

1. The RDAC must explicitly work to benefit/improve quality of life for both rare disease AND under-served chronic illness patients, regardless of rarity.

1.a. Any disease can suddenly stop being "rare," as research improves and more patients are diagnosed. There are stigmatized conditions that are currently considered rare because they're underdiagnosed (e.g. hEdS), but those patients still deserve healthcare resources and improved quality of life.

2. The RDAC must have explicit ethics and conflict of interest policies that prohibit pharmaceutical and insurance companies (or anyone) from profiting from the RDAC, or steering its goals, research, contracts, or policy in a personally enriching or beneficial manner, rather than benefiting

patients

2.a. Pharma must explicitly be excluded in any capacity among the "minimum of 20" council members, or otherwise listed as an essential presence on the RDAC.

2.b. The same goes for lobbyists. No entity of any kind invested in anything other than improved healthcare and quality of life for marginalized people.

3. The RDAC must center and prioritize the involvement, voices, and perspectives of multiply-marginalized people, such as BIPOC, LGBTQ+ people, immigrants, houseless Oregonians, incarcerated Oregonians, Oregonians of minority religion or culture, and immigrants with rare diseases or chronic illness

3.a. The RDAC must prioritize multiply-marginalized groups when considering

board membership, contracts, studies, hiring for support staff roles, and any other circumstance where the opportunity to choose between a pool of diverse candidates or options presents itself.

3.b. Specialists or other professionals who are disabled or chronically ill must be prioritized for RDAC board roles over non-disabled Oregonians.

4. Bill language must be precise, specific, and restrictive regarding funding, to prevent lobbyists, insurance companies, pharmaceutical corporations, or any other entity which may attempt to use the RDAC for its own purposes, contrary to the interest of disabled Oregonians, influencing the RDAC.

5. Appointment methodology, including selection and vetting process for appointees must be public, detailed, and

transparent. There must also be a method for patients and the community to provide feedback and register concerns about prospective appointees before they are appointed.

5.a. The bill's current language requires the governor to appoint, but a governor has no inherent quality or qualification which makes them well-suited to decide membership on a council meant to serve disabled people, especially without any mechanism for comment, criticism, or other feedback.

6. The author must include disabled people and disability orgs in the authorship process, as any bill author would for any piece of legislation affecting any other marginalized group, or turn over the bill to someone who will.

And we REJECT the anti-trans republican

co-sponsors.