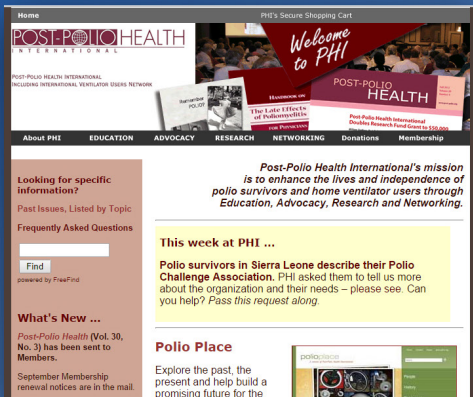
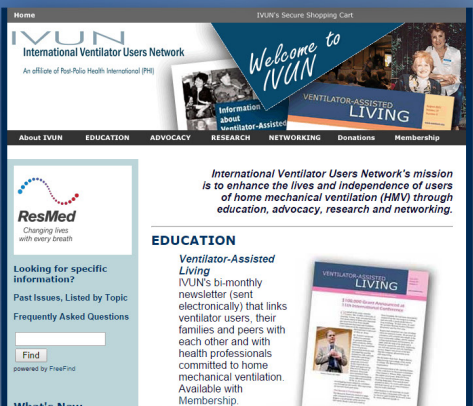


Report for 2011-2012



post-polio.org

What and Who



ventusers.org

Program Highlights



polioplace.org

Organizational
Information

Financial Information

PHI: What and Who

Incorporated in 1960 as the International Iron Lung Polio Assistance, Inc., today Post-Polio Health International, including International Ventilator Users Network, continues its 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 the maintenance of www.post-polio.org, www.polioplace.org and www.ventusers.org and its extensive networking with polio survivors, ventilator users, families, health professionals and the groups who provide service and products.



Message from Chair and Executive Director



William G. Stothers, Chair,
Board of Directors



Joan L. Headley,
Executive Director

There are many interesting aspects to facilitating a not-for-profit. Post-Polio Health International is no different in general ways, but we think it is special in so many ways. The following words come to our mind.

- Longevity:** PHI's official organizational status began in 1960 – fifty-two years ago.
- Flexibility:** The organization has had five names in 54 years and created an affiliate group, the International Ventilator Users Network – changing as needs change.
- Loyalty:** Many contributors of time, expertise and financial support have been doing so for more than 30, 40, 50 years – the heart of the organization.
- Opportunity:** Polio survivors and ventilator users have written for PHI/IVUN publications or spoken at its conferences or events – exposing their talents to others.
- Instigator:** Numerous groups around the world can trace their beginnings to *Rehabilitation Gazette*, Gazette International Networking Institute (GINI), PHI or IVUN – meeting the needs in their communities.
- Booster:** Individuals and groups are encouraged to participate in self-help – find help and help others – paying it forward.
- Vetter:** PHI and IVUN holds to high standards in publishing and promoting information – not everything on the internet is true.
- Preserver:** PHI/IVUN collects and shares experiences of polio survivors and ventilator users – for today and for posterity.

The Board of Directors and staff work closely together constantly querying each other about the organization's goals and processes. Are we meeting the needs of our Members? Are we holding true to the independent living philosophy? Are we providing that important link between people with disabilities and the health professionals?

Next, is a review of our work in 2011 and 2012. It highlights our projects and activities, and each ultimately affects an individual on a very personal level. That is what non-profits do, what we do.

Board of Directors (2011-2012)

William G. Stothers – *President/Chairperson*
San Diego, California

Lawrence C. Becker, PhD – *Vice President (2011)*
Fellow of Hollins University, Professor of Philosophy Emeritus, College of William and Mary, Roanoke, Virginia

Marny K. Eulberg, MD – *Secretary*
St. Anthony's Family Medical Center, Denver, Colorado

Saul J. Morse – *Treasurer (2011), Vice President (2012)*
Legal Counsel, Brown Hay & Stephens, LLP, Springfield, Illinois

Richard (Rich) W. Hokamp – *Assistant Treasurer (2011), Treasurer (2012)*
Attorney-At-Law, 2310A Rutger Street, Saint Louis, Missouri

Brenda Jo Butka, MD
Respiratory Care & Pulmonology,
Vanderbilt Stallworth Rehabilitation Hospital
Nashville, Tennessee

Selma Harrison Calmes, MD (2011)
Anesthesiologist (semi-retired)
Culver City, California

Soonja Angela Cho
Aurora, Colorado

Elizabeth Lounsbury
Markstay, Ontario, Canada

Frederick M. Maynard, MD
Physiatrist (semi-retired)
Marquette, Michigan

Allison Roller, MA
Ann Arbor, Michigan

Sue Suter (2011)
Urbana, Illinois

John A. Thorner, J.D., CAE (2011)
American Society of Anesthesiologists
Park Ridge, Illinois

Martin B. Wice, MD
Center for Advanced Medicine, Neuroscience Center
Saint Louis, Missouri

Daniel J. Wilson, PhD
Muhlenberg College
Allentown, Pennsylvania

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



Front row from left to right: Sheryl Rudy, SherylzArt, newsletter and web designer; Joan L. Headley, Executive Director; Gayla Hoffman, Gayla Hoffman Associates, newsletter editor.

Back row from left to right: Brian Tiburzi, Assistant to the Executive Director; Lucky Leong, LLC, Certified Public Accountant; Todd Harrell, AAMS, Edward Jones.

Program Highlights 2011

Post-Polio Health International (PHI)

- Launches Polio Place (polioplac.org) funded by the Roosevelt Warm Springs Foundation.



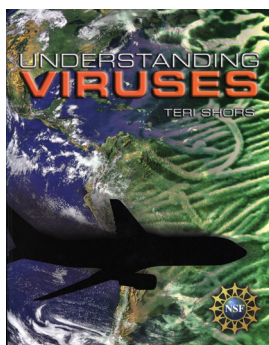
- Launches *Post-Polio Health Care Considerations for Families and Friends* funded by the Reynolds Foundation, Marquette, Michigan.

- Distributes \$25,000 each from The Research Fund to study the *Role of Oral Glutathione in the Improvement of Health Outcomes among Persons with the Late Effects of Poliomyelitis*, Claire Z. Kalpakjian, PhD, MS, Department of Physical Medicine and Rehabilitation, University of Michigan, Ann Arbor, Michigan and for *Characteristics of poliomyelitis and post-polio patients among Jews and Arabs in Jerusalem*, Zeev Meiner, MD, Department of Physical Medicine and Rehabilitation, Hadassah Medical Center, Jerusalem, Israel.

- Collects \$4,500 for members of Sendai, Japan, support group whose homes were damaged in the tsunami.

- Organizes awareness campaign of WE'RE STILL HERE! focusing on accessibility of places of worship.

- Provides photos for chapter about polio and post-polio in *Understanding Viruses* (Jones & Bartlett Learning) by Teri Shors.



- Provides archival information to Lauro S. Halstead, MD for "A Brief History of Postpolio Syndrome in the United States" published in the *Archives of Physical Medicine and Rehabilitation* (Volume 92, August 2011).

- Provides archival material to Bess Williamson, PhD, candidate for the academic journal, *American Studies*.

- Donates \$5,000 to the Roosevelt Warm Springs Development Fund to benefit the Ann Johnson Heritage Center in recognition of the dedicated work of the staff at Roosevelt Warm Springs Institute on Rehabilitation during PHI's 10th International Conference (2009).

- Contributes funds to five polio survivors in need to purchase special shoes and braces.



International Ventilator Users Network (IVUN)

- IVUN educates on "competitive bidding" for payment of respiratory assists devices (RAD).

Program Highlights 2012

Post-Polio Health International (PHI)

- Selected a team at Texas Woman's University that will evaluate "The Effects of Whole Body Vibration on People with Post –Polio Syndrome" to receive \$25,000 from The Research Fund in 2013.

- Contributes article to PN, February 2012, "30 Years Later...We're Still Here!" written by Gayla Hoffman, editor of *Post-Polio Health*.

- Encourages passage of the United Nation's Disabilities Treaty during the annual October WE'RE STILL HERE! awareness campaign.



- Names existing fund to purchase shoes or bracing for survivors in need, the Joyce and Arthur Siegfried Memorial Fund in collaboration with the Polio Network of New Jersey, that contributed \$7,500 to the fund. Joyce Houser Siegfried was a founding member of the New Jersey group, and Arthur, her husband, was former chair.

- Contributes funds to five polio survivors in need to purchase special shoes and braces.

- Provides additional archival material to Bess Williamson, PhD, candidate for the academic journal, *American Studies*.

International Ventilator Users Network (IVUN)

- Presented poster entitled *Flying While Using a Vent: Is there a problem? Who can solve it and how?* at the 13th International Conference on Home Mechanical Ventilation to be held March 15-17, 2012 in Barcelona, Spain.

- Assumes ownership of vent-users@googlegroups.com on the death of founder ventilator user Sandra Stuban.

- Begins series of educational conferences calls for long-term ventilator users funded by the March of Dimes.



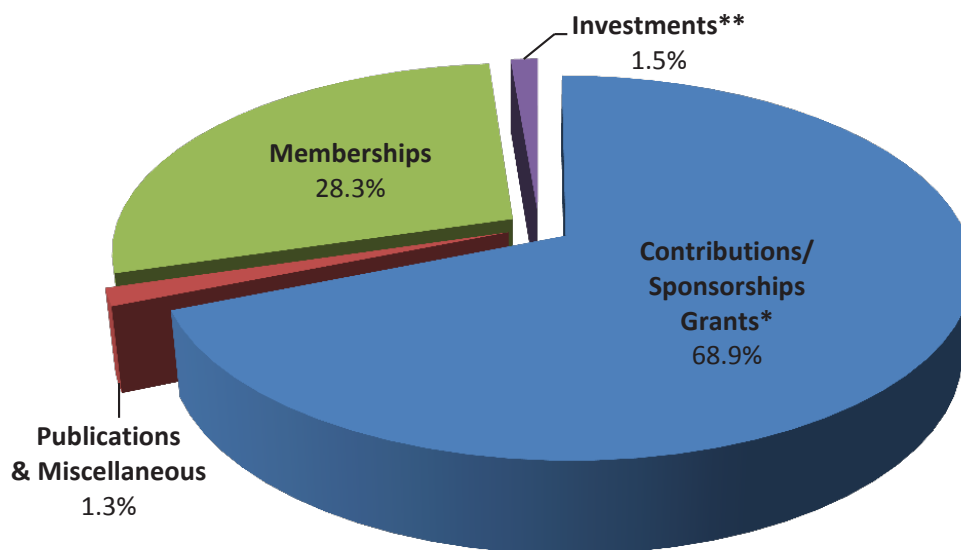
Organizational Information 2011

- Gayla Hoffman edits *Post-Polio Health* and *Ventilator-Assisted Living*.
- Nancy Baldwin Carter writes monthly column for *PHI's Association Member Communiqué*.
- PHI Board adds three new Members: Soonja Cho, Aurora, Colorado; Elizabeth Lounsbury, Markstay, Ontario; and John Thorner, Park Ridge, Illinois.
- PHI Board meets in Chicago in November for strategic planning.
- Joan L. Headley speaks in April at the Polio Network of New Jersey annual meeting and participates in a panel discussion at the June *Festival of International Conferences on Caregiving, Disability, Aging and Technology* in Toronto.
- She also speaks at the August 31 – September 2 *Post-Polio Syndrome – a challenge of today* in Copenhagen, Denmark, and participates as a faculty member at the September Post-Polio Wellness Retreat, Bay Cliff Health Camp, Big Bay, Michigan.
- Brian Tiburzi attends the June *Festival of International Conferences on Caregiving, Disability, Aging and Technology* in Toronto, Canada, and the First European Conference, *Post-Polio Syndrome – a challenge of today*, in Copenhagen, Denmark.

Organizational Information 2012

- Joan L. Headley speaks in June at the Colorado Post-Polio Conference.
- Joan L. Headley joins the board of the Rehabilitation Foundation for Disabled Persons, Inc.
- PHI Board votes to organize its 11th International Conference in St. Louis in 2014.

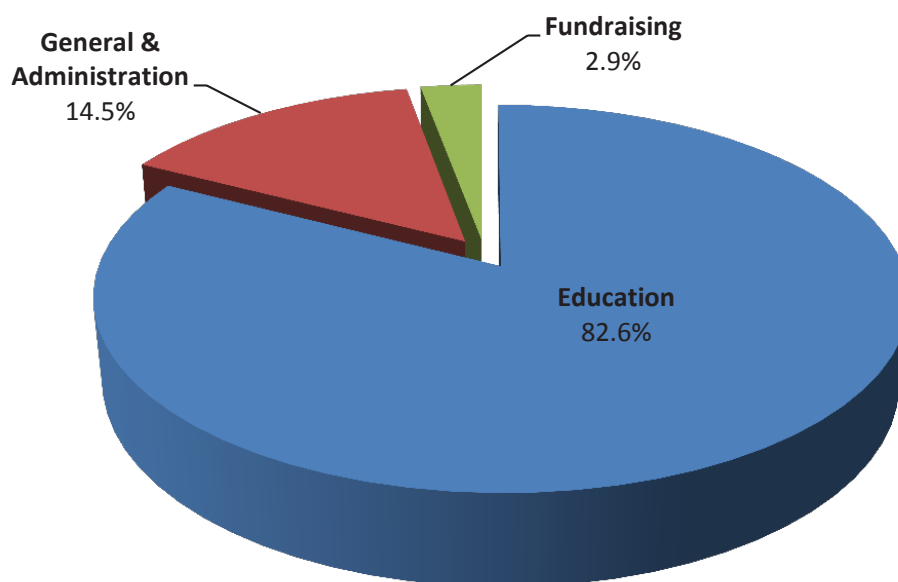
Funding Sources 2011 – \$300,736



*Includes \$119,515 of contributions and \$87,502 of contributions released from restrictions (\$50,000 to Research Awards).

**Does not reflect unrealized loss from investment activities in the amount of \$1,830.

Expense Allocation 2011 – \$308,943



Statement of Assets, Liabilities and Net Assets – Cash Basis

December 31, 2011

ASSETS

Current Assets

| | |
|----------------------------------|----------------|
| Cash and cash equivalents | \$ 77,581 |
| Investments at fair market value | <u>169,523</u> |
| Total Current Assets | <u>247,104</u> |

Fixed Assets

| | |
|---------------------------|----------------|
| Office equipment, at cost | 3,242 |
| Accumulated depreciation | <u>(2,309)</u> |
| Net Fixed Assets | <u>933</u> |

| | |
|-----------------------|--------------------------|
| Long-Term Investments | <u>601,025</u> |
| TOTAL ASSETS | <u><u>\$ 849,062</u></u> |

LIABILITIES

Current Liabilities

| | |
|-----------------------------|-----------------|
| Payroll withholding payable | <u>\$ 2,427</u> |
|-----------------------------|-----------------|

NET ASSETS

| | |
|--------------------------------|--------------------------|
| Unrestricted | 335,968 |
| Temporarily restricted | <u>510,667</u> |
| Total Net Assets | <u>846,635</u> |
| TOTAL LIABILITIES & NET ASSETS | <u><u>\$ 849,062</u></u> |

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

Year Ended December 31, 2011

CHANGES IN UNRESTRICTED NET ASSETS

REVENUES

| | |
|--|----------------|
| Memberships | \$ 85,181 |
| Contributions | 119,515 |
| Publications | 3,407 |
| Miscellaneous | 588 |
| Investment income | 4,543 |
| Unrealized loss on investments | (1,830) |
| Contributions released from restrictions | 87,502 |
| TOTAL UNRESTRICTED REVENUES | 298,906 |

EXPENSES

| | |
|----------------------------|----------------|
| Education | 255,105 |
| General and administrative | 44,783 |
| Fundraising | 9,055 |
| TOTAL EXPENSES | 308,943 |

| | |
|-------------------------------------|----------|
| DECREASE IN UNRESTRICTED NET ASSETS | (10,037) |
|-------------------------------------|----------|

CHANGES IN TEMPORARILY RESTRICTED NET ASSETS

| | |
|---------------------------------------|----------|
| Contributions | 57,326 |
| Investment income | 21,555 |
| Gain on sale of securities | 504 |
| Unrealized loss on investments | (20,929) |
| Net assets released from restrictions | (87,502) |

| | |
|---|----------|
| DECREASE IN TEMPORARILY RESTRICTED NET ASSETS | (29,046) |
|---|----------|

| | |
|------------------------|----------|
| DECREASE IN NET ASSETS | (39,083) |
|------------------------|----------|

| | |
|---------------------------------|---------|
| NET ASSETS AT BEGINNING OF YEAR | 885,718 |
|---------------------------------|---------|

| | |
|---------------------------|-------------------|
| NET ASSETS AT END OF YEAR | <u>\$ 846,635</u> |
|---------------------------|-------------------|

The Research Fund – 2011

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, 2011, The Research Fund assets were \$601, 024.89. The Research Fund is a special fund containing dollars given to support research into post-poliomyelitis and neuromuscular respiratory conditions. The organization distributed \$50,000 in awards in 2011.

Major Contributors – 2011

Contributions, Sponsorships and Grants

\$20,000 and over

Roosevelt Warm Springs Foundation
Estate of Mildred Annice Smith

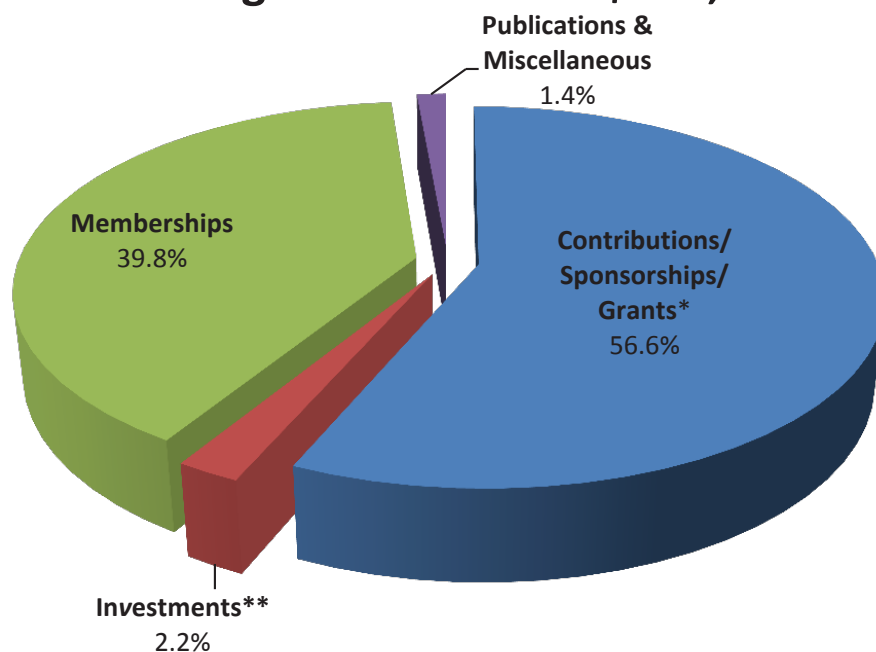
\$10,000 and over

Helen Ford
The Chervenak-Nunnallé Foundation
ResMed, Inc.

\$5,000 and over

Estate of Alan D. Fiala
Betty Ezydorski Trust
Passy-Muir Inc.
Philips Respironics, Inc.
Clark Callahan
The Edouard Foundation
Polio Network of New Jersey

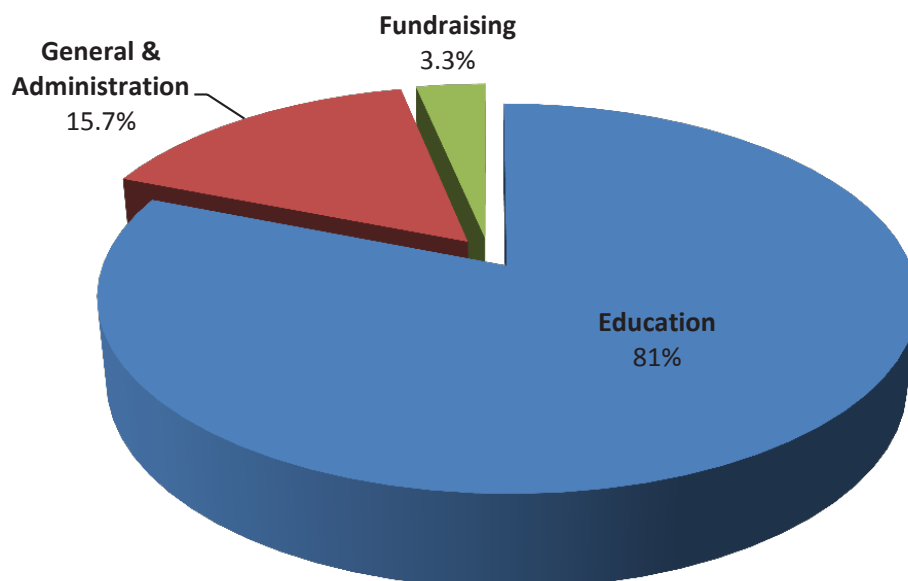
Funding Sources 2012 – \$216,425



*Includes \$86,161 of contributions and \$9,571 of contributions released from restrictions.

**Does not reflect unrealized loss from investment activities in the amount of \$16,089.

Expense Allocation 2012 – \$216,128



Statement of Assets, Liabilities and Net Assets – Cash Basis

December 31, 2012

ASSETS

Current Assets

| | |
|----------------------------------|----------------|
| Cash and cash equivalents | \$ 60,126 |
| Investments at fair market value | <u>200,722</u> |
| Total Current Assets | <u>260,848</u> |

Fixed Assets

| | |
|---------------------------|----------------|
| Office equipment, at cost | 3,243 |
| Accumulated depreciation | <u>(2,683)</u> |
| Net Fixed Assets | <u>560</u> |

| | |
|-----------------------|--------------------------|
| Long-Term Investments | <u>682,136</u> |
| TOTAL ASSETS | <u><u>\$ 943,544</u></u> |

LIABILITIES

Current Liabilities

| | |
|-----------------------------|-----------------|
| Payroll withholding payable | <u>\$ 2,585</u> |
|-----------------------------|-----------------|

NET ASSETS

| | |
|--------------------------------|--------------------------|
| Unrestricted | 352,355 |
| Temporarily restricted | <u>588,604</u> |
| Total Net Assets | <u>940,959</u> |
| TOTAL LIABILITIES & NET ASSETS | <u><u>\$ 943,544</u></u> |

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

Year Ended December 31, 2012

CHANGES IN UNRESTRICTED NET ASSETS

REVENUES

| | |
|--|----------------|
| Memberships | \$ 86,161 |
| Contributions | 112,933 |
| Publications | 2,432 |
| Miscellaneous | 575 |
| Investment income | 4,879 |
| Loss on sale of securities | (126) |
| Unrealized gain on investments | 16,089 |
| Contributions released from restrictions | <u>9,571</u> |
| TOTAL UNRESTRICTED REVENUES | <u>232,514</u> |

EXPENSES

| | |
|----------------------------|----------------|
| Education | 174,868 |
| General and administrative | 33,936 |
| Fundraising | <u>7,324</u> |
| TOTAL EXPENSES | <u>216,128</u> |

| | |
|-------------------------------------|---------------|
| INCREASE IN UNRESTRICTED NET ASSETS | <u>16,386</u> |
|-------------------------------------|---------------|

CHANGES IN TEMPORARILY RESTRICTED NET ASSETS

| | |
|---------------------------------------|----------------|
| Contributions | 17,821 |
| Investment income | 23,345 |
| Loss on sale of securities | (155) |
| Unrealized gain on investments | 46,498 |
| Net assets released from restrictions | <u>(9,571)</u> |

| | |
|---|---------------|
| INCREASE IN TEMPORARILY RESTRICTED NET ASSETS | <u>77,938</u> |
|---|---------------|

| | |
|------------------------|--------|
| INCREASE IN NET ASSETS | 94,324 |
|------------------------|--------|

| | |
|---------------------------------|----------------|
| NET ASSETS AT BEGINNING OF YEAR | <u>846,635</u> |
|---------------------------------|----------------|

| | |
|---------------------------|-------------------------|
| NET ASSETS AT END OF YEAR | <u><u>\$940,959</u></u> |
|---------------------------|-------------------------|

The Research Fund – 2012

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, 2012, The Research Fund assets were \$682,135.93. The Research Fund is a special fund containing dollars given to support research into post-poliomyelitis and neuromuscular respiratory conditions.

Major Contributors – 2012

Contributions, Sponsorships and Grants

\$10,000 and over

Helen Ford
The Chervenak-Nunnallé Foundation
The March of Dimes
ResMed, Inc.

\$5,000 and over

Polio Network of New Jersey
Bonnie & Eric Helpenstell
Robinett Lee
Philips Respironics, Inc.

IVUN thanks its Members
for their support. If you
are not yet a Member,

Join IVUN!

Support International
Ventilator Users
Network's educational,
research, advocacy and
networking mission.
Rates Effective July 2007

IVUN membership levels make it easy to start taking advantage of timely and important news and activities relating to home mechanical ventilation. Select your level below and return it with your check or credit card information. Memberships are 100 percent tax-deductible.

☐ **\$30 Subscriber**

Quarterly newsletter of your choice:

☐ Ventilator-Assisted Living OR ☐ Post-Polio Health

☐ **\$55 Subscriber Plus**

Both quarterly newsletters:

Ventilator-Assisted Living AND Post-Polio Health

☐ **\$100 Contributor**

ALL the benefits of Subscriber Plus AND
Resource Directory for Ventilator-Assisted Living
and Post-Polio Directory;
discounts on special publications
and IVUN's sponsored meetings

☐ **\$150 Sustainer**

ALL the benefits of Contributor AND

One additional complimentary gift membership to:

☐ Person of your choice (include name and address) or

☐ Person who has expressed financial need to IVUN

Membership at the following levels includes ALL benefits PLUS special recognition in IVUN publications:

☐ **\$250 Bronze Level Sustainer**

☐ **\$500 Silver Level Sustainer**

☐ **\$1,000 Gold Level Sustainer**

☐ **\$5,000 Platinum Level Sustainer**

☐ **\$10,000 Gini Laurie Advocate**

Name _____

Affiliation _____

Address _____

City _____ State/Province _____

Country _____ Zip/Postal Code _____

email _____

Phone (include area/country code) _____

Fax (include area/country code) _____

I am enclosing a check for \$_____ made payable to
"Post-Polio Health International." (USD only)

Please charge \$_____ to this credit card:

☐ VISA ☐ MasterCard ☐ Discover

Card No. _____

Exp. Date _____

Name on Card _____

Signature _____

Send this form to: Post-Polio Health International
4207 Lindell Blvd, #110
Saint Louis, MO 63108-2930 USA
314-534-0475 314-534-5070 fax

PHI Thanks its Members
for their support. If you
are not yet a Member,

Join PHI!

Support Post-Polio Health
International's educational,
research, advocacy and
networking mission.
Rates Effective July 2007

PHI membership levels make it easy to start taking advantage of timely and important news and activities relating to the late effects of polio. Select your level below and return it with your check or credit card information. Memberships are 100 percent tax-deductible.

☐ **\$30 Subscriber**

Quarterly newsletter of your choice:

☐ Post-Polio Health OR ☐ Ventilator-Assisted Living

☐ **\$55 Subscriber Plus**

Both quarterly newsletters:

Post-Polio Health AND Ventilator-Assisted Living

☐ **\$100 Contributor**

ALL the benefits of Subscriber Plus AND
Post-Polio Directory AND
Resource Directory for Ventilator-Assisted Living;
discounts on special publications
and meetings sponsored by PHI

☐ **\$150 Sustainer**

ALL the benefits of Contributor AND

One additional complimentary gift membership to:

☐ Person of your choice (include name and address) or

☐ Person who has expressed financial need to PHI

Membership at the following levels includes ALL benefits PLUS special recognition in PHI publications:

☐ **\$250 Bronze Level Sustainer**

☐ **\$500 Silver Level Sustainer**

☐ **\$1,000 Gold Level Sustainer**

☐ **\$5,000 Platinum Level Sustainer**

☐ **\$10,000 Gini Laurie Advocate**

Name _____

Affiliation _____

Address _____

City _____ State/Province _____

Country _____ Zip/Postal Code _____

email _____

Phone (include area/country code) _____

Fax (include area/country code) _____

I am enclosing a check for \$_____ made payable to
"Post-Polio Health International." (USD only)

Please charge \$_____ to this credit card:

☐ VISA ☐ MasterCard ☐ Discover

Card No. _____

Exp. Date _____

Name on Card _____

Signature _____

Send this form to: Post-Polio Health International
4207 Lindell Blvd, #110
Saint Louis, MO 63108-2930 USA
314-534-0475 314-534-5070 fax



POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

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