ANNUAL REPORT 2013-2014

Post-Polio Health International's mission is to enhance the lives and independence of polio survivors and home ventilator users through Education, Advocacy, Research and Networking.

For more than 50 years ...

- 1960 International Iron Lung Polio Assistance, Inc.
- 1964 Iron Lung Polios and Multiplegics, Inc.
- 1983 Gazette International Networking Institute, Inc.
- 1985 dba International Polio Network
- 1987 dba International Ventilator Users International
- 2003 Post-Polio Health International, including International Ventilator Users Network



POST-POLIO HEALTH INTERNATIONAL INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

4207 Lindell Boulevard #110 Saint Louis, MO 63108-2930 USA 314-534-0475

Review of 2013

Education

Post-Polio Health International (PHI)

- Updated Remember Polio? Have you heard about the late effects of polio? brochure.
- PHI's 11th International Post-Polio Conference theme and date (May 31–June 3, 2014) established.





International Ventilator Users Network (IVUN)

- Educational conference calls summarized for print and digital distribution. http://ventusers.org/edu/confcalls.html#pas
- Judith R. Fischer <u>resigns</u> as editor of *Ventilator-Assisted Living*. Gayla Hoffman becomes editor.
- Joan L. Headley replaces Judith Fischer as consultant to the Home Care Network of the American College of Chest Physicians.

Research

- Awarded \$25,000 to a research group from Texas Woman's University in Houston to explore the use of whole body vibration for polio survivors.
- Approved extension for University of Michigan Glutathione Study. <u>Final report</u> received in the fall.
- Expanded topics in call for proposals for The Research Fund and increased the annual amount to \$50,000 or \$100,000 for two years.

Networking

Post-Polio Health International (PHI)

- Reorganized the <u>Post-Polio Directory</u> combining health professionals and support groups by country and state.
- Joan L. Headley joined the Advisory Board of Healthy Aging with Long-Term Physical Disabilities Rehabilitation and Research Training Center (RRTC).

- Joined Twitter @polioplace.
- Increased funds for individuals in need to purchase shoes or bracing to \$800.

International Ventilator Users Network (IVUN)

Contributed to <u>International perspectives on spinal cord injury</u>

Advocacy

Post-Polio Health International (PHI)

- Sent <u>Letter to Editor</u> to St. Louis Post-Dispatch
- WE'RE STILL HERE! campaign focused on What Disability Has Taught Me

International Ventilator Users Network (IVUN)

Published Flying While Using a Ventilator

Review of 2014

Education

Post-Polio Health International (PHI)

■ Held PHI's 11th International Conference: Promoting Healthy Ideas on May 31–June 3.

Conference Program

Session Handouts

- Added <u>Post-Polio Experts Present (Video Series)</u>, a series of timely informational videos presented by dedicated experts who have significant experience in managing post-polio problems and in advocating for the survivors of polio, to <u>Polio Place</u>.
- Added responsive design to Polio Place to improve viewing on phones.

Research

■ Announced first \$100,000 research award to a team led by Dr. Antonio Toniolo, Varese, Italy, for "Poliovirus genome in patients with post-polio syndrome (PPS): Defining virus mutations by novel genome sequencing methods and investigating possible treatments with antiviral antibodies and drugs."



Networking

Post-Polio Health International (PHI)

- Researched and published <u>The Iconic Iron Lung and Polio Survivors in the USA</u>
- Surveyed PHI Membership about post-polio care from primary physicians and post-polio clinic specialists and published <u>Results and Observations</u>; <u>Post-Polio Medical Care</u>: <u>Post-Polio Specialists and Primary Care Physicians</u>
- Sponsored Colorado Post-Polio's Wellness Retreat

International Ventilator Users Network (IVUN)

■ Judith R. Fischer and Joan L. Headley awarded the Margaret Pfrommer Memorial Award in Long-term Mechanical Ventilation from the American College of Chest Physicians at CHEST 2014 in Austin, Texas. Their lecture was titled "Ventilator Users Can Survive the System with Your Help."

Pfrommer Lecture PowerPoint
Pfrommer Lecture Script
Pfrommer Lecture Handouts

Advocacy

■ WE'RE STILL HERE! campaign distributed <u>15 lectures</u> that provided information and advice to the health professionals who treat polio survivors and to survivors and their families.

Mission, Methods and Movers

Incorporated in 1960 as the International Iron Lung Polio Assistance, Inc., today Post-Polio Health International, including International Ventilator Users Network, continues is mission of enhancing the lives and independence of polio survivors and home ventilator users through education, advocacy, research and networking.

It continues its publication of *Post-Polio Health, Post-Polio Directory, Ventilator-Assisted Living,*

Resource Directory for Ventilator-Assisted Living, Home Ventilator Guide and www.post-polio.org, www.polioplace.org and www.ventusers.org, www.ventusers.org.



Message from PHI Board President and Executive Director

PHI and IVUN are governed by a Board of Directors (see list on next page) and advised by groups of health professionals, polio survivors and ventilator users. We are focused by our time-tested mission of enhancing the lives and independence of polio survivors and home ventilator users through education, advocacy, research and networking.

A mission must be more than words. Action is required.

PHI and IVUN's actions are guided by three principles.

I. Build bridges and bonds not bureaucracies.

Our periodic international conferences, the most recent in 2014, are designed to help individual polio survivors live the best life possible as they move through the decades. Participants are invigorated and ready to incorporate what they learn into their own lives.

Our conferences serve as a model and a gathering place for other groups to meet and exchange ideas. Interdependent groups, with similar missions, are challenged to pass on knowledge and to maintain a relationship with PHI and IVUN as they facilitate their own community-based groups meeting the needs in their country, state or city.



PHI's 11th International Conference, 2014

Access to knowledge is still key, not investing in controlling bureaucratic structures.

II. Promote participation and process not personalities.

Our organization consistently promotes individual participation and responsibility. With our storehouse of resources, we provide information and connections to assist individual polio survivors and ventilator users of any age as they attend school, explore opportunities, work, maybe marry and have children, age, and develop new medical conditions.

Individual participation can be hindered by architecture, attitudes, institutional bias and corporate decisions. We continue to advocate to eliminate these barriers.

III. Honor health and hope not helplessness.

Poliomyelitis, we later learned, would sneak back on us. It was not news we expected or wanted to hear. In the vast repository of the internet, it is easy to find messages that raise doubts about the future, assign blame to past and present physicians, to ourselves for our choices, and offer blanket cures, all of which make us feel helpless.

We purposefully included "health" in our new name more than a decade ago. It was in response to the realization that our strong desire to live independently went hand in hand with being healthy – in body, mind and spirit.

Being healthy in all these areas of our lives provides us hope – not a false hope – but the kind of hope that comes with the peace of mind that we are making choices to the best of our ability to maximize our function and independence.

William G. Stothers
President/Chairperson (2013-2014)

Joan L. Headley, MS Executive Director

Board of Directors (2013-2014)

William G. Stothers – *President/Chairperson (2013-2014)* San Diego, California

Saul J. Morse -Vice President (2013-2014)

Legal Counsel, Brown Hay & Stephens, LLP, Springfield, IL

Marny K. Eulberg, MD - Secretary (2013-2014)

St. Anthony's Family Medical Center, Denver, Colorado

Brenda Jo Butka, MD (2013-2014)

Respiratory Care & Pulmonology, Vanderbilt Stallworth Rehabilitation Hospital Nashville, Tennessee

Richard (Rich) W. Hokamp -Treasurer (2013-2014)

Attorney-At-Law, Saint Louis, Missouri

Soonja Angela Cho (2103-2014)

Aurora, Colorado

Sandra Loyer, LMSW (2014)

University of Michigan Health System (ret), Ann Arbor, Michigan

Elizabeth Lounsbury (2013-2014)

Markstay, Ontario, Canada

Frederick M. Maynard, MD (2013-2014)

Physiatrist (Semi-retired), Marquette, Michigan

Allison Roller, MA (2013-2014)

Ann Arbor, Michigan

Martin B. Wice, MD (2013-2014)

Center for Advanced Medicine, Neuroscience Center Saint Louis, Missouri

Daniel J. Wilson, PhD (2013-2014)

Muhlenberg College, Allentown, Pennsylvania

Mohammed Yousuf (2013-2014)

Founder and President, EquallyAble Foundation Chantilly, Virginia

Staff

Joan L. Headley, MS

Executive Director St. Louis, Missouri

Brian M. Tiburzi

Assistant to the Executive Director

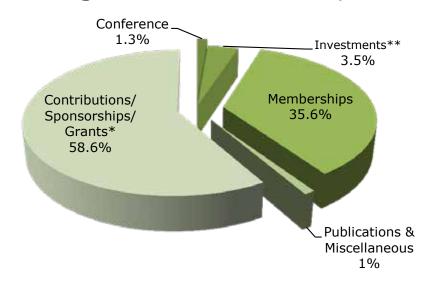
St. Louis, Missouri

Special thanks to

Sheryl Rudy, SherylzArt, newsletter and web designer **Gayla Hoffman**, Gayla Hoffman Associates, newsletter editor **Lucky Leong**, **LLC**, Certified Public Accountant **Todd Harrell**, **AAMS**, Edward Jones Consultant

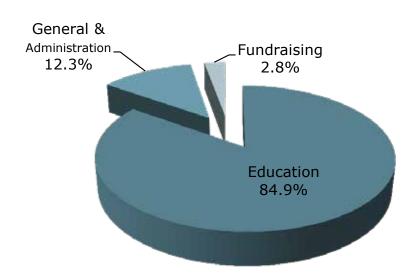
Financial Information 2013

Funding Sources 2013 - \$238,021



^{*}Includes \$94,183 of contributions and \$45,372 of contributions released from restrictions.

Expense Allocation 2013 - \$242,383



^{**}Does not reflect unrealized gains from investment activities in the amount of \$15,580.

Statement of Assets, Liabilities and Net Assets – Cash Basis

December 31, 2013

ASSETS

Current Assets	
Cash and cash equivalents	\$ 96,675
Investments at fair market value	208,852
Total Current Assets	305,527
Fixed Assets	
Office equipment, at cost	3,243
Accumulated depreciation	(2,907)
Net Fixed Assets	336
Long-Term Investments	799,163
TOTAL ASSETS	\$1,105,026
LIABILITIES	
Current Liabilities	
Payroll withholding payable	\$ 2,741
NET ASSETS	
Unrestricted	363,573
Temporarily restricted	738,712
Total Net Assets	1,102,285
TOTAL LIABILITIES & NET ASSETS	\$1,105,026

Statement of Revenues, Expenses and Other Changes in Net Assets - Cash Basis

Year Ended December 31, 2013

CHANGES IN UNRESTRICTED NET ASSETS

INCREASE IN TEMPORARILY RESTRICTED NET ASSETS

INCREASE IN NET ASSETS

NET ASSETS AT END OF YEAR

NET ASSETS AT BEGINNING OF YEAR

REVEI

REVENUES	
Memberships Contributions Publications Conference Miscellaneous Investment income Gain on sale of securities Unrealized gain on investments Contributions released from restrictions	\$ 84,902 94,183 1,983 3,221 380 7,537 443 15,580 45,372
TOTAL UNRESTRICTED REVENUES	253,601
EXPENSES	
Education General and administrative Fundraising	213,609 22,074 6,700
TOTAL EXPENSES	242,383
INCREASE IN UNRESTRICTED NET ASSETS	11,218
CHANGES IN TEMPORARILY RESTRICTED NET ASSETS	
Contributions Investment income Loss on sale of securities Unrealized gain on investments Net assets released from restrictions	87,077 31,419 (38) 77,022 (45,372)

150,108

161,326

940,959

\$1,102,285

Major Contributors, 2013

\$30,000

Donald Dickinson

\$20,000 and over

Roosevelt Warm Springs Foundation

\$10,000 and over

CareFusion Helen Ford The Chervenak-Nunnallé Foundation

\$5,000 and over

Edouard Foundation Grifols, Inc. Bonnie and Eric Helpenstell Bruce Lambert Geraldine M. Robinett Lee Philips Respironics

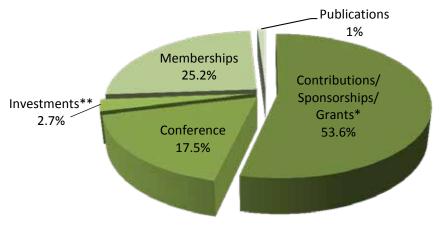
The Research Fund

A major component of PHI's mission is to fund research projects that have the potential to benefit polio survivors and users of home ventilators. To that end, PHI established a Research Fund in 1995. Contributions to the Research Fund are called "restricted assets" because PHI may use these monies only for their intended purpose – i.e., to fund research projects; stated another way, PHI may not use "restricted assets" to meet general operating expenses.

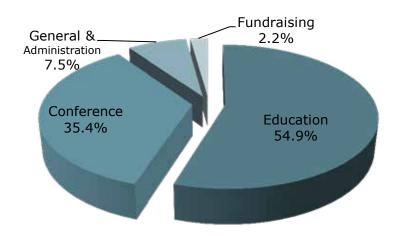
On December 31, 2013, The Research Fund assets were \$799,162.93. The Research Fund is a special fund containing dollars given to support research into post-poliomyelitis and neuromuscular respiratory conditions. The organization distribute \$25,000 in awards in 2013.

Financial Information 2014





Expense Allocation 2014 - \$344,345



^{*}Includes \$112,180 of contributions and \$56,895 of contributions released from restrictions.

^{**}Does not reflect unrealized gains from investment activities in the amount of \$3,630.

Statement of Assets, Liabilities and Net Assets – Cash Basis

December 31, 2014

_			
^			-
ч	-	-	•
$\boldsymbol{\Gamma}$		_	_

Current Assets	
Cash and cash equivalents	\$ 93,845
Investments at fair market value	191,333
Total Current Assets	285,178
Fixed Assets	
Office equipment, at cost	3,243
Accumulated depreciation	(3,132)
Net Fixed Assets	111
Long-Term Investments	822,462
TOTAL ASSETS	\$1,107,751
LIABILITIES	
Current Liabilities	
Payroll withholding payable	\$ 4,054
NET ASSETS	
Unrestricted	338,069
Temporarily restricted	765,628
Total Net Assets	1,103,697
TOTAL LIABILITIES & NET ASSETS	\$1,107,751

Statement of Revenues, Expenses and Other Changes in Net Assets – Cash Basis

Year Ended December 31, 2014

CHANGES IN UNRESTRICTED NET ASSETS

NET ASSETS AT END OF YEAR

REVEI

REVENUES	
Memberships Contributions Publications Conference Miscellaneous Investment income Loss on sale of securities Unrealized gain on investments Contributions released from restrictions	\$ 79,522 112,180 2,699 55,116 291 8,632 (124) 3,630 56,895
TOTAL UNRESTRICTED REVENUES	318,841
EXPENSES	
Conference Education General and administrative Fundraising	121,770 189,215 25,913 7,447
TOTAL EXPENSES	344,345
DECREASE IN UNRESTRICTED NET ASSETS	(25,504)
CHANGES IN TEMPORARILY RESTRICTED NET ASSETS	
Contributions Investment income Loss on sale of securities Unrealized gain on investments Net assets released from restrictions	39,615 40,582 (906) 4,520 (56,895)
INCREASE IN TEMPORARILY RESTRICTED NET ASSETS	26,916
INCREASE IN NET ASSETS NET ASSETS AT BEGINNING OF YEAR	1,412 1,102,285

\$1,103,697

Major Contributors, 2014

\$30,000 and over

Roosevelt Warm Springs Foundation

\$10,000 and over

Helen Ford Alan Love Bonnie and Eric Helpenstell The Chervenak-Nunnallé Foundation Res Med, Inc. Charles Wuller

\$5,000 and over

Clark Callahan Geraldine M. Robinett Lee Bruce Lambert Rehabilitation Foundation for Disabled Persons

The Research Fund

A major component of PHI's mission is to fund research projects that have the potential to benefit polio survivors and users of home ventilators. To that end, PHI established a Research Fund in 1995. Contributions to the Research Fund are called "restricted assets" because PHI may use these monies only for their intended purpose – i.e., to fund research projects; stated another way, PHI may not use "restricted assets" to meet general operating expenses.

On December 31, 2014, The Research Fund assets were \$822,461.51. The Research Fund is a special fund containing dollars given to support research into post-poliomyelitis and neuromuscular respiratory conditions. The organization voted to distribute \$50,000 in 2014.



4207 Lindell Boulevard #110 Saint Louis, MO 63108-2930 USA