Maryland Department of Health
Rare Disease Advisory Council

Wes Moore, Governor · Aruna Miller, Lt. Governor · Meena Seshamani, M.D., Ph.D., Secretary

The Honorable Brain Feldman, Chair
The Honorable Cheryl Kagan, Vice Chair
Maryland Senate
Education, Energy, and the Environment
2 West Miller Senate Office Building
Annapolis, Maryland 21401

Re: SB0421
Support, with amendments

February 6, 2026

Dear Chair Feldman and members of the Education, Energy, and the Environment Committee,

I am writing on behalf of the Maryland Rare Disease Advisory Council (RDAC) in support, with amendments, of Senate Bill 421. The RDAC is a legislated Governor's Advisory Council tasked with improving access to care and outcomes for people in Maryland living with Rare Disease. Sickle Cell Disease is a relatively common rare disease in Maryland. It, like many others, waxes and wanes with periods of good health and periods of severe pain and/or chest syndrome and an increased risk of strokes.

We support all provisions of this legislation but recommend its extension beyond sickle cell disease, and even rare disease, to chronic health conditions. Individuals with asthma or diabetes may also suffer hospitalizations and/or illness precluding regular attendance to class. Nevertheless, these individuals should have accommodations to support their educational attainments and completing their degrees in the expected time frame. While we acknowledge that the Americans with Disabilities Act (ADA) allows for individuals with these chronic conditions to receive academic accommodations, it is clear that extra safeguards need to be put in place to ensure that those who require accommodations receive the accommodations they need. Further, we recommend that this bill be extended to all levels of education rather than just colleges and universities. This legislation, once revised to broaden its scope by the addition of the words "and other chronic conditions" after "sickle cell disease," should serve to increase awareness of the commonness of chronic medical conditions and the needs for institutions of higher education to accommodate students' need to encourage success.We also recommend adding the Rare Disease Advisory Council, Developmental Disabilities Council, and the Secretary's Advisory Council on Hereditary and Congenital Disorders to the Statewide Sickle Cell Steering Committee on the list of Committees tasked with ensuring appropriate and comprehensive educational materials.

Best,

Ada Hamosh, Chair