

Testimony for public hearing public health committee February 20, 2015

Arianna Peterson  
(860) 287-7077  
219 Howe ave, apt. 3L  
Shelton, CT 06484

Dear chairman Ritter, Chairman Gerratana, And members of the Public Health Committee:

I writing in regards to the development of a rare disease council. I believe this would be a huge benefit to families who have a loved one with a rare disease. I have witnessed a family friend struggle to find assistance for her children who have a rare disease. It is an awful thing to struggle and have to advocate for a loved one, especially when there is not a lot of knowledge on the subject. It is frustrating because if not many people are aware of a rare disease then things such as insurance or other types of assistance becomes a struggle. Knowledge is power, and if a council was formed it could promote not only awareness but assist the families in ways to alleviate financial burdens, identify insurance issues and provide whatever resources are available. Furthermore, I believe this council could by its existence create a type of community.

I greatly thank you for your time in reading this.

Sincerely,

Arianna Peterson.