

Submitter: Kathleen Zinno
On Behalf Of:
Committee: House Committee On Behavioral Health and Health Care
Measure, Appointment or Topic: HB2457

Dear Chair Nosse and Members of the House Behavioral Health and Health Care Committee,

Thank you for taking the time to review HB2457. As a rare disease patient myself I have seen how the lack of representation impacts every facet of our community from healthcare to housing. There are unique considerations that are often missed when considering only the larger population. The creation of the RDAC will help provide the watch dog supports these patients and caregivers need.

There was additional language drafted by a local advocate based upon other RDACS in the country that encompass what the patients of Oregon feel is needed to adequately have our concerns heard. NORD became involved in the recent years, but has been minimally responsive to the concerns brought up and ultimately did not address direct questions about the secondary language and dismissed our concerns.

We are requesting that these modifications be added into the current bill language and resubmitted for consideration

Oregonians deserve to have fair representation nothing about us without us.

Here are some specific items that we feel will keep the RDAC patient-oriented:

-RDAC must explicitly work to benefit/improve quality of life for both rare disease AND under-served chronic illness patients, regardless of rarity. This is necessary, in part, because any disease can suddenly stop being "rare." In fact, I do not believe that hypermobile Ehlers-Danlos Syndrome would be considered rare under the current bill language, even though patients are routinely refused diagnosis for reasons including supposed rarity, and are among the most medically-underserved disabled people in the state.

-RDAC must have explicit policies that prohibit pharmaceutical and insurance companies (or anyone) from profiting, or steering goals/research/contracts/policy in a way that would benefit them instead of patients, including ethics and conflict of interest policies. Additionally, we would like for pharma to *not* be explicitly included in any capacity among the "minimum of 20" council members.

-RDAC must center multiply-marginalized people, such as BIPOC with rare

diseases/chronic illness, transgender people with rare diseases/chronic illness, immigrants with rare diseases/chronic illness (etc) and must prioritize those groups when considering membership (and must prioritize specialists/professionals who are also patients over non-disabled specialists) in those board roles.

-RDAC must have some clarity / restrictions regarding funding as we do not want lobbyists or pharma influencing the RDAC.

-Appointment methodology must be transparent and there must be some methodology for patients to provide feedback about prospective appointees. I believe that current language tasks the governor with appointing, but I'm not sure the governor is qualified, especially without any mechanism for comment, criticism, or other feedback. (And we are currently seeing the effects of unqualified appointments on a national scale.)

-Author must include disabled people and disability orgs in the authorship process, as the authors of HB2002 did (and as any bill author would for any piece of legislation affecting any other marginalized group).