

Gleanings

THE OFFICIAL NUMBER ONE NEBRASKA POST-POLIO NEWSLETTER

OCTOBER

1986

XXXXXXXXXXXXXXXXXXXXXXXXXXXX

XX

QUOTE OF THE MONTH:

NEBRASKA POLIO CLINIC A REAL POSSIBILITY SOON

"Each polio patient is different with a unique set of problems and must be evaluated in the light of his specific disability. The most important thing is for the medical profession to become aware that these people do not respond to the usual methods of treatment and require skill in interpreting their needs... The medical profession has been minimally concerned about fairness to these patients."

Ann A. Bailey, M.D.

"It would not be difficult to have a polio clinic," says Dr. Erich Streib, director of neuromuscular clinics at the Nebraska Medical Center in Omaha. "Mainly I need to find out if your people (NPSA members) are interested."

Dr. Streib said that he wanted to get into doing some polio research about a dozen years ago, but had no access to polio survivors. The late effects of polio is a topic that interests him, especially as related to ALS (Lou Gehrigs disease).

"We need to discuss the realistic aspects of this," he says. "We don't want people to be disappointed. A lot of people who had polio have complaints not related to the disease."

Dr. Streib intends to bring some equipment to demonstrate certain means of evaluation to the Oct. 5 Omaha area meeting. "I will talk a little bit about what polio does," he says, "but mainly I'd like to have an informal discussion with the members of the group. I want to
See pg. 2, col. 3

XXXXXXXXXXXXXXXXXXXXXXXXXXXX

STATE COORDINATOR TO GO TO ST. PAUL AREA MEETING

Nancy Carter, NPSA State Coordinator, will speak at the September 28 meeting of the St. Paul area support group being organized by Richard Hanisch, M.D.

The meeting will begin at 2 p.m. at the Howard County Hospital. Come on over!

XXXXXXXXXXXXXXXXXXXXXXXXXXXX

'TIS THE SEASON

Ask your doctor about flu and pneumonia shots.

XX

SALES STILL NEEDED IN HAPPENINGS FUND RAISER

The good news is that there is still time to buy a HAPPENINGS book at the October Omaha area support group meeting. The bad news is that individual sales by members will have to pick up considerably if we are to achieve our goal of selling 500 books this year. Since we sold 350 books last year, and with the additional 40 or 50 sales at the stores this year, 500 is certainly an a-

chievable goal if we each get out there and do our part! We can get an extra dollar for each book if we make our goal of 500! Please help! Also, bring your money from sales to the October meeting.

Alice Hauck, HAPPENINGS Fund-Raiser Chairman, reports that we sold 40 coupon books at Saturday's Bakers Store sales. Judy Kellerman,
See pg. 2, col. 3

XX

WILL THERE BE A CURB CUT?
by Marcia Bredar

For the past six months, I've been in "another world"--the World of Wheelchairs(WW). Severe pain in my shoulders and neck, plus surgery several months ago gave me no choice. I reluctantly gave up my crutches and braces for life in the WW-- not necessarily the fast lane.

I've had a wheelchair for over 20 years but used it mainly at home. Did my eyes get opened because of the experience! The extra planning that accompanied every trip or errand was really amazing, as well as frustrating.

Would there be a curb cut? Would there be handicapped parking? Would there be a steep grade to maneuver? Would the aisles and doorways be wide enough? And last, but certainly not the least, would the bathroom be accessible?

Although I expected the additional planning, I wasn't aware what sitting in a wheelchair all day would do to my psyche. Mainly it was the constant reminder that I was having additional health problems, was not feeling well, and there was no relief in sight.

As the weeks and months passed, I grew more comfortable with the WW, almost to the point where it didn't bother me anymore, or so I thought. It wasn't un-

til I went back to work on the crutches and braces, that I realized that I hadn't been as comfortable in the WW as I had thought.

Using the crutches and braces again gave me a real "lift." Obviously it was the biggest sign to me that I had once again "recovered."

Although many medical personnel may diminish the difference between walking with aids and the use of a chair, there is a big difference, not only physical but psychological. The next time you are forced to use a chair, remember that any depression you may feel is probably natural and realize that there is going to be an adjustment period, even if your medical providers refuse to acknowledge it.

XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX

NPSA IN THE NEWS,TV-WISE

NPSA was briefly in the limelight on two television channels this month. Millie Schwindt, Lincoln member, was interviewed by Channel 10/11, and Nancy Carter was on Channel 3's news. Watch Channel 7 for Marcia Bredar, also, as their film of her has not yet been played.

XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX
GLEANINGS welcomes contributions--send articles to P.O. Box 37139 Omaha, NE 68137.

XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX

CLINIC--From pg 1, col 3

hear what they think is important."

If you believe that having a polio clinic in Nebraska is important, this is your chance to MAKE A DIFFERENCE. Be at Rejoice Lutheran Church, 138th and Center, 2 p.m., October 5. Your NPSA has gotten it this far. Now it's up to you to show up and talk with this doctor about what you want and feel you need.

XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX

HAPPENINGS From pgl,col3

Chip and Nina Mackenzie, and Marcia Bredar led the troops through a lot of hard work for us in the stores, and did some valuable public relations work for us there, finding a number of people requesting information. Paula Bonkiewicz and her team will sell at the final Baker's this Saturday, the 19th.

Jeanne Richardson provided us with gorgeous blue and white table decorations and signs for the stores, and Cindy Haag assisted Alice with coordination and telephoning.

XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX

NEEDED

Someone to volunteer to come to NPSA office and type one day a month. Must have good typing skills. Call Nancy at 895-2475 or write P.O. Box 37139, Omaha 68137.

XX

GABY'S GLIMMERINGS

by Cynthia Gabrielli Haag

At one of the meetings, a gentleman approached me to ask why I didn't write about the difficulties of those in wheelchairs and braces. I responded that I could write only about that which I experienced. I found myself almost apologizing for the fact that I wasn't more handicapped and maybe not a good spokesman. I pondered this conversation a good deal.

What I concluded from it is that while it is true that I do not know what it is like to be in a wheelchair, I do know what it is like to be incapacitated and deteriorating. I do not appear to be seriously handicapped. However, appearances can be deceiving.

While I am still able to walk and function, I am finding that I am more incapacitated than previously and, like other polio survivors, am deteriorating.

A problem that polio survivors have who can walk and appear fairly "normal" is that their handicap is not apparent. This brings about a problem in itself. It causes others to overestimate your capabilities and place higher expectations on you than they would if your handicap could be seen. If you are in a wheelchair or have braces, people will often make fewer demands

of you. But since I appear "normal," people often assume I can do more than I can. Most all of us polio survivors are recognizing that we have been driven to be as "normal" as possible. Out of lifetime habit, I continue to abuse my body.

It is my feeling after talking to other members handicapped in unobservable ways that, although I am very grateful that I am not in a wheelchair, I still suffer a lot of problems from my condition. I hold in common with those of you in wheelchairs many of the same difficulties. I too am deteriorating and I too have fears and suffer. This is our bond as members.

XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX

POSTER CHILDREN SOUGHT FOR ORAL HISTORY PROJECT

If you are a former poster child and would like to be interviewed for a research project that will be published, contact Marilyn Phillips, Ph.D., Associate Professor of English, 1140 Martin Place, Ann Arbor, MI 48104 (313)761-9816.

The project will document oral histories, emphasizing participants' memories and reflections on their experiences as media figures.

XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX

HAPPY HALLOWEEN!

XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX

TANK-LIKE VEHICLE MAKES FOR MORE MOBILITY, EASE

Production is scheduled to begin this month on Access, a Personal Transport Vehicle (PTV), designed by an Australian paraplegic to provide the ultimate in mobility.

In addition to wheels, the PTV has tank-like treads which lower to climb changes in elevation, such as stairs and curbs. Only 25 inches wide and 42 inches long, the PTV is said to meet VA Class III specifications and other acceptable safety standards.

Jim Hinson, Marketing VP of NATCO Corporation (who sells the chair in the United States) says, "People may be limited physically, but society makes people handicapped because of barriers. The PTV is designed to eliminate a lot of this problem."

For more information, call (415) 349-9664 or write NATCO, 1175 Chess Drive, Foster City, CA 94404.



PTV

XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX

