

# Analysis of Reddit Reveals JAK Inhibitor Questions Among Atopic Dermatitis Patients

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## ABSTRACT

Reddit is a popular social media website that is increasingly being used as a source of health information and discussion, especially among the younger population. We analyzed the subreddit “eczeJAKs” (a group whose “about” statement is: “Janus Kinase Inhibitors for Th2 Dermatitis”), and found many gaps in patient knowledge, showing areas for future improvement.

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## INTRODUCTION

Reddit is the 7th most visited site in the United States (US) and has become an popular forum for health-related discussions.<sup>1</sup> According to a 2021 study, users ages 10-19 comprise 21% of Reddit users, with nearly half of users being under the age of 29.<sup>2</sup> Furthermore, users seeking health-related information on Reddit are among the most likely to enact the information in their lives.<sup>3</sup>

Approximately 13% of children in the US have atopic dermatitis (AD).<sup>4</sup> Patients with AD are known to heavily engage on Reddit, forming subreddits, or specific discussion boards related to distinct AD topics.<sup>1</sup> With the recent FDA approval of Janus kinase inhibitors (JAKi) for AD treatment, a subreddit was formed on January 16, 2020. The analysis of a subreddit can provide physicians with valuable information regarding patient care.<sup>1</sup> By familiarizing oneself with concerns expressed on a widely utilized social media platform, physicians can gain additional insight into the patient’s perspective about treatment and use this information to strengthen anticipatory guidance, counseling, and the patient-provider relationship.

## MATERIALS AND METHODS

The authors analyzed all 219 posts on the “eczeJAKs” subreddit (a group whose “about” statement is: “Janus Kinase Inhibitors for Th2 Dermatitis”), which has 1,006 subscribers as of May 28, 2023. Each post was placed into one of 15 categories (Table 1).

## DISCUSSION

Our analysis of the “eczeJAKs” subreddit demonstrates helpful data regarding the AD patient experience on JAKi, highlighting patient gaps in knowledge that physicians can improve on. The highest proportion of posts was questions in the general experience category, followed by side effects. Therefore, we

TABLE 1.

The Proportion of Posts by Category

Category	Number (N=219)	%
Side effects	36	16.4%
Usage Instructions	17	7.8%
General Experience	60	27.4%
Efficacy	15	6.8%
Insurance Coverage and Finances	12	5.5%
Concurrent Use with Other Medical Interventions	3	1.4%
Obtaining prescription	13	5.9%
Timeline for Symptom Improvement	5	2.3%
Miscellaneous	9	4.1%
Updates to Medication via Clinical Trials, News, and Media	28	12.8%
Fear/Concern	9	4.1%
Mental Health	3	1.4%
Patient-Provider Relationship	4	1.8%
Tobacco/Alcohol	2	0.9%
Covid	3	1.4%

suggest that physicians emphasize potential side effects when taking JAKi. To date, the most common reported adverse effects of oral JAKi are upper respiratory infections, nasopharyngitis, nausea, headache, and acne.<sup>5</sup> Providers could also emphasize that itch-relief can be seen as early as the first 24 hours of treatment.<sup>5</sup>

Surprisingly, we found a number of undocumented side effects described in the posts. While these side effects may offer a broader patient perspective, they are difficult to classify and

TABLE 2.

Example of Posts by Category and Subcategory			
Category	Subcategory	Example Post Title	Example Post Excerpt
General Experience	Topical Steroid Withdrawal	opzelura: getting these weird bumps after i stopped using opzelura after they cleared (the instructions say to stop using when clear). is anyone else experiencing this? I feel like my skin is getting addicted to it like with steroids :(	Photo of Rash
Usage Instructions	N/A	Rinvoq twice daily?	"Hey all, I am on Rinvoq 30mg/once daily for AD. I am wondering if anyone has any input about splitting this pill between two times of the day?"
Updates to Medication via Clinical Trials, News, and Media	Clinical Trial	Can't use grape fruit during trial...	Hey to whoever is reading this, I've been in a study for about a year now for upadacitinib and my skin has been doing good but as I was reading the consent form I came across it saying that "consumption of grape fruit or grape fruit juice may affect levels of upadacitinib and increase risk of side effect" Can anyone explain how grape fruit does this effects the levels and does it include oranges as well??
	News/Media	US Congresswoman questions Abbvie (Rinvoq) CEO on shady corporate practices	Link to Video of Congresswomen
Side Effects	Conjunctivitis	Eye Issues	Anyone have any eye issue develop or any eye issues solved since switching to JAKS?
	Upper Respiratory Infection	Stopping RINVOQ for a week due to an infection	I have to take antibiotics for an infection and need to temporarily stop RINVOQ. I was wondering if anyone else has stopped RINVOQ for a short period. Did you flare up? Did it work again after restarting treatment?
	Muscle Pain	Can anyone help me with Rinvoq?	Was on Rinvoq 30mg a day for about 2 months and started with bad RANDOM aches all over my body especially my right leg, soles of my feet and back and shoulders (feels like bone pain). Sort of like twinges and stuff but finding it hard to function on a day to day basis or put full weight on my right leg and tiredness. Has anyone else experienced this I know its a long shot but worth a ask.
	Fatigue	Rinvoq and fatigue	Anyone experienced fatigue as a side effect while starting rinvoq? I've been on it for a week and I'm wondering if the fatigue will go away.
Fear/Concern	Cancer	Cibinqo (abrocitinib) cancer concerns?	However my only concern about cibinqo is my doctor warned me that there's a small potential chance it may increase risk of cancer? Has anyone else been warned of that in their clinical trial testing or their doctor or have heard of what percent of their test subjects got cancer? I tried googling and there's very minimal articles that mention some risk of lymphoma or skin cancer which worries me a bit.

should be interpreted with caution given the lack of verification methods. It is possible that some mentioned side effects will appear in pooled forums before more conventional clinical awareness develops. For example, text-mining of online healthcare forums can identify novel side effects, helping target post-marketing drug surveillance.<sup>6</sup>

Mentioned side effects not included in the prescribing information for JAKis include depression, delayed wound healing, and gynecomastia.

Delayed wound healing may be plausible given the growth factors and cytokines necessary for wound healing utilizing the JAK/STAT intracellular signaling pathway for gene transcription.<sup>7</sup>

Regarding the general usage instructions category, many posts centered on the shingles vaccine, pointing to an area that may require greater clarification from physicians. Similarly, a post mentioned grapefruit usage in a clinical trial, suggesting that physicians may need to elaborate on dietary issues. Notably, prescribing information for upadacitinib recommends that

physicians advise their patients against the consumption of grapefruit as increased levels of the drug occur when co-administered with strong cytochrome 3A4 inhibitors (grapefruit, ketoconazole, clarithromycin), raising the risk of adverse reactions.<sup>8</sup>

Finally, we came across a significant number of posts expressing widespread unease and doubt about JAKis. Despite shared decision-making and anticipatory guidance, it appears that there is still a great deal of trepidation surrounding these medications.

### CONCLUSION

The “eczeJAKs” subreddit has undergone substantial growth since its creation. We expect this subreddit to continue growing as JAKi use increases for AD. Misinformation can easily spread given the posts are not verified by health professionals. With such a high number of youths using social media, there is concern that the shift towards health-focused social media may weaken the patient-provider relationship and create mistrust towards conventional medicine, as in topical steroid withdrawal syndrome.<sup>9</sup>

Furthermore, we believe that a significant amount of posts could have been prevented with greater patient education. A common theme throughout the subreddit was lack of proper time given from the dermatologist or the dermatologist being too busy to answer follow-up questions. Such concerns call for solutions that may entail interdisciplinary collaboration, online patient portals, patient support groups or advocacy organizations, better online education resources, and for better or for worse, even the use of artificial intelligence in the future.<sup>10</sup>

### DISCLOSURES

D. Lio reports research grants/funding from AbbVie, AOBiome, and Regeneron/Sanofi Genzyme; is on the speaker's bureau for AbbVie, Eli Lilly, Galderma, Hyphens, Incyte, LEO Pharma, L'Oreal, MyOR Diagnostics, ParentMD, Pfizer, and Regeneron/Sanofi Genzyme; and reports consulting/advisory boards for AbbVie, Almirall, Amyris, AOBiome, Arbonne, ASLAN Pharmaceuticals, Burt's Bees, Castle Biosciences, Codex Labs, Concerto Biosciences (stock options), Dermavant, Eli Lilly, Exeltis, Galderma, IntraDerm, Johnson & Johnson, LEO Pharma, L'Oreal, Menlo Therapeutics, Micros (stock options), Pfizer, Pierre-Fabre, Regeneron/Sanofi Genzyme, Theraplex, and Unilever. In addition, Dr. Lio has a patent pending for a Theraplex product with royalties paid, and is a Board member and Scientific Advisory Committee Member of the National Eczema Association. Kripa Ahuja reports no conflict of interest. Grace DeSena reports no conflict of interest.

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