
Awake in Philly

Community Education Group

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Meeting Minutes for Wednesday, January 8, 2003

Source: <http://www.awakeinphilly.org/Meetings/2003/Jan2003/minutes.pdf>

A. OPENING STATEMENTS

Michele J. called to order the regular meeting of the *Awake in Philly Community Education Group* at 6:30 P.M. on Wednesday, January 8, 2003 in the Conference Room at the Northeast Regional Branch of the Free Library of Philadelphia. After calling the meeting to order, Michele J. led the group in reciting the Pledge of Allegiance. Michele N. then welcomed everyone, followed by her reading the standard disclaimer.

B. RESEARCH OPPORTUNITY

Michelle Szarak, the Clinical Coordinator, and Madeline Duffy, the Patient Programs Coordinator. They are from CNS Clinical Trials, which is seeking participants in on-going clinical trials. For more information, call 1-888-RX-TREAT (1-888-798-7328).

The University of Pennsylvania is looking for siblings who have been diagnosed with apnea. For more information, call Adonna Mackley at 215-349-8980.

C. DISCUSSION

Tonight's guest speaker is Dr. Ronald L. Kotler from Pennsylvania Hospital. Dr. Kotler has more than 17 years of experience in sleep medicine, and he has served as the respiratory director at Pennsylvania Hospital for the past 10 years.

When going to see a doctor for sleep-related problems, Dr. Kotler says he will ask some general questions of patients, including:

- What time do you go to bed?
- What time do you get up?
- Do you watch television while falling asleep?
- How long does it take you to fall asleep?
- How do you feel when you first wake up, do you feel well rested or as if you just laid down?
- Do you take stimulants through the day to keep you energized?
- Do you move in your sleep?
- Where do you work/what kind of job do you do?
- Do you take a nap after work?

After the question-and-answer session with Dr. Kotler, he will then perform a complete physical exam on you, checking to see if you have high blood pressure; if your legs are swollen; and will perform a cardio-vascular exam to see if there are any problems with your heart. If he detects anything, or feels there could be a problem, he will send you for more intensive testing.

During the exam the doctor will observe your mental status, such as if you are sleepy or alert. Dr. Kotler said he often does a thyroid screen (TSH).

If these exams show you have symptoms of a potential sleep disorder, Dr. Kotler said he will order a two-night sleep study. On the first night, wires will be connected to your body to monitor breathing problems and any movements during sleep.

The second study will only be given if you do, indeed, have a sleep disorder such as sleep apnea. An interesting comment by Dr. Kotler was that about five percent of all people with obstructive sleep apnea also suffer from narcolepsy.

This is the titration night – meaning the techs in the sleep lab will determine the appropriate treatment pressures on an xPAP machine.

Dr. Kotler said there are three treatment options for sleep apnea.

The first one he mentioned, noting that it is the most effective and successfully, is the xPAP machine.

The second option is the use of oral devices which are custom made by an oral surgeon. They pull the jaw forward, and can help alleviate snoring, and, at times, apnea, in mild and low-end moderate cases.

Finally, the third option that Dr. Kotler mentioned, was surgery. There are several types, and none of which are given the effectiveness of xPAP. One procedure he mentioned, the UPPP, trims the uvula (the piece of tissue hanging at the back of your throat), allowing the throat to remain open during sleep. This often is not a cure for apnea, and basically affords an end to snoring. There are other procedures that can be tacked onto the UPPP, providing a little more assistance to those with apnea. Dr. Kotler noted that anyone seeking a surgical cure to apnea should seek qualified doctors who have experience with apnea patients, and understand what “cure” and “success” means to the doctor. Often these words mean snoring or apnea is reduced – not eliminated to a doctor, while, for the patient, those words ring of “no more apnea.”

The final surgical procedure mentioned by Dr. Kotler was gastric bypass surgery. This surgical *may* (Dr. Kotler emphasized this greatly) help if you are 100 or more pounds over weight. Again, he noted, that this is not a cure-all, and weight may only play a small factor in apnea. He said that losing weight may help reduce the number of apneas, but not eliminate it in all patients. For some people, apnea is strictly anatomical. Another option, if weight is the key factor for someone with “transient apnea” is to lose weight.

After being diagnosed, if you ever have to visit the hospital or emergency room, be sure to take your own xPAP machine with you, said Dr. Kotler. “Don’t assume the hospital will have an xPAP on-hand. If they do it may not be as comfortable as yours,” he said.

When going in for surgery, be sure you talk with the anesthesiologist about your apnea. One question for you to ask the anesthesiologist is how much experience they have dealing with people who have been diagnosed with apnea. If the surgical team is not prepared prior to the start of the procedure, you could suffer and apnea once you are unconscious. At that point, it could be fatal, as the anesthesia relaxes and paralyzes the tissue at the back of the throat. If the anesthesiologist attempts to intubate you at that point, it could be impossible. The option at that point would be an emergency tracheotomy – an incision into the throat to create an artificial airway. A simple way many experienced anesthesiologists deal with apneics is to intubate them with a fiber optic tube prior to administering anesthesia. The patient would be numb in the throat for the procedure, called Awake Fiber Optic Intubation, although the throat would be numbed.

While discussing your care with the anesthesiologist, also ask how you will be monitored during recovery, as well as during any post-operative time. Dr. Kotler also suggested it wouldn’t

be a bad idea to ask that cardiac and oxygen monitors be used following surgery to detect any potential problems for 24 hours.

There are many dangerous medications for people who have apnea. Dr. Kotler said narcotics and benzodiazapines. Valium and Atavan are two examples of benzodiazapines. Percodan, Vicodin, and Percoset are three examples of narcotics. Following many surgical procedures, morphine is often administered. For someone with apnea, it could prove fatal because it relaxes the muscles so much that you could stop breathing. Sleeping pills may also cause problems, so it is suggested you speak with your doctor about any type of sleep aid, including an over-the-counter remedy, prior to use.

In terms of over-the-counter (OTC) meds, Sudafed (Pseudoephedrine Hydrochloride) and other remedies that act with a “stimulant” effect should first be approved by your treating healthcare provider as they could cause insomnia or other issues with sleep maintenance.

Dr. Kotler said, “You have to be pro-active with your healthcare. If you’re pro-active, you’re more likely to get the care you deserve and need.”

A new book, *Hospital Survival Guide*, by Dr. David Sherer should be hitting bookstores in March. Dr. Kotler suggested it as important reading.

D. INDIVIDUAL DISCUSSION/SUPPORT ISSUES

Two people at the meeting wanted to know if surgery could cure their particular cases of apnea. Dr. Kotler told them they should speak with their sleep specialist.

Another person wanted to know what could be done to help eliminate the claustrophobic feeling associated with wearing a nasal xPAP mask. Dr. Kotler said there are many different styles of masks available, including full-face masks and nasal pillows. He said those in the field should work closely with patients to ensure all issues, including claustrophobia are addressed and handled. He mentioned that Marc Johnson, a tech at Pennsylvania Hospital’s sleep lab, works closely with patients to find the proper mask and setup, helping to ensure the patient gets off to a good start with xPAP.

One person wanted to know if there are any specific exercises that can be performed to tighten the tissue in the throat, thereby eliminating apnea. Dr. Kotler said throat exercises may help people with emphysema, but there are no reported benefits to those with apnea.

E. ACKNOWLEDGEMENT OF SPONSORS

Awake in Philly sponsors, in alphabetical order, include [B.F. Ascher & Co., Inc.](#); [Free Library of Phila. \(NE Regional Library\)](#); [Maril Products](#); and [Respironics, Inc.](#). The winner of tonight’s drawing for a Control III Home Care Kit, donated by Maril Products, was Irvin Rosen, of Philadelphia.

F. AGENDA FOR NEXT MEETING

The next meeting is slated for Wednesday, March 12, 2003 at 6:30 P.M. in the Conference Room at the Northeast Regional Branch of the Free Library of Philadelphia. The speaker will be Howard Hymen, a disability attorney, who will speak on “*Legal Issues and Sleep Disorders.*”

G. ADJOURNMENT

Dave Jackson adjourned the meeting at 8:24 P.M.