

Polio Perspective

December 2014

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Energy Token and How They Can Help Manage Our PPS Lives

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First you have to work out how much each task that you do each day takes you. We are all different so whilst you can look at what someone else has done you will still need to do it for yourself and I can now do less per token than I could when I first started this idea.

Start listing the tasks that you have to do each day, like getting up and going to bed, getting dressed and undressed, whatever you need to do to eat meals, etc. Here are a few ideas.

Get up out of bed and going to bed at night

Dressed/Undressed – look at stages of dressing and undressing as well. Washing self, having a shower or bath, washing hair, shaving face and other bits if necessary

Shopping for and making and eating meals.

Any housework items that you have to and still need to do.

Driving to and doing appointments.

Attending Church or other club outings.

Take an average day of normal everyday stuff and you have 10 x your currency. \$10 or £10. So try spreading the funds out across the day... Might be 50pence/cents to get up and dress. £1 or \$1 to drive in easy traffic for an hour but if you went on winding country road then 15 mins.

Take ironing how many items can you iron before you really should sit down and take a break. Say four items and then for you how many cents/pence can you spare out of your average day for that.

Once you have a basic idea of the length of time you can do each activity that you do over a week or month if you add in medical appointments then you can start charting.

7 days x 24 hours – you may have to get up a few times at night so you have to factor this in if you do. If not then just start from normal getting up to going to bed time.

First I start with the things I have to do like medical appointments. I block them in and then think how long will I need to rest before and after to cope with that. Block that out as resting time. Then add in the normal daily stuff. Now we all know we have to be clean to go to medical appointments but do we have to do it that morning? Should we have a bath or shower early evening the night before and just wash the bits they are going to look at on that morning. ;-)

Blocking times out to do and to rest soon shows you that if you want to do something that there is no room for can you modify what's already there. Can you ask someone to help you do all or part of another task?

Hilary Boone, Polio Survivors Network. hilary.boone@poliosurvivorsnetwork.org.uk Feb. 25, 2014

Polio Acronyms

by Micki Minner

In this newsletter, I thought I would explain some of the abbreviations used in reporting Polio stories in the news. So many acronyms are so difficult to figure out! Let's start with some basic acronyms about polio and polio vaccinations:

VDPV – Vaccine derived Polio Virus – someone who has got a case of acute polio from a vaccine

WV – Wild Virus – which is the polio virus that lives in the wild such as in un-treated bodies of water

IPV – Inactivated Polio Vaccine, this is the DEAD virus or the Salk Vaccine, no one can get polio from this vaccine. The USA only uses this IPV or Salk Vaccine

OPV – Oral Polio vaccine, this is the attenuated or weakened virus that is used to give protection against polio. It is commonly known as the Sabin vaccine, and has a lower rate of protection, and it is possible to get VDPV (vaccine derived polio virus) from this OPV (Oral Polio Vaccine)

VAPP – Vaccine Associated Paralytic Polio – this is an acute case of polio that causes paralysis, AND comes from the vaccine.

ACIP – Advisory Committee on Immunizations – a regulatory group of physicians that review the latest information and data to publish advisories.

WHO – World Health Organization, this is the international organization that helps administer and monitor contagious diseases around the world.

CDC – Center for Disease Control – the organization based out of Atlanta that works with creating vaccines, fighting known and unknown viruses around the world.

AFP – Acute Flaccid Paralysis, the description of one of the symptoms of acute polio.

Type 1, Type 2, and Type 3 – are SEROtypes of Polio. There are three “strains” or serotypes of Polio. ALL three serotypes of polio can have any of the three main symptoms of acute polio, which are Paralytic, Non-Paralytic and Bulbar.

I hope these definitions help when trying to understand and read the news about Polio and the Polio

Dr. Richard Bruno's Biography

taken from International Centre for Polio Education

BIOGRAPHY

Richard L(ouis) Bruno is internationally known as the world's foremost expert on Post-Polio Sequelae (PPS, also known as "post-polio syndrome"), the unexpected and often disabling symptoms -- overwhelming fatigue, muscle weakness, muscle and joint pain, sleep disorders, heightened sensitivity to anesthesia, cold intolerance, and difficulty swallowing and breathing -- that occur in 75% of paralytic and 40% of non-paralytic polio survivors about 35 years after the poliovirus attack. (1)

Bruno, a research and clinical psychophysiologicalist trained at the New York State Psychiatric Institute, began studying PPS and treating polio survivors in 1982, when he was a fellow in the Department of Rehabilitation Medicine, Columbia University College of Physicians and Surgeons. (2) In 1984, Bruno organized and is chairperson of the International Post-Polio Task Force, which promotes PPS research, education and treatment in 25 countries. (3)

Bruno left Columbia and, in 1989, created and directed the Post-Polio Rehabilitation and Research Service at Kessler Institute for Rehabilitation, the first center for the study and comprehensive treatment of PPS (4), and in 1998 created The Post-Polio Institute at Englewood Hospital and Medical Center (5), which was closed in 2010. Bruno is now director of the International Centre for Polio Education, the new home of the International Post-Polio Task Force. (6)

PPS RESEARCH

Bruno's work has documented previously unrecognized characteristics of polio survivors and PPS symptoms:

- * Intolerance to cold that causes muscle weakness and pain in polio survivors (7)
- * The occurrence of muscle contractions throughout the body that can disturb sleep in polio survivors (8)
- * Polio survivors' "Type A" behavior that promotes PPS symptoms. (9)
- * Polio survivors' childhood and physical and emotional abuse lead to Type A behavior, denial of PPS and refusing treatment for PPS. (10)
- * Poliovirus damage to the vagus nerve and brain stem can cause gastroparesis and vaso-vagal symptoms in polio survivors. (11)
- * Difficulty with attention, memory and word finding are PPS symptom and are not symptom of

dementia. (12)

* Poliovirus-damage to the brain stem's "Brain Activating System" and a loss of dopamine-producing neurons is the underlying cause of polio survivors' profound fatigue, the most common and most disabling PPS symptom. (13)

* Poliovirus damage to brain stem and spinal cord neurons causes to be polio survivors to be more sensitive to the effects of anesthetics and twice as sensitive to pain. (14)

* Building on the work of Dr. David Bodian, (15) Bruno described the presence of extensive poliovirus damage throughout the brain and spinal cord even in cases of "non-paralytic" polio and in muscles seemingly unaffected by the poliovirus, calculating that there are 150,000 undiagnosed polio survivors in the US. (16)

PPS TREATMENT

Dr. Alan McComas' clinical confirmation (18) of David Bodian's findings from autopsies of polio survivors and monkeys infected with polio (that polio survivors had to lose more than 60% of motor neurons for weakness to be apparent), McComas' finding that untreated polio survivors with muscle weakness were losing motor neurons at a rate of 7% per year, (18) and his own clinical experience and international surveys of more than 2,000 polio survivors, convinced Bruno that exercise - an additional load on the reduced number of remaining, poliovirus-damaged neurons - was contraindicated in the treatment of PPS: "When patients were recovering from polio, we made them exercise their muscles and told them to 'Use it or Lose it.' Now it is just the opposite. The byword is "Conserve to Preserve." (19)

Bruno concluded that PPS was neither a "disease" nor related to a lingering poliovirus infection, but "is caused when nerves damaged earlier by the poliovirus become tired and overworked." (20) "However," he warns, "ALL OTHER diagnoses must be excluded before a diagnosis of PPS can be made." (1)

What is more, polio-related problems themselves, e.g., sleep disorders, must be treated before a diagnosis of post-polio fatigue can be made. (8)

"Dr. Bruno said his studies have indicated that symptoms can be reduced quite a bit if polio survivors take two 15-minute breaks during the day, and put their feet up and rest." (21) Unfortunately, Type A behavior and fear of abuse, as polio survivors experienced in childhood, must be addressed through behavioral psychotherapy before most polio survivors are ready to change their lifestyles, use discarded assistive devices and "Conserve to Preserve." (9, 10)

PPS EDUCATION

To educate polio survivors and the medical community, Bruno edited three special issues of the journal "Orthopedics" devoted to PPS (22). He also distilled and translated his scientific work into lay language and, in 2002, published *The Polio Paradox: What You Need To Know*. (23) To treat polio survivors' stress and reduce Type A behavior, Bruno also wrote *How To Stop Being*

Vampire Bait: Your Personal Stress Annihilation Program in 2004. (24) He has also written The Polio Survivors Handbook, series of monographs for polio survivors on the cause and treatment of PPS (e.g., 25) and, for many years, wrote monthly as columns about PPS for "New Mobility" ("The Post-Polio Forum") (26) and "ACTION" ("T'N'T for Polio Survivors"). (27) His new book, The Post-Polio Anthology, is in press.

As part of his efforts to educate about PPS, Bruno has been interviewed by "Newsweek", "The New York Times" and "USA Today." He has appeared on NBC's "Today" Show and ABC's "Good Morning America", on CNN, the "CBS Evening News," ABC News "Nightline," on the BBC, CBC, National Public Radio and on The Discovery Channel and The Learning Channel. (28)

ADVOCATE AND ADVISER

Polio survivors themselves, the medical profession and government health agencies around the world have been unaware of PPS and needs of polio survivors. Bruno serves as adviser to post-polio support groups on four continents.

In 1987, Bruno was first asked to advise the U.S. Congress on post-polio related issues and successfully lobbied for a Post-Polio Clinic at the then-new National Rehabilitation Hospital. (29) In 1985, he helped to draft the Social Security Disability Insurance (SSDI) regulations for PPS and, with Senators Tom Harkin and Bill Bradley, won their release in 1987. (30) In 2003, Bruno drafted and, with Congressman Steve Rothman and Senator Arlen Specter, won release of the Social Security Ruling for Post-Polio Sequelae to stop denials of SSDI for PPS. (28) Bruno also drafted the Department of Veterans Affairs policy on the treatment of service members who have PPS and has advised the Departments of State and Justice on disability-related issues (17, 30)

In 2006, both the House of Representatives and the Senate passed proclamations drafted by Bruno naming 2006 as "THE YEAR OF POLIO AWARENESS," sponsored by Congressman Steve Rothman and Senator Arlen Specter (31) Congressman Rothman recognized Bruno on the House floor: "I also want to take this opportunity to recognize my constituent, a very tireless worker on behalf of those suffering the aftereffects of polio, Dr. Richard Bruno. As the director of the Post-Polio Institute and International Center for Post-Polio Education and Research, and chairperson of the International Post-Polio Task Force, Dr. Bruno is at the forefront of the movement to educate parents about the need to vaccinate their children against this debilitating virus. This resolution, Madam Chairman, would not be on the floor today without Doctor Bruno's help. I am grateful for his work and commitment to this cause." (31)

In 2013, Bruno was asked by the Indian Parliament to create a program for the diagnosis and treatment of India's eight million polio survivors who are developing PPS. Bruno is developing Internet Post-Polio Clinics, the first to be held in Gujarat Hospital, where he will train local doctors and then oversee their evaluation and treatment of individual patients via video link to

India. Bruno's training materials and the evaluation and treatment sessions will be recorded and made available via the Indian Medical Association website.

POLIO VACCINATION

In 2007, while reviewing data from the Centers for Disease Control, Bruno became aware that polio vaccination in the U.S. had dropped since 2005, especially among the poor. Bruno was very concerned because there had been five cases of polio in unvaccinated Minnesota children in 2005 and a case of polio imported from Mexico. Bruno warned on Minnesota Public Radio: "We start getting not just five cases as in Minnesota, but 50 or 500 cases of polio. Parents are going to wake up and say, 'We should be vaccinating.'" (32)

Bruno was afraid that unvaccinated children in cities with large immigrant populations would be vulnerable to exposure to a visitor carrying the poliovirus, as had just happened in Australia: "The CDC estimates that nearly 93% of US children 19-35 months old are vaccinated against polio. Ninety-three percent sounds good, until you realize that leaves more than one million toddlers unvaccinated. What is worse, toddlers below the poverty line have even lower polio vaccination rates, 89.5% in Newark and 87% in New York City, a rate equal to Asian countries that include Cambodia, Mongolia and Vietnam. These statistics are especially frightening considering the ease of air travel to the US from Pakistan, Afghanistan, India and Nigeria, where polio has never come under control, and from the ten African and Asian nations that were polio-free but where the poliovirus has been reintroduced. What will happen when a healthy-appearing but polio-infected international traveler lands at an airport and travels through a poor community? Every American child must receive all four doses of the injectable, inactivated polio vaccine. America's polio epidemic could be just a plane ride away." (33)

The International Post-Polio Task Force then created The National Immunization for Polio Prevention in Infants and Toddlers -- or "NIPP IT" -- Campaign to promote polio vaccination in every state. Polio vaccination rates have increased, but the Bush administration refused Bruno's request that travelers from polio endemic countries provide proof of polio immunization before allowing entry into the U.S.

Bruno also advocated for universal polio vaccination and lobbied against a bill in the New Jersey Legislature that would allow parents to forgo polio vaccination because of a "personal opposition" to vaccines: "There's no reason why every child in America shouldn't be vaccinated against polio. Parents should demand it, and school districts should demand that every kid that comes into kindergarten be vaccinated against polio and all diseases." (34) The "personal opposition" to vaccines bill never passed.

LINK BETWEEN POST-POLIO FATIGUE AND CHRONIC FATIGUE SYNDROME

Bruno's work finding damage to the brain activating system as a result of poliovirus-damage to brain stem neurons led to his "Brain Fatigue Generator" model of post-viral fatigue syndromes. (13) Using poliovirus-damage to the brain activating system as a model, Bruno described other viruses that did similar damage to the same brain areas attacked by the poliovirus and therefore also could cause chronic fatigue. (35) His post-polio research found that fatigue was associated with clinically impaired attention on neuropsychological testing, a blunted ACTH response to stress and white and gray matter lesions on MRI in the brain's activating system, findings indistinguishable from those in patients with chronic fatigue syndrome (CFS). (35)

In 1999, Bruno performed the first study of the psychophysiology of chronic fatigue in children and adolescents, confirming that chronic fatigue is related to impaired attention that is likely due to brain activating system damage, findings presented to the N.I.H. State of the Art Workshop on Chronic Fatigue in Adolescents. (36) Bruno served on the Committee on Standards for the Evaluation and Treatment of Chronic Fatigue Syndrome and wrote "Rehabilitation of CFS: A Multidisciplinary Approach" for the 2002 Consensus Manual for the Management of Chronic Fatigue Syndrome published by the New Jersey Academy of Medicine. (37)

BEYOND POLIO AND POST-POLIO SEQUELAE

Bruno's interests and research reach beyond polio and PPS, including the physiology and pharmacology of depression (38), the cause and treatment of chronic pain (39), the prediction of behavior and treatment outcomes in patients with chronic pain and brain injuries (40), the societal response to disability (41) and Buddhism in relation to coping with disability (42). Bruno is also the reluctant expert on the psychopathology of "apotemnophilia," a condition in which non-disabled individuals are attracted to those with disabilities, pretend to be disabled and want to become disabled. (43) Bruno's work has been published in journals as varied as Stroke, Biofeedback and Self-Regulation, the Journal of Chronic Fatigue Syndrome, Neurology, Disability and Society, the Journal of Clinical Psychiatry, Psychophysiology, Sexuality and Disability, the American Journal of Medicine, Annals of the New York Academy of Sciences and all three American journals of physical medicine and rehabilitation.

HONORS AND AWARDS

Bruno has received numerous honors for his work, including the New Jersey Pride Award in Health (44), inclusion in nine Who's Who publications and a Doctor of Humanics degree honoris causa from Springfield College. (45) Bruno also was selected to present the 45th Annual John Stanley Coulter Lecture to the annual meeting of the American Congress of Rehabilitation Medicine entitled, "Post-Polio Sequelae and the paradigms of the '50's: Newtie, Ozzie and Harriet versus paradigms of caring and a future for rehabilitation in America." (46)

A Fallen Woman

By Millie Malone

First of all, I want to assure you that with all the political talk of repealing this and stopping that, the law of gravity is still in effect. If politicians wanted to repeal a law, I wish they'd start with that one. But no, a couple of weeks ago, I stepped on something, perhaps a piece of lint or my own shadow, in my kitchen and down I went. Gravity works. I became a fallen woman.

As a polio survivor, it is against my own rules to call for help. You know what I'm talking about. I wallowed around on the floor and moaned and groaned and finally got up. My polio affected leg was absolutely NOT cooperating with this process. The other leg, tired of being my go-to leg for all these years was less than willing as well. Some days, you know, I wish I had someone living with me to help in these situations, but on further thought, do I really want another human, presumably someone I care about, to see me thrashing around on the floor like a landlocked whale? Especially since I wouldn't let them help me up in any case. It would only lead to that person accusing me of being stubborn. A stubborn polio survivor? Surely no such thing exists!

Those of you who know me are aware that I use whining as pain relief. My theory is that if I whine to a few people, it thins out the pain by spreading it over a larger area and makes it easier to bear. Well, I whined to the wrong person. My brother. He got his knickers all in a twist and even when I protested that I'd be fine and, no, I did not want to come to his house which is actually less accessible than my apartment, he and my friend Sheri dragged me to the emergency room. I got Xrays of my knee and also of my pinky finger on my left hand which I'd included in the fray. The knee was only sprained, the finger was broken. As I'd told Jerry and Sheri, there is nothing that can be done if the damage does not result in a broken bone. I'd fractured that same leg back in '91 and nearly had to use a gun to get my doctor to even Xray it at that time. When I prevailed (as I always do because let's face it, I don't quit till I win), he gave me the largest off the rack brace he had on hand and sent me home. The brace was enormous and slid down every time I stood up, so it was money thrown away.

This doctor had the nurse tape my finger to its neighbor, but did absolutely nothing about the sprained knee. He told me to stay off of it, did not say for how long, wrote a prescription for crutches which the nurse insisted on setting for a person 2" taller than stumpy old me and we came home.

For the next few days, I concentrated on trying to be 2" taller than I actually am, whined about the crutches hurting my armpits, and tried to adjust them myself. It should have been easy, but in addition to the broken finger on my left hand, I also had injured the ring finger on my right hand, and the thumb on my right hand has been wonky for years. Not gonna happen. My granddaughter, bless her heart, stopped by, adjusted the crutches with her young, ungnarled hands and also, while she was there, stripped and remade my bed for me.

My apartment is pretty accessible. I can get my power chair all over, even into the bathroom. I have to use the crutches to get to my computer, on the far side of my bed, but other than that, I can manage better than I thought. I have a shower chair, so no problems there. I decided to call Meals on Wheels and that solved the problem of trying to cook while standing on one leg. Have I mentioned that the leg, my Good Leg, had a Not Good hip? It doesn't take much to get bursitis in that hip, which is not something I want to deal with.

So, basically, I'm doing fine. Yes, I'm falling apart and no, they don't make parts for this old body that was built during the War, (not the Revolutionary War, before you ask),but I do wish this tightrope that I traverse every day would quit twisting. I used to set a goal for myself: I'll be walking as usual in three weeks. No, I don't do that anymore. The current goal is to very slowly and gently stretch my leg as straight as it will go a few times a day, gradually start putting a little bit of weight on the foot while I'm cussing my crutches, use the power chair as much as possible and someday, hopefully soon, I'll be able to get around again as I used to. Meanwhile, I'm rather enjoying being lazy. Oh, and thanks for listening to me whine. My pain is much less now.

Web Corner

Twelve Types of Building with Accessibility Concerns

<http://www.accessadvocates.com/12-types-buildings-accessibility-greatest-concern/>

Jann Hartman's Blog:

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

Rancho Los Amigos New Website

<http://www.ranchoppsg.com/>

New Drug Might Spur Nerve Regrowth

<http://www.npr.org/blogs/health/2014/12/03/368058568/a-drug-might-heal-spinal-injuries-by-sparking-nerve-growth>

Free Medication Possibilities

<http://www.publix.com/pharmacy-wellness/pharmacy/pharmacy-services/free-medication-program>

How to Understand Someone With Chronic Pain

<http://m.wikihow.com/Understand-Someone-With-Chronic-Pain>

Researchers Discover Vaccine Resistant Polio Virus

http://www.upi.com/Health_News/2014/11/05/Researchers-identify-vaccine-resistant-strain-of-polio/2501415209985/#ixzz3IRN4Agyn

A Wealth of Articles for Polio Survivors from PHI

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

High Occurrence of Vitamin D deficiency in people with neuromuscular diseases

<http://www.newswise.com/articles/high-prevalence-of-vitamin-d-deficiency-across-the-board-in-neuromuscular-disease#.VFetti4u1pA.facebook>

Bracing for the Falls of an Aging Nation

http://www.nytimes.com/interactive/2014/11/03/health/bracing-for-the-falls-of-an-aging-nation.html?ref=us&_r=1&smid=fb-share

A Little Bit of Humor

(thanks to Jann Hartman)

For those of you who watch what you eat. Here's the final word on nutrition and health. It's a relief to know the truth after all those conflicting medical studies.

1. The Japanese eat very little fat and suffer fewer heart attacks than the British or Americans.
2. The Mexicans eat a lot of fat and suffer fewer heart attacks than the British or Americans.
3. The Japanese drink very little red wine and suffer fewer heart attacks than the British or Americans
4. The Italians drink excessive amounts of red wine and suffer fewer heart attacks than the British or Americans.

5. The Germans drink a lot of beers and eat lots of sausages and fats and suffer fewer heart attacks than the British or Americans.

CONCLUSION: Eat and drink what you like. Speaking English is apparently what kills you.