



## I. GRANT PROPOSAL SUMMARY SHEET

To obtain an electronic version of this application, visit [www.chescocf.org](http://www.chescocf.org)

This page will be shared electronically with Grant Panel Members & Fund Advisors + posted online.

**Date: 03/26/26**

### Contact Information

Organization Name: ALS Hope Foundation.  
 Address: 550 Pinetown Rd, Suite 120  
 Fort Washington PA 19034  
 Phone: 215-568-2426  
 Website: [www.alshf.org](http://www.alshf.org)  
 Year Incorporated: 1999  
 FEIN: 23-3010389

ED/CEO Name: Jamey Piggott  
 ED/CEO E-mail: [jamey@alshopefoundation.org](mailto:jamey@alshopefoundation.org)  
 Board Chair Name: Dr. Terry Heiman-Patterson  
 Board President  
 Board Chair Approval (check here):   
 Primary Contact Name: Anne Rohricht  
 Primary E-mail: [anne@alshopefoundation.org](mailto:anne@alshopefoundation.org)

### Organization Information:

#### Field/s of Interest:

<input type="checkbox"/>	Arts, Culture, Heritage	<input type="checkbox"/>	Education, Library	<input type="checkbox"/>	Environment, Animals	
<input checked="" type="checkbox"/>	Health	<input type="checkbox"/>	Human Services	<input type="checkbox"/>	Social Justice, Civic Engagement	
<input type="checkbox"/>	Religion	<input type="checkbox"/>				If other, please describe:

### Mission:

Our Foundation exists to make a difference in the lives of people living with ALS and their loved ones through care, education and research; more specifically we strive to provide:

1. Clinical centers of excellence for the CARE, support, and treatment of people living with ALS,
2. Programs that promote EDUCATION about diagnosis, treatment, and care.
3. Clinical and basic RESEARCH programs leading to improved care and a cure.

This much needed support is generated through fundraisers, private donations and grant opportunities.

### Geographic Area Served (If not all of Chester County, specify primary Chester County regions served):

Our Foundation primarily serves the greater Philadelphia community. However, it is important to note that our outreach and footprint have been expanding over the past year. This growth is attributable to the addition of some strategic collaborations and to the rapid growth in our internal initiatives that are reaching patients and families throughout the country, and beyond our borders in several cases. Additional details about these partnerships and programs are included in our enclosed grant proposal.

### Describe Population Served & Annual Number of People Served. (Include Chester County # &/or % served.)

At the heart of the ALS Hope Foundation's work is our unwavering commitment to the patients and families we serve, providing them with unparalleled multidisciplinary care and resources needed to navigate their journey. In FY 25, we delivered unparalleled care and support to our community as outlined below.

<b>Patients Served</b>	256 patients were served by the MDA/ALS Center of Hope Clinic.
<b>ALS Patients</b>	Of the total, 127 were individuals specifically diagnosed with ALS.
<b>Clinic Visits</b>	422 multidisciplinary clinic appointments conducted (Average visit: 3-4 hours).
<b>Home Visits</b>	68 specialized Home Visits conducted via the Hope Bridges Home Program.
<b>Counseling &amp; Support</b>	155 vital emotional Counseling Sessions provided.
<b>Support Groups</b>	48 Virtual Support Group Sessions held, engaging 82 unique participants from 12 US States & Canada

**Annual Budget \$ 1,479,000**

73% of budget for program expenses

11% of budget for administrative expenses

16% of budget for fundraising expenses

*100% = total*

5 FT & 5 PT # of Full-Time Equivalent Paid Staff

8 # of Board Volunteers

35-40 # of Active Non-Board Volunteers

300/yr # of Volunteer Hours

**Top 3-5 funding sources:**

During FY25, donations and contributions were our largest revenue source as shown below:

Funding Source	Category Description	FY25 Amount
Individual & Foundation Contributions	Direct support from private donors and mission-aligned family foundations.	\$714,370
Special Events & Fundraisers	Revenue generated through signature events like the Gala of Hope and Run for Hope.	\$340,579
Program Service Revenue & Other	Revenue from workshops, specific grants, and miscellaneous operational support.	\$122,446

We were fortunate to have received several significant donations during FY25 from various private foundations and/or individuals who are committed to advancing the needs of the ALS community. Please see our 990 for additional details if needed.

**This grant proposal is for:**  x  Direct Service Programs & General Operating &/or   Capacity Building

**If Capacity Building Proposal, the focus is:**

Contingency Planning	Partnerships, Collaborations	Merger, Closure
Mission, Vision, Strategy	Board Engagement & Leadership	Marketing, Communication
Resource Development	Operations	Technology
If other, please describe:		

**Grant Amount Requested from the Community Foundation: \$ 20,000**

**Proposal Summary: (a few sentences, please)**

The ALS Hope Foundation is requesting \$20,000 to sustain and scale our Direct Service Programs during a period of strategic organizational growth. Following a record year of providing multidisciplinary care to 256 patients and conducting over 400 clinic visits, we have expanded our professional team to meet the increasing complexity of ALS care and research advocacy. This funding will provide the essential general operating support needed to maintain our clinical excellence and ensure that our expanded infrastructure continues to deliver seamless, high-touch support to families in Chester County and the greater Philadelphia region.



## GRANT PROPOSAL NARRATIVE

*Provide clear, concise information in 1-3 pages. Please be brief.*

1. Nonprofit's overall aims, key initiatives, key achievements & distinctiveness
2. Funding request
  - What specific needs & issues are being addressed, via what programs and services?
  - Why is it important to fund this now?
  - How will results & impact be demonstrated?

## ALS HOPE FOUNDATION RESPONSES:

### Q1 – ALS Hope Foundation Key Initiatives, Achievements & Distinctiveness

As outlined in our grant summary, our Foundation primarily serves the greater Philadelphia community. However, our outreach and footprint have been expanding over the past year or so. This growth is attributable to the addition of some strategic collaborations and to the rapid growth in the direct services and internal programs supported by our own team members.

These include the following:

#### Collaborations:

Collaboration is a crucial component of our core values at the ALS Hope Foundation. We truly believe that when we work together progress is accelerated and our impact amplified. We are proud to share our key partners and collaborative alliances:

- Your ALS Guide

"Your ALS Guide" is a free, comprehensive, and user-friendly educational resource designed to improve the quality of life for families impacted by ALS (Amyotrophic Lateral Sclerosis). It is a major collaborative initiative, often highlighted in partnership with organizations like the ALS Hope Foundation, to provide trusted, practical information in one central location.

- End The Legacy

End the Legacy is a powerful, relatively new, patient-led organization that focuses entirely on the unique needs of the community impacted by inherited forms of ALS and Frontotemporal Dementia (FTD). The ALS Hope Foundation acts as a key partner and fiscal sponsor to End the Legacy, helping to provide the infrastructure and support necessary for their work. Together, we successfully presented a national community summit to foster collaboration between researchers and families dealing with genetic ALS.

- Veterans ALS Action Committee

The Veteran ALS Action Committee (VAAC) is a dedicated working group focused on increasing awareness, education, and access to resources for U.S. veterans living with ALS and their families. The ALS Hope Foundation often works in close collaboration with the VAAC to ensure that veterans,

whose ALS is often deemed service-connected, receive specialized care and have access to cutting-edge research opportunities.

- Wendy's Wish 911

Wendy's Wish 911 is a critical, proactive program focused on bridging the dangerous knowledge gap between individuals living with ALS (and other neurological conditions) and the first responders who are often the first on the scene during an emergency. The program was founded by ALS advocate and warrior Wendy Hendrickson in collaboration with the ALS Hope Foundation and The Griffin Gives Foundation.

- ALS Untangled

We are proud to be a sponsoring partner of ALS Untangled, providing essential support and a free, international online resource that provides scientific, evidence-based reviews of alternative and off-label treatments (AOTs) for people living with ALS (PALS). Its core purpose is to help PALS and their families make informed decisions about treatments they often read about on the internet, which can be expensive, unproven, and potentially harmful.

- Hope Loves Company

Our partnership with Hope Loves Company underscores its commitment to comprehensive family support. Hope Loves Company is the only non-profit organization in the United States dedicated to providing emotional and educational support to children and teenagers who have a loved one living with ALS. It recognizes that children experience unique forms of grief, anxiety, and confusion when a family member is diagnosed with a terminal illness.

### **Direct Service Programs / Initiatives:**

- Hope Bridges Home Program

Recognizing that the progression of ALS often makes travel to a clinical setting impossible, this program brings expert care directly to the patient. Through specialized home visits, our team provides the same high level of multidisciplinary support found in our clinic, ensuring that mobility challenges never result in a lack of care.

- Pappas Family Equipment Closet

The financial burden of ALS is compounded by the immediate need for expensive, specialized medical equipment. Our Equipment Closet provides a critical solution by loaning power wheelchairs, communication devices, and other daily living aids at no cost to the family. By eliminating the wait times and high out-of-pocket costs often associated with insurance, this program ensures that patients maintain their independence, dignity, and safety throughout every stage of their journey.

- ALS Hope North

Unlike our collaborative partnerships, ALS Hope North is a direct, in-house extension of our own organization. In January 2026, we officially expanded our footprint into the Greater Boston area with the hiring of Ashley Corbin as a core member of our team. Ashley comes to us from ALS One and was able to bring an established network of connections, contacts, and events with her. Working directly under our banner, Ashley is already bringing our vision and mission to the New England ALS community with several awareness and fundraising events scheduled for this spring.

- PCORI Initiative

We are currently spearheading a vital initiative funded by the Patient-Centered Outcomes Research Institute (PCORI). This program represents a shift in how we approach ALS: moving from "research

on patients” to “research with patients”. Throughout 2026, we will be hosting collaborative workshops and focus groups to bridge the gap between researchers and the ALS community, ensuring that the lived experience of our families is the driving force behind new care models and clinical trials.

- BCI Research (Brain Computer Interface)

Our BCI team has been working on several projects towards our assistive technology efforts. In general, BCI’s use different types of brain wave potentials that are triggered by visualizing a target and then translated into an action. Specifically, we are working to develop BCI controlled communication, controls of a home assistant, and even control of a wheelchair. Currently, we are designing three paradigms to compare which one works best for pALS and a wheelchair to eventually integrate with the best suited system.

- Expanded Support Group Network

We continue to provide a lifeline for our community through our monthly support groups. These sessions offer a safe space for PALS and CALS to share resources, navigate challenges, and find emotional support, ensuring that no one has to face an ALS diagnosis alone.

## **Q2 – ALS Hope Foundation Funding Request**

### **What specific needs & issues are being addressed, via what programs and services?**

The ALS Hope Foundation addresses the critical gap between medical diagnosis and the daily reality of living with a neurodegenerative disease. While hospitals provide clinical care, our Foundation provides the critical support necessary to navigate the complexities of ALS. This request specifically supports the staffing costs associated with supporting our mission and the ALS community.

### **Why is it important to fund this now?**

We are currently at a pivotal inflection point. In early 2026, we expanded our internal team with two additional full-time staff members to support the rapid growth of initiatives. While these hires were strategically necessary to meet a record-breaking demand for services, they represent a significant increase in our fixed operating costs.

Funding is urgent now to ensure that this growth is sustainable. Without dedicated support for our personnel, we risk a "capacity gap" where the demand for our specialized care outpaces our ability to provide it. This grant will serve as a bridge, allowing our team to maintain our 4-star Charity Navigator level of efficiency while executing the most ambitious service schedule in our 27-year history.

### **How will results & impact be demonstrated?**

We measure success through both quantitative data and qualitative patient outcomes. Impact will be demonstrated via:

- Service Metrics: Tracking the number of patients served (with a goal to exceed the 256 reached in FY25) and the number of multidisciplinary appointments completed.
- Geographic Reach: Documenting the expansion of services within Chester County and the greater Philadelphia region.
- Organizational Health: Highlighting the successful execution of our 2026 milestones, including the 8th Annual Gala of Hope and the successful rollout of the PCORI workshops, which are only possible through a fully-supported professional staff.
- Financial Stewardship: As detailed in our inaugural Annual Report, we maintain a rigorous focus on fiscal transparency, ensuring that 73% of every dollar goes directly into program expenses

