

POST-POLIO HEALTH

FORMERLY POLIO NETWORK NEWS

SAINT LOUIS, MISSOURI WWW.POST-POLIO.ORG

Report from the 2003 recipient of The Research Fund Award

Participants, Their Health Status and Data about Menopause

Claire Z. Kalpakjian, PhD, Project Manager, Model Spinal Cord Injury Care System, Department of Physical Medicine and Rehabilitation, University of Michigan, Ann Arbor, Michigan (UM-Polio-Research@med.umich.edu)

This brief report from *Women with Polio: Menopause, Late Effects, Quality of Life, and Psychological Well-Being* describes its participants, post-polio health status and menopause characteristics of the women. A total of 1,283 individuals participated in this study, which is a response rate of 42%. Polio survivors completed an extensive survey that was mailed to the researchers. Incomplete or questionable data were verified by telephone. This rich dataset will allow our team to examine a variety of factors related to the menopause experience of women who had polio, providing a foundation for future studies examining the menopause transition in women with physical disabilities. The participation of men in this study will allow us to examine gender differences with respect to physical and emotional well-being.

DEMOGRAPHICS The demographic composition of this sample (See Table 1.) is typical of other studies of polio survivors conducted in the United States with respect to age, ethnicity (over 95% are Caucasian), education, work status and marriage. Survivors from nearly all 50 states participated. One of the most potentially informative aspects of this sample is its wide age range, from the youngest at 34 years old to the oldest at 99. This age span will allow my colleagues and I to closely examine the influence of age not only on the menopause transition, but also in the incidence of co-morbid diseases and post-polio health and emotional well-being. The availability of census data also will allow us to compare certain variables, such as education, to see if large differences exist between polio survivors and the US population as a whole.

HEALTH AND PHYSICAL ACTIVITY Despite a variety of health problems, 71% of participants rated their health as good or better. In comparing their health to a year

Table 1. Demographic Profile of Sample

	WOMEN	MEN	TOTAL GROUP
Sample size	71% (910)	29% (373)	1,283
Average age	63.3 ± 9 years	67 <u>+</u> 10 years	64 <u>+</u> 9.5 years
Average age at polio onset	8 <u>+</u> 7 years	10 <u>+</u> 8.5 years	8.7 <u>+</u> 7.4 years
Married	61%	75%	65%
Education			
High school	17%	11%	16%
College	57%	48%	55%
Graduate	24%	37%	28%
Work status			
Retired	58%	73%	62%
Working	30%	27%	29%
Other	12%	0%	9%

ago, 57% rated it as about the same or better. Co-morbid, or other health problems not directly related to post-polio, were reported by the sample in 11 general areas, such as cardiovascular, metabolic and musculoskeletal. The most commonly reported health problems were cardiovascular in nature, such as high cholesterol (24%) and/or high blood pressure (38%). More than half of the sample (59%) reported engaging in much less physical activity than their peers. Performing both basic (bathing, dressing) and intermediate (running errands or housework) tasks were problematic for many individuals.

continued on page 2

Table 2. Average severity rating (1-5 [slight to extreme] scale) and percentage from the IPPS MUSCLE WEAKNESS INVOLVED (3.35)MUSCLE WEAKNESS UNINVOLVED (2.71)MUSCLE **ATROPHY** (2.55)JOINT PAIN (3.15)MUSCLE PAIN (3.98)**FATIGUE** (3.38)SLEEP PROBLEMS (2.90) BREATHING **PROBLEMS** (2.57)**SWALLOWING PROBLEMS** (2.14)COLD INTOLERANCE (3.11)CONTRACTURES (2.74)CARPEL TUNNEL (2.73)

Participants, Their Health Status and Data about Menopause

continued from page 1

POST-POLIO HEALTH Not surprisingly, 1952 was the peak year that participants contracted polio; years ranged from the earliest in 1912 to the latest in 1982. Our team developed a new scale, now called the Index of Post-Polio Sequelae (IPPS), for this study to measure the severity of commonly reported late effects problems. Preliminary analysis showed that this is a useful and reliable scale.

IPPS assesses the degree of severity among 12 commonly reported problems, ranging from slight (1) to extreme (5). Table 2 shows the percentage of participants reporting

at least slight severity on each of the 12 problems along with the average severity rating for each.

MENOPAUSE Contrary to speculation that women with disabilities may experience menopause, or the cessation of menstruation, at an earlier age than non-disabled women, women in this sample who had a natural menopause experienced their final menstrual period at age 50. As expected, the vast majority of women in this sample were post-menopausal. Far fewer were perimenopausal, and a very small percentage had experienced no changes in their menstrual cycle.

USE OF HORMONE REPLACEMENT THERAPY (HRT)

The new findings from the Women's Health Initiative have raised serious questions regarding the efficacy and safety of HRT. Almost three-quarters of the women in the study had used HRT at one time and 39% of women were using HRT at the time of the study, which is higher than most national estimates. (National estimates of HRT use among women are difficult to establish because a variety of factors, such as ethnicity, socio-economic

status and/

60%

80%

100%

40%

0

20%

or physician's recommendation, can influence HRT use.) More than half reported no side effects. For women who discontinued HRT use, the most common (60%) reason cited was concerns over safety. Future data analysis will examine the relationship of HRT use to physical and emotional well-being and intensity of menopause symptoms.

COMMUNICATION WITH HEALTH CARE PROVIDERS AND EXPERIENCE OF MENOPAUSE Communication with health care providers about menopause was mixed. Overall, 73% of women had discussed menopause with their health

Current Treatment Advice for HRT

Prior to the WHI (Women's Health Initiative) study findings, the FDA had approved three indications for the use of estrogen and estrogen-progestin products in post-menopausal women. Two of the three indications have now changed to include consideration of alternative treatments:

- Treatment of moderate to severe symptoms of vulvar and vaginal atrophy (such as dryness, itching and burning) associated with menopause. When these products (estrogen and estrogen-progestin) are being prescribed solely for the treatment of symptoms of vulvar and vaginal atrophy, topical vaginal products should be considered.
- Prevention of post-menopausal osteoporosis (weak bones). When these products are being prescribed solely for the prevention of post-menopausal osteoporosis, approved non-estrogen treatments should be carefully considered. Estrogens and combined estrogen-progestin products should only be considered for women with significant risk of osteoporosis that outweighs the risks of the drug.
- Treatment of moderate to severe vasomotor symptoms (such as hot flashes and night sweats) associated with menopause. This indication has not changed. Estrogen-containing products are the most effective approved therapies for these symptoms.

Excerpted from: FDA Consumer (March-April 2003, Vol. 37, No. 2) "The Estrogen and Progestin Dilemma: New Advice, Labeling Guidelines" www.fda.gov/cder/drug/infopage/estrogen_progestins.

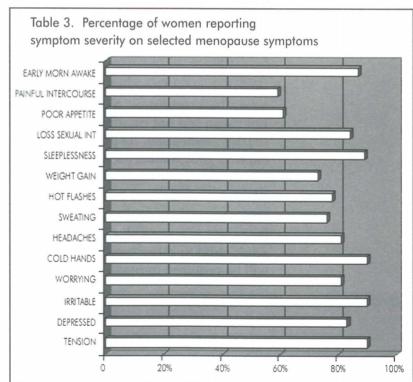
care providers, and, of these, 31% initiated the discussion. Only 50% were satisfied with the information they received. The majority of women (78%) did not feel their access to information about menopause was limited because of their disability. In general, women had a positive or neutral experience of menopause.

MENOPAUSE SYMPTOMS Table 3 shows the percentage of women in the sample reporting some degree of menopause symptom severity. The specificity of menopause symptoms remains at the center of much debate, and this is especially true of emotional symptoms such as depression. Research has not unquestionably shown that there is a significant relationship between menopause and mood, and many suggest that other factors present in mid-life, such as high stress family and job demands, make a larger contribution to mood disturbance than menopause itself. Perhaps most importantly for women with physical disabilities, virtually

nothing is known about their experience of symptoms and the interaction of physical disability and menopause.

This research project that examines menopause in women who are post-polio is one of the first of its kind in menopause research. It provides an important foundation for launching future studies to more closely examine the various physical and emotional aspects of this important biological transition in women with physical disabilities.

Several manuscripts are already in the works, and one currently under review is in a leading menopause professional journal. Our team plans to submit a manuscript examining the psychometric properties of the Index of Post-Polio Sequelae (IPPS), again, one of the first of its kind in the published literature. In addition to professional dissemination, a final report to Post-Polio Health International will be available by the end of February 2004 along with a



"About six weeks ago, I fell and broke both of my legs. While my injuries were not life-threatening, I had peace of mind, because my husband and I completed our advance directives ten years ago. I ask other polio survivors ..."

ARE YOU PREPARED? Advance Directives

Debbie Hardy, Volunteer Editor, Whittier, California

Advance directives allow your voice to be heard if you are no longer able to speak for yourself. Signing one is personal and can be frightening. None of us wants to think about becoming incapacitated and no longer being able to make decisions for ourselves. But accidents happen every day, and we should be prepared. It is important to make these decisions while you are capable, so that there is no confusion regarding the medical treatment you prefer as you near the end of life.

Generally, two documents are completed: a living will and a medical power of attorney (durable power of attorney for health care).

Living Will Do not confuse a living will with a regular will. A living will only applies to and deals with issues regarding your health/medical care. It is a written statement that informs health care providers what type of life-prolonging treatments or procedures to perform or not to perform if you are in an irreversible medical state or have a terminal condition. A living will does not mean "do not treat" or withholding of pain medication. Its purpose is to express your wishes for medical treatment, and, if the situation necessitates, to die with dignity as you define it.

If you become incapacitated without a living will, someone else — your spouse, adult child or other family member — will be required to make these difficult

ADVANCE DIRECTIVES are recognized in all 50 states and the District of Columbia as legally binding. But, be sure to check the special requirements in your state at www.partnershipforcaring.org/Advance/documents_set.html, or by calling Partnership for Caring at 800-989-9455, your local library, or hospital.

decisions. With your wishes in writing, it can be less confusing and agonizing for the significant people in your life.

Medical Power of Attorney Living wills cannot cover all situations. That is why you need a medical power of attorney or durable power of attorney for health care. It allows you to choose *any* person to make medical decisions for you and/or make certain that your wishes are carried out if you should become temporarily or permanently unable to make decisions for yourself. Be sure that the person you specify agrees to accept this responsibility, and discuss with him or her how you would like matters handled.

After completing your advance directives, make sure that your family and health care providers have a copy and/or know where it is kept.

During their lifetime, many people change their mind about their preferences regarding end-of-life and/or medical treatment. If capable, you may cancel or change your living will or medical power of attorney at any time, even if you are in the hospital. If you do so, provide all of the necessary people with the dated revised copy.

Advance directives allow you to make choices. If you do not have an advance directive and become unable to make decisions for yourself, you will be given full medical care appropriate for your condition.

You do not need an attorney to fill out forms for a living will and/or a medical power of attorney; however, you may wish to consult with one if you have any questions.

Healthy Eating: Fat Facts

Jann Hartman, Baltimore, Maryland (jann@comcast.net)

% Daily otal Fat 6g Saturated Fat 1g Trans Fat 0g

Sugars 2g Vitamin A 0% Calcium 0% Unsaturated fats include polyun-/itamin F 6% saturated as well as monounsaturated liacin 2% osphorus 6% fats and are better for your body and Percent Daily Values are based on a 2,000 calori diet. Your daily values may be higher or lower depending on your calorie needs: are often called the "good" fats. For healthy eating, we should consume mostly unsaturated fats. Polyunsaturated fats have been shown to reduce LDL cholesterol, but they may also is of trans fat should be as low as po reduce HDL ("good") cholesterol. Monounsaturated fats can reduce Carbohydrate 4 LDL cholesterol without affect- (** Intake of trans fat should be as low as po ing HDL cholesterol.

ur bodies need fats, as well as carbohydrates and protein, in order to function properly. Carbohydrates and proteins each have four calories per gram. Fats are calorie dense with nine calories per gram. However, not all fats are created equal. That's why choosing and using healthier fats is very important. Saturated fats and trans fats (or trans-fatty acids) are both problematic. Saturated fats can contribute to higher LDL ("bad") cholesterol and have been linked to chronic conditions such as stroke, breast cancer and coronary heart disease.

Saturated fats are found in animal foods like butter, as well as "tropical" oils such as coconut or palm oil, or cocoa butter. These are the fats that tend to stay solid at room temperature. And, they have been listed on food labels since 1993.

Trans fats are harder to identify because they are not yet required to be listed on nutrition labels.

Many health professionals believe that trans fats may raise LDL cholesterol even higher than saturated fats. Trans fats are created by adding hydrogen to vegetable oil to make it a solid fat such as shortening or stick margarine. The term "partially hydrogenated" on an ingredient list means that the food contains trans fats.

They are often found in processed foods and baked goods. Even healthy sounding sports or "nutrition" bars often contain trans fats. Trans fats also occur naturally in foods such as dairy products, some meats and other animal-based foods.

Be sure to choose oils carefully and use polyunsaturated fats such as corn, sunflower, soybean and safflower oils. Monounsaturated fats, such as those in olive, canola and peanut oils, are even healthier. Avocados, nuts, nut oils and seeds are also great sources of good fats. But, be cautious when choosing nut butters (for instance, peanut butter and other nut spreads) as these often contain additional sugars and other additives, and are mostly hydrogenated. And, as always, use any fats in moderation.

While some European countries have banned trans fats, Canada and the United States have decided to require the labeling of trans fats. Some US companies have already added trans fat to their Nutrition Facts, which will be a requirement in January 2006.

Remember, until then, you can recognize that a product contains trans fats by the term "partially hydrogenated." The knowledge we obtain from reading and comparing labels enables us to select healthier foods to keep ourselves as fit as possible.

Polio survivor Jann Hartman has a dearee in Home Economics and Nutrition, and has written and lectured on nutrition for the past 20 years. She has been living with post-polio syndrome since 1989.

Nutrition Facts

tal Fat 6g

Trans Fat 0g

odium 115mg

otal Carbohydrate 19 Dietary Fiber 2g

Calories from Fat 50

096

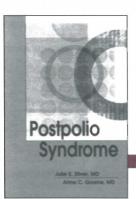
Vitamin C 0%

Thiamin 29

Vitamin Bs 2%

Iron 29

She contributed a previous article, "Foods that Shut Down Stress," to the Summer 2003 issue of Post-Polio Health.



Reviews of Postpolio Syndrome

(ISBN 1-56053-606-3) by Julie K. Silver, MD, and the late Anne C. Gawne, MD, has been released by Hanley & Belfus, an affiliate of Elsevier (www.elsevierhealth.com). The book (336 pp.) retails for \$29.95.

The editors assembled many of the leading medical specialists, researchers and allied health professionals who have extensive clinical experience with polio survivors, to compile a text that describes the diagnosis and evaluation of post-polio syndrome, treatment interventions, psychological and lifestyle issues and co-morbidity issues of polio survivors. The book is appropriately detailed for clinical use and is written and organized logically in a very readable presentation.

Postpolio Syndrome is a resource that I would highly recommend to any health professional treating polio survivors, because it addresses the many problems a large percentage of polio survivors are experiencing, as well as recommended interventions to alleviate or avoid these problems.

Paul E. Peach, MD, Palmyra Post-Polio Clinic, Albany, Georgia

This book is an excellent single source review of the literature about post-polio. It is scholarly, comprehensive, and extremely well-referenced and documented. The language is quite technical and requires at least a moderate understanding of medical terminology. I was pleased to see a chapter by a podiatrist on foot problems.

The chapters seem written as separate "review articles," so many chapters' introductory paragraphs contain the same background information and are unnecessarily repetitious.

Marny K. Eulberg, MD, Post-Polio Clinic, St. Anthony's Family Medical Center West, Denver, Colorado The book has not been "dumbed down" to the point of vague generalities. Most sections are fairly easy to read, but some will require effort to get the greatest benefit.

Several contributors emphasize the importance, or at least the helpfulness, of being evaluated in a clinic that has access to a team of medical specialists. Every polio survivor is different, and having nurses, therapists, orthotists, pulmonologists and other specialists available for consultation can assist in diagnosis and treatment.

I am a ventilator user, so I was particularly interested in the pulmonary information contained in the book. Pulmonary issues are discussed in several chapters, but Chapter 7, written by John Bach, MD, and Jose Vega, MD, PhD, is devoted exclusively to this topic. If a person wants detailed information about pulmonary function, appropriate testing and the maintenance of pulmonary health, this chapter is essential. It is the best I've read to date.

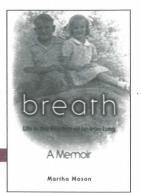
My only significant complaint is that the book is paperback. I have limited upper extremity strength and keeping the pages open is difficult.

A puzzle to me is the spelling of "postpolio" in the title and throughout the book. The standard spelling in most of the medical literature includes a hyphen, i.e., "post-polio." This may be nit-picky, but it was first thing that I noticed.

Richard L. Daggett, Polio Survivors Association, Downey, California (polioassociation@comcast.net)

Breath: Life in the Rhythm of an Iron Lung

(ISBN 1-878086-95-2) by Martha Mason is published by Down Home Press, P.O. Box 4126, Asheboro, North Carolina 27204, and has a retail price of \$24.95 (300 pp.).



This is the 30th polio memoir or biography that I have read. It is also one of the very best, if not the best. I first heard of Mason through an article in the general press than I categorize as pity articles. You know the kind. Girl gets polio, lives 55 years in iron lung, what a hero! I was fully prepared to ignore the book until a friend of mine gave it a rave review.

I knew something was up, when immediately following the introduction, Ms. Mason quoted from The Talmud, "We do not see things as they are; we see things as we are." (Well, I guess I have already admitted that.)

She has written the book in three parts and does not start at the beginning, but much later in her life at a point when her mother, who has been her caretaker, has entered a period of what I will refer to, with apologies, as senility. Ms. Mason never refers to it that way but quite beautifully and lovingly describes her mother and her condition.

It isn't until part two that we go back to her childhood that she shared with her brother, Gaston. From there, she weaves her story — their story — through grade and high school and finally to Wake Forest College (now University)in North Carolina, to graduate summa cum laude.

I freely admit that it doesn't take a great deal to move this old polio survivor, now a 24/7 ventilator user, to tears. Ms. Mason repeatedly moved me back and forth between tears and laughter and sometimes had me doing both at the same time.

From early in her childhood, her goal was to write. While at Wake Forest, a Dr. Edgar E. Folk was one of her professors and mentors. In coaching her to add details and nuances to her writing, he would often say to her, "Make me smell strawberries!" Martha, I smelled the strawberries.

Larry Kohout, Edina, Minnesota (lkohout@mn.rr.com) is currently editor of PPASS Times, newsletter of the Post-Polio Awareness & Support Society of Minnesota.

Books about the polio experience on www.post-polio.org

Post-Polio Health International has compiled a listing of books about the polio experience at www.post-polio.org/ ipn/books.html.

To list a book, please send a review copy of the book to PHI, 4207 Lindell Boulevard, #110, Saint Louis, MO 63108.

Royalties Donated to Post-Polio Health International

Daniel R. Williams' book, *Keep Smiling and Never Give Up!* was released October 7, 2002 — 45 years to the day he entered an iron lung for treatment of acute poliomyelitis. The book chronicles the seventeen years of his life from age 14 to his marriage in 1974. Williams details his experiences in two "respo centers" (Ohio and Michigan), five hospitals and four nursing homes until he and his bride, Kaye, move into an apartment.

Dan generously designated part of the royalties of the sale of his book to Post-Polio Health International. To purchase a copy, in hard cover (\$24.00) or paper-back (\$17.00), send your check to Indiana Polio Survivors Association (IPSA), 3005 North Countryview Drive, Muncie, IN 47304.

Post-Polio Health International's (formerly Gazette International Networking Institute) **Annual Report 2001-2002** is online at www.post-polio.org/annrep0102_a.html. To obtain a print copy, contact the PHI office at 314-534-0475 or info@post-polio.org.

Need a scooter?

Post-Polio Health International has two more \$500 grants available to assist polio survivors in purchasing a scooter.

Contact Justine Craig-Meyer (314-534-0475, info@post-polio.org) for an application.

Mary Kay and
David Basham, Jr.,
California, made
these grants possible
with their generous
contribution in
memory of June
Fortezzo, an aunt
of Mary Kay's who
had polio.

FOF A group of physical therapy students at Gannon University in Erie, Pennsylvania, recently completed a study to answer the question of whether fear of falling (FOF) impacts the quality of life of polio survivors.

The study used a survey to measure fear of falling, confidence in one's balance and quality of life. One hundred seventy-two (172) of 315 surveys were accurately completed and analyzed. The vast majority of the sample were between 50-79 years of age. Most surprising in the results was the overwhelming presence of fear of falling (95%). Likewise, the confidence that this group has in their balance was severely decreased. The sample group also reported below-average quality of life as a result of their physical status.

Although these results may not be surprising to anyone with post-polio problems, it is important information for health care providers. Fear of falling is often not assessed, despite it being a life-altering problem. Individuals with post-polio problems need to report their fear of falling to their health care provider, so that they get assistance with reducing their risks for falls, improving their balance, and thus, overall, improving their quality of life.

Additional information is available at www.gannon.edu/survey/pps/index.html. If you would like a print copy of the results, contact: Kris Legters, PT, DSc, NCS, Gannon University, 109 University Square, PAC 3023, Erie, Pennsylvania 16541.

Use a manual chair? Need an assist?

For individuals who cannot easily manage a power chair, or for those who find pushing their manual chairs difficult, here is a new option. Outfitted with e.motion® power-assist wheels (www.frankmobility. com), my manual wheelchair can be propelled with very little effort. The power assist wheels slip on and off just like the standard wheels do. Power can be set for 50 or 80% assist and can be adjusted to compensate for unequal arm strength. The two disc-size batteries are easily charged on or off the wheels and can be put in or taken out while sitting in the chair. Friends can easily disassemble the entire wheelchair and put it into a car. No van or lift needed!



Jane Dummer, Baltimore, Maryland (Dummersings@hotmail.com)

"The results of using this system have been a decrease in pain in my damaged shoulders, greater comfort navigating around my apartment and more freedom on excursions. My fatigue has been reduced and I sleep better."

European post-polio veterans speak to members of the European Parliament



Johan Bijttebier, Post-Polio België, and Peter Jay, British Polio Fellowship, (third and fourth from left, respectively) address members of the European Parliament.

Twelve polio survivors, representing six countries (Belgium, France, Germany, Holland, Ireland, United Kingdom) in the European Union, met in November 2003 to consolidate their efforts on behalf of the Union's polio survivors and to highlight their problems before members of the European Parliament. Europe's post-polio organizations are invited to join this newly organized group called European Polio Union (EPU), which will meet again June 5-6, 2004.

For more information, contact Johan Bijttebier of Post-Polio België (johan.bijttebier@pandora.be).

Post-Polio Health International's brochure, Information about the late effects of polio for polio survivors, for families and friends and for health professionals is available online (www.post-polio.org/ipn/aboutlep.html) in Chinese, Farsi, French, German, Italian, Japanese and Spanish.

Contact PHI (314-534-0475, info@post-polio.org) for print copies or bulk pricing.

Trouble Using Medical Equipment?

The Rehabilitation Engineering Research Center (RERC) on Accessible Medical Instrumentation is conducting a survey to learn about difficulties that people with disabilities have using medical equipment, such as devices used for diagnosing and treating medical problems.

If you want your voice heard, check out www.rerc-ami.org/second/starter.htm or call Erin Schwier at 800-832-0524.

Memorabilia?

Katherine Ott , National Museum of American History, Smithsonian Institution, is looking for old equipment and memorabilia of the early polio epidemics for a special exhibit to be opened in 2005 to educate the public about the epidemics, the vaccine and the legacy of polio. April 12, 2005 is the 50th anniversary of the longawaited announcement that the Salk polio vaccine was safe and effective.

If you have materials to donate, contact Ott (OTTK@sil.edu, 202-357-3006).

Trouble when flying?

The US Department of Transportation announces its toll-free hotline numbers, staffed daily from 7:00 am to 11:00 pm EST.

800-778-4838 (voice) 800-455-9880 (TTY)

Special Thanks

s we begin 2004, the Board of Post-Polio Health International would like to thank everyone for their financial support, the steady stream of compliments and the candid comments about how we can improve our publications and our work on your behalf.

In mid-December, we were honored to receive a very generous bequest from Alma and Herbert Wallace from the Cleveland, Ohio area. Alma retired 20 years ago after years of running a travel business, and lived quietly with her husband, who preceded her in death by just a few months. Their bequest confirms that our 45-year organization makes a difference in the lives of people who, in turn, ensure that others benefit, too.

Our continual goal is to reach more people with our message of independent living through better health.

> Frederick M. Maynard, MD President of the Board Post-Polio Health International, including International Ventilator Users Network

We thank our supporters for their contributions to our work ...

In honor of ...

Judy Antley Linda Bieniek Richard Bruno, PhD Judith R. Fischer Jim & Judy Headley Joan Headley **Becky Hopkins** & family

In memory of ...

Arlo **Bud Blitzer** Carl E. Badgley, MD **Jean Brainard Boebel** Aimee C.H. Braun Lorna S. Eby Mary Ann Farrington June Fortezzo Edwin Fredrickson **Jack Genskow Kaye Harding** Clela Headley Mr. & Mrs. Kieran Kelly Michael Lowen Frederick M. Maynard, MD Susie & John Morrison Richard Owen, MD Harriet Weltman Sally Williamson

Bob McCown Maureen Norris Casev Patelski Richard Peavey Clarence Perry Armand J. Savaria John Scalise, Ir. Douglas Schultz **Donald Wartenberg** Marian Weis Ruth Weye Joseph & Margaret

Wincenc

The New York-based Edouard Foundation contributed \$10,000 in November 2003 to The Research Fund. Established in 1995, as a capital fund of Post-Polio Health International, the fund's income is used to support the work of selected researchers seeking scientific information leading to eventual amelioration of the consequences of poliomyelitis and/or neuromuscular respiratory disorders. Thanks to the contributions of our members and supporters, The Research Fund now has \$345,000 invested for research.



The First Annual **Curt Kettner Post-**Polio Syndrome Golf Tournament was held in October. All proceeds from the event were contributed to The Research Fund.

Kettner displaying his swing. All participants played the front nine using one hand.

We thank our supporters for their contributions to The Research Fund ...

In honor of ...

Paul & Virginia Margaret Hoffman Chase **Becky Hopkins** Debra Hansen & family

In memory of ...

Libby Jean Caplan Rose Clarke Jenny Danielson Sylvia Fleming Edwin Frederickson Clela Headley Harold Heath Charles G. Howe

Walter W. Kinnunen Dan Lambert Maurice Love Doris Muhleback Virginia Palmer Dr. Lubow Pronchick **Betsy Ross** Dot Wilt

CALL FOR PROPOSALS for The Research Fund of PHI

How much?

\$25,000 for 2005

Deadline?

March 1, 2004 for Phase 1

Decision:

October 15, 2004

Details at www.post-polio.org or call 314-534-0475.



POST-POLIO HEALTH INTERNATIONAL INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

MEMBERSHIP OPPORTUNITIES

International and USA membership levels are the same. (US dollars only)

\$15 Supporter

Access to www.post-polio.org Access home mechanical ventilation information at www.post-polio.org/ivun Networking opportunities Information about relevant events Support of Post-Polio Health International's educational, research, and advocacy efforts Opportunities to participate in research 100% tax-deductible

\$25 Subscriber

All of the benefits of Supporter, AND ...

Quarterly 12-page newsletter of your choice: Post-Polio Health OR Ventilator-Assisted Living 100% tax-deductible

\$45 Subscriber Plus

Signature

All of the benefits of Subscriber, AND ...

Both quarterly newsletters: Post-Polio Health AND Ventilator-Assisted Living 100% tax-deductible

\$75 Contributor

All of the benefits of Subscriber Plus, AND ...

Post-Polio Directory Resource Directory for Ventilator-Assisted Living Discounts on special publications, such as Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors Discounts on meetings sponsored by

Post-Polio Health International 100% tax-deductible

\$125 Sustainer

All of the benefits of Contributor, AND ...

One additional Subscriber Membership for designated person or to a person who has expressed financial need to Post-Polio Health International \$100 is tax-deductible.

Use the form below to join today!

If you are a current member, give this form to a friend, family member, or health professional.

I am becoming a Subscriber Member for \$20 because	MEMBERSHIP LEVEL Supporter, \$15 Subscriber, \$\$\$ \$20	
Current Member		
City		
State/ProvinceCountry	☑ Post-Polio Health OR ☐ Ventilator-Assisted Living	
recommended Post-Polio Health. Please discount his/her upcoming membership by \$5.	□ Subscriber Plus, \$45	
	□ Contributor, \$75	
Please send to	□ Sustainer, \$125	
Name	Please send the additional subscription of ☐ Post-Polio Health OR ☐ Ventilator-Assisted Living TO: Name Address	
Institution		
Address		
City		
State/Province		
Zip/Postal Code	City, State/Province	
Country	Country Zip/Postal Code _	
Phone Fax (area/country code)	Or, donate this complimentary subscription to perso selected by Post-Polio Health International.	
Email	□ Other \$	
PAYMENT OPTIONS		
☐ Enclosed is my check made payable to		
Post-Polio Health International. (US dollars only)	<u>POST-P@LIO</u>	
□ OR, charge my: □ VISA □ MasterCard □ Discover	4207 Lindel	
Card # Exp. date	Saint Louis, MO 6310	

Send to:



II Blvd., #110 08-2915 USA 314-534-5070 fax THE MISSION OF POST-POLIO HEALTH INTERNATIONAL, including International Ventilator

Users Network ... is to enhance the lives and independence of polio survivors and home mechanical ventilator users through education, advocacy, research and networking.

ANNOUNCING FOR 2005 ...

Ninth International Conference on Post-Polio Health & Ventilator-Assisted Living

THURSDAY, JUNE 2, 2005 through SATURDAY, JUNE 4, 2005 Saint Louis, Missouri

Ideas for program?

Send them by March 15, 2004 to:

Conference Co-Chairs
Audrey King and William Wischmeyer
Post-Polio Health International (PHI)
Including International Ventilator Users Network
4207 Lindell Boulevard, #110
Saint Louis, MO 63108-2915 USA
314-534-0475, 314-534-5070 fax
info@post-polio.org, www.post-polio.org

POST-POLIO HEALTH

FORMERLY *POLIO NETWORK NEWS*SAINT LOUIS, MISSOURI USA

ISSN 1066-5331

VOLUME 20, No. 1 WINTER 2004
Issued Quarterly

FOITOR

Joan L. Headley, MS Executive Director, PHI

GRAPHIC DESIGN Sheryl Rudy

Special Thanks to ... Saul Morse

©Copyright 2004 by Post-Polio Health International. Permission to reprint must be obtained from Post-Polio Health International (PHI).

Sponsored in part by



The Winter 2004 issue of Post-Polio Health features ...
Report from the 2003 recipient of The Research Fund Award ...
Are You Prepared? Advance Directives ... Healthy Eating: Fat Facts ... and more!



POST-POLIO HEALTH INTERNATIONAL INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK 4207 LINDELL BOULEVARD, #110 SAINT LOUIS, MO 63108-2915 USA Non-Profit Org. U.S. Postage PAID PERMIT No. 210 JEFFERSON CITY, MO