

THE OFFICIAL NUMBER ONE NEBRASKA POST-POLIO NEWSLETTER

AUGUST

1988

IMMANUEL TO HOLD POST-POLIO SPLASH CLASS

Immanuel Rehab Center announces its new Post-Polio Splash Class, to be held Tuesdays and Thursdays, August 23-September 23, 3 to 3:30 p.m.

Carol Smolsky, Aquatics Program Coordinator, explains that the class is for persons who can get in and out of the pool with minimal assistance, and who can stand on their own. "We hope to be able to increase flexibility and help decrease pain," says Carol.

See pg 5, col 1

HASTINGS GROUP TO HEAR MARLENE ORTON

Don't miss the excitement at the July 31 meeting of the Hastings Area Support Group!

Marlene Orton, NPSA Board member from Syracuse, will be there to talk about her experiences with the Late Effects of Polio and to answer questions.

Our new Hastings Area Representative, Judy Bradford, promises a lively afternoon of fellowship and information. Be at Room 1 (through the cafeteria) at Mary Lanning Hospital at 2 p.m.

PATSY ASKS FOR HELP--CASH OFFERED

Patsy Kravchuk, our dynamic Omaha Pleasure Pac chairman, is in full gear and charging ahead, reminding us that now is the best time to sell Pleasure Pac.

This fundraiser is NPSA's major source of cash for the year. This is what keeps GLEANINGS going and the information flowing. So we really need your help with this one in the Omaha and Lincoln areas.

By now you probably have been called and asked to do some selling for NPSA. Please do! How easy it would be if EVERYONE sold a few coupon books!

Ask your relatives, your neighbors, your friends. What about the folks you play, cards with, see at church or at work? Most people want to help NPSA once they hear about Post-Polio Syndrome and learn what we do. You can be a good PR person for NPSA and make sales at the same time!

Nobody loses with coupon books--everyone eats out or buys things at retail stores or attends cultural events. Why shouldn't they do these things cheaper, with coupon books purchased from NPSA?



PATSY KRAVCHUK

And if you make your sales NOW, ahead of everyone else, before the books come out on September 2, you'll have a clear shot at it! (And maybe even win our \$50 cash prize for the most books sold!)

So why not! Start selling today! Get a stack of promises for NPSA.

HELP FOR SURVIVORS

Tricyclic antidepressants taken at one-third to one-half the usual dosage have reduced pain for some polio survivors. Mestinon has reduced fatigue for some polio survivors. Avoid narcotics and tranquilizers. Ask your doctor.

RECIPE PLEA HUGE SUCCESS--COOKBOOK AT PRINTER

It was nip and tuck all the way. At first the recipes just dribbled in, one this day, another that. We knew we'd never get enough. And then during the last two weeks, whoosh--bulging envelopes flooded the mailbox. then we knew we'd never get them all processed in time. But we did. What a delicious response!

Our cookbook is plump with 550 recipes (our limit) from almost 350 people. You're going to love it--everything from Jamaican Pickapeppa Appetizer to Heavenly Hash. We even have a unique Breakfast/Brunch section that is sure to be unequaled.

And talk about contributors-we have recipes from members and friends from all over the USA and even Canada. Plus a few surprise contributors.

We received some really fine recipes that didn't get in the book--limitations, logistical problems, whatever. BUT, every person whose contributions got here by the June 30 deadline has at least one recipe in the book. And who knows--we may be looking at Son of Cookbook one of these days, and get to use a lot of those extras from this time.

What we ended up with is a super, finely tuned cookbook chock full of absolutely yummy stuff TO DIE FOR. We thank you all for your tremendous response. (Betcha I can guess what Santa's going to be stuffing into a lot of NPSA stockings come Christmas!)

More later!



NPSA MEMBERS TO RECEIVE DISCOUNT

Jeanne Richardson, longtime NPSA booster, has opened Arts and Flowers, a shop full of fresh and silk flowers. green plants, paintings, and other fascinations. It's at 7400 Main in Ralston, 556-9970, inside The Olde Grainery

Mall.

Using her influence to have a ramp installed, Jeanne has made the place wheelchair accessible so that she can offer all of her NPSA friends a permanent 15% discount.

Right on, Jeanne!

LINCOLN NOTICE

NPSA's Lincoln Area Support Group will not meet in August. Watch for notice of a terrific lineup on September 11, a new meeting day.

FROM OUR PLACE TO YOURS

It takes only a few people doing a lot of work to bring you this monthly newsletter. Some of you have expressed an interest in the process. Here's how it works:

Nancy Carter writes the articles (except those with a byline), types them into the computer, prints them out, cuts and pastes them into the desired format, and sends this on to Chip Mackenzie.

Chip transfers the items from IBM to MacIntosh. where he works them into the format and prepares them for the laser printer. He's also in charge of labels.

The newsletter then goes from laser to offset and is picked up by Lyle and Virginia Walker who label and bundle them according to strict government regulations. Lyle then travels to the one P. O. accepting this mail, weighs and pays, and GLEANINGS is headed toward your home.

It is entirely a labor of love, and we know from the great responses we receive that many of you appreciate it.

DR. PERRY TELLS IT LIKE IT IS

In an open letter for polio survivors, Jacquelin Perry, M.D., of Rancho Los Amigos Medical Center in California, explains that the problem so many of us are having now is a result of muscle fibers being destroyed when we had polio, leaving the remaining musculature to function at a higher demand than normal. "As a result, "says Dr. Perry, "the muscles are wearing out earlier."

She explains that post-polio "normal" strength is really 25-40% less than true normal, and that although this is enough for us to be able to carry on in a normal fashion, the demand on our bodies is 2 to 2 1/2 times usual intensity. In time we exceed the "buffer zone" that allows us to accept strain for a considerable period without showing loss, and then the loss is very prominent.

"The answer," says Dr. Perry, "is redesigning your lifestyle to avoid those tasks that cause the symptoms of persistent fatigue, muscle soreness, and/or a sense of weakness after use."

Survivors are cautioned not to take on any exercises until we have worked out a lifestyle that avoids strain. Only then should we attempt those of short duration (5 repetitions) or moderate intensity (50-75% of your own capacity). Then if these exercises cause any pain, persistent fatigue, or increased weakness, STOP.

"This means that just the mechanics of living are suffi-



DR. PERRY

your muscles," says Dr. Perry. Most of us were able to resume very active and profitable lives after we had polio. "Now it is necessary to recognize that excessive

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strain was being experienced," explains Dr. Perry, "and that lifestyles must be changed to accommodate this situation."

NPSA MEMBER HELPS GET PARKING FOR HANDICAPPED

Let's get out the banners for Delores Bray! Word comes to us that this NPSA Holdrege Area Representative provided input to the Holdrege Chamber of Commerce and the City Council that has resulted in gaining up to 11 handicap parking stalls in Holdrege.

This means that downtown Holdrege, the library, and the City Auditorium will all be better able to serve those in wheelchairs. A most worthwhile accomplishment.

'Tisn't life that matters!

Tis the courage you bring to it.

Hugh Walpole

NEWS FROM GRAND ISLAND

by Lorraine Harders NPSA G. I. member

The Grand Island Area NPSA Support Group met on June 26. Eileen Harms from Classy Chassis spoke about Professional Toning System tables. Barb Warford demonstrated her "Little Rascal."

The group meets the fourth Sunday of each month at 2 p.m. in the O'Brien Conference Room at St. Francis Medical Center.

CURTIS NAMED LINCOLN CO-REPRESENTATIVE

Arleen Curtis, Lincoln NPSA member, has been named Co-Representative of the Lincoln Area Support Group. Peggy Moe, who has served as Representative for some time, says, "Arleen has been doing so much of the work hereshe really ought to get credit for it."

So, hats off to Arleen--NPSA needs more go-getters like her to help us in our mission of serving polio survivors.

LATE EFFECTS CLASSIFICATION NUMBER REVEALED

We have received several requests for the International Classification of Diseases number for the Late Effects of Polio. The number is 138. You will want to discuss with your doctor the pros and cons of using this designation.

LINCOLN MEMBER VISITS SPALDING REHAB CENTER

by Arleen Curtis Lincoln NPSA member

Lincoln member Vera DeBuhr reported on her experiences at Denver's Spalding Rehabilitation Center at the June Lincoln Area NPSA Support Group meeting. The diagnostic clinic for post-polio occurs once a month, usually the last weekend of the month, beginning on Thursday at 4 p.m. and ending Saturday afternoon. The cost of the clinic can vary from \$800 to \$1200, depending on the number of tests and activities judged necessary in each case. Housing costs are extra, but there are relatively inexpensive housing units nearby.

On Thursday, there was a slide presentation showing physiological aspects of the original polio and post-polio.

Staff members (doctor, dietitian, therapists, etc.) were introduced and presentations made. Vera reported an exhausting day on Friday, beginning with blood tests and an appointment with the doctor who did an EMG on her leg muscles only. Other participants had both leg and arm muscles tested. She visited with the dietitian, had a pulmonary function test, a physical therapy evaluation (at which time she was issued a cane and ordered to use it), an occupational therapy test where muscle strength was tested, and x-rays were taken of spine and legs.

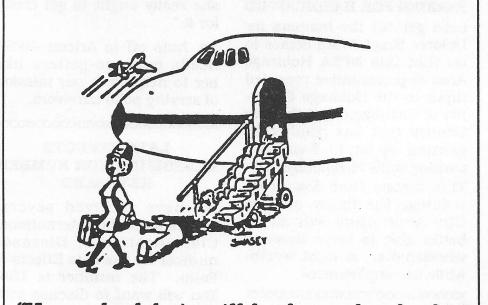
On Saturday, there was a presentation on stress management, followed by family counseling, since families need to understand and need

help dealing with our new problem.

Finally, the results of all the testing were reported, and Vera wasn't sure whether she should laugh or cry when the doctor assured her that she was NOT mentally unstable and did indeed have Post-Polio Syndrome. (Sixty percent of the patients seen at the clinic had been advised by their doctor that they were mentally ill!) returned to Lincoln with knowledge, advice, a set of light exercises to be done three times a week, and "peace of mind" (what a relief to know that she wasn't mentally unbalanced as her Lincoln doctor had reported in her medical file). Vera was advised to change doctors! NOTE: There are many polio clinics throughout the United States, five in Colorado alone. Contact NPSA for specifics.

GLEANINGS ARTICLES SOUGHT

We welcome your contributions and suggestions to GLEANINGS. Articles should be up to 2/3 of a typewritten page in length. Subject matter should be polio related, and personal stories or expressions of opinion are always enjoyed. The deadline for articles to GLEANINGS is the second Sunday of each month. We may have to edit any article to fit our format and space limitations.



"Your wheelchair will be down shortly, Sir"

Lifted with permission from Edmonton Post Polio Support Group Newsletter

SPLASH--from pg 1, col 1

The fabulous new pool at Immanuel sports a floor that can be raised to the level of the floor around it so that wheelchair patients in therapy situations can be rolled directly onto the floor of the pool. Then the floor is lowered to the depth of water needed for that patient's treatment.

Although the magic floor will probably not be in operation for the Splash Classes, the pool's water will be maintained at the 92-96 degree level recommended for post-polio swimming.

A doctor's prescription and release form are necessary for registration for the \$50 course, and you must take your own suit and towel. Classes will be led by a physical therapist. For more information, call Carol at 572-2288.

Because of ease of movement in the water, swimming is the one universally recommended type of exercise for polio survivors. Even so, we are cautioned that strengthening exercises of any kind may not be appropriate, and that high repetition/high resistance exercises can be quite harmful.

Remember Dr. Perry's rule of thumb: If your exercises cause any pain, persistent fatigue, or increased weakness, STOP.

KEARNEY MEMBER TO DISCUSS SISTER KENNY CLINIC

Holdrege Area Representative Delores Bray reports that Che Che Kolling, Kearney NPSA member, will speak at the Holdrege Area meeting on August 6.

Che Che will describe her recent trip to Sister Kenny Polio Clinic. You can get in on the information and fellowship at 2 p.m. at Phelps Memorial Health Center.

And for a report on their July meeting, ask the fourteen who had such a blast at the cookout!

WE HEAR FROM OUR MEMBERS

Keep up the good work. We enjoy every bit of it. Here is a bit for expenses.

Ray Gregor Elgin, NE

I've been encouraged many times by GLEANINGS. Hindsight is always better than foresight, and I realize now I should have had more respect for my body throughout the years. A sense of humor is a must. Patience with people who are well and have no patience with us whatsoever is important also. It has taught me a lot about reaching out to others who are suffering from one thing or another. Keep up the good work, and may God richly bless you.

Jean Bose Broken Bow, NE

Enclosed us a check towards the publication of your monthly newsletter. Thank you so much for mailing GLEANINGS to me; it is an informative newsletter. Good luck to you and all fellow post-polios.

> Christa Atkins Ozark, MO

Enjoy your paper--keep up the good work for polio survivors.

R. E. Sabers
Salem, S. D.

Here's a small contribution--wish it could be more. Am looking forward to reading the cookbook.

Virginia Peters Valley, NE

IN THE GOOD OLD SUMMERTIME

What a lovely summer it has been! These months have always been a time to see relatives and old friends--getting together to reminisce and share our lives with each other once again.

But now something new has been added. NPSA allows me the opportunity to make new friends from all over the country--even Canada--and it's a joy!

A few folks dropped by recently from polio groups in Texas and Iowa. We got to know each other a little, compare notes, exchange experiences. I even got to drag out my soapbox in a plea for more organization, more unity among support groups, begging for each state to develop its own overall postpolio alliance.

NOTICE NOTICE NOTICE

Rita Johnson of Nebraska's Vocational Rehabilitation Service will give us an idea of how Rehab can help each of us at the August 7 meeting of NPSA's Omaha Area Support Group.

Come to the north side of the IBM Building at 450 Regency Parkway and park on the top level. We'll greet you at the door.

The meeting starts at 2 p.m. Come early. Chat with folks. Maybe have a cookie, something cool to drink. See you there!

It's a wonderful thing to be able to associate with people from all over and to feel that we're all friends, working together, pulling for the same goals. There's an exhilarating pitch to being pioneers, blazing the trail. And here we are, right in the midst of it. Ain't it grand!

P.S. to our Goofy-Words-People-

Use-To-Avoid-Saying-We're-Handicapped List: Get out your pencils, folks. Are you ready? Now we're the ABLE DISABLED. No foolin'.

This latest is reported to us by our friend John McKee in New Mexico who swears it's legit. And you thought you'd heard 'em all...

nbc

WANT TO GO ON A CRUISE?

After our fun Omaha Area Support Group Meeting on cruises, Jeanne Richardson, an Omaha member, is looking for other NPSA members who would like to get together for an exciting time aboard a luxury liner to SOME- WHERE. When? Where? How much? If the idea appeals to you, contact Jeanne and work out the details. Four people are already interested. It's 5078 So. 86th Parkway #3, Omaha, 68127, 331-4655.

NEBRASKA TICKETS AVAILABLE

Two tickets (one person in a wheelchair and one attendant) are still available for the September 4 Nebraska-Utah football game. Call Warren at 333-3894.

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

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