

THE OFFICIAL NUMBER ONE NEBRASKA POST-POLIO NEWSLETTER

JULY

1987

STREIB RESIGNS: UNMC POLIO CLINIC ON HOLD

Due to the July 1 resignation of Erich Streib, M.D., ending his affiliation with the University of Nebraska Medical Center, plans for a Polio Clinic there have suffered a major setback.

Dr. Streib was in charge of neurological clinics and had begun the work necessary to put together a polio clinic which was expected to be in operation by the end of this year. "Just when I thought I had it solved, I have to start all over again," says Michael Sorrell, M.D., chairman of UNMC's Department of Internal Medicine.

"Dr. Streib was the perfect man for this," says Sorrell. "We are actively looking for that kind of neurologist--one with the background of working with muscles, as Dr. Streib did. The question remains how soon we'll be able to find one."

Dr. Sorrell expressed his desire to set up a multi-disciplinary evaluation clinic for polio survivors, and said we would be kept informed.

OMAHA MEMBERS ASKED TO GET JUMP ON HAPPENINGS

Judy Kellerman, Omaha NPSA member, has been named Chairman of our 1987 HAPPENINGS coupon book fundraiser and has begun whipping the project into shape.

"It's time for everyone to start mentioning this to their friends and relatives so they will buy their books from us and not from someone

else," says Judy.

This is NPSA's major fundraising effort of the year--we must sell at least 500 books. Last year many enthusiastic NPSA salesmen did a wonderful job for us. We want to make it even easier this year by getting a head start on sales. So start making a list!

POST-POLIO CLINIC OPENS AT YOUNKER IN DES MOINES

Younker Rehabilitation Center in Des Moines opens a Post-Polio Clinic this month to be headed by Physical Medicine and Rehabilitation Specialist Mark Wilson, M.D.

Jeanne Osborn, the clinic's R.N., says the clinic will schedule four post-polio patients the second and fourth Tuesday of each month to begin with.

"The sessions will last about two hours," she says. "Patients will be seen by Dr. Wilson, a P.T., an O.T., and a rehab nurse." Additional types of evaluations will be scheduled as

necessary.

Patients will be accepted through physician referral only, and will be asked to forward results of all recent diagnostic testing and other pertinent records ahead of time.

For further information call Jeanne at 515-283-6432 or Dr. Wilson at 515-283-6874 or write at 1200 Pleasant, Des Moines, IA 50309.

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An elephant—a mouse built to government specifications.

Robert Heinlein

NEED SHOE? ODD SHOE EXCHANGE MAY BE OF HELP

Jeanne Sallman has moved to Arizona, and she's taken her shoes with her.

Jeanne runs the National Odd Shoe Exchange. "We run a mate shoe service--single shoes, mismatched shoes--and a one glove service," says Jean, who took over as director of the operation in 1983 after being a member since her teens because a birth defect left her with a smaller right foot.

A fee of \$22.50 for children and senior citizens includes \$7.50 membership dues. Adults 18 to 62 are charged a fee of \$32.50. "We don't refuse anyone help if they can't afford the fee," says Jean, "but we have no other funding." Members are asked to give the exchange a year to fill their needs. If they're not successful, the fee is returned. With 15,000 members, they have a better chance than many of being able to help.

Jeanne reports that many shoe stores donate single shoes to the exchange, and these are given free to members.

The National Odd Shoe Exchange was founded in 1942 by Ruth Feldman of St. Louis, a polio survivor now living in California.

You can reach Jeanne at P.O. Box 56845, Phoenix, AZ 85079, 602-246-8725.

DICHOTOMY or,
WHY IS POST-POLIO SYNDROME
LIKE A POND OF WATER FOWL?
by M. R. Galda, NPSA Omaha member

Because it is full of pair-a-ducks.

"Use it or lose it" says this exercise-crazy world.

"Use it and lose it" say the post-polio experts. They are both right, of course. In the same body, maybe even in the same limb, both advices are true, even if not possible.

In the effort to keep strong what we have and yet not lose what is weak, we concentrate very hard on what our bodies tell us. We note every muscle ache; count every nerve twitch; quarter our Mestanon pills for exact calibration of our fatigue. We go into transcendental meditation to eliminate effects of stress; into visualization techniques to promote healing (Grow, little anterior horn cell sprout, grow). All this tends to make us very selfcentered.

But we have always been told by our mentors that true happiness comes only from self-denial, from forgetting ourselves and having concern for others. And indeed, haven't we all found great relief, although temporary, whenever we got absorbed in activities and thoughts outside of ourselves.

Should then we be intro-

verts or extroverts? Again, the answer is "yes." We must rest long and frequently; exercise wisely and well. We must develop a mind-set that conditions our cells to regenerate and build endurance. We must find new activities that do not tax nerves and muscles, but draw us out into the concerns of others.

GARAGE SALE BIG SUCCESS: NPSA THANKS ALL HELPERS

It was a family affair! Katherine Taylor, husband Mike, and parents Elizabeth and Sonny Massouris labored diligently toward the success of NPSA's garage sale, and it paid off!

"I really enjoyed doing it," says Katherine, a veteran garage sale producer. "And so did everyone else."

With proceeds of \$245 and not a scrap left to sell, this family ought to be mighty proud of their hard work for NPSA! And how could we have done it without the donations of goods from all of you! So thanks to everyone for a job well done!

INFORMATION ABOUNDS AT GINI POLIO CONFERENCE
by Charles Mackenzie, Omaha NPSA member

The International Polio Conference sponsored by G.I.N.I. in St. Louis June 3-7, attracted nearly 700 participants from more than 20 countries around the world. The conference concentrated on the symptoms associated with late effects of polio, on treatment and research, and on coping with the changes in our lives brought about by the late effects.

MUSCLE WEAKNESS
Post-Polio Muscular Atrophy (PPMA) appears to
be a defect in nerve
function of unknown
cause. Even Post-Polios
without PPMA show evidence of active ongoing
denervation. Neil Cashman, M.D., (Montreal
Neurological Institute)
reported that in those



DR. CASHMAN & MACKENZIE

with PPMA, the nerve fails to conduct the nerve impulse properly. Research is just beginning to try to identify the type of defect. Unaffected limbs are now believed to show weakening of up to 50-60% using new methods of measurement.

A drug called Mestanon,

used in myesthenia gravis, has been tested in Post-Polio patients by Dr. Cashman, and shows clear improvement in fatigued patients in a small study. However, he is hesitant to recommend use of the drug, as long-term effects on muscle function are unknown.



PEGGY MOE, DIANE MCENTEE LINCOLN SUPPORT GROUP

EXERCISE

The general guideline offered was that affected muscles should never be exercised to the point of fatigue. Find your personal limit and be very careful not to go beyond. If you are tired for an extended period of time after exercise, you have probably gone too far.

FATIGUE

The most generally-agreed-to agent to improve function is sleep
and rest. Lauro Halsted, M.D., (National
Rehabilitation Hospital)
reported marked improvement with a short nap,
especially if he could
sleep. Stress is believed to play an important, although difficult
to quantify, part in
Post-Polio problems.

RESPIRATION

While many people clearly have deficient respiration, the importance of respiratory testing was emphasized. With the weakening of respiratory muscles, many people have marginal respiration. This reduced capacity can be evaluated by measuring the total expiratory capacity and monitoring its changes with time. duced capacity can be a factor in fatigue. It is also a consideration during surgery because the weaker muscles may take longer to recover from general anesthetics and depolarizing muscle relaxants.



DR. JACQUELIN PERRY

Scoliosis surgery should be approached with caution in that it may 1) reduce mobility by preventing use of available musculature, and 2) may reduce respiration which may be fatal. While surgery was only peripherally discussed, it is important to keep the entire body in mind when considering surgery.

Sleep apnea is possible due to weakened muscles and reduced vital capacity. Early morning headache and mailaise and daytime sleepiness may be evidence of sleep apnea.



HONORARY NEBRASKAN DR. WEBSTER CASH

The importance of avoiding smoking (and cigarette smoke) if you have reduced respiratory capacity was emphasized. Ernest Johnson, M.D., (Ohio State University Hospital) related a sign he had seen once in a small airplane: "If you have to smoke, please step outside."

PAIN

Pain was one of the more complicated topics discussed. The importance of proper diagnosis was emphasized. The principal sources of pain are 1) muscle strain due to overuse, 2) joint and muscle pain due to im-



CARTER & JUDY RAYMOND POLIO NETWORK DIRECTOR

proper function, and 3) post polio muscular atrophy.

Nancy Carter, President of NPSA, discussed her painful experiences. She reported that the only consistently effective therapy is rest. The importance of stress on pain was emphasized by several speakers.

DIET

emphasis Placing on weight control was stressed. Annette Hise (Gaylord Hospital, Connecticut) recommended the following steps: 1) reduced calories, 2) modification behavior and 3) maximum allowable exercise.

ENVIRONMENT

William Rea, M.D. (Environmental Health Center,
Dallas) reported that
preliminary studies suggest that the Post-Polio
patient may be more
susceptible to environmental pollution, including smog, chlorinated water, plastics,
pesticides and many others.

COPING

Coping appeared to be more traumatic for the

less disabled, people who have not incorporated their handicap into their self-image. one of many coping workshops, two of the participants were in tears. One woman who wore a leg brace on one leg had never worn a dress! she required two leg braces and was terrified of what to tell friends. Many of the other participants emphasized the importance of self-image in accepting and coping with others.

The self-reliant nature of the handicapped was emphasized. As this changes over time, major family stresses may be produced. Additional financial stresses add to aging difficulties.



MR. & MRS. BOB GREISS SUTTON NPSA MEMBERS

STRESS

Paul Duckro, Ph.D., discussed the general characteristics of controlling stress. He mentioned the variety of attitudes, relaxation activities and social interactions which assist in controlling stress. Much of what he said is perhaps summed up in the following "You can't afquote: ford to hate what you do or what you are."

GABY'S GLIMMERINGS by Cynthia Gabrielli Haag

Today I called a woman I have recently become acquainted with. In our last conversation she expressed concern for one of her daughters. I was called to see if she was coming over as she had planned. She said, "No. My daughter was killed in a car accident last week, so I won't be able to come today." I was, of course, stunned. This was not the daughter she had expressed concern about.

This is something we have no control of-death. We cannot control the where, when, or how of our own death nor that of those we love. Little did this woman know that it was this daughter who would be facing an even bigger crisis than any trouble her other daughter might have. And worrying about her daughter could not have prevented the accident, because we cannot possibly know when this will be the last car ride, the last walk or the last breath.

The two biggest moments of our life, birth and death, we have the least control over. What then makes us so certain that we can perfectly control the moments in between? There are choices we can make and some events we CAN control. But a lot of things occur in life over which we have no power. And we panic when things are out of our control. Too many of us try to plan our lives meticulously and are devastated when our plans go awry.

We polio survivors have been through this. We fought so hard to get back control of our lives. And now we find ourselves going backwards. We did not plan this and we are terrified of the possible loss of control.

Our initial victory over our polio problems gave us the notion that life was something within our own inner resources to direct. This was only partially true. As we face our new post-polio problems we must begin to accept that there are some things over which we have no say so. And we need to get over our terrible fear of this and accept life as it comes to us and look for the roses amidst all the thorns.

We need to find humility to face life with acceptance and serenity and stop railing against that which we are powerless to change. There are still some things over which we have no control. Not the least of which is our own attitude. All our worry and fear can change nothing except to make us more ill.

It rained this afternoon and I was hoping to do yard work. Oh well, I'll write this and do my laundry.

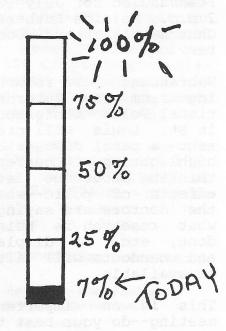
ADDRESS CHANGES NEEDED

If you are planning a move, remember to send NPSA your address change. The Post Office will not forward your GLEANINGS, so to continue receiving the newsletter you'll have to let us know where you are!

GLEANINGS is now being read in 36 states and two foreign countries-we want to be a part of your life wherever you qo!

NPSA APPEAL PROGRESS

We're moving upward, oh so slowly! If you receive this newsletter and have not contributed to NPSA's appeal, please do so today. NPSA is not funded by the government or any agency; our only funds come directly from individual donations. Please help us keep NPSA alive!



SPEAKING UP FOR ONE AND ALL

Recently I attended a satellite conference on Technologies for the Physically Challenged (we'll get to that little euphemism at another time). The purpose was to show us (the viewers at 144 sites across the country--handicapped and able-bodied alike) new devices that might change the lives of, provide new freedom for, the handicapped.

In their introduction. the makers of the video program name what they apparently believe to be primary disabilities people might have who could use this equip-ment--such things as

NOTICE NOTICE NOTICE CHANGE CHANGE CHANGE

Because NPSA's Omaha support group's regular July meeting falls on the weekend of the July 4 holiday, it has been rescheduled for July 12, 2 p.m., Rejoice Lutheran Church, 138th and Center.

Nebraskans just returning from the International Polio Conference in St. Louis will present a panel discussion highlighting current thinking about the late effects of polio--what the doctors are saying, what research is being done, etc. A display and handouts will also be available.

This is an important meeting--do your best to get there!

M.S. and spinal cord injury, for instance. The word polio is not even hinted at.

Come on now! Polio is second only to stroke among causes of paralyzing conditions in this country, and yet those in the business of helping the handicapped don't even consider it when listing possible existing handicapping circumstances?

Why is this? Have we burrowed so deep into the closet that even our health care providers have forgotten we exist?

You bet your sweet bippy we have! We've almost insisted on it, haven't we? We've been going to doctors for years, telling them when we had chicken pox and that our mothers had diabetes, but we somehow neglect to mention that we had polio. We tell our neighbors about the car

wreck we had in '72 and about the time the bee sting made us swell up like a melon, but we don't tell them we had polio.

It's like this, folks: if we want help with the polio problems we are beginning to experience, we had better start talking. We had better start letting the world know we are alive and kicking.

People don't develop devices, establish clinics, train professionals for segments of society that don't exist. We have to make them aware that we are here-get their attention--dance on their table!

Some of us are up against it already. All of us have to help. We're going to have to rustle up the courage to speak out and make ourselves heard.

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