

PHI's mission is supported by its Membership.

An Afghan Polio Survivor's Journey

Like many polio survivors, Shapari was too young to remember most details about contracting polio. “My parents said I had come down with a fever. Soon,” she recalls, “I lost sensation and energy in both my legs.” As a young girl growing up in Afghanistan, Shapari remembers not being able to run and play with her classmates. Each day, she looked forward to her father coming to pick her up and take her home.



Shapari with diploma from Gandhara University. Courtesy of UNHCR Pakistan.

In fifth grade, events out of her control once again dramatically changed the direction of her life. Conflict had broken out near her home in Afghanistan, and her family, fearing for their safety, fled across the border into Pakistan, where they settled as refugees in the city of Peshawar.

Life was not easy as a refugee, let alone one with a disability, but Shapari's parents managed to enroll her in a local school. Her parents described her as a hard-working and bright student, but, without proper medical care, her physical

condition continued to worsen. Weakness in her hands made it difficult to even hold a pencil.

With the help of supportive teachers, Shapari managed to reach the 12th grade. However, her physical ailments and ever-present social stigmas surrounding disability in Pakistan pushed her into depression. For the next three years, she barely left home.

Concerned about her condition, Shapari's mother urged her to get out and go spend time with her sister. As her mother pushed her in her wheelchair, Shapari had a fateful encounter that would alter the course of her life. “As we were on our way to my sister's home in Hayatabad, an old bearded man saw my mother pushing me in a wheelchair,” Shapari recalls. The man suggested she visit Habib Physiotherapy Complex and meet with Dr. Mahboob Ur Rahman, its founder and director.

Dr. Mahboob Ur Rahman, who can be found in PHI's *Post-Polio Directory*, has been assisting Afghan refugees and other polio patients since the 1980s when he established a free polio clinic in Peshawar, a city of roughly two million people 35 miles from the Afghan border. He opened Habib Physiotherapy Complex in 1997 and has also arranged free polio camps in different districts all across Khyber Pakhtunkhwa province in northwestern Pakistan.

Once she arrived at the Habib clinic, Shapari was able to receive proper rehabilitative care. After approximately three months of treatment, she no longer required the use of a wheelchair to get

continued on page 2

around. After six months, Shapari was able to walk without the use of crutches or orthotic support.



Shapari with her mother (right). Courtesy of UNHCR Pakistan.

Dr. Mahboob Ur Rahman became a sort of mentor to her and helped get her a scholarship to work toward a BSc in Physiotherapy at the Mahboob College of Physiotherapy/Mahboob Medical Institute, an initiative made possible by the support of various NGOs operating in the country. The United Nations High Commissioner for Refugees (UNHCR), the Commissionerate for Afghan Refugees and the International Rescue Committee have been instrumental in supporting

the institution's rehabilitation and physiotherapy training program. In particular, UNHCR supports the training by covering tuition fees, course material costs, transportation and stipends for trainees.

Shapari also received a DAFI scholarship through UNHCR. Funded by the Government of Germany and administered by UNHCR, the Albert Einstein German Academic Refugee initiative, known by its acronym DAFI, grants scholarships to deserving young refugees enrolled in Higher Education Commission (HEC) recognized universities, colleges and polytechnics in Pakistan.

Shapari thrived in the program, but problems with her health interrupted her plans. Showing determination, Shapari pushed on and eventually graduated last year from Gandhara University Peshawar's physiotherapy program. She has since returned to Afghanistan to help treat those with disabilities who might find themselves in similar circumstances to hers as a child.

Shapari's journey shows what is possible when polio survivors in that part of the world are given access to proper medical care, education and other forms of social support. "I told myself, I have polio, but polio does not have me." ■

POST-POLIO HEALTH

Winter 2020

Vol. 36, No. 1

ISSN 1066-5331

Editor: Brian Tiburzi, MA
editor@post-polio.org

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

©2020 Post-Polio Health International (PHI).
Permission to reprint must be
obtained from Post-Polio Health
International (PHI).

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.

How to contact PHI

Executive Director
Brian Tiburzi, MA
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.poliplace.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.

Living with Polio as an Adult in the Philippines

Sel Alonde

I am in my mid-30s, single without a family of my own yet and living with polio. My focus is on working and living a purposeful life. The things that get me through living with polio are acceptance and my ability to let things go, along with a good support system, medical team, sense of humor, faith and love.

Family and Work

My family helps with most of the household chores. My only tasks are to cook twice a week and do the dishes after dinner because most of the day I'm gone working my day job. From Monday to Friday, I work as an HR representative at our community hospital. On Sundays, I teach piano. Most of my students are children. I feel blessed because this job sort of just landed on my lap. The music school is only three blocks from my home, and it lets me express my passion for music.

I only have Saturdays off for now, but I am planning on slowing things down and working only half-days on Sundays. I feel slowing down might be best due to the polio. I feel I'm running on a battery that can't be recharged.

My Hospital Care Staff

Since contracting polio at 4, I've been going to the same rehab center in University of Santo Tomas (UST) Hospital. The head of the Apolinario Rehab Center, Dr. Ophelia Reyes, retired to the US when I was 23 years old. But my ortho family have been the same people until just two years ago. It's so important to have the same team and not constantly have to change doctors. They come to know you and can, for instance, customize a fitted leg brace for me for a lower cost and in less time than other places. They are my angels.

Challenges

A big challenge now is that the orthotists resigned (or were laid off) from the hospital where I've gotten my braces since the time I was four. I don't want to transfer to a new hospital because

my entire support team is there at "my hospital." The new guys haven't been able to make my new brace work even after many fittings. I compare it to having a good seamstress—the one you've been with a long time will

know all the tricks to make it fit right the first time. Hospitals sometimes seem to favor "innovative" new braces rather than relying on traditional approaches and experienced technicians.

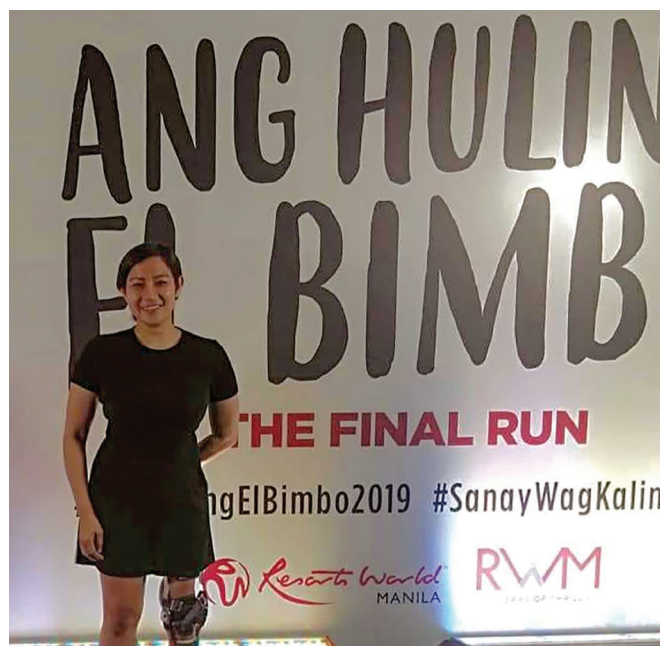
The fitting and adjustments are elixirs for us polio survivors wearing KAFO/AFOs. Adjusting it twice a year or having a "tune-up" every three months works best for me. When I follow this schedule, my leg is less fatigued after walking. However, it is costly. In the Philippines, it is next to impossible to find help to pay for a brace. Many with disabilities that are in need of braces end up in wheelchairs even though they could walk if they had a KAFO. I wish there was more funding for braces so these people could live a more purposeful life.

Psychological support is almost nonexistent here. There are very few support groups around even though I know many people who would like to share their experiences in a group setting.

Getting around is also difficult. Transportation is costly for people with a disability. Use of accessible private vehicles is expensive. Public transport is not very friendly to people with disabilities and using it to commute is difficult.

Acceptance and Letting Go

I think it's important that I learn to accept that things should slow down for me, that keeping up the normal hustle and bustle of my life might lead to regret. There is so much beauty in taking it slow and appreciating all the in-between time now that I'm an adult. Before, I use to put so much importance on belonging and competing. But fulfilling dreams is not just about reaching milestones and racking up "accomplishments." I've learned there are advantages to taking things more slowly. It makes me listen to my body and heart more closely. It helps me know what I was put in this world for—fulfilling my mission and being a good human being. Because having that, even with polio, makes living a great joy. ■



A Polio Survivor's Guide: Funding Resources for Medical & Adaptive Equipment

POST-POLIO HEALTH
INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

M MICHIGAN MEDICINE
UNIVERSITY OF MICHIGAN

UC DAVIS
HEALTH

An Important New Resource from PHI

Living well with a physical disability in the United States is an expensive proposition. Most medical insurance coverage is very limited, sometimes nonexistent, for expenses needed to acquire necessary medical equipment, even ventilators for people who are unable to breathe adequately or wheelchairs for people unable to walk. “Medically necessary” criteria for coverage are not uniform between plans; co-pays or coverage limitations can be burdensome and spending limitations often lead to poor quality items. Almost no insurance plans contribute to costs for architectural modifications of homes, vehicles, clothing or adaptive equipment that could increase one’s independence, productivity and/or quality of life. Consequently, many US citizens with physical impairments feel like they pay an “American surtax on disability.”

PHI, with assistance from the University of Michigan Department of Physical Medicine and Rehabilitation and University of California, Davis

Department of Physical Medicine and Rehabilitation, have compiled a directory of funding resources from around the country for medical and adaptive equipment. The project was completed by a team of investigators coordinated by PHI board member Sunny Roller with the goal of compiling a list of potential resources available to assist people with disabilities obtain the adaptive medical and rehabilitative equipment and environmental modifications they determine that they need. Besides doing a deep search of the internet, the team reached out to a multiple consumer and professional networks. The end result is a list of valuable resources organized by state that any polio survivor can have access to.

View the new directory, *A Polio Survivor's Guide: Funding Resources for Medical and Adaptive Equipment*, at www.polioplace.org/sites/default/files/files/PHIFundsDirectory2020.pdf. ■

New PHI Website to Go Live This Spring

PHI is preparing to roll out a completely rebuilt website this coming March. The new site will have the same URL, www.post-polio.org, but will look and function much different than the current site. We've kept all of the same great, trusted information you've relied on over the years, but adapted it to a new user-friendly design that should make finding the answers to your most pressing questions that much easier.

"As we've added new information, articles and PHI publications to the current site over the years, we've realized that it has made the site difficult to navigate for some," explained PHI Executive Director Brian Tiburzi. "In addition, we wanted to take advantage of some of the newer features that have been developed in recent years."

One of those new features we're most excited about is our new interactive directory that lets users search for the nearest support groups or health professionals based on their location. Users will be able to let their device automatically detect their location (or they may select a state from a drop-down), which will then display a list of nearby results alongside a map marking the location of each. Users will no longer have to load a PDF and scroll through page after page to find their country or state.

The new website will also automatically convert to a mobile-friendly design when viewing it on your phone or tablet. In addition, the new site will be designed to meet current ADA website accessibility standards.

Look for a special announcement this spring alerting you that the new site is now live, as well as a guide to some of the site's exciting new features. ■

The screenshot displays the new website interface for Post-Polio Health International. At the top, a navigation bar includes links for About, Networking, Research, Education, and Support Us, along with a search icon. The main header features a large image of a woman standing next to a golf cart, with the text: "Here to support the community of polio survivors and spread knowledge on the late effects of polio." Below this are buttons for "Learn more" and "Make a donation".

The content area is divided into several sections:

- Materials to Keep You Up-To-Date:** A section with a circular graphic containing three portraits and the text "POST-POLIO HEALTH INTERNATIONAL". It includes the subtext "Providing you with up-to-date, quality information on living well with the late effects of polio" and a "PURCHASE PUBLICATIONS" button.
- Connect with Providers from All Over the World:** A section with a globe icon and the text "Connecting you with other portfolio survivor support groups and helping you find health professionals that can answer your questions". It features a "SEARCH ONLINE" button.
- Share Your Story:** A section with a circular graphic containing a portrait and the text "Polio AND ME" by Ken Dalton. It includes the subtext "Explore the past, the present, and help build a promising future for the world's polio survivors at PolioPlace.org" and an "EXPLORE POLIOPPLACE.ORG" button.

A dark blue banner below these sections states: "There is an estimated 11-15 million polio survivors around the world" with an "ABOUT POLIO" button.

The footer contains three columns of information:

- For Health Professionals:** "Becoming an Intelligent Consumer of Physical Therapy Service" with a "MORE RESOURCES" button.
- Latest News and Events:** "PHI Awards \$100,000 for New Research in 2015-2017" with a "MORE NEWS" button.
- Giving Aid to Cause:** "We're Still Here! Annual Advocacy Awareness Campaign" with a "MORE ADVOCACY" button.

The bottom of the page includes the organization's name, office address (4110 St. Louis, MO 63108-2930 USA), hours (Monday-Friday 8:30 am-4:30 pm CT), contact information (314-534-0475 phone, 314-534-5070 fax), and social media icons for Twitter and Facebook.

PHI: *My husband had polio when he was three. He's now 74. About two years ago, his body started breaking down. Long story short, he now uses a power chair to go all but the shortest distances. We moved into a ranch and made some modifications so that he could get around better. Things are better now, but for a long time he was angry and depressed by his worsening health. Several people remarked to me during that time that he needed to develop better coping skills. I understand the concept, but it was never suggested what, specifically, he could have done to adapt better to his new limitations. What are some coping strategies you would suggest for those now aging into a disability?*

Response from Rhoda Olkin, PhD:

I'm going to address what it is like as a person with polio when your body starts to fail you. My colleague will address the issues about coping.

You say your husband has been "angry and depressed by his worsening health." Let's parse this: Angry? Of course! Those of us with polio worked hard to keep our bodies going strong. To watch ourselves have more impairments and be less agile and functional, well, that sucks. And to have others judge how we are coping? Completely unacceptable. Does the butterfly say to the caterpillar "You really should be flying, you know"?

Depressed? Hopefully not clinically so, but if it is indeed a diagnosable depression that should be addressed as depression is treatable. (See page 8.) But if it's really sadness, and does not reach the level of clinical depression, that is very understandable. Diminution of functions lead us to new phases of life, ones in which we are frailer.

His worsening health? Not necessarily. Health and disability are related but not entirely overlapping conditions. One can have significant limitations in activities of daily living (ADL) and still be in very

good health. However, poor health tends to bring with it limitations in ADL. So regular check-ups that don't let polio overshadow other health factors should be yearly events.

But how are you? How is it to watch someone struggle with declining function? How does your husband's anger and depression affect your relationship? You are in this with him, and your well-being should not be overlooked. Nor should the importance of the relationship be minimized—social support is one of the most important factors in aging well. So, what about your emotions? Are you angry or depressed? Fed up with others making silly suggestions? Finding your own coping stretched to limits? Remember to take care of yourself just as much as you help your husband.

Response from Stephanie T. Machell, PsyD:

"Coping skills" is one of those buzzy, nebulous phrases people throw around, taking for granted that the person it's being thrown at knows what it means. But what are they?

Coping skills are the learned strategies we use to function in our lives. They are



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.

formed by the interaction of circumstances and life experiences with hereditary traits. We may develop new ones in response to novel situations, and the ability to do this flexibly could itself be considered a coping skill. We are more likely to be aware of them when we are trying to develop new ones, but once developed, they tend to function automatically. Depending on circumstances they may be adaptive (“good”) or maladaptive (“bad”). Those that were once adaptive can become maladaptive when circumstances change.

Like all polio survivors, your husband developed a set of coping skills that served him well for many years. In the process of rehabbing he was taught to persevere in spite of pain and push himself past his physical limits. These skills helped him navigate the world as it was then and to have the best possible life, forming his identity as an overachiever always striving to overcome.

Post-polio syndrome changes everything. Finding out that the skills that served them so well may have contributed to the development of severe symptoms can leave polio survivors feeling betrayed and cheated, even uncertain who they are. They may experience anger or grief. Memories of their polio experiences can also surface.

These are valid reactions. Like all polio survivors your husband needed to have them. Being able to do so is a coping skill, as is learning when and where to express them, and how to use them productively. For example, anger can provide energy for making needed changes. Grieving the

loss of something important, including changes in our health, helps us move forward into the next phase of our life.

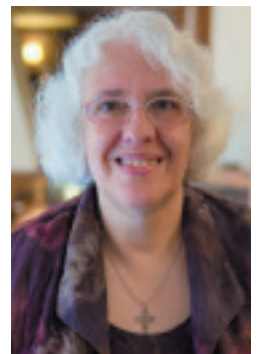
It’s normal for these feelings to come and go over time. However, getting stuck in them drains valuable energy. If this is happening to your husband, there are a variety of therapies and techniques that can teach him specific coping skills, such as cognitive behavioral therapy (CBT)

The coping skills we most often encourage polio survivors to develop are energy conservation and pacing.

and mindfulness. There are many self-help books and classes that teach the basic techniques and apply them to various problems. If your husband needs more help, working with a therapist experienced in issues around adjusting to aging and disability and/or grief could be helpful.

The coping skills we most often encourage polio survivors to develop are energy conservation and pacing. Using them well involves not just cutting back on activities and resting more. Being aware of how his energy levels and pain wax and wane through the day can help your husband develop a pattern of activity and rest that works for him. Within this it’s important that he finds ways of doing the things that give his life light and color, even if this means he needs to rest more afterwards. ■

Dr. Stephanie T. Machell is a psychologist in independent practice in the Greater Boston (MA) area. She specializes in working with those affected by polio and other physical disabilities. Her father was a polio survivor.



The Beck Depression Inventory is a test that measures the severity of a person's depression. This self-report measure is not to be used as a diagnostic tool but only serves to assess the severity of depressive symptoms. This questionnaire consists of 21 points, each point contains of a number of statements. Please read the following carefully and select the one that best describes your health during the past two weeks. The scoring scale is at the end of the questionnaire.

- | | |
|--|--|
| <p>1. 0 I do not feel sad.
1 I feel sad
2 I am sad all the time and I can't snap out of it.
3 I am so sad and unhappy that I can't stand it.</p> <p>2. 0 I am not particularly discouraged about the future.
1 I feel discouraged about the future.
2 I feel I have nothing to look forward to.
3 I feel the future is hopeless and that things cannot improve.</p> <p>3. 0 I do not feel like a failure.
1 I feel I have failed more than the average person.
2 As I look back on my life, all I can see is a lot of failures.
3 I feel I am a complete failure as a person.</p> <p>4. 0 I get as much satisfaction out of things as I used to.
1 I don't enjoy things the way I used to.
2 I don't get real satisfaction out of anything anymore.
3 I am dissatisfied or bored with everything.</p> <p>5. 0 I don't feel particularly guilty
1 I feel guilty a good part of the time.
2 I feel quite guilty most of the time.
3 I feel guilty all of the time.</p> <p>6. 0 I don't feel I am being punished.
1 I feel I may be punished.
2 I expect to be punished.
3 I feel I am being punished.</p> <p>7. 0 I don't feel disappointed in myself.
1 I am disappointed in myself.
2 I am disgusted with myself.
3 I hate myself.</p> <p>8. 0 I don't feel I am any worse than anybody else.
1 I am critical of myself for my weaknesses or mistakes.
2 I blame myself all the time for my faults.
3 I blame myself for everything bad that happens.</p> <p>9. 0 I don't have any thoughts of killing myself.
1 I have thoughts of killing myself, but I would not carry them out.
2 I would like to kill myself.
3 I would kill myself if I had the chance.</p> <p>10. 0 I don't cry any more than usual.
1 I cry more now than I used to.
2 I cry all the time now.
3 I used to be able to cry, but now I can't cry even though I want to.</p> <p>11. 0 I am no more irritated by things than I ever was.
1 I am slightly more irritated now than usual.
2 I am quite annoyed or irritated a good deal of the time.
3 I feel irritated all the time.</p> <p>12. 0 I have not lost interest in other people.
1 I am less interested in other people than I used to be.
2 I have lost most of my interest in other people.
3 I have lost all of my interest in other people.</p> <p>13. 0 I make decisions about as well as I ever could.
1 I put off making decisions more than I used to.
2 I have greater difficulty in making decisions more than I used to.
3 I can't make decisions at all anymore.</p> | <p>14. 0 I don't feel that I look any worse than I used to.
1 I am worried that I am looking old or unattractive.
2 I feel there are permanent changes in my appearance that make me look unattractive
3 I believe that I look ugly.</p> <p>15. 0 I can work about as well as before.
1 It takes an extra effort to get started at doing something.
2 I have to push myself very hard to do anything.
3 I can't do any work at all.</p> <p>16. 0 I can sleep as well as usual.
1 I don't sleep as well as I used to.
2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
3 I wake up several hours earlier than I used to and cannot get back to sleep.</p> <p>17. 0 I don't get more tired than usual.
1 I get tired more easily than I used to.
2 I get tired from doing almost anything.
3 I am too tired to do anything.</p> <p>18. 0 My appetite is no worse than usual.
1 My appetite is not as good as it used to be.
2 My appetite is much worse now.
3 I have no appetite at all anymore.</p> <p>19. 0 I haven't lost much weight, if any, lately.
1 I have lost more than five pounds.
2 I have lost more than ten pounds.
3 I have lost more than fifteen pounds.</p> <p>20. 0 I am no more worried about my health than usual.
1 I am worried about physical problems like aches, pains, upset stomach, or constipation.
2 I am very worried about physical problems and it's hard to think of much else.
3 I am so worried about my physical problems that I cannot think of anything else.</p> <p>21. 0 I have not noticed any recent change in my interest in sex.
1 I am less interested in sex than I used to be.
2 I have almost no interest in sex.
3 I have lost interest in sex completely.</p> |
|--|--|
-
- Interpreting The Beck Depression Inventory**

Having completed the questionnaire, add up the score for each of the 21 questions by counting the number to the right of each question you marked. *Use the table below as a guideline to interpret your score. This is only a guideline. If you have concerns about your mood, please consult a professional.*

Total Score	Levels of Depression
1-10	These ups and downs are considered normal.
11-16	Mild mood disturbance
17-20	Borderline clinical depression
21-30	Moderate depression
31-40	Severe depression
over 40	Extreme depression

Opportunity to Participate in Research

You are invited to participate in a research study entitled, “Falls and Fear of Falling in Adults who Require Wheelchairs for Locomotion.” To participate you must be an adult who:

- ◆ Is at least 18 years old.
- ◆ Has a neurological diagnosis (such as but not limited to post-polio syndrome, spinal cord injury, multiple sclerosis) for at least six months.
- ◆ Use a wheelchair (manual or power) at least 75% of your mobility time inside your home and 100% of the time outside your home.
- ◆ Has a computer with internet access.
- ◆ Is able to read and understand English.

If you are interested in completing an anonymous online survey about your medical condition, falls, risk of falling, and fear of falling, please click on this link:
<https://www.psychdata.com/s.asp?SID=183112>

It will take you up to about 20 minutes to complete it. People who complete the survey will be eligible for a drawing for a \$20 gift card. People who live in the greater Houston area and agree to be contacted for in-person testing of one transfer in/out of their wheelchairs and sitting balance will be paid \$20 cash after consenting to and completing this testing that requires no more than one hour.

You may contact Carolyn Da Silva, PT, DSc at cdasilva@twu.edu or 713-794-2087 for more information or questions. She is a professor in the School of Physical Therapy at Texas Woman's University and physical therapist at the post-polio out-patient clinic at TIRR Memorial Hermann Rehabilitation and Research in Houston, Texas. ■



TEXAS WOMAN'S
UNIVERSITY™



**Alliant
International
University**

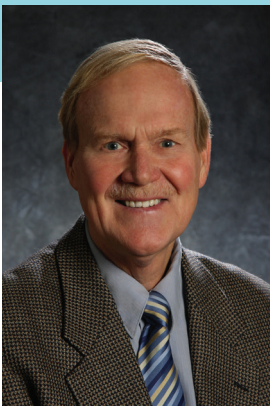
New Survey Opportunity

Marco Gomez, a PsyD doctoral student at Alliant International University who is living with Cerebral Palsy is seeking participants for a survey. Participants must have a physical disability or low vision/blindness, be over 18 years of age, live in the United States, and have participated in psychotherapy at least once since the age of 18 and/or are currently

seeing a licensed mental health professional for therapy (i.e., psychologist, clinical social worker, marriage and family therapist).

You may view the flyer at:

www.polioplace.org/sites/default/files/files/RecruitmentFlyer.pdf, which contains the link to the survey. ■



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: *Thank you for the help you have given me in the past. I'm a 79-year-old male who developed polio at the age of four. I was in an iron lung for several weeks then treated at home with Sister Kenny's hot baths and massage. My left leg was paralyzed but improved over the years to a point that I could walk with a dropped foot and limp. At around 45 years of age, leg weakness set in and I was diagnosed with post-polio syndrome. I went from a cane to crutches to a walker and now to a mobility scooter. I spend about 98% of the day on the scooter and can walk with the walker for about ten feet before fatigue sets in. When I walk, I drag both my leg and foot.*

I have seen neurologists and orthopedic surgeons and was just referred for ankle fusion surgery to alleviate the dropped foot and tendon and ligament damage. That will, of course, require a long recovery period and the possible side effects. Aside from controlled high blood pressure and bullous pemphigoid I am in pretty good health.

Based on the above, do you believe that an ankle fusion is a good option for me?

Dr. Maynard: I am sorry to learn that you are still struggling. I would recommend against doing an ankle fusion because it would potentially only solve one of your problems that are making walking so difficult and energy-consuming for you. Additionally, there are other easier and completely safe alternatives to ankle fusion, such as a fairly rigid plastic AFO brace, perhaps with some movement allowed, which would likely do the same thing as a fusion for helping your walking. And, I agree with you that the post-op recovery period may well be long and arduous with additional surgical risks not insignificant. All of these considerations make an ankle fusion rank poor on a risk/benefit ratio evaluation.

Your continuation of using a scooter for almost all mobility and doing regular "therapeutic exercise" short-distance walking for general health, and for the continued ability to do essential short distance upright walking occasionally as the need arises may be your better options for good physical and emotional/social health. If the independent "therapeutic walking" option requires you to need a little coaching from a PT and consideration of an AFO, ask your primary physician or your rehab physician for a referral.

Question: *I fell nine weeks ago, breaking my distal femur and patella and spraining my distal ACL. A physical therapist comes to my home every week. X-rays show my bones are healing well. This week I'm working on starting to walk stairs, but it's extremely difficult because of my kneecap. I believe the PT is being cautious, knowing about my post-polio condition. I'm taking small steps with a walker, but I feel my kneecap is very unstable. Is this typical for others (not just those with prior polio) with this type of injury? I am 68 years old. I've walked normally in the past (with a limp). At this time, my primary doctor, orthopedic doctor and my PT are positive I'll be walking again.*

Right now, I'm concerned about my future. What is your opinion? Do you think I could strengthen my kneecap again? Should I give it more time for healing? I was so

used to walking without help. Polio affected my right leg and left arm, so I can't use crutches and even using a walker is a bit of a challenge.

Dr. Maynard: The key to the recovery of your ability to walk will be the strength of your quadriceps muscle, the large thigh muscle which attaches to the kneecap and produces straightening and stability of the knee. It is always a long and slow process to re-strengthen the quadriceps after a distal femur fracture, and it is even harder in a polio survivor with any involvement of that muscle from polio. If you have always limped from a weak right quadriceps, you will definitely have a long, slow recovery of strength and may never get back to your pre-fracture level of strength in that leg.

Therefore, I would strongly encourage you to be evaluated and followed through your recovery by a Physical Medicine and Rehabilitation physician who can collaborate with your physical therapist and orthopedic surgeon on the intensity and other details of your recovery rehab program. You will likely benefit from some type of orthotic device and walking aides when your fracture has healed sufficiently to begin safe weight-bearing on the fractured femur. The physiatrist's input and expertise will be important to decide the detail of bracing and walking aides, the intensity and progression of exercises, and when to reduce/eliminate the bracing and walking aides.

At only nine weeks post-fracture, it is way too early to be hopeless about walking again. It will take you a minimum of one year to work your way toward maximum possible recovery of strength and, consequently, of walking ability. It would be ideal if you could have your rehab evaluation performed by a post-polio expert, such as one listed in PHI's *Post-Polio Directory*. Otherwise your nearest PM&R provider who is experienced with neurologic and orthopedic rehabilitation should prove adequate. The referral should be for "Evaluation for and supervision of a rehabilitation program to recover walking ability after a femur fracture in a post-polio involved leg." ■

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.

Contributions to PHI's education, advocacy and networking activities

In Memory of

Mary Peters Aegler
Maurine Dorsey
Patricia Gladden
Meral Goknar
Ronald S. Hanson
Sonia Ruth Jividen
Dorothy Knight
Nick Mantzios

Patricia A. Marshall
Daniel Matakas
David I. McDonald
Joan Miller
Mary Margaret Mohsen
Thomas S. Reed II
Mark Rosenblatt
B. Gayle Twiname

In Honor of

Marny Eulberg
John & Jean Fialka
Morton Freilicher
Bonnie Levitan
Larry & Anne Mercer
John & Pat Shortall

Contributions to The Research Fund

In Memory of

William G. Ohme

In Honor of

Anne Shortall & Rob Murphy

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

Not 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 *PHI Membership Memos* in January, March, April, June, July, September, October 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).

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.

Inside *Post-Polio Health*

Vol. 36, No. 1, Winter 2020

An Afghan Polio Survivor's Journey ... 1
Living with Polio as an Adult in the Philippines ... 3
Promoting Positive Solutions ... 6
Ask Dr. Maynard ... 10

☐ \$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 _____