



The Polio Post

Ohio Polio Network Newsletter

Editor: Alice Sporar Summer 2011 Issue

Margaret J. Meyer

March 9, 1939 - June 24, 2011

by Alice Sporar

The disability community has suffered a great loss with the death of Margaret Meyer, who passed away as a result of post-polio respiratory complications.

Margaret contracted polio at braces, crutches, and a childhood, high school, used a power wheelchair in her active life style. After college she worked for the 1960 she married Bob survivor, and they raised two full time Mom after her first she and Bob became active disability issues in the

A list of some of her

She and Bob maintained the Ohio Chapter of the National Foundation in their home, support, information, and various disabilities and was newsletter.



Margaret and Bob Meyer at their daughter's wedding

the age of seven. She used wheelchair during her and college. Later she order to continue attending business Navy Department. In Meyer, also a polio children. Margaret was a child was born, but both volunteers involving 1960s.

accomplishments follows:

office of the Northeast Spinal Cord Injury where she offered peer referral to people with editor of the Chapter

She and Bob were part of the group who co-founded Services for Independent Living (SIL), the first independent living center in Ohio.

Margaret was on the Board of Directors and then was employed by SIL in the position Peer Counseling Coordinator and later became Program Director and for a time was Interim Executive Director.

She was an organizer and participant in the group who blocked buses on Public Square in order to obtain wheelchair accessible public transportation.

Margaret and Bob were present at the White House for the signing of the ADA in 1990.

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Margaret J. Meyer by Alice Sporar

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Later she met with President Clinton to discuss issues facing people with disabilities.

She facilitated the first Greater Cleveland Post Polio Support Group.

She was inducted into the National Hall of Fame for Persons with Disabilities in 1999.

She fought for and lived out the concept of providing home based care, rather than being sentenced to life in a nursing home.

Aside from disability issues, Margaret was an artist and loved music.

One of the most important things in Margaret's life was her faith. She converted to Catholicism in 2006 and became a member of St. Andrew's Byzantine Catholic Church.

Margaret was married to the late Bob Meyer for forty-two years. She was the mother of Jennifer Demas (Mike) and the late Robert. She is also survived by four grandchildren, Michael and Christopher Demas and Brandon and Bailie Meyer.

Margaret and I have been friends since high school. She was a role model for me, showing me how to live life independently, and she was a true friend. She will be missed by many.

NEWS & NOTES

• POST-POLIO INFO

For information on post-polio issues, join Post-Polio Health International. Memberships run from \$30 to \$150 per year, depending on what level you choose. For more information, contact Post-Polio Health International at 314-534-0475, 4207 Lindell Blvd. #110, St. Louis, MO 63108, or www.post-polio.org. Educating ourselves about the effects of post-polio syndrome is important and may save our lives.

OPN Board Meeting
Saturday, September 24, 2011
Westerville, OH Library
Noon - 3 PM

OPN members are welcome to attend. OPN is looking for members interested in becoming Board Members. If you are interested or have agenda items for the Board Meeting, please contact Patrick Kelly, pkelly03@sprynet.com

Corset Issues

By Alice Sporar

This article may be of interest to any of you who wear a cloth corset with steel stays.

In 2009, I decided it was time for a new corset, as the one I was wearing wasn't offering the support it did when new. Any of you who wear one, know what I mean. My provider is Leimkuehler, Inc. When I contacted the orthotist, he said that there was a change in frequency, and Medicare will only pay for one every five years, now. I decided to sign an Advanced Benefits Notice and proceed. Freeman in Michigan manufactures the corset and Leimkuehler fine tunes the customizing.

After numerous requests for more information, several pictures, and other annoying requests, Medicare denied the coverage. Leimkuehler appealed on my behalf, but that, too, was denied. By that time, it was 2011. I paid Leimkuehler, since I had signed the ABN.

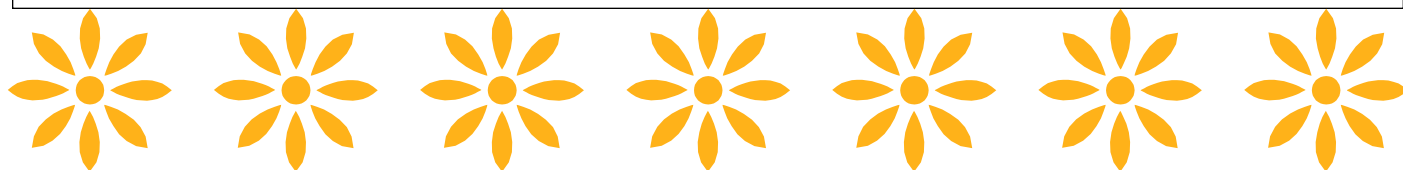
I decided to appeal on my own behalf, but instead of appealing according to Medicare's rules, I sent a letter to the administrator of Medicare in Baltimore, Dr. Donald Berwick. I explained, in detail, exactly why I had to wear a corset and why the present corset was no longer supporting me. For example, if I don't wear a corset, my torso just shrinks down inside itself, because my abdominal and back muscles are too weak to hold me up. Also, I requested that Medicare return to the previous policy of paying for a corset whenever the patient and his/her personal physician decided it's necessary as opposed to a clerical person or physician who has no knowledge of polio, making that decision. I copied the letter to the three Cleveland area congressional representatives, the two Ohio senators, and to President Obama.

Assistants from Congressman LaTourette's, Senator Brown's, and Senator Portman's offices offered to help me. Quickly I received a letter from a Medicare office in Chicago, with the necessary forms for all the appeal steps and with information on how to change the policy. After I filled out all the forms, but before I mailed them, I received a call from Leimkuehler saying that Medicare had sent a check for their portion of the corset, which meant that, now, my supplemental insurance would pick up the rest, and Leimkuehler would reimburse me.

I've sent thank you letters to the administrator of Medicare and to Congressman LaTourette, Senator Brown, and Senator Portman. I'm still working on getting the policy reversed to what it was previously.

I thought readers would be interested in knowing that you have the power to make changes.

If you're interested in working on changing the policy, contact Donald M Berwick, MD, Administrator, Centers for Medicare & Medicaid Services, 7500 Security Boulevard, Baltimore, MD 21244. Also, contact your Congressman/woman at House of Representatives, Washington, DC 20515 and, in Ohio, contact Senators Rob Portman and Sherrod Brown, at US Senate, Washington, DC 20510. If you have any questions or comments, email me at amsporar@worldnetoh.com or call 440-942-1557. For some reason, I am unable to receive email from yahoo customers, but I'm working on it.



BEWARE VESICARE!

NO POLIO SURVIVOR – NO ONE WITH BREATHING PROBLEMS SHOULD TAKE VESICARE

By Richard Bruno, PhD

A polio survivor was given VESicare on November 18th. Four days later she was too exhausted to leave the house. The next day, all she did was sleep. By Wednesday, she was unable to stay awake. When she was awakened she stared into space, unable to understand or respond to questions. Even more frightening, her ability to breathe was compromised and she was placed on a ventilator.

VESicare was stopped on November 24th. The next day, Thanksgiving, she was still unable to stay awake on her own but, when prompted, did try to eat. She discovered that her stomach and intestines had shut down.

Unfortunately, VESicare has an extremely long half-life. It would take her body anywhere from 10 to 14 days for the VESicare to clear out. During those days, although she mostly slept, she became progressively more aware and mentally sharp when awakened, but she could only eat very small amounts.

On the 15th day after VESicare care was stopped, she awoke. She was able to stay awake on her own and was her usual intelligent and funny self, albeit easily tired. Today, one month after waking from her VESicare-induced stupor, she is eating normally; still requires the ventilator at night; and at times throughout the day when her diaphragm is unable to push enough carbon dioxide out of her lungs. She will need the ventilator for the rest of her life.

WHAT ARE THE MORALS OF THIS STORY?

FIRST, no polio survivor – no one with breathing problems – should take VESicare. VESicare not only turns off the bladder, but also turns off the stomach and intestines and enters the brain. VESicare is known to block activity brain areas damaged by the original polio infection, the brain activating system. In fact, the FDA has recently required VESicare's manufacturer to add "somnolence" to VESicare's list of side effects. (Somnolence? How about coma?) VESicare is also known to block brain diaphragm stimulating neurons. I am concerned that VESicare will very likely have the same effect in other polio survivors, especially those who originally had bulbar polio or any polio survivors who have breathing problems, such as central sleep apnea. What's more, I am also worried that individuals who have both difficulty breathing and bladder problems and might be prescribed VESicare – those with muscular dystrophy, multiple sclerosis, traumatic brain injury – might have a similar reaction.

SECOND, polio survivors can have difficulty blowing off carbon dioxide and should not be given oxygen without having their carbon dioxide monitored, since oxygen levels can be normal while carbon dioxide can become dangerously high.

THIRD, a polio survivor should never take a drug that is anti-cholinergic or that enters the brain without your doctor researching the side effects. The coma you prevent will be your own.

Richard Bruno, PhD is Chairperson of the International Post-Polio Task Force & PPS Institute. He may be reached for consultation at postpolioinfo@aol.com

Contributed by Barb Mayberry, President, Naples PPSG, May 6, 2011.

BAPPG EDITOR'S NOTE: Be sure to have your Pharmacist check ingredients of similar prescription drugs, such as Detrol®, Ditropan®, etc.

Reprinted from Second Time Around, June 2011, publication of Boca Area Post Polio Group, Boca Raton, FL.

Visitable Homes, Visitable Communities

What Is Visitability?

Most homes have steps at every entrance, and have bathroom doors that are narrower than other interior passage doors.

Visitable homes have:

- One entrance with zero steps
- 32 inches clear passage through all interior doors, including bathrooms
- At least a half bath (preferably a full bath) on the main floor

Visitable homes are deliberately designed with basic access by residents who do NOT have disabilities. Visitability is a campaign for these features to become standard in virtually all new homes, through legislation, voluntary implementation, market forces and strong advocacy from interested individuals.

What Are The Benefits?

- Residents in the community can **welcome guests** who use wheelchairs or walkers, or have some other mobility impairment such as stiffness, weakness or poor balance. When Visitability is in place, mobility-limited people are **not isolated by architecture**.
- If a family member develops a disability through illness, accident or aging, the person and their family are more likely to be **able to remain in their existing home**, rather than having to do major, expensive renovation—or move to another house, or a nursing home.
- **All residents find it easier** to bring in baby strollers, grocery carts, heavy furniture, etc.
- Visitable homes **enhance sale and resale** in an era where the senior demographic is growing rapidly. Buyers are attracted to homes that welcome their aging parents and provide easy-use convenience for themselves.
- Visitability features cost little up front — unlike the much higher after-the-fact cost of retrofitting features.

Zero-step entrances on new homes are nearly always **easy to construct**, on flat or hilly terrain. The entrance can be at the front, side or back, wherever is most feasible for the topography. A zero-step entrance can usually be incorporated without a “ramp” by grading so that the sidewalk meets a porch. For the 40% of homes built on a concrete slab, the zero-step entrance is typically extremely easy. For homes with basements or crawl spaces, solutions such as siting the home properly on the lot, using a porch as a bridge to the sidewalk, lowering the first-floor rim-joint, creative use of small retaining walls, constructing the zero-step entrance from the garage and other methods provide low-cost zero-step entries.

- Visitability features **make fiscal sense** for society as a whole. For instance, as of 2004, the average cost for one year of nursing home care exceeds \$50,000 per person ¹ — 62% of which is paid with public dollars. ²

More on Doors

All interior passage doors need to be a **minimum of 2'10"**, which leaves 32" clear space when the door is open at 90 degrees. Although 2'10" doors are not yet commonly stocked in home improvement stores, they are readily available from the door companies where professional builders buy their supplies. 3'0" doors are excellent where space permits. Pocket (sliding) doors are another way to obtain 32 inches of clear passage space. Special attention needs to be paid to the

More on Doors

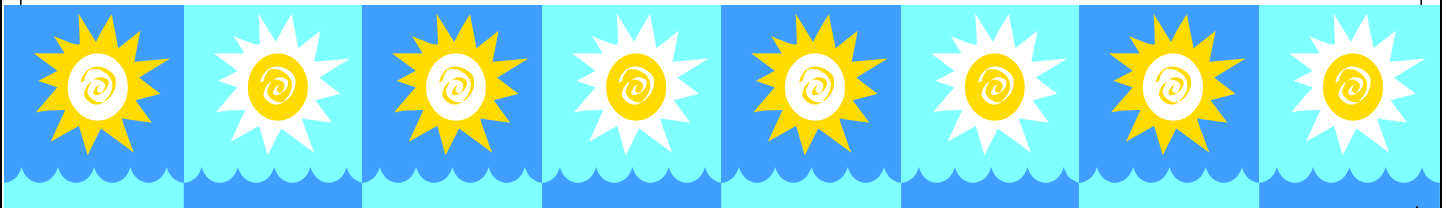
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Do any developments already incorporate Visitability?

Yes. For more information, visit the Concrete Change website at www.concretechange.org.

¹ GE Financial Survey, 2003, http://www.gefinancial.com/pressroom/releases/20030803_nursingcosts.html

² "Medicaid and Long-term Care," Kaiser Commission on Medicaid and the Uninsured, May 2004



Protect Yourself --Don't Become a Statistic

By Mark S. Vass

This article was published in "Special Living," in 2002.

Last August, I left my house for about twenty minutes to get my daily dose of caffeine and doughnuts. Upon my return, I noticed the front door literally in pieces. At that exact moment, I heard noises coming from the back of the house. I quickly realized that someone was in my home, and they probably knew that I was there also. I immediately turned to make my exit, while at the same time praying that whoever was violating my home would not put a bullet in my back. That was the longest twenty feet I've ever traveled.

I was very lucky. During the next four hours of talking with detectives and crime scene personnel, I was told something that I didn't want to hear--my home was probably picked because the perpetrators knew that I had a disability and wasn't a threat. I was an easy target.

Like it or not, people with disabilities, just like elderly people and children, are more prone to criminal activity. Although members of the disability community strive not to carry labels, this is one we can't outrun. So what's the answer? According to Officer Scott Bradburn of the Keller, Texas Police Department--common sense. Officer Bradburn told me, "Even though I don't put the disability community in the same category with elderly people and small children, many of the same tips apply to all three groups."

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Protect Yourself --Don't Become a Statistic By Mark S. Vass

(Continued from page 6)

You don't want to be a prisoner in your own home, so let's discuss something as simple as going outside to get your mail. Most of us have at least one neighbor that we feel can be trusted. Why not wait until your neighbor is home, then go outside to get your mail while they keep an eye on you. There's nothing wrong with this. If you don't feel comfortable asking for a neighbor's help, wait until a busy high-neighborhood-traffic time of the day, between 5 pm and 6 pm, to go out in your yard. Neighbors driving by your house can say, "I know that person, and everything seems to be okay." Regarding this issue, Officer Bradburn says, "An attack is less likely to happen during the time when neighborhood traffic is heavy as opposed to one o'clock in the afternoon or after dark."

Don't overlook some basics of home ownership--window and door locks. Does each one of your doors contain a deadbolt lock? Is the strike plate secured to the door casing with standard one inch screws, or is it secured with four inch screws that anchor into the studs on the opposite side of your door jamb?

When my house was broken into, I did not have the latter--I do now. Finally, just because your windows have a basic locking mechanism, this doesn't mean that they're secure. Look for "auxiliary window locks" at the hardware store. These are small pieces of metal with a thumbscrew that attaches to the window's sliding rail.

Although creating a safe environment for you and your family may cost a few dollars, there is a positive side to this process--financially speaking. Contact your homeowner insurance agent, and ask them how adding security features to your house can drastically reduce your insurance premium.

Let's face it--hanging around the homestead is not the only place you may be a target. What about going to the grocery store or the mall? The possibilities are endless; in the parking lot, unloading or loading a wheelchair, walking with packages in your arms, and in public restrooms. I'm not trying to scare you into never leaving your favorite easy chair, but I am being realistic. Just because you're 80 years old, or in a wheelchair, or use one or two canes to walk does not mean you're defenseless.

Think about the psyche of the criminal who targets people with disabilities. One of the main reasons they do this is because they think that those with disabilities are unable to defend themselves. Those who use a manual wheelchair or walk on canes, probably have a little more upper body strength than they realize. Add to this the fact that the last thing a criminal is expecting is for someone to take a swing at them with a cane. I was passing by a local karate dojo and noticed two students in wheelchairs. I later spoke with the instructor, and was surprised to learn that there is a lot a person with multiple health issues can do regarding self-defense. I'm not advocating one solution over another. I am, however, suggesting that you contact local self-defense groups and ask questions.

Officer Bradburn emphatically states, "The key issue is, you don't ever want to put your life in jeopardy. You need to keep all these rules in the back of your mind and do whatever you can, but never at the potential expense of your life."

A personal attack or robbery can be a very traumatic event but it's your responsibility to provide as much information for the police as you can. Record in your mind things like the criminal's race, gender, estimated height, approximate weight, color and length of hair, and what he/she was wearing.

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Protect Yourself --Don't Become a Statistic By Mark S. Vass

(Continued from page 7)

If you saw him/her drive off, what type of vehicle was it, what direction did it go, and what about a license number?

Finally do you use an assistance dog? If so, keep in mind that as assistance dog partners, we know that they are not guard or attack dogs, but most criminals don't know this. This threat alone may be enough to ward off a potential attacker or thief.

The following are some basic steps you can take to safeguard yourself while in your home.

- Install a peephole in your front door. If you use a wheelchair, there are peepholes that provide a very wide angle, allowing you to see the entire person from any height.
- If you aren't expecting visitors, contractors, cleaning people, etc., don't feel obligated to open the door. More importantly, don't yell out, "Who is it?" This is only telling a potential criminal that you're home.
- If you do have someone you don't know well come into your house, make sure that your valuables, such as, personal checks, cash, keys, credit/debit cards, and jewelry are not out in the open. Put these items in a secure area, where somebody wouldn't expect them to be.

Safeguards for home and when going out at night.

- Law enforcement agencies suggest that shrubs and trees should be no taller than one inch below window sills.
- What type of outside lighting do you have at your house? Do your lights have motion detectors on them?
- If you don't have motion sensors on your lights, do you have timers on them? Do they automatically turn on after the sun sets?
- There is safety in numbers. If you are going out, ask someone to go with you, if possible.
- If you're headed toward your car, make sure that you have your key in hand before getting to your vehicle. Would-be thieves watch for people who get to their cars, then become distracted looking for their keys. The criminal uses the element of surprise to his/her full advantage. Be ready to open your door, get in your car, and lock the doors as soon as you get there.
- Park close to the building entrance and to bright lights.

Reprinted from Branching Out, newsletter of the Indiana Polio Survivors Association, Inc. (IPSA), Winter 2002.



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