

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

Potential Advisory Panel Recommendations (and/or Findings) to the Legislature

Topic #1: Gene-editing in Health and Bioscience

Topic / Issue	Potential Recommendations (and/or Findings) <i>(Italics indicate that a concrete recommendation has not yet been proposed; the Panel may wish to make findings on these issues instead of recommendations.)</i>	Notes
Discrimination	<p>Expand on federal Genetic Information Nondiscrimination Act (see attached NIH Human Genome Research Institute Summary of GINA) by enacting a state law prohibiting discrimination based on genetic information in additional types of insurance: for example, long-term care insurance and disability insurance.</p> <ul style="list-style-type: none"> • See LD 1085, An Act Relating to the Use of Genetic Information for Insurance Purposes (Rep. Hymanson) (did not pass in 130th Legislature) 	
Cost and access to gene therapy	<p><i>a) Are there ways to do the following - while considering issues of equity in access (for example, folks with private versus public health insurance):</i></p> <ul style="list-style-type: none"> • <i>decrease cost of gene therapies or gene-editing-derived medicines in Maine?</i> • <i>decrease related costs: transportation, lost work for caregivers, etc.?</i> <p><i>b) Are there ways to encourage more clinical trials of gene therapies in Maine (investments in medical research talent and infrastructure)?</i></p>	
Workforce issues	<p><i>Are there ways to encourage more of the following professionals to practice in the State: (a) genetic counselors; (b) geneticists; (c) neurologists?</i></p>	
Informed population	<p>Increase investment in public pre-K to grade 12 as well as post-secondary education in genetics, gene-editing, related technologies and the regulatory framework.</p>	

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Economic development - biotechnology	<i>Are there ways to foster a more vibrant biotechnology sector in Maine?</i>	