

THE OFFICIAL NUMBER ONE NEBRASKA POST-POLIO NEWSLETTER

JANUARY

1988

CARTER TO MEET WITH POLIO SURVIVORS IN NORTH PLATTE & SCOTTSBLUFF

Polio survivors in western Nebraska are invited to meet with NPSA's director, Nancy Carter, to discuss what's happening in post-polio today and to learn more about this organization.

She will speak in the Platte Room at Great Plains Regional Center in North Platte at 2 p.m., Sunday, January 24.

On Tuesday, January 26, Nancy will speak in the Scottsbluff Room at West Nebraska General Hospital at 7 p.m.

Coffee and goodies will be on hand, and there will be plenty of time to ask questions and chat with Nancy and the others present. Please make plans to come and bring your family and friends!

HELP FOR FATIGUE

Get a handicap parking permit and reduce unnecessary output--don't spend all of your energy in the parking lot!

NEW DISABILITY INFORMATION AVAILABLE TO NPSA MEMBERS

The December Omaha Area NPSA Support Group was treated to an informative discussion regarding disability claims by a man who knows--Jim Faulkenberry, Social Security Disability Examiner.

If you have worked 20 out of the past 40 quarters and paid into the system at that time, says Jim, you are entitled to disability benefits if you meet the "requirements".

Jim pointed out the importance of your doctor's giving specific, detailed evidence to support the claim that you are unable to engage in significant gainful activity due to a medically determinable impairment.

It is not enough for your doctor to say, in his response to the Social Security query, that you are disabled and unable to work. He must substantiate this with facts from your record.

Recent changes in Social Security's Program Operations Manual System reflect an awareness of the problems now being encountered by polio surviviors, including such factors as fatigue, weakness, pain, and cold intolerance.

Those of you considering filing for disability payments may find it helpful to call or write NPSA for information. We can help you understand specifically what your doctor needs to do in your behalf, and will send copies of material that will show your doctor exactly what the government wants. See our address and phone number on page 4.



CERTAIN SURVIVORS WARNED NOT TO USE NARCOTIC ANTIDIARRHEAL MEDICINE

An article in the POLIO NET-WORK NEWS, published by our St. Louis affiliate GINI, warns against the use of anti-diarrheal medicines containing narcotics if you are a person with paralysis of the trunk muscles or diaphragm.

Pulmonologists and respiratory therapists express their concern that these medicines may decrease the respiratory drive, especially in debilitated people who may be more sensitive to respiratory depressant effects and those who may also have less body mass, thus causing them to have a stronger adverse reaction to the medicine.

Susan Sortor, RRT, Dallas Rehabilitation Institute, urges those with disabilities to read the labels carefully on anti-diarrheal medicines that often contain narcotics, such as Lomotil, paregorics, etc.

St. Louis' Oscar Schwartz, M.D., at St. Mary's Health Center, advises travelers to take along Pepto Bismol or Kaopectate. If the diarrhea lasts longer than 48 hours, one should see a physician due to the risk of dehydration.

CHRISTMAS CELEBRATED BY NPSA SUPPORT GROUPS

Santa was kept busy by NPSA this year as two of our area support groups held Christmas parties.

Both Kathy Hendrickson, Grand Island Area Representative, and Delores Bray, Holdrege Area Representative, report that, though they may not have had any chestnuts roasting on an open fire, their groups had plenty of other goodies and some wonderful fellowship at their holiday galas.

They send warm wishes for a Happy New Year to their brothers and sisters in NPSA throughout the state.

HAPPY HOLIDAYS

POLIO TAPES TO BE SEEN AT THREE JANUARY MEETINGS

Three NPSA area support groups have scheduled viewing our tapes from this summer's International Polio Conference in St. Louis.

PAIN will be seen at the Holdrege area meeting on January 2; the Norfolk area group will see PAIN on January 10; and the Chadron area group will show FATIGUE on January 17.

These are excellent tapes, full of helpful information for polio survivors. Take your family and friends to see them, too!

STAYING HEALTHY WITH PPS

by Marie Galda, NPSA Omaha member

The confusion in the mind of the health professional first facing the growing prevalence of post-poliomyelitis syndrome is exceeded only by the confusion in the mind of the polio survivor when he first faces his growing symptoms.

We must do our best to help our doctors to weed out complaints stemming from other causes. And we must try to follow the dictates of general good health to keep ourselves in the best possible physical condition.

To do this, follow scrupulously every health and hygiene rule you have ever heard or read of. Be a health nut, limited only by common sense. (CAUTION: not a health-FOOD nut, nor an exercise nut.) Then when you approach the best you can be, you can tell others what post-polio syndrome is. Note that this will be achieved not in days or weeks, but in a lifetime of conscious endeavor.

We can make the job of those puzzling over this new phenomenon of PPS much easier if we approach health professionals and researchers as people glowing with good physical and mental health, but troubled with unexplained loss of stamina and endurance, rather than as confused complainers. And we will be a lot more comfortable, too.

LEARNING TO LIVE WITH POST-POLIO by Carol Barre Montpelier, Vermont

I read in post-polio support group newsletters from various states, "you've got to adjust to doing less, or finding ways to do things with less strain". My gut twists. So far I'm not in that boat. but I COULD be. If, as it seems, we have so much in common, then it looks to me as though the "typical" overachiever polio survivor will resist this advice with a passion. Even when it comes from another polio survivor. it brings up all my welllearned defenses: "That's giving in." "But I'm different." "If I can't, I must."

My suspicion is that for many writers of the advice, those defenses may still be operative--these adjustments are seen as a necessary evil, an unavoidable compromise with pain or future disability. The recommended adjustments seem to come from an internal place of anger-fear-resignation.

That is not what I want. Furthermore, I don't think it will "sell".

What I want is to LEARN something from these new aspects of our dis-ease. If the first round with polio taught me stick-to-itiveness and courage, maybe the lessons now are about grace, about allowing others to love and support me, about letting go of fear. Maybe the

lessons are about appreciating and loving this body which has been serving me so well at such great cost with so little reward.

Is there anybody else out there for whom "service to others" was a major prop for the façade that proved to me that I didn't need any help myself (Thank you anyway)? When someone offers to lend a hand does it stimulate anger rather than warm appreciation? These last few years I've been learning that GIVING service without ACCEPTING service creates burnout. I realized it was a subtle way for me to put down others as "needy".

Is there anybody else out there who is discovering that "putting the past behind you" DIDN'T WORK? I've been learning recently that there are ways to go back and heal the past. The baggage I've been carrying all these years is HEAVY, damn it! and it's OLD! and I've decided to let some of it go. But first, it seems, I have to be willing to SEE WHAT IT IS that's been weighing me down. Sometimes that's scary. But in the process I've also been learning I'm a lot more like everybody else than I would have believed three or four years ago. Maybe I'm learning it's O.K. to be a little less "Special".

It's sure a lot less lonely.

HOLDREGE GROUP ADDS TO NPSA STATE COFFERS AGAIN

One more time, NPSA's trusty Holdrege Area Support Group has come through with a \$50 donation from their on-going aluminum can fundraiser.

Many thanks for a job well-done!

GI TV FEATURES NPSA

NEW COOKBOOK PRO-VIDES EASY RECIPES FOR THE LIMITED

From the APPA NEWS, the Atlanta Post Polio Association's newsletter, edited by our friend Webster Cash, we learn of an interesting new cookbook by Patricia Galbreath, nationally-syndicated columnist.

It's called TIPTOEING THROUGH THE KITCHEN, and is designed to meet the needs of individuals who are limited by low energy levels, use of a wheelchair or walker, arthritis, or limited use of hands.

To order send \$10.95 (which includes postage and handling costs) to Sunshine Publishing Co., P.O. Box 470261, Ft. Worth, TX 76147.

Thanks for the tip, Web!

A CHRISTMAS CAROL

Fa la la la la ... Just makes you want to sing, doesn't it. The holiday season. No doubt about it. There's excitement in the airan expectant atmosphere, like something wonderful, delightful is about to happen, and we will all love each other and be merry until it does. And so, of course, it does.

Time was when the Carters decorated the house for days, transforming the entire place into a delicate Christmas fantasy. The cooking started in mid-November with hand-dipped English toffees, and didn't stop until the last guest, belching delicately, waved farewell on New Year's Day.

Even then it was exhausting. Now it is impossible.

NOTICE NOTICE NOTICE CHANGE CHANGE

In an effort to avoid having a meeting over the New Year's Holiday weekend, our Omaha January meeting will be changed to Sunday, January 10 at 2 p.m.

Dick Bennett, recently named Outstanding Handicapped Federal Employee of the Year, will talk with us about MAKING THE MOST OF WHAT WE HAVE.

It's sure to be a worthwhile afternoon--join us in the comfy chairs of FDR at 10825 Farnam in Old Mill South! See ya there!

But not to worry. There's more than one way to stuff a turkey!

In a flash of inspiration, Hubby and I invited over a young couple for their first holiday feast together.

Zealous does not begin to describe their enthusiasm. Terrific, they said. They would provide the turkey, they said. And the dressing, potatoes, gravy, veggies... Leave it to them. We were assigned only something yummy for dessert.

I had grave doubts. I envisioned their bustling in at noon, frozen bird in hand, expecting it to be ready for the tooth by three. Or if they did know enough to cook the thing, I secretly questioned their ability to provide a product that would not poison us all as they brought it, dripping with salmonella, to the table. Could I let go?

Could someone else actually do Christmas?

Meanwhile, the two dashed around putting the meal together. They couldn't wait--the bird went into the oven at midnight. Then they dozed off. Several hours later, fire trucks clanging and screaming into the neighborhood sent them rushing to the kitchen, certain their inattention had set the house on fire, reducing their prize gobbler to ashes. They emerged ecstatic. The blaze was down the street, and by now the turkey was, well-perfect.

And so was the day. Friendship, fun, good food. And I was able to enjoy myself without the fatigue that would force me to bed for two weeks, paying dearly for my pleasure. See what I mean about singing?

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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.

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