Annual Report 2005/2006
for Post-Polio Health International,
including International Ventilator Users Network

Message from President of the Board

Lawrence C. Becker, PhD
President
Volunteer Board of Directors

The body of this report will document the range and reach of PHI's activities, which seem to grow substantially every year. The board provides general oversight of these day-to-day matters, but in 2005-2006 devoted most of its attention to two special projects. One was PHI's ninth international conference, held in June, 2005. Several ad hoc committees of board members helped the office staff with this large undertaking, and we were all gratified by its success. One especially satisfying outcome was the creation of a formal network of polio support groups under the auspices of PHI. These Association Members now receive regular bulletins from our executive director about new research, new books, upcoming conferences or other events related to polio, and other information of interest to the support groups – information that goes well beyond what we can publish in the newsletters.

The second special board project during this biennium was strategic planning. We face a daunting challenge. Obviously, polio survivors from the pre-vaccine years are aging and declining in number.[1] Yet new initiatives and additional efforts are required of our staff on many fronts, and this will continue for decades. Simultaneously, it is increasingly difficult for us to counter the growing public attitude that "polio is over" – or at least that it will be over as soon as the worldwide eradication effort is complete. This attitude leads to neglect of the needs of polio survivors, and indifference toward the organizations devoted to meeting those needs.

The board's response has been to develop a detailed estimate of the demographic realities over the next 20 years (with respect to the size and age distribution of its core constituency), and to develop a reasonable, revisable set of goals for the organization in the years ahead. Those efforts are now beginning to bear fruit.

Briefly: The board has reaffirmed PHI's existing mission, with its central commitment to serving its core constituencies. In addition, however, the board has defined two related initiatives which promise to enhance the pursuit of that mission. One of these initiatives is the creation of a comprehensive digital resource designed to organize and preserve the history and lessons learned from the polio epidemics of the early and mid-20th-century, as well as the subsequent study of post-polio sequelae. The other initiative is to undertake a greater and more focused international outreach to parts of the world that are underserved by existing support groups and networks of polio survivors.

We are excited about these initiatives, and pleased that we have already secured a major planning grant to help us get started on them. The next two years will be eventful. Stay tuned.

–Lawrence C. Becker, PhD

[1]For example: In 1994-95, the US government's annual National Health Interview Survey (administered by the CDC) made a special effort to estimate the number of self-reported polio survivors then living in the United States. That estimate was roughly one million, reduced by further epidemiological study to approximately 940,000. Assuming that the mortality rate among polio survivors is no higher or lower than the average for the entire US population, we estimated that in 2006, roughly 775,000 polio survivors remained. Of these, 426,000 describe a medical history clearly consistent with paralytic polio and/or one that clearly places them at risk for post-polio sequelae. It is a vivid reminder of the effectiveness of the vaccines to note that in 2006, 89% of self-reported polio survivors in the US were 55 or older, and 53% were 65 or older. Extrapolating to 2016, 98% of US polio survivors will be 55 or older, 86% will be 65 or older, and 42% will be 75 or older. We believe there is a similar age distribution of polio survivors elsewhere in the world where vaccines ended polio epidemics by the early 1960s.

Dear Members of Post-Polio Health International and International Ventilator Users Network,

Joan L. Headley, MS
Executive Director

PHI's day-to-day activities and choices are driven by its mission. In the following pages, we list just a few monthly highlights of our educational, advocacy, networking and research efforts. In reality, through our website, email, mail and phone conversations, we educate, advocate, network and promote research on a daily basis. The quotes throughout this report reflect a small sampling of those interactions.

Building on our new name chosen in 2003, our focus is on health. Choosing "Strategies for Living Well" as the theme of our Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living in 2005 was a response to our Members, who tell us, "We know the problems; we need solutions."

Disseminating solutions is our mandate.

We search for solutions that are already available, so as not to re-invent the wheel. We search for experts to create the information that is unique to polio survivors and users of home mechanical ventilation. The Christopher and Dana Reeve Foundation recognized our ability to access experts and create new information by granting us $20,000 to address the problems ventilator users face when going to the emergency room.

As a result of discussions at the Conference, we now address more aggressively the needs of support group coordinators worldwide. *A PHI Communiqué,* an e-newsletter, is sent monthly to Association Members. It features a "Leadership" column written by veteran support group coordinator Nancy Baldwin Carter.

The point: We want to hear from you, our Members. We depend on you for guidance. We also depend on you for financial support.

We have challenging years ahead of us of serving a population that has increasing needs, but a decreasing population. We have taken on the challenge of sharing our processes and knowledge with the world's younger polio survivors, and of preserving our legacy. As polio survivors, we have successfully functioned in society and profoundly changed it by helping to develop and promote the independent living philosophy.

Joan L. Headley, MS
Executive Director

Governing Board

Board of Directors (2006)

*denotes members of 2005 Board

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University of Michigan Health System, Ann Arbor, Michigan

***Martin B. Wice, MD**
Medical Director, Department of Rehabilitation Medicine
St. John's Mercy Medical Center, Saint Louis, Missouri

***William Wischmeyer**
Saint Louis, Missouri

Daniel J. Wilson, PhD
Muhlenberg College, Allentown, Pennsylvania

Mission of Post-Polio Health International

Post-Polio Health International's mission is to enhance the lives and independence of polio survivors and home ventilator users through education, advocacy, research and networking.

Highlights of 2005-2006

EDUCATION

www.post-polio.org/edu/

Post-Polio Health and *Ventilator-Assisted Living* are the organization's major educational tools. Published quarterly, each 12-page newsletter features original articles focusing on practical, as well as the medical, topics that will assist readers in living independently. PHI granted 53 permissions to reprint from its newsletters in 2005; 121 permissions to reprint in 2006.

"My husband and I both had polio when in college. Your publication is the most comprehensive we've found."

–John and Mary, California

"Would you please send me two copies of the last newsletter? I have given mine away!"

–Betty, Arkansas

January 2005

The Post-Polio Clinic Directors Network meets monthly on the third Tuesday at 6:00 pm ET. The conference calls are a collaboration of PHI and Conemaugh Health System, Johnstown, Pennsylvania.

February 2005

Board President Frederick Maynard, MD, spoke to polio survivors in Bradenton, Florida. His visit was hosted by Bay Area Physical Therapy.

"The three women attended a post-polio meeting last year in Saint Louis, and they decided to come home and start a local group."

–The Hutchinson News, Kansas

June 2005

More than 340 people from 13 countries and 34 states attended Post-Polio Health International's **Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living: STRATEGIES FOR LIVING WELL** (www.post-polio.org/net/conf9.html). The conference, held in Saint Louis, Missouri, was featured in an article by Deborah Shelton in the *St. Louis Post-Dispatch.*

January 2006

International Ventilator Users Network received a $20,000 Health Promotion grant from the Christopher and Dana Reeve Foundation (www.ventusers.org/edu/valnews/VAL_20-1p3.pdf) to explore and address the problem of inadequate or inappropriate treatment of adult users of home mechanical ventilation in emergency situations. Virginia Brickley, Elmhurst, Illinois, is the Program Leader.

"I must say the information on the subject of disability and the effects of polio is quite informative and the design (of the newsletter) is excellent."

-Lee Roy, via email

April 2006

IVUN Members participated in a focus group about the benefits and barriers of telehealth. (www.ventusers.org/edu/valnews/VAL_20-3p4-7.pdf) The survey was conducted by PHD Medical, Quebec, Canada.

May 2006

At the request of the National Institute of Neurological Disorders and Strokes (NINDS), PHI's Medical advisory Committee Chaired by Martin B. Wice, MD, reviewed and revised the NINDS "Post-Polio Syndrome Fact Sheet."
(www.ninds.nih.gov/disorders/post_polio/post_polio.htm)

August 2006

Joan L. Headley participated in a panel discussion at the Leadership Exchange in the Arts and Disability (LEAD) Conference at the Kennedy Center for the Performing Arts, Washington, DC.

October 2006

Nancy Baldwin Carter and Joan L. Headley contributed a chapter, "Support Groups: Keeping Them Active and Useful." to the second edition of *Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome* edited by Lauro S. Halstead. MD. (www.nrhrehab.org/About+NRH/Publications/414.aspx)

November 2006

IVUN Members assisted Deshae E. Lott, PhD, Louisiana State University in exploring sexual activity and chronic illness. (www.ventusers.org/edu/valnews/VAL_20-4p4-9.pdf)

ADVOCACY

www.post-polio.org/adv/

April 2005

To promote awareness and to commemorate the 50th anniversary of the development of the polio vaccine (April 12, 1955), PHI created note cards and bookmarks with a "Nautilus and Butterfly" logo and the phrase "Transcending Limitations: Giving Wings to the Future." (www.post-polio.org/edu/pphnews/pph21-1p7.pdf)

July 2005

Members of IVUN assisted Betty Seigel, Arts Access Coordinator of the Kennedy Center for the Performing Arts in collecting information and suggestions to assure access to America's arts venues. (www.ventusers.org/edu/valnews/VAL_20-2p6-8.pdf)

"The work you do is so invaluable to me. Thank you."

–Jill, England

October 2005

IVUN's Consumer Advisory Committee wrote and circulated "Current Threats to Ventilator Users in Cost-Cutting Proposals from Medicaid and Other Medical Insurance: A Resolution" which was signed by more than 650 individuals. The Resolution was sent to the President, National Governor's Association, State Legislature Councils, and several Senators and Governors.

RESEARCH

www.post-polio.org/res/

"Thank you for giving me some direction regarding the steps I can take to stay active and healthy."

–Linda, Texas

January 2005

A $25,000 grant from The Research Fund was awarded to a Johns Hopkins Team led by Noah Lechtzin, MD, MHS, Division of Pulmonary and Critical Care Medicine, to Study Early Use of Noninvasive Ventilation. (www.ventusers.org/res/johnhop.html)

December 2006

Noah Lechtzin, MD, MHS, Division of Pulmonary and Critical Care Medicine, Johns Hopkins University reported that survival from time of diagnosis (www.ventusers.org/edu/valnews/VAL_20-4p1-2.pdf) was nearly one year long in subjects with ALS who were started on noninvasive positive pressure ventilation when their forced vital capacity (FVC) was 65% of predicted versus those who were started when their FVC was less that 65% of predicted.

NETWORKING

www.post-polio.org/net/

"Thank you very much for a copy of the Tenth Anniversary 1968 issue of the Toomey J Gazette *that contained the article I wrote. I'm happy to see someone is still 'out there' for post-polio people."*

–Jean, Minnesota

April 2005

Joan L. Headley presented at the 10th International Conference on Home Mechanical Ventilation in Lyon, France.

PHI contributed numerous photographs and documents for the "Whatever Happened to Polio Exhibit?" at the National Museum of American History, Smithsonian Institution, Washington, DC.

Joan L. Headley was quoted by several media contacts regarding the 50th Anniversary of the development of the Salk vaccine, including the *Baltimore Sun, New York Times* and the local NPR affiliate.

Polio survivors Ray Taylor, Linda Bieniek and Joan L. Headley participated in Rotary's 100th Anniversary Parade as members of the Rotarian Action Group, Polio Survivors and Associates.

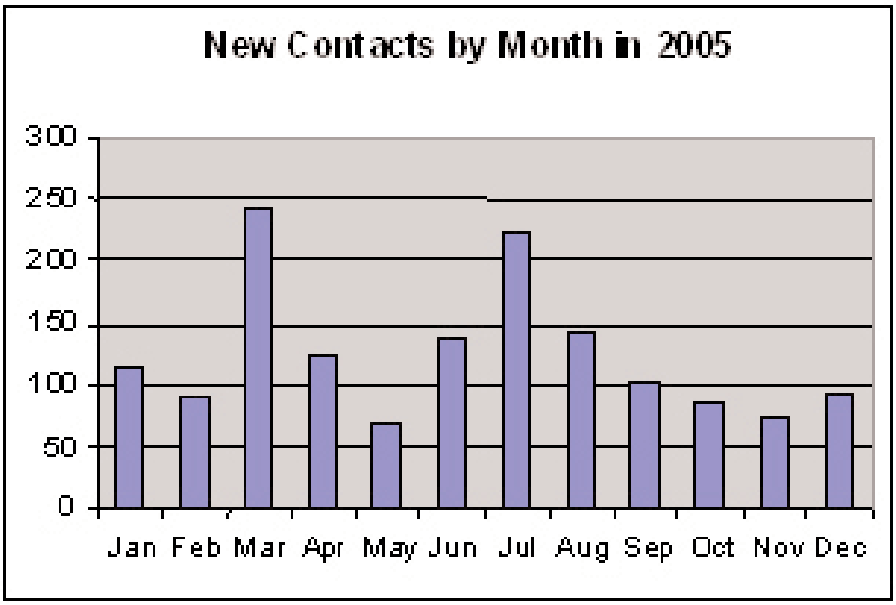
August 2006

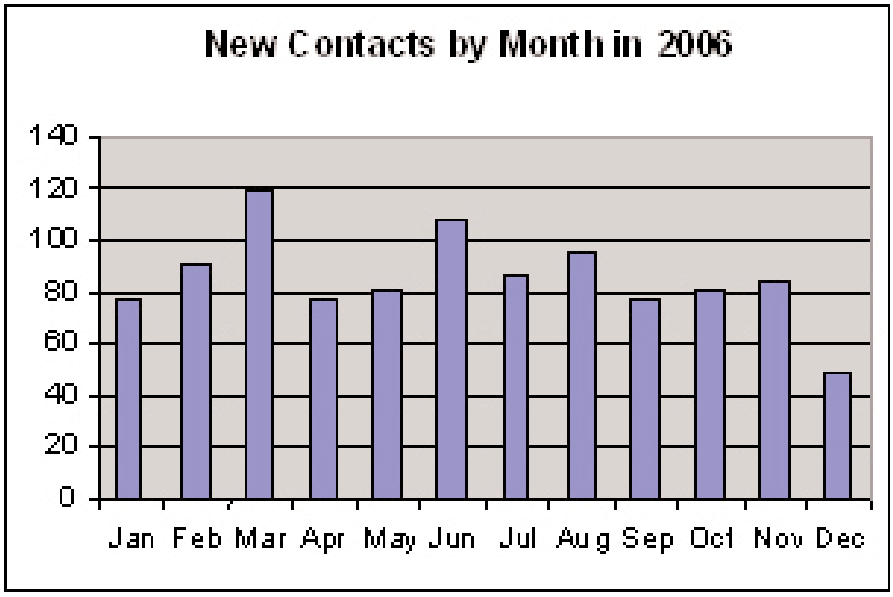
To memorialize polio survivor Gilbert Goldenhersh, his family created the Gilbert Goldenhersh Memorial Tribute Fund to assist polio survivors living in Missouri to purchase equipment, shoes, etc. to help them live independently. His children and their families fondly remember his goal to be independent and his generosity in thinking of others.

Statistics 2005

"A friend of mine told his brother, a polio survivor, about the disease and probably saved his brother's life. Thank you for continuing to educate and help."

–Kate, via email





"Fighting disability is one thing but one cannot fight age."

-Juliana, Germany

POST-POLIO HEALTH INTERNATIONAL, INC.

STATEMENT OF ASSETS, LIABILITIES, AND NET ASSETS - CASH BASIS

December 31, 2005

ASSETS	
Current Assets	
Cash	$ 94, 007
Investments	710,474
Total Current Assets	804,481
Fixed Assets	
Office equipment, at cost	12,299
Accumulated depreciation	(5,091)
Net Fixed Assets	7,208
TOTAL ASSETS	$ 811,689
LIABILITIES	
Current Liabilities	
Payroll withholding payable	$ 3,667
Accounts payable	6,359
Notes payable	35,769
Total Current Liabilities	45,795
NET ASSETS	
Unrestricted	383,741
Temporarily restricted	382,153
Total Net Assets	765,894
TOTAL LIABILITIES & NET ASSETS	$ 811,689

POST-POLIO HEALTH INTERNATIONAL, INC.

STATEMENT OF REVENUES, EXPENSES, AND OTHER CHANGES IN NET ASSETS - CASH BASIS

Year Ended December 31, 2005

CHANGES IN UNRESTRICTED NET ASSETS	
REVENUES	
Memberships	$ 77,147
Contributions	109,276
Publications	17,219
Conference	73,294
Investment income	16,425
Capital gain distributions	16,496
Gain on sale of securities	1,357
Unrealized gain on investments	8,443
Miscellaneous	20
Contributions released from restrictions	49,198
TOTAL UNRESTRICTED REVENUES	368,875
EXPENSES	
Conference	86,680
Education	180,399
General and administrative	41,651
Fundraising	18,258
TOTAL EXPENSES	326,988
INCREASE IN UNRESTRICTED NET ASSETS	41,887
CHANGES IN TEMPORARILY RESTRICTED NET ASSETS	
Contributions	41,726
Net assets released from restrictions	(49,198)
INCREASE IN TEMPORARILY RESTRICTED NET ASSETS	(7,472)
INCREASE IN NET ASSETS	34,415
NET ASSETS AT BEGINNING OF YEAR	731,479
NET ASSETS AT END OF YEAR	$765,894

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

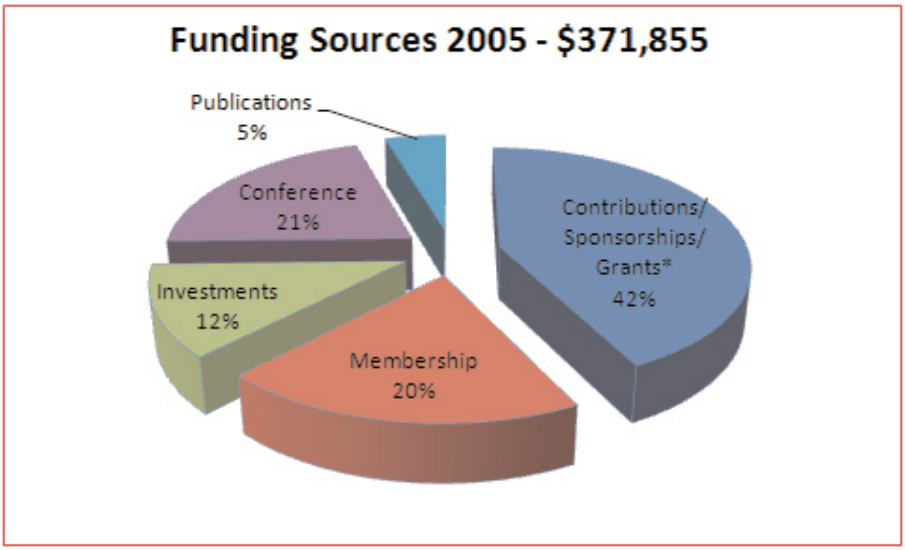
2005

Beginning Balance	$417,884.29
Ending Balance	$470,033.62

Amount Given

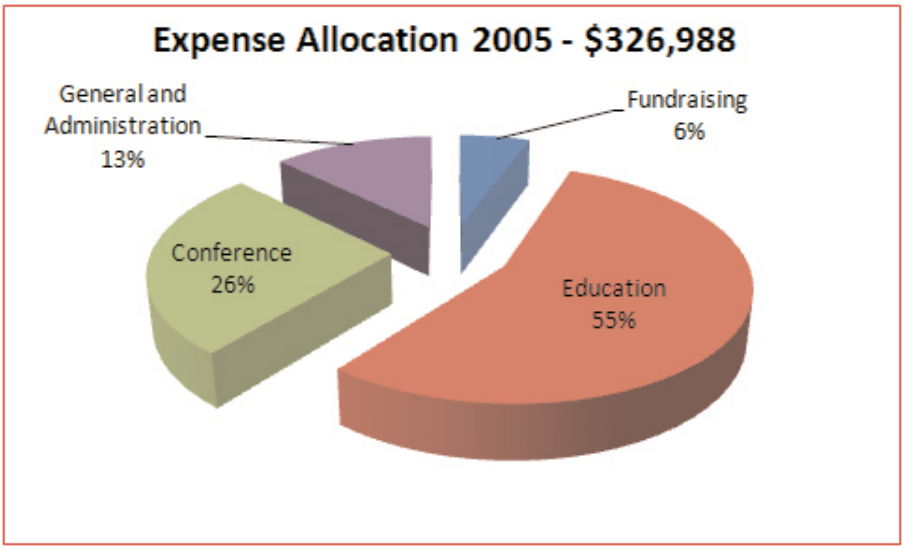
$25,000 to a team of researchers at Johns Hopkins University

Funding Sources 2005



*Include $116,567 of contributions and $10,048 of contributions released from restrictions.

Expense Allocation 2005



POST-POLIO HEALTH INTERNATIONAL, INC.

STATEMENT OF ASSETS, LIABILITIES, AND NET ASSETS - CASH BASIS

December 31, 2006

ASSETS	
Current Assets	
Cash	$ 29,112
Investments	864,237
Total Current Assets	893,349
Fixed Assets	
Office equipment, at cost	12,299
Accumulated depreciation	(7,975)
Net Fixed Assets	4,324
TOTAL ASSETS	$ 897,673
LIABILITIES	
Current Liabilities	
Payroll withholding payable	$ 4,177
NET ASSETS	
Unrestricted	437,676
Temporarily restricted	455,820
Total Net Assets	893,496
TOTAL LIABILITIES & NET ASSETS	$ 897,673

POST-POLIO HEALTH INTERNATIONAL, INC.

STATEMENT OF REVENUES, EXPENSES, AND OTHER CHANGES IN NET ASSETS - CASH BASIS

Year Ended December 31, 2006

CHANGES IN UNRESTRICTED NET ASSETS	
REVENUES	
Memberships	$ 80,168
Contributions	116,567
Publications	11,458
Investment income	19,673
Capital gain distributions	23,644
Gain on sale of securities	433
Unrealized gain on investments	49,001
Miscellaneous	125
Contributions released from restrictions	10,048
TOTAL UNRESTRICTED REVENUES	311,117
EXPENSES	
Education	186,836
General and administrative	48,241
Fundraising	22,105
TOTAL EXPENSES	257,182
INCREASE IN UNRESTRICTED NET ASSETS	53,935
CHANGES IN TEMPORARILY RESTRICTED NET ASSETS	
Contributions	83,715
Net assets released from restrictions	(10,048)
INCREASE IN TEMPORARILY RESTRICTED NET ASSETS	73,667
INCREASE IN NET ASSETS	127,602
NET ASSETS AT BEGINNING OF YEAR	765,894
NET ASSETS AT END OF YEAR	$893,496

The Research Fund

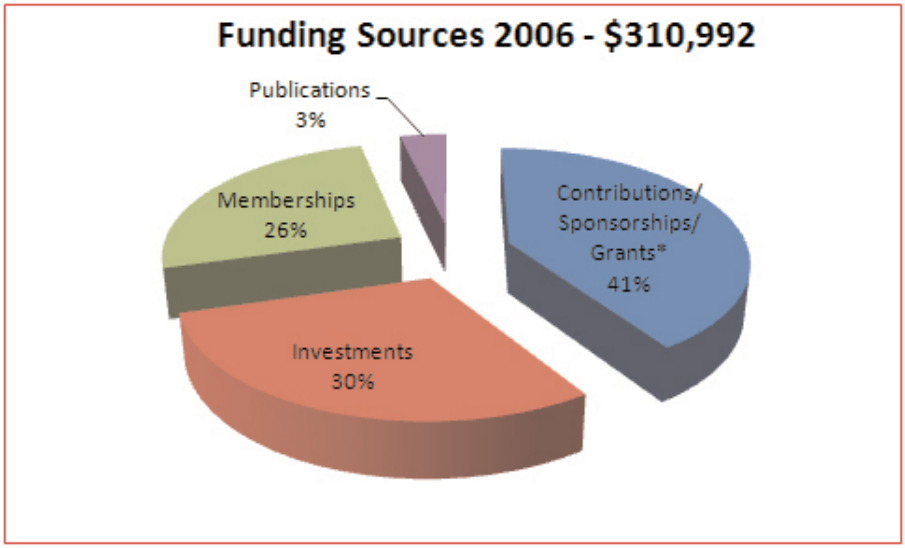
A major component of PHI's mission is to fund research projects that have the potential to benefit polio survivors and users of home ventilators. To that end, PHI established a Research Fund in 1995. Contributions to the Research Fund are called "restricted assets" because PHI may use these monies only 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

2006

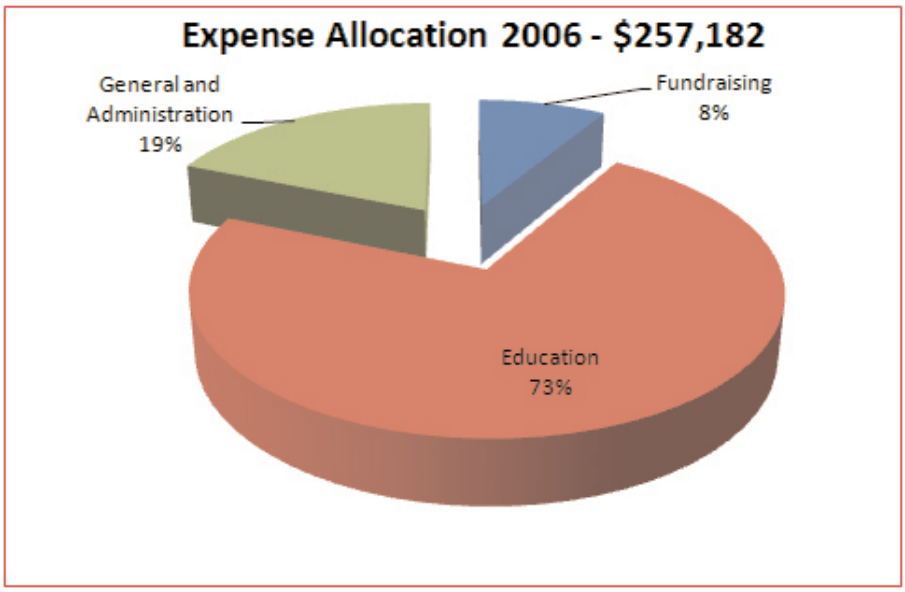
Beginning Balance	$470,033.62
Ending Balance	$566,389.26

Funding Sources 2006



*Includes $109,276 of contributions and $49,198 of contributions released from restrictions.

Expense Allocation 2006



2005

Contributions, Sponsorships and Grants
($10,000 and over)

Edouard Foundation

Passy-Muir, Inc

ResMed, Ltd

Respironics, Inc

Roosevelt Warm Springs Foundation

Contributions, Sponsorships and Grants
($5,000 and over)

March of Dimes

2006

Contributions, Sponsorships and Grants
($10,000 and over)

Bonnie Pomeroy

Christopher Reeve Foundation

Clark S. Callahan

Edouard Foundation

Pulmonetic Systems, Inc.

Thomas W. Rogers Trust

The Robert & Katleen Tabor Charitable Gift Fund

Contributions, Sponsorships and Grants
($5,000 and over)

Dale Medical Products

ResMed Ltd.

Respironics, Inc.

In June 2003, Gazette International Networking Institute changed its name to Post-Polio Health International. At the same time it became a Membership organization. Donations were received from 487 individuals, including memorials and additional donations beyond subscriptions fees during the last half of 2005. There were 449 individual donations to The Research Fund in 2005.

In 2005, the transition to a Membership organization was completed. In addition to annual Memberships, 487 individuals contributed additional and memorial donations. There were 449 individual donations to The Research Fund.

In 2006, 521 individuals gave to The Research Fund; 166 individuals gave memorial or honor donations. All other donations were Membership donations.

Donors' names are provided upon reguest (info@post-polio.org).

2005 & 2006

Special Acknowledgements

Barbara Duryea, MSN, RN, CPHQ, Johnstown, Pennsylvania
Coordinator of monthly conference calls for
post-polio clinic directors

Judith R. Fischer, MSLS, Cypress, California
Volunteer Editor of *Ventilator-Assisted Living*

Debbie Hardy, Whittier, California
Volunteer Editor of *Post-Polio Health*

Karen Hagrup, St. Louis, Missouri
Weekly In-House Volunteer

Deshae E. Lott, PhD, Bossier City, Louisiana
IVUN Survey on Chronic Illness and Sexual Activity

Ray Taylor, Southern Pines, North Carolina
Polio Survivors and Associates Rotarian Action Group

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Maria J. Gray, (2005/2006)

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