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**Would you like to serve on the  
executive or on a committee?  
Contact Faye Joudrey or  
Ginny Phillips.**

**PRESIDENT'S LETTER**

This has been a summer filled with challenges, pain, and much joy. I arrived in PEI for the summer on July 3rd and within an hour I fell and injured my back. I was taken to hospital by ambulance and spent 9 days getting pain controlled. I spent the rest of my summer using a walker or scooter when I was not lying on cold packs.

However, the best medicine and distraction for me was the August 1st week-end when my 4 children, their partners, and seven grandchildren arrived for a family reunion and celebration with Carlyle and me on our 50th wedding anniversary. We have a musical family so we had asked for musical gifts only. They put on a concert for us and 85 other friends and relatives that overwhelmed me with joy and love. It was a great distraction from pain! I have enough memories from that time to last a lifetime! I am back in Halifax now and hoping to get rehabilitated and regain some strength while assessing what new lifestyle changes I now must make.

At the May meeting Linda Muise presented me with a beautiful bouquet of flowers on behalf of Polio Nova Scotia. The next day Linda Haven arrived at my door with a large decorated anniversary cake that I was able to freeze and enjoy with my family in August. I thank all of you for your thoughtfulness, even though you really caught me by surprise.

We have not made plans for a fall meeting yet, but that will be added to the Newsletter when Linda gets all the information she needs. Next spring will mark the 20th anniversary of Polio Nova Scotia so if anyone has any ideas to share please let Linda or me know.

Ginny Phillips

**THE EDITOR'S MESSAGE**

What beautiful fall weather we are having down here in Yarmouth. I am hoping that everyone else is experiencing the same. Hope everyone had an enjoyable summer even though it was a bit rainy and we had two tropical disturbances already.

It is once again time to be thinking of the "Fall Meeting." This year we are going to be trying something different. We will be having the meeting on a Saturday afternoon. Someone thought it might give the out of town people a better opportunity to attend. It is our informal meeting and we are going to be discussing what the future will be for our group. We need your input into this so we hope that you will make an effort to attend.

Those of you who weren't able to attend the spring meeting missed a very interesting one. Dr. Donald C. Brown Founding Director, Dept of Family Medicine, at Dalhousie University Medical School, came and gave us a couple of demonstrations on medical hypnosis for sleep disturbance, pain, and stress. This was very informative and enjoyable.

Looking through some old newsletter I came across "The Ten Commandments of PPS." They were written in 1999 but it is something that never changes and it is good advice. Hope you enjoy them.

See you on October 24th at 2pm.  
Linda

## The Ten Commandments of PPS

***After 15 Years of digging, archaeologists from The Post-Polio Institute have unearthed 10 definitive "commandments" for treating post-polio sequelae.***

*By Richard L. Bruno and Nancy M. Frick, June 1999*

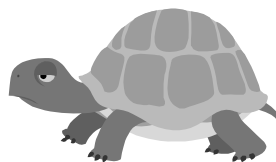


### **1. Listen to Your Body**

Polio survivors often turned themselves off from the neck down after they got polio. The first step in treating PPS is to listen to yourself: to what you feel, physically and emotionally, when you feel it and why. Our most powerful tool in treating PPS is the daily logs our patients keep that relate activities to their symptoms. Sometimes, however, you can listen too much: to salesmen who say some herb or supplement will "cure" PPS, to fellow survivors who warn that you will eventually have every possible PPS symptom, and to friends and family members--and the voices in your own head--saying you're getting lazy. Polio survivors need to listen to their own bodies, not to busybodies.

### **2. Work Smarter, Not Harder**

Many polio survivors believe that if they walk around the block five times a day, spend an hour on the exercise bike and take extra trips up and down stairs, their muscle weakness will go away. The opposite is true: The more you overuse your muscles, the more strength you lose. Muscles affected by polio lost at least 60 percent of their motor neurons; even limbs you thought were not affected by polio lost about 40 percent. Most disturbing is that polio survivors with new muscle weakness lose on average seven percent of their motor neurons per year, while survivors with severe weakness can lose up to 50 percent per year! Forget about "use it or lose it." You need to "conserve it to preserve it." Stretching may help pain, and nonfatiguing exercise for specific muscles can prevent you from losing the strength you have after you get a brace. But polio survivors need to work smarter, not harder. Remember the Golden Rule for polio survivors: If anything causes fatigue, weakness or pain, don't do it. Or do lots less of it.



### **3. Go Slow and Steady**

The follow-up study of our patients showed that taking two 15-minute rest breaks per day--that's doing absolutely nothing for 15 minutes--is the single most effective treatment for PPS symptoms. Another study showed that polio survivors who pace activity--that is, who work and then rest for an equal amount of time--can do 240 percent more work than if they push straight through. Our patients who take rest breaks, pace activities and conserve energy have up to 22 percent less pain, weakness and fatigue. But polio survivors who quit or refuse therapy have 21 percent more fatigue and 76 percent more weakness. For polio survivors, slow and steady wins the race.

### **4. Be Kind to Your Neurons**

Using crutches or braces are not signs of failure or of "giving up." You use one third of the energy--and look better walking--using a short leg brace on a weakened leg. Muscles and joints hurt and nerves die after decades of doing too much work with too few motor neurons. So why not use a brace, cane, crutches --dare we say even a wheelchair or scooter--if they decrease your symptoms and make it possible to finally take

## The Ten Commandments of PPS - continued

that trip to Disney World? We know, you'll slow down and take care of yourself "when you're ready." And you'll use a wheelchair "when there's no other choice." Well, you don't drive your car until it's out of gas. Why drive your body until it's out of neurons?



### 5. Say No to Drugs, Unless ...

Five studies have failed to find any drug that treats PPS. And no studies show that herbal remedies or magnets reduce symptoms. Don't think that you can apply a magnet or pop a pill to make your PPS disappear. Pain, weakness and fatigue are not-so-subtle messages from your body telling you that damage is being done. Masking symptoms--with magnets or morphine--will not cure the damage. However, two studies have shown that polio survivors are twice as sensitive to pain as everyone else and usually need more pain medication for a longer time after surgery or an injury.

### 6. Sleep Right All Night

The majority of polio survivors have disturbed sleep due to pain, anxiety or sleep disorders such as sleep apnea or twitching muscles. However, you may not be aware that you stop breathing or twitch. If you awaken at night with your heart pounding, anxiety, shortness of breath, choking or twitching, or if you awaken in the morning with a headache or not feeling rested, you need a sleep study. "Post-polio fatigue" may be due to a treatable sleep disorder.

### 7. Turn Up the Heat

Polio survivors have cold and purple "polio feet" because the nerves that control the size of blood vessels were killed by the poliovirus. Actually, your nerves and muscles function as if it's 20 degrees colder than the actual outside temperature! Cold is the second most commonly reported cause of muscle weakness and is the easiest to treat. Dress in layers and wear socks made of synthetic fabrics like breathable fiber polypropylene that hold in your body heat.



### 8. Eat Breakfast or Else

Mom was right. Many polio survivors eat a Type A diet: no breakfast, coffee for lunch and cold pizza for dinner. A recent study shows that the less protein polio survivors have at breakfast the more severe their fatigue and muscle weakness during the day. When our patients follow a "hypoglycemia diet" (16 grams of low-fat protein at breakfast and small, non-carbohydrate snacks throughout the day) they have a remarkable reduction in fatigue. Protein in the morning does stop your midday yawning.

### 9. Anesthetize with Care

Polio survivors are easily anesthetized because the part of the brain that keeps them awake was damaged by the poliovirus. They also stay anesthetized longer and can have breathing trouble during and after

## The Ten Commandments of PPS - continued

anesthesia. Even nerve blocks using local anesthetics can cause problems. You should have lung function tests before having a general anesthetic. Your complete polio history and any new problems with breathing, sleeping and swallowing should be brought to the attention of your surgeon or dentist--and especially your anesthesiologist--long before you go under the knife. You should never have same-day surgery or outpatient tests (like an endoscopy) that require an anesthetic.



### 10. Do Unto Yourself as You Have Been Doing for Others

Many polio survivors were verbally abused, slapped or even beaten by therapists or family members after they had polio to "motivate" them to get up and walk. So polio survivors took control, becoming Type A superachievers, doing everything for everyone except themselves. Many polio survivors do for others and don't ask for help because they are afraid of being abused again. Isn't it time you got something back for all you've done for others? Accepting assistance is what can keep you independent. Appearing "disabled" by not doing for others and asking for help may be frightening, but they are also the best ways to manage your PPS.

*Richard L. Bruno is the Director of The Post-Polio Institute at New Jersey's Englewood Hospital and Medical Centre, and Chairperson of the International Post-Polio Task Force. Nancy M. Frick is Executive Director of Harvest Center in Hackensack, N.J. Articles describing the research mentioned above can be found online at: [http://websitesbycook.com/poliosurvivors/the\\_ten\\_commandments\\_of\\_pps.html](http://websitesbycook.com/poliosurvivors/the_ten_commandments_of_pps.html)*

## My Polio Experience

### Twice Lucky! By Caroline Scott



At age three I developed a sudden illness that was diagnosed as polio. My memory of it really does not exist. However my older sister and brother assured me that it had occurred. My family had moved recently and the older ones were beginning to adjust to new schools and hopefully new friends. Quarantine disrupted their teenage lives again. While I often questioned the reality of my illness, in retrospect I was showing the less obvious effects – intolerance to cold, inability to do repetitive exercises and reduced endurance. Since there were no paralytic effects, I thought it was just the way I was made.

Fast forward some sixty years to the rapid onset of a viral-like illness with rapidly increasing weakness. I was unable to climb stairs or get up out of a chair, was falling, and had neck stiffness and pain primarily in my arms and legs. Then admission to hospital where neurological examinations with EMGs showed both old (polio) and new damage. That more recent illness gave me a sense of what others had experienced back during the years of polio epidemics – the incapacity, the pain, the wondering if I would improve, the long days and months of physiotherapy. My first time in the pool was an experience I won't forget – lying on a stretcher and being lowered into the water, unsure about my ability to float or move. As you would expect, the buoyancy made movement much easier and the future looked bright. I also became familiar with what it was like to require a wheelchair with all its problems – some great and some less so – access to buildings, bumps and holes in sidewalks and pavements, elevator buttons too high, hills that no one else would think were hills. People were amazingly helpful but the loss of independence, even temporarily, was truly enlightening.

Once again, although lengthy, my recovery was remarkable. However during that illness as an adult, I was privileged to share several weeks in a large (10 bed) open neurology ward with others suffering from major illnesses. I came to the absolute realization that being an inpatient or out-patient served only to increase my sense of wonder and admiration for those whose lives were interrupted, often as children, and who didn't have the good fortune I was given.

## Same Great Programs, ONE Great Name!

Easter Seals Nova Scotia is a local charity whose programs and services enhance the health, mobility, and independence of Nova Scotians with physical disabilities.

During its 78 year history, the name of our organization has changed a number of times. Since 1985, Easter Seals Nova Scotia has also been known to many as the *Abilities Foundation of Nova Scotia*. While this name has served our cause well, we have decided to relinquish this dual identity for the purpose of strengthening our message in the community.

From now on, we will assume one public identity – Easter Seals Nova Scotia - a name with worldwide recognition and long history of supporting people with physical disabilities in our communities.

Our aim at Easter Seals Nova Scotia stays as it always has, to create high quality programs and services for Nova Scotians with physical disabilities in areas of

- *Active Living* - Camp Tidnish and Take PART therapeutic recreation programs
- *Family and Community Support* - New Leaf Enterprises, Community Outreach, Polio Support network, and resource sharing
- *Assistive Devices* - Wheelchair Recycling Program and financial assistance for personal equipment.

Explore our new website at [www.easterseals.ns.ca](http://www.easterseals.ns.ca) for more information about these opportunities, our fundraising events, and ways that you can contribute.

## Book Reviews

### **Walking Isn't Everything** by Jean Denecke

The book describes what it was like to be a woman with a disability in the 1950's. It is available in both paperback and electronic formats suitable for assisted-reading devices and software. Paperback \$16.95 eBook formats \$12.95 Place your order on line at [www.CrystalDreamsPublishing.com](http://www.CrystalDreamsPublishing.com)

### **Love, War & Polio: the life and Times of Young Bill Porteous**

by Timothy James Bazzett

This is a bio/memoir kind of book, but it is also a wonderful primer on polio for the uninitiated, as well as on the WWII era. This book can be found by contacting [www.RatholeBooks.com](http://www.RatholeBooks.com)

## In Memoriam

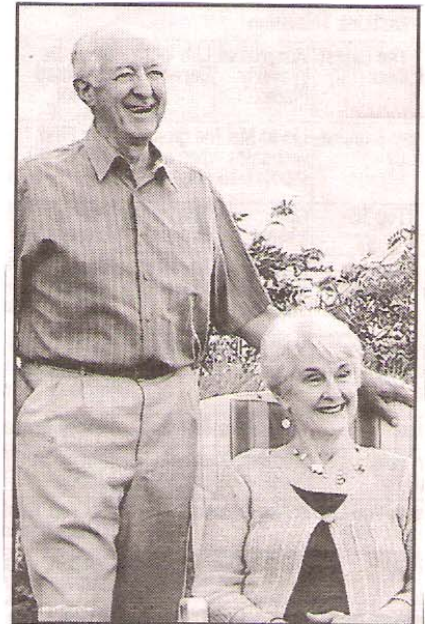


Mary Kyte of Port Hawkesbury and Yarmouth

## Mission Statement

## Announcements

Ginny and Carlyle Phillips  
50<sup>th</sup> Wedding Anniversary



### PHILLIPS

#### 50th Wedding Anniversary

Carlyle and Ginny Phillips of Halifax hosted a family reunion as well as celebrated their 50th wedding anniversary on August 1st at the "Family Compound" at Stanley Bridge, PEI. Attending were their four children and spouses, Brigham (Briar), Bruce (Karen), Michael (Crystal), and Heather (David), grandchildren (Alyssa, Julia, Joanna, Ramona, Molly, Calixa and Linden), as well as numerous relatives and friends. A musical celebration was provided by the children and grandchildren. Carlyle and Ginny have inspired and fostered a love of music in their children that has been passed on to the next generation as well. This is only one of the great gifts they have given. Love to Pops and Grammie from your children and grandchildren.

### Disclaimer:

*The opinions expressed in this newsletter are those of the individual writers and do not necessarily constitute endorsement or approval by Polio Nova Scotia or Easter Seals Nova Scotia.*