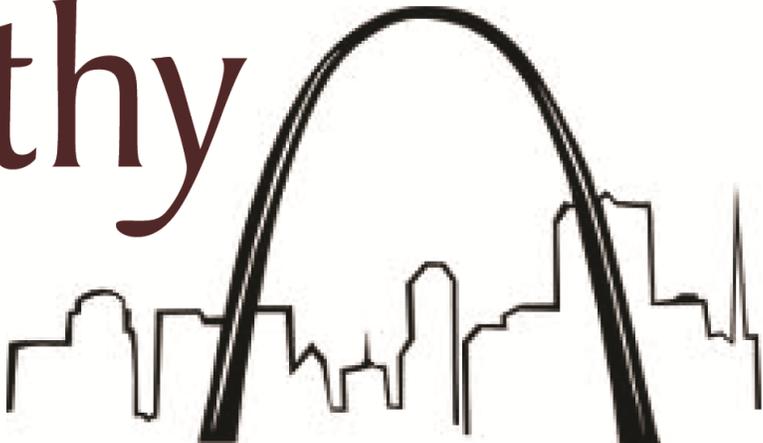


# Promoting Healthy Ideas

A stylized black and white line drawing of the St. Louis skyline, featuring the Gateway Arch as the central element. The arch is a thick, dark line, while the buildings behind it are represented by thinner, simpler outlines.

PHI's 11th International Conference

## Session Handouts

Saturday, May 31<sup>st</sup>, 2014  
Through Tuesday, June 3<sup>rd</sup>, 2014  
Hyatt Regency St. Louis at The Arch

**POST-POLIO HEALTH**  
INTERNATIONAL

POST-POLIO HEALTH INTERNATIONAL  
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

## Location of sessions on the Second Floor

- The Saturday afternoon Pre-Conference Session will be held in Regency A.
- The Saturday evening dinner will be held in Regency D. *Ticket is required.* Sunday and Monday dinner are not included. Join your friends for dinner in the hotel or area. See [www.explorestlouis.com](http://www.explorestlouis.com).
- The Sunday, Monday, Tuesday sessions will be held in Regency A, B, C, D and the specific room for each session is identified in this Program Schedule along with an abstract. An exception is “Exploring Exercise” which will be held in the Fitness Center and Room F.

**Questions from the audience** will be submitted to the speaker/moderator in writing unless otherwise announced in the session.

Post-Polio Health International thanks the presenters for providing the content of this book. If you share this information, you *must* acknowledge the authors of the material and state the following: *Prepared for Post-Polio Health International's 11<sup>th</sup> Conference: Promoting Healthy Ideas, May 31- June 3, 2014.*

**EMERGENCIES:** Call 911 and then call 55 in the hotel so they are alerted and can direct the emergency crew to you.

Saint Louis University Hospital is a Level One Trauma Center located at 3635 Vista at Grand Blvd., St. Louis, MO 63110, 3635 Vista at Grand Blvd, 314- 577-8000. To contact the Emergency Department directly, please call 314-577-8777. (3.8 miles; 6 minutes depending on traffic)

Barnes-Jewish Hospital Emergency Room, a Level One Trauma Center, is located at 400 S. Kingshighway Blvd., St. Louis, MO 63110, 314- 362 – 9123. (5 miles; 6-7 minutes depending on traffic)



POST-POLIO HEALTH INTERNATIONAL  
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

Welcome to St. Louis in 2014! Over the span of the past 33 years, PHI has coordinated 11 educational conferences for the post-polio community.

Each conference has been instrumental in identifying, articulating and solving problems and instigating action. PHI has always encouraged the involvement of survivors in their own communities. We are proud to welcome representatives from groups who can trace their beginnings to us, and we are proud that we have served the survivors of polio for almost 55 years.

I have always resisted the common practice of saying “all polio survivors,” because the over-generalization can unfairly stereotype survivors and prevent us from transcending our limitations. Undoubtedly though, we are bound by a common and unique experience and spending time with others has long-lasting effects.

Our theme, *Promoting Healthy Ideas*, asserts PHI’s view that we individually can, and must, be part of the solution as we age with a disability. For this reason, PHI’s goal at this conference is to arm each participant, including survivors, family members and health professionals with information and connections.

Thank you for coming. You are why we organize these meetings and why so many dedicated individuals volunteer their time and expertise.

Lastly, a message from our Board of Directors: Post-polio -- what does the future hold? We want your suggestions regarding the future of Post-Polio Health International. What kinds of programs would you find most helpful? To what extent should we rely on electronic means of disseminating information to our members and the wider world? Should PHI focus its efforts on polio survivors in the United States, Canada and the developed world or on the younger polio survivors in places like Africa, Asia and Latin America? Are you aware of the activities of International Ventilator Users Network (IVUN)? Should the organization continue and/or expand its activities related to survivors' breathing problems? Should IVUN continue and /or expand its activities to all medical conditions where home mechanical ventilation is an option? (e.g. SCI, ALS, etc.).

We will be providing various avenues for you to let us know what directions you think PHI should take going forward. The first opportunity is the closing session on Tuesday, June 3, which will be led by Dan Wilson and Bill Stothers, Members of the PHI Board. We invite you to join the conversation.

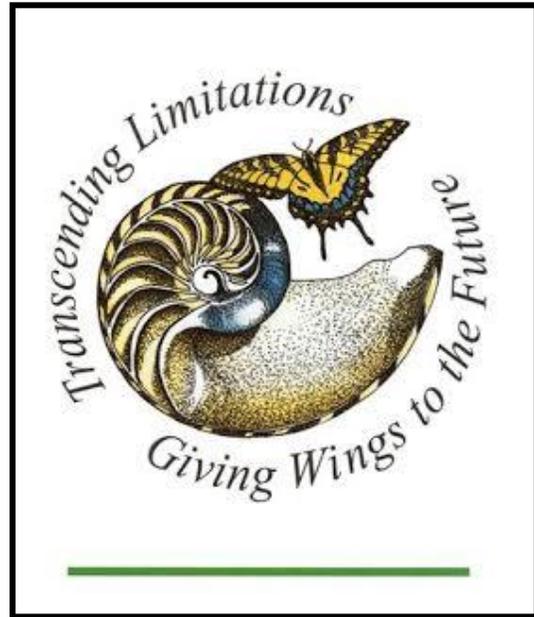
Joan L. Headley, Executive Director

Sunday, June 1, 10:45 – 12:00 pm  
Spirituality: It's Personal  
Alison (Sunny) Roller, MA

## Spirituality In Stillness: To Transcend, Transform, Then Transfuse

### Definitions

1. **Spirit** is “an animating or vital principle held to give life to physical organisms.”
2. **Spirituality** is defined differently by a variety of authors. There does seem to be a recurring theme, however. Spirituality is awe-inspiring and gives life meaning.<sup>1</sup> It refers to the core part of our beings that enable us to transcend any experience at hand and seek meaning and purpose, to have faith, to love, to forgive, to pray, to meditate, to worship and see beyond the physical here and now. Spirituality is the inner force that animates human life. Spirituality is related to religion, but is not the same.
3. **Religion** means being affiliated with a specific community, doctrine and set of rituals...and while religions aim to foster and nourish spiritual life—and spirituality is often a salient aspect of religious participation—it is possible to adopt the outward forms of religious worship and doctrine without having a strong relationship to the transcendent.”<sup>2</sup> Spiritual capacities enable one to transcend any experience at hand and seek meaning and purpose, to have faith, to love, to forgive, to pray, to meditate, to worship and see beyond the here and now. <sup>3</sup> Muldoon and King go on to say that spirituality is the spirit that animates human life, the inner force that fuels how we think and behave. It is breath, wind and spirit that give us life.<sup>4</sup>
4. **Inspiration**, then, is the act of breathing in, or a “divine influence or action on a person believed to qualify him or her to receive and communicate sacred revelation.”
5. **God**: the supreme or ultimate reality; the Being perfect in power, wisdom, and goodness who is worshipped as creator and ruler of the universe.
6. **Holy Spirit** is the spirit of God; the presence of God as part of a person's religious experience.
7. **Meditation** is a contemplative reflection or mental exercise designed to bring about a heightened level of spiritual awareness, trigger a spiritual or religious experience, or train the



<sup>1</sup> Kaye, J., & Raghavan, S.K. (2002). Spirituality in Disability and Illness. *Journal of Religion and Health*, 41(3), 231-242.

<sup>2</sup> Tate, D. G. & Forchheimer, M. (2002). Quality of Life, Life Satisfaction, and Spirituality: Comparing Outcomes Between Rehabilitation and Cancer Patients. *American Journal of Physical Medicine and Rehabilitation*, 81(6), 400-410.

<sup>3</sup> Kuhn, C. C. (1988). A Spiritual Inventory of the Medically Ill Patient. *Psychiatric Medicine*, 6, 87-99.

<sup>4</sup> Muldoon, M.H., & Kinf, J.N. (1991). A Spirituality for the Long Haul: Response to Chronic Illness. *Journal of Religion and Health*, 30(2), 99-108.

mind in a specific way. It can also include guided imagery, free association, and even hypnosis. Meditation is usually a longer and more intensive activity than prayer. (Newberg and Waldman)

8. **Transcend** means to rise above, to go beyond, to exceed, to excel.
9. **Transform** means to change the form of, to metamorphose, and to change in shape or appearance, to change in nature, disposition, heart or character.
10. **Transfuse** is to cause to pass from one to another, to cause to be instilled or imbibed.

### Key Ideas

- *The wonder of stillness, meditation and contemplation can combine with the power of physical disability to help us transcend and transform our post-polio disability. Once that has happened, if we choose, we can effortlessly transfuse people around us with their own renewed sense of enthusiasm, hope and inner strength.*
- *Some say that spiritual transcendence can help us face our physical differences and challenges "with a clearer perspective, rising above the limits and pain initially imposed by the disability." It's nice to think: "we are all spirits on earth who just happen to have a body."*
- *Thinking about the steps to meditation:*
  - *We can be still and take time to focus on the positive—in the here and now,*
  - *We can tune ourselves into the universe that I find inside me as opposed to outside of me.*
  - *We need to be still and call upon God to be with us in the present moment. It's more than prayer because prayer often involves a request of some type.*
- *Connecting to the divine spark within can transform our countenance. We are transformed with a spirit that glows from within.*
- *When you think of it, there is great irony in knowing that because we have lost muscle power, we have the potential to give muscle, vitality and strength to the world. And we don't even have to say a word.*

**Sunday, June 1, 10:45 am – 12:00 pm**  
**Travel Opportunities**  
**Bill & Barb Gratzke ([bbgratzke@aol.com](mailto:bbgratzke@aol.com))**

A modified, accessible RV may be your answer for vacations or to visit friends and family. You can travel at your leisure and have your assistive devices with you. No more carrying things in and out of a hotel. Also RVs may be the ideal solution for some on limited incomes. You can get free parking and a part-time income at many campgrounds and parks. You can relocate for good weather conditions or just to find a different view out your window. Below are some suggestions on where to start looking in the US:

(1.) **Factory direct and customized to your needs:** *Winnebago*, has a special section - Ability Products [www.winnebagoind.com/products/commercial/ability](http://www.winnebagoind.com/products/commercial/ability) ; *Newmar* [www.newmarcorp.com](http://www.newmarcorp.com) ; *K & D Custom Coach* ( 574-537-1716) Goshen, IN Mfg. of custom accessible RV's, [www.kdspecialtyvehicles.com](http://www.kdspecialtyvehicles.com) ; *Foretravel Motorcoach* in Nacogdoches, TX (800-955-6226)

(2.) **New - already customized:** *HL Enterprise* in Elkhart, IN has Harbor View Travel Trailers with 7 different floor plans and a park model that are all wheelchair accessible. Most of the trailers could be towed with a full-size lift van, if needed. Call John at (574-294-1112 ext. # 35) to find dealers in the US or visit. [www.hlenterpriseinc.com](http://www.hlenterpriseinc.com) ; for the *Newmar's Canyon Star 3911* visit their web site to find a dealer near you [www.newmarcorp.com](http://www.newmarcorp.com).

(3.) **Used that was customized by the owner** (find used by owner at [www.disableddealer.com](http://www.disableddealer.com); [rvproperty.com](http://rvproperty.com) ; [handicappedtravelclub.com](http://handicappedtravelclub.com) ; Craigslist and EBay

(4.) **New or used standard RV and have it made accessible by a mobility company:** *Creative Coach* in Lakeland, FL [www.creativecoach.com](http://www.creativecoach.com) (863-984-3439); *Clem's RV Sales* in Ellwood City, PA (800-747-1540) sells RV's and can get them modified.; *Star Tracks* in Elkhart, IN (574) 596-5331 specializes in building custom handicap accessibility for RV's and other modes of transportation. Their engineers can even design to any specification with any degree of automation needed. They can put a lift system in ceiling and automate so you can control RV functions through your cell phone. [www.startracks.org](http://www.startracks.org) ; *Mobility Works* (corporate# 330-633-1118) has multiple location in U.S. [www.norcalmobility.com](http://www.norcalmobility.com) (800-225-7361)

**Tips:** RV rallies (i.e. FMCA & Good Sam) offer seminars to teach you how to make your RV experience the best possible; [www.rv-dreams.com](http://www.rv-dreams.com) is a great place to go to look at expenses to expect when you own an RV; Use [www.rvparkreviews.com](http://www.rvparkreviews.com) to get find best campgrounds; [www.handicappedtravelclub.com](http://www.handicappedtravelclub.com) is a group of RVer's and those that just love to travel; go to [www.roadtripamerica.com](http://www.roadtripamerica.com) and put wheelchair accessible in the search engine to find accessible sight-seeing places. Find out what is on every exit of Interstates by book "Exit Now". Check out work programs of Parks and Campgrounds where you park free and work P-T.

**Sunday, June 1, 10:45 am – 12:00 pm**  
**Travel Opportunities**  
**Jean Hartley**

Up, up and away! Many prefer air travel for domestic and international trips. The advantage is time and speed. For some, the downside can be cost, airport layovers, and less comfort than the “old days”.

Jean will share her experiences as a senior traveling alone in coach class to 34 countries. Most of her travels have been to “hard places” as a teacher: Africa, Russia, and Eastern Europe. Lately she is accompanied by her Pride scooter stored in cargo. Her survival secrets are not new:

1. RESEARCH your destination carefully through books/articles by disabled writers who “know”, specialized websites, and friends/agencies at your destination.
2. PLAN your air travel 3 to 5 months ahead using a combination of on-line services, airline personnel and travel agents.
3. SPEAK the language of the locale or find a native-speaker companion.

The survival secrets are many but comforting if your journey is to be safe and memorable.

Join Jean for her part in Sunday’s Travel Panel at 10:45 am, view her website, [www.accessiblehawaii.com](http://www.accessiblehawaii.com), YouTube video, and new book “Go Beyond.”

Jean Hartley, Director of the nonprofit organization Accessible Hawaii.

Kailua Kona, Hawaii

Sunday, June 1, 10:45 am – 12:00 pm  
Assessment: Our Home  
Cyndi Jones

## Basic Home Access, Visit-Able Communities © Concrete Change 2011

### What Is Basic Home Access? (Also known as “Visitability” or “Inclusive Home Design”)

Visitability is a policy campaign to make key access features standard practice in virtually ALL new houses. Most homes have steps at every entrance, and bathroom doors narrower than other doors. Basic Home Access involves a fundamental change in construction practices to include the three key features essential for visitability:

- One entrance with zero steps.
- 32 inches of clear passage through all interior doors, including bathrooms.
- At least a half bathroom on the main floor, preferably a full bath, and preferably with designated maneuvering space.

Visitable homes have *at least* these three features. A few additional, low-cost Universal Design features may be incorporated-- but to apply to virtually ALL new houses, the list must be short; include the essentials; and be cost-effective. When space allows, including a full bath and bedroom space on the main floor makes a home not only visitable but livable for people with mobility impairments.

### What Are The Benefits?

- Basic access has **major health benefits**: Fewer falls because people (especially older people) don't have to try to manage a step and an entry door at the same time. Less stress on caregivers, whose disabled family members can enter and exit their own homes without being carried and fit through their own bathroom doors. Less depression because people with disabilities can visit the homes of their friends and extended family.
- If disability occurs, the disabled person and their family are more **able to remain in their existing home and community** --- rather than facing expensive renovations, or being forced to move to a different house or a nursing home.
- **All residents find it more convenient** to bring in baby strollers, grocery carts, bicycles, furniture and other items that don't move easily through narrow doors or up steps.
- Residents can **welcome guests** who use wheelchairs or walkers or have other mobility impairments. When basic access is in place, **mobility-limited people are included, not barred by architecture** from visiting others.
- Visitability features **enhance sale and re-sale** in an era where the older demographic is growing rapidly. 88 million U.S. residents will be over 65 by 2050, more than 20% of the population (Census Bureau 2008).
- Visitability is a **“green” issue**. Tearing out existing doors to install wider doors and remodeling existing entrances wastes money, energy and materials. Experienced remodelers state that 75% to 90% of all disability-related remodeling costs would be saved if a zero-step entrance and adequate bathroom door widths were already in place.

- Zero-step entrances on new homes are nearly always **easy to construct**, on flat *or* hilly terrain. The entrance can be at the front, side, back, or through the garage--- wherever is most feasible for the topography--- and nearly always can be achieved without a “ramp,” by grading so that the sidewalk meets a porch. For the 40% of houses built on a concrete slab, constructing the zero-step entrance is usually extremely easy. For houses with basements or crawl spaces, several solutions provide low-cost, attractive zero-step entrances.

What about **townhouses** (attached single-family)? There are also Visitability “best practices” for townhouses. See the townhouse text and photos at [www.concretechange.org](http://www.concretechange.org) in the “Construction” section.

- **The basic features cost little on new construction**---typically **zero to \$100** for a home built on a concrete slab, or about **\$600 dollars** for a home built with a basement or crawl space. In contrast, a typical cost of widening just one narrow interior door is \$700, and a typical cost of retrofitting for a step-free entrance is \$4,000 (often much higher).
- Visitability **makes fiscal sense** for society as a whole. **25%-60% of all houses built now will have, over the lifetime of the house, a resident with a severe, long-term mobility impairment.**<sup>1</sup> As of 2005, the average cost for one year of nursing home care exceeded \$64,000 per person per year<sup>2</sup> – 64% of which is paid with public dollars.<sup>3</sup> And, nearly 60% of all nursing homes residents enter directly from a hospital.<sup>4</sup> Architectural barriers are a force keeping many people from coming home from the hospital to their own homes.

### More on Doors and Bathrooms

All interior passage doors—including bathroom doors-- need to provide at least 32" of clear passage space when the door is open at 90 degrees. A 2'8" door does not suffice. 2'10" doors are readily available from the wholesale companies where professional builders buy supplies. Standard 3'0" doors are also excellent where space permits. Pocket (sliding) doors are another way to obtain 32-inch clearance.

Adding square footage is *not* necessary to accommodate a usable bathroom. Usually the existing plan already offers enough wall space for a wide door. If additional inches are needed, they can be shaved from an adjoining room.

It's not essential (although it can be helpful) to have a large turning diameter inside a residential bathroom. Even a small half-bath can accommodate the recommended 48" by 30" rectangles of open floor space beside commodes, sinks and tubs. In a small bathroom, the door can be hinged to swing out to give a person using a mobility aid enough room to shut the door when inside the room.

### Is Visitability Already Happening?

To some extent, yes. Federal law requires that every unit of new multi-family residences must have basic access if the building has an elevator, and every ground-floor unit in buildings without elevators. What about single-family houses? Whole neighborhoods of VISIBLE houses built for the open market already exist in Georgia, Texas, Arizona, Illinois, Ohio and elsewhere. These 50,000+ houses to date have resulted through policy decisions and legislative action. But the great majority of new single-family houses still are built with steps at all entrances and narrow doors. The change comes about through people being proactive to make it happen.

<sup>1</sup> "Aging and Disability: Implications for the Housing Industry and Housing Policy in the United States," *Journal of the American Planning Association*, Summer 2008.

<sup>2</sup> *Met Life*, 2005

<sup>3</sup> U.S. Department of Health and Human Services, 2007

<sup>4</sup> *Centers for Medicare and Medicaid Services (CMS) minimum data sets*



Sunday, June 1, 10:45 am – 12:00 pm  
Pain: It Gets Our Attention  
Frederick M. Maynard, MD

## Pain Problems in Post-Polios: References/Readings

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10. Waring W, Maynard F, Grady W et al : Influence of Appropriate Lower Extremity Orthotic Management on Ambulation, Pain and fatigue in the Post-Polio Population. Arch Phys Med Rehabil 70 : 371-375, 1989.

Sunday, June 1, 1:15 – 2:30 pm  
Assessment: Our Abilities  
Presenter: Hilary Boone

**Effective communication between patient and practitioner results in better outcomes.**

**Demonstration and discussion on tips for patients based on personal and others experiences.**

**Manual Muscle Testing is a form of assessing reported weakness.**

**If our first action produces a strong response then the tester will move on missing our lack of muscle endurance.**

**Time allowed for appointments varies.**

**We need to be selective on which issue/s we raise.**

**Looking honestly at how we do actions, realizing and noting the difference between now and an earlier time will provide more pertinent information and aid our assessing health professionals.**

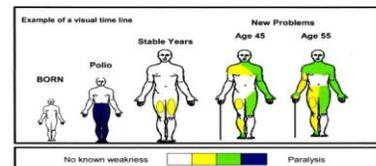
**Polio Survivors Network**  
www.poliosurvivorsnetwork.org.uk



PRESENT

## **'MY POLIO LIFE'**

A Self Assessment Patient Questionnaire  
to assist you with collating information on  
your Life as a Polio Survivor



### **My Polio Life - A Self Assessment Tool**

Created in May 2007 - Updated August 2011

**POLIO SURVIVORS NETWORK**  
PO Box 954, Lincoln, Lincolnshire, LN5 5ER, U.K.  
Tel: +44 (0) 1522 888601  
info@poliosurvivorsnetwork.org.uk  
www.poliosurvivorsnetwork.org.uk/publications/

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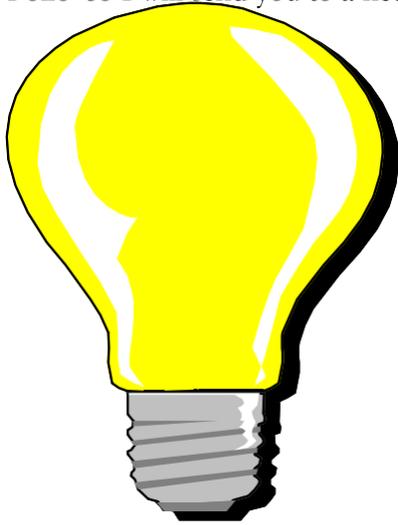
I would like to tell you a bit about 'my polio life' and how this led to the development of the self assessment tool. I had waist down paralytic polio age 5 in 1952 with good recovery probably due to my parents taking me out of hospital to swim in the sea every day once out of isolation. After operations on both feet at ages 12/13 I gained awards in Swimming, Lifesaving, Judo, Canoeing etc.

I was a mum with two children, fit, active and worked 60+ hours with average 12 more voluntary hours. However, In October 1988 I slipped on a wet patch on a school corridor and had pain in my left arm which progressed to weakness, fatigue and gradual functional decline of all my daily activities. As a Swimming Teacher and Senior Lifeguard who was always on the go I found it very difficult accepting what was happening to me. 7 weeks of pain killers and physio led to three weeks in hospital on neck traction then home for a months wait to see a neurologist. I thought about MS and because I had trouble remembering stuff late in the day Alzheimers as well.

Six months later and still no diagnosis. My Consultant suggested I go back to teaching swimming in the school hydrotherapy pool to see if I could cope. I managed ok but got quite a shock how weak I was when I went back to Life-saving training. How was I going to retake my Bronze Medallion needed for insurance to teach and lifeguard? As a strong willed determined polio survivor who had never given up on anything I trained almost every day for two months. At my final practice - 3 minutes are allowed to swim two lengths then tow your rescued body two lengths... and I came in at 4 minutes 15 seconds. Then I had to pull myself out of the water holding onto the hands of the 'towed body', stand and then pull them out of the pool. My Club Tutor said he was sorry but he was taking my name off the list for the exam the following week saying 'Go back to see your doctor because there is definitely something wrong with you. I went to see my GP who examined my arms again. You must have had this done 'Grip my hand tight, now link your hand with mine and try and push me over, do the same but this time pull me over.' I passed as normal, grade 5, told nothing wrong with my arms as before. It was not till some years later that I found out that all the health professionals thought that I was malingering and that this 'weakness' was all in my mind. I had to give up all my swimming teaching and lifeguarding work because being unable to retake my Bronze Medallion I now had no insurance. This was devastating, not only coping with what I knew to be real problems but having to give up jobs and voluntary work that I loved. Thankfully I found a job at the local Day Centre for the physically

handicapped and as an extra started learning British Sign Language. I continued to comply with the physiotherapy regimes set for me but I just got weaker.

In November 1995 - seven years later - I attended the Orthopaedic Clinic for the result of my MRI scan and was told by the Locum Doctor who I had not seen before 'I am glad you are better'. I replied 'I am not better, I have continued to deteriorate for 7 years now, I had polio as a child could that have something to do with my problems?' He replied 'Oh, I had another patient last year saying the same thing and found out there is something called 'The Late Effects of Polio' so I will send you to a neurologist.'



**It was like a light being switched on....**

**To learn that other Polio Survivors were reporting similar problems....**

**That it was first medically recorded in 1875.**

**It's most commonly called Post Polio Syndrome.**

**Post Polio Conferences started in 1980**

**This could be the reason for my 7 years of reported symptoms...**

**I was not going mad. I don't have MS and Alzheimers, it might be related to my Polio. It was such a relief.... But....**

**Sadly it took two more years and starting again at a second hospital before I received a confirmed exclusion diagnosis of the Post Polio Syndrome.**

Then in January 1998 I received a copy of a medical report from a neurologist with a statement that stunned me, 'on neurological examination of the legs, power at the left hip knee and ankle was normal'. My left quads were my weakest polio damaged muscles how could power be normal?

I arranged a private physiotherapist muscle assessment and again read 'left leg normal'. Then I remembered I had always wondered how I had passed a medical for the Police in 1969 when I could not run or rise from a squatting position. I decided that no health professional would report facts he did not believe to be true so there must be something wrong with the form of assessment used on me, namely Manual Muscle Testing done a single time.

Confirmation of my thoughts came in May 2002 when Dr. Halstead replied... [excerpt. 'If done only a single time it can give an erroneous idea of the true muscle strength and endurance'].

Dr. Maynard replied.. [excerpt - 'You have done a brilliant job of describing a real problem for polio survivors and health professionals that is, the limitations of Manual Muscle Testing']

Further research added more - W.J.W. Sharrard, M.D. . Muscle recovery in poliomyelitis. Journal of Bone and Joint Surgery (BR) 1955;37:63-9 [excerpt - 'muscle grades of 3 were given to individuals with 85% denervation of the muscles']. Luiese Lynch in 'Manual Muscle Strength Testing of the Distal Muscles' [excerpt - 'It does not measure the ability of the muscle to function as part of a movement pattern']

If we self-assess and look at all our actions of daily living and compare how we used to do each action and how we do it now and we can see a change we can give our health professionals more detailed information. Instead of just saying 'my legs are weaker' add 'this is worrying me because two years ago I could climb a flight of stairs as most people do, but now I have to go up right leg first each step and in the last six months have to stop halfway to rest and get enough energy back to climb the rest..' If you can visually demonstrate **the changes** with a couple of photos showing physical ability and/or a timeline of coloured in bodies, or graphs showing decline it really does help.

**Monday, June 2, 9:00 – 10:30 am**  
**Staying Active: Mind and Body**  
**Beverly Schmittgen**

Almost 3 years ago, my husband and I made a very good decision to change our lifestyle. Due to our declining physical strength and endurance, it was time to move out of our large house with its 1 acre of land and move into a more manageable residence. Sometimes, with age comes wisdom! We chose a lovely new ranch house in a 55+ active seniors Del Webb community not far from where we had been living. It came with lawn care, snow removal and lots of social activities at the community lodge. I especially liked the friendly people that we met at the first few social events we attended. It seemed like we could be on a perpetual vacation! More fun and less physically-taxing work would be the motto of our new lifestyle.

It didn't all happen easily, of course—major change never does. Downsizing required us to spend several months dealing with all of our accumulated “stuff.” That meant sorting, discarding, selling, reorganizing and planning—both emotionally and physically challenging tasks. The question “What do we want or need to take to our new house and where will we put it?” had to be answered for each and every item. Despite all the work, difficult decisions and daily fatigue, we finally got settled in our new home just in time for the holidays. The first event we attended with other people in our new community was a lovely Christmas dinner dance. We were greeted warmly when we arrived and sat with friendly folks during the evening. That broke the ice. I soon decided I wanted to get more involved with activities at our lodge. I began participating in events that would expand my horizons mentally, strengthen my body physically and bring satisfaction to me emotionally.

First, I decided to try one of the exercise classes at the pool. I knew I should be doing more exercise to keep from losing strength and endurance. The lodge has a large inviting heated swimming pool where several classes take place weekly. I discussed the water aerobics class with the instructor and told her about my limitations. She encouraged me to adapt any of the exercises to my own abilities. She assured me that everyone in the class is very supportive of each other and that others also have physical difficulties. I tried it and liked it! I now attend this class for an hour twice a week on a regular basis. I enjoy it because everyone is so friendly and the instructor makes it fun! I discovered that I'm more flexible afterwards and have fewer joint pains, so it's been very successful! In the summer months, we use the outdoor pool where the sunshine and resort-like ambiance make it even more enjoyable. What a treat!

Soon after getting settled into our new home, I began carefully reading the monthly newsletter for other activities in our community that seemed interesting and mentally stimulating. The book club was a “natural” for me and they welcomed me instantly as a new member. I found I got to know people easily in this small group during our monthly meetings. I've read books I probably wouldn't have known about otherwise and have expanded my horizons greatly by discussing them. Keeping an open mind and stretching myself intellectually has been very beneficial, I decided. Other ways I've kept mentally active is to attend lectures at the Lodge to learn about local history, health concerns, travel, improving driving skills, bird feeders, etc., etc. I'm especially appreciative of the ease of parking and entering the Lodge where the walks are always cleared of snow and the parking is convenient. It is so much easier than attending events at buildings or homes that have stairs at the entrance or inadequate handicapped parking. I think I attend more events when I know I can arrive safely and without becoming overly tired.

Being with people I enjoy has increased my inner strength. I began reaching out to new people in our community at social events and during creative activities which have kept my spirits high. Attending Bingo Nights, a Derby Party, a Hawaiian luau and lots of potlucks are examples of the many fun times my husband and I have had at the Lodge.. By the time Memorial Day arrived half-way through our first year here, we felt much more acquainted with our neighbors. It lifted our spirits to attend the heart-warming veterans recognition and flag-raising ceremony on Memorial Day followed by a huge buffet breakfast at the Lodge. This event kicked off varied summer fun including day trips and lunch at interesting nearby places, an outdoor military concert on the lawn for the Fourth of July and a bus trip to Blossom Music Center for a picnic and outdoor concert. When fall approached, I decided to join the Glee Club since they seemed to be having a lot of fun singing familiar music. The group welcomed me into their fold and again I found myself making new friends. I found that singing makes me feel uplifted. I've enjoyed the weekly practice sessions which prepare us for our annual Christmas and spring concerts both at the Lodge and at nearby nursing homes. Sharing our music is an act of love, I believe! And now I converse with Glee Club members at many other events such as lectures, arts and crafts classes, and drama and music performances at the Lodge. It has been very rewarding to become a "joiner" and to extend myself beyond my previous pursuits.

All in all, moving into this seniors community has been one of the best changes in lifestyle I could have made at this time of my life. At last I'm not the only person who has physical limitations. No one here even seems to notice how differently I walk, and they certainly don't ask me any embarrassing questions. People are very considerate and often offer to help by opening a door or carrying something for me into the Lodge. I'm finding that lots of other residents have health issues which is why they moved here! I'm also learning to ask for help when I need it. I think I've finally accepted the fact that I cannot be totally self-sufficient and strong! It is not a weakness to accept this need to change and adapt—in fact, adapting to change is the only way to keep on living a satisfying life!

I will say that the most difficult adaptations I've had to make is when we travel. My husband and I have had many marvelous travel experiences taking tours in distant countries and locations. I thought I could continue going on tours by adjusting the amount of walking I do in a day and going at a slower pace. This worked for a few years, but on the last 2 trips we took, I found that I needed a wheelchair to be able to do much touring at all! My decreased energy level often left me exhausted by the end of a day and then I found I wasn't enjoying the trip. We have concluded that joining a tour group and taking long-distance flights just aren't feasible any more. Our new plan is to travel within the U.S. by car or minivan. That way, we can take my transport wheelchair or my scooter with us to take advantage of handicapped accessible sidewalks and buildings. We can also control the number of activities we do in a day, so that I can get sufficient rest and enjoy the sightseeing that suits our ability levels. Sometimes "less" really is "more"—focusing on fewer places at a slower pace for more in-depth enjoyment. My traveling days are not over yet, just adapted to my current abilities and interests.

In summary, I am so glad that we decided to "take the leap" of making a major change in our lifestyle. We are happy that we downsized before we were forced into it. Change is hard, but we also learned it has been very rewarding. I love this new lifestyle of being involved with like-minded people, living in a welcoming community of active senior citizens, and participating in activities that enhance my mental, physical and spiritual well-being. By adapting to change, I have been greatly rewarded with new friends and a new lease on life!

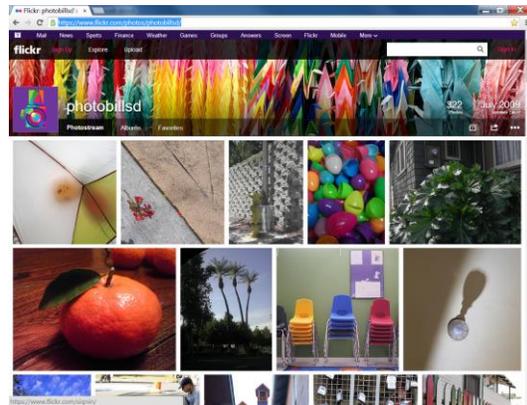
**Monday, June 2, 9:00 - 10:15 am**  
**Staying Active: Mind & Body**  
**William G. Stothers**

Resources:

This link is to my blog:  
<http://stothers.blogspot.com>



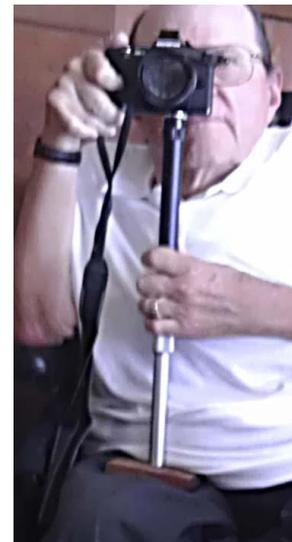
This link is to my photos on  
[www.flickr.com/photos/photobillsd](http://www.flickr.com/photos/photobillsd)



And here are some of the photo gizmos that I have put together to make it easier for me to handle my camera.



With a crutch tip on the bottom, this pole (originally meant to be a photo light holder) is height adjustable. A machinist created the cross piece which fits over the wheelchair crossbar to add more stability.



This is an old, old monopod that I have had for years. A friend recently crafted a nice piece of wood to provide more stability when I rest the pod on my thigh. I use this more than any other pod.

Replace the camera with this little device and it holds my smart phone. The next photo shows my phone in the holder, as someone takes the photo with a phone without such a holding gizmo.



Here is the phone holder (it's adjustable) with the monopod. There are several models on the market.

**Monday, June 2, 9:00 – 10:15 am**

**Let's Talk About the Spine: Medical Overview**

**Carol Vandenakker-Albanese, MD**

The spine: supports the trunk, stabilizes the limbs, protects the spinal cord and nerve roots, and allows multidirectional movement

### **Effect of Paralytic Polio on the Spine**

The polio virus attacks the cell body of motor nerves in the spinal cord, resulting in paralysis or partial paralysis of muscles. This causes asymmetry of skeletal or spine support and spine bone growth may be affected.

These changes result in: loss of bone strength, altered body mechanics, secondary deformity, increased stress on spine segments, and increased stress on supporting soft tissue. Related spinal Problems in the polio survivor include: spinal deformity, osteoporosis, accelerated degeneration, and symptoms related to nerve impingement secondary to spine degeneration can mimic post-polio syndrome.

### **Spinal deformity/ Scoliosis**

Risk of scoliosis in a polio survivor is 30%, Results from: asymmetric weakness of trunk muscles (intercostal, abdominal, paraspinal), pelvic weakness, tilt and/or leg length difference. The progression of curve correlated to degree of weakness and age at onset of curve. Bracing is often not successful in preventing progression and surgical fusion often recommended.

Risk of dramatic increase during adolescent growth spurt, however progression can continue after skeletal maturity due to degenerative changes: asymmetrical disk degeneration, vertebral compression fractures, lateral slippage of vertebrae (spondylolisthesis). Progression can cause: pain, nerve impingement, an unbalanced spine, bony pressure points, reduced lung function.

### **Osteoporosis**

Polio survivors are at increased risk of osteoporosis based on: reduced peak mass, reduced muscle action on bone, and reduced mobility.

Spine (vertebral) fractures may occur with falls / trauma or spontaneously if bone is very weak. Vertebral compression fractures may contribute to progression of spinal curves

### **Spine Degeneration**

Spine degeneration is common in the general population. Polio survivors often have increased stress on the spine related to loss or asymmetry of muscle support and altered mechanics of movement. Spinal curves often progress with degenerative changes. Degeneration in the spine can start with disc degeneration or arthritis in the facet joints. Degeneration in one area puts increased stress on the other structures and eventually degeneration occurs in both. Slippage of vertebrae, enlargement of joints and ligaments, and bulging discs all reduce the space around nerves (stenosis) and can result in nerve compression. Single level nerve compression can cause pain, weakness and/or loss of sensation in specific pattern in a limb. Pain may be constant or intermittent. Pain may be related to position or activity.

Spinal stenosis refers to narrowing of the spinal canal. It is commonly a result of degenerative changes including disc bulging, facet and ligament hypertrophy and osteophytes. Onset of symptoms is often gradual with progressive increase but may be acute. Symptoms can include: loss of balance, pain in buttocks or legs, deep ache in the legs that increases over time while standing or

walking. Pain is usually relieved with sitting, less when walking with shopping cart or walker (forward flexed position), and may confused with symptoms of post-polio syndrome.

Symptoms related to spine degeneration include: back pain, leg pain and/ or weakness, loss of sensation, change in bowel/ bladder control, difficulty breathing, increased fatigue, increased loss of balance, increased frequency of falls. Problems related to the spine may be confused with the symptoms of post-polio syndrome: new weakness, increased fatigue, leg pain with walking/ relieved with rest, increased difficulty breathing.

### **Treatment of Spinal Disorders**

Medical evaluation is important to identify cause of symptoms and focus treatment (Spine specialist). Treatment options for spine conditions include: physical therapy, medications for pain control, bracing, injection procedures, and surgical intervention for nerve impingements and unstable spine.

The pain medications commonly used include: acetaminophen (used in moderation – least side effects), anti-inflammatories (may cause gastritis/ ulcers), narcotics (cause drowsiness, fatigue, constipation, and tolerance) and neuroleptics (also cause drowsiness, “spacey” feeling)

Spine bracing is safe but not always tolerated. Braces may be semi-rigid or rigid. They reduce motion and provide support. They can be custom molded, semi-custom, or off-the-shelf. They may be uncomfortable, especially with sitting, but they do not cause harm.

Spinal injection procedures may be very helpful for inflamed nerves or joints. Nerve blocks can help alleviate pain from joint degeneration, but relief is usually temporary. If pain is severe surgical intervention may be considered. Surgery is also indicated when there is nerve compression with loss of function or an unstable spine. Spine surgery is often major surgery with significant risk involved.

Preferred management of spine conditions is conservative. A conservative program may include topical medications and modalities, change in lifestyle, activity modification and an exercise program that includes strengthening, stretching and cardiovascular conditioning . This treatment is usually taught through physical therapy.

### **Summary**

Spine problems in polio survivors are common. Common problems include:

- Scoliosis or other spinal deformity
- Osteoporosis
- Degenerative changes
- Nerve compression

Problems related to the spine may be confused with symptoms of post-polio syndrome:

- New weakness
- Increased fatigue
- Leg pain with walking/ relieved with rest
- Increased difficulty breathing

Treatment options include:

- Pain medications
- Bracing
- Injections
- Surgery
- Physical therapy

**Monday, June 2, 9:00 – 10:15 am**

**Let's Talk About the Spine: Physical Therapy Intervention**

**Cynthia Henley, PT and Kathryn Wollam, PT**

### **Introduction**

Physical therapy treatment for spinal pain and dysfunction requires a multifaceted approach. Treatment follows a detailed evaluation and is specific to the needs of each patient. No two backs are the same even with the same diagnosis.

### **Modalities**

Modalities are often utilized in the physical therapy treatment of spinal pain. Following an evaluation, a physical therapist will determine the appropriate modality for each patient situation.

The therapeutic application of heat and cold has long been utilized for pain control. Heat accelerates the metabolic process by increasing circulation. This helps flush out the waste products of a muscle spasm and reduces pain. Local cooling decreases the metabolic process thereby decreasing the inflammatory response. It offers an analgesic effect by decreasing nerve conduction and muscle contractibility. People with a history of polio are often less tolerant to the application of cold. Using moist heat adjacent to the cold usually makes it tolerable.

Myofascial release and soft tissue mobilization have been found to be effective in the treatment of back pain. Massage brings increased circulation to the area; aids in the release of muscle spasms; allows stretching of abnormal fibrous tissue; and increases extensibility of the soft tissues.

Ultrasound is a modality that uses sound waves to treat pain and promote healing. The thermal effects of continuous ultrasound cause increased friction and heat on a molecular level. This promotes healing by increasing the metabolism of the cells in the soft tissue.

Electrical stimulation can reduce pain by sending small electrical impulses through electrodes placed on the skin to underlying nerve fibers. Pain reduction can occur by blocking the pain signals to the brain or by causing a release of endorphins, natural chemicals in the brain which act as an analgesic.

This form of electrical stimulation is commonly known as TENS (transcutaneous electrical nerve stimulation). TENS should not be confused with EMS (electrical muscle stimulation) which can be used to stimulate a muscle contraction.

### **Therapeutic Exercise**

Therapeutic exercise refers to physical activities prescribed to improve function, correct an impairment or obtain a state of well – being by restoring strength, endurance, flexibility, stability and balance.

The first objective of the therapeutic exercise is to assist the body in reducing pain and inflammation. Once that is achieved, often in conjunction with modalities, the exercise focuses on improving range of motion, increasing muscle strength and endurance.

With polio affected muscles, if an exercise is too strenuous, certain signs of overuse may occur within 24-48 hours. These signs include muscle cramps or spasms, muscle twitching, moderate to severe muscle pain and extreme fatigue. This needs to be reported to your physical therapist so the exercise program can be modified.

*Stretching, Strengthening, Conditioning:* Muscle flexibility and joint range of motion are achieved through stretching and movement. The stretching helps lubricate the joints and prepare the nervous system.

Hold a stretch position for 20-30 seconds. Don't bounce into the stretch. People with spinal issues often have tightness in their lower back and hamstrings muscles. However, if paresis of the hamstring occurred with polio, these muscles are often overly flexible. Do not overstretch weak flexible muscles

Strengthening exercises are performed with resistance using weights, stretch bands, or your own body. Often the core muscles are weak with spinal issues. However, when complicated by a history of polio, the exercise guidelines must be observed. Increase resistance and number of repetitions cautiously. Watch for signs of overuse.

Endurance exercises engage large muscle groups over a longer period of time. When the muscles have good endurance, they will support the spine and provide postural stability throughout the day. When easily fatigued, the spine is subject to more biomechanical stress.

*Aquatic Exercise:* An excellent way to achieve improved flexibility, strength and general condition is with aquatic exercise. Aquatic exercise is very beneficial, as the buoyancy of the water will help to support weak muscles and decrease joint stress while it can also provide resistance to strong muscles. Exercises can be modified in the water and core muscles can be strengthened by using the resistance of moving both arms at one time.

### **Body Mechanics**

Body mechanics refers to the way we move during daily activities. Good body mechanics may protect the back from pain and injury. Adjustments during daily activities may be required to accommodate body changes related to aging, spinal dysfunction and polio related issues. Movement methods used in the past may not be safe and effective with the physical changes.

Good body mechanics and proper positioning can help protect your spine and may help alleviate some associated problems with digestion, swallowing and breathing. Following are some basic guidelines to help you with good body mechanics: of course, this can be difficult depending on your physical limitations. Supports, braces and positioning devices can help with proper body mechanics.

*When lifting an object:* Stand with feet apart, back straight. Bend from knees, not the waist. Get close to the object. Lift the object using your arm and leg muscles. Do not use your back muscles. Pivot to turn, do not twist. Ask for help if you are unable to lift the object.

*When carrying an object:* Hold the object close to your body. Do not carry things that are too heavy for you. The seat of a rolling walker can carry your lunch tray, a laundry basket or groceries and take the stress off of your spine.

*Sitting:* Sit on a supportive chair with armrests. Use a small pillow, rolled towel or lumbar roll to support your lower back. Sit on a wedge shaped cushion if there is significant atrophy of one buttock in comparison to the other. Do not sit for long periods of time. Get up and change positions.

### **Conclusion**

Physical therapy evaluation and treatment of spinal dysfunction provides intervention and guidelines for the long term management of symptoms. To maintain the results achieved in physical therapy, compliance with a realistic exercise program, simple lifestyle modifications and small adjustments to movement is essential. Improvements in spinal health and a general sense of well-being can be attained.

**Monday, June 2, 10:45 am – 12:00 pm**  
**Moving You to Better Health with the Lebed Method**  
**Laura Dowell, PT, CLMT**



**Healthy-Steps**, Moving You to Better Health with the Lebed Method, is a therapeutic exercise and movement program with wonderful music designed to help you thrive! Offering wellness programs for everyone, from young adults to seniors, regardless of health, age or ability level, the Healthy-Steps program has the potential to improve overall wellness, range-of-motion, balance, strength and endurance, as well as emotional well-being and self-image. A specialized program for children, "Creative Rhythms", is even available to serve the needs of children with Cancer or other chronic illnesses or medical conditions.

The program was developed in 1980 for Breast Cancer Survivors; **ADDITIONALLY**, it is now being used in many wellness centers, senior facilities and hospitals in the US and Internationally for chronic illnesses in addition to upper and lower extremity Lymphedema. It helps seniors, those with MS, Parkinson, Chronic Fatigue, Fibromyalgia, all cancers and many more chronic illnesses.

Healthy Steps takes traditional physiotherapy movements out of the clinical setting and translates them into dance and exercise language, providing a more motivating environment. Specially selected music stimulates patients to move more freely than they normally would and redirects their minds away from pain and limitation and instead toward feeling the movement through the music. The group setting also allows patients to see improvement in the physical abilities of others, reinforcing that it is also possible for them, too! As patients progress through the Healthy-Steps program, most may see improvement in the following ways:

- \*Increase in over-all range of motion, flexibility and strength
- \*Is particularly helpful in increasing upper body mobility
- \*May help decrease risk of Lymphedema and reduce swelling
- \*Reduce frozen shoulder
- \*Improve overall posture
- \*Assist in structurally re-balancing the body
- \*Increase positive body image
- \*Elevate self-esteem
- \*Provide a supportive environment with other survivors
- \*Decrease depression
- \*Improve quality of life
- \*Create empowerment

**SURVIVING IS IMPORTANT, BUT THRIVING IS ELEGANT!**

Healthy-Steps is offered in over 700 locations worldwide.

**Join us today, and move toward better health!**

**For more information please contact: Laura Dowell, PT, CLMT**

Email: [lmjra3@charter.net](mailto:lmjra3@charter.net) or call: 314-650-2995

The following is the Healthy Steps Lesson Plan presented to the Post-Polio Health International Conference June 2, 2014\*\*

<b>Routine/Music</b>	<b>Movements</b>	<b>Intended Outcomes</b>
<b>Lymphatic Opening (Warm up)</b>	Breathe (blow pinwheels/bubbles) Head/neck, shoulders, Contractions (Front/side), breathe, Torso lengthening, Marching, Head/neck	Increase lymphatic drainage, ROM, gentle stretching
<b>Beatles 1 Celebration</b>	Shoe shine, Close the door, Bow and arrow and circle the world	ROM, balance, DF, weight shift, coordination, UE/upper back stretch,
<b>Break</b>		Social interaction, rest
<b>Sweet Inspiration-seated</b>	Marching, Toe touch front/side, Snappy rainbow Heel/Toe	LE strengthening/ROM (hip flex, abd/add, DF/PF) UE ROM
<b>Under the Boardwalk</b>	Spine roll ups/Palm trees, 2 step fwd/sway, 2 steps bkwd sway, Side step/shake water off, showgirl strut	Trunk flexion/ext, balance, weight shift,
<b>Break</b>		Social interaction, rest
<b>Signed, Sealed Delivered</b>	Supremes, Step Touch, Lift a heavy tray, showgirl strut	Balance, weight shifting, UE ROM,
<b>Cool Down I Hope You Dance</b>	Singing/Closing comments	Breathing, benefits of a group

Healthy-Steps is offered in over 700 locations worldwide.

**Join us today, and move toward better health!**

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Email: [imdjra3@charter.net](mailto:imdjra3@charter.net) or call: 314-650-2995

\*\*Healthy Steps requires that only Certified Lebed Method instructors teach Healthy Steps classes.

**Monday, June 2, 1:15 - 2:30 pm**  
**Exploration of Faith and Disability**  
**Cyndi Jones, MDiv**

### **Exploration of Faith & Disability**

Can we have a disability and also have faith?

What is it about disability that prompts total strangers to approach you to “lay hands on you,” or to tell you, “If you had faith, you would be healed”?

There are many scriptures that talk about healing a person with a disability, but seldom in the context of living as a person of faith with a disability.

From the pews to the pulpits to academia, there is an emerging movement for a contextual theology of disability to be heard.

Join us in this conversation on people with disabilities as people of faith.

Readers of the Bible may not recognize disability present in a story unless the story explicitly says “blind”, “deaf”, “lame” or some such designation. There are, however, many stories about disability in the bible that will only be recognized by those in the disability community. Some of these stories imply that God has a disability and others show how God engages people with disabilities right from the beginning.

God enjoyed walking in the garden with one who didn’t know good from evil or even the fact that he was naked. His name was Adam. Today we might consider Adam mentally impaired, but this is not named in the bible. And why would it be named since Adam was the one doing the naming, he may not call himself disabled.

Why, when God blesses Jacob does he cause Jacob to become disabled? Is disability part of God’s blessing? Why does God select Moses to be His spokesperson when Moses himself needs a speech interpreter?

Why does God need a rainbow to remind him to not flood the earth? Why did God engraved us on the palm of his hand so he would not forget us? Does God have a memory problem?

In the Laborers in the Vineyard parable, from the Gospel of Matthew, the last ones hired say that the reason they are still standing around at the end of the day is because “No one has hired us.” This could be a quote from someone with a disability today -- always the last ones hired.

What became of these stories in the intervening years that has allowed disability to be pushed so far from the religious center and how can we reclaim our stories?

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**Monday, June 1, 1:15 - 2:30 pm**  
**Support Groups: What Works**  
**Jean Graber**

Learning and Sharing Polio's Legacy

Legacy means “that which is handed down”.

We are the last major group of survivors to have personally experienced the effects of polio. The fear and uncertainty of the future was very real to us and our families. And yet, nearly everyone grew up believing nothing was impossible –there was always a way to do what we set out to do in life!

The Central Kansas Polio Survivors Group decided to connect today's school-age children with our own growing up years. We had four goals: They would learn about polio and experience a few of its effects first-hand. They would know that continued immunization prevents polio. They would learn that disabilities of any kind do not make persons less valuable. They would realize that barriers in their own lives need not be insurmountable.

We wanted to offer teachers a variety of venues through which to present the information. All are included in curriculum standards of fifth grade–through middle school. The teachers choose what parts best fit their own students. Author Peg Kehret's book, Small Steps, her autobiography of having polio, serves as the cornerstone of the Traveling Trunk. Most teachers have read it aloud as a pre-teaching tool for their students. A few have read a chapter or two and then incorporated some activities. Most all include the trunk primarily in their social studies/history time. Each teacher does a pre and post checklist inventory of the trunk's contents as well as an ending survey evaluating the trunk's results with their students. The trunk has to be scheduled around the best time for student learning and teacher presenting, student testing, and holidays! Every teacher prefers a month or six weeks of “trunk time”! Each year teachers say they find something more in the trunk to add to their lesson plans.

Contents of the Traveling Trunk include:

An antique wooden crutch for display and a pair of crutches for use  
Two DVD's – sound of a real iron lung and The Bluebird Song  
References to You Tube Videos  
Replicas of hot packs for students to actually try on  
Seven children's books relating to polio  
12 survivors' quotes to display  
Graphs for math about polio and accompanying activities  
Photo album (several stories, variety of pictures, list of actual Sister Kenney exercises, etc.)  
Three copies of Small Steps  
Riddle Card activity  
5 copies of Polio's Amazing Stories with learning activity  
Plush bluebird to go with the song  
Two different-sized shoes worn by a member  
Nose clips, straws, and alcohol wipes for breathing activities  
Child's shoe brace and a corset brace worn by members  
24 laminated polio pictures for teaching tools and/or display

The Teacher's Manual offers many additional activities.

Hands-On learning: The Hot Packs

Learning to Mirror-Read

Experimenting with Crutches

Experimenting with Breathing Restrictions

Polio-related words to spell or define

Activities involving writing: Connecting with an Author

Connecting with a Polio Survivor

Connecting with Polio's Past

**We invite you to come take a look and ask questions!**



**Monday, June 2, 1:15 – 2:30 pm**  
**Support Groups: What Works**  
**Beth Kowall, MS, OTR**

2013 Survey Results from the  
Post-Polio Resource Group of Southeastern Wisconsin

1. Introduction to group and survey
  - a) Purpose of survey
  - b) Changing needs and priorities of members
  - c) Results will assist in future planning
2. Survey
  - a) Design of survey
  - b) Topics in survey
    - 1) Demographics
    - 2) General meetings/programs
    - 3) Newsletter
    - 4) Website
    - 5) Final question- open ended question
  - c) Results to be reported in newsletter
  - d) Sixty-nine percent return rate
3. Results
  - a) Demographic information
    - 1) Fifty-two percent of members are over 70 years old
    - 2) Symptoms experiencing
    - 3) Beneficial aspects of membership
  - b) General meetings/programs
    - 1) Beneficial aspect of meetings
    - 2) Program topics of most interest
    - 3) Trend of declining attendance at meetings
  - c) Newsletter
    - 1) Overwhelmingly most important aspect of membership
    - 2) Members suggestions for content
    - 3) Members prefer hard copy of newsletter
  - d) PPRG website
    - 1) Underutilized website and why
    - 2) Members get information from other sources
  - e) Final question- open ended question
4. Conclusions – our “Call to Action”
  - a) What we learned from members input
  - b) How to implement this information for future planning
  - c) Overall, survey was a very positive experience

## Ten Instant Stressbusters

1. **BREATHE, BREATHE, BREATHE.** The amazing power of feeling more relaxed begins with taking three deep breaths and slowly exhaling. Stop stressed-out shallow breathing.
2. **MOVE, WIGGLE, STRETCH.** To dissipate anxious feelings loosen up taut muscles and move around.
3. **FOCUS ON NOW.** Although you have to plan for the future and take care of responsibilities, don't forget to enjoy the present moment.
4. **SAY A CALMING PHRASE.** Develop a phrase that helps you such as "All is well," or "This, too, shall pass." Keep repeating it.
5. **FOCUS ON POSITIVE POSSIBILITIES.** Stop terrorizing and assuming the worst may happen. Visualize things going the way you want and feeling happy about it...POSSIBILIZE!
6. **EMBARGO JUNK FOOD.** What you eat affects your mood. Reduce sugary, caffeinated, or non-nutritious food. Try eating a banana, some turkey or drink chamomile tea. All contain natural relaxants.
7. **TAKE A HIKE.** Get out or connect with Mother Nature in some way. Touch your feet to the ground to literally 'get grounded.'
8. **DO SOMETHING ENJOYABLE.** Whether it's gardening, organizing, or engaging in a special hobby, etc., build in some fun time.
9. **SMILE.** Studies show whether you mean it or not, smiling releases mood-enhancing endorphins.
10. **TAKE A MENTAL HEALTH DAY.** Sometimes you just need a break to rebalance. You deserve it.

*For more free tips, tools and strategies see [www.whyworrybook.com](http://www.whyworrybook.com)*

# THE FIVE MINUTE MENTAL MARINADE

To quickly reset and rebalance both psychologically and physiologically, do the following exercise. It should take about 5 minutes or longer if you wish. It's a great "bad-biochemistry" buster and something especially to do before bedtime!

- **CROSS** your hands over your heart.
- **CLOSE** your eyes and take 5 deep, slow breaths.
- **RECALL** 5 positive things about your life.
- **FOCUS** on a beautiful scene, someone you love,  
or something you love to do.
- **TAKE** 5 deep, slow breaths.
- **RELAX** and marinate in the feeling!

*For more free tips, tools and strategies see [www.whyworrybook.com](http://www.whyworrybook.com)*

**Monday, June 2, 1:15 - 2:30 pm**  
**Update on Anesthesia**  
**Selma H. Calmes MD, Retired Anesthesiologist**

Many polio patients fear anesthesia. Multiple surgeries in childhood were common for those who had polio and anesthesia care then was not as sophisticated as it is today. Modern anesthesia is much improved since the time of polio epidemics! In this session, an anesthesiologist familiar with modern anesthesia practice and polio will answer recent, common questions asked by post-polio patients. If time, the audience can ask their own questions.

1. “Do I really need to have a colonoscopy? It requires anesthesia, and I’m afraid of that.”

Colon cancer is the third most commonly diagnosed cancer and the third leading cause of death from cancer in the US. About 5% of Americans will be diagnosed with colon cancer in their life-time. Colonoscopy (looking at the lower part of the intestine with a flexible telescope, to identify early/possible colon cancer) is currently the most accepted way to identify early colon cancer; it has been well-documented to save lives because early lesions can be identified and removed. Newer tests (virtual colonoscopy, stool DNA mutation tests and immunochemical Fecal Occult Blood Tests (FOBT) have been developed recently, but only virtual colonoscopy has been compared with colonoscopy. It compares favorably, but it is not possible to treat lesions found. If lesions are found, you must still have colonoscopy. There may also be problems with insurance payment for virtual colonoscopy.

Colonoscopy is recommended for everyone over age 50 years, earlier if you have a family history of colon cancer or other risk factors. You must have a bowel prep, to remove stool so the endoscopist can see lesions, and anesthesia (sedation) is usually given for patient comfort—bowel inflation with gas, to distend the colon, is needed, and is uncomfortable.

You need to commit to getting screened somehow for colon cancer. Which screening is best depends on you and your MD’s experience. Colonoscopy should be done by an experienced Board-Certified gastroenterologist, in a certified out-patient facility. The risk of anesthesia is small compared to the risk of colon-cancer.

2. Why is it so hard to link up ahead of time with the anesthesiologist who will do my case?

Daily anesthesia staffing is a complex equation! It is extremely difficult to know ahead of time who will be doing which case on a particular day. There is a constant flux of anesthesia staff (people get sick), other needed staff such as techs, incoming emergency cases, obstetric anesthesia cases, cases may move from one OR to another and so on. And, anesthesia group size is increasing; it is not unusual to have groups of over 100 anesthesiologists.

So, what can you do, given these problems? Two helpful possibilities follow:

- a. If at all possible, try to have your operation at a major university hospital. This gives the best chance of getting quality care (not only anesthesia care). Check its accreditation data on the Joint Commission for the Accreditation of Health Care Organizations web site. Many states also have hospital quality data on the web. Most academic hospitals also have pre-operative clinics in which patients are screened

ahead of time. These are extremely helpful in identifying and preparing for difficult patients. They also have an array of expert physicians in many areas. Especially important here is ICU care and MDs capable of handling respiratory failure postoperatively.

- b. Use your surgeon to lead the way to the anesthesia department. Surgeons and anesthesiologists work together daily and often become “teams,” making it easier for them to work together on a difficult patient. When an operation is being planned, explain your post-polio issues (scoliosis, pulmonary failure and a history of iron lung use are red flags here!) and ask that they be noted during scheduling and also if the surgeon could speak with the anesthesia department ahead of time, to warn anesthesia staff you’re coming and what the issues are.

3. What’s new in anesthesia that I need to know?

This is a brief listing. Answers will be expanded as time allows in the session.

- a. Better measurement of quality of care in anesthesia and better recognition of where problems are and how they could be improved.
  - b. Increasingly sophisticated knowledge of ventilation problems and better management of respiratory problems postop.
  - c. Recognition that many patients are left with residual neuromuscular block and the possible complications.
  - d. The desirability of using *both* regional anesthesia and general anesthesia together, for improved outcome.
  - e. Shortages of standard anesthesia medications are happening, due to changes in the pharmaceutical industry. This has caused many problems.
  - f. Does the medical literature document anesthesia problems for post-polio patients? A 2013 review found no unusual problems and that regional anesthesia was not reported to cause worsening of PPS.
4. What are the issues in bariatric (intestinal surgery that can facilitate weight loss) surgery for post-polio patients?

This sounds like a “quick fix” for obesity but is an area full of possible problems. There are no reports of post-polio patients having bariatric surgery.

Possible problems relate to the disease obesity (diabetes, presence of sleep apnea, presence of a fatty liver, the increased difficulty of anesthetizing obese people), where the procedure is done (out-patient facility/in a hospital), the procedure done (lap band or gastric bypass) and who does the operation. Lap band (placing a flexible plastic band with an injection port around the upper stomach and inflating the band as needed) sounds simple and quick, but the bands can have complications and may need to be removed.

Best results come from dedicated teams, including a dietitian, at academic medical centers. Long-term follow-up is essential!

**Monday, June 2, 3:00 – 5:00 pm**  
**My New Reality**  
**Joyce Tepley**

Excerpts from Joyce Ann Tepley's book, *Thriving Through It – How They Do It: What It Takes to Transform Trauma Into Triumph*

**Introduction**

Within a few days of the fiftieth anniversary of Edmund Hilary and Tenzing Norgay's first ascent of Mount Everest, Gary Guller broke through the clouds of the highest point on earth, proudly standing on its summit with his four Sherpa companions. It was May 23, 2003. Just as the team was about to give up by being stuck at 26,000 feet due to one-hundred-mile-per-hour winds, the winds died down, and the sun broke through. Gary and his Sherpas, with ropes and ladders, slowly climbed the last 3,035 feet on the glistening, icy snow for seventeen hours.

Many people have climbed through the treacherous conditions of the death zone to reach the 29,035-foot peak since Hillary and Norgay, but this climb was unique because Gary only had one arm and the teammates who backed up his ascent were also disabled. Team Everest 03 Challenge Trek started out in the middle of March reaching Nepal Base Camp 1 at 17,600 feet a month later. They were acclimating to the physical and mental rigors of their quest. Five members of the team used wheelchairs, two were hearing impaired, another had a prosthetic leg, and the last two members had severe pain due to fibromyalgia and arthritis.

Experiencing high altitude sickness, gastric difficulties, and subzero temperatures, the team trudged on. They wouldn't have been able to endure, let alone ascend, without the support of fifteen Sherpas, eighty porters, thirteen yak/cows, and nineteen able-bodied team members. Usually only one in ten people who attempt the thirty-mile trek make it to the first base camp, but on Team Everest, eight members with disabilities were able to claim their place in history. The Sherpas wove special baskets to carry those members who moved themselves in wheelchairs, but some decided to drag their own paralyzed legs over rocky terrain or stay in their ruggedly made wheelchairs to make the climb.

At the top of the world, seventy-five days from when they began, Gary, Nima Dawa, Namgya, Pemba Tenzing, and Da Nima fell to their knees crying and gave thanks to Chomolungma, the Mother Goddess of the World, the Endless Source of Sustenance, in Tibetan Buddhism. Staying only twenty minutes because of the time it took to descend and needing to get off the mountain before the rainy season, Gary returned to camp suffering from snow blindness. Triumphant and welcomed by his remaining teammates, he wrote in his journal that, in his career as a mountaineer, he looked up at the mountains for inspiration. Being at the highest place on the earth, he could "look up no further." It was hard for him to believe that he was there witnessing the "most beautiful site [he'd] ever seen."

Would you say Gary and his teammates were thrivers? The determination, detail of planning, belief in a greater purpose, and support of each other certainly proves they were. You don't have to climb Mt. Everest to be a thriver. In the next two sections of this book, I invite you to read about these ordinary people, just like you, from all walks of life, who their peers know as thrivers. My wish is to honor them, following the advice of Tenzing Norgay, "Be great, but make others great." Keep in mind that thrivers are self-determined but not self-made as you delight in their stories.

**Bio sketch of Joan Headley, one of the 20 thrivers interviewed in 2000 for *Thriving Through It – How They Do It*.**

## **Joan Headley, Organization Director (53) Post-Polio Syndrome**

Joan's parents were tenant dairy farmers in Bryan, Ohio. "We worked for halves, as it was called, so whatever we made we got half." She remembered her mother's lush vegetable and flower garden and a large extended family of uncles, aunts, and cousins nearby.

Joan loved wandering the fields and helping her mother tend her garden with her older sister and younger brother. On the other hand, the forty-five cows they were responsible for held them back from traveling.

"There were many things we always felt like we couldn't do because we had to be home in the morning to milk the cows and had to be home by five at night to milk the cows. There were times when you just didn't like the cows."

When Joan was an infant and beginning to walk, she dragged her left leg. They took her to a doctor in Toledo, some distance from home, where she was diagnosed with polio. She was a year old. That didn't stop her from being a tomboy, playing football and basketball and physically keeping up with the other children in school.

Her mother was a major influence and role model in her life because she worked hard to provide the extra money needed to send her children to college. It was rare for families at that time, in that area of Ohio, to be able to send three children to college. Her mother took a job at the La Choy food-processing factory, getting up at three in the morning and coming home at dusk with bloody, cut hands from picking chicken meat off bones all day. Joan's brother got his PhD in chemistry; her sister got a master's degree in molecular biology. Joan felt that her college years studying biology and working on her teaching degree were some of the most fun times of her life.

After teaching for many years, she became bored with the same curriculum and decided to try her hand at something else. She was also getting physically weaker, often sleeping most of the weekend. She was aware of a networking organization that sponsored conferences for people with disabilities and kept them in touch with each other all over the world. The founder, Gini Laurie, also spearheaded bringing together medical personnel, researchers, and people with polio who were experiencing more debilitation thirty years after the onset of the disease. Out of those conferences grew support groups, clinics, a diagnostic name, and treatment protocols. Gini, however, was dying of cancer and needed to pass the torch of directorship. Joan interviewed for the position and became the executive director, a role that gives her satisfaction in being able to contribute her talents to a greater cause.

Because she was so young when she got polio, it is an integral part of her, so she thrives "because of" her disability.

Monday, June 2, 3:00 - 5:00 pm  
Exploring Exercise

### A Statement about Exercise for Survivors of Polio

*Post-Polio Health* (ISSN 1066-5331) Vol. 19, No. 2, Spring 2003)

**Advising all polio survivors not to exercise is as irresponsible as advising all polio survivors to exercise.**

Current evidence suggests that exercises are often beneficial for many polio survivors provided that the exercise program is designed for the individual following a thorough assessment and is supervised initially by knowledgeable health professionals. Polio survivors and their health professionals who are knowledgeable about the complete health status of the individual survivor should make the ultimate decision on the advisability of exercise and the protocol of the exercise program.

Clinical research studies support exercise programs that are prescribed and supervised by a professional for many polio survivors, including those with the symptoms of post-polio syndrome. (See [References](#).)

Acute paralytic polio can result in permanent muscular weakness when the viral infection leads to death of anterior horn cells (AHCs) in the spinal cord. Recovery from paralysis is thought to be due to the re-sprouting of nerve endings to orphaned muscle fibers creating enlarged motor units. Recovery is also attributed to exercise that facilitates the enlargement of innervated muscle fibers. For example, some polio survivors regained the use of their arms and have walked for years with crutches. Others regained the ability to walk without the aid of braces, crutches, etc., and have continued to walk for decades.

The increased muscle weakness recognized in those with post-polio syndrome is believed to occur from the degeneration of the sprouts of the enlarged motor units. The premature death of some of the AHCs affected by the poliovirus is speculated to also cause new weakness, and some new weakness is caused by disuse, or a decline in activity or exercise.

**There is agreement that repetitive overuse can cause damage to joints and muscles, but can repeated overuse and excessive physical activity accelerate nerve degeneration or nerve death? This is the crux of the physical activity/exercise debate.**

Physical activity is movement occurring during daily activities. Exercise is defined as planned, structured and repetitive body movement.

Therapeutic exercise is conducted for a health benefit, generally to reduce pain, to increase strength, to increase endurance and/or to increase the capacity for physical activity.

**Polio survivors who over-exercise their muscles experience excessive fatigue that is best understood as depletion of the supply of muscle energy.** But, some polio survivors' weakness can be explained by the lack of exercise and physical activity that clearly leads to muscle fiber wasting and cardiovascular deconditioning.

**The research supports the fact that many survivors can enhance their optimal health,** their range of motion and their capacity for activity by embarking on a judicious exercise program that is distinct from the typical day-to-day physical activities. These same polio survivors need not fear "killing off" nerve cells, but do need to acknowledge that the deterioration and possible death of some nerve cells may be a part of normal post-polio aging.

**Exercise programs should be designed and supervised** by physicians, physical therapists and/or other health care professionals who are familiar with the unique pathophysiology of post-polio syndrome and the risks of excessive exercise. Professionals typically create a custom-tailored individualized exercise program that is supervised for two-four months. During this period, they will monitor an individual's pain, fatigue and weakness and make adjustments to the protocol, as needed, to determine an exercise program that a polio survivor can follow independent of a professional.

**When designing a program, these general principles are followed to achieve specific goals and/or maintenance levels.**

- The intensity of the exercise is low to moderate.
- The progression of the exercise is slow, particularly in muscles that have not been exercised for a period of time and/or have obvious chronic weakness from acute poliomyelitis.
- Pacing is incorporated into the detailed program.
- The plan should include a rotation of exercise types, such as stretching, general (aerobic) conditioning, strengthening, endurance or joint range of motion exercises.

***Polio survivors who experience marked pain or fatigue following any exercise should hold that exercise until contacting their health professional.***

Researchers and clinicians cannot make a more definite statement until additional studies on the long-term effects of exercise and the effects of exercise on function and quality of life are undertaken.

**- Criteria for diagnosis of post-polio syndrome**

**- Prior paralytic poliomyelitis with evidence of motor neuron loss,** as confirmed by history of the acute paralytic illness, signs of residual weakness and atrophy of muscles on neurologic examination, and signs of denervation on electromyography (EMG).

**- A period of partial or complete functional recovery** after acute paralytic poliomyelitis, followed by an interval (usually 15 years or more) of stable neurologic function.

**- Gradual or sudden onset of progressive and persistent new muscle weakness or abnormal muscle fatigability** (decreased endurance), with or without generalized fatigue, muscle atrophy, or muscle and joint pain. (Sudden onset may follow a period of inactivity, or trauma or surgery.) Less commonly, symptoms attributed to post-polio syndrome include new problems with breathing or swallowing.

**- Symptoms persist for at least a year.**

**- Exclusion of other neurologic, medical and orthopedic problems as causes of symptoms.**

SOURCE: [Post-Polio Syndrome: Identifying Best Practices in Diagnosis & Care. March of Dimes, 2001.](#)

References are available at <http://www.post-polio.org/edu/pphnews/pph19-2a.html>



Tuesday, June 3, 9:00 - 10:15 am  
Proven Energy Boosts  
Betsy Thomason, RRT

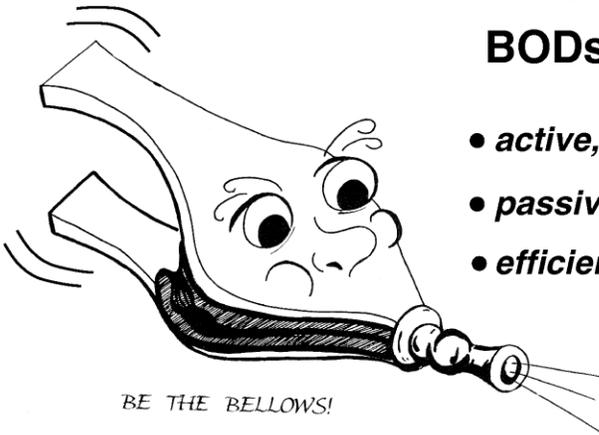
## BREATHING TRAINING: DEVELOPING A USER - FRIENDLY BODY

*Featuring*

### the BreatheOutDynamic system

#### BODs

- *active, spine-stretching outbreath*
- *passive, relaxed inbreath*
- *efficiency for energy and relaxation*



- Purse lips / pull in belly
- Focus on exhalation
- Relax for inbreath
- Use images / imagination
- Exhale on exertion
- Think Positive: I CAN DO THIS
- Be patient - You are changing habit patterns. Muscles are slow learners.
- Use BODs every day
- When in DOUBT, blow OUT!



Betsy Thomason, BA, RRT  
36 Mountain Ave., Park Ridge, NJ 07656 • 201-930-0557

BT Breathing Training, LLC offers individual and group BODs instruction for people who want to improve—even maximize—their physical ability, experience increased energy, and manage stress. **For more information, visit the website [www.btbreathingtraining.com](http://www.btbreathingtraining.com).**

**Tuesday, June 3, 9:00 - 10:15 am**  
**Proven Energy Boosts**  
**Carol Elliott**

These are exercises that I find useful in bringing more energy into my daily life. These routines, practiced alone or in combination, have helped revitalize my daily challenge with PPS. Most of these stretches and gentle exercises can be done while seated. As always, check with your healthcare provider to be sure these activities are suited for your unique medical situation.

### **Qi Gong**

Qi Gong (pronounced *chee-gong*) is a gentle form of exercise and movement. It dates back thousands of years to ancient China. The word “qi” (or “chi”) means “life force” and the “gong” means “accomplishment or skills that is cultivated through steady practice.” It is similar to yoga and tai chi with slow, natural movements that assist in stretching, breathing and improving mood. I have found good routines using the following video DVDs:

- *Qi Gong for Seniors*<sup>TM</sup> (with Lee Holden and Karen Holden, his mother)
- *Qi Gong for Upper Back and Neck Pain*<sup>TM</sup>

Website: <http://www.exercisetoheal.com/>

### **Yoga**

Seated yoga is wonderful for gently stretching stiff joints. Mindful breathing cleanses the mind/body to become your best self for the day. Here are several resources that are easy to access on the Internet, *YouTube* and TV.

*PolioPlace* (**visit this website often**): <http://www.polioplace.org/front>

- *Yoga for Post-Polio patients* by John P. Murtha Neuroscience Institute. © 2004 Conemaugh Health System. (Yoga instructor, Judith Sullivan).

Website: <http://www.polioplace.org/resources/yoga-post-polio-patients>

### **Seated Exercises**

There are many resources for seated, low-impact exercises. The most can be found on TV and on *YouTube*. These are some of my favorites.

- *Sit and Be Fit*<sup>TM</sup> with MaryAnn Wilson. A non-profit organization committed to healthily aging. © Sit and Be Fit 2011.

Award-winning TV exercises broadcast since 1987, and recognized by the National Council on Aging (NCOA) as a "Best Practice" program in healthy aging. (Check your local TV listings for daily morning programs.) Also many excellent, award-winning workout DVDs and tapes and audio recordings. Features small exercise ball and light weights.

Website: <http://www.sitandbenefit.org/>

And DVDs specifically for post-polio workouts and *YouTube* short demos

Website: <http://www.sitandbenefit.org/postpolio>

- *Sample Exercises for Polio Survivors* from the **PolioPlace** website

Website: <http://polioplac.org/living-with-polio/sample-exercises>

- *Stronger Seniors: Chair Exercise for Balance and Posture with Anne Burnell*

Website and YouTube videos: <https://www.youtube.com/user/StrongerSeniors>

## **Resistance Band Exercises**

Another way to get smooth, gentle exercise without using weights is using resistance bands. There are many on the market, each with varying degrees of resistance. I use a specially designed chair with four low-impact resistance cables attached to the chair—two for the arms and two for the legs. The chair also has a back support built in and is lightweight and comes ready to use. The chair comes with DVD workout routines for various age and ability groups.

- *The Resistance Chair® Exercise & Rehabilitation System*. ©VQ ActionCare, LLC.

Website: <http://www.vqactioncare.com/home/>

**Tuesday, June 3, 10:45 am – 12:00 pm**  
**Post-Polio Research: Update on PHI-funded Research**  
**Antonio Toniolo, University of Insubria, Varese, Italy**

**Remnants of poliovirus genome in patients with post-polio syndrome but not in their family members**

**Antonio Toniolo and Andreina Baj**

**Laboratory of Medical Microbiology, University of Insubria and Ospedale di Circolo, Varese (Italy)**

In humans, the only evidence for persisting poliovirus infection has been found in individuals with deficiencies in B lymphocytes and low or absent immunoglobulins.

Over the last 4 years, we conducted an observational study of PPS in a cohort of polio survivors who were attending Northern Italy Hospitals for neuromuscular problems. Consenting family members and controls were also investigated. Results of virology studies (detection of poliovirus genome and virus activity) show that a persistent low-level infection is associated with PPS. So far, however, we have been unable to demonstrate that the persisting virus does play a role in the development of this progressive disorder.

In the investigated cohort, 97/107 individuals have been shown to have developed PPS 15 or more years after the acute attack. Family members of PPS patients (n=45) were also studied, together with a control group represented by healthy blood donors and controls with neurologic disorder other than PPS (n=47). Specimens included: cerebrospinal fluid, peripheral blood leukocytes, live cells of duodenal mucosa, skeletal muscle, peripheral nerve.

Poliovirus genomes were detected in 82/97 patients with PPS (85%) and in 3/92 controls (3.3%). Type 1 poliovirus was the most prevalent (61% of cases), followed by type 2 and type 3 (12% and 9%, respectively). Some cases (18%) could not be typed. Based on clinical history, 22/107 poliomyelitis cases were associated with polio vaccination (18%). In vitro, leukocytes of poliovirus-positive PPS patients did produce enhanced levels of inflammatory mediators as compared to leukocytes of healthy donors. This is in line with a pathogenic hypothesis indicating that chronic inflammation is a hallmark of PPS.

Serum immunoglobulin levels were measured in PPS patients, their family member, and controls. As compared to healthy blood donors, levels of IgG1, IgG2, IgG4 and IgA were significantly reduced both in PPS patients and their family members. IgM levels were not significantly different. This suggests that modest immunoglobulin deficiencies may be present in individuals who developed clinical manifestations after being hit by poliovirus as well as in their family members. We also measured titers of neutralizing antibodies to the 3 poliovirus types in sera of PPS patients, their family members, and healthy controls. No significant differences were found.

The results lend support to the idea that residual poliovirus activity does persist in PPS patients and that virus persistence could be of pathogenic significance. To clarify a possible causative link between virus persistence and PPS, we are going to check whether poliovirus is detectable in a cohort of polio survivors who, in spite of age, failed to develop the late consequences of polio. The expected result is that people with stable polio will not be harboring poliovirus.

Our data also show that poliovirus cannot be found in family members of PPS patients, i.e. that virus is not transmissible within families. This finding tells that PPS people are “not infectious” and has

reassuring implications. Taken together, these data indicate that novel virology methods might offer the possibility of identifying, among polio survivors, those with chronic poliovirus infection. In perspective, it may be envisaged to treat them with antiviral therapies either for preventing PPS or for blocking its progression.

**Acknowledgments:** work supported by Post-Polio Health International (St. Louis, MO) and Regione Lombardia (Milan, IT). We are grateful to Joan Headley and Frans Nollet for their continuous encouragement and support. The contribution of Neurologists who provided samples of their PPS patients is gratefully acknowledged: Giorgio Bono, Salvatore Monaco, Laura Bertolasi, Franco Molteni, Luisa Arrondini. Finally, we recognize the essential contribution of virologists who dedicated their time and efforts to this noble task: Martina Colombo, Giuseppe Maccari, Merja Roivainen.

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