

THE OFFICIAL NUMBER ONE NEBRASKA POST-POLIO NEWSLETTER

DECEMBER

1985

TUPPERWARE FUND-RAISER FOR ALL MEMBERS IN STATE

Omaha Tupperware dealer Nina Mackenzie is donating to the Nebraska Polio Survivors Association 20% of the purchase price of each item bought through our organization until Christmas.

If you need Tupperware or are considering buying some for gifts, why not help the organization by ordering from Nina? You could also have a Tupperware party or just make individual sales to friends and family.

If you sell over \$100 worth, you will receive a thank you gift. The



Nina Mackenzie

SPOTLIGHT: NEW HELP FOR SLEEP APNEA

In 1948 Marvin Pekny was placed in an iron lung. A 21-year old polio patient, Marvin graduated to a rocking bed after about four months, and within another year was home free, breathing all on his own.

Thirty-seven years later, Marvin, a member of the Omaha support group, was again in an iron lung.

The current problems began in 1976 when Marvin had pneumonia. He was given a tracheostomy and seemed to get better. Then a curious thing beqan to happen--Marvin couldn't stay awake during the day. He fell asleep while driving, while talking on the phone, during business meetings. "One time I fell asleep while walking into a room and toppled over onto the floor," he says. He was always sleepy.

Finally he saw a pulmonary specialist who determined that Marvin's breathing was so depressed at night that he wasn't getting enough oxygen in his blood, and the high levels of CO₂ were literally putting him to sleep. After other treatments failed, seven years ago he was fitted with a chest shell and began using a portable respirator at night. That seemed to solve the problem.

However, lately it began again. "I'd wake up with severe headaches and couldn't stay a-wake," says Marvin.

His problem was diagnosed as respiratory failure, and an iron lung was brought from Kansas City to keep him breathing. Marvin was then tested again and told that he has sleep apnea, periods of temporary cessation of respiratory effort during sleep.

He was then put on nasal CPAP (Continuous Positive Air Pressure), a device developed in 1983 and 1984 by Dr. Mark Sanders of the University of Pittsburgh Medical School, and generally available only since December 1984. With a mask forcing a continuous flow of air into his nose, 10 centimeters of positive air pressure keep his airway open. "I use it at night," says Marvin, "and the shell, too. I'm feeling See page 2, column 3

SHOPPING CARTS FOR THE DISABLED NOW AVAILABLE

The Sit 'n Shop is the newest in convenience for the disabled shopper. Ray Davis, inventor and president of American Distributing Co., has adapted an E & J wheelchair with a basket device which can hold up to 40 pounds of goods. He has also developed a motorized version, a three-wheeled cart with hand controls and basket.

Tina Brossau, operations manager, says, "Most people who are buying the chairs (for stores) are not handicapped, so they don't realize how important the chairs are to the elderly and the disabled."

Grocery stores and shopping centers find that they can increase their customer base at the same time they do the community a service by providing the Sit 'n Shops.

For more information, write American Distributing Co., 2615 Market Street, Garland, TX 75041 or call toll-free 1-800-527-4609.

NEWSPAPER FUND-RAISER BENEFITS ORGANIZATION

Our thanks to Paul Thele and his parents Jim and Sue for the great job they did on the newspaper drive fund-raiser for the NPSA in honor of grandmother Thelma Kalber, one of our members.

MEMBERS FROM HASTING, GRAND ISLAND ENJOY TALK

Erma Ocker, Hastings area representative, along with Marge Lippstrue and Kathleen Hendrickson, arranged for a most informative support group meeting October 20 at the Hastings Elks Country Club. Members of the Hastings and Grand Island support groups attended.

Dr. James W. Hervert of Hastings described the physical aspects of acute poliomyelitis as well as the late effects of polio, and advised members how to care for themselves both physically and psychologically.

SPOTLIGHT--from pgl,col3

a lot better."

Advised to lose 30 pounds in order to eliminate the breathing problems made worse by excess weight, Marvin will return for more testing after his dieting has had a chance to work.

In the meantime, he's back on the job as supervisor for special education in Harrison Co., Iowa, and is not at all sorry to see his iron lung sent back to Kansas City.

MERRY CHRISTMAS HAPPY NEW YEAR!

TUPPERWARE FUND-RAISER--from page 1, column 1

two top sellers with total sales of \$300 will receive the prize they choose from a special booklet--maybe a Fieldcrest blanket or a Pierre Cardin telephone or a designer watch.

Tupperware has a terrific new line of ovenware --pieces that go directly from the freezer to a 500° oven without a hitch, and are also microwave and dishwasher safe. All Tupperware has a lifetime guarantee.

It makes super wedding, shower, birthday, or Christmas gifts. Seventy-five items under \$6 make great stocking stuffers. Maybe you could sell promotional gifts to a business in your

area. Whatever it is, get 'em from Nina!

To receive your catalog, call her at (402) 551-9497 or write her at 5624 Pierce, Omaha, NE 68106. She will give you the details for ordering at that time.

Your purchase will go to putting out the newsletter to over 700 persons monthly, and to sending information packets to the many people monthly who are just learning about the late effects of polio and who depend on us for help.

This is your opportunity to do your bit for the NPSA and get the Tupperware you and your friends need in the bargain. DON'T DELAY!

GABY'S GLIMMERINGS
by Cynthia Gabrielli Haag

I just turned off my TV. I was watching a "super-crip" show. These are stories of people with handicaps who have over-come incredible odds to become gymnasts with one arm, run across a whole country on one leg, ski one-legged, or play piano with their feet.

At first, I cried, was inspired, and felt motivated by such shows. I applauded the recognition their courage brought to the courage of all the handicapped. But eventually my feelings began to change to anger. Not all of us can be supercrips and it's not fair to throw these human marvels in our faces as though to say, "You ought to be ashamed." I don't think I should have to feel guilty if I can't be that stupendous.

People think that if someone with one arm can propel her body on parallel bars, then someone with two arms should be able to. Appearances can be deceiving. These shows can cause the public to have unrealistic expectations, which tends to make the handicapped feel isolated and misunderstood.

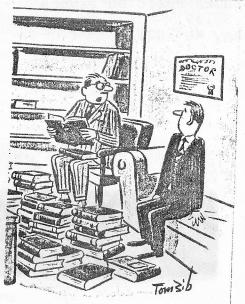
I wish just once I'd see a portrayal where they can't conquer the mountain. Sometimes life is like that. Not always. But it's not always like it is with supercrip, either. It's the lack of balance in presenta-

tion that bothers me.

It never occurs to people the negative consequences such overuse of muscles can cause. may choose to take the risk to achieve a goal. But many of us wish to protect what's left of our bodies. We should not have to live with such high expectations to "perform" that we abuse ourselves. Some of the ordinary things we have done, like walk or live independently, are just as stupendous as one-legged skiing. doesn't make exciting script, but it's real!

The greatest discovery in our generation is that human beings, by changing the inner attitudes of their minds, can change the outer aspects of their lives.

William James



"Yours is a most unusual case . . ."

ADDRESS CHANGES NEEDED

Please notify us if you change your address. Send your old address along with your new one so we can keep our mailing list current and not waste money by sending mail that you will never receive.

Send to Nebraska Polio Survivors Association, Box 37139, Omaha 68137.

ABSTRACT
ORTHOPEDIC MANAGEMENT OF
POST-POLIO SEQUELAE
by
Jacquelin Perry M.D.

193 patients were seen for pain and increasing muscle weakness. The causes of pain were posture problems associated with weak musculature, fixed deformities, and muscle overuse. Mechanical strain was the common denominator.

Knee hyperextension (48%) and curvature of the spine (15%) were the most frequent complaints.

The authors emphasize the importance of proper knee bracing to prevent knee hyperextension from getting worse. Good bracing can reduce the mechanical stress on the knee.

The authors advocate the use of crutches to redistribute body weight from the spine to the arms for some cases of curvature of the spine. A corset can also bennefit some patients. Surgical correction of spinal curvature was not used or advocated by the author in this study.

The author reccomends a therapeutic program of avoiding overuse of affected muscles by life style modulation.

Orthopedic function is directed at preserving function by relieving strain.

Ted Vergith M.D.

A DOCTOR RETIRES

Dr. Ann Bailey has retired. After a lifetime of service, devoting the last nine years to working with polio and other patients in Warm Springs, Georgia, she has decided to hang up her stethoscope and take life easy caring for her three young grandsons in Arizona while her daughter goes to medical school.

I first saw Dr. Bailey last year, after months of desperate searching for someone who could relate to the strange things happening to my post-polio body. I sat in her Warm Springs office and described a severe pain that I have. Her hand went right to it. She touched the spot. "Is this where it is?" she asked. I

NOTICE NOTICE NOTICE

Florence Hansen, Director of Social Work at University Medical Center will be the guest speaker at the December 1 meeting of the Omaha support group, 2 p.m. at Rejoice Lutheran Church, 138th and Center. She will give us further tips on HOW TO TALK WITH YOUR DOCTOR. This should be a most interesting meeting!

Florence is donating her \mathbb{Z} time and expertise to prepare this program and H be with us, so let's all make a real effort to attend and let her know we appreciate her support!

couldn't believe it! Six other doctors hadn't been able to find the pain, even when the area . was circled in red on my skin. And yet she knew without being told. A weight was lifted; a light began to shine.

How was it that she understood her polio patients so well, grasped so easily what many other doctors still fail to comprehend? Dr. Bailey says simply, "If you listen to the patients, they'll tell you."

She believes that polio people are special. "I don't know of any other group of patients who were as motivated and devoted as polio patients," Dr. Bailey says. "They just refused to be handicapped. They wanted to be one of the crowd; they didn't want to be differ-It was their most ent. outstanding quality.

That's why it makes me so angry when doctors say these new symptoms are all in their head, that there's nothing wrong. It couldn't be true."

Dr. Bailey continues to supply the vaccine to her patients who find relief from pain through immunotherapy treatment. And no doubt she will continue to answer her patient mail and do other things to help, but she has retired. "I'll miss it," she says. "It is a part of you. I know I'll miss it."

And we will miss her. But we will remember the knowledge and the human kindness she has given us, and wish her Godspeed in this new role as Nanny in the Great Western Desert. May she someday realize what she has meant to us all. nbc

Nancy B. Carter Nebraska Polio Survivors Box 37139 Omaha, NE 68137



Nancy Carter 5647 S. 148th Flz. Omaha, NE 68137