



Patient Input Template

Name of the Drug and Indication	Tofacitinib for Juvenile Idiopathic Arthritis
Name of the Patient Group	Arthritis Society Canada, Canadian Arthritis Patient Alliance, Canadian Spondyloarthritis Association, Cassie + Friends, Psoriasis Canada
Author of the Submission	Margretha Gonsalvez with input from Laurie Proulx, Brenda Delodder, Jennifer Wilson, and Antonella Scali

1. About Your Patient Group

Arthritis Society Canada is dedicated to extinguishing arthritis. We represent the six million Canadians living with arthritis, and the millions more who are impacted or at risk. Fueled by the trust and support of our donors and volunteers, Arthritis Society Canada is fighting the fire of arthritis with research, advocacy, innovation, information and support. We are Canada's largest charitable funder of cutting-edge arthritis research. We will not give up our efforts until everyone is free of the scorching pain of arthritis. Arthritis Society Canada is accredited under Imagine Canada's Standards Program. For more information, visit www.arthritis.ca.

The Canadian Arthritis Patient Alliance (CAPA) mission is to support people living with arthritis—and those who support them—so they can thrive. At CAPA, we believe that people living with arthritis are the true experts in navigating life with their condition. Their voices are essential in shaping better policies, advancing research, improving clinical care, and educating others. We're here to support people with arthritis to live their best lives—free from unnecessary barriers at work, in health care, and in their personal lives. Through patient-informed resources, policy papers, and innovative projects, we aim to make life better for the arthritis community. We share updates, resources, and advocacy work through our website, monthly newsletters, and social media platforms like Facebook, BlueSky, Twitter, YouTube, LinkedIn, and Instagram. Plus, all our resources are reviewed by our Medical Advisory Committee to ensure they're backed by the latest scientific evidence.

The Canadian Spondyloarthritis Association is the only patient-led organization in Canada solely dedicated to supporting people living with spondyloarthritis (SpA). CSA is the voice for Canadians living with SpA, which includes Axial Spondyloarthritis and Peripheral Spondyloarthritis, Ankylosing Spondylitis (AS), Psoriatic Arthritis (PsA), Enteropathic Arthritis and related conditions. CSA develops and delivers innovative programs to educate, support, advocate and raise awareness for patients, caregivers, and healthcare professionals. www.sparthritis.ca

Cassie + Friends is the only Canadian charity 100% dedicated to children and families affected by juvenile arthritis (JA) and other childhood rheumatic diseases. Founded in 2007 by parents determined to fill critical care gaps and accelerate progress toward a cure, we've grown into a national and international leader advancing solutions across the pediatric rheumatology landscape. Working closely with patients, families, researchers, and every pediatric rheumatology team in Canada, our programs tackle urgent challenges like mental health, treatment access, injection anxiety, and shared decision-making. We've raised over \$4.5 million, funded \$1.8 million in research, and invested \$500,000 in pediatric rheumatology

mental health. Today, we're leading efforts to centre patient and parent voices in research through initiatives like PAVE and UCAN, with whom we co-hosted a 2024 global Family Day and Scientific Conference. Through our pillars—Connection, Action, Research, Education, and Support—we're creating a future where no child waits for the treatment or care they need. Learn more at cassieandfriends.ca.

Psoriasis Canada is Canada's trusted experts on psoriatic disease, offering community, resources, and hope for a better future for those affected and those who care for them. Our vision is that people affected by psoriatic disease in Canada live fully while we strive together towards a cure. Psoriasis Canada is a recent consolidation of the Canadian Psoriasis Network and the Canadian Association of Psoriasis Patients.

2. Information Gathering

Information gathered for this submission was obtained from contact with several JIA families and findings from the [2022 Make Rheum for Youth Survey](#), an international survey of 56 participants (50% from Canada) launched by the Canadian Arthritis Patient Alliance and Take a Pain Check Foundation to better understand the needs of youth and young adults (ages 12-30) with rheumatic disease. Two of the co-authors have lived experience of JIA and helped to shape the submission.

3. Disease Experience

Juvenile idiopathic arthritis (JIA) affects about 3 in 1,000 children, which makes it more common than most chronic childhood diseases. The term idiopathic means "unknown." JIA can affect children at any age and is the most common type of arthritis for people under the age of 17. JIA causes persistent joint pain, swelling, and stiffness. Some children may experience symptoms for only a few months, while others may experience symptoms for the rest of their lives.

Six major types of JIA are under consideration for this review. Extended oligoarthritis affects four or fewer joints and is often accompanied by eye disease such as uveitis. Children with polyarthritis have five or more joints involved and may affect the joints of the jaw and neck. Those who test positive for rheumatoid factor (RF+) may experience low-grade fevers, rheumatoid nodules, anemia, and an overall feeling of being unwell. Systemic JIA can affect not only a child's joints and skin, but also internal organs. It is often accompanied by a high spiking fever that lasts at least 2 weeks and a skin rash. Juvenile psoriatic arthritis usually occurs in combination with psoriasis. Psoriasis may begin many years before any joint systems become apparent. Those with enthesitis-related JIA may have tenderness where the bone meets a tendon ligament or other connective tissue and is accompanied by joint inflammation of arthritis.

JIA may include a variety of symptoms that can change from day-to-day, and not all symptoms are shared by all children with the disease. The effects of JIA on the child can depend on the severity of his/her symptoms, treatment, and frequency of flare-ups. The pain that many children with JIA experience can affect daily activities such as getting out of bed, brushing one's hair or buttoning up shirts. One parent noted that *"swelling is the aspect of JIA that is hard to control."*

JIA also affects the ability for children to participate in physical activities, school participation, and children's emotional and psychological well-being. According to the Make Rheum for Youth Survey, 89% noted that living with a rheumatic disease affected their mental health and 79% are worried about their overall health. A large number of participants also expressed concerns about attending school (64%) and securing a job (62%) due to their rheumatic disease. Over half of survey respondents noted they do not

know how to access workplace accommodations. Almost 70% of survey respondents noted they feel they are treated differently by school or work because of their rheumatic disease.

Future workforce participation can be affected by the disease with restrictions on what kind of work people with JIA can pursue depending on their current and future health status, particularly in the context of unemployment for youth and young adults. One JIA parent noted *"My teenager wishes they could consider a career in the arts (they love costuming and sets in theatre) instead of a less interesting career that assures them health benefits and good income to pay for the expensive drugs their JIA requires. My heart is broken."* One of the co-authors also noted that JIA is *"not taken seriously enough and with urgency. I knew time was ticking so I finished my final diploma at age 18. These are hard realities many youth and young adults face with this disease as the condition follows them into adulthood."* With increasing new technologies and fewer availability of entry-level positions, there may be even less job opportunities for youth, especially those living with disabilities like JIA..

Many people experience barriers in participation in school due to complex and burdensome school accommodation processes which can pose additional barriers to school participation. Two in three survey respondents noted they find it difficult to access school accommodations. When asked what they would change about living with a rheumatic disease, one survey respondent noted: *"I would change the education system in order to make it easier to access accommodations."*

Youth with JIA can also experience barriers in navigating care and sometimes their young age impacts the power dynamics with physicians and healthcare professionals. Some may not be taken as seriously by providers and this was supported by the Make Rheum for Youth survey results where one in four survey respondents did not feel their treating physician listened to them. When asked what they would change about living with a rheumatic disease, one survey respondent noted: *"I would like to have more doctors take my symptoms more seriously and help improve my quality of life."*

Over half the Make Rheum for Youth survey respondents (55%) are worried about having medications reimbursed once they finish school. A similar proportion do not know how they will pay for medications once they finish school. When asked what they would change about living with a rheumatic disease, one survey respondent noted *"I would want universal drug coverage"* People with JIA are aware of and concerned about how they will manage the transition from pediatric to adult care which can begin as young as age 12. Close to two-thirds of the Make Rheum for Youth survey respondents noted they do not know how to navigate drug insurance plans, further adding to their fears and anxiety for the future.

Adolescence can be a challenging time for many people and causes additional stress and anxiety for people with JIA. Additionally, given the changes to their bodies, 43% of survey respondents said they do not feel good about themselves and their bodies. When asked what they would change about living with a rheumatic disease, one survey respondent noted *"I would change the depression, isolation, and mental health burden that goes along with it"*. Close to 80% of survey respondents are worried about their mental health.

JIA can also impact participation in many activities given the fluctuating nature of the symptoms, like pain, fatigue, brain fog, etc. The condition can impact dating and relationships given the influence of the disease on a person's confidence and sense of self. Many of the Make Rheum for Youth survey respondents noted support from family (69%), while two in five did not feel supported by their romantic partner and friends in managing their disease.

JIA also has a significant effect on parents and caregivers. While experiences may vary, it is challenging when there is a feeling of limited control over the health of one's child which can cause ongoing stress, fatigue, and anxiety. All the care activities around a child living with JIA: medical appointments; administering medication; dealing with side effects; working with the school; balancing parental work obligations and family commitments have an enormous toll.

4. Experiences With Currently Available Treatments

The treatments available for childhood rheumatic diseases like JIA have significantly improved over time. Despite this, little has been done to address the often extreme anxiety and pain of infusions, blood draws and home injections hasn't changed. Giving a small child or teen an injection - often weekly - can be terrifying for both the child and their caregivers. The injection itself can be painful and uncomfortable, and it may also lead to mental health issues like panic and anxiety, making the child more reluctant to adhere to their treatment plan. For parents, who are suddenly thrust into the role of medical caregiver, having to administer treatments that cause pain for their child is an added burden too.

"My son developed severe anxiety after using Humira. We worked with a psychologist but ultimately had to switch to infusions in the hospital."

"We spent months working with a psychologist through the pediatric pain clinic. The fear wasn't about the actual pain, it was just the fear of the idea of the needle. We needed to do CBT therapy along with exposure therapy for many months. During that time I was so afraid of the future because he wasn't getting the medication he needed."

"My daughter needs injections but is afraid of needles. So far the hardest part is that they need to put her to sleep with an iv to even take blood and my daughter screams and pleads for them to stop but the procedure has to happen. It's devastating for all of us."

"The pain of the drug going in (not the injection itself) was excruciating...became a constant dread over our lives. We tried many, many strategies to help but nothing worked."

Many parents and caregivers also face financial challenges in accessing current treatments: cost of medications; associated travel and time off work for treatment; cost of extended healthcare such as physiotherapy. Youth and young adults surveyed also worried about affording the cost of medications once they graduate. Treatment decisions should be based on the best available evidence and informed discussions between health care providers, patients, and their caregivers on the benefits and risks

5. Improved Outcomes

Response to medications in children with JIA can vary significantly – certain medications may be effective for some while not effective for others. Some treatments will only manage the disease for a short period of time before the child's immune system adapts to a particular drug and becomes non-responsive to it, resulting in the need to switch to another medication. As tofacitinib is an oral medication, administration may be easier for children and caregivers instead of injections. Additional treatment options have the potential to ease the burden on patients, their families, caregivers and the healthcare system. One JIA family noted *"Listing Tofacitinib on Canadian formularies would mean increased access for families through more traditional means, eliminating barriers to access."*

6. Experience With Drug Under Review

Four JIA families shared their experience with tofacitinib:

“Since starting Xeljanz...day to day anxiety is significantly reduced. She is sleeping better, is happier, more outgoing and engaging...We are praying Xeljanz is approved.”

“Tofacitinib (Xeljanz) has significantly decreased the clubbing on my son’s fingers. The swelling on his knees and wrists are better. The Xeljanz significantly improved my son’s condition...my son is less self conscious now especially when wearing shorts, he says his friend no longer notice the swelling on his knees.

“While it was ultimately not the right treatment for her, there were many benefits. Most notably, the switch to oral medication made a profound impact on the quality of life and enabled a return to more normalcy. This included the administration of the drug...but also the portability of it meant we could more easily travel, or even leave the house for an evening knowing another trusted caregiver could administer it. I’d consider this to be hugely impactful for our rural families who may face increased barriers accessing shipment of fragile drug materials.”

“One issue that I’ve had with it is my cholesterol. I had high HDL on Actemra, but it wasn’t a concern because my ratio was good. But since starting Xeljanz, my LDL is also raised enough that I had to start some meds to lower it. Other than that, I experienced no other side effects and overall, I’m pretty happy with it.”

While experience with tofacitinib was positive with the contacted families, accessing it has been challenging for some:

“Sick Kids managed to get us a 3 months sample supply while we tried to secure coverage with our insurance...we have been provided with a rolling 3 months supply but are absolutely on our last three months and will need to start paying out of pocket...It has caused some stress for my husband and I as we come up with a plan to fund the meds (line of credit). Going back to Enbrel will be devastating.”

“We were very fortunate to have our Rheumatologist working closely with Pfizer to help access compassionate care so we could access the drug. From a health equity perspective, I would hate to think of anyone who doesn’t have this support to gain access.”

7. Companion Diagnostic Test

Not applicable

8. Anything Else?

The proposed scope for tofacitinib in JIA should reference emerging efficacy data (e.g., case series showing remission in sJIA with tofacitinib) and the consideration of upadacitinib—a selective JAK-1 inhibitor. Since pediatric patients are typically considered in later phases of drug development, off-label evidence should be considered and JAK-inhibitor class effects.

We question the selection of ACR-70 and ACR-90 as primary efficacy endpoints and suggest referring to the OMERACT core outcome domains in Juvenile Idiopathic Arthritis. The OMERACT domains use a collaborative process involving patient research partners, methodologists, researchers and clinicians to decide on important patient outcomes. Patient-reported outcomes must also extend beyond generic quality-of-life metrics to capture domains critical for children and adolescents—specifically, school participation, engagement in social activities, and caregiver/parent burden.

Finally, safety outcomes should distinguish adverse-event profiles across JAK inhibitors: for example, tofacitinib has higher rates of herpes zoster compared to more selective agents like upadacitinib, and infection risks may vary by JAK-1 vs JAK-3 selectivity.

Appendix: Patient Group Conflict of Interest Declaration

To maintain the objectivity and credibility of the reimbursement review process, 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. CDA-AMC 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.

No

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.

No

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.

Arthritis Society Canada

Company	Check Appropriate Dollar Range			
	\$0 to 5,000	\$5,001 to 10,000	\$10,001 to 50,000	In Excess of \$50,000
AbbVie		x		
Amgen			x	
Flexon Industries		x		
Fresenius Kabi Canada Ltd	x			
GlaxoSmithKline Inc.		x		
Innovative Medicines Canada	x			
J+J Shared Services			x	
Jamp Pharma Corp		x		
Janssen Inc.			x	
LivCorp Inc.	x			
Medline Canada Corporation				x
Nordic Pharma Inc.				x
Organon Canada Inc.				x
Pfizer Canada SRI/Pfizer Canada ULC				x

Sandoz Canada Inc.	x			
Sanofi Canada			x	
SoloPill Inc.		x		
UCB Canada Inc.		x		
Wellesley Therapeutics			x	

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: Margretha Gonsalvez
 Position: Manager, Public Policy and Government Affairs
 Patient Group: Arthritis Society Canada
 Date: June 25, 2025

Canadian Arthritis Patient Alliance

Company	Check Appropriate Dollar Range			
	\$0 to 5,000	\$5,001 to 10,000	\$10,001 to 50,000	In Excess of \$50,000
AbbVie Corporation			x	
Apothecare Inc.		x		
Arthritis Research Society of Canada	x			
AstraZeneca Canada		x		
Aspeya			x	
CADTH	x			
Canadian Rheumatology Association	x			
Centre of Aging SMART	x			
CIHR			x	
CIUSSS Centre	x			
Dalhousie University	x			
Government of Canada (Canada Summer Jobs)		x		
Government of Canada (Canadian Heritage)	x			
Innomar Strategies Inc.	x			
Innovative Medicines Canada			x	

Janssen Inc.		x		
McGill University Health Centre	x			
McMaster University			x	
Ottawa Heart Institute	x			
Patient Commando	x			
Pfizer Inc. (USA)			x	
Queen's University	x			
RI-MUHC, CORE	x			
Save Your Skin Foundation	x			
Sparkplug Coffee	x			
The Arthritis Society		x		
UCB Canada Inc.			x	
University of British Columbia		x		
University of Calgary	x			
University of Ottawa	x			
University of Saskatchewan	x			
University of Toronto	x			
University of Waterloo	x			

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Name: Laurie Proulx
 Position: Managing Director (part-time)
 Patient Group: Canadian Arthritis Patient Alliance
 Date: June 26, 2025

Canadian Spondyloarthritis Association

Company	Check Appropriate Dollar Range			
	\$0 to 5,000	\$5,001 to 10,000	\$10,001 to 50,000	In Excess of \$50,000
Abbvie				x
Pfizer			x	
UCB			x	
Novartis			x	

Janssen			x	
Organon		x		
Augurex		x		
Aspeya		x		

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: Brenda Delodder
 Position: Executive Director
 Patient Group: Canadian Spondyloarthritis Association
 Date: July 3, 2025

Cassie + Friends

Company	Check Appropriate Dollar Range			
	\$0 to 5,000	\$5,001 to 10,000	\$10,001 to 50,000	In Excess of \$50,000
Amgen			x	
Sobi			x	

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: Jennifer Wilson
 Position: Executive Director
 Patient Group: Cassie + Friends
 Date: June 25, 2025

Psoriasis Canada

Company	Check Appropriate Dollar Range			
	\$0 to 5,000	\$5,001 to 10,000	\$10,001 to 50,000	In Excess of \$50,000
AbbVie			x	
Amgen			x	
Arcutis			x	
Bausch Health			x	

Boehringer Ingelheim Canada			X	
Boeringer Ingelheim International			X	
Janssen Inc.				X
Pfizer (CPN)			X	
Sun Pharma (CAPP)			X	
Takeda (CAPP)			X	
UCB			X	

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: Antonella Scali
 Position: CEO
 Patient Group: Psoriasis Canada
 Date: June 25, 2025