

# What Did You Say?

**Special points of interest:**

- Read how one person is making a difference
- Did you know you can register to donate your temporal bones "that others may hear?"
- A new internet resource is explained
- It is important to recognize stress
- Are you a chocoholic?
- What is the difference between all these "ologists?"

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## Raising Public Awareness One Person at a Time

Rae Nell Gibbs recently was the recipient of the Greatest Improvement Contest award for her local TOPS (Take Off Pounds Sensibly) support club, and placed second in the state of Texas for her division. She was asked to give an informative and inspirational speech about what she had been through and where she was headed.

Fun Day was attended by about 60 people for lunch, singing, and Rae Nell's speech. Rae Nell gave her talk on Ménière's Disease. She handed out Ménière's Resources brochures and showed them the DVD, "Ménière's: A Photographic Journey" by Danny Pancy.

"I told people about how I went deaf in my right ear, how I was



**"Being overweight is a lot like having a chronic illness."**

already overweight when Ménière's struck, and how I got depressed and just got heavier. For a while I didn't do anything; therefore, the pounds just kept coming on."

Once Rae Nell found support through the internet Ménière's forum at [www.menieres.org](http://www.menieres.org) and

got a handle on her condition, she found TOPS. (See [www.tops.org](http://www.tops.org).) She went on to explain how important it is to always have someone to support you and be there for you.

"Being overweight is a lot like having a chronic illness. Unlike the chronic illness, there is a cure for being overweight, and in my situation the first step began with me," Rae Nell said.

"I am an obesity survivor who lives with a chronic illness, but I am by no means a victim," she states

Congratulations to Rae Nell Gibbs on her weight loss, overcoming depression, and her positive attitude about Ménière's Disease!

## The Meniere's Network

Meniere's Resources, Inc. is dedicated to raising public awareness and providing educational literature and support for people with Ménière's and other vestibular disorders.

A resource available from the Ear Foundation is the Meniere's Network. The Meniere's Network is actively involved in

educating health professionals and the public about Ménière's Disease. Misunderstanding has often unfairly burdened those who cope with the condition. Meniere's Network has a newsletter, educational materials and listings of local support groups in the USA and other countries. If you join, you will receive this information, can meet fellow

"Menierians," and also provide a valuable service to other people suffering from Ménière's Disease by giving an insider's perspective on ways to improve their quality of life on a day-to-day basis.

If you are interested in joining, you may learn more at [www.earfoundation.org/programs](http://www.earfoundation.org/programs).



### **Your diet can affect the symptoms of Ménière's Disease.**

Specific items in one's diet have been known to affect the symptoms of Ménière's Disease: hearing loss, tinnitus, ear fullness, and vertigo. These items include sodium, caffeine, and alcohol. In addition, many believe there may be an association between Ménière's Disease and food allergies.

## **Dietary Considerations in the Treatment of Ménière's Disease**

A reduced salt (sodium) diet is often recommended to patients who have Ménière's Disease and other inner ear problems. There is little scientific rationale, but dietary salt restriction seems to affect the fluid in the inner ear and helps alleviate the symptoms of Ménière's Disease in many patients.

Sodium is a mineral that occurs naturally in some foods and is added to many foods and beverages. Most of the sodium in the American diet comes from table salt, which is 40 percent sodium and 60 percent chloride. One teaspoon of salt contains about 2,000 milligrams of sodium.

Sodium attracts water into the blood vessels and helps maintain normal blood volume and blood pressure. Sodium is also needed for the normal function of nerves and muscles. How much sodium do you need? Although some sodium is essential to your health, you need very little. The National Research Council of the National Academy of Sciences suggests that a "safe and adequate" range of sodium intake per day is

about 1,100 to 3,300 milligrams for adults. That is well below the amount that most American adults consume.

Reducing sodium intake to control Ménière's Disease entails more than just "not adding salt." One must know the sodium content of foods eaten. Further information on the sodium content of food can be gained from a number of books. "Meniere's Disease: A Dietary Guidebook," is available from the Ear Foundation of Baptist Hospital, 2000 Church Street, Box 111, Nashville, TN 37236. Telephone 800-545-HEAR. Another book is "Low Salt Diet for Meniere's Disease," by Brian McCabe, M.D., University of Iowa Department of Otolaryngology, Iowa City, IA, 52242.

Meniere's Resources, Inc. website features monthly low sodium recipes.

Alcohol is another dietary component common in the American diet. Alcohol can profoundly affect the vestibular system and can cause dizziness even in the absence of disease. People with Ménière's Disease should significantly reduce

their alcohol intake.

Caffeine is another item that can affect the symptoms of inner ear disease. Caffeine stimulates the central nervous system and can worsen Ménière's symptoms. Caffeine can be found not only in coffee and tea, but also in soda, chocolate and over-the-counter medications.

Sodium, alcohol, and caffeine primarily affect the symptoms of Ménière's Disease. They do not alter the cause of the disease nor do they cure it. But their avoidance many times can reduce the annoying symptoms.

Some researchers believe that allergies to certain foods can also worsen the symptoms of Ménière's Disease. Recent studies have shown that patients with Ménière's Disease have a higher rate of allergy than the general population. If you are suspicious that you may have a food allergy that is affecting your symptoms, keep a diary of your food intake. Compare your diet with your episodes of Ménière's to see if there is any relation. Discuss this with your doctor.

## Managing Stress

For Ménière's patients, stress can bring its own set of problems. Many physicians believe that there may be some connection between stress and the onset of Ménière's Disease. In other words, stress may be more than just an inconvenience for the Ménière's sufferer — it may be a factor in an attack of Ménière's.

We encourage you to work closely with your physician about your individual case of Ménière's Disease and seek his/her advice regarding your intention to begin a stress-management plan.

To deal with stress, you must first become aware of it. You should recognize and identify the situations and circumstances in your life that cause stress.

There are different types of stresses that occur in your life.

Minor hassles are stresses that are "daily happenings." Some positive minor hassles are a call from a friend during busy work hours, unexpected guests, or planning for a social gathering. Some negative minor stresses include traffic jams, lost car keys, disagreements with spouse or friend, and work frustrations. These types of stresses are minor irritants which can accumulate and add to constant stress.

Major changes are any changes, whether positive or negative, that impact your life. Positive stresses can be events such as receiving a promotion, having a new baby, and getting married. Negative stresses can include losing a loved one or losing a job. These stresses force you to adapt to a new way of life. The adaptation can be just as stressful as the stressor.

Stress overload is when you find that you are overwhelmed with circumstances beyond your control. Situations at home and at work combine to an unmanageable degree. A feeling of not knowing what to do next is common with this stress.

Feeling helpless can result when you have stress but do not know what the source is or how to manage it. This stress causes its victims to feel there is "no way out" or that escape from circumstances is impossible. These victims allow outside forces to take control of their lives.

Seeking intervention from an outside source, a friend or a trained professional, can help to sort through feelings and ways to deal with those stresses.



**While you cannot control stress, you can control your reaction to it. Turn stress from being an enemy into making it work for you.**

## ENT or Neurotologist?

What is a neurotologist?

Otolaryngologists (also called ear-nose-and-throat, or ENT, doctors) are physicians who have advanced training in disorders of the ear, nose, throat, and head and neck. Otologists, or neurotologists, are physicians who, in addition to their ENT requirements, continue their specialized training for an additional year or more in the

diagnosis and treatment of disorders of the ear.

Otolaryngologists and neurotologists/otologists are the physicians who typically treat disorders of the ear (or hearing mechanisms) requiring medical or surgical solutions.

Note that the neuroTologist is different from a neurologist.. A neurologist is a specially trained

physician who diagnoses and treats disorders of the nervous system, whether caused by disease or injury. This includes diseases of the brain, spinal cord, nerves, and muscles.

Because Ménière's Disease shares symptoms or mimics other disorders, you may be referred to visit any of these physicians.

**This newsletter is intended to reach out to others and offer support, comfort and advice. It is in no way intended to take the place of examination, diagnosis, opinion, or treatment provided by a licensed and qualified health professional.**

## People Helping People

Meniere's Resources, Inc.

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

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Ménière's Disease is a disease of the inner ear. The cause is unknown and the disease is incurable. Ménière's is characterized by four main symptoms, although those diagnosed with Atypical Ménière's may not have all symptoms.

- Violent rotational vertigo affecting balance
- Tinnitus – ringing or roaring in the ears
- Aural fullness – sensation of pressure in the ear
- Fluctuating hearing loss that can become permanent

Each of us is different and our symptoms progress at varying rates, in one or both ears, and we may or may not respond successfully to medical treatment or surgery.

*We're on the web!*

[www.menieresresources.org](http://www.menieresresources.org)

By joining together, we can overcome the isolation of our disease and unite our voices to raise public awareness, and provide family, friends, and professionals with information about how this disease affects our lives.



**Request a free brochure about the bone registry "That Others May Hear"**

## Give the Gift of Hearing and Balance

### **NIDCD National Temporal Bone, Hearing and Balance Pathology Resource Registry**

If you have hearing loss, a balance problem, or facial nerve paralysis, you can help find new treatments and cures for ear problems by donating your temporal bones to scientific research.

Thanks to those who contributed their temporal bones in the past, many advances in understanding and treating ear disorders have been made. Researchers have gained new

knowledge about hearing, balance, and facial nerve problems, and have developed effective new medical and surgical treatments. These involve hearing loss due to aging (presbycusis), otosclerosis, Benign Positional Vertigo, and Ménière's Disease.

Why is temporal bone donation so important? Because the structures of the auditory and vestibular systems are inaccessible during life. The only way to study their pathology and anatomy is by examining the temporal bone after death.

Donors are also encouraged to include records of hearing tests and ear surgeries.

All temporal bone donations to the NIDCD (National Institute on Deafness and Other Communication Disorders) bone registry come through the Registry's Boston office and are then assigned to one of the active collaborating laboratories around the country. Massachusetts Eye and Ear Infirmary  
243 Charles St.,  
Boston, MA 02114-3096  
phone: 800-822-1327

You can enroll now or learn more about the temporal bone registry by visiting the website at [www.tbregistry.org](http://www.tbregistry.org).