



Gleanings

THE OFFICIAL NUMBER ONE NEBRASKA POST-POLIO NEWSLETTER

JANUARY/FEBRUARY/MARCH

2008

A TRIP TO REMEMBER

by Marilyn Bachmann, RN
Omaha, Nebraska

After much soul searching, I went on my first medical mission. My husband came along and was part of the painting crew. There were thirty five in this group: two doctors, two pharmacists, four RN's and one med student. The rest of the group were going to paint the town church and put in a water purification system. We were all asked to collect as much medicine and medical supplies that we could and put 50# of supplies in the extra suitcase each of us was asked to bring. For months all of us solicited doctors and pharmacies and packed the supplies in a corner of our living room.

We were gone twelve long days and actually saw patients three of the days. Four hundred patients came through and the Guatemalans that were helping us turned many more away. This is the sixth trip sponsored by the Roman Catholic Archdiocese of Omaha led by Father Damien Zuerlein and Father Carl. Another trip is planned for next summer.

I must tell you that the people whom I saw in the clinic were very ill. They were invested with parasites and worms and had no medical care or medicines. So they were thrilled we were there. The reality of mortality in Huehuetenango,

Guatemala is: No. 1--pneumonia and bronchopneumonia; No. 2--diarrhea; No.3--multiple trauma.

These poor people have no insurance, no medicare, no medicaid, no money, and no health care.

I cannot tell you how good it made us feel to be able to give the medications directly to the Guatemalans (no middle men).

You cannot believe how beautiful this country is but yet so poor. Someone said, "God must provide all this beauty to help the spirit of the poor to stay alive."

Marilyn Bachmann, a polio survivor, and her husband, Fran, live in Omaha. She recently gave an expanded and illustrated talk about this trip for the Omaha/Council Bluffs/Lincoln Area Support Group meeting at Bloomfield Forum, on February 3.

OMAHA / COUNCIL BLUFFS/LINCOLN AREA SUPPORT GROUP MEETINGS

SUNDAY, MARCH 2--2:00 P.M.
BEAUTIFUL SAVIOR LUTHERAN CHURCH

PROGRAM: JOHN DULANY will share his experiences in New Orleans and the Gulf Coast area helping with the cleanup and damage repair after Hurricane Katrina. He will have many pictures and notebooks available for all to see

Directions to the new Beautiful Savior Church. The former church building was at 90th and Q St. Now go to 96th and Q St. and go south about one and one half miles. The church is across from the La Vista Police Station. The address is 96th and Melissa. This street is half way between Harrison St. and Giles St. You enter the building on the east side.

SUNDAY, APRIL 6--2:00 P.M.
BLOOMFIELD FORUM
PROGRAM BY TOM ROTH,
SONGS AND HEALTH TIPS

SUNDAY, MAY 4, 2:00 P. M.
BEAUTIFUL SAVIOR LUTHERAN CHURCH. PROGRAM TO BE ANNOUNCED LATER.

SAVE THE DATE !

3RD ANNUAL

POLIO SURVIVORS REUNION

OCTOBER 5, 2008

FIELD CLUB OF OMAHA

CANCELING PLANS

by Janet R. Vanthournout
Sanibel Island, Florida

We're enjoying a vacation at the Gulf of Mexico on Sanibel Island, Florida, because I love to shell along the sandy shoreline. Sanibel is well known the world around for wonderful shelling. Low tide is the very best time to collect shells, I think. I particularly love to do this when the tide is perfect just at daybreak. The phenomena only occurs a few days a month for tides are circular and follow different patterns every day of the month. They flow in accordance with gravity and the cycle of the moon. At any rate, this morning was one I've been anticipating with joy all month for the tide was supposed to be low at the perfect time.

I was down the beach though not nearly where I had intended to shell when I noticed a dark cloud rising on the western horizon. It was approaching quickly. Disappointed, I decided to turn and head back to our condo for I know it's dangerous to be caught at the beach during a thunderstorm. People have been injured or killed by lightning strikes while on the beach and it's not all that uncommon an incident in Florida. One must be very aware of conditions, then plan accordingly... or in the case of my plans to shell, one must cancel accordingly.

While I was tromping home, my husband was biking. He found shelter off the trail in a nearby grocery store when the squall hit. There he met two other men who were also sheltering. They hailed from Wisconsin and are also vacationing. The men began chatting and discussed an article all had read in the newspaper today. It mentioned a highway backup on the Interstate roadway between Wisconsin and Illinois for twelve hours due to bad weather. People were caught in their cars, stranded, for a long time before the road was finally

cleared of ice and snow.

This story and my own experience caused me to think. Gee, have you noticed how reluctant people of today are to cancel their plans? They buzz off in bad weather expecting to reach a distant location despite weather warnings, ill feelings, or even a persistent knocking sound in their vehicle.

We polio people tend to push downward our bodily messages yelling in painful ways that we need to stop and rest. We often overlook warnings and then find ourselves in some sort of trouble down the road.

My sons, one a business man and traveler of frequency and the other an airline pilot, told me one day recently that five hundred scheduled air flights were canceled due to inclement weather. Both boys were inconvenienced. Many travelers were irate. They apparently wanted and expected to fly despite dangers, real looming dangers, which airline companies recognized even though they probably lost money and customers when planes were grounded.

I wonder, why do people today fear canceling or changing plans? Have many of us lost our common sense? Sometimes situations dictate that we *should* change or cancel plans and for good reason. Why does that tend to upset us so much? Do we fear there will be no tomorrow? Perhaps we're becoming so accustomed to doing things our own way... the only way... that we're lost our perspective. Maybe we just can't cope with disappointment.

I'm thinking that it is time for us to rethink our wishes. We have to give ourselves "permission" to change plans when situations dictate. We post-polio people may have greater measure of weight to cancellations when are experiencing cycles of unwell feelings. Maybe we have to tell our families or friends that we cannot make a

a special date, long planned, because we are just not up to it. We can change our plan to a different time or date handling our event when circumstances are better... just like the airlines.

The bottom line is: Why take dangerous chances? As for me, I will have to do my shelling some other morning when the tide is low. Disappointed, I canceled my walking trip right in the middle of discovering delightful finds, because it's just not possible to "run" down the beach at the last minute seeking safety. I must pay attention when a storm threatens, for I'm too slow to act quickly.

PPS FORUM

Q. You have written so much about cold intolerance and "polio feet" that I hate to ask another cold question. My feet are always frozen, beginning in the fall. But my hands get like ice in winter inside the house. I feel silly but sometime, when no one is home, I wear mittens inside. I can't eat or do anything with them on, but at least I'm warm. Do you have a better solution than mittens for my cold hands?

Wearing gloves or mittens inside the house is not silly. But, there's a better way.

For polio survivors who don't know, our 1985 National Post-Polio Survey found that cold caused muscle weakness in 62 percent of polio survivors, muscle pain in 60 percent and fatigue in 39 percent. As for the problem with regulating body temperature, our 1983 laboratory study found that polio survivors' nerves function as if it's 20 degrees colder than the temperature of their skin.

When it comes to controlling body temperature, polio survivors have three problems to consider. First, the poliovirus damaged the hypothalamus, the brain's

Continued on page 6

**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!

CONTRIBUTIONS

SUPPORTING PATRON (up to \$2,000)

Lamoine McConville, McCook NE

BUILDERS (up \$999.00)

The Struve Foundation, Deshler NE

Kay Norwalk, Omaha NE

Walter and Lucia Onisk, Omaha NE

Dr. Edward Roche, Bellevue NE

Barbara Stenning, Portsmouth RI

James Zeman, Aberdeen SD

FRIENDS (up to \$99.00)

Glenda Andrew, Council Bluffs IA

Phyllis Bischof, Willow Springs MO

Marlene Daluga, Munster IN

Micnael Havelik, Omaha NE

Mavis Hill, Sioux City IA

Karen Humlicek, Dodge NE

Leonard Jansa, Garner IA

Helen Jasa, Fremont NE

Denis Jensen, Lincoln NE

Cynthia Starman Kelly, Lincoln NE

Joan Kyhn, Omaha NE

Randy Moore, Missouri Valley IA

Elizabeth M Nelson, Lacey WA

Ted Ostrand, Ansley NE

Don Owen, Shreveport LA

Marlene Perkins, Lincoln NE

Barbara Rinehart, Jackson OH

Deanne Rowen, Wessing SD

Dwaine Schmit, Bellwood NE

Ann Tuton, Mills NE

Lillian Vankat, Omaha NE

Mary Lee Vitton, Omaha NE

Joan M Weber, Lincoln NE

Vertis Boysen, Sioux City IA

Alice Wessebm Red Oak IA

Vicky Longwell, Lincoln NE

Meryle Fritz Sr., Omaha NE

MEMORIALS

In memory of VIRGINIA WALKER, Bellevue NE
from

Mrs. Millie Cherney, Bellevue NE
Mr. & Mrs. Bob Fisher and Robin, Bellevue NE
Mrs. & Mrs. Bob Carter, Bellevue NE
Mr. & Mrs. Craig Bradshaw, Kearney NE
Mr. & Mrs. Greg Bridge & Family, Lincoln NE
Mr. & Mrs. Roger Davick, Bellevue NE
Mr. & Mrs. Pat McGinn, Omaha NE
Ms. Frances A. MacDonald, Novato CA
Mr. & Mrs. Joseph Privitera, Omaha NE
Mr. & Mrs. James Schaefer, Lincoln NE
Mr. Ken Kass, Omaha NE
Mr. & Mrs. Kenn Leischner, Columbus NE
Mr. & Mrs. Dan Lunzmann, Auburn NE
Mr. & Mrs. Duane Armstrong, Lincoln NE
Mr. & Mrs. Neil Berry, Universal City TX
Mr. & Mrs. Scott Vala, Gretna NE
Mr. & Mrs. Val Chickinelli, Ralston NE
Mr. & Mrs. Robert Cruise & Family, Columbus NE
Mr. & Mrs. Bill Swantz, Columbus NE
Mr. & Mrs.. Larry Scherf, Clarinda IA
Mrs. Vadis Blenis, San Antonio TX
Mr. & Mrs. Sam Olds, Omaha NE
Mr. & Mrs. Steve Koll & Family, Lincoln NE

In memory of WARREN and MARY KELLY
from
Lorraine Hickok, Casper WY

In memory of GARY RUSSMANN, Avoca IA
from
Joan Bredehoft, Columbus NE

automatic computer that is the body's thermostat. Second, the poliovirus killed spinal cord neurons that cause muscle around the veins in your skin to become smaller, so they stay engorged with warm blood even when it's cold outside your body. When warm blood pools in those big veins near the surface of the skin, heat in the blood radiates into the air and the skin gets very cold and looks purple, or even blue. That's what causes "polio feet. And here's the third problem: Muscle contractions help pump blood back toward the heart. But because polio survivors have smaller leg muscles due to atrophy, more blood tends to pool in the legs.

So, since your body can't regulate its own temperature, you have to do it. Polio survivors should dress as if it's 20 degrees colder than the temperature outside their bodies by dressing in layers, so you can regulate your body temperature by adjusting the amount of insulation covering your body. I've mentioned wearing heat-retaining sock liners or even long-johns made of the woven, breathable plastic fiber, polypropylene, to keep your legs and feet warm. Now, computer age technology has provided new products that can help your hands.

V a l u - t e k (www.cleanroom.consumables.com), which makes clothing for super clean rooms where computer chips are made, also makes lightweight gloves that are designed for dexterity. We tested three gloves on polio survivors whose hands are cold inside. The nylon "Glove Liner" (VITGNLR-1/1 and the "Conductive Glove" (VIGCONKT), made of polyester knit, have full-length fingers. Of the two, the polyester knit is warmer, but somewhat thicker. There is also a nylon glove liner (VTGNLR-1/2) with half-fingers that allow more dexterity but isn't as warm. Polio survivors found that the gloves keep

their hands warm and allow them to use their fingers to read, to eat and even to knit, but they liked the nylon "Glove Liner" with full fingers best. The gloves come by the dozen, so you can launder them and have some to wear. The glove liners are about \$13 a dozen. The conductive gloves are about \$42 a dozen. Since these are disability-related products, they should be tax deductible.

But, remember to stay warm, the key is to get warm from the get-go. Dress immediately after showering, when your skin is warm and rosy. And, whether you're being chilled by a Northeast wind in February or by excessive air conditioning in August, cover not just your hands and legs, but also your upper body - especially your upper body - especially your neck to prevent muscle spasms and headaches due to cold causing your muscles to spasm.

Remember, too, that during the change of seasons, fluctating weather can have a yo-yo effect on body temperature. Fall and spring can bring even more chills and muscle spasms as the thermomometer goes up and down, from day to night and

and from day to day. These are the times when polio survivors' temperature-challenged bodies can't decide if they should sweat to stay cool or shiver to stay warm.

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 Centre. His e-book, How to STOP Being Vampire Bait: Your Personal Stress Annihilation program, is now available through Post Polioinfo@aol.com.

NPSA WEB PAGE

ne-polio.org

CHIP MACKENZIE
Webmaster

WANT TO USE OUR ARTICLES?

Feel free to use our articles exactly as they are written. Please give credit this way: From GLEANINGS, Nebraska Polio Survivors Association, P.O. Box 45139, Omaha, NE 68145-0139. If you wish to edit an article, contact NPSA for permission.

Marian Barnett, Executive Director
Nebraska Polio Survivors Association
P.O. Box 45139
Omaha, NE 68145-0139
402/341-0710 - website: ne-polio.org
e mail: mjbarnett@att.net

Return Service Requested

NON PROFIT
ORG.
U.S. POSTAGE
PAID
Omaha, NE
Permit No. 1575