John Collins Senate Health Committee Testimony

May 14, 2025

Hello Chairman Huffman, Vice Chair Johnson, Ranking Member Liston, and Members of the Committee:

Thank you for giving me the opportunity to share my story today. I am here to speak about the significant financial assistance the ALS Association has provided to my family and me, as we navigate the challenges of living with ALS.

My wife will speak to the personal support we've received, but I'd like to focus on the financial assistance and how it has helped us maintain some quality of life during this difficult journey.

The ALS Association has been instrumental in helping to alleviate some of the significant costs we face:

- **Wheelchair Ramp**: I needed a wheelchair ramp to maintain my independence at home. While the full cost for the ramp was in the thousands of dollars, the ALS Association was able to provide a grant, covering a portion of this essential modification.
- **Bathroom Renovation**: Accessibility in my bathroom was a necessity for safety and ease of use. The total cost of this renovation was also in the thousands, but with the help of a grant from the ALS Association, we were able to make this critical modification without completely depleting our savings.
- **Electric Wheelchair**: The ALS Association loaned us an electric wheelchair, which was an absolute lifesaver. The cost of a new one would have been in the thousands, but thanks to their lending closet, we didn't have to bear the full cost ourselves.
- **Shower Buddy**: One of the most expensive pieces of equipment we needed was a specialized shower chair, costing around $10,000 when purchased new. Again, thanks to the ALS Association's lending closet, we were able to borrow this vital piece of equipment and avoid a massive out-of-pocket expense.
- **Cleveland Clinic ALS Clinic Visits**: At no cost, the ALS Association has helped navigate regular visits to the Cleveland Clinic's ALS clinic. These visits are critical for my care, and seeing all my providers at the clinic in one appointment has been invaluable.
- **Wheelchair Accessible Van**: While I do not have assistance available from the ALS Association for a new wheelchair-accessible van, this is another example of the high costs we face—tens of thousands of dollars. This is a significant barrier for those of us needing specialized transportation.

- **Widening Doors for Wheelchair Access**: To ensure I can move freely throughout the house, the doors needed to be widened. This cost was in the thousands, and unfortunately, there is no current grant available for this type of home modification.

I hope this testimony illustrates the overwhelming financial burden of living with ALS, and the immense relief the ALS Association has provided, often covering thousands of dollars in costs. I am grateful for their support, but as you can see, there are still many areas where assistance is limited, and every dollar counts in the fight to maintain some semblance of independence and quality of life.

Thank you again for your time and consideration.

John Collins

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May 14, 2025

Senate Health Committee

Chairman Huffman, Vice Chair Johnson, Ranking Member Liston, and Members of the Committee,

My name is Cynthia Collins, and I am the wife of John Collins, who has been living with ALS. I would like to express my gratitude for the opportunity to share with you the critical importance of continued funding and support for ALS programs.

To begin, I would like to provide you with a brief background on John. He is a 1978 graduate of Akron Garfield High School and a 1998 graduate of the University of Akron, where he earned his degree while working full-time. It took him ten years to accomplish this, demonstrating his perseverance and dedication. John has always enjoyed outdoor activities, including camping and hunting with friends, as well as hobbies like woodworking and tending to a vegetable garden.

John and I led a fulfilling life—working, spending time with family and friends, and pursuing our individual passions. He had a successful forty-year career as a maintenance manager, reliability engineer, and project engineer in the chemical industry, and it was his plan to continue working until the age of sixty-seven or longer, as he truly enjoyed his job.

However, in April of 2023, our lives took an unexpected turn. John began experiencing weakness in his legs, frequent unsteadiness, and several falls within a short time. We were referred to a neurologist, Dr. Cambier, who initially diagnosed John with MSA (Multiple System

Atrophy), but recommended a second opinion. In November 2023, after further testing, Dr. Kolychev diagnosed John with ALS and referred us to the ALS Clinic at the Cleveland Clinic. The news was both shocking and devastating.

In just 18 months, John experienced twelve falls. He was unable to continue working, as he could no longer safely navigate the plant or climb stairs to access the machinery. I became his full-time caregiver, assisting with daily tasks that many take for granted. This abrupt shift brought confusion, uncertainty, and emotional stress into our lives. To understand ALS better, I turned to the internet, where I was overwhelmed by the vast amount of information about the disease's progression and its impact on those living with it.

During our first six-month check-in at the Mellen Center at the Cleveland Clinic, I was introduced to the ALS Association. This connection brought me a sense of relief and, ultimately, a wealth of resources. Our care services coordinator, Jackie Kelly, introduced us to various support groups, both local and national, that met virtually. These groups are facilitated by dedicated coordinators who provide a space for people affected by ALS—whether patients, caregivers, family members, or friends—to share experiences and gain insights. The emotional support we receive from these groups has been invaluable, especially in learning how others cope with the challenges of ALS. Through these discussions, I have found strength and solidarity, knowing that John and I are not facing this journey alone.

The support groups also provide practical advice, such as recommendations for medical equipment like Hoyer lifts, walkers, beds, and ramps for home modifications. They share information about where to obtain such equipment and alternative funding options. These resources have been crucial as we navigate the complexities of ALS, and they offer guidance that helps us plan ahead, both medically and emotionally.

On the financial front, while John and I believed we had planned well for retirement, the reality of ALS has required us to dip into our savings to cover the cost of necessary medical equipment and home care. The expenses continue to rise, and we are finding that insurance, including Medicare and additional private insurance, often fails to cover many of the costs. The ALS Association has been an essential resource, helping us understand the next steps and providing information on grants that assist with funding these critical needs.

Additionally, the ALS Association has pointed us toward other organizations that offer financial assistance, considering the different financial situations of ALS patients and their families. Through their guidance, we have been able to access local loan closets for medical equipment, which has been a lifeline during this time.

As we all know, there is no cure for ALS—yet. The number of individuals diagnosed with this disease continues to grow daily. However, there is hope, support, and a sense of community, and it comes from organizations like the ALS Association. We sincerely hope that the state of Ohio will continue to fund these vital services, as they are medically and financially necessary for families like ours who are battling this disease.

We welcome any questions or further discussion on this matter. Thank you for your time and for the opportunity to share our story.

Sincerely,
Cynthia Collins

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