Report for 2011-2012

What and Who

Program Highlights

Organizational Information

Financial Information
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  

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.
Post-Polio Health International (PHI)

- Launches Polio Place (polioplace.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).
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.
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.

---

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.
Financial Information 2011

Funding Sources 2011 – $300,736

- Contributions/Sponsorships Grants*: 68.9%
- Memberships: 28.3%
- Publications & Miscellaneous: 1.3%
- Investments**: 1.5%

*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

- Education: 82.6%
- General & Administration: 14.5%
- Fundraising: 2.9%
## Post-Polio Health International, Inc.

### Statement of Assets, Liabilities and Net Assets – Cash Basis

December 31, 2011

### ASSETS

**Current Assets**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>$ 77,581</td>
</tr>
<tr>
<td>Investments at fair market value</td>
<td>169,523</td>
</tr>
<tr>
<td><strong>Total Current Assets</strong></td>
<td><strong>247,104</strong></td>
</tr>
</tbody>
</table>

**Fixed Assets**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Office equipment, at cost</td>
<td>3,242</td>
</tr>
<tr>
<td>Accumulated depreciation</td>
<td>(2,309)</td>
</tr>
<tr>
<td><strong>Net Fixed Assets</strong></td>
<td><strong>933</strong></td>
</tr>
</tbody>
</table>

**Long-Term Investments**

<table>
<thead>
<tr>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>601,025</td>
</tr>
</tbody>
</table>

**TOTAL ASSETS**

<table>
<thead>
<tr>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>$ 849,062</td>
</tr>
</tbody>
</table>

### LIABILITIES

**Current Liabilities**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Payroll withholding payable</td>
<td>$ 2,427</td>
</tr>
</tbody>
</table>

### NET ASSETS

**Unrestricted**

<table>
<thead>
<tr>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>335,968</td>
</tr>
</tbody>
</table>

**Temporarily restricted**

<table>
<thead>
<tr>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>510,667</td>
</tr>
</tbody>
</table>

**Total Net Assets**

<table>
<thead>
<tr>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>846,635</td>
</tr>
</tbody>
</table>

**TOTAL LIABILITIES & NET ASSETS**

<table>
<thead>
<tr>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>$ 849,062</td>
</tr>
</tbody>
</table>
Post-Polio Health International, Inc.

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

Year Ended December 31, 2011

CHANGES IN UNRESTRICTED NET ASSETS

REVENUES

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memberships</td>
<td>$ 85,181</td>
</tr>
<tr>
<td>Contributions</td>
<td>119,515</td>
</tr>
<tr>
<td>Publications</td>
<td>3,407</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>588</td>
</tr>
<tr>
<td>Investment income</td>
<td>4,543</td>
</tr>
<tr>
<td>Unrealized loss on investments</td>
<td>(1,830)</td>
</tr>
<tr>
<td>Contributions released from restrictions</td>
<td>87,502</td>
</tr>
</tbody>
</table>

TOTAL UNRESTRICTED REVENUES  298,906

EXPENSES

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>255,105</td>
</tr>
<tr>
<td>General and administrative</td>
<td>44,783</td>
</tr>
<tr>
<td>Fundraising</td>
<td>9,055</td>
</tr>
</tbody>
</table>

TOTAL EXPENSES  308,943

DECREASE IN UNRESTRICTED NET ASSETS  (10,037)

CHANGES IN TEMPORARILY RESTRICTED NET ASSETS

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td>57,326</td>
</tr>
<tr>
<td>Investment income</td>
<td>21,555</td>
</tr>
<tr>
<td>Gain on sale of securities</td>
<td>504</td>
</tr>
<tr>
<td>Unrealized loss on investments</td>
<td>(20,929)</td>
</tr>
<tr>
<td>Net assets released from restrictions</td>
<td>(87,502)</td>
</tr>
</tbody>
</table>

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  $ 846,635
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
Financial Information 2012

Funding Sources 2012 – $216,425

- Contributions/Sponsorships/Grants*: 56.6%
- Memberships: 39.8%
- Publications & Miscellaneous: 1.4%
- Investments**: 2.2%

*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

- Education: 81%
- General & Administration: 15.7%
- Fundraising: 3.3%
Post-Polio Health International, Inc.

Statement of Assets, Liabilities and Net Assets – Cash Basis
December 31, 2012

**ASSETS**

Current Assets

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>$60,126</td>
</tr>
<tr>
<td>Investments at fair market value</td>
<td>200,722</td>
</tr>
<tr>
<td>Total Current Assets</td>
<td>260,848</td>
</tr>
</tbody>
</table>

Fixed Assets

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Office equipment, at cost</td>
<td>3,243</td>
</tr>
<tr>
<td>Accumulated depreciation</td>
<td>(2,683)</td>
</tr>
<tr>
<td>Net Fixed Assets</td>
<td>560</td>
</tr>
</tbody>
</table>

Long-Term Investments                     682,136

TOTAL ASSETS  $ 943,544

**LIABILITIES**

Current Liabilities

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Payroll withholding payable</td>
<td>$2,585</td>
</tr>
</tbody>
</table>

**NET ASSETS**

Unrestricted  352,355

Temporarily restricted  588,604

Total Net Assets  940,959

TOTAL LIABILITIES & NET ASSETS  $ 943,544
Post-Polio Health International, Inc.

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

Year Ended December 31, 2012

CHANGES IN UNRESTRICTED NET ASSETS

<table>
<thead>
<tr>
<th>Category</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memberships</td>
<td>$86,161</td>
</tr>
<tr>
<td>Contributions</td>
<td>112,933</td>
</tr>
<tr>
<td>Publications</td>
<td>2,432</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>575</td>
</tr>
<tr>
<td>Investment income</td>
<td>4,879</td>
</tr>
<tr>
<td>Loss on sale of securities</td>
<td>(126)</td>
</tr>
<tr>
<td>Unrealized gain on investments</td>
<td>16,089</td>
</tr>
<tr>
<td>Contributions released from restrictions</td>
<td>9,571</td>
</tr>
<tr>
<td><strong>TOTAL UNRESTRICTED REVENUES</strong></td>
<td><strong>232,514</strong></td>
</tr>
</tbody>
</table>

EXPENSES

<table>
<thead>
<tr>
<th>Category</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>174,868</td>
</tr>
<tr>
<td>General and administrative</td>
<td>33,936</td>
</tr>
<tr>
<td>Fundraising</td>
<td>7,324</td>
</tr>
<tr>
<td><strong>TOTAL EXPENSES</strong></td>
<td><strong>216,128</strong></td>
</tr>
</tbody>
</table>

INCREASE IN UNRESTRICTED NET ASSETS

<table>
<thead>
<tr>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>16,386</td>
</tr>
</tbody>
</table>

CHANGES IN TEMPORARILY RESTRICTED NET ASSETS

<table>
<thead>
<tr>
<th>Category</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td>17,821</td>
</tr>
<tr>
<td>Investment income</td>
<td>23,345</td>
</tr>
<tr>
<td>Loss on sale of securities</td>
<td>(155)</td>
</tr>
<tr>
<td>Unrealized gain on investments</td>
<td>46,498</td>
</tr>
<tr>
<td>Net assets released from restrictions</td>
<td>(9,571)</td>
</tr>
<tr>
<td><strong>INCREASE IN TEMPORARILY RESTRICTED NET ASSETS</strong></td>
<td><strong>77,938</strong></td>
</tr>
</tbody>
</table>

INCREASE IN NET ASSETS

<table>
<thead>
<tr>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>94,324</td>
</tr>
</tbody>
</table>

NET ASSETS AT BEGINNING OF YEAR

<table>
<thead>
<tr>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>846,635</td>
</tr>
</tbody>
</table>

NET ASSETS AT END OF YEAR

<table>
<thead>
<tr>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>$940,959</td>
</tr>
</tbody>
</table>
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 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

ANN1112