



Gleanings

THE OFFICIAL NUMBER ONE NEBRASKA POST-POLIO NEWSLETTER

JUNE/JULY/AUGUST

2007

Weighing Risk

by Janet R. Vanthournout
Sanibel Island, Florida

My thoughts have turned to the risks one takes in life and for what reasons a person decides to take a risk. For example, I had my heart set on going out very early yesterday morning during low tide along the Gulf of Mexico to collect shells on this wonderful Sanibel Island beach. I find the most fabulous shells during low tide early in the morning before most people climb out of bed. However, I was very disappointed. When I rose at 4:30 AM and walked into the living room to open the shades my eyes were temporarily blinded by a flash of lightening. Oh no! A sudden squall was about to break.

I stood in the darkened room staring through the window towards blackness I knew to be the shoreline and contemplated as more flashes appeared in the clouds. Should I go outdoors ... or should I return to my warm bed? This wasn't so much a matter of fatigue as safety and I realized this. Fifteen minutes later, I had enough evidence. It just wouldn't be smart to expose myself to a lightning strike along the beach. No shell was worth that. I returned to bed and pulled the covers up tightly.

This morning was another story. Skies were clear and stars shown brightly. Low tide was half an hour later today so

I didn't have to be very concerned about spending much time in darkness which which can be very spooky when you are alone with the BIG water, a BIG sky and only your little high intensity flashlight. I have given more than a passing thought to the unwelcome stranger who might not be looking for shells but rather meeting a lone woman on a deserted beach. Somehow, the idea of such a stranger just isn't so frightening when it's soon going to be light. In fact, I often have long conversations with complete strangers during daylight hours on the beach and have met nice folks from all over the world.

Today, walking along the beach just before sunup, I encountered a stranger ... a burley man who first ignored my shouted "hello," then after the third yell as he neared mumbled something about "taking pictures." He didn't have any light at all and seemed scary to me. I stayed near the far edge of a tidal pool away from this person and quickly got past him while watching over my shoulder to be sure he moved along in the opposite direction ... and my thoughts turned to fears.

Fear and risk, now there are words to consider. I would even go so far as to add the word 'pain' to that short list. Besides concerning myself with risks of going to the beach alone I have worried over the same sort of life altering risk with some fear before undergoing surgery. Usually, I have put off surgery as

going to the beach during an electrical storm. The risk outweighs the possible good outcome.

In my case, I would eventually succumb to surgery. This would always be due to pain. Pain eventually overcame all my objections. So, maybe pain and pleasure are closely linked. I went outdoors in the dark despite risks this morning due to thoughts of great pleasure in hunting shells. This led to the lurking photographer who temporarily worried me though passed without incident. Surgery seems to have been that way, too. Knee surgery more than a year ago worried me very much beforehand. Tendon surgery many years ago was the same. They turned out to be temporary concerns. Once I recovered and finished rehab, I felt better than in decades. I knew positively through hindsight my surgeries were worth the risks.

What I'm saying is that one must weigh risks. Sometimes there are good reasons to take a risk. In my case the ability to walk better without pain was surely worth the risk. There are some not so good reasons we do or don't take risks, too. They may have to do with emotions like fear or anticipated pleasure. This can work for or against us. Maybe that's why we sometimes take chances or don't consider taking *worthwhile risks* at all.

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NOT ONLY TO YOU BUT TO
NEBRASKA POLIO SURVIVORS ASSOCIATION**

Your regular contributions make it possible for Nebraska Polio Survivors Association to carry out its mission. Monthly contributions are an easy way to contribute to NPSA, rather than only once a year. Think about it. Maybe this year more of you will seriously consider this.

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 is a 501(c)(3) non-profit corporation and your contributions are fully tax deductible for tax purposes.

There are several ways to designate your contribution: *General Contribution, Memorial Contribution, Special Purpose Contribution, or Contribution in honor of _____.*

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NPSA is a 501(c)(3) non-profit corporation. All donations are deductible for tax purposes.

Please send contributions to NPSA, PO Box 45139, Omaha NE 68145-0319.

Checks payable to NEBRASKA POLIO SURVIVORS ASSOCIATION.

Yes, I want to make a contribution to Nebraska Polio Survivors Association. I know that my gift will make it possible for NPSA to help 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, newsletters, and advocacy for issues concerning them.

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MEMORIALS

**In Loving Memory of my
beloved husband, Don LeDuke
from
Katherine LeDuke, Elwood NE**

HOSPICES

by Patricia Meierhenry, R.N.
Lincoln, Nebraska

Nebraska Hospice is getting ready to observe twenty five years as an organization next year. And still, a lot of folks do not realize what hospice is, and how it can help. Let me try to enlighten those of you who read this news letter.

The origin of the word *hospice* comes from the Crusades, when a hospice was a place of rest for the Crusaders, a place for a bath, a meal, and a safe place to sleep on their journey. The root of the word is the same found in hospitality.

In the late 1900's, Irish nuns established sanctuaries for dying individuals and called them hospices. The modern movement originated in London, at a place called St. Christopher's, under the guidance of Dame Cecily Saunders. In the 50's, when Elizabeth Kubler-Ross was writing the ground-breaking *Death and Dying*, Dr. Saunders was observing the same things in England. The needs of the dying patients were not being met. These needs were not just physical, but emotional and spiritual, as well.

Saunders converted a building into a place where people who were facing the end of life could come and be cared for, and she called it St. Christopher's because he is the patron saint of travelers. These people would be on their last journey. She promised that they could have visitors at any time of day, and these visitors could be family, friends, children, and pets. This was in the days of strictly regulated visiting hours when children were not allowed in hospitals. She also promised that everything that could be done to control symptoms would be done, such as pain, nausea, constipation, anxiety, insomnia, and the emotions that accompany a terminal diagnosis.

Saunders soon demonstrated that our

ideas of how much pain medicine could be administered and how often, were completely incorrect, and that many patients were dying in pain that could be controlled. St. Christopher's is still the model for hospice care world wide today.

In the late 70's, some volunteers in Connecticut came together with a plan to build something like St. Christopher's. Since a building would cost a great deal of money, they agreed to provide hospice type care in homes until the building was erected. Hospice now became a philosophy, rather than a particular place, and the early care was done entirely by volunteers who embraced that philosophy. These were medical personnel, clergy, and lay men and lay women with the notion that care of the dying could be done in a much better way than it was being done in the United States at the time.

Today, hospice is a formal, reimbursed program of care that requires that the patient have a six month life expectancy (if the disease progresses as expected) and he or she elects not to pursue any more treatment. Instead, the focus becomes comfort and quality, and "getting affairs in order." Although many of the patients have cancer, hospice also provides services for heart disease, kidney disease, emphysema, dementia and the neurological conditions like ALS. Care encompasses the patient and the caregivers, and involves a medical director, nurses, aides, social workers, therapists, chaplains, and volunteers. Medical equipment can be provided in the home, and those involved taught to use it. They can also be taught to administer medications and treatments. There is always someone on call to trouble shoot over the phone or to make an extra visit.

It is fully covered by Medicare and Medicaid, and most private insurers have

a hospice component. If they do not, they will often negotiate in lieu of hospitalization. All hospices in Nebraska are Medicare certified, which means they meet those standards, and all are obligated to provide care, even when there is no means of reimbursement.

In 2006 the Nebraska Hospice and Palliative Care Partnership was formed, numbering over sixty organizations including the 36 hospices, major health care associations, and fourteen community end-of-life coalitions. The word *palliative* comes from the Latin *palladium* which means to cover. The goal would be to improve care and conditions for the chronically ill as well as the terminally ill.

This organization now has a full time executive director, Jon Krutz, and several staff people. There is a website, www.nehospice.org, and the results of the recent statewide End of Life Survey can be viewed there. The organization works to bring educational opportunities for health care professionals, as well as the average citizen, regarding end of life decisions. They promote the use of advance directives, especially the durable power of attorney for health care, as a way for us to communicate our wishes for end of life care. They sponsor an annual End of Life conference every spring, bringing national speakers in varying areas of expertise.

It behooves all of us to be informed about end of life dilemmas. No one really wants to consider his or her own mortality. Especially in these days of medical technology, it is important to communicate our wishes. Another website you may want to visit on this quest would be www.fivewishes.org. These five wishes will help you spell out your values and desires.

Let's Dance!

by Millie Malone Lill

There are lots of shows on TV that highlight dancing. *Dancing With the Stars*, the ballroom dancing competition on PPS, *So you Think You Can Dance*, all of these are wonderful. I watch them intently, longing to be able to do what those people do.

There are only a few things stopping me. For one thing, I do not have two left feet. Functionally, I don't have even one left foot. The clothing or lack thereof on the female dancers would be absolutely indecent on my grand motherly body. I do still have my girlish figure. It's just that nowadays I keep it stored in many many layers of bubble wrap to preserve it. And, of course, I'd probably run over quite a few toes in my power wheelchair.

Here's a fantasy for you. The music comes up, the lights dance around the floor, reflected from the huge mirrored ball that revolves as it hangs from the center of the ceiling. John Travolta, in ties and tails, strides lithely onto the floor. He reaches for his partner, me. I glide gracefully over to him via Jazzy 1103, ramming the footplate delicately against his shin bone. He twirls away. I follow. He twirls again. Again, I follow. Finally he breaks into a dead run and leaps off the stage. I do not follow. My mother might have raised the odd idiot or two, but I wasn't one of them.

As I watch these TV shows, I have always pointed out to my legs exactly what they should do. Do they listen? Not on your life. They maintain that they have lugged my body around all these years with only half or less of the motor neurons those legs on the TV shows have. They remind me that I am still able to stand and do dishes, walk in my kitchen, climb into my bed at night, all without benefit of Personal Assistant. Apparently, they think

this is above and beyond what I should expect of them. As a little reminder, my right leg, the Good One, gives me a tiny spasm. Not enough to make me scream, but enough to knock the idea of dancing completely out of my head.

I have danced, though. In the polio chat room on the internet, David Brock and I used to cyberdance all over the room. The other girls in the chat room would cut in and we would whirl and twirl, having a wonderful time while sitting at home in our power chairs.

I've also danced with my husband. At his son's wedding, he held me and we slowly swayed to the music of Ann Murray as she sang, "May I Have This Dance For the Rest of My Life." It was wonderful. I'm pretty sure the judges of *Dancing with the Stars* would object to our technique but swaying in the arms of a big good looking man is close enough for me.

OMAHA/COUNCIL BLUFFS/LINCOLN AREA SUPPORT GROUP

June 3, 2:00 p.m. Beautiful Savior Lutheran Church, 90th and Q Streets. Program by the "Branson Bunch.."

July (no meeting)

August 5, 2:00 p.m. Bloomfield Forum, 9804 Nicholas Street. Old fashioned sing-a-long. Planning for the October 7 Annual Polio Survivors Reunion at The Omaha Field Club.

Mark the Reunion Date NOW.

THIS IS AN EVENT YOU WILL NOT WANT TO MISS.

October 7 - 1 to 4 p.m.

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