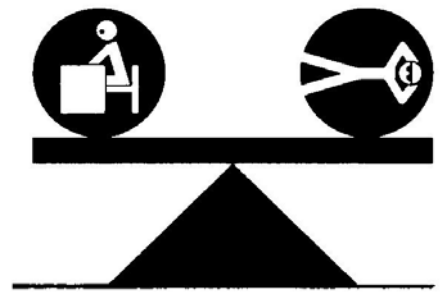


POST POLIO PACER

Conserving Strength and Energy through Pacing
April 2009 — Madison, Wisconsin
Madison Area Post Polio Support Group Newsletter



Shingles Vaccination: Should Polio Survivors Receive One?

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When polio survivors began asking about the shingles vaccination, PHI polled 19 doctors (experienced in treating polio survivors) for their recommendations. No conclusion could be drawn from their varied responses. Also, currently there is no experimental data regarding whether or not polio survivors should get this vaccine. Therefore, the most prudent thing to do is to study available information, talk with your physician about your individual circumstances, and then make your own decision.

The Vaccine: In 2006, a vaccine called ZOSTAVAX® was licensed to prevent shingles in people over age 60. In the clinical trial, the vaccine was successful in 51% of the participants 60 and older, and was most effective in those aged 60 to 69. Shingles-related pain was also reduced in many of those receiving the vaccine.

Precautions: The Centers for Disease Control and Prevention (CDC) says those who should not get this vaccine are people who

have had a life-threatening allergic reaction to gelatin, the antibiotic neomycin, or any other component of the shingles vaccine. The CDC advises those who have severe allergies to inform their doctor when considering the vaccine.

Because the shingles vaccine contains the live though weakened chickenpox virus, the CDC does not recommend the vaccine for individuals with the following: a weakened immune system due to HIV/AIDS or another disease that affects the immune system; a history of cancer affecting the bone marrow or lymphatic system, such as leukemia or lymphoma; treatment that affects the immune system, such as steroids for organ transplants, or radiation/chemotherapy for cancer; and active untreated tuberculosis.

Individuals who are moderately or severely ill (including those with a temperature of 101.3° or higher) should wait to get their vaccine until they are well.

The Disease: Approximately one million cases of shingles (also known as herpes zoster) occur in the United States each year, generally in people over age 50. Varicella-zoster virus (VZV), the same virus that causes chickenpox, causes shingles. Anyone who had chickenpox is at risk for shingles because the chickenpox virus remains in the nervous system for the rest of one's life. Certain circumstances, such as stress or immune deficiency, can cause the virus to reactivate and move back down the nerve fibers to

Consult your personal physician about receiving a shingles immunization and to be sure that you have received all of your adult shots.

the skin, causing the rash of blisters that is the hallmark of shingles.

Shingles may begin as a sensitive or burning feeling in the skin that turns to a rash, usually down a certain nerve on one area and one side of the body. Shingles blisters then form for a number of days before they pop and finally crust over and heal. The entire process can take several weeks.

Symptoms and Complications: Fever, chills, upset stomach and headache can indicate shingles. Very rarely, shingles can result in pneumonia, hearing difficulties, blindness, encephalitis or death. A common complication of shingles is nerve pain. When this pain continues for more than a month, it's known as postherpetic neuralgia, which occurs in more than 40% of those over 60 who have had shingles. This can be devastating. In some cases, certain medications may be used to alleviate the situation.

Interesting Facts: People who have had shingles can get it again. Only people who had chickenpox or chickenpox vaccine can get shingles; the chickenpox virus stays in the body forever. Shingles is not contagious. However, a person who never had chickenpox or the chickenpox vaccine can get chickenpox from someone with shingles.

Cost: The cost of the vaccine ranges between \$195 and \$220, and it is covered by most private insurers. In one area of the US, the vaccine is administered in pharmacies for a cash fee of \$220. Plan D picks up from \$25 to the full amount, depending on the coverage one has chosen. Medicare itself won't pay for the vaccine, though it will pay a \$20 administration fee. Getting the best price may take a few phone calls in each separate locality.

ZOSTAVAX® (Zoster Vaccine Live) is a registered trademark of Merck & Co., Inc.

Wise Choices

Feeling Better with Shingles

See your doctor at the first sign of shingles. It often begins as burning or shooting pain and tingling or itching on one side of the body, followed by a blistering rash. Early treatment can help shorten the length of infection and reduce the risk of other problems.

Your doctor may prescribe:

Antiviral drugs to help kill the varicella-zoster virus.

Steroids to lessen pain and shorten the time you're sick.

Antidepressants, anticonvulsants or analgesics to reduce pain.

Things you can do:

Get enough rest and eat well-balanced meals.

Try to relax. Stress can make the pain worse.

Dip a washcloth in cool water and apply it to your blisters to ease the pain.

Do things that take your mind off your pain. Watch TV, read books, talk with friends, or work on a hobby.

Source: NIH News in Health

Resources

NINDS Shingles Information Page

www.ninds.nih.gov/disorders/shingles/shingles.htm

Centers for Disease Control and Prevention (CDC)

1600 Clifton Rd., Atlanta, GA 30333 USA

Public Inquiries:

404-498-1515 / 800-311-3435

Shingles Vaccine; What You Need to Know

www.cdc.gov/vaccines/pubs/vis/downloads/vis-shingles.pdf

Eradication of Polio

By Carole Ann Parsons

Reporter for the Post Polio Pacer

The majority of younger individuals in the non-medical world are unaware of Poliomyelitis—a disastrous virus that attacks the central nervous system resulting in acute paralysis. Most people, in general, do not know that three forms of the Polio-virus exist. Those forms are Spinal Polio, Bulbar Polio, and Bulbospinal Polio (respiratory).

Why has this virus become so unknown when almost 60 years ago it threatened, horrified, killed and disabled thousands of our children, teenagers and even adults? The most significant reasons are Dr. Jonas Salk (1952) and Dr. Albert Sabin (1962) who developed the Polio vaccines which protected most of America's people and eliminated the majority of this dreaded virus. The statistics: hundreds of thousand cases were decreased to just hundreds.

Unfortunately, the Third World Countries have been devastated for multiple years by outbreaks of polio as a result of governmental economic impoverishment. Miraculously, an eight country vaccination campaign began in Africa on February 2009. More than 53 million children were immunized in Nigeria and seven of its bordering countries. An acute outbreak of wild poliovirus type 1 in Sudan has created a critical risk of international dissemination. Initially the virus was confined to Southern Sudan and Western Ethiopia: however, now it has spread to Kenya, Uganda and Northern Sudan. Active, urgent measures have been taken to eradicate polio from the continent of Africa.

Thank heavens; the polio virus will be finally eradicated someday soon.

Information derived from:

[Disability World](#)

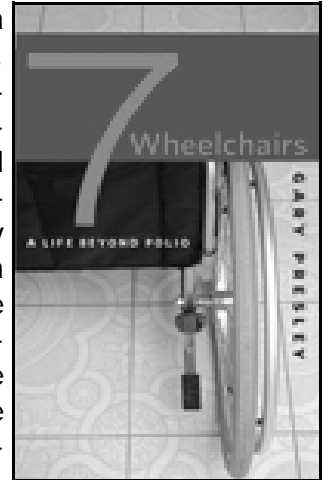
[World Health Organization](#)

The Book Shelf

Seven Wheelchairs by Gary Presley

Below are several authors' impressions of this book.

"*Seven Wheelchairs* is a compelling account of one man's struggle to learn to live well with a significant disability. Presley's memoir powerfully recounts the physical and psychological challenges he faced during his long recovery from polio. It is also a moving story of how the love and care of his parents and later his wife helped him enjoy life seated in his wheelchairs."— Dan Wilson, author, *Living with Polio: The Epidemic and Its Survivors*.



"Alternating between sardonic and blunt, Gary Presley maps out an almost-fifty-year trek from infantile paralysis to post-polio syndrome to bonding with his power chair, Little Red; from helpless, passive cripple to defiant Gimp. Presley was paralyzed in the worst possible stage of life—late adolescence—in the 1960s when people like him were pitied and scorned, and he survived with his spirit strong and his lust for life intact. Read this unvarnished account of life at 'boob high,' and walk away with a new definition of 'disabled.'"— Allen Rucker, author, *The Best Seat in the House: How I Woke Up One Day and Was Paralyzed for Life*.

"Although Gary Presley is unable to move or breathe without assistance, his life literally jumps off these pages as he shares with us in painful, powerful, and poetic detail how he has found a lifetime of joy through one hard-earned, courageous breath at a time."— Susan Parker, author, *Tumbling After: Pedaling Like Crazy after Life Goes Downhill*.

"The tragic irony that caused paralysis in Gary Presley at age seventeen, just as he approached the cusp of adulthood, went on to flavor his bittersweet view of life, temper his rage at the injustice of his fate, gladden his heart toward his wife, Belinda, and, most fortunately for his readers, provide him with the time, insight, and humanity that enabled him to write this searing but ultimately loving memoir. It's a story so biting honest that Presley's readers sometimes cringe before turning the page, but so extremely well written that we keep turning page after page after page—not only for the gripping story but also for the beauty of the prose."—Peggy Vincent, author, *Baby Catcher: Chronicles of a Modern Midwife*.

In 1959, seventeen-year-old Gary Presley was standing in line, wearing his favorite cowboy boots and waiting for his final inoculation of Salk vaccine. Seven days later, a bad headache caused him to skip basketball practice, tell his dad that he was too ill to feed the calves, and walk from barn to bed with shaky, dizzying steps. He never walked again. By the next day, burning with the fever of polio, he was fastened into the claustrophobic cocoon of the iron lung that would be his home for the next three months. Set among the hard-scrabble world of the Missouri Ozarks, sizzling with sarcasm and acerbic wit, his memoir tells the story of his journey from the iron lung to life in a wheelchair.

Presley is no wheelchair hero, no inspiring figure preaching patience and gratitude. An army brat turned farm kid, newly arrived in a conservative rural community, he was immobilized before he could take the next step toward adulthood. Prevented, literally, from taking that next step, he became cranky and crabby, anxious and alienated, a rolling responsibility crippled not just by polio but by anger and depression, "a cripple all over, starting with the brain." Slowly, however, despite the limitations of navigating in a world before the Americans with Disabilities Act, he builds an independent life.

Now, almost fifty years later, having worn out wheelchair after wheelchair, survived post-polio syndrome, and married the woman of his dreams, Gary has redefined himself as Gimp, more ready to act out than to speak up, ironic, perceptive, still cranky and intolerant but more accepting, more able to find joy in his family and his new found religion. Despite the fact that he detests pity, can spot condescension from miles away, and refuses to play the role of noble victim, he writes in a way that elicits sympathy and understanding and laughter. By giving his readers the unromantic truth about life in a wheelchair, he escapes stereotypes about people with disabilities and moves toward a place where every individual is irreplaceable.

Gary Presley was born in 1942 in Long Beach, California; he now lives and writes in Springfield, Missouri. Between 1965 and 2000 he worked in insurance sales and commercial radio. His essays published in the Springfield News-Leader, Ozark Mountaineer, Missouri Review, Salon.com, Notre Dame Magazine, and New Mobility.

<http://www.uipress.uiowa.edu/books/2008-fall/presley.htm>

Editor's note: Not only does *Seven Wheelchairs* look like a good read, there are four other books to peruse. Use the website above for purchase information for *Seven Wheelchairs*.

POST-POLIO SUPPORT GROUP MEETINGS

The Post Polio Resource Group of Southeastern WI meetings are held at the Easter Seals Kindcare Recreation Center located in Holler Park at 5151 S. 6th St., midway between Grange & Layton Ave., Milwaukee (just north of the Airport Spur). Social time from 1:00 to 1:30 pm.; meeting from 1:30 to 3:30 pm.

April 18: This is a Laughing Matter—Diane Kane

May 16: The History of Polio and Post-Polio -Dr. Jeffery S. Cameron, M.D., Physical Medicine & Rehabilitation, Columbia-St. Mary's Hospitals.

Check the PPRG website <www.pprg.org> for program details.

Madison Area Post Polio Support Group

Saturday, May 9 there will be an open discussion and an opportunity to provide questions you would like to have answered by Holly Jellinek, Ph.D, Licensed Psychologist at the July meeting. Her topic on **Saturday July 11** will focus on "Living with Post Polio with Good Mental Health".

The **Janesville Post Polio Support Group** meets from 1-3 p.m. at the Mercy Health Mall, 1010 N. Washington St., Janesville, WI on the first Friday of May, June, August, October and Nov. Contact Art Arnold at UncleBunks@aol.com if you wish information on speakers.

The Western Wisconsin Post-Polio Resource Group will meet on April 18 for "open discussion" from 12:30 to 3:30 at the Tri-County Memorial Hospital Community Room, Whitehall, WI. For more information call Betty Marsolek at 715-985-3801 or e-mail at bmarsolek@trivest.net

Editor's Note: If other Post-Polio Support Groups within Wisconsin would like publicity about your group, please send me an e-mail with meeting site, dates, speaker's name and topic.

F.Y.I.

Need to conserve your energy? Check out the blog at www.graceryoung.com. Grace R. Young, MA, OTR/L, a polio survivor and a retired occupational therapist, writes about various topics relating to living with a disability.

Post Polio Health 10th International Conference, April 23 to 25, will be held in Warm Springs, GA. Information about the 3 day program, registration form & options for lodging & transportation are online at www.post-polio.org. Also there are pictures of the facilities & grounds of the Roosevelt Warm Springs Institute for Rehabilitation, site of the conference.

Thoughts about Food

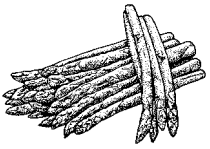
Editor's note: Susan Smith Jones, Ph.D., of the American Holistic Health Association provides much information about using food as medicine in this four page online article. This is part 1 of the article, with other parts to follow in subsequent issues.

Nature encourages health and balance. In nature's splendor we find all of the food we need to radiate with a healthy glow. While the foods we eat are only one aspect of being healthy, diet is definitely an important part. Studies reveal that eight of the ten leading causes of death in North America are directly related to diet. That's a sobering statistic and yet we are all responsible for the foods we eat. Nobody shoves the food down our throats. Many of us make the wrong food choices every day by consuming foods that were never intended for our body and contribute to most common major diseases.

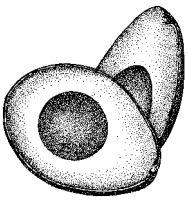
This article is about how to use food as medicine - to make the best food choices to reduce your risks of heart disease, hypertension, diabetes, obesity, Alzheimer's, arthritis, common forms of cancer, premature aging, vision problems and mental dysfunction, and offer ways to increase your energy, vitality and a sense of empowerment over your body and life.



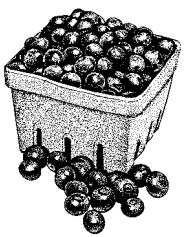
Almonds - What can be easier to snack on when you're hungry and on the go? Two ounces, or about 40 almonds, give you more than 50 percent of your daily requirement of magnesium, a mineral that's important for heart health. Almonds are also a good source of calcium, vitamin E, potassium, folate (the plant form of folic acid), fiber and monosaturated fat, all heart-healthy nutrients. In 2002, a study published in *Circulation* found that after eating about 2 ½ ounces of almonds a day for one month, participants had significantly reduced their total cholesterol and lowered several other risk factors for heart disease as well.



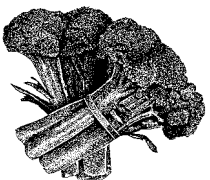
Asparagus - A superior alkalizing vegetable, asparagus has the ability to quickly change the pH of the body as evidenced by how rapidly you can smell it in your urine after you eat it. The odor is the result of asparagus changing the body chemistry and eliminating wastes while it breaks down its constituents of nitrogen, sulphur and ammonia. Just 20 calories in six spears, asparagus is a good source of folate, beta carotene and potassium. Asparagus is also a powerful antioxidant. Antioxidants are substances that knock out free radicals, thus affording cellular protection.



Avocados - Often referred to as nature's butter, avocados are rich in phytochemicals. They have about a quarter of the calories of total fat of dairy butter, by weight. And ounce for ounce, they provide more heart-healthy monosaturated fat, vitamin E, folate, potassium and fiber than other fruits. Yes, it is a fruit. Avocados contain the antioxidant glutathione and are the number one fruit source of the cholesterol-lowering phytosterol. Evidence suggests that these valuable subnutrients may help prevent certain types of cancers and heart disease.



Blueberries - Known as an excellent laxative, blood cleanser and antioxidant, blueberries are the only food that has been shown to not just prevent, but also actually reverse abnormal physical and mental decline. Despite their small size, one cup of blueberries contains only 80 calories. Referred to as the "brain berry," blueberries are packed with red pigments that have been linked to prevention – and even reversal - of age-related mental decline and anti-cancer effects.



Broccoli - A supreme superfood, broccoli has been proven effective as a food medicine against cancer, heart disease and a host of other serious con-

ditions. First it destroys any carcinogenic compounds that you've ingested, and then it creates enzymes that eat up any carcinogens left over from that reaction. It's also a good source of beta carotene, calcium, magnesium, vitamin B-3, vitamin B-5, vitamin C, potassium, folate, chlorophyll and fiber.



Cantaloupe - Cantaloupe is an excellent cleanser and rehydrator because of its high water content. Like all melons, for maximum benefit, eat cantaloupe alone. This beautiful fruit has lots of zinc, which is important for the prostate gland. It's also a powerhouse of potassium with 1/4 cantaloupe providing 1/4 of your daily potassium requirements!



Chili Peppers - Chilies-or hot peppers-add spice and interest to many foods. Chilies raise your endorphin level and are a cornucopia of nutrients, including beta carotene and vitamin C. In fact, chilies are so rich in vitamin C that they have been used as natural remedies for colds, coughs, bronchitis and sinusitis around the globe.

Cinnamon - Cinnamon is a highly versatile flavoring as well as a carminative that relieves bloating and gas. Adding cinnamon to food, especially to sugary ones, helps normalize blood sugar by making insulin more sensitive. So find ways to add cinnamon to sweet foods such as fresh fruit.

Coconut - Coconut butter (also referred to as coconut oil) is a raw saturated fat containing mostly medium-chain fatty acids, which the body can metabolize efficiently and convert to energy quickly. Added regularly to a balanced diet, it may help lower cholesterol by promoting its conversion into pregnenolone, the precursor to many hormones, including progesterone. Rich in magnesium, potassium, zinc, folate and vitamin C, coconut also helps regulate thyroid function.

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We **need** people to bring new ideas for speakers, topics, books to read and discuss, etc. Call or e-mail (see e-mail list) one of the people listed above to suggest program topics or speakers, volunteer to organize one meeting program, share your knowledge (or find an expert) about becoming a non-profit organization or volunteer your talents (financial, organizing, etc.) as a committee member.

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Names in bold are new to the list or have an address change. Welcome Robert & Joyce Montgomery.

To add your name and/or up-date your e-mail address to this list, notify Marcia Holman at: wghmch@chorus.net

POST POLIO PACER is a quarterly newsletter published in January, April, July & October for polio survivors, the Madison Area Post Polio Support Group, health care professionals and interested persons to share information and to promote friendships. Articles in this newsletter are for information; medical advice is always necessary.

Disclaimer: The opinions expressed in this publication are those of the individual writers and do not imply endorsement by Easter Seals Wisconsin or the Madison Area Post Polio Support Group





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A NEWSLETTER FROM THE MADISON-AREA POST POLIO SUPPORT GROUP

Mark your calendars!

LOCATION:

Monona Garden Family Restaurant
6501 Bridge Rd., Monona
Noon to 2:30

Saturday, May 9, 2009—Open discussion

Questions, comments & topics pertinent to PP survivors & family members are welcome.

We are also soliciting topics/questions you wish Dr. Holly Jellinek to discuss in July. Suggestions will be provided to her to aid in her presentation.

Saturday, July 11, 2009

**Holly Jellinek, Ph.D.,
Licensed Psychologist**

**“Living with PP with Good Mental
Health”**

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