ALS United Ohio

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Testimony on 2026-2027 State Budget

Request for Support to Continue $1M, annually (in Executive Budget) for Support & Services to Those With ALS Across the State

House Health Committee

The Honorable Jean Schmidt, Chair

The Honorable Kellie Deeter, Vice Chair

The Honorable Anita Somani, Ranking Member

Ohio Statehouse

Columbus

March 5, 2025

Written Testimony Presented by:

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Good morning Chairwoman Schmidt, Vice Chair Deeter, Ranking Member Somani, and members of the Health Committee. I am testifying today, representing people with ALS in Ohio and want to thank those who are here who supported funding for ALS in the last budget cycle. We brought people with ALS and their spouses and caregivers to the Statehouse two years ago to meet with our legislators and to testify for the need for additional attention and support in the state for ALS and you responded to the firsthand stories and to our request and we are grateful! Please see our attached State Funding Outcomes Report for 2024 to see how we invested the money provided by the state.

My 2nd reason for being here today is to ask you to support continuing $1M per year in the biennial budget – an allocation which is already included in the Executive Budget.

(What is ALS?)

Many of us know ALS as Lou Gehrig's disease, but ALS is also known as Amyotrophic Lateral Sclerosis (ALS). It's an insidious disease that takes away everything.

ALS is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. ALS slowly destroys the connections between the brain and the muscles. It gradually robs people of the ability to speak, eat, walk, and eventually – to breathe.

In fact, most people with ALS experience total paralysis and death within five years of diagnosis, or even sooner. Very sadly, the typical lifespan from time of diagnosis is 2 – 5 years. My own mother was diagnosed at age 59 with ALS and only lived for one year.

Only 10% of ALS cases are familial; 90% of ALS cases strike at random without regard to age, gender, ethnicity, income, profession, or prior health status. In other words, ALS can strike anyone, at any time. For unknown reasons, veterans are twice as likely to develop ALS as the rest of us, regardless of their branch of service or whether they served in peacetime or war. It is considered a service-related illness by the Department of Defense.

There is no cure for ALS. Not even significantly life-prolonging treatments.

(Role of ALS United Ohio)

Our organization - - ALS United Ohio -- provides people living with ALS, and their families, with **FREE** services and support to manage their diagnosis, that may not otherwise be available. Those services include case management by nurses and social workers, support & education groups, equipment loans, bereavement groups, children's programs, newsletters, home visits, and patient financial grants, among other services. In addition, we provide credentialed healthcare professionals who help staff three hospital-based multidisciplinary ALS clinics in the state. We do not bill for services, nor receive insurance reimbursements. We have made significant progress in ALS care throughout Ohio over the past two decades through private funding, however…the needs still far outweigh the services we can provide.

(Our Request for $1M each year, for 2 year budget cycle-keep what is in the Executive Budget)

Our testimony today is in support of $1M, for each year of the biennial budget - - what is already included in the Executive Budget – for critical services for people with ALS in Ohio. The language for this earmark – adjusted line item 440485 – can be found in H. B. No. 96, page 3747 and in Table 6 of the LSC Redbook for the Department of Health.

Our organization provides case management by licensed healthcare professionals – nurses and social workers – who personally support and help people with ALS take advantage of the **free services** we have to offer. We provide the opportunity for our clients and their caregivers to meet – IN PERSON – with our nurses and social workers, in educational and exchange groups, facilitated by our healthcare staff. Among the 10 different support groups that we run, there are virtual opportunities, as well. We also loan out equipment…something as simple, yet critical as a transfer bench or rollator walker to something as complex as a speech generating device or a power wheelchair. We purchase some smaller equipment items for patients, which we have shipped directly to their homes. Our services also include financial grants to help cover a small amount of the costs of care that patients incur.

We bear significant expense to provide essential services to people in Ohio with ALS. A majority of our funding comes from individual donations, fundraising events, community foundations and corporate support. Although we can not explain the reasons why, over the past 5 years our patient population has risen by nearly 20 percent. Last year, we served 587 people with ALS and their caregivers and family members. This additional funding from the state will continue to assist in meeting the needs of increasing numbers of patients who contact us for help and support.

In addition, without our durable medical equipment program, people with ALS face numerous barriers to obtaining life sustaining equipment, including:

- Waiting periods through Medicare or private insurance
- Insurer limits on type or quantity of device provided
- High deductibles and co-insurance for the equipment

- Lack of coverage for specialized equipment with necessary tailoring to specific needs
- General lack of insurance access or being under-insured due to facility placement.

In closing, I'd like to read a testimonial from one of our ALS Caregivers:

"Not sure where we would be, without ALS United Ohio and the equipment and grant they have made available. Because our insurance company chose to preserve profits, we were turned down for equipment that Medicare calls the standard of care for ALS patients, so ALS United Ohio stepped in with help. Your organization loaned us so much equipment - Canes, rollators, food utensils and pen holders, slide boards, cushions, toilet risers, two ventilators (turned down by our insurance company, despite it being the standard of care), a voice amplifier, computer for voice (our insurance company wanted to wait out Mary dying before they would agree to pay for a purchase of one), suction machine, nebulizer, and your grant helped us purchase a motorized wheelchair. We couldn't have afforded all these things, together, much less individually. Also, we had no idea of things that could be of help, and the ALS United Ohio team offered advice, suggestions, and items to try, as well as helped us apply for social security disability. Mary is on disability and I'm retired; so defunding would be devastating for us; so, thank God for your organization."

By supporting this request, you will be making a tangible difference in the lives of people like those whose testimonies are provided, and so many others who are living with ALS today and whom we are here representing.

Thank you Chairwoman Schmidt, Vice Chair Deeter, Ranking Member Somani, and distinguished Committee Members for your time, attention, and consideration.

I'm happy to answer any questions you have -

OUTCOMES SUMMARY

Ohio Operating Budget allocation for ALS United Ohio in year one of the 2024/2025 budget cycle - $539,253

ALS United Ohio
ALSohio.org

$163,000
TO BRING A NEW ALS MULTIDISCIPLINARY CLINIC TO DAYTON AT PREMIER HEALTH

Beginning in October, people with ALS in the Dayton area will have access to a local ALS Multidisciplinary Clinic. Premier Health was interested in creating this specialized center of care but lacked funds. ALS United Ohio invested a portion of its state funding into the creation of this essential clinic and is partnering in its operation.

Premier Health

$67,000
TO THREE EXISTING ALS MULTIDISCIPLINARY CLINICS

Specialized interdisciplinary care has been shown to extend lives and improve quality of life for people with ALS. ALS United Ohio collaborates with these state-of-the-art multidisciplinary ALS clinics at the University of Cincinnati and OhioHealth in Columbus, and has a close relationship with the clinic at The Ohio State University.

- ***$37,000 to OhioHealth***
- ***$20,000 to University of Cincinnati***
- ***$10,000 to The Ohio State University Wexner Medical Center***

$75,667
FOR NEW MEDICAL & ADAPTIVE EQUIPMENT

State funding has allowed ALS United Ohio to say “yes” to more people and more requests than ever before. This amount represents one month of AdaptAbility program items as well as new items for the loan program, including eight Obi automatic feeders, shown here.

$59,557

FOR REIMBURSEMENT GRANTS TO OHIOANS WITH ALS - ELIGIBILITY NOW EXPANDED TO INCLUDE VETERANS WITH BENEFITS

Quality of Life Reimbursement Grants provide each registered ALS patient with up to $1,200 per year for disease-related expenses. Thanks to state funding veterans who are receiving benefits are also now eligible for these grants, and we will no longer have to turn anyone away because funds are depleted before the end of our fiscal year.

$128,029

CARE SERVICES TEAM SALARIES & BENEFITS

Our licensed professionals provide one-on-one case management for people and families with ALS, important for continuity of care. Care services team members assess needs, provide guidance, supply equipment, connect with local resources, and help families plan. We allocated three months of State funding for the salaries and benefits for six licensed and two support professionals.

$46,000

CUSTOM PATIENT & CAREGIVER DATABASE

ALS United Ohio is in the process of creating a custom database to track our unique care services work with patients and caregivers. This will ease administrative burdens of staff and enhance data accuracy, tracking, and measurement.

SAME MISSION, SAME PEOPLE, NEW NAME

Our organization has undergone a positive change in name and structure as of September 2023 when we separated from The ALS Association, headquartered in Arlington, VA.

We are now a completely independent organization in the state of Ohio, without any constraints of a national organization.

This move allows us to keep 100% of the funds we raise and receive in Ohio, allows our staff to continue reporting locally and allows our local board of directors to continue to govern in ways that best fit the local needs of Ohioans with ALS.

Had we stayed under the control of The ALS Association, we would have lost all local autonomy and our local chapter would have been eliminated. Our raised funds would have been both taken in and distributed by the Association in Arlington, VA, our staff would have reported to the national Association, and our Board of Directors would have lost all governance authority.

ALS United
Ohio

We assure you that any dollars provided by you - the state legislators - to ALS United Ohio are guaranteed to stay right here in the state where you have asked them to be invested!

ALS United Ohio

YOUR LOCAL IMPACT

February 1, 2024 - January 31, 2025

The number of people diagnosed with ALS continues to increase each year, and these people and families are thankful that you are there for them. Once again, a record number of people received free services because of your donations. Below are the numbers behind your impact on the lives of people and families living with ALS for our most recent fiscal year, which ended January 31, 2025.

FREE SERVICES PROVIDED:

587
people with ALS served by ALS United Ohio

180
new ALS patients registered with ALS United Ohio

482
patient visits through ALS clinics at OhioHealth, University of Cincinnati, and Premier Health

373
pieces of durable medical equipment loaned to people with ALS

163
home and office visits to those with ALS

903
people attended support groups or Education & Exchange meetings

103
dining kits provided to people with ALS

430
adaptability items gifted to people with ALS

111
smart home items gifted to people with ALS

85
children received a backpack containing age-appropriate ALS resources and fun items

$222,020
distributed in Quality of Life reimbursement grants to 203 people

22,000
people received the monthly email or print newsletters

ALS United
Ohio

Words of Support from
People Living with ALS and Their Caregivers Related To:

Patient Grant Program
Equipment Program

These are **Free Services** Provided by ALS United Ohio

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Survey Responses to Patient Grant Program:

- *"Thank You! The grant helped me get and afford a carrier for my mobility chair. Now I'm not stuck relying on other equipment at the store. I can go places I couldn't before."*
- *"ALS as a disease is such a struggle. The financial impact just compounds the pain. Having grant money provides a little bit of good news. Thank you."*
- *"…I used the grant money to install a ramp. Bob could then go outside and it gave him great independence."*
- *"I would like to thank you from the bottom of my heart. After getting the diagnosis and dealing with all the stress that it brought, it lifted some of the worrying and stress about financial strain the disease brought."*
- *"It gave me the financing to use a device, which I can communicate on with family and friends. I am thankful for those funds. Thanks so very much."*
- *"Thank you and God bless you for your help. Will never forget the help you gave us."*
- *"This grant is much appreciated and helped our family be able to afford the Tobi speech device we needed to order. ALS comes with so many expenses and this grant program is a huge help to our family."*
- *"It made me feel loved and cared for (The Caregiver)."*
- *"Thanks for helping us out and for recognizing the financial hardships associated with this disease. Please continue your important work!"*
- *"Your organization has always been the easiest, friendliest and goes above and beyond. Thank you."*
- *"This patient has so many obstacles. Having access to your support and resources has lifted her spirits."*
- *"We feel blessed and thankful for your help. We tell everyone we know how you have helped us. That their donation to ALS has helped us."*
- *"We have such appreciation for the support that greatly impacted us."*
- *"The program has always worked well for us. The grant allowed us to purchase things we would have tried to do without."*
- *"In receiving this grant we were able to have a stairlift for my wife that has truly saved her life. Thank you again.'*
- *"My husband loves his liftchair and the comfort it provides. Thank you for making this purchase possible. The process was easy and we are so grateful."*

- *"Thank you for helping my family build a ramp and taking some of the financial burden out of our lives. God Bless."*
- *"We are very grateful for this grant! It is so helpful and certainly helps relieve a little of the burden of this disease."*

Survey Responses to Equipment Program:

I am writing in support of the equipment loan program. So far, a raised toilet seat and shower seat have been delivered to my home, which have been invaluable. I live alone and would be unable to shower without the shower seat. It was easy to put together and install and has been a great thing for me. Same with the toilet seat as I not only have ALS but am also elderly, and am unable to sit lower; it also aids me in getting back up again. I am hoping to get the adjustable bed tray as well, as my arms are affected by the ALS and I am having difficulty feeding myself.

The program that loans equipment to individuals in need is a HUGE gift. This diagnosis took me by surprise and has been devastating but help from ALS United Ohio in so many ways has given me hope and immense support. I hope the legislators will vote for the equipment loan program. I never realized how many folks were affected by this debilitating disease until I became one of them.

Thank you,

Terry H., Lebanon, OH

I received a cane bed assist handle. I would not be able to get out of bed without it by myself. My goal is to continue living independently for as long as possible. The equipment provided helps to assist in continuing to living at home.

Tiara R., Celina, OH

My husband has been recently diagnosed with ALS. The loan program which has been very beneficial. We have been loaned a wheelchair and rollator, which have been helpful in keeping the costs down for all the other items we must buy and the home remodeling we must do. I can foresee this disease will become very expensive and anything and any help we can get is so appreciated. I have also received a grabber, over bed table and over toilet aid. If we did not have these free items many people who desperately need them would go without because of the costs. Thank you!

Suzie P., Columbus, OH

I’m writing to tell you how we benefited from ALS United Ohio. My husband was diagnosed a year ago in March. He was a firefighter for 32 years and was in need of a double lung transplant from complications from COPD from years of firefighting. When he was diagnosed with ALS in March of 2021 this made him ineligible for the surgery, which was devastating. We were immediately introduced to the ALS community and became aware of the ways they could help us.

The disease progressed rather fast and we were in need of much equipment. Whitney, our Care Services Coordinator, has been amazing helping with ramps for our house, portable toilet, hospital table and more. They helped with a grant that we were able to use for medical bills that were not covered. I know we will be in need of a bed and transfer equipment when he is no longer able to get out of bed. These are just a few things that has helped us with. Whitney would meet us whenever we were in need of another piece of equipment. Please, if there is any way for more funding we definitely would appreciate it. Not only for my husband but for all living with ALS in Ohio.

Thank you,

Theresa C. and John C., Lebanon, OH

I was diagnosed with ALS in December 2021. Since then, I was provided a walker, which is great for getting around the house. I was also provided with a wheelchair and without that I could not get out. It has given me great freedom. Also, a commode which keeps me from constantly climbing stairs and preserves my energy. I was also given many small gadgets to help me eat and drink. I could not have done it without their help.

The help they provide is second to none. We could not afford all the extra they supply with the extra cost of medicine. So much cost goes into making this disease manageable, they are a vital asset to those of us struck down with ALS. It is comforting to know they are always there to help and provide answers. Any support they receive on our behalf would be a Godsend and much appreciated.

Thank you,

Teresa B., Columbus, OH

As co-facilitator of an ALS United Ohio Support Group, I have seen many people with ALS throughout my 16 years of being part of this group. Once someone receives the diagnosis of ALS, the rest of their lives are spent making their environment comfortable and convenient and trying to make their lives "normal." For the coordinator of this task, which is usually a spouse or family member in cooperation with the patient, it's a full time job.

Not all insurances cover all equipment, so where does the money come from? In addition to this task, the caregiver may be responsible for maintaining the household, holding down a full time job, coordinating time spent with and obligations to children, and finding time for themselves. It can also involve all the paperwork and time to challenge negative decisions by insurers. Even after jumping through all the hoops required, often no money can be found and the person with ALS goes without the necessary equipment to make their life as convenient and comfortable as possible.

Your positive support of this equipment legislation will be greatly appreciated not only by the people with ALS and their family and friends, but also those of us who support them through their journey of navigating this disease.

Sincerely,

Pamela M. Cusick, MSW, LSW

Co-Facilitator of the Columbus Area Support Group

I would like to take a moment to express my thankfulness for helping me navigate ALS with my spouse.

Tony was diagnosed in 2019 and passed in 2022. During our journey, we were unsure and unaware of resources and they always pointed us in the correct direction.

We are so thankful for the equipment loan program where we received items such as transfer boards and a portable commode and other items.

This was essential to our living a life as normal as possible and helped us stay injury free.

Many times were unaware we were at a specific stage in the disease, until we tried the equipment and realized it was designed for that particular stage of progression.

This loaner equipment is so important to ALS patients and caregivers, as many of these items are too expensive to be purchased out of pocket and inaccessible otherwise.

Aneeka D., Sidney, OH

As my health care needs have increased, I have benefited very much from the equipment I have already received. This includes a walker and two bed canes, without which I wouldn’t be able to get in and out of bed. As my condition worsens, my equipment needs will intensify and it would be very comforting to know that assistance will be available.

Bill N., Columbus OH

My name is Taylor G. and I live in Cincinnati, OH. I have ALS and I thank you. I am able to continue living at home. They have provided me with three amazing machines that enable me to, first of all, continuing to live, and secondly, to live in my home. The machines are the cough assist machine, the suction machine, and thirdly the breathing machine. I can’t express how grateful I am for these complicated electronic devices that afford me more time with my loved ones and friends. It is so important for ALS patients to have the legislative support which Ohio could give them. There are simply not enough donated funds in the organization to provide for the significant needs of those afflicted with ALS. We would all be grateful for such financial assistance!

Gratefully,

Taylor G., Cincinnati, OH

My name is Kevin R. and I have ALS. I have directly benefitted from convenience items and equipment loaned to me by ALS United Ohio. Early into my disease progression I was provided special eating utensils so that, although my hand function was deteriorating, I still could eat independently. It eased my stress at losing my quality of life. That quality of life was prolonged further by many other items provided by my chapter. Rollator. Gate belt. Bed rail. Ramps. Shower chair. Detailing how each item gave me and my family a quality of life we thought was lost would take pages and pages of typing with my eyes.

Not just myself but my family benefits from these items as they allow my independence to be elongated and provide the mental scaffolding to keep engaging with those around me. Not just my family, but other Ohioans who can see me as a normal member of this great state and nation see me not locked away waiting to die, but out and about.

Kevin R., West Chester, OH

I have a slow progression but over the last few years I have become dependent on equipment to keep living as independently as possible. The first few years this wasn’t that important, but now I could not live alone without many of the things ALS United Ohio has lent or given to me. For example, I have borrowed a manual wheelchair, a walker, a portable ramp, and a Hoyer lift. They have bought me toilet and shower chairs and a bed cane. These are things I cannot live without. Their loan closet has made a big difference for me and others with ALS. Funding for this program is essential to living with ALS. I still want to live my best life and the right equipment makes this possible. The help I have received has taken some of the burden away. I am now 99% wheelchair bound. I can still transfer on my own but my arms are getting weaker. So I know the loan program will be used many more times as I keep plugging along.

In fact, just this morning, I slid off my wheelchair trying to transfer and had to call 911 for help. They had to use the Hoyer lift to get me off the floor. This lift was given to me from ALS United Ohio. Thank God I had it!!

Your organization is a resource for any question I have and I appreciate the warmth and kindness they have shown me. I know whatever comes up, I have a place to call and people to help me.

Thank you for your time,

Becky R., Columbus, OH

The diagnosis is brutal. After losing my sister-in-law to this horrible disease in 2015, my husband was diagnosed in 2020. A blood test determined that it is not genetic, just ironic. My husband Hugh has lost his ability to communicate and his body is increasingly getting weaker. So far we have received a VOCSN to assist in his breathing and a computer with eye gaze. The VOCSN is needed to help him breathe deeper and keep his diaphragm working. The computer is necessary for his verbal communication and things like the news and Facebook. I don't know what the future holds for us, but we appreciate the equipment ALS United Ohio is able to provide to make my husband's life as comfortable as possible. The equipment is also helpful to the caregivers that watch their loved ones get weaker and more dependent on the help provided by your organization. My prayers for my husband are for his non-suffering days ahead. The only way my prayers and all the people suffering with ALS prayers will be answered is by the useful equipment provided to patients and caregivers that make life as beautiful as possible.

Thank you for your support,

Liz D., Beavercreek, OH

The equipment program and funding has been a blessing for me and my family. As time passes on and my symptoms continue to progress, I realize that I can still progress too with life. I don’t have to give up what ALS tries to strip away.

The loan program and funding has provided me with tools, gadgets, technology and monies so that I can continued to eat, cook, dress, communicate and even shower on my own. Things that everyday healthy people may take for granted every day. I just want to feel purposeful in my family and the relationship with your organization has given me ways to continue to do it. I’m so grateful and blessed to get their help.

Sincerely,

Kari R., Harrison, Ohio

Sheila Baker, my deceased friend, received equipment on loan in Cincinnati. The two pieces of equipment that were most important were the walker and the communication board. Sheila's ALS progressed very rapidly where it was difficult for her to walk. The loss of her voice was devastating and the communication board was her only way to speak. How grateful we were to have these supplies loaned to us.

Lois M., Cincinnati

The equipment loan program has been critical in keeping my brother, Robert, safe. ALS progresses at different rates for different people. Robert's disease has moved faster than our family can anticipate and his equipment needs have changed rapidly. The loan program has supported his progression with a dining kit, rollator (seated walker), bed cane, and more recently, a gait belt.

A couple of weeks ago we realized he was losing his ability to navigate the three steps to leave the house. Fortunately, your organization had a temporary ramp to loan. On our way to the loan facility, I saw firsthand how the disease disables the muscles and is unpredictable. On the last step Robert got slightly off balance and was unable to hold on to the railing and unable to right himself. He fell hard, like a tree, on the concrete steps and luckily did not hit his head. We have installed the temporary ramp and he can now come and go from his home safely. The process for installing a permanent ramp is underway, but requires approvals, bidding, and construction. His need for a ramp was immediate. The equipment loan program is enabling Robert to go to medical appointments, meetings, and have quality of life during this time. We are extremely grateful for the variety of equipment and the immediate availability, because things have changed so quickly.

Mary H., Dayton, Ohio

Not sure where we would be, without ALS United Ohio and the equipment they have available. Because UHC chose to preserve profits, we were turned down for equipment that Medicare calls the standard of care for ALS patients and ALS United Ohio stepped in with help. One thing we never knew was that equipment we did have and worked perfectly, a week later could be of no use, because Mary's ALS was so fast progressing. Canes, rollators, food utensil and pen holders, slide boards, cushions, toilet risers, two ventilators (turned down by UHC, despite it being standard of care), voice amplifier, computer for voice (UHC wanted to wait out Mary dying on that with a trial), suction machine, nebulizer, and grant help on a motorized wheelchair. We couldn't have afforded all these things, together, much less individually and something only useful for a week because of the progress of the disease. Also, we had no idea of things that could be of help, and the ALS United Ohio team offered advice, suggestions, and items to try, as well as help applying for social security disability. Mary is on disability and I'm retired; so defunding would be devastating for us; so, thank God for your organization.

Tim A., Centerville, OH

My late husband who died of ALS in April 2020 benefited greatly from the loaned equipment from your organization. When he was FIRST diagnosed we were told that we'd need a transfer chair and other items which we picked up. These things were incredibly helpful in getting him to and from doctor's appointments initially and later even moving him from room to room in our house. I had no idea what was in store for us, but you anticipated our needs on several levels. When I visited the place where equipment is stored I realized what was available and how useful it would be to patients. In our case, my husband declined very rapidly and we didn't need things we had anticipated such as a portable ramp out of our house. BUT (and this is quite important) I knew things were available at no cost! This provided some relief to me at that time. I'm sure many others suffering from this disease are using this equipment daily and they, too, know that things will be available as their loved one’s need. It is vital to continue this service.

Karen E., Fairfield Township, OH

Hello my name is Zoe D. I am a young mother and caregiver for my mom who was diagnosed last April. My mom's ability and function has declined rapidly, so it's hard to keep up with basic mobility and quality of life. But I knew I could always call ALS United Ohio; they have helped us with everything from nutrition, mobility, comfort, troubleshooting, guidance, and personal care all in practical, concrete ways. As a mom and caregiver, my schedule often becomes consumed with personal care demands and simply making ends meet. The loan program has been an indispensable aid in this regard as they have mailed items to us, coordinated pickup times from different locations, and even brought items to our house if we couldn't make it out to pick them up. The equipment program is a priceless asset to the ALS community, especially since it's free and much of the equipment and care options for ALS have a high price tag. The program provides security and a financial "break" for families affected by ALS while helping meet their needs. Overall, the ALS equipment program is an invaluable resource.

Zoe D., Dayton, OH

My father was diagnosed with ALS in 2017. He had bulbar onset and very rapid progression. We contacted the ALS United Ohio. The equipment we received was a wheelchair, an eye tracking tablet that helped my father’s mobility and communication. He was not able to speak at all without that machine. Without their support my father would have been isolated completely from his family and friends without the ability to communicate.

Now, unfortunately, I have been diagnosed with ALS myself. At 38 y/o I know the hard times that are coming for me. Your organization is going to be instrumental in helping me traverse these trying times. I will need help with mobility and communication as well. It's amazing to be able to rely on your organization for these things. Funding is paramount to allow those of us with ALS to better live our lives.

Kind Regards,

Blake M., Liberty Township, OH

I just wanted to add my voice in support of the possibility of additional funding for supporting the availability of equipment for those suffering with ALS. My wife and I were extremely thankful to be able to use several items provided by ALS United Ohio, including an adjustable bed, hand rails, bedside commode, walker, and several other items. ALS presents unique difficulties because of the changing course of the disease and the variability of its symptoms. Having a repository for items that are only needed temporarily is a cost-effective means of insuring that needed items are available without the need to purchase items that will only be used for a short period of time. Dealing with the consequences of this devastating disease is already difficult and the availability of supportive equipment was immensely helpful to us. My wife passed away a year ago but I know that if she were still alive she would express her appreciation and strong support for making such items available for others who suffer from this illness. Thank you for your consideration.

Keith C., Cincinnati, OH

My brother, who is now deceased, suffered Developmental Disabilities plus had ALS the last 5 years of his life. He lived in a group home on a limited income. We used the equipment loan program for lots of equipment throughout his life with ALS. We used a shower chair that had a head/neck support, leg & foot supports, plus arm rests. Without this chair we could never have showered him. We also used a Hoyer lift, and used toileting & shower slings. We sourced, on our own, a used Therapy Support mattress & electric hospital bed. We did use a transport chair from the loan program. Once he passed we donated back to the loan program literally everything we possibly could for another individual suffering from this disease to use. Equipment is very expensive and sometimes difficult to source. We donated his custom wheelchair to an individual w/ALS. The chair was adjustable in every manner and a new seat or back could be purchased. The Loan program is a very valuable asset!

Jack & Pat W., Lebanon, Ohio