

**POLIO PERSPECTIVE**  
**MARCH 2016**

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Good morning - I am usually just reading never commenting but feel the need to let you all know my latest "thing" a FITBIT. Its a longer story as how I got to this point but Ill just tell you about what it is and why I like it. and No its not an advertisement there are lots of these things out there - my hubby just happened to get me the one called a FITBIT.

So I have PPS like all of you. I am tired, overweight, out of shape, and feeling miserable about my broken body. My hubby's work has a new "fit for life" program that he has been losing weight (we are both a lil chunky) So he earns points from his work program and with his points (bless his little heart) he orders me a FITBIT!!

My first thought "what in the hell am I gonna do with that thing? Its Ugly. Its plastic. I am fat, can't exercise and I like my comfort food!! end of story" Well a few days after he got it for me I got it out of the box and logged it into computer and my phone to see what it does. I am not tech-savvy but it was pretty easy to do.

So I put it on and wear it for the day. It didn't do anything!! It just sat there on my arm and didn't do a damn thing!! Stupid FITBIT. So next morning when I logged into computer I went and looked at my FITBIT dashboard. How cool!! it knew how long I slept, how many times I was restless and how many times I woke up!! I know I don't sleep and well now I could see it!! How the heck can it know that?

As I look around more on the dashboard it knew how many steps I took, my heart rate for the whole day! hmmm this thing is kind of cool! More searching and I found I could set limits on things - 2500 steps!! omgosh! I gave up counting my steps years ago! ( I use a wheel chair for shopping and getting around outside of our house). I also found on dashboard I can log food and it will tell me calories in and out. It will also track exercise! LOL LOL LOL this body don't exercise!

Guess what guys..... I joined the local gym with a pool! I will tell you it felt so good the first time I went in (warm pool & a hot tub) I went a little overboard. 2hrs the first day - did 3 days of it in a row. Not swimming really just flailing around in the deep end of the pool with one of those pool noodles. moving my legs and arms back and forth. It felt so good to be doing something! I over did - I was exhausted when I got home. pain at night was unbearable, slept worse than I had in a long time! OK so maybe Ill cut back a lil on the pool time. 2 days a week and I do an actual exercise class in the deep end of the pool. Not so bad. Im still exhausted when I get home but I feel good and I track my swim time with my FITBIT and it shows my heartrate and calories burned.

Now here is the other miracle of my FITBIT. I can log my food. hehehe I already know I eat to much! But I start to log it anyways. By logging my intake it tells me my calories and how many I have left for the day. The first few days of logging my food I saw how much I was going over (way over) my calorie limit. (its all portion size - I am learning I can eat what I want but just not so much!)

OK so I guess I am getting carried away here with my FITBIT rant! I just wanted you guys to know it might be worth a try to try one. It is making me more aware of things I was choosing to ignore. I actually had a salad for lunch the other day and I liked it!!!!!! and I am really down 2 whole pounds! My goal is 50 ;- ) may take me a year or more to get there but I think I might actually have a shot at it ;- )

**Bruno Bytes**  
**by Dr. Richard Bruno**

**On the topic of Hip Replacement after Steroid Injections** (3/3/2016)

Dr. Bruno's Post: A warning - Too much medicine isn't always good medicine. . .

Study: Hip Replacement Too Soon After a Steroid Injection Increases Infection Risk

Released: 2-Mar-2016 12:05 AM EST

Source Newsroom: [Hospital for Special Surgery](#)

Newswise — Patients considering hip replacement surgery would do well to wait three months if they've had a steroid injection to relieve hip pain, according to a study by Hospital for Special Surgery (HSS) researchers.

"The risk of developing an infection after surgery increased significantly in patients who had a hip replacement within three months of receiving a steroid injection," said William Schairer, MD, lead study author. "However, in patients who had a steroid injection and then waited three months or longer to have the surgery, there was no increased risk at all."

Researchers reviewed thousands of patient records in California and Florida databases for their study, which was presented at the annual meeting of the American Academy of Orthopaedic Surgeons (AAOS) on March 2, in Orlando, Florida.

An injection of a steroid into the hip joint is a common treatment to relieve pain and inflammation in patients with arthritis. This the first large population study to provide strong evidence of an increased risk of surgical site infection in patients who have hip replacement 12 weeks or sooner after the injection, according to the researchers. They note that the immune system is weakened by corticosteroids, and this may contribute to the higher infection risk.

"Hip replacement is a common and safe procedure that relieves pain and improves quality of life, and overall, the risk of developing a joint infection is low," said Seth Jerabek, MD, an orthopedic surgeon at Hospital for Special Surgery and senior study author. "Although the risk is low, an infection is one of the most dreaded complications of joint replacement. Patients often need to undergo additional surgery, receive intravenous antibiotic treatment, and are off their feet during a lengthy recovery. "

For their study, investigators looked at the Statewide Ambulatory Surgery and Inpatient Databases for Florida and California from 2005-2012, which included more than 177,000 patients who had hip replacement surgery for osteoarthritis. Researchers narrowed down the list to those who had received steroid injections prior to surgery and reviewed follow-up records to determine which of those patients developed a surgical-site infection within one year of hip replacement.

Patients were grouped into those who received NO injection; those who had hip replacement within 6-12 months of an injection; those who had the surgery within 3-6 months; and those who had hip replacement within 0-3 months of receiving an injection.

The infection rate was 2.06% in non-injection patients and jumped to 2.81% in those who had the surgery from 0-3 months after an injection, representing an increased risk of 40 percent. There was no statistically significant increase in infection risk in patients who had hip replacement from 3 - 12 months after the injection.

"Based on study findings, we recommend that elective hip replacement surgery be deferred for at least three months from an injection to avoid the elevated risk of infection," said Dr. Jerabek. "However, in some cases, such as patients who are still in a great deal of pain after the injection, it may not be feasible to wait. This is something the patient and doctor should discuss to determine what will provide the most benefit and least risk to the patient."

<http://www.newswise.com/articles/view/648996/?sc=mwhn>

### [On the topic of Incontinence in Women with Osteoporosis](#) (3/8/2016)

Dr. Bruno's Post: Most interesting in this article is the importance of POSTURE (with or without fractures) in "controlling dripping." (See THE POLIO SURVIVORS HANDBOOK for painless (and maybe peeless) posture).

[http://well.blogs.nytimes.com/2016/02/24/treating-incontinence-in-women-with-osteoporosis/?emc=eta1&\\_r=1](http://well.blogs.nytimes.com/2016/02/24/treating-incontinence-in-women-with-osteoporosis/?emc=eta1&_r=1)

### [On the topic of Drug Side Effects](#) (3/10/2016)

Dr. Bruno's Post: So many Coffee House members ask about drug side effects and drug interactions. Here's a good site to bookmark in your web browser that I use to look for both, plus an interesting TED talk about finding drug interactions using "big data".

<http://www.drugs.com/sfx/>

### On the topic of “Parkinson’s Like” Symptoms (3/11/2016)

Original Post: Do any of you have and I use a word carefully, Parkinson type movements of your arms, where they move randomly in a twitching like movement and do not listen to you?

Dr. Bruno’s Response: Involuntary limb movements, twitching and muscles jumping, is not uncommon in polio survivors and is a sign of overuse. The poliovirus did indeed damage the dopamine producing parts of the brain; you know a dopamine deficit is the cause of Parkinson's and is also what our research has shown to cause post-polio fatigue.

So why isn’t there a higher incidence of Parkinson's in polio survivors than the general population?

Back at the 1949 conference on polio, the man who discovered the brain activating system was asked to comment on why polio survivors who had encephalitis, could be in a coma as a result of damage to dopamine brain activating neurons but that polio survivors only incredibly rarely (and by rarely I mean a handful of cases) had symptoms of Parkinson's. His disturbing conclusion was, "If the poliovirus did that much damage to dopamine producing neurons in the brain, individuals had no tremor because they did not survive."

Additional Post: I have this in my legs but not in my arms, mainly at night in bed.

Dr. Bruno’s Response: That's the norm for polio survivors. But any muscle can twitch and jump any time of the day. There are many kinds of tremors. Some look like the Parkinson's "pill rolling" tremor in one or both hands where the thumb moved back-and-forth & the wrist turns when the hands are at rest. Others have the hands shaking only when they are being used. And sometimes the entire arm or both arms shake.

## **POLIO SURVIVORS EXERCISE? NO WAY !**

*Dr. Richard L. Bruno, Chairperson*

*International Post- Polio Task Force*

*and*

*Director The Post-Polio Institute*

*and*

*International Centre for Polio Education PostPolioInfo.com*

In January I shoveled snow and my left leg became very weak. My knee buckled twice but I caught myself before I fell. I went to my doctor and he sent me right to physical therapy. In the first session I was on the treadmill for 10 minutes, on the bike for 5 and I did straight leg raises with weights around my ankles. I barely made it home, where I fell to the kitchen floor. My legs are even weaker now and they are always burning. Don't polio survivors need exercise to make weak muscles stronger?

Your body is answering that question for you. But let me tell you about the research on exercise in polio survivors. There have only been about half a dozen small studies that tested around 12 subjects each. And although 90% of the subjects were said to have "Post-Polio Syndrome" or reported new muscle weakness, their legs were stronger than yours.

Subjects were able to ride a bike for 5 minutes and then straighten their legs many times while a weight was attached to the ankles 2 to 4 times a week for from six weeks to two years--something you couldn't do one time. The studies tested polio survivors' ability to strengthen their quadriceps muscle, the

muscle in the front of your upper leg that allows you to lift your lower leg up off the floor while you're sitting and to "lock" your knee. The quadriceps is the muscle that gave out when you fell in the kitchen. The studies differed in the way exercises were performed. Two studies asked polio survivors to limit the number of leg lifts if they felt fatigue, told them to rest between bouts of exercise and increased the amount of weight lifted only if there was no "excessive fatigue." Other studies described their exercise regime as "high-intensity," "heavy resistance," or "aggressive." Two studies required polio survivors do five minutes on an exercise bicycle before they did as many as 30 leg lifts three times each week. In the most aggressive study polio survivors did five minutes on the bicycle followed by a 60 minute exercise class twice a week for 5 months! A polio survivor who is able to do that kind of exercise doesn't have PPS.

Clearly, the subjects in the studies had more strength, more endurance, more ability to function and fewer symptoms than you do or do the patients we treat. Still, when you read the researchers' conclusions it sounds like exercise is just the thing to restore muscle strength in polio survivors with PPS: "a supervised training program can lead to significant gains in strength."

Unfortunately, when you look at the studies finding the benefits of exercise are far from clear. Only 53% of those who exercised had an increase in leg muscle strength of about 26%. Twenty-six percent of subjects had no change in strength while 21% had a decrease in strength of about 10%. So, more often than not, exercise either had no effect or actually decreased muscle strength.

But there's more. Well, actually less. Only three studies asked whether exercise had an impact on polio survivors' ability to function in their daily lives. In one study where exercise was limited by fatigue, there was no measurable change in muscle strength over 2 years, although half of the subjects thought their walking and stair climbing had improved. In one aggressive study there was a 29% muscle strength increase, no improvement in subjects' ability to do their daily activities, but an increase in muscle fatigue of from 150% to 300%! Muscle fatigue also increased by 21% in another aggressive study in which strength increased by 36%. You have to ask what good comes from any small increases in muscle strength that are not related to improved functional ability but are related to muscle fatigue that increases more than strength does.

Dr. Alan McComas' performed a study showing that polio survivors who are not treating their muscle weakness and were getting weaker lost 7% of their motor neurons each year. McComas concluded that "polio survivors should not engage in fatiguing exercise or activities that further stress metabolically damaged neurons that are already overworking." Muscle weakness is a sign of neurons failing and dying.

I know that you were taught to "use it or lose it" and to exercise until you "feel the burn." But when you feel the burn you are burning out your neurons. What's the bottom line regarding exercise to strengthen newly weakened muscles? Don't.

## FOR CRYING OUT LOUD

*by Millie Malone Lill*

Do you have a problem letting others see you cry? I've been in a discussion with other polio survivors and many of us do have that problem. For many years, I would let no one see my tears. Even when my husband of 34 years died and my heart was shattered, no one saw me cry. Why?

Perhaps it was because so many of us had polio as small children. I was four. We were torn from our

families, put into isolation, some of us not seeing our parents or siblings for months at a time. The nursing staff was overwhelmed during the epidemics and some of them lost their patience with weepy children.

I was one of the lucky ones in that I was not abused in the hospital. However, many were. I've heard of nurses threatening to put crying children in a dark closet if they didn't stop that caterwauling. Sometimes this threat was carried out. One little girl had nightmares and woke up screaming. The nurse did put her in a dark closet. Would you be surprised to learn that this did not stop the nightmares? One woman said that her nurse told her the plug would be pulled on her iron lung if she cried.

It's hardly surprising that so many of us have difficulty crying where others can see us. When my beloved died, I remained dry eyed at his visitation and at his funeral. I suppose people saw me as hard hearted and uncaring. That was not the case. I cried myself to sleep many nights and always burst into tears when coming home to my empty house, the house where so many of my hours were spent caring for that dear man in the 13 years of his serious illness. But only in private. Never, ever where I could be seen.

Another reason, in my opinion, for this difficulty is that we don't want to appear vulnerable. It's far too easy for a disabled person, child or adult, to be bullied. Bullies love to see our tears. They live for that. If you are unable to defend yourself physically, you must find another way. By not letting anyone see your vulnerability, by never crying no matter what, you might seem stronger than you actually are.

Now that I am old, I have learned that it is OK to cry. It's OK to let others see my vulnerability. It does not imply that I am weak, merely that I am human. It took a long time to trust my friends enough to let them see my tears. Now, however, because of my polio support groups and the incredible sharing experiences, the interaction between my fellow polio survivors, I am finally able to let others see me shed tears.

I have learned to stand up to bullies. Surprisingly, there are people even at my age who will try to bully those of us who are noticeably different. My power chair caused me a lot of problems when I first moved into my independent senior housing apartment. Some of the other residents attacked me for having to use my chair when they have seen me walk. Several people insisted that I go to a nursing home. At first, I took it like a blow to the heart. For awhile, I let their wrong opinion stand. Finally, though, I had enough and I had someone come and explain the Fair Housing Act to a gathering of my fellow apartment dwellers. I answered questions at that meeting and I asked some, as well.

It takes courage to let people see you cry, but I know you, my fellow polio survivors, are definitely not lacking in that trait. Take heart. We have overcome so much that letting others see we are human is absolutely OK.

## **Web Corner**

### **Scientists Discover Non-Opioid Relief of Pain**

**<http://www.nih.gov/news-events/scientists-discover-non-opioid-pain-pathway-brain>**

## **CDS Guidelines Aim to Reduce Addiction Risk**

**<http://www.nytimes.com/2016/03/16/health/cdc-opioid-guidelines.html?ref=health&r=1&login=email>**

## **Polio Place Medical Articles**

**<http://www.nytimes.com/2016/03/16/health/cdc-opioid-guidelines.html?ref=health&r=1&login=email>**

## **Respiratory Muscle Weakness and PPS**

**<https://lindaonwheels.wordpress.com/category/breathing-problems-pps/respiratory-muscle-weakness-and-post-polio-syndrome/>**

## **The Disability Digest**

**<http://www.thedisabilitydigest.com/>**

## **Drug Side Effects**

**<http://www.drugs.com/sfx/>**

## **Some Imported Dietary Supplements and Nonprescription Drug Products May Harm You**

**<http://www.fda.gov/ForConsumers/ConsumerUpdates/ucm466588.htm>**

## **A World Free of Polio the final steps**

**<http://www.nejm.org/doi/full/10.1056/NEJMp1514467?query=infectious-disease&>**

## **Monkeys Drive Wheelchairs Using Only Their Thoughts**

**<http://www.newswise.com/articles/view/649000/?sc=mwhn>**

## **Fibromyalgia Mystery Solved**

**<http://dailymedicalresearch.com/fibromyalgia-mystery-finally-solved-2/>**

## **A Little Bit of Humor**

A man was looking for someone to paint his porch. So he hired a young lady and told her what to do. After about 30 minutes, the lady came to the door and said, "I'm done."

The man asked, "How did you get done so fast?"

The lady said, "It was hard at first, but it got easier towards the end. And by the way, it's a Ferrari, not a Porsche."