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## PHI-Funded Research published in *Scientific Reports*, July 2017

### Team's new methods validated; second article in progress

**“Revealing enterovirus infection in chronic human disorders: An integrated diagnostic approach”** authored by Angelo Genoni, Filippo Canducci, Agostino Rossi, Francesco Broccolo, Konstantin Chumakov, Giorgio Bono, Jorge Salerno-Uriarte, Alessandro Salvatoni, Alberto Pugliese & Antonio Toniolo was published online in *Scientific Reports* 10 July 2017. They chose to make the article open access and so it is freely available at <http://rdcu.be/t4V4>.

Lead researcher, Antonio Toniolo, MD, Professor of Medical Microbiology, University of Insubria, Varese, Italy, reports, “This paper provides the evidence and justification for polioviruses being still present in the bodies of polio survivors after so many years.”

“I am glad that the results have been validated by an expert in the field, Konstantin M. Chumakov, PhD, Office of Vaccines Research and Review (OVRR) at the Food and Drug Administration. As an aside, he is the son of the famous Russian virologist Michael Chumakov who introduced the American poliovirus vaccines in the former Soviet Union. By 1959, the elder Chumakov organized the first mass production and clinical trials of the Oral Poliovirus Vaccine (OPV) made from live attenuated strains developed by Albert Sabin.

“We are preparing a full paper on post-polio with data from over 100 polio survivors now that the technicalities of the method have been approved for publication.”

Basically, the study shows that the protracted persistence of poliovirus in post-polio survivors can be demonstrated by analyzing blood leukocytes for the presence of virus. The original method set up in Italy is based on the *in vitro* cultivation of blood leukocytes and the further examination by genomic methods, i.e., polymerase-chain reaction (PCR) followed by virus genome sequencing. In addition to that, investigators have also been able to show that persistent polioviruses maintain their ability to produce virus structural proteins when propagated in cell cultures. Thus two independent lines of evidence point to the conclusion that—decades after the initial acute poliovirus attack—a minimal population of

mutated virus remains still present in a portion of polio survivors.

The authors speculate that the presence of persistent poliovirus could be responsible for chronic inflammation (probably within the central nervous system and skeletal muscles). Studies are progressing with the idea of finding antiviral drugs capable of blocking the ongoing poliovirus replication in poliovirus-positive polio survivors.

The evidence provided by the study also provides support for the administration of intravenous immunoglobulins to post-polio subjects (an international clinical trial is currently ongoing with the support of Grifols, an immunoglobulin manufacturer). An additional possibility may be represented by the therapeutic administration of the existing poliovirus vaccines.

The team of researchers received funds from PHI both in 2009 (\$25,000) and in 2014-15 (\$50,000 each year). For details, see [www.polioplace.org/phi-funded-research](http://www.polioplace.org/phi-funded-research).

*Scientific Reports* is part Nature Research, the home of high impact scientific and medical information in print and online. The Nature Research portfolio includes Nature ([www.nature.com](http://www.nature.com)).

The Research Fund receives donations from PHI Members, families and the estates of survivors.

*It is impossible to thank everyone who supported me during my 30 years at GINI/PHI, serving 28 years as executive director. I thoroughly enjoyed the notes I received.*

## **I never wanted to be a red bird or a blue bird.**

I am, like everyone else, defined by nature and nurture. I am retiring because I am 70 years old, in good health, and I have my list. My parents treated me as an equal to my brother and sister, although later in life they revealed they thought I was “babied.” My sister had distressing bouts of asthma and my brother was the boy they wanted. I thought they were instead!

The memory most relevant to my 30-year-long distant relationship with you happened in 1953 in first grade. I vividly remember looking at the bulletin board from my front row seat and seeing our names listed under a cut-out of a red bird or blue bird. The teacher explained we would earn points and a winner would be declared. I don’t recall which group I was in, but I knew I didn’t want to be better (or worse) than my friends. I just wanted to be me. After all, I had stood in another room listening to my mother strongly instructing her brother never to call me Hopalong again. I interpreted that as “You are fine, as you are, even though different.”

In my job at PHI, I soon learned that there were many polio survivors all defined by their own nature and nurture.

The challenge for me as executive director: How do I meet the needs of all polio survivors? Our founder, Gini Laurie, had said in a presentation that polio survivors needed two things: accurate information and a connection to those with similar experiences. That has been the focus of the work—accurate information and access to those with similar experience and knowledgeable health professionals who have our best interest at heart.

The challenge for you as polio survivors: Determining what information pertains to you and your situation and applying it, so that you can be a polio survivor living the best you can “considering” and more. We have varied upbringings, opportunities and physical problems. Being honest with ourselves and then with our families and health professionals is important.

It seems to me (and maybe I am projecting) that the answers to the tough questions are not found ultimately on the “outside” but on the inside. Let me reassure you, I am not a great philosopher. Tom Sellick, who plays a small town police officer, Jesse Stone, on TV, advises, “The information is out there. All you have to do is let it in.” Every time I hear him say that, I think of us.

I know each of us has been affected by our experience of having had polio. While there are commonalities, we are each unique and that is a good thing. We are in control of what we “let in” and in how we act on it.

And, I have complete confidence that our acquired knowledge and experience translates into wisdom.

May we all be wise, Joan L. Headley, Executive Director

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

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# Survey of Health Professionals with Experience in Post-Polio Patient Care

Joan L. Headley, Executive Director, Post-Polio Health International, St. Louis, Missouri

**T**he most consistent comment to PHI for the last 30 years has been that “health professionals don’t understand.” We surveyed survivors about their health professionals in 2014. Those surveyed were connected with PHI, which may have skewed the results, but in general the picture they painted was not so dire.

(See **Post-Polio Medical Care: Post-Polio Specialists and Primary Care Physicians** (Vol. 30, No. 4)

[www.post-polio.org/edu/pphnews/PPH30-4fall14p3-5.pdf](http://www.post-polio.org/edu/pphnews/PPH30-4fall14p3-5.pdf).)

The next logical step was to survey health professionals who have experience in managing the care of polio survivors. PHI developed a survey with the assistance of Carol Vandenakker-Albanese, MD, Marny Eulberg, MD, Frederick Maynard, MD, and Martin Wice, MD — all physicians with 30+ years of experience.

The survey was distributed to health professionals in the *Post-Polio Directory* (both current and past) and through the *PHI Association Member Communiqué* and social media.

## Who responded?

Fifty-two health professionals responded. Thirty were physicians. Twenty-two were allied health professionals, three were behavioral health specialists and one a massage therapist.

Sixty-three percent practiced in the United States. The other countries represented were Australia, Brazil, Canada, Denmark, India, Ireland, Korea, Nepal, Netherlands, Turkey and the United Kingdom.

Forty of the respondents were practicing professionals. The range of experience of the 52 was 2–43 years.

Fifty percent had  $\geq 20$  years of managing post-polio care. In addition, 62% practiced in a teaching hospital/rehabilitation center, 46% in an urban setting and 42% were in private practice.

## Their practices

Practicing professionals reported seeing on average 101 patients a year (range 5–600), while retired professionals reported seeing 32 a year.

Sixty-four percent required/requires a referral to see them and 34% reported they always communicated with their patients’ primary care physician; 34% did if asked; 14% reported that they attempted communication.

Fifty-eight percent reported being part of a post-polio clinic; 66% described the clinic’s approach as multidisciplinary.

**Training** (They were asked to check all that applied, so the sum is greater than 100.)

Eighty-four percent received part of their training on the job/personal interest/personal reading; 38% at professional meetings (CME); 32% said it was part of their medical residency; 8% medical school (CME). Other sources of training were fellowships, post-polio specialist colleagues and survivors/patients.

Forty-three of the 50 said there is a need for more training about PPS in their specialty. Additionally, 49 of 50 said there is a need for continuing education about post-polio syndrome. The one dissenting opinion stated, “Continuing education implies that there is a large population of patients with this condition. It would be difficult to obtain such formats.”

In ascertaining what training they provided, 66% reported that residents saw patients with them (38% some of the time; 28% all of the time).

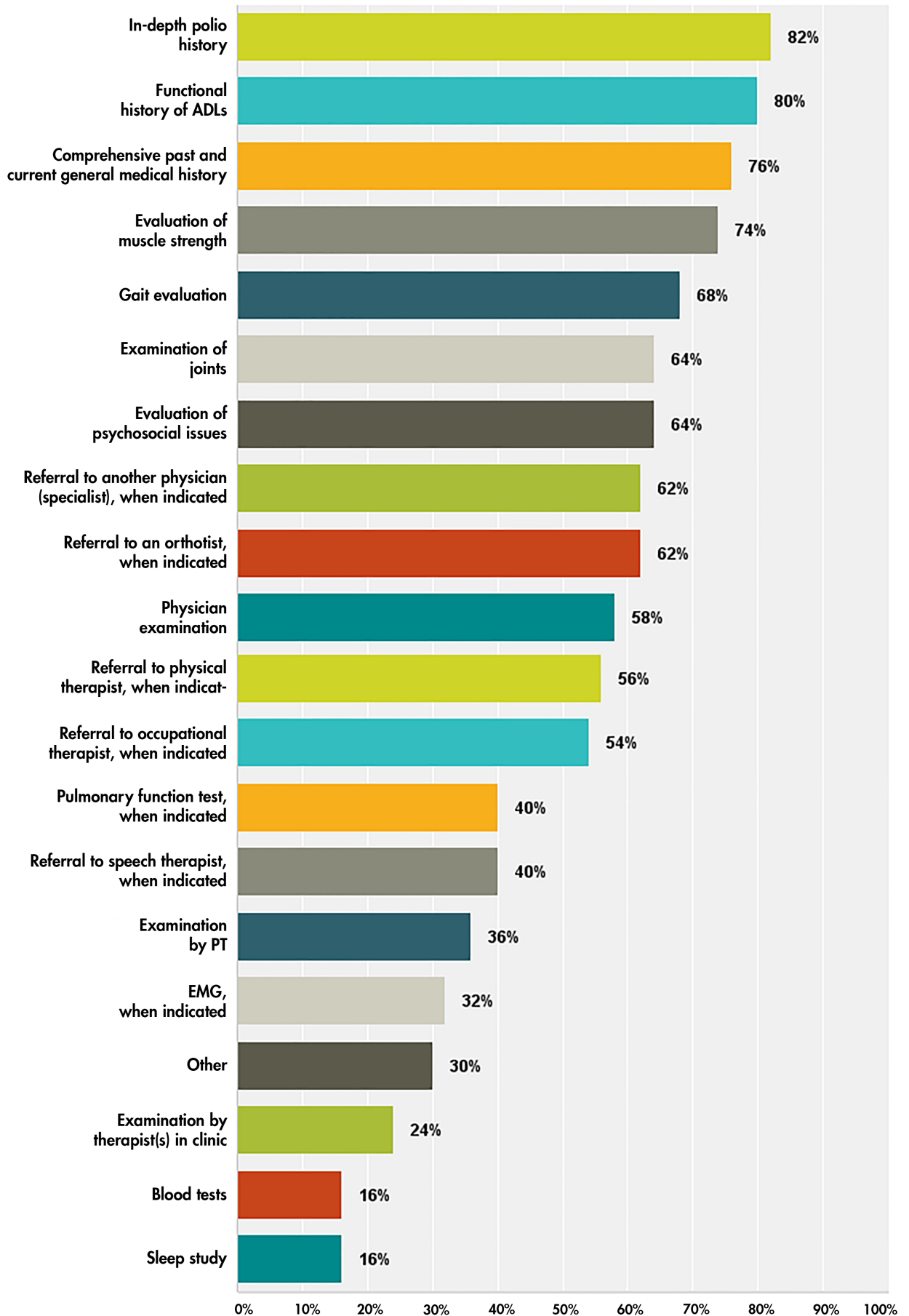
Eighty-four percent reported that they lectured about post-polio syndrome, including post-polio seminars and support groups.

## What did they tell us about treatment?

The following three charts depict information about the initial evaluation and the most common complaints and recommendations.

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**They were asked to check all is/was part of their initial post-polio evaluation.**



They ranked the following classic complaints in order of most commonly reported.

		ranking							
		1	2	3	4	5	6	7	Avg.
complaint	Fatigue	22	7	8	10	1	1	0	2.27
	New weakness	4	18	12	6	8	0	1	3.00
	Pain	7	12	13	8	7	2	0	3.04
	Functional decline	11	8	7	14	5	1	2	3.10
	Chronic long-standing weakness	4	4	8	7	18	3	4	4.17
	Breathing	1	0	1	2	5	22	11	5.86
	Swallowing	0	0	0	2	4	15	23	6.34

### The top 7 most common recommendations

Ranking	Recommendation	Most common placement
1	Patient education (referral to websites, support groups, books)	11 placed 1 <sup>st</sup>
2	Pacing advice	7 each placed 1 <sup>st</sup> and 3 <sup>rd</sup>
3	Exercise/Physical therapy	9 placed 1 <sup>st</sup> ; 8 placed 5 <sup>th</sup>
4	Mobility devices (canes, crutches, scooters, wheelchairs, etc.)	13 placed 3 <sup>rd</sup>
5	Bracing, lower extremity	9 placed 4 <sup>th</sup>
6	Counseling/psychological support	6 placed 6 <sup>th</sup>
7	Family education	6 placed 7 <sup>th</sup>

### They were asked, “What complicates the management of the care of polio survivors?”

Co-morbidities (77%) were mentioned as the greatest complication in managing care. One professional pointed out the need to “learn differential diagnosis of depression vs PPS,” and not just the more commonly mentioned conditions such as osteoarthritis, hypothyroidism, spinal stenosis, fibromyalgia, etc.

Patient expectations was listed by 35% and “are often difficult to handle in my experience.”

Length of appointments, typically too short, was mentioned by 27%. It was noted that “complexity and uniqueness of patients requires customization.”

Other complications include:

- Older individuals with other physical, social and emotional issues.
- Lack of patient compliance due to past negative experiences with health professionals in the acute phase of polio disease.
- Inadequate access to medical records or accurate health history.

- Absence of objective evidence criteria, such as a biomarker.

### What are/were the major challenges of managing post-polio care?

Many of the comments could be categorized into Emotional Issues, Education (lack of) and Funding, but also mentioned were:

- You can’t regrow an anterior horn cell.
- Lack of anything that really helps those with upper body issues.
- Sleep Labs do not monitor hypoventilation. There are very few physicians knowledgeable about respiratory insufficiency in PPS.
- Lack of evidence for successful interventions e.g., exercise or medications. Lack of expertise among orthotists.
- Avoiding the medical management model.

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## Emotional Issues

- Emotions of the patient in dealing with past polio and adjustments to new decline in function and stamina; affects identity.
- Each affected so different physically and emotionally and you must go carefully and work against their previous expectations.
- Patients' fear of the future.
- Helping patients make wise decisions for the future—"change management."
- Set in their ways and when they have problems, they may not be open-minded enough to try method B or C, when A no longer works.

## Education (or lack of)

- Facilitating patient, family and caregiver education.
- Misinformation on the internet.
- Unnecessary testing rather than focus on health, behavior choices and function and people who prefer to "disable" someone rather than treat a correctable problem. ("Yeah, it matters that you are fat." Or abuse alcohol or drugs.)
- The patient leaves the polio clinic and continues treatment at home with less knowledgeable professionals.

## Funding

- Not enough support for the management of patients (interdisciplinary team is the ideal situation).
- Inadequate healthcare coverage.

**What advice would you give other professionals in your specialty about post-polio care?** The many thoughtful answers could be categorized into Process and Patient Care.

## Process

- Make the commitment. Don't do a half-hearted job. Not "business as usual."
- Seek information and contact specialists. Share knowledge and experiences.
- Make a substantial collaboration with PM&R specialists; learn some basic rehabilitation medicine principles.
- Read books on polio and post-polio syndrome and the psychological implications, take continuing education courses, subscribe to *Post-Polio Health*, participate in post-polio support groups.
- Be willing to educate and to involve family as desired by patient.

- Understand the developmental issues related to age of onset of polio and of PPS, and what the cultural surround was at the time.
- Have a sense of humor. Be patient. Cannot cure or get them back to when young.
- Care of post-polio patients can be very rewarding. Patients are grateful for your expertise because they often have searched for someone to help them. Fabulous group of people.

## Patient Care

- Stated many times: *Listen to the patient*. Each and every concern of post-polio patient should be taken seriously, meticulously and should not be neglected.
- Look at the whole person! Look for any other reason besides polio for symptoms.
- Ask about trauma associated with both the original polio experience AND related to the onset of PPS, including issues of mistrust in medical settings.
- Align expectations with their capabilities and activities.
- Be aware of exercise guidelines for post-polio patients.
- Treat each patient as unique. There is no cookie-cutter approach.
- Spend time on education. Communicate with patient.
- Be gentle, but specific.
- Really need to get to know the patient and meet him/her halfway. Incremental changes are better than any big changes all at once.

## Bigger Picture Conclusions

Education and training of today's health professionals is happening. Much of the training is done in the academic centers where experts have the time to teach and also have access to students.

The responses to the survey emphasize the breadth of problems people who had polio are having and the need for a multidisciplinary approach.

The responses suggest a major focus is on mobility, which is a concern of many post-polio patients.

Behavioral health issues were mentioned several times indicating that health professionals recognize the need to pay attention to their patients' mental health.

In fact, the experts affirm the importance of post-polio health, including the physical, emotional, social, psychological and spiritual. ■

# *A Tribute to My Mother, Viola Fidler*

Connie Pate, Austin, Texas

**M**y mother will celebrate her 100th birthday on September 23, 2017.

The word “survivor” suggests that, somewhere along the way, someone was a “victim.” That’s about the last word I would ever use to describe my mother.

On her 27th birthday in 1944, she woke up feeling as if she was getting the flu and by the next day, her left leg and arm were paralyzed.

At the time, she was a wife and mother to a five-year-old, a two-year-old and a six-month-old. The doctors advised her not to have any more children, but five years later I was born.

My parents lived in rural North Dakota where treatment facilities were few and far between. My mother spent several months in a hospital 100 miles from home wrapped in warm towels and doing hours of physical therapy known then as Sister Kenny treatments.

When the time came for her to have a trial visit at home, she was excited to see her family and vowed to herself (a very strong-willed lady) that she’d show the doctors she could go home for good. She did exactly that!

As long as I lived at home, I never saw her miss a day of doing her “floor exercises” which she learned from the medical staff trained in the methods of Sister Kenny.

When she was 70, I bought her an exercycle which she rode three miles a day until age 88 when she moved into a nursing home.

In addition to being a hard-working farm wife and mother of four, she was president of the Ladies Aid at our church, spearheading several humanitarian initiatives for Baptist missionaries in Africa.

She also volunteered as a counselor at the summer camp sponsored by the church. She was a counselor, my dad ran the candy store, and I was a camper.



As a 14-year-old, it wasn’t that much fun for me!

My mother was always ready to lend a helping hand where she could. She always had an endless supply of Kellogg’s Rice Krispies Treats for her grandchildren, providing them with a fond memory.

She set an incredible example of how to overcome challenges. I knew that anything that I might confront as a child was minor compared to what she overcame as a polio survivor.

She’s also set an amazing example of how to age with grace and dignity and to this day never complains. (Well, maybe a little about the arthritis in her hands!)

As she approaches her 100th birthday, she lives as full a life as any 100-year-old can who’s lived with polio for 73 years.

I swear she wakes up every morning wondering what blessings the day will bring her and is thankful for every one she receives.

In 1944, she happened to be in the wrong place at the wrong time, but she has never thought of herself as a victim or let polio define who she is. ■

In the Fall 2009, *Post-Polio Health* (Volume 25, Number 4), PHI introduced a column with a title based on the initials PPS. The purpose of the column was to acknowledge and address the fact that we as polio survivors are not only physical beings with physical concerns, but that we are psychological, social and spiritual beings.

The column's success years later is due to the knowledge, professionalism and dedication of the contributors. Their contribution to the post-polio community is hard to measure, because it is still true for many that discussing the psychological effects of having had polio is "not done." I believe that having an opportunity to read about it, though, is a good first step.

For this issue, I asked them to write about themselves. After eight years, it is time you get to know them better! With gratitude to Stephanie and Rhoda, Joan L. Headley

### **Response from Stephanie T. Machell, PsyD:**

My dad had polio at age 33, a few years before I was born. Once he was released from rehab the vocational counselors at Morgan Memorial signed him up for a milk-testing course. He did this job, which involved standing for hours in cold barns and lifting 50-gallon milk pails and jugs of sulfuric acid, full-time for years. Until he broke his polio leg he continued to do it part-time while working full-time as a herdsman on the farm at a state school for people with developmental disabilities and in a factory where his math skills got him promoted into accounting.

By the time I was six my dad gave up his brace and crutches. He walked with a heavy limp, but with the exception of driving a standard shift he found ways to do everything that mattered to him. I thought it was cool he could do things like climb a ladder, "bad" leg flapping in the breeze while his "good" one (and arms) did the work. But it was just what he did, not heroic or inspirational, though watching the effort surely contributed to my work ethic!

Polio left Dad with more than a "bad" leg. Throughout my childhood he made meaning out of what was clearly a traumatic experience for him through a narrative of misdiagnosis and confusion, pain, creeping paralysis, rehabilitation and recovery. Though this likely contributed to my adult ability to tolerate trauma narratives, it also made me prematurely

aware that we're all eligible to develop life-threatening conditions.

By the time I graduated from college he was on SSDI because no one wanted to hire a 59-year-old with a disability, even someone more than willing to work. It wasn't long before he began experiencing weakness, again walking with a brace and crutches as well as needing naps and rest breaks that allowed him to remain physically active, working on my cousin's farm, gardening and taking long walks with my mom. A few months before he died at age 88 he was still shoveling snow for his neighbors, falling constantly because dementia made him believe he no longer needed a brace. The way he lived with PPS showed me the importance of doing what gives your life light and color.

As they aged, my parents remained fiercely independent. Neither wanted my brother or me to become their caregivers, which taught me that while family caregiving is right for many people, it can be a bad choice for others.

Some lessons are taught by what didn't happen. Though they communicated their caregiving wishes, my parents were secretive about their health and other important issues, to a degree where not knowing became burdensome to us offspring, due to wondering if things really were all right with them. And my mother's difficulty in talking about her own issues meant that by the time she disclosed that she'd prob-



**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.



ably had polio when she was four she was near the end of her life.

I wish we could have discussed these things. I've never heard a family member complain of having too much information. Of all the things I learned as the child of polio survivors, the importance of communication about needs and experiences is perhaps the most important.

### Response from Rhoda Olkin, PhD:

When my son was five-months-old I dropped him on the rug. This might be the nightmare of every parent with a disability. He's 30 now, so I guess he survived. But I never felt as disabled as I did when my kids were babies. Having lived with polio since age one, I was used to being able to do most of the things I wanted to.

But early parenting involves lots of lifting and carrying — into and out of cribs and car seats and highchairs, from floor to changing table. If I couldn't figure out how to do some of these things on my own, I couldn't parent independently.

I learned adaptations, as did they. I bought a large scooter, affixed a bike seat to the back (for my son) and a large basket onto the front (for my infant daughter). I attached a ladder to the changing table and taught them how to climb as early as possible. They never ran away from me (no fun in that if I didn't chase them) and learned to stay within voice distance. We did lots of crafts, and on my slow days we sat on my king-sized bed eating pizza and watching TV. When my foot was swollen from heat, my daughter and I did "upside-down reading"—laying on our backs with our feet elevated.

The early years of parenting were all about physical accommodations. The tasks of parenting elementary and middle school kids were carpools, activities and playdates. By then I was well aware of the effects on me of parenting with a

disability. But I didn't know the effects of having a mother with polio on them.

Turning to the professional literature on parents with disabilities was disheartening, as there were many problems in the studies: conflating disability with illness, ignoring key differences across disabilities, and examining only negative effects.

Consequently, I, along with colleagues at Through the Looking Glass in Berkeley, conducted a study on parents with disabilities raising teens. We gathered perspectives from the parents and their teens, and comparison parents without disabilities and their teens, who lived in the same neighborhood (Olkin, Abrams, Preston, & Kirshbaum, 2006).

We found that the families were more alike than different: same bedtimes, same number of dinners eaten as a family per week, equal attention to homework.

But there was a key difference—the families in which a parent had a disability had about \$15,000 less in earnings per year than the comparison families, and they paid more out of pocket for assistive technology and housing accommodations. This is consistent with my own experience; about 20-25% of my salary goes to out-of-pocket disability-related costs.

There are many things I wonder about in terms of my (now grown) children, regarding the effects of my disability on them. I would like to think they are more sensitive to diversity and differences than their peers, but in the study just cited we found that all parents believe this to be the case for their children.

I know they worry more about me, about my falling, or needing more physical and financial help, about increasing fatigue. These are my worries too, but I wish they were not my children's worries.

They still turn to me for their needs, which is as it should be. ■

**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.





Frederick M. Maynard, MD

## Ask Dr. Maynard

Send your questions for Dr. Maynard to [info@post-polio.org](mailto:info@post-polio.org).

See other questions at [www.post-polio.org/edu/askdrmay.html](http://www.post-polio.org/edu/askdrmay.html).

In the Winter 2009, *Post-Polio Health* (Volume 25, Number 1), PHI instituted the “Ask Dr. Maynard” column because he was already answering many medical questions for Members and it made sense to share his wisdom extensively. (He and other Members of PHI’s Board of Directors and Medical Advisory Committee have answered many questions over the years.) Dr. Maynard has the ability to critically analyze a situation, draw on his vast knowledge of the literature and his years of clinical experience, and then respond to each individual respecting their intelligence and encouraging them to take charge of their healthcare decisions. His approach is appreciated by many survivors, emulated by health professionals and one that I am so grateful that I could pass along to you. —Joan L. Headley

**Question:** *I am looking for an article that explains post-polio syndrome. The significance of finding the right article is being able to convey the information to my Uncle Phillip’s verbally abusive 35-year-old son who thinks his dad is “not trying hard enough,” and his nagging wife who is always trying to force him into physically demanding activities. He goes to bed a lot of the time in pain. I’m hoping to shed some light on the seriousness of his condition and be able to explain what his central nervous system can and cannot do even at his best. How would you explain it?*

**Answer:** There are many good articles that explain what PPS is and I will list some of my favorites at the end of this answer. The ideal reading about PPS for helping your Uncle Phillip would emphasize the importance of avoiding overuse of muscles in order to reduce pain and fatigue symptoms and to prevent worsening of weakness.

However, your greater challenge may be how to encourage your “nagging” aunt and “verbally abusive” cousin to care enough about your uncle’s well-being to read anything about the problems of older polio survivors.

They most likely will need a trusted authority figure, such as a specialist physician, to say that your uncle has PPS and to explain that any declines in his energy or ability to do things is due to his medical condition of PPS and not due to “laziness” or “giving in to aging.”

Your uncle himself may be in some denial about his declining abilities, possibly from a “fear of giving up” or “giving in.” He, too, may need to learn much more about PPS in order to be a better advocate for himself and to avoid being pushed or derided by family in ways that worsen his symptoms.

One strategy you may use to help convince him that YOU are concerned about his condition (based on your readings about PPS) is to make it clear to him that a comprehensive post-polio evaluation may help him.

If he is diagnosed with PPS, you and he can encourage his wife and son to come to a doctor’s visit with him where they can ask questions and, hopefully, learn to be concerned about his condition.

After all, if he loses further functional abilities, he will be less useful to them and their frustrations that lead to nagging and berating will get worse. If they can be led to become concerned, then they will want to read articles that will be of further use to their understanding of why he can’t do as much as he used to do or as much as they would like him to do.

The problem of family members not understanding or accepting declining functional abilities of aging polio survivors is unfortunately fairly common.



- ▷ Professional counseling, as well as patient/family educational resources such as those on the following list, can be very helpful for improving these circumstances. ■

#### Suggested Educational Resources:

*Post-Polio Health Care Considerations for Families & Friends*, Joan L. Headley, MS, and Frederick M. Maynard, MD, with Stephanie T. Machell, PsyD, and Holly H. Wise, PT, PhD, (2011), Polio Place, Post-Polio Health International, retrieved July 11, 2017, [www.polioplace.org/sites/default/files/files/HCC.pdf](http://www.polioplace.org/sites/default/files/files/HCC.pdf)

*Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome*, Lauro Halstead, MD, (2006), Washington, DC: National Rehabilitation Hospital Press: ISBN 978-0966167665.

*Aging with a Disability: What the Clinician Needs to Know*, Bryan Kemp and Laura Mosqueda (editors), (2004), The Johns Hopkins University Press: ISBN 0-8018-7816-0.

*Post-Polio Syndrome: A Guide for Polio Survivors & Their Families*, Julie K. Silver, MD, (2002), New Haven, Connecticut: Yale University Press: ISBN-13: 978-0300088083.

“Post-Polio Patient: Psychological Issues,” Margaret Backman, PhD, *Journal of Rehabilitation* (53:4, 1987) and *The Post-Polio Experience: Psychological Insights and Coping Strategies for Polio Survivors and Their Families*, (2006) Margaret E. Backman, iUniverse, Inc: ISBN 0-595-38639-3.

*Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors (revised edition)*, Frederick M. Maynard, MD and Joan L. Headley, MS. (editors) (1999), Gazette International Networking Institute: ISBN 0-931301-04-1.

## A Tribute to Volunteers

Post-Polio Health International runs on volunteers. Its Board of Directors, Medical and Consumer Advisory Committees, newsletter columnists, authors of newsletter articles, contributors to [polioplace.org](http://polioplace.org), and conference speakers all volunteer their expertise and time. What they all have (had) in common is that they are bright, thoughtful and caring. Many have a personal connection to polio and happily do their part to support the mission of PHI.

Polio survivor, Karen Hagrup, pictured here, comes to the office to assist with renewal notices. She is the “certified stuffer.” Her monthly visit is followed by that of Sanda Rosenblum, the sealer, whose mother had polio. They are the individuals who volunteer in person and have provided me with many conversations as I contemplated decisions. I am grateful.

—Joan L. Headley



## PHI-Funded Research published in *Scientific Reports*

continued from page 1

### Call for Proposals for PHI Research Fund Grant *Deadline for 2018: Monday, October 2, 2017*

Funding in the amount of \$50,000 is available from Post-Polio Health International and International Ventilator Users Network for research to be completed in 2018. Application for the funds must be received by October 2, 2017. (Applicants may apply for \$100,000 for a study taking two years to complete.)

Researchers can choose to apply for one of the two grants described below.

*The Thomas Wallace Rogers Memorial Respiratory Research Grant* to study the management of neuromuscular respiratory insufficiency or to explore historical, social, psychological and independent living aspects of long-term home mechanical ventilation

*The Post-Poliomyelitis Research Grant* to study the cause(s), treatment and management of the late effects of polio or to explore historical, social, psychological and independent living aspects of living with polio.

The research must have the potential to improve the lives of polio survivors or users of home mechanical ventilation. For details on the application process and to access the form, see [www.polioplace.org/phi-funded-research/new-request-2018-award](http://www.polioplace.org/phi-funded-research/new-request-2018-award). ■

POST-POLIO HEALTH INTERNATIONAL  
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

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

## WE'RE STILL HERE! 2017 Photo Contest Aging with Dignity!

Aging is inevitable and well-earned. Aging with the late effects of polio is perplexing and challenges our inner resources. Aging grants wisdom and time for reminiscing.

What photo represents your acquired wisdom? What photo would best represent your approach to aging? Send us a photo that illustrates aging from your point of view!

Post-Polio Health International will select a grand prizewinner (\$150 USD) and four runners up (free PHI Membership for two years).

**Deadline to submit a photograph to [info@post-polio.org](mailto:info@post-polio.org) is 12:00 pm CST on Thursday, September 28, 2017.**

The runners-up will be announced October 9-12 with the announcement for grand prize to follow on October 13th.



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#### Contest rules:

- Print or digital (JPEG with a minimum of 300 dpi) photographs will be accepted. Print photographs will not be returned.
- Identify the location and date of the photograph and include a short statement about aging with dignity as a polio survivor. Submitting a caption is optional.
- Each person is limited to submitting two photographs.

**NOTE:** By submitting the photograph to PHI you are confirming that the photograph is your property/work. You are agreeing to its limited use by PHI. PHI will state with the winning photos the following: Photo by (Name). Permission to use must be obtained through PHI. Decision of the judges is final.