Nebraska NPSA Polio Survivors Association

GLEANINGS

June – July 2015

Fit Bit Sit Fit

By Millie Malone Lill

There is a gadget on the market that straps to your wrist and tells you how many steps you've taken. It's called a Fit Bit. I can't tell you very much about it because I avoid such things. I'm in the Fitness Protection program. It probably tells you that you need to get up and move around at regular intervals and generally nags you to do all the stuff we polio survivors are not supposed to do. I wouldn't be surprised if it has a meter on it to show you how much guilt you should be feeling for not having abs of steel.

I wish there was something similar, let's call it a Sit Fit, a device that would scold polio survivors when they do too much. I would like a screaming alarm that comes on when we even think "I can do that. I can walk the couple of blocks/the flight of stairs/etc. required" Maybe we could incorporate a mild electric shock. I think a Taser would perhaps be overkill, although lying on the ground twitching might be the only rest some of us over achievers get.

For me, standing up from a chair is weight lifting. I will never have abs of steel. I have buns of Jell-O, if that counts, but I doubt it does. Every day I read Facebook. Since I have grown grandchildren, I read posts from their friends and other people their age. One young woman bemoans the fact that she has large feet. Puhlease! I'd be very happy to have large feet if they were both large. I have one medium sized foot and one tiny foot. Another young woman thinks she is too tall. "Short men like short women. Tall men like short women. What do tall women get?" You mean besides crowns at beauty pageants, the stuff off the top shelf, a good view at parades?

It's kinda hard to take these complaints seriously when you are at elbow level… and worse, if they are facing away from you... in your power chair.

Millie's Column (Continued on p. 2)

Zeus Shows Off His Service Dog Skills to NPSA Group

By Elaine Allen

Zeus, a service-dog-in-training, can fetch a pair of slippers, unload a dryer full of clothes, and "power-pull" his master out of a chair.

The 95-pound, black-lab mix paid a visit to the NPSA group during its April 12th meeting, accompanied by Merri Hackbarth, director of service dogs for Domesti-Pups, a Lincoln-based non-profit organization.

Domesti-Pups started with one dog 14 years ago, she said. Dogs are adopted from a shelter or rescued from a puppy mill and are matched with people who need assistance. The dogs are trained to help people with balance and mobility issues, who are hearing-impaired, have seizure disorders, or other physical needs.

Prospective service dogs are given a temperament test. Out of 100 tested, only ten dogs pass the test. After the physical test, only seven remain and by the time the dogs graduate from their training period, there usually only three left. A lot of labs and golden retrievers and mixes make good service dogs, Hackbarth said.

Zeus, the Service Dog (continued on p. 3)

Caregivers Ministry Is Deacon's Call

Eldon Lauber has served as a pastoral associate and deacon at St. Columbkille Catholic Church in Papillion, Nebraska, for over 20 years. Ten years ago he became the primary care provider for his mother, who lived two hours from Papillion. From that stressful experience he recognized a special ministry that was needed: Ministering to caregivers. Lauber spoke to a small group of NPSA members at the May 2015 meeting.

From his experience with his mother, he began to understand the role of caregivers and the toll it takes on their health. "They get lost in the shuffle of taking care of their loved ones," Lauber explained. "Full-time care almost consumes them."

Lauber holds a Master's degree in Pastoral Ministry and his research found that six out of every ten caregivers die before the person for whom they're caring. "I started thinking of a better way to reach out to these caregivers."

In a parish of 3,000 families, he wondered, "How can we do this? We already had a bereavement support group. Maybe a caregivers' support group? When I proposed the idea five years ago, our pastor, Father Damian Zurlein, wholeheartedly agreed. I pulled together a core group called TLC for Caregivers." Open to the entire community, TLC for Caregivers is a faith-based support group designed to nurture the mind, body and spirit.

Lauber said all kinds of caregivers participate in the groups: those who care for people with cancer, ALS, MS, and Parkinson's, a polio survivor, profoundly deaf children, and children with genetic birth defects. Groups are about eight members and meet at various times, for not more than 1-1/2 hours. Caregivers go beyond the meeting by providing support for one another. "I marvel at the strength of these people," Lauber said. "It's our Christian duty, to love God and our neighbor." He reminds people to pray for caregivers. "If you know people like that, it's important to reach out and ask them how they're doing. Encourage them. The biggest challenge in our ministry is to help caregivers to ask for help. When you have that kind of knowledge, it's important to pass that on to someone else who's going through it. Share your experience," he suggested. The deacon said he feels "blessed that this ministry to develop into what I envisioned. It's a joyful ministry."

Millie's Column *(continued from p. 1)*

"Let's design a gadget for us, for polio survivors, the 'I Can Do This Myself' people."

Let's design a gadget for us polio survivors, the 'I Can Do This Myself' people. It should have the aforementioned alarm when we get those crazy thoughts that if we ignore PPS it will go away. In addition, an air horn-type beeper would be handy for when we become invisible in our chairs. A remote control that would automatically re-park illegally-parked cars taking up our handicapped spots would be nice. Perhaps a reward of some kind for not overdoing? I'm not saying we should never move, but with the 'Type A' polio personality, that is not the problem. Our normal, daily activities are usually plenty. Add in some fun stuff, subtract the stuff that uses up our energy but is not fun...I'm thinking housework, shoveling the walk, stuff like that...and it would be ideal.

I'm open for suggestions here, folks. Anything that makes our lives easier. How about that meter I'm always wanting? You know, the one that tells you when you have used up one half of your energy for the day and how much of your day is left so you can budget accordingly. We could incorporate a blood pressure monitor, a thingie that reads your pulse, tells you when you need a nap, sedates you when you refuse to take your nap, and a flashing message that says, Sit Down. NOW! If you have any idea how to get this thing manufactured, please let me know. Funding would be good, too. I'll be here waiting.

Zeus, the Service Dog *(Continued from p. 1)*

The choice of a breed for a person is also determined by the energy level needed. For example, a young girl with seizures needed a dog with high energy, while the woman who will be adopting Zeus has multiple sclerosis and needs a large, low-energy dog. “It’s very important to look at personalities to match the person with the dog,” Hackbarth explained.

“The dogs also help break down barriers for people with disabilities. People who see those who are in wheelchairs or scooters, that's what they see. But with a service dog, that diverts the attention and breaks down the barrier.”

Once the dogs are matched to a person, they are turned over to inmates in one of Nebraska’s correctional facilities, where the inmates train a dog for the specific needs of the person who the dog will serve. Because training dogs take so much time and attention, inmates cannot work at a job inside the facility and they don't get paid to train the animals. The inmates work with the dogs for nearly a year before the dogs are turned over to their new masters.

Dogs are trained to open and close doors and refrigerators, unload a clothes dryer, to turn lights on and off. Zeus demonstrated his skills during the meeting. He carried a purse, closed a door, picked up keys, and pulled Hackbarth up from a sitting position.

Hackbarth explained that insurance companies usually will not cover the expense of purchasing and training a dog. She said most people find outside funding or hold special fundraising events to help defray the cost of obtaining a service dog.

For more information, contact Domesti-Pups: info@domesti-pups.org

IN THE NEWS & RESOURCES

Domesti-Pups
PO Box 4782
Lincoln, NE 68504
Toll-Free: 1-866-515-PUPS
Email: info@domesti-pups.org
Web: http://www.domesti-pups.org/

TLC for Caregivers
Deacon Eldon Lauber
Saint Columbkille Parish
402-339-3285, ext. 105
Email: Ellauber@archomaha.org

Hotline for Disability Services
301 Centennial Mall S, Box 94987
Lincoln, NE 68509
Toll-Free Number: 1-800-742-7594
Email: shari.bahensky@nebraska.gov
Web: www.cap.ne.gov/hotline_services

Nebraska Chapter of the March of Dimes:
Mary Larsen, Director Program
Services/Advocacy Government Affairs
11640 Arbor St. Suite 102
Omaha, NE 68144
Phone: 402-496-7111
Email: MCLarsen@marchofdimes.com

Polio Health International’s Post-Polio Directory: www.post-polio.org/net/pdirhm.html

History of Polio website:
http://86735198.nhd.weebly.com/
NPSA’s 30th Anniversary Video:
https://vimeo.com/105055161

SAVE THE DATE

Sunday, October 4, 2015
NPSA's 31st Annual Reunion

Featured Speaker:

Polio Health International

Executive Director

Joan Headley

Watch for reservation details in the August-September issue of **GLEANINGS**

Thank You to Our Donors

No matter the amount contributed, each gift helps NPSA achieve its mission. All gifts are fully tax-deductible because we are a 501(c)(3) non-profit organization. Please consider NPSA in your charitable giving for 2015. We're grateful to our donor for the gift received from *April 21 through June 16, 2015:*

Mr. David Rockenbach, Crete, Nebraska

2015 NPSA Meetings

July 12: The Hunger Collaborative and Homemade Ice Cream Social
August 2: Marjorie Farris, Life-Long Learner
September 13: To be announced
October 4: Annual Reunion
November 1: To be announced

Our meetings are held on the first Sunday of each month from February through November, unless it's a Sunday before or after a national holiday. We meet between 2:00 – 4:00 p.m. at the Bloomfield Forum Community Room, 9804 Nicholas Ave., Omaha, NE. Everyone is welcome to attend. Coffee and refreshments are served during the social hour. If you're in the Omaha metro area, you're welcome to join us!

Nebraska Polio Survivors Foundation

Board of Directors

President:
Edward B. Roche, Ph.D.
117 Bellevue Blvd S
Bellevue, NE 68005-2440
Home: 402-292-3781
Work: 402-559-4645
Email: ebroche@cox.net

Vice President and Secretary
Kusum Kharbanda, Ph.D.
770 N. 93rd St., Apt. 4B4
Omaha, NE 68114-2674
Work: 402-995-3752
Email: kkharbanda@unmc.edu

Treasurer
Larry Weber, CPA
Weber & Thorson PC
11205 Wright St. Ste 220
Omaha, NE 68144-4719
Work: 402-330-9900
FAX: 402-330-4022
Email: larry@weberthorson.com

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4011 N. 15th St.
Lincoln, NE 68521
Home: 402-477-2188
Cell: 402-326-3266
Email: groth@neb.rr.com

Executive Director
Elaine J. Allen
PO Box 6076
Omaha, NE 68106
Voice mail: 402-932-5426
Email: npsa.org@hotmail.com

Polio Survivors Sought for Genomics Study

Dear Polio Survivor,

Polio was an enormous threat to many all over the world. It is estimated that there are about 10 to 20 million polio survivors worldwide. Although vaccination fortunately eliminated polio in North America, polio is still spreading in some parts of the world.

An unanswered question is why some people developed complications, such as paralysis, while others did not. Most people who were infected did not develop paralysis. It is possible that there is a genetic predisposition to developing polio, that is, some people may have a variation in their genes that led to complications when they were infected with the polio virus.

Our research team at McMaster University is conducting a study to find out whether there was a genetic susceptibility that led some people to develop paralysis following infection with the polio virus. If you are a polio survivor you may be interested in taking part in this study. This would mean completing a questionnaire and sending us a saliva sample. Participating would help us to gain important knowledge and understanding about why some people developed paralysis and others did not and how the immune system may have responded to the polio virus. The information could help the development of therapies for polio and related viruses which continue to pose a threat to vulnerable people worldwide.

We started our study in Canada working with the March of Dimes Canada and expanded to include Polio survivors in the United States. As of December 9th, 2014, we have enrolled about 1,161 people. We are now hoping to enroll participants from international sites including all European countries, Australia and New Zealand and continue to welcome Canadian and American participants as well.

If you are possibly interested in participating please contact McMaster University at 1.888. 541. 2821 or email polio@mcmaster.ca for more information.

Sincerely,

Mark Loeb MD, MSc, FRCPC
Professor, Departments of Pathology and Molecular Medicine and Clinical Epidemiology and Biostatistics
and
Michael G DeGroote Chair in Infectious Diseases, Division Director, Infectious Diseases, McMaster University, MDCL 3200, 1280 Main St. W, Hamilton, Ontario, Canada

(Editor's note: The researchers sent this letter to NPSA, asking it be printed. NPSA did not solicit this research and is reprinting it as a public service and in keeping with its mission to promote research into polio and post-polio effects.)

June – July 2015

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PO Box 6076
Omaha, NE 68106

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NPSA Mission Statement

The mission of Nebraska Polio Survivors Association is to educate the public and the health care community concerning polio and post-polio syndrome and to respond to the needs of individuals who suffer from the syndrome through group meetings, educational programming and newsletters, financial and other support of research concerning the syndrome and the circulation of research results.

Are you moving? Do you have a friend or family member who survived polio and who would like to receive *Gleanings*? Return this form with your address changes or the name and address of your friend/family member.

Name: ____

Street Address: ____

City/State/Zip: ____

If you'd prefer to receive an **email** version of *Gleanings* instead of a mailed paper copy, please send us an email. In your message, include your name and postal address with your email address to npsa.org@hotmail.com. Thank you for helping us to keep our mailing list current and accurate.