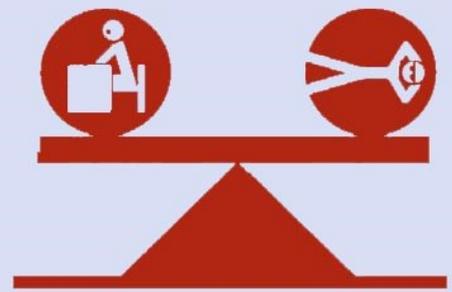


# POST POLIO PACER

*Conserving Strength and Energy through Pacing*  
*April 2018 — Madison, Wisconsin*  
*Madison Area Post Polio Support Group Newsletter*  
*MAPPSG formed in 1985 — This Is Our 33rd Year!*



## Gail Beckwith's Backstory

*By Kathleen Blair*

After rereading Beckwith's story "**Life Changed in an Instant**" (Pacer, November 2017), I again feel awed at this polio survivor's courageous and positive attitude.

Gail revealed her earliest memories about the onset of polio during a recent telephone interview. She was only two and one-half years old at the time, so some of the following includes what she has been told by her mother:

It was August of 1955 – the last polio epidemic before the Salk vaccine became available. She suffered flu-like symptoms for about two days. Her mother called the doctor who said, "There is nothing we can do."

Gail remembers being close to her father. She vaguely recalls sitting on the front porch one day waiting for him to come back from an errand. When her mother called her to come in for lunch she could not stand up. Both legs were paralyzed. This was her first significant memory of the onset of polio.

She was admitted to St. Mary's Hospital in Madison and by then her arms as well as both legs were affected. Gail's memories of the hospital, how long she stayed, etc. are blurred. Most significant is how much she remembers fearing the hot baths and the therapy that followed. Soon after being taken out of the whirlpool and laid back into bed the therapist would appear and work on exercising her arms and legs – **an extremely painful process for this little girl**. Gail would

scream during the whole session as reported by her mother.



Strength finally returned to all but her left leg. Gail was fitted with a brace on her left leg and crutches before being released from the hospital. She has worn a brace ever since. However, during her better years she was able to walk about the house without the brace on, especially to bathe or to go swimming.



When Gail and her family cleared out her mother's attic a few years ago, they found the tricycle that would have been hers before polio changed her life. She is having the seat refurbished and will keep it with her favorite keepsakes.



Throughout her school years Gail spent almost the entire summer in the hospital having surgeries to stabilize her ankle and tendons.

She went to kindergarten in Madison. Her parents moved to a farm in 1955 just outside of Stoughton and Gail attended a one-room country school for grades one through four. Then the one-room schools were closed and all students were brought into the public schools in Stoughton by bus.

Gail happily reports that she was treated like everyone else in school, managing to get to all her classes even going up and down stairs with her classmates. In gym class she was told, "Do what you can" and she did. She also credits her parents with treating her fairly as they treated her siblings. Clearly, Gail grew up with a positive, "can do" attitude.

Thoughts of Camp Waubeek bring back three happy summer adventures during Gail's preteen years. Counselors were wonderful – they were cheerful, always funny, and gave the campers great opportunities to learn to swim and enjoy many fun activities: archery, baseball, arts and crafts. They even took the

campers on a Wisconsin Dells boat ride. Gail said she is especially grateful that they taught her to swim – a beneficial exercise for polio survivors.

It's curious to note that after spending so much of her childhood in hospitals, Gail chose nursing as her career. She completed her training at Milwaukee County General Hospital School of Nursing.

After many years of service as a registered nurse, Gail landed a triage job where she could stay off her feet, answer telephone calls and earn a good salary. She regards this as a lucky break.

Gail and her husband, Don, have twin sons who live in the Stoughton area and a daughter in Colorado Springs. They are the proud grandparents of seven precious grandchildren.

*It was a special privilege to interview Gail as she described her early childhood experiences in such a positive way. For the "rest of the story" please revisit the November 2017 Pacer and read her own courageous account of Gail and Don's life today.*

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## F.Y.I.

### **Lightweight Wheelchairs mentioned by Dr. Bruno on Facebook**

The website below has an interesting array of foldable, power wheelchairs, chairs that climb stairs, etc. It also has rehab equipment that might be of interest. Check the website <<https://www.wheelchair88.com.my/>>

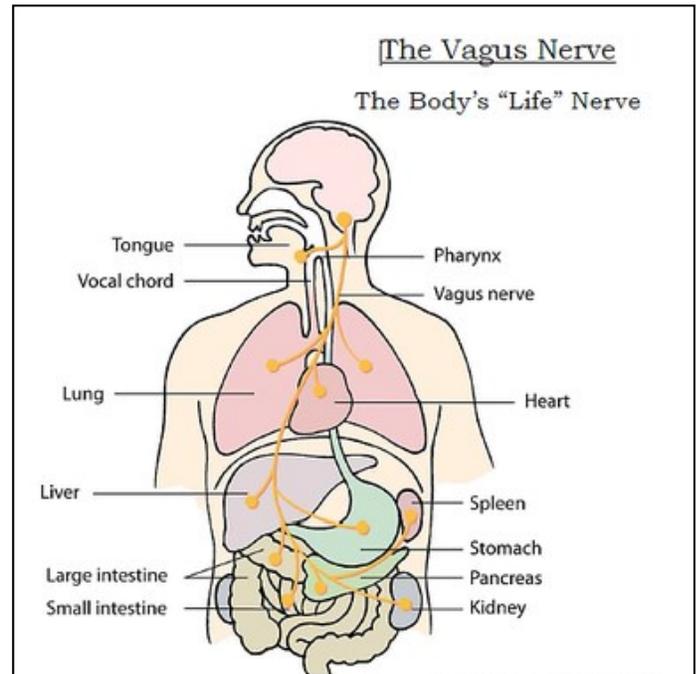
### **Matia Robotics**

While this amazing machine may not be applicable to most post-polio survivors since it was designed for individuals with spinal cord injury (paraplegia) to enable them to stand

and move about with complete control, this youtube is worth watching. The Matia is very expensive, but enhances the person's mobility to do activities that require the ability to stand and reach items in cupboards, book shelves, closets, etc.



<<https://www.youtube.com/watch?v=oy1FcDx8cQ0>>



## On the topic of the Vagus Nerve and Swallowing—from Bruno's Bytes

**Original Post:** I have issues with the vagus nerve when I swallow. Sometimes when I try to swallow it goes up my throat into the nasal passage instead of going down. It doesn't matter if it's liquid or food. Is that from the polio damage to the vagus nerve?

**Dr. Bruno's Response:** Yes. The vagus nerve and brain stem control centers (see diagram) control swallowing from the back of the throat down to the end of the digestive system and were damaged by the poliovirus. Polio survivors' digestive "snake" has too little vagal activity throughout. This is why people with acute polio couldn't swallow liquids. With no place else to go, the liquid came out the nose.

Today, vagus damage causes trouble swallowing as well as constipation. Anyone with swallowing difficulty needs a barium swallow study to find out what's happening from mouth to stomach and to make sure that there is no obstruction or pocketing in the esophagus or throat, or non-polio related conditions that also could cause problems swallowing.

## Are You Looking for an Accessible Vacation Spot?

Read the "Letter to the Editor" below:

Diane Miller writes:

"In the January 2018 issue of the Post Polio Pacer you requested information about accessible vacation spots.

Welcome HOME Bed & Breakfast is still up and running. This is our 20th anniversary.

Located in the Village of Newburg (although our mailing address is West Bend) in Ozaukee County we are within a 15 minute drive from Cedarburg, West Bend and Port Washington (Lake Michigan). In a half hour you can get to Sheboygan or Milwaukee.

Welcome HOME B&B is set on 18 rural acres with trails that meander around the grounds, through prairie and woodland. You'll find plenty of resting areas along the way - benches picnic tables, and a Little Free Li-

brary. Come play horse shoes, corn hole, and other yard games. Make s'mores at the raised fire pit - built in memory of Kayleen Brereton - or on our charcoal grill.



The lodging accommodations are in one wing of our wheelchair-friendly design home. Guest space is accessed through a private entry which allows guests to come and as go as they please. The no-step entry door is located under the carport - keeping both guests and luggage dry in all of Wisconsin's weather.

Two bedrooms and two bathrooms are available for guests. Reserve both and you have the entire B&B to yourselves. Occupy just one bedroom and you may meet new friends who are staying in the other bedroom. Shared guest space includes a screen porch off the bedrooms, family room with gas fireplace, cable TV, a library of books and board games, a kitchenette and mudroom.

The Sara Room is furnished with a queen size bed plus a love seat that folds out to a twin bed.

The Penney Room has a queen size bed plus an adjustable twin (head and foot of bed). Height of bed does not adjust.

The sofa in the family room folds out to a queen size bed - for groups/families who need a little more sleeping space than the two bedrooms provide.

We have a Hoyer lift, shower chairs, bedside rails, reachers and grabbers available for guest use. Unlike the DNR cabins, we provide all bedding (pillows, sheets, blanket, comforters), robes, towels, hand soap and shampoo, kitchen items. You, of course, are welcome to bring your favorite pillow!

Overnight rate for 2018 is \$75 for the first 2 people in a room. Each additional person in the room is \$25 per night.

This rate includes a help-yourself to a leisurely breakfast each morning - bakery, jams, peanut butter, boiled eggs, cereal, fruit, beverages.

Check out of web sites (we have 2) to see some photos. I'd be delighted to answer any questions via email

<[welcomhomebb@gmail.com](mailto:welcomhomebb@gmail.com)>

or phone (262 675-2525)

[www.welcomehouseof.org](http://www.welcomehouseof.org)

[www.welcomhomebb.com](http://www.welcomhomebb.com)

We are also on Facebook:

Welcome House Of wheelchair-friendly Modification Examples and at Welcome HOME Bed & Breakfast"

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## Shoulder Problems in Polio Survivors

Dr. William DeMayo, MD

DeMayo's Q & A Clinic

<http://www.papolionetwork.org/demayos-q-a-clinic.html>

**Question:** I am now 86 and contracted polio when I was three. The polio left me with paralysis in my left arm, the muscles of my stomach and I have a slight curvature of the spine. Over the years I have been doing fine and even bore 5 children.

About two years ago I developed horrible pain in the upper part of my right arm. I am allergic to NSAIDs so I use Tylenol which gives me occasional partial relief. I also use creams such as Blue Emu and have had therapy. Also, occasionally I use Icy hot electrodes. The pain is with me daily however it does not interfere with my sleep. I am able to be fully responsible in my daily requirements but with pain. I am truly blessed that I am not dealing with worse.

I was curious if you may have any recommendation so that I can make the pain leave. I have also been told I have arthritis in the area.

**Reply:** Shoulder problems in the elderly can be very difficult to rehabilitate and this is especially true in the polio population. A comprehensive review of shoulder problems is well beyond the scope of this article, but I will share some perspectives that may be helpful.

First, it is important to remember that the shoulder joint is inherently unstable without muscular support. Polio survivors with weak-

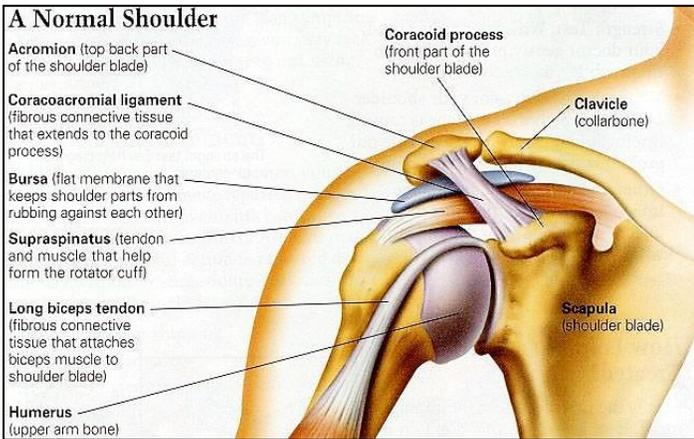
tion, to bear weight on crutches/walkers, or to push a wheelchair. The shoulder is simply not designed for this kind of regular weight bearing function.

Given the history and location of your pain, arthritis of the humeral head and “cup” (a.k.a. glenoid fossa) is a likely component of the problem you described. Other possible contributing sources of pain, however, should always be evaluated. Although not likely in this case, polio survivors should always be aware of other diagnoses to consider when you have a complaint of shoulder pain.

- A pinched nerve of the cervical spine (neck) can radiate pain to the shoulder.
- Myofascial pain (chronic muscular pain) can develop in the periscapular muscles around the shoulder.
- If falls have occurred then traumatic injuries such as a humerus fracture or shoulder separation (torn or partially torn ligaments between bones in the shoulder) should be considered.

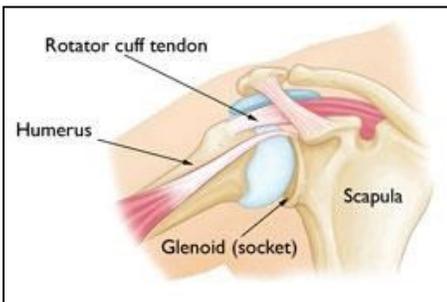
Additionally, there are multiple chronic inflammatory problems that occur frequently in the shoulders of polio survivors. These can lead to abnormal shoulder biomechanics (abnormal movement within the shoulder) that over time can contribute to arthritis. It can be important to treat these inflammatory problems early rather than simply endure the pain because problems can snowball as one gets older. Some of these inflammatory problems include:

- Bicipital Tendinitis (inflammation of the biceps tendon- see large photo upper left)- often presents with anterior shoulder pain and tenderness.
- Bursitis (inflammation of the fluid-filled sac depicted here) is often associated with other

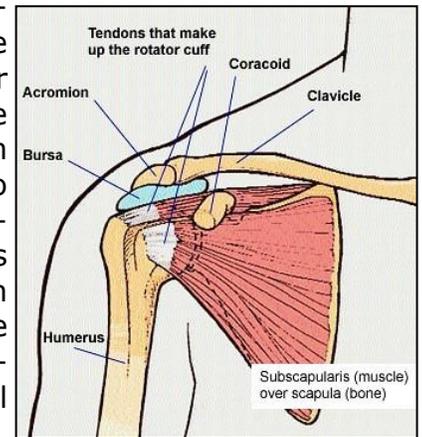


ness of shoulder muscles can learn to substitute but are clearly at much higher risk for subsequent problems such as arthritis, shoulder impingement, bursitis, and tendinitis because the shoulder simply cannot function as it was originally designed. In order to understand this fully, a basic knowledge of shoulder anatomy is essential (see above). One only has to glance at the shallow “cup” (socket) of the shoulder blade which articulates with the humeral head in order to appreciate the importance that soft tissues play in stabilizing the joint during normal use.

Without normal muscle strength, the ball simply does not move normally within the socket. When the ball does not move normally within the socket, other muscles are over-used, leading to possible muscle and tendon problems.



Many polio survivors with leg weakness rely on their arms and shoulders to get up from a sitting posi-

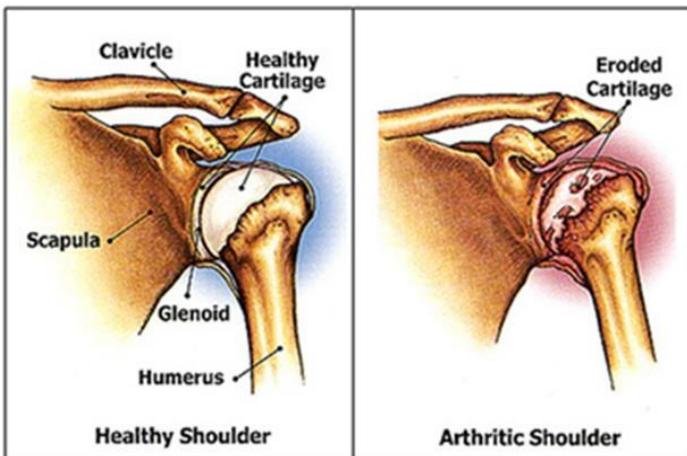


problems. It is more common in individuals with shoulder weakness or abnormal biomechanics.

- Rotator Cuff Tendinitis (inflammation of the tendon portion of the rotator cuff muscles that stabilize the shoulder joint) left untreated this can progress to partial or complete rotator cuff tear resulting in inability to raise one's arm or rotate the arm outward. Impingement (pinching) of the rotator cuff tendon is sometimes due to a bony spur on the under surface of the acromion. If present, this bony spur can often be removed quite easily with arthroscopic surgery and is a good example of early minor surgical intervention that can prevent significant disability later.

Some of these inflammatory problems can be responsive to oral/topical anti-inflammatories, injected anti-inflammatories (avoid multiple) and ultrasound/physical therapy. Additionally, stretching and strengthening exercises can often help restore more normal biomechanics relieving pain and preventing further problems. Most rehabilitation physicians and physical therapists are well-versed in shoulder biomechanics and treatment.

Once severe arthritis has developed within the shoulder joint, pain can be quite difficult to treat. The choices you have made are reasonable to continue if they provide some relief. Oral or injected steroids can also be very helpful but should not be overused. The results can be variable with improvement in pain for days, weeks or months. Although you mentioned that you are "allergic" to non-steroidal anti-inflammatory medications



(NSAIDs), it is important to distinguish this from intolerance. An allergic response typically produces a rash. Intolerance can often be avoided by protecting the stomach or using a different class of NSAID. Topical NSAIDs are also now available.

Surgical replacement of the shoulder has significantly improved in recent years. Polio survivors pose an extra challenge however, due to weakness of the muscles stabilizing the shoulder and osteoporotic bones. In severely arthritic shoulders, replacement surgery can provide a dramatic reduction in pain, but risks need to be assessed carefully and I would always recommend more than one orthopedic opinion.

Lastly, it is important to be aware of adhesive capsulitis (frozen shoulder). With any of the above shoulder problems, reduction in shoulder range of motion over a significant period of time can lead to restriction in the shoulder capsule. This sets up an inflammatory cycle whereby more pain is produced, leading to less range of motion that leads to even further tightness and more pain. Maintaining shoulder range of motion is essential and can be achieved through relatively simple home exercises taught by most physical therapists.

I hope this information helps. I encourage you to see a shoulder specialist to discuss your particular shoulder issue. Bringing a friend or loved one can help you to be sure questions get answered. Don't hesitate to say you will think about their suggestions if you need time to consider them (especially if surgery is recommended).

Don't be surprised if you feel you need to see more than one specialist to find one that you feel confident in. It will likely be worth the investment of time and energy.

Dr. William DeMayo, MD. February, 2017

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 March 2018 <papolionetwork@gmail.com>

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**POST POLIO PACER is a quarterly newsletter published in January, April, July & October for polio survivors, the Madison Area Post Polio Support Group, health care professionals and interested persons to share information and to promote friendships. Articles in this newsletter are for information; medical advice is always necessary.**

**Please request permission from the editor to reprint articles from the Post Polio Pacer.**

*Disclaimer: The opinions expressed in this publication are those of the individual writers and do not imply endorsement by Easter Seals Wisconsin or the Madison Area Post Polio Support Group.*



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**A NEWSLETTER FROM THE MADISON-AREA POST POLIO SUPPORT GROUP**

**Mark your calendars!**

**2018 meeting dates:**

**May 12, July 14, Sept. 8 & Nov. 10**

**LOCATION:**

**Monona Garden Family Restaurant  
 6501 Bridge Rd., Monona  
 Noon to 2:30**

**May 12, 2018**

**Melissa Lauf & Traci Miller share  
 their experiences on the Mercy Ship**

**July 14, 2018**

**Rita Giovannoni, Project Manager, for  
 Independent Living, Inc.'s  
 Tennyson Senior Living Community, planned  
 for Madison's northeast  
 neighborhood, will highlight features of the in-  
 dependent living apartments, assisted living &  
 memory care facilities.**

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