

## The Dragon

By Millie Malone Lill

Once upon a time, a Dragon roamed the earth. It swam in polluted water and it flew from country to country. It bit little children mostly, but sometimes the Dragon managed to snag an adult as well. It would grab its victim's spinal column and spread its venom, the polio virus, throughout the body, shot gunning throughout the system and killing half or more of the motor neurons. If enough neurons were killed off, the victim was paralyzed. But even those who were not paralyzed lost half or so of their working neurons.

Human bodies are wonderfully made, and the remaining neurons rushed to the defense of their fallen comrades, seeing to it that the orphaned muscle groups had a way to send and receive messages with the brain. The more that was asked of these valiant helper neurons, the more they responded.

"There you go!" the doctors and nurses told us. "We've made you completely well. Go on your way, do whatever anyone else does. You are cured!" They believed it and they made us believe it. We pushed ourselves as hard as we could, not knowing that those hardworking helper neurons were getting tired. The Dragon slept.

Years later, the Dragon stirred in his sleep. He could sense the fatigue of those foster parent neurons that had adopted the orphaned muscle groups. He smiled in his sleep because he knew that part of his venom made us believe we

could do whatever we wanted physically. Many of us were into sports and fitness regimens, trying desperately to convince ourselves we were cured of Polio. We served in the military, we ran in marathons, we had professional careers. We were just like everyone else. Weren't we?

One by one, then in groups, those overworked foster parent neurons dropped out of service. Some died of natural old age, as all neurons do over time, and some just collapsed from stress and fatigue. The muscle groups they

were fostering were now, once again, orphaned. Some of the muscles refused to do anything, others decided to twitch or spasm or cramp. There was no communication between them and the brain, so they didn't know what they were expected to do. If fewer than half the neurons were damaged, we didn't expect to get Post-Polio Syndrome, but even those with non-paralytic polio suffered. Now there was pain in muscles and joints. Still, we soldiered on, but it took us three times as



Dragon by Kim Kanhwan

much effort to do the same things our peers without polio did. We were so tired all the time, but after all this time we were used to ignoring the pain and fatigue. *(Continued on next page.)*

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We went to Physical Therapists, who urged us to try harder. "Work harder, you can do it. Use it or lose it," they urged us. So, we tried harder. The overworked neurons gave up in droves. We could no longer do what we did before no matter how hard we tried.

Paraphrasing Yoda, it was "Try or try not, there is no do!" You cannot strengthen a muscle that has no working motor neurons attached to it. It's like trying to tune a radio that is not plugged in.

It took a long time for the medical community to accept what was happening. Some of us, when complaining about the pain and fatigue were referred to mental health professionals, especially those who had no paralysis or atrophied limbs. After a lifetime of overachieving, we had suddenly gotten lazy, in their opinion. Finally, due to the efforts of people like Dr. Richard Bruno, Dr. Lauro Halstead and others, Post-Polio Syndrome was accepted.

Now we no longer tell polio survivors, "Use it or lose it." We say, "Conserve to preserve." We break our tasks down into smaller chunks. Work awhile, then rest for that same amount of time. If it takes more than ten minutes to recover from whatever we were doing, we do less. If it hurts to do something, we don't do it or do a lot less of it. Try to save every motor neuron we can.

Thanks to Rotary International, now there's a muzzle on the Polio Dragon, but it only remains in place if we are diligent about vaccinating our children. If we grow lax in that endeavor, the Polio Dragon could awaken and spread his venom in the world again.

*(Editor's note: The Dragon was first published in Polio Perspective and is used with permission of the author.)*

### 2019 NPSA Remaining Meetings

*Sept. 8: Superior Van & Mobility  
(Delayed one week because of Labor Day)*

*October 6: Reunion (See Invitation on Page 5)*

*November 3: Kohls Pharmacy & Homecare*

We meet at Bloomfield Independent Living, 9804 Nicholas Ave., Omaha, NE,

### **2019 List of Donors**

*Thank you to our donors who sent gifts to NPSA from May through July. As a non-profit organization, we rely on the gifts from our members and other generous donors who support our mission.*

*We encourage anyone who finds value in this newsletter, or anyone who wants to honor a polio survivor or memorialize a departed loved one or friend, to send a tax-*

*deductible gift to the address listed below.*

Sandy Fischer, Bettendorf, IA

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*Your gifts to NPSA can be sent at any time during the year to this address:*

Nebraska Polio Survivors Association  
PO Box 6076  
Omaha, NE 68106

## Thou Shalt Not Fall

By Chip Mackenzie

Falling has been a fact of my life since I was infected with polio at the age of six. I have strong arms and fast reflexes, so falling was not a problem... until it was. But I have found ways to protect myself and still enjoy life.

My last fall was from my wheelchair. Because I damaged my left knee, I have lost the ability to stand on the left leg and pivot. My right leg was the stronger one, but polio had affected the proprioceptors that allow a person the ability to sense the position of the leg. So, I kept falling because the right leg was bent, but I did not sense it. I knew that another fall would result in more loss of function.

Also, I had been noticing how many older people seem to have a fall prior to their death. I needed to figure out how to prevent future falls.

I spend most of my waking hours in my chair. Because of the knee injury, I use a slide board to get into my wife's car and into my bed. With a little care, both transfers can be done safely. I slide from my chair into a shower chair.

Staying safe in my chair is made more difficult by my often-damaged shoulders. I've had right shoulder rotator cup surgery, but my left shoulder is way past the time when it can be repaired. To get greater function from my arms, I need to stretch my shoulders, which are strong but hurt when transferring and standing up. The pain I was feeling was due to a combination of muscle imbalances and limited motion.

In addition to shoulder stretching and strengthening exercises, I stretch my back daily. If I am loose enough, I can bend over to pick things up quite safely. But bending over in my chair is made more difficult by the three-inch air cushion I sit on. I place one or both feet on the floor, which gives me a more stable base. For a long reach, I use one hand to hold myself in the chair while I pick things up with the other. Ideally, I hold on to a table or counter when I bend over.

Some time ago, I ordered a lift seat. I opened it up, put it on my chair, sat down and then bent over too far. After I picked myself up from the floor, I read the instructions which warned about bending over too far.

I own at least 10 or 15 grabbers. I use them to pick up the dogs' training pads and grab dishes off the floor after the dogs finish cleaning them.

It is part of my personality to do things I should not be able to do or should not do. Last year when my wife, Mary Ellen, broke her femur, I took over taking out the trash and moving the garbage cans down the sloping driveway

to the street. Fortunately, Mary Ellen reminds me to put on my seat belt, so I haven't been injured moving trash cans. However, on rare occasions, I lose control of a can, but my seat belt keeps me safely in my six-wheeled "ATV". In the winter, I still use the snow blower on the first 8 feet of driveway.

Being in my chair hasn't slowed me down much. Recently, a neighbor stopped his SUV and asked me if I was obeying the speed limit as I raced down the driveway to get the mail. My attitude has always been that if I must use a chair, I might as well have some fun. There's no point in growing old if you can't continue to have fun!



*Chip and Mary Ellen at a 2017 NPSA meeting.*

## Madonna Rehabilitation Hospitals

By Chip Mackenzie

John Glenn, Vice President of Development for the Madonna Foundation, welcomed NPSA members who visited the new Madonna Rehabilitation Hospital in west Omaha during the June 2<sup>nd</sup> monthly meeting. John's mother had polio, so he knew something about the journey we are on.

The Madonna Rehabilitation Hospitals are in the top 3% of rehabilitation hospitals in the country. The first hospital was in Lincoln, NE, and started as a nursing home. They had a waiting list for their rehabilitation services as soon as the hospital was completed. The Omaha hospital was built a couple of years ago but it, too, has a waiting list for rooms.

These hospitals specialize in doing whatever is required to rehabilitate the patient. This includes focused physical therapist attention and the latest in electronic equipment. If the needed equipment does not exist, they collaborate with UNO's Biomechanics Lab to create what is needed. All rooms have a pull-out double bed, so family members can stay in the patient's room if needed.

The Omaha Madonna facility is expanding its staff of physiatrists, physicians whose specialty is Physical Medicine and Rehabilitation (PM&R). They treat a wide

variety of medical conditions affecting the brain, spinal cord, nerves, bones, joints, ligaments, muscles, and tendons.

This specialty is important to most polio survivors as we need doctors who understand what we are facing and who will be creative in treating our symptoms and limitations. Unfortunately, most physiatrists do not have a focus on Post-Polio Syndrome (PPS). As a group, NPSA hopes to help educate Madonna's physiatrists about PPS and related issues.

## Post-Polio Online Resources

### Atlanta Post-Polio Association:

[www.atlantapostpolio.com](http://www.atlantapostpolio.com)

### NPSA Website: [www.ne-polio.org](http://www.ne-polio.org)

Facebook page:

[www.facebook.com/NebraskaPolioSurvivorsAssociation](https://www.facebook.com/NebraskaPolioSurvivorsAssociation)

### PA Polio Survivors Network:

[www.papolionetwork.org](http://www.papolionetwork.org)

### Post-polio Health International:

PHI offers many helpful resources online.

Home Page: [www.post-polio.org](http://www.post-polio.org)

Provider Directory (PDF): [www.post-polio.org/net/PDIR.pdf](http://www.post-polio.org/net/PDIR.pdf)

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**Reunion Invitation**

*You are invited to the*

Nebraska Polio  
Survivors Association  
**35<sup>th</sup> Annual Reunion**  
**Sunday, October 6<sup>th</sup>**

Featured Speaker:

**Dr. Kevin J. Collins**



Physiatrist, North Little Rock, Arkansas

1:30 to 4:00 p.m.  
Bloomfield Independent Living  
Community Room  
9804 Nicholas Avenue  
Omaha, Nebraska

Catered buffet meal will be served at  
2:00, followed by Dr. Collins's presentation  
and a discussion.

**Registration Fee:**

\$15 per person, in advance  
\$20 per person, at the door

Registration form on next page.



## NPSA Mission Statement

The mission of the 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.

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**NPSA 35<sup>th</sup> Annual Reunion Registration Form**  
**See invitation inside on Page 5**

**Name(s):**

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**Address:**

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**Number Attending:**

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**Registration amount enclosed (\$15 per person in advance):**

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Return this form and your registration fee no later than Saturday, September 28<sup>th</sup>, to  
PO Box 6076, Omaha, NE 68106