

ANNUAL REPORT 2015-2016

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.



1960s

Donna McGwinn and
Mickie McGraw



1970s

Imogene Pritchard



1980s

Joe Laurie, Gini Laurie, Justin Dart



1990s

Joan L. Headley, Frederick M.
Maynard, MD, Judith R. Fischer,
D. Armin Fischer, MD



2000s

Spirit of the ADA Torch,
Bill Stothers, Carol Cox,
Cyndi Jones



2010s

Joan L. Headley, Judith R.
Fischer, Curtis N. Sessler, MD

POST-POLIO HEALTH
INTERNATIONAL

POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

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post-polio.org ■ polioplacel.org ■ ventusers.org ■ ventnews.org

Message from PHI Board President and Executive Director

Our first mutual message to our Membership and donors was a review of 2009-2010, seven years ago. At that time the Board reaffirmed its mission to provide solid information to its core constituents, recognizing new technologies as a way to reach polio survivors around the world.

Against that general statement of mission, we present our summary of 2015-2016 more specifically by listing goals and actions accomplished by Post-Polio Health International (PHI) and International Ventilator Users Network (IVUN).

Our message would be incomplete if we didn't thank the many volunteers committed to PHI and IVUN. The organization attracts special people – people who are giving, caring and independent and creative thinkers, who are willing to contribute ideas, opinions, time and funds. Many admit that the success of the organization is in their own best interest and others know that their contributions help those who can't give back at this moment in their life.

While enumerating our service to polio survivors and ventilator users and the health professionals who treat them, we are ever cognizant of the decrease in the population of our core constituents and the onward march of technology that affects our methods and operations.

With this in mind, the Board of Directors of PHI continues to reevaluate its mission and methods.

Lastly, we want our Membership to know that The Research Fund and Polio Place (www.polioplace.org) have had a powerful impact on the polio survivors and ventilator users worldwide who are outside of our core Membership. You made that possible.



William G. Stothers

Chair
Post-Polio Health International
San Diego, California



Joan L. Headley, MS

Executive Director
Post-Polio Health International
Saint Louis, Missouri

Photo courtesy of Fran Henke

To review prior organizational reports starting in 2001, [visit here](#).

Board of Directors (2015-2016)

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Ann Arbor, Michigan

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St. Louis, Missouri

Brian M. Tiburzi
Assistant to the Executive Director
St. Louis, Missouri

Special thanks to

Sheryl Rudy, newsletter and web designer

Gayla Hoffman, Gayla Hoffman Associates, newsletter editor

Lucky Leong, LLC, Certified Public Accountant

Todd Harrell, AAMS, Edward Jones

The Research Fund, established in 1995, comprises 78% of PHI's assets.

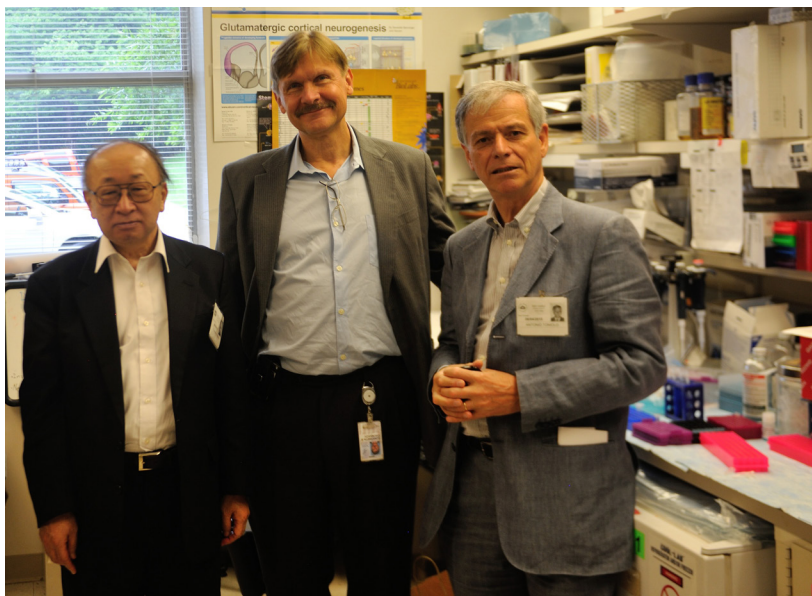
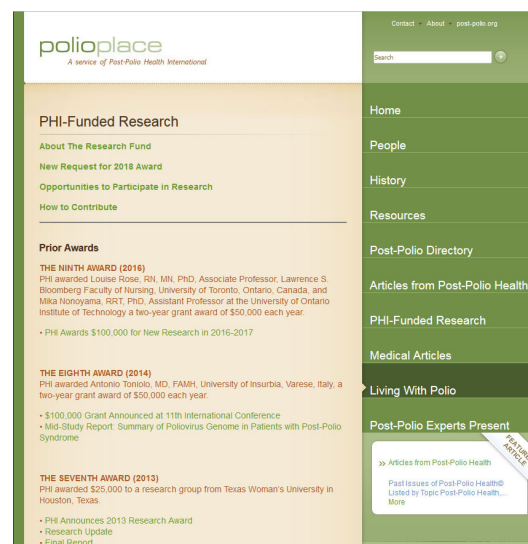
The funds are earmarked and restricted for "seeking scientific information leading to eventual amelioration of the consequences of poliomyelitis and/or neuromuscular respiratory diseases," as established in 1995.

In 2014, the PHI Board of Directors decided to offer a grant annually with a maximum of \$50,000 each year and allowing researchers to apply for work completed in a two-year period (i.e., \$100,000). They also expanded the call to "the management of neuromuscular respiratory insufficiency or the late effects of polio and to explore historical, social, psychological and independent living aspects of long-term home mechanical ventilation or living with polio." ([See call for proposals for 2018.](#))

The first grant of this magnitude, "Poliovirus genome in patients with post-polio syndrome (PPS): Defining virus mutations by novel genome sequencing methods and investigating possible treatments with antiviral antibodies and drugs," was awarded in 2014 to a team with researchers in Italy and the United States (*See photo.*) Antonio Toniolo, MD, Professor of Medical Microbiology, University of Insubria, Varese, Italy, leads the study team in Italy and collaborates with Konstantin M. Chumakov, PhD, Office of Vaccines Research and Review (OVRR) at the Food and Drug Administration, in the United States.

The Research Fund Review Panel, comprised of experts in research and persons with disabilities, selected a two-year grant in 2015 for 2016-2017 entitled "Cough Assist: use education needs, health service utilization and outcomes." The lead researchers are Louise Rose, RN, MN, PhD, Associate Professor, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, Ontario, Canada, and Mika Nonoyama, RRT, PhD, Assistant Professor at the University of Ontario Institute of Technology.

[PHI-Funded Research](#)
(Prior awards)



Left to right: Drs. Takashi Onodera, Konstantin Chumakov and Antonio Toniolo at National Institutes of Health discussing how to apply novel sequencing methods for examining poliovirus isolates of PPS cases.

Polio Place

The PHI Board of Directors determined in the late 2000s that it would create a place on the internet to house all of the organization's publications and activities, from 1958 to present. Their commitment—a place for all things polio—was on behalf of polio survivors worldwide. With the financial support of the Roosevelt Warm Springs Foundation (RWSF), Polio Place was born.

The information on [Polio Place](#) is available for free to survivors and families all over the globe. It is also helpful for advocates and health professionals to use and to adapt for their own country and situation.

Its content is historical, medical, practical and personal.

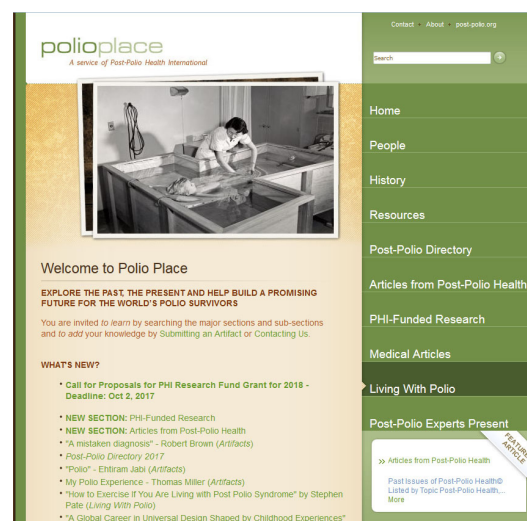
Polio Place uses Drupal™, an open-source web content management platform and is in a simplified format to make it easier for individuals in developing countries to access the knowledge.

PHI continually adds content to Polio Place in all of its areas.

In 2015, PHI improved the function of the [Living with Polio](#) section and expanded its content. The section now contains 270 separate entries about Living with Polio.

In 2016, PHI added 11 additional videos to its [Post-Polio Experts Present \(Video Series\)](#)

PHI's recent project has been to translate seminal articles into Spanish and Turkish.



International Ventilator Users Network in Review (2015-2016)

Education, Networking, Advocacy

Goal: *Provide easier access to IVUN resources.*

- In February 2015, International Ventilator Users Network (IVUN) changed the way of delivering [Ventilator-Assisted Living](#), its bimonthly newsletter. The newsletter is now published immediately on IVUN's new site www.ventnews.org and Membership is notified by email.
- The popular [Resource Directory for Ventilator-Assisted Living](#) is now located on the front page.

Goal: *Expand information about, for and by younger adult ventilator users.*

- IVUN published the life stories of seven ventilator users highlighting their education and employment experiences in *Ventilator-Assisted Living*. Meggin, Joel, Kristen, Annalies, Nicolas, Deborah and Justin represented individuals with muscle myopathy, spinal cord injury, Congenital Central Hypoventilation Syndrome (CCHS), Mitochondrial Cytopathy, Spinal Muscular Atrophy Type 1 and centronuclear myopathy.

Goal: Promote mutual understanding of ventilator user and healthcare professional perspectives of HMV.

- Post-Polio Health International (PHI) and the International Ventilator Users Network (IVUN) contributed \$67,000 to The CHEST Foundation, the philanthropic arm of the American Academy of Chest Physicians (ACCP) to endow the Margaret Pfrommer Endowed Memorial Lecture in Home-Based Mechanical Ventilation at the professional group's annual meeting.

PHI's gift assures that home mechanical ventilation will always be a topic at the annual meeting and assures that younger physicians will be exposed to the philosophy, skills and techniques of providing care for adults and children with neuromuscular disease who live at home on mechanical ventilation.

- Joan L. Headley is a consultant on the ACCP Home-Based Mechanical Ventilation and Neuromuscular Disease NetWork Steering Committee.
- The reorganized *Ventilator-Assisted Living* features a section called "Recent Relevant Publications," which includes summaries and links to selected professional, disability, disease journals and newsletters, encouraging each group to read what the other is reading.

Goal: Listen to users of home mechanical ventilation.

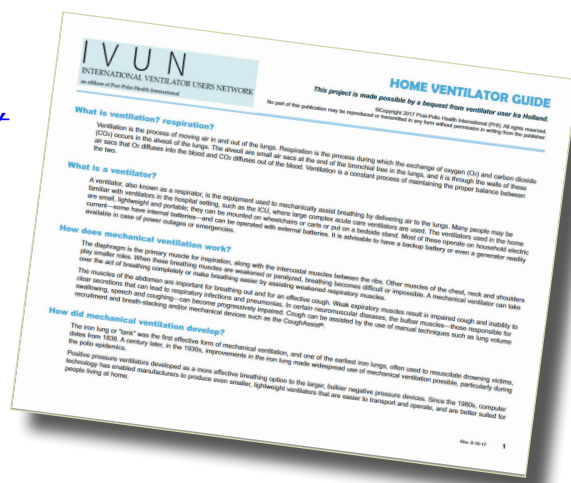
- Joan L. Headley, presented data from a [survey of ventilator users](#) and health professionals in Lyon, France, the site the 2nd Joint International Meeting of Journées Internationales de Ventilation à Domicile (JIVD) and European Respiratory Care Association (ERCA) held March 26-28, 2015.
- The reorganized *Ventilator-Assisted Living* features a section called "Ventilator Users Speak," in which they can formally share their experiences and concerns.

Goal: Track new, recalled and obsolete ventilator equipment.

- IVUN continually updates its [Home Ventilator Guide](#), a chart of the technical details of devices used for home mechanical ventilation that is arranged by modes and includes important manufacturing and out-of-service dates.
- IVUN coordinated with Respironics Colorado to assure that those in need of obsolete equipment had an opportunity to receive any available donations.

Goal: Explain and influence government policies related to HMV.

- IVUN participates in discussions and letter-writing campaigns to effect change in the policies and payments for home mechanical ventilation use.



Post-Polio Health International in Review (2015-2016)

Education, Networking, Advocacy

Goal: *Promote positive images of post-polio life.*

- The PHI-instigated WE'RE STILL HERE! campaigns ran photo contests depicting Show Me accessibility! And Family Life!

Goal: *Provide expert guidance about post-polio medical and psychological problems.*

- *Post-Polio Health*, PHI's quarterly print newsletter answers universal questions about post-polio syndrome by experts Frederick M. Maynard, MD, and Stephanie Machell, PsyD, and Rhoda Olkin, PhD.

- PHI's Medical Advisory Committee reviewed the content about post-polio syndrome on UpToDate™ and DynaMed, two commonly used evidence-based clinical decision support resources for health professionals.

Goal: *Examine the status of polio survivors living outside the US.*

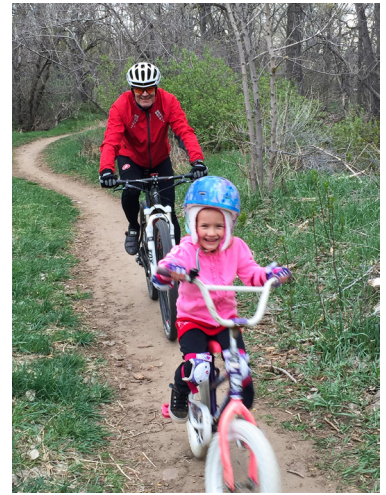
- *Post-Polio Health* featured articles about the need for post-polio services in Australia, India and Turkey.
- PHI staff answers post-polio questions of survivors from around the world generated by their accessing www.polioplace.org. (See page 4 or 5 about [Polio Place](http://www.polioplace.org).)

Goal: *Address the two major concerns expressed by aging survivors: weight and housing.*

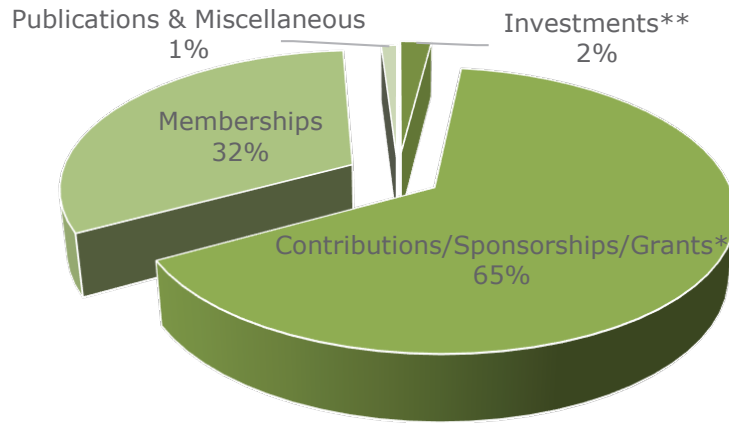
- [Post-Polio Health](#) featured articles written by polio survivors Karen Hagrup, Beverly Schmittgen and Joyce Tepley in which they explained their choice of a housing solution for survivors with new weakness.
- [Post-Polio Health](#) featured articles about nutrition and healthy weight loss by survivor advocates Anne Crocker and Sunny Roller.

Goal: *Educate about government policies.*

- PHI published guides to obtaining Social Security Disability Insurance (SSDI), to navigating the steps to obtaining the best mobility device or breathing device, and an examination of the history and current state of the ICD-10 codes that are relevant to post-polio medical problems.



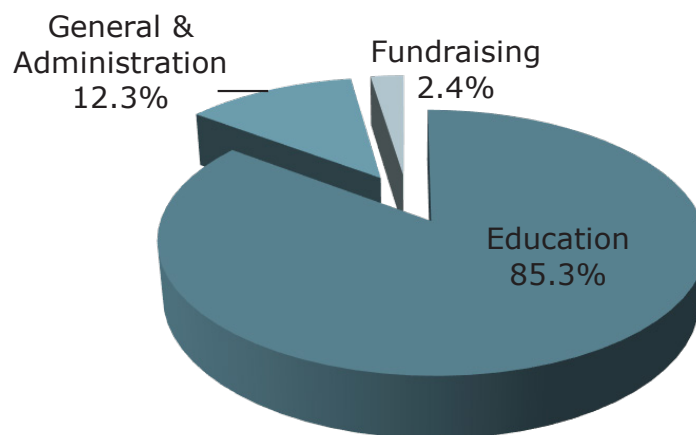
Funding Sources 2015 - \$272,221



*Includes \$103,249 of contributions and \$75,775 of contributions released from restrictions.

**Does not reflect unrealized loss from investment activities in the amount of \$7,064.

Expense Allocation 2015 - \$292,780



**Statement of Assets, Liabilities and
Net Assets – Cash Basis**

December 31, 2015

ASSETS

Current Assets

Cash and cash equivalents	\$101,581
Investments at fair market value	<u>167,530</u>
Total Current Assets	<u>269,111</u>

Fixed Assets

Office equipment, at cost	1,798
Accumulated depreciation	<u>(1,798)</u>
Net Fixed Assets	<u>0</u>

Long-Term Investments	<u>742,759</u>
TOTAL ASSETS	<u><u>\$1,011,870</u></u>

LIABILITIES

Current Liabilities

Payroll withholding payable	<u>\$ 3,350</u>
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NET ASSETS

Unrestricted	326,933
Temporarily restricted	<u>681,587</u>
Total Net Assets	<u>1,008,520</u>
TOTAL LIABILITIES & NET ASSETS	<u><u>\$1,011,870</u></u>

Statement of Revenues, Expenses and Other Changes in Net Assets – Cash Basis

Year Ended December 31, 2015

CHANGES IN UNRESTRICTED NET ASSETS

REVENUES

Memberships	\$ 89,652
Contributions	103,249
Publications	2,498
Investment income	7,598
Gain on sale of securities	513
Unrealized loss on investments	(7,064)
Contributions released from restrictions	75,775

TOTAL UNRESTRICTED REVENUES	272,221
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EXPENSES

Education	249,759
General and administrative	36,068
Fundraising	6,953

TOTAL EXPENSES	292,780
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DECREASE IN UNRESTRICTED NET ASSETS	(20,559)
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CHANGES IN TEMPORARILY RESTRICTED NET ASSETS

Contributions	13,039
Refunded research grant	9,423
Investment income	35,883
Loss on sale of securities	(857)
Unrealized loss on investments	(56,331)
Net assets released from restrictions	(75,775)

DECREASE IN TEMPORARILY RESTRICTED NET ASSETS	(74,618)
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DECREASE IN NET ASSETS	(95,177)
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NET ASSETS AT BEGINNING OF YEAR	1,103,697
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NET ASSETS AT END OF YEAR	\$1,008,520
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Major Contributors, 2015

\$44,000

Estate of Doris A. Jones

\$10,000 and over

Helen Ford

The Chervenak-Nunnallé Foundation

\$5,000 and over

Geraldine M. Robinett Lee

Bonnie & Eric Helpenstell

Estate of Annette Katherine Johnson

Bruce Lambert

Richard A. Miro

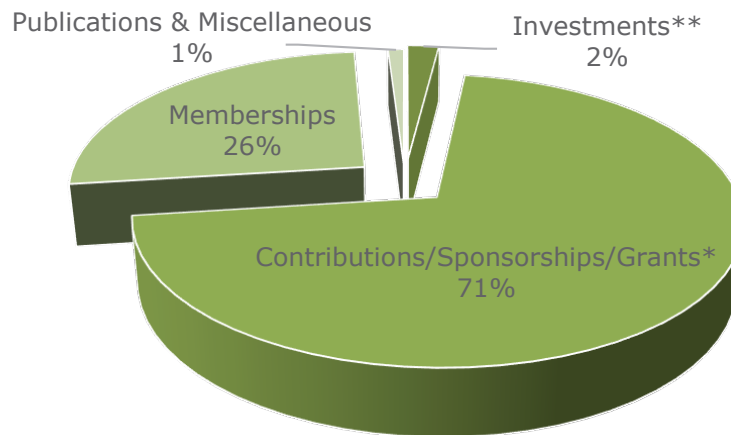
The Research Fund

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*.

On December 31, 2015, The Research Fund assets were \$742,758.94. The Research Fund is a special fund containing dollars given to support research into post-poliomyelitis and neuromuscular respiratory conditions. The organization distributed \$49,988.00 in awards in 2015.

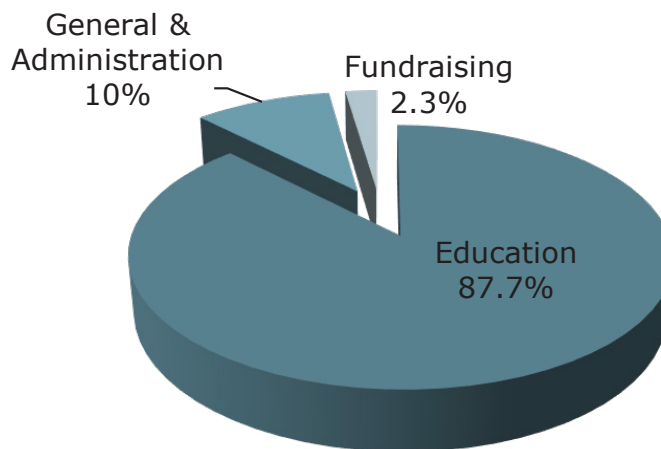
Financial Information 2016

Funding Sources 2016 - \$295,093



*Includes \$74,035 of contributions and \$136,462 of contributions released from restrictions.
**Does not reflect unrealized gains from investment activities in the amount of \$6,628.

Expense Allocation 2016 - \$337,349



Post-Polio Health International, Inc.

**Statement of Assets, Liabilities
and Net Assets – Cash Basis**

December 31, 2016

ASSETS

Current Assets

Cash and cash equivalents	\$ 75,824
Investments at fair market value	<u>170,945</u>
Total Current Assets	<u>246,769</u>

Fixed Assets

Office equipment, at cost	1,798
Accumulated depreciation	<u>(1,798)</u>
Net Fixed Assets	<u>0</u>

Long-Term Investments	<u>685,591</u>
TOTAL ASSETS	<u><u>\$932,360</u></u>

LIABILITIES

Current Liabilities

Payroll withholding payable	<u>\$ 2,924</u>
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NET ASSETS

Unrestricted	291,305
Temporarily restricted	<u>638,131</u>
Total Net Assets	<u>929,436</u>
TOTAL LIABILITIES & NET ASSETS	<u><u>\$932,360</u></u>

**Statement of Revenues, Expenses and
Other Changes in Net Assets – Cash Basis**

Year Ended December 31, 2016

CHANGES IN UNRESTRICTED NET ASSETS

REVENUES

Memberships	\$ 77,151
Contributions	74,035
Publications	1,868
Investment income	5,582
Loss on sale of securities	(5)
Unrealized gain on investments	6,628
Contributions released from restrictions	<u>136,462</u>
TOTAL UNRESTRICTED REVENUES	<u>301,721</u>

EXPENSES

Education	295,926
General and administrative	33,775
Fundraising	<u>7,648</u>
TOTAL EXPENSES	<u>337,349</u>

DECREASE IN UNRESTRICTED NET ASSETS (35,628)

CHANGES IN TEMPORARILY RESTRICTED NET ASSETS

Contributions	40,807
Investment income	24,195
Loss on sale of securities	(978)
Unrealized gain on investments	28,982
Net assets released from restrictions	<u>(136,462)</u>

DECREASE IN TEMPORARILY RESTRICTED NET ASSETS (43,456)

DECREASE IN NET ASSETS (79,084)

NET ASSETS AT BEGINNING OF YEAR 1,008,520

NET ASSETS AT END OF YEAR \$929,436

Major Contributors, 2016

\$20,000 and over

Roosevelt Warm Springs Foundation

\$10,000 and over

Greater Boston Post Polio Association

The Chervenak-Nunnallé Foundation

\$5,000 and over

Geraldine M. Robinett Lee

Bonnie & Eric Helpenstell

The Research Fund

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On December 31, 2016, The Research Fund assets were \$685,590.54. The Research Fund is a special fund containing dollars given to support research into post-poliomyelitis and neuromuscular respiratory conditions. The organization distributed \$50,000 in awards plus \$67,000 to the Margaret Pfrommer Endowed Memorial Lecture in Home-based Mechanical Ventilation in 2016.



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