

March 9, 2022

**RE: Testimony in Favor of Raised House Bill 5260 Public Health Committee
An Act Establishing a Rare Disease Council**

Dear Chairs Steinberg and Daugherty Abrams, Ranking Members Petit, Hwang, and Somers and Members of the Public Health Committee

BioCT represents over 250 Connecticut life sciences companies, academic institutions, service providers and patient organizations, many directly engaged in the research, development and manufacturing of innovative products to improve patients' lives and public health as well as driving economic growth.

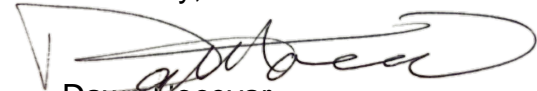
Thank you for to the Public Health Committee for bringing this bill to the floor. Establishing a Rare Disease Council will addresses an issue that has been ignored the past several years. Rare diseases, defined as any disease that affects fewer than 200,000 people in the United States, are unfortunately not a rare phenomenon.

According to the National Institute of Health, there are over 7,000 different types of rare diseases and it is estimated that upwards of 25 to 30 million people live with them in the U.S. alone; 300,000 of them are residents of Connecticut. By establishing an on-going council, people who live with rare diseases will once again have a voice in government to advocate for their issues and help make the Connecticut health care system more robust and responsive to their needs.

Connecticut is home to many bioscience companies focused on rare diseases like Alexion, Rallybio, Lambda Vision, Boehringer Ingelheim, AI Therapeutics, Vanessa Biotech, Sema4 and others. Connecticut also has important non-profit rare disease companies such as Jackson Laboratory. Passing this legislation will support these companies and all the rare disease patients in Connecticut.

BioCT and our members are very supportive in passing this bill. Thank you for your consideration.

Sincerely,



Dawn Hocevar
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