



# Gleanings

THE OFFICIAL NUMBER ONE NEBRASKA POST-POLIO NEWSLETTER

APRIL/MAY/JUNE/JULY

2008

## EXCELLENT PROGRAMS PRESENTED AT MARCH AND APRIL SUPPORT GROUP MEETINGS

Showing a DVD and passing around a notebook of pictures, John Dulany, husband of polio survivor, Karen Dulany, illustrated his role in the intensive and often difficult clean up and repair work done in New Orleans after Hurricane Katrina. John graciously answered many questions after he finished his presentation.

The lovely new Beautiful Savior Church building was an excellent venue for this fine presentation.

Popular singer, Tom Roth, son of Gene and Barbara Roth, immediately grabbed the attention of those present at the April meeting at Bloomfield Forum by saying that he needed help from the polio survivors present, because he knew very little about polio and its late effects.

Several short but poignant stories followed, most of which were shared publicly for the first time by the polio survivors.

Afterwards Tom sang several songs from the 60's and 70's with many joining in. The group appreciated this opportunity to be involved in the program.

Have you attended a polio support group lately?

You will find that today's support groups focus on positive and helpful topics.

Visit our group. You will be glad you did.

Visit our website for program announcements and information. [www.ne-polio.org](http://www.ne-polio.org)

Visit the website of Post-Polio Health: [www.post-polio.org](http://www.post-polio.org) and learn how you can become a member of this fine organization.

## OMAHA / COUNCIL BLUFFS / LINCOLN AREA SUPPORT GROUP.

**MAY 4-2:00 P.M.** Beautiful Savior Lutheran Church. *Future programs brain storming session.*

**JUNE and JULY - No meetings**

**AUGUST 3-2:00 P.M.** Bloomfield Forum. *Branson report.*

**SEPTEMBER 7-2:00 P.M.** Beautiful Savior Lutheran Church. (This is a year when Labor Day weekend does not interfere with the support group.)

**NOVEMBER 2 -2:00 P.M. Bloomfield Forum**

DECEMBER, JANUARY, FEBRUARY - NO MEETINGS

**MARCH 1 - 2:00 P.M. Beautiful Savior Lutheran Church**

Please let us know program topics you would like to have addressed at our support groups. Email: [mjbarnett@att.net](mailto:mjbarnett@att.net), phone: 402-341-0710; mail: NPSA, Box 45139, Omaha NE 68145-0139

*Please add the following date to your calendar now.*

**SUNDAY  
OCTOBER 5, 2008**

**Annual POST-POLIO REUNION  
Field Club of Omaha  
12:15 - 4:00 p.m.  
(Dinner served at 1:00 p.m.)**

**Interesting speaker**

**Attend the October 5 Reunion**



## Polio Survivors Ask... Nancy Baldwin Carter, Omaha, Nebraska

**Q:** I keep hearing about the shingles vaccination. Should polio survivors get one?

**A:** Currently there is no experimental data regarding polio survivors getting this vaccine. PHI polled nineteen doctors (experienced in treating polio survivors) about your question and received a variety of responses. The most prudent thing to do seems to be to study the information we provide below, talk with our doctors about our individual circumstances, and then each make our own decision.

**THE VACCINE:** In the year 2006 a vaccine called Zostavax was licensed to prevent shingles in people over age 60. In the clinical trial, the vaccine was successful in 51% of the participants 60 and older and was most effective in those aged 60 to 69. Shingles-related pain may also be reduced in many of those receiving the vaccine.

**PRECAUTIONS:** The Centers for Disease Control says those who should not get this vaccine are people who have had a life-threatening **allergic reaction to gelatin**, the antibiotic **neomycin**, or **any other component of shingles vaccine**. They advise those who have severe allergies to inform their doctor about this.

They also recommend certain people do not get shingles vaccine (which contains live though weakened chickenpox virus): Individuals who have a **weakened immune system** because of HIV/AIDS or another disease that affects the immune system, treatment with drugs that affect the immune system, such as steroids, cancer treatment such as radiation or chemotherapy, a history of cancer affecting the bone marrow or lymphatic system,

such as leukemia or lymphoma. Those with active untreated **tuberculosis** and those who are **pregnant** or might be pregnant should not get the vaccine.

Individuals who are moderately or severely ill (including those with a temperature of 101.3° or higher) should wait to get their vaccine until they are well.

**THE DISEASE:** Approximately one million cases of shingles (also known as *Herpes Zoster*) occur in the United States each year. The same virus that causes chickenpox causes shingles. When people recover from chickenpox, the virus lies lurking in the nervous system for the rest of their lives. Certain circumstances (perhaps stress or immune deficiency or something else) reactivate this virus and cause shingles. This usually occurs after age 50.

Shingles may begin as a sensitive or burning feeling in the skin that turns to a rash, usually down a certain nerve on one area and one side of the body. Shingles blisters then form for a number of days before they pop and finally crust over and heal. The entire process can take several weeks.

**SYMPTOMS AND COMPLICATIONS:** Fever, chills, upset stomach, and headache can indicate shingles. Very rarely, shingles can result in pneumonia, hearing difficulties, blindness, encephalitis or death.

A common complication of shingles is nerve pain. When this pain continues for more than a month, it's known as postherpetic neuralgia, which occurs in more than 40% of those over 60 who have had shingles. This can be devastating. In some cases, certain medications may be used to alleviate the situation.

**INTERESTING FACTS:** People who've had shingles can get it again. Only people who had chickenpox or chickenpox vac-

cine can get shingles; the chickenpox virus stays in the body forever. Shingles is not contagious. However, a person who never had chickenpox or the chickenpox vaccine can get **chickenpox** from someone with shingles.

**COST:** A number of factors determine what the shingles vaccine costs individuals. For example, in Omaha, Nebraska, the vaccine is administered in pharmacies for the cash price of \$220. Plan D picks up from \$25 to the full amount, depending on the coverage one has chosen. Medicare itself won't pay for the vaccine, though it will pay a \$20 administration fee. Getting a firm price may take a few phone calls in each separate locality. Source: *Post-Polio Health International*, [www.post-polio.org](http://www.post-polio.org)

## PPS FORUM-- Dr. Richard Bruno

Last August, The Centers for Disease Control reported that about 92 percent of U.S. toddlers are vaccinated against polio. Ninety-two percent sounds pretty good, until you realize that leaves more than *1 million* U.S. children unvaccinated. What's worse, between 2005 and 2006, polio vaccination dropped by more than 2 percent in 20 states, while in 10 large cities polio vaccination dropped nearly 3 percent. While any reductions in polio vaccination are troubling, the location of the cities and states where vaccination dropped is frightening. The cities are major points of entry into the United States—New York, Philadelphia, Houston and Seattle—where a nearly 4 percent average drop in vaccination was reported. Toddlers living in poverty in cities have the lowest polio vaccination rates—below 87 percent in Boston, Indianapolis, Memphis and Phoenix, and below 85 percent in Detroit, Houston and Seattle—rates

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**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 \_\_\_\_\_.*

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

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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

Signature \_\_\_\_\_ (PrintName) \_\_\_\_\_

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City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Phone \_\_\_\_\_ Email \_\_\_\_\_

**Thank You!**

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## CONTRIBUTIONS

### **PATRONS--up to \$1,999.00**

Anonymous (*United Way*)

Cathy Thill, Omaha NE (*United Way*)

### **BUILDERS--up to \$999.00**

Bryce Biffar, Omaha NE (*United Way*)

Frank Johannsen, Bayard NE

Lisa Kyhn, Omaha NE (*United Way*)

Dr. Edward Roche, Bellevue NE (*United Way*)

Dr. Edward Roche, Bellevue NE

Richard Thill, Omaha NE (*United Way*)

Michael Regier, Marilyn Lehman, John Regier, Hampton NE

Linda Rehberg, Springfield NE

Union Pacific, Washington DC & Doralu Streeter, Papillion NE

### **FRIENDS--up to \$99.00**

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Laura Weindorf, Malverne NY

Barbara Yearsley, Dunbar NE

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**PPS Forum.** from page 2, column 3  
lower than in Western Pacific countries that include Cambodia and Mongolia.

The states with drops in vaccination are on our borders with Mexico and Canada, Arizona, Texas and New Mexico reported reduction in polio vaccination as did 70 percent of the states that border Canada. Montana had a 6 percent decrease and Maine dropped 7 percent. Even Minnesota had a decrease, which is both frightening and incomprehensible, since five Minnesota children caught polio in 2005 after coming in contact with someone who imported the poliovirus across the U.S. border.

Polio's recent importation into America and the drops in vaccination have prompted the International Post-Polio Task Force to create the National Immunization for Polio Prevention in infants and Toddlers - or "NIPP IT" - Campaign. "NIPP IT" aims to "nip in the bud" America's next polio epidemic by having each state's department of health to declare a "NIPP IT" week to prompt parents, health care professionals and state health officials to ensure that all American children receive four doses of the injectable, inactivated polio vaccine. The IPTF launched the NIPP IT Campaign in partnership with "Every Child by Two" (ECBT.org), co-founded by former first lady Rosalynn Carter and former first lady of Arkansas, Betty Bumpers to promote immunization of all children by age 2.

Said Carter, "Our country has come so far to protect against polio through universal vaccination. We cannot afford to relax our efforts because polio is still a real problem in parts of the world and can easily be transported back to the U.S. We cannot risk a single child to this terrible disease."

Proving Carter's point, in 2007 an unvaccinated Pakistani college student flew to

Australia, bringing with the naturally occurring polio-virus and Australia's first case of polio in 21 years. Australia's recent experience proves that we must be concerned about poliovirus being flown into the U.S., given the ease of air travel from Pakistan, Afghanistan, India and Nigeria, where polio has never come under control, and from the 10 African and Asian nations that had been polio-free, but where the polio-virus has been reintroduced.

The children who had polio in Minnesota in 2005 and the Pakistani student in 2007 are canaries in the mine shaft. What will happen when a polio-infected traveler arrives in one of America's potential polio pockets, like New York City and passes poliovirus to the estimated 34,000 infants and toddlers there who are not immunized?

December 2007's Post-Polio Forum described studies finding Provigil ineffective in reducing post-polio fatigue. The FDA has now warned that serious and sometimes fatal conditions have been associated with Provigil: Stevens-Johnson syndrome and toxic epidermal necrolysis

(coughing, aching, headaches, chills and fever, followed by a red rash across the face and trunk that can spread and blister) puffy, swelling skin, and a sometimes fatal multiple organ damage. Provigil also is associated with psychiatric symptoms, including anxiety, mania, hallucinations and suicidal thoughts, and caution is advised when giving Provigil to people with a history of psychosis, depression or mania. The FDA warns people to immediately stop Provigil and contact health care professionals if these symptoms occur.

*Dr. Richard Bruno is chairperson of the International Post-Polio Task Force and director of The Post-Polio Institute and International Centre for Post Polio Education and Research at Englewood Hospital and Medical Center.*

## Web Master Chip Mackenzie

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