

Gleanings

THE OFFICIAL NUMBER ONE NEBRASKA POST-POLIO NEWSLETTER

NOVEMBER

1988

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IN LINCOLN AREA? COME
TO NOVEMBER MEETING!

by Arleen Curtis

The Lincoln Area NPSA Support Group will meet **SUNDAY, NOVEMBER 13** at 2 p.m. at the American Lutheran Church, 4200 Vine Street.

The program will deal with relaxation as well as Dr. Bernie Siegel's outlook on healing with positive visualization.

Our speakers need you. We need you. **PLEASE COME!**

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**CAUSE OF LATE EFFECTS
STILL UNKNOWN**

by Burk Jubelt, M.D.

Associate Professor of Neurology, and Director, Post-Polio Clinic, Northwestern University, Chicago
The etiology, or cause, of the Post-Polio Syndrome (PPS) and PPMA (new weakness with or without atrophy) is not known. Numerous theories or hypotheses have been proposed. None has been proven. Four of these theories are thought by most researchers to be more likely.

The leading theory is that there is a dropout of new nerve terminals from the reinnervating motor nerve

See pg 3, col 1

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LONG AWAITED-FOR COOKBOOKS NOW AVAILABLE

The cookbooks are here!

And they are as gorgeous as we promised, with full color cover and tabbed dividers holding in place 550 indexed recipes from nearly 350 members and friends of NPSA.

Recipes range from Crab Rangoon to Grandma's Easy Noodles, from Watermelon Pie to Russian Meat Loaf, from Garden Spiral Salad to

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LINCOLN PLEASURE PAC SALES UNDERWAY

Peggy Moe and Arleen Curtis, NPSA Co-Representatives for the Lincoln Area, are leading their sales team onward and upward as they near the end of their Pleasure Pac coupon book campaign.

Early sellers for the Lincoln Area group are Frank Cejka, Millie Schwindt, Virginia Kuta, Marlene Perkins, Sandy Flaherty, and Michael Hendricksen.

"It's incredibly easy to sell them," says Arleen. "Just about anyone you speak to is a possibility. I left one at

Mexican Orange Fudge. A unique Breakfast/Brunch section is a special feature.

These fantastic books will be wonderful gifts--Christmas, birthday, anniversary, wedding, shower, thank you, **WHATEVER**. People will love them! And at only \$7 each, they are a terrific bargain.

To order yours, use the form on page 4 of this newsletter.

the chiropractor's and he bought it; I showed it to the lone clerk at the savings and loan company--another one sold."

NPSA owes a big thanks to our Lincoln members who are willing to help us keep going by donating their time and energy to this effort. These are Gold Star people.

Pleasure Pacs will be available till November 1 --call Arleen at 467-1288 or Peggy at 489-7026. At only \$18 each, you won't find a better deal in town!

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HASTINGS GROUP TO HEAR PHYSICAL THERAPIST

The November 13 meeting of the NPSA Hastings Area Support Group will feature Vic Kennel, a Physical Therapist with offices in York and Geneva. Vic is a member of NPSA, and has helped us in many ways.

Come to the Imperial Mall at 2 p.m. We look forward to seeing you there!

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WHEN YOU GET YOUR COOKBOOK--Please check your recipes for errors. If corrections are needed, notify us so we can publish them in GLEANINGS.

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DO YOU HAVE AN HOUR?

Often we have jobs to be done in the state office that require more manpower than we have at hand. Things like running copies, stapling, wrapping packages for mailing, inserting pages, etc.

The work cannot be taken to your home, and we have three steps to our front door.

We would like to have a file of names of people we can call on to volunteer an occasional hour or two when these jobs come up. Will you help us? Do you know someone else who can?

If so, call Nancy, 895-2475.

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North Platte...

NPSA is looking for someone in the North Platte area to help us establish a support group there. Can you help?

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KEEPING ACTIVE--ONE MAN'S EXPERIENCE

by Charles Mackenzie,
Omaha NPSA member

As one of the younger members of NPSA, I am concerned about how to stay as active as possible as I get older. With two young kids and a wife who would rather be vacationing, this presents a serious problem. With a sedentary occupation, the urge to sit down and stay there without moving is very alluring.

Over the last several years, I have made several changes in my lifestyle which are beginning to bear fruit. The following are some of the things I have found to help me to lead a more active life.

1. Assistive Devices: I now use two canes. Using two canes rather than one made a great difference due to my particular muscular imbalances. It is commonly not muscular weakness but muscular imbalances that cause the most difficulties.

2. Wheelchairs: I use wheelchairs or motorized carts for all long distances (I now define long distances as anything over about 200 feet). I recently manned a booth for four days at a major conference. I used a motorized cart and made it through the week with energy to spare. Shifting to a wheelchair can be one of the more awkward transitions for one able to walk well, but not far.

3. Exercise: I have been involved in an aquatic exercise class since last fall. The improvements have been slow but encouraging. Some

observations: My polio-affected muscles have improved very little. My sides are still very weak and I can't walk very far without fatiguing. Fortunately I was aware that these muscles would probably not improve. Although I have had more than my share of aches and pains, I have noticed no weakening of affected muscles nor any extended fatigue. The latter are important because overuse of affected muscles may result in permanent loss of function.

The biggest change is in my respiratory capacity. I am able to swim further than I have in years. When I first started, I could swim one lap before a shortage of air made me stop. I now swim six pool lengths fairly comfortably. My flexibility is markedly improved. I can turn my neck better than I have in years and can even lie on my stomach with my hands stretched out above me.

While I will always be limited, judicious use of exercise, wheelchairs, and canes appear to offer hope that I will be able to continue to lead an active life as I grow older. I try to look at how I am living my life. I try not to let my physical limitations dictate the activities in which I participate. I do not hesitate to involve family and friends. I do not let my physical limitations be a handicap.

cell. When the acute poliomyelitis occurred, many motor cells died. The remaining motor nerve cells had to send out new nerve terminals to supply signals to the muscle fibers which had lost their nerve cells. Many years later (30-40 years after the original polio) these new nerve terminals may be contracting and dropping out. This theory is supported by single fiber electromyographic (SFEMG) studies and by some muscle biopsy studies. Why these nerve terminals would drop out is also not known even though theories have been suggested.

An alternate theory is that the motor nerve cells themselves are dying. Possibly after supplying more muscle fibers than normal, the motor nerve cells remaining after the acute polio can no longer maintain this increased metabolic demand (of supplying too many muscle fibers) and begin to die earlier in life than normal. A few muscle biopsy studies support this theory.

A third theory is that PPMA is an auto-immune problem, that is, a person's immune system (antibody, white blood cells) attacks her/his own tissues. This theory could overlap with the two above as the immune system could attack either nerve terminals or the motor nerve cells or both. This auto-immune reaction might occur because proteins in the nervous system were

permanently altered by the original poliovirus infection. This theory is supported by the finding of unknown antibodies in the spinal fluid and the finding of white blood cells (inflammation) in the spinal cords of patients with PPMA.

The fourth hypothesis is that the poliovirus may have come back or reactivated in some way. There is no convincing data to support this theory, but whenever there is inflammation, the possibility of an infection is suggested. However, poliovirus antibodies are not increased in PPMA patients and poliovirus has not been isolated from the throat, stool or spinal fluid. Thus, if poliovirus is present at all, it could only be in the spinal cord in a very altered form since infectious virus cannot be recovered from anywhere

else. This would be a very atypical and unusual poliovirus infection, but this theory cannot be excluded for sure until spinal cords are examined. In any case, PPS and PPMA patients are in no way an infectious risk to others. This is not a problem or worry.

In this brief review, I've only mentioned the most frequently discussed possible causes. Maybe another will turn out to be the actual one. As you can see, we have a lot of work to do to solve the question of the Post-Polio Syndrome. Again, let me emphasize that there is no hard evidence to support an active poliovirus as the cause and PPS patients are NOT infectious or contagious.

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"No, I don't have a handicapped permit, but I have sinus trouble!"

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ANNIVERSARY CELEBRANTS ENJOY HOLDREGE AREA MEETING

A well-attended meeting focused on progress as NPSA's Holdrege Area Support Group celebrated its third anniversary October 1.

Marlene Orton, NPSA Board member from Syracuse, gave a slide presentation showing NPSA today, emphasizing the Holdrege Area group's role in our growth.

Much fellowship was enjoyed as Area Representative Delores Bray cut a beautifully decorated cake. Those devoting extra effort to the day were Cleone Groen, Edith Johnston, Violet Grove, Glenna Zern, Ruth Larson, LaVern Zern, Roger Bice, Clinton Larson, and Floyd Bray.

Congratulations!



Marlene Orton and Delores Bray

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ENERGY HELP

Amantadine or Symmetrel has been helpful for some polio survivors with energy problems. Ask your doctor.

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**CAMPAIGN OVER, BUT OMAHA PLEASURE PACS
STILL AVAILABLE**

Our Omaha Super Salespersons really did a job this year in NPSA's Pleasure Pac fundraiser. A-1 in sales and winner of the \$50 bonus is Kayla Howard, who was way ahead of the pack with 104 coupon books sold. Karen Dulany also showed her exceptional sales skills by selling 54 books.

A terrific line-up of talented workers sold over 30 books each: Betty Whitmore, Mike Kravchuk, Lorri Linenbrink, Georgia Whiteaker, Bill Nolan, Gloria Kass, Judy

Kellerman, and Florence Maxwell. All will take home a free Pleasure Pac for their extraordinary efforts.

Although we were short our 1500 book goal by nearly 200 books, everyone working on this project did such an outstanding job for NPSA that there is nothing to do but cheer. Let us thank all our salespersons and their fearless leader Patsy Kravchuk for this wonderful success.

Pleasure Pacs can still be obtained from NPSA--call 895-2475.

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**SOCIAL SECURITY
DISABILITY HELP FREE
FROM NPSA**

NPSA still provides free information helpful to those applying for Social Security Disability. Included are the recent (July 1987) changes in Social Security's Program Operations Manual System that reflect an awareness of the difficulties now being encountered by polio survivors. Everyone involved--you, your doctor, and your SS examiner--should be aware of these changes.

Send for your pamphlet today.

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PEOPLE WHO NEED PEOPLE

A good friend of mine has moved to Kansas City. It's one of those things you wish never had to happen.

I've been fortunate over the years to have found a number of REAL friends. You know what I mean. The kind of folks you can count on in a pinch. People you can talk with for hours, and be amazed to find that more than ten minutes has gone by. People you can tell your secrets to, and know that no one else will hear them. People who trust you with their souls.

Debbie is special. She has a uniquely kind and generous spirit. And a great curios-

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NOTICE NOTICE NOTICE

Who among us hasn't had moments of depression when dealing with our changing polio bodies? How can we and our loved ones learn to understand and accept these changes?

Kathleen Lyons-Meyer, Therapist at Omaha Psychiatric Associates, will help NPSA's Omaha Area Support Group with these and other issues at the November 6 meeting, 2 p.m., IBM Building, 450 Regency Parkway.

It will aid our discussion if you will bring your families and friends with you.

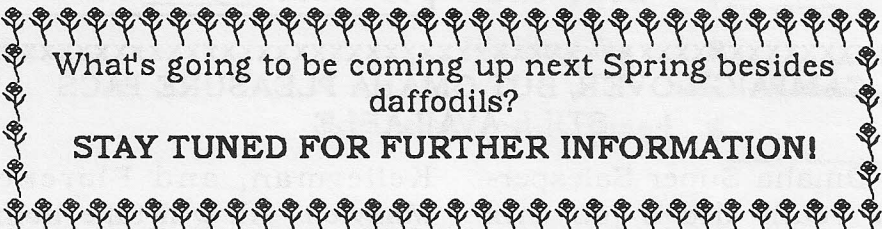
We need you for this one-- will you be there? Please come!

ity about life. Whoever lingers in her path is blessed. I've had some rough times this past year, and Debbie was always there. When I was up against it, she pitched in to do for me what I could not do for myself. She understands that in order to help someone, you have to give what they need, not what YOU want.

When I couldn't find a ride to the doctor, she didn't sympathize with me; she took me there. When company was coming and my refrigerator resembled the back end of a garbage truck, she didn't bring me a begonia; she cleaned the fridge.

She patterned our relationship to fit my physical limita-

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tions. If I couldn't handle lunch, we'd just sit and chat. No demands. This is a friend.

Many of us, finding ourselves less and less able to dance in the social whirl of life, are hard put for companionship. Our old buddies have things to do, places to go; they seldom stop for us. When they do, often it feels like charity.

How rare, then, for someone to insist on honest, unconditional friendship. No big deals. No fanfare. No public acclaim. Just friendship.

"...in the dew of little things, the heart finds its morning and is refreshed." Gibran.

Lucky Kansas City.

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