Gleanings

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Elaine Allen's Biography

I am pleased to be joining the Nebraska Polio Survivors Association as your new Executive Director. I'm originally from northwest Iowa and attended high school in Sioux City, where my mother still lives. My degrees are in journalism and mass communication from Iowa State University. My husband, Dr. Chris Allen, teaches journalism at the University of Nebraska-Omaha. We have been married for 24 years and have two adult children, Sarah and Joe. Sarah works at the University of Arkansas-Fayetteville. Joe works at West Corporation in Omaha. We have lived in Omaha since 1996.

My experience, both professionally and as a volunteer, includes fundraising events for my church, St. Columbkille in Papillion, and for educational and non-profit organizations. For several years, I've worked for Client Resources, inc. as a technical consultant at many of the larger companies in Omaha, including Blue Cross Blue Shield of Nebraska, ConAgra, First Data, and Northern Natural Gas. I recently started a contract at Mutual of Omaha.

I enjoy singing and listening to all kinds of music, attending Omaha Symphony concerts, and performing in the Omaha Press Club Show as well as occasional productions at the Chanticleer Theatre in Council Bluffs, Iowa.

I look forward to working with the membership and the Board to accomplish the mission of the NPSA.

POLIO RETURNS TO CRIPPLE ANGOLA AND ITS NEIGHBORS

By Cecile de Comarmond (AFP) –

LUANDA — Linda Afonso's right leg is stiff and atrophied but she does not know the name of the disease that made it that way.

The 13-year-old lives in Cacuaco, a sprawling slum in the northern suburbs of the Angolan capital, Luanda. When she was a small child, her leg became partially paralysed.

"My parents took me to the hospital, but they couldn't do anything," she said.

Afonso doesn't know the name of her disease because polio, the acute viral infection that can cause irreversible paralysis or death, was eradicated in Angola in 2002, shortly after she caught it.

Despite Angola's crumbling health infrastructure and poor sanitation in the slums of Luanda -- where thousands of refugees fled during the country's 27-year civil war -- health workers managed to eliminate new polio infections from 2002 to 2005.

But just as anti-polio campaigners chalked up another victory in the international fight against the disease, a strain of the virus reappeared, thought to have been carried by Indian workers employed on post-war rebuilding projects.

In 2010, Angola registered 32 new cases of polio in the Luanda area, in the east of the country and in the exclave province of Cabinda.

The virus also spread to two neighbouring countries where it had been considered eradicated -- 93 cases were reported in the Democratic Republic of the Congo (DRC) and 50 in Congo.

The region was responsible for two-thirds of the cases recorded in Africa last year.

"We imported the polio virus from India and unfortunately exported it to Congo and the DRC," Health Minister Jose Van-Dunem told AFP.

"That's why we have the responsibility, from a moral standpoint, to eradicate it."

POLIO VACCINATION DROPS IN THE US, especially among poor infants and toddlers

Dr. Bruno advocates universal vaccination for polio.

In 2005, polio was reported in five unvaccinated Minnesota children and in one Arizona adult caused by the live polio vaccine no longer used in the US, meaning poliovirus was imported into the country. These cases caused Dr. Bruno to create THE NATIONAL IMMUNIZATION FOR POLIO PREVENTION IN INFANTS AND TODDLERS -- "NIPP IT" -- CAMPAIGN to promote vaccinating the nearly one million poor US children CDC estimates are unvaccinated against polio.

"We start getting not just five cases as in Minnesota, but 50 or 500 cases of polio. Parents are going to wake up and say, 'We should be vaccinating.' The price of not vaccinating is much higher than the potential price of vaccinating."

"The CDC estimates that nearly 93% of US children 19–35 months old are vaccinated against polio. Ninety-three percent sounds good, until you realize that leaves more than one million toddlers unvaccinated. What is worse, toddlers below the poverty line have even lower polio vaccination rates, 89.5% in Newark and 87% in New York City, a rate equal to Asian countries that include Cambodia, Mongolia and Viet Nam. These statistics are especially frightening considering the ease of air travel to the US from Pakistan, Afghanistan, India and Nigeria, where polio has never come under control, and from the ten African and Asian nations that were polio-free but where the poliovirus has been reintroduced. What will happen when a healthy-appearing but polio-infected international traveler lands at an airport and travels through a poor community? Every American child must receive all four doses of the injectable, inactivated polio vaccine. America's polio epidemic could be just a plane ride away."

The 2010 outbreak of polio in Russia makes a first-world polio epidemic a clear and present danger. In 2010, that the American Academy of Pediatrics warned of a North American polio epidemic because of unvaccinated children.

IT'S A MIRACLE

by Millie Malone Lill

How many times has this happened to you? You go into a store without your power chair because you had no way to load it, you came in a friend's car, or you hadn't expected to go in at all. Of course, in these cases the store's electric scooter is already in use. Then you meet someone who doesn't know you very well and they say, "Oh, how wonderful! You don't need your wheelchair anymore! I'm so glad to see you walking!"

What, exactly, is the proper reply to this? Snarling and cursing at them seems rude. Kicking them would cause you to fall on your keister. Smiling and nodding will only encourage them in their endeavor to get you out of your wheelchair and back with the 'normal' people. I don't know about you, but personally, I get very very tired of explaining that I should be using my chair and that

I will pay for this trip big time. Especially since about 2 seconds into this explanation, I can see their eyes glazing over.

The people who say this are well meaning as well as totally ignorant of the workings of PPS. They buy into the ‘confined to a wheelchair’ mindset. Try explaining to an able bodied person that if you use your power chair part of the time, you can do without it part of the time. In most people’s minds, if your hiney ever touches the seat of a wheelchair, you are trapped in that thing forever. Even some of ‘us’ don’t quite get that. I’ve spoken to hundreds of polio survivors over the years and there is an almost universal theme. “I’m going to walk as long as I can. I don’t want to give in and start using a wheelchair.” I’ve also heard, “What will the neighbors think? I don’t want my friends to see me like this.”

OK, let’s take this thing apart. Without your wheelchair, you lurch from one place to another because...guess what? You’ve had polio! You have one leg shorter than the other, which, trust me, is not the optimal means to attain grace. You will not look more like a ‘cripple’ in a wheelchair than you do lurching across the floor, clutching walls and furniture. Face it, people, that makes you look like a drunk. It also uses up energy like crazy. If you have neighbors or friends who will think less of you for doing what’s best for you, maybe you should move and get new friends.

If you use a power chair to shop, to go for a stroll in the neighborhood, or to carry things from here to there, you will save your energy for things you can’t do in a chair. I can’t use my chair in my kitchen or bathroom, but I can and do use it otherwise. Believe it or not, you can use the chair part time. Really. Would I lie to you?

That doesn’t answer the original question, however. If you thought I knew the answer to that question...what do you say to the people who believe your walking is a miracle...you are in for a disappointment. If you know the answer, please let me know.

Web Corner

Here you can some interesting links to information on PPS on the Internet.

http://www.i-sites.net/ppsrl/reslist.html

PolioPlace (http://www.polioplace.org/), an internet repository for medical and practical information, historical records and artifacts, launched on January 30, the 129th anniversary of Franklin D. Roosevelt's birth.

PolioToday.org is published by the Salk Institute for Biological Studies. This website is designed to raise awareness of post-polio syndrome and to be a resource for polio survivors. Dr. Jonas Salk, who developed the first safe and effective polio vaccine, founded the Salk Institute in 1960.
http://poliotoday.org/

Dr. Richard Bruno’s webpage:
http://www.postpolioinfo.com/

(Via Micki Minner) for those of us on Medicare...this is wonderful..there is now a QUALITY Information Officer...if we run across a medical service..we can complain or have oversight to poor quality services (like those x-ray people that don't accommodate disabled patients, etc.) Or perhaps the physical therapy people that don't believe in Post polio...yeah...be EMPOWERED
http://www.mondaq.com/unitedstates/article.asp?articleid=122536&email_access=on

And here is a dancer, a polio survivor, on Cirque de Soleil. He uses crutches to dance. Amazing.
http://www.youtube.com/watch?v=aR_P8kInWEE

THE EFFECTS OF COLD ON POLIO SURVIVORS

From The Post-Polio Institute and The International Centre for Post-Polio Education and Research postpolioinfo@aol.com

Dr. Richard L. Bruno

Polio survivors are extremely sensitive to changes in temperature. At merely cool temperatures, most polio survivors report that their feet have always been cold to the touch, their skin a purplish color. However, as polio survivors have aged, 50% report "intolerance to cold" and that their limbs have become more sensitive to pain as the temperature decreases.

Cold was reported to cause muscle weakness in 62% of polio survivors, muscle pain in 60%, and fatigue in 39%. When polio survivors were cooled in the laboratory from 86o F to 68o F, motor nerves functioned as if they were at 50o F and polio survivors lost 75% of their hand muscle strength. But, although polio survivors are twice as sensitive to pain as those without polio, no increase in pain sensitivity was found at lower temperatures.

The reason polio survivors have such trouble with cold is that the parts of the central nervous system that should control body temperature were damaged by the poliovirus. In the brain the hypothalamus (the "automatic computer" that controls the inner bodily environment) was damaged by the poliovirus, including the body's "thermostat" and the brain area that tells your blood vessels to constrict. In the spinal cord, the nerves that carry the message from the brain that tells the capillaries in the skin to contract when it's cold were also killed by the poliovirus.

Thus, polio survivors are unable to stop warm blood from flowing to the surface of the skin as the outside temperature drops. This allows loss of heat from the blood near the surface of the skin and causes the limbs to cool. When the limbs cool, arteries carrying blood to the skin and veins that should carry blood out of the skin narrow passively as they get cold, trapping blue venous blood in the capillaries and causing the feet to look blue and to become even colder. The cold skin chills the motor nerves, causing them to conduct more slowly and to be less efficient in making muscles contract. The cold also chills tendons and ligaments (like putting a rubber band in the freezer) making movement of weak muscles more difficult. As polio survivors know, it takes hours under an electric blanket or a long, hot bath to warm cold legs and regain strength.

However, when polio survivors take a hot bath, blood vessels do exactly the opposite of what they do in the cold. Polio feet and legs become bright red as arteries and veins relax and blood rushes to the skin. Then, when polio survivors stand to get out of the tub, they can feel dizzy or even faint as blood pools in their legs and causes their blood pressure to drop The pooling of blood in the feet also explains why polio survivors' feet swell, swelling that increases as they get older. And polio survivors' easily losing body heat explains why they have an increase in symptoms, especially cold-induced muscle pain, as the seasons change.

Polio survivors need to dress as if it were 20o F colder than the outside temperature. They need to dress in layers and wear heat retaining socks or undergarments made of polypropylene (marketed as Gortex or Thinsulate) that should be put on immediately after showering when the skin is warm.

Polio survivors need to remind doctors that EMGs or nerve conduction tests must be performed in a room that is at least 75o F to prevent false abnormal readings and that a heated blanket is necessary in the recovery room after polio survivors have surgery.

BASKET OF FLOWERS/BASKET OF PEOPLE

Excerpt from LaVonne Schonneman's How to Cope Books:

This is a story in praise of support groups.

Not long ago I had the rare privilege of speaking to our support group in Centralia, Washington. I was invited back to my old home town (from which I graduated high school in 1958) to give some tips on coping to the members of the polio survivors support group. This group serves Lewis and Thurston counties.

You might think I went there to give information -- but as always happens in a meeting of a group of polio survivors, I got far more than I gave. It is best illustrated by this simile.

After the meeting was over, I was presented with a lovely basket of silk flowers from the hospital's own gift shop. This was my "thank-you" for coming. But it is me who should be thanking them.

That wicker basket is crowded with a cheery profusion of assorted varieties of flowers. Daisies with golden petals and faces of fuzzy brown, snowy white daisies with yellow centers, carnations, chrysanthemums, in all size and colors. Short and tall, small and large, standing up straight or bending over from the weight of their lovely heads. Big leaves, little leaves. Thick stalks, fragile stems. This basket now sits near my desk in the office because then I can look at it and remember what those flowers really symbolize.

They are symbols of the lovely faces of the beautiful people I met that night. It was a rainy, cold night and some people had driven from as far away as Olympia, Yelm and Silver Creek. They came in cars using hand controls, on crutches, braces wheelchairs or leaning on canes. A few walked in alone or unassisted by family members or friends. As I looked around the long crowded table into the faces of these polio survivors I couldn't help feeling honored to be in such distinguished company. Good grooming and neatness is a hallmark of polio survivors.

What I had to say meant very little because the real meat and potatoes of the meeting came forth when each person had a turn to open their heart and share. The depth of experience and knowledge was staggering. One tall lady, whom I'd admired as she walked in on her own two feet confessed that her paralyzed throat muscles were her main source of worry and consternation. She explained how she'd learned to eat and swallow after being told she'd never do that again. A second person, spoke of falling out-of-doors while weeding under the rhododendron. Outside WEEDING! She always carries a totebag into which go her tools and the portable telephone.

One person spoke of bladder weakness and the others described ways they'd learned to manage the consequences. Some health problems cannot be corrected or solved -- but new methods of dealing with the consequences were offered. (Many men and women contact me with questions regarding this problem. A future article is planned on this subject.)

It is difficult to whip the old, tired body into doing what we want most of the time, so I couldn't help admiring the perserverance of a person who had worked all day then come straight to this meeting. Apologizing for not having been able to transport another member who lived on the way. Since that person hadn't even made it back home all day and had come straight from work to the meeting.

There was the friend who took extra literature for another polio survivor who couldn't come out that night. New faces searching for information found established members willing and eager to share what they could. Handicaps were minimized as members discussed how they'd adjusted for this or that weak limb. These people kept right on working, having babies and raising families despite difficulties that would have made a weaker-spirited person give up.

The ingenious solutions, the never-ending quest for new information, techniques and devices to assist was incredible. There was a person who decided it was too hard to do housework on two crutches so had thrown one away 30 years earlier. It was dismaying to think it might be time to start using two again. Doing housework with one crutch for all those years deserves a gold medal, I think!

One lady was pregnant, when she got polio, but went on to deliver a normal, healthy baby, and raise it! A fellow was driving many miles away for the right type of physical therapy. I heard names of doctors, clinics, therapists and brace people exchanged. Never fear that the careless or thoughtless medical professional escapes notice. They are logged into the memories of the polio survivors right alongside the caring, concerned professional. Never worry that inept methods, inattentiveness, or lack of dedication to the patient goes unnoticed. Those names were exchanged and duly noted. I just sat back and watched that lively information exchange in awe. Some polio survivors were heading into their 5th or 6th decade. They told personal histories, shared tips and encouraged one another. Seldom could they be brought out to the point of confessing a fear or worry. When one did, the others offered solutions and ideas. But, above all, empathy and understanding. This is a commodity that is greatly needed by polio survivors -- especially those suffering the late effects of polio.

Sometimes people had additional burdens. New, or other, health problems, the loss of a job or a caretaker. There were a couple of close friendships among the members. They helped each other, listened to one another and found new strength in the ability to open the anxiety closets and let their worst fears into the bright light of one another's gaze.

Sometimes it was painful, but it was like lancing a boil. When the poison drains away, the patient feels better. Some conclusions I came to were:
The post polio problems seem to come after a trauma or insult to the body or mind like -a broken ankle -loss of a spouse -a severe illness (flu) -prolonged exertions (hiking up or down several flights of stairs or hurrying to catch a plane or bus) -a new, additional) illness (arthritis)

The need to slow down is always resisted because it's seen as going back to the past but the truth is that NOT SLOWING DOWN brings on more weakness.

Polio survivors are very well-informed about their conditions. Often the medical professional they see (unfortunately) is not informed.

Fear that the new weakness is a downhill spiral (the way to combat this is to reassess your remaining strength and plan not to over-do).

Knowledge is power, there is strength in numbers, and we CAN regain control of our lives.

If the power and determination of that group of polio survivors could be harnessed and put on the playing field with the Washington Husky football team, I feel sure the Huskies would go home with their tails between their legs.

The next day, on the drive home, we passed the tulip fields outside the small town of Mossyrock. I stopped and took several pictures of the long, straight rows of tulips planted exactly the same distance apart. Each color represented in rows. They were like soldiers, lined up in perfect order. They'd been tended carefully and I know (since my husband is a gardener) only the strongest and best were allowed to survive on display there.

No matter how beautiful the tulip fields appeared, each exactly like its neighbor, I couldn't help thinking how much more I preferred the colorful variety of my own basket of flowers, with their individual and unique faces peering back at me from across the room. As I gaze into the heart of each one, I remember those unique faces of the Centralia Polio survivors group and my heart swells with pride because they are all mine to keep. My new friends to carry in my heart forever. The rain didn't ruin them nor the cold drive them away.

In the end, I know that they will be the strongest survivors.

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Scheduled Meetings for 2011

We are planning to have meetings at Bloomfield Forum 98th and Nicholas in Omaha, NE on the following dates, subject to change. Watch the newsletter online at www.ne-polio.org for changes:
March 6
April 3
May 1
August 7
Sept. 4
October is our annual reunion. Date will be announced later.
Nov. 6
No meetings in June, July, December or January.
We are planning to talk to a rep from the Omaha Metro Transit company on handicapped buses at the March meeting.

NPSA WISHES TO THANK

all who have so generously donated to our group:
Robert G. Zeman, Chadron, NE
Charles L. Zeman, Chadron, NE
Cynthia Starman Kelly, Lincoln, NE
Barbara J. Stenning, Portsmouth, RI
Doralu Streeter, Papillion, NE

and the following memorials to Vernon Lynn Boyd:
Luella, Leon & Diana Mae Lipsett, Medford, OK
Norvey & Naveda Ely, Medford, OK
Busy Mom’s c/o Marion Magnaus, Medford, OK
Mabel Boyd, Omaha, NE
Bruce Boyd, Arlington, VA
Craig Lemke & Susan Boyd, Omaha, NE
Wayne & Chris Kendall, North Branch, MN
Bryan Parr & Antonio Gomez, Washington, DC

We at NPSA appreciate your thoughtfulness.

P.P.S. IN UNDER TWO MINUTES

by Con Ingram

Have you tried to explain Post Polio Syndrome to a friend, then half way through you notice them nodding off? Try this two minute drill.

Our brain communicates with our muscles through the nerves. Polio destroys these nerve cells causing our muscles to die.

The beautiful thing about nerves is that they help each other. When one goes down others help out, so a person can lose many nerve cells and not experience much dysfunction.

Most polio survivors have been living in this state of fewer cells for years. If they were very young when they contracted Polio they may have grown up thinking this was normal.

All people's nerve cells die off with age. For the normal person, having many nerve cells, this is not a problem. For those of us that have been living with a reduced number of nerve cells, this can result in a variety of symptoms including weakness, fatigue and pain.