

Polio perspective

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SURVIVOR GUILT

International Post Polio Conference. First time for Atlanta, first time for me. I almost had some kind of breakdown the night before, just knowing that I was going to a place where there were hundreds of crippled people, not people like me but crippled people. The ones that you look at and feel sorry for and you're glad it didn't happen to you. And you know it should have happened to you, and it did. But you have hidden it all this time, hidden it under pants and boots and long skirts and oh my god, it's summer again...

Summer means one thing to you when you have something to hide. Exposure. Those people at the conference can't hide. They have to carry their signs around with them. Oh yes, I'm guilty. At the age of four, I got in the way of a virus, wasn't smart enough or quick enough or strong enough or good enough to stay out of the way of the virus. Just like I wasn't strong enough or good enough or brave enough to get away from my brain damaged cousin when his hands would come sneaking under the sheet to touch me and make me ashamed and I can't tell anybody. And it's my fault I'm crippled but I

can't let anybody know and I can't tell anybody and I am ashamed.

Now I am going to a conference of all these other shamed people and I will say I am one of you but I haven't suffered as much as you. I haven't carried around the steel and wood and plastic and pain for all to see. I covered it up and pretended it wasn't there and when others ask, are you limping?... I say, I'm just tired. It's ok. It was just polio. No problem. No cripple here. Don't tell. Nobody will know.

And then I went. I went to the conference. And there they were. Riding around on their little scooters of every type, sporting every type of cane and crutch. High tech, high mobility, high spirits. In spite of the news, which is not good, and the physical states, which were not strong, the spirits were optimistic and dedicated to self-education and survival. These are, after all, the Polio Survivors. That's what we're called. Polio Survivors. And here I am, suffering from Survivor Guilt because I can walk in unsupported wearing semi-Normal shoes, with an almost-Normal gait. I can breathe without assistance. I could be one of the medical practitioners, you can't tell from looking at me. I might not be a Survivor. But I am. A lucky one. I got good care from the beginning, back in 1949. Lots of them didn't. I had surgeries that accomplished the purpose of keeping me walking without pulling other joints out of place. I'm sorry that I walked in and they didn't. I wish they were all as lucky as me.

Everybody is smiling and trading tales of hot wet wool and childhood indignities so profound that they demand to be treated lightly and everyone smiles and laughs and adjusts in their seats and remembers. Or not. Some don't remember the fork in the karmic path, the experience which created and defined their life from that moment on. They seem to feel deprived; they want to know the reality of the crippling blow, to own it as it owns them. They complain of amnesia, questions its origin. Was it the fever, the trauma, should I get hypnotized? Some say, with regret, I was only 2. One, the one who sat by me with her little legs in the plastic and metal and leather braces and her little feet in the plain white shoes with no cute little straps and no cute little bows, this one said: I was paralyzed from the neck down at the age of five months. And a hush hits the room like a quick small wind and then the discussion goes on. They don't remember what the rest of us remember, the night of body breaking pains and fevers and nauseas and stiffness and spinal taps and quarantine and abandonment and fear and muscle spasms that contorted the body so that some medical practitioners put them in a body cast and the spasms kept right on happening anyway.... and he laid in the cast and screamed for two days. They don't have that shade of childhood memory and they feel cheated.

They talk to us about the reasons we have all begun to regress, to lose the strength we gained so long ago and held day by day only to slip back into conditions past. Post Polio Syndrome, it's called. Some who have walked have reverted to braces and crutches; some who breathed outside the iron lung now have permanent holes in their throats covered by colorful bandannas. Some who moved on crutches are now on scooters and wheelchairs. They tell us that No, it's not Polio happening again. It's just that any one or all of the following changes is happening because Polio happened to you long ago and the cause is this or that or both and it is causing any number of the following symptoms and it might happen to you and it might not and it might go all the way to fill in the blank or it might not. But it's pretty likely that you wouldn't be here if you weren't already having some of the symptoms, so inform yourself, do the right thing with your body and get your head right for what's ahead. And be sure to see our nice

vendors out in the hall with several different types of wheelchairs, scooters, braces, canes, crutches, treatment plans, oxygen dispensers, van conversions and electromagnetic devices which may or may not alleviate some of your pain.

I am not the only Lucky Survivor. The other Normal looking ones are the other Lucky Survivors. And when I talk to them, they, like me, are getting new information here. They, like me, have never been around a bunch of full-tilt Polio Survivors before, in full wheel. They, like me, are scared to death. This is scaring me to death, the white haired man says. He had paralysis in the right arm and shoulder and left leg, got quarantined with his grandmother who, one day, took off his shoulder brace and said, you're not ever going to get strong with this on and she massaged him with olive oil every day and one day he got this excruciating headache and his head started drawing back and they rushed him to the hospital arching ever further back and they put a needle into his spine and drew out fluid and his headache went away and his neck stopped arching and he was ok. Only he had no muscles in his right arm and shoulder and his left leg, but that wasn't anything that couldn't be overcome; and he looked Normal to me. Another man who says that he was the baby in the family and a shy quiet little boy, he says, this is scary. He was paralyzed on his whole right side and he's always had problems, but he had good care and he coped well and he's had a pretty Normal life. His wife makes fun of him and accuses him of malingering and using Polio as a handy excuse when he says that he is tired. He looks at me with his sweet eyes behind his little round glasses and we recall the way it was and we express our plans to cry when we get home, but not now.

Magnetic Therapy

By Dolores Sieg

A double-blind, placebo-controlled study of 50 people with post-polio syndrome found evidence that magnets are effective for relieving pain. 2 The magnets or placebo magnets were placed on previously determined trigger points (one per person) for 45 minutes. (Trigger points are sore areas within muscle that, when pressed, cause relief in other areas of the muscle and conversely, when inflamed, cause pain in other parts of the muscle.) In the treatment group, 76% of the participants reported improvement, compared to 19% in the placebo group.

As can be seen Fibromyalgia is very different from PPS

Fibromyalgia

A 6-month, double-blind, placebo-controlled trial of 119 people with fibromyalgia compared two commercially available magnetic mattress pads against sham treatment and no treatment. 36 Group 1 used a mattress pad designed to create a uniform magnetic field of negative polarity. Group 2 used a mattress pad that varied in polarity. In both groups, manufacturer's instructions were followed. Groups 3 and 4 used sham treatments designed to match in appearance the magnets used in Groups 1 and 2. Group 5 received no treatment.

On average, participants in all groups showed improvement over the 6 months of the study. Participants in the treatment groups, especially Group 1, showed a trend toward

greater improvement; however, the differences between real treatment and sham or no treatment failed to reach statistical significance in most measures. This outcome suggests that magnetic mattress pads might be helpful for fibromyalgia, but a larger study would be necessary to identify benefits.

A previous double-blind, placebo-controlled study of 30 women with fibromyalgia did find significant improvement with magnets compared to placebo. 3 The women slept on magnetic mattress pads (or sham pads for the control group) every night for 4 months. Of the 25 women who completed the trial, participants sleeping on the experimental mattress pads experienced a significant decrease in pain and fatigue compared to the placebo group, along with significant improvement in sleep and physical functioning.

A single-blind study of somewhat convoluted design provides weak evidence that a gown made from a special "electromagnetic shielding fabric" can reduce fibromyalgia symptoms. 72 The rationale for using this fabric is, however, somewhat scientifically implausible.

<http://www.upmc.com/healthatoz/pages/HealthLibrary.aspx?chunkid=33778>

It is interesting that Magnetic therapy helps Peripheral Neuropathy

Peripheral Neuropathy

A 4-month, double-blind, placebo-controlled crossover study of 19 people with peripheral neuropathy found a significant reduction in symptoms compared to placebo. 4 Participants wore magnetic foot insoles during the day throughout the trial period. Reduction in the symptoms of burning, numbness, and tingling were especially marked in those cases of neuropathy associated with diabetes.

Based on these results, a far larger randomized, placebo-controlled, follow-up study was performed by the same researchers. 53 This trial enrolled 375 people with peripheral neuropathy caused by diabetes and tested the effectiveness of 4 months of treatment with magnetic insoles. The results indicated that the insoles produced benefits beyond that of the placebo effect, reducing such symptoms as burning pain, numbness, tingling, and exercise-induced pain

Dolores Sieg, RN

Post-Polio Thoughts

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Movin' On

We're talking civil rights here. Big Time. "Our crowning achievement of the 20th Century," as Justin Dart, Jr. called it—the passage of the Americans with Disabilities Act—the ADA. On July 26 we celebrated its anniversary. Twenty years of freedom.

Immediately after the ADA went into effect, it became clear that this Act would alter more than the law. Attitudes all across the country began to change, as well.

People everywhere began to see us in a different light. A much-loved comic strip suddenly featured a popular teacher who used a wheelchair. Individuals with disabilities began popping up in TV commercials. Smiling strangers held a heavy door for us—or realized we had a place in line. We became visible.

Of course challenges followed. Many of us remember the goofy Catch-22 court decisions that limited the ADA definition of disability to its most useless extreme. More than one piece of outrageous nonsense belched up by official detractors even left us concluding that the only people eligible for ADA protection against job discrimination would be those too disabled to work. Obviously, we needed to clarify.

So Congress moved in to tighten up the language in the ADA, making it harder to misinterpret, more difficult to distort. On September 25, 2008, the Amendments to the Americans with Disabilities Act was signed into law.

The purpose of this Act is “to restore the intent and protections of the Americans With Disabilities Act of 1990.” No more twisting what Congress meant out of shape by Supreme Court rulings or others’ wrong interpretations.

To begin with, the definition of disability remains the same (“an impairment that substantially limits one or more major life activities, a record of such an impairment, or being regarded as having such an impairment”), except in the Amendments, Congress makes it clear that this is to be understood in the broadest way possible.

Let there be no doubt. If I’m disabled because I have only one leg, but my loss has been corrected by the use of a prosthetic device—guess what? I’m still disabled. Some people’s idea that my impaired body is no longer disabled because I’m wearing a brace or because glasses improve my myopic vision, simply will not wash anymore.

Take a look at these Amendments online. Or perhaps better yet, start by clicking onto the PHI website’s informative article, [“The ADA Amendments Act of 2008.”](#) A word here, a phrase there—now nobody can miss the teeth in this Act. Look all the way through. Think about what we know about discrimination on the basis of disability. See how we view a “reasonable accommodation.”

Oh no, we’re not home free yet. There will still be those who try to ignore what’s right for those of us who are disabled. We have more changes to make, many roads left to travel. But we’re on our way.

Today the contest is different—we have the ADA to fight for us. Look at the outcome when a U.S. District Court reminded the State of Florida of the ADA-guided Olmstead decision (the Supreme Court’s 1999 integration mandate). When that state tried to install a quadriplegic into a nursing home instead of providing her with the required services allowing her to live at home, they lost the battle. ADA to the rescue.

The ADA has a way of convincing people of our mutual and equal worth, and that each one of us has a role to play in achieving this equality. Today we have ADA power to count on—thanks to legions of contenders from the disability world and our fighting, caring friends.

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Source: Post-Polio Health International (www.post-polio.org)

NEW JERSEY DISTRIBUTES POLIO SURVIVOR WARNING CARDS

By Dr. Richard Bruno

FOR THE MANY WHO RECENTLY HAVE BEEN E-MAILING ABOUT PAIN
MANAGEMENT, ANESTHESIA & SURGERY...

NEW JERSEY DISTRIBUTES POLIO SURVIVOR WARNING CARDS.

The New Jersey Department of Health has printed and distributed 10,000 wallet-sized cards with vital information on anesthesia dangers in polio survivors and on Post-Polio Sequelae, a disabling condition affecting the state's 50,000 polio survivors.

Created by Dr. Richard Bruno, Director of the International Centre for Polio Education, the yellow, double-sided card was suggested by the Ocean County post-polio support group to comply with New Jersey Senator Loretta Weinberg's "Post-Polio Sequelae Public Awareness" bill.

"Doctors have forgotten about North America's nearly two-million survivors of the polio epidemics of the 1940s and 1950s," said Dr. Bruno, who is also chairperson of the International Post-Polio Task Force. "Because of damage the poliovirus did to the stem of the brain, polio survivors are easily sedated and often get too much anesthesia." Bruno has seen polio survivors end up on a ventilator in intensive care after minor surgery or even a colonoscopy.

The New Jersey DOH card features a prominent, red "ANESTHESIA WARNING!" and lists easy sedation and difficulty breathing and swallowing as problems that can be avoided by using lower doses of anesthetics in polio survivors. The card also lists increased sensitivity to cold and pain as post-operative problems in polio survivors.

"The poliovirus kills neurons in the brain and spinal cord that produce the body's own morphine," Bruno explained. Bruno's research has found that polio survivors are twice as sensitive to pain as those who didn't have polio. He recommends a general rule of thumb for treating polio survivors—"The Rule of 2": two times the usual amount of pain medication for two times as long, and the usual amount of anesthesia divided by two.

"All doses of medication must be adjusted for individual polio survivors," Bruno cautioned. "And, polio survivors should never have same-day surgery because of excessive sedation from even appropriate doses of anesthesia."

The flip side of the DOH card lists the "late-effects of polio," called Post-Polio Sequelae, overwhelming fatigue, muscle weakness, muscle and joint pain, sleep disorders, cold intolerance and breathing and swallowing difficulties that can develop in midlife.

"Doctors are also unaware of Post-Polio Sequelae, or say that they 'don't believe' in PPS," said Bruno. "PPS is very real and very treatable if polio survivors can reduce the 'overuse-abuse' of their remaining, overworked poliovirus-damaged neurons."

Groups may request cards by going online to NJ.gov/health/feedback.shtml. More information about anesthesia concerns and Post-Polio Sequelae can be found at PostPolioInfo.com.

http://www.northjersey.com/community/announcements/83518047_N_J_State_Health_Department_distributes_polio_warning_cards_Bergen_COunty_.html
New Jersey Department of Health

nj.gov

CUTE, OR NOT SO MUCH?

By Millie Malone Lill

To many people, this may seem trivial. Perhaps it is, but I find it very annoying and I'm betting you do, too. When my friend and I are out toodling around in our power chairs, people say we are cute. My friend sees it as a compliment, but I see it as condescending and inappropriate.

Cute is for puppies, kittens, and children. I am a senior citizens and I have no desire to compete with the aforementioned group in a cute-a-thon. Oh, make no mistake, I like being told I am attractive, pretty, or that I look good for my age. OK, I'll get real, not that last one so much. It's better than being called cute, though.

"Cute" implies that we are more decorative than useful. Since I am not all that decorative, it puts my usefulness status at a very low ebb. I don't appreciate that. Being seen as cute makes me feel trivialized. Not important. Too helpless to be any good for anything. A cartoon, perhaps.

We polio survivors have been through a lot. Can you imagine a military veteran enjoying being called cute? Don't think so. He/she has served our country and should be treated with respect. We polio survivors have struggled, too, defied death in many cases, have contributed greatly to the common good. It was because of us that the ADA came into effect. We were the first group of disabled people to survive and thrive. We are not "cute."

No one who knows me at all will see me as stuffy or prim. I enjoy a good laugh, but I don't like feeling like the butt of a joke. Like all of us, I've endured surgeries, casts, braces, walkers, crutches and The Dreaded Power Chair. My disability does not define me, nor does it make me "less than."

When people think of me as cute, they seem to think it is OK to talk down to me, stand too close to me, pat me on the shoulder/head even if they do not know me, or dismiss me as an unimportant member of society. I'm seen as no longer relevant. My intellect is judged by the fact that I am in a chair. Maybe some people sit on their brains, but I'm not one of them.

We are many things: parents, teachers, accountants, grandparents, writers, sisters, brothers...the list goes on and on. What we are not is "cute." And if I'm called cute one more time, I'm going to hold my breath till I turn blue! That will show them!

UN-INaccessibilities...

Can you
visit my
little apartment
(Inaccessible) house?
Just a few steps (each a mountain
to me!)

The loo?
'Round the corner,
sliding door (won't close and

can't get to toilet - no room!) Oh!
Go home...
Next time?
There is not one.
Why? (Couldn't get through door,
up steps or navigate tiny
crowded
rooms or
tight furnishings.)
I don't refuse invites
for fun, whimsically. So,
stay home.
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Web Corner

Good information about what vaccines we need:

<http://www.cdc.gov/vaccines/schedules/easy-to-read/adult.html>

Jonas Salk's 99th birthday celebration:

http://worldsciencefestival.com/blog/jonas_salks_99th_birthday

Polio-free Countries Still Face Threat:

http://www.huffingtonpost.com/2013/11/21/polio-free-countries_n_4317043.html

Benefits Check Up:

<https://www.benefitscheckup.org/>

Choosing a wheelchair:

<http://vimeo.com/79396398>

Polio Eradication Declared an Emergency:

http://www.huffingtonpost.com/2013/11/13/polio-eradication-emergency-priority-21-nations_n_4266656.html

Wheelchair Travelers on Airlines May Get Better Access?

<http://blog.amsvans.com/wheelchair-traveler-on-airlines-may-get-better-air-access/>

Long before surgery, polio survivors should read this:

<http://www.postpolioinfo.com/library/surg.pdf>

Ruling on NYC disaster plans may have far-reaching affect:

<http://www.npr.org/2013/11/09/243998312/ruling-on-nyc-disaster-plans-for-disabled-may-have-far-reach>

One of two types of polio may have been wiped out:

<http://www.leaderpost.com/health/remaining+types+polio+viruses+wiped+seen+year/9149295/story.html>

A Little Bit of Humor

A man realized he needed to purchase a hearing aid, but he felt unwilling to spend much money. “How much do they run?” he asked the clerk.

“That depends,” said the salesman. “They run from \$2.00 to \$2,000.”

“Let’s see the \$2.00 model,” he said.

The clerk put the device around the man’s neck. “You just stick this button in your ear and run this little string down to your pocket,” he instructed.

“How does it work?” the customer asked.

“For \$2.00, it doesn’t work,” the salesman replied. “But when people see it on you, they’ll talk louder!”