

Advisory Panel To Better Understand and Make Recommendations Regarding the Implications of Genome-editing Technology for the Citizens of the State

Potential Recommendations (proposed prior to Oct. 19, 2022 Meeting)

Discrimination

Vote

1. Enact a state law prohibiting discrimination based on genetic information in categories of insurance beyond the health insurance anti-discrimination provisions of the federal Genetic Information Nondiscrimination Act of 2008, [Pub. L. No. 110-233](#) (see NIH summary [here](#)).
 - **Options (should specify when voting)**
 - (1) specifically recommend reintroduction of legislation similar to LD 1085, *An Act Relating to the Use of Genetic Information for Insurance Purposes*: either as introduced or as amended by a minority of the committee (see text & summaries of these proposals [here](#)); or
 - (2) recommend HHS committee develop the legislation.

Cost and access to gene therapy

Vote

2. Recommend that, in making appointments to the Rare Disease Advisory Council (established by [P.L. 2021, ch. 740](#)) the DHHS Commissioner appoint either a person over age 18 whose rare disease is the result of a single-gene disorder (member ¶L) or a parent or guardian of a child whose rare disease is the result of a single-gene disorder (¶M), or both. [Specify whether to add: ideally the member or member's child would be eligible for or enrolled in a clinical trial involving gene therapy for the rare disease?]
 - **Options (should specify when voting)**
 - (1) Advisory Panel write letter to Commissioner Lambrew—in which case chairs should be authorized to approve the text of the letter;
 - (2) recommend that the HHS Committee send a letter; or
 - (3) recommend HHS Committee introduce legislation amending the council's enabling legislation to require such appointments.
3. Urge the Rare Disease Advisory Council to specifically address gene therapy and its costs in distributing educational resources to providers and patients regarding treatment for rare diseases (duty ¶D) and in developing recommendations to improve patient quality of life and reimbursement for such treatments (¶E).
 - **Options (should specify when voting)**

The same options exist for this potential recommendation #3 as for potential recommendation #2 above. The Advisory Panel may choose to combine the two (for example, write a combined letter) or take different approaches to the two potential recommendations.
4. Urge the Office of Affordable Health Care (established by [P.L. 2021, ch.459](#)) to examine not only past drivers of health care costs but also future cost-drivers, such as gene therapies and related treatments, which may have a large up-front cost but might also dramatically improve the lives of patients with rare diseases and yield long-term savings for patients and insurance carriers.
 - **Options (should specify when voting)**
 - (1) Advisory Panel send letter—*should authorize chairs to approve*; or
 - (2) recommend HHS Committee send a letter.

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Workforce Development/Support

Vote

5. Establish (or consider establishing) a professional licensing or registration program for genetic counselors in the State.
 - **Options (should specify when voting)**
 - (1) Recommend HHS Committee draft legislation requiring mandatory licensure of qualified genetic counselors in Maine;
 - (2) Recommend HHS Committee draft legislation providing for voluntary registration of qualified genetic counselors in Maine (could be a formal licensing-like scheme or more informal, for example directing a specific entity/agency to periodically make publicly available a list of qualified genetic counselors);
 - (3) Recommend HHS Committee draft legislation directing a specific organization (need to specify) or the Dept. of Professional and Financial Regulation to explore the sunrise review criteria in [32 M.R.S. §60-J](#) and report back to the Legislature on the pros and cons of establishing a professional licensing program for genetic counselors, including examining the impact on insurance coverage.
6. Encourage (or require) Department of Economic & Community Development to host an annual statewide conference on Gene-editing research being performed in post-secondary schools and the private sector in order to facilitate the development of partnerships between industry and education.
 - **Options (should specify when voting)**
 - (1) Advisory Panel send a letter to DECD encouraging the creation of such a conference—*should authorize chairs to approve the letter*;
 - (2) Recommend HHS Committee send a letter to DECD encouraging the creation of such a conference; or
 - (3) Recommend HHS Committee enact legislation requiring DECD to convene such a conference.
7. Create a statewide registry of gene-editing technology research and product development.
 - **Questions to answer before voting**
 - (1) Who maintains the registry?
 - (2) Is the registry mandatory or voluntary?
 - (3) If mandatory, who must use the registry: public entities (university and state government); any publicly-funded research; private entities?
 - (4) How to suggest pursuing this recommendation
 - a. If mandatory—recommend HHS committee adopt legislation?
 - b. If voluntary—recommend HHS committee adopt legislation; Advisory Panel send letter to recommended entity to create the registry; or recommend HHS committee send such a letter?

K-12 and Higher Education

Vote

8. Increase state investment in public pre-K to grade 12 and post-secondary education in genetics, gene-editing and related technologies.

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9. Raise standards beyond those in the NexGen Science Standards for public K to grade 12 education in genetics, gene-editing and related technologies.

○ **Options (should specify when voting)**

(1) Advisory Panel send a letter to Maine Dept. of Education encouraging increased K to grade 12 education on genetics and related technologies through one of the following means:

- a. Amend Maine's rules (Dept. Ed. Rules [Ch. 132](#)) governing the statewide System of Learning Results to adopt specific genetic competencies—if so, specify how to develop these competencies?
- b. Develop more resources for teachers for expanded (but optional) genetics teaching content?
- c. Something else—need to specify?

If choose this option, *should authorize chairs to approve the letter*; or

(2) Recommend HHS Committee (or EDU Committee) send the letter--need to specify what the letter will recommend (see above).

10. Increase professional development opportunities for pre-K to grade 12 educators in Maine related to genetics, gene-editing and related technologies.

○ **Options (should specify when voting)**

(1) Recommend HHS Committee propose legislation to create a grant program (administered by FAME or Dept. of Education?) to support professional development for pre-K to grade 12 educators in Maine?

(2) Advisory Panel send a letter to (pick one or both):

- a. the Maine Dept. of Education to explore options to increase professional development and report back to the Legislature—*should authorize chairs to approve the letter*; and/or
- b. Maine's congressional delegation to increase federal funding/grant opportunities for science professional development;

(3) Recommend HHS (or EDU Committee) to send the letter.

11. Encourage (or require) the University of Maine System, Maine Community College System and Maine Dept. of Education to jointly sponsor an annual (?) Genetics Education Summit in order to build more connections between UMS, M CCS and the primary/secondary education system in the State regarding the teaching of genetics and related technologies (and workforce preparation?).

○ **Question to answer before voting:** what are the goals of the Summit? (what information should be shared, what type of connections are desired and for what purpose, is the focus on better general genetics education or specific types of workforce development pathways, etc.)

○ **Options (should specify when voting)**

(1) Advisory Panel send a letter to UMS, M CCS and Dept. of Education encouraging the creation of such a summit--*should authorize chairs to approve the letter*;

(2) Recommend HHS Committee send a letter to these entities encouraging the creation of such a conference; or

(3) Recommend HHS Committee enact legislation requiring the annual convening of such a conference.

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12. (Dr. Wray's proposal):

Enhance the existing [Biomedical Research Support program](#) at Hancock County Technical Center to promote Genetics, Genetic Counseling, Genomics and Healthcare services training and offer the enhanced program across additional Maine career and technical education centers.

Further Study

Vote

13. (Co-chairs' proposal)

The Legislature should enact legislation directing the Maine Department of Agriculture, Conservation and Forestry (DACF) to study both:

- (a) the current uses and applications of gene-edited organisms and gene-editing technologies in the State's agriculture and forestry industries, including the potential this technology may provide to enhance those industries in the future; and
- (b) the impact that gene-editing technologies and gene-edited organisms may have on the State's organic farming industry—specifically, whether current state and federal legal and regulatory safeguards maintain the appropriate balance between the potential benefits of gene-editing technologies to non-organic farmers and the importance of preserving the integrity of organic farming methods and products.

The Advisory Panel could include in its recommendation that the legislation require DACF to submit a report or report(s) with its findings and recommendations, including any recommended legislation, on these issues to the ACF Committee, which would be authorized to report out legislation related to the report.

14. (Co-chairs' proposal)

The HHS Committee should report out legislation establishing a new legislative study (to be comprised of the same categories of members as the current Advisory Panel) to examine the laws and bioethical considerations related to genetics, genetic information, and gene-editing technologies. The duties of the legislative study should include:

- (a) Reviewing Maine statutes related to genetics, genetic information, and gene-editing technology for the purpose of identifying laws that are outdated or no longer applicable as well as laws that should be amended to reflect advances in scientific understanding and technologies; and
- (b) Examining newly enacted legislation in other states and recent, high-profile court decisions related to genetics, genetic information and gene-editing technology to identify emerging legal issues created by newly developed technologies; and

In completing its duties, the legislative study should consult with the Maine Judicial Branch. The legislative study should be directed to submit a report, with its findings and recommendations, including any recommended legislation, to each committee of the legislature with jurisdiction over any of the subject matters included within those recommendations.