

THE OFFICIAL NUMBER ONE NEBRASKA POST-POLIO NEWSLETTER

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CAUTION URGED IN USE OF EXERCISE, FITNESS SALONS

In the past few months, NPSA has received comments and inquiries regarding a chain of exercise salons featuring isometric equipmenta system supposedly based on a concept originally used by people with polio and other diseases.

We must remember that we are no longer polio patients. Now we are dealing with post-polio, and the treatment may be entirely different from previous protocols.

Strengthening exercises of any kind may not be appropriate for everyone. We are told that high repetition/high resistance exercises can be quite harmful.

Entering into an exercise program without specific recommendations of a physician who understands post-polio complications and who appropriately monitors your physical status can do great harm. Please check with a reliable medical source before you begin any exercise regime.

HAPPY HOLIDAYS!

SPOTLIGHT: THE MACKENZIE CHALLENGE

We call him Chip. Others may refer to him as Charles W. Mackenzie III, or as Dr. Mackenzie. But however he's known, he's NPSA's chief computer person as well as Vice-President of our Board of Directors and Program Chairman of the Omaha support group. He's a very big element in the success of NPSA.

Though born in New York City, Chip grew up in Sacramento, California, where he contracted polio in 1952 at age six.

"I don't remember much about it," he says. "I do know that one day they put me next to an iron lung and I fiddled with the knobs. Somebody noticed before any harm was done, but they hung a note on the lung that said 'Don't put that kid near this machine'."

After working his way through crutches and braces on both legs, Chip was walking freely, though somewhat unpredictably, within two years. He was out of school over a year, and when he returned, he found that things had changed.

"Kids made fun of me. I was unable to interact with my

peers and became a loner very quickly. Beyond any question, it totally changed my life. I basically have spent most of my life trying to recover from what happened back then."

Later, with a BS in chemistry behind him, Chip married pretty Nina (another tireless worker for NPSA) and headed for his PhD in biochemistry at USC. "Nina was an elementary teacher in Inglewood then," he says. "I called her my Blonde Scholarship."

Chip took a job at the University of Minnesota. Heidi and Timmy (now in grades 7 and 3 at Brownell-Talbot, and stars of the Campfire PSA on Omaha TV) were born and he came to UNMC where he was an Assistant Professor of Pharmacology.

See Pg 3, Col 3



CHARLES MACKENZIE

IT WORKS, IT WORKS!!! by Tim Zingale Rolfe, IA NPSA member

Having had polio at the age of four and being 40 years old now, I am a prime candidate for Post-Polio Syndrome. After having achieved my highest potential between the ages of 22 and 35, I have been slowly but steadily losing endurance, stamina, and strength, with increasing joint and muscle pain, for the last five years. During my peak, I used a long left leg brace and a cane for walking, and many times not even the cane.

Now, I am 80% of the time in an electric wheelchair. I am not strong enough to push a manual chair, or to hold my head and neck up all the time, so an electric chair with a high back supports me so I don't have to. The chair and I have learned to tolerate and even enjoy each other.

I was in Rochester about two months learning to cope again, and to help introduce my new lifestyle to the family and members of the church where I am pastor. During this process, something wonderful and exciting began to happen. I was less tired, less grumpy, less unhappy, and not using every drop of energy fighting to do the normal things such as walking. Life was more enjoyable. I came to see that the system worked. The long-feared and

dreaded wheelchair was working. I was better.

Now I am learning just how that 20% of the time I spend out of the chair should be used. I have to learn how much I should do and how much I should let the chair do.

There is a sense of incongruity to all of this. From one view inside of myself, I see myself weaker, more dependent, less able because I am in a wheelchair. But from another view, I know I am more able to cope with life in a richer way now, from the chair. I have gone more places with the family, had to take fewer naps, been happier, and even people at church have told me they can tell I am less tired, my handshake is stronger.

Please don't be afraid to give in, or adjust, or cope in another way to your polio. As my doctor said, "You polios have adjusted all along; this is just one more adjustment. You will make it; you always have."

I have a feeling that down the road I will have that "natural feeling" once again about the wheelchair and myself as I had when I walked with a cane and leg brace, that natural feeling that said, "That's me, who I am, I am OK, I am coping, and I enjoy life."

OMAHA GROUP GIVES THUMBS UP TO NEW FDR MEETING SITE

Omaha area members attending NPSA's November support group meeting gave a five-star rating to their new facility at First Data Resources.

The soft, comfy chairs received cheers of appreciation, and many commented on the great accessibility and friendly atmosphere. Barb Pieper's double chocolate cookies didn't hurt a thing, either!

Hope to see you there December 6--bring a friend!

LINCOLN SALES FOR NPSA MEAN PROFIT

Diane McEntee and Peggy Moe, Area Representatives, report that the Lincoln area group sold 32 of Lincoln's HAPPENINGS books, netting a \$160 profit for NPSA. Hats off to those who helped with this project!

TUPPERWARE OPEN HOUSE SCORES BIG

NPSA's recent Omaha Tupperware fundraiser was a great success, adding cash to our coffers while allowing many friends the opportunity to replenish their stock of Tupperware over coffee and cookies.

Thanks to all who took orders for us and to those who made purchases. We need you all!

Mackenzie--from pg 1, col 3

NEW PRODUCT GETS CHAIRS THROUGH NARROW DOORS, OTHER TIGHT SPOTS

An eight-month-old California company created to market a wheelchair-narrower has found lively interest in its product.

The narrower, a small piece of equipment which mounts on the arms of most collapsible chairs, can pull the sides of the chair together from 1/4" to 10", enabling users to squeeze through tight spots which have previously been barriers to their mobility.

"One of the biggest problems wheelchair users have is getting through areas with narrow doors, whether it's at home or when traveling," says Robert Davis, owner of Access International, marketers of the device. "Most of the time you only need an extra inch or two to get through."

No modification of the chair is necessary, and the \$149.95 narrower is easy to install. The handle working the unit can be operated by the person in the chair. "If you can push your own chair, you can do this," says Davis.

The device was invented by an engineer in South Carolina who had a friend in a wheelchair. One day, says Davis, the engineer was pushing his friend to the bathroom. Without thinking that the door might be too narrow, he rammed the chair into the doorway, throwing his friend to the floor. He saw the problem and sought to correct it.

You can find out more about this interesting product and where you can purchase it by calling toll free 1-800-627-7697.

CARTER SPEAKS OF LATE EFFECTS, NPSA

Nancy Carter, NPSA Director, carried the post-polio message to the November 19 Omaha Nursing Association's meeting at St. Joseph Hospi-She also spoke at a recent Symposium on Collagen Vascular Disorders at Mid-Plains Community College in North Platte.

Part of NPSA's mission is to spread the word about the late effects of polio and about this organization.

HELP FOR PAIN

Many polio survivors are discovering that an egg crate matress cover, available at most department stores, makes lying in bed much more comfortable.

Eventually, however, he became aware that drastic changes were occurring in his body. Lecturing became very difficult, exacting too great a toll physically. Walking was a big problem, and he started using a cane, occasionally a wheelchair.

"By 1984 I decided to go on an exercise binge, but failed to improve my ability to get around. It's gotten harder and harder since then."

Subsequently, Chip resigned from UNMC, and, using his passion for computers as the impetus, started DataChip, a modestly international corporation which sells a reference data program called RefBase for people doing research.

"It's helped with the fatigue," says Chip. "I don't have to move around so much, so I don't get as fatigued. The pain is still bad, and it affects my entire system--I get irritible, feel nasty. Rest is helpful. I constantly fight to find the balance between becoming a vegetable and being as active as possible."

"NPSA has helped the whole family. Nina and the chil-

> dren now realize what's happening, and I understand it better. I've done more thinking about it and have a better awareness of acceptance. I've found I have to adapt, change the ways I do things to make through life. That's a challenge."

MEMORIALS

IN LOVING MEMORY OF WILEY MITCHELL from Adeline Mitchell Hebron, NE IN LOVING MEMORY OF WILEY MITCHELL Mr.& Mrs. W. O. Baldwin from Hebron, NE

SEEMS LIKE OLD TIMES

(The following is an edited version of a letter written by NPSA's own Joan Lehnhoff (Mrs. Henry Lehnhoff) as a kick-off for the Omaha Junior League's 1947 fund drive for the National Polio Foundation. This was a year after Joan got polio herself. It may bring back memories for many of us.)

Dear Helen:

Where have I been? she says! Why haven't I written? she says! OH BROTHER! You asked for it and you shall certainly hear about it.

I've had polio, little flower. Real live polio--and I'm still running my eighty horsepower chassis on about a five horsepower motor. Mine was a facial and throat paralysis and the finer points of swallowing and eating have gone by the board for awhile. (How lucky I am that it will all clear up in time.)

The amazing thing to me about polio was the fierce and horrible pain connected with it--an acute stage that

NOTICE NOTICE NOTICE

James Faulkenberry, Social Security Disability Examiner, will talk with us at NPSA's Omaha support group's December 6 meeting about POST-POLIO DISABILITY CLAIMS--THE GOVERN-MENT'S PERSPECTIVE.

Join us at 2 p.m. in our new digs at First Data Resources, 10825 Farnam in Old Mill South. Bring your family and friends for a happy afternoon of fellowship and information.

See you there!

lasted two weeks, but seemed eternity at the time. Had you ever heard of that? I hadn't--I'd always thought of it as a crippling disease with no pain.

Forgive a little preaching, baby, but if Cindy or Phoebe had it to go through next summer--I know you'd do and give everything in your power to save them.

Well, you know that drive for National Foundation which comes on every year the last two weeks in January? The one they pass the plate for in the movies? I've always thought in my own selfish way, "Oh, what a crashing bore-bring on Greg Peck" as I dropped in a little silver when the plate went by.

YOU know the feeling.

...Seriously, Helen--think it over--and give up that new suit or lamp right now--just to insure you'll never meet the day when you'll wish with all your heart you had. Hank and I think they'll find a vaccine before long, the way they did for smallpox--but meantime, it's the most horrible thing I know about, and I know you'll agree if you've had any personal contact with it.

Must fly now--I hear Johnny, and he's still my boss, you know. Write me when you can.

My love to you,

JOAN

NPSA thanks Cornhusker Business Machines, 7425 Dodge Street, for the use of their laser printer in the production of this month's newsletter.

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