

PHI's mission is supported by its Membership.

Michigan Support Group Collaborates with OUWB School of Medicine

Tim Brown, Southeast Michigan Post-Polio Support Group

Typically, when one joins a support group, he or she might expect to share similar experiences with others, to find solutions to problems from others, to be able to listen and learn from speakers on related topics, perhaps even to occasionally meet at a restaurant with others from the group for lunch or dinner. The Southeast Michigan Post-Polio Support Group (SEMiPPSG) has indeed been providing all those benefits to its members for nearly 30 years. In addition to what is usually expected, we have also found a way to add yet a new dimension to the support group.

A common remark from polio survivors at group meetings is that they feel their doctors or medical service providers having little or no knowledge of polio or post-polio issues. Knowing this, several individuals who were both leaders of the support group as well as board members of the Michigan Polio Network (MPN), the Michigan statewide network of polio survivors, were determined to find a way to use its resources to address this problem. Bonnie Levitan, who also sits on the PHI board, and I took the lead on this effort. We reached out to the Oakland University William Beaumont School of Medicine (OUWB), a partnership between one of Michigan's top universities (Oakland University) and the state's largest health system (Beaumont Health).

We contacted the dean's office and scheduled an appointment to discuss what we viewed as an opportunity to raise awareness of polio survivors' issues among their medical students and perhaps even the teaching staff.

OUWB was founded upon the principal of providing a unique teaching experience to its medical students,

which includes such values as kindness, awareness and consideration of the human experience, as opposed to simply viewing the patient as a bundle of facts. A committee of very highly placed school administrators and professors scheduled a meeting with us to listen to our presentation. It was an impressive group who responded positively to what was said and indicated that they were receptive to adding issues surrounding polio to their program. As a result of this meeting, MPN was soon named a "Community Partner" in their COMPASS community engagement mentor program.

Following that initial meeting, we were put in touch with a first-year medical student who asked if MPN would participate in her three-year Capstone Research Project. MPN agreed and soon after mailed questionnaires to 700 polio survivors from our membership list. The four-page questionnaire was entitled, "An Assessment of (Michigan) Polio Survivors to Identify Longterm Sequelae of Polio: Educational Tool for Medical Students."

This turned out to be a highly successful venture between MPN and the student, with well over 50% of those polio survivors responding. The final results highlighting the lifelong experiences of this large group of polio survivors were summarized and shared with the student's classmates and made available to all future incoming students.

MPN was also invited to speak at an OUWB scheduled "Lunch 'n' Learn," an educational seminar at which lunch is provided to students while they listen to speakers discuss medical topics. The focus of this particular Lunch 'n' Learn was "Caring for Unique Populations: The Case of Polio," hosted by the school's chief of neurology. Bonnie and I were also invited to speak to the large auditorium full of students, staff and faculty, and answer their questions about polio and living with the after-effects.

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When the class was dismissed, a small group gathered with even more questions. Among them was Dr. Tracey Taylor, Associate Professor of Microbiology in the Department of Foundational Medical Studies and current Assistant Dean for Diversity and Inclusion. She was interested in learning more about the post-polio support group, so we invited her to attend several SEMiPPSG meetings and speak with the group. Since then, an ongoing relationship with Dr. Taylor has developed, resulting in involvement in a second student's Capstone Research Project, currently in its final stages.

During her first and second year of school, the medical student with whom SEMiPPSG is currently involved, Marlin Amy Halder, interviewed a number of volunteers from the support group—some in focus groups and some individually—to gather facts and information for her project, “Post-Polio Syndrome and Polio Survivor Biographies.” Amy was mentored by Dr. Taylor, and her research team included another medical student peer, Lucas Nelson, as well as a qualitative research expert, Dr. Tracy Wunderlich.

Amy, now a third-year medical student, has been working with the research team to identify common trends and experiences derived from living with the

effects of having been infected with polio early in life. Nearing the conclusion of her efforts, Amy created a poster which summarized the methodology and the results of her research and submitted it as part of the 10th Annual William Davidson Medical Education Week conference. Her poster (pg. 3) was awarded first place as the 2021 Poster Winner in the Education Research Category and displayed at the school for all to view.

Following Amy's final submission of the findings of her research, Drs. Taylor and Wunderlich plan to explore the possibilities of combining the results of the two post-polio studies with which SEMiPPSG has been involved to date with the intention of submitting for publication so that others can also benefit from the work.

In the meantime, we are discussing with Dr. Taylor a potential third post-polio project with another incoming medical student. And the members of the group are anxious to again share their experiences to further increase awareness of polio and post-polio syndrome among the staff and medical students of OUWB and beyond. ■



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Post-Polio Health International's mission is to collect, preserve and make available research and knowledge to promote the well-being and independence of polio survivors, home ventilator users, their caregivers and families, and to support the health professionals who treat them.

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Post-Polio Research Update

Aug. 28, 2021

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1

INTRODUCTION

Prior to the development of vaccines in 1954 and 1960, polio virus infected over 55,000 children per year in the United States; approximately 21,000 of those infections lead to paralysis. 30-40 years following recovery from polio virus infection, many survivors suffer from post-polio syndrome (PPS) – a new weakening in muscles that were previously affected by polio, as well as in muscles that were not originally affected. There are no studies to the authors' knowledge that explore the combination of polio experience and PPS, major experiences that polio survivors share in terms of life history, and how they managed to deal with certain disruptions in their lives, such as being taken away from school and separation from family.

2

OBJECTIVE

The objective of this mixed-method study is to explore the intersection of quality of life and life course theory as it relates to a sample of polio survivors in the United States by working with the Southeast Michigan Post-Polio Support Group.

3

METHODOLOGY

- Open-Ended Questions & T/F Quality-of-Life Surveys
- 3 Focus Groups & 6 One-on-One Interviews
- Developed a script for questions and used rev.com for transcription following analysis by at least 2 research personnel
- Approved by OU IRB: 1400610-1

4

RESULTS

It is the tiredness that gets you down (n = 18)	
True	12 (66.67%)
Not True	6 (33.33%)
I would much rather do things by myself but I cannot (n = 18)	
True	12 (66.67%)
Not True	6 (33.33%)
I have lost friends as they do not understand my condition (n = 17)	
True	2 (11.76%)
Not True	15 (88.24%)
I worry I am not going to get better (n = 18)	
True	8 (44.44%)
Not True	10 (55.56%)
I do not want to have to ask other people do things for me (n = 16)	
True	11 (68.75%)
Not True	5 (31.25%)

5 RESULTS

Poliomyelitis Survivors & Common Themes of Their Stories



6

CONCLUSION

Quantitative: The significance of having kids with worrying less about health conditions deteriorating or health not getting better shows that support systems plays a big role in health outcomes on patients living with chronic conditions. The sample questions show that survivors want to be independent.

Qualitative: Major themes highlighted on the left shows that chronic illness has major implications on life and physicians need to be aware of them when treating patients.

Richard Hardine

People with disabilities and older adults in the past had primarily lived in institutions to address their current conditions. With life spans increasing, the development of vaccines and healthier living, it was realized that changes needed to be identified and addressed for their individual disabilities, independence and safer lifestyles. Federal legislation was enacted that prohibited discrimination against people with disabilities and provided them access to public buildings and transportation. The Veterans Administration, Easterseals and other institutions worked on developing standards that would benefit all those with a disability.

States also started to create accessibility standards, leading to the 1968 Architectural Barriers Act, which focused on building design for outside access to buildings, internal access to the building's rooms and services, i.e., bathrooms, elevators and offices for public use. New technology in orthotics and prosthetics allowed for even more people to become mobile and get involved in their community, care for themselves, have a social life and visit others.

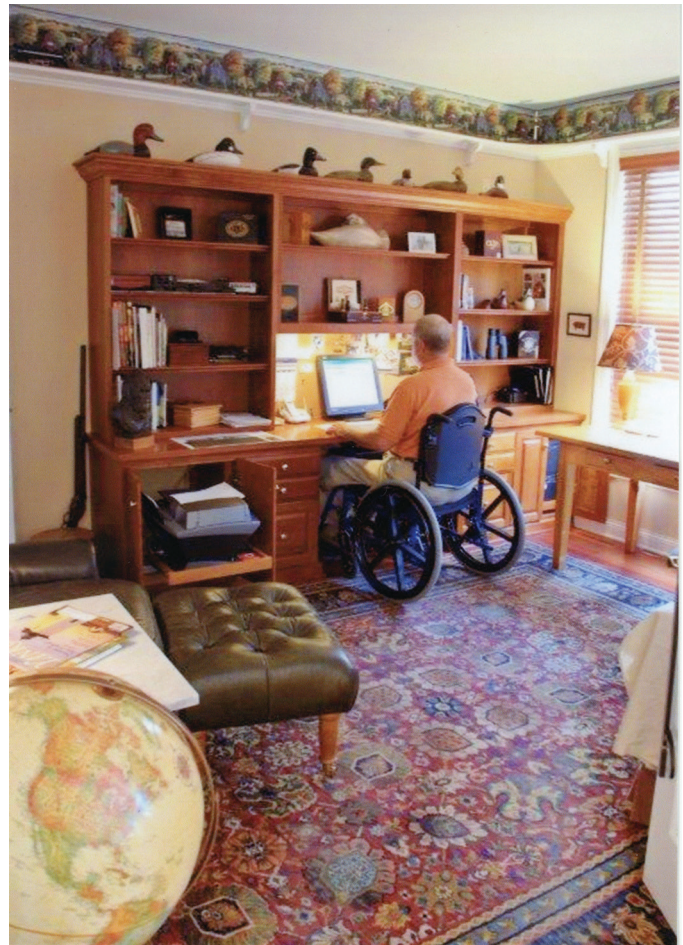
As baby boomers grew older, the growing importance of universal design led to improvements in accessibility in the home—with modifications ranging from simple faucet bath fixtures, lighting and appliances, as well as their location.

Universal design products and environments are to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. Working groups of architects, product designers and environmental design researchers have developed seven universal design principles for use in evaluating existing designs, guiding the design process, and educating both designers and consumers about the characteristics of more usable products and environments.

Principle One: Equitable Use¹

The design is useful and marketable to any group of users.

- ◆ Provides the same means of use for all users: identical whenever possible; equivalent when not.
- ◆ Avoids segregating or stigmatizing any users.
- ◆ Provisions for privacy, security and safety should be equally available to all.



Principle Two: Flexibility in Use

The design accommodates a wide range of individual preferences and abilities.

- ◆ Provides choice in methods of use.
- ◆ Accommodates right or left-handed access and use.
- ◆ Facilitate user's accuracy and precision.
- ◆ Provides adaptability at the user's pace.

Principle Three: Simple and Intuitive Use

Use of the design is easy to understand regardless of the user's experience, knowledge, language skills or current concentration level.

- ◆ Eliminates unnecessary complexity.
- ◆ Is consistent with user expectations and intuition.
- ◆ Accommodates a wide range of literacy and language skills.
- ◆ Arranges information consistent with its importance.

- ◆ Provides effective prompting for sequential actions.
- ◆ Provides timely feedback during and after task completion.

Principle Four: Perceptible Information

The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.

- ◆ Uses different modes (pictorial, verbal, tactile) for redundant presentation of essential information.
- ◆ Provides adequate contrast between essential information and its surroundings.
- ◆ Maximizes legibility of essential information in all sensory modalities.
- ◆ Differentiates elements in ways that can be described (i.e., makes it easy to give instructions or directions).
- ◆ Provides compatibility with a variety of techniques or devices used by people with sensory limitations.

Principle Five: Tolerance for Error

The design minimizes hazards and adverse consequences of accidental or unintended actions.

- ◆ Arranges elements to minimize hazards and errors: most used elements, most accessible; hazardous elements eliminated, isolated or shielded.
- ◆ Provides warnings of hazards and errors.
- ◆ Provides failsafe features.
- ◆ Discourages unconscious action in tasks that require vigilance.



Principle Six: Low Physical Effort

The design can be efficiently and comfortably with a minimum of fatigue.

- ◆ Allows user to maintain a neutral body position.
- ◆ Uses reasonable operating forces.
- ◆ Minimizes repetitive actions.
- ◆ Minimizes sustained physical effort.

Principle Seven: Size and Space for Approach and Use

Appropriate size and space is provided for approach, reach, manipulation, and use, regardless of user's body size, posture or mobility.

- ◆ Provides a clear line of sight to important elements for any seated or standing user.
- ◆ Makes reaching to all components comfortable for any seated or standing user.
- ◆ Accommodates variations in hand and grip size.
- ◆ Provides adequate space for use of assistive devices or personal assistance.



It must be acknowledged that the principles of universal design in no way comprise all criteria for good design, only universally usable design. Certainly, other factors are important, such as aesthetics, cost, safety, gender and cultural appropriateness. These aspects should be taken into consideration as well.

When we designed and built our home, all seven of the principals were utilized. The house is at grade so there are no steps to enter the five exterior doors. We have carpet walkways in the garage between the two cars for safe footing. The halls are all four

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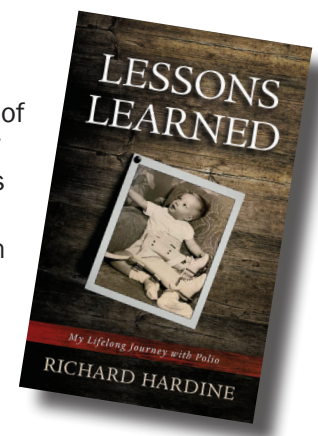


feet wide, and doors have three-foot openings. The bathroom sink is open underneath to provide room for my legs while sitting in a wheelchair. The bathrooms and toilets have three feet of open space on either side for transferring from a wheelchair. There is a large roll-in shower with no curb to step over. In the kitchen, the center island is low enough to access from a wheelchair. The toaster in the kitchen is in a pullout drawer for safe access.

In my professional capacity, I developed a residential accessibility survey to assist in collecting data on existing homes. In addition, I developed a client survey for gathering information on the client, their physical limitations, visual limitations, hobbies, ability to transfer, long-term prognosis and even medications that might have negative side effects.

The type of disability, current and potential future limitations, their self-confidence and motivations, and even the abilities of the caregiver have to be understood and addressed in order to ensure a positive long-term living situation while adapting to living with a disability. ■

Richard Hardine is the author of *Lessons Learned: My Lifelong Journey with Polio*. His articles include “Universal Design,” “Housing Design Breaks Down Barriers” and “Planning to Build Your Retirement Home Using Universal Design.”



1. Rosetti, Rosemarie. “The Seven Principles of Universal Design.” *Action Magazine*, Dec. 2006.

WE'RE STILL HERE! 2021

This past October marked PHI's 15th annual awareness campaign. For many, the past couple of years have been challenging, as the pandemic upset our normal routines. PHI heard from many of you seeking advice on exercise and nutrition in order to offset the effects of living a less active lifestyle.

This "WE'RE STILL HERE!" campaign, PHI asked to hear from those of you who had found ways to break out of your pandemic ruts and stay active and healthy. We asked you to submit a photograph and a descriptive paragraph or two about changes you've made to your routine or diet in order to lead healthier, more balanced lives. We thank all of those who chose to share their experiences with us. Following are the winning entries as decided by our panel of judges.

GRAND PRIZE WINNER

*Corina Zalace,
Niceville, Florida*



Adapt! You must adapt! It is something I had to learn over the past 71 years since contracting polio at the age of two. I became a master at adapting, usually enjoying the challenge. Then the COVID pandemic hit, and my very active lifestyle came to a screeching halt. I had been confined to a wheelchair since 1986 because of my childhood polio, but that had never stopped me from being out and about, driving my lift-equipped van with hand controls everywhere there were roads—and some places where there were just dirt trails.

But no more. My classes closed, and I had to give up my college studies to become a licensed art therapist. I was teaching art to adults and children. That had to stop. COVID definitely put a damper on my life.

So, I had to go back—back to adapting to new situations. Spending hours at home away from friends and other people was challenging. My brain went back into adapting mode again. I began talking

more on the phone with family and friends, which always brought joy to my heart. Yet, that did not fill all the time I had to spend at home.

I still had so much free time at home. I had to do something. First, I saw my stacks of books around the house, waiting to be read. So, I began reading, and read until I had finished them all over the course of the next year. I also love to puzzle. And I love working on my art. To be able to draw and paint became a huge emotional release for me.

My biggest advantage every day was that I had married my best friend. We spent hours every day helping each other with our projects, planning new ones, reading together or just enjoying each other's company. As for exercise, taking my service dog out and pushing my wheelchair outside in the fresh air boosted my spirits. Yes, it was a challenging time, but I am so grateful how polio in my early years taught me to enjoy being an adaptable and flexible person.

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FIRST RUNNER-UP

Sunita Dodani, MD, Norfolk, Virginia

I am a physician cardiologist and polio survivor. I contracted polio in all four limbs at the age of two. Today, I am 51 years old and have a beautiful life and family—a loving husband and a 16-year-old son. I faced many challenges growing up with polio in Pakistan. Yes, I was born in Pakistan, and we were minorities. Pakistan is a Muslim country and raising a Hindu woman with a disability is next to impossible. However, even though my family pressured my parents to give me to the orphanage, my parents provided me with extensive physiotherapy—day and night. My muscle strength in my arms improved, and after four years, I started to wear surgical braces for mobility and started walking slowly. Since then, these braces have been part of my body.

Becoming a cardiologist and a cardiovascular researcher was my mom's wish. She always told me that what I had gone through—living life with polio in a country where there is no respect for women—would better help me understand patients' pain and perform cutting-edge scientific research.

COVID hit us last year, and it has been more than 18 months now that we healthcare providers have been working day and night in hospitals. I am the founding director of a healthcare institute where work has tripled due to the COVID pandemic. I am responsible for running the institute and taking care of COVID-related work on patients. This has been very stressful, and on top of that, social distancing further exacerbated and limited my exercise.

To keep healthy, I swam for 30 minutes at least four days a week. Social distancing and the closure of fitness centers has reduced my mobility. It's been 18 months since I have been to a fitness center and swam. However, as we say, where there's a will, there's a way.

Since last year, I have started doing yoga every day for 30 minutes. The beauty of yoga is that it can be done on a bed or in a chair. These yoga breathing and muscle strengthening exercises are easy for polio survivors to relax, alleviate COVID-related anxiety and stay calm during this unprecedented time. Further, being a physician cardiologist myself, I've always paid attention to what I eat, as every increase in weight causes a significant burden on our joints.

My message to all my fellow polio survivors is to stay active and move muscles by spending at least 30 minutes a day on yoga. There are tons of chair yoga exercises on the internet. Secondly, to remain safe, please get the vaccination if you have not already. This is important. Last but not least, eat a healthy, small amount and avoid unnecessary stress. Everything happens for a reason. This COVID has come. It will go, too. Just trust yourself and be happy, no matter whatever the situation is.



SECOND RUNNER-UP

Peggy Thornburg, Athens, Georgia

I contracted polio at four months of age—14 months before the vaccine was available. I was treated at Breckenridge Hospital in Austin, Texas. I was reported to be the youngest child to survive polio that month. I was treated with Sister Kenny hot packs. Luckily, polio didn't affect my lungs, and I grew up singing in the schools I attended over the years.

Fast forward to the COVID epidemic, which put a stop to singing for a while. After a short hiatus, I went back to singing again through Zoom with my four groups here in Athens, Georgia—Athens Choral Society, Athens Symphony Chorus, Meridian Women Chorus and Chapelwood Choir. Those days were very enriching during the pandemic year. It was like vocal aerobics.

We videotaped the sessions for the community at large, who used to hear us perform quarterly at Hodgson Hall on the campus of University of Georgia. Many let us know how enriching these Zoom performances became for them during the year. Singing is excellent for the lungs. Endorphins go through the body, which leads to strengthening the whole body when done every day.

In August of 2015, I was diagnosed with stage 4 ovarian cancer. With this came months of weight loss because my peritoneal area prevented me from eating. After chemo and a grueling de-bulking surgery to remove some cancer, I had gotten down to 125 lbs.

Recently, after years of chemo, CTS and blood draws, I found I had gained weight and had to get the weight off. I started a low-carb, high-protein diet with lots of roasted and sautéed veggies. I lost 10 pounds. I'm still working on this. It is a lifetime struggle. Cutting out white sugar was essential for me. If I eat rice with veggies, I use brown rice. It can be boring but must be done.

I use a scooter now after years of walking with crutches, though I still use crutches in my home. I can now get out of a chair easier. Weight is my enemy; I must not let it get the upper hand. Life is easier now.

THIRD RUNNER-UP

Dianne Wall, Winter Springs, Florida

I was given a love and talent for music and became a registered music therapist, as well as a professional singer. I have always used my music therapy to exercise/stretch, as well as keep my spirits up, but during the pandemic, I used my music to stay healthy and calm.

I knew I needed to stay engaged with people, even when we were isolating, so I used technology to stay connected. I have been the director of many choirs during the years, but during this pandemic, I had my first virtual choir with my church's children's choir that I was directing. Since we could not meet in person, I learned how to use Zoom and another app called Loom. We also used FaceTime.

I recorded MP3s and sent them to the children's parents. Our big accomplishment was a singing Christmas card that was played on the church's YouTube channel. I had each one record themselves using their cellphones and send me their MP3 recording. I used my recording software to lay down each recording as a track and blended them all together. It took many hours, but it was a labor of love.

Staying healthy is an attitude of gratitude for me, and thanks to technology, I was able to practice that immensely.

FOURTH RUNNER-UP

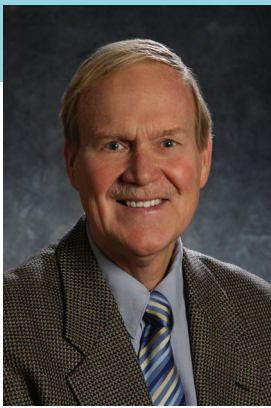
Brenda Ferguson, Tallmadge, Ohio

One of the most important things in my daily life is to find a way to bring sunshine into another person's life. So, I journeyed into the world of learning how to craft homemade greeting cards to send to those downhearted to help lift them out of the feeling of hopelessness COVID-19 has ingrained in them. I began by immersing myself in a group of five very close friends (all acquaintances from church) to learn the basics. Then, each day I would address and mail several cards—not only to people I knew well, but especially to those that I didn't. It has been such a joy to hop on my scooter and go to the mailbox daily and drop in a handful of cards!



Especially hard hit were those in poor health, people all alone, and the elderly who seemed to not quite understand what the illness was all about. I have to admit, a couple of times, I reminisced about how I felt being in isolation when stricken with polio at age three and being unable to see or talk to my family. Everyone has suffered greatly in one way or another the past couple of years from the pandemic, and even the smallest thing we can do to lift one another up is so important.

Another joy of mine is to stay in touch with others and make several calls daily, especially to those housebound, to cheer them up. I always end the call with how important it is to “keep looking up” and encourage them to believe that better days are ahead. We will see a big “rainbow,” prayerfully one day soon. Let's keep smiling ... it may be tough some days, but we will get through this! ■



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/living-with-polio/articles-post-polio-health#AskDrMaynard

Question: *About 20 years ago at one of your conferences, the state of the art said “neurogenesis in muscles affected by polio was limited. The nerves died, new sprouts formed new nerves, but these new sprouts only had a 50-year life span, and thus, post-polio. Therefore, don’t overuse your affected muscles.”*

I need new motor neurons in my left calf. I’m studying neuroscience this semester and read that adult neurogenesis occurs in the dentate gyrus, subventricular zone, striatum and cerebellum. The striatum has motor function.

Is there new data? Is it still true that overuse will kill those original sprouts and therefore the new nerves? Is exercise now recommended, or is stem cell injection the only way to form new motor neurons in degraded muscle?

Dr. Maynard: Thank you for your thoughtful questions concerning neurogenesis after paralytic polio. The leading theory for post-polio syndrome remains distal degeneration of enlarged motor units many years later after the initial polio infection with nerve damage. There is little new data to explain what triggers the late degeneration. Compared to 20 years ago, most clinicians who see many polio survivors recognize that “exercise” remains important for preventing further weakening and that too much exercise (as manifest by transient overuse weakness) is likely to hasten weakening from further denervation of enlarged motor units.

I recommend careful individual evaluation to consider possible exercise prescriptions to meet realistic goals and to be compatible with one’s past and current (examination-based) capabilities and functional demands (intensity and duration of daily activities).

Stem cell injections have shown some promise for neurogenesis in the central nervous system but NOT in motor nerve cells of the spinal cord whose long axons reach voluntary muscle and are the basis of the peripheral nervous system.

Question: *I have recently been diagnosed with post-polio syndrome by a neurologist. I am 76 years old now and contracted polio when I was four. I remember my mom putting hot mustard plasters on my neck and shoulder. I read about Sister Kenny and her methods of treating polio. What can I do to reduce muscle tightness and poor mobility in my affected left leg? I find it hard to sleep. When I go to bed the muscle gets tighter, and I keep waking up with pain. Should I use heat? I take a muscle relaxant, and it helps slightly. I would appreciate your input.*

Dr. Maynard: Painful nighttime tightness in weakening polio-affected legs can usually be helped by both stretching exercises, especially before retiring for the night, as well as by careful consideration of options for reducing overuse of weak or weakening muscles. Both options require careful evaluation by knowledgeable rehabilitation professionals (doctors and therapists) and electromyographic testing (EMG) may be helpful in

confirming your diagnosis of PPS, as well as the extent and severity of nerve loss in your symptomatic extremity. Mild oral analgesic medication and/or analgesic topical creams can be of additional help for pain control but are rarely sufficient for lasting relief/resolution of symptoms without the former actions.

Question: *I am a 74-year-old polio survivor. I have facial nerve involvement with paralysis of the right side of my face. Now I have problems with chewing, so I have to use a hand under my mandible to push it up. I have also started having laryngospasms with severe inspiratory stridor which has resulted in calling the EMS twice. Have you seen or heard of patients with these problems with post-polio syndrome? Could you advise me on how to deal with these problems?*

Dr. Maynard: Facial nerve weakness from polio is a well-known, although not common, aspect of bulbar polio. New later-life problems with chewing might be from further weakening of facial muscles but laryngospasms are a sign of aspiration from weakness of the throat muscles that protect the larynx and airways during swallowing. Dysphagia, or trouble swallowing, is a common new symptom among bulbar polio survivors. Given the severity of your laryngospasms, you urgently need a swallowing study (barium videofluoroscopy) and evaluation by a speech language pathologist and ENT physician to determine your best options for management to prevent choking complications, such as aspiration pneumonia or life-threatening laryngospasms. ■

In Appreciation

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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