

From: [Lee, Judy E.](#)
To: [Lahr, Pat](#); [Wolf, Sheldon](#)
Subject: FW: Patient and disability concern with SB 2031
Date: Tuesday, January 17, 2023 1:40:26 PM

Senator Judy Lee
1822 Brentwood Court
West Fargo, ND 58078
Home phone: 701-282-6512
Email: jlee@ndlegis.gov

From: Hogan, Kathy L. <khogan@ndlegis.gov>
Sent: Tuesday, January 17, 2023 1:22 PM
To: -Grp-NDLA Senate Human Services <ndlashumserv@ndlegis.gov>
Subject: FW: Patient and disability concern with SB 2031

Here is additional information on the QALY concerns in 2031

Sent from [Mail](#) for Windows

From: [Thayer Roberts](#)
Sent: Tuesday, January 17, 2023 1:18 PM
To: [Hogan, Kathy L.](#)
Subject: RE: Patient and disability concern with SB 2031

Dear Senator Hogan –

Thank you for your response. We are very appreciative of your interest in ensuring nondiscrimination in health care and your willingness to discuss this issue with us.

The Quality-Adjusted Life Year (QALY) is a discriminatory metric that assigns less value to disabled life and has the implications of limiting access to needed treatments for people with disabilities and chronic illnesses. Oklahoma recently passed a very robust [QALY ban bill](#), which was [praised](#) by the patient and disability community. It would be wonderful to see North Dakota take similar steps. We have put together a template piece of legislation for states looking to enact robust patient protections in health care decision making, including banning the use of the QALY, which can be found [here](#).

Unfortunately, there is not simple language that can be added to SB 2031 to address this concern. Canada overtly uses QALYs at both at the federal and provincial level when determining pricing and coverage of drugs. Since this bill directly links to Canadian pricing, there isn't a way to remove or bar the use of the QALY, which is our concern. In Canada, many patients, particularly those with rare diseases are unable to access the treatments they need as they are deemed too expensive to treat.

For this reason, a [2019 report](#) from the National Council on disability was direct in recommending that the United States should not reference prices established in other countries that rely on the use of the QALY. Canada is one of these countries.

I'm sorry I am not able to recommend a "quick fix" for this specific bill, but I would be happy to bring patient and disability stakeholders to the table to discuss with you alternate methods to address health care costs that are patient-centric and do not discriminate. Again, we are very appreciative of your interest in this issue.

Thank you,
Thayer

From: Hogan, Kathy L. <khogan@ndlegis.gov>
Sent: Saturday, January 14, 2023 3:57 PM
To: Thayer Roberts <thayer@pipcpatients.org>
Subject: RE: Patient and disability concern with SB 2031

I would love to see potential language we could add to the bill to address this concern.

Kathy Hogan
Rep District 21, Central Fargo



From: Thayer Roberts <thayer@pipcpatients.org>
Sent: Friday, January 13, 2023 8:35 AM
To: Lee, Judy E. <jlee@ndlegis.gov>
Cc: Cleary, Sean <scleary@ndlegis.gov>; Clemens, David <dclemens@ndlegis.gov>; Hogan, Kathy L. <khogan@ndlegis.gov>; Roers, Kristin <kroers@ndlegis.gov>; Weston, Kent <kweston@ndlegis.gov>
Subject: Patient and disability concern with SB 2031

Dear Chairwoman Lee:

I am reaching out on behalf of the Partnership to Improve Patient Care (PIPC), a coalition of patient and disability organizations with a goal of advancing principles of patient-centeredness in our evolving health care system.

Our coalition has concerns about the use of the Quality-Adjusted Life Year in health care decision making due to its discriminatory implications and wanted to share some concerns with the piece of legislation that you are considering, SB 2031 that would reference rates of prescriptions drugs from a third party, the Canadian government, which relies on the QALY for coverage and reimbursement

decisions. I have attached a detailed letter outlining the discriminatory implications of the QALY and the history of robust opposition to its use in public policy dating back to the George H.W. Bush Administration in 1992.

PIPC understands the need to enact policies to bring down health care costs and would be happy to work with you and bring appropriate patient and disability stakeholders to the table as you explore policies to meaningfully lower the cost of health care while maintaining patient access to needed treatments. I appreciate your consideration of the attached letter. Please let me know if you have any questions or would like to discuss.

Sincerely,

Thayer Roberts

Thayer Surette Roberts

Deputy Director

Partnership to Improve Patient Care

100 M Street SE - Suite 750

Washington, DC 20003

(508)843-1688 (cell)

Connect with PIPC:  