

# Anxiety Associated With Parenteral On-Demand Treatment For Hereditary Angioedema (HAE)

Autumn Burnette,<sup>1</sup> John Anderson,<sup>2</sup> Hilary Longhurst,<sup>3</sup> Sally van Kooten,<sup>4</sup> Markus Heckmann,<sup>4</sup> Sherry Danese,<sup>5</sup> Ledia Goga.<sup>4</sup>

<sup>1</sup>Division of Allergy and Immunology, Howard University Hospital, Washington, DC, USA; <sup>2</sup>AllerVie Health, Birmingham, Alabama, USA; <sup>3</sup>Department of Clinical immunology, Auckland Hospital, Auckland, New Zealand; <sup>4</sup>KalVista Pharmaceuticals, Inc.; Cambridge, Massachusetts, USA; <sup>5</sup>Outcomes Insights; Agoura Hills, California, USA

## Background

- HAE is characterized by recurrent and unpredictable episodes of subcutaneous or submucosal swelling which can affect the abdomen, extremities, genitals, face, and larynx
- HAE attack frequency is highly variable among individuals and over time<sup>1</sup>
- Symptoms of an HAE attack can be painful and debilitating, potentially interfering with the ability to conduct daily activities (work, school, social activities)<sup>2</sup>
- Although self-administration of on-demand parenteral treatments has enhanced overall HAE attack management, the associated level of anxiety and treatment burden remain unknown

## Rationale

- This survey evaluated the anxiety associated with HAE attacks and use of on-demand treatment

## Methods

- People living with HAE were invited to participate in a focus group discussion in collaboration with US HAE Association (HAEA) and HAE International (HAEi)
- In total, 32 individuals with HAE participated in one of four 2-hour focus groups, held between November 2021 and March 2022
- Focus group attendees were invited to complete a pre- and post-focus group online survey
- Inclusion criteria enriched for patients managing HAE by treating attacks with on-demand treatment only (icatibant injection or C1 esterase inhibitor), versus those experiencing attacks while on long-term prophylactic treatment
- Patients provided informed consent
- Patient privacy was protected by use of pseudonyms; patient health records were not accessed

## References

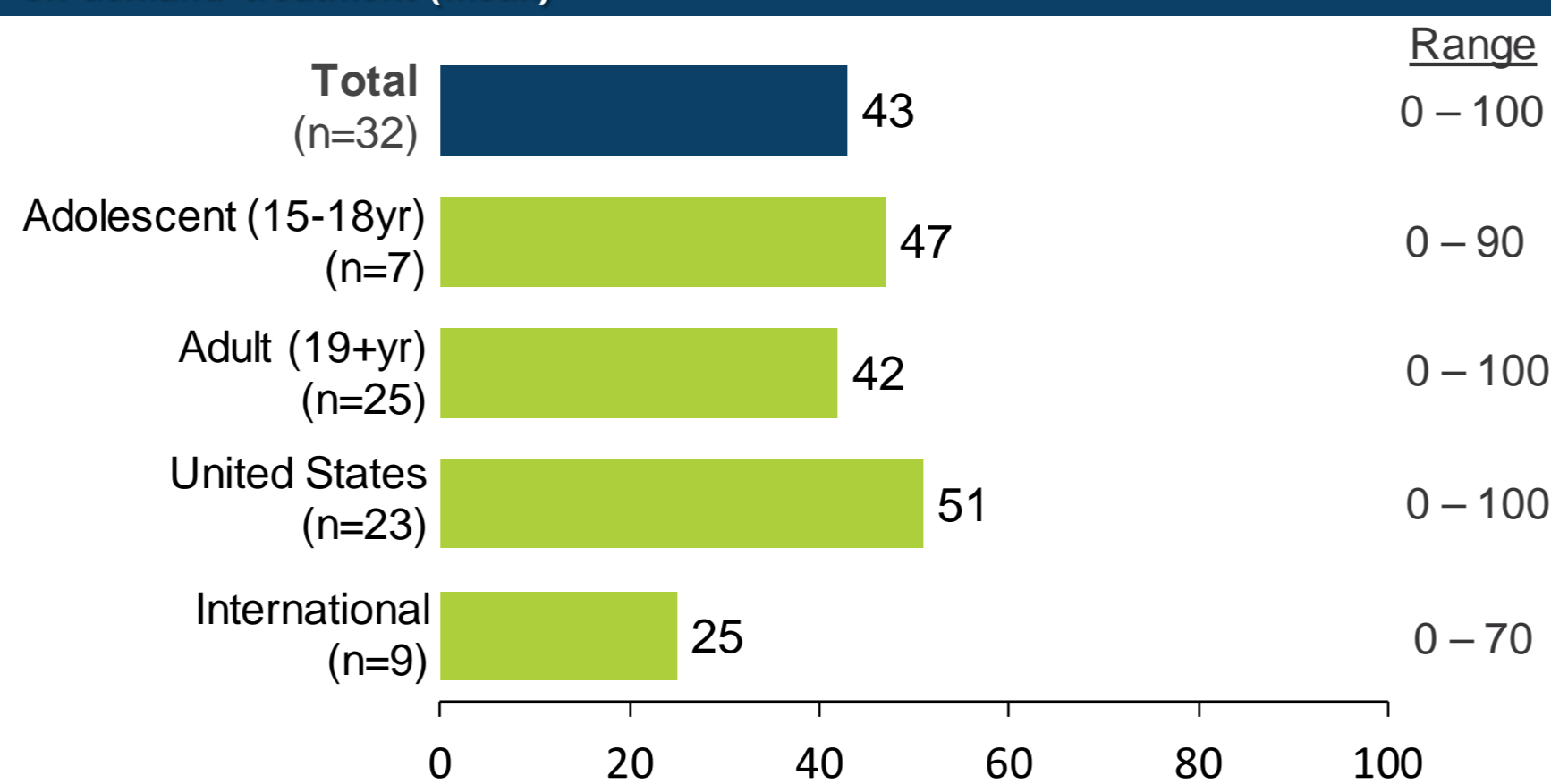
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**Table 1. Baseline demographics**

Characteristic	Total (n=32)*	Adolescent (15-18yr) (n=7)	Adult (19+yr) (n=25)	On-demand only therapy (n=21)*	Prophylaxis with on-demand (n=10)*
<b>Location, % (n)</b>					
United States	72% (23)	100%	64%	67%	80%
International**	28% (9)	–	36%	33%	20%
<b>Current Age, yr Mean (Range)</b>	33 (15 - 72)	17 (15 - 18)	37 (19 - 72)	36 (15 - 72)	27 (16 - 51)
<b>Age of Diagnosis, yr Mean (Range)</b>	16 (0 - 40)	11 (3 - 16)	17 (0 - 40)	17 (0 - 40)	13 (0 - 26)
<b>Type of Therapy</b>					
On-demand only	68%	50%	72%	100%	–
Prophylaxis with on-demand	32%	50%	28%	–	100%
<b>Attacks Per Year, Mean, Median, (Range)</b>	33, 17.5 (0 - 170)	13, 10 (1 - 36)	38, 25 (0 - 170)	42, 30 (4 - 170)	14, 6 (0 - 50)

\*A total of n=32 respondents completed either the pre- or post-survey. n=2 respondents only did the pre-survey, n=1 respondent only did the post-survey, n=29 completed both.  
\*\* Australia (n=1), UAE (n=1), Germany (n=2), Sweden (n=1), Poland (n=2), Saudi Arabia (n=1), UK (n=1)

**Figure 1. Rate your level of anxiety (Scale 0 to 100) when anticipating the use of on-demand treatment (mean)**



Patient-reported level of anxiety, scale 0 to 100, related to treatment only, beyond potential anxiety associated with HAE attack.

## Results

**Table 2. Survey questions and responses**

When first recognizing that you are having an HAE attack, what specifically worries you and causes you anxiety?	Total (n=32)	Adolescent (15-18yr) (n=7)	Adult (19+yr) (n=25)	United States (n=23)	International (n=9)
I am uncertain about the severity, pace and duration of the attack	68%	83%	64%	77%	44%
My plans for the day(s) are interrupted	19%	17%	20%	14%	33%
I don't have the medication with me	16%	–	20%	5%	44%
I am not sure if I need to go to the Emergency Room	10%	–	12%	5%	22%
Whether or not to take medication	6%	–	8%	5%	11%
I need to find a space to take my treatment	6%	–	8%	–	22%
I am anxious that the medicine will not work quickly enough	3%	–	4%	–	11%
Nothing	6%	–	8%	9%	–
<b>When you begin to recover from your attack, does your overall anxiety about the attack decrease? (% responded "Yes")</b>	<b>87%</b>	<b>100%</b>	<b>83%</b>	<b>86%</b>	<b>89%</b>
If yes, describe what it feels like to have your anxiety decrease as you first begin to recover					
• Feel sense of relief	72%	100%	63%	72%	71%
• Feel physically better	48%	33%	53%	44%	57%
• Feel more in control	8%	--	5%	11%	--

**Table 3. Survey question and responses**

If you feel anxiety when anticipating use of on-demand treatment, why do you feel that way?*	Total (n=32)	Adolescent (15-18yr) (n=7)	Adult (19+yr) (n=25)	United States (n=23)	International (n=9)
Pain of icatibant injection**	86%	100%	81%	90%	71%
Unsure if the treatment will work effectively (potential for rebound effect)	86%	60%	91%	80%	100%
Unsure if the treatment will work quickly	85%	100%	82%	80%	100%
Injection needle	82%	80%	81%	90%	57%
Lack of access to a suitable/private area	74%	100%	69%	75%	72%
Do not want to disrupt a current or planned activity	63%	60%	64%	60%	71%

\*% ranked in top 5 responses

\*\* includes participants that report anxiety of anticipated pain of icatibant injection, although icatibant is not listed as the primary on-demand treatment

## Conclusions

- HAE attacks and limitations of current on-demand treatments produced high levels of anxiety and significant burden on daily activities, and overall quality of life
- Anxiety may be due to a combination of factors, with increased anxiety reported prior to administration of parenteral on-demand treatment and uncertainty of therapeutic response ranking among the highest
- Anxiety decreased due to a sense of relief upon recognition of initial signs of recovery during an attack
- Although there have been clear advancements in HAE treatment options, patients still experience significant anxiety when anticipating the use of current on-demand therapies

## Disclosures

This study was sponsored by KalVista Pharmaceuticals, Inc. All authors met the ICMJE authorship criteria and had full access to relevant data. The authors had full editorial control of the data presented and provided final approval of all content. Neither honoraria nor payments were made for authorship.  
Autumn Burnette – Speaker Bureau and/or Advisory Board/Consultant: CSL Behring, Takeda, Pharming, KalVista Pharmaceuticals and BioCryst  
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