

---

# Annual Report 2004

---



Post-Polio Health International  
Including International Ventilator Users Network  
4207 Lindell Boulevard, #110  
Saint Louis, MO 63108-2915 USA  
INFO@POST-POLIO.ORG, WWW.POST-POLIO.ORG  
314-534-0475, 314-534-5070 FAX

## Message from the President of the Volunteer Board of Directors



**Frederick M. Maynard, MD**  
President  
Volunteer Board of Directors

*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.*

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

This year was one of continuing maturation as a membership organization committed to providing leadership for improved quality of life for survivors of polio and for individuals with respiratory insufficiency. I am particularly pleased with the expanded use of the Internet as a means of giving people useful information for their lives – imagine over 30,000 visits a month. The Post-Polio Clinic Directors meetings and PHI's monthly Board meetings occur through conference calls facilitated by preparatory e-mail communications – truly a miracle of modern technologies that allow geographically separated people to work together.

In 2004, PHI provided direct help to a few polio survivors through a grant from the SPIN Foundation and from private donations. The Board received an informative report from our second Research Fund recipient. Perhaps even more exciting was learning that the project we funded enabled the University of Michigan researchers to receive more than two million dollars of new funding to continue the work we helped start – truly a successful example of “seed funding” by our modest-sized and relatively new Research Fund.

PHI Board members and staff were very busy in 2004 because of the preparations for our Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living. The hard work of Audrey King and William Wischmeyer surely paid off in a highly successful conference this past June.

The PHI Board endorsed the idea of growing our national and international potential for advocacy through Association Memberships, an expansion of our change to a membership-based organization in 2003. We hope that many of our friends in local, regional and nationally focused post-polio organizations will accept our formal offer of PHI affiliation so we can all work together more cost-effectively for improved knowledge and services that enhance the lives of people dealing with the long-term effects of polio and/or long-term ventilator use. I hope that reading this report will help renew your commitment to joining us in this effort.

A handwritten signature in black ink that reads "Frederick M. Maynard". The signature is written in a cursive, flowing style.

Frederick M. Maynard, MD  
U.P. Rehabilitation Medicine Associates, PC  
580 West College Avenue, Marquette, Michigan 49855  
fmaynard@penmed.com



**Joan L. Headley, MS**  
Executive Director

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

Two key activities come to mind when I think of 2004. One was the challenge and excitement of planning our ninth international conference to be held in 2005. In a world that by necessity changes its focus as a result of a weather system or the decision of a political system, it is difficult to pick a date, topics and presenters more than a year in advance. With the guidance of the Co-Chairs, Audrey King, Canada, and William Wischmeyer, USA, and the dedicated Board of Directors and advisory committees, an ambitious program entitled “Strategies for Living Well” was created.

The other event, speaking of ambitious, was my participation in the Japanese Ventilator Users Network nationwide symposia about the independent living of ventilator users in Japan. The talented, energetic and philosophically-driven team coordinated a symposium that was offered in three cities – Sapporo, Tokyo and Osaka over an eight-day period. The sessions were presented by other invited guests – ventilator user Audrey King, Canada; ventilator user Adolf Ratzka, PhD, Sweden; pulmonologist E.A. “Tony” Oppenheimer, MD, Los Angeles, California; along with Japan’s independent living and ventilator-assisted children advocates, ALS organizations, etc.

The rest of the year was consumed by fulfilling our mission of educating, advocating, networking and promoting research. We have compiled some numbers for you, which address quantity, and we care about numbers, but we care more about quality. We strive hard to offer quality and from what we hear from Members, we do just that.

With thanks,

A handwritten signature in black ink that reads “Joan L. Headley”.

Joan L. Headley, MS  
Post-Polio Health International  
Including International Ventilator Users Network  
4207 Lindell Boulevard, #110  
Saint Louis, Missouri 63108-2915  
director@post-polio.org

## EDUCATION

### Publications

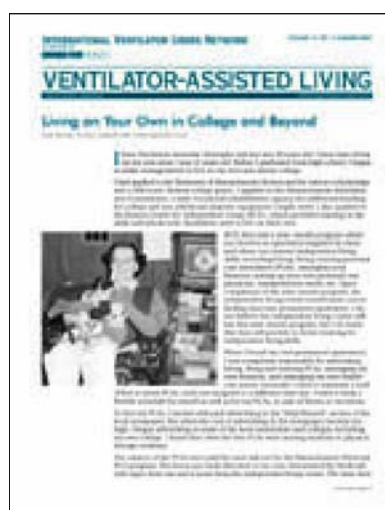
Post-Polio Health International and its affiliate International Ventilator Users Network (IVUN) granted 93 permissions to reprint articles from its publications – *Post-Polio Health* and *Ventilator-Assisted Living*. The requests came from four countries, eighteen states and nine provinces.

At the request of its Membership for information that is practical and assists in day-to-day living, Post-Polio Health International featured articles about nutrition, shoulder pain, sleep and breathing problems, long-term care and advanced directives in *Post-Polio Health*, its quarterly newsletter. The 12-page newsletter also featured the findings of PHI's 2003 Research Fund team from the University of Michigan in Ann Arbor and updates about the use of intravenous immunoglobulin in Sweden and Norway. Readers were also exposed to the story of polio in Japan, with its striking similarities to the North American experience and to very personal articles by survivors, sharing what they have learned.



*"You do a marvelous service to all of us survivors and you do it so well."*

-Martha Mason



*Ventilator-Assisted Living* continued its eighteen-year tradition of featuring stories about ventilator users from all over the world. Topics included safety, e.g., backup vents and elective surgery precautions; quality of life for 24-hour vent users and small children; recreation, e.g., scuba diving and swimming. Each issue also featured the latest in ventilatory-related technology and conferences and meetings focusing on home mechanical ventilation.

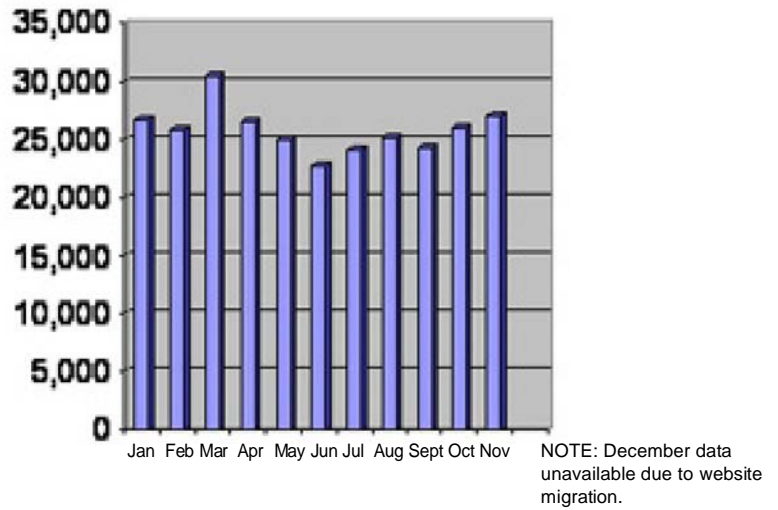
*"This is a very belated thank you for all the assistance you gave as I was preparing for my laminectomy and spinal fusion at L4-5. I am currently working through OT and I am walking better than I have in years."*

-Marylou Anderson

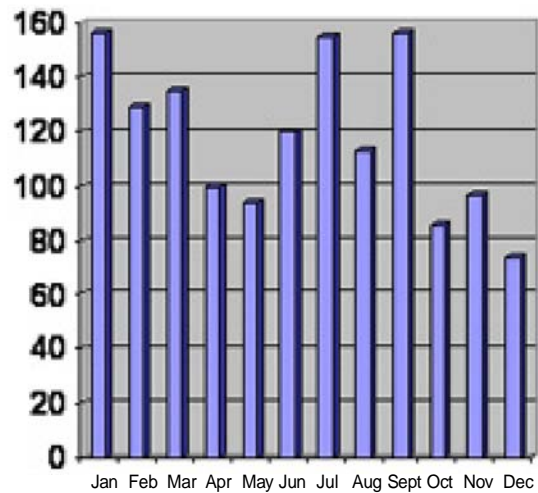
*"I just wanted to tell you how impressed I am with IVUN's website. I wish I had come across your site sooner. So much of what I have learned in the 20+ years of disability has come from trial and error and dumb luck."*

-Ines Gaudet

### Website Visits by Month in 2004



### New Contacts by Month in 2004



## NETWORKING

*"Since it is hard for Korean polio survivors to visit the Post-Polio Health International website because of the language barrier, we think it would be a great help if we could translate articles into Korean and distribute them widely."*

-Korean Polio Association

*"With the information provided by PHI, I wrote my paper without difficulty, and in the end, when it was graded and returned, I received an 'A' on the paper."*

-Kaitlyn Luangrath

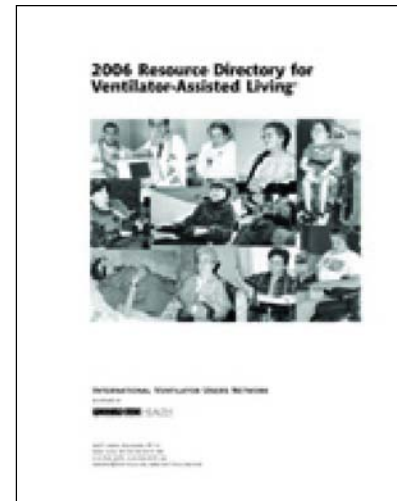
*"It has been great to finally find a source of information that is based on fact and real experience."*

-Tony Kaufenberg



Each March, Post-Polio Health International (PHI) updates its print and online **Post-Polio Directory** of post-polio clinics, health professionals and support group leaders and resources persons from around the globe. It has been called, "the place to start" for local resources.

Each October, International Ventilator Users Network, an affiliate of PHI, updates its print and online **Resource Directory for Ventilator-Assisted Living** of health professionals, ventilator users, ventilator equipment and aids with the manufacturers, and related organizations, associations and foundations. It has been called a "gold mine."



The "Can You Help?" and "What Works" areas of PHI's website – [www.post-polio.org](http://www.post-polio.org) – offer opportunities for polio survivors and ventilator users to interact with others.



**Claire Kalpakjian, PhD**

### **The Second Award**

"Women with Polio: Menopause, Late Effects, Life Satisfaction and Emotional Distress" was the title of PHI's second research grant awarded to a team of researchers from the University of Michigan Medical Center, led by Claire Kalpakjian, PhD.

The primary objective of the study was to explore the relationship between menopause and late effects for women with a history of polio. Similarly, little is known about the interaction of physical disability and menopause. In an effort to highlight the unique contribution of menopause, men with a history of polio served as a control group.

Kalpakjian submitted a preliminary report in August and a final report in early 2005. Summaries of the work published in *Post-Polio Health* have been translated into Korean and Turkish. She also submitted manuscripts to *Menopause* and *Disability and Rehabilitation* and both were accepted for publication in 2005.

On the strength of her work funded by The Research Fund of Post-Polio Health International, Kalpakjian and a colleague were awarded a 3-year \$450,000 grant from the National Institute of Disability and Rehabilitation Research to study the menopause transition in women with spinal cord injury.

### **The Third Award**

PHI's call for proposals for its third award of \$25,000 was answered by 11 applicants. Eight were from the USA; three were from international researchers. The Research Fund Review Panel selected 7 proposals and invited the researchers to submit the required elements for Phase 2 of the process. After careful review and deliberation, the Panel recommended a project submitted by Dr. Noah Lechtzin, Johns Hopkins University, to explore if earlier introduction of noninvasive ventilation prolongs survival in people with a neuromuscular condition.

The value of The Research Fund on December 31, 2004 was \$418,000.

# Major Activities

## January

^ PHI offered \$4,000 in assistance to polio survivors and ventilator users for purchasing braces, modified shoes or a scooter. The funds from private donations and the SPIN Foundation, Chicago, were given away by year's end.

## March

^ Judith Fischer, editor of *Ventilator-Assisted Living*, represented IVUN at the ALS Association 2004 Leadership Development and ALS Clinical Conference in Woodland Hills, California.

^ IVUN assisted ventilator users who use old ventilatory equipment to transition to new repairable equipment and to find unused equipment, including iron lungs, to be used for parts.

^ Joan L. Headley attended the book launching of *Walking Fingers: The Story of Polio and Those Who Lived With It*, edited by Sally Aitken, Helen D'Orazio and Stewart Valin, in Montreal, Canada.



**Helen D'Orzaio, Sally Aitken and Stewart Valin**

## April

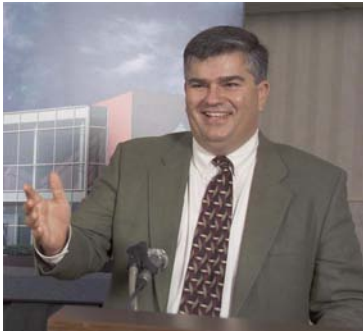
^ Frederick M. Maynard, MD and Joan L. Headley presented at the New Jersey Polio Network (NJPN) annual meeting and accepted an award given to PHI for "dedicated service since 1958 to polio survivors and ventilator users worldwide."



**Joan Headley, Frederick Maynard and Jean Csaposs at NJPN's annual meeting.**

^ Katharine Ott, PhD, National Museum of American History, and Cyndi Jones, California, polio survivor and publisher of *Mainstream* magazine, explored the Gini Laurie archives in Saint Louis to select documents for the "Whatever Happened to Polio?" exhibit to open in April 2005 at the Smithsonian Institution to commemorate the 50th Anniversary of the development of the Salk vaccine.





**William DeMayo, MD**

## June

^ In collaboration with the John P. Murtha Neuroscience & Pain Institute, Johnstown, Pennsylvania, the home of a comprehensive post-polio clinic, PHI assisted in the launching of monthly Post-Polio Clinic Directors meetings. The telephone conference calls are held the third Tuesday of each month and are moderated by William DeMayo, MD. The directors discussed the use of statin drugs, exercise, fatigue, pain and health and wellness in 2004.

^ Joan L. Headley participated in a panel discussion at the annual meeting of The Society for Disability Studies held in Saint. Louis. She talked about the role of Gini Laurie in the local and international independent living movement.

^ IVUN Consumer Advisory Committee members Audrey King, Toronto, Canada, and Adolf Ratzka, PhD, Sweden, and Medical Advisory Committee member and pulmonologist E.A. "Tony" Oppenheimer, MD, from Los Angeles, California, joined Joan L. Headley for Japan Ventilator Users Network (JVUN) three symposia. The symposia, that drew over 1,000 people, were a dream of JVUN founder Kimiyo Sato, Sapporro. JVUN produced a video of the symposia with extensive interviews of the guest speakers and Japanese ventilator users.

Joan L. Headley visited post-polio groups in Osaka and Tokyo.



**(l to r) Adolf Ratzka, Kimiyo Sato, Dr. Oppenheimer, Joan Headley, Audrey King**

**Joan Headley (far right) with post-polio group in Osaka.**



## July

^ The Board of Director's voted to create a Post-Polio Health International Consumer Advisory Committee and a separate International Ventilator Users Network Consumer Advisory Committee.

## August

- ^ PHI distributed information at an exhibit booth at the Saint Louis Assistive Technology Fair.
- ^ PHI distributed the preliminary report from a team of researchers at the University of Michigan, Department of Physical Medicine and Rehabilitation, exploring the difference between menopause in women with disabilities and nondisabled women. The team was the recipient of The Research Fund's second award (\$25,000).

## September

- ^ Joan L. Headley presented at the annual meeting of the Post-Polio Support Group of the Lehigh Valley.
- ^ Alan Fiala, ventilator user and polio survivor, Falls Church, Virginia, represented PHI at a workshop hosted by the Christopher and Dana Reeve Paralysis Resource Center. The purpose of the workshop was to develop "Public Health Action Plan" for persons living with paralysis.
- ^ The Japan Polio Survivors Network was granted permission to translate PHI's *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*.

## October

- ^ Judith R. Fischer attended the annual meeting of the American College of Chest Physicians in Seattle, representing IVUN at the meetings.
- ^ IVUN accepted donation of five used PLV-100s to distribute to persons in need in other countries. Ventilators were shipped to Israel, Mexico, Pakistan and Turkey.
- ^ The Board of Directors accepted The Research Fund Review Panel's recommendation to award its third grant to Dr. Noah Lechtzin, Johns Hopkins University, who will investigate if the earlier use of noninvasive ventilation will prolong survival in those with a neuromuscular disorder.



Joan Headley presenting at Johnstown meeting.

## November

- ^ Joan L. Headley presented at a one day meeting sponsored by the John P. Murtha Neuroscience & Pain Institute, Johnstown, Pennsylvania.

## December

- ^ Organización Post-Polio México was granted permission to translate sections of the PHI's *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors* for their website.

## *Special Acknowledgements*

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

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

Claire Kalpakjian, PhD, University of Michigan Medical Center  
The Second Research Fund Award recipient

Audrey King, Toronto, Canada  
Conference Co-Chair, Ninth International Conference on Post-Polio Health  
and Ventilator-Assisted Living: Strategies for Living Well

William Wischmeyer, Saint Louis, Missouri  
Conference Co-Chair, Ninth International Conference on Post-Polio Health  
and Ventilator-Assisted Living: Strategies for Living Well

## *Contributors*

### **Sponsorships and Grants** (\$5,000 and over)

Edouard Foundation

Ira Holland Trust

March of Dimes

Puritan Bennett Division of Tyco Healthcare

ResMed Ltd.

Thomas W. Rogers Trust

### **Matching Funds from**

Bank of America

General Motors Foundation

Morgan Stanley Annual Appeal Campaign

There were 858 individual donations to the general fund in 2004.

There were 2651 individual donation memberships in 2004.

There were 675 individual donations to The Research Fund in 2004.

Donors' names are provided upon request ([info@post-polio.org](mailto:info@post-polio.org)).

*Special thanks to  
Ira Holland, New York,  
for remembering  
Post-Polio Health  
International in his  
estate and contributing  
to the work of  
International Ventilator  
Users Network.*

## Financial Statements

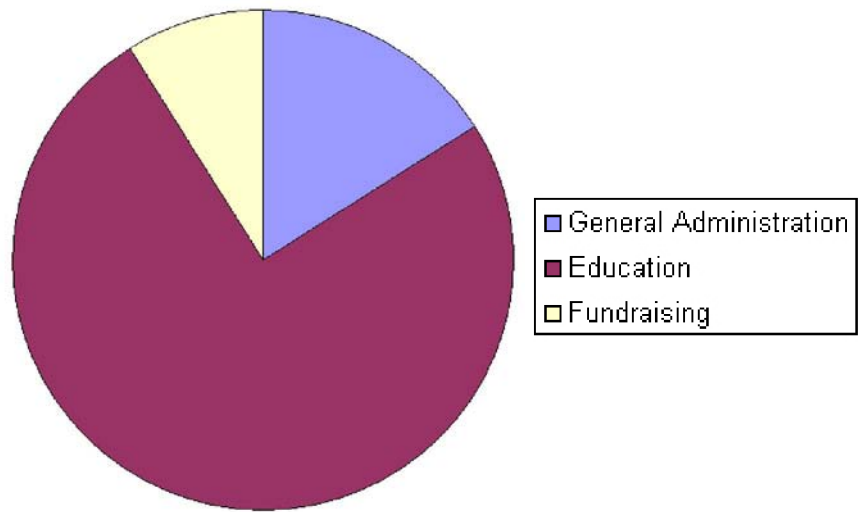
### Post-Polio Health International, Inc. Statement of Assets, Liabilities, and Net Assets - Cash Basis December 31, 2004

ASSETS		
Cash		\$ 44,273
Prepaid expenses		9,848
Investments		676,510
Office equipment		9,491
Accumulated depreciation		(8,643)
	TOTAL ASSETS	\$731,479
NET ASSETS		
Unrestricted		\$341,854
Temporarily restricted		389,625
	TOTAL NET ASSETS	\$731,479
CHANGES IN UNRESTRICTED NET ASSETS		
REVENUES		
Memberships		\$84,178
Contributions		62,204
Publications		7,901
Investment income		15,099
Capital gain distributions		589
Gain on sale of securities		1,969
Unrealized gain on investments		35,354
Miscellaneous		0
Contributions released from restrictions		36,236
	TOTAL UNRESTRICTED REVENUES	\$243,530
EXPENSES		
Education		\$170,186
General and administrative		36,003
Fundraising		21,725
	TOTAL EXPENSES	\$227,914
	INCREASE IN UNRESTRICTED NET ASSETS	\$15,616
CHANGES IN TEMPORARILY RESTRICTED NET ASSETS		
Contributions		\$82,157
Net assets released from restrictions		(36,236)
	INCREASE IN TEMPORARILY RESTRICTED NET ASSETS	*45,921
	INCREASE IN NET ASSETS	61,537
	NET ASSETS AT BEGINNING OF YEAR	669,942
	NET ASSETS AT END OF YEAR	\$731,479

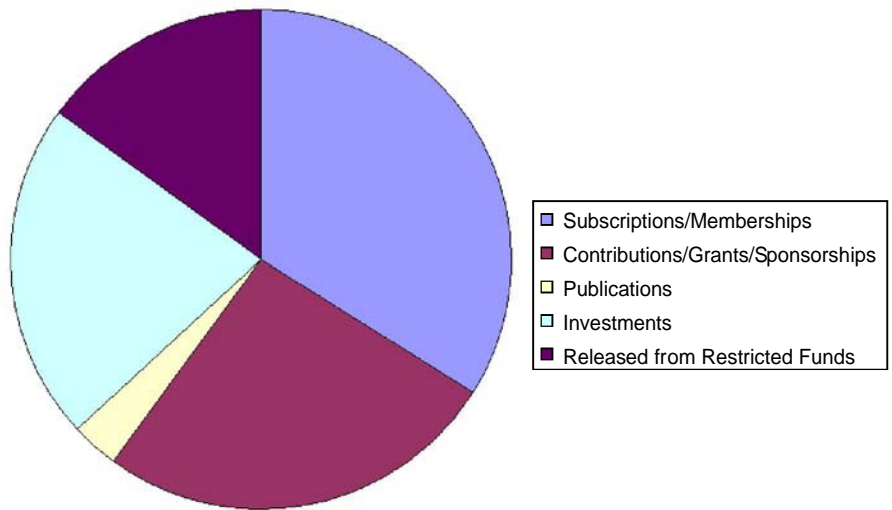
\*A major component of PHI's mission is to fund research projects that have the potential to benefit polio survivors and users of home ventilators. To that end, PHI established The Research Fund in 1995. Contributions to The Research Fund are called "restricted assets" because PHI may use these monies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

**Expense Allocation 2004 - \$227,914**



**Funding Sources 2004 - \$243,500**



## *Board, Committees and Staff*

### **Board of Directors**

Frederick M. Maynard, MD, *President/Chairperson*  
U.P. Rehabilitation Medicine Associates, PC  
Marquette, Michigan

Lawrence C. Becker, PhD, *Vice President*  
Professor Emeritus, William & Mary  
Roanoke, Virginia

Judith R. Fischer, MSLS, *Secretary*  
Cypress, California

Gayla Hoffman, *Assistant Secretary*  
Public Relations Consultant  
Saint Louis, Missouri

Rich Hokamp, *Treasurer*  
Attorney-At-Law  
Saint Louis, Missouri

Linda L. Bieniek, CEAP  
La Grange, Illinois

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

Judith E. Heumann, MPH  
Advisor, Disability and Development, World Bank  
Washington, DC

Beth Kowall, MS, OTR  
Post-Polio Resource Group of Southeastern Wisconsin  
Greenfield, Wisconsin

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

Martin B. Wice, MD, Past President/Chairman  
Medical Director, St. John's Mercy Rehabilitation Center  
Saint Louis, Missouri

William Paul Wischmeyer  
Affiliate Associate Professor, Washington University School of Architecture  
Saint Louis, Missouri

## **Honorary Board**

Augusta S. Alba, MD (retired)

Coler Goldwater Specialty Hospital and Nursing Facility  
Roosevelt Island, New York

Henry Betts, MD

Rehabilitation Institute of Chicago, Chicago, Illinois

Hugh G. Gallagher (deceased)

Author, historian, and advocate, Cabin John, Maryland

Allen I. Goldberg, MD, MM, FAAP, FACPE, FCCP

Director, Pediatric Home Health, Loyola University Medical Center,  
Maywood, Illinois

Jacquelin Perry, MD, DSc (Hon) (retired)

Medical Consultant, Post-Polio Service

Rancho Los Amigos National Rehabilitation Center, Downey, California

Anna Eleanor Roosevelt

Chicago, Illinois

Max J. Starklof Institute for Disability Strategies, Saint Louis, Missouri

Gertrud Weiss (deceased)

Bundesverband Polio e.V. Germany, Rosenheim, Germany

## **Consumer Advisory Board**

William Paul Wischmeyer, *Chair*

Affiliate Associate Professor, Washington University School of Architecture  
Saint Louis, Missouri

Richard L. Daggett

Polio Survivors Association, Downey, California

Laura Hershey

Consultant, writer, advocate, Denver, Colorado

Mirsada Karadzic

International Institute of Saint Louis, Saint Louis, Missouri

Audrey J. King, MA

Psychologist, researcher, advocate, Don Mills, Ontario, Canada

Barbara Rogers

Respiratory Resources, New York, New York

William Wendling

Wendling Communications, Cleveland, Ohio

### **Medical Advisory Committee**

Martin B. Wice, MD, *Chair*

Medical Director, St. John's Mercy Rehabilitation Center  
Saint Louis, Missouri

Selma H. Calmes, MD

Anesthesiology, Olive View/UCLA Medical Center, Los Angeles, California

Marinos C. Dalakas, MD

National Institute of Neurological Disorders & Stroke (NINDS)  
Bethesda, Maryland

Burk Jubelt, MD

Department of Neurology, SUNY Health Science Center, Syracuse, New York

Julie G. Madorsky, MD

Clinical Professor of Rehabilitation Medicine

Western University of Health Services, University of California-Irvine  
Encino, California

Frederick M. Maynard, MD

U.P. Rehabilitation Medicine Associates, PC, Marquette, Michigan

E.A. (Tony) Oppenheimer, MD, FACP, FCCP

Pulmonary Medicine (retired), Los Angeles, California

Oscar Schwartz, MD, FCCP, FAASM

Advantage Pulmonary, Saint Louis, Missouri

Mark K. Taylor, MLS, CPO

Director, Clinical and Technical Services, Orthotics and Prosthetics Center  
University of Michigan, Ann Arbor, Michigan

Daria A. Trojan, MD

Assistant Professor, Physical Medicine and Rehabilitation,  
Montreal Neurological Institute and Hospital, Montreal, Quebec, Canada

### **Staff**

Joan L. Headley, MS, *Executive Director*

Justine N. Craig-Meyer, BA

*Assistant to Executive Director/Member Services*

Sheryl R. Rudy, *Graphic Designer/Webmaster*

### **Consultants**

Doris Jones, *Accountant*

Lucky L. Leong, LLC, *Certified Public Accountant*



## How You Can Support This Vital Work

### **Join Post-Polio Health International including International Ventilator Users Network.**

Membership donations are 100 percent tax deductible as permitted by law.

### **Encourage others you know – family, relatives, friends – to join in supporting this cause.**

For \$15 each, they, too, can be Members.

### **Consider increasing the level of your Membership.**

### **Send a donation.**

### **Memorials & Tributes.**

### **Offer to provide services in-kind if you have skills you can share or a business that can provide a useful service.**

### **Donate gifts in-kind, such as needed equipment or products.**

To offer "Gifts-in-Kind" sponsorships, or to ask about the needs of PHI, contact Joan L. Headley, Executive Director, at 314-534-0475 or [director@post-polio.org](mailto:director@post-polio.org).

### **Visit [www.post-polio.org](http://www.post-polio.org) and [www.post-polio.org/ivun](http://www.post-polio.org/ivun)**

periodically to keep up-to-date on the latest disability events, legislative and advocacy efforts, and news affecting polio survivors, ventilator users, their families and friends.

### **LEAVE A LEGACY by investing in the vital work of Post-Polio Health International including International Ventilator Users Network.**

One simple and effective way to leave a legacy is to make a bequest in your will or living trust to support a cause dear to your heart or to a loved one. Post-Polio Health International including International Ventilator Users Network would value immensely being included in tax-saving estate planning – through wills, trusts, annuities, real estate, life insurance policies, and stocks, bonds and mutual funds.

Many qualified retirement plans are over-funded and, depending on a person's tax level, may be taxed up to 85 percent before one's children or heirs receive money.

Designating a non-profit as a subsequent beneficiary of a qualified fund will allow the remaining amount to go to the charity with no taxes owed at the time of the person's death. We recommend that you consult a financial and/or legal professional for specific information as to the legal or financial considerations that apply to your situation.

PHI's Federal I.D. No. 34-0961952