



**Biotechnology Innovation Organization**  
1201 New York Avenue, NW  
Suite 1300  
Washington, DC, 20005

February 9, 2023

Chair Noor and Members of the House  
Human Services Finance Committee  
State Office Building  
St. Paul, MN 55155

Dear Chairman Noor and Committee Members,

The Biotechnology Innovation Organization (BIO) thanks the committee for the opportunity to comment on our support for HF 988 (Reyer). This legislation will provide continued funding for the advisory council on rare disease and continue to give a strong voice to the rare disease community in Minnesota.

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.

Continuing to fund the advisory council on rare diseases will give patients and caregivers affected by rare diseases a unified voice. These individuals will continue to have a forum to make recommendations about pressing health care issues of rare disease patients. This advisory committee will continue to give the state a compelling ability to improve knowledge, awareness, and management of rare diseases in Minnesota. The RDAC brings together various stakeholders in the healthcare ecosystem to improve and provide advice on public policy, access, equity, research, diagnosis, treatment, and education related to rare diseases.

BIO and its members support continued funding for the Rare Disease Advisory Council to ensure the rare disease community has a strong voice in our state. Thank you for the opportunity to comment on this legislation and for your support of HF 988. Please do not hesitate to contact us for any further information.

Sincerely,

A handwritten signature in blue ink that reads "Lilly Melander".

Lilly Melander  
Director, State Government Affairs – Midwestern Region  
The Biotechnology Innovation Organization (BIO)

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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>