

SB2031

Senate Human Services Committee

Senator Lee Chair

Senator Lee and Members of the Committee,

My name is Donene Feist and I am the Director for Family Voices of North Dakota. Our work as you know, includes working with families who have children and youth with disabilities and chronic health conditions.

We stand today in opposition to SB2031. While I do believe there needs to be cost control for many medications, I do not want to do so at the risk of many families that we represent.

We hear from families on a regular basis the high costs of prescriptions. For some of our families pricing absolutely makes prescriptions inaccessible even with the best of health insurance. We understand and support cost controls. For some it means milk on the table, we get it.

A big reason we are in opposition of this bill is potentially the use of the quality adjusted life year (QALY). My understanding is using this measure will put many of the children we serve who have a chronic health illness/disability life value being of less worth than the general public.

Many of our children are already denied some medications by insurance companies, would this exacerbate that scenario?

Some of our children's families have come before you with medical conditions that are so rare that their only recourse is medication that is very expensive and in some instances experimental of which insurance denies. Would this bill worsen this?

In 2015, we passed the Right to Try Bill, would **this indirectly** affect those children and adults being part of experimental studies?

Hence, if there is no guarantee that this will not affect children, youth and adults with disabilities based on the QALY we have to oppose.

Again, that does not mean, we do not believe that pharmaceuticals are outrageously priced. We do believe they are.

I sure do not want anyone discriminated against based on their illness or disability

Thank you for your time

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