

## Submission of Patient Evidence

Please send completed submission and/or any additional relevant information to the Ontario Public Drug Programs, Patient Evidence Submission, 5700 Yonge Street, 3<sup>rd</sup> Floor, Toronto ON M2M 4K5, fax to 416 327-8123 or email to [PatientSubmission.OPDP@ontario.ca](mailto:PatientSubmission.OPDP@ontario.ca).

### Section I - Author Information

Date (yyyy/mm/dd) 2014-12-29		Drug and Indication Tocilizumab (Actemra SC) / Rheumatoid Arthritis		
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### Section II - Conflict of Interest Declaration

The author and the patient group must declare any potential conflicts of interest that may influence or have the appearance of influencing the information submitted. Examples of conflicts of interest include, but are not limited to, financial support from the pharmaceutical industry (such as educational/research grants, honoraria, gifts, and salary), as well as affiliations or personal/commercial relationships with drug manufacturers or other interest groups.

Sources of grants and support received by CAPA in the last year include: AbbVie, Amgen Canada, Arthritis Alliance of Canada, The Arthritis Society, Canadian Rheumatology Association, Hoffman-LaRoche, Janssen, Novartis, Ontario Rheumatology Association, Pfizer Canada, Rx&D and UCB Pharma. Additionally, CAPA has also received support in the past from: Canadian Institutes for Health Research, Schering Canada, Scleroderma Society, and STA Communications.

### Section III - Impact of the Disease/Condition

What symptoms and problems do patients have as a result of the disease/condition? How does the condition affect day-to-day life? For example, are there activities that patients are not able to do as a result of the condition?

Rheumatoid Arthritis (RA) is a serious, disabling auto-immune disease that causes joint inflammation, pain and fatigue. It is a systemic disease and is accompanied by numerous co-morbidities, such as cardiovascular disease, Osteoporosis and lung disease. Patients are typically diagnosed when they are between the ages of 25 and 50 and it affects three times more women than men. There is currently no cure for RA – once a person develops RA, they live with it for the remainder of their life.

All daily activities of a person's life are affected who have RA. For those whose RA is not well controlled, day to day activities, such as participating in post-secondary education, becoming and staying employed, taking care of oneself, walking, cooking, grocery shopping, house work, being in a relationship, getting married, having and caring for children, and social activities can be extremely difficult and in some cases, impossible to undertake. It is also well documented that if RA is left undiagnosed, within a decade of its onset, 50% of people with RA are no longer able to work.

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**Treatment outcomes that matter most to patients**

What are the most important aspects of the condition that patients would like to see addressed by treatments?

In terms of treatment efficacy and side effects, what are patients getting from the existing treatments and what would patients like new treatments to do differently?

Are there other practical implications to be considered in determining the value of a treatment? For example, how do treatments impact patients' or caregivers' daily routine or lifestyle?

In addition to the drug cost, are there other financial implications to patients or caregivers (e.g. *traveling cost, time away from work, drug disposal issues, drug administration supplies*)?

People with RA simply want to live independent and productive lives. It is important to keep joints functioning and for people to live fulfilling lives (including having a family, job, etc). Getting inflammation under control to minimize joint damage and fatigue is important. Currently there is no way to predict who will respond to which medications which is why patients need a number of medication options in order to effectively manage the disease.

While side effects of existing treatments may vary, they can include: nausea and vomiting, extreme fatigue, decreased immune function (as current medications are immuno-suppressant in nature), injection reactions, and for biologics, auto-immunity is often developed to treatments after prolonged exposure to them. Intravenous medications pose additional difficulties as patients often have vein scarring stemming from years of intravenous treatments. The option of using self-injectable Actemra would ease the pain, bruising and general difficulties in obtaining an IV line.

Patients may also face scheduling issues for infusions and need to take time off work or find someone to deal with family commitments (e.g. babysitting young children). The ability to self-inject Actemra would address these issues by allowing for a faster mode of administration which could be easily incorporated into patients busy daily lives.

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**Information from patients who have used this drug**

*For patients who have used this drug as part of a clinical trial or from a manufacturer's compassionate supply or have purchased it through other means (private insurance or paid out of pocket).*

What positive and negative impacts does the drug have on the condition?

Which symptoms is the drug best or worst at treating (*advantages and disadvantages*)?

What difference does the drug make to patients' long-term health and wellbeing?

What are the side effects of the drug, which ones are patients prepared to put up with, and which ones do they find unacceptable?

How does the drug compared with other available treatments in terms of efficacy, side effects and other practical implications (*e.g. administration, time, costs*)?

Actemra is currently only reimbursed in its IV form which causes some burden on the patients. For example, the three people reached by CAPA reported that they had to travel to a clinic to receive their drug – as opposed to some IV biologics that are administered at home. The time involved in receiving the medication is significant and time consuming (approx. 1.5 hours plus travel time). One member, a 39 year old woman with RA, shared that it takes “a total of 2.5 hours of time away from work” every month. Another woman with RA mentioned that she did not like to receive Actemra at the clinic because it made her feel “like we are cattle, squashed in a clinic with uncomfortable chairs, with people who do not speak to each other, not even the nurses”. She added that having to come to a clinic every 4 weeks will prevent her from travelling for longer periods of time when her husband retires. She also shared that IV is painful, especially when the nurses “blows your vein, and you are left with massive bruises”. A common issue raised by patients is that many have significant vein scarring after years of intravenous therapy. This scarring makes it extremely difficult for nurses to insert the IV needle. One member reported that she endured approximately 8 IV attempts before the nurse inserted the needle correctly. It would be preferably that patients have the choice of self-injecting.

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**Confirmation of Authorship:**

I declare that I am the sole author of this submission and confirm that no other parties had input into the submission.

**Signature**

Date (yyyy/mm/dd)

2014-12-02