Report for 2009-2010

Post-Polio Health International
Including International Ventilator Users Network

EDUCATION
post-polio.org

ADVOCACY
ventusers.org

NETWORKING

RESEARCH
polioplace.org
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

MESSAGE FROM THE CHAIR OF THE BOARD

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

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**TREASURER**  
Legal Counsel, Brown Hay & Stephens, LLP  
Springfield, Illinois

Richard (Rich) W. Hokamp  
**ASSISTANT TREASURER**  
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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
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 (polioplace.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

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.
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 Neuromuscular 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 disabili-
ties 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).
Financial Status – 2009

Funding Sources 2009 – $289,950

- Contributions/Sponsorships/Grants* 43%
- Memberships 29%
- Conference 19%
- Publications 1%
- Investments** 8%

*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

- Education 68.5%
- Conference 19%
- General & Administration 10.4%
- Fundraising 2.1%
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 160,772
- Total Current Assets 280,503

**Fixed Assets**
- Office equipment, at cost 12,299
- Accumulated depreciation (11,807)
- Net Fixed Assets 492

**Long-Term Investments** 563,132

**TOTAL ASSETS** $844,127

**LIABILITIES**

**Current Liabilities**
- Payroll withholding payable $2,079

**NET ASSETS**

**Unrestricted** 337,121

**Temporarily restricted** 504,927

**Total Net Assets** 842,048

**TOTAL LIABILITIES & NET ASSETS** $844,127
## Statement of Revenues, Expenses, and Other Changes in Net Assets – Cash Basis
Year Ended December 31, 2009

### CHANGES IN UNRESTRICTED NET ASSETS

**REVENUES**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memberships</td>
<td>$ 82,721</td>
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<tr>
<td>Contributions</td>
<td>94,216</td>
</tr>
<tr>
<td>Publications</td>
<td>2,916</td>
</tr>
<tr>
<td>Conference</td>
<td>56,004</td>
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<tr>
<td>Investment income</td>
<td>23,013</td>
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<tr>
<td>Gain on sale of securities</td>
<td>69</td>
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<tr>
<td>Unrealized gain on investments</td>
<td>107,022</td>
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<tr>
<td>Contributions released from restrictions</td>
<td>31,080</td>
</tr>
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**TOTAL UNRESTRICTED REVENUES** $397,041

**EXPENSES**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conference</td>
<td>51,560</td>
</tr>
<tr>
<td>Education</td>
<td>186,732</td>
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<tr>
<td>General and administrative</td>
<td>28,372</td>
</tr>
<tr>
<td>Fundraising</td>
<td>5,829</td>
</tr>
</tbody>
</table>

**TOTAL EXPENSES** 272,493

**INCREASE IN UNRESTRICTED NET ASSETS** 124,548

### CHANGES IN TEMPORARILY RESTRICTED NET ASSETS

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td>56,185</td>
</tr>
<tr>
<td>Net assets released from restrictions</td>
<td>(31,079)</td>
</tr>
</tbody>
</table>

**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-polio myelitis 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

- Contributions/Sponsorships/Grants* 65.8%
- Memberships 30.1%
- Investments** 2.1%
- Publications 1.3%
- Conference 0.7%

*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

- Education 88%
- Fundraising 3%
- General & Administration 9%
Post-Polio Health International, Inc.

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 151,367
Total Current Assets 257,775

Fixed Assets

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

Long-Term Investments 628,935

TOTAL ASSETS $888,265

LIABILITIES

Current Liabilities

Payroll withholding payable $2,547

NET ASSETS

Unrestricted 346,005
Temporarily restricted 539,713

Total Net Assets 885,718

TOTAL LIABILITIES & NET ASSETS $888,265
## Changes in Unrestricted Net Assets

### Revenues

<table>
<thead>
<tr>
<th>Revenue Type</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memberships</td>
<td>$69,562</td>
</tr>
<tr>
<td>Contributions</td>
<td>104,696</td>
</tr>
<tr>
<td>Publications</td>
<td>2,979</td>
</tr>
<tr>
<td>Conference</td>
<td>1,808</td>
</tr>
<tr>
<td>Investment Income</td>
<td>4,757</td>
</tr>
<tr>
<td>Loss on sale of securities</td>
<td>(434)</td>
</tr>
<tr>
<td>Unrealized gain on investments</td>
<td>10,402</td>
</tr>
<tr>
<td>Contributions released from restrictions</td>
<td>47,748</td>
</tr>
</tbody>
</table>

**Total Unrestricted Revenues**: $241,518

### Expenses

<table>
<thead>
<tr>
<th>Expense Type</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>205,137</td>
</tr>
<tr>
<td>General and administrative</td>
<td>21,475</td>
</tr>
<tr>
<td>Fundraising</td>
<td>6,126</td>
</tr>
</tbody>
</table>

**Total Expenses**: 232,738

**Increase in Unrestricted Net Assets**: 8,780

### Changes in Temporarily Restricted Net Assets

<table>
<thead>
<tr>
<th>Revenue/Expense Type</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td>27,661</td>
</tr>
<tr>
<td>Investment Income</td>
<td>19,099</td>
</tr>
<tr>
<td>Loss on sale of securities</td>
<td>(78)</td>
</tr>
<tr>
<td>Unrealized gain on investments</td>
<td>35,956</td>
</tr>
<tr>
<td>Net assets released from restrictions</td>
<td>(47,748)</td>
</tr>
</tbody>
</table>

**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-polio myelitis 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 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 ___________________________
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

Should you be interested in making a larger contribution, please consider:

- **$5,000 Platinum Level Sustainer**
  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 ___________________________
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