

# WAKE-UP CALL

FROM THE AMERICAN SLEEP APNEA ASSOCIATION

FALL 2006

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

There was no bull at the September meeting of **Capital District A.W.A.K.E.** in Albany, N.Y., when the topic was "What's Your Beef About CPAP/BiPAP?" The featured speaker (who undoubtedly did more listening than talking) was registered respiratory therapist Ken Plowman. While it may be unusual for an A.W.A.K.E. meeting to be specifically designated as a gripe session, **Mission & South Orange County A.W.A.K.E.** in Mission Viejo, Calif., reports they've found that it's crucial to set aside a block of time to allow people to vent (pun intended).... Michigan's **Charlevoix Area Hospital A.W.A.K.E.** looked west for inspiration for its summer picnic, and found that cowboy hats and bandanas go well with CPAP masks. **Western Pennsylvania A.W.A.K.E.** in Pittsburgh and **Central Ohio Sleep Disorders A.W.A.K.E.** in Columbus also celebrated the season with potluck picnics.... The hot topic as the weather cooled down, addressed by **Fox Valley A.W.A.K.E.** in Appleton, Wis., **Evanston A.W.A.K.E.** in Evanston, Ill., and **Morton Plant Mease A.W.A.K.E.** in Dunedin, Fla., was heated humidification.... **Nashoba Valley A.W.A.K.E.** in Ayer, Mass., held its introductory meeting in May, as did **East Bay A.W.A.K.E.** in Fremont, Calif. And there's a lot going on in Michigan. **Northeast Central Michigan A.W.A.K.E.** launched at multiple sites in July, while **South Central Michigan A.W.A.K.E.-Hillsdale** is taking shape in Jackson.... At long last, there will be an A.W.A.K.E. group in **Washington, D.C.**, headquarters of the Association. And it will be an unusual one – the target membership is adolescents, the oft-overlooked victims of OSA.

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

## A THEORY OF COMPLEXITY Apnea Research Takes a New Twist

You're diagnosed with Obstructive Sleep Apnea, and prescribed CPAP therapy. Needless to say, the treatment takes some getting used to, but you persevere. But even though you're on the mask every night and your spouse reports that your snoring has decreased, you're still dragging during the day. So your doctor decides to ratchet up the pressure, assuring you that it's not unusual to have to do a little tweaking along the way, and that this should do the trick.

But it doesn't; you feel worse than ever. Before you were diagnosed with OSA, you weren't aware of the number of times you awakened. But now you're conscious of how little time you're unconscious. You dread going to bed, knowing that what awaits you is a night of fragmented, restless, unrestful sleep.

You – and perhaps your doctor as well – are mystified. Is it possible that CPAP, the machine that delivers well-being to millions, is backfiring on you?

In a word, yes. According to a recent study at the Mayo Clinic Sleep Disorders Center, in as many as 1 in 7 people with Obstructive Sleep Apnea, the use of CPAP triggers another syndrome, Central Sleep Apnea.

A neurological malfunction in which the brain periodically fails to instruct the body to breathe, CSA syndrome is normally rare, occurring in people who have severe neurodegenerative diseases or congestive heart failure. But for reasons not yet understood, the mechanical introduction of air into the lungs can delude the brain into thinking it can take the night off. The result is that CPAP resolves the obstructive problems, but breathing becomes erratic and irregular. And the patient, predictably, does not improve.

"This phenomenon has been observed for years," according to pulmonologist Timothy Morgenthaler, the lead investigator of the Mayo study. "Patients appear to have Obstructive Sleep Apnea, but when they put on a CPAP machine, they start to look like Central Sleep Apnea Syndrome patients.

"Even with our best treatment," Dr. Morgenthaler continues, "they still have moderate to severe sleep apnea, and subjectively they don't feel that they're doing very well." Though this paradoxical response to CPAP has long been recognized by sleep clinicians, very little was known about its prevalence. To remedy this lack of data, Dr. Morgenthaler and his colleagues conducted a retrospective study of a group of patients at their clinic. The results were published in the September issue of the journal *Sleep*.

The researchers began with a group of 251 people who had come to the clinic for polysomnographic studies in a single month. Of these, 222 had originally been diagnosed with OSA, defined as 5 or more episodes per hour of apnea (cessation of airflow for at least 10 seconds) or hypopnea (decline in airflow for the same duration accompanied by oxygen desaturation), while 1 person had CSA. To achieve a better weighting,

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AMERICAN  
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# A LETTER FROM EXECUTIVE DIRECTOR ED GRANDI



DARRELL PAPER

Welcome to the fall issue of the WAKE-UP CALL. In each edition of our newsletter, we strive to provide information and insight to the members of the

American Sleep Apnea Association. We welcome your reactions and suggestions. Are we covering the topics that are important to you? If not, what would you like to see in these pages?

In addition to communicating with our members in print and on the phone, one of the joys of my job is meeting the people who have made significant

contributions to sleep apnea research and treatment. In late September, I spent time with CPAP inventor Colin Sullivan (profiled in the last issue of the WAKE-UP CALL) at the 8th World Congress on Sleep Apnea. I was struck by the unassuming nature of this man who has had such an impact on the lives of millions. Dr. Sullivan granted me a short interview, which you can hear at [www.apneasupport.org/sullivan.mp3](http://www.apneasupport.org/sullivan.mp3). In August, around the time of the Pro Football Hall of Fame induction of Reggie White, I had the opportunity to meet Sara White, Reggie's widow, and to thank her for all her efforts to raise awareness about the disease that contributed to the death of her husband.

Our mission continues to be education about diagnosis and treatment of sleep apnea, support for those facing challenges in compliance with treatment, and advocacy

on behalf of patients.

Among our greatest assets are our support groups – those that meet in person under the auspices of our A.W.A.K.E. network, and the virtual group that convenes on the Internet at [www.apneasupport.org](http://www.apneasupport.org). I am grateful to the coordinators and moderators who give of their time and talent to organize these groups and keep them going.

If you agree that the work of the American Sleep Apnea Association is important, please consider an end-of-the-year charitable gift. Are you a federal employee? If so, you can include the ASAA in your Combined Federal Campaign donation.

If you are interested in doing more to help secure the future of the association, contact me to discuss how planned giving will ensure that the ASAA will be available to the next generation of apnea patients. ■

## ASK THE DOCTOR

**Q** I use an Auto Set CPAP machine religiously and take Provigil for daytime sleepiness. Why am I still tired? And why is it so difficult to lose weight?

**Joanne M.**  
Rancho Mirage, Calif.

**A** Residual sleepiness in a person with sleep apnea can have several sources. Make sure you are getting enough sleep – 7 to 8 hours every night. Have your equipment checked for proper function and make sure your mask is up to date. Are other things, such as environmental conditions or a partner who snores, disrupting your sleep? In addition, there are primary conditions of sleepiness that may need to be explored. This and your Provigil dose should be discussed with your sleep doctor.

Weight issues and sleep can overlap, but other lifestyle and hormonal factors should also be considered. Are you getting regular aerobic exercise? Are there other health conditions that could contribute to weight gain (e.g., thyroid disease, menopause), or are you on medications that can add weight? These should be reviewed with your primary physician; follow-up with a nutritionist may be helpful.

**Rochelle Goldberg, M.D.**  
King of Prussia, Penn.

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.

**Complex**, continued from p. 1

20 additional patients whose PSG studies were indicative of CSA were added to the study population. After excluding people with heart disease, the researchers were left with a group of 219.

The PSG's the patients had undergone were split-night studies, with a diagnostic phase followed by a CPAP treatment phase, in which the pressure was adjusted upward until the obstructive events were eliminated. If central events emerged, a still higher pressure was applied to see if the apneas would remit. Both REM and non-REM responses were scrutinized.

Reviewing the PSG data, the researchers determined that only 174 of the group suffered from Obstructive Sleep Apnea, while 14 had Central Sleep Apnea. The remaining 31, primarily men, were classified as suffering from Complex Sleep Apnea Syndrome, or CompSAS.

"The patients with CompSAS begin with quite disturbed sleep, with an average AHI of 32.3 per hour.... After CPAP, abnormal respiratory patterns remained, with an average residual AHI of 21.7 per hour, mostly due to residual central apneas in NREM sleep," the study authors write in Sleep, adding that "with such disturbed sleep, CPAP is not ... an adequate treatment modality."

So what would be adequate? That question was beyond the scope of the Mayo analysis, and the paper concludes with the understated comment that "treatment of these patients ... merits additional study." But the article does allude to the work of Harvard sleep physician Robert J. Thomas, who is exploring the use of supplemental oxygen and even carbon dioxide in managing Complex Apnea. Pharmaceutical treatments, including benzodiazepines, may also prove beneficial.

While no simple solution can now be proposed for what is, by definition, a complex problem, patients who suspect they might have this form of sleep apnea need to work with their doctors to optimize their treatment. Autotitrating devices are contraindicated for CompSAS, while newer, sophisticated machines designed to compensate for respiratory control defects show some promise. And when it comes to pressure settings, more isn't better. The goal is to find a level that minimizes obstructive events without precipitating central ones. ■

The Centers for Medicare and Medicaid Services recently recognized Complex Sleep Apnea Syndrome (CompSAS) as a distinct form of sleep apnea.

The sleep field is becoming a crowded place, with more scientists working on more disorders than ever before. Which means that at most medical conferences, only a small number of presentations are devoted to sleep apnea.

The exception is the **World Congress on Sleep Apnea**, which is held at three-year intervals, most recently in September in Montreal. This was the eighth of these conferences, which bring together all the specialties involved in the diagnosis and treatment of sleep apnea – ear, nose, and throat doctors; pulmonologists; neurologists; dentists – for three days of intense interaction.

This year’s congress coincided with two anniversaries, whose importance was recognized by the plenary speeches. The first was the publication 50 years ago of a paper that correlated obesity with “ventilatory insufficiency” and dubbed

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the condition the Pickwickian Syndrome. The name came from Charles Dickens’ book “The Pickwick Papers,” in which there appears a corpulent character, a boy named Joe (a.k.a. Young Dropsy), whose somnolence is so extreme that he falls asleep – and snores – while standing upright.

The centerpiece of the paper, which was published in the American Journal of Medicine, is a case history of a middle-aged man who decided to seek medical help after he fell asleep at a poker game – while holding a full house. Though the paper does not refer to “sleep apnea” – that term was not used until 1975 – it is considered a pivotal development in the identification of the disorder, and was cited by Peretz Lavie, Ph.D., Director of the Lloyd Rigler Sleep Apnea Research Laboratory in

Haifa, Israel, in his opening remarks on the “History of Sleep Apnea Research.”

Another, even more pivotal event, was commemorated in the closing remarks. This was the publication, 25 years ago, of an article in The Lancet entitled “Reversal of Obstructive Sleep Apnoea by Continuous Positive Airway Pressure Applied Through the Nares.” Marking the beginning of modern CPAP treatment, this paper was written by Australian physician Colin Sullivan (profiled in the previous issue of the WAKE-UP CALL), who took the dais to speak on “Nasal CPAP – Its History and 25 Years of Development.”

But all was not nostalgia at the Congress. More than 300 presentations covered aspects of sleep apnea, ranging from the genetic to the metabolic to the acoustic. Such a variety and abundance of material does not lend itself to easy summarization, but sleep physician and ASAA board member David Rapoport, who attended the congress along with association chair Dave Hargett and executive director Edward Grandi, says he walked away with two impressions, one relating to diagnosis and the other to treatment. On the diagnostic front, Dr. Rapoport says that there is “a growing recognition of the need for ambulatory monitoring.” Home sleep studies are a contentious issue, but Dr. Rapoport says he felt a “groundswell” of support for them among the doctors attending the congress.

As for treatment, Dr. Rapoport was struck by the emerging consensus that “sleep apnea is a chronic disease that needs to be managed like other chronic diseases.” In practical terms, this would mean involving registered nurses and other medical personnel in the follow-up care of patients.

The 9th World Congress on Sleep Apnea will be held in 2009 in Seoul, Korea.

For 20 years, the **Associated Professional Sleep Societies**, made up of members of the American Academy of Sleep Medicine and the Sleep Research Society, have gathered annually for four days of scientific presentations, symposia, and preliminary viewings of studies in progress on various aspects of sleep, both healthy and disordered. The ASAA participated as an exhibitor at the 2006 conference, held in Salt Lake City in June.



*British author Charles Dickens created a classic portrayal of sleep apnea in the figure of Joe in “The Pickwick Papers.” The publication of one of the earliest medical papers on the condition, labeled the Pickwickian Syndrome by its authors, was commemorated at the 8th Annual World Congress on Sleep Apnea. The illustration above is by cartoonist Thomas Nast for the American edition of the book, published in 1873. Nast is best known for his drawing of another corpulent character – Santa Claus.*

At it, we spoke directly with sleep doctors and technicians to let them know what the association is doing to educate the public, and provided them with patient education material to distribute in their sleep centers or labs.

The Sleep Societies conference is also the occasion for our annual A.W.A.K.E. Network coordinators meeting. This year, Minneapolis’ Colleen Bazzani spoke to the group about her experience running one of the larger groups in the network.

**The American College of Chest Physicians – Sleep Institute** hosted a two-day conference in early September entitled “Continuity of Care for Obstructive Sleep Apnea Patients.” The meeting brought together representatives from the CPAP manufacturers and home-care companies with sleep physicians and sleep apnea patients. The objective was to develop a consensus document on the proper care of OSA after diagnosis.

Currently, there is confusion about the roles of the primary care physician, sleep physician, and home care company in follow-up care, potentially resulting in a difficult period of adjustment for the patient. The final document is scheduled for publication in CHEST, the monthly journal of the ACCP, in 2007. ■

The ASAA has joined with several other sleep-related organizations to form the **National Sleep Awareness Roundtable (NSART)**. NSART brings together non-profit patient and professional groups with government agencies such as the Centers for Disease Control and Prevention and The National Institutes of Health to raise awareness of sleep disorders and their societal costs.

The roundtable is modeled after the Colorectal Cancer Coalition and the Hepatitis C Roundtable, partnerships that have succeeded in focusing attention and resources on these conditions. A set of articles of organization has been drafted and each participating organization will need

to approve them before becoming a voting member. Plans are to formally announce the new group during National Sleep Awareness Week in early March 2007.

**The Centers for Medicare and Medicaid Services (CMS)** made an important decision that affects the American Sleep Apnea Association membership. Earlier this year, the CMS assigned codes to two dental procedures that utilize oral appliances in the treatment of Obstructive Sleep Apnea. This is the first step in securing insurance coverage, but according to informed sources at an Academy of Dental Sleep Medicine meeting, the establishment of reimbursement value is still many months away.

The second newsworthy item from CMS is the formal recognition of Complex Sleep Apnea [see cover story] as a distinct

type of the disease. Previously, CMS recognized Obstructive Sleep Apnea and Central Sleep Apnea as the only two forms of the disorder for which there is treatment. Complex Sleep Apnea involves both obstructive and central events, and requires a treatment strategy that differs from traditional CPAP therapy.

**The NIH Reform Act of 2006**, passed by the House, is cause for concern in the sleep community. By eliminating funding for each institute, and giving institute directors the authority to eliminate centers, H.R. 6164 could jeopardize the National Center on Sleep Disorders Research, which is not specifically protected by the bill.

The ASAA monitors these issues on behalf of its members and reports on them as information becomes available. ■

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