

August 3, 2012

Hon. Fred Horne
208 Legislature Building
10800 97 Avenue
Edmonton, AB T5K 2B6

Dear Minister Horne,

On behalf of Arthritis Consumer Experts (“ACE”) and Alberta residents living with arthritis, I congratulate you on your reelection as MLA for Edmonton-Rutherford and your reappointment as the Minister of Health and Wellness.

Last year, ACE, one of Canada’s leading arthritis patient education and advocacy organizations, revealed in its JointHealth™ Report Card on Provincial Formulary Reimbursement Listings for Biologic Response Modifiers that Alberta has fallen in ranking for meeting basic standards for reimbursement access to publicly funded arthritis medications. Even though your province covers the same number of medications as Saskatchewan and Quebec, which should put Alberta in second place, it lost points for having overly restrictive criteria for certain inflammatory arthritis medications. This means that people who depend on financial assistance from Alberta’s drug benefit plan are routinely being denied a treatment their physicians say they require.

Of particular concern to us, is the overly restrictive criteria that must be met for patients to have coverage for tocilizumab (Actemra®) to treat rheumatoid arthritis, which is why I am writing today. I would like to invite you to meet with ACE so we can begin the process of improving the outcomes for those living with arthritis and to reduce the disease’s burden on individuals and on the healthcare system. To help you have a better understanding about the impact of arthritis and the importance of simplifying the criteria to obtain coverage for tocilizumab, I have included a backgrounder and a patient interview with this letter.

We will be publishing a new Report Card in September, which will be mailed out to our members and JointHealth™ subscribers, as well as to doctors' offices and other key stakeholders across Canada. Will you take steps to improve your province's ranking by making it easier for people who live with rheumatoid arthritis to access tocilizumab?

Thank you,

A handwritten signature in black ink, appearing to read "Cheryl Koehn". The signature is fluid and cursive, with the first name "Cheryl" written in a larger, more prominent script than the last name "Koehn".

Cheryl Koehn
President and Founder of Arthritis Consumer Experts
Person with rheumatoid arthritis
www.jointhehealth.org

cc: Steve Long, Executive Director, Pharmaceutical Funding and Guidance, Alberta Health and Wellness

BACKGROUND ON ARTHRITIS IN CANADA

Inflammatory arthritis (e.g. rheumatoid arthritis, ankylosing spondylitis and psoriatic arthritis) places a tremendous burden on individuals, their families, and Canadian society:

1. More than four million people live with osteoarthritis and approximately 600,000 Canadians live with an inflammatory form of arthritis. People living with rheumatoid arthritis make up 0.9% of the Canadian adult population, or about 272,000 individuals across Canada. That percentage is expected to increase to 1.3% over the next 30 years. Approximately 0.74% of the employed labour force, or 1 in 136 workers, are suffering from RA. Within a generation, this will increase to 1.5%, or 1 in 68 workers.
2. While we wait for cures for inflammatory arthritis, a combination of medications called disease modifying anti-rheumatic drugs (DMARDs) and biologic response modifiers is the gold standard in treatment for moderate to severe inflammatory arthritis.
3. Provincial drug formulary reimbursement access to biologic response modifiers is unequal across the country, which means some Canadians living with these severe forms of arthritis have fewer treatment options, or have to “jump through more hoops” to qualify for financial assistance to treat their disease, compared with other citizens with cancer, diabetes and HIV.
4. Each person living with inflammatory arthritis responds differently to each medication or combination of medications, and no single biologic response modifier is effective in everyone's disease. Because the criteria for reimbursement on formularies are different across Canada, some people lack the same choices as others. Every Canadian, in consultation with their arthritis specialist, deserves the same right to consider their personal risk factors and choose the best medication for their disease.
5. Early diagnosis and treatment of RA with cost effective DMARDs and, for those who do not respond to traditional DMARDs, public reimbursement access to biologic response modifiers, would result in cumulative savings of almost \$39 billion to Canadian society over the next 30 years, which is a reduction of over \$5 billion in direct costs and nearly \$34 billion in indirect costs.

References:

The Impact of Arthritis in Canada: Today and Over the Next 30 Years. Full report available at the Arthritis Alliance of Canada website: <http://www.arthritisalliance.ca/home/index.php>

Life with Arthritis in Canada: A personal and public health challenge. Full report available on the Public Health Agency of Canada website: <http://www.phac-aspc.gc.ca/cd-mc/arthritis-arthrite/lwaic-vaaac-10/index-eng.php>

PATIENT EXPERIENCE WITH TOCILIZUMAB (ACTEMRA®)

Arthritis Consumer Experts is an organization that represents people who live with arthritis, so we regularly connect with consumers to ensure we fully understand their needs. Here are the results of a conversation with someone who lives with rheumatoid arthritis to find out his experience with the biologic medication, tocilizumab:

How does RA affect your day-to-day life?

Without: Before taking Actemra, day-to-day life was challenging, but that was a long time ago. I was in the hospital when I went off Humira and was waiting for a new medication (after ten years, Humira stopped working, and I got pustules and psoriasis). My knee was seriously affected, swollen from knee to foot. The hospital thought it was an infection. I was there for 26 hours over the long weekend. Afterwards, I went to a specialist and he figured it out immediately. Then I went on Orencia, but it didn't work. I had to trial it for a year, then the doctor recommended I take Actemra. It took time for the approval process to work. I waited for Actemra more than three months. First the paperwork had to go to a doctor, then over to a nurse, then over to drug company, and then to Blue Cross. I was on methotrexate while I waited.

With: Actemra started working really quickly and right away I was able to play golf 3 times per week, ride my bike, and garden. Overdoing it might mean I am stiff in the morning, but it's the best medication I have tried in 33 years, so far. I am starting to develop fungus or psoriasis on my right hand, which may be the medication or the immune system slowing down.

Tell us about the effects taking tocilizumab (Actemra) has had on your day-to-day life?

I am able to do pretty much what I want to do. I still get a little fatigue and have problems sleeping, but I feel reasonably normal.

What other medications or treatments do you currently take, or have taken in the past, for RA?

Only one now, but for 33 years I took several types and these are the main ones:

- * I started on gold, which worked, but I gave up on it because it was working and I figured I didn't need it anymore. Later, I tried to go back on it, but it didn't work that time.
- * I had been on methotrexate for 20 years, but would feel nausea and yucky for a couple days later.
- * Humira. I was on a drug study for 5 years, but stayed on the medication for 10, until pustules formed on my hands, feet, arms, and legs, which came and went, but then got steadily worse until the doctor said to stop.
- * Orencia, which didn't work at all.

* Celebrex, which didn't do anything.

* Arava, which caused me to lose hair. Luckily, my hair came back when I stopped.

* Cortisone injections. At least ten on hands, elbow, and knee.

What do you expect from Actemra?

To live relatively pain free, no joint damage, with preferably little or no side effects.

Does Actemra meet any special needs that are not met by other medications or treatments?

It works.

Is Actemra easier to take than other medications?

No, because you have to plan your life around it. Since it's an infusion, I have to go to a clinic. Another drawback is you can't take it with you when you travel. I could take it in other parts of Canada, but not the States. It's actually cheaper to fly back home once a month to take the medication.

Does Actemra reduce your visits to the hospital?

I haven't been to the hospital since I started taking it.

Does Actemra reduce your days off work?

I'm retired, but it doesn't stop me from working on my acreage.

Are Actemra's side effects acceptable or intolerable?

Acceptable, so far. I feel dizzy and nausea after the infusion, but no worse than when taking methotrexate. I have psoriasis that started about six months ago. I'm taking cream for it that's not working. It gets worse a week after infusion and then starts to get better. It is nothing to worry about yet, but it could be connected to the medication.