

The Polio Perspective

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Post-Polio Protein Power: Eat Well, Be Well

By Dr. Richard L. Bruno

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"Breakfast? Sorry, don't have the time. In the morning there's too much to do, like showering and dressing and getting to work. I grab a cup of coffee (or two or three) and maybe a donut at work..."

"Lunch? Don't think so. I'm still catching up from my late start in morning. I grab a cup of coffee (or two or three) and maybe wolf down half a Big Mac..." "Dinner? I'm either too tired or hungry as Patton's Third Army. I either defrost a piece of pizza and drag myself into bed or eat everything that isn't nailed down!"

"So why am I totally exhausted but can't stop gaining weight?" Americans are not very good at taking care of themselves. American's with disabilities are no better, and maybe a little worse, at self-care because it takes so much time to do things non-disabled folk do in a flash, like showering and dressing. There's hardly any time or energy left for planning meals, shopping, cooking ... or even eating. However, people with disabilities pay a higher price for lack of self-care than do people without disabilities. For those who use wheelchairs good eating habits and proper nutrition are essential, not only for general good health, but also to prevent bowel and urinary problems, to prevent weight gain, and to maintain a decent level of energy.

Polio Survivors vs. Breakfast. One group of people with disabilities shows the consequences of poor eating habits: North America's 1.8 million polio survivors. Nearly 76 percent of polio survivors experience Post-Polio Sequelae (PPS), the often disabling symptoms -- fatigue, muscle weakness, joint and muscle pain, cold intolerance, and difficulty sleeping swallowing, breathing -- that occur about 40 years after their original bout with polio. PPS requires polio survivors to use new assistive devices or aids they discarded years ago, like braces, canes, crutches, wheelchairs and scooters, to slow down and to rest during the day. The problem is, polio survivors are Type A, hard working, pressured,

perfectionist super-achievers who have pushed themselves beyond their physical limits and allow no time for self-indulgent luxuries -- like food. Polio survivors don't want to slow down or rest, not only because they're afraid if they are less Type A people won't like them, but also because they are afraid of gaining weight if they become more sedentary. But they shouldn't be afraid. Food is good! Eating properly doesn't lead to becoming fat, it actually reduces PPS symptoms.

Dr. Susan Creange at the Post-Polio Institute discovered that polio survivors with blood sugar levels in the low normal range have as much difficulty paying attention and concentrating as would diabetics with blood sugars as low as if they had taken too much insulin.

"Polio survivors' 'Type A diet' -- three cups of coffee for breakfast, skipping lunch and eating pizza for dinner -- is actually starving their nervous systems' and causing PPS symptoms," says Creange. The relationship between diet and PPS was seen in the 1998 National Post-Polio Survey: the less protein polio survivors had at breakfast the more severe were their daily weakness and fatigue.

Why do polio survivors function as if they have low blood sugar and report more symptoms when they don't eat protein at breakfast? Because polio survivors are running their nervous systems on "half a tank of gas." About 50 percent of all brain stem and motor neurons were killed decades ago by the polio virus. What's worse, the metabolic apparatus, the internal power plant, of the neurons that survived the original polio virus infection was severely damaged.

So polio survivors have been running their full-tilt, Type A lives on half the normal number of neurons, neurons that are less able to use their only source of fuel, blood sugar. Dr. Creange found that even normal levels of blood sugar were not enough to fuel the remaining polio virus-damaged, metabolically impaired neurons. And that's where protein at breakfast comes in.

Protein: The fuel that keeps on giving. Protein provides a long lasting, "slow release" supply of blood sugar throughout the day. Polio survivors who had protein for breakfast reported less PPS symptoms because their fuel tank stayed full longer. They didn't need to "fill up" throughout the day with short-lasting sugar fixes, like soda or candy bars.

When we ask our post-polio patients to eat protein every day at breakfast, and have small, non-carbohydrate snacks throughout the day, they report an almost immediate reduction in nearly all the symptoms of PPS, especially fatigue. But "protein power" diet is neither a fad nor a miracle: it's just common sense. No engine can be expected to run without gas.

And having protein at breakfast isn't good only for polio survivors. Mom was right: breakfast is the most important meal of the day for everyone, but especially for people with damaged or compromised nervous systems. Folk with MS (for whom low energy and fatigue can be disabling) those with ALS and Guillian-Barre Syndrome need to feed their damaged neurons first thing in the morning. Those with spinal cord injuries, CP and spina bifida, who use more energy just getting showered and dressed than does a nondisabled person who runs a mile, also need protein early and often. It's a good idea to eat breakfast before showering to "break your fast" and fill your tank before your neurons need the fuel.

Our patients worry that using a wheelchair, resting more and having breakfast will cause them to get fat and have more PPS symptoms. A four-year follow-up study found that U.S. and Swedish polio survivors, living their typical "use it or lose it" lifestyles without using new assistive devices or resting, lost equal amounts of leg muscle strength, about 2 percent per year. However, when subjects from the two countries were looked at separately, the Swedes gained only 6 ounces per year, while the Americans gained over 2 pounds; that's 220 percent more weight! Although weight gain alone is not responsible for the progression of muscle weakness in polio survivors, it is Americans' high fat, Big Mac diet that causes them to get fat. You can fuel your neurons, feel stronger and less fatigued without gaining weight, if you choose low fat, low cholesterol sources of protein. In fact many of our patients,

even as they slow down, sit down more, and use a scooter, lose weight (about a pound per week) if they eat more protein, reduce portion size and limit carbohydrates.

We aren't recommending one of those "all protein, no carbohydrate" diets. We aren't recommending a "diet" at all, but a method for eating healthy every day. We suggest 16 grams of protein at breakfast; that's about 1/4 of the daily protein requirement (70 grams) for a 150-pound person. (Always check with your doctor, especially if you have kidney problems, before changing your diet and ask to have your cholesterol measured at your yearly check up.)

Look at the list protein-rich foods and select different breakfasts so you can have a variety throughout the week. Remember, you want foods that have more grams of protein than they do fat. Eat well and be well

PROTEIN-RICH FOODS:

You need 16 grams of low-fat protein at breakfast. Note: measures in grams.

GREAT	Protein	Fat
Cottage cheese, light, 1 cup	28.0	2.3
Salmon, 3 oz.	17.0	5.4
Yogurt, 8 oz.	12.0	4.0
Tofu	10.0	5.9
2% milk, 1 cup	8.0	3.0
Bagel	6.0	1.4
Egg Beaters, 1/4 cup	5.0	0
HIGHER FAT		
Swiss cheese, 1 oz.	8.1	7.8
Slim Fast Meal on the Go	8.0	5.0
Lite'n Lively Cheese, 1 oz.	6.4	4.3
Hard boiled egg	6.1	5.6
Cream cheese Lite, 1 oz.	2.9	4.7

LOWER PROTEIN	Protein	Fat
Quaker Life	5.2	1.8
English muffin	4.5	1.1
Oatmeal, 1 package	4.4	1.7
Cheerios 1 1/2 cups	4.3	1.8
Shredded wheat 1 oz.	3.1	0.6
Total 1 cup	2.8	0.6
NOT GREAT		
Bacon 3 strips	5.8	9.4
Egg McMuffin	17.0	32.0
Peanut butter 1 Tbs.	4.6	8.2
Coffee	0	0

PROTEIN POWER BREAKFASTS:

12 minute breakfast:

2 hard boiled eggs (12 g) and an English Muffin (4.5 g)

8 minute breakfast:

3 scrambled egg whites (10 g) and a bagel (6 g)

6 minute breakfast:

Toasted bagel (6 g), lite cream cheese (3 g) and 1 glass 2% milk (8 g)

4 minute breakfast:

Yogurt (12 g) and 1 ounces of low-fat cheese (6 g)

2 minute breakfast:

1/2 cup low-fat cottage cheese (14 g)

HELLO!

Listen up, Brain. We body parts have had a meeting and we want to bring a few things to your attention. You don't know everything, you know. As Left Leg of this conglomeration, I would appreciate it if you would keep from insinuating that I'm worthless. If I weren't here, even damaged as I am, you would topple over. The polio virus did a number on me, I admit that. And, OK, I'm not pretty. I won't lie, I know that I'm skinnier than Right Leg, but look how hard I've tried to be everything you want in a leg. It is not my fault that I was left with so few motor neurons that I can barely function.

And I'm Right Leg. I've been hauling this whole body around since we were four years old. I'm doing pretty good, I think. I believe a few less Twinkies and Pepsi might be helpful. I'm not Super Leg, you know!

This is Back, here. There are times when I realize I'm giving you more grief than you can handle. Sorry about that. You have to realize that with Left Leg being less useful...hold on, Left Leg, I did not say useless! I just mean that with your not being your old self (there, is that better?) there's a bit of a twist on me and I can't help complaining about it. I agree about the Twinkies, by the way.

Right Arm speaking. Sorry about dropping your grandmother's crystal bowl the other day. I did help you sweep it up. However, we need to talk about those crutches. I'm just not meant to do the work that Legs were designed for. Left Arm and our Hands have just about had it. It's no wonder we are losing our grip! We think you should at least try to have a little consideration for us. Polio zapped us, too. Not as bad as Legs, but still, we also lost a lot of neurons and we've worked very hard to help you get places and do things.

This is your Right Hip talking. With the difference in length between Right Leg and Left Leg and the slight twist in Back, life is not wonderful for me and Left Hip. Sometimes the scoliosis twists us till we are almost dizzy. We would definitely vote for fewer Twinkies, too.

So, as spokespart, for this body, I, Left Leg, have some suggestions. One is to try really hard to eat healthier. Come on, it's hard enough to drag you around without your gaining even more weight. Another suggestion is that you show a little appreciation for us. We've worked really hard for you for a very long time, under conditions that would make a lesser body give up the ghost. It hurts our feelings when you stand in front of the mirror and disparage us. "Oh, look how crooked I stand. I list to port and I fall so easily." You complain that we aren't pretty. Well, excuse me, but it wasn't our fault, really that you look like this. Blame it on Polio, he's the Bad Guy. He tried to kill you, but we didn't let him. He tried to make your life sad and lonely, but we didn't let that happen.

OK, lecture over. You can go back to what you were doing. No, not that exercise bike! Don't you ever listen? Conserve to Preserve. Pace. Give it up, Spanky, you are never going to be an athlete, but you can have a good life anyhow. Most athletes abuse their bodies even more than you do, and many of them have to retire at an early age from working too hard.

What's that you say, Brain? You couldn't live without us? Darn right and don't you forget it!

HOW DO I FIND A POST POLIO DOCTOR?

The Doctor's Problem Is Our Problem

It is a real problem for Post Polio survivors that most doctors are not current in their knowledge of polio and Post Polio Syndrome. Polio is "irrelevant today" in that there is sufficient illness' that need to be studied in medical universities and research centers that doctors and students don't have time for "historical diseases", like small pox and polio, that have been eradicated (or nearly so in the case of polio) by vaccines. Don't be surprised if your primary physician is unacquainted with Post Polio Syndrome. When you bring the subject up and he seems vague as how to proceed, you have a dilemma of what to do.

If you get on well with your physician, education him. A concise pamphlet for that purpose is available for downloading. It was originally written by Dr. Warren Anderson and the Medical Advisory Board of the Post Polio Program Easter Seal Society of Oregon. It is updated and maintained by the Medical Advisory Board of the Polio Outreach Advisory Counsel, A Working Advisory Council to the Easter Seal Society of Washington.

You may view this pamphlet now:

[PPS Pamphlet, View Now](#)

For your printer, download:

[Pamphlet, Word Processors \(50K Zip\)](#)

There are several formats (Word, WordPerfect, RFT, and ASCII line printer). Hand, or mail, a neatly printed copy to your physician, and take a copy to any new doctor you visit. Several other pamphlets and manuals are available on Post Polio Syndrome. Check the Quick Links page for other suggestions, and other PPS websites will have more. It may be that your present physician is not interested in pursuing medical information that you

provide. This is his style of medical practice. It is easier to change doctors than to change doctor's minds. Start shopping for a replacement.

The Evaluation

If you are a polio survivor, it is imperative that you undergo a series of simple tests and observations, conducted by trained medical personnel, to determine your present physical condition. Therefore, your first task is to locate the nearest Post Polio doctor or clinic. Then call and talk to a counselor, and wrangle an appointment. About a month after the evaluation there will be a follow-up meeting with the doctors to discuss the results of the first visit, and you will be given recommendations and help to deal with your situation.

At this time the way I know to locate a post polio clinic is to make inquiries on the news conferences. Write a message to "All" and state where you are located and that you wish to visit a clinic for evaluation. Sound advice will be forthcoming.

Whether you currently have symptoms that may relate to post polio syndrome or not, do get an evaluation at a post polio clinic as soon as possible. The information that is generated will be heartening if all is well, and invaluable if there is a problem.

"Two heads are better than one" I have always heard. I've found that this is especially true when I started to deal with Post Polio Syndrome. Because Post Polio people are scattered far and wide networking on the Internet is a major enabling tool for us. network - Pronunciation: 'net-"work:

a: an interconnected or interrelated chain, group, or system.

b: a system of computers, terminals, and databases connected by communications lines.

The online Webster Dictionary

<http://www.m-w.com/>

When I looked up the word network, both of these definitions seemed relevant to what is being done on the Internet. By interconnecting our computers, we people with a common concern or a common interest can interrelate; we share our troubles, share our solutions, rejoice together. This is a resource that we modern polio survivors are blessed to have. This Post Polio Syndrome thing has been troubling polio survivors all through history, but just recently has it been legitimized by giving this condition a label. Because there were no statistical data and case histories collected on significant numbers of polio survivors in the past, Post Polio Syndrome was not observed as a distinct category of disease. As a result, mis-diagnosis of patient symptoms often had grim results. I have been most disturbed by what has happened to my friend that was diagnosed as psychosomatic and malingering to explain exhaustion and fatigue. I later learned this mis-diagnosis is unsettlingly common.

There are two aspects of the Internet that endow power to Internet users. The first is access to information. (This is the subject of the next section; Book-up.) The other is the ability to communicate with other Internet users, which number in the hundreds of millions. There are other Post Polio Survivors out there. The task is to find and communicate with them. Those who have gone before us have shown us how.

NETNEWS

There are a number of Netnews conferences dedicated to the interest of the disabled and some of these are specifically dedicated to polio. There is a newsgroups named:

alt.support.post-polio.

You can subscribe to this like you would any other news group. Search the "all newsgroups" list on your news reader program for other polio related groups by searching on the word "polio". Do this on a regular basis, as newsgroups appear and disappear when there is an interest in some subject not currently covered. Try it out.

MAIL LIST

Join a polio mail list. This is a group of people interested in the subject of polio that write messages to one another or to "ALL". Each message is sent to everyone who subscribes to this service. You needn't write anything when you first sign on, but you could and you would be welcomed.

The following is shamelessly copied from Ernie Wollering "Post Polio Internet Resources" mailing list.

polio-life@eskimo.com - A 'Few holds barred' discussion. Some folks have flinched at the tone, occasionally. " The Polio Life list is an unmoderated, user maintained list dedicated to exploring the full range of ideas and activities of persons who have survived polio. The focus is intended to be on polio survivors as complete individuals with varied lifestyles, experiences and beliefs who belong to the broad disability community.' The model for the list is not a support group but rather a forum where people with a common experience or interest in polio can share experiences and insights. Topics might include (but are not limited to) medical issues, as well as recreational, intellectual, social, political, disability rights and advocacy, and literary interests of the list members."

To subscribe to polio life send an e-mail to:

polio-life-request@eskimo.com

In the "Subject:" field type: subscribe

Some other groups to sample are:

post_polio@yahoogroups.com - "A laid-back low-key, no-beefs list"

polio-list@eskimo.com - Information exchange.

To *book-up*, a term from my school days, is to become familiar with the known literature on a subject. The documents available on the web about polio are varied and extensive. Post Polio Syndrome websites have links to collections of medical articles and extracts, information in the form of FAQ (frequently asked questions) files, links to newsletters and periodicals on polio and it's ramifications, and so forth. The handiest thing is that most of these websites contain pointers to other websites that are sources of information about polio and Post Polio Syndrome. Once you start searching the Net, if it's there, you will find it.

A good place to start looking for general information on polio is the "Lincolnshire Post-Polio Network - Main Gate to Polio and Post-Polio Information." Click on the link below and bookmark the site after you log-on. [Lincolnshire Post-Polio Network](#)

Another excellent source of medical information is Ernie Wollering's [Post Polio Syndrome, Recently Published Medical Articles](#). Bookmark this site, also.

[Polio Medical Articles](#)

With this start, you will soon find the information that will best serve your needs. Open the links and follow their trail. Ask questions when you get wedged.

THE WEB CORNER

Finding may lead to new treatments for neurodegenerative disease and stroke:

<http://www.medicalnewstoday.com/releases/263848.php>

Recognizing Typical Coping Styles of Polio Survivors Can Improve Re-Rehabilitation

<http://www.ippo-world.org/ppsinfo/articles/maynard/rerehab.html>

Move Over Nursing Homes, There is Something Different:

<http://www.npr.org/2013/07/24/196249703/move-over-nursing-homes-theres-something-different>

Post Polio Directory 2013

<http://www.post-polio.org/net/PDIR.pdf>

Save Our Shoulders:

http://www.mossrehab.com/index.php?option=com_docman&task=doc_view&gid=67&Itemid

List of Famous Polio Survivors:

http://en.wikipedia.org/wiki/List_of_poliomyelitis_survivors

Prickly Painkiller

<http://www.scientificamerican.com/article.cfm?id=prickly-painkiller>

What are my preventive care benefits?

<https://www.healthcare.gov/what-are-my-preventive-care-benefits/>

Random Harvest ebooks

<http://www.postpolioinfo.com/randomharvestinfo.php>

A NEW and UNIQUE PUBLISHER

“The ‘What if?’ and the ‘Why not?’ for and from voices that have been silent.”

New York (Friday July 12, 2013): random harvest, a new and unique e-book imprint, was inaugurated today by editor-in-chief Bob Storrs.

“I wanted to create a platform from which people whose voices have been ignored, silenced or drowned out by the din of the XBox, TMZ, 24/7 news cycle can be heard,” said Storrs, a long-time magazine editor, reporter and feature writer. “The goal of **random harvest** is to tell stories, be they fact or fiction, by and about people with disabilities, people of color, the LGBT and religious communities that are presented from a unique point of view and have a distinctive voice.”

The **random harvest** editors are looking for prose and poetry that are sharp, surprising and even shocking -- works that ask "What if?" and "Why not?" -- that engage readers' hearts and heads, allowing them to learn and to feel.

"We want to find the "novel" novel, the collection of essays, poetry or short stories that look at life from a previously unviewed angle, that speak truth to power and take readers to places that they have never before been -- and perhaps were afraid to go -- but ultimately are grateful that they have taken the trip," said Storrs.

randomharvestbooks.com: A NONPROFIT CO-OP FOR A CAUSE

(Editor's note: You will find my book Hot Water, Orange Juice and Kids prominently featured on this page.)

A LITTLE BIT OF HUMOR

A US Navy cruiser anchored in Mobile, Alabama for a week's shore leave.

The first evening, the ship's Captain received the following note from the wife of a very wealthy and influential plantation owner:

"Dear Captain, Thursday will be my daughter Melinda's Debutante Ball. I would like you to send four well-mannered, handsome, unmarried officers in their formal dress uniforms to attend the dance."

"They should arrive promptly at 8:00 PM prepared for an evening of polite Southern conversation. They should be excellent dancers, as they will be the escorts of lovely refined young ladies. One last point: No Jews please."

Sending a written message by his own yeoman, the captain replied: "Madam, thank you for your invitation. In order to present the widest possible knowledge base for polite conversation, I am sending four of my best and most prized officers."

"One is a Lieutenant Commander, and a graduate of Annapolis with an additional Masters degree from MIT in fluid technologies and ship design."

"The second is a Lieutenant, one of our helicopter pilots, and a graduate of Northwestern University in Chicago, with a BS in Aeronautical Engineering. His Masters Degree and PhD. in Aeronautical and Mechanical Engineering are from Texas Tech University and he is also an astronaut candidate."

"The third officer is also a Lieutenant, with degrees in both computer systems and information technology from SMU and he is awaiting notification on his Doctoral Dissertation from Cal Tech."

"Finally, the fourth officer, also a Lieutenant Commander, is our ship's doctor, with an undergraduate degree from the University of Georgia and his medical degree is from the University of North Carolina. We are very proud of him, as he is also a senior fellow in Trauma Surgery at Bethesda."

Upon receiving this letter, Melinda's mother was quite excited and looked forward to Thursday with pleasure. Her daughter would be escorted by four handsome naval officers without peer (and the other women in her social circle would be insanely jealous).

At precisely 8:00 PM on Thursday, Melinda's mother heard a polite rap at the door which she opened to find, in full dress uniform, four very handsome, smiling Black officers.

Her mouth fell open, but pulling herself together, she stammered, "There must be some mistake."

"No, Madam," said the first officer. "Captain Goldberg never makes mistakes."

