

THE OFFICIAL NUMBER ONE NEBRASKA POST-POLIO NEWSLETTER

1988

POLIO WORKSHOP JUNE 3-5 IN ST. LOUIS

Once again, the Gazette International Networking Institute and the International Polio Network will sponsor the Support Group Leaders Workshop in St. Louis.

Mark your calendars for June 3-5, and meet hundreds of other polio survivors at the Sheraton St. Louis for three days of inspiration and information.

Everyone is invited, so double up with a friend to cut expenses, and learn what's happening on the cutting edge of polio groups throughout the USA.

If you can go, write GINI, 4502 Maryland Avenue, St. Louis, MO 63108 for details.

PATIENTS' RIGHTS ENCOURAGE ASKING OF MANY QUESTIONS

Often some of us have found ourselves intimidated by doctors and others in the medical community. Many of us were brought up to believe that physicians are GOD,

See pg 2, col 3

Jerry Ciocon, M.D., of the University of Nebraska Medical Center's Section of Geriatrics and Gerontology, is asking for NPSA's assistance.

If you are age 60 or older, you can help him get the information he needs in order to discover whether post-polio is a significant problem among persons in that age bracket. If it is, a program will be developed to work with polio survivors in UNMC's new rehabilitation center.

"Expansion at UNMC will see a rehabilitation center in the building now housing NPI," says Ciocon. "We may be in

RAMSEY SPEAKS IN GRAND ISLAND

Grand Island Area Publicity Chairman, Lorraine Harders, announces that Norma Ramsey of Kearney will speak at their February 28 meeting concerning handicap accommodations. Norma has done an outstanding job of emphasizing the necessity for improving accessibility in Nebraska.

You'll want to hear her. Be there at 2 p.m. at the St. Francis Medical Center.

operation by the end of this year.

"We will be responding to the needs of the people we work with in Geriatrics, who are older adults. We would like to know if a major emphasis should be placed on postpolio treatment."

Ciocon has developed a questionnaire for NPSA members over 60 that is printed on page 5. You can help by completing the form and mailing it back to NPSA today--just tear it off, fold it and tape it shut, place a 22-cent stamp on the front, and drop it in your mailbox.



DR. JERRY CIOCON

PUT ON A HAPPY FACE

by Stanley Baldwin Hebron NPSA member

My sister, Nancy Carter, is the editor of this newsletter. In one short month nearly 40 years ago, she and my two brothers and I all got polio. In fact, I shared a room with Nancy for a while. One brother and I walked away with no visible damage. The other brother wore a brace for a year or two, but he later played college football and limps so slightly that you wouldn't notice. Nancy got her head kicked off.

In recent years, she has suffered increasingly from Post-Polio Syndrome. The last three months have been especially treacherous. An acquaintance suggested that I write her a little note to "cheer her up." The outsider meant well. But I'm not real strong on "cheering up" Nancy. It seems to me that people who want to put a happy face on pain are more concerned about their own comfort than they are about my sister. I want her to know that I care even if I can't fully understand and that she doesn't have to put on any jolly show for me. Oh, I'll make a bad joke now and then. She will too. Some even say that each of us has "a good sense of humor." But when it hurts, please, no smile faces.

I'm not real big on "courage" either. When Nancy was a kid, people loved to talk about how "brave" and "spunky" she was. Baloney.

Courage involves some kind of choice, and polio isn't that sporting. Sure, Nancy has her share of guts and more. But that's not what it's about. It's about not asking someone in pain to be a plucky little trouper just so others can feel comfortable. I want my sister to know that I grew to love her a whole lot for being exactly who she really is.

ON THE FLIP SIDE

by Erma Ocker Hastings NPSA member

We've heard so much about what has happened to the people with Post-Polio Syndrome. We've heard about the many problems they have encountered. But...there must be many of us who have not yet had them.

The GLEANINGS has really helped to teach us how to care for ourselves. It says to slow down and to rest when you are tired. But most of all, we need to have a positive attitude. Do not become depressed by the information! Most of us will get along just fine.

I had Bulbar polio when I was 15 years old. I have a partially paralyzed throat. It is very quick to tell me when to "take it easy."

It is very interesting to read how others are getting along. Here's hoping you are doing well also. RIGHTS from pg 1, col 1

and one doesn't question God. It sometimes seemed that we didn't count.

Luckily, things have changed. Now we know that we MUST ask questions. We are encouraged to be informed and to participate in our medical care in order to help avoid mistakes.

The Federation of Nurses and Health Professionals offers a free pamphlet on Patients' Rights that may be of much help to you. Here are some of its points:

- l. You have the right to consent to any medical treatment--you can refuse any drug, test, procedure, or treatment.
- 2. You have the right to know the medical consequences (risks and benefits) of any treatment, drug, procedure, test.
- 3. You can check yourself out of a hospital regardless of your condition.
- 4. You must be informed if you are being used in a

research project.

- 5. You should always receive considerate and respectful care.
- 6. You can have your bill explained to you, no matter who pays it, and it should always be itemized.

For the entire pamphlet, which contains many other ideas, write to FNHP/AFL, P. O. Box 1930, Washington, D. C. 20013.

ENJOYING LIFE

by Armine Kuhlman Lead, SD, NPSA member

I was two years old when I had my baffling polio attack in western Kansas. My parents had homesteaded 22 miles north of Lakin. In those days of 1912, doctors were rare. My grandmother was the main "medicine man" and the midwife who officiated when most of my 31 first generation cousins were born. When my left arm and leg were not normal, my parents and various doctors were bewildered.

Hard work, plenty of exercise, good food were the CURE-ALL of those times. I fought daily to excel for many years at various situations since. There was no victory without pain and effort. I was lucky to keep up with the crew.

I taught grade school for eight years. I had as high as 25 pupils in my room. In the summer I went to school at Fort Hays State College. was encouraged to study more of the plant and animal worlds at University of Nebraska. My banker loaned me \$75 to start college. I had lots of part time jobs. When I received my MS in Agronomy and Botany, there were no college debts to pay in 1942. The good Lord guided me.

After 31 years of working in the USDA, I emptied my desk at the Newell Field Station in South Dakota. I wondered what to do in trying to enjoy my life of retirement. After my wife took me on a six week Canadian trip, there was no thought of work for me.

Since moving to Lead in the Black Hills in 1973, I've been busy each day. After my wife and I finished considerable remodeling and carpenter work with our hands, we enjoyed golf in the morning and trout fishing in the afternoon. We were eating fish four or five days each week.

In the past four years, PPS has been progressively taking over on the function of my arms and legs. I started using a cane, and now crutches are essential.

In May 1988, my legs and arms started losing strength when I lifted myself with crutches on any stairs. We installed two chairglides between two floors and the basement of our home. We like our home very much. We like the forested Black Hills.

In winter my crutches are equipped with "snow shoes." My wife pushes my wheelchair, which is kept in the car. We enjoy our many friends. We ENJOY LIFE.

Blessed is the man who, having nothing to say, abstains from giving us wordy evidence of the fact.

George Eliot

LINCOLN GROUP TO HEAR BAUSCH

Peggy Moe, NPSA Lincoln Area Representative, reports that Diane McEntee has planned a special meeting for February 27. Maureen Bausch, a music therapist, will demonstrate the role music can play in the development of our well-being.

Make the effort to be there--2 p.m., American Lutheran Church, 42nd and Vine. You'll be glad you did!

ACCESSIBLE HOME FOR SALE

Custom-built, fully accessible home. Huge rooms. Two fire places, one in master bedroom. Roll-in shower. Many other niceties. \$83,000. Call Sharon Madara, 334-5500 or 334-1460.

HOLDREGE GROUP TO VIEW TAPE

The March 5 meeting of the NPSA Holdrege Area Support Group will see the tape "Psychology of Disability." This is one of the tapes made at last summer's International Polio Conference in St. Louis, and is one you won't want to miss.

Area Representative Delores Bray urges you to be there at 2:30 p.m., Phelps Memorial Health Center.

CONTRIBUTIONS

We thank the people listed below who have responded to NPSA's appeal by sending a donation.

BUILDERS--Individuals who contributed \$100 to \$499

BILL HULA, Blue Rapids, KS

FRIENDS--Individuals who contributed up to \$99

BILLY AND JUNE ALLISON, Steilacoom, WA SALLY B. ANGUS, Onawa, IA DARLENE BREHM-SEXTON, Woodbine, KS D. T. DAVENPORT, Hebbronville, TX BILL DICKSON, Ellsworth, NE

How I do look forward to the GLEANINGS each month as there is ALWAYS something in it that really hits home!

Dolores King Lingle, WY

G. ROGER ELLEY, Hastings, NE D. T. DAVENPORT, Hebbronville, TX BILL DICKSON, Ellsworth, NE

Thanks for the February GLEANINGS. As usual, I found some good and needed information.

J. W. Meeks Germantown, TN

JUDITH A. HARRINGTON, Marion, IA PAT JOHNSTON, Thedford, NE DELORES R. KING, Lingle, WY LOIS KOERWITZ, Hebron, NE I am enclosing a small donation to NPSA. I learn a great deal from your newsletter. Thanks so much.

Judy Harrington Marion, IA

IMA E. LACY, Scottsbluff, NE ROBERT P. LUDACKA, Omaha, NE

The GLEANINGS just gets better with each issue. I'm so thankful for it--and to know I'm not in this alone.

Beverly Crosse Council Bluffs, IA

NAOMI J. McCAFFERTY, Whitney, NE MRS. RAYMOND McCAY, Clatonia, NE JIM McMANUS, Lincoln, NE J. W. MEEKS, Germantown, TN

Enclosed is a small donation to NPSA. Thanks for sending the GLEANINGS--it's well done and very much appreciated.

Shirley Wilcox Ellsworth, NE

KARL W. OTTE, Wayne, NE SHIRLEY J. ROEMMICH, Scottsbluff, NE SHIRLEY L. WILCOX, Ellsworth, NE

Just a note to tell you how much I enjoyed the GLEANINGS. Also enclosed is...a donation.

Darlene Sexton Woodbine, KS

EXCEPTIONAL BOOK SPEAKS TO EXCEPTIONAL PATIENTS AND THEIR M. D.'S

The blurb for the book LOVE, MEDICINE AND MIRACLES says "Miracles are happening to exceptional patients every day--patients who have the courage to work with their doctors to participate in and influence their own recovery. LOVE, MEDICINE AND MIRACLES shows you how."

It's true. The book by Yale University teacher Bernie Siegel, M. D., is packed with suggestions for all of us-those with major physical problems as well as those who simply want a more peaceful, happy life.

Although a cancer surgeon, Siegel discusses healing for everyone, with great emphasis on the role our minds play in disease and wellness. His ideas for becoming an "exceptional patient" are outstanding. And he talks directly to other doctors-some frank words that many need to hear.

We highly recommend the book. Buy one for your doctor, too, and make a lot of people happy. In paperback at your local bookstore.

ARE YOU OVER AGE 60?

If you are age 60 or over, please answer the following questions to help—the University of Nebraska Medical Center to know if post-polio is a prevalent and important problem among older adults. If it is, Geriatrics will include a program for polio survivors in their new rehabilitation center.

Please complete this form:

| Your age now Age at initial attack of polio |
|--|
| Initial involvement (paralysis when you first had polio) Please check 🗸 |
| left arm left leg trunk |
| right arm right leg neck/face |
| Were you in a breathing machine when you first had polio? Please check ✔ |
| YesNo |
| Residual involvement (paralysis left after initial improvement) Please check 🗸 |
| left arm left leg trunk |
| right arm right leg neck/face |
| Are you having new symptoms? (If so, please check ✔ which) |
| new muscle weakness Where? |
| muscle and/or joint pain Where? |
| easily fatigued respiratory problems |
| Other (describe) |
| How long have you had these new problems? |
| Do you still walk without assistance? Yes No |
| Do you need a cane/crutches to walk? Yes No |
| Do you use a wheelchair/cart? Yes No |
| Thank you for answering these questions. PLEASE MAIL THEM BACK TO US TODAY! Just tear off this sheet, fold it with the address on the other side. |

| | | |
|------|---|-------------------------|
| | | Place 22¢ stamp here |
| | | |
| То: | Nebraska Polio Survivors Association P.O. Box 37139 Omaha, Ne 68137 | |
| | | |
| | | |
| | fold here | |
| | | |
| | | |
| | | |

THANKS TO NPSA

by June Allison Steilacoom, WA, NPSA member

I was born and raised in Omaha and had polio at age eleven. I married an Air Force man and have been around the world since leaving Omaha in 1961.

Over the years I have experienced many things the doctors had no answers for. When stationed in hot climates, I had several heat strokes with severe headaches. I don't remember a lot about my polio, but I do remember starting out with a severe headache. I

still suffer today with severe headaches and the doctors still can't explain why.

I've had all kinds of muscle and swallowing problems over the years that the doctors couldn't find a cause for and would lead me to believe these problems existed in my head. Sometimes in discouragement I would wonder if they were right.

My sister lives in Omaha and usually I come to Omaha once a year. Last year's visit was truly a blessing for me.

My sister had visited a health fair, and knowing my health problems, she saw NPSA there and got information for me. While I was visiting her I was able to talk with Nancy Carter and also attended one of the meetings. I can't begin to tell you how wonderful it felt to know others were having problems like I was. It was such an encouragement to me. I am also grateful for the GLEANINGS, so full of wonderful information. THANKS!

希希希希 HAPPY ST. PATRICKS DAY 希希希希

MEMORIALS

IN LOVING MEMORY OF BOB NEWKIRK from Rita Ryan Omaha, NE

IN LOVING MEMORY OF
ROBERT M. TODD
from Carol, Polly, George & Diane
Harney Street Bingo

IN LOVING MEMORY OF ROBERT M. TODD from Marguerite Leonard Omaha, NE

IN LOVING MEMORY OF
ROBERT M. TODD
from Mr. & Mrs. Francis Conner
Omaha, NE

IN LOVING MEMORY OF
ROBERT M. TODD
from Mr. & Mrs. Carl Kellerman
Omaha, NE

IN LOVING MEMORY OF
ROBERT M. TODD
from Mr. & Mrs. Richard Bellino
Papillion, NE

IN LOVING MEMORY OF
ROBERT M. TODD
from Mr. & Mrs. Ray Donovan
Omaha, NE

IN LOVING MEMORY OF ROBERT M. TODD from Mr. & Mrs. Everett Pester

IN LOVING MEMORY OF
IRMA HENDERSON
from Esther & Woody Dillman

In the past month we've gotten a lot of mail from people frustrated by the lack of response, understanding, and informed polio treatment they receive from those in the medical profession.

Ah, yes.

The truth is, however, that a lot of this is at least partly our own fault.

Here's a little story to illustrate: One lady wrote that she has frightening "attacks." She hasn't mentioned them to her doctor. "He wouldn't believe me unless I had one right in front of him," she said, "and then he wouldn't know what to do about it. So I don't tell him."

See? The doctor doesn't know his patient's problem exists because she doesn't talk about it; therefore, he isn't even trying to understand or to find a solution. She isn't talking to him about it because past experience has conditioned her to believe that he doesn't under-

NOTICE NOTICE NOTICE

One of the common problems experienced by post polio survivors is chronic pain. The March 6th meeting of the NPSA Omaha area support group will feature a representative from the UNMC Pain Clinic who will discuss what they have to offer in learning to live with chronic pain.

Come to First Data Resources, 10825 Farnam in Old Mill South at 2 P.M. See ya there!

stand and has no solution.

This is a no-win situation.

The doctor can't give help and the patient can't get help.

We have to learn to be responsible for getting what we need from our doctors. We must realize that physicians are statistic/test oriented. That's what they learn in medical school. They don't comprehend being confronted with something for which they have no test, no pill, because they have been trained to believe that we WANT procedures, drugs, operations. They do not know that what we really want is for them to listen to us, to respond to us as human beings. We have to teach them to be people oriented.

We have to be bold. We have to take that chance and risk a turnoff by insisting that they pay attention to US, to what we say, to how we feel. We must let them know what is important to us.

Isn't it better to find out for sure whether a doctor will work with us before we waste any more time and money on one who won't? And we may be pleasantly surprised. We may discover that, with a little coaxing, our M. D. can be everything we always wanted in a doctor.

Sure there are bad apples. Leave 'em cold. It's simply adios, farewell, so long, and toodle-oo to these folks.

But let's do our part. Let's make our doctors know who we are and what we require from them. Who can say--we could change the face of medical practice to something very caring, compassionate, personal. And our physicians might be happy to learn that we don't expect them to perform magic after all.

nbc

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.

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

NON PROFIT ORG US POSTAGE PAID OMAHA, NE PERMIT NO 1575