

# SLEEP WINDMILLS: PUBLIC HEALTH ADVOCACY

by Frank Roman MD JD



I have never told Dr. William C. Dement that I've always fancied him to be the heroic figure Don Quixote of La Mancha and myself as his sidekick, Poncho Sanchez. (Of course better looking, with a lower body mass index and a Mercedes instead of a mule) fighting windmills, i.e. the Federal government, but I digress. Let me start from the beginning:

One day in 1988 as a pulmonary fellow at Michigan State University, I hid in the medical library from my attending physician. Looking through the stacks of books I stumbled onto the book SOME MUST WATCH WHILE SOME MUST SLEEP by William C. Dement (W.W. Norton & Co., 1976). For unknown reasons, I was drawn to this book by the unusual title and the illustrations on the cover and text of naked people, which turned out to be the artwork of Pablo Picasso including The Dream, Faun and Sleeping Woman, and Sleeping Nude. Think what you may but it was 1988 and there was no Internet to surf. This was basically a victimless crime except for the attending physician, who was looking for me to do scut work. I read all 121 pages that afternoon and was particularly fascinated by the passion and work up to that time by Dr. Dement and a few others in the field of sleep. During my reading I was both intrigued by the fascinating stories in the book and upset over being born to late to participate in the pioneering work in this field. That same day I picked up a volume of Sleep which revealed the state of knowledge at that time and with all due respect to the researchers most of the work was done on rats with articles for example, on hypoxia induced sleep disturbance in rats and sleep deprivation in

the rat. Michigan State University had a sleep center under the leadership of Dr. Paul Gouin and chief technologist, Pamela Minkley who both were very active in training other healthcare professionals locally and around the country. After some initial training at Michigan State University in sleep medicine, I opted out of my third year in pulmonary medicine and went to Scripps Clinic and Research Foundation in La Jolla, California to complete a one year sleep medicine fellowship under Drs. Milton Erman, Merrill Mitler, Rosa Hyduk, and Steven Poceta. During my fellowship I had the opportunity of finally meeting Dr. Dement in person and he autographed my illegally obtained copy of Some Must Watch While Some Must Sleep (I wonder how much is a 20 year over due fee). To this day it ranks only second to my autographed copy of Dr. Seuss's Sleep Book obtained approximately at the same time in California (I never told Dr. Dement that either). Even as far back as 1990, Dr. Dement was a strong advocate on public health policy regarding sleep disorders. It was an exciting time in the field as he was the chairman of The National Commission on Sleep Disorders Research, which finally published their results in 1993 Wake Up America: A National Sleep Alert.

However it was in 1994 when Dr. Dement and I started collaborating on projects. I was embraced by Dr. Dement after wearing down my congressman with fre-

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quent letters, meetings, and faxing his Washington, D.C. office 56 business days in a row. Since then I've had the honor and privilege of working with him on several projects. Looking back on my career the most fun activities have been public advocacy. We started our own little group called Wake Up America and I actually had polo shirts printed up. If memory serves me, we commandeered an empty conference room at the APSS meeting in Nashville, Tennessee in 1995 and gave a workshop on public advocacy with the help of the late Tom Hobbins, Kristin Rice, and Mike Davis. Dr. Dement and I paid out of our own pockets the lunch that was provided at this workshop. At that time it seemed most people were more interested in the free lunch than the workshop. In March 1995 we had our first March on Washington with over 100 sleep professionals and patients marching on Capital Hill and addressing sleep disorder issues. The most fun we had was the following year on May 29, 1996 with the Great American Sleep Walk where an estimated 800-1,000 sleep professionals, friends and patients marched on Capital Hill to once again address the lack of funding for the National Sleep Center and the devastation of sleep disorders. During that same period of time Kristin Rice and I surveyed the U.S. Congress with the sponsorship of a congressman who is presently incarcerated but that's another story. Although more than ten years ago some of the findings are still relevant: 82% of members of congress reported that their constituents did not call or write regarding sleep disorders. On a personal note 44% of the congressional members admitted to snoring and 3% gave symptoms suggesting sleep related breathing disturbances. 35% complained of waking up non-refreshed most mornings and 32% admitted to episodes of inappropriate sleep while driving and during committee work or hearings. Every two years there is a new Congress and I would dare say that the knowledge in general regarding sleep disorders has increased thanks to the work of our professional societies, patient advocacy groups, and the excellent work done by the National Sleep Foundation located in Washington D.C. I'm also willing to speculate that there is an increase in snoring, unrecognized sleep apnea, and other sleep disorders in the members of congress and their staff as we all grow older and more obese. It is important that we continue to lobby Congress and other federal agencies regarding the potential devastation of sleep deprivation and other sleep disorders. There are still so many windmills to go after.

Despite the progress and successes we've had in the field of sleep medicine it is important to continue to attack more and more windmills. For example, as some of these issues as addressed on the web site for the National Sleep Foundation include on the federal side: (1) advocacy for funding to help support several federal programs that are underway to expand research and awareness on the impact of inadequate sleep. These agencies would include the Federal Railroad Administration and the National Institute for Occupational Safety and Health. (2) Advocate for increased research at the National Center on Sleep Disorders Research, Department of Defense, Department of Transportation, and other federal agencies. (3) Advocate for federal funding for educational programs aimed at primary care practioners to increase the likelihood of proper diagnosis and treatment of sleep disorders.

The sleep profession has grown by tremendous leaps and bounds in recent years. Our professional

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societies, The American Academy of Sleep Medicine, The Association of Professional Technologists and Sleep Research Society are fiscally sound, strong, and thought leaders in both the medical field and general public. It is important that we continue to support our professional societies in whatever capacity we can. Our professional societies have professional administrators and lobbyists who forward our mission and goals on a day to day basis. We must continue to support our professional societies monetarily and through volunteer work as much as possible. However at the same time we should accept the challenge and opportunities to help the general public in terms of public awareness and helping formulate public health policy. It is important to remember that helping patients was the reason why we all got into this field to begin with. Sleep disorders and sleep deprivation is still considered by many to be the largest unrecognized public health problem in this country.

I have never told Dr. Dement this but I love the old man and would still go after the largest windmill. However the reality is I cannot keep up with his energy and passion and therefore am requesting help. With the beginning of every year many of us take stock of our lives and make resolutions to improve our personal lives but wouldn't it be better if we also took stock of our professional lives and resolved to improve the lot of others? Therefore I am urging each and every one of you to become advocates for sleep in your professional societies and the National Sleep Foundation. I can promise you that you will not be paid, not be recognized, not be appreciated, but you will have the personal satisfaction of helping so many other people you will never meet.

By the way, the first week of this year I took my son to the Cleveland Museum of Art to see Barcelona, a traveling exhibit of art from Spain, which among others included paintings from Pablo Picasso. It seems that on that day long ago in 1988 I also got hooked on his art.

*Frank Roman MD is a diplomat of the American Board of Sleep Medicine and a Partner, Neurosurgery and Neurology Associates of Massillon, OH. Dr. Roman also received his law degree from the University of Akron Law School.*

**New Identity...** *Continued from previous page*

The newest supporting activity of The Joint Commission is the Public Policy Initiatives. Launched in 2001 with a major study of the nurse staffing crisis, The Joint Commission acknowledged some significant health care quality and patient safety issues. Each Public Policy initiative involves an expert roundtable, a national summit, issuing of a white paper, and implementation of follow-up strategies. To date, The Joint Commission has convened nine Roundtables and issued four white papers. The public policy initiatives will continue, as there is no shortage of topics in need of study and review.

This is the plan for transition of The Joint Commission's leadership over the next year. Similar to our own organizations, we can anticipate virtually continuous change in the accreditation body also. In fact, the rapidity of change is likely to increase in the short term. There has been an outcry from the general public, legislators and policy makers, and the healthcare community for a higher priority on health care quality and patient safety. This is also the plan for The Joint Commission.

*David Gourley, RRT is a veteran therapist and former Department Director, now Vice President of Regulatory affairs at Chilton Memorial Hospital, Pompton Plains, NJ. He can be reached at Dag29@aol.com*

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