

What Did You Say?

Meniere's Resources, Inc.

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Ménière's Research Survey



Please help others by participating in this Ménière's Survey. You will be assisting in future research efforts. Results will help physicians better understand how Ménière's affects their patients.

James D. Hainlen, Vice President of the International Hearing Foundation, has created this survey. He also suffers from Ménière's. The purpose of this survey is to find out about your personal experience with Ménière's Disease.

He reports, "I have attended the Ménière's support group in Minneapolis for five years and during that time have developed an 11-page survey for

people with Ménière's. The questions on it were developed over the course of a year with many revisions in language after suggestions from the support group. I have also had the survey analyzed for statistical reliability by a friend who has a PhD in statistics and is the State Demographer for Minnesota. Further wording changes were suggested by a Psychiatrist who made sure that no questions were medical diagnosis. Finally, the head researcher for Ménière's at the University of Minnesota studied the survey and suggested questions that would mirror current research efforts in Ménière's Disease."

Hainlen will run the statistical analysis on a number of questions. He will use a statistics expert to do the various tests on the data.

The results will be tallied when there are enough responses to make valid conclusions. Please send the responses back in printed form by mail. A person with Ménière's and a person without Ménière's (as a control group) should fill out two separate surveys and mail them to the address below, in the same envelope if possible.

The survey is confidential. Your name cannot be associated with the answers in any way.

Please return the completed surveys by August 1, 2008 to James Hainlen, 1206 South Third St., Stillwater, MN 55082.

Use this link to access the survey:

<http://www.menieresresources.org/Main/2008ResearchSurvey>

Ménière's sufferers, audio specialists, and the folks at the lab who know how to put all this together. The estimated cost of the project is \$10,000. Donations and grants will fund the project. Your help would be appreciated.

Virtual Reality Vertigo Project

Mary Nelson, a Ménière's sufferer, is working on a project with the Johnson Simulation Center, a virtual reality lab in Pine City, MN. They will produce a simulation of a vertigo attack. The simulation will be used as a

teaching tool for ENTs and neurotologists, and also as an educational device for family members of those who have Ménière's. This is a HUGE project and involves a team of research doctors, artists, simulation and game designers,

Special points of interest:

- Participate in a Research Survey and help doctors
- Help fund a special virtual reality vertigo simulation project
- See what others with Ménière's are doing!!
- What's happening to raise Meniere's awareness?
- Keeping track of your meds

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CD by Ménière's Musicians

Several people with Ménière's have long planned to put their musical talents together and do a jazz CD. This recently came to fruition, with some of the musicians recording their parts around the country and the mixing and mastering done in Toronto. This is an amazing project since several have hearing loss!

Goes to show, life goes on, we can still be productive and use our skills and gifts! Congratulations to all the people involved in this project for following through on their dream!

All of the participants are afflicted with Ménière's Disease and/or hearing loss. They live through the U.S and Canada. Bill Ellison came up with "Staggered" as a name for our group by using initials from the band member's names. It also adequately described the affect on a person with Ménière's.

The CD was made to promote awareness about Ménière's Disease and to aspire accomplishments despite afflictions. It's a tribute to The Great American Songbook with a jazz, swing; blues feel with a few surprises.

Songs include:

A Kiss to Build a Dream On
Deed I Do
Honeysuckle Rose
I'm Beginning to See the Light
I'm Confessin' (That I Love You)
It's Only a Paper Moon
Nevertheless (I'm in Love with You)
Stormy Weather
Summertime
S'Wonderful

Who contributed?

STACEY NYBORG lead vocals,
 GEORGE GROSMAN vocal, lead guitar
 ANTHONY PANACCI piano
 RON HEFNER drums
 BILL ELLISON bass
 DEREK DARLING guitar, harmonica
 INGO ANDERSEN harmonica on track 8

Recorded and mixed at Trax Ahead
 by Anthony Panacci
 Mastered and produced by George J. Grosman
 Design by Daniel Pancy
 Layout by Keith Ryan
 Pressing by Accudub

Information: www.Staggered.biz
www.georgegrosman.com



Staggered CD—Pre-order now!

Stacey says, "I am turning to family and friends to help me defray the costs of pressing the CD by pre-ordering your copy of "Staggered", a tribute to the Great American Songbook. The cost is \$20 per CD with free shipping. A percentage of the proceeds will be donated to Meniere's Resources, Inc."

"Staggered" will be ready for release by the end of July or first part of August. Our website is under construction. See www.staggered.biz

How to order:

You can mail a check to:
 Stacey Nyborg
 Apt #4
 Vale, OR 97918
 S_nye26@yahoo.com

Ménière's Goes to the Art Fair

Daniel Pancy, who has Ménière's and MAV will have a booth at the Brownstone Days art fair in Washburn, WI July 27-29. He is selling hand-crafted etched olive oil bottles. Proceeds from the sale will go to Meniere's Resources, Inc.

Danny is a member of the Washburn Chamber of Commerce and is the city's official photographer.



Olive Branch bottle with pour spout

For those of you who can't make it to Wisconsin for the art fair, you can purchase these same beautiful amber green, green, blue, or teal bottles etched in the design of your choice at the Meniere's Store.

www.shopmenieresresources.highowersites.com/crafts.html

New Manual on Home Makeover Coming Soon

Have you ever wondered if there weren't some things you could do to your home that would make it more Ménière's friendly? How can you make laundry day easier? Is there technology that will help you wake up in the morning, not burn the hamburger, or remember an appointment? How do you manage small children when you have vertigo?

These topics and more are discussed in the Meniere's Resources manual which will be entitled,

“Ménière's Makeover: Improving Your Quality of Life, Health, Safety and Confidence in Your Home.”

This spiral-bound 8 1/2x11 manual will address every room of the house, includes photos and links to websites where you can order flashing smoke detectors, medical ID bracelets, visor cards for your car, phone technology and even has tips for mailing items from home and avoiding the post office, lighting,

acoustics, stairs, kitchen cabinets, recycling, the shower, closets and the yard.

The manual is in the editing stage and will be published and for sale in our Meniere's Store soon. Watch for it! It could change your life and make you feel safer in your home surroundings!

Thanks to TelTex who is underwriting the cost of printing the manuals for us!

Ménière's Awareness Day in New Hampshire

Ruth Coole, a Ménière's sufferer and advocate, wrote to Governor John H. Lynch of New Hampshire and was granted May 1, 2008 as Ménière's Disease Awareness Day. Ruth received a printed proclamation and a meeting with the Governor. She presented him with a Ménière's DVD, buttons, brochures and magnets. She had her photograph made with the Governor and her proclamation in hand.

Ruth took full advantage of the opportunity by submitting news releases to her local newspapers and was excited to see them printed. She told her personal story with Ménière's Disease and helped raise public awareness by doing so.

Each of us can do the same thing in our own states. Contact your Governor's office online. They sometimes have fill-in forms for requesting a

proclamation date or you can find the address of your State's governor to write and request a special day set aside. Be sure to list a contact name and phone number or email address for verification. Newspapers like personal interest stories e-mailed to them, but remember these are only printed when there is space available. Smaller newspapers are more likely to comply.

Get the Facts on Your Medications

Whenever you get a new prescription, ask your doctor or pharmacist these questions:

- What am I taking this medication for?
- How do I take the medication?
- If I need to take it three times a day does that mean at breakfast, lunch, and dinner or every eight hours?
- Do I need to take it all, or should I stop when I feel better?
- How long will I be taking it?
- Can I get a refill? How often?
- Does this new prescription mean I should stop taking any other medications I 'm taking now?
- What are the brand and generic names?
- Is a generic available that treats this condition?

Source: Your medicine: Play It Safe, Published by the National Council on patient Information and Education and the Agency for Healthcare Research and Quality.

Meniere's Resources, Inc.

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Kansas City, MO 64138

Email: info@MenieresResources.org

Store: <http://www.shopmenieresresources.highpowersites.com/page/page/5207322.htm>

Print your own Ménière's brochures:
<http://www.menieresresources.org/Resources/Brochures>

Low Sodium Recipes:
<http://www.menieresresources.org/Resources/RecipeOfTheMonth>

People Helping People



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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.

This support includes participating in research, offering assistance to those family members who are struggling to cope with the changes in our lives when Ménière's strikes. We also hope to help our own physicians better understand what we are going through.

Medications and Summer



Summer calls for special precautions

sensitivity.

Some medications, when combined with exposure to ultraviolet light, can cause the skin to burn, break out

Certain medications can make you extra-sensitive to the sun's rays, as well as ultraviolet light from sunlamps and tanning booths. This reaction is called photo-

in a rash, itch, turn red, or discolor.

Not everyone has the same reaction to the same drugs, but certain antibiotics-tetracyclines and sulfa drugs-and blood pressure medication that contain a **diuretic such as hydrochlorothiazide (HCTZ) will** commonly cause photosensitivity reactions.

Since there are many other drugs that can also cause reactions, you should ask your doctor or pharmacist if the medication you are taking requires you to take special precautions for sunlight exposure. You should also read the accompanying information or packaging inserts for over-the-

counter and prescriptions drugs.

If you are taking a medication that causes photosensitivity, be sure to avoid direct sunlight or prolonged exposure to the sun. Wear clothing and accessories that protect your skin from the sun, and use a good sunblock (SPF15 or higher), but remember that these protections will not totally block ultraviolet radiation from your skin.

Written by: Ted Collins, R.Ph, is pharmacist who advises the WEA Trust.

