

POLIO DEJA VIEW

Central Virginia Post-Polio Support Group

www.cvppsg.org

October - November 2004

Carol T. Ranelli, Editor

October 2nd Meeting

2:00 pm at Children's Hospital, 2924 Brook Road, Richmond

We will discuss **Dr. Lauro Halstead's comments from the Annual Retreat**

and have a **BROWN BAG AUCTION** to support the Social Committee's cost for the Christmas luncheon. Please bring an item in a brown bag along with a "clue" as to its contents.

November 13th Meeting

PLEASE NOTE: Due to the "Teddy Bear Run" held at Children's Hospital on the first Sat., which gives us limited parking, we will meet on the second Saturday in November.

2:00 pm at Children's Hospital, 2924 Brook Road, Richmond

Our speaker will be Shawne Soper, PT, MBA

She will discuss Adaptable Home Designs as well as having an in-home assessment for making adaptations to your home for safety and convenience

Mark your calendars for our annual Christmas get together.

December 4th !!

More information in the next newsletter.

Join us for our Mid-Month Luncheon Get Togethers

Wednesday, **October 13th** at 11:30 we will meet at **The Cheesecake Factory at Stony Point Fashion Park**. This is located on the north side of the mall facing Chippenham Parkway and next to Dillard's.

Please call Linda VanAken no later than Monday, October 11th to make a reservation: 778-7891

Wednesday, **November 3rd** at 11:30 we will meet **at Crab Louie's Seafood Tavern** in Sycamore Square in the Village of Midlothian
(mid-month is too close to our Nov. 13th meeting and Thanksgiving)

Please call Carol Ranelli no later than Nov. 1st to make a reservation: 794-7359

AGING GRACEFULLY

"Aging Gracefully May be Life Extending," ran a Reuters headline in July 2002, referring to results of a research study. But can the concepts of "aging" and "grace" really be combined? They can be indeed!

With age comes the benefits of wisdom and clear perspective. These gifts, if appreciated, can contribute much to family and community. Yet, aging "gracefully" is not always easy. Even while acknowledging that they have arrived at a stage in life when chronic disorders may multiply and health is more fragile, older adults must learn to discard the negative stereotypes of old age and relearn what it means to age in America. No one doubts that this may require deep resources of courage and patience.

However, many of America's mature citizens already have discovered strategies for graceful aging. Foremost is the old favorite: "positive thinking."

Researchers have noticed that individuals with strong spirituality tend to live longer as well as have healthier habits and better overall health. The particular study that inspired the Reuters headline quoted above was led by Dr. Becca R. Levy of Yale University. It focused on 660 adults ages 50 and older from an Ohio town. In 1975, participants were asked to respond to various statements such as, "As you get older, you are less useful" and "Things keep getting worse as I get older." Then, 23 years later, their attitudes (based on those same questions) were compared with their longevity. Dr. Levy and her team found that the adults who showed positive self-perceptions toward aging had a distinct survival advantage, living an average of 7.5 years longer than others.

Their longer survival did not seem to depend on any other factor (age, sex, socioeconomic status, loneliness, or health).

This study seems to confirm the link between health and attitude, body and mind – a link that today has become accepted in many medical school curricula.

One of the most inspiring examples of positive mind/body self-healing is that of Norman Cousins, editor of the *Saturday Review of Literature*, who showed that taking charge and using humor as medicine could actually conquer disease. He was way ahead of the medical schools, which were at a loss in finding the connection between the body and mind in the healing process. But in 1964, he was diagnosed with ankylosing spondylitis, a highly painful, crippling condition that causes disintegration of spinal connective tissue. He wrote in his book, *Anatomy of an Illness*, that he became aware that hospital life was depressing him. So he checked himself out, moved into a hotel where the food was decent and watched funny movies. He hired a nurse who read him humorous stories. He discovered that laughter has the power to conquer pain; 15 minutes of laughter could guarantee him 2 hours of pain-free sleep. He also followed a regimen of high-dose vitamin C. Finally to the amazement of his doctors, Cousins reversed a supposedly irreversible disease. "I have learned," he wrote, "never to underestimate the capacity of the human mind and body to regenerate – even when the prospects seem most wretched."

Despite the changes that growing older entails, staying as active and involved as possible are key to staying positive and maintaining your health. The end result is a rewarding life in harmony with others, in short, aging gracefully.

Reprinted from PPSG Chronicles, Bethlehem, P.A, Volume II, No. 2, June 2004

Reprinted from the July-August, 2004 Central Florida PPSG Newsletter

EATSMART By Jean Carper

Ten Best Nutritional Points

Every meal can easily include several points on this no-nonsense list.

Details about specific nutrients are fascinating. But in tracking down the fine points, don't lose sight of the big picture. Here are 10 solid, sweeping actions that will get you the best nutrition bank in 2004.

☐ **Eat seven to nine servings of fruits and vegetables a day.** Antioxidant-packed, they can cut your risk of heart disease up to 70%, diabetes 40%, lung cancer 30% and breast cancer 20%, studies show. Tops in antioxidants: prunes, raisins, blueberries, blackberries, garlic, kale, cranberries, raspberries, strawberries, spinach.

☐ **Eat fatty fish two or three times a week.** That provides enough omega-3 fat to help prevent heart disease, arthritis and brain dysfunction. Fish oil protects brain cells, and suppresses inflammation and irregular heartbeats. In a new study, eating fish just once a week cut the risk of Alzheimer's disease 60%. Best: salmon, sardines (fresh and canned), mackerel, herring.

☐ **Restrict red meat to once or twice a week.** Recent evidence ties red meat (beef, pork, veal, lamb) to increased cancer of the colon, pancreas, breast, prostate and kidney. Reason: Carcinogens form in meat during cooking. Worst methods: frying, barbecuing. Best: baking, stewing, boiling, microwaving.

☐ **Eat 25 grams of fiber a day.** Most adults eat less than half that. Fiber lowers cholesterol and blood pressure; cuts the risk of heart disease, diabetes and cancer; and helps control weight. Super sources: All-Bran, Fiber One, oat-bran cereals (check labels), dried beans, barley.

☐ **Use olive oil primarily; avoid trans fats.** Olive oil is the main choice of people who live the longest and have the least heart disease, cancer and other chronic diseases. Deadliest: trans fats in some margarines and baked goods, such as doughnuts – they clog arteries more than saturated animal fats do.

☐ **Eat "good" carbs.** Slash "whites" – bread, sugar, potatoes – that cause rapid spikes in blood sugar. Such foods can double your odds of heart attack, diabetes and certain cancers, and make you fat. Eat carbs that produce a slow rise in blood sugar. Best: legumes (including peanuts); whole-grain, high-fiber breads and cereals; fruits and vegetables.

☐ **Drink three or more cups of tea a day.** "Real" tea (not herbal) helps save you from heart disease, cancer, osteoporosis, infection, age-related mental decline, dental cavities and weight gain. In one study, three cups a day cut the risk of heart attack 11%. Brewed caffeinated green tea has the most antioxidants; bottled and instant teas have the least.

☐ **Eat nuts every day.** A mere 3/4 ounce of nuts (almonds, walnuts, pecans, peanuts) daily slashed the risk of heart disease and diabetes 30% and Parkinson's disease 43% in Harvard studies. Daily consumption of nuts and peanuts, including peanut butter, helped control weight in other research.

□ **Shave portions by one-third to half.** Gigantic portions are a major cause of weight gain and obesity. In studies, adults given a large serving ate 30% more calories than when given a small one. Kids, too, devoured 25% more calories when served oversized portions. If it isn't on the plate, you aren't tempted.

□ **Take a daily multivitamin/mineral pill.** It can erase subtle deficiencies that make you more prone to infections and chronic diseases, including cardiovascular disease, cancer and bone fractures. Many leading authorities now urge all adults to take a daily supplement.

Contributing Editor Jean Carper is a nutrition authority. Contact her or sign up for a free e-mail newsletter at JeanCarper.com.

**Too Many People Ignore Chronic Pain:
Pain Medication, Physical Therapy, Better Coping Skills All Help Ease Pain
By Jeanie Lerche Davis**

Reviewed By Michael Smith, MD on Thursday, May 06, 2004 WebMD Medical News

May 6, 2004 -- The majority of chronic pain sufferers put off seeing a doctor. Many are in denial about their constant pain. They shrink their lives to fit their condition, a new survey shows.

The nationwide random survey, released today by the American Chronic Pain Association, provides a snapshot of how chronic pain affects quality of life. The survey results are based on telephone interviews with 800 people who have chronic pain.

Pain Sets In Early for Some

Anyone can develop chronic pain -- but it commonly occurs in older adults or others with health conditions, such as diabetes, arthritis, or back problems. However, persistent pain is not a normal part of aging. And even people in their 20s and 30s develop chronic pain.

Treatment typically involves prescription painkillers or other medication, physical therapy, exercise, and therapy to develop better coping skills. Alternative treatments -- like acupuncture and yoga -- can also help. While chronic pain cannot be cured, it can be managed well enough to significantly improve the quality of your life. "Pain really can affect your quality of life -- emotionally, physically, how we deal with stress, how active we are, says Penney Cowan, executive director of the American Chronic Pain Association." And, unfortunately, many people don't get treatment until they are

practically nonfunctional." At age 25, Cowan felt the first symptoms of fibromyalgia -- chronic, widespread muscle pain -- and ignored it for two years until it nearly incapacitated her. In fact, chronic pain often begins much earlier than most people realize. And among people between ages 18 and 34 with chronic pain, 82% of them are affected emotionally by their chronic pain, the survey showed. "We're seeing a lot of younger people experiencing pain, more than you would expect," Cowan tells WebMD. "I think it's the more active lifestyle we're leading, a lot more sports-related injuries. We need to educate people on preventing pain and on getting adequate treatment immediately to hopefully avoid long-term pain."

Quality of Life Seriously Affected

Careers and personal lives are affected by the pain, says Cowan. "Employers, people in general don't realize how debilitating it can be. Pain is invisible. People can't see that anything hurts. If they see you acting OK, they think you're good to go for everything. That might not be true."

Among the survey results:

- Women are more likely to be affected emotionally by their pain than men.
- 70% of pain sufferers feel greater stress and 55% feel less motivation as a result of their pain.
- Nearly three in ten men have flagging libido due to chronic pain.
- 41% of workers with chronic pain say their pain adversely affects their ability to put in a full day's work.
- Three in ten say it affects their ability to get to work.
- One in six employed people living with chronic pain say it has adversely affected their career advancement opportunities.

Treatment Works

Treatment *does* offer relief, says Cowan. "We have to learn to live with the pain, manage it, apply better coping skills, pace ourselves, and know our abilities. The big message is, realize that there are things you may not be able to do. But don't dwell on that, focus on what you *can* do."

Her survey showed the positive effects of getting treatment:

- 81% of people seeing a doctor for pain report being very satisfied.
- 86% of people taking prescription pain medication are also using alternatives, like physical therapy, massage, and meditation.

However:

- 56% of those taking pain medications worry about side effects.
- 52% report drowsiness and 41% say they have had nausea from pain medications.

"Pain is not simple," says Cowan. "Finding the right doctor can be difficult. Doctors and nurses are not really trained in pain management. They're trained in diagnosis and treatment of disease, but not in managing pain. And because it's complex, treating pain takes a team approach, with the patient playing an active role."

Start with your primary care doctor, she advises. "You have to start at the beginning, rule out certain causes. You may have to see a few specialists. Even then, there aren't always clear answers." The bottom line: If you have pain, taking an active role will help bring relief, Cowan says. "When you do that, you *can* start living again."

SOURCES: Penney Cowan, executive director, American Chronic Pain Association. American Chronic Pain Association. WebMD Medical Reference from Healthwise: "Chronic Pain."

Reprinted from the Polio Epic News in AZ and the Florida East Coast PPSG Newsletter, Sept-Oct 2004

NEW STUDY REPORTS POST-POLIO WOMEN EXPERIENCE MENOPAUSE DIFFERENTLY THAN NONDISABLED PEERS

ST. LOUIS, September 3 – Women with late effects of polio experience menopause differently than their non-disabled peers – physiologically, physically and psychologically – according to a new study funded by Post-Polio Health International, headquartered here.

A team of researchers from the University of Michigan Health System in Ann Arbor conducted a nationwide study to explore the experience of menopause for the 500,000 women in the US with a history of polio. To highlight the unique contribution of menopause, men with a history of polio also participated and served as a control group.

In their final report "Women with Polio: Menopause, Late Effects, Life Satisfaction and Emotional Distress," the researchers present significant findings:

* Severity of post-polio symptoms was significantly related to severity of menopause

symptoms, especially in four areas: sensory (numbness, tingling, constipation, dry eyes), psychological (tension, moodiness, depression, irritability), sleep (sleeplessness, cold hands and feet), and vasomotor (hot flashes, sweating).

* Greater menopause symptom severity was significantly related to lower emotional well-being.

* Women who were further along in menopause had more severe post-polio symptoms and more difficulty with activities of daily living than did post-polio men of the same age.

* Women approaching menopause were more satisfied with their lives and less unhappy than post-polio men their age, but women who were at least five years into menopause were more stressed out than post-polio men the same age.

* More post-polio women (39 percent) use hormone replacement therapy (HRT) than their non-disabled sisters (23 percent). However study participants using HRT did not report an

improvement in post-polio symptoms, and in fact, women using HRT who were more than five years into menopause reported more severe late effects of polio than post-polio men of the same age; this same difference was not found between women not using HRT and men their same age.

* Hysterectomy rates among women in this study – nearly 35 percent – were significantly higher than the average rate for U.S. women (21 percent).

* Rates of education achievement among these polio survivors were significantly higher than the national average. They were married at similar rates, but were employed at lower rates than similarly aged non-disabled peers, except for women over age 65 who were employed at similar rates as non-disabled peers.

* In general, women in this study had an overall positive (45%) or neutral (35%) experience of menopause; comparatively, far fewer had a negative experience (18%) of menopause.

“This study provides the first solid evidence that post-polio women experience menopause differently,” said Joan L. Headley, Post-Polio Health International executive director. “Post-polio women should educate themselves and their health care providers about the differences in their experiences. While there is much more to be learned about menopause in the context of disability, this study is an important first step toward future generations of menopause studies that no longer ignore women with disabilities.”

Researchers Claire Z. Kalpakjian, Ph.D., principal investigator and project director, and Denise G. Tate, Ph.D., co-principal investigator, both from the University’s Department of Physical Medicine and Rehabilitation, and

Elisabeth H. Quint, M.D., co-investigator, from the Department of Obstetrics and Gynecology, studied almost 1,000 post-polio women, aged 34 to 99 from 49 states during 2003.

“Of the 30 million women with physical disabilities in the United States, more than 16 million are over the age of 50, constituting a large and growing population of women who have been relatively understudied with regards to the psychological and physical experience of menopause,” the

researchers said. “Women with disabilities in general have long been neglected in rehabilitation research. As such, little is known about the unique biological milestones women experience as they age and the interaction of physical disability and these biological changes.”

The complete report is available on Post-Polio Health International’s website, www.post-polio.org (click on Research). Post-Polio Health International actively promotes education, research, advocacy and networking among the post-polio community to enhance the lives and independence of polio survivors and home ventilator users. Its Research Fund was established in 1995 to seek scientific information leading to eventual amelioration of the consequences of poliomyelitis and/or neuromuscular respiratory diseases.

Scaling “The Wall” by Millie Malone

Reprinted with permission of Triad Post Polio Support Group newsletter *The Seagull*, September, 2004

You can't do it. You can't scale “The Wall.” You know the one I'm talking about – the infamous “Polio Wall,” the thing you hit when you overdo. You know the drill. You bop along, feeling fine, thinking that you can do another hour's worth of whatever you're doing, even though you know you might be pushing it. Then, all of a sudden there it is – The Wall- looming large. Your muscles are totally out of strength, with no energy to take another step.

What do you do when you hit The Wall? You crash – that's what you do. You may pay for trying to scale The Wall with a stumble, a few days in bed, even a fall. Perhaps you will be lucky and be able to remain somewhat vertical, though sadly out of plumb, but pay you will. In my own case, I will stagger around for a few days in a zombie-like state, hurting all over, ears ringing, and incoherent. Rather a high price to pay for another hour's worth of shopping, missing a couple of hours of sleep or any of a multitude of things that can pull the trigger that pops The Wall up in front of me.

Why do we keep hitting The Wall? There is Drs. Bruno and Frick's theory that all polio survivors have Type A personalities. They think that we strove so hard to overcome the original polio and its aftermath that we cannot slow down even now that PPS has reared its tired head. Do we hit The Wall because we're Type A? I don't know. But I do know that sensible able-bodied people will take a break when they are tired. They will call in sick when they are ill. Not us polio survivors, though. Nope. Can't be thought of as wimpy. Must keep up with the pack. Actually, we must be *ahead* of the pack to be “comfortable.” But comfortable for a polio survivor means comfortably aching in every muscle, comfortably stumbling, comfortably falling down. If we stopped before we hit The Wall, people might think we are “crippled” or in some way not as capable as our family, friends or co-workers. We must outdo everyone even if we undo ourselves. We must scale The Wall. It is the POLIO WAY!

The Way must change. We are wearing out our remaining motor neurons when we overdo. We must learn to “Conserve to Preserve.” If we want any quality of life, this is a lesson we must learn. I have heard it over and over again: I am working as hard as I can to stay out of a wheelchair.” However, if we stop working as hard as we can and use a wheelchair, we will be able to walk around our houses without falling down, without pain, for years to come. I now use a power wheelchair. It makes the difference between being able to go into one store and dragging my weary body home or being able to spend a couple of hours leisurely browsing through all the items on display and returning home with enough strength left over to get back in the house.

It is hard for us to “give in,” to allow ourselves to use the aids that we need, like canes, braces, walkers, scooters or wheelchairs. But why is it so hard? No one thinks you are being a wimp if you drive your vehicle to the store. It's too far to walk, so you drive. If it is too far for you to walk around the mall, why not use another kind of vehicle. Vehicles are merely tools, after all, be they cars or scooters or power chairs. I think we don't want to return to the days when we had braces, crutches and that damnable wheelchair. We feel we have failed if we go back to using those aids again.

But we have not failed! Polio survivors have struggled valiantly, have gotten an education, married, raised a family and did everything that an able-bodied person could do and often, things they couldn't

do! It should be no disgrace to use whatever tool it takes to keep doing and enjoy the rest of our lives. If using a wheelchair conserves enough energy to go to a ball game with our grandchildren, where is the harm?

Let's slow down, smell the roses, go slowly enough to enjoy the view and make our bodies feel better and last longer. WE have earned this, we deserve it and we should not be ashamed to do it. It's time we all got in our scooters and power chairs and drove AROUND The Wall.