Gleanings

The Official Number One Post Polio Newsletter of Nebraska
April/May 2011

Omaha's Metro Area Transit system recently changed its name from MAT to Metro. Along with the new name, a new logo began appearing on freshly-painted blue and white buses. Although Metro's name is new, its mission remains the same: provide accessible and affordable transportation to metro area residents, including people with disabilities, the poor, minorities and non-English speakers.

At the NPSA's March 6th meeting, Metro Marketing Director Linda Barritt talked to the members present about the history of the American with Disabilities Act (ADA) and the role Omaha's bus system played in forming the ADA's transportation guidelines in 1991. Because of its early actions in serving the disabled population, Omaha became the benchmark used for medium transit system markets in the United States.

All of Metro's policies are guided by ADA laws and T-HUD restrictions. "There isn't a thing Metro does that isn't tied to Federal regulations," Barritt said. For example, federal rules require all bus signs be written in any language where more than 5 or 10% of the community speaks a second language. On Metro buses, all signs are written in English and Spanish and some are written in other languages, too.

Metro's MOBY service for people with disabilities actually preceded the ADA, which is now 20 years old. MOBY's original service for the disabled allowed transportation only for "504" or life-sustaining activities: doctor appointments, work, and school. Once the ADA was enacted in 1991, MOBY was required to drop the life-sustaining restrictions and provide "no more or no less" service than what is available on regular, fixed routes.

"MOBY is an advance reservation curb-to-curb transportation service for residents of the metropolitan area and American with Disabilities Act (ADA) eligible persons visiting within Omaha's city limits, who, as a result of their disabilities are unable to use conventional ADA fixed-route Omaha Metro bus service," according to the Metro's website. People with disabilities who want to use the MOBY service go through a certification process to qualify for the service. A Citizen's Advisory Committee reviews the certification process. For more information on obtaining certification, MOBY, and ADA compliance, check out Metro's website: http://ometro.com/rider-guide/mobyada

Barritt explained that MOBY complements Metro's regular bus service, running evenings but with limited service on Sundays. A Personal Care Attendant may ride on MOBY for free, and a companion pays the regular MOBY fare.

SAVE THIS DATE

Annual Membership Dinner
Sunday, October 2, 2011
1:00-4:00 PM
Field Club of Omaha
3615 Woolworth Ave.
Omaha, NE 68105
Guest Speaker: Nebraska State Senator Gwen Howard
Entertainment: To Be Announced
More details to com in June/July iss of Gleanings and on our website:
http://ne-polio.org

MOBY's fare is $2 per trip but the actual cost of each trip to Metro is $19, Barritt explained. A regular adult bus fare is $1.25 per ride but someone with a MOBY ADA Card or Metro Photo ID may ride for half-fare on a fixed-route bus for 60 cents. Metro's bus and MOBY fares are subsidized by Federal funds and local tax revenues. Fares generate only 7-8% of Metro's revenues. Fares have not been increased in more than 10 years but may have to go up in the near future, she said. Diesel fuel costs are up to $3.99 per gallon. It takes 100 gallons to fill a Metro bus.

Barritt suggested a few actions that people with disabilities can take to make their MOBY trips better:

Call for a MOBY trip no later than 24 hours in advance. You may schedule a trip up to 2 weeks in advance.

If you are taking MOBY to a medical appointment, ask the medical professional when the appointment might be over so MOBY can plan the pick-up time more efficiently.

In spite of the belt- tightening Metro continues to do and the challenges of keeping up-to-date with the evolving federal regulations, Barritt says she still loves her job after 25 years. The NPSA members who attended the March meeting appreciated her for taking time from her personal life on a Sunday afternoon to talk with them.

~By Elaine Allen~

Save Your Sanity through Poetry

LaVonne Schoneman, Seattle, Washington

Saving sanity through poetry sounds like a motto from an old 1950s TV program. Nevertheless, I believe it has often saved me. Reading beautiful thoughts of another poet or jotting down my own, even during pain, helps me. Reading about someone else who had the same feelings helps me realize I am not alone. Others may get this same release through a cherished hobby. Gardening is my husband's choice.

Before anyone says, "I can't do that anymore," let me hasten to assure you we all lose bits and pieces of ourselves along the way from youth to age. Making a hoop shots, dancing 'til dawn, or climbing a mountain may beyond your scope today, but so many other things are not. I call them my "free fixes."

We can find magic in cobwebs, intricate weavings, more delicate than handmade lace. Hidden in the beauty of growing things – an Amaryllis started from a bulb in winter keeps our spirits up as we watch it push up through the soil day by day. The silly song of a grandchild can sound more lovely than an aria by a world famous tenor. A dandelion can mean more than a dozen hothouse roses when delivered by a loving child. Music really does have the power to charm and soothe. Petting the cat, grooming the dog, feeding the fish ... choose your pleasure. Admire the wrinkles in someone's face, spouse, stranger or yourself. Look deep into the eyes of your family members or friends as you converse.

DO take time daily to really converse. If you live alone, you can still get that connection through telephone or e-mail. The post-polio support group I check in with on the World Wide Web offers a caring group of people with like problems and who readily shared solutions twenty-four hours a day. Concentrating one's flagging energy on uplifting things is so beneficial. In this season of political hammering we need to limit the amount of time we allow such assaults.

When you find yourself reading a story or watching a movie that makes your stomach churn or gives you the feeling you need to wash your mind out with Grandma's lye soap and hot water, S-T-O-P! Give yourself permission to do something else – something aesthetically pleasing (uplifting, fun, silly). Read the comics, watch a happy video, appreciate the rain or snow or sunshine ... listen to the wind blow. A positive attitude is all it takes – and that costs nothing.

OUR READERS WRITE

Here are a few excerpts from letters we have received:

"...I really enjoyed your column in the last letter I received from your support group. Great read by LaVonne, too." from Alma Studer

From Sharlene Pekny about Marv Pekny:
"Wanted to let you all know that Marv got dropped in bathroom 2 weeks ago and broke his right tibia and fibula, a clean break so no surgery but has cast full length of leg so SERIOUS mobility problems. Almost like a quad. He is at Select Speciality Hospital in Omaha. Shar

Marvin N. Pekny 301 Buena Vista Circle
Council Bluffs IA 51503-1743

Shar's e-mail address: shar.pekny@cox.net

Hi, fellow survivors. Greetings to you! I hope my note will find you well. Would you believe that in April I will be here in the Advent Christian Village for eleven years?

It's the middle of the night and of course the best time for me to do all my writing. I believe the last two months have been the worst time I have been through in years. At the present time I am very depressed, upset, anxious, stressed out, and very lonely in my old age. And my willpower is kind of shot about not eating. I can't take one step without my crutches and spend most of my time on my scooter riding around the village, on my recliner watching TV, or sitting here in front of my computer half the night typing my flyers, and corresponding with over twenty post–polio support groups from California to Maine, and from Wisconsin to Texas. An awful lot of people out there are in the same condition as me, or even in worse shape.

I saying prayers all the time-but I guess the Lord is testing me, to see how much I can take. I'm still hoping I have a few more years to "smell the roses" and make a few more trips around the country in my van.

Please say a couple of prayers for me if you can and drop a line or give a call when you have time.

Jack Briggs
Advent Christian Village
PO Box 4095
Dowling Park, FL 32064

"Hello

I really enjoy your issue of Gleanings!!.....and your article. One relates to every part of it. I would like to send a message to Dr. Bruno, but when I use the email address printed in the newsletter it will not go through sending. Thanks for any changes in his address or info that you may be able to offer. I am to be scheduling surgery for a knee replacement and need a bit of advice from him in re to that.

Bonnie Arnold
arnoldabbypi@aol.com

(*Editor's note: The correct email address for Dr. Bruno is* postpolioinfo@aol.com*)*

POST-POLIO SYNDROME AND THE SHINGLES VACCINE

BY PAUL G. DONOHUE, M.D.

DEAR DR. DONOHUE: About two months ago, I wrote you inquiring about the shingles vaccine for polio victims. Will the vaccine cause the polio virus to reactivate, or will it cause a severe case of shingles? -- N.J.

ANSWER: People born after the polio vaccine became available in 1955 have little appreciation of what a dreaded illness it was. Polio is coming close to being eradicated worldwide. That goal hasn't been achieved, but it appears to be doable.

Many people who suffered from the paralysis caused by polio are now faced with another problem -- post-polio syndrome. The muscle strength they regained after the initial infection is being lost, and pain is re-emerging. That's not because the polio virus has come back to life; it's because nerves that took over for nerves killed by the virus are now degenerating.

I referred your question to Post-Polio Health International, an organization that should be known to all victims of polio and all those suffering from post-polio syndrome. They have had experience fielding such questions. Their medical experts see no reason not to take the shingles vaccine. It does not reactivate the polio virus. Nor does it cause post-polio patients to have a severe case of shingles.

Post-polio patients ought to contact Post-Polio International and learn about its many services available to previous victims of polio. Its website is www.post-polio.org.

WEB CORNER

Our site, Nebraska Polio Survivors Association:
http://ne-polio.org/

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

NPR - polio doctor:
http://www.npr.org/templates/story/story.php?storyId=103892252

Gates Foundation:
http://www.gatesfoundation.org/polio/Pages/default.aspx

Summary of Anesthesia Issues for the Post-Polio Patient
http://www.post-polio.org/edu/hpros/sum-anes.html

Understanding Polio
http:www.stuff.co.nz/manawatu-standard/news/tribune/4853527/Understanding-polio

Post-Polio Suport on the Alabama-Florida-Mississippi April Newsletter
http://www.postpoliosg.org/

Back Issues of The Lincolnshire Polio newsletter
LincPIN Volume 6
www.poliosurvivorsnetwork.org.uk

Access to Medical Care for Individuals with Mobility Disabilities
www.ada.gov

Polio Outbreaks in Central Africa and South Asia

| Polio Tips and Techniques

by Dr. Richard L. Bruno

Last November, an unusual polio outbreak occurred in The Congo Republic. A “wild” (naturally-occurring) Type I poliovirus, imported from Angola, has paralyzed at least 409 and killed 170. What is unusual is that those affected are not children under five but adults 15 to 29 and that 41% have died, versus the norm of 15% in an epidemic. Historically, more deaths do occur when older individuals get polio, but not nearly half. This epidemic, in a country that had been polio free for 10 years, adds to the continued outbreaks in countries where polio remains endemic: Afghanistan, India, Nigeria and Pakistan.

There is an aspect of the Congo epidemic that is not unusual: There has been no mention of it in the American press. However, there was wide-spread attention given to a polio outbreak in May 2010. A wild Type I poliovirus imported from India triggered an epidemic in Tajikistan that spread to three other previously polio-free countries and all the way to Moscow, affecting 476. This outbreak was more typical; 86% of those initially infected were children and 6% died.

This European pandemic caused the American Academy of Pediatricians in July 2010 to warn that “Low immunization rates in parts of U.S. could pave way for polio outbreak [showing] how precarious our control of the disease can be when immunization rates fall below the target level of 90%. The polio immunization rate in Tajikistan is 87%.” The article goes on to warn that “polio immunization rates are lower than 90% in many areas of the United States” because of parents having “no recent experience” with polio, “concerns about vaccine safety and religious objections to immunization. With increasing globalization, the United States could be just an asymptomatic traveler away from an outbreak." Remember, 70% of individuals infected with the poliovirus have no symptoms but can carry and spread the disease.

In 2007, the International Post-Polio Task Force began the National Immunization for Polio Prevention in Infants and Toddlers—or "NIPP-IT"—Campaign, when CDC reported drops in polio vaccination and that one million US infants and toddlers were unvaccinated against polio. The NIPP- IT motto: "America's next polio epidemic could be just a plane ride away."

This theme was adopted by an August 2010 Houston Chronicle editorial: "Polio's return to Tajikistan has raised some unsettling questions. International medical activists had planned to snuff out the disease by 2000. What's going wrong? The ongoing problem seems to be a mix of factors. Some are political, such as Muslim leaders in Nigeria who originally branded the vaccine a western sterilization plot. Meanwhile, isolated tribes or subcultures can harbor the disease."

Not mentioned were the effects of war and corruption, lack of sanitation, basic public health and medical infrastructure and that the Sabin oral vaccine mutates and actually causes polio.

The editorial concludes, "Houston residents have reason to watch this battle and wish its warriors well. Even if polio is almost gone, the last cases will always be only a plane ride away from our own city." Indeed, Houstonians need worry. CDC found that Houston has the lowest polio vaccination rate of any reported US city—87%—a drop of 5% from last year.

"Polio outbreaks highlight our global vulnerability to infectious disease," said Dr. Robert Scott, chair of Rotary's polio eradication effort. "It reinforces the fact that polio 'control' is not an option, and only successful eradication will stop the disease."

Unfortunately, eradication is not happening in spite of $800 million spent on vaccination. In 2010, polio was at all time high in Pakistan, primarily in the war-torn tribal areas bordering Afghanistan.

Perhaps it is time to admit that polio eradication is not possible given the political and social conditions in the Third World. Perhaps the millions being raised for polio eradication would be better spent, as the Chronicle proposed, "improving health care or hygiene more broadly," and, as Dr. Scott prescribed, a "fast, large-scale, high-quality immunization response" to any polio outbreaks, plus treatment for polio survivors and those with Post- Polio Sequelae.

The International Post-Polio Task Force has proclaimed 2011 "The Year of Getting Serious About Polio," serious about vaccinating America's children, about treating the world's 20 million polio survivors who have post-polio sequelae and about containing—not eliminating—polio.

Dr. Richard L. Bruno is Chairperson of the International Post-Polio Task Force and Director of The Post-Polio Institute and International Centre for Post-Polio Education and Research. E-mail through PostPolioInfo.com.

From Micki Minner on Facebook
Just as an informational note to everyone: the NEW Amendment to the ADA law states, that a person does not have to PROVE they have a disability to anyone to gain their civil rights under the ADA law, either with employment, access to medical care, public accessibility or service dogs. Yep, if you is a gimp or grump, and you have any bodily function limited even temporarily, you are eligible for protection under the ADA!

Remaining 2011 Meeting Dates
May 1st
June 5th
July 10th (delayed one Sunday because of the Independence Day weekend)
August 7th
Sept. 11th (delayed one Sunday because of Labor Day weekend)
October 2nd (Annual Dinner)
Nov. 6th
No meetings in December or January

A Little Editorializing from Your Editor:

So many disabled polio survivors and so few handicapped parking spaces. And yet, people who are not disabled will often park in one of those rare spaces, "just for a minute" to run (and sometimes they do literally run) into the store for "just a few items."

Someone sent me this little snippet that could be cut out and taped to the windshield of the offending vehicles:

Parking Challenged?

YOU ARE PARKED IN A SPACE CLEARLY DESIGNATED FOR DISABLED PERSONS PLEASE CIRCLE THE STATEMENT WHICH BEST DESCRIBES YOUR HANDICAP

I don't read good.
I suffer from terminal laziness.
I have Attention Deficit Disorder. Huh?
My inner child was bugging me for ice cream.
My shoes are too expensive to walk in.
Wheelchair symbol? I thought it was a rocking chair!
My religion forbids acts of common courtesy.
I ignore OTHER laws, why not this one?
I AM disabled... by a painfully swollen ego.

First Quarter 2011 Donors

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Axiom EPM

Dog Training

Every morning, I take my little dog for a 'walk.' She walks, I roll. Fiona is about the size of a sack of sugar in reality, but in her heart she is a Giant Great Dane. She reminds me of so many of my polio survivor friends. She may have limits but she will go right to the edge of them as often as possible. She will try so hard to pull me in my power chair, urging me to go faster than that.

However, Fiona has taught me some good lessons. She has been on a leash her entire life, just as we polio survivors are on our own Post Polio Leash. Therefore, she knows that there are certain things she can't do and she has developed strategies for such occasions. When she goes to check on her friend Brer Rabbit, who lives under a large patch of spreading yew, she knows that there is a post to maneuver around. She knows how to go around an obstacle that prevents her from reaching her goal. If her leash does get tangled, she knows how to untangle it.

We could learn from this little dog. Well, I could. Maybe the rest of you are well aware of your Polio Leash. I keep forgetting it's there. Fiona knows that when she reaches the end of her leash, she has to back up or go a different direction. After all, there sits Momma, on the other end of that leash in a big power chair. Seven pounds of dog cannot pull over 300 lbs. of Momma and chair combined. Sometimes she tries. Most often, she backs off in favor of something more doable.

Fiona has more sense than I do. I know that there's a big Momma on the end of my leash, too, but I try to fool myself into thinking I can change that if I try hard enough. If I just do it this way, or maybe if I do it that way...I don't learn as quickly as Fiona does.

Fiona knows enough to ask for help when she needs it, too. Mostly, like all of us, she is very independent, but faced with an empty water dish, she knows she needs help. She will then ask for me to fill it up. Seems simple, doesn't it. Yet when I need something that I know I cannot do for myself, do I have enough sense to ask for help? Usually not. I'll still climb on my step stool, knowing full well that my bad hip will complain loudly and might, just for spite, dump me on the floor. I could wait until my nephew, who lives just down the hall, stops by and ask him to reach that high shelf. But do I? No. I don't want to bother him. Fiona has no compunction whatsoever in asking me to do little things for her. If her dog toy is under the couch, she shows me that she can't reach it and I use my grabber to get it for her.

Fiona is a lovely little companion and teacher. She will bring her toy to me so I can throw it and she can chase it. Sometimes she drops it on the floor in front of me. I tell her, "Fiona, I can't reach it." Then she will pick it up, put her front paws on my lap and deposit the toy (dog spit and all) on my knee. She is willing to train me, but I have to learn to cooperate. Someday maybe I'll accept my leash as graciously as she accepts hers.

~by Millie Malone Lill~

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