Gleanings

THE OFFICIAL NUMBER ONE NEBRASKA POST-POLIO NEWSLETTER
NOVEMBER 1988

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!

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 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.

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

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 Cezka, Millie Schwindt, Virginia Kuta, Marlene Perkins, Sandy Flaherty, and Michael Hendrickson.
"It's incredibly easy to sell them," says Arleen. "Just about anyone you speak to is a possibility. I left one at 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!
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!

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

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.

North Platte...

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

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 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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COOKBOOK ORDER FORM

The Cookbooks are here, and how well you have done! Your contributions have given NPSA a Cookbook we can really be proud of—we thank you for your fine efforts. Our great cooks deserve a round of applause for sharing their special recipes with all of us. In fact, we received so many excellent recipes that we could not fit them all into the book because of our 550 recipe limit. We did try very hard to include at least one recipe from each contributor who observed the July 1 deadline, however, and hope that we accomplished this.

Now everyone can have these recipes. If you have not yet seen these super Cookbooks, you have a treat in store! They are not just wonderful guides to the best cooking ever—the first three pages are devoted to explaining about post-polio and NPSA so that those who need us can find us.

Will you help us spread the word about NPSA and the Late Effects of Polio?

Will you donate a Cookbook to your local library?
Will you sell a few books to friends?
Will you help your local support group in this endeavor?
Do you have some other way of distributing these books?

You may order as many books as you wish. All orders will be filled in the order in which they are received—don't let us run out before you get your order in.

If you live in an area where there is an NPSA support group, you can purchase your books from them if you want to avoid mailing fees. If you order from us, please use the following form:

I want _____ books at $7 each—Total $_______
Mailing fee $_______
Total amount enclosed $_______

MAILING FEE-IN USA:
1-5 books—$2.50
6-10 books—$3.75
People ordering from Canada will receive a separate bill for the mailing fee.

SEND CHECK OR MONEY ORDER ONLY, payable to NPSA
(Please allow several weeks for delivery)

Send books to:
Name ___________________________ Telephone # (_____)_____________________
Street ________________________________________________________________
Town ___________________________ State ________ ZIP ______________

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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!

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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.
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 curious-

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!

foreign and domestic

What's going to be coming up next Spring besides daffodils?

STAY TUNED FOR FURTHER INFORMATION!

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