December 18, 2012 (No. 24)

Members of Post-Polio Health International (PHI) and International Ventilator Users Network (IVUN):

Thank you for your continued support of our educational, advocacy and networking activities, and for your support of the separate Research Fund. Remember that PHI creates www.polioplace.org and www.ventusers.org, too. End-of-the year donations are accepted online at http://shop.post-polio.org or by mail. PHI’s Board of Directors and Staff wish you and your loved ones a peaceful and happy holiday season.

PHI Announces 2013 Research Award Recipient

Post-Polio Health International (PHI), St. Louis, Missouri, has awarded a $25,000 grant to study the effects of using an innovative machine that has shown early promising results with frail elders and people with various neurologic conditions in pain reduction, strengthening and bone density improvement.

The Board of Directors of PHI unanimously approved the recommendation of its Review Panel to support the proposal from Texas Woman’s University, Houston, Texas. The study – Effects of Whole Body Vibration on People with Post-Polio Syndrome – will be led by Carolyn Kelley, PT, DSc, NCS.

"PHI’s Research Fund is supported by its Members,” states Joan L. Headley, executive director of PHI, “and many of them tell us that they are interested in studies that can advise them now. Many also want to participate in research.”

Kelley comments, “Dr. Carlos Vallbona, TIRR-Memorial Hermann Rehabilitation and Research, Texas Woman's University, and I are honored to have this opportunity. We
are very aware of the difficulties that many polio survivors experience with exercise attempts for general health. We hope to increase understanding of the use of whole body vibration for people who walk or ride for mobility.”

Kelley (ckelley@twu.edu) explains that because this is an interventional study, people will need to either reside in the Houston metropolitan area or be able to stay in Houston for about three months.

More details about this study and updates from the 2011 recipients will appear in the February 2013 issue of Post-Polio Health (Vol. 29, No. 1).

The RRTC on Aging with a Physical Disability, a research center at the University of Washington in Seattle, Washington, is pleased to announce the launch of their new website. The website is a resource for people aging with post-polio syndrome, including Aging Well with Physical Disability Factsheets. Other updates include new ways to stay connected to their research and find out what they are learning through a News Blog, a quarterly e-Newsletter, and Facebook and Twitter pages.

Fitness Learning Systems, Harrison, Ohio, is offering Post-Polio Water Work: Conserve to Preserve, a course for health-fitness professionals who want to learn about appropriate exercise for people with post-polio syndrome. Created by Mary Essert, BA, ATRIC, with Vickie Ramsey, PR, CPC, this course is available for $44.95 with CEC/CEUs through select organizations and for $32.50 without credits. For ordering more info, click here or call 1-888-221-1612.

POLIO Selbsthilfe e.V. (Germany) has published Aspects of the Post-Polio-Syndrome (second edition) written by Peter Brauer, MD. Orders may be placed at www.polio-selbsthilfe.net. An English translation is also available.

International Journal of Integrated Care recently published articles from the Growing Older with a Disability 2011 Conference. The articles include the Toronto Declaration, the Conference report, 3 Editorials and 22 Conference Abstracts.

Joan L. Headley, Executive Director
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Joan L. Headley, Executive Director
Greetings from Post-Polio Health International in St. Louis

WE'RE STILL HERE! ... AND WE VOTE!

PHI’s sixth annual awareness and action week is October 7-13, 2012. Help distribute the non-partisan letter and let our political leaders know that WE'RE STILL HERE! Print out the letter, Letter for distribution Oct. 3-5 (pdf), and mail it to President Obama, Candidate Mitt Romney, your current legislators, governors, etc. Let them know our concerns. Here is the letter in Word so you can cut and paste the letter in their “contact us” page on their websites. Suggestions for distribution contains mailing addresses and links to other addresses. Join the campaign!
Information about Voting

- Absentee and Early Voting - National Conference of State Legislatures
- Long Distance Voter
- US Election Assistance Commission
- Disability Vote Project

Health News You Can Use

- What You Should Know for the 2012-2013 Influenza Season and from Ask Dr. Maynard
- Video Looks at the Science of Yoga and from Polio Place
- Test All Baby Boomers for Hepatitis C: CDC

Polio in the news

Toronto International Film Festival features polio survivor Mark O’Brien’s story “After he writes an article about sex and the disabled (he types with a pencil in his mouth), he realizes that while he’s always assumed he would always remain a virgin, that might not be the case.” The film called “The Sessions” will open in limited release October 26.

Telluride 2012: Bill Murray drew on sister’s experience to play FDR

Joan L. Headley, Executive Director
Greetings from Post-Polio Health International in St. Louis where it is hotter than our normal late-July hot. The US Centers for Disease Control and Prevention offers general advice and for the elderly (defined as 65 and over).

- Heat Stress in the Elderly
- Extreme Heat Prevention Guide
- Hot Weather Tips

Tomorrow, July 26th, is the 22nd anniversary of the signing of the Americans with Disabilities Act (www.ada.gov). US disability rights leaders report that the Senate markup and vote on the Convention on the Rights of People with Disabilities (CRPD) has been scheduled in Washington, DC, on the anniversary: Thursday, July 26 at 9:30am in Dirksen G-50. The United States International Council on Disability (USICD), of which PHI is a member, requests that people attend to show support for the action. People who are not in the DC area, can follow one of the appropriate links below to sign on as either an individual or, if authorized, as an organization. Here is the Letter from the USICD (and how to sign it). Link to the Full Letter; Click here to sign on as an INDIVIDUAL; Click here to sign on your ORGANIZATION. The USICD also has responded to reasons given by some groups as to why US participation is not a good idea. Check them out point by point.

Links to recent post-polio related abstracts:

- Intravenous immunoglobulin treatment of the post-polio syndrome: sustained effects on quality of life variables and cytokine expression after one year follow up
- Post-polio syndrome: impact of hope on quality of life
- Stroke Risk in Poliomyelitis Survivors: A Nationwide Population-based Study (Taiwan)
- Living with polio and postpolio syndrome in the United
September 2012 Meetings

SEPTEMBER 17 (8:30am to 4:00pm)
Pain and Pain Management, Victoria Inn, Winnipeg, Manitoba, Canada. Guest speakers: Carol Vandenakker, MD, University of California-Davis Medical Center, Sacramento, California, and a panel composed of Barbara Shay, PhD, University of Manitoba Physical Therapy Department, Cheryl Hnatiuk, OT, and Jim Derksen. Contact Estelle at eib@mymts.net.

SEPTEMBER 29 (9:00am to 3:00pm)

Your summer issue of *Post-Polio Health* (Vol. 28, No. 3) is at the printer and will be in your mailbox by mid-August. It contains information about PHI’s 2012 WE’RE STILL HERE!... AND WE VOTE campaign. Watch for the insert and participate in educating current and potential legislators about our concerns.

And finally, PHI has posted all issues of *Polio Network News* (Fall 1987 - Winter 2003) on Polio Place. Go to History, Collections, PHI (Post-Polio Health International) Collections and link on Polio Network News.

Joan L. Headley, Executive Director
Greetings from Post-Polio Health International in St. Louis

- PHI’s Review Panel of its Research Fund is reviewing five grant proposals submitted to PHI/IVUN for a $25,000 award to be given in 2013.

- PHI’s staff continues to add information to Polio Place thanks to many of you. Check out “What’s New” on the home page. PHI invites you to send photos of yourself and family, friends, being active and involved in life for the home page. We have visitors from around the world asking questions about what they can and can’t do. Pictures help tell the story.

- Reminder: For WE’RE STILL HERE! October 7-13th, The August issue of Post-Polio Health will include a form letter that you can mail to your sitting legislators and hopeful candidates. It will inform them about polio and its survivors and enumerate the major issues facing the post-polio population worldwide. Help us create the list. What is your greatest concern? What issues should we list to educate our legislators about our needs? Send them to info@post-polio.org by July 2, 2012.

Update from FDA…..

.... on Bisphosphonates (June 27, 2012): Researchers at the Food and Drug Administration (FDA) have taken a close look at the long-term benefit of bisphosphonates, a class of medications widely prescribed to treat osteoporosis. Some patients may be able to stop using bisphosphonates after three to five years and still continue to benefit from their use. If you’re one of the 44 million Americans at risk for osteoporosis—a disease in which bones become weak and are more likely to break—you may be taking bisphosphonates. Learn more about the risks and benefits of long-term use, and steps you can take to reduce your risk of osteoporosis - such as exercise - FDA.gov.
Reminder: PHI published Calcium, Vitamin D and Bisphosphonates, Oh My! (Vol. 27, No. 3) and More Research About Bisphosphonate Treatment in Polio Survivors (Vol. 28, No. 1).

....article on Medline Plus: Vitamin D Plus Calcium Tied to Longer Life

From Members:

- A new post-polio support group has formed in Marin County, north of San Francisco. The group meets in San Rafael. Anyone interested in attending or being notified of the meetings should contact FrancineAllen@comcast.net.

- We are moving to Springfield, Missouri, and I would like to communicate with anyone familiar with health professionals and facilities in the area. Contact Janluvsbaskets@aol.com.

Aging (or Stuck) in Place
William Stothers, San Diego, California (wstothers@cox.net)

With an aging population and a lousy economy, the notion of “aging in place” is a hot topic. How can we live out our so-called golden years independently, without being forced to leave comfortable surroundings for what seems to be a warehouse of sad, worn out “old people”?

Aging in place promises that we can stay in our own homes, self-reliant and in control. For polio survivors in North America, who pride themselves on their independence and self-reliance that was drummed into them from their early rehab days, maintaining control and independence is a Big Deal.

Personally, I am one of those aging in place. For 30 years, my wife and I have lived in the same house in a great neighborhood. We have a wonderful local market around the corner, accessible public transit a block away. We are happy here.

We manage to get done those things around the house that we cannot physically do through an informal “time-banking” arrangement whereby neighbors help us with tasks we can’t do, and we help them with things they find difficult.
But as I look ahead, I can foresee a day when this informal situation begins to fray and unravel as our functional abilities decline, increasing our need for household assistance and decreasing our ability to help others in equal exchange.

We don’t want to be stuck in place.

What then? An assisted living facility? A retirement/nursing home? These are not attractive choices, at least for us.

Other options exist. Eleanor Smith, polio survivor, founder of Concrete Change, and visionary behind the concept of “visitability,” lives one option: Co-housing.

This is an idea first explored in Denmark, and is growing in interest and popularity in the United States. The Cohousing.org website explains it this way: “Cohousing is a type of collaborative housing in which residents actively participate in the design and operation of their own neighborhoods. Cohousing residents are consciously committed to living as a community. The physical design encourages both social contact and individual space. Private homes contain all the features of conventional homes, but residents also have access to extensive common facilities such as open space, courtyards, a playground and a common house.... The need for community members to take care of common property builds a sense of working together, trust and support. Because neighbors hold a commitment to a relationship with one another, almost all cohousing communities use consensus as the basis for group decision-making.”

Eleanor Smith, who uses a wheelchair full time, had long wanted to belong to an intentional community, and in the late 1990s, she got involved with a small group of like-minded people in the Atlanta area. They acquired 20 acres of land and worked with a developer to create East Lake Commons. This co-housing project is one of the largest in the country with 67 houses. Most projects are in the 20 to 40 house range.

Of course, from the start, Eleanor pushed visitability. And the finished project embraces it. In an essay on the Cohousing website, Eleanor describes how she can visit her neighbors, hang out on the porch and interact generally. As a result of her tireless work, visitability is gaining a strong foothold in new cohousing projects, and even is being worked into remodels and renovations of old ones.

Eleanor Smith’s community is age and gender diverse, with adults, families and children. East Lake Commons is quieter than downtown urban Atlanta, but it resonates with the
sounds of nature and the activity of children.

Senior cohousing is an emerging area, both in additional initiatives and in the fact. Given low turnover in cohousing communities, normal aging and new disability is turning some of those communities into senior communities, with new challenging circumstances.

As we polio survivors wake up daily to new adventures in living, we face questions about how we can best manage our circumstances and thrive. Cohousing moves the idea of aging in place into a richer, more invigorating concept of aging in community. It may not be for everyone, but it seems to offer an integrated way of living, participating and sharing in community life and activities.

➢ For more information on cohousing go to: http://www.cohousing.org/

➢ For Eleanor Smith’s essay on her experience go to: http://www.cohousing.org/cm/article/visitability

➢ For more on "visitability” go to: http://concretechange.org/

Bill Stothers is a long time editor and consultant on media and disability policy. He edited Mainstream, a national advocacy and lifestyle magazine for people with disabilities and major newspapers in Toronto and San Diego. He is a member of the Board of Directors of Post-Polio Health International and currently serves as its Chair.

Source: Post-Polio Health International (www.post-polio.org)

Joan L. Headley, Executive Director
Greetings from Post-Polio Health International in St. Louis

*Post-Polio Health* (Volume 28, Number 2) is in the mail to Members. Articles include “What Having Had Polio Causes, Might Cause and Does Not Cause,” “Promoting Positive Solutions,” “Ask Dr. Maynard,” “IVIg Update” and more.

This also issue announces

**WE’RE STILL HERE!**

October 7-13, 2012

[www.post-polio.org](http://www.post-polio.org)

**New Group in Wisconsin**

A new post-polio support group is forming in Wisconsin Rapids. The first meeting was held April 24th. Survivors and families in the area are welcome to join at any time. Contact Faith at fionesan@wroinstitute.com for details.

**Thanks Jay**

PHI received an artifact from Jay Bryant for Polio Place. Check out [Jay’s photo](http://www.post-polio.org) with John and Annie Glenn. You, too, can share your thoughts and accompanying letters, photos, memorabilia. Just [complete the form online](http://www.post-polio.org) or email info@post-polio.org.

**Read it somewhere...maybe it was here.**

PHI has posted a PDF of all of its [PHI Membership Memos](http://www.post-polio.org) on [www.post-polio.org](http://www.post-polio.org) in the Networking section.
A BETTER LIFE
AARP Bulletin, June 2007

Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska

It’s time we got this straight: palliative care is not the same as hospice.

As Karen Rafinski put it in June’s AARP Bulletin, “Palliative care is about making the most of life with a serious illness, whether the disease is terminal or not.” While this could mean patients with life-limiting illnesses, it means those who may be recovering from grave conditions such as cancer or stroke, as well.

And guess what: It can also be us—certain polio survivors, perhaps still living at home but not necessarily bedridden, who simply want a better life. They may be severely affected by pain, for instance, or chronic weakness or stress—survivors using ventilators or those losing more muscle mass—others additionally affected by complications of aging. A better life. We’re talking quality here (not to mention quantity—at least one study shows patients living longer for having been involved in palliative care).

Todd Sauer, MD, Medical Director at Nebraska Medical Center’s three-year-old Palliative Medical Service in Omaha, says, “We are experts at helping to manage symptoms. We bring comfort to patients far earlier than they would find by merely seeking end-of-life care. We also offer help in making decisions. We meet with families and patients to discuss options, to open their lives to a variety of possibilities.”

Traditionally, palliative care programs use a team approach. Teams are often made up of a physician (probably different from our primary care doctor, though the palliative doctor does work with others to coordinate care), nurse practitioners, social workers, and chaplains, as well as patients and, at times, family members. Such teams cover a wide range of symptoms by addressing physical, emotional, and spiritual issues.

A holistic approach to one of our major concerns, pain management, may be used. In addition to medication, it’s possible to try massage therapy, acupuncture, or any of an assortment of relaxation techniques, such as yoga and other meditation methods. Much attention is paid to the type of pain involved. Emotional pain is far different from a nagging rotator cuff, yet both kinds of pain must be tended to. Many patients undergoing standard treatment for their specific disease discover that palliative programs add an amazingly helpful layer of support.
In Omaha, members of the palliative care team make home visits at any stage of a patient’s illness. “While a doctor can’t be available to visit people in their homes 24/7,” says Dr. Sauer, “we do the best we can. We also make every effort to help families caring for their loved ones at home.” Check with your doctor about what Medicare covers.

Not all palliative care programs are alike—and neither are all patients. We need a good fit. Shop around—check out the list of what’s available in your locality at getpalliativecare.org (see Step 2) or ask your doctor for a referral.

What to look for? As an example, Dr. Sauer is board certified in Family Medicine with a subspecialty in Hospice and Palliative Medicine. He’s Fellowship trained, comes into the picture with outstanding credentials. Here’s a family physician who liked treating families enough to move on to devote time and effort to becoming skilled in the world of palliative care. Those all have to be clues.

Today you and I may believe we don’t have a reason for palliative care—could be we’re not sure, or we’re thinking maybe later it would be a good idea. How could it hurt to get in touch with a palliative care doctor and discuss options?

O.K. Have you looked it up yet? The word “palliative”? Alleviation of symptoms. To mitigate. To reduce the severity.

Sweet, sweet sounds to my ears. What do you think...

Nancy Baldwin Carter, B.A, M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.

Published in PHI Association Members Communiqué, April 15, 2011(No. 60)

Joan L. Headley, Executive Director
Greetings from Post-Polio Health International (PHI) in St. Louis

Your issue (Vol. 26, No. 4) of Post-Polio Health will be mailed next week. Articles in the Fall issue feature living alone, successful bracing, advice about exercise, thoughts about advertised “cures” and more. We invite you to suggest topics for future articles and welcome questions to be asked of Dr. Maynard, a physiatrist, and psychologists, Drs. Machell and Olkin.

News from Disability Connection, The Quarterly Newsletter of Disability.gov (October 2010)

- The Pass It On Center is creating national and state resources to foster the appropriate reuse of AT so that people with disabilities can get the affordable AT they need in order to live, learn, work and play more independently. Click here - Assistive Technology Exchange Networks – to find the program in your state.

- Community Health Centers provide care for you even if you have no health insurance. You pay what you can afford, based on your income. Find a community health center near you. Health centers provide checkups when you’re well, treatment when you’re sick, complete care when you’re pregnant, immunizations and checkups for your children, dental care and prescription drugs for your family and mental health and substance abuse care if you need it.

News about US Medicare

Open enrollment for your Medicare plan begins November 15th. To compare plans, go to the official Medicare Plan Finder.

Intended for journalists, you will find extensive information about Medicare’s Fall Open Enrollment Period (also known
**International’s mission is to enhance the lives and independence of polio survivors and home ventilator users through Education, Advocacy, Research and Networking.**

Remember to check [www.post-polio.org](http://www.post-polio.org) and [www.ventusers.org](http://www.ventusers.org) often! We add a new message each week. Send your ideas for “This week at…” to info@post-polio.org

Post-Polio Health International
including International Ventilator Users Network
4207 Lindell Blvd., #110
St. Louis, MO 63108-2930
314-534-0475 phone
314-534-5070 fax
[www.post-polio.org](http://www.post-polio.org)
director@post-polio.org

as the Annual Coordinated Election Period, or ACEP) that begins on November 15 and lasts through December 31. **The Medicare Rights Center** reminds you that “this year, Medicare consumers need to be aware of changes taking place in 2011 in order to make the best informed decision during Fall Open Enrollment.” Check out **Fall Open Enrollment Period resource.**

**News about new rights, benefits and protections taking effect under the Affordable Care Act.**

These changes include:

- Insurance protections for [children with pre-existing conditions](http://www.post-polio.org).
- Prohibiting [lifetime dollar limits](http://www.post-polio.org) on most benefits.
- Access to [free preventive services](http://www.post-polio.org) such as blood pressure, diabetes and cholesterol tests, as well as many cancer screenings, including mammograms and colonoscopies.

**For Your Health**

On October 13th, the **US Food and Drug Administration** issued a [warning](http://www.post-polio.org) that there is a possible risk of a rare type of thigh bone (femoral) fracture in people who take drugs known as bisphosphonates to treat osteoporosis.

**It's flu season.** Protect yourself by getting a flu shot soon. Check the US Centers for Disease Control and Prevention site for [details](http://www.post-polio.org).

**A Potpourri of Books**

The book, *Passages in Caregiving: Turning Chaos into Confidence*, by Gail Sheehy, is an important contribution to the world of healthcare for those with chronic debilitating conditions, writes Nancy Caverly, OTR, Mexico, Missouri. Sheehy, who wrote the first “Passages” book about life in 1967, is an excellent story teller and provider of extensive information about caregiving.

She tells the story of her husband, Clay Felker, the founder of *New York Magazine*. He was diagnosed with a skin tumor on his neck which progressed to the throat, causing him to lose his voice, have a tracheostomy and a feeding tube. With the combined efforts of his journalistic peers, the doctors who cared for him, his circle of friends, his two daughters and his wife, he was able to live for 17 years...
after the initial diagnosis mentoring young journalists.

As the primary caregiver for her husband, Sheehy chronicles life of a “care receiver” (Clay) and caregiver (herself) as moving through a labyrinth. Each medical event or life change brings another pathway leading to the center. She carefully documents events and offers strategies for coping with life at each change. Her footnotes, bibliography, index and references to healthcare agencies and groups are excellent source material for aging parents, spouses, children and friends.

It would be helpful for all family members to read the book and share their insights into how each may contribute to the life of a family member who needs frequent or constant support. It should be a “required reading” text for every healthcare provider. Her understanding that one person cannot provide the necessary care and also care for oneself is fundamental to the book. She is able to negotiate the maze only with considerable assistance from the people already mentioned. This ability is helped by the fact that she has many connections and is a woman of means, which is not the case for everyone.

The book is available in bookstores for $25, or on the internet at both Amazon.com and Alibris.com.

**So Far Away: Twenty Questions and Answers for Long-Distance Caregiving** from the National Institute on Aging addresses some issues unique to long-distance caregiving. If you’re responsible for the care of a loved one who lives far away, you’re not alone. About 7 million adults nationwide are long-distance caregivers.

**Proceedings: The Effect of Ankle Foot Orthoses (AFOs) on Balance**, the official findings of the state-of-the-science conference, June 22-24, 2010, sponsored by the American Academy of Orthotists and Prosthetists, is available by calling 301-617-7805 or by purchasing online at [www.oandp.org](http://www.oandp.org).

**Non-Invasive Ventilation and Weaning: Principles and Practice** edited by Mark Elliott, Stefano Nava and Bernd Schonhofer is now available. Check out the [Table of Contents](#) (Chapter titles and authors). Polio survivor and ventilator user Linda
Bieniek was a contributing author to a chapter entitled “Psychological issues for the mechanically ventilated patient.” The hard cover, 648 page book is a Hodder Arnold Publication: London, UK, 2010 and dispatched from and sold by Amazon.co.uk. (£149.00).

The Politics of Polio in Northern Nigeria by Elisha P. Renne, University of Michigan, has been described by Murray Last, University College London, as "A remarkable exploration of ordinary Muslims' often skeptical response to polio and other vaccinations promoted by their government and WHO. Renne may not persuade you that Muslims' fears were justified, but she ensures you will understand their rationale. An invaluable, provocative text for all those involved in promoting 'global' health."

Chasing Polio in Pakistan: Why the World’s Largest Public Health Initiative May Fail by Svea Closser, Assistant Professor of Anthropology, Middlebury College, analyzes local politics, social relations, and global political economy in the implementation of a worldwide public health effort, with broad implications for understanding what is possible in global health, now and for the future.

Update on the Eradication Effort

The Global Polio Eradication Initiative reports

A head to head trial against current poliovirus vaccines has found that the new bivalent oral vaccine against poliovirus, which targets both the remaining types of poliovirus concurrently, induces a stronger immune response than the traditional trivalent vaccine and a similar immune response to the latest monovalent (monovalent type 1 or monovalent type 3) vaccines. The study is reported in the October 2010 The Lancet.

As of October 5, there have been 706 cases globally this year (635 type 1 and 71 type 3), compared with 1,126 cases at this time last year (387 type 1, 735 type 3, four type 1/3 mixtures). 17 countries have reported cases in 2010, compared with 21 at this time last year.
PHI posts “Reports from PHI's Members.”
Want to share your activities? Send the information to info@post-polio.org.

Joan L. Headley, Executive Director
Greetings from Post-Polio Health International (PHI) in St. Louis

October is here! WERE STILL HERE!

October 10-16, 2010

is PHI-organized WERE STILL HERE! week. Individual Members and post-polio groups around the world are asked to create activities of awareness regarding the late effects of polio during this time. Thanks to those of you who have made plans.

Each year PHI suggests a focus and this year, we, along with Rotary International and Polio Survivors and Associates, encouraged visits to your local Rotary meeting to thank them for their eradication efforts, to remind them of the contributions of people with disabilities and to remind them of the needs of younger polio survivors in the developing world and of aging survivors worldwide. Check out the materials provided for your use.

What are the facts? Carol Pandak, Manager, Division of PolioPlus, and Rotarians Ann Lee Hussy and Al Bonney of Polio Survivors and Associates, a Rotary Action Group, have supplied answers to questions about the polio eradication effort. Joan L. Headley, Executive Director of PHI, answered questions about the late effects of polio. Two documents are available: “A Rotarian’s Primer on Polio Eradication and Polio Survivor Support” and “Questions and Answers for a Visit to Rotary.”

Rotary International’s The Rotarian (September 2010) featured an article about polio survivors – Polio’s Second Act.

Columnist Nancy Baldwin Carter reminds us that Opportunity Knocks and we shouldn’t miss this chance.
Here is a **Thank you and request to help PHI’s mission.**

Polio survivor and freelance writer Reji Mathew writes about PHI and WE’RE STILL HERE! in this month’s blog [http://rejimathewwriter.com](http://rejimathewwriter.com). Check out her blog, dedicated to exploring themes of health and wellness of persons living with paralysis, neurological, and progressive medical conditions.

Look under “Rotary” in your phone book or use the “Club Locator” on the website of Rotary International. If they are booked that week, accept any week available.

**Joan L. Headley, Executive Director**
Greetings from Post-Polio Health International (PHI) in St. Louis

Your issue (Vol. 26, No. 3) of *Post-Polio Health* is in the mail. Articles in the summer issue discuss swallowing problems, switching to hand controls and obtaining a power wheelchair. The issue also includes the practical columns of Frederick Maynard, MD, and Stephanie Machell, PsyD and Rhoda Olkin, PhD.

"Dr. Donohue" featured a question about post-polio in his July 1, 2010, nationally syndicated column, and in his response he advised readers to contact Post-Polio Health International (PHI), "an organization devoted to helping post-polio patients, can provide you with detailed information." As a result, PHI received more than 125 phone calls and a noticeable increase in visits to [www.post-polio.org](http://www.post-polio.org) during the next two weeks.

The majority of the callers were in their late 70s and early 80s. Most of them knew about the late effects of polio but were glad to connect with us, a trusted source with a reputation that provides factual, up-to-date information.

I appreciate the opportunity to talk with fellow survivors to find out what is on their minds, and if there is an oft-repeated issue. Several survivors, coincidently perhaps, but worth noting, reported an increase in their spinal curves resulting in new severe back pain, inability to sleep lying down, and problems with digestion. Many spoke about the changes they had made in their lives - using canes and walkers to prevent falling; moving to assisted living centers where they felt safe and had found companionship; remodeling baths, kitchens and home entrances, so they could stay in their home; and keeping a wheelchair at home and one at church.

While some were from larger cities, many were from smaller communities where self-help groups and self-identified post-polio experts are scarce.
Thank you, Dr. Donohue. We appreciate your interest in guiding survivors to the help they need.

**The 20th Anniversary of the ADA**

The Missouri History Museum (St. Louis) created a special exhibit, The Americans with Disabilities Act: Twenty Years Later, that will be open from June 26, 2010 to June 6, 2011. Check out the related website - [actionforaccess.mohistory.org](http://actionforaccess.mohistory.org). PHI’s founder Gini Laurie is featured in the “Independent Living Movement” section. The site and the exhibit include photos from the PHI archives.

**International Disability Rights**

Follow the success of the adoption of [Convention on the Rights of Persons with Disabilities](http://www.un.org/disabilities/convention/).

**WERE STILL HERE!**

**October 10-16, 2010.**

Visit a Rotary Club luncheon meeting telling them WE’RE STILL HERE! Suggestions and ideas available. Read more...

**Upcoming Post-polio Meetings**

**Kansas**

AUGUST 7 from 9:00 am to 4:00 pm, “Learning and Sharing Polio’s Legacy,” Delos V. Smith Senior Center - 101 West 1st Ave, Hutchinson, Kansas. Contact Central Kansas Polio Survivors, Jean Graber at jgraber3@earthlink.net. Presenters include: Timothy A. Crater, MD, FACP, John G. Fan, MD, Joan Headley, PHI, and David P. Calvert, Attorney at Law.

**Maine**

SEPTEMBER 25, 2010. The Post-Polio Support Group of Maine will embark on their 25th year of operation with a celebration at the Calumet Club in Augusta, Maine. Guest speaker: Joan L. Headley. Check [www.ppsgm.org](http://www.ppsgm.org) or contact info@ppsgm.org.
AUGUST 31 – SEPTEMBER 2. Post-Polio Syndrome – a challenge of today. Hotel Crowne Plaza Copenhagen Towers, Copenhagen, Denmark. Click here for the first announcement and call for papers. Hosted by P T U (The Danish Society of Polio and Accident Victims) and European Polio Union.

From Disability.gov
Pre-existing Condition Insurance Plan
The U.S. Department of Health and Human Services has announced a new Pre-existing Condition Insurance Plan (PCIP) that will offer coverage to uninsured Americans who have been unable to get health coverage because of a pre-existing health condition. PCIP will provide a new health coverage choice for Americans who have been uninsured for at least six months, have been unable to get insurance because of a health condition, and are a U.S. citizen or are residing in the U.S. legally. For more information about the Plan visit HealthCare.gov or download the brochure The Affordable Care Act: What It Means for Those with Pre-Existing Conditions in PDF format.

Long-Term Care
Many people may not realize that Medicare and most health insurance plans don’t pay for long-term care. Long-term care provides help with basic daily living activities for people who have a chronic illness or disability. Sometimes called personal assistance, it may include help with everyday activities like dressing, bathing and using the bathroom. Long-term care can be provided at home, in the community, in assisted-living facilities or in a nursing home. It’s important to start planning for long-term care early to maintain independence and to make sure individuals get the care they may need in the future. For more information on long-term care and the new Community Living Assistance Services and Supports (CLASS) Program visit HealthCare.gov. The Aging and Disability Resource Centers also provide information about, and access to, long-term care.

Filling the Medicare Part D "Donut Hole"
If you have Medicare prescription drug coverage and have to pay for your drugs because of the "donut hole" in coverage, in 2010 you’ll get a one-time, tax-free $250 rebate from Medicare to help pay for your prescriptions, if you are not already receiving Medicare Extra Help. These checks started going out in mid-June. Checks will be mailed monthly throughout the year as beneficiaries enter the coverage gap. This information is also available in Spanish.

Joan L. Headley, Executive Director
Greetings from Post-Polio Health International (PHI) in St. Louis

- Membership renewals notices for July are in the mail.
- Ventilator-Assisted Living (Vol. 24, No. 3) was distributed earlier this week.
- PHI’s Research Fund panel of experts is reviewing 6 applications to determine who will be invited to submit Phase 2 information.
- You will receive your next Post-Polio Health in August. Watch for articles about swallowing, purchasing power chairs, hand controls and the columns “Ask Dr. Maynard” and “Promoting Positive Solutions.”

Fact Sheet on Health Reform

The Affordable Care Act's New Patient's Bill of Rights
Fact sheet on the new Patient's Bill of Rights under the Affordable Care Act, which will help children (and eventually all Americans) with pre-existing conditions gain health care coverage and keep it, protect all Americans' choice of doctors and end lifetime limits on the care consumers may receive. The departments of Health and Human Services, Labor and Treasury have issued regulations to implement the new Patient's Bill of Rights.

Message from Medicare
Medicare beneficiaries will soon receive information in the mail about the immediate benefits they may see from the new Affordable Care Act. The first benefit that several million Medicare beneficiaries will receive is a one-time check for $250, if they enter the Part D donut hole and are not eligible for Medicare Extra Help. The donut hole, or coverage gap, is the period in the prescription drug benefit in which a beneficiary pays 100 percent of the cost of their drugs until they hit the catastrophic coverage. Next year, all beneficiaries who enter the gap will get a 50 percent discount for covered brand name Part D drugs. Also
beginning next year, Medicare beneficiaries will get preventive care services like colorectal cancer screening and mammograms without cost-sharing, in addition to an annual wellness visit. A fact sheet about Medicare and the new health care law is available in English and Spanish.

**Books/Booklets**

- **A 10-page illustrated booklet on visitability** that contains a rationale for visitability; photos of visitable houses; a sample house plan; detailed standards, language and illustrations that can be used as models for proposed visitability laws is available from the [RERC-UD at State University of New York, Buffalo](http://www.udeworld.com/visbooklet/visitabilitybooklet.pdf).

- **Not Just Polio: My Life Story (Paperback)** by Richard Lloyd Daggett. Daggett lives in southern California and has written extensively on disability and the human condition. Richard has appeared in several film and television documentaries about polio. He is president of the [Polio Survivors Association](http://www.poliosurvivors.org) and serves on the board of The Amigos Fund of Rancho Los Amigos National Rehabilitation Center.

- **The Polio Years in Texas: Battling a Terrifying Unknown (Paperback)** by Heather Green Wooten. Drawing extensively on archives and personal interviews, Wooten relates the Texas polio/post-polio story in detail adding vital local and state knowledge to the more-known national story. The book has recently received Best Book of the Year awards from two Texas history organizations: the Texas Historical Commission (T. R. Fehrenbach Book Award) and the East Texas Historical Association (Ottis Lock Book of the Year Award).

**For Your Health**

- **National Center on Physical Activity and Disability (NCPAD)** is an information center concerned with physical activity and disability. Check out these links.
  - [Understanding Weight Loss](http://www.ncpad.org/weightloss)
  - [Weight Smart Column: Calorie Counting](http://www.ncpad.org/weightsmart)

- **The Food and Drugs Administration (FDA)** in the United States says that at least 1 death occurs per day and 1.3 million people are injured each year due to medication errors. [Drugs.com](http://www.drugs.com) provides the public
with information "to better manage their own health care and to assist in the reduction of medication errors." The site features a “Pill Identifier” and an “Interactions Checker.”

- Stroke is the third leading cause of death in the United States, and the primary cause of disability.”
  
  **Check out the Health Center - Stroke.**

  **Remember:** The National Stroke Association recommends to Act F.A.S.T. with this simple test:

  **FACE:** Ask the person to smile. Does one side of the face droop?

  **ARMS:** Ask the person to raise both arms. Does one arm drift downward?

  **SPEECH:** Ask the person to repeat a simple sentence. Are the words slurred? Can he/she repeat the sentence correctly?

  **TIME:** If the person shows any of these symptoms, time is important. Call 911 or get to the hospital fast. Brain cells are dying.

- **Recommended Vaccinations for Adults.** The Advisory Committee on Immunization Practices, which provides guidance on vaccination for children and adults in the United States, publishes a regular update on adult immunization schedules and doses. Are you covered? Check out the latest recommendations, including special information for international travelers, at [www.cdc.gov/vaccines/default.htm](http://www.cdc.gov/vaccines/default.htm).

- The U.S. Department of Health and Human Services has announced a new website called [HealthCare.gov](http://HealthCare.gov). This new tool lets consumers take control of their health care by connecting them to information about quality, affordable health care coverage. HealthCare.gov is the first central database of health coverage options--from Medicare to the new [Pre-Existing Conditions Insurance Plan](http://Pre-Existing Conditions Insurance Plan), with information from more than 1,000 private insurance plans. HealthCare.gov answers questions that relate to [people with disabilities](http://people with disabilities) and health care, and also has information about insurance plans and community services in every state. Take a [video tour](http://video tour) of this new website.

Groups assisting polio survivors...

...in [Democratic Republic of the Congo](http://Democratic Republic of the Congo)
...in Bihar, India
...in Mexico. (Mexico Second National Post-Polio Syndrome Symposium)
...in Nigeria

About Polio Eradication


- The Polio Eradication Research and Product Development team at the World Health Organization published the 6th edition of the Polio Pipeline newsletter. This issue gives an overview research has played in informing and finalizing the new Global Polio Eradication Initiative (GPEI) Strategic Plan 2010-2012, which was endorsed by the World Health Assembly in May.

Interested in sharing your opinion?

Do You Live in Southern California?
The Polio Survivors Association, [www.polioassociation.org](http://www.polioassociation.org) is surveying Southern California polio survivors to find out the name of your HMO, the name of the medical group you use, and your opinion of the "polio care" provided by your primary care doctor, physical therapist and the various specialists you may see for polio-related issues. The survey will be used as a basis for working with HMOs to provide CME training for the area health professionals. Email info@polioassociation.org to obtain a copy of the survey questionnaire.

Survey for Spanish speaking survivors: Please contact the post-polio group (list below) closest to you to read about the survey, to understand what will be done with the results and to obtain a password to access the survey. To read about the survey (in Spanish), [click here](#).

- Asociación Postpolio Madrid (APPM), [www.postpoliomadrid.org](http://www.postpoliomadrid.org)
- Organización Mexicana para el Conocimiento de los Efectos Tardíos de la Polio, A. C. (OMCETPAC), [www.postpoliomexico.org](http://www.postpoliomexico.org)
- Asociación De Polio Y Post-Polio De Cataluña (APPCAT), [www.appcat.org](http://www.appcat.org)
- Asociación Polio Pospolio Argentina (APPA) / Asociación Incluir, [ar.groups.yahoo.com/group/poliopostpolioargentina](http://ar.groups.yahoo.com/group/poliopostpolioargentina)
www.incluir-argentina.org.ar

- Asociación De Afectados De Polio Y Síndrome De Post-Polio De Castilla Y León (POLIOCYL), poliocyl.blogspot.com

- Asociación Gaditana De Personas Con Síndrome Post-Polio (AGASI), www.agasi.org.es

- Asociación Valenciana Para La Defensa De Afectados De Polio Y Postpolio (ADUNCITAS), www.polio-pv.org/html

**Take a survey about media & disability issues:** The purpose of this survey, which takes about 30 minutes, is to have you evaluate the media and its representation of people with disabilities and their issues. Participation in this project is completely voluntary. You can refuse to answer any question and you can stop participation at any time. Click [here](#) to begin.

**Joan L. Headley, Executive Director**
Greetings from Post-Polio Health International (PHI) in St. Louis

Post-Polio Health (Volume 26, Number 2) is in the mail. You will receive your copy within the next two weeks. Feature articles include

- **What Your Voice is Saying About You: Vocal Changes and the Late Effects of Polio** by Mary Spremulli, MA, CCC-SLP
- **Our Journey to India** by Holly H. Wise, PT, PhD and Sunita Dodani, MD, PhD
- **Persisting Noninfectious Genome Fragments of Poliovirus in PPS Patients** by Antonio Toniolo, MD and his team of researchers from Italy.

The issue also includes the popular columns **Ask Dr. Maynard** and **Promoting Positive Solutions** by Stephanie T Machell, PsyD and Rhoda Olkin, PhD. Send your questions to info@post-polio.org.

**FYI**: Select articles from past issues of *Post-Polio Health (Polio Network News)* are online at Past Issues, Listed by Topic and Past Issues, Listed by Date.

**Post-Polio Community Calendar** lists upcoming conferences. Additions may be sent to info@post-polio.org.

Two 2011 conferences ask for abstracts

- **AUGUST 31 –SEPTEMBER 2, 2011. Post-Polio Syndrome - a challenge of today.** Hotel Crowne Plaza Copenhagen Towers, Copenhagen, Denmark. Watch www.polioconference.com for details. The First Announcement will be distributed this week. Hosted by PTU (The Danish Society of Polio and Accident Victims) and European Polio Union.

- **JUNE 5 - 8, 2011. Festival of International Conferences on Caregiving, Disability, Aging and Technology,** Sheraton Centre Toronto Hotel, Toronto, Ontario, Canada. Check out the **Call for Abstracts.** Lead organizations are March of Dimes.
News You Can Use

From the Office of Disabilities Employment Policy
The Job Accommodation Network (JAN) has a newly spruced-up website. What is JAN? The Job Accommodation Network (JAN) is the leading source of free, expert, and confidential guidance on workplace accommodations and disability employment issues, including self-employment and entrepreneurship options for people with disabilities.

From MediNurse
MediNurse provides these pointers for spring cleaning of medicine cabinets.

- Almost everything in your medicine cabinet, including sunscreen and over-the-counter medications, has an expiration date and should be thrown out and replaced when they become outdated.
- Holding onto unused medication increases the chance of unintentionally grabbing a bottle and taking the wrong medication.
- Traditional advice has been to dispose of unused drugs by flushing down the toilet or putting in the trash. Neither is a good idea. It is best to check with your local pharmacy to find out if they will take back unused or expired prescriptions. Another option, better than putting in the sewer system, is crushing the pills, dissolving them in water, then mixing in something to absorb the ingredients such as coffee grounds, flour, cat litter or sawdust, and placing the mixture in a sealed plastic bag before disposing in the trash.
- Do not use pills if they appear discolored or powdery.
- Do not use capsules that are cracked, leaking or sticking together.
- Do not use liquids that have become cloudy, filmy or hardened; do not use any creams that have cracked. Liquids and creams can also be mixed with coffee grounds, flour, cat litter or sawdust, and then sealed in plastic bags for disposal in the trash.
- It is not recommended to keep any medication for more than one year. The medication could become less potent or more potent depending upon the drug. This could create a harmful situation.
- Actually the medicine cabinet in your bathroom is one of the worst places to store medications! The
temperature and humidity are typically higher than other rooms in your house, creating a hostile environment that can make medicines less potent. Medicines are best stored in cool, dry places out of direct sunlight, and always out of the reach of children.

- A kitchen cabinet may be a good alternative, as long as it’s not near the sink, or using a dresser drawer in the bedroom. Sealing pill bottles in a zip-lock bag will help keep moisture away.

From Disability.gov
Healthcare Reform – What’s In It For You? Find out the ways the new healthcare reform law will affect Americans with disabilities, including changes to Medicaid and long-term services and supports that will allow people to stay in their homes instead of a hospital, nursing home or intermediate care facility.

Polio in the News

From the World Health Organization
Polio in Tajikistan, first importation since Europe certified polio-free

From UN News Centre
Polio outbreak in Tajikistan spurs UN vaccination campaign

From UNICEF- United States Fund
Bringing polio vaccine to migrant communities in India

Joan L. Headley, Executive Director
Updated Post-Polio Directory

Post-Polio Health International’s 2010 Post-Polio Directory is now online. PHI Members (Contributor and above) may request a print copy by emailing info@post-polio.org. The Post-Polio Directory is continually updated. Send your changes and additions to PHI at info@post-polio.org.

DEADLINE EXTENDED: Post-Polio Health International’s deadline for Phase 1 of proposals for the 2011 $25,000 research award has been extended to March 31, 2010. Details are available at www.post-polio.org/res/rfcall.html.

Now on PHI’s Website

Summaries of Post-Polio Research from Around the World. PHI invites institutions to send summaries of their post-polio research.

Leslie Drawdy, PT, DPT, from the Tucson area, shares her Physical Therapy—Tips for Successful Treatment of Clients with PPS.

Reminder!

Want a sticker for your vehicles ... car, truck, wheelchair, scooter? PHI has a quantity of 4” by 4” bumper stickers available for a donation to Post-Polio Health International. Recommended donation: 1-10 ($1.00 each); 11-50 ($,.70 each); 51-100 ($,.50 each). Send your request and payment to PHI, 4207 Lindell Blvd., #110, St. Louis, MO, 63108-2930. Obtain a sticker and start a conversation!
For Your Health

Avoid Maalox Mix-Ups (Wed, 17 Feb 2010) Choosing the wrong liquid Maalox product for your condition can have harmful consequences. Click on the above link to learn how to avoid mix-ups.

AAN Guideline Evaluates Treatments for Muscle Cramps
A new guideline from the American Academy of Neurology recommends that the drug quinine, although effective, should be avoided for treatment of routine muscle cramps due to uncommon but serious side effects. The guideline is published in the February 23, 2010, issue of Neurology®, the medical journal of the American Academy of Neurology.

On the Internet

Social Security’s newest online service – an application for Medicare benefits: This new online application, which takes less than 10 minutes to complete, is for people reaching the Medicare eligibility age of 65 who want to delay filing for Social Security retirement benefits. To learn more, click here.

Health Care Reform Bill and Debate Available on Government Printing Office’s Federal Digital System. (These are very large files.) Direct links to H.R. 3590, Patient Protection and Affordable Care Act and H.R. 4872, Health Care and Education Reconciliation Act of 2010 and to the Congressional Record containing the vote.

More Oral Histories: Polio– A Living History, a British Polio Fellowship Heritage Project, features fifty (50) oral polio history interviews and photos.

Books

New Edition for 2010 Donde no hay doctor covers a wide range of topics from diarrhea to tuberculosis, from helpful and harmful home remedies to nutrition and vaccinations. This brand new edition contains new and updated information on: childhood vaccinations; HIV prevention and medicines; treating serious injuries; the resurgence of yaws; drug resistance and changes in STD and malaria medications; the differences in signs of heart attacks in women and men; asthma treatment; new treatments for
scabies and head lice. To purchase the new 2010 edition of *Donde no hay doctor*, visit [www.hesperian.org](http://www.hesperian.org), or phone the book orders department toll free: 888/729-1796. Order five or more copies of any Hesperian book and receive a 20% discount. *Donde no hay doctor* is also available for free download [here](http://www.hesperian.org).

![The Calliper Kids](image)

**The Calliper Kids** - Eleven Life Journeys of Polio Survivors is a project of the Knox-Yarra Ranges Polio Support Group in Victoria, Australia. For details, contact joansgra@bigpond.com.

![Walking Isn't Everything](image)

**Walking Isn't Everything** was written by Jean Denecke about her experience of living with polio (what it was like to get polio, her experiences with various hospitals and doctors, and her experience in the Roosevelt Foundation facility in Warm Springs, Georgia).

![A View from the Quiet Corner](image)

**A View from the Quiet Corner** contains the poems and reflections of Alan A. Malizia.

![Who Hit the Down Button](image)

**Who Hit the Down Button** by Phyllis Porter Dolislager is appropriately subtitled Life with a Chronic Illness Or Disability.

**Ideas for Lillian?** [Lilwil937@aol.com](mailto:Lilwil937@aol.com)

I had polio at 6 months. Now at age 87 years, I can no longer assume the pose for urinating, while in public bathrooms. The bars surrounding the commode were great until now. I use a power wheelchair and can get into the cubicle but trying to stand over the toilet is no longer an option. Once, I accidently sat down and had to get my husband into the bathroom to help me up. Thank goodness for cell phones. Most toilets are too low for me. When
visiting, I take my portable lift with me, but trying to use this when out for the day has not worked. I have tried using pads, but have difficulty in emptying my bladder. I have BYO on occasion but need a solitary room. Public bathrooms are a “no no” for a male to enter. (There are unisex bathrooms in some places, which helps.) Is there anything available to make it possible for me to be away from home for an extended period possible? Does anyone have any other ideas?

Joan L. Headley, Executive Director
January, 2010 (No. 5)

The Research Fund of PHI

Post-Polio Health International’s deadline for Phase 1 of proposals for the 2011 $25,000 research award is Friday, March 5, 2010. Details are available at [www.post-polio.org/res/rfcall.html](http://www.post-polio.org/res/rfcall.html). If you have questions, call Joan L. Headley at 314-534-0475 or email director@post-polio.org.

Post-Polio Directory

PHI is updating its Post-Polio Directory for 2010. Click on [Post-Polio Directory](http://www.post-polio.org) and check your entry. To assist you, note that the Clinic listings start on page 4; Health Professional on page 11; Support Groups on page 20. Please check your listing and send any changes, additions or deletions to info@post-polio.org.

Festival of International Conferences on Caregiving, Disability, Aging and Technology – FICCDAT 2011 will be held June 5-8, 2011 in Toronto, Canada. The two lead organizations of the Festival are March of Dimes Canada and Toronto Rehabilitation Institute. FICCDAT 2011 will bring together six important and different conferences all focused on enhancing the lives of seniors, persons with disabilities and their family caregivers. The conferences in the festival are Growing Older With A Disability; RESNA/ICTA (Rehabilitation Engineering and Assistive Technology Society of North America); Advances in Neurorehabilitation; Caregiving in the 21st Century; 34th Canadian Medical and Biological Engineering Conference; and International Conference on Best Practices in Universal Design.

All six conferences are now accepting abstracts, which are due December 1, 2010. To learn more about the Festival and the opportunities to present, go to [www.ficcdat.ca](http://www.ficcdat.ca). Online registration is also available. Early bird registration closes April 1, 2011. When you visit the site, it will ask you to sign up and you will then receive future updates.

The Immortal Life of Henrietta Lacks is a new book by Rebecca Skloot, an award-winning science writer in the subjects of science and medicine. The book, to be released...
this month, tells the story of the African-American woman Henrietta Lacks and her cell line – known as HeLa cells – that have been used in biomedical research since the 1950s. David Rose, archivist at the March of Dimes, says, “HeLa cells were instrumental in the development of the Salk polio vaccine, and Ms. Skloot used the resources of the March of Dimes Archives for a portion of her research.” HeLa cells have been used to advance research in in vitro fertilization, cloning and gene mapping. The bioethical implications of the use of HeLa cells in scientific research have paramount significance today as we grapple with a host of complex issues in medicine, genetics and reproduction.


The Disability and Health Journal special issue features "A Disability Perspective on the Issue of Physician Assisted Suicide." This issue is open to the public for free.

NIH News in Health article entitled Things Forgotten Simple Lapse or Serious Problem? tells us that occasional forgetfulness is a normal part of life. In most cases, it’s no cause for alarm—unless it begins to hamper your daily activities.

Transition Policies of drug plans are to assure uninterrupted access. The Medicare Rights Center reports that this time of year “people with Medicare discover that their Medicare private drug plan will no longer cover a medicine they need. Consumers affected include: members of drug plans that dropped certain drugs from their list of covered drugs in 2010 or imposed new restrictions on a covered drug in the new year; consumers who switched plans but failed to check that all their medicines are covered under their new plan; and many of the one million low-income people with Medicare who were randomly reassigned to a new drug plan because their 2009 plan no longer qualified for a full premium subsidy.

“To help minimize the negative impact of plans’ restrictions on consumers, drug plans are required to have a transition policy to ensure that new members have uninterrupted access to drug therapy that started before they joined, and that existing plan members do not face interruptions to drug therapy when their plan imposes new coverage restrictions in the new year. Transition policies are effective for the first 90 days of the new plan year, and require that plans cover at least one 30-day supply of drugs even if they are not on the formulary, and also require that plans override their restrictions.”

**Home Heating Help:** The U.S. Department of Health and Human Services (HHS) has announced the release of an additional $490 million in funding to help eligible low-income homeowners and renters meet home energy costs. These [Low-Income Home Energy Assistance Program](http://www.medicarerights.org/pdf/partd_appeals_manual.pdf) (LIHEAP) contingency funds will provide states; territories; tribes and the District of Columbia with additional assistance to pay heating and electricity costs. Contact the LIHEAP program in your state to find out if you are eligible for help.

**From Israel:** A three-judge panel of the Supreme Court ruled on Monday that 50 survivors of polio from the pre-state British Mandate for Palestine qualify for benefits under the compensation law for polio survivors. The language of the law would not allow compensation for those who lived, for example, in the Golan Heights or eastern Jerusalem, or those who were even treated for the disease in the Land of Israel but did not make aliyah (officially immigrate) until after they had the disease, according to the majority opinion. The dissenting justice said that while the law was based on the state obligating itself to compensate the individuals, the obligation did not apply to anything before it came into existence.

**From Canada:** The Government of Canada announced it will make a donation of five million doses of the H1N1 flu vaccine, as well as a $6 million contribution to support the World Health Organization’s (WHO) global pandemic relief efforts. The five million vaccine doses amount to 10% of Canada’s total vaccine order, a donation which is in line with that of other developed countries. The $6 million, provided by the Canadian International Development Agency (CIDA), will enable the WHO to support H1N1 vaccination programs in developing countries. Amid rumblings that the H1N1 epidemic was “fake,” the World Health Organization issued an [official statement](http://www.medicarerights.org/pdf/partd_appeals_manual.pdf) defending it processes and conclusions.

**What Spoon do you Use?** A new study from Cornell found
that using kitchen spoons to measure liquid medication tends to lead to significantly over- or underdosing. The researchers found that the students (almost 200) underdosed by more than 8 percent when using medium-size spoons and overdosed by an average of almost 12 percent -- but up to 20 percent more -- when using larger spoons. Yet, participants were confident that they had poured correct doses in all the test cases.

**Students and Polio and its Late Effects:** PHI is often asked to provide information for students studying polio and the late effects of polio. This week we received a request from a senior in high school whose project is “to design and make a product that would assist a person with polio in his everyday life.” Do you have any ideas for him? If so, send them to jdeal62664@yahoo.com.

**Reminder to those who Attended PHI’s 10th International Conference**
From the IRS: From the US Department of Treasury, *Internal Revenue Service, Publication 502*, Medical and Dental Expenses, page 11.)

Medical Conferences: You can include in medical expenses amounts paid for admission and transportation to a medical conference if the medical conference concerns the chronic illness of yourself, your spouse or your dependent. The costs of the medical conference must be primarily for and necessary to the medical care of you, your spouse or your dependent. The majority of the time spent at the Conference must be spent attending sessions on medical information. *The cost of meals and lodging while attending the conference is not deductible as a medical expense.*

Joan L. Headley, *Executive Director*
Happy Holidays from the Board and Staff of PHI. We thank you for your Membership support, which is vital during these challenging times.

Note: Our 2007-2008 Report is online.

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.

Remember to check www.post-polio.org and www.ventusers.org often!

We add a new message each week. Send your ideas for “This week at...” to info@post-polio.org

Post-Polio Health International

PHI’s Newsletter: Post-Polio Health

Post-Polio Health now online

PHI has posted Post-Polio Health (Vol. 25, No. 4) on its website – www.post-polio.org. You have received your print copy. PHI Members are invited to view the online Fall issue.

Reminders

Have a question for the newsletter columns – “Ask Dr. Maynard” by Frederick M. Maynard, MD, and “Promoting Positive Solutions” by Stephanie Machell, PsyD, and Rhoda Olkin, PhD? Send them to Brian at info@post-polio.org.

The team at the Aging Rehabilitation Research and Training Center at the University of Washington is interested in what you, as a person with prior polio, think would be the most useful topics on aging for them to research. Send your ideas to Mark P. Jensen, PhD, University of Washington, Department of Rehabilitation Medicine, Seattle, Washington, at agerrtc@u.washington.edu.

Info for Medicare recipients:
November 15th Started the Limited Period to Review And Change Plans

Check out the US Department of Health and Human Services Centers for Medicare & Medicaid Services Open Enrollment Center.

Remember to utilize the services of your State Health Insurance Information Programs (SHIIP or SHIP).

Check out this message from the Medicare Rights Center, a national, nonprofit consumer service organization that works to ensure access to affordable health care for older adults and people with disabilities through counseling and advocacy, educational programs, and public policy initiatives.
Health News from NIH

Don’t Fear the Flu: Arm Yourself with the Facts
Many people are worried and confused as the new H1N1 virus spreads across the globe. But it’s not much different from the seasonal flu we see every year. Learn the facts about H1N1.

Featured Web Site: Keep the Beat: Deliciously Healthy Eating

FDA's MedWatch Safety Alerts: November 2009

Plavix and Prilosec Drug Interaction

PLVs Discontinued as of 12/31/2009
Service is expected until 12/31/2014. In late November, Philips Respironics sent a letter announcing the discontinuation of the PLV-100, PLV 102b and PLV-102. If you use one of these products, check out the letter for details. The company is suggesting the Trilogy100 as the replacement product.

Breathing & Sleep Symposium
The videos from the Breathing & Sleep Symposium at the Salk Institute held on November 1 are available on line at: www.poliotoday.org.

Polio Survivors and Pop Music
As part of his research into disability and pop, Prof George McKay (Greater Manchester, UK), has published an academic article on polio survivors and popular music entitled: 'Crippled with nerves: Popular music and polio.' It appears in the Cambridge University Press journal Popular Music, volume 28, issue 03, pp. 341-365.

Joan L. Headley, Executive Director
THANK YOU

...for your response to our electronic survey that we asked you to pass on to your adult children, spouse and/or personal attendant. The information we gathered was very insightful. Some of you expressed your appreciation for the support of your families, and they, in turn, expressed that they may be ready with the information, but expressed an honest fear that they may not be emotionally ready to be your medical advocate. All of the opinions will assist us as we continue the project.

...for your continued financial support of PHI and IVUN and the personal messages you send noting how the organization’s work has enhanced your continued independent living. Ventilator-Assisted Living (Vol. 23, No. 3) is in the mail to the Membership.

Information Sources for Seasonal Flu and H1N1

Be sure to utilize credible sources and consult your trusted family physician.

One-stop access to U.S. Government H1N1, avian and pandemic flu information

2009-2010 Seasonal Influenza Vaccines from the US Food & Drug Administration

CDC: Influenza (Flu) from the Centers for Disease Control and Prevention (CDC)

The Lancet’s H1N1 Resource Centre from collaborative effort by the editors of over 40 Elsevier-published journals

Pandemic (H1N1) 2009 from the World Health Organization

Stopping the Spread of Germs at Home, Work & School from the CDC
If you missed it on PHI’s August 16, 2009
“This week at PHI....”

INFORMATION FOR PEOPLE WITH DISABILITIES ABOUT H1N1 VIRUS from long-time disability activist and educator Lex Frieden (lex.frieden@uth.tmc.edu) with contributions by Kim Dunn, MD, and Gerard Francisco, MD (The University of Texas Health Science Center at Houston, USA).

Plan now for October 11-17, 2009. Click on logo for updates.


Want a sticker for your vehicle-car, truck, wheelchair, scooter? PHI has a quantity of 4” by 4” bumper stickers available for a donation to Post-Polio Health International. Recommended donation: 1-10 ($1.00 each); 11-50 ($.70 each); 51-100 ($.60 each). Send your request and payment to PHI, 4207 Lindell Blvd., #110, St. Louis, MO, 63108-2930.

Obtain a sticker and start a conversation!

November Meeting in Southern California
People living in the Southern California area who have breathing and sleep problems as a result of a neuromuscular condition are invited to a complimentary half-day meeting at the Salk Institute in La Jolla, California, on November 1, 2009 (Sunday). Please go to www.post-polio.org or www.ventusers.org to view the brochure under "This week at...."

Have you expressed your opinion about healthcare reform?
Link here to connect with your legislators.
Several disability-related groups are encouraging people with disabilities to contact their Congress person and/or Senator asking them to be sure that any minimum benefit package includes DMEPOS - durable medical equipment, prosthetics, orthotics and supplies.

The US Capitol phone number is 1-877-210-5351 or 202-224-3121. Ask to be connected to your representative.

Joan L. Headley, Executive Director
PHI Wants Your Opinion and Your Help

We at PHI have observed an increase in requests from adult children of polio survivors, spouses and personal attendants. They are seeking information so they can better understand your health issues and better advocate for you within the system.

We are calling upon you and your adult children, spouses and personal attendants to help us focus on the issue and find solutions by completing the short questionnaires that are attached. After you complete the first questionnaire, we ask that you "volunteer" your adult children, spouses and personal attendants to complete the second attachment called "For Advocates," by forwarding it to them.

This is a survey to gather your opinions and thoughts that will be used to guide us. Your comments will not be used in any other way without your permission. Your participation is voluntary. We look forward to your insights. Please respond by September 2.

PHI’s Newsletter: Post-Polio Health

Post-Polio Health now online.

PHI has posted Post-Polio Health (Vol. 25, No. 3) on its website – www.post-polio.org. PHI Members can access the Summer issue.

10th Conference Info

CD-ROM of Program Booklets Now Available: Daily program booklets (Thursday–60 pgs; Friday–98 pgs; Saturday–70 pgs) from PHI’s 10th International Conference: Living with Polio in the 21st Century are now available. In PDF format on a single CD, the files contain abstracts and handouts. Here is a sample of what is on the CD.

From Thursday: Polio – The Legacy of Warm Springs
From Friday: Benefits and Techniques of Aquatic Therapy
From Saturday: Bladder Inconveniences

Order form & domestic pricing information. Print and mail.
Order form & international pricing information. Print and mail.
Opportunity to Participate in Research

Polio survivors are invited to participate in Aging with a Physical Disability Survey Study from the Aging Rehabilitation Research and Training Center, Department of Rehabilitation Medicine at the University of Washington.

News You Can Use

From the Harvard Heart Letter
Read When the Lights Suddenly Go Out to learn more about the causes of fainting and actions you can take to avoid it. Contact Raquel Schott at Raquel_Schott@hms.harvard.edu for a complimentary copy of the newsletter.

From National Women's Health Report: Health & Wellness for Women of Color
Learn more about the unique health challenges faced by women of color in the latest issue of the National Women's Health Report: Health & Wellness for Women of Color. Included in this issue: a chart that explains health risks and offers suggestions for avoiding them, health resources tailored for women of color and recommendations for working within the community to make health a priority. Order or download your free report to learn more.

Joan L. Headley, Executive Director
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.

Remember to check www.post-polio.org and www.ventusers.org often!

We add a new message each week. Send your ideas for “This week at...” to info@post-polio.org.

Post-Polio Directory 2009 now online.

PHI’s popular Post-Polio Directory has been updated and posted in the “Networking” section of www.post-polio.org. The Directory is updated continually online at www.post-polio.org/net/PDIR.pdf.

The Post-Polio Directory is a benefit of these Membership levels: Gini Laurie Advocate, Platinum, Gold, Silver, Bronze, Contributor and Sustainer. If you would prefer a print copy of the newly updated Post-Polio Directory, please notify info@post-polio.org.

FYI: The Resource Directory for Ventilator-Assisted Living is also a benefit of your Membership level and is available at www.ventusers.org/net/VentDIR.pdf.

10th Conference Info

"The Spirit of Warm Springs" was evident as the staff at Roosevelt Warm Springs Institute for Rehabilitation (RWSIR) in Warm Springs, Georgia, welcomed 436 registrants during the three-day meeting. In attendance were survivors, family members and health professionals from 11 countries (46 individuals) and 39 states and the District of Columbia.

CD of Program Booklets Now Available: Daily program booklets (Thursday–60 pgs; Friday–98 pgs; Saturday–70 pgs) from PHI’s 10th International Conference: Living with Polio in the 21st Century are now available. In PDF format on a single CD, the files contain abstracts and handouts.

Order form & domestic pricing information. Print and mail.
Order form & international pricing information. Print and mail.

PHI redesigned its general information flyer for the conference. See link. Remember POLIO? Have you heard about the LATE EFFECTS OF POLIO?

Opportunity to Participate in Research

Are you a cancer survivor who had limitations in activities of daily living prior to your cancer?

Joan L. Headley, Executive Director