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IF MY BODY WERE A CAR

If my body were a car, this is the time I would be thinking about trading it in for a newer model. I've got bumps and dents and scratches in my finish and my paint job is getting a little dull, but that's not the worst of it.

My fenders are too wide to be considered stylish. They were once as sleek as a little MG; now they look more like an old Buick.

My seat cushions have split open at the seams. My seats are sagging. Seat belts? I gave up all belts when Krispy Kremes opened a shop in my neighborhood.

Airbags? Forget it. The only bags I have these days are under my eyes. Not counting the saddlebags, of course.

I have sooooo many miles on my odometer. Sure, I've been many places and seen many things, but when's the last time an appraiser factored life experiences against depreciation.

My headlights are out of focus and it's especially hard to see things up close.

My traction is not as graceful as it once was. I slip and slide and skid and bump into things even in the best of weather.

My whitewalls are stained with varicose veins. It takes me hours to reach my maximum speed. My fuel rate burs inefficiently.

But here's the worst of it—almost every time I sneeze, cough or sputter . . . either my radiator leaks or my exhaust backfires.

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.

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

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 infrared 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.

- The earlier you apply a brace the better because you will reduce some of these strains and problems down the line.
- The lighter the brace the better because it will take away the strain during the swing phase when you have to 'carry' the brace.
- 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.
- 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.

- 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.

- 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.

- 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”.

Dr. Keenan then told the audience that they had helped produce a booklet, freely available on the Einstein Website, to help us save our shoulders.

Booklet - Save Our Shoulders: A Guide for Polio Survivors by Jennifer Kuehl, MPT, Roberta Costello, MSN, RN, Janet Weschler, PT. Investigators, Mary Klein, PhD, Mary Ann Keenan, MD, Albert Esquenazi MD available for download at:

http://www.einstein.edu/rx_files/yourhealth/mrri_sos9510.pdf

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BURNING PAIN

By Richard Bruno

Note: This column is for information purposes only and is not intended as a substitute for professional medical advice.

Q.

I have developed burning pain in my butt that starts in my smaller left cheek. The pain is in both cheeks by mid-afternoon. By dinnertime I can't sit anymore. I also have pain in my right hip and the right side of my neck. Doctor s say that I don't have pressure sores, but they can't explain what's happening. I have tried foam cushions, which are too hard and hot, and gel cushions, which are hard, hot and too

heavy. What's happening and what can I do?

What's happening is that you have FDD: "Franklin Delano Derriere." You may know that FDR had almost no muscle over his ischial tuberosities, the bones in your lower pelvis on which you sit. If your bum hurts sitting on a cushion, imagine the pain Roosevelt must have experienced sitting in his wooden wheelchair that had no cushion at all.

You're developing pain because, as your butt muscles get smaller over time, your ischial tuberosities are pressing harder on the thinning tissue underneath. Your doctors don't find pressure sores on your skin because fortunately, polio survivors don't typically get decubitus ulcers since they have intact sensation and good blood flow to the skin. In 24 years we have never seen a polio survivor with a pressure sore. But we're seeing more and more cases of FDD.

As you've discovered, foam and even gel are often not soft enough to cushion an unpadded bum. What you can try is a light, air-filled cushion that gives you gentle support as it distributes weight away from your ischial tuberosities. The granddaddy of air-filled cushions is the "BBD," Bye-Bye Decubiti (around \$250 at easypivot.com), an inflatable pillow with "dimples" that help distribute your weight. A newer "dual-chamber" version allows you to fill the left and right sides with different amounts of air.

Roho Dry Floation cushions, with rows of air filled cell cells that redistribute pressure as the user moves, can be purchased online (SpinLife.com or Southwest Medical) for around \$280. Star cushions (around \$425 at starcushion.com) have about 100 banana-shaped cylinders that fill with air. Some cushions are designed to fill all cylinders with the same amount of air. Others allow the front and back halves to be filled with different amounts of air, allowing you to raise up your small buns in back so that they are level with your relatively larger thighs up front. Some cushions allow the front and back and the left and right portions of the cushion to be filled individually to give stability to polio survivors who have, say, a smaller left cheek but a larger right leg.

The newest and most expensive air cushions are from Aquila (around \$675 at aquilacorp.com). Instead of having many identical air-filled cylinders, their Custom Air cushion has 18 compartments, long and flat in front to support the thighs, smaller, wedge-shaped or round in back to support the butt. Each compartment has about 2 inches of foam at its base. Off-the-shelf, Aquila cushions let you inflate the front and back compartments separately. But, the company says it will custom-build cushions that will allow you to inflate any grouping of compartments to conform to your unique shape. Also, Aquila cushions inflate with a blood-pressure cuff bulb (versus a bicycle tire-type pump for the other cushions) attached to an electronic LED pressure display, so that you can actually "see" how much air is in the compartments.

Once you find a cushion that will tenderly cradle your skinny bum, you also have to consider how the rest of you is positioned. For your butt to be comfortable, you have to make sure that your footrests are at the proper height and angle and that you have a solid back with lumbar support, like the Jay 2 back (sunrisemedical.com), not just the canvas sling wheelchair back.

Proper bum and back positioning will also fix the right hip and neck pain you get late in the day. That pain may be due to muscles shortening and going into spasm as you lean right to shift your weight off the cheek that hurts. Too, you could have bursitis in your hip, also due to putting too much pressure on your right hip joint as you shift your weight away from the offending cheek.

So, all things being "unequal," the fix for your FDD may be, as is spring "in the air."

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