

POST-POLIO HEALTH

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Polio, Devalued Bodies and Disability

Rodney Hume-Dawson, California State Polytechnic University, Pomona

It is, perhaps, a very opportune time to be discussing devalued bodies. After all, we live in very precarious times socially and politically.

Similarly, these are also interesting times for the disability community. On the one hand, our rights and hard work for disability justice are still unfamiliar and ambiguous to many around the world. While on the other hand, academia is forging ahead into uncharted territories through the academic discipline called disability studies.

My interest in the issue of devalued bodies and the problem of what constitutes mobility and walking in contemporary society derives from my own personal experience with polio. I was diagnosed with poliomyelitis at the age of 18 months. I spent countless hours in the hospital for a multitude of reasons that included surgeries, rehabilitation, physical therapy, limb measurements, construction, fitting and walking rehearsals with new braces. As a toddler, I never felt or thought anything was different about me. Perhaps, I was naïve. Though, even as I was introduced to my first pair of braces and crutches, I still did not notice any difference.

It was not until I was about seven or eight that I first experienced an awareness of my difference—as a result of being encouraged to participate in a national crusade that came with a promise of being able to walk again. I was confused because, in my own eyes and mind, I was fine. However, the world saw me as different. This was the beginning of my political awakening. It was the beginning of my stance in defining who I was. It was the beginning of saying YES to my spiritual self—my true being. I want to publicly declare that I am DISABLED AND PROUD! I AM HAPPY WITH WHO I AM—YES, WITH MY CRUTCHES AND BRACE, I AM HAPPY. I AM HAPPY TO BE ALIVE AND TO BE HERE TODAY. I choose to challenge the myth that the polio body is not worthy or valuable due to its paralysis.

We as a society have failed to acknowledge that walking with crutches and rolling with wheelchairs are themselves forms of walking, ones that were created by rehabilitation experts. We have failed to embrace polio survivors as a people who have taught us to accept our bodies even though it might walk/roll or perform life's daily functions differently. We have failed to promote that not all forms of walking are the same.

The fact of the matter is that polio bodies have always been devalued.

Polio was one of the most misunderstood and feared diseases in the 20th century. It was sometimes referred to as infantile paralysis or “thecrippler of children,” and even the strongest of children were more susceptible to getting the disease than some of the weakest seniors. Those who managed to survive were left with twisted backs, withered limbs and bodies that no longer could run and play. It is no wonder that the “normates” are mostly afraid of these bodies. If we are to be honest, it is these kinds of bodies that are perceived as abnormal and that cause discomfort in mainstream American culture and society.

This space where disabled and/or polio bodies are threatened and devalued is where disability justice



Rodney Hume-Dawson

From the Executive Director



Brian Tiburzi

People often ask me how I came to work for Post-Polio Health International. “You sound too young to have had polio,” I often hear. And while not quite true (there was a small outbreak among the Amish in the Midwest shortly after my birth), polio had been virtually eradicated from the U.S. by the time I was born.

I began working at PHI shortly after finishing grad school nearly a decade ago. I had wanted to work for a non-profit, but I’ll admit I didn’t know a lot about polio at the time, much less about the late effects of polio. Sure, I had familiarized myself with the basics prior to interviewing and, of course, I knew that FDR and a few other famous people had contracted polio, but I didn’t really have a personal connection to polio. My father’s cousin was a polio survivor, but I’d only ever met her a few times, and I didn’t find out she had polio until after I began working here.

Since I have begun working here, though, I have been amazed at the number of friends and acquaintances (even a teller at my bank who glanced at my paycheck) who, after having told them I worked for PHI, would tell me of a relative of theirs who had had polio. However, I often spoke to people who called PHI and told me they didn’t know any other polio survivors where they lived. They would confess that they sometimes felt isolated from others because of the physical decline their bodies were undergoing. Some felt it was difficult to convey to their spouse or children or friends what they were going through. They were looking for others who could relate to their situation. Many of these callers were surprised to find out there are an estimated 350,000–500,000 polio survivors living in the U.S. today and perhaps as many as 15 million worldwide.

Part of PHI’s core function is to help polio survivors connect with each other. Whether it’s by connecting people to local support groups or, more recently, through social media like Facebook and Twitter (@PolioPlace), networking has always been an important part of what we do and traces its roots all the way back to PHI’s founder, Gini Laurie.

Gini served as a volunteer in the 1950s at the Toomey Pavilion Respiratory Center in Cleveland, Ohio. Reflecting in her later years, Gini commented that it was “apparent [polio survivors] had two vital needs—people and information. They wanted to keep [up] with each other and wanted to share information about their lives and equipment.”

Gini and her husband, Joe, started to meet those needs by building a heated pool with a lift at their home, where they held annual reunions of the alumni of the respiratory center. In 1958, that same year, they started publishing *Toomeyville Jr. Gazette* (see www.polioplace.org/GINI), featuring news of how polio survivors managed at home.

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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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is greatly needed. Disability justice, as described by disability advocate Mia Mingus, is a “political understanding of disability and ableism, moving away from a rights based equality model and beyond just access, to a framework that centers justice and wholeness for all disabled people and communities.”¹

Disability justice challenges us to embrace, to love, to empathize, to be friends with, and to see people with disabilities as one of us. It is doing more than securing rights for disabled people; its aim is to challenge the status quo and the very meaning of disability. It is asking all of us to make a more just world for all of our disabled brothers and sisters, including survivors of polio.

I have spoken openly about what I believe healing means and choose to do so in this space because I want to reflect on the fifth principle of disability justice, which is recognizing wholeness.

The moral or religious model views disability as a form of punishment inflicted on a person and or his or her family. Growing up in Sierra Leone in the 1980s, I was urged to attend spiritual Christian crusades for the purpose of receiving my wholeness. I needed to stand in front of 5,000 people to receive my healing. Some of my affectionate friends and family members were convinced that with prayers and Godly intervention, I would be healed. In their eyes, because I was on crutches, I was not complete. I do not mean to devalue the power of prayer or their genuine affection for me, but only to point out that they did not see my wholeness because of how people with crutches are perceived and valued in that society. They meant well but did not understand the ramifications of their actions. Walking with crutches does not mean that you are less than. I am a human being first and foremost. I have inherent worth. Simply, I stand up against the societal notions of perfection and normalcy that devalues certain bodies that fall outside the norm.

Historically, polio survivors found a way to cope and adapt to many of the social obstacles that they encountered. Many of these survivors became the agents of the disability rights movement, the architects of the Americans with Disabilities Act and the pioneers of disability studies. They included Ed Roberts, father of the independent living movement; Judith Heumann, a former Assistant Secretary of Education under President Clinton and co-founder of the World Institute on Disability; and Justin Dart, Jr., co-founder of the American Association of People with Disabilities, and one of the instrumental figures that helped pass the American with Disabilities Act of 1990.

In spite of the devaluing of polio bodies in American society and across the globe, polio survivors and others joined forces to lobby against discrimination. “They demanded ‘equal access’ to public transportation, public accommodations and telecommunications, to school and work, to ‘independent’ or ‘congregate’ living in the community rather than in institutions.”²

The story of the emergence of the disability rights movement and its academic arm—disability studies—could not be told without acknowledging the prominence of polio survivors among the movement’s leaders. Heumann, Roberts and Dart all played central roles in the early years of the disability rights and independent living movement. Scholars and artists such as Irving Zola, Paul Longmore and Anne Finger all were instrumental in gaining recognition for a new interdisciplinary approach to disability known as Disability Studies. What all of these individuals have in common is not only a shared passion for the rights of people with disabilities, but a grounding of that passion in their personal experience with polio and its aftermath.

It is doing more than securing rights for disabled people; its aim is to challenge the status quo and the very meaning of disability.

The discrimination and prejudice those polio survivors and other people with disabilities faced in the middle of the twentieth century led to the struggle for change in the streets and in the law. The disability rights movement was not as visible as the civil rights movement, but it took place in the same venues where African-Americans protested, the streets and the courts.³ Lawsuits were filed, demonstrations took place, new organizations were born and a number of disability rights leaders helped pave the way for a better America.

The disability rights movement started with survivors of polio who were courageous and unafraid to challenge the status quo. In 1970, wheelchair user and polio survivor Judith Heumann filed a lawsuit against the New York City Board of Education when her application to secure a teaching certificate was denied because of her obvious impairment. The board explained that people with disabilities were perceived as fire hazards. Heumann was asked to

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WE'RE STILL HERE!

October 8-14, 2017

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

October 8-14 marked PHI's 11th annual WE'RE STILL HERE! campaign, with the goal of increasing awareness of the fact that while polio may be nearing eradication, there remain millions of polio survivors across the globe—survivors who, given the proper support and assistance, continue to thrive and live accomplished and fulfilling lives. PHI's annual campaign seeks not only to let the public know of our accomplishments, but also to make them aware of polio survivors' unique health needs and challenges.

This year's campaign encouraged survivors to participate in our photo contest and help show others how those living with the late effects of polio are aging with dignity. Aging is inevitable and well-earned, but comes with its own challenges. We hoped to show the myriad ways survivors approach aging while continuing to live out their years with dignity. Most importantly, we hoped to show the world that WE'RE STILL HERE!



CONTEST WINNER Bill Lach

In 1956, at the age of 10, I was struck down with polio. At the time we were living in Oak Park, Illinois. I was transferred by ambulance from West Suburban to Cook County Hospital in Chicago, where I spent six days almost completely paralyzed. For the first two days, I laid on a gurney in a hallway due to overcrowding. On the third day, I was moved into one of the wards alongside 11 others who had contracted polio. Around day 21, I was released and went home to recover, a process that took about two years.

Bill Lach (left) and son, Chris, 2017.

According to my parents, I was the only one in my ward to make it out alive. The only reason that I am able to write this memoir is that my mother, who was a nurse at that time, had made sure that I received two of the three Salk vaccines shots.

As with many polio survivors, I became an over-achiever in attempting to rebuild my body. I started wrestling in junior high and continued through high school. In college, I swam competitively and continued to swim daily during my working years and into retirement.

At age 40, I learned to barefoot on water and proceeded to teach my son. The image on the right is Chris and I on Mark Twain Lake, Perry, Missouri, July 18, 1987.

Almost every year since, when given the opportunity, I go barefooting as a birthday present to myself and as a reminder that I am a SURVIVOR.

I will, as the years begin to rapidly creep up on me, eventually succumb to some additional late effects of polio. I am beginning to sense this now in some of my everyday activities.



This year, being the 30th year, Chris and I decided to attempt to recreate the high five. We traveled from Springfield to Ashland, Missouri, where Lake Paragon is located. On the second attempt, we succeeded. In barefooting, the strongest and most skilled always take the far end of the boom. And so it is that our roles have become reversed as I continue to age with dignity.

FIRST RUNNER-UP

Ray Raymond

At 23, after trying for an entire year, my husband, Ray, finally stood on a moving surfboard in waters off Santa Cruz, California. Intending to surf for the rest of his life, he moved to Hawaii.

The tendons in his polio-affected knee gave out in late 2013, which he thought would end his surfing.

After a year of searching for the right brace, a brilliant orthotist here created the perfect KAFO brace to support his leg and foot while tolerating the ocean's saltwater. Ray has relearned to surf and also competes in paddle races as a prone paddler, proving that life-long limitations and occasional setbacks cannot quell his need to live a full life into his senior years.

The above photo was taken at Ali'i Beach, Haleiwa, Hawaii in May of 2017. Ray was just ending a ride down a four-foot wave. Once he felt stable, he moved first to one knee, then to a standing position, with a constant focus on maintaining his balance. Finally, he shifted into the "goofy-footed" stance, with the dominant foot in a forward position (versus at the rear) for steering the board.



—Betty Bodlak Raymond

SECOND RUNNER-UP

Margaret lafigliola

I contracted polio when I was nine months old (back in 1949). Since that time, I've had to make numerous accommodations to my lifestyle in order to live a fulfilling life. I have been married for 45 years now and have three children and five grandchildren. All of which have given me great joy.

This photograph was taken in our backyard in Aurora, Ohio on August 21, 2017.

I have always loved gardening, especially now, with my grandchildren. I didn't want to give it up due to my increasing post-polio weakness. My husband and I researched raised gardening ideas. After looking at models, my husband was able to make me a raised garden. It is so easy to weed and pick vegetables. What joy it has given me!



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THIRD RUNNER-UP Carol Ferguson

My husband surprised me with a cruise to Bermuda (our original honeymoon location) for our 40th anniversary. Little did I know, he surprised me with not only our adult children being on board, but the fun of experiencing two top items on my bucket list—swimming with dolphins and deep sea fishing.

Neither was easy; neither was accessible. I'm so glad that didn't stop me. The lifejacket held me up in the water just fine. Every moment was marvelous.

I want always to enjoy fun, life-changing experiences as I age.
I want my bucket list to be empty!



FOURTH RUNNER-UP Joy Carey

I had polio at age four and am now 68. I have been living and sailing aboard my sailboat, *Kelaerin*, since 1991. My husband and I have been sailing around the world since 2002. We have visited more than 50 countries and sailed around 60,000 miles to date. I love to travel and it is my intent to “drop dead while traveling” when my time comes. This photo is of me on Ninigo Island, Papua New Guinea, with my new friend Elizabeth and her sister. ■

PHI Welcomes New Board Members and Staff

PHI recently hired a new executive assistant to work in the office and has added three new members to its Board of Directors since summer. Get to know a little more about each below. Also, PHI would like to note our sincere appreciation for the contributions and expertise that long-time board member Rich Hokamp has provided the organization over the years and wishes him the best of luck as he moves on to other endeavors.

Board

William M. DeMayo, MD

Dr. DeMayo has over 30 years of clinical experience in the field of Physical Medicine and Rehabilitation. In 1986, he received his MD degree from Columbia University, College of Physicians and Surgeons and completed his residency in Physical Medicine & Rehabilitation at Columbia-Presbyterian Hospital. For over 15 years, he served as Medical Director of the post-polio clinic of Conemaugh Health System in Johnstown, PA.

This past October, Dr. DeMayo moved to Abu Dhabi in the United Arab Emirates where he is currently serving as Director of Physical Medicine and Rehabilitation for Specialized Rehabilitation Hospital (www.srh.ae), which will have the first acute inpatient rehabilitation unit in the UAE when it opens in the spring of 2018. Dr. DeMayo has an interest in telerehabilitation and looks forward to the application of this technology to serve polio patients in the US and abroad by connecting them remotely with experts in the field.

Dr. DeMayo is board certified by The American Board of Physical Medicine and Rehabilitation. He is also board certified in the subspecialty of Spinal Cord Injury Medicine.

Mark Mallinger, PhD

Currently, Mark Mallinger is Emeritus Professor of Applied Behavioral Science at the Graziadio School of Business, Pepperdine University. Prior to entering academia, Dr. Mallinger pursued a diverse career in industry. As a financial analyst for a Fortune 500 manufacturing company, he was responsible for managing multimillion dollar projects. Leaving the financial arena, he joined an executive search firm and assumed a number of roles, including manager of administrative services. Remaining in the service sector, but shifting to the art field, he was named director of one of Los Angeles' leading graphic arts galleries.

As a consultant, Dr. Mallinger has worked with companies representing a wide range of industries, such as gas and oil, retail, food and beverage, manufacturing, aerospace, information systems, financial institutions, health care, municipal agencies

and education. His work in health care focused on large-scale change. In addition, Dr. Mallinger provides training and development in executive coaching, team building, performance assessment, leadership, motivation and goal setting.

“Being a polio survivor, naturally, is one of the primary reasons for my interest in joining the board. In addition, my desire to be able to make a difference is a key driver of my intentions. I attended PHI's 11th International Conference in 2014 and was an invited presenter at the event. My presentation expressed the struggles, both physical and emotional, of my battle with polio since the age of 8. The opportunity during the conference to meet a number of survivors raised my interest in becoming more engaged with the organization. I am currently semi-retired, teaching one course per year in Pepperdine University's Executive MBA program.”

Mike Mrozowicz

Mike currently resides in Highlands Ranch, Colorado. He had a 42-year career with John Deere and has extensive experience in accounting, finance and operations. He is a CPA and has a BS in Accounting as well as an MBA.

“As a polio survivor (1952), I would like to utilize the skills that I have developed through work and volunteer activities to find ways to improve the quality of life of those of us impacted by musculoskeletal limitations.”

Mike has been married for 32 years to his wife, Lisa, and has two adult sons, Jonathan and Ryan.

Staff

Anne Marshall

Anne recently joined PHI as Assistant to the Executive Director. Anne is a 2016 graduate of the University of Missouri. She earned BAs in Psychology and Sociology, with a certificate of Multicultural Studies. During that time, Anne completed research on narcissistic attitudes in social media users and the cognitive effects of alcohol on its users through computer performance using electroencephalography. She enjoys hiking state and national parks in her free time. ■

QUESTION: *I am 76 years old and live alone in my own home. I am getting weaker, but I still drive and have an active enough social life that loneliness is not an issue for me. The problem is that keeping up my home is getting harder and harder. I pay a neighborhood boy to do the yardwork, but I am forced to rely on the generosity of neighbors to get certain things done around the house—moving anything moderately heavy, getting up to change the lightbulbs in the ceiling, and all those other chores that are too difficult for me to do on my own, but too trifling to be able to hire someone to come do them. I feel I am becoming too much of a burden on those around me, yet I am not ready to give up living in my own home.*

Response from Stephanie T. Machell, PsyD:

Your situation sounds ideal, enviable even. You are fortunate to have so much support available for you to age in place. We should all have such helpful neighbors!

Of course you wouldn't want to take advantage of their generosity—but are you really doing so? I often hear polio survivors express concerns about being a burden. Because many polio survivors pride themselves on being independent, needing to ask for even modest amounts of help seems to raise this fear. And since anxiety makes it difficult to “read” others' reactions, you may be interpreting your neighbors' neutral or even positive responses as signs that you are asking too much.

As always, the best way to find out is to voice your concerns. Tell them your fears about becoming a burden and ask them to give you honest feedback. Of course, if they tell you they enjoy helping you, you may not believe them. And if they tell you your demands are excessive, or that they would prefer not to do certain things, you may be hurt. Or you may not have the sort of relationship where talking about something so personal would be comfortable.

Another option for figuring out whether you're asking too much is to make a list of all the tasks you've solicited help with over the past few months. Beside each, write the name of the neighbor who helped and how long it took. If you can honestly do so, also note their reactions to being asked—or if they took the initiative and offered assistance.

Once you're finished, read it over. Does it look like you're asking too much of anyone/everyone? Or are you surprised and pleased to discover how little help you really need? Did anyone seem annoyed? Did anyone seem happy to help because it's the “neighborly” thing to do?

If you decide you're uncomfortable relying on your neighbors there are other ways of getting help with small tasks. In Massachusetts, some towns offer tax incentives for those who volunteer such help. High school students may exchange help for community service credits. Some churches offer help even if you don't attend. Your local senior center should know what resources are available.

You can also hire a handyperson—maybe even one of your neighbors! Ask friends or your senior center for recommendations. There are websites for task help, but remember not all do rigorous screening, so be sure to ask for references.



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.

Whether or not your neighbors view you as a burden, it may be helpful to address your fears of becoming one. Reflecting on this on your own or with the help of trusted others can help you understand where these feelings come from and how you can address them. If you belong to a post-polio support group, this topic is likely to spur lively discussion. However, given that it's a fear many who are aging share, it could be productively discussed in a variety of settings—including over lunch with friends!

Response from Rhoda Olkin, PhD:

How well I know what you are describing! I, too, am aging with polio and finding various activities of daily life more difficult. As people with disabilities, we have to constantly balance our finite portions of energy, money and time. The more we have of any one of these, the less the need for the others. But the converse unfortunately is true as well—the less energy or time we have, the more money we need. Problems arise when we are short on all three.

So, my first question is about money. There are many problems associated with living with polio that money can address. Ordering groceries or even meals online, for example, is a bit more expensive, but saves lots of schlepping. I myself pay someone to come to the house four days a week for about 1–2 hours a day, to do those tasks I cannot do (and there are many, from emptying the dishwasher to doing laundry to changing the sheets to buying more dirt for the garden, etc.). This takes a nice chunk out of my paycheck, so there I have to make trade-offs by conserving money elsewhere. But I am still employed full-time, and can

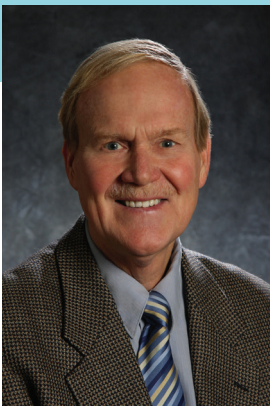
afford to do this. Not everyone can. But there might be a compromise—can you hire someone two hours per week, and save those tasks for those two hours? If you knew someone would be there one day a week to do all those things you find difficult, could the tasks wait until those two hours? In two hours someone could move furniture, change lightbulbs, bring in heavy items from the car, clean the bathroom, water plants. (In California, I would suggest paying \$15/hour—in less expensive parts of country you might pay less, though you want reliability and loyalty, so it might be worth \$30/week.)

But assume for the moment you simply could not manage that amount of money. There are other options. If you qualify for meals on wheels, you might save energy not shopping and cooking, which would allow you to do other tasks. If you belong to a religious organization, they might have volunteers to help. If you have a particular skill, you could trade your skills with a neighbor in exchange for household tasks. If there is a high school student who wants to go to college, you could offer to write a letter of recommendation in return for his or her help over the school year. You could consider a roommate who would have a reduced rental rate in exchange for tasks. Lastly, consider a smaller residence in a retirement community, where you can get a range of services. Although moving can be impractical, or undesirable, most people who move to a retirement community say they wish they had done so sooner, as life is easier.

None of these choices are easy. Each is a trade-off of one thing for another. Only you can decide which trade-off is worth it to you. ■

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.

See other questions at www.post-polio.org/edu/askdrmay.html.

Question: *I was recently diagnosed with cancer. My oncologist has recommended chemotherapy. Are there any specific concerns polio survivors should have regarding chemotherapy that my oncologist might not be aware of? How will it affect my post-polio weakened muscles? Are there specific side-effects that tend to be more severe among patients with a prior history of polio? Is there anything I can do to mitigate this? What sort of pre-planning would be most helpful?*

Answer: There are several special concerns related to a polio survivor's undergoing cancer chemotherapy treatment (CCT). Firstly, please understand that your decision to agree to a recommendation for CCT will always involve the weighing of risks versus benefits of the treatment. Thus, your first issue will be gaining an understanding of the likelihood that the CCT will be curative, possibly curative (what are the odds of cure?), or strictly palliative (that is, living longer—what are the odds and for how long?). The answers to this issue will affect your balance of weighing risks and benefits.

The first special issue for polio survivors (PSs) to consider is the short-term expected side-effects of the specific chemotherapeutic agent(s), or drug(s), being recommended. Many, but not all, CCT drugs are given by IV infusion and leave even able-bodied people very weak and exhausted for approximately one to three days after receiving them. For PSs with PPS-related weakness and fatigue and/or precarious safe independent functioning in walking and ADLs, they may need to plan on considerable amounts of additional assistance for routine daily activities after receiving CCT because they will likely have exaggerated and/or prolonged short-term debilitation (i.e., being “completely wiped out”). This side-effect may pose serious and unique challenges for PSs with significantly compromised ventilatory capacity. These problems are usually worth planning to endure if the CCT is expected to be curative. In other circumstances the severity of this problem may alter the risk-benefit equation; and a decision to “try CCT” can be reconsidered after experiencing for yourself what happens after the first course or dose of the CCT.

The second special issue for PSs to consider is: Do any of the specific chemotherapeutic agents recommended in a course of CCT have any known “neurotoxic side-effects.” Peripheral neuropathy is the most common of these. If they do (and many do), these side-effects are more likely to occur or be worse among PSs because they already have vulnerable and often overworked motor nerve cells. In my experience, the later slow development of increased weakness and fatigue, sometimes with distal sensory loss, is more common among PSs a year or two after a course of CCT involving known neurotoxic agents. With some neurotoxic drugs, dietary changes and/or specific vitamin supplementation can sometimes reduce these risks and should be tried. With some agents a reduced or minimum dose may be worth considering, since it is likely these side-effects are dose dependent.

In summary, pre-planning for special needs is important for PSs undergoing CCT. Maintaining as much physical activity and exercise as possible during and after a course of CCT is recommended, with professional assistance of rehabilitation professionals as indicated. Thoughtful individual consideration of both short-term and long-term risks and benefits is encouraged. ■

demonstrate how she used the bathroom, but she told the doctor that unless it was a requirement for her to teach children, she was not going to do it.³

Through the resilience of polio bodies, we learn that all bodies matter. These bodies matter because they are worthy. They matter because polio bodies are sacred bodies that teach us about what it means to live with broken and rejected bodies. They matter because they have experiences that can instruct us in new ways of living and seeing the world. They matter because they exhibit the power of the human spirit. ■

1 Taormina-Weiss, Wendy. "In Pursuit of Disability Justice." *Disabled World*. 2013.

2 Longmore, Paul K., and Lauri Umansky, eds. *The New Disability History*. NYU Press, 2001.

3 Fleischer, Doris Zames, and Frieda Zames. *The Disability Rights Movement: From Charity to Confrontation*. Temple University Press, 2001.

Gini also realized networking could serve other goals. In 1959, she led a letter-writing campaign in support of national attendant care legislation. It was unsuccessful, but showed her the importance of collective action.

"Networking links people who share common needs or common goals," she wrote. "Networking is a support system. It is a method of self-organizing. It is the structure of a social movement. Most of all, it is a method by which people get things done."

Anyone paying even cursory attention to the health care debate that consumed Washington for much of the year can see that this is self-evident. From the more visible protests from groups such as ADAPT to the quieter campaigns from organizations urging their members to call their congressional representatives and make their position known, disability organizations demonstrated the power of networking and collective action to advocate for our shared interests. We saw that when we band together, we amplify our voice and let others know that "WE'RE STILL HERE!"

—Brian Tiburzi, Executive Director

In Appreciation

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

Please contact us if we made an error.

Contributions to PHI's education, advocacy and networking activities

In Memory of

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