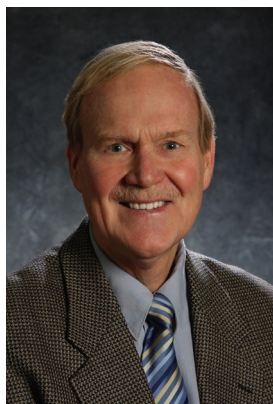


PHI's mission is supported by its Membership.



Frederick M. Maynard, MD

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.

[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

continued on page 3



TEXAS WOMAN'S
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OPPORTUNITY TO PARTICIPATE IN RESEARCH

You are invited to participate in a research study entitled, "Falls and Fear of Falling in Adults who Require Wheelchairs for Locomotion." To participate you must be an adult who:

- ◆ Is at least 18 years old.
- ◆ Has a neurological diagnosis (such as but not limited to post-polio syndrome, spinal cord injury, multiple sclerosis) for at least six months.
- ◆ Uses a wheelchair (manual or power) at least 75% of your mobility time inside your home and 100% of the time outside your home.
- ◆ Has a computer with internet access.
- ◆ Is able to read and understand English.

If you are interested in completing an anonymous online survey about your medical condition, falls, risk of falling, and fear of falling, please follow this link:
www.psychdata.com/s.asp?SID=183112

It will take you up to about 20 minutes to complete it. People who complete the survey will be eligible for a drawing for a \$20 gift card.

You may contact Carolyn Da Silva, PT, DSc at cdasilva@twu.edu or 713-794-2087 for more information or questions. She is a professor in the School of Physical Therapy at Texas Woman's University and physical therapist at the post-polio out-patient clinic at TIRR Memorial Hermann Rehabilitation and Research in Houston, Texas. ■

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PHI's mission is to enhance the lives and independence of polio survivors and home mechanical ventilator users through education, advocacy, research and networking.

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Moving? Change of address?

Notify PHI before you move by calling 314-534-0475
or email info@post-polio.org, and tell us your old
and new addresses.

Away temporarily?

Send us your second address and dates you will be there
and we'll do our best to send you newsletter.

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.

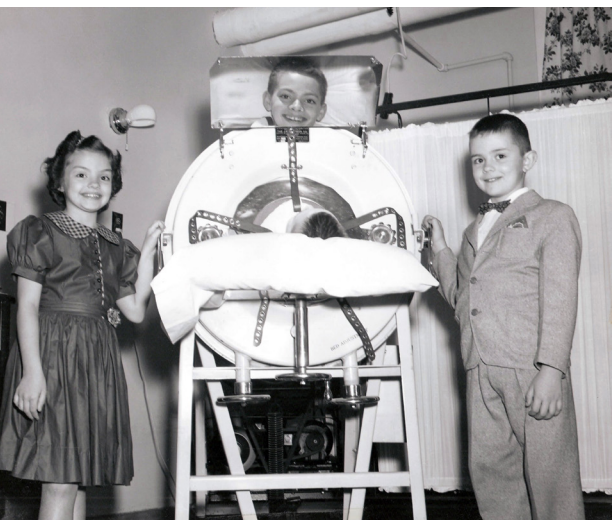
I invite you to join us at PHI in spreading this message. ■

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

Lawrence C. Becker (1939-2018)

Lawrence C. Becker, who served on the Board of PHI from 2000 to 2011, died on November 22, 2018 in Roanoke, Virginia. He was 79. Charlotte, Larry's wife of 51 years, predeceased him on September 18, 2018. Larry served as president of the Board from 2006 to 2009. He was instrumental in encouraging the Board to think about the future of PHI given the decreasing number of polio survivors in the United States. As a final gift to PHI, Larry included a bequest to the organization in his will.

A native of Nebraska, Larry developed polio when he was thirteen. He spent several months in an iron lung. Polio also left him without the use of his arms.



November 1952, Larry Becker with siblings Sharyn and Michael.

Larry received a BA in history (1961) from Midland College in Fremont, Nebraska, and then a MA (1963) and PhD (1965) in philosophy from the University of Chicago. Following graduation, Larry had a distinguished career as a college professor and philosopher. From 1965 to 1989, he taught at Hollins College in Roanoke, rising to the rank of Professor.

In 1989, he became The William R. Kenan, Jr., Professor in the Humanities and Professor of Philosophy at the College of William and Mary. He retired in 2001 and became a Fellow at Hollins College until his death. I recently met a former student of Larry's who spoke very highly of his teaching. In addition to his philosophical interests, Larry was a great fan of jazz.

Larry was a distinguished philosopher working primarily in the areas of ethics, including disability ethics. He wrote five books on ethics, justice and stoicism.



Lawrence C. Becker

With his wife Charlotte, he co-edited *The Encyclopedia of Ethics*. Larry wrote numerous scholarly articles in philosophy and ethics and frequently presented papers at philosophy conferences.

Larry believed that five strategies were essential to living well with a disability. First, *agency*. Become and remain an agent not a patient. Learn to become an effective agent for yourself. Second, *focus on abilities, not disabilities*. Focus on what you can do, not what you can't do. Third, *take a whole life perspective*. Construct a plan for your life and revise it as necessary. Fourth, *seek to achieve internal harmony*. Try to harmonize the various components of your life. Fifth, *recognize brick walls*. Learn to distinguish real walls from illusionary ones. Learn your limits. Larry discusses these strategies in "Developing a Personal Philosophy About Disability" that is available for viewing on PHI's Polio Place (www.polioplace.org/personal-philosophy-disability).

Larry was a bright, warm, and humane colleague. He was a fine teacher and excellent philosopher who helped PHI move forward. He will be missed by all who had the opportunity to know and work with him.

Daniel J. Wilson
Vice President, PHI Board

In early 2018, Post-Polio Health International awarded their tenth grant to a team of researchers from the Amsterdam UMC, location AMC, in the Netherlands. The study is led by Frans Nollet, MD, PhD, head of the Department of Rehabilitation of the AMC, and director of Amsterdam Movement Sciences research institute, and coordinated by Eric Voorn, PhD, postdoctoral researcher.

The study will be conducted in rehabilitation centers in the United States and the Netherlands, and the goals are:

- 1) to evaluate the effectiveness of a personally-tailored aerobic training program according to the B-FIT training guideline on physical fitness, physical functioning and quality of life of individuals with PPS, and
- 2) to evaluate patient and healthcare professional satisfaction with the use of the training guideline.

The B-FIT guideline is based on findings from the process evaluation of an RCT that we recently performed in the Netherlands, experiences of patients and care professionals, and scientific literature on exercise physiology. B-FIT is personalized in that it is adapted to the individual's needs and physical capacities. A previous pilot study in two rehabilitation centers in the Netherlands demonstrated its potential for clinical practice. Since the B-FIT training guideline was written in the Dutch language, a more comprehensive study is needed to determine the effectiveness and

usability of the B-FIT training program in PPS on an international scale.

What has been accomplished so far?

During the first months of the project the B-FIT training guideline was adapted in such a way that it better fits neuromuscular rehabilitation care in the United States. For instance, the information about the Dutch physical activity guidelines was replaced with information about the recently published physical activity guidelines for Americans. After this, translation of the guideline was initiated as well as the development of a website to support practitioners in using the guideline. Meanwhile the procedures for research contracts and IRB approval have been initiated for two sites in the United States.

As of December 2018, Tim Veneman joined the research team. He is an exercise physiologist at the Rehabilitation Department of the AMC and will be working as a PhD candidate on this project.

What are the team's next steps?

It is expected that the first patients in the United States will be recruited early 2019. Furthermore, the team aims to add one or two more US sites to achieve the recruitment of 30 participants that is needed for this study.

Rehabilitation centers with interest in participation in this study can contact Eric Voorn for further details (e.l.voorn@amc.uva.nl). Presentation of preliminary results at an international conference is projected for late 2019. ■

PHI elects Saul J. Morse as its new President

In November, Saul Morse was elected President of PHI after serving on the Board since 2002 and as Vice President since 2011. He is an attorney in Springfield, Illinois who has focused his practice on legislative matters, health law, insurance and municipal law. He also engages in a general practice.

He has served as General Counsel to the Illinois State Medical Society and to ISMIE Mutual Insurance Company, the largest insurer of professional liability of physicians in the State of Illinois. In 2010 with the passage of the Affordable Care Act, he was asked by the Illinois Department of Insurance to establish and manage an insurance pool for individuals with pre-existing health conditions. That high-risk pool was established within six weeks and managed by him for two years. In that time, he provided oversight, management and approval for the expenditure of in excess of \$40,000,000 in health care services to over 3,500 individuals. He has practiced in the Circuit Court, Fourth District Appellate Court, Illinois Supreme Court, and submitted briefs on behalf of clients to the United States Supreme Court.

Saul has served in the past as a member of the Board of the Illinois Comprehensive Health Insurance Plan, the Illinois Human Rights Commission, and as Chair of the Illinois Guardianship and Advocacy Commission, all entities of the State of Illinois whose boards are appointed by the Governor. He served as Chair of the Board of the Community Foundation for the Land of Lincoln. He is currently involved with several entities in addition to PHI. He is a member of the Board of Directors of the University of Illinois Foundation and the Chair of the Board of Visitors of the College of Applied Health Sciences at the University of Illinois Urbana-Champaign.

The Pennsylvania Polio Survivor's Network

How We Began Our Mission of Service

Carol Ferguson

My post-polio journey was long, painful and truly confusing. Happily, in the fall of 2013, I was finally “there.” Polio was no longer defining my life. Had I discovered the limitations that came with disability? Yes. Had I discovered new and pain-free abilities? Yes. I had been given the gift of understanding what was happening and complete acceptance of my new limitations. I was a polio survivor who was truly thriving. With that, came a new kind of energy.

For two years I had been writing the fascinating, joyful, painful and truly memorable survivor stories of my friends. Although active in my support group, my new energy was looking for more. I knew without question that in the end, I had been truly blessed in my care. I read every PHI newsletter from cover to cover and in early spring 2014 discovered their international conference would soon be held in St. Louis. I told my husband I wanted to go. He responded, “You can’t travel alone.” Poor guy, I will never forget the look on his face as he dropped me off at Philadelphia airport on my bright red scooter, suitcase under my feet. From that moment, my life changed.

There was kindness everywhere I turned in the form of smiles, patience and people willing to help. Although nervous when I arrived at the conference location, I was excited as well. I was thrilled my daughter-in-law was joining me and that I could engage her in my “new” world. She is curious, loving, funny and kind and was the perfect companion, attending sessions one after another for two days.

The first night, while waiting outside the dining room, I met a kind gentleman, also from Pennsylvania. As I was sitting and he was standing, I could not read the MD next to his name—Bill DeMayo. Little did I know he was a rehabilitative physician, one of the featured professional speakers for the weekend and an incredibly nice man. There at dinner was Daniel Wilson, PhD, who I had met years before and whose advice was significant in my complex diagnosis.

The next day, when I heard Dr. William DeMayo speak, I was fascinated. His integrative treatment program for polio survivors had the same philosophy as the one I had successfully completed in New Jersey. I met, listened to, laughed with and learned so much from so many amazing people that

weekend; my head was spinning. While on the flight home, I focused on how truly blessed I was and how I knew my life had changed forever. I finally found a place for my newly found energy.

While in St. Louis, I had met outstanding professionals from all over the world and fellow survivors who had become post-polio support group leaders in their various states. I knew from my own experience and from the stories I had the opportunity to write, that Pennsylvania seemed to be behind other states regarding information about post-polio diagnosis and care. At that time, there were four active support groups in our state. Gathering information to share with their groups was cumbersome and had to be gathered from numerous places.

Everyone was struggling with interesting and credible programing to bring to survivors at meetings.

Gathering a supportive “team” became a necessity. My ever-supportive husband and two close friends were my sounding board for some great (and not so great) ideas. One, who is filled with wisdom, was interested in the topic because of her love for me and for her brother who is also a survivor. The third in our initial journey was a man I met in the local support group. Paralyzed from the neck down at age two, his journey with polio was one that I could not imagine. His sense of humor and ability to be very “grounding” all at the same time were the perfect combination. Over the next few months, I learned how to launch a website, use Facebook and call complete strangers for advice. Our total financial investment was the \$90 we had spent for the website.

November 2014, we were ready to go. We were devoted to our mission statement: “To Be in Service Providing Information to all Polio Survivors, Post-Polio Support Groups, Survivor’s Families and their Caregivers.” Our website put information from multiple credible sources in one place.

Prior to launching the website, we asked every contributor for their permission to publish their work. I will never forget the response from then PHI Executive Director Joan Headley. As was typical of her work, she not only read every article but found more than one typo! I was truly grateful for her attention to detail. The idea of “Bruno Bytes” was born and our first month’s publication was uploaded. At the same time, we were truly naive as to the power of the internet.

Gathering a supportive “team” became a necessity.



Eastern Pa. attendees at the “Post-Polio Care,” 2017 Conference. This event was live in Eastern, Central and Western PA, thus connecting over 200 survivors and caregivers at one time. Rotarians from 3 locations were on hand to assist.

More than four years later, our mission of service is more intact than ever. Our team has grown to be what we call a “joyful ragtag bunch” of nine volunteers. (Four of us are survivors who are geographically spread throughout PA). We serve ALL Polio survivors regardless of where they are from and charge no dues. We rely solely on, and are grateful for, *all* donations.

- ❖ Our newsletter (www.papolionetwork.org/newsletter.html) is published each month, all over the US and abroad, for no charge (by email); in both regular and large print formats.

- ❖ Our website (www.papolionetwork.org) is updated regularly. The biographies of our regular contributors are clearly visible with a simple click on their name.

- ❖ We have hosted/sponsored two conferences and a worldwide webcast. We have published the videos from all three, thus allowing the information to be shared. (www.papolionetwork.org/post-polio-care-video.html)

- ❖ We have communicated with and introduced ourselves to every hospital, senior residence community, neurologist, home health care agency and oral surgeon in the State of PA.

- ❖ April is now “Polio Awareness Month,” passed unanimously by our PA State Representatives. Each year, we launch a new “initiative” during that month.

- ❖ We have become active on the Immunization Coalition for our State. (Two of us attended as exhibitors and speakers at the PA State Immunization Conference). We published a Polio Immunization card being sent to new mothers in three counties.

- ❖ “Team Survivor” (quite simply a means by which survivors and our families can become part of the solution) has raised enough funds to vaccinate more than 32,000 children in the most war torn areas of the world.

- ❖ We happily do presentations about the “Polio Truths” throughout the State of PA. In 2018, we did 30+ events.

- ❖ We actively engage in the Senior Health Fairs (sponsored by our Representatives) held throughout PA.

- ❖ We have hosted two events in the Pittsburgh area (home of the Salk vaccine). The positive press in that area resulted in a significant number of survivors and their caregivers being able to gather and renew with one another.

In December of 2014, we made the decision that we would continue to be active as long as it is necessary. It is our dream that post-polio care will become “mainstream” for health care professionals and survivors. Until that happens, and as we venture into a new year, we are focused on answering the question from PHI asked us to write this article: “What motivates your group to continue?”

We are blessed to be able to work with amazing professionals who truly care about polio survivors and the long-term effects of polio. The opportunity to read and publish their work on a regular basis is something we will never take for granted and want to continue. The positive response from health care professionals when we talk about the “Polio Truths” has motivated us as well. When we do presentations, we encourage their questions and concerns. We are grateful for their wanting to attend and be open to ideas.

Most of all, it is the positive response from polio survivors all over the US and abroad to our work that has been humbling and truly inspiring. The four survivors on our team see the effects of polio as something that we “have” but not something that will continue to define us. The non-survivors, truly wonderful family and friends on our volunteer team, are focused on our energy, *not* on our disability. That combination has resulted in what we believe to be a positive and encouraging message when discussing the reality of the *very* painful and difficult effects of polio. ■

QUESTION: *My husband, like myself, was a polio survivor. He passed away last summer. I wouldn't say I'm depressed, but I feel lonely a lot. I have kids and grandkids nearby that still visit regularly. I have couple of good friends who I still get together with for breakfast every few weeks. I'm grateful for the love and support they bring me. But sometimes I feel like they don't really understand what it was like to have had polio, or what it's like to deal with the late effects of polio. I didn't have to explain these things to my husband. He knew what it was like. I live in a fairly small town in Kentucky and don't know any other polio survivors. I've looked for support groups in your Directory, but sadly, there aren't any near me. My kids tell me to use Facebook, but I don't use the computer much and didn't really like Facebook when I tried it. I guess my question is: how do I keep from feeling so isolated? How do I find others that might know what I'm going through?*

Response from Rhoda Olkin, PhD:

How might we think about friendships? How many do we need? How do we get more? To explore this, do an exercise with me.

- (a) Draw a circle in the middle of the page. Put the names of your most intimate people in that circle. It might be a partner, a parent, kids and grandkids.
- (b) Now draw a second circle surrounding the first. In this circle write the names of the people you call when you need to talk, or who you would tell when something bad happens. If your partner dies, who do you reach out for?
- (c) Next, draw a third circle around the second circle. In this circle put the names of those you might have lunch or go to a movie with. You talk to each other, maybe even a lot, but not about deeply personal or painful topics.
- (d) Keep drawing these concentric circles until you have run out of people in your life.

The inner circle is generally the smallest. Even those with large extended families are usually closest to only some of them. Which circle could use more people in it? You can't just go out and make a new best friend on demand. But you can increase the people in that third circle, the ones to go with you to a restaurant or event. I used to think the first two inner circles were the most important. My litmus test was would I rather stay home and watch TV or go see this person? But this is a really bad litmus test for an introvert such as myself; I would always rather stay home! However, as a psychologist I know the research on socializing—it is vital for a longer and more fulfilled life.

For me, the people in circle number two tend to be people who have personal disability experience in themselves or family, or who have worked in the disability community. It does really help when friends 'get it' without much explanation. But all of my friends are disability-affirmative, i.e., they consider my disability needs in any outings, never make me feel I am holding them back, and are open to talking frankly about disability.



Dr. Rhoda Olkin is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology. She is a polio survivor and single mother of two grown children.

It is the third circle where you can have some control. Joining a group of some sort is one way. For example, I joined a writing group that meets once a month. So now I have seen these people about a dozen times over the last year. It isn't intimate, but we now have a shared history, and a common interest in writing. Whether it's gardening, quilting, ceramics, reading, art history—join (or even start) a group.

Response from Stephanie T. Machell, PsyD:

No wonder you feel lonely at times. You lost not just a husband, but a comrade who understood the polio experience from the inside. Of course, you want to be around others who get it.

Finding those others may not be easy, but it will be worth the effort. And they may not live that far away. Often, I meet one or more polio survivors who live in the same small town, each of whom will tell me there are no other polio survivors in the area. Unless they participate in support groups, most of the polio survivors I know don't know any other polio survivors personally.

So how might you find them without using the computer? Network! Ask everyone you feel comfortable asking if they know any and, if so, would they introduce you. Don't assume that they would have mentioned it before. And don't assume their friends and friends of friends don't and ask them to ask, and so on.

You could broaden your search by organizing a gathering for area polio survivors. All you need is a meeting space and a time you can use it. Often churches,

libraries, senior centers or hospitals will have space you can use.

Make up a simple flyer and send it to medical providers (don't forget your own), ministers, and senior centers and other community organizations within however many miles of your town you want to cover. Post it on community bulletin boards and advertise in the events section of your local paper(s).

The initial gathering can be a social time with a brainstorming session for ways people might like to connect both formally (support groups or regularly scheduled gatherings) or informally (exchanging contact info and keeping in touch).

What if you do all this and still don't find any other polio survivors? Others aging with disabilities face many of the same issues. You could try connecting with them in the ways mentioned above and see if they will provide the support you're seeking.

Or you could give Facebook another try, this time for the specific purpose of connecting with other polio survivors. You can follow and/or join only polio-related groups, where you can post requests for those who live in your area to contact you. You can post a similar request on the PHI website, and/or advertise that you are starting a support group if you decide to do so. The internet may never become your favorite way of communicating. But being able to connect with polio survivors from all over the world might win you over. ■

Dr. Stephanie T. Machell is a psychologist in independent practice in the Greater Boston (MA) area. She specializes in working with those affected by polio and other physical disabilities. Her father was a polio survivor.



Polio survivors and other young people with disabilities often face a daunting future in the Democratic Republic of Congo (DRC). Most come from families too poor to pay for even the most basic support, such as braces, to help them walk. And most are excluded from mainstream schools and community life because of their disability. Without help, many are left to literally crawl along the margins of society with little chance of a better life.

Since it was founded by a group of young people with disabilities in Kinshasa in 1999, StandProud and our partner organization, l'Association Congolaise "Debout et Fier" (ACDF), have helped more than 5,000 young people across the DRC to walk again. We tailor support for every young person we help. In many cases, providing some relatively inexpensive treatment and equipment is all that is needed to dramatically improve a young person's mobility and significantly change their life forever.

Since 1999, StandProud and ACDF have grown and expanded, establishing and maintaining six brace-crafting workshops across the DRC—in Kinshasa, Lubumbashi, Bunia, Butembo, Goma and Kalemie—that provide free equipment for as many disabled Congolese young people as possible. And there are StandProud organizations registered as non-profits in United States, the United Kingdom and Switzerland with all volunteer staff.

Although our beneficiaries are primarily children who were paralyzed by polio during the first years of their lives, or who become paralyzed as a result of ill-advised injections in their hips during treatment for malaria or other diseases, we also help young disabled people suffering from spasticity, those born with club feet, and people with spinal cord injuries who were previously confined to wheelchairs.

StandProud and ACDF use a variety of approaches to improve the mobility of the people we help, and to ensure that these improvements are maintained.

This work includes bracing, corrective surgery and casting, and replacing poor quality equipment. But helping a disabled child with their immediate physical needs is only part of a good solution. Any assistance will have only limited impact unless it is also accompanied by additional support.

To achieve this, we supplement our brace-making and treatment activities with an education and skills training programs to help our beneficiaries become more active members of their communities. Parents are taught about the importance of sending their disabled children to regular school along with their non-disabled siblings, and provided with some basic assistance with school fees to encourage attendance.

Our professional training equips our beneficiaries with the skills to become program managers, accountants, IT experts, and brace-makers, and we are proud to include lawyers, medical doctors and physical therapists among the "graduates" of our program. We provide employment where possible to many of the young people who have benefitted from our programs.

Having a staff made up of former beneficiaries helps build self-confidence for new arrivals. And seeing other people with a disability managing a large operation and doing most of the work involved makes an enormous impression on both children with a disability and their families visiting our facilities for the first time. Our staff members not only craft the equipment for new arrivals and teach them to walk, but also treat minor illnesses, help them with their homework, and even physically carry them around until they can manage on their own. As a result, the young people are surrounded by positive images reinforcing the message that people with physical disabilities still have many important capacities and can play useful roles in society.

To complement our other work, StandProud and ACDF also employ a unique approach for supporting young people with disabilities in the DRC, including confidence building, an “extended family approach” and providing rehabilitation homes where young people can stay before and after their treatment.

At StandProud we also believe that we need to do what we can to prevent disability, to help ensure that our impact on the environment is minimal and to build an organization that is sustainable and meets the needs of young people in the future. To help prevent more young people being exposed to polio, we collaborate with the Global Polio Eradication Initiative, Rotary International and Rotary clubs in the DRC, to encourage all Congolese to vaccinate their children against polio. And we collaborate with other initiatives across the DRC to improve water quality, sanitation systems and poor hygiene practices that are at the root of polio infection.



Photo courtesy of Derek Jeter

We also work to reduce our impact on the environment. StandProud and ACDF use only recycled scrap metal, purchased locally, to construct our braces. Metal braces are easily repaired, unlike plastic braces, and we do thousands of repairs each year. We use recycled leather to make our brace straps, belts and corsets. And we use second-hand shoes, also purchased locally, in which to “set” the braces.

Despite the unrelenting political crisis in the DRC, and some of the worst poverty in the world, we continue to work to seek out and partner with people and organizations from around the world to assist young people with disabilities in the DRC to increase their mobility, reclaim their dignity and have the opportunity to integrate into the society around them.

Find out more about the work we do or become a StandProud supporter now at www.standproud.org or write to us at info@standproud.org. ■

In Appreciation

Thank you for recognizing your friends and loved ones with contributions to the activities of PHI and IVUN and for your generous Membership contributions. *Please contact us if we made an error.*

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