

Polio Perspective

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THE EFFECTS OF COLD ON POLIO SURVIVORS

by Dr. Richard L. Bruno

Polio survivors are extremely sensitive to changes in temperature. At merely cool temperatures, most polio survivors report that their feet have always been cold to the touch, their skin a purplish color. However, as polio survivors have aged, 50% report "intolerance to cold" and that their limbs have become more sensitive to pain as the temperature decreases. Cold was reported to cause muscle weakness in 62% of polio survivors, muscle pain in 60%, and fatigue in 39%. When polio survivors were cooled in the laboratory from 86o F to 68o F, motor nerves functioned as if they were at 50o F and polio survivors lost 75% of their hand muscle strength.

But, although polio survivors are twice as sensitive to pain as those without polio, no increase in pain sensitivity was found at lower temperatures. The reason polio survivors have such trouble with cold is that the parts of the central nervous system that should control body temperature were damaged by the poliovirus. In the brain the hypothalamus (the "automatic computer" that controls the inner bodily environment) was damaged by the poliovirus, including the body's "thermostat" and the brain area that tells your blood vessels to constrict.

In the spinal cord, the nerves that carry the message from the brain that tells the capillaries in the skin to contract when it's cold were also killed by the poliovirus. Thus, polio survivors are unable to stop warm blood from flowing to the surface of the skin as the outside temperature drops. This allows loss of heat from the blood near the surface of the skin and causes the limbs to cool. When the limbs cool, arteries carrying blood to the skin and veins that should carry blood out of the skin narrow passively as they get cold, trapping blue venous blood in the capillaries and causing the feet to look blue and to become even colder. The cold skin chills the motor nerves, causing them to conduct more slowly and to be less efficient in making muscles contract. The cold also chills tendons and ligaments (like putting a rubber band in the freezer) making movement of weak muscles more difficult.

As polio survivors know, it takes hours under an electric blanket or a long, hot bath to warm cold legs and regain strength. However, when polio survivors take a hot bath, blood vessels do exactly the opposite of what they do in the cold. Polio feet and legs become bright red as arteries and veins relax and blood rushes to the skin. Then, when polio survivors stand to get out of the tub, they can feel dizzy or even faint as blood pools in their legs and causes their blood pressure to drop.

The pooling of blood in the feet also explains why polio survivors' feet swell, swelling that increases as they get older. And polio survivors' easily losing body heat explains why they have an increase in symptoms, especially cold-induced muscle pain, as the seasons change. Polio survivors need to dress as if it were 20o F colder than the outside temperature. They need to dress in layers and wear heat retaining socks or undergarments made of polypropylene (marketed as Gortex or Thinsulate) that should be put on immediately after showering when the skin is warm.

Polio survivors need to remind doctors that EMGs or nerve conduction tests must be performed in a room that is at least 75o F to prevent false abnormal readings and that a heated blanket is necessary in the recovery room after polio survivors have surgery

How to Apply for Social Security Disability

From the International Centre For Polio Information

<< I had polio in 1952 and one leg has always been in a long leg brace. I am a computer analyst and now have severe fatigue. I fall asleep at my computer. But from what I read on the Internet, everyone who had polio gets denied for Social Security Disability, even when they hire a lawyer and appeal the denials. Either I will get fired or I just wont be able get out of bed and go to work. I have no choice but to keep working. >>

You do have a choice! It is not true that it is Social Security Administration (SSA) policy to deny Social Security Disability Income (SSDI) payments to polio survivors. In 1985 we wrote the document that allows polio survivors to get SSDI, called the POMS for Evaluation of the Late Effects of Poliomyelitis (24580.010). In 1987, we worked with Senator Bill Bradley to force SSA to release the POMS, which is when polio survivors started getting SSDI. What's more, in March, 2002, the SSA Commissioner agreed to our request to convert the POMS into what is called a "Social Security Ruling" that binds adjudicators and administrative law judges decisions about disability for polio survivors. The Social Security Ruling, SSR 03-1p.; Titles II and XVI: Development and Evaluation of Disability Claims Involving Postpolio Sequelae, was released on July 2, 2003. SSA has also agreed to "retrain" SSA personnel to properly review polio survivors' applications for SSDI. "The Ruling is more inclusive than the POMS and uses the term "Postpolio Sequelae" to describe all of the late-onset symptoms polio survivors experience, not only post-polio syndrome -- new muscle weakness in those who had paralytic polio -- but also 'early advanced degenerative arthritis, sleep disorders, respiratory insufficiency, and a variety of mental disorders (having) an etiological link to either the acute polio infection or to chronic deficits resulting from the acute infection." According to the Ruling "any one or a combination of these disorders...will constitute the presence of 'postpolio sequelae' and can be grounds for granting SSDI.

For the first time sleep disorders, 'problems with attention, reduced concentration capacity, inability to persist in tasks, or memory problems' are recognized as causes of disability.

The Ruling also recognizes The Post-Polio Institute's research on the psychological effects of polio and PPS, that "traumatic psychological experiences associated with acute polio infection are revived when polio survivors recognize the onset of further weakness and functional loss. Many polio survivors endured a life-threatening infection as young children. They may have spent extended periods away from their homes and families while hospitalized with paralysis or respiratory dysfunction, or while undergoing multiple orthopedic surgeries. Often they endured many months, or sometimes years, of hospitalization and rehabilitation. The psychological effect of perceiving the onset of further weakness, fatigue, respiratory dysfunction or joint pain, many years following the acute infection, can be significant," and lead to disabling "anxiety and depression...mood changes and social withdrawal." Any of these symptoms can be the cause of inability to work and grounds for granting SSDI. The Ruling also recognizes that "many individuals with medically severe polio residuals have worked despite their limitations." The Ruling states that "the new onset of further physical or mental impairments (even though they may appear to be relatively minor) in polio survivors may result in further functional problems that can limit or prevent their ability to continue work activity. Postpolio sequelae may effectively alter the ability of these individuals to continue functioning at the same level they maintained for years following their initial polio infection."

So, SSA can and does grant SSDI for polio survivors. What's more not one of our patients has ever been denied SSDI. Why? It's all in the details And you don't need a lawyer to get SSDI:

1. Read and print the Social Security Ruling for Post-Polio Sequelae;
2. You can do the application on-line at SSA.gov. Or, ask the Social Security Administration office to mail you the SSDI application form (SSA-3368-BK). Tell the SSA office you can't come in to pick up or fill out the forms because you "physically can't" make the trip.

<http://www.ssa.gov/online/ssa-3368.pdf>

3. There is a phone interview before or just after you get the forms. This is not a big deal. SSA just wants to briefly hear why you think you're disabled and collect general information. But get the name, phone number and address of the adjudicator working on your case, the head of that local SSA office and the head of the office where your case will be decided. You will be asking your Congresspeople to write to these individuals.
4. Before the phone interview and before you fill out the application form, make a list of work-related disabilities and symptoms. On one side of a piece of paper list the things you can't do that are job-related (e.g., can't stay awake at your desk, can't focus attention, have to read the same paragraph over and over, can't lift or stand or carry). Then, on the other side of the page list the SPECIFIC symptoms that prevent you from doing the job related activities. Use the wording in the Social Security Ruling (e.g., "I can't focus attention because of severe fatigue; I can't stand for more than 5 minutes because of left leg muscle weakness; I can't walk for more than half a block because of loss of endurance"). Mention the number of time you have fallen and if falls have increased in the past year (Falls or "being unsafe" on your feet are required for Medicare to pay for PPS treatment. Medicare starts two years after you get SSDI). Mention times you almost fell asleep while driving. Be brief and clear in describing the symptoms and limitation. Remember: For every work-related problem, describe the symptom that disables you; for every symptom, tell what task it prevents you from doing.
5. Do illnesses, injuries or conditions" limit your ability to work? This is the only thing SSA wants to know. Avoid the kitchen sink approach. Don't list everything that has ever happened to you, polio-related or not. Limit your answers to illnesses, injuries or conditions" that limit your ability to work. The Ruling says "old records are not required," so you don't have to have records of childhood surgeries or even hospitalizations for polio. Also, do not include records of illness or hospitalizations you have had as an adult unless you have another condition that also limits your ability to work. If you are not disabled from work by allergies, an ulcer, a hip replacement, high blood pressure, osteoporosis, successfully treated sleep apnea, a heart attack -- even a heart transplant -- DO NOT list those diagnoses, the medications you take for them, hospitals where you were treated, or the doctors you saw for them. Don't even list blood tests or X-rays you've had unless they directly relate to the "illnesses, injuries or conditions" that limit your ability to work. SSA reviewers will sometimes look at the first doctor's report -- maybe a note from your GP of 5 years ago -- that says "Had allergy shot. No other problems" and deny you SSDI for PPS because you have no disabling symptoms. If you have "illnesses, injuries or conditions" that do not limit your ability to work, SSA doesn't need to know about them.

The more doctors and conditions and tests you list, the more likely it is that SSA will not even get all the reports, making the process take longer than it needs to. The best thing you can do is list only one doctor -- your PPS doctor -- who knows about PPS and will write clear reports about your inability to work due to specific PPS symptoms referring to the symptoms described in the Ruling. Your doctor need to read the Ruling before writing the report for SSA.

However, if you have PPS and then had a heart attack, and you now have limited stamina because of PPS and because your heart is not pumping enough blood, you have two conditions that together disable you from working. In this case, list your PPS doctor and your heart doctor. You can have several conditions that add together to cause a work disability. Also, it is important that each doctor write a report to SSA describing the your PPS symptoms and the impairments they cause. The report should also include the severity of any residual weakness, as well as the onset, pattern, and severity of any new physical or mental deficits. A description of current functional limitations and restrictions on physical and mental activity should be included.

6. List home-related limitations in the same way as work-related limitations, e.g., "I can no longer do laundry, shop, cook, yard work, because of fatigue and muscle weakness. Now my husband/wife/children have to do these jobs." SSA wants to make sure you are limited on the job and at home.

7. Use the "In spite of..." argument. Mention assistive devices you use, especially new ones, and that you still can't work "in spite of" using these devices, decreasing activity at home and getting reasonable accommodation at work (e.g., "In spite of getting a long leg brace that I was able to discard when I was 10 years old, using a wheelchair for the first time in my life, getting a stair-glide in my house, sleeping for 30 minutes at lunch, and leaving work early every day, my fatigue is still increasing and I fall asleep at my desk ").

8. Again, use symptoms described in the Ruling. If you work at a desk, brain fatigue will likely be the cause of your work disability. If you do physical work or type at a computer, physical fatigue, loss of endurance, or specific leg, arm, hand or muscle weakness may be the cause of your work disability. Stay away from mentioning any type of pain, especially back pain. It usually doesn't help to mention joint or muscle pain even when it is caused by work-related duties or is associated with muscle weakness, because it is almost impossible to get SSDI due to pain. Also, never mention depression, anxiety or medications you take for them unless these symptoms prevent you from working. Depression is an automatic rejection unless you live in a mental hospital.

9. In the "Remarks" section at the end of the application, briefly summarize ALL OF your answers and describe your work disability as caused by your specific PPS symptoms, again linking each work limitation to a given symptom and using the wording in they Ruling. Also, mention long-standing polio "disabilities" that are not problems. SSA decides that you are work disabled based on your age (50 or older), levels of skill and schooling. If you load trucks and graduated from the 8th grade, SSA won't expect you to go to college to get a "sedentary" career. But, if your are a college grad and have trouble walking, SSA will say you have the education and skills to do something that doesn't require walking. Some people with severe fatigue, but who have always used a leg brace, have been denied SSDI because SSA said, " Your leg has always been paralyzed and should not affect your working at a desk job." You should say something like, "The fact that I have always used a long leg brace and that my arm has always been weak has nothing to do with my disabling post-polio fatigue today."

10. The Ruling states that polio survivors' description of symptoms and limitations to their own physicians and psychologists are the primary factors when it comes diagnosing PPS and inability to work. An EMG and functional capacity evaluation have been removed from the evaluation process for PPS. The Ruling also states that only in "select cases, where severity of the impairment is unclear, an examination by a physician or psychologist who is knowledgeable about polio and postpolio sequelae is appropriate, if such a specialist is available." SSA can ask for what's called a "Consultative

Examination" if there is not enough information in your doctor's reports to determine if you are work disabled. However, many polio survivors find SSA sending them for a consultative examination to a neurologist -- or even a psychiatrist -- who knows nothing about PPS. SSA policy states that your treating doctor is the "preferred source" for the consultative examination, unless your doctor's records contain "conflicts or inconsistencies" or "prior experience indicates that the treating (doctor) is not a productive source of clear information" (cite SSA Regulations 404.1517 and 404.1519G). You have the right, and SSA regulations require, that your own doctor be consulted FIRST if there are unanswered questions or if a consultative examination is necessary.

11. You took the time to vote, so put that vote to use. SSA gets very careful when they know your Senators and Congressperson are watching over their shoulder. Send a letter like this and attach the Social Security Ruling:

Dear Senator/Congressperson:

I am a polio survivor of the 19XX epidemic. I have been working for XX years as a YOUR JOB but am now unable to work because of Post-Polio Sequelae (PPS).

Many polio survivors are being denied SSDI because SSA personnel do not know there has been a policy in place since 1987 -- the POMS for the "The Late Effects of Poliomyelitis" (24580.01) -- allowing polio survivors to receive disability benefits. SSA adjudicators wrongly use the listing for "Acute Anterior Poliomyelitis" (11.11) to determine eligibility for SSDI for those with Post-Polio Sequelae. Polio survivors are now disabled, not by polio paralysis or "motor disorganization, but most commonly by disabling fatigue due to Post-Polio Sequelae. To insure that SSA personnel no longer inappropriately deny polio survivors, a Social Security Ruling for Post-Polio Sequelae (Social Security Ruling, SSR 03-1p.; Titles II and XVI) was released by Commissioner Barnhart on July 2, 2003 (please see enclosed).

Would you please contact SSA ADJUDICATOR'S NAME and HEAD OF THE SSA OFFICE at the YOUR TOWN Social Security office, 555-555-5555, at THIS ADDRESS. Please ask them to consult the Social Security Ruling for Post-Polio Sequelae and make a decision about my disability based on the Ruling, SSA's own procedures and guidelines, and on the actual cause of my not being able to work, LIST CAUSE(S).

Include copies of your letters to the Congressperson and the Social Security Ruling with your application. Call your adjudicator at the SSA office about once a month to see where things stand. It should take about 6 weeks from the time your doctor sends in the report for you to get your first check.

12. Since it's the government mistakes do happen and you may get denied. If you are denied, read the reason for denial, which may be because of the adjudicator's not having read or misreading the Social Security Ruling. Find out the specific reason for the denial. Then do two things. FIRST, ask for an On-the-Record Administrative Review of your denial to determine if the guidelines in the Social Security Ruling were followed and the latest policies about PPS were applied. Write your Senators and Congressperson and ask them to request an On-the-Record Administrative Review:

Dear Senator/Congressperson:

I am a polio survivor of the 19XX epidemic. I have been working for XX years as a YOUR JOB but am now unable to work because of Post-Polio Sequelae (PPS). But I have been denied SSDI.

Many polio survivors are being denied SSDI because SSA personnel do not know there has been a policy in place since 1987 -- the POMS for the "The Late Effects of Poliomyelitis" (24580.01) -- allowing polio survivors to receive disability benefits. SSA adjudicators wrongly use the listing for "Acute Anterior Poliomyelitis" (11.11) to determine eligibility for SSDI for those with Post-Polio Sequelae. Polio survivors are now disabled, not by polio paralysis or "motor disorganization, but most commonly by disabling fatigue due to Post-Polio Sequelae. To insure that SSA personnel no longer inappropriately deny polio survivors, a Social Security Ruling for Post-Polio Sequelae (Social Security Ruling, SSR 03-1p.; Titles II and XVI) was released by Commissioner Barnhart on July 2, 2003 (please see enclosed).

*Would you please contact the SSA ADJUDICATOR'S NAME and HEAD OF THE SSA OFFICE at the YOUR TOWN Social Security office, 555-555-5555, at THIS ADDRESS. As a Member of Congress you can ask for an Administrative Review of my denial to determine if the Social Security Ruling was followed. Please ask for an **On-the-Record Administrative Review** of my denial and ask Social Security to make a decision about my disability based on the Social Security Ruling, their own procedures and guidelines, and on the actual cause of my not being able to work, LIST CAUSE(S).*

Send copies of your SSDI application, denial notice from SSA, the letters posted here from SSA and the Social Security Ruling to your Congressperson and Senators.

If you cannot get or are not successful with an On-the-Record Administrative Review appeal immediately. Discuss with your doctor the specific reason for the denial and asking him/her to also write a letter to SSA. You have a right to two local appeals and then a hearing before an Administrative Law Judge (ALJ). The ALJ's ruling can be appealed as well. If you follow this procedure, you won't need a lawyer even for the appeal. About 90% of the cases that come before the ALJs have their denials overturned, so there is a xxxrwlght at the end of even that tunnel.

But, if you are denied at any stage you can choose to file a NEW application for SSDI if you have new medical information or functional limitations. It will be as if the first application and denial(s) didn't happen. However you just have to find out your "last insured date." SSA only goes back 17 months from the filing date to establish the onset of disability and retroactive benefits. The money you get is based on the past 17 month of earnings. So if you file a new application and have been out of work for a while you will get less in SSDI benefits.

Applying for SSDI can be a kind of "game" that you can win if you follow the rules!

Of Sandals and Street Fairs

by Millie Malone

Summer is over, but this is the best time of year for a street fair here in Iowa. September and October are beautiful with cool mornings and evenings and warm temperatures during midday. However, I must warn those Able Bodied Persons who attend these street fairs. I will attend any and all accessible activities in my area. The streets may be blocked off to vehicular traffic, but my wheelchair will still be able to toodle all over the place. Therefore, do not wear sandals to a street fair in Denison, Iowa. There may be other places that also should be off limits to anything but steel toed work boots, but definitely take heed if you are going to be in Denison.

What brings me to this conclusion, you ask? Well, I attended the Tri-City Barbecue here a week ago and, while maneuvering my way through the crowds in an attempt to enter the supermarket, I inadvertently, really, I swear it was totally by accident, ran over a man's foot. In my defense, I completely forgot that my 180 lb. power chair, with its bright red and yellow seat cover, and containing my own not insubstantial and also gaudily clothed body, was invisible. I did not allow for that fact when the nice couple offered to make a path for me through the crowd. How was the sandal-wearing person to know that they were making the path for an invisible, though brightly colored wheelchair? So, of course, he barged right in front of me, sticking his stocking clad, sandal shod toesies right under my wheels. To our mutual chagrin, even invisible wheelchairs are quite heavy.

It seems that pain renders invisibility null and void. As he was howling in pain, he looked right at me and said, "Hey! You ran over my foot!" I apologized several times as he hopped up and down, holding his injured foot, but he appeared to remain unmollified. Had he been wearing the recommended steel toed work boots, he would not even have noticed, but sadly that was not the case. Perhaps, once his toenail grows back, he might consider wearing those boots.

I've thought about getting an airhorn to help me weave my way through crowds, but someone once told me that an unexpected airhorn coming from an invisible power chair could cause a heart attack. I wouldn't want that! Running over an entire prostrate person might tip my invisible chair over! Then where would we be? I am visualizing a herd of people trying to climb over a heap containing an invisible chair, an invisible woman, and possibly a very visible sandal-wearing man. Probably not, though. I'm pretty sure that I did enough damage that Mr. Sandal Man could be driving his own invisible chair for awhile. So sorry!

Web Corner

Report Identifies Game Changers for U.S. Health Care

http://www.nlm.nih.gov/medlineplus/news/fullstory_148528.html

First human polio virus clinical trial raises hope for curing cancer

<http://www.commdiginews.com/health-science/first-human-polio-virus-clinical-trial-raises-hope-for-curing-cancer-16188/#E3WFhaB8z5I3eqmZ.99>

Dr. Henry Writes More on Brain Fatigue

<http://postpoliolitaffac.wordpress.com/2014/09/18/dr-henry-writes-more-on-post-polio-brain-fatigue/>

Get a Medicare-Approved Wheelchair

<http://www.transfermaster.com/blog/view-post/Get-a-Medicare-Approved-Wheelchair>

DARPA is funding the development of a soft, fabric-based exoskeleton

<http://www.engadget.com/2014/09/12/darpa-harvard-soft-exosuit/>

Handling the Truth

<http://www.spinalcordinjury-paralysis.org/blogs/20/2259>

Potential 'solution' on polio vaccination being tested

<http://www.bbc.com/news/health-29218173>

City Council OKs 'Visitability' Rules; All New Homes Must Be Wheelchair Accessible

<http://kut.org/post/city-council-oks-visitability-rules-all-new-homes-must-be-wheelchair-accessible>

Post-Polio Internet Resources

<http://www.i-sites.net/ppsr/reslist.html>

FDR's Polio: The Steel in His Soul

<http://time.com/3340831/polio-fdr-roosevelt-burns/>

A Little Bit of Humor

The Bet

The strong young man at the construction site was bragging that he could outdo anyone in a feat of strength. He made a special case of making fun of one of the older workmen. After several minutes, the older worker had had enough.

"Why don't you put your money where your mouth is?" he said. "I will bet a week's wages that I can haul something in a wheelbarrow over to that building that you won't be able to wheel back."

"You're on, old man," the young guy replied.

The old man reached out and grabbed the wheelbarrow by the handles. Then he turned to the young man and said, "All right. Get in."