

THE OFFICIAL NUMBER ONE NEBRASKA POST-POLIO NEWSLETTER

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1989

POLIO UPDATE 89

NPSA POLIO CONFERENCE SLATED FOR APRIL 1

This is the most exciting announcement NPSA has ever made: The NPSA Polio Conference will be held on Saturday, April l.

Several of the world's leading researchers and clinicians will present a day of polio information, talking about the latest findings and answering your questions.

It's a star-studded line-up:

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CASHMAN VIDEO ON LINCOLN AGENDA

The NPSA Lincoln Area Support Group will meet Sunday, January 8 at 2:00 p.m. at the American Lutheran Church, 4200 Vine Street.

We will be view a videotape of a speech by Dr. Neil Cashman from the Montreal Neurological Institute. Dr. Cashman is one of the world's leading polio researchers and clinicians.

It was heartening to have over 20 people in attendance at the last two meetings. Come join us.

NEIL CASHMAN, M.D.— neurologist now at Montreal Neurological Institute, Montreal, Quebec, Canada

JACQUELIN PERRY, M.D.— Chief of Pathokinesiology Service (and USC Professor of Orthopaedics) at Rancho Los Amigos Medical Center, Downey, California

AGUSTA ALBA, M.D.— Pulmonary and swallowing specialist at Goldwater Memorial Hospital, New York City SYBIL KOHL, CSW-ACP, ACSW--Houston, Texas, specialist working with social/psychological aspects of living with a disability

This is a day you cannot afford to miss. Mark your calendars now, and plan to be at the Red Lion Inn in Omaha on April 1 for this outstanding conference.

And keep reading GLEANINGS—many details and a registration form will follow.

Les Teichroew, R.N., M.A., of Ottawa, Ontario, Canada, has called on NPSA to help distribute his copyrighted paper, "Post-Polio: A Critical Literature Review," to those interested in having a representative, informative study of what has been written about Post-Polio.

The 27-page review includes a brief history of polio and its treatment as well as the section on Post-Polio, with its sub-sections on terminology, causes, symptoms, functional consequences, treatment, and inci-

dence.

A 132-item reference bibliography follows the review. Doctors might find this very helpful.

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

TIME TO REST AND RENEW

by Marion Davis, M.D. Jones, OK

Control is something every postpolio person has worked very hard to achieve in various ways and to various degrees. First is the superhuman struggle to breathe independently on a respirator or rocking bed, or the massive effort to wiggle a big toe, or move a thumb a half inch. That is the start of taking control of one's life after Polio.

Next in the recovery of the control process may be renewed control of a paralyzed bladder or leaning to operate a brand new wheelchair after the big body sag gets a semblance of control. Another step may be putting on a back brace and long leg brace and attempting to control a pair of crutches that seem to have a mind of their own.

Later, come new driving techniques with hand controls and finding a job to bring about at least partial financial independence. Driving a car seems to represent the ultimate in control and freedom. Behind the wheel of a car, a disabled person feels a part of the world - with power beneath the hood, wheels that go far and sometimes fast, and control of the power steering like you wouldn't believe. That is control to its fullest. That is independence and 'being normal'.

Then, 30 or 40 years down the highway of life, come the late effects of polio - Post-Polio syndrome, Post-Polio muscular atrophy. Call it what you will, the changes that creep up on the Post-Polio body and mind bring

about alarming limitations, devastating discomfort, frightening dependency, and the hard-won control starts slipping.

A weakened leg may suddenly refuse to move from accelerator to brake. A fatigued arm reaches for a casserole in the oven and goes into space or totally balks at gripping the dish. Once agile fingers that could run a scale on a piano, type a letter or thread a needle with efficiency suddenly refuse to perform the fine movement of putting on an earring or tying a shoe. A formerly upright back that has supported the trunk so straight and proud for so many years gradually starts folding forward, and bringing about sagging bust and drooping head. Driving a car and loading a wheelchair become too much.

The hard-earned independence is slipping away. The eagerly sought control over life is moving beyond our grasp. This is not the end of the road although there are times when we may be convinced that it is. There is an answer.

A revision in lifestyle is the answer. The Polio survivor, whether experiencing mild or severe Post-Polio syndrome, must give himself permission to slow down, to accomplish a little less than the superhuman achievements of the past.

For the first time since the Polio virus short-circuited the anterior horn cells that send the messages to tell muscles to move, the Polio

See pg 5, col 3

STRESS

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by Peggy Moe NPSA Lincoln member

Stress-I guess it finally caught up with me. No matter how much I want the knot in my stomach, the tears and frazzled nerves to go away--it's still here. So I have to change what I can in my life to try to deal with it.

Being a Lincoln Area Representative for NPSA has been very rewarding, and I have learned a lot. But it is a lot of work and has become very stressful for me. I've been trying to do too much. So my physician and family have convinced me it is time for me to resign as co-representative, and to take a break from these responsibilities for awhile.

I have learned that just having a chronic illness causes stress because it strains your body, your mind, and your spirit. So just learning how to cope day by day is stressful. The stress you feel, chronic illness and pain all feed on one another. I needed to try to break this pattern.

It's difficult for me to admit I'm having problems because I can't handle stress. It makes me feel wimpy and out of control. But I know that it is so. It's the right thing for me to do for now.

INGENUITY, KINDNESS SELL MANY NPSA COOKBOOKS

NPSA is so lucky. We have some wonderful members and friends.

Take, for instance, Lucile Thomas of Hebron. Lucile decided she just wanted to do something nice for NPSA. So she placed an ad in the local paper, set up an NPSA Cookbook display in the window of Thomas' Jewelry, and put herself in the cookbook-selling business. Soon Elaine O'Neal began doing the same thing in her Hebron beauty shop, and before long the Thayer County Bank followed suit. Kindness is catching.

Omaha's Judy Kellerman took a box of books to her church's Christmas Bazaar to sell, and Sue Morfeld of Norfolk has been pushing the books for us at flea markets around the state.

Judy Bradford, Hastings Area Representative, had a neat idea. For the Hastings Area group's NPSA Cookbook and Bake Sale at Imperial Mall, she gift wrapped a number of our books and displayed them with a sign reading "Gift Wrapped for Your Special Cook." Terrific.

In Metairie, Louisiana, Fern Brownsberger took a number of books to sell to her polio group members there. Ima Jean Davison and Jean Slagle of Ogallala hung a flyer at work and sold NPSA Cookbooks for us.

Chadron Area Representative Sheryl Marchant has had wonderful success selling the books to residents of nursing homes for gifts to their families and friends.

The Editor of the Polio Survivors Newsletter of the Pacific Northwest in Seattle and Joan Headley of the International Polio Network in St. Louis both volunteered to mention our Cookbook in their publications.

The stories go on and onwe cannot begin to tell you about all of the great

things people are doing in our behalf. We are truly blessed.

If you want a Cookbook or want to help us sell them, you can still order from NPSA. The books are \$7 each, with a USA mailing fee of \$2.50 for l to 5 books and \$3.75 for 6 to l0 books. We will bill the mailing fee separately in shipments outside the USA.



Lucile Thomas

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CONTRIBUTIONS

We thank the following people who have sent cash contributions to NPSA.

BUILDERS--Individuals who contibuted \$100 to \$500 JO ANN LEHNHOFF, Omaha, NE

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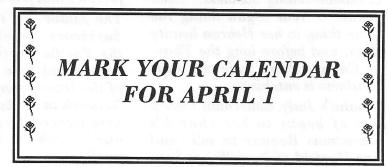
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We thank those of you who have also sent contributions with your cookbook purchases.

MEMORIALS

In Loving Memory of Wiley Mitchell

From Marie Mitchell Hebron, NE



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CHADRON GROUP TO VIEW VIDEO

The NPSA Chadron Area Support Group will meet Sunday, January 15th at 2 p.m. at 529 Beech St., Chadron.

Area Representative Sheryl Marchant reports they will be viewing a videotape of a speech by Dr. Neil Cashman from the Montreal Neurological Institute. Dr. Cashman is one of the world's leading polio researchers and clinicians.

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HASTINGS GROUP TO HEAR SPEAKER

Pat Ohmstead of Landmark Toning and Tanning will we speaking to the NPSA Hastings Area Support Group at their January meeting.

The meeting will be on January 8th at 2 p.m. in the Community Room in the Imperial Mall, Hastings.

KNOW THE SIGNS OF RESPIRATORY INFEC-TION

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The Delaware Valley Polio Survivors Newsletter names the early symptoms of respiratory infection, stressing the importance of taking action to prevent a cold from turning into pneumonia:

Increased temperature Cough (productive or not) Sputum (changes in color, quantity, or thickness)

Shortness of breath

Fatigue

Changes in breathing patterns Blue tint of nails and lips

Chest tightness

Pain on deep inspiration

Sore throat

Runny nose

Earache

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INFORMATION NUMBER

If you are interested in knowing more about how Social Security works for you, call toll free l-800-937-2000. They will send you a form so that you can learn about your earnings benefits and get an estimate of how much you would receive if you were to get disability payments or retire.

HOLDREGE GROUP TO HEAR DR. CASHMAN

Delores Bray, NPSA Holdrege Area Representive, says the NPSA Chadron Area Support Group will be viewing a videotape of a speech by Dr. Neil Cashman from the Montreal Neurological Institute.

They will meet Saturday, January 7th at 2:30 p.m. at the Phelps Memorial Health Center in Holdrege.

TIME SOMEBODY TOLD ME

Time somebody told me
That I am lovely, good and real
That my beauty could make hearts stand still.

Time somebody told me
That my love is total and so complete
That my mind is quick and full of wit
That my lovin' is just too good to quit.

It's time somebody told me
How much they want, love, and need me
How my spirit helps set them free
How my eyes shine full of white light
How good it feels to hold me tight.

Time somebody told me.

So I had a talk with just me...nobody else... 'Cause it was time somebody told me.

Submitted by Judy Bradford Hastings NPSA member TIME—from pg 2, col 2

survivor must learn to rest more. She can no longer push beyond the point of fatigue. He can no longer exercise past the point of pain. They can no longer work at two jobs, raise a family and volunteer for a dozen jobs in that many organizations.

It is time to rest and renew. Overworked muscles must be protected from strain. Jangled nerves must be allowed to restore themselves. Frazzled minds must stop pushing to remember and ragged emotions must have a chance to collect themselves. Both must be set on crusamatic for a while.

Only then will restoration take place. Then we will be back in control of our lives once again.

NPSA OFFERS VIDEOS FOR COST OF MAILING

Learn more about the Late Effects of Polio. Hear what leading polio doctors have to say about your polio problems. Borrow NPSA's VHS videos from the Fourth International Polio Conference (1987).

This offer is for Nebraska residents only at this time. Send your name, address, and phone number along with the title of the tape you want to view (one at a time, please). Enclose a check made out to NPSA for \$2.65 to cover the cost of Priority Mailing the tape to you. You must return the tape by Priority Mail within seven days—on time and undamaged.

These are the titles: l. Muscle Weakness

- 2. Fatigue
- 3. Pain
- 4. Sleep, Breathing, and Swallowing
- 5. Exercise/Weight Control
- 6. Bracing, Mobility, and Seating
- 7. Psychology of Disability
- 8. Coping With Stress

We will also loan a tape of the Bernie Siegel, M.D., author of the bestseller LOVE, MEDICINE, AND MIRACLES, entitled AN EVENING WITH DR. BERNIE SIEGEL. The same guidelines apply for borrowing all tapes.

BUCK AND WING-ING IT

Sounds idyllic, doesn't it-early retirement; hours, days, months spent at my leisure, lounging around with a book in one hand and a soda in the other.

No hacking through ice and snow on darkened winter mornings to get to work on time. No pressure to meet daily deadlines. No tangled traffic, no impossible bosses.

Ah--but also no paycheck. It's not the loss of income that bothers me so much, though goodness knows that's a major adjustment in itself. It's the way I feel not being ABLE to earn a living that is hard to deal with.

Apparently along the way I learned that personal worth is measured in dollars. In order to BE SOMEBODY, I had to be paid for what I did. "That good-fornothing hasn't had a job in months." "Of course he knows what he's talking about, he earns six figures." Credibility, validity

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NOTICE NOTICE NOTICE CHANGE CHANGE CHANGE

Jane Smith, a Clarkson Hospital nurse, will give a slide presentation regarding PAIN AND HUMOR at the January meeting of NPSA's Omaha Area Support Group.

Since our regular meeting date falls on New Year's Day, we have rescheduled for January 8. Be there at 2 p.m.--IBM Building, 450 Regency Parkway (use the North door).

See you then for much information, fun, and fellowship!

as human beings are somehow transmitted through earning power.

I always tried to be the best. Sometimes people asked me to work for them, and when they did that, I held all the cards. I could dictate the terms. Here's what I'm worth to you. ...what I am worth.

Then one day I could no longer continue physically in my profession; I had to find a sedentary job. Yet it meant a paycheck. Somebody still thought I was worth something.

But for the past four years I have known that I could no longer do what it takes to hold a job. Occasionally my head would try to kid me into believing that if I did this-or that-my body would miraculously rev itself into action again and I'd be back in business.

But in my heart I knew it wasn't true. And after a brief period of trying one more time to reclaim what I used to have, who I used to be, I'd sink back to the realization that it wasn't working--and neither was I.

I've had to face the fact that this is it. I am who I am today. Yesterday is gone. And TODAY I'm o.k. with that. But, oh, there are times when I'd sure like to be out there under the lights tapdancing.

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