



Gleanings

THE OFFICIAL NUMBER ONE NEBRASKA POST-POLIO NEWSLETTER

NOVEMBER/DECEMBER

2006

POLIO SURVIVORS REUNION OUTSTANDING

One hundred two polio survivors, friends and families from the Omaha, Lincoln, and Council Bluffs area gathered at the Field Club of Omaha on October 1 for a gala reunion which included a sumptuous meal with a choice of entree of salmon, chicken, or steak. The Field Club of Omaha sits in the heart of an older but lovely historic area of Omaha with many beautiful homes. The weather was perfect and the food and excellent service by the Field Club staff could not have been better. Each table was beautifully decorated by Barbara and Shelly Roth.

Todd Roth did an excellent job in providing valet parking for the guests with guidance from Terrence Connelly and Gene Roth..

As the guests arrived inside the Club, they were greeted by Deanna and Ron Block, formerly from Lincoln, later Columbus, and now North Platte.

NPSA Board President, Gene Roth,

was master of ceremonies and introduced former board president, Shirley Marsh, who drove from Lincoln to Omaha with Vera DeBuhr for the occasion. Other board members present, Drs. Kusum Kharbanda and Edward (Ted) Roche, Terrence Connelly and Marian Barnett were also introduced.

Tom Roth, son of Gene and Barbara Roth, sang several songs from the '70's genre. Roth is a well known singer from Lincoln, having appeared in leading roles in area musicals and is a popular entertainer in Lincoln.

The afternoon concluded with a drawing of names of polio survivors led by Terrence Connelly. The prizes were gift certificates to several Omaha restaurants.

It was a great afternoon and Nebraska Polio Survivors hopes to make this an annual event.

See insert inside for pictures of the Reunion

OMAHA/COUNCIL BLUFFS/LINCOLN AREASUPPORTGROUP.

**SUNDAY, NOVEMBER 5
- 2:00 PM at Beautiful Saviour
Lutheran Church, 90th and Q
Streets, Omaha.**

**PROGRAM by Dr. Edward (Ted)
Roche with helpful suggestions that
make travel easier for him.**

**As many of you know, Dr. Roche
uses an electric wheelchair most of
the time, yet Roche and his wife,
Victoria, travel extensively. Each
year they go to New York City for
the theater offerings on Broadway.
Over Labor Day this year they vis-
ited the Grand Tetons.**

**We hope to see many of you who
attended the Reunion at the support
group. You will find the sharing that
takes place at the meetings and the
friendliness and openness of those
attending exceptional.**

**The December 3 meeting will also be
held at Beautiful Savior Church
and the program will be announced
at the November meeting.**

**We would like to know what things
you would like discussed or pre-
sented at these support group meet-
ings. Please let us know.**

REAR END ALIGNMENT

by Millie Malone Lill

Ever since moving up here, I have felt that I'm on a downhill slide. I've had pain, I mean real pain, for about the first time in my experience. I've always known I was lucky, PPS-wise, to have escaped the pain. I guess Mr. Pain is now able to move a whole lot faster than I can.

It started with fatigue. I'm well versed in the fun and games the Polio Dragon enjoys with us, so I just tried to rest more. I am an antsy person, so lying down is not something I enjoy. Neither is sleeping. What if I miss out on something? There are so many enjoyable things to do, why would I want to lie still and be quiet? I began taking afternoon naps.

The pain didn't really go away. Isn't it supposed to go away if we follow the rules and do as we know we ought? Mr. Pain was not playing fair! I tried turning my back on him and going about my business. That just gave him a chance to bite me in the...uh...backside. And he bit hard!

Finally, I gave in to what my husband had been telling me. I hate to give in, it's so much like defeat, you know? Jaan has had a chiropractor that he really liked for many years, whereas I'd had only one 'adjustment' where in my 300 lb. osteopathic doctor did a handstand on my back, all the while saying 'let me know if this is too hard.' Exactly what he expected me to say or how he expected me to say it as I watched my intestines cascading out of my ears, I do not know. You can surely see why I was reluctant to try this again. But the pain was keeping me from even the fun stuff. Mind you, I don't

mind so much if I'm unable to scrub floors or dust, but it was interfering with the things I wanted* to do.

In an effort to get an opinion that agreed with mine, I spoke to some friends. One of them recommended a chiropractor. Another told me she knew of a man who was not licensed, but who did a wonderful job and was better than any chiro she'd ever gone to. He was also a few miles closer than the chiro and I'd actually even met him once, as he is also a minister. He spoke at our church one Sunday. I gave up and made an appointment.

My friend went with me to ensure that John knew he had to be very careful with me because of the PPS. She used to be a nurse and she knows about polio and is willing to support me in taking care of myself. That's a blessing all its own. John had me lie on the massage table while he manipulated all the sore spots. I am absolutely sure he found every one. I had a jammed hip, a popped rib and an impinged sciatic nerve. No wonder I was in pain.

One hour later, my legs were (temporarily, I'm sure) both the same length, I could breathe more easily and the pain had changed from grinding to merely 'there.' I was warned that for the next couple of days, I would feel as if I'd been run over by a truck. He did not lie. But even though I still ache, it is a different pain. I can lift my 'good' leg to put sox on. I can walk with less discomfort.

I made another appointment for next Thursday. I will go in for another rear-end alignment. And as many as John thinks necessary after that. Who knows, once my rear end is aligned, maybe he'll help me get my head on straight.

Bring on the Nuts

by Tammie Scholz
*Nutrition & Health Specialist,
Nebraska State Unit on
Aging, Health, and Human Services*

Throughout history, nuts have been a food staple around the world. In some cultures where nuts are considered part of the daily dietary regime, both blood cholesterol levels and the incidence of heart disease are notably lower.

For the vast majority of people, nuts are nutritious, health-promoting foods. When eaten in moderation (25-50 grams per day, a small handful) as part of a varied, nutritious diet, they may assist in reducing the risk of heart disease and diabetes. In addition, several studies have shown that eating nuts does not lead to weight gain and may help in maintaining a healthy weight.

The nutrient profile for nuts is quite impressive. Nuts are cholesterol and sodium free. They contain protein, have a wide range of essential nutrients, including several B group vitamins, vitamin E, minerals such as iron, zinc, potassium and magnesium, and provide a good amount of fiber.

As for fat, yes, nuts are relatively high in fat, but most of that fat is unsaturated. This is important because it is the saturated fat that can raise blood cholesterol levels, which can increase the risk of heart attack or stroke. The unsaturated fat, which the type of fat found primarily in nuts, may actually help to decrease the low-density lipoprotein (LDL, or "bad" cholesterol) levels.

You can heighten the rich flavor of nuts by roasting them. Preheat oven to

See page 6, column 3

YOUR REGULAR CONTRIBUTIONS ARE VERY IMPORTANT!

Adequate financial support is essential for Nebraska Polio Survivors Association to continue to carry out our mission.

What is our mission?

Our mission 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.

TO do this, we must have adequate financial support. When you make a contribution to NPSA, be assured that you are helping this organization do the work it was created for. How long has it been since you have reviewed your contribution?

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

There are several ways to contribute: 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

**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!

Our Reunion Friends





What A Day - Food & Friends!

Dinner Was Wonderful!



Much Laughter Was Heard.....





Can We Do This Again.....



We Hated To Go!

CONTRIBUTIONS

Builders--\$100 to \$499

Robert Griess, Sutton NE
Pat and Gleason Grimes, Milford NE
Dr. Edward Roche, Bellevue NE

Friends--Up to \$99

Irene Blomquist, Omaha NE
Sherrie Corbin, Anchorage AK
Lois Darrington, Griswold IA
James DeBauche, South Sioux City NE
Vera DeBuhr, Lincoln NE
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Helena Stroh, Omaha NE
Richard Tusa, Fort Collins CO
James VanEtten, Lincoln NE
Lillian Vankat, Omaha NE
Barbara Widick, Farnam NE

BOOKS ---Excellent Holiday Gifts

SNAPSHOTS by Nancy Baldwin Carter and the cook book, *THYME TO EAT* by Patsy Kravchuk and Janet Nichting are excellent books and make great gifts.

They may be ordered from Nebraska Polio Survivors Association,
P.O. Box 45139, Omaha NE 68145-1939. Prices include shipping.

***SNAPSHOTS* - \$12.00** (All profits go to NPSA)

***THYME TO EAT* - \$24.00**

Q. I have trouble swallowing but no one believes me. Food doesn't get stuck in my throat, but seems to lodge somewhere behind my breast bone., My swallowing study was normal and the doctor doesn't believe I have a problem. But, food sticks and it hurts when it does, Do other polio survivors complain about this?

They surely do. It's hard enough to "swallow" having PPS without doctors refusing to believe you're having trouble swallowing.

Most polio survivors at the Post-Polio Institute report having only occasional, mild difficulty swallowing. The difficulty is usually high in the throat: not being able to get down pills, largish pieces of meat and, maybe even more often, difficulty clearing their own secretions. A barium swallow study (eating and drinking food containing barium and having a vide taken with an X-ray camera) usually shows mild muscle weakness in the throat or sometimes, as in your case, no problem at all. This negative finding is just like a muscle test of an arm or leg not showing weakness in the doctor's office, even though you feel weaker or even stumble at the end of the day as you get more tired.

Polio survivors also have swallowing problems below the throat. What you describe - food getting stuck behind your breast bone in the esophagus (the tube connecting the throat to the stomach) is not uncommon in polio survivors. The muscles of the throat and esophagus should contract in a coordinated sequence, like a snake's muscles move, to inch food downward and into the stomach. Food gets stuck when the esophagus doesn't contract and its muscles go into spasm, not unlike back muscles going into spasm when your leg muscles are too weak to hold you up. Food usually gets stuck right behind the top of the breast bone. When it

does, it's painful and scary. Even if food makes it down to the bottom of the esophagus, in some polio survivors the "valve" just above the stomach doesn't open, preventing food from entering, a condition called achalasia.

Why do polio survivors have trouble with muscles from their throats to their stomachs? Fifty years ago, Dr. David Bodian discovered that every polio survivor had some damage to neurons in the brain stem, the so-called "bulb" of the brain. When this damage was severe and breathing control neurons stopped working, bulbar polio was diagnosed,. But the most common Bulbar polio symptom was trouble *swallowing*, not trouble breathing, because the poliovirus also damaged the bulbar neurons that control the vagus nerve, which activates and coordinates muscles from your throat down to your stomach.

Unfortunately, 99 percent of gut doctors have never seen food get stuck in the esophagus and don't know what to do about it. We've found that a low dose of the muscle relaxants Klonopin and Bentyl, taken 30 minutes before eating can relax the esophagus and allow food to slide down more easily.

But wait! There's more! Vagus damage likely explains our 1985 Post-Polio Survey finding that diarrhea, colitis, ulcers and constipation are as much as six times more common in polio survivors than in the general population. Some polio survivors report that their stomachs don't empty, a condition called gastroparesis.

Others have their intestines abruptly stop moving - as a side effect of medication, surgery, a gall bladder attack, or for no reason at all - a condition called paralytic ileus. Often, the muscles of the stomach and intestines get moving again on their own,. But, sometimes the drug Reglan is needed

to jump-start the stomach and intestines. Also, polio survivors need to try to prevent gut slowing by being careful when taking drugs that are anticholinergic (drugs that cause dry mouth) since they block the activity of the vagus nerve.

Finally, polio survivors who have a chronic sore throat, husky voice, or burning in the chest should be evaluated for reflux by an ENT doc, who'll look at the upper throat and vocal cords, and a GI doc, who may do a gastroscopy to look down your esophagus and into your stomach. If you have a gastroscopy, make sure the doc goes light on the anesthesia and uses the anesthetic Propofol, since it's short-acting and allows polio survivors (usually) to wake quickly.

(Dr. Richard Louis Bruno is director of The Post-Polio Institute at Englewood Hospital and Medical Center. Email postpolioinfo@aol.com.)

NPSA WEBSITE UNDER CONSTRUCTION

Thanks to Chip Mackenzie with the assistance of John Barnett, a website for NPSA is under construction. We expect it to be available soon.

HELPFUL WEBSITES (from Pat Grimes)

- www.post-polio.org
- www.postpoliobrangers.com
- www.polionet.org
- www.postpolioinfo.com/postpolio

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: MAY YOU ALL HAVE :
: A JOYOUS :
: HOLIDAY SEASON :
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