

# MISOPHONIA

A Center for Strategic Philanthropy  
Giving Smarter Guide



**MILKEN INSTITUTE**



# ABOUT US

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## **ABOUT THE MILKEN INSTITUTE**

The Milken Institute is a nonprofit, nonpartisan think tank. We catalyze actionable solutions to persistent global challenges by connecting human, financial, and community resources to those who need them. Guided by a conviction that the best ideas, under-resourced, go nowhere, we conduct applied research, convene luminaries from competing viewpoints, and construct programs and initiatives designed to achieve our overarching mission of building meaningful lives.

## **ABOUT THE CENTER FOR STRATEGIC PHILANTHROPY**

The Milken Institute Center for Strategic Philanthropy (CSP) believes philanthropy has the opportunity and obligation to take on big risks to test bold ideas. We conduct deep due diligence across a range of issue areas, promote creative and well-informed giving strategies, and advise families and foundations on where and how to channel their philanthropy to maximize a return on their investment.

## **ACKNOWLEDGMENTS**

We would like to thank the artist, Dan Bejar, for the cover image.

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# EXECUTIVE SUMMARY

Several research studies have found that as many as one in five people report strong feelings of disgust, rage, or anxiety in response to very specific sounds such as other people chewing or tapping. However, a subset of these individuals experience responses so great that they are unable to participate in key activities like spending time with their family, attending school, or maintaining social relationships. When these individuals seek medical help, they are often met with confusion, skepticism, and minimal support. These individuals are suffering from a condition known as misophonia; however, misophonia cannot be found in medical textbooks, is predominantly unknown to clinicians, and is not yet recognized by insurance companies.

## WHAT IS MISOPHONIA?

Misophonia is a condition in which specific sensory sensations, such as a particular sound, lead to a strong physical and emotional response. The stimuli causing the response are often referred to as “triggers.” Common triggers include the sound of people eating, nasal noises like sniffing, and sounds associated with fidgeting like clicking a pen. Exposure to triggers causes the misophonia sufferer to experience a stereotyped physical and emotional response, which includes an increased heart rate, sweating, and activation of stress or anger response. People describe feeling intense anxiety, rage, fear, or the desire to flee.

While scientific research in this field is nascent, several studies have shown that misophonia is real, can cause extreme distress, and is correlated with key differences in brain activity.

## THE STATE OF THE FIELD

Researchers have shown that individuals with misophonia respond to trigger sounds differently than the general population; however, many questions remain. For example, it is not known how misophonia develops, or what the prognosis is once a person experiences misophonia. There are no objective measures to determine if a person experiences misophonia and no scientifically vetted therapeutic strategies once a diagnosis is made. Beyond the scientific questions, many clinicians and researchers are not aware of misophonia and therefore unable to help patients. Additionally, clinicians who do advise patients suffering from misophonia report not being able to bill insurers for misophonia consultations. Overall, these gaps leave misophonia patients unable to navigate information, find clinicians, or identify potential therapeutic strategies. Research in the field is fragmented and highly siloed, with individual groups studying specific facets of the condition, such as neural responses, and minimal collaboration among disciplines.

## PHILANTHROPIC OPPORTUNITIES TO ACCELERATE MISOPHONIA RESEARCH

Philanthropic capital can play a pivotal role in biomedical research, especially in emerging scientific disciplines, as donors’ funding can support pilot studies needed to develop an evidence base that will attract additional research grants from larger grant programs. Smart philanthropic programs can accelerate progress by promoting interdisciplinary collaboration and principles of open science. These principles are extremely important for a young field like misophonia, which has been fragmented among medical specialties. Donors’ early funding of research will help lay the foundation of the field.

# EXECUTIVE SUMMARY

The Milken Institute's Center for Strategic Philanthropy (CSP) was engaged by The REAM Foundation to determine how philanthropic capital can best support efforts to research, diagnose, and treat misophonia. Below are the six primary philanthropic opportunities that CSP identified.

## **Support descriptive studies of misophonia**

Misophonia is largely not understood or characterized. Philanthropic support of fundamental studies to understand the condition, how physiological systems are engaged in the acute response, and how the condition develops will be pivotal to developing new therapeutic strategies.

## **Focus on developing diagnostic tools**

While several self-assessment tools have been developed for misophonia, none are scientifically validated. Additionally, there are no objective or standardized measures to determine if an individual experiences misophonia, and if so, to what degree. Philanthropic capital can support the development of new and validated diagnostic tools that can assess the presence of misophonia that will help accurately assess the prevalence and impact of misophonia within the population.

## **Improve studies of prevalence and impact**

Once improved diagnostic tools are developed, further research is needed to understand the prevalence and impact of misophonia. These studies will also be important in identifying common co-morbidities and characterize the spectrum of disability caused by the condition.

## **Fund robust clinical trials**

Well-executed clinical trials are necessary to determine if a specific therapeutic approach is effective for a specific condition. While several misophonia research groups have begun working on clinical trials, the majority of these studies are small and do not compare

the experimental treatment to placebo controls or the absence of treatment. Philanthropy can drive higher quality clinical trial design but will require sufficient funding to ensure the inclusion of appropriate patient diversity and necessary controls.

## **Build a rigorous knowledge base**

As researchers learn more about misophonia, philanthropic organizations can play a vital role in developing unbiased content for patients and physicians. These organizations can bring additional resources to increase advocacy efforts, which will promote public funding of misophonia research and acknowledgment of misophonia by key medical organizations, such as the American Psychiatric Association.

## **Bring the field together**

Finally, across any philanthropic effort, funders should focus on strategies that will foster collaboration and interdisciplinary research within the field. Philanthropic funding can target research programs that cross multiple disciplines, require data sharing or collaboration, or ask funded researchers to contribute to the field through mentorship or other activities.

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STRONG FEELINGS OF  
DISGUST, RAGE, OR  
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CHEWING OR TAPPING.**

# PHILANTHROPIST FOREWORD

Our journey with misophonia started when our daughter began exhibiting symptoms as a young child. Family dinners around our kitchen table and riding in the car together were becoming increasingly difficult, as one of our daughter's primary triggers for overwhelming rage and disgust is the sound of our voices. We did not understand what was happening.

Fortunately, one of her healthcare providers had heard of misophonia, and she was diagnosed with the condition at the age of 12. We quickly learned that misophonia was a relatively unknown disorder, having only been named in the last 15 years, with few existing organizations dedicated to research or patient information. While misophonia has had coverage in mainstream media, very little science has been published. Our family searched unsuccessfully to find support and any effective options to help our daughter and us manage the condition.

While misophonia has been a significant challenge for our family, we are committed to making a difference in the field for our daughter and others who are struggling. To start, we helped produce the movie *Quiet Please*, a documentary focused on the psychological effects of misophonia. The film promotes awareness and understanding and helps others know that they are not alone.

We then engaged the Milken Institute's Center for Strategic Philanthropy to conduct the thorough landscape scan referenced within this Giving Smarter Guide and uncover the most important research priorities. We are now launching a misophonia research grantmaking program and have committed to significantly investing in misophonia research to ensure that the best scientists are working hard to help families like ours and yours. **There is hope.**



## PHILANTHROPIST FOREWORD

We see a lot of potential in the field, particularly in the promise of early researchers and their work. We also aim to inspire more scientists in the fields of neurology, psychology, and audiology to study misophonia.

We are committed to investing in accelerating progress toward treatments and ultimately a cure, but we know that we can't do it alone. Government funders, philanthropists, industry, and the patient community will each have an important role to play. We hope this guide will help us all to better navigate the path forward.

Many thanks to the Milken Institute, the staff of The REAM Foundation, and the subject matter experts who contributed their valuable time and effort to informing this report. We are filled with hope and confidence that answers are out there. Together, we will find them. Please join us in the fight against misophonia.

Steve and Diane Miller  
The REAM Foundation

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# MISOPHONIA OVERVIEW

Misophonia was first characterized in 2001 as “an abnormally strong reaction of the autonomic and limbic systems in response to sound.” In common terms, this means that individuals who suffer from misophonia respond to sound with a strong stress response (increased heart rate, skin perspiration), and activation of the brain regions involved in regulating emotions. Functionally, people with misophonia describe feeling intense anger, disgust, or anxiety in response to specific sounds—referred to as triggers—such as chewing. However, the volume of the sound does not seem to play a role in the physical response. In fact, people who suffer from misophonia report the same feelings regardless of how loud the sound is. Furthermore, many people report that seeing a visual cue associated with the specific trigger sound creates a similar level of discomfort. For example, if apple crunching is the trigger for someone experiencing misophonia, they will likely feel the same physical and emotional response regardless of whether the person eating an apple is directly beside them or across the room beyond earshot.

Since the initial description of misophonia, researchers and clinicians have verified that when an individual who suffers from misophonia is exposed to trigger sounds, they experience emotional and physiological responses, like increased heart rate, in addition to the activation of specific brain regions. Interestingly, the physical and emotional response is not elicited when the person makes the sound themselves. Additionally, there are some reports that a person suffering from misophonia responds most strongly to trigger sounds produced by individuals they are emotionally close to, such as a spouse or parent.

Many individuals living with misophonia have suggested that they experience the same feelings in response to specific visual cues or tactile sensations, such as seeing a person twirl his or her hair or the

## COMMON AUDITORY TRIGGERS

- PEN CLICKING
- GUM CHEWING
- APPLE EATING
- COUGHING
- THROAT CLEARING
- KEYBOARD TAPPING
- RUSTLING OF PLASTIC
- SNIFFLING
- JOINT CRACKING
- SLURPING



# MISOPHONIA OVERVIEW

feeling of certain fabrics, which are not associated with a sound. This suggests that misophonia or a similar phenomenon may extend to other sensory modalities.

## PATIENT VOICES

It makes me jump off my chair and I'll have to do something to make it stop, which is not the case with all of my other triggers. It's not like a sound you don't like, it's much more than that, it's completely different. It's something I feel in my stomach, like extreme anxiety. Or suddenly I feel overwhelmed, I can't think anymore, it just takes over everything.

*-Margot Noel, BBC World Service*

On one level I'll feel this intense rage, and then there's a whole other level going on where I'm trying to referee my responses, where I say, 'I know this isn't normal.'

*-Jennifer Smith, NJ Advance Media*

I've had an issue with sounds since I was in elementary school. My earliest memory of it is staring down a girl in my class who compulsively cleared her throat. By the time I got to college, I couldn't focus during exams. I can't tune the sounds out. In fact, once I hear them, they're the only things I can focus on.

*-Marisa Hillman, Popsugar.com*

At present, however, scientists and clinicians are unable to determine whether the sound sensitivity associated with misophonia is functionally different from similar emotional responses to other sensory inputs.

Finally, while misophonia seems to develop in childhood, there has been no published research on misophonia in children or adolescents, leaving a large gap in our understanding how the condition develops and the best ways to treat it.

### MISOKINESIA

Some researchers have begun using the term misokinesia to distinguish the response elicited by seeing certain movements or behaviors, such as fidgeting. However, it is not clear whether misokinesia is truly different from misophonia or simply a variation of misophonia.

# NEUROBIOLOGY OF MISOPHONIA

Misophonic reactions appear to be a complex response to sensory information from specific contexts. Case studies and scientific studies of the response suggest that many biological, sociocultural, auditory, and learning systems are involved. These systems are important to understand because they all likely play a role in the physiological response to misophonic triggers. Below, the systems linked to misophonia are described.

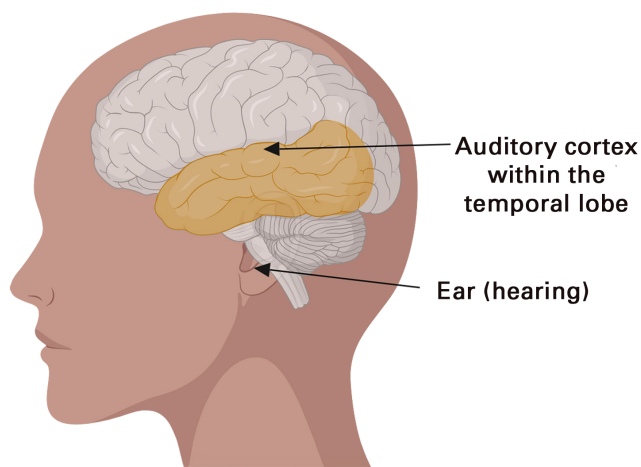
## AUDITION & AUDITORY PROCESSING

The auditory system is the sensory system responsible for the sense of hearing. It includes the complex structures within the ear and the neural structures in the brain, such as the auditory cortex, that are responsible for processing sound. Changes in either the physical structures (ear) or neural structures can alter the ability to perceive, understand, and respond to sound.

In misophonia, the most common triggers appear to be auditory triggers. There is some evidence that the auditory cortex of the brain in people who experience misophonia responds differently to neutral auditory stimuli than those without.

### Figure 1. The Auditory System

Core Components of the Auditory System



Sound waves are sensed by specialized cells in the ear, and neural responses are transmitted to the brain to allow sound perception. The primary auditory cortex is located within the temporal lobe (shown in yellow) of the brain.

Source: Milken Institute.

# NEUROBIOLOGY OF MISOPHONIA

## ATTENTION

Attention is the process of selectively concentrating on discrete information or sensory inputs. Attention allows individuals to identify the source of sensory cues and can lead to “tuning” of the relevant neurons in the brain to the sensory information.

In misophonia, patients report the inability to refocus their attention on other cues when a trigger stimulus is present.

## LEARNING AND MEMORY

Learning is the process of acquiring or modifying new or existing knowledge, skills, preferences, or behaviors. Learning occurs as an individual interacts with the environment and allows for the individual to predict future events based on current information. Thus, the individual can optimize behavior to the specific conditions. Specific types of learning include:

**Habituation:** One of the simplest forms of learning, habituation is the process of decreasing or ceasing response to an unimportant repeated or prolonged stimuli.

Figure 2. Habituation



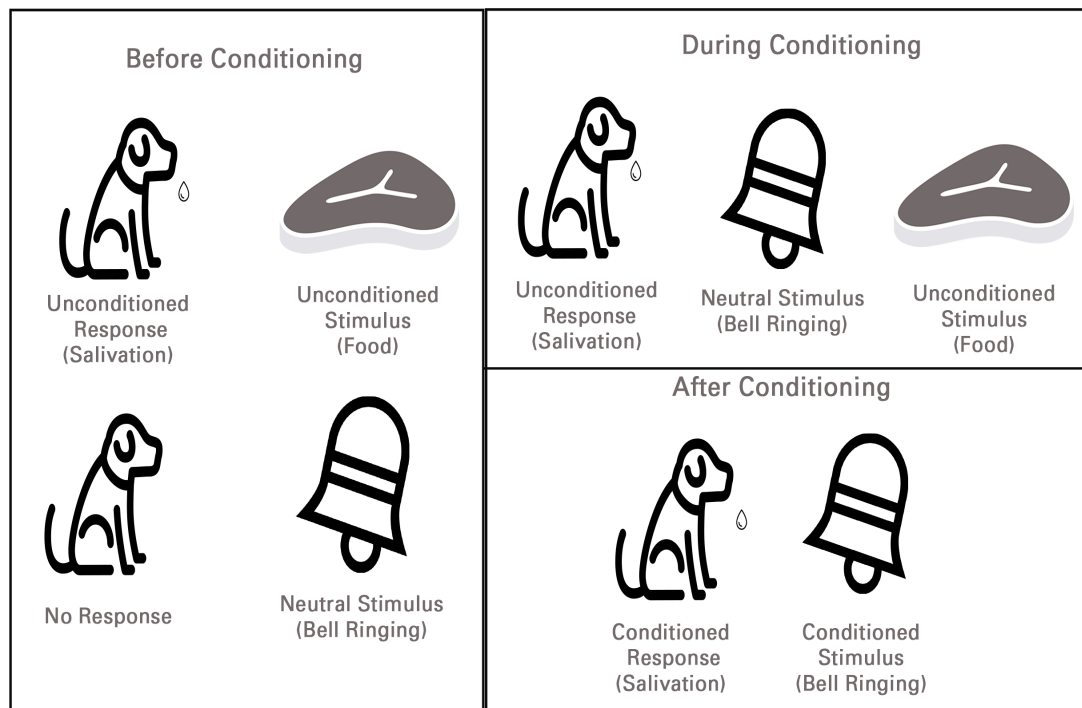
Source: Milken Institute

**Habituation** is a learning process in which an organism decreases a fear or stress response with repeated exposure. In the example to the left, a woman moves into an apartment in the city. As she attempts to settle in, she is extremely bothered by the noise from the park across the street. Her annoyance and sensitivity to the sounds decrease over time.

# NEUROBIOLOGY OF MISOPHONIA

**Classical Conditioning:** One of the earliest described mechanisms of learning, shown through Ivan Pavlov’s dogs, involved the simultaneous presentation of a highly salient stimulus (food) with a neutral stimulus (bell ringing). In the classic example, the physiologically relevant stimulus elicits a response such as salivation. But after repeated pairing, the bell (a previously neutral stimulus) elicits the same response (salivation) in the absence of the food. Pavlov referred to the learning as a “conditioned reflex.” Since this early work, classical conditioning has been studied and is thought of as a stereotypical mechanism of learning.

**Figure 3. Classical Conditioning**



Source: Milken Institute.

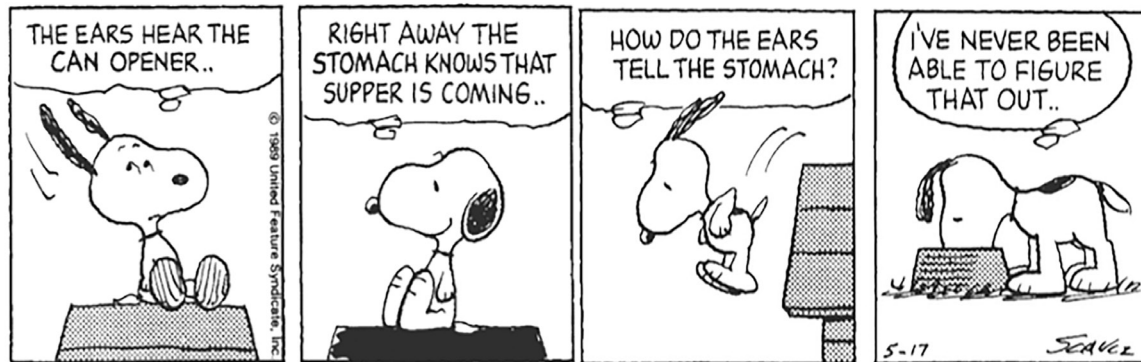
Classical conditioning describes a processing of pairing stimuli or experiences such that the organism is able to associate previously unrelated information. In the example above, the dog is shown salivating in response to food as an unconditioned response and not responding to the bell ringing because it is a neural stimulus. During conditioning, the dog is presented the food paired with the ringing bell such that the dog begins to associate the sound of bell with the food. Over time, the ringing bell alone is able to drive a salivation response, as though the food is present.



# NEUROBIOLOGY OF MISOPHONIA

Neural imaging of misophonia patients showed activation of brain regions important to learning and memory. Many people experiencing misophonia describe specific events or situations that trigger the response and describe the inability to stop responding no matter how long the stimulus is present.

**Figure 4. Snoopy's Conditioning**



Source: ©PEANUTS, © 1989 Peanuts Worldwide LLC.

## SOCIAL EVALUATION

Social evaluation is the process of evaluating other individuals and their behaviors.

Many of the misophonic triggers are sounds or sensory sensations caused by another person (rather than one's self or an inanimate object). Furthermore, several researchers have noted that there seems to be an assessment that sound or action is socially unacceptable, perhaps mediating the misophonic response.

## EMOTION

Emotions are characterized by mental and physiological responses to the environment and situations that are expressed through physical changes such as facial expression, heart rate, and perspiration. Common emotions include happiness, sadness, anger, fear, disgust, and surprise.

# NEUROBIOLOGY OF MISOPHONIA

People with misophonic reactions report feelings of disgust and anger, in addition to feelings of anxiety in response to the misophonic trigger. Additionally, a recent neural imaging study found that regions of the brain associated with high-order emotional regulation, such as the anterior insular cortex, were engaged during a misophonic response. High-order emotional regulation includes processes such as emotional awareness and empathy, both of which are thought to integrate complex information from many regions of the brain to drive the response.

## **INTEROCEPTION (PERCEPTION OF INTERNAL BODILY STATES)**

Interoception is the process of assessing and evaluating one's own internal physiological state. People with increased interoceptive sensitivity have an increased ability to perceive internal bodily cues such as heart rate, hunger, temperature, and pain. It is thought that this difference in perception may play a role in heightened emotional responses to specific situations.

There is a growing body of knowledge suggesting that the perception of bodily states can feed back to influence emotions and perceived importance (salience). Recent work has also found that people with misophonia report increased awareness of internal sensations, suggesting that interoception may play a role in the misophonic response.

## **RESPONSE INHIBITION**

Response inhibition is the conscious suppression of behavior that is determined to be inappropriate or unnecessary. Response inhibition is a hallmark of higher-level, executive function and broadly thought to be regulated by the prefrontal cortex in the brain. Neural development of the prefrontal cortex, and by extension executive function, are thought to continue to develop through early adulthood.

People with misophonia report intentionally controlling their behavior following a misophonic trigger to avoid overtly responding with anger or disgust.

# NEUROBIOLOGY OF MISOPHONIA

Because effort is exerted to control one's own response, it seems that misophonics may be overly critical of their own behavior, often feeling a loss of control, following an emotional reaction.

## WHAT CAUSES MISOPHONIA

At present, it is not known what causes misophonia. However, misophonia appears to develop in childhood, on average around age 12. However, no studies have definitively shown when misophonia develops and case-reports suggest that misophonia may develop in much younger children. Childhood and adolescence are critical periods in neural development, as the brain is extremely receptive to learning, and many neurologically based conditions have childhood and teenage onsets. Several hypotheses have emerged to explain how misophonia develops. These hypotheses, not necessarily mutually exclusive models, are outlined below.

## CONDITIONED RESPONSE

The first hypothesis for misophonia development is that misophonia is formed through fear/emotion learning, known as classical conditioning. Classical conditioning occurs when a trigger stimulus (potentially a sound) is paired with a harmful emotional response, like fear or disgust. Based on this model, a person experiences the trigger sound in close proximity to an unpleasant experience. The unpleasant experience causes a physiological response and, over time, the sound becomes associated with the unpleasant experience, such that the sound alone is able to directly elicit the physiological response.

## CHILDHOOD HEARING LOSS

Audiologists have described similarities in tinnitus, hyperacusis, and misophonia. Tinnitus and hyperacusis are known to follow hearing loss (temporary or permanent). Several researchers have suggested that misophonia patients may also have experienced temporary hearing loss as children (based on in-clinic, self-reported data). The hypothesis is that temporary hearing loss primes the auditory system to be over-sensitized. As a result of increased sensitivity, some

## RELATED AUDITORY CONDITIONS

**Tinnitus** is characterized by the perception of ringing in the ears. However, research has shown that altered neural activity in the brain, rather than changes to the ear, typically underlie the condition.

**Hyperacusis** is a condition in which individuals perceive certain sound frequencies as much louder than they are. This condition seems to arise from a change in the way the brain processes sound rather than initial processing in the ear.

# NEUROBIOLOGY OF MISOPHONIA

sounds may be perceived as unpleasant. The unpleasant nature of sound may become associated with specific sounds leading to misophonia.

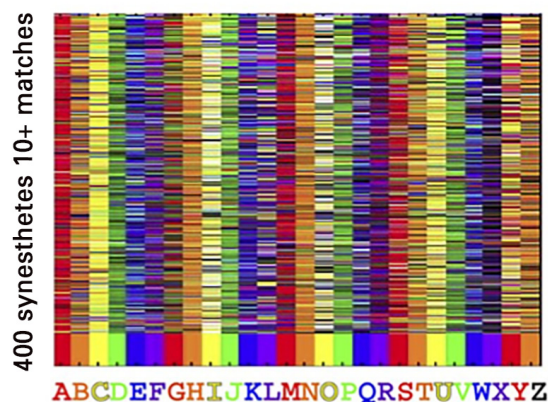
## SPURIOUS LEARNING

Over the last two decades, the field of synesthesia has established that, during development, the brain learns associations that are not relevant. A key example is associating colors and letters based on the dominant Fisher-Price magnet set of the 1980s (A is red, B is orange, C is yellow, D is green). While the child's brain learns the color with the letter, the information is not relevant to later learning how to spell. Learning theory suggests that the color-letter association should be lost over time. Researchers have found that the associations between sensory modalities most commonly occur in parts of the brain that are near to one another. Interestingly, the auditory cortex is very near the anterior insular cortex (AIC), which appears to be involved in the abnormal emotional response associated with misophonia. Perhaps the proximity in the auditory cortex and the AIC is leading to spurious associations between these two regions, ultimately causing misophonia in a similar manner to how synesthesia develops.

## SYNESTHESIA

Synesthesia is a neurological phenomenon in which one sensory modality leads to simultaneously experiencing a secondary sensory modality or cognitive pathway. A common form of synesthesia is the association of sounds with colors.

**Figure 5. Color Associations in a Subset of Synesthetes**



The graphic shows the results of 400 synesthetes with 10 or more letters matching the Fisher-Price alphabet magnet set, manufactured predominantly in the 1970s and 1980s. Each column corresponds to a letter-color association, and each row displays a participant's response. Overall, the rate of matched association exceeds chance, suggesting that spurious learning may drive synesthesia.

Source: Witthoft, Nathan, Jonathan Winawer, and David M. Eagleman. 2015. "Prevalence of Learned Grapheme-Color Pairings in a Large Online Sample of Synesthetes." *PLoS One* 10 (3): e0118996.



# NEUROBIOLOGY OF MISOPHONIA

## HEIGHTENED INTEROCEPTION

Research has shown that conscious bodily perception can modulate the emotional response. For example, an elevated heart rate can contribute to a heightened sense of anxiety even when the external circumstance does not warrant an anxious response. One hypothesis is that people with misophonia are more aware of and sensitive to their peripheral responses, including those that are emotionally induced. Once an emotional response is triggered, some people respond with greater magnitude. For example, if mealtime is unpleasant, and a family member audibly chews his or her food, the emotional response to the unpleasant mealtime may be greater in some individuals. Over time, that response becomes associated with the sound of chewing creating trigger sounds. This association leads to triggers, which under normal circumstances are below the threshold to produce an emotional response, but which now cause a misophonic response.

## FAMILIAL OR GENETIC PREDISPOSITION

There is increasing evidence that misophonia can run in families. One recent study of 15 individuals with misophonia in a single family in Brazil suggests that the condition may be heritable. While this implies that there may be specific genetic contributors, we are not aware of any peer-reviewed studies that identify specific genes associated with misophonia.

## PSYCHIATRIC TRAIT

Several clinicians and researchers with a background in psychiatry have suggested that the majority of individuals seeking care for misophonia have a co-morbid psychiatric diagnosis, such as generalized anxiety disorder or post-traumatic stress disorder. However, misophonia is not consistently experienced within a specific psychiatric patient population, and there does not seem to be a specific psychiatric diagnosis common to all misophonia sufferers. Two research groups report an association with anxiety disorders broadly, and two groups report an overlap in a subset of obsessive compulsive disorder (OCD) symptoms.



## NEUROBIOLOGY OF MISOPHONIA

Because the presentation of misophonia appears to be highly stereotyped while co-morbidities are heterogeneous, some researchers have speculated that misophonia is a trait that signals a difference in the way the brain responds to sensory stimuli. In a similar example, a recent study found that synesthesia, which is a trait, not a disorder on its own, occurs in approximately 30 percent of children with autism. In summary, misophonia may be more common in individuals with specific neuropsychiatric disorders and may indicate that the brains of individuals who experience misophonia simply respond to the world in a different way than people who do not experience it.

# DIAGNOSIS AND PREVALENCE

Many individuals who believe they suffer from misophonia are met with confusion, skepticism, and very little assistance when they seek medical help. As there is sparse medical information available on the condition, most clinicians do not know what misophonia is and are unable to diagnosis it. In 2013, a group of researchers in Amsterdam proposed diagnostic criteria that could be used to determine whether a patient has misophonia. These proposed criteria have not yet been accepted by the American Psychiatric Association, however.

## **Proposed diagnostic criteria:**

- A. The presence or anticipation of a specific sound, produced by a human being (e.g., eating sounds, breathing sounds), provokes an impulsive, aversive physical reaction, which starts with irritation or disgust that instantaneously becomes anger.
- B. This anger initiates a profound sense of loss of self-control with rare, but potentially aggressive, outbursts.
- C. The person recognizes that the anger or disgust is excessive, unreasonable, or out of proportion to the circumstances or the provoking stressor.
- D. The individual tends to avoid the misophonic situation, or if he/she does not avoid it, endures encounters with the misophonic sound situation with intense discomfort, anger, or disgust.
- E. The individual's anger, disgust, or avoidance causes significant distress (i.e., it bothers the person that he or she has the anger or disgust) or significantly interferes in the person's day-to-day life. For example, the anger or disgust may make it difficult for the person to perform important tasks at work, meet new friends, attend classes, or interact with others.

## DIAGNOSIS AND PREVALENCE

F. The person's anger, disgust, and avoidance are not better explained by another disorder, such as obsessive-compulsive disorder (i.e., disgust in someone with an obsession about contamination) or post-traumatic stress disorder (i.e., avoidance of stimuli associated with a trauma related to threatened death, serious injury, or threat to the physical integrity of self or others).

The lack of diagnostic agreement has made it difficult for clinicians to find accurate and timely information or to bill insurance companies for services. For individuals with misophonia, these are major barriers to receiving health-care.

### DIAGNOSTIC TOOLS

Presently, there are no objective tests for diagnosing misophonia. However, several self-report scales have been developed to determine the presence of and severity of misophonia. These questionnaires typically ask a person whether specific sounds lead to emotional responses such as anger, and to what degree the emotional response impacts one's life. For a self-report scale to be most effective in the clinic, it needs to be validated and shown to identify correctly individuals who suffer from misophonia while excluding false positives and false negatives. Unfortunately, none of the developed questionnaires has been validated. However, four of the most commonly used tools show key commonalities in how scientists and clinicians are describing misophonia.

#### FALSE POSITIVES AND NEGATIVES

**False Positive:** Falsely receiving a positive diagnosis for a specific disease when one does not actually have that disease or illness.

**False Negative:** Falsely receiving a negative diagnosis for a disease when one does have that disease or illness.



# DIAGNOSIS AND PREVALENCE

## MISOPHONIA ASSESSMENT QUESTIONNAIRE

The Misophonia Assessment Questionnaire was the first clinical assessment tool developed for misophonia. It was designed by audiologist Dr. Marsha Johnson to assess the degree to which misophonia interferes with an individual's life. It contains 21 statements that patients rate on a scale of 0 ("not at all") to 3 ("almost all the time"). This scale focuses on "sound issues," which some have argued would make it difficult to distinguish between misophonia and other sound intolerance conditions.

1. My sound issues make me unhappy.
2. My sound issues create problems for me.
3. My sound issues have made me angry.
4. I feel that no one understands my problems with certain sounds.
5. My sound issues do not seem to have a known cause.
6. My sound issues make me feel helpless.
7. My sound issues interfere with my social life.
8. My sound issues make me feel isolated.
9. My sound issues create problems for me in groups.
10. My sound issues negatively affect my work life.
11. My sound issues make me feel frustrated.
12. My sound issues impact my entire life negatively.
13. My sound issues make me feel guilty.
14. My sound issues have been classified as "crazy."
15. I feel that no one can help me with my sound issues.
16. My sound issues make me feel hopeless.
17. I feel that my sound issues will only get worse with time.
18. My sound issues impact my family relationships.
19. My sound issues have affected my ability to be with other people.
20. My sound issues have not been recognized as legitimate.
21. I am worried that my whole life will be affected by sound issues.

# DIAGNOSIS AND PREVALENCE

## THE AMSTERDAM MISOPHONIA SCALE

The Amsterdam Misophonia rating scale asks individuals to rate the degree to which exposure to misophonia triggers disrupt daily life. It is adapted from an obsessive-compulsive scale known as the Yale-Brown Obsessive-Compulsive Scale and was originally published in 2013. The scale specifically states that misophonic “sounds” can refer to any misophonic trigger, including sound, sight, touch, or motion.

Question	0	1	2	3	4
How much of your time is occupied by misophonic sounds?	None	Mild	Moderate	Severe	Extreme
How much do these sounds interfere with your social, work, or role functioning?	None	Mild	Moderate	Severe	Extreme
How much distress do the misophonic sounds cause you?	None	Mild	Moderate	Severe	Extreme
How much effort do you make to resist the (thoughts about the) misophonic sounds?	Always makes an effort to resist	Tries most of the time	Makes some effort	Yields to all misophonic sounds	Completely and willingly yields to all obsessions
How much control do you have over your thoughts about the misophonic sounds?	Complete control	Much control	Moderate control	Little control	No control
Have you been avoiding doing anything, going any place, or being with anyone because of your misophonia?	None	Mild	Moderate	Severe	Extreme

# DIAGNOSIS AND PREVALENCE

## MISOPHONIA QUESTIONNAIRE

The Misophonia Questionnaire was developed by researchers at the University of South Florida and published in 2014. This questionnaire consists of three separate scales to individually describe symptoms, behavioral responses, and severity.

The **first section** lists eight items and asks how sensitive the individual is to specific types of sounds in comparison to other people. Each item is rated on a scale of 0 to 4 (0 meaning not at all true and 4 meaning always true).

1. People eating (e.g., chewing, swallowing, lips smacking, slurping, etc.).
2. Repetitive tapping (e.g., pen on table, foot on floor, etc.).
3. Rustling (e.g., plastic, paper, etc.).
4. People making nasal sounds (e.g., inhale, exhale, sniffing, etc.).
5. People making throat sounds (e.g., throat clearing, coughing, etc.).
6. Certain consonants and/or vowels (e.g., “k” sounds, etc.).
7. Environmental sounds (e.g., clock ticking, refrigerator humming, etc.).
8. Other: \_\_\_\_\_

The **second section** probes emotional and behavioral responses to the trigger sounds. This section has 11 items, also rated on a scale from 0 to 4 (0 meaning never and 4 meaning always). These questions ask how often the individual takes a specific action or has a specific feeling after becoming aware of the sound.

1. Leave the environment to a place where the sound(s) cannot be heard anymore?
2. Actively avoid certain situations, places, things, and/or people in anticipation of the sound(s)?
3. Cover your ears?
4. Become anxious or distressed?

## DIAGNOSIS AND PREVALENCE

5. Become sad or depressed?
6. Become annoyed?
7. Have violent thoughts?
8. Become angry?
9. Become physically aggressive?
10. Become verbally aggressive?
11. Other: \_\_\_\_\_

The **final section** of the questionnaire is a 15-point scale asking the individual to rank the severity of the sound sensitivity. This section is based on the National Institute of Mental Health Global Obsessive-Compulsive Scale and modified to reflect misophonia symptoms.

1-3	Minimal within range of normal or very mild sound sensitivities. I spend little time resisting or being affected by my sound sensitivities. Almost no or no interference in daily activity.
4-6	Mild sound sensitivities. Mild sound sensitivities that are noticeable to me and to an observer cause mild interference in my life and which I may resist or be affected by for a minimal period of time. Easily tolerated by others.
7-9	Moderate sound sensitivities. Sound sensitivities that cause significant interference in my life and which I spend a great deal of conscious energy resisting or being affected by. Require some help from others to function in daily activity.
10-12	Severe sound sensitivities. Sound sensitivities that are crippling to me, interfering so that daily activity is "an active struggle." I may spend full time resisting my sound sensitivities or being affected by them. Require much help from others to function.
13-15	Very severe sound sensitivities. Sound sensitivities that completely cripple me so that I require close supervision over eating, sleeping, and so forth. It is hard to function on a day-to-day basis because of this.

# DIAGNOSIS AND PREVALENCE

## MISOPHONIA ACTIVATION SCALE

This 11-point scale was created by Misophonia-UK, a not-for-profit organization as a guide to help clinicians and patients assess the severity of misophonia reaction. The organization refers to it as “a work in progress.”

Level	Reaction
0	Person with misophonia hears a known trigger sound but feels no discomfort.
1	Person with misophonia is aware of the presence of a known trigger but feels no, or minimal, anticipatory anxiety.
2	Known trigger sound elicits minimal psychic discomfort, irritation, or annoyance. No symptoms of panic or fight-or-flight response.
3	Person with misophonia feels increasing levels of psychic discomfort but does not engage in any physical response. Sufferer may be hyper-vigilant to audio-visual stimuli.
4	Person with misophonia engages in a minimal physical response—non-confrontational coping behaviors, such as asking the trigger person to stop making the noise, discreetly covering one ear, or by calmly moving away from the noise. No panic or fight-or-flight symptoms exhibited.
5	Person with misophonia adopts more confrontational coping mechanisms, such as overtly covering their ears, mimicking the trigger person, engaging in other echolalias, or displaying overt irritation.
6	Person with misophonia experiences substantial psychic discomfort. Symptoms of panic and a fight-or-flight response begin to engage.
7	Person with misophonia experiences substantial psychic discomfort. Increasing use (louder, more frequent) of confrontational coping mechanisms. There may be unwanted sexual arousal. Sufferer may re-imagine the trigger sound and visual cues over and over again, sometimes for weeks, months, or even years after the event.
8	Person with misophonia experiences substantial psychic discomfort. Some violence ideation.
9	Panic/rage reaction in full swing. Conscious decision not to use violence on trigger person. Actual flight from vicinity of noise and/or use of physical violence on an inanimate object. Panic, anger, or severe irritation may be manifest in sufferer's demeanor.
10	Actual use of physical violence on a person or animal (i.e., a household pet). Violence may be inflicted on self (self-harming).



# DIAGNOSIS AND PREVALENCE

## EPIDEMIOLOGY

Several researchers have begun using some of the scales described above to assess the incidence of misophonia in the general population. Several notable studies have found that clinically significant misophonia is relatively common in the general population.

- A 2014 study of 483 American undergraduate college students found nearly 20 percent reported clinically significant misophonia symptoms.
- A 2017 study of 415 Chinese college students found 6 percent of respondents reported clinically significant misophonia symptoms.
- A 2018 study of 451 American undergraduate students as well as 377 online participants found 15.6 percent experience misophonia.

Despite these reports, many researchers have noted concerns with the reported high rates of misophonia because the tools have not been validated, and all measures rely on self-reporting—a methodology notorious for over-representing the actual rates. It is likely that nearly 20 percent of the population experiences a less disruptive form of misophonia, but a smaller fraction of the population experiences significant life disruption such as the inability to attend school, maintain relationships, or pursue employment goals.

# TREATMENT AND INTERVENTION

While the scientific and clinician communities have not identified a treatment or set of treatments for misophonia, several therapeutic approaches have been suggested and are being used in some clinics. There is no robust data on any treatment to guide or set outcome expectations; however, individual case-reports suggest that treatment may be helpful for some individuals.

## WHERE TO SEEK TREATMENT

The study of misophonia crosses several disciplines; the types of clinicians and therapists that might be helpful for individuals managing misophonia are also quite varied. Patients should seek care providers who are familiar with misophonia and related conditions. Misophonia patients may find that audiologists, psychiatrists, and/or psychologists are able to identify strategies to manage the condition.

## AUDIOLOGISTS

Audiologists specialize in hearing and balance disorders. Audiologists can help individuals who believe they have misophonia determine if another audiological disorder, such as tinnitus or hyperacusis, is present and may account for or contribute to the discomfort. Additionally, audiologists may be able to recommend techniques to mask the trigger sounds and determine appropriate next steps.

## PSYCHOLOGISTS

Psychologists are trained to help people manage and cope with mental health problems and/or life challenges. Psychologists generally use a variety of therapy techniques broadly referred to as talk therapy. Psychologists may be able to help individuals with misophonia develop coping skills to manage misophonia.

## PSYCHIATRISTS

Psychiatrists specialize in the diagnosis and treatment of mental health disorders. The limited epidemiological studies of misophonia

# TREATMENT AND INTERVENTION

suggest that many people with misophonia also suffer from other mental health conditions, such as anxiety disorders. Psychiatrists can provide recommendations for treatment, and where appropriate, medication for diagnosed mental health conditions. While there are no approved therapeutics for misophonia, treatment of additional conditions may help manage misophonia symptoms.

## EXPERIMENTAL INTERVENTIONS

Many therapeutic approaches have been proposed for misophonia. These approaches span many facets of the misophonic experience; however, no approach has achieved field-wide recognition for efficacy.

## SOUND MASKING

Several audiologists have suggested that “gain” may play an important role in developing strategies to manage misophonia. The basic principle is that any sound is more extreme in the absence of appropriate background noise and, conversely, equivalent sounds are perceived as relatively lower in the presence of high background noise. The auditory system adjusts its overall “gain” or sensitivity in the presence of background sound. Based on this insight, audiologists suggest a simple intervention of using background music or sound to mitigate misophonia. This is a common strategy suggested for other audiology disorders such as hyperacusis and tinnitus.

## EXPOSURE THERAPY (HABITUATION)

Exposure therapy was developed to slowly reintroduce stressful stimuli that individuals are managing through avoidance strategies. Avoidance strategies can exacerbate the negative emotion associated with specific stimuli because individuals are not able to re-learn positive or neutral associations. Exposure therapy is based on the concept of habituation in learning, whereby an unimportant, repeated, and/or prolonged stimuli elicits decreasing responses from the individual. This therapy is most commonly used for OCD patients. Currently, an exposure therapy clinical trial is underway for adults

# TREATMENT AND INTERVENTION

with misophonia. However, exposure therapy is relatively untested for use in children and therefore unlikely to be recommended for children or adolescents dealing with misophonia.

## **SOUND THERAPY (WEARABLE AND NON-WEARABLE)**

A related approach suggested by audiologists is to record the trigger sound for the misophonia patient and either mix the trigger sound with background noise or with acoustic components to allow the individual to learn to become habituated to the sound. The patient is thus given control of the sound, its volume, and frequency. This method is related to exposure therapy (described above) but without the controlled context of a clinical setting. Additionally, there is precedent to use hearing aids to deliver the sounds to patients with other auditory disorders such as hyperacusis.

## **STRESS REDUCTION TECHNIQUES**

As several research groups have begun to identify linkages between anxiety and misophonia, some clinicians are suggesting a variety of approaches to reduce stress. While all stress reduction techniques for managing misophonia are understudied, the following have been suggested: meditation, vagus nerve stimulation, and the use of autonomous sensory meridian response (ASMR) stimuli.

## **COGNITIVE BEHAVIORAL THERAPY**

Cognitive behavioral therapy (CBT) is the most widely used practice for improving mental health. CBT focuses on solving current problems and changing patterns of behavior, emotion, and cognition. CBT works by helping patients re-associate new emotions to troubling memories or by consciously thinking through problems more effectively. Researchers orchestrated a large open trial to study the use of CBT for misophonia. The publication reports that roughly half of patients had a reduction in misophonia severity. However, it is not clear what percentage of patients would resolve misophonia on their own. Additionally, CBT treatment would require that the treating clinician be trained in misophonia management.

### **ASMR DEFINED**

The Autonomous Sensory Meridian Response (ASMR) is an experience characterized by a tingling sensation of the skin and positive emotions elicited by specific auditory or visual stimuli. Whispering is one of the most commonly recognized stimuli; however, Bob Ross painting videos are commonly cited as enjoyable due to the ASMR response.

# KEY BARRIERS AND PHILANTHROPIC OPPORTUNITIES

While many individuals report experiencing misophonia, clinicians and researchers are still working to understand what misophonia is and how to help those who suffer from it. Through a systems-based analysis and discussions with key opinion leaders, we have identified six barriers preventing progress in the field and have outlined philanthropic opportunities to address these needs. The philanthropic opportunities were identified in collaboration with leaders in the field, including researchers, clinicians, funders, and advocates.

## **BARRIER 1: MISOPHONIA IS LARGELY UNCHARACTERIZED**

The first scientific report defining misophonia was published in 2001. Since then, a number of researchers have published case-reports and small studies confirming that a subset of the population experiences a strong emotional response following exposure to specific sensory stimuli (typically auditory and to a lesser extent visual). However, only a few studies have included methodical characterization of individuals who experience these reactions. A greater scientific foundation is needed to understand several facets of the condition.

### **1. Physiological systems involved in misophonic response**

A few studies have shown that individuals with misophonia display distinct physiological responses, such as increased skin conductance (a marker of stress and fight-or-flight response activation) and heart rate. However, more thorough characterization is needed if we are to understand how the relevant physiological systems are regulated to drive misophonia and lead to a stereotyped response.

### **2. Psychological symptoms**

Misophonia sufferers report a complex physical and emotional response to specific sensory stimuli, most commonly reporting acute anxiety, anger, disgust, or rage. Researchers have suggested that misophonia may be more common in individuals



## KEY BARRIERS AND PHILANTHROPIC OPPORTUNITIES

with auditory disorders such as tinnitus, as well as specific psychological conditions, including obsessive-compulsive and anxiety disorders. Additionally, individuals who experience misophonia commonly report using avoidance strategies to cope with negative emotional experiences. A thorough assessment of psychological functioning in this population could elucidate relationships with other better-characterized conditions or common co-morbidities.

### **3. Functional and structural brain measurements**

One brain imaging study has been published on misophonia. In this work, misophonia sufferers were shown to have increased activity in the anterior insular cortex, a region of the brain engaged in emotional experience, as well as changes in the connections between key brain regions involved in inhibiting unwanted behaviors. Brain connectivity studies could shed light on many facets of the condition; however, these studies are typically costly and require very specialized equipment and expertise.

### **4. Development progression and natural history**

While the vast majority of research on misophonia to date has been on adults at a single timepoint, clinicians have noted that severe symptoms seem to develop in early teen years, with annoyance to specific sounds present throughout childhood. The current reported age of onset (12) could be misleading, however, because it depends on parental memory and is subject to reporting errors and bias. Additionally, due to the absence of longitudinal studies, physicians are unable to provide any insight on long-term patient prognosis or assess the long-term efficacy of interventions. Finally, no peer-reviewed studies have looked into genetic/ familial risk associated with the development of misophonia.

### **5. Assessment of spectrum-like nature of misophonia**

A number of clinicians and researchers have suggested that misophonia exists on a spectrum where many people may experience annoyance but a subset experience truly disabling symptoms. However, these differences are currently undescribed using traditional clinical assessments.

# KEY BARRIERS AND PHILANTHROPIC OPPORTUNITIES

## PHILANTHROPIC OPPORTUNITY: SUPPORT DESCRIPTIVE RESEARCH FOR MISOPHONIA

Support for studies that elucidate what misophonia is and how it develops will create a foundation of understanding to develop scientifically based treatment approaches. Below, we outline five general areas where research is critically needed.

### 1. Interdisciplinary patient characterization of misophonia

Studies with functional collaboration among scientists and clinicians from disparate disciplines (audiology, psychology, and neuroscience) will be important for fostering consensus of the condition.

### 2. Pediatric and adolescent studies

Clinicians and researchers across disciplines unanimously agree that misophonia develops in childhood or adolescence, but there have been no studies of these age groups. Any work to understand the development and progression of misophonia in children will be highly important for the field.

### 3. Assessment of neurological structure and activity

The brain underlies sensory perception, emotional response, and behavior; however, studying the structure and activity of the brain requires sophisticated tools and specialty expertise. Understanding how neural systems are different in people suffering from misophonia will lead to better understanding of the condition and likely provide insight on appropriate treatment strategies.

### 4. Longitudinal study

The vast majority of research on misophonia to date has been on adults at a single timepoint. The lack of longitudinal studies precludes insight on long-term patient prognosis or assessing the long-term efficacy of interventions.

# KEY BARRIERS AND PHILANTHROPIC OPPORTUNITIES

While longitudinal studies are more difficult and costly, such studies will inform how misophonia changes over time. Clinical professionals may then discuss prognosis with patients and assess the efficacy of interventions.

## 5. Spectral nature of misophonia

Epidemiological studies suggest that up to 20 percent of the general population experiences misophonia. However, clinicians who see misophonia sufferers have suggested that a small subset of the population experiences a more severe form of misophonia. These differences suggest that misophonia may exist on a spectrum. Further research should focus on understanding these differences and what drives the relative disability among individuals.

In all work to understand and characterize misophonia, we recommend that studies consider population diversity, the spectral nature of misophonia, and the potential dependence of social context on the response.

## **BARRIER 2: THERE IS NO CONSENSUS TOOL TO IDENTIFY MISOPHONIA IN AN INDIVIDUAL**

There is an acute need for diagnostic tools to characterize misophonia within a population. The ideal tool would allow rapid, non-invasive, objective assessment to determine if an individual suffers from misophonia and to what degree. The development of such a consensus self-assessment tool would allow comparison of research across the field.

## **PHILANTHROPIC OPPORTUNITY: SUPPORT THE DEVELOPMENT OF DIAGNOSTIC TOOLS**

Diagnostic tools are vital to the study and treatment of any condition. These tools define who suffers from a specific condition and, therefore, who will most likely benefit from treatment. Ultimately, multiple tools will likely be necessary to identify misophonia across populations (adult

# KEY BARRIERS AND PHILANTHROPIC OPPORTUNITIES

vs. pediatric) and to determine degree of severity. At present, misophonia is insufficiently understood, and there are no paths to the development of a scientifically grounded diagnostic instrument.

To move the field toward the development of diagnostic tools we recommend:

## **1. Support for characterization studies that are linked to diagnostic tool development**

Because scientists and clinicians are still working to understand and describe misophonia, it is exceptionally difficult to develop tools to identify the condition. Studies that pair the development of diagnostic tools with research that increases our basic understanding of the condition will lead to accelerated development of an objective measure for misophonia.

## **2. Sponsor development of a consensus self-assessment tool**

Four of the most common self-report assessment tools are outlined in the diagnostic section above. However, these tools were developed by individual groups and have not been validated. Sponsoring researchers to come together to develop a consensus tool and supporting the validation of the consensus instrument would allow the field to adopt a single, standardized self-report tool. Additionally, this would allow for better comparison among studies.

## **BARRIER 3: PREVALENCE AND IMPACT ARE UNKNOWN**

Several self-report survey-based studies have suggested that 20 percent of the population experience significant life disruption due to misophonia. However, many within the researcher/clinician community believe that this is an overestimate, as many survey respondents may empathize with misophonia but not experience meaningful changes in quality of life. The overestimate in prevalence may result in an underestimate of the degree of disability caused by severe cases of misophonia and misrepresent the characteristics of individuals with

# KEY BARRIERS AND PHILANTHROPIC OPPORTUNITIES

misophonia. Ultimately, to assess prevalence, the field will need to use an objective measure of misophonia or a validated self-assessment tool in a representative population sample. Finally, there have been no studies to assess the impact (quality of life and financial cost) on individuals and their family members.

## **PHILANTHROPIC OPPORTUNITY: SUPPORT MISOPHONIA PREVALENCE STUDIES**

While these studies will remain difficult in the absence of validated and consensus-driven measures of misophonia, many researchers and clinicians felt that they were necessary and that findings would dramatically improve scientific knowledge and funding potential within the field.

### **1. Assess misophonia in a non-enriched population**

Assessment of misophonia in a representative community sample (such as a primary school) to develop prevalence and incidence rate projections.

### **2. Determine the impact of the condition**

Analyze the quality of life and economic impact of misophonia for individuals with varying degrees of misophonia-driven disability. Also, develop a model of impact based on accurate prevalence data.

## **BARRIER 4: CLINICIANS DO NOT HAVE A THERAPEUTIC TOOLBOX TO HELP MISOPHONIA PATIENTS**

Several research teams have embarked on clinical studies to assess specific therapeutic strategies, such as cognitive behavioral therapy. However, many of these studies have not included critical components such as a control population, which would allow clinicians and payers to determine whether a therapy is more effective than no treatment or a placebo treatment.

## **PHILANTHROPIC OPPORTUNITY: SUPPORT ROBUST CLINICAL TRIALS FOR MISOPHONIA**

As the research supporting misophonia continues to develop, the research to support interventional strategies will also need to advance.



# KEY BARRIERS AND PHILANTHROPIC OPPORTUNITIES

Overall, we identified several key areas to improve future clinical research.

## **1. Biological basis for interventional strategy**

Many of the current interventional strategies for misophonia are based on similarities in its presentation to other, better-characterized disorders, such as hyperacusis, obsessive-compulsive disorder, or anxiety disorders. As the fundamental science to characterize misophonia develops, treatment studies should build upon these findings to focus new treatments on the biological basis of misophonia.

## **2. Direct comparison of interventions**

The majority of published studies have assessed a single interventional strategy using self-report measures and found some patient benefit. However, there is essentially no information on the differential efficacy of intervention strategies.

## **3. Identification of best treatment for patient sub-populations**

Related to the lack of data on differential efficacy, there is no information on what treatment strategies are best suited to different “types” of misophonia patients. Several researchers have suggested that sub-populations could include those distinguished by age and emotional response (anger, anxiety, or disgust).

## **4. Integration of clinical trial best practices**

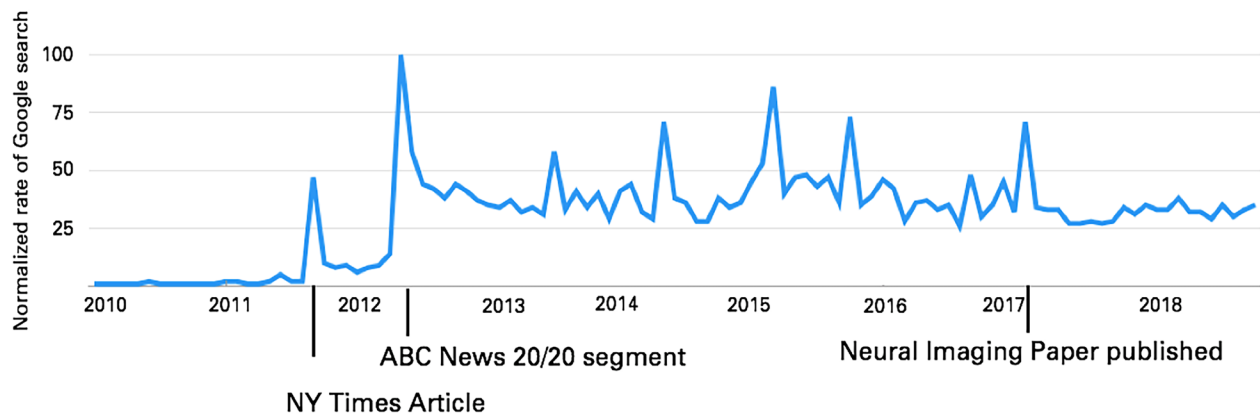
None of the published studies on intervention strategies has been funded through typical large funders, such as the National Institutes of Health or other institutions that can field studies large enough to include control groups. As a result, the field has no data on how placebo effects may impact intervention assessments, how strategy efficacy might vary by provider, or how interventions will scale to a population. As the field is able to attract additional funding, sample sizes in treatment trials will naturally increase, but researchers will need to include collaborators with extensive clinical trial experience to design and assess the interventions.

# KEY BARRIERS AND PHILANTHROPIC OPPORTUNITIES

## BARRIER 5: PHYSICIAN AND PUBLIC AWARENESS IS LOW

Despite a significant number of mainstream articles discussing misophonia in terms that the general public can relate to and understand, the clinical community is largely unaware of the condition. Physicians report not knowing which specialists are most appropriate to refer misophonia patients to for evaluation and treatment. The lack of an insurance reimbursement code for misophonia further limits physician awareness. Medical reimbursement codes provide a standard means for physicians to report patient diagnosis and obtain insurance reimbursement. In the absence of a reimbursement code, medical practices struggle to bill for and therefore treat medical conditions.

**Figure 6. Rate of “Misophonia” Occurrence within Google Search**



Source: Google Trends Data.

The Google Trends tool was used to determine the relative rate of misophonia being used as a search term between 2010 and 2018. Overall, the rate of search was extremely low prior to mid-2011, when a New York Times article featured misophonia. Approximately a year later, ABC News featured misophonia on 20/20. Since the 2012 news segment, the rate of misophonia search has remained higher, with brief increases likely corresponding to news articles in mainstream media. Most recently, in February 2017, the first neural imaging paper was published and many news outlets highlighted the finding, leading to the most recent increase in misophonia searches.

# KEY BARRIERS AND PHILANTHROPIC OPPORTUNITIES

Despite the coverage of misophonia in prominent media, the degree of patient suffering it causes is still broadly misunderstood and underestimated among the public. Key institutions, such as public schools, need health resources that are better informed about the condition, its symptoms and treatment. Such resources can provide validation of the experience as well as strategies for helping individuals find treatment.

## **PHILANTHROPIC OPPORTUNITY: BUILD GREATER BASE OF ACCESSIBLE MISOPHONIA KNOWLEDGE**

There are many ways to amplify physician and public support. While increased commentary in mainstream media highlights an upsurge in public interest in misophonia, the majority of the coverage discusses the phenomenon without providing insight on why the condition occurs or how to manage it. Further effort should focus on translating scientific findings for the general public and on providing actionable information for physicians and health systems. We outline key activities below to improve access to reliable information about misophonia.

### **1. Develop misophonia training materials for clinicians**

While there is not yet consensus on treatment strategies for misophonia, health-care providers should have access to scientifically sound information about what misophonia is and the best specialists to refer potential patients to. These materials should target audiologists, psychologists, and family practitioners.

### **2. Develop an online resource for parents**

Misophonia seems to develop most often in childhood. Parents are left navigating unusual and potentially difficult behaviors in their children with little help or empathy from health-care providers and educators because the condition is not generally recognized in medical practice. In other medically relevant areas, online resources have proven to be helpful tools for parents seeking to understand and address their children's symptoms and advocate for them. These tools should focus on explaining what misophonia is, what is known about the biology of the condition, and provide resources and coping strategies for those suffering from it.

# KEY BARRIERS AND PHILANTHROPIC OPPORTUNITIES

## **3. Advocacy for insurance reimbursement codes and sufficient payment for providers**

In the absence of insurance reimbursement, many health-care systems do not have a means to receive payment for treatment services. Misophonia does not have a reimbursement code for Medicaid and Medicare. This gap essentially makes misophonia an “unbillable” condition within U.S. health-care systems, preventing progress and awareness. Additionally, misophonia is not outlined in the most recent primary psychiatric diagnostic manual, The Diagnostic and Statistical Manual of Mental Disorders (DSM-5). Acknowledgment of misophonia in either case will require further scientific work and advocacy and will lead to greater patient access to scientifically based health care for misophonia.

## **BARRIER 6: THE INTERDISCIPLINARY NATURE OF THE FIELD HAS LED TO FRAGMENTATION**

Misophonia appears to be a complex condition involving many physiological and psychological processes. Audiologists, psychologists, and neuroscientists are involved in understanding the condition and developing therapeutic strategies. However, scientists and clinicians in each of these disciplines approach misophonia from unique perspectives. Very little interdisciplinary research has occurred, which has limited cross-disciplinary patient characterization and problem solving.

## **PHILANTHROPIC OPPORTUNITY: USE FUNDING AS A MEANS TO BRING THE FIELD TOGETHER**

Scientific philanthropy can play a pivotal role in addressing the fragmentation of the research within the field. A philanthropic funder, with an eye for coordination and collaboration, can drive increased field-wide consensus and accelerate progress within the field far beyond individual “one-off” gifts. Any funder looking to move into this area should consider:

- Bringing scientists together from different disciplines to understand misophonia and test treatment strategies.
- Community data-sharing practices.
- Potential utility of an interdisciplinary steering committee to articulate field priorities and identify areas of field-wide consensus.

# KEY INITIATIVES

## **INTERNATIONAL MISOPHONIA RESEARCH NETWORK (IMRN)**

The IMRN consists of a group of researchers who support scientific study to improve the treatment and management of misophonia. The IMRN Research Advisory Board consists of 26 clinicians and researchers across research disciplines. These advisors collaboratively discuss research directions for the field and fundraise for research projects focused on misophonia. Additionally, the IMRN works to develop online materials for patients, physicians, and parents to facilitate improved understanding of misophonia and options for coping strategies and symptom management.

## **MISOPHONIA ASSOCIATION**

The Misophonia Association brings together patients and clinicians to support education, advocacy, and research for individuals suffering from misophonia. This group has hosted five conventions to bring patients together to discuss and learn about misophonia.



# MISOPHONIA ADVISORY GROUP

We graciously thank the scientists and advisors who participated in the Milken Institute, Center for Strategic Philanthropy Misophonia Retreat in July 2018. The informative discussions before, during, and after the retreat were critical to identifying the key unmet needs and ideal philanthropic opportunities to benefit patients and advance misophonia research.

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# REFERENCES

Aazh, Hashir, Don McFerran, and Brian C. J. Moore. 2018. "Uncomfortable Loudness Levels among Children and Adolescents Seeking Help for Tinnitus and/or Hyperacusis." *International Journal of Audiology* 57 (8): 618–23. <https://doi.org/10.1080/14992027.2018.1453617>.

Baguley, D. M., T. E. Cope, and D. J. McFerran. 2016. "Functional Auditory Disorders." *Handbook of Clinical Neurology* 139: 367–78. <https://doi.org/10.1016/B978-0-12-801772-2.00032-1>.

Brout, Jennifer J., Miren Edelstein, Mercede Erfanian, Michael Mannino, Lucy J. Miller, Romke Rouw, Sukhbinder Kumar, and M. Zachary Rosenthal. 2018. "Investigating Misophonia: A Review of the Empirical Literature, Clinical Implications, and a Research Agenda." *Frontiers in Neuroscience* 12: 36. <https://doi.org/10.3389/fnins.2018.00036>.

Bruxner, George. 2016. "'Mastication Rage': A Review of Misophonia - An Under-Recognised Symptom of Psychiatric Relevance?" *Australasian Psychiatry: Bulletin of Royal Australian and New Zealand College of Psychiatrists* 24 (2): 195–97. <https://doi.org/10.1177/1039856215613010>.

Cavanna, Andrea E. 2014. "What Is Misophonia and How Can We Treat It?" *Expert Review of Neurotherapeutics* 14 (4): 357–59. <https://doi.org/10.1586/14737175.2014.892418>.

Edelstein, Miren, David Brang, Romke Rouw, and Vilayanur S. Ramachandran. 2013. "Misophonia: Physiological Investigations and Case Descriptions." *Frontiers in Human Neuroscience* 7: 296. <https://doi.org/10.3389/fnhum.2013.00296>.

Ferreira, Gabriela M., Ben J. Harrison, and Leonardo F. Fontenelle. 2013. "Hatred of Sounds: Misophonic Disorder or Just an Underreported Psychiatric Symptom?" *Annals of Clinical Psychiatry* 25 (4): 271–74.

Hillman, Marisa. 2018. "I Have Misophonia — and It's Not the Joke Everyone Thinks It Is." *POPSUGAR*. June 14, 2018. <https://www.popsugar.com/node/44746852>.

Janik McErlean, Agnieszka B., and Michael J. Banissy. 2018. "Increased Misophonia in Self-Reported Autonomous Sensory Meridian Response." *PeerJ* 6: e5351. <https://doi.org/10.7717/peerj.5351>.

## REFERENCES

Jastreboff, Margaret M., and Pawel J. Jastreboff. 2001. "Hyperacusis." *AudiologyOnline*. June 18, 2001. <https://www.audiologyonline.com/articles/hyperacusis-1223>.

Jastreboff, Pawel J., and Margaret M. Jastreboff. 2015. "Decreased Sound Tolerance: Hyperacusis, Misophonia, Diplacusis, and Polyacusis." *Handbook of Clinical Neurology* 129: 375–87. <https://doi.org/10.1016/B978-0-444-62630-1.00021-4>.

Kamody, Rebecca C., and Garry S. Del Conte. 2017. "Using Dialectical Behavior Therapy to Treat Misophonia in Adolescence." *The Primary Care Companion for CNS Disorders* 19 (5). <https://doi.org/10.4088/PCC.17102105>.

Kumar, Sukhbinder, Olana Tansley-Hancock, William Sedley, Joel S. Winston, Martina F. Callaghan, Micah Allen, Thomas E. Cope, Phillip E. Gander, Doris-Eva Bamiou, and Timothy D. Griffiths. 2017. "The Brain Basis for Misophonia." *Current Biology: CB* 27 (4): 527–33. <https://doi.org/10.1016/j.cub.2016.12.048>.

McGuire, Joseph F., Monica S. Wu, and Eric A. Storch. 2015. "Cognitive-Behavioral Therapy for 2 Youths with Misophonia." *The Journal of Clinical Psychiatry* 76 (5): 573–74. <https://doi.org/10.4088/JCP.14cr09343>.

McKay, Dean, Se-Kang Kim, Lauren Mancusi, Eric A. Storch, and Christopher Spankovich. 2018. "Profile Analysis of Psychological Symptoms Associated With Misophonia: A Community Sample." *Behavior Therapy* 49 (2): 286–94. <https://doi.org/10.1016/j.beth.2017.07.002>.

Spencer Kent | NJ Advance Media for NJ.Com 2018. "Do Chewing Sounds Drive You Insane? Have You Heard of Misophonia?" June 24, 2018. [https://www.nj.com/news/index.ssf/2018/06/do\\_chewing\\_sounds\\_drive\\_you\\_insane\\_have\\_you\\_heard.html](https://www.nj.com/news/index.ssf/2018/06/do_chewing_sounds_drive_you_insane_have_you_heard.html).

Quek, Tian Ci, Cyrus SH Ho, Carol C. Choo, Long H. Nguyen, Bach X. Tran, and Roger C. Ho. 2018. "Misophonia in Singaporean Psychiatric Patients: A Cross-Sectional Study." *International Journal of Environmental Research and Public Health* 15 (7). <https://doi.org/10.3390/ijerph15071410>.

Rouw, Romke, and Mercede Erfanian. 2018. "A Large-Scale Study of Misophonia." *Journal of Clinical Psychology* 74 (3): 453–79. <https://doi.org/10.1002/jclp.22500>.

## REFERENCES

Sanchez, Tanit Ganz, and Fúlvvia Eduarda da Silva. 2018. "Familial Misophonia or Selective Sound Sensitivity Syndrome: Evidence for Autosomal Dominant Inheritance?" *Brazilian Journal of Otorhinolaryngology* 84 (5): 553–59. <https://doi.org/10.1016/j.bjorl.2017.06.014>.

Schröder, Arjan, Rosanne van Diepen, Ali Mazaheri, Diamantis Petropoulos-Petalas, Vicente Soto de Amesti, Nienke Vulink, and Damiaan Denys. 2014. "Diminished N1 Auditory Evoked Potentials to Oddball Stimuli in Misophonia Patients." *Frontiers in Behavioral Neuroscience* 8: 123. <https://doi.org/10.3389/fnbeh.2014.00123>.

Schröder, Arjan E., Nienke C. Vulink, Arnoud J. van Loon, and Damiaan A. Denys. 2017. "Cognitive Behavioral Therapy Is Effective in Misophonia: An Open Trial." *Journal of Affective Disorders* 217: 289–94. <https://doi.org/10.1016/j.jad.2017.04.017>.

Schröder, Arjan, Nienke Vulink, and Damiaan Denys. 2013. "Misophonia: Diagnostic Criteria for a New Psychiatric Disorder." *PloS One* 8 (1): e54706. <https://doi.org/10.1371/journal.pone.0054706>.

Schwartz, Paula, Jason Leyendecker, and Megan Conlon. 2011. "Hyperacusis and Misophonia: The Lesser-Known Siblings of Tinnitus." *Minnesota Medicine* 94 (11): 42–43.

Tavassoli, Teresa, Lucy Jane Miller, Sarah A. Schoen, Jennifer Jo Brout, Jillian Sullivan, and Simon Baron-Cohen. 2018. "Sensory Reactivity, Empathizing and Systemizing in Autism Spectrum Conditions and Sensory Processing Disorder." *Developmental Cognitive Neuroscience* 29: 72–77. <https://doi.org/10.1016/j.dcn.2017.05.005>.

Wallis, Lucy. 2018. "The Crunch of an Apple Makes Me Want to Run Away," November 20, 2018, sec. Stories. <https://www.bbc.com/news/stories-46193709>.

Webber, Troy A., Patricia L. Johnson, and Eric A. Storch. 2014. "Pediatric Misophonia with Comorbid Obsessive-Compulsive Spectrum Disorders." *General Hospital Psychiatry* 36 (2): 231.e1-2. <https://doi.org/10.1016/j.genhosppsych.2013.10.018>.

Witthoft, Nathan, Jonathan Winawer, and David M. Eagleman. 2015. "Prevalence of Learned Grapheme-Color Pairings in a Large Online Sample of Synesthetes." *PloS One* 10 (3): e0118996. <https://doi.org/10.1371/journal.pone.0118996>.

Wu, Monica S., Adam B. Lewin, Tanya K. Murphy, and Eric A. Storch. 2014. "Misophonia: Incidence, Phenomenology, and Clinical Correlates in an Undergraduate Student Sample." *Journal of Clinical Psychology* 70 (10): 994–1007. <https://doi.org/10.1002/jclp.22098>.