## KENAITZE INDIAN TRIBE TRIBAL RESEARCH REVIEW ORDINANCE

# ORDINANCE NO. 2016-03 ADOPTED July 15, 2016 Amended and Rescinded April 20, 2023

#### **Section 1. Authority and Purpose**

- A. Authority. The Kenaitze Indian Tribe's ("Tribe") Constitution, Art. X, Sec. 3, provides that the Tribal Council shall promote and protect the peace, safety, health, education and general welfare of the Tribal Members, and shall encourage, guard, and foster traditional cultural practices of the Kenaitze Tribal Members, including the arts, crafts, language and customs of the Tribe. Research information and data generated by and about Kenaitze individuals, communities and culture represent inalienable intellectual properties of the Kenaitze Tribal Members over which the Tribal Council will provide oversight.
- B. Purpose. The Tribal Council adopts this Ordinance to establish a means by which Tribal research policies will be administered. The Tribal Council has a responsibility to protect and preserve the culture of the Tribe and to ensure that research activities are conducted in a way that does no harm to the culture of the Tribe. The Tribal Council recognizes the value of medical, social and physical science research. The Tribal Council also recognizes the need for present and future individual Tribal Members to be free from immediate or long-term effects of harmful, intrusive, ill-conceived or otherwise offensive research and investigation procedures. To carry out this purpose, the Tribal Council hereby establishes a Kenaitze Tribal Research Review Board ("Board").

#### Section 2. Definitions

The following words and phrases, whenever used in this Ordinance, shall have the following meanings:

- **A.** "Board" means the Kenaitze Tribal Research Review Board that is established by this Ordinance.
- B. "Tribal Council" means the Kenaitze Tribal Council.

- **C.** "Human Being" means a living or nonliving individual (including ancestral remains) about whom a researcher conducting research obtains information or data through interaction with the individual, involving physical procedures by which data are gathered, and/or manipulations of the individual or the individual's environment.
- **D.** "Informed Consent" means a prospective participant's voluntary agreement, based upon adequate knowledge and understanding of relevant information, to participate in research or to undergo a diagnostic, therapeutic or preventative procedure. In giving fully informed consent, the participant may not waive any legal rights, or release the applicant Researcher, funding source or agents thereof from liability for negligence.
- **E.** "Intellectual Property" means intangible products of human intellect, including cultural information, knowledge, uses, skills and practices that are developed, sustained and passed on from generation to generation within a community, often forming part of its cultural or spiritual identity.
- **F.** "Research" means the use of systematic methods to gather and analyze information for the purpose of proving or disproving a hypothesis, evaluating concepts or practices or otherwise adding to knowledge and insight in a particular discipline or field of knowledge or to demonstrate or investigate theories, techniques or practices. For the purpose of this Ordinance, research includes, but is not limited to, the following:
  - 1. Basic and clinical research including, but not limited to DNA;
  - 2. Behavioral studies;
  - 3. Anthropological and archaeological studies;
  - 4. Community and cultural-based research, including but not limited to interviews, questionnaires, surveys and participant observation:
  - 5. Practice-based research;
  - 6. Cultural or historical research;
  - 7. Linguistic research; and
  - 8. Feasibility and other studies designed to develop, test and evaluate basic data in all phases of environmental and public health.

- **G.** "Publication" means the dissemination of any intellectual property, information, data or compilation, including but not limited to: verbal and/or written reports, studies, articles, theses, books, manuscripts, sound recordings, film and video, media interviews, computer databases, field notes, illustrations, photographs, collected material artifacts, replicas, biological specimens and ancestral remains and communications through electronic media, Tribe's website, including the internet. Publication also includes dissemination of information in any derivative form, such as translations.
- **H.** "Researcher" means any person, including but not limited to, Tribal employee, Tribal Member, organization, business or other entity which conducts or participates in the collection of data for research.
- **"Sukdu"** means traditional or legendary stories and oral histories, which embody Tribal values and are often used as teaching tools. Every attempt shall be made by the researcher to preserve the integrity of the Tribe's traditions, stories and history.
- **J.** "**Tribe**" means the Kenaitze Indian Tribe.
- K. "Research Permit" or "Research Agreement" means a signed document with the agreed upon terms under which research on the Tribe or Tribal Members will be conducted.
- "Vulnerable Adults and Children" means those individuals who are abandoned, or are mentally or physically incapacitated by physical conditions or by drug or alcohol induced conditions.

#### Section 3. Research Review Board

- A. <u>Composition</u>. The Board shall be composed of at least five (5) Members, who shall serve five (5) year staggered terms. Members shall be appointed by the Tribal Council. A Tribal Member may also petition the Tribal Council for nomination. The membership of the Board: May include one (1) non-Tribal Member.
- 2. Shall include the following:
  - a. A Tribal Council Member;
  - b. A Tribal Elder;

- c. The Tribal NAGPRA Officer or other cultural representative;
- d. Two (2) Tribal Members
- e. May include one (1) non-Tribal Member;
- 3. May include as Ex-Officio Members:
  - a. A Member with medical expertise, such as the Health Systems Director or designee;
  - b. A Member with scientific expertise outside of the medical field, such as an anthropologist, archaeologist or social scientist familiar with Alaska Native culture.
- **B.** The Board may request assistance from other persons with specialized knowledge in the review of any application, proposal or manuscript, as external consultants.
- **C.** incarcerated The Board shall include in its reviewing body one or more individuals who have a particular concern for the welfare of vulnerable adults or children if research involves such individuals.

#### D. The duties of the Board shall include:

- 1. Develop and submit to the Tribal Council a statement of guiding principles governing the Board in the discharge of its responsibilities for protecting the rights and welfare of human beings, including but not limited to, Tribal Members and the Tribe.
- 2. Identify research priorities of the Tribe.
- 3. Review Research Proposal Packets and make final recommendations to Tribal Council, pursuant to procedures developed by the Board and approved by Tribal Council. Review recommendations shall be guided by the principles in Section 5 of this Ordinance. Review procedures will minimally include:
  - a. Review of initial Research Proposal Packets on a quarterly basis, with a process for conducting initial review within thirty (30) days upon Researcher's request;
  - b. Annual review of each approved research project during the term of the project; and

- c. Review of each proposal by a quorum of at least three Members, unless a procedure for expedited review has been approved by the Tribal Council, which shall be determined on a case-by-case basis.
- 4. Report noncompliance, unanticipated problems and provisions for suspension or termination of Research approval to the Tribal Council and the Researcher, pursuant to procedures developed by the Board and approved by the Tribal Council.
- May present a plan to the Tribal Council for registration of the Board as an Institutional Review Board with the Federal Office for Human Research Protection and secure and maintain registration as directed by Tribal Council.
- 6. Establish uniform provisions protecting the Tribe's interests that must be included in all Research Agreements, including:
  - a. A description of the research methods to be used and the products that may result from the research;
  - A declaration of the ownership of intellectual property rights for any products that may result from research, either through data collection or publication;
  - c. Provisions for the researcher to report on the results of research to the Tribe and to the participants;
  - d. Provisions for the Tribe and the individuals participating in research to receive access to the data collected;
  - e. It is often in the Tribe's interest to share public information about programs, services, culture and values. The Tribal Council Chairperson and the Executive Director are the official spokespersons for the Tribe and are the only individuals who can, at will, make public statements to representatives of the news media on the Tribe's behalf. The Tribal Council Chairperson or the Executive Director may delegate some or all of this authority to a designated Council Member or employee on a case-by-case basis. News media requests for interviews, comments, audio, photography or video recordings should be referred to the Communications Manager or the Executive Director. Requests shall be shared with the Tribal Council Chairperson and Vice-Chairperson in a timely manner.

Provisions for participants and the Tribe to receive a fair and appropriate return for cooperation in Research (whether monetary, in-kind labor, or acknowledgment) and the sharing of any profit resulting from Research; and

f. A guarantee that researchers and other potential users shall protect privacy and confidentiality for any information concerning Tribal culture, traditions, sukdu, spiritual beliefs or other matters that the Tribe or individual participants identify as confidential.

#### Section 4. Research Permit

- A. A researcher must apply for and receive a Research Permit prior to undertaking any research within the jurisdiction of the Tribe or on Tribal property, or which otherwise concerns Kenaitze individuals as an identifiable group.
- **B.** Researchers shall apply for a Research Permit by submitting a Research Proposal Packet to the Board.
- C. The Board shall review each Research Proposal Packet and prepare a recommendation to the Tribal Council on whether to grant a Research Permit.
- **D.** The Tribal Council shall have final authority to approve research proposals after reviewing the Board's recommendation.
- **E.** Prior to beginning Research, a Researcher whose Research Proposal has been approved shall enter into a Research Agreement specific to the Research so that studies proceed in a manner that is both culturally sensitive and relevant to the participants and the Tribe.
- **F.** The Tribe may assess reasonable fees for costs associated with reviewing proposals.

#### Section 5. Guiding Principles for Research

- **A.** Research will be evaluated in accordance with Kenaitze Indian Tribe Ordinance 2007-01, Environmental Protection for Tribal Lands, Article 7.
- **B.** All research shall be aligned with Kenaitze Traditional Values:

- 1. Naq'eltani "great spirit, creator" "pure love, pure truth"
- 2. Ts'itsatna "ancestors"
- 3. Yinihugheltani "one's spirit"
- 4. Qiz'unch' "the right way, the truth"
- 5. Ada "care, concern, tenderness"
- 6. Nadesnaqa "our Elders"
- 7. Nagh'utdalts'ina "our neighbors"
- 8. Ch'anikna "children"
- 9. Nanutset "our history, before our time"
- 10. Nakenagh "background, lineage"
- 11. Henu "work, job, task"
- 12. Nudnelyahi ch'u qeneshi "plants and animals"
- 13. Daggeyi "fellowship"
- 14. Ey'uhqats'dalts'iyi "subsistence, living upon the outdoors"
- 15. Na'ini "strength, courage, sobriety, humility"
- 16. Naghet'a "our honesty"
- 17. Chiqinik "thank you"
- **C**. The Tribal Council also adopts the following guiding principles for Research:
  - Informed Consent: Research should not be conducted until there has been full consultation with all potentially affected participants and each has approved the research after full disclosure. Full disclosure consists of, at a minimum:
    - a. Potential benefits and/or harm to the participants of research;

- b. All relevant affiliations of the person(s) or organization(s) seeking to undertake research;
- c. All sponsors of research; and
- d. Intended future uses of the data.
- 2. Claims to ownership of intellectual property that may be created through Research as defined in Section 2, E.
- Immediate Risks and Benefits: Research shall be of immediate benefit to the Tribe and/or Tribal Member participants, and the risks associated with research shall be less significant than the benefits to be gained.
- 4. **Confidentiality:** Individual participants and the Tribe have the right, at their discretion, to exclude from publication and to have kept confidential any information concerning their culture, traditions, sukdu, spiritual beliefs or other personal data.
- 5. Respect: Researchers shall respect the integrity, morality, and spirituality of the culture, traditions, and relationships of Tribal Members with the world, and shall avoid imposing external conceptions and standards. Researchers and the Tribe shall not assume that they believe in the same things or share the same goals and expectations. Good communication is required for research to take place in a proper and productive manner. The Researchers shall not impose their beliefs/concepts upon the Tribal Members.
- 6. **Empowerment:** Research authorship shall be shared between the Tribe and the Researcher. The Researcher shall involve Kenaitze Tribal Members through hiring and training to the maximum extent feasible.
- 7. **Equity:** Researchers and the Tribe shall bring equity to any Research contract, agreement or understanding. Equity is a sharing of resources, which can include financial benefit, community knowledge, networks, personnel and political or social power. The parties shall continuously review equity over the duration of a Research Agreement.
- 8. **Self-Determination:** The Tribe and its Members shall have the right to self-determination. Researchers and associated organizations shall acknowledge and respect such rights.

- 9. Valid Existing rights: The Tribe has valid existing rights and interest over air, land, water and the natural resources within them that the Tribe has traditionally inhabited or used, together with all traditional and scientific knowledge, intellectual property, and traditional resource rights associated with such resources and their use.
- 10. **Inalienable Rights**: The Tribe and its Members have inalienable rights to their traditional territories, the natural resources within them, and associated traditional knowledge.
- 11. **Traditional Guardianship.** The Tribe acknowledges responsibility to preserve and maintain its role as traditional guardians of the earth, including but not limited to, hunting, fishing and gathering wild, renewable/natural resources and cultural heritage. Researchers shall ensure that in designing and conducting Research, they respect the obligation of the Tribe to protect natural resources.

### Section 6. Sovereign Immunity

Nothing in this Ordinance shall be construed as a waiver of the sovereign immunity of the Tribe, or its Tribal Council Members, the Members of the Board, Tribal employees, or any other Tribal officers or agents.

#### **CERTIFICATION**

Voting in Favor:	6
Voting Against: _	0_
Abstaining: <u>0</u>	

- DocuSigned by:

Ronette Stanton

Rohette Stanton, Chairperson

— DocuSigned by:

Brenda Smith, Secretary