# CADTH

# CADTH COMMON DRUG REVIEW Patient Input

# Infliximab (Renflexis)

(Merck Canada Inc.)

Indication: rheumatoid arthritis (adult), ankylosing spondylitis (adult), adult Crohn's disease, pediatric Crohn's disease, fistulising Crohn's disease (adult), adult ulcerative colitis, pediatric ulcerative colitis, psoriatic arthritis, plaque psoriasis (adult)

CADTH received patient input for this review from:

**Arthritis Consumer Experts** 

The Arthritis Society (AS)

The Arthritis Society (PS)

The Arthritis Society (RA)

September 26, 2017

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# Patient Group Arthritis Consumer Experts

# 1. About Your Patient Group

Arthritis Consumer Experts (ACE) is a national patient-led organization that provides science-based information, education and support programs in both official languages to people with arthritis. ACE serves consumers living with all forms of arthritis by helping them take control of their disease and improve their quality of life.

Arthritis Consumer Experts is committed to the following organizational objectives:

- To inform, educate and power people with arthritis to help them take control of their disease and improve their quality of life;
- To provide evidence-based information in reader-friendly language to people with arthritis, the public, governments and media;
- To provide research decision-making training to people with arthritis to help them participate meaningfully in research organizations and in consultations with government.

ACE's membership and program subscribers include people with arthritis, their families, their caregivers, rheumatologists, and other health professionals, elected officials, and senior government bureaucrats.

Link to website: www.jointhealth.org

# 2. Information Gathering

The information was gathered through Arthritis Consumer Experts' (ACE) call for patient input issued on August 14, 2017 and day-to-day interactions with people living with rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis and plaque psoriasis, its work with clinical researchers in Canada, and through discussions with consumers and scientific members of the ACE Advisory Board. The data was gathered in Canada between the years 2016-2017.

# 3. Disease Experience

# How does the disease impact the patients' day-to-day life and quality of life?

The patients' day-to-day lives are greatly affected by their rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis or plaque psoriasis. Unlike most people who can take their physical/mobility abilities for granted, people living with RA, AS, PsA and plaque psoriasis must always consider the state of their disease and decide what they can (and cannot) cope with or achieve, how they can go about it, and how much help they may need.

- **Plaque psoriasis:** Patient A has been living with plaque psoriasis since he was 16-years-old. He experiences severe joint pains, especially in the hip, knee, ankle, elbow and spine. He finds it very difficult to bend his fingers. Occasionally, he will experience headaches.
- Plaque psoriasis: "I'm a patient suffering from rheumatoid arthritis and I take methotrexate injections, which caused plaque psoriasis to appear on my body, my scalp, and my ears", said Patient B. She added: "My plaque psoriasis created thick white scales of skin that I was scratching until they bled and those pieces were all over my floors, my car, and on all areas around me. I was seeing certain plaques get bigger and new ones appear elsewhere." Mentally, she was feeling frustrated, worried and tormented because her rheumatologist informed her that she would have to wait until her body was 99% covered with those infected wounds before her case was taken seriously.
- **Plaque psoriasis:** Patient C said that pain, fatigue, stiffness, and loss of function are the most prevalent and troublesome symptoms of the arthritis component of her PsA. She experiences skin sensitivity, redness, flaking, and pain for her plaque psoriasis. She describes her life with PsA and plaque psoriasis as follows: "My symptoms make daily activities harder and require pacing and prioritizing of activities. For example, even doing daily activities,

such as showering, putting on clothing, cooking meals or walking up stairs is painful, and requires more effort and time to do. Because completing daily activities take more time, I am more likely to stop doing social and creative activities due to limited time and energy and increased pain. I can ask for assistance but that is not always available. I stopped working due to pain and fatigue. When my psoriasis is visible and flaking occurs, I feel distressed and embarrassed. I am reluctant to do activities and sports like swimming that would expose my body, arms, and legs in public."

- Rheumatoid arthritis: The symptoms that Patient D experiences from her RA are swelling and inflammation in her joints. She also has a weakened immune system. This summer, she had ear and eye problems, in addition to getting lumps on her buttocks and neck.
- Rheumatoid arthritis: Patient E has been living with RA since July 2015. Because of the medication therapy she's on, her RA symptoms are controlled.
- **Psoriatic arthritis:** According to Patient F, PsA affects her every day. With medications, she can walk 45 minutes per day and do most of the household chores. She needs help with dishes, floor washing, vacuuming and shopping. She can shower but has trouble getting in and out of a bath tub. She has a raised toilet seat and a cushion to sit on. She cannot sit more than 30 minutes at a time because of ischial bursitis.
- Ankylosing spondylitis: Patient G has been living with AS since March 2013. He experiences stiffness and pain in his low back, hand, foot, and neck. He is unable to sit down on a chair for more than 30 minutes.

### How does the disease impact the caregivers' day-to-day life and quality of life?

Patient A, C, D, E and G did not provide input for this section.

According to Patient B, her husband is retired and available to help her out with house chores and drive her around when her back and knees are bad. The downside is that helping her with disease management has reduced the time her husband is available to do part-time consulting work, recreational activities, and socialize with friends.

Patient F needs help with many household chores, including dishes, floor washing, vacuuming and shopping. Her husband has to drive her to her specialist appointments in another city. She is limited to what she can do when she cares for her young grandchildren.

### Are there any aspects of the illness that are more important to control than others?

In general, patients are concerned about adverse effects over a prolonged period. All the patients agree that they will take the medication that is most effective and that poses the least chance of adverse effects. The patients we interviewed living with plaque psoriasis fear they may develop PsA and vice versa.

Patient D, E and G did not submit input for this section.

For Patient F, pain and stiffness are most important to control. She also wants to be as independent as possible and be able to walk and do her own self-care.

# 4. Experiences with Currently Available Treatments

Patient A did not provide comments for this section.

Patient B did not wish to disclose the name of the medication she is on but notes that there is a great improvement on her scalp and there is less itchiness around the scaly areas. Side effects of her medication include heartburn and dizziness. She is paying for the medication through private health insurance.

Patient C is using a combination of Enbrel and methotrexate. This combination has helped to reduce the number of joints with active inflammation, especially for peripheral joints. As a result of this combination therapy, her psoriasis is under control. Occasionally, she would experience gastrointestinal upset and mucus membrane irritation from using

methotrexate; however, she can take folic acid to reduce these adverse effects. She does not experience any side effect from using Enbrel.

Patient D is currently taking Xeljanz for her RA. She noticed that when she stops taking Xeljanz, the swelling in her ankles goes down. According to Patient D, her doctor tells her she suffers from venous insufficiency but she observed that when she stops the medication, her swelling goes down. "I get all sorts of infections that I never used to have before I started taking the medication," she explained. She is frustrated because she's not sure if her headaches and swelling is from her medication or from her disease.

Patient E has tried Humira, Orencia, and Actemra. Her doctors determined that Actemra was unsuitable due to her diverticulosis. Currently, she is on Rituxan and methotrexate injections. It was to her understanding that if she does not respond well to the biologics, she will not respond well to the biosimilar.

Patient F is using Remicade for her PsA. It has worked for the last 70 doses. She had no side effects with Remicade or Enbrel. Enbrel also worked very well on her psoriatic arthritis, better than Remicade, but it stopped working on her plaque psoriasis. She also takes Tylenol Arthritis around the clock because she has allergies to NSAIDs. She is not on any patient assistance or support program. Her doctor fills out the paperwork to get special authority to cover Remicade cost.

Patient G took anti-inflammatory drugs until July 2014. Along with his medication therapy, he would do yoga and swim. However, the medication did not help his AS. From July 2014, he took Humira, while continuing to swim and do yoga. He started with taking two shots per month and is currently taking one per month. He thinks that is he is back to 75% normal.

# 5. Improved Outcomes

Patients believe that the more options there are, the better. Having more options could mean better access to medication, having a backup plan in case the current therapy treatment stops working, and having an economically sound solution in case the current therapy treatment is no longer covered under an insurance plan. As well, they feel that the best treatment is one that has the fewest adverse effects.

Patient F is not sure how biosimilar infliximab would work but is concerned that biosimilar would not work the same.

# 6. Experience with Drug Under Review

None of the patients providing input have experience with using infliximab (Merck) to treat their RA, AS, PsA or plaque psoriasis.

# 7. Anything Else?

Arthritis Consumer Experts is providing this patient input submission based on patients who responded to our current and previous patient inputs for the treatment of RA, AS, PsA and plaque psoriasis. Some of the patients living with plaque psoriasis indicated to ACE they developed psoriatic arthritis as a result of their plaque psoriasis or vice versa.

# **Appendix 1: Patient Group Conflict of Interest Declaration**

To maintain the objectivity and credibility of the CADTH CDR and pCODR programs, all participants in the drug review processes must disclose any real, potential, or perceived conflicts of interest. This Patient Group Conflict of Interest Declaration is required for participation. Declarations made do not negate or preclude the use of the patient group input. CADTH may contact your group with further questions, as needed.

1. Did you receive help from outside your patient group to complete this submission? If yes, please detail the help and who provided it.

This submission was expressly written by the staff of Arthritis Consumer Experts, free from advice or influence from any outside individual, group or company.

2. Did you receive help from outside your patient group to collect or analyze data used in this submission? If yes, please detail the help and who provided it.

This submission was expressly written by the staff of Arthritis Consumer Experts, free from advice or influence from any outside individual, group or company.

3. List any companies or organizations that have provided your group with financial payment over the past two years AND who may have direct or indirect interest in the drug under review.

Over the past 12 months, ACE received grants-in-aid or research funding from: Amgen Canada, Arthritis Research Canada, AstraZeneca Canada, Canadian Biosimilars Forum, Canadian Institutes of Health Research, Celgene, Eli Lily Canada, Hoffman-La Roche Canada Ltd., Merck Canada, Novartis, Pfizer Canada, Sandoz Canada, Sanofi Canada, St. Paul's Hospital (Vancouver), UCB Canada, and the University of British Columbia. ACE also receives unsolicited donations from its community members (people with arthritis) across Canada.

I hereby certify that I have the authority to disclose all relevant information with respect to any matter involving this patient group with a company, organization, or entity that may place this patient group in a real, potential, or perceived conflict of interest situation.

- Names:Cheryl Koehn, President<br/>Anita Chan, Program CoordinatorPatient Group:Arthritis Consumer Experts
- Date: September 26, 2017

Patient Group The Arthritis Society (AS)

# 1. About Your Patient Group

The Arthritis Society has been setting lives in motion for over 65 years. Dedicated to a vision of living well while creating a future without arthritis, The Society is Canada's principal health charity providing education, programs and support to the over 4.6 million Canadians living with arthritis. Since its founding in 1948, The Society has been the largest non-government funder of arthritis research in Canada, investing more than \$190 million in projects that have led to breakthroughs in the diagnosis, treatment and care of people with arthritis. The Arthritis Society is accredited under Imagine Canada's Standards Program. The website www.arthritis.ca provides more detailed information.

# 2. Information Gathering

The Arthritis Society had 27 people living with ankylosing spondylitis respond to a social media request for information for this CADTH submission. The data was gathered from August 30 to September 18, 2017 in Canada. Of those 27 respondents, 12 had experience with infliximab.

### 3. Disease Experience

It is important to highlight that ankylosing spondylitis (AS) impacts people in all aspects of their lives. Living with AS is challenging. Symptoms that respondents indicated as having the greatest impact on their day to day life included pain, fatigue and stiffness. Symptoms had an impact on daily activities that people without AS take for granted like the ability to walk distances, sit for a period of time (in a class or movie), standing for any length of time, and doing chores around the house. People also indicated the disease had an impact on their emotional health and the ability to enjoy their hobbies. Here is what we heard from people living with AS:

- "I deal with a stiff, inflexible spine. Spasms, hunched posture, difficulties expanding my chest to breathe. Fatigue and sleep disruptions. Depression/anxiety, isolation, hopelessness."
- "I experience pain, stiffness, and exhaustion. I cannot stand for long, or walk more than 50 metres."
- "I had to stop running and scuba diving."
- "Challenging for me: lifting, twisting arms, walking distances, pulling or pushing things, sitting, and sleeping for long periods."
- I have in my neck, middle back, lower back, SI joints and hips, as well as the bottoms of my feet.
- "I have pain and inflammation in my sacroiliac joints, pain and inflammation in my thoracic spine, fatigue and uveitis."
- "I experience back pain, joint pain, fatigue, and bowel issues. I have difficulty putting dishes in dishwasher, washing floors, shopping, walking, personal hygiene and simply dressing."
- "I have pain and stiffness in the morning, gradually improving with activity, but worsening with sitting. This affects my ability to study at law school, sit in long classes, etc. AS currently affects my ankles, so that I cannot run."
- "Severe lower and thoracic back pain, peripheral arthritis, enthesitis. I can no longer sit upright for longer than 15-20 minutes. Bending is very difficult, even at slight angles. Walking and stretching no longer alleviates the back pain and, in fact, aggravates it on most days. Laying down is the only relief that is provided other than opioid medication. This disease has taken over my life."
- "Pain, stiffness, fatigue. I can no longer run. Nor can I do laundry, vacuuming, or much other housework. I cannot ride a bicycle. I often cannot attend plays, concerts, or movies."
- "Chronic pain and fatigue, morning stiffness, sacroiliitis. Exercise is difficult, cleaning my house is extremely hard, managing symptoms while in school causes issues with attendance and overall performance."

- "Pain and stiffness in SI joints, lower back, knees, and ribs. I have some stiffness when waking up in the morning and find some household chores a challenge like cleaning the shower, vacuuming, and mowing the lawn. Fatigue can be an issue when I get close to time for medication and when stress increases. Flare ups of my AS will increase my pain and stiffness and I sometimes need the use of a cane to help with mobility. Fatigue is extreme during a flare."
- "Symptoms: pain in shoulder joints, neck, elbows, jaw, hips, legs, back pain, extremely tired, pain in eyes, hurts to breathe, shortness of breath. As a result of the disease I have trouble walking, getting out of bed, bending over, which has caused me to be unable to do some things that I love. I am unable to be the Mother I want to be because of my limitations. I have had to give up gardening which was my all time favourite hobby."

# 4. Experiences with Currently Available Treatments

As each person is unique, it is inevitable that individuals will react differently to treatments. In some cases, the body may develop a resistance to medication requiring changes in the treatment plan. As a result, it is essential for patients to have access to an array of medications including: disease modifying anti-rheumatic drugs (DMARDs), biologics and methotrexate; in order to provide options to allow for individualized approaches to disease management.

There are adverse effects that can be present with the treatment of AS including fever, weight loss, tiredness, stomach pain, easy bruising or bleeding, feeling light-headed or short of breath, rapid heart rate, nausea, itching, loss of appetite, lowered ability to fight infection, allergic reactions etc. Those side effects also demonstrate the importance of having different treatment options available.

The cost of some medications used in the treatment of AS are high and require private insurance coverage through work or a family member, or coverage through a provincial program or a pharmaceutical company program. Without support options some individuals would not be able to access their medications. People living with AS have stated:

- "NSAIDs and other pain medications were so short acting that keeping on top of the pain was impossible, usually
  resulting in pill fatigue and constant reminders of illness. Enbrel was amazing for my AS, it gave me remission for
  almost 10 years."
- "I have been on several NSAIDs that did not help or hide the pain at all. I've been on Humira which worked amazing for 1.5 years of treatment until it stopped working and my inflammation went through the roof. I had a flare up in my ankles for a month and a half and was not able to walk. Then I got put on Cimzia and it's working well. I hop back and forth throughout the months adjusting. Sometimes I need to take it once a week and others times once every two weeks. It depends on how bad my pain and swelling are."
- "Different anti inflammatory medications, diets and moderate exercise. Nothing worked until Remicade. Side effects: two bad infections, one of the ankle and one of the knee needing hospitalisation for one week. Accessing: now retired due to the disease and on private health insurance. No difficulties in receiving treatments at all."
- "Methotrexate and DMARDs not effective. NSAIDs mild effects. Remicade very effective. I need to travel one hour to an infusion clinic. Cost - used up my \$100,000 drug plan lifetime maximum. No issues with infusions. Ongoing chronic sinusitis. Sinus surgery scheduled."
- "Humira failed plus caused horrible headaches. Cimzia never worked. Naproxen caused severe bruising as did Cimzia and Humira. Percocet works for about 2 hrs. Remicade seems to work for about 4 weeks with infusions now on Saturdays."
- "I have tried: Etanercept (5 months) no response, Adalimumab (6 months) no response, Infliximab (1 infusion) severe adverse reaction at 50% of infusion, did not continue on advice of rheumatologist, Golimumab (1 injection) adverse reaction, did not continue on advice of rheumatologist, Methotrexate (6 months) adverse reaction, discontinued. I am also allergic to NSAIDS so those are not an option. My situation is unique as I had to travel out of province to be diagnosed and for follow-up (received treatment at clinics in home province), but then had to stop because I became too ill for travel after the Remicade treatment. This adverse event was four years ago. Since then I have not been seen by a rheumatologist in my home province as the rheumatology clinic here will not see me. I have severe breathing issues and have been on high-dose prednisone since this event (20-50mg per day). No one

seems to think this is a big deal. So yes, I have had HUGE issues in accessing treatments, follow-ups and care in general."

- "\*NSAIDs on my fourth one. They help a little. \*Enbrel this biologic failed me. It gave me optic neuritis. \*Prednisone helps with the fatigue and keeps me able to work. Terrible side effects, including significant weight gain. \*Exercise is not well tolerated. \*Forearm crutches, without which I could not walk. \*Now taking Cosentyx, which helps."
- "The only medication that has worked in the past was Sulfasalazine. It made the pain manageable and was easy to take in pill form. My disease has progressed so it stopped working. I had an allergic reaction to Celebrex as it causes me to vomit. Remicade was fine but didn't improve my pain at all. I didn't mind getting injections it was just another appointment in my eyes. I did end up getting a lot of flus and colds while on it which made it difficult to keep up in school. I switched to Cimzia but got too anxious to do the self injections. It wasn't helping with pain so I switched back to Remicade and reacted negatively with vomiting. After the second reaction my rheumatologist decided I shouldn't have Remicade anymore so I am now waiting to try Cosentyx."
- "I have taken other medications for my AS. All have helped me manage my symptoms and allowed me to live a "normal" life. However, I have developed resistance/reactions to all medications I have taken so far within 6 months to 2 years. So far, I have been able to tolerate Remicade the longest. I have been taking it for over 3 years and have had my AS stable within a few months of beginning treatment. Other treatments were done by auto injections which was nice to be able to do when convenient. I get my Remicade in a clinic and the nurses are the best! Yes I may need to take time off work to get it, but the pros of this medication outweigh the convenience factor."

# 5. Improved Outcomes

AS patients have identified several outcomes that should be considered when evaluating new therapies including minimum side effects and alternative drug administration solutions. People living with AS told us:

- "Coverage for all Canadians. Insurance companies not allowed to force patients to take biosimilars. They are not bio equivalents and I feel it presents us with more risks given the reduced data on side effects and interactions."
- "Would like an inexpensive oral medication so that I can travel and not be tied to infusion schedule."
- "Cost effective treatment with less risk of cancer. Would be willing to take an inconvenient treatment with less cancer risk."
- "I don't like taking harsh pills, they all have made me sicker. I'd like to see alternative sources for healthier approach to keeping my inflammation down. My life would be completely different if there was a medication that actually worked and never gave me worse side effects. I could go back to work again!"
- "I would like to remove the fatigue factor. Improving the process of time it takes for a medication to work. It is such a waiting game of how long you have to try a medication to know if it will work and determining the frequency of administering it."."
- "I had a very bad experience with Remicade. I knew the risks before taking it, but what I didn't realize was how I would be abandoned by every doctor around me when everything went bad with the infusion. I have had consistent breathing issues since that infusion, yet no one will help me. I am not looking to assign blame, but expect someone to be there when there is a problem that a drug creates or exacerbates. The pain I live with is agonizing on some days. Would I trade that for another risk like I took with Remicade, knowing what I know now? I'm not sure. You can live with back pain, but you can't live without breathing. Certainly, if a drug could control my disease enough to minimize the pain, it would give me some quality of life, but someone has to ensure that patients receive adequate care during and after you cannot let people cope simply on their own with major side effects. There has to be a safety net."
- "I would like to see better options or more options for doctors who specialize in the disease or at least other medical options that can provide advise or things to try. More economical options would also be great, luckily I have been able to get my Humira covered under my drug plan but if not I would not be able to afford the treatment. I am starting to wonder as well what the long term effects are of the medications I am on which is why after talking to my GP I am trying Celebrex again as it is supposed to be easier on your body than Naproxen. If there were more

concrete evidence and/or studies around other options that have worked for some people that would be great i.e. diets, herbal supplements, etc."

- "Better pain control. Better treatment of fatigue. EARLIER DIAGNOSIS. It's ridiculous how long patients have to wait for a proper diagnosis -- mean time is 11 years for women. Trade-offs: well, I tolerate some pretty awful side effects now. A lot would depend on what the new therapy accomplished."
- "Improvement in chronic pain is my main goal as well as slow down the progression and damage my disease is causing. I would like to experience less immunosuppressive symptoms like getting sick all the time. It made it difficult to keep up with life."
- "This treatment is working for me. I wouldn't change anything about it! For me, I have a life that I can do most all things and that means everything. I've been on the bottom before and have been off work, not well, and greatly reduced mobility. Remicade gives me my freedom and sanity for which I am grateful."
- "My life would be less depressing if I found a treatment that works. It's really hard to wake up every day in pain, and to push through that pain to keep going. I am hoping to find a treatment that eventually works. The trade-offs I consider when choosing therapy are usually about the side effects, the possible side effects of biologics are very scary, but I am willing to over look them to try and live a normal life."

# 6. Experience with Drug Under Review

For some people infliximab is well tolerated and for others there are side effects that include tiredness, stomach pain, easy bruising or bleeding, feeling light-headed or short of breath, rapid heart rate, nausea, itching, loss of appetite, lowered ability to fight infection, allergic reactions, chronic sinusitis etc. Here is what people living with AS who experienced infliximab told us:

- "Still using. It seems to work. Infusion clinics can be difficult due to operating hours. Side effects were primarily with loading doses."
- "I was had a colonoscopy that proved an inflamed ilium. I was switched to the medication to help with Crohn's. The drug cleared up my gut inflammation and worked for my AS but unfortunately, I had a terrible reaction after the 5th infusion. Paradoxical pustular psoriasis defection my scalp, finger nails, and entire body. I was put on Stelara which treated the skin and gut but not my AS. I am presently back on Enbrel with some gut inflammation returning."
- "I have access through private insurance. Benefit is no more flare ups of pain. Disadvantage is the infections. Side effects are tiredness on the days following the injection and it is very manageable. It is easier than pills without bad stomach effects. I've been on Infliximab since 2012 and not stopping."
- "I have access through my employer insurance. The benefits are pretty much instant relief of severe pain. Was able to continue to work and maintain active lifestyle. My side effect is chronic sinusitis. I am still on infliximab after 15 years."
- "No benefits to Remicade, I did not complete first infusion. Had major adverse reaction where my body became very cold, developed cough, sore throat, raspy voice, chest pain. This was at 50% of infusion. Infusion was stopped for 10 minutes. It was then restarted. Symptoms became worse. Injection stopped again. Was given Benadryl injection. Symptoms abated. Infusion restarted. Symptoms came back worse. Infusion stopped. Given another Benadryl injection. No response. Given another Benadryl injection. No response. Given another hydrocortisone injection. Symptoms start to abate once again. Injection stopped and not restarted. I was kept at the outpatient clinic until stable, another 3-4 hours and sent home with no further follow-up. My symptoms remained for 4-6 weeks. I could barely walk. Chest pain, shortness of breath, cough was once again triggered 6 weeks later when I was given a Golimumab injection. These symptoms have remained ever since. The only thing that alleviates is prednisone. So no, I am not still taking Remicade."
- "Remicade was paid for by my provincial health coverage so there was no cost to me. I worked with a pharmacy called Bioscript to receive my medication and they were great and made sure my medication would be at the clinic on time for my infusion. Infusions were fine, I don't mind having an IV and it was just another appointment. Sometimes I would feel really tired and drained after and would just want to lay on the couch. I didn't get any pain

relief but MRI showed slowed disease progression. I ended up reacting with vomiting during infusions and doctors decided it wasn't for me anymore."

- "I get Remicade at an infusion clinic. I have private insurance, government health insurance, and manufacture compassionate supply. This stuff isn't cheap! I do have side effects during the infusion, so I take some other medications such as Benadryl. The other medications manage the side effects. Clinic infusion is very easy. Takes a couple hours in comparison to an auto-injector, but again, the results of Remicade on my AS are well worth it. I am currently still taking Remicade."
- "I have access to Inflectra through BC fair Pharmacare and my own insurance. It is administered at my rheumatologists office. The disadvantages are the fact it takes so long to administer and the risk of potential side effects. So far I have had no side effects; I am two doses in. I do not feel any different yet, but am hoping my symptoms get better after being longer on the drug. This therapy is not easier than others as I have to take a lot of time out of my day to get treatment, however, the plus point is that after I have had my loading doses, I will only need to go in for treatment every 8 weeks."
- "For years, AS dictated my life while I bounced from medication to medication. I would find one that worked for awhile and then would react and have to move to the next. Everyone is different in how they tolerate medications and what they have for symptoms. There are a few options out there to explore until you find one that works well for you. I am thankful to have found Remicade, it honestly has improved my life and well-being."

# 7. Biosimilar

Here are the concerns, thoughts and expectations held by patients that responded to our request for feedback:

- "I feel more clinical trials need to be performed and data collected on the safety of these new drugs. Having already had a terrible reaction to a medication, making switches cannot be taken lightly. Currently my insurance company is denying coverage for Enbrel despite my 10 year history of success with the medication. They will only cover the biosimilar. Given my terrifying reaction to alternative TNF blockers, you can imagine my hesitation make another switch. It has taken 1 year for my hair and fingernails to grow back and now an insurance company's overhead costs take precedence over my health?"
- "For now the insurance pays for Remicade. If they want me to switch I will have to since one injection for me costs \$5500 and I have one every 6 weeks."
- "I have concerns about drug effectiveness over time for biosimilar...quality control methods may not be as rigorous. Less expensive drug would be good for me financially."
- "I would think the biosimilar needs to be tried and proven before use on patients. If I were to switch it should be only done as a test and if unsuccessful would not be an alternative to me. Meaning I would have to return to innovator."
- "Better chance of not stressing about affording it. I am on Inflectra which I thought was a biosimilar. Seems to work great."
- "I would be more likely to take them if cheaper and equally effective."
- "None. I doubt that I will ever be able to take a biologic without it killing me. However, if I could, even a biosimilar would still be too expensive. My insurance will not pay for either and I do not have money to pay out of pocket."
- "Would still have the same concerns as with regular biologics and that is what is the long term effect. I am nervous
  that if I stay on Humira or another that it may shorten my lifespan due to the effects on my body/organs. If the risks
  were the same, I would likely opt for a more inexpensive biosimilar if they provided the same results as a biologic."
- "I wouldn't really have any problem with those. So far I haven't had to pay for any biologics as they were covered by the government or the company patient program."
- "I have a fully comprehensive drug plan, but at some point my insurance carrier may request me to use biosimilars for cost savings."

- "I volunteer with the CSA so I am familiar about biosimilars. No I am not concerned. Currently on Cimzia biologic and it is not working so well. I believe I will be switched at my next rheumatology appointment to a different medication."
- "I do not know enough about this to comment. If this refers to a "knock-off" medication that allows some treatment
  at a lower cost, then I would assume that it could work for some. It would depend on how it treated the AS... if
  partial treatment then likely not worth it. I have 3 financial supports to help with this medication, but it treats my AS
  in entirety so I make it work. If I had to choose to have one drug that I could afford that helped some vs. not taking
  any drug because I couldn't afford it, that's a different question."
- "I do have concerns about biosimilars. I do not know why my rheumatologist put me on Inflectra and not Remicade. I would have preferred to have Remicade as its been around longer."

# 1. Anything Else?

It is The Arthritis Society's position that:

- biosimilars have a role to play in the care and management of those living with inflammatory arthritis;
- biosimilars will offer more choice for those living with inflammatory arthritis and have the potential to lower health care costs and increase access to treatment;
- biosimilars, while similar to the innovator biologic, are not identical and cannot be considered generic versions of innovator biologics;
- consistent, universal, unique biosimilar naming practices should be implemented to facilitate tracking of what specific medication is received by a patient;
- a process for post-market surveillance must be put in place to track long-term safety and efficacy of biosimilars;
- all producers of biologic medications whether innovator or biosimilar should provide a robust program of patient and physician support; and
- until conclusive evidence determines that switching is safe, switching should not be permitted for patients who are stable on an existing course of biologic treatment except at the express discretion of the physician in consultation with their patient.

From a person living with AS:

"As mentioned before, I would like to see mandatory follow-up for patients taking these drugs. These drugs can do a lot of damage, but it seems like everyone is so busy reassuring patients about their safety that they forget about the 1 or 2 people where things go terribly, terribly wrong. No doubt many people have benefited from these treatments, but there has to also be some accountability."

# **Appendix 1: Patient Group Conflict of Interest Declaration**

To maintain the objectivity and credibility of the CADTH CDR and pCODR programs, all participants in the drug review processes must disclose any real, potential, or perceived conflicts of interest. This Patient Group Conflict of Interest Declaration is required for participation. Declarations made do not negate or preclude the use of the patient group input. CADTH may contact your group with further questions, as needed.

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No

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Abbvie				Х	
Celgene				Х	
Eli Lilly				Х	
GSK		Х			
IMC	Х				
Janssen				Х	
Merck				Х	
Novartis				Х	
Pfizer				Х	
Roche			Х		
Sandoz	Х				
Sanofi			Х		
UCB				Х	

I hereby certify that I have the authority to disclose all relevant information with respect to any matter involving this patient group with a company, organization, or entity that may place this patient group in a real, potential, or perceived conflict of interest situation.

Name:Deanna BowlbyPosition:Senior Manager, Education ProgramsPatient Group:The Arthritis SocietyDate:September 26, 2017

# Patient Group The Arthritis Society (PS)

# 1. About Your Patient Group

The Arthritis Society has been setting lives in motion for over 65 years. Dedicated to a vision of living well while creating a future without arthritis, The Society is Canada's principal health charity providing education, programs and support to the over 4.6 million Canadians living with arthritis. Since its founding in 1948, The Society has been the largest non-government funder of arthritis research in Canada, investing more than \$190 million in projects that have led to breakthroughs in the diagnosis, treatment and care of people with arthritis. The Arthritis Society is accredited under Imagine Canada's Standards Program. The website www.arthritis.ca provides more detailed information.

# 2. Information Gathering

The Arthritis Society had 21 people living with psoriatic arthritis respond to a social media request for information for this CADTH submission. The data was gathered from August 30 to September 20, 2017 in Canada. Of the 21 respondents, eight had experience with the infliximab.

# 3. Disease Experience

It is important to highlight that psoriatic arthritis (PsA) impacts people in all aspects of their lives. Living with PsA is challenging. Symptoms that respondents indicated as having the greatest impact on their day to day life included significant pain, fatigue, stiffness and limited range of motion in the joints. All symptoms had an impact on daily activities that people without PsA take for granted like the ability to walk distances, hold a phone, stand for any length of time. People also indicated the skin sensitivity, redness, flaking, and pain from plaque psoriasis had considerable impact. Here is what we heard from PsA patients:

- "Knee and heel pain. Swollen and painful fingers and toes. On bad days I cannot walk because of pain and cracked skin on my feet."
- "Severe fatigue affected my ability to keep my job. My hips and legs fail, causing falls. I am on permanent disability."
- "I have difficulty walking and going down steps. I am tired a lot of the time. Joints in my feet are tender and swollen some days that makes it difficult to wear some types of shoes. Shoes for a professional office setting are a thing of the past. My skin is dry and flakey on elbows, knuckles, around ears. Using a public washroom can be a challenge. I will often plan shorter activities with rest periods between. Any social activities after 10 pm are out of the question. I am asleep by then. I loved to walk, especially outside, and can't anymore."
- "Pain, swelling, and fatigue. I cannot walk long distances, stand for too long or sit for too long. I have trouble playing my piano, writing lengthy notes or holding my phone. I cannot lift anything beyond 25lbs. I hurt all the time."
- "Chronic pain related to spinal involvement (stenosis). Costocondritis. Swelling of hands and feet. Fatigue. I cannot do any high impact sports or activities. Limited mobility."
- "Joint pain, tissue swelling around the joints, hot. I have difficulty with walking, lifting, housecleaning, cooking, gardening, shoveling snow, and standing for long periods of time."
- "Decreased ability to stand/walk for prolonged periods of time. Severe fatigue."
- "I am no longer able to work due to pain and joint deterioration. I have had several replacements."
- "I cannot walk for more than a block, trouble bending to pick things up, grasping and maintaining a hold onto objects."

# 4. Experiences With Currently Available Treatments

As each person is unique, it is inevitable that individuals will react differently to treatments. In some cases, the body may develop a resistance to medication requiring changes in the treatment plan. As a result, it is essential for patients to have access to an array of medications including: disease modifying anti-rheumatic drugs (DMARDs), biologics and methotrexate; in order to provide options to allow for individualized approaches to disease management. This is what we heard from people living with PsA:

- "Methotrexate and DMARDs not effective. NSAIDS mildly effects. Remicade very effective. I travel 1hour to infusion clinic. Cost - used up my \$100,000 drug plan lifetime maximum. No issues with infusions. Ongoing chronic sinusitis. Sinus surgery scheduled."
- "Remicade infusions for 10 years made it so I never knew I was disabled. Worked normally and lived as if I never had a disability. Then it stopped working and turned my life upside down. Tried Simponi and Stelara, now Humira and still permanently disabled."
- "Humira failed plus caused horrible headaches. Cimzia never worked. Naproxen caused severe bruising as did Cimzia and Humira. Percocet works for about 2 hrs. Remicade seems to work for about 4 weeks at a time, with infusions now on Saturdays."
- "NSAIDS have helped for short periods of time but then caused stomach issues resulting in more medication. Prednisone was used in the beginning to help get disease under control until I was able to start Methotrexate. I had to drive an hour and a half to get to a rheumatologist. I was lucky to have benefits in the beginning but when they were lost and I was waiting for approval for ODSP my medicine was very expensive especially since we were unemployed. Methotrexate worked well with pain medication and trigger point injections, I also have fibromyalgia. Recently been in more pain so Remicade was added. I had good results in the beginning and my infusion clinic was only 15 minutes away. Unfortunately after 4 doses it stopped working and now I'm awaiting approval from Trillium for funding Enbrel. I have been blessed that most of my disease related costs have been covered by ODSP."
- "NSAIDS alone did nothing for me. Cannot have sulfa based drugs. Methotrexate after 11 years gives me a foggy brain. Remicade was my wonder drug with improvement noted within two weeks, however I did need time off work every six weeks."
- "Sulfasalazine: worked for about two years, giving good relief until I developed lupus. Ice: helped reduce inflammation and burning sensation. Icy GeI: a cooling gel with menthol gave the fastest relief and penetrates deeply. Mobicox: minimizes the pain level. Methotrexate (used for both PSA and Lupus): minimizes the inflammation, but causes exhaustion for two full days. Does not totally take joint pain away. Access to treatment: I have a wonderful team of doctors (family doctor, rheumatologist, dermatologist and neurologist who work together. Wish that there was more coverage for fees for therapies and Aquasize classes as they are expensive and not all private insurance policies give enough coverage. The biggest challenge was an employer who refused to adjust my physical duties at my job despite my disability. They gave me such a difficult time and made work environment so miserable, to make me quit since firing for health challenges is illegal. I finally quit and opened a home based business in the same field."
- "Methotrexate (pills) resulted in upset stomach and vomiting rendering it useless. Methotrexate injections: No efficient enough they added prednisone. Ended Methotrexate due to constant diarrhea. Enbrel, stopped working after a year. Cimzia, stopped after a year. Currently on Cosentyx 300mg."

# 5. Improved Outcomes

PsA patients have identified several outcomes that should be considered when evaluating new therapies including drug administration (pills vs infusion or self-injections), impact on fatigue and cost. People living with PsA told us:

- "Ability to be able to work AND maintain my house AND leisure activities. I can live with a day knocked down in bed if the rest of the month I am not fatigued all the time."
- "Would like an inexpensive oral medication so that I can travel and not be tied to infusion schedule."

- "I would like to remove the fatigue factor. Improving the process of time it takes for a medication to work. It is such a waiting game of how long you have to try a medication to know if it will work and determining the frequency of administering it."
- "I would love to have a non-injectable option that would keep the disease from progressing and not put any
  additional stress on my liver or other organs. If I could feel less exhaustion and less nausea on a different treatment
  it would positively impact my personal and professional life. I'm not sure about trade-offs. I would have to consider
  the options when they were presented and discuss what would work for my personal and professional wellbeing."
- "Love to see a treatment that is covered for most, pill form and little side effects. I would love to be able to work in my field and not be in constant pain. I would love to even take a medication and not worry about the damage it's doing to my liver or if it will cause cancer."
- "I do consider side affects of medication. Daily life would be better if medications didn't "wear off" over time. medications that do work seem to stop working after a period of time. Also the cost is prohibitive. I am lucky to have insurance but the approvals take a long time."

# 6. Experience With Drug Under Review

For some people infliximab is well tolerated and for others there are side effects that include tiredness, stomach pain, injection site reactions, feeling light-headed or short of breath, rapid heart rate, nausea, itching, loss of appetite, lowered ability to fight infection, allergic reactions, chronic sinusitis etc. Sometime people who have used biologics for a longer period of time have difficulty finding a suitable vein for injection. Here is what PsA patients who experienced the drug in review told us:

- "My employer insurance covered infliximab. The benefit of infliximab was pretty much instant relief of severe pain. I
  was able to continue to work and maintain active lifestyle. My side effect was chronic sinusitis. I am still on infliximab
  after 15 years."
- "Remicade was the most successful drug I ever had. Initially paid for by my employer, then private blue cross, compassion in between, and NHIB. The only disadvantage was taking time off work to get infusion. I only had one side effect or reaction to infusion, which was a complete body flush where I overheated. It was only once for a few minutes while getting infusion. I found it an easy process where a few hours every six weeks gave you a normal life. I no longer take Remicade as my original rheumatologist passed away and my new rheumatologist said it's didn't seem to be working enough for me and instead of increase, switched me out. I am now three medications later and still little satisfaction of medication results."
- "My rheumatologist set me up with a clinic in his office and took care of applying for compassionate care to cover the costs. I had no side effects. They had trouble finding my vein sometimes but I prefer that to injecting myself. I am no longer receiving Remicade due to it stopped working after 4 doses."
- "Results were almost instant. Without it I would not been able to work as long as I did. One side effect I found was day of treatment and the day after I am tired and freezing cold but manageable. I still take Remicade."
- "Private insurance covered costs. I had a severe allergic reaction to it (severe inflammation of skin and eyeballs) and discontinued after two attempts at use."
- "Private insurance covered the costs for me. No side effects. It helped relieve stiffness and also helped relieve psoriasis. Easy to use via IV. Stopped taking last year, thought it stopped working but turned out it was working better than I thought, new pain was brought on by damaged nerves."

# 7. Biosimilar

Here are the concerns and expectations held by patients:

- "My main concern is that they will be forced on patients by insurers regardless of efficiency and patient response."
- "Concerns about drug effectiveness over time for biosimilar...quality control methods may not be as rigorous. Less expensive drug would be good for me financially."

- "I would think for the biosimilar it would be responsible to be tried and proven before use on patients. If I were to switch it should be only done as a test and if unsuccessful would not be an alternative to me. Meaning I would have to return to innovator."
- "Better chance of not stressing about affording it. I am on Inflectra which I thought was a biosimilar. Seems to work great."
- "There would be no impact for me as the majority of my drug costs are covered by my employer."
- "I have no concerns in this area. Less expensive would be good. I pay \$0 right now each month for Enbrel but I know these high cost drugs are impacting overall insurance premiums."
- "Similarly effective I don't know about that, I would want the drug to work exactly as the Remicade does. I'm a chocoholic and I wouldn't eat something that said it tasted similar to chocolate."
- "I have a fully comprehensive drug plan, but at some point my insurance carrier may request me to use biosimilars for cost savings."

# 8. Anything Else?

It is The Arthritis Society's position that:

- biosimilars have a role to play in the care and management of those living with inflammatory arthritis;
- biosimilars will offer more choice for those living with inflammatory arthritis and have the potential to lower health care costs and increase access to treatment;
- biosimilars, while similar to the innovator biologic, are not identical and cannot be considered generic versions of innovator biologics;
- consistent, universal, unique biosimilar naming practices should be implemented to facilitate tracking of what specific medication is received by a patient;
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- all producers of biologic medications whether innovator or biosimilar should provide a robust program of patient and physician support; and
- until conclusive evidence determines that switching is safe, switching should not be permitted for patients who are stable on an existing course of biologic treatment except at the express discretion of the physician in consultation with their patient.

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GSK		Х		
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Name:Deanna BowlbyPosition:Senior Manager, Education ProgramsPatient Group:The Arthritis SocietyDate:September 26, 2017

# Patient Group The Arthritis Society (RA)

# 1. About Your Patient Group

The Arthritis Society has been setting lives in motion for over 65 years. Dedicated to a vision of living well while creating a future without arthritis, The Society is Canada's principal health charity providing education, programs and support to the over 4.6 million Canadians living with arthritis. Since its founding in 1948, The Society has been the largest non-government funder of arthritis research in Canada, investing more than \$190 million in projects that have led to breakthroughs in the diagnosis, treatment and care of people with arthritis. The Arthritis Society is accredited under Imagine Canada's Standards Program. The website www.arthritis.ca provides more detailed information.

# 2. Information Gathering

The Arthritis Society had 19 people living with rheumatoid arthritis respond to a social media request for information for this CADTH submission. The data were gathered from August 30 to September 20, 2017 in Canada. Of those 19 respondents, four had experience with the drug in review.

# 3. Disease Experience

It is important to highlight that RA impacts people in all aspects of their lives. People living with RA experience a variety of symptoms that can greatly affect their daily lives, from swollen and stiff hands, fingers, feet and toes, to feeling pain in joints of the body, experiencing morning stiffness and swelling which makes getting out of bed and dressing a real challenge. Living with ongoing disease related fatigue can severely impact the ability to enjoy a well-rounded life. People living with RA told us:

- "Joint pain, fatigue, mobility challenges; I have given up some activities that I used to love (e.g. softball) and daily chores can be difficult at times."
- "Flare-ups, chronic pain, swelling, fatigue, and irritability. I've never been able to participate in high impact sports or activity. During activities I get tired a lot easier and have to take more breaks."
- "Fatigue and chronic pain hold me back. My lowered immune system makes me hyper-aware and I avoid social situations."
- "I am less active, more tired. I am unable to work a full time job in my trained career, as my husband travels and dealing with the home, family and job is more than I can handle. I feel as though my life has been snatched away."
- "Energy levels and pain dictate my daily living. I often have difficulty with household chores (washing/scrubbing/vacuuming), occasionally with cooking; and I have to tailor my recreational activities around heat and joint soreness. I have had to give up yoga (cannot weight bear on hands/wrists)."
- "My symptoms include inflammation of foot and knees, fatigue and difficulty walking."
- "Fatigue, pain, stiffness and swelling. It is hard to walk and work."
- "Swelling, pain, stiffness limits my activity, limits my ability to exercise."

# 4. Experiences With Currently Available Treatments

As each person is distinct, it is inevitable that individuals will react differently to treatments. In some cases, the body may develop a resistance to medication. As a result, it is essential for patients to have access to an array of medications including: disease modifying anti-rheumatic drugs (DMARDs), biologics and methotrexate; in order to provide options to allow for individualized approaches to disease management. This is what we heard from people living with RA:

• "I've been on many medications, such as Remicade, Methotrexate, Enbrel, Actemra, Orencia, naproxen, prednisone, sulfasalazine, Humira, just to name a few. Some medications come with side effects, such as methotrexate with

nausea, and prednisone with irritability. Some injections sting going in. Most of the infusions I've had, I've never had an issue with side effects. Having to travel for appointments can be a lot. While I was getting infusions at Sick Kids Hospital, that was normally an all day thing. But now that I'm getting them at an infusion clinic it only takes a couple of hours. I find that most of the medications work for me for a while, but eventually stop working."

- "Sulfasalazine, Plaquenil, Methotrexate ...not great Methotrexate and Remicade, effective until I got a serious infection. Methotrexate and Enbrel, currently working well enough."
- "Methotrexate is what I am currently using. It is less expensive, but leaves me fatigued and nauseated the first few days after injection. Also currently taking Plaquenil and it leaves me tired. Both seem to keep my RA from getting worse, but feeling unwell doesn't make me feel better."
- "I've had varying success with a wide range of drugs: Plaquenil, Sulphasalazine, Leflunomide (these did not work well on my RA symptoms); methotrexate, Humira (with these RA was well-controlled but side effects became too difficult to manage); Xeljanz (RA is well-controlled and side effects are minimal; I think I've been taking this for 2 years now, almost 3); there may be others that I am forgetting. The cost of Xeljanz is very expensive and I initially had issues getting coverage but now it is covered by my Blue Cross. I have difficulty swallowing large pills but so far this has not been an issue with RA meds. Eventually I became unable to self-inject methotrexate and had to switch to the pill form; self-injection is not an option anymore so this limits the meds that I can try."
- "First was Plaquenil. Now have eye damage. As a result now only use naproxen, ibuprofen, sometimes Celebrex and muscle relaxants (to help with fibromyalgia). Very little benefit found through meds. May ease some days but not eliminate. Movement seems to give best relief but not always an option during flare ups."
- "Currently in remission due to pregnancy/post-partum period (full year of remission + going on 5 months postpartum). Pre-pregnancy I was on Plaquenil 400 mg daily and continue to be on that. Discontinued Methotrexate (subq 2 times weekly 0.5 CC). In combination these helped to slow the progression of my diseases and eased some pain but side effects (extreme nausea and fatigue) were debilitating. Treated with maximum dose of Gravol almost daily; tried Ondansetron, did not lessen my nausea. Naproxen maximum dose and Tylenol maximum dose were taken pre-pregnancy when pain/inflammation were high; took those between 3-7 times per week. Currently taking 500 mg Tylenol at max dose to manage pain in order to continue breastfeeding for as long as possible. Would like to stay off of Methotrexate for as long as possible intense side effects of nausea and fatigue were debilitating and needle fatigue was also a problem."
- "Gold, Plaquenil, Arava ,Methotrexate-not helpful. Remicade helpful but gained 80 pounds. Humira worked but shut down immune system completely. Actemra so far so good."
- "Hydroxychloroquine, Methotrexate, previously Naproxen. Hydroxychloroquine works and caused no side effects, but needed addition of Methotrexate. Methotrexate works and helped get me back into remission, but causes some nausea for a few days. Then I tried reducing the dose of Methotrexate but symptoms turned, so I do need the 25 mg/week of MTX. No problem accessing treatment until the recent Canada-wide shortage of Methotrexate injectable with preservative 2 ml vials."
- "I am on Plaquenil it works ok however I seem to have a lot of side effects when I take other medications for other ailments (fibromyalgia, BED) mouth ulcers, weight gain, painful underarm lumps, nose bleeds. Not enough support for treatment exercise programs, education, work place programs."

# 5. Improved Outcomes

RA patients have identified several outcomes that should be considered when evaluating new therapies including reduced side effects, costs and alternative drug administration solutions. People living with RA told us:

• "I always wonder what I would do if I lost my health insurance; the drugs are very expensive so I would not be able to afford them otherwise. Xeljanz seems to be working well for now. Methotrexate worked great for several years (I was willing to live with the nausea every week) but then it began to affect my pancreas and I had to stop it. I'm starting to worry that when/if Xeljanz stops working, what is left for me to try? Will I be able to keep working? Fatigue certainly seems to be not only a symptom of RA but a side effect from some drugs. This above all others makes it difficult to work because you are not really "sick" so you can't stay home but you are also not well enough to perform at your

best. I've long given up on paying attention to the many potential and serious side effects listed with each drug. For example, I will take a chance on developing cancer if the drug doesn't make me feel unwell on a daily basis."

- "Be able to be my old self and get my strength back. Being able to go back to work and not feel tired all time and in so much pain from damages done by RA."
- "Less side effects. I am relatively young and hopefully have many more years to consider when evaluating longer term side effects. Would definitely trade-off less severe side effects for a better quality of life today."
- "Would like to see more infusions, that also give you the option to get infusions done at home or injection rather than infusion completely."
- "Would like to see a regime that improves my quality of life by reducing joint pain and inflammation with fewer side effects like intense nausea and fatigue. Susceptibility to infection is also a key suppressing immune function can be a problem as I work with high needs students and am a mother and am therefore exposed to bacterial and viral illnesses regularly. Also interested in treatments with better long term potential in terms of efficacy for duration of use (longer than 5 years for a drug before needing to switch) as well as fewer long term side effects such as damage to liver and kidneys."
- "Effective treatment with minimal side effects, and minimal worries about drug supply and cost."
- "I am fairly controlled with Actemra. Weight gain biggest concern. Migraines with methotrexate."
- "I want to be able to be more active for me and my child. I want to feel better. I would try just about anything at this point to make this happen."

# 6. Experience With Drug Under Review

Here is what RA patients who experienced infliximab told us:

- "Cost wasn't an issue as the government covered it. A huge disadvantage was that I had to travel to Sick Kids Hospital to get it. The time it takes to travel, see my doctors before I get the medication, and do blood work. It normally made the infusion an all day event. I had no side effects. An advantage would be that the medication worked for a bit. It wasn't easier to take because of the length of time it took up. I am not on it anymore, as it stopped working for me."
- "Took Remicade when it first came on market. First drug that worked. Completely improved my life but I kept gaining weight. Stopped when Humira became available. Lost gained weight. Also no weight gain with Actemra."
- "I had to go to a clinic for 3 hours every six weeks for an infusion. I had to use Benadryl after and I had headaches, but it was effective until I got a serious infection. But I prefer the Enbrel I am on now, managed at home, by me, quick and mostly painless, no real side effects that I can't manage."

# 7. Biosimilars

Here are the concerns and expectations expressed by patients:

- "I probably still wouldn't be able to afford it."
- "I feel that taking biologics is already somewhat risky but what choice do I have. If I don't take them, then the RA gets worse. I feel similarly about any new drug. The cost doesn't usually come into play right now because I have health insurance. Without the insurance, cost would definitely be a factor."
- "Minimal expectations. Have become discouraged with the arthritis treatments out there. Would hope more drugs will lead to more with less side effects, and more effective in general."
- "No, I wouldn't and cost wouldn't be an issue since my medications are covered."
- "If less expensive, there is better chance of coverage through my benefits provider. Having access to one or more biosimilars also means better potential for long term treatment if there are more options of drugs to try."
- "My insurance pays for my treatment. Cost of drug not bad for me but I'm sure other people would like lower cost."
- "Concern about effectiveness and safety. Lower cost is always welcome as long as it's effective and safe."

- "If it's cheaper and works as well as Embrel, I'd be happy with it."
- "No impact I have a good drug plan"

# 8. Anything Else?

It is The Arthritis Society's position that:

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