



March 24, 2026

Honorable Kirk Talbot
Chairman, Louisiana State Senate Insurance committee
P.O. Box 94183
Baton Rouge, LA 70804

Dear Chairman Talbot:

I am writing on behalf of Color of Gastrointestinal Illnesses (COGI) to raise serious concerns about the proposed SB 401. COGI represents communities affected by inflammatory bowel disease (IBD), digestive disorders, gastrointestinal cancer and associated chronic illnesses and who experience health disparities due to health system failures.

I founded COGI based on my own personal experience as a Black woman. I have been on 16 medications, from pills to injections to suppositories. I started having rectal bleeding at the age of 13 yet was not diagnosed with Crohn's disease until 2018 after a 30-year journey. And even with diagnosis, I did not get an advanced therapy prescribed until December 2023. That medication changed my life. Yet, I also recognize that I have a progressive disease and my health has been forever impacted by a delayed diagnosis and delayed prescribing of the advanced therapy I needed.

To achieve optimal health outcomes, policymakers must consider how their actions may unintentionally create more barriers for our patients to access to treatment. Due to the historic perception that people of color are not impacted by IBD, it often takes far too long for patients in our community to get an accurate diagnosis. Given this delay, it is essential that once we are diagnosed, we are able to quickly and efficiently access the medications we need – additional delays only enhance the disparities in care that patients of color already face.

Therefore, COGI has real concerns that this policy proposing to reference international prices may lead to Louisiana patients experiencing the same care denials and delays that are seen in other countries. Other countries treat less effective and older drugs as therapeutic alternatives, despite evidence that shows they are not necessarily interchangeable for patients in the real world. Patients with Crohn's disease are often forced



to cycle through many treatments before finding the one that works for them. The experience of patients in other countries should be a warning not to model their systems of health care.^{1,2,3}

I am also very concerned that the legislation does not include safeguards to prevent this new Board from referencing quality-adjusted life years (QALYs) and similar measures known to devalue people with disabilities and serious chronic conditions. It is widely understood that QALYs and measures devalue people living with disabilities and chronic conditions as part of the formula or “math” used to calculate cost effectiveness.⁴ Yet these are the studies used in other countries to ration health care against people with disabilities and serious chronic conditions.⁵ In light of the implications for devaluing disabled lives, the National Council on Disability, an independent federal agency advising policymakers on disability policy, has recommended avoiding QALYs and similar measures in decisions related to coverage and reimbursement, including by avoiding reference to prices in other countries.⁶ Entities like the Institute for Clinical and Economic Review (ICER) here in the U.S. similarly views QALYs as the “gold standard” for measuring health care value, yet the legislation does not safeguard against use of their value assessments.

We urge state policymakers to focus their work on addressing the egregious use of utilization management and adverse formulary placement of certain drugs by payers that is at the heart of affordability and access challenges for patients. Louisiana should not model its health systems on those of foreign nations that do not value care for people living with disabilities and serious chronic conditions, nor embrace the use of QALY-based value assessments that were created to ration health care. In doing so, payers will be encouraged to make decisions related to their formularies and coverage based on biased value standards that ultimately makes it harder for patients to access the care they need.

¹ NHS Can’s Keep me Alive, https://urlisolation.com/browser?clickId=40ACFB1B-C01F-4DA5-B81A-521FF512C561&traceToken=1768663684%3Bphrma_2_hosted%3Bhttps%3A%2Fwww.mirror.co.uk%2Fnews%2Fhea&url=https%3A%2F%2Fwww.mirror.co.uk%2Fnews%2Fhealth%2Fnhc-cant-keep-alive-son-35582859

² Canada, https://urlisolation.com/browser?clickId=3C0D25B4-4498-4681-BD61-BAAC1AEDCFB1&traceToken=1768664055%3Bphrma_2_hosted%3Bhttps%3A%2Fwww.cbc.ca%2Fnews%2Fcanada%2Fsa&url=https%3A%2F%2Fwww.cbc.ca%2Fnews%2Fcanada%2Fsaskatoon%2Fbiologic-pharmaceutical-drugs-medications-biosimilars-patients-1.6721293

³ New Zealand, https://urlisolation.com/browser?clickId=A6277C7A-5C21-4FCD-95D0-20E968E1F859&traceToken=1768663924%3Bphrma_2_hosted%3Bhttps%3A%2Fwww.rnz.co.nz%2Fnews%2Fnation&url=https%3A%2F%2Fwww.rnz.co.nz%2Fnews%2Fnation%2F536416%2Fkiwis-call-for-wider-access-of-newly-funded-cancer-drug

⁴ Browne J PhD, Cryer DR JD, Stevens W PhD. Is the QALY Fit for Purpose? [Internet]. AJMC; 2021 Jul 13; Available from: <https://www.ajmc.com/view/is-the-qaly-fit-for-purpose->

⁵ Undark, Is the Medication You’re Taking Worth Its Price?, January 27, 2020. <https://undark.org/2020/01/27/medicine-qaly/>
⁶ National Council on Disability. Quality-Adjusted Life Years and the Devaluation of Life with Disability [Internet]. National Council on Disability; 2019 Nov. Available from: https://www.ncd.gov/assets/uploads/reports/2019/ncd_quality_adjusted_life_report_508.pdf



We appreciate your consideration of our concerns and hope that this bill will not advance as proposed.

Sincerely,

A handwritten signature in cursive script that reads "Melodie N. Blackwell". The signature is written in black ink and is centered on the page.

Melodie Narain-Blackwell
President
Color of Gastrointestinal Illnesses