

Gleanings

Nebraska Polio Survivors Association

June/July 2011

NPSA Happenings

by Elaine Allen, NPSA Executive director

Two dynamic speakers presented their international perspectives at our May and June meetings of the Nebraska Polio Survivors Association. On May 1st, a journalism professor described his recent trip to Kabul, Afghanistan. And on June 5th, the rabbi from Omaha's Temple Israel told his story as a polio survivor growing up in Israel and immigrating to the United States.

May 1st: Dr. Chris Allen

Dr. Chris Allen, associate professor of communication at the University of Nebraska-Omaha (UNO), visited Kabul University last December to assess the teaching needs of the journalism faculty. He showed our group photos he took of the people he met and the places he visited. In the interest of full disclosure, Chris is my husband.

The people of Kabul live in an overpopulated city hazy with air pollution and open storm sewers, and where the busiest streets have very few traffic control devices. "I think I saw maybe one stop light and one stop sign in the whole city," Allen said. People build homes on the mountainsides surrounding Kabul. "They're squatters, in essence, because the land is free," he said, noting that no building standards exist for these houses, with no running water, nor any sewage systems.

As part of its Center for Afghanistan Studies, UNO has a permanent presence in Kabul: a compound where UNO staff members live and guests stay, and the UNO Press, where textbooks and other materials are printed for the teacher

education program. Teachers come from all over Afghanistan to attend UNO's Teacher Education classes during their school breaks. They crowd into dark, small, unheated classrooms to learn how to teach their students.

One school in Kabul, the Daoud School, teaches mostly orphans. The school day is split into two sessions a day, so the orphans can attend half-days and then go out and beg the rest of the day. The future of the school was in doubt, however, as Allen received word the school's director, Daoud, was evacuated to India with his wife, Firazon, who was in danger from the Taliban because of her association with the UNO Teacher Education program.

(Continue on page 2)

Anesthesia Use in Polio Survivors: What's New?



By Selma H. Calmes, MD

Do we know anything new about anesthesia for polio survivors? By reviewing reports in medical journals we find that in the last two years (2008-2010), there were five case reports (each about a single post-polio patient having anesthesia) in the medical literature and one study of a group. We will look at useful aspects of these cases and also comment on two other aspects of anesthesia care that are important.

(Continued on page 3)

NPSA Happenings (continued from page 1)

He showed slides of a street vendors selling vegetables and beggars, mostly orphans, who dodge traffic to clean windshields with dirty rags or try to sell visitors maps of Kabul “for a \$10,000 starting price! They love to negotiate the price of everything,” Allen joked.

Guards armed with automatic weapons greeted them at the door of most stores and restaurants. “When we went to a local pizza place, I didn’t think it was wise to take a photo of the guard holding an AK-47,” he said. Despite the presence of military personnel and armed guards, Allen said he felt relatively safe, since he was not allowed to venture out alone in the city.

In a reciprocal visit, UNO hosted five Kabul University faculty members from late March to early June. Another UNO professor will make another trip to Kabul in September.

June 5th: Rabbi Aryeh Azriel

Rabbi Aryeh Azriel has been a peace and social justice activist for his entire career. The rabbi has a delightful sense of humor and generously sprinkled his June 5th talk with stories of how he uses his sense of humor to cope with his physical as well as his spiritual challenges.

“I used to curse at God,” Azriel said, “because I couldn’t join the Israeli Army like all my friends. I stopped cursing and became grateful for my polio when my friends started coming home in body bags from the 1967 Six Day War.”

Rabbi Azriel was born in Israel in 1949 and, at six months old, was infected with the polio virus. He was paralyzed from the waist down until he was 15, when he underwent orthopedic surgery that enabled him to walk with a brace on his right leg. “The orthopedic surgeons used me as a model. I had 14 surgeries by the time I was 14,” the rabbi said. “My left leg is extremely strong but my right

leg is worthless without my brace.” He began wearing the brace 16 years ago, when he broke his leg.

“I fly a lot and so I get a lot of massages from the TSA security guards because of my brace,” he joked.

Azriel says his congregation became active in social justice in part because of his polio. “When I came here for my interview, they knew I had polio and created a ramp for me to walk up for my interview. Me coming to their congregation opened their eyes” to accessibility issues as well as to peace and social justice causes. He recently completed a successful capital fundraising campaign to build a new synagogue at the future Tri-Faith Center, the only one of its kind in the world. Temple Israel, an Islamic mosque, and an Episcopal church will be built in a complex on the same site in western Omaha.

Nothing, not even 9/11 and TSA security, has stopped him from traveling all over the world. He described Prague and Venice as very difficult to navigate without a wheelchair. In Budapest, he bought a walker with a seat. Israel is very accommodating, mostly because so many people have been injured or lost limbs in the various wars and bombings.

He’s planning a trip to New York with a group of his students. He bought a cane so he can “do New York” and keep up with them. “Walking in New York at 61 is harder than at 35,” he said. As he ages, he acknowledged that his post-polio symptoms might limit his ability to perform his rabbinical duties. “I have to walk hospital corridors and bury members of my congregation. Those things are hard to do in a wheelchair or scooter,” he said.

But, Rabbi Azriel from Temple Israel ended his talk with a spiritual perspective. “The whole world is a very narrow bridge and the only thing is for us not to be afraid. The atmosphere of

paranoia after 9/11 was poisonous. The issue is not to get stuck on the bridge. Jews are constantly walking on the bridge.”

Anesthesia Use in Polio Survivors: What's New? (Continued from page 1)

Three of the five case reports were about regional anesthesia (RA). Regional anesthesia means that a local anesthesia drug, such as lidocaine, is injected to numb nerves in the back (spinal or epidural) or other body locations such as arms or legs (various nerve blocks). It is very safe and is preferred to general anesthesia, because it blocks the pain signals coming from the surgery site to the brain. This is very favorable for patients' well-being. However, some operations can't be done with regional anesthesia. It is often technically hard to do RA in post-polio patients with scoliosis, especially if Harrington rods are present.

There is a new tool to help place RA: portable ultrasound (US) devices that help anesthesiologists find exactly where to administer the anesthesia. This technique is now commonly used in the United States, especially in teaching hospitals. One of the five cases was the first to report using US to place a spinal anesthetic in a post-polio patient with Harrington rods. Another case of regional anesthesia involved severe scoliosis and reported using a computed tomography (CT) scan to look at a post-polio patient's back anatomy before trying spinal anesthesia. Both techniques helped the anesthesiologists know where to place the needle for local anesthesia successfully and easily. The third case report on regional anesthesia was about a nerve block of the leg for postoperative pain relief after surgery on that leg.

The group study was from Brazil and reported on 123 patients having 162 operations, mostly orthopedic surgery. Mean patient age was young - 35 years, and only three patients had serious medical diseases in addition to having had

polio. Regional anesthesia was used for 64 percent of patients. No significant anesthesia complications occurred. These patients were followed for 22 months postoperatively, and there was no change in neurologic status.

This study documents that young post-polio patients do well during anesthesia, especially with RA. However, American patients are much older, in their 70s and 80s, and so also have diseases of aging, such as heart disease, diabetes and hypertension, all significant for anesthesia risk. Often, these diseases of aging are much more important than any post-polio issues. So, we still need a large group study of the U.S. polio population during anesthesia.

What do we learn from these reports? First, this is increasing evidence that RA can be safely used in post-polio patients. And, so far, there is no evidence that PPS gets worse after RA. (This had been a concern after inflammatory proteins were found in the spinal fluid of some post-polio patients.) Technical difficulties can be overcome by using US or CT imaging. Also, regional anesthesia can safely be used for postop pain relief. So polio patients can experience the many benefits of modern anesthesia care!

The importance of two other aspects of anesthesia care for post-polio patients is becoming clearer: the need for preoperative pulmonary function tests and sleep apnea issues. Respiratory muscle function gets worse as we age, especially for those who had polio. It is important to know what a particular patient's pulmonary status is before most operations, especially upper abdominal or chest operations. This is measured with pulmonary function tests (PFTs) by a pulmonary physician. Those who used iron lungs should definitely have preop PFTs, because they seem to be at higher risk for postop respiratory failure. Lung function should be optimized by treating any infection, controlling bronchospasm and assisting coughing before high-risk patients have major surgery, and a pulmonologist needs to be involved in the postop care.

Sleep apnea is common in post-polio patients, and many need CPAP /BiPAP devices. Sleep apnea is well-documented to be a risk factor for anesthesia incidents, both at the beginning of anesthesia and, especially, at the end of the case as patients begin to breathe on their own. Useful guidelines are in place to improve safety during anesthesia. Patients with sleep apnea, especially those on CPAP /BiPAP, should let the surgeons know this early in the surgery scheduling process, so they can alert everyone on the surgical team.

Patients should bring their CPAP devices to the hospital and, after the breathing tube is removed, CPAP should begin. This requires someone to set up the machine, usually a respiratory therapist. If regional anesthesia is used, the CPAP device can even be used during the procedure, although not all anesthesiologists are comfortable with this.

Should we make any changes in the present recommendations for anesthesia for polio survivors? Regional anesthesia (RA) appears to be safe for post-polio patients, and the benefits - in terms of pain relief and anesthesia safety - are worth a possible small risk. So, the recommendations stand as is. It is essential to realize that the recommendations are not based on actual data; there is no significant data yet about how polio patients actually do during anesthesia.

Reprinted from *Post-Polio Health* (formerly called *Polio Network News*) with permission of *Post-Polio Health*

Our Readers Write

Dear Millie,

I am a polio survivor. I have appreciated "The Gleanings" newsletter. It has helped me to keep up on information dealing with polio.

I do not need to receive it by mail. You can take my name off the subscriber list. I will use the online site.

Thank you for your assistance.
Elaine Johnson

Client Assistance Program (CAP)

402-471-3656

Hotline for Disability Services

402-471-0801

Toll-Free: 800-742-7594

Web: www.cap.ne.gov

The Nebraska Client Assistance Program (CAP) is a free service to help you find solutions if you have any questions or concerns regarding services from:

* Vocational Rehabilitation

* Nebraska Commission for the Blind and Visually Impaired, or the

* Centers for Independent Living

The Hotline for Disability Services is an information and referral resource for Nebraskans with disabilities. Hotline Specialists assist in identifying programs and services available to persons with disabilities and how to contact agencies that can meet their needs. Families of persons with disabilities also may use the Hotline.

Available Mondays – Fridays 8 a.m. – 4:30 p.m.
(Central Time), except on state holidays

FOUR LETTER WORDS

by Millie Malone Lill

One is not supposed to use four letter words in mixed company. Or in any company, truthfully. However, what about my very least-loved four letter word? CAN'T. Yes, that's the one. I loathe that word. It was never a part of my vocabulary till the last few years. Oh, when I was young, I heard it a lot. "You CAN'T do that. You are too (fill in the blanks: young, short, unprepared). Of course, as a polio survivor, that meant I had to be sure and do that forbidden thing as soon as possible if not sooner. Its corollary, MUST, had an equal and opposite effect. Upon hearing that word, my heels would automatically dig in, my ears would flatten themselves to my skull, I'd get all squinty-eyed with rebellion and I WOULD NOT do whatever followed that dread word.

Now things have changed. PPS has pulled a switcheroo on me. I find myself using that horrid C word. I look at the shelves in my cupboard. Can I reach that top one? Not a hope. The C word floats ominously near the surface. OK, what if I stand on my stepstool? Ummm...my bad hip fairly screams that obscenity at me, along with a few others. I used to be married to a tall man, so the top cupboards were not a problem, but that ship has sailed, along with the ability to climb on the stool.

What is the solution, then? For me, it means getting rid of my kitchen table and chairs, which I rarely use because I eat in front of the TV or computer or use the dining room table. If I put a base cabinet in there and equip it with sliding shelves, I will have plenty of storage space and the upper shelves of the wall cabinets can just be that way. They can taunt me with their empty spaces and I won't care.

If only that were the only time the dreaded C word came up. When asked to do something that I know is going to be too difficult, it would be wonderful if I could learn to wrap my reluctant tongue around that word and say, "Sorry. I C....C....C...." It just won't come out. So I end up overdoing, straining already overworked neurons.

There was a time when, living in a very cold and snowy climate, I was forced to say the C word on a daily basis. My polio affected leg makes walking in deep snow difficult, if not impossible. My foot bends upward and puts an awful strain on my leg muscles. Slick surfaces are equally dangerous. I fell a lot up there. My neighbors were wonderful, but they could not hold my hand every time I left the house.

Now, I live in a barrier free building and can avoid at least the daily use of the C word. Some things are just no longer an issue. Now I'm working on learning a new word to use when people ask me to do things that would require me to use the C word. It's quite a simple word, really. You just form your mouth into a circle, place your tongue on

the roof of your mouth and say, "NO." Be careful with this word, as, if the request comes from someone you truly care for, it can easily turn into, "Noo..OK."

In an emergency, I give you permission to use that four letter word. It's alright to say, "I can't." Do it with a smile and I'm sure you will be forgiven.

Meeting Dates

July 10- (because of July 4th weekend, meeting will be held following Sunday)
Speaker: Greg Fisher, Prime Home Care
Topic: Exercises for people with limited mobility

August 7-Speaker: Margo Reikes,
Communication Director, Better Business
Bureau of Nebraska

September 11- (because of Labor Day weekend, meeting will be held the following Sunday)
Topic: To be announced.

October 2-Annual Reunion Dinner, Field Club of Omaha. IA and NE members: Watch for postcard invitation in mid-August

No meetings in December or in January, 2012

Donations

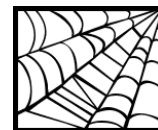
Your donations to the Nebraska Polio Survivors Association (a501 c3 non-profit organization) are tax-deductible and help the mission of the NPSA.

Dixie L. Eldridge
 Marie R. Galda
 Helen Jasa
 Leonard Jansa
 Susan Kneten
 Elizabeth Massouris
 Eddie Moody
 John S. Schnack
 Mary Thomas
 Kenneth Zoeller
 Kathryn Barrett

Gifts in memory of Marvin Pekny, a long-time member who died in May 2011, are still being received and have totaled nearly \$2,000 as of this printing. A partial list of memorial gifts in Marvin's name appears below. The remainder of his memorials will be published in the August/September issue of Gleanings.

Ward & Parker Bean
 Ed and Emma Chance
 Pat & Connie Conlon
 E. Irene Dodder
 Farmers National Company
 Janie and Harry Hoch, Jr.
 Brian and Diane Hunter
 Paul and Phyllis Otto
 Janelle Maricle
 Jim & Mary Mason
 Network CB
 Stephen and Jacquie Rallis
 Duane F. Atteberry

Your donations may be sent to:
Nebraska Polio Survivors Association
PO Box 6076
Omaha, NE 68106-6076



Web Corner

Our site:

<http://ne-polio.org/>

Post Polio Syndrome

<http://www.traveldoctoronline.net/post-polio-syndrome-MTEyMDI3ODc=.htm>

The June 2011 newsletter from the Rancho Los Amigos Post-Polio Support Group is now online. The newsletter features a report based on Dr. Vance Eberly's presentation to the Rancho support group. Dr. Eberly is the orthopedic specialist in the Rancho Los Amigos National Rehabilitation Center polio clinic. You can view the report by going to the support group's web site:

www.ranchoppsg.com or by clicking this link:
http://www.ranchoppsg.com/2011-6_newsletter.pdf

Polio Place:

<http://www.polioplace.org/history/artifacts/thistletown>

Assistance Dogs give gift of independence:

<http://www.calgaryherald.com/health/Assistance+dogs+give+gift+independence/4773046/story.html>

Information on Disabilities Exchange:

<http://www.disabilityinfo.org/mnip/db/rdb/ResourceDetail.aspx?id=10812>

Disaboom Outreach.

Disabled Dealer Magazine. Handicap Classifieds of New and Pre-Owned Wheel Chairs, Adaptive Equipment

<http://www.disableddealer.com/>

Information on the free Medline search service is available at:

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi>

Nebraska Polio Survivors Association

PO Box 6076

Omaha, NE 68106-6076

FAX: 402-932-5429

Voice mailbox: 402-932-5426

Board of Directors

President

Eugene Roth

4011 N. 15th St.

Lincoln, NE 68521

Home: 402-477-2188

Cell: 402-326-3266

Email: groth@neb.rr.com

Vice President

Edward B. Roche

117 Bellevue Blvd A.

Bellevue, NE 68005-2440

Home: 402-292-3781

Work: 402-559-4645

Email: ebroche@cox.net

Secretary

Barbara Roth

4011 N. 15th St.

Lincoln, NE 68521

Home: 402-477-2188

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

Executive Director

Elaine J. Allen

5809 S. 107th St.

Omaha, NE 68127

Home: 402-331-5784

Cell: 402-657-5048

Personal email: allen233@cox.net

NPSA email: NPSA.org@hotmail.com

At-Large Member

Kusum Kharbanda, Ph.D

770 N. 93rd St., Apt. 484

Omaha, NE 68114-2674

Home: 402-399-8490

Work: 402-346-8800 ext, 3736

Email: kkharbanda@unmc.edu

Newsletter Editor

Millie Malone Lill

214 S. 20th St., Apt. 215

Denison, IA 51442

Home: 712-267-8078 *new number*

Email: mil.lill@gmail.com

SAVE THE DATE

Oct. 2nd Annual Reunion Dinner

Guest speaker: Nebraska State Senator Gwen Howard

Entertainment: Tom Roth

Mistress of Ceremonies: Storyteller Rita Paskowitz

Location: Field Club of Omaha

Time: 1-4 PM

Nebraska Polio Survivors Association

PO Box 6076

Omaha, NE 68106-6076