Driving Change: Priming the Navajo Nation Genetic Research Policy Development

Honorable Council Delegate Jamie Henio (24th Navajo Nation Council)
Mr. Walter Phelps (23rd Navajo Nation Council Delegate)

Dr. Frank Sage
NCAI General 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 Náábk’iyáti’ 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.
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.
MAJOR TOPICS IN THE GENETIC POLICY

Policy topics include:

1) Support NNHRRB regulations
2) Abide by Navajo privacy and confidentiality laws
3) Encourage cultural considerations (i.e. payment for a ceremony)
4) Require community approvals that include spiritual advisors and traditional practitioners
5) Enforce sanctions (consequences) if there are violations
WHY SHOULD THIS MATTER TO THE NAVAJO PEOPLE?

- Genetics is advancing rapidly, and is leaving out certain groups of people
- Most genetic studies only include white populations
- Genetics has the potential to improve our knowledge of disease and health outcomes

Genetic studies done

- 96% White
- 4% Not White

Bustamante, Nature, 2011
FUTURE EFFORTS

- Obtain input from the faith-based healers and traditional leaders
- Obtain input from Navajo Nation government officials
- Provide education to the Navajo community (i.e. chapter houses, clinics, schools)
- Gather opinions/comments from the Navajo people
Mr. Walter Phelps (23th Navajo Nation Council Delegate)
ESTABLISHING THE WORKING GROUP
DISCUSSIONS WITH NIH AND RESEARCHERS
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?
PERSPECTIVES ON GENETICS RESEARCH ON THE NAVAJO NATION

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)
CONCERNS ABOUT GENETIC RESEARCH

How important is it to include the following parts in a policy on genetic research?

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<th>Not important</th>
<th>Important</th>
<th>Very Important</th>
<th>No Opinion</th>
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</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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<td>Benefit to Navajo tribe</td>
<td>5</td>
<td>19</td>
<td>67</td>
<td>10</td>
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<td>Researchers should be Navajo</td>
<td>16</td>
<td>20</td>
<td>51</td>
<td>15</td>
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<td>Community engagement</td>
<td>8</td>
<td>22</td>
<td>60</td>
<td>9</td>
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<tr>
<td>Data sharing protections</td>
<td>5</td>
<td>18</td>
<td>67</td>
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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%)
AHE’HÉÉ’
(THANK YOU)

Working Group Co-chairs:
- Honorable Jamie Henio (24th NN Council Delegate)
- Mr. Walter Phelps (23rd 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 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:
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Funding:
NHGRI RM1 HG009042-03S2

Navajo Nation Human Research Review
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- 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