

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

**Revised for 9/21/22 Meeting:**  
new information is highlighted

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

Topic / Issue	Potential Recommendations (and/or Findings) <i>(Unnumbered italic text indicates that a concrete recommendation has not yet been proposed; the Panel may wish to recommend further study of these ideas or propose findings instead.)</i>	Notes
General	<p><i>Should there be a State policy on gene editing? Pro? Con? Nuanced?</i></p> <p><b>[Staff questions:</b> <i>What should be in the policy? How should the policy be adopted: New study commission? Legislatively adopted policy? Legislative Committee or this Advisory Panel send a letter to the Governor to request adoption of a policy?</i>]</p>	
Discrimination	<p>1. Expand on federal Genetic Information Nondiscrimination Act of 2008, <a href="#">P.L. No. 110-233</a>, by enacting a state law prohibiting discrimination based on genetic information in additional types of insurance: for example, long-term care and disability insurance.</p> <ul style="list-style-type: none"> <li>• See, for example, <a href="#">LD 1085, An Act Relating to the Use of Genetic Information for Insurance Purposes</a> (Rep. Hymanson) (did not pass in 130<sup>th</sup> Legislature)</li> </ul>	<p><i>An NIH summary of the federal law was included with the second meeting materials.</i></p>
Cost and access to gene therapy	<p><i>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"> <li>• <i>decrease cost of gene therapies or gene-editing-derived medicines in Maine?</i></li> <li>• <i>decrease related costs: transportation, lost work for caregivers, etc.?</i></li> </ul> <p><i>Are there ways to encourage more clinical trials of gene therapies in Maine (investments in medical research talent and infrastructure)?</i></p> <p>2. Advisory Panel send a letter to the Rare Disease Advisory Council, created by <a href="#">Public Law 2021, ch. 740</a>, recommending that it elevate considerations of gene therapy costs when performing its duties under <a href="#">22 M.R.S. §1700-B(4)(D) and (E)</a>:</p> <p>D. Identify and distribute publicly available educational resources to providers of health care in order to foster recognition of symptoms of and treatment for rare diseases among patients of those providers;</p> <p>E. Evaluate the systems for delivery of treatment for rare diseases in place in the State and develop recommendations to improve quality of life and to provide services and reimbursement for those services for persons with rare diseases;</p>	<p><i>The Advisory Panel may receive more information related to these questions during its 4<sup>th</sup> meeting (on Oct. 19<sup>th</sup>), which is focused on Gene-editing in Systems and Institutions.</i></p>

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	<p>3. Advisory Panel (or Committee?) send a letter to the DHHS Commissioner recommending individuals, or types of individuals, who should be appointed to the Rare Disease Advisory Council, in line with the statutory requirements in <u>22 M.R.S. §1700-B(2)</u>:</p> <ul style="list-style-type: none"><li>A. Three physicians who practice in the area of cardiology, emergency care, neurology, oncology, orthopedics, pediatrics or primary care and provide care to persons with rare diseases;</li><li>B. Two registered nurses who provide care to persons with rare diseases;</li><li>C. Two administrators of hospitals that provide care to persons with rare diseases, or their designees;</li><li>D. One representative of the department who provides education concerning rare diseases or the management of chronic conditions;</li><li>E. One representative of the department who is responsible for epidemiology services;</li><li>F. One representative of the department who is responsible for administering the MaineCare program;</li><li>G. The Superintendent of Insurance within the Department of Professional and Financial Regulation, or the superintendent's designee;</li><li>H. One person representing an insurer operating in the State;</li><li>I. One person representing biopharmaceutical companies;</li><li>J. One geneticist practicing in the State;</li><li>K. One person representing an academic research institution in the State;</li><li>L. Two persons over 18 years of age who have had or currently have a rare disease;</li><li>M. Two parents or guardians who each have a child with a rare disease; and</li><li>N. One representative of an organization dedicated to providing services to persons with rare diseases.</li></ul> <p><b>[Staff Question:</b> Who (specific individuals or types of individuals) do you recommended?]</p> <p>4. Advisory Panel (or Committee?) send a letter to the Office of Affordable Health Care, created by <a href="#">P.L. 2021, chapter 459 (attached)</a>, recommending it examine not only the past drivers of health care costs but also future cost-drivers like gene therapies and gene-editing-derived medicines? Potentially relevant statutory duties from 22 M.R.S. §3122(3):</p>	
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	<p><b>Duties.</b> . . . The office shall, at a minimum, use data available from the Maine Health Data Organization, established pursuant to Title 22, chapter 1683, and the Maine Quality Forum, established in Title 24-A, section 6951, to:</p> <p>A. Analyze health care cost growth trends and correlation to the quality of health care;</p> <p>B. Analyze health care spending trends by consumer categories, payer type, provider categories or any other measurement that presents available data in a manner that may assist the legislative oversight committee in understanding health care cost drivers, health care quality and utilization trends, consumer experience with the health care system or any other aspect of the health care system;</p> <p>C. Monitor the adoption of alternative payment methods in this State and other states that foster innovative health care delivery and payment models to reduce health care cost growth and improve the quality of health care;</p> <p>D. Based upon the data obtained and the analysis pursuant to paragraphs A to C, develop proposals for consideration by the legislative oversight committee on potential methods to improve the cost-efficient provision of high-quality health care to the residents of this State;</p> <p>Other suggestions?</p>	
<p>Workforce issues</p>	<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> <p>5. Establish a mandatory professional licensing program for genetic counselors in the State.</p> <p>Other suggestions?</p>	<p><i>See OPLA Memo on Maine’s Genetic Counselor Workforce.</i></p> <p><i>See Public Comment from Lisa Harvey-McPherson regarding genetic counselor licensure (may be coming).</i></p>
<p>Informed population / K-12 and higher Education</p>	<p>6. Increase <b>investment</b> in public pre-K to grade 12 and post-secondary education in genetics (beyond Mendelian genetics), gene-editing and related technologies and the regulatory framework.</p> <p>7. Raise <b>standards</b> for K-12 education in genetics (beyond Mendelian genetics), gene-editing and related technologies and the regulatory framework:</p> <ul style="list-style-type: none"> <li>• Advisory Panel send a letter to the Maine Department of Education encouraging increased K-12 education on genetics and related technologies; <b>and/or</b></li> </ul>	<p><i>Additional information requested from DOE:</i></p> <ul style="list-style-type: none"> <li>• <i>Maine high schools that offer STEM-related endorsements/certifications on their diplomas.</i></li> <li>• <i>STEM-specific programs available in the state, at</i></li> </ul>

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	<ul style="list-style-type: none"> <li>Advisory Panel send letter to Maine Dept. of Education to include specific genetic competencies [<b>Staff question:</b> <i>who created these standards? <sup>1</sup></i>] in K-12 curriculum.</li> </ul> <p>8. Decrease barriers to student field trips to tour cutting-edge laboratories, agricultural technology farms and related companies (ex: allow parents to drive).</p> <p><i>Are there ways to develop, encourage, or incentivize more collaboration between the Maine Community College System and the University of Maine System and public pre-K to grade 12 in order to allow for advance training in genetics?</i></p>	<p><i>either public high schools or CTE programs.</i></p>
<p>Informed population / Community education</p>	<p><i>Is there a way to invest in community genetics education beyond school systems - perhaps utilizing existing community infrastructure such as libraries and religious organizations/institutions?</i></p> <p><i>Is there a way to compile a dictionary or annotated bibliography of key terms, which could be used as a go-to guide for individuals and organizations within the State? [<b>Staff questions:</b> <i>what terms should be included? What should be the source of and/or who should write the definitions? What is the specific purpose or audience of the dictionary? How will the dictionary reach that audience?</i>]</i></p> <p><i>Could the model of Community-based Research Protocols be adapted for education and outreach purposes? [<b>Staff questions:</b> <i>What are these protocols? Where can they be found? Would they be mandatory? For whom? Public or Private entities?</i>]</i></p>	
<p>Industry / Education Partnerships</p>	<p><i>Are there ways to develop, encourage, or incentivize public-private partnerships related to genetics education and training – to create pathways from K-12 public education institutions to Maine biotechnology center jobs?</i></p> <p>9. Convene a statewide conference, perhaps hosted by the Department of Economic and Community Development, 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.</p> <p>Other suggestions?</p>	

<sup>1</sup> We were unable to locate a set of genetics core competencies for high school students. The Genetics Society of America has created a list of core concepts and competencies for undergraduate education, see <https://genetics-gsa.org/education/genetics-learning-framework/>, however.

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<p>Informed Population?</p>	<p>10. Create a statewide registry of gene-editing technology research and product development.  <b>[Staff questions: Who maintains the registry? Should it be mandatory? Voluntary? Include both public (university, state government) and private research?]</b></p>	
<p>Economic development - biotechnology</p>	<p><i>Are there ways to foster a more vibrant biotechnology sector in Maine?</i></p> <ul style="list-style-type: none"> <li>• <i>First Suggestion: Establish a new technical board at Maine Technology Institute?</i></li> </ul> <p><b>Staff notes:</b></p> <p><i>MTI was established by statute to “encourage, promote, stimulate and support research and development activity leading to the commercialization of new products and services in the State's technology-intensive industrial sectors to enhance the competitive position of those sectors and increase the likelihood that one or more of the sectors will support clusters of industrial activity and to create new jobs for Maine people. The institute is one element of the State's economic development strategy and will contribute to the long-term development of a statewide research, development and product deployment infrastructure.”</i> <a href="#">5 M.R.S. §15302(2)</a>.</p> <p><i>MTI accomplishes these goals by “disburs[ing] funds through grants to private companies, targeted technology incubators and nonprofit research laboratories,” “fund[ing] necessary precursors to commercialization of products and services, including the development of new technologies and processes, the development of product concepts and the manufacture of prototypes,” and providing start-up organizational and developmental grants.</i> <a href="#">5 M.R.S. §15303(1), (2)</a>.</p> <p><i>Grant funding derives from annual state appropriations, private sector investments, loan repayments and investment returns.</i><sup>2</sup></p> <p><i>MTI’s work focuses on the following statutorily defined “targeted technologies”:</i> “biotechnology, aquaculture and marine technology, composite materials technology, environmental technology, advanced technologies for forestry and agriculture, information technology and precision manufacturing technology. These targeted technologies may be amended only by the Legislature.” <a href="#">5 M.R.S. §15301(2)</a>.</p> <p><b>See attached description of targeted technologies from MTI website</b></p>	<p><i>The Advisory Panel may receive more information related to economic development during its 4<sup>th</sup> meeting (on Oct. 19<sup>th</sup>), which is focused on Gene-editing in Systems and Institutions.</i></p>

<sup>2</sup> See Maine Technology Institute, *Annual Report 2021* at 10, available at <https://www.mainetechnology.org/docs/MTI-Annual-Report-FY21.pdf>.

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	<ul style="list-style-type: none"> <li>• <i>Suggestion: Leverage the Maine Seed Capital Tax Program to support the development of Biotechnology in the State.</i></li> </ul> <p><b>Staff notes:</b></p> <p><i>The Maine Seed Capital Tax Credit program, established by <a href="#">10 M.R.S. §1100-T</a>, “seeks to incentivize private equity investment in small businesses by offering investors an income tax credit [of up to 40%] of their investment in an eligible Maine business.” The credit reduces “the investment risk to investors by . . . guaranteeing a return of a portion of their investment by way of an income tax credit.”<sup>3</sup></i></p> <p><i>For an investment to be eligible for the tax credit, the investor must satisfy certain statutory requirements and the business must, among other things, be located in Maine; have annual gross sales of \$5 million or less; and be one of the following:</i></p> <ul style="list-style-type: none"> <li>○ <i>A manufacturer;</i></li> <li>○ <i>A value-added natural resource enterprise;</i></li> <li>○ <i>Engaged in the development or application of <b>advanced technologies</b>;<sup>4</sup></i></li> <li>○ <i>Provide a product or service that is (or is projected to be) sold or rendered predominately outside Maine;</i></li> <li>○ <i>Certified as a visual medial production company.</i></li> </ul> <p><b>See attached description of the program from the FAME website.</b></p>	
Other?		

<sup>3</sup> See Office of Program Evaluation and Government Accountability (OPEGA), *Evaluation of the Maine Seed Capital Tax Credit* at 4 (August 2021), available at <https://legislature.maine.gov/doc/6954>.

<sup>4</sup> The phrase “advanced technologies” is not defined in the statutes governing Maine Seed Capital Tax Credit program. In its August 2021 report on the program, OPEGA observed that the Legislature may wish to consider amending the program’s definition of “eligible business” to more closely “align with the State’s economic priorities”—for example, by amending the program statute to target the same seven targeted technology sectors that are the focus of the Maine Technology Institute. *Id.* at 23-24.