WE’RE STILL HERE! 2018 Essay Contest

October 7-13 marked PHI’s 12th annual WE’RE STILL HERE! campaign, with the goal of increasing awareness of the fact that while polio may be nearing eradication, there remain millions of polio survivors across the globe. Survivors who, given the proper support and assistance, continue to thrive and live accomplished and fulfilling lives. PHI’s annual campaign seeks not only to let the public know of these accomplishments, but also to make them aware of polio survivors’ unique health needs and challenges.

This year’s campaign encouraged survivors to write a short essay and help show others who or what has enabled them to thrive and show the world that THEY’RE STILL HERE, whether it be the support of family or friends, a piece of adaptive equipment such as a power chair or brace, modifications to their home, changes brought about legislation such as the ADA, or a local program that has allowed them to age in place. We wanted to hear how polio survivors have overcome the obstacles in their lives and gone on to age successfully with a disability.

CONTEST WINNER
“I’m Still Here”

Diana Sprague
Lakeland, Florida

In August 1952, at 11 months of age, I contracted poliomyelitis. My mother and I were hospitalized, and I spent my first birthday in the hospital. My family and sheer determination have allowed me to thrive and succeed. Family members said that my father was determined that my mother and I would walk again. Dad continued the physical therapy even though my mother and I would scream in pain. My older brother by five years became my champion. Bill pulled me around in his little red wagon and sled.

At age seven, I could no longer walk with aides, so surgery was done to lengthen my left leg. The surgery was done in early May 1959 and was experimental. All the ligaments and tendons in my left leg had to be stretched. While in the hospital, I decided that I wanted to be a nurse. After four months in late September, the cast was removed. My leg had atrophied and had no feeling. I was very disappointed when I found I could not walk and had to spend several more months in a wheelchair.

My father purchased a sidewalk bicycle for me to ride for therapy to strengthen my legs. It had solid rubber tires, no air. This was difficult to ride since we lived on a farm with no sidewalks, just grass and white rock. The therapy continued with the bicycle until I turned 13 and was discharged as a polio patient. I received my first bicycle with air tires that year for Christmas. If someone told me that I could not do something, it made me more determined. My parents never treated me different than my siblings. I always found a way to accomplish tasks, though maybe not the traditional way. If there is a will, there is a way.

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My rehabilitation scholarship sponsor said that I could not be a nurse because I wouldn’t last ten years. They insisted that I be a laboratory or x-ray technician. I declined the scholarship and continued my dream of being a nurse. I worked for 30 years as a nurse. There are still challenges on my journey of life, but I will face them with support of my family and determination to keep going. My nursing education is a valuable tool for me and others. Yes! We Are Still Here!

FIRST RUNNER-UP
“I’m Still Here”
Mary Herness
Whitehall, Wisconsin

The year was 1951, late August, when the polio epidemic was rampant across the country. I was a 13-year-old farm girl living near Pigeon Falls, Wisconsin, looking forward to being an eighth grader at our local school. When flu-like symptoms progressed to a frightening diagnosis of bulbar polio, my life changed drastically!

An ambulance rushed me from Eau Claire to Madison, Wisconsin, where a vacant iron lung waited. Thankfully, oxygen and intravenous feeding helped me survive without an iron lung. After months in hospitals undergoing therapy and making adaptations, I returned home and to school. Helpful people were key to my survival. My daily farmer parents were supportive, making countless sacrifices and helping keep my attitude optimistic about future plans. The teacher prepared the students for my return to school. Those schoolmates became “first responders” helping me. They carried my lunch tray, picked up dropped pencils and even hoisted me up from unexpected falls. Friends remained friendly with no fear of contracting polio from me. Relatives sent cards and gave encouragement. Our pastor changed the confirmation date so I could participate. Years later, my husband would be understanding of my physical limitations and assist in helping design our home to fit my needs.

The diagnosis of polio did not change me or my goals. My type-A personality helped, never doubting my goals to attend college, become a teacher and raise a family. The qualities of optimism, self-direction, commitment and the feeling that anything is possible prevailed. Although I was bitter at first about why I had polio, this changed later to openness without blame.

During my post-polio years, I have altered several aspects of my life. Routine chiropractor visits, comforting therapeutic massages and regular appointments with a family practitioner are vital to my wellbeing. I’ve had a hip replacement, prolapsed bladder repair and cataract surgery. As a direct result of the bulbar polio, my swallowing and choking problems must be dealt with daily. Tough meats, seedy fruits, vegetables, nuts and spicy or overly sweet foods all cause bouts of choking. I eat slowly, chew foods thoroughly, and crush pills. Exercise for my heart problems are a daily requirement. Yes, they’re all unwelcome sacrifices, but I’m still here!

My rehabilitation scholarship sponsor said that I could not be a nurse because I wouldn’t last ten years. They insisted that I be a laboratory or x-ray technician. I declined the scholarship and continued my dream of being a nurse. I worked for 30 years as a nurse. There are still challenges on my journey of life, but I will face them with support of my family and determination to keep going. My nursing education is a valuable tool for me and others. Yes! We Are Still Here!

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editor@post-polio.org
Designer: Sheryl R. Rudy
webmaster@post-polio.org

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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.

How to contact PHI
Executive Director
Brian Tiburzi, MA
director@post-polio.org

4207 Lindell Blvd., #110
Saint Louis, MO 63108-2930 USA
Phone: 314-534-0475
Fax: 314-534-5070
info@post-polio.org
www.post-polio.org
www.polioplace.org

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Away temporarily?
Send us your second address and dates you will be there and we’ll do our best to send your newsletter.
Now that I am 80 years old, I continually have to adapt. Currently, I am a widow, mother of three sons, grandmother of ten and a survivor of a serious heart attack. Why am I still here? I remain committed to goals in my work with genealogy, with unending desire to keep learning and with a love for family and friends.

SECOND RUNNER-UP
“Leg Bone”

Rita A. McGovern
Lombard, Illinois

“Don’t forget your leg bone, Gramma!” I was visiting my son and his family, and my five-year old grandson came into the guestroom in the morning to wake me up to play. “But I have to get dressed,” I told him. “I’ll be downstairs as soon as I can.” That’s when he reminded me to put on my leg brace (my “leg bone” to him). He and his twin sister loved to take turns wearing it when I took it off for the night. They had to hop because they couldn’t bend their knee since it covered them from heel to hip. They thought it was a hoot!

When I was five years old, my mother asked me why I was walking funny. When my father came home from work, she asked me to walk for him. I went to bed that night, and the next morning when I awoke and put my feet on the floor, I collapsed to the ground. My right leg wasn’t working anymore. I was diagnosed with polio but didn’t know that at the time. All I knew was my mother was very angry with me because I couldn’t walk. I overheard her ask my aunt why this had to happen to her. I learned to hide my disability whenever possible and to excel in any activity that didn’t involve the use of my right leg (Honor Roll, Student Council, Class Officer, etc).

I was diagnosed with post-polio syndrome in 1981 and pictured my future in a wheelchair. But thanks to a wonderful orthopedic surgeon who has managed to keep me mobile by surgically reconstructing things inside my ankle and foot and a skilled orthotist who has fabricated various AFOs through the years to adapt to my changing outside limb, I am walking tall and proud.

Sixty-six years have gone by since the day I fell to the ground beside my bed, and next month I will be going to my twin grandkids’ sixteenth birthday party. They might not remember wearing my “leg bone,” but I certainly will. It was a life-changing moment for me because it gave me a reassuring perspective of myself. I am accepted and loved for who I am. I am a polio survivor and very grateful that I am still here.

THIRD RUNNER-UP
“Jonathan”

Corina Zalace
Niceville, Florida

Jonathan gives me freedom I never had before in my later life. I’ve suffered from polio since contracting it at age two in Indonesia. I was born into a Dutch family and lived there while my dad was working for the Dutch East Indies Trading Company. Polio broke out in 1950, and I was one of two children who got it. The other child died. After the doctor did a spinal tap and diagnosed me with polio, I was sent home for my mother to care for me, since there were no facilities in Indonesian hospitals to treat this disease or provide any aftercare. So, I was sent to a Dutch masseuse who worked on me with the wool packs, massages and electrical stimulation. Slowly I regained use of my left leg, but my right leg always remained mostly paralyzed. Somehow, I managed to limp badly along in my younger years, with the doctors believing that the more I used my right leg, the more function I would get back.

I had my first surgery at age five, and over the years I got worse with post polio syndrome. Using a right long leg brace and two Canadian crutches proved more difficult as time went by. After many more surgeries to correct my gait and straighten out my back (with a full C2-S1 fusion and 95 surgeries to date), I finally succumbed to a wheelchair. It brought me much freedom, but not for going places. I needed a special friend to give me the freedom I needed to be

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myself and allow me to do what I love most—travel. I needed to get out of my house and go places.
I searched for my friend, and he was there waiting for me. He gave me the freedom I so desperately needed, and he is faithfully there for me. He is reliable and never complains. What a friend. I love Jonathan, my wheelchair lift van.

As a kid, I took her commitment for granted, especially the chauffeuring until age 24, when I learned to drive.

Corrective surgery was performed in February of 1963, and for three months my mom drove daily from our house to the hospital bringing me a comic book and my math homework (that was the only way I was allowed to pass 5th grade). She drove 36 miles round trip on the only route available back then—the Pali Highway—a winding road which, of course, meant nothing to me as a ten-year-old. Only once, due to heavy rain, did she fail to visit.

In 2000, my husband and I visited “the islands.” We visited the places I lived, and we drove the same route my mom drove each day. It was only then that I fully comprehended the distance and driving conditions. Upon my return to the “mainland,” I went to Mom and delivered the biggest hug to say, “THANK YOU.” Tears were shed.

I’ve known enough people to know that not all moms make these kinds of sacrifices for their kids. Maybe it was because of her Missouri upbringing; maybe it was because she was a Marine Corps wife; maybe it was because she really, really loved me. NEVER in all our years together did she ever say, “Well, if it wasn’t for me, you wouldn’t be the success you are today.”

During her final two years of life, I was honored to be her caregiver. There I was with braces and crutches pushing her in a wheelchair, and never once did I regret the effort to do for her what she had done for me—we were a team! And “I’m Still Here” because of “Mom!”

Information about prior campaigns can be found on Polio Place at www.polioplace.org/category/blog-tags/were-still-here.
At PHI, we often get calls and emails from polio survivors looking for resources in their community. Often, it’s for help in making home modifications or assistance with transportation. Two excellent places to start are a Center for Independent Living (CIL) or an Area Agency on Aging (AAA).

What are CILs?
The first Center for Independent Living was established in 1972 when Ed Roberts, a polio survivor, and other students with disabilities from the University of California at Berkeley demanded control over their lives and full access in their communities. When some people first hear the name, they mistakenly believe a Center for Independent Living is a type of residential facility. Rather, CILs are non-profit organizations which assists seniors and people with disabilities who want to increase personal freedom and live more independently. CILs are managed and staffed by people with disabilities, are located in the communities they serve, and assist people with all types of disabilities.

The foundation of CIL services is the peer relationship—people with disabilities assisting other people with disabilities as role models, mentors and partners. Each Center is unique because it offers services based upon the particular needs of its community. However, all CILs offer services broadly in the following core areas:

- Information and Referral
- Peer Support
- Individual and Community Advocacy
- Independent Living Skills Training

Currently, there are 340 Centers for independent living, with more than 224 satellite locations. A center’s service area may cover anywhere from a single county to a dozen in less populated areas. Today, 60% (1,911) of the US counties receive service from a CIL.

What can they do for me?
As noted above, available services vary from center to center, but in general CILs can assist with the following: locating accessible, affordable housing; providing peer counseling; providing benefits counseling; offering information on or supplying assistive devices such as raised toilet seats, shower benches, grab bars or ramps; finding accessible public transportation; or arranging for personal assistance services.

Where do I find the center that serves my area?
The Independent Living Research Utilization (ILRU) program has a clickable map online that can quickly locate the center nearest you. The listing for each CIL displays which specific counties each Center serves. You can find it at www.ilru.org/projects/cil-net/cil-center-and-association-directory.

What are AAAs?
Area Agencies on Aging, like CILs, trace their roots back to the early 1970s. Area Agencies on Aging were formally established in the 1973 Older Americans Act (OAA) as the “on-the-ground” organizations charged with helping vulnerable older adults (60+) live with independence and dignity in their homes and communities. You do not have to have a disability to be eligible for services provided by an AAA.

As of 2016, there were 622 AAAs serving older adults in virtually every community in the nation. Like CILs, AAAs are set up to meet the unique demands of their communities they serve and to provide programs that support the health and independence of older adults in those communities, which is why they are not all exactly alike.

What can they do for me?
AAAs are tasked with developing and delivering a range of long-term services and supports (LTSS). All AAAs offer services in five core areas:

- Elder Rights
- Caregivers
- Nutrition
- Health & Wellness
- Supportive Services

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Four nights and three days in the Rocky Mountains at the Rocky Mountain Village. Fifty campers—polio survivors, spouses and children. People from all around the United States. High energy, laughter, seeing old faces and making new friends, trying new things, learning about the world of polio and aging, time alone exploring the trails and paths of the camp or enjoying the quiet by the lake. Sharing and caring with and for each other. Thirty-eight events and hiking trails, fishing and swimming, and off-campus excursions.

Individual attention—massage therapy, physical therapy, zip line and climbing wall, bracing, recovering from falling, gait training, acupuncture, hearing screenings.

Group activities—Loving Movement of Your Hands, plant and tree walk, Drumming with Jonah Berger, Taiji and Qigong.

Lectures and discussions—the wisdom of aging, being prepared for life’s surprises, resources for the aging population, keeping your brain active, making end of life decisions, technology as assistive devices, medical marijuana, caregiving and caregivers, identity theft.

Evening entertainment—storytelling, singer and guitarist, movie.

The event is best described by those who were there:

I can’t thank you enough for the spectacular polio retreat! The whole retreat was phenomenal! I enjoyed everything. I’ll never forget it ... you are amazing to organize and run this together. I really appreciate all your hard work and efforts.

I had a marvelous time, and everything was so well done. You had great variety with the sessions and entertainment. (I wasn’t expecting evening entertainment too.) I learned a great deal, especially about specific areas of concern. The networking was invaluable as well. My vegetarian food was delicious and hearty.

I’d never had a massage, nor climbed a climbing wall (I use that term loosely in my case!) or experienced a zip line. I loved the pool with the spectacular views.

I heard some whining and complaining ... but for me, it was The Best. One evening, I watched the stars come out framed by the mountains while swimming and hot tubbing. I had the whole place to myself, too. I walked every trail and sat in the fishing gazebo early one morning watching the trout jump and cavort.

I’m setting up a slide show for my support group next week, also presenting all the materials from the retreat. The swag bag was a really nice touch. I’m still flying high from the whole thing and already emailing with some people.

– Cathleen Casey
Sue Brandon, in response

As with many things, giving is the joy of life. It is attendees such as you that make all the work so worthwhile. We love seeing light bulbs go off when someone learns or connects information that makes a difference to them. My heart smiled as I walked around the main lodge and saw groups of people chatting and laughing. One of our main goals was to have people connect.

You are such an adventuresome woman grabbing hold of life and trying new things. Kudos! May you continue to cherish new adventures and stay well.

I hope that your goal to re-energize the Portland support group and possibly bring a few folks to the 2020 Retreat comes to fruition. You definitely have the spirit and drive to make that happen. If we can be of any help, please let us know.

Comments from other attendees:

Far surpassed my expectations. I have knowledge to help me deal and to share with my doctor. – B.T.

Want to come back next time. This is the first time I have been with other polio survivors and it was a wonderful experience!!! – L.D.

I am so grateful we (my spouse and I) decided to come on the way from Florida to a family reunion in Estes Park this year with my siblings and spouses. Really learned a lot! And thank you for letting Stan and I volunteer. I loved it! – C.Z.

Special thanks to Marny, Margaret and Sue for all your help and extra kindness. From Rx to popcorn, wine and cheese. These thoughtful things were the icing on a very fine cake. – L.J.

And a thank you for the Wheat Ridge Rotary who provided grants for polio survivors to attend: Many thanks for your generous scholarship towards our attendance at the recent post-polio retreat. It was my retirement gift to myself, which made by your scholarship even more affordable.

The retreat was a wonderful way to jump start my new adventure or, shall we say, journey. The people, seminars and setting were incredible. I truly appreciated your contribution and wish your future efforts are as appreciated as this one. – J.D. and A.M.H.

Look for the next camping experience in 2020!
**PHI:** Recently a woman contacted PHI to ask for advice about how to communicate with her spouse that their current living situation was no longer suitable for her. She felt that she was forcing him into assisted living—something he doesn't want—and was experiencing guilt about this. We asked our regular columnist, Dr. Machell, what advice she would offer.

**Response from Stephanie T. Machell, PsyD:**

I commend you for recognizing your limitations as a caregiver. As you have experienced, caregiving takes a toll on the caregiver. Rather than feeling guilt over what you can’t do, think of how awful you (and your husband) would feel if you overextended yourself and became ill and/or resentful. Knowing your limits preserves your ability to provide the most important thing a spouse can provide—your companionship and love.

It sounds like both of you feel forced into choosing assisted living. Have you explored other options? Because most people prefer to age in place, a range of services exist to facilitate this. Depending on your husband’s (and family’s) needs, there are programs that provide everything from personal care to nursing care to various therapies.

If home renovations are needed there are even some programs that will help defray the costs and/or provide low or no interest loans. And even if renovations are needed, aging in place may be less expensive than assisted living. Insurance (including Medicaid) may cover some or all of the cost. Your local council on aging or other elder service program can provide information and help you consider the options.

If assisted living is the best (or only) option in spite of your husband’s objections, or your husband is also against having home care provided by someone other than you, communicating honestly about how best to meet your needs and his is usually the best approach. Be clear but empathic, provide concrete examples of needs he has that are difficult for you to meet, and emphasize the benefits of these being provided by someone more skilled than you, including allowing you to enjoy each other’s company and preserving your health. Be prepared that no matter how diplomatic you are he may be angry and that you may feel even guiltier than you do right now.

If having this conversation feels too overwhelming, you might enlist others to help. Choose those whose opinion he (and you) respect. If you have friends who have made this transition (especially if they are happy with their choice) you might encourage him to speak with them.

No matter where it’s provided, your husband’s need for increased levels of care likely brings up many feelings about aging with a disability, including grief and fears about loss of independence. It might even trigger memories of his polio experiences. It will help if he feels empowered to make as many choices about this as possible. And if he (or you) feel overwhelmed by the process or feelings it evokes, support groups and/or psychotherapy can help.

**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.
QUESTION: I had bulbar polio when I was three years old. My parents told me I spent time in an iron lung. I am now 70 years old. I don’t currently have any breathing problems. But because of my history, I know it’s a possibility in the future. I know PHI has a whole website dedicated to breathing problems, but I just can’t bring myself to research the issue. I don’t even like seeing an article on the topic in my inbox or when searching for post-polio information. I would rather not deal with the stress and worry until it’s bad enough to have to see the doctor. Am I being foolish?

Response from Rhoda Olkin, PhD:
No, you are not being foolish. In fact, you are being wise. I suspect that if you are not having breathing problems by age 70 there is a chance you won’t ever have them, barring another medical condition (and absence of history of smoking).

I am chuckling a bit, though, remembering how I “developed” breathing difficulties every time I read an article about breathing problems! So, I stopped reading the articles about breathing and swallowing difficulties.

Avoidance is a problem when it prevents us from taking necessary actions. Researching something you actually have could be important information seeking. Researching something there is a slight chance you might get in the future doesn’t make sense unless (a) there is a high risk of the problem, and (b) there are preventive measures you should be taking now.

Ask yourself if there is anything you might do differently if you knew you would have some breathing difficulties in the future.

When we have the flu, we don’t tend to research the flu. Instead we focus on rest and getting better. But okay, flu passes. What about something more permanent or serious, like emphysema? Personally, I would research treatment options, including both Western and Eastern medicine (often called complementary and alternative medicine) approaches. But this is after I got the diagnosis, not before.

Life’s too short to spend time reading things that make us more anxious when there is no compelling reason to do so. Go sit under a tree and read for fun, keep on breathing, and may you live happily to a ripe old age.

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.
Question: I had polio at age 5 and am now 76. I have weakness in all four limbs. My legs have been weak for a long time while my arms and shoulders started getting weaker 2-3 years ago. I cannot lift my left arm past my shoulder. My right arm is better but not good.

The PT here at the retirement home we are in suggests that I do strengthening exercises for my shoulders and scapula. I wonder about that since all four limbs are weak. I have a walker and a power wheelchair, though they urge me to use the walker rather than the wheelchair. I wonder if that's the best advice.

Answer: It is never easy to know if later-life new weakness in a polio survivor is from PPS or from other common age-related problems such as shoulder tendonitis/bursitis that leads to restricted shoulder movement and weakness. Since your arm/upper limb weakness is quite recent, I would recommend you be evaluated for physical therapy (or other) treatments for the shoulder to restore good passive movement and for strengthening exercises. If guidelines for gentle (non-vigorous) strengthening exercises are followed, there is no risk of damage and some benefit is likely. You may wish to read and show your therapist the Position Statement by PHI on Exercise for Polio Survivors (www.post-polio.org/edu/pphnews/pph19-2a.html).

Regarding the issue of using your walker versus your power wheelchair for daily mobility, this strictly depends on how far and how often you walk, as well as how effortful and how safe it is for you to walk with the walker. Certainly, it benefits general health to continue to do at least some upright weight-bearing walking for as long as possible, assuming it can be done without undue risk of falling or of straining shoulders/arms/hands.

An excellent resource for you to read about preserving strength and function in the shoulders is a 30-page booklet titled “SOS—Save Our Shoulders: A Guide for Polio Survivors” authored by Kuehl, Costello and Wechsler and which is available on Polio Place (www.polioplace.org/sites/default/files/files/Save-Our-Shoulders.pdf).

Question: I am now age 89 and am plagued by extreme tiredness with sleepiness/drowsiness and terrible balance issues. My history includes a triple arthrodesis of the right ankle with a tendon transfer. My polio in 1947 was treated with the Sister Kenny Treatment—can still smell the hot, steamy wool blankets.

I try to do some mostly stretching exercises and wonder if I should challenge myself with more vigorous ones. I weigh 160 lbs. and have shrunk to 5’9” from 6’2”. I have had a lumbar laminectomy, discectomy, plus a cervical fusion. I just want to prevent further deterioration. Or do I accept these symptoms?

Answer: I am concerned to hear about your “extreme tiredness with sleepiness/drowsiness” symptoms because they are suggestive of pulmonary and/or cardiac function decline. Nocturnal breathing disorders (sleep apneas and/or nocturnal hypoventilation) are common in older polio survivors and perhaps you should seek evaluation of your breathing capacities. Another diagnostic possibility could be slowly developing heart failure that can lead to declining blood flow to the brain and associated drowsiness/tiredness. This is a common occurrence among “very old seniors (>age 85),” particularly those with any history of hypertension, diabetes or cardiovascular disease.
I would encourage you to seek a good comprehensive medical evaluation at a good geriatric clinic. If you still reside in southeast Michigan, the Turner Geriatric Clinic is a good option. After such an evaluation, a physician could give you individual advice on how much and what types of exercise to pursue. Otherwise, all I can suggest is to remain as active as you can and to do it safely.

The fact that you are balance-challenged is not surprising and probably can’t be improved much. Making good adaptations for your balance impairments through optimal choices of “adaptive equipment” and type of activities to prioritize is your personal challenge. This is inevitably based on your individual preferences and priorities in life as well as your current safe functional capacities.

CILs vs. AAAs—What Are They and How Can They Help Me?
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Supportive services can include in-home services, homemaker and chore services, transportation and legal services. Some AAAs even provide for minor home repairs or small modifications to make your home more accessible. Nutritional programs often provide home-delivered meals to those in need. Most AAAs also provide insurance counseling and case management. AAAs can help consumers transition from hospital back to their home, as well.

Programs are designed to help those with the most economic or social need, but they are not means-tested. Anyone 60 or older can access services provided under the OAA.

Where do I locate my Area Agency on Aging?
All AAAs have local hotlines or websites to provide consumers with information and assistance, so if you know the name of your local AAA, start there. Alternatively, you can find a AAA by ZIP code via the Eldercare Locator website (www.eldercare.gov) or you can speak with an information specialist by calling 800-677-1116.

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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