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## AFM and Polio Survivors

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*There have recently been several media reports about Americans developing a “polio-like illness” known as Acute Flaccid Myelitis (AFM) that leaves them partially paralyzed. Because PHI has received many calls from members about this topic, Dr. Fred Maynard was asked to write about what AFM is and to share his thoughts about how polio survivors might be able to help those who are affected by it. His response follows.*

[Editor's note]

AFM is the descriptive name given to a clinical condition characterized by the sudden (acute) onset over one to three 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 AFM, 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 U.S. 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 (Ref. 1).

### 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

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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 [[www.cnn.com/2018/12/03/health/afm-polio-support-group/index.html](http://www.cnn.com/2018/12/03/health/afm-polio-support-group/index.html)] 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 ([www.polioplace.org](http://www.polioplace.org)).

The essentials of AFM rehabilitation, as with acute polio rehabilitation, include 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 encouragement 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 be used.

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

Ref. 1: Martin JA, Messacar K, Yang ML, et al. Recognition and Management of AFM in Children. *Neurology* 2017;89: 129-137.