

Testimony of Stephen Sappington

Patient Advocate

U.S. Senate Special Committee on Aging Hearing:

Our Commitment: How the Older Americans Act Uplifts Families Living with Aging-Related Diseases

November 5, 2025

Hello Chairman Scott, Ranking Member Gillibrand, and members of the Committee. My name is Steve Sappington. I'm 73 years old, married to my wife Dee for 51 years, and I was diagnosed with Parkinson's disease in 2015. We have five sons and nine grandchildren who keep us busy and motivated.

For about three years before my diagnosis, Dee and I noticed strange changes in my health. I was taking tiny steps instead of my usual long strides. My once-clear handwriting became illegible. We went to Longwood Gardens and I suddenly couldn't smell the thousands of blooming flowers. My hands began to shake, and my balance started to deteriorate. We had no idea what Parkinson's disease was. Dee urged me to see our family doctor, who referred me to a neurologist. When I was diagnosed, I was upset — and frankly, in denial.

A friend of Dee's who also had Parkinson's kept telling me about a local boxing program called Rock Steady Boxing. She said it was life-changing. I wanted nothing to do with it. *Why would I want to go to a boxing class?* I was angry and ignoring the obvious. But eventually, I gave in and went to observe a class, finding it interesting and fun. Everyone there had Parkinson's, each at different stages, and the exercises were designed specifically to combat symptoms of the disease. Everyone was friendly and welcoming. I started going to the free, hour-long classes four to six times a week. The results came slowly but surely: better balance, improved strength, and a huge boost in mood. I went religiously for 18 months. Then I learned the funding for the classes was in jeopardy.

After talking with the gym owner and certified trainers, I realized I couldn't let the classes stop. More than 200 older adults with Parkinson's were benefiting from these free classes. I decided to start a nonprofit in late 2017 to raise money to keep them going. In April 2018, I helped create Rally Against Parkinson's (RAP) to keep the classes going. Getting it started took a lot of work. We were a group of unpaid volunteers — all seniors, most living with Parkinson's — who had no experience running fundraisers. We learned on the job because we knew what these classes meant to us.

We applied for a Community Grant-in-Aid through the Community Outreach Office. We were denied the first year, but the next year we received half of what we requested — about \$10,000. The full cost to run the program was more than \$30,000 a year, so we organized several fundraisers annually to make up the difference. RAP has always been a no-cost program, using 100 percent of every dollar raised to pay for the classes.

When COVID hit and gyms closed, we didn't stop. We quickly adapted by holding socially distanced classes in the gym's parking lot and launching Zoom sessions for those who couldn't or preferred not to leave home. As the program grew, we expanded to our

local YMCA and secured a county grant to purchase equipment. Today, our program includes four in-person classes each week, two livestream classes added during the pandemic, and two additional sessions hosted at the YMCA.

At 71, I decided it was time to step back and was fortunate to find another volunteer — a young 65-year-old — to take over as president. My neurologist calls me “a miracle.” He says it’s rare to see someone with Parkinson’s remain at the same medication level for eight years. I credit that to consistent exercise and the community built through programs like RAP.

Programs like ours are possible because of the foundation created by the Older Americans Act (OAA). Local OAA-funded services, including transportation, congregate and home-delivered meals, caregiver support, adult day services, and other supportive programs, make it possible for older adults like me to stay active and connected.

These services work together:

- Transportation helps participants get to classes and support groups.
- Nutrition programs provide meals that support health and energy.
- Caregiver support allows family members to continue their vital role.
- Title III supportive services give local agencies the flexibility to meet community needs.

Without this infrastructure, many older adults wouldn’t be able to participate in programs that improve their health and well-being.

Despite progress, several challenges remain. Many older adults are unaware of available services, underscoring the need for culturally competent outreach – particularly to low-income, rural, and minority communities. Even when programs are accessible, transportation barriers often prevent participation; funding through the OAA helps address these gaps. Additionally, sustaining free or low-cost programs is difficult due to limited unrestricted funding. These initiatives rely heavily on consistent public investment and strong local partnerships to remain viable.

To ensure that older adults with Parkinson’s and other age-related diseases can thrive, I respectfully recommend that Congress:

1. Reauthorize the Older Americans Act this year and maintain or increase funding for:
 - Title III nutrition programs

- Title III B supportive services (including transportation and in-home supports)
Caregiver support programs
2. Provide dedicated outreach and capacity-building funding so local agencies can reach underserved seniors, including those in rural and minority communities.
 3. Support flexibility for virtual and hybrid programming, such as livestreamed exercise classes, so homebound seniors can stay active and connected.
 4. Sustain funding for transportation and meal programs, which are foundational to participation in community exercise and wellness programs.

As a patient advocate, I'm encouraged by Congress's bipartisan passage of the National Plan to End Parkinson's Act, now being implemented by the federal government. This law creates the first-ever whole-of-government strategy to prevent, diagnose, treat, and ultimately cure Parkinson's disease. It also establishes a federal advisory council to coordinate research and services across agencies and address the needs of caregivers and families.

From my perspective, this effort complements the Older Americans Act. The OAA ensures that people like me can live well today, while the National Plan builds the roadmap for tomorrow. Together, they represent hope: hope for better quality of life now, and hope for a future without Parkinson's disease.

We don't yet have a cure for Parkinson's and we need strong federal investment in research to get there. While researchers work every day toward that goal, I'm proud to do my part through studies like the Parkinson's Progression Markers Initiative (PPMI) to help advance our understanding of Parkinson's Disease. Programs funded and authorized under the Older Americans Act keep people like me moving, connected, and cared for. They make the difference between being isolated at home and living a full life with community, purpose, and dignity.

Thank you for considering these requests. I welcome follow-up questions and will gladly help the Committee understand how OAA services directly improve outcomes for people living with Parkinson's and their caregivers.