February 18, 2025

Maryland House of Delegates
ATTN: Committee on Health and Government Operations
House Office Building, Room 240,
Annapolis, MD

Re: HB 1007 – Regarding Privacy of Genetic Testing Results

On behalf of the EveryLife Foundation for Rare Diseases, we are pleased to submit testimony in support of HB 1007. The EveryLife Foundation is a nonprofit, nonpartisan organization dedicated to empowering the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments, and cures.

Genetic tests play a pivotal role in timely diagnosis, treatment, and disease management for the approximately 1 in 10 Americans living with a rare disease. However, concerns regarding privacy and discrimination have deterred many from seeking genetic testing. HB 1007 addresses some of these concerns by prohibiting life, long-term care, and disability insurers from accessing genetic test results and from making coverage decisions based on such information. This legislation provides much-needed protection against discrimination and financial repercussions for individuals with genetic predispositions.

We support this bill for the following reasons:

- **Protection from Discrimination:** With 80 percent of rare diseases being genetic in origin,[i] genetic testing that rapidly informs appropriate patient care and treatment is fundamental to rare disease patients' health and well-being. However, genetic tests are still out of reach for thousands of rare disease families as many face barriers such as obtaining insurance, lack of access to expert clinicians, and fear that insurers will unfairly deny coverage or increase rates due to their genetic information. By ensuring rare disease patients in Maryland are not vulnerable to discrimination from certain insurers based on their genetic test results, HB 1007 promotes equity in healthcare access and empowers individuals to make informed decisions about their health.

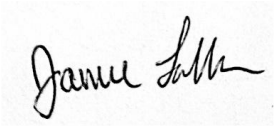
- **Reducing the Rare Disease Diagnostic Odyssey:** For rare disease patients, living with unanswered questions has long played an outsized role in their diagnostic odyssey. Navigating a rare disease diagnosis can require more than 6 years and 17 medical interventions, on average, after symptoms begin.[ii] These can include hospitalizations, emergency room visits, out-of-state specialist appointments, and other health-related activities.[ii] A recent study revealed that for some rare diseases, the economic impact of a delayed diagnosis can be over $500,000 per patient.[iii] Genetic testing plays a crucial role in shortening a patient's diagnostic journey by identifying individuals at risk of developing certain diseases and, as a result, decreasing financial and other burdens on families and the health care system. By safeguarding the privacy of genetic information, this bill encourages more individuals to undergo testing, facilitating early intervention, and potentially saving lives.

- **Advancement of Rare Disease Research:** Approximately 95% of rare diseases do not yet have an FDA-approved treatment.[iv] Access to genetic data is essential for advancing rare disease research and developing targeted therapies. By working toward ensuring the confidentiality of

genetic information, this legislation promotes participation in research studies and clinical trials, driving progress towards improved treatments and cures for rare diseases.

Genetic testing enables rare disease patients to make informed choices about their health. We look forward to working with you to ensure these individuals do not face penalties for making this decision. Please support HB 1007.

Sincerely,



Jamie Sullivan
Vice President of Policy
EveryLife Foundation for Rare Diseases

Emily Stauffer
Associate Director of State Policy
EveryLife Foundation for Rare Diseases

CC:
Michael Pearlmutter, Chief Executive Officer, EveryLife Foundation for Rare Diseases
Annie Kennedy, Chief of Policy, Advocacy and Patient Engagement, EveryLife Foundation for Rare Diseases
Vicki Seyfert-Margolis, Chair, Board of Directors, EveryLife Foundation for Rare Diseases

---

[i] National Human Genome Research Institute, Accessed April 2024. *Rare Genetic Diseases*, www.genome.gov/dna-day/15-ways/rare-genetic-disease.
[ii] EveryLife Foundation for Rare Diseases, February 2021. *The National Economic Burden of Rare Disease Study,* www.everylifefoundation.org/burden-landing/
[iii] EveryLife Foundation for Rare Diseases, September 2023, *The Cost of Delayed Diagnosis in Rare Disease: A Health Economic Study*, www.everylifefoundation.org/delayed-diagnosis-study/
[iv] Fermaglich, Lewis J, and Kathleen L Miller, June 2023. *A Comprehensive Study of the Rare Diseases and Conditions Targeted By Orphan Drug Designations and Approvals Over the Forty Years of the Orphan Drug Act." Orphanet journal of rare diseases vol. 18,1 163.*