

# When Science Outpaces Native Political Will:

*The relationship of science to  
emerging indigenous partnerships*

Theodore A. Mala, MD, MPH

Marjorie K. Mau, MD, MS, FACP

14<sup>th</sup> International Congress on Circumpolar Health –  
Yellowknife, Northwest Territory, Canada

July 10 – 16, 2009

# Native Perspectives on Research

- Native Case Studies: Alaska & Hawai'i
- 'New' Era of Community Engagement & Participatory Research
- Native Wisdom – Scientific Evidence
- Research that Benefits Native People

# An issue of trust

- Native Americans have trust issues with both research and the Federal government
- Native sovereignty
- Do the benefits to the tribe outweigh trust issues?



# Specimen Bank: Case in Point

- The collection of biological materials
- Use and consent issues
- Benefits:
  - pre diagnostic markers
- Prevalence (e.g. *Helicobacter pylori*)
  - Individual identification

# Specimen Bank: Case in Point

- Management: IHS, CDC, AK Native Tribal Health Organizations and State of Alaska (Public Health) Working Group
- Policies for the future
  - Consent to be in a research study
  - Consent to store and test samples
  - Option for individuals to opt out of stored specimens



# Tribal questions

- Who owns the data?
- How will it be used?
- Do tribes have control of the final product (ie publications)?
- Who has access to these data?



Teens



20s



30s



40s



50s



60s



70s



80s

## **A Woman's Risk of Getting Breast Cancer Increases with Age.**

**Risk is 1 in:**

**>28,000**

**19,608**

**622**

**93**

**33**

**17**

**11**

**9**

# Consent issues



- How was/is consent obtained?
- Ethics of the researchers
- Ethics education for Native entities
- Cross-cultural training of researchers





# Empowering Tribes

- Training of individuals to do research in their communities
- Explaining of benefits to tribes
- Identifying PI's to do this research
- Utilizing focus groups

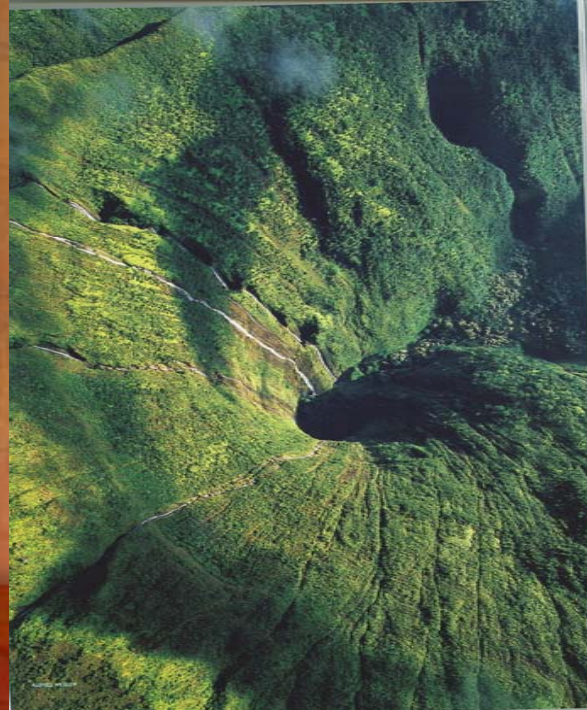
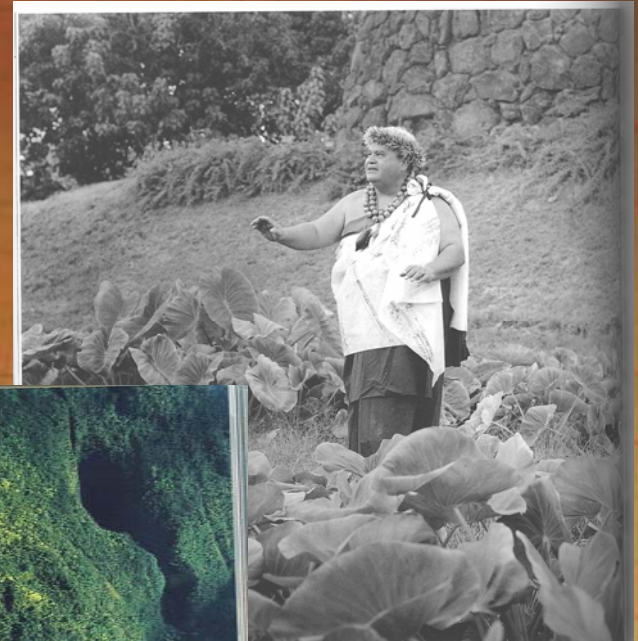
Alaska Native Medical Center  
Anchorage, Alaska



Dr. Ted Mala  
[tmala@scf.cc](mailto:tmala@scf.cc), 907-729-4955

# Who are Native Hawaiians?

- ~500 AD: indigenous people of Hawai'i
- 1778: James Cook arrived
- 1893: Illegal overthrow of Hawaiian Kingdom by American businessmen





# Queen Lili'uokalani

(1838-1917)

Reigned 1891 - 1893

“I do under this protest, and impelled by said force, yield my authority until . . . the United States shall . . . undo the action of its representatives and reinstate me in the authority which I claim as the constitutional sovereign of the Hawaiian Islands.”

January 17, 1893

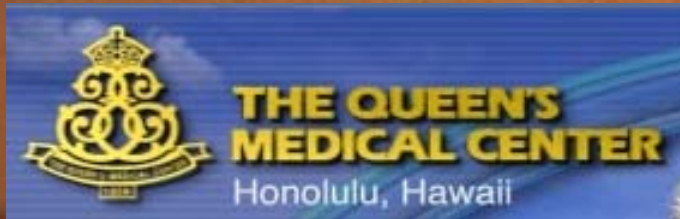


Native Hawaiians  
continue to struggle  
to recover their  
LAND and  
SOVEREIGNTY



# Malama Pu'uwai Study

A Research Partnership: Department of Native Hawaiian Health & Queens Medical Center



**John A. Burns School of Medicine**  
University of Hawai'i at Manoa

NIH-NHLBI U01 HL 079613

# The Malama Pu'uwai Project

- **Mission**: to address and reduce cardiovascular disparities, specifically heart failure, in Native Hawaiians and other Pacific Island Peoples
  - Research Studies, Training and Community Engagement
- Consists of 4 interrelated studies on heart failure among Native Hawaiians & Other Pacific Islanders
  - Randomized Control Trial
  - Community Health Worker Echo
  - Ethnic differences in Heart Failure
  - Family Heart Health History Study

# ‘Ohana (Family) Heart Health History

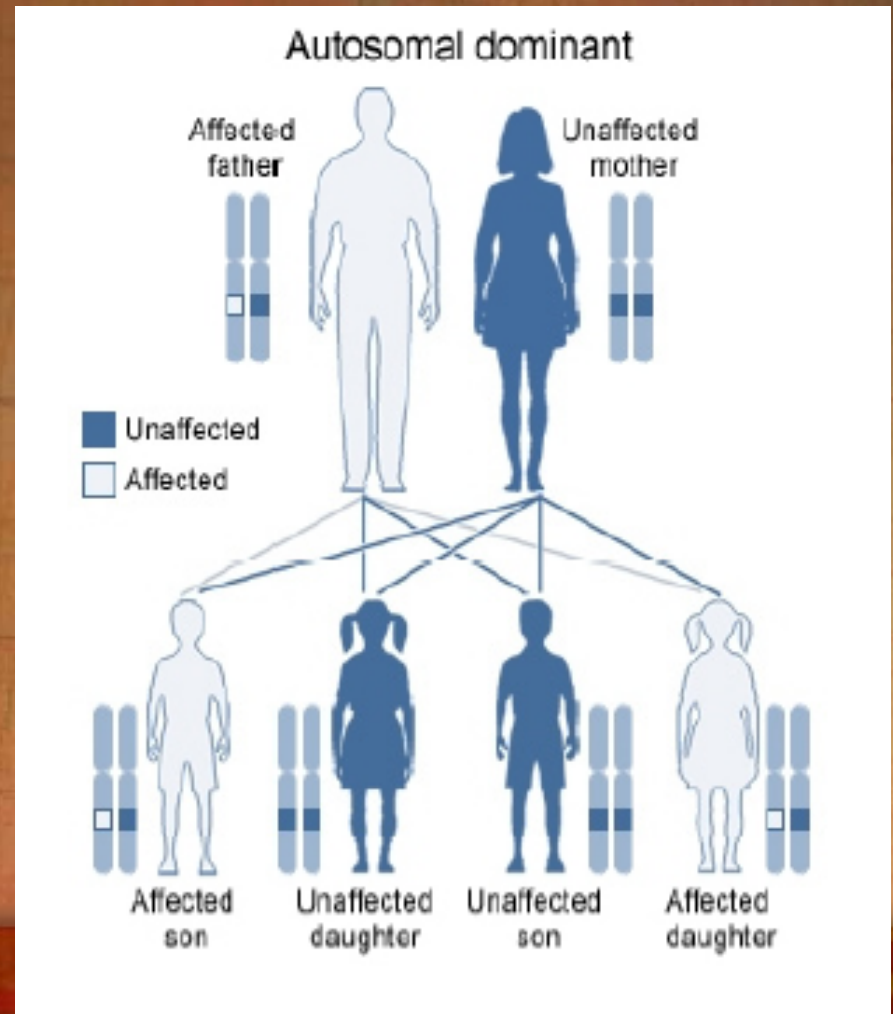
- **Purpose:** Identify & collect detailed family health histories in Native Hawaiian patients with diagnosed heart failure.
- **Research Question:** Are there inherited forms of cardiomyopathy that might explain excess heart disease?





# ‘Ohana Heart Health History Study

- Native Hawaiian Probands with Diagnosed Heart Failure Identified & Enrolled (N=10)
- Detailed Family Histories were constructed for each family.



# (Somewhat) Unexpected Findings: Inherited Cardiomyopathy in Native Hawaiians

- Predominant pattern of inheritance – **autosomal dominant**
  - Patterns of inheritance – allows genetic risk stratification
- Automatic Implantable Cardiac Defibrillator – Life-saving treatment in diagnosed cardiomyopathy
  - Non-invasive method for screening family members
- How best to inform family members about this potentially life-saving treatment for a genetic disease?

# Currently: 'Ohana (Family) Heart Health History Study

- Specific Aim completed

- On the  
the  
– I

**Scientific/Research Pause**  
to allow for families, native &  
clinical communities to learn of  
results & suggest future steps

- Goals for  
families (and larger community – native &  
clinical)

# John A. Burns School of Medicine



at University of Hawai'i

So the question arises...

How to do Research with Native  
Communities?

Some thoughts worth considering...

# Community Engagement & Participatory Research: *Beyond Cross-cultural Communications*

Researchers need a stronger understanding of...

- Meaningful partnerships with communities
- Context – community, cultural, literacy
- Trust – building, sustaining, strengthening
- Power-sharing – knowledge, budget, resources
- Community needs – understand benefit of research

**AND Practical Experience / Mentorship on achieving them**

What does Community Engagement *Mean*?

What is *Meaningful* Community Engagement?

... at it's HEART is...

Intersection of the complementary efforts of members of the lay community, health practitioners & medical & public health researchers to improve health.



# Key Ethical Issues in Native Communities

- Preparing for research in Native communities
- Developing the collaboration or partnership
- Informed consent issues
- Community knowledge collection
- Research data management
- Sustainability of research efforts



# ‘Ohana Heart Health History: Lessons Learned

## Sustainability is KEY for Native Communities

- Sustainability for Communities means tangible benefits resulting from the study findings
  - How will this benefit our community?
  - Will we be teaching this new knowledge to the next generation?
  - Will there be better ways to keep our people healthy?
- Researchers need to engage in ACTIVE Listening
  - able to touch the essence of what the family/community needs may be.

