



The Lighthouse

Coastal Empire Polio Survivors Association, Inc.
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Shining light on post-polio health

www.coastalempirepoliosurvivors.org



The President's Message...

January 2009

Happy New Year, CEPSA Members and Friends!! I wish for you and yours a healthy, happy 2009.

Your executive council and I look forward to a successful year for our group. We are planning programs and activities to support, inform, and inspire. Your attendance is important, and so are your ideas. Please call me or any of the officers, committee chairs, or care team leaders with your suggestions for CEPSA.

As a new year begins many of us rethink our goals and intentions for ourselves. I set goals all the time (some achieved, some not), but I do not make New Year's resolutions.

My PPS goals include getting more rest nightly, doing relaxation exercises daily, calling CEPSA friends more often, and continuing to read the most recent information on the late effects of polio. Some of my wishes for CEPSA this year include: increasing our publicity/visibility to locate more polio survivors; offering speakers to local organizations, such as Rotary, to tell our story; using the power of the group to attain improved access and sensitivity for individuals with disabilities; networking with other disability organizations, such as LIFE, to accomplish more for the greater disability community; continuing to emphasize the importance of immunizations in children to prevent another polio epidemic in this country; planning some joyful, renewing activities for the members. I encourage you to plan your personal PPS goals and CEPSA goals for this year.

The January 24th program will be "Adjustments: Mobility, Pain Management, and Tricks of the Trade." We will have three 15-minute small-group discussions on each of the topics. You will have an opportunity to rotate to each group. Then we will reassemble to have a leader of each group summarize the input from that area. Prepare to share your ideas, concerns, and successes in dealing with each of these. "Tricks of the Trade" will involve talking about devices, techniques, or methods in dealing with disability. Please feel free to bring any items to show during your small group discussion. Tell us addresses or websites for ordering a particularly helpful device. Those can be printed in our newsletter.

Mark your calendar for Saturday, January 24, 10:30am. See you soon!

Cheryl Brackin

PPS Forum
By Richard Louis Bruno

January 2009

Heidi Roger, founder of SafeMinds, wants parents to have the right to refuse all vaccinations, since she believes vaccines cause autism. No matter that 15 research studies have found no relationship between vaccines and autism. "Autism," writes Roger, "... is not better than measles ... and maybe not better than polio. Death may be better than autism."

Unfortunately, with poliovirus being imported into the United States and causing polio in unvaccinated children since 2005, if Roger has her way, her opinion may become reality. If American parents are allowed to say "no" to the polio vaccine, autism could be replaced by children caught in a U.S. polio epidemic.

Several state legislatures are considering Roger's request to allow parents a right that already exists in 20 states: to refuse vaccinations because of a "philosophical objection," not because of a medical contraindication or religious opposition. New Jersey State Sen. Robert Gordon recently said, "It leaves people like me very confused when parents worry that the vaccines cause autism."

Here are three misconceptions debunked, which hopefully will end any confusion and make clear the danger of "philosophical objections" to legislators across America.

"Unvaccinated children are nothing to be afraid of."

This conclusion, by vaccine opponent Barbara Flynn, is far from true. At least 85 individuals are infected with and can spread the poliovirus for every one person who is paralyzed, even though the infected individuals have no polio symptoms at all. These silent carriers could spread poliovirus without warning to America's more than 1 million polio unvaccinated infants and children.

"We don't have a measles outbreak here or anything like that."

This recent statement by Evelyn Ain, co-founder of a New York anti-vaccine group, is wrong. The United States is currently experiencing its largest measles outbreak since 2001 — 131 cases from January to July 2008. Sixty-six percent of the sick children were unvaccinated because their parents demanded vaccine exemptions. Eleven percent have been hospitalized, primarily for pneumonia, although measles can cause seizures, meningitis, encephalitis, blindness and brain damage.

The largest measles outbreak is in Ain's own state, with cases in 15 other states from Pennsylvania to Hawaii, the result of travelers importing measles virus from Japan, Europe and Israel. Worldwide, there are 20 million cases of measles each year leaving 242,000 children dead. Prior to the 1963 introduction of the measles vaccine in America, there were up to 4 million U.S. cases annually, with about 48,000 children hospitalized, 500 deaths and 1,000 left with neurological disabilities.

"If there was an outbreak, there would be enough vaccine to go around — and ample time to vaccinate children."

This statement by Ain is also wrong. Continuous vaccination against polio, measles and rubella is necessary to protect children. Pediatrician Edward Rothstein reminded The New York Times that before the rubella vaccine in the 1960s, up to "60,000 babies were born with small heads, or deaf, or blind or with cataracts" because rubella infected pregnant mothers. Dr. Rothstein also remembers polio filling hospitals full of "iron lungs, hundreds in a room, with kids who couldn't breathe." At its peak in 1952, polio sickened 58,000 Americans, paralyzed 35,000 and killed more than 5,000.

The problem with all vaccines for polio, measles, rubella, diphtheria and whooping cough — is they are victims of their own success. Parents in their 20s and 30s can't remember the devastation, death and disability caused by diseases they have never seen. But, young parents hear television personalities and read official-looking websites warning that autism is caused by vaccines. Scientific evidence may someday link vaccines to autism. However, the history of the past 100 years leaves no question that polio, measles and rubella do cause neurological damage, disability and death that are prevented by vaccination.

There should be no confusion. If legislatures allow philosophical exemptions, they're playing "vaccine roulette," betting on an unproved decrease in autism while ensuring the return of America's disabling and deadly plagues. Last September, the animal-rights group PETA put up billboards proclaiming a link

between pasteurized cow's milk and autism, bearing the slogan, "Got Autism?" A recent study linked autism to rain. Maybe state legislatures will ban cows and clouds instead of vaccines. Before any action is taken, please write to your governor (addresses at PostPolioInfo.com) and ask that philosophical exemptions not be permitted or be rescinded.

Dr. Richard Bruno is chairperson of the International Post-Polio Task Force and director of The Post-Polio Institute and International Centre for Post-Polio Education and Research at Englewood Hospital and Medical Center. E-mail PostPolioInfo@aol.com.

Reprinted from the disability lifestyle magazine New Mobility 888/850-0344, www.newmobility.com.”

Happy Birthday

Gigi Veccia – 5

Gloria Sullivan – 8

Lorraine Frew – 10

Penny Smith - 10

Harriet Merritt – 14

Jim O’Kelley – 23

Tammy Hewitt – 29

Welcome New Members

Ann Finley – Warner Robbins, GA

Penny Smith – Brunswick, GA

CEPSA OFFICERS – 2009

President: Cheryl Brackin

Vice President: Lorraine Frew

Secretary: Adrienne Stallworth

Treasurer: Marty Foxx

Members-at-large- Janet DiClaudio

Terri Dunnermann

Committee Chairpersons

Publicity - Cheryl Brackin

New Members, Mailing -

Beverly Jarvis

Fund-Raising - Richard Graham

Hospitality - Janet DiClaudio

Care Team Co-Chairs: Betty Goff

and Lavonne Calandra

Polio Awareness & History -

Diane Davis

Immunization Awareness -

Harvey Varnadoe

Newsletter, Website, Bylaws –

Jim Veccia

Our Care Team Leaders for 2009

Cheryl Brackin

Janet DiClaudio

Lorraine Frew

Richard Graham

Ruth Parham
Jim Veccia

Dot Parkhurst

Voluntary Dues of \$15.00 may be paid to Marty Foxx; her mailing address is: 21 East 61st Street, Savannah, GA 31405.

Please try and make your payment this month either at our January meeting or else by mail. This way, the Executive Board can plan its budget. Thank you!

Member Concerns

Janet DiClaudio Richard Graham
Ruth Parham Tom Schendorf
Dan Shehan Gloria Sullivan Roy Tillotson

QUOTE of the MONTH

“Blessed is the season which engages the whole world in a conspiracy of love.”

Hamilton Mabie, American essayist

Vaccination Rates Drop

The International Post-Polio Task Force has announced a National Immunization for Polio Prevention in Infants and Toddlers Year (NIPP IT YEAR) to ensure that all American children are immunized against polio by age two.

The US Centers for Disease Control (CDC) has reported alarming drops in polio vaccination in twenty states and in ten large US cities, along with importation of poliovirus across US borders. They estimate that more than one million US toddlers are unvaccinated.

Children living in poverty have the lowest polio vaccination rates— below 87% in Boston, Indianapolis, Memphis and Phoenix.

The polio vaccine has been a victim of its own success. We must do more to vaccinate America's children against this deadly and disabling disease. America's next polio epidemic could be just a car or plane ride away.

International Post-Polio Task Force.

**Our CEPSA members and their friends have given more than dues to our organization.
Thank you to our generous 2008 sponsors and supporters:**

- Knox Foundation
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- Low Country Presbyterian Church of Bluffton, SC
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- Harvey Varnadoe
- Gene & Beverly Jarvis
- Ed & Adrienne Stallworth
- Cheryl Brackin honoring Dianne Falgiani

- Sheila Tillman honoring Cheryl Brackin
- Tony Tedona
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- Barry Turner
- Helen Thorpe
- Alan Williams
- Don Brittingham
- Kenneth Salter
- Katherine Hunter
- Wayne Ellis
- Lillian Ellis
- Eileen Boyle
- Kenneth Tornvall honoring Jim Veccia
- Ronald Stewart honoring Jim Veccia
- Jim & Gigi Veccia
- Lynda Soss
- Cathy Zomer
- Mildred Roberts in memory of Jim Walker
- Naomi Rogers
- Jason Wilson
- Vivian & James O'Kelley
- Charlotte Richter
- Hattie Evensen
- Mary Ann Chance
- Ayesha Brown honoring Ruth Parham

Jane Dummer, Baltimore, Maryland, polio survivor

From Fifth International Polio & Independent Living Conference in Saint Louis

I am qualified to speak about fatigue because I fade right after lunch. When I agreed to speak, I realized very quickly I was going to discuss something which is global, yet something I really cannot define for you. So what am I going to say? Fatigue is a normal part of living. Perhaps I can say something about what I have experienced that would help people who do not yet know they have polio-related fatigue to see how it may be different from the fatigue that anyone who is alive has.

I had polio many years ago and did fine with a brace and cane while pursuing normal activities for about 30 years. I knew my baseline. I have always been limited in what I could do, but within the parameters of my limitation, I was able to carry on a fairly normal existence. About ten years ago, I started to develop weakness and pain. Much of the weakness was in my better leg, which started giving way on occasion. I was very concerned.

But I was not aware that I had overall fatigue until the day I was coming back from a meeting in an enormous federal complex in Baltimore. About halfway back, my better leg started to shake. I stopped dead in my tracks. I had to sit down; I did not move. After I rested, I limped over to my desk. I sat in a state of "zombie-ism" for about two hours, thinking, "This is it! You know you have to go to meetings in other buildings. You need a wheelchair."

I bought a wheelchair that afternoon. (I did not buy the right kind, but that is another lecture!) The next day I rode over to the same place and back in my wheelchair, and I was absolutely amazed! I came back as rested as when I had left for the meeting. I was able to work for the rest of the afternoon. At that particular moment, I realized that over a period of three or four years, I had gradually been curtailing my activities to deal with chronic overall, unaccustomed fatigue (about which we hear so much), and I did not even know I was doing it! I am a very pragmatic person. As a general rule I deal with things in a straightforward manner, but it really shocked me to think how much I had altered lifestyle and didn't even know it!

In the last couple of years, it has been obvious that fatigue is my main problem. I could not ignore it forever. It has had an impact on my job, on my social life. I had a nap before lunch today, and that is why I am here. I am

good for six hours. I have an eight-hour-a-day job.

What helps me the most is rest. I asked if I could take a rest period on my lunch hour at work. I was nervous because I knew they were going to think I was not doing a competent job if I could not stay awake for eight hours. It was hard to go and ask, but I did it. They agreed.

About three weeks later my supervisor said, "Jane, I am just not sure this rest period is working out." I said, "What do you mean?" She said, "Before you started to take that nap you were so docile and quiet all afternoon, I didn't have to worry about supervising you. Now I do not what you are going to stir up!"

One of the biggest things about fatigue as a polio survivor is its assault on your self-esteem. You suddenly cannot do what you have always done. You may start an activity and cannot continue it. You may have to work part-time. You may have to forego the promotion because the job might be too taxing. If you let it, these circumstances hurt your self-esteem. I think the trick is to take as much control as you can. Make your own choices and be aware that you can change them! You have to alter your lifestyle and see what works for you. That is what I am doing. I am trying things, and if they do not work, I drop them and I try something else. I am going to look at part-time work, think about disability retirement, and look at getting some hobbies that are not so taxing. I am trying to focus on quality of life, retain my sense of humor, and learn. I am trying to listen to my body, not deny what is going on, and live within it. I came here to share with people like you, to learn from you, and hopefully to help you.

www.post-polio.org