

Impact of Hereditary Angioedema (HAE) Attacks on Quality of Life and Activities of Daily Living

Paula J. Busse,¹ Teresa Caballero,² Sally van Kooten,³ Sherry Danese,⁴ Ledia Goga³

Presenter: Douglas H. Jones⁵

¹Department of Medicine, Division of Clinical Immunology, The Mount Sinai Hospital; New York, New York, USA; ²Department of Allergy, Hospital Universitario La Paz, Hospital La Paz Institute for Health Research (IdiPAZ), CIBERER U754; Madrid, Spain; ³KalVista Pharmaceuticals, Inc.; Cambridge, Massachusetts, USA; ⁴Outcomes Insights; Agoura Hills, California, USA; ⁵Rocky Mountain Allergy at Tanner Clinic; Layton, Utah, USA.

Background

- HAE is characterized by recurrent and unpredictable episodes of subcutaneous or submucosal swelling affecting the abdomen, extremities, genitals, face, and larynx
- HAE attack frequency is highly variable among individuals and over time¹
 - Average for untreated patients, every 2 weeks
- Symptoms of an HAE attack may be painful and debilitating, potentially interfering with the ability to conduct daily activities (work, school, social activities)²
- Although self-administration of on-demand parenteral treatments has enhanced overall HAE attack management, HAE disease burden may remain

Objectives

- To listen to HAE patients' experiences and recommendations
- Learn about how patients recognize the initial signs and symptoms related to HAE attacks
- Identify factors that influence patient's decision-making process for initiating, delaying, or forgoing on-demand treatment for HAE attacks
- Identify the impact that delaying or forgoing on-demand treatment has on daily activities
- This report describes the impact of HAE attacks on quality of life and activities of daily living for people with HAE

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 treating attacks with on-demand treatment only, versus those experiencing breakthrough attacks while on prophylactic treatment

Acknowledgments

We thank Douglas H. Jones, MD, FAAAAI, FACAIAI for presenting this work on behalf of the authors.

References

- Lumry W, Castaldo A, Vernon MK, Blaustein MB, Wilson DA, Horn PT. The humanistic burden of hereditary angioedema: impact on health-related quality of life, productivity, and depression. *Allergy Asthma Proc.* 2010;31(5):407-14.
- Bygum A. Hereditary angioedema—consequences of a new treatment paradigm in Denmark. *Acta Derm Venereol.* 2014;94(4):436-41.

Results

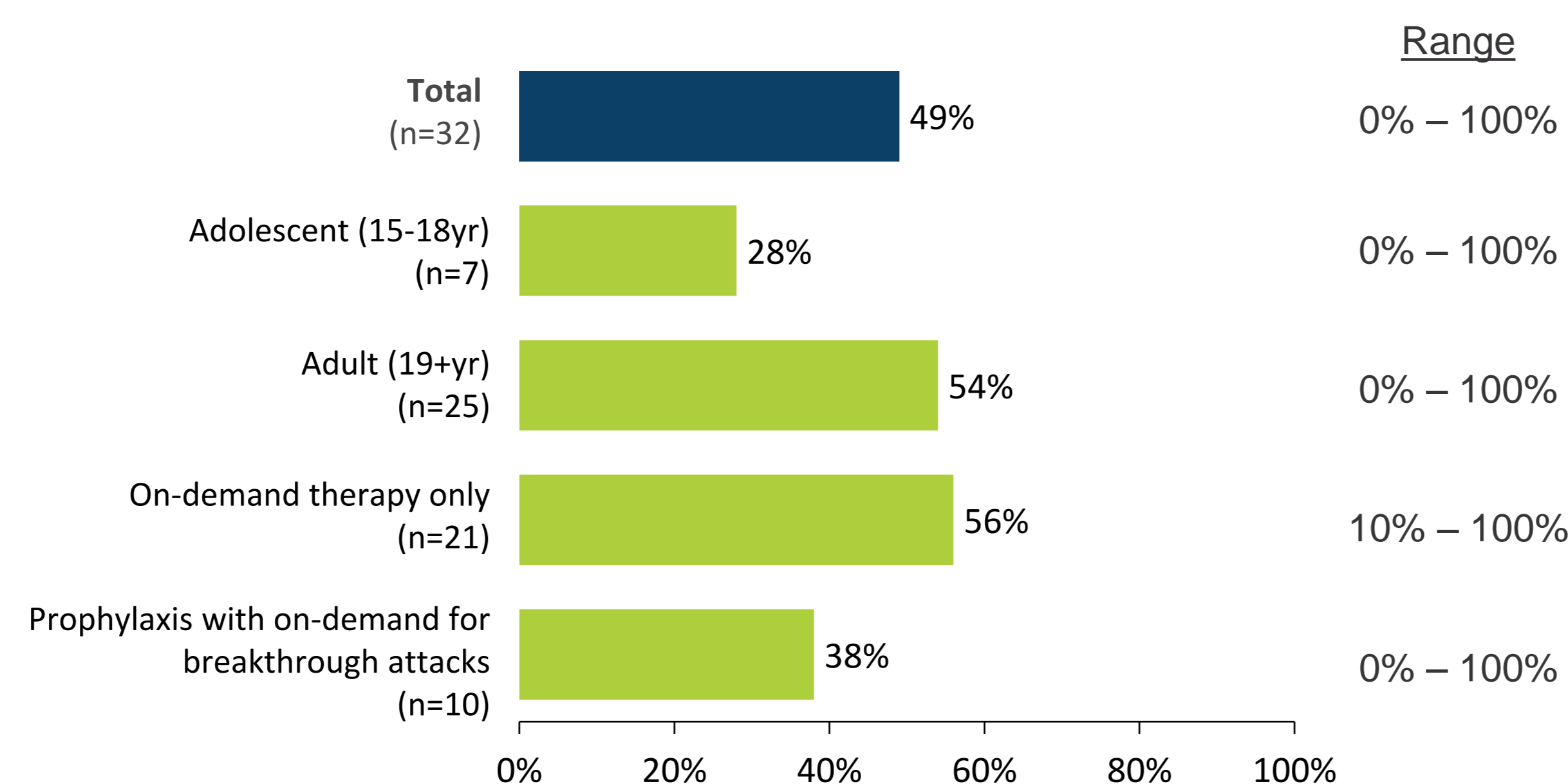
Baseline demographics					
	Total (n=32)*	Adolescent (15-18yr) (n=7)	Adult (19+yr) (n=25)	On-demand only therapy (n=21)*	Prophylaxis with on-demand for breakthrough attacks (n=10)*
Location					
United States	72%	100%	64%	67%	80%
International**	28%	—	36%	33%	20%
Current Age, yr Mean (Range)	33 (15 - 72)	17 (15 - 18)	37 (19 - 72)	36 (15 - 72)	27 (16 - 51)
Age of Diagnosis, yr Mean (Range)	16 (0 - 40)	11 (3 - 16)	17 (0 - 40)	17 (0 - 40)	13 (0 - 26)
Type of Therapy					
On-demand only	68%	50%	72%	100%	—
Prophylaxis with on-demand for breakthrough attacks	32%	50%	28%	—	100%
Attacks Per Year, Mean, Median, (Range)	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), Nordics (n=1), Poland (n=2), Saudi Arabia (n=1), UK (n=1)

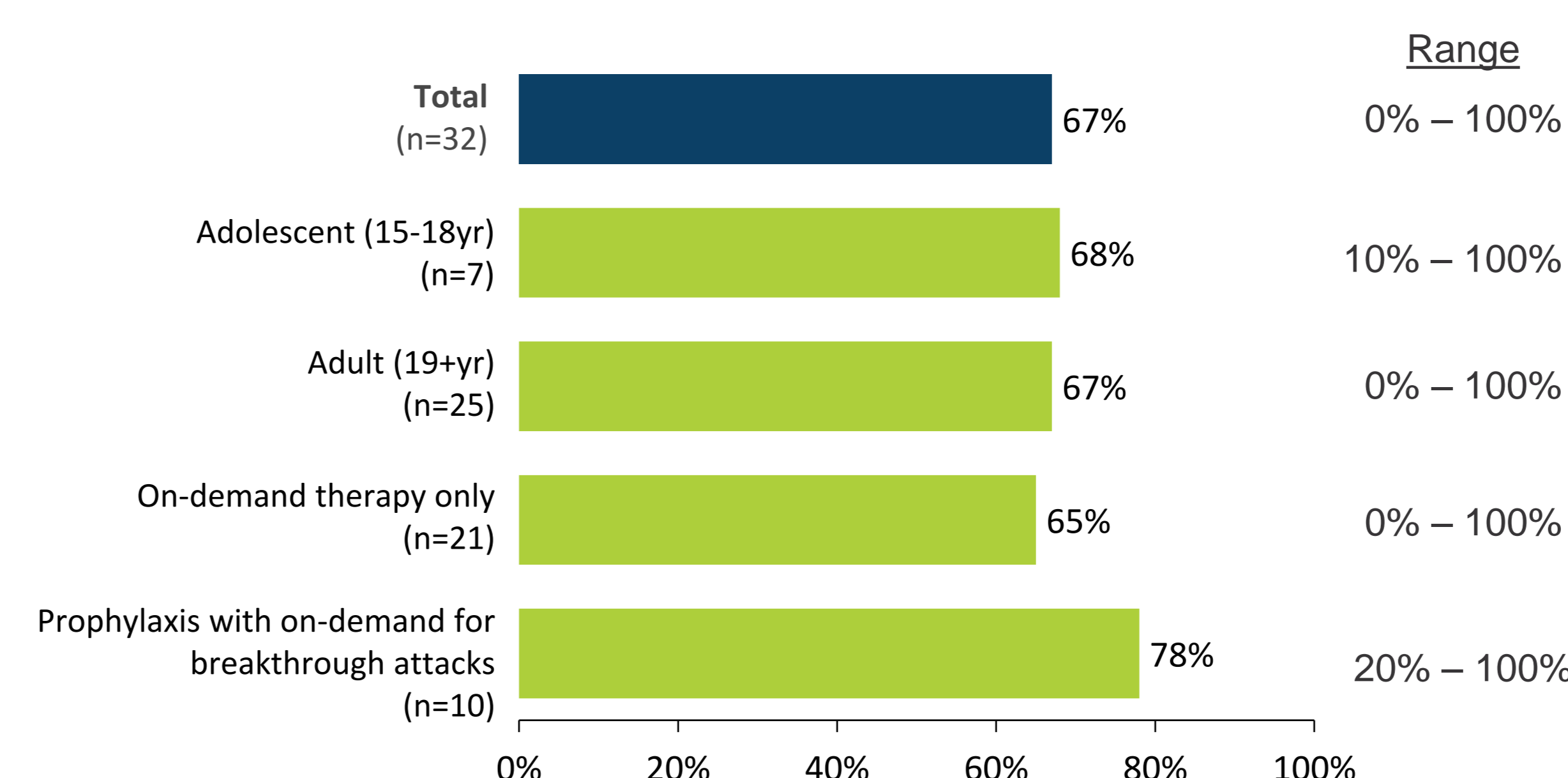
What is the most significant impact of HAE on your life?					
	Total (n=32)*	Adolescent (15-18yr) (n=7)	Adult (19+yr) (n=25)	On-demand only therapy (n=21)*	Prophylaxis with on-demand for breakthrough attacks (n=10)*
I cannot count on participating in important events and activities in my life	58%	67%	56%	67%	40%
Unpredictability of attacks causes anxiety and negatively impacts my mental health	39%	17%	44%	38%	40%
It is time-consuming to manage HAE (e.g., managing prescriptions / insurance, attacks)	19%	0%	24%	19%	20%
I have become resilient and determined to advocate for myself and others	16%	33%	12%	10%	30%
I have to endure painful and sometimes disfiguring attacks	13%	17%	12%	10%	10%
I feel judged by poorly informed healthcare providers and by society in general	10%	0%	12%	14%	0%
I question having children that might inherit HAE	10%	0%	12%	14%	0%
Nothing	6%	17%	4%	5%	10%

*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.

How often (percent of time) do you feel less than your 100% self because of HAE?



When you do not treat an attack, how often do your plans for the day change?



Conclusions

- HAE attacks produce a significant disease burden on mental health, daily activities, and overall quality of life
- An untreated attack resulted in a change of daily plans for two thirds of respondents
- More than half were unable to participate in important events or activities
- Nearly half feel 'less than 100% themselves' due to HAE
- Although there have been clear advancements in treatment options, there remains a significant opportunity to improve the lives of people with HAE

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.
Paula J. Busse – Advisory Board/Consultant and/or Grant/Research Support: CSL Behring, KalVista Pharmaceuticals, Inc., BioCryst Pharmaceuticals, Takeda, Regeneron, and Novartis
Teresa Caballero – Advisory Board/Consultant and/or Grant/Research Support: BioCryst Pharmaceuticals, CSL Behring, KalVista Pharmaceuticals, Inc., Merck & Co, Novartis, Octapharma, Pharming, and Shire/Takeda.
Sally van Kooten – Employee of KalVista Pharmaceuticals, Inc.
Sherry Danese – Consultant fees from KalVista Pharmaceuticals, Inc.
Ledia Goga – Employee of KalVista Pharmaceuticals, Inc.
Douglas H. Jones – Advisory Board/Consultant/Speaker: Amerimmune Allergy Testing, Inc., KalVista Pharmaceuticals, Inc., Pharvaris, Astra-Zeneca, BioCryst Pharmaceuticals, Regeneron/Sanofi, Zurvita Corporation, Pharming, and Shire/Takeda

Presented: ACAAI 2022 Annual Scientific Meeting, November 10 – 14 in Louisville, Kentucky.

Please scan this QR code to view the poster after the congress.

