

Part I

A Gentle Death

Nancy Baldwin Carter, BA, MEd Psych, Omaha, Nebraska, n.carter@cox.net

My mother has been on my mind. She's been gone now for ten years. Death finally came to her after several merciless years of progressive suffering and pain in the nursing home she had selected to take care of her. We had all discussed end-of-life issues with Mother; we knew this was exactly the quality of life she hoped to avoid.

She had a Living Will, as does everyone in our family. She could trust my brother, as her durable power of attorney for health care. He would do his best to see that her written instructions were followed should she become incapacitated. She had no idea that 65% of physicians surveyed said they wouldn't necessarily follow a Living Will. As it turned out, that simply was not what she needed, anyway.

Mother was conscious and capable of making her own decisions right up to the miserable end. She saw no way out. Pain medication clouded her mind and reminded her that this was not what she called living. The last few months of her life were a nightmare. Nothing she knew about could help her avoid that, living where she did.

Options do exist, each offering its own difficult choices: Hospice, Palliative Care programs, Death with Dignity possibilities, for instance. What's good about them all is that those choices can be the patient's. Or we believe they can.

Surveys show that 80% of Americans want to die at home. I'm one of those – let me go on my own terms: a peaceful end, nodding off in my comfy bed with

my husband holding my hand as he wishes for Shakespeare's flights of angels to sing me to my rest.

Likely? Well ...

Death can be far more difficult than we might imagine. So much about death cannot be accurately predicted, even when we hope we have it all arranged. Our bodies may not respond as we hoped. Just when we think the process is under control, something else unexpected can emerge, often causing even more extreme suffering.

Understanding how to deal with issues of the dying often requires help from trained professionals. It's difficult for patients and their families to know how to approach the situation; many are reluctant even to want to. Helping to develop plans for that final exit may seem totally out of the question. Beyond that, saying goodbye to a loved one becomes unthinkable for some, too painful to imagine. Meaningful discussions with our physicians and counselors can guide us to a reasonable approach to managing the sort of outcome we desire.

Examining alternatives is a good way to start. In fact, it might make all the difference. Reports show that while in 1989 only 15% of those over 65 in the general population died in their homes, by 2007 that figure had risen to 24%. A good increase. However, much higher percentages (77 to 97%) of at-home deaths exist for those enrolled in certain end-of-life programs. So learn facts, inspect details. Uncover possibilities, ask

End-of-life issues are difficult to think about and consequently avoided. Avoidance results in last-minute decisions that are based on incomplete facts and misconceptions. This is the first in a periodic series about this important topic.

Few of us became what we thought at age 10 that we wanted to be. But Dr. Jacquelin Perry did.

“I knew at about age 10 that I wanted to be a doctor,” she said. “I read every medical book in the Los Angeles Library.”

She achieved her goal and practiced medicine until a week before her death on March 11 at age 94, despite having lived with Parkinson’s disease for a number of years. She was Emeritus Chief of Rancho Los Amigos National Rehabilitation Center’s Polio and Gait Clinic and its Pathokinesiology Program.

During her nearly six decades at Rancho in Downey, California, she pioneered many clinical breakthroughs and new surgical techniques that would bring her many honors and awards. But to the polio community, it was her work with polio patients in the 1950s and later in the 1980s for which she is best known.



Jacquelin Perry, MD (left)

Dr. Perry earned her medical degree from the University of California-San Francisco and went into orthopedic surgery, not a field that the few graduate women doctors then pursued. She joined the medical staff at Rancho in 1955, one of only 10 female orthopedic surgeons in the country.

She developed surgical techniques for straightening curved spines and fusing shattered vertebrae. One technique, developed in collaboration with Dr. Vernon Nickel, was for paralyzed polio patients, who had been in iron lungs (Rancho was one of the respiratory polio centers funded by the March of Dimes). It used a “halo” device to stabilize weakened necks and immobilize the spine, neck and head. It is still widely used in hospitals to stabilize a fractured neck.

Through her laboratory research, Dr. Perry became the world’s foremost expert on gait analysis and authored *Gait Analysis: Normal and Pathological Function*, which became the standard textbook for orthopedists, physical therapists and rehabilitation professionals. She had a prolific publishing career, authoring more than 400 peer-reviewed publications and nearly 40 book chapters that were noted for their rigorous scientific standards. She was also widely sought as a speaker. In 1996, the Jacquelin Perry Neuro-Trauma Institute and Rehabilitation Center was opened at Rancho.

continued on page 10

POST-POLIO HEALTH

Spring 2013

Vol. 29, No. 2

ISSN 1066-5331

Editor: Gayla Hoffman
editor@post-polio.org

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

©2013 Post-Polio Health International (PHI).

Permission to reprint must be obtained from Post-Polio Health International (PHI).

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

How to contact PHI

Executive Director
Joan L. Headley, MS
director@post-polio.org

4207 Lindell Blvd., #110
Saint Louis, MO 63108-2930 USA
Phone: 314-534-0475
Fax: 314-534-5070
info@post-polio.org
www.post-polio.org
www.polioplacement.org

PHI sends PHI Membership Memos via email. Be sure to set your spam filter to receive emails from info@post-polio.org.

Moving? Change of address?

Notify PHI before you move by calling 314-534-0475 or email info@post-polio.org, and tell us your old and new addresses.

Away temporarily?

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



Richard Daggett

Neurogenic Bladder What Are My Options?

Richard Daggett, Downey, California, richard@polioassociation.org

If you've ever attended a post-polio support group, or participated in a conversation with another polio survivor, you might hear this question: "Do you think my pain is related to polio?" The answer: "It might be related, but it might not be related."

In recent months I asked myself a similar question, and gave myself a similar answer. But, since I am incurably inquisitive, I decided to try to find a more satisfying answer to the question, "Could this be polio related?"

I had a severe case of bulbospinal polio at age 13 in 1953 and was in a tank respirator (iron lung) for about six months. Although I had a moderate recovery, I was still visibly disabled – impaired pulmonary capacity and walked with a noticeable limp. And, as with many of us, I've had my share of post-polio issues.

About a year ago I began feeling that something wasn't right. For more than a month I had mild nausea, bloating and general malaise. I just didn't feel well. My primary doctor was on vacation, so in desperation I went to a local emergency unit. I must have looked dreadful because they saw me right away.

After an exam and an abdominal X-ray, the doctor came in to my cubicle and said, "You look like you are seven months pregnant." He wasn't smiling. It turns out I was retaining urine – three liters of urine!

It must have been building up over time. I had no pain and I thought I was urinating well – at least as well as any man my age. I was given a Foley catheter and I made an appointment with my urologist for the next day. The urologist said we should wait a couple of weeks, with the catheter in place, and then he would do some tests.

When I returned, he did a cystoscopy and a complete urodynamic study. This was uncomfortable, but not very

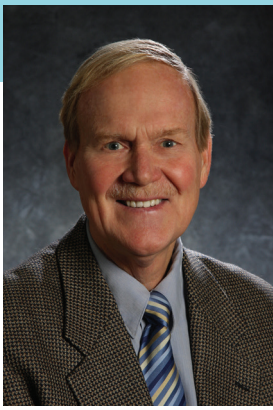
painful. He said the tests indicated I had a neurogenic bladder. I learned that a neurogenic bladder is a dysfunction that results from interference with the normal nerve pathways associated with urination. Hmm. Normal nerve pathways? Polio?

When I asked my urologist if this condition could have anything to do with polio, he said he doubted it, but seemed open to the idea. Most polio-related medical literature describes polio as a disease of the motor nerves. But having had bulbar polio, I know that polio damage can include more than just skeletal muscles. I began a serious search of available medical literature to see if I had missed something in my previous studies.

As I was searching I learned that a good friend had also been diagnosed with this condition and also had to have a Foley catheter. We are about the same age, and both of us had bulbospinal polio. And, in the past few months, I have heard of others with varying degrees of neurogenic bladder. Talking to these polio survivors re-awakened memories of my polio onset. I remembered being catheterized at the same time I was put in the tank in 1953. I remember telling the doctor I didn't need a catheter, and he replied, "You might need one pretty soon, and I'd rather we do this before you need it." These memories encouraged me to continue my research.

I found several references to neurogenic bladder on the Internet, and some of these mentioned polio. Almost all of these sites said something similar to: A neurogenic bladder is the result of

continued on page 10



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: Several years ago my right ankle muscles gave out after a cortisone shot. I wear a brace to steady this leg. Now, after two bad falls, my left hip will need replacement. My current orthopedic physician wanted to give me a cortisone shot, and I refused, recalling the reaction from my ankle. Now I am frightened about hip replacement, because I fear after the trauma of surgery, it will cause my leg to completely give out, putting me in a wheelchair. Since my left leg was the stronger of the two, I am confused about the decision to have surgery.

A: Your concern about another cortisone injection is appropriate because some people have side-effect reactions to the “vehicle” ingredients contained in the specific cortisone injection drug preparation. However, a hip injection with cortisone is usually safe when done under fluoroscopic (X-ray) guidance. A trial test with a small dose put under your skin could clarify any negative or allergic reaction to the cortisone preparation to be used in the hip.

Regarding your fear of undergoing a hip replacement surgery, I would agree that it is a big operation with many possible risks. Before having it done, I would strongly recommend a thorough evaluation by a non-surgeon, rehabilitation medicine physician to learn of any other options for your specific symptoms. Even if the second opinion agrees that hip replacement surgery is a good option, the assessment would be useful for planning post-operative rehabilitation needs that may include need for a longer hospital stay in a rehabilitation unit, prolonged help at home or a nursing facility during the recovery period of several months when full weight-bearing activity will be limited, and/or pre-operative exercises and equipment needs evaluated in advance.

In general, hip replacement in a post-polio limb with very significant long-existing weakness should not be done except to limit constant pain at rest, and in these cases post-operative walking will not be anticipated or be only minimal. In a post-polio limb with only minimal/modest weakness at the hip and thigh (probably like your “good” leg), replacement surgery can be considered to relieve severe pain associated with weight-bearing walking and moving-about activity in order to permit those activities to continue to be done. In that case the risks and benefits are similar to people who didn’t have polio, and the important thing is to plan ahead for anticipated special post-operative rehabilitation needs.

Question: I am posting this question for my husband who had polio at age 2. He was affected quite seriously and was not able to stand on his own. He recovered completely, and now at age 52, is seeing signs of post-polio syndrome (PPS) that include weakness and atrophy of his thigh muscles. While consulting a neurologist in India, it came up that the weakness should start in calf muscles first and affect those muscles more. While my husband has seen weakness in calf muscles, the atrophy in his thighs is more significant. Are there other reasons for this? Also, my husband got an EMT done in 2009 and the doctor is advising him to get another one. Is this necessary? We have to pay for all tests ourselves.

A: It is not unusual for later life weakening and atrophy (PPS) to occur in the thigh muscles and not the calf muscles, or be worse in the thigh muscles, which are the more impactful muscles to affect walking. This fact in itself should not drive one to be particularly concerned about a disease/diagnosis other than PPS.

I don't know what an EMT test would be. Perhaps you meant an EMG, or electromyography? EMG is done with needle insertions into the muscle with a recording electrode and it provides information on the normal healthy functioning of the nerves and muscles, which can help explain why atrophy is occurring, including from PPS. If he had an EMG about three years ago, I would not think it necessary to repeat, unless it was entirely normal then, and yet the atrophy is progressing. Ask the doctor recommending it exactly why it is being recommended and how results would affect treatment.

Question: I had a Grice-Green procedure in 1955 to correct toe drop and weak foot muscles in my right foot secondary to polio. I have had outstanding results since then. Though I have a gait specific to my disability, I am a hiker and can walk with good hiking boots for as far as eight miles. This is becoming more difficult as my ankle is becoming more pronated. The original surgery fused the right subtalar joint on the right foot and the tendon transfer was attached on the right so that the foot toes out to the right and the ankle collapses more. I am having more difficulty walking for any distance with just sneakers and an orthotic for foot support. Is further corrective surgery ill advised?

A: After 55 years of use, what is likely wearing out is your tendon transfer. This can result in more foot pronation and troubles. Your two options are an AFO designed to support your ankle/foot or to consider some type of surgery, likely a fusion. The latter is rarely done in older people because of circulatory concerns and slow bony fusion, with new pain problems common. The other limitation is expert surgeons who use effective procedures — I know of only very few and the best ones are very selective in who they will do a procedure on.

If you are committed to pursuing a surgical opinion, let us (PHI) know where you live so we can attempt to find some recommended names or institutions in your part of the country for you. I can't guarantee or endorse them, but we are willing to use our networking resources to find some surgeons for you to consult and get opinions if you desire.

Question: I scraped and cut my leg that is most affected by polio. It has not healed after two months. (I am not diabetic.) My family physician is sending me to a wound clinic. What can I expect at the wound clinic? Have you seen slow healing in polio survivors? Do you have any other advice?

A: There are many reasons for delayed healing of cuts on the leg, especially in older people. It is not an expected result of post-polio residual weakness. However, many aging polio survivors develop other conditions, some related to their long-term polio limitations that may contribute to slower healing. A referral to a wound clinic is a good idea. They will look into possible superficial infection as a cause of the poor healing and treat it if necessary. They will evaluate your leg circulation, including venous flow carrying blood out of the leg to prevent swelling and edema. They are also experts at the optimal type of cleansing routines and dressings for the sore.

In my experience, the most common factor contributing to poor healing in polio survivors is insufficient attention to controlling swelling and edema. Frequent and lengthy periods of having the leg elevated are difficult but can be very important to successful healing. One should maintain a good activity level to prevent new weakness from inactivity, while still avoiding longer periods of standing, walking or having the feet down. Also using some type of supportive wrapping or support stockings when on your feet can also be very helpful. These suggestions can be discussed and considered with the wound clinic staff (usually nurse clinicians as well as doctors). ■

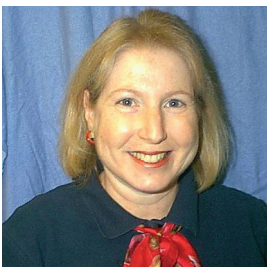
PROMOTING POSITIVE SOLUTIONS

QUESTION: *I am a 62-year-old happily married mother of two. I have a history of bulbar polio and have started speech therapy for new swallowing difficulties and problems with vocal endurance. Thus far, I have been able to adjust to every change brought on by post-polio syndrome, but this new change is really hard for me. My speech therapist is instructing me to “conserve my speech.” I am known in my friend and family circle as an outgoing person and a gifted conversationalist. I have been feeling great loss for not being able to be spontaneous verbally. I know the strategies will help in conserving my voice, but I am stuck in grief. Any thoughts?*

Response from Rhoda Olkin, PhD:

Before we deal with potential loss, let us consider what might be happening regarding swallowing and vocal endurance. You mention your speech therapist, and I am not clear what training that implies, whether that person is a medical doctor or someone trained in correcting speech problems. If that person is not an MD, I strongly advise you to seek a consultation with an otolaryngologist, i.e., an ear-nose-throat doctor.

My rationale is twofold. First, to be told to make a major life change such as conserving speech should depend on a thorough evaluation of the problem and any possible remedies, and I would want more than one opinion and at least one of those to come from someone who had examined my apparatus and could give me a cogent explanation of the problem.



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.

Second, it is too easy to ascribe everything to polio.

I went through about five years of thinking I was having swallowing problems – my throat seemed to seize up sometimes when eating, especially when fatigued. I went to an otolaryngologist, who was able to look down my throat (through the nose and down – really really really not as bad as it sounds!) and demonstrate that everything was functioning. She even had me eat dry crackers in front of her and show her what was happening as I swallowed and talked. Turns out nothing was wrong. I therefore learned to relabel swallowing difficulties as anxiety, eat slower and relax a bit more.

Regarding speech, I do lose my voice easily, but I teach, so I certainly cannot talk less. What I do is take short speech breaks about every 15 minutes (I ask students a question), and use a microphone when talking to more than about 10 people, so I don't have to raise my voice to project. I certainly talk as much as I ever did. And yes, sometimes my voice gets raspy and I am quiet for a bit, but by then probably everyone is sick of hearing me anyway! So consider (a) investigating the issue further; (b) using a microphone as needed; (c) going about your life the same as ever.

Okay, so suppose you investigate further and it does become clear that you have to “conserve speech.” As much as I doubt that this is necessary, it is worth considering how to tolerate and manage any major life changes brought by aging and disability, because if it isn't speech, it might be something else. You say you are “stuck in grief.” Are you perhaps thinking this is a necessary stage towards the mythical ideal of acceptance? Because it isn't.

If you are experiencing grief, you need to make sure it is not depression, because depression is very treatable. I do think grief and loss are parts of the process of living with polio, because over time

our abilities change and we have to shed some beloved activities. These activities have to be replaced with equally beloved activities. Speech might take second place to writing, for example. Communication is the goal, and there are myriad ways to communicate these days (email, texting, Facebook, Twitter, etc.). So reducing speech does not equal reduction in communication.

QUESTION: *I am a 79-year-old male who had mild polio. At every annual medical visit, my doctor urges me to manage my stress and feels strongly about meditation. I have tried it and don't like it. Sitting in a room, closing my eyes focusing on my breathing feels boring, and I don't get it. I have read many articles pointing to the health benefits of meditating, but I can't get into it. Is there another approach to stress management that has the same evidence base in terms of effectiveness?*

Response from Stephanie T. Machell, PsyD:

As you've discovered with meditation, it doesn't matter what the evidence base says: the best stress management technique is the one you'll do! It sounds like you've done your research, and so you know that the reason meditation works is because it "resets" your nervous system such that you become less reactive and more reflective.

Being less reactive to stress helps your body because when you react, the sympathetic nervous system pumps out adrenaline. Once the threat is past, the parasympathetic nervous system pumps its own chemicals to clean up the adrenaline. It takes nine times as long for this cleanup to happen – and it results in additional muscle pain and fatigue, which someone with even mild PPS cannot afford.

Meditation is especially effective at accomplishing this.

There is no right or wrong way to meditate and many different techniques. If what turns you off is the silence, solitude and

eyes being closed, you could try keeping your eyes open and doing it in a pleasant place outdoors. Meditating with others in a class at your local hospital or senior center creates a very different experience. Or you could use one of the many available tapes or music.

If meditation itself is the turn-off, there are other things you can do to reduce your stress that have a good evidence base. If you are able to do so, deep breathing takes very little time and can be done any time anywhere. You can learn to do progressive muscle relaxation or visualization exercises from a tape, a book or a class. Autogenic training, which combines a body scan with specific relaxation techniques, appeals to some people.

There are more active approaches to managing stress as well. If you are able to do it, exercise, especially gentle yoga, has been found to be beneficial. Attending religious services, engaging in social activities, doing volunteer work, spending time with friends and loved ones or engaging in a hobby all reduce stress. For those who love animals, research shows spending time interacting with them has health benefits. Writing, especially journaling, is another technique that has a good evidence base. Getting out in nature, even if it's only your own backyard or looking at a beautiful view from the comfort of your car, has also been proven to reduce stress.

continued on page 9



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.

A Gentle Death

continued from page 1

questions. If one option sounds appealing, consider that one. If another does not, then do not choose that one; move on, keep looking. Here are some choices:

Death with Dignity

The Oregon Death with Dignity Act is one option. Although voters in the state of Washington passed a nearly identical law in 2008, and in 2009 the Montana Supreme Court approved progress made in such a law in that state, the Oregon Death with Dignity program provides information from 15 years of its successful operation. Other states have Death with Dignity Acts in various stages of development. Since 1997, adult Oregon residents (there is no minimum residency requirement) who are able to make and communicate health care decisions and have been diagnosed with a terminal illness that will lead to death within six months may enter a program to request medication helping them end their own lives in a “humane and dignified manner.”

Of course, it’s not that easy. Safeguards abound. Every part of the program is strictly regulated. A patient wanting the lethal doses must first register: sign and date an application form that is also witnessed by at least two others, one of whom is not a relative, not someone who would profit by the patient’s death, not the patient’s attending physician and not

anyone connected to the patient’s health care facility, if there is one. These witnesses must swear the patient is capable and is making the request voluntarily, without being forced.

This is a tightly-run ship. Nobody merely trots in and is given a handful of pills. A prescribing physician and a consulting physician must confirm the patient’s diagnosis, his prognosis and his capability. A psychiatrist or psychologist must examine any patient whose judgment seems impaired. Many sorts of examinations and determinations are required. All of this happens before the patient is accepted into the program. The law must be followed – and it is a stringent law.

Check Out These Facts:

- ◆ Only terminally ill patients can register for the Oregon Death with Dignity option. Statistics from this program’s records show that of the 77 deaths in 2012, 67.5% were 65 or more years old, 97.4% were white, 42.95% had at least a bachelor’s degree and 75.3% had cancer.
- ◆ The patient is totally in charge of taking the lethal medication and is never required to do so. Many do not ever take the pills. They merely want them on hand for peace of mind, a measure of security, in case the day comes when the disease becomes intolerable.
- ◆ Between 1997 and 2013, prescriptions for lethal medications under this law were written for 1,050 patients, and 673 of them died from taking those meds. During 2012, 67 died from ingesting the medications, which were prescribed for 115 patients.
- ◆ Other viable options to the Death with Dignity program must be explained by the prescribing physician to the patient before his choice is made.

Live for today ...



But plan for tomorrow.

Nancy Baldwin Carter, a Nebraska native, contracted polio in 1948 at age 11. With BA and MEd Psych degrees, she began her career as a high school English teacher and moved on to administering adult education programs in Missouri and Kentucky. Carter founded Nebraska Polio Survivors Association in 1984 and was its initial director.

She was a contributing author to Dr. Lauro S. Halstead’s *Managing Polio: A Guide to Living Well with Post-Polio Syndrome* in 1998 as well as its second edition in 2006. Carter has written three series of columns for Post-Polio Health International – “Leadership,” “Polio Survivors Ask ...,” and “Post-Polio Thoughts.”

Promoting Positive Solutions

continued from page 7

If none of the above appeals to you, how about laughter? Laughter yoga, where groups of people gather and laugh for an hour (really!), is an up and coming stress reduction technique. Watching funny movies or television shows, listening to comedy or reading humorous books is a stress reduction technique most people enjoy.

I would be remiss if I didn't point out that if your stress levels are extremely high and you are having difficulty managing them on your own, you might want to see a mental health professional for a consultation. In addition to talking about the issues that may be causing your stress, he or she can help you learn effective stress management techniques. ■

continued from page 8



- ◆ Actions taken under this law are not, in any way, legally considered to be suicide.
- ◆ Participating in this program has no effect upon a patient's insurance policy (life, health, accident or annuity).
- ◆ Extensive thorough records are kept on every patient's involvement in an Oregon Death with Dignity Act program and are available to the public.

Deciding on a preferable end-of-life plan can be challenging. Some patients "partner" with other programs as they seek comfort and care in their final months. Not surprisingly, records show that well over 90% of individuals in the Oregon Death with Dignity Act program were enrolled in hospice when they received their lethal prescription or when death came. Many seem to believe that this combination of options lies closest to providing relief from worry about losing their quality of life and dignity as they move nearer to the end. And most choose to meet death in the quiet comfort of their own homes. ■

PHI Elects Two New Board Members

Post-Polio Health International welcomes two new directors who were elected at a recent board meeting: Sandra Loyer of Ann Arbor, Michigan, and Mohammed Yousuf of Fairfax, Virginia.

In addition to teaching, Loyer has more than 30 years' experience in social work in a variety of fields from neurosurgery to spinal cord injury to primary care. Currently she is in private practice and is a military family life consultant to the U.S. Department of Defense. Her community and volunteer activities include board president of the Samaritan Counseling Center and member of the board of the Ann Arbor Center for Independent Living. She holds an AB degree from Ohio University and an MSW degree from the University of Michigan.



Sandra Loyer

"I bring to the board a lot of experience working with people who have had polio and all the knowledge I have learned from them. I have years of experience working with families and have developed an understanding of their needs and ways to help them meet those needs. Over the years, I have listened very carefully to my patients and clients and try hard to understand their particular situation, culture and belief system. I do not believe in a 'one size fits all' approach. My military experiences have expanded my horizons in understanding the human condition. I look forward to both learning from my participation in the PHI board and to actively contributing."

Yousuf is an engineer and disability rights activist whose previous positions include product design and project engineering for Chrysler Corporation and General Motors. Currently he is a research engineer for the U.S. Department of Transportation. He is founder and president of the Equally Able Foundation and co-chair of the ADAMS Accessibility Committee which works to improve inclusion and disability awareness. He holds BS degrees in Electronics & Communication Engineering from Osmania University in India and an MS degree in Computer Engineering from Wayne State University in Michigan.



Mohammed Yousuf

"As a person who has lived with polio most of his life, I know how important PHI could be to those who have been on this journey. I believe that PHI is the only organization that is still working to enhance the lives and independence of polio survivors, and that means a lot to me. Those of us who have lived through difficult times know what independence means, what mobility means. Through PHI, we can make a difference in the lives of people who have had polio and people with disabilities. I hope to make a difference by bringing to the board my personal experiences of dealing with disability, running a disability organization and working in research areas that touch both people with and without disabilities." ■

continued from page 3

interrupted bladder stimulation at the level of the sacral nerves. This may result from certain types of surgery on the spinal cord, sacral spinal tumors, or congenital defects. It also may be a complication of various diseases, such as syphilis, diabetes mellitus or poliomyelitis.

This was a partial help, but none of these references pointed to any reasons for polio to impact the bladder muscles. The only two published medical articles I could find were references in the *Journal of the American Medical Association* in 1948 and the *Journal of Urology* in 1936.

Regardless of the cause, the next question for me was what were my treatment options? The obvious first step was the indwelling, or Foley, catheter placed while I was in the ER. This eliminated the urine retention. This also brought almost instantaneous relief from my nausea and malaise. After I stabilized and all the tests were completed, my urologist suggested intermittent catheterization. This procedure requires that a person insert a disposable catheter several times a day. Because of my limited arm and hand strength this was very difficult for me. It was also fairly uncomfortable.

I have been using a Foley catheter, replaced monthly, for about one year.

It is not recommended to use one beyond that length of time because of the risk of infection, erosion of urethral tissue and other complications. If my urethral Foley catheter needs to be discontinued, a relatively common solution is to have a suprapubic catheter. This is an out-patient procedure to place a catheter into the bladder through a small incision in the lower belly. My friend with the neurogenic bladder has had a suprapubic catheter for several months and has had no problems. It is much more comfortable than the urethral catheter.

Another possible treatment is a “pacemaker” for the bladder. The one I have researched is the Medtronic InterStim®, used to treat incontinence and also retention problems. This small apparatus uses wires surgically implanted in the sacral nerves to stimulate the bladder muscles. Based on my research, I am not inclined to have such a surgical procedure at this time.

Decision time is rapidly approaching, and I will make my decision in consultation with my urologist. I welcome feedback from other polio survivors, and will post a medical update in a future issue of *Post-Polio Health*. ■

Jacquelin Perry, MD, 1918-2013

continued from page 2

When polio survivors in the 1980s began to experience symptoms of extreme fatigue, muscle weakness, joint pain and breathing difficulties, Dr. Perry was one of the first – along with PHI founder Gini Laurie and Dr. Lauro Halstead – to identify the condition as the late effects of polio.

She told the *New York Times* in 1985 that polio survivors “just push themselves more than most of us. They’ve put up with signs of strain to live a normal life. I always say people who had polio are overachievers, because so many of them are out to prove they can do just as well as those who didn’t have it. But now the strain has accumulated, and tissues are aging prematurely.”

Dr. Perry’s advice: “Modify your lifestyle to accommodate your new reality,” and “Listen to your body and adopt a program that avoids the strain.” ■

Jimmo V. Sebelius Approved

Who? In January 2011, the Center for Medicare Advocacy (www.medicareadvocacy.org) filed a motion in United States Federal District Court on behalf of five individuals and five organizations against the Secretary of Health and Human Services (Kathleen Sebelius).

Why? The motion alleged that the standard that Medicare used for years – denying coverage of service for people on Medicare with medical conditions that are not expected to improve, i.e., the “improvement standard” – was unlawful. Denial of services was also explained by the fact that people needed services, such as physical therapy and occupational therapy, for “maintenance services only.”

What happened? A federal judge in Vermont approved the settlement to end Medicare’s longstanding practice of requiring people to show improvement to continue to receive services on January 24, 2013.

What’s next? The Centers for Medicare and Medicaid Services (CMS) is revising its Medicare Benefit Policy Manual and numerous other guidelines, etc., to make it clear that coverage of skilled nursing and therapy services are not dependent on an individual’s potential for improvement. They will also launch a nationwide educational campaign to alert Medicare beneficiaries with chronic conditions of the new guidelines. This change applies to Part A and Part B and for services in a skilled nursing facility, home health, inpatient rehabilitation therapy and outpatient therapy. There are other finer points/restrictions that will be described in the upcoming documents, and all other Medicare requirements must still be met.

When does it take effect? It is in effect now, and, the settlement goes back to January 18, 2011.

How does it affect U.S. polio survivors? First of all, for individuals who were denied service after January 18, 2011, paid for them out of pocket and appealed, the settlement outlines a re-review process. Secondly, this is the law now. Challenge providers if they deny a need for skilled maintenance care for anyone meeting other qualifying Medicare criteria.

For more details, go to the website of the Center for Medicare Advocacy (www.medicareadvocacy.org) and click on Updated Jimmo News from CMS. www.medicareadvocacy.org/hidden/highlight-improvement-standard ■

THANK YOU

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

Etta Chagy
Dellis S. Markowski

William G. Ohme
Desha N. Sanders, Jr.

Contributions to the Research Fund ...

In Memory of

Charles Patrick Colby, Jr.
Maxine Ellis

William G. Ohme
Desha N. Sanders, Jr.

Contributions to the Gilbert Goldenhersh Memorial Tribute Fund ...

Michael Schwartz
Rita Worth, in honor of a speedy recovery

Not yet a Member?

Join PHI for just \$30 a year (Subscriber Membership) and receive your own copy of *Post-Polio Health* four times a year (February, May, August, November), plus eight *PHI Membership Memos* via email. For \$55 (Subscriber Plus Membership), join PHI and IVUN and also receive *Ventilator-Assisted Living* via email six times a year (February, April, June, August, October, December) and six *IVUN Membership Memos*.

You can join online at <http://shop.post-polio.org> or send (or fax, 314-534-5070) this form to: Post-Polio Health International, 4207 Lindell Blvd, #110, Saint Louis, MO 63108-2930 USA. Questions? 314-534-0475 .

\$30 Subscriber

Post-Polio Health (quarterly)

\$55 Subscriber Plus

Both *Post-Polio Health* (quarterly) AND *Ventilator-Assisted Living* (bi-monthly)

Name _____

Affiliation _____

Address _____

City _____ State/Province _____

Country _____ Zip/Postal Code _____

email _____

Phone (include area/country code) _____

I am enclosing a check for \$ _____ made payable to “Post-Polio Health International.” (USD only)

Please charge \$ _____ to this credit card:

VISA MasterCard Discover

Card No. _____ Exp. Date _____

Name on Card _____

Signature _____

POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

4207 Lindell Boulevard, #110
Saint Louis, MO 63108-2930 USA

**Plan to Attend
PHI's 11th
International
Conference
May 31-June 3, 2014**

Hyatt Regency St. Louis
at The Arch

MAY 2014

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
25	26	27	28	29	30	31 PHI's

JUNE 2014

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
1 Promoting Healthy Ideas	2	3	4	5	6	7

Inside Post-Polio Health

Vol. 29, No. 2, Spring 2013

- A Gentle Death ... 1
- Jacquelin Perry, MD ... 2
- Neurogenic Bladder: What Are My Options? ... 3
- Ask Dr. Maynard ... 4
- Promoting Positive Solutions ... 6
- PHI Elects Two New Board Members ... 9

Maximum Increased

The Joyce and Arthur Siegfried Memorial Fund and the Gilbert Goldenhersh Memorial Tribute Fund (Missouri residents only) have funds available to assist survivors in need to purchase bracing, or modified or custom-made shoes. The maximum amount available per person is now \$800. To obtain an application and an explanation of the process, email info@post-polio.org or call 314-534-0475.