Kenya Polio Survivors Embrace Yoga

Alicia Helion, PhD, Eshiakula, Kenya

“Habari Asabuhi, Karibu!”

The students receive my Swahili greeting before we begin practicing yoga in one of the most unlikely places: rural western Kenya. These yoga students are primarily polio survivors, and they are attending classes at the Amani (peace in Swahili) Educational Center. At this center, people with disabilities and HIV practice yoga, hear guest speakers on health-related topics and have fellowship.

Here, in a tiny village called Eshiakula, yoga classes are often the only “medical care” people with disabilities can access. There are free clinics, but the few dollars it costs to get to the town is more than most can afford. So many participants have untreated medical conditions, often living with severe pain. Further, many deal daily with the stress of discrimination, poverty and living with a disability. Yoga offers them a reduction in pain, increased flexibility and strength and a respite from stress.

Though the center opened in 2013, the seeds were planted in 2008, when I took my first service trip to Africa to work in Mozambique. I was touched by the wonderful spirit of the people. They had such perseverance, great joy and immense generosity. Every summer, I went back to work in Africa.

In 2011, I made my first visit to Kenya where I taught HIV prevention to people with disabilities and classes on stress reduction, nutrition and medication adherence. The participants told me that stress reduction was particularly important for them as they have intense stress daily and need better ways to manage; they asked me to come back the next year with even more knowledge on how they could reduce stress. I returned, armed with many more techniques to offer them, including yoga. I was amazed by the benefits people experienced after practicing yoga just a few times. They asked me to learn more about yoga and come back again!

In 2013, when I decided to leave my job as a professor to work in the health field, it felt like an obvious choice to open a health education center in Kenya, with a focus on stress reduction. I wanted to include yoga, and I planned to tailor classes to those with disabilities, allowing everyone to reap the benefits. After taking a yoga teacher training program, a workshop on continued on page 9
Saturday, May 31
3 pm  Pre-Conference Orientation for first-time attendees
Maximizing Your Conference Experience presented by Joan L. Headley, PHI Executive Director
Review: Late Effects of Polio & Your Health presented by Frederick M. Maynard, MD
6 pm  Opening Dinner featuring One World, a dance/theater performance about disability and human rights.
This unique event is a collaboration between the DisAbility Project of That Uppity Theatre Company and
Common Threads Dance Company. Note that the Opening Dinner is not included in the registration fee
and requires a special ticket purchase.

Sunday-Tuesday, June 1-3
Educational sessions aimed at Promoting Healthy Ideas begin at 9 am daily. All sessions are timed to include
presentations, reactions and discussions. Lunch is included in the registration fees.
Tuesday’s program features a discussion of post-polio research and the future needs of polio survivors.

To review daily program specifics, visit PHI’s website, post-polio.org.
Information about hotel reservations (online or by phone) and conference
registration forms can also be downloaded from the PHI website. Note that
conference registration cannot be completed online, but must be printed
out and mailed in with payment.

A printed registration packet can be mailed upon request by contacting
Brian Tiburzi at info@post-polio.org or by calling 314-534-0475.

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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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**The Iconic Iron Lung and Polio Survivors in the USA**

Joan L. Headley, PHI Executive Director, St. Louis, Missouri

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PHI is frequently asked how many iron lungs are still in use. Respironics Colorado reports renting iron lungs to three individuals and providing parts and service to four other patients who own their device. All of these iron lungs were made by the J.H. Emerson Company, Cambridge, Massachusetts. However, the history of ownership and maintenance of the iron lung used by the majority of polio survivors in the United States is complex and warrants recording, using the PHI archives.

Point of reference: A brochure revised in June 1946 (seventh printing) entitled Respirators: Locations and Owners was published by The National Foundation for Infantile Paralysis (NFIP). Basil O’Connor, president of NFIP, explains in the introduction that it is a list of the adult cabinet type respirators or “iron lungs.” The list totals 1,211 in the contiguous 48 states plus Washington, DC, and Hawaii. Owners included hospitals, the U.S. Army, fire departments, chapters of the NFIP, American Legion and other service groups, county medical societies and individual physicians and local citizens.

*A timeline can more easily tell the rest of the story.*

**1968**

James C. Campbell, a graduate of the University of Colorado, worked for the IBM Data Processing Division for 11 years before he started LIFECARE International, Inc. He was the Chairman and CEO of the private company from April 1968 to October 1996. The company designed, manufactured, distributed and serviced the successful PLV-100 (1984) and PLV-102 (1985) volume ventilators, among other devices.

**1969**

LIFECARE became a dealer of products for the Puritan-Bennett, Emerson, Monaghan and Thompson Respiration companies. The company then entered into a contract with the March of Dimes to maintain, for a monthly fee, respiratory equipment provided by the March of Dimes to the surviving polio population. The respiratory equipment (e.g., the Monaghan 170-C, Thompson Bantam and Maxivent, Huxley, etc.) was scattered around the country in “equipment rental pools.” Survivors received letters telling them of the switch from working directly with the March of Dimes to LIFECARE. A March 5, 1969, letter from the Metropolitan Chicago Chapter of the March of Dimes says, “As you undoubtedly know, public support of the March of Dimes has markedly decreased since the success of the Salk and Sabin vaccines.” It further explains that “… it is necessary to consider other available resources” and suggests “… it is possible that you may qualify for assistance with this expense through the Medical Assistance Program, which is financed jointly by the State of Illinois and the Federal Government.” Some survivors thought that the equipment they received from the March of Dimes was “their property,” and they were surprised when another entity became involved.

**1970**

J.H. Emerson stopped manufacturing their model of iron lung. The prototype was made in 1931. The exact number manufactured is not readily known but thousands were manufactured, “with limited production during the 1960s,” according to a May 2004 company letter.

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continued on page 4
1976
LIFECARE worked with Medicare and Medicaid to provide ventilators at home as a reimbursed benefit and helped establish the home ventilator industry.

1983
LIFECARE converted the last March of Dimes equipment rental pool center in Augusta, Georgia, to a LIFECARE District Office, one of 18 offices.

1984
LIFECARE International, Inc. purchased the March of Dimes equipment in the rental pools that it had been maintaining. Before the sale, March of Dimes notified those on the program in a March letter that it would be the payer of last resort. The rental and maintenance fee paid to LIFECARE was first by Medicare, Medicaid or private insurance. March of Dimes continued to pay for those without any other method of support. Some survivors never revealed that they had other means of support, adamant that the March of Dimes should pay. It did.

1987
March of Dimes and LIFECARE agreed to add the PVV (portable volume ventilator) to the program.

1988
LIFECARE established its Shared Services program, now part of Respironics Colorado, to assist dealers in providing ventilators to users. This included the polio survivors who received their first equipment from the March of Dimes.

1991
The number of polio survivors in the LIFECARE/March of Dimes collaboration was 348, of which 35-38% depended completely on the March of Dimes.

1993
Because its contract with LIFECARE would expire in March of 1994, March of Dimes evaluated its situation and decided that it would no longer accept new polio survivors to the program as of January 1. They stated in January 25, 1993 memo, “Patients currently receiving financial assistance will be requested to complete a financial assistance questionnaire, which will be evaluated based upon need. Current patients meeting the criteria will be grandfathered.” The letter provided a referral list of other groups to ask for assistance.

They further explain that their mission for the last 35 years has been to prevent birth defects and infant mortality and “forms the basis for its appeal for support from the public.” Some polio survivors receiving the letters were concerned that private insurance, Medicare or Medicaid would not help pay for their home respiratory equipment. They did in most cases. The March of Dimes continued to cover 100% of the expenses for those unable to obtain other financial assistance.

1996
Respironics purchased LIFECARE International, Inc. In the late ‘90s, March of Dimes and Respironics agreed to add the PLV-100 to the program.

2004
Parts to service the J.H. Emerson iron lung were harder and harder to find. Respironics notified all of the individuals (and their physicians) who were renting an iron lung from them of the situation. The company offered three options in a May 10, 2004, statement:

“Transition to an alternative device as soon as feasible;
Continue using the Iron Lung Device with the understanding that if the device fails Respironics Colorado may not be able to repair the device;
or,
Accept donation of the device and pursue other support and repair options. As a company regulated by the Food and Drug Administration and other quality system certification organizations, we have limitations on the suppliers and repair sources we can qualify and accept into our quality system. However, the owner of the device, in this case the patient, may seek such repairs from a non-regulated third party.”

Photo credit: PHI Archives
Again, polio survivors who used the iron lung and their families were concerned and frustrated. Opinions ranged from “it is understandable that repairing a device made that long ago would be difficult” to “a multi-million dollar company should be able to just make the parts.” Through the next months, survivors and their physicians worked with the company to resolve the issue the best they could for each situation.

A few iron lung users switched to positive pressure ventilation via a nasal or face mask. Some switched to the Porta-Lung, developed by polio survivor W.W. “Sunny” Weingarten and made available in 1988. Weingarten designed the smaller, lighter-weight device so he could travel extensively. The Porta-Lung was distributed by LIFECARE.

How many chose which option is proprietary knowledge, but PHI assisted in locating iron lungs that had been purchased and were in storage and no longer in use, so a working back-up could be stored near each iron lung user or warehoused (in Houston) for parts.

Unfortunately, a rumor started that Respironics was gathering iron lungs to destroy them or sell them to Third World countries, so they wouldn’t have to maintain them. Consequently, a few iron lungs were not made available to the Respironics technicians.

**2008**

Respironics was purchased by Philips Healthcare. In January, they ceased the distribution of the Porta-Lung, which is powered by a negative pressure ventilator, e.g., the NEV-100, a Respironics product. The company sent letters of notification to all of its clients and durable medical equipment companies about the stoppage of their distribution of the Porta-Lung, adding that it could be purchased directly from Porta-Lung, Inc. The memo continues, “Depending on customer demand, inventory levels and parts accessibility, Respironics will continue to provide support for both the NEV-100 and the Porta-Lung through December 31, 2010.”

**2014**

Fortunately, to PHI’s knowledge, every individual to this day has had their iron lung serviced. This includes those who accepted the iron lung as a gift with the idea they would assume responsibility for repair.

Unfortunately, individuals who use the NEV-100 to power the Porta-Lung (the device they switched to when the iron lung was “iffy’) are searching for a replacement for the NEV-100 and the Porta-Lung. Respironics Colorado is reasonably sure that they have stockpiled parts to meet the needs of their NEV-100 and Porta-Lung customers.

As an addendum, the Respironics Colorado clients who use the PLV-100 and PLV-102, were notified in November 2009 that these ventilators would no longer be serviced after December 31, 2014.

PHI’s affiliate International Ventilator Users Network (IVUN) organized a series of conference calls, funded by the March of Dimes, in late 2012 and in 2013 explaining the options that individuals should explore to find replacement equipment. The PowerPoint slides and summaries of these calls are available at www.ventusers.org/edu/confcalls.html#pas.

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**Are there more iron lungs in the USA?**

To PHI, the number that is the most important is the number of people who use them. Next in importance is the ability to maintain them for their lifetime.

What is the total number of iron lungs in the USA today? No one knows for certain, although someone on Wikipedia asserts that there are 19 in Houston, Texas. That number cannot be confirmed by post-polio experts in Houston. One could speculate that this is the number rumored to be in the warehouse collected for back-ups and spare parts.

Some are in museums. Some may still be in hospital basements. Some may be in homes, still in use and not part of the March of Dimes/LIFECARE/Respironics story told here.

If you personally know of an iron lung in the United States, let PHI know so that it can be recorded on PHI’s website. Reporters, who often ask that question, will be glad to know the answer.
Response from Rhoda Olkin, PhD:

It is good to get feedback about a previous column. I am sorry my answer seemed too superficial. I can assure you I do understand the psycho-emotional turmoil that accompanies decreases in independence, as I too age with polio and find my abilities declining and my need for assistance increasing.

Let me address the two key aspects of your comments. The first aspect is about what you call “loss of independence.” Why put this in quotes? Because I want to reframe it. Having someone help you with tasks or even doing them for you is not the same thing as loss of independence. I have someone who does my laundry, changes the sheets, goes grocery shopping, cleans, runs errands, changes light bulbs and scoops up the dead mice my cats bring me as gifts, but I still consider myself independent. That’s because I ask her to do those things, and because doing or not doing these tasks myself in no way defines who I am. Independence is not an either/or – either you have independence or you don’t – but a matter of degrees of independence.

As I notice changes in my functioning, I have to make adjustments. For example, I use a wheelchair more in the house than I used to, and walking the few steps from stove to sink with a pot full of boiling water and noodles became scary. So now I have a microwave container for making noodles that allows me to make them myself. Or sometimes I ask my assistant to make a big pot of noodles at the beginning of the week. But neither the change in how I do things nor the assistance in making noodles affects the essence of me: I am not defined by the noodles I make! But let’s think of a harder example: At one point I had to give up using woodworking tools, hence letting go of a major hobby of mine. Of course this was a harder adjustment than the noodle-making problem. I had to find different hobbies, and truthfully, the new hobbies were not as satisfying as woodworking, so this change required more personal readjustment than I would have wanted. Yes, I was sad, but not depressed.

Which brings me to the second point, about depression, and your assumptions: (a) that depression will accompany changes in independence, and (b) that polio survivors have a right to be depressed. I take issue with both of these points. And I say that as someone who has had more than my share of depression in my life. Depression is not a necessary or even usual response to changes in functioning. It should not be expected, it should not be thought of as typical, and it should be aggressively treated. Generally it is not the decrement in functioning per se that is the root of any depression, but the loss of socialization and activities that lead to depressed mood.

Longevity is most associated with continued socialization, so work on that aspect of life. And if living alone, I recommend cats – they don’t need walking, there are automatic feeders and litter boxes and they cuddle!
QUESTION: At a recent meeting, someone found it fun to mock me as she spoke. My body is quite misshapen and the brace makes me appear to look stiff and odd. She focused on me in a friendly, humorous way as if seeking my approval for doing her performance so well. Earlier, I saw another member go through a similar act mocking a woman who is not disabled, but does have a unique way of speaking. There will be more meetings and I haven’t decided the best way to handle this. How would you suggest I respond?

Response from Stephanie T. Machell, PsyD:

Even children know that mocking others in this way is unacceptable. Though some people have conditions that prevent them from understanding how their behavior affects others it seems unlikely there would be two people in the group with such conditions. More likely the mockers think they are funny. But their behavior makes them bullies. And bullies thrive on reactions – the group’s as well as the target’s.

If the group enjoys the performance or is fearful of confronting the bully, and/or the target has an interesting reaction, the mocking will continue. You don’t indicate how the rest of the group or the other woman who was mocked reacted. But because two members of the group mocked two other members, and because the member who mocked you seemed to think you should have enjoyed her performance, it sounds like mocking others is part of the group’s “culture” and acceptable for at least these two members.

Depending on your personal style there are many ways of dealing with the situation. If you are comfortable with confrontation you can bring the issue up in the group. Be prepared that if this really is part of the group’s culture, the members may support the mockers, and that if they do, you may be scapegoated in some way. If not, the group may be glad you spoke up!

You can wait for a repeat performance. When the mocker looks for a reaction, you can say something. For example, “I never cared for that sort of humor.” Or, “Was that supposed to be me?” Or, “I wonder why you would do that?” Or, “Imitation is the sincerest form of flattery.” Or, “Isn’t that interesting? Can you do Cagney?” Or, as Miss Manners used to recommend, just look at the person without reacting.

Or you could say, “Good thing this isn’t a workplace. You could be fired for doing that!” Remember, if it is a workplace or somewhere else where rules exist about bullying you can report the mocker to HR or whoever else enforces the rules. Or if this is a group you can leave, you could decide you don’t want to be part of a group that has this culture.

Is the other woman who was mocked someone you feel comfortable speaking with? Two people confronting a bully – or a culture of bullying – may be more effective.

Whatever you decide to do, the most important thing is to remain calm and non-defensive. The less reactive you are, the less interesting you are as a target, and the less likely it is that the bully can interpret your response as defensive or hurt so the show can go on.

Dr. Stephanie T. Machell is a psychologist in independent practice in the Greater Boston area and consultant to the International Rehabilitation Center for Polio, Spaulding-Framingham Outpatient Center, Framingham, Massachusetts.

Her father was a polio survivor.
**Ask Dr. Maynard**

*Frederick M. Maynard, MD*

**Send your questions for Dr. Maynard to info@post-polio.org.**

**See other questions at www.post-polio.org/edu/askdrmay.html.**

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**Question:** I am 66, and I had polio at age 3. My muscles are feeling weak, so if you know what I can do about it I would be grateful. I am depressed about this.

**Answer:** Your concerns about muscle weakening along with muscle and joint pains are the classic post-polio syndrome problem. Try to be thankful if it has not become a big concern until your mid-60s, because it can begin and limit many polio survivors in their 40s.

What you can do about your problem depends a lot on what the primary causative factors for the weakening are, and you will have to take a major role in figuring this out, ideally with the help of your physicians and therapists.

First, one needs to fully look into your general health: thyroid disease, anemia. Vitamin D and other deficiency syndromes, heart and lung disease, depression, sleep disturbances, obesity, etc.

Second, is your weakening a result of gradually doing less and less because when you try to do more it hurts? This is the “vicious cycle” of pain/rest/weakening/more pain with activity/less activity/weakening/fatigue. Options for breaking up this cycle often take analysis by rehabilitation professionals to decide where to start interventions.

Treating the pain and trying to focus on feasible exercise for strengthening muscles, where possible, are one part of the solution. Another part is often doing activities differently, including walking with braces or canes. Water exercises are often a great option for stretching, strengthening and conditioning. Complementary and alternative medicine methods are helpful for controlling pain. Treating any sleep disturbance is very important, and nutrition must be considered.

In other words, management must be comprehensive with the goal of making you sufficiently comfortable and functional to continue to live a satisfying life, even if that means giving up some things and doing some things differently. There are a lot of resources that can help with these challenges.

I hope these general thoughts help you take charge and begin putting together a plan to help yourself by improving or dealing with your weakening and its consequences.

**Question:** I have post-polio syndrome, and I have also been diagnosed with a viral infection. Will the viral infection take longer to clear up since I have post-polio syndrome?

**Answer:** Recovery time after viral infections in polio survivors has not been studied. There is no reason to expect that the basic healing mechanisms of the body are altered as a direct result of previous remote poliomyelitis infection.

Nevertheless, what has been observed is that the time it takes for polio survivors to return to their normal activity levels as a result of an infection that caused weakness and fatigue is often longer. This is true after any severe infection-related illness, viral or otherwise, as well as other severe illness related to a heart problem, intestinal problem, trauma, surgery, etc.

The common issue is if the illness is severe enough to result in a major limitation and a decrease in a person’s usual activity level. The reduction in activity level leads to underuse muscle weakness faster among most paralytic polio survivors. After the primary illness-related, activity-limiting symptoms are resolved, recovery of their usual muscle strength will take longer.
Some people have estimated that it take polio survivors up to 12 times longer to recover from the effects of bed rest.
See www.post-polio.org/edu/phnpphnews/2012-2.html#liv

In summary, your recovery time from a viral illness will depend on how severe the infection is relative to limiting your activity, how long the limitations persist, and the severity and extent of polio involvement of your muscles.

**Question:** Have any studies been done to determine if polio affects sexual functioning?

**Answer:** I am unaware of any medical studies of sexual function in polio survivors. Conventional medical opinion is that polio did not affect sexual functioning of survivors, and the history of normal potency in men who have had polio and fertility among women polio survivors would support this opinion as accurate. Let me know if you have any specific concerns about this broad topic.

**Question:** I am a 61-year-old female who has recently been diagnosed with post-polio syndrome. I am looking for the latest research on improving muscle function in the affected limb. Are there new medicines that can improve muscle functioning?

**Answer:** Research studies have demonstrated that muscle strength and endurance can be improved among polio survivors, even those diagnosed with PPS, through individually designed exercise programs that are monitored and advanced slowly over three to six months. The major challenge is to find a personally optimal intensity of resistance and of duration to achieve desired results (a goal) without any negative consequences (side effects such as pain or activity-limiting fatigue).

There are no medicines that research has clearly shown to be effective for specifically improving muscle functioning of post-polio survivors. Clinical experience suggests that medicines to control pain that interfere with activity or exercise may help restore or improve lost muscle function. Taking medicines to control or cure other general health problems can also be important for permitting improvements in muscle function by promoting participation in exercise and/or activity. However, all medicines must be monitored for possible negative side effects.

It is also important to remember that a healthy diet with sufficient protein, optimal fat and calories and generous vitamins and minerals is critical for optimal muscle functioning. Limiting high stress, having optimal sleep and achieving good emotional health are also all important for obtaining and maintaining limb muscle function through optimal activity and exercise.

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**Kenya Polio Survivors Embrace Yoga**

adapting yoga for people with disabilities, and fundraising for four months, I was ready to go to Kenya! I returned to Eshiakula in late 2013, having secured a building and enough funds to get started.

Located about seven miles from the town of Mumias, which is known for its sugar-cane processing plant, Eshiakula is several miles from any paved road, with only a few shops which residents refer to as “the shopping center.” This remote location is one of the reasons it was an ideal place for a health education center – there are no NGOs providing any services here, no health center, and apart from a school (which few can afford), there are not many educational opportunities.

Many of the 50 members at the Amani Center have survived polio. In a massive country-wide effort, polio vaccinations were given last fall, but in even the recent past, polio vaccines have been inaccessible due to finances and/or lack of knowledge. And once a person has contracted polio, they often lack the

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funds to get proper medical care. Most of the post-polio participants at the center are farmers, raising a few crops and maintaining a few animals on small plots of land; the money they make is not enough to provide daily food much less to seek out specialized medical care.

People in Eshiakula are turning to the Amani Educational Center to improve their health and well-being without having to pay large fees or travel great distances. The center offers health education workshops, yoga classes and general education such as an English course, computer literacy classes and guest speakers on subjects like agriculture and entrepreneurship.

The center is run by its own group members, with an elected chairperson and other officers attending to the daily operation of the center. Several members are currently training one-on-one with me in an internship program at the center; these women will offer yoga classes and other workshops at the center once I return to the United States.

Since participants cannot hope to run the center through their own meager finances, they are seeking ways to secure additional funds through grants, donations and income-generating activities. Members are currently planning to make and sell soap and are considering opening a greenhouse. They hope the funds raised will be enough to support the center, with maybe even a bit left over to support themselves. Their first plan is to create a larger space for the Amani Center; the one-room school/studio/office is full to capacity for many of our health seminars and we have had to turn people away from our yoga classes due to lack of space.

It will cost $4,000 to buy a large plot of land near the Eshiakula shopping center and build a suitable building. Amani Center members have already planned to keep costs low and community involvement high by building the structure themselves, even making the bricks by hand. Their excitement about the center is contagious!

It isn’t surprising that the community members are passionate about keeping the Amani Educational Center going strong: the members are feeling the benefits, especially from practicing yoga. Some polio survivors report improved flexibility, more strength or just “feeling better” overall.

Rukia, a 29-year-old woman who has use of only one leg, says she can travel further distances because of practicing yoga. Nicodemous, in his 40s and having lost one leg to polio, is able to dig in his fields with less pain. He says, “I used to dig a small portion before yoga. But now, I can dig even a big portion without feeling chest pain ... because of yoga.” He looks earnestly at me and says, “Let yoga continue!”

Alicia Helion grew up on a farm in North Dakota. She earned a bachelor’s degree in Psychology from North Dakota State University, master’s degree from Brown University and a PhD from the University of Wisconsin in Milwaukee where she specialized in Health/Social Psychology. Her focus is on how to effectively provide health information across cultures. She was an Associate Professor of Psychology at Lakeland College, Sheboygan, Wisconsin, until 2013, when she chose to open the Amani Educational Center.

To learn more about the Amani Centre, check out the Facebook page at www.facebook.com/ AmaniEducationalCenter or send an email to AmaniCenterKenya@gmail.com.
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