A Cautionary Tale about Post-Polio Shoulder Surgery: One Story, Three Perspectives

Sunny Roller, MA, Ann Arbor, Michigan, and Frederick M. Maynard, MD, Marquette, Michigan

One must be very careful about choosing to have orthopedic shoulder surgery, especially if one is a polio survivor with a complicated disability. This is the story of Liina Paasuke, our friend with polio who recently had shoulder surgery. It is our hope that by presenting it and our individual perspectives on it, readers—both consumers and professionals—will more fully understand the issues and benefits of the choice to have, or to prescribe, shoulder replacement surgery (also known as Total Shoulder Arthroplasty or TSA).

Liina Paasuke (left) connects over coffee with Frederick M. Maynard, MD.

Liina contracted polio at age 17 months. As a preschooler, she underwent several surgical procedures on her severely paralyzed legs. When she began mainstream schooling at age 6, she was able to walk using bilateral long leg braces, a corset and forearm crutches.

After high school graduation, Liina earned an MA in Guidance and Counseling at the University of Michigan (U-M) which commenced her 36-year career with the Michigan Department of Vocational Rehabilitation at U-M, counseling people who had physical disabilities. During her young adulthood, Liina was entirely independent in all personal and advanced activities of daily living (ADLs). She walked as far as she needed to go using her devices with minimal difficulty. She drove a car with hand controls. In 1979, she purchased a three-bedroom home that she still lives in today.

Although Liina’s general health remained excellent, by the early 1980s she found it increasingly difficult to walk long distances and experienced symptoms of Carpal Tunnel Syndrome. Adapting to these issues in 1984, she obtained her first electric scooter.

Over the next 20 years, she slowly gained 25 pounds and gradually decreased the amount of time and distance that she walked due to increased effort and greater fatigue. By 2006, she was essentially ambulatory inside her home only. She began dragging her right foot during swing and could not negotiate a single step. By 2010, due to slowly declining strength and endurance, she could no longer complete bathing and toileting in a regular bathroom. With assistance from her church, she was able to remain independent in her home with a remodeled scooter-friendly bathroom, bedroom and kitchen.

Beginning in 2012, she developed increasing right shoulder pain. After her physiatrist diagnosed her with rotator continued on page 3
PHI’s Joan Headley to retire

Joan L. Headley has announced her retirement, effective September 1, 2017. She began her work with the organization in 1987 and has been Executive Director of Post-Polio Health International for 28 years.

Joan informed the PHI Board of Directors of her intention “with a sense of accomplishment ... My vision was to go beyond awareness and to provide substantive information that could benefit individuals targeted in our mission, regardless of level of disability, personal philosophy or economic status.

“In addition to polio survivors and users of home mechanical ventilation, a vital part of this effort has been the substantial collaboration with many dedicated healthcare professionals. I have had an opportunity to work with and for extraordinary people.”

“Joan L. Headley has been in a real way the heart of PHI for nearly three decades,” PHI’s Board of Directors said. “She will be greatly missed.”

The Board also reaffirmed “our mission of providing accurate and reliable information regarding post-polio syndrome and home mechanical ventilation through Polio Place (polioplace.org and ventnews.org) and through direct contact with our staff.”

A search has begun to hire an executive director to replace Joan and to maintain PHI’s operations.

Building on the work of advocates Gini Laurie and Judith Fischer, Joan greatly expanded networking among polio survivors, ventilator users and medical professionals across the globe during her tenure.

PHI emerged under her leadership as the acknowledged worldwide hub of information regarding post-polio issues, home ventilator use, and independent living education and advocacy.

Joan coordinated seven of PHI’s international conferences. She presented at 70+ meetings, speaking on topics related to post-polio issues, home mechanical ventilation and disability rights. She served on the Post-Polio Task Force (1997) and served on the March of Dimes International Conference executive steering committee (2000).

The networking focus of the international conferences was intentional. Leaders and potential leaders learned, linked up and created new organizations. Joan says, “I think we should be proud of PHI’s years of information dissemination to groups around the world encouraging them to ‘do it their way.’”

Another accomplishment under her leadership was the creation of PHI’s Research Fund in 1995. The ability to fund grants elevated PHI a step above the many other information givers. The fund has supported 10 grants since 2001.

She directed the development and growth of communications from PHI and International Ventilator Users Network (IVUN). IVUN was established in 1987 to build upon the polio survivor history of using ventilation at home and to promote its use for other diagnoses.

PHI’s publications include Post-Polio Health, Ventilator-Assisted Living, the PHI Membership Memo and an Association Membership Communiqué for post-polio support groups and organizations. Other resources include the Post-Polio Directory, the Resource Directory for Ventilator-Assisted Living and the Home Ventilator Guide. Additionally, PHI and IVUN has taken positive advantage of social media.

Joan, who had polio in 1948 at 15 months, received a degree in biology from Huntington University, Huntington, Indiana, in 1969. In 1974, she received her MS in Education from Indiana University. She taught junior high science and high school biology for 18 years before joining the organization.

—William G. Stothers, President of the Board of Directors
A Cautionary Tale about Post-Polio Shoulder Surgery

continued from page 1

cuff tendonitis, she had some short-term benefit from several bouts of physical therapy (PT) over the next three years. Nevertheless, she lost range of motion (ROM) and strength in the right shoulder. Severe pain became more frequent.

By late 2015, Liina decided to investigate surgical options for her right shoulder problems. She was concerned that further worsening would jeopardize her independence. Her primary goals were to maintain the ability to walk a little in her home, to stand up after toileting and to reach higher. Her secondary goals were to decrease pain and increase ROM in the right shoulder.

She met with an orthopedic specialist in upper limb joint replacements who performed “Reverse Total Shoulder Arthroplasty” (rTSA). In this procedure, the head of the humerus is removed and replaced by a shallow cup that articulates with a rounded ball (head) which is implanted firmly into the glenoid fossa of the scapular bone. This newer procedure is thought to restore better motion and strength in people whose shoulder rotator cuff muscles or tendons are irreparably torn or frayed from degeneration.

The surgeon led her to believe that after an rTSA her arm would be as good as before. However, she was unable to have him answer specific questions regarding the eventual post-operative function of the arm for routine weight bearing, which was critical for her to stand up to transfer. He said that the right shoulder would need to remain immobilized and bound to her chest for six weeks and thereafter she could gradually do anything she wanted to do and was capable of doing with that shoulder.

Despite reservations, she decided to proceed with the surgery. To prepare, she arranged to stay at a local rehabilitation center. The rTSA was done on April 13, 2016 and three days later, she was discharged to the rehab center.

During rehabilitation, while her right arm was immobilized, she was dependent in all ADLs. She received therapy services and gained some modified independence in self-care using her non-dominant left upper arm and shoulder. In spite of earlier threats of discharge before she was independent in basic ADLs, she did complete a nine-week stay in the rehab center before going home. She could now perform basic ADLs from her scooter with great difficulty—involving much time, effort and ingenuity.

She received home therapy services for three months and increased the strength and ROM of the right shoulder. By five months post-surgery she was able to do ADLs with only mild to moderate additional effort. She still could not stand up again after normal seated bathroom toileting.

Her primary goals were to maintain the ability to walk a little in her home, to stand up after toileting and to reach higher.

Her right shoulder ROM was good and she had no significant shoulder pain. When she began outpatient PT, her therapist noted surprising strength deficiencies in her shoulder’s scapular stabilizing muscles, which he determined had not been targeted for strengthening during her home PT exercises. He began strengthening exercises for the right scapular stabilizing muscles and advanced her generalized upper body-strengthening program in order to assist her with the goals of reaching up and standing independently after seated toileting.

At seven months post-surgery, she felt ambivalent about whether the surgery had been “worth it”, but she was more hopeful about the chances of reaching her primary goals. She remained quite taken aback by how long her recovery was taking. Looking back, she felt that her surgeon had misled her with false expectations, conflicting messages and unresponsive communication. He had implied that recovery would be easy.

continued from page 1
She gradually recognized not only his lack of knowledge concerning polio survivors’ potential challenges after surgery, but also what seemed to be an insensitive disregard for her disability. She worried more than ever about staying independent.

Frederick M. Maynard, M.D.
The Post-Polio Physician’s Perspective

One important lesson from Liina’s story is the need for people with chronic lower limb motor disabilities to identify their goals for having any shoulder surgery. This is particularly true for any functional goals that have been lost and are hoped to be regained, or for functional goals critical for independence that are in jeopardy of being lost.

While pain reduction and improved ROM may be desired, and are considered likely to be obtained from a successful surgical procedure, the achievement of any eventual post-operative goals dependent on higher levels of upper limb strength are harder to predict, as are the anticipated timeframes for accomplishing them. Due to many unpredictable intervening variables, their achievement may require prolonged challenging effort by both professionals and patient. Honest and frank discussion about this reality pre-operatively between surgeon and patient can mediate any disappointing results.

A second lesson is discovering how little is known about the unique post-operative needs of people with chronic lower limb motor disabilities after a new reconstructive orthopedic procedure on the shoulder joint. Achieving successful restoration of weight-bearing function with the shoulders and upper limbs has not been thoroughly studied. Given the impressive results of TSAs for reducing pain and restoring functional ROM for non-disabled patients, these procedures are likely to be offered to and considered by people with chronic lower limb motor disabilities more frequently in the next ten years.

Certainly, people with spinal cord injuries, post-polio, spina bifida, cerebral palsy, muscular dystrophy and other neuromuscular conditions commonly develop shoulder pain. A medical literature review identified two reports that addressed outcomes of TSA among a few people with paraplegia (including two polio survivors). Medical and surgical complications were numerous among them. Functional outcomes beyond pain reduction and ROM were not addressed.

Just as hip and knee joint replacement surgery has become commonplace for treating age-related dysfunction of these joints, shoulder joint replacement is becoming more widely and readily available. Many efforts to improve designs of utilized hardware and for surgical tactics, such as rTSA, are likely; but specific study, or even note, of the special needs, problems, complications and outcomes for people with chronic lower limb disabilities seems unlikely.

For the present, I recommend great caution when considering TSA for people who rely on routine weight bearing with their shoulders. Not enough is known about functional outcomes, particularly long-term outcomes related to risk of hardware loosening.

Clear goal identification for having any procedure, excellent communication between patient and surgeon about goals and special needs, and consideration of second opinions are also recommended.

Additionally, I am promoting that further scientific investigation be conducted by my surgical and rehabilitation colleagues into post-operative strength and functional outcomes experienced by patients who regularly use their shoulders to bear their full body weight.
Liina Paasuke/The Post-Polio Surgical Patient’s Perspective

Nine months post-surgery, Liina reports that the pain in her right shoulder is gone and she is slowly regaining her strength and function, but is still not back to her pre-surgery capabilities. Astonished by the potent consequence of short-term muscle disuse for polio survivors, she has been dismayed by several post-surgery shockers.

First, her total upper body strength is diminished, on both the right and the left sides. Second, crutch walking is now grueling and, right after the operation, she could not even move her right leg to take a step, as she was able to before the surgery. Third, Liina is now functionally able to do more activities than she could right after her surgery, but she has also needed a greater number of expensive environmental supports. Often overwhelmed now with a sense of exhaustion when doing basic activities, she cautions post-polio consumers to “carefully weigh any surgeon’s expectation against reality.”

Sunny Roller/The Post-Polio Friend’s Perspective

As a polio survivor whose disability is similar to Liina’s, I have witnessed her steadfast struggle. Learning from Liina, I offer the following take-home lessons:

- Research non-surgical alternatives, considering future implications of not having the surgery.
- Know that muscle disuse in a polio survivor zaps strength and function and is inevitable in any immobilized post-operative limb. Assume that the post-surgical rehabilitation will take much longer than expected.
- If surgery is prescribed, get a second or third opinion from non-surgeon post-polio specialists.
- Prepare thoroughly before the surgery. This includes:
  - Making sure the surgeon’s team is informed about the precautions for anesthesia and recommended surgical recovery room procedures for polio survivors.
  - Finding the best place for your rehabilitation based on location, skill, and knowledge of polio survivor issues.
  - Recruiting a loyal patient advocate who will persevere and stand up for you through the whole process.
  - Tapping into your social network for advance pledges of assistance.
  - Gathering information about potentially crucial resources.
  - Talking with occupational therapists about home rehabilitation needs.
  - Talking with physical therapists about alternate ways to move about during post-surgery rehabilitation.
  - Identifying post-polio specialists who will agree to consult with your health care professionals about specific post-polio issues.
- Understand that recovery will not be easy, but it might be worth it. Weigh the pros and cons judiciously.

This is indeed a cautionary tale.
Questions to Ask the Orthotist

Marny Eulberg, MD, Wheat Ridge, Colorado

Polio survivors experiencing old or new muscle weakness may benefit from some of the new or improved bracing technology. Some may be needing a brace for the first time in their lives and wonder what materials and designs are available to them.

Survivors who wore bracing in their younger days, but then were able to “graduate” from the braces, may be seeking the help of an orthotist (brace maker) for the first time in years.

For some long-time brace users, the trusted orthotist that they have worked with for decades is now retiring and it is difficult to find someone who can make a brace using the tried and true materials or to locate someone who can repair old braces.

The questions, concerns, and needs of each of these groups are frequently different. It is important that multiple factors and desires be considered in the design of a brace or it may end up in a closet or basement and never be worn. This benefits no one except, perhaps, the orthotic company’s bottom line.

Below is list of questions and advice to guide survivors as they discuss new bracing with a new orthotist.

What problem is the brace going to address? Drop foot? A knee that is unstable, or buckles (collapses forward)? A deformity of a foot, ankle, knee? A painful joint? Or a combination of all of the above?

What are the credentials and qualifications of the orthotist?

Details matter: Ask questions and get answers to YOUR satisfaction and level of understanding.

Explain to me how this brace will address/solve my particular problem(s).

Show me what it will look like.

Can I try an off-the-shelf model or a sample so I can experience what it will be like to wear it?

If it will be on the leg I use for driving (or other important activities, such as depress pedals on a piano), how will it impact my ability to do those activities?

What choices of a brace do I have?

What are the pros and cons of each of these brace designs?

What kind of footwear can I wear with this brace?

Will I need a different size shoe than I am currently wearing?

Can I wear it without shoes? (This reflects personal preference or cultural/religious requirements.)

Consider care of the brace.

Can it be worn in the water?

If there are joints, do they need to be oiled? If so, what kind of oil should I use?

Are there springs/joints/screws that might break or fall out? If so, can I get spare parts to have on hand and be taught how to do my own repairs?

How do I recognize a problem or impending problem with the brace? What do I do if I suspect a problem?
Other details to discuss.

Will gait training be recommended as part of the program? If so, who should do the gait training, what does it entail?

How much will the brace cost?

How much is my insurance likely to cover? How much will I have to pay out of pocket?

Are there any warranties or guarantees?

What kind of follow-up is recommended? (Most braces do require some adjustment initially and over time.)

Finally, technology is changing and bodies also change, especially if one is experiencing post-polio syndrome, so it is a good idea to check in with an orthotist at least once every 3-5 years.

www.polioplace.org

The staff of Post-Polio Health International has been adding information to www.polioplace.org for the last seven years. One purpose of the website is to make available all of the organization’s materials from the past 59 years. The materials allow visitors to “Explore the past, the present and help build a promising future for the world’s polio survivors.”

Two new sections have been added recently. The tab “PHI-Funded Research” features the articles and final reports of the ten grants PHI has supported since 2001. The latest addition is an indexed listing of major articles from past issues of Post-Polio Health (formerly Polio Network News).

Under the rotating photographs, there is always a list of the information that has been added recently. We keep the Medical Articles, Resources (Books, Web, Multimedia) up-to-date and continue to add to Living with Polio, and to the History section with scans from our archives.

You are invited to be a part of this enduring website by searching your baby books, scrapbooks, yearbooks and your prized collections looking for memories of your life as a polio survivor to share with others. The “Artifacts” section includes scans of photographs, letters, newspaper clippings along with a narrative describing the memory.

If you are interested in helping us stockpile our history, contact us through www.polioplace.org/history/artifacts/submission-information or email to Brian Tiburzi at info@post-polio.org.

Our story is important. Your unique personal story is, too. Be a part of the legacy.

—Joan L. Headley, Executive Director
QUESTION: I was recently asked why I never attended post-polio meetings unless I speak and why I didn’t ask questions of the internet groups of polio survivors. I immediately knew the answer—those situations make me feel vulnerable, so I avoid them. Is this a healthy way of coping?

Response from Stephanie T. Machell, PsyD:

There’s no one healthy way of coping. Some people thrive on information and group interactions. Others don’t. I know many polio survivors who don’t attend support groups. Usually this is because they have experienced groups that became negative, either judging/ scapegoating certain members or spending the majority of group time complaining and never discussing solutions. Groups like that, whether in person or online, would make anyone feel vulnerable!

Limiting your exposure to information can be healthy. It’s important to know your limits so you don’t become overwhelmed by the volume and/or repetition of information. Knowing groups and meetings cause you to feel vulnerable means you can control your exposure to them.

Then again, it depends on what you mean by vulnerable. Vulnerability, as in openness to experience and/or others, can be a way of making connections. It requires trust that your experience and limits will be respected. Again, if this hasn’t been your experience in groups it is understandable why you wouldn’t want to be vulnerable in them.

If you mean that the information you receive, or the condition of others attending the group, bring up fears about the future that cause you to feel personally vulnerable, avoidance may still be healthy—to a point. I often tell my clients that the “healthiest” stance for a polio survivor is a combination of acceptance and denial, in varying proportions. If your avoidance keeps you from dealing with important or necessary issues, meeting people who could be friends and allies, or from learning about things that could improve your quality of life, it isn’t helpful, and it probably isn’t healthy.

Rather than avoiding groups altogether, it might be useful to consider what you lose by not going, and what you might gain by participating. If choosing to go only when you are presenting helps you to feel in control, and lack of control is part of what makes you feel vulnerable, is there another way to control the situation?

For example, you might ask questions of trusted others in private messages rather than exposing yourself to the entire online forum, or only attend meetings where information you need will be shared. You could sit in the back and leave if things feel too overwhelming, or take breaks and return. If you’re worried what others will think, you can develop a “sound bite” speech to explain that you are pacing yourself/practicing good self-care/drank too much coffee and needed the bathroom/in denial (if the person asking is a fellow polio survivor, he/she will likely laugh).

It’s also all right to decide groups really aren’t your thing and you’d rather not waste precious energy on dealing with them. Those who use groups and forums aren’t better adjusted or coping better—they’re coping differently. Obtain information in ways that make you comfortable and you will be coping just fine!

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.
QUESTION: Every day I find there is something that annoys me—a truck parked in front of a ramp, someone without a handicapped sticker parked in the handicapped spot, a store counter that is too high, someone remarking on how well I drive my scooter. How do I decide which to respond to, and how to respond?

Response from Rhoda Olkin, PhD:
This is a great question as it is one that faces everyone with a disability. The experiences you are describing are called ‘microaggressions.’ These are everyday insults, put-downs, slights, due to your disability status. The intent of the speaker (“I was only joking.”) is not what is important in a microaggression, but the impact on the recipient.

For example, sometimes when I back into an elevator in my wheelchair someone will say to me “you drive that thing really well.” Why should this bother me? First, because each person believes they are the first to remark on this amazing skill of mine, when in fact I hear it a lot. Second, it means they are primarily noticing me as a wheelchair user, not a person. And third, of course, I drive the wheelchair well—I’ve had lots of daily practice. I don’t comment on how well people use their legs!

But what about the store counter that is too high? How can I be upset about that, it’s nobody’s fault. Well, of course it is. Think of how many people were involved in the design of a store, who signed off on the plan, and the number of employees who see the height of the counter and don’t think about its accessibility. The counter represents the failure of many professionals to recognize that people with disabilities will need to be served at a counter that is too high.

These are things you notice, that upset you, that you encounter very frequently. The sheer number can get you down. Plus, each time you have to decide if and how you are going to respond. That uses emotional energy. So what’s a person to do? Here are a few guidelines I’ve developed.

List priorities. For example, Itzhak Perlman, the renowned violinist who had polio and walks with crutches, has made accessibility at concert halls his priority. What would be your priority?

Have responses ready. When someone says to me “you drive that really well,” I say “yes I do,” and let it go. It is not worth the energy. But when someone says “you’re going to get a speeding ticket in that thing!” I am more irritated, so I say “and you’ll get one when you run.” Maybe this will make them think about it a bit.

Target the right person. There is absolutely no point in yelling at the 19-year-old part-time worker behind that too-high counter. He has no power. If you are going to take action, call for the manager or write to the headquarters of the company.

Choose battles wisely. There are many battles out there. Try to choose those that fit your priorities, and, importantly, those you can win.

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.
The she is a polio survivor and single mother of two grown children.
Question: I contracted polio at 10 months old in 1953 and it affected my left leg (knee down) and right foot. It’s been recommended to me recently to try using an FES Bike with the goal of strengthening my upper leg muscles. Has anyone experienced a gain in muscle strength after using such a machine? I am luckily blessed with almost no pain. My goal is to strengthen my upper leg muscles which are now getting weaker due to post-polio affects. I have fallen twice in the last two years, when my knees gave out for no apparent reason.

Answer: Please don’t become involved with regular use of an FES bicycle. It will not benefit you and may cause you harm. I will try to explain why. And, I will add that anyone recommending FES for a polio survivor with residual weakness and post-polio syndrome does not understand the basis for muscle weakness after a poliovirus infection, let alone what is happening with PPS.

FES (Functional Electric Stimulation) is used to stimulate nerves going to muscles when a person is unable to fire those nerves themselves through voluntary effort or intent. The classic example is after a spinal cord injury when nerve pathways in the spinal cord have been damaged, and therefore, messages from the brain “to move” a leg muscle are blocked from reaching the motor nerve cells in the lower spinal cord that are still alive, and capable of sending a signal to the muscle to contract.

The FES bicycles are a very sophisticated way to electrically stimulate leg muscles in the correct sequences to contract and power the bicycle wheel mechanism. Regular use of this device does strengthen the otherwise weakened and paralyzed leg muscles. What makes this beneficial is primarily the cardiopulmonary conditioning benefits derived from exercising the paralyzed legs.

People with a history of polio have residual weakness after their viral infection due to the death of significant portions of the motor nerve cells that normally innervate and provide the signal to the limb muscles. They have a reduced population of functioning nerve cells and they are usually connected to more muscle cells and tissue than in a non-polio person (3-6 times more). This is largely responsible for the rapid fatiguing of post-polio muscles with repetitive high-resistance work.

If one was to “artificially” stimulate the surviving motor nerves of a polio survivor with a modality such as FES, all of the nerve cells will fire each time the electrical stimulus occurs. They will never get any rest-and-recovery time between repetitions, such as normally occurs with repetitive voluntary effort when groups of nerves fire together and then rest, while their cohort nerves fire in rotating on and off.

There are good reasons to be concerned that repetitive use of FES in polio-involved muscles may become “overworked” and sustain some damage that may hasten further degenerative changes already occurring in PPS muscles (i.e., post-polio weakened muscles that are weakening further due to post-polio syndrome).

I hope that this explanation helps you understand why I made such a strong negative statement about your potential use of an FES bicycle in the opening of this response.
To help yourself with weakening of proximal leg muscles, stick with non-fatiguing relatively low repetition and high resistance (for your muscle strength) exercises. Go to www.polioplace.org/living-with-polio and select “exercise” in Category. If these do not help enough to prevent falling, then pursue other options such as the use of canes/crutches or bracing. I would recommend a comprehensive post-polio evaluation and view this on Polio Place (www.polioplace.org/post-polio-evaluation).

A Message from Dr. Calmes

Selma Calmes, MD, retired anesthesiologist, informs PHI that she no longer can accept consults or questions regarding anesthesia. She reports that she has kept notes on all of the consultations and hopes to compile the information for the benefit of all once she is feeling better.

PHI wishes to thank her for her hours of volunteer work assisting polio survivors facing surgery. Her dedication and caring approach was tireless.

Family

The next issue of Post-Polio Health (Volume 33, Number 3) will feature comments by polio survivors about the importance of family to them, particularly as they age and get weaker. Would you like to participate? The word limit is 350 and a photo would be welcomed. The deadline is no later than June 15, 2017.

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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Inside Post-Polio Health
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A Cautionary Tale about Post-Polio Shoulder Surgery ... 1
Questions to Ask the Orthotist ... 6
Promoting Positive Solutions ... 8
Ask Dr. Maynard ... 10