



# What Did You Say?

## Ménière's Research Survey Results (cont. on page 2)

The statistician will be setting up and running stats on the survey results. When statistics are compiled, they will be shared with Dr. Papparella, Dr. Graupner, Dr. Jung to see what they think are the best ways of reporting the data. Survey author Jim Hainlen will write his thesis, then begin writing articles based on the data. Here is a general summary of the results:

There was remarkable similarity in the age when the disease first strikes people. More females responded than males. The progression of the disease is similar. Fewer people have had endolymphatic sac surgery than suspected. For most, the surgery has been positive. People are taking over 30 different medications that fall into 5 categories: antiemetics (for dizziness), diuretics, anxiolytics-benzodiazepanes (anxiety), steroids, allergy medication, and other (pain, antidepressants, endocrine medication, herbal medications).

Most people by 55-60 years of age are not working. Most people who are not working had to stop early because of Ménière's. A high percentage of people have or are working on getting disability. Very few people have tried the Meniett Device and only one person said it was highly effective. Doctors

spend virtually no time talking about exercise or general healthy living. There is a very high level of dissatisfaction with many ENT's. When Ménière's people find a good ENT they are grateful and feel strongly that this doctor is a partner in helping them to cope with the disease. Family doctors are judged to be mostly unhelpful and surprisingly many times harmful to patients, particularly on an emotional level.

Those people with Ménière's who try to, or do exercise regularly are typically more positive about their lives. Those people who do no exercise are more likely to write long paragraphs with a much more depressed view of their lives. Many Ménière's people suffer because they perceive that they are putting their spouse or partners in a bad position because they constantly need their physical assistance to get around. Plus they turn to them for emotional support. They worry about what this will do to the long-term relationship. The subject of intimacy came up several times and it is difficult to approach sexual intimacy with the uncertainty of Ménière's. The answers on visual and motion perception lacked similarity al-

though most people with a certain level of Ménière's found motion and depth perception to be triggers. Weather change was almost a 100% trigger for a Ménière's attack or would worsen one already in progression. Tinnitus is seemingly not quite as devastating as vertigo. People are more able to learn to live with tinnitus. Many spouses/partners who answered as the non-Ménière's person answered the tinnitus section (but did not answer the other questions). It is more common to have tinnitus symptoms and when severe, tinnitus causes loss of sleep and takes a huge emotional toll.

People who do not have a Ménière's support group in their area desperately want a group where they can talk to someone in person - not an on-line support group.

Once a Ménière's attack starts most people report that nothing can stall or stop it. There were many ways people have of dealing with it. The most common is to lie down, make the room dark, and try to rest or sleep. Some people use ice packs but most people get chilled and have to put on extra clothes or put on a blanket. Some

## Survey Summary (continued from page 1)

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are able to do relaxation routines/meditation and for a very small percentage that helps. Most people feel lucky to make it to a bed or the floor and meditation is out of the question. Pain was more common than expected. Generalized headaches, headaches in a specific location, burning sensations, and chest pain were common. Crying and tears affect some people. Stress, worry, and exhaustion were strong triggers for almost everyone. Diet played a role for many, but most interesting was that several responded that having one beer helped with dizziness. Most people do not have a systematic way to catalog

their Ménière's symptoms. Most do not think chiropractic, homeopathic, or acupuncture makes a difference. Massage feels good and relaxes the body - so many people get regular massages but they do not feel it changes the symptoms.

Walking is by far the most common exercise with treadmill or stationary bike also common. Many people use light weights to maintain strength. Again they do not feel it changes the Ménière's but it changes their mental outlook and also keeps the body stronger so falls are not as common for them. Many have tried balance exercises but have given

up. Very few people do eye exercises. They get dizzy just trying to move their eyes and the day is wrecked. People who do Tai Chi or Yoga feel strongly that it helps their mental attitude but doesn't improve Ménière's.

Those who have deeply held religious beliefs feel that prayer and faith help them get through. Other people were dismissive and said it was of no benefit.

Some people report they have developed a greater empathy for people with chronic disease. They also report greater appreciation for good days and an acceptance of bad days.

## Meniere's Resources, Inc. Annual Meeting

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The 2008 Annual Meeting for our non-profit organization will be on Sat., November 8, at 7 p.m. Central Time.

We will be meeting electronically as our By-Laws permit to review the year, receive financial reports, plan for upcoming

events and projects, and elect officers.

If you would like to participate or have an item for our agenda you may contact us at [info@menieresresources.org](mailto:info@menieresresources.org)

***Annual Meeting***  
***November 8, 2008***  
***7 p.m. Central Time***

Everyone is invited to participate; the meeting is open to the public. Your input is appreciated and every person makes a difference.

**Join us on November 8!**

## “Staggered” CD

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The Ménière's Jazz CD is still in production. Given the fact that most of the musicians involved have Ménière's Disease, hearing loss, or a form of vestibular imbalance, our eager goal to have had the project completed by summer was a bit ambitious. We hope to have the CD avail-

able in time for Christmas.

If you would like to pre-order your copy of “*Staggered*”, they are available for \$20.00 (includes postage for US customers only). ***This CD is dedicated to those with Ménière's Disease and other vestibular***

***disorders. A portion of the proceeds will be donated to Meniere's Resources, Inc.***

For more information on how to pre-order your copy or for information about “*Staggered*”, please email Stacey Nyborg,

[Stacey@staggered.biz](mailto:Stacey@staggered.biz)

# Tinnitus Tinnitus Tinnitus

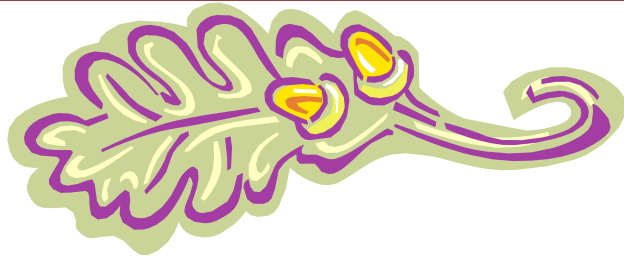
## What is Tinnitus?

Tinnitus represents one of the most elusive mysteries facing audiologists and other hearing health care professionals. It is one of the classic symptoms of Ménière's Disease (along with rotational vertigo, fluctuating hearing loss, and aural fullness.) Tinnitus refers to a auditory perception not directly produced by an external sound. It can range from high pitch to low pitch, consist of multiple tones or just noise (no tonal quality at all). It may be constant, pulsed or intermittent. It may begin suddenly, or come on gradually. It can be perceived in one ear, both ears, or in the head.

## Who has Tinnitus?

As many as 50 million adults experience tinnitus, with more than 10 million seeking help for the condition. Occurrence is increasing due to exposure to loud noise from music and people in the military.

Because tinnitus is subjective, two individuals may report similar tinnitus characteristics yet be affected in significantly different ways. The severity of tinnitus and how it affects one's life is largely influenced by the individual's reaction to the tinnitus. Many tinnitus sufferers report interference with sleep, concentration, and attention to detail. Some are depressed and anxious. Many people with tinni-



Consult your doctor or an audiologist who is knowledgeable about tinnitus to help manage your tinnitus.

tus also suffer from hyperacusis, an inability to tolerate even moderate-level sounds. The onset of tinnitus often coincides with a change (emotional, physical or social) in one's life situation. Tinnitus has both a physiological and psychological component.

## What treatments are available for the Tinnitus patient?

While there is no known cure for most forms of tinnitus, it is not true that *"nothing can be done about it."* It is important to try to identify and resolve a cause before deciding on the management approach. None are universal cures, but most tinnitus sufferers can find varying degrees of relief from one or a combination of the following.

**Counseling.** A trained professional will help the patient deal with the stress, distress and distraction associated with tinnitus. One method employed is cognitive-behavioral therapy.

**Hearing Aids.** Amplification of background sounds may reduce the

loudness of tinnitus or even mask it. In addition they may help by relieving stress associated with hearing loss.

**Masking.** The use of an externally produced sound to cover up, inhibit or alter production of tinnitus can offer temporary, partial or complete relief for some tinnitus sufferers. Sound-producing devices, tabletop sound generators, CDs and tapes may help.

**Medications.** There is no single medication that works for all patients. Some antidepressants and anti-anxiety medications help. Consult your physician.

*Educate yourself about the nature of tinnitus and methods for managing and relieving your associated problems.*

**Stress Management.** The close relationship between stress and tinnitus disturbance underscores the

need to maintain one's composure and logic when trying to manage tinnitus.

**Support Groups.** Groups offer a forum for sharing experiences and useful strategies with others.

**Alternative Approaches.** There is no scientific data showing consistent benefit from hypnosis, acupuncture, homeopathy, vitamins, or chiropractic; though some reports indicate benefit. Your physician should be kept apprised of any of these treatments you are using.



*Manage stress, learn to relax, and maintain composure*



**MENIERE'S RESOURCES,  
INC.**

8831 Ditzler  
Kansas City, MO 64138

E-mail: [info@menieresresources.org](mailto:info@menieresresources.org)

Print your own Ménière's brochures:  
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**We're on the web**  
[www.menieresresources.org](http://www.menieresresources.org)

*Meniere's Resources, Inc. is a non-profit, educational and charitable organization under section 501c3 of the Internal Revenue Service Code. We have the goals of raising public awareness about Ménière's Disease and providing support and encouragement to those suffering from Ménière's or other vestibular disorders.*

## Looking for a Unique Christmas Gift?

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Shop at the Meniere's Resources Store! We have photography, Ménière's awareness items, art, crafts, jewelry, oil bottles, CDs and the proceeds go to Meniere's Resources.

It's a great way to shop on-line, save time and travel and contribute to a good cause. Check it out!

[http://www.shopmenieresresources.higpowersites.com/page/  
page/5207322.htm](http://www.shopmenieresresources.higpowersites.com/page/page/5207322.htm)

## Service Dogs

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Assistance Dogs service about 20,000 people in the United States. More than 60 non-profit programs train and place these dogs nation-wide.

A **Hearing Dog** is specially trained to assist a person who is deaf or hard of hearing primarily in the home setting. The dog is trained to respond to sounds such as a smoke alarm, baby cry, doorbell, alarm clock, car horn, computer beeps, etc. and alert his or her deaf partner that these sounds have occurred. Some hearing dogs also are trained to work in public settings. Some hearing dogs master additional tasks, enhancing communication between family members.



*Service Dogs have public access rights under ADA.*

Applicants are screened and interviewed. If you are accepted, your name will be placed on a waiting list. When a dog that seems to be a "good match" for you is available, you will need to go for training classes yourself. These generally last several weeks. Costs for the fees for dog and training vary by agency. You must be able to travel to the

training site and expenses for travel and meals are your responsibility. A graduation ceremony completes the training process.

A **Balance Dog** is specially trained to assist people who use canes or crutches by lending balance support or stability. They may also assist those who fall in getting back on their feet by providing a stable support when a person is not available.

They can also assist people in walkers or wheelchairs by retrieving dropped objects or pull open doors. They also provide assistance in a medical crisis.

**Check the internet for Service Dog training in your area.**