

THE OFFICIAL NUMBER ONE NEBRASKA POST-POLIO NEWSLETTER

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MARCH OF DIMES FUNDS POST-POLIO RESEARCH

The National March of Dimes has awarded two grants for use in postpolio research.

Dick Leavitt, Science Editor for Corporate Communications at the White Plains, N.Y., headquarters, says that \$52,000 or \$54,000 (he wasn't sure which) will be divided by Theodore Munsat, M.D., of Tufts U. in Boston and Lauro Halstead, M.D., of The Institute of Rehabilitation and Research in Houston for their separate one-year studies.

Dr. Munsat, a neurologist and president of the American Academy of Neurology, will investigate the use of a particular hormone known to encourage growth of nerve fibers for its possible use in slowing or stopping nerve damage in P.P.M.A., according to Leavitt.

Well known to polio survivors, Dr. Halstead, who heads a polio clinic and is dealing with the late effects of polio himself, will conduct a practical investigation See pg. 2, col. 3

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CENTER SPECIALIZES IN BRACES AND SHOES

The Orthopedic Service Center in Mission, KS, a suburb of Kansas City, offers a variety of services for the disabled. As a brace shop they make and repair braces and prosthetics. In conjunction with their adjoining Comfort Shoe Shop, they also do a great deal of shoe work, including creating custom made shoes.

Andrew Gold, owner and operator, says the establishment has been there for eight years.
"We are in this business because we belong in this business," says Gold. "We have the expertise needed to do this kind of work."

And he has the credentials to prove it.
Starting as an apprentice to a custom shoe maker in New York City,
Gold worked his way up to assistant, and then took over when his mentor retired. He also attended N.Y.U. for two and one-half years, coming away with a degree in orthotics and prosthetics.

"We see a lot of polio survivors," Gold says.

"In fact, it's because of them that we do so much with shoes. We kept getting more and more demand for shoes from people who wanted a better selection."

One of the services offered by the center is custom made shoes. A plaster cast of the customer's foot is made and then a model is made from that. Gold or his assistants then fashion the bottom or inside of the shoe which is sent with the model to another company which finishes the upper part of the shoe. The process takes about six weeks and usually costs \$225 to \$300 a pair.

Other shoe work includes making inserts to make up for the difference in size, and a shoe with an extra-depth insole for mismated sizes.

Gold emphasizes that
there is only one flat
fee for their work; follow-up and adjustments
are not charged for.
"We want to encourage
people to come in for
adjustments so their
shoes and braces are
See pg. 2, col. 2

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NORMA RAMSAY SPEAKS TO HOLDREGE SUPPORT GROUP

A recent program for the Holdrege area support group featured Norma Ramsay of Kearney discussing architectural barriers.

Mrs. Ramsay worked as an advocate of those need-ing handicapped accessibility during the renovation of downtown Kearney.

"Many government agencies are helping with accessibility for the handicapped so they can use public places," said Mrs. Ramsay. "As of January 1, 1977, all new public buildings and buildings with 50 percent or more remodeling are required to be accessible."

Mrs. Ramsay emphasized that people without handicapping conditions have no way of knowing or understanding what changes are needed unless they are told. "When changes are needed," she said, "people need to be informed about these needs."

TUPPERWARE FUNDRAISER ENHANCES NPSA TREASURY

Nina Mackenzie, Omaha Tupperware dealer, reports that those members participating in her fundraiser provided nearly \$1300 in orders, 20% of which goes to the state organization's treasury. Five members sold over \$100 worth—a terrific job, well done!

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BRACES--from pg. 1, col3

wearable and fit well,"
he says. "We like to
continue to follow-up-it's part of our commitment."

The operation is housed in a building designed for the disabled and is completely accessible, according to Gold. Also, wheelchairs are provided for use on site, so you don't have to take your own.

"We have a unique set-up here," comments Gold.
"There is no other company like ours near here that has integrated all of these orthopedics services."

You can reach them at 5501 Johnson Drive, Mission, KS 66202 or (913) 362-3232. Be sure to make an appointment before going down.

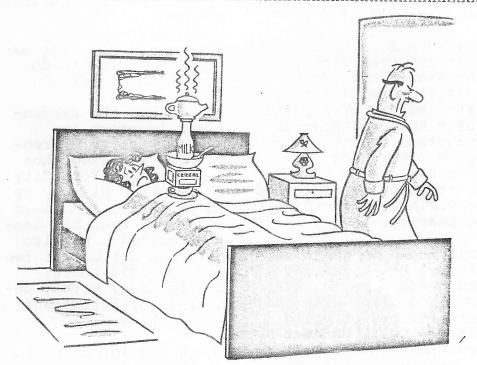
GRANTS--from pg. 1, coll

to determine what aggravates and what mitigates P.P.M.A., says Leavitt, in an effort to determine what people with the problem should be doing about it.

When asked whether mail from polio survivors throughout the country urging the March of Dimes to get involved in post-polio research had anything to do with their allowing the grants, Leavitt said he did not know.

#### FOR SALE

Portable wheelchair: Everett & Jennings Traveler. Footrest plus leg braces. Excellent condition. Only used inside. \$200. Call Council Bluffs 323-2798 or 323-5049.



"There you are, dear - breakfast in bed."

GABY'S GLIMMERINGS
by Cynthia Gabrielli Haag

When I was in college, I had to do a paper on a poem by Keats entitled ODE TO MELANCHOLY. It was a complicated piece. However, in analyzing it I learned a simple truth. The theme is that without sorrow one could not truly experience joy and vice versa. For me this was an explanation of my polio experience. With the deep pain and struggle with polio, I learned to intensely feel the joys of life. And along with all the negatives that came with polio have come beautiful experiences that non-handicapped people miss.

These joys and sorrows are laced through my childhood memories. The sorrow of not being able to walk hand-over-hand across the monkey bars is linked with the joy of discovering I could hang by my knees and pull myself up to sit on top. I dare say no other child could feel the ecstasy I felt sitting on top of the world thus.

Although we polio survivors have had many experiences that have reduced our self-concepts,
we have all had the enlarging experiences of
surviving and conquering. Non-handicapped
people do not know how
they would handle tragedy. We know we are
strong and our sense of
self has grown in this
area. And we have had

intense joy at each accomplishment because we know the tremendous struggle that went into it.

I think of the joy of gradually seeing my lifeless left arm lift a heavy sandbag. I remember the heady feeling as I drove my first new car out of the lot. Most people would be happy at such a time, but not as happy as this young girl who had been told she couldn't drive. All those obstacles overcome ...my first apartment, getting my degree, my first teaching job, my marriage to Joe ... all the things "they" predicted would never hap-

At this time of year a person's thoughts turn to all the joys we've been given. And I am deeply grateful for the experiences of ecstasy and knowledge of self that polio has given me. I am aware that the nonhandicapped have missed not only my sorrows, but my joys, also. These experiences are really beyond putting into words, or understanding, but I know you understand for you've had them, too. To the world these are small things, usually overlooked or taken for granted. For us they are mountain-top experiences which they will never know. They are opportunities for a grateful heart to grow.

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HOUSE OF LLOYDS WORKERS CONTRIBUTE TO NPSA

Delores Bray, Holdrege area representative, reports that the House of Lloyds demonstrators in her area have participated in a fund-raising project for the NPSA, donating 50% of their profits to our state organization.

Hats off to these fine folks!

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ABSTRACT
NEUROMUSCULAR SYMPTOMS IN PATIENTS
WITH OLD POLIONYELITIS
by
M. C. Dalakas et al

Some patients with a past history of acute poliomyelitis experience not only a residual muscle weakness from the initial illness, but also develope, many years later, a slowly progressive muscle weakness.

The authors used chemical and microscopic techniques to examine muscle tissue biopsies from late poliomyelitis patients.

The authors coined the phrase late progressive post-poliomyelitis muscular atrophy (late-PPMA) to describe the symptoms of ten of the seventeen patients who showed signs of new motor neuron disease.

Some of the previously affected motor neurons that escaped death have remained in a borderline or below normal state of functioning, after a period of time, these neurons can not maintain their metabolic demands and subsequently cease functioning.

The authors conclude that an immune response or persistent low grade virus infection are possible contributing factors in late-PPMA. The authors reccomend further study in these areas.

Ted Vergith M.D.

## A LITTLE CLOUT NEVER HURT NOTHIN'

Several people have written to say that they loan their newsletters to polio friends to read or that they make copies of our mailings and give them to others who have had polio. Under most circumstances, this would be most commendable--saves us a buck, helps keep friendships blossoming.

However, this very act of kindness might be harming us all. By passing on our organization's information rather than insisting that other polio survivors contact us, the person meaning only to spread the word might actually be diluting our effectiveness.

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S. M. Wong, in charge of recreation for the disabled at UNO, will present a program on fitness for the disabled at the January 5 meeting of the Omaha support group -- 2 p.m., Rejoice Lutheran Church, 138th and Center.

Mr. Wong's program at UNO is supported by the Hattie B. Monroe Foundation, and is open to the public.

Let's all get out of the post-holiday doldrums by actively supporting this speaker who is donating his afternoon to our cause!

See you there!

Like it or not, this is a numbers game. If we tell doctors, legislators, or persons who hold the pursestrings for research grants, for instance, that we know the names and addresses of 200 polio survivors, we won't even get a buzz out of them. If we can identify 2,000 polios. we might begin to catch their interest. If we are 20,000 strong, we will definitely have some eyes opening, some ears listening. This is called clout.

No matter what changes we want made--doctors to take us seriously, recognition in getting disability, more effective insurance coverage, whatever -- we aren't going to get them unless we have clout.

Currently the Nebraska Polio Survivors Association has about 725 polio survivors on our mailing list. No one really knows how many survivors there actually are in 

Nebraska, but we do know we've only begun to scratch the surface. there are over 300,000 of us in the USA, as it is estimated, then Ne-braska has a long way to go to account for our share.

Here's what you can do to help: urge everyone you know who has had polio to contact us. severity of disability is unimportant here; whether or not a person fits easily into the mainstream of society is not of consequence in this instance.

What matters is that we all stand up and be counted! It's an easy way to help each other, and it may be the only way to let the world know that we are here and that we mean to be dealt with.

Do us all a favor--do your bit to make this an organization with clout!

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WEATHER NOTICES Listen to KFAB for notification of bad weather meeting cancellations in Omaha.

All support group meetings WILL BE HELD if at all possible -- we're a hearty lot!

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