
Report for 2007-2008

www.post-polio.org ... www.ventusers.org

What We Do

Our mission is to enhance the lives and independence of polio survivors and home ventilator users through networking, education, advocacy and research.

Our role is as a timely, accessible, enduring and authoritative source for the information necessary to enhance the lives and independence of polio survivors and home ventilator users that is distributed to individuals, support groups, medical professionals, government agencies, journalists and authors.

Our modus operandi is to publish newsletters, handbooks, position papers and directories; maintain substantial websites to increase access to resource material; convene international conferences; represent and advocate for the post-polio and home ventilator user communities; and fund research likely to have direct consequences for the health and independence of our constituents during their lifetimes.

Who We Are

We are our Members:

PHI including IVUN became a Membership organization in 2003 with individual levels of financial support ranging from \$30-\$10,000. PHI also facilitates information among the support group network through its Association Memberships.



Lee Bekir, Conference Chair, Fred Maynard, MD, Joan L. Headley, Jean Csaposs and Joan Swain at the Polio Network of New Jersey's 18th annual conference.



We are our Governing Board (2007-2008):

Lawrence C. Becker, PhD
President/Chairperson
Professor of Philosophy Emeritus,
College of William and Mary
Fellow of Hollins University
Roanoke, Virginia

William G. Stothers
Vice President
The Center for an Accessible Society
San Diego, California

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

Gayla Hoffman
Assistant Secretary
Saint Louis, Missouri

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

Richard 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, Olive View/UCLA Medical Center
(retired)
Sylmar, California

John R. Fisk, MD
Orthopedic Surgery, Southern Illinois University
School of Medicine (retired)
St. Helena Island, South Carolina

Judith E. Heumann, MPH
Director, Department of Disability Services,
Government of District of Columbia
Washington, District of Columbia

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

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

Martin B. Wice, MD
Medical Director, St. John's Mercy
Rehabilitation Hospital
Chesterfield, Missouri

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



MESSAGE FROM THE CHAIR OF THE BOARD

The Board of Directors of PHI met face-to-face in 2007 and 2008 to consider several projects, some of which looked backward through the history of polio. Our monthly board meetings are usually future-oriented, but this approach proved necessary for planning ahead and yielded important new opportunities.

In 2007, we completed a demographic report on Polio Survivors in the US, 1915-2000: Age Distribution Data. The research results informed our ongoing strategic planning and strengthened our acquaintance with archivists in the polio and post-polio communities. It also put us in touch with historians and demographers who have special knowledge of polio epidemics and polio survivors. These deepened relationships will have beneficial results for PHI for years to come.

In 2007-2008, this historical and demographic work laid the foundation for securing funding from a private foundation for a major project: PHI will create an online repository of historical, medical and practical about polio and living with polio. The ultimate aim is to preserve our past – not only our historic past, but also our processes as a consumer-based, networking organization. Most importantly, we want to preserve our proven, reliable and workable coping strategies that improve the lives of polio survivors.

In 2008, we explored other locations for our periodic international conference typically held in St. Louis, Missouri, and in the fall, we developed tentative plans for our 10th international conference to be held at historic Roosevelt Warm Springs Institute for Rehabilitation in Warm Springs, Georgia.

During 2008, we were also occupied with making sure that PHI's endowments and budgets remained as stable as possible through the world-wide financial crisis and deep recession. I can report that the Board's conservative investment strategies and the Executive Director's tight budget controls made it possible for us to get through this rough time without diminishing or interrupting the services that define our mission. As was the case for almost every sector of the economy, PHI's resources were temporarily compromised. But our success during this difficult time has been very encouraging for the future, and we remain on a steady, productive course. We thank all of you who made special contributions to this effort.



Lawrence Becker conversing with board members Brenda Butka, MD, (l.) and Marny Eulberg, MD (r.).

–Lawrence Becker, PhD



Our History

Post-Polio Health International (PHI)

is a relatively new name (2003) for an organization that officially began its work in 1960 (<http://www.post-polio.org/about/history.html>) and for many years was variously known in polio circles as the *Rehabilitation Gazette* or Gazette International Networking Institute (GINI), in honor of Gini Laurie (<http://www.post-polio.org/about/ginilaurie1.html>), our founder. Before her death in 1989, she formed International Ventilator Users Network (IVUN) (<http://www.ventusers.org/>) to provide information to all users of home mechanical ventilation (HMV) no matter what the medical condition.

We are our Staff:

Located in St. Louis, Missouri, our office is staffed by our executive director, Joan L. Headley, and two full-time staff members during 2007, with the help of ad hoc contractors and consultants. In 2008, PHI reorganized its office structure, reducing its onsite personnel to two and increasing its contract personnel.

We are our Volunteers:

Many activities of Post-Polio Health International including International Ventilator Users Network are orchestrated by staff but are accomplished by dedicated polio survivors, ventilator users, family members, health professionals and friends of the organization.

Special recognition:

Judith R. Fischer, Cypress, California, continues to dedicate her talents and time to International Ventilator Users Network as IVUN Information Specialist. Fischer unselfishly contributes her editing skills in honor of her husband the late D. Armin Fisher, MD, and her friend and our founder, the late Gini Laurie.

Nancy Baldwin Carter, Omaha, Nebraska, combines her skills, wit and personal experience to write articles and columns that assist PHI in publishing information that responds to the needs of its Members and to counter misinformation.



Gini Laurie (upper left) with two polio survivors at a gathering in the 1960s. Below are two of the Toomey j Gazette news magazines, forerunner of today's quarterly newsletter, Post-Polio Health.



Karen Hagrup, St. Louis, Missouri, is PHI's faithful and meticulous "certified stuffer" of envelopes. Her donation of time each Wednesday is invaluable.

Debbie Hardy, Whittier, California, assists PHI by critiquing submissions to the organization and by editing articles. Her insights provide us with a valuable perspective.

MESSAGE FROM THE EXECUTIVE DIRECTOR

From my vantage point, I am struck by our dichotomous situation.

The office fields numerous phone calls, emails and letters daily from survivors and their loved ones. The requests from younger survivors with computer access in countries such as Pakistan, India, Ethiopia and Iran are on the rise. The questions can be very specific – seeking help in the time of medical crisis, or very general – preparing for the future.

At the same time, the organization dutifully plans ahead. The common response from outsiders is, “Polio? Nobody gets polio. You should plan on switching your mission.”

Our exploration into the numbers shows that in 2021 there will be 418,000 survivors in the United States with 230,000 in need of post-polio information. The worldwide numbers of polio survivors is indeed decreasing from an annual case count of 350,000 in 1987 to less than 2,000 in 2008. Some of the 350,000 who had polio in 1987 are now 20-plus years old living with polio’s effects.

To me, as a polio survivor, the question is: How many people does it take to be considered important or worthy of an organization and support? The PHI Board’s response has been: We are committed to serving our core constituency and at the same time to preserving our processes and our accumulated knowledge for other survivors around the world.

To that end over the last two years, we have created a plan to address the dichotomy. We are collecting and preserving our past while monitoring the needs and finding solutions for today.

We are behind schedule. The culprit: the economic downturn that not only affected the staffing of our organization but also those with whom we do business.

We are moving forward with our plans. We thank you for your faithful Membership. I invite you to contact me personally if you want to help us in our endeavors with your talents or with an increase in your financial commitment.

The past is our foundation, the present is our affirmation, and the future is our motivation.



Joan L. Headley (r.) with board member Gayla Hoffman.

–Joan L. Headley



Our 2007-2008 Activities

PHI Association Communiqué:

Sent monthly, this email communicated with post-polio support groups and organizations that are Association Members. In 2007, PHI featured a **Leadership Series** (<http://www.post-polio.org/net/leadcol.html>) written by polio survivor Nancy Baldwin Carter. In 2008, Carter's column featured responses to "Polio Survivors Ask." Groups were encouraged to "cut and paste" and distribute these well-documented columns.

Board chair Lawrence Becker, PhD, prepared a document exploring the **number of polio survivors in US.**

(<http://www.post-polio.org/PolioSurvivorsInTheUS1915-2000.pdf>)



WE'RE STILL HERE!, a post-polio awareness campaign, was launched in 2007. The purpose of the yearly campaign, also publicized in 2008, is to remind the general public that polio survivors throughout the world are living and succeeding, making a difference in their communities, and facing obstacles to receiving appropriate health care and living independently.



Author and PHI/IVUN Board member, Dan Wilson, PhD, addressing a group at John P. Murtha Institute of Neuroscience in Johnstown, PA.



Websites:

A new website – www.ventusers.org – was created for International Ventilator Users Network (IVUN), an affiliate of Post-Polio Health International. The new site averaged 7,500 unique visits each month, with an average of 275 visits per day.



PHI's website – www.post-polio.org – averaged 800 visits per day with monthly visits in the 26,000 range. Popular downloads for both sites are the networking tools *Post-Polio Directory* (<http://www.post-polio.org/net/PDIR.pdf>) and *Resource Directory for Ventilator-Assisted Living* (<http://www.ventusers.org/net/VentDIR.pdf>).



Australian Visitors – In April 2008, Mary-ann Liethof, Community Officer (right), and Jill Pinkington, polio survivor and volunteer (center), from the Post-Polio Network of Victoria, Australia, visited St. Louis on its five-week tour (<http://www.polionetworkvic.asn.au/study-tour/>) of North American polio centers. The visitors interviewed Joan L. Headley and thanked her for the networking activities that helped make the trip a reality.

Along with the well-used Internet option, PHI offers the personal touch of responding to phone calls. PHI's quarterly newsletter, *Post-Polio Health*, and IVUN's *Ventilator-Assisted Living*, are available in print to Members.

PHI and IVUN history and current activities were added to Wikipedia.

Remember Polio Membership brochure was created.



Paralysis Task Force – In April 2007, Joan L. Headley, Executive Director, participated in the Christopher and Dana Reeve Foundation sponsored Paralysis Task Force.



Take Charge, Not Chances, created with funds from the Christopher and Dana Reeve Foundation, was successfully completed and translated into Spanish.



Our 2007-2008 Activities, continued

The Research Fund, created in 1995, furthered its goal of providing seed money to researchers exploring the causes of problems experienced by the survivors of polio. In 2008, PHI received the report (<http://www.post-polio.org/edu/pphnews/pph24-2p1-5.pdf>), *Regulatory T cells as a Biomarker of Post-Polio Syndrome*, from its fourth grant recipient, Rahnuma Wahid, PhD, Department of Microbiology and Immunology, University of Arkansas for Medical Sciences, Little Rock, Arkansas. Later in the year, PHI awarded its fifth grant to a team led by Dr. Antonio Toniolo from the University of Insubria in Varese, Italy, to advance noninfectious virus detection (<http://www.post-polio.org/edu/pphnews/pph24-4fa08p1.pdf>) in polio survivors.



PHI and IVUN are *Your* PHI and IVUN

Post-Polio Health International including International Ventilator Users Network is a Membership organization.

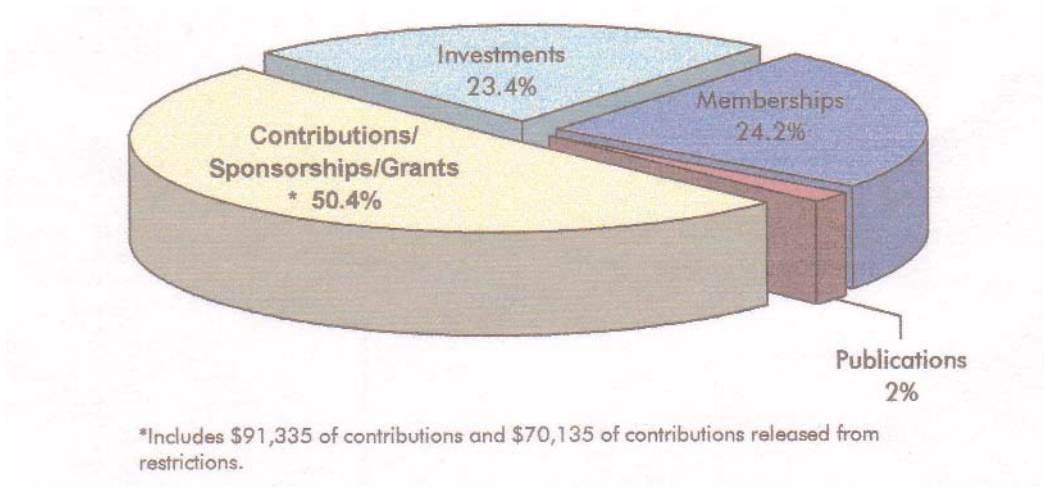
- The Membership determines the content of the newsletters and guides the development of projects by asking questions and articulating their needs.
- The Membership volunteers its solutions by writing articles and by interacting through email supporting other members, assisting with the time-tested *modus operandi* of the organization.
- The Membership recognizes the uniqueness of PHI and IVUN's mission and contributes financially to support its work.
- The supporting Membership continues its support knowing that many of the benefits are free to others.



Our Financial Status – 2007

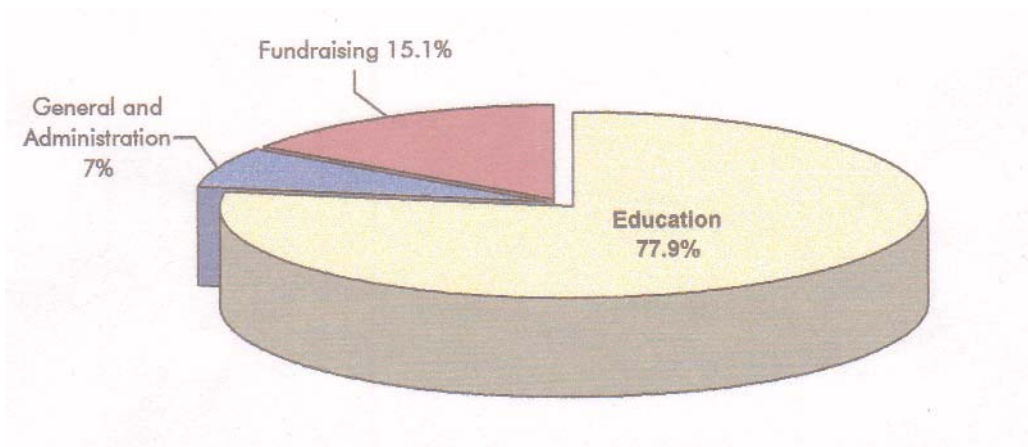
Funding Sources 2007

Funding Sources 2007 – \$321,083



Expense Allocation 2007

Expense Allocation 2007 – \$300,573



Statement of Assets, Liabilities, and Net Assets – Cash Basis
December 31, 2007

ASSETS

Current Assets

Cash \$ 24,594

Investments 916,086

Total Current Assets 940,680

Fixed Assets

Office equipment, at cost 12,299

Accumulated depreciation (9,764)

Net Fixed Assets 2,535

TOTAL ASSETS \$ 943,215

LIABILITIES

Current Liabilities

Payroll withholding payable \$ 3,695

NET ASSETS

Unrestricted 458,185

Temporarily restricted 481,335

Total Net Assets 939,520

TOTAL LIABILITIES & NET ASSETS \$ 943,215

Statement of Revenues, Expenses, and Other Changes in Net Assets – Cash Basis
Year Ended December 31, 2007

CHANGES IN UNRESTRICTED NET ASSETS

REVENUES

Memberships	\$ 77,761
Contributions	91,355
Publications	6,504
Investment income	28,750
Capital gain distributions	38,216
Gain on sale of securities	39
Unrealized gain on investments	8,223
Miscellaneous	100
Contributions released from restrictions	<u>70,135</u>

TOTAL UNRESTRICTED REVENUES \$ 321,083

EXPENSES

Education	243,123
General and administrative	45,540
Fundraising	<u>20,910</u>

TOTAL EXPENSES 300,573

INCREASE IN UNRESTRICTED NET ASSETS 20,510

CHANGES IN TEMPORARILY RESTRICTED NET ASSETS

Contributions	95,649
Net assets released from restrictions	<u>(70,135)</u>

INCREASE IN TEMPORARILY RESTRICTED NET ASSETS 25,514

INCREASE IN NET ASSETS 46,024

NET ASSETS AT BEGINNING OF YEAR 893,496

NET ASSETS AT END OF YEAR \$ 939,520



The Research Fund

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

On December 31, 2007, The Research Fund assets were \$481,335. The Research Fund is a special fund containing dollars given to support research into post-poliomyelitis and neuromuscular respiratory conditions.

Major Contributors – 2007

Contributions, Sponsorships and Grants

\$10,000 and over

Edouard Foundation

ResMed, Ltd

Roosevelt Warm Springs Foundation

\$5,000 and over

Dale Medical Products

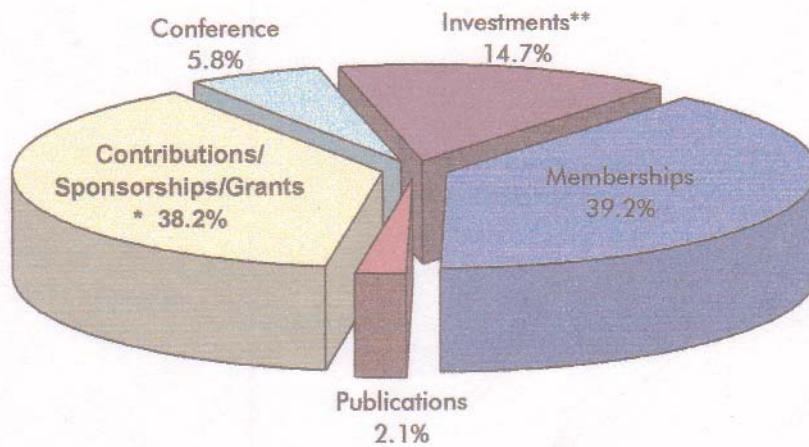
Respironics, Inc.

In addition to the above contributions, PHI received donations from 2335 individuals, with another 308 contributing to The Research Fund.

Our Financial Status – 2008

Funding Sources 2008

Funding Sources 2008 – \$203,030

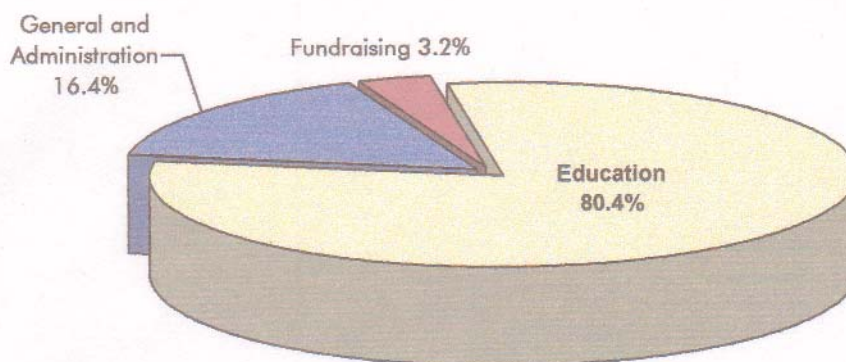


*Includes \$66,210 of contributions and \$11,322 of contributions released from restrictions.

**Does not reflect net losses from investment activities in the amount of \$194,915.

Expense Allocation 2008

Expense Allocation 2008 – \$223,758



Statement of Assets, Liabilities, and Net Assets – Cash Basis
December 31, 2008

ASSETS

Current Assets

Cash and cash equivalents	\$ 68,885
Investments at fair market value	<u>141,773</u>
Total Current Assets	<u>210,658</u>

Fixed Assets

Office equipment, at cost	12,299
Accumulated depreciation	<u>(10,823)</u>
Net Fixed Assets	<u>1,476</u>
Long-Term Investments	<u>482,369</u>
TOTAL ASSETS	<u>\$ 694,503</u>

LIABILITIES

Current Liabilities

Payroll withholding payable	<u>\$ 2,109</u>
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NET ASSETS

Unrestricted	212,678
Temporarily restricted	<u>479,716</u>
Total Net Assets	<u>692,394</u>
TOTAL LIABILITIES & NET ASSETS	<u>\$ 694,503</u>

Statement of Revenues, Expenses, and Other Changes in Net Assets – Cash Basis
Year Ended December 31, 2008

CHANGES IN UNRESTRICTED NET ASSETS

REVENUES

Memberships	\$ 79,726
Contributions	66,210
Publications	4,174
Conference	11,733
Investment income	26,462
Capital gain distributions	3,403
Loss on sale of securities	(751)
Unrealized loss on investments	(224,029)
Contributions released from restrictions	<u>11,322</u>
TOTAL UNRESTRICTED REVENUES	<u>\$ (21,750)</u>

EXPENSES

Education	179,781
General and administrative	36,660
Fundraising	<u>7,317</u>
TOTAL EXPENSES	<u>223,758</u>

DECREASE IN UNRESTRICTED NET ASSETS (245,508)

CHANGES IN TEMPORARILY RESTRICTED NET ASSETS

Contributions	9,703
Net assets released from restrictions	<u>(11,321)</u>

DECREASE IN TEMPORARILY RESTRICTED NET ASSETS (1,618)

DECREASE IN NET ASSETS (247,126)

NET ASSETS AT BEGINNING OF YEAR 939,520

NET ASSETS AT END OF YEAR \$ 692,394



The Research Fund

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

On December 31, 2008, The Research Fund assets were \$482,369.72. The Research Fund is a special fund containing dollars given to support research into post-poliomyelitis and neuromuscular respiratory conditions. Additionally, PHI had \$37,721.64 earmarked for an uncompleted project. These restricted funds will be spent only as the project progresses.

Major Contributors – 2008

Contributions, Sponsorships and Grants

\$10,000 and over

Edouard Foundation

Helen Ford

ResMed, Ltd

\$5,000 and over

Dale Medical Products

Respironics, Inc.

In addition to the above contributions, PHI received donations from 2084 individuals, with another 67 contributing to The Research Fund.



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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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:
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- \$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