



**Tigerlily  
Foundation**  
*Beauty. Strength. Transformation.*

April 2, 2024

**RE: The Negative Impact of a Proposed Drug Affordability Board on Illinoisans Living with Cancer**

Honorable Members of the Illinois Legislature:

The Tigerlily Foundation is a national women's health and oncology organization dedicated to education, advocacy, and hands-on support for young women before, during, and after cancer. I write to you today to express our organization's concerns over House Bill 4472, legislation that would establish a Health Care Availability and Access Board in Illinois. **Establishing this Board and the actions they would take in Illinois would block access to essential medicines that Illinoisans rely on to manage symptoms and lead healthier lives, particularly for patients living with cancer and other complex and chronic conditions, and members of historically underserved communities further exacerbating already existing health disparities that Illinois has committed to decrease.**

Price setting policies that often accompany these boards – most commonly known as prescription drug affordability boards (PDABs) – such as upper payment limits (UPLs), fail to protect access to timely and effective care and can actually increase risks for patients who need consistent access to medications to manage their health. UPLs limit reimbursement for hospitals, doctors, and pharmacists who dispense effective treatments that help patients manage a chronic condition. As a result of the proposed PDAB, or Health Care Availability and Access Board in Illinois, patients could be forced to search elsewhere to access medications they need and could end up delaying or forgoing critical treatments altogether, which often leads to adverse health consequences and can lead to higher medical costs in the future. In addition, establishing a PDAB (or the Health Care Availability and Access Board) in Illinois could divert critical research resources elsewhere and have a chilling effect on the development of new medicines for patients who have limited or no treatment options today for their condition.

For patients who are diagnosed with complex cancers like triple negative breast cancer (TNBC), an aggressive form of cancer that has limited treatment options, timely and equitable access to medications and treatments prescribed by one's physician is critical. I know this all too well as a triple negative breast cancer (TNBC) survivor myself. However, drug price controls can unintentionally threaten vital pathways for patients to access cutting-edge medicines that can help them survive such illnesses. This is a step backward and will make patients face the reality I faced at my diagnosis; being told I have no target treatment options. I and this community have worked too hard for the past 17 years to come this far to the point where we now have four approved targeted treatment options for TNBC to steal that from those in the near future who will be diagnosed with this and other currently hard-to-treat diseases.

While we commend the Illinois legislature and other elected leaders in Illinois for exploring solutions that alleviate health care access and affordability challenges and reduce health disparities, any policy solution must not come at the expense of vulnerable communities in Illinois, particularly Black and brown communities who already face disproportionate barriers. TNBC, among other cancers and chronic conditions, disproportionately affects Black women, and establishing a PDAB in Illinois would have disastrous consequences on access to care, future innovative treatments, and efforts to achieve health equity.



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On behalf of the communities that the Tigerlily Foundation serves, we thank you for your leadership in seeking policy solutions to address barriers to care that Illinois patients continue to face. However, HB 4472 falls short of that goal.

Please do not hesitate to contact me directly at [maimah@tigerlilyfoundation.org](mailto:maimah@tigerlilyfoundation.org) if the Tigerlily Foundation can be a resource to you and your staff.

Sincerely,

Maimah Karmo  
Founder & CEO  
Tigerlily Foundation