

**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:

ALS Ohana of Hawaii

Amount of State Funds Requested: \$ 370,261.00

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 community based and clinical care services will be provided at no cost to people living with ALS and their families in 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 to directly participate in the search for effective treatments and cures for ALS.

Amount of Other Funds Available:

State: \$ 0.00
Federal: \$ 0.00
County: \$ 0.00
Private/Other: \$ 55,994.00

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

\$ 200,000.00

Unrestricted Assets:

\$ 200,000.00

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, Suite 405
City: Honolulu State: HI Zip: 96813

Contact Person for Matters Involving this Application

Name: Natalie Fonda	Title: President and Treasurer
Email: Nataliejones@alshana.org	Phone: 808-258-9388

Federal Tax ID#:

State Tax ID#

Authorized Signature

President and Treasurer

Name and Title

1/17/19

Date Signed

received
1/17/19 1:40p RR

Application Submittal Checklist

The following items are required for submittal of the grant application. Please verify and check off that the items have been included in the application packet.

- 1) Certificate of Good Standing (If the Applicant is an Organization)
- 2) Declaration Statement
- 3) Verify that grant shall be used for a public purpose
- 4) Background and Summary
- 5) Service Summary and Outcomes
- 6) Budget
 - 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](#))
- 7) Experience and Capability
- 8) Personnel: Project Organization and Staffing

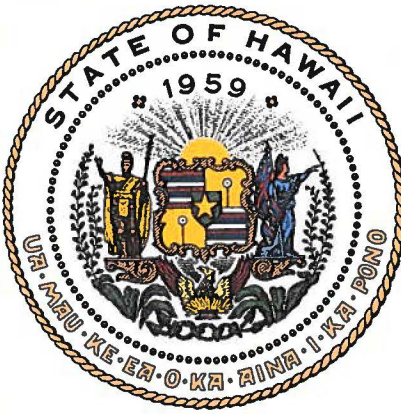


NATALIE FONDA, PRESIDENT & TREASURER

AUTHORIZED SIGNATURE

PRINT NAME AND TITLE

DATE



Department of Commerce and Consumer Affairs

CERTIFICATE OF GOOD STANDING

I, the undersigned Director of Commerce and Consumer Affairs of the State of Hawaii, do hereby certify that

ALS OHANA (OF HAWAII)

was incorporated under the laws of Hawaii on 09/23/2013 ; that it is an existing nonprofit corporation; and that, as far as the records of this Department reveal, has complied with all of the provisions of the Hawaii Nonprofit Corporations Act, regulating domestic nonprofit corporations.



IN WITNESS WHEREOF, I have hereunto set my hand and affixed the seal of the Department of Commerce and Consumer Affairs, at Honolulu, Hawaii.

Dated: January 15, 2019

Director of Commerce and Consumer Affairs

**DECLARATION STATEMENT OF
APPLICANTS FOR GRANTS PURSUANT TO
CHAPTER 42F, HAWAII REVISIED 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.

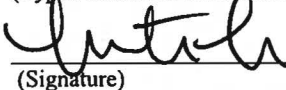
- 3) If the applicant is a non-profit organization, it meets the following requirements pursuant to Section 42F-103, Hawaii Revised Statutes:
 - a) Is determined and designated to be a non-profit organization by the Internal Revenue Service; and
 - b) Has a governing board whose members have no material conflict of interest and serve without compensation.

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.

ALS Ohana of Hawaii

(Typed Name of Individual or Organization)



(Signature)

1/7/15

(Date)

Natalie Fonda

(Typed Name)

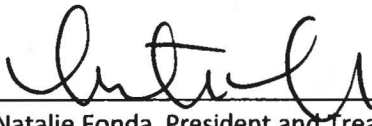
President and Treasurer

(Title)

§42F-102 Applications 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. Each request shall state:

- (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. [L 1997, c 190, pt of §3; am L 2014, c 96, §6]

Pursuant to the paragraph above, I verify that the grant applied for shall be used for a public purpose.
Please see attached request.



Natalie Fonda, President and Treasurer, ALS Ohana of Hawaii

Date: 1/17/19

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. Certificate of Good Standing (If the Applicant is an Organization)

If the applicant is an organization, the applicant shall submit one (1) copy of a certificate of good standing from the Director of Commerce and Consumer Affairs that is dated no earlier than December 1, 2018.

Please see attached Certificate of Good Standing.

2. Declaration Statement

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

Please see attached Declaration Statement.

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. ([Link](#))

Please see attached verification of public purpose.

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 practical help needed to maintain a meaningful 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, ALS Ohana of Hawaii (ALSOH) will partner with The ALS Association Golden West Chapter (GWC), a nonprofit organization that has been serving the ALS community in Hawaii for many years, and formally since 2014. The mission of the GWC is to discover treatments and cures for ALS, and to serve and empower people affected by ALS to live their lives to the fullest.

In September 2010, The ALS Association Golden West Chapter was created as a result of a legal merger of the Greater Los Angeles and Greater Bay Area Chapters of The ALS Association. Local families established the Greater Los Angeles Chapter in the mid-1980's to provide significant and meaningful assistance to all persons with ALS, their families, caregivers and health professionals in its service area, and to support the search for a cure. The Greater Bay Area Chapter was formed in the same way for the same purpose at approximately the same time. All GWC services are provided free of charge to the ALS community.

ALSOH has successfully partnered with the GWC to deliver programs in Hawaii since 2014, as the two organizations' missions are closely aligned and they share a deep commitment to provide Hawaii's ALS community with the best possible care while simultaneously advancing the search for effective treatments and cures for ALS.

2. The goals and objectives related to the request

The goals and objectives related to this request are designed to ensure excellence in ALS care in the State of Hawaii at no charge to people with ALS and their loved ones and include:

- A. Maximizing access to care, support and community resources to help people live longer and better with ALS by:
 - Providing professional Care Management services for all people with ALS
 - Offering a minimum of 20 support groups during the grant period for people living with ALS and their loved ones

- B. Expanding the reach and effectiveness of the GWC's *Excellence in ALS Care Initiative* and wraparound model of care in Hawaii by:
 - Supporting increased Care Management hours and opportunities to increase clinical care partnerships
 - Expanding Equipment Loan Program activities including purchases, repairs, shipping, training, etc.
 - Providing ongoing training and support for physicians and clinicians serving people with ALS

- Conducting comprehensive community outreach to educate the public about ALS, connect people to available services and to promote early referrals for services

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 gradually robs a person of the ability to walk, talk, swallow, and eventually, to breathe, while the five senses, and typically a person's mind, continues to function normally. 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, for unknown reasons, U.S. military veterans are twice as likely to be diagnosed with ALS than civilians. There is little known about the causes of ALS and there are no known cures.

Most people diagnosed with ALS are unfamiliar with the disease, as 90% of all cases are not related to a family history of the disease. Due to the progressive and highly variable nature of the disease, it may take a while 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 clinic 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 dramatically 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 confused patients and caregivers.

Medical complications associated with ALS are many, and include aspiration pneumonia, neck and back pain, excessive saliva, skin sores and more. 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 even more precarious because physicians and healthcare professionals 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 community based and clinical care services will be provided at no cost to people living with ALS and their families in Hawaii; ensuring that the ALS community is provided with

invaluable support. The *Excellence in ALS Care Initiative* embodies ALSOH's and the GWC's core value that no one should be alone with ALS and positions the ALS community to directly participate in achieving our shared vision – a world without ALS.

4. Describe the target population to be served

The target population to be served includes people of all ages, many of whom are extremely vulnerable due to physical, financial, medical, emotional and social hardships including individuals diagnosed with ALS, their family members and family caregivers, and professional ALS caregivers and healthcare providers, ALS and neurodegenerative disease researchers and public health professionals, as well as colleagues, friends and community members.

5. Describe the geographic coverage

The geographic scope of the grant includes the entire State of Hawaii. The GWC serves approximately 50 people with ALS each year in Honolulu, which represents 73% of the predicted ALS population and a 63% increase since the GWC launched services in Hawaii in 2014. Prior to launching services in 2014, the ALS community was largely unsupported by medical care, education and trained support. As a result of GWC and partner organizations efforts in Hawaii, more clients are seeking care services and the Chapter is exploring options to expand services for underserved members of Hawaii's ALS ohana.

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

Research has proven that expert medical, community and home-based care helps people with ALS live better and longer with the disease than the two FDA-approved drugs. (The medications only extend life approximately 2-4 months; proactive, robust care is proven to extend the life of a person with ALS by 6-12 months.) The *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 that emphasizes coordination and collaboration among expert 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 designed to benefit the entire ALS community.

The scope of work, tasks, and responsibilities for executing the *Excellence in ALS Care Initiative* in Hawaii incorporates the key programmatic elements as follows:

Professional ALS Care Management: Every person with ALS in Hawaii who is connected to ALSOH and the GWC will be provided with access to a professional GWC Care Manager and comprehensive ALS care services designed to help people with ALS, their family members and professional caregivers find solutions for their changing circumstances as the disease progresses, including the loss of the ability to move, swallow, speak and eventually, to breathe. Hawaii's Care Managers 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. Each Care Manager will also participate as a member of multidisciplinary ALS clinic teams, including satellite clinic teams. In this way, Hawaii's Care Managers will serve as a bridge from the home and community to the broad array of professionals who make up a multidisciplinary clinic team, including neurologists, pulmonologists, speech language pathologists, physical and occupational therapists, nutritionists and others, all of whom are essential to the proactive and comprehensive treatment of ALS.

Through in-home, video conferencing, emails, and phone consultations, as well as during clinic visits, Hawaii's Care Managers will make assessments and troubleshoot issues, and create or coordinate a treatment plan that is continually updated to respond to the specific and unique needs of every person with ALS. Hawaii's Care Managers will serve as advocates 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.

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, potential treatments 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. The GWC has successfully incubated Hawaii's first multidisciplinary ALS clinics ensuring that residents of Hawaii do not have to leave the state to seek multidisciplinary clinical care.

Equipment Loan Program: Ninety percent of people diagnosed with ALS will require adaptive equipment in order to remain safe, comfortable, mobile and in communication as the disease progresses. The GWC's equipment loan program makes it possible to provide loans of vital 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 is life-sustaining (ie: 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 lifestyle, 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 GWC Care Management team will oversee assessments and referrals, ordering, pick up, delivery, inventorying, and cleaning and repairing equipment provided during the grant period for Hawaii's ALS community.

Support Groups: Support groups are crucial learning forums focused on promoting strategies for meeting the challenges of living with ALS. Monthly support 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. Online resources and communities such as email forums, livestream events, social media pages, and videos on YouTube and other sites help people connect with ALS resources in the community and each other. Both organizations conduct support groups throughout the State of Hawaii. Both organizations will 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 and more. During the grant period, ALSOH and the GWC will host at least 20 ALS support groups throughout the state.

Education, Awareness, Outreach 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 and social workers and other experts in the field and ask direct questions of these experts. The GWC also organizes regional community events designed to bring the entire ALS community together in an effort to raise public awareness and inspire action in the fight against ALS.

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

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

Each Quarter, grant activities will include:

- Care Management Services for all people with ALS living in the state of Hawaii in contact with the Golden West Chapter
- A minimum of 5 support groups conducted on multiple islands
- A minimum of 8 people with ALS supported via a Multidisciplinary Clinic visit
- A minimum of 4 Equipment Loan Program activities such as a consultation, purchase, delivery and/pick up
- Outreach activities throughout the state
- Documentation of all services provided

In addition to the above stated activities, in Quarter one, ALSOH and the GWC will plan grant activities and confirm dates for all outreach and training events.

In addition to the above stated activities, in Quarter two, the GWC will draft a constituent survey.

In addition to the above stated activities, in Quarter three, the GWC will circulate a constituent satisfaction survey.

In addition to the above stated activities, in Quarter four the GWC will analyze survey results and generate a report of findings.

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

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 assessments

The GWC 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* and wraparound model of care and will continue to do so 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 measure of effectiveness that will be reported will include:

- the number of Care Management engagements
- the number of equipment loans provided, as well as the number of equipment purchases and repairs made
- the number of support groups held on each island and the number of attendees at every support group
- the number of multidisciplinary clinic team client engagements
- the number of trainings for medical and allied health professionals and the attendance numbers
- the number of community outreach events conducted
- formal survey results and analysis

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](#))

Please see attached budget forms.

2. The applicant shall provide its anticipated quarterly funding requests for the fiscal year 2020.

Quarter 1	Quarter 2	Quarter 3	Quarter 4	Total Grant
\$92,565.25	\$92,565.25	\$92,565.25	\$92,565.25	\$370,261.00

3. The applicant shall provide a listing of all other sources of funding that they are seeking for fiscal year 2020.

Other sources of funding for fiscal year 2020 includes revenue from general contributions, community events, grants and major gifts.

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 2020 for program funding.

Federal: N/A
State of Hawaii GIA: 2016-17
County of Hawaii GIA: 2016-17
County of Hawaii GIA: 2017-18

6. The applicant shall provide the balance of its unrestricted current assets as of December 31, 2018.

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 Association Golden West Chapter 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.

The GWC led the charge to develop and launch a professional wraparound system of care to benefit for the ALS community more than 15 years ago in Los Angeles, California. At the request of families residing in Hawaii who were aware of the strength and scope of the available services in California, the GWC brought this expertise and evidence based model of multidisciplinary care to the state in 2014. GWC Care

Services staff typically have a variety of degrees and licenses and work experience relevant to the ALS community in fields such as social work, respiratory therapy, occupational therapy, physical therapy, speech therapy and nursing. They also serve as ambassadors to the patient and medical community seeing to collaborate and affiliate with experts, researchers, community organizations, vendors, the media, and other institutions that may serve the ALS community.

The GWC currently serves approximately 75% of the predicted ALS population in Hawaii, since launching services in 2014 the GWC's caseload has increased by more than 60%. Prior to launching services in 2014, the ALS community was largely unsupported by medical care, education and trained support. As a result of GWC 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 and explore opportunities to expand services for underserved members of Hawaii's ALS ohana.

Lastly, for the sixth year in a row, the largest nonprofit evaluator in the country, Charity Navigator, has award The ALS Association Golden West Chapter with its highest rating, four stars. This rating recognizes the Chapter's commitment to transparency and efficiency. Only 7% of nonprofit organizations in the country achieve Charity Navigator's highest rating for six consecutive years.

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

- In 2016 ALSOH secured a Grant In Aid from the State of Hawaii to implement the GWC's *Excellence in ALS Care Initiative*. In addition to providing Care Management services and equipment loans throughout the state, successful milestones included the launch of ALS Multidisciplinary Clinics to serve people of Hawaii with ALS and numerous educational and support programs offered throughout the state.
- ALSOH received County of Hawaii Grant In Aid awards in 2017 and 2018 to execute the GWC's Care Services programs on the neighbor islands.
- In 2017, the GWC 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. For this request, the GWC will provide facilities necessary to conduct activities including office space and storage units. The office space is in Honolulu and is a centralized location for conducting Care

Services and Community Outreach related business and meetings; the storage units are maintained on a number of 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.

ALSOH is a strictly volunteer organization and will contract with the GWC to provide staff to implement and execute the proposed program. ALSOH volunteers will provide advisory input and additional support as needed.

The proposed staffing pattern relies on GWC staffing and infrastructure and is as follows:

- Two FTE GWC Care Managers
- One FTE GWC Regional Director of Community Outreach
- One FTE GWC Regional Assistant

Oversight and supervision will be provided by the GWC's VP of Care Services and the VP of Community Outreach. Additional program support will be provided by the GWC's Care Services Assistant, Database Manager and outside professional services related to support group facilitation, trainings for professionals and individuals, youth program consultants and others as needed.

Care Managers: GWC Care Managers are established health professionals living in the State of Hawaii who are trained to help people living with ALS. Hawaii's first professional ALS Care Manager is a Registered Occupational Therapist who has identified and recruited many healthcare professionals to embrace the GWC's multidisciplinary program model for ALS care. With the support of the community and in order to increase efficiencies, the Chapter has expanded Care Management services in Hawaii to include part time professionals who reside on and serve the neighbor islands and seeks to increase Care Management hours for Hawaii's ALS community.

Hawaii's Care Managers visit with people with ALS, throughout the state, in their home, as well as at clinic, in the hospital and skilled nursing facilities if necessary. They provide consultations via phone, email, text and videoconference. Hawaii's Care Managers facilitate support groups, consult with support group facilitators who are independent contractors, assess the needs for durable medical equipment and augmentative communications equipment, and serve as key informants to the medical community and multidisciplinary clinic teams.

Community Outreach: The GWC's Regional Director of Community Outreach, has two decades of nonprofit fundraising experience in education, human services, and the performing arts arenas. With a working knowledge of Hawaii's significant array of local community resources, the Regional Director of Community Outreach is well positioned to raise revenue, generate awareness and connect with organizations throughout Hawaii in order to ensure the best possible outcomes for the ALS community.

Administrative Assistant: The request for funding includes increasing the GWC's Regional Assistant position to full time. The Regional Administrative Assistant is extremely knowledgeable and capable and supports both the GWC's Regional Director of Community Outreach and Care Managers in Hawaii.

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 will enter into an agreement to contract for services with the GWC, a nonprofit certified to do business in the State of Hawaii.

This grant will fund the collaboration to execute this evidence based model of care through GWC program staff in Hawaii, including two FTE Regional Care Managers (one Supervising and two serving neighbor islands), one full time Regional Director of Community Outreach, and one FTE Administrative Assistant to execute the program plan. The Hawaii based staff members work in tandem and will be supervised by the GWC'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.

Please see attached proposed organization 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 2019-20 the activity funded by the grant if the grant of this application is:

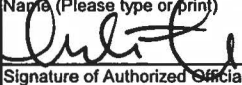
- (a) Received by the applicant for fiscal year 2019-20, but
- (b) Not received by the applicant thereafter.

ALSOH and the GWC are dependent upon philanthropy to meet budgeted revenue goals each year. Each organization strives to maintain a diverse portfolio for community engagement and support including appeals and platforms related to: events, major gifts, direct marketing/mail, events, online giving and deferred or estate gifts. Each organization has been successful in launching and sustaining programs in Hawaii and will leverage state funding whenever possible to attract additional philanthropic investment and support.

BUDGET REQUEST BY SOURCE OF FUNDS

Period: July 1, 2019 to June 30, 2020

Applicant: ALS Ohana of Hawaii (ALSOH)

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	262,131			36,435
2. Payroll Taxes & Assessments	15,198			3,054
3. Fringe Benefits	22,272			1,505
TOTAL PERSONNEL COST	299,601			40,994
B. OTHER CURRENT EXPENSES				
1. Airfare, Inter-Island	5,400			
2. Insurance	0			
3. Lease/Rental of Equipment	0			
4. Lease/Rental of Space	0			15,000
5. Staff Training	0			
6. Supplies	2,500			
7. Telecommunication	4,800			
8. Utilities	0			
9. Travel, Inter-Island: Lodging	2,700			
10. Travel, Inter-Island: Ground Transportation	1,260			
11. Travel, Inter-Island: Meals per diem	1,800			
12. Mileage	4,500			
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TOTAL OTHER CURRENT EXPENSES	22,960			15,000
C. EQUIPMENT PURCHASES	47,700			
D. MOTOR VEHICLE PURCHASES	0			
E. CAPITAL	0			
TOTAL (A+B+C+D+E)	370,261			55,994
SOURCES OF FUNDING		Budget Prepared By:		
(a) Total State Funds Requested	370,261	Natalie Fonda (808) 531-2765		
(b) Total Federal Funds Requested	0	Name (Please type or print) Phone		
(c) Total County Funds Requested	0			
(d) Total Private/Other Funds Requested	55,994	Signature of Authorized Official Date		
TOTAL BUDGET	426,255	Natalie Fonda, President & Treasurer, ALS Ohana of Hawaii Name and Title (Please type or print)		

Applicant: ALS Ohana of Hawaii (ALSOH)

POSITION TITLE	FULL TIME EQUIVALENT	ANNUAL SALARY A	% OF TIME ALLOCATED TO GRANT REQUEST B	TOTAL STATE FUNDS REQUESTED (A x B)
Supervising Regional Care Manager	1.00	\$115,154.00	100.00%	\$ 115,154.00
Neighbor Island Care Manager	1.00	\$72,800.00	100.00%	\$ 72,800.00
Regional Director of Community Outreach	1.00	\$85,155.00	100.00%	\$ 85,155.00
Administrative Assistant	1.00	\$52,984.00	100.00%	\$ 52,984.00
VP of Care Services	1.00	\$97,893.00	6.00%	\$ 5,873.58
VP of Community Outreach	1.00	\$143,800.00	6.00%	\$ 8,628.00
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
TOTAL:				340,594.58

JUSTIFICATION/COMMENTS: The VP of Care Services and VP of Community Outreach are providing supervision and support for all grant activities.

BUDGET JUSTIFICATION - EQUIPMENT AND MOTOR VEHICLES

Period: July 1, 2019 to June 30, 2020

Applicant: ALS Ohana of Hawaii (ALSOH)

DESCRIPTION EQUIPMENT	NO. OF ITEMS	COST PER ITEM	TOTAL COST	TOTAL BUDGETED
Low tech durable medical equipment (ie: transport wheelchairs, shower chairs, etc.)	40	\$100.00	\$ 4,000.00	
Low tech augmentative communication devices (ie: switches, boards, chimes, etc)	40	\$30.00	\$ 1,200.00	
High tech DME and AAC devices (ie: reclining w/c, w/c battery, ramp, ipad, etc.)	20	\$1,200.00	\$ 24,000.00	
Back up electricity generators	15	\$1,000.00	\$ 15,000.00	
Marine batteries	10	\$350.00	\$ 3,500.00	
TOTAL:	125		\$ 47,700.00	

JUSTIFICATION/COMMENTS:

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

JUSTIFICATION/COMMENTS: N/A

BUDGET JUSTIFICATION - CAPITAL PROJECT DETAILS

Period: July 1, 2019 to June 30, 2020

Applicant: ALS Ohana of Hawaii (ALSOH)

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: 2017-2018	FY: 2018-2019	FY:2019-2020	FY:2019-2020	FY:2020-2021	FY:2021-2022
PLANS						
LAND ACQUISITION						
DESIGN						
CONSTRUCTION						
EQUIPMENT						
TOTAL:						
JUSTIFICATION/COMMENTS: N/A						

GOVERNMENT CONTRACTS, GRANTS, AND / OR GRANTS IN AID

Applicant: ALS Ohana of Hawaii (ALSOH)

Contracts Total:

	CONTRACT DESCRIPTION	EFFECTIVE DATES	AGENCY	GOVERNMENT ENTITY (U.S. / State / Haw / Hon / Kau / Mau)
1	Excellence in ALS Care: Professional Services	July 2018-June 2019	County of Hawaii	Hawaii
2	Excellence in ALS Care: Equipment Loan Program	July 2018-June 2019	County of Hawaii	Hawaii
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**ALS OHANA
2018 TREASURER'S REPORT**

OPENING BALANCE AS OF DECEMBER 31, 2017

\$ 2,141.53

Deposits to Account

Date	Item	Amount	
2/7/2018	County of Hawaii Grant final Payment 2017	\$ 3,625.00	
2/20/2018	Contribution Check (Donation)	\$ 48.00	
3/13/2018	Contribution Check (Donation from Travelers)	\$ 100.00	
5/18/2018	Direct Deposit Amazon Smile	\$ 5.00	
6/12/2018	State of Hawaii Grant in Aid Fund	\$ 150,000.00	
7/26/2018	Contribution in memory of Martha Paul	\$ 50.00	
8/15/2018	County of Hawaii Grant Payment 1	\$ 5,862.50	
9/4/2018	State Grant Final Payment	\$ 50,000.00	
8/21/2018	Reef Donation from Mikala Jones video	\$ 15,000.00	
10/29/2018	Network for good donations	\$ 50.00	
11/14/2018	ALSA Reimbursement for 1/2 of insurance	\$ 1,400.50	
12/19/2018	Network for good donations	\$ 75.00	
			<u>\$ 226,216.00</u>
			\$ 228,357.53

Debits to Account

Date	Item	Amount	
1/15/2018	Jennifer Shack (Check 1077) Reimbursement for ALS party raffle gifts	\$ 208.57	
1/29/2018	Rehabilitation Hospital of the Pacific (check 1080) for ALS Support Group Venue	\$ 125.00	
1/30/2018	Natalie Fonda (Check 1081) Reimbursement for Mailing County Grant Package	\$ 19.08	
2/6/2018	Transfer of County of Hawaii Final Payment to Collaborative Partner ALSA	\$ 3,625.00	
5/3/2018	Reimbursement to Natalie Fonda for Annual Report Filing	\$ 12.00	
6/22/2018	Transfer of State of Hawaii Grant in Aid Funds to Collaborative Partner ALSA	\$ 150,000.00	
7/1/2018	Reimbursement to Natalie Fonda for Camp Gigi Banner	\$ 87.95	
8/15/2018	Payment to Hawaii.Gov for Annual Filing	\$ 3.50	
8/16/2018	Transfer of County Grant to Collaborative Partner ALSA	\$ 5,862.50	
9/7/2018	Transfer of State Grant to Collaborative Partner ALSA	\$ 50,000.00	
9/10/2018	Aiea Copy center for ALSA Walk Signs	\$ 227.72	
9/26/2018	Philadelphia Insurance Companies	\$ 2,801.00	
12/20/2018	Uahi Island Grill (Christmas Catering)	\$ 942.41	
12/19/2018	Jennifer Shack (Check 1094) ALS Christmas Party Raffle Gifts	\$ 108.96	
12/13/2018	Natalie Fonda (Check 1091) ALS Christmas Party Raffle Gifts	\$ 109.79	
			<u>\$ 214,133.48</u>
			<u>\$ 14,224.05</u>

BALANCE AS OF December 31, 2018

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 404
Honolulu, HI 96813

1/17/19

Date

Hawaii Excellence in ALS Care Initiative

Program Organization Chart

