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Looking Back on the Americans with Disabilities Act 30 Years Later



President Bush signs the Americans with Disabilities Act at the White House, July 26, 1990. Sharing the dais are (standing left to right): Rev. Harold Wilkie; Sandra Parrino, National Council on Disability; (seated left to right): Evan Kemp, Chairman, Equal Opportunity Commission; and Justin Dart, Presidential Commission on Employment of People with Disabilities. Courtesy George Bush Presidential Library and Museum.

This past July marked the 30th anniversary of the passage of the Americans with Disabilities Act (ADA). This landmark piece of legislation followed years of pressure from disability rights activists, of which polio survivors were an integral part—people such as Justin Dart, Ed Roberts, Judith Heumann and others. The ADA allowed people with disabilities to challenge societal barriers that excluded them from their communities and would have a profound impact in making America a more inclusive society.

We asked a handful of polio survivors to reflect on the legacy of the ADA—its promise, its shortcomings and the work that still needs to be done.

We Should Celebrate. But There Is Still Work to Do.

Judith Heumann

I was 18 months old when my parents learned I had polio. It was 1949, and things that were typical for children were not so typical for me. I was denied the right to go to school because the staff did not know how to accommodate a student who could not walk. Instead, I received just two-and-a-half hours of home instruction each week. People like me who did not fit into a neat little box had no laws to protect them. We were not advancing in our education and no one had expectations for our futures.

This discrimination continued when I pursued my teaching career. Though I passed all my exams, I was denied

a teaching license in 1970 because New York City's Board of Education thought I could not safely evacuate my students in case of a fire. There was no one who looked like me—who used a wheelchair—fighting for this right. I filed a lawsuit and I won.

I began to see other disabled people fighting for inclusion, and I found empowerment in our collaboration. On April 5, 1977, more than a hundred of us occupied a San Francisco federal building for what became known as the 504 Sit-in. We had fought with the Carter administration to sign regulations implementing Section 504 of the Rehabilitation Act of 1973, which prohibited programs that received federal

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**WE'RE
STILL
HERE!**

OCTOBER 11-17, 2020
www.post-polio.org
www.polioplace.org

WE'RE STILL HERE! WEEK OCTOBER 11-17, 2020

PHI's 14th annual awareness campaign will run October 11–17, 2020. This year has been truly challenging for all of us. Our normal routines have been upended. The activities we used to enjoy have been closed off to many of us. No more eating out at restaurants or going to see a film or taking in a ballgame.

For many of us, this pandemic threatened to isolate us. But slowly we learned to adapt. Maybe we pulled some chairs out on the lawn and chatted with the neighbors from a safe distance. Instead of attending our grandkids' birthdays, we celebrated on Facetime or Zoom. Maybe we picked up some takeout and had a socially-distanced picnic outside with a couple friends. In other words, we found ways to stay connected, to remain visible.

This "We're Still Here!" campaign, PHI wants to celebrate that. We're asking you to submit a photograph and a few descriptive paragraphs about a way you've found to stay connected with others during the pandemic.

Post-Polio Health International will select a grand prizewinner (\$150 USD) and four runners-up (free PHI Membership for two years). The winning entries will be published in the fall issue of *Post-Polio Health*.

The runners-up will be announced October 12-15 with the announcement for grand prize to follow on October 16th.

Contest rules:

- ◆ Email your submission to info@post-polio.org (Subject: WSH 2020 Contest) or mail it to our office at 50 Crestwood Executive Ctr, Suite 440, St. Louis, MO 63126.
- ◆ Include your name, mailing address, phone and/or email.
- ◆ Each person is limited to submitting one entry.

Deadline to submit an entry to info@post-polio.org is 5:00 pm CDT on Friday, October 2, 2020.

POST-POLIO HEALTH

Summer 2020

Vol. 36, No. 3

ISSN 1066-5331

Editor: Brian Tiburzi, MA
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Designer: Sheryl Prater

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International (PHI).

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

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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.



Judith Heumann

funding from discriminating against disabled people, but after years of asking, 504 still had not been signed. We occupied the building for almost a month until our demands were met. Section 504 was key because it laid the foundation for the Americans with Disabilities Act.

The ADA helped open building doors, allowed us to earn an education and made it illegal to discriminate against a qualified person for employment.

We should celebrate the strides we have made. But there is still work to do. The way society thinks about disability needs to evolve, as too many people view disability as something to loathe

or fear. By changing this mentality, by recognizing how disabled people enrich our communities, we can all be empowered to make sure disabled people are included.

Judith Heumann, a former PHI board member, is an international disability rights activist who served in both the Clinton and Obama administrations. Her memoir, *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist*, was released in February. This essay first appeared in the *New York Times*.

“The ADA is not good enough.”

William Stothers

Wow!

As those of us who labored and lobbied and advocated for passage of the ADA 30 years ago, last month’s anniversary of the signing was a time to remember and celebrate the changes that the law has brought about. The landscape of the United States has definitely become more accessible. Life for disabled people—actually, for everyone—has improved.

But I must say that what heartens me most is the reaction among the first ADA Generation: “The ADA is not good enough.” Expectations have soared. They demand more. It’s just not good enough that all public facilities are not accessible; that accessible facilities are not matched with policies that make access functional; that programmatic access remains spotty at best.

The ADA Generation is pushing into leadership positions in activism as well as professions across the board. Its members are multicultural, confident and adept at new technologies.

I, for one, am delighted. And, to echo Justin Dart, the father of the ADA, “Lead on! Lead on!”

William Stothers is a past President of the PHI Board of Directors.

Uncovering Hidden Histories of the ADA

Karen Hagrup, PhD

The future of the ADA depends on all of us. Right now, we need our collective voices to tell more of the truth about how far we’ve come and what still needs to be done. That means we have to be able to see what the ADA has actually meant for disabled people in their complicated everyday lives. Personally, I’m weary, and I’m hopeful. It makes sense that my feelings about the 30th anniversary of the ADA are mixed; for me, the ADA has been a mixed bag.

I’m weary because when the ADA first became law, I was one of the early people to test the strength of the law through legal action. In practice, this was a traumatizing experience for me. I’m still integrating and recovering from that period in my life. Suing the university where I worked in the early nineties meant not only that I needed the law because of discrimination I was facing, but also that I must go through an ugly legal battle that dovetailed with difficulties at home, some of which were based in cultural ableism that I had to withstand in my own marriage. I know in a very personal way that there can be a lot of pain, heartache, and even reproduction of oppressive systems even within anti-ableist legislative wins and wider political and social movements.

I’m also weary because my disabled friends, many of whom are white like I am, have often shared with me stories about their parents helping instill in them a sense of ownership of their lives and self-worth, against the backdrop of a wider culture that dehumanized them for being disabled. While I am grateful that my friends got this message, I can now see how it intersected with their whiteness and reinforced assumptions about how they mattered as white people above people of color.

It’s a complicated thing to be a white physically disabled person who both needs to feel whole in their humanity and simultaneously needs to interrogate their privilege and unlearn their learned superiority. Those intertwined parts of white disabled identity

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need to be worked with honesty and care. As Corbett O'Toole argues, white disabled people need to learn how to relinquish the disability rights mic to QTBIPOC disabled people.

I have long been able to see the importance of a cultural lens to social change work. I have known that legal campaigns would not be enough and that the ADA and the first 30 years of its implementation were not adequately capturing and attending to the social experience of disability.

And yet, I'm also hopeful. I'm hopeful because the ADA has provided us with ways to take legal action based on discrimination. It has contributed to a normalization of accessibility in the built environment, curb cuts and ramps, the addition of sign language interpreters at public speaking events, and the choice of adding captioning (some okay, some low quality) in television programs. Because of the ADA, there are many more wheelchair accessible restaurants and places that serve the general public. Information about accessibility is included in many marketing statements like brochures and web pages.

I am hopeful because the Paralympics show how people with all kinds of disabilities are using a variety of adaptive equipment in amazing ways. I am hopeful because, in addition to facing serious challenges to be more race and gender inclusive, Hollywood is being called out more for giving disabled roles to non-disabled people. I am hopeful because architects are designing accessible beautiful features in their public buildings, features that are preferred by a large variety of people. I am hopeful because computers and all kinds of devices include accessible technology for all kinds of disabilities.

I'm also hopeful because I am moving through and healing the ways that I was traumatized by my experience bringing legal action under the ADA. And I am getting in touch with the ways that I am proud of being one of the early people to test the legal limits of the ADA. I am proud of being part of the ADA's overlooked history of individual sacrifices to fight for the ADA in unglamorous ways, one institution at a time.

With this newfound pride, I am actively telling my story more publicly now, and I can see all the work that I have done to get to a place where I am ready and can tell my story widely. And I'm hopeful because telling my story means that more of the truth of the deeply complex experience of disability identity and disability history will be written down and shared. And when I look around now, I can see more and more disabled people telling their personal

stories, capturing more of the social history that I know to be so important for the ADA and disability liberation to keep going strong.

It's important to be able to see the good and the bad together. If I were only hopeful, I could miss the pain and struggle and possibly reproduce shame and silence. If I were only weary, I might give up and contribute to the surrender of others in a fight that still needs conviction.

Thirty years after becoming law, we need to keep studying the social history of the ADA to learn about its true legacy. Working with my daughter to write down my life story is one way that I'm making sure that one more disabled person is included in history and more of disability history is socially and culturally informed.

Karen Hagrup is an anti-Skinnerian educator and mother, a disabilities studies pioneer, and a staunch Obama supporter, who has spent her life fighting for people's rights and joy, her own included.

Polio Survivor Friends and the ADA

Richard Daggett

Polio survivors were the first large disability group to attempt the transition from hospital to home, despite very severe functional limitations, often including ventilator dependence. We knew that this could be both safe and cost effective. We also knew that many obstacles remained.

Younger polio survivors were often excluded from public schools; there was no "mainstreaming" as we know it today. When I left the hospital, I was sixteen. I had a noticeable limp, but I walked well. Even so, my school district decided that it would not be "safe" for me to attend high school. I was assigned a home teacher. I benefited academically by having a home teacher, but my social life surely suffered. And I missed taking science lab courses and other in-person studies.

Many adult polio survivors faced architectural and social barriers to employment. Few commercial buildings were wheelchair accessible, and people with a noticeable disability were seldom seen in the front office.

Despite these barriers, or perhaps because of them, polio survivors were the driving force for disability rights, including the ADA. Justin Dart, Ed Roberts, Judy Heumann, Paul Longmore and numerous others were polio survivors. I am honored that these pioneers were my friends and colleagues.

Many others wrote letters, made telephone calls, and peacefully demonstrated. In 1675, Sir Isaac Newton wrote, “If I have seen further it is by standing on the shoulders of giants.” As we celebrate the 30th anniversary of the Americans with Disabilities Act, we must honor these “giants” who paved the way. We must also acknowledge that there is still work to be done.

Richard Lloyd Daggett is the author of *Not Just Polio: My Life Story* and is president of the Polio Survivors Association.

The ADA and Accessibility

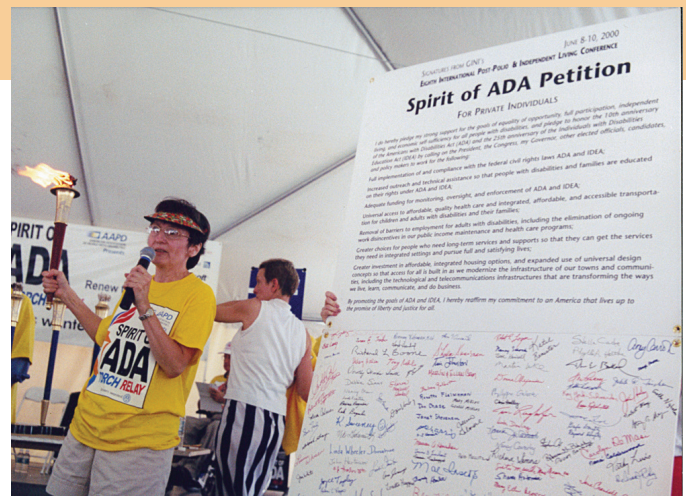
Joan Swain

In 1950, when I returned home after five months in the rehab hospital, I was eager to try on my post-polio life as a senior in high school. That’s when I found out that the world was made up of stairs ... starting with my bedroom. That one was resolved by switching with a sibling. The others required more creative thought.

One of my first challenges was a trip to the dentist’s office, located at the head of a stairway that went straight up from street level in town. We came up with the idea of asking the local police department if they could loan us the help of one of their young officers. They agreed, and another problem was solved. I used crutches and braces and grew better at handling stairs over time, but they were always a challenge. I’ll never forget how those young officers helped me get around in those first days of dealing with polio, though.

Imagine the changes the ADA offered! There would be elevators to reach that dental office. Or more likely it would be in a one-floor building along with other medical offices. Ramps and curb-cuts would add to accessibility. Schools became accessible to children who earlier would have been isolated in special schools instead of with their friends and neighbors. And I could likely have attended class with my friends instead of studying with a tutor those last few months of high school.

In April of 1949, I had turned 17 and learned to drive in my family’s pre-WWII stick-shift Plymouth. Ready to drive again, I would need hand controls like those they were installing in cars used by homecoming veterans with serious leg problems. I had ridden in a black Buick convertible equipped with such hand controls the past summer. A family friend who used to build racing cars offered to build hand controls in the Oldsmobile my parents had recently bought.



Past PHI president Joan Headley in 2000 at the Spirit of ADA Torch Relay marking the 10th anniversary of the ADA and the 25th anniversary of the Individuals with Disabilities Education Act (IDEA).

And, happily, they let me drive it to the junior college I was attending nearby. Freedom!

Hand controls gave new independence to many drivers with disabilities, but they could not provide the parking places that would be needed. That was done by the ADA, which required businesses to allocate space and build a specific numbers of parking spaces. The ADA made public bathrooms, hotels, roadside inns, restaurants, parks, buses, trains and a vast inventory of additional features more accessible, and today makes travel by people with disabilities a welcoming opportunity.

With all that the ADA offers, do I still have needs that aren’t met? In a word, yes. I drive a ramp van, that is, a minivan with a ramp that folds away and then lowers from the side of the van so that I can drive in and out on it with my scooter. In New Jersey, there are often new smaller-sized accessible parking spaces and only one or two of the old standard-sized accessible spaces. The problem is that the smaller parking spaces do not allow room for the ramp to be lowered from the side of the minivan for the scooter to ascend or descend! If the two standard-sized handicap spaces are full, the only way to park is to take two standard parking spaces and park on an angle within the space created. However, that often earns you a parking violation!

Joan Swain is a founder of the Polio Network of New Jersey, where from 1991 to 2017 she edited both their quarterly *Newsletter* and *Newsline*, the monthly newsletter of the Raritan Valley Post-Polio Support Group. She is retired from Sanofi-Aventis US and lives at Fellowship Village Senior Living in Basking Ridge, New Jersey. ■

“Vote as if your life depended on it ... because it does.”

Justin Dart’s memorable quote has perhaps never been more relevant than it is this year. This November, it is critical to make sure that you, your family and your friends make their voices heard at the ballot box (or through the mail).

Approximately 23% of the American electorate—over 35 million individuals—are people with disabilities. In the 2016 election, it was estimated that only 16 million turned out. Voting is an essential way to make our collective voice heard and ensure that vital programs and services are protected.



This election could have a tremendous impact on issues vital to polio survivors, such as funding for home and community-based services,

access to affordable health care, and the future of Medicaid and Medicare. In recent years, we’ve even seen attempts to weaken enforcement of the Americans with Disabilities Act.

Take time to learn what each of the candidates say on these issues. The American Association of People with Disabilities (AAPD), the National Council on Independent Living (NCIL), and the REV UP Campaign developed a presidential candidate questionnaire that they distributed to the major party presidential candidates.

Joe Biden’s answers can be found at www.aapd.com/wp-content/uploads/2020/03/Vice-President-Biden_AAPD-and-NCIL-Presidential-Questionnaire.pdf. The Trump campaign declined to answer the survey, so voters will have to rely on an examination of his first 3½ years in office. Some of these issues are also addressed in the Health Care section of his campaign website at www.promiseskept.com/achievement/overview/healthcare/.

Voting During a Pandemic

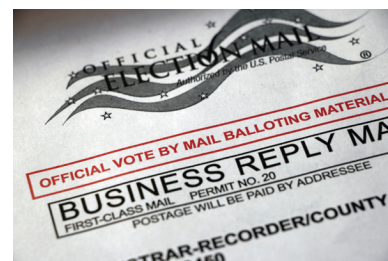
The pandemic makes voting safely this November particularly fraught. If possible, consider alternatives to voting in person on Election Day. Know what your state allows regarding absentee and mail-in voting, especially since several states have changed their rules due to the pandemic.

In all but eight states, you may request a mail-in ballot without needing a reason or by citing a fear of contracting COVID-19. Some states have enacted different rules for those over 60 or 65 years of age. For mail-in voting, a handful of states automatically mail out ballots to all registered voters, but in most you’ll have to apply for one. The rules for your particular state should be posted on the website of your state’s secretary of state. A handy directory can be found at www.e-secretaryofstate.com.

Because the postal system may see a larger than usual volume of ballots this election, it is recommended you mail your ballot well in advance of the deadline. Read and follow the mail-in ballot instructions carefully. A signature is nearly always required, and some states require you to sign in two places. Also, depending on the state, you may need to get your ballot notarized. Some ballots must be placed inside a dedicated security envelope, which in turn goes inside a mailing envelope.

If you choose to vote in person, consider ways to limit your risk of contracting coronavirus. Early voting is available in about 40 states and can be a convenient way to avoid the crowded lines typically seen on Election Day. In 2018, 16 million voters voted this way. The time frame

for early voting varies by state,



ranging from the week to about 45 days before the election and typically ends a few days before Election Day.

If you do decide to vote in person on Election Day, remember to double-check the location of your polling station. Because of a shortage of poll workers, it may not be the same as in the past. There may be longer lines this year, so try going in the middle of the day when lines are typically at their shortest.

The CDC has released some guidance on ways you can stay safe at the polls: www.cdc.gov/coronavirus/2019-ncov/community/election-polling-locations.html#VoterRecommendations. One good piece of practical advice is to bring your own pen to mark your ballot, or stylus if you are voting electronically. ■

Voter Resources

The AAPD's REV UP network is composed of state and national coalitions that work to advance the Disability Vote. REV UP's mission is to foster civic engagement and protect the voting rights of Americans with disabilities.

www.aapd.com/advocacy/voting/

The U.S. Election Assistance Commission (EAC) has a page with voting resources for individuals with a disability. www.eac.gov/voter_resources/resources_for_voters_with_disabilities.aspx.

Nonprofit Vote is another good resource and has a state-by-state listing of resources regarding voting and accessibility.

www.nonprofitvote.org/voting-in-your-state/special-circumstances/voting-with-a-disability/

Rock the Vote has a state-by-state listing summarizing election changes for November's vote and links to each state's rules on mail-in and absentee voting. www.rockthevote.org/how-to-vote/nationwide-voting-info/covid-19-voting-information/



Zappos Launches Test Program for Single Shoes

The popular online footwear retailer Zappos has launched a test program to sell single and mismatched shoes. They will be starting with a small number of brands and styles (with a full range of size and width options). Currently, the brands offered are Nike, BILLY Footwear, Converse, Kizik, New Balance, Plae and Stride Rite. If successful, they plan to include a larger selection of brands and styles in the future. You can learn more about the program and shop for shoes at www.zappos.com/e/adaptive/singleshoes.



Introducing PHI Spark

In September, PHI will be launching a new initiative to aid local support groups. Dubbed "PHI Spark," these monthly email communications will provide inspiration and ideas to help keep local groups connected and networking. We realize that the current environment is making it harder than ever for support groups to get together.

As an example of how PHI aims to help, one of the first PHI Sparks will be announcing the new PHI Speaker Series. Support groups will be able to choose from a list of experts speaking on a range of subjects which groups can arrange to speak at one of their Zoom meetings in exchange for a donation. The presentations will be recorded and uploaded to our site at a later date so other PHI members can view them.



Looking for a Corset Manufacturer

From a Member: I'm looking for a company that manufactures the good old-fashioned corsets that we had at one time. They were made of cloth with steel stays. No one in the Cleveland area makes them. My local orthotic company will measure, fine-tune and repair them. We were using a company in Michigan, but they are either out of business or are no longer responding to our attempts to contact them. I don't care where a company is located, as long as they can produce the product. The corset, as we know it, is technically called a spinal orthosis.

My corset is no longer supporting me. I'm having difficulty sitting properly, and it's affecting my breathing and digestion.

You can contact me, Alice Sporar, by phone at 440-942-1557 or email at amsporar@worldnetoh.com.

PHI: *It seems like they're constantly coming out with new or changing information regarding COVID-19. How do I find the line between staying informed and consuming so much news that it makes me anxious?*

Response from Rhoda Olkin, PhD:

This is a timely and very relevant question for all of us. We are more isolated as we shelter in place, while we consume more news. The information regarding COVID-19 can feel contradictory and confusing. It's easy to feel overwhelmed. However, there are starting to be clearer trends as medical professionals learn more about this new coronavirus. Masks and social distancing are the main factors that reduce transmission of this highly infectious disease.

Where can one turn for reliable information? I recommend listening to medical professionals, and not to politicians. Good sources are the physicians and researchers who appear regularly on MSNBC, and those from Johns Hopkins and the University of Washington. I pay attention to Dr. Fauci, as he is very experienced in pandemics. And I try *not* to pay too much attention to what my friends say—although many of them are very careful, others are more casual.

It's no use arguing because, ultimately, we each make our own decisions. I err on the side of caution, but I'm privileged in that I live in a house with a backyard and have a job I can do online. Others have fewer options, are frontline workers, or need a paycheck.

Obviously as polio survivors we have special fears about getting the virus, whether because of worries about our breathing or a history of negative hospital experiences. We know that a vaccine can wipe out some diseases. But the initial COVID-19 vaccines are more likely to be like the seasonal flu vaccine—about 50% effective, and only for a limited time. Thus, it seems we are in this for the long haul. Therefore, choose one to two trustworthy sources, stick with those only, and ignore the rest. Use your own best judgment—I trust you.

... choose one to two trustworthy sources, stick with those only, and ignore the rest. Use your own best judgment ...

Be mindful as well of what *else* you are doing with your time. Balance is key. If news and staying informed puts drops of anxiety water into the glass, you need to do things to take the water out of the glass, so that it never spills over. Reading fun things, creating, planting and gardening, laughing, deep breathing—these are ways to decrease the water level. And remember that *this too shall pass*, even if not as quickly as we would like.



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.

PHI: *Some of my family seem to have gradually let down their guard as the pandemic has ground on. My youngest daughter, who lives nearby, lets my grandkids go on playdates and she regularly jogs with a group of friends. I don't want to tell them not to visit me, but when I gently suggest that she be more careful, she blows me off and says I'm being overly cautious. I feel like I'm being forced to choose between my health and my family.*

Response from Stephanie T. Machell, PsyD:

Of course you don't want to be forced into such a choice. It's awful not to get to spend time with your family, especially your grandkids. But imagine how awful it would be for everyone if you got COVID-19—especially if you got it from them.

You said your suggestions to your daughter have been “gentle.” It's time to be more assertive in how you express your concerns. Because she is dismissing your concerns, I wonder whether she understands what getting COVID-19 could mean for a high-risk person like yourself and how that would affect your entire family. Be clear with her about the possible consequences of a severe case and that even “mild” cases appear to lead to serious complications (including for healthy low-risk people like her and your grandkids!).

If she responds by telling you how low your risk is (about 20% of cases are severe), you could compare this with the risk of death from playing Russian Roulette (1 in 6, or about 16%), an activity I doubt she'd want you or her children to pursue.

Let her know how frightening it is for you to be placed at risk by her choices, and how worried you are about her family's safety. Engage her in conversation about what she is doing to protect herself and your grandkids. Is she meeting her friends outdoors, wearing masks and social distancing? Are your grandchildren

doing the same? Are the people she interacts with also taking precautions both with her and when they are with others, and how confident is she that they are trustworthy? Is she part of a social “pod” that interacts only with other members?

Remind her that all these precautions make interactions safer but do not eliminate risk altogether. Many high-risk people who avoid going out become infected by family members who are going out but taking precautions. Discuss ways you can be together safely, enjoying each other's company at a distance. Outdoors is best, in a private yard (if you have one), large porch or deck, or at either end of a driveway. If you're able, you can go for (masked) walks or hikes or to outdoor attractions where social distancing is possible.

It's hard not to have physical contact with your grandkids. If they're old enough to understand and follow rules, there are pictures online of safe(r) ways of hugging. You could make a game of it, with prizes for the most creative way of sending love to each other. For example, one of my clients got creative with her granddaughter and “sent” hugs back and forth via the family dog!

Remember, you are still the parent. You have a right to defend your space and yourself by setting boundaries and making rules. Protecting yourself protects your family as well. Best of luck navigating this difficult time! ■

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.





Frederick M. Maynard, MD

Ask Dr. Maynard

Send your questions for Dr. Maynard to info@post-polio.org.

See other questions at www.polioplace.org/living-with-polio/articles-post-polio-health #AskDrMaynard.

Question: *I've been a PHI member for many years. I just finished your article "A Cautionary Tale"—an eye-opener. Recently, I've been diagnosed with advanced end-stage primary osteoarthritis of the right shoulder, some rotator cuff damage and a spur. Reverse replacement was recommended. I was told cartilage replacement was not an option.*

I am an 84-year-old female who contracted polio at age four—complete paralysis. Two-and-a-half years later I shed the crutches and braces and went to kindergarten with nothing but a contracted right leg and a limp. I started swimming 40 years ago and with few restrictions have led a normal, active life.

I began feeling the late effects of polio slowly about 20 years ago, with significant weakness in the last two. I'm still mobile with use of a cane, walker and scooter, but cannot safely walk across the room without aid. I've been unable to swim for over a year due to a spinal collection of bulging discs, fractures and permanently damaged back muscles—all from falls.

I have untreated osteoporosis—T-scores of -3.7, with Prolia recommended. I asked the surgeon about success rate with osteoporosis and he said it was 70–80%. There could be a fracture during surgery or afterwards. He recommended Prolia, but I didn't think to ask him how bone-building will get along with that prosthetic.

I asked for and will begin a three-month therapy program to deal with functioning during rehab but haven't agreed to surgery yet.

I'm concerned about falling but fear using a scooter will weaken my legs. I feel there will be some arm atrophy in already weakened muscles that may not be recoverable.

Dr. Maynard: I agree that you are facing some difficult choices that all involve risks! Results from reverse shoulder arthroplasties have generally been good from the standpoint of gaining a pain-free shoulder with good/full Range of Motion. There will be some loss of strength, but if your right arm had minimal involvement from polio and post-polio, the degree of new weakness should not limit your functioning, with one exception. Your right arm may not be sufficiently strong for very much weight-bearing with your right upper limb. Certainly you wouldn't be able to use it for 4–6 months after the surgery for any cane use. Can you walk safely with the cane used with the left upper limb?

You will need to think through how you can stand up, transfer and move around safely by yourself in the post-operative period, or will you need regular assistance? Remaining safe from falls will be extremely important because of your significant osteoporosis, the precariousness of your strength and need to do things differently because only being able to use the left arm/hand for mobility.

Due to all these concerns, you are wise not to agree to surgery if you can get by without it by making significant changes in your use of the presumably painful right shoulder. If you must proceed with surgery, then doing therapy first to practice Activities of Daily Living using only the left upper limb and planning for a safe living situation with necessary help does make sense. You are correct to insist on it! ■

Why I enjoyed *Crip Camp: A disability revolution*

Baldwin Keenan

My wife, Roni, and I were in early COVID-19 stay-at-home. I fastened my leg brace and took what, in a later anticlimactic post-polio revelation, would be one of my last walks for exercise. I was listening to NPR and caught the close of a review of *Crip Camp*. It was soon to be released by Barack and Michelle Obama's production company, Higher Ground Productions. I usually quickly forget the names of movies or shows that I hear about. This title was catchy and very personal. Albeit during the entire time frame of the documentary story, I had traveled in a parallel, self-induced, trajectory. Shortly, *Crip Camp* showed up on Netflix, and we were taken in completely.

I internalized so many connections to what we I lived and am living through. Roni, in her way, did as well. That is all I am going to say about the film itself. Ant more would spoil the tale and its making. Until I was pulled down by the late effects of polio in 2000, my wage-earning life had been fourteen years of heavy construction, followed by twenty years of late nights and early mornings of union organizing. Concurrently, there was the myriad of activities that came with an ever-evolving, very good marriage which produced three wonderful children. Corrective boots, shoes or molded inserts got me through. Despite becoming progressively more tired in the afternoons, I refused to see myself as disabled. The disability movement was not one I would associate with. Sound familiar?

It seems ironic to me now that on sunny days in the mid-70s I had joy-filled times pushing wheelchair-bound, Ron Kovic on the Venice Boardwalk while roller-skating. I had met him on an anti-war march. With words unspoken, I was

bonded to this kind Vietnam War veteran as he helped ease the loss of two of my friends who had not escaped suicidal war nightmares. Two decades later, I was thrilled that *Born on the Fourth of July* brought his story to the big screen. It saddens me that I took no notice of politically famed Judy Heumann, with whom I share a common disability.

Even when movie theaters find a way to open without too much risk of spreading COVID-19, there is little hope that this documentary will be picked for screening. Roni and I deeply connected with the remarkable cinematic portrayal of uplifting struggle and joy. Watch it now at home! ■

CRIP CAMP

Rating: R (for some language including sexual references)

Genre: Documentary

Directed By: Nicole Newnham, Jim LeBrecht

Runtime:
106
minutes

Studio:
Netflix



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