



# Perspectives on Genetic Research: Results from a Survey of Navajo Community Members

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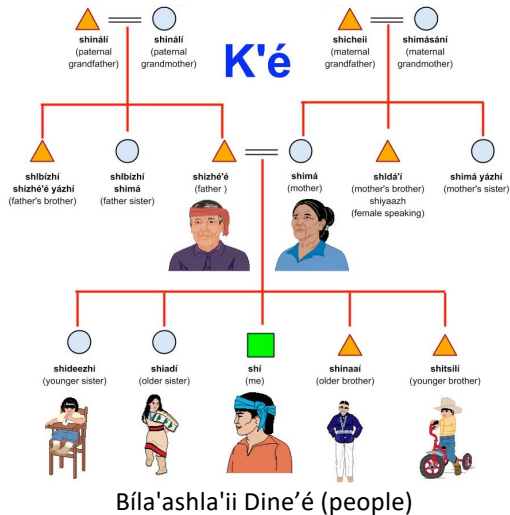
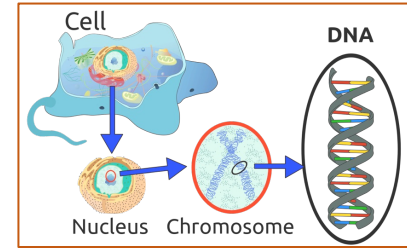
DINÉ POLICY  
INSTITUTE

Photo credit: Nanibaa' Garrison

# Diné concepts of genetics

What is genetic research?

The study of genes (DNA instructions) and their role in the way traits are passed from one generation to the next.



Dibé (sheep)



Naadáq' (corn)



1977 - DNA Sequencing begins

**Genetics is not new to the Navajo people.**

A moratorium on Genetic Research conducted within the Navajo Nation was approved in April 2002.

HSSCAP-20-02

RESOLUTION OF THE  
HEALTH AND SOCIAL SERVICES COMMITTEE  
OF THE NAVAJO NATION COUNCIL

Approving a Moratorium on Genetic Research Studies Conducted Within the Jurisdiction of the Navajo Nation Until Such Time that a Navajo Nation Human Research Code has Been Amended by the Navajo Nation Council



A moratorium on Genetic Research conducted within the Navajo Nation was approved in April 2002.

A STUDY OF THE BLOOD GROUPS AMONG THE  
AMERICAN INDIANS

CLARA NIGG

From the Department of Bacteriology, University of Kansas, Lawrence

Received for publication August 1, 1925

In 1923 Coxa and Deibert (1) studied the percentage distribution of the four Landsteiner blood groups in the North American Indians in order to investigate the question of the relation of the American Indian race to the northeastern Asiatic races (Chinese, Japanese, Koreans), since it has been thought that the American Indian is of Mongolian origin. Their results in comprising 862 full-blooded Indians showed the following occurrence: group I 77.7 per cent, group II 20.2 III 2.1 per cent, group IV one individual.

***Inbreeding Coefficients of the Ramah Navaho Population***

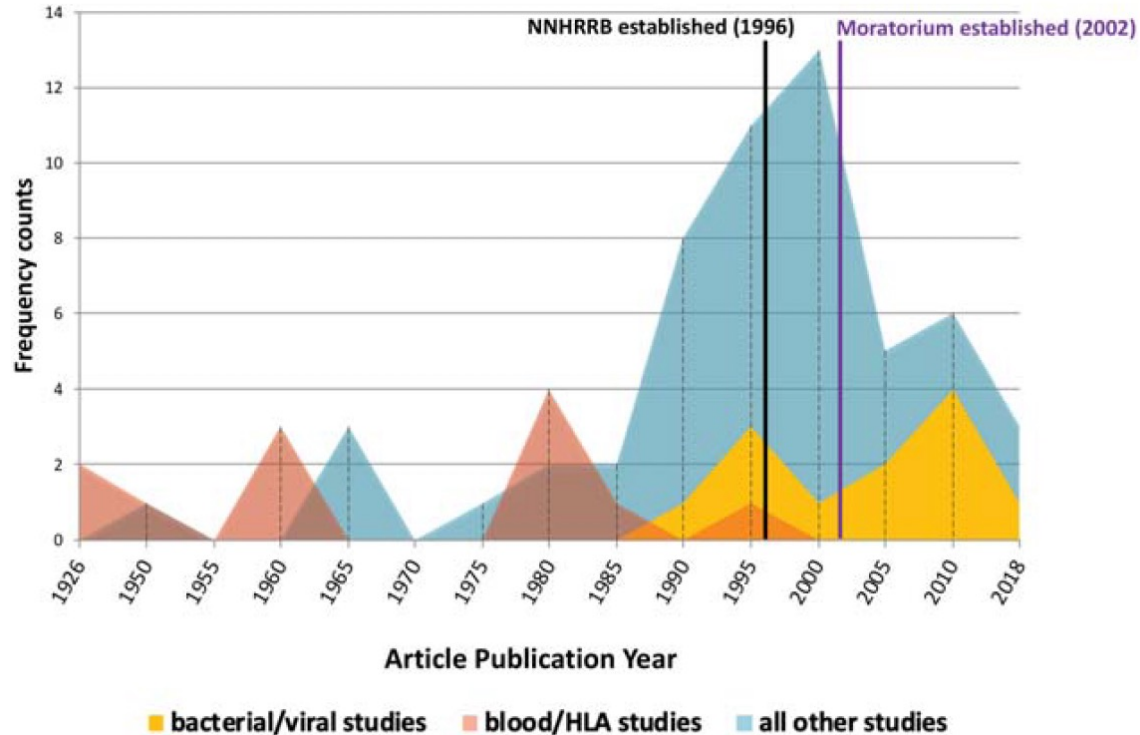
J.N. SPUHLER<sup>1</sup> AND CLYDE KLUCKHOHN<sup>2</sup>

**Hereditary Nonpolyposis Colorectal Cancer in a Navajo Indian Family**

Henry T. Lynch, Thomas J. Drouhard, Guy S. Schuelke, Karen A. Biscione, Jane F. Lynch, and B. Shannon Danes



# History of Genetic Research Involving Navajo People



# Goals & Objectives

## Goals

- Assess the attitudes and perspectives of Navajo people on genetics research.
- Increase knowledge of the peoples' concerns and recommendations regarding future policy.
- Generate data to inform Navajo leaders, policy development groups, research oversight bodies, and the general community.

## Objectives

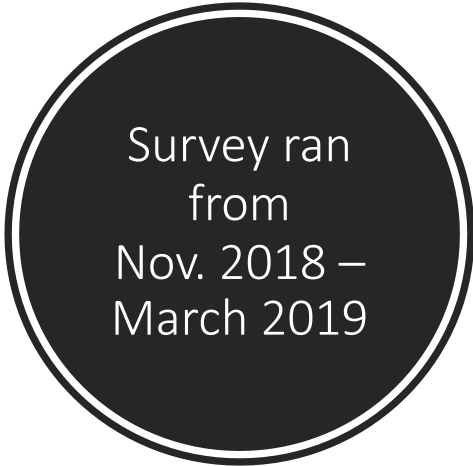
- Identify community views with interviews, surveys, and deliberative discussions.

# Community Survey on Genetic Research Perspectives



Katrina G. Claw, Nicolas Dundas, Michael S. Parrish, Rene L. Begay, Travis L. Teller,  
Nanibaa' A. Garrison, Franklin Sage

*Paper published in 2021*



## Opinions on Genetics?

### What do you think about genetic research on the Navajo Nation?

Take part in the online survey:

<http://bit.ly/navajogenetics>

It should take 5-10 minutes to complete and you can enter a raffle drawing for a \$25 gift card.

#### Contact information

Email: [navajogenetics@gmail.com](mailto:navajogenetics@gmail.com)

Call or text: (928) 421-3855

*The Perspectives on Genetic Research in the Navajo Nation Survey project has been approved by the Navajo Nation Human Research Review Board*



#### Perspectives on Genetics in the Navajo Nation Survey

**PURPOSE:** We are conducting a survey about Navajo opinions and perspectives on genetic research. The overall results from this survey will be used to inform the development of a policy relating to genetic research on the Navajo Nation. Your participation in this interview is completely voluntary. Any information revealed on the survey will be kept anonymous. The survey will take approximately 5-10 minutes to complete, and you are welcome to enter into a raffle drawing at the end of the survey. At the end of the survey study, we will raffle off twenty gift cards in the amount of \$25 for survey participants. Thank you for your time. Ahééee'!

#### DEMOGRAPHICS:

What tribe(s) are you enrolled with? Please check all that apply.

- Diné (Navajo) Nation
- Other tribe(s), please list: \_\_\_\_\_
- Other ethnicity, please list: \_\_\_\_\_
- I am not Native American.

Do you currently live on the reservation?

- I primarily live on the Navajo Nation
- I primarily live off of the Navajo Nation (e.g., Urban)
- I am transitional, I live on and off the Navajo Nation
- None of the above

Age:  18-30  61-75  
 31-45  76+

46-60

How do you identify?

- Man
- Woman
- Two Spirit/ LGBTQ (Lesbian, Gay, Bisexual, Transgender, or Queer)
- Other: \_\_\_\_\_

What is the highest level of education you have completed?

- Middle school  Bachelor's Degree
- Some High School  Master's Degree
- High School Diploma/ GED  Professional Degree (JD, RN, MD)
- Vocational School  Doctorate Degree
- Some College

What is your current religion, if any? Please check all that apply.

- Traditional Navajo  Mormon
- Azee' Bee Nahagha (Native American Church)  Atheist
- Christian  None of the above
- Catholic  Other: \_\_\_\_\_

Which agency are you affiliated with?

- Western
- Central
- Northern
- Eastern
- Fort Defiance
- Not sure/Not applicable

Please provide your Chapter affiliation: \_\_\_\_\_

Study #19W-17281, approved by the IRB/HRB  
For more information: Email: [navajogenetics@gmail.com](mailto:navajogenetics@gmail.com) or Call/text: (928) 421-3855



# Sections of the Survey

Knowledge, Values, and Beliefs

Knowledge on Research and Moratorium

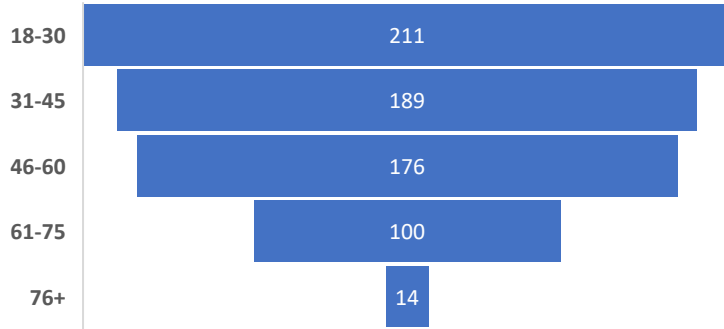
Biospecimens and Data

Concerns about Genetic Research

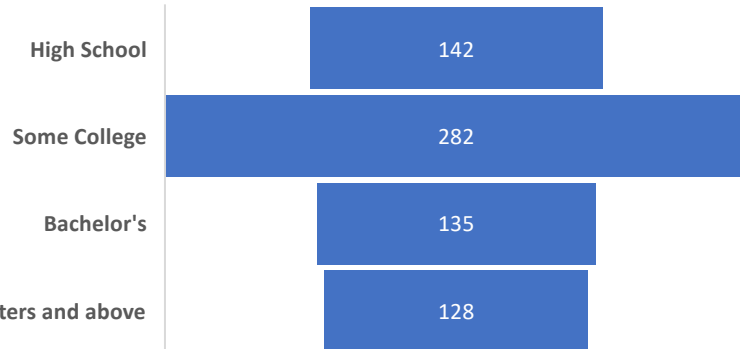
Policy Recommendations and Moratorium

# Navajo respondents to the survey (N = 690)

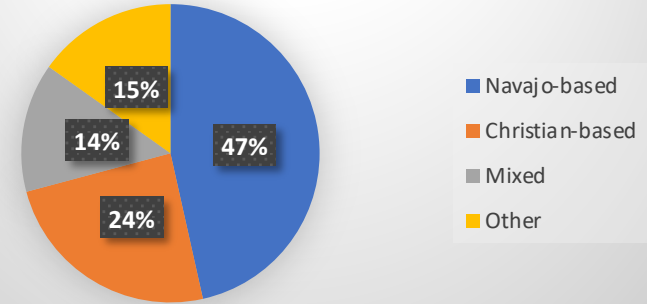
## Age Range



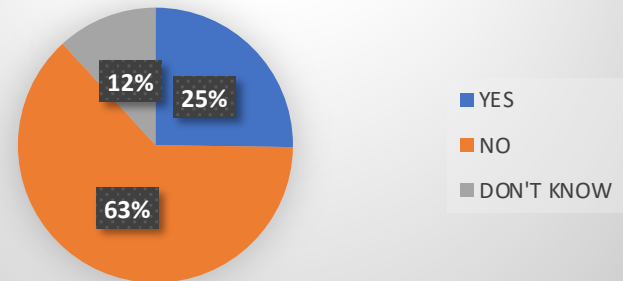
## Education attainment



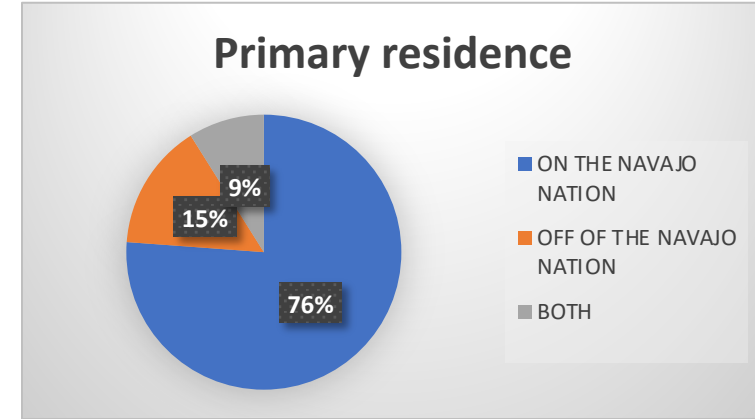
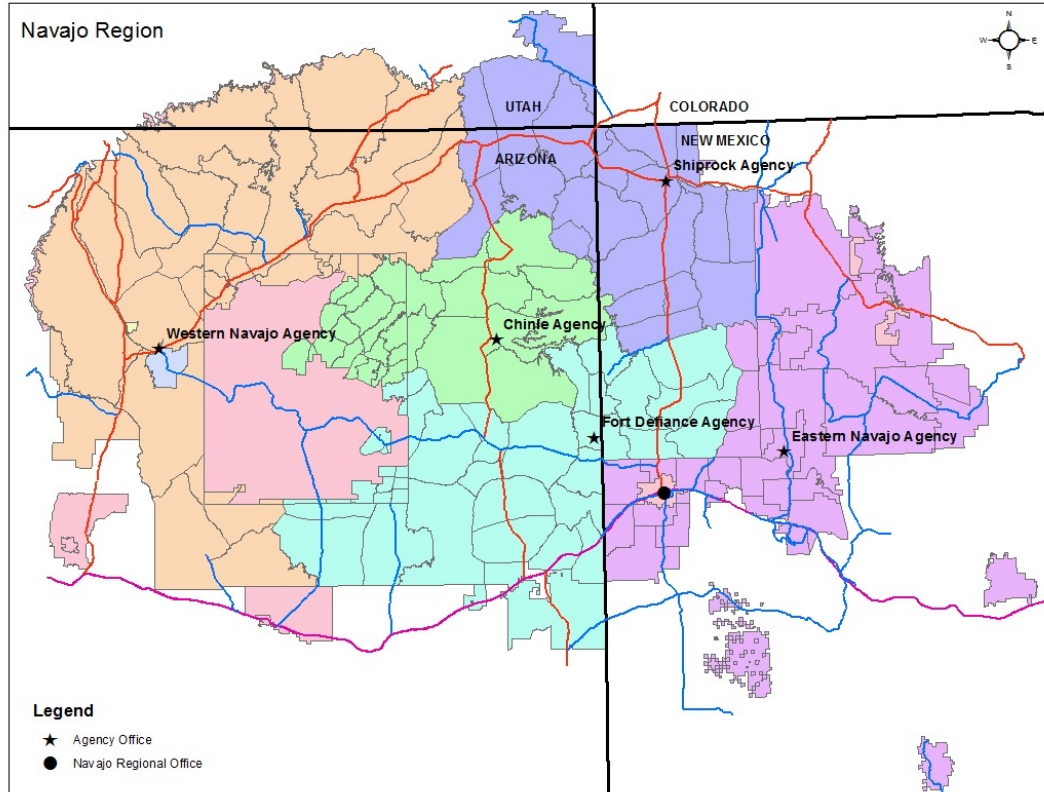
## Beliefs



## Knowledge of the Moratorium



# Navajo respondents to the survey (N = 690)



- Respondents were from throughout the Navajo Nation and most lived primary on the Navajo Nation.

# Summary of data analysis

- We found no significant differences between age, gender, religious/spiritual beliefs, or agency affiliation with knowledge levels of genetics, participation in relation to beliefs, and donation of biospecimens

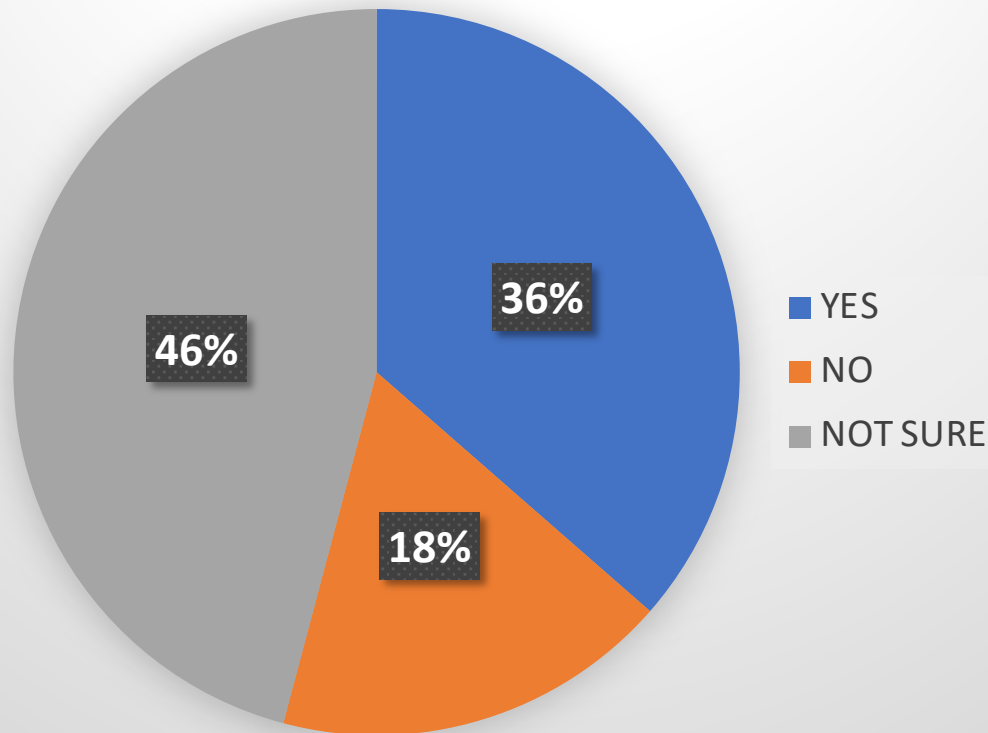
	Would you donate biospecimens for research if...			Lift moratorium?
	Community engagement	Approval by NNHRRB	Disease affecting Navajo people	Yes, we should end the moratorium
Knew about moratorium	✓	✓	✓	✓
Did not know about moratorium	✗	✗	✗	✗

✓ all p-values were significant

# Policy Recommendations and Moratorium

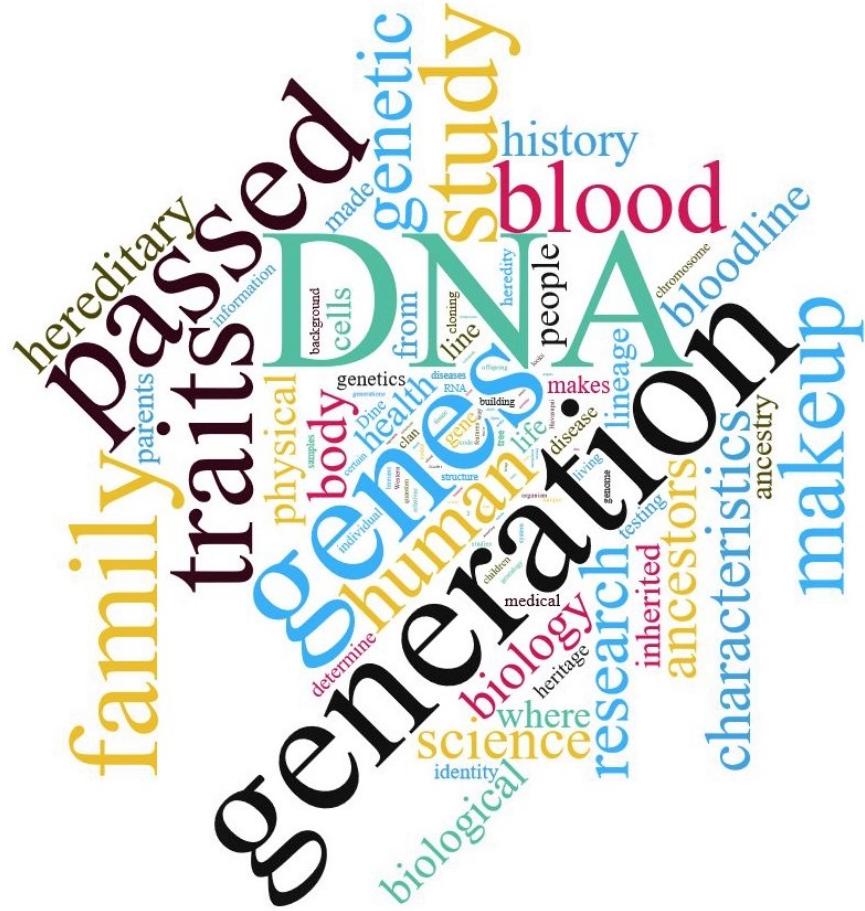
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Should the Navajo Nation end the moratorium on genetic research?



Most commonly used terms to describe “genetics”

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# Themes from overall responses to open-ended ?s

## 1. Need more information and education on genetics and the moratorium

“I wonder why it’s been this long and even I wasn’t aware of it.”

“Eventually I can see the moratorium being lifted, but there are still a lot of unethical researchers and [the] community [is] still not knowledgeable about research issues to make the right decisions. Need more education in the community about issues related to research.”

# Themes from overall responses to open-ended ?s

## 2. Conflicted about the moratorium and genetic research

“Moratorium [on] genetic research [was] implemented for a reason. Lifting may cause disparities of misuse.”

“I think lifting the ban will benefit the Navajo people.”

“This isn’t a simple question of ‘yes, it should be lifted’ or ‘no, it should not be lifted.’ The NN need to have the proper staff, resources, policies, procedures, and infrastructure in place to exercise appropriate oversight and to protect our people.

Without those in place, I would not support a lift of the moratorium. I support genetic research but only if it’s done in an ethical manner, with proper consent and transparency with the tribe, people, participants involved, and for their benefit.”



# Themes from overall responses to open-ended ?s

## **3. Importance of health research to Navajo people**

“I feel that giving away a piece of me, however helpful it may be to ‘research’ and to bettering our Native community.”

“I think genetic research related to health is important for a population as small as ours. I don’t think genetic research for molecular anthropological and similar research is important.”

“If this research can help reduce the risk of cancer, I would fully recommend [this] research to be done.”

# Conclusion & Future directions

## Conclusion

- We had good representation from all age ranges, educational levels, and from Navajos living on the Navajo Nation.
- Most Navajo people did not know about the moratorium and are conflicted about lifting it.
- More education and consultation are needed!

## Future directions

- Surveys of other stakeholder groups.
- Distribute findings to tribal leaders, community, and the Navajo Genetic Research Policy Development Working Group.
- Increase educational outreach and genetic literacy with NARCH pilot grant.

# Ahéhee'

- Navajo Nation Genetic Research Policy Development Working Group
- Honorable Council Delegate Jamie Henio (24<sup>th</sup> NNC)
- Former Council Delegate Walter Phelps (23<sup>rd</sup> NNC)
- Navajo Nation Human Research Review Board
- Navajo Government Development Office
- Navajo Department of Health

## CONTACT INFORMATION

email: [navajogenetics@gmail.com](mailto:navajogenetics@gmail.com)



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## Funding

### Seattle Children's Hospital

- Pediatric Pilot Fund
- Health Equity Fund
- Treuman Katz Center for Pediatric Bioethics

### University of Washington

- Information School

### National Institutes of Health

- K01 Research Scientist Development Award (Garrison)
- F32 Postdoctoral Fellowship (Claw)
- RM1 Administrative Supplement Award (Garrison)
- NHGRI R25 (Claw)
- **NARCH pilot grant (Claw and Garrison) funded!!!**