

Submitter: Rebecca Ambrose  
On Behalf Of: Rare Disease Communities  
Committee: House Committee On Behavioral Health and Health Care  
Measure, Appointment or Topic: HB2457

I object to the requests in the letter submitted by Julia Laxer. I have to dissent to the effort to lump in conditions like fibromyalgia with rare disease. Rare Disease communities suffer chronically but they are markedly different than "chronic disease" issues. If Ms. Laxer would like to establish a chronic disease advisory council I would support that effort. However, I do not support the effort to drown out the already unheard voices of the Rare Disease community. Rare diseases often involve unique challenges, such as limited research funding, a lack of treatment options, and the need for targeted advocacy, which are not typically the same challenges faced by chronic diseases in general.