

Issue 12

Autumn 2007



COAST
CENTRAL OHIO ADDISON'S SUPPORT TEAM

COAST News

Milestones

COAST celebrates 3 years!

Three years ago this October, the very first meeting of the Central Ohio Addison's Support Team took place in Columbus. Now it's time to celebrate, reflect, and move into the future!

Please join us at our next meeting,

1 p.m.

Saturday, October 13, 2007

at the North Congregational United Church of Christ, 2040 W. Henderson Road, Columbus. The church is located between 315 and Sawmill on the north side of Henderson. It is fully accessible.

The agenda will include discussions of new research and how to become involved with it, and guidelines for steroid

medication requirements for surgery and dental procedures. Of course we'll also have our usual sharing of questions and concerns about living with Addison's Disease. We'll also make plans for 2008, so be thinking of what programs you think would be beneficial for our membership.

Following that, it's party time! Birthday cake will be served, and members are encouraged to bring a snack to share.

Family members and friends are always welcome to participate in COAST meetings.

For questions or directions, or to RSVP, please contact Betsey at 614-854-0926, or Heb30@aol.com.

Research

New Addison's medication on the horizon

A new product to treat adrenal insufficiency is in Phase II clinical trials at the National Institutes of Health. Chronocort is the first circadian endocrine treatment for congenital adrenal hyperplasia and adrenal insufficiency. Chronocort™ uses a modified release technology to provide a delayed-and-sustained release profile of hydrocortisone to mimic the natural overnight and early morning hormone levels found in healthy individuals. This is considered important in controlling

both actual disease symptoms and also reducing unwanted side effects resulting from excess steroid treatment. Phoqus, the pharmaceutical development company, believes Chronocort will provide better control of congenital adrenal hyperplasia, Addison's disease and hypopituitarism.

At this time clinical trials are limited to those with Congenital Adrenal Hyperplasia (CAH), but Phoqus plans Phase III clinical trials in those with Addison's Disease early next year, lasting until mid-2009. The company expects Chronocort to

be available for the CAH indication in late 2008, followed a year later with the launch for use in Addison's.

Congenital adrenal hyperplasia (CAH), and both Primary and Secondary Addison's disease (AD) are chronic diseases, and thus long-term corticosteroid replacement is required. Current treatments for these diseases are immediate-release hydrocortisone or the longer

Please see "Chronocort..." on page 4

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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.

Your medications

Bone-building drugs linked to rare jaw condition

Addisonians taking oral bisphosphonates to treat or prevent osteoporosis or osteopenia should be aware of potential risks when undergoing certain dental procedures, and alert the dentist to the fact that you take these bone-building medications.

Common bisphosphonates include Fosamax, Boniva and Actonel. They are often prescribed for those with adrenal insufficiency because steroid use is known to accelerate bone loss.

Relying on a small but growing number of reports linking bisphosphonate drugs to incidences of osteonecrosis of the jaw (dead bone tissue), a panel of experts convened by the American Dental Association believes dental patients who are taking oral bisphosphonate

drugs should discuss the risks they face when undergoing procedures that involve the jaw bone, such as tooth extraction or placing implants, with their dentist.

Dentists and their patients should carefully consider these procedures, as well as alternative dental therapies. Patients may also want to discuss this information in the context of their overall health and treatment options with their physician.

The ADA recommends that a comprehensive oral evaluation be carried out on all patients about to begin therapy with oral bisphospho-

nates (or as soon as possible after beginning therapy), and that patients on these drugs be educated on maintaining oral hygiene, which is the best way to prevent oral diseases that may require dental surgery.

Common bisphosphonates include Fosamax, Boniva and Actonel.

The ADA notes that dentists, generally, will not need to modify dental treatments based solely on oral bisphosphonate therapy. Further, patients should understand that the risk for developing osteonecrosis of the jaw is considered very small and that the vast majority of patients taking an oral bisphosphonate do not develop any oral complication.

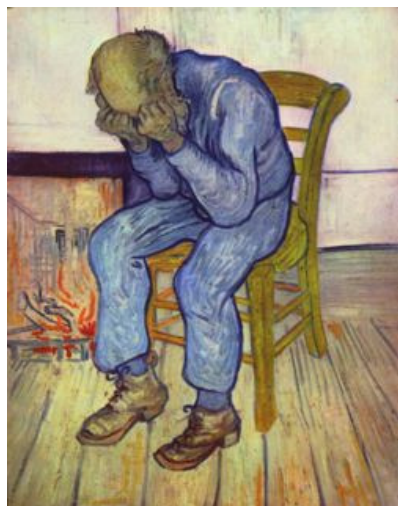
Research

Depression and Chronic Disease: disabling combination

Depression is more damaging to everyday health than chronic diseases. And if people are ill with other chronic conditions, depression makes them worse, a recent study by the World Health Organization (WHO) found.

In the study, published in the Sept. 8 issue of *The Lancet*, the research team analyzed data on more than 245,000 people from 60 countries participating in WHO's World Health Survey.

The 1-year prevalence of experiencing a depressive episode, angina, arthritis, asthma, and diabetes were 3.2%, 4.5%, 4.1%, 3.3%, and 2.0%, respectively.



The rates of depression in subjects with at least one chronic disease ranged from 9.3% to 23.0%. In other words, people with a chronic disease were significantly more likely to have depression than those without a chronic disease. While Addison's Disease was not one of the specific conditions in the study, the findings might be applicable to people with it or other chronic diseases.

"We report the largest population-based worldwide study to our knowledge that explores the effect of depression in comparison with four other chronic diseases on health state," the researchers wrote.

Dr. Somnath Chatterji of WHO, who led the study, said researchers calculated the impact of different conditions by asking people questions about their capacities to function in everyday situations — such as moving around, seeing things at a distance and remembering information.

The researchers assigned a number between 0 and 100 reflecting a person's relative health score.

"Compared to the chronic physical illnesses of angina, arthritis, asthma and diabetes, depression produces the most decline in health," Chatterji said. "Having depression over and above a physical illness significantly worsens health even further," he said.

Please see "Depression..." on page 3 to continue reading this article.

Depression and Chronic Disease, *continued*

The most disabling combination studied was diabetes and depression, the researchers said.

Depression needs to be recognized and treated as an urgent public health priority, Dr. Chatterji said. "Persons with physical illnesses should also be examined for depression and treated appropriately. Primary care providers must learn to recognize and manage concurrent physical illnesses and depression to reduce disease burden and improve population health," he added.

Often, however, doctors don't bring up the topic of depression with their patients. "Depression co-occurs with many disorders," says Paddy Kutz, Executive Director of Mental Health America of Licking County. "Quality of life can be impacted by getting the right treatment."

She suggests carefully completing the checklist of depression symptoms on this page. "If a person thinks they might be depressed based on these symptoms, they need to check it off, rip out the list, and go *immediately* to their primary care doctor."

She stresses that if your doctor is unable or unwilling to refer you to a psychiatrist for treatment, you

Checklist of the Symptoms of Depression

- ◇ Persistent sad, anxious, or "empty" mood
- ◇ Feelings of hopelessness, pessimism
- ◇ Feelings of guilt, worthlessness, helplessness
- ◇ Loss of interest or pleasure in hobbies and activities that were once enjoyed, including sex
- ◇ Decreased energy, fatigue, being "slowed down"
- ◇ Difficulty concentrating, remembering, making decisions
- ◇ Insomnia, early-morning awakening, or oversleeping
- ◇ Appetite and/or weight loss or overeating and weight gain
- ◇ Thoughts of death or suicide; suicide attempts
- ◇ Restlessness, irritability
- ◇ Persistent physical symptoms that do not respond to treatment, such as headaches, digestive disorders, and chronic pain

Check off the symptoms you are experiencing. If you think you might be depressed, tear out this list and take it to your doctor.

should make an appointment with a different doctor, because mental health is too important to ignore. There *are* treatments and, as this recent study emphasizes, untreated depression can worsen your management of Addison's Disease.

In 2000 scientists rated depression as the disease which had the fourth greatest public health impact globally. By 2020 it is predicted it will have jumped to second place. It is estimated that at some point in their lives, one in five women and one in

10 men will suffer from depression. The new WHO study emphasizes the importance of treatment for depression in conjunction with treatment for other chronic illnesses.

To learn more about depression and Addison's Disease, plan now to attend the January 12, 2008 COAST meeting, which will be held in Pataskala, in Licking County just east of Columbus. Paddy Kutz, of Mental Health America, will be our guest speaker.

Share your experience

Response: Is dry mouth part of Addison's?

In the last issue of COAST News, a member asked, "I am having a lot of trouble with dry mouth. Have you heard of any other Addisonians having trouble with that?" We asked you to respond, and you did!

Here's what we learned:

Dry mouth is not generally listed as a symptom of Addison's Disease, but at

least one member said she also suffers from unexplained dry mouth since the onset of AD.

Two people said that although they hadn't experienced it, their dentists had warned them of dry mouth due to Addison's, with possible resulting gum damage. The dentists had advised them to chew sugar-free gum during the day, as well as sipping

water often.

Another member who had experienced dry mouth while undergoing chemotherapy responded, "Recaldent makes a paste for dry mouth "MI Paste". It's a topical paste with bio-available calcium and phosphate." You can learn more about MI Paste at www.gcamerica.com/mipaste.html

Thanks to all who responded!

Chronocort clinical study, continued from page 1

acting corticosteroids dexamethasone or prednisone. Currently available formulations of these corticosteroids do not mimic the difficult-to-achieve natural circadian levels of cortisol in the body, and consequently on a daily basis patients may be continuously over-dosed or under-dosed. The quality of life of these patients is very poor and has been compared to sufferers of congestive heart failure.

Hydrocortisone - the exogenous version of cortisol - is generally considered the treatment of choice. However it has a short half-life and it is recommended that, when taken orally, hydrocortisone should be taken three times daily to better approximate normal cortisol production. Cortisol is normally secreted in bursts throughout the day and night. In the intervals between bursts, cortisol levels drop. It is felt by many endocrinologists that these low levels may be important in preventing side effects from excessive cortisol. However, the three-times-a-day regimen is inconvenient for patients. As a result, compliance can be poor, leading to poor long-term control of the disease symptoms.

Thus, patients on hydrocortisone may either be prescribed from the outset, or switched once compliance issues occur, to prednisone or dexamethasone. These molecules are more potent and have a much longer half-life, so may be administered once daily to improve compliance. However, the potency and half-life make it much easier to over-treat these patients. Over-treatment can lead to Cushingoid symptoms and long term suppression of the hypothalamus-pituitary-adrenal axis (the HPA axis), as well as significant side effects. These can include weight gain, glucose intolerance, hypertension, increased susceptibility to infections, bone thinning, easy bruising, fragile skin, mood swings, insomnia, avascular necrosis of bone, abdominal striae, cataracts, and acne.

Current leading medical opinion is to therefore seek a "steroid sparing" regimen wherein as little steroid as possible is given to patients suffering from these diseases. Phoqus—as well as adrenal insufficient patients around the world—hope that the clinical trials of Chronocort demonstrate that it can safely mimic the normal circadian rhythm, and thus better treat Addison's Disease and CAH.

For more information about Chronocort, see: <http://www.phoqus.com/fPR07083001.html>, and <http://www.phoqus.com/finformation.html>. To learn how you can become involved in the studies at the National Institutes of Health, go to www.clinicaltrials.gov, or call NIH Patient Recruitment at 1-800-411-1222.



New Graves' Disease support group forming in Columbus

Men and women with Graves' Disease (autoimmune hyperthyroidism) are invited to attend the first regularly scheduled meeting of the Central Ohio Graves' Disease Support Group at 1 p.m. on Sunday, October 14, 2007, at The McConnell Education Hall at The Eye Center, 262 Neil Ave., Suite 160, Columbus. Families are welcome to attend.

Graves' Disease, hyperthyroidism, often co-occurs with Addison's Disease (see related article on Page 5 of this newsletter).

For more information, contact Barbara Erickson, support group leader, at (614) 431-6854, lilly139@hotmail.com, or email cindy@ohioeyesurgeons.com.

Yes, COAST still needs your help!

A wise person once said, "Many hands make light work." And it's still true! COAST can be a successful support group only if everyone pitches in and does what they can to make it work. If you or someone in your family can make a few phone calls to arrange speakers for our April, July, and October 2008 meetings, more Addisonians will come to the meeting, and everyone will benefit. 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](tel:614-854-0926); Heb30@aol.com).

Inheritance in autoimmune Addison's: the extended family profile

Two members of The Addison's Disease Self-Help Group in the United Kingdom recently worked with a researcher from Churchill Hospital in Oxford, England to look at health profiles of extended families of Addisonians. They analyzed data from the group's 2003 international survey of 614 patients who listed all health conditions occurring in their families, including those apparently unrelated to adrenal failure. Responses were compared to those of a well-matched control group of 612 people who did not have Addison's Disease.

"Autoimmune hypoadrenalism frequently occurs in association with other organ-specific autoimmune diseases, both endocrine and non-endocrine. These conditions are

recognized to occur in the extended family, but their prevalence has been hard to determine, because of the rarity of the disease," wrote Katherine White, John Wass and Alyson Elliott.

The profile of associated conditions identified in males and females varied, reflecting the female predominance of autoimmune disease. In every incidence of Addison's, females had a higher rate of incidence than males. (i.e.: The rate of maternal Addison's was 1.7%, compared to just 0.2% of paternal Addison's; 0.9% of maternal grandmothers compared to 0.3% of paternal grandmothers, etc.) Addison's among siblings and children also showed a female preponderance: sisters were more likely to have it

than brothers, and daughters more likely than sons.

Related autoimmune conditions—hypothyroidism, vitamin B12 deficiency and vitiligo—were all found in extended families at rates that bore out that female predominance, and Also demonstrated a relationship to Addison's Disease.

The study authors concluded, "These findings suggest that the immediate relatives of autoimmune Addison's patients should be screened for the possible development of associated autoimmune conditions."

To read the abstract, go to www.endocrine-abstracts.org/ea/0013/ea0013P114.htm

Should you be screened for Celiac Disease?

A Swedish study published in the Journal of Clinical Endocrinology and Metabolism this summer concludes that there is a highly increased risk of Addison's Disease in people with Celiac Disease, and therefore recommends "that individuals with AD should be screened for CD." Celiac disease is a digestive disease that damages the small intestine and interferes with absorption of nutrients from food. People who have celiac disease cannot tolerate a protein called gluten, which is found in wheat, rye, and barley. Celiac disease affects people differently; symptoms may occur in the digestive system, or in other parts of the body. For example, one person might have diarrhea and abdominal pain, while another person may be irritable or depressed. In fact, irritability is one of the most common symptoms in children. Other symptoms can range from muscle cramps to an itchy skin rash, among others. Because of this vast array of symptoms, CD is now recognized as a multi-organ disorder. CD is diagnosed by simple blood tests that measure autoantibodies. For more information about Celiac Disease, go to: <http://digestive.niddk.nih.gov/ddiseases/pubs/ceeliac/#1>

Who we are, and what we do

The Central Ohio Addison's Support Team (COAST) was founded in the autumn of 2004. A support group of the National Adrenal Diseases Foundation (NADF), we are a group of people who want to make life better for those with Addison's Disease.

COAST does not engage in the practice of medicine. COAST is not a medical authority, nor does it claim to have medical knowledge. In all cases, COAST recommends consulting your doctor regarding treatment.

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 Disease
- To help educate health professionals to have a greater awareness of Addison's Diseases, and
- To make the general public aware of Addison's Disease.

We meet four times a year, always on the second Saturday of the month. Upcoming meetings are:

October 13 - Columbus

January 12, 2008 - Pataskala

April 12 and July 12, 2008, locations to be announced.

To get involved, contact Betsey at HEB30@aol.com (614-854-0926), or Heather at HNagy@columbus.rr.com (740-964-6306).

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TEAM**

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*Next COAST Meeting:
1 p.m. Saturday, October 13, 2007*

Pass the Salt, Please!

Spinach balls

Fall and early winter are a wonderful time for celebrations— from Halloween to New Year's Eve. These delicious little treats are always welcome at parties and potlucks. You can also use the mix to make patties that can be fried up on the stove for a quick, easy dinner. If you're watching cholesterol, substitute Benecol (but not the "light" version) for the butter, and EggBeaters for the eggs. The spinach balls are rich in bone-building calcium and magnesium.

2 10-ounce packages frozen spinach, thawed and drained
2 cups dry stuffing mix (not cubes)
1 cup grated Parmesan cheese
6 large eggs, beaten
1 1/2 sticks (3/4 cups) butter or margarine, room temp.
1/2 teaspoon salt
Pepper to taste

Mix all ingredients together and shape into walnut-sized balls. Place balls on a cookie sheet, and freeze until hard. When frozen, remove from cookie sheet and place in an airtight container in the freezer. These store very well until you are ready to cook them.

When ready to serve, put the spinach balls back on the cookie sheet, and bake them in a preheated 350-degree oven for 20-30 minutes, or until they are starting to brown. Makes about 60 spinach balls, or 20 servings.