Driving Change: Priming the Navajo Nation Genetic Research Policy Development

Ms. Beverly Becenti-Pigman, Dr. David Begay, Ms. Rene Begay, Dr. Frank Sage

NCAI Break-out Session

June 26, 2019
NAVAJO NATION GENETICS POLICY DEVELOPMENT (NNGPD) WORKING GROUP KNOWLEDGE

Navajo Nation Human Research Review Board (NNHRRB)

Navajo Department of Health

Navajo Government Development Office

Office of the President and Vice President

Navajo researchers from various Universities including Diné College

Cultural and traditional groups: Diné Hatáálii Association, Navajo Medicine Men’s Association, and Azéé’ Bee Náághahá of Diné Nation

Community stakeholders
WHO ARE WE?

Establishment
Established and authorized by the Health, Education and Human Services (HEHS) Committee (Legislation No. 0030-18) and Náábik’iiyi’iʼí Committee (NABI)
- February 13, 2018
- Sponsor: Council Delegate Walter Phelps

Mission
The mission of NNGPD Working Group is to develop a comprehensive genetic research policy for and with the Navajo Nation and provide amendments to the Navajo Nation Human Research Code to guide the Navajo Nation and Researchers in conducting genetic research.
HISTORY AND NNHRRB

Ms. Beverly Becenti-Pigman
Support research that **promotes and enhances the interests and the visions of the Navajo people**: to encourage a mutual and **beneficial partnership between the Navajo people and researchers**

Interface different cultures, lifestyles, disciplines, and ideologies together in a way that improves, promotes, and strengthens the health of the Navajo people.

- **Meets monthly** in Window Rock, AZ
- **Includes all professionals**: doctors, community members, scientists, ethicists
- **Read** several research **proposals** each month, and **monitor** ongoing studies
WHAT IS THE RESEARCH PROCESS?

1. Create question(s) with community
2. Obtain IRB, tribal, and community research approval
3. Gather data
4. Analyze the data
5. Draw conclusions with community input/expertise
6. Provide education and results to the community
7. Draft a paper for publication after tribal approval
Ban on genetic research was needed in order for the Navajo people to discuss how genetics could provide benefits.

After consultation with Health and Human Services Committee, tribal leaders, traditional healers, and people with Western scientific training, the Navajo Nation recognized a lack of policies or guidelines for genetic research protocols.
CULTURAL AND TRADITIONAL PERSPECTIVES

Dr. David Begay
Weaving the Strands of Life
(líná Bitłool)
&
Diné Ways of Knowing
DNA is in Everything
EDUCATION AND OUTREACH

Ms. Rene Begay
Radio Q&A (KTNN)

Radio Forum #1

Listen Live!

KTNN FORUM

Strands of Life
Iina Bili'ool

Genetic Research and Efforts to Develop a Genetic Research Policy for the Navajo Nation

MARCH 07, 2019
6-8 PM MST
AM 660
FM 101.5
www.ktnnonline.com

Radio Forum #2

Recording available at http://www.mnhrrb.navajo-
HANDS ON ACTIVITIES

Build a Sheep Activity

DNA Extraction from Strawberries
GENETIC EDUCATION THROUGH SOCIAL MEDIA AND WEBSITE
(NAVAJO AND ENGLISH)
ININVOLVEMENT OF RESEARCH STUDY

Dr. Frank Sage
Before today, did you know about the Navajo Nation’s moratorium on genetic research?

Have you heard of any discussions about genetic research by the Navajo Nation government?
Because of my spiritual values, I would not participate in genetic research.

How likely are you to donate your biospecimen if what was being studied was a disease that affected your community? (e.g. cancer, diabetes)
How important is it to include the following parts in a policy on genetic research?

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<thead>
<tr>
<th></th>
<th>Not important</th>
<th>Important</th>
<th>Very Important</th>
<th>No Opinion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tribal oversight</td>
<td>11</td>
<td>20</td>
<td>59</td>
<td>10</td>
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<tr>
<td>Cultural knowledge</td>
<td>5</td>
<td>20</td>
<td>66</td>
<td>8</td>
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<tr>
<td>Benefit to Navajo tribe</td>
<td>5</td>
<td>19</td>
<td>67</td>
<td>10</td>
</tr>
<tr>
<td>Researchers should be Navajo</td>
<td>16</td>
<td>20</td>
<td>51</td>
<td>15</td>
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<tr>
<td>Community engagement</td>
<td>8</td>
<td>22</td>
<td>60</td>
<td>9</td>
</tr>
<tr>
<td>Data sharing protections</td>
<td>5</td>
<td>18</td>
<td>67</td>
<td>9</td>
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</table>

All values are percentages (%).
Should the Navajo Nation lift the moratorium (ban) on genetic research?

- **Yes**: 256 (37%)
- **No**: 126 (18%)
- **Not Sure**: 313 (45%)
Working Group Co-chairs:
- Honorable Jamie Henio (24\textsuperscript{th} NN Council Delegate)
- Mr. Walter Phelps (23\textsuperscript{rd} NN Council Delegate)

Navajo Government:
- Dr. Jill Jim (DOH)
- Mae-Gilene Begay (DOH)
- Ramona Antone-Nez (DOH / Epi Center)
- Edward Dee (ONGD)
- Emmett Kerley (ONGD)
- Raymond Tsosie (ONGD)
- EJ John (ONGD)
- Crystal Cree (ONGD Commissioner)
- LeTanya Thinn (ONGD Commissioner)
- Antonio J. Ramirez (OPVP)

Navajo Nation Human Research Review Board:
Bevery Becenti-Pigman (Chair)
Michael Winney (DOH)
Dr. David Begay (UNM)
Dr. Mark C. Bauer (Diné College) *
Ursula Knoki-Wilson (IHS)

Navajo Academics and Researchers:
- Dr. Nanibaa' A. Garrison (UW, Seattle Children's)
- Dr. Katrina Claw (UW)
- Dr. Gilbert John (Colo State U)
- Dr. Jani C. Ingram (NAU)
- Rene Begay (UC Denver)
- Perry Charley (Diné College)
- Dr. Franklin Sage (Diné College)

Administrative Support:
- Nicolas Dundas (Seattle Children's) *

Funding:
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Advisors and Consultants
Traditional Practitioners:
- David Johns (DHA)
- Michelle Kahn-John (DHA)
- Lorenzo Max (DHA)
- Leroy Thomas (ABNDN)
- Anson Etsitty (DHA/ABNDN)
- Kenneth Maryboy (NMMA)

Community members:
- Janene Yazzie
- Hazel James
- David Tsosie
- Bess Tsosie
- Daniel Tso
- Robert Tohe

* All are Navajo except those with an Asterisk