

THE OFFICIAL NUMBER ONE NEBRASKA POST-POLIO NEWSLETTER

1989

OMAHA GROUP DONATES COOKBOOKS TO LIBRARY

Thanks have been received from Michael Phipps, City of Omaha Library Director, for the gift from NPSA's Omaha Support Group of our fabulous cookbook.

"My mouth waters just looking at some of the recipes," wrote Mr. Phipps.

Look for the books in the Social Sciences Department in each Omaha branch library.

POLIO LITERATURE REVIEW AVAILABLE FROM NPSA

A 27-page review of polio literature written by Les Teichroew, R.N., M.A., of Ottawa, Ontario, Canada, can be ordered from NPSA.

The copyrighted paper, "Post-Polio: A Critical Review," includes a brief history of polio and its treatment as well as the section on Post-Polio, with its subsections on terminology, causes, symptoms, functional consequences, treatment, and

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COOKIE HELPS NPSA BRING HOME THE BACON

Eight years ago two life-long chums, Barb Kushner and Leslie "Cookie" Hoberman, sat at one of life's crossroads deciding whether or not to go into business together.

"Barb had seen a coupon book in Washington and felt it would go great here," says Cookie. "I thought it was the dumbest thing I'd ever heard of. Then I saw the book..."

The two immediately set up shop, creating Pleasure Pac. Cookie's husband, Jerry, gave them office space in Tires, Inc., and they began selling.

"The book that year was awful," laughs Cookie. "It cost \$29 and had about 250-300 coupons in it."

With good advise from New Orleans counterparts, the two quickly improved the product. The 1989-90 Pleasure Pac will have over 900 coupons in Omaha and over 450 in Lincoln, all of them tickets to most special offerings.

"Our emphasis in this business is on long-term rela-

tionships. The most important thing is to maintain a high level of honesty with all parties," says Cookie. "This is why we are so successful."

Much of the money used to produce NPSA's Polio Update '89 in April was earned by our selling Pleasure Pac last year. Because of that affiliation, Cookie learned about Post-Polio Syndome, taking time to study the subject, and even devoting one of her TV interview programs to the topic.

"A most fearful thing for me is to physically debilitate," Cookie says. "To have conquered a disease as a child and then to have it attack you later in life is like a double jeopardy. I identify with this."

Cookie likens the post-polio situation to that of AIDS. "It is truly life to them--encouraging research, finding a cure. I understand the commitment of your group to your cause."

As plans develop for this year's campaign, Patsy
See Pg 2, Col 3

IBM OFFERS HELP FOR PERSONS WITH DISABILITIES

The IBM Corporation has created a National Support Center for Persons with Disabilities. Individuals with special physical problems can now find products and services available to assist them in using IBM computers by calling a toll free number at the Center.

A new Federal law stating that computers must be accessible to disabled government workers has spawned a wealth of equipment and systems for persons with all sorts of limitations.

For instance, keyboards are available for those who can type only with one hand, one finger, or with reduced fine motor control. Keyboards can be redefined to be right-or left-handed. There are mouthsticks, handsticks, and head pointers.

If the standard keyboard cannot be used, a replacement may be available. A membrane keyboard is for those who can press on a flat surface but cannot punch keys. An expanded keyboard features larger keys for those needing a bigger target while miniature keyboards help those with extremely limited range of movement.

Some systems accept a spoken command, using a previously stored voice pattern to compare with the incoming sound. When the computer hears the voice it has stored, it activates the keys for that command.

In order to speed up the rate of input, shorthand versions of a word or a phrase can be automatically turned into fully spelled words by certain systems.

Other programs assist with such things as operating switches for lights, televisions, or other appliances for those with serious motor control problems.

A special program offering IBM Personal System/2 computer products at a discount is available to eligible persons with disabilities.

Information offered from IBM lists equipment and services from every company that provides it--not necessarily IBM. You can call the Center at 1-800/426-2133 or write them at PO Box 2150, Atlanta, GA 30055.

Literature from Pg 1, Col 1

incidence.

Medical professionals will find the 132-item reference bibliography following the review very helpful.

To order copies for you and your doctor, please send your name and address to NPSA along with a check for \$2.50 for each review to help pay for copying and mailing. Be sure to ask for REVIEW so we'll know what you are ordering.

YOU CAN PURCHASE POLIO UPDATE '89 TAPES TODAY

If you have not yet purchased tapes of the speakers at Polio Update '89, you are missing a good bet!

High quality tapes are available in a handy album for \$20 for a set of five. Individual tapes can be purchased for \$5 each.

The five tapes include Augusta Alba, M.D., Neil Cashman, M.D., Sybil Kohl, CSW, Jacquelin Perry, M.D., and the panel discussion.

You will note that if you order the album, you will receive all five tapes for the same price as four individual tapes.

We strongly urge you to hear these speakers. Make your order today from Dicobe Tapes, 1707 Farrell Drive, Bellevue, NE 68005, or call 402/291-3381.

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Cookie from Pg 1, Col 3

Kravchuk, NPSA's intrepid Pleasure Pac chairman, has revealed a sales goal of 2,000 books. Cookie mentioned the number to her secretary, who seemed skeptical that NPSA could sell so many books.

"I told her, 'These folks can do it,'" says Cookie. "'You don't understand the dedication of this group. They are fighting for something. They'll get out there and sell."

Right on, Cookie!

NEW REALITY

by Colleen Brouillette St. Paul, NE

Polio Update '89 was such an eye-opener for my husband and me that I would like to share some thoughts we've had since that time.

First of all, for the past nine years I've experienced all the classic symptoms of Post-Polio Syndome, and with my husband's nudging in the right direction, began using a cane for balance and stability last Fall (after MY last fall).

As I've experienced all these quirks of ours, I have explained the aches and pains, fatigue, depression of a new disability, etc. to a very dear and understanding spouse. He has been so very helpful and supportive, both physically and emotionally: the first to get a handle on any new literature on PPS and in general, an all-around support group of one in our home.

So, after all these years I've assumed he understood completely all the details we are dealing with concerning PPS.

However, at some point during the day of Polio Update, I detected a note of sadness on his face, but it was also one of reluctant acceptance. It was then that he fully realized the extent of PPS as we listened to outstanding speakers, one after another, explain the "wall" and indepth slides of what has

occurred with post-polio onset.

As we discussed the lectures on our drive home, I realized that Mont had finally admitted my disability to himself. He commented, "I listened but I did not HEAR you" and "I must admit I couldn't give in to the fact before."

What a relief for him, and me, to loosen that burden of heavy feelings. No, I'm not the same physically, but I'm still OK, and realize my husband wants the very best for me. However, for now THIS is my best. But, what a relief to be able to share in that nasty old reality of life as it is.

I have a feeling there were many more out there experiencing similar feelings and facing some new realities.

ANTHOLOGY FOCUSES ON THE PHYSICALLY HANDICAPPED

A 1985 compilation of literature about the physically handicapped includes 45 short stories and poems written by such well-known authors as Anne Tyler, Richard Wilbur, and Louis Simpson.

The anthology, DESPITE THIS FLESH: THE DISABLED IN STORIES AND POEMS, is edited by awardwinning poet Vassar Miller. University of Texas Press.

NPSA OFFERS HELP FOR THOSE MAKING SOCIAL SECURITY DISABILITY CLAIMS

Getting Social Security Disability is a difficult and timeconsuming process for most handicapped persons.

NPSA has written several pages of suggestions that should be helpful for anyone contemplating getting into the battle.

The guidelines will be helpful for your doctor, also, and emphasize the changes made by Social Security to include Post-Polio Syndrome in their manual.

You may have your free copy by writing NPSA and specifying what it is you want.

LINCOLN GROUP TO VIEW DEMONSTRATION

NPSA Lincoln Area Representative Arleen Curtis will welcome a physical therapist to the Lincoln Area Support Group Meeting on June 11.

Range of motion exercises will be demonstrated and discussed.

Come to American Lutheran Church, 42nd and Vine at 2 p.m. We need you there!

NOTICE

NPSA's Board of Directors will meet Sunday, June 4, 1989, at 3:30 p.m. at the IBM building, 450 Regency Parkway.

COOKBOOK ORDER FORM

My absolute favorite recipe in your cookbook is Judy Kellerman's CORN CASSEROLE (page 41). I have served it for company several times, and everyone loves it.

Ann Mosser

Virginia Walker's CHOP SUEY CASSEROLE (page 54) is perfectly delicious and so easy to prepare. It's going onto my long-time favorite list.

Eleanor Baldwin

I especially like the recipe for OVERNIGHT COFFEE CAKE (page 109) by Gloria Kass. It is so easy because you mix it the night before and pop it in the oven the next morning. It is great for brunch.

Georgia Whiteaker

RUNZA CASSEROLE (page 55) by Denise

Spale is wonderful and so easy to fix on a busy day. You can't go wrong with this one.

Judy Kellerman

Sue Mackiewicz' OVEN STEW (page 22) can go into the oven before I leave for shopping, and be ready to eat when I get home. A terrific idea.

Pat Edney

There's nothing better than Bill Carter's CRAB RANGOON (page 2). It's easy to fix and is sooooo good. Most impressive.

Marlene Orton

Deborah Tiffny's CARAMEL BROWNIES (page 122) are a special treat. They're the thing when you need to take goodies to a gathering.

Bill Carter

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ENERGY SAVERS FROM A POLIO SURVIVOR

by Vera L. DeBuhr Lincoln, NE.

Here are some tips that help me to save energy. I no longer make plans to do things that will be too taxing on the energy, and I tell people, when asked for a commitment, that I will be able to do so only when I get up that particular morning and see how I feel. I don't feel guilty anymore because I can't keep up with other people's energy. And I take one day at a time.

I no longer let people put guilt trips on me because I can't or don't feel up to doing something they want me to do. Just because my disability isn't showing on the outside, is no reason that I don't feel it on the inside.

I call a store ahead of time when I am going to do some shopping, to see that the things that I need are in stock. I don't waste energy this way.

Also, I ask the managers of the stores to see about a motorized cart for use in their stores.

One particular store had only one handicap parking space. I went to the manager and said, "If you value my business, you will get more handicap parking spaces for us." They did.

Remember that word from the Mickey Mouse Club?

STICK-TO-IT-EVNOUS

by LeEdda Hinsley Omaha, NE

Back when our THIRTY SOMETHINGERS were sitting cross-legged three feet from the TV? It sounded like a good idea then. Don't give up. You can do it.

Now, us FIFTY SOME-THINGERS are having to change our thinking. Relax our mind-lock, so to speak. Because for us, it just ain't so.

For years it was like THE LITTLE ENGINE THAT COULD. "I can do it."

We have to learn we can't do it. It is not an easy lesson. We go kicking and screaming off into the recesses of our minds in protest. What we could do just a few years ago, or just a few weeks or even days ago, we have found that now we can't. We have found the limits of what we could do are constantly shrinking.

Yet, we can't stop entirely and give up. Life isn't that easy. As long as there is a breath of life, we have to keep trying to maintain what we have without losing it. Maybe that's where the challenge lies.

We must learn to appreciate what we can do and give thanks. I guess our motto should be accept and adjust. I get great comfort from this Bible passage: Psalm 118-124. "Rejoice and be glad, for this is the day the Lord has made." Each day is a gift and should be lived as such.

HASTINGS GROUP LOOKS AT WEIGHT CONTROL

Judy Bradford, Hastings Area Representative, invites everyone to the June 11 NPSA Hastings Area Support Group Meeting at The Kensington at 2 p.m.

Nancy Breunig, Dietitian at Hastings Regional Center, will talk about weight control. A low-calorie surprise will be served.

Bring the family and have a good time!

COOKOUT ON AGENDA FOR HOLDREGE GROUP

NPSA's Holdrege Area Support Group will be treated to a cookout at the home of Holdrege Area Representative Delores Bray on June 3 at 6 p.m.

Delores reports that her group is still selling cookbooks. Way to go!

FDR AND ME

I never before realized how much Franklin Delano Roosevelt did for me. Oh, I knew he was an inspiration, and his "The only thing we have to fear is fear itself" has stuck with me in various crises, but I didn't know about his role in the treatment of polio until I read Hugh Gallagher's FDR's SPLENDID DECEPTION (Dodd, Mead Co.).

In October of 1924, seeking help for his own paralysis, FDR ventured to Warm Springs, GA, where he had heard that the naturally 89 degree water had a therapeutic effect. He adored the place instantly, swimming for hours in the morning, sunning and cruising the gorgeous countryside later in the day.

Through a newspaper article, word spread of Roosevelt's attempt to "swim to health," and soon others stricken with polio arrived on the scene.

NOTICE NOTICE NOTICE

A. L. Lorenzo, M.D., of the VA Medical Center's Rehabilitation Service, will speak at 2 p.m. June 4 at NPSA's Omaha Area Support Group Meeting. The talk will focus on evaluation of post-polio problems. Bring your questions.

Come on out for an afternoon of fellowship and information.

became "Doctor Roosevelt," devising exercises and treatment procedures for his "patients," even inventing an underwater therapy table still seen today.

He loved the companionship, the joy of the place. It was "a world of sunlight and warm water, laughter, encouragement, and hope." FDR had the insight to realize the need for creating "a rehabilitation center in which the psychological and social aspects of being handicapped were acknowledged to be fully as important as the medical treatment."

Using two-thirds of his fortune, FDR bought the former resort of Warm Springs and personally developed it into a haven for those with polio, building ramps, walkways, cottages, exercise courts, and working out a plan for future growth. FDR wanted polio treatment to be affordable for everyone needing it in this country. He wanted to spread the knowledge gained at Warm Springs so that trained hospital workers all over the USA could provide the best therapy. He wanted to establish research programs.

In order to do these things he founded the National Foundation for Infantile Paralysis, then backed the creation of the March of Dimes as a national neighborhood project to raise money for that Foundation. His efforts made polio a household name.

I can see that my own recovery and perhaps much of my attitude toward my limitations was largely due to FDR's creative enthusiasm and understanding. We need such a force today.

nbc

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

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