

THE OFFICIAL NUMBER ONE NEBRASKA POST-POLIO NEWSLETTER

APRIL

1988

LINCOLN SUPPORT GROUP PLANS SPECIAL MEETING

If you missed last month's NPSA Lincoln area support group meeting featuring music therapist Maureen Bausch, one opportunity to enrich your lives in a very special way has slipped past you. Those present found it a most rewarding program.

The March 26 meeting, at 2 p.m., American Lutheran Church, 42nd and Vine, will feature a video from the International Polio Conference with renowned polio doctors discussing muscle weakness.

This is your chance to hear what some of the best polio clinicians and researchers in the country have discovered about our problem. Please come!

WHO IS OUR OLDEST SURVIVOR?

Franklin NPSA member Marjorie Townsend asks an interesting question: who is our oldest polio survivor? We know we have a number of members in their 80's, but we don't have specifics.

If you are over age 80, tell us your age and we'll try to come up with the winner in this category.

YOUNKER REHAB PLANS WORKSHOP

Frederick Maynard, M.D., University of Michigan post-polio authority, will be the chief speaker at the May 27 Post-Polio Management Update workshop to be held from 8 a.m. to 4 p.m. at Howard Johnson Convention Center in Des Moines.

Registration fee of \$20 (\$40 for health providers) includes coffee and rolls, lunch, and handouts. All registrations must be received by May 12 (none will be taken at the door).

To register, send a check

made out to IMMC along with your name, address, phone number, and tell them if you are in a wheelchair (so that tables can be arranged accordingly) to Jeanne Osborn, Younker Rehab, 1200 Pleasant Street, Des Moines, IA 50309. If you want more information, write Jeanne or call her at 515/283-6432.

Howard Johnson is off Exit 131 at 4800 Merle Hay Road. You can call there at 515/278-4755 for rooms.

The workshop has been approved for CE for nurses and doctors.

CHRYSLER OFFERS HANDICAPPED BUYERS INFO, MONEY

So far three Nebraskans have received reimbursement checks for up to \$500 through Chrysler Motors' Physically Challenged Assistance Program, according to John Martel, P-CAP manager.

"We get about 50 calls a day from all over the country," says Martel. "We have reimbursed 350 customers nationwide, and sent out lots of information."

Chrysler's P-CAP is a twofold operation. First, a Resource Center was established to provide information to consumers regarding various types of adaptive equipment such as wheelchair lifts and tie-downs, hand controls, and six-way power seats. The equipment is not sold by Chrysler, but they will send you this driving-aid and conversion information free as a service.

Then, if you buy any of these devices and have them installed (whether for the driver or a passenger) in a new Chrysler product within six months of purchase,

See pg 3, col 3

by Kathy Hendrickson NPSA Wood River member

Did you ever plan to do something and then have your bubble burst because you were not properly informed? Well, I did!

On impulse I decided to make a trip from Hastings to Caliente, Nevada, to see my son.

I called the AMTRAK toll-free number, and the operator assured me that there were handicap accommodations-in fact, a special car just for handicaps. They would have a ramp to put me on and off the train. I would find out in days to come how much of this was TRUTH and what was FICTION.

I left January 14th from Hastings. They put me on the train via ramp and escorted me to the so-called handicap section, which was anything but. They had no bars to help you up or down--no seats you could get up from without help. The temperature was COLD. The only true accommodation was a handicap bathroom, which needed to be at least a foot longer, but was usable.

The trip back was a whole new ballgame. To begin with, the conductors did not know how to set up the ramp--my son had to show them. Then we were delayed by derailment and missed our connection and were forced to lay over in Salt Lake City. We were taken to a hotel to

spend the night. What a bummer--would you believe a new 15-story hotel with only one handicap toilet, and that in the convention center! They did not have one sleeping room with handicap facilities--I couldn't get my chair through the bathroom door.

I decided to crawl into the toilet and back to a couch to get in my chair. Well, I hit another snag--the couch was too high. So I had to crawl to phone for help. Who did they send--the security guard, and he demanded to know what I was doing on the floor. Believe me, I told him in flatout terms. He wasn't long getting me up.

The next morning we were back on the train in a car marked HANDICAPS AND ELDERLY ONLY with very little heat in sub-zero weather.

I had a lunch with me so I wasn't hungry until midafternoon when two very sweet old ladies offered to bring me a sandwich when they went to eat. The man in charge refused to allow this-said the steward had to do it. Those little ladies were mad as wet hens. We rang the bell off and on for about 40 minutes before a steward finally showed up. It took another hour to get my sandwich, and believe me, everyone from the conductor on down heard about it from those dear little ladies!

WARNING

One of our members made an appointment to see, for the first time, a local doctor knowledgeable of post-polio. This neurologist shares an office with several other doctors. The M.D. did not introduce himself when he entered the room, and our member did not ask his name, but was highly irritated at his lack of understanding of post-polio and his insistence that there was nothing wrong with her. For this she was charged \$100.

Later she discovered that this was not the doctor she had made the appointment with--that the office made a substitution without her permission and, indeed, without even mentioning it to her.

When you make an appointment, tell them you will see only the doctor you want; ascertain the name of the physician seeing you before allowing the examination to begin; and LEAVE IMMEDIATELY IF THIS IS NOT THE PERSON YOU WANT TO SEE. An orange is not a banana, even though they may be in the same fruit basket.

HOLDREGE GROUP FEATURES FISCHER

Delores Bray, NPSA Holdrege Area Representative, reports that their April 2 meeting will host Andrea Fischer from Alma who will discuss Reflexology.

Be there at 2:30, Phelps Memorial Health Center.

CONTRIBUTIONS

We thank the people listed below who have supported NPSA by sending a donation.

FRIENDS--Individuals who contributed up to \$99

KATHLEEN BONYHADY, Lincoln, NE MARCIA BREDAR, Omaha, NE ELNA CALLOW, Coalinga, CA

I feel guilty sending such a small amount, and only hope there are hundreds sending in this much so it will add up..

Lillian Morfeld Carroll, IA

NANCY DAVISON, Omaha, NE DARREL HARTLINE, Omaha, NE

I enjoy reading your GLEANINGS newsletter and look forward to your informative articles. I am enclosing a small donation...

Morton A. Solomon Aurora, CO

JUDY IRONS, Lincoln, NE FRANK JOHANNSEN, Bayard, NE LEE'S JEWELRY, LEE DEKARSKE, Norfolk, NE I have enclosed a small donation to be used or added to the support Appeal. I am very grateful to be on the GLEANINGS list. I thank you so much for the information "Help for Pain" in the November issue. I showed it to my doctor in Scottsbluff and he said it was very good for nerve damage pain...it has been a great help.

Marcelene Stegeman Sidney, NE

LILLIAN MORFELD, Carroll, IA SUE ROOSMANN, Lincoln, NE

Enclosed is a donation for NPSA. I wish it could be more.

Nancy Davison Omaha, NE

MORTON A. SOLOMON, Aurora, CO MARCELENE STEGEMAN, Sidney, NE

I enjoy reading the GLEANINGS, so a little something for postage.

Darrel Hartline Omaha, NE

MEMORIALS

IN LOVING MEMORY OF CLARENCE CORLISS

> from Mr. & Mrs. W. O. Baldwin Hebron, NE

IN LOVING MEMORY OF MARGARET CONRATH

from Lyle & Virginia Walker Bellevue, NE



HOW TO SEND A MEMORIAL OR COMMEMORATIVE GIFT TO NPSA

Many people prefer to send a cash gift to the health organization they support in loving memory of a departed relative or friend. Others find sending such a gift a worthwhile way to commemorate birthdays, anniversaries, and other occasions.

If you would like to participate in NPSA's efforts in this way, fill out the form below and send it, along with your check, to Nebraska Polio Survivors Association, P. O. Box 37139

Omaha. NE 68137.

A card will be sent to the person you indicate which reads:

(for memorials) A Gift To

Nebraska Polio Survivors Association has been made in memory of JOE SMITH

by Mary Doe 444 North Street Sometown, NE 68888 (for commemoratives)
A Gift To
Nebraska Polio Survivors Association
has been made in honor of
the l0th Wedding Anniversary of
BILL and MABEL JONES
by

Jerry and Jane Blue 222 Hickory Street Sometown, NE 68888

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Each Gift to NPSA is Deductible for Tax Purposes

HELP FOR THOSE WITH CHEWING/SWALLOWING PROBLEMS

If you have trouble chewing and/or swallowing, here are some suggestions for better eating:

You can enjoy the same food the rest of the family is having by processing the cooked product in a Vita Mix 3600. This amazing machine will mix, blend, puree, liquify virtually any food from peas to roast beef.

If you can eat it lumpy, blend only a little; if you need thin liquid, puree till smooth, adding milk, broth, or juice till it's the consistency you need. (Vita Mix also heats food or makes ice cream: grinds grains, coffee beans. etc.; and goes from raw wheat to bread dough in about ten minutes.) Call 1-800/848-2649 for ordering and other information.

THE NON-CHEW COOK-BOOK by J. Randy Wilson provides soft food recipes in five categories, often utilizing a blender. An excellent nutritional analysis per serving appears for each recipe, as well as an informative introductory section on nutrition. Use of canned soups and other canned goods, cheese, and salt makes many of these recipes extremely high in sodium, but you cn easily adjust ingredients. No suger is used. From Wilson Publishing, Inc., P. O. Box 2190. Glenwood Springs, 81602-2190, \$14.95 + \$2.50 postage and handling.

Experiment a little and find out what works for you. Often warm foods and drink go down easier than cold-why not heat your juice in the microwave for a minute? If it's just the opposite for you, avoid the heated. If you have a "polio throat," turn your head toward your weak side to prevent "pocketing" of food. Take small bites, chew well, and drink lots of water (warm?) between bites.

Bon appetit!

TODAY'S CHUCKLE

My 83-year-old dad has just been diagnosed as having polymyositis, a disease causing muscle degeneration. His arms and legs are very weak, and he becomes fatigued with little exertion. He's heard me complain of these same symptoms often. regarding my Post-Polio Syndrome. So he tells everyone, "I have PPS too--that stands for Polio Parent's Syndrome."

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Chrysler--from pg 1, col 1

Chrysler will reimburse you up to \$500. Forms for reimbursement are obtained from your Chrysler dealer.

For more information, write P-CAP, P. O. Box 159, Detroit MI 48288 or call 1-800/255-9877.

NEW PRODUCTS ON DISPLAY

Abilities Expo, featuring over 200 exhibits devoted exclusively to products and services for the disabled, will be held June 10, 11, and 12 at the Los Angeles Convention Center. \$3 will be charged for admission, with children under 12 admitted free.

Typically, this exposition, the largest in the nation, displays the latest advances in numerous aids for the disabled. For instance, this year you can see a CHARIOT, Honda's road-going vehicle that will carry you and your wheelchair in comfort and safety. Or Able Phone 100, a cordless, handsfree telephone system. Or a wheelchair that climbs stairs. Or an air mattress overlay that converts any bed into a therapeutic flotation unit. Or water skis for the disabled. Or wheelchairs that help you stand to reach high shelves. Or a torso support for use in the car.

In addition to an amazing array of products, there will be a dozen or so one-hour workshops, daily demonstrations by the National Foundation for Wheelchair Tennis. demonstrations by disabled artists, and career opportunity booths.

And some really super news: Abilities Expo Midwest will be held in St. Louis in conjunction with the 1989 International Polio Conference, May 31-June 4--keep this space open on your calendar for 1989!

FLASH BACK! FLASH BACK! 1954

by Delores Bray NPSA Loomis member

I will never forget finally coming back to reality after the high fever was gone. I was 25, the mother of three. We all had polio together. My two year old and my baby had few after-effects. Now the baby is having post-polio problems.

My seven year old was almost completely paralyzed. She spent three months in an iron lung. She was down the hall and around the corner, but I didn't see her for six weeks. I couldn't go to her and of course she couldn't come to me.

What an awful feeling to know your first-born was possibly dying and you couldn't even go hold her hand. She got out of the lung, paralyzed from the waist down. My parents cared for her at home as they

NOTICE NOTICE NOTICE CHANGE CHANGE

The NPSA Omaha Area Support Group will meet April 10 rather than on Easter. A big bash is being planned to honor those who have helped us by volunteering huge hunks of time and effort this past year.

Please be there to help us celebrate--there will be plenty of goodies and fun for everyone.

Come to FDR, 10825 Farnam in Old Mill South, 2 p.m.

had in the hospital. My mother was a practical nurse. My daughter lived 15 months and contracted bronchial pneumonia. There was no strength to fight it off.

I worried about her, my babies who were with relatives, and my husband whose life fell apart on his 30th birthday. I couldn't even comfort him.

I still remember the wet, stinky wool hot packs. I was allergic to wool and itched terribly. The nights were lonely and you took them an hour at a time.

After you were better, it was therapy and then the fun of wheelchair races down the hall, going to the cafeteria and seeing my daughter.

Sometimes I wonder how all of us polio survivors stood it, but I guess that is why we are survivors. Just remember we are in this together and I love you all.

UNMC QUESTIONNAIRES NEEDED

If you are over age 60 and have not yet mailed back the questionnaire appearing in last month's GLEANINGS, please do so today.

The University of Nebraska Medical Center's Section on Geriatrics and Gerontology wants to help polio survivors in their new rehabilitation center, but they have to know there is a need before a program can be developed. We can show them the need exists by giving them the information on these questionnaires.

NPSA thanks Connecting Point (formerly CBM Computer Center), 7425 Dodge Street, for the use of their laser printer in the production of this month's newsletter.

Nancy B. Carter Nebraska Polio Survivors Assoc. P.O. BOX 37139 Omaha, NE 68137 (402) 895-2475

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