



THE COORDINATING CENTER
INSPIRED SOLUTIONS

Committee: House Health and Government Operations

Bill Number: House Bill 290 – Public Health - Rare Disease Advisory Council

Hearing Date: February 14, 2023

Position: Support

The Coordinating Center supports *House Bill 290 – Public Health – Rare Disease Advisory Council*. The bill establishes a permanent advisory council to provide recommendations to State agencies to improve access to care for people with rare disease.

The Coordinating Center, which was established in 1983, has a long history of coordinating health care and support services for people with rare diseases. As Maryland’s provider of case management services for Maryland Medicaid’s Rare and Expensive Case Management Program (REM) we coordinated care for 4,477 REM participants in FY2022, the highest number in the history of the REM Program. We support this legislation because it will provide a focused effort on improving State policies that impact individuals and families impacted by rare diseases.

The bill provides for a comprehensive approach for reviewing State policies. In particular, we want to thank the sponsor for including the issue of continuity of care for people with rare diseases in an emergency. With the COVID-19 pandemic, we saw the impact of the shortages of medications, supplies, and health care providers on the lives of people with rare diseases. We can use this recent experience to improve planning for emergencies in the future.

We have many resources on rare diseases in our state. The Advisory Committee is an opportunity to bring together those resources – including researchers, health policy experts, and providers – to improve the lives of Marylanders with rare diseases.

We ask for a favorable report. If we can provide any additional information that is helpful, please contact Robyn Elliott at relliott@policypartners.net or (443) 926-3443.