



GLEANINGS

June - July, 2014

ST. LOUIE BLUES

By Millie Malone Lill

Thanks to the generosity of NPSA, who paid my registration fee, to Judy and Don Eades, who provided transportation, and to Jann Hartman who provided a hotel room, I attended my first ever PHI (Post-Polio Health International) conference in St. Louis this year. I have always wanted to attend, but this kind of help made it doable.

At 4:00 on Friday morning, May 30th, I arose and dragged myself through the process of getting ready to leave. Until then, I'd been blissfully unaware of the existence of 4 a.m., but I'd snagged a ride with a family friend who was going to the zoo in Omaha with my granddaughter and her sons. They, obviously, set the timetable, not me. They got me to Omaha, where Don and Judy picked me up. We were off.

I slept about half the way to St. Louis, but was awake enough on arrival to realize that the GPS on Don's van saw a detour that no longer existed. We made a little trip across the bridge into Illinois, then back to Missouri and to the Hyatt Regency. After a little bit of confusion about hotel rooms, we settled in for the night.

Saturday afternoon was orientation, followed at 6:00 p.m. by a banquet and entertainment. "One World" was performed by the DisAbility Project of That Uppity Theatre Company and Common Threads Dance Company. It was a moving performance that left many of us with tears in our eyes.

My presentation about coping by using humor took place on Sunday morning. Three of us shared the time slot. Hannah Hendrick went first, teaching us some breathing exercises and healing touch exercises. Then I gave my speech. Melissa

Gatlin was third, showing us some yoga moves that could be done seated or lying down.

St. Louie Blues (continued on p. 4)

ADAPTIVE TECHNOLOGY IS THE CORE OF SIEBERT'S BUSINESS

By Elaine J. Allen

Mobility has been Bill Siebert's business since 1978, when he adapted a van for a disabled friend in Glenwood, Iowa. He small, lowering floors in mini-vans and adding in-floor lifts. As Siebert's business grew, he encountered liability issues, particularly NTSA crash testing, which caused him to adapt and grow his business.



Drew Bronson spoke to NPSA members during the May 2014 meeting.

Today, Siebert Mobility has shops in four locations: Des Moines and Glenwood, Iowa; Omaha, Nebraska, and Bentonville, Arkansas.

Siebert Mobility (continued on p. 2)

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Siebert Mobility *(continued from p. 1)*

Adapting and tailoring equipment to each individual's needs are the goals of the staff at Siebert Mobility. One of Siebert's adaptive technology specialists, Drew Bronson, spoke to a gathering of 14 NPSA members on Sunday, May 4, at the Bloomfield Forum in Omaha, telling them, "When people are coming from as far as six hours away, we need to make it work. We have to find out what are their needs before they get to the shop."

Bronson sees his work at Siebert for the past eight years as a natural progression of his college degree in film studies and mass communication from the University of Nebraska-Lincoln. "Every day in my business is an ongoing documentary. How do I make a story out of that?"

He said he has become the master of 'what if?' "I love to get in the shop with the mechanics. I'm an idea man. Any ideas you have, I'll forward them on to our conversion guys."

Bronson said a trip to Mexico changed his perception of mobility for the disabled. "I saw a girl with no legs and she could get around pushing herself." If that girl could adapt, Bronson realized he could help others adapt.

Siebert Mobility's services have evolved over the years. Technicians work on a variety of adaptive hand controls, hand knobs, reduced effort and zero-effort spinner knob steering devices. "Electric Mobility Controls, or joy sticks, to use for steering are amazing to see," Bronson said.

However, before adapting hand controls, driver evaluations must be made. Technicians try to have every option available to allow people to try out before choosing mobility equipment.

Also, a person can rent a van if one is needed on a temporary or occasional basis. Siebert will soon sell trucks on its lots and possibly SUVs and the MV1, the first mobility vehicle built from the ground up. Siebert's 24/7 tech support and services are available for all equipment they



sell for the life of the vehicle or equipment as long as you own it.

Siebert offers other services besides vehicle modifications, Bronson said. They work on inside home modifications such as stair lifts and outside home modifications such as porch lifts and ramps. In addition, Siebert is vendor for many of the popular scooters and power chairs.

Financing and funding agencies work with Siebert to get people the kinds of mobility equipment they need. One of those agencies is Nebraska Easter Seals Financing, which offers loans 2% below market. For more information about this financing program, go to this web address: <http://www.easterseals.com/ne/our-programs/respice-community-support/alternative-financing.html>

Kohl's of Omaha Begins Sales as First Chairiot Solo Dealer in the U.S.

Omaha-based Kohl's Pharmacy & Homecare is the first U.S. dealer to Chairiots, 7.5-foot-long electric cars that are designed for people in wheelchairs and cost about \$19,000.



Photo reprinted with permission of Kohl's Pharmacy

"Being able to provide a vehicle that basically allowed spontaneous personal mobility seemed to us like a real market opportunity," says Chairiot Mobility's president and CEO. The article about this wheelchair-accessible electric car first appeared in the May 6th edition of the Omaha World Herald. *(The link to the article:* <http://www.omaha.com/article/20140506/LIVEWELL26/140509121>)

St. Louie Blues *(continued from p. 1)*

Judy and I tried to cover as many of the presentations as possible, so I would attend one and she another. While I was doing my presentation, Judy attended one called "Advice on Solo Aging." Judy attended a presentation on Travel Opportunities and I went to "Assessment: Our Home."

At 10:15 each morning, there was a half hour break, with a snack provided. Then we got our box lunches, which consisted of way too much food. Everyone gave me their bags of potato chips and I kept them because I can't stand to waste food. Don took that opportunity to tease me about being a potato chip hoarder. At the end of the conference, I had a WalMart sack of individual bags of potato chips which I took along to Branson and shared with everyone.

By Sunday afternoon, I was really missing my little dog, so I went to the Support Dog Demonstration to get a little dog hair on my lap. It was very interesting to see the Lab/Golden mix dog as he performed his duties for us. There is zero chance of my dog ever picking up my dropped keys and handing them back to me, or doing any of the other jobs this big dog did. Her idea of protection means she will choke a burglar to death on all the hair she sheds and that is the extent of her duties as far as she is concerned.

Judy attended "Relatives of Survivors: Three Perspectives", which she found very interesting. I went to "Assessment: Our Abilities" with Hilary Boone. Hilary explained how physical therapists should assess our abilities, by doing many repetitions of a movement rather than just one time through. We often have the strength to do a movement once, but not the stamina to do it multiple times. This is an important fact to document when applying for disability.

Judy attended "Passing in the Shadow of FDR" and learned about "passing" as an able-bodied person and the effects that has on our bodies. I was exhausted at this point and went to my room for a short nap. That evening there was an interesting group discussion on being a polio

survivor. Almost all of the attendees were there, sharing their stories. I found it informative and made me rather proud of being part of this high achieving, never-say-die group.

On Monday, I attended a presentation on Staying Active. It was led by 3 people, one of whom was a Physical Therapist who worked with people who had Cerebral Palsy. He thought PPS was similar. He was wrong. The other two were very well informed, however. Judy went to a presentation on sleeping.

Later in the day, I went to a Weight Management presentation and Judy attended Communicating for Understanding. After lunch, woman who arranges affordable cruises for disabled people. She is a polio survivor who uses a scooter full-time.

Other topics covered during the convention: Support Groups: What Works; My New Reality; Proven Energy Boosts; and a rather dull

recitation of the Lessons from The Rehabilitation Research & Training Center on Aging with a Physical Disability. We also attended a Discussion of Future Needs of Polio Survivors.

I felt that I learned a lot at this conference. Not just from the various presentations, but also from many of the approximately 200 attendees. There were people there from Australia, Brazil, England, India and Canada. Many of them were familiar to me from Facebook, and a few were longtime email friends. It was so good to meet in person people I'd been "talking" to online for 18 years or so.

No one was sure when the next conference would be held, but the consensus was probably five years down the road. I am looking forward to the possibility of attending that one, too!

Millie's e-book, **Hot Water, Orange Juice 'n' Kids...** is now available online.

All proceeds from its sale support a fundraising project for the International Centre for Polio Education.

To learn more, go to this website:

<http://www.postpolioinfo.com/index.php>



IN THE NEWS

(Editor's note: In response to feedback on our readers' survey earlier this year, GLEANINGS will reprint news articles related to polio and post-polio when they are available for republication.)

WHO Declares International Health Emergency on the Spread of Polio

The World Health Organization (WHO) declared the international spread of wild poliovirus in 2014 a Public Health Emergency of International Concern. Calling the spread of polio an 'extraordinary event' and a public health risk to other countries, the WHO said a coordinated international response is essential.

Nine countries participated in the WHO informational session in late April: Afghanistan, Cameroon, Equatorial Guinea, Ethiopia, Israel, Nigeria, Pakistan, Somalia and the Syrian Arab Republic.

By the end of 2013, 60% of polio cases were caused by the international spread of wild poliovirus, with increasing evidence that adult travelers contributed to this spread. If unchecked, this situation could result in failure to eradicate globally one of the world's most serious vaccine-preventable diseases.

The consequences of further international spread are particularly acute today given the large number of polio-free but conflict-torn and fragile countries which have severely compromised routine immunization services and are at high risk of re-infection. According to the WHO, these countries would experience extreme difficulty in mounting an effective response were wild poliovirus to be reintroduced

Correction: In the April-May issue of Gleanings, a story about hearing loop technology appeared. Reverend Mary Dyer was identified as a Unitarian minister. She is an ordained minister in the Unity Church. The company that she and Reverend Sheryl Butler work for is called Hearing Access Solutions. They recently installed hearing loops in the City Hall council chambers in Sioux City, Iowa.

Pakistan, Cameroon, and the Syrian Arab Republic pose the greatest risk of further wild poliovirus exportations in 2014. According to the WHO declaration, these countries should:

- officially declare, at the level of head of state or government, that the interruption of poliovirus transmission is a national public health emergency;
- ensure that all residents and long-term visitors receive a dose of OPV or inactivated poliovirus vaccine (IPV) between 4 weeks and 12 months prior to international travel;
- ensure that those undertaking urgent travel within 4 weeks, who have not received a dose of OPV or IPV in the previous 4 weeks to 12 months, receive a dose of polio vaccine at least by the time of departure as this will still provide benefit, particularly for frequent travelers;
- ensure that such travelers are provided with an International Certificate of Vaccination to record their polio vaccination and serve as proof of vaccination;
- maintain these measures until at least 6 months have passed without new exportations and there is documentation of full application of high quality eradication activities in all infected and high risk areas; in the absence of such documentation these measures should be maintained until at least 12 months have passed without new exportations.

Similar recommendations were made for the countries infected with wild poliovirus but not currently exporting the virus: Afghanistan, Equatorial Guinea, Ethiopia, Iraq, Israel, Somalia and particularly Nigeria. *(Edited from the WHO statement, issued on May 5, 2014.)*

Related News Stories:

["Disease of Pakistan's Poor Now Worries the Affluent,"](#)
New York Times, May 10, 2014

["UN: Spread of Polio is a World Health Emergency,"](#)
www.Huffington Post, posted May 5, 2014

CIA to Stop Using Vaccinations as a Covert Operations Tactic

The CIA famously used a vaccination program as a ploy to gain information about the possible whereabouts of Osama bin Laden in Pakistan. That effort didn't succeed, and the doctor involved was sentenced to a prison term. But the revelation had immediate effects — particularly in the fight against polio.

(Shared on our Facebook page from www.npr.org.)

DONOR GIFTS Received April 11 – June 16, 2014

NPSA wishes to thank the following donors for their generous support of our mission:

Anonymous via United Way of the Midlands
Sandy Fischer, Bettendorf, IA
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Consider NPSA for Memorials, Honorariums or Planned Gifts

In addition to annual and matching gifts, there are other ways to give to the Nebraska Polio Survivors Association. You might want to honor a polio survivor who you admire or respect. Memorial gifts honor a family member or friend who has passed away.

You may donate through your estate plan without giving any money right now, or you can make a gift that will return an income to you, such as an annuity. All of these gifts are referred to as planned gifts, because you are planning to provide the gift at a later date. If you would like to consider a planned gift to NPSA, please contact one of the NPSA Foundation Board members listed on this page.

Backwards PINS at ATMs: An Urban Myth

First National Bank of Omaha's Corporate Security & Safety department encourages everyone to be aware and properly informed of an urban myth making the rounds again on the Internet and in social media.

The myth, which has circulated for a number of years, suggests if you are being forced by

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someone to remove cash from an ATM, simply enter your PIN number backwards and the machine will automatically notify the police of your location and that you are in danger.

Please be advised this will NOT work! ATMs are not programmed to provide an alert if the PIN is entered backwards. This type of criminal activity at ATMs is rare, but you should always exercise good judgment when using a remote ATM, particularly at night or when you're alone.



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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.

SAVE THE DATE!

SUNDAY, OCTOBER 5, 2014

TO CELEBRATE OUR 30TH YEAR OF HELPING POLIO SURVIVORS

NPSA was founded in 1984 by Nancy Baldwin Carter. Our program will include a historical video featuring interviews with our founder and some of our members.

Nebraska and Western Iowa Polio Survivors, Family and Friends:

Watch the mail for your invitation in August.