

THE NAVAJO NATION  
LEGISLATIVE BRANCH  
INTERNET PUBLIC REVIEW PUBLICATION



LEGISLATION NO: \_0241-24\_

SPONSOR: Carl R. Slater

**TITLE: An Action Relating to the Health, Education and Human Services and Naabik'iyáti' Committees; Re-Establishing the Genetics Policy Working Group and Recognizing the Navajo Nation Genetics Policy Statement**

**Date posted: November 06, 2024 at 6:00PM**

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**LEGISLATIVE SUMMARY SHEET**

Tracking No. 0241-24

**DATE:** November 4, 2024

**TITLE OF RESOLUTION: AN ACTION RELATING TO THE HEALTH, EDUCATION AND HUMAN SERVICES AND NAABIK'ÍYÁTI' COMMITTEES; RE-ESTABLISHING THE GENETICS POLICY WORKING GROUP AND RECOGNIZING THE NAVAJO NATION GENETICS POLICY STATEMENT**

**PURPOSE:** This resolution, if approved, would re-establish the Genetics Policy Working Group and recognize the Navajo Nation Genetics Policy Statement.

**Final Authority:** Naabi'kiyati Committee

**Vote Required:** Simple Majority

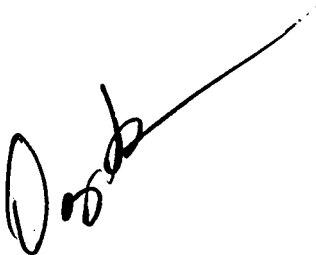
**This written summary does not address recommended amendments as may be provided by the standing committee. The Office of Legislative Counsel requests each Council Delegate to review the proposed resolution in detail.**

5-DAY BILL HOLD PERIOD                       
Website Posting Time/Date                       
Posting End Date: 11-11-24  
Eligible for Action: 11-12-24

PROPOSED STANDING COMMITTEE RESOLUTION  
25th NAVAJO NATION COUNCIL—SECOND YEAR, 2024

INTRODUCED BY

\_\_\_\_\_  
Primary Sponsor



TRACKING NO. 0241-24

AN ACTION  
RELATING TO THE HEALTH, EDUCATION AND HUMAN SERVICES AND  
NAABIK'ÍYÁTI' COMMITTEES; RE-ESTABLISHING THE GENETICS  
POLICY WORKING GROUP AND RECOGNIZING THE NAVAJO NATION  
GENETICS POLICY STATEMENT

BE IT ENACTED:

**Section One. Authority recognizing**

- A. The Navajo Nation established the Health, Education and Human Services Committee (“HEHSC”) as a Navajo Nation Council standing committee and as such empowered HEHSC to establish policy and to promulgate rules and regulations governing health on the Navajo Nation. *See* 2 N.N.C. §§ 164 (A)(9), 400 (A), 401 (B)(1) (2015); *See also* CO-45-12.
- B. The Naabik'iyáti' Committee is a standing committee of the Navajo Nation Council empowered to oversee the conduct and operation of entities of the Navajo Nation not otherwise under the oversight authority of other standing committees. *See* 2 N.N.C. §§ 164 (A)(9), 700 (A), 701 (A)(2) (2015); *See also* CO-45-12.
- C. The Naabik'iyáti' Committee has the authority to delegate its responsibilities and authorities to other standing committees and appropriate entities provided that the Committee first approve rules and regulations governing such delegations and to rescind delegations. 2 N.N.C §701 (B).

1       **Section Two. Findings**

- 2       A. The Navajo Nation Health Research Code was established through Navajo Nation  
3       Council Resolution CO-106-95.
- 4       B. In August 2001, the former Health and Social Services Committee, now HEHSC, and  
5       the Navajo Nation Health Research Review Board (“Board”) held a joint work session.  
6       The Committee directed the Board to prohibit any investigations, research or studies  
7       regarding genetics and to develop educational material for the public prior to the  
8       development of the Navajo Nation policy on genetic studies. *See* HSSCAP-20-02.
- 9       C. In 2002, the Navajo Nation approved a moratorium on genetic research conducted  
10      within the Navajo Nation, in resolution IGRJN-86-02, until the “Navajo Nation Health  
11      Research Code is amended and approved by the Navajo Nation Council.”
- 12      D. In 2002, CAP-16-02 amended the Navajo Nation Health Research Code, renaming the  
13      title as the Navajo Nation Human Research Code which is codified at 13 N.N.C. §3251  
14      et. seq.
- 15      E. February 12, 2018, the Naabik’iyáti’ Committee established the Navajo Nation  
16      Genetics Policy Working Group (“Working Group”). The Working Group was  
17      established to develop a comprehensive genetic research policy for, and with, the  
18      Navajo Nation and provide amendments to the Navajo Nation Human Research Code  
19      to guide the Navajo Nation and researchers in conducting genetic research. *See* NABIF-  
20      09-18 attached as **Exhibit A**.
- 21      F. In August 2018, the Working Group held an in-person meeting to discuss drafting the  
22      Genetics Research Policy, beginning discussions on the work of developing a genetics  
23      research policy, and providing education to the community. The meeting was held at  
24      the Navajo Nation Museum in Window Rock, AZ. **Exhibit B**.
- 25      G. The Working Group developed the *Ethical Concerns of Conducting Genetics Research*  
26      *with Indigenous People* and began educating the public through an online presentation  
27      in October 2018 with Diné College Public Health.
- 28      H. In November 2018, the Working Group held a conference at Northern Arizona  
29      University in Flagstaff, AZ. The conference topic was Cultural and Traditional  
30      Understanding of Genetics.

- 1 I. In March 2019, the Working Group held an in-person meeting to discuss developing a  
2 train-the-trainer model. The meeting was held at the Navajo Nation Museum in  
3 Window Rock, AZ. Additionally, the Working Group presented *Perspectives on*  
4 *Genetics Research from the Navajo People* to the Diné Hatalii Association. The  
5 presentation was held at the Tsehootsooi Medical Center in Fort Defiance, AZ.
- 6 J. In April 2019, the Working Group held an in-person meeting to hold a train-the-trainer  
7 session, inviting the Navajo Nation Council. At this meeting, the Working Group  
8 drafted a logo design for the Working Group. Later, the Working Group held a  
9 conference titled *Weaving the Strands of Life and Diné Ways of Knowing* and presented  
10 *Perspectives on Genetics Research from the Navajo People* to the IHS Chinle Hospital.
- 11 K. In June 2019, the Working Group presented at the National Congress of American  
12 Indian Mid-Year Conference the presentation title *Genetics Research: Tribes Taking*  
13 *Action*.
- 14 L. In the Summer of 2019, the Working Group published *Weaving the Strands of Life*  
15 *(Inl Bit[ool]): History of Genetic Research Involving the Navajo People* in the Human  
16 Biology. **Exhibit C**.
- 17 M. In October 2019, the Working Group held a conference at the Navajo Nation Museum  
18 in Window Rock, AZ. The conference topic was *Perspectives on Genetics Research*.
- 19 N. In December 2019, the Working Group closed out the year by holding an in-person  
20 meeting to discuss cultural considerations in developing the genetic research policy.  
21 The meeting was held at Northern Arizona University in Flagstaff, AZ.
- 22 O. In January 2020, the Working Group presented at the Indigenous Genomics  
23 Conference. The presentation was titled *Navajo Nation Genetics Policy and Weaving*  
24 *the Strands of Life*.
- 25 P. Due to the COVID-19 pandemic, all meetings and conversations were put on hold  
26 through 2020 and into 2021.
- 27 Q. Conversations and meetings resumed in October 2021, when the Working Group  
28 presented *Perspectives on Genetics Research* during their Bi-Annual Conference  
29 which was held online.
- 30

1 R. In December 2021, the Working Group published *Perspectives on Genetic Research:*  
2 *Results from a Survey on Navajo Community Members* in *Frontiers in Genetics*.  
3 **Exhibit D.**

4 S. In January 2022, the Working Group restarted their meetings through Zoom.

5 T. The Working Group has provided an updated presentation, titled *Report on Navajo*  
6 *Nation Genetic Research Policy*, dated May 17, 2023. **Exhibit E.**

7 U. In April 2024, the Working Group held an in-person meeting at the Department of  
8 Behavioral and Mental Health Services in Window Rock, AZ, to discuss the draft copy  
9 of the genetics policy statement, code amendments and research updates.

10 V. The Board has been working on amendments to the Navajo Nation Human Research  
11 Code, including amendments to incorporate policies for future regulations regarding  
12 genetic research within the Navajo Nation. Membership of the Working Group includes  
13 members of the Board.

14 W. The mission of the Working Group is to develop a comprehensive genetics research  
15 policy for, and with, the Navajo Nation and provide amendments to the Navajo Nation  
16 Human Research Code. *See Exhibit F.*

17 X. It is in the best interest of the Navajo Nation to authorize the re-establishment of the  
18 Navajo Nation Genetics Policy Development Working Group (“Working Group”)  
19 which may include integral community stakeholders such as the Office of Navajo  
20 Government Development, Navajo Department of Health, the Navajo Nation Human  
21 Research Review Board and other stakeholder entities as necessary.

### 22 23 **Section Three. Navajo Nation Genetics Research Policy Statement**

24 The Naabik’iyáti’ Committee hereby recognizes the following as the official statement  
25 of policy on genetics research that guides the Working Group in the development of genetic  
26 research policies, codes, and regulations for the Nation:

27 The policy of the Navajo Nation is to ensure that all genetic and genomic research is  
28 conducted to promote the well-being and health of all life, and to ensure that all genetic  
29 and genomic research, which includes Navajo people, plants, animals, ecosystems and any  
30 other associated forms of life found on the Navajo Nation, will be conducted in a culturally

1 safe manner to include Diné culture to prevent any potential harmful genetic and genomic  
2 research conducted by researchers and/or all applicable parties.

3 The Navajo Nation retains ownership over any intellectual property, products and  
4 services, and all other outcomes that may come from genetic and genomic research with  
5 Navajo participants and all associated forms of life within the Navajo Nation during any  
6 step of the research process. Navajo Nation will determine when the data will be shared for  
7 the benefit of the Navajo Nation. This policy is grounded in accordance with the principles  
8 found in The Foundation of the Diné, Diné Law and Diné Government as codified in 1  
9 N.N.C §§ 201-206, any ambiguities should refer to these principles.

10  
11 **Section Four: Re-establishing the Navajo Nation Genetics Policy Development**  
12 **Working Group to complete the genetics research policy for the Navajo Nation with**  
13 **the necessary code amendments**

- 14 A. The Naabik'iyáti' Committee hereby re-establishes the Navajo Nation Genetics Policy  
15 Development Working Group ("Working Group") to complete their proposal of  
16 necessary amendments to the Navajo Nation Code so that a Navajo Nation Genetics  
17 Research Policy may be adopted. The Working Group shall exist and operate as  
18 authorized pursuant to the 2002 Moratorium on Genetic Research, as outlined in  
19 HSSCAP-20-02 and IGRJN-86-02.
- 20 B. The Working Group shall continue these tasks until necessary code amendments are  
21 adopted and the moratorium on genetics research is lifted.
- 22 C. The general purpose of the Working Group is to develop a comprehensive genetic  
23 research policy for and with the Navajo Nation and provide the necessary code  
24 amendments to guide the policy.
- 25 D. The specific purposes of the Working Group include, but are not limited to, the  
26 following:
- 27 1. Develop genetics research policies; by generating data to guide the  
28 development of a culturally sound policy; by
  - 29 2. Understanding and giving prominence to Diné people's views and
  - 30 3. Establishing appropriate research methodologies.

1 E. The Working Group shall have the authorities necessary to implement and accomplish  
2 the purposes set forth above and specific responsibilities and authorities as follows:

- 3 1. The Working Group shall collaborate with programs, departments and entities  
4 within the Navajo Nation and federal and state agencies to achieve the purposes  
5 and goals described herein.
- 6 2. The Working Group should collaborate with programs and departments within  
7 the state and federal government to improve the Navajo Nation's processes for  
8 genetics information sharing and coordination of resources in regard to  
9 conducting research.
- 10 3. The Working Group and the Board shall work together in the development of  
11 the code amendments, policies and procedures regarding genetic research. The  
12 Board shall provide the draft amendments to the Working Group to be  
13 incorporated into any code amendments, polices, procedures, and/or regulations  
14 necessary to complete the purposes described within.
- 15 4. The Working Group shall report its findings and recommendations to the  
16 Health, Education and Human Services Committee at the end of the second and  
17 fourth quarters of each Navajo Nation fiscal year.

18 F. The Working Group Voting Members shall consist of fourteen (14) members as follows:

- 19 1. A representative of the Naabik'iyáti' Committee of the Navajo Nation Council;
- 20 2. Three (3) representatives from the Navajo Department of Health ("NDOH"),  
21 appointed by Director of NDOH;
- 22 3. Three (3) representatives from the existing Navajo Nation Genetics Research  
23 Policy Working Group, appointed by the existing group members;
- 24 4. Three (3) representatives from the Navajo Nation Human Research Board,  
25 appointed through a Board resolution;
- 26 5. A medicine person or spiritual advisor,
- 27 6. Three (3) representatives from Navajo communities who have extensive  
28 cultural or medical experience and knowledge in genetics research, associated  
29 genetics study, and/or education in the field of genetics.
- 30



- 1 G. The medicine person/spiritual advisor and the three (3) community representatives  
2 shall be selected by a majority of the Working Group members.  
3 H. Non-voting membership and other participation is permitted.  
4

5 **Section Five. Working Group Operation and Administration**

- 6 1. The Working Group shall elect a Chairperson and may create additional Officer  
7 positions as needed. The Working Group may create a process by which these Officers  
8 are to be selected.  
9 2. The Working Group shall operate by resolution with a majority of Working Group  
10 members constituting a quorum. A quorum consists of the ten (10) appointed members,  
11 until the medicine person/spiritual advisor and the three (3) Community  
12 Representatives are selected.  
13 3. The Working Group shall establish its own meeting rules and utilize either the Rules  
14 for Standing Committees or Robert's Rules of Order until their own meeting rules are  
15 adopted.  
16 4. The Working Group members employed by the Navajo Nation shall not be  
17 compensated, but shall receive reimbursement for mileage, meeting, and travel  
18 expenses at the rates set forth in the applicable Navajo Nation Travel Policies.  
19 5. The Working Group members shall serve until the next Navajo Nation Council is  
20 seated. Members can be considered voting Working Group members until  
21 appointments are identified, for up to six (6) months after the seating of the incoming  
22 Council. Voting members may be removed for lack of attendance by a two-thirds (2/3)  
23 vote of all Working Group members.  
24 6. The Office of the Speaker, Office of Legislative Services, and other necessary  
25 legislative branch programs shall provide technical assistance, clerical, and  
26 administrative assistance. The Navajo Nation Department of Justice and the Office of  
27 Legislative Counsel shall provide legal assistance and guidance to the Working Group.  
28 7. Navajo Nation laws, policies, and regulations shall apply to the Working Group and its  
29 members.  
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8. In accordance with 2 N.N.C 701 (B), the Naabik'íyáti Committee hereby delegates oversight authority over the Navajo Nation Genetics Policy Development Working Group to the Health, Education and Human Services Committee of the Navajo Nation Council.