ACSPA
CPD

Canadian Skin Patient Alliance
Alliance canadienne des patients en dermatologie

pour les patients, par les patients

Via email: plan.commentaires.inscription@inesss.qc.ca

August 11, 2021

National Institute of Excellence in Health and Social Services (INESSS)
Medicines Department
2535, boulevard Laurier, 5th floor
Quebec City (Quebec) G1V 4M3

Dear Sir/Madam:

Re: Projets des médicaments biologiques ou biosimilaires

On behalf of the Canadian Skin Patient Alliance (CSPA), thank you for the opportunity to provide input regarding two ongoing stakeholder consultations regarding biologic and biosimilar medications: (1) the appropriateness of adjusting or optimizing the dosage of biologic drugs for certain conditions, including dermatology, and (2) the appropriateness of a prior trial with a standard immunosuppressant. In the absence of specific details about the scope of the projects, please consider this general feedback on these topics.

Many people living with skin disorders, such as psoriasis, morphea, hidradenitis suppurativa (HS), also experience comorbidities that include rheumatic disease and inflammatory arthritis. As such, we support the feedback to these consultations provided by The Arthritis Society as it relates to skin patients also living with rheumatic disease and inflammatory arthritis.

The Canadian Skin Patient Alliance (CSPA) is a national non-profit organization dedicated to advocating, educating and supporting Canadians living with skin diseases, conditions and traumas. We also serve as an umbrella organization for our Affiliate Members – other Canadian patient groups that deal with specific skin disorders.

Skin disorders are often diminished, disregarded, and dismissed. They are more than "just a rash". Skin disorders often reflect imbalances in inflammatory and other systems, and can be caused by allergens, viruses, cancer, bacteria, fungi, genetics, wounds, hormones, and other disorders. Skin disorders can cause devastating impacts on those living with them, including infections, stigma, discrimination, comorbidities and mental health disorders. Diseases that cause itch, including atopic dermatitis and psoriasis, can adversely impact sleep and focus.

For many people living with severe dermatologic conditions such as psoriasis, pemphigus, atopic dermatitis, and hidradenitis suppurativa (HS), biologics have been life-changing. Many of the medicines available to treat moderate and severe skin disorders were initially developed for other purposes and have become part of the skin treatment toolbox (e.g., methotrexate developed for cancer, cyclosporine developed for preventing organ rejection, etc.). The development of more tailored treatment options for skin disorders – including biologics – provides patients with hope that the underlying pathology of their skin disorders will be addressed and risks of developing comorbidities will decrease, rather than only treating their symptoms.

Public drug plans must support flexible dosing and off-label use for dermatology conditions

It is common for dermatologists to tailor biologic treatment to the individual needs of the patient, which may include changing the dosage or frequency of biologic treatment from the standard amounts that are reimbursed by public plans. Public plans must support flexible dosing for some medications, such as adalimumab for HS. Patients may also require a different biologic for a short period of time – such as to address a flare. Some patients who experience a flare may be transitioned to a different biologic to address the flare, and then transitioned back to the biologic they were using before the flare as part of their treatment plan.

Access to off-label indications, such as the use of rituximab to treat pemphigus, is also critical. Without access to these medications, this disease, which causes blisters on the skin, the lining of the mouth, the thin covering of the penis, the vagina, and other mucous membranes, can be fatal. Inappropriate delay or denial of therapy for these disorders can cause harm to patients, and increased costs to the health system.

When Patient Support Programs are available from biologics or biosimilar manufacturers, these changes can be implemented swiftly to address the patient's best interests. It is essential that the government of Quebec incorporate flexibility into its public drug program so that dermatology patients are able to have their treatment plan tailored to their individual needs.

Public drug programs must recognize and address the impacts of copayments

Patient Support Programs also cover copayments for patients. We appreciate the steps that the Quebec government has taken to reduce the copayments of patients who are using biologic or biosimilar medications. However, for some people the minimum copayment under the government's plan is still too high and navigating public programs that may exist to offset these costs for those who qualify can be challenging.

In recent years, the CSPA has not heard from many patients seeking access to biologic or biosimilar medications – in large part, because of the PSPs that are set up to support patient access to these treatments - though this may still preclude access for some people. However, the CSPA hears regularly from patients who are seeking support to afford new topical medications, which can cost around $120 for more than a month's supply. When compared to the overall cost of biologics and biosimilars, the minimum copayments may not seem unreachable, but we hear from patients that costs around this level can prevent them from accessing safe, effective and appropriate prescription drugs to treat their skin disorders.

We are encouraged that INESSS is undertaking these projects and look forward to their results. In the meantime, we would be pleased to provide any additional information or address any questions that the review team may have. We also look forward to continued engagement as the review progresses in order to help ensure that the patient community voice is reflected. Please do not hesitate to reach out to us.

Sincerely,

Rachael Manion
Executive Director

This letter has also been endorsed by the following organizations:

CAPP ACPP
Canadian Association of Psoriasis Patients
Association canadienne des patients atteints de psoriasis

Canadian Psoriasis Network
Réseau canadien du psoriasis

Hidradenitis & Me
Support Group