

January 19, 2018

Dear GIA Application Reviewers,

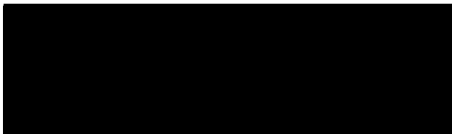
ALS Ohana of Hawaii is pleased to submit an application to the House Committee on Finance and Senate Committee on Ways and Means on behalf of Hawaii's ALS community.

Hawaii's ALS community is greatly benefitting from services provided by ALS Ohana of Hawaii and The ALS Association Golden West Chapter, each organization has served the ALS community for many years but the two organizations began formally collaborating in 2014. Working together, the often intense and varied needs of the ALS community are being addressed, including the medical, financial, social and quality of life issues that make living with a fatal neurodegenerative disease extraordinarily challenging.

Recognizing that until scientists discover effective treatments and a cure for ALS, many members of Hawaii's elected leadership, including the late Senator Inouye, have been steadfast supporters of programs that increase access to community based, expert ALS care providers, improve access to benefits for people with ALS and advance research on national and local levels. Funding from the State of Hawaii to support the Excellence in ALS Care Initiative, a comprehensive program that encompasses vital Care Services and Community Outreach efforts, will help to extend life and meaningfully improve quality of life for Hawaii's ALS community.

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

Sincerely,

A large black rectangular redaction box covering the signature of Natalie Fonda.

Natalie Fonda
President & Treasurer, ALS Ohana of Hawaii

House District(s) _____

Senate District(s) _____

**THE TWENTY-NINTH 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 NATALIE W. FONDA

Title President & Treasurer

Phone # 808-258-9388

Fax # 808-599-3736

E-mail Nataliejones@alsohana.org

3. TYPE OF BUSINESS ENTITY:

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

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 2019: \$318,615

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:

NATALIE FONDA, PRESIDENT & TREASURER
NAME & TITLE

1/19/18 ^{n.f.}
DATE SIGNED

JAN 19 2018 RO 1:42 PM

Application for Grants

Please check the box when item/section has been completed. If any item is not applicable to the request, the applicant should enter "not applicable".

I. 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 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, 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 a cure 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 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:

- I. Maximize access to care support and community resources in Hawaii to help people live longer and better with ALS by
 - A. Providing Care Management Services for all people with ALS living in the state of Hawaii identified by the Golden West Chapter
 - B. Providing a minimum of 3 support groups per year per island for people living with ALS
 - C. Serving a minimum of 20 people with ALS via Multidisciplinary Clinical Care teams
 - II. Expand the reach and effectiveness of the Excellence in ALS Care Initiative in Hawaii by
 - A. Increasing Care Manager hours to serve the ALS community on Oahu and Oahu's neighbor islands
 - B. Hiring an administrative assistant to support Care Management and Community Outreach activities
 - C. Securing office space to conduct business and meetings; hold orientations, trainings and support services; and house and operate an Equipment Loan Program
 - D. Expand Equipment Loan Program inventories and support equipment repairs and refurbishments on Oahu and Oahu's neighbor islands
 - E. Providing ongoing training and support for physicians and clinicians serving people with ALS
 - F. Conducting a comprehensive outreach program to educate the public about ALS, available services and promote early referrals
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. 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.

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; and

The target population to be served includes people 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

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 which only extends life 2-4 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 ALS Care Management:

The GWC Care Management staff 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 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 that are developed on Oahu and its neighbor islands, including satellite clinics. 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 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, a cure for ALS. The GWC has successfully incubated the first two multidisciplinary ALS clinics in Hawaii so that people living with ALS in Hawaii do not have to leave the state 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 operates an equipment loan program designed 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, 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.

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, livestream events, 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 other experts in the field. 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 the GWC will:

- Provide a minimum of 5 support groups across multiple islands
- Serve a minimum of 5 people with ALS through Multidisciplinary Clinics
- Provide Care Management Services for all people with ALS living in the state of Hawaii identified by the Golden West Chapter
- Maintain an Equipment Loan Program that addresses the issues of people living with ALS throughout the state of Hawaii
- Conduct outreach activities
- Conduct at least one training for medical and allied health professionals serving the ALS population and circulate a post training survey

In addition to the above stated activities, in Quarter one, the GWC will:

- Hire a Part Time Care Manager to serve Oahu's neighbor islands
- Employ a part time administrative assistant
- Secure office space to conduct business and meeting; hold orientations, support groups, and trainings; and operate an Equipment Loan Program
- Secure storage space for Equipment Loan Program activities on the Islands of Hawaii, Kauai, and Maui

In Quarter two, the GWC will:

- Increase Administrative Assistant hours to full-time for the duration of the grant period
- Expand Equipment Loan Program inventories on Oahu if needed, and expand Equipment Loan Program inventories on the islands of Hawaii, Kauai and Maui

In Quarter three the GWC will circulate a constituent satisfaction survey.

In Quarter four the GWC 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; and

Program effectiveness will be assessed in the following ways: informal and formal surveys of clients and partners, 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.

ALSOH and the GWC will document:

- the number 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

ALSOH and the GWC will report all survey results.

III. 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](#))

BUDGET REQUEST BY SOURCE OF FUNDS

Period: July 1, 2018 to June 30, 2019

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	217,500			
2. Payroll Taxes & Assessments	17,400			
3. Fringe Benefits	32,625			
TOTAL PERSONNEL COST	267,525			
B. OTHER CURRENT EXPENSES				
1. Airfare, Inter-Island	4,510			
2. Insurance				2,800
3. Lease/Rental of Equipment				1,600
4. Lease/Rental of Space	35,100			
5. Staff Training				2,000
6. Supplies				16,000
7. Telecommunication				4,500
8. Utilities				7,200
9. Licensing & Fees				1,000
10. Mailing				585
11. Mileage				5,000
12. Vehicle Rental				4,000
13. Postage & Shipping				1,900
14. Printing & Photocopies				4,790
15. Auto Fuel				320
16. Lodging				18,372
17. Other travel				10,000
18				
19				
20				
TOTAL OTHER CURRENT EXPENSES	39,610			80,067
C. EQUIPMENT PURCHASES	11,480			
D. MOTOR VEHICLE PURCHASES				
E. CAPITAL				
TOTAL (A+B+C+D+E)	318,615			80,067
SOURCES OF FUNDING		Budget Prepared By:		
(a) Total State Funds Requested	318,615	Natalie Fonda 808-258-9388		
(b) Total Federal Funds Requested		Phone		
(c) Total County Funds Requested		1/19/18		
(d) Total Private/Other Funds Requested	80,067	Date		
TOTAL BUDGET	398,682	<i>PRESIDENT NATALIE FONDA</i> Name and Title (Please type or print)		

BUDGET JUSTIFICATION - PERSONNEL SALARIES AND WAGES

Period: July 1, 2018 to June 30, 2019

Applicant: ALS Ohana of Hawaii

POSITION TITLE	FULL TIME EQUIVALENT	ANNUAL SALARY A	% OF TIME ALLOCATED TO GRANT REQUEST B	TOTAL STATE FUNDS REQUESTED (A x B)
Care Manager	1.0 FTE	\$94,171.88	100.00%	\$ 94,172
Care Manager	0.5	\$56,503.13	100.00%	\$ 56,503
Regional Director of Community Outreach	1.0 FTE	\$87,822.00	100.00%	\$ 87,822
Office Assistant	1.0 FTE	\$29,028.00	100.00%	\$ 29,028
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
TOTAL:				267,525
JUSTIFICATION/COMMENTS:				

- 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 2019.

Quarter 1	Quarter 2	Quarter 3	Quarter 4	Total Grant
\$79,654	\$79,654	\$79,654	\$79,653	\$318,615

3. The applicant shall provide a listing of all other sources of funding that they are seeking for fiscal year 2019.

Other sources of funding for fiscal year 2019 include revenue from community outreach 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 2019 for program funding.

Please see document Attachment 1.e. provided earlier in this section.

6. The applicant shall provide the balance of its unrestricted current assets as of December 31, 2017.

Please see the attached ALS Ohana of Hawaii Treasurer's Report.

IV. 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.

BUDGET JUSTIFICATION - EQUIPMENT AND MOTOR VEHICLES

Period: July 1, 2018 to June 30, 2019

Applicant: ALS Ohana of Hawaii

DESCRIPTION EQUIPMENT	NO. OF ITEMS	COST PER ITEM	TOTAL COST	TOTAL BUDGETED
Durable Medical Equipment (walkers, wheelchairs, ramps, etc)	12.00	\$175.00	\$ 2,100.00	
Augmentative Communication Devices (voice amplifiers, call chimes, etc)	12	\$80.00	\$ 960.00	
Adaptive Electronic Aids (switches, head mouse)	12	\$200.00	\$ 2,400.00	
Adaptive Bathroom Equipment (bedside commode, tub bench, etc)	12	\$85.00	\$ 1,020.00	
Equipment Cleaning and Repairs	10	\$500.00	\$ 5,000.00	
TOTAL:	58		\$ 11,480.00	

JUSTIFICATION/COMMENTS:

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

JUSTIFICATION/COMMENTS:

BUDGET JUSTIFICATION - CAPITAL PROJECT DETAILS

Period: July 1, 2018 to June 30, 2019

Applicant: _____

FUNDING AMOUNT REQUESTED						
TOTAL PROJECT COST	ALL SOURCES OF FUNDS RECEIVED IN PRIOR YEARS		STATE FUNDS REQUESTED	OF FUNDS REQUESTED	FUNDING REQUIRED IN SUCCEEDING YEARS	
	FY: 2016-2017	FY: 2017-2018	FY:2018-2019	FY:2018-2019	FY:2019-2020	FY:2020-2021
PLANS						
LAND ACQUISITION						
DESIGN						
CONSTRUCTION						
EQUIPMENT						
TOTAL:						
JUSTIFICATION/COMMENTS:						

GOVERNMENT CONTRACTS, GRANTS, AND / OR GRANTS IN AID

Applicant: ALS Ohana of Hawaii

Contracts Total: 207,500

	CONTRACT DESCRIPTION	EFFECTIVE DATES	AGENCY	GOVERNMENT ENTITY (U.S. / State / Haw / Hon / Kau / Mau)	CONTRACT VALUE
1	Care Management and Community Outreach			State	200,000
2	Care Management			County of Hawaii	7,500
3					
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ALS OHANA
2017 TREASURER'S REPORT

OPENING BALANCE AS OF DECEMBER 31, 2016

\$ 2,379.13

Deposits to Account

Date	Item	Amount
2/1/2017	Travelers Contribution Check	\$ 24.00
4/25/2017	Travelers Contribution Check	\$ 40.00
5/12/2017	Direct Deposit from Amazon Donation	\$ 17.52
8/1/2017	County of Hawaii - Grant Semi-Annual	\$ 3,625.00
8/16/2017	Paypal Transfer of Contributions	\$ 500.00
9/1/2017	Travelers Insurance Donation	\$ 48.00
9/27/2017	Paypal Transfer of Contributions	\$ 593.73
10/24/2017	Travelers Insurance Donation	\$ 75.41
11/8/2017	Contribution Check from Travelers	\$ 58.00
11/16/2017	Direct Deposit from Amazon Donation	\$ 6.30
		<u>\$ 4,987.96</u>

\$ 7,367.09

Debits to Account

Date	Item	Amount
2/1/2017	Natalie Jones (Check 1068) Reimbursement for Express Mailing - ALSA Grant	\$ 23.75
3/10/2017	Jan R. Medusky (Check 1070) Reimbursement for Airfare/parking Hilo Grant Interview	\$ 220.60
5/10/2017	Natalie Jones (Check 1071) Reimbursement for Hawaii Compliance Express	\$ 12.00
7/19/2017	Payment for Annual Report Filing (Internal)	\$ 3.50
8/1/2017	Transfer Payment to ALSA for County of Hawaii Grant (Check 1072)	\$ 3,625.00
11/2/2017	Payment to Woolley Brothers Printing for ALS Ohana Hats for ALSA walk (1073)	\$ 209.54
11/2/2017	Payment to Woolley Brothers Printing for ALS Ohana Shirts for ALSA walk (1074)	\$ 115.58
11/4/2017	Reimbursement to Natalie Fonda for Postage for State Grant Contract (Check 1075)	\$ 7.00
12/8/2017	Reimbursement to Natalie Fonda for ALS Christmas Raffle Gifts (Check 1076)	\$ 228.59
12/13/2017	Payment to Uahi Grill for Catering ALS Christmas Raffle (Check 1077)	\$ 780.00
		<u>\$ 5,225.56</u>

BALANCE AS OF December 31, 2017

\$ 2,141.53

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

N

1/19/18

Date

800 Bethel St., Suite 404
Honolulu, HI 96813

ALS Ohana of Hawaii and The ALS Association Golden West Chapter have a long and 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 or cared for someone with ALS, so they know the devastation caused by the disease and they 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 provided by the GWC are grounded in an evidence based model of multidisciplinary care and oversight is provided by an experienced healthcare professional. GWC Care Managers have and develop extraordinary expertise with ALS and serve as a vital resource to people living with ALS and their families. GWC Care Managers consult with each individual diagnosed with ALS and their loved ones and act as a key informant to the medical clinic-based team. Care Managers facilitate support groups, provide loans of durable medical equipment and augmentative communications devices, and help to organize 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." In this way, people living with ALS can have direct access to the only model of care that clinical research has proven to help people live up to three times longer than the two 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 in Hawaii.

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

- 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, as well as the number of outreach events and professional training activities .
- ALSOH can provide historical data and metrics pertaining families engaged, support groups sponsored, respite care grants and socialization and outreach activities.

In July 2016 ALSOH was granted a GIA from the State of Hawaii to have the GWC implement the *Excellence in ALS Care Initiative*. Notice to Proceed was issued in December 2017, In addition to providing Care Management services and equipment loans throughout the state, successful milestones thus far have included the launch of ALS Multidisciplinary Clinics to serve people of Hawaii with ALS and numerous educational and support programs throughout the state.

In November 2017, additional GIA funding was secured by the GWC in the City and County of Honolulu to improve infrastructure for serving residents of Honolulu.

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.

Facilities are not presently available. However, the GWC secured funding through the City and County of Honolulu to establish an office in Honolulu and hire a part time Administrative Assistant; that grant will end on October 31, 2018. The GWC intends to expand role of the Administrative Assistant and continue to utilize the office space to serve all residents of Hawaii with funding from the State. The office space will provide a centralized location for conducting Care Services and Community Outreach related business and meetings; offering trainings and client support services; housing equipment and more.

V. 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 GWC's Hawaii based team has extensive experience with ALS.

Care Managers: The GWC Care Manager who has been serving Hawaii's ALS community since the launch of the *Excellence in ALS Care Initiative* in Hawaii is a Registered Occupational Therapist. 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 healthcare professionals to embrace the GWC's multidisciplinary program model. Hawaii's Care Manager visits with people with ALS in their home, as well as in hospital and skilled nursing facilities. She provides consultations via phone, email, text and videoconference. Her medical knowledge, combined with her warm and empathic approach, enable her to reach even the most withdrawn, private and remote individuals who are living with ALS to offer vital services and support. Hawaii's Care Manager facilitates support groups and consults with support group facilitators who are independent contractors in Hawaii, she assesses the needs for durable medical equipment, augmentative communications equipment, and serves a key informant to the members of the

multidisciplinary clinic teams on Oahu. She will be responsible for mentoring a part time Care Manager to serve Oahu's neighbor islands. Preferably, the part time Care Manager will have ALS experience and a background in social work or a medical discipline related to ALS.

Community Outreach: The GWC's Regional Director of Community Outreach, recently hired in August of 2017, has worked in the nonprofit arena for over 20 years, in education, human services, and the performing arts. A resident of Hawaii for over 9 years, she has extensive experience in improving lives and building community for those she serves. 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: ALS Ohana of Hawaii 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.

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 1.5 FTE Regional Care Managers, one full time Regional Director of Community Outreach, and one hourly Administrative Assistant at 30 hours per week 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.

3. 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

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.

There is no pending litigation or outstanding judgement to disclose.

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 2018-19 the activity funded by the grant if the grant of this application is:

- (a) Received by the applicant for fiscal year 2018-19, 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: 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.

5. 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, 2017.

Please see attached.

6. Declaration Statement

**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)



(Sig

1/19/18

(Date)

Natalie Fonda, President & Treasurer

(Typed Name)

(Title)

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

Please see attached.

7. 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](#))

The grant will be used for a public purpose pursuant to Section 42F-102, Hawaii Revised Statutes.