



www.ohiopolionetwork.org



**OHIO POLIO NETWORK'S
30TH ANNIVERSARY
& 2023 CONFERENCE**

**Saturday, October 7, 2023
Tuscora Park
161 Tuscora Avenue, N.W.
New Philadelphia, OH 44663**

WELCOME

The Ohio Polio Network Board would like to welcome you to the 2023 Ohio Polio Network Conference. It is a time to focus on post-polio syndrome and its many facets. We hope to gain from this experience and take home some new perspectives that will help us in our everyday lives. We also hope to meet new people and above all, enjoy the day. Thank you for coming.

President

Patrick Kelly

Vice-President

Brenda Ferguson

Recording Secretary

Judy Peascoe

Treasurer

Bob Boyce

Support Group Liaisons

Susie Cull

Aldeen "Monica" Wilford

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Amy Smith

Zoom Administrator

Bob Boyce

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Chuck Albert

Warren Peascoe

Nelson Sommers

Advisory Board

Dorsett, Roswell B., MD

Hayek, Anthony A., DO

Hubbell, Susan L., MD

Marzano, Roger, CPO, C.PED

Nikki Wingerson

The Ohio Polio Network

- ◆ educates polio survivors, their families, concerned professionals, and the public.
- ◆ promotes research.
- ◆ publishes “The Polio Post” quarterly.
- ◆ maintains the Ohio Polio Network website www.ohiopolionetwork.org.
- ◆ serves as a clearinghouse to collect and disseminate information.
- ◆ assists in organizing local support groups.
- ◆ sponsors conferences and workshops.
- ◆ is Ohio’s connection to Post-Polio Health International (PHI) www.post-polio.org.

The Late Effects of Polio

In 1955, when the Salk and Sabin vaccines brought an end to the annual summer nightmare of polio epidemics, most Americans put thoughts of polio out of their minds. Once those who actually had polio regained maximum function through rigorous and extensive therapies, it was believed that the level of recovery would be permanent.

However, in recent years, many survivors have been reporting that their bodies are changing; and in many instances, their quality of life is being adversely affected. The symptoms most frequently described are increased fatigue, muscle weakness and pain, respiratory difficulties, and intolerance to cold. These problems range from unpleasant to severely debilitating.

Polio survivors pushed themselves and their doctors to learn what was happening. The result was the identification of late effects of polio - also called post polio sequelae or post polio syndrome.

Ohio Polio Network

In 1987, several local post polio support groups in Ohio began to meet together to exchange program plans, membership techniques and fund raising ideas. They soon realized they could work together to hold state-wide activities that each group could not sponsor by itself. This led to the formation of the Ohio Polio Network with polio survivors and interested professionals on its board under the sponsorship of the Ohio Easter Seal Society, Inc. In 1993, the Ohio Easter Seal Society’s Board voted to combine with the Local Easter Seal Chapter in the Cleveland area and surrounding counties.

The Ohio Polio Network (OPN) became an independent organization on September 1, 1993. OPN is a non-profit & tax exempt organization under: IRS 501(c) 3 and Public Charity 901 (a)(2). Contributions are tax deductible.

OPN’s activities include assistance with local support groups, promotion of research into the effects of post-poliomyelitis, collection and dissemination of information, education of individuals and concerned professionals, provision of a newsletter to members, organization and support of state conferences, help with referrals to knowledgeable professionals, and the solicitation of funds for the accomplishment of these services.

OPN is the Ohio contact for Post-Polio Health International (formerly GINI), an international network whose mission is to enhance the lives and independence of polio survivors and home mechanical ventilator users by promoting education, networking, and advocacy among these individuals and healthcare providers.

Ohio Polio Network Conference

Agenda

9:30 am	Registration (Coffee/tea/water & breakfast rolls)
10:00	<i>Independent Living Centers and People with Post-Polio Syndrome</i> John Ballard Executive Director Tri-County Independent Living Center
12:15 pm	Break
12:30	Lunch
1:30	<i>Rotary's Post-Polio Syndrome Advocacy</i> Julie Brandle District Governor Rotary Int. 6630
2:30	30th Anniversary Cake Conference Group Photo Bernice Krumhansl Award Presentation
2:45	Post-Polio Open Forum Roundup
3:30	OPN Meeting Election of OPN Board
4:00	Door Prize (Must be present to win) Adjournment



John Ballard

Executive Director

Tri-County Independent Living Center

“Independent Living Centers and People with Post-Polio Syndrome”

John has served as the E.D at Tri-County Independent Living Center of Akron, Ohio since 2017 and has worked or served as a volunteer and housing developer in disabilities since 1968.

As a freshman at the University of Akron in 1973, he moved into the first group home in the area and at age 20, in response to a crisis, he became a provider for the Ohio Dept. of DD and began opening group homes, shared living homes and independent living, now Ardmore, Inc. At 25, he became Summit County’s Director of Residential Services and was asked to transition 3500 individuals back home from institutions.

John also worked 35 years in the petroleum industry. Mary Lou and John have lived 33 years in Akron and have two wonderful daughters.

But his only claims to fame are: LeBron’s first sponsor in 1999 and singing to the Queen at St. George’s Chapel in 1972.

Advancing Independence Network

Formerly known as Tri-County Independent Living Center, we are a non-residential, non-profit 501© (3) organization whose Board of Directors and staff is comprised of a majority of persons with various disabilities. Our direct services to individuals with significant disabilities result in greater levels of independence and community integration/functioning. There are no age requirements for services which are provided without regard to race, color, religion, sex, age, national origin, or disability.

Our mission is to empower citizens with disabilities to be in charge of their lives and participate as members of their communities.

Through our collective strength, we advocate for the elimination of societal barriers and strive to achieve community accessibility and acceptance.

Our purpose is to assist people with significant disability to live independently and to serve the community at large by helping to create an environment that is accessible to all through technical assistance and systemic advocacy.

We accomplish this by the following programmatic operations:

- Direct Services
- Advocacy
- Collaborating with other community partners in Portage, Stark, Summit and Wayne Counties



Julie Brandle

District Governor

Rotary Int. 6630

Rotary's

Post-Polio Syndrome Advocacy

Julie is the president and a founder of Metis Construction Services, a female-owned commercial general contractor located in Kent. Metis completes ground-up, renovation, and facilities maintenance projects throughout Ohio, along with recent projects in WA, ID, IN, PA, IL, KY, MI, MO, DE and NY. With over 25 years of experience in sales, marketing, and public relations, Julie oversees these areas of expertise for Metis along with being an integral part of the management team that designs and manages the overall business strategy.

Julie is a committed community advocate and currently serves on the boards of Kent State University's Construction Management department, the Portage Development Board (economic development),

Akron Civic Theatre, Akron Urban League, Greater Akron Chamber, MCAAP (and ABC (Associated Builders and Contractors) Northeast Ohio, as well as the Hattie Larlham and Coleman Foundations. Julie volunteers for Habitat for Humanity, Rebuilding Together, and the Girl Scouts of Northeast Ohio. Julie is a Lifetime Gold Award Girl Scout and holds the adult honors of Women of Distinction and the Thanks Badge. She is a past president of the Rotary Club of Akron and is the 2023-2024 District Governor for Rotary District 6630 (50 clubs in Northeast Ohio).

Julie is a graduate of Cuyahoga Falls High School, as well as Bowling Green State University where she earned a double major in Interpersonal and Public

Communication and Soviet Studies, as well as a travel grant scholarship to study in Kiev, Ukraine. She is a graduate of Goldman Sachs 10k Small Businesses, Scalerator NEO, Leadership Portage County, and Leadership Akron's Class 37. She is also a licensed realtor(1995) with Berkshire Hathaway Stouffer Realty and holds National Association of Home Builders certifications in Green Building, Aging in Place, New Construction Sales and Master New Construction Sales.

Julie and her husband Steven (Metis EVP of Construction Operations) reside in Brimfield Twp. They have one daughter, Kimberly, a BGSU '21 graduate of the College of Education and an Intervention Specialist with Anthony Wayne Local Schools.

Governor Mike DeWine's Proclamation "September 2023 - Ohio Polio Awareness Month" Celebrating the Ohio Polio Network's 30th Anniversary by the Akron Post-Polio Support Group September 9, 2023



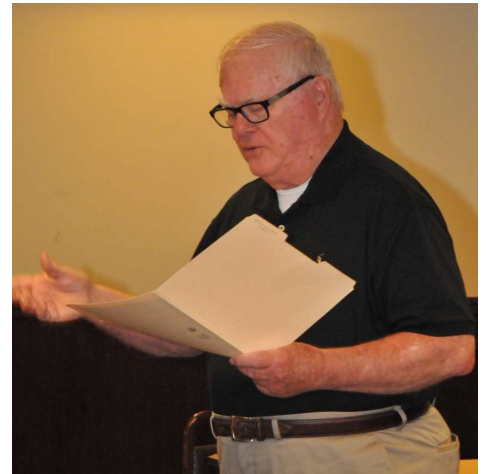
Ohio Polio Network 30th Anniversary Cake



OPN Vice-President Brenda Ferguson presents the proclamation to those attending the celebration.



OPN Board Member Nelson Sommers and Marcia Boote



Jim Rayl presents a story to the group



(l-r) Tom Boggs, OPN Board Member Bob Boyce, Jo Ann Boggs, Roger Plaster, Karen Plaster, Bud Boote, Keiichi Minatodani



Janet Rayl and Jim Rayl

September 2023 - Polio Awareness Month in Ohio

Proclamation

by Governor Mike DeWine

WHEREAS, Before the Salk and Sabine Vaccine of the 1950's, the threat of Polio, the "Dread Disease", previously known as Infantile Paralysis, the pandemic of the day, was feared by every family, and,

WHEREAS, This "Dread Disease" spawned an equally fearful offspring, years after its initial attack, known as Post-Polio Syndrome or "The late Effects of Polio", to further debilitate many people who survived their initial bout of Polio, and,

WHEREAS, Polio is still a threat to people who have not been vaccinated, and Post-Polio Syndrome is still a threat to persons who have had Polio, and,

WHEREAS, There are an estimated 300,000 Paralytic Polio Survivors in the United States today, of whom as many as 75,000 or more experience the Late Effects of Polio, and,

WHEREAS, according to research, between 25% and 40% of Paralytic Polio survivors will fall victim to Post-Polio Syndrome, including all Polio Survivors residing in the State of Ohio, and,

WHEREAS, Conserving energy and limiting activities are the only defense against the fatigue, pain, muscle weakness, difficulty breathing, swallowing, depression, swelling of limbs, sensitivity to cold, joint and muscle pain, weight gain and atrophy brought about by "The Late Effects of Polio", and,

WHEREAS, The Ohio Polio Network, and the Post-Polio Support Groups around the State and surrounding area, are dedicated to meeting the needs of Polio Survivors, and

WHEREAS, September 1, 2023 will mark the 30th year since the Ohio Polio Network was established in 1993,

NOW THEREFORE, be it resolved that I, Mike DeWine, Governor of the Great State of Ohio, due hereby proclaim the Month of September, in the year 2023 as

Polio Awareness Month

in Ohio and encourage all its citizens to be more aware of the often debilitating effects of Post-Polio Syndrome, following the initial attack of Polio.



Advancing
Independence

NETWORK

Thank You

Ohio Polio Network
For assisting so many
Ohioans in need



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Post-Polio Information Websites

- OPN Resources Page <http://ohiopolionetwork.org/id7.html>
- Jonas Salk Legacy Exhibit <https://www.sph.pitt.edu/about/history-mission/salk-legacy-exhibit>
- Post-Polio Health International <https://post-polio.org/>
- Post-Polio Resource Locator <https://post-polio.org/networking/directory/>
- Post-Polio Directory 2021 [https://www.polioplace.org/sites/default/files/files/PDIR-2021Hsec\(1\).pdf](https://www.polioplace.org/sites/default/files/files/PDIR-2021Hsec(1).pdf)
- TIRR Memorial Hermann Texas Medical Rehabilitation and Research Post-Polio Syndrome page <https://memorialhermann.org/services/conditions/post-polio-syndrome>
- Motor Neuron Diseases <https://catalog.ninds.nih.gov/sites/default/files/publications/motor-neuron-diseases.pdf>
- Clinical Trials Post-Polio <https://clinicaltrials.gov/search?cond=Post-Polio%20Syndrome%20>
- Boca Area Post Polio Group Boca Raton, FL <http://postpolio.wordpress.com/>
Each newsletter contains a page listing Post-Polio Zoom Meetings for various groups.
- Polio Survivors Network <https://www.polionetwork.org/>



World Polio Day is a time for Rotary members, public health advocates, and all who want a world free from polio to come together, recognize our progress in the fight to end polio, and talk about the actions we need to take in order to end polio for good. Rotary International <https://www.rotary.org/>



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2023 Ohio Polio Network Bernice Krumhansl Advocacy Award

This award is presented to a polio survivor or other individual who is an outstanding advocate -- a person who has worked actively in support of improving the lives of polio survivors and people with other disability issues. Prior recipients are not eligible to be nominated. This award was originally established by the OPN Board in 1988. It was called the **People First/Disability Second Award**. It was later changed to the Bernice Krumhansl Advocacy Award in honor of Bernice Krumhansl's untiring efforts in working with polio survivors to help them maintain their quality of life.

Bernice worked for 34 years at St. Luke's Medical Center, retiring in 1986 as director of the physical therapy department. She specialized in working with polio patients. Bernice wrote many articles on a variety of subjects, including a textbook on physical therapy. She also traveled extensively on a lecture circuit. Her cousin, Bill Krumhansl, said it best: **"She was special because she healed the old-fashioned way. She healed with her hands, with her heart, and with her head."**

Recipients of the Bernice Krumhansl Advocacy Award

1988	Ida Hagar	1996	Dave Livingston
1989	Carolyn Melvin	1997	Frank Craig
1990	Jackie Hamler		Becky White
1991	Greg Larbes	2003	Fran Willemsen
1992	Winnie Walker	2010	Patrick Kelly
1993	Betty Sugarman	2012	Ernest W. Johnson, MD
1994	Marianne Weiss	2015	Brenda Ferguson
1995	Greg Nemunaitis, MD	2018	Alice Sporar



2018 Bernice Krumhansl Award

Alice Sporar

Ohio Polio Network

www.ohiopolionetwork.org

President: Patrick Kelly (740-374-0538)

Treasurer/Membership: Bob Boyce (832-250-0155)

Editor of *The Polio Post* : Brenda Ferguson (330-671-7103)

Local Post-Polio Support Groups

<u>Akron</u> Brenda Ferguson (330) 671-7103 Bob Boyce (832-250-0155)	<u>Central Ohio Polio Network (Columbus)</u> Aldeen "Monica" Wilford (614) 581-6979 Susan Cull (614) 204-4089	<u>Coal Grove (Ironton)</u> Aldeen "Monica" Wilford (614) 581-6979 Susan Cull (614) 204-4089	<u>Defiance Area (Northwest Ohio)</u> Aldeen "Monica" Wilford (614) 581-6979 Susan Cull (614) 204-4089
<u>Greater Cleveland</u> Alice Sporar (440) 942-1557	<u>HELPS (New Philadelphia)</u> Winnie Walker (330) 339-6910	<u>Miami Valley (Dayton)</u> Chuck Albert (615) 939-2174	<u>Mid-Ohio Valley Parkersburg WV</u> Warren Peascoe (304) 295-4233 Nancy Murphy (304-615-6512)
<u>Stark County (Canton)</u> Linda Conrad (330) 877-2632	<u>The Polio Connection (Greater Cincinnati)</u> Amy Smith (513) 259-3511	<u>Toledo Post Polio Connection</u> Sandy Foss (419) 893-8110 Pat Novak (419-898-3130)	<u>Wooster & Wayne County</u> Vivian Gray (704) 994-9199

2023—2025

Ohio Polio Network Board Nominees

Chuck Albert

Bob Boyce

Susan Cull

Brenda Ferguson

Patrick Kelly

Linda Orsburn

Judy Peascoe

Warren Peascoe

Amy Smith

Nelson Sommers

Monica Wilford

Arlene Zachritz

The Ohio Polio Network Board nominees will be voted upon as a group by the OPN members during the OPN Meeting. Nominations may be made prior to the vote. If you are interested in joining the Board, we encourage you to nominate yourself. The OPN Board is made up of volunteers. We need new members with fresh ideas.

Meetings use zoom and are normally on a Friday and scheduled monthly or as needed. The OPN Board has a website and a quarterly newsletter.

**Thank you for your contributions to the
2023 OPN Conference!**

Martha Adamsky	Chuck Albert	Susan Cull	Janice Deeter
Hank Deneski	Gretchen Estreicher	Patty Evans	Brenda Ferguson
Teddi Gideon	Vivian Gray	Henry Hershberger	Jonas Hershberger
Judi Jacobs	Patrick Kelly	Jacob Miller	Pat Novak
Beverly Schmittgen	Paul Seib	Amy Smith	Nelson Sommers
Kevin Sykora	Dan Wells	Monica Wilford	Nikki Wingerson
Arlene Zachritz			

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Winnie Walker and the
H.E.L.P.S.
Post-Polio Support Group
and **YOU** for coming and
participating in the
Conference.