranging between 160/90 and 200/110. I have been on medication since then but there is no change thus far. At times I feel so weak after taking medication. My question: Is there a link between post-polio and high blood pressure?

A: I can absolutely reassure you that your history of polio has nothing to do with why you have developed severe hypertension at a young age. If medications have not controlled the hypertension, you need to see a specialist. I am concerned you have another condition that is producing the hypertension as a symptom, and that other condition needs to be identified. ■

For recognizing your friends and loved ones with contributions to support the unique mission of PHI and IVUN. PHI strives to publish an accurate list. Please contact us if we made an error.

Contributions to PHI's education, advocacy and networking activities ...

In Memory of

Jean Ann Cherner
Maxine Ellis
L. Gregory Hooper
Leo Lovell
Robert Thomas O'Brien
Loren Smith
Calvin Davis Turman

In Honor of

Linda Bieniek
Disabled activists
Marny Eulberg, MD
John & Jean Fialka
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Seeking Volunteers for Research Study

Would you like to participate in a research study to study the effects of a new exercise machine called whole body vibration on people with post-polio syndrome? Carolyn Kelley, PT, DSc, NCS is conducting a study at Texas Woman's University in the Texas Medical Center using this machine with polio survivors. Before we can learn if whole body vibration can help people with post-polio syndrome, we need to make sure it is not too intense or harmful, so we will measure muscle cramping and strength, effort, pain, sleep problems, fatigue and walking ability (if you can walk).

You can sign up if you are between 40 and 85 years old and you have no active medical problems such as a fracture, cancer, or blood clot. You cannot participate if you have any internal metal rods or joint implants.

You need to be able to stand for up to 20 minutes in spaced short time periods or be able to sit in a wheelchair with your feet on the platform, leaning forward onto your knees for up to 20 minutes.

If you are interested, please contact Carolyn Kelley at ckelley@twu.edu or 713-794-2087. ■

Inside Post-Polio Health

Vol. 29, No. 1, Winter 2013

- On Losing A Polio Mom ... 1
- From the Director ... 2
- Navigating the Seating and Mobility World ... 3
- Research Update ... 6
- Promoting Positive Solutions ... 8
- Ask Dr. Maynard ... 10



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