



Gleanings

THE OFFICIAL NUMBER ONE NEBRASKA POST-POLIO NEWSLETTER

SEPTEMBER/OCTOBER

2007

FIELD CLUB REUNION --SUNDAY, OCTOBER 7

Nebraska Polio Survivors Association will host a second Reunion for polio survivors, family, and friends at the Omaha Field Club on Sunday, October 7, 2007. A reservation sheet is enclosed

EARLY RESERVATIONS ARE APPRECIATED!

We realize that most of those who will attend live in the Omaha/Lincoln/Council Bluffs area. However, we want to let all polio survivors know that if you will be or can plan to be in Omaha on October 7, no matter where you ordinarily live, you are invited to attend this gathering. Please let us know prior to September 25.

GREAT TIME AT AUGUST SUPPORT GROUP MEETING

With the excellent piano accompaniment provided by Virginia Kirwan and the fine vocal leadership of Bill Smythe, the voices of polio survivors, spouses and friends rang out from the air conditioned meeting room at Bloomfield Forum, Omaha, on a very hot Sunday in August.

Everyone present thoroughly enjoyed singing many "old favorites," and discovered the superior talent of polio survivors, Virginia Kirwan and Bill Smythe.

Virginia is a classically trained pianist and

also has the ability to "play by ear." Bloomfield Forum has a lovely grand piano and Virginia certainly "tickled" the keys! She told us that she regularly plays for all types of groups, schools, nursing homes, retirement centers etc..

Bill Smythe is a very good singer as well as song leader, and directs a group of singers at Bloomfield Forum. He also prepared the song books. He is a retired Episcopal priest, and he and his wife, Ann, reside at Bloomfield Forum along with polio survivors, Martha Anthony, Marie Galda, and Florence Maxwell.

THANKS, VIRGINIA AND BILL, FOR THE GREAT AFTERNOON. IT WAS A SPECIAL TREAT FOR ALL OF US. WE HOPE YOU WILL DO THIS AGAIN.

SUPPORT GROUP SCHEDULE

SEPTEMBER - no meeting due to Labor Day weekend.

OCTOBER 7 - REUNION AND DINNER - OMAHA FIELD CLUB - 1:00-4:00 P.M. (see enclosed reservation sheet.) Valet parking will be offered by members and friends of Nebraska Polio Survivors Association. Please do not tip these kind people and there is NO charge for this service.

NOVEMBER 4 - 2:00 P.M.
BEAUTIFUL SAVIOR
LUTHERAN CHURCH

The church will have moved into it's new building. The new address will be in the next issue of GLEANINGS.)

DECEMBER and JANUARY,
NO meetings due to demands and pressures of the the holiday season.

FEBRUARY 3, 2008 - 2:00 P.M.
BLOOMFIELD FORUM, 9804
NICHOLAS STREET, OMAHA.

At the Edge

by Janet R. Vanthournout
Batavia, Illinois

This has been a trying time. My husband's cancer again loomed out of control. We've recently returned from Northwestern Memorial Hospital in Chicago, IL, where we spent two weeks. Dick had an autologous (his own cells) stem cell transplant. I remained with him at the hospital during the preliminary mega dose of chemotherapy, the 'rescue' infusion of his previously treated and frozen stem cells and initial recovery. We were confined in an isolation room within an entire ward separated from the rest of the hospital. People had to use a double air-lock door to enter and exit the place. However, this is not the focus of my thoughts right now. What I'm thinking about is my post-polio friends who may be in more fragile conditions than me and who also must cope with a serious illness of a spouse when that person could be *the one* counted on to aid the post-polio. This is a dilemma for thought. I really have few answers to the problem.

What I do know is I had to pay particular attention to the fact of my own health while at that the same time coping with his. I realized I had to eat as normally as possible and try not to let worry cause me to overtire. If there's anything I've learned about myself and other post-polios, it's that we need our rest. Developing a routine relieves stress even the sort of being away from home and in the hospital. One must cut activities to the basics. . . eat, sleep and exercise.

Of course there's little normal rest for anyone in a hospital because the work there continues day and night, seven days a week. Illness cares little about time of day or night. It must be addressed now. I counted seventeen different interruptions one particular night when my husband needed treatments, care, vitals checked

and various medications,. However, we both came through the experience better off than one might think. The reason? We rested between interruptions and did our best, both of us, to choose healthy meals. We moved about the ward as much as allowed, he in a mask, gown and latex gloves while pushing an IV pole and me walking alongside him trying to keep my replaced knee from becoming stiff or swollen from disuse. Thirteen laps around the nursing station, we were told, is a mile. We tried for that goal.

We're home now. I won't say we're not at all tired. We are but we're both resting today, me at the computer keyboard and he watching a baseball game on TV from his lounge chair. Dick is recovering well. I'm helping him as much as possible but limiting activities mostly to fixing our meals and keeping up with laundry. We've advised all visitors to please stay away at least two weeks. Neither of us is up to company and he's supposed to be very careful about exposure to any sort of illness until blood counts rise.

We've been through a trial. It's been an experience. One of my friends sent me an e-mail recently. In it was the following poem. It certainly struck me as apt to our situation. I think you'll like it, too. The author is an English poet born in 1926 and still living. Here's the poem..

Come to the Edge
by Christopher Logue

Come to the edge.
We might fall.
Come to the edge.
It's too high!
COME TO THE EDGE!
And they came,
And he pushed,
And they flew.

THANK YOU FOR SHARING

by NPSA Staff

Recently we received an email from polio survivor, Bonnie, relating very unpleasant experiences she recently had. One with a physician over the use of anesthesia for polio survivors and the other with her husband who told her to stop being so stubborn and start taking more pain pills. There is, however, a bright side to this story.

The next day after her husband's remark, Bonnie's home health provider came in "bright and her cheery self." She took one look and asked, "feeling a little down today?" and then said, "tell me about it" and Bonnie did..

The provider said, "you know, there are those who just do not understand and after all, they actually don't have any way of understanding something they have never experienced, do they? We need to turn to those who DO understand and who are able to give the things that we mostly need, whether it is information or just the gentle acceptance of the fact that we do have pain and there is a name for it and needs understanding beyond what some are able to give."

The home health provider continues to sense the needs Bonnie has in the emotional department as well as her physical limitations. Bonnie says, "She is my very own Kubler Ross in so many ways. I am forever thankful for her."

Bonnie would like to offer other polio survivors some of the advice that has been given to her. She says she will not turn down anyone who needs to talk about post-polio syndrome. Her email address is: abbypi@hotmail.com.

We welcome positive stories about coping with the late effects of polio.

POLIO SURVIVORS GALA REUNION

and

COMPLIMENTARY DINNER

Provided by a contribution to Nebraska Polio Survivors Association by an anonymous donor for an afternoon of fellowship and good food!! Songs by Tom Roth. Plus an interesting speaker.

SUNDAY, OCTOBER 7, 2007

1:00-4:00 PM

FIELD CLUB OF OMAHA
3615 WOOLWORTH AVENUE - OMAHA NE

**Bring your spouse or companion or care giver or family member
or a friend *(no young children, please)*.**

Reservations must be received by NPSA no later than September 30---

Early reservations are appreciated. For reservations please mail the registration form below to Marian Barnett, 3401 Poppleton Ave., Omaha NE 68105-1939, or phone: 402-341-0710, or email: marian.barnett@cox.net or mjbarnett@att.net.

Please be sure that whatever method you use to make reservations, the choice of entree is indicated.

Name _____

Address _____

Phone _____ **Email** _____

Broiled New York Strip Steak _____ Marinated Chicken Breast _____ Atlantic Salmon Filet _____

Name _____

Address _____

Phone _____ **Email** _____

Broiled New York Strip Steak _____ Marinated Chicken Breast _____ Atlantic Salmon Filet _____

**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

Signature _____ (PrintName) _____

Address _____

City _____ State _____ Zip _____

Phone _____ Email _____

• Thank You!

Q: *I have osteoporosis and acid reflux. I just read that the anti-reflux drug I'm taking may cause my bones to get thinner. I am already taking Fosamax, which I also just read can cause my jawbone to die! Should I stop both these pills?*

Polio survivors are finding themselves between drugs and a soft place, that soft place being their bones. Last year, osteonecrosis -bone death - - was reported in the jaws of 63 polio survivors taking bisphosphonates, drugs that are given to increase bone density. Fifty-seven received intravenous bisphosphonates as treatment for cancer. But, six took Fosamax, the well-known oral, anti-osteoporosis medication. Dentists across the country have reported about 50 cases of jaw osteonecrosis. Given that about 3 million women take Fosamax, 50 is a small number of cases. Even if you assume that only about 1 percent of problems caused by a given medication are reported, jaw osteonecrosis would occur in only two-tenths of 1 percent of women taking Fosamax. Still, if it's your jaw that's dying, who cares about percentages? So, the FDA now wants labels on all bisphosphonates to warn about the possibility of osteonecrosis.

If drugs to treat osteoporosis aren't causing enough worry, in late 2006 a study of nearly 150,000 people over 50 found that taking proton pump inhibitors (anti-acid reflux drugs like Nexium) for more than a year increased their risk of a hip fracture by 44 percent. The higher the dose and the longer the drugs were taken, the risk of a hip fracture, especially among men, rose nearly 200 percent. The increased risk of fracture may be caused by proton pump inhibitors interfering with your body's ability to deposit calcium inside your bones to increase their strength. This unfortunate side effect of proton pump inhibitors is a two-headed dragon for polio survivors. The first head

is that polio survivors with paralysis, both female and male, have osteoporosis more frequently because they either haven't been "pushing" on their bones by standing on their legs (the result of using a weight-bearing brace, crutches or a wheelchair) or because their weak or paralyzed muscles haven't been "pulling" on bones. It's the pushing and pulling that makes calcium bind inside bones so they won't become brittle.,

The second dragon's head is that our 1985 Post-Polio Survey found that gut problems, including ulcers and acid reflux, are between six and 15 times more common in polio survivors than in the general population. To make things worse, sleep apnea, which have found in 25 percent of our Post-Polio Institute clients, may increase reflux.

Oh, and another "head" has just reared its ugly self. A 2007 study of 5,000 adults 50 years old and older found that daily use of the newer antidepressant medications (selective serotonin reuptake inhibitors - SSRIs - like Prozac) decreased bone density by as much as 4 percent and doubled the chance of breaking a bone. What's more, the higher the dose of an SSRI, the risk of falling increased by 50 percent.

So, what's to be done about your belly, brain and bones? All female polio survivors, and males who have muscle weakness or paralysis, should have a DEXA bone density scan to determine if they have osteoporosis or osteopenia, a lesser decrease in bone density that still increases your risk of fracture. If you have decreased bone density that still increases your risk of fracture. If you have decreased bone density, ask your doctor if you could try to increase calcium, vitamin D and protein before starting a bisphosphonate. If you need medication, ask about using calcitonin, a hormone that also increases calcium inside your bones,

or the non-bisphosphonate drug, Evista, while you also increase calcium, vitamin D and protein.

If you are taking a proton pump inhibitor or an SSRI, ask your doctor if increasing calcium would be helpful in combating these drugs' unwanted effects on bone density and falling. And, postmenopausal women should talk to their gynecologist about whether hormone replacement is an appropriate treatment.

Unfortunately, fatiguing exercise or walking to "push and pull" on bones is not a treatment osteoporosis or osteopenia in polio survivors, since exercise can cause muscle weakness and exactly what you're trying to prevent: a fall and a fracture.

(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.)

**remember--
SUNDAY
OCTOBER 7**

**FIELD CLUB OF
OMAHA**

1:00 - 4:00 P.M.

See you then

CONTRIBUTIONS

Builders--up to \$499.00

Thomas Barnett, McLean VA
Nancy and Don Greenberg, Omaha NE
Pat and Gleason Grimes, Milford NE
Dr. Edward Roche, Bellevue NE
Doralu Streeter, Papillion NE
Michael Taylor, Council Bluffs IA

Friends--up to \$99.00

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Sue Thorson, Sioux Falls SD
Mary Lee Vitton, Omaha NE
Ray Williams, Billings MT

MEMORIALS

In memory of Leora Hamdorf, Harlan IA
from Karen Dulany, La Vista NE
from Nebraska Polio Survivors Association Board

In memory of Patsy Matthews
from Kim Malcolm, Randolph IA

In memory of Neal Ratliff, Bassett NE; Albert Wasson, Ainsworth NE; and Charles Weichman, Atkinson NE
from Lorne E. and Lorraine K. Hickok, Casper WY

POST-POLIO BRANSONGOERS REUNION

**May 30 - June 1, 2008 (Weekend
after Memorial Day)**

Settle Inn: 1-800/677-6906. Please reserve now. No charge on your credit card until you check in. \$62 per night, including tax - up to 4 people per room. Includes continental breakfast.

Service dogs are allowed (no additional charge). Other animals: \$10 per night. The Hospitality Room is in Building C. There are only a few accessible rooms in "C." If you need one but are not severely mobility-challenged, please ask for Building "A" or "B."

Registration: \$45.00 per person. This includes snacks, soft drinks and bottled water in the Hospitality Room all weekend, lunch and supper on Friday, Saturday and Sunday. Polio Stories book update, calendar, copying, hand-outs, speaker fees, VCR or CD of reunion, equipment rental, etc.

For further information or questions you might have, please contact Pat Grimes, patgrimes@alltel.net.

CLOSING THE GAP

The date of this interesting conference is October 16-17, 2007, and it will focus on how computer technology can enhance the lives of people with disabilities and special needs. Topics include the role of technology in special education, rehabilitation and independent living.

The conference will be held at the Sheraton Bloomington Hotel, 79800 Normandale Blvd., Bloomington, Minnesota and the adjacent Hotel Sofitel, 5601 W. 78th St., Bloomington, Minnesota. These are the official hotels of the conference. All conference activities are held at these two hotels located 10 minutes of the Minneapolis-St. Paul International Airport. Limo, taxi, and mobility assistance services are available. Hotel airport shuttles available for Sheraton Bloomington Hotel, Country Inn & Suites Bloomington West and Crowne Plaza Minneapolis West.

For more information, visit:
<http://www.closingthegap.com/conf/index.lasso>

A bit of humor—from The Older Nebraskan's Voice, Spring 2007

An elderly woman called the hospital and said, "Hello, I'd like to talk with the person who gives the information regarding your patients. I want to know all the information from top to bottom, The voice on the other end of the line asked, "What is the patient's name and room number?" The woman replied, "I'd like to know information about Gail Davenport in Room 302."

The voice replied that Mrs. Davenport was doing very well. Her blood pressure is fine. Her blood work came back as normal. She's going to be taken off the heart monitor in a few hours and her doctor is going to send her home tomorrow.

The caller responded, "Thank Goodness! So her test came back normal and she is getting off the heart machine in a couple of hours! That's fantastic! And it is wonderful news she is being released tomorrow."

The phone voice then said, "I take it you must be a close family member or a very close friend." And the caller replied, "I'm not a close family member or friend. I'm Gail Davenport in room 302! My doctor never tells me anything."

WANT TO USE OUR ARTICLES?

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