

PA Polio Survivors Network

Information and Inspiration for All Polio Survivors and Their Families *Serving the Keystone State and Beyond* www.polionetwork.org

February 2019

Our Mission:

To Be in Service Providing Information to Polio Survivors, Post Polio Support Groups, Survivor's Families and their Caregivers.

It's February, the month of hearts, love and here in the US, the celebration of our presidents.

A big part of the topic of love includes taking care of ourselves. As we find ourselves in the height of Flu season we found a fascinating article about the ability to improve our own immune systems. How can we do that? On the whole, our immune system does a remarkable job of defending us against disease. But sometimes it fails: A germ invades and makes us sick. Part 1 of our two part series from Harvard Health can help.

Another key to caring for ourselves is making our homes "safe" as we require more and more assistive devices. We have two articles that have outstanding information.

We like to cover some of our most frequently asked questions. AFM (acute flaccid myelitis) and it's heartbreaking similarities to Polio is coming up on a regular basis. We've had help from Richard L. Bruno, HD, PhD, a physician from NY Presbyterian Hospital and the CDC.

Speaking of Dr. Bruno, he goes right to the "heart" of the matter when it comes to Polio survivors and the need for Cardiac Rehabilitation. This article is the latest to be updated and added to the <u>Encyclopedia of Polio and PPS</u>.

This year, we celebrate President's month with a quote from July 26, 1990.

"Last year, we celebrated a victory of international freedom" (referencing the Berlin Wall). "And now I sign legislation which takes a sledgehammer to another wall, one which has for too many generations separated Americans with disabilities from the freedom they could glimpse, but not grasp. Once again, we rejoice as this barrier falls for claiming together we will not accept,

we will not excuse, we will not tolerate discrimination in America".

President George W. Bush

(as he signed the Americans with Disabilities Act)



Here's the answer to a fun question. WHY does February have 28 days ?

The Gregorian calendar's oldest ancestor, the first Roman calendar, had a glaring difference in structure from its later variants: it consisted of 10 months rather than 12. In order to fully sync the calendar with the lunar year, the Roman king Numa Pompilius

added January and February to the original 10 months. When he reorganized the calendar's dates to fit the new format, Numa tried to avoid having months that consisted of an even number of days, as Roman superstition held that even numbers were unlucky. But in order to reach the 355 days of the lunar year (354.367 to be exact, but he rounded up to keep it odd), 1 month out of the 12 needed to contain an even number of days. This is because of simple mathematical fact—the sum of any even amount of odd numbers will always equal an even number. So Numa chose February, a month that would be host to Roman rituals honoring the dead, as the unlucky month to consist of 28 days. From the Encylopedia Britannica

How To Boost Your Immune System

Helpful Ways to Strengthen Your Immune System and Fight Off Disease

What Can You do to Boost Your Immune System?

The idea of boosting your immunity is enticing, but the ability to do so has proved elusive for several reasons. The immune system is precisely that — a system, not a single entity. To function well, it requires balance and harmony. There is still much that researchers don't know about the intricacies and interconnectedness of the immune response. For now, there are no scientifically proven direct links between lifestyle and enhanced immune function.

But that doesn't mean the effects of lifestyle on the immune system aren't intriguing and shouldn't be studied. Researchers are exploring the effects of diet, exercise, age, psychological stress, and other factors on the immune response,

both in animals and in humans. In the meantime, general healthy-living strategies are a good way to start giving your immune system the upper hand.

Healthy Ways to Strengthen Your Immune System

Your first line of defense is to choose a healthy lifestyle. Following general good-health guidelines is the single best step you can take toward naturally keeping your immune system strong and healthy. Every part of your body, including your immune system, functions better when protected from environmental assaults and bolstered by healthy-living strategies such as these:

- Don't smoke.
- Eat a diet high in fruits and vegetables.
- Exercise regularly. *
- Maintain a healthy weight.
- If you drink alcohol, drink only in moderation.
- Get adequate sleep.
- · Take steps to avoid infection, such as washing your hands frequently and cooking meats thoroughly.
- Try to minimize stress.

Increase Immunity the Healthy Way

Many products on store shelves claim to boost or support immunity. But the concept of boosting immunity actually makes little sense scientifically. In fact, boosting the number of cells in your body — immune cells or others — is not necessarily a good thing. For example, athletes who engage in "blood doping" - pumping blood into their systems to boost their number of blood cells and enhance their performance — run the risk of strokes.

Attempting to boost the cells of your immune system is especially complicated because there are so many different kinds of cells in the immune system that respond to so many different microbes in so many ways. Which cells should you boost, and to what number? So far, scientists do not know the answer. What is known is that the body is continually generating immune cells. Certainly it produces many more lymphocytes than it can possibly use. The extra cells remove themselves through a natural process of cell death called apoptosis - some before they see any action, some after the battle is won. No one knows how many cells or what the best mix of cells the immune system needs to function at its optimum level. **Immune System and Age**

As we age, our immune response capability becomes reduced, which in turn contributes to more infections and more cancer. As life expectancy in developed countries has increased, so too has the incidence of age-related conditions.

How to Boost your Immune System (Part 1) continued

While some people age healthily, the conclusion of many studies is that, compared with younger people, the elderly are more likely to contract infectious diseases and, even more importantly, more likely to die from them. Respiratory infections, influenza, and particularly pneumonia are a leading cause of death in people over 65 worldwide. No one knows for sure why this happens, but some scientists observe that this increased risk correlates with a decrease in T cells, possibly from the thymus atrophying with age and producing fewer T cells to fight off infection. Whether this decrease in thymus function explains the drop in T cells or whether other changes play a role is not fully understood. Others are interested in whether the bone marrow becomes less efficient at producing the stem cells that give rise to the cells of the immune system.

A reduction in immune response to infections has been demonstrated by older people's response to vaccines. For example, studies of influenza vaccines have shown that for people over age 65, the vaccine is much less effective compared to healthy children (over age 2). But despite the reduction in efficacy, vaccinations for influenza and *S. pneumoniae* have significantly lowered the rates of sickness and death in older people when compared with no vaccination.

There appears to be a connection between nutrition and immunity in the elderly. A form of malnutrition that is surprisingly common even in affluent countries is known as "micronutrient malnutrition." Micronutrient malnutrition, in which a person is deficient in some essential vitamins and trace minerals that are obtained from or supplemented by diet, can be common in the elderly. Older people tend to eat less and often have less variety in their diets. One important question is whether dietary supplements may help older people maintain a healthier immune system. Older people should discuss this question with a physician who is well versed in geriatric nutrition, because while some dietary supplementation may be beneficial for older people, even small changes can have serious repercussions in this age group.

Diet and Your Immune System

Like any fighting force, the immune system army marches on its stomach. Healthy immune system warriors need good, regular nourishment. Scientists have long recognized that people who live in poverty and are malnourished are more vulnerable to infectious diseases. Whether the increased rate of disease is caused healthy immune system by malnutrition's effect on the immune system, however, is not certain. There are still relatively few studies of the effects of nutrition on the immune system of humans, and even fewer studies that tie the effects of nutrition directly to the development (versus the treatment) of diseases.

There is some evidence that various micronutrient deficiencies — for example, deficiencies of zinc, selenium, iron, copper, folic acid, and vitamins A, B6, C, and E — alter immune responses in animals, as measured in the test tube. However, the impact of these immune system changes on the health of animals is less clear, and the effect of similar deficiencies on the human immune response has yet to be assessed.

So what can you do? If you suspect your diet is not providing you with all your micronutrient needs — maybe, for instance, you don't like vegetables — taking a daily multivitamin and mineral supplement may bring other health benefits, beyond any possibly beneficial effects on the immune system. Taking mega doses of a single vitamin does *not*. More is not necessarily better.

*Note: The word "exercise" has a different meaning for every Polio survivor. Next month – Part 2. Supplements, Stress, Effects of the Cold and Exercise.



A Home Safety Checklist for Wheelchair Users

When adapting your home for a wheelchair user, it's imperative to

understand and anticipate the kind of challenges they face daily. It ranges from general movement through the house to maintaining personal hygiene, using the bathroom and the kitchen and handling objects such as knobs, light switches, and various equipment.

To make sure your home is safe for a family wheelchair user, tick the following items off of your safety checklist. **General Lavout**

Even if you can't knock down walls and change the original floor plan, there are still certain tweaks you can make to the general layout to make it more wheelchair-user-friendly.



Firstly, consider the doorways in your home. As the standard wheelchair footprint is 30x48in, doorways must be 32in wide at least and turning circles in the rooms must leave enough room for maneuvering the wheelchair on the spot, which is 60x60in.

Furthermore, tables and desks should be at the height of 28 to 32in and the typical knee clearance height under them should come somewhere between 27 and 29in. Finally, to have the outside home access wheelchair-friendly, maximum access ramp slope should be 1:12 and the general ground slope in aisles, driveways and parking spots 1:48.

Lighting

An aspect that's commonly overlooked in a wheelchair-friendly home is lighting, as it's generally designed for healthy individuals who can easily stand up and walk to reach and operate light switches and lamps. But, from the point of view of wheelchair users, light switches placed behind countertops or doors are too high and impossible to reach.

All hard-to-reach switches, such as those behind kitchen countertops or the ones higher than 44in, should be moved to the height of at least 36in. For a job like this, consider contacting a local emergency electrician who can also become your to-go-person in future, should any issue arise. Discuss with him changing to larger rocker switches, as they are much easier to use.

One lighting hack that can be beneficial to all household members, wheelchair users included, is navigational lighting. Modern LED lights can be conveniently placed at the base of floorboards in hallways, doorways, around handrails and door locks to minimize the struggle of finding switches in the dark.

Stairways and Corridors

Stairways are commonly the biggest issue for wheelchair users, whether they're indoors or outdoors. Make sure handrails are installed properly, capable of supporting user's full weight, with enough spacing from the wall to allow a full and firm hand grip and with extra length beyond the first and last step for additional support. Avoid using rugs, runners or mats as they can rise and wrinkle and cause slips and tripping hazards.

Kitchens and Bathrooms

Kitchens and bathrooms are particularly problematic for wheelchair users, so their design and layout must prioritize mobility and safety. The height of countertops, including ovens and burners in the kitchen, and vanities and sinks in the bathroom, should accommodate wheelchair armrests which are at a height of 29in. Also, most of these surfaces don't allow much space beneath them for a closer access, so it's necessary to plan a knee recess of about 30-32in wide. Lower cabinets can also be adjusted with pull-out shelves and racks and a hose attachment on the faucets makes washing much easier.

In bathrooms particularly, there should be enough handrails, seats and benches for support, curb less showers for easy entrance and exit, and flushes and fittings that are easily operated from a seated position. For additional safety, make sure if the wheelchair user has any reduction, Home Safety Checklist (continued)

in limb sensation so you might need to install anti-scald control in the shower and on taps. Fire Safety

With limited and slow mobility, wheelchair users need to be accommodated in cases of fire hazards. There should be a personal evacuation plan drawn up and precisely explained to the user and everyone in the household. There should also be a suitable fire exit cleared of any obstacles and clutter at all times.

With these considerations in mind, any wheelchair user will feel utterly comfortable, mobile and safe in their home.



Creating Accessible Homes

From HGTV

Entrances, bathrooms and kitchens create logistical and aesthetic challenges.

Retrofitting homes to provide ease and comfort for the disabled takes more than simply meeting accessibility standards. "You have to listen to your clients," says a co-owner of Curb Appeal Renovations in Fort Worth, Texas.

Curb Appeal recently renovated a home for a wheelchair-bound man who was 6'7" tall and his wife, who also was 6 feet tall. He uses a higher wheelchair and requires other adjustments to standards for typical disabled people. "You should follow the guidelines, but you have to meet their needs," he says.

Current standards, for instance, require 36-inch-wide doors, but remodelers consider those to be "knucklebusters," to use the term favored by an owner at T&L Design-Build in Canton, Ohio. He tries to create 42-inch-wide doorways to aid wheelchair users who pilot themselves.

"Exterior home entrances pose the first challenge for designers. Most stay away from the home's front, putting ramps at the rear or in the garage. But the required 1:12 slope ratio 'can take up an entire garage stall,' " He often uses reconditioned or used lifts, building a 4.5-footsquare platform for maneuvering. The President of Gehman Custom Builder Inc. in Harleysville, Pa., typically creates L-shaped ramps to compress the needed space. "Each one is really custom," he says. Landscaping often helps the ramps blend with the home's exterior.

Bathrooms create the largest challenge, as they typically are small spaces that lack maneuvering room. "We try to expand the bathroom into an adjacent room or create a new bath from a spare room," Gehman says. "Curbless" showers that allow wheelchairs to roll right into them are popular for these spaces. The President of Home Tech Renovations in Philadelphia, sometimes notches the existing floor joists to slope the shower correctly.

In kitchens, removing floor cabinets around sinks and installing plumbing pipes tight against the back wall can allow wheelchair users to roll up to the sink. Setting sinks and other countertops at 30 inches rather than 36 also aids disabled cooks.

The key challenge for remodelers is that homeowners want a look that is functional but also aesthetically pleasing. "When they have to sell their home, they don't want to sell it as having a handicapped bathroom but as having a very nice, high-end, larger bath." That can be achieved by placing half-walls rather than bars around the toilet and installing thin but sturdy rails that resemble towel racks. Curb Appeal often uses the curbless shower base but installs it with cultured marble or ceramic tile walls "so it doesn't look like a barrier-free shower."

Designers expect that this type of work will grow and product lines are expanding to accommodate that growth. The need will become particularly great as aging baby boomers look to remain in their homes or see their own parents move in with them. "Some are finding that it's cheaper to remodel the home to fit their needs than to move into a nursing home". For more tips and requirements for designing for disabled homeowners, visit the <u>Americans with</u> Disabilities Act website.

(This article was abbreviated from the original). https://www.hgtv.com/remodel/interior-remodel/creating-accessible-homes





Cardiac Rehabilitation: Should Polio Survivors Just Say No?

Richard L. Bruno, HD, PhD.

Director, International Centre for Polio Education www.postpolioinfo.com

Let me begin with the conclusion: in nearly 37 years of evaluating, treating and studying polio survivors I have never seen one who has had a heart attack, heart bypass surgery or heart failure who has 1) been able to do exercise required for cardiac rehabilitation or 2) suffered as a result of their inability to do cardiac rehabilitation.

Cardiac rehabilitation exercises the heart muscle and the "skeletal" (limb and diaphragm) muscles. The purpose is not only to exercise the heart but also to exercise skeletal muscles in order to treat "muscle deconditioning" to improve muscle strength and endurance and to reduce fatigue and shortness of breath.

First, polio survivors muscle weakness is not due to deconditioning or muscle atrophy but results from a reduced number of remaining, poliovirus-damaged neurons losing their ability to function as a result of failure from decades of overuse. Adding cardiac rehabilitation exercise -- swimming, trying to work out on a treadmill, exercise bicycle or upper extremity exercise "bike" – on top of the overuse polio survivors experience just doing their daily activities will decrease muscle strength and endurance. Second, polio survivors' reduced muscle strength and endurance makes it nearly impossible for them to raise their heart rate into the "cardiac conditioning zone" and keep it there.

There are few studies of heart exercise in polio survivors. In one, polio survivors did five minutes of bicycle exercise followed by a 60-minute exercise class twice a week for 5 months. (Obviously any polio survivor who was able to do five minutes of bicycle exercise followed by a 60-minute exercise class twice a week for 5 months did not have Post-Polio muscle weakness or fatigue and did not have PPS!) In this torturous study, polio survivors' legs became 4% weaker while their maximum heart rate during exercise increased only by 12 beats per minute. This study demonstrates the trade-off: there is no benefit to exercising your heart slightly if you thereby stress and kill off poliovirus-damaged motor neurons.

All that being said, it's important to note that cardiac rehabilitation is not just exercise. It involves working with your doctor and a nutritionist to use medication and diet to manage cholesterol and weight, reduce blood pressure, eliminate smoking and, perhaps most important, reduce stress!

So, talk to your doctor about "Conserving to Preserve" your remaining, poliovirus-damaged neurons to treat PPS, at the same time helping your heart be the best pump it can be.

A "Bruno Byte" on the Topic of AFM and the Polio Virus (10/5/2018)

Dr. Bruno's Original Post: AFM is not, NOT the Polio Virus! From the CDC:

- CDC is concerned about AFM, a serious condition that causes weakness in the arms or legs.
- From August 2014 through October 2018, CDC has received information on a total of 396 confirmed cases of AFM across the US; most of the cases have occurred in children.
- Even with an increase in cases since 2014, AFM remains a very rare condition. Less than one in a million people in the United States get AFM each year.
- While we don't know the cause of most of the AFM cases, it's always important to practice disease prevention steps, such as staying up-to-date on vaccines, washing your hands, and protecting yourself from mosquito bites.

Additional Post: I understand that it's not the Poliovirus but is it a similar enterovirus? Dr. Bruno's Response: The polioviruses are only three of more than 10 enteroviruses, the majority of which can cause symptoms identical to polio. It's still unclear which viruses cause acute flaccid paralysis in the United States but it could be several. Remember there are 60,000 cases of non-polio enterovirus paralysis in India every year caused by several different non-polioviruses.

Additional post: I wonder if these kids were vaccinated for Polio?

Dr. Bruno's Response: Since the cause isn't the poliovirus I wouldn't think the polio vaccine would be an issue. The vaccines are *very* specific to the virus.

<u>The Encyclopedia of Polio and Post-Polio Sequelae</u> contains *all* of Dr. Bruno's updated articles, monographs, commentaries, videos and "Bruno Bytes" https://www.polionetwork.org/encyclopedia



Mysterious Polio-like Virus also Causes Neurological Symptoms

By Keith Roach, M.D. Nov 19, 2018

DEAR DR. ROACH: I am reading about an illness called acute flaccid myelitis that is baffling scientists. Isn't this just polio renamed? -- V.A.

ANSWER: Acute flaccid myelitis is indeed a medical mystery. The current outbreak absolutely is **not** caused by polio, however. Many people are referring to it as "polio-like" because it causes sudden neurological symptoms, especially weakness and especially in young children, just as polio did before the vaccine was adopted. However, the diagnosis of polio requires finding poliovirus, and the people affected in the current outbreak have been tested for, and do not have, poliovirus. The last case of polio originating in the United States was in 1979.

Vaccination for polio is still important, however, because it potentially can be brought by a traveler from one of the few areas where there Is still wild polio.

There have been outbreaks of acute flaccid myelitis in the United States and Canada every fall for years; however, it seems to be increasing in incidence since 2014. It remains a rare disease, on the order of one person per million per year.

There is a virus related to poliovirus called enterovirus D68 that is suspected to be one of several causes of acute flaccid myelitis. West Nile Virus is another suspected cause. The Centers for Disease Control and Prevention tests samples from affected children with the condition and has not consistently found a single cause.

There is no specific treatment for AFM, just as there is no treatment for polio when it affects the nerves.

Supportive treatment in the early phase, and physical and occupational therapy during convalescence are the only accepted treatments. The prognosis is variable, with some children having excellent recoveries and others having more significant neurological impairment.

https://www.arcamax.com/healthandspirit /health/keithroach/s-2146022





Once Again, We Have an Opportunity to Become Part of the Solution.



AFM/Polio Study

This outstanding Study at Johns Hopkins is still looking to increase the number of Polio survivors who participate.

The feedback we've had from Polio survivors who have participated has all been good. Participation is easily accomplished and both Dr. Duggal and her Research Assistant are lovely to work with. It is NOT necessary for you to be online.

Objective: We are trying to understand why some people get better quickly after an infection and others may have breathing problems, and still others may have neurologic symptoms or paralysis. We would like to compare the cells and DNA of persons with severe symptoms with those who may have been exposed to the same virus, but did not have the same severe outcomes.

Participation: Saliva sample and brief questionnaire

Contact information for those interested:

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"I can see why they made February the shortest month of the year."

For those of us in the US, here's some fun Presidential Trivia

John F. Kennedy was the first president to hold a press conference on TV.

William McKinley was the first president to campaign by telephone.



"Man, Abe Lincoln's team must have been pretty bad! They only had four scores in seven years!"

George Washington was the only American president to be unanimously elected.

Franklin Pierce was the first president to have a Christmas tree in the White House.

John Adams and Thomas Jefferson both died on the 50th Anniversary of the Declaration of Independence in 1826.

Franklin Pierce gave his 3,319-word inaugural address from memory, without the aid of notes.

To set a good example for the country Rutherford B. Hayes banished liquor and wine from the White House. Because of the ban, his wife was known as "Lemonade Lucy."



We are truly grateful for your kind words of support.

Your generous <u>donations</u> are the key to helping our work continue.



Do you have a topic you would like us to cover? Please let us know. Always feel free to contact us.

<u>The Polio Network Team</u>

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