



# Wake-up Call

from the American Sleep Apnea Association

CELEBRATING OUR 21ST YEAR

FALL 2011

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

So there they were Sept. 27, eight models in their PJs on the runway at the fashion show sponsored by the **Fox Valley A.W.A.K.E. Group** of Appleton, WI.

Only the fashions the models were modeling were the latest thing in PAP machine masks. The eight models were therapists on the staff of the Appleton Medical Center or Thedacare at Home, a durable medical equipment company.

Vicki Roehrig, the Thedacare sleep respiratory therapist who's the convener of the A.W.A.K.E. group, thought the open-to-the-public event might attract 60 or so folks, but 90 packed themselves into the meeting room.

"It was standing room only," she reported.

Unlike most A.W.A.K.E. groups, Fox Valley meets only twice a year. The next gathering will be in March or April on a date not yet set. As for mid-winter meetings, forget it. "You know what winter is like out here," Roehrig said. January low temperatures in Appleton average 10 degrees Fahrenheit, and on one bitterly cold January day in 1951 plunged to 30 degrees below zero.

There's plenty of warmth, though, when Fox Valley does meet, as was evidenced by the exploration of fashionable face masks. People pick their masks "first on the basis of appearance," Roehrig said, thinking back to her experience with the 140 people a month Thedacare at Home fits with PAP equipment. "But later they think comfort is the most important thing to consider."

Families turned out in numbers for the September event, attracted by only modest publicity—a brief piece in the local newspaper and the usual flier that was circulated through the surrounding Fox River Valley, which embraces the cities of Kaukauna and Neenah-Menasha as well as Appleton. ■

### A.W.A.K.E. — ALERT, WELL, AND KEEPING ENERGETIC

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Letter from the Executive Director .....	p. 2
ASAA in Brief .....	p. 3
News from Washington .....	p. 3

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## Want more NIH sleep research? Submit more grant requests, says Michael Twery



Michael Twery, Ph.D.

The Sleep Research Society last spring urged its members, scientific researchers in the sleep field, to continue to press Congress to maintain funding for sleep research through the National Institutes of Health and the Centers for Disease Control.

Michael Twery, director of the National Center on Sleep Disorders Research at the National Heart, Lung and Blood Institute, doesn't oppose efforts to keep a steady flow of money pouring into sleep research in the 27 institutes and agencies of the NIH. But lack of money, in his view, is

not the main brake on launching new research on sleep and sleep health.

The more immediate barrier is the shortage of top-quality grant proposals, he said in a recent interview. To cite just one example, "We've never received an application for a Phase III study for cardiovascular outcomes from sleep apnea." (A Phase III study is a very large double-blind clinical study involving hundreds, sometimes thousands, of test subjects conducted at a number of research centers across the country, usually over an extended period of time. Researchers say Phase III studies are extremely difficult to design.)

### Does treating OSA stop heart disease later?

Such a study would, among other things, possibly offer definitive evidence as to whether treatment of sleep apnea heads off the subsequent development of heart disease. It's generally assumed that it does, but confirmatory evidence is slight. In addition such a study likely would add information as to how OSA damages the cardiovascular system. There are a variety of hypotheses about the mechanisms of damage, but again, hard evidence is limited.

The National Institutes of Health, the main source of U.S. government funds for health research, receives about 80,000 biological and medical research project proposals a year, Twery said. After these applications are sifted and rated, mostly by hundreds of review panels, or "study sections," of scientist-volunteers, the NIH goes on to provide funds to initiate around 10,000 new projects in addition to continuing the financial support of multiyear projects started in earlier years. The continuing projects generally number around 35,000. That means that for a proposal to get funding it must rank in the top 10 to 12 percent of the applications a study section reviews.

Studies designed to provide information about mechanisms, that is, explain why things happen, generally are favored by study sections over projects that simply detail what happens, Twery said.

### The NIH spends \$20 billion a year on research

The \$20 billion in research funds that the NIH disburses annually is allotted less on the basis of budgetary requirements than on the ranking given to individual proposals by these peer reviewers. Consequently, in order to get more money spent on sleep research, "we need to receive more applications," Twery said. Ultimately, sleep researchers must convince their scientific colleagues

Twery, continued on p. 2

## A letter from Executive Director Edward Grandi



**A**s the end of the year approaches, my thoughts inevitably turn to questions of money. Will our income by Dec. 31 be enough that we'll be able to close out the year with our books in balance? Or even better, Will there

be a surplus big enough that we'll be able to schedule some important programming in 2012 that we couldn't swing this year?

Ultimately you, the supporters of the American Sleep Apnea Association, hold the answer to those questions. You know the ASAA's work and you know of its importance to yourselves and to those millions of OSA patients who don't even know yet that they suffer from this serious, life-shortening disease.

Elsewhere in this issue of *Wake-up Call* you can read how Judith Grare took the first anniversary of the tragic premature death of her son Brian Grare as an opportunity for a memorial benefit that raised \$8,950 for the ASAA's work. The ASAA board of directors and I are deeply moved by this generous outpouring of support.

But it doesn't take a death in the family to find ways to help both small and large.

Have you become a member or renewed your membership in the ASAA in the last 12 months? Did you choose to pay \$50 or even \$100 for your membership rather than the \$25 minimum?

Dec. 31 will soon be here. Even though you've already paid for your membership, are you able to add an end-of-year donation?

If you are involved in an A.W.A.K.E. group or other gathering of OSA patients, will you ask others in the group to join the ASAA? When you get a "Yes," you've recruited a new supporter of this organization.

How about hosting a donor dinner, a fairly simple way to raise money? Here's how.

Get a DVD of our educational video and copies of our brochure from me. Invite a group of your friends to a meal to learn about and support a cause that you care deeply about. Ask them to bring their checkbooks or be prepared to make an online donation by credit card. Prepare and serve a pleasant sit-down or buffet meal. After dinner, show our 10-minute video, hand out the brochures, and ask for tax-deductible donations to the ASAA from those who care to make them.

Want to give a donor dinner a try?

—Edward Grandi

Twery, continued from p. 1

that their proposed research is worthwhile compared to the myriad other applications vying for attention and money.

### More attention to circadian biology

Working with the Sleep Disorders Research Advisory Board, Twery's center is overseeing the drafting of a new NIH sleep research plan that will replace the current 2003 plan when it is adopted. While the plan has not yet been unveiled, participants in discussions of the draft say that the link between sleep and circadian biology gets much greater stress in the draft than it does in the 2003 plan.

*Much of modern life interferes with the rhythms of sleep.*

Circadian biology is the study of how the human body's processes—hormonal, metabolic, organic—change during the course of the day. Circadian rhythms play a role in when and how long we sleep. Eating and taking medicine may affect our bodies differently depending on the time of day we engage in such actions. But much of modern life interferes with these rhythms, which re-

search suggests are hard-wired into our genetic makeup. Electric lights, shift work, two-job employment, irresistible home entertainment, all override what the body is calling for in the flow of each 24 hours.

While he emphasized repeatedly during a two-hour conversation that sleep research is directed primarily by sleep researchers, not by his office or the NIH, Twery returned repeatedly to the unanswered questions of how the body is affected by too little sleep.

"There are a huge number of research possibilities in the relationship between sleep duration and general health," he said.

### The irreplaceability of uninterrupted sleep

Research over the past decade, he continued, has made it clear that "metabolic health requires uninterrupted sleep," that is, piecing out a short night's sleep with a nap or two during the following day for a total of eight hours is not the equivalent of seven or eight solid hours of sleep.

"People are relatively insensitive to not getting enough sleep or rest," Twery said. "... By the time the individual notices it, the damage is already done."

Telephone interviews conducted by the Centers for Disease Control and Prevention report that in every state 8 to 20 percent of adults say they never get enough sleep, Twery said. The numbers increase among the young, reaching their highest among high school seniors, 80 percent of whom say they never get enough sleep. Among the most alarming of the statistics Twery reported: Of those teenagers who said they regularly got less than five hours sleep a night, 15 percent volunteered that they had attempted suicide.

"In my mind this is pretty alarming," Twery said. "... We're not saying that sleep is the cause, but it may contribute... These are [young] people who need to go to the doctor."

He continued: "Why don't you see this kind of information in any public health campaigns? It's because evidence is needed.... The public health systems are driven by data, evidence."

### The CDC offers irreplaceable warning signals

The CDC reports, though they are irreplaceable as warning signals, are based on self-reporting. They don't provide scientific evidence. They raise questions and point to areas where scientific investigation is needed. What are the physical evidence that a child, teenager, or adult is getting enough sleep? What



Brian Grare

**N**o one should die of a heart attack at age 28. But obstructive sleep apnea patient Brian Grare did. He died in his sleep on Sept. 6, 2010, although his physicians had earlier seen no evidence of cardiovascular disease. His PAP machine was still thrumming away when his body was found.

Judith Grare, of Califon, NJ, Brian Grare's mother, who is a nurse, decided that a particularly appropriate way to mark the first anniversary of her son's untimely death would be to stage a fund-raising event for the benefit of the American Sleep Apnea Association.

"I wanted us to do something Brian would have wanted us to do," Judith Grare said. "I wanted to raise awareness about sleep apnea."

The event was held Sept. 24 at the firehouse in Califon, a picturesque borough 45 miles west of New York City. (Califon, population 1,076, has 170 buildings listed in the National Register of Historic Places, most of them examples of high Victorian design.)

"This is a small town where everyone knows each other," Grare said. The 190 tickets sold filled the firehouse almost to capacity. When the ticket sales proceeds were totted up, the silent auction completed, the other contributions accounted for, and the expenses paid, the net for the ASAA was \$8,950.

Grare chose a football theme for the party. The firehouse was decorated with the colors of NFL teams, and the food and drink offered were, in her words, "anything you could use at a tailgate party."

Football fan Brian loved hot dogs, she said, and on offer to party participants were all the 50 possible toppings Brian and his best friend Ryan Goracy had once concocted for a hot dog stand they had set up. Despite that culinary inventiveness, Judith Grare said, Brian never put anything on his own hot dogs except ketchup.

Much what was served at the benefit, including 200 hot dogs, was donated by local vendors, as were the bulk of the items offered at the silent auction. Liverpool guitarist and singer Kenny Cunningham, now a New Jersey resident, entertained with music for all ages, said Grare.

At the time of his death Brian Grare was a successful certified public accountant, his mother said. He owned his own home, "had a dog in the back yard," and had been married just short of four months.

Unlike many sleep apnea patients, Brian was not obese. Standing six foot two, he weighed 190 pounds. His severe OSA was diagnosed when he was 25. It was determined in a sleep study his physician recommended because he was complaining of daytime fatigue and frequently found himself falling asleep at work.

Positive airway pressure therapy was prescribed, Judith Grare said, but the PAP machine did little to reduce his apnea-hypopnea index. In September 2009 he had UPPP surgery that removed his uvula and much of his soft palate, but the surgery also did little to reduce his AHI. At the time of his death he was considering having lower jaw advancement surgery, one of the most complex surgical approaches to OSA.

"This is all something I'll never quite understand," Grare said. ■

are the processes by which inadequate sleep causes physical and metabolic damage? If the sleep health of the nation improved, how much money might that save the health care system?

Michael Twery would like researchers to be finding definitive answers to these questions and more. And he would like you to know what the answers are as well. ■

## Waking up sleepy drivers

**T**he second ASAA-sponsored national conference on the hazards of sleep apnea in transportation, the first to touch on all modes of federally regulated transportation, closed on Nov. 9 to a chorus of calls to move from talk to action in diminishing fatigue-related accidents.

Co-sponsors of the two-day Sleep Apnea and Multi-modal Transportation Conference, held in Baltimore, were the Federal Motor

### NEWS FROM



### WASHINGTON

Carrier Safety Administration and the Federal Railroad Administration. Aviation and maritime experts and a wide variety of transportation industry representatives also participated.

Don Osterberg, an official of the major trucking company Schneider National, described to conference participants the impact of his company's screening of its drivers for sleep disorders and the mandatory treatment for those who test positive for sleep apnea. He reported that preliminary findings of the program's effect show a significant reduction in accidents. The tools for addressing the hazards posed by sleepy operators are in hand, he said, and the time for simply thinking about the problem has passed.

The Schneider findings were supported by another researcher, Stephen Burks of the University of Minnesota, who reported data suggesting that the risk of accident involvement for truckers dropped after one night of positive airway pressure therapy.

Dr. Jeffrey Durmer, chief medical officer of Fusion Sleep, who has extensive experience in treating truck drivers for sleep disorders, said, "Sleepiness is as much an epidemic as obesity."

Conference participants explored the economic burden of untreated sleep apnea in the transportation workplace, with Durmer and others noting that employers who had no programs in place to screen for and treat sleep disorders were already paying a significant price. Introducing screening will reduce costs, Durmer said.

"Nothing drives safety like lowering your costs," interjected Mark Rosekind, a member of the National Transportation Safety Board.

Secretary of Transportation Ray LaHood had originally been scheduled to keynote the conference, but had to withdraw to join President Obama on a trip. His pinch-hitter was Anne Ferro, administrator of the FMCSA, who offered an update on Department of Transportation efforts to improve transportation safety by dealing with sleep disorders. ■

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## A watchful PAP machine

Philips Respironics has unveiled an upgraded positive airway pressure device it's promoting as the near equivalent of a house call.

The REMStar Pro with AutoIQ, as it's called, has the capability of checking the sleeping apnea patient breath by breath over several nights, automatically adjusting the air pressure delivered according to the patient's responses and electronically reporting to the physician what it's found and done.

Once the device has completed this process of determining an ideal therapy pressure for the patient and putting it in place, it then checks back every 30 hours to see how the patient is progressing and to make any adjustments indicated. These findings and changes are electronically passed on to the care team as well.

The announcement is careful to note

that the physician is always free to set boundaries for the device or to override its decision-making capability and choose a fixed therapy pressure. Nonetheless, it hints that the machine may know best.

"AutoIQ is one intelligent sleep therapy solution that is always curiously smart and powerfully convenient," says Philips Respironics. ■

### IS YOUR MEMBERSHIP UP TO DATE?

- 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).

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FALL 2011

Published by

The American Sleep Apnea Association

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This newsletter provides general medical information about sleep apnea. Individuals with personal health concerns about sleep apnea, or other sleep disorders, should seek advice from a doctor who concentrates in sleep medicine.

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