



Wake-up Call

from the American Sleep Apnea Association

CELEBRATING OUR 21ST YEAR

SPRING 2012

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

A .W.A.K.E. is an essential program to the American Sleep Apnea Association. Support groups of the A.W.A.K.E. Network enable us to be on the front line of raising awareness about sleep apnea and its dangers. Many who attend A.W.A.K.E. groups attest that the meetings provide them a lifeline to successful treatment.

Participation in an A.W.A.K.E. group provides patients with continuing support following their diagnosis and the beginning of treatment. As patients well know, for most of them sleep apnea is a chronic disease and treatment a lifetime affair. And for many, compliance with proper and adequate use of a PAP device is no picnic. A.W.A.K.E. helps.

The A.W.A.K.E. Support Network is represented by groups in all 50 states. There are also groups in India and Canada. For those who live too far from the nearest A.W.A.K.E. group to participate regularly, the ASAA's Apnea Support Forum—www.apneasupport.org—provides an alternative helpful route to patient-to-patient counsel and assistance.

A.W.A.K.E. coordinators are committed to educating and providing the latest treatment options for individuals affected by sleep apnea. A.W.A.K.E. meetings offer peer support, normalization, a variety of problem-solving techniques, practical information, and resources. To locate an A.W.A.K.E. support group in your area visit the ASAA web site, www.sleepapnea.org/support/a.w.a.k.e.-network-map.html.

If you are an ASAA member and there is an A.W.A.K.E. group near you, we encourage you to drop by one of its meetings and get acquainted. You may find that regular participation will be helpful to you. And while you're there, encourage those you meet to become ASAA members. Members like you are the best recruiters of new members.

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

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

From a calamity came forth a career Advocate Tracy Nasca knows OSA first-hand



Tracy Nasca

Was Tracy Nasca one of the lucky ones or one of the unlucky ones? It all depends on how you look at some of the key moments of her life.

After struggling for years with profound daytime sleepiness, she was finally diagnosed in 1989 with severe obstructive sleep apnea, one of the first women to be identified as a victim of what was then believed to be almost entirely a disease of overweight middle-aged men.

But the diagnosis and prescription of a PAP machine did not lead directly to better sleep and improved health. Nasca hated the machine, especially the face mask, which insisted on leaking unless she fastened its straps so tight that her nose was cut and cheeks bruised by morning.

"I was a CPAP failure," said Nasca, who is one of the patient members of the American Sleep Apnea Association Board of Directors. "I was delivered my equipment and then left to fend for myself."

The first year, a year of struggle

A year of struggling with her therapy passed before Nasca sought a second opinion, this time from Dr. Joseph Kaplan, director of the Mayo Sleep Disorders Center in Jacksonville, FL. (Nasca, at that time a Florida resident, now lives in Minnesota.) Kaplan called for a two-night sleep study, the first night to assess the severity of Nasca's OSA, the second for a titration study to determine the appropriate pressures to reduce or eliminate the apnea events.

Almost at once the Mayo team determined why Nasca's face mask was so uncomfortable. It was the wrong size, a medium, when her facial structure was better suited for a small. And the titration study indicated that Nasca would be better assisted by a bilevel device that delivered different pressures for inhalation and exhalation.

"Within two weeks of being given the right equipment, all my symptoms disappeared," she recalled.

"I was an almost instant success when I was given the right tools, the right mask, bilevel pressure, and some education, said Nasca. "That set in motion a realization that there must be a huge number of patients out there like me."

This was the moment at which bad luck—a lifetime of sleep apnea—turned into better luck—an effective treatment plan—and finally into good luck: a new career.

Mentoring sleep apnea patients on AOL

Nasca discovered that she could help others to achieve PAP compliance by sharing the details of her own experience and her steadily increasing knowledge about sleep apnea. Before long AOL, one of the earliest internet platforms, invited her to become a message board moderator on sleep problems, and over the next five years she found herself hosting online chats not only about sleep apnea but also restless leg syndrome, narcolepsy, and other lesser known sleep problems.

Nasca, continued on p. 2

Her following grew and her work caught the attention of Dr. James O'Brien, a Boston internal medicine physician, pulmonologist, and sleep specialist. O'Brien wanted a role in a web site that would educate the medical community about sleep disorders. Nasca wanted to expand outreach to patients and to encourage them to be proactive in their health care. Out of their conversations was born a new portal, Talk About Sleep, www.talk-about-sleep.com, which went on line in 2000 with O'Brien as president and chief executive officer and Nasca as vice president and senior vice president for support. From its inception the site has pursued the twin visions of educating health professionals and raising the awareness of patients.

Concern to passion to career

As time moved by Nasca realized that patient advocacy had become a career.

"My mission today remains to get those at risk for sleep apnea to be diagnosed and to become proactive in their health care," she said. "All too often cardiovascular problems have already set in by the time a diagnosis is made."

One direct way to pursue this proactivity, she said, is to join patient-centered advocacy organizations like

the ASAA and to become active in A.W.A.K.E. groups and on the Apnea Support Forum.

"I feel honored to have been asked to join the ASAA Board of Directors," Nasca said.

Since joining the board, Nasca has focused primarily on strengthening the support forum, one of the ASAA's main tools in facilitating patient-to-

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patient exchange of information, and in nurturing the CPAP Assistance Program, which provides donated PAP devices to patients who need them but lack adequate health insurance or other resources to pay for them.

"Health care is just a shambles now," Nasca said. "People have lost their jobs and their health insurance. CAP is delivering equipment to people whose lives are at risk."

Coping with an emergency

According to ASAA executive director Edward Grandi, Nasca has played a key role in moving CAP toward a sounder footing. "CAP was launched a year ago to deal with an emergency situation," he said. "There was and is an urgent need to get PAP devices into the hands of sleep apnea patients who need them and lack the ability to pay for them. But the launch was made without a fully fledged plan. Tracy Nasca and Mark Seager, CAP's coordinator, have been invaluable in our continuing effort to transform the program into a sounder, better planned and resourced operation."

The painful fact is that other than the ASAA's modest CAP effort there is in the United States no program to provide life-enhancing, life-saving PAP devices to impoverished sleep apnea patients who have no health insurance. CAP has had considerable and continuing success in acquiring PAP equipment for distribution, both new and "gently used" devices. The more troublesome challenge has been locating funds to pay for shipping the equipment to recipients and to cover the administrative costs of the program.

"We are extremely fortunate to have someone like Tracy Nasca on board to wrestle with these issues," Grandi said. ■

A letter from Executive Director Edward Grandi



As I write, we still don't know whether the Affordable Care Act will survive the multiple constitutional challenges leveled against it. Given the significance of the

decision and the political controversy that surrounds the case, the decision is likely one of the last that the U.S. Supreme Court will announce before it adjourns for the summer in June.

Our concern about health care reform, even before the ACA was enacted, has been that the diagnosis and treatment of sleep apnea not get lost when it came time to determine what the "essential health benefits" should be. We have used every opportunity possible to remind the government that

sleep apnea is a common and very serious disorder. We have worked to make them aware that it is linked to a number of other life-threatening conditions and that health insurance should cover both its diagnosis and treatment. Currently, this is not always the case.

Under the ACA, the decision about what should be included was given over to the states, with the Department of Health and Human Services providing a guidance document. The challenge now is to alert the various insurance exchanges as they come into being that coverage for sleep apnea must be part of any policy that they put in place.

I spend a good part of my time in Washington meeting with the health staff of members of Congress and officials of federal agencies, alerting them to the importance that diagnosis

and treatment of sleep apnea has in improving the health of Americans. The launching of the state health exchanges further complicates my task. But we do have allies. The ASAA is collaborating with other health advocacy organizations that are concerned about what is included as an "essential health benefit." Our plan is to develop a set of recommendations that can be shared with the exchanges as they develop their policies.

Your assistance would be invaluable in this effort. You know and care about sleep apnea. Write to your state representative and let him or her know that sleep apnea needs to be covered in your state's insurance exchange.

—Edward Grandi

Crucial sleep data on the chopping block

The sleep study program of the Centers for Disease Control and Prevention, the nation's largest collector of data

NEWS FROM



WASHINGTON

about the sleep patterns of Americans, is again under threat.

The 2013 federal budget proposed by the Obama administration, which is now under study in Congress, recommends creation of a \$379 million "Coordinated Chronic Disease Prevention and Promotion Program" that will be funded by block grants to the states. Funds that support a number of current CDC activities are to be swept into these block grants—including the minuscule \$845,000 that currently pays for the sleep study program.

It is because of the CDC's ongoing gathering of sleep data that we know that Americans of all ages, and particularly adolescents and young adults, are sleeping less every year. While the experts do not yet agree on how much sleep is enough, numerous studies demonstrate that long-term sleep deprivation is associated with cardio-

vascular disease, diabetes, obesity, depression, and automobile accidents, often fatal.

The CDC sleep study program was launched in 2008 with a budget of a bit less than \$1 million. Some modest cuts in subsequent years have reduced it to its present level, but it would appear that the proposed block grants to states would defund it entirely and eliminate its surveys and analysis.

The budget proposed last year by the Obama administration also included the apparently unintended consequence of doing away with the CDC sleep study program, but as it happened, Congress failed to adopt an appropriation bill and the activities of the CDC, including the sleep study program, continued to be paid for through a so-called "continuing resolution."

ASAA executive director Edward Grandi is currently working with members of Congress and members of their staffs to oppose the consolidation and lay the groundwork to detach the sleep study program from the package of activities proposed for folding into the block grants to states and to establish sleep as a distinct separate operation within the CDC. ■

Hargett Award

A year ago the ASAA established the Dave Hargett Memorial Award, an opportunity to honor the most creative conveners or other leaders of A.W.A.K.E. groups. Hargett, a sleep apnea patient who served a number of years as chair of the ASAA Board of Directors, was a passionate supporter of the A.W.A.K.E. Network. He died in 2010.

If you are a member of an A.W.A.K.E. group, we invite you to submit a nomination of someone in your group (or another group) for the award. Nominations can be e-mailed to award@sleepapnea.org or mailed to ASAA, 6856 Eastern Ave. NW, Suite 203, Washington, DC 20012.

Nominations should not exceed 100 words in length and should offer specific examples of how the person you are nominating has strengthened the group, stimulated the thinking of participants, provided important new information, and generally supported the efforts of sleep apnea patients to comply with their prescribed therapy.

Nominations must be received by July 1.

ASAA IN BRIEF

Every once in a while we receive a letter that we need to share with *Wake-up Call* readers in full because it explains so clearly and in such human terms how ASAA programs make a difference. This letter came from Medford, MA, to Mark Seager of Tracy, MN, who coordinates our CPAP Assistance Program:

"I am happy to report that my client received her CPAP machine, and she has begun using it. She had a little technical difficulty at first as she did not have the hose hooked up properly. Luckily another colleague in my office knew how to assemble the CPAP machine. She was able to get it working in no time. My client has just been using the machine for a couple of days, but already has noticed that her headaches have subsided, and she said she feels more rested.

"As an undocumented immigrant

in Massachusetts, my client is only eligible for emergency medical care. However, she has multiple chronic health conditions that at times compromise her ability to take care of her children. Hopefully, with the CPAP machine she will begin to feel better. She is a very hard-working mother who loves her children dearly. I have been working with this woman and her family for about two years; her resilience and integrity in the face of great hardship has been an inspiration to me.

"I am very thankful for your donation. When I made the call to you, I had no idea that I was calling Minnesota! When you returned my call 15 minutes later, I couldn't believe you were willing to make the donation without income documentation, residency in Minnesota requirements, or the completion of a lot of paperwork. I would have been willing to jump through

hoops for this machine, but you just made everything so easy. You heard a story of someone in need and you responded without hesitation. You provided the machine and even paid the postage to mail the equipment. I think you have a very big heart. I trust your kindness and generosity will have its reward.

"I wish the best of luck to you in your business and in your life."

Recently, the CPAP Assistance Program had to suspend receiving requests for donated machines for a time in order to deal with a considerable backlog of applications and a shortage of funds to pay shipping charges. The program will resume as the backlog is cleared. Your contributions in any amount will help keep it going.

More information is available at www.donatedcpap.org. ■

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THE QUESTION BOX

Q My three-year-old son was diagnosed with sleep apnea and had tonsil and adenoid surgery. A follow-up sleep study showed he still has OSA. We got a CPAP last week for him to wear at night. The problem is, we can't get him to wear the mask. He has sensory sensitivities, and any time we try to put the mask on with headgear, he freaks out. We tried a sticker chart and he will put the mask (by itself) up to his face for 15 seconds. But we haven't yet been able to fit it with the headgear—or even fully attach the headgear when he's wearing it. Does anyone have any suggestions for getting him to wear the mask?

A This is what worked for us. Because it is a health issue, we made it non-negotiable. Our son has sensory issues too, and can't even have the windows down in the car without screaming. (He has autism.) We figured that it is like his seatbelt. You just wear it, whether you want to or not. We lost a lot of sleep the first week or so, but he finally accepted it. We just kept putting it back on, and back on, and back on. He does take sleep meds and I have heard that can help if your child isn't on them already. I rented some new movies I knew he would enjoy. I let him watch those while he was awake as long as he was wearing his mask. He would say, "I need a drink of water," "I need to go to the bathroom." We would do those, and put the mask right back on when he was done. He still doesn't like it, but he wears it, every night, most of the night. Good luck!

Adapted from an exchange on the ASAA Apnea Support Forum, www.apneasupport.org. The answer is by Jo in Utah

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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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