



The Polio Post

Ohio Polio Network Newsletter
Winter 2019 Issue

OHIO POLIO NETWORK CONFERENCE
SATURDAY, SEPTEMBER 19, 2020
TUSCORA PARK,
NEW PHILADELPHIA, OHIO
By Brenda Ferguson

We wish to invite all polio survivors, their family & friends to our semi-annual Post-Polio Conference held by the Ohio Polio Network.

It may seem far away, but it's really not...next year's conference will be held on Saturday, September 19, 2020 at Tuscora Park in New Philadelphia, OH. We have two excellent speakers who will provide us with outstanding information to help educate post-polio survivors. They are:



Dr. Anthony A. Hayek, D.O. – is a Physical Medicine & Rehabilitation specialist in Akron, OH. He attended and graduated from Ohio University College of Osteo Medicine in 1993, having over 26 years of diverse experience, especially Physical Medicine and Rehabilitation, which is the medical specialty concerned with diagnosing, evaluating and treating patients with physical disabilities. His experience and expertise in polio/post-polio is vast. He is affiliated with many hospitals, including Cleveland Clinic Akron General Medical Center, Edwin Shaw Rehab Institute, Summa and St. Thomas Hospital. Dr. Hayek also cooperates with other doctors and physicians in medical groups including Summit Rehabilitation Medicine, Inc. Dr. Hayek's focus will be on "Attaining the Best Life Possible with Post-Polio."



Michael K. McGovern – is Chair of the Rotary International PolioPlus Committee. He has served as the Chair of Rotary International's PolioPlus Committee since 2014. In this role, he is the volunteer leader of Rotary's largest humanitarian project, the global eradication of polio. Rotary is the spearheading partner of the Global Polio Eradication Initiative and has donated over \$2.0 billion to ending polio and has worked with other partners to reduce the number of polio endemic countries from 125 in 1988 to 2 today. Mike joined Rotary in 1985 as a member of the Rotary Club of South Portland-Cape Elizabeth, Maine in a multitude of positions and has spoken at Rotary events on the Polio Oversight Board of the Global Polio Eradication Initiative. Mr. McGovern's focus will be on "Eradication of Polio & the Role of Rotary in the Process."

Editor: Alice Sporar



Inside this Issue

What is the Disability Integration Act?	2
2019 OPN Donors	3
Post-Polio Syndrome	5
Wheelchair Travel	7
The Benefits of Having Friends with Similar Disabilities	8
Post-Polio Contact Information	9



What is the Disability Integration Act?

The Disability Integration Act (DIA) is a civil rights, bipartisan and bicameral legislation, introduced by Senators Charles Schumer, Minority Leader (D-NY) and Cory Gardner (R-CO) in the Senate and Representative Jim Sensenbrenner (R-WI) in the House, to address the fundamental issue that people who need Long Term Services and Supports (LTSS) are forced into institutions and losing their basic civil rights. The legislation (S.117, H.R.555) builds on the 25 years of work that ADAPT has done to end the institutional bias and provide seniors and people with disabilities home and community-based services (HCBS) as an alternative to institutionalization. It is the next step in our national advocacy after securing the Community First Choice (CFC) option.

DIA Support letter with 852 Organizations sent to the Hill today – supporting bill and its movement in the 116th Congress

Today ADAPT and National Council on Independent Living (NCIL) in solidarity with **852** civil and human rights, faith based, justice reform, housing advocacy national, state and local organizations sent a letter of support to the House of Representatives leadership. The letter is in support of the Disability Integration Act of 2019 (DIA) (H.R. 555) supporting this historic civil rights bill and its movement in this congress.

In the 116th congress the bipartisan, bicameral DIA civil rights bill was introduced on January 15, 2019, which was the 90th Anniversary of the birthdate of the Rev. Dr. Martin Luther King, Jr. ADAPT and NCIL celebrated this milestone with a program created and implemented by Black disabled women in the movement. The focus of the event was to honor the memory of King and his fight for civil rights in this country. The event led by Anita Cameron a Black queer disabled woman and longtime ADAPT activist evoked the history of not only the Black civil rights movement but the history of ADAPT and its founders who went to Selma and learned from King and other civil rights leaders.

See press release: <https://adapt.org/press-release-disability-community-celebrates-the-reintroduction-of-the-disability-integration-act/>

The DIA (H.R. 555) was introduced by Rep. Jim Sensenbrenner in the House with 42 Cosponsors and Minority Leader Chuck Schumer (D-NY) and Senator Cory Gardner (R-CO) S. 117 with 24 Cosponsors. From the introduction ceremony: “I am proud to re-introduce this bill, because all Americans should share in the American Dream, and that begins in the community in someone’s own home,” said Representative Sensenbrenner.

In the first five months of this year ADAPT and NCIL members worked long and hard to garner **230 bipartisan** Cosponsors on H.R. 555, which include the majority of members in all of the committees of jurisdiction for the legislation. DIA is supposed to be worked in the House Energy and Commerce Committee. But ADAPT and NCIL have been told by Chairman Rep. Frank Pallone (D-NJ) that this bill will not move in the near future, although the rules presented by Speaker Pelosi clearly state that bills must have at least 218 (approximately half of the 116th Congress) on them before any action takes place.

(See ADAPT press release June 19, 2019 – Pallone Obstructing DIA’s Movement: <https://adapt.org/pallone-obstructing-dias-movement/>) 230 bipartisan – <https://www.congress.gov/bill/116th-congress/house-bill/555/cosponsors>

On July 26, 2019 we celebrate the 29th Anniversary of the Americans with Disabilities Act of 1990 (ADA). This is the civil rights law for people with disabilities and the premise of this law is the guarantee of community integration for this community. Last month we celebrated the 20th Anniversary of the Supreme Court Case titled *Olmstead v Lois Curtis*. This is the case that recognized the fundamental equality of those with disabilities. It stated that people with disabilities have the right to live in the most integrated setting possible for their needs. This means that they cannot be forced to live in institutions.

The DIA is the next civil rights legislation in this imperative work to ensure that all people with disabilities do in fact get to live in the community. It strengthens Olmstead’s integration mandate and creates a federal civil rights law, which addresses the civil rights issue that people with disabilities who are stuck in institutions cannot benefit from many of the rights established under the ADA.

(Continued on page 4)



**2019
OHIO POLIO NETWORK DONORS**

Gretchen Estreicher

Thomas Maurer

Olivia Stevens-Sommers

Amelita D'Angelo-Ritz

Richard Robbins

Victoria Stevens-Sommers

Patrick Kelly

Beverly Schmittgen

Kevin Sykora

Nancy Lincoln

In Memory of David Livingston

Marilyn Bauman

Brenda Ferguson

Beverly Schmittgen

Marilyn Fabritius

Patrick Kelly

Annette Will

In Memory of Ruby Adams - Donald Donahue

In Memory of Robert Hadley - Arlene Zachritz

In Memory of James Zachritz - Arlene Zachritz



We thank everyone who has been so generous and supported the Ohio Polio Network.

Post-Polio Health International

4307 Lindell Blvd. #110

St . Louis, MO 63108-2930

Phone:0314.534.0475

Fax: 314.534.5070

Post-polio.org

Email: info@post-polio.org

What is the Disability Integration Act? (Continued)

This important civil rights bill picks up where Olmstead left off. It enshrines in Federal statute the right to live in the community, which Olmstead recognized. It gives people with disabilities and seniors the right to demand that states and insurers remove the obstacles, which stand in the way of their integration. It takes what disability advocates have learned in working for integration in the past eighteen years and gives disability advocates another and a more powerful tool to effect that integration.” This quote is from Steve Gold one of the SCOTUS *Olmstead v. Lois Curtis* litigators. (written in 2017)

This legislation will protect all the freedom of disabled and elderly Americans and is written with purposeful Intersectionality, the critical race theory that encompasses the fact that people with disabilities are all parts of life. The disabled like many are usually multi-marginalized because they are of all races, religions, non-religious, LGBTQIA, refugees, immigrants, incarcerated and formerly incarcerated. It is in this solidarity that **852** Civil and Human Rights, Faith Based, Justice Reform, housing, national, state and local organizations support of DIA and the movement of the bill in the 116th congress.

The many organizations supporting this bill understand that the communities they advocate for every day include people with disabilities or have family or friends with disabilities and DIA will ensure that they are part of our community in this country as the ADA and Olmstead case intended.

We call on Congress, specifically the House of Representatives to pass this imperative civil rights legislation today!

FREE OUR PEOPLE!

To find out more on the bill go to: <http://www.disabilityintegrationact.org/>

To read the full letter go here: [DIA Organizations Support Letter July 2019](#)

To see the full list of 851 Organizations supporting DIA go to: <http://www.disabilityintegrationact.org/dia-supporter-list/>

If your organization would like to join the list of supporters for this bill please go to: <http://www.disabilityintegrationact.org/support-the-disability-integration-act/>

For more information on this bill or to join in the work please contact Dara Baldwin, Director of National Policy for Center for Disability Rights, Inc. at dara.baldwin@ncdr.us or 202 -919-5725

DON'T FORGET....IT'S TIME TO RENEW YOUR 2020 OPN DUES

It's that time again – time to renew your 2020 dues. The dues membership timeframe is September 2019 - August 2020 so if you haven't sent in your yearly \$10 dues yet, kindly submit it to our OPN Treasurer, Judi Jacobs at: 464 17th St. NW, Barberton, OH 44203 soon. If you have any questions, you can reach Judi at 330/745-5312. Your annual support of OPN is greatly appreciated!



Post-polio syndrome

History of polio

Poliomyelitis is a disease caused by a virus that attacks nerves that control motor function. Polio (infantile paralysis) has nearly been eradicated from nearly every country in the world since the approval of the Salk (1955) and Sabin (1962) vaccines.

In 2013, only three countries (Afghanistan, Nigeria, and Pakistan) remained polio-endemic, down from more than 125 in 1988.

The World Health Organization (WHO) estimates that 12 million people worldwide live with some degree of disability caused by poliomyelitis.

The National Center for Health Statistics estimates about one million polio survivors in the United States, with almost half reporting paralysis resulting in some form of impairment. The last major outbreaks of polio in the United States were in the early 1950s.

What is post-polio syndrome?

For years, most polio survivors lived active lives, their memory of polio mainly forgotten, their health status stable. But by the late 1970s, survivors who were 20 or more years past their original diagnosis began noting new problems, including fatigue, pain, breathing or swallowing problems, and additional weakness.

Medical professionals called this post-polio syndrome (PPS).

Some people experience PPS-related fatigue as a flu-like exhaustion that worsens as the day progresses. This type of fatigue can also increase during physical activity, and it may cause difficulty with concentration and memory. Others experience muscle weakness that increases with exercise and improves with rest.

Research indicates that the length of time one has lived with the residuals of polio is as much of a risk factor as age. It also appears that individuals who experienced the most severe original paralysis with the greatest functional recovery have more problems with PPS than others with less severe original involvement.

Post-polio syndrome appears to be related to physical overuse and, perhaps, nerve stress. When the poliovirus destroyed or injured motor neurons, muscle fibers were orphaned and paralysis resulted.

Polio survivors who regained movement did so because non-affected neighboring nerve cells began to “sprout” and reconnect to what might be considered orphaned muscles.

Survivors who have lived for years with this restructured neuromuscular system are now experiencing the consequences including overworked surviving nerve cells, muscles, and joints, compounded by the effects of growing older. There is no conclusive evidence to support the idea that post-polio syndrome is a reinfection of the poliovirus.

Managing PPS

Polio survivors are urged to take care of their health in all the usual ways – by seeking periodic medical attention, being nutrition-wise, avoiding excessive weight gain, and by stopping smoking or overindulging in alcohol.

Survivors are advised to listen to their body's warning signals, avoid activities that cause pain, prevent overuse of muscles, and conserve energy by avoiding tasks that are nonessential, and by using adaptive equipment when needed.

(Continued on page 6)

Post-polio syndrome (Continued)

Post-polio syndrome is not typically a life-threatening condition, but it may cause significant discomfort and disability. The most common disability caused by PPS is deterioration of mobility.

People with PPS may also experience difficulties performing daily activities such as cooking, cleaning, shopping, and driving. Energy-conserving assistive devices such as canes, crutches, walkers, wheelchairs, or electric scooters may be necessary for some people.

Living with post-polio syndrome often means adjusting to new disabilities; for some, reliving childhood experiences of coming to terms with polio can be difficult. For example, moving from a manual to a power chair can be tough.

Fortunately, PPS is gaining increasing attention in the medical community, and there are many – professionals who understand it and can provide appropriate medical and psychological help.

In addition, there are PPS support groups, newsletters, and educational networks that provide up-to-date information about PPS while assuring survivors that they are not alone in their struggle.

Franklin D. Roosevelt, polio survivor



Franklin D. Roosevelt, seldom seen as a polio survivor, with Ruthie Bye and Fala, 1941

Resources

If you are looking for more information on post-polio syndrome or have a specific question, our [information specialists](#) are available business weekdays, Monday through Friday, toll-free at 800-539-7309 from 9am to 5pm ET.

Additionally, the Reeve Foundation maintains a fact sheet on PPS with resources from trusted Reeve Foundation sources. [Check out our repository of fact sheets](#) on hundreds of topics ranging from state resources to secondary complications of paralysis.

We encourage you to also reach out to post-polio syndrome support groups and organizations, including:

[Post-Polio Health International](#) offers information for polio survivors and promotes networking among the post-polio community. PPHI publishes numerous resources, including the quarterly Polio Network News, the annual Post-Polio Directory, and The Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors. PPHI is the evolution of the GINI organization, founded as a mimeograph newsletter by Gini Laurie in St. Louis 50 years ago. 314-534-0475.

[Post-Polio Institute](#) is the home of Richard Bruno, clinical psychologist specializing in fatigue, pain, and stress – as well as PPS. *Sources: Post-Polio Health International, Montreal Neurological Hospital Post-Polio Clinic*

Wheelchair Travel

About John Morris Accessible Travel Guru Shares His Disability Story

Welcome to **Wheelchair Travel — Accessible Travel Blog**, a catalog of what I've learned while exploring the world with one hand, a passport and my power wheelchair.



My name is John Morris.

In the Fall of 2012, a car accident changed the course of my life. Severe burns laid claim to three of my limbs, making me a triple amputee. Shock, fear, anger, sadness, hopelessness. Yes, I grappled with all of those emotions. But that's not what I'm here to talk about.

Before my disability, I was a traveler. I took flights for no other reason than to fly. I explored destinations all around the world, sometimes for only a day or two. Travel was, in effect, my first true love.

I refused to surrender that to disability.

And so, more than a year after my car accident, with bedsores, amputations and all, I took my first trip as a disabled person... to Los Angeles. It was a joyous occasion—my alma mater, Florida State University, won the college football national championship game. And I was there.

But planning that trip was difficult. The internet was filled with unreliable information about traveling with a disability. Nothing I read prepared me for what traveling with a wheelchair is actually like. As I began to take more trips—to Washington, D.C., then to Boston, Seattle and finally to Beijing, China—I asked myself, why hasn't someone created a resource that tells me what I need to know?

I want to Open Your World (and mine).

I traveled for more than a year before launching WheelchairTravel.org. And what was initially envisioned as a place where I could share a few tips has grown to become a **diverse community of readers and [guest writers](#) from every corner of the world.**

The reality is, **more than 1% of the world's population uses a wheelchair.** And nearly 20% have a disability that limits one or more activities of daily living. So there is certainly a market for accessible travel, and my readership is proof of the demand.

Just like me, wheelchair users know that the majority of **online resources for wheelchair accessible travel** are limited and unreliable. With this site, I aim to disrupt that unacceptable status quo. I write only about the places I have visited and the experiences I have had from the seat of my wheelchair. If I cannot be confident in the accuracy of information, I will not publish it. I am committed to providing my readers with the tools to access the world independently or with friends/family/caregivers.

(Continued on page 8)

Wheelchair Travel (continued)

In addition to writing about travel destinations, I also throw in a bit of my **disability advocacy**. I praise businesses that serve everyone equally, criticize those that do not, and defend them against unfair criticism. It is my hope that business leaders will act on my call to create accessibility for all. But my most important work is educating readers about [what to expect](#) when traveling with a mobility impairment.

Together, we can be partners in forging a path forward for our disabled peers and the people who join our community every day. Get out there and see the world with me!

The Benefits of Having Friends with Similar Disabilities

What was this research about?

Friends play important roles in our lives. They can make us laugh, lift our spirits, and give us information or advice. People with physical disabilities may feel a special connection with friends who have the same disability, such as people they meet in support groups. One person with MS told us, “I think it’s a matter of feeling less self-conscious around [other people with MS] because they don’t see you the way other people see you.” Another person, who is blind, said about her blind friends: “We all immediately share a common bond, and have an understanding and camaraderie with each other right away.” In this study, we wanted to find out if people who had more friends sharing their disability were happier with their lives.

What did the researchers do?

We conducted two survey studies. First, we sent a survey to about 70 adults who were legally blind. On the survey, we asked the respondents to count all of their friends who were also blind, and all of their friends who were not. Then we asked them to rate how satisfied they were with their lives overall.

Then, we sent a similar survey to about 1,500 people with either muscular dystrophy (MD), multiple sclerosis (MS), post-polio syndrome (PPS), or spinal cord injury (SCI). We asked these respondents to count how many of their friends had their physical condition and how many friends had any physical disability. As in the first survey, we also asked them about their overall quality of life. Finally, we asked these respondents how severe their physical limitations were as a result of their disability condition.

What did the researchers find?

In both surveys, we found that respondents who listed more friends with disabilities said they were happier with their lives overall than respondents with less friends having disabilities. In the first survey, this connection held up no matter how many friends without disabilities the respondent had. In the second survey, we also found that almost half of the respondents listed no friends with disabilities. For these respondents, there was a strong link between having more severe physical limitations and lower overall quality of life. However, for the respondents with at least one friend having a disability, that link was weaker, meaning that their physical limitations had less impact on their quality of life. Interestingly, the results applied to having friends with any physical disability, even if the friends had different disability conditions.

How can you use this research?

If you have a physical disability, sharing experiences with others in a similar situation can bolster your well-being. Sometimes, it can be hard to find friends with similar disabilities. The following organizations may have support groups in your area: [Post-Polio Health International](#), [National MS Society](#), [Muscular Dystrophy Association](#), [United Spinal Association](#) You may also want to find your local Center for Independent Living (CIL): <https://www.ilru.org/projects/cil-net/cil-center-and-association-directory> To learn more about the power of social support, check out our research summary on [The Power of Social Support](#), or our article on [How to Stay Physically Active](#) and [How to Bounce Back](#).

Original Research Article:

[Silverman AM, Molton IR, Smith AE, Jensen MP, Cohen GL. Solace in solidarity: Disability friendship networks buffer well-being. *Rehabil Psychol.* 2017 Apr 10. DOI: 10.1037/rep0000128. \[Epub ahead of print\]](#)

Reprinted from PHI Membership Memo, April 27, 2017, (No. 56)

OPN BOARD AND ADVISORY BOARD

President

Patrick Kelly
Marietta, OH
(740) 374-0538

Vice-President

Brenda Ferguson
Tallmadge, OH
(330) 671-7103

Secretary

Susan Cull
Columbus, OH
(614) 204-4089

Treasurer

Judi Jacobs
Barberton, OH
(330) 745-5312

Support Group

Liaison

Judith Peascoe
Vienna, WV
(304) 295-4233

DB Administrator

Nelson Sommers
Cuyahoga Falls, OH
(330) 807-6085

OPN Board

Bob Boyce
Akron, OH 44333
Cell: 832-250-0155

OPN Board

Patricia L Novak
Oak Harbor, OH
(419) 898-3130

OPN Board

Warren Peascoe
Vienna, WV
(304) 295-4233

OPN Board

Aldeen "Monica" Wilford
Gahanna, OH
(614) 581-6979



OPN Advisory Board

Anthony Hayek, D.O.
Edwin Shaw Rehab
Akron, OH
(330) 784-9306



OPN Advisory Board

Greg Nemunaitis, MD
MetroHealth
Cleveland, OH
(216) 778-3850

OPN Advisory Board

Robert W. Shields, Jr, MD
Cleveland Clinic
Cleveland, OH
(800) 223-2273

OPN Advisory Board

Nikki Wingerson
Stow, OH
(330) 686-1071

POST-POLIO SUPPORT GROUPS

Akron

Brenda Ferguson
(330) 671-7103
Judi Jacobs
(330) 745-5312

Central Ohio Polio

Network (Columbus)

Aldeen "Monica" Wilford
(614) 581-6979
Susan Cull
(614) 204-4089

Coal Grove

(Ironton)

Carolyn Melvin
(740) 532-7572

Defiance Area

(Northwest Ohio)

John Schatz
(419) 782-4699

Greater Cleveland

Alice Sporar
(440) 942-1557

HELPS

(New Philadelphia)

Winnie Walker
(330) 339-6910

Lorain County

(& Western Cuyahoga County)

Annette Will
(440) 365-9511

Miami Valley

(Dayton)

Arlene Zachritz
(937) 433-1186

Mid-Ohio Valley

Parkersburg WV

Warren Peascoe
(304) 295-4233

Stark County

(Canton)

Linda Conrad
(330) 877-2632



The Polio Connection
(Greater Cincinnati)

Charles Humerickhouse
(513) 777-3083



Toledo Post Polio
Connection

Sandy Foss
(419) 893-8110

Wooster & Wayne
County

Vivian Gray
(330) 264-2270

The Polio Post is published quarterly. All articles are due according to the following schedule:

<u>Issue</u>	<u>Date Due</u>
Spring	March 1st
Summer	June 1st
Fall	September 1st
Winter	December 1st

Please forward letters and articles to the return address on the newsletter or e-mail: amsporar@worldnetoh.com

Membership Categories:

- Basic - \$10.00
- Donations – An annual list of people who have made a donation in any amount will be published in the December Issue of *The Polio Post* and on the website.
- Special Gifts

OPN is a non-profit & tax exempt organization under: IRS 501(c)3 and Public Charity 509 (a) (2).

Make checks payable to:
 Ohio Polio Network
 c/o Judi Jacobs
 464 17th St NW
 Barberton, OH 44203

Alice Sporar - Editor
 Nelson Sommers - Formatting/Publishing
 Judi Jacobs & Brenda Ferguson- Printing & Mailing
 Patrick Kelly - Advisor

Disclaimer Notice:

The thoughts, ideas, and suggestions contained in this publication are those of the writers and do not necessarily constitute an endorsement or approval of the Ohio Polio Network. The articles are for information only.

Consult your health care provider before beginning any new medications, nutritional plans or any other health related programs.

Select One: New Membership Renewal Change of Address

The OPN Membership Year is (September 1 – August 31)
 Annual Membership payment is due in September.

Name: _____

Address: _____

City: _____ State: _____ Zip Code _____

Phone Number: _____

E-mail Address: _____

The Polio Post
 c/o Alice Sporar
 7251 Olde Farm Lane
 Mentor, OH 44060-3995



www.ohiopolionetwork.org

