Issue 13

Winter 2008



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COAST News

New Meeting Location!

"Addison's and Depression" January meeting topic

The January COAST meeting will feature a talk on "Addison's and Depression" by Paddy Kutz, Executive Director of Mental Health America of Licking County, and will be held at a new location to better meet the needs of members living east of Columbus. Paddy Kutz is a recognized expert in mental health, and should have some good information and suggestions for those of us dealing with Addison's Disease.

The meeting will be held:

1-3 p.m., Saturday, January 12 at the

Licking Co. Family YMCA 355 W. Broad Street, Pataskala

The YMCA is located at 335 W. Broad Street (State Route 16) in Pataskala, Ohio, about 20 miles east of Columbus.

Directions from the EAST or WEST: Take Interstate 70 to Exit #118, State Road 310 (exit signs say "Pataskala"). Go north on 310 four miles, to where the road T's at Broad Street, SR16. Turn left (west) and go a half mile. The YMCA is set back from the road on your left. Take the driveway back to the parking lot, and enter through the marked door. We'll meet in the aerobics room. For directions from other locations, please consult your favorite online map service.

The meeting will start at 1 and end promptly at 3. All Addisonians and those who care about them are invited to attend. Just this once, please do not bring a snack to share. Refreshments will be provided.

If you have questions about this meeting, contact COAST@columbus.rr.com.

Pharmacist will speak in April— We need your questions for him now!

You'll have an opportunity to learn more about your medications at the April COAST meeting. Pharmacist Charles Knueve will be our featured speaker. Dr. Knueve works with pharmacy students from Ohio Northern University when they do internships at his pharmacy. He would like your questions about medi-

cations in advance so he can assigns them to these students to research before the meeting, and reporting back in language we can all understand.

Because Dr. Knueve and several of our members are from the western part of the state, this meeting will probably be held in the Dayton area. The exact location will be announced in the Spring COAST News.

Please submit your questions about meds to: COAST@columbus.rr.com.

We'll forward them to Dr. Knueve.

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Have a happy, <i>HEALTHY</i> 2008!	

The Central Ohio Addison's Support Team does not engage in the practice of medicine. COAST is not a medical authority, nor does it claim to have medical knowledge. The content of this newsletter is intended as information and sharing of experience only, and is not in any way a substitute for proper and expert medical care. In all cases, COAST recommends that you consult your own doctor regarding any course of treatment or medication.

Disaster Preparedness

Emergency supplies—more than just your meds

Fires in the west, hurricanes in the south— fortunately, those of us in Ohio seldom have to evacuate our homes. But the occasional ice storm, flood, or other natural disaster can occur with very little advance notice, and that can be a problem for those with chronic illnesses such as Addison's Disease.

In addition to basic emergency supplies, Addisonians need supplies to manage their health. This includes:

Medication and Supplies - Because missing even even one day of medication can be dangerous, it's a good idea to have two weeks' worth of supplies on hand, a full month if you can. They include:

Daily medications—your oral steroid(s), and any other meds you require.

Emergency medications—injectable steroid, syringe, and alcohol wipes, hand sani-

tizer, and Band-Aids. **Documentation** - Personal records are often one of the hardest things to replace. Items to keep on hand include:

Extra prescriptions for each medication signed by a doctor, and a list of all medications taken and dosages. If you make copies of the scrips before you have them filled, you'll at least have a record that they exist.

Contact information - doctors' and pharmacists' names and phone numbers, family names and phone numbers, and a copy of your insurance card.

Food Keep at least a three-day supply of nonperishable food on hand at all

times. These foods can include:

In addition to basic emergency

supplies, Addisonians need

supplies to manage their health.

- Canned items - fruits and vegetables, tuna, other canned meats, and beans.

- Drinks powdered milk or shelf-stable milk, juice, and especially clean water.
- Boxed items crackers, dried fruit, nuts.

It's also a very good idea to have a flashlight,

battery-operated radio, and a first-aid kit.

If you need to go to an emergency shelter, se sure to identify yourself as an Addisonian to the emergency authorities when you get there. And ALWAYS wear your medical alert bracelet!

Travel

Addison's plaque at Jane Austen Center in Bath, England

Most Addisonians learn early on about the three famous people who share their disorder: President John F. Kennedy, singer Helen Reddy, and writer Jane Austen. Austen developed Addi-

son's Disease in early 1817. At that time, the condition had not be identified, and always Iresulted in death. For Jane Austen, death occurred on July 18, 1817. A remarkably prolific and popular writer, Austen still has fan clubs around the world. The Jane Austen Center in Bath, England, where Austen lived in 1801, recognizes Austen's medical condition with a plaque

on the wall. It reads:

occur in all age groups and is not specific to either men or women.

HISTORY OF THE DISEASE

The condition was first identified by Dr. Thomas Addison in 1849. The disease was not associated with Jane Austen until 1964. In his published article 'Jane Austen's Last Illness" F. A. Bevan used Jane's own accounts of her symptoms contained in her letters to establish a link and used quotations to substantiate his the-



SYMPTOMS OF THE DISEASE

Sufferers of Addison's Disease experience weight loss, muscle weakness, fatigue, low blood pressure, and in some cases a darkening of the skin. In a letter to her niece, Fanny, dated 23 March, 1817, Jane writes, "I have had a good deal of fever at times, and indifferent nights, but am considerably better now, and recovering my looks a little, which have been bad enough, black and white and every wrong colour."

CAUSES OF THE DISEASE

Addison's Disease can be caused by a deficiency of the hormone Cortisol which is produced in the body's adrenal glands. Among other responsibilities, Cortisol's primary function is to help the body respond to stress. In a letter to her brother Charles, dated 6 April, 1817, Jane states,

"A few days ago my complaint appeared removed, but I am ashamed to say that the shock of my uncle's will brought on a relapse."

(The Austens had been expecting a considerable inheritance from James Leigh Perrot, which they did not receive upon the reading of the will.)"

"ADDISON'S DISEASE — BRIEF DE-SCRIPTION

Addison's Disease is a rare hormonal disorder affecting on average one in one hundred thousand people. It can

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Holidays, Stress, and Addison's Disease

It's a wonderful time of year—finding the perfect gifts, welcoming family members home, participating in religious services, hosting parties, traveling, decorating, baking, and doing all the things that make the holiday season perfect. Striving for the picture-perfect holiday gathering, though, can be very stressful—and can lead to life-threatening crises for Addisonians! When you have Addison's disease, even though you follow your medication plan carefully, things happen which can create stresses on your body, causing a deterioration in your condition. Unlike people who do not have Addison's, your adrenal gland can't respond to increased demands. You need to avoid stress or prepare for stressful situations and know what to do to prevent an adrenal crisis.

Here are a few tips to keep the holidays healthy:

Eat regularly. Don't skip meals or go for a long time without food. Eat a well balance diet, and make sure you drink plenty of fluids.

Balance active periods with rest. Don't overdo! Your family would rather have YOU there, healthy, than have a pictureperfect tree and Christmas dinner while you're in the hospital. Don't be afraid to make things easier on yourself. Ask others to bring a dish, help with the dishes, or help decorate. If you're tired, take a nap; don't do "just one more thing." Don't sweat it if you mail your packages a little late; it just extends the holiday season for the recipients! Find ways to simplify meals. Use disposable dishes, order a whole meal from your favorite supermarket, or celebrate at your favorite restaurant. Have housequests? Don't be shy about asking them if they'd mind running the vacuum or throwing a load of towels in the wash.

If you don't feel well, stop immediately and take care of yourself. If you continue to feel unwell, don't hesitate to call your doctor or go to the emergency room. Fear of "ruining Christmas" can be deadly!

Follow your doctor's directions for increasing your daily doses of prescribed steroids during stressful times - emotional crisis, overexertion, infection, illness or injury.

While Addisonians are often warned against exertion in hot weather, many notice that they need extra meds in very cold weather, especially if they are very active. Several COAST Members have noticed that shoveling snow—physically demanding in the best of conditions, can be particularly draining in extremely cold weather. Also mentioned: active winter sports such as skiing, snowboarding, snowshoeing, and even building snowmen with the kids. Stay in tune with your body, and get inside and warm when necessary. You may also need to "bump" your steroid a bit.

Educate a family member or a friend about Addison's disease. Explain that they should immediately seek medical help for you if they find you unconscious or physically unable to take your medication by mouth. Explain that they must con-

Share the load!

Volunteers keep COAST moving!

Every COAST meeting brings new volunteers, and the October meeting was no exception. Thanks to Marianne Kowalchuk for volunteering to contact newly-diagnosed Addisonians, and to Ann Stollenwerk for securing a pharmacist to speak at our April meeting!

We still need people to arrange for our July and October 2008 meetings. We have ideas for speakers—we just need someone to follow up and make the phone calls. If you'd like to do this to help support others with Addison's Disease, let Betsey know (614-854-0926;

Heb30@aol.com). We'd also like to hear from you if you have an idea for a program or speakers, or if you'd share your story in this newsletter.

COAST is an all-volunteer chapter of the National Adrenal Diseases Foundation. Our goals are:

- To provide a caring network to support people with Addison's Disease.
- To supply up-to-date information to people with Addison's
- To help educate health professionals to have a greater awareness of Addison's Disease.
- To make the general public aware of Addison's Disease.

Here are the volunteers who make COAST possible:

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COAST CENTRAL OHIO ADDISON'S SUPPORT TFAM

97 Lawrin CT SW Pataskala, OH 43062

Next COAST Meeting: 1 to 3 p.m. Saturday, January 12, 2008

Pass the Salt, Please!

Cherry Almond Oatmeal Cookies

With their bone-building almonds, anti-oxidant packed cherries, and high-fiber, cholesterol-busting oatmeal, these treats are much better for you than the usual run-of-the-mill cookie! The best part is their irresistible flavor! They're guaranteed to please!

1 teaspoon baking soda

1 1/4 cups butter or Benecol

3/4 cup dark brown sugar 1 teaspoon salt

1/2 cup sugar or Splenda 1 cup slivered almonds

1 egg or egg substitute 3 cups quick or old-fashioned oats

2 teaspoons almond extract 1 cup dried cherries

1 1/2 cups all-purpose flour

Preheat oven to 375 degrees.

Beat margarine and sugars until fluffy. Beat in egg and almond extract. Add combined flour, baking soda and salt; mix well. Stir in oats, almonds, and cherries. Drop by rounded tablespoonfuls onto ungreased cookie sheets. Bake 8-9 minutes for chewy; 10-11 minutes for crunchy cookies. Cool 1 minute on cookie sheet. Remove to wire rack. Store tightly covered. Makes about 80 cookies.

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