

**A N N U A L  
R E P O R T**

**Gazette  
International  
Networking  
Institute**

*Coordinator of International Polio Network  
and International Ventilator Users Network*

Now

**POST-POLIO HEALTH**  
INTERNATIONAL

POST-POLIO HEALTH INTERNATIONAL  
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

**2001  
&  
2002**

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## Vision

*To lead the worldwide effort to improve the lives of polio survivors and ventilator users.*

## Mission

*To enhance the lives and independence of polio survivors and home ventilator users through education, advocacy, research, and networking.*

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# Who We Are

## GINI Is Now Post-Polio Health International

Gazette International Networking Institute (GINI) has changed its name to Post-Polio Health International. The Board's decision in 2002 reflects a more focused scope of services and broader constituency and includes development of a new membership structure to strengthen the organization's advocacy role.

The new name, Post-Polio Health International, is meant to project the broadest meaning of "health," encompassing the physical, emotional, social, psychological, and spiritual aspects of individuals' lives. The new name also reaffirms an ongoing interest in international issues.

"We knew that GINI meant only 'post-polio' or 'home ventilator use' to those who knew our past. We decided to focus on the future — knowing that our founder, Gini Laurie, would have agreed," said Frederick M. Maynard, MD, board president. "And in Gini's tradition, board and staff have worked hard to roll out the new plans."

While the majority of the people it serves are polio survivors, Post-Polio Health International (PHI) will continue to respond to the needs of all ventilator users through its affiliate, International Ventilator Users Network. Historically, the first ventilator users were polio survivors who had used iron lungs. Now, a growing number of people with a variety of conditions use home mechanical ventilation.

The newsletters have been renamed *Post-Polio Health* (replacing *Polio Network News*) and *Ventilator-Assisted Living* (formerly *IVUN News*). Future issues of both will feature new formats and more news. *Rehabilitation Gazette* was discontinued, and pertinent cross-disability information will be incorporated into both of the newsletters.

Support group leaders and organizations with similar missions will still be able to depend on our storehouse of knowledge and reserve of interconnected people. PHI will continue to collaborate with health professionals and equipment manufacturers and will identify additional entities with compatible goals and philosophies to create influential relationships to further the mission.

The new membership structure is designed to strengthen Post-Polio Health International's ability to advocate for its constituents. Current members are encouraged to invite others — relatives and friends — to support our cause by becoming members and by supporting our sponsors.

## Our Founder



Virginia Grace "Gini" Laurie  
1913-1989

*"I prefer to think of it as an interdependent living movement."*

Laurie's volunteer experiences in a polio respiratory ward in Cleveland, Ohio, in the 1950s led her to found the organization that continues to work for and with ventilator users and polio survivors.

## Honorary Board

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Coler Goldwater Specialty Hospital  
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Author, historian, and advocate  
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*Graphic Designer*

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*Accountant*

Lucky L. Leong, LLC  
*Certified Public Accountant*

## Questions for the Executive Director and Board President



Frederick M. Maynard, MD,  
Board President, and  
Joan L. Headley, MS,  
Executive Director

## What were high points of GINI's 2001 and 2002?

**JOAN:** 2001 was the year in which we planned to focus on the *inner workings* of GINI. The goal was to have a board retreat in April 2002 to discuss how to strengthen the organization internally so that we could do a better job of what people see as our *external work* for polio survivors and vent users.

In addition to our normal publications and speaking schedule, two other **information/communications activities** stand out.

First, we became the dissemination arm for two March of Dimes informational pamphlets about the late effects of polio. We coordinated the translation into Spanish and French and sent out some 8,000 reports to doctors and other health care professionals.

Second, we collaborated with Journées Internationales de Ventilation à Domicile (JIVD) and other groups on the Eighth International Conference on Home Mechanical Ventilation in Lyon. Board member Linda Bieniek spoke about how she works with her health care professionals. Judith Fischer, Board member and editor of the ventilator newsletter moderated a session, and I talked about the history and philosophy of the independent living movement.

In terms of **advocacy** in the year, among other things, I attended a World Health Organization meeting in Oslo in April. The importance of the session was that the recommendations we developed were sent to the United Nations. Disabled people have worked for years to have meaningful input to the priorities and decisions of the UN.

It was concluded that, when creating programs for people with disabilities, it is extremely important to involve disabled people from the beginning and throughout the process to make the programs most effective.

We also funded **research** last year. We awarded a \$20,000 research grant to a group in Toronto to research "Ventilator Users' Perspectives on the Elements of Health-Related Quality of Life." The final report can be found at [www.post-polio.org/QofLFINALREPORT-Sept2002.pdf](http://www.post-polio.org/QofLFINALREPORT-Sept2002.pdf).

We've screened another group of proposals for a second research grant and awarded a \$25,000 grant in October 2001, to a team at the University of Michigan. This study will focus on the effects of menopause on female polio survivors, and will use men as a control group. No research has been done comparing the effects of polio on women and men.

We also conducted a **readership survey** in 2001. I want to thank our loyal readers for their support and encouragement. Believe me, this means a great deal to all our contributors and helps us to decide what to change and, more importantly, what not to change.

In 2002, our Board of Directors met to plot a course to assure the organization's existence for at least another 40 years.

**FRED:** The Board retreat was an exciting opportunity for us. As a far-flung organization operating on a shoestring, we almost always meet by telephone. This retreat allowed us to meet face-to-face, and that was great.

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Of course, the purpose of the retreat was to become a more effective lobbying organization for ventilator users and polio survivors. Part of that effectiveness means raising more money to realize a higher level of effectiveness.

But another part of effectiveness is simply making decisions on what we should do next. We're an international organization but, like local organizations, we struggle with identity issues. Like local organizations, we have empowered people to get on with their lives — and many have, very effectively. So, the question becomes, what's next?

These are the kind of questions we asked ourselves at the retreat. Who are we — and who should we be? What should our mission be for the future? What do the people we support most need?

In answering those questions, we examined issues such as changing our name, becoming a membership organization and many other matters.

The point is that we continue to search for ways to be more effective advocates and more effective information suppliers/supporters for the people we represent.

### *What changes have there been in recent years in GINI clients?*

**JOAN:** Our constituency does change. We'd like to think that people would continue to want our information as their life needs change. But we've solved some problems for people, so they move on. And, we are pleased with the evidence of being a successful organization. But, that means that we add and lose about the same number of actively involved people each year.

By all accounts, the ventilator population is growing. And what we've learned from ventilator users who had polio through the years is transferable to this new population. We have much to offer people who are considering the use of a ventilator or to those who use a ventilator at home. Our challenge is to help them find us when they most need us.

Obviously, the U.S. polio population is aging. But we get more and more requests from people with polio in countries where it has not been eradicated. And this is another challenge for us. Can we help these 12-20 million polio survivors — and how? Do we have or can we secure the resources we need to find out their needs and modify our information to fit their situation?

Also, because we all are aging, we have to integrate issues of disability with issues of aging. The question is, how can the disability community work more effectively with the aging community?

Another related issue is that some of the top researchers and medical professionals involved with the late effects of polio and with considerable knowledge about home mechanical ventilation are retiring or thinking about retirement. How can we sustain their knowledge or replace it?

One thing that hasn't changed in our constituency — something that we see over and over — is that the doctors making decisions for people may not be as informed as they should be.

We continue to try to bridge the gap between polio survivors and vent users and health care professionals to allow people to take more control of their care and their lives. That is the constant.

**FRED:** The question of exercise has really come to the fore for lots of people. They wonder, am I doing enough? Or am I doing too much exercise? The answer is very individual. We can't generalize.

We have assigned the task of writing a statement about exercise to our Medical Advisory Committee.

The other related point is that the polio community is certainly aging. Now they're moving into their 60s. So, more and more people will face questions of handling the financial dimensions of care and rehabilitation. And more people will have questions on how they can continue to live independently as they age.

## What are GINI priorities?

**JOAN:** Our number one priority is to maintain our quality of information and work, in spite of the economy, and to make that information available to people who need it, in spite of their economic situation. Doing so will require making some decisions.

At the retreat, we all were enthusiastic about becoming a membership organization. Maybe it's something we should have done a long time ago. Right now, people feel like members. They call with questions, and we treat them like members. The fact is, that has a cost. Becoming a membership organization would recognize that reality.

## In 2003, GINI became a membership organization and changed its name to Post-Polio Health International, including International Ventilator Users Network.\*

**FRED:** In my mind, we need to change our name and create a membership organization. If we were a membership organization, we could say with more credibility how many people we actually represent. Also, when people pay even a small amount for membership, it reflects the true strength of an organization and what it can accomplish. So, if polio survivors want to do more, they should be willing to step up and help fund additional activities.

What can we do more effectively as a membership organization?

First, with a credible membership base, we could be a more effective campaigner for research on, for example, nerve regeneration, more effective exercises for aging people, better bracing and other equipment issues.

Second, with a credible membership base, we could be an even more effective advocate for the legitimate needs of our members with insurance companies and government.

Third, we want to continue to be a positive voice for self-empowerment. We want to continue to help people get more out of their lives.

In my opinion, we've always been best at the third area. The first two areas of promoting research and advocacy, we could and should be more effective than we have been. Although, we do more advocacy than we communicate to our constituents. We have been too quiet in our success. I believe that becoming a membership organization would help us realize the significantly higher level of effectiveness we believe we can and should achieve.

### \*Our Names Through The Years

1960	International Iron Lung Polio Assistance, Inc.
1964	Iron Lung Polios and Multiplegics, Inc.
1970	Rehabilitation Gazette, Inc.
1983	Gazette International Networking Institute, Inc.
1985	Doing business as International Polio Network
1987	Doing business as International Ventilator Users Network
2003	Post-Polio Health International including International Ventilator Users Network



Joan L. Headley, MS  
Executive Director



Frederick M. Maynard, MD  
Board President

# What We Have Done

## BY THE NUMBERS....

4.25	Number of people who receive information and/or referrals <i>every day of the year.</i>
8,000	Number of copies of March of Dimes publications distributed in 2001 and 2002.
22,000	Number of copies of annual directories and newsletters distributed in 2001 and 2002.
300,000	<i>At 18 per hour of every day of each year;</i> number of website “hits” in 2001 and 2002.
3 + 38 + You	People who made all of this service possible: 3 full-time paid employees; 38 volunteer Board and Committee members; and (most importantly) members and supporters.

## 2001 and 2002 Achievements

### EDUCATING AND NETWORKING

#### Publishing and Distributing Information

##### ■ Newsletters: *Polio Network News*, *IVUN News*, and *Rehabilitation Gazette*

*“I save your issues (something I never do for other newsletters) because I have found them so interesting and have no doubt I will use them again.”* –Health Professional

*“You provide reliable, up-to-date information about post-polio syndrome and ventilator issues. I live in a rural area and am only loosely connected with the healthcare system. Information is crucial!”* –Survey Respondent

*“I can always anticipate questions from my patients after each edition.”* –Health Professional

*“As a result of appearing in *IVUN News*, we made contacts that after 5 years are still maintained and a great deal of respiratory/vent knowledge exchanged.”*  
–Survey Respondent

#### **Newsletter Features**

An entire volume of *Polio Network News* described “Breathing Problems of Polio Survivors,” the benefits and types of mechanical ventilation for polio survivors.

*“I had been having problems sleeping at night. I would dream I couldn’t breathe. I took the issue of ‘Breathing Problems of Polio Survivors’ to my doctor. He ordered a sleep study. I now have a ventilator and sleep all night. It is a blessing ...”* –Polio Survivor



Series in *Polio Network News* encouraged survivors to explore options for resolving the psychological effects of early polio experiences on their current health and life choices.

*“Thanks for the ‘Healing Polio Memories’ article. After years in hospitals, I have many negative memories, including sexual abuse. I have yet to consider these issues, finding myself shocked that I utilize all the protective coping patterns on your list. Thanks for helping me understand this.”* –Polio Survivor

*“Don’t let anyone tell you that there aren’t resources out there. ‘Treatment Approach Options’ grid identified a wide range of resources for improving emotional, relationship, psychological, and physical health.”* –Health Professional

*“You produce such consistent quality that it is just expected.”*  
–Director of a national disability organization

Concern about polio survivors worldwide prompted an interview with a young woman from Bosnia who relayed the adjustments of moving to the United States.

*“I love traveling and meeting young polio survivors who are leading the way in their own countries. It reminds me of when we were young and what we did.”*  
–Board member Judith Heumann, MPH, Adviser, Disability and Development, World Bank.

#### ■ Directories: *Post-Polio Directory* and *IVUN Resource Directory*, in print and online

*“The Post-Polio Directory makes it possible for me to advise and direct polio survivors all over the USA and internationally.”* –Survey Respondent

*“I’m pleased to be listed in the directory of professionals. It has brought some patients to my practice.”* –Health Professional

#### ■ Website, [www.post-polio.org](http://www.post-polio.org)

Inaugurated online versions of the *Post-Polio* and *IVUN Resource Directories*.

Added newsletter articles, support group meeting schedules, legislative issues, disability networking events, and *translations of brochures on post-polio issues into German, Portuguese, and French*.

Received approximately 300,000 hits during 2001 and 2002.

*“First of all, I want to tell you that it seems to me that your site is the most complete and realistic on the subject.”* –Polio Survivor

*“I found your name on the website and am so grateful that you were there to listen and help me understand what is happening with my mother.”* –Daughter of a Polio Survivor

### Providing Information and Referrals

#### ■ Over 3,100 new contacts via phone, mail, email

*“Before I had a hysterectomy I called for info on surgery and post-polio and was sent some back issues with good articles. I copied them and took them with me to see the surgeon and anesthesiologist. Everything went beautifully and I am very thankful that the info was available.”* –Survey Respondent

*“As a sponsor, GINI meets needs of individuals. We can refer inquiries to GINI.”*  
–Survey Respondent

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## Assisting Support Groups

Feedback from independent surveys revealed that support group leaders highly value the fair, balanced opinions and encouraging advice that Executive Director Joan Headley provides.

*“Joan Headley and her staff do a great job. They are always willing to respond to calls or letters in a warm, caring manner.”* –Survey Respondent

*“I value the availability of Joan to answer any questions I may have. I have run three support groups and have been a resource person for 17 years and I have been asked so many questions I could not answer, but knew that the answer could always be found by calling Saint Louis.”* –Support Group Leader

*“Someone always listens and offers help, suggestions.”* –Survey Respondent

## Collaborating with Other Organizations

### ■ MARCH OF DIMES (MOD)

Educated over **8,000 healthcare professionals, persons with disabilities, and others** through the MOD publications *“Post-Polio Syndrome: Identifying the Best Practices in Diagnosis and Care”* and *“Guidelines for People Who Have Had Polio.”*

As participants of the **MOD’s Warm Springs Conference** Joan Headley, MS, and Board President Fred Maynard, MD, contributed to the development of the best practices identified in their brochures.

Provided **Spanish and French translations** and posted on organizations’ websites, [www.post-polio.org](http://www.post-polio.org) and [www.mod.org](http://www.mod.org).

*“Information about treatments for various difficulties with post-polio has been helpful to have to educate my doctor who is too young to know much about polio. He was very pleased to have the March of Dimes info from Warm Springs because their practice now has maybe a dozen patients with this condition.”* –Survey Respondent

### ■ JOURNÉES INTERNATIONALES DE VENTILATION À DOMICILE (JIVD)

Eighth International Conference on Home Mechanical Ventilation in France, 2001. Working in conjunction with JIVD, Judith Fischer, MSLS, Board Secretary and *IVUN News* editor, and Joan Headley assisted in planning consumer sessions. Headley outlined “Concepts of Independent Living and IVUN’s History” while Board member Linda Bieniek offered options for “Staying Healthy” including a checklist on “Managing a Chronic Respiratory Condition.”

*“... of particular value were the sessions on ‘Living Arrangements for Ventilator Users’ ... and ‘Ethical Issues in Long-term Ventilation’ ... I had the opportunity to examine the new laptop LTV1000™ and the new CoughAssist™.”* –Anthony Giles-Peters, Australia

*“Your talk helped me realize the effect of events besides my husband’s illness on our family. Thank you for helping me understand that.”* –Conference Faculty Member

### ■ CONEMAUGH HEALTH SYSTEMS

Co-sponsored “Train the Trainers” for Stanford University’s **Chronic Disease Self-Management Program (CDSMP)** in Pennsylvania, 2002. Joan Headley joined Barbara Duryea, and Carol Yoder in promoting, recruiting, and training 22 individuals to offer this program to polio survivors. Five teams of two have already provided the program in their local areas.

Educated health professionals attending **Conemaugh Health Systems' Post-Polio Symposium** in New Jersey, 2002. Joan Headley, who assisted in developing the program, explained "Surviving Post-Polio: Notes from the Last 15 Years."

*"I'm leaving here with a different perspective on handling my disability." –Polio Survivor*

*"As my great niece said about running cross-country in junior high school: saying it is a lot easier than doing it! The same is true for aging polio survivors who want to make changes in their life. The CDSMP provides a new way of thinking about doing things we many times say we are going to do."*

–Joan Headley, CDSMP trainer

## ■ ABILITIES EXPO/METRO CHICAGO

The banner, "Do You Know a Polio Survivor?" attracted almost 100 people to the exhibit booth. Workshops on "Creating an Action Plan for Wellness" and "Counselors and Psychotherapists: Specializing in Working with Clients with Physical Disabilities and Chronic Medical Conditions" were led by Board member Linda Bieniek, CEAP.

*"I came back to the Abilities Expo solely to thank you for telling me last year about the CoughAssist™. I now have one and it has changed my life — I can breathe better." –Polio Survivor*

*"Your organization is a lifeline for so many of us." –Polio Survivor*

*"The handouts from this workshop were worth the trip to Abilities Expo." –Psychotherapist*

## Contributing to Conferences and Meetings

- Joan Headley presented at eight conferences and meetings sponsored by local and regional support groups on topics ranging from post-polio research to the importance of creating a supportive healthcare team.
- **Post-Polio Resource Group of Southeastern Wisconsin's 2002 Conference** featured Board President Maynard on "Empowerment for Self-Management of Post-Polio Syndrome" and Joan Headley on "The Keys to In(ter)dependent Living."
- In 2002, Board member Judith Heumann, MPH, delivered the keynote on "Post-Polios Continuing to Lead the Way" and Board President Maynard described "The Pain in Gain: When Is It Worth It?" at **New Jersey Polio Network's 12th Annual Conference**.
- Board member Linda Bieniek presented on "Strategies for Developing Healthy Relationships" at **Post-Polio Resource Group of Southeastern Wisconsin's** fall 2002 meeting.
- "Setting the Stage for Wellness," led by Karen Kennedy, MSW, RSW, and Board member Linda Bieniek, opened the **Ontario March of Dimes Wellness Retreat** in 2001. Linda Bieniek also facilitated a workshop on "Developing a Wellness Action Plan."
- Working in conjunction with NIVnetwork.com and Respiratory Resources, IVUN's Judith Fischer and Consumer Advisory Committee member Barbara Rodgers planned and coordinated the **Noninvasive Ventilation Alternatives in Neuromuscular Disease Conference** in California.

Attendees at Executive Director Joan Headley's presentations have remarked:

*"You back up your comments with facts."*

*"You and Halstead made it worth being here."*

*"We were thinking of disbanding, but so many people came to hear you, we will continue."*

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## Recruiting Health Professionals

- **American Thoracic Society, American College of Chest Physicians, and FOCUS Respiratory Care Conference:** *IVUN News* editor Judith Fischer represented IVUN at the annual meetings. Executive Director Joan Headley joined her in recruiting health professionals at the 2002 FOCUS conference.

*“I think it is important to recruit doctors and PTs so that polio survivors can find professionals who understand our condition and special needs.”* –Survey Respondent

- **American Lung Association of Kentucky Pulmonary Care Symposium, 2002.** Pulmonetics sponsored Board member Linda Bieniek’s presentation about the needs of ventilator users in “Ventilators To Go.”

*“Thank you for saying that patients have the right to choose to live on a ventilator.”*  
–Physician Attendee

## Advocating for Constituents

**“If we’re not talking about our needs, who is?”** asserted Board member Judith Heumann, MPH, at the New Jersey Polio Network 2002 Conference.

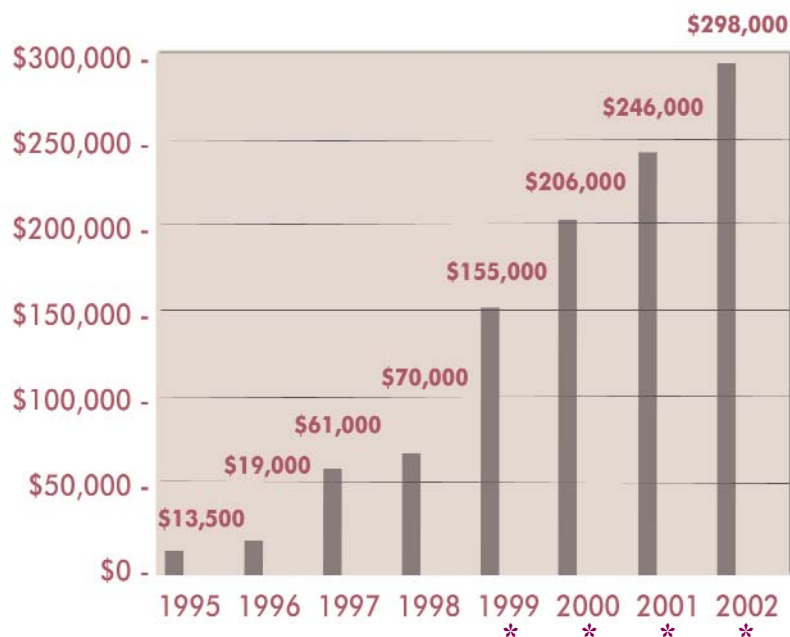
- **World Health Organization:** Joan Headley participated in the 2002 global conference on *“Rethinking Care from the Perspective of Disabled People”* in Norway. Delegate recommendations were forwarded to the United Nations for its member states.
- **Social Security Administration (SSA):** Commented on proposals in SSA’s guidelines for the late effects of polio and recommended additional experts to review the changes. SSA increased its training of adjudicators through a video on handling post-polio claims.
- **Federal Trade Commission:** Provided ventilator user and expert contacts for viewpoints on a pending merger of manufacturers. The merger was not approved.
- **Department of Justice:** Researched and presented obstacles ventilator users experience when traveling with a ventilator. Board Member Judith Heumann, MPH, represented the organization at the meetings.
- **Centers of Medicare and Medicaid Services (CMS):** Asserted concerns about proposed changes in the billing code for bi-level pressure devices used by ventilator users with neuro-muscular conditions. Advocated for reimbursement of CoughAssist™, granted in 2002.

*“We need someone to advocate for us with Medicare about medical equipment.”*  
–Survey Respondent

## Funding Research through The GINI Research Fund (now The Research Fund)

The Research Fund, established in 1995 to further enhance the lives of polio survivors and ventilator users, has awarded two grants.

### ■ Research Fund Income



### ■ Research Fund Awards

\*\$10,000 contribution from the Edouard Foundation

#### Year 2000

##### **The Thomas Wallace Rogers Memorial Respiratory Research grant — \$20,000**

“Ventilator Users’ Perspectives on the Important Elements of Health-Related Quality of Life.”

Researchers: Mark Tonack, MA, Senior Researcher, Toronto Rehabilitation Institute, and Research Associate, West Park Health Care Centre; polio survivor and ventilator user Audrey King, MA, Vice Chair, The Center for Independent Living in Toronto; Dina Brooks, PhD, Assistant Professor, Department of Physical Therapy, University of Toronto, and Research Associate at West Park Health Care Centre; and Roger Goldstein, MD, Professor of Medicine and Physical Therapy, University of Toronto, and Director of Respiratory Medicine, West Park Health Care Centre.

The final 115-page report of the perspectives of 26 ventilators users in the community (Toronto and Edmonton, Canada) with long-term use of home mechanical ventilation due to neuromuscular disability or traumatic injury can be downloaded at [www.post-polio.org/QofLFINALREPORT-Sept2002.pdf](http://www.post-polio.org/QofLFINALREPORT-Sept2002.pdf).

#### Year 2003

##### **The Post-Poliomyelitis Research Grant — \$25,000**

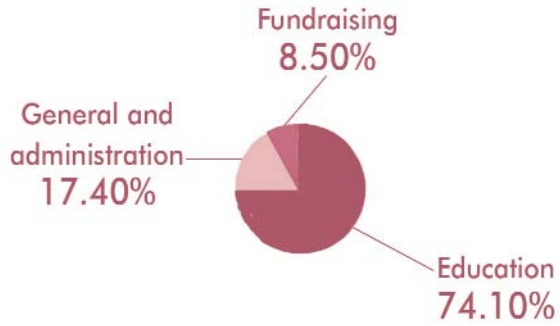
“Women with Polio: Menopause, Late Effects, Quality of Life, and Psychological Well Being.”

Research Team from the University of Michigan, Ann Arbor: Claire Kalpakjian, PhD, Postdoctoral Research Fellow in the Department of Physical Medicine and Rehabilitation, and Denise G. Tate, PhD, Professor, Department of Physical Medicine and Rehabilitation, Principal Investigators; Elisabeth H. Quint, MD, Department of Obstetrics and Gynecology, Co-Investigator; and Sunny Roller, MS, polio survivor, advocate, and consultant.

The final report will be published in early 2004.

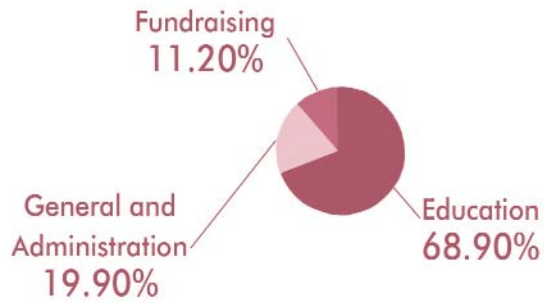
■ Expense Allocation 2001

\$225,128



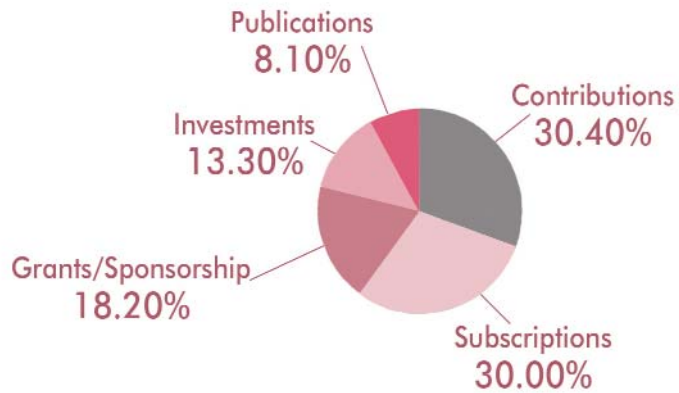
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\$209,577

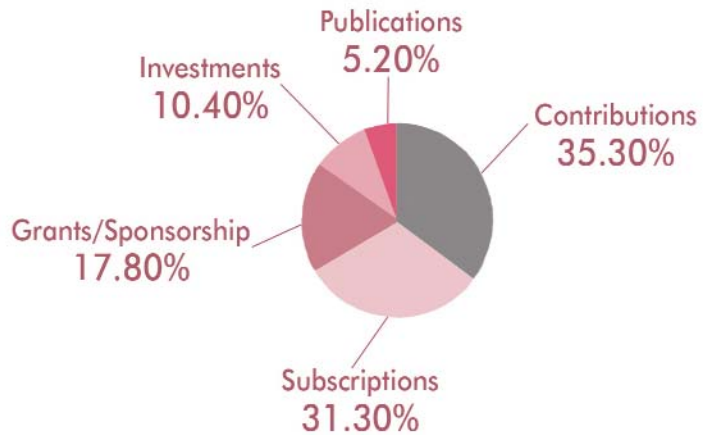


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■ Funding Sources 2001



■ Funding Sources 2002



Gazette International Networking Institute, Inc.

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

Year Ended December 31, 2002

CHANGES IN UNRESTRICTED NET ASSETS

REVENUES

Subscriptions	\$ 64,296
Contributions	104,891
Publications	10,664
Investment income	15,375
Capital gain distributions	2,277
Gain on sale of securities	3,744
Unrealized gain on investments	(54,940)
Miscellaneous	76
Contributions released from restrictions	<u>4,197</u>

TOTAL UNRESTRICTED REVENUES 150,580

EXPENSES

Education	144,438
General and administrative	41,723
Fundraising	<u>23,416</u>

TOTAL EXPENSES 209,577

DECREASE IN UNRESTRICTED NET ASSETS (58,997)

CHANGES IN TEMPORARILY UNRESTRICTED NET ASSETS

Contributions	69,708
Net assets released from restrictions	<u>(4,197)</u>

INCREASE IN TEMPORARILY RESTRICTED NET ASSETS 65,511

INCREASE IN NET ASSETS 6,514

NET ASSETS AT BEGINNING OF YEAR 526,869

NET ASSETS AT END OF YEAR \$ 533,383

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*Every attempt was made to insure the accuracy of this list. We apologize for any error or exclusion.*

## How can you support this vital work?

- ◆ **Join Post-Polio Health International including International Ventilator Users Network.** Membership fees 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.**
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- ◆ **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.