

WAKE-UP CALL

FROM THE AMERICAN SLEEP APNEA ASSOCIATION

FALL 2005

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

The **North East Polysomnograph Society** invited ASAA Director Edward Grandi to its annual summer meeting, where he participated in a panel on forming support groups using A.W.A.K.E. Network guidelines. Moderated by sleep technician Theresa Shumard, the panel presented a packed house of current and prospective A.W.A.K.E. coordinators with information on how to form and fund a group, and strategies for having good meetings.... The prize for best title for a meeting goes to **Northern Michigan Hospital Sleep Center A.W.A.K.E.** in Petoskey, Mich., which in August heard “The Buzz on Caffeine” from nurse Trudy Day.... A close runner-up is **Northwest New Jersey A.W.A.K.E.**, in Dover, N.J., which tackled the question “Who Is That Masked (Wo)Man?” at a spring meeting.... Another Michigan group, **A.W.A.K.E. of Charlevoix**, held its first meeting in July, with a presentation on diet and exercise.... The members of **RMH A.W.A.K.E.** in Harrisonburg, Va., exercised their wits at their July meeting by playing Sleep Triv-O-Fortune, a game that tested their knowledge of sleep disorders and sleep hygiene.... At the June meeting of **A.W.A.K.E. of Macon County** in Decatur, Ill., Terence R. Woods, M.D., spoke on “Surgery for Sleep Apnea.” The summer issue of the WAKE-UP CALL featured a debate on this controversial subject.... To find the **A.W.A.K.E.** group closest to you, visit www.sleepapnea.org.

NOT IN THE MOOD?

Believe It Or Not, Your CPAP Can Help

How’s your love life? It’s not a question you’re likely to hear from your doctor, either when you’re first diagnosed with sleep apnea or after you’re in treatment, when your adjustment to CPAP might well involve concerns about how to deal with this third party—or party spoiler—in your bed.

Even in the supportive environment of an A.W.A.K.E. group, or in the anonymity of the ASAA’s online bulletin board, people are likely to be hesitant to discuss the sexual ramifications of their condition and treatment.

But an enterprising nurse from the University of Pennsylvania has brought some much-needed light into the bedrooms of people with sleep apnea. And her findings should be encouraging to everyone with the condition, and to their partners.

Terri Weaver, a Ph.D. in nursing at Penn who specializes in sleep apnea research, was the designer and principal investigator of a seven-center study into the connection between OSA and sexuality. Working with a group of 148 untreated OSA patients, Dr. Weaver and her team of researchers looked at how sleepiness and lack of energy affected their sexual relations. The group was then reexamined after three months of CPAP use.

The researchers asked the OSA patients—and a control group of people with no known sleep disorders—how sleepiness or tiredness affected three

aspects of their sexuality: desire, becoming aroused, and achieving orgasm. Among the OSA patients, all three aspects were impaired, with the worst results found among those with the worst OSA.

“When we looked at aspects of daily function that could be affected by sleepiness or tiredness, we found that all

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



AMERICAN
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LETTER FROM THE EXECUTIVE DIRECTOR



ILLUSTRATION

ED GRANDI

Since the last newsletter was distributed, there has been a lot of activity at the association. Between our research fund campaign, dealing with state and federal agencies on issues of concern to our constituency, and planning for Sleep Apnea Day 2006, our small office has been bustling. Here are highlights of what we've been doing.

As announced in the summer WAKE-UP CALL, we have launched a campaign to raise \$50,000 for our Sleep Apnea Research Fund, a sum that will be matched by the American Thoracic Society, the organization that will select and administer the two-year grant. We anticipate that the project we fund will be a pilot study that will get future support from the National Institutes of Health.

So far, we have raised \$4,000, most of which has come from the sale of 1,200 SLEEP-A.W.A.K.E. wristbands. You can buy a wristband—and help advance research into sleep apnea—for \$2. We have plenty of wristbands available, so please consider purchasing several to hand out over the holidays. Memorial donations and contributions we receive from United Way campaigns also go into the research fund.

The ASAA tries to be the definitive source of information on all issues concerning sleep apnea, and in light of the summer WAKE-UP CALL's cover story on traveling with CPAP, we were concerned when we heard that baggage screeners were preventing people from carrying their machines onto planes.

We contacted the Transportation Security Administration (TSA) and found that in fact there has been a change in the rules: Airlines can

require that medical devices, formerly exempt from carry-on restrictions, be checked if an opaque component shows up on the X-ray. The ASAA is working to get this policy reversed, but in the meantime, travelers need to beware.

After a Missouri newspaper reported that Medicaid recipients in the state would not be covered for CPAP treatment after the first of September, I contacted the Division of Medical Services (DMS), which oversees the Medicaid program. DMS informed me that the report was not correct.

Missourians currently on Medicaid (and CPAP) have until November 1 to have their physician complete a medical exception form indicating that the CPAP is necessary to prevent the need for a higher level of care, and all new participants will be required to furnish this form at the time the request for the device is submitted.

March 30, 2006 is Sleep Apnea Awareness Day. We are working to make it bigger and better than it was last year. We are planning events in Washington, D.C.; the Chicago area; and possibly in southern California. If you are interested in helping with the planning, please let me know.

As a part of the lead-up to these events, we would like to get proclamations from cities, counties, and states/provinces in the United States and Canada designating Thursday, March 30, 2006 as Sleep Apnea Awareness Day. A copy of the proclamations and the names of those who helped secure them will be added to our web site. Please let me know if you can help with this part of the project.

If you have not visited the Apnea Support Forum (www.apneasupport.org), you should. The Forum is becoming the international gathering place for patients to exchange information.

A very big thank-you goes to the people who serve as moderators of the Forum. Linda, Liz, Dave, Mike, and Vicki have contributed countless hours to make sure visitors to the message board and weekly chats feel welcomed and supported.

Your financial support makes it possible to do all that we do. As you plan your year-end giving, please remember the American Sleep Apnea Association. ■

A COMMUNITY SERVICE ANNOUNCEMENT

Adult Men and Women Who Have Or Exhibit Symptoms of Sleep Apnea Are Needed for a Research Study

Do you snore? Are you tired or fatigued? If so, you may be eligible to participate in a research study examining the effectiveness of a treatment for Sleep Apnea. Participation lasts 7–9 months and includes 2 training sessions, 4–5 overnight sleep studies, 3 days of testing, and 2 meetings with a physician.

If interested, please call the study staff at:

St. Lukes Hospital, Chesterfield, Missouri
(314) 205-6026

Brigham and Women's Hospital, Boston, Massachusetts
(617) 527 3501 ext. 146

St. Mary Medical Center, Walla Walla, Washington
(509) 522-5845

University of Arizona, Tucson, Arizona
(520) 626-7104

Stanford University, Palo Alto, California
(650) 736-8871

HOW'S YOUR LOVE LIFE?

One Couple's Experience

After 25 years of marriage you get to know the sleeping patterns of your spouse pretty well. Me, I'm a light sleeper and an early riser. My wife is just the opposite. In fact, she sleeps so soundly she didn't even notice my snoring back before I got my CPAP machine 18 months ago.

At first, the machine was intimidating. It took several days to understand how to work it. It took several weeks to get comfortable with the mask and hoses. This transition period did not leave a lot of time for or interest in intimate moments at bedtime.

I was nervous at first about whether or not the equipment would get in the way. It didn't. The mask is easy to remove and the machine is on the nightstand and within arm's reach to turn off.

Since I normally go to bed by 10 p.m. and my wife usually goes by midnight, either I have to stay up late or she has to go to bed early for us to share an intimate moment. All I can say is that since I started treatment I stay up late more times than I used to.

"I was nervous at first"

When I asked my wife if she had noticed this change she said she had, and was happy with it. She also said that since CPAP treatment I'm less tired and cranky and more fun to be with.

My wife and I easily agree that things are better in the bedroom than they were before CPAP.

— Rich Scheer

Continued from p. 1

were impaired in untreated OSA," says Dr. Weaver. "This includes intimate and sexual relationships. The more severe the OSA, the more they were affected.

"We looked for other factors that might be related to these results, but no others could be identified," adds Dr. Weaver. "Neither marital status, nor gender, race, or blood oxygen level during sleep. Only participants' rating of their sleepiness was significantly related."

"What we have shown here is that use of CPAP actually improves sexual relationships."

Following three months of CPAP treatment, the OSA patients were less sleepy and reported improvements in the three study areas—desire, arousal, and orgasm—and in overall sexuality, though they did not quite reach the level of the control group. Those with the most severe OSA made the greatest gains.

The improvement was related to the level of CPAP compliance. More than two-thirds of those who used the machine 6–7 hours a night indicated that they no longer had sexual problems.

Among people who used it for less than 2 hours a night, only about a third reported that their sexual functioning was normalized.

According to Dr. Judith Reishtein, a nurse researcher in the Center for Sleep and Respiratory Neurobiology at the University of Pennsylvania who assisted in the analysis of this study, "It is not surprising that the sleepiness and tiredness brought on by OSA interfere with intimacy.

"However, many people think the cure is as bad as the disease, that using CPAP would interfere with their ability to be intimate," she adds. "What we have shown here is that use of CPAP actually improves sexual relationships."

So...here's one more reason to wear your CPAP. All night (okay, you can take it off to have sex), every night. ■

ASK THE DOCTOR

Q I am a counselor working in addiction recovery and believe our patients have a higher than average incidence of sleep apnea. Have there been any studies into this connection?

Mary McCusker, M.Ed.

Faulkner Hospital
Jamaica Plain, Mass

A We see significant numbers of recovering drug addicts at our sleep disorders center, and I agree with your impression that the incidence of OSA is high. Two factors may be involved: the weight gain that is common during rehab and the fact that OSA occurs with greater frequency among African-Americans. It's also possible that the OSA is a side effect of certain prescription drugs, such as methadone and sleeping pills.

As for alcohol addiction, I know of no increase in the incidence of OSA after withdrawal. Alcohol itself greatly increases apnea, but only while the person is intoxicated.

David M. Rapoport, M.D.

Director of Research,
Sleep Disorders Center,
NYU School of Medicine

Q I have been using a CPAP machine for 10 months. During that time I have had three cases of bronchitis and have a constant feeling of heaviness in my chest. Prior to using the CPAP machine I might have had bronchitis two or three times in my life. Are there any reported cases of chest infection or similar problems?

Ray Cranston

Anaheim, California

A One possibility is that the CPAP is causing rhinitis and sinus infection and this may be causing a resultant bronchitis. If this is the case, heated humidification should help. And it's important to let the mask, tubing, and humidifier dry between uses, or they can be a source of problems.

Kathe G. Henke, Ph.D.

Sleep Disorders Center
of Virginia

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.

MY BROTHER ROBERT'S STORY

My younger brother Robert was treated in one form or fashion for sleep apnea over the last decade. He had UPPP surgery and nose surgery, which did little to reduce the problem. He used CPAP and BiPAP at different times. Most recently he used CPAP. He and I have been treated by use of machines for some time. I use BiPAP now and have been treated since 1987.

Both Robert and I have battled overweight and Robert was doing a great job of keeping his weight in check. In October of last year Robert had his knee replaced and did well with that recovery. He was released in late November from treatment.

In January Robert traveled to Las Vegas to work the National Consumer Electronics Show. This show keeps sales people running from morning to night and I think he was exhausted by the last day of the show.

On Saturday morning, January 8, 2005, his boss called and got no answer at his room. He sent another salesman to check on Robert. When they arrived Robert was non-responsive and CPR was started. He was treated and transported to a local hospital. He did not respond to the efforts and was pronounced dead. He was 47 years old.

We had an autopsy done by his home state examiner. They concluded that

Robert did not have a blood clot, did not overdose on pain pills, and did not have too much to drink. He just failed to use his machine when he went to bed. The final conclusion by his family doctor and the examiner was that he died because he didn't use his machine.

I'm convinced that if he had worn his machine I would not be telling this story now. So take heed, follow your treatment orders, use your machine and follow up with your doctor when needed.

Robert was a great man and a wonderful brother. I will miss him. Don't let this happen to someone you love.

—David Odell, Columbia, S.C.

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I'd like to be enrolled as a member of the ASAA, and receive a subscription to the WAKE-UP CALL.

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

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I'd like to enroll my friend/family member in the ASAA and subscribe him/her to the WAKE-UP CALL.

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Mail this form with your check made payable to **The American Sleep Apnea Association**
ASAA, 1424 K St. NW, Suite 302, Washington, DC 20005

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