

Exploring Misophonia

*An Anthology of Sufferer and
Professional Perspectives*

*Edited by Shaylynn Hayes
and, Research Edited by
Dr. Jennifer Jo Brout, PsyD*

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DEDICATION

*Dedicated to the pursuit of science and answers and to the brave
Sufferers of Misophonia that live with this condition day in and day
out.*

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Thank you for all you do.

Introduction

Misophonia International started in 2015 as an advocacy project, information site, and a resource to help bridge the gap between researchers, advocates, and sufferers (or concerned relatives). Misophonia International does not solicit donations personally, we are an advocacy resource that works closely with researchers, and supports the work of ethical and outstanding researchers and scientists. All donations go directly to the research programs at reputable universities. It is our goal to provide an accurate reflection of current scientific ideas, as well as sufferer and family perspectives.

We accept submissions from both scientists and sufferers in an attempt to facilitate a conversation around our disorder. It is our goal to disseminate information and help persons identify Misophonia. We provide coping resources and information documents for schools, parents, and medical professionals. Misophonia International works alongside the brilliant researchers of **The International Misophonia Research Network**, and provides resources such as books, PDFs, and articles that reflect the current scientific basis of the disorder. We do note that information is rapidly changing, and that these ideas are subject to editing as the science moves forward. It is our hope that Misophonia

sufferers, advocates, professionals, doctors and researchers can work together in a multidisciplinary approach to wellness and treatment.

Misophonia International includes many writers that submit on a volunteer basis. We are forever thankful to these individuals and their commitment to the cause.

Misophonia International is an advocacy, Information, and news site dedicated to the disorder Misophonia. Much of this anthology was collected for our website and past magazine issues.

Misophonia International works in collaboration with the International Misophonia Research Network in order to connect sufferers of Misophonia with the researchers that are studying their lesser-known condition.

Exploring Misophonia is our first anthology that features articles from researchers and sufferers of Misophonia. These articles date from 2015 to '17, and features fresh voices on Misophonia. As research and perceptions of the disorder change you may expect further anthologies and texts on the disorder.

Section 1: What is Misophonia?

The Origin of Misophonia and Its Research

Dr. Jennifer Jo Brout, PsyD

Almost every article about the origin of misophonia begins like this: “Misophonia, which means ‘hatred of sound’ was termed by Jastreboff and Jastreboff in 2001.”

After this cursory mention of the Jastreboff’s and their role in naming misophonia, academic authors often jump to their own interpretations about the disorder.

This leaves readers wondering why these two esteemed doctors at Emory University thought to conceive of a new disorder in the first place.

In order to comprehend a newly proposed disorder, it is important to understand its history. If we don’t, members of the medical community often regard these disorders as “unreal” because descriptions of them have been haphazardly built out of ambiguous bits of information that ultimately don’t add up to anything grounded in theory. I like to call this process the “dominos of disbelief”.

Misophonia is a very real condition that has unfortunately fallen victim to this phenomenon. In order to help put together the puzzle pieces of misophonia, let’s talk about the conception of the disorder, and the doctors who named it.

While working in their audiology clinic, the Jastreboff’s (who happened to be married) observed that some people reacted to sounds, such as chewing, pencil tapping,

keyboard typing, and coughing, with high levels of irritability, sometimes to the extent of rage, or disorientation. This group of patients responded to “repetitive” and “pattern based noises.”

Unlike their patients with hyperacusis (a disorder in which individuals feel pain in response to loud sounds), individuals with misophonia appeared to respond to “repetitive” and pattern-based sounds with autonomic arousal. That is, upon presentation of such stimuli, patients reported rising stress levels (such as elevated heartbeat, muscle tension and sweating) along with strong negative emotions. This was different from what the Jastreboffs had seen with regard to other forms of “decreased sound tolerance” such as tinnitus (ringing in one or both ears), hyperacusis, and phonophobia (fear of sound often secondary to hyperacusis).

Due to the high cost of research the Jastreboffs did not study their misophonia theory, but ventured to begin treatment at their clinic based on methods previously used for tinnitus and hyperacusis. Since then a small body of academic literature coupled with a great deal of popular press has emerged replete with consistent misunderstandings about the Jastreboff’s original concepts. Let’s begin to set the record straight.

Although the Jastreboff’s suggested that misophonia involves negative associations between auditory, cognitive and emotional areas of the brain, they

did not view misophonia as a “psychiatric disorder” and certainly not any specific one such as Obsessive Compulsive Disorder (personal communication, 2015). Similarly, the Jastreboff’s ideas about misophonia treatment were based on neuroplasticity (the brains ability to reorganize itself based on making new associations). This treatment has its roots in their tinnitus and hyperacusis retraining therapy. It is not simply “exposure therapy” as it is often described. Unfortunately, both research and treatment has followed some of these misconceptions.

Taking this step back, how should we conceptualize misophonia? I think a judicious way to describe the disorder is as one in which auditory stimuli provokes a neurophysiological response with accompanying negative, emotions, cognitions and behavior. Misophonia should not be referred to as a psychiatric disorder.

How should therapists treat misophonia? Therapists and doctors must be very clear that treatments are all experimental at this point and that efficacy studies will hopefully ensue. Therapists can also help sufferers cope by consulting and communicating with other clinicians across disciplines, and taking the initiative to utilize individualized strategies for each client.

Most of all, therapists and doctors can help by taking the time to learn about this easily misunderstood disorder, and sharing this knowledge with misophonia sufferers. As a psychologist who has misophonia (and who has raised a

child with the disorder) I know this: In the case of misophonia knowledge may not be “power” but it can help take some of the “power” out of the disorder.

What Is The Best Treatment For Misophonia?

Dr. Jennifer Jo Brout, PsyD

Misophonia Treatment is an important subject. Since sufferers are wrought with a life-altering condition the first question most ask is, “What is the Treatment for Misophonia?”. Unfortunately, we do not have an approved therapy or medication for misophonia yet. There is no official misophonia treatment. There are only a small number of studies, and none of them include follow up. The IMRN is focused on research, but in the meantime you may find support with the following professionals.

There are different kinds of therapists who can offer support, and teach you physiologically based and mental strategies to help you cope with misophonia. You can lead a productive life while we gain ground with research. However, you should be wary of anyone who claims they have “the cure” or who promises high success rates for misophonia treatment, until more research is done and we have more evidence.

Please be wary of false cures, and further-more, if a person is recommending drugs please note that there is no medical basis for this. You may talk to your doctor about medications but do not take unsolicited medical advice on medication via the

There are no single specific behavioral or device-based treatments that have been rigorously tested scientifically and shown to efficaciously treat Misophonia. At this point, there only are early small scale uncontrolled and pilot studies that have not yielded definitive results. Accordingly, patients seeking services for Misophonia are encouraged to ask treatment providers to disclose (a) which interventions will be used to help treat Misophonia, (b) the rationale for such approaches in light of available scientific evidence, and (c) any potential risks a particular treatment may pose.

There is no scientific evidence that any specific medication treats Misophonia. However, doctors are able to prescribe medications “off label,” which means that they can suggest you try medications developed for other problems that they believe may help reduce difficulties related to Misophonia. If a doctor prescribes medications for Misophonia, we believe it is appropriate that patients be aware that such medications are experimental. In such circumstances, we suggest patients ask their doctor to disclose (a) the clear rationale for the use of such medications and (b) any possible side effects and risks. The following professionals may be able to help you:

Audiologists: Traditionally, Audiologists have been allowed to practice with a Master’s degree. However, students entering Audiology programs in the near future will obtain doctoral degrees. An Audiologist with proper training may

help by evaluating if you have Misophonia, although there is no approved “test” for Misophonia yet and it is not in any diagnostic manual. Audiologists may provide you with personally-fitted earplugs that may or may not generate non-offending noise to mask the noises that bother you.

Counselors or Psychologists: Most Counselors have Masters degrees, but some have doctoral degrees. Most Psychologists have a doctorate, as it is required in order to use the term “psychologist”. Some cognitive psychologists feel that Misophonia should be classified under Obsessive Compulsive and Related Disorders (previously termed “OCD” in the DSM-IV-TR) in the DSM-5. While there may be neurological and behavioral overlaps, there is no compelling evidence that this overlap exists, or that OCD treatment will help patients.

Psychiatrists: Psychiatrists can prescribe medication to treat symptoms and conditions that may accompany the condition (such as anxiety, insomnia, feelings of rage/fear/depression, etc.). However, there are no medications that have been tested or considered for the disorder.

Neurologists: A neurologist is an Medical Doctor (MD) who specializes in disorders that affect the brain, the spine, and the nerves, such as Epilepsy, migraine, Alzheimer’s and

Tourette's (as some examples). Neurologists and psychiatrists may sometimes overlap, as they can both treat psychiatric conditions. However, neurologists treat a broader range of disorders. Anyone who has sudden onset of any changes in mood or sensory perception, should see a neurologist to rule out other disorders. People often confuse neurologists with neuroscientists. Neurologists are MDs; they went through medical school. Neuroscientists are also doctors, but they are Ph.D.s, not Medical Doctors. Neuroscientists study the brain.

The Difference Between Misophonia and Hyperacusis

JC Cohen

Which of these do you hate?

Plates clattering

Pens clicking

Motors idling

Ice rattling

Bass thumping

Paper crinkling

Coins jingling

All of them?

Diagnosis: Hyperacusis.

Say what?

Hyperacusis and misophonia are often confused. Both are sometimes lumped under the umbrella heading of “decreased sound tolerance.”

And in both cases, coping strategies are similar: Judicious use of earplugs or ear protection, and avoidance of situations that will expose you to the noise.

For the Average Joe — and even for a doctor or audiologist — it’s hard to tell them apart.

But conflating hyperacusis and misophonia is akin to saying that a sprained ankle and an ingrown toenail are the same. Both involve a lower extremity and both make you limp.

Hyperacusis and misophonia are completely different conditions.

Hyperacusis is noise-induced pain, usually developing from an injury caused by excessive noise exposure. Ordinary sound is often perceived so loud as to be felt as pain. It’s often accompanied by other results of trauma — the

pressure feeling called aural fullness, the ringing in the ears called tinnitus and a constant burning pain in the ear canal.

Misophonia is noise-induced rage, an instantaneous reaction, probably hard-wired and possibly inherited. It has nothing to do with the loudness or frequency of a sound, and everything to do with the meaning or context. A trigger sound, even a soft one, causes anger, rage or panic. Triggers can also be visual or olfactory.

Both are poorly understood and under-researched. To encapsulate the difference in one quick soundbite? Hyperacusics hate loud sounds; misophones hate soft sounds.

A more nuanced list of key differences, can be seen below:

CAUSE

H: Often a physical injury or illness — excessive noise exposure, a blow to the head, Lyme Disease, floxic poisoning, ME/Chronic Fatigue.

M: Appears to be hard-wired and inherited.

ONSET

H: Usually after acoustic overexposure, injury or illness.

M: Usually suddenly in late childhood or early adolescence.

WHAT A BAD NOISE FEELS LIKE IN THE MOMENT

H: Pain in the ear canal.

M: Rage, anger, panic.

ACCOMPANYING SYMPTOMS

H: Aural fullness or pressure, tinnitus (ringing in ears), pain in ear canal. These symptoms often are confined to the ear (though they can involve the scalp, jaw and neck). They usually manifest with a delayed reaction, with symptoms lingering for days, weeks or months.

M: Racing heart, sweaty palms, tight chest. These symptoms often involve the whole body. They usually come on instantaneously, dissipating after the trigger noise ends.

LOUDNESS DISCOMFORT LEVEL (LDL) TEST

H: Results are U-shaped, usually lowest in the high/low frequencies and highest in the mid-frequencies. Threshold of loudness discomfort is usually well below 100 dB and can be 0 dB in severe cases.

M: Results mirror the shape of the audiogram curve. For someone without hearing loss, the line is straight across. Threshold of loudness discomfort is usually well above 100 dB, close to 120 dB or higher.

HOW IT BEHAVES OVER TIME

H: Often improves slowly over weeks, months or years; then worsens immediately with noise exposure.

M: Often stays stable or worsens slowly over a lifetime.

THE LOUDER, THE BETTER?

H: No. Louder means additional ear pain.

M: Yes. Louder means more ability to drown out triggers.

EXAMPLE: THE PARADE PASSES BY — SIRENS, HORNS
AND 76 TROMBONES

H: Months of lingering fullness, ringing, sensitivity and
pain.

M: Yippee!

Section 2: Sufferer Perspectives

A Typical Day at The Office

Vicki Sladowski

It is Monday morning again. I make it a point to arrive at the office about 10-15 minutes early to avoid the “morning rush” filtering in the building. I quietly enter the office making it safely to my office and immediately close the door. 8 am is approaching and everyone begins to arrive. Do they go to their desk and begin their day? Of course not, voices from the kitchen echoes down the hall seeping through the walls. Loud voices, shrilly voices, squeaky voices all making my ears bleed. Shut up! Misophonia triggered! Giggle giggle cackle. “How was your weekend?” How long does it take to make a cup of coffee? You pour it in a cup add sugar and cream and you are done.

Do you NOT have work to do? Oh no, here they come. CLICK CLACK! STOMP! STOMP! As they trudge to their desk like the Jolly Green Giant. Can anyone walk normally? What are they wearing, cement shoes? Time to chat with their cubicle neighbors. These people do not speak in normal voices, they talk as loud as they possibly can. Pay attention to me! I often wonder why they talk loud enough for the entire office to hear yet they have to repeat these stories several times. Trust me, we ALL heard about your weekend the first time.

My coworker arrives and turns her walkie talkie on. As soon as the first call blares, I snap. “Can you please turn that

off?” She is aware that I suffer from Misophonia and tries her best not to trigger me so she shuts it off. We keep the door closed to block out the office noises but the walls and doors are thin so it only muffles them a bit. Then it begins...

Knock knock! Knock knock! Grrr. Please just come in. An employee walks in and starts to speak Spanish in a loud and high pitched voice. Tune it out, just tune it out. I can’t all I hear is rattling like the adult voices in a Peanuts show. Although the conversation only lasts a few minutes it seems like hours. I am trying so hard to focus on my work. When they exit our office it never fails that they leave the door ajar. A blast of sounds floods through the open door like a tidal wave in my head. I develop a knot in the pit of my stomach, nausea sets in as I close the door again.

Down the hall, the owner of the company is screaming on the phone to someone. It sounds like he is standing right next to me screaming in my ear. He is so loud and angry I can see the vein bulging in his neck through the walls. Someone walks in his office. SLAM! I jump. Why bother closing the door? We can all still hear his conversation because his normal voice is yelling.

More knocking on our door, more loud talking. I cannot take it. The sound of my keyboard and mouse clicking is driving me crazy. My blood is boiling as heat rises to my face. I would love to jump out of this window. Deep breathing, trying to give my complete focus to my job, but now there is

someone in the office next door, the walls are vibrating with the sounds of their conversation. Mumble mumble mumble. Why is everyone so loud?

Lunchtime, probably one of the WORST times of the day. I eat my lunch at my desk because the last place I can be is in our kitchen. Eating noises, dishes clanging, this room is bane of my existence. Regardless, I still cannot escape the obnoxious commotion of lunchtime. The kitchen is down the hall, but it sounds like it is right next to me. Deafening voices, laughing, cackling, this is a very rowdy crowd of people.

Strange how they always say how much they dislike each other but put them in a room and they become the noisiest crowd imaginable. Irrately I blurt out “What the hell are they doing in there?” My coworker senses that I am at my limit. She gets up and walks down the hall, things quiet down. When she returns she tells me that she asked them to quiet down. Thank God! I am on the verge of tears but I should hold it in. I find myself rocking to try to calm down, but it doesn’t work. A loud page blasts through my phone, I jump up grab the phone and toss it. Sadly, it does not break, so I leave my phone off the hook so I do not have to hear the PA system.

Conversations... Why don’t these people understand simple office etiquette? They attempt to have a conversation by shouting at each other from several cubicles away. Is it really

that difficult to walk over to someone's cubicle and speak in a normal voice; or here is a novel idea, we have these devices on our desks called telephones, all you need to do is pick it up and talk to the person. This is an office not a playground. Have you ever heard of using an inside voice? There is no need for everyone in the office to hear your conversation.

Every office has the obnoxious employees that insist the only way to talk is to talk if they speak over each other. Piercing nasal voices, one trying to out speak the other. Isn't there a quieter way to get your point across? Will you please just SHUT UP?

I am being paged by the owner to report to his office. Most likely he wants to ask me something that could easily be handled over the phone. I peek my head in his office. "What did you need?" He replies in a loud gruff voice, "HUH? WHAT? Uh.... Um, uh... hang on a second, oh I forgot what I wanted." That gun is about to explode in my head. By mid-day I am emotionally and physically exhausted. My trigger tolerance is off the charts; I am anxious, nauseous and have a migraine. There is not a safe place to go to avoid the triggers. I have to hold my anger inside which feeds my anxiety. This place is like Miracle Grow for my triggers. I want to crawl out of my skin. Major sensory overload. Is it time to go home yet?

Some days are worse than others, working in Human Resources we constantly have employees in our office asking

questions, complaining, etc. Many work in a loud production area, so they tend to speak louder without realizing it. Constant triggers all day long, staplers, shoes, talking, sneezing, phones ringing, the list is endless.

Finally, it is 4:00, time to go home! I am so wired from the day's events. I really need to decompress. The moment I walk in the door the chaos continues. Dogs jumping all over me- happy to see me, wanting their dinner... NOW! The kids rush downstairs to greet me, not even giving me a chance to put my purse down. The only thing I want to do is sit down and relax which I finally get to do around 6:00. It has been a long day, thankfully I only have to do this once a week.

You are probably wondering, "why don't you find another job?" I have spent 28 years of my life at this company; I grew up here. We are family. Sure they trigger me like crazy but I know deep in my heart that some of these people will always be there to support me.

The Up-Coming School Year

Sharon Mousel

Getting through school with misophonia is always a struggle. Last school semester, for example, I took several three hour long classes, and I had to wear over the ear headphones for those classes. Wearing headphones for a long period gave me a headache, and I could barely concentrate on the lecture even though my triggers were mostly blocked out. I had wished with all my heart that I took classes that weren't three hours long back then, but now that it's all over, it's but a distant memory... Or so I would think. This fall semester, and the semester after, I'm going to be studying at SDSU. Junior level classes are once a week and two to three hours long.

Additionally, these classes are mostly taught at night, when I'm more of a "get my classes done during the day so I have time to do my homework at night" kind of person. I work best at night, so when I was looking at the classes I had to take, I grew anxious at the thought of changing my entire schedule. Any sort of change freaks me out, and I have to mentally prepare myself for that change, and to work with that change. I will have to get used to doing homework during the day; I would have to ask a relative to pick me up at night, as my father takes anxiety medication that makes him drowsy at night; I will have to try to stay awake during class, which in turn could make my misophonia more sensitive. I could go on and on.

Fortunately, enough for me, my professors have been approachable and understanding when it comes to misophonia. What I have been doing is emailing them about it, and asking them if I can wear headphones during class. I explain that by doing so, I'll be able to retain information better and focus on the lecture since my triggers will be blocked. Every professor has let me do this, and it's thanks to them that I've been able to even pass my classes.

However, I wouldn't have been able to do this in high school. My school was very strict and didn't allow electronics whatsoever. Most of my teachers were unapproachable, and even the ones that were wouldn't have let me use headphones if I needed them because "rules were rules". So, how did I cope in high school? Earplugs. That was all I needed at the time, but as I've grown, misophonia has gotten worse, and I've been using headphones during my college classes. Perhaps my college experience has been different, but from what I've seen, teachers are more open and understanding to the student. They will let you have accommodations. There have been times when I can't email the professor, so I bring and wear my headphones anyway, and they don't say anything. They really don't care, as long as you're there to learn. This is great for those too shy to talk to their professor about their misophonia, because you really don't have to. Unless they confront you, you really don't need to let your professor know (unless they have a rule about electronics, then perhaps you should explain

briefly. I've had a professor like that, and he was ok with me using my headphones after I explained).

To sum it up:

-Change is inevitable, whether it's in school or in your daily life. How one deals with that change is up to them. I deal with it by mentally preparing and realizing it will be okay. There will be suffering, but in the end, it will be ok.

-College is amazing once you get by spending money for books, classes, and other materials. Have fun. Make friends. Professors are more understanding than teachers in high school, so wear headphones if you need to. The way you learn isn't important, as long as you're learning.

Surviving The Workplace

Deb Hathaway

In my limited experience, the one thing that those of us suffering from Misophonia have in common is that most of our triggers typically stem from one primary source: people. People make the sounds that cause our lives to be disrupted and stressful.

Necessity forces us to encounter these triggers each and every day because we can't really avoid being around people. Well, I can't; every lottery ticket I have ever purchased seems to have been faulty, so

I go to work five days a week in a jewelry and gift shop where I must endure a litany of noises that make my heart race and my anxiety spike. Being in customer service means that I can never, ever, be rude to the customer, even when they inspire a black tornado of rage within me.

Coping mechanisms are a must because my job is what allows me to buy the wine I need when I get home after dealing with people all day. (Just kidding. Don't drink to self-medicate unless you're okay with ending up in a room full of weeping loved ones armed with letters about how your drinking has negatively impacted their lives.) My coping mechanisms vary, depending on the type of trigger with which I am confronted.

Working in a jewelry store means being surrounded by glass

cases and women who are very conscious of their appearance. Many of these women have long, acrylic nails that they just cannot help but drum against the glass. This happens several times a week. Every time, my immediate reaction is the desire to grab that hand and slam it into the case.

It doesn't take a rocket scientist to know that breaking someone's fingers might make them a bit less likely to buy that pair of earrings that they were inquiring about, and a bit more likely to incur the assistance of the authorities. Neither of those outcomes are likely to put you in good standing at your job. Instead, I stop whatever I'm doing and stare at the hand.

I stare hard. I stare like a kitten's life depended on it. Sometimes, the nail drummer notices me staring and they get the point. More often than not, they do not. In my mind, I'm snapping off every one of those fake nails and throwing them in her face.

As I imagine how shocked and horrified she would look as I bounced Lee Press-On Nails off her forehead, I am able to mitigate the storm of fury and panic that is roiling inside of me. So now you know, if you drum your nails in front of me, I will be fantasizing about harming your manicure, your fingers, and possibly your face.

Dealing with the general public means that it is virtually impossible to completely avoid gum chewers (or Satan's Elves, as I refer to them). I know for a fact that it is possible

to chew a piece of gum without it sounding as though you are consuming your face from the inside. Some folks seem to be infuriatingly unaware of this and will chomp, smack, and snap that gum like it owes them money. Staring them down doesn't work. Staring only brings the gum into focus and swells the sea of anxiety.

The only way to deal with a gum smacker is to put a finger in my ear. I do it subtly, like I'm scratching or playing with my earring. I have found that one finger in one ear is enough to make the noise tolerable and keep me from reaching out and squeezing the chewer's lips closed.

As you know, Misophonia almost always means an intense reaction to the sound of someone chewing. This can make lunch breaks at work the fuel of nightmares. I've told a few of my co-workers about my Misophonia, and they have been gracious enough to accommodate me by allowing me solitude in the breakroom. This allows me to enjoy my lunch without having to sit across from a co-worker who eats gravel sandwiches.

On occasions when I do have to share the breakroom, I've found that chatting helps to take the focus away from that pinecone and glass shard salad on which my breakroom buddy is chowing down. I talk about the weather.

I talk about kittens. I talk about kittens dressed for the weather. As a result, I'm reasonably certain that at least one co-worker thinks I'm insane. I'm okay with that. If it takes making her think that I'm crazy in order for me to keep

from going crazy, I call that a win.

Misocentric Misophones

Shaylynn Hayes

Several of my friends have had to take leaves of absence from the Misophonia support community. They aren't leaving because of altercations. Most are leaving because they simply need to take a break. We can become so misocentric that we drown in our own thoughts and ideas. Our disorder weighs heavily upon us, like water, and holds us down. Personally, I left the groups entirely.

That's why I'm proposing this term. Sometimes we can become misocentric misophones. I have a couple of thoughts on this. It's not just an obsession with our disorder, it goes a lot deeper.

Some of us have grown so intertwined with misophonia that the miso, or hate, has become the centre point of our days and even our lives. We can become trapped by anxiety. Will there be a trigger? Will they accept me? What if something happens? How dare they not respect me! It goes on and on and on until the only thoughts left pounding at our brains are thoughts of misophonia.

If we let this hatred and reflection control our lives then the good moments are going to wither away like the bad. They will become one and the same. I can't let myself fall into this trap. Sure, it may be healthful to vent our aggressions, but what happens when venting becomes toxic?

Misocentric can also mean that we are spending so much of our time, energy, and resources thinking about Misophonia that we've simply forgotten that there are people out there who don't understand. They do not have the disorder. They do not understand how you think or how you feel. If we fall into this trap, how will we be able to have a nuanced conversation that explains our point of view?

We must always remember that we are more than our disorders. We have good days and we have bad. Yes, we have challenges, but who doesn't? If we spend all of our time thinking about what's wrong with us, we forget to enjoy what is right. Instead of being misocentric misophones, we must make sure that we are creating a world in which we can live. While researchers are doing their best to find answers, we must take charge of our lives. Our peace of mind is something that we must fight for every day.

Respect and Compassion

Paul Dion

When the conversation turns to relationships, I often run into some recurrent themes. Sometimes, people complain about the lack of empathy and respect they receive from others. Other people wonder if they will find someone who can tolerate their misophonia.

Some spouses/partners/family members are antagonistic or even abusive in their mocking and intentional goading. This is alien to me and it saddens me every time I read that someone experiences this. Bullying or deliberate triggering for amusement is not normal in a healthy relationship.

While people with misophonia have to own their condition, they do NOT need to get grief for having it. And certainly not from the people who should be allies; friends, partners and family.

Misophonia is real – not made up. This may be part of the problem. A condition that makes a person overtly emotional over something as mundane as a sound can seem odd. To a person unfamiliar with sound sensitivity, such a thing may seem suspect. Awareness is crucial in resolving any conflict so familiarization with misophonia is important. With familiarity comes understanding and perhaps respect.

Interpersonal relationships are complex, so communication is vital. It may be surprising that the sound of one's sneeze

has caused another person distress. But most people completely understand that another person may be allergic to dogs. We can thank time and millions of dogs and dog-lovers for the knowledge we have about that fact.

Many people with misophonia are reluctant share the fact that they have the condition. This further complicates matters and presents a sort of catch-22. Without openness there is less chance of understanding. But with it comes an opportunity for discomfort. A bit of bravery and willingness to take a chance is necessary. Is it worth it? I think that it is.

Isn't it wise to find out early in a relationship if the person you are with has the level of empathy you need? Again with the dogs, if you had a precious pet, you'd want to know soon on if your potential mate was allergic to it. The number of available empathetic people in the relationship pool is an unknown. But so is the number of dog-lovers. Lots of cat-people out there... but they say there's a pot for every lid. I hope that's true.

I can attest to the fact that many people with misophonia have successful long-term relationships. I've read about their healthy partnering and many of them have children. Sometimes people worry about having children in case the children trigger them. I'm sure that happens. But people make it work every day.

I have had two long-term relationships, one of 18 years and the other now going strong in its 24th year. We have two daughters and 2 grandchildren. Triggers? You bet! Yet,

somehow we thrive and enjoy our lives just like people without misophonia.

Empathetic partners? They're out there but they don't necessarily come that way. Sure, there must be a seed of compassion in a person's heart to be generous but communication and sharing are great teachers. Time is also necessary. Allow for trial and error and some bumps in the road. But always be open to the possibility of having the loving relationships you so deserve!

Everything Will Be Ok

Jennifer Jo Brout and Emily H. Brout

Jennifer: I know most of you know me as a “research advocate.” However, I didn’t become a research advocate over night. My journey, like every other parent, is a long and complicated one. I will spare you the many noble and sordid details. Yet, with the permission of my daughter (who was both the catalyst for, and my closest partner in this journey), I am sharing a little bit of her story with you.

Below is an essay my daughter wrote when she was 14 years old for a 9th grade assignment. She is now 21. Currently she is a junior at N.Y.U., majoring in Sociology and minoring in Creative Writing. She struggled with what we were calling at the time “auditory over-responsivity” (as well as general Sensory Over-Responsivity.) As you will read in Emily’s essay, the auditory symptoms are strikingly similar, if not exactly the same. However, that is another matter.

Emily still struggles with the same symptoms. Yet, proudly I say that she is an independent, social, strong and highly functional person. I know that I might sound as though I am bragging. However, I share this with you to give you hope. As you read what Emily wrote when she was 14, you might not think she would become the person she is today (which includes having been the lead singer in a band signed to Warner Brothers from age 16-19 with her siblings, a highly accomplished student, and a poet and creative writer who just got her first story published).

Life with Misophonia is very difficult. It affects children and families in ways they may not be aware of, or may not understand until years later. However, when you are feeling the most hopeless, that is likely to be the time your child is looking to you for strength.

I never promised Emily that her symptoms would go away, but when she very young I often said, “Everything will be okay”.

My Happy Place

By Emily Brout (at age 14, 2008)

I have this disorder that makes one over-responsive to certain noises, touches, and smells. The best way I can explain it to someone who does not have the disorder is to ask you to imagine that you were slowly scratching your fingers across a chalkboard, both feeling the chalk under your nails and hearing that horrid sound it creates. Imagine that this makes you feel disoriented, fearful, even tormented, and it lasts a much longer time than you can stand, only going away very slowly.

For me what caused the most torture in life was, and still at times is, repetitive sounds. One would be surprised how many repetitive sounds surround us, such as chewing, the ticking of clocks, typing, sniffles, coughs, clearing of throats, and even breathing!

A close second would be touch, such as the feeling of suede or newspaper or even a tag on the back of my shirt. Then

there is smell. I could not even deal with simple tasks like opening a refrigerator to get some juice without getting chills up my spine from the horrible and powerful odor it released. Also the smell of certain perfumes would also make me physically ill.

Getting by as a child with such issues, I needed a place to go to when I had break downs (which was very often). This place was my bedroom closet.

It is about eight years ago and I am sitting in my bright piercing red family room with my loved ones. “Its time to eat” my father would say. I was determined to try to eat with my family like a normal child. “I know I can do it.” I tell myself I can. We are going to have Chinese food. I know this because I can smell its wretched odor from upstairs. Soon “ Sweet Me” would no longer exist, but instead some one would, someone horrible.

We’re are eating dinner now and my sister picks up a shiny fork with tips as sharp as needles and stabs it into her chicken and this causes its juices to pour out, and leave an imprint on her plate. A droplet of sweat crawls inch by inch down my back from the horrible anticipation of the chewing noise soon to come. My sister slowly opens her mouth and brings her dinner closer and closer to her lips. She sees me staring at her and her pupils widen. With this simple sign I know she knows what is about to happen. “Crunch”, and I hold my breath. “Crunch”!!! With every crunch I get closer to the point where I can no longer contain myself. I have to

get out of here or, or,I don't know!

I get up from the chair and my mother panics, her eyes saddening and I know that she is suffering because she knows I am suffering. I look at my sister and I see her innocent facial expression. Her big puppy dog eyes staring mine down and her lip quivering slightly. I grab her plate out of her frozen hands, and with all my anger throw it onto the floor. It breaks into small little pieces; white and sharp against the marble checkered floor with a loud crash. Yet, it's still not over; the feeling of complete helplessness and not being able to control myself is not over even though the chewing is.

I run upstairs past the living room, past the never-ending tick of the clock from my living room. I pass the room that smells of an unbearable odor that I cannot even describe. I run away from everything, all feelings sounds and smells that have caused me to become this monster. I finally arrive to my room, but it's not my room that makes me feel at ease. The place I am looking for is my small but long white closet. As I open the door my eyes see the one slender pole that is placed horizontally across the closet and bolted into each end of it. The shelf above me full of board games, clothing and toys is about seven feet above my head. As I walk to my left I see my special place. In the corner of my closet lay a blanket covered in pink flowers soft silky, no cotton, warm, and heavy.

I fall into this corner and wrap the blanket around me. The

pressure of it helps me calm down faster. I place my self with my head leaning forward against the corner of my closet, and bang my head a few times out of sheer disappointment. I try to relax. I close my eyes and sit on my wet blanket full of sweat and tears and go into the fetal position, I turn on my little stereo and play my Nirvana CD and try to get lost in the music. That's the beauty of music. Sometimes it can be repetitive and irritating but when it is well written and played the right way it gives us bliss. Finally minute after minute I start to calm down. I feel the air against the tip of my nose. Breath after breath, air flows in and backs out of my nostrils. The pressure of my blanket, with Kurt Cobain's infectious voice, and with the darkness and safe feeling I get from being in my simple and slim white closet makes everything truly okay.

Art and Misophonia

Victoria Macneil LeBlanc

Misophonia sufferers often spend a lot of time searching for a cure, or a few good coping methods. It's just a way of life for many of us. Some find it difficult to cope with the disorder, but for others, it's as easy as creating some art. Whether they write, create music, paint, draw, or sculpt, these creative people find great solace in this form of therapy. There are many ways that they practice this, but it all comes down to self-expression. Whatever they do, they do it as a way to create something personal, and that's part of the beauty. Art therapy is a way to creatively express oneself, and it can promote healing, meditation, and coping. In the psychological community, it is seen as a way to develop yourself and as a way to cope with any issues you may face.

A quick, informal survey that gathered around 50 votes was done in a group of artists with misophonia. It showed that most respondents agreed that creating art is a way to process their thoughts and emotions, and a non-verbal way to express emotions. They also agreed that creating art is a good way to express themselves and let out negative emotions. And there are even more benefits. They can create something they are proud of, they can turn pain into something beautiful, and it can be a distraction from triggers. There may be even more uses for art therapy out there, but these are some of the best and most common ones. This goes to show exactly how useful art therapy is to

many people, and shows promise for the large number of sufferers who have never attempted to use art as a form of therapy. Moreover, sharing the art that they create seems to be a great help to many sufferers. The community of artists with sensory processing disorders is a small, tightly knit group that seems to find great joy in sharing what they're proud of and seeing the art that others create. This is a great support system for all of them. It is a positive, safe space for everyone, whether they create art or just like looking at it.

When they need someone to talk to, that's taken care of. When they want to discuss art and share what they're proud of, they're able to. Simply put, art therapy groups are a safe, happy place for people to go, a place where they can forget their issues for a while and just enjoy human creativity. This level of love and support is important for anyone who is currently coping with misophonia.

Best of all, art therapy is easy to start. It can be as easy as starting a diary and doing some writing, or creating some lyrics based on your feelings, or picking up your cellphone and snapping some nice pictures. You don't need to be talented and you don't need much equipment, you just need to be open minded and ready to express yourself. If you can do that, then you may be a step away from finding some peace of mind very soon.

Misophonia and Your New Job

Robert Hakes

This year, I've been placed in the unfortunate situation of having to find a new job twice. Not only is it hard enough finding a job to begin with (I have complications beyond Misophonia: I'm pretty much stuck to anything that allows me to sit down), but there's always that sense of anxiety about starting one when you finally get it. Then the thoughts of Misophonia kick in.

When I got my job earlier this year, it was in a call center, which involved credit cards and purchasing on the behalf of card holders. This means a lot of training time (five weeks to be exact) instead of the normal two days it takes to train a cashier, or a lot of other jobs that only require on-the-job training. This meant confined spaces and the potential for triggers.

I was nervous, but I hadn't worked in almost a year and this job looked promising, with good pay. So I go to my first day, sit down with my classmates (small class, only eight; things are looking up) and instantly I spot Mr. Nose-Breather. You know the kind: breathe like they're constantly active and haven't cleaned out their nose since they were born. Oh, and the nostril sighs (because those are needed every fifteen to twenty minutes to show you they're still breathing). So we're an hour into the day and one-seventh of my classmates are triggering me. Not the worst odds I guess. We go into the class with assigned seating. Mr. Nose-

Breather sits across the room, but still somehow manages to be louder than a jet engine. The woman next to me is an absolute sweetheart—until the gum comes out. Two-sevenths triggering me now, and we're only an hour and a half into my job. There's five weeks of this.

Within the next hour, Mr. Nose Breather discovers the free apples in the break room. He claims each apple has as much caffeine as a cup of coffee (apples contain 0mg of caffeine per apple), and has apparently decided to become a horse and eat every apple in his path. He even starts bringing bags of apples to work. I don't know why apples were his thing—maybe I should have informed him that he wasn't a horse and that apples don't contain caffeine. Anyway, training class was now a litany of crunch-crunch, whistle-whistle, sigh, smack, crunch, sigh. You might be wondering how this description is productive, positive, or even relevant (other than serving as an insight into how my mind works when I'm triggered), but I promise there is a happy ending.

The solution was actually quite easy and comfortable; I was even able to obtain it without the uncomfortable situation of telling someone that he's basically a machine producing every sound I hate. I found some nice noise-cancelling earplugs that still let in non-electronic voices (my job had high security, working with credit and all), and sent a quick email to my instructor:

Tom,

I suffer from a condition called Misophonia, and some of the sounds in this class trigger me. This gives me problems with paying attention. Do you mind if I use ear plugs while in class?

Very quickly and discretely, I got a response:

Robert,

That is fine. I looked it up and I'm sorry you have to suffer through this. It sounds like it's difficult to manage.

From that day on I was relieved of my problem. I found that using the name of the disorder (or possibly sending an article about Misophonia) allowed the people it affected to look into it and see that it was a real thing. They were quickly able to see why I was having problems concentrating.

So there is hope after all! It just takes patience and the ability to educate others. People may never understand exactly what you're going through, but at least they'll be able to make sure that you don't go through it alone.

Having Misophonia is not unlike having an allergy to other humans. Would you go on a date knowing for certain that you are 'allergic' to this person who you haven't even met yet? You might be able to suppress your symptoms of Misophonia for the first date, maybe even during the first few, but eventually the person you are dating is going to find

out you are keeping a secret. How will this person react? Will they be supportive? Will they mock and reject you, as so many have before? Or perhaps they will try to understand and help, but soon give up and forget? Wait a moment, that's right—the general public does understand and appreciate allergies. So too will the person you're just beginning to date likely appreciate that allergies are real. She (I say 'she' because I date women) may have some allergies of her own. She has seen commercials for allergy medication, so she has an association with you. Yet even so, Misophonia barely seems real to her or to others. Since Misophonia sufferers don't exhibit any tangible symptoms, only severe anxiety and depression, it's that much more difficult to explain to others that we live with this condition. As opposed to allergies, Misophonia is known to almost no one in the world. When I explain it to people, they often see it as a plea for attention or even something to joke about.

Unfortunately, living with Misophonia is essentially a 'people allergy'. Dating is difficult enough without adding this awful hurdle. I went on a first date earlier this week. I met (anonymous) on a dating app. She looked a bit too pretty to be talking to me, so I presumed her photos were lying. On the contrary: when I saw her she was stunning, and we hit it off. The first hour at the loud local bar passed as easily as it could. Whenever I got too relaxed, she'd flash a smile with her sparkly brown eyes or touch my arm with her tanned hand, and the butterflies would be all up in my throat. Although I declined to drink with her (as I've long

since stopped), she seemed genuinely respectful of my decision. We had similar interests and goals, and the conversation never felt stale. Then it was time for the real test: eating. We walked over to a Thai restaurant, laughing the whole way. By the time our food came, I was so famished that I'd almost forgotten about my Misophonia. However, I was promptly reminded when she began slurping her coconut chicken soup as if she were trying to make as much noise as possible. When she tried my noodle dish, she chewed with her mouth wide open. I was let down, knowing that this could never work. You might say, "Just ask her to chew with her mouth closed!" Maybe I will. But I know this relationship will not work. Not only would it be a gigantic favor to ask (it's rare that someone is able to continuously remember to chew quietly), but how can we begin a relationship when I am already trying to change her?

I may not be explaining this well enough and I don't expect most people to understand my situation, but it makes sense to me, as it always has. Finally (thanks to the internet) I know I'm not alone. I'd love to meet someone different—someone who was able to refrain from triggering my Misophonia but still able to be everything else I want in a partner. But I realize this may be asking too much, and I don't see it happening. I've got to beat this disorder and then worry about finding love. To do it the other way around seems impossible.

When I was a kid, 'Misophonia' was not a word. 'Internet' was not, either. I grew up sure I was mentally damaged. I

grew up feeling alone and unable to cope. Now, though, I take vast solace in knowing I'm not alone. I feel lucky to be alive during this period when Misophonia is better known, and I wonder at how rough it must have been for all the Misophonia sufferers before me. It also helps that I recently found out that a close friend has Misophonia (she posted something about it on Facebook). I'm grateful for this comfort and I'm also confident that a cure for Misophonia is on the way. Until that day, however, I'll be single.

In the last twenty years, I've dated hundreds of women. I certainly haven't been intimate with each, but I've always gotten to know them on some level, shallow or deep. Every single one of them has triggered me, just as every other person in the world does. I've 'come out' as a Misophonia sufferer to many of them, almost always with negative results (though there have been exceptions). I'm nearly thirty-six now, and because of Misophonia it's hard to believe I will ever have a relationship that lasts beyond a few months. I just don't know how it will be possible—how can I get close to a partner when I'm 'allergic' to her?

The Price of Misophonia

Kelly McDowell

I was born in Columbia, South Carolina. I was brought up in a mid-lower class neighborhood and had a pretty good childhood. My mother died from complications of Multiple Sclerosis when I was 8 years old. My father was a fireman and has been my main source of everything that is good in this world. Despite only having one parent, I didn't really feel like I was missing anything. I still got to play outside with my friends until it got dark, swim every day during the summer, and help dad cook despite getting food all over the walls. My dad got remarried when I was 13. My new step mom had two children who were both older than me. We've blended well and taken the "step" out of 'step-family'.

I started playing violin in 6th grade. When I got to high school, I was able to audition for the District Orchestra which was the advanced version of orchestra. My best friend and I were both accepted the same year. During the summers we auditioned and played for the Youth Symphony, which taught us a lot more than what we were learning in school. One of the perks of being in the District Orchestra was that the orchestra got invited to play at Carnegie Hall in New York City once every 4 years. We played on Father's Day 1997, just 2 weeks after graduation. My dad is still waiting for me to trump that Father's Day present.

I met my husband on AOL love personals. We talked for

about 4 or 5 months before we decided to meet. Once we met we knew it was love at first sight for both of us. We dated for a year, were engaged for a year, and have now been married for 8 years. Like every married couple we had our ups and downs. My Misophonia started developing in my early 20's. I had no clue why I was having sound issues. I didn't understand how all of the things my husband did were making me anxious. For years I never said anything; I just assumed I was weird. One day I had a bad moment at the movie theater (where people were chewing popcorn, rattling plastic wrappers, and sucking on their drink straws) and I couldn't take it anymore. I got up and walked out before the movie really got started. My husband came out to find out what was wrong and I was in a panic. I was breathing heavily, sweating, and just not with it. I told him that I didn't know what was wrong with me, but all the noises were keeping me from enjoying the movie. I told him to go back in and keep watching- I'd just sit and wait. A couple more things like that happened, where I would have panic attacks. My husband started getting mad at me, telling me it was all just an act and to quit doing it because I was embarrassing him. I was only doing it for attention, he said. I explained to him that it wasn't something I could control and that I didn't want those things to bother me. He didn't believe me, so I started hiding it again. I started staying home more and letting him go out alone so I wouldn't embarrass him. Eventually he fell in love with someone else and we divorced. I don't totally blame my divorce on Misophonia. A little bit, yes; but there were so many more

issues as well.

Once I got settled into my own place after we separated and divorced, I still had all the hearing issues and had started developing touch and visual triggers as well. One day I had a really bad time at work where all these things were bothering me. When I got home I googled “Why do noises bother me so much?” The first few results had a word called Misophonia in the headline. I decided to check it out. After that I was constantly doing research on what this was, trying to find a cure, trying to find more people like me. My eyes were opened to everything and I felt so relieved that I wasn’t going crazy. I started telling everyone about my condition. For the last 8 years I have worked at the vet clinic that my ex-husband’s family owns and runs. Being in that family for so long and working with them for a long time, they figured out pretty quickly that I got upset about noises. When I explained to them that Misophonia was a real condition, everyone was really receptive. My mother-in-law even paid for my entry fee and hotel room for the annual Misophonia Conference in Orlando, Florida last year! It was nice having people around that understood (to a degree) why I often had to get up and run out of the room.

Since finding out about Misophonia I have found an audiologist in my area who has actually heard of the disorder before. She did a hearing test on me and we discussed treatment options. I have tried CBT, relaxation therapy, hypnotherapy, and I have gone through 3 different devices for my ears. I have spent at least \$3,000 on

equipment and travel (I traveled to Asheville, North Carolina to try hypnotherapy), and nothing has helped. My hearing is a bit different than a lot of people's (from what I've read on Facebook groups). The white noise does nothing for me- brown noise is what is best because I tend to hear all the low tones. Unfortunately, I found out about the brown noise too late. I have already exhausted all my money and even owe family members for the white noise generators that cost \$1,500. I am very interested in getting the word out there about Misophonia so the medical community and insurance companies can help provide help for those of us that are trying to shield ourselves from the noises. I have developed depression, I have panic attacks at work, and I purposely avoid contact with people unless it's online. I work a full time job because I have to keep a roof over my head. I use earbuds most of the day to help. I play calming music and I started taking anxiety meds to help with the effect of the noises; I have Xanax to help if I have a particularly hard day. This is what I'm reduced to because of Misophonia. I have started taking trips because I refuse to be a shut in. I tend to go to places that have peaceful sounds like waterfalls, nature sounds, streams and beaches. I go alone to these places and have learned to like them.

In doing my research and talking to family about my newfound condition, I discovered that my mother had Misophonia. I've heard stories from my dad, grandfather, and aunt about different noises that bothered her. My dad would say that when he came home from getting groceries

she would have to go to the other end of the house, because she couldn't stand the sound of the plastic bags. There's been a question in the Misophonia community about whether the disorder is genetic or not. My mother, for the 8 years I knew her, was paralyzed from the neck down and could not talk because of Multiple Sclerosis. I didn't discover my issues with noise until my early 20's, and she'd had no chance to teach me to not like noises. I can't imagine being in my mother's situation- hearing all those noises and not being able to do anything about it.

Misophonia is very new to the medical world, but we are such an advanced society that the situation can only get better. We need science, discovery, research and technology. The only way to do that is by voicing publicly the ups and downs of our Misophonia.

Misophonia and Its Family Impact

Victoria MacNeil-LeBlanc

Misophonia can have a major, negative impact on any relationship you're in. This is the sad truth for the majority of sufferers out there. A lot of misophonia sufferers end up fighting with their families quite a bit. It can be hard for anyone to share a living space with their parents and siblings, doubly so when they have misophonia. A lot of my memories of my childhood include quite a bit of fighting with my parents. We are very close now and always have had great relationships, but there was a lot of arguing and emotions. Luckily, I'm an only child, because I can only assume that I would have lost my mind if I had to deal with a loud younger sibling or an older sibling who wouldn't respect me, and whatever else people with siblings had to go through.

My parents are my biggest triggers, as much as they avoid triggering me. My dad loves music and works with music. This means that he listens to it all the time, which would drive me crazy as a child. Some people like having the television on as background noise, but he likes listening to the oldies radio station. Hearing muffled noises triggers me and I would hear them for hours at a time, which was my version of hell. This became way worse when he got an expensive, powerful sound system that provides clearer, louder music that can be heard basically throughout our entire house. I've thought of stealing the remote to that

stereo and snapping it many times. He would also never use headphones when he would play computer games or work on his sound effects and music cues for his job as a sound tech for a theatre, which meant that every few months he would spend hours on end creating a whole new sound script for the play his workplace was performing. He often just told me to stay upstairs on those days.

The most common, universal issue for misophonia sufferers is dealing with family meals. A lot of families hold dinners near and dear to their hearts, as it is, ideally, a time where everyone gets together and enjoys a meal together while they have a nice conversation. This can be nearly impossible for sufferers. The thought of being within a few feet of a group of people chewing and talking and using utensils can be a nightmare, yet so many people are forced to eat with their families. Large parties with extended family can be even worse, like holiday dinners, as eating dinner together goes from a few people like your parents and siblings at the table to suddenly including all of your aunts and uncles, cousins, nieces and nephews, and grandparents.

The problem is that a lot of family members find that misophonia sufferers are either faking it or trying to control them. Of course, we know this is not true, but it is understandable. Reactions to being triggered can often be very noticeable and might seem dramatic to people who don't suffer from misophonia. Here's the positive part: There are ways to avoid a lot of common fights. It starts with knowledge. If you nicely let your family know that you

do have this neurological disorder and that you'd appreciate their help, chances are that they will attempt to help you. Using coping methods is also a major help. There's no reason to eat dinner silently, so try putting on some white noise or music in the background. If you know you're going to be triggered, like it's taco night and you hate crunching noises, just don't eat together on that specific night.

Families may also find ways to avoid triggering you entirely. For example, they might learn to just not eat snacks if you're in the room. If their nose is stuffy or running, they may just blow it instead of sniffing or breathing loudly. Fights are caused by a lack of understanding, so you can avoid them by spreading awareness and information. Remember, families are meant to love and support you.

How To Help A Loved One With Misophonia

Tom From www.AllergictoSound.com

Misophonia can be scary, confusing and upsetting for the people around us.

I get a steady stream of emails from people each month asking: “What can I do? How can I help?”

There is an army of mums, dads, brothers, sisters, partners and best friends who want to understand and be there and help, but don’t know where to start. The problem is, with little guidance or professional help on offer, we’re all desperately trying to feel our way around a disorder about which very little is known and let’s face it, it’s hard. The good news is, if you’re close to someone with misophonia there are things you can do to help.

But before we get started a quick public service announcement... If you’re the parent, sibling, lover or friend of someone who has misophonia, thank you. The fact that you’re reading this book shows, beyond measure, that you care. Thank you for being there and for wanting to understand and wanting to help. It might feel like we don’t appreciate you (especially when we’re flashing a dagger-like glares at you across the kitchen table when you accidentally bang your fork) but we do.

Ok, let’s get back to business. Here are 6 actionable things you can do to help:

1. Understand that it’s not your fault – The fear-flight-fight response that your loved one feels every time they hear certain sounds is just a part of their brain (the amygdala) misinterpreting that sound as a danger signal. If you happen to have made the

‘trigger’ sound then you might be in their line of fire, but you’re not the cause of the disorder, it’s not your fault. Any upset or tantrum that ensues isn’t really directed at you as person, even if it might feel exactly like that!

2. Try to avoid being confrontational – Most (reputable) studies indicate that misophonia is a neurological condition. In other words it isn’t ‘learnt’ and won’t just go away or lessen over time. Saying that “you just need to get over it” or to “stop overreacting” is a bit like screaming at blind person: “START SEEING!”. They can’t help it and it will only make things worse and cause the situation to escalate. Getting frustrated is totally understandable but will raise tensions and leave both of you feeling hurt or upset. Remember, your loved one likes this disorder even less than you and would do anything to make it stop. The physiological reaction caused by a trigger sound won’t go away, but over time they will find ways to cope.

3. Don’t let misophonia dictate how you live your life – It’s bad enough we have it, you shouldn’t have to suffer as well! Try to be considerate and mindful, but don’t feel like you have to tread on eggshells whenever you’re around that person. I know this is hard, particularly for mums and dads (no one wants to see their child in pain) but if you’re constantly tip-toing around each other you’ll both be stressed and on edge all the time and it can make things worse. It’s important that your loved one is able to find coping mechanisms and support that works for them in different environments.

4. Remain calm and level during an episode – Misophonia causes high stress levels in your loved one's body (causing cortisone and adrenaline to race around their system) during an episode. The best way to help them calm down and reset is to try to be patient and understanding. You don't have to endorse their behaviour (particularly if they're being aggressive) but let them know you're there for them and that you don't think they're 'stupid' or 'weird'. Try to speak softly and calmly and without judgement until the moment has passed.

5. Give them space but let them know that you're there if they need you – Sometimes they may experience a total sensory overload and will just need to get out of the room. It might seem like they're being rude or childish but they're probably doing this as much for you as they are for themselves. Moving away from the situation gives them time to reset and prevents them from lashing out and saying something they don't mean and might later regret. In calm moments, if it seems appropriate, try talking to them about how it misophonia makes them feel. You'll get a much better understanding of the disorder and they'll feel supported and less alienated.

6. Allow them to use tools and devices to help mask sounds in difficult situations – Putting on some background music or even having the TV on during mealtimes can work wonders, others find white noise can help. Adding another layer of sound in the background often helps to dull the intensity of a misophonic

reaction. Sometimes that's not enough and as any misophone will tell you, the humble set of earphones is always a close ally! If you're a parent, let your son or daughter use earphones or headphones in their room when they're trying to concentrate.

That's it. I hope you found some of these helpful. Even if you're able to act on just one of these points, it really could help to alleviate the stress and anxiety that misophonia can cause. With the right management and encouragement people with misophonia can develop and hone coping mechanisms that enable them to live a wonderful and fulfilling life.

Advocacy Not Sensationalism

Shaylynn Hayes

Having a disorder that few have heard of is frustrating. Having a disorder that is becoming more and more misunderstood by the day, is absolutely terrifying. When you see Misophonia in the press you are shown a disorder that's classified as, "chewing rage", "sound rage" and other derogative terms. The truth of the matter is that my Misophonia is much more than that.

What these sensationalist articles don't say is how difficult it is to get out of bed when your sensory system is over-loaded. How fabrics, aromas, and other stimuli can hit you in the face. The world of sensory over-load is much larger than auditory over-responsivity, and yet, the media continues to portray us as sound haters.

My sensory disorder makes it hard for me to attend family functions, go out with friends, and sometimes it even makes me unable to leave my bed. If I've had triggers accumulate too much in that week I will become lethargic and if I don't slow down I get a migraine. My brain and body are in a constant fight with the world around me. Another proponent of the disorder I have, as do others, is a reaction to visual stimuli. This has often been overlooked by the media. For many of us, swaying, leg-shaking, and other visual sensations can cause the same fight/flight/freeze response. Paired with smells that make us uncomfortable,

and fabrics, this can often mean that the entire world becomes a battleground.

There is no differentiation between visual triggers and auditory triggers for me. Both are absolutely infuriating and have made my day-to-day life nearly impossible. Though I keep going and try to raise awareness where I can, the truth remains that some days I just can't face the stimuli. As a 22 year old this has had a huge impact on my life. Due to triggers I was forced to switch from my brick and mortar university to an online option. Socializing has become a pain. Relationships are strained.

When starting misophoniaawareness.org I was scared and confused. I had no idea what I faced, but I moved forward. Today I can say that I have been working as hard as I can to help relieve stigma for Misophonia sufferers. But, media makes this hard. We are constantly feeling belittled as stories show misophonia sufferers in exaggerated situations, often perpetrated as “weird”, “unusual” or “strange”. We are not a story to laugh at. We are real people that are struggling with the world around us. Each and every day persons with Misophonia know that they will likely face fight or flight. While our bodies are in the modern age, our brains are left in the kill or be killed world of man vs. nature.

I am frustrated by our treatment by internet memes. I am frustrated that disorders that are not vetted are treated as

little more than a talking point for laughter. Advocates for all disorders need to band together and help the world understand that we are more than a label. We are individuals that are fighting as hard as we can to live a normal life. Some days we fail — but other days we are able to live comfortably. Some days we meet in the middle. This is not a sign of weakness but strength.

Misophonia is not chewing rage. It is not sound rage. The rage we feel is often after there are no other emotions left. We are first scared, uncomfortable, and unable to control our emotions. Then, the anger comes when we realize there is little left to feel. We are constantly trapped in our own minds — the world becoming a strange mixture of sensory overload.

Section 3: Professional Perspectives

Supporting a Misophone

Dr. Linda Girgis, MD.

Misophonia is an often misunderstood disorder. Those who suffer from this disorder also suffer from many common misperceptions. Social relationships stand in jeopardy due to lack of knowledge of this condition and failure to provide appropriate support.

Many of us hate certain sounds. However, we can usually tune it out and get on with our daily routines. Patients with misophonia often cannot. Many of them suffer problems with social interactions because of this disorder. And, someone who has never experienced this disorder can never have a true understanding of it. Many people suggest fixes that are not reasonable for a person with this disorder. They are not able to just ignore it or tune it out. They simply cannot exist in the presence of that sound.

How can we support those with misophonia?

Be empathetic. This is true for any disorder. Try to see how the sound makes the other person feel, not how it would make you feel. You already know that. Try to feel what they feel when faced with a sound trigger. Those suffering are not just being dramatic but have a real disorder.

Don't suggest solutions that will not work. Telling someone with misophonia to just tune it out is not going to work. These lame suggestions just serve to trivialize their suffering. Don't you think that if they could just tune it out or ignore it they wouldn't have already tried that? This is a real disorder not ruled by thought control. It needs real treatments.

Never make fun. Do you make fun of someone who is blind or paralyzed? Do you make fun of someone who has seizures? No, because that is just mean. Misophonia is not funny.

If someone close to you is afflicted with this disorder, try to educate yourself. The more you know, the more you can help. Understanding the intense emotional response someone is having may help you offer better support and assistance.

If someone is presented with a triggering sound, try to remove the sound source or the person from the sound source. This will help limit the intensity and duration of the emotional response.

If you know someone who you think may have misophonia, help them seek medical help. While there are still no good treatments for misophonia, there are some now that are

being shown to be effective in some patients.

Understand that misophonia can interfere with a person's social functioning. Many experience intense anger. It is not you it is directed at but rather an automatic rigid anger that arises from the trigger.

Remember that it is often not easy to avoid sound triggers. A person with misophonia does not control what sound they will be triggered by. Imagine if that sound is the sound of cell phones ringing. How can anyone avoid that unless they live in a closet? Triggering sounds will happen. Be prepared to take immediate action.

Be supportive, always. We are all human after all.

Patients with misophonia suffer from a rare misunderstood disorder. They did not choose this for themselves and they have no control over it. Maybe it is time we all try to more supportive? One day, we may need their support in return.

What is Music Therapy?

Dr. Dorita Berger, Interviewed by Dr. Brout

Dori, would you tell us about music therapy in general?

What is it?

Music Therapy can be better described by saying music-based treatment, because it is a treatment in which various elements of music are applied to address human health issues. Music, as many know, contains six elements, including rhythm, tonality (melody), timbre, harmony, dynamics, and form, and variations thereof.

Any one or more of these can be directed toward treatment interventions to address a variety of health needs. Music-based treatments are applied to a variety of diagnoses, including ASD, Sensorimotor issues, Parkinson's, ADHD, Alzheimer's and various dementias, PTSD, Strokes, COMA and other conditions involving consciousness, pain management, cardiac problems, and so much more.

Many people confuse music therapy with “just listening to music”. Would you tell us about the difference and the overlaps?

Music-based treatment, aka music therapy, is a clinical intervention provided by a specially trained and credentialed (Board Certified, Licensed, etc.) clinician. There is a difference between music as “therapeutic”, and music

therapy.

So, how would you describe “just listening to music”?

Music can be “therapeutic” when listened to recreationally. Listening to music may induce mood changes, memories, relaxation, release stress, help concentration and task attention, and more. But that is not “treatment” – it is like a self-medicated treatment, and yes, it’s good, but it is “in the moment.”

Then, how would you describe Music-based treatment?

Music-based treatment has goals and objectives for changes and functional adaptations related to an individual’s current situation to enhance better coping and responses to problems.

How does Music-based treatment work, then?

If you’re an anxious person, you want a music-based clinician who can administer the kind of music intervention that will ultimately strive to more permanently release anxiety. Another way to look at this, is that you want a therapist who can utilize music to alter the function of the brain’s amygdala (moving the individual’s nervous and physiological system from high arousal to calmer). A music-

based clinician can help you mediate fight/flight with music. Anxious people, and people with misophonia, both tend to have higher arousal systems, involving fight/flight. When a person is in fight/flight the HPA Axis (Hypothalamic-Pituitary-Adrenal) shoots catecholamine in the blood stream (cortisone, adrenalin, etc.), and other hormonal and physiological processes occur. It is generally unhealthy for the body to be frequently and excessively activated like this.

Oh, so you are saying that music-based treatment can affect changes in the neurological/physiological system?

Yes. Sensorimotor and Neurologic Music Therapy treats all sorts of issues in persons of all ages. In essence, ‘just listening’ does not require a music-based clinician, but music-based treatment does, because it is interactive, and active interaction with music is a whole-brain activity that can address areas of function that ‘just listening’ omits (e.g., motor function, visual, tactile, etc.). I approach from a physiologic perspective, with the belief that even “psychology” is physiology!

I am so glad to hear you say that! Dori, one of the ideas I have always had, which we have discussed on and off for almost a decade, is that of using music as a “tool” for down-regulating the nervous system specifically for people who are auditory over-responsive. However, for

people with misophonia, this might be counter-intuitive because certain noises are so bothersome. In other words for people with misophonia music itself can be a double-edged sword.

I think there are several ways music-based treatment can approach interventions for people with misophonia. As we've talked about, we can work on utilizing music as a means of down-regulating or "calming the system".

I'm remembering an article from years ago...it was an academic article entitled "What Gives You Chills" or something like that. The main point was that while there are some universal elements that apply to what make music calming and/or up-regulating, personal choice is really where one needs to begin. For example, I know you find classical music to be relaxing, whereas for me (a person with misophonia) most classical music is highly aversive to me. In fact, what I find calming is kind of random, and certainly not genre specific. I'm guessing it is probably the same with most people with misophonia.

Of course, remember that listening to music and Music-based treatment are different. However, you are right (and this is particularly pertinent to misophonia). Finding the right music for the therapist to work with is going to be

challenging. This is uncharted territory and we need to be careful.

I would think the best place to start is to ask the individual.

Absolutely. And once, we begin working with music a person likes, we can deconstruct the elements of that music that he or she likes. Remember before I was talking about the different elements of music; rhythm, tonality (melody), timbre, harmony, dynamics, and form...

Yes.

Also, we can work with frequencies. If a person is discomforted by high frequencies, for example, you can add just a tiny bit of high frequency into music so that the brain can adapt.

That's interesting.

Well, this is why I pointed out that Music based treatment is a lot more than just listening and that it involves use of the whole body. Expressing music, making music is not the

same as listening and that can be a big part of music therapy treatment as well.

Of course, and you have done so much work in this regard for people with SPD, and Autistic Spectrum Disorder etc. who of course are often auditory over-responsive (which is similar to or may be a variant of misophonia). While we are on the subject, would you describe from your experience the difference of these disorders?

The main difference that I have found between ASD and SPD is the ability to modulate behavior, and control responses more functionally by persons with SPD vs. persons with ASD. In ASD, socialization difficulties are usually very evident, whereas in SPD they are not. In ASD, cognitive delays, language delay or difficulty with the social elements of language (which includes variations in pitch, or prosody, knowing when the timing is right to interject in a conversation, etc.) and slower information processing are most always present. However, in SPD these elements are not necessarily present. In other words, individuals with SPD and ASD share the sensory issues but those with SPD do not have the significant cognitive/social/language impairment. In terms of behavior, then SPD and ASD look very different, and I, for one, never confuse the two. It's almost like asking what's the difference between a man with

black hair, and a woman with black hair. Characteristics of each are entirely different, although they both have black hair!

Well-stated Dori! I would add that people with Misophonia have extreme reactivity to certain noises and have great difficult modulating behavior because of the underlying fight/flight response that is triggered by this stimuli. I don't think Misophonia is defined by any cognitive or language delays. However, there is no official definition yet. Speaking of which, many people with misophonia are also bothered by the visual perception of movement (often specifically of other people's movement). Do you think music therapy might help with this?

I know music therapy can address this issue, with movement activities. And a mirror. In other words, what if "the other person" was in the mirror? I have many ideas for helping with visual interruptions of perception. I have a friend with ASD ("Asperger's") who has a terrible, terrible stutter. He told me that when he speaks in person to someone, the visual movements he sees of the other person causes him to stutter very badly. However, when he speaks on the phone to the person, he's better with language flow! So I suggested that he practice talking to his image in his mirror, and this changed the visual distraction. In music-

based treatment, I would have us play fun instruments in front of a mirror, sing in front of the mirror, move our bodies, while singing before a mirror, and more.

That is really interesting Dori and this is really something that should be researched further! I have a question about art therapy. How is it different from music therapy? Do music and art therapists have different training?

I am not really qualified to talk about training of art therapists, except to note that art therapy is more a psychologically-based treatment – express your feelings through color, design, etc. Music expression does that also, but with the clinician who also participates with the client in music-making! Or – within a group. Art is individual, like the “just listening to music” vs. making music with another. The art therapist doesn’t make art with the client – the client is left to be inside his/her own head, without other external influences, while making music is collaborative with the clinician – we both make music with each other, and I will guide toward reaching an objective of self-expression, reduction of anxiety, and recognition of self. So yes, art therapists have different training as far as the treatment goals, objectives, and approaches. Art therapy’s main objectives are psychological (mind), while music therapy’s goals and objectives are mind-body – the whole persons, including muscles, joints, movements, etc. We

don't just sit in a chair and draw, paint, sculpt for a final result. We (music therapists) move, play, sing, share, interact, in a temporal manner – in the here and now and gone manner. (Unless we notate the music for future rendition – which does happen at times). Please understand, though, that I'm not comparing as to whether one or another is better – I have worked with art therapists and music, which was an ideal great advantage! It's fun and a no-lose intervention for all.

I know that you also research in the field and write books. Would you tell us about that?

My books and research involve behavior characteristics of particular neurologic and sensorimotor difficulties. I have four published books, my first being on the subject of Performance Anxiety in musicians, but the following three books involve music and how physiology plays a role in treatment of various diagnoses through music interventions. My books can be found at Amazon, under my name Dorita Berger, and some of my writings are posted on Academia.edu, including my research paper. My books have descriptions of case studies. And.... I am now in the process of writing my 5th book, a kind of 'non-academic' book for parents, titled "Kids 'n' Music: Thinking Beyond The Spectrum". It's not an "academic" book, but a quick read with advice. Titles of my other books: Eurhythmics For Autism and Other Neurophysiologic Diagnoses: A

Sensorimotor Music-Based Treatment Approach (JKP, 2015); The Music Effect: Music Physiology And Clinical Applications (JKP 2006, with Daniel J. Schneck); Music Therapy, Sensory Integration and The Autistic Child (2002, JKP); and Toward The Zen Of Performance: Music Improvisation Therapy For Developing Self-Confidence In The Performer.

That's amazing Dori. I don't know how you find the time to write all of these books! As my final question, would you please tell us a little more about yourself? How did you get started as a music therapist?

I started music when I was 5 years old, after being taken to the movies to see "A Song To Remember", which is the life of Chopin – well, as Hollywood saw it. But the music (played by Arthur Rubinstein, by the way) was so gorgeous; all I wanted to do was to play the Piano!

Imagine, even at the age of 5, a child can already sense emotions in music! I began piano lessons then, in my native Argentina, and continued studying once we relocated from Argentina to New York City. And that was my life. I attended the High School of Music & Art in NYC, then went on to graduate in Piano Performance from Carnegie Mellon Univ. (I wanted to go out of town of course), returning to NY to attend graduate studies at Juilliard. Performed here and there, mostly chamber music, married, had kids, travelled, moved to different locations as a result of my

husband's profession, so performing became limited.

Then when one of our two daughters became a serious and excellent student on the violin, I helped her attend Juilliard, Aspen, and all the spots for upcoming performers, in addition to concertizing with her at many locations. And one day, I read an article about a Music Therapy clinic working with Autistic children, and what they described I thought to myself, "I've already done that.... Maybe I should get the degree". I had worked with children, taught them, did improvisation, movement, etc. So I thought why not?

My intention was actually to work with psychiatric adults. So I attended NYU's music therapy program, and two years later, Master's Degree and Board Certification in hand, I was on my way to working at a special school for Neurodevelopmentally Delayed children – as in, Autism. When I started to work, I realized that I was incorporating my Dalcroze Eurhythmics training as interventions for sensorimotor deficits! And that ultimately led me to author several book dealing with music, physiology, sensorimotor systems, Autism, and more.

Thank you very much Dori. Please feel free to add any comments you would like.

Thank you for your interest in my work, my background, and me.

I am very supportive of your magazine, and the work you are doing to bring about awareness of misophonia. It similar to my discussions to people of Scotopic syndrome in which there is such visual processing issues due to light glaring on a piece of paper that then distorts and convolutes the image on the page – especially the writing on the page. Teachers expect special needs and sensory sensitive students to read the book that is lying flat on the desk, without ever considering that perhaps life refraction is disturbing the image and the student simply can't make out what, precisely, is on the page!! So much is taken for granted, for lack of awareness, so I thank you for the work you are doing to bring about awareness of misophonia, which I think everyone experiences, at one time or another!

Preliminary Findings Exploring Over-Reactivity To Auditory Stimuli And The Amygdala

Joseph E. LeDoux Interviewed by Dr. Brout

JENNIFER: Joe, can you explain the difference of conscious and non-conscious learning?

JOE: Imagine two cars in the highway with several people in each of them. Both cars are tuned to the same radio station. A Hard Day's Night is playing when an unexpected patch of ice causes a crash between the two cars. Although no one is seriously injured, they all experienced some pain and discomfort. Later on, the song will trigger the same body reactions, such as increased heart rate or sweat, and also remind them of the accident. But these are separate memories of the brain. One is implicit (non conscious) and the other explicit (conscious).

JENNIFER: So the memory of the pain and discomfort of the crash occurs without any conscious awareness and can in fact include physiologic responses, such as increased heart rate, sweating, etc. of which we are not in voluntary control?

JOE: Yes, that's right.

JENNIFER: How do you do this in your lab?

JOE: To achieve a deep understanding of the brain mechanisms that go on in real life situations, such as the car crash, scientists have to design experiments that are simplified versions of the real-life situation. In order to simulate non-conscious or implicit learning we utilize Pavlovian or classical conditioning to see how our rodent subjects make associations between previously neutral and negative stimuli. With this approach we have been able to determine that two different regions of the amygdala, its Lateral and Central nuclei, are necessary for this kind of learning. The brain pathways that carry the information (for the neutral and aversive stimuli) converge in the lateral amygdala. It then communicates with the central amygdala, which for its part, sends information to lower brain areas that control the body reactions mentioned above.

As a result of learning, the neutral stimulus can flow more easily through the circuit to elicit the responses. We assess this by measuring neural activity in these areas before and after learning. And what we find is that amygdala neurons are more active after learning—more activity in the lateral amygdala means that the central amygdala will also be more

active, and so will its outputs. The net result is a bigger behavioral response.

JENNIFER: But what happens if some people, or rodents, are more vulnerable to respond to stimuli with greater reactivity in the first place?

JOE: We know that in any such situation of danger, different people respond differently. Some respond strongly and other weakly, and still others are in the middle. Many scientific studies focus on the middle or average response. This was useful in identifying which areas of the amygdala are important, but ignores the fact that rats, and people, respond differently.

JENNIFER: So, are you saying that most of the work that is done on learning and conditioning does not consider these possibly constitutional, or inborn, differences in reactivity?

JOE: Yes.

But to make up for this neglect we have thus begun study rats that respond strongly and weakly to the neutral stimuli.

We use these to then explore the hypothesis that neural responses in the amygdala are predictive of strong and weak behavioral responses to threats. Our initial studies confirm this and allow us to proceed to our main object.

JENNIFER: Would you tell us a little about the next part of the study?

JOE: We hypothesize that neural responses in different parts of the amygdala predict different reasons for auditory and other kinds of sensory stimuli to elicit exaggerated responses. As previously mentioned above, the lateral nucleus is the sensory input region of the amygdala and the central nucleus is the behavioral output region. An individual might respond more to a stimulus because her lateral amygdala is overly sensitive to the threat value of the stimulus, or because her central amygdala is overly reactive.

JENNIFER: How will this help people with difficulties related to over-responding to auditory information?

JOE: The new knowledge that we will obtain will shed light on how neural mechanisms in the amygdala contribute to auditory over-responsivity.

JENNIFER: I would imagine this will help with an understanding of how conditioning of implicit memories are learned and studied, and may have implications for people who suffer with disorders in which auditory over-responsivity is an issue.

JOE: Yes, this work could lead to new ways to diagnose and treat auditory over-responsivity. If we simply use the behavioral output we may miss the fact that some people are over sensitive and others overreactive due to wiring. If this is the case, it makes sense that they would need different treatments.

JENNIFER: Do you think the study will also add to knowledge about the specific type of auditory stimuli that might be aversive to specific people? For example, you used repetitive auditory stimuli which might have implications in particular disorders in which auditory gating (the process by which irrelevant information is filtered from the higher cortical centers of the brain in order to avoid overloading) is an issue?

JOE: We have been using repetitive stimuli for a while because that's necessary to get reliable neural responses.

But now that we know that stimulus repetition is a factor that is of clinical interest it might be possible to design studies that can directly isolate the contribution of repetition to hypersensitivity and/or hyperactivity.

JENNIFER: This sounds very promising! Thank you very much for taking the time to do this interview.

Healing Without Hurting

Jennifer Giustra-Kozek, LPC interviewed by Shaylynn Hayes

What is your field of expertise?

I am a board-certified psychotherapist with a Master of Science in Counseling and a Bachelor's degree in English/Criminal Justice. I have worked in private practice for over 16 years treating clients with an array of mental health disorders including Asperger's, depression, anxiety, SPD, OCD and ADHD.

Do you believe that sensory issues (SPD), Misophonia and autism disorders are on the rise?

Absolutely Yes! We are facing an epidemic. The number of children diagnosed with an autism or a related disorder has grown exponentially. This is a crisis. In 1975, about one out of every 5,000 children had autism. Today, one in every 17 children have a life threatening food allergy, and even more have numerous food sensitivities. About 1 in 68 children has been identified with autism spectrum disorder (ASD) according to estimates from the CDC. Some estimate that it is closer to 1 in 45 boys. 1 in every 10 boys are being medicated for ADHD; the CDC reports that as much as 1 in 6 children have some sort of developmental disorder. Also, research studies conducted by the SPD Scientific Work Group suggest that 1 in every 6 children experience sensory

symptoms that may be significant enough to affect aspects of everyday living. This was unheard of a few decades ago. All of these disorders are closely tied.

Do you believe that our environment is leading to an increase of these disorders? Are our modern dietary practices and harmful food chemicals contributing to autism spectrum disorders and sensory problems?

Unequivocally, YES! The issues are systemic. We are living in a toxic world. All of the toxins in our food and environment were making us sick. All of the pollutants, including chemicals, dyes, artificial ingredients, genetically modified foods and heavy metals are what our American culture is now built upon. These pollutants are integrated into every aspect of our lives from the toxins in our atmosphere, to the foods we eat to the medications we take to the clothes we wear to the cosmetics we use. We are poisoning ourselves, and the consequences are starting to show with the incredible rise of neurological issues, and diseases like cancer, asthma, diabetes, and countless autoimmune disorders like autism.

In addition, our poor diets, depleted soil and processed food is completely void of any whole food nutrients and loaded with neurotoxic chemicals. When tested we discover, most of the persons with such disorders are completely deficient in important brain minerals, vitamins and amino acids that create our feel good hormones and help our brain fire

properly. Remember: Bad gasoline causes engine damage and poor performance, and an empty gas tank cannot run at all!

I have discovered that although well intentioned, many mainstream doctors are too quick to prescribe medication to cover up symptoms without digging deeper to find the underlying causes and numerous nutritional deficiencies often plaguing us. I am here to say, there is no such thing as a genetic epidemic. Everyone must become educated about the causes of these disorders, so that we can start appropriate treatment as early as possible.

So, it's not just genetics? How else does our environment affect us?

When we seek help from a naturopath, Defeat Autism Now doctor, Integrative Neurologist, Functional Medicine Doctor or a Medical Academy of Pediatric Special Needs doctor, it becomes more obvious. Testing reveals that many of our children have numerous genetic mutations. According to the International Journal of Environmental Research and Public Health, "Accumulating evidence points to the involvement of epigenetic modifications as foundational in creating ASD pathophysiology."

The environment in which we live and breathe, genetically modified foods and the chemicals we eat and inject have a direct influence on the expression of our genetic code, by

altering the expression of genetic information. In the study of disease, researchers in the field of epigenetics are increasingly finding that the “turning “on or off” our genes are preventing us from detoxing these toxins effectively. These mutations inhibit the body’s ability to digest food, transport substances between cells, and utilizing important nutrients appropriately.

According to Raphael Bernier, the lead author, and UW associate professor in the Department of Psychiatry and Behavioral Sciences and the clinical director of the Autism Center at Seattle Children’s. “Our children have multiple mutations, perhaps hundreds, yet to be discovered.” Bernier suggests that a diagnosis solely based on behavioral analysis, is missing an important component. Testing genetic mutations could guide families on how to better care for themselves and their children.

What is Sensory Processing Disorder and Misophonia?

Sensory integration disorder and Misophonia are not recognized in the DSM-5; however, many will agree that it is a very real condition. It is neurologically based and causes difficulties with taking in, processing, and responding to environmental stimuli. It occurs when sensory signals are not received through the senses in an organized way. This can cause inappropriate responses, behavioral problems, anxiety, and challenges in performing everyday tasks.

Specifically, Misophonia is a relatively unexplored chronic condition in which a person experiences autonomic arousal (analogous to an involuntary “fight-or-flight” response) to certain innocuous or repetitive sounds such as chewing, pen clicking, and lip smacking. Misophonics report anxiety, panic, and rage when exposed to trigger sounds, compromising their ability to complete everyday tasks and engage in healthy and normal social interactions.

How did you first hear about Misophonia?

I first learned about Misophonia from numerous parents through social media. It appeared that a severe sound sensitivity often goes hand in hand with sensory integration disorders and other spectrum disorders. Interestingly, since discovering the name for this disorder, I have learned that many of my clients have it – along with my own father. It appears although I knew it existed, I didn’t have a name for it until now.

In regard to a holistic approaches, what do you suggest to help alleviate the harshness of sensory stimuli?

Although we are all bio-individual and it is never a one-size-fits all, and there is no magic bullet. I suggest finding

doctors that can conduct a complete metabolic workup and reinforce the importance of gut healing. This is such a key component in my day-to-day conversation with those who are trying to heal themselves and their children. A workup would include testing for metabolic, immunologic and digestive conditions. Unfortunately, only addressing one piece of the puzzle often yields a less than positive outcome.

Traditionally, ADHD and autism spectrum disorders are diagnosed by therapists such as myself, psychologists, and psychiatrists, who recommend traditional therapy and medications to address neurological symptoms. Parents are told that their child's diagnosis is complex and multifactorial in nature; a result of genetic, psychological and others factors widely unknown. Most doctors are taught to treat the emotional and mental component of these disorders with medication. Yet, the physical or medical issues these children often share are rarely noted or discussed. Some of those include eczema, asthma, chronic illness, gastrointestinal distress, food sensitivities, yeast overgrowth, leaky gut syndrome, malnutrition, hypoglycemia, adrenal fatigue, hormone imbalances, and sleep disturbances. Typically, proper testing also reveals high levels of heavy metal and environmental toxins relative to neurotypical children.

What are some of the other important things to keep in

mind & investigate when treating SPD & Misophonia?

A good start is to eliminate all processed food from the diet and limit exposure to as many environmental toxins as possible. These foods & environmental triggers contribute to a child's sensory, attention, mood, focus, and sleep issues.

It's important to be consistent with your treatment strategies and goals. Treating intestinal permeability and other issues may take time, hard work and perseverance. E.g. If you need to eliminate certain offending foods as part of the protocol – cheating will delay the healing process!

Test for PANS/PANDAS – caused by Lyme Disease or untreated Strep infection.

Identify and treat any mineral deficiencies. Magnesium and potassium deficiency can be linked to fatigue, weakness, irritability, and sensory integration issues as well as depression, and anxiety. Minerals help to send signals through the nervous system.

Aluminum toxicity and other heavy metals can lead to sensory issues.

Homeopathic remedies such as Nux Vomica is used to treat irritability, impatience, digestive ailments, insomnia, and sensory integration issues.

Essential Omega-3 fatty acid deficiencies can lead to SPD.

Investigate genetic mutations. If an individual has the MAO-A mutation balancing and regulating serotonin levels becomes a very important factor in managing people with sensory system imbalances such as touch, sound, etc.

The reflexes are vitally important for the proper development of the brain, nervous system, and sensory systems. Research has shown that the brain has a tremendous amount of neuroplasticity. Brain training therapies such as Brain Balance, Integrative Reflex, Vision & Neurofeedback can make a world of difference. Research has shown that the brain has a tremendous amount of neuroplasticity. Brain training therapies such as Brain Balance, Integrative Reflex, Vision & Neurofeedback can make a world of difference. Research has shown that the brain has a tremendous amount of neuroplasticity. Brain training therapies such as Brain Balance, Integrative Reflex, Vision & Neurofeedback can make a world of difference. Research has shown that the brain has a tremendous amount of neuroplasticity. Brain training

therapies such as Brain Balance, Integrative Reflex, Vision & Neurofeedback can make a world of difference. Brain therapy trainings such as neurofeedback, integrative reflex, vision, Auditory Integration Training (AIT) and Brain Balance Therapy™ can make a world of difference.

Therapeutic message, cranial sacral therapy, chiropractic, acupuncture and other bodywork practices are also worth a try.

And the most important advice I can give is to TRUST YOUR GUT! You know your child and your own body best. Our intuition is our best guide!

Miren Edelstein Interview

Interviewed by Dr. Jennifer Jo Brout

Would you tell us a little bit about yourself and what you study?

I am an experimental psychology Ph.D. candidate at the University of California, San Diego. I am studying Misophonia under Dr. V.S. Ramachandran and music cognition (specifically absolute pitch) under Dr. Diana Deutsch. In 2011 I received my B.A. in psychology and music from the University of California, Berkeley. Additionally, I've been a violinist since I was 5 years old, so when I'm not conducting research I can be found performing all around southern California in orchestras, chamber groups, bands and theatrical productions.

How did you get interested in Misophonia?

Back in 2011 (my first year of graduate school), my advisor Dr. Ramachandran received an email from a member of a Misophonia support group inquiring if we could begin some research on the disorder. At the time, no one had really heard of Misophonia, so we decided to invite a few members of the support group to the lab for preliminary interviews and testing. To an extent, I could relate to some of the negative feelings experienced by these Misophonia sufferers, because nobody loves the sound of another person loudly chewing gum or clicking their pen in class. For the most

part these are sounds that people consider to be annoying, and I'll admit I was a little skeptical at first as to whether this phenomenon was an actual condition or whether these individuals were simply more vocal than others about their sound issues. However, after talking to a few individuals and understanding the toll that Misophonia had taken on the quality of their lives, I realized that the disorder was definitely worth a further look. Ultimately, it was the severity of these people's reactions paired with a lack of experimental research that inspired us to conduct our first study.

Some of our readers are familiar with your published paper on Misophonia, but some are not. Would you mind describing your study for us and telling us about your findings?

Our paper, "Misophonia: Physiological Investigations and Case Descriptions," consisted of two main experiments. Experiment one was a series of interviews with self-identified Misophonic individuals. Since there were no official diagnostic criteria at the time, our goal was mainly to elaborate on the symptoms and behaviors associated with the condition, in hopes of gaining a more concrete understanding of the Misophonic experience.

It was in experiment two, however, that we actually collected physiological data. Experiment two was

particularly important because, until recently, the only evidence we had was subjective reports from people describing autonomic arousal to certain sounds. Therefore, the goal of experiment two was to see if Misophonics actually show a quantitatively different physiological reaction to certain sounds than non-Misophonic individuals. The experimental design was such that Misophonic and non-Misophonic individuals were asked to view and listen to a series of videos and sounds (some of which we knew they disliked and some of which we considered neutral). While listening to/viewing these, they were simultaneously hooked up to electrodes that measured their skin conductance response (SCR). This equipment is sensitive enough to detect trace amounts of sweat produced from acute emotional reactions.

In addition to collecting this physiological data, we also had participants provide subjective ratings for each clip they saw or heard (on a 0-4 scale, 0 meaning the clip caused no discomfort at all and 4 meaning the clip caused extreme discomfort and anxiety). We found that Misophonic individuals showed heightened ratings and skin conductance responses to auditory but not visual stimuli (relative to non-Misophonic individuals). Additionally, we found evidence that Misophonics find similar stimuli to be aversive and non-aversive on a subjective level. The results of experiment two largely appear to validate the severity of Misophonia beyond anecdotal descriptions, and provide the

first physiological evidence in support of this.

A link to the full paper can be found here: <http://journal.frontiersin.org/article/10.3389/fnhum.2013.00296/full>

What do you think your particular area of research might add to the larger body of Misophonia research?

I believe that our particular area of research is unique in the sense that it provides both qualitative and quantitative evidence for Misophonia. The goal of our first study was to validate the experiences of Misophonia sufferers by showing that there are indeed both psychological and physiological differences in how they process certain sounds. In our future work, we intend to build upon the findings from our first study in order to develop possible strategies or inventions that may be utilized for treatment.

Are there any ways in which you think this research might one day translate into treatment for sufferers, or is it too early to make that connection?

I certainly believe that our research may one day translate into treatment for sufferers – after all, treatment is the ultimate goal. However, as research on Misophonia is still in its infancy, we are currently focusing only on trying

understand all of the ‘ins-and-outs’ and quirks of the condition. I believe that once we have a clear understanding of how certain factors can modulate the severity of the Misophonic response, we will be more equipped to devise the most effective means of treatment. Currently, our lab is just beginning a new study that (if successful) may have potential application for treatment. I will definitely keep you posted about that.

I am sure that, since your paper was published, press reporters have asked you about Misophonia. What do they usually ask you? Do you find it difficult to explain the kind of work that you do to press reporters?

Speaking with press reporters can sometimes be tricky, as they have a tendency to sensationalize your research. For the most part though, I would say that I have had positive experiences with the reporters I’ve spoken to, and have been satisfied with the way in which they have portrayed my work to the public. I tend to receive a lot of questions about treatment and cures, a topic I do not feel qualified to speak on at the moment as we simply haven’t found an end-all, standardized treatment yet. Therefore, a strategy that I actively employ when speaking to reporters is to stick strictly to the data and what we already know. If something is still speculation, it is important that it is portrayed as such and not as fact. This can sometimes be difficult when dealing with a topic like Misophonia, on which little research has been conducted, but I’ve found that it is the

most effective way to avoid widespread inaccuracies.

You have told us that you are also interested in music. Would elaborate on that and how that applies to your work (and/or inspires you in any way)?

As a lifelong violinist, sounds have always been a huge part of my life. In fact, all of the research I do with both of my advisors revolves around sound, but in two very different ways. With Dr. Deutsch, I study sounds specifically in the context of music, or sounds that people generally enjoy. However, with Dr. Ramachandran I study Misophonia, which is almost the completely opposite scenario. Although I do not suffer from Misophonia, I do feel that my musical background has afforded me a unique perspective when conducting research on it, as I am well aware of the ways in which sounds can evoke profound emotions in people.

If you could set up a lab with a team of cross-disciplinary researchers to study Misophonia, from which disciplines would you choose these individuals (neuroscience, audiology, etc.)?

I think it would be extremely beneficial to have neuroscientists and audiologists, as well as clinical psychologists, psychiatrists, and physicians, all collaborating

together to conduct Misophonia research. Right now, a major problem for Misophonia research that needs to be addressed is the lack of communication between various fields of study. Researchers from different disciplines all have unique and valuable perspectives on the topic, but this information is not being communicated in an effective manner across groups. I believe that an interdisciplinary research environment, while simultaneously promoting a more unified dissemination of knowledge, will be the most effective at fostering breakthroughs in the field.

Rare Disease and Stigma

Dr. Linda, Interviewed by Shaylynn Hayes

**Could you tell us about your affiliation with SERMO?
Who are they/what do they do?**

SERMO is the largest online network exclusive to only physicians. On the site, we collaborate about cases and talk about general things in healthcare. And some socializing as well. If I have a difficult case I need help with, I can create a post on SERMO and get online help from my colleagues.

I am a medical advisor for SERMO, they want to be sure they keep physicians' voices in what they do. I also am one of their "hub ambassadors": I write articles for the obesity and rare disease hubs. These are learning hubs for educational purposes. And I am one of their blog columnists.

**You write about rare diseases and medical conditions:
what are some of the rarest you've come across in your
practice?**

I have had a few rare disease patients in my practice. The rarest was Moyamoya syndrome*.

As a doctor, when a patient comes to you with a rare

disorder that you have never heard of it, how might you handle it?

Most of the rare disease patients I have seen are already seeing specialists and I am treating them for other problems (acute infection, etc). I will research the disease and try to educate myself about their disease. And, I will try to ensure that they are indeed seeing the right specialists for their disease.

Since they are harder to diagnose, do you find it a challenge to get patients to open up about their rare disorders? Have you ever felt a patient was holding back in fear of being judged?

Yes, this is a big problem. Many rare disease patients that I have treated feel that people don't understand them. And the truth is, science doesn't because many of these diseases we just don't know enough about. I feel some of rare disease patients do feel stigmatized, judged, and misunderstood. I find that parents of kids with rare diseases are more likely to open up about their child's rare disease.

What advice can you give to patients that are scared to confront their doctor with a condition that you, or many others, have never heard of?

It is very important that your doctor know everything about

your medical condition. If we don't, we will not be able to give you the best care. As doctors, we are trained to be non-judgmental. However, doctors are human and this may not always be true. If you are seeing a doctor who you feel you cannot be completely open with, you need to find a new one. You need to trust your doctor and vice versa.

If I have a patient with a condition that I never heard of, I will tell them so. And ask them to tell me how it has affected them. I will then do my best to try to learn as much as I can about that disease. If I am to give my patients my best medical advice, I need to know as much as possible.

And, when I don't know what to do, I will try to find the best available specialist to help.

Do you believe the current system in the US properly cares for patients with rare and unheard of conditions?

No. We are not even doing a good job giving proper care to patients with common chronic conditions. All too often, insurance companies are denying diagnostic tests and medications. And this is especially worse for rare disease patients who may require unusual diagnostic tests to diagnose their conditions. Also, research monies are going to the most lucrative disease and little is being spent towards researching rare disease.

If a patient came to you with Misophonia, a condition that is nearly impossible to diagnose, how would you help a patient to acquire accommodations from either work or school?

I write many letters of medical necessity for my patients for various conditions, including work and school accommodations. I would ask the pt what would help them to be able to function better and feel more comfortable at work or school. And then I would send a letter outlining what accommodations are necessary.

Do you believe there is a large stigma that still affects persons that have rare disorders?

I believe there is. And I think until; more research is done and we start understanding these disease better, it will unfortunately remain.

Is there anything else you might like to add?

I am very passionate about rare disease patients. I have written articles about how I believe they are being harmed in our current health system. Our healthcare system (3rd party payers, governmental plans) are more geared to cost savings and not giving patients the best care. And rare disease patients are being hurt because of this.

It is scary enough having a disease. But, when it is a disease

that few other people have and even doctors don't understand it, it is horrifying.

I think we should all try to put ourselves in the shoes of a rare disease pt for a few moments and imagine how scary it must be .And then, we all need to step up and do better by them, from doctors to researchers to teachers to society. All of us, individually and professionally.

* Moyamoya disease is a rare, progressive cerebrovascular disorder caused by blocked arteries at the base of the brain in an area called the basal ganglia. It's so dark and small.

Mercede Erfanian Interview

Interview by Dr. Jennifer Jo Brout

Jennifer: Can you just tell us a little bit about yourself, and how you got interested in research in general?

Mercede: As long as I can remember, I have been pretty curious and energetic. When I was younger this curiosity manifested in the form of destroying things in order to understand how they worked. This ongoing sense of discovery in me eventually led me to do research. Research can feed my soul and satisfy my sense of discovery.

Eventually I wanted to know why, and people may behave in different situations. This yearning for knowledge led me to the field of psychology. I studied clinical psychology for my bachelor's and master's degrees, taking intensive courses in affective neuroscience in Maastricht University. This helped me to specify my area of expertise to mood, anxiety and OC related disorders.

Jennifer: How did you get interested in Misophonia?

Mercede: I was doing a study titled "Synesthesia in bipolar and schizophrenic patients: a comparative study of their relationship with abstract thinking" in 2013. This opened the door to misophonia, as misophonia and synesthesia could be similar from a neuroscientific standpoint. In short, one way to define synesthesia is provoking one sense by another, like, hearing colors or seeing sounds(Chromesthesia). Misophonia could be almost the same phenomena, which could be:

"provoking an emotion by a sound or scene or even a touch.

Jennifer: Would you mind describing your study for us?
What was your most important finding?

Mercede: While there is still no agreed set of criteria for misophonia and the research is in its infancy, we tried to clarify the very particular criteria for misophonia. Some researchers believe misophonia should be subsumed as "decreased sound tolerance" while other researchers assume it should be classified under OC related disorders.

In this study, we introduce a wide range of emotional and physical characteristics, and thoughts, as well as an elaborate list of auditory, visual, and tactile triggers, nature of triggers, age of onset, family history, comorbidity with

other disorders and phenomena, and severity, to try and get a wider, more exact inventory of the characteristics of Misophonia.

Jennifer: What do you think your particular area of research might add the larger body of misophonia research?

Mercede: My area of research would suggest a number of diagnosis techniques and treatments for misophonia, although it is highly recommended to study misophonia thoroughly to find out different risk factors, epidemiology and etiology that are still ambiguous. I believe it is essential to do more research in order to fully understand the nature of misophonia before jumping to propose treatment.

Jennifer: If you could set up a lab with a team of cross-disciplinary researchers to study misophonia from which disciplines would these individuals be (e.g. neuroscience, audiology, etc.?)

Mercede: In my opinion, the most efficient multi-disciplinary team of research would consist of general practitioners, psychologists, psychiatrists, neuroscientists, audiologists and audiometrists. A general practitioner would evaluate the physical symptoms of misophonia and

differentiate them from other similar physical manifestations. A Psychologist or psychiatrist could study the behavior and mental process of Misophonics as well as their affective and thought related aspects of disorder and copy strategies.

A neuroscientist would identify any brain dysfunction in Misophonics and possible connection of misophonia with other affective and cognitive phenomena. An audiologist could diagnose and monitor the vestibular system of the ear or the presence of other auditory problems and the possible damage to auditory system and cortex. An audiometrist, would administer audiometrist tests to enable the rehabilitation of hearing loss and differentiate Misophonics from other “decreased sound tolerance.

The Misophonia Test Measurement Mess

Dr. Jennifer Jo Brout, PsyD

Psychologists and researchers know that developing a scale to diagnose a newly proposed disorder is not an easy task! Rather, it is an arduous process that includes extensive validation and reliability studies. At the most rudimentary level a diagnostic test should have validity (i.e. it should test what it purports to test) and reliability (i.e. it should produce consistent and stable results over time). Yet, developing a test in order to diagnose any new disorder is paradoxical. One needs tests in order to diagnose, yet one needs to know what they are diagnosing in order to develop a test! In the past, test development and research have moved together somewhat reciprocally. Scales were updated along with new research findings and with new conceptualizations of disorders.

However, in the age of the Internet and in the case of newly termed disorders, the cart is most definitely moving before the horse.

Misophonia has fallen victim to this phenomenon, and misophonia scales of all kinds can be found with a push of a few buttons. Tests devised by misophonia sufferers, advocates, researchers and clinicians are muddled on the Internet. Ideally, researchers, clinicians and sufferers alike would utilize each others' resources to develop misophonia measures. Yet, that is not what is happening. Despite good

intentions, we are in a misophonia measurement mess.

I am not a test developer. However, I offer a brief review of what is “out there” so that you can further evaluate these issues. Note, I am using only three examples (the most widely used scales).

Misophonia Activation Scale (MAS-1): This was devised by advocates of the nonprofit group Misophonia UK. The scale was developed in 2010, but on the website the scale is appropriately referred to as a “work in progress” and offers many disclaimers about its development. The test measures both physical sensation as well as emotional responses. A level of 0 describes a person with misophonia who hears a trigger but experiences no discomfort. A level of 10 describes “actual use of physical violence on a person or animal, or self-harm.”

Thoughts: Even though the test developer makes all of the appropriate disclaimers, this test has been widely used by sufferers and researchers alike. In addition to the need for validation, the widespread use of this scale correlates physical violence with misophonia. While the feeling of “rage” is often associated with misophonia, studies have not explored to what degree, if any, trigger sounds actually produce violence in people with misophonia. In addition, the test may not discriminate misophonia from other disorders. Therefore, for example, some of the violent activity associated with misophonia may be due to confounding with other disorders such as Intermittent

Explosive Disorder, or Conduct Disorder as some examples.

The Amsterdam Misophonia Scale (A-MISO-S): This scale was developed at the Amsterdam Medical Center in order to measure the severity of misophonia symptoms. It is a 6-item scale (with a range of 0–24). The scale addresses the time an individual spends occupied by misophonia, how much the misophonia sounds interfere with the individual's social and work functioning, the individual's level of anger in response to sounds, level of resistance against the impulse, how much control the individual has over thoughts and anger, and how much time an individual spends avoiding misophonia situations. Scores range from 0–4 are considered subclinical misophonic symptoms, 5–9 mild, 10–14 moderate, 15–19 severe, 20–24 extreme.

Thoughts: The scale developers adapted a version of the Yale-Brown Obsessive-Compulsive Scale (Y-BOCS). The scale's authors' state the rationale for using the adapted Y-BOCS is that "Similar adaptations of the Y-BOCS have appeared to be reliable and valid measures of symptom severity in other obsessive-compulsive and impulse control disorders." Possibly the authors are hinting at convergent validation in this case. When measuring a construct (e.g. ideas or levels of a disorder that cannot be easily quantified) it is common to compare a new test to an older test that has been extensively studied. If the new test correlates highly with the "tried and true" test, then this adds evidence that the new test is measuring the same construct, or disorder. However, OCD and Misophonia are

not the same constructs, or disorder. Unless I am missing something, this is confusing. Regardless, as aforementioned, validating a scale is an arduous evidence gathering process. Perhaps comparing OCD and Misophonia is a piece of the puzzle. However, I'm still not clear as to why the Y-BOCS was adapted to measure a disorder of decreased sound tolerance. In addition, as far as I can see, no other studies for validity and reliability of the scale have been done, yet perhaps they are in process.

Misophonia Assessment Questionnaire (MAQ): The MAQ was devised by a seasoned audiologist who has worked with tinnitus, hyperacusis and misophonia patients since the Jastreboffs' termed the disorder in 2001. One can score between the "subclinical range" and the "extreme range". The questionnaire includes 63 items presented within a likert-type rating scale.

Thoughts: The Questionnaire is simple, straightforward and makes no claims beyond what it is; a questionnaire that indicates how much the individual's life is impacted by "sound issues". Since all of the questions are phrased using this term the questionnaire may confound misophonia and other disorders of decreased sound tolerance. However, it is not "diagnostic" in nature, and is more in line with the kinds of measures one would expect to see relative to where the research for misophonia is at this point in time. As is true of all the other measures, there are no reports of validation or reliability studies.

In conclusion, it seems that there are no scales for misophonia that have proper validation and reliability studies. Clearly, we need to develop scales, but they must be carefully developed so that conceptualization of the disorder is not further confused. While we all want to validate the disorder, it does not help to put the cart before the horse.

Misophonia and the Sensory World

Susan Nesbit OT/L, OT(C) by Dr. Jennifer Jo Brout

Would you explain the A. Jean Ayres original theory of Sensory Integration (in just a few very general sentences)?

In the 1960s, Dr. Ayres described Sensory Integration Dysfunction (SID), including tactile defensiveness. She suggested that children who over-react to touch (e.g., they do not like getting their hair and nails cut, will not wear certain textures of clothes, and avoid activities such as finger painting) have a protective tactile system that is always on. The discriminative tactile system (e.g., knowing that you're feeling the keys in the bottom of your purse without looking at them) is not overriding the protective tactile system, and the unimportant tactile information does not get filtered out. With the bombardment of protective tactile information, the child with tactile defensiveness is in a pattern of fight-or-flight (e.g., he is unable to sit still and feel the keys in his hands). Dr. Ayres further proposed that activities with deep pressure (e.g., hugging and jumping) enable the discriminative tactile system to override the protective tactile system so the unimportant tactile information can be filtered out and the child can be available for learning. Imagine a child with tactile defensiveness playing on a seesaw. The seat with the protective tactile system (sympathetic nervous system) stays up, causing the child to flail (to wildly swing his arms and legs) with anger

and other negative emotions. The seat with the discriminative tactile system (parasympathetic nervous system) does not go up, so the child is unable to enjoy the seesaw. Children need to balance the seesaw by alternating the seat for the protective tactile system going up (so they can run if they see a fire) with the seat for the discriminative tactile system going up (so they can sit still without flailing, and they can have fun and learn in a safe environment).

Would you explain the more recent conceptualization of Sensory Processing Disorder?

In the 1980s, other scholars proposed that defensiveness exists in other sensory channels, and several other types of sensory defensiveness were labeled and described, including auditory (sounds), visual (sights), and olfactory (smell). Because the protective and the discriminative tactile systems address only tactile defensiveness, and not defensiveness in the other sensory channels, the more recent scholars theorized that the amygdala is the filter, with the inhibitory fibers not overriding the excitatory fibers. The excitatory fibers are constantly firing, thereby letting in the unimportant information so a person is wired for fight, flight, or freeze. The sympathetic and the parasympathetic nervous systems are not balanced. These scholars suggested using activities that provide deep pressure and slow, linear movement to help the inhibitory fibers override the

excitatory fibers.

Moving into the 21st century, Dr. Lucy Jane Miller coined the terms more commonly used today. Sensory Integration Disorder is now referred to as a Sensory Processing Disorder (SPD), which is an umbrella term with three primary diagnostic categories: (a) Sensory Modulation Disorder (SMD), (b) Sensory Discrimination Disorder (SDD), and Sensory-Based Motor Disorder (SBMD). Each diagnostic category has subtypes.

SMD has three subtypes: (a) Sensory Over-Responsivity (SOR), (b) Sensory Under-Responsivity (SUR), and sensory craving (SC). Persons can have SOR, SUR, and/or SC in one or more of the various sensory channels. Sensory channels include: auditory (sounds), visual (sights), tactile (touch), pain, olfactory (smells), gustatory (tastes), proprioception/ vestibular (position/movement), air temperature (hot or cold), and interoception (e.g., hunger pangs). Persons with SOR perceive the input from one or more of the sensory channels as noxious, harmful, or threatening. For example, a child with an auditory over-responsivity might cover his ears when someone whistles or jangles his keys. In contrast, persons with SUR barely perceive the input from one or more of the sensory channels. For example, a child with bumps and bruises might feel little pain. And a person with SC seeks input from one or more of the sensory channels.

Examples include a child touching and/or smelling objects as he walks through a room, a child who seeks movement having difficulty sitting still, and a child who seeks proprioceptive input (pressure) intentionally bumping into things, including people.

SDD has six subtypes: (a) Auditory, (b) Visual, (c) Tactile, (d), Taste/Smell, (e) Position/Movement, and (f) Interoception

SBMD has two subtypes: Dyspraxia and Postural Disorder. Persons with dyspraxia (poor motor planning) have problems doing new or unfamiliar tasks such as learning to tie shoelaces. They do not learn to tie the shoelaces automatically (without thinking), and when they feel stressed, the task of tying is even more challenging. Postural disorders include poor balance and low muscle tone.

Do only children have Sensory Processing problems?

Sensory processing disorders cannot be cured. Therefore, adults have sensory processing disorders. Many adults were not diagnosed as children, however.

Would you explain how SPD might relate to Misophonia

sufferers? Is there a specific subtype that might overlap?

Misophonia and auditory over-responsivity might overlap. (Note: SPD is used interchangeably with the term auditory over-responsivity. To be in sync with others, I will use the term SPD when referring to a sensory modulation disorder, including auditory over-responsivity.)

Misophonia is a strong dislike or hatred of specific sounds. Persons with misophonia dislike, soft or loud repetitive sounds, especially sounds made by the mouth. Triggers include chomping food, slurping a drink, snapping gum, humming, and whistling. Other triggers include opening a bag of chips, cracking knuckles, and texting with the volume on. (Note: Sounds are not triggers when the person with misophonia makes them. Sounds are triggers when another person makes them.)

When exposed to a trigger, persons with misophonia feel anger, disgust, and hate. In contrast, persons with hyperacusis feel pain from loud and/or high-pitched sounds such as sirens and alarms, screeching breaks on subways or buses, silverware clanking against dishes, children's screams, and clapping. Some loud, repetitive triggers overlap with the triggers for misophonia. For example, silverware clanking against dishes is listed as a trigger for

each condition.

Persons with SPD dislike all of the above sounds. The emotional manifestations (anger, disgust, and hate) and the behaviors (fight, flight, or freeze) of persons with misophonia and SPD seem similar.

Some persons diagnosed with misophonia are reported to have visual sensitivities in addition to their auditory sensitivities. The term misokinesia has been used to mean a hatred of movement. Persons with misokinesia strongly dislike seeing movements such as someone twirling her hair around and around her finger, someone moving his leg up and down while sitting, and someone chewing food or gum with his open mouth.

Persons with SPD typically have problems in more than one sensory channel; therefore, over-responsiveness to inputs such as visual and tactile in addition to auditory over-responsivity suggest SPD. However, the auditory sensory channel might be the only sense affected in SPD. Therefore, the question of whether misophonia and SPD are linked needs to be investigated. Please bear in mind that the current lack of research does not rule out a potential link between these two conditions.

SPD is thought to be a neurodevelopmental condition, meaning that it is a disorder within the brain that affects emotions, self-control, attention/memory, and learning throughout the lifespan. Research is ongoing; however, the neurobiological mechanisms and the implicated structures in the brain are not well documented. The etiologies (causes) are unknown, but a genetic vulnerability is possible in some persons with SPD. Fewer studies exist for misophonia. Whether this condition is neurological or learned from experiences is controversial. Research is needed to investigate the similarities and the differences between SPD and misophonia and to investigate the possible co-occurrence of these conditions.

The potential exists that some persons have been misdiagnosed, and an incorrect diagnosis could lead to the wrong treatments, which could worsen the symptoms. The causes of misophonia and SPD could be different. Causes guide treatments. Therefore, research to find the causes for misophonia and SPD is important.

Would you explain how Occupational Therapists have been involved with SPD kids and adults, as clinicians?

Occupational therapists evaluate for SPD with informal tests

(observations and interviews) and with formal tests that are standardized for validity and reliability. Formal tests include the Sensory Profiles and the Sensory Processing Measures. These two batteries of tests use age-appropriate and environmentally appropriate (home versus the classroom) forms.

Occupational therapists have been treating children and adults diagnosed with sensory integration disorder (SID), now called sensory processing disorder (SPD), since the 1960s. Some persons come for intervention in a sensory gym with a variety of swings, climbing structures, balls, bolsters (rolls), mats, and other equipment to provide body movement and proprioception (deep pressure). The other sensory systems are treated as well. For example, sensory bins are used for persons with tactile problems.

Occupational therapists work with students in schools, giving teachers suggestions to help students with SPD stay on task. Suggestions include providing movement by sending the student on errands such as taking the class attendance to the office and/or allowing him to sharpen the pencils; providing movement while sitting by using a wobble chair or a standard chair with a wobble cushion; providing pressure against the student's torso (trunk) by allowing him to sit backward in his chair; providing movement and pressure on different body parts by allowing

the student to switch positions (e.g., alternating between a sitting position – including sitting on his legs, a standing position, and stomach lying on the carpet); and providing structured fidgeting by allowing the student to rub his hand(s) across Velcro taped inside the top of the desk, twist the pieces at the top of a fidget pencil, play with a fidget toy, and/or press his feet against TheraBand tied around the legs of his desk. Occupational therapists also work with parents, giving home programs with sensory activities and making suggestions for modifying (changing) the home environment. The goals of classroom and home modifications are to reduce the number of noxious stimuli and to provide ways to stay calm or regain composure when triggered.

SPD has no cure. However, the symptoms can be temporarily lessened through a variety of treatments, including sensory diets. Similar to a diet of food, the input from a sensory diet does not last indefinitely in the body. The input lasts 1-2 hours, or less when stressed by noxious stimuli.

Sensory diets include activities for pressure and movement. Activities can include hiking, walking, or running; doing animal walks (e.g., elephant, bear, rabbit, frog, duck, and crab); wheelbarrow walking; floor or chair pushups; “play” wrestling; bouncing on a hopper ball (they come in adult

sizes); jumping (e.g., up and down with both legs together or jumping jacks) on the floor or a mini-trampoline (use a regular trampoline if one is available); playing on a variety of swings, climbing structures, and slides; doing yoga (classes and books/flash cards are available for adults and children); using fidget toys; manipulating Play-Doh or modeling clay; and coloring mandalas (beginning at the center). Doing heavy work, including taking out the garbage, mowing the lawn, carrying the laundry, and pushing furniture to vacuum, can be included in a sensory diet.

Would you explain from your perspective what might be happening to a person with misophonia when they feel “overloaded”:

I am a pediatric occupational therapist, and I have misophonia and SPD. To avoid becoming overwhelmed by triggers, I control my environment as much as possible. For example, I ask persons not to whistle or crack their knuckles. I leave the room if someone is chomping food. I have been called controlling; however, the alternative is melting down or shutting down.

When initially triggered, I typically remain calm. I can think and be proactive. I can stay calm until the frequency

(number) of the triggers increases, the intensity (strength) of just one trigger increases, and/or the duration (length of time) of just one trigger extends. When the triggers accumulate, I become overwhelmed.

When I become overwhelmed, I am unable to think and I become reactive. I have an “adult” meltdown by snapping at the person whom I view to be noxious or by crying. I try to save my crying until I am alone, but I’m not always successful. If I don’t have a meltdown, then I shut down (withdraw) and I do not listen.

I can become overwhelmed with sound triggers alone, but with the addition of other triggers – sights, smells, being hot, and/or being hungry – I more easily become overwhelmed and I have a bigger meltdown or I withdraw more deeply. I experience what I call the “additive effect,” which I’ll describe later in a different question.

Do you think there are ways OT’s can help people with Misophonia in terms of helping calm down when they feel “rage” or “fear” or “overloaded”?

For persons with SPD, and possibly with misophonia, I suggest using a sensory diet (examples given above). When I’m unable to leave the negative situation to do some of the activities such as walking, I hug myself by squeezing my

torso with my arms crossed, and I cross my legs at my knees and my ankles (I'm flexible). Sometimes I clasp my hands together and squeeze – under the table when possible – I try to be inconspicuous. (Note: I've successfully explained to social workers and psychologists who work with persons with SPD that by crossing my arms around my body and by crossing my legs, I'm not communicating that I'm closed to them and not listening. Instead, through the pressure provided in these positions, I can remain calm to listen.)

I also try to reframe my negative thoughts by thinking about something positive; e.g., this meeting will be over in 15 minutes and then I'll get a gourmet coffee. Sometimes, sounds that I enjoy are mingling with the sounds that I hate, and I try to focus on the sounds that I enjoy. For example, if someone is triggering me on the NYC subway, I'll try to listen to the wheels moving along the tracks. Sometimes I visualize walking in a forest surrounded by the sounds that I love (e.g., a waterfall gliding over the rocks into a pond, the rustle of the pine needles under my feet, and the singing birds perched in the trees). I visualize watching the white, fluffy clouds moving across the cerulean-blue sky. I stop to smell the roses. I feel the rain on my skin. Sometimes I breathe deeply, counting as I inhale and exhale. Sometimes I progressively relax my muscles. But when I'm tipped over the edge and I cannot think, visualizing the triggering person getting run over by a tractor-trailer truck is helpful. (Note: Reframing,

mindfulness, visualization, deep breathing, and progressive muscle relaxation, work for me only when the triggers are few, not intense, and not lasting a long time.)

We know that seeing an OT for therapy is the best option because therapy is personalized. However, are there any general concepts related to sensory overload that might help people with misophonia cope in their daily lives?

Sensory information accumulates. Imagine a set of triggers: You're at a low level of arousal and your alarm clock rings. You push the snooze button and it goes off again in only 5 minutes, and you're still tired. You get out of bed and step on a toy. You go to make coffee and discover that you have no cream. You pick up the cereal box and it opens on the bottom, spilling onto the floor. Your child will not get dressed. You finally leave the house and back the car out of the garage, hitting your child's bicycle. By now, even a person without misophonia or SPD might be on a high level of arousal (sensory overload). Before driving your car, try to take a break to reset your level of arousal from high to normal.

To describe what I call the additive effect, I'll use my auditory and visual triggers in a mathematical equation. I'll give a score of 2 (for mathematical purposes only; I'm not

using a scale to rate how much I hate the trigger) to hearing someone chomping his food. And I'll give a score of 2 for seeing that person chewing with his mouth open. In this scenario, $2 + 2$ does not equal 4. Instead, $2 + 2$ equals 5.

Along the same lines are there any easy-to-do techniques that people might be able to learn that might help them manage?

When possible, modify your environment to reduce the frequency (number), the intensity (strength), and the duration (length of time) of the triggers. Modifying the environment is helpful for persons with misophonia and/or SPD.

For persons with SPD, I gave examples of activities for a sensory diet in an earlier question. Identify the sensory activities that work best for you. Do a sensory diet for 5-10 minutes. Because the sensory activities are part of a diet, you may need to do them every one-two hours. You may need to do them more often if triggered. Another easy-to-do technique is self-hugging, as described in an earlier question.

Bear in mind that if the cause of misophonia is different than the cause of SPD, then a sensory diet may not be

effective for misophonia. Some scholars speculate, however, that misophonia also could be neurologically based, and perhaps the same structures in the central nervous system (the brain) are involved.

In the next question, I'll recommend a book in which the authors provide ideas to help you determine your level of arousal – low, normal, or high. The authors teach you to identify “how your engine runs.” You will learn, for example, to identify when you're approaching a high level of arousal, which means that you're approaching sensory overload. The authors also guide you to identify the sensory activities that could work best for you. (Note: A caregiver can use this book to help children with SPD.)

If you live with a person with misophonia or SPD, I suggest allowing that person to have control, or at least perceived control, to create a structured and supportive environment. By perceived control, I mean giving choices; however, every choice is acceptable to you. In an example: You need to do two errands and take your child along. You know that she dislikes the noises in the stores. You can give her the choice of which store she'd like to go to first. You can say, “I know you hate shopping (empathy); however, we need to shop for dinner and buy daddy a new hammer. Which store would you like to go to first? The grocery store or the hardware store? You are setting limits with two acceptable choices.

You also can problem solve together by asking her how she can cope (be less angry) with the noise. Bear in mind that persons with misophonia and SPD are controlling to reduce the triggers (noxious stimuli) to prevent sensory overload.

Recommended Websites

<http://spdfoundation.net>

The SPD Foundation leads the word in research, education, and awareness for Sensory Processing Disorder (SPD). You'll find many gems by surfing this website. The topics include: (a) treatment for SPD, (b) research findings, (c) resources such as downloadable flyers (e.g., tips to build resilience in a child with SPD, a symptoms checklist, and a sensory diet with summertime tips), books (e.g., books written for children to help them understand SPD), (d) links to websites selling merchandise, and (e) news.

<http://www.alertprogram.com>

This website offers a one-page PDF handout explaining the Alert Program. They sell a book called "How Does Your Engine Run: A Leaders Guide to The Alert Program for Self-Regulation." This book has step-by-step instructions and activities to identify and change how alert a person feels (level of arousal). Many therapists, teachers, and parents

have taught themselves how to do the program by reading this book. The program can be used to help others or yourself.

<http://www.thesensoryspectrum.com/sound-sensory-overload-may-like-child/>

This website has a video that simulates being on “sound sensory overload.” This video helps persons who do not live with this disabling condition experience the sensations. This website also sell items that can be used in a sensory diet.

Recommended Books

A thorough list of books can be found on the website for the Sensory Processing Foundation.

Sensational Kids: Hope and Help for Children With Sensory Processing Disorder (SPD) – Revised Edition, by Lucy Jane Miller and Janice Roetenberg.

No Longer A SECRET: Unique Common Sense Strategies
for Children with Sensory or Motor Challenges, by Doreit
Bialer and Lucy Jane Miller.

M. Zachary Rosenthal, Ph.D. Interview

Interview by Dr. Jennifer Jo Brout

Jennifer: What is the difference of an “emotion” and a “physiological state” such as the fight/flight response?

Zach: Emotions are widely considered to have three basic parts: (1) personal experience, (2) expressive behavior, and (3) physiology. This means that all emotions have underlying physiological components. One cannot experience or express emotion without underlying central and peripheral nervous systems. For example, our brains and bodies are wired with so-called “fight,” “flight,” and “freeze” systems to help us sense and respond to stimuli that may be threatening. These systems can be triggered by all sorts of cues, and when this happens, our physiology dynamically responds in complex ways, we approach, avoid, escape, or become immobile, and we may subjectively label our experience with particular emotional states. Another way to think about the difference between emotions and the physiological states of fight and flight is this: Our brains and bodies respond to threat cues, whether the cues truly are threatening or not, by activating a web of circuitry that functions to help us adapt and respond to these cues. Emotions are commonly a part of this process, but not all emotions are associated with an underlying fight or flight response.

Jennifer: So, Zach the lines between psychiatric disorders and disorders with underlying neurological causes are blurred? Is it fair to say that we are in a time during which we don't quite have cohesive and accurate terminology and that this could be confusing to people?

Zach: I think it is fair to say that psychiatric problems have neurophysiological and environmental influences, and that many physical health problems, including those that some would call "neurological," also are influenced by both biology and the environment. It would be so much easier to understand if there were simply such things as mental health problems and neurological problems, with completely different causes. But that is not the way it is. Scientists have a hard time understanding how all these things work, so it is no wonder when this is hard for the others to understand.

Jennifer: I'm not holding you to this or making this your responsibility. However, I saw on Wikipedia that Misophonia was described as a neuropsychiatric disorder? Some people call it a neurological disorder, and others call it a psychiatric disorder. If people asked me what it should be called what should I say? Again, I'm not asking you to classify this disorder but it's very confusing to people.

Zach: I can see why it might be confusing to people. I have people in my own family who struggle with symptoms consistent with misophonia. They wonder what it

happening. And they ask me! I would say that it is a syndrome which is not yet understood scientifically. This makes it hard to classify it in a category. The data and clinical anecdotes suggest it is a very real phenomenon, and it is hard to imagine how it could not involve neurological functions associated with sensory processing and the regulation of defensive motivational brain responses to particular sounds. The automatic response to certain sounds appears to resemble behavior consistent with what some have called the “survival circuitry,” which is to say emotional responses that function to move the person away from the sounds as efficiently as possible. The anger response that occurs around others is very interesting, as anger is a functional emotion we have when others are blocking us from our goals to approach desirable things or escape from unpleasant things. So I am not sure that misophonia is all about anger per se, or whether anger is the response to the cue when it is unpleasant, cannot be easily avoided, and the attribution made is that the person causing the sound “should” stop doing so. The other interesting thing is that misophonia symptoms seem to co-occur with various psychiatric problems. We need to do scientific research to determine whether and when misophonia symptoms should be expected in specific psychiatric disorders, non-specifically across mental health problems, or whether it commonly occurs without any co-occurring mental health problems.

Jennifer: Thank you for that great explanation. How would

a person know the difference if they were experiencing and emotion or if they were experiencing a physiological reaction?

Zach: Emotions can be thought of as separate categories, such as when we say we feel anger, sadness, joy, and the like. In each of these subjective experiences or emotional expressions, there are complex underlying physiological reactions to environmental cues taking place. Alternatively, some researchers believe emotions are better described dimensionally with components of (1) emotional arousal from low (e.g., calm) to high (excited) and (2) emotional valence from low (very unhappy) to high (e.g., very happy). From this way of thinking, emotions are complex, ongoing, interactive and changeable events with physiological underpinnings that occur in response to environmental cues (both outside and within the body). In both the categorical and dimensional ways of thinking about emotions, there are underlying physiological reactions that happen immediately before, during, and after emotions. So emotions have physiological foundations. Not all physiological reactions, on the other hand, occur during acute emotional states. When I have the physiological reaction of salivation in response to thoughts about key lime pie, I may not use emotion to describe my reaction. Instead, I might say I am hungry, ready for dessert, or the like. If I react with sleepiness when watching a TV show, I might describe feeling tired or sleepy. And so on.

Jennifer: Makes sense! What is the state of the field regarding conditioned versus inborn or genetic response or behavior?

Zach: When trying to make sense of complex health problems, we used to talk about nature versus nurture, conditioning versus genes, and environment versus biology. But what we now know--and in hindsight this is embarrassingly obvious-- is that these are overly simplistic false divisions. These things that once were apparent distinctions as “either/or” now are becoming logically combined as “both/and.” The question is no longer whether a phenomenon is caused by conditioning or something physiological. The question is how and in what important ways do nature and nurture interact to predict human behavior? Nature and nurture reciprocally influence each other, likely in many ways and at many levels of analysis, their effects pinging and ponging off of each other. Genes and the environment interactively influence each other. The environment influences genetic expression, and genetic expression influences the environment. As an example, it would be overly simplistic, and flatly incorrect to assert that a disorder such as PTSD or OCD is caused by genes independent of any environmental influence. Genes impact conditioning, learning, and memory, and these processes influence the way in which we express ourselves in our environment, which influences how the world responds to us, which then impacts our underlying biology. It also would

be overly simplistic to say that these problems are singularly caused by conditioning in the absence of any underlying biological influences. Conditioning processes are both biologically and environmentally influenced.

Jennifer: So Zach, what you are saying is that the question of nature versus nurture isn't really the right question anymore, especially in psychiatry. I know this is putting the matter very simply but I want to be very clear. The thinking about this has changed a lot, even since I was in graduate school. Many of us grew up thinking about nature versus nurture (or genetic versus environmental) as very separate ideas.

Zach: Yes. But this is also true outside of psychiatry. For example, environmental stressors can elicit neurobiological changes, and these changes can then influence how someone lives, which of course impacts how the world treats them, which then can influence their neurobiology. It is back and forth kind of thing throughout life.

Jennifer: Okay, in that case... We now know that even if identical twins both have the same "genes", one twin might manifest symptoms of OCD, or any neurological or health related disorder, while the other may not. This is because genes and the environment interact with one another. Genes

can be “turned on” and “turned off” according to factors in the environment, and within the individual human being. So, it’s a lot more complicated than we thought it was, and the take home message is that both nature and nurture contribute to human behavior in a complex and interactive way. Would you say that is a good synthesis of what you said?

Zach: Well said!

Jennifer: Thank you! Having said that, are there any specific disorders or diseases for which there is a clear distinction between a genetic cause versus an environmental cause?

Zach: The search for genetic causes in psychiatry is ongoing. Many researchers with and a whole lot of research funding are dedicated to the search for clear genetic markers of psychiatric disorders. Although there are data suggesting some psychiatric disorders are associated with certain polymorphisms, this is very different than concluding genes cause the disorder. On the other side, there are many examples of environmental correlates or predictors of psychiatric problems, but these environmental causes may also have genetic correlates. In addition, where there are data supportive of genetic correlates to psychiatric disorders, these genetic factors typically account for small

amounts of the variance in the disorder and do not appear to be specific to individual disorders per se, but rather to groupings of disorders. The serotonin transporter gene polymorphism, for example, can be found in some people with mood disorders, but is not found in one specific mood disorder.

Jennifer: So, to restate what you said...There are “neuropsychiatric” disorders that have been associated with particular gene polymorphisms. By polymorphism, you are talking about differences in genes that occur over a long time within portions of the population, for example people with Depression? For the sake of simplicity, can we just call them “gene differences” for now?

Zach: Sure.

Jennifer: These “gene differences”, however, that are found in depression, don’t only appear in depression. They might also appear in bipolar disorder, and other mood disorders. In other words, these “gene differences” appear in groups of disorders, such as mood disorders but they don’t really single out any particular disorder. So, the process for finding a cure for a disorder isn’t as simple as just finding “the gene”.

Zach: Absolutely correct. As much as we would all like to find a gene for each problem, or even a set of genes for each problem, the reality is that things are not that simple.

Jennifer: It is interesting; you mentioned serotonin, which is a neurotransmitter (a chemical messenger of neurologic information stated simply). You said, that genetic differences regarding serotonin have been found in people with mood disorders, but not specific to one particular mood disorder? I'm assuming this is true of the many different neurotransmitters we hear about all the time in terms of their associations with mental and other health disorders (e.g. dopamine, etc.) Is that correct?

Zach: Correct. It is important to remember that as advanced as we are in understanding physiology and human behavior compared to 100 years ago, there is a whole lot that we don't know yet. In 100 years, I suspect people will look back at this time we are in and recognize that we oversimplified the role of neurotransmitters and the relationship between things like dopamine and human behavior. Just as brain regions do many different things rather than only one thing, so too do neurotransmitters like dopamine more than one thing.

Jennifer: So, again while the discovery, for example, of

serotonin's or dopamine' relationship to numerous psychiatric or health disorders has been very helpful in some ways (e.g. medications) because of the complexity of the genetic/environment interaction, we can neither fully account for how neurotransmitters correspond with different disorders, nor have precision medications been mastered yet?

Zach: I think that is fair to say. There is a lot more precision needed. We are in an era of personalized medicine, where the goal is to understand for whom which interventions will work, and how. In order to understand what will work, for whom, to treat symptoms of misophonia, much much more research is needed.

Jennifer: I think you are also saying that gene polymorphisms or “gene differences” that have been identified in relationship to groups of disorders don't account for what one can observe in terms of the different behavior of a person with depression or OCD (again just using those as examples). So, while, it is certainly helpful to identify gene/disorders associations, I'm not going to wake up next year and hear on the news that “they found the gene for OCD” or “depression” and thus the cure will be available in a year? Is that fair to say?

Zach: I will be surprised if that happens.

Jennifer: So will I. Ha ha. So, just to clarify my original question then, are there any specific disorders or diseases for which there is a clear distinction between a genetic cause versus an environmental cause? What are those disorders or diseases?

Zach: There are genetic disorders that may co-occur with certain psychiatric disorders (e.g., fragile X). And there are physical diseases with genetic components that are not singularly caused by genes and are influenced by environmental factors (e.g., Type II diabetes). But there are not psychiatric disorders caused only by genes in the absence of any environmental influences.

Jennifer: So, again for purposes of clarification, I'm going to rephrase and please let me know if this is correct. There are genetic conditions (such as Fragile X) for which we know the associated gene involved. Yet even in these genetic disorders environment can play an influence on how an individual is affected. In addition, even in regard to these genetic illnesses, because of this new way of thinking about genetic and environmental interaction we don't really know how any of this will play out in medicine or psychiatry in the next decade. We do know that in regard to psychiatry,

and possibly health in general, we just cannot attribute a disorder only to genes. We are kind of in a new era of the way we think about genes and the environment. Is this fair to say?

Zach: Absolutely!

Jennifer: Then we really can't say anymore that there are any disorders in psychology for which maladaptive behaviors are definitely attributed to conditioning rather than inborn traits?

Zach: If you open up the DSM-5 and pick a disorder at random, the research investigating the etiology of the disorder will likely point to environmental influences associated with basic process underlying such things as learning, memory, emotion, social cognition, and attention, all of which are critical to conditioning. Even those traits we see early in life can be and are influenced by the environment.

Jennifer: Please continue...

Zach: Conditioning involves attention, learning, memory, and emotion. These processes are critical in the etiology (or multiple causes) and maintenance of all psychiatric disorders.

Jennifer: Are you saying that there are other factors having to do with an individual's personality and neurological processing that affect conditioning? In other words, conditioning isn't a simple cut and dry process, as we might believe based on how, for example, it is still represented in popular press?

Zach: Yes.

Jennifer: So again, we are talking about the interaction of nature and nurture (genetics and environment) in terms of any DSM-5 disorder?

Zach: Exactly.

Jennifer: Zach, do you think there are particular bodies of research we can pull from that already exist in order to begin the study of misophonia?

Zach: I do. I think we need to work together with those who study and treat neurological problems, such as neuropsychiatrists, neuropsychologists, audiologists and occupational therapists. I also think that we need to do research with child and adult psychologists, so that behavioral interventions can be developed, tested, and disseminated based on discoveries made by basic scientists.

Jennifer: Other than overlapping with other disorders, what might be a better way of characterizing Misophonia (just from what you know about it)?

Zach: I suspect misophonia symptoms may not be uniquely found in any one psychiatric disorder, but instead may be a transdiagnostic problem observed across those with different disorders. I also believe it is possible that misophonia symptoms may be observed on a spectrum of severity from low and irritating to high and debilitating among individuals with different psychiatric symptoms. Although some with misophonia symptoms likely meet criteria for various psychiatric disorders, I think it is quite possible that misophonia may not overlap with any psychiatric disorder, and may be something that emerges in some who do not meet criteria for any existing psychiatric disorder.

Jennifer: So, misophonia may be a stand-alone disorder, and symptoms of misophonia may manifest in psychiatric and/or health disorders as well. Likely there will be a range in severity of symptoms, and we have seen some very preliminary data in terms of this (as well as a lot of self-reporting that corresponds with ranges in severity). Classification is not easy, is it? In other interview I think I will address the reasons classification is important, and how difficult it is to do it!

All right, Zach, one final and somewhat more personal question...you are a renowned psychology practitioner as well as a researcher. Would you tell us a little bit about how you feel when you are faced with a patient who has a condition with which you cannot help based on traditional therapies?

Zach: What a great question! When this happens I often feel inspired and motivated to innovate. I try to make sense of where the gap may be between the patient's problems and the evidence base for behavioral therapies and behavioral principles that may be applied. I make and test hypotheses about possible psychological processes (those that are both biologically and environmentally influenced) that are amenable to change. But if the patient is non-responsive or not interested in contemporary cognitive and/or behavioral approaches, I look to consult, work with a

group of others across different disciplines, or refer the patient to treatment options that she or he may find more suitable. Or, in even better circumstances, I use my training as a behavioral scientist to try to scientifically investigate ways to develop new treatments for the problem.

Dr. Kumar's Breakthrough Study

Jennifer Jo Brout, PsyD and Michael Mannino, PhD can.

Dr. Sukhbinder Kumar, and his team from the Institute of Neuroscience at Newcastle University and the Wellcome Centre for NeuroImaging at University College London (UCL) published a groundbreaking misophonia study, which recently appeared in *Current Biology*.

What makes this study “ground-breaking?”

In an interview with Dr. Kumar, he explains the study and what it might mean for people with misophonia. Dr. Kumar states that his team's findings provide “strong evidence that misophonia is a “real disorder. Specifically, using Magnetic resonance imaging (MRI) Kumar's team found identifiable differences in the brains of misophonic individuals. The study reveals numerous important findings.

First, there is a notable difference in the connectivity in the frontal lobe between the cerebral hemispheres in people with misophonia. The difference appears to be due to higher myelination in the ventromedial prefrontal cortex (vmPFC). The vmPFC sits almost right above the eye-socket, the bottom middle towards the front of the brain. It is involved in processing and regulation of emotions like fear and empathy, and decision making.

“The higher myelination in this area of the brain in misophonia subjects suggests abnormal connectivity”

The myelin sheath cells are surround the connecting axons of neurons, allowing for, and increasing electrical conductivity between brain cells. Without this, cells could not communicate properly.

Also, the ventromedial prefrontal cortex is central to understanding misophonia because it is part of a complicated network of connections between numerous other areas of the brain. It both receives sensory information, processes that information and influences the functioning of many other brain areas including those involved in memory, olfaction and perhaps of great importance, the amygdala (where fight/flight is mediated and where salience, or importance, is assigned to incoming sensory stimuli).

Dr. Lorenzo Díaz-Mataix (LeDoux Lab, NYU) comments: “In the study we are conducting, we explore individual different responses in rodents induced by acoustic stimuli, [which they associate with threat]. The auditory threat then triggers neural activity in the amygdala behavioral responses (freezing), autonomic activity (increases in heart rate, blood pressure) and the release of stress hormones. These neural, behavioral, autonomic, and endocrine responses vary across individuals, with some rats consistently responding strongly and others weakly to the same stimulus. This work relates to the Kumar study since the Insula connects directly with the Amygdala. We believe that our experiments under controlled laboratory conditions will complement and will add to our understanding of brain

circuits that underlie symptoms related to threat processing in psychiatric conditions, including misophonia.”

The study also revealed that a major area involved in the brain’s ability to pick out what it thinks are “salient” ,or important, stimuli (the anterior insular cortex, or AIC) showed greater activation for misophonia subjects responding to trigger sounds. The AIC is involved in processing emotions and integrating sensory stimuli (such as sounds) from the both the outside world and from within the body.

Here, “salient” means picking out or paying attention to something that stands out from its neighbors, like off-color in the case of vision, or in this case, an off sound.

Importantly, this area also showed abnormal “functional” connectivity to other brain regions highly involved in processing emotions, including the amygdala, the vmPFC, and the posteromedial cortex (PMC), also involved in emotional regulation.

Dr. Kumar hypothesizes that the difficulty in processing sensory information in these brain networks leads to a “mismatch between how a person perceives their physical state and what their physical state really is”. This refers to an often overlooked sense “interoception”, which allows us to accurately perceive our body states. As an example, Dr. Kumar explained, “that a person may feel as though they have a dry mouth. Yet objectively there mouth is not dry”. Dr. Kumar is very interested in this finding and is

continuing research on how this relates to misophonia.

The take home message here is that due to this aberrant connectivity those with misophonia misinterpret the common misophonic trigger sounds in a way that causes their bodies to respond as though they are under threat. The amygdala is the part of all this that takes all this “mis”information, and then tells the body, ‘lets do something about this‘.

Dr. Kumar hopes that this study will help lead to treatment. Treatment possibilities include learning ways to self-regulate (or bring down the nervous system arousal). We also spoke about the potential of memory reconsolidation therapy. Memory reconsolidation therapy would involve changing the physiological response to the trigger sound. This was developed in the Joseph LeDoux lab at NYU and has been successfully trialed in rodents, and is currently being trialed successfully in human beings for Post Traumatic Stress Disorder and for phobias.

Dr. Joseph LeDoux comments: This seems like an important and well-conducted study by research team from a leading functional imaging center published in a top-tier journal implicating the insula cortex in auditory responsivity in misophonia. As the study shows, notes the insula is well situated to play a role processing sounds as threats given that it receives auditory inputs and is also connected with the amygdala and medial cortical areas. I was surprised that the anterior insula was found to be acoustically responsive

in this study since most the posterior insula is usually found to be the sensory (including auditory) responsive region. Regardless, this seems to be an important advance in linking symptoms in misophonia to the brain.

Dr. Kumar adds that this study validates misophonia is it's own disorder. It cannot be classified within any psychiatric or specific neurological disorder. When asked if he thought misophonia should be classified as neurological or psychiatric, Dr. Kumar explained that the lines between psychiatric and neurological are blurred. "Many psychiatric disorders are neurologically driven", and this differentiation may be irrelevant."

Section 4: Misophonia Resources

Website Resources

www.misophoniainternational.com: for sufferer stories, research news, advocacy stories, and resources for coping skills.

www.misophonia-research.com: for current news on research, biographies on researchers, and in-depth information on research studies.

www.misophoniakids.com: a comprehensive resource for children and their parents, including coping skills for children with Misophonia.

www.misophoniaproviders.com: a list of providers (audiologists, psychologists, psychiatrists, MDs, etc) that have heard of Misophonia and are willing to see patients with the condition. Carefully curated by Dr. Jennifer Jo Brout.

[Full of Sound and Fury: Suffering With Misophonia](#): a book on Misophonia by Shaylynn Hayes, featuring interviews with other sufferers.

Sample Accommodation Letter

Dr. Jennifer Jo-Broun has generously allowed for a sample letter for disability accommodations. Please note that this was written for a university student. Since Misophonia has no cure or official diagnosis this letter can be brought to your doctor to help formulate an accommodation plan based on your own person needs.

THIS LETTER IS FOR A SAMPLE ONLY. IT CANNOT BE USED ON ITS OWN, WITHOUT A DOCTOR RE-WRITING.

If you are unsure if your doctor will provide a letter, and would like advice, please contact Jennifer.

Explanation of Disorder

The term Misophonia literally means “hatred of sound. Rather, they have highly aversive reactions to specific patterned-based sounds, and some are also over-responsive to visual stimuli.

Individuals with these kinds of auditory and visual over-responsivity (similar to what has been known as Sensory Processing Disorder, subtype, SOR) have demonstrated autonomic arousal and decreased habituation in neuroscience and physiologic studies since 1999. What does this mean for [Name Omitted]?

When [Name Omitted] encounters everyday auditory (and visual stimuli) that most people would not notice, her brain

misperceives, or processes this stimuli as though it were dangerous. As a result, she experiences physiological arousal up to and including what we all know of as the flight/fight reaction. This is not something that is within [Name Omitted]'s control, and is part of an involuntary autonomic nervous system response. This happens in milliseconds without conscious mediation.

As such, sufferers, feel bombarded by both noise and visual stimuli. Once this bombardment occurs [Name Omitted] may feel a variety of physical discomforts such as nausea, dizziness, as well as what one might describe as increasing mental and physical tension and a more subjective need to “flee” (or more simply stated) leave the place in which offending stimuli exists. Again, this is a fight/flight reaction that is beyond [Name Omitted]' control. If she is unable to “flee” or leave the environment in order to get away from the aversive stimuli, her adrenaline level continues to elevate, and other hormonal and physiological changes related to the fight/flight response occur, culminating in what many people describe as experience, “a severe anxiety attack”, “rage”, or “panic”.

In addition, 15 years of research on individuals with Sensory Over-Responsivity has also shown a deficit in habituation. That is, once the fight/flight system is set off, the part of the nervous system that is normally activated in order to put the “brakes” on fight/flight does not act efficiently. Thus, for [Name Omitted], normal everyday sensory stimuli is overloading and causes her to become severely dysregulated,

but also the way her particular nervous system works disables her ability to calm down.

Unfortunately, it is impossible to predict what auditory or other sensory stimuli might cause reactivity. Often the stimuli vary, and change over time. In addition, levels of reactivity may vary from day to day and in association with stress, rest and other daily living factors. To date, there is no cure for this condition. Occupational Therapy has helped in regard to some elements of Sensory Processing Disorder. However, there is as of yet no treatment for auditory of visual over-responsivity, or most certainly not for the condition now described as Misophonia.

As such, it is extraordinarily difficult for people with this condition to lead functional lives. The problem is not simply one of dealing with the continually overloaded and dysregulated system. The problem extends to the toll this takes on one's body. Individuals with this problem often become extremely tired, or conversely develop sleep difficulty. They may also suffer from depression because this is a difficult condition with which to live, with no treatment and little understanding within even the medical community as of yet.

There are times that exposing oneself to an environment full of sensory stimuli is both physically and psychologically overwhelming to the extent that recent research describes many sufferers living very isolated lives, and others often feeling the need to stay at home where they can control the

sounds and light levels (for example).

Both SPD/SOR research and the new Misophonia research both suggest that severity of the disorder runs on a continuum, with some people experiencing it as much more severe than others and with possible variations throughout the lifespan.

At this point in time there are no validated severity measures from which a doctor can determine an individuals' level of life impairment or functioning, and most sufferers (as well as psychologists) are using practical daily living skills and management plans to try to assist until further research on the etiology and treatment of this disorder is developed.

Recommendations

[Name Omitted] should to take quizzes and tests in a room separate from others. This will allow her to minimize sensory stimuli to which she may react.

[Name Omitted] should be allowed to leave the classroom for small breaks when needed. Sensory stimuli is cumulative and therefore frequent breaks can be helpful

However, she should also be given the following options whenever possible:

[Name Omitted] should also be allowed to digitally record her classes. This would ensure that she would benefit from all class lecture if she is unable to attend class, needs to

leave class frequently and/or misses educational opportunity during class due to the distraction often caused by her condition

Considering the sensory and misophonia issues coupled with her history of anxiety and depression (and the ways in which these disorders interact and overlap) [Name Omitted] is going to need advocacy from within the school in regard to explaining her condition to her professors. Given the physical and mentally impairing effects of this condition and related anxiety and depression, considerations should be given to [Name Omitted] if she is unable to attend class.

Following are suggestions for this:

In the event that [Name Omitted] misses class her note-taker should give her class note and ideally that same person would be responsible for also recording the class so that [Name Omitted] can keep up with class discussions

Dr. Jennifer Jo-Brout, IMRN

Want to download a PDF copy?

Go on the web and download:

www.misophonaiinternational.com/accommodation-letter-template/

How To Explain Misophonia

From Full of Sound and Fury: Suffering With Misophonia

Do you want to explain Misophonia to others, but have trouble bringing it up?

When you know that you have to tell a person about your disorder (especially trying to explain Misophonia), it can be stressful – the anxiety, fear, and anticipation can be enough to keep your mouth firmly shut, and continue your suffering. However, it's important that you go through with it. Keeping things bottled up will not help your disorder, or your life – I promise you that. Consider the tips below when you're going to confront someone. You may want to adjust the conversation depending on whom you're talking to, but these tips should help you when thinking about how to act, what to do, and what to say. It's a good idea to make sure you're not triggered at the time of the conversation. During a trigger, your anger is heightened and you may perceive the person as a threat. It's important that you are prepared to explain Misophonia in a positive manner. No one wants to feel attacked.

Prepare yourself with research and website links that can be helpful to explain Misophonia to the person you're about to approach. Make sure that they will understand that it is a real condition, and that you are serious.

Keep your mood stress-free, and ensure that you are relaxed

beforehand. Try to have a bath, some tea, some light television, or something you enjoy before you have the conversation. If you're stressed or tired, the conversation may go south quickly. It is important that you are in a good mood for the conversation.

Choose a location in which you know there will be little to no triggers. Try to be somewhere that you and the other individual are both comfortable. If this is not possible, try to become familiar with the place beforehand (such as talking to the person in their office before-hand, and asking if you can meet another day, when you have more time, or are prepared).

During

During the conversation, your aim should be to keep it positive and informative. You should provide examples of what triggers you, even if they are not the same ones that trigger you in the environment with the person. It's important that they understand it is not just when you are around this person, and that this disorder impacts several aspects of your life. Do not make it all about them.

It may be helpful to print off articles that explain Misophonia, and what it is. Since research is minimal, some of the websites listed at the end of this book can be helpful for learning about Misophonia.

If the person triggers you during the conversation, identify it but not in an aggressive manner. Excuse yourself, and

explain that what they are doing is one of the things that cause a reaction. Politely ask if they can stop or if there is a way, they can adjust their behaviour. Make sure they understand you are not blaming them, but that the condition is serious.

Do not apologize for Misophonia or make excuses. Say that it is a neurological condition, and that you have it. Be matter-of-fact, and explain that unfortunately there is no cure.

Discuss a way that you can let them know you are being triggered, without being offensive, or turning to anger. If the conversation starts to go sour, or the person does not understand – excuse yourself. Do not let anger turn into a confrontation. Explain that you were merely explaining your feelings, and that this has a huge impact on your life. Leave before it becomes more serious, often leaving is a statement of its own.

Afterwards

Chances are, after you explain Misophonia to another person, they will still trigger you. It can be hard for a person to recondition things that they are used to doing, and even harder to remember. Unlike you, this person does not deal with Misophonia on a day-in-day-out basis, so it's unlikely that it's something they consider regularly. Do not blame them for this, and do not hold it against them. Unless the person is trying to trigger you and disregards your feelings entirely, you should be mindful that they are probably not

out to get you, and that is merely a reaction from Misophonia.

If you have to remind them that they are triggering you, be polite.

Leave the room and if they ask why, explain that you're being triggered.

Try to remain positive; do not engage when you are angry.

Boss or Administration

Misophonia is challenging to discuss with others. Your boss should be a person that you trust and that you can approach with issues that involve your work performance and comfort in the workplace. For some people, their boss is intimidating and a person that they would rather not confront. Either way, it is best to go into this conversation prepared. You should explain Misophonia is a neurological condition that can't be helped, though there is little information and no cure yet. Ask your boss if there is anything they can do to help, and assure them that, you are committed to the job, and are asking for the betterment of not just you, but your performance. If your boss is not supportive, you should be armed on the laws reflecting accessibility in your region.

Coworkers

Co-workers can be tricky. You have to play nice when you have a job. This is especially worrisome for those that work

in an office environment. A lot of workplaces are starting to allow snacking on the job, and this causes a lot of triggers. Being polite can go a long way with other workers, no matter the situation. However, sometimes coworkers aren't willing to stop something that they believe is 'their right'. Approach the co-worker when you aren't triggered and inform them that you have a medical condition, and ask them if they would be willing to help accommodate you. If they are not willing to help and further the situation, inform your boss. You should already have told your boss about your Misophonia and discussed the possibility of accommodations. If you are lucky, you may be able to convince your boss to speak with your co-worker. Remind everyone involved Misophonia a neurological condition that you cannot control.

Friends

I now refuse to spend time recreationally with people who do not respect my Misophonia. It was a hard adjustment at first – but the people who truly care about me are able to respect my condition. Friendship, like dating, should be based on mutual understanding and trust. You should not have to pressure your friend to respect your needs and wishes, and your friend should not feel attacked by your sudden rage at noises or visuals. Be sure to explain to your friend that you do not mean anything by your displeasure, and that you truly value their time and your relationship. Ask if you can have gatherings in trigger-neutral zones, and plan your outings so that the possibility of a trigger is

minimal. This can be hard, since a lot of friendships involve activities that involve noises or visual stimuli. Try to pick outings that have noises that you are comfortable with. For example, I'm fine with the sound of bowling balls and pins crashing. Bowling is a great way to hang out with friends because most of the people I can see are standing – which means not shaking any body parts, and the rest of the facility is usually dark. A great friend will understand that you are not doing this to be nitpicky and will want to make you feel better. However, you must understand that they have emotions too, and that you should try not to attack them when triggered.

Family

Those nearest and dearest are often the worst triggers. We spend a lot of time with our loved ones, and in general, we seem less forgiving when it comes to their behaviours. Day in and day out with the same people can be stressful for any situation. Even if you do not live with a family member, the intensity of the relationship can still cause Misophonia triggers to be worse. My first ever “trigger person” that I knew of was my mother. At first, every time she shook her foot, it was a major fight. We're talking volcanic eruption on both sides. You didn't want to be there when she played music and when she sang. I know it isn't her fault that she does these things, and they never used to bother me. Misophonia doesn't always make sense.

Romantic Partners

Ah, romance, the place where we're supposed to accept the other individual regardless of their inconsistent behaviors. Misophonia is the devil in your ear nagging at you. Your partner clinks their spoon in a bowl, taps their fingers, or shakes their leg. Maybe they like to whistle. At first, you may try to ignore it, but eventually the triggers can become worse and worse. The honeymoon is over, and Misophonia changes all of your emotions. Like friends and family, you need to be able to discuss your Misophonia with your partner. Hard work and honesty are going to be the key in going forward. Your partner must respect your condition and the role it plays in your life, and you must understand and respect your partner's emotions when it comes to being the trigger, and living their life with you.

Roommates

Like family, these people are there on a day-to-day basis. However, unlike family, there may not be enough of a personal relationship that you can confront the individual in a positive manner. Sometimes our living arrangements are out of our control. You may be living in a dorm room, an apartment, or another communal situation. Money, and other uncontrollable forces often lead to the necessity of living with a stranger, or even an acquaintance. Ideally, we would never live with someone whom we didn't have a good relationship with. Unfortunately, reality isn't always a perfect picture. If you're going to be living with a new person, you should discuss your Misophonia before moving in. Try to be sure that the person you're going to live with

truly understands your needs, and establish ground rules. Explain that you are not trying to dictate them and that you are merely suffering from a neurological condition. If they, or a current roommate, do not respect these ground rules, perhaps you should consider a different living arrangement, if possible. Living with your triggers should be only a last resort. While you cannot avoid triggers in every aspect of your life, the home should be a neutral place where you can relax and have a sanctuary, for the sake of your health and sanity.

Section 5: Research Studies & Programs

2018 Studies

These studies are likely to begin within 2018. If you are reading an older copy of this book, you should check **www.misophonaiinternational.com** or **www.misophonia-research.com** for updated research news. We update these sites regularly. This list has been updated as of January 2018.

Memory Reconsolidation Study

Dr. Jennifer Jo Brout, and IMRN

Research of misophonia is in the very early stages.

Therefore, misophonia sufferers and their loved ones are without definitive answers to many essential questions about the underlying mechanisms of the disorder, and possible treatment. However, the small amount of research on misophonia provides evidence that misophonic sounds bring about changes in the autonomic nervous system. Like the accelerator pedal in a car, misophonic trigger sounds quickly rev up the engine of our flight/fight system. One reason for this may be that when an individual with misophonia is exposed to certain sounds, their brain misinterprets these sounds as being dangerous, harmful or toxic. As a result, within milliseconds and without conscious thought, the sympathetic nervous system is thrown into high arousal. In other words, in response to trigger sounds, the body is readied for “fight/flight,” as hormonal and physiological changes take place. While this neurological and physiological response is meant to protect the body from harm, in misophonia it leads to a cascade of negative emotional, cognitive and behavioral responses. The

amygdala is a part of the brain that is involved in mediating the flight/flight response.

Research at the LeDoux Lab at NYU has addressed this reactivity in the amygdala in a rodent sample. In this study, rodents taught to associate a repetitive sound with an unpleasant stimulus. Although all the animals were exposed to the exact same stimuli, their reactions to the repetitive unpleasant sound was very different. Depending on the intensity of the reactions, they were separated into three groups: (1) typical responders, (2) under responsive, and (3) over responsive. The last group of animals demonstrated the strongest autonomic nervous system reaction in association with the repetitive auditory stimuli. By presenting the sound multiple times, researchers attempted to extinguish its unpleasant value . Results showed that the over responsive rodents (those who showed higher responses after the initial presentation of the sound together with the unpleasant stimulus) did not extinguish the physiological response (fight/flight) induced by the sound, while this responses were lost in the other two groups. This suggests that the animals showing extreme

reactions could not “un-learn” the association they had stored in memory. Similar to the over-responsive rodents, misophonic individuals show strong reactivity to auditory stimuli. Since the brain works in a similar way in rodents and in humans, it is possible that misophonics are resistant to extinguish the emotional responses induced by their triggering sounds.

In the LeDoux lab, scientists have also studied a phenomenon often referred to in people as relapse prevention. Relapse is a significant problem in terms of many behavior therapies that attempt to either extinguish a particular response to particular stimuli, and/or make new and more positive associations between stimuli and nervous system responding. Interested in disorders such as anxiety and Post Traumatic Stress Disorder (PTSD), scientists in the LeDoux lab sought ways to re-associate aversive stimuli and high autonomic nervous system arousal in rodent samples, but without relapse. Through a process called **memory re-consolidation**, scientists at the LeDoux Lab achieved this in rodents, and we propose to translate this into human research, specific to misophonia.

Memory is consolidated when it is moved from our short-term memory into our long-term memory. Once the memory is encoded it is referred to as a memory trace (or engram).[1] However, contrary to what we may think, recalling memory (or activating a memory trace) is not like watching a recording that replays consistently every time we watch it. Instead, each time we retrieve a memory it alters slightly, as it reconsolidates. In other words, previously consolidated memory are retrieved and then consolidated again. Research on memory reconsolidation has demonstrated that the association between a particular stimuli and high autonomic nervous system arousal can be changed when memory is unstable (at the time of reconsolidation). The result is that while the memory itself is retained, the association between the particular harmful stimulus and the high autonomic arousal is diminished. Using variations of memory reconsolidation-based interventions other researchers have used this for phobias and PTSD.

For misophonia sufferers, this approach may result in the development of new associations between trigger sounds and reduced fight/flight activation in the autonomic nervous

system. In order to translate this research into those with misophonia, we propose to conduct a clinical trial at Duke University, in consultation with the LeDoux Lab.

[1] A memory trace is a way to theoretically describe the physical representation of a memory in the brain

Why Are We Triggered By Similar Sounds?

Dr. Jennifer Jo Brout, and IMRN

This sound study at Duke University aims to find out why we're triggered by the sounds that we are.

Currently the Duke Sensory Processing and Emotion Regulation program is collaborating with Dr. Sukhbinder Kumar (Newcastle University) and Mercedes Erfanian (University of Maastricht) through the International Misophonia Research Network to better understand misophonic trigger sounds.

“I have wanted to do this study for 15 years” says Dr. Jennifer Jo Brout of the IMRN. “we always look to the sufferers and study what is wrong with them but we never think to deconstruct the sounds to find out why these triggers line up so closely...why do all of us have aversive reactivity to the so many of the same sounds?”

The researchers all feel that with more knowledge about the sounds the disorder will be better characterized and the potential for treatment will be more easily and more efficiently formulated. Dr. Stephen W. Porges (Indiana University Bloomington) has already done a pilot study in

association with IMRN but the research needs to be further expanded to really shed light on this issue. The researchers are currently donating their time to begin this study and hope to find resources, which will allow for more of the misophonia researchers to contribute.

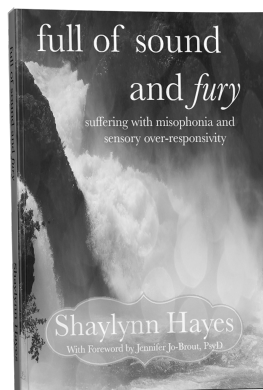
Exploring Misophonia is brought to you on behalf of
Misophonia International
(www.misophonaiinternational.com) and the
International Misophonia Research Network
(www.misophonia-research.com).

Misophonia International started in 2015 as an advocacy project, information site, and a resource to help bridge the gap between researchers, advocates, and sufferers (or concerned relatives). Misophonia International does not solicit donations personally, we are an advocacy resource that works closely with researchers, and supports the work of ethical and outstanding researchers and scientists.

The IMRN was formed to facilitate cross disciplinary research in misophonia and conditions related to auditory over-responsivity. Founded by Jennifer Brout, PsyD, the IMRN aims to connect sufferers and researchers to accurate and current information related to the disorder.

Want to read more about Misophonia?

Full of Sound and Fury: Suffering With Misophonia was written by a sufferer of Misophonia, in order to help other sufferers. Including interviews with real sufferers, the book aims to put names to a disorder that is known by few. Misophonia is a neurological condition that causes a fight/flight/freeze response to certain audial and visual stimuli. Written by a sufferer, *Full of*



Sound and Fury, is a book about Misophonia's life impact. It can start as early as four in the morning. Your upstairs neighbor stomps his feet. All of a sudden, you go from being half-asleep and calm to a nervous wreck. You're tired, exhausted, and you're angry. How dare he stomp around and have no regard for your feelings or personal space? Rationality plays no part with Misophonia. Logically, you know he has no idea how loud he's being – but the response is the same. Shaylynn Hayes writes about her experiences, as well as others' in a way that can teach the general public about the disorder, as well as resonate with sufferers. With a foreword and research information by Dr. Jennifer Jo-Brouet, *Full of Sound and Fury* is just the starting place when it comes to dealing with Misophonia.



ABOUT THE EDITORS

Shaylynn Hayes is a misophonia advocate and sufferer. She has written *Full of Sound and Fury: Suffering With Misophonia* and runs the advocacy site Misophonia International.

Dr. Jennifer Jo Brout is a School Psychologist and Psych Doctor that has been advocating for misophonia for 2 decades.

She runs the International Misophonia Research Network (IMRN) and facilitates research.