June 2017

**Our Mission:**
*To Be in Service Providing Information to Polio Survivors, Post Polio Support Groups, Survivor’s Families and their Caregivers.*

**Assistive Devices: The “Power” of Becoming More Mobile**

In April and May we explored the sometimes complex issue(s) involving the choosing and purchase of Assistive Devices. This month we reflect on the experiences of Polio Survivors and how they have managed the often difficult transition from walking on their own to using a mobility device.

Post-Polio Health International has given us permission to share an outstanding article by Polio Survivor Linda Wheeler Donahue. Linda gets to the “heart” of how truly difficult this transition can be.

To quote Dr. Richard Bruno, PhD. “Polio Survivors – you are all the same and you are all different”. That couldn’t be more true when discussing mobility devices. We have an honest assessment of that issue from the outstanding blog: Rolling Without Limits. We would all love to own these beautiful new, feather light power chairs. What is true is that not everything is right for everyone of us. That’s why both Dr. Bruno and Dr. DeMayo always suggest we work closely with a Physical Rehabilitation Physician (Physiatrist), Physical Therapist and Occupational Therapist when making these life changing decisions.

Along this same theme, we have a new “Bruno Byte” Tidbit: “The ‘Power’ of Moving to the Right Chair”. Do we see a wheelchair as being bound and tied or the path to freedom?

**From Mobility Devices to Life on the Stage**

It is our pleasure to bring you another Survivor Story from the Keystone State. Muriel McCarthy Geigert was born in London at the start of WWII. Her lessons in “staying alive” and joyful through her post Polio journey are truly an inspiration for us all.

**DeMayo’s Q & A Clinic**

Dr. DeMayo is on vacation this month. For those of you who missed his April article “Power Mobility Equipment – How to Go About Making the Right Purchase Decision” now may be the time to read it. He takes the “legalize” and confusion out of the Medicare Regulations. This article is available in PDF format for easy sharing [HERE](#).

All Dr. DeMayo’s articles are available in PDF format (on the bottom of this page on our website). [HERE](#)

Do you have a question or Dr. DeMayo? Please email us: papolionetwork@gmail.com
Transitioning to a Wheelchair: An Exploration of Our Fundamental Fears

By: Linda Wheeler Donahue, Professor Emeritus of Humanities
President, The Polio Outreach of Connecticut

When actor Christopher Reeve sustained his spinal cord injury in a horse riding accident, he went immediately from Superman to Man in Wheelchair. In contrast, some polio survivors, myself included, go through a lengthy, angst-ridden decision-making process before we plunk ourselves down in a wheelchair. We listen to the recommendations of our physicians, and we sheepishly explore the idea with our loved ones. We recognize that using a wheelchair would keep us from tripping and falling. It would help us conserve our limited energy and surely would make daily life a lot easier. Why, then, is this decision so emotionally intricate and agonizing?

Let's go back to our beginning. Does this sound like you? You contracted polio as a baby, child or young adult and endured a long hospitalization. You were separated from your family at a tender age and may still have some psychological wounds from that trauma. You emerged using braces and crutches for mobility. However, in many cases, your medical professionals gradually eliminated those aids.

You made an impressive recovery, walking unaided for many decades. Then years after onset, you began to experience weakness, fatigue and pain. You were diagnosed with post-polio syndrome. You now use a cane for support in walking; possibly, you were fitted for a brace and/or forearm crutches, and you find that motorized shopping carts at the grocery store are of colossal help to you. But, life is still much more difficult with the late effects of polio.

Did you once adore concerts in the park? Now you decline to go because walking on that uneven grass is far too difficult for you. You stay home.

Did you once savor the fun of cruising the mall with your daughter-in-law? Now you decline to go because that much weight-bearing and walking is far too painful. You stay home.

Did you once thrill to walking the boardwalk at the beach, absorbing the sights and sounds of the ocean atmosphere? Now you decline because the length of that long, winding boardwalk is too much to manage. You stay home.

You and your polio medical professionals recognize that the time has come for you to use a wheelchair for most of your mobility needs. However, the thought of appearing in public in a wheelchair fills you with dread. The key phrase is "appearing in public." Alone in your home, you love the way you can move smoothly, gracefully, and without pain and fatigue. But the image of using your wheelchair out in public terrifies you. Why? You realize on a rational level that using a wheelchair would be very liberating. But that rational base is overpowered, indeed almost buried, by the negative emotions that shout: "No! No wheelchair for me!“ Let's examine some of the contributing factors for this resistance.

- As a child, you received considerable praise for your attempts to walk unaided.
- Much of your self-esteem is wrapped up in the fact that you are still able to walk.
- Society places an inordinately high value on walking.
- The wheelchair makes it virtually impossible to be a "passer," that is, to pretend you are non-disabled.
- It is the image of a wheelchair that is, indeed, the universal symbol of disability.

These are only surface reasons. The deeper, overriding reason for your reluctance stems from a negative association of ideas. Think of an algebraic equation: YOU are on one side of the equation and DISABLED is on the other. That association of ideas is laden with shameful emotional overtones. Why? Because, historically, people with disabilities are stigmatized. They occupied a low rung on society's "A List."

I remember the various social cliques in high school. Teenagers were ranked in hierarchal order as

(Continued . . . .)
"preppies, jocks, greasers and nerds." Very few kids with disabilities landed in the most popular crowd, and we absorbed that message like water into a sponge. Although those classifications have undergone various transformations over the years, I have a sense that we still long to belong to the "popular crowd."

Our resistance to using a wheelchair is intimately connected to our unwanted view of ourselves as disabled. We are influenced by a deep-rooted prejudice in society that it must be better to be ambulatory than to be in a chair. For example, there may be no greater medical triumph than getting someone "up out of a chair."

How my heart pounded with dread and self-consciousness the first semester I wheeled into the faculty meeting. That wheelchair gets the credit for "outing" me. I now had to admit to the world that I was, indeed, a Person with a Disability. Ever since that day, the liberation has been mine!

- It is an important healing step to act on the belief that it is okay to be YOU and to know that the consumerist driven, stereotypical images of "attractive" and "popular" are oppressive falsehoods rather than the truth. It is stunningly appealing for a person with a disability to exhibit confidence and self-acceptance. People are not used to seeing this. When you perceive others' positive responses and you realize these responses are to YOU, as you are, you will be freed. When you receive positive reactions to the real you, not despite your disability, nor because they are unaware of your disability, but to YOU, you will shed a burden you may have carried around since adolescence.

If you love the comfort and ease of using your chair in private but dread the thought of using it in public, you can use the power of your human consciousness to restructure your perceptions and free yourself. You were paralyzed by polio; don't be paralyzed by society!

Are you still suffering from antiquated tapes playing incessantly on your internal tape recorder? If so, it is time to erase those old tapes. You can trade in your negative thought patterns for powerful new positive beliefs. You can liberate yourself and claim your rightful place in society.

Think about sitting proudly, head held high, in your sleek manual chair or perhaps zipping around in your sporty, power chair. Visualize yourself maneuvering gracefully over the grass at the concert in the park. How lovely the grounds look when you are no longer fearful of tripping. How sweet the evening air as the melodic musical sounds touch your heart.

Picture yourself on a swift mobility scooter at the shopping mall with your favorite friend, scooping up bargains. You can "shop 'til you drop" and still have energy to go out to dinner.

Visualize yourself traveling the length of the boardwalk at the ocean. Your senses overflow with the ambiance of the seashore. Since you have no pain or fatigue, you are much more free to hear the seagulls scream, to smell the salty sea breeze, and to celebrate the sheer joy of this outdoor experience. I know that this is still a difficult decision. Generally speaking, I think we are in a climate in which the mobility-limited person has to swim upstream against self-imposed inner conflict, as well as from family and friends who are caught up in the "use it or lose it" mantra. If we are to make optimal advantage of wheelchair mobility, we need a lot more people willing to swim upstream, proudly and confidently, to change that climate. Won't you join me in the swim?

Dread of using a wheelchair is based on old emotional baggage. Toss that baggage out. Wheel with pride and flaunt your self-acceptance. You will be a role model to all who encounter you.

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"When you sit in a wheelchair, you lose your height and you become an ‘it’. You are a disability. “ "I am tired of being a human interest story, a brave handicapped musician. I am a musician for whom life is not easy. But then, is life easy for anyone?"

Itzhak Perlman
I recently got a new wheelchair built for me and for my physical problems. I’ve now had it for just about 3 weeks and it’s been a miracle worker for me. However, in sharing my photos and excitement I’ve discovered a rather annoying part of the disabled community – people giving advice to make things lighter.

I’ve gotten comments like: "Oh wow! With that cushion and that back isn't it super heavy?" followed by "Take off that back and change it out!" Also "You don't need that kind of cushion! It is terrible for me and heavy! Try this instead!" And "I can't believe people use wheelchairs that heavy! I took everything off mine!"

I’m glad some folks out there are able to use lightweight chairs with almost nothing on them. For me however? My disability affects me in a lot of ways. I’ve got severe scoliosis as well as unstable joints which affect my spine. I need a higher back for support, and thanks to the dump in my chair, I am sitting up straight in my wheelchair for the first time ever. My cushion is heaven sent and works wonderfully for me and my physical issues.

Wheelchairs and customization are not one size fits all. There’s a reason we go to a PT and OT and Seating Specialists. Not everyone is able to get a bare bones wheelchair because it’s not physically safe for everyone. Everyone has different needs and different things they want out of their wheelchairs.

We must be mindful of our comments and of how we react to someone sharing their new mobility aid(s) with us.

www.transfermaster.com/blog/view-post/A-bare-bones-super-light-chair-is-not-ideal-for-everyone

"This is a monument to freedom – the power of every man and woman to transcend circumstance, to laugh in the face of fate, to make the most of what God has given."

Statue Dedication by:
William Jefferson Clinton,
January 10, 2001
The “Power” of Moving to the Right Chair
A “Bruno Byte” Tidbit
From Dr. Richard L. Bruno, PhD.

**Question:** I'm new to the group, and had a sharp decline this year. I'm barely able to walk at night with my walker, without my braces on. I have a wheelchair. I'm afraid of the future. I'm getting a commode chair and a shower chair with a bench. I'm getting a nurse's aide to help me with the shower and dressing. I just got a bi-pap machine. It's all overwhelming me. I want to stay in my home, but plan for the future. I know I'll be wheelchair bound some day and the reality terrifies me.

**Additional Post:** Use a wheelchair now when you can get in and out of it as you need to. Don't wait until you have to be in one most of the time. I have had an electric scooter for 18 years now. I don't like sitting on it but it sure gets me loads and loads of places that I could not without it and it saves me wasting energy. Without it my life would have been so limited. Aids are there to help us manage our energy levels so we can do more of what we want. I know the changes are hard to take.

**Another Post:** I love my scooter and it takes me everywhere. Nothing slows me down. I've been places I didn't think I'd ever be able to go again.

**Another Post:** Start using your wheelchair now. I fought using mine for the longest time, but looking back I wasted a lot of strength doing that. Once I adjusted to seated life? I had tons more energy to DO things and enjoy life rather than struggle with pain.

**Dr. Bruno's Response:** There have been lots of questions about power wheelchairs recently. The current Medicare requirements are [HERE](#). Note: The Requirement is now Upper Extremity Function NOT Strength! Therefore, pain and decreased range of motion that limit function (that make pushing a manual wheelchair inappropriate) would qualify you for a power wheelchair. Talk to your rehabilitation physicians (Physiatrist) so they can help you get the equipment that is right for you.

To walk is human, to roll divine! You may be wheelchair-bound. You may be Alabama-bound. But no one need ever be "confined" to a wheelchair. A wheelchair does exactly the opposite of confinement: it opens up your entire world! Get a head start and get a power wheelchair for distance before you need it so that you can conserve and never be "confined".

**Wheel Chair “Bound”**

**The Freedom to Roll? “Divine”**
Forever on Stage  
Survivor Muriel McCarthy Geigert  
(Written by Helen Urban)

Muriel McCarthy Geigert was born in London in 1935. She is one of five children. She has three brothers and one sister. In 1940, due to the war time bombing of the city, her family was evacuated from London to Wales. Her father was away serving in the British military at the time. It was shortly after this, while her family was living at a boarding home in Porthcawl, Wales that her mother noticed something was wrong with Muriel’s legs.

While trying to get her up to go to school one morning, four year old Muriel told her mother “my legs feel funny”. Her mother got her up and she fell to the floor. A doctor was called and evaluated her using a series of pinpricks to her feet and legs. They discovered she had no feeling in her legs or feet. They did not want the locals to panic about her ailment, which was called “Infantile Paralysis”. Her family was quickly moved to another residence to live by themselves. Muriel’s two brothers, ages six and one were not affected by the disease.

Her mother was determined that Muriel would recover. She rubbed her legs with warm cloths, warm oil and moved/exercised her legs over and over. Her left side was weaker than the right. Muriel remembers this being very painful but is thankful for her mother’s relentless determination. Muriel stayed occupied during her recovery by drawing, looking through her mother’s photographs and playing with a box of buttons. When Muriel watched her little brother learning to walk, the process fascinated her. It looked like fun, so she decided to copy his actions by getting down on the floor and pulling herself up supported by chairs and the sofa. She would move from one to the other and thus started walking! This set the theme for Muriel’s life. She loves to have fun and has never stopped moving.

Even though there was still the threat of bombs, her family moved back to London. Her mother homeschooled Muriel and her siblings.

The polio left her with deformed feet so Muriel walked on the outer edges of her feet to compensate for it. Her very determined mother signed her up for dance lessons try to strengthen her legs and re-align her feet. In spite of her passionate efforts, her left foot was always too weak to do classical ballet. That didn’t stop Muriel’s determination to dance. She turned her focus on “modern” dance techniques. Her mother’s foresight was an unforeseen blessing as dance would become a major part of Muriel’s young adult life and would eventually lead to her meeting her future husband.

Her career in entertainment took off at the age of 15 when she went to work for The Bouglione Brothers Circus in Liverpool as part of an acrobatic troop. She learned to jump on and off horses as they rode around the ring. When the circus went on tour, Muriel returned home. Her father tried to convince her to go back to school but she wasn’t interested. She wanted to perform! She found a job in a clothing store while she auditioned for various dance companies in her spare time. She eventually auditioned and was admitted to the Blue Bell Ballet Company in Paris. The job took her to Italy where she was required to die her hair blonde for the
performances. For the next four years, she danced for Blue Bell Ballet in Italy and France.

After returning to England, she worked in films as an extra and eventually was hired as a showgirl for Ron Dillon and the Dillionaires. During the dance routines, she was required to leap from a staircase. It was during one of these leaps that she landed on her weak left foot which gave way. She ended up with a sprained ankle but continued with the show using an ace bandage. She successfully continued to work in London’s West End Theaters while using added ankle support.

Muriel eventually joined the Combined Services Entertainment (CSE), the British version of the United Service Organizations (USO). In 1959, there was a conflict in Cyprus and 50,000 British troops were stationed there. She was sent to Cyprus with the CSE to entertain them. It was there during a party at the American base that Muriel met and fell in love with Daniel Geigert, an American Marine. Muriel stayed in Cyprus and got a job at a hotel as a dancer in the hotel’s shows. They were married the following year on April 9, 1960. Shortly thereafter, Daniel retired from the military and they moved to the US, to the Olney section of Philadelphia.

Daniel worked in sales and Muriel worked for an insurance company. They were blessed with three children, Theresa, Paul and Maureen. Muriel stayed at home to raise her family. In 1972, they moved out of the city to Warrington, PA. Muriel was devastated when she lost Daniel to a sudden heart attack in 1993.

Once her children were grown, Muriel decided to look for another career. She answered an ad in the local newspaper for a job at a golf club that had just opened in the area. She was drawn to the job through her memories of Daniel’s love of golf.

After 17 years of joyful service to members and staff of the club, she retired in 2016. Some of the weakness that Polio left her with had become more significant and retirement was inevitable. Throughout her time at the golf club, Muriel’s love for dance and theater would periodically shine through. On various holidays and themed events, she would dress in character. Some of her most notable characters were Betsy Ross, Madame Defarge (Bastille Day), Mrs. Santa Claus, the Queen of England, Ingrid Bergman (Casa Blanca), Miss Piggy (she gave ballet lessons), and Mickey Mouse (as the Wizard), and an Italian gentleman (handing out cannoli’s). She was still entertaining and making everyone around her happy!

Muriel is happily enjoying retirement and loving life! She traveled to Paris with her sister and daughter in 2016. While there, she visited The Lido Theater where she performed prior to her two year dancing career in Italy and France; as a blonde, of course! She will be traveling to Italy this fall and hopes to visit some of the venues where she performed. Muriel is an inspiration to us all as she displays her love for people and life each day.

Nothing stops Muriel from living her life to the fullest – not even Polio!
A Reminder: Both A Paralyzing Fear and Polio Revisited are available in their entirety, on our website HERE. Share this historical information with your families.

We are truly grateful for your kind words of support. Your generous donations are the key to helping our work continue.

Do you have a topic you would like us to cover? Please let us know.

Always feel free to contact us.
The Pa. Polio Network Team

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