April 5, 2020

The Honourable Patty Hajdu
Minister of Health
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Dear Minister Hajdu:

We are writing to you to express our concerns about the current drug shortages experienced by people living with autoimmune rheumatic diseases.

People living with rheumatic diseases are vulnerable at the best of times, relying on many medications to maintain a reasonable quality of life and participate in activities of daily living. Since the media reported the potential of hydroxychloroquine (Plaquenil) as a treatment for COVID-19, many people living with rheumatic diseases such as systemic lupus erythematosus (SLE), rheumatoid arthritis (RA), vasculitis, Sjögren's Disease, and other autoimmune rheumatic conditions, have reported difficulties in accessing their medications.

Now is the time to remove any barriers to patients accessing hydroxychloroquine, especially those whose conditions are currently well-controlled by this medication as part of their treatments. As leaders of the arthritis patient community in Canada, we ask that you take definitive action now to guarantee a supply of hydroxychloroquine to people living with rheumatic conditions.

We appreciate that the COVID-19 pandemic is an unprecedented health and social challenge for the country. The lives of all Canadians are being affected and many have made sacrifices to help society and support the elderly, people with chronic health conditions, and their neighbours. People living with rheumatic disease are especially vulnerable during the pandemic as they take medications that suppress their immune systems. In addition, patients can suffer disease flares when medication is withdrawn which can be a serious consequence of drug shortages. The current pandemic and associated media reporting are generating some misinformation and fear among patients.

People living with rheumatic conditions need to retain their supply of hydroxychloroquine to control their disease and minimize flares. Flares are periods of heightened disease activity that may severely impact a person's ability to function, possibly change a patient's treatment plan which is often determined through a process of trial and error, trigger health emergencies that require hospitalization, and result in long-term damage. Canada needs to ensure priority access to hydroxychloroquine for patients with rheumatic conditions including SLE and certain types of inflammatory arthritis. We are supportive of the Canadian Rheumatology Association's Position Statement on COVID-19 and Hydroxychloroquine Supply. A stable supply of the medication will reduce the need for health care services by people with rheumatic disease. This is particularly important since the health care system is operating at or above normal capacity, and resource challenges will only be intensified throughout the pandemic.

Hydroxychloroquine is a well-established and evidence-based treatment for many rheumatic conditions. It is often used in combination with other disease-modifying anti-rheumatic medications and takes 4-6 weeks to impact a patient's health. Many patients rely on this medication to keep pain and inflammation under control as well as the systemic manifestations of their disease such as kidney disease and cardiovascular disease. Given its strong, evidence-supported track record in treating rheumatic conditions, hydroxychloroquine is on the World Health Organization's List of Essential Medicines as a disease-modifying agent used in rheumatoid disorders. It is an important part of the treatment plan for many people living with rheumatic disease, and for some individuals' hydroxychloroquine is one of the only effective treatments available for their condition.

Our community supports research to identify evidence-based treatments for COVID-19 including providing the necessary supply of hydroxychloroquine for clinical trials. In fact, the Arthritis Society is currently funding a new research initiative that takes advantage of the existing cohort of RA and SLE patients who are already on these drugs and under long-term observation by rheumatologists. The study will evaluate their response to COVID-19 exposure – an initiative that can proceed without adding strain to the drug supply since these patients are already receiving the medication. During this public health crisis, well-designed clinical studies like this are needed to determine the efficacy of hydroxychloroquine and other potential treatments for COVID-19.

The <u>Canadian Pharmacists Association's</u> recommendation is that "pharmacists must use their professional judgment to question the appropriateness of any prescriptions they receive for these medications that are outside the usual indications. This is important to protect patients from unnecessary adverse effects and to protect the supply of these medications for those patients who rely on them for treatment of medical conditions for which they are indicated." We appreciate that significant efforts have been made by various provincial pharmacy, physician and government bodies to support the evidence-informed decision making to address these challenges, but it is not enough. We continue to hear reports from patients who are having difficulties in accessing hydroxychloroquine in many provinces, most notably Quebec though we have also heard reports from Ontario, British Columbia and Saskatchewan.

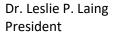
In Quebec, INESSS issued a directive that hydroxychloroquine access should be limited to people living with SLE, children with juvenile idiopathic arthritis (JIA) and pregnant women. While we understand these are difficult times and there are supply challenges, we are very concerned about the potential negative impact for affected patients such as those living with Rheumatoid Arthritis and Sjögren's Disease. Lupus Canada has conducted an online survey to determine the impact of the pandemic on Canadians living with lupus and 72% of respondents are worried about access to their medications. It is critical that action is taken to manage supply to ensure patients currently on this medication continue to receive it.

We hope that we can work with you, and our greater community, to ensure that people living with rheumatic diseases do not suffer unintended consequences of the COVID-19 pandemic.

Respectfully yours,

Lauris Proulx

Laurie Proulx 2nd Vice-President & person living with RA Canadian Arthritis Patient Alliance



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