

Polio Perspective

November 2014

Editor: Millie Malone

Publisher: Wilma Hood

IN THIS ISSUE

PPS Is a Medical Condition

By Ray Jajko

Time is Passing Quickly

By Raheem Ahmed

Post-Polio Sequelae: Preventing Ultimate Burnout

By Dr. Richard L. Bruno

Holidaze

By Millie Malone

Web Corner

A Little Bit of Humor

POSTPOLIO IS A MEDICAL CONDITION

By Ray Jajko

Post-Polio is a medical condition that, at least for me, keeps on “taking”. It’s taken my abilities to walk, lift my arms, roll over in bed, and other assorted “take-it-for-granted” gifts. I’d be dishonest if I said such “taking” didn’t bother me...at times I simply hate it with a deep passion and I don’t know how much I want to live this way. But when I come right down to it, I do love my life so much...a wonderful wife (Susie), a great fur-baby (Ben), a new and warmer start in Florida, great new friends, and more. While facing such greatly diminished physical capacity it is important for me to perhaps brag a little and give myself a mental pat on the back for finding new things I CAN do. I can no longer walk or wield a hammer, but NOW I CAN DEPOSIT A CHECK IN MY BANK ACCOUNT WHILE SITTING IN MY WHEELCHAIR AT MY DESK!!! Sure, some technology folks set it up, but I learned how to use the tools they created AND DID IT MYSELF. It’s the same as the hammer I used to swing...others made it but I learned to use it. Others made my shoes but I walked in them. There are times when I allow myself to mourn my Post-Polio losses, and it’s natural and healthy for me to do so. But, it is at least as important for me to find joy in my remaining and new abilities. ...last evening I used my “Smartphone” (sometimes it acts pretty dumb) to deposit (a check) in our bank account. This morning I reviewed our account online and sure enough, the check I deposited last night has been credited, the funds are available and the check image can be clearly viewed. It kind of feels like I learned how to do magic!!! The point is recognizing all that I CAN do and not glumly live only with what I can no longer handle. SO...GOOD JOB, RAY, GOOD

TIME IS PASSING QUICKLY

By Raheem Ahmed

Time is passing rather quickly it will soon be Christmas again. My energy levels do not recharge to former levels and I am learning to do more with less or as some would say, “working smarter, not harder”.

It seems, in a twisted way that having PPS is a blessing. How often did we totally appreciate what we had?

My outlook on many aspects has changed and it is now easier to see things from different viewpoints. Since the economic crises, the rich complain that society hates them and the poor feel that they are being exploited. Greed has never been quantifiable, but it should never be under estimated.

Governments measure progress in terms of GDP. Neighbours do not communicate, despite earning more money. What is happiness? And why do we consistently aspire to have bigger and faster processing electronic goods, when in reality most will never manage to learn all the features of the current goods they possess.

The basic skills of cooking and sewing have been lost. Yet we waste considerable money, eating processed foods which do not do us any favours, except help us gain weight. The weight we gain puts more stress on our weak joints, which leads to more time recuperating as we are sedentary. Can our diets replenish the calcium, magnesium, or iron that our bodies would have got from fresh produce. Packaging for food weighs more than the food, why do we get charged to dispose of this extra packaging we never requested?

It is cheaper to replace a shirt then replace a few stitches or buttons. It seems only yesterday, that it was viable to spend good money on a decent pair of shoes and then visit a cobbler to have the shoes repaired over the next few years. Today it seems necessary to replace shoes frequently and repairing them is a thing of the past. More waste for the trash, keep replacing everything and society supposedly progresses.

We live beyond our means, but that is now a way of life. We borrow into the future and leave a legacy of debt behind. Some day we will realize that not chasing what you think is compulsory, will free us to enjoy what we already have.

Post-Polio Sequelae: Preventing Ultimate Burnout

By Dr. Richard L. Bruno

It's 8:00 p.m. and only one light is burning at corporate headquarters. Mr. Gray, MBA, the 55-year-old CEO, is awakened by the phone. He lifts his head from the desk to answer and hears his wife asking when he's coming home. Feeling as if he weighs a ton, his muscles burning, Mr. Gray wheels himself to the car and, with barely enough strength to pull his chair in behind him, drives home. He greets his kids, rolls into the bedroom and throws himself on the bed. It's the third night this week he has gone to bed without dinner and slept in his clothes.

The alarm rings at 5 a.m. A clean suit and a three cups of coffee later, Mr. Gray is on the road again. Driving to work he hears the same faint "sizzling" sound he hears every morning -- a sound like electricity arcing between two frayed wires. But on this, as on every other morning, he ignores the "sizzling," ignores his increasing fatigue and muscle weakness and pain. He has a corporation to run. There's no time to "give in" to his body. But he does wonder: "What is that "sizzling sound?"

Well, Mr. Gray, that metaphoric "sizzling" is the sound of your nerves burning out. Nearly 80 percent of North America's 1.8 million polio survivors hear the same sound as they, too, experience Post-Polio Sequelae (PPS). PPS are the unexpected and often disabling symptoms -- new fatigue, muscle weakness, joint pain, cold intolerance -- that occur about 40 years after the original bout with polio. Unfortunately, most polio survivors are just like Mr. Gray: hard working, time-conscious, perfectionistic superachievers who, as a way of life, push themselves beyond their physical limits. Polio survivors ignore the "sizzling" sound, refuse to give up control, refuse to "give in" to new fatigue and weakness and pain even though their bodies are begging them to stop.

Post-Polio Past

Why won't polio survivors listen to their bodies and slow down? When you understand what it was like to have had polio, you can appreciate why polio survivors feel that "giving in" to PPS is the same as giving up their lives. "During the epidemics," says PPS researcher Nancy Frick, a polio survivor herself, "polio was America's summer terror. The adorable March of Dimes poster children, in heavy metal braces and leaning precariously on their crutches, were everywhere saying, 'Give money to find the polio vaccine. Don't let your child become a cripple like me!'"

When the polio vaccine arrived in 1954, the poster kids were needed no more. Their braces, crutches and wheelchairs were evidence of a horror that Americans wanted to forget. "So polio was eagerly forgotten by everyone," Frick says, "including those disabled by it. To be accepted back into society, polio survivors had to look 'normal' again. And since buildings were totally inaccessible, even paraplegic polio survivors had to be able to walk if they wanted to go to school or get a job."

So polio survivors were ripped away from their families for months or years and admitted to rehabilitation hospitals where they underwent multiple surgeries and draconian physical therapy. Many were verbally abused, slapped or even beaten with rubber truncheons by therapists or family members to "motivate" them to walk. "Is it any wonder that polio survivors discarded their braces and crutches when they came home from the hospital," asks Frick? "I have a theory that polio survivors would have done almost anything to look 'normal' and stop the abuse."

In the 1995 International Post-Polio Survey, Frick put her theory to the test. She surveyed more than 1,000 polio survivors, asking about the experiences surrounding their polio, including hospitalization,

surgeries and emotional and physical abuse by family members, peers and medical professionals. She also measured their Type A behavior, sensitivity to criticism and failure, and asked whether they had been evaluated or treated for PPS.

"As in our two previous post-polio surveys," says Frick, "polio survivors were 21 percent more Type A and 15 percent more sensitive to criticism and failure as compared to nondisabled controls." A more upsetting finding was that polio survivors reported 34 percent more emotional abuse and 94 percent more physical abuse than did controls. "All of that 'extra' abuse was related to polio survivors looking disabled," says Frick. And those who were abused were at least 15 percent more Type A and sensitive to criticism than polio survivors who were not abused. "It is no mystery that polio survivors today refuse assistive devices that make them look more disabled," says Frick. "Using crutches or a wheelchair feels like painting a bullseye on your chest with the words, 'Abuse me, I'm disabled!'"

Frick's findings may also explain why polio survivors are so reticent about even being evaluated for PPS. "About 78 percent of polio survivors said they were not treated with concern by medical staff when they had polio," she says. "Those who were not treated well became very Type A and very sensitive to criticism and failure as adults." Frick's research suggests that Type A behavior developed as a protection against criticism and failure. She found that polio survivors who are the most Type A today are most likely to refuse treatment or even evaluation for their PPS. Frick concludes, "Type A polio survivors refuse to treat their PPS and use assistive devices as a protection from the kind of abuse they experienced as children."

So, to protect themselves from abuse, polio survivors became Type A superachievers. As Frick's two previous surveys show, more polio survivors marry and go to college than do nondisabled Americans. Polio survivors work more hours of overtime and take fewer sick days than any other group. They became the leaders of their communities and the chief executives of the world's largest corporations. They become Mr. Gray. That's why their nerves have started to "sizzle."

Post-Polio Present

Since we know that PPS are not caused by the return of the poliovirus that's been hiding in the body for decades, nor are the result of some new disease, the simplest explanation is that poliovirus-damaged neurons are mad as hell and aren't going to take it anymore.

New Muscle Weakness and Pain. When polio struck, large numbers of neurons in the brain stem were damaged by the poliovirus. For those who had paralysis, the poliovirus damaged 90 percent of the neurons in the spinal cord that run the muscles, and nearly half of those neurons died. The surviving but damaged neurons are less able to manufacture acetylcholine, the chemical that nerves release to make muscles contract. Yet the damaged neurons were still able to send out sprouts--like extra telephone wires--to turn on muscle fibers orphaned when their motor neurons were killed by the poliovirus. This sprouting allowed many people who were totally paralyzed during the initial polio attack to actually walk out of the hospital months later.

But since polio-damaged, over-sprouted motor neurons have been doing more than triple duty for 40 years, even polio survivors with minimal loss of function have been heading for a fall. "Sprouted motor neurons can no longer make muscles contract as forcefully as they once did, or for as long as they once could, because their internal metabolic "factory" is failing after years of overworking," says Jerald Zimmerman, Chief of Rehabilitation Medicine at Englewood Hospital and Medical Center. "Muscles become weaker and hurt as they try to do more work than they are able to do." And because weakened muscles can no longer support the joints, polio survivors' shoulders and elbows ache and their knees

start to bend backward. "As metabolically-damaged neurons fail, standing, walking, pushing a wheelchair--sometimes even swallowing and breathing--become more difficult or more painful," explained Zimmerman.

This metabolic failure theory of PPS was demonstrated in 1997 by A.J. McComas of Canada's McMaster University. McComas counted the number of remaining motor neurons in polio survivors and then followed them for two years. McComas found that a limb weakened by polio had only 40% of the normal number of motor neurons. Even limbs that were thought not to have been affected by polio have only 60% of the motor neurons they should have. Two years later, 78 percent of polio survivors reported a decrease in muscle strength and had lost an average of 14 percent of their motor neurons, nearly twice the rate of loss expected in healthy subjects ten years older. Most alarming was the finding that the two survivors who reported the greatest decrease in strength had each lost 50 percent of their motor neurons over the two years. While these findings are frightening, they are also a guide to a rational treatment for PPS. "Our findings make clear that polio survivors should not be treated using electrical stimulation that causes muscle contraction," warns McComas, "nor should they engage in fatiguing exercise or activities that further stress metabolically damaged neurons that are already overworking."

"Brain Fatigue." While new muscle weakness and pain are reported by more than 75 percent of polio survivors, the most common PPS symptom is fatigue. During the past eight years, my team at The Post-Polio Institute at New Jersey's Englewood Hospital and Medical Center has found that "brain fatigue" -- when polio survivors can't concentrate and have trouble staying awake as the day goes on -- is associated with a severe inability to focus attention and a marked reduction in the brain-activating hormone ACTH.

Magnetic resonance imaging revealed damage to the brain-stem neurons responsible for activating the brain, damage also found during autopsies of polio survivors done 50 years ago. A study published in 1998 describes our measurement of polio survivors' brain waves and the hormone prolactin. Prolactin increases in the blood when there is too little of the most important brain-activating neurochemical, dopamine. Our finding that polio survivors with the most fatigue had the highest prolactin levels and the slowest brain waves suggests that they do not make enough dopamine to fully activate their brains.

A dopamine shortage would explain their difficulty focusing attention, and other symptoms of post-polio "brain fatigue." This conclusion is supported by our finding that bromocriptine -- a drug that substitutes for dopamine in the brain -- reduces the symptoms of post-polio brain fatigue in survivors who do not respond to the conservative treatments of choice for PPS:

- reducing physical and emotional stress,
- using assistive devices,
- conserving energy,
- resting and pacing activities.

Post-Polio Future

With the coming of PPS, the future might look bleak for polio survivors. Both the March of Dimes Birth Defects Foundation and the U.S. Congress have refused to set aside funds for PPS research. And two recent drug studies -- one testing insulin-like growth factor-1 (IGF-1) and another studying pyridostigmine (Mestinon) have failed to show any "significant impact on quality of life, fatigue or muscle strength," according to PPS researcher Daria Trojan. Even our study found that bromocriptine reduced symptoms only in polio survivors who were the most severely disabled by fatigue.

But the future is not bleak. Research during the past decade has shown that the conservative treatments of choice for fatigue are very effective in managing PPS. Polio survivors need to follow the "The Golden Rule for PPS:" If something you do causes pain, fatigue or weakness, don't do it (or do less of it)!"

"The Golden Rule" does not mean that polio survivors should sit home and become couch potatoes. "The Golden Rule" does mean that polio survivors should stop exhausting themselves, especially with exercise. Many survivors are prescribed -- or actually ask for -- the kind of physical therapy they had right after polio: exercising to the point of exhaustion. But several studies show that pumping iron will not increase the strength of muscles that are becoming weaker, and can actually cause an irreversible loss of strength and possibly the death of motor neurons. No free weights, exercise bikes, tread mills or Thighmasters for polio survivors. "Feeling the burn" means nerves are burning out. Stretching, however, helps decrease pain and increase range of motion. And gentle, non-fatiguing exercise can be useful for some polio survivors to help maintain muscle strength and tone, especially after getting a new brace.

Several studies show that changing survivors' physically and emotionally stressful Type A lifestyle is the best way to reduce weakness, fatigue and pain. One study shows that polio survivors who pace activity -- that is work and then rest for an equal amount of time -- can do 240 percent more work than if they push straight through the task. Another study shows that survivors use three times less energy walking if they use a short-leg brace on a weakened leg. And the follow-up study of The Post-Polio Institute's six week program of behavior modification, physical and occupational therapy shows that polio survivors who comply with treatment -- pace activities, conserve energy, take two 15-minute rest breaks a day, and use assistive devices (a brace, cane, crutches, wheelchair or scooter) -- have up to 22 percent less pain, weakness and fatigue 16 months after therapy ends. But polio survivors who refuse or quit therapy have 21 percent more fatigue and 76 percent more weakness 16 months after leaving The Institute.

And there's the rub. It's only the refusal to listen to that "sizzling sound" that causes PPS to continue or progress. "The treatments for PPS may sound simple but they are not," says Nancy Frick. "Polio survivors have to deal not only with their bodies giving out on them again, but also with their long-buried emotional pain." And it is those painful experiences of the past and memories of abuse, the fear of giving up "protective" Type A behavior and terror of looking disabled, that stop polio survivors from treating their PPS.

So the most difficult aspect of treating PPS is not deciding whether a shorter long-leg brace will be most helpful. The challenge is helping polio survivors face the pain of their abusive pasts and accept appearing more disabled now -- by slowing down, asking for help and using new adaptive equipment -- so they won't become more disabled later in life. That's why behavior modification and psychotherapy are required to help survivors accept their "second bout" with polio, change their super-achieving lifestyles and deal with the fear of looking disabled.

As Mr. Gray would tell you, this whole PPS business stinks. But isn't it far better to manage PPS now than to be forced to give up everything you do because you are too weak and fatigued to function? I know, you'll slow down and take care of yourself "when you're ready." You'll use a wheelchair "when there's no other choice." Well, you don't drive your car until it's out of gas. Why drive your body until it's out of neurons? Isn't it time to listen to the "sizzling sound?" Isn't it time to take care of yourself? To paraphrase one famous polio survivor who refused to take care of himself, "You have nothing to

fear but fear itself."

Red Flags for Polio Survivors

[Mis]Diagnosis: Many polio survivors have been incorrectly told they cannot have PPS because they didn't have paralytic polio. The National Institute of Health has just studied pairs of identical twins, one who had paralytic polio and one who had non-paralytic polio. Seventy-one percent of those who had paralytic polio have PPS. The surprise is that 42 percent of those who had non-paralytic polio also have PPS. The lesson: Don't let a doctor tell you it's all in your head just because you didn't have paralytic polio.

Anesthesia: Polio survivors are anesthetized very easily because the part of the brain that keeps you awake was damaged by the poliovirus. They also stay anesthetized longer and can have significant complications from anesthesia. Even nerve blocks with local anesthetics can cause problems. All polio survivors should have lung function tests before having a general anesthetic. "Polio survivors with a lung capacity below 70 percent may need a respirator or respiratory therapy after surgery," says Dr. Augusta Alba.

Your complete polio history and any new problems with breathing, coughing or swallowing should be brought to the attention of your surgeon or dentist--and especially your anesthesiologist--long before you go under the knife. Also, polio survivors should never have same-day surgery or precodures requiring anesthetic.

Pain: Two studies have shown that polio survivors are twice as sensitive to pain as everyone else and need more pain medication for a longer time after surgery or an injury. However, survivors have had to develop an extremely high pain tolerance to deal with their increased pain sensitivity and are not likely to become addicted to pain medications.

Sleep: The majority of polio survivors have trouble sleeping due to pain, anxiety or sleep disorders, such as sleep apnea or generalized random myoclonus (GRM). GRM is muscles in different parts of the body twitching and jumping throughout the night and "waking up" the brain. Amazingly, most polio survivors aren't aware that they stop breathing or twitch. If you awaken with a headache, with your heart pounding, short of breath or don't feel rested in the morning, call a local sleep disorders center for a sleep study.

Trauma: Eighteen percent of Post-Polio Institute patients reported that their PPS begin after trauma, including medical illnesses, surgeries, fractures, falls, and especially auto accidents. Regardless of the type of trauma or location of the injury, the most common new symptom was muscle weakness (55%), followed by pain (34%) and fatigue (11%). Twenty-six percent of patients had new symptom in the injured area plus one other nearby location. For example, 40% of those who injured one leg developed weakness or pain in the other leg. (This is a common problem for polio survivors, who compensate for injury to one part of the body by overusing another part whose nerves were also damaged by the poliovirus.) The good news is that 86% of patients regardless of the cause of trauma or severity of their injuries had significant reductions in pain, fatigue and muscle weakness after complying with therapies known to be effective in treating PPS: reducing physical and emotional stress, using appropriate assistive devices, energy conservation, adequate rest and the pacing of activities.

Dr. Richard L. Bruno is chairperson of the International Post-Polio Task Force and director of The Post-Polio Institute and The International Centre for Post-Polio Education and Research.

Holidaze

By Millie Malone

By the time you read this, Thanksgiving will be looming large and then comes The Big C...no, not Cancer, Christmas! Shopping, crowds, overeating, gaining weight, all the usual holiday activities. It's difficult for polio survivors to deal with some of this.

Personally, I shop online as much as I can. I usually keep a "stash box" with gift items in it. I shop all year round, looking for bargains or for items I think will please someone on my Christmas list. Actual shopping, as in a store, is something I do not enjoy. I enjoy it least on Black Friday or Boxing Day, the day after Christmas.

People lose their minds on those two days. A woman who is a sensible, kind hearted, compassionate person the rest of the year, may turn into a wild eyed maniac composed mostly of elbows, knees and gimlet-eyed glares. Do not, and I cannot stress this enough, do NOT get between this woman and the bargain she has her heart set on. She will clamber right over you, standing on your lap if need be, to get to The Bargain. Thankfully, this type of woman, your Serious Shopper, does not wear stiletto heeled shoes. No, she will wear comfortable walking shoes because she plans to be on her feet till the stores all close and the night watchman drags her to the sidewalk, armed with a gun and a drooling Doberman Pinscher. Those stilettos could puncture an artery if she is forced to climb over you. The walking shoes will merely leave bruises.

Take my advice and stay home on Black Friday unless your power chair has caterpillar tracks to bulldoze your way through a crowd, and armor plating would be advisable, too. A helmet, goggles, and a stainless steel jump suit would be suitable Black Friday Shopping Wear. Boxing Day, December 26, is not quite as dangerous, but can also be very unpleasant if you have a low tolerance for anger, disappointment, and grumpy sales people. You can't blame the sales staff for being cranky. The same item Mrs. Super Shopper nearly killed people to reach on Black Friday often turns out to be not what was wanted after all. So back she goes on Boxing Day to return it in the bashed in box that was thrown at her by the ungrateful child/husband she was trying so hard to please.

Overeating is the holiday sport I do enjoy. All those Thanksgiving pies, the stuffing, the turkey (which is not that highly caloric if you eat a human sized portion, but where's the joy in that?) Mashed potatoes, cranberry relish, cornbread stuffing...very hard to resist. I have one thing going for me: I don't care much for pumpkin and there is an unbreakable rule that any treat made in the month of November must, by law, contain pumpkin. Pumpkin lattes, anyone? So all I have to do is remind myself that whatever tempting looking treat is giving me the come-hither look, it likely has pumpkin in it. In December, I can avoid almost all chocolate baked goods because the December unbreakable rule is that all chocolate must be accompanied by peanut butter. I hate peanut butter. I do have a hard time trying to convince myself that pecan pie or cornbread stuffing have either pumpkin or peanut butter in them.

And of course, the Number One Holiday Pastime is...drumroll, please...gaining weight! In all modesty, I must admit that I am a heavy weight Champion in that division. I will try, truly I will, to substitute celery for cornbread, lettuce for pecan pie, and sugar free carob cookies for mashed potatoes. Really. Honest, would I lie? By the way, I have a nice section of ocean front property in Iowa for sale, if you are interested.

Web Corner

Check up on whatever benefits you might have coming:

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

Jann Hartman's blog:

<http://havescooterwilltravel.blogspot.com/>

Paralyzed Man Does Something "More Impressive Than Walking On The Moon:

http://www.huffingtonpost.co.uk/2014/10/21/darek-fidyka-paralysed-man-walks-again_n_6019462.html?1413879159

Gary Presley's Blog

<http://www.garypresley.com/2014/10/not-smart-enough-or-brave-enough.html?spref=fb>

Video made to celebrate Nebraska Polio Survivors Association's 30th Anniversary

<http://vimeo.com/105055161>

Videos celebrating Jonas Salk's 100th year

<http://www.salk.edu/news/videos.html?list=jonas-100>

Having a good quality of life from your wheelchair:

<http://www.transfermaster.com/blog/view-post/Having-a-Good-Quality-of-Life-from-your-Wheelchair>

Some videos from Post Polio Health International

<http://www.polioplace.org/post-polio-experts-present-video-series>

Test Your Knowledge: Medical Remedies from 1919

http://www.medscape.com/viewarticle/832741?src=wnl_edit_specol&uac=46348SJ

Inventor Rolls Out Mind-Controlled Wheelchair

<http://www.transfermaster.com/blog/view-post/Inventor-Rolls-out-Mind-controlled-Wheelchair-1>

A Little Bit of Humor

Wise Things...

1. Regular naps prevent old age... especially if you take them while driving.
2. Having one child makes you a parent; having two makes you a referee.
3. Marriage is a relationship in which one person is always right and the other is the husband!
4. They said we should all pay our tax with a smile. I tried, but they wanted cash.
5. A child's greatest period of growth is the month after you've purchased new [school uniforms](#).
6. Don't feel bad. A lot of people have no talent.
7. Don't marry the person you want to live with, marry the one you cannot live without... But whatever you do, you'll regret it later.
8. You can't buy love. But you pay heavily for it.
9. True friends stab you in the front.
10. Forgiveness is giving up my right to hate you for hurting me.
11. Bad officials are elected by good citizens who do not vote.
12. Laziness is nothing more than the habit of resting before you get tired.
13. My wife and I always compromise. I admit I'm wrong and she agrees with me.
14. Those who can't laugh at themselves leave the job to others.
15. Ladies first. Pretty ladies sooner.

16. It doesn't matter how often a married man changes his job, he still ends up with the same boss.

17. They call our language the mother tongue because the father seldom gets to speak.

18. Saving is the best thing. Especially when your parents have done it for you.

19. Wise men talk because they have something to say; fools talk because they have to say something.

20. Real friends are the ones who survive transitions between [address books](#).