



Polio Hero News



SPRING 2019

THIRTEEN VOLUNTEERS NEEDED for Belmont Physical Therapy Class, Tuesday, April 16th, 2019 - 10am - Noon (lunch to follow) This is your chance to teach Physical Therapy students how to evaluate a polio patient. Each volunteer is given 3-5 students to relate your polio story to. The students will do a short manual muscle exam and evaluation. You would need to wear comfortable loose warm-up type clothing (there is no undressing). This is a fun class and somewhat of a Mini Support Group Meeting during lunch provided by Belmont. To volunteer or for information and directions call Nickie Lancaster - 1/615/889-3007.

OVER THE LAST 32 YEARS WE HAVE LEARNED.....

That polio survivors must become experts in their own condition, and be the active, assertive manager of their own health care. Keep a file of polio materials and important post-polio information.

Polio survivors should find a good "quarterback physician" who will take care of the whole person and coordinate information from any specialists.

It is OK to say "I hurt", to get angry, depressed, frustrated, and grieve; to know that polio survivors are not imagining their symptoms. To realize that they are not alone. It is our old "Polio doctors" who are all dead or retired and we are still here.

Polio survivors should view canes, braces, wheelchairs, scooters, etc. as friends and realize that there is not a magic pill, shot or "cure" for post-polio. Supportive care keeps us active and productive. (And we are all aging.) **REST** is not a dirty word! Turn off the lights and lighten up... the grass will still be there tomorrow. Delayed fatigue is common - if you vacuum today, you may not be able to get up day-after-tomorrow. Learn to say, "I don't do that anymore!" **GET HANDICAP PARKING!** You may get from point A to point B, but you want to be able to get back to point A.

Remember, your doctor has technology you need, but you have information your doctor very much needs. Don't forget that your dentist or oral surgeon also need to know that you are a polio survivor and what late effects of polio you are experiencing. N. Lancaster, RN



PH Joan Dougherty and 2018 Belmont PT class.

BULOW ORTHOTICS - formerly Applied Orthotics - has moved to 6736 Charlotte Pike, Nashville 615/933-6896. **HOMELIFTS OF NASHVILLE's** new owner is Rich Eller. They still provide the same great service for stair lifts and elevators as did the late founder Alan Jensen. Still located at 3901 Charlotte Ave., Nashville 615/385-5438

Strength does not come from physical capacity. It comes from an indomitable will.

—Mahatma Gandhi

Dr. William DeMayo, MD once said, **"You need to figure out what your capacity is without overdoing."**

From the KANSAS POLIO CONNECTION, August 2001 **Sally Rosenthal wrote:** "While I generally dislike describing oneself in terms of a disability. I have come to see the absolute relevance of it in relationship to polio. The

social phenomenon of the experience really does shape and define this subculture. People who call themselves "polios" (I once heard Judy Heumann describe herself this way on an NPR show, and do so very articulately) are, I think, reflecting pride, like Vietnam vets do, in having been through a type of battle that will never occur again in this country. People who use it want to be remembered as its veterans."

PH of TN Note: Polio survivors are veterans with all the battle scars and, sometimes, "post traumatic stress". When we say, "I had polio" some of the younger generation have a blank stare (even health care professionals). They don't have a clue as to what you are talking about.. "There is no more polio", is an often remark, like we don't know what we are talking about. They know more about dinosaurs than polio, much less post-polio. To them I say, "Google it!"



POLIO HEROES OF TENNESSEE Support Group • Nickie Lancaster, R.N., *Group Leader and Coordinator*
529 Albany Drive • Hermitage, Tennessee 37076-1422 • Phone: 1 (615) 889-3007 •
a program of Easter Seals Tennessee, 750 Old Hickory Blvd., #2-260, Brentwood, TN 37027

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PHI & IVUN's STATEMENT ON AFM, March 2019
by Frederick M. Maynard, MD



Post-Polio Health International has asked the polio support groups to spread this message from Dr. Maynard

AFM is the descriptive name given to clinical condition characterized by the sudden (acute) onset over 1-3 days of a floppy (flaccid) severe muscle weakness (paralysis). There are several neurological conditions that can cause acute flaccid paralysis but modern testing can show if the condition results from inflammation in the spinal cord (myelitis). For centuries the poliomyelitis virus was the major cause of Acute Flaccid Myelitis but it has now been virtually eliminated (less than 30 cases worldwide in 2018) through massive vaccination efforts. Unfortunately, there are other viruses that can invade the nervous system of infected people and also produce a myelitis that sometimes results in death of motor nerve cells in anterior horn areas of the spinal cord and in variable degrees of scattered weakness in muscles of limbs, trunk, breathing, swallowing and the face.

History of AFM - Since 2012 there have been scattered outbreaks of AFM in the U.S> thought due to several different viruses: Enterovirus D-68 and D-70, Coxsackie A-71, and West Nile. The latter is spread by mosquito bites but the others spread between people. These viral infections commonly produce flu-like symptoms and only rarely cause paralysis. Only specialized testing can confirm a cause for AFM. Children appear to develop AFM from these viral infections much more often than adults. *While there may be some differences between the clinical pictures of cases due to different viruses, they seem to be minor and all cases with residual paralysis closely resemble cases of poliovirus-caused paralysis. Thus, newspapers often refer to "polio-like paralysis".*

The Centers for Disease Control and Prevention (CDC) has been monitoring cases of AFM in the US for at least a decade. Since 2016 there have been 100-200 cases yearly, and in 2018 the CDC became concerned enough to appoint an AFM Task Force of distinguished physicians as scientific counselors to their public health efforts for prevention of new cases. *At present there are no apparently effective medical treatments for cases with residual paralysis. While most cases show some improvement over the first year after onset, most appear to have some degree of permanent residual weakness.*

AFM Rehabilitation - Little has been said in the medical literature about therapy and rehabilitation for people with residual weakness from AFM. Information for parents and families from the CDC does mention that "doctors will recommend Physical Therapy or Occupational Therapy to help with arm or leg weakness from AFM". *The CDC AFM Task Force has no members who are rehabilitation specialists. As a result of limited information about what people with residual AFM weakness can expect in the way of recovery and functional restoration, and sometimes due to health care professionals being uncertain of what to prescribe for involved children, parents can become very anxious, confused and sad. A recent CNN story highlighted this situation. One physical therapist was able to help a young child improve their functional recovery only because she looked up older information about polio rehabilitation and followed similar treatment techniques. Another story tells of a mother who longed for support and guidance from other parents of AFM-weakened children, but her son was the only one of his kind. She found tremendous help and relief by taking her son to a post-polio support group meeting where other people who had had similar problems as children could share life experiences. She was able to observe and learn firsthand about polio survivors' successful adaptive behaviors and to receive "peer guidance" and reassuring support about recovery and rehabilitation efforts, child rearing techniques and long-term outcomes.*

PHI's Helping Role - We at PHI are calling attention to the CNN story because we want to encourage PHI members to watch for possible opportunities for them and their polio friends to be available to other AFM-affected people and to offer similar support, as well as to steer them to information about polio rehabilitation and its outcomes on PHI's Polio Place website.

The essentials of AFM rehabilitation, as with acute polio rehabilitation, includes the following:

- * Individually designed exercise programs to slowly increase strength, maintain joint and muscle flexibility and control pain.
- * Encouragement of functional adaptations with or without adaptive specialized equipment (e.g. braces, crutches, wheelchairs, etc.) for regaining optimal independent mobility and self-care.
- * Emotional support and encouragements to establish high self-esteem and optimism about the future.
- * Consideration of rehabilitative surgery options for restoring function, usually timed after improvements from other efforts have reached a plateau and to be appropriate for childhood growth and development.

I shared the CNN story with physician members of PHI's Medical Advisory Committee and asked them about their experiences with AFM patients. Several members had seen a few cases of AFM. *All who responded agreed that rehabilitation services/programs modeled after and like those used effectively for people with paralytic polio to be used.*

I invite you to join us at PHI and IVUN in spreading this message.

(Ref 1 Martin, JA, Messacark, Yang ML, etal. Recognition & Management of AFM in Children, NEUROLOGY 2017; 89: 129-137)

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