Medical Xpress

Patient-powered research community, MyApnea.Org, aims to redefine sleep apnea research outcomes

June 10 2015

Credit: MyApnea.Org

A new web-based community portal, MyApnea.Org, is recruiting patients, caregivers and those at risk for sleep apnea to join a growing community of patients and researchers to better understand sleep apnea through information sharing, support and research. The network brings together patients, researchers and health care providers to work together in the same virtual community to improve diagnosis and treatment, with the ultimate goal of improving the quality of life for those who suffer from sleep apnea.

"There has never before been this level of collaboration among patients, researchers and clinicians aimed at solving the challenges of sleep apnea ," said Susan Redline, MD, MPH, principle investigator of the Sleep Apnea Patient Centered Outcomes Network (SAPCON), of which MyApnea.Org is the public face. "The network is open to anyone diagnosed with sleep apnea (whether or not they are currently being treated) or at-risk of the condition and caregivers. Children with apnea are often overlooked, so we are particularly eager to have parents or caregivers join on behalf of their children," she added.

Sleep apnea, a common and potentially life-threatening sleep and breathing disorder, affects more than 25 million people, yet it is estimated that about 80 percent of people go undiagnosed. People who suffer have repeatedly interrupted breathing during sleep, sometimes hundreds of times during the night and often for a minute or longer. Left untreated, sleep apnea increases the risk for high blood pressure, heart attack, stroke, and other medical conditions. People who are at risk for sleep apnea include those who have a family history or loud snoring, or are overweight or have other conditions such as diabetes and heart disease.

SAPCON is coordinated by the Division of Sleep and Circadian Disorders at Brigham and Women's Hospital (BWH) in collaboration with patient volunteers from across the country and sleep apnea patient advocacy and research organizations. Steering Committee members include Dr. Judith Owens, the Director for Sleep Medicine at Boston Children's Hospital, Dr. Vishesh Kapur, Director of Sleep Medicine for the Division of Pulmonary and Critical Care Medicine at University of Washington in Seattle, WA and Nancy H. Rothstein, MBA, The Sleep Ambassador and patient. SAPCON is part of PCORnet, the National Patient-Centered Clinical Research Network, a historic national research venture that invites people across the nation to share health information and to guide the course of comparative effectiveness research for a

many serious and chronic diseases. Funded by the Patient-Centered Outcomes Research Institute (PCORI), MyApnea.Org is one of 29 individual networks that will comprise a national "network of networks" dedicated to conducting patient-centered health research. MyApnea.Org is one of the Patient-Powered Research Networks within PCORnet, which are organized and governed by patients and their partners and focused on a particular condition.

Through MyApnea.Org, members have access to tools that will help manage their condition, and enable them to connect with and learn from others like them. Initially, researchers will focus on questions and results that are most important, practical and empowering to those impacted by sleep apnea. Members are able to suggest a research idea that they would like to know more about and this suggestion can then be voted on by other members of the community. The highest ranking questions are periodically examined, and researchers explore the existing scientific literature related to that question. If there is a significant amount of data on the topic, then it is synthesized and a plain language summary is provided to members. If researchers discover a gap in knowledge, then the question will be endorsed as a topic for future research.

"It seems as if research is generally driven by funding organizations, which oftentimes is not reflective of the needs of patients. By having large amounts of data provided by and for us, we can now drive the research agenda. This is a way to democratize research—to generate understanding on the part of the researchers and patients together," said Kathy Page, who has sleep apnea and is a member of MyApnea.Org's Patient Engagement Panel.

"This portal is one of the most direct ways to empower patients that I've ever seen. The feedback each member gets about his or her own health indicators can be a powerful means for improving their understanding of sleep apnea and its impact on their individual health and well-being,"

Redline said. "This approach empowers researchers, too. We'll have vast amounts of data and a platform for conducting comparative effectiveness research, which is critical for understanding the best ways to diagnosis and treat sleep apnea. We've learned a lot about the condition, but we still know too little about its management. We have the potential to start pinpointing which treatments produce the best results for particular kinds of patients."

Provided by Brigham and Women's Hospital

Citation: Patient-powered research community, MyApnea.Org, aims to redefine sleep apnea research outcomes (2015, June 10) retrieved 2 May 2024 from https://medicalxpress.com/news/2015-06-patient-powered-myapneaorg-aims-redefine-apnea.html