

POLIO EPIC, Inc.

Serving Arizona Polio Survivors since 1985

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June—July 2019

I hope you have found it interesting to read some of our members "life stories" in the Newsletter. Each story is unique and shows clearly that we do need help from each other to survive and work through some of the "storms" of life we have had to endure. The connections we have made with others, whether family, friends or polio survivors, keeps us from needing to go it alone. I am so very thankful for each one of you.

Joanne Yager, President



In the summer of 1959, I was living with my parents and one sibling on the island of Guam. My father was in the Air Force, and we lived in a Quonset hut that was renovated to hold military dependent families. I was 2 years old, and my sister was not quite a year old.

We both got sick at the same time, with flu like symptoms and my mother took me to the closest hospital, which was a 7th Day Adventist Hospital. Luckily, the doctor there told my mother to immediately take me to the ComNav (Naval Command) hospital. My chief symptom at that time was paralysis on the entire right side of my body. My sister, however, seemed to be fine after some initial problems with breathing and stomach distress.

Once we arrived at the hospital, the doctors did not want to believe I had polio. They assumed, since I was already vaccinated before leaving the states 2 years earlier; that I could not have polio. They did three spinal taps, and all 3 taps came up negative for meningitis, the blood work was sent to Kyoto AFB hospital in Japan. All 3 times, the test showed positive for Poliomyelitis. As my mother told the story, the doctors still did not believe the tests, and sent me to that hospital as a 2-year-old without my parents. According to records, I stayed in the hospital for over 9 months, when I "magically" appeared to regain use of my paralyzed side of the body. We all know that this was quite common in polio survivors, but also led to the mistaken belief that once we recovered from the

General Membership Meetings Every 2nd Saturday at Encompass Health Hospital; 2650 North Wyatt Dr. 10:00 A.M. - 12:00 Noon (except July, August & December)

Board of Director Meetings held on 1st Thursday of each month at Ward 6 Offices at 3202 E 1st St, Tucson 10:00 A.M.—12:00 Noon (except July) All Welcome

The opinions expressed in this publication are those of the individual writers and do not necessarily constitute an endorsement or approval by POLIO EPIC, INC. If you have personal medical problems, please consult your own physician

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The General Membership Upcoming Meetings

May 11th, 2019— Report from long time member, **Russell Amling**, on his recent honor-flight and directed Member sharing, lead by Jim Coleman. Jim will be leading a discussion on changes and adaptations to our homes, and living independently in our own homes with a disability! Bring photos of your adaptations and work-arounds!

June 8th, 2019— Annual Business Meeting and call for board members! Sign up, volunteer and help the direction of the group to provide valuable resources for all of our members. We will also be taking nominations for those that wish to participate on the board of directors! We also play some polio related games and have fun!

July and **August** have no meetings, because of the Summer heat. We will be back again in September! **September 14th, 2019**. This will be the beginning of our new fiscal year for Polio Epic.

Wadleigh/Immler Grants

These are grants of up to \$1,500, lifetime available to polio survivors in Arizona. These grants can help with items that you need, as a disabled person with Post Polio Syndrome. Grants are limited to items that you are unable to afford, or insurance will not pay. We had two long term members give money to our group, expressly to help Polio Survivors. We have been successfully helping polio survivors with Frank Wadleigh's gift since 2003, and now, Charles Immler (of North Carolina) has graciously added to that amount. Hence, we changed the name from Wadleigh to Wadleigh/Immler Funds.

You may access the application from our website on Polio Epic, Inc. at www.polioecho.org and print or fill out electronically and send. There is a mailing address attached to the application and guidelines. When the application is received, the board will vote on the application, and approve or deny the funding. The approved applicant will then receive the appropriate funding. If you have already received "some" of your lifetime limit, then we will check our records, in order to assure that you can get up to your lifetime limit!

acute polio, we were *completely* recovered . A year later, my father was transferred back state-side, and my parents made a decision that affected the rest of my life. They decided that since I was “cured” there was no reason to let anyone know about my having had polio as a child. I was clumsy, but nothing that couldn’t be hidden from myself and the general public. I spent years of my life assuming that I was clumsy, and always had falls and tumbles because of a laziness or inability to use my gross motor skills. I also had a very abusive family, and at one point when I was around 7 or 8 years old, I overheard my father calling me “damaged goods”, and I believed that for years. This is where I learned to become what Dr. Maynard calls a “passer”. A coping style or technique for polio survivors that manifests itself by forgetting you had polio, and compensating for it by doing everything that anyone else can.

My father decided that I needed to “hide” my limp, and made a wooden brace for my right leg. Whenever my leg would drift to the outside, the nails in the wooden brace were designed to poke into my leg to remind me to walk straight. I still have those scars today, both emotionally and physically.

Years later, as an active young woman, I started having nightmares about a burning fire being applied to my back, and someone putting a white sheet over my head (like at the morgue). I eventually went to a psychologist with my mother. (my family was not getting any sleep either from my screams). When I told the psychologist about my dreams, from the side of the room, I heard my mother say, “I thought you would have forgotten about all that”. Immediately the psychologist and I exclaimed at the same time...remembered what? That was the first time I found out about having had polio in my life, that burning fire, and sheet over my head was remembering spinal taps, and being tied down I also found out that my fear of being alone in silence stemmed from being left in an isolation ward for almost the entire 9 months I was in the hospital. Funny how finding out about the reasons for fears helps you overcome them!

When I was about 35-39 years old, I started having more problems. I was an avid Tennis player, and could not pivot on my right leg anymore. I was a backpacker, and my right leg would start twitching so badly it quit working. I couldn’t bowl anymore, because my right arm could not hold the 16 lb. bowling ball I was used to lifting. I started having problems going up and down the steps of my 3-story home. There is nothing worse than being stuck on a floor, and having to butt-bump your way down the stairs.

I was also going through fertility treatments. I could conceive, but never carry a pregnancy past 6 months. My doctor was totally confused. He suggested that I take my computer skills, go to the local hospital, and look up any information I could find about my issues and late effects of polio. The doctor had to write a permission slip for me to use the hospital library computer. At that point, in 1991-1992, there wasn’t much known in the general public about Post Polio Syndrome.

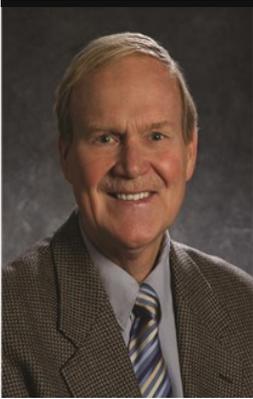
That doctor found a place in Atlanta (30 miles away) that dealt with spinal cord issues and polio survivors. The doctor in charge, had been trained at Warm Springs. My doctor received a questionnaire from the Shepherd Spinal Center. He warned me, if the symptoms don’t match up, they will probably not call you back. I agreed, filled it out, and sent it to in. I got a call right away. They wanted to do an evaluation. I spent 3 days, getting testing and evaluated for Post Polio Syndrome. That is where I was officially diagnosed.

It has been a long battle to be recognized and believed. I have had doctors say things like I am too young to have had polio. I have had them say that since I didn’t have any atrophied limbs, I could not have had polio. I have had doctors say that since I was so physically active, the problem must be psychosomatic. Yep, I have heard all those lines, as many of you have!

Luckily, I found the computer again led me to enlightenment. I found a listserv group called SJU (St. John's University), I found AOL Disability Café with Tom Walter's Group. I found a friend in the that group (*love you, Maureen Sinkule*), and I learned. When I moved to Tucson, I found Polio Epic. Having a support group means the world. I have learned, and hopefully been able to take that learning to deal with this disability in my life. I feel that I am a happier, healthier and active person, because of these support groups. Find a group that works for you, whether it is on-line or in-person...find your "tribe" that will help you live that happier life.

Michelle "Micki" Minner

AFM and Polio Survivors



Frederick M. Maynard, MD

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.

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 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] 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).

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.

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www.post-polio.org
www.polioplace.org

PHI's mission is supported by its Membership.

POLIO EPIC MEMBERSHIP FORM AND DUES

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Enclosed is membership fee of \$10.00 per person for one calendar year (**Sep 2018– Aug 2019**) New Fiscal year started 9-1-18

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Make checks payable to Polio Epic, Inc. and return to P.O. Box 17556,

Tucson, AZ 85731-7556

PLEASE NOTE: OUR FISCAL YEAR DIFFERS FROM CALENDAR YEAR—The New FISCAL year for Polio Epic, Inc., began on September 1st, 2018. So, dues sent in from now on will be for the next 2018-2019 year, and the label will show 2018 if you are current.

If you receive this newsletter via email, you will receive a yearly email in September to remind you. If you are not sure, then call Micki Minner at 520-307-0174, or email: Mickiminner@msn.com . Micki will be glad to check our membership roles to find the last date you paid your dues! THANK YOU for supporting our organization, and the services we provide to Polio Survivors in Arizona.

Polio Epic NEWSLETTER

Southern Arizona Post-Polio Support Group
P.O. Box 17556
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FREE MATTER FOR
THE BLIND AND
DISABLED

RETURN SERVICE REQUESTED

Correction Notice: Last Issue of our Newsletter, the pictures of the cars covered up the author's name of Janna L. Guyer Peyton. We want to recognize her, as sharing her love of transportation and apologize for her name not being shown!

EXCITING NEWS



Our Webmaster has developed a YOUTUBE Channel for Polio Epic, Inc.! Hooray! If you go to <http://Youtube.com> ; you will find a search address bar at the top of the screen, then merely type in Polio Epic, Inc., and you will see a display of our channel! Jim Coleman has been working to get all of our presentations recorded, and you will find Dr. Eulberg's and my presentation there on the website! You can learn while sitting home in your pajamas!

You can also subscribe to this channel and receive emails whenever a new video is posted!