

WAKE-UP CALL™

FROM THE AMERICAN SLEEP APNEA ASSOCIATION

FALL 2004

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

Joplin, Missouri. Circleville, Ohio. Decatur, Illinois. These are just a few of the cities that have launched A.W.A.K.E. support groups in the last few months.

Established in 1988 to help alleviate the sense of isolation felt by people struggling with sleep apnea, the A.W.A.K.E. network is a crucial part of ASAA's mission.

Many of the people who contact ASAA's Washington, D.C., headquarters are in search of an A.W.A.K.E. group in their neighborhood. Most often, these are people who have been recently diagnosed with apnea, have embarked on CPAP therapy, and are badly in need of support as they adjust to this new way of life.

With nearly 200 groups across the country, and new ones being formed all the time, ASAA is usually able to direct the callers and e-mailers to a group not too far from their homes. What they find when they attend the first meeting depends on which group they join. All A.W.A.K.E. groups subscribe to certain ASAA guidelines, but their programming varies. Some groups are more social, holding events such as a picnic by the lake; others keep the focus on the medical.

Future newsletters will feature news of the activities of the A.W.A.K.E. network members and announce the locations of new groups. And coming soon to our web site: a search engine that will make it easier for you to find contact information for the A.W.A.K.E. group near you.

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

THE YOUNG AND UNRESTED

OSA Affects Thousands of Children

The primary activity of the brain during the first year of life, sleep plays a complex and crucial role in a child's development, from infancy through adolescence. But all too often, childhood sleep is disrupted, disturbed, and inadequate. And all too often, sleep problems in children — including Obstructive Sleep Apnea (OSA) — go undiagnosed and untreated.

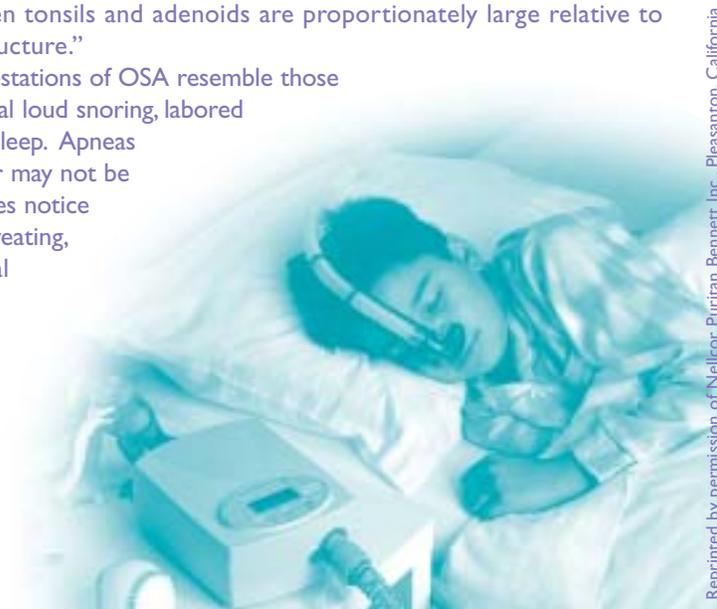
If allowed to persist, sleep difficulties can severely undermine a child's physical and psychological well-being. Writing in "Current Problems in Pediatric and Adolescent Health Care," Drs. Judith A. Owens and Manisha Witmans state: "Mood problems in children with sleep disturbances are virtually universal." But mood is only part of the picture. According to Owens and Witmans, "Higher-level cognitive functions, such as cognitive flexibility and the ability to reason and think abstractly, also appear to be sensitive to the effects of disturbed or insufficient sleep. Finally, health outcomes of inadequate sleep [range from] an increase in accidental injuries [to] potential deleterious effects on the cardiovascular, immune, and various metabolic systems, including glucose metabolism and endocrine function."

OSA is relatively common in the pediatric population, afflicting an estimated 1 to 3 percent of children between the ages of 2 and 18, with boys and girls being equally affected. It can occur at any point in infancy, childhood, or adolescence, but, according to Owens and Witmans, OSA "is most likely to present in children between the ages of 2 and 6, when tonsils and adenoids are proportionately large relative to the airway and facial structure."

The nighttime manifestations of OSA resemble those observed in adults: habitual loud snoring, labored breathing, and disrupted sleep. Apneas (breathing pauses) may or may not be evident. Parents sometimes notice that their children are sweating, or are sleeping in unusual positions. Enuresis (bed-wetting) can also be a presentation of OSA.

Unlike adults, write Owens and Witmans, children with OSA do not typically complain of sleepiness during

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the day, and do not display overtly “sleepy” behaviors such as yawning. More often, pediatric OSA is associated with behavioral manifestations that seem paradoxical, such as increased activity. Other behavioral indicators include emotional lability, anxiety, low frustration tolerance, deficits in cognition and attention, impulsivity, and aggression.

Because these clusters of behaviors are identical to those found in children with Attention Deficit Hyperactivity Disorder (ADHD), Owens and Witmans urge that all children who are experiencing behavioral and academic difficulties be evaluated for sleep disorders. In fact, the doctors recommend that all children be screened for sleep problems, advising pediatricians to make a sleep history part of the routine check-up.

What if the sleep history indicates a problem, in particular a problem with breathing? According to Owens and Witmans, the child suspected of having OSA should be evaluated for growth abnormalities (obesity or failure to thrive), nasal obstruction (hyponasal speech), and mouth breathing. This evaluation is particularly important in the presence of other risk factors for OSA, such as asthma and allergies, gastroesophageal reflux, and a positive family history. To assess the size of the tonsils and the posterior pharynx, an oropharyngeal exam should be performed. The clinician should also search for evidence of secondary cardiovascular complications, such as pulmonary hypertension.

As is the case with adults, the definitive diagnostic tool is the overnight polysomnogram, a technician-supervised, monitored sleep study. With appropriate equipment and a well-trained staff, write Owens and Witmans, polysomnography can be performed on children at all ages and stages of development. However, pediatric polysomnography is not available in all sleep laboratories. Diagnostic alternatives that are currently being explored but not yet in widespread clinical use are abbreviated polysomnography (“nap studies”), oximetry (measurement of the oxygen saturation of the blood), and audio- and videotape recordings.

In otherwise healthy, non-obese children, adenotonsillar hypertrophy is

The American Sleep Apnea Association (ASAA) was an exhibitor at the **Associated Professional Sleep Societies (APSS)** meeting in Philadelphia in early June. Held annually, this is the premier medical meeting for sleep and sleep disorders, attended by more than 5,000 sleep medicine doctors, technologists, researchers, dentists, and industry representatives. We participate in this convention to make sure that the sleep professionals know about ASAA and the ways in which we educate their patients. We were particularly pleased by the number of inquiries about the A.W.A.K.E.

Network and the interest in starting new support groups. We will be following up on these inquiries and will soon see more A.W.A.K.E. groups around the country.

In the exhibit hall, we posted signs at the booths of exhibitors who are members of our Industry Roundtable, recognizing them publicly as financial supporters of the ASAA. The focus of the CPAP manufacturers this year was on new interfaces—masks and nasal inserts—rather than on any major advancement in CPAP devices themselves. There was no major news on the research front about sleep apnea.

the most common contributing factor in OSA, and the first line of treatment is adenotonsillectomy. Removal of the adenoids and tonsils resolves the problem in more than three-quarters of children, resulting in significant objective improvement in neuropsychological measurements of attention, reaction time, and cognitive functioning. Furthermore, the procedure is not infrequently followed

REMOVAL OF THE ADENOIDS AND TONSILS RESOLVES THE PROBLEM IN MORE THAN THREE-QUARTERS OF CHILDREN

by a growth spurt, a further sign of the complex relationship between sleep and development.

For children who are not candidates for surgery, or for those continuing to have breathing difficulties even after surgery, positive airway pressure is a treatment option. Either as CPAP (continuous positive airway pressure) or B-PAP (bilevel positive airway pressure), it has proven effective in a wide range of patients, including infants. Infants using CPAP with a follow-up of 2-4 years have been reported to have less sleep fragmentation and improved daytime behavior.

According to Owens and Witmans, “Positive pressure settings need to be evaluated regularly, since pressure requirements change as children grow and develop. Side effects of positive airway pressure include nasal congestion, rhinorrhea, or dryness, irritation, eye redness from mask leak, skin breakdown and aerophagia. Heated humidification is often added to the circuit to increase patient comfort and has been shown to improve compliance in adults. Mask fit and comfort are crucial factors in determining effectiveness and patient compliance. With the assistance of psychologists and occupational therapists, this treatment has been successfully used even by children with developmental delay.”

Other treatment options include oral uvulopharyngoplasty (UPPP), but this procedure has not been well studied in children, and Owens and Witmans warn that UPPP may worsen the severity of OSA in some pediatric cases. “As for oral appliances,” they write, “concern about their impact on facial growth and development has prevented their widespread use in the pediatric population. However, older adolescents may benefit from this therapy.”

In short, help is available for the more than 300,000 children in the United States who are affected by OSA. And for that, we can all breathe a sigh of relief. ■

ASAA STATEMENT ON INITIAL PATIENT INSTRUCTION ON CPAP

Patients newly diagnosed with sleep apnea whose doctors have recommended pressure therapy have a right to be informed and knowledgeable about the medical device prescribed for them.

The physician — ideally in consultation with the patient — writes a prescription for a particular type of pressure device and interface (mask, tubing, humidification, etc.). Most often, a licensed durable medical equipment supplier fills the prescription. At this point, the patient, who is the consumer, needs instruction on the practical aspects of the specific machine and interface, including maintenance and replacement supplies.

It is crucially important that instruction on the care and use of the prescribed device come from an informed

healthcare provider. The instructor does not necessarily need to be an MD, but must be someone able both to set up the equipment and clearly explain how it is to be used and maintained.

Because of aggressive cost-containment practices, some insurers are arranging for the equipment to be shipped directly to patients, along with a centralized number for them to call to get answers to their questions. Sometimes an instructional video is included in the package.

The ASAA does not support this practice of “drop shipping” CPAP machines. It believes that better patient instruction results in better long-term compliance, which is in the best interest of the patients and the insurers. The cost of such instruction — which should

include information on how to obtain additional information and supplies — is minor compared to the benefits of successful CPAP therapy.

However, recognizing the constraints of the current healthcare system and current practice, the ASAA recommends that in cases where the health insurance does not provide for direct patient instruction on the equipment, the machine should be shipped to the prescribing physician. (Alternatively, the patient should bring the machine to the doctor’s office.) The physician can then verify the fit of the mask, address patient concerns and educational needs, and reinforce the importance of the therapy. The healthcare provider should be reimbursed appropriately for this office visit. ■

FROM THE EXECUTIVE DIRECTOR

“A good night’s sleep.” I did not fully appreciate the meaning of that phrase until I joined the American Sleep Apnea Association (ASAA) as its executive director in May.

After having spoken to and corresponded with many of you over the past few months, I am now acutely aware of what it means to go without a good night’s sleep.

You have told me of the challenges of using the CPAP machine, and of feeling alone in this process. You have also told me of feeling that your life has been given back to you by the CPAP, of having a sense of well-being that you had not felt in a long time.

The goals of the ASAA are education, support, and advocacy. We will continue to educate the general public and the medical community about the symptoms of sleep apnea. We will continue to offer information on treatment options. We will continue to provide support to those with questions and concerns. We will continue to facilitate the A.W.A.K.E. network of support groups, which for many is the key to treatment compliance.

Finally, we will speak up on behalf of those living with sleep apnea. We will work with government and industry to make certain your voices are heard.

This newsletter is one of the ways ASAA will keep you informed of developments in the field. We plan to publish the WAKE-UP CALL four to six times a year. Our website — www.sleepapnea.org — is another source of information. We are currently revising it to make it easier to navigate. Please visit the site and let us know what you think.

For us to achieve our goals, we need your help. By joining ASAA, you make it possible for us to be the unified voice of those with sleep apnea. Your financial support enables us to produce educational bulletins and to be a resource to those who call with questions.

If you haven’t renewed your membership in the association, please consider doing so, to help keep the American Sleep Apnea Association strong. ■



ED GRANDI

PHOTO BY BILL SANDA

ASK THE DOCTOR

Q I have had a snoring problem since I was a child. Is it possible to be a chronic snorer and not have sleep apnea? I believe I do have it (per my husband’s description), and am having a sleep study, but I am curious.

—Lynette Butler, Walnut Grove, Missouri

A Chronic snoring is one symptom of sleep apnea, but not all persons who snore have sleep apnea. We estimate that perhaps 40% of persons who snore may have sleep apnea. Symptoms such as daytime sleepiness, your husband’s observations of pauses in your breathing during sleep, and/or associated factors such as high blood pressure, do make it more likely that you have sleep apnea. If you have these symptoms, having a sleep study to determine if you have apnea is definitely a good idea. Keep in mind, though, that even primary snoring can have a disruptive effect on your sleep and that of your bedpartner!

—Rochelle Goldberg, MD

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.

NEWS FROM WASHINGTON

There are two issues before the **Centers for Medicare and Medical Services (CMS)** of interest to the sleep apnea community.

The CMS is evaluating a request to provide reimbursement for CPAP machines prescribed on the basis of an unattended or home study. Their decision will have an impact on the acceptability of the use of home studies for evaluating the need for treatment of sleep apnea.

The proponents on either side of the argument are very firm in their positions. There are those who argue that only an in-lab study is a thoroughly reliable way to evaluate a patient for sleep apnea and for that reason home studies should not be used.

Others agree that in-lab studies may in fact be "the gold standard" but argue that there are too few labs to accommodate the number of studies that need to be done.

The CMS expects to make a decision in January 2005.

The other issue they are considering is a request from the manufacturers to have CMS assign a unique reimbursement code for the automatic adjusting (APAP) machine.

Unlike the traditional CPAP machine, which provides one fixed continuous pressure within and between breaths, and the bilevel, which delivers one fixed level of pressure for inhalation and another fixed level for exhalation but does not readjust or vary breath to breath, the APAP makes adjustments of pressure continuously based on changing conditions of the patient both within and between breaths.

The American Academy of Sleep Medicine has concluded, based on clinical research, that the APAP is more effective than the CPAP for certain users. The cost of the APAP is significantly higher.

At issue is not whether CMS will cover this type of machine for Medicare patients — it will — but whether participants in other insurance plans will be reimbursed for their APAPs. New medical devices must have a code number in order to be eligible for coverage by private insurers, and CMS is the only entity now authorized to assign such codes.

Previously, coding could be done by the insurance companies themselves, but a provision of the Health Insurance Portability and Availability Act (HIPAA) expressly forbids that practice.

A decision from the CMS is due in October. ■

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