



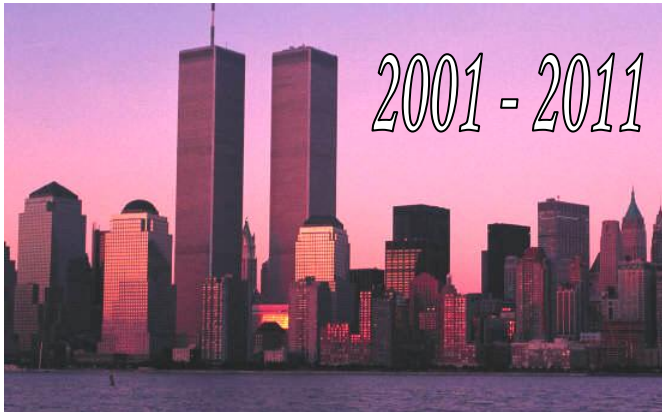
SECOND TIME AROUND

A Publication of the Boca Area Post Polio Group

September 2011

"Sharing and Caring Together"

Volume 14 Issue 9



In Memory

**WEDNESDAY
September 14, 2011**

Ten Minutes With . . . Danny Kasper

**Topic . . . *Haven't Seen You in Awhile –
Come Share & Let's Catch Up***

Let's Do Dinner . . .

Tuesday, September 20 @ 5:00 PM

Mama's NY Pizza Restaurant

11419 W. Palmetto Park Road, West Boca Raton

561-488-0066 for directions

(Shoppes of Loggers Run – 1st light west of 441

NW corner of Palmetto Park Road & Ponderosa)



Next Meeting

Date: October 12, 2011

Dining Around: October 18, 2011

AUGUST `10 UN-MINUTES

The following is from August 2001 Un-Minutes written 10 years ago by the late Manny Halpern, recording secretary.

As there was no August meeting, I thought I would fill this space by giving some of my thoughts on the Boca Area Post Polio group. One of the reasons I so enjoy our (almost) monthly meetings is that we "leave Robert at home," as Maureen is so fond of saying. (Robert's Rules of Order prescribes very formal rules for conducting meetings, involving making motions, seconding, etc.; our meetings are much more informal.) The Spanish River Church provides convenient, comfortable and accessible facilities and there are always drinks and snacks available. Many people bring their own brown bag lunch.

New attendees are given a chance to introduce themselves and are made to feel welcome. The program may consist of a speaker, film, or demonstration and is always informative. Occasionally our program is given over to a discussion by all members on a particular topic of interest. One of my favorite parts of the meeting is the "10-minute presentation" given by a different person each month. Every story is at the same time familiar and unique. If you think you are the only one to have had a particular experience, you are probably wrong. By the way, if you have never given a 10-minute presentation, or if your last one was some time ago, consider volunteering for a future

meeting. It's not as difficult or as scary as you think.

Besides our meetings, we go every month to some convenient restaurant in the area for dinner in the summer or lunch in the winter. The dates, time, place and directions are always given in this newsletter. No reservations are necessary, all you have to do is show up, and you can order whatever you like. This is a great opportunity for unstructured conversation on any topic, making new friends, or renewing old friendships. Many people find they can help each other by sharing rides, or finding other interests in common.

I find that this group does a lot more than simply inform us about our post-polio condition – telling us what we should be doing and what we should not be doing. It affords a unique opportunity to interact with people who have had similar experiences to our own. I can honestly say that were it not for my association with this group, (and my employment as a math tutor) I would have serious concerns about my continued sanity.

On a personal note, I deeply appreciate the many cards, phone calls and other contacts I had with members of the group during my recent illness. This came at a time when I was really feeling the lowest. Thanks to all for your concern!

Submitted by: Manny Halpern

BAPPG appreciates the generosity of the following people who enable the printing of this newsletter:

Nadia Amato
Michele Sosnick
Selma Ephross

In memory of Elio & Julia Cori

WITH MANY THANKS

We wish to thank the many benefactors* who have given so generously to the Boca Area Post Polio Group.

Thomas Cannon
Anonymous
Louis & Minnie Nefsky
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In memory of Elio & Julia Cori
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Alexander Patterson
Eddie & Harriet Rice
Elio Cori & Josephine Hayden
In memory of Julia Cori
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In memory of "Aunt Frances"
Jeanne Sussieck
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Sarasota Post Polio Support Group
Paul J. Ritter, Jr.
Aben & Joan Johnson
Danny Kasper
In appreciation of "Mr." Joel & Maureen
Wildrose Polio Support Society

*Names remain for 1 year.

ASK THE EXPERT

UCLA Neurologist and PPS expert
Dr. Susan Perlman answers your questions.

Dear Dr. Perlman: Six years ago I was experiencing uncontrollable full body and limb jerking. Since that time I have done a survey on our IPPSO bulletin board and found that 33 percent of our then 230 members were all having either daytime or nighttime “twitches” (gentle twitches) or daytime or nighttime full body jerking. This twitching and/or jerking seems to be preceded by fatigue or, for me, palpitation of a trigger point.

I have been on Klonopin for the past 20-plus years to keep this under control. I have to take two pills if I start an episode. I take 4mg of Klonopin each night and as needed during the day. I have noticed that I am much better since getting out of a toxic relationship and losing 60 lbs. I would really appreciate if you could shed more light on this twitching/jerking issue. - *Shari Fiksdal*

Dear Shari: There are a variety of involuntary movements that can occur in post-polio, caused by the spontaneous discharge of bundles of skeletal muscle fibers, which are remodeled and unstable from the original polio. Many polio survivors notice fasciculations – small, painless, involuntary muscle contractions (twitching) – visible under the skin. There is also an increased occurrence of restless legs syndrome (RLS), an irresistible urge to move one's body to stop uncomfortable or odd sensations (burning, itching, or tickling sensation in the muscles). This typically occurs at night, but may occur during the daytime as well. It is best treated with drugs

that stimulate dopamine (levodopa/carbidopa or Sinemet, Mirapex, Requip).

Periodic leg movement of sleep (PLMS) is a sleep disorder where the patient moves limbs involuntarily during sleep and has problems related to the movement (typically disturbed sleep and excessive daytime sleepiness). This also responds to dopamine medications.

Finally, myoclonus – brief, involuntary twitching of a muscle or a group of muscles – may be caused by muscle contraction or cessation of muscle contraction and can be severe enough to actually move the limb. This sounds more like what you describe above, causing full body jerking at its worst. It responds well to clonazepam (Klonopin).

Dear Dr. Perlman: I have PPS, and at the end of the day I am so stiff and in pain regardless of how much I have done. Of course it is much worse if I have done too much. What causes the stiffness? I find that Celebrex really helps, I just hate to take it all the time. I have noticed that getting into a warm water pool helps to relieve the pain. (By the way, I learned so much from your videos on poliotoday.org. Thank you!)

- *Donna Rafferty*

Dear Donna: Stiffness and pain after a day of activity can arise from joints, soft tissues attached to joints (ligaments, tendons), or muscles. Stiffness is usually caused by swelling of these structures. Irritation of a joint with arthritic changes or of a ligament, tendon or muscle that has had too much pressure put on it causes release of inflammatory chemicals (e.g. prostaglandins). These chemicals open up

small blood vessels that allow fluid to seep out into the joint or soft tissue, making it stiff or swollen. Prostaglandins and other inflammatory chemicals can also trigger pain receptors.

Celebrex, ibuprofen, and other “non-steroidal anti-inflammatories” block the production of prostaglandins and help reverse the stiffness and pain. A warm water soak will open up larger blood vessels, which bring more circulation to wash away the prostaglandins that are already there.

Dear Dr. Perlman: I came across some current research being conducted that was posted on the internet in which people with chronic fatigue syndrome were being tested with vitamin B12 and some drugs. I decided to take the B12 and haven't looked back since it made such a wonderful difference to my energy levels. I take 2,000 mg a day. It has worked for me, but is there medical facts that show vitamin B12 could increase energy levels in all people with PPS?
- Stella Newall

Dear Stella: There is no specific research in people with PPS with respect to the effects of B12. The research in Chronic Fatigue Syndrome needs further validation. However, individuals taking B12 often report improved energy levels, and B12 has been used for this for over 50 years.

Dear Dr. Perlman: Polio survivors are always in search of healthful ways to encourage wellness. There is no dispute that safe drinking water is essential to good health. Today you have many options such as: tap water filtered within communities,

tap water additionally filter through your refrigerator, various types of bottled water available for purchase and a plethora of home water-filtering systems. Many of these home water-filtering systems are on the expensive side and often make claims that their product will greatly improve health. However, after investigation, I am not sure there is scientific fact to back those claims.

Can you give us a water rule of thumb as it applies to polio survivors to help us sort out fact from fiction? We would all be appreciative of knowing if one approach works significantly better than another to encourage good PPS health.

- Gladys Swensrud

Dear Gladys: *Consumer Reports* magazine has done several reviews over the years of safe drinking water. They agree that bottled water needs more supervision as to its source and quality. The House Energy and Commerce Subcommittee on Oversight and Investigations on July 9, 2009, sent letters to 13 bottled water companies requesting documents related to testing of bottled water and lists of names and locations of each company's water sources. The move followed a July 8 hearing at which federal officials pushed Congress to impose for more stringent safety guidelines for bottle waters (Read: “Is Tap Water Safer Than Bottled?” from the Consumer Reports Safety blog for more details.

In May 2007 there was a thorough discussion of how to decide what pure water approach is best for your home.

Dear Dr. Perlman: Are there any current studies in stem cells being pursued to specifically address PPS?
- Richard

Dear Richard: There are no current studies of the use of stem cells in patients with PPS. There are a number of animal studies of the use of stem cells in amyotrophic lateral sclerosis, or Lou Gehrig's disease, (to replace spinal cord motor neurons), which will have direct application to PPS.

Dear Dr. Perlman: How can I lose weight when I do not have the use of my right leg. I had an evaluation and was told the poliovirus had affected all the muscles in my body, and exercise was not recommended. I walk with the assistance of a leg brace and crutch. I believe that once my weight drops (30 lbs), I would get around much better. Any suggestions you can offer I greatly appreciate. Thank You,
- Tammy Powell

Dear Tammy: Weight loss for any of us depends on some type of regular conditioning exercise and on reducing calories. The least fatiguing way for a polio survivor to exercise is in the pool. There are many published studies that show that polio survivors can exercise safely and gain better strength and endurance with non-fatiguing exercise.

If you have a PPS-related question for Dr. Susan Perlman, please e-mail it to poliotoday@salk.edu or submit it on the discussion forum titled "Ask the Expert" in the Community section of this website.

Source: http://poliotoday.org/?page_id=578
Reprinted from SFBAPS, CA, March 2010.

TASTE THE COLORS

By Dr. Mehmet Oz



Foods with bright, rich colors are more than just nice to look at. They're also packed with flavonoids and carotenoids, powerful compounds that bind the damaging free radicals in your body, lowering inflammation. (Sadly, skittles do not count.) Eat nine fistfuls of colorful fruits and vegetables each day and you'll reap the benefits without having to give up other foods. Whenever I shop the produce aisle, I'm reminded that these foods are often more powerful than the drugs sold in pharmacies. My favorites are arugula and blueberries.

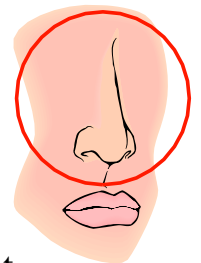


Reprinted from *The Seagull*, NC, April 2010.

TAKE A DEEP BELLY BREATH

By Dr. Mehmet Oz

Do this anywhere, anytime. Push out your bellows and suck air through your nose until your lungs are full. They'll fill with nitric oxide, a chemical found in the back of your nose that opens up blood vessels. The dose of oxygen will make you feel happier and more alert. This is my secret technique for calming down before a show or a tough stitch in the OR.



Reprinted from *The Seagull*, NC, April 2010.

DID YOU KNOW?

Peel a banana from the bottom and you won't have to pick the little "stringy things" off of it. That's how the primates do it.



Take your bananas apart when you get home from the store. If you leave them connected at the stem, they ripen faster.

Store your opened chunks of cheese in aluminum foil. It will stay fresh much longer and not mold!

Peppers with 3 bumps on the bottom are sweeter and better for eating. Peppers with 4 bumps on the bottom are firmer and better for cooking.

Add a teaspoon of water when frying ground beef. It will help pull the grease away from the meat while cooking.

To really make scrambled eggs or omelets rich, add a couple of spoonfuls of sour cream, cream cheese, or heavy cream in and then beat them up.



For a cool brownie treat, make brownies as directed. Melt Andes mints in double broiler and pour over warm brownies. Let set for a wonderful minty frosting.

Add garlic immediately to a recipe if you want a light taste of garlic and at the end of the recipe if you want a stronger taste of garlic.

Leftover snickers bars from Halloween make a delicious dessert. Simple chop them up with the food chopper. Peel, core and slice a few apples. Place them in a baking dish and sprinkle the chopped candy bars over the apples. Bake at 350 for 15 minutes!!! Serve alone or with vanilla ice cream.

Reheat Pizza Heat up leftover pizza in a nonstick skillet on top of the stove, set heat to med-low and heat till warm. This keeps the crust crispy. No soggy micro pizza. I saw this on the cooking channel and it really works.



Easy Deviled Eggs Put cooked egg yolks in a zip lock bag. Seal, mash till they are all broken up. Add remainder of ingredients, reseal, keep mashing it up mixing thoroughly, cut the tip of the baggy, squeeze mixture into egg. Just throw bag away when done – easy clean up.

Expanding Frosting When you buy a container of cake frosting from the store, whip it with your mixer for a few minutes. You can double it in size. You get to frost more cake/cupcakes with the same amount. You also eat less sugar and calories per serving.

Reheating refrigerated bread To warm biscuits, pancakes, or muffins that were refrigerated, place them in a microwave with a cup of water. The increased moisture will keep the food moist and help it reheat faster.



Newspaper weeds away Start putting in your plants, work the nutrients in your soil. Wet newspapers, put layers around the plants overlapping as you go, cover with mulch and forget about weeds. Weeds will get through some gardening plastic; they will not get through wet newspapers.



Broken Glass Use a wet cotton ball or Q-tip to pick up the small shards of glass you can't see easily.

No More Mosquitoes Place a dryer sheet in your pocket.. It will keep the mosquitoes away.



Squirrel Away! To keep squirrels from eating your plants, sprinkle your plants with cayenne pepper. The cayenne pepper doesn't hurt the plant, and the squirrels won't come near it.

Flexible vacuum To get something out of a heat register or under the fridge, add an empty paper

towel roll or empty gift wrap roll to your vacuum. It can be bent or flattened to get in narrow openings.

Reducing Static Cling Pin a small safety pin to the seam of your slip, and you will not have a clingy skirt or dress. Same thing works with slacks that cling when wearing panty hose. Place pin in seam of slacks and -- ta da! -- static is gone.



Measuring Cups Before you pour sticky substances into a measuring cup, fill with hot water. Dump out the hot water, but don't dry cup. Next, add your ingredient, such as peanut butter, and watch how easily it comes right out.

Foggy Windshield? Hate foggy windshields? Buy a chalkboard eraser and keep it in the glove box of your car. When the windows fog, rub with the eraser! Works better than a cloth!

Reopening envelope If you seal an envelope and then realize you forgot to include something inside, just place your sealed envelope in the freezer for an hour or two. Viola! It unseals easily.



Conditioner Use your hair conditioner to shave your legs. It's a lot cheaper than shaving cream and leaves your legs really smooth. It's also a great way to use up the conditioner you bought but didn't like when you tried it in your hair...

Goodbye Fruit Flies To get rid of pesky fruit flies, take a small glass, fill it 1/2" with Apple Cider Vinegar and 2 drops of dish washing liquid, mix well. You will find those flies drawn to the cup and gone forever!

Get Rid of Ants Put small piles of cornmeal where you see ants. They eat it, take it "home," can't digest it so it kills them. It may take a week or so, especially if it rains, but it works & you don't have the worry about pets or small children being harmed!

INFO ABOUT CLOTHES DRYERS The heating unit went out on my dryer! The gentleman that fixes things around the house for us told us that he wanted to show us something and he went over to the dryer and pulled out the lint filter. It was clean. (I always clean the lint from the filter after every load clothes.) He told us that he wanted to show us something; he took the filter over to the sink, ran hot water over it. The lint filter is made of a mesh material - I'm sure you know what your dryer's lint filter looks like. Well, the hot water just sat on top of the mesh! It didn't go through it at all! He told us that dryer sheets cause a film over that mesh, that's what burns out the heating unit. You can't SEE the film, but it's there. It's what in the dryer sheets to make your clothes soft and static free -- that nice fragrance too, you know how they can feel waxy when you take them out of the box, well this stuff builds up on your clothes and on your lint screen. This is also what causes dryer units to catch fire & potentially burn your house down with it! He said the best way to keep your dryer working for a very long time (& to keep your electric bill lower) is to take that filter out & wash it with hot soapy water & an old toothbrush (or other brush) at least every six months. He said that makes the life of the dryer at least twice as long!

How about that?! Learn something new every day! I certainly didn't know dryer sheets would do that. So, I thought I'd share!

Note: I went to my dryer & tested my screen by running water on it. The water ran through a little bit but mostly collected all the water in the mesh screen. I washed it with warm soapy water & a nylon brush & I had it done in 30 seconds. Then when I rinsed it the water ran right thru the screen! There wasn't any puddling at all!

That repairman knew what he was talking about!

Contributed via email Jo Hayden, member, 2/21/08.

THE ROLE OF THE FLUSH TOILET IN THE SPREAD OF POLIO

At a recent wedding reception I attended in Raleigh, North Carolina, I sat next to a lovely lady who was a long time friend of the bride, they both had worked in Public Health before their retirements. Pam (not her

real name) volunteered that her husband was suffering from post polio syndrome, which is a re-occurrence of many of the problems of polio even though the person may have been free of problems for many years. As she finished up her story about her husband, she asked the ladies at our table if anyone knew what was the cause of the polio epidemics of the 40s and 50s? No one at the table had a clue so she supplied the answer. She said, "It was the widespread use of the flush toilet."



I lost a teenage friend to polio in the mid 40s; her death left an indelible mark on my young life. The scourge of polio kept us from congregating in large groups, going to the movies or swimming in public pools. While I was intimately aware of polio, I did not know the flush toilet was the culprit behind the epidemics.

When I returned home after the wedding, I researched the connection between

polio and the flush toilet. While ironic, it is true, improved sanitation was the root of the dreaded epidemics.

Poliomyelitis is said to have first occurred nearly 6,000 years ago in the time of the Ancient Egyptians. The evidence for this is in the withered and deformed limbs of certain Egyptian mummies. (See "Poliomyelitis – A Guide For Developing Countries; including Appliances and Rehabilitation" by Ronald L. Huckstep; Published by Churchill Livingstone.)

From Wikipedia I learned that before the 20th century, there were cases of polio, but they were few and no major outbreaks occurred. The question then is how did polio emerge from centuries of obscurity to becoming a killer in just a few decades? The answer lies in a major change in sanitation practices. Before the advent of modern indoor plumbing and sewer systems, many cities had open sewers that were no more than gutters with outhouses in the backyard. Almost everyone had, at one time or another, been exposed to polio, and with open sewers and outhouses the norm – there was ample opportunity to contract polio.

Polio-viruses infected generations of babies, who were protected in part by antibodies passed on to them by their mothers. When a child became infected with the polio-virus the results were flu-like or cold-like symptoms. The diagnosis of polio was rare because the symptoms were often indistinguishable from other childhood diseases.

Cases of paralytic polio began to rise once changes in public sanitation and other health measures came about, such changes as purification of the water supply and milk

pasteurization. Better hygiene meant that babies and young were not receiving some immunization from their mothers. When the disease struck older children or adults, it was more likely to take the paralytic form.

In northern Europe and the United States, epidemics of paralytic polio began to appear in the late 19th and early 20th centuries, though small. Polio's full impact wasn't felt in the United States until the summer of 1916, when an outbreak resulted in 27,000 people paralyzed, and 6,000 deaths. The 1916 epidemic caused widespread panic and thousands fled the city to nearby mountain resorts. Movie theatres were closed, meetings were canceled, and the public gatherings were almost non-existent. Children were warned not to drink from water fountains; and children were told to avoid amusement parks, pools, and beaches.

From 1916 onward, a polio epidemic appeared each summer in at least one part of the country, with the most serious occurring in the 1940s and 1950s. In the United States, it would be the 1952 polio epidemic that marked the worst outbreak in the nation's history. Of the nearly 58,000 cases reported that year; 3,145 died and 21,269 were left with mild to disabling paralysis. Statistically, more children died of polio in 1952 than of any other infectious disease.

For more details visit *Bulbar Polio*, and *Polio*. Also see: *Polio and Clean Water* by John H. Lienhard. *The Crippling History of the Poliomyelitis Virus* by Dr. Patrick Treacy. (About midway down the page.) An extensive collection of articles on Polio from the Health Heritage Research Services of Canada.

Source: Courtesy of Toiletology 101 <http://www.toiletology.com/Polio-Toilet.shtml>

Reprinted from *FECPPSG*, FL, March/April 2010.

Graphic: <http://www.mrkerrison.co.uk/index7.htm>

CLEAN AND SIMPLE

If you've relied on "old-fashioned" cleaning solutions like vinegar for years, congratulate yourself. You've known all along what younger generations are now realizing.



More and more households are turning to environmentally friendly cleaning products that don't contain harsh chemicals. Equal parts white vinegar and salt, for example, makes a great all-purpose surface cleanser.

Baking soda is another tried-and-true cleaning staple. It's a scouring cleanser that's easy on surfaces, or can be added to a load of laundry to remove perspiration odors.

Not only are solutions like these chemical-free, they also cost a lot less than store-bought cleaning products – making the notion of going green about keeping more green in your pocket.

Reprinted from *Good Times*, FL, Spring 2010.

TIP

Every week, eat two three-ounce servings of seafood high in omega-3 fatty acids, such as salmon. It's good for your heart and your joints!



Reprinted from *Good Times*, FL, Spring 2010.

DON'T EVER STOP DREAMING



Don't ever be reluctant
to show your feelings
when you're happy, give in to it.
When you're not, live with it.

Don't ever be afraid
to try to make things better
you might be surprised at the results.

Don't ever take the weight of the
world on your shoulders.
Don't ever feel threatened by the future;
take life one day at a time.

Don't ever feel guilty about the past
what's done is done.
Learn from any mistakes
you might have made.

Don't ever feel that you are alone
there is always somebody there
for you to reach out to.

Don't ever forget that you can achieve
so many of the things you can imagine . . .
It's not as hard as it seems.

Don't ever stop loving
don't ever stop believing;
don't ever stop dreaming your dreams.

YEP! WE ARE GOING, AGAIN!!!

Join BAPPG on our ninth trip –
an amazing 7-night cruise to the Eastern
Caribbean. Celebrity's *Solstice* will depart
on **Saturday,**

January 29,
2012 from Port
Everglades [Ft.
Lauderdale, FL]
visiting Puerto
Rico, St. Thomas
& St. Maarten.



**Five (5) Inside accessible cabins are
left,** starting at **\$879.83** per person which
includes all tax and port charges. Ship is
accessible as seen by my eyes!

*So, if you just think you'd like to go, a
deposit will hold your stateroom. Don't
miss out!*

Contact Maureen at 561-488-4473 or
BAPPG@aol.com for questions, roommates,
or scooter rental.

***Patricia from FL and Gary from MO
need roommates. Anyone interested?***

Call Judith at 561-447-0750, 1-866-
447-0750 or Judith@travelgroupint.com for
booking/transfers & mention BAPPG.

Your RCCL status is honored on
Celebrity Cruise Line.

Thirty-four cruisers have booked already!!

Deposit fully refundable until 11/1/11.

CARS AND LIFTS

At our last meeting [Coastal Empire Polio Survivors Association, Inc.] we briefly touched upon the need to have the correct car for a lift to carry either a scooter or a power chair. Richard stressed the fact that if you are in the market for a newer car and see yourself needing a scooter or chair, either now, or in the foreseeable future, then you had better make your choice of a car a good one. The car you choose should be able to handle a 'class 3' hitch. Mostly all your full size SUV will handle it, but they may not be the type of auto you are seeking and may be too difficult to get into. A good alternative might be a smaller SUV that is rated for a class 3 hitch, but much smaller and easier to step into. Many vans also are a good choice as they can either take a hitch or else an inside lift can be adapted to lift and swing the chair inside. This way nothing will show on the outside. Any car you might be thinking of purchasing always check with the manufacturer to be sure it will handle a class 3 hitch. You can double check the information either online, or from a mobility company. They will give you the true story. If you have a chair or scooter why not make yourself completely mobile by adding the lift to your car.

CHAIRS AND SCOOTERS

Power chairs have smaller bases than in the past, allowing greater maneuverability indoors and improved power and suspension, allowing for greater access outdoors.

Today's power tilting system tilt and/or elevate to assist the user with both positioning and mobility. Seating systems

today provide optimal postural support and positioning to help enhance respiration and swallowing.

Some persons with PPS may prefer a scooter to a power chair. Smaller sizes of scooters will fold down and into smaller sections, but still each section may be too heavy for some, the process of disassembly and reassembly can be cumbersome, and a lift may still be required to raise heavier components, such as the batteries into a vehicle.

Scooters can also be more prone to tipping over.

Information about power chairs and scooters taken from *Managing Post-Polio* by Lauro Halstead, MD.

Reprinted from *The Lighthouse*, GA, March 2010.



BEGINNING WITH THE RIGHT ATTITUDE

I remember sitting in a very crowded restaurant, some years ago, during a business luncheon. Sam, an old friend from the insurance business, was my table companion. We had just ordered our meal when the headwaiter seated a middle-aged woman and her mentally retarded son next to us. Immediately, my luncheon companion became uncomfortable. When the retarded boy caught his eye, he reacted so quickly that he spilled some water on the cloth. Normal conversation was impossible, and I suggested that we leave and finish our discussion in my office.

Later on, I broached the subject to Sam. He told me that he had never been comfortable in the presence of handicapped people. He said he had great difficulty with his mother-in-law, who had suffered a stroke and was now living in a nursing home. It upset him so much to visit her that he had long since given up accompanying his wife on weekend visits. This was obviously something that he felt awkward about, since he was, by nature, a rather warm and compassionate person.

What does one do in a situation like this? Sam was a success-oriented individual who put a high premium on physical appearance and well-being. He had been blessed with good health all his life, and, other than a skiing accident in which he broke his leg, he had suffered little. Sam admitted to me that he was disturbed with his attitude and wished that he felt differently. He was now in a position where he was apt to see more disability (we all do

as we get older) and knew that he was making other people uncomfortable. Where could Sam begin?

Another man of my acquaintance wears a glass eye (probably called a prosthetic device). I found myself uncomfortable with him in face-to-face conversation simply because I was confused about which eye was real. The artificial eye did not focus and did not move, and it took a little time before I could get used to the fact that the good eye was really “talking” to me. Once I identified that and remembered which eye it was, I had no difficulty relating to the man in a normal manner. I became much more comfortable and now do not even consider this to be a problem.

When you come to the place where you do not remember that the person to whom you are speaking is handicapped, you probably have developed an attitude and a proper mindset that will make it possible for you and the handicapped person to become friends. It is when the handicapping condition stands between you and is an obstacle to normal relationships that you have a problem.

How can we get past this?

Fear of the Unknown

Almost always, the fear of the unknown determines how we respond. When a disability is thoroughly understood and “handled,” either physically or psychologically, it is always easier to cope.

One of my friends with cerebral palsy tells a very amusing story of traveling on the New York City subways. She was

constantly confronted by people who did not understand her spastic movements and would ask about her condition. There was never much time for an explanation, and she obviously could not go into the forms of brain injury that are responsible for cerebral palsy. Instead, she hit on a couple of phrases that she thought would satisfy most people, so that if she was leaving the subway car and was asked, "What's the matter with you?" her stock phrases were "ski jump" or "lead poisoning"!

In addition to providing some fun in an otherwise embarrassing encounter, these phrases brought some measure of the known to a condition that was (is) largely *unknown*.

There is still a great deal of mystery surrounding handicapping conditions such as cerebral palsy, multiple sclerosis, stroke, muscular dystrophy, and mental retardation, to mention only a few of the common disorders. It is probably because these are largely permanent and irreversible physical maladies that the mystery persists. The causes are unknown and there are no cures.

If medical science cannot change or reverse such conditions, how can we, as ordinary citizens and friends or potential friends of the handicapped, make any difference in the life of a handicapped person? Are there things we should know and apply?

The answer is YES! *If we cannot change the physical condition, then we MUST change the environment in which the handicapped person lives. And the environment CAN BE CHANGED!*

We are a part of that environment, and we can greatly influence other parts of it, Or to put it another way, we can bring to bear what we know to enhance and improve the life of the disabled person.

Treating Disability "Normally"

What should be comforting to all of us as we encounter people with chronic disabilities is the fact that *virtually no chronic condition is contagious or "catching" in anyway*. This, and this alone, should help us all to realize that contact with handicapped people in no way jeopardized our own health. Armed with this bit of information, we can then go a step further in confronting the disability in the person we want to befriend.

Imagine walking into your office one morning and finding that your associate has his arm in a cast. What would be your first question? "How did it happen?" "What did you break?" "How long will you be in a cast?" these are natural questions raised when a person injures himself and obviously faces a convalescence. This is the cue for how we address the disabled person.

Most disabled people have those around them who "look past" their disability. They think they are being noble by ignoring the fact that the person they are talking to has an obvious physical or mental handicap. *It is a good rule that if the handicapped person we are dealing with has normal or near-normal intelligence, it is perfectly appropriate to ask him about his disability.* The very same questions are appropriate that would be addressed to the person with a broken arm. It is the normal course of friendly conversation. You will find that this

clears the air immediately and makes you aware of the fact that you have an obstacle to get by in “getting to” the “person” sitting in the wheelchair. In my experience, virtually every disabled person presented with this issue has preferred to confront people with the issue of his handicap early in their association.

Where a handicapped individual is *not able* to communicate or interpret his own disability, it may be in order to inquire of family members concerning the handicapping condition. It makes *them* feel comfortable and has the same basic effect as it would have on a disabled person.

There is an important clue in this bit of behavior that is the key to all relationships that one may have with handicapped people and their families. It is the principle of normalization. *Do what you believe to be “normal” under ordinary circumstances.* The illustration of the broken arm applies here.

Not all handicapped people and their families will respond to this approach. There may be people who still disavow that fact that they have a problem and are not anxious for you to bring it up. If you sense this to be the case, then you must react differently. As a general rule, confronting the disability in a forthright manner is almost always the best way.

Source: *How To Be A Friend To The Handicapped*, by Leslie D. Park, Vantage Press, Inc.

Reprinted from *The Sunshine Special*, FL, July/Aug 2008.

BAPPG Editor’s Note: *We are people first who happen to have a disability.*

Dr. Paul Donohue

TREATMENTS FOR ANNOYING TINNITUS



Dear Dr. Donohue: My son-in-law has tinnitus, a ringing in the ear. His doctor seems to think nothing can be done for it except some medication. Do you know of anything that can be done to alleviate it?
- R.C.

Dear R.C.: Tinnitus is ear noise described as ringing, hissing, buzzing, roaring or pulsating in sync with the heartbeat.

If you put a normal person in a soundproof room, that person develops tinnitus in a short time. The noises of the outside world, constantly bombarding the ears of a normal hearing person, suppress the inner noises of tinnitus. The point is that one big cause of tinnitus is hearing loss. The outside noises aren't heard, so the affected person hears tinnitus noises. If hearing loss is the cause, hearing aids can improve hearing and decrease tinnitus.

Other tinnitus causes include a buildup of ear wax. A tumor of the hearing nerve is another possible cause. Caffeine and nicotine make tinnitus worse. Some thyroid conditions can be responsible. Medicines can produce it – drugs like aspirin, anti-inflammatory medicines and the water pill furosemide.

A tinnitus masker, a device like a hearing aid, emits a sound similar in pitch to the tinnitus sound, and that often blocks tinnitus. The audiology department of the Cleveland Clinic uses a procedure called neuromonics in selected patients. A special device delivers music and a sound customized specifically for each patient so the patient can accustom the brain to block out tinnitus.

Have your son-in-law contact the American Tinnitus Association at 800-634-8978. Its web site is ata.org.

Reprinted from *Sun Sentinel*, FL, 11/13/08.

Contributed by Jane McMillen, member.

DID ROOSEVELT HAVE POST-POLIO SYNDROME? DISABILITY ENCYCLOPEDIA?

The medical evidence is limited by the absence of any continuous medical history from 1928 to 1944. These 16 years witnessed FDR in the governorship and the presidency. Apart from intermittent examinations to document his health for the electorate and to treat chronic sinusitis by his White House physician, Ross McIntyre, there is no record of his various illnesses. The laboratory reports during his presidency were stored under a pseudonym at the U.S. Naval Hospital in Bethesda, Maryland, and could not be found after his death. The most comprehensive and authoritative report was made by Howard Bruenn, a young cardiologist who treated him from March 27, 1944, to April 12, 1945. Bruenn, diagnosed him with hypertension, hypertensive heart disease, left ventricular cardiac failure, and acute bronchitis. He recommended bed rest, limited work up to four hours per day, digitalis, a light and easily digestible diet, restricted salt, codeine for cough, sedation at night for sleep, and gradual weight reduction. The gaunt, haggard facial appearance of his last days was due to the loss of weight. Bruenn treated him for 12 months with no significant reduction in blood pressures, which fluctuated widely, from 170/88 to 240/130. Despite occasional chest pain, with one notable episode of substernal pain, FDR avoided an acute myocardial infarct or stroke until April 12, when he died from a massive cerebral hemorrhage. He was 63.



The confirmation of post-polio syndrome (PPS) cannot be made from Bruenn's clinical notes. The only evidence we have is completely anecdotal. Members of his family and of his inner circle of White House aides reported that he had lost muscle strength and endurance as early as 1941. The evidence is consistent with current criteria for diagnosing PPS after 15 years of neurological and functional stability. Moreover, he had less time for aerobic exercise such as swimming and for periodic rest such as frequent vacations due to the unprecedented stress of the world war. He was intolerant to cold, requiring extra warm blankets at home and while traveling to distant lands. After April 1944, Bruenn stopped his swimming in the White House pool because of hypertension. Although some of these symptoms may be caused by vascular disease, they are also indicative of PPS.

Did the late effects of polio contribute to his hypertension and hypertensive heart disease? In my conversations with Bruenn, he said that FDR's blood pressures were essentially normal during his first two terms. He was very active, swimming almost daily in the White House pool, traveling to Warm Springs, and going on frequent fishing trips for relaxation. The muscles in his legs were atrophied, so he used only his arms for moving his wheelchair and for swimming. During the war years, polio prevented him from managing muscle weakness and getting proper rest. Other causes of hypertension, such as renal disease, were absent.

Final analysis? Yes, FDR had Post-Polio Syndrome.

Reprinted from *Polio Epic, Inc.*, AZ, Apr/May 2009.

Graphic: <http://americanhistory.si.edu/polio/howpolio/fdr.htm>

Nursing in practice:

FAILURE TO DIAGNOSE POST POLIO SYNDROME “AFFECTS THOUSANDS”

Healthcare professionals were today (15 October 2008) urged to increase their awareness of Post Polio Syndrome (PPS), as a recent survey carried out on behalf of the British Polio Fellowship revealed that 55% of GPs are unable to diagnose the debilitating effect of the condition.

An estimated 120,000 people in the UK today were affected by polio – now largely eradicated in the UK. Up to 80% of these will develop PPS, a neurological condition which can be as debilitating as polio itself.

PPS can arise 20-40 years after the initial disease. Symptoms include: muscle wastage, muscle and joint pain, and mental and physical fatigue, as well as impaired circulation and breathing. However, proper diagnosis and treatment can stabilize and reduce the progress of PPS and dramatically improve lives. Without treatment, symptoms will deteriorate, affecting not only the lives of the individuals concerned and their families, but having a knock-on economic impact through withdrawal from working life, dependence on benefits and increased use of NHS services.

Graham Ball, Chief Executive of the British Polio Fellowship said: “PPS is a major problem for many thousands of people and for those who aren't diagnosed. Their symptoms will deteriorate. “We know from our members that many people who have

had polio may not be aware that PPS might affect them and therefore not understand their symptoms. If their GP also doesn't recognize the symptoms, then what chance do they have? There is clearly an urgent requirement for GP's to be trained in the diagnosis of PPS.” The British Polio Fellowship is calling for a Read Code to be created for PPS and for all cases of polio to be registered by each GP surgery to facilitate faster recognition of the condition.

It also urges government support for the development and implementation of training modules in PPS across the primary care field, and for PPS to be reviewed by the National Institute for Health and Clinical Excellence, leading to accepted national guidelines on diagnosis, treatment and management of PPS. The survey's findings are supported by a further British Polio Fellowship survey carried out amongst the organization's 8,500 members. This revealed that it takes a shocking average of six years to get a diagnosis for PPS.

Dr Steve Sturman, Consultant Neurologist at City Hospital, Birmingham said: “PPS is a serious condition but early diagnosis can alleviate symptoms and delay deterioration. “Many medical personnel could be unknowingly working with someone with undiagnosed PPS – from physiotherapists, to nurses and GP's. We urgently need to raise the profile of this disease and ensure that everyone with PPS is getting the treatment they need.”

Reprinted from *Polio Epic, Inc, AZ, Apr/May 2009.*

Play a leading role in your care.

TAKE CHARGE OF YOUR HEALTH

When you're sitting in the doctor's office wearing a paper gown, it can be easy to forget you're in charge.

Modesty aside, however, it's your duty to make sure your health care needs are being met. Doctors have the medical training, but you know yourself. So speak up and take an active role in your care.



To begin, never be shy about asking your doctor questions. If you don't understand the answer, ask again. If you have uncertainties about medicines, your pharmacist is another great resource.

If you have a new diagnosis or your doctor is giving you a lot of information, take notes and ask for printed materials to take home. Consider bringing someone with you to the doctor, especially if you have trouble hearing.

It's also important to talk honestly with your doctor about your lifestyle and how you've been feeling. Before your appointment, write down things you'd like to discuss.

Keeping an organized file of insurance and health records can save you time, especially if you see multiple doctors. The more detailed the better, but be sure to include this information:

1. Names and phone numbers of people to call in an emergency.
2. Contact information for all of your doctors.
3. Details about health insurance you may have in addition to Medicare, including ID numbers and customer service contacts.
4. A list of current medications and dosages.
5. Details of major illnesses, hospitalizations and surgeries, including dates.

And never forget: It's your health, so be proactive in taking care of yourself and seeking information.

HOW TO PREPARE

As you get ready for your next doctor's visit, use this checklist to remember what to bring with you:

- A file of your insurance and health records.
- Information about how you've been feeling lately, including new or worsening symptoms.
- Updates about any changes in your lifestyle, such as different sleeping habits or a new living arrangement.
- Questions you want to ask, starting with the most important first, written down to help you remember them.
- All your medications, including vitamins and supplements, in their original bottles so your doctor can check for possible interactions or medication errors.

Reprinted from *Good Times*, Spring 2010.



COMMENTS

Doreen Chandler, Auckland, New Zealand:

We recently “found” your “SECOND TIME AROUND” newsletter on the net and were so taken with it that we have included several of your articles in our newsletter “PolioHAPPENINGS” issue 57 for June 2011 and have already received much comment on them from many of our members. Special mention has been made about the article by Cheryl Elliott ‘The Polio Family’ which so closely relates to so many of us. We admire your ‘sharing and caring’ attitude which is the same as we work with here. Congratulations on your 15th Anniversary, we celebrated our 20th on the 29th of March 2009. I formed the Group in 1989 after being President of the United Disabled Club 64, which was a Club for all disabilities, for 5 years. We have over 200 members and usually publish our newsletter prior to our quarterly Group meetings but decided to cancel the June meeting this year as so many of our members are finding the cold winter weather harder to cope with. I am very involved with the Group in Hawaii and was instrumental in restructuring their Group to run on similar lines to ours, in the early 1990’s, and we visit Hawaii regularly to renew our friendships up there. My husband Ramon is an Amateur Radio ‘ham’ operator and has many friends there and all over the world. I know that Jane and Larry Marcum who are very close friends of ours enjoyed joining you on one of your cruises. I contracted polio in 1958 at the age of 27. I was married with 2 children aged 6 and 19 months and was expecting another which I ‘lost’ during my 2 year stay in hospital. I used to be able to walk with calipers [braces] and crutches but have been wheelchair bound and cannot stand or walk since 2000. It doesn’t stop us from enjoying a very full life style though.

We are good friends of Tessa in Western Australia and have met her twice at conferences in Auckland in 1994 and Melbourne in 2000. She is a very fine lady and does so much to help polio survivors. Kind regards to all at Boca PP Group. Take care and best wishes. *President, Auckland Post Polio Support Group, Inc.*

Nadia Amato, Sarasota, FL: Thank you so much for your help!!! I look forward to receiving “Second Time Around” every month. Keep up the good work!

Wayne R. Rosen, CPO, Pompano Beach, FL: What an awesome newsletter!!

Rick Van Der Linden, Hemet, CA: Good job on the newsletter. I always read it through. Wish I had time to cruise with you kids. I’m honored you reprinted my article, and thanks for giving proper credit. *Editor, PPS Manager*

Gary Elsner, Boca Raton, FL: The newsletter is great!!



Contributed by Phyllis Varacalli, FL, 5/27/08.



MARK YOUR CALENDAR!

Central VA Post-Polio Support Group will host its 11th Annual Fall Retreat, Friday, October 14-16, 2011, Holiday Inn Express Hotel & Suites, Ashland, VA. Contact Linda ChatNLinda@aol.com 804-778-7891.

MISSION STATEMENT

- To help polio survivors become aware that they are not alone and forgotten.
- To share our thoughts and feelings with others like ourselves.
- To network with other support groups.
- To share information and encourage each other to carry on.
- To educate the medical profession in diagnosing and treating Post Polio Syndrome.
- To always maintain a positive attitude.

Boca Area Post Polio Group collects no dues and relies on your donations. If you would like to make a contribution please make your check payable to **BAPPG**.

Thank you for your support!

Maureen Sinkule
11660 Timbers Way
Boca Raton, FL 33428
561-488-4473

Carolyn DeMasi
15720 SE 27 Avenue
Summerfield, FL 34491
352-245-8129

Jane McMillen, Sunshine Lady - 561-391-6850

Flattery will get you everywhere!
Just give us credit:
Second Time Around, Date
Boca Area Post Polio Group, FL



SPREAD THE WORD. We would love to hear from you. If you know of someone who would like to receive our newsletter, send us the information below and we will gladly add them to our growing mailing list.

Name _____

Address _____

City _____ ST _____ Zip _____

Phone _____ Email _____

Comments _____

BOCA AREA POST POLIO GROUP
11660 Timbers Way
Boca Raton, FL 33428

**FREE MATTER FOR THE
BLIND OR HANDICAPPED**

RETURN SERVICE REQUESTED

MONTHLY MEETING

11:30 – 1:30 PM

Second Wednesday of each month
Spanish River Church

2400 NW 51 Street, Boca Raton
(corner of Yamato Rd. & St. Andrews Blvd.)

Sunset Room of Worship Center
Entrance and parking on west side

BOCA AREA POST POLIO GROUP

A Ministry of Spanish River Church

FOUNDERS

Carolyn DeMasi Maureen Sinkule

COMMITTEE MEMBERS

Pat Armijo	Jo Hayden
Irv Glass	Sylvia Ward
Effie Daubenspeck	Jane McMillen
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Danny Kasper	Nancy Saylor

E-mail: bappg@aol.com

Website: www.postpolio.wordpress.com

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