



# Gleanings

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THE OFFICIAL NUMBER ONE NEBRASKA POST-POLIO NEWSLETTER

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2007

## POST-POLIO HEALTH INTERNATIONAL AWARDS RESEARCH GRANT TO UNIVERSITY OF ARKANSAS TEAM

ST. LOUIS, Dec. 19, 2006 – Post-Polio Health International, headquartered here, announced that it has awarded a \$25,000 research grant to a team from the University of Arkansas for Medical Sciences (UAMS), Little Rock. The researchers propose to determine whether there is a unique signature, or disease biomarker, in the immune system of individuals with post-polio syndrome (PPS) that would enable a more definitive diagnosis of PPS.

PPS is a slowly progressive neurodegenerative disease that occurs many years later in individuals previously affected by paralytic poliomyelitis due to the poliovirus infection. The causes of PPS are unknown but it is characterized primarily by new muscle weakness that negatively affects the quality of life of survivors.

Biomarkers are biological measures found associated with specific diseases. They are useful because they can assist in disease diagnosis or provide a means of monitoring disease development and progression.

The researchers at UAMS recently detected the increased presence of a distinct immune cell population in the blood of

individuals with PPS but not healthy individuals, although the number of donors examined was small. The detected cells represent a recently described subtype of T cells, known as regulatory T cells (Tregs).

The research award from Post-Polio Health International will fund a small pilot study that will determine whether development of PPS is associated with increased numbers of Tregs and whether the Tregs found in individuals with PPS have unusual properties as compared with those in healthy individuals

“We are very grateful to PHI for their support of this research. Although the research is in its very early stages and our initial results need to be rigorously tested in a much larger group of individuals with PPS, a biomarker for PPS that can be potentially measured in an individual’s blood should enable a more rapid and more definitive diagnosis of this debilitating disease,” said Principal Investigator Dr. Rahuma Wahlid, Postdoctoral Research Assistant, Microbiology and Immunology Department, at the University of Arkansas for Medical Sciences.

“A definitive diagnosis of PPS is difficult because it is based on past history, which may be lost or incomplete, or dependent on recall. The diagnosis is complex and unreliable because many symptoms of PPS overlap those of other diseases in-

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## OMAHA / COUNCIL BLUFFS/LINCOLN SUPPORT GROUP MEETING SCHEDULE

**APRIL 1** - 2:00 p.m. Beautiful Savior Lutheran Church, 90th and Q Streets. Program by Charles (Chip) Mackenzie, Ph.D, and polio survivor. He will share the positive insights he has discovered in his own life which will include stories from a book he is writing.

**MAY 6** - 2:00 p.m. Bloomfield Forum, 9504 Nicholas Street, (program to be announced--check our website: [www.ne-polio.org](http://www.ne-polio.org)).

**JUNE 3** - 2:00 p.m. Beautiful Savior Lutheran Church, 90th and Q Streets. (program to be announced--check our website).

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If you haven't attended a support group meeting or it has been a long time since you have, plan to attend a meeting of this group.

You will find the members welcoming, the meetings interesting and helpful for polio survivors, families, care givers and friends..

You will want to return.

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## GRANT--from page 1, column 2

cluding osteoarthritis, fibromyalgia, hypothyroidism and a number of neurological conditions. Because available treatments are limited, finding a definitive test for PPS would not only help with a diagnosis but would also help develop potentially more effective therapies," said Joan L. Headley, executive director of Post-Polio Health International.

Others on the UAMS team in addition to Dr. Wahid include Dr. Marie Chow, Professor, Departments of Microbiology and Immunology, and Pathology and Dr. Katalin Pocsine, Assistant Professor of Neurology.

Post-Polio Health International's Research Fund was established in 1995 to seek scientific information leading to eventual amelioration of the consequences of poliomyelitis and/or neuromuscular respiratory diseases. This is the fourth grant to be awarded. Complete reports on the first three research studies- Ventilator Users' Perspectives on the Important Elements of Health-Related Quality of Life; Women With Polio: Menopause, Late Effects, Life Satisfaction and Emotional Distress; Timing of Noninvasive Ventilation for Patients with Amyotrophic Lateral Sclerosis are available on Post-Polio Health International's website, [www.post-polio.org](http://www.post-polio.org) (click on Research).

Post-Polio Health International actively promotes education, research, advocacy and networking among the post-polio community to enhance the lives and independence of polio survivors and home ventilator users.

*The following is an excerpt from an email sent by Dr. Richard Bruno.*

Not from Tennessee? You may not know the name Steve Cohen. If you don't, write it down. Because, if you're a polio survivor anywhere in these United States, freshman Democratic Representative and polio survivor Stephen Cohen has become your Congressman,

Although getting to Washington was always on his mind, Cohen was working hard in Tennessee. A practicing lawyer, Cohen was elected to serve as a Shelby County commissioner, helped create a community-funded regional hospital and served for twenty-four years as a State Senator.

Some of Cohen's passion for public service and health care can be related to polio, which he had at age 5.

Cohen is one of not even a handful of polio survivors in the public eye who admits to having Post-Polio Sequelae. "I limp more than I used to. The past year, when I'm standing, I feel like I'm going to lose my balance." Cohen also says he gets more tired than he used to.

Cohen knows what he has to do now. "Take two rest periods, sit when you can and save your neurons."

Cohen was planning to manage his PPS even before he was sworn in. He asked for a ground floor suite in the House office building closest to the Capitol, right next to the escalator going to the subway that travels to the Capitol building. Cohen is also thinking of getting a Segway.

Cohen plans to help polio survivors and promote polio vaccination during 2007. He has been asked to join the Disability Caucus with another polio survivor, Missouri Congressman Ike Skelton.

Delayed gratification and persistence. A winning combination for one polio survivor from Tennessee and 1.63 million polio survivors across the U.S.

## LINCOLN EAST HIGH SCHOOL STUDENT PREPARES POLIO DOCUMENTARY

Lisa Beth Amen, a Junior at Lincoln East High School, recently completed a short documentary for her Advanced Placement U.S. History class and for the Nebraska "National History Day" state competition. This year's theme was "From Tragedy to Triumph."

Lisa's father originally suggested the polio theme and she later learned from the NPSA office about Shirley Marsh who lives in Lincoln. Lisa interviewed her and this interview became a major part of the documentary.

After the interview with Marsh, Lisa decided to use politics as the focus of her project. On the national level with Franklin Delano Roosevelt and with Marsh on the state level, she depicted two people who had polio as adults yet achieved major political successes: Roosevelt as President of the United States and Marsh as a Nebraska State Senator for sixteen years.

Lisa is a very busy person with many outside activities. For example, she is a member of Lincoln East's Varsity Debate Team (Public Forum) and has been a volunteer at Tabitha Nursing Home in the beauty shop for five years. She plans to go to college, obtain a bachelor's degree in accounting and later a master's degree. But, as she says, "this may change in the future."

Nebraska Polio Survivors Association sends our best wishes to this very bright young woman for her future achievements as well as commend her for this project.

**YOUR REGULAR CONTRIBUTIONS ARE VERY IMPORTANT  
NOT ONLY TO YOU BUT TO  
NEBRASKA POLIO SURVIVORS ASSOCIATION**

Your regular contributions make it possible for Nebraska Polio Survivors Association to carry out its mission. Monthly contributions are an easy way to contribute to NPSA, rather than only once a year. Think about it. Maybe this coming year more of you will consider this.

*The Mission of Nebraska Polio Survivors Association is to educate the public and the health care community concerning polio and post-polio syndrome and to respond to the needs of individuals who suffer from the syndrome through group meetings, educational programming and newsletters, financial and other support of research concerning the syndrome and the circulation of research results.*

NPSA is a 501(c)(3) non-profit corporation and your contributions are fully tax deductible for tax purposes.

There are several ways to designate your contribution: *General Contribution, Memorial Contribution, Special Purpose Contribution, or Contribution in honor of \_\_\_\_\_.*



**YOUR CONTRIBUTIONS ARE LIFE LINES FOR NEBRASKA POLIO SURVIVORS ASSOCIATION**

NPSA is a 501(c)(3) non-profit corporation. All donations are deductible for tax purposes.

Please send contributions to NPSA, PO Box 45139, Omaha NE 68145-0319.

Checks payable to NEBRASKA POLIO SURVIVORS ASSOCIATION.

Yes, I want to make a contribution to Nebraska Polio Survivors Association. I know that my gift will make it possible for NPSA to help educate the public and the health care community concerning polio and post-polio syndrome and to respond to the needs of individuals who suffer from the syndrome through group meetings, educational programming, newsletters, and advocacy for issues concerning them.

\_\_\_\_\_ \$3,000 \_\_\_\_\_ \$2,000 \_\_\_\_\_ \$1,000 \_\_\_\_\_ \$500 \_\_\_\_\_ \$100 \_\_\_\_\_ \$50 \_\_\_\_\_ \$25 \_\_\_\_\_ Other

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**Thank You!**

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## MEMORIALS

In memory of Jane Davenport Wilshusen, Omaha NE  
from her mother, Winnie Davenport, Omaha NE

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# FREE HELP WITH PERPLEXING ISSUES

by Nancy Baldwin Carter

Aimee McKim is in the “helping” business. For the past three and a half years, she’s been executive director of VAS (Volunteers Assisting Seniors), a non-profit organization helping people over age 55—and often younger folks who are disabled.

“VAS has served 4,200 people this past year,” says Aimee. “Right now we have a paid staff of three, plus 40 volunteers. Everyone receives formal training and then is required to take continued education each spring and fall to active status.”

VAS programs that may interest NPSA members:

- **Homestead Exemption**—Seeking property tax relief? Depending on income and the homestead’s value, seniors and those with disabilities may be eligible for a Nebraska Homestead Exemption. New applicants need to get an application from their County Assessor’s office and take it to VAS for guidance in filling out the form and understanding the in’s and out’s of the program.
- **Legal Referral**—Low-income seniors needing legal assistance may find a pro bono attorney through VAS. Seniors who can afford to pay may also be referred to reliable attorneys in specific fields. Attorney list is updated yearly, and client experiences are evaluated regularly.
- **Conservators**—In cases where someone is needed to manage the finances of a Senior through a court-appointed conservator program, VAS can provide trained volunteers.
- **Insurance**—VAS offers a great deal of information and personal attention to guide clients through the Medicare maze. Confused by all the Plan D options? Volunteers can take a list of your medications, plug it into the Medicare program computer, provide an easy answer to the least-expensive plan for your situation, and lead you through signing up for the plan you choose. Need help applying for Social Security Disability Insurance? Not sure about Medicare Advantage plans? Wondering what Medicare is—what it covers, how it works, what it means to you? Or how to resolve an ongoing Medicare-related problem? Looking for one-on-one insurance counseling?

The above programs are operated by VAS only in Cass, Dodge, Douglas, Sarpy, and Washington Counties in Nebraska. Call (402) 444-6617 to arrange for an appointment if you live in any of these counties. The final program, Insurance, is provided through SHIP (Nebraska Senior Health Insurance and Information Program), and is thus also available throughout the rest of the state. Call 1-(800) 234-7119 if you live outside the counties mentioned above and are interested any of the insurance options mentioned. Other states offer SHIP as well.

“We’re always looking for senior volunteers,” Aimee says. Check the VAS website at [www.volunteersforelderly.com](http://www.volunteersforelderly.com) for more information. Their accessible office is at 1941 South 42<sup>nd</sup> Street, Suite 502, Omaha, NE 68105.

These services are free and are "funded by foundations, individuals, corporations, and through contracts with the Eastern Nebraska Office on Aging, and the Nebraskas Department of Insurance through a grant with the Center for Medicare & Medicaid Services." The Association of Junior Leagues, Inc., created VAS in 1977.

## A GREAT CYCLE !!

by Janet R. Vanthournout  
Batavia, Illinois and  
Sanibel, Florida

I'm writing today from my Sanibel home. Life seems to be so pleasantly busy in this 'retirement' mode. There's morning shelling to do when tides are low, visitors to entertain and there are still household chores. These are all reasons I've not told you what's been on my mind so much lately. However, today is the day.

You've heard again and again about my post-polio cycles of muscle and tendon pain, about tumbles taken on ice or wet flooring, decisions made because of greater disability and aging but today I'm going to tell you about a fabulous cycle ... a GREAT cycle that has been blessing me the past number of months.

I find I can walk better. I feel generally better. My shoulders don't hurt. I sleep better. Oh, I still don't do activities like run or bike ride. A shopping trip takes more energy than I like to spend doing it BUT ... I am physically better than I've been in several decades. That's saying something amazing! I can even manage a flight of stairs ... one flight, that is, without becoming breathless if I do it only a couple times a day.

It seems that I've made progress in my physical being rather than regress. What in the world would have caused this 'opposite' in my cycles, I wonder? I've thought about this question a lot. Here's what answers have appeared.

A list of things have contributed to my new-found well-being.

1. I retired from work and learned to take it easier when overuse caused injury to my limbs. I began a deliberate program of paying attention to my body speaking ... especially when it was yelling "Ouch!" I quit activities that hurt. Sometimes I would lie down for a nap or sat with my feet propped on my plastic waste basket under the desk to write letters to friends. I spent more time reading and even propped the

book on a pillow when holding it caused aches in my hands and wrists.

2. I had my knee in the 'good leg' replaced. I had protected the polio leg so many decades that the good knee wore out causing enough pain to curtail my activity. In fact, I had trouble walking at all.

3. When the knee was replaced my surgeon slightly shortened the good leg. This may sound odd to some folks but my good leg was longer than the once atrophied and still somewhat affected polio leg. This caused unbalance. I realized that my whole body was impacted by this imbalance but really had no true idea just how much. Since my knee was replaced and my legs 'balanced' the upper and lower back, hip and joint pain that nagged me most of my life disappeared. I can stand again for an entire conversation with someone. I can walk distances again. I can even bend to pick something off the floor without feeling like I'm going to topple on my nose.

4. Because I can walk for exercise I have been motivated to lose weight. I wasn't grossly overweight but I did have extra pounds. I've lost them easily due to walking daily and also a somewhat better diet

with larger helpings of vegetables and smaller helpings of breads and meat. I have even cut my red meat intake to a couple times a week for my doctor suggested it might help my cholesterol levels. Well, something has because the last test results showed my cholesterol as 'normal.' This was a first in forty years. Tell me, what post-polio person isn't thrilled to get a medical test back with 'normal' registered somewhere?

In the past, I never thought I could feel so good. In fact, sometimes during post-polio cycles I wondered what life would be like as I aged. The image conjured wasn't pleasant ... and I have close relatives who have lived beyond the age of one hundred years. Yikes!

I can now say that this particular era in my life is the very best. I'm soon going to celebrate my 64th birthday. I feel better than I have since my late teens and early twenties. I have no idea ~~how long this~~ 'Great Cycle' will last but you can bet I'll enjoy it day by day.

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