Patient perspective and satisfaction with JAK-inhibitor treatment for alopecia areata: Results from the 2025 VOICES-AA study by the National Alopecia Areata Foundation

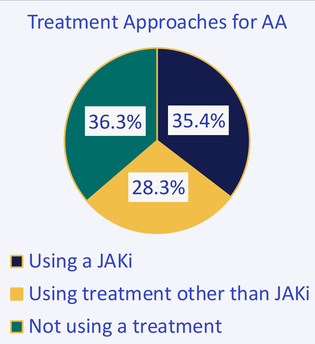
Authors: George C. Gondo, MA[1]; Arash Mostaghimi, MD, MPA, MPH[2]

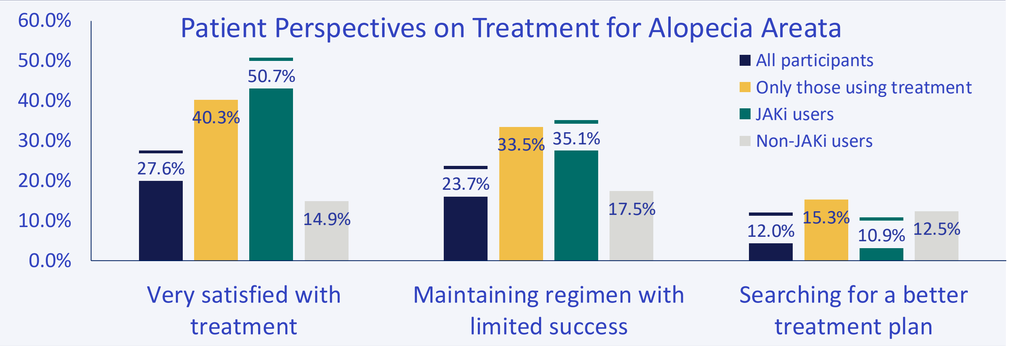
Affiliations: 1 – National Alopecia Areata Foundation, USA; 2 – Brigham and Women's Hospital, Boston, MA, USA

Key Takeaways:

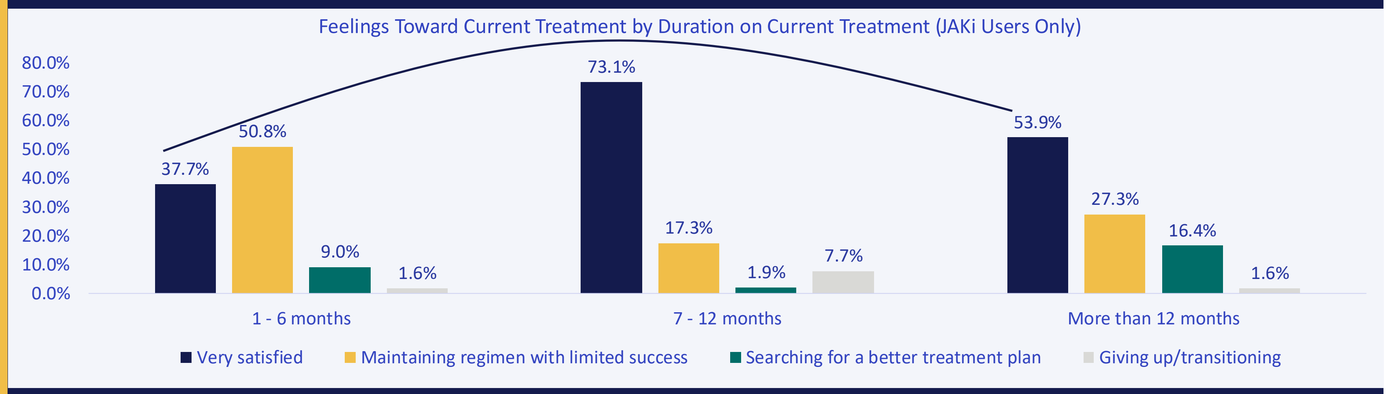
Despite higher treatment satisfaction, utilization of JAK inhibitor treatment among individuals with alopecia areata remains low. Increasing patient education about JAK inhibitors – especially regarding safety – may increase uptake of this treatment option among patients.

- Treatment satisfaction is higher among JAKi users (50.7%) than non-JAKi users (14.9%)
- Nearly two-thirds of non-JAKi users are either maintaining their treatment regimen with limited success or are searching for a better treatment plan
- JAKi users may be abandoning treatment too soon
- Educating health care providers (HCPs) and patients may improve uptake of JAKi

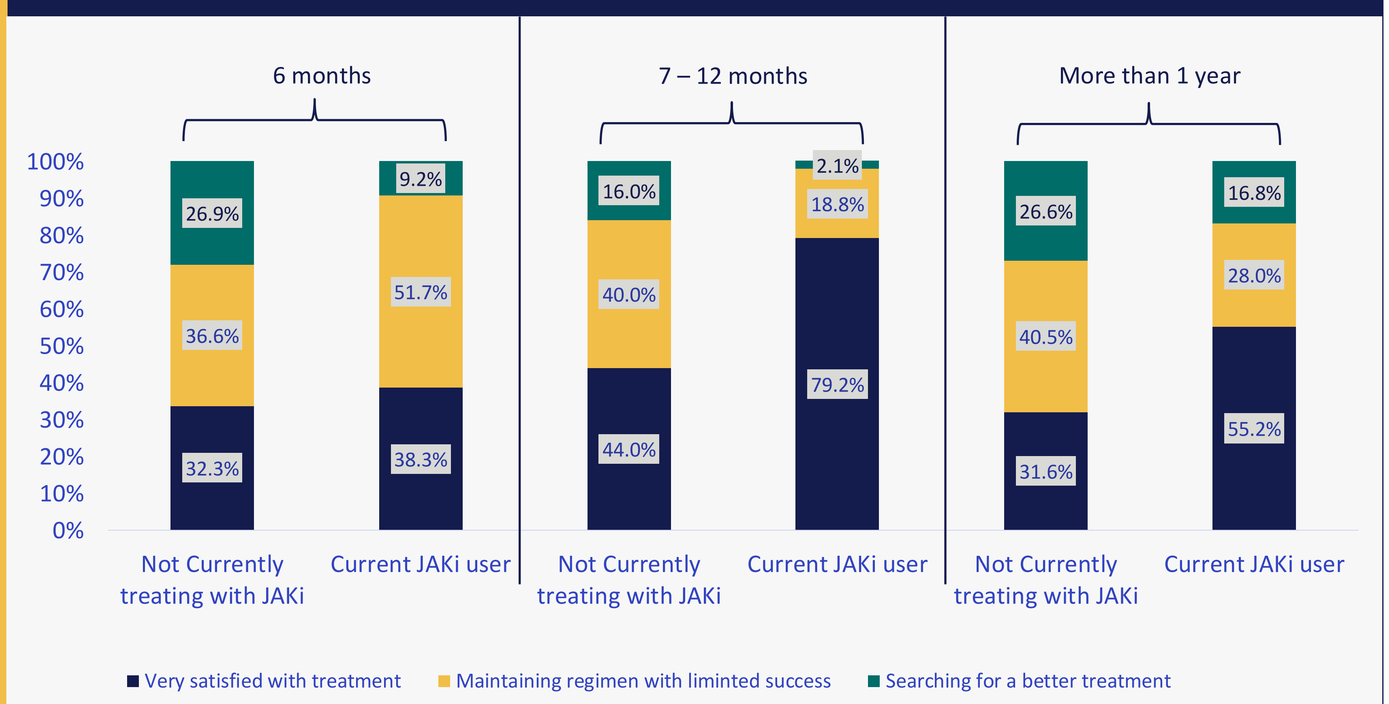




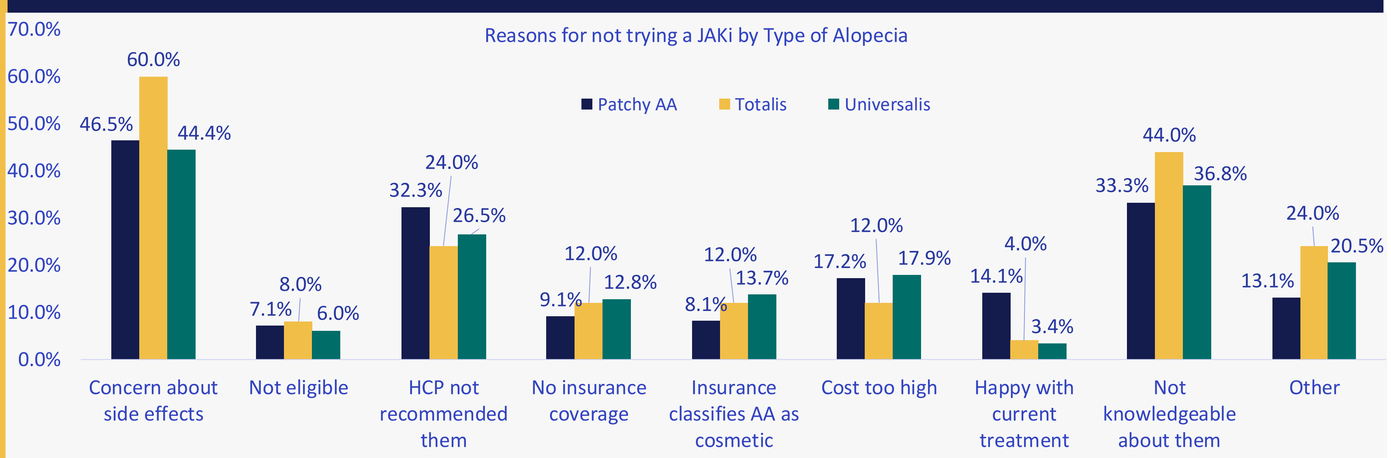
- Compared to those not treating with a JAKi, JAKi users reported higher rates of treatment satisfaction at 7 – 12 months and > 1 year
- Percentage of JAKi users who give up on treatment increases after 6 months
- Percentage of JAKi users who start searching for a better treatment plan increased after 1 year



- Regardless of the duration on current treatment, most non-JAKi users are either maintaining their regimen with limited success or were searching for a better treatment



- Regardless of disease severity, concern about side effects, lack of knowledge, and no recommendation from HCP were the most common reasons for not trying a JAKi
- Patient reported reasons for not trying a JAKi may be modifiable through patient and provider education



INTRODUCTION

Alopecia areata (AA) is a chronic, immune-mediated inflammatory disease affecting approximately 2% of the global population. While characterized by visible hair loss, the condition is driven by a collapse of hair follicle immune privilege, triggering an inflammatory attack on the follicle itself. Beyond its physical manifestations, AA often has a profound impact on emotional well-being and overall quality of life. Until recently, effective therapies for severe cases were nonexistent. perspectives and satisfaction with these new treatments.

The Values, Outcomes, and Insights from Community Experiences Survey (VOICES-AA) was conducted by the National Alopecia Areata Foundation (NAAF) to better understand the lived experiences of individuals living with alopecia areata and parents of individuals living with AA, including impact of disease on quality of life, and health care utilization and treatment patterns. Using data from the VOICES-AA survey, this study explores patient perspectives on JAK inhibitors, including utilization of JAK inhibitors among patients with AA, their satisfaction with these treatments, and barriers to their uptake.

METHODS

A cross-sectional survey of individuals with AA 18 years of age or older, and parents of children living with AA. Potential participants were drawn from the National Alopecia Areata Foundation's constituent database and from a third-party recruiter. The survey was conducted from November 2025 to March 2026.

RESULTS

A total of 852 people participated in the survey. Participants were mostly White (79.1%), female (63%), 63% reported an annual income > $75,000 (USD), and 72% have attained at least a college education. All self-reported receiving a diagnosis of AA by a dermatologist. 35.8% of participants reported having patchy alopecia, 13.5% reported having alopecia totalis, and 50.7% reported having alopecia universalis. Nearly three-fourths (74.8%) of participants were diagnosed with AA before the age of 40.

Overall treatment usage was high (63.7%), including 35.4% currently using a JAK inhibitor to treat their AA. Among all study participants, 53.8% have been on their current treatment for more than 6 months, including 41.4% who have been on their current treatment for more than 12 months. Overall treatment satisfaction was low (27.6%), though it nearly doubled to 50.7% for participants using a JAK inhibitor. Satisfaction with JAK inhibitor treatment varied by duration of treatment. Satisfaction was highest among those who have been on their current treatment for 7 – 12 months (73%) and lowest among those on treatment < 6 months (37%).

Among participants not using a JAK inhibitor, the most common barriers to adoption were concern over side effects (45%), a lack of knowledge about the treatment (35%), and their healthcare provider had not recommended they use a JAK inhibitor (29%).

Response	N (percent)
Age	
Under 18 years of age	162 (19.9%)
18 – 29 years of age	85 (10.4%)
30 – 39 years of age	84 (10.3%)
40 – 49 years of age	168 (20.6%)
50 – 59 years of age	116 (14.3%)
60 years of age and over	199 (24.4%)
Gender	
Male	311 (36.5%)
Female	537 (63.0%)
Race	
White/Caucasian	666 (79.1%)
Black/African American	79 (9.4%)
Asian/Asian American/Pacific Islander	30 (3.5%)
Latinx	31 (3.6%)
Multi-racial	25 (2.9%)
Other	11 (1.3%)
Age when diagnosed with AA	
Under 18 years of age	362 (44.5%)
18 – 29 years of age	95 (11.7%)
30 – 39 years of age	152 (18.7%)
40 – 49 years of age	104 (12.8%)
50 – 59 years of age	64 (7.9%)
60 years of age and older	37 (4.5%)
Duration of living with AA	
1 year or less	45 (5.3%)
2 – 3 years	153 (18.0%)
4 – 6 years	172 (20.2%)
7 – 10 years	99 (11.6%)
11 – 20 years	127 (14.9%)
21 – 30 years	93 (10.9%)
More than 30 years	163 (19.1%)
Household income	
Less than $30,000	58 (6.8%)
$30 – less than 75,000	137 (16.0%)
$75 – less than 100,000	155 (18.2%)
$100 – less than 250,000	318 (37.3%)
More than $250,000	66 (7.7%)
Prefer not to answer	118 (13.8%)
Education level	
Some high school	6 (.7%)
High school diploma/GED	43 (5.0%)
Some college	90 (10.6%)
Associates degree	77 (9.0%)
Bachelor's degree	279 (32.7%)
Master's degree	243 (28.5%)
Doctoral degree	45 (5.3%)
Professional degree	55 (6.5%)
Other	4 (.5%)
Hair loss episode > 6 months	
Yes	650 (85.9%)
No	107 (14.1%)
Experienced Hair Regrowth	
Yes	503 (65.4%)
No	266 (34.6%)
Type of AA	
Patchy	297 (35.8%)
Totalis	112 (13.5%)
Universalis	420 (50.7%)

DISCUSSION

Utilization of JAK inhibitors remains low among individuals with alopecia areata. Despite lower utilization, individuals who use a JAK inhibitor to treat their alopecia areata report higher treatment satisfaction than those using other prescription treatments. Satisfaction with JAK inhibitor treatment is associated with duration on treatment, with treatment satisfaction peaking at 7 – 12 months and declining slightly after being on treatment for more than 12 months. Patient-reported barriers to using a JAK inhibitor suggest that increased education is needed, especially on the topic of safety and adverse treatment effects.

CONTACT

George Gondo, MA
Chief Mission Officer
National Alopecia Areata Foundation
george@naaf.org

RESEARCH POSTER PRESENTATION DESIGN © 2019
www.PosterPresentations.com