Polio Survivors Serving Others

Information & Inspiration
For All Polio Survivors and their Families

The PA Polio Network

www.papolionetwork.org

May, 2023

Our Mission:

To Be in Service Providing Information to Polio Survivors, Post Polio Support Groups, Survivor's Families and their Caregivers.

Inside this Issue:

Honoring Mothers: All over the US we celebrate Mother's Day in May. Survivor Laura Vittorioso sees her mother as her unsung hero. It was her special gift of wisdom and strength that brought her paralyzed little girl home from the hospital in 1953. In spite of her disability, Laura's mother raised her to be a strong, independent young woman. Many survivors see their mothers as the unsung heroes of their lives.

PPS Physicians: This topic comes up on a regular basis. What kind of physician should polio survivors see to take care of their new and often exhausting symptoms? All over the world, we hear professionals refer survivors to Rehabilitative Physicians (Physiatrists). Many physiatrists are DO's – are they a "real" doctor? We are sharing an article that can help explain: *Neurologist-Physiatrist-Rehabilitative Physicians: What's the Difference?*

Polio Survivors with Post-Polio Sequelae (PPS)
Often have all or Some of the Following Symptoms:

- EASILY SEDATED, and can be difficult to wake
- Can Have Difficulty BREATHING and SWALLOWING with Anesthesia
- HYPERSENSITIVE to PAIN and COLD.

They often need a heated blanket and Increased pain medication post-op.
And may have:

Overwhelming Fatigue — Muscle Weakness — Muscle and Joint Pain — Sleep Disorders
Cold Intolerance — Difficulty Swallowing — Difficulty Breathing — Sensitivity to Anesthesia

We have a special page on our website that looks at these issues/concerns.

Survivors all over the US and Abroad have the Anesthesia Warning Card that uses a QR code to bring physicians a direct link not only to the articles but of equal importance – the biographies of the authors of those articles. It was 2016 when Dr. William DeMayo suggested we use it on the cards, giving physicians quick and easy access to the information. A bit ahead of his time, it has proven to be one of our most successful projects. As a result, we can easily update existing and add new information without anyone needing a new card.

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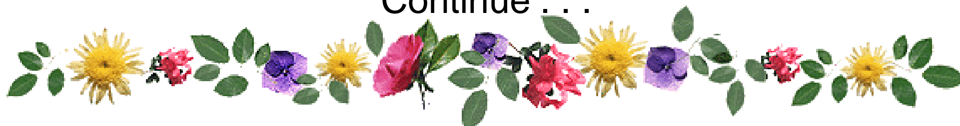


We are happy to welcome Norma M. Braun, MD to the list of outstanding professionals that have contributed their work to this ongoing project. With her article "*Preparing for Surgery for Post-Polio or Other Chronic Respiratory Disorder Patients*" she joins: John R. Bach, MD, Richard L. Bruno, HD, PhD, Selma Calmes, MD, Polio Denmark and four physicians from the University of Manitoba in Canada in an article for Anesthesiology Magazine.

You can find all the articles on our website: www.papolionetwork.org/-anesthesia-warning

Neurologist-Physiatrist-Rehabilitative Physicians: What's the Difference?

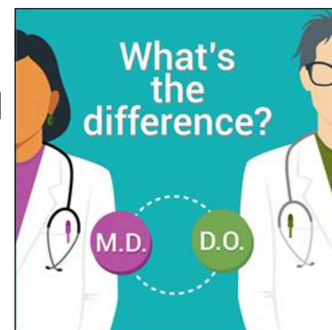
PA Polio Survivors Network

Whether in the US or Abroad, these concerns are the same for Polio survivors. The positive impact of polio survivors seeing a Rehabilitative Physician (physiatrist) for care. What *is* a Rehabilitative Physician (physiatrist) ? Is that the same as a neurologist? Some are DO's and some are MD's. Are they the same?

What is a Rehabilitative Physician?

A rehabilitation doc (a phys-EYE-a-trist) does a medical residency learning to help people thrive with their disabilities: Physiatrists, or rehabilitation physicians, are nerve, muscle, and bone experts who treat injuries or illnesses that affect how you move. Rehabilitation physicians are medical doctors who have completed training in the medical specialty of physical medicine and rehabilitation (PM&R).

What is the difference between an MD and a DO ?



A doctor of osteopathic medicine (DO) is a fully trained and licensed doctor who has attended and graduated from a U.S. osteopathic medical school. A doctor of medicine (MD) has attended and graduated from a conventional medical school.

The major difference between osteopathic and allopathic doctors is that some osteopathic doctors provide manual medicine therapies, such as spinal manipulation or massage therapy, as part of their treatment.

After medical school, *both* MD's and DO's must complete residency training in their chosen specialties. They must also pass the same licensing examination before they can treat people and prescribe medications. (Source: the Mayo Clinic)

What is a Neurologist?

A neurologist is a doctor of medicine (MD) *or* a doctor of osteopathy (DO) who specializes in diseases of the nervous system. Some neurologists subspecialize in neuromuscular diseases, which is a subspecialty of diseases of the peripheral nerves (nerves in the arms and legs), the neuromuscular junctions (the nerve muscle junction), and the muscles, which includes the problems of the post-polio patient. Through their

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specialized knowledge of neuromuscular diseases, electromyography (EMG), and neuro-rehabilitation, these neurologists are able to diagnose and treat conditions causing pain, weakness, numbness, and tingling. (From Post-Polio Health International)

About Physical Medicine & Rehabilitation

What is Physical Medicine and Rehabilitation?

"Physical medicine and rehabilitation (PM&R), also known as physiatry or rehabilitation medicine, aims to enhance and restore functional ability and quality of life to those with physical impairments or disabilities affecting the brain, spinal cord, nerves, bones, joints, ligaments, muscles, and tendons. A physician having completed training in this field is referred to as a physiatrist. Unlike other medical specialties that focus on a medical "cure," the goals of the physiatrist are to maximize patients' independence in activities of daily living and improve quality of life. "Physiatrists are experts in designing comprehensive, patient-centered treatment plans, and are integral members of the care team. They utilize cutting-edge as well as time-tested treatments to maximize function and quality of life for their patients, who can range in age from infants to octogenarians."

Practice Settings

"PM&R physicians practice in a variety of clinical settings, including inpatient and outpatient facilities. They have a broad range of knowledge including musculoskeletal, neurological, rheumatological and cardiovascular systems.

Some of the common diagnoses and populations seen by inpatient physiatrists include spinal cord injury, brain injury (traumatic and non-traumatic), stroke, multiple sclerosis, polio, burn care, and musculoskeletal and pediatric rehabilitation. Inpatient physiatrists are often trained using collaborative team skills and work with social workers and other allied health therapists (e.g., physical, occupational and speech) to manage these issues.

Outpatient physiatrists manage nonsurgical conditions including orthopaedic injuries, spine-related pain and dysfunction, occupational injuries and overuse syndromes, neurogenic bowel/bladder, pressure sore management, spasticity management, and chronic pain.

Outpatient physiatrists are typically found in multidisciplinary groups consisting of other physiatrists, orthopaedic surgeons and/or neurosurgeons."

What is a Physiatrist?

Physical Medicine and Rehabilitation (PM&R) physicians, also known as physiatrists, treat a wide variety of medical conditions affecting the brain, spinal cord, nerves, bones, joints, ligaments, muscles, and tendons.

"PM&R physicians are medical doctors who have completed training in the specialty of Physical Medicine and Rehabilitation (PM&R), and may be subspecialty certified in Brain Injury Medicine, Hospice and Palliative Medicine, Neuromuscular Medicine, Pain Medicine, Pediatric Rehabilitation Medicine, Spinal Cord Injury Medicine, and/or Sports Medicine. "

Specifically, PM&R physicians:

•Treat patients of all ages

•Focus treatment on function

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•Have a broad medical expertise that allows them to treat disabling conditions throughout a person's lifetime
•Diagnose and treat pain as a result of an injury, illness, or disabling condition
•Determine and lead a treatment/prevention plan
•Lead a team of medical professionals, which may include physical therapists, occupational therapists, and physician extenders to optimize patient care
•Work with other physicians, which may include primary care physicians, neurologists, orthopedic surgeons, and many others.
•Treat the whole person, not just the problem area

Depending on the injury, illness, or disabling condition, some PM&R physicians may treat their patients using the following procedures/services:

•EMG/Nerve Conduction Studies
•Ultrasound guided procedures
•Fluoroscopy guided procedures
•Injections of spine
•Discography, Disc Decompression and Vertebroplasy/Kyphoplasty
•Nerve Stimulators, Blocks and Ablation procedures - Peripheral and Spinal
•Injections of joints
•Prolotherapy
•Spasticity Treatment (Phenol and Botulinum toxin injections, intrathecal baclofen pump trial and implants)
•Nerve and Muscle Biopsy
•Manual Medicine/Osteopathic Treatment
•Prosthetics and Orthotics
•Complementary-alternative medicine (i.e. acupuncture, etc.)
•Disability/impairment assessment
•Medical/legal consulting

Why Visit a PM&R Physician

"Physical Medicine and Rehabilitation (PM&R) physicians, also known as physiatrists, treat a wide variety of medical conditions affecting the brain, spinal cord, nerves, bones, joints, ligaments, muscles, and tendons. By taking the whole body into account, they are able to accurately pinpoint problems and enhance performance without surgery. Consider seeing a PM&R physician if:

•You had an accident, or you have an injury or chronic condition that has left you with pain or limited function
•You're contemplating or recovering from surgery
•You have an illness or treatment for an illness that has diminished your energy or ability to move easily
•You're recovering from the effects of a stroke or other problems related to nerve damage
•You have chronic pain from arthritis, a repetitive stress injury, or back problems
•Excess weight makes it difficult to exercise or has caused health problems

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•You think you're too old to exercise
•Life changes such as childbirth or menopause have created new challenges to your physical function"

Getting Started

"A PM&R physician will thoroughly assess your condition, needs, and expectations and rule out any serious medical illnesses to develop a treatment plan. A clear understanding of your condition and limitations will help you and your PM&R physician to develop a treatment plan suited to your unique needs."

Tailoring Your Plan

"You need the right type of exercise to effectively overcome fitness obstacles. A runner may have gained weight after being sidelined by a knee injury. A PM&R physician can prescribe tailored, low-impact activities that burn calories without aggravating the injury, simultaneously prescribing physical therapy and use of a brace to strengthen and support the knee. Another patient may be suffering from chronic neck pain. The PM&R physician might prescribe medication, stretching, and massage for short-term pain relief, as well as strengthening exercises to prevent future pain. If surgery is a necessity, PM&R physicians work with patients and their surgeons before and after surgery. By directing your treatment team and collaborating with other health care professionals, a PM&R physician is able to specially design a treatment program tailored to you."

Understanding And Identifying Your Goals

"Do you want to strengthen an injured muscle, find relief from chronic pain, or walk up the stairs without being winded? A PM&R physician can work with you to determine realistic short- and long-term goals.
Along the way, he or she will help you to find relief from pain, achieve successes in rehabilitation or exercise programs, overcome your setbacks, and reassess your goals if necessary."

Conditions & Treatments
Evaluated by Physical Medicine and Rehabilitative Physicians

"PM&R physicians (or physiatrists) evaluate and treat patients with short- or long-term physical and/or cognitive impairments and disabilities that result from musculoskeletal conditions (neck or back pain, or sports or work injuries), neurological conditions (stroke, brain injury or spinal cord injury) or medical other conditions. Their goal is to decrease pain and enhance performance without surgery."

Note: Poliomyelitis/Post-Polio Syndrome is listed under the topic:
Pain-Neuromuscular Medicine Rehabilitation

Article Source: www.aapmr.org/about-physiatry/about-physical-medicine-rehabilitation
The AAPM&R provides listings of its member rehabilitation physicians by state."
https://members.aapmr.org/AAPMR/AAPMR_FINDER.aspx

Welcome Dr. Norma Braun.

We are happy to share that she has joined the list of professionals that have published an article for direct access on our webpage and our Anesthesia Warning Card.

Norma M. T. Braun, MD, FACP, FCCP is a pulmonologist in New York, New York and is affiliated with Mount Sinai Morningside and Mount Sinai West Hospitals. She received her medical degree from Columbia University Vagelos College of Physicians and Surgeons and has been in practice since 1982.

- Medical School - Columbia University College of Physicians & Surgeons
- Internship - Medicine & Surgery NYU/Bellevue Hospital Center
- Residency - Internal Medicine NYU/Bellevue Hospital Center
- Fellowship - Pulmonary & Critical Care Saint Luke's-Roosevelt Hospital Center
  - Certifications –
    - o Pulmonary Disease
    - o American Board of Internal Medicine

Dr. Braun is a Clinical Professor in the areas of Pulmonary Medicine, Sleep Medicine and Critical Care.

With her article "*Preparing for Surgery for Post-Polio or Other Chronic Respiratory Disorder Patients*" she joins: John R. Bach, MD, Richard L. Bruno, HD, PhD, Selma Calmes, MD, Polio Denmark and four physicians from the University of Manitoba in Canada in an article for Anesthesiology Magazine.

Note: The Anesthesia Warning Card and Symptom Checklist for Polio Survivors are easily available for download. www.papolionetwork.org/-anesthesia-warning

Note: You can watch the lecture that Dr. Braun did for Post-Polio Health International

Preparing for Surgery for Post-Polio or Other Chronic Respiratory Disorder Patients

By Norma M. Braun, MD

CAREFUL PLANNING RESULTS IN PREVENTABLE COMPLICATIONS

1. PCP – Pulmonologist directly communicate with SURGEON(S) & ANESTHESIOLOGIST BEFORE ANY SURGERY & REVIEW IN DETAIL WHAT IS PLANNED & WHAT THE PATIENT NEEDS & WHY.
2. ALL comorbidities (other disorders such as Diabetes, kidney or other organ disorders) are attended to.

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3. Make sure TEAM has list of ALL meds, including supplements as some may need to be stopped before surgery (Example: Fish-oil increases bleeding; Biotin interferes with accurate blood tests for heart damage)

GIVE TEAM CELL PHONE NUMBER FOR PCP/PULMONOLOGIST

4. PRE-PROCEDURE REGIMEN FOR PATIENTS IN WRITING:

a. Eat lightly soft foods-soups 2 days before surgery (less residue => less to poop)

b. Take laxatives the day before surgery with Dulcolax &/or Miralax as post op anesthesia effects, bed rest & pain meds => CONSTIPATION & attempts to move bowels is painful with intrinsic inhibition = MORE STOPPAGE. Some may need enema(s) to clear.

c. BRING ALL medications AND supplements on day of surgery so medication choices will be compatible, more effective with fewer potential adverse effects.

d. Good oral hygiene (brush, floss, rinse. For some patients an oral antiseptic mouthwash, such as Chlorhexidine) Use as rinse, swirl, spit twice a day before & day of surgery, EVEN IF NOT EATING BEFORE SURGERY - AS ORAL BACTERIA MULTIPLY OVERNIGHT ("morning mouth"). Reduces risk of post-op pneumonia.

e. Counsel on risks of STANDARD doses of pain meds (opiates, sedatives); use lower doses or alternatives.

(Can always give more but cannot remove once in). Make sure TEAM is aware of YOUR past adverse experiences or allergies to medications, tape, any adhesive dressings.

NO NEUROMUSCULAR BLOCKING DRUGS EVER USED.

5. If possible, have PCP or Pulmonologist PRESENT DAY OF SURGERY OR IN RECOVERY ROOM SO SHE/HE CAN CHECK PATIENT & WITH TEAM CARING FOR PATIENT. NURSES ARE USUALLY HAPPY TO HAVE THIS INPUT

6. If needed, ALLOW PCP/PULMONOLOGIST to take CHARGE over all non-surgical aspects of patient's postoperative care (takes the load off the surgical team). They may be relieved to add this MD to the post-op team.

7. If deemed appropriate, ICU bed post-op for closer monitoring.

8. For patients who already use non-invasive ventilators, extubate & restart HOME UNIT (patient familiar, acclimated & trusts system which allows sooner discharge).

Note: Hospital Biomed Dept. has to clear Home units before use.

- Can arrange to have unit in the hospital & checked on the day of surgery so by the time it is needed it is ready. The patient & the durable medical equipment company (DME) who provides the patient's vent brings the vent to the hospital, where the patient's MD arranges for Biomedical to clear the unit for post-op use.

9. If using Cough assist systems before surgery, restart as soon as possible per allowance by surgical site as to what unit will be preferred.

10. Respiratory Therapists are contacted prior to surgery to be on hand to facilitate any use of ventilation devices, oversee clearance, use of cough assists & nebulizer therapies.

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11. Chest Physical therapy may be needed.
    - Use of Ambu bag (manual resuscitator which is applied to airway or mouth to increase lung expansion, prevents atelectasis & helps mucous clearance from airways with breath stacking & bigger air volumes) can help to reduce atelectasis (lung units collapsed) which reduces the supplementary oxygen levels & mobilizes more mucous. The larger air volume increases stretch of the chest & the recoil from decompressions mobilizes secretions better so suctioning is less needed & endotracheal tubes can be removed sooner. Less risk for pneumonia too.

This all takes time & it is not well compensated by insurances. This regimen allows reduction of patient anxiety which improves the outcomes.

Less anxiety => less stress => less stress hormone release => better outcomes.

Having a trusted MD in proximity & taking over facilitates healing.

Many doctors fear to operate on patients who use ventilators. Pulmonologist can advocate strongly as these patients can be approached the same as other patients with only a little more attention to an individual's specific condition(s).

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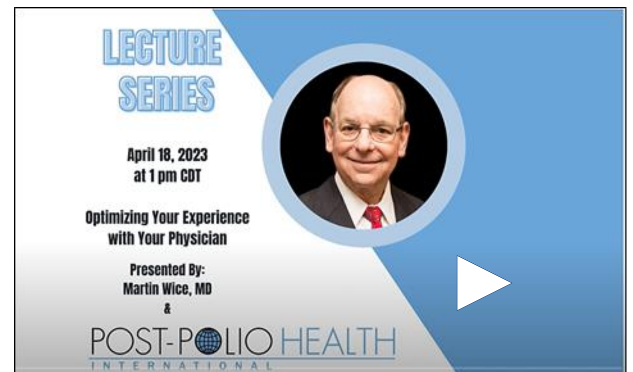
Optimizing Your Experience with Your Physician

A part of their 2023 Lecture series, Post-Polio Health International has shared their conversation with Martin Wice, MD.



Dr. Wice is the past medical director of the Department of Physical Medicine and Rehabilitation at Mercy Hospital in St. Louis, MO, where he established the post-polio clinic in 1987. For 8 years of his career, joined the faculty of Washington University in St. Louis where he continued to see post-polio patients, before retiring in July 2019. He has held multiple positions on the PHI board, including President. He remains on the PHI Medical Advisory Committee.

You can the 2023 Lecture Series on the PHI YouTube Channel:

www.youtube.com/watch?v=yGrVMrjlIlY

My Beautiful, Unassuming, Unsung Hero

Remembering My Mother

By Laura Vittorioso

Laura and her Mom
Laura's Wedding Day, 1976

This Mother's Day I'm remembering my mother; a beautiful, delicate unassuming person who brought me through my initial bout with Polio and the resulting rehabilitation and surgeries. Mothers of Polio survivors are the unsung heroes of that time. They were the ones who performed the required stretching of paralyzed limbs, put the casts on our legs at night to stabilize paralyzed limbs, taught us how to put on our braces, how to walk again, and carried us up and down stairs. All the while, they encouraged us.

An active toddler, I was 20 months old when I got sick in July, 1953. My mother had gone to the hospital to have her 3rd child. My older brother stayed with my grandparents and I went to stay at my aunt's house in Revere, MA. Although I have no memory of it, my aunt took me and my cousins to Revere Beach. My cousin and I came down with the "summer gripe" (also known as the summer "flu"). A few weeks later, I stopped walking and resumed crawling. That was the red flag to my mother. The family doctor was called and came to the house. He suspected Polio. I was immediately taken to Boston's Children's Hospital for a spinal tap which confirmed it. According to relatives (other than my parents), I was placed in an iron lung for a short period (probably as a precaution). Both legs were completely and permanently paralyzed. I was confined to the Polio ward at Boston Children's for the initial recovery. My parents were not allowed to visit and *never* spoke about what happened while I was there. It must have been very difficult for both of them.

It was never clear if my cousin, who was just six months older than me, actually had Polio, although there was some talk about a weak leg that did resolve. At 71, he doesn't appear to have any late effects of Polio. I was close to 3 when I was sent to the New England Sanitorium to learn how to walk with braces and crutches. I was there for about 6 months. I never walked while I was there - I think I was just too traumatized being away from my mother. But once home and after a time, I did eventually start walking with those braces and crutches.

My mother dealt with my paralysis in a matter-of-fact, somewhat "hands-off" approach. Not that she didn't worry a great deal about me, but she left me alone to figure things out. When it was time for me to start learning how to walk with braces and crutches, she didn't nag, she would lay the braces beside me each morning and then left me to either put them on or not. If I didn't, she wouldn't reprimand me, but instead said, "Maybe tomorrow."

She allowed me the freedom to go out and play with my older brother and the other kids on the street. If they teased me or stole my doll, she didn't run interference, but would calmly tell me to go back out and settle it myself. I remember one time the kids were playing kick

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ball and I wanted to play, but the other kids shunned me away saying, "You can't play, you're crippled." I ran home crying to my mother and she consoled me and then said, "Now go back out and show them how you can play."

When it was time to register me for kindergarten, my mother was told the school could not accept me unless I could go to the bathroom and put on my coat and boots by myself. My mother said, "Not to worry, Laura can that and more." She was then told the school couldn't be responsible if I fell, but my mother wasn't deterred, she said, "Her older brother Michael (who was six) will walk her to and from school and stay by her side going up and down the stairs." Michael was a character always telling a joke or being funny. One time when I was going down the stairs at school, I must have been in first grade, I got laughing so hard I fell down the remaining 3-4 stairs. I was fine, but Mike got reprimanded by the teachers. It was a lot of responsibility for a young child.

In those days there was no ADA. Those severely disabled from Polio were sent to special schools. My mother realized how upset I would be to be sent away again, so every effort was made to keep me home and in public school. Fortunately, I was able to manage the stairs and the short walk to our neighborhood school.

Because of multiple surgeries, I lost a lot of my 7th and 8th year. My mother recognized how much I had lost and allowed me a great deal of freedom to go out by myself and socialize with friends. She always supported me emotionally (and reprimanded me when needed). Always encouraging me to be my best and work toward my goals. There was a time in my late teens/early twenties when I became very discouraged with roadblocks that were preventing me from obtaining my career goals. It was my mother who gave me a pep talk in her gentle, but firm way to not give up. I could accomplish my goals if I just stayed on track.

When I was finally able to purchase a car and have it outfitted with hand controls it was my mother who rode with me while I had my permit. I was taking night classes at the time and my mother would go with me to the classes so I could get the driving practice. She would wait for me in the college library while I was in class. This was a big commitment of her time and the drive to the college at night on country roads was not always easy, but she did it for me. She sacrificed her time so that I could continue my college education.

My mother was my best friend and confidant. Our bond created because of Polio was very strong. She was the one who saw me through my most difficult times. I think many Polio survivors would agree. Sadly, she developed Alzheimer's disease at age 68. Over time she forgot I was her daughter, but she always seemed to know I was someone she was close to. We listened to music together and went for rides to get an ice cream cone, a favorite activity. I was glad that in the end I could be the one supporting her as she had done for me all of my life. She died peacefully at age 79.

Laura Vitorioso

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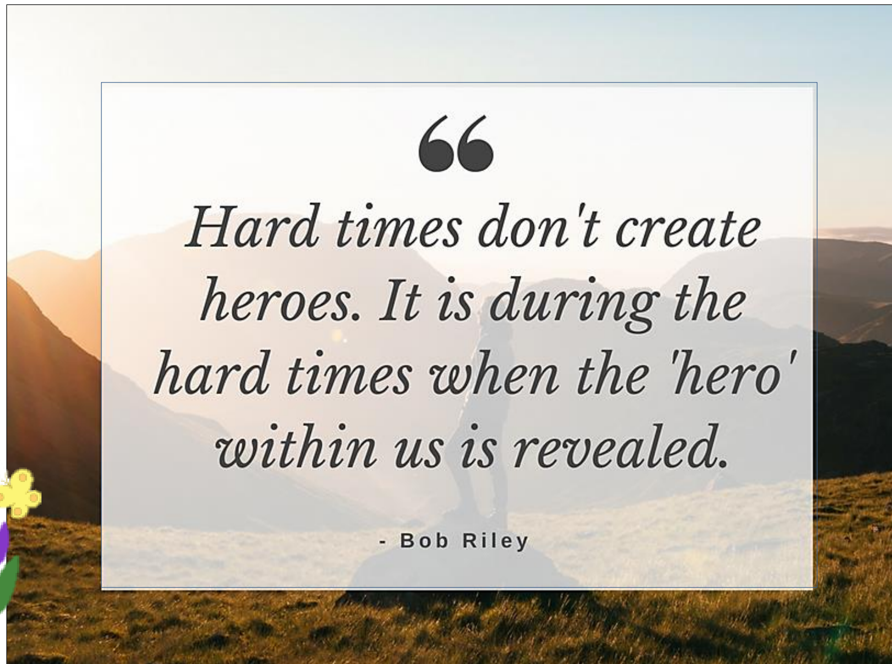
Laura had polio at 20 months old. "I was told as a young child by the physical therapists that I would have to work harder and be better than those who were not disabled. 'The world doesn't owe you a living' I was told. It was an either/or situation. You either worked hard to achieve some type of normalcy or you were left behind to stay at home and not participate in society.

I never wanted to *be* my disability; I wanted to be like everyone else. I went about my life as if I wasn't disabled; however, it would trip me up every so often as a reminder. Now it is a constant reminder. I have to make decisions every day about what I can and cannot take on.

Many of the ailments I've been dealing with for the past twenty years, I attributed to 'getting older with polio'. My primary care doctors didn't seem to understand my symptoms either, often sending me for repeat sessions of physical therapy for the purpose of muscle 'strengthening' to build up my weakening muscles. PT always left me feeling more fatigued and spent. Instinctively I've realized over the years that I can no longer do what I used to do; that I need to slow down because of the muscle pain and fatigue. But this (Post-Polio Syndrome) is difficult for us who have built our lives on over doing to compensate for our disability."

Laura wrote a personal reflection of *The Polio Paradox* by Richard L. Bruno, HD, PhD
You can find it in our July, 2022 newsletter and on our website:



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