

Lived Experience Advocating for Research Needed

LEARN About Misophonia

April 2nd, 2025



TOP RESEARCH PRIORITIES

- Treatments/interventions
- Developmental/longitudinal studies through the lifespan
- Causes and mechanisms
- What is happening in the brain
- Relation to comorbidities
- Managing anticipatory anxiety
- Understanding triggers
 - Visual
 - Speech-related
 - Variability
 - Physical effects
- Qualitative lived experience studies

ADDITIONAL RESEARCH PRIORITIES

- Impact on family functioning
- Best practices to raise awareness
- Genetics
- Spectrum of severity
- Effectiveness of coping mechanisms, including devices (e.g., headphones)
- Cross-cultural considerations
- Sexual arousal in presence of triggers
- Significant hormonal shifts
- SSRIs

LIVED EXPERIENCE INSIGHTS

STUDY DESIGN SUGGESTIONS

- Use personalized recordings of triggers
- Expand to environmental sounds, not just human
- Use visuals along with sounds
- Clearly state from the beginning if participants will be exposed to trigger sounds
- Follow up with results
- Improve recruitment
 - Describe the condition instead of relying on everyone recognizing “Misophonia”
 - Post on Tik Tok
- Provide educational/scientific information for participant and for their family, friends, and clinicians

WHAT RESEARCHERS SHOULD KNOW

- Shorter studies are more feasible
- Limiting inclusion criteria can cause major disappointment
- Place and time influence severity of triggers
- Everyone with Misophonia has an individual experience
- The whole family is affected
- Time and money are a major concern
- It is exhausting to constantly explain yourself and consider every move throughout the day to avoid triggers

LIVED EXPERIENCE INSIGHTS

WHAT DOCTORS SHOULD DO

- Validate the patient by acknowledging Misophonia is real
- Work with the family
- Research and educate themselves
- Target anticipatory anxiety
- Include occupational therapists in treatment team

WHAT DOCTORS SHOULD NOT DO

- Rely on the patient to educate them
- Invalidate the patient
- Offer medication as the first option
- Exposure therapy

WHAT DOCTORS SHOULD KNOW

- Having to educate providers as a patient is discouraging, exhausting, and frustrating
- There is a fear of being misdiagnosed
- Everyone with Misophonia has an individual experience
- The whole family is affected
- Time and money are a major concern
- It is exhausting to constantly explain yourself and consider every move throughout the day to avoid triggers

FEEDBACK SURVEY DATA

There were 80+ participants in the webinar. **28 members of the lived experience community, 2 researchers, and 2 clinicians** completed our feedback survey and reported:

100% Would attend a similar event in the future

97% Would recommend this event to a loved one, friend, etc.

100% Believe we were successful in offering clinicians and researchers a better understanding of the lived experience

96% Of lived experience community members feel empowered to share their story and contribute to the solution

100% Of researchers agree they learned something that will help improve their research studies

100% Of clinicians agree they learned something that will help improve their clinical care

FEEDBACK SURVEY DATA

WHEN ASKED TO DESCRIBE THEIR EXPERIENCE AT THIS EVENT IN ONE WORD, PARTICIPANTS SAID:



THANK YOU TO OUR FACILITATORS:

Natasha Biscoe, Clinical Psychologist Trainee

Jennifer Jo Brout, Psy.D., LPC

Julia Campbell, Ph.D., CCC-A. F-AAA

Lisa Fox-Thomas, Ph.D., CCC-A

Lucy Grant, Clinical Psychologist Trainee

Jane Gregory, DClinPsy

Heather Hansen, Ph.D.

Ashley Moskovich, Ph.D.

Zach Rosenthal, Ph.D.

A special thank you to our lived experience participants for bravely sharing their stories. Your participation has already sparked new ideas for improvement in the field.