

**THE THIRTIETH LEGISLATURE**  
**APPLICATION FOR GRANTS**  
**CHAPTER 42F, HAWAII REVISED STATUTES**

Type of Grant Request:

☐

Operating

☐

Capital

Legal Name of Requesting Organization or Individual:   Dba:

Amount of State Funds Requested: \$\_\_\_\_\_

Brief Description of Request (Please attach word document to back of page if extra space is needed):

Amount of Other Funds Available:

State:           \$\_\_\_\_\_

Federal:       \$\_\_\_\_\_

County:       \$\_\_\_\_\_

Private/Other: \$\_\_\_\_\_

Total amount of State Grants Received in the Past 5  
Fiscal Years:

\$\_\_\_\_\_

Unrestricted Assets:

\$\_\_\_\_\_

New Service (Presently Does Not Exist): ☐   Existing Service (Presently in Operation): ☐

Type of Business Entity:

☐

501(C)(3) Non Profit Corporation

☐

Other Non Profit

☐

Other

Mailing Address:

City:

State:

Zip:

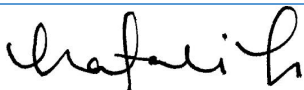
Contact Person for Matters Involving this Application

Name:

Title:

Email:

Phone:



Authorized Signature

Name and Title

Date Signed

## Application for Grants

*If any item is not applicable to the request, the applicant should enter "not applicable".*

### **I. Certification – Please attach immediately after cover page**

#### **1. Hawaii Compliance Express Certificate (If the Applicant is an Organization)**

If the applicant is an organization, the applicant shall submit one (1) copy of a Hawaii Compliance Express Certificate from the Comptroller of the Department of Accounting and General Services that is dated no earlier than December 1, 2024.

#### **2. Declaration Statement**

The applicant shall submit a declaration statement affirming its compliance with [Section 42F-103, Hawaii Revised Statutes](#).

#### **3. Public Purpose**

The applicant shall specify whether the grant will be used for a public purpose pursuant to [Section 42F-102, Hawaii Revised Statutes](#).

### **II. Background and Summary**

This section shall clearly and concisely summarize and highlight the contents of the request in such a way as to provide the State Legislature with a broad understanding of the request. Please include the following:

#### **1. A brief description of the applicant's background;**

ALS Ohana of Hawaii is a community based, volunteer-led organization that was founded nearly two decades ago by two nurses. One of the nurses took care of her husband with ALS for more than 25 years, the other nurse was diagnosed with ALS. ALS Ohana founders and supporters believe that people affected by ALS in Hawaii should live with the support, compassion and the practical help needed to optimize quality of life. ALS Ohana formally incorporated in 2013 and the current board is composed of individuals who are living with ALS or have ALS caregiving experience. In addition to providing direct vital care support to individuals and families living with ALS at no charge, ALS Ohana of Hawaii partners with other community-based organizations to deliver formal, comprehensive care services to people living with ALS in Hawaii.

For the purpose of this program and request, ALS Ohana of Hawaii (ALSOH) will partner with the ALS Network, formerly ALS Golden West and also previously known as the ALS Association Golden West Chapter (GWC), a nonprofit organization that has been serving the ALS community since the mid-1980s, with formal services starting in Hawaii in 2014. All ALS Network services are provided free of charge to the ALS

community.

ALSOH has successfully partnered with the ALS Network to deliver programs in Hawaii since 2015. Hawaii's ALS community greatly benefits from the two organizations' aligned mission priorities and shared commitment to provide Hawaii's ALS ohana with the best possible care while simultaneously accelerating the search for effective prevention strategies, treatments and cures for ALS.

2. The goals and objectives related to the request;

An evidence based, wraparound care approach to improving outcomes for the ALS community, the ALS Network's *Excellence in ALS Care Initiative* is designed to address the medical, social, emotional and financial challenges facing people diagnosed with ALS. By providing a continuum of care at no charge to clients, the ALS Network emphasizes coordination and collaboration among caregivers, social workers, and health care providers in clinical and community and home-based settings. That continuum of care also includes opportunities to advance ALS research and public awareness initiatives that benefit the entire ALS community.

Goals and objectives related to this request include:

- A. Ensuring access to high quality, specialized care, support and community resources for the state's ALS community
- B. Expanding the reach and effectiveness of the ALS Network's *Excellence in ALS Care Initiative* and wraparound model of care in Hawaii by:
  - Providing training and support for physicians, clinicians and caregivers serving people with ALS
  - Conducting community outreach and engagement activities to educate the public about ALS, to connect people with available services, to promote early referrals for services, and to identify new mission aligned program and research partners for the ALS community

3. The public purpose and need to be served;

Amyotrophic Lateral Sclerosis or ALS, also known as Lou Gehrig's Disease, is a devastating and fatal neuromuscular disease that robs a person of the ability to walk, talk, swallow, and eventually, to breathe. It is now understood that up to 40% of people diagnosed with ALS may experience cognition issues. ALS affects women and men of all ages, ethnicities and from all socioeconomic backgrounds. As with other neurodegenerative diseases like Alzheimer's and Parkinson's, aging is a primary risk factor and, everyone is at risk. For unknown reasons, U.S. military veterans are twice as likely to be diagnosed with ALS than civilians. Today, we are learning more about the potential causes of ALS, but as with related neurodegenerative diseases, there are still no cures for ALS.

Most people diagnosed with ALS are unfamiliar with the disease, as only 10-15% of all cases are related to family history or known genetic causes. Due to the progressive and highly variable nature of the disease, it may take nearly a year to receive a diagnosis and the learning curve about living with ALS is often steep and

overwhelming. Nearly all people diagnosed with ALS are unable to earn a living and remain at home throughout the course of the disease as clinical care takes place on an outpatient basis. ALS is an incredibly isolating disease and managing the progression of ALS is emotionally, physically, and financially draining. The annual costs for 24/7 home care, coupled with the cost of necessary equipment (including speech, mobility, respiration, transportation, etc.) in the later stages of the disease can easily exceed \$200,000 per year.

Medical care for people with ALS is a complex venture, as the disease progression varies widely and there is no test to confirm an ALS diagnosis. Few doctors, home care providers, allied health professionals or nursing home staff are trained in the unique respiratory, feeding and endurance concerns associated with ALS, often resulting in conflicting recommendations, accelerated disease progression, and frustrated, vulnerable patients and caregivers.

Many medical complications are associated with ALS, including aspiration pneumonia, neck and back pain, excessive saliva, skin sores and more. Until there are effective medical treatments and cures, the best form of treatment proven to improve quality of life and extend life expectancy relies on expert, proactive, collaborative multidisciplinary care. In Hawaii the situation for people with ALS is even more precarious because few providers offer robust multidisciplinary clinical care and other physicians and healthcare professionals in neurology, pulmonology, and respiratory, physical and occupational therapy, are often untrained and lack knowledge regarding best practices in ALS care, especially those in urgent care and emergency room settings.

Through the *Excellence in ALS Care Initiative*, essential care services will be provided at no cost to people living with ALS and their loved ones; ensuring that Hawaii's ALS community is provided with crucial support. The *Excellence in ALS Care Initiative* embodies ALSOH's and the ALS Network's core value that no one should be alone with ALS and positions the ALS community to directly participate in achieving our shared vision – curing ALS together.

4. Describe the target population to be served; and

The target population to be served includes residents of Hawaii of all ages and backgrounds, in all counties in the State of Hawaii. Primary grant beneficiaries are individuals diagnosed with ALS and their loved ones, family caregivers, professional caregivers, healthcare providers, ALS and neurodegenerative disease researchers and public health professionals. The general public will also benefit from grant activities.

5. Describe the geographic coverage.

The geographic scope of the grant includes the entire State of Hawaii; the ALS Network serves approximately 95% of the state's predicted prevalence, along with their loved ones, and offers bereavement support for those who have lost loved ones to ALS. Prior to 2015, Hawaii's ALS community was largely unsupported, especially on Honolulu's neighbor islands. As a result of collaborative efforts by ALSOH and the ALS Network, Hawaii's ALS community has improved access to vital programs and services, including those who are traditionally underserved and underrepresented, and are highly vulnerable as a result of being homebound or geographically isolated.

### **III. Service Summary and Outcomes**

The Service Summary shall include a detailed discussion of the applicant's approach to the request. The applicant shall clearly and concisely specify the results, outcomes, and measures of effectiveness from this request. The applicant shall:

1. Describe the scope of work, tasks and responsibilities;

Until effective treatments and cures for ALS are discovered and readily available, expert medical, community and home-based care is known to help people with ALS live longer and better. The few FDA-approved medications for ALS only extend life approximately 2-6 months.

The scope of work, tasks, and responsibilities for executing the *Excellence in ALS Care Initiative* in Hawaii, at no charge to the ALS community, incorporates the key programmatic elements as follows:

Professional ALS Care Management: Every person with ALS in Hawaii who is connected to ALSOH and the ALS Network will have access to a professional ALS Network Care Manager and comprehensive care services designed to help people with ALS, their loved ones, and professional caregivers find solutions for their changing circumstances as the disease progresses. Hawaii's Care Manager will connect individuals and families to essential information, community resources, educational opportunities, other people with ALS and their families, and access to free loans of durable medical equipment (power wheelchairs, etc.) and technology (augmentative communication devices, speech generating devices, adaptive switches, etc.) necessary to make living with ALS easier.

Hawaii's Care Manager visits people diagnosed with ALS throughout the state, in their home, in the hospital, and skilled nursing facilities if necessary. The Care Manager is available for consultation with clients, including loved ones, via phone, email, text and videoconference and attends ALS clinic appointments.

During client consultations, Hawaii's Care Manager makes assessments and troubleshoots issues, and can create or coordinate a care plan that is continually updated to respond to the specific and unique needs of every person with ALS. Hawaii's Care Manager serves as an advocate with insurance companies and government agencies on behalf of clients and assist with referrals to medical, legal, financial, transportation, in-home health care and counseling services.

Hawaii's Care Manager is an integral member of multidisciplinary ALS clinic teams, both in person and online, serving as a bridge from the home and community to the broad array of professionals who make up a multidisciplinary clinic team. Clinical specialists include neurologists, pulmonologists, speech language pathologists, physical and occupational therapists, nutritionists and others, all of whom are essential to the proactive treatment of ALS. Hawaii's Care Manager also facilitates support groups, educational programs, and supports community activities. (See next sections.)

ALS Multidisciplinary Clinics: ALS clinics and centers for ALS care and research combine multidisciplinary medical treatment as well as clinical research opportunities to identify the causes, prevention strategies, potential therapies, and ultimately, cures for ALS. During a single clinic visit, either in person or via telehealth platforms, a person with ALS is examined by a number of specialists, including a neurologist, nutritionist, respiratory therapist, speech therapist, physical and/or occupational therapist, social worker and others essential to the care team. Including a professional ALS Care Manager as a member of the clinic team ensures the effective coordination of the clinic visit, treatment plan and follow-up appointments. People with ALS are encouraged to schedule clinic visits every three months to monitor progression of the disease and address medical issues. The ALS Network partnered with Kaiser Permanente nearly 10 years ago to help launch a Recognized Treatment Center in Honolulu and works closely with medical teams at Queens Hospital and the VA. And in response to the global pandemic in 2020, the ALS Network facilitated new telemedicine partnerships with ALS Certified Treatment Centers of Excellence at UCSF and Loma Linda University to ensure clinical care when in person clinic visits are not feasible. ALSOH and the ALS Network seek opportunities to partner with other medical providers to bring vital clinic services to all clients in the state.

Equipment Loan Program: Ninety percent of people diagnosed with ALS will require adaptive equipment in order to remain safe, comfortable, mobile and to communicate as the disease progresses. The ALS Network's equipment loan program makes it possible to provide loans of critical medical and assistive equipment to people with ALS at no charge. This equipment includes wheelchairs, respiratory equipment and high-tech communication devices as well as low-tech canes, walkers, adaptive switches and alphabet boards – items that are crucial for activities of daily living and oftentimes are life-sustaining (i.e.: respiratory devices and generators). This loan equipment is essential for people with ALS who lack adequate insurance coverage, have limited financial resources, or who experience long waiting periods while customized equipment is assembled and delivered. The equipment loan program features devices that help decrease isolation and maintain independence and quality of life as muscle function deteriorates. Many pieces of equipment are used by individuals and families and returned when no longer needed for recirculation if possible. The ALS Network Care Services team oversees assessments and referrals, ordering, pick up, delivery, inventorying, and cleaning and repairing equipment provided during the grant period for Hawaii's ALS community.

Connection Groups: Connection groups are highly valuable learning forums and supportive environments focused on promoting strategies for meeting the challenges of living with ALS. Monthly connection groups feature both educational speakers and small group discussions and are open to all people with ALS, caregivers, family members and friends at no charge. Since 2020, connection groups have been conducted online, with in person gatherings taking place for those who are able to meet in person. The ALS Network also offers online resources and communities such as email forums, livestream events, social media pages, and videos on YouTube and other sites, to help people connect with ALS resources in the community and each

other. ALSOH and the ALS Network seek opportunities to produce community-focused, innovative, unduplicated programs that address some of the most urgent needs facing Hawaii's ALS community including: caregiver issues, programs for young people living with loved ones with ALS, best practices in ALS care for maintaining wellness, participating in ALS research, and more.

Education, Awareness, Outreach Events, and Special Programs: Special educational events and programs with expert speakers on a range of topics, including current clinical trials, disease treatment and management, caregiver support, and more are highly valued and well-attended. Education and outreach opportunities give people with ALS, their family members and caregivers a chance to hear directly from doctors, researchers, therapists and social workers and other experts in the field and ask direct questions of these experts. The ALS Network also organizes regional community events designed to bring the entire ALS community together, including the Hawaii Walk and Roll to Cure ALS, in an effort to raise public awareness and inspire action in support of the ALS community. The annual ALS Network's Research Summit is a renowned program organized by scientists for scientists that is designed to foster collaboration and learning and to accelerate discovery of therapies and cures for ALS.

2. Provide a projected annual timeline for accomplishing the results or outcomes of the service;

During the 12-month grant period the program will benefit approximately 75 people living with ALS plus hundreds of their loved ones, including family members, friends, colleagues, and caregivers of all ages as well as community members, medical professionals, research and scientists, and many individuals who have lost loved ones to ALS.

Each Quarter, grant activities will include:

- Care Management Services for people diagnosed with ALS and their loved ones
- A minimum of 3 connection groups hosted online and facilitated by Hawaii's Care Manager (1 per month). Clients are also invited to attend any of the ALS Network's monthly online support groups (20 per month), as some are focused on topics of interest (ie: for veterans, for trach and vent users, for those with familial ALS, young families living with ALS and much more).
- A minimum of 10 people with ALS supported via a multidisciplinary clinic visit
- A minimum of 15 Equipment Loan Program engagements

In addition to the above stated activities, in Quarter one, ALSOH and the ALS Network will plan grant activities and confirm dates for all outreach, family programs, and training events. It is anticipated, based on past annual activities, that at least two of these types of events will take place to benefit the State of Hawaii's ALS community during the grant period.

3. Describe its quality assurance and evaluation plans for the request. Specify how the applicant plans to monitor, evaluate, and improve their results; and

Program effectiveness will be assessed in the following ways:

- achievement of key quantitative goals related to programs and services
- informal and formal surveys of clients and partners
- staff and volunteer assessments

The ALS Network records and reviews client data on a monthly basis in order to track resource allocation, client needs, areas in need of improvement and to ensure the success of every element of the *Excellence in ALS Care Initiative*. The ALS Network will provide reports throughout the grant period.

4. List the measure(s) of effectiveness that will be reported to the State agency through which grant funds are appropriated (the expending agency). The measure(s) will provide a standard and objective way for the State to assess the program's achievement or accomplishment. Please note that if the level of appropriation differs from the amount included in this application that the measure(s) of effectiveness will need to be updated and transmitted to the expending agency.

The measures of effectiveness that will be reported will include:

- the number of clients engaged by Hawaii's Care Manager
- the number of equipment loans provided
- the number of Hawaii connection groups offered, and attendance numbers
- the number of multidisciplinary clinic team client engagements
- the number of trainings for medical and allied health professionals
- the number of community outreach events conducted, and attendance numbers

## **IV. Financial**

### **Budget**

1. The applicant shall submit a budget utilizing the enclosed budget forms as applicable, to detail the cost of the request.
  - a. Budget request by source of funds ([Link](#))
  - b. Personnel salaries and wages ([Link](#))
  - c. Equipment and motor vehicles ([Link](#))
  - d. Capital project details ([Link](#))
  - e. Government contracts, grants, and grants in aid ([Link](#))
2. The applicant shall provide its anticipated quarterly funding requests for the fiscal year 2026.

Quarter 1	Quarter 2	Quarter 3	Quarter 4	Total Grant
\$118,044.50	\$118,044.50	\$118,044.50	\$118,044.50	\$472,178.00

3. The applicant shall provide a listing of all other sources of funding that they are



seeking for fiscal year 2026.

4. The applicant shall provide a listing of all state and federal tax credits it has been granted within the prior three years. Additionally, the applicant shall provide a listing of all state and federal tax credits they have applied for or anticipate applying for pertaining to any capital project, if applicable.

N/A

5. The applicant shall provide a listing of all federal, state, and county government contracts, grants, and grants in aid it has been granted within the prior three years and will be receiving for fiscal year 2026 for program funding.

Federal: N/A

State: GIA 2023 (funding still pending)

County of Hawaii GIA: 2021-2022

County of Hawaii GIA: 2022-2023

We have secured no contract commitments for fiscal year 2025 program funding.

6. The applicant shall provide the balance of its unrestricted current assets as of December 31, 2024.

Please see attached Treasurer's Report.

## **V. Experience and Capability**

### **1. Necessary Skills and Experience**

The applicant shall demonstrate that it has the necessary skills, abilities, knowledge of, and experience relating to the request. State your experience and appropriateness for providing the service proposed in this application. The applicant shall also provide a listing of verifiable experience of related projects or contracts for the most recent three years that are pertinent to the request.

ALS Ohana of Hawaii and the ALS Network have long and successful track records for providing essential, high impact services and support to Hawaii's ALS community. Each organization is mission and data driven bringing professionalism, accountability, stability and strong relationships to benefit all aspects of work conducted on behalf of the ALS community.

ALSOH is a volunteer based organization with many years of experience providing outreach and support services to ALS families. ALSOH volunteers have all lived with or cared for someone with ALS and have a special appreciation for the needs of ALS families in the state.

The ALS Network led the charge to develop and launch a professional wraparound system of care to benefit for the ALS community more than 20 years ago, starting in Los Angeles, California. At the request of families residing in Hawaii, the ALS Network brought this expertise and evidence-based model of multidisciplinary care to the State of Hawaii in 2014. ALS Network staff are professionals with degrees, licenses and work experience relevant to serving the ALS community in fields such as social work, respiratory therapy, occupational therapy, physical therapy, speech therapy and nursing. Staff also operate as ambassadors to members of the medical, academic and scientific communities seeking to collaborate and affiliate with experts, researchers, community organizations, vendors, the media, and other institutions that serve those with ALS.

Since 2014, the ALS Network's caseload in Hawaii has increased by more than 60%. As a result of the ALS Network and partner organizations' efforts in Hawaii, more clients are seeking care services. State GIA funding would provide essential support to meet the needs of the current caseload. The ALS Network and ALSOH will leverage state support to secure new funding to build capacity to pilot innovative projects that respond to emerging needs of Hawaii's ALS ohana and capitalize on novel approaches to enhance and expand services as well as engage more people in the search for effective prevention strategies, treatments and cures for ALS.

In 2020, in an effort to keep the ALS community safe, connected and to ensure continuity of care, the ALS Network shifted from providing primarily in person programs and services to offering all programs and services online. This was incredibly important as people with ALS are highly susceptible to respiratory infection, as the respiratory system is compromised with ALS and infections are often fatal. During the time that we were safer apart, the ALS Network expanded services by leveraging telehealth technology and today, we are offering "hybrid" programs and services to ensure accessibility and inclusivity for the homebound, geographically isolated or regionally far, and health conscious/precautious members of the ALS community. The virtual options extend to clinical care too.

Lastly, since 2014, the largest nonprofit evaluator in the country, Charity Navigator, has awarded the GWC with its highest rating, four stars, in recognition of the ALS Network's commitment to transparency and efficiency. Only 5% of nonprofit organizations achieve this accomplishment.

Listing of verifiable experience of related projects or contracts for the most recent three years that are pertinent to the request:

- ALSOH received County of Hawaii Grant In Aid awards in 2022, 2023 and 2024 to execute the ALS Network's Care Services programs. ALSOH is currently waiting for a payment related to a State Grant in Aid award for 2023-2024 as well.
- In 2022, 2023, and 2024 the ALS Network secured a City and County of Honolulu Grant in Aid to provide Care Services and programs for Honolulu's ALS community.

## **2. Facilities**

The applicant shall provide a description of its facilities and demonstrate its adequacy in relation to the request. If facilities are not presently available, describe plans to secure facilities.

ALSOH does not utilize facilities to operate programs, its functions are supported by donated space for board meetings and volunteer activities. For this request, the ALS Network will provide facilities necessary to conduct activities including office space and storage units. Currently, the ALS Network maintains a centralized office location in Honolulu for conducting Care Services and Community Outreach related business and meetings; Storage units are maintained on a number of islands to support equipment loan program activities. Most programs and services are offered online or via hybrid in person and virtual formats to ensure inclusivity, access and safety.

## **VI. Personnel: Project Organization and Staffing**

### **1. Proposed Staffing, Staff Qualifications, Supervision and Training**

The applicant shall describe the proposed staffing pattern and proposed service capacity appropriate for the viability of the request. The applicant shall provide the qualifications and experience of personnel for the request and shall describe its ability to supervise, train and provide administrative direction relative to the request.

The proposed staffing pattern relies on the ALS Network's Hawaii staff members and infrastructure as follows:

- One full time ALS Network Care Manager
- One full time ALS Network Assistant Director of Community Outreach
- One full time Equipment Loan Program Coordinator

The ALS Network's Care Manager is a trusted healthcare professional who is trained to help people living with ALS and travels throughout the state to ensure access to care. In addition to serving the client community, Hawaii's Care Manager is also at the forefront of identifying potential multidisciplinary care and research partners and providing training to ancillary healthcare professionals in the field about ALS care.

The ALS Network's Assistant Director of Community Outreach is a valued member of the team who is well positioned to serve the state's ALS community, generate awareness, engage constituents and key stakeholders, and connect with organizations throughout Hawaii in order to ensure the best possible outcomes for the ALS community.

The ALS Network's Equipment Loan Program Coordinator is a highly qualified and knowledgeable professional who is an expert in adaptive equipment for ALS clients. From helping people navigate issues, questions and choices related to complex rehab technology to low tech medical supplies, this ALS Network team member has the positive attitude, calm temperament and tenacity to assist individuals and family members find solutions for loss of body function proactively, and when sudden needs arise.

Ongoing oversight and supervision will be provided by the ALS Network's VP of Care Services and the VP of Community Outreach; these expenses will not be charged to the grant. Additional in-kind program support will be provided as necessary by the ALS Network's Care Services Assistant, Director of Care Services, Director of Data Management, Director of Marketing and Communications, administrative staff and leadership team.

## **2. Organization Chart**

The applicant shall illustrate the position of each staff and line of responsibility/supervision. If the request is part of a large, multi-purpose organization, include an organization chart that illustrates the placement of this request.

ALSOH does not employ staff and will enter into an agreement to contract for services with the ALS Network, a nonprofit certified to do business in the State of Hawaii.

This grant will fund the collaboration to execute this validated model of care executed by ALS Network staff in Hawaii. The Hawaii based staff members work in tandem with each other and will be supervised by the ALS Network's management team (Vice President of Care Services and Vice President of Community Outreach) to ensure best practices are implemented and peer support is available.

ALSOH and ALS Network leadership teams will convene to confirm activities and progress in accordance with stated goals in this application.

Please see attached proposed program organizational chart related to the request.

## **3. Compensation**

The applicant shall provide an annual salary range paid by the applicant to the three highest paid officers, directors, or employees of the organization by position title, not employee name.

ALSOH does not pay any officers, directors or employees.

## **VII. Other**

### **1. Litigation**

The applicant shall disclose any pending litigation to which they are a party, including the disclosure of any outstanding judgement. If applicable, please explain.

N/A

**2. Licensure or Accreditation**

The applicant shall specify any special qualifications, including but not limited to licensure or accreditation that the applicant possesses relevant to this request.

N/A

**3. Private Educational Institutions**

The applicant shall specify whether the grant will be used to support or benefit a sectarian or non-sectarian private educational institution. Please see [Article X, Section 1, of the State Constitution](#) for the relevance of this question.

N/A

**4. Future Sustainability Plan**

The applicant shall provide a plan for sustaining after fiscal year 2026 the activity funded by the grant if the grant of this application is:

- (a) Received by the applicant for fiscal year 2026, but
- (b) Not received by the applicant thereafter.

ALSOH and the ALS Network are dependent upon philanthropy and public funding to meet programmatic and budgeted revenue goals each year. Each organization has been successful in launching and sustaining programs in Hawaii and will leverage state funding to attract additional philanthropic investment and support.

The ALS Network strives to maintain a diverse portfolio for community engagement and support including campaigns and appeals related to: events, direct marketing, foundation funding and corporate support, major gifts, planned gifts, and more. Funds raised by the ALS Network in Hawaii are reinvested in support for programs and services that benefit Hawaii's ALS community. If the State of Hawaii Grant in Aid funding is not continued beyond this grant period, these sources of funding will help sustain grant activities after fiscal year 2025-26.

Public funding is an essential component of support for the ALS community - that support comes at a time when people are extremely vulnerable in every way – physically, mentally, financially, to name a few. The safety net of care and resources is critical to combat this disease. Without public funding, the ALS community is reliant on itself to fund the care model that is effective and to fuel scientific discovery, but the reality is that brain health is everyone's issue and, as we learn more, we will likely discover that this neurodegenerative disease, like many others is a true public health issue. From the factors that contribute to a diagnosis to the impact on family caregivers, public solutions and support sustains progress that benefits the ALS community today, and those who will be diagnosed in the future.

**DECLARATION STATEMENT OF  
APPLICANTS FOR GRANTS PURSUANT TO  
CHAPTER 42F, HAWAII REVISED STATUTES**

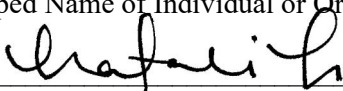
The undersigned authorized representative of the applicant certifies the following:

- 1) The applicant meets and will comply with all of the following standards for the award of grants pursuant to Section 42F-103, Hawaii Revised Statutes:
  - a) Is licensed or accredited, in accordance with federal, state, or county statutes, rules, or ordinances, to conduct the activities or provide the services for which a grant is awarded;
  - b) Complies with all applicable federal and state laws prohibiting discrimination against any person on the basis of race, color, national origin, religion, creed, sex, age, sexual orientation, or disability;
  - c) Agrees not to use state funds for entertainment or lobbying activities; and
  - d) Allows the state agency to which funds for the grant were appropriated for expenditure, legislative committees and their staff, and the auditor full access to their records, reports, files, and other related documents and information for purposes of monitoring, measuring the effectiveness, and ensuring the proper expenditure of the grant.
- 2) If the applicant is an organization, the applicant meets the following requirements pursuant to Section 42F-103, Hawaii Revised Statutes:
  - a) Is incorporated under the laws of the State; and
  - b) Has bylaws or policies that describe the manner in which the activities or services for which a grant is awarded shall be conducted or provided; and
- 3) If the applicant is a non-profit organization, it meets the following requirements pursuant to Section 42F-103, Hawaii Revised Statutes:
  - a) Is determined and designated to be a non-profit organization by the Internal Revenue Service; and
  - b) Has a governing board whose members have no material conflict of interest and serve without compensation.
- 4) The use of grant-in-aid funding complies with all provisions of the Constitution of the State of Hawaii (for example, pursuant to Article X, section 1, of the Constitution, the State cannot provide "... public funds ... for the support or benefit of any sectarian or nonsectarian private educational institution...").

Pursuant to Section 42F-103, Hawaii Revised Statutes, for grants used for the acquisition of land, when the organization discontinues the activities or services on the land acquired for which the grant was awarded and disposes of the land in fee simple or by lease, the organization shall negotiate with the expending agency for a lump sum or installment repayment to the State of the amount of the grant used for the acquisition of the land.

Further, the undersigned authorized representative certifies that this statement is true and correct to the best of the applicant's knowledge.

\_\_\_\_\_  
(Typed Name of Individual or Organization)

  
\_\_\_\_\_  
(Signature)

\_\_\_\_\_  
(Date)

\_\_\_\_\_  
(Typed Name)

\_\_\_\_\_  
(Title)

**VERIFICATION OF PUBLIC PURPOSE**

**APPLICANTS FOR GRANTS PURSUANT TO  
CHAPTER 42F, HAWAII REVISD STATUTES**

The undersigned authorized representative of the applicant certifies the following:

The applicant meets and complies with all of the following standards for the award of grants pursuant to Section 42F-102, Hawaii'i Revised Statutes, Application for grants.

Requests for grants shall be submitted to the appropriate standing committees of the legislature at the start of each regular session of the legislature.

The applicant has provided:

- (1) The name of the requesting organization or individual;
- (2) The public purpose for the grant;
- (3) The services to be supported by the grant;
- (4) The target group; and
- (5) The cost of the grant and the budget.

The undersigned authorized representative certifies that this statement is true and correct to the best of the applicant's knowledge.

ALS Ohana of Hawaii

(Typed Name of Individual or Organization)



\_\_\_\_\_  
(Signature)

January 13, 2025

\_\_\_\_\_  
(Date)

Natalie Fonda

(Typed Name)

President and Treasurer

(Title)

**BUDGET REQUEST BY SOURCE OF FUNDS**

Period: July 1, 2025 to June 30, 2026

Applicant: ALS Ohana of Hawaii

<b>BUDGET CATEGORIES</b>	<b>Total State Funds Requested (a)</b>	<b>Total Federal Funds Requested (b)</b>	<b>Total County Funds Requested (c)</b>	<b>Total Private/Other Funds Requested (d)</b>
<b>A. PERSONNEL COST</b>				
1. Salaries	379,565	0	0	0
2. Payroll Taxes & Assessments	29,715			
3. Fringe Benefits	17,898			
<b>TOTAL PERSONNEL COST</b>	<b>427,178</b>			
<b>B. OTHER CURRENT EXPENSES</b>				
1. Airfare, Inter-Island	12,000			
2. Insurance	3,000			
3. Lease/Rental of Equipment				
4. Lease/Rental of Space	25,000			
5. Staff Training				
6. Supplies	2,500			
7. Telecommunication	2,500			
8. Utilities				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				
<b>TOTAL OTHER CURRENT EXPENSES</b>	<b>45,000</b>			
<b>C. EQUIPMENT PURCHASES</b>				
<b>D. MOTOR VEHICLE PURCHASES</b>				
<b>E. CAPITAL</b>				
<b>TOTAL (A+B+C+D+E)</b>	<b>472,178</b>			
<b>SOURCES OF FUNDING</b>		Budget Prepared By:		
(a) Total State Funds Requested	472,178	Natalie Fonda		
(b) Total Federal Funds Requested	0	Name (Please type or print) Phone		
(c) Total County Funds Requested	0			
(d) Total Private/Other Funds Requested	0	Signature of Authorized Official Date		
<b>TOTAL BUDGET</b>	<b>472,178</b>	Natalie Fonda, President and Treasurer, ALS Ohana of Hawaii		
		Name and Title (Please type or print)		



## BUDGET JUSTIFICATION - PERSONNEL SALARIES AND WAGES

Period: July 1, 2025 to June 30, 2026

Applicant: ALS Ohana of Hawaii

POSITION TITLE		FULL TIME EQUIVALENT	ANNUAL SALARY A	% OF TIME ALLOCATED TO GRANT REQUEST B	TOTAL STATE FUNDS REQUESTED (A x B)
Care Manager		1.25	\$117,400.00	100.00%	\$ 117,400.00
Equipment Loan Coordinator		1	\$68,200.00	100.00%	\$ 68,200.00
Assistant Director of Community Outreach		1	\$82,500.00	100.00%	\$ 82,500.00
Advocacy Manager (client engagement)		0.25	\$90,000.00	25.00%	\$ 22,500.00
Care Services Assistant		0.25	\$54,666.00	25.00%	\$ 13,666.50
Marketing and Communication Coordinator		0.5	\$52,000.00	50.00%	\$ 26,000.00
Database Manager		0.25	\$87,820.00	25.00%	\$ 21,955.00
Director of Care Services		0.25	\$109,375.00	25.00%	\$ 27,343.75
					\$ -
					\$ -
					\$ -
					\$ -
					\$ -
					\$ -
<b>TOTAL:</b>					379,565.25
<b>JUSTIFICATION/COMMENTS:</b> All paid positions are ALS Network personnel who will ensure that deliverables are met.					

**BUDGET JUSTIFICATION - EQUIPMENT AND MOTOR VEHICLES**

Period: July 1, 2025 to June 30, 2026

Applicant: ALS Ohana of Hawaii

DESCRIPTION EQUIPMENT	NO. OF ITEMS	COST PER ITEM	TOTAL COST	TOTAL BUDGETED
			\$ -	
			\$ -	
			\$ -	
			\$ -	
			\$ -	
<b>TOTAL:</b>			N/A	

**JUSTIFICATION/COMMENTS** The project doesn't include costs for any equipment.

DESCRIPTION OF MOTOR VEHICLE	NO. OF VEHICLES	COST PER VEHICLE	TOTAL COST	TOTAL BUDGETED
			\$ -	
			\$ -	
			\$ -	
			\$ -	
			\$ -	
<b>TOTAL:</b>			N/A	

**JUSTIFICATION/COMMENTS:** The project doesn't include costs for any motor vehicles.

**BUDGET JUSTIFICATION - CAPITAL PROJECT DETAILS**

Period: July 1, 2025 to June 30, 2026

Applicant: ALS Ohana of Hawaii

FUNDING AMOUNT REQUESTED						
TOTAL PROJECT COST	ALL SOURCES OF FUNDS RECEIVED IN PRIOR YEARS		STATE FUNDS REQUESTED	OTHER SOURCES OF FUNDS REQUESTED	FUNDING REQUIRED IN SUCCEEDING YEARS	
	FY:2023-2024	FY:2024-2025	FY:2025-2026	FY:2025-2026	FY:2026-2027	FY:2027-2028
PLANS						
LAND ACQUISITION						
DESIGN						
CONSTRUCTION						
EQUIPMENT						
<b>TOTAL:</b>	<b>N/A</b>	<b>N/A</b>	<b>N/A</b>	<b>N/A</b>	<b>N/A</b>	<b>N/A</b>
<b>JUSTIFICATION/COMMENTS:</b> This project does not include costs associated with capital projects.						

**GOVERNMENT CONTRACTS, GRANTS, AND / OR GRANTS IN AID**

Applicant: ALS Ohana of Hawaii \*There are no active Government Contracts, Grants and/or Grants in Aid at this time.

Contracts Total: -

	<b>CONTRACT DESCRIPTION</b>	<b>EFFECTIVE DATES</b>	<b>AGENCY</b>	<b>GOVERNMENT ENTITY (U.S./State/Hawaii/ Honolulu/ Kauai/ Maui County)</b>	<b>CONTRACT VALUE</b>
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					
13					
14					
15					
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25					
26					
27					
28					
29					
30					

## ALS OHANA

2024

## TREASURER'S REPORT

OPENING BALANCE AS OF DECEMBER 31, 2023

\$ 4,246.85

**Deposits to Account**

<u>Date</u>	<u>Item</u>	<u>Amount</u>
1/11/2024	1st half County of Hawaii Grant	\$ 10,000.00
4/15/2024	Donation	\$ 200.00
		<u>\$ 10,200.00</u>

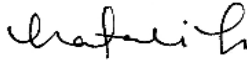
\$ 14,446.85

**Debits to Account**

<u>Date</u>	<u>Item</u>	<u>Amount</u>
1/30/2024	Philadelphia Insurance 09/23-09/24	\$ 1,419.00
2/7/2024	Transfer of County of Hawaii GIA to ALSA	\$ 10,000.00
9/24/2024	Philadelphia Insurance 09/24-09/25	<u>\$ 2,818.00</u>
		<u>\$ 14,237.00</u>

\$ 209.85

As treasurer of ALS Ohana of Hawaii, I hereby certify that the data and information contained in this report is true and accurate.



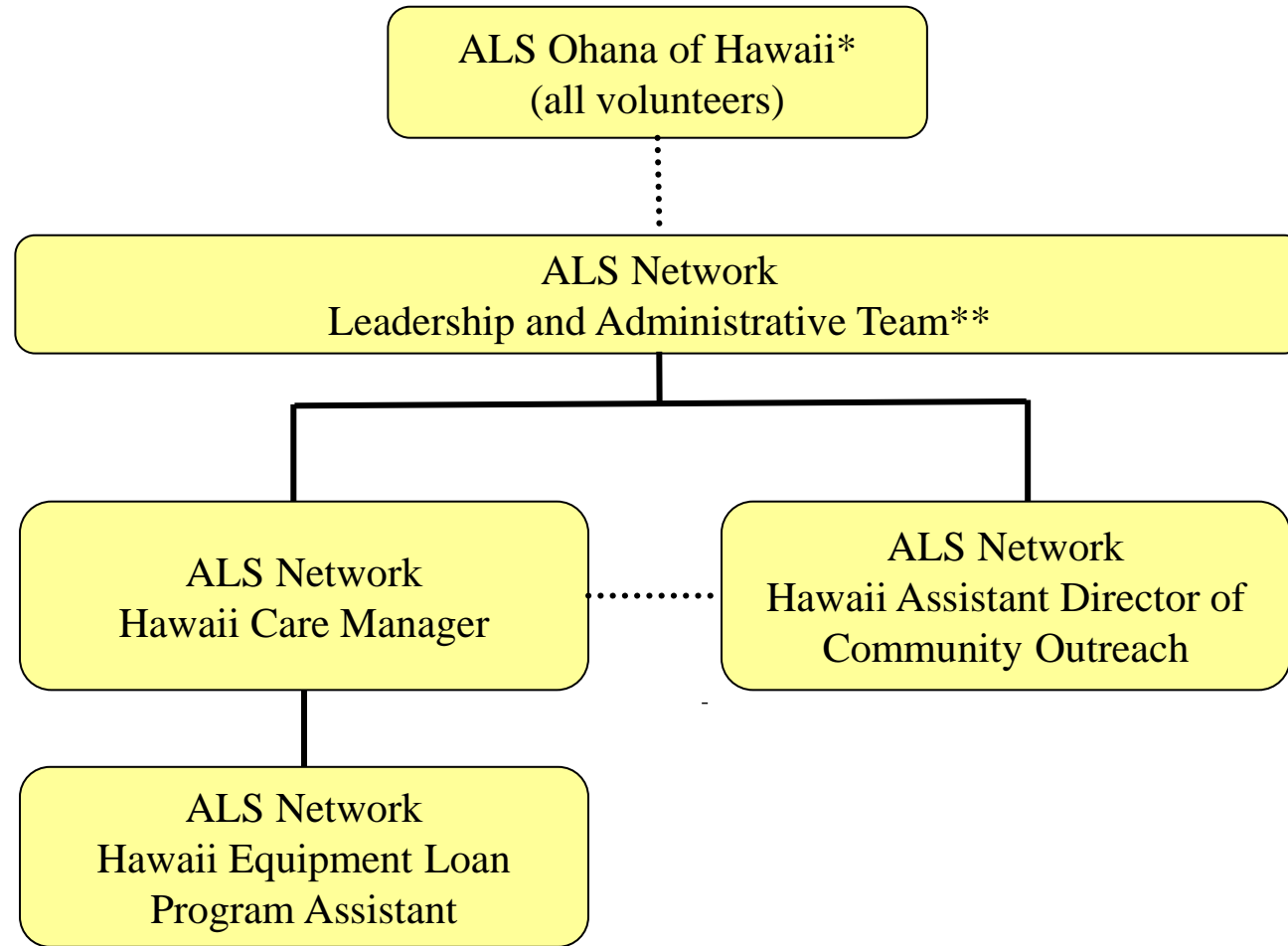
1/13/2025

Natalie Fonda, Treasurer  
800 Bethel St., Suite 405  
Honolulu, HI 96813

Date

## Proposed Program Organizational Chart

\*Positions not charged to the FY25-26 State of Hawaii Grant in Aid



\*\*The ALS Network Leadership and Administrative team includes many professionals focused on supervision, marketing, data, and related support.