

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

Type of Grant Request:

Operating                       Capital

Legal Name of Requesting Organization or Individual: Db:

ALS Ohana of Hawaii

Amount of State Funds Requested: \$ 200,000

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

ALS Ohana of Hawaii requests funding in support of the the Excellence in ALS Care Initiative, an evidence based, wraparound model of care designed to help a vulnerable population, those diagnosed with ALS and their loved ones, live longer and better by addressing the significant medical, social, emotional and financial challenges they face. That continuum of care also includes opportunities to advance ALS research and awareness activities to benefit the entire ALS community.

Amount of Other Funds Available:

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

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

\$ 200,000

Unrestricted Assets:

\$ 9307.58

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 404

City: Honolulu                      State: HI                      Zip: 96813

Contact Person for Matters Involving this Application

Name: Natalie Fonda	Title: President and Treasurer
Email: nwfonda@hotmail.com	Phone: 808-258-9388

Federal Tax ID#: [REDACTED]	State Tax ID#: [REDACTED]
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Authorized Signature

Natalie Fonda, President and Treasurer  
Name and Title

1/17/22  
Date Signed

## 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



AUTHORIZED SIGNATURE

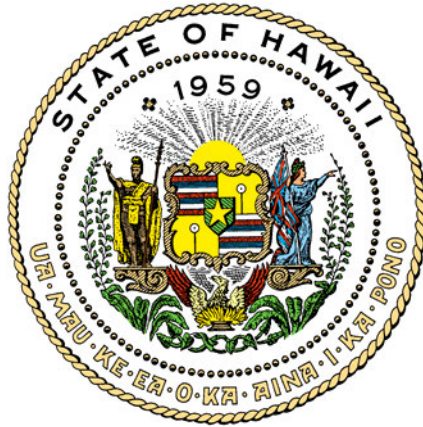
NATALIE FONDA, PRESIDENT AND  
TREASURER

PRINT NAME AND TITLE

1/17/22

DATE

# CERTIFICATE OF GOOD STANDING



## 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: December 28, 2021

Director of Commerce and Consumer Affairs

## 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:

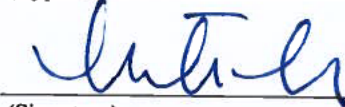
- 1) The applicant meets and will comply with all of the following standards for the award of grants pursuant to Section 42F-103, Hawaii Revised Statutes:
  - a) Is licensed or accredited, in accordance with federal, state, or county statutes, rules, or ordinances, to conduct the activities or provide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



(Signature)

1/17/22

(Date)

Natalie Fonda

(Typed Name)

President and Treasurer

(Title)

## VERIFICATION OF PUBLIC PURPOSE

**VERIFICATION OF PUBLIC PURPOSE**  
**APPLICANTS FOR GRANTS PURSUANT TO**  
**CHAPTER 42F, HAWAII REVISED STATUTES**

The undersigned authorized representative of the applicant certifies the following:

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

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

The applicant has provided:

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

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

ALS Ohana of Hawaii

(Typed Name of Individual or Organization)



(Signature)

1/17/20

(Date)

Natalie Fonda

(Typed Name)

President and Treasurer

(Title)



# NARRATIVE

INCLUDING:

BACKGROUND AND SUMMARY

SERVICE SUMMARY AND OUTCOMES

EXPERIENCE AND CAPABILITY

PERSONNEL: PROJECT ORGANIZATION AND STAFFING

# 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, 2021.

### **2. Declaration Statement**

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

### **3. Public Purpose**

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

## **II. Background and Summary**

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

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

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

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.

ALSOH founders and supporters believe that people with 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.

ALSOH has successfully partnered with the GWC to deliver programs in Hawaii since 2014. 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 cures for ALS.

## **2. The goals and objectives related to the request**

The goals and objectives related to this request are to:

- Deliver high quality, greatly valued, unduplicated services to help residents of the State of Hawaii live longer and better with ALS.
- Improve and maximize access to care support and community resources in Hawaii for the ALS community
- Increase the number of people with ALS served in Hawaii
- Discover and reach people living with ALS in the earlier disease stages

## **3. The public purpose and need to be served**

ALS affects individuals 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. About one in every 400 adults will be diagnosed with ALS.

ALS is a neurological disease that affects the nerve cells in the brain and spinal cord responsible for controlling voluntary muscles. The progressive degeneration of the motor neurons, which reach from the brain to the spinal cord, and from the spinal cord to the muscles throughout the body, eventually leads to complete paralysis. However, due to the variability in how the disease manifests (ALS can begin with symptoms affecting the upper or lower body) and progresses (some people have a very quick progression and lose their battle with ALS a few short months after diagnosis or the start of symptoms, while others live for a few years or for decades with the disease affecting movement and speech and adapting to those losses), the experience of living with ALS is quite different for each individual and their loved ones. Yet in most cases, in the later stages of the disease, people with ALS become completely paralyzed. In over 140 years since ALS was first discovered, scientists have not discovered a medication to slow, stop, reverse or cure the disease. Today, there are medications commonly used for ALS symptom management but none that meaningfully slow disease progress, including the three FDA-approved drugs; they only extend life by 2-4 months. However, evidence shows that robust, proactive, community-based, multidisciplinary care can enhance quality of life and extend life 3-4 times longer than any available medication. Until there are effective therapies for ALS, ALSOH and the GWC exist to ensure access to expert care and to advance the search for treatments and cures.

The highly variable and progressive nature of the disease as described above, may lengthen the time it takes to receive an ALS diagnosis, and the learning curve about living with ALS is often steep and overwhelming. Given the incapacitating nature of ALS and the average age of diagnosis (between 40-70 years old), most people remain at home, unable to continue to earn an income if they were employed when diagnosed. The full-time daily care requirements for someone who is paralyzed can be intense, and typically caregiving is provided by family members, as most households cannot afford to hire professional caregivers for 24/7 coverage. Family caregivers typically perform care support duties during the day and evening, and overnight, over weekends and on demand. Family caregivers who are employed outside the home may become the primary, or the only, source of household income which adds even more demands, responsibilities and stress. The financial and emotional burden of providing daily care around the clock at home is significant; most people are unprepared for the incredible hardships they encounter as a family caregiver. The annual costs for full-time 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 are provided at no cost to people living with ALS and their families in Hawaii, ensuring that the ALS community is provided with vital specialty care and 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.

On an annual basis, approximately 400-500 individuals in the state of Hawaii benefit from the GWC's Excellence in ALS Care Initiative. Hawaii's ALS community is extremely geographically isolated from resources that are essential to improving health and quality of life after an ALS diagnosis; expert medical care, vital adaptive durable medical equipment, communication devices and other valued psychosocial supports, are often not readily available for those living with ALS and their loved ones. Without the GWC's presence in those communities, many living with ALS simply would not have access to a coordinated, wraparound model of care.

The Chapter's approach is unduplicated and tailored for each client and their loved ones. The cornerstone component of our efforts in Hawaii is professional care management, provided by experts in ALS care. The primary role of the GWC's Lead Care Manager in Hawaii is to help people living with ALS and their loved ones access information, resources, equipment, community, and expert advice to maintain and maximize their health, safety, and quality of life. The GWC provides clients with access to local information and resources, as well as the opportunity to connect with clinicians who specialize in ALS, obtain durable medical equipment and augmentative communication devices, understand and navigate insurance benefits, provide guidance around home modification, help find professional caregivers, connect with others living with ALS, and much more.

In 2020, in an effort to keep the ALS community, a highly vulnerable community, safe from the severe effects of COVID-19, within 30 days, all programs and services that were traditionally offered as in person activities were converted to utilize telehealth approaches for program delivery. This transformation served to increase community engagement and access to services and to enhance community connection from the comfort and ease of one's home.

GWC support groups were conducted online, resulting in double the attendance from prior years. New groups for specific populations and interests were created, including those for Spanish

language speakers, trach/ventilator topics, familial ALS, veterans, groups that focus on caregivers and loved ones, bereavement, LGBTQ, and the pursuit of mindfulness practices.

In 2020, the GWC created and implemented new safety protocols to meet the needs of families facing ALS who required life sustaining durable medical equipment and augmentative communication devices in order to move, speak, and breathe. Factors related to the pandemic including the loss of employment outside the home and the lack of access to in person clinician visits led to increased demand for equipment loan support from the GWC.

Another significant example of how telehealth strategies have greatly benefited Hawaii's ALS community relates to access to multidisciplinary clinical care. Prior to 2020, the only Hawaii residents with access to robust multidisciplinary clinical care were Kaiser Permanente members who could travel to Honolulu. The GWC has close partnerships with Certified Treatment Centers of Excellence in California that now provide online access to specialty teams to all of Hawaii's residents. Issues around insurance, state licensing, and logistics prohibited being able to offer this kind of specialized care in Hawaii prior to the pandemic. As with in person clinic visits, the GWC's Lead Care Manager participates as a member of the clinic team and provide the coordination to ensure that individualized care plans are followed.

The ALS community faces many barriers when seeking access to care – a shortage of clinicians with ALS expertise, physical endurance limitations, lack of access to needed durable medical equipment to support physical function and quality of life, lack of wheelchair accessible transportation, inability to use technology or the internet and challenging mental states stemming from the diagnosis (anxiety, loneliness, depression, fear, and more) – all of these contribute to people with ALS from obtaining the help they need. The GWC and ALSOH are committed to addressing these issues in Hawaii.

#### 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, other loved ones, colleagues, friends and community members, and healthcare professional and those pursuing neurodegenerative disease research and therapy development. The target population includes individuals of all ages, ethnicities, income levels, physical ability, and mental/intellectual function. The target population is comprised of veterans and civilians, the homeless and those living in skilled nursing facilities as well as asset-limited, income constrained individuals and families.

#### 5. Describe the geographic coverage.

The geographic scope of the grant includes the entire State of Hawaii.

### **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 up to four times longer with the disease than the three FDA-approved drugs for ALS which only extend 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 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 Care Management: The GWC will provide professional Care Management for every person with ALS, along with their family members and caregivers, connected to ALSOH and the GWC in Hawaii. Comprehensive care management is essential as people living with the disease require solutions for changing circumstances as the disease progresses, including the loss of the ability to move, swallow, speak and eventually, to breathe. GWC Hawaii based staff (GWC-HI) will connect individuals and families to essential information, community resources, medical and research experts, educational opportunities, other people with ALS and their families, and provide access to free loans of durable medical equipment (power wheelchairs, etc.) and technology (speech generating devices, adaptive switches, etc.) necessary to make living with ALS easier. Hawaii's lead Care Manager will also participate as a member of multidisciplinary ALS clinic teams that are developed to serve Hawaii's ALS community. In this way, GWC-HI staff 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, GWC-HI staff 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. GWC-HI staff 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 Certified 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. During a single clinic visit, a person with ALS consults with a number of specialists, including a neurologist, nutritionist, respiratory therapist, speech therapist, physical and/or occupational therapist, social worker, GWC Care Manager, and others essential to the care team.

Having a GWC 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. As noted in a previous section, prior to 2020, the only multidisciplinary ALS clinic in the State of Hawaii was Kaiser Permanente in Honolulu. During the pandemic, the GWC partnered with ALS Certified Treatment Centers at UC San Francisco and Loma Linda Medical Center, to offer virtual clinical services to clients in Hawaii. They are now able to access a specialist for a consultation, and can continue with ongoing care if they choose. To reduce travel burdens on Hawaii's ALS community, the GWC seeks to develop additional clinical partners and

teams in Hawaii, on Honolulu and the neighbor islands, including with the two ALS specialists who have recently joined the neurology team at The Queens Medical Center in Honolulu.

Durable Medical Equipment and 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 offers equipment loans in Hawaii in order to provide essential medical, adaptive and assistive equipment to people with ALS at no charge. This equipment includes power and transport wheelchairs, respiratory equipment and high-tech communication devices as well as low tech devices such as 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 that 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 to help people connect with ALS resources in the community and each other.

Community Outreach, Education and Awareness: ALSOH and the GWC organize educational programs and webinars featuring 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 (in person when safe and online when required) 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

The projected annual timeline for accomplishing the results or outcomes is a 12-month period from July 1, 2022 through June 30, 2023. All activities are ongoing on a monthly basis.

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:

- monthly review of data and outcomes,
- achievement of key goals related to programs and services
- informal and formal surveys of clients, program participants, and community partners

This information will be regularly compiled and reviewed on a monthly and annual basis in order to determine ways to improve outcomes and ensure the program's future 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
- The number of equipment loans
- The number of clients who access multidisciplinary clinical care

Additionally, ALSOH and the GWC will informally survey clients and program participants to gauge:

- satisfaction with services provided
- an increase in knowledge of available community resources and sense of community connection and engagement

## **IV. Financial**

### **Budget**

1. The applicant shall submit a budget utilizing the enclosed budget forms as applicable, to detail the cost of the request.
  - a. Budget request by source of funds (Link)
  - b. Personnel salaries and wages (Link)
  - c. Equipment and motor vehicles (Link)
  - d. Capital project details (Link)
  - e. Government contracts, grants, and grants in aid (Link)
  
2. The applicant shall provide its anticipated quarterly funding requests for the fiscal year 2023.

Quarter 1	Quarter 2	Quarter 3	Quarter 4	Total Grant
\$50,000	\$50,000	\$50,000	\$50,000	\$200,000

3. The applicant shall provide a listing of all other sources of funding that they are seeking for fiscal year 2023.

ALSOH will seek funding for fiscal year 2023 from individuals, families, foundations, corporations and public sources.



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 2023 for program funding.

The applicant was approved for a state grant in fiscal year 2017. The applicant has also been awarded government contracts for program funding from the County of Hawaii in 2018, 2019, 2020 and 2021. These contracts supported the ALSOH-GWC collaboration to provide Professional Care Management and support an Equipment Loan Program for the County of Hawaii's ALS community. ALSOH has a GIA application pending with the County of Hawaii for funding in 2022-23.

6. The applicant shall provide the balance of its unrestricted current assets as of December 31, 2021.

See attached.

## **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.

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 grassroots, volunteer based organization that provides outreach services to ALS families. ALSOH volunteers have all lived with ALS, so they know the devastation caused by the disease and the have a special appreciation for, and meaningful insights into, the needs of ALS families. ALSOH volunteers visit with families, help them make connections to professional resources in the community, attend support groups and provide them with meals and food baskets and gatherings during the holidays and throughout the year to reduce isolation and provide respite.

The GWC had a similar start almost three decades ago and has been providing a professional wraparound system of care for people living with ALS in Hawaii since 2014; these services are grounded in an evidence-based model of multidisciplinary care. Hawaii's lead 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 address the issues that a person with ALS will face. 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.). The GWC continues to identify medical providers willing to partner for the purpose of establishing a “one stop shop” so that people living with ALS can have direct access to the only model of care that is proven to help people live up to four times longer than the only FDA approved drugs for ALS. The GWC’s collaborative approach ensures that we can provide the best possible access to care for the ALS community.

The GWC’s Community Outreach efforts are also key to achieving our objectives related to access to Care Services (including client engagements and collaborations), reducing isolation, empowering people with ALS and their loved ones, and more. In addition to augmenting Care Service related engagements, our Community Outreach efforts are designed to raise ALS awareness in the general community and to generate support for a neurodegenerative disease that can strike anyone at any time.

The passion and commitment of the volunteers of ALSOH offered in collaboration with the professional expertise and evidence-based model of care provided by the GWC, creates a program with great impact to those living with ALS. Both ALSOH and the GWC offer decades of experience with the activities related to this request including consultation, in home support, advocacy with healthcare and insurance providers, training medical partners, launching clinics, executing successful community events and more.

Both ALSOH and the GWC have significant experience with public funders. ALSOH has been a recipient of State of Hawaii GIA funding in the past and has been successful in securing and administering GIA funds provided by the County of Hawaii. The GWC has been the recipient of GIA awards from the City and County of Honolulu and public funds from the State of California. Both organizations are capable of providing services and accurately reporting results related to publicly funded activities.

Both ALSOH and the GWC have been providing the above services for the prior three years, and long before that too. Each organization can provide historical data and metrics related to the following:

- number of people served
- support groups offered
- clinic visits conducted
- direct assistance grants provided
- equipment purchases and loans expedited
- community outreach activities offered
- in service programs for healthcare providers facilitated

## **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 has no facility needs and GWC facility needs are limited at this time, as most work takes place online and on location with clients in their homes or onsite with collaborative partners, including local community organizations and medical providers.

## **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 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 (gained largely through personal experience) in reducing the feeling of isolation of those living with ALS. For the purpose of this request, ALSOH will engage the GWC to provide the full scope of professional care services required to support Hawaii's ALS community. The GWC's Hawaii based team has extensive experience with ALS and with Hawaii's community resources and will be provided with administrative support and supervision.

The GWC's Lead Care Manager, a Speech and Language Pathologist (SLP), provides care management services to people throughout the state of Hawaii. The Lead Care Manager serves as a vital resource for people living with ALS and health care professionals. The Lead Care Manager visits with people living with ALS and their loved ones in their home, online, as well as in hospital and skilled nursing facilities. The Lead Care Manager also facilitates support groups, assesses the needs for durable medical equipment, augmentative communications equipment, and is a key informant to the members of the multidisciplinary clinical team.

The GWC's Assistant Director of Community Outreach has extensive relationship building skills, deep knowledge of Hawaii's array of local community resources, and works closely with members of Hawaii's ALS and neuromuscular disease community. This community professional connects with clients and organizations throughout Hawaii in an effort to ensure that every person living with ALS is properly supported.

The GWC's Equipment Loan Coordinator has significant expertise surrounding the needs of the ALS community and the wide range of adaptive durable medical equipment including augmentative communication devices that can be used to best support people with ALS and their loved ones. This individual works closely with all members of the GWC team in order to safely deliver necessary equipment, and provide needed training for the person with ALS and their family members and caregivers.

The GWC's Hawaii based staff will have administrative and supervisory support by GWC staff including a Care Services Assistant, Family Outreach Coordinator, Vice President of Care Services, and Vice President of Community Outreach.

### **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 is a volunteer run organization with a President & CEO/Treasurer, Vice President and Secretary. ALSOH will enter into an agreement to contract for services with the GWC, a nonprofit incorporated in California 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 at least one full time Lead Care Manager, one full time Assistant Director of Community Outreach and one full time Equipment Loan Coordinator to execute the program plan. Project staff will have administrative and supervision support from GWC staff.

**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 is a volunteer-based organization with no paid officers, directors or employees of the organization.

**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 2022-23 the activity funded by the grant if the grant of this application is:

- (a) Received by the applicant for fiscal year 2022-23, but
- (b) Not received by the applicant thereafter.

ALSOH and the GWC rely upon philanthropy to meet budgeted revenue goals each year that are directly connected to program expenses. Currently, neither organization charges the ALS community for programs or services rendered and neither receives funding 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 campaigns, events, public and private grants, and estate gifts. Each organization has been successful in launching and sustaining programs in Hawaii and, in reality, the donors that support programs that are essential to the welfare of the ALS community are people who themselves have been affected by ALS.

The needs of the ALS community are complex and highly variable under normal circumstances; navigating the significant health concerns related to COVID for the ALS community are compounded by the challenging economic environment which has led to a decrease in donations in support of the ALS community for the past two years in a row. ALSOH and the GWC intend to leverage state funding to attract additional philanthropic investment and support during this prolonged pandemic period.

As noted above, in large part, donations in support of the ALS community come from the ALS community. Prior to the global pandemic, highly visible and community focused in person events, were a strong source of funding and provided valuable opportunities to develop relationships with new donors. Both ALSOH and the GWC are uncertain about the feasibility of conducting events in person this year and anticipate that many families, donors, and partners will continue to experience financial hardships for the foreseeable future. And if our organizations are able to host gatherings, there will be new and increased expenses associated with conducting them safely. Lastly, federal relief loans and grants will not be available to offset decreases in donations and increases in expenses.

Given all of the above, support for vulnerable families living with ALS in Hawaii is crucial at this time. State funds will be used to maintain core programs in this interim period while ALSOH and the GWC seek dedicated philanthropic support from individuals, families, corporations and foundations. In this way, after the funding period, ALSOH and the GWC will be poised to accomplish more for those who rely on our partnership to deliver high quality, impactful and innovative approaches that ensure access to care for Hawaii's growing number of ALS patients, and advancing opportunities for those patients to participate in ALS research.

## TREASURER'S REPORT

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

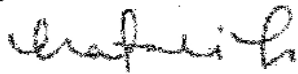
**Debits to Account**

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>

**BALANCE AS OF December 31, 2018**

**\$ 14,224.05**

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



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

12/31/18

Date

ALS OHANA  
2019 TREASURER'S REPORT

OPENING BALANCE AS OF DECEMBER 31, 2018

\$ 14,224.05

**Deposits to Account**

<u>Date</u>	<u>Item</u>	<u>Amount</u>
2/15/2019	Amazon Smile Direct Deposit	\$ 8.30
5/9/2019	Amazon Smile Direct Deposit	\$ 5.00
6/13/2018	County of Hawaii Grant Payment 2	\$ 5,862.50
8/1/2019	Hawaii Annual Filing	\$ 3.50
11/12/2019	Amazon Smile Direct Deposit	\$ 12.40
		<u>\$ 5,891.70</u>

\$ 20,115.75

**Debits to Account**

<u>Date</u>	<u>Item</u>	<u>Amount</u>
6/14/2019	Transfer of County Grant to Collaborative Partner ALSA	\$ 5,862.50
9/12/2019	Philadelphia Insurance	\$ 2,837.00
9/12/2019	Printshop Hawaii for ALS Team Walk	\$ 224.48
8/12/2019	Annual Report Order	\$ 3.50
9/12/2019	Annual Report Order	\$ 3.50
10/15/2019	CPA Collective 2018 tax returns	\$ 1,388.48
12/10/2019	Reimbursement to Natalie Fonda for ALS Christmas Party Gifts for Raffle	\$ 86.69
12/10/2019	Reimbursement to Jan Meduskt for ALS Christmas Party Gifts	\$ 145.80
12/16/2019	Reimbursement to Jennifer Shack for ALS Christmas Party Gifts	\$ 130.71
12/26/2019	Uahi Grill: Food for ALS Christmas Party	\$ 843.75
		<u>\$ 11,526.41</u>

\$ 8,589.34

**BALANCE AS OF December 31, 2019**

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



1/10/2020

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

Date



ALS OHANA  
2020 TREASURER'S REPORT

OPENING BALANCE AS OF DECEMBER 31, 2019

\$ 8,589.34

**Deposits to Account**

<u>Date</u>	<u>Item</u>	<u>Amount</u>
2/20/2020	Direct Deposit from Amazon Smile	\$ 5.89
2/24/2020	Check from Sandra Maxwell donation	\$ 200.00
5/21/2020	Direct Deposit from Amazon Smile	\$ 7.79
7/28/2020	1st half County of Hawaii grant - Professional care program	\$ 6,875.00
7/28/2020	1st half County of Hawaii grant - Equipment loan program	\$ 3,562.50
8/13/2020	Direct Deposit from Amazon Smile	\$ 11.07
11/12/2020	Direct Deposit from Amazon Smile	\$ 7.74
11/25/2020	Reimbursement from ALSA for 1/2 insurance and accountant fee	\$ 2,022.27
12/22/2020	Reimbursement from ALS Support group for wreaths	\$ 454.55
		<u>\$ 13,146.81</u>

\$ 21,736.15

**Debits to Account**

<u>Date</u>	<u>Item</u>	<u>Amount</u>
6/12/2020	The CPA Collective - 2019 Tax returns	\$ 628.27
6/12/2020	Kit Zulueta - 2017- 2020 website renewal	\$ 800.00
7/28/2020	Transfer to ALSA 1st half County of Hawaii grant - Professional care program	\$ 6,875.00
7/28/2020	Transfer to ALSA 1st half County of Hawaii grant - Equipment loan program	\$ 3,562.50
7/28/2020	Reimbursement to Natalie Fonda for Camp Gigi shirts	\$ 225.24
7/28/2020	Annual Report Filing	\$ 3.50
9/2/2020	Reimbursement to Natalie Fonda for Camp Gigi Box items, mailing	\$ 295.06
9/15/2020	Philadelphia Insurance Annual Premium	\$ 1,450.00
10/7/2020	Philadelphia Insurance Annual Premium	\$ 1,338.00
12/10/2020	Reimbursement for ALS Holiday party gifts	\$ 151.72
12/12/2020	Reimbursement to MacHoover for Christmas wreaths	\$ 477.24
		<u>\$ 15,806.53</u>

**BALANCE AS OF DECEMBER 31, 2020**

**\$ 5,929.62**

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



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

1/18/2021

Date

ALS OHANA  
2021 TREASURER'S REPORT

OPENING BALANCE AS OF DECEMBER 31, 2021

\$ 5,929.62

**Deposits to Account**

<u>Date</u>	<u>Item</u>	<u>Amount</u>
2/22/2021	Amazon Smile Donation Direct Deposit	\$ 5.89
2/26/2021	Donation	\$ 97.10
3/18/2021	County of Hawaii 2nd half of grant	\$ 10,437.50
5/24/2021	Amazon Smile Donation Direct Deposit	\$ 9.60
8/10/2021	Amazon Smile Donation Direct Deposit	\$ 23.91
8/25/2021	County of Hawaii 1st half of grant	\$ 11,650.00
9/10/2021	Donation from Judie Carlstrom for Camo Gigi	\$ 2,000.00
11/22/2021	Amazon Smile Donation Direct Deposit	\$ 7.19
12/20/2021	Donation from Jan Medusky	\$ 5,000.00
		<u>\$ 29,231.19</u>

\$ 35,160.81

**Debits to Account**

<u>Date</u>	<u>Item</u>	<u>Amount</u>
1/6/2021	Bea Arnople - Volcano Hawaii - Terryn Plaque	\$ 307.96
3/18/2021	ALS Association - Final transfer of County of Hawaii Grant	\$ 10,437.50
8/20/2021	Payment to the CPA collective for 2020 taxes (check 1117)	\$ 628.27
8/10/2021	Direct transfer to HI Gove for annual filing	\$ 3.50
9/9/2021	ALS Association - Transfer of 1st half of County of Hawaii Grant	\$ 11,650.00
9/6/2021	Philadelphia Insurance	\$ 2,826.00
		<u>\$ 25,853.23</u>

**BALANCE AS OF December 31, 2021**

**\$ 9,307.58**

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



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

12/31/2021

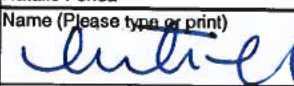
Date

## BUDGET PAGES

## BUDGET REQUEST BY SOURCE OF FUNDS

Period: July 1, 2022 to June 30, 2023

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)
<b>A. PERSONNEL COST</b>				
1. Salaries	228,342			
2. Payroll Taxes & Assessments	25,858			
3. Fringe Benefits	34,416			
<b>TOTAL PERSONNEL COST</b>	<b>288,616</b>			
<b>B. OTHER CURRENT EXPENSES</b>				
1. Airfare, Inter-Island	5,400			
2. Insurance	0			
3. Lease/Rental of Equipment	0			
4. Lease/Rental of Space	15,000			
5. Staff Training	2,500			
6. Supplies	2,500			
7. Telecommunication	4,800			
8. Utilities	0			
9. Travel, Inter-Island: Lodging	2,700			
10. Travel, Inter-Island: Ground Transport	1,260			
11. Travel, Inter-Island: Meals per diem	1,800			
12. Mileage	5,000			
13. Equipment Loan Program (repairs/shipping)	10,000			
14. Direct Assistance Grants	10,000			
15.				
16.				
17.				
18.				
19.				
20.				
<b>TOTAL OTHER CURRENT EXPENSES</b>	<b>60,960</b>			
<b>C. EQUIPMENT PURCHASES</b>	<b>10,000</b>			
<b>D. MOTOR VEHICLE PURCHASES</b>				
<b>E. CAPITAL</b>				
<b>TOTAL (A+B+C+D+E)</b>	<b>359,576</b>			
<b>SOURCES OF FUNDING</b>		Budget Prepared By:		
(a) Total State Funds Requested	200,000	Natalie Fonda	808-258-9388	
(b) Total Federal Funds Requested	N/A	Name (Please type or print) Phone		
(c) Total County Funds Requested	N/A			
(d) Total Private/Other Funds Requested	159,576	1/17/22		
		Signature of Authorized Official Date		
<b>TOTAL BUDGET</b>	<b>359,576</b>	President and Treasurer		
		Name and Title (Please type or print)		

## BUDGET JUSTIFICATION - PERSONNEL SALARIES AND WAGES

Period: July 1, 2022 to June 30, 2023

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)
Lead Care Manager	1	\$99,367.00	100.00%	\$ 99,367.00
Equipment Loan Coordinator	1	\$65,470.00	100.00%	\$ 65,470.00
Assistant Director of Community Outreach	1	\$99,625.00	100.00%	\$ 99,625.00
Administrative Assistant	1	\$59,760.00	5.00%	\$ 2,988.00
VP of Care Services	1	\$145,408.00	6.00%	\$ 8,724.48
VP of Community Outreach	1	\$156,224.00	6.00%	\$ 9,373.44
Family Outreach Coordinator	1	\$61,357.00	5.00%	\$ 3,067.85
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
				\$ -
<b>TOTAL:</b>				<b>288,615.77</b>
<b>JUSTIFICATION/COMMENTS:</b>				
The VP of Care Services and VP of Community Outreach are providing supervision and support for all grant activities. The Administrative Assistant and Family Outreach Coordinator are providing support for grant activities.				

## BUDGET JUSTIFICATION - EQUIPMENT AND MOTOR VEHICLES

Period: July 1, 2022 to June 30, 2023

Applicant: ALS Ohana of Hawaii (ALSOH)

DESCRIPTION EQUIPMENT	NO. OF ITEMS	COST PER ITEM	TOTAL COST	TOTAL BUDGETED
Augmentative Alternative Communication devices	20.00	\$250.00	\$ 5,000.00	
Durable Medical Equipment	20	\$250.00	\$ 5,000.00	
			\$ -	
			\$ -	
			\$ -	
<b>TOTAL:</b>	40		\$ 10,000.00	
<b>JUSTIFICATION/COMMENTS:</b>				

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

# BUDGET JUSTIFICATION - CAPITAL PROJECT DETAILS

Period: July 1, 2022 to June 30, 2023

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: 2020-2021	FY: 2021-2022	FY:2022-2023	FY:2022-2023	FY:2023-2024	FY:2024-2025
PLANS						
LAND ACQUISITION						
DESIGN						
CONSTRUCTION						
EQUIPMENT						
<b>TOTAL:</b>	<b>N/A</b>					
<b>JUSTIFICATION/COMMENTS:</b> ALSOH does not request funds for capital projects at this time.						

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

Applicant: ALS Ohana of Hawaii (ALSOH)

Contracts Total: -

	<b>CONTRACT DESCRIPTION</b>	<b>EFFECTIVE DATES</b>	<b>AGENCY</b>	<b>GOVERNMENT ENTITY (U.S./State/Hawaii/ Honolulu/ Kauai/ Maui County)</b>	<b>CONTRACT VALUE</b>
1	N/A				N/A
2					
3					
4					
5					
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## PROPOSED PROGRAM ORGANIZATIONAL CHART

**ALS Ohana of Hawaii  
FYE23 State of Hawaii GIA  
Proposed Program Organizational Chart**

