

PHI's mission is supported by its Membership.

## Let's Clink Our Champagne Glasses!

Sunny Roller, MA, Ann Arbor, Michigan



*"We must SEE the delicious beverage – then TASTE the lovely wine – FEEL it on our tongue – SMELL the sweet aroma from the glass – lastly, we need to use our fifth sense so we 'clink' the glasses and HEAR the delightful sound ..."*

**I**t's time for us to have a wonderful party – a celebratory bash – to raise our glasses and communally toast having had polio. Three cheers for polio! We will clink together; then we will drink together!

What! Salute having had polio? Sound crazy? Maybe, but let's think about it. One of the smartest and healthiest things we might do at this time in our lives is to celebrate the gifts that polio actually gave us – the many wonderful life moments that happened to us *because* we had polio, not *in spite of* having had polio.

*Hip, Hip, Hurrah!* 1888, oil on canvas by Norwegian-Danish painter Peder Severin Krøyer

*... we have become the masterpieces themselves. And we flourish.*

This is a controversial, highly-charged topic because having had polio was not easy. But for the sake of debate, let's take a moment to broaden our thinking patterns here beyond the borders of "not easy." Let us invoke a little more expansive view of our lives, especially when it comes to renewing our personal sense of meaning. Yes, yes. We all want to see polio eradicated worldwide because it kills and paralyzes people. No. No. We would never wish polio on anyone, nor, if we could live life over, would we ever ask to have it again. However ... we got it, were disabled by it, suffered and struggled with it, and have been mastering the art of living well with it for decades now.

Looking back, we know it's true – a growing number of us have consciously turned living well with polio into not just

a goal, but a creative art form. We have not only been the adroit composers of our unique personal adaptations, attitudes and alliances; we have become the masterpieces themselves. And we flourish.

I believe one of our secrets to thriving with polio is that we, first and foremost, quietly dismissed all those who gawked at us with pity, volunteered to Biblically heal us, needlessly tried to fix us, or gazed at our bent feet rather than into our eyes. As we have matured, we have learned to reject the shame and stigma of disability. What a freedom! We found out that such negativity gets old and is not useful. Out of necessity, we have had to become introspective from time to time, which inescapably fostered our personal character development. We have learned to be assertive when needed, to

continued on page 6

# WE'RE STILL HERE!

October 12-18, 2014  
[www.post-polio.org](http://www.post-polio.org)

## “Post-Polio Experts Present” posted on Polio Place during **WE'RE STILL HERE!** week.

Fourteen videos were added to PHI's website, [www.polioplace.org](http://www.polioplace.org), during the week of October 12-18th. The timely informational videos permanently posted on the site are presented by dedicated experts who have significant experience in managing post-polio problems and in advocating for the survivors of polio. The presenters provide information and advice to the health professionals who treat polio survivors and also to survivors and their families. Ranging from 10 to 30 minutes, the videos include:

**Components of a Post-Polio Evaluation**, Frederick M. Maynard, MD

**Components of Comprehensive Post-Polio Management**,  
Carol Vandenakker-Albanese, MD

**Importance of Posture**, Holly H. Wise, PT, PhD

**Polio and Anesthesia**, Selma Calmes, MD

**Ways to Avoid Respiratory Complications of Postpoliomyelitis**,  
John R. Bach, MD

**Sleep Hygiene**, William M. DeMayo, MD

**Are Polioviruses playing a pathogenic role in the late consequences of polio?**,  
Antonio Toniolo, MD, FAMH (English and Italian)

**Poliomielite**, Sheila Jean McNeill Ingham, MD, PhD (Portuguese)

**Relationships**, Stephanie T. Machell, PsyD

**Disability Affirmative Therapy**, Rhoda Olkin, PhD

**Self-Advocacy and Community Advocacy**, William G. Stothers

**Developing a Personal Philosophy about Disability**, Lawrence C. Becker, PhD

**Growing Older with Grace**, Audrey J. King, MA (Psych)

**Spirituality in Disability**, Cyndi Jones, MDiv

The series “Post-Polio Experts Present” was underwritten by a grant from the Roosevelt Warm Springs Foundation. ■

## “Improvement standard” update

In *Post-Polio Health*, (Volume 29, Number 2), PHI reported on a court ruling ending Medicare's longstanding practice of requiring people to show improvement to continue to receive services. Medicare was charged with launching an educational campaign to alert beneficiaries with chronic conditions of the new guidelines.

As a result of *Jimmo vs. Sebelius*, Medicare stated that “Coverage of skilled nursing care or therapy to perform a maintenance program does not turn on the presence or absence of a patient's potential for improvement from the nursing care or therapy, but rather on the *patient's need for skilled care*. Skilled care may be necessary to improve a patient's current condition, to maintain the patient's current condition, to prevent or slow further deterioration of the patient's condition.”

The new guidelines can be found at [www.cms.gov/Regulations-and-Guidance/Guidance/Transmittals/Downloads/R179BP.pdf](http://www.cms.gov/Regulations-and-Guidance/Guidance/Transmittals/Downloads/R179BP.pdf). They explain the “need for skilled care” and the documentation needed to obtain approval from Medicare. ■

*Results and Observations***Post-Polio Medical Care: Post-Polio Specialists and Primary Care Physicians**

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

**P**ost-Polio Health International created a survey asking polio survivors about their post-polio medical care. The survey, *Post-Polio Medical Care: Post-Polio Specialists and Primary Care Physicians*, was posted online and a version was also published in *Post-Polio Health* (Volume 30, Number 2).

Data was gathered from 632 people; 496 completed the survey online and 136 copies received by mail were entered manually. Partial information was also entered.

Several expressed frustration at having to choose on the survey between seeing a post-polio specialist or seeing a primary care physician. Sheila Michael, California, said, "Over 20 years ago, I saw two post-polio clinic physicians (because of living in two separate locations) for evaluations and recommendations. These were shared (by me) with my primary physicians, as well as providing them information about the late effects of polio. Since then, my primary physicians have managed my post-polio care/needs with my input."

The results show that 53% have been seen by a post-polio specialist. Twenty-nine

percent heard about the specialist at a support group meeting while 21% were referred by their primary care physician. Location proved to be the main reason a specialist was chosen, with 58% visiting the closest one geographically. "Heard they were the best" was the second reason given (38%).

Northern California expert Carol Vandenaeker-Albanese, MD, states, "Because there are very few polio specialists around the country, it is not surprising that many polio survivors have never seen a 'post-polio' specialist. Most physiatrists do have basic knowledge of the effects of polio and PPS and are a good place to start if there are problems that a primary care doctor cannot manage."

Frederick Maynard, MD, Marquette, Michigan, adds, "Although there are no official criteria for designating or certifying a physician as a 'post-polio specialist,' the survey results suggest that the designation by reputation or by self-report is generally appropriate, since needs are being met, as judged by 'patient satisfaction.'"

continued on page 4

*Location proved to be the main reason a specialist was chosen ...*

**POST-POLIO HEALTH**

**Fall 2014**

**Vol. 30, No. 4**

ISSN 1066-5331

Editor: Gayla Hoffman  
editor@post-polio.org

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

©2014 Post-Polio Health International (PHI).  
Permission to reprint must be  
obtained from Post-Polio Health  
International (PHI).

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

**How to contact PHI**

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

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

continued from page 3

Thirty percent had first visited a specialist more than 15 years ago. Twenty-eight percent report their first visit within the last five years (15% in the last two years).

Some 62% do not see a specialist on a regular basis, with “I moved,” “he moved or retired” and “distance and travel problems” as the reasons mentioned by one-third of the survivors.

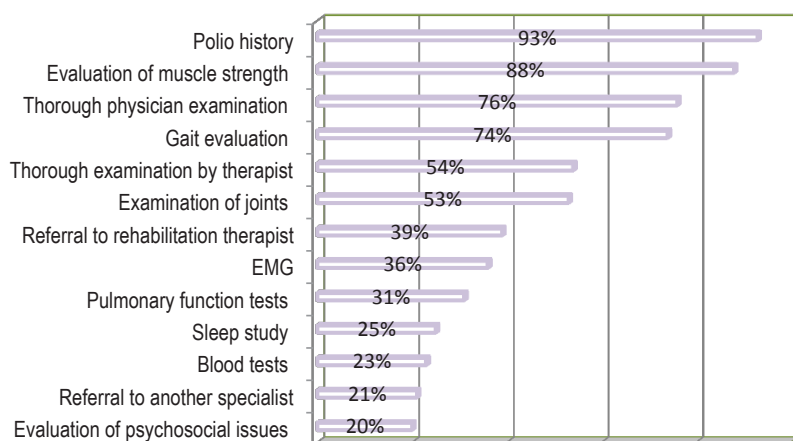
Other comments included, “surgery not feasible,” “surgery done,” “got the diagnosis of PPS, got on SSDI,” “found out I did not have PPS,” “advice was unrealistic – stop all walking,” “taught me how to manage my symptoms,” and “got the message – no cure. So, I will track my own gradual disintegration.”

Another 58% did not have an appointment in 2013. Forty-nine reported that the specialist did not report to their primary care physician. If they did, it was most often after the visit.

### Evaluation factors

The chart below represents what was part of the evaluation by a post-polio specialist. The percentage of what is typically included was both impressive and telling.

Many survivors added in the “other” category the recommendations they received. Bracing was listed most often, following by physical therapy and swallowing/sleep studies. Others received useful exercises and surgery.



The top five benefits of visiting a specialist were:

- ◆ Answered my questions fully/satisfactorily (75%)
- ◆ Access to assistive technology (braces, wheelchairs, etc.) (60%)
- ◆ Provided assurance to me (57%)
- ◆ Specified optional exercises/activity modifications to me (54%)
- ◆ Eliminated other neurological/musculoskeletal conditions (40%)

Other benefits included in the comments in this section were “have made contact in case I get worse and need a physician,” “got a disabled parking placard,” “guidance on diet and pacing,” “taken seriously,” “confirmed it was not just depression” and “the visit served as a ‘photograph’ of my current strengths/weaknesses.”

### Satisfaction factors

When asked to rate their *satisfaction with the care received by the designated post-polio specialist* on a scale of 1-4, the average was 3.32, with 54% rating their satisfaction as excellent.

When asked what accounted for a good or excellent rating, the top chosen responses were:

- ◆ Good communicator (65%)
- ◆ Years of experience (63%)
- ◆ Not in a hurry (63%)
- ◆ Straightforward (63%)
- ◆ Thorough (looks for causes/symptoms) (55%)

Polio survivors who have not seen a post-polio specialist depend on their primary care physician. One-third report that they discuss their post-polio at every visit and 43% discuss post-polio only when the need arises.

About 40% list themselves as the one who helps manage their care. Others checked were orthopedist, neurologist, physical therapist, local physiatrist, pulmonologist and added to the list were pain specialist, spine specialist, massage therapist, chiropractor, acupuncturist and the Veterans Administration.



When asked to rate their *satisfaction with their care received by their primary care physician* on a scale of 1-4, the average rating was 2.05, with only 9% rating it as excellent. One survivor reports that her primary visits her at home on occasion.

When asked what accounted for a good or excellent rating for their primary care physician, the top chosen responses were:

- ◆ Good communicator (75%)
- ◆ Not in a hurry (67%)
- ◆ Refers when needed (66%)
- ◆ Thorough (looks for causes/symptoms) (58%)
- ◆ Problem solver; good analytical skills (51%)

The survey was constructed to find the positive experiences of our Members. All was not positive with some survivors feeling that they were not listened to or where not allowed enough time to be appropriately examined. Survivors also report problems of getting the attention of their physicians, some of whom have never heard of PPS and of others who admit lack of experience.

One survivor definitely stated, “I would not go to a physician who does not want to learn.” Another commented, “I rely on *Post-Polio Health* publications.”

### **Communication skills are key**

Experienced post-polio specialist William DeMayo, MD, Johnstown, Pennsylvania, commented, “Responses to the question of what rates a good or excellent specialist are particularly interesting. Those who are looking for a post-polio specialist often cite a specific expertise as the main reason to see a specialist, yet nearly equal weight is given to communication skills, time spent, and being straightforward and thorough. It is possible that physicians with these traits gravitate toward post-polio as a specialty or that they simply have more interest in this population and that interest itself is meeting the patients’ needs. I myself love to hear about survivors’ life experiences,

determination and their focus on improving function and to learn from them.

“As for polio survivors who have not seen a post-polio specialist and depend on their primary care physician, I would encourage them to bring up that history every visit in some way. They may be severely underestimating how interested their physician might be in their life experiences. I have found individuals with polio, by and large, always focus on what they can do, not on what they can’t do. I wonder if it might be helpful in their relationships with primary care physicians to apply this same ‘can do’ attitude.”

Dr. Maynard adds, “I would encourage polio survivors who believe their needs are not being met in their local communities to travel to a post-polio specialist’s clinic, hopefully, with all pertinent medical records from medical providers they have seen previously and with the support of their primary physician. (However, medical records of the acute disease are difficult to find and not necessarily that beneficial.)”

Dr. Vandenakker reports that her team “has taught self-advocacy to all our patients with disabilities for years. It is important for everyone to be involved and direct their health care, especially individuals with conditions less familiar to many physicians and healthcare providers. I encourage my patients to find a primary doctor, who listens and is willing to work with them, because I rely on the primary doctor to evaluate other medical conditions that may contribute to symptoms of weakness and fatigue, such as heart disease, thyroid dysfunction or diabetes. I also encourage them to rely on other resources like *Post-Polio Health International* for post-polio specific information.” ■

***“I rely on  
Post-Polio  
Health  
publications.”***

continued from page 1

surround ourselves with loved ones, to think positively, get educated, find good resources and enjoy life along the way.

Perhaps most importantly, we have learned to accept ourselves as we are. Many of us have evolved in our thinking to appreciate and lovingly embrace what used to be our primary nemesis – polio. In order to find peace and contentment, we have had to make friends with our disability. Not overcome it. Not hide it. And not fight it.

Someone at the recent PHI Conference in St. Louis reflected, “Life doesn’t get easier, but it does get better.” Perhaps one reason life with polio is better is because we have become wise enough to embrace all of it – cause and effect. Polio has made us who we are today.

Our physical differences don’t matter much anymore because we are all beginning to look like everyone else our age anyway. We, however, know a bit more about aging gracefully, because we started sooner than all of our friends. We are aging *with* a disability. Many of our friends are aging *into* disability. If they’ll let us, we can actually help them with their new adjustments.

Our polio experience has given us everything from spontaneous moments of delight to life-long personal relationships we never would have had otherwise. Let’s take a long moment to praise, appreciate and clink our champagne glasses to all we

have received, known and loved because of our polio ... these have been polio’s gifts to us.

“What gifts,” you may ask, “did polio *possibly* give to me?” What is there to celebrate, to be grateful for? To open your thinking process, here is what a group of fellow polio survivors have shared from personal experience:

- In 1964 I got to view Michelangelo’s Pieta at the New York World’s Fair for as long as I wanted to because people in wheelchairs were allowed to sit about 50 feet from the magnificently mesmerizing statue instead of having to stand on the conveyor belt being moved slowly past the statue. I could marvel at every fold in Mary’s gown carved from that huge hunk of white marble. (*Clink!*)
- First, through all the wonderful polio survivors I have met, I have gained so much insight into life and all its inevitable ups and downs. Second, I have grown personally and I believe I have become much more sensitive to “the moment” and the value of self-reliance. These are blessings that came with polio. (*Clink!*)
- I would never have been invited to travel to India to teach about the late effects of polio, ride an elephant and see the majestic Taj Mahal shine in the rain like a glazed luminescent pearl. (*Clink!*)
- I don’t think I will ever be grateful for having had the disease. However, I am grateful for the opportunities that have come my way while dealing with the disability ... the very special people I have met along my journey, the extraordinary experiences that I have encountered, and the drive I have developed to succeed in life. (*Clink!*)
- I would not have met and married my husband if it hadn’t been for how struck he was by the contrast between my strong personality and my polio enhanced body with leg braces and a cane. I moved with effort due to my severe scoliosis, but stood proudly in a line of therapist colleagues introducing myself to lead

Polio survivor **Sunny Roller** is a post-polio educator and researcher and has authored professional and consumer



literature on the late effects of polio and wellness programs for polio survivors. A PHI Board member, she has a new blog, Conversations on Living Well with Polio, [sunnyrollerblog.com](http://sunnyrollerblog.com).

a discussion group at a conference he was attending. He picked my discussion group and pursued my attention. Forty years later we still wonder how, of all the people in the world, we found each other and how good it still is. *(Clink!)*

● A few years ago I had the opportunity to watch a superb young documentary filmmaker at work with her small crew, and to see how she turned much of what I said during a lengthy interview of more than an hour into images throughout the hour-long film. My voice was heard for no more than a couple of minutes but the film itself is crowded with images she found in the March of Dimes archives and other places – almost all of them completely unrelated to me personally, but some of which she spotted just by recalling our taped conversation. I learned a lot from this about the art of filmmaking. No doubt I could've learned roughly the same thing without the dubious benefit of having had polio. But in fact, in this case, the benefit arrived because of the polio. *(Clink!)*

● Polio has given me the ability to view life and situations “outside of the box.” This has enabled me to do the many, many challenging things that I have

accomplished in ways that would not be typical for most people. *(Clink!)*

● I learned to never feel sorry for myself; there are others worse off than me. *(Clink!)*

● It has enabled me to relate to issues others with disabilities are facing. *(Clink!)*

● I have met many wonderful, interesting people through my polio connections. Because of my polio, I have a worldwide network of supportive post-polio associates that I can link up with anytime. They are like “friends-on-call!” As a traveler, that’s an especially gratifying (and quite helpful) advantage. *(Clink!)*

● If I hadn’t studied post-polio treatments in Europe, I would never have encountered a European lover who made me feel like Sophia Loren on a scooter. *(Clink!)*

Now it’s your turn. Lengthen the list and join the party. It’s our time to celebrate! ■

## Thank You

*For recognizing your friends and loved ones with contributions to support the unique mission of PHI and IVUN. PHI strives to publish an accurate list. Please contact us if we made an error.*

### Contributions to PHI’s education, advocacy and networking activities ...

#### In Memory of

Joe Axton	Alan D. Fiala
Valerie Brew-Parrish	Kristen Norma Gruenawald
Margaret (Bonnie) Brown	Dorothy Pettit
Judith Ellis-Snyder	Thomas S. Reed, II
Edie Elterich	

#### In Honor of

Margaret Phelan Reed

### Contributions to the Research Fund ...

#### In Memory of

Valerie Brew-Parrish  
Mary Ellen Kollodge  
William G. Ohme, Jr.

#### In Honor of

Allen D. Yoho

*Partner abuse has been front and center in the news lately. We asked our two columnists to address the issue for people with disabilities.*

**Dr. Olkin addresses male to female partner abuse in heterosexual relationships:**

If you are being abused by a partner, I want to say two things to you right at the start: (a) You are not alone; (b) It is not your fault. And the third thing is that there is help and hope, but you have to take the first step.

Let's back up and discuss what we know about partner abuse. There are early warning signs: he came on strong at first, with lots of romance; isolating you from friends and family; being suspicious of you and your whereabouts; getting angry over small things; calling you names or putting you down; speaking disparagingly of women in general and previous partners specifically; he is possessive and jealous; he does favors for you that put you in his debt; he pressures you or forces you to have sex; he treats you one way in public and another way in private; nothing is ever his fault. Abuse never stops on its own, and the level of abuse tends to escalate over time. Women are more likely to be killed by a partner than a stranger (this is not true for men).

There are many reasons women stay, though studies indicate that they do eventually leave, usually by a five-year follow-up. Why do they stay? When this question was posed publicly (#whyistayed) after press about the NFL, 121,000 women posted responses. In contrast, only 40,000 posted to #whyileft. Women stayed due to feeling powerless, for fear of further and worse abuse, because he swore it was the last time, because of the children, for financial

constraints, because they loved him. And why do women leave? Because of the effect of witnessing violence on the children, because the abuse was now directed at the children, because the abuse was escalating, because someone offers a lifeline, because it's no way to live.

Abuse carries specific risks for women with disabilities. She is more easily injured, injuries can take longer to heal, the sum total of disability plus injury can be more debilitating than without the disability. She may need assistance in activities of daily living, safe houses might not be wheelchair accessible, she may depend on the health insurance of her spouse. Additionally, there are types of abuse specific to women with disabilities, such as dismantling an automatic door opener, taking the battery out of an electric wheelchair or scooter, refusing to help her with necessary tasks, breaking assistive devices, removing car adaptations.

The main thing that allows abuse to continue is silence. It happens in secret. The woman feels ashamed, embarrassed, at fault. But see paragraph #1! Make a plan to survive: (a) Do not tell your partner you are leaving, as that tends to increase the level of violence and attempts to hold you at all costs. (b) Pack a bag with your important things (cash, keys, personal documents). (c) Share a secret safe word with those you trust to signal that you need help. (d) Get a restraining order. (e) Call the National Domestic Violence Hotline: 800-799-



Rhoda Olkin, PhD

**Dr. Rhoda Olkin** is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology.

She is a polio survivor and single mother of two grown children.



SAFE (7233) or 800-787-03224 (TTY for the deaf and hard of hearing).

About two weeks ago a female student shared for the first time that she had been living with an abusive husband for ten years. As she told me I could see the anxiety, the shame, the fear of my judgment. But yesterday she came back to tell me that sharing her story with me lifted a huge weight off her, that she was so much better, knowing she was moving on. This could be you.

**Dr. Machell addresses female to male and same sex partner abuse:**

Intimate partner violence (IPV) isn't just about male perpetrators and female victims. Men can be abused by a female partner. And in same-sex relationships men are abused by men and women are abused by women.

Abuse can be physical, sexual, emotional, psychological or economic. Withholding of medication, assistive devices or care; keeping someone from medical appointments; or threatening nursing home placement, competency evaluation or the removal of their children are forms of abuse too. Abuse, regardless of the form it takes or the gender of perpetrator and victim, is always about power and control. The cycle of abuse and the blaming of the victim by the perpetrator are also the same.

Given the level of underreporting, I believe the statistics on the frequency of men abused by female partners are meaningless. It is wrong to assume

that such abuse is primarily emotional or psychological. Regardless of size or physical strength differentials, women can and do physically and sexually abuse men.

No matter what form the abuse takes, men abused by women report feeling shame and isolation. They may question their masculinity, or believe that others would, especially if as often happens the abuser states or implies this is why the abuse is occurring. When male victims disclose abuse, they may experience or fear they will experience skepticism and ridicule. And even without false accusations by the abuser, many people, including police and judges, assume the abuse must be mutual.

In the recent past, abuse in same-sex relationships has been more openly acknowledged. In spite of this, in my own practice I have seen gays and lesbians who are connected with their own communities and comfortable with their identities – nevertheless experiencing ambivalence about leaving abusive relationships. It is much harder for those who are less comfortable and/or who live in less enlightened parts of the country. If they are not out, their perpetrators may threaten to out them. Reporting the abuse, even telling a friend or family member, may out them anyway. Police and others may not take abuse between same-sex partners seriously. Even if they do leave, victims may not be able to access shelters or protective orders. And a closeted victim may have few or no supports among family or friends.

continued on page 10



Stephanie T. Machell, PsyD

**Dr. Stephanie T. Machell** is a psychologist in independent practice in the Greater Boston area and consultant to the International Rehabilitation Center for Polio, Spaulding-Framingham Outpatient Center, Framingham, Massachusetts.

Her father was a polio survivor.

## Looking for Volunteers!

### The RRTC on Promoting Healthy Aging for People Aging with a Long-Term Physical Disability

For the last 5 years, our research group has followed 389 polio survivors who are experiencing the late effects of polio or post-polio syndrome. This group of volunteers has filled out a survey for us about every year or every few years. You may already be one of our very valued volunteers – thank you for your participation!

Now, we have new funding and we're looking for a small number of new volunteers to join the survey. We'd like every voice to be heard and counted in our survey – and especially those from underrepresented or minority backgrounds. For that reason, we are launching a new effort to enroll new individuals to our team of survey volunteers. We are currently looking for individuals with post-polio syndrome (or late effects of polio) who identify themselves as African American, Hispanic, Asian American or Native American. Men (of all backgrounds) are also especially encouraged to participate.

#### What's the skinny on the surveys?

- 3 surveys over the next 5 years.
- Paper surveys mailed out to your home filled out with a pen.
- About 45 minutes to fill out.
- Questions ask about quality of life, resilience, coping and symptoms you may experience, like pain or fatigue. We will also ask a set of questions about your health care.
- We will send you a check for \$25 for each survey you fill out and return to us.

**Interested?** Contact us! 1-866-928-2114 or [agerrtc@uw.edu](mailto:agerrtc@uw.edu)

**Want to know more about us?** Connect with us:

Online: [agerrtc.washington.edu](http://agerrtc.washington.edu)

Facebook: [facebook.com/agingRRTC](https://facebook.com/agingRRTC)

Twitter: [twitter.com/AgingRRTC](https://twitter.com/AgingRRTC)

Join our Quarterly E-Newsletter List: Email us at [agerrtc@uw.edu](mailto:agerrtc@uw.edu)

## Promoting Positive Solutions

continued from page 9

Some men in same-sex relationships report being told that leaving shows they aren't really gay or that they believe gay relationships are wrong because men are naturally violent and this is a natural part of sexuality between men. Men who are conflicted about being in a same-sex relationship may even believe that the abuse is punishment that they deserve.

Women abused in same-sex relationships often feel especially isolated, especially if they believe that women are never perpetrators of abuse. Because lesbian communities are small and interconnected, it may be difficult for the victim to escape her perpetrator without disconnecting from her support systems. Women in same-sex relationships who don't identify as lesbians may feel additional confusion and shame.

All people with disabilities are twice as likely to be victims of IPV as those who are temporarily able-bodied. While being

targeted due to physical weakness or vulnerability seems obvious, many people with disabilities are at high risk for emotional and psychological abuse due to poor self-image. For example, an abuser can exploit or reinforce a polio survivor's belief that he or she is less attractive or desirable and therefore lucky that anyone would want them. Individuals who have experienced trauma or who have attachment issues may also be more vulnerable to all forms of IPV. And if the abuser also provides care, transportation or income for the victim, it becomes even more difficult to leave.

If IPV is happening to you, no matter what the perpetrator tells you, it isn't your fault. You don't deserve it. And you can leave.

The recommendations for leaving safely and the phone numbers in Rhoda's response will work for you too. Use them. Be safe. ■

## In “Thriving,” Tepley Recounts Stories of Triumphant over Trauma

In 1995, Joyce Ann Tepley became the principal advocate for her father-in-law's care during the last few years of his life. Even though she was an experienced clinical social worker who knew how to negotiate resources, she was constantly frustrated by the lack of coordinated care and impediments placed by nursing home and hospital staff regarding the preservation of his dignity and management of his pain. She wondered if there was a better way and why some people seemed to thrive or flourish through the hardest times in their lives. After he died she happened to find an organization called the Health Forum that offered a fellowship program sponsored by the American Hospital Association. It was called Creating Healthier Communities, encouraging best practices across the United States.

She was accepted into the year-long program and chose as her project 20 people with long-term physical disabilities from all walks of life who were referred to her as thrivers. (One of them was PHI director, Joan L. Headley.) She wanted to know what they all had in common. Through taped interviews asking each person the same questions, she discovered particular personality traits, beliefs and support they each told her they had.

With 40 hours of interviews, she took a break to figure out how to write what she discovered in a way that anyone would want to read it. She took several creative non-fiction writing classes and then marketing for authors courses. She wanted to honor the people who generously shared their life stories with her – ordinary people who live extraordinary lives but who do not think of themselves as heroic.

The book, *Thriving Through It – How They Do It: What It Takes to Transform Trauma Into Triumph*, is divided into three sections: *My Who's Who of Thrivers*, *What Kind of Person is a Thriver?* and *My Findings*. The book provides something for everyone who has ever gone through difficult times.

Tepley describes herself as a thriver. What did she learn in writing the book? “I am not going to be that careful anymore.” She will rest when need be, but she will push herself now. “This is my last hurrah. I spent much of my life being fearful. I am not afraid anymore.” ■



Joan L. Headley, a thriver, with polio survivor and author, Joyce Tepley at PHI's 11th International Conference. Tepley donated \$500 from book sales to PHI.

### Not yet a Member?

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

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

#### ☐ \$30 Subscriber

*Post-Polio Health* (quarterly)

#### ☐ \$55 Subscriber Plus

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

Name \_\_\_\_\_

Affiliation \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State/Province \_\_\_\_\_

Country \_\_\_\_\_ Zip/Postal Code \_\_\_\_\_

email \_\_\_\_\_

Phone (include area/country code) \_\_\_\_\_

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

Please charge \$\_\_\_\_\_ to this credit card:

☐ VISA ☐ MasterCard ☐ Discover

Card No. \_\_\_\_\_ Exp. Date \_\_\_\_\_

Name on Card \_\_\_\_\_

Signature \_\_\_\_\_

POST-POLIO HEALTH INTERNATIONAL  
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

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

Non-Profit Org.  
U.S. Postage  
PAID  
Jefferson City, MO  
Permit No. 210

## **Thriving Through It – How They Do It** **What It Takes to Transform Trauma into Triumph**

by Joyce Ann Tepley ([www.joyceanntepley.com](http://www.joyceanntepley.com)) can be purchased at Amazon.com, Barnes & Noble, and iUniverse.

Her websites are [www.thriverlivingcommunity.com](http://www.thriverlivingcommunity.com) and [www.thrivingthroughit.wordpress.com](http://www.thrivingthroughit.wordpress.com).

### **Inside *Post-Polio Health***

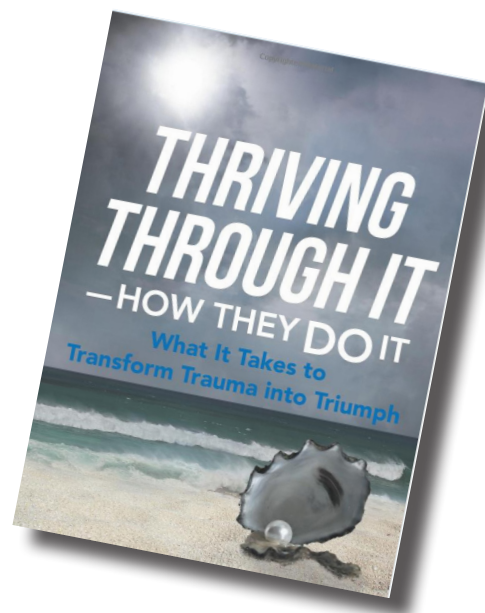
Vol. 30, No. 4, Fall 2014

Let's Clink Our Champagne Glasses! ... 1

WE'RE STILL HERE! ... 2

Post-Polio Medical Care: Post-Polio Specialists  
and Primary Care Physicians ... 3

Promoting Positive Solutions ... 8



See Page 11 for a description of the book.