

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

Type of Grant Request:

Operating Capital

Legal Name of Requesting Organization or Individual: Db:

ALS Ohana of Hawaii

Amount of State Funds Requested: \$ 213,835

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

The request for funding for the Excellence in ALS Care Initiative will ensure that essential care services will be provided at no cost to people living with ALS and their families in the State of Hawaii, including professional care management support groups, equipment loans and more. The Excellence in ALS Care Initiative supports an extremely vulnerable population and positions the ALS community and general public to directly participate in the search for effective prevention strategies, treatments and cures for ALS, a debilitating and fatal neurodegenerative disease.

Amount of Other Funds Available:

State: \$ 0
Federal: \$ 0
County: \$ TBD
Private/Other: \$ TBD

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

\$ 67,500 expected within the next 12-18 mo

Unrestricted Assets:

\$ 5,021.82

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:

800 Bethel Street, Ste. 405
City: State: Zip:
Honolulu HI 96813

Contact Person for Matters Involving this Application

Name: Natalie Fonda	Title: President and Treasurer
Email: nataliejones@alsohana.org; alsohanahawaii@gmail.com	Phone: 808-258-9388

Federal Tax ID#: 	State Tax ID#:
----------------------	--------------------

Authorized Signature

Natalie Fonda, President & Treasurer

Name and Title

1/18/2024

Date Signed



STATE OF HAWAII
STATE PROCUREMENT OFFICE

CERTIFICATE OF VENDOR COMPLIANCE

This document presents the compliance status of the vendor identified below on the issue date with respect to certificates required from the Hawaii Department of Taxation (DOTAX), the Internal Revenue Service, the Hawaii Department of Labor and Industrial Relations (DLIR), and the Hawaii Department of Commerce and Consumer Affairs (DCCA).

Vendor Name: ALS OHANA (OF HAWAII)

Issue Date: 01/18/2024

Status: **Compliant**

Hawaii Tax#: [REDACTED]
New Hawaii Tax#:
FEIN/SSN#: XX-XXX2415
UI#: No record
DCCA FILE#: 240428

Status of Compliance for this Vendor on issue date:

Form	Department(s)	Status
A-6	Hawaii Department of Taxation	Compliant
8821	Internal Revenue Service	Compliant
COGS	Hawaii Department of Commerce & Consumer Affairs	Exempt
LIR27	Hawaii Department of Labor & Industrial Relations	Compliant

Status Legend:

Status	Description
Exempt	The entity is exempt from this requirement
Compliant	The entity is compliant with this requirement or the entity is in agreement with agency and actively working towards compliance
Pending	A status determination has not yet been made
Submitted	The entity has applied for the certificate but it is awaiting approval
Not Compliant	The entity is not in compliance with the requirement and should contact the issuing agency for more information

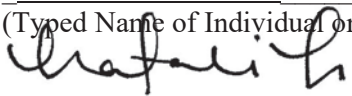
**DECLARATION STATEMENT OF
APPLICANTS FOR GRANTS PURSUANT TO
CHAPTER 42F, HAWAI'I REVISED STATUTES**

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, Hawai'i 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, Hawai'i 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, Hawai'i 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, Hawai'i 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.

ALS Ohana of Hawaii
(Typed Name of Individual or Organization)
 1/18/24
(Signature) (Date)

Natalie Fonda President and Treasurer
(Typed Name) (Title)

**VERIFICATION OF PUBLIC PURPOSE
APPLICANTS FOR GRANTS PURSUANT TO
CHAPTER 42F, HAWAII REVISED 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 Revised Statutes, Application for grants:

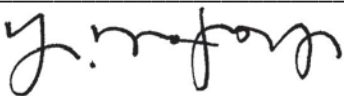
Requests for grants shall be submitted to the appropriate standing committees of the legislature at the start of each regular session of the legislature.

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)

1/18/24

(Date)

President and Treasurer
(Title)

Natalie Fonda
(Typed Name)

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, 2023.

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 (ALSOH) is a community based, volunteer-led organization that was founded nearly two decades ago by two nurses whose lives had been touched deeply by ALS. The husband of one of the nurses lived with ALS for 25 years, and she was his caretaker. The other nurse was diagnosed with ALS herself. ALSOH founders and supporters believe that people affected by ALS should live with the support, compassion, and the practical help needed to optimize quality of life.

In addition to providing direct vital care support to individuals and families living with ALS at no charge, ALSOH partners with other community-based organizations to deliver formal, comprehensive care services to people living with ALS in Hawaii. ALSOH has successfully partnered with ALS Golden West (ALSGW), a nonprofit organization that has been serving California's ALS community since the mid-1980s, and Hawaii's ALS community since 2014.

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 advancing the search for effective prevention strategies, treatments, and cures.

2. The goals and objectives related to the request:

The ALSGW'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. It emphasizes coordination and collaboration among expert caregivers, social workers, and health care providers in clinical, community and home-based settings so that the primary environments of a person living with ALS are considered and they can live with as much dignity and independence as possible. As an evidence-based, wraparound care approach, ALSGW's *Excellence in ALS Care Initiative* includes opportunities to advance ALS research and public awareness efforts designed to 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 ALSGW's *Excellence in ALS Care Initiative* and wraparound model of care in Hawaii by:
 - Providing training and support for physicians, clinicians and caregivers;
 - 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 program and research partners for the ALS community.

3. The public purpose and need to be served:

Amyotrophic Lateral Sclerosis (ALS) is a fatal neuromuscular disease that robs a person of the ability to walk, talk, swallow, and to breathe. ALS does not discriminate: it affects women and men of all ages, ethnicities and socioeconomic backgrounds. For unknown reasons, U.S. military veterans are twice as likely to be diagnosed with ALS than civilians. Currently there are no effective treatments or cures for ALS.

Most people diagnosed with ALS are unfamiliar with the disease, as only 10% of all cases are related to family history. Most people diagnosed with ALS have a 2- to 5-year life expectancy. Until there are effective treatments and cures, access to proactive, expert care has been studied and is proven to be the best way to extend life expectancy and improve quality of life after an ALS diagnosis.

A person with ALS progressively loses the ability to move, speak, swallow, and breathe. They experience relentless physical paralysis and are at high risk of death due to respiratory infection as the disease progresses. To meet the challenges of daily living, people with ALS need multiple interventions and medications to maintain safety and quality of life. Many of these interventions are not covered by insurance, and individuals may not have access to other resources to afford “out of pocket” purchases and expenses.

ALS is an incredibly isolating disease and managing the progression of ALS is emotionally, physically, and financially draining for the entire household. 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. 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 and vulnerable patients and caregivers.

The best form of medical treatment proven to improve quality of life and extend life expectancy involves expert, proactive multidisciplinary collaborative care. In Hawaii, the situation for people with ALS is precarious due to the lack of specialists in the state. However, ALSGW has long established and important relationships with Kaiser Permanente and The Queens Medical Center in Honolulu to ensure robust, local, multidisciplinary clinical care. Outside of these institutions, healthcare professionals in the fields of neurology, pulmonology, and respiratory, physical and occupational therapy with ALS patients on their caseloads are often untrained and lack knowledge regarding best practices in ALS care, especially those in urgent care and emergency room settings.

Through ALSGW's *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 ALSGW's foundational value that no one should be alone with ALS and positions the ALS community to directly participate in achieving our shared vision – creating a world without ALS.

4. Describe the target population to be served:

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 through awareness.

5. Describe the geographic coverage.

The geographic scope of the grant includes the entire State of Hawaii. ALSGW serves approximately 95% of the state's predicted prevalence, along with their loved ones, as well as bereavement support for those who have lost loved ones to ALS. Prior to offering comprehensive care services, Hawaii's ALS community was largely unsupported, especially on Honolulu's neighbor islands. As a result of collaborative efforts by ALSOH and ALSGW, 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, low-income, 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 there are effective treatments and cures for ALS, expert medical, community, and home-based care is known to help people with ALS live better and up to 12 months longer with the disease than any other form of therapy. 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 ALSGW will have access to a professional Care Manager and comprehensive care services designed to help people living with ALS, their loved ones, and professional caregivers find solutions for their changing circumstances as the disease progresses. The Care Manager will connect individuals and families to essential information, community resources, educational opportunities, other people with ALS and their families, 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.

The 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 and loved ones via phone, email, text and videoconference, and attends ALS clinic appointments. During client consultations, the 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. The Care Manager serves as an advocate with insurance companies and government agencies on behalf of clients and assists with referrals to medical, legal, financial, transportation, in-home health care and counseling services.

The 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 the 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. The Care Manager also facilitates support groups, educational programs, and supports community activities (please 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, 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.

ALSGW successfully partners with The Queens Medical Center and Kaiser Permanente, a Recognized ALS Treatment Center in Honolulu. And a number of years ago, in response to the global pandemic, ALSGW facilitated new telemedicine partnerships with ALS Certified Treatment Centers of Excellence at UCSF and Loma Linda University to ensure clinical care for Hawaii residents when in person clinic visits were not feasible. ALSOH and ALSGW are always open to opportunities to partner with additional medical providers who are committed to offering vital clinical services to clients.

Equipment Loan Program: Ninety percent of people diagnosed with ALS will require adaptive equipment in order to remain safe, comfortable, mobile and communicative as the disease progresses. ALSGW's equipment loan program makes it possible to provide loans of critical medical and assistive equipment 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 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 ALSGW Care Services team oversees assessments and referrals, ordering, pick up, delivery, inventorying, cleaning and repairing equipment provided during the grant period for Hawaii’s ALS community.

Support Groups: Support groups are highly valuable learning forums focused on promoting strategies for meeting the challenges of living with ALS. Monthly support groups – offered online and in-person – feature both educational speakers and small group discussions and are open to all people with ALS, caregivers, family members and friends at no charge. ALSGW 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 ALSGW 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 and maintaining wellness, participating in ALS research, grief and bereavement, and more.

Education, Awareness, Outreach Events, and Special Programs: Special educational events and programs with expert speakers on a range of topics, including caregiver support, current clinical trials, treatment management, wellness 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, social workers, and other experts in the field, and ask direct questions of these experts. ALSGW also organizes regional community events designed to bring the entire ALS community together to raise public awareness and inspire action, including the Hawaii Walk to Defeat ALS. ALSGW’s ALS 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.

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 an anticipated 75 people living with ALS and hundreds of their loved ones, family members,

friends, colleagues, and caregivers as well as community members, medical professionals, researchers, and scientists who have lost loved ones to ALS.

Each quarter, grant activities will include:

- Comprehensive Care Management Services for people diagnosed with ALS and their loved ones.
- A minimum of 3 support groups hosted in person and facilitated by the Care Manager (1 each month). Clients are also invited to attend any of ALSGW's monthly online support groups (20 per month), as some are focused on specific topics of interest (i.e.: 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 Q1, ALSOH and ALSGW will 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 goals related to programs and services
- Informal and formal surveys of clients and partners
- Staff and volunteer performance assessments

ALSGW records and reviews client data monthly 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*. ALSGW 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 the Care Manager
- The number of equipment loans
- The number of support 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 2025.

Quarter 1	Quarter 2	Quarter 3	Quarter 4	Total Grant
\$53,458.75	\$53,458.75	\$53,458.75	\$53,458.75	\$213,835

3. The applicant shall provide a listing of all other sources of funding that they are seeking for fiscal year 2025.

ALSOH is seeking funds from the County of Hawaii in fiscal year 2025 and donations from private donors.

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 2025 for program funding.

Federal: N/A

State of Hawaii GIA: 2023-2024

County of Hawaii GIA: 2021-2022

County of Hawaii GIA: 2022-2023

County of Hawaii GIA: 2023-2024

6. The applicant shall provide the balance of its unrestricted current assets as of December 31, 2023.

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 ALS Golden West 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 Hawaii.

Over four decades, ALS Golden West has spearheaded many care, research and advocacy focused initiatives to benefit the ALS community. In addition to developing and promoting the multidisciplinary wraparound model of care that is codified in the California Health Code as a result of public policy efforts by our organization, it has partnered with many institutions to incubate and launch ALS Certified Treatment Centers of Excellence and multidisciplinary clinics throughout California and Hawaii. Working closely with ALS clinicians, ALSGW is leading efforts to pursue developing practice parameters and clinical guidelines to ensure better access to home health and durable medical equipment.

In order to improve care and quality of life for people with ALS today, ALSGW's programs also focus on advocacy at local, state and federal levels as well as ALS research to accelerate therapy development. Serving the largest ALS population in the country, ALSGW plays a prominent role in promoting and recruiting for clinical trials and natural history studies.

Since 2014, ALSGW's caseload in Hawaii has increased by more than 60%. As a result of ALSGW and partner organizations' efforts in Hawaii, more clients are seeking care services. State of Hawaii GIA funding would provide essential support to meet the needs of the current caseload. ALSGW 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 local services as well as engage more people in the search for effective prevention strategies, treatments and cures for ALS – these efforts will have global impact.

Related contracts over the past three years that are pertinent to this request:

- ALSOH received County of Hawaii Grant In Aid awards in 2021, 2022, and 2023, to execute the ALSGW's Care Services program.
- In 2021, 2022 and 2023, ALSGW (formerly called the Golden West Chapter of the ALS Association and soon to be renamed and rebranded, the ALS Network) secured a City and County of Honolulu Grant in Aid to provide a variety of 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 as the Care Manager meets clients and their loved ones in their homes, in clinic settings, and virtually, and everyone else on the care team in clinic settings or virtually. This ensures inclusivity, access, and safety. Currently, ALSGW maintains a centralized office location in Honolulu for conducting Care Services and Community Outreach related business and meetings. Storage units are maintained on several islands to support equipment loan program activities.

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 ALSGW's Hawaii staff members and infrastructure as follows:

- One full time ALSGW Care Manager
- One full time ALSGW Regional Director of Community Outreach
- One full time Equipment Loan Program Assistant

Oversight and supervision will be provided by ALSGW'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 ALSGW's Care Services Assistant, Director of Care Services, Director of Data Management, Director of Marketing and Communications, and administrative staff.

ALSGW's Care Manager is an established and trusted healthcare professional based on Oahu who is trained to help people living with ALS. In addition to serving the client community, the 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 of ALS care.

ALSGW's Regional Director of Community Outreach is a successful and 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.

ALSGW's Equipment Loan Program Assistant 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 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.

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 ALSGW, 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 ALSGW staff in Hawaii. The Hawaii based staff members work in tandem with each other and will be supervised by ALSGW'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 ALSGW 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 2024-25 the activity funded by the grant if the grant of this application is:

- (a) Received by the applicant for fiscal year 2024-25, but

(b) Not received by the applicant thereafter.

ALSOH and ALSGW 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.

Both ALSOH and ALSGW strive to maintain a diverse portfolio for community engagement and support of the ALS community, and the two organizations collaborate for both purposes. ALSGW actively drives campaigns and appeals related to: events, direct marketing, foundation funding and corporate support, major gifts, planned gifts, and more. Funds raised by ALSGW in Hawaii are reinvested in support of 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 may be used to help sustain grant activities after fiscal year 2024-25.

BUDGET REQUEST BY SOURCE OF FUNDS

Period: July 1, 2024 to June 30, 2025

Applicant: ALS Ohana of Hawaii

BUDGET CATEGORIES	Total State Funds Requested (a)	Total Federal Funds Requested (b)	Total County Funds Requested (c)	Total Private/Other Funds Requested (d)
A. PERSONNEL COST				
1. Salaries	213,835			
2. Payroll Taxes & Assessments	29,325			
3. Fringe Benefits	20,600			
TOTAL PERSONNEL COST	263,760			
B. OTHER CURRENT EXPENSES				
1. Airfare, Inter-Island				
2. Insurance				
3. Lease/Rental of Equipment				
4. Lease/Rental of Space				
5. Staff Training				
6. Supplies				
7. Telecommunication				
8. Utilities				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				
TOTAL OTHER CURRENT EXPENSES				
C. EQUIPMENT PURCHASES				
D. MOTOR VEHICLE PURCHASES				
E. CAPITAL				
TOTAL (A+B+C+D+E)	263,760			
SOURCES OF FUNDING		Budget Prepared By:		
(a) Total State Funds Requested	213,835	Natalie Fonda 808-258-9388		
(b) Total Federal Funds Requested		Name (Please type or print) Phone		
(c) Total County Funds Requested	50,000	1/18/24		
(d) Total Private/Other Funds Requested		Signature of Authorized Official Date		
TOTAL BUDGET	263,835	Natalie Fonda, President and Treasurer Name and Title (Please type or print)		

BUDGET JUSTIFICATION - PERSONNEL SALARIES AND WAGES

Period: July 1, 2024 to June 30, 2025

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)
GW Hawaii Care Manager	1	85438	100.00%	\$ 85,438.00
GW Hawaii Assistant Director, Community Outreach	1	71657	100.00%	\$ 71,657.00
GW Hawaii Equipment Loan Program Coordinator	1	56740	100.00%	\$ 56,740.00
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
TOTAL:				213,835.00
JUSTIFICATION/COMMENTS: Based on the number of people living with ALS residing in and visiting the State of Hawaii, our program partner, ALS Golden West will augme				

BUDGET JUSTIFICATION - EQUIPMENT AND MOTOR VEHICLES

Period: July 1, 2024 to June 30, 2025

Applicant: ALS Ohana of Hawaii

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

JUSTIFICATION/COMMENTS:

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

JUSTIFICATION/COMMENTS:

BUDGET JUSTIFICATION - CAPITAL PROJECT DETAILS

Period: July 1, 2024 to June 30, 2025

Applicant: ALS Ohana of Hawaii

FUNDING AMOUNT REQUESTED						
TOTAL PROJECT COST: N/A	ALL SOURCES OF FUNDS RECEIVED IN PRIOR YEARS		STATE FUNDS REQUESTED	OTHER SOURCES OF FUNDS REQUESTED	FUNDING REQUIRED IN SUCCEEDING YEARS	
	FY: 2022-2023	FY: 2023-2024	FY: 2024-2025	FY: 2024-2025	FY: 2025-2026	FY: 2026-2027
PLANS						
LAND ACQUISITION						
DESIGN						
CONSTRUCTION						
EQUIPMENT						
TOTAL:	N/A	N/A	N/A	N/A	N/A	N/A
JUSTIFICATION/COMMENTS: not applicable at this time						

GOVERNMENT CONTRACTS, GRANTS, AND / OR GRANTS IN AID

Applicant: _____

Contracts Total: -

	CONTRACT DESCRIPTION	EFFECTIVE DATES	AGENCY	GOVERNMENT ENTITY (U.S./State/Hawaii/ Honolulu/ Kauai/ Maui County)	CONTRACT VALUE
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					
13					
14					
15					
16					
17					
18					
19					
20					
21					
22					
23					
24					
25					
26					
27		10			Application for Grants

28														
29														
30														

ALS OHANA
2022 TREASURER'S REPORT

OPENING BALANCE AS OF DECEMBER 31, 2022

\$ 9,307.58

Deposits to Account

<u>Date</u>	<u>Item</u>	<u>Amount</u>
1/5/2022	Reimbursement 1/2 insurance	\$ 1,413.00
3/3/2022	Amazon smile donation	\$ 15.67
5/24/2022	Amazon Smile Donation Direct Deposit	\$ 12.56
7/14/2022	County of Hawaii 2nd half Grant	\$ 11,650.00
9/2/2022	Amazon Smile Donation Direct Deposit	\$ 14.86
10/18/2022	County of Hawaii 1st Half grants	\$ 15,000.00
10/28/2022	Donation	\$ 250.00
11/21/2022	Amazon Smile Donation	\$ 16.64
		<u>\$ 28,372.73</u>

\$ 37,680.31

Debits to Account

<u>Date</u>	<u>Item</u>	<u>Amount</u>
1/1/2022	Natalie Fonda - reimbursement for ALS Christmas gifts	\$ 186.94
7/14/2022	ALS Association - Transfer of 2nd half County of Hawaii Grant	\$ 11,650.00
9/10/2022	Philadelphia Insurance - 9/22-9/23	\$ 2,864.00
9/21/2022	CPA Collective - 990-N 2021 Taxes	\$ 52.36
10/18/2022	ALS Association - Transfer of 1st half of County of Hawaii Grant - professional	\$ 10,000.00
10/18/2022	ALS Association - Transfer if 1st Half County Grant - Equipment	\$ 5,000.00
11/15/2022	Rembursement to MacHoover for Halloween Gift Baskets for ALS families	\$ 271.98
12/16/2023	ALS Foundation of Hawaii - Raffle prizes for Christmas Party	\$ 100.00
12/15/2022	Payment to A Catered Experience for ALS Christmas Party Food	\$ 1,000.00
12/15/2022	Reimbursement to Natalie Fonda for ALS Christmas party raffle gifts	\$ 323.10
		<u>\$ 31,448.38</u>

BALANCE AS OF December 31, 2022

\$ 6,231.93

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



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

1/17/2023

Date

ALS OHANA
2023 TREASURER'S REPORT

OPENING BALANCE AS OF DECEMBER 31, 2022

\$ 6,231.93

Deposits to Account

Date	Item	Amount
2/13/2023	Amazon Smile	\$ 10.25
3/26/2023	Donation	\$ 200.00
5/4/2023	Amazon smile Donation	\$ 5.00
5/22/2023	Amazon Smile Donation	\$ 20.24
7/14/2022	ALS Association - Transfer of 2nd half of County of Hawaii Grant - professional	\$ 10,000.00
7/14/2022	ALS Association - Transfer if 2ndHalf County Grant - Equipment	\$ 5,000.00
11/20/2023	Donation	\$ 40.00

\$ 15,275.49

Debits to Account

Date	Item	Amount
3/27/2023	Payment to CPA Collective for Attorney General Letter	\$ 94.24
7/15/2022	ALS Association - Transfer of 2nd half of County of Hawaii Grant - professional	\$ 10,000.00
7/15/2022	ALS Association - Transfer if 2nd Half County Grant - Equipment	\$ 5,000.00
10/10/2023	CPA Collective - Tax filing	\$ 52.36
9/10/2022	Philadelphia Insurance - 9/22-9/23	\$ 1,339.00

\$ 16,485.60

BALANCE AS OF December 31, 2023

\$ 5,021.82

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



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

Date
12/31/2023