WAKE-UP CALL

FROM THE AMERICAN SLEEP APNEA ASSOCIATION

CELEBRATING OUR 20TH YEAR — WINTER 2010

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

The perennial topic of what's available in CPAP masks and how to use them continues to attract the attention of A.W.A.K.E. groups around the country. As winter approached, **Two Virginias A.W.A.K.E.**, Bluefield, WV, found a new approach to an old theme. Physician assistant Jennifer Riffe spoke to the group in November on "Coping with cold, flu, and pneumonia with CPAP usage."

"Sleepy Tule" A.W.A.K.E., Tulare, CA, nixed a move to change the group's name at its November meeting. "Tule" is a reference both to the Tule Indians of California's Great Central Valley, and to the Tule fog that rolls in to shroud much of the valley most winters.

Dr. Fred Silver, a psychologist, spoke to **South Tahoma A.W.A.K.E.**, Lakewood, WA, about cognitive behavioral therapy at the group's November meeting. The topic stirred notable interest, reported organizer Sally Jones.

Carroll Hospital Center A.W.A.K.E., Westminster, MD, pursued a similar theme in November with a talk by nurse Melissa Murdock on using guided imagery for relaxation. Tinia Byers, the network director, reported that the session attracted more men than women and that most of them "were very into the session."

As the new year began, **Central Ohio Sleep Disorders Support Group**, Columbus, OH, bade farewell to Karen Hedden who has helped organize the group's meetings at Riverside Sleep Diagnostic Center for many years. Hedden has transferred to the hospital's obstetrics/gynecology department. In its newsletter the group also noted that Riverside Hospital accepts donations of used CPAP and BIPAP machines for distribution to sleep apnea patients who lack health insurance. Other A.W.A.K.E.groups might want to look into developing similar donation programs.

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

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It's 2010, and the ASAA turns 20!

The In those early days, "apnea" was a word unknown

Frank Adams has a vivid recollection of the first time he heard the word "apnea." As he tells the story, one day in the early 1980s he and his wife Margaret, then resident in Brookline, MA, were listening to Susan Stamberg of National Public Radio as she interviewed a physician expert in sleep disorders.

"Apnea victims," said the doctor, tended to be chronically drowsy, to experience severe morning headaches, to find it difficult to stay awake, and to snore loudly enough to disturb their bed partners. Margaret and Frank looked at each other, and she said, "That's you!"

Stressing the human touch put a face on the moon in this early logo of the ASAA.

There were some startling twists and turns in the path that led from that chance acquisition of new information about a nagging physical problem to Frank Adams's becoming one of the founders of the American Sleep Apnea Association. The ASAA was brought into being 20 years ago this year.

From the outset, Adams promoted a patient-driven, patient-controlled organization. That style of operation, in which physicians and other health care professionals work shoulder to shoulder alongside sleep apnea patients and their advocates, remains in place to this day. It distinguishes the ASAA from many of the other organizations that alert the public to the challenges of specific illnesses.

The formal organization of the American Sleep Apnea Association occurred in Washington, DC, May 20, 1990, as 16 men and women were elected to the ASAA board of directors and the association's bylaws were reviewed and adopted. Four physicians were elected the officers: Paul Suratt, president; John Remmers, vice president; David P. White, secretary; and Philip Smith, treasurer.

Adams was elected to the board and to the executive committee. Subsequently, the surviving record does not indicate precisely when, he became first chair of the ASAA board, a post that first custom and now the bylaws reserve for a patient-representative member of the board.

Two planning meetings had preceded the formal launch. Minutes of the later of the two, held two months before the founding meeting, make it clear that the planners were moving in the direction of creating a patient advocacy and support organization. One key participant in the meeting was Lucy Seger, the founder of the A.W.A.K.E. Network, which had been launched five years earlier in Pittsburgh, PA. By then the network had grown to 47 groups. Seger, who worked at the time for the University of Pittsburgh Medical Center, said in a recent interview that she and a colleague, Joyce Black, led and promoted the network as volunteers.

"As it grew, it got to the point I couldn't do it anymore, even with Joyce's help," she said. A.W.A.K.E. needed a sponsoring organization and Seger hoped the nascent ASAA might be it. Her hope bore fruit.

Central, *continued on p. 3*

A Letter from Executive Director Edward Grandi

Late last fall I found myself hobnobbing with folks who spell the disease "apnoea." That is to say, I was participating in the annual patient meeting of our British counterpart, the Sleep Apnoea Trust Association. SATA, which was founded some years after the ASAA, works in areas parallel to ours: education, support and advocacy.

The gathering I attended was SATA's 15th meeting. We convened in a classroom building of John Radcliffe Hospital, Oxford University's main teaching hospital. The meeting draws around 300 people annually.

I found the meeting similar to one of our A.W.A.K.E. group meetings. It included a lecture session conducted by their medical liaison, the noted British sleep physician Prof. John Stradling, and his staff; support group discussions called "chat shops"; and an equipment fair.

I had learned of SATA soon after joining the ASAA through the organization's newsletter, which we receive. I struck up an e-mail correspondence with one of their board members and suggested I attend their annual meeting as a way of building a stronger bond between our two groups. I was pleasantly surprised to receive not only an invitation to attend but also an invitation to speak. My talk was headlined in their program as "OSA in the USA."

My brief presentation gave the audience, more than 200 people seated in an old-style lecture hall with rows of seats climbing to the ceiling, a sense of the difference between Britain and United States in the way sleep apnea is diagnosed and treated. A summary of my talk is available at www.sleepapneaed.blogspot.com under the heading "When was the last time someone called something you did brilliant?"

Many came up to me during the buffet lunch to say my talk was brilliant. Since this was the first time a representative from the U.S. group had attended their meeting, many also shared comments about family they have in the United States and the political situation here.

Prior to the meeting I was the guest of SATA's chairman Frank Govan and his wife Wilma. Also joining us was the chair of the Scottish Association of Sleep Apnoea, Jean Gall. My visit with them was an opportunity for us to discuss areas where our organizations could work together on issues affecting apnea patients on both sides of the Atlantic. We agreed to stay in touch and to find opportunities to cooperate where we could for the benefit of all.

—Edward Grandi

Central, *continued from p. 1*

Also present at the March planning meeting was Al MacLean, president of the Sleep Apnea Association of Alberta, who described how his organization based in the Canadian prairie province had moved from having an all-lay board to a board that was a mix of lay people and health professionals. Their goal was to promote awareness of sleep apnea and share information about how best to treat it.

At a time like the present, when sleep apnea is finally entering the general public consciousness as a serious health problem and people's lives can be extended and improved by its diagnosis and appropriate treatment, it is difficult to imagine an era when the disease was little known and its most effective treatment was uncertain. That's the era in which Frank Adams learned his problem had a name, the era in which the ASAA was born.

The first CPAP device was developed in 1981 by Prof. Colin Sullivan at Royal Prince Albert Hospital in Sydney, Australia, but two or three years later vigorous discussion continued in the United States as to which kind of medical specialists should treat obstructive sleep apnea. Pulmonologists, ear-nose-throat doctors, even psychiatrists (some of whom felt they had discovered the disease) were in contention, as Adams recalls it.

> *In those first days, "apnea" was a word unknown*

Adams ended up in the hands of an ENT specialist who recommended surgical removal of his uvula and all the fatty tissue in his throat. To his later regret, Adams agreed to the procedure. His decision culminated in a five-hour operation in 1984.that left Adams with a tracheostomy. He opened the trache at night for sleep, corked it closed in the daytime so he could speak. With high hopes Adams reported for his first sleep study after the surgery. The report was a shock During sleep, he was told, he'd suffered more apneic episodes than he had before the operation.

The operation and the subsequent sleep study had occurred in Norfolk, Va. "I started driving home to Massachusetts," Adams recalled. "The farther I got toward home, the more furious I got. 'Surely this can't be true,' I said to myself." Unfortunately it was.

But then Adams met Dr. J. Woodrow Weiss, at that time and now a pulmonologist on the faculty of Harvard Medical School and on the staff of Boston's Beth Israel Deaconess Hospital. Seven months after Adams's drastic operation, Weiss recommended letting the tracheostomy close and prescribed a CPAP machine. A quarter-century later Adams now lives in retirement in Asheville, N.C., and continues to sing praises of Weiss and to sleep every night—soundly—with his CPAP machine humming in operation.

He can laugh—a little—about the wrong road he took when he first sought treatment for his OSA. "On one of my trips to the dentist after my surgery," he recalls, "the guy took one look down my throat and commented, 'My, that's quite a piece of engineering youve got there.'"

More seriously, he was and is convinced that patients need the best information to make the best choices. "I was impatient with the idea of an information-dispensing organization that was dominated by doctors and medical equipment makers," he says, as he underscores his belief in a patient-led organization.

Effective A.W.A.K.E. groups, with strong leadership by patients, were key to amplifying the voice of patients in the ASAA as the organization built its programs, Adams recalled. He said he and his allies put considerable effort in launching a newsletter aimed patients and commissioning a design for it that was eye-catching and wouldn't be overlooked. Lucy Seger, the A.W.A.K.E. network founder, was relentless in her defense of patients' needs, he added.

In pursuit of his vision, Adams says, he found an ally in Woodrow Weiss. Like Adams, Weiss took a seat on the ASAA board of directors when the association was created. Subsequently Weiss served as ASAA president. ■

At the ASAA golf tournament: from left, Oscar Chavez, Roberto Morales, and Sam Remine.

Truckers, regulators, docs to meet on apnea

In May, the American Sleep Apnea Association will conduct the first-ever national conference on sleep apnea and trucking.

NEWS FROM

WASHINGTON

By its very nature, sleep apnea among vehicle operators is a major health and safety concern for the entire transportation industry, but it's a matter of particular urgency among long-haul truckers. One study suggests that as many as 28 percent of commercial drivers may have the illness.

Another, unrelated controlled investigation showed that people with obstructive sleep apnea, the commonest form of the disease, had a risk of being involved in a traffic accident six times greater than the average driver and had a seven times greater risk of being involved in multiple accidents.

The conference, to be held May 12 at Westin Hotel at Baltimore-Washington International Airport, is cosponsored by, the Federal Motor Carrier Safety Administration and the American Trucking Associations. Representatives of the Owner-Operator Independent Drivers Association, the largest organization of truck drivers, and Schneider National, a major interstate trucking firm will participate as speakers in the meeting.

Keynote addresses at the reception the evening before the conference will be delivered by Christopher Hart, vice chairman of the National Transportation Safety Board, and Anne Ferro, the newly appointed administrator of the FMCSA.

Through a combination of lectures and panel discussions focused on the central issues, the ASAA hopes to foster a collaboration among affected trucking, health and public policy groups that will lead to greater awareness of the hazards of OSA and to better focused efforts on reducing those hazards.

Edward Grandi, the ASAA executive director, noted that the challenges facing the conference participants are considerable.

"Considering the perceived expense associated with diagnosis and treatment, the potential loss of income for drivers, and the need for additional research and thoughtful regulation, the issue becomes quite complex," he said. "Nonetheless, through this meeting great strides are likely to be made toward overcoming some of the stumbling blocks that have slowed progress up to this point."

For Don Osterberg, senior vice president for safety at Schneider National, facing up to the challenge of OSA and doing something about it is just good business. "As far as a return on investment is concerned," he said, "we've found that not only have we reduced crash frequency and severity, we've improved fleet retention. We've seen dramatic reductions in health care costs with drivers after they've been diagnosed and treated."

"The trucking industry continues to grapple with the tough questions and issues surrounding screening and treatment for sleep apnea," said Dave Osiecki, vice president for safety, security and operations of the American Trucking Association. "This event is a significant step forward and we encourage industry stakeholders to participate."

More information is available at the conference web site, www.satc2010.org. ■

ASAA IN BRIEF

The ASAA sponsored a first annual charity golf tournament in Las Vegas, NV, in November under the leadership of Dr. Robert M. Reyna of the Sleep Center of Nevada and Sam Remine of American Home Patient.

The two were assisted by Brian Cox and Thomas Lazo of the investment firm Waddell & Reed and Steve Woo of Bear's Best Las Vegas golf course.

Between 45 and 50 golfers turned out for the 7 a.m. teeoff Nov. 7, according to Remine, who said the event was intended to focus attention on the health hazards of sleep apnea and lead to the formation of an A.W.A.K.E. group in the Las Vegas area.

Unfortunately no golfer drove a hole in one and won the prize and Audi automobile promised by Nationwide Insurance and Desert Audi of Las Vegas. Planning is already underway for the second annual tournament, Remine said.

In October ASAA executive director Ed Grandi discussed the challenges of sleep apnea with members of the National Commission on Correctional Health Care at the organization's annual meeting in Orlando, FL.

In his talk Grandi drew attention to the possible relationship between sleeping problems and aggression, anger and impulsivity, especially among youthful offenders. He also pointed to studies suggesting that sleep apnea may be a factor contributing to aggression in sex offenders.

Appropriate treatment for prisoners with sleep apnea is problematic in some correctional facilities, especially the introduction to cells of special equipment like CPAP devices. But Grandi suggested the payoff in improved prisoner behavior might outweigh the potential cost in management issues and money.

The NCCHC was launched as an independent nonprofit organization by the American Medical Association in the 1970s, following publication of an AMA study that found health care in the nation's correctional institutions inadequate, disorganized and lacking in uniform standards. Its mission to educate the managers of jails and prisons on good health care, to establish standards, and to accredit those institutions that comply with the standards.

In December Grandi took the message of sleep apnea and safety to a group of employees of PEPCO, the utility firm that is the primary electric power company serving the District of Columbia and the adjoining Maryland suburbs. ■

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ASK THE DOCTOR

My physician has recommended polysomnography in an overnight sleep study. What is he talking about?

During an overnight sleep study, activities from many body systems and organs are recorded. It is a painless procedure that should not cause you any discomfort. No needles are used and you will not receive any electrical shock. You will be connected by many sensors and wires to the recording equipment. Typically recorded as you sleep are the electrical activities of your brain (electroencephalogram or EEG), your muscles (electromyogram or EMG), your eyes (electrooculogram or EOG), heart (electrocardiogram or EKG), your breathing pattern, snoring, body positions and blood oxygen levels. A continuous video of you asleep is often included as well. Put them all together and you've got polysomnography. That in turn will show whether you have sleep apnea and how severe your case is.

Adapted from *Questions & Answers About Sleep Apnea*, by Sudhansu Chokroverty, M.D., F.R.C..P, F.A.C.P. (Jones and Bartlett Publishers, 2008).

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☐ I'd like to be enrolled as a member of the ASAA, and receive a subscription to Wake-up Call. Enclosed is a check for $25 (one-year membership). I would like a medical-alert style

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WINTER 2010

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