



**NORD**<sup>®</sup>  
National Organization  
for Rare Disorders

Alone we are rare. Together we are strong.<sup>®</sup>

February 5, 2024

The Honorable Brian K. Lohse  
Iowa House of Representatives  
Iowa State Capitol  
1007 East Grand Avenue  
Des Moines, IA 50319

The Honorable David E. Young  
Iowa House of Representatives  
Iowa State Capitol  
1007 East Grand Avenue  
Des Moines, IA 50319

The Honorable Megan L. Srinivas  
Iowa House of Representatives  
Iowa State Capitol  
1007 East Grand Avenue  
Des Moines, IA 50319

Re: Keep **House File 2157** Relevant for all People with Rare Conditions

Dear Representatives Lohse, Srinivas, and Young;

The National Organization for Rare Disorders (NORD) is the leading independent advocacy organization representing the more than 30 million Americans living with a rare disease. At NORD, we believe that all patients should have access to quality, accessible, innovative, and affordable health coverage that is best suited to their medical needs. On behalf of the estimated one in ten Iowans with a rare disorder, NORD has been proud to support HF2157, legislation that would expand access to biomarker testing. However, it is vital that HF2157 is not limited to one disease area in order for the legislation to fully benefit our community. We encourage you to utilize the language from SF2159 to ensure the bill covers proven and necessary testing.

Biomarkers are characteristics, such as radiographic abnormalities or biological molecules found in blood, tissue, or other bodily fluid that can be objectively measured to determine the sign of a condition or disease. The result of a biomarker test can be used to assess how well a patient responds to a treatment for a disease or condition, as well as determine the best course of action for a patient.<sup>i</sup> This can significantly improve patient outcomes; for instance, in rare cancers, including pediatric cancers, this can mean that treatments can be targeted specifically for the genetic or molecular makeup of the tumor.<sup>ii</sup> Biomarker testing allows for targeted care and precision medicine, thus decreasing the treatment time and increasing the likelihood of survivorship for patients.<sup>iii</sup> While currently biomarker testing is often used in oncology,

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biomarker testing can benefit patients in many disease groups, including autoimmune diseases, and research is underway that may unlock benefits in other rare conditions. **That is why it is essential that HF2157 remain disease agnostic.**

Limiting the scope of HF2157 to cover only biomarker testing in oncology will dramatically lessen the impact of this legislation now and in the future and means that many patients will not be able to benefit from future innovation in biomarker testing. This change would be detrimental to the rare disease community and would force NORD to reconsider our support for this legislation. We urge you to adopt the language in SF2159 to ensure all relevant patients can benefit from this quickly evolving aspect of precision medicine, and to swiftly advance the legislation out of your subcommittee.

Thank you for your attention to this matter. For any questions, please contact me at [lviscarra@rarediseases.org](mailto:lviscarra@rarediseases.org).

Sincerely,



Lindsey Viscarra  
State Policy Manager, Western Region  
National Organization for Rare Disorders

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<sup>i</sup> Biomarkers. ONS. (n.d.). Retrieved December 7, 2022, from <https://www.ons.org/genomics-taxonomy/biomarkers>

<sup>ii</sup> Biomarker testing for cancer treatment. National Cancer Institute. (n.d.). Retrieved December 7, 2022, from <https://www.cancer.gov/about-cancer/treatment/types/biomarker-testing-cancer-treatment#:~:text=Biomarker%20testing%20is%20a%20way,how%20certain%20cancer%20treatments%20work>.

<sup>iii</sup> Biomarker testing for cancer treatment. National Cancer Institute. (n.d.). Retrieved December 7, 2022, from <https://www.cancer.gov/about-cancer/treatment/types/biomarker-testing-cancer-treatment#:~:text=Biomarker%20testing%20is%20a%20way,how%20certain%20cancer%20treatments%20work>.