

# WAKE-UP CALL

FROM THE AMERICAN SLEEP APNEA ASSOCIATION

S U M M E R 2 0 0 5

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

People who run support groups also need support, and they received it in June at the annual **A.W.A.K.E. Coordinators** meeting, held this year in Denver. The meeting brought together 44 current and prospective A.W.A.K.E. group leaders from around the country for a spirited exchange of information.... While they were in Denver for a medical conference, ASAA Executive Director Edward Grandi and Chairman Dave Hargett dropped in on the **St. Anthony Sleep Disorder Center A.W.A.K.E.** group meeting.... The month before, Mr. Grandi was the featured speaker at the meeting of **A.W.A.K.E. North County** in Vista, Calif.... **Elk Grove Village A.W.A.K.E.** group, coordinated by Dave Hargett, is celebrating its 10th anniversary. In May, the Illinois-based group toured a new sleep clinic.... **Carroll Hospital Center A.W.A.K.E.** in Westminster, Md., also had a birthday. It's nine years old.... Speaking of getting older: "Sleep Issues With Aging" was the topic of **Central Costa County A.W.A.K.E.'s** meeting in April. Pulmonary physician Harry J. MacDannald was the speaker for the group, which is based in Walnut Creek, Calif.... Three A.W.A.K.E. groups grappled with the nettlesome subject of health insurance at their spring meetings. **Northern Palm Beaches A.W.A.K.E.** in Jupiter, Fla., had a presentation on "How Medicare and Private Insurance Regulations Affect the Sleep Apnea Patient." **At University Health Systems A.W.A.K.E.** in Greenville, N. C., billing manager Susan

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

## TO CUT OR NOT TO CUT?

**Sleep Apnea Surgery is a Hotly Debated Treatment Modality**

### PRO +

There's only one way that people with obstructive sleep apnea can be cured, not merely treated, and that's through surgery. Properly done, surgery opens up a constricted upper airway and keeps it open, all night, every night.

This is not to say that everybody with sleep apnea should rush to go under the knife. CPAP should be the first-line medical treatment. But the unfortunate reality is that for large numbers of patients, CPAP fails. The data are clear: Outside of a laboratory setting, the majority of people prescribed CPAP are not able to utilize the device properly and consistently over the long term.

The prognosis becomes even worse when you analyze the prevailing standards for CPAP treatment. A person is considered CPAP-compliant if he or she uses the machine 4 hours a night for 5 days a week. Since most people need 7-8 hours of restorative sleep to maintain their physical and emotional well-being, this is

### CON -

Offering upper airway surgery to sleep apnea patients who do not comply with CPAP is like offering cardiac surgery to hypertensive patients who do not take their blood pressure medication regularly.

CPAP is an indisputably safe, effective therapy for people with sleep apnea. Certainly, lack of compliance with the therapy is a significant problem. But the solution to the problem lies in better education and support for CPAP users, not indiscriminate cutting.

Only about 2 percent of people with sleep apnea even have anatomic abnormalities that are amenable to surgery. For the vast majority of patients, surgery is of no benefit, and can even be harmful.

Proponents of the surgical approach tend to downplay the risks and exaggerate the rewards of the procedures they perform. Adverse side effects are relatively common. Meanwhile, the benefits of surgery are largely theoretical, given the lack of well-controlled, long-term studies.

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The text in the position statements above was adapted, in part, from a debate that took place at the conference of the American Thoracic Society. In that debate, the pro-surgery position was presented by **Dr. Nelson Powell**, a nationally known otolaryngologist (ear, nose, and throat physician) who is the co-director of the Stanford University Sleep Disorders and Research Center. **Dr. Barbara Phillips**, a professor at the University of Kentucky College of Medicine and director of the Samaritan Sleep Center, spoke in opposition. The full texts of the doctors' position papers will be published in the September issue of the *Journal of Clinical Sleep Medicine*. To order a copy of the publication, call 708.492.0930.

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AMERICAN  
S L E E P  
A P N E A  
ASSOCIATION

# LETTER FROM THE EXECUTIVE DIRECTOR



ED GRANDI

I have two exciting developments to report in this issue of the WAKE-UP CALL. The first is the American Sleep Apnea Association wristband. Inspired by the Lance

Armstrong and the Susan G. Komen foundations, whose wristbands have been enormously effective at raising awareness of and research funds for cancer, the ASAA decided to introduce

a band of its own. It sports the association's colors — teal and periwinkle — in a tie-dye design. The phrase "Sleep-A.W.A.K.E." is debossed on the outside; on the inside is our web site address. You can view a picture of the wristband, which we are selling for \$2, at [www.sleepapnea.org](http://www.sleepapnea.org).

Our goal is to raise \$50,000 for sleep apnea research from the sale of the wristbands and other designated donations. This amount will be matched by the American Thoracic Society, which will solicit and review research proposals, choose which one to fund, and administer the grant.

I hope all ASAA members will purchase a wristband, and that some of you will consider making an additional gift to help us reach our \$50,000 goal. An order form is enclosed with this newsletter. We ask that you fill it out and send it to our office along with a stamped, self-addressed envelope and a check made payable to the ASAA.

The second development is the establishment of the Apnea Support Forum. Designed by ASAA volunteer Mike Sussman, this virtual support group was launched in June, and logged more than a thousand unique visitors in its first week. It features an online bulletin board and a chat room. In the future, we hope to use the Forum for moderated "Ask the Doctor" discussions. You can link to it through our main web site, or directly at [www.apneasupport.org](http://www.apneasupport.org).

Since my last letter to you, I have spent quite a bit of time on the road, representing the ASAA at the American Thoracic Society conference in San Diego and the Associated Professional Sleep Societies conference in Denver. I want to take this opportunity to stress the importance of our participation at medical conventions. Our booth in the exhibition halls at these events provides us with a space where we can speak directly to physicians and other health professionals — and they can speak directly to us. We give them copies of our educational materials, which they in turn can distribute to patients in their offices. And they let us know if there are issues that we should focus our attention on. These conversations are always productive.

In addition, by sitting in on the scientific sessions, we are able to stay abreast with advances in research and treatment. At the educational sessions of the American Thoracic Society's conference, I heard a fascinating presentation on basic science research into breathing.

Our attendance at some of the conferences is underwritten by special grants from our corporate sponsors. In other instances, we pay our expenses out of the general operating funds of the Association. In other words, your membership dues and donations help get us to these meetings. We are grateful for your ongoing support. ■

## ASK THE DOCTOR

**Q** I have heard that the symptoms of Central Sleep Apnea can resemble Alzheimer's Disease — i.e., someone diagnosed with Alzheimer's may actually have CSA. Is this correct?

Gregg Manazir  
Green Cove Springs, N.C.

**A** Sleep apnea may impair cognition to some extent. However, this impairment is usually in the sub-clinical range. Sleep apnea is not a cause of dementia. Conversely, having a CNS disorder that affects the brain may be associated with an increased likelihood of central apnea. This is the case following strokes. Whether Alzheimer's Disease is a cause of sleep apnea has not been adequately studied. The decision to proceed with a sleep study depends on a bundle of considerations including sleep-related symptoms, daytime symptoms, and other co-morbidities. If there is any concern, I would bring this up to the attention of the physician caring for the patient.

M. Safwan Badr, M.D.  
Harper University Hospital  
Detroit, Mich.

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. ■

*A.W.A.K.E. Continued from p. 1*

Pope discussed "Insurance Issues Surrounding CPAP/Bilevel." And a representative from Provide Medical attended the first meeting of **Northwestern Pennsylvania A.W.A.K.E.** in Seneca.... Another hot topic as summer approached was "Traveling With CPAP." Featured in the spring newsletter, the subject was discussed by **A.W.A.K.E. in the Parish** in Metairie, La.; **Capital District A.W.A.K.E.** in Albany, N.Y.; and **A.W.A.K.E. in Central Pennsylvania** in Hershey.... **Hanover A.W.A.K.E.** in Hanover,

Penn., **Tangipahoa A.W.A.K.E.** in Hammond, La., and **Our Lady of Lourdes Sleep Disorders Center** in Acadiana, La., think we all need to relax. In April, the Hanover group offered a presentation by Kristen Orwick on stress management and relaxation techniques. Tangipahoa's speaker was Nicki Solomito, whose lecture was entitled "Exercise Your Right To Relax." The Acadiana group presented hypnotherapist Rob Rue.... A.W.A.K.E. has gone international. We have our first group in Canada, **BC A.W.A.K.E.** It's in Burnaby, British Columbia. ■

# SLEEP APNEA AWARENESS DAY A ROUSING SUCCESS

Sleep Apnea Awareness Day — a day devoted to increasing recognition of the symptoms of Obstructive Sleep Apnea and the importance of treatment for the condition — took place on March 31. This was the sixth year that the American Sleep Apnea Association has set aside a date for an intensive campaign to reach out to the estimated 16 million Americans who suffer from undiagnosed OSA. But it was the first year that the ASAA has partnered with another organization — the **National Sleep Foundation**, which designated March 28-April 3 as National Sleep Awareness Week — in an effort to more effectively spread the word to the widest possible audience.

By many measures, the campaign, which ran throughout the month of March and culminated on the 31st, was a success. More than 20,000 “snore score” flyers — which provide a simple screening tool for people who may be at risk — were distributed around the country. Traffic on the ASAA web site was up throughout the month, spiking sharply on the 31st. Phone calls to the association increased. And Sleep Apnea Awareness Day received coverage in several regional and national newspapers.

“I was gratified by the level of interest,” says ASAA Executive Director Edward Grandi. “We accomplished much of what we set out to achieve, and have built a strong foundation for future efforts.”

A major achievement of this campaign was the first-ever Sleep Apnea Awareness lecture, co-sponsored by the **American College of Chest Physicians Sleep Institute** and held on March 30 at the Carnegie Institution

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**“We have built a strong foundation for future efforts.”**

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in Washington, D.C. Entitled “Catching Our Breath — Reflections on the Diagnosis and Treatment of Obstructive Sleep Apnea,” the lecture was delivered by sleep specialist Dr. David Rapoport, an associate professor of medicine at New York University and a member of ASAA’s board of directors.

In his 45-minute talk, Dr. Rapoport provided a substantive yet accessible overview of the science of sleep apnea to an audience of patients, physicians,

industry representatives, and others. His presentation was followed by a lively question and answer session in which OSA patients talked about their struggles with the disease and the challenges of treatment.

“It was a lot of fun,” says Linda Duyer, an OSA patient who’d been diagnosed a few months earlier. “Being there with scientists, educators, different people with different backgrounds — I really enjoyed it. And I was quite impressed with Dr. Rapoport. He was so easy to listen to. And it was encouraging to hear that he expects a lot of advancements in the field.”

The event yielded several unintended yet valuable consequences. An encounter between Ms. Duyer and another patient, Mike Sussman, led to the creation of [apneasupport.org](http://apneasupport.org), a virtual support group that the ASAA launched in June. And an actual D.C. group is in development.

Planning for Sleep Apnea Awareness Day 2006 is now underway. Next year, the Association hopes to hold additional events in other parts of the country. If you would be interested in organizing an activity in your area, or if you can help with flyer distribution, please contact our office in Washington. ■

## PRO *Continued from p. 1*

clearly an inadequate level of treatment, with potentially severe consequences.

Given the limitations of CPAP therapy, surgery has a major role to play in the management of sleep apnea. Sadly, there is a perception in the sleep community that surgical procedures for OSA are complicated, risky, and of unproven benefit. This is not the case. About half the patients who undergo the most common operation, the uvulopalatopharyngoplasty (UPPP), will experience a significant improvement in their condition.

However, much better results can be achieved when the UPPP is combined with other procedures. Reconstruction of the entire upper airway — which entails the removal of nasal obstructions and modification

of the tongue in addition to the palate procedure — can lead to a cure in at least 90 percent of cases. (A cure is defined as 20 or fewer apneas per hour, oxygen saturation of 90 percent or better, and resolution of excessive daytime sleepiness.)

As is the case with any surgery, the results are dependent on the surgeon’s experience and skill. And surgery may not be the best option for every patient. But it’s an option that every patient deserves to have. ■

## CON *Continued from p. 1*

In fact, only UPPP has been extensively evaluated, and the data reveal its inadequacy as a treatment. In the short term, UPPP brings about a mean decrease in the Respiratory Disturbance Index (RDI) of 38 percent.

While statistically significant, this so-called “success” leaves patients with a clinically unacceptable level of sleep-disordered breathing. Long-term, the results are even worse, with half of all responders relapsing.

Then too, patients who have undergone surgery and whose breathing is still compromised are much more difficult to manage medically. Their altered palates and uvulas mean they cannot use auto-titrating CPAP devices, and they often require full-face masks and chin straps.

Some day, surgery may offer a real alternative to CPAP therapy. But that day has not yet arrived. ■

In May, the American Sleep Apnea Association was an exhibitor at the annual conference of the **American Thoracic Society (ATS)**, which is celebrating its centennial. Held this year in San Diego, this conference is the premier international forum for physicians and scientists involved in pulmonary medicine. It was attended by more than 14,000 research physicians.

The ASAA is a member of the Thoracic Society's Public Advisory Roundtable, a group of organizations that represent the interests of pulmonary patients. An important role of the Roundtable is to bring the patient perspective to the educational sessions held at the conferences. In

San Diego, the ASAA arranged for Richard Hayes, a participant in the North County A.W.A.K.E. group, to speak to two different assemblies. By sharing his personal experiences with the scientists, Mr. Hayes brought a human dimension to the scientific exchanges.

In June, the ASAA attended the **Associated Professional Sleep Societies** conference in Denver, Colo. This conference brings together the majority of researchers and clinicians in the sleep field. The Association participates as an exhibitor, providing educational material to sleep physicians and allied personnel.

During the conference, the ASAA held a meeting of its Industry Roundtable, the

association's corporate supporters. Each year we invite a scientist involved in sleep apnea research to make a presentation to the Roundtable.

This year, in space donated by Respironics, one of our founding Board members, Dr. Kingman Strohl, gave a talk on sleep apnea and genetics.

The conference is also an opportunity for medical device manufacturers to unveil new products. On display at the exhibit hall was the new ResMed S8 Escape, a very compact CPAP device. Fisher & Paykel presented its new CPAP device, the Sleep Style 600, which employs a heated hose to eliminate the problem of condensation in the tube. ■

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

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**SUMMER 2005**

Published by

The American Sleep Apnea Association

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