

# WAKE-UP CALL

FROM THE AMERICAN SLEEP APNEA ASSOCIATION

SPRING / SUMMER 2006

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

The end of winter seemed to inspire giddiness in a number of A.W.A.K.E. groups. We received several reports of Spring Flings, but the prize for playfulness goes to **Rockingham Memorial Hospital A.W.A.K.E.**, in Harrisonburg, Va., which offered “Who Wants To Be a Millionaire – the Sleep Edition” at its March meeting.... In April, **UNC Neurology Sleep Support A.W.A.K.E.** in Chapel Hill, N.C., took a look at “What a Sleep Study Shows.” The last issue of the WAKE-UP CALL had a cover story on this topic.... Also in April, **Anderson A.W.A.K.E.**, in Anderson, S.C., had its first meeting.... At the April meeting of **West Metro A.W.A.K.E.** in St. Louis Park, Minn., 169 people heard physician Phillip Rapport speak about the Pillar Procedure, the palate implant from Restore Medical that was written up in the Winter 2005 issue of the newsletter.... In May, ASAA Executive Director Edward Grandi visited **Carroll Hospital Center A.W.A.K.E.** in Westminster, Md., on the occasion of its 10th anniversary. Vajira Gunawardane, medical director of the Advanced Pain Management Center, was the speaker.... The following month, **Augusta Medical Center A.W.A.K.E.**, in Augusta, Va., offered a talk on “Sleeping With Pain” by Douglas DeGood, Ph.D.... **A.W.A.K.E. of Central Kentucky**, in Radcliffe, was the first group we know of to make use of the association’s PowerPoint presentation on “The Importance of Healthy Sleep,” and reports that it got a great response at its March meeting. The presentation is available on request to all meeting coordinators.... The ASAA is considering switching to an electronic format for meeting summaries, and welcomes input from group leaders.

## MEET THE MAN BEHIND THE MASK

### 25 Years Ago, Colin Sullivan Created CPAP

You’re tired, and eager to get into bed and go to sleep. But if you’re a CPAP user, you have more to do than put on your pj’s, brush your teeth, and fluff your pillow. There’s the water level to be checked, the hose connections to be tightened, the head gear and mask to be fiddled with. While you’re fussing with all this equipment, you may well wonder how such a goofy contraption came to be at your bedside. Just whose idea was it, anyway?

Unlike many other inventions, whose origins are shrouded and disputed, it’s easy to answer this question. CPAP was invented by a 35-year-old Australian pulmonologist with a flair for engineering by the name of Colin Sullivan. And it’s even possible to put a date to his breakthrough: April 18, 1981, when a British medical journal, The Lancet, published an article with Dr. Sullivan as the lead author entitled “Reversal of Obstructive Sleep Apnoea by Continuous Positive Airway Pressure Applied Through the Nares.”

The Lancet paper looked at five patients, and modestly concluded that airway pressure was “a useful adjunct to the treatment of this disorder ... well suited to in-hospital management.”

On the occasion of the 25th anniversary of CPAP, the WAKE-UP CALL spoke at length by telephone with Dr. Sullivan (pictured below), still busy tweaking his device at Sydney University, where he serves as a professor of medicine.

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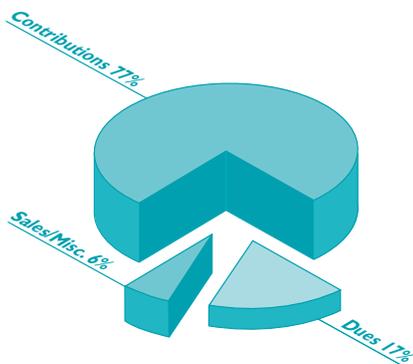
A.W.A.K.E. - ALERT, WELL,  
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# A LETTER FROM EXECUTIVE DIRECTOR ED GRANDI

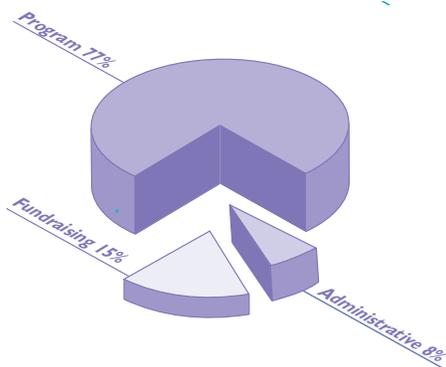
May 1st marked the second anniversary of my appointment as the executive director of the American Sleep Apnea Association. I am heartened by the progress made by the association and energized to do more: More to help those who are not yet diagnosed and more for those facing challenges in treatment.

The membership of the ASAA continues to grow. We gain new members every month and, even more important, many of you choose to stay with us when we send out renewal notices. For this, I sincerely thank you. There is strength in numbers.

## INCOME FY 2005



## EXPENSES FY 2005



I am pleased to report that on March 30, we held our second Sleep Apnea Awareness Day lecture at the Carnegie Institution in Washington, D.C. Our speaker was Timothy Trysla, an attorney with the firm of Alston and Bird. Before joining the law firm, Mr. Trysla was senior policy adviser to the administrator of the Centers for Medicare and Medicaid Services. His lecture, entitled "Sleep Apnea: Cost and Consequences," focused on the role of the federal government in

the treatment of sleep apnea. We were fortunate to have the American College of Chest Physicians – Sleep Institute as a co-sponsor again this year.

In other Sleep Apnea Awareness Day activity, ASAA members and our A.W.A.K.E. network of support groups distributed thousands of snore score flyers around the country.

In this issue of the newsletter, I report on the finances of the American Sleep Apnea Association. Our financial situation improved significantly during the last fiscal year, with the budget growing to \$220,143 from \$148,222 the year before. We increased the revenue to the association by 48.5 percent while increasing administrative and fundraising costs by only 3 percent.

The revenue breaks down as follows: \$169,418 from contributions, which include monies from our corporate sponsors, Combined Federal Campaign gifts, and individual donations; \$36,808 from membership dues; and the balance from the sale of videos and publications. Most noteworthy is the doubling of income from membership dues, thanks to both those who joined and those who rejoined. The expenses were \$171,557 in program, \$17,272 administrative, and \$32,713 fundraising.

A complete copy of our audited financial statement can be seen in the archive section of "About the ASAA" on our web site ([www.sleepapnea.org](http://www.sleepapnea.org)).

April 18, 2006 marked the 25th anniversary of a pivotal moment in the treatment of sleep apnea. On that date, the British medical journal *The Lancet* published an article entitled "Reversal of Obstructive Sleep Apnoea by Continuous Positive Airway Pressure Applied Through the Nares." The lead author of this article – and the creator of the device that many love to hate – was Dr. Colin Sullivan, profiled on the cover page of this newsletter.

A couple of recent developments. First, I have joined the ranks of the bloggers, keeping a web log when I travel on behalf of the ASAA. You can read the entries at [www.sleepapneaed.blogspot.com](http://www.sleepapneaed.blogspot.com). Second, we have entered into an agreement with Alberto Servin, a pulmonologist with an interest in sleep medicine, to translate our patient education

bulletins into Spanish and to oversee *Ayuda en Apnea del Sueño*, a Spanish-language section in [apneasupport.org](http://apneasupport.org), our online support group.

The ASAA will participate in the first-of-its-kind National Patient Sleep Conference the weekend of October 27th at the Hilton Hotel near the Mall of America in Bloomington, Minn. This will be an excellent opportunity to participate in a number of patient education sessions on the spectrum of sleep disorders and sleep health issues. Many of the CPAP manufacturers will be on hand, offering their own educational presentations as well as displays of their latest masks and devices. For registration information, visit [talkaboutsleepp.com/conference](http://talkaboutsleepp.com/conference) or contact me.

You have probably noticed that this issue of the newsletter is a combined spring/summer edition. This was the result of changes we needed to make in our production process, but it also gave us the opportunity to add two pages of editorial content. We hope you enjoy reading the additional material, and look forward to a time when we'll be able to provide you with a six-page WAKE-UP CALL each quarter. ■

## ASK THE DOCTOR

**Q** I would like to ask the doctors if they know whether there is a connection between sleep apnea and cancer.

**Ann P.**  
Dallas, Ga.

**A** If the cancer encroaches on the airway, that would increase the likelihood of obstructive episodes. I do not know of a causal relationship between sleep apnea and cancer. But cancer, like OSA, is strongly associated with obesity, so the two conditions might occur at the same time.

**Kingman Strohl, M.D.**  
Professor of Medicine  
Case Western Reserve University

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.

# SLEEP APNEA AND EMPLOYMENT ISSUES

*I got a shocker yesterday... I was let go from my job as a hotel marketing director. I have severe OSA and over the last few months it's really impacted my ability to function, let alone to be at the top of my game. The brain fog, short-term memory loss, time out of the office for doctors' appointments, mornings dead to the world after near-sleepless sleep studies – they really took a toll. The general manager was doing some reorganizing, and I was an easy target.*

— From a posting by “Mesaboog”

*I was terminated from my job as a correctional officer because I fell asleep on the job. I had put in four requests for a shift change, because I was having trouble adjusting to the graveyard hours I was on. I could not help falling asleep. I was doing all that I could to get on days where I would have functioned better. Any ideas on this? I have put in a grievance.*

— From a posting by “Killarney”

Stories like these appear regularly on the SASAA forum ([www.apneasupport.org](http://www.apneasupport.org)), and are always met with sympathy, outrage, and legal advice. Alas, the sympathy may be more useful than the advice, which however well intentioned is sometimes off the mark.

“A lot of the legal advice people provide on the forum is just not accurate,” says Doug Brown, an attorney concentrating in employment law who is a patient member of the ASAA’s board of directors.

While making it clear that he cannot comment on any particular case, Mr. Brown spoke with the WAKE-UP CALL about the employment rights of people with sleep apnea, which if not successfully treated can have a severe negative impact on job performance, resulting in disciplinary action and sometimes termination.

“People tend to assume that their job is protected because they have a medical condition,” says Mr. Brown. “That’s not

the way it works. It is very important to remember that the existence of a disability does not preclude an employer from requiring an employee to follow work rules, meet safety requirements, and to meet the quantity and quality of work expectations for the position.”

However, it is true that federal – as well as state and sometimes local – legislation exists to protect people with disabilities in the workplace, most notably the federal Americans with Disabilities Act (ADA), which applies to employers with more than 15 employees.

According to Mr. Brown, the ADA legislates that “employers cannot discriminate against an otherwise qualified individual with a disability, on the basis of that disability, if the individual can perform the essential functions of the job.”

But what if the employee needs help to perform these functions? Is an

**Sullivan**, continued from p. 1

“When we were writing the paper,” says Dr. Sullivan, “we had no idea how many people had sleep apnea. At one point after I’d set up my sleep lab in 1979, I thought I’d seen everybody in Sydney who had it. But then another lot would come along.”

While the paper mentions the possibility of long-term treatment, that wasn’t the thrust of Dr. Sullivan’s initial work. At the beginning, he viewed CPAP as a research tool, a way to study the mechanisms of breathing during sleep. Then, as he began to think of it in clinical terms, his focus was on emergency interventions.

“We viewed it as a short-term rescue therapy,” says Dr. Sullivan. “We thought we’d use it to get people better – give them a week’s sleep – and that would give us time to work out a surgical way of treating the problem.”

The patients were the ones who made him see that CPAP could be more than a stopgap on the way to the operating room. In February of 1981, Eddie M., a patient undergoing experimental CPAP who had lost his job because of his inability to stay awake, told Dr. Sullivan that he would love to use the machine at home. So, outfitted with a modified vacuum-cleaner motor and custom-made fiberglass mask glued over his



*The first CPAP machines that Dr. Sullivan manufactured used a 60-watt blower made to power spa baths.*

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“Sleep Apnea: The Phantom of the Night,” Dr. Sullivan writes of the “mirth and contempt” that surrounded the subject. People – especially his medical colleagues – couldn’t believe he was studying something so trivial as *snoring*.

So how did Dr. Sullivan become a pivotal figure in a field that hardly existed at the time?

He was born and raised in Sydney, one of three active brothers who were always doing things with their hands. He thought he would be an engineer when he grew up, probably an aeronautical one, since he loved airplanes.

But through a friend, he became interested in physiology, which he viewed as “engineering of the body.” After receiving his basic medical training, he became a pulmonologist, primarily treating people with asthma and cystic fibrosis.

He went on to do post-graduate work, including a traveling fellowship in Toronto. His primary focus during these years was on what the Aussies call “cot death,” or Sudden Infant Death Syndrome. At the time, the prevailing theory (since discredited) was that SIDS was due to a respiratory failure – essentially a terminal apnea. Still, neither he nor his colleagues looking at

nose with dental adhesive, Mr. M. became the first to use CPAP in his own bed.

“He’s still on it,” says Dr. Sullivan. Eddie M., whose sleep apnea was so severe that his only option seemed to be a tracheostomy, is now 75, retired from his job as the manager of a large corporation, and very healthy.

But when Dr. Sullivan became involved in sleep apnea in 1979 – and for a number of years thereafter – his work was met with derision. In an essay in the book

ADA-covered employer required to provide it? The answer is yes, but with some provisos. According to the language of the act, the needed “accommodation” must be “reasonable” and not pose “an undue hardship” to the employer, taking into consideration “the nature and cost of the accommodation” as well as the “overall financial resources of the facility.”

And most crucially, the employee must be able to function in such a way that he does not “pose a direct threat to the health or safety of other individuals in the workplace.”

“For example,” explains Mr. Brown, “a truck driver with OSA, treated or untreated, who repeatedly falls asleep at the wheel and is involved in traffic accidents, can be fired and cannot claim discrimination.”

In other words, the ADA, oft invoked in online and real-life support groups as providing blanket protection against termination, is more nuanced

than that. And in that nexus of nuances, there is room for interpretation – not to mention litigation.

It’s important to realize that the ADA does not establish which medical conditions are considered disabilities. The 1990 act merely defines a disability as “a physical or mental impairment that substantially limits one or more of the major life activities.” It further qualifies the definition by saying the disabled individual must have “a record of such an impairment” or “be regarded as having such an impairment.”

Is sleep apnea such an impairment? The ADA is silent on this, as it is on all specific medical situations. But according to the Job Accommodation Network, an advice center funded by the Office of Disability Employment Policy of the Department of Labor, “Some people with sleep disorders will have a disability under the ADA and some will not.” The determination is based on the facts of an individual’s medical and employment situation.



In the absence of specific guidelines, the onus is on the individual to prove he is impaired and entitled to legal remedy. This is not easy.

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respiratory mechanisms during sleep, through both animal and human models, thought that sleep apnea was a significant problem for adults.

This is particularly ironic, because Dr. Sullivan now believes that his mother’s premature passing was the result of sleep apnea. As he writes in “Sleep Apnea: Phantom of the Night,” his mother had always been a heavy snorer – so heavy that she slept in a separate room from his father. One morning, Colin Sullivan awakened unusually early, jolted by an unaccustomed silence. He went into his mother’s bedroom, and found her dead.

This was in 1967, when he was a medical student who had never heard of sleep apnea. By the time his Toronto fellowship concluded in 1977, he had done the first sleep study on a patient with OSA. In 1979, back in Sydney, he set up the first Australian sleep lab, working somewhat surreptitiously out of a vacant storeroom at the university. The next year, he organized the first international conference on sleep and breathing.

At that meeting, he was able to view the first endoscopic photographs, taken by sleep pioneers Elliot Weitzman and Christian Guilleminault, of the upper

airway closing during sleep. But like all the other researchers in the emerging field of sleep medicine, he didn’t know exactly what he was seeing. Was the airway simply collapsing? Was it actively contracting? Was something neurological going on? Something mechanical?

While continuing his research into respiratory activity during sleep in animals, normal human subjects, and the handful of seriously ill patients he was trying to treat

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***Neither he nor his  
colleagues thought that  
sleep apnea was a  
significant problem.***

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as well as test, Dr. Sullivan pondered these questions. And then the eureka moment: Perhaps he could hold the airway open by applying pressure through it.

He had a volunteer eager to test this idea: a construction worker who had fallen asleep on a job’s scaffolding who was scheduled for a tracheostomy.

Dr. Sullivan jerry-rigged a blower, some hoses, and a mask, and cranked it up. “I’ll never forget,” he recalls. “As I turned up the pressure, he suddenly went into REM sleep. It was amazing.”

By 1985, Dr. Sullivan had 100 patients on custom-made CPAP devices. And then, over the next few years, as the devices began to be manufactured commercially, he stopped counting.

These days, he’s working on a number of fronts, many of them involving babies. He’s involved in fetal sleep studies. He’s investigating using low levels of CPAP on pregnant women, both for their health and the health of their unborn children. He’s created masks that can be worn by infants with sleep apnea, and is applying that miniaturization technology to the development of less cumbersome devices for adults. He’s advocating for the identification of at-risk children, so they can receive orthodontic interventions that will improve their upper airway functioning and stave off adult apnea.

But he’s no longer pulling all-nighters, trying to get sleep apnea recognized as a serious medical problem. That work has been done, and he’s entitled to some sleep. And yes, he has started to snore. ■

# THE ACHE THAT DOESN'T END

## Fibromyalgia: A Mysterious Ailment That Afflicts Millions

Just because you have sleep apnea doesn't mean that you're immune to other sleep disorders. Someone with Obstructive Sleep Apnea (OSA) can also suffer from primary insomnia, restless legs syndrome, or any number of sleep disturbances. In fact, it may well be that having one sleep problem makes you more likely to have another, though the research on this is still preliminary.

In this article, the first of an occasional series in the WAKE-UP CALL about conditions characterized by disordered sleep, we take a look at fibromyalgia. Our source for this information is sleep physician Rochelle Goldberg, president of the American Sleep Apnea Association.

Characterized by muscle pain and fatigue, fibromyalgia afflicts an estimated 7-10 million Americans, primarily women. It is associated with fragmented and non-restorative sleep, and some researchers and clinicians believe that sleep disturbance is a key feature of the syndrome. In sleep studies, absence of deep sleep and an alpha-delta pattern in the brain waves are common.

Poor sleep, however, is not diagnostic of fibromyalgia. According to the 1990 American College of Rheumatology, the two diagnostic criteria are 1) a history of body-wide pain for at least three months and 2) the presence of pain in 11 of 18 points on physical examination. The pain is from the muscles, not the joints, which distinguishes it from arthritis, and often emerges during repetitive movement.

"Fibrositis" was first described in the beginning of the last century, but it was not until 1981 that the term "primary fibromyalgia" came into use. In the 1970s, sleep researcher Harvey Moldofsky, M.D., discovered that people deprived of stage-4 sleep (deep sleep) have tender points. Two years later Hugh Smythe, M.D., reported on tender points in his fibrositis patients, the same as those found by Moldofsky.

Other commonly associated symptoms are anxiety and depression. People who suffer from fibromyalgia also frequently complain of tension headaches or migraines, irritable bowel syndrome, irritable bladder, and premenstrual syndrome. Symptoms are generally subtle at first, but worsen over time. They may be

present for many years, often starting in the 20s-30s, before a diagnosis is made. There is no blood test or X-ray that confirms the condition.

The goal of fibromyalgia treatment is lessened muscular pain, reduced fatigue, and enhanced sleep. To achieve it, a combination of medications may be used, including antidepressants, benzodiazepines (e.g., clonazepam), muscle relaxants (e.g., cyclobenzaprine), analgesics, anti-inflammatory medications, and even anti-epileptic medications.

Some of the pharmacological treatments are thought to be effective because they help stabilize sleep. Other medications, including gaba-hydroxybutyrate — an agent approved for treatment of narcolepsy — are currently under investigation. Injections of numbing medications in the tender points can also be helpful.

If you suspect that you have fibromyalgia, you should seek out a doctor, typically a rheumatologist, with experience in treating the disorder. Further information is available on the National Fibromyalgia Research Association website ([www.nfra.net](http://www.nfra.net)). ■



**Employment**, continued from p. 4

"The courts generally put a pretty strong burden on an individual to show that he is protected," says Mr. Brown.

In addition to the ADA, the other important federal law is the Family and Medical Leave Act (FMLA), which entitles people with serious health conditions to up to 12 weeks of unpaid leave. But like the ADA, the FMLA is not universal.

"It only applies to employers who have 50 or more employees within a 75 mile circle," says Mr. Brown. "And it only applies to individuals who have worked for the employer for at least a year and have worked more than 1,250 hours in the prior 12 months."

So what does all this mean for people with sleep apnea?

First and foremost, to invoke the protection of the ADA, or claim the FMLA benefit, you have to let your employer know of your medical situation. If you don't inform your employer — and there could be good reasons why you would choose not to — you cannot later claim discrimination on the basis of a disability.

If you do opt to reveal your condition to your employer, perhaps in order to request an accommodation such as a modified work schedule, be aware of the limitations of the protections available to you. But also be aware of the many resources available to you if you believe you are being unlawfully discriminated against.

These include the Equal Employment Opportunity Commission (EEOC), which enforces the ADA regulations. The website [www.eeoc.gov/](http://www.eeoc.gov/) provides information on contacting the local EEOC office and on filing a charge. Information about the FMLA is available from the Wage-Hour Division of the U.S. Department of Labor's website at [www.dol.gov/esa/whd/fmla/index.htm](http://www.dol.gov/esa/whd/fmla/index.htm).

Most states also have civil rights commissions that will pursue complaints of discrimination. If you feel you need to hire an attorney, your local bar association can probably refer you to someone who specializes in employment law.

But the best advice that we can give you here is not legal, but medical. If you have sleep apnea, get treatment. If the treatment isn't working well, get better treatment. Yes, it can be a challenge, but it's a piece of cake compared to litigating over a lost job. ■

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 putting these conditions on the map.

The American Sleep Apnea Association collaborated with the **Living Heart Foundation (LHF)** in a series of health screening events in the week before

the Super Bowl, played in Detroit in February. We distributed copies of our educational materials at several venues in and around the city. The first was a community health fair held in the new downtown YMCA, at which residents could pick up a broad range of information about heart-health, diabetes, and sleep apnea.

We also visited a charter school established by the Detroit Lions, where we spoke with teenagers and gave them valuable information that they could share with their parents. Finally, we were a resource at the sports medicine clinic of the Henry Ford Hospital, where, over two days, 50 retired NFL football players received a cardiovascular health screening.

In mid-March, ASAA's Edward Grandi attended the second **Pediatric Sleep Medicine Conference**, held on Amelia

Island Plantation in Florida. This two-day meeting, which brought together more than 50 physicians and other health professionals who treat the broad range of sleep disorders in children, was an opportunity to learn about developments in this rapidly growing field.

On the first day, there was a very interesting talk about the connection between Attention Deficit Hyperactivity Disorder (ADHD) and Periodic Limb Movement Disorder (PLMD) in children. The second day of the meeting brought together those sleep specialists who are specifically interested in treating pediatric sleep apnea. This discussion, led by Dr. Christian Guilleminault from Stanford University, resulted in a set of treatment recommendations that were reported to the larger assembly. ■

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Bracelet       Necklace

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**SPRING/SUMMER 2006**

Published by

The American Sleep Apnea Association

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