

House District _____

Senate District _____

**THE TWENTY-EIGHTH LEGISLATURE
APPLICATION FOR GRANTS
CHAPTER 42F, HAWAII REVISED STATUTES**

Log No: _____

For Legislature's Use Only

Type of Grant Request:

GRANT REQUEST – OPERATING

GRANT REQUEST – CAPITAL

"Grant" means an award of state funds by the legislature, by an appropriation to a specified recipient, to support the activities of the recipient and permit the community to benefit from those activities.

"Recipient" means any organization or person receiving a grant.

STATE DEPARTMENT OR AGENCY RELATED TO THIS REQUEST (LEAVE BLANK IF UNKNOWN): _____

STATE PROGRAM I.D. NO. (LEAVE BLANK IF UNKNOWN): _____

1. APPLICANT INFORMATION:

Legal Name of Requesting Organization or Individual:
ALS Ohana of Hawaii

Dbas: ALS Ohana

Street Address: 800 Bethel Street, Suite 404
Honolulu, Hawaii 96813

Mailing Address:
Same

2. CONTACT PERSON FOR MATTERS INVOLVING THIS APPLICATION:

Name JAN R. MEDUSKY

Title Vice President & Secretary

Phone # 808-531-2765

Fax # 808-599-3736

E-mail JanMedusky@alshana.org; medusky@meduskyandco.com

3. TYPE OF BUSINESS ENTITY:

- NON PROFIT CORPORATION INCORPORATED IN HAWAII
- FOR PROFIT CORPORATION INCORPORATED IN HAWAII
- LIMITED LIABILITY COMPANY
- OTHER
- SOLE PROPRIETORSHIP/INDIVIDUAL

6. DESCRIPTIVE TITLE OF APPLICANT'S REQUEST:

EXCELLENCE IN ALS CARE INITIATIVE

4. FEDERAL TAX ID #: _____

5. STATE TAX ID #: _____

7. AMOUNT OF STATE FUNDS REQUESTED:

FISCAL YEAR 2016: \$ 202,028

8. STATUS OF SERVICE DESCRIBED IN THIS REQUEST:

- NEW SERVICE (PRESENTLY DOES NOT EXIST)
- EXISTING SERVICE (PRESENTLY IN OPERATION)

SPECIFY THE AMOUNT BY SOURCES OF FUNDS AVAILABLE
AT THE TIME OF THIS REQUEST:

STATE \$ 0

FEDERAL \$ 0

COUNTY \$ 0

PRIVATE/OTHER \$ 0

TYPE NAME & TITLE OF AUTHORIZED REPRESENTATIVE:

[Redacted Signature]

JAN R. MEDUSKY, VICE PRESIDENT & SECRETARY
NAME & TITLE

01/22/2016
DATE SIGNED



RECEIVED
1/22/16 *jm*

I. Background and Summary

1. A brief description of the applicant's background

ALS Ohana of Hawaii ("ALSOH") is a community based, volunteer-led organization that was founded by two nurses, one whose husband was diagnosed with ALS and the other who actually had ALS.

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. 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 is no known cure.

ALSOH 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. ALSOH formally incorporated in 2013 and the current three member 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, ALSOH 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, 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 lead the fight to treat and cure ALS through global research and nationwide advocacy while also empowering people with Lou Gehrig's Disease and their families to live fuller lives by providing them with compassionate care and support.

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 share a deep commitment to provide Hawaii's ALS community with the best possible care while simultaneously advancing the search for effective treatments and a cure for ALS.

2. The goals and objectives related to the request

The goals and objectives related to this request are to:

- Maximize access to care support and community resources in Hawaii to help people live longer and better with ALS
- Expand the reach and effectiveness of the Excellence in ALS Care Initiative in Hawaii

- Increase the number of people with ALS served in Hawaii
- Reach people living with ALS in the earliest stages of the disease.

3. The public purpose and need to be served

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.) can easily exceed \$200,000 per year.

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 in Hawaii living with ALS, family members and family caregivers, professional caregivers, colleagues, friends and community members.

5. Describe the geographic coverage

The geographic scope of the grant includes all of the Hawaiian Islands.

II. Service Summary and Outcomes

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 one FDA-approved drug which only extends life two to four months. The *Excellence in ALS Care Initiative* is designed to address the medical, social, emotional and financial challenges of 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 policy initiatives that benefit the entire ALS community.

The scope of work, tasks, and responsibilities for executing the *Excellence in ALS Care Initiative* is as follows:

Professional Full-Time Care Management: The GWC's full-time professional Regional Care Manager will provide every person with ALS connected to ALSOH and the GWC in Hawaii with comprehensive care services to help people with ALS, their family members and professional care givers 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 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. The Care Manager will also participate as a member of multidisciplinary ALS clinic teams that are developed on each Hawaiian island, including satellite clinics. In this way, Hawaii's Care Manager 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 treatment of ALS.

Through in-home visits, emails, and phone consultations, as well as during clinic visits, the Care Manager 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. The Care Manager will serve 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.

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, a cure for ALS. Currently, the GWC is in the process of establishing Hawaii's first multidisciplinary ALS clinics so that people living with ALS in Hawaii do not have to travel to the mainland to seek multidisciplinary clinical care. 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. Having Hawaii's 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.

Durable Medical Equipment and Alternative Augmentative Communication Loan Program: In order to assist people with ALS to remain safe, comfortable, mobile and in communication as the disease progresses, the GWC maintains equipment loan closets in Hawaii in order to provide essential medical, adaptive 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. This loan equipment is essential for people with ALS who lack adequate insurance coverage 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.

Support Groups: Both ALSOH and the GWC offer support groups in Hawaii as they 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. The GWC also offers and hosts online resources and communities such as email forums, social media pages, and videos on YouTube to help people connect with ALS resources in the community and each other.

Education and Awareness: ALSOH and the GWC organize educational seminars with expert speakers on a range of topics, including caregiver support, current clinical trials, treatment management, wellness and more. These 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 more. 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 a 12 month period from February 1, 2016 through January 31, 2017, the program will benefit approximately 75 people in Hawaii living with ALS and hundreds of their loved ones, family members, friends, colleagues and care givers as well as community members, medical professionals, and individuals who have lost loved ones to ALS. We anticipate that, in total, approximately 800 people will benefit from and be connected to this program.

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: informal and formal surveys of clients and partners, data and outcomes, and achievement of key goals related to programs and services. This information will be regularly compiled and reviewed in order to determine ways to improve on outcomes and ensure the program's success.

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.

Measures of success that will be reported to the state include:

- The number of people with ALS served
- The number of ALS caregivers served
- The number of support groups offered
- The number of people attending support groups
- The number of public programs produced
- The number of public program attendees.

III. Financial

Budget

1. The applicant shall submit a budget utilizing the enclosed budget forms as applicable, to detail the cost of the request.

Please see attached.

2. The applicant shall provide its anticipated quarterly funding requests for the fiscal year 2017.

Quarter 1	Quarter 2	Quarter 3	Quarter 4	Total Grant
\$50,507	\$50,507	\$50,507	\$50,507	\$202,028

3. The applicant shall provide a listing of all other sources of funding that they are seeking for fiscal year 2017.

Other sources of funding in fiscal year 2017 will include philanthropic gifts from individuals, families, foundations and corporations.

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 and grants it has been and will be receiving for program funding.

The applicant has not received and will not receive government contracts for program funding in prior fiscal years or in fiscal year 2017.

6. The applicant shall provide the balance of its unrestricted current assets as of December 31, 2015.

Please see attached.

IV. Experience and Capability

A. 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.

ALSOH and The ALS Association Golden West Chapter have a successful track record of providing essential services and support to Hawaii’s ALS Community. Both organizations have extensive expertise in supporting those living with ALS.

ALSOH is a volunteer based organization that provides outreach services to ALS families. ALSOH is a grass-roots organization founded by volunteers who know first-hand what it means to live with ALS. ALSOH volunteers have all lived with ALS, so they know the devastation caused by the disease and the have a special appreciation for the needs of ALS families. Their experience with ALS enables them to develop meaningful insights into the needs of each family. These volunteers visit with families, help them make connections to professional resources in the community, attend support groups and provide them with food baskets and gatherings during the holidays to reduce isolation and provide respite.

The GWC has been providing a professional wraparound system of care for those living with ALS in Hawaii since 2014. The services of the GWC are managed by a dedicated healthcare professional who provides expert care management services to people living with ALS and their families throughout the state. The services provided by the GWC are grounded in an evidence based model of multidisciplinary care. The GWC Care Manager consults with each individual diagnosed with ALS and their loved ones, acts as a key informant to the medical clinic-based team, facilitates support groups, provides loans of durable medical equipment and augmentative communications devices, and organizes community education programs, advocacy and outreach events. The GWC works to recruit and collaborate with the medical disciplines required to treat a person with ALS. The GWC multidisciplinary model of care combines the community and home based services that people living with ALS need every day, with clinic based medical services (neurology, physical therapy, occupational therapy, speech therapy, nutritionist, gastroenterologist, pulmonologist, respiratory therapist, nursing, etc.) to create a “one stop shop” so that people living with ALS can have direct access to the only model of care that clinical research has proven helps people live up to three times longer than the only FDA approved drug for ALS.

The grass-roots based passion and commitment from the volunteers of ALSOH offered in collaboration with the professional expertise and evidence-based model of care provided by GWC, creates a program with impact to those living with ALS on Oahu and the neighbor islands.

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

- ALSOH can provide historical data and metrics pertaining families engaged, support groups sponsored, respite care grants and socialization activities.
- GWC can provide historical data and metrics related to Direct Care Management activity as measured by caseload, number and frequency of contacts and engagements, referrals, loans of durable medical equipment, support group meeting frequency and attendance.

B. 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.

N/A

V. Personnel: Project Organization and Staffing

A. 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 GWC’s Hawaii based team has extensive experience with ALS. Regional Care Manager: Our Care Manager is a Registered Occupational Therapist, provides care coordination services to people throughout the state of Hawaii. Her expertise in the care and management of people living with ALS is well known throughout the state. As a result, she has identified and recruited many professionals to our multi-disciplinary team. Our Regional Care Manager visits with ALS patients in their home, as well as in hospital and skilled nursing facilities. Her medical knowledge combined with her warm and empathic approach enable her to reach even the most withdrawn, private and remote ALS patient to

offer service and support. She works directly with our support group facilitators, assesses the needs for durable medical equipment, augmentative communications equipment, and is a key informant to the members of the multi-disciplinary team.

Community Outreach Coordinator: Our Community Outreach Coordinator has extensive experience in working with Hawaii's ALS and neuromuscular disease community. Her working knowledge of Hawaii's significant array of local community resources enables her to connect with organizations throughout Hawaii in an effort to ensure that no person living with ALS goes unrecognized and unsupported.

Volunteers: ALSOH has a committed group of volunteers whose mission is to reduce the isolation of people living with ALS. Incorporated in 2013, the volunteers for this organization have a strong track record of outreach and expertise in reducing the feeling of isolation of those living with ALS.

B. 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 incorporated on the mainland and 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 one full time Regional Care Manager and one full time Regional Director of Community Outreach, to execute the program plan. The two staff members work in tandem and will be supervised by the GWC's management team (Director of Care Services and VP of Community Outreach) to ensure best practices are implemented and peer support is available.

C. Compensation

The applicant shall provide the annual salaries paid by the applicant to the three highest paid officers, directors, or employees of the organization by position.

N/A

VI. Other

A. 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

B. 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

C. 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

D. Future Sustainability Plan

The applicant shall provide a plan for sustaining after fiscal year 2016-17 the activity funded by the grant if the grant of this application is:

- (1) Received by the applicant for fiscal year 2016-17, but**
- (2) Not received by the applicant thereafter.**

ALSOH and the GWC are dependent upon philanthropy to meet budgeted revenue goals each year. Currently, neither organization receives funding from government sources or payments from third-party payers for services. Each organization strives to maintain a diverse portfolio for community engagement and support including appeals and platforms related to: 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. Our intention is to leverage state funding to attract additional philanthropic investment and support.

E. 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, 2015.

Please see attached.

ALS OHANA
2015 TREASURER'S REPORT

OPENING BALANCE AS OF DECEMBER 31, 2014

\$ 8,355.86

Deposits to Account

<u>Date</u>	<u>Item</u>	<u>Amount</u>
2/9/2015	Contribution Check (1)	\$ 100.00
		<u>\$ 100.00</u>

\$ 8,455.86

Debits to Account

<u>Date</u>	<u>Item</u>	<u>Amount</u>
1/12/2015	Check 1040: Nancy Fujio Reimbursement for Christmas Party decorations	\$ 32.85
1/24/2015	Check 1041: Natalie Jones Reimbursement for Cake Paul's Going Away Party	\$ 32.44
2/27/2015	Check 0142: Michelle Izon for Zac Izon Memorial	\$ 50.00
2/27/2015	Check 1043: Natalie Jones for Reimbursement for Salad for Support Group	\$ 12.54
3/9/2015	Check 1044: Rehab of the Pacific for Support Group Venue	\$ 200.00
5/18/2015	Check 1045: Rehab of the Pacific for Support Group Venue	\$ 200.00
6/3/2015	Check 1046: David Kurata for Sheriff Services for Memorial	\$ 120.00
7/1/2015	Check 1047: Natalie Jones Reimbursement for Kauai Trip	\$ 198.40
7/9/2015	Check 1048: Natalie Jones reimbursement for rental call Kauai Trip	\$ 62.35
7/27/2015	Funds Transfer for Ehawaii.gov Annual Report Filing	\$ 3.50
8/12/2015	Check 1049: Philadelphia Insurance for annual premium	\$ 1,139.00
9/21/2015	Check 1050: Woolley Brother for T-shirt Printing for ALS Walk	\$ 223.11
9/23/2015	Check 1051: Philadelphia Insurance Co. (Libaility)	\$ 1,663.00
9/23/2015	Check 1052: Reimb. Natalie Jones for USPS Mailing of Shirts (Board Approved)	\$ 7.55
11/20/2015	Check 1053: Rehabilitation Center of the Pacific (Support Group Venue)	\$ 200.00
12/9/2015	Check 1054: Reimb. To Kahala Howser ALS Xmas Party Gifts	\$ 285.89
12/9/2015	Check 1055: Reimb. To Terryn Davis for ALS Xmas party gifts	\$ 556.40
12/9/2015	Check 1056: Penelope Chun reimb. For ALS xmas party decorations	\$ 224.75
12/9/2015	Check 1057: Nancy Fujino reimb.for ALS xmas party decorations	\$ 34.24
12/15/2015	Check 1058: Payment to Uahi Grill for catering ALS Xmas Party	\$ 890.05
		<u>\$ 6,136.07</u>

Closing Balance as of December 31, 2015

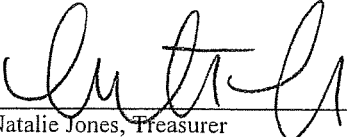
\$ 2,319.79

ALSA ACCOUNT FOR ALS OHANA OF HAWAII

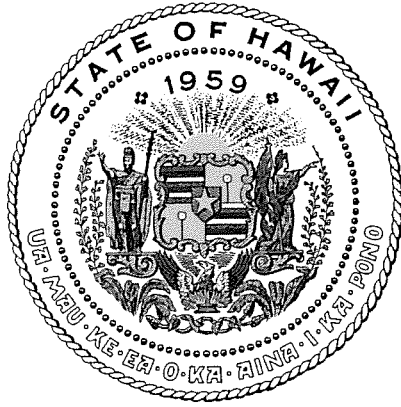
\$ 4,000.00

BALANCE AS OF December 31, 2015

\$ 6,319.79


 Natalie Jones, Treasurer

1/6/16
 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

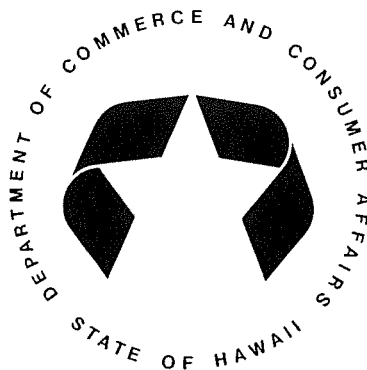
ALS OHANA (OF HAWAII)

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 13, 2016

Director of Commerce and Consumer Affairs



BUDGET REQUEST BY SOURCE OF FUNDS

Period: July 1, 2016 to June 30, 2017

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	145,676			
2. Payroll Taxes & Assessments	11,620			
3. Fringe Benefits	21,032			
TOTAL PERSONNEL COST	178,328			
B. OTHER CURRENT EXPENSES				
1. Airfare, Inter-Island	14,200			
2. Insurance				
3. Lease/Rental of Equipment				
4. Lease/Rental of Space				
5. Staff Training				
6. Supplies				
7. Telecommunication				
8. Utilities				
9. Lodging	9,500			
10.				
11.				
12.				
13.				
14.				
15.				
16.				
17.				
18.				
19.				
20.				
TOTAL OTHER CURRENT EXPENSES	23,700			
C. EQUIPMENT PURCHASES				
D. MOTOR VEHICLE PURCHASES				
E. CAPITAL				
TOTAL (A+B+C+D+E)	202,028			
SOURCES OF FUNDING		Budget Prepared By:		
(a) Total State Funds Requested		Louise Clements	818-865-8067 x231	
(b) Total Federal Funds Requested			Phone	
(c) Total County Funds Requested			01/22/2016	
(d) Total Private/Other Funds Requested			Date	
TOTAL BUDGET	202,028	Jan R. Medusky, Vice President & Secretary Name and Title (Please type or print)		

BUDGET JUSTIFICATION - PERSONNEL SALARIES AND WAGES

Period: July 1, 2016 to June 30, 2017

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)
Regional Care Manager	1.0 FTE	\$101,857.00	100.00%	\$ 101,857.00
Regional Director of Community Outreach	1.0 FTE	\$76,471.00	100.00%	\$ 76,471.00
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
TOTAL:				178,328.00
JUSTIFICATION/COMMENTS:				

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

The undersigned authorized representative of the applicant certifies the following:

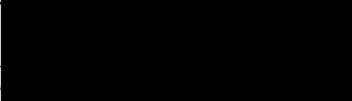
- 1) The applicant meets and will comply with all of the following standards for the award of grants pursuant to Section 42F-103, Hawaii Revised Statutes:
 - a) Is licensed or accredited, in accordance with federal, state, or county statutes, rules, or ordinances, to conduct the activities or provide 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)



01/22/2016

(Date)

Jan R. Medusky

(Typed Name)

Vice President & Secretary

(Title)

ALS Ohana of Hawaii
800 Bethel Street, Suite 404
Honolulu, Hawaii 96813
JanMedusky@alsohana.org
(808) 531 – 2765

January 22, 2016

Dear Application Reviewers,

ALS Ohana of Hawaii is pleased to submit an application to the House Committee on Finance and Senate Committee on Ways and Means on behalf of Hawaii's ALS community.


For many years, Hawaii's ALS community has not had access to local care services and support system. In recent years, this has changed with the creation of ALS Ohana of Hawaii and the launch of Care Services programs provided by The ALS Association Golden West Chapter in Hawaii. Our organizations working together have transformed the experience of people living with ALS in Hawaii. People living with ALS, including their families and caregivers, are no longer alone to face the challenges of living with a fatal, neurodegenerative disease that robs a person of the ability to speak, swallow, move and breathe.

Hawaii as a state has been a leader at the forefront of national public policy efforts and Elroy Chun, Peggy Chun's widower, has helped to inform state elected officials about the great needs of people living with ALS. Because veterans are at twice the risk of being diagnosed with ALS than civilians, Senator Inouye was instrumental in ensuring that veterans diagnosed with ALS enjoy full service connected disability benefits upon diagnosis. The Senator also helped to establish the ALS Research Program at the Department of Defense.

We are grateful for the opportunity, for the first time, to apply for state funding to offset direct Care Services expenses necessary to provide the very best model of care for people living with ALS. Right now, the ALS community, a community experiencing extreme hardships while they are dealing with the relentless progression of the disease and loss, are bearing the burden of these expenses.

Please let us know if you require additional information. On behalf of the Board of Directors of ALS Ohana of Hawaii and the Board of Directors of our collaborative program partner, The ALS Association Golden West Chapter, thank you for your consideration.

Sincerely,



Vice President & Secretary