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## Promoting Positive Solutions for Aging with Polio: Highlights from PHI's May Town Hall

On May 15, 2023, Rhoda Olkin, PhD, and Stephanie Machell, PsyD, led a town hall, Promoting Positive Solutions for Aging with Polio, as part of PHI's 2023 Educational Series. Below are some excerpts from the event.

The full recording can be viewed at <https://post-polio.org/education/post-polio-experts-present/>.

**QUESTION:** I'm in my 70s. My husband and I still aren't retired. We both work in real estate. Are there services for polio survivors that are free, like exercise groups? Everything seems so expensive when it's related to post-polio.

**Rhoda Olkin, PhD:** That's a really excellent question. There's what I call the disability tax—things we have to pay for that nobody else has to pay for. There should be a local post-polio support group [near you] which is free. There are many in California. I don't know where you are, but try to see if you can find a local polio support group because that's the group

that tends to know about different resources in your local area. The other tip I have is if you need something like a grab bar, don't go to a medical store. Go to somewhere like CVS or Walgreens. It's cheaper than other places. As soon as something's in a medically-oriented store, it's more expensive.

**QUESTION:** I am almost 80; I am also still working. My husband passed away a year ago. I knew I was going downhill the last 25 or 30 years, but I didn't realize until I was completely on my own how much he did for me—simple things like carrying in the groceries or things that you don't even think about, such as dropping me at the door so I didn't have to walk. Travel was our hobby. I'm going to be traveling by train soon. I probably won't bring my own scooter with me and will just rent one at the hotels that I stay at. Does anybody have any tips on how to travel alone? I'll pack very light with a small suitcase on wheels. I can walk about 30 feet before I have to stop. Am I crazy to try to take a train trip given what I've told you so far?

**Olkin:** I'm considering a train trip from Vancouver to Banff, but I'm in the San Francisco area, so it's all about the logistics of getting from one place to the other. You can, in fact, take an Uber or Lyft if you're in a city that's big enough that they have accessible ones. You can request a wheelchair-accessible one. You actually could take your own scooter if you wanted. Or there are taxis that will take scooters or wheelchairs. Could you do a shorter trip to try it? That would be my suggestion, so that you feel more confident even if everything works out.

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### TOWN HALL

Promoting Positive Solutions  
for Aging with Polio

Presented By:  
Stephanie Machell, PsyD  
&  
Rhoda Olkin, PhD



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My rule of thumb is one thing goes wrong every trip, and you just don't know which thing it's going to be. And I like to know that when that thing goes wrong, I'm still going to be okay. So, I have tried several things when something goes wrong. I've gotten stranded at airports, for example, but I've always managed to somehow get to where I need to go. So, it's a good thing to try it out on shorter trips.

**QUESTION:** What perspective can you share with us on dealing with asking for help when so much of our lives we've been toughing it out through our challenges as polio survivors? How do I transition from doing everything myself to letting others help without perceiving that as another loss?

**Stephanie Machell, PsyD:** It's hard sometimes to give an answer that's going to fit everybody's specifics because everybody's in a different situation, but I think what I would stress is that you're not going to go from 0 to 60. You're not going to suddenly be able to just do this with great ease. Think about what your lowest cost ask is. Who can you ask that you feel will give you a "yes" to your request, and who will it hurt least for you if they say "no." Build up your muscle a little bit with asking.

As a child of a polio survivor, we like being asked. So, you might want to ask one of your children—if you have children—as your first ask. Spouses are

more complicated. I always say that the hardest role in the polio family is the polio spouse. But think about who you can experiment with this on and then just see how it goes and build it up gradually.

**Olkin:** A lot of it has to do with how you think about asking for help. When you frame it as, "I can't do this, and I am dependent on someone else to do it," that's a very negative framing. But if you think about it in terms of, "I can do this with assistance," that's a less negative way to frame it. But I like that idea that Stephanie said of exercising the asking muscle. I think that's really a nice way to think about it.

**QUESTION:** Some friends do not understand my issue of fatigue and either question my words or want to tell me I am just fine. What's the best way to help them understand?

**Olkin:** When most people say the word fatigue, what they mean is, "I really need a good night's sleep, maybe two, and then I'll be fine." What we mean by fatigue is, "If I've left something in the kitchen, it's going to stay in the kitchen because I can't get from the bedroom to the kitchen." That's a very different level of fatigue, and it is hard to help other people understand what that's like.

I actually wrote a book called *Teaching Disability*, and one of the exercises in it is about how to make people without a chronic illness or disability understand

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

Designer: Sheryl Prater

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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.*

### How to contact PHI

50 Crestwood Executive Center #440  
Saint Louis, MO 63126 USA  
Phone: 314-534-0475  
Fax: 314-534-5070  
info@post-polio.org  
www.post-polio.org  
www.polioplace.org

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Be sure to set your spam filter to receive emails  
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### 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.

fatigue and the way that you have to parcel out your energy over the week. One way I have tried to explain it to people is that recovery time is measured in days, not hours. And imagine you went on a hike that was just much, much more than you are used to ever doing—like maybe you went three-and-a-half miles up a mountain and three-and-a-half miles down a mountain, and you’ve never taken a walk more than maybe a mile. You would feel a level of fatigue that would take you a day or two to recover from.

Now imagine that the recovery is compromised because you’ve overused muscles and don’t have others to spare. So, it is very hard to explain to others, but I think the main thing I’m trying to get across is that this is not just about sleep. This is about muscles being worn out and needing to rejuvenate. And because you don’t have backup muscles, when they give out, they give out, and there’s nothing left.

I’m still working and so people see me popping around work, and I look fine. They don’t know that the day after I’ll be lying in bed. Sometimes I have to tell them that this is the cost for me of doing this. This is what I have to do to be able to do this. So, it does take some self-disclosure. The other thing I was really interested in is that sometimes they want to tell me I’m just fine. I did a study on women with disabilities and the kinds of micro-aggressions they experience. And one of them was, “You look fine. How come you’re not fine?” Somehow the way you look means you’re okay. I think that happens to women more than men.

**QUESTION:** I’m 87 years old and suffering not only from PPS-related fatigue but also long COVID fatigue. How much should I push through? I worry about damage. My fatigue gets severe and makes me breathless. I’ve had thorough health exams, all normal. I practice all the help tips that you have spoken about and use assistive devices. Would either of you have any advice for someone in that situation

**who’s dealing with either PPS-related fatigue or fatigue that’s been made worse by COVID?**

**Machell:** I think that the things that Rhoda said earlier regarding fatigue would certainly apply to this situation, except, of course, you have a multiplier on your fatigue. What she was talking about with muscle fatigue and the need for muscles to recover, sometimes you don’t know what’s going to happen until you push yourself past something. It’s frustrating to have to take the time that you need to take to rest and recover, but what I often tell my clients is to think about the things that give your life light and color and try to prioritize those with the energy you have, especially when you’re in a recovery time with long COVID. We don’t know how long that’s going to be.

When you’re in a period where you’re going to have diminished strength, be gentler with yourself. Try to let go of the things you absolutely don’t have to do. See if you can strengthen your “asking” muscles, as it were, to get the support you need. Imagine yourself convalescing. I realize that may be problematic for some of you who had trauma with your convalescence from polio, so that might be triggering some feelings, too. The simple answer would be to see how much energy you do have and try not to push past that amount. Or as Rhoda had said earlier, build in a recovery day if you know you’re going to need it.

I’m seeing that there are a number of questions about emotional pain. Unfortunately, we can’t deal with them right now, but I would strongly encourage people to write to us, and we’ll try to take the time to answer them.

**Brian Tiburzi:** Thank you, Stephanie. If you have questions of that nature, you may send them in an email to [info@post-polio.org](mailto:info@post-polio.org), and we will pass them along to Drs. Machell and Olkin. ■

## WE'RE STILL HERE! WEEK—October 8–14, 2023

PHI's 17th annual post-polio awareness campaign will take place October 8–14, 2023. We are once again inviting you to help contribute to another successful campaign. Spread the word about the late effects of polio and remind the world that WE'RE STILL HERE!

This year's theme centers around the idea of adaptation; particularly, what adaptations you've employed to participate in your favorite interests and hobbies. Perhaps you use an assistive device to provide support and stability while engaging in activities such as walking, hiking or gardening.

If you enjoy painting or drawing, maybe you use modified brushes or adaptive grips to hold the tools more comfortably. Those who love to cook might take advantage of modified utensils or make modifications to their kitchen.

Wheelchairs designed for different terrains, such as all-terrain or sports wheelchairs, might allow you to participate in activities like sports, outdoor adventures or even wheelchair dancing. Voice recognition software, adaptive keyboards or touchscreens may help you engage in writing, blogging or creating digital art.

Polio survivors are nothing if not resourceful. When our disability throws up a roadblock, we find a way around it. We want to hear from you about the ways you've found to keep pursuing your passions.

### How to participate:

Send a picture and short description (1–2 paragraphs) of an adaptation that has allowed you to participate in a hobby or activity.

### How to submit:

◆ Email your submission to [info@post-polio.org](mailto:info@post-polio.org) (Subject: WSH 2023) OR mail it to our office at 50 Crestwood Executive Ctr #440, Saint Louis, MO 63126.

◆ Include your name, mailing address, phone and/or email.

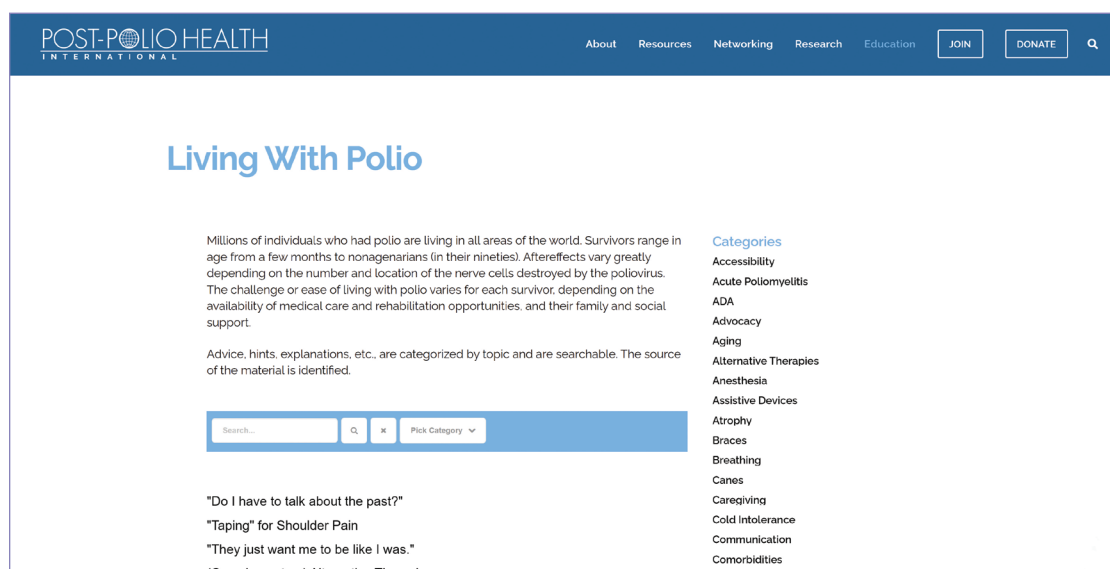
Post-Polio Health International will feature select submissions on our social media accounts and website during WE'RE STILL HERE! week. We will also highlight the best submissions in the fall edition of *Post-Polio Health*. ■



If you've visited [www.post-polio.org](http://www.post-polio.org) lately, you may have noticed some exciting new features that have been added to the site.

## Living with Polio

PHI is pleased to introduce a major new addition to the website. The new “Living with Polio” section can be accessed under the “Education” tab in the menu. The newly added section contains 263 entries under 95 different categories pertaining to living with the late effects of polio. Find practical information to help answer your questions on a range of topics from anesthesia to weakness and everything in between. This searchable database includes previously published articles, essays, blog posts, *Handbook* excerpts, and more from PHI's extensive archives.



## Ask the Doctor

Have a medical question about the late effects of polio but can't quite find the answer you're looking for on our website? PHI's Medical Advisory Committee is here to assist. Our new “Ask the Doctor” service lets you tap into the expertise and knowledge of PHI's volunteer physicians, who together have decades of experience treating polio survivors. Just fill out the form at <https://post-polio.org/ask-the-doctor/> and one of our volunteer physicians—Marny Eulberg, MD; Frederick Maynard, MD; Carol Vandenakker Albanese, MD; Martin Wice, MD—will be in touch.

What can PHI's volunteer physicians help with? They can answer questions specific to some sub-groups of polio survivors that may not be answered in PHI's more general statements—such as ‘What type of exercise(s) would you recommend for a polio survivor with weakness of one leg?’ but they will not be able to answer very specific questions such as ‘What is the best exercise for me?’ or ‘What is the best brace for me?’

**Disclaimer:** PHI offers this program as an educational service but it in no way is a substitute for medical care by a personal healthcare provider. Our physicians/other healthcare providers can only make suggestions that you, in turn, will need to discuss with your healthcare provider. They cannot treat you or write prescriptions for you. Interactions in writing, verbally, or even by video cannot replace the value of an in-person evaluation. ■



## Terry Weaver, CO, Fairfax, Virginia

### NOMINATED BY CAROL DEXTER

If it were up to me, I would nominate Terry as my Sirius Star, the brightest star in the galaxy. I have been stuck with poorly constructed and ill-fitting KAFOs through the years, costing me hundreds of dollars for a device that ends up taking up space in the back of my closet. And then I found Terry Weaver, orthotist extraordinaire.



Terry Weaver, CO

With the increased popularity of carbon fiber and plastics, the fabrication of metal KAFOs is becoming a lost art, making it a challenge to find an orthotist who is familiar with the old-fashioned metal uprights. Terry suggested that because I have worn a metal KAFO my entire life and am still fairly active, a plastic brace would not be my best option despite the fact that it is easier to make.

He understood my desire not only to have a durable KAFO but also a brace that was as aesthetically pleasing as possible. With patience and skilled craftsmanship, Terry fabricated a solid metal KAFO using heavier uprights, thicker leather on my straps, and sturdier buckles. The result was a well-fitting, comfortable, supportive and durable KAFO.

Terry is able to empathize and listen with compassion to my needs. He is aware of just how much I depend on my brace to maintain my independence. Terry has walked the proverbial mile with me, giving me legs to stand on and allowing me to thrive. If a strap wears out, or I need a new spring, he is always prompt with repairs.

He even fine-tuned my KAFO and shoe build-up prior to my son's wedding so that I would have the confidence in knowing that my step and gait would be optimal, and I could enjoy the activities without the fear of falling.

Thank you, Terry, for making a difference in my life. Your talent has greatly enhanced the quality of my life. You have put a spring (no pun intended) in my every step!

### ABOUT TERRY WEAVER

Terry Weaver is an American Board for Certification (ABC) Certified Orthotist. He has worked full-time in the field of orthotics and prosthetics since 1974, following a five-year apprenticeship with his father Cecil F. Weaver, also a Certified Orthotist. Terry joined Orthotics Solutions in 2005. He is very skilled in fabricating orthotics using metal, plastics and other materials.

Terry is married with two sons and enjoys spending time with them, as well as his two grandchildren. His weekends include hunting, fishing and working on a beef farm that he owns. Terry especially looks forward to Sundays during the fall, when he can watch his favorite football team, the Washington Commanders.

## *To spotlight your Shining Star:*

PHI's Shining Star campaign invites readers to honor the health professionals, past or present, who have made a positive difference in their lives. It's an excellent opportunity to honor these extraordinary individuals in a meaningful way and support your post-polio cause.

- ◆ Simply donate to PHI in honor of your special healthcare professional. This could be a doctor, psychologist, any type of therapist, chiropractor, nurse, dentist, home health aide, or someone you know that has provided exceptional care and concern and helped you with your individual needs.
- ◆ Submit a short biography and a photo of the person along with a paragraph or two about why you nominated them. Then send it to [info@post-polio.org](mailto:info@post-polio.org). We will follow up and contact you.
- ◆ You will be recognized as a donor in their honor. They will receive a letter of recognition and thank you from PHI, and their story will be showcased on our website. ■

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## UPCOMING PHI WEBINARS

Past webinars in PHI's 2023 Educational Series can be viewed on our YouTube channel at [www.youtube.com/@post-poliohealthinternational](https://www.youtube.com/@post-poliohealthinternational).

### LECTURE SERIES

**Join Us On  
July 18, 2023  
at 1 pm CDT  
for a discussion on  
Exercise Guidelines for  
Polio Survivors**

**Presented By:**  
**Carol Vandenakker Albanese, MD**  
&




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### TOWN HALL

**Join Us On  
August 22, 2023  
at 1 pm CDT  
for a discussion on  
Accessible Travel**

**Presented By:**  
**Candy Harrington**  
&



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## The Autumn Ghost: How the battle against a polio epidemic revolutionized modern medical care by Hannah Wunsch

Selma H. Calmes, MD, anesthesiologist (retired), Olive View/UCLA Medical Center

If we have to go to a hospital now, the care is very different from when we had polio. Today, hospital care involves lots of complicated equipment and lots of staff who are capable of managing multiple medical problems; these needs were certainly evident in the recent COVID epidemic. How did we get from the relatively simple hospital care of the past, when we had polio, to this more complicated hospital care of today?

A new book from Hannah Wunsch, *The Autumn Ghost: How the battle against a polio epidemic revolutionized modern medical care*, (Greystone Books, 339 pages) tells the story.

Wunsch is a critical care anesthesiologist in Canada and has cared for many critically ill patients. The problems presented by polio patients during polio epidemics in the 1940s and 1950s led to major improvements in the care of polio patients. These advances became the new standard of care for *all* critically ill patients, and patients in the contemporary era are now much more likely to survive as a result.

Those who were hospitalized with polio in the past may want to read this interesting and well-written book to learn about what happened to cause this change.

This gripping story, centered in Copenhagen, Denmark, begins amidst the devastation of World War II. Denmark was invaded by Germany on April 19, 1940. Polio appeared in Denmark in 1944. Copenhagen's Blegdam Hospital, the only communicable disease hospital in Denmark, began to fill with patients.

It was to become *the* polio hospital. (The hospital was also a center for resistance activities. Jews were smuggled into the sprawling hospital and then smuggled out to the nearby northern coast and taken in

small boats across the Oresund Strait to neutral Sweden, only a few miles away. Nearly all Danish Jews were saved by this smuggling effort.)

The number of polio patients soon became overwhelming, and many patients lost the ability to breathe as their muscles of respiration were paralyzed by polio. Artificial ventilation was not often used. There was little understanding of this, and devices were expensive, not easily available, and not easy to use.

The Blegdam only had six cuirass ventilators (cuirass ventilators had a plastic covering for the chest). Negative pressure was applied to pull the chest wall out, allowing air to enter the lungs, producing a breath. There was only one iron lung, and as many as 50 patients arrived each day needing ventilation.

The United States at this time used expensive and difficult-to-manage iron lungs to breathe for paralyzed polio patients. The US's national polio organization, the March of Dimes, provided the needed financial resources to purchase and move iron lungs around. No Blegdam Hospital staff had experience with artificial ventilation at this time of increasing need. Polio patients had little chance of surviving.

When the next polio epidemic appeared in 1952, polio care still had not improved; especially since there was still no easy way to ventilate the paralyzed patients who could not breathe for themselves. The Blegdam's physicians were deeply concerned and tried to find possible solutions.

One of Copenhagen's few trained anesthesiologists, Bjorn Ibsen, (then working at the nearby University Hospital) had trained for a year in the United States (at Massachusetts General



Hospital in Boston) and had learned there of a simple and safe way to breathe for anesthetized patients, the Waters to-and-fro circuit. This technique was often used in the US at that time to deliver anesthesia to patients having surgery. This consisted of a breathing tube that was connected to a gas source via tubing and also to a bag that the anesthetist could squeeze to breathe for the patient if needed.

*These advances became the new standard of care for all critically ill patients, and patients in the contemporary era are now much more more likely to survive as a result.*

Ibsen was asked to come to the Blegdam to examine a possible polio patient, 12-year-old Vivi Ebert. She was admitted the day before and was struggling to breathe as her polio progressed. After a careful examination and review of her X-rays, Ibsen realized she could be ventilated with the to-and-fro system. He worked to assemble the needed equipment and drugs and arranged for a surgeon to do a tracheostomy so he could ventilate Vivi more easily.

Multiple issues arose as Vivi was treated. At first, her outlook did not look good. But Ibsen was experienced in dealing with difficult situations and persisted. Other doctors who were watching left to eat lunch, thinking that this experiment would fail and Vivi would die. But Ibsen was experienced and managed effectively. The other physicians returned from lunch

to find Vivi sleeping. Vivi went on to live another 19 years and lived a surprisingly full life.

This new therapy then began for other paralyzed polio patients. This called for massive resources: rubber breathing tubes, suction tubing, oxygen sources, carbon dioxide absorbent and, most importantly, people to squeeze the bag that breathed for the patients. There were so many polio cases that there weren't enough medical students, so dental students filled in.

Later improvements in laboratory studies of respiratory gases would make it easier to sort out the problems that can occur. Modern ICU care was on its way! ■



# A Brief Reflection on the Legacy of Judy Heumann

Joan L. Headley, Past Executive Director of PHI

When PHI asked me to write about Judy Heumann, I wondered what I could say that already hasn't been said.

Her life's story includes polio at the age of 18 months, the struggle to attend school with non-disabled children, and the rejection by the New York City school system to be a teacher because she was in a wheelchair.

This experience and other roadblocks to involvement in family and community life initiated a trajectory that included founding an early independent living center, leading a takeover of a federal building in San Francisco, and two presidential appointments. She traveled worldwide on behalf of people with disabilities and was even featured in the Oscar-nominated film, *Crip Camp*.

Judy possessed a great intellect. She saw the big picture and realized that systems needed to change so that people with disabilities, including herself, could realize their dream.

She was unwavering in the fight and outspoken when treated as a second-class citizen. Nevertheless, Judy advocated with dignity and was gracious when pointing out one's faulty thinking.

Her heart was big. Her faith was constant. Her sense of humor, although necessarily bottled up many times, was clever, even wicked.

We stayed in touch after I retired five years ago. Our last communication was about "the so many things that we would've wanted to do but never got to do."

Upon hearing of her death, I recalled another past conversation of ours in which I complimented her on all she had accomplished for us.

She looked at me and said, "Do you really think so?"

I was shocked. She was serious. My response left no doubt.

On March 4, 2023, her advocacy leadership ended.

I call on all of us to continue our advocacy in her name. Knowing this, I'm sure she would break out that memorable great smile. ■



Joan Headley (left) and Judy Heumann prepare for a march in support of disability rights in Saint Louis, Missouri, 1995.

## LEARN MORE ABOUT JUDITH HEUMANN

### In Print

*Being Heumann: An unrepentant memoir of a disability rights activist*  
(2020, Beacon Press. 240 pp.)

*Rolling Warrior: The Incredible, Sometimes Awkward, True Story of a Rebel Girl on Wheels Who Helped Spark a Revolution* (2021, Beacon Press. 224 pp. For young adults)

### Online

Polio Place—<http://www.polioplace.org/people/judith-e-heumann>

JudithHeumann.com

“A Brief But Spectacular take on the disability rights movement”  
(PBS NewsHour, [www.youtube.com/watch?v=2PnUza4FPz8](http://www.youtube.com/watch?v=2PnUza4FPz8))

“Our fight for disability rights – and why we’re not done yet” (TED Talk,  
[www.youtube.com/watch?v=uJr4wGcLNsA&t=18s](http://www.youtube.com/watch?v=uJr4wGcLNsA&t=18s))

### On Film

Crip Camp: A disability revolution (Netflix)

## In Appreciation

Thank you for recognizing your friends and loved ones with contributions to the activities of PHI and IVUN and for your generous Membership contributions.

*Please contact us if we made an error.*

### Contributions to PHI's education, advocacy and networking activities

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or send (or fax 314-534-5070) this form to:  
Post-Polio Health International, 50 Crestwood  
Executive Ctr #440, Saint Louis, MO 63126 USA.  
Questions? 314-534-0475.

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