

Good day – – I am asking you to please support bill HB 2457 for a Rare Disease Advisory Council.

I live in Medford and [My 28-year-old has an extremely rare genetic disorder](#). His disorder [NR4A2-Related Neurodevelopmental Disorder](#) has less than 30 individuals worldwide that are identified in medical literature and probably less than 100 people total in the world with it considering that the world has over 8 billion people. It is extremely rare.

I do believe having a Rare Disease Advisory Council would be a wonderful thing. I should add that my son's genetic changes to the NR4A2 gene is also a gene that is implicated in Alzheimer's, Parkinson's, and also if you raise the level of the protein that that gene makes it is protective for recurrent Parkinson's. Currently, there is a group of researchers in Europe that have applied for a grant to study the NR4A2 gene because the outcome might be beneficial to my son, but also might benefit people with those disorders also.

Another point to consider is that chromosome testing has went from \$5 billion down to approximately less than \$500. Because of the lower price we will see more and more rare genetic disorders and disease is found. I imagine there will be someday when a child will be born and they will not do a PKU test, but they will do a chromosome test. So having a central clearing house at a state level will be more and more necessary.

Oregon is known for a state that is ahead of the curve of the rest of the United States. My late father Hank Henry used to work with Governor Tom McCall back in the 50s governor Tom McCall also was way ahead of the curve.. And I do believe this would be something that would be ahead of the rest of the nation. I am a former Republican, former independent, and now an unaffiliated voter.

Sincerely
Joe Henry
Medford, Oregon