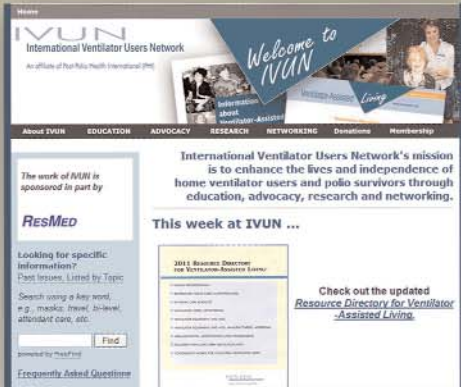


Report for 2009-2010



post-polio.org

EDUCATION



ventusers.org

ADVOCACY



polioplace.org

NETWORKING

RESEARCH



Bill Stothers

MESSAGE FROM THE CHAIR OF THE BOARD

Following the exciting and successful Conference at Roosevelt Warm Springs Institute for Rehabilitation in the Spring of 2009, Post-Polio Health International focused with renewed vigor on its goals of serving our core constituencies with solid information and resources for dealing with the late effects of polio, and maintaining independence as we survivors advance in age.

At the same time PHI increased its efforts to reach out to polio survivors in other parts of the world where our information and experience may be helpful. The explosion of new forms of technology and information dissemination offers great hope for sharing our resources.

PHI continues to fund and support research, which “seek(s) scientific information leading

to eventual amelioration of the consequences of poliomyelitis and/or neuromuscular respiratory diseases.” The PHI Board of Directors has also re-affirmed that all income from funds dedicated to the Research Fund will be used for research projects. One project was funded in 2009, and two projects were funded for 2011.

The opportunities – and challenges – are great. The Board of Directors of PHI has embraced these prospects with enthusiasm. Having assumed the chair of the board after our 10th International Conference (2009), I have been awed and thankful for the energy and dedication of the members of the Board, who volunteer great amounts of time and creativity to advancing PHI’s mission. With their continued efforts, as well as the exceptional service of our Executive Director Joan L. Headley and her assistant Brian Tiburzi, I am confident that PHI will make significant progress toward our goals.

–William G. Stothers

PHI Board of Directors (2009-2010)

William (Bill) G. Stothers
PRESIDENT/CHAIRPERSON
The Center for an Accessible Society
San Diego, California

Lawrence (Larry) C. Becker, PhD
VICE PRESIDENT
Professor of Philosophy Emeritus,
College of William and Mary
Fellow of Hollins University
Roanoke, Virginia

Marny K. Eulberg, MD
SECRETARY
St. Anthony's Family Medical Center
Wheat Ridge, Colorado

Saul J. Morse
TREASURER
Legal Counsel, Brown Hay
& Stephens, LLP
Springfield, Illinois

Richard (Rich) W. Hokamp
ASSISTANT TREASURER
Attorney-At-Law
Saint Louis, Missouri

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

Selma Harrison Calmes, MD
Anesthesiology (retired)
Culver City, California

John R. Fisk, MD
Orthopedic Surgery, Southern Illinois
University School of Medicine (Retired)
St. Helena Island, SC

Judith E. Heumann, MPH
Special Advisor on International
Disability Rights
U.S. Department of State
Washington, DC

Frederick (Fred) M. Maynard, MD
Physical Medicine & Rehabilitation
(retired)
Marquette, Michigan

Allison (Sunny) Roller, MA
University of Michigan Health
System (retired)
Ann Arbor, Michigan

Sue Suter
Urbana, Illinois

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

Daniel J. Wilson, PhD
Professor of History
Muhlenberg College
Allentown, Pennsylvania

MESSAGE FROM THE EXECUTIVE DIRECTOR



Joan L. Headley

It was a busy year – 2009 – with some firsts for a 51 year old non-profit.

For the first time since 1981, PHI held its international conference (10th) outside of St. Louis, Missouri. The site, Roosevelt Warm Springs Institute for Rehabilitation (RWSIR), proved to be a memorable location because of its history and the “spirit of Warm Springs” exemplified by its welcoming staff.

Another first for PHI, with the experience of board members Frederick Maynard, MD and Sunny Roller, was the pre-conference Post-Polio Wellness Retreat at RWSIR’s Camp Dream.

We continued the activities (see pages 4-8) that you all expect from us as PHI and IVUN and for some that we served in 2009-10, it was a first. There are still survivors who never heard of post-polio problems or never experienced them until now. Finding PHI is such a relief to them and many of you can relate to that feeling. In fact, your Memberships make our work possible.

A first in 2010 was the hiring of Gayla Hoffman as editor of *Post-Polio Health* and *Ventilator-Assisted Living*. The transition from me to her was seamless, because of her talent and professionalism.

The freed-up time allowed me to focus on two very important projects during 2010, with the assistance of Brian Tiburzi, PHI’s other fulltime employee.

For the first time, PHI created information not written specifically for survivors, but for their families and friends. With funding from The Max and Phyllis Reynolds Foundation and The Chervenak-Nunnallé Foundation, post-polio experts worked on “Post-Polio Health Care Considerations for Families and Friends.”

The second project that occupied much of 2010 was the development of a website that will serve for years to come as the “portal” for all things polio and post-polio.

PHI continues to meet the information needs of polio people today and at the same time we must focus on the long-term future.

We are committed to preserving our history, medical information and our “survival” information for those who are younger, those in less developed counties who will be more isolated than we, and for posterity.

With funds from the Roosevelt Warm Springs Foundation, Polio Place (polioplac.org), a new easy to update website with flexible structure and varied content was born. There is much to add from your personal artifacts and hints for living with polio to educational materials for health professionals to translation of the site into other languages. The possibilities are endless.

With all the talk of history and the future, I want to assure you that we focus first on you and today.

–Joan L. Headley

HIGHLIGHTS OF MISSION ACTIVITIES IN 2009-2010

EDUCATION



10th International Conference: Living Well with Polio in the 21st Century

- April 23-25, 2009 at Roosevelt Warm Springs Institute for Rehabilitation (RWSIR) in Warm Springs, Georgia.
- Attended by 436 survivors, family members and health professionals from 11 countries (46 individuals) and 39 states and the District of Columbia.



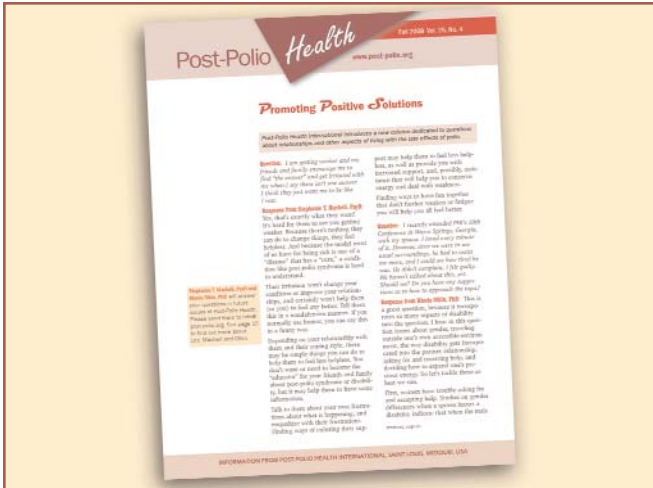
- CDs of the daily program booklets that included abstracts and handouts (Thursday–60 pages; Friday–98 pages; Saturday–70 pages) were distributed in PDF format on a single CD. Photographs can be found in a Facebook album of Post-Polio Health International (PHI).

Post-Polio Wellness Retreat

- April 19-25, 2009 at RWSIR's Camp Dream.
- Attended by 60 participants including spouses.



- Videos of the Retreat are posted on www.post-polio.org:
 - [Post-Polio Wellness Retreat](#)
 - [Adaptive Cardio at the Post-Polio Wellness Retreat](#)
 - [Seated Exercises at the Post-Polio Wellness Retreat](#)
 - [Kayaking at the Post-Polio Wellness Retreat](#)
 - [Bowling at the Post-Polio Wellness Retreat](#)
 - [Cycling at the Post-Polio Wellness Retreat](#)



Promoting Positive Solutions

- A new column in *Post-Polio Health*.
- Answers questions about living with the late effects of polio.
- Written by experienced mental health professionals Stephanie Machell, PsyD and Rhoda Olkin, PhD.

Monthly Membership Memos added to Newsletter Information

- *PHI Membership Memos* are sent via email in months *Post-Polio Health*, our 12-page quarterly newsletter is not sent.
- *IVUN Membership Memos* are sent via email in months *Ventilator-Assisted Living*, our 8-page bi-monthly newsletter is not sent.

Health Professional Education

- IVUN Consumer Advisory Board Member Linda Bieniek contributed a chapter in *Non-Invasive Ventilation and Weaning: Principles and Practice* edited by Mark Elliott, Stefano Nava and Bernd Schonhofer.

Executive Director Joan L. Headley was interviewed and quoted in the chapter entitled "Psychological issues for the mechanically ventilated patient." The book was published by Hodder Arnold Publication: London, UK, 2010 and is available at VitalSource Bookshelf.

- PHI, in collaboration with the John P. Murtha Neuroscience and Pain Institute in Johnstown, Pennsylvania, coordinates monthly educational conference calls for health professionals worldwide.

Experts presented lectures about bracing for post-polio, sleep-disordered breathing, aging with the late effects of polio, current post-polio research, and an explanation of IVIg in post-polio. The group also discussed the cause and consequences of falls and decided to develop a questionnaire to learn more.

- PHI Board Member Lawrence C. Becker, PhD, was featured in a Sara Colt production, “The Polio Crusade,” produced for the PBS series, *The American Experience*. The program was based on “Polio: An American Story” by David Oshinsky. Oshinsky (pictured below) was a featured speaker at the 10th International Conference (2009).



- WE'RE STILL HERE! is an annual outreach campaign of Post-Polio Health International, whose aim is to bring attention to the needs of polio survivors, while encouraging survivors and groups to help make a difference in the world.



In 2009, PHI challenged survivors to remedy one accessibility barrier in their community.

- In 2010, PHI collaborated with Polio Survivors and Associates (PSA) and Rotary International (RI) to encourage survivors to visit a Rotary Club luncheon meeting to discuss polio and post-polio. PHI, PSA and RI created materials to use at the meetings.
 - A Rotarian Primer on Polio Eradication and Polio Survivors Support
 - Questions and Answers for a Visit to Rotary
- Flying with a Ventilator became more difficult post 9/11. IVUN advocated with the manufacturers of portable ventilators, the Federal Aviation Administration and the Department of Justice. IVUN created several pertinent resources to assist vent users in flying with a ventilator and flying while using a ventilator.

www.post-polio.org

- Post-Polio Health International maintains www.post-polio.org, a website that allows free access to all.



In 2009 ...

Average unique visits per month = 10,318
 Average unique visits per day = 458
 Most visited pages: *Post-Polio Directory*,
Late Effects of Polio brochure,
Post-Polio Health newsletter topic list

In 2010 ...

Average unique visits per month = 11,453
 Average unique visits per day = 516
 Most visited page: *Post-Polio Directory*
 Average total of pages viewed per month:
 38,688

- Post-Polio Health International maintains the [*Post-Polio Directory*](#). With its listings of three major sections (post-polio clinics, health professionals and support groups), the *Directory* is downloaded on average 1,000 times per month.
- PHI networks the world's post-polio support groups/organizations by sending a monthly *PHI Association Membership Communiqué*.

www.ventusers.org

- International Ventilator Users Network maintains www.ventusers.org, a website that allows free access to all.



In 2009 ...

Average unique visits per month = 3,841
 Average unique visits per day = 171
 Most visited pages: *Home Ventilator Guide*,
Resource Directory for Ventilator-Assisted Living,
Ventilator-Assisted Living newsletter topic list

In 2010 ...

Average unique visits per month = 4,846
 Average unique visits per day = 206
 Most visited page: *Home Ventilator Guide*
 Average total of pages viewed per month:
 13,301

- International Ventilator Users Network maintains the [*Resource Directory for Ventilator-Assisted Living*](#) and the [*Home Ventilator Guide*](#). Both contain comprehensive information that networks ventilator users, families and non-profits, health professionals and companies that provide equipment and service to users of home mechanical ventilation. The guide is downloaded on average 1250 times per month; the *Directory*, 525.

www.post-polio.org

- Post-Polio Health International's Executive Director spoke at the Toronto-Peel Post-Polio Support Group's 25th Anniversary celebration in May 2010. She also spoke at the August 2010 "Learning and Sharing Polio's Legacy," in Hutchinson, Kansas. The day-long conference was coordinated by Central Kansas Polio Survivors.
- PHI distributed \$2,500 to polio survivors in need of funds to pay for bracing and/or custom-made shoes. Survivors were from Alabama, California, Georgia, Kansas, Mississippi, Minnesota and Oklahoma.

www.ventusers.org

- International Ventilator Users Network attended Breathing and Sleep: Solutions for People with Neuromuscular Disorders, November 2009, and *Breathing & Sleep*, November, 2010 at the Salk Institute for Biological Studies La Jolla, California, and the 2009 and 2010 annual meetings of the American College of Chest Physicians (CHEST).

RESEARCH

- In early 2009, PHI received the final report FINAL REPORT: Persisting Noninfectious Genome Fragments of Poliovirus in PPS Patients from a team from University of Insubria, Varese, Italy, led by Antonio Toniolo, MD, PhD, Professor of Medical Microbiology and Virology.
- In September of 2009, PHI issued a "Call for Proposals" for The Research Fund for Post-Poliomyelitis and Neuro-muscular Respiratory Research. By the deadline in 2010, six proposals were received from the US and three other countries.

One withdrew and three were asked to submit materials for Phase 2. The Review Panel composed of health professionals, research experts and people with disabilities recommended to the organization's

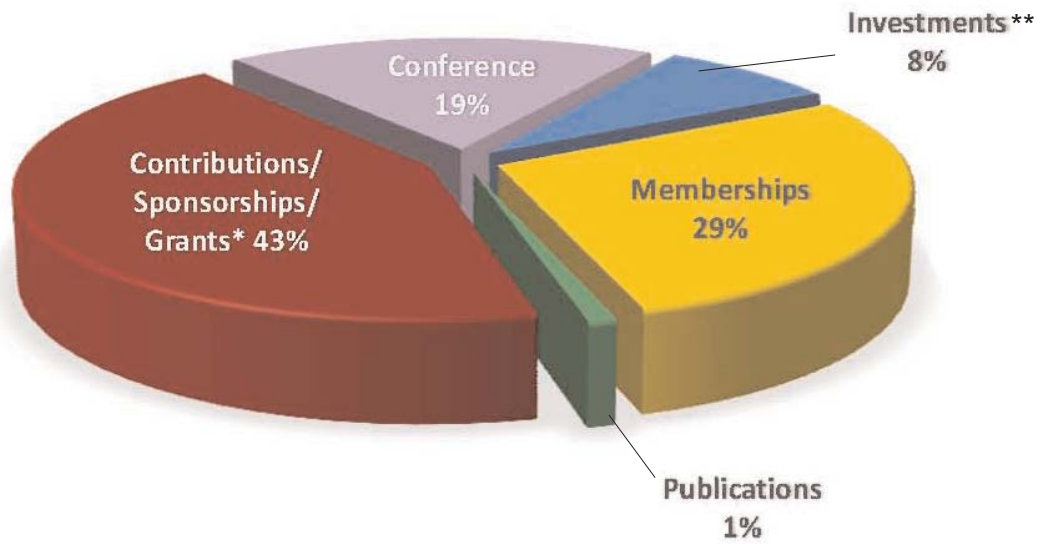
Board of Directors that two \$25,000 grants be awarded for work done in 2011. The teams selected were from the University of Michigan (USA) and Hadassah University Hospital (Israel).



Drs. Meiner and Schwartz (Israel) and Joan L. Headley (PHI).

Financial Status – 2009

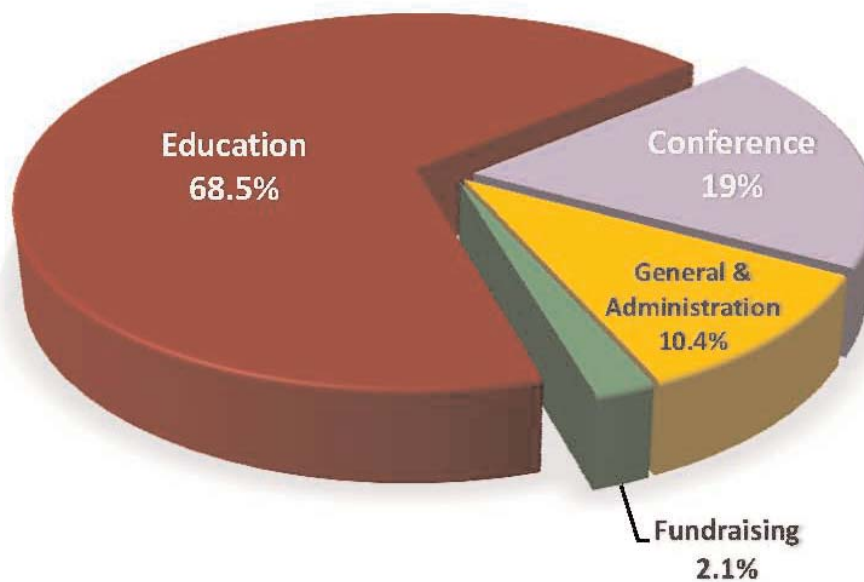
Funding Sources 2009 – \$289,950



*Includes \$94,216 of contributions and \$31,080 of contributions released from restrictions.

**Does not reflect unrealized gains from investment activities in the amount of \$107,022.

Expense Allocation 2009 – \$272,453



Statement of Assets, Liabilities, and Net Assets – Cash Basis
December 31, 2009

ASSETS

Current Assets

Cash and cash equivalents	\$ 119,731
Investments at fair market value	<u>160,772</u>
Total Current Assets	<u>280,503</u>

Fixed Assets

Office equipment, at cost	12,299
Accumulated depreciation	<u>(11,807)</u>
Net Fixed Assets	<u>492</u>

Long-Term Investments	<u>563,132</u>
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TOTAL ASSETS	<u>\$ 844,127</u>
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LIABILITIES

Current Liabilities

Payroll withholding payable	<u>\$ 2,079</u>
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NET ASSETS

Unrestricted	337,121
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Temporarily restricted	<u>504,927</u>
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Total Net Assets	<u>842,048</u>
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TOTAL LIABILITIES & NET ASSETS	<u>\$ 844,127</u>
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Statement of Revenues, Expenses, and Other Changes in Net Assets – Cash Basis
Year Ended December 31, 2009

CHANGES IN UNRESTRICTED NET ASSETS

REVENUES

Memberships	\$ 82,721
Contributions	94,216
Publications	2,916
Conference	56,004
Investment income	23,013
Gain on sale of securities	69
Unrealized gain on investments	107,022
Contributions released from restrictions	<u>31,080</u>
TOTAL UNRESTRICTED REVENUES	<u>\$ 397,041</u>

EXPENSES

Conference	51,560
Education	186,732
General and administrative	28,372
Fundraising	<u>5,829</u>
TOTAL EXPENSES	<u>272,493</u>

INCREASE IN UNRESTRICTED NET ASSETS 124,548

CHANGES IN TEMPORARILY RESTRICTED NET ASSETS

Contributions	56,185
Net assets released from restrictions	<u>(31,079)</u>

INCREASE IN TEMPORARILY RESTRICTED NET ASSETS 25,106

INCREASE IN NET ASSETS 149,654

NET ASSETS AT BEGINNING OF YEAR 692,394

NET ASSETS AT END OF YEAR \$ 842,048

The Research Fund – 2009

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*. In actuality, PHI funds its research grants only with the interest and dividends generated by the Research Fund's investments.

On December 31, 2009, The Research Fund assets were \$563,131.74. The Research Fund is a special fund containing dollars given to support research into post-poliomyelitis and neuromuscular respiratory conditions. Additionally, PHI had \$82,847.32 earmarked for an uncompleted project. These restricted funds will be spent only as the project progresses.

Major Contributors – 2009

Contributions, Sponsorships and Grants

\$10,000 and over

Chervenak-Nunnallé Foundation
Helen Ford
ResMed, Ltd
Roosevelt Warm Springs Foundation

\$5,000 and over

Clark Callahan
Dale Medical Products
Phyllis and Max Reynolds Foundation
Philips Respironics, Inc.

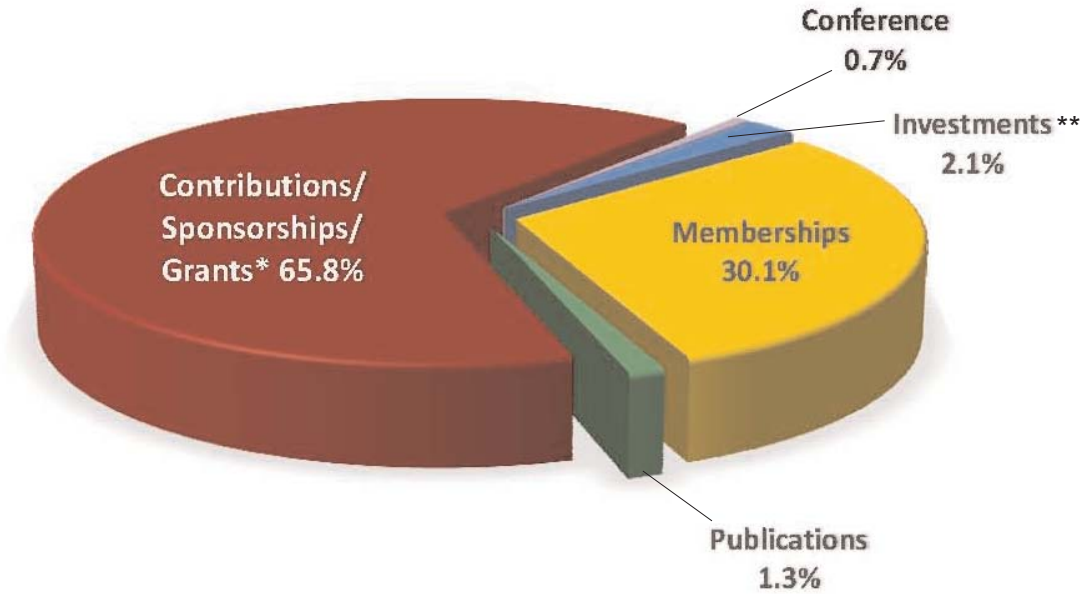
Volunteers

Volunteers are vital to Post-Polio Health International and International Ventilator Users Network. The staff would like to give special recognition to the following select few out of the many volunteers throughout the Network who make the organization viable and a "living" entity.

- The Board of Directors volunteer their time and talent to oversee the organization and to monitor its mission.
- Drs. Frederick M. Maynard, Stephanie T. Machell and Rhoda Olkin generously contribute their words of wisdom each quarter in the *Post-Polio Health* columns "Ask Dr. Maynard" and "Promoting Positive Solutions."
- Judith R. Fischer continues as IVUN Information Specialist, assuring that the *Resource Directory for Ventilator-Assisted Living* and the *Home Ventilator Guide* is accurate and up-to-date.
- Nancy Baldwin Carter writes thought-provoking articles for *PHI's Association Member Communiqué*.
- Karen Hagrup faithfully assists us in the office with our communications with you as a "certified" envelope stuffer.

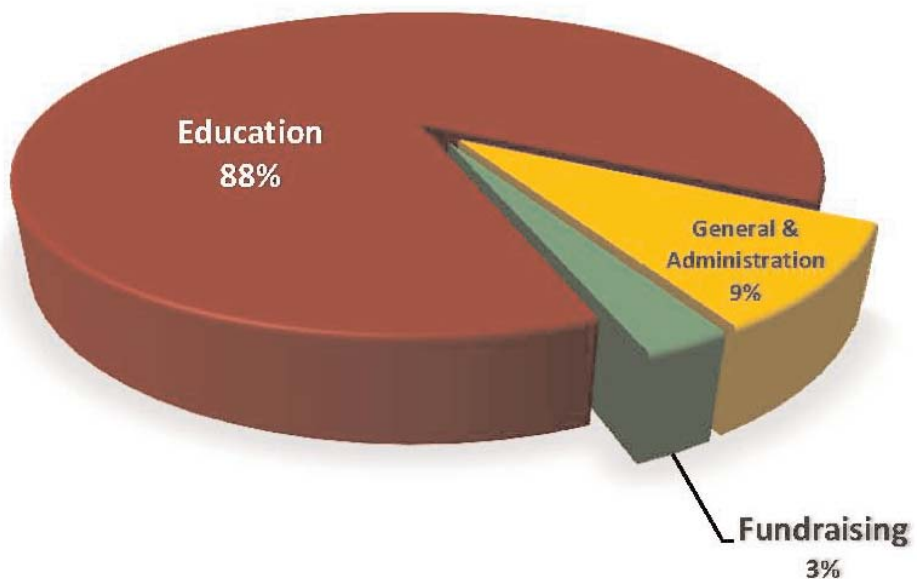
Financial Status – 2010

Funding Sources 2010 – \$231,550



*Includes \$104,696 of contributions and \$47,748 of contributions released from restrictions.
**Does not reflect unrealized gains from investment activities in the amount of \$10,402.

Expense Allocation 2010 – \$232,738



Statement of Assets, Liabilities, and Net Assets – Cash Basis
December 31, 2010

ASSETS

Current Assets

Cash and cash equivalents	\$ 106,408
Investments at fair market value	<u>151,367</u>
Total Current Assets	<u>257,775</u>

Fixed Assets

Office equipment, at cost	3,242
Accumulated depreciation	<u>(1,687)</u>
Net Fixed Assets	<u>1,555</u>

Long-Term Investments	<u>628,935</u>
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TOTAL ASSETS	<u>\$ 888,265</u>
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LIABILITIES

Current Liabilities

Payroll withholding payable	<u>\$ 2,547</u>
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NET ASSETS

Unrestricted	346,005
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Temporarily restricted	<u>539,713</u>
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Total Net Assets	<u>885,718</u>
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TOTAL LIABILITIES & NET ASSETS	<u>\$ 888,265</u>
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Statement of Revenues, Expenses, and Other Changes in Net Assets – Cash Basis
Year Ended December 31, 2010

CHANGES IN UNRESTRICTED NET ASSETS

REVENUES

Memberships	\$ 69,562
Contributions	104,696
Publications	2,979
Conference	1,808
Investment income	4,757
Loss on sale of securities	(434)
Unrealized gain on investments	10,402
Contributions released from restrictions	<u>47,748</u>
TOTAL UNRESTRICTED REVENUES	<u>\$ 241,518</u>

EXPENSES

Education	205,137
General and administrative	21,475
Fundraising	<u>6,126</u>
TOTAL EXPENSES	<u>232,738</u>

INCREASE IN UNRESTRICTED NET ASSETS 8,780

CHANGES IN TEMPORARILY RESTRICTED NET ASSETS

Contributions	27,661
Investment Income	19,099
Loss on sale of securities	(78)
Unrealized gain on investments	35,956
Net assets released from restrictions	<u>(47,748)</u>

INCREASE IN TEMPORARILY RESTRICTED NET ASSETS 34,890

INCREASE IN NET ASSETS 43,670

NET ASSETS AT BEGINNING OF YEAR 842,048

NET ASSETS AT END OF YEAR \$ 885,718

The Research Fund – 2010

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*. In actuality, PHI funds its research grants only with the interest and dividends generated by the Research Fund's investments.

On December 31, 2010, The Research Fund assets were \$628,934.98. The Research Fund is a special fund containing dollars given to support research into post-poliomyelitis and neuromuscular respiratory conditions. Additionally, PHI had \$49,148.23 earmarked for an uncompleted project. These restricted funds will be spent only as the project progresses.

Major Contributors – 2010

Contributions, Sponsorships and Grants

\$10,000 and over

Chervenak-Nunnallé Foundation
Helen Ford
ResMed, Ltd
Roosevelt Warm Springs Foundation
Robert & Kathleen Tabor Charitable
Gift Fund

\$5,000 and over

Clark Callahan
Covidien, Inc.
Dale Medical Products
Edouard Foundation
Passy-Muir
Philips Respironics, Inc.

Staff

The day-to-day work of Post-Polio Health International (PHI) is completed by the following full-time staff in the St. Louis, Missouri, office.



Joan L. Headley, Executive Director



Brian M. Tiburzi, Assistant to Executive Director

Editorial, accounting and design services are provide monthly by the following contracted individuals.

Gayla Hoffman, St. Louis, Missouri
Lucky L. Leong, CPA, St. Louis, Missouri
Sheryl Rudy, SherylzArt, St. Louis, Missouri

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!

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- \$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

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- \$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) _____

ANN0708 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



POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

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SAINT LOUIS, MO 63108-2930 USA

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