

Canadian Spondylitis Association 2967 Dundas Street West #1280 Toronto, Ontario M6P 1Z2

spondylitis.ca

December 2, 2022

The Honourable Jean-Yves Duclos Minister of Health Brooke Claxton Building, Tunney's Pasture Ottawa, Ontario K1A 0K9

Dear Minister Duclos,

I am writing regarding the proposed updates to the Patented Medicine Prices Review Board (PMPRB) Guidelines. As a non-profit organization representing the estimated 1-2% of Canadians living with Spondyloarthritis (SpA), we recommend that the federal government consider further consultation with all stakeholders that will be affected and suggest that any final decisions be delayed until a more comprehensive approach is taken to better understand the impact that could be felt by people in our community and the healthcare system.

The Canadian Spondylitis Association (CSA) provides information, support and awareness for people with SpA, a group of inflammatory arthritis conditions that affect the spine, joints, eyes, digestive system and other parts of the body, including Ankylosing Spondylitis, Psoriatic Arthritis, Enteropathic Arthritis and Juvenile Idiopathic Arthritis.

One of the main priorities of CSA is our focus on patient advocacy. In many cases, those that we serve are unable to voice their concerns or are unaware of the long-term impacts of major government decisions. We want to ensure that their best interests are considered, and we believe an inclusive approach with government and stakeholders will ultimately result in better outcomes for all.

Living with SpA is painful, debilitating and involves many health complications from chronic pain, fatigue, digestive issues, psoriasis, anxiety and depression. Most begin experiencing symptoms in their young adult years, when they should be completing their education, embarking on careers and entering into relationships with partners and starting families. Without proper diagnosis and treatment, disease progression may worsen and irreversible damage can occur, leaving people unable to work and having difficulties with even the most mundane activities of daily living.

It is imperative that people with SpA have access to as many treatment options as possible, because patients react differently to various forms of treatment and some can lose effectiveness over time, needing to be replaced with new therapies. New, innovative therapies that have been introduced in recent years that have restored many patients to better health and are allowing them to live a much better quality of life as a result.

We appreciate the complexities of the Canadian health care system and advocate for affordable access to healthcare for all patients, while also recognizing and supporting the government's objective to make prescription medicines and therapies more affordable. Our concern is that the draft PMPRB guidelines may have unintended negative consequences with pharmaceutical innovations coming to Canada in a timely fashion. Canadians may not be able to access new medicines or therapies that they need. We urge the federal government to pause and reflect on all potential negative consequences and include an impact assessment before any final guidelines are implemented.

Thank you for your consideration on this matter.

Sincerely,

Dr. Elie Karam

Jeffrey D. Beach Chair, Board of Directors **Executive Director**