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Frederick M. Maynard, MD

Reflections on the Post-Polio Movement and Where We Are Today

An interview with Fred Maynard, MD

PHI: *Starting in the early 1980s, PHI organized a series of international conferences to address new problems that were starting to show up in the large cohort of polio survivors that contracted polio in the epidemic years of the late-'40s to mid-'50s. As you look back on that period, what stands out to you?*

Fred Maynard: In the early '80s, interest in the late effects of polio and what was going on with polio survivors was brand new. And that's what made it intriguing—nobody understood it. People were experiencing something; their strength was declining, and functional abilities were changing. Everybody was looking for answers.

Besides the inquisitiveness, there were lots of legitimate concerns about polio survivors' health and functioning. And there was a lot of fear, and at times even catastrophizing terror. Due to the overwhelming fear in many people, sometimes we as caring physicians felt like the biggest thing we could do was to try to reassure them that this was not an awful disease like ALS. We said it was not going to kill them, and it was unlikely to put them in a wheelchair if they walked normally without aids.

By the second PHI conference in 1985, research into the current health and functional status of people with a past history of polio—that is, polio survivors—had really started to take off in the U.S. We had a lot of people from Europe, South America and Asia that trickled into

our early meetings in the '80s as their survivor population began experiencing the same things, although the peak of their populations' concerns probably lagged by 5–15 years behind what seemed to be going on in North America.

PHI: *What were some of the issues the physicians involved were focused on in those years?*

FM: During a lot of those years, besides just trying to describe in more detail what was going on and separating fact from fiction, we were really trying to understand the reasons why polio survivors were getting weaker and suffering so much from fatigue and also having so many pain problems. By the mid-'80s the term “post-polio syndrome” (PPS) was being used by many people as a convenient label for these symptoms and concerns. We, the medical people involved, probably spent the next five years, in large part, arguing about what the term PPS meant and trying to come up with a uniform definition for it so that we were speaking the same language.

You can still run into definitional misunderstandings today because it isn't, even 40 years later, totally uniform. There are two terms that are used interchangeably much of the time but do have some distinct meaning. One is “the late effects of polio” (LEoP), which is an all-inclusive term. It isn't implying any particular cause for symptoms other

continued on page 2

than that they are probably related to a person's past history of polio and are commonly experienced among polio survivors later in life. The other term, "post-polio syndrome," started out being used to describe the common triad of symptoms (pain, weakness and fatigue) that were being so frequently reported. Later, its definition was expanded and refined, and it is now even recognized by some international classification groups as a distinct neurological disease of its own. While PPS must still be considered a late effect of polio, its specific definitional criteria recognizes that it does not universally occur in all polio survivors.

"They also wanted to stimulate and encourage the medical establishment to pay attention to their problems, to study them, and to offer better treatments."

PHI: *How did this compare with what polio survivors were primarily concerned with at that time?*

FM: Well, during the years of descriptive research and definitional controversy, polio survivors were primarily concerned with trying to get help for themselves, as well as reassuring and supporting their friends and cohorts by sharing ideas for successful treatment for and/or adaptation to disabling symptoms.

They also wanted to stimulate and encourage the medical establishment to pay attention to their problems, to study them, and to offer better treatments. While this has occurred, it has been slow and spotty.

Medical research into the LEOp has largely ceased in the United States. We used to have perhaps 30–50 locations advertising themselves as post-polio clinics. Over the last 10–20 years, that number has shrunk significantly. A lot of these have ended, and you don't hear much specifically about post-polio clinics anymore. Today, post-polio patients have largely been turned over to the general and non-specialized medical system.

A similar trend has been seen with post-polio support groups. More and more of these are folding, as well, and PHI has been left more and more, almost by default, trying to hold together the remnants of the polio community in the U.S. Nevertheless, locally experienced and personalized support services are often more meaningful and likely to give immediate help.

PHI: *Do you see any commonalities among polio survivors who have been involved in the post-polio movement over the years?*

FM: I have observed that the polio survivors who have been most involved with the whole post-polio movement are people who are the seekers—the ones that

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

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seek out information, who are willing to face problems, learn about them and try to learn what there is to do about them. They're not the people who are deniers and run away from things and don't pay attention. There were those people around from the beginning who thought, "Oh, I'm not one of those polio survivors who has PPS and is having trouble. I'm perfectly fine." And many of them were okay, but many of them also were having problems and didn't want to pay attention to them because they were afraid of being identified with somebody who they saw as much more disabled and therefore undesirable than themselves.

Denial of disability is not a totally new phenomenon. Throughout the post-polio movement, we have had many people who came out of the closet about their polio history and identity as a polio survivor. This topic can be an interesting discussion in and of itself. However, presently I think most survivors are over that type of denial. This is not to say that some polio survivors aren't still newly discovering that there is such a thing as the late effects of polio and post-polio syndrome, but I think in the United States we don't see that very often anymore. Even in Europe, they've probably hit their peak of demand for post-polio medical and rehabilitative services; but in much of the developing world, unmet needs are vast.

PHI: *Looking forward, what are some major issues polio survivors should be concerned about?*

FM: So, one of the big questions that polio survivors now have on their mind is where we are going from here. If I try to break that question down into areas of concern and needs, it seems to me that one issue is determining the best strategies for continuing to experience a high level of satisfaction and happiness in your life when you're getting older, losing functional capacities from PPS and from general aging, dealing with losses of friends and family, experiencing community and societal change, etc.



Frederick M. Maynard, speaking at a PHI conference, circa mid-1990s.

While those things happen to everyone and are part of life's challenges for all, this reminder does not offer much reassurance to the aging polio survivor who has faced a lifetime of challenges. And of course, everyone's coping skills are additionally challenged right now by the COVID epidemic, with its attendant fears, isolation and divisions.

A lot of post-polio people I know have recently said, "Well, we've been through this talk about the LEOp and PPS many times. We've kind of solved everything we think is possible to be solved. What's on our mind to be concerned about at this point in our life are two other things that are in a slightly different sphere." And while I am not an expert on these topics, I have been around a long time watching and listening to the concerns of aging polio survivors. Now I'm also part of the same demographic group that is facing these issues. Thus, I have some thoughts on them to share.

One important issue is where to live and reside in your older years. How do you maintain a living environment for yourself that is still optimal for what you want to do and can realistically still do with your life? Answering this often involves getting help. Many polio survivors, and lots of other older people, too, need physical help to maintain their physical environment. Whether it's mowing your own lawn, or shoveling

continued on page 4

your own snow, or cooking, or whatever you're doing, all of those things come up as needing help. And while most of us feel like we'd rather be in our own house, if it's not barrier-free, that ultimately may be much more limiting.

Polio survivors also may face the need for physical assistance with basic care needs, which can be very stressful emotionally and financially. So, you always have to be open to the possibility of making a change in favor of an environment that is better suited for you.

“Everybody has to go through the pros and cons of individual options and figure that out for themselves.”

The negative aspects of physical barriers often have to be weighed against the positives of social and emotional supports available in a familiar locale. There is no uniform answer to this question. Everybody has to go through the pros and cons of individual options and figure that out for themselves. Certainly, talking to other people with experience and a broader knowledge of all the different potential resources and solutions that can be brought to bear on facing that question can be useful. So, sharing experiences and raising questions or concerns on a personal level or a broader basis is certainly fair game for a conversation like this with your long-term friends among the polio survivor community.

PHI: *Are there any issues that you feel haven't received enough attention?*

FM: One important issue relates to planning for the end of one's life. This is a psychosocial and spiritual issue older people need to think about. As a group, polio survivors are good at facing problems and have learned to not run

away from them. We know we're human; our life as we know it will end. I have learned that the end of life can become a nasty scene, especially when your last days are out of your control and turned over to the medical system. At times, the end of life can seem pretty violent, isolated and impersonal. This is not what a lot of us want.

While we don't always know what we want and can't always know what we are going to need or what our circumstances will be, we can put some thought and effort into planning our last days and clarify what care and treatments we desire.

Polio survivors are great planners. They have had to be. I hope most have made plans for their last days with advanced directives and living wills, but it is good to remind people of these options. It can also be very helpful to talk with peers, as well as with family, friends and clergy about your concerns, fears and desires.

PHI: *Any message you'd like to leave our readers with?*

FM: Currently PHI remains actively involved with its mission to improve the health and well-being of polio survivors through education, advocacy, networking and research. It also strives to constantly adapt its specific services to the most important pressing needs and concerns of polio survivors. I encourage all of you to communicate with PHI often about your ideas, needs and concerns. ■

Independence at Home

Richard Hardine

Living with a disability and dealing with new lifestyle changes can be challenging. These changes can affect your self-image, vision of success and overall well-being. If you find yourself relying more and more on caregivers, it might be a good time to investigate making changes around your home.

Understanding and accepting your diagnosis and prognosis is key to maintaining a comfortable, healthy and happy lifestyle. The changes to your home can be simple or quite involved.

A medical team composed of experienced physicians, physiatrists, physical and/or occupational therapists will be key in helping you develop a plan for living independently. In addition, an architect, experienced building contractor and electrician can offer guidance in making successful changes and adaptations within your home. Your age, level of disability, physical attributes and current living conditions will factor into the plan.

The first step will be to determine your current and anticipated physical abilities, living conditions, outside assistance in your daily routine, and activities of daily living.

The second step consists of a comprehensive site visit by your care providers. This will help identify what should be modified to simplify your everyday functions, increase your independence, and maintain a safe environment.

Measurements should be taken of door widths, toilet heights, access to kitchen equipment, safe transfer to tub, bed and chair. Location of equipment such as your hot water heater, furnace and electrical panel should be reviewed, to name just a few. Medicines, self-care and emergency phone numbers should be listed as well.

Ideally, all your daily activities should be covered so you can function and live as safely and independently as possible. Strength and endurance need to be considered, not only currently but what you anticipate it may be in the future. The care team should explain the mechanical devices and other work that should be considered for your independence and safety.

There are sample pages from two surveys on the following pages (6 and 7). I designed these to help individuals with disabilities assess their living environment. The Residential Accessibility Survey is designed and used to assess the accessibility of your home. A sample from the 10-page survey is on page 6.

The Client Survey focuses on physical activities. A sample is on page 7.

The surveys can be used together or separately. Please contact PHI (314-534-0475, info@post-polio.org) for a copy of the complete surveys. ■

continued on page 6

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

SAMPLE OF THE RESIDENTIAL ACCESSIBILITY SURVEY

INSIDE DOORS AND CORRIDORS	ARE THE DOORWAYS AND HALLWAYS WIDE ENOUGH TO MOVE THROUGH?	G YES	G NO
	IS THE HALL WIDE ENOUGH TO TURN A WHEELCHAIR AROUND?	G YES	G NO
	ARE THE THRESHOLDS FLUSH?	G YES	G NO
	IF NOT, DOES THIS PRESENT A PROBLEM?	G YES	G NO
	DO THE DOORS AVOID OPENING INTO THE HALLWAY OR OTHER SPACES WHERE THEY MAY BE A BARRIER?	G YES	G NO
	IF A WHEELCHAIR OR OTHER WALKING AID IS USED, ARE THE WALLS, CORNERS, DOORS, PROTECTED FROM SCRAPING?	G YES	G NO
	PROBLEMS:		
SOLUTIONS:			
STEPS AND STAIR CASES	ARE THE STAIRS IN THE HOME EASY TO CLIMB?	G YES	G NO
	ARE THEY IN GOOD CONDITION?	G YES	G NO
	DO THEY ALLOW FOR GOOD FOOTING?	G YES	G NO
	IS THERE CARPET OR OTHER TYPES OF COVER ON THE STEPS?	G YES	G NO
	IS IT SECURE AND FASTENED?	G YES	G NO
	ARE THERE ANY SHARP EDGES ON THE STEPS?	G YES	G NO
	ARE THERE HAND RAILINGS ON BOTH SIDES OF THE STEPS AND ARE THEY SECURELY MOUNTED?	G YES	G NO
	IS THERE ADEQUATE SPACE TO MOVE FREELY UP AND DOWN THE STAIRS?	G YES	G NO
	ARE THE STAIRS WELL LIGHTED?	G YES	G NO
	IF THE STEPS ARE TOO STEEP OR DIFFICULT TO USE, IS THERE A STAIR LIFT?	G YES	G NO
	ARE THERE ANY SUNKEN OR RAISED ROOMS IN THE HOME?	G YES	G NO
	PROBLEMS:		
	SOLUTIONS:		
	KITCHEN	IS THERE ADEQUATE SPACE TO MOVE AROUND IN THE KITCHEN? (MINIMUM REQUIREMENTS FOR WHEELCHAIR IS 5 FOOT RADIUS.)	G YES
IS THERE ADEQUATE LIGHTING IN THE WORK AREA FOR COOKING, CLEANING, AND FOOD PREPARATION?		G YES	G NO
IS THE KITCHEN VENTILATED?		G YES	G NO

SAMPLE OF THE CLIENT SURVEY

BATHROOM

1. Sink/Lavatory Area

Any access concerns? _____ Sink? _____

Height/depth of the sink/lave comfortable for you? _____

Present height _____ Preferred height _____

What height range is best for storage? _____

Is there a need for open space below the sink and vanity? _____

Does the present faucet operate easily for you? _____

Comments _____

2. Bathtub/Shower Area

Do you prefer a bath? _____ Shower? _____

Is your bathtub easy to use? _____

Is there a tub/shower seat? _____ Is there a need? _____

Is there a hand-held spray? _____

Can the controls be reached from both a sitting and standing position? _____

Are the controls easy to use? _____

Present type and location _____ Preferred type and location _____

Is the bathtub/shower floor non-slip? _____

How will you approach/transfer to the bathtub/shower? _____

Comments/Concerns _____

Question: *I'm a 58-year-old woman who contracted polio when I was three. My family was living at the time in Vietnam. A couple of years later, we emigrated to the United States. My parents told me not to mention to the other kids that I had had polio. (My case wasn't severe. I recovered with few obvious physical effects, so I guess I'm what some would call a "passer.") Perhaps they wanted to spare me from any stigma of having had polio, but I think I really internalized it as shame, and I've carried that with me through all of my adult life. Now, as I've aged into a disability, I find myself struggling with these feelings more and more. My parents are still living, and we have a good relationship, but they often try to change the subject or dismiss me when I bring it up.*

Response from Rhoda Olkin, PhD:

It is not unusual for any of us who survived polio to internalize the pervasive stigma we experienced. That stigma comes from messages about disability in media, from peers, in advertising, and even from our own families. It is perhaps the stigma that comes from our own parents that is hardest to shake. So, the inclination is to try to change our parents. Unfortunately, this is highly unlikely to be successful for many reasons. Some countries put a premium on qualities of children that make them more able to work and to marry. Disability, inasmuch as it detracts from these qualities, is seen as decreasing the value of the person.

Another view your parents may hold is the moral model of disability. This is a common model in many Asian countries. In the moral model, the disability is seen as a reflection of the inner character of the person and even of the family. On the negative side of the moral model that reflection is a blemish—evil thoughts, bad character, moral indiscretions. It carries great shame and stigma. (There is a positive side to the moral model as well, i.e., that one can be blessed with a

disability; that is something for another discussion another time.)

If you cannot change your parents, and in fact they don't even want to discuss it, I suggest you not waste energy trying for the unlikely chance of breaking through. Instead, work on eroding the sense of stigma and shame that you internalized. There are several avenues that might help: polio support groups, groups that include many types of disabilities, reading of all types (biographies by people with disabilities; about the models of disability; studies about disability and stigma), and of course professional therapists who practice disability-affirmative therapy.

This journey towards greater self-acceptance does not happen all at once. Start by no longer trying to 'pass.' Use any assistive device that helps you. Be matter-of-fact about your disability with others. Casually mention it in conversations with your parents (e.g., "I didn't go to the outing because of my polio-related fatigue") so that it is out in the open (but without expecting them to respond). You are a person who survived polio, so be loud and proud.



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.

Response from Stephanie T. Machell, PsyD:

It was common for polio survivors, especially those who could “pass” as nondisabled, to be told not to talk about having had polio. Not only was polio stigmatized, but those with disabilities of any kind faced barriers to full participation in American society. Passing permitted access to educational or work opportunities while minimizing the likelihood of experiencing disability-related bullying or microaggressions.

Passing comes at a price. The need to pass means that the true self is unacceptable and stigmatized. Though the passer appears outwardly successful, she internalizes the shame attached to the stigmatized identity. Maintaining a passing identity involves deception and the constant risk of being exposed.

For you, as for many other polio survivors, exposure came via the late effects of polio. New or worsening disability may cause passers to feel betrayed, both by their bodies and by those who encouraged them to pass. Memories and feelings related to the polio experience may return, sometimes intensely.

It's natural that you want to speak with your parents about this. Before you do, it's best to address the ways you internalized shame about having had polio and the effects this has had on your life with supportive but uninvolved others. Online or in-person polio support groups help reduce the isolation shame creates by allowing you to connect with others who are dealing with the same issues. Therapy that focuses on disability and identity can help you heal your internalized shame

and develop skills for aging well with a disability.

Once you've done this work you may decide you no longer need to talk to your parents about your experiences. If you still want to do so, think about what you want from the conversation. Consider how you will feel if they continue to minimize your issues or try to defend their actions. You might speak first with siblings and/or supportive family members to enlist their help. Those who are older may have valuable insight into how your family coped with your illness.

After you've prepared, prepare your parents. Let them know you want to find a time to talk about your polio experience. Be clear that it's not your intention to blame them and that though you understand some of what you will say may be hard for them to hear you hope they will hear you out. If you want an ally present, ask their permission for this, and ask them if there is anyone they would like to invite. Sharing this column with them and/or suggesting they browse the PHI website will help them understand your experience better while also recognizing that it is a common one for polio survivors and their families.

If they refuse, respect their wishes. You can ask again in the future. Or you can suggest they let you know when they're ready to talk. They may need more time. Or they may never be ready. Painful as it may be, forcing the issue could damage the good relationship you have. ■

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.



Remembering Bruce Sachs

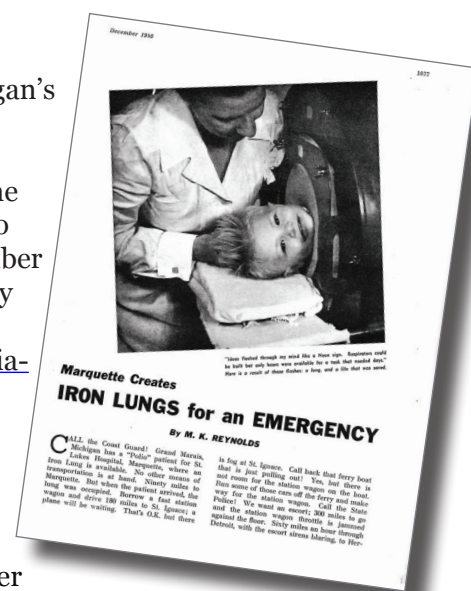
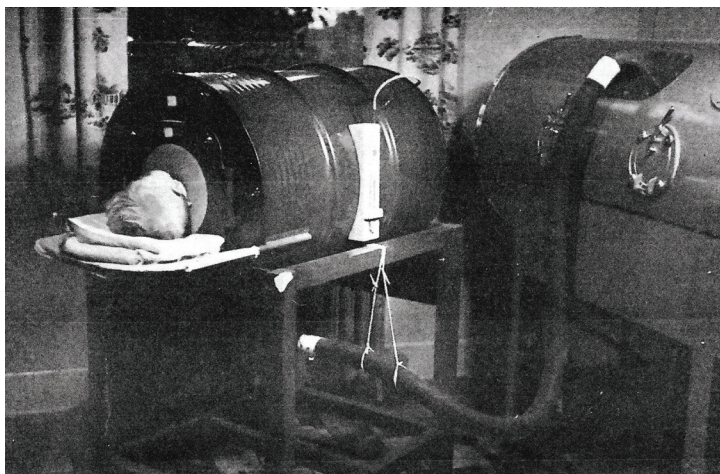
We at Post-Polio Health International were saddened to learn of the passing of Michigan polio survivor and advocate Bruce Sachs on March 7, 2022. Bruce was born on July 15, 1939, in Baraga, Michigan. He contracted polio at 13 months of age and spent the next nine months in the hospital. Bruce eventually learned to walk with the aid of a built-up shoe and long leg brace. Bruce wrote of his childhood, “I grew up in a small town with no handicapped education classes; therefore, I was encouraged to do everything the other children did. I played baseball, went fishing, walked with my dog, and tried to be as good as I could at everything. My dad taught me all the outdoor activities and my parents encouraged me to do whatever I could, with few restrictions.”

After earning his Elementary Teaching Certificate and master’s degree in Educational Leadership, Bruce worked as an elementary school teacher for 42 years for the Livonia School District in the Detroit metro area. Upon retirement, he volunteered at a post-polio clinic as a greeter, helped facilitate the Southeast Michigan Post-Polio Support Group, and was chairman of the Michigan Polio Network for 12 years.

PHI board members Dr. Fred Maynard and Sunny Roller recently wrote a two-part article about Bruce’s early life and later advocacy for *The Mining Journal*, the daily newspaper of Marquette, Michigan. The article can be found at https://www.miningjournal.net/news/superior_history/2022/05/marquettes-early-generosity-reciprocated-in-unforeseen-ways/.

Part 1 covers Bruce’s early life, including his bout with acute polio. An outbreak of polio at the time on Michigan’s Upper Peninsula, along with a shortage of iron lungs, required area residents to improvise some creative solutions. A detailed account by Max K. Reynolds of the effort to construct emergency respirators for area polio patients, including Bruce, was published in the December 1940 issue of *Hygeia*, a “health magazine” produced by the American Medical Association. The full article can be accessed at <https://post-polio.org/marquette-hygeia-dec1940/>.

Bruce himself required the use of a so-called “trailer unit”—essentially a 50-gallon oil drum retrofitted with a sling bed and hooked up by hose to an adjacent commercial iron lung (see image below). Single drums were big enough to be used by infant and toddler patients. For older children, they improvised by welding two drums together. Additional respirators were constructed out of wood.



Part 2 of their article deals with Bruce’s later advocacy on behalf of polio survivors and his own battle with the late effects of polio. In addition to his work with the Michigan Polio Network, Bruce and his wife, Dianne Dych-Sachs, attended 13 post-polio wellness retreats at Bay Cliff Health Camp in Marquette, Michigan. They spent recent winters in Florida and were also active in the Boca Area Post-Polio group. Bruce was 82 years of age. ■

Post-Polio Resource Directory

Do you have a physician that provides excellent care and is knowledgeable about the late effects of polio? PHI is looking to expand our directory (www.post-polio.org/networking/directory/) and is seeking recommendations from members like you. If you know of a potential candidate for inclusion in the directory, please contact us at info@post-polio.org or 314-534-0465.

Need Help Purchasing a Brace or Shoes?

Did you know? PHI has a special fund to assist with the purchase of a brace or custom-made shoes. The Joyce and Arthur Siegfried Memorial Fund provides grants of up to \$800 to assist polio survivors with out-of-pocket costs.

The fund was established in 2012 through an initial gift of \$7,500 from the Polio Network of New Jersey (PNNJ) in honor of Joyce and Arthur Siegfried, early advocates for the needs of polio survivors. Joyce Siegfried helped organize the first New Jersey Conference on the Late Effects of Polio in 1990, which led to the creation of the Polio Network of New Jersey in 1991.

Sadly, PNNJ recently decided to cease operations. Their legacy will live on, however, thanks to a sizable new grant to the Siegfried Memorial Fund. PHI would like to thank their president, Lottie Esteban, and the rest of the network for so generously providing for the needs of polio survivors wherever they may reside. You can learn more about the fund and download an application at <https://post-polio.org/siegfried-fund/>. Or contact PHI at 314-534-0475, info@post-polio.org.

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Seeking Volunteers for PPS/COVID Research

Mike Kossove, Professor Emeritus, Adjunct Professor of Microbiology, Touro University, School of Health Sciences, is seeking volunteers for a research project, "The Effects of COVID on Polio Survivors." Of particular interest for this project are those polio survivors who have PPS. If you were sick from COVID, did it exacerbate your PPS? If so, please contact him at jpspolio@hotmail.com (include "Polio" in subject line), explaining how it affected you. If you'd like to remain anonymous, please let him know. Thank you for your participation.

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Inside *Post-Polio Health*

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Reflections on the Post-Polio Movement
and Where We Are Today ... 1

Independence at Home ... 5

Promoting Positive Solutions ... 8

Remembering Bruce Sachs ... 10

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