

# Patient Communities and Personalizing Sleep Medicine: MyApnea.Org

Emily Kontos, ScD, ScM; Susan Redline, MD, MPH

*Brigham and Women's Hospital and Beth Israel Deaconess Medical Center, Harvard Medical School, Boston, MA*

A new web-based community portal, [www.MyApnea.Org](http://www.MyApnea.Org), is mobilizing a community of patients, researchers and health care providers to work together to identify better ways to screen, treat, and prevent sleep apnea. *MyApnea.Org* is the public face of the Sleep Apnea Patient Centered Outcomes Network (SAPCON), a patient-powered research network that was formed to improve comparative effectiveness research by focusing on patient-centered outcomes. This type of research asks: *Of available treatment alternatives, which treatments are most effective, and for which patients?*

There has never been a more urgent time in sleep medicine and oral health for patient and stakeholder participation in such a national comparative effectiveness research initiative. With escalating health care costs, payers are demanding higher levels of evidence to justify the use of diagnostic tests and treatments and are asking for data that provides value to the patient and health care system. Many insurers restrict how sleep tests and treatments are delivered; however, those requirements often reflect a generalization of data from studies that were conducted at highly specialized referral centers and were not intended to be used without the support of a full team of committed sleep health professionals.

The need for comparative effectiveness and patient-centered research is especially relevant for Dental Sleep Medicine. For example, there is growing evidence that mandibular advancement devices (MADs) play an important role in the management of patients with sleep apnea. However, there remain critical questions on which patients benefit the most from this treatment, and when this treatment should be offered in the course of sleep apnea management. Answers to those questions require data on large numbers of well-characterized patients, allowing for both subgroup and prospective analyses. Although recent research has shown equivalent blood pressure improvement with use of MADs compared to CPAP, it is clear that patient-reported outcomes, including improvement in sleepiness, fatigue, and sleep quality, as well as overall satisfaction with treatment, are important outcomes for patients as well as for health care systems. Developing the evidentiary base for health care decisions will require that careful consideration of the cost-benefit of alternative treatments, including impact on health outcomes and quality of life.

Patients commonly express frustration over the lack of sleep apnea treatment options, especially the paucity of information that addresses which options would work best for them. Patients also often find that their treatment may be influenced by which specialist they happen to see, rather than information on their own set of risk factors or personal preferences. Finally, patients often are disappointed by the level of support available

to aid them in understanding how to adjust to given treatments or to overcome barriers. They are often interested in learning technical and behavioral tips that allow them to better use their prescribed devices and to follow healthier sleep routines, and be further supported by trusted peers. For these reasons, patients are increasingly looking to form communities where they can access and share information, support one another, connect to dedicated professionals, and also contribute data to advance everyone's understanding of sleep apnea.

In response to these needs and opportunities, *MyApnea.Org* is inviting people with (or at-risk of) sleep apnea to share information, provide support, and to help design, direct, and participate in sleep research. A broad and collaborative effort is what is needed to generate the evidence necessary for deciding which diagnostic studies and treatments are most effective. Studies of large numbers of individuals from across the US (and the world) are needed to achieve the sample sizes necessary for identifying which patients benefit most (or might be harmed) from alternative sleep apnea treatments, such as MADs. Rather than the traditional "one size fits all" approach to treatments and research, *MyApnea.Org* hopes to use information on health risk factors, biomarkers, background, and type of sleep apnea to tailor treatments that are likely to be most effective for individual patients. In such a way, data will be generated to allow a patient with a given set of risk factors (based on airway size, body fat distribution, time in REM sleep, etc.) to be offered treatments most likely to benefit him or her. Furthermore, research that addresses the outcomes that matter to patients (e.g., fatigue in women, behavioral problems in children) will ensure that the results are relevant and would improve the health and well-being of patients with sleep apnea. It is also an exciting time in sleep research as technological advances currently present numerous opportunities for improving sleep apnea diagnosis and management. Examples include telemedicine, newer ambulatory monitoring devices, mHealth devices, and sophisticated oral appliances and pressure devices. However, without good evidence on what works best, such technologies can be misused. *MyApnea.Org* is building a platform to conduct such large-scale patient-driven comparative effectiveness research.

Patient members of *MyApnea.Org* have the opportunity to complete a series of health related surveys, nominate, and vote on research questions and can participate in forums to discuss how patient-centered research should be conducted. After completing the patient reported outcomes surveys, patients are able to see their answers in comparison with the rest of the patient community. Through these research communities patients can identify what questions are most important

and can co-develop proposals with health care and oral health providers and scientists to address these needs. To date, over 3,000 members have contributed patient reported outcomes survey data and members have identified 54 research topics that over 3,000 members have endorsed.

The empowering strength of MyApnea.Org lies in the breadth and diversity of its membership. MyApnea.Org already has enrolled over 6,700 members and will soon begin enrollment of parents of children with sleep apnea. The portal attracts more than 1,000 new visitors a day and sees over 25,000 page views a month. MyApnea.Org maintains high retention rates, with 60% of our visitors returning within a week and over 80% returning within a month. Members come from every state in the U.S. as well as 41 countries world-wide. The forum provides a vibrant and engaged patient community with over 1,500 current posts on 190 different topics. Topics span a wide range of topics. For example, the thread on oral appliances has had over 1,600 views. In addition, there have been extensive discussions related to sinus issues and sleep apnea and the need for appropriate oral appliances. A consistent theme throughout the discussion forum is the desire for alternative treatments to mainline therapies such as CPAP. Many patients are not fully aware of the array of treatment modalities that may be available to them. Participation in MyApnea.Org and communication with other patients and providers offers them the opportunity to learn more not only to help direct future research but to also better empower the management of their own health care.

Sleep researchers and providers are also encouraged to join MyApnea.Org. After becoming a member, providers are prompted to create their own specific landing page with a unique web address and welcome message for their patients. These personalized web links enable providers to promote the site among their patient panel and when patients register for the site using the personalized link, providers and patients are connected within the MyApnea.Org database. Once a provider has at least 20 patients registered for the site they are able to view the aggregate patient reported outcomes for their patient panel and compare results against the entire patient community.

The key message to pass along to dental health patients is that it is now easier than ever for patients with sleep apnea to play an active role not only their health care but in the research that is driving the decisions behind their health care. This is ever so important in the area of sleep health where the persisting gaps in knowledge are a significant deterrent to equitable health. MyApnea.Org, already has enrolled more than 6,700 members in this national effort. We encourage dental clinicians to refer patients with sleep apnea to join the patient-powered research network MyApnea.Org and to remind them that their data has the power to move the dial in sleep health. Similarly, we encourage dental clinicians and researchers to consider using the data provided within MyApnea.Org for future investigations. As further comparative effectiveness research is generated, dental practitioners and researchers will have a better understanding of which patients benefit from mandibular devices and how best to screen and manage a wide array of patients.

## CITATION

Kontos E, Redline S. Patient communities and personalizing sleep medicine: MyApnea.Org. *Journal of Dental Sleep Medicine* 2016;3(2):41–42.

## SUBMISSION & CORRESPONDENCE INFORMATION

Submitted for publication December, 2015

Accepted for publication January, 2016

Address correspondence to: Susan Redline, MD, Harvard Medical School, Department of Medicine and Division of Sleep Medicine, Brigham and Women's Hospital and Beth Israel Deaconess Medical Center, 221 Longwood Avenue, Room 225, Boston, MA 02115; Tel: (617) 732-4013; Fax: (617) 732-4015; Email: sredline@partners.org

## DISCLOSURE STATEMENT

This was not an industry supported study. The authors have indicated no financial conflicts of interest.