

# WAKE-UP CALL

FROM THE AMERICAN SLEEP APNEA ASSOCIATION

S P R I N G 2 0 0 7

## ASAA A.W.A.K.E. NETWORK NEWS

After a blockbuster March opening attended by 100 people, **A.W.A.K.E. in the Seacoast Area** in Dover, N.H., reconsidered its plans to meet quarterly and will meet bimonthly or possibly even monthly.... Michigan's **Traverse City Area A.W.A.K.E.** also reports it got off to a good start at its March meeting.... Both **A.W.A.K.E. Across the Hudson** in Kingston, N.Y., and **Northern Michigan Hospital Sleep Center A.W.A.K.E.** in Petosky, Mich., chewed over the subject of dental appliances in late-winter meetings. The WAKE-UP CALL plans to write about this treatment option in a future edition.... **Southwest Mississippi A.W.A.K.E.** of McComb, Miss., helped demystify the sleep study (covered in the Winter 2006 newsletter) at a February meeting, and reports that its members really appreciated the information. The topic was also covered by **Morton Plant Mease Sleep Disorders Center A.W.A.K.E.** in Safety Harbor, Fla.... Which brings us to **Western Slope A.W.A.K.E.** in Grand Junction, Colo., which met to discuss the slippery subject of "Billing of Sleep Studies and What Insurance Covers".... Doug Masini spoke on "Nighttime Eating Disorders" at a meeting of **A.W.A.K.E. of Bristol** in Bristol, Va., while **Rockingham Memorial Hospital A.W.A.K.E.** in Harrisonburg, Va., had a dietician speak on daytime eating choices that foster good sleep.... Both **Ocean County A.W.A.K.E.** in Toms River, N.J., and **West Metro A.W.A.K.E.** in St. Louis Park, Minn., had meetings on Restless Legs Syndrome.... **A.W.A.K.E. in the Quiet Corner** in Putnam, Conn., had a lively April meeting at which they explored the information available on CPAP manufacturers' web sites....

A.W.A.K.E. - ALERT, WELL, AND KEEPING ENERGETIC

## FEMALE TROUBLES

### OSA Increases Threefold During Menopause

Let's say you're a woman, aged 50 or thereabouts, and you're sleeping badly and waking up feeling even worse. Being a woman, you're likely to go to a doctor, and there you're likely to be told, "Oh yes, that's normal at your age. Once you get through menopause, your sleep problems will clear up."

But the fact is, what many pre- or peri- or just-plain menopausal women are experiencing at night isn't normal at all – it's the onset of Obstructive Sleep Apnea, and it isn't going to clear up on its own.

OSA – comparatively rare in young women – is estimated to increase three-fold as women go through the change of life. For reasons that are not well understood, falling levels of the female hormones estrogen and progesterone, and rising levels of the male hormone testosterone (also found in women), lead to a loss of muscle tone in the airway, and consequently to obstructive blockages. This is the case even when you factor out the weight gain that often accompanies menopause.

"Physicians tend to trivialize sleep problems in [middle-aged] women," says Dr. Terry Young, a pioneering epidemiologist in the field of sleep apnea who has just completed a seven-year study on women and sleep. "The doctors will tell you, 'Oh, it will go away,' and neglect what could turn out to be a serious underlying sleep disorder.

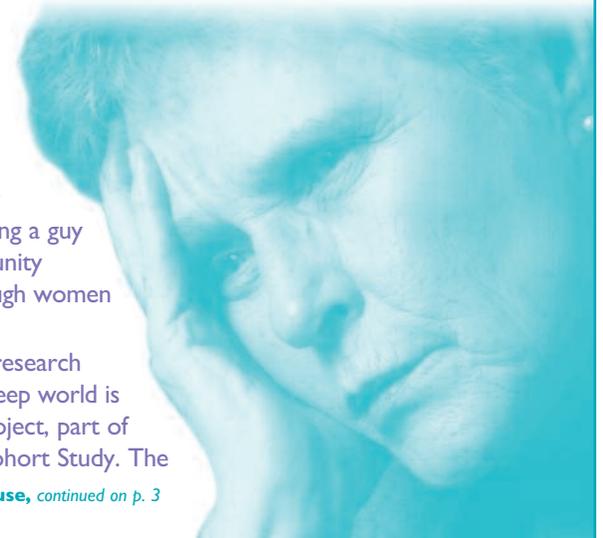
"Sleep problems in women need to be aggressively investigated, just as they are in men," Dr. Young concludes.

Dr. Nancy Collop, of the Division of Pulmonary/Critical Care Medicine at Johns Hopkins, agrees that "there's a bias in who gets referred" for sleep studies. The old literature, she says, would indicate that the prevalence of OSA is 8 to 1 in men over women. But in fact, she says, it's more like 3 or 4 to 1, and after menopause it's 1 to 1.

In other words, the notion that sleep apnea is a condition that largely affects men is incorrect. Far from being a guy thing, sleep apnea is an equal-opportunity ailment, particularly later in life – though women typically have less severe cases.

The final results of Dr. Young's research have not yet been published, so the sleep world is awaiting the definitive data on her project, part of the University of Wisconsin Sleep Cohort Study. The

*Menopause, continued on p. 3*



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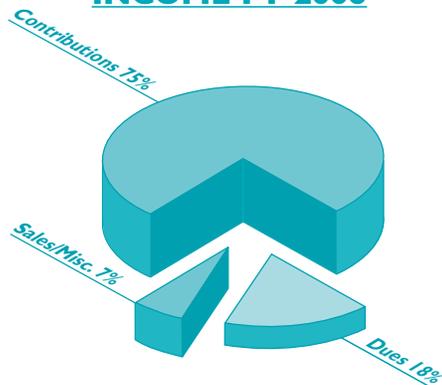


AMERICAN  
SLEEP  
APNEA  
ASSOCIATION

# A LETTER FROM EXECUTIVE DIRECTOR ED GRANDI

The spring newsletter is where I discuss the financial condition of the American Sleep Apnea Association and mark the anniversary of my becoming its executive director.

## INCOME FY 2006



I am pleased to report an increase in financial support for the work of the ASAA. Income to the organization grew by a healthy 14 percent in 2006, to \$251,073. The largest area of growth was in memberships, with revenues rising nearly 20 percent.

I am also happy to report that less than 25 cents of every dollar donated to the ASAA goes to administrative and fundraising expenses.

Above are charts breaking out the income and expenses. The association's audited financial statement for fiscal year 2006 is available on our web site. Click on the "About the ASAA" link on our home page and go to the archive section.

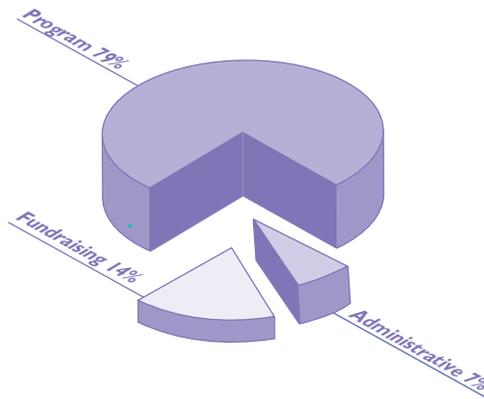
I begin my fourth year as the executive director of the association with a sense of expectation, and not just because the organization is on firm ground financially. From the vast numbers of inquiries we receive from the media as well as the public, it is clear that we are widely viewed as a reliable source of information on sleep apnea. We are positioned for growth as the world comes to realize what we already know – sleep apnea is a serious condition that requires treatment to improve and preserve the lives of those afflicted by it.

I am heartened by what we have accomplished so far: regular newsletters, an expanding network of support groups, our online support forum, and more. But there is still much work that remains to

be done, work that you make possible by your membership dues and donations. Thank you for your continuing support.

On March 7, we held our third Sleep Apnea Awareness Day lecture – with

## REVENUE FY 2006



three speakers. The entire program is available on our web site, courtesy of a generous grant from its longtime sponsor, the American College of Chest Physicians – Sleep Institute. A DVD will be available in the future. I hope you will take the opportunity to view the event.

I mentioned in the last newsletter that the association had received a grant from

ResMed to develop a grassroots campaign to help sleep apnea patients and their families communicate with the federal government on matters of importance to them. Earlier this year we opened a virtual Legislative Action Center (LAC) at [www.sleepapnea.org/advocacy](http://www.sleepapnea.org/advocacy). I encourage all of you to visit the site and become involved in the Apnea Advocacy Action Program.

Also thanks to ResMed, the ASAA has developed the CPAP Assistance Program (CAP). Refurbished CPAP machines from ResMed will be distributed through our A.W.A.K.E. Network of support groups around the country.

The machines are intended for people who have received a diagnosis of sleep apnea and a valid prescription for a CPAP machine, but lack health insurance and the resources to cover its costs. Inquiries about machines will be referred to the closest participating A.W.A.K.E. group for its review.

Postscript: Do you shop at Amazon? If so, please use the portal to it on the ASAA web site. The association receives a referral fee for every purchase made that way. It's not a lot, but every little bit helps! ■

## ASK THE DOCTOR

**Q** I'm a 50-year-old man in very good physical shape, but with a terrible case of sleep apnea. I use a mask, but every once in a while I take a night off, and some nights I wear it for about five hours, and sleep two or three hours without it. Am I putting myself at risk for a heart attack, which I know can be the result of untreated sleep apnea, or am I using it enough to fend off heart damage?

**Andy H.**  
Columbia, Tenn.

**A** There is increasing evidence of an association between sleep apnea and cardiovascular disease. For instance, one study suggests that a diagnosis of sleep apnea results in a higher chance of a heart attack three to five years later. Another study shows that the diagnosis of sleep apnea increases the chance of stroke. But no study has been detailed or big enough to conclude

that those who use CPAP are at lower risk than those who do not.

So what to do? After a diagnosis of sleep apnea, and with successful adaptation to CPAP, it makes sense to use CPAP on a "regular" basis. Currently we consider use above 50 percent to be acceptable, as this rate of adherence is the norm for treatment of any chronic disease (arthritis, hypertension, etc.).

Will one die off CPAP for a night or for a week? The effects of sleep apnea probably accumulate over time. The substrate for a heart attack is a narrowing of the coronary arteries. Nocturnal angina is associated with unrecognized and untreated sleep apnea, and is provoked by the blood pressure surges and hypoxia caused by obstructive apneas. So I really can't advise you to use CPAP on an irregular basis, especially if you have risk factors for coronary artery disease.

**Kingman Strohl, M.D.**  
Case Western Reserve University  
Cleveland, Ohio

*WAKE-UP CALL welcomes questions from readers, and will publish them as space permits. Letters may be edited for length and clarity. We regret that it is not possible to provide personal replies to all questions.*

The third annual **Sleep Apnea Awareness Day Lecture** was held on the morning of March 7th in a Grand Hyatt hotel ballroom in downtown Washington, D.C. This year the association was fortunate to have three speakers, each providing a unique perspective on sleep apnea.

First up was Nancy Rothstein, who joined the ASAA Board of Directors last year. The wife of a snoring apneic, she spoke about the challenges of living and sleeping (or not sleeping) with someone who has the condition. Her personal experience led her to become an activist working to raise awareness about the dangers of sleep apnea.

Next on the dais was Ashley Keenan, with a touching story of how her teenaged years were disrupted by the onset of sleep apnea, misdiagnosed for many years as depression and Attention Deficit Disorder.

A savvy psychiatrist's suspicion that she might have a sleep problem led to a sleep study and CPAP treatment, which turned her life back around. Now a college student – and once again earning A's – Ms. Keenan is using her experience to help other young people through her work with a mental health agency in Rhode Island.

Lastly, Dr. Terri Weaver of the University of Pennsylvania delivered the keynote address. In her talk – entitled “Snoring and Sleep Apnea: The Effects on the Family” – Dr. Weaver buttressed the remarks made by Mrs. Rothstein and Ms. Keenan with statistics from a number of studies documenting the negative impact on quality of life of untreated OSA.

**The American College of Chest Physicians – Sleep Institute** underwrote the event, providing the funds to record the lecture and make it available for broadcast over the Internet.

In another, critically important initiative, the **ResMed Corporation** is providing funding to fill a major gap in the delivery of care to people with OSA. Each quarter, ResMed will donate 25 reconditioned (to factory specifications) CPAP machines to the ASAA for distribution to people who have been prevented from getting treatment because they do not have the insurance and private means to cover the cost of a device.

To be eligible to receive one of these donated machines, patients must have a valid prescription and access to a homecare company to set the pressure according to the prescription. They will also have to obtain a mask on their own.

The machines will be distributed through the A.W.A.K.E. network of support groups. Groups participating in the program will have asterisks by their names in the database on the ASAA web site. ■

#### Menopause, continued from p. 1

project followed 240 women in their 40s and 50s, using in-home polysomnography and diaries to track changes in menstruation and sleep.

Interestingly, the study – which included women on Hormone Replacement Therapy (since largely discredited) and those who underwent hysterectomies – did not directly test for hormonal changes. Dr. Young claims that the daily diary entries provided a more precise and accurate reading of hormonal activity than would have been gleaned from blood work.

Whether gauged anecdotally or in the lab, there is no question that changing hormones are to blame for the increased incidence in OSA in menopausal and post-menopausal women. But exactly which hormones are responsible, and how do they exert their effect?

Medicine has a way to go before it can answer those questions, though there are intriguing clues out there. According to Dr. Collop, women with polycystic ovary disease, a condition characterized by high levels of testosterone, have 10 times the incidence of sleep apnea as do women without the disease

Pregnancy provides some information. Dr. Collop says expectant women tend to

hyperventilate, which indicates that progesterone, which rises dramatically during pregnancy, affects respiration.

And what about those millions of women on Hormone Replacement Therapy, most of whom stopped taking the pills once it was shown that the therapy carried cancer risks that far exceeded its benefits, except for short-term treatment of acute menopausal symptoms?

According to the two scientists interviewed for this article, a couple studies showed that women on HRT were less likely to have sleep apnea. But a large-scale, randomized trial was never performed, and hormones were never prescribed specifically for sleep apnea. And with the current knowledge of HRT's dangers, that's not going to happen.

Nevertheless, the answers, and possibly a therapy, are somewhere in the hormones. “The ideal thing would be to figure out why pre-menopausal women don't get sleep apnea,” says Dr. Collop. “If we knew that, it could lead to a potential therapy for everybody.”

Until that day arrives, the advice for women is the old, familiar refrain: Get tested, get treated, stay compliant.

According to Dr. Young, women in her study cohort who developed OSA and

started using CPAP for it were “unbelievably compliant,” perhaps not surprising in a group so closely monitored. But Dr. Young believes that women in general can be expected to be treatment-compliant, and that the idea that female vanity is a hurdle to CPAP use is an unfounded prejudice.

Dr. Collop is not so sure. “The findings on compliance are inconsistent,” she says. “I think CPAP therapy is difficult for women.

“Snoring is considered masculine,” she continues. As a result, women might be reluctant to acknowledge that they snore, and hesitant to do something about it. Especially when “doing something” means slapping on a mask after you've applied an expensive layer of Vital Youth Crème Serum With Green Tea Extract and Mango Puree.

One final interesting observation about women and sleep apnea. Researchers have found that sleep apnea often first manifests in women exclusively during REM sleep, a phenomenon not observed in men. Then, over time, it presents during other sleep phases. At this point, no one knows what to make of this. It may just be that while men and women are more alike when it comes to sleep apnea than was previously believed, they are still different in mysterious ways. ■

## NEWS FROM WASHINGTON

The American Sleep Apnea Association launched the **Apnea Advocacy Action Program (AAP)** earlier this year as a part of Sleep Apnea Awareness Day 2007. A critical element of the program is the Legislative Action Center, which can be found on the resources page of the association's web site – [www.sleepapnea.org](http://www.sleepapnea.org) – under the tab “advocacy.” Through this online center ASAA members and others can send messages to Congress and Federal Agencies on matters of concern to apnea patients.

The Advocacy Program's first call to action is an appeal to Congress to provide additional funding to the **Centers for Disease Control and Prevention**

(CDC) for data collection on sleep and sleep disorders. Currently the CDC does not gather any information on sleep among Americans. We urge you to visit our web site and express your support of this important research, and to subscribe to the AAP so we can keep you informed of future advocacy efforts.

There is some news to report on the ever-contentious matter of unattended home studies in the diagnosis of sleep apnea. **The Centers for Medicare and Medicaid Services (CMS)** opened a period of public comment on the issue from March 14 to April 14, in response to a formal request by the **American Academy of Otolaryngology – Head and Neck Surgery** that the CMS reconsider their opposition to home studies.

This issue was last visited in 2004, when the CMS held a public hearing to receive testimony about the use of unattended studies. The CMS decided at that time not to reverse their long-standing position against home studies. This decision – from the largest provider of health insurance in the country – influenced the policies of other insurance providers.

Since then there has been considerable discussion on the question of unattended studies, including a letter to the editor from the ASAA that was published in the *Journal of Clinical Sleep Medicine*.

It is possible that the CMS will now reconsider their earlier action and will modify their position. A decision is expected by mid-September. We will continue to follow this and other issues affecting apnea patients. ■

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Enclosed is a check for \$25 (one-year membership). I would like a medical-alert style

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