



Committee: House Health and Government Operations Committee

Bill Number: Senate Bill 188 – Public Health - Rare Disease Advisory Council

Hearing Date: March 21, 2023

Position: Support

The Maryland Nurses Association (MNA) supports *Senate Bill 188 – Public Health - Rare Disease Advisory Council*. This bill will create a rare disease advisory council that includes a registered nurse or advanced practice registered nurse licensed and practicing in the state with experience treating rare diseases.

There is always a need for nurse support for those affected by a rare disease. There are 7,000 or more rare diseases that have been identified and approximately 25-30 million Americans who have been diagnosed with at least one.ⁱ Rare diseases can include infectious diseases, birth defects, genetic disorders, and cancers. Some of these rare diseases can be discovered on newborn screening tests. Unfortunately, many rare diseases are not currently tracked, so it is hard to definitively state how many rare diseases there are. This bill will help increase the knowledge base about rare diseases so people with a rare disease can be diagnosed early, given lifesaving treatment, and allowed to have as comfortable, pain-free, and productive a life as possible.

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

ⁱ <https://minoritynurse.com/importance-of-raising-awareness-of-rare-diseases/>