



# Cleanings

February - March 2012

## FREE TALKING BOOKS, SO YOU CAN KEEP ON READING!

By David Oertli, Director of the Talking Book and Braille Service, Nebraska Library Commission.

Nebraskans who experience Post-Polio Syndrome qualify for free talking books from the Nebraska Library Commission (NLC).

You don't need to give up the pleasure of reading just because you struggle to hold up a book, turn its pages or read regular-sized print - not when recorded books, magazines and playback equipment are free to any qualifying Nebraskan.

The NLC's Talking Book and Braille Service, working with the Library of Congress, offers audio books and magazines on digital cartridges. The book collection includes nationwide bestsellers, westerns, biographies, history and romances. Our Prairie Lane Studios record

books and magazines about Nebraska or the Great Plains.

An easy-to-use digital player is loaned to each borrower. It has large buttons, excellent sound quality and can play books or magazines straight through without moving side-selector switches or turning cartridges over. All materials are mailed to borrowers and returned to the Talking Book and Braille Service postage-free.

To qualify for Talking Books, you need to have an application signed by a medical or eye-care professional such as a doctor, nurse, physician assistant, physical therapist or social worker.

Application forms for free service can be printed from this online file: <http://www.nlc.state.ne.us/TBBS/applyfor-service.aspx>

### Postponed to March 4: First NPSA Meeting of 2012

Our March 4 program will feature a return visit by Greg Fisher, exercise therapist from **Prime Home Care-Compassionate Care Hospice**, who will lead the group in exercises for people with limited mobility.

Due to poor road conditions, our February meeting was cancelled. **Jeff Reinhardt, New Horizons Editor and Public Affairs Director for the Eastern Nebraska Office on Aging**, will be rescheduled for the May or June meeting.

NPSA meets from 2 to 4 p.m. in the Community Room of the Bloomfield Forum, 9804 Nicholas Ave., just north of the Westroads Mall in Omaha, Neb.

For more information about the NPSA meetings, please contact [npsa.org@hotmail.com](mailto:npsa.org@hotmail.com) or visit our website at [www.ne-polio.org](http://www.ne-polio.org).

**David Oertli will be the featured guest at the April 1 NPSA meeting.**

## WALKING A TIGHTROPE

By Millie Malone Lill, *Gleanings* columnist

You know how we polio survivors have to “walk a tightrope” between doing so little that we lose function and doing so much that we... well, lose function? I was doing really well, balancing things in such a way that I had very little pain and could handle what pain I did have.

Then I had to have the sleep studies. Remember my last column, when I wrote about the nights I spent in a bowl of cold spaghetti in the amorous embrace of anorexic octopuses? I was doing well up until then.

The second sleep study showed that I needed a CPAP. I told the respiratory tech that CPAP is not recommended for polio survivors. Since he had no knowledge of PPS, he truly didn't believe me. My doctor was also skeptical. I succumbed. Not my usual MO, but I was outgunned. To be honest, I still often feel that I don't really have PPS and that if I just ignore it, it will go away. Note to self: that doesn't work!

The CPAP arrived. I explained to the respiratory technician about my claustrophobia with face masks, so the tech substituted nasal pillows. I tried on all the attachments and sat in a chair while

the tech showed me how to run the CPAP. Sitting up, I did OK. The problem started when I tried to sleep with it that night.

I was told that I could ‘ramp’ the pressure setting from a low of 4 to be increased to a 9 over a period of 25 minutes. I was so sure I could do this! I did expect it to wear me out by the second night, but you know me - I'll try anything once. If I like it, I will do it a bunch of times.

My little dog Fiona sleeps with me. She did not like the looks of the CPAP. She looked at the hose stuck on my face and I felt like I could read her mind: “Hey! Didn't I warn you about the vacuum cleaner? Didn't I tell you it would attack you at some point? And here it is, trying to suck your brains out!” I assured her I was fine, but she was unconvinced and pawed at my hand until I opened my palm and let her rest her head in it. I think she thought she might be able to catch my brain on the way out.

Twenty minutes later, I had to take the thing off. My chest muscles in my back were hurting so badly, I felt as if I'd tried to go up a flight of stairs carrying a heavy load. I had to sit up for a couple hours and convince my lungs that I was not going to let my diaphragm quit. I lay down then for a few hours and tried to sleep for a little while.

My back hurt for three days, which set off the IBS, so then my back hurt and my stomach hurt.

Thank heaven it finally all settled down. I'm telling you all of this just to warn you to be careful about that tightrope. When I fell off it, I think it wrapped itself around my neck and tried to kill me.

*To reach Millie Malone Lill, you can send a message to her email address:*

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*Or send your comments to:*

**NPSA**

**PO Box 6076**

**Omaha, NE 68106**

**Email: [Npsa.org@hotmail.com](mailto:Npsa.org@hotmail.com)**

## I REMEMBER...

By Kate Atkinson, daughter of the late Leonard Jansa

Please accept this donation in memory of my beloved father, Leonard Jansa, who passed away at age 86 on Nov. 3. He enjoyed your newsletter and said he often learned something new about the disease he struggled with since he was 24 years old.

My dad was a trooper, the bravest, strongest man you will ever meet. He suffered from all three kinds of polio, and was in an iron lung for one year. He shouldn't have survived.

But he was a survivor, and maintained independent living until one day before his death. Post-Polio Syndrome took his leg and arm functions in these last few years, but never his spirit.

He was confined to a wheelchair the last 10 years or so. He purchased a motorized scooter, which was his lifeline. We moved him to Iowa and an assisted living center around seven years ago, which helped his peace of mind and gave him assistance as his lifeline when he needed it. Please mention his name if you can in your newsletter in memoriam, and the donation in his name.

Leonard Jansa was our hero. It was a sad holiday without him, but I was the luckiest daughter on earth to have and love him for 57 years.

In Memoriam:

## TERRENCE CONNELLY

FEBRUARY 28, 1937 - JANUARY 20, 2012

Polio survivors in the Omaha metro area are remembering Terrence Connelly, who recently passed away.

“Terry was a Board member. He used to be very active,” Ted Roche, NPSA board vice president, said. “He was responsible for getting the Field Club for our first reunion luncheon. The board used to meet in his home.”

NPSA member Karen Dulany recalled Connelly as “a very nice man.”

Connelly attended his last NPSA meeting in June, 2011, when Rabbi Aryeh Azriel from Temple Israel Synagogue spoke to our group.

A 1956 graduate of Cathedral High School in Omaha, Connelly was employed by EMC Insurance Co. for over 35 years. He is survived by four brothers, five sisters, 19 nieces and nephews, and 26 grandnieces and grandnephews.

Memorials may be sent to Mercy High School or St. Joan of Arc Grade School.

**Mark Your Calendars:  
NPSA Annual Reunion  
Sunday, October 7, 2012**

More details will appear in future issues of Gleanings.

We are grateful for all gifts we receive from our donors. If you wish to support NPSA's mission, please send checks to:

**NPSA  
PO Box 6076  
Omaha, NE 68106**

The Nebraska Polio Survivors Association is a 501(c)(3) non-profit organization. Your gifts are tax-deductible.

## NPSA DONORS

From December 1, 2011, through January 31, 2012, the following donors contributed a total of \$715 in gifts, including memorials.

### In Memoriam

**Leonard Jansa:**  
Kate Atkinson

### Elizabeth Massouris:

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### Annual Gifts:

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## Book Corner

Please help spread the word about a new resource available for polio survivors and their families and healthcare teams: *Traveling Without A Spare: A Survivor's Guide to Navigating the Post-Polio Journey*, written by physician and polio survivor Wenzel A. Leff, MD. The book may be ordered at [www.TravelingWithoutASpare.com](http://www.TravelingWithoutASpare.com).

Excerpt from the website:  
*"In Traveling Without A Spare: A Survivor's Guide to Navigating the Post-Polio Journey, the author draws from his own polio experience and his forty-plus-year career in Internal Medicine, to provide polio survivors – and their families, caregivers, and healthcare team – a clearer understanding of the stages and complexities of polio. This informative book will help survivors evaluate their own bodies and condition, and empower them to make the most of their remaining strength and mobility."*

**Polio on the “Other Side of the World”**

By NPSA Executive Director Elaine J. Allen

Since September 2011, my husband and I have been living on the other side of the world: **Muscat, Oman**.

Before we left, the NPSA Board agreed to allow me to manage this wonderful organization remotely. I'd like to express my thanks to the board and to acknowledge the excellent assistance of MaverickPR, a team of PRSSA members at the University of Nebraska Omaha.

Before leaving, we received polio booster shots in case we made a trip across

the Arabian Sea to India. We haven't travelled there yet, but we've been to Nepal on India's northeastern border.

No sooner had we gotten settled than I began to notice frequent stories about polio eradication efforts on this side of the world, where the wild polio virus is still actively infecting children.

Here are a few headlines and summaries from polio-related stories I've been following on this side of the world during the past six months:

*“NEWS IN BRIEF: Bihar Reported No Polio Case in Last One Year,” Oman Daily Journal, Sept. 13, 2011*

Bihar is a district in northeast India where no cases of polio were reported from September 2010 to September 2011. In 2009, Bihar had recorded the second-highest number of polio cases in India.

*“India Close to Wiping Out Polio: Minister,” Muscat Daily, Oct. 25, 2011*

Quoting the article: *“Ridding itself of polio would be a major symbolic milestone for a nation desperate to move past its image as a Third World country and take its place as a major global player.”* Neighboring Afghanistan and Pakistan continue to have polio outbreaks.

*“WHO Hails India's New Polio Eradication Record,” Muscat Daily, Jan. 15, 2012*

In a news release, the World Health Organization commended India's one year of being a ‘polio-free nation,’ calling it a major achievement. However, only three days later, this discouraging story appeared:

*“Afghan Polio Cases Rise, Govt Appeals to Militants,” Muscat Daily, Jan. 18, 2012*

Quoting the article: *“Afghan President Hamid Karzai urged militant insurgents to allow health teams to vaccinate children in war-torn parts of the country, where polio cases have risen sharply. A total of 80 cases were reported in Afghanistan last year, a three-fold increase over 2010, the Afghan health ministry said, marking a major setback in the drive to eradicate polio worldwide.”*

While the NPSA's mission is “to educate the public and the health care community concerning polio and post-polio syndrome,” as individual members I hope you continue to raise awareness that polio has not been eradicated from **this** side of the world.

## NPSA Board of Directors

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*and*

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### **Executive Director**

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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.

NPSA was founded in 1984 by Nancy Baldwin Carter.



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