



Colorado Post-Polio Connections

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What polio is or what it affects or causes:

By Marny Eulberg, M.D., director, Post Polio Clinic at St. Anthony's Hospital, Denver

- ✓ Polio kills or damages the anterior horn cell(s) in the spinal cord and thus results in no information being sent to the muscle fibers of **any** “voluntary” (striated) muscle i.e. any muscle that can be controlled by thought such as “I think I’ll point at that object with my index finger”; this includes the muscles of the hand, arm, shoulder, neck, trunk, back, abdominal wall, entire leg and foot, face including muscles used in chewing, and muscles used for breathing and for the initiation of swallowing (the latter are known as “bulbar” muscles). **It does not affect the cardiac (heart) muscle or smooth muscle which is in the walls of the GI tract (esophagus, stomach, intestines) or the walls of the urinary bladder.**
- ✓ Atrophy (wasting) of a muscle(s) or the “skinny” arm or leg is a result of the muscle not getting any messages from the nerve that it needs to work.
- ✓ “Polio leg” (the cold to the touch) happens because of blood pooling in the weakened extremity, radiant heat loss, and some lack of blood vessel constriction that normally happens when exposed to cold temperatures. *However it is **not** “poor circulation” as is commonly understood; it is **not** due to decreased arterial blood flow to the area (unless the person has another medical condition that causes blockage of the arteries) and will not cause delayed healing or the need for amputations that can happen with arterial insufficiency.*

(Continued on page 3)

In My Opinion . . .

I like using words. I try hard to use words that best convey the ideas I want to share and will most accurately tell me what I want to know. I know that words have different meanings for different people and that the emotion that a word can evoke can color that meaning.

That is why, as I put together this issue of the Connections, I spent time thinking about the words that are being used in the articles written by Dr. Marny Eulberg and Dr. Lauro Halstead. They are talking about two words, the word, “polio,” and the word, “cause” as it relates to polio. The words, the definitions, in their articles taught me that my carpal tunnel syndrome may have been the result of using a cane or crutches, a consequence of having polio. On the other hand, I spent a lot of years doing handicrafts and using computers which can also be contributors to the condition. So, having had polio may have contributed to carpal tunnel syndrome, but it is not necessarily and always the cause.

Then, there is the problem of those extra pounds I carry. Polio didn't make me overweight. Inactivity, overeating and a busy life style caring for a family and working full time did that to me. Perhaps having had polio and the resultant fatigue and difficulty in walking, particularly those years when I refused to use a leg brace, contributed to my lack of motivation to concentrate on the work and the vigilance that is needed to better care for myself.

Between Dr. Eulberg's explanation of what polio is and what it is not, and Dr. Halstead's information about comorbidities and secondary diseases, we have a vocabulary that can be applied to the words “polio” and “cause” which we can use in our own lives, with our families and friends and at the doctor's office. We can be clearer in our minds about the consequences of aging, and aging with a disability. For me, knowing about and understanding what is happening brings a sense of peace, and I can deal with the results of whatever comes my way.

Other topics are covered in this issue. One is the biography of Martha Logan. Her story is one of grit and determination. She is a living example of keeping on with a positive attitude and living a full life when everything else goes wrong.

Our Colorado Post-Polio Conference in May was well attended and the information that we learned was well worth our time. We had over 80 people in attendance, including polio survivors from New Mexico, Montana and Florida. I believe we all came away with some new insights and with some connections, both with old friends and new. Thank you, Marlene Harmon, Nancy Hanson, and crew for a job well done.

In April, a discussion group was held for wearers of the Dynamic Bracing Solutions brace. Group process veterans know the value of talking about shared experiences in terms of the common feelings, and the practical help that comes from insights of others who have had the same issues. This group was significant in that it showcased the hope that the participants felt, a feeling they shared, not only with each other but with their audience. We all came away feeling that there is some help out there that will enhance the quality of our lives, and we acknowledged how much work it takes to achieve that place in life.

Margaret C. Hinman, editor

What Polio Is . . . (Continued from p. 1)

- ✓ Polio can cause muscle fatigue and being unable to perform one more repetition of an action from overuse of a weakened muscle. [Normal muscle fibers contract and relax in a 1:4 ratio (contraction =1, then relaxation =4); some studies have shown muscle fibers in a polio survivor having a 1:2 contraction to relaxation ratio therefore allowing much less recovery time between contractions!]
- ✓ Polio can be a cause of unexplained generalized fatigue “the polio wall”. This may be due to the increased work of doing daily activities e.g. it takes twice as much energy and oxygen consumption to walk with two crutches as it does for a person with two normal legs to walk. And Dr. Richard Bruno proposes that it may also be due to some polio virus damage to the reticular activating center in the brain. **But many other medical conditions can also cause fatigue including diabetes, thyroid conditions, hormonal imbalances, obesity, and depression to name a few.**
- ✓ Polio can cause muscular pain, especially an achy, burning, or sore feeling. This is likely due to overuse of the muscle and people describe it as the same feeling one has when they go skiing for the first time in winter or work out for the first time. Others who were old enough to remember when they contracted polio describe it as feeling like the muscle pain they had with acute polio.
- ✓ Sometimes muscle cramps can also result from overuse, but they can also be due to low potassium levels or low calcium levels or, especially the cramps in the calves that awaken people at night for unknown reasons.
- ✓ The results of polio such as an abnormal position of a limb around a joint, having to use one leg for the majority of the weight bearing during one’s lifetime, or using the arms and shoulders for crutch walking or propelling a manual wheelchair can result in “wear and tear” degeneration of joints, tendons, and ligaments. It is not unusual for persons with one leg weakened by polio to need a joint replacement of the knee and/or hip on their “good” leg.
- ✓ Unusual pressures around a nerve, as happens in a crutch user or cane user at the wrist, can cause nerve compression problems such as carpal tunnel syndrome.

Polio is not/does not cause/affect . . .

- ✓ Sensation (ability to feel light touch, hot/cold) *so-o it does not, directly, cause numbness or tingling*
- ✓ Proprioception (ability to tell if foot is flat on floor or at an angle, to tell if foot is depressing accelerator or not, or if knee is straight or bent)
- ✓ Food getting stuck in the lower esophagus (in the mid chest or lower) – an esophageal motility problem or blockage causes this!

(Continued on page 4)

What Polio Is . . . (Continued from p. 3)

- ✓ Spasticity (increased muscle tone) in limbs
- ✓ Diarrhea, abdominal pain, or rock hard bowel movements (but decreased abdominal muscles may make it more difficult to expel the bowel movement)
- ✓ Vision
- ✓ Hearing
- ✓ Taste
- ✓ Dizziness, vertigo [*Polio/PPS may cause balance problems because weakened muscles may not respond quickly to “right” yourself when pushed or thrown off your base of support – one patient eloquently said “My balance problem is in my feet not in my head!”*]
- ✓ High blood pressure or heart disease
- ✓ Cancer of any kind
- ✓ Obesity (***but the decreased ability to exercise can result in less calories used for energy output and therefore if calories consumed are greater than the calories used for exercise fat will be produced.***)

Many thanks to the following volunteers who made this newsletter possible:

Jeanine Ellison-Fisher, Delores Glader, Nancy Hanson, Margaret Hinman, Marlene Harmon, Barbara Nickelson. Woody Trosper and the mailing crew.

The following information is excerpted from Halstead, Lauro S., M.D. **Managing Post-Polio, A Guide to Living and Aging Well with Post-Polio Syndrome, 2nd edition.** Washington D.C., NRH Press. 2006. pp.56-59.

COMORBIDITIES

Comorbidities are concurrent, but unrelated illnesses or medical conditions that may impact your overall health and/or ability to function. For example, you might have both PPS and a chronic health problem such as diabetes, heart disease, arthritis, high blood pressure, thyroid problems, or cancer, or an infectious disease such as influenza or pneumonia. The risk of many of these health problems increases with age, so it's important to be aware of how they relate to PPS as you get older.

Comorbidities may significantly affect your ability to “perform” at your usual level. For instance, you might have heart disease and be experiencing fatigue, which might result from both conditions. If you have more than one diagnosis, it is important for you and your health care providers to consider how each condition might contribute to your symptoms. Talk with your doctor if you have symptoms of other illnesses or medical conditions, difficulties managing chronic health problems, or questions about the interaction of PPS and comorbidities.

SECONDARY DISABILITIES

Secondary disabilities are those that occur when persons disabled by a particular injury or illness become further disabled because of a second injury or illness. (Continued on page 5)

Secondary Disabilities (*Con't from p. 4*)

For example, a polio survivor who uses a short leg brace but doesn't need assistive devices such as crutches might become further disabled by a fall causing a hip fracture. In this case, the person might now need the short leg brace and a cane. Also, he or she might be unable to walk as far as he or she could before the fall. The secondary disability is not the fall or hip fracture; rather, it is the increased difficulty in walking. By contrast, the fall is the event that caused the disability, and the hip fracture is the injury or impairment.

Another example might be a polio survivor who sustains an injury to his or her rotator cuff (the group of muscles and tendons in the shoulder that allow overhead activities) and now is unable to style his or her hair. The secondary disability is the *new difficulty required to do something*. In this case, styling the hair becomes more difficult or even impossible, thus resulting in a secondary disability.

Sometimes secondary disabilities persist despite treatment of the inciting injury or illness. For example, in the case of the person who sustained a hip fracture, the fracture will certainly heal with appropriate treatment. However, the person might be unable to walk as easily as he or she did before the fracture and might always need to use a cane for stability. In other cases, when an underlying injury such as a rotator cuff tear goes undetected, getting appropriate medical treatment may cure the injury and eliminate the secondary disability.

Both comorbidities and secondary disabilities can result in the loss of the ability to function in one's usual capacity. As mentioned above, because polio

survivors often are functioning at a maximal level without many energy reserves, even a small change in health status can result in an inability to continue to perform at their usual level. Even a subtle shift may cause a pronounced effect.

The good news is that many, if not most, medical conditions can be effectively treated by experienced health care providers. Therefore, seeking early treatment of new symptoms can help minimize the effects of comorbidities and secondary disabilities.

Book Review: Living With Polio. The Epidemic and Its Survivors by Daniel J. Wilson

Reviewed by Edith "Woody" Trosper

Daniel J. Wilson, the author of this book, had polio in 1955. About thirty years later, he began to develop the symptoms of post-polio syndrome. At about the same time, he noticed that the wide-spread fears of the AIDS epidemic seemed "eerily reminiscent of fears from the polio era." As a professor and a writer, he became interested in the many years of literature about the earlier epidemics. He soon decided that there were many scientific writings on polio, but there were few writings by those whose lives were "altered by their encounter with the polio virus. The book is organized around the experience of having polio, recovering from the disease, and living with a disability in the second half of the twentieth century . . . [including] the physical and emotional consequences of the late effects of polio."

Wilson did not find that there was a "typical polio experience" among the persons who had written about their memories. *(Continued on page 6)*

Book Review *(Continued from page 5)*

These writers were among the less than 2% of those infected who had aftereffects of the virus. The author studied over 150 personal polio narratives, which were about evenly divided between men and women. He also studied films, internet blogs, and newsletters from post-polio groups. All these different writings cover mainly the period from 1940 on; few writings by earlier patients were found. Also, most of the writings were by polio survivors who were white and usually middle-class; only a handful of accounts were written by African-Americans and/or those who were poorer. "In fact, the disabilities of polio, by forcing young men and women to focus their energies on their educations, enabled some polio survivors to improve their social and economic status."

Most of the polio narratives start with a drawn-out diagnosis; up to 22% of these were at first a misdiagnosis. Only the dreaded spinal tap was definitive, if it was ever done. Also dreaded was the quarantine and isolation that the eventual diagnosis brought to patient and family. Most dreadful of all was the knowledge that the diagnosis of polio might bring months or years of painful exercises, conspicuous braces, public embarrassment, etc.

This embarrassment, the author felt, was primarily based on the failure to fit into "the Protestant work ethic" of the period--the "conformist years following World War II when fitting in politically, socially, and economically was highly valued." This work ethic assumed that "hard work inevitably brought rewards," and less-than-perfect outcomes were the fault of the person who did not work hard enough. This ethic "fostered feelings of guilt and unworthiness

that made adjustment to any remaining disability more difficult." There was no allowance for outcomes that fell short of complete recovery and "normality." There was no realization of the problems that these attitudes would bring later in life, especially when post-polio syndrome ruled out "hard work."

The author returns often to these psychological problems of polio survivors, which he feels have not been stressed in some earlier writings. He also associates these attitudes with the feelings of "failure and defeat" which came with post-polio syndrome. For polio survivors, both earlier and later, depression was a frequent result.

Patients who were entering the rehabilitation phase of their original recovery were subject to the attitude then current, that the doctor's decision was not questioned. After the acute stage of the disease, splinting and the despised hot packs were replaced with physical therapy. (Frequent shortages of enough physical therapists are mentioned.) One topic described fully was "learning to fall." Later on came decisions about braces, crutches, wheelchairs, and even surgery--often without input from the patient or parents. The attitude of medical personnel toward parents, in fact, was frequently negative--it was felt that they offered patients unrealistic recovery expectations and were obstructive to other decisions. Many polio survivors remembered the stringent limits on family visits.

There were several facets of the polio experience that the author covered slightly differently from other writers, sometimes in depth. Among these were the specific problems *(Continued on page 7)*

Book Review *(Continued from page 6)*

that men had, the perceived sadism and indifference to pain of physical therapists and doctors, segregation, and the acute and long-term iron lung experience (including struggles to breathe unassisted). The assistance given by the National Foundation for Infantile Paralysis (later the March of Dimes) was discussed, but not in depth; it was noted that in the 1950's they gave more than \$26 million per year assistance--although not to everyone. Warm Springs was not discussed in depth, nor was Franklin Delano Roosevelt (although he was seen as a model for success by some patients).

The middle chapters of the book are entitled "Going Home to a Long Recovery," "Resuming Life after Polio," and "Living with Polio." The experiences of the writers are used to expand on these topics, with anecdotes about every-day problems plus in-depth discussions. One topic discussed often was the problems faced by parents who were the ones who had survived polio, and were faced with the care of young children. Another topic was the short recovery period, followed by death, of those who had evidently lost hope in a possible future or "lost the will to live."

Chapter 9 is entitled "An Old Foe Returns: Post-Polio Syndrome." Many of the polio narratives were concluded by describing a long and resistive period before acceptance of this diagnosis. Doctors who deny the condition are also discussed, again with their misdiagnosis results. Both the physical and psychological problems associated with the final diagnosis are also discussed. The helpfulness of post-polio groups was included.

This book was well written, with the author's own opinion and polio experience inserted only occasionally. Because of the serious topic, it takes quite a while to finish reading all 251 pages. At the finish the reader feels very well-educated, especially about the psychological aspects having polio. The footnotes and index sections at the end are extensive. The book was published in 2005, and it still seems to be quite up to date.

Martha Logan: Mother, Teacher, Homemaker

By Barbara Nickelson

Spending time with Martha Logan is always an energizing experience. She has a delightful sense of humor, her eyes twinkle, and there always seems to be a smile on her face. She is a good listener and gives thought to her responses. Martha has an interest in cooking and has self-published two cookbooks, *Martha's Marvelous Morsels* and *Second Helpings of Martha's Marvelous Morsels*. She is also in the process of editing her latest book on her memoirs. A most beautiful black cat with a white chin patch used to share the house with Martha and Russ, and I know Martha enjoys watching the birds and squirrels in the back yard...so did the cat! In addition to these hobbies she has taught in elementary school, tutored, held reading groups for the neighborhood children, and belongs to Alpha Delta Kappa, a teaching sorority.

Raised on a farm in the Piney Woods of eastern Texas near Tyler; Martha Logan contracted polio in January of 1945. At the age of ten, she had a severe headache, spasms in her right arm, high fever and a stiff neck.

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Martha Logan *(Continued from page 7)*

She was taken to a hospital in Jacksonville, Texas with a temperature that elevated to 106°. Doctors eventually sent her on to *Parkland Hospital* in Dallas, Texas. At *Parkland*, doctors wanted to place Martha in a polio ward. Her mother would not allow it and was adamant that they didn't know that she had polio.

Martha remembers having a spinal tap done resulting in the diagnoses of polio. There was a month isolation period that followed due to the polio. While at *Parkland Hospital*, Martha shared a room with Lynette Murphy. The hospital was 125 miles from her hometown and, without a car, visits from her family were impossible. Lynette's mother was a comfort to Martha when she stayed and looked after Lynette and Martha. There was such a lonely feeling when Lynette got well enough, after a week, to go home. She took her mother with her and Martha had to remain alone in the room. Legs and an arm were paralyzed, and nurse's visits were seldom. There were no "call" buttons as we now know. Nursing staffs were stretched thin with the war, soldiers to care for, and the outbreak of polio.

After the two-week isolation period, another move was in store for Martha. She was taken to a Masonic hospital, *Scottish Rite Hospital for Crippled Children* in Dallas and placed in a ward of 20 girls. Shortly after her arrival there was an outbreak of mumps and measles and the hospital staff placed everyone under quarantine for two weeks! Martha had been unable to see any of her family for almost two months.

In spite of these hardships, there were many pleasant memories here. She can remember sipping cold pop on a hot summer day; "goose liver" sandwiches with a cold, stainless steel cup of milk, and mutton stew. Food tasted better with company. They had a piano player in Sunday school and they would sing to the music. There were also Easter egg hunts, gifts, and toys. Special visitors included Governor Coke Stevenson (TX), Doak Walker (football player), and Elsie the Cow (a real live cow).

This was also the beginning of an attitude that would carry her through the years. She had an attitude of "can do". She just knew she would walk again even though the doctors told her, "You may never walk again." She pushed herself and worked hard in physical therapy and began to see progress in moving. Physical therapy was done every day except Saturday and Sunday. A big hot tub, known as the Hubbard Tub, was used for exercise. For three months she had been flat on her back and then, gradually began to sit up by March. Her bones cut into her hips; legs tingled and were cold and purple.

Between the years of 1945 and 1947, she had muscle transplants to help her lift her feet and prevent drop foot. Tendon surgery helped her right hand hold items. Through all of this Martha told herself, "Where there's a will, there's a way."

School in Bullard, Texas had its challenges. Martha walked with a limp, her legs were weak and she could fall easily. For a while she wore a brace on her right arm. In school she became a learner, going on to Tyler Jr. College and East Texas State Teachers College in Commerce, Texas. She became

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Martha Logan *(Continued from page 8)*

an elementary school teacher in 1957 at Chapel Hill near Tyler, Texas and moved to Colorado in 1958 to teach, for 26 years, in School District 50, Westminster.

1987 brought changes again as she retired due to PPS gradually weakening her leg muscles, and she had to begin using a wheelchair part of the time. Her thoughts on that time were, "You learn to ask for help, but it is not an easy thing to do."

One of her most supportive friends on this journey has been her husband, Russell, of almost 47 years. They had a very unusual beginning, meeting in 1958 only to have Russ go off to the navy, literally, the next day.

It would be two years before their paths would cross again. By that time, Martha was in Colorado and they met again at a mutual friend's house. He came around the corner of the house, saw Martha inside, and winked at her. That wink changed history! Now, there is their daughter, Amber, who has also been a positive influence in the world.

"There are times when the daily challenges seem great. I think we all have that feeling at different times." It is frustrating to want to do something and you are not able to, or you have to ask for help to complete any task you start. After her shoulder replacement surgery in 2003, Russ has become the full time caregiver. Things we often take for granted are the daily tasks that she depends on Russ to help her through. Washing up, taking medications, transferring to her wheelchair, getting meals on the table, grocery shopping, getting her in

and out of bed, plugging in the wheelchair for a recharge, transferring and the list goes on. Jokingly, Martha adds these words of wisdom, "Get yourself a good man! "

Anytime I ask how she manages to be so chipper I get similar responses, "I enjoy life. I can breath, talk and laugh. I have many friends and I reach out to them. The telephone is my lifeline." She may have felt isolated as a youngster but she is very connected now. Martha reaches out to her friends in any way that will brighten their day. She makes it a point to know her friends intimately and encourage them. Not only has she learned to count her blessings but also she is very good at recognizing them.

Now, there is yet another challenge she is facing. She was diagnosed with ovarian and peritoneum cancer in 2008. As she has done all of her life, she won't dwell on the negative, accentuates the positive and lives in the moment. "Build your support system and they will support you. That's what makes this a beautiful day."

Like a beautiful flower that is well tended, she truly has bloomed where she has been planted.

The **2008 Colorado Post-Polio Educational Conference** would not have been possible without the help of so many who donated their time, funds and products. **Many thanks to the following:**

Volunteers: Gloria Aemmer, Jan Hamilton, Nancy Hanson of Easter Seals Colorado, Marlene Harmon, Margaret Hinman, Pat Jenni, Richard Johns, Michael McAllister, Barbara Nickelson, Paul Puma, John Smith, Ileta Smith, and Woody Trospen.

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The Colorado Post-Polio Educational Conference—May 2008

Here are some of the highlights of the Colorado Post-Polio Educational Conference that was held on May 10, 2008.

85 polio survivors, their families and their friends learned about a variety of topics. Although most of the participants were from Colorado, people came from Kansas, New Mexico, Arizona, Montana and Florida.

Kathryn Arbour, Board of Directors of Easter Seals Colorado, and president/owner of Capabilities, a store that specializes in products for people with disabilities, gave the welcoming speech. Then, Marlene Harmon, Chairperson of the Colorado Post-Polio organization introduced Dr. Marny Eulberg who started off the conference by discussing two topics.



Dr. Eulberg shared her assessment of some research on post-polio survivors and aging done by the Mayo Clinic. The research concluded that people with post-

polio do not age any differently than normal people ages 40 to 60. The research assessed two nerves, in the thumb and the toes of 38 people over time. Dr. Eulberg's assessment was that the researchers chose insignificant muscles and that there may be different findings on larger muscles.

Dr. Eulberg also shared the slides of her visit to Warm Springs, Georgia, site of the 2009 National Post-Polio Conference. Then, Carol Beebe talked about her experiences as a patient there, including some information about how her mother reacted to Carol's illness and the hospital.



Cindy Welbon, a polio survivor and Mary Kay Provosnick, a volunteer with Freedom Service Dogs, talked about the value of having a service dog. Cindy's service dog is her stability when she walks, using him in harness to help her walk.

Mary Kay brought a Freedom Service dog-in-training. Freedom Service dogs are rescued from shelters and are trained specifically for the new owner, learning how to do the tasks needed to help the quality of life of the handicapped person.





outreach to disabled persons, conducts a clinic which does seating and mobility evaluations, conducts research and provides education related to their services.

At the end of the conference, Tracie Wickham, Easter Seals Colorado's Director of Aquatics/Cardio/Nutrition provided the attendees with information and statistics about the benefits of aquatic therapy for many illnesses. Her list included diabetes, arthritis, fibromyalgia syndrome, obesity, hypertension, and osteoporosis. Aquatics can reduce stress and improve functioning that has lasting effects on the person.

After lunch, Cary Johnson from the 1st Judicial District Attorney's Office talked about how to prevent identity theft. One practice that savvy people can do is to only carry a driver's license, one check, and one credit card in their purse or wallet. All other ID's, including car registrations and insurance cards can be left home as both police and medical authorities can have that information later, if it is ever needed. Colorado law says that the medical profession must treat first and get information later. Social security numbers should not be on a person or on any form of identification. The Medicare card, which has a social security number on it, should be copied and all but the last four digits of the card should be blackened out. That is all that is needed to access Medicare by your medical professionals.



Julia Beems, Outreach Coordinator for assistive Technology Partners at the University of Colorado, Denver, demonstrated a variety of helpful items and strategies that can help persons with disabilities. The items included long handled combs and brushes, gripper tools and door hinges that can replace regular hinges and allow a wheel chair easier access into a room. Technology Partners does



AND BY THE WAY . . .

Some polio survivors brought up questions about the following issues in relation to having had polio. **Remember, these are questions which need to be answered by a medical professional and are not a statement of fact.**

- Coughing and breathing problems—perhaps with a smoking diagnosis, but are they partly caused by polio?
- Upper GI, swallowing—is this related to polio and what do I do?
- Chewing difficulties—has the doctor considered post-polio in his/her evaluation?
- Sometimes tart and real sweet foods affect some people’s breathing. Is that a consequence of having had polio?
- Bladder problems, incontinence and bladder infections—If the polio virus has affected the whole nervous system, is this condition partly the result of post-polio?
- Peripheral Neuropathy—is this related to a polio paralyzed limb, then affecting another limb because of over use? Is this the result of diabetes?
- Tingling feelings—is this related to polio?
- Muscle spasms and muscle cramping—how are these related to polio?
- Carpel tunnel syndrome—did the use of crutches cause this problem?
- Blood pooling in the feet—is this common among polio survivors? Is this the result of no or minimum use of a limb?

Here are some questions and comments that polio survivors have asked in relation to comorbidities and the fact that polio may be a factor:

- I don’t know, and don’t really understand if the condition or disease is connected to polio or not.
- I don’t understand what is happening to me.
- My attitude is that I will adjust to whatever comes my way. But, what do I have to do until there is an answer or a solution?
- Has the doctor taken polio and/or post-polio into consideration when diagnosing a problem and recommending a treatment?
- Who are the specialists who know about polio?
- Where does one find correct and accurate information about your medical problems?
- Don’t take what the doctor says as absolute without post-polio being considered.
- Be aware that when getting a diagnosis for a problem, the doctor may not know about polio and post-polio syndrome.
- “Polio is a designer disease. It never affects two people the same way.”
- Common diseases of older people such as high blood pressure, diabetes and obesity are not caused by polio but due to lack of exercise, and/or heredity.
- What is the appropriate protocol for calling Dr. Eulberg, or any other polio specialist?

Talking about physical rehabilitation, more than 50 years after having had polio.

By Margaret C. Hinman

Their faces showed their joy. Their words expressed hope for a brighter future. Their stories related their hard work and frustrations. And they shared the potential and actual positive results of their time spent learning to walk again, more than 50 years after having had polio. The nine participants in a discussion group that met in late April 2008 in Denver were part of a small group of people nationwide who have embarked on a return to physical rehabilitation after many years away from it. For many of them, this was first time in rehabilitation since they learned to walk again after the onset of polio in childhood. And, in spite of the time and effort that they have taken, given the choice, they would do it again, and recommend that others look at doing the same.

Their experience involves a team/cooperative effort on the part of survivors who want to slow the decline of mobility and functionality as they age and professionals who have helped them in the process. The professional team includes a polio doctor/specialist, an orthotist and a group of physical therapists. All have been instrumental in helping the survivors through the hard and long work of relearning gait and balance after years of using other compensatory gait patterns.

The survivors—The participants in the group included both men and women, all with the after-effects of polio impacting their lower limbs. Six of them are wearing one short leg brace (AFO), two are wearing a long leg brace (KAFO) and one is wearing two short leg braces. Each of them has

made a commitment to not let the effects of polio and aging make them more dependent on crutches and/or wheel chairs for as long as possible. And, they have been willing to do long hours of exercising and retraining muscles in order to learn how to walk correctly. In the process, many have improved the strength of muscles weakened by disuse atrophy, an unanticipated result of the therapy.

They report improved life styles, increased self esteem, more energy, and reduction of fatigue. Several have even reported weight loss. Some are now hiking in the mountains; some are playing golf and bicycling, and at least one is anticipating the time when she will be dancing. All are using less energy in daily living activities. They report increased flexibility, particularly in the trunk area of the body. One participant told the story of her son who walked by her in an airport when he came to pick her up. He did not recognize her because she no longer walked “like a pretzel.”

The polio doctor/specialist--The polio doctor/specialist, and a member of the discussion group, is Dr. Marny Eulberg, director of the Colorado Post Polio Clinic at St. Anthony Central hospital in Denver. Dr. Eulberg is herself a polio survivor who, when faced with the possibility of having to go from a short leg brace (AFO) to a long leg brace (KAFO), began to research various bracing systems that were available across the country. At the suggestion of a former polio patient, she was introduced to a bracing system that would prevent her from having to go into a KAFO. Her experience and her example inspired the participants to acquire the same style brace that she wears.

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Talking About . . . *(Continued from p. 13)*

Dr. Eulberg has directed the Colorado Post Polio Clinic for 23 years. During her tenure at the clinic she has been committed to providing the most reasonable and least invasive solutions to the problems that face polio survivors. This has included such interventions as bracing when needed for mobility and wheel chairs for those with a significantly increased risk of falling and who have no other safe alternatives available to them. She has also made recommendations for how to treat broken bones of survivors, as well as making referrals to specialists when comorbidities and secondary disabilities occur. Her success with her own brace has inspired her to share the good news with other polio survivors who can benefit from it.

She is very aware of the need for polio survivors to be independent and of the difficulty that they have in changing their life styles to accommodate the effects of aging on them. So, when she was introduced to the new bracing system, she was able to accurately assess the ultimate results of its use and design. However, like the others in the discussion group, she was not able to predict the amount of time dedicated to daily practice, the months and years it takes to retrain the mind to direct the body to move correctly when walking, and the effort it takes to relearn how to walk again. After four years in physical rehabilitation using the brace, she admits that she still has more to learn. It took her the better part of a year to learn to walk unaided in the new system.

The orthotist/brace maker—
Marmaduke Loke, from San Diego, California, is the co-developer and primary

orthotist of Dynamic Bracing Solutions. His bracing system has made more normal walking a reality. All in the group are using his bracing system which is different from any other bracing they have ever used.

The braces are custom made. At the beginning of the bracing process a careful evaluation of data gathered by video-taping the client is used in analyzing in detail how each person walks. The wearer is then casted and the brace is modified to correct deformities, such as fallen ankles and leg length differences. Such deformities diminish the wearer's ability to walk more efficiently and with less fatigue and many of them can be improved or corrected with properly designed and fitted orthoses. The Dynamic Bracing Solutions braces address those concerns. The completed brace works to correct the deformities and is constructed to facilitate a correct gait pattern.

The brace is designed along the same principles as modern prostheses. By using improved stability in its design and making use of a dynamic response with ground surfaces, wearers of the brace stand taller and straighter, and walk without the "polio gait" that identifies the polio survivor. And, this is usually accomplished without the aid of crutches or canes.

A unique characteristic of the DBS system identified by a member of the discussion group is that the orthotist continues to monitor the progress of the wearer after acquiring the brace, providing modifications to the brace as needed, and giving feedback and encouragement to help with the wearer's progress.

The participants in the discussion group recognized, as does Mr. Loke, that the

brace is only a tool that is used to make the wearer walk more efficiently. They also recognized that the success of the process is dependent on the wearer being willing to do the work, the rehabilitation, necessary to achieve his or her goals. They also noted that Dr. Eulberg's example was the impetus for acquiring the brace and learning the system, using the brace as the tool to make it happen.

The physical therapists—Several physical therapists in Colorado were identified as being invaluable in helping the wearers to learn to walk again. In northern Colorado, Dee Ann Vink, who practices in Fort Collins, has helped at least two DBS wearers during their learning process. Kristin Manzo, in Colorado Springs, uses water therapy and WATSU, a water massage technique, which has helped at least one DBS wearer to be able to walk correctly. That wearer now enjoys walking and hiking in the mountains. In the Denver metropolitan area, Maggie Hanlon and David Bookout of Independent Physical Therapy have been the mentors for many DBS wearers. All of these physical therapists know polio survivors, know how to improve gait and balance and now have knowledge of how to train wearers in DBS.

During the discussion, all of the participants spoke of how much they valued the talent and expertise of their physical therapists. The DBS system includes a CD with training exercises on it, and Mr. Loke encourages the wearers to video tape their progress and then send it to him for feedback and suggestions. However, the group members have depended on their local physical therapists to provide frequent and immediate feedback and additional training and practice. This has helped prevent the

client from learning incorrect walking patterns. It has also helped in moving through the steps in the learning process. Many of the participants have developed relationships with their therapists so that not only do they get technical assistance, they have a professional that can act as a mentor, a cheerleader and task master, as needed.

The observers--As the polio survivors talked about their experiences, a group of about 30 observers listened and, at times, shared their insights into the process. The observers included physical therapists, orthotists, and friends and family of the discussion members, as well as Mr. Loke. Also in the audience were several people with neurological disorders that have resulted in paralysis of their lower limbs. This included not only polio survivors but also a stroke survivor and a person with Charcot-Marie-Tooth disease. After the discussion group, members were available to answer questions that observers had.

All of the observers were interested in what is involved in the process and the results of the physical rehabilitation of the participants. They learned of the physical, social and emotional aspects of the survivors' experiences so that they could take away from the conversation how they could benefit, either as a person who would potentially embark on a similar journey or as a professional who can help with that journey.

At the end of the day, people left with the feeling that the discussion group was a benefit for the participants and for the observers. All had an appreciation of what is involved in attempting physical rehabilitation 50 or more years after having had polio.

This Is Your Newsletter-----

Colorado Post-Polio Connections is a newsletter by and for polio survivors, their friends and others who are interested in being part of our network. The editors and staff invite your contributions to the newsletter. If you have comments, articles, or suggestions for topics for future issues, please email us at post-poliocolo@comcast.net or write to us:

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Please include your name, address, phone number and email address in any correspondence. To change mailing information, contact Nancy Hanson at 303-233-1666, ext. 237 or email her at www.nhanson@eastersealscolorado.org.

Our next issue will focus on respiratory issues facing polio survivors. We need suggestions from you as to what questions you have about respiratory problems and what you have done about them for the “And by the Way. . .” column.

Disclaimer

The opinions expressed in this newsletter are those of the individual writers and do not necessarily constitute an endorsement or approval by Easter Seals Colorado or the Post-Polio Advisory Council. If you have personal medical problems, consult your own physician.

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