

# POST-POLIO HEALTH INTERNATIONAL

## ANNUAL REPORT 2019-2020



# LETTER FROM THE PRESIDENT

Daniel J. Wilson, PhD

---

Since 1960 Post-Polio Health International (PHI) has been the premier source for information, education, and advocacy regarding the late effects of polio. Established by Gini Laurie, PHI has brought polio survivors and other men and women with disabilities together to share ideas, encourage one another and work with allies in the medical professions. We have gotten the message out through newsletters, web sites, social media and direct contact with those who call or email the PHI office.

PHI grew out of a newsletter for iron lung patients in a Cleveland hospital into an international networking organization. In the early 1980s PHI was one of the first organizations to draw attention to the many polio survivors beginning to experience what became known as post-polio syndrome. PHI sponsored and organized the first international conference on post-polio syndrome in 1981. Since then, there have been ten additional conferences bringing together polio survivors, physicians, physical therapists and other health professionals, family members and other supporters. The goal of these conferences was to share the latest information on post-polio syndrome and to encourage additional research that could better the lives of polio survivors and other disabled individuals.

We have also published several booklets about post-polio syndrome for polio survivors. Through our

newsletter, web sites and support for post-polio support groups, we continue to be a source of accurate information on the late effects of polio, home mechanical ventilation, and living well with a disability.

PHI has seen several changes over the past two years. We have moved our office, upgraded and refreshed our website, enhanced our social media presence and instituted new programming for support groups. In addition, we have transferred our archives to the University of Massachusetts Amherst where they will soon be digitally available to polio survivors, scholars and medical professionals. And we have met the challenge of the Covid-19 pandemic.

Your continued support through memberships, donations and bequests is vital to the health of PHI. We are a membership supported organization and could not pursue our efforts at education, advocacy, and networking without the help of our members and supporters.

As with many non-profits organizations, funding remains a challenge and we are truly grateful to those individuals, businesses and organizations that support us financially. We encourage you to continue to support PHI so that we can continue the vital work that we have done for some sixty years.



# 2019-2020 in Review

Brian Tiburzi, Executive Director

---

Post-Polio Health International and International Ventilator Users Network have undertaken major initiatives over the past two years to secure our legacy and share our vast trove of accumulated resources with the public.

In 2019, PHI reached an agreement with the University of Massachusetts Amherst in which UMass agreed to permanently house our extensive archival materials, amassed over the past six decades. We are pleased that they will be joining one of the country's premier disability-related collections. In addition, they will be digitizing and making much of this collection available online. We are excited that our members, researchers and the general public will soon have access to these valuable materials.

Later that year, PHI began the process of overhauling and rebuilding our main organizational website, [www.post-polio.org](http://www.post-polio.org). The old website had been built on a platform that was no longer equipped to meet the needs of our members. PHI worked with a local firm that specializes in building websites for nonprofit organization and that had previously designed Polio Place ([www.polioplace.org](http://www.polioplace.org)).

Our goal was to provide easier access to pertinent information that polio survivors need to live healthy, independent lives. We moved the PHI Directory online and created an interactive map to help you quickly find resources near your home. The website also features a section with the latest news and events so you can stay current on what's happening in the post-polio community. The website was completed and went online in June of 2020. We have received overwhelmingly positive feedback, but continue to incorporate suggestions and update the site to improve our members' experience.

Also in 2019, IVUN completed the process of transferring [www.ventusers.org](http://www.ventusers.org) over to our newer, more modern website at [www.ventnews.org](http://www.ventnews.org). Similar to the changes to PHI's website, we hope the new IVUN site will help users more easily find the information they are looking for.

In that same vein, we updated and simplified many of our forms. Members have likely noticed changes to their membership renewal and donation forms. We created a new brochure to more clearly explain to the public and prospective members who we are and what we do. We also revamped our social media outreach. PHI created a new account on Instagram (@postpoliohealth), which has allowed us to connect with those unfamiliar with our organization.

This past year, 2020, marked PHI's 60th year in existence. It has been perhaps one of our more challenging years, both for the organization and for our members. The COVID-19 pandemic touched nearly every aspect of our lives. As polio survivors, we now find ourselves dealing with a whole new set of challenges in addition to those of living with the late effects of polio. But like many of you, PHI adjusted to this new reality and has continued to provide the same level of service as the past.

In an effort to more closely assist local post-polio support groups, we recently launched a new initiative – PHI Spark. This monthly e-newsletter seeks to provide inspiration and ideas to help local groups stay connected with their members and each other. The new PHI Speaker Series made post-polio experts available to speak with support groups over Zoom. The recordings have been placed on our new website for all of our members to view and learn from.

# BOARD OF DIRECTORS

2019-2020

---

## President

**Daniel J. Wilson, PhD**  
Bethlehem, Pennsylvania

## Vice President

**Mark Mallinger, PhD**  
Malibu, California

## Secretary

**Marny K. Eulberg, MD**  
Mountain & Plains Post Polio Clinic  
Wheat Ridge, Colorado

## Treasurer

**Mike Mrozowicz**  
Highlands Ranch, Colorado

## Paulette Bergounous

Sparks, Nevada

## William M. DeMayo, MD

Specialized Rehabilitation Hospital  
Abu Dhabi, United Arab Emirates

## Bonnie E. Levitan

Grosse Pointe, Michigan

## Frederick M. Maynard, MD

Marquette, Michigan

## Saul J. Morse

Springfield, Illinois

## Padma H. Reichwald, MS SBB

Wappingers Falls, New York

## Allison Roller, MA

Ann Arbor, Michigan

## William G. Stothers

San Diego, California

## Carol Vandenakker Albanese, MD

UC Davis Department of PM&R  
Sacramento, California

## Martin B. Wice, MD

Saint Louis, Missouri

## STAFF

### Brian Tiburzi

Executive Director  
St. Louis, Missouri

### Anne Greiwe

Assistant to the Executive Director  
St. Louis, Missouri

## Special thanks to

**Sheryl Prater** - newsletter and web designer

**Lucky Leong, LLC**, Certified Public Accountant

**Todd Harrell, AAMS**, Edward Jones

**POST-POLIO HEALTH INTERNATIONAL, INC.**  
**STATEMENT OF ASSETS, LIABILITIES,**  
**AND NET ASSETS – MODIFIED CASH BASIS**

**December 31, 2019**

**ASSETS**

Current Assets

Cash and cash equivalents	\$ 71,549
Investments at fair market value	73,539
Total Current Assets	<u>145,088</u>

Fixed Assets

Office equipment, at cost	1,798
Accumulated depreciation	(1,798)
Net Fixed Assets	<u>-</u>

Long-Term Investments

719,190

**TOTAL ASSETS**

\$864,278

**LIABILITIES**

Current Liabilities

Payroll withholding payable	<u>\$ 1,580</u>
-----------------------------	-----------------

**NET ASSETS**

Unrestricted	191,886
Temporarily restricted	<u>670,812</u>

Total Net Assets

862,698

**TOTAL LIABILITIES & NET ASSETS**

\$864,278

**POST-POLIO HEALTH INTERNATIONAL, INC.**  
**STATEMENT OF REVENUES, EXPENSES AND**  
**OTHER CHANGES IN NET ASSETS – CASH BASIS**

**December 31, 2019**

**CHANGES IN UNRESTRICTED NET ASSETS**

REVENUES

Memberships	\$ 68,017
Contributions	85,459
Publications	3,182
Investment Income	4,292
Loss on sale of securities	(2)
Unrealized gain on investments	5,688
Contributions released from restrictions	54,423
TOTAL UNRESTRICTED REVENUES	<u>221,059</u>

EXPENSES

Education	\$207,175
General and administrative	33,590
Fundraising	4,950
TOTAL EXPENSES	<u>245,715</u>

DECREASE IN UNRESTRICTED NET ASSETS (24,656)

**CHANGES IN TEMPORARILY RESTRICTED NET ASSETS**

Contributions	13,450
Investment income	25,507
Loss on sale of securities	(1,741)
Unrealized gain on investments	65,701
Net assets released from restrictions	(54,423)

INCREASE IN TEMPORARILY RESTRICTED NET ASSETS 48,494

INCREASE IN NET ASSETS 23,838

NET ASSETS AT BEGINNING OF YEAR 838,860

NET ASSETS AT END OF YEAR \$ 862,698

**POST-POLIO HEALTH INTERNATIONAL, INC.**  
**STATEMENT OF ASSETS, LIABILITIES,**  
**AND NET ASSETS – MODIFIED CASH BASIS**

**December 31, 2020**

**ASSETS**

Current Assets

Cash and cash equivalents	\$ 31,680
Investments at fair market value	51,616
Other Current Assets	8,564
Total Current Assets	91,859

Fixed Assets

Office equipment, at cost	1,798
Accumulated depreciation	(1,798)
Net Fixed Assets	-

Long-Term Investments

740,726

**TOTAL ASSETS**

**\$832,585**

**LIABILITIES**

Current Liabilities

Accounts Payable	\$ 11,802
Payroll Protection Loan	22,140
Total Current Liabilities	33,942

**NET ASSETS**

Unrestricted	105,028
Temporarily restricted	693,615
Total Net Assets	798,643

**TOTAL LIABILITIES & NET ASSETS**

**\$832,585**

**POST-POLIO HEALTH INTERNATIONAL, INC.**  
**STATEMENT OF REVENUES, EXPENSES AND**  
**OTHER CHANGES IN NET ASSETS – CASH BASIS**

**December 31, 2020**

**CHANGES IN UNRESTRICTED NET ASSETS**

REVENUES

Memberships	\$ 59,182
Contributions	44,617
Publications	2,836
Investment Income	2,891
Gain on sale of securities	438
Unrealized gain on investments	4,435
Contributions released from restrictions	23,303
TOTAL UNRESTRICTED REVENUES	<u>137,702</u>

EXPENSES

Education	\$ 188,654
General and administrative	28,821
Fundraising	7,084
TOTAL EXPENSES	<u>224,559</u>

DECREASE IN UNRESTRICTED NET ASSETS (86,858)

**CHANGES IN TEMPORARILY RESTRICTED NET ASSETS**

Contributions	8,191
Investment income	21,711
Gain on sale of securities	53,063
Unrealized gain on investments	(33,046)
Investment management fees	(3,814)
Net assets released from restrictions	(23,303)

INCREASE IN TEMPORARILY RESTRICTED NET ASSETS 22,803

DECREASE IN NET ASSETS (64,055)

NET ASSETS AT BEGINNING OF YEAR 862,698

NET ASSETS AT END OF YEAR \$ 798,643





# RESEARCH

In December of 2019, PHI's Board of Directors adopted a new resolution regarding the Research Fund:

Whereas the PHI Board of Directors established the PHI Research Fund to support medical, social scientific, and historical research to further the well-being of the post-polio population and home ventilator users by funding specific grant proposals and special projects.

And whereas the PHI Board feels that these efforts should also include funding the gathering, organizing and disseminating of relevant research information to its members, medical professionals, and the general public through responding to individual inquiries, publishing newsletters, maintaining the websites, and participating in conferences.

Be it resolved that the Board of PHI may approve the use of money from the Research Fund in support of specific research grants and projects and to support the indirect operating costs of PHI in support of research as defined above (in paragraphs 1 and 2). Specific grants and projects will be referred to the Research Committee for consideration and approval before coming to the whole PHI Board for final approval. The President of the Board will annually appoint a special ad-hoc committee to determine the percentage of overhead and indirect costs in support of the PHI research effort for the coming year to be drawn from the Research Fund subject to final Board approval.

## Current Status of The Research Fund

On December 31, 2020, The Research Fund assets were \$703,059.

There are two active research grants:

**"Cough Assist: use education needs, health service utilization, and outcomes"**

Principal Investigator: Louise Rose, RN, MN, PhD, King's College London and Mika Nonoyama, RRT, PhD, Assistant Professor at the University of Ontario Institute of Technology

**"B-FIT! A guideline to individualized exercise in post-polio syndrome"**

Principal Investigator: Eric L. Voorn, PhD, and Frans Nollet, MD, PhD, Academic Medical Center Amsterdam

# MAJOR CONTRIBUTORS

2019

---

**Polio Outreach of Washington**

**Estate of Lawrence C. Becker**

**Bonnie & Eric Helpenstell**

**The Edouard Foundation**

**Clark Callahan**

2020

---

**Polio Outreach of Washington**

**Estate of Lawrence C. Becker**

**Bonnie & Eric Helpenstell**

**The Edouard Foundation**

**Clark Callahan**

POST-POLIO HEALTH  
INTERNATIONAL

Post-Polio Health International  
including International Ventilator Users Network

50 Crestwood Executive Ctr, #440 ■ Saint Louis, MO 63126-1916 ■ USA  
314-534-0475 ■ [www.post-polio.org](http://www.post-polio.org) ■ [info@post-polio.org](mailto:info@post-polio.org)