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February 6, 2023

The Honorable Melony Griffith  
Chair, Senate Finance Committee  
Miller Senate Office Building, 3 East Wing  
11 Bladen St., Annapolis, MD 21401

Re: Testimony in Support of Senate Bill 188: Public Health - Rare Disease Advisory Council

Submitted By: The Biotechnology Innovation Organization (BIO), Washington, DC

Dear Chair Griffith and Committee Members,

The Biotechnology Innovation Organization (BIO) thanks the committee for the opportunity to comment on our support for SB 188 (Lam). This legislation to establish an advisory council on rare disease would give a strong voice to the rare disease community in Maryland.

BIO is the world's largest trade association representing biotechnology companies, academic institutions, state biotechnology centers and related organizations across the United States and in more than 30 other nations. Our members are committed to advancing science and improving the health and well-being of our planet using biotechnology.

Of the more than 7,000 known rare diseases, approximately 80% are genetic. Fifty percent of all rare diseases affect children, while 30% die before the age of 5 years.<sup>1</sup> Only 5% of all rare diseases have treatments available to patients.<sup>2</sup> Rare disease patients typically have complex conditions that come with their own unique set of challenges that they must face from testing and disease management, as well as insurance coverage difficulties.

The creation of an advisory council on rare diseases will give patients and caregivers affected by rare diseases a unified voice. These individuals will finally be provided a forum to make recommendations about pressing health care issues of rare disease

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<sup>1</sup>National Institutes of Health, <https://www.nichd.nih.gov/newsroom/resources/spotlight/020116-rare-disease-day>. Accessed: December 1, 2019.

<sup>2</sup> <https://innovation.org/about-us/commitment/research-discovery/rare-disease-numbers>



patients. This advisory committee would give the state a compelling ability to improve knowledge, awareness, and management of rare diseases in Maryland, and bring together various stakeholders in the healthcare ecosystem to improve public policy regarding rare diseases. The results will be a great aid to patients, their families, and caregivers.

Thank you for the opportunity to comment on this legislation and for your support of SB 188. Please do not hesitate to contact us for any further information.

Sincerely,

/s/

Laura Srebnik

Director, State Government Affairs – Eastern Region

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