

A Thousand Faces of Inequity

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Canadians striving to live well with systemic lupus erythematosus (SLE) often struggle to access potentially life-changing medications, depending on where they live and medication insurance coverage. Despite advocacy attempts by rheumatologists and the lupus community, change is slow, causing huge negative impacts on the healthcare system, economy, and the lives of those affected.

SLE affects 1 in 2,000 Canadians with greater female predilection (1 in 1,000)¹ and affects more Black, Indigenous, and people of colour (BIPOC) compared to white people. Many national and international lupus registries have reported on the need to urgently reduce disease activity to avoid long-term damage while acknowledging the need to limit the total steroid burden due to associated damage.^{2,3}

Health Canada's approval of Bellysta™ (belimumab) in 2011 was heralded as a game-changer, especially for those who had exhausted all SLE treatments. Unfortunately, a negative recommendation from the Canadian Agency for Drugs and Technologies in Health (CADTH) for SLE in 2011 and 2018 (re-submission) meant that for a long time, public formularies across Canada did not list this drug except as an exceptional drug in Quebec and for a time in Alberta.

Hope was rekindled with the 2021 Health Canada approval of Saphnelo™ (anifrolumab), which received CADTH approval and in recent months was listed on the public formulary in Alberta, Quebec and Ontario as well as on the Non-insured Health Benefits for First Nations and Inuit (NIHB). Moreover, a new listing of belimumab for the indication of lupus nephritis is currently under review in many provinces after receiving a positive CADTH review. Other than Quebec, however, belimumab is not available to Canadians with SLE under public coverage unless Glaxo Smith Kline pursues a re-submission to CADTH for a third time and obtains a positive review.

Optimism grows that public coverage and, therefore, access to these biologics will increase across Canada in the coming year; however, this may also serve to emphasize the disparity amongst those who will still be ineligible. A 2021 survey on access to healthcare and pharmaceuticals during the pandemic confirmed that 21% of Canadian adults do not have any private prescription

insurance to cover medication costs, with higher percentages in seniors, immigrants, and racialized persons.⁴ Many people with lupus fall into this category. Moreover, differing coverage criteria between provinces mean that when someone lucky enough to be on a lupus biologic in Quebec moves to British Columbia, they may lose medication coverage and disease control. The short- and long-term implications for patients are significant.

Beyond lack of public coverage, other reasons for disparities in coverage include no compassionate or bridging programs, limited co-pay by pharmaceutical companies (maximum 50%), and tight criteria by private insurers and public formularies, which limit drug eligibility. The latter reflects the ongoing complacency that payers have regarding steroids in lupus patients — that, contrary to recently published guidelines, lower doses remain acceptable long term, a situation that would never be accepted by rheumatologists for inflammatory arthritis patients. Even standard-of-care lupus medications such as mycophenolate mofetil have restricted access in particular provinces (e.g. Alberta) which exacerbates this inequity.

Advocacy at all levels is needed to raise awareness of disparities in health outcomes between BIPOC and white people and address the inequity in access to new medications for Canadians with lupus. Lupus Canada took this issue to Parliament Hill in December 2023, emphasizing the need for equitable drug access for lupus patients.

"Lupus is an under-recognized chronic autoimmune disease that requires attention from the Canadian government, as well as key decision-makers. Publicly funded lupus-specific treatments will save lives, generate long-term health care savings and ultimately increase the quality of lives of those who are managing this debilitating disease."

– Leanne Mielczarek, Executive Director, Lupus Canada

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