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## Moving Forward: Adapting to the Ottobock C-Brace

Yvonne Collery



Linda, 1960

Both my mother and Linda contracted polio during the 1955 epidemic. Linda and her family lived in the apartment below us, and she and I grew up together. Linda was just 11 weeks old when she contracted polio and was left with paralysis in her right leg. Since learning to walk, she has relied on a rigid KAFO brace for mobility.

Last spring, Linda needed repairs for her KAFO brace, only to discover that her long-time orthotist had closed up shop. Searching online for alternatives, she came across the Ottobock C-Brace and was immediately intrigued. She reached out to the Manhattan branch of Hanger Clinic, listed as a supplier, and was connected with Brian Leone, an orthotist experienced in computerized braces. And so, her long journey began.

### What is a C-Brace?

The process of acquiring a computerized brace (in Linda's case, the Ottobock C-Brace) is long and arduous. Linda had her initial consultation appointment in June 2024, and after several months she received her finished C-Brace and was able to begin using it in physical therapy in November 2024.

Now, you might be asking how the C-Brace differs from an ordinary KAFO. A C-Brace is a computerized brace. It is not a robotic brace—meaning there is no motor in the knee joint, so it won't do the work for you. Each brace is custom fabricated from carbon fiber by a technician and includes components

for the thigh, lower leg, ankle and foot. A computerized component designed by Ottobock is then integrated into the brace by a technician.

What makes the C-Brace revolutionary is its ability to enable walking with knee flexion. This enables users to walk with a centered, upright posture and a more natural gait. The computer system continuously monitors the user's gait through three sensors, which react thousands of times per second to the user's movement. Based on this input, the system regulates hydraulic resistance, controlling the flexion and extension of the knee joint with each step.

Another extraordinary function of the C-Brace is its ability to enable users to perform Dynamic Movement Patterns. Simply put, these refer to any movement beyond straight, forward perambulation (forward walking). This includes stepping backward, moving sideways, climbing stairs with alternating steps, even riding a bicycle, among other multidirectional activities.

Ottobock offers an app called *The Cockpit*, which allows users to switch between different functions. Many C-Brace users may even be able to walk without a cane, freeing both hands for various activities while standing or walking.

Leone pointed out that individuals who used a cane or walker prior to using the C-Brace may still require the assistive device, but the improvements in walking with a more upright, less compensatory

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Brian Leone, CPO, makes adjustments to Linda's C-Brace.

gait pattern will reduce stress on other joints and muscles in the rest of the body, which makes pursuing a C-Brace well worth it for those who are good candidates.

Leone also stated that the post-polio population faces the greatest challenges in using the C-Brace's Dynamic Movement functions. This is due to the severity of weakness in the affected limb, hips and trunk.

Additionally, the vast majority of the post-polio population in the United States is now over the age of 65 and has relied on rigid KAFO braces for many decades. While age-related limitations exist in any population, it is essential to evaluate each potential C-Brace user on an individual basis.

Now for the good news: You have the opportunity to try out the C-Brace and decide for yourself. Your orthotist either has access to or can obtain a generally sized sample C-Brace from Ottobock.

During your appointment, your orthotist will assess you, provide some initial training, and allow you to walk with the C-Brace in a supported and controlled environment. If you are determined to be a good candidate, your journey with the C-Brace can begin.

### Next Steps

Now that you and your orthotist have decided to move forward with this process, your next step is to see a physiatrist. Your physiatrist will conduct a thorough physical exam, review your medical history, and determine whether you meet the criteria for successfully using a C-Brace. If approved, you will begin the lengthy acquisition process.

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Now comes the paperwork. Your orthotist will need to complete and submit numerous forms to your insurance company. This process requires hours of detailed work on the part of the orthotist.

## The Insurance Process

As the majority of the U.S. post-polio population is now of Medicare age, we will focus on Medicare guidelines here. In 2024, Medicare officially approved the Ottobock C-Brace as medically necessary for individuals meeting a specific criteria. To qualify, a person must have a history of prior brace use, and the need for a computerized brace must be medically justified for their specific condition. Trunk stability and sufficient strength to operate the C-Brace must also be demonstrated.

Because Medicare offers a variety of plans, you will need to check with your specific plan to determine coverage. Approval or denial can vary significantly from person to person. Leone emphasized that simply wanting to walk upright, navigate uneven terrain, or wanting to go cycling or dancing are not considered valid justifications for Medicare coverage. The C-Brace is a costly device, ranging from \$75,000 to \$85,000.

In requesting coverage for Linda, Leone wrote that the C-Brace was deemed necessary because “Linda’s long use of a rigid KAFO brace was causing old/current compensatory gait habits to negatively affect other joints of the body. By having her use a C Brace, we [could] make her a more functional community ambulator.” Additionally, Brian highlighted a broader health benefit, “With an improved gait and reduced pain, Linda will engage in more life-enhancing physical activity, benefiting her cardiovascular health and ultimately prolonging her life.”

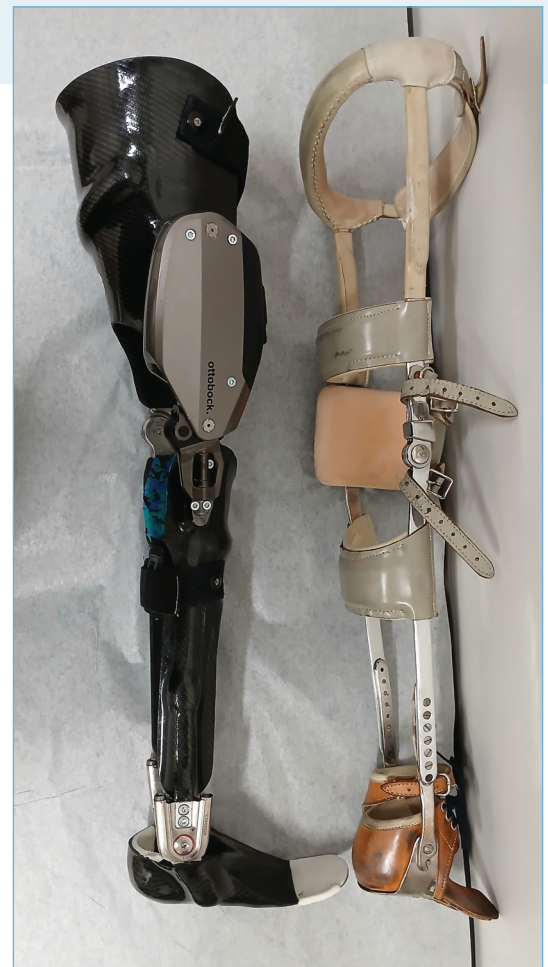
## Not a Brace for Everyone

Leone emphasized, “The C Brace is not for everyone, but for those who are the right candidate and meet the right criteria, the outcome can be significant, and in some cases, life changing.”

When assessing a candidate, Leone looks for several additional key factors after testing for core and hip strength. He explains, “The person must be accepting of new technology, and if not a fluent tech user, they must be willing to learn. They should not be afraid of significant change, must be highly motivated, and need to be mentally flexible. Most importantly, they must be willing to put in lots and lots of hard work.” Linda, he noted, proved to be an excellent candidate.

## Looking Ahead: Part Two ... And Now the Work Begins!

After a long and arduous process, Linda finally received her approval letter and took the next steps toward getting her C-Brace. In Part Two, we’ll follow Linda’s journey as she begins the challenging yet rewarding phase of using and adapting to her new brace. From the detailed fitting process to the intensive physical therapy sessions that pushed her beyond her comfort zone, we’ll look at what it took to fully integrate this life-changing device into her daily life. ■



*Ottobock C-Brace (left) next to a traditional brace.*

# The Threat to Section 504: What's at Stake for the Disability Community

For nearly 50 years, Section 504 of the Rehabilitation Act has been a cornerstone of disability rights in the United States. This landmark legislation, enacted in 1973, prohibits discrimination against individuals with disabilities in programs and activities that receive federal funding. It laid the foundation for future protections, including the Americans with Disabilities Act (ADA). However, recent legal and political challenges have placed Section 504 under threat, raising concerns about the future of accessibility and inclusion for millions of Americans.

## BACKGROUND

Seventeen Republican-led states, spearheaded by Texas, have recently filed a lawsuit challenging a new federal rule that classifies gender dysphoria as a disability under Section 504 of the Rehabilitation Act. This rule, introduced by the Biden administration, requires federally funded entities to provide accommodations for individuals with gender dysphoria, extending protections similar to those already granted to people with other disabilities. The states argue that this regulation imposes undue financial and administrative burdens and coerces them into compliance by threatening the loss of federal funding. They also contend that the federal government has overstepped its authority by broadening the definition of disability.

Disability rights advocates and families of individuals with disabilities have expressed concern that the lawsuit could have far-reaching consequences. Although the attorneys general involved insist their challenge is limited to the gender dysphoria rule, some fear that language within the lawsuit could set a precedent for undermining Section 504 as a whole. If the courts rule broadly against the federal government's authority to interpret and enforce disability protections, it could weaken longstanding rights for individuals with disabilities, potentially restricting access to essential accommodations and services.

As this legal battle unfolds, its implications extend beyond the issue of gender dysphoria. A ruling that limits the en-

forcement of Section 504 or narrows the definition of disability could impact millions of Americans who rely on these protections. Advocates and policymakers continue to closely monitor the case, emphasizing the need to preserve the hard-won rights established over the past five decades.

## IMPACT ON THE DISABILITY COMMUNITY

If the lawsuit against Section 504 results in a ruling that weakens federal enforcement or narrows the definition of disability, it could have serious consequences for individuals living with a disability. Here are some specific ways this could impact the disability community:

**Healthcare Access:** If hospitals and clinics receiving federal funding are no longer required to accommodate certain disabilities under Section 504, patients who use wheelchairs or other assistive devices might face increased barriers to receiving necessary care. A hospital could argue that it is not obligated to provide specialized equipment or trained staff, making emergency and routine medical care riskier for individuals with complex medical needs.

**Education:** Students with disabilities currently rely on Section 504 to ensure schools provide accommodations such as individualized learning plans, assistive technology and personal aides. If the law is weakened, schools could reduce or eliminate these supports, making it harder for students with disabilities to receive a quality education in an inclusive setting.



*Judy Heumann speaking in favor of enacting Section 504 regulations prior to the 1977 sit-in protests.*

Credit: Hollynn D'Lil

**Employment Protections:** Section 504 ensures that employers receiving federal funding, such as government agencies and contractors, provide reasonable accommodations for employees with disabilities. A weaker Section 504 could allow employers to deny workplace adjustments like remote work options, flexible hours or accessibility modifications, forcing individuals with disabilities out of the workforce.

**Public Accommodations and Transportation:** Public transportation services that receive federal funding, such as buses and trains, must be accessible under Section 504. If these requirements are loosened, individuals who use wheelchairs, ventilators or other assistive devices could face increased barriers to mobility, making it harder to travel to work, school or medical appointments.

**Home and Community-Based Services:** Many people with disabilities rely on Medicaid-funded home care services to live independently rather than in institutional settings. If Section 504's enforcement weakens, states might reduce these programs, forcing individuals into nursing homes or hospitals against their wishes, severely impacting their quality of life.

**Legal Precedent for Future Rollbacks:** A broad ruling against Section 504 could set a precedent for challenging other disability rights laws, including the Americans with Disabilities Act (ADA). This could lead to further restrictions on accessibility requirements, workplace protections, and legal recourse for discrimination.

In summary, the potential weakening of Section 504 threatens the ability of individuals with disabilities to access healthcare, education, employment, transportation and independent living. The disability rights movement, which included prominent polio survivors such as Judy Heumann, Ed Roberts and Justin Dart, fought tirelessly for these protections. Advocates now worry that this lawsuit could undo decades of progress.

## HOW WE CAN TAKE ACTION

It is crucial for those living with a disability and their allies to stay informed and engaged. Here are a few ways to advocate for the protection of Section 504:

**Raise Awareness:** Share information about these threats with your community and legislators.

**Contact Elected Officials:** Urge your representatives to oppose efforts that would weaken Section 504 and other disability rights laws. If you live in one of the 17 states filing the lawsuit, contact your state's Attorney General.

**Join Advocacy Groups:** Organizations such as the Disability Rights Education & Defense Fund (DREDF) and the American Association of People with Disabilities (AAPD) are actively working to defend these protections.

**Tell Your Story:** Personal experiences can be powerful in illustrating the importance of Section 504. Whether through social media, testimony or community forums, sharing how these laws impact your life can influence policy decisions.

The challenges facing Section 504 are real and significant, but the disability community has a long history of resilience and advocacy. Protecting this foundational law is essential to ensuring equal opportunities and rights for all individuals with disabilities. By staying informed, speaking out, and taking collective action, we can work to safeguard the hard-won protections that so many depend on. ■



# The Impact of Aging on Driving and Resources Available to Assist with Planning

Peggy P. Barco, OTD, OTR/L, CDRS, FAOTA, Professor, Program in Occupational Therapy, Washington University School of Medicine in St. Louis

Advancements in medical science have significantly improved the diagnosis and treatment of various health conditions, enabling many of us to live longer, healthier lives. As we age, maintaining our quality of life becomes increasingly important, and for many aging adults, the ability to drive plays a critical role in preserving independence. Driving allows individuals to stay connected with their communities, engage in meaningful activities, and access essential services.

However, the aging process brings unique challenges, including medical conditions that may impact driving ability. Vision impairments such as glaucoma, macular degeneration and cataracts can affect safety while driving in certain conditions. Neurological and physical conditions, including Parkinson's disease, dementia, diabetes, heart disease, arthritis and strokes, may influence cognitive and motor function related to driving. Additionally, medications, often taken in combinations, can cause side effects that may impact alertness and reaction time. These factors have the potential to compromise driving safety, not only for the individual but for others on the road as well.

Uncertainty about driving safety with various health conditions is a common concern individuals and families have. Not all health conditions impact driving safety and every individual's health course is very unique. The availability of resources to help guide decision making related to driving safety when faced with medical concerns and life transitions can be very helpful.

## STEPS TO ASSESS AND PLAN FOR DRIVING SAFETY

**Consult Your Physician:** Discuss how any medical conditions or medications may impact your driving safety.

**Assess Your Own Driving Abilities** by asking yourself these questions:

- Have I been in accidents or received traffic tickets since the onset of my health condition?
- Are there any unexplained scratches or dents on my vehicle?
- Have I had any close calls or near-miss accidents?
- Do I feel more anxious when driving?
- Have family members or loved ones expressed concern about my driving?

**Consult with an Occupational Therapy Driving Rehabilitation Specialist:**

A valuable resource that many individuals may not be aware of is an Occupational Therapy Driving Rehabilitation Specialist. These professionals are occupational therapists who have extra training, knowledge and expertise in evaluating how various health conditions impact driving ability and providing recommendations to improve safety.

OT Driving Rehabilitation specialists can provide comprehensive driving rehabilitation evaluations with a referral from a physician. These evaluations are focused on determining best recommendations related to driving and various health conditions.

Occupational Therapy Comprehensive Driving Evaluations are typically 3 to 4 hours and include the following:

- Assessment of vision, motor and cognitive functions specific to driving and the individual's health condition.
- Observing driving performance in the real world using a vehicle equipped with a passenger side brake for safety.
- Providing personalized recommendations based on the evaluation results. These recommendations can include continuing to drive as usual, recommendations or modifications in driving routines for improving safety, recommendations for adaptive equipment, training to enhance driving skills, or transitioning from driving and identifying alternative transportation options.

As occupational therapy driving rehabilitation specialists, our goal is to find ways to help individuals continue driving for as long as they can safely do so. At Washington University Program in Occupational Therapy, we understand the importance of independence and approach these decisions with both professionalism and empathy, ensuring that individuals receive the guidance they need to make informed and safe choices. ■



Peggy P. Barco

**Resources (available to the public) that you may also find useful below:**

Evaluate your driving ability (AAA):

<https://exchange.aaa.com/safety/senior-driver-safety-mobility/evaluate-your-driving-ability/>

How to Understand and Influence Older Drivers (NHTSA)

<https://www.nhtsa.gov/older-drivers/how-understand-and-influence-older-drivers>

We Need to talk (AARP)

<https://www.aarp.org/auto/driver-safety/we-need-to-talk/>

*For further information regarding driving assessments contact Peggy Barco, at Washington University Medical School, Program in Occupational Therapy ([barcop@wustl.edu](mailto:barcop@wustl.edu), <https://otservices.wustl.edu/items/driving-evaluations/>).*

**QUESTION:** *I had a triple arthrodesis in my teens to correct a turned ankle tendency. The cartilage is gone, and when I walk my ankle bones grind. Is this a problem? What could be done to help? I am 78 years old and in good health.*

**Answer from Marny Eulberg, MD:** Many polio survivors have had triple arthrodesis surgeries on their ankles to prevent the turned ankle tendencies. What many physicians, physical therapists and polio survivors don't realize is that that type of surgery has about a 50% failure rate—because either a solid fusion didn't happen or it broke down over the years after the surgery (the areas where the bones were supposed to be fused together are actually quite small and years of walking and forces created by walking working against the fusion can result in the fusion coming apart). In order to allow the bones to fuse—the cartilage along each joint was removed. I suspect that the cartilage that you mentioned being gone is from some of the other joints surrounding the area of the triple arthrodesis. Any time a fusion is done to bones around a joint, it creates extra stress on the joints above and below the fusion.

The grinding itself indicates that you are developing some wear and tear arthritis in the joints. Of course, that is not a good thing long term, but intervention is only needed if you have pain in addition to the grinding. Sometimes pain doesn't develop for several years after the grinding has begun. There is nothing that can be done to restore the cartilage. If you develop pain or instability in that ankle/foot, then your choices will be 1) living with the pain, 2) using a cane in the opposite hand, a walker or a wheelchair, 3) a well-designed custom made brace/boot that will provide external support and take some of the stress off the bones of the ankle, or 4) a surgical fusion of the ankle joint which will eliminate any motion in that ankle joint. The surgery would likely require you to not put any weight on that leg for two to three months and "hopping" on one leg is not so easy when one is in their 70s-80s even with the use of a walker.

**Answer from Frederick Maynard, MD:** Grinding in the ankle that was fused by triple arthrodesis in the past is not a problem of concern if it is not painful. If there is some minimal pain, you could consider a simple cloth/leather anklet that you wear on longer walks, particularly on undeveloped surfaces. If it gets worse, you would need a full orthopedic evaluation with imaging to try to pinpoint the exact origin of the symptoms and then consider various treatment options. I hope these thoughts help.

**QUESTION:** *I am going to schedule a left-shoulder replacement soon and would like to know if recovery will be more difficult with atrophied left paraspinal muscles. I had polio at eight years of age and was paralyzed from my neck down. I made a remarkable recovery and am now 77 years old. I have never needed mobility aids, but I do have PPS, especially in my core area. Any tips you might have regarding physical therapy precautions or other insights which would aid my post-surgical recovery would be much appreciated.*

**Answer from Frederick Maynard, MD:** If you have visible atrophy of your left paraspinal muscles in the upper chest or neck areas, weakness of your scapular stabilizing muscles may complicate your recovery from shoulder arthroplasty. I would recommend pre-op assessments by a Physical Medicine & Rehabilitation (PM&R) physician and a physical therapist that can be involved with your post-op rehabilitation planning in conjunction with the orthopedic surgeon who does the procedure. It will be important to avoid overuse of any polio-involved muscles during post-op exercises.



Marny Eulberg, MD



Frederick M.  
Maynard, MD



If your overall postural and leg strength is sufficient for you to not need upper extremity devices (e.g., canes, crutches, walkers) for walking, then you should be a good candidate for shoulder arthroplasty to relieve significant pain and/or reduced range of motion. Shoulder arthroplasty (especially “reverse shoulder arthroplasty”) can result in some decrease in the maximum strength of some shoulder movements, but this is not significant for those who have no regular need for routine high strength of shoulders, as in lifting oneself for transfers or walking with devices, or if previous polio did not significantly affect the shoulder muscles. Your PM&R physician can also consider doing electrodiagnostic testing, as they think necessary, for assessing your shoulder muscles for degree of old polio involvement. ■

**Have a medical question about the late effects of polio?** PHI’s Medical Advisory Committee is here to assist. Just fill out the form at <https://post-polio.org/ask-the-doctor/>, and one of our volunteer physicians will be in touch. Please allow up to five business days for a response.

**What can PHI’s volunteer physicians help with?** They can answer questions specific to some sub-groups of polio survivors that may not be answered in PHI’s more general statements—such as “What type of exercise(s) would you recommend for a polio survivor with weakness of one leg?” but they will not be able to answer very specific questions such as “What is the best exercise for me?” or “What is the best brace for me?”

DISCLAIMER: PHI offers this program as an educational service but it in no way is a substitute for medical care by a personal healthcare provider. Our physicians/other healthcare providers can only make suggestions that you, in turn, will need to discuss with your healthcare provider. They cannot treat you or write prescriptions for you. Interactions in writing, verbally or even by video cannot replace the value of an in-person evaluation.

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## Need Help Purchasing a Brace or Custom-Made Shoes?

**WE CAN HELP!** The Joyce and Arthur Siegfried Memorial Fund offers up to \$800 to polio survivors who need assistance purchasing these items.

Joyce and Arthur Siegfried were pioneer advocates for polio survivors. Mrs. Siegfried attended the 1987 PHI (GINI) conference and took “pages and pages of notes” back to the Raritan Valley Post-Polio Support Group, which she founded that year. She helped organize the first New Jersey Conference on the Late Effects of Polio in 1990, which led to the creation of the Polio Network of New Jersey in 1991. She died in 2004, after many years as the organization’s treasurer and leader of the Raritan Valley Support Group. Mr. Siegfried was a long-time PNNJ board attorney and also served as president, retiring in 2010 a year before his death.

In 2012, the Polio Network of New Jersey ([www.njpolio.org](http://www.njpolio.org)) established The Joyce and Arthur Siegfried Memorial Fund at Post-Polio Health International with an initial gift of \$7,500.

Before completing the application, please make note of the following.

- ❖ Polio survivors from any country may apply.
- ❖ The maximum amount of funding available per individual within a two-year period is \$800.
- ❖ Payments are made to brace or shoe companies and not to individuals.
- ❖ Funds are not available for buying two pairs of different sized shoes.

To apply, download an application at <https://post-polio.org/siegfried-fund/> or call 314-534-0475. ■

## A LEGACY OF HEALING:

# Honoring Dr. Arthur Weiland and the Hospital That Changed My Life

Bruce Miller

**E**arly last year on the 31st of January, I attended a bust unveiling ceremony at the Nicklaus Children's Hospital for Dr. Arthur H. Weiland, founder of the hospital originally known as the Variety Children's Hospital. I was eager to go and show my respect and gratitude. It was thanks to the founding vision of Dr. Arthur Weiland that Variety Children's Hospital was able to open its doors on March 20, 1950, just as a polio epidemic was spreading across the United States. Variety Children's Hospital soon became known as the southern center for children suffering from polio.



I contracted polio around the age of one and became paralyzed from the neck down. I spent time in an iron lung and was then transferred to the Variety Children's Hospital in Coral Gables. It is because of Dr. Weiland and his team of caring professionals that I was able to recover to live a healthy and productive life. When I was seven, Dr. Weiland, who was an orthopedic surgeon, took muscles from both sides of my abdomen and over the course of six operations inserted them into my feet and legs, making it possible for me to walk—though, it did require a couple of years of wearing leg braces and numerous years of physical therapy.

I was by no means an athlete in school or college, but I have always been most grateful for the blessing of being able to walk, ride a bicycle, and swim, among other activities. I traveled the world, ran my own business, got married (now 47 years) and had two wonderful children, who in turn have given us six healthy grandchildren.

In my early sixties, I began to notice that I would become fatigued while walking shorter and shorter distances, and my breathing became more difficult. By the time I was 67, I purchased a Travel Scoot, which allowed me to continue traveling and attending trade shows for my business. When I turned 71, I sold

my business and retired in order to concentrate further on my health and spend more time with my family. These days, I try to incorporate some physical exercise daily while also including some deep breathing and exhaling exercises.

It was last year when I went to the bust unveiling ceremony that I was informed of the post-polio support group and subscribed to this newsletter. I am grateful for the valuable information and the contacts made since then. I am also most grateful for the explanatory video posted by Dr. Marny Eulberg describing her experience as a physician with PPS. I sent this link to my physicians, numerous close friends, and family, so they could better understand my relatively new reality. ■

## 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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