

# POLIO DEJA VIEW

Central Virginia Post-Polio Support Group

August - September 2006

*Carol T. Ranelli, Editor*

visit our website at [www.cvpmsg.org](http://www.cvpmsg.org)

## **August 5<sup>th</sup> Meeting**

2:00 pm at Children=s Hospital, 2924 Brook Road, Richmond

General Discussion of questions, concerns, and the up-coming Retreat in September.

## **September 9<sup>th</sup> Meeting**

PLEASE NOTE: This is the second Saturday, due to Labor Day

2:00 pm at Children=s Hospital, 2924 Brook Road, Richmond

Our speaker will be Mr. Joe Thomas, Manager of Safety, Health and Environmental Programs with the national construction firm where he works. Joe will speak on:

### **“Disaster Planning for the Home”**

**This should be an interesting and informative program which we all can benefit from.**

**\*\*\*\*\* 2006 Annual Retreat!! \*\*\*\*\***

**Please make your reservations by August 31<sup>st</sup> for our annual Retreat. Because we are having the retreat at a commercial hotel this year, it is imperative that we get our reservations to them by this date.**

**This is a lovely facility at a bargain price. We are fortunate to have two nationally known speakers with us on Saturday. All information and the weekend itinerary are in this issue, along with registration information.**

We will hold our annual election of officers at the September meeting. The slate of officers is as follows:

Carol Kennedy, President  
Henry Holland, First Vice President  
Frances Thomas, Second Vice President & Program Chairman  
Linda VanAken, Treasurer  
Mary Ann Haske, Secretary

If anyone is interested in serving as an officer or on a committee, we would love to have you join us. We appreciate any participation by members in the group. It seems the same members step up to get the work done that benefit the entire support group. Remember: our energy is as precious as your's!

- CTR, Editor

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REMINDER: We have a number of audio and video tapes in our support group library. Many of these date back to the early 1990's and include past PPS conferences, etc. I won't use the newsletter space to list all of them (that would take several pages), but if anyone is interested in knowing what we have and would like to borrow some, please call me and I will let you know what we have on any particular topic.

- C. Ranelli, Editor

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**Mid-Month Lunch**

**Wednesday, August 16<sup>th</sup> we will meet at  
Bookbinder's Grill**

1244 Alverser Drive, which is off Huguenot Rd, near Chesterfield Town Centre and Circuit City. Turn onto Alverser Dr. at DSW Shoe Warehouse. The restaurant is in the group of buildings with Schwarzschild Jewelers, MOTO Photo and Coldstone Creamery

**Call Bev Lordi by August 14 with your reservation – 746-3864**

Because our meeting is on the second Saturday in September and our Retreat will start on Sept. 22, we will not have a mid-month lunch in September.

**AGENDA FOR THE SEVENTH ANNUAL  
CENTRAL VIRGINIA POST-POLIO SUPPORT GROUP RETREAT  
SEPTEMBER 22-24, 2006**

**FRIDAY, SEPTEMBER 22, 2006**

3:00- 5:00 PM	Check-in and room assignments
5:00- 6:30 PM	Social hour in the conference room
6:30- 7:30 PM	DINNER
7:30- ????	Visiting & games

**SATURDAY, SEPTEMBER 23, 2006**

**The Hotel Pool is open from 7 til 10, so feel free to use at your leisure.**

6:00- 9:30 AM	Open BREAKFAST
9:00- 10:00 AM	Registration for day only participants. Mary Anne DeTrana will conduct a Feldenkrist exercise session for those interested
9:00- 3:30 PM	Massage sessions available (sign-up at check-in or see Carol Kennedy)
10:00- 11:30 AM	"My Polio Path: How I Went From Survivor to Thriver", Nationally known speaker <b>Linda Wheeler Donahue</b> , President of Polio Outreach of Connecticut
12:00- 1:00 PM	LUNCH
12:00- 4:00 PM	Vendors displays
1:00 PM	Massage sessions continue until 4
1:00- 2:00 PM	<b>Katherine Ott, PhD.</b> , Curator of the "Whatever Happened to Polio" exhibit at the Smithsonian National Museum of American History, Washington
2:00- 3:30 PM	Rest period
3:30- 5:00 PM	Partners session with Dave VanAken Group discussion for PPSers
5:00- 6:00 PM	Social hour in the conference room
6:00- 7:00 PM	DINNER
7:00- ????	Social hour, sharing, games

**SUNDAY, SEPTEMBER 24, 2006**

6:00- 9:30 AM	Open BREAKFAST
10:00- 11:00 AM	Quiet time, sharing, meditation
11:00 AM	Check out

## **SEVENTH Annual Fall Retreat !!!**

**It's time to reserve a room for our Seventh Annual Fall Retreat from Friday, Sept. 21<sup>st</sup> at 3:00 until noon, Sunday, Sept. 23<sup>rd</sup>.**

The Retreat will be held at the Holiday Inn Express Hotel & Suites in Ashland, VA ([www.hiexpress.com/ashlandva](http://www.hiexpress.com/ashlandva)). This is located right off Rt. 95, just north of Richmond and will be convenient for everyone. We have tentatively reserved 15 guest room/suites and all six handicapped accessible rooms.

**The bedrooms will be on a first come – first serve basis.**

The hotel serves a multi-course breakfast and we have arranged to have two dinners and a lunch catered by a local caterer. We will have the use of the conference rooms, heated indoor swimming pool, hot tub and exercise facility.

The suites have microwaves and refrigerators, TV, coffee makers and hair dryers. There is a sitting area separate from the bedroom. This facility opened a year ago and is beautifully decorated and maintained.

**We are thrilled to offer all of this for \$110.00 per person based on double occupancy for the entire weekend, including all meals.** (This is less than the last Retreat at Camp Easter Seals and we have a much nicer facility.)

**If you want to come just for the day on Saturday, the 21<sup>st</sup>, the cost will be \$50 person which includes lunch and dinner.**

**We are excited that Linda Wheeler Donahue has agreed to be our weekend guest and our Saturday morning speaker. We have used several of her fine articles in our past newsletters. Linda writes and speaks about flourishing with a disability and making good choices to create a positive lifestyle.**

**She will speak on "My Polio Path: How I Went From Survivor to Thriver."**

Linda is President of the Polio Outreach of Connecticut. She is a polio survivor, a disability activist, writer, speaker, and professor emeritus of humanities. She has published over a hundred articles worldwide on subjects of positive living, disability dignity, and increasing happiness through conscious choices. A long-time advocate of disability rights, Linda was invited by President Bush, Sr. to attend the signing of the Americans with Disabilities Act in 1990. She is a frequent presenter at conferences, focusing on the social/emotional complexities of disability. Her avocation is tending to her gardens, with a collection of over 50 rose bushes.

We have again arranged to have two massage therapists join us on Saturday from 9 until 4. They will charge \$20 for a 20-minute session. You may schedule a double session if you desire. Sign up for the massage schedule will be during registration on Friday afternoon...or upon arrival on Saturday if time slots are still available. We need to know ahead of time how many people will be interested in this service. Please respond on your registration form.

Dave VanAken will again conduct a "Partners Session" on Saturday afternoon for those interested. We are arranging to have several local medical equipment companies there on Saturday showing

their products and answering questions.

**Final reservations and complete payment should be received by Linda VanAken by August 31<sup>st</sup>. For those who send in an early deposit – the remainder is due by August 31<sup>st</sup>.**

## **Registration Form for September Retreat**

Friday, September 21<sup>st</sup> until Sunday, September 23<sup>rd</sup>

Please mail to: Linda VanAken, 14606 Talleywood Ct., Chester, VA 23831

WITH check made out to: **"CVPPSG"**

Final payment has to be received by **August 31<sup>st</sup>**.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Number of Persons attending: \_\_\_\_\_

Type of Room accommodation: \_\_\_\_\_ (single or double) Handicap accessible?  
\_\_\_\_\_

If you are single and sharing a room, who will be your roommate?  
\_\_\_\_\_

Are you interested in scheduling a massage therapy session? \_\_\_\_\_

Will you be attending just for the day on Saturday? \_\_\_\_\_ Number attending \_\_\_\_\_

Do you have any special dietary requirements? \_\_\_\_\_  
(We cannot change the pre-set menu unless there are specific needs)

Price for the weekend (2 nights and 5 meals) \$110 per person based on double occupancy

Price for Saturday only (includes lunch and dinner) \$50 per person

Amount of check sent: \_\_\_\_\_

Remember, all rooms, including the handicap accessible rooms, are on a first come-first serve basis.

Your registration form, with a \$30 deposit, guarantees your room.

If you know you will be attending, please send your registration in early.

Thank you.

## **PPS in Under Two Minutes**

By David Graham

reprinted from "The Seagull" Triad Post-Polio Support Group, Greensboro, NC

Have you tried to explain post-polio syndrome to a friend, then halfway through you notice them nodding off? Try this two minute drill:

Our brain communicates with our muscles through the nerves. Polio destroys these nerve cells causing our muscles to die.

The beautiful thing about nerves is that they help each other. When one goes down others help out, so a person can lose many nerve cells and not experience much dysfunction.

Most polio survivors have been living in this state of few cells for years. If they were very young when they contracted polio they may have grown up thinking this was normal. All people's nerve cells die off with age. For the normal person, having many nerve cells, this is not a problem. For those of us that have been living with a reduced number of nerve cells, this can result in a variety of symptoms including weakness, fatigue and pain.

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I would like to remind members who shop at Ukrops to go to the Benevolink website and designate their accumulated funds as Ukrops Valued Customers to CVPPSG. It is a quarterly requirement so you must designate every quarter.

**To register or designate go to this web site -**

**<http://www.benevolink.com/main.aspx>**

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### **A Study in Pain Relief and Magnet Therapy**

A small magnet strapped to post-polio patients' most sensitive sore spots reduced pain acutely in a study of 50 people at Baylor College of Medicine and The Institute for Rehabilitation and Research (TIRR) in Houston. Results of the double-blind study were published in the November 1997 issue of the Archives of Physical Medicine and Rehabilitation. "The majority of patients in the study who received treatment with a magnet reported a significant decrease in pain, and most of the patients who were given a placebo, or inactive magnet, reported very little or no improvement," said principal investigator Dr. Carlos Vallbona. He is a professor of family and community medicine and physical medicine and rehabilitation at Baylor and director of the Post-

Polio Clinic at TIRR.

Vallbona evaluated the magnet therapy in adults diagnosed with post-polio syndrome who were experiencing arthritic pain in the joints or had identifiable points of pain in their muscles. Thirty-nine women and 11 men participated in the study. Most were in their 50s and had developed post-polio syndrome during their 40s.

All patients were asked to press on the "trigger point" where they felt the severest pain and rank that pain on a scale of one to 10, with 10 being the worst. The patients were then randomly given an active or inactive magnet to strap against their trigger point for 45 minutes. After the magnets were removed, patients rated the intensity of their pain again. Twenty-nine participants received an active magnet. Their average score of pain was 9.6 before the treatment, and 4.4 after wearing the magnet. The placebo group had an average pain score of 9.5 before treatment, and 8.4 afterward.

The low-intensity magnets, less than a half-inch thick and slightly stronger than refrigerator magnets, were available in four formats to accommodate different areas of the body: a credit-card-size rectangle, a six-inch strip almost two inches wide, a disc the size of a silver dollar and a disc the size of a CD.

"Seventy-six percent of the patients who had the active magnet reported a decrease in pain, but only 19 percent of the patients treated with a placebo felt an improvement," Vallbona said. None of the patients reported any side effects from the treatment.

"We do not have a clear explanation for the significant and quick pain relief observed by the patients in our study," Vallbona said. "It's possible that the magnetic energy affects the pain receptors in the joints or muscles or lowers the sensation of pain in the brain.

The Baylor-TIRR study consisted of one treatment per patient and did not evaluate how long the reported pain relief lasted. Vallbona said more research is needed to determine whether magnet therapy should be recommended as an alternative to the standard treatments for pain in post-polio patients, such as physical therapy, support braces, muscle relaxants, anti-inflammatory drugs and other medication.

BIOflex, Inc., a company in Corpus Christi, Texas, provided magnets for the study.

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**FYI: For members of our support group who use to have orthopaedic shoe work done at Powell's:** due to requests to resume offering specialized shoe services, they have. Joe Byrd heads up the shoe department. Powell's moved last year to 2034 Dabney Rd, Suite C, in Richmond. Many thanks to Powell's for again offering their services!



## **ANALYZING YOUR GAIT: The ROLES OF EXERCISE, BRACING OR SURGERY?**

A review of Dr. Esquenazi and Dr. Keenan's presentation at Post-Polio Health International's 9th International Conference on Post-Polio Health and Ventilator Assisted Living: Strategies for Living Well, St Louis, MO, June 2 - 4, 2005.

Dr. Alberto Esquenazi, is a rehabilitation physician and Director of the Gait & Motion Analysis Laboratory at Moss Rehabilitation Hospital in Philadelphia. Dr. Mary Ann Keenan, is an orthopaedic surgeon and Professor of Orthopaedics and Chief of the New Orthopaedics Service at the University of Pennsylvania.

**"As you know quite well there is not a lot of expertise out in the real world in the realm of post polio syndrome. Unfortunately it's a disease that we don't learn in medical school. It is a disease that is not taught in health care in general but is one that is critical to individuals like you."** [Esquenazi]

"There is no better way to treat Post Polio than to prevent it, so we are always encouraging people to think about polio prevention" [Esquenazi]

Both doctors ran the largest Post Polio Clinic in the mid Atlantic for ten years. The combination of both members of their team afforded them the privilege of dealing with many complex cases over the years. They learned much from Polio Survivors about their condition and experiences and were able to implement that knowledge into the care of other patients. Due to local politics they have ended up working in separate establishments but developed some special arrangements to continue collaborating. They have a multi disciplinary approach and encourage periodic evaluations. They educate their patients and believe peer support is critical so are always surrounded by patients only too willing to help. They counsel patients on modified exercise programs, on activity adjustments, on weight control, bracing and in a few circumstances surgery.

Dr. Esquenazi defined polio, post polio and the nature of polio muscle weakness. He explained how braces help to substitute for that weakness, and how in his clinic they optimise brace alignment and fit.

"Acute poliomyelitis is an infection of the anterior horn cells in the spinal cord and usually it will present as a febrile episode with weakness, with stiffness and with pain." [Esquenazi]

There are about 1.5 million polio survivors alive today in the U.S.A. [USA population of 297 million, about 0.5%] and about 20 million polio survivors in the world [World population of 6,455 million, about 0.3%].

PPS usually presents a variety of problems, muscle weakness, overuse syndrome, nerve injuries, joint derangement, and the natural aging process.

He stated that patients tend to overestimate the strength of their muscles and often present with pain in, say, one area. However, it is not a focal disease but a systemic disease and affects the whole body. It had a larger affect in the areas where clinical paralysis and weakness were seen. He described polio as "throwing a large bucket of black paint at a white wall, ending up with one large blob and lots of little blotches everywhere else. That's POLIO."

Dr. Esquenazi went on to discuss Manual Muscle Testing, describing it as the old way that testing was done! i.e. basically grading muscles from 0 [with no muscle strength] to 5 [normal muscle strength]. "That is the way it was done and is continuing to be done in many places. We have learned now that that is not a good way to do it. We now use hand held dynamometry as a way to test strength because a grade 5 muscle—normal—could

have as much as 30% weakness before Manual Muscle Testing could detect it.”

According to Dr. Esquenazi, the meat of the matter is calf weakness, and everyone needs to appreciate what this means. He explained that our calf muscles have to hold our whole body weight when we are in the stance phase, to prevent us falling. That we have to lose a huge amount of calf weakness before it is detected by strength testing. When we walk we take many steps which is what needs to be assessed, not just one step.

He explained how we also underestimate the demands that we place on our muscles every day: just sitting, keeping our head and back straight plus demands on our legs to cross them and move them around. Then add walking! Also as we get older we tend to get a little bigger, and he added that Americans tend to get a little bigger than the bigger, adding to problems and producing fatigue.

A review of the information provided by the 500 patients in their clinic showed that most patients complained of fatigue. A large number complained of muscle pain, joint pain, muscle weakness, new muscle weakness, cold intolerance, atrophy, problems with walking (almost 80%) and stair climbing.

He then talked about the consequences of trying to walk. He explained that we have been compensating for decades, and our joints pay a price for that. He showed a film of a lady with a large amount of back flexibility in her knee joint, stretching, straining and damaging not only muscles and tendons, but also skin, nerves and vessels—ending up with a complaint of pain.

He said “many of you got to the age of 17 and 18 and decided ‘No more braces’ with the thought that ‘if I can get rid of my braces then I am better.’ Unfortunately we know now that that was not a good idea. Plus you hide your braces. President Roosevelt worked endlessly to hide his so that he did not appear to be ‘disabled’.”

In their Gait Laboratory they put a series of little infra-red sensory stickers on a patient that allows them to convert the human figure into a computer animation so they can measure how we walk in great detail. This can be manipulated and rotated and viewed from any perspective. They can measure the speed, symmetry and displacement of joints and do this without and then with bracing.

He then showed a slide of a gentleman carrying a very large toolbox and asked why do you think this patient came to visit us. There was a lot of laughter when the first person called out, ‘His fingers are tired’. ‘Yes, and he is also likely to get backache and shoulder problems. Can you guess his job?’ I replied, ‘something very strenuous because he is a polio survivor’. Dr. Esquenazi told us that he is a maintenance engineer in a huge Casino with endless corridors and has to carry all that he might need with him; that he wrote to his employers and the Union to explain that he needs to put wheels on this toolbox so that he can retain his health and job.

He then went on to explain that there are two phases to walking, the stance phase when the foot is on the ground and the swing phase when the leg is off the ground. Braces and adaptive postures can do a great job at substituting for stance phase muscles but there is nothing to help swing phase muscles so they are very vulnerable to overuse.

“There are old style and new style braces but unfortunately the new style braces, even though they are lighter and more visually appealing, have become more and more ones that are brought out from a factory and shoved on a patient. The art of making braces is dying.”

He explained that people are not going into training, that Insurance Companies do not want to pay for braces, and that dealing with polio survivors is a pain because they know what they want and it never comes out right.

What does a brace do for us? It substitutes for weak muscles. The brace produces support to the leg when standing, and when walking, where the foot is in the stance phase. In general it does nothing in the swing phase although there are a few exceptions. Braces do nothing for us when we are sitting—although sometimes they make our leg uncomfortable.

Weak calf muscles mean that the tibia bone is not held strongly, and wants to fall forward, tending to make the knee buckle. So what do we do? We use our hand to push back on our thigh, or maybe just snap our knee back into hyperextension. The next thing we do is to take short steps, which do not strain our legs as much. We may complain that we cannot keep up with our friends and are fatiguing, but it could just be taking short steps—longer ones might cause our knee to buckle. Or we may walk with our knee stiff so that it does not have to make that effort. The answer is to put a brace on it.

Braces [AFO's: ankle foot orthosis] come in all colors and shapes so the first step is to try to pick one that is visually acceptable to the patient. Although it might not seem the first criterion, they want us to wear it. Secondly it must be properly mechanically built. Thirdly it must not hurt. He asked how many patients in the room wore braces; how many have a sore or callous and a few people kept their hands up. He explained this was not unusual; that we are willing to tolerate calluses, rubbing, high pressure, because it lets us do more, but this is not acceptable and it shows how tolerant we can be. "Go back and have your brace reassessed."

In his clinic they tend to use braces that are hinged and have movement—although that is not universal—because when the foot hits the ground it needs to get flat to make us stable. If the foot is not allowed to do that then we need to make extra effort, bend our knee early, flex our hip earlier, and do things to accommodate this, which will usually strain our thigh muscles.

Back knee deformity is another very frequent problem usually aggravated if the foot is stuck in a toe down position. A long time ago surgery to stabilize the knee was sometimes to put your foot into a fixed position pointed down. It can be prevented but it's not easy once it's started and we tend to need a long leg brace. Long leg braces KAFO's [knee ankle foot orthosis] come in many flavors and shapes. At their clinic they like to use braces that are not locked at the knee if at all possible.

Where feasible they like to allow ankle movement but this has advantages: moving the foot up and down gives a more natural gait, adding a little spring to kick the foot up if necessary— and disadvantages: it has the potential for unwanted ranges of motion; the brace can become loose, the joints not doing what they are supposed to, and they require more maintenance, replacing parts and pieces where necessary.

In their clinic they use spring assisted braces, ultra light-weight carbon graphite and the newest of all, weight activated braces that lock as your weight goes down on them and unlocks as your weight comes off. While not without problems they work for some people.

Shoulder and wrist problems when walking! Dr. Esquenazi said they have learned that if we have weakness in our legs then we will end up with problems in our shoulders and wrists, either from pushing a wheelchair, pushing ourselves up to stand, or leaning heavily on crutches. He then showed film of a patient who helped with their research, followed by an animation showing how she stood up from a chair. "She uses her head and twists her pelvis in an awkward manner. Now we can try and figure out what is causing this. Think hard of the extra problems, the extra stress and strain on her shoulders and wrists if she weighed more."

Sometimes they can make braces for upper limbs but they are a little harder to do and less effective than lower

limb braces.

“Key Issues to remember.

1. The earlier you apply a brace the better because you will reduce some of these strains and problems down the line.
2. The lighter the brace the better because it will take away the strain during the swing phase when you have to ‘carry’ the brace.
3. Where possible have your brace optimized for alignment at least twice a year. Remember you take it off at night and stand it against the nightstand and it falls over and could now be out of alignment. If you think it now feels a little stiff, or has a kink in it, get it checked out.
4. Your relationship with your Orthotist is long term. Find a knowledgeable and preferably bracing experienced physician to work as your advocate. Take a third person with you to help ensure that you both understand what you are saying.
5. You are taking the brace home —the brace maker will tell you it looks good — but does it feel comfortable?”

“I will now hand over to my colleague Dr. Mary Ann Keenan.”

Dr. Keenan started by talking about Exercise, saying, “We have found out that it is really difficult to truly improve muscle strength.” She said that they do see, and can measure, some improvement in muscles strength after adjustments with bracing, lifestyle, weight etc, but they think that once people have stopped abusing their muscles they just recover their base line strength. It is very important to continue to exercise to maintain that strength and flexibility and prevent disuse weakness.

Their guidelines are:

- Low resistance and low impact – not exercising against a lot of force. Water exercises sometimes are helpful as you have the buoyancy of the water to support you against the resistance of the water.
- Short duration -say two minutes -of exercise for each area of the body, rotating the different muscle groups.
- Do not exercise any group of muscles to the point of fatigue.
- Take frequent rest periods.

Dr. Keenan then went on to talk about surgery. Surgery is not a huge part of caring for people with post polio problems but if you do need surgery then it’s important to have an

- Anesthesiologist – “who understands the issues of post polio and the need to go light on all their many drugs.”
- Surgeon – who accepts and practices the holistic approach to surgery, someone who goes beyond looking at the leg in question, to both legs, arms and in fact the whole body.

- Knee surgeon – who understands how the foot impacts on the knee, how a weak calf can lead to knee problems.

People who have a little weakness in their calf have to use their quadriceps in the front of their thigh more strenuously leading to kneecap problems, grinding of the kneecap and tendonitis in the thigh muscle. If the calf is even weaker with back-knee then you can have more serious problems. Dr. Keenan has seen patients who have had their knee scoped a couple of times, by good surgeons, nibbling away at their meniscus because of tears, who did not realize that the problem was being caused by the weakness in the calf. It is really important for health professionals to look for the underlying cause.

She explained that she performs surgery for pain relief, correction of deformity, on occasion redirecting some muscles' forces with tendon transfers, stabilizing joints and to reshape a leg or foot so that a brace can be made which will provide good structural support. "Getting rid of that brace was a 50's and 60's idea but it is no longer appropriate".

Dr. Keenan tells all her patients that there is a lot she can do for our legs but we have to save our shoulders, the key to our independence. We need to minimize the mechanical force we put on our shoulders, e.g. pushing up to get out of chairs, leaning heavily on crutches etc.

Dr. Keenan then went on to talk about specific problems.

**Rotator Cuff Problems** – caused by overuse of shoulders. MRIs are taken of the shoulder joint, but Dr. Keenan ensures that this also covers the muscles that control that joint; looking at the actual tears in greater detail, and also to get some concept of the quality of the muscles that work that joint. If the muscle is filled with fat then you know it does not have much muscle strength. To reattach the tendon there needs to be enough muscle fiber to work the shoulder again. Rotator Cuff Surgery is a big investment of patients' and family's time because during recovery you cannot use that arm whilst the shoulder is healing. It is imperative to look at what actions caused the tear so that you modify how you do the action to prevent it occurring again. Some strength can be lost but overall the results are good.

**Carpel Tunnel Syndrome** – surgery is not always necessary. It may be as simple as changing grips on canes and crutches, or better leg bracing so you don't have to lean so heavily on aids. Where this has been going on for some time with significant arthritis, where really severe, she might stabilize the wrist to get rid of the pain but this takes away the motion so she tries to avoid this type of surgery.

**Equinus** – toe down position. When you walk and your toes go down first instead of your heel. It is like having a built-in doorstep pushing you backwards and jamming your knee backwards. Here she lengthens the Achilles tendon to get the flexibility back again and get the foot flat on the floor but the trade off is loss of some strength. This tightens the toes so they snip the tendons to allow the foot to lie flat in the shoe.

**Cavus** – a high arched foot. To help you get a foot or foot and brace into a shoe your foot needs to be flatter. If there is no arthritis they can release the ligament on the bottom of the foot and let the bones go back into their normal position. If there is a lot of arthritis then they add a little wedge of bone. She showed a video of a patient whose foot and ankle were fused in the toe down position with the idea that it would push her knee back/stabilize her knee and so not need a brace. Now in her 50's she was having knee pain so Dr. Keenan cut through the mass of fused bone to flatten the foot and gave her a new brace, which solved her problem.

**Valgus** – foot that rolls over and pronates, flat foot. Having this type of foot can make it difficult to fit a brace,

so realigning the foot into a better position will give a better base of support. Abnormal feet put abnormal forces on knee and hip which can cause pelvic wiggle movements and back strains, causing knock knee or valgus deformity. This can be caused by one leg shorter, weakness of hip muscles, tightness of the band on the side of your leg, or a crooked foot. A lot of different factors to be considered before treating. It may just need a lift on your shoe and a cane, or Dr. Keenan may need to release some tendons, realign the bone and sometimes if significant arthritis replacement joint surgery is necessary.

**Varus** – bow legs. There is no surgery to tighten up the ligament and joint capsule behind the knee. Long leg bracing can control this unless it's really severe with lots of arthritis when knee replacement is considered.

**Quadriceps weakness** -very common in polio survivors. The quadriceps are the muscles that help us stay upright. If our knees are flexed – not able to straighten them – then we ask the quads for more help. If we have weak quads and flexed knees then we are more vulnerable to falls and we lean more heavily on our arms. If bracing does not work then surgery is considered to lengthen some tendons, cut the bone, realign the knee or replace the joint.

**Hip flexion problems** -make us lean forward and put strain on our muscles and back using up an enormous amount of energy to compensate; energy which we are already short on as polio survivors and should not be wasting.

“If you let go of a plastic skeleton it collapses. It is the muscles that control the flexibility of joints and depending on where your body weight is in relation to how a joint moves normally, then you either need to have the muscles control that flexibility or a brace that controls it.”

**Joint replacement** – for polio survivors there are a lot of special considerations regarding all the other implications of the combinations of patients' muscle strengths. It is imperative that patient and medical personnel work as a team. Patients need to understand the ultimate restrictions that this surgery will place on them. If you have already damaged a normal joint then you will wear out the metal and plastic joint in the same way unless you change how you do actions. Other leg deformities have to be corrected as well and it may be necessary to use a lower leg brace as well.

- Contracture of a joint – you don't have normal motion. You can have laxity in one direction or the other because of stretched out ligaments and joint capsules. With little muscle strength you need to compensate.
- Bones – if you have a lot of weakness or paralysis in a limb then bones are much weaker, and there may be more osteoporosis, making fixation of the knee or hip joint challenging.
- Hip Abductor and Hip Extensor Muscles – you need pretty reasonable strength of these muscles to keep the ball and cup of the hip joint together. There is a certain inherent stability to a ball and cup design and they can pop out of position if you don't have the muscle strength to hold it together.
- Arthritic hip and low muscle strength – make it impossible to do a hip replacement and alternatives have to be considered.
- Constrained hip joint replacements – not used with polio survivors with weak muscles because it is just going to transmit all the forces onto the bone making it weak or osteoporotic and the replacement rip out from its setting. An alternative to get some pain relief might be to control the position of the leg by cutting the

pelvis making a roof over the hip joint. A video was shown of a lady who had this surgery and six years later is still walking and has pretty reasonable relief of pain.

**Planning for surgery and post-op rehabilitation** – Dr. Keenan coordinates with Dr. Esquenazi and the team at Moss Rehab and all treatment is pre approved. As surgery realigns the leg the brace maker comes into the operating room to make the mold and it's fast tracked so rehabilitation can proceed.

Dr. Keenan then showed short videos of two patients.

1. A 56 year old with bad deformity presenting with back pain. She has no muscle strength in left leg, significant weakness in right leg. Left arm also completely paralysed. Total knee replacement, long leg brace for left leg and short leg brace for right leg. 14 years later and she is still walking and going well. BUT she had to promise me that she would never stand on her left leg without the brace to protect it.
2. Knee bending inwards – valgus or severe knock knee, given total knee replacement. Shown walking two weeks after surgery with the knee joint locked to protect some tendon repairs. Now able to walk without the knee joint locked because as much motion as possible is wanted. This shows her two years post op and it is now six years later and she is still doing quite well.

**Special considerations for polio survivors pre surgery** – because of weakness, paralysis, osteoporosis, and/or abnormal shaped bones, there needs to be a lot of work done ahead of time.

- Look at the whole person not just the leg, or both legs, and how they do actions of daily living.
- Each patient is different and we need to understand that the pattern of strength and weakness, and the compensations that have been developed over time.
- Coordinate with anesthesia team regarding anesthesia and for inter and post operative pain management.
- Coordinated team approach with rehabilitation and bracing.
- Custom joints may need to be made.

As Keenan stated, "Our job is to avoid your garage or closet being filled with a bunch of failed and discarded devices".

*Compiled by Hilary Hallam from notes taken at the presentation and an audio record.*

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**From Henry's Desk** *by Henry Holland*

## Polio and the Meaning of Life

Has your life with polio provided you with more insight and understanding regarding the meaning of life? Many of us were invaded by an invisible virus early in our lives. For some that virus killed or severely damaged anterior horn cells (motor cells) in our spinal cords. That virus could also invade the brain and result in death. Even if we survived the initial invasion many of us were left with the mark of polio. Four years ago I wrote an essay on the "Mark of Polio." You can refer to that article on our group's website at <http://cvppsg.org/henrydesk/>

If one has memory of this initial invasion, a question that one would wonder is "Why is this happening to me?" Many of us were children or young adults and trying to understand the randomness of polio attacks is still a puzzle today. We were innocent victims and for a variety of reasons our individual bodies did not resist this viral invasion or overcome it with no resultant damage. Many did experience non paralytic polio and may have never known that this virus invaded their gastrointestinal tracts. All through history many people of knowledge often connected evil events as being controlled by God or some other deity. If God brought about this evil, then the individual or his or her family must have committed some sin to justify this punishment. Infectious diseases have ravaged humans since recorded history. The number of lives lost to bubonic plague, tuberculosis, typhus, cholera, pneumococcal pneumonia, human immunodeficiency virus and many other infectious diseases can only be estimated through history. When compared to many infectious diseases polio does not rank high with great numbers or in causing a great number of fatalities.

The biology or pathogenesis of polio became better understood during the last century. This understanding helped bring about the development of two vaccines to prevent polio. We all hope that these vaccines will eventually eradicate polio from the earth. Without polio there is no Post-Polio Syndrome (PPS). Thus, the eradication of polio will also eradicate PPS in time.

The psychosocial impact of polio on individual lives is difficult to measure. For so many this disease caused emotional withdrawal, lowered self esteem, a feeling of disadvantage and being unable to compete with peers in physical endeavors. Many of us never ran again or skipped again or even walked again without braces. Others were not able to walk even with braces. The message from those that encouraged us was that "If you try hard enough, you can walk again."

Failure to overcome the adversities of polio damage often increased the feelings of guilt that many of us already felt. Fortunately studies and biographies have revealed that many of us achieved by sublimating our lost abilities into other achievable pursuits. The social pain during adolescence in relating to peers and in the "dating" behavior of the time often led to a self perception of not being normal and of being unattractive. We now know that the vast majority of handicapped polio survivors married and often parented children, much like our physically healthier peers.

Many of us have sought spiritual or religious insights to better understand and cope with the polio reality that life had bought on us without warning. That search might lead us into involvement in an



established religion, the religion of our parents or it might be a totally individual soul searching pilgrimage that is independent of an established religion. Personally, I have remained in an established religion. That religion is Christianity and my denomination is protestant. I have found the church to be a community of loving souls and many who attend have experienced a broken spirit. I admire the late theologian Reinhold Niebuhr's definition of the church:

"The Church is curiously a mixed body consisting of those who have never been shaken in their self-esteem or self-righteousness and who use the forms of religion for purposes of self-aggrandizement; and of the true Christians who live by a "broken spirit and a contrite heart."

I have my doubts as to whether God intervenes in human lives. However, there are certain unexplained blessings that have entered my life. The event of polio in my life was probably random choice, but the resultant experience has been a blessing. Yes, I really mean that, a blessing. Also, I really cannot explain how I got through college and medical school and graduated debt free. I was so naïve as to how vulnerable I was at the time. As a hospital intern I contracted and survived pneumonia and its long aftermath and hopefully have given something back. I cannot explain the miracle of Brenda (my wife of forty-one years) entering my life when I least expected such a blessing. I saw myself as the doctor in *Of Human Bondage*, but Brenda changed all of that thinking. I cannot explain the blessings of the three pastors in my life, the many teachers and my many friends. I feel blessed as a physician because of all I have learned about life from my patients over the last forty years. Again I was unexpectedly blessed when I first attended a meeting of the Central Virginia Post Polio Support Group in September 1991. To see, hear and feel a reflection of my own experiences in what other polio survivors and caregivers shared helped me to expand my understanding of the meaning of life.

Because of polio many of us had to confront the feeling of not loving ourselves. That feeling could often result in feeling unloved. Hopefully, many of us learned to love ourselves, often because others loved us. This dynamic is alive in our Post Polio Support Group. We have learned to love one another and readers; I feel that is the meaning of life.

About a century ago another physician gave us these words that speak to his understanding of his quest:

"He comes to us as One unknown, without a name, as of old, by the lake-side; He came to those men who knew Him not. He speaks to us the same word: 'Follow thou me!' and sets us to the tasks which He has to fulfill for our time. He commands. And to those who obey Him, whether they be wise or simple, He will reveal Himself in the toils, the conflicts, the sufferings which they shall pass through in His fellowship, and as an ineffable mystery, they shall learn in their own experience Who He is."

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