THE LIGHTHOUSE Coastal Empire Polio Survivors Association, Inc. Shining Light on Post-Polio Health

November/December, 2012 Newsletter www.coastalempirepoliosurvivors.org

Vol. XV, No. 9



The President's Message...

My term as President ends on December 31, 2012. It has

been an honor to serve in this position for the third time. I could not have done it without the help of our Board members (in Alphabetical order): Cheryl Brackin, Lavonne Calandra, Carlos and Wanda Clas, Diane Davis, Michael and Terri Dunnermann, Marty Foxx, Lorraine Frew, Betty Goff, Richard Graham, Adrienne Stallworth, Harvey Varnadoe and Jim Veccia. Thank you one and all.

We had a great birthday party with three members sharing their polio stories in April. We attended the 2012 Rotary District 6920 Annual Conference at the DeSoto Hilton Hotel in Savannah, Georgia in May. We had an exhibit that included the iron lung, which was the main attraction.

Tom Schendorf and I were interviewed about CEPSA by Jody Chapin and Tim Guidera on WTOC's Mid-Morning Live.

We received a check for \$1,000 from Dan Vaden Chevrolet-Cadillac for their Extra Mile Award for our Navigational Guide for Scooters and Wheelchairs for the Historic District.

We have many things yet to be done in 2013. They will be left in the very capable hands of Cheryl Brackin. She will lead us in the right direction. Please congratulate her, wish her well, and give her your support.

I hope to see all of you next year.

Janet DiClaudio

President

Community

"Somewhere, there are people to whom we can speak with passion without having the words catch in our throats.

Somewhere a circle of hands will open to receive us, eyes will light up as we enter, voices will celebrate with us whenever we come into our own power.

Community means strength that joins our strength to do the work that needs to be done.

Arms to hold us when we falter.

A Circle of healing.

A Circle of friends.

Someplace where we can be free."

-Starhawk, Dreaming in the Dark: Magic, Sex and Politics (1982)





General Meeting Minutes October 27, 2012

President Janet DiClaudio called the meeting to order at 10:40 am. She then welcomed Reverend Edward and Lillian Ellis, Ruth Parham and her guests, as well as Dick Warden's friend Jamie Thomson.

Cheryl Brackin led the Pledge of Allegiance.

The inspiration was given by Terri Dunnermann, who read a poem "A Song of Gladness" by James William Foley.

Minutes from the September meeting posted in our news letter were motioned to be approved as written.

The Treasurer's report was given by Marty Foxx. She pointed out that the newsletter is now costing extra postage since its expansion from 8 to 12 pages.

We discussed forming a committee to meet with the Savannah Post Master in early 2013 to request free postage for our newsletter mailing.

The report was approved as submitted.

Committee Reports:

The Nominating committee chair Jim Veccia proposed a slate of officers: President-Cheryl Brackin, VP/Secretary-Michael Dunnermann, Treasurer-Marty Foxx. A motion was made, seconded, and approved to accept the proposed slate of officers for 2013. All committee chairs retained their positions for the coming year.

Old Business:

<u>Skidaway Rotary</u>: Tom had no new updates to report.

Harvey reported that he and Tom visited the home of Lorraine Frew, who is our candidate for a shower modification.

<u>Meeting location</u>: There is no meeting in November, and the December 1st event, our banquet, is at the Hilton Garden Inn at noon. Cheryl continues to look for a new location for our General Meeting.

<u>Polio Stories</u>: Janet reminded everyone to write them for preservation in our "Book of Memories".

Fund-Raisers: Delores McCall reported their church was having a Benefit Gospel Sing on Nov. 3rd at the Pine Haven Baptist Church in Brunswick.

<u>Care Team Leaders</u>: The Leaders were reminded to update member information for the directory when they make their calls.

<u>**Banquet Speaker:**</u> Jim met Penny's minister Reverend Jim McIlrath when they spoke at the Brunswick Rotary. They recommended him as our December banquet speaker.

Program:

Pain Management was the topic presented by Harvey Varnadoe, RN. He gave a very informative presentation, discussing many topics. Harvey did not have time to complete his presentation and will continue it at a future meeting.

The meeting was adjourned at 12:47 pm at that time we began our program of Sharing our Strengths.

Respectfully submitted, Michael Dunnermann, Vice-President/Secretary.

Attendance:

Cheryl Brackin, Wanda Clas and Carlos Clas, Esther Simmons, Della Simmons, Janet DiClaudio, Michael Dunnermann, Terri Dunnermann, Harvey Varnadoe, Delores McCall, J.E. McCall, Tom Schendorf, Marty Foxx, Harvey Varnadoe, Dick Warden & Jamie Thomson, Ross Smith, Penny Smith, SteveHess, Nancy Hess, Lavonne Calandra, Betty Goff, Ruth Parham with Myra Braswell, Alison Todd. Reverend Edward Ellis, Mrs. Lillian Ellis, Jim Veccia, Gigi Veccia, Sissy Morel.



October 11, 2012 The Rotary Club of Brunswick

CEPSA and Rotary International's Effort to Eradicate Polio Worldwide CEPSA Speakers: Penny Smith and Jim Veccia.

by Penny Smith

On October 11, Jim Veccia and I spoke before the Brunswick Rotary Club's regular luncheon meeting at the Brunswick Country Club. We were invited to be there by Reverend Jim McIlrath.

I spoke to the group about my own story of contracting polio in 1949 at the age of seven. I recalled the history of polio epidemics, which really only began in the 20th century of sanitation, and what summers in the late 40's and early 50's were like in the cities where epidemic polio was rampant. I told them about how I became sick and what my course of treatment was like, comparing and contrasting with the treatment others had at the same period. I explained about post-polio syndrome coming along as we age and bringing unexpected paresis/weakness to many of us who thought we had beaten the disease many years ago.

Jim then told about the forming of support groups for those experiencing PPS and, of course, how CEPSA came to be founded. He elaborated on CEPSA's collaboration with Rotary in the Savannah and Hilton Head areas, our combined efforts to raise funds for fighting polio worldwide through our "Heel to Toe for Polio" walks on the Beach. He explained how, through these efforts and some grants from Rotary, etc., CEPSA was able to help both our own members and others not affiliated with us to obtain mobility products and maintain them. He told how we had collaborated with Savannah disability groups and the Chamber of Commerce to map out handicapaccessible thoroughfares for touring downtown historic districts and that that project continues in an advisory capacity to identify handicap-friendly businesses in the historic district.

We were well-received by the members, and there was a Q&A period after each of our talks. Our spouses Ross and GiGi accompanied us.

E-mail to Wanda Clas from Penny Smith. 07 November, 2012.

HOLIDAY BANQUET December 1, 2012



HILTON GARDEN INN 5711 Abercorn St., Savannah, GA 31405 12:00 Noon

Below is the menu for our Annual Holiday Banquet. You will be receiving a call from your Care Team Leader, asking if you will be attending the banquet on December 1, 2012, for total number attending, and your preference for your entrée. It is important that they receive an answer. If they leave a message please return their call. We need to have this information so the Hilton Garden Inn can order the correct amount of each entrée and know the number attending. There will be no assigned seating, so if you are coming with several people and are planning to sit together, seating will be open to choice. Those wishing to sit together with family or friends should arrive early.

BANQUET MENU SELECTION

Garden Salad

Iceberg Lettuce with Cucumbers, Tomatoes and Carrots. Served with Ranch Dressing.

Plated Baked Chicken

Baked Chicken served with Rice Pilaf and Green Beans.

Plated Roasted Tilapia

Roasted Tilapia served with Tomato Caper Relish, Rice Pilaf, and Vegetable.

Plated Vegetable Lasagna

Vegetable Lasagna served with Sautéed Seasonal Vegetables.

Dessert

Chef's Choice of Assorted Pies

If you have recently decided to attend (after telling your Care Team Leader you would not be attending), call Lavonne (912-354-2020) to make reservations. Payments by check would be greatly appreciated. If you have committed to attend but <u>do not</u> come, you will be responsible for the whole \$18.00 (not the \$10.00 you would be paying) that CEPSA will have to pay for you. Thank you for your understanding in this matter.

***CEPSA dues of \$15.00 are due in January. If attending the Banquet you might want to add it to your Banquet check.**

HOLIDAY BANQUET SPEAKER



Reverend Jim McIlrath First United Methodist Church, Senior Minister

Reverend McIlrath is a graduate of Asbury College in Wilmore, Kentucky, has attended Asbury Seminary, and was graduated from Candler School of Theology at Emory with a Master of Divinity. During his ministry, Reverend Jim has served on various boards and agencies of the South Georgia Conference including the Conference Board of Ordained Ministry, the Conference Worship Committee, and as a Trustee at Epworth By The Sea. He is entering his 32nd year in the ministry.

Reverend McIlrath has been very involved with youth and children in his various ministry appointments. He has also been involved in the communities that he has served with local ministerial associations, UMCOR, Habitat for Humanity, and the Rotary Club.

Jim and Debbie are both talented musicians. Debbie remarked while visiting FUMC, "You might hear Jim sing, but you won't hear me preach."

The McIlrath's have three grown children all involved in ministry and praise and worship teams in their local churches. They are also proud grandparents of three granddaughters.

Jim came to Brunswick a year and a half ago from Warner-Robbins where he served as senior minister of Grace UMC.

Newsletter Changes



This issue of THE LIGHTHOUSE has been expanded to 16 pages especially for the holiday season. Since we don't have a December newsletter, we thought you might enjoy an expanded issue this time.

Sadly, starting with the January, 2012 edition, we may be cutting down the newsletter on a monthly basis to 8 pages or less. The articles will not be as many.

This postage was not in the budget. If you multiply this by 9 issues per year, it adds up.

We will do our best to bring you as much information as possible in the shorter format, and we hope you have enjoyed the past year's issues of THE LIGHTHOUSE.

Pain Management Program October 27, 2012

with Harvey Varnadoe



Our speaker for the October 27, 2012 meeting was Harvey Varnadoe,RN. His topic was pain management. Harvey had so much great information to share that we ran out of time. We are going to have him come back and continue at a future meeting.

Here are some key points that Harvey addressed:

- 1. PPSers have different levels of pain.
- 2. 90% of pain is caused by some form of inflammation.
- 3. The duration of pain can be classified as either chronic pain or acute pain.
- 4. Chronic Pain is pain that lasts a long time, sometimes even after a situation is resolved.
- 5. Acute Pain is pain that resolves itself quickly.
- 6. Pain is a "red light signal" that something is wrong.
- Do not take any medicine, including over the counter medicines or vitamins, without consulting with your doctor first. Some combinations of medicines can cause problems. Ex: Omega 3 reduces inflammation, but it has a side effect, it lowers the clotting factor. It can block blood pressure medicines so that they are not as effective.
- 8. If you are seeing several doctors, make sure they are all aware of the medications each is prescribing for you.
- 9. Pain should not be ignored.
- 10. Different medicines will work differently on each person.
- 11. People are sensitive to different drugs.
- 12. Inflammation is damage or trauma to an area of the body.
- 13. 1st and 2nd degree burns hurt, whereas 3rd degree burns do not because the nerve endings are gone.

Harvey spoke about <u>some</u> of the different types of pain such as those below:

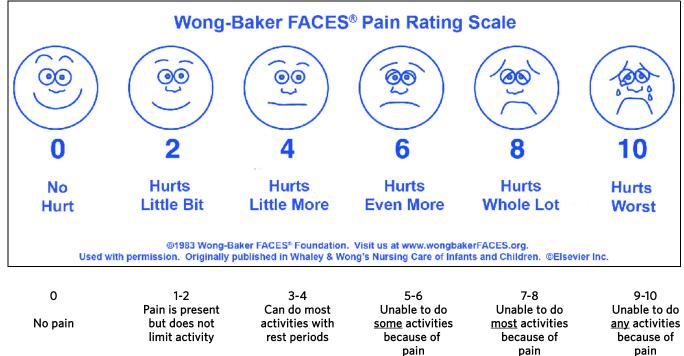
- 14. Neuropathic Pain-is caused by damage or disease affecting any part of the nervous system involved in bodily feelings.
- 15. Somatic Pain-is pain emanating from muscles, skeleton or skin.
- 16. Visceral Pain- is a deep, harder-to-find pain.
- 17. Phantom Pain- is pain felt in a part of the body that has been lost or from which the brain no longer receives signals.
- 18. PPSers usually have an elevated white blood cell count which can be due to inflamation and again, inflamation causes pain.
- 19. There are enzymes that help with pain.
- 20. Depression plays a major role with pain.
- 21. If you are in pain for a long time, you can become low in sodium and may need electrolytes.
- 22. Testosterone can increase pain tolerance.
- 23. Estrogen decreases pain tolerance.
- 24. Ladies should be careful when there is lower abdominal pain and vomiting or pain between shoulder blades. Get an EKG; you may be having a heart attack.
- 25. Diabetes can cause a lot of pain and circulation problems. Eventually the diabetic person stops feeling pain in the lower limbs if the pain nerves finally short out.
- 26. Shingles causes severe pain and can be alleviated with a numbing agent, such as a lidocane patch. Check with your doctor first.
- 27. There are several drugs that are effective for releiving pain. Consult with your doctor to see which is right for you.
- 28. Ice and heat are great to relieving pain. An electric heating pad can be very helpful with pain relief.
- 29. Pain is usually worse in the afternoon and at night.
- 30. Exercise is a natural alternative as pain therapy. You and your doctor together can determine what the best exercise is for you.

Remember:

- Everything discussed does not work for everyone.
- Doctors should be finding the root of your pain, not just prescribing medications for pain.
- Consult with your doctor first!

Go to pages 6-7 for more information.

The Wong-Baker Faces Pain Scale uses schematic faces to help people communicate about their level of pain during clinical exams. Originally developed for children, it is now used in many healthcare settings where language barriers or communicative disorders interfere with communication. (This scale is useful when describing your pain your health-care provider.)



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PUMPKIN PIE? DIG IN, HAVE SECONDS



Suzy Cohen, Ask The Pharmacist

Dear Pharmacist: My husband is a glutton this time of year. He overeats. He drinks too much eggnog and eats too much pumpkin pie. He says that it's OK because there are health benefits. Are there? *E.S., Buffalo, NY*

Dear E.S.: He's a funny guy! I assure you that there are no health benefits to overeating. As for eggnog, hey, it's better than beer!

But the pumpkin pie does have some powerful health benefits, especially for men. I could easily justify two slices of pie because pumpkin is nutritious. It's a great source of fiber, vitamins C and E, as well as minerals.

Pumpkin's bright orange color should tell you that it's packed with carotenoids such as natural beta carotene, lutein and zeaxanthin. Those nutrients protect your eyesight and soften fine lines.

Eat pumpkin on a daily basis. Buy pumpkin seeds at the health food or grocery store. I sprinkle them on top of my salad.

When you think pumpkin, think prostate. More than half of

men older than 50 have trouble with their prostate. Moms, start feeding your teenage sons pumpkin seed right now, for prostate protection later in life.

Pumpkin contains phytosterols. One of these, beta sitosterol, may improve cholesterol ratios, relieve benign prostatic hyperplasia, prostatitis, low libido and other bladder problems in men. I think it's even more helpful when combined with saw palmetto, DIM, pygeum, stinging nettle or pumpkin seed oil. Read the label on your prostate formula to make sure that it has some of these ingredients.

High levels of dihydrotestosterone have been associated with an enlarged prostate. Pumpkin contains natural compounds that reduce those levels.

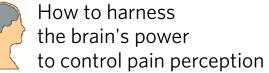
Pumpkin is a powerful anti-inflammatory (think joint pain), and unlike some arthritis medications, this winter fruit won't damage your gut lining.

Pumpkin may ease depression too because the seeds contain L-tryptophan, which raises levels of "happy" serotonin in your brain. Pumpkin is high in minerals that support immune function, heart rhythm, bone integrity and blood pressure.

This information is not intended to treat, cure or diagnose your condition. Visit DearPharmacist.com. Reprinted from Sun Sentinel, FL, 11/26/08. Contributed by Jane McMillen, member.

Reprinted from "Second Time Around", Boca Area Post Polio Group, Boca Raton, FL; Oct 2009

NEW FINDINGS ON PAIN RELIEF



Laura Tibbitts, who has had chronic shoulder pain since a horse-riding accident eight years ago, stared at a computer screen displaying an image of a small flickering flame. As she focused on her pain – visualizing it as a knife stabbing her shoulder – both her pain and the flame on the monitor increased. But when she distanced herself by focusing her thoughts and energy on her big toe, the point farthest from her shoulder, her pain diminished, along with the flame on the screen.

Tibbitts was participating in a Stanford University study that uses a new technology called functional magnetic resonance imaging (fMRI) to display the brain's response to pain and to train patients to change that reaction. The machine focuses on a brain region believed to control perception and regulation of pain; the flame is a computer-generated representation of increased or decreased blood flow to that area.

The Stanford research and related work elsewhere are creating new approaches to pain management. "We're learning that the human brain has an innate and largely untapped capacity for controlling pain," says Jon-Kar Zubieta, M.D., a pain researcher at the University of Michigan. The prospect of using that capacity is particularly important because most painkilling medications cause potentially serious side effects and often fail to control pain, especially chronic pain. While it's too soon to ask your doctor for fMRI training, experts say the research has already yielded insight into pain-control strategies that people can adopt on their own.

Placebos & Pain

When you bang your shin or hit your thumb with a hammer, your first reaction is to rub the injured spot. That instinctive response interferes with the transmission of pain signals to the spinal cord and then to the brain. But your emotions and beliefs also play a role in controlling pain. For example, stress seems to activate a pain-suppressing response from the brain; that's why injured soldiers or athletes often feel no pain until the crisis passes. And your brain can limit pain if it thinks you've received only a sugar pill, or placebo.

Conversely, inappropriately negative beliefs about pain can magnify it by causing your muscles to tense up or your brain to exaggerate the discomfort.

To better understand the body's pain-modulating system, Zubieta and colleagues studied how the brain reacts to placebos. "We learned that when people think they're getting real painkillers, their brain releases endorphins," the body's natural opiates, Zubieta says. That finding shows that what's going on in people's heads has a real, measurable effect on the body, and suggests that if they could harness that ability they might be able to better control their pain." he says.

Brain Training

That's exactly what Tibbitts was doing in the Stanford University study. She and seven other chronic-pain sufferers were taught mental strategies for controlling pain, such as focusing on distracting or soothing images. They were then placed in the fMRI machine and asked to try increasing or decreasing their pain, using whichever strategy they liked best. Other participants used the techniques to control acute pain caused by a moderately heated pad touching their skin.

"The real-time imaging provided sophisticated biofeedback that let patients see how successful they were in increasing blood flow to a part of the brain that controls pain and identify the strategies that worked best for them," says Sean Mackey, M.D., Ph.D. Director of the Stanford Neuroimaging and Pain Lab.

After the training, the volunteers in both groups reported less pain. More than half of the chronic-pain group said the training reduced their pain by at least 50%, typically for several hours. Mackey hopes that such training, repeated often enough, will provide even longer relief, "Like exercising your body, the training, may eventually strengthen the brain's pain-regulation system," he says. Or, it may teach people to control their excessive reactions to pain.

Relief Without The Machine

Tibbitts has continued doing the mental methods at home, without the fMRI, with continued success. Considerable research backs up her experience. For example, a July 2006 study of 57 patients with cancer pain found that distraction or relaxation techniques provided substantial short-term benefits. In a longer, one-year-trial, those methods reduced chronic jaw pain in 50% of the participants, compared with 29% of those who got standard care.

Similarly, confidence in your treatment often translates into better results. In one study comparing acupuncture and massage, back-pain sufferers who felt enthusiastic about their assigned therapy before starting were five times as likely to experience substantial benefits as the skeptical volunteers. Other research show that people who know they're taken a painkiller report considerably more relief than those given the same drug without their knowledge.

What You Can Do

Here are some mental approaches that chronic-pain sufferers could try now, either on their own or with the help of a pain specialist. Either way, experiment to find which methods work best. Try to do each of them for 15 to 20 minutes, and repeat as needed.

• Redirect attention from the painful region to other parts of the body, as when Tibbitts focused on her big toe.

• Concentrate on something else. Pursuits you like – listening to music, reading, or even daydreaming – may be particularly effective, studies suggest.

• Practice relaxation methods, such as deep, abdominally-based breathing.

• Try to perceive the pain as harmless or weak rather than damaging, severe, or overwhelming. It may help to discuss your fears with your doctor, who may reassure you, for example, that you really can resume normal activity without worsening the pain.

• Envision soothing or healing images. "Sometimes I would imagine little men with shovels scooping out my pain," says Tibbitts, "While other times I imagined snowflakes falling on my shoulder and cooling it."

In addition to those steps, try to develop confidence about your treatment and ability to manage pain:

• Learn about the physiology and management of your pain. For example, teaching back-pain sufferers that physical activity doesn't further harm the back can improve pain control, studies have found. And a comprehensive understanding of your pain-treatment options, including how they work and how to use them safely and effectively, might create a greater sense of control.

• Express your preferences. If you feel strongly about particular treatments, ask your doctor to provide a therapy that suits you better.

• Find a confident physician whom you trust. In one study, patients whose doctor firmly assured them they'd soon be well recovered faster than others who got the same treatment but no reassurance.

Pain Management:

What Works?

In addition to the mental strategies described in the main report, most people should treat the common types of pain listed below by making lifestyle changes. If those don't help, ask your doctor about other options, including drugs and alternative therapies.

ARTHRITIS

• Lifestyle measure: Lose excess weight and do low-impact exercises recommended by a health or exercise professional.

• Rheumatoid arthritis: avoid triggers, such as stress, infection, and insufficient sleep.

• Drugs: Acetaminophen or, if that doesn't help, ibuprofen, naproxen, or salsalate (a prescription relative of aspirin). For rheumatoid arthritis: corticosteroids, such as prednisone, for short-term relief; for long-term relief, methotrexate (Rheumatrex), or the new bioengineered drugs, such as etanercept (Enbrel) or infliximab (Remicade).

• Alternative therapies: Acupuncture or relaxation techniques, such as biofeedback, guided imagery, or massage, especially for osteoarthritis. Also consider glucosamine and chondroitin.

BACK PAIN

• Lifestyle measure: For acute pain, apply a cold pack for the first day or two, then a heating pad; resume gentle exercise as soon as possible.

• For chronic pain: loose excess weight and do back exercises, preferably recommended by a specialist.

Drugs:

• For acute pain: acetaminophen, aspirin, ibuprofen or, if it's severe, short-acting opioids, corticosteroids, or possibly muscle relaxants.

• For chronic pain: tricyclic antidepressants, such as amitriptyline (generic, Elavil), anticonvulsants such as gabapentin (generic, Neurontin), or possibly long-acting opiods or surgery.

• Alternative therapies:

• For chronic pain: relaxation, cognitive-behavioral training, or yoga.

• For acute or chronic pain: spinal manipulation massage, or acupuncture.

HEADACHE

• Lifestyle measure: Identify possible triggers (such as red wine, chocolate, or stress) or underlying causes (such as hypertension, sinus infection, or caffeine or drug withdrawal).

Drugs:

• Acetaminophen or ibuprofen, possibly combined with caffeine (generic, Anacin, Excedrin Migraine).

• Triptans, such as sumatriptan (generic, Imitrex), to treat migraines, and beta-blockers, such as propranolol (generalic, Inderal), to prevent them.

- Alternative therapies:
 - Relaxation techniques

NEUROPATHY (from diabetes, shingles, or chronic pain).

• Lifestyle measure: Treat underlying condition, such as diabetes.

Drugs:

• Tricyclic antidepressants, such as amitriptyline (generic, Elavil), or anticonvulsants, such as gabapentin (generic, Neurontin).

• Nerve-block injections or surgery, especially for facial or head pain caused by nerve damage.

• Alternative therapies: Seek referral to pain clinic if pain persists.

Don't let pain take root

Persistent pain can actually damage the nerves that transmit the message, causing additional, ongoing pain. That's why some people feel pain long after injuries heal, diseases are cured, or limbs are amputated. Diseases such as diabetes and shingles can also sometimes damage the nerves, causing chronic pain. In addition, entrenched negative ideas about pain can intensify it (see main story). All those factors add another reason to aggressively treat the pain itself as well as any underlying conditions that can damage the nerves.

Reprinted from The Sunshine Special, FL, May/June 2008.

Reprinted from "Second Time Around", Boca Area Post Polio Group, Boca Raton, FL; Jan 2010

Counting Your Blessings:

How Gratitude Improves Your Health



By Bruce Campbell

Gratitude has long been extolled by religion and in recent years, has drawn attention through books such as The Simple Abundance Journal of Gratitude. Now, thanks to new research, there is scientific evidence that gratitude produces health benefits.

The research is summarized in Robert Emmons' new book *Thanks!: How the New Science of Gratitude Can Make You Happier* (Houghton Mifflin, 2007). Emmons and his colleagues at the University of California at Davis are among the pioneers in research on gratitude, part of a larger movement called positive psychology. Positive psychology, instead of focusing on illness and emotional problems, studies health-promoting behavior and the pleasurable parts of life.

Emmons' book reports on several studies. In the first, he and his colleagues divided participants into three groups, each of which made weekly entries in a journal. One group wrote five things they were grateful for. Another group described five daily hassles and a control group listed five events that had affected them in some way. Those in the gratitude group felt better about their lives overall, were more optimistic about the future, and reported fewer health problems than the other participants. Results from a second study suggested that daily writing led to a greater increase in gratitude than weekly practice.

A third study reproduced the results among a group of people suffering from various neuromuscular diseases, including post-polio syndrome, which has symptoms similar to those in CFS. People using daily gratitude journals reported more satisfaction with their lives and were more optimistic about the future than the control group. Interestingly, the gratitude group also reported getting more sleep, spending less time awake before falling asleep and feeling more refreshed in the morning.

In a related study, researchers at the University of Connecticut found that gratitude can have a protective

effect against heart attacks. Studying people who had experienced one heart attack, the researchers found that those patients who saw benefits and gains from their heart attack, such as becoming more appreciative of life, experienced a lower risk of having another heart attack.

The research on gratitude challenges the idea of a "set point" for happiness, a belief that, just as our body has a set point for weight, each person may have a genetically-determined level of happiness. The set point concept is supported by research that shows that people return to a characteristic level of happiness a short time after both unusually good and unusually bad events. But the research on gratitude suggests that people can move their set point upward to some degree, enough to have a measurable effect on both their outlook and their health.

Summarizing the findings from studies to date, Emmons says that those who practice grateful thinking "reap emotional, physical and interpersonal benefits." People who regularly keep a gratitude journal report fewer illness symptoms, feel better about their lives as a whole, and are more optimistic about the future. Emmons conclusion is that gratitude is a choice, one possible response to our life experiences.

Getting Started

If you would like to increase the level of gratitude in your life, here are five suggestions for getting started.

1) Keep a Daily Gratitude Journal

This is probably the most effective strategy for increasing your level of gratitude. Set aside time daily to record several things that you are grateful for. (Typically, people list three to five.) You can write when you get up or at the end of the day. Pick a time that you will consistently have available. You can use a book like the Journal of Gratitude or write on loose-leaf paper or a notebook. The important thing is to establish the daily practice of paying attention to gratitude-inspiring events and to write them down. In Emmons' words, the act of writing "allows you to see the meaning of events going on around you and create meaning in your own life." For an example of the use of a gratitude journal, see Joan Buchman's article <u>The HealingPower of Gratitude</u>.

2) Use Visual Reminders

Two obstacles to being grateful are forgetfulness and lack of awareness. You can counter them by giving yourself visual cues that trigger thoughts of gratitude. Emmons says he puts Post-It notes listing his blessings in many places, including on his refrigerator, mirrors and the steering wheel of his car. Another strategy is to set a pager, computer or PDA to signal you at random times during the day and to use the signal to pause and count blessings.

3) Have a Gratitude Partner

Social support encourages healthy behaviors, because we often lack the discipline to do things on our own. Just as you may be more likely to exercise if you have an exercise partner or participate in a class, you may be able to maintain the discipline of gratitude more easily if you have a partner with whom to share gratitude lists and to discuss the effects of gratitude in your life. Emmons says, "If we hang out with ungrateful people, we will 'catch' one set of emotions; if we choose to associate with more grateful individuals, the influence will be in another direction. Find a grateful person and spend more time with him or her."

4) Make a Public Commitment

We feel accountable when we make commitments to others. In our self-help course, we have people set weekly goals for themselves. The fact that the goal is made publicly to a group, makes it more likely that people will follow through. For a discussion of how to achieve short-term goals, see the chapter on goals and targets in our course text, available in the Online Books section of the Library.

5) Change Your Self-Talk

We all carry on an inner dialogue with ourselves that is often called "self-talk." When this inner conversation is negative, our mood is usually low. Research has shown that we can change our mood by changing the tone of the things we say to ourselves. For an introduction to this approach, called cognitive therapy, and a description of a three-step process to change your selftalk, see the article "Taming Stressful Thoughts" (reference below).

Related Articles

The Healing Power of Gratitude

FMS patient and self-help group moderator Joan Buchman's account of the life-transforming effects of a daily gratitude journal.

Taming Stressful Thoughts: Making Thoughts Work for You

A hands-on introduction to Cognitive Therapy, describing a three-step process for making your "self-talk" more accurate and more positive.

Related Website

Gratefulness.org

A website with articles, message boards, a newsletter and other resources

"Holiday Syndrome" TIPS AND TECHNIQUES FOR TREATING POST-POLIO SEQUELAE by Richard L. Bruno

Q. If the accepted theory of post-polio muscle weakness is that our motor neurons are dying, why do I improve with rest after having a period of severe weakness when I overdo it? Even though I can become completely lame, the loss is temporary if I rest up for a day or a week.

A. You're describing a symptom that PPS researchers have totally ignored: "transient weakness." We call it "Holiday Syndrome." Polio survivors complain that their muscles become significantly weaker in December, after they have done too much Christmas shopping, but have strength return in January after they rest.

But something dangerous is happening to cause the transient weakness of "Holiday Syndrome." Remember that the poliovirus killed off at least 50% of our motor neurons. The neurons that weren't killed were damaged by the poliovirus but were able to sprout -- send out extra "telephone lines" -- to talk to the muscle fibres that were orphaned when their motor neurons died.

After polio you were left with less than half of your motor neurons--neurons that not only are over-sprouted, but also have cell bodies that are smaller than normal, have damaged protein-making "factories," and have been severely overworked for the past 50 years. When you experience transient weakness we think you have overloaded your neurons' protein-making factories and drained their reserves.

After you rest, the neurons' protein supply increases and you are able to use your muscles again. But every time you drain your motor neurons, we think you are doing damage that eventually causes permanent weakness as the drained neurons die.

Think of what would happen to your car battery if you left the headlights on every night. You get up the first morning and your battery is flat. You jump-start the battery and drive off. The next night you leave the lights on, jump-start the battery again, and drive away. But after about a week the battery will no longer take a charge and you won't be driving anywhere!

Canadian PPS researcher Alan McComas found that polio survivors who are getting weaker over time lose 7% of their motor neurons per year, that's 7% on top of the 50% they have already lost! Prevent transient weakness -- and permanent weakness -- by resting before your muscles become weak, let alone become completely lame. Remember: You can replace your car's battery but you can't replace your motor neurons. So give yourself a holiday gift that keeps on giving: Save those neurons!

Campbell, Bruce. "Counting Your Blessings: How Gratitude Improves Your Health." The CFIDS & Fibromyalgia Self-Help Program. <<u>http://www.cfidsselfhelp.org</u>>.

Reprinted with permission from Dr. Richard L. Bruno.

Please visit Dr. Bruno's website <<u>www.postpolioinfo.com</u>>.

Happy Birthday*



November Deno Caloudas - 1 Charlotte Richter - 4 Ann Chance - 11 Pixie Winters - 12 Deloris Manor - 21 Judy Frick - 23 Hilda Fields - 25 Beverly Polin - 25 Velma Underwood - 26

December

Diane Falgiani - 2 Sally Luck - 15 JE McCall - 21 Betty Goff - 22 Diane Davis - 27 January Gigi Veccia - 5 Lorraine Frew - 10 Brenda Mills - 10 Penny Smith - 10 Harriett Merritt - 14 Linda Graham - 15 Jim O'Kelley - 23

*PLEASE...

let your Care Team Leader know if your birthday is listed incorrectly. We are trying to get all the dates listed correctly, but we need your help.

Member Concerns

Diane Davis, Terri Dunnermann, Lorraine Frew, Archie Ivey, Patrina Jonhson, J.E. McCall, Harriett Merritt, Eunice Newcomer, Jan Schendorf & Jim Veccia.

Please keep these members in your prayers.

Prayer Request

Ruth Parham asked for a prayer request from the group for her son Wakil. He is having a difficult time recovering from an injury to his leg. Please pray for Wakil's health and for a speedy recovery.

Quote of the Month



"As we express our gratitude, we must never forget that the highest appreciation is not to utter words, but to live by them." -John Fitzgerald Kennedy

In Memoriam



It is with great sadness that we say goodbye to CEPSA member Hugh Munn. Hugh gave his very inspirational polio story at our April anniversary party. Our deepest condolences to Hugh's wife Linda who was always by his side, their two daughters, Sarah Elizabeth Munn Hobbs and Melissa Christine Munn, and to their family. Our prayers are with them all. Below is a portion of Hugh's obituary published in "The State" on October 20, 2012.

<htp://www.legacy.com/obituaries/thestate/obituary.aspx?n=hugh-emersonmunn&pid=160538979#fbLoggedOut>



Hugh Emerson Munn IRMO - Hugh Emerson Munn, 70, stepped into heaven with two strong legs on Oct. 19, 2012, surrounded by his loving wife, Linda Munn, and their daughters Sarah Hobbs and Melissa Munn. Born in Camden, S.C. on Sept. 29, 1942, he was a son of the late Sarah Sheffield Munn and Lockard Archie Munn. The Munns' fairytale

marriage began in 1972, but the magic started in 1966 when Linda first heard his smooth DJ voice on WNOK. She called in to request songs every evening for weeks, and Hugh finally got the hint and invited her to tour the station. That, as they say, was all she wrote. Earning both his bachelor's dearee in journalism and his master's degree in criminal justice from the University of South Carolina, Hugh was well suited for his 26-year career as the respected chief spokesperson for the State Law Enforcement Division. After he retired in 2002, he began his second career, teaching in the School of Journalism and Mass Communications at USC. He also served as a consultant to the U.S. Justice Department's Office of Juvenile Justice and Delinquency Prevention, DOJ's Office of Victims of Crime, and the National Center for Missing and Exploited Children. In lieu of flowers, the family suggests donations to the American Cancer Society, 128 Stone Mark Lane, Columbia SC 29210 or New Heights Church, 5501 Broad River Road, Columbia SC 29212. Please sign the online guest book at www.dunbarfunerals.com.

For Your Information

If you would like a copy of the health form that CEPSA has available, please ask Lavonne Calandra. She can send you a blank, fill-able form that you can fill in on your computer. This form can be done all at once or it can be saved and finished at your leisure. If you prefer a paper copy of the form, Lavonne has those available also. Once completed, you can print out as many copies as you want and give to all your doctors and therapists.

A link for the article about "The Sessions" and its director, Ben Lewin, is below. The movie focuses on the relationship between polio survivor Mark O'Brien, played by John Hawkes, and a sex therapist, played by Helen Hunt. The director Ben Lewin is also a polio survivor. The movie is in theaters now.

<<u>http://online.wsj.com/article/SB1000087239639044402420457</u> 8045031788719490.html>

Article submitted by Cheryl Brackin from "<u>The Wall Street Journal</u>," Oct. 12, 2012.

Belated Retirement Congratulations



Marie McManus retired from the BB&T Bank in Hampton, SC in March of this yr. She worked with that company for 25 yrs. Marie is very happy in her retirement.

We wish Marie lots of well deserved rest and lots of happy days ahead. Congratulations on your retirement.

From an e-mail from Cheryl Brackin. 10 November, 2012.

For Marie

Retirement is a time For feeling glad to be alive, A time when friendships blossom And enthusiasms thrive.

A chance to do the special things You always wished you could. Retirement is a special time For knowing...life is good.

-Author Unknown

Thank You

Lorraine Frew wishes to express her gratitude for the prayers, Get Well cards, well-wishes, visits, phone calls, and the gifts of food. They have meant the world to her and she appreciates them all.

She is still recovering and it is a slow process. Lorraine is having a difficult time getting back movement in her arm. She is not yet able to use her dominant hand to write. Driving was out of the question until she obtained a key adapter that makes it easier to turn the key in the ignition.

Please continue to pray for her as she continues to work hard to regain her independence. Her fighting spirit is a lesson to us all.

The articles, seminars, thoughts, ideas and suggestions mentioned in this newsletter are provided as a public service and do not express or imply endorsement by CEPSA, CEPSA's THE LIGHTHOUSE or its editors. They are for your information only. Consult with your doctor or health care provider before beginning any new medication, product or program. CEPSA, CEPSA's THE LIGHTHOUSE and its editors do not assume any responsibility for an individual's actions.

7 DON'TS



Don't smoke – Experiment from experts proves that smoking a cigarette after meal is comparable to smoking 10 cigarettes (chances of cancer is higher).

Don't eat fruits immediately – Immediately eating fruits after meals will cause stomach to be bloated with air. Therefore take fruit 1-2 hours after meal or 1 hour before meal.

Don't drink tea – Because tea leaves contain a high content of acid. This substance will cause the Protein content in the food we consume to be hardened, thus difficult to digest.

Don't loosen your belt – Loosening the belt after a meal will easily cause the intestine to be twisted and blocked.

Don't bathe – Bathing will cause the increase of blood flow to the hands, legs & body, thus the amount of blood around the stomach will therefore decrease. This will weaken the digestive system in our stomach.

Don't walk about – People always say that after a meal walk a hundred steps and you will live till 99. In actual fact this is not true. Walking will cause the digestive system to be unable to absorb the nutrition from the food we intake.

Don't sleep immediately – The food we intake will not be able to digest properly. This will lead to gastric [*sic*] & infection in our intestine.

Reprinted from *The Seagull*, NC, May 2008. Reprinted from Second Time Around, Aug 2009-Publication of Boca Area Post-Polio Group, Boca Raton, FL.



The Editors would like to thank Cheryl Brackin for all the help and support with THE LIGHTHOUSE. Cheryl volunteered and has done a phenomenal job proofing the newsletter and making us look good. Her support in getting the newsletter out right and on time is very much appreciated. Most members do not know that Cheryl has been there all year helping us out and hasn't gotten the credit she deserves. We appreciate all the accolades, but she deserves them equally. Let her know!

A big thanks to Jim Veccia for helping us jump right into the newsletter. He always believed in us even when we were terrified with the thought of trying to fill his shoes. Jim, we can never fill your shoes, but we are honored to follow in your footsteps.

To everyone who has participated, one way or another with the newsletter, we are so grateful for you. Keep those articles, comments and suggestions coming. This is a group effort and together we can continue to put out meaningful information.

Have a safe and happy holiday and may the New Year bring you peace, health and happiness.

Carlos & Wanda Clas

Thank You Pine Haven Baptist Church

176 Old Cate Road, Brunswick, GA for having a Benefit Gospel Sing on November 3, 2012, and donating the proceeds to CEPSA.

Your love, support and donations are very much appreciated.

In Concert for the Love Offering Sing were:

The Undone Quartet

of Brunswick, GA



The Harmony Sisters of Brunswick, GA



& God's Own Gospel Singers of Darien, GA



Thank You Southern Gospel Music Promotions & CEPSA Members Delores & J.E. McCall.

Managing Your Need

in Relationships



Presented at the Sixth International Post-Polio and Independent Living Conference (June 1994) by Margaret E. Backman, PhD, Clinical Psychologist, New York, New York

As a psychologist, I tend to hear the problem-side of relationships. And what I often hear when I speak with groups like this are comments such as "What do I do? My husband won't listen to me. He's tired of hearing about my problems."

I am not thinking just about husbands and wives: I am thinking about lovers, friends, children, siblings, and parents. I am also thinking about how the effects of post-polio syndrome can upset the balance in these relationships, and everyone has to get in balance again, often creating a new type of relationship.

In fact, one of the issues that we talk about in therapy is how to handle your dependency needs: how to have them and manage them in relationships; how to avoid letting them become a burden to you or to others; and how to avoid predicaments where anyone who says "I'm going to take care of you" gets into your life.

Another kind of relationship in which dependency plays a role that can cause conflict may occur when you are living with or caring for an elderly parent. In one such case, the person who had had polio started developing symptoms of post-polio syndrome as he aged. At the same time, his elderly mother was getting older and becoming more dependent. She began making more demands and did not understand that her child (now an adult) also needed some care. We are all getting to that age where we are becoming caregivers of parents or older relatives. What do you do when all of a sudden your own functioning is being compromised, and yet you are expected to care for someone who does not understand or does not want to understand your new problems? There is no easy solution.

Relationships with children, of course, can be another source of stress. The direction that the stress takes depends, in part, upon the age of the child; but regardless of age, children -even if they are twenty or thirty years old -- do not like to see parents becoming weak, becoming less than the strong people they once were. Children are often slow to realize that parents need help and are unable to do what they once did. So there may be a lot of denial in the family that puts a lot of pressure on the relationship between parent and child. When you experience a slowly progressive disability like the late effects of polio, it has an effect on the way you relate to others and they to you, particularly those with whom you live. As your condition changes, roles also begin to change. One difficulty is that your symptoms and needs may not always be obvious. You may dislike having to keep reminding others that you need assistance. Your family and friends may encourage you to continue to do things that are now difficult for you. They may be partly in a state of denial, having their own problems and anxieties in accepting your changing condition. Tempers can flair and resentments can build. What can you do?

- Keep the lines of communication open.
- Share literature about your condition.
- Talk with others about your situation and the changing roles.
- Look for ways to change behaviors. Find new ways of talking with and helping each other. Be an active participant in managing your needs.
- Set limits. Learn how and when to ask for help.
- Remind people if they need prompting. Do not expect others to always remember or anticipate your needs.
- Find people outside of your family and primary relationships for additional support. Be aware of your own feelings and those of others.
- Recognize others' contributions and show appreciation. Refrain from manipulation by laying guilt or referring to yourself as a "burden." Remind yourself that others close to you also have days when they may feel afraid, anxious, angry, and tired.

We are talking about empathy. A relationship is a unit in which feelings converge and diverge. It is a give and take. Keep reminding others of what you want and how you feel. You may become irritated when you have already told people over the weeks or years that sometimes you get very tired. Do not take their forgetfulness as a personal insult. Just quietly learn gentle ways of reminding them again that you are feeling tired. Seek individual counseling or family therapy if problems continue.

Naturally I have a bias in this direction, being a therapist myself. I am concerned when I see the lists of treatment teams set up by some of the medical centers and I realize that no psychologist or other mental health professional is on them. The OT is on there; the PT is on there. Occasionally they include a social worker, which usually means someone to handle the practical matters related to benefits or placement. I ask all of you to urge your medical professionals to think more about your mental health -- to have them not be afraid of emotions. A physician once said to me (in another context, as I work with people with various illnesses and conditions besides polio), "God bless them! Somehow they cope!" And I thought, "Would you say that of patients who had a pain in their leg or their back? No, you'd treat them or send them to a professional with experience in that area to help stop the pain."

Emotional pain can be dealt with as well. Problems in relationships can cause pain, too, and that pain can be dealt with by those with professional training. I hope that you will feel it a strength, not a weakness, on your part to seek help for any problems that arise in your relationships.



Marriage Axioms Involving a Partner with Post-Polio



- 1. No matter how hidden, polio is the third entity in the marriage.
- 2. The non-disabled partner must be able to identify with disability.
- 3. The effects of polio cannot be integrated into a marriage if the experience of polio is not integrated in the polio survivor.
- 4. It's not just the physical effects of polio that adds extra stress on a marriage. It's how the partners deal with the emotional and mental effects.
- 5. Disability tends to exaggerate all the ordinary issues of marriage.
- 6. When post-polio syndrome enters a marriage, "for better or for worse, in sickness and in health" must be dealt with sooner rather than later.
- 7. The partner with polio will most likely be an overachiever.
- 8. When post-polio syndrome enters a marriage, the partner with polio must begin to do less and, consequently, the non-disabled partner must begin to do more.
- 9. For a healthy marriage, the non-disabled partner must have a degree of unselfishness and the disabled partner must have a degree of ego strength.
- 10. A good marriage is based on monotony (routine) and familiarity with occasional change. Too much change, too quickly makes the relationship unstable.

Reprinted from "Library of Articles", Central Virginia Post-Polio Support Group, Richmond, VA.

From Henry's Desk..... Polio and Discrimination by Dr. Henry Holland

According to the Merriam Webster Dictionary, discrimination is: 1: the process by which two stimuli differing in some aspect are responded to differently: 2: the quality or power of finely distinguishing and 3 a: the act, practice, or an instance of discriminating categorically rather than individually; b: prejudiced or prejudicial outlook, action, or treatment such as racial discrimination.

Throughout our country's history discrimination has had an ongoing presence. Women, people of color, some immigrants, some religious groups, some with a different sexual identity and those with physical or mental disabilities are among those who have been the recipients of discrimination. Most of you that are reading this article are survivors of polio. Have you experienced the sting of discrimination because of your history of polio? Perhaps you have some objective evidence or memory of discrimination related to polio. Perhaps you cannot describe any objective evidence of discrimination, but maybe you have experienced the feeling of discrimination.

I know that this issue is a sensitive one. One's perception of others could easily be a misperception. With this thought in mind I asked ten active members of the Central Virginia Post-Polio Support Group regarding their experience or feeling about discrimination. These ten members included some who had a visible mark of polio, some who had a visible mark of polio but could hide it and some who passed for able bodied until Post Polio Syndrome. Below I will list the eight questions asked and share some of the responses.

1. As a survivor of polio do you feel you experienced any form of discrimination or prejudice?

Three responders did not feel they had experienced any discrimination related to polio. The other seven did. A few unique examples follow:

There were times when I started a new job, I felt like I had to prove myself.

Yes, in school I could not earn A in phys ed since I could not run, only B I got in high school; so made me 10th in class rather than at the top.

Yes, in college getting into a fraternity and after professional school – to some extent in the lack of opportunities for work with excellent groups; thus I have been self employed for most of my career.

I have not felt discrimination. I kept the fact that I had polio to myself and did not speak about it to anyone in elementary school, junior high or high school. I doubt that my peers or teachers noticed. I was very thin so having an arm that was even thinner than the other was not obvious. When in OT school I was a bit of a celebrity during labs teaching muscle testing because I actually had weakness which made it much more exciting to learn on me as a partner. I knew what I could physically do and not do. In public I never attempted activities with my right arm that would have revealed weakness or difficulty.

2. If you had a visible physical disability from polio (atrophy, limp, orthotic devices, curvature of spine or limbs, etc), were you ever called a "cripple" or overheard comments to that effect?

Three responders reported "No." The other seven were called derogatory terms. Here are a few examples:

The only recollection I have was that when my mom and I went shopping as a smaller child, other children would stare at me. It didn't hurt my feelings as much as make me angry and I know I made the comment "What are you looking at!?" more than once.

I was called "gimp" as a child often because I was in a cast and used crutches (doctor efforts to correct drop foot).

Yes, I was called a cripple by a few peers, felt stares and once was called Quasimodo.

I have muscle wasting in my right shoulder, elbow, hand and thenar eminence. In street clothes, it took a very observant person to notice. I worked with many therapists in other departments who did not notice. In contrast to this, young children would often notice my hand and ask why it looked like it did.

I had a limp but I don't ever remember hearing comments. I was pushed out into the middle of Grove Ave. into traffic while riding my velocipede. I also was beaten up every day on the way home from kindergarten because I could not run away from the kids. The solution was to send me home 15 minutes before dismissal. I did not think that was a good way to handle it. As a senior citizen, I was attending a Board meeting of the condo and one woman wanted to make a law that no more wheelchair people could move in!

3. Even if you have no objective evidence of being the victim of prejudice or discrimination, did you ever "feel" that way?

Four members stated "No." A few of the positive responses are below:

Yes, I was turned down for a job for which I was highly qualified, and had been told by the interviewer that I definitely had the job, but she changed her mind when she saw me. I had obvious scoliosis at the time, but could walk without problems.

Who among us hasn't felt "different"? Or asked "Why did this happen to me?" and shed some tears as a young child or especially a teenager. I was aware that I wasn't asked out on dates in high school, but went out with groups of friends instead. Most teenage girls with obvious polio had to have dreamed of a romantic boyfriend, etc. which didn't happen. By the time I got to college, I had enough self confidence to be gregarious, social, humorous, etc. and a new social life opened up. I never looked back; and although I was very aware that I had a physically disability, I didn't dwell on it. I guess I felt people were "attracted" to the person and overlooked any physical difference.

Polio affected my self image. I felt somewhat "inferior" but I don't remember anyone trying to make me feel that way.

I think I just felt I had to try so much harder to be normal in every way.

4. Do you think having polio caused you to receive more attention after you regained a level of stability (the acute phase was over)? If so, what kind of attention?

This question got more positive answers than any other. Here are some of the responses.

When I returned from my first hospitalization at age 6, I remember the neighbors coming in and asking to see me walk. I know now that, for them, it was somewhat of a miracle that I could walk (I had not walked since I was 10 months old), but at the time I felt humiliated and exploited.

I have an older brother (5 yrs. older) and I've often wonder if he had some form of resentment because I got more attention (or at least I thought I did). He was a wonderful big brother then and now, so he certainly didn't show any resentment. I certainly got some benefits from having polio. I was in the newspaper often, photographed with First Ladies, dignitaries, fund raising, etc. I know I was protected and got special treatment from my aunts, uncles, cousins, etc.

Yes, small town, everyone wanted association on our newspaper coverage than other teenagers for accomplishments

I generally denied or avoided getting help as I tried in every way I knew to be normal. During the first year back in school my best friend carried my books.

I think there were two kinds of attention. One was the attention that appeared to be done to "help" me but really seemed sadistic to me. The other was done perhaps in a more concerned way. (That does not mean I wanted that attention.) One example of the first kind was in kindergarten when we had to run races or do skipping races. I could not run and I did a sort of half skip hop thingy. The teacher made me go the same distance as the other kids and they finished before I even covered half the distance. That would have been uncomfortable but the kicker was that the teacher and kids all jeered at me the whole time that I was trying to catch up.

5. If you did get more attention did you like the attention or did you try to avoid the attention?

The majority of the responders attempted to avoid attention related to polio. Two admitted that they enjoyed the attention. Here are some of the responses.

I never turned down special treatment. I can't say it was horribly obvious and no one else my age was overlooked because of it. That would have bothered me.

I try to avoid attention which is why I was resistant to using a scooter in stores. After a while I realized that people in the grocery store were not paying any attention to me. I use it now without concern about what others are thinking.

I was allowed to "help" the PE instructor since I couldn't play basketball, etc but I don't remember either liking or avoiding the attention.

6. Did you ever feel you were the subject of pity from others?

The majority did not feel that they were the object of pity from others. A few answered "Yes."

ARRRRRG! Yes

Yes, some childhood peers, a few adults at church.

When I first started using the scooter/ wheelchair at schools I could see the pity in the eyes of the adults I would encounter in the hallway. As they got used to it they just saw me and that look was no longer in their eyes. I think that anyone who has a

visible limitation receives pity occasionally from people they do not know. (Except in the grocery store!) When people know you well, pity is not there because they just see you.

7. Did you feel that being a survivor of polio ever hampered you in the work place?

The majority of responders stated "No."

Yes, I was turned down for a job for which I was highly qualified, and had been told by the interviewer that I definitely had the job, but she changed her mind when she saw me. I had obvious scoliosis at the time, but could walk without problems.)

No, but as a passer, few knew. However, I was limited in type of job since I could not walk or stand for long periods.

Yes, everything was harder to do and I did a lot of compensating, finding alternative ways of doing things and used sublimation like trying to make good grades.

I think I am going to include college in this answer, too. When I was at U of R in the 50's, I had a math class on the men's campus. The 10 minutes between classes was not adequate for me to walk from one side of the lake to the other. I would not make it in time. The professor would lock me out of the classroom and make me beg to come in. I had to throw apology letters over the transom before he would open the door for me. (Can you imagine that now??? Lawsuit time, for sure!)

8. Did you feel that being a survivor of polio hampered you in social settings?

One half of the responders reported "No." Others reported "Yes." Here are some of their responses.

Slightly, I cannot stand up long; so cocktail parties were out. I could not play sports with friends. In high school and college people noticed my limp and commented.

Yes, during adolescence I avoided dances or proms until I was a class officer and I had to go to the prom because I was in charge of it. It was extremely difficult asking a girl to go with me.

Polio did make me unsure of myself as an adolescent in terms of self image. I wasn't comfortable at dances, for example.

It may have made me shyer around boys but I may have been that shy anyway. Most guys I met or dated did not even know that I had polio. I was concerned that my "little arm" would not be found attractive.

I guess I could say maybe a little bit. I tried to play tennis in high school because my friends did but I could not do that. I always felt awkward dancing.

What does this little survey reveal? Actually not much is unexpected. As a reality of our polio generation, discrimination and prejudice were generally denied or we simply dealt with it. It wasn't until twenty years ago with the passage of the American with Disabilities Act that polio survivors began to be more assertive in regard to realizing that we had certain rights as polio survivors. As a result many more buildings, both public and private, are more accessible than fifty or more years ago. Earlier in our lives we were more motivated to adapt to the environment as it existed rather than seek to change the environment. Some of us clearly had feelings of being subject to discrimination; even if there was not much we could do about it.

Reprinted from "Polio Deja View", Central Virginia Post-Polio Support Group, Richmond, VA; Oct-Nov 2010

CONTRIBUTIONS

The Coastal Empire Polio Survivors Association is a non-profit corporation, which is tax exempt under IRS code 501c(3). We have no paid employees, only volunteers dedicated to helping all polio survivors. Your financial support is appreciated at any level suggested below:

- * CEPSA Member \$15.00 annual voluntary donation
- * CEPSA Supporter \$25.00 \$50.00 \$100.00 \$300.00 Other
- * CEPSA Memorial or Honor Gift any amount
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23 East 61st Street, Savannah, GA 31405.

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Shining Light on Post-Polio Health

HOLIDAY BANQUET December 1, 2012 HILTON GARDEN INN 5711 Abercorn St., Savannah, GA 31405 12:00 Noon CEPSA's next meeting is on Saturday, January 26, 2013, 10:30 AM at The Exchange on Waters, 6710 Waters Avenue, Savannah, GA 31406