



# SLEEP MATTERS

EDITION #1, VOLUME 2, JANUARY 20, 2017

## Report from the 2016 SRN & PCORI-funded SLEEP<sup>2</sup> MEETINGS

The Sleep Research Network annual meeting and SLEEP<sup>2</sup>, a Patient-Centered Outcomes Research Institute (PCORI) funded meeting, were held from October 6-7<sup>th</sup> in Bethesda, MD. The 2-day meeting was attended by nearly 100 registrants who represented researchers, providers, patients, industry, and other stakeholders. A summary of the proceedings is listed below.

### SRN MEETING Oct 6<sup>th</sup>, 2016

Three keynote speakers and a panel of NIH representatives attended the SRN meeting. The focus was on facilitating cross-institutional collaborations and the resources available to support these efforts. **Irene Katzan, MD, MS** from The Cleveland Clinic focused on opportunities for collaborative research using the electronic health record. **Lisa Meltzer, PhD** from the University of Colorado Medical School discussed the use of the PROMIS Sleep Health Item Banks for Patient-Reported Outcomes for sleep in children, and **Stephen Wisniewski, PhD**, University of Pittsburgh, and **Antonello Punturieri, M.D., Ph.D.** (NIH/NHLBI) discussed opportunities for collaborative sleep trials through the Pulmonary Trials Cooperative Network Management Core (NEMO). The annual **NIH ROUNDTABLE** included representatives from 11 NIH institutes and 3 centers and offices representing the National Center for Sleep Disorders Research (NCSDR) & Trans-NIH Sleep Research Coordinating Committee. Seventeen individuals participated in the networking blitz and gave overviews of their ongoing work and upcoming projects with a focus on how developing new collaborations would facilitate their work. The SRN Young Investigator travel awardee poster session, with 10 presenters, was held on the evening of October 6<sup>th</sup>. This session was designed to facilitate further collaborations among all attendees.

Highlights of the Pediatrics Workgroup, one of three workgroups that met to discuss how to facilitate interinstitutional collaborations are summarized on the next page.

## *Networking Opportunities in Sleep Medicine*

Saturday June 3<sup>rd</sup>, 2017,  
Boston, MA

### SRN PCORI SLEEP<sup>2</sup> Engagement Meeting

#### SAVE THE DATE

June 3<sup>rd</sup>, 2017  
Boston, MA

Contact Cody Havens  
([chavens@email.arizona.edu](mailto:chavens@email.arizona.edu))  
if you want email updates  
about this activity.

## *Contribute to this Newsletter*

We are inviting submissions to this newsletter that could feature collaborative research that you may be doing in sleep and circadian sciences. Please send a maximum 1000 word write-up to the Editor.

**PEDIATRICS WORKING GROUP** (led by Lisa Meltzer, PhD and Daniel Buysse, MD). The Pediatrics Workgroup identified several potential themes that have high priority in pediatric sleep research, including those related to behavioral sleep medicine. High-priority areas with potential for cross-institutional collaborations include:

- Early screening and diagnosis of pediatric sleep disorders, with focus on identification of sleep apnea and other sleep disorders, their effects on function, and the implementation of efficacious interventions in routine care settings.
- Health disparities in pediatric sleep, given the potential for sleep to influence physical, mental, and cognitive health, further studies could focus on identifying the nature of sleep health disparities, and strategies for the remediation of such disparities.
- Opportunities for pragmatic clinical trials and comparative effectiveness trials including:
  - Promoting treatment adherence, e.g., with treatments for pediatric sleep apnea
  - Melatonin vs. behavioral treatment for pediatric insomnia
  - Stimulants vs. behavioral sleep treatment for ADHD
- Normal trajectory of sleep across development with a focus on longitudinal tracking of sleep duration, sleep timing, and sleep quality from infancy through adolescence. This should include looking at how sleep is related to physical and mental health outcomes.
- Adolescent sleep health, including epidemiological investigations of adolescent sleep health and the implementation of behavioral or health promotion interventions.

**Opportunities** for developing partnerships to improve pediatric sleep health were identified and include:

- PCORI funding opportunities. A particular advantage may accrue from the involvement of strong stakeholders in the form of parents and parent groups.
- PCORNet. This network could be leveraged to address pediatric sleep medicine topics.
- Schools, school districts. In addition to being key stakeholders on the issue of school start times, school groups may also be important partners for topics related to pediatric and adolescent sleep health.

**Remaining Needs & Questions:** Although it is relatively easy to identify priority topics related to pediatric sleep, sleep disorders, and sleep health, figuring out how to promote multi-site research related to these topics is still challenging. Some of the remaining needs and questions include the following:

- Gathering stake-holders including patients and advocacy groups, pediatric sleep researchers and existing work-groups within the pediatric community.
- Optimal methods for conducting regional and national assessments of pediatric sleep.
- How to best incorporate input from PCORI on how to involve and add pediatric participants to ongoing studies.
- Identification of other sources of funding for pediatric sleep work (NIH, PCORI, other agencies and foundations).
- Identifying the best models for multi-site engagement that the pediatric sleep research community can model.

Individuals with ideas for facilitating these pediatric sleep research activities are encouraged to contact Cody Havens at [chavens@email.arizona.edu](mailto:chavens@email.arizona.edu).

Workshops from the **genetics** and **wearable technologies** working groups will be disseminated in upcoming issues of the SRN newsletter.

### **INAUGURAL SLEEP<sup>2</sup> MEETING**

Strategically Leverage Engage and Empower PCOR in Sleep was held coincident with the SRN meeting on October 7<sup>th</sup> 2016 and included patients, researchers, providers, industry, and other stakeholders across the entire span of sleep research from topic generation, to conduct of studies, to disseminating and implementing the research findings. Highlights of the meeting included a talk by **Joe Selby, MD, MPH**,



Julie Flygare, JD, Joe Selby, MD, MPH, & Sai Parthasarathy, MD at inaugural SLEEP<sup>2</sup> meeting in Bethesda, MD



Rebecca Fuoco MPH speaks about communicating with patient partners

Executive Director of PCORI, who focused on how a patient-centered approach facilitated the management of chronic medical conditions; **Julie Flygare, JD**, from Project Sleep, who gave an insightful and moving plenary speech that detailed her experiences as a patient and provided recommendations for patient-centered healthcare in sleep medicine and for ensuring that patient needs are central to future research efforts; **Rebecca Fuoco, MPH**, from Project Sleep, gave a plenary on how researchers can best engage and communicate with patient partners to facilitate work in sleep medicine with an excellent overview of “patient-centered” language in scientific writings; and **Jon Puro MPA-HA**, PIOCHIN CDRN, who discussed how PCORI supported Clinical Data Research Networks could enhance the pace, ease, and scale of research.

**Additional activities included a PCORI MOCK GRANT REVIEW** led by co-chairs Dr. Jerry Krishnan, MD, PhD (University of Illinois) and Dr. David Au, MD, MS (University of Washington), and the **SLEEP<sup>2</sup> Networking Blitz** which included 90 second presentations from 10 researchers and patient and patient-advocacy groups. Besides the co-chairs the grant panelists included Drs. Reena Mehra (Cleveland Clinic), Charles Atwood (University of Pittsburgh), Katie Sarmiento (University of California San Diego), and Clete Kushida (Stanford University). Patient and patient-advocacy panelists included Ms. Carolyn Aird, MPH, Ms. Nancy Callicotte, and Ms. Kathy Page. Two funded PCORI-grants were reviewed and the areas of importance to PCORI applications such as patient-centeredness and patient-stakeholder engagement were discussed in detail.



PCORI Mock Grant Review Panel at SLEEP<sup>2</sup> Meeting

A combined talk on “PCOs and Research Priorities for Sleep Apnea: What we learned from focus groups” was presented by Darrel Droblich of the **American Sleep Apnea Association (ASAA)** and Dr. Sairam Parthasarathy, which was based on a survey administered by the ASAA and University of Arizona through social media and other portals. The survey results provided attendees with a sense of patient-centered outcomes (PCOs) in patients with sleep apnea in relation to those with other medical conditions, such as chronic obstructive pulmonary disease, and differences in reported PCO's between patients and providers.

**Multiple Patient-Stakeholder Engagement Resource (MPSER).** Thirty-seven individuals have signed on to be part of the MPSER. The MPSER is a collection of patients and stakeholders with a range of expertise and interest in sleep and circadian rhythms. This sleep-specific patient-stakeholder engagement resource is designed to help both junior and established researchers in conducting patient-centered outcomes research (PCOR). The overarching goal of the MPSER is to engage patients, scientists, and other stakeholders across the entire span of sleep research from topic generation to conduct of studies to disseminating and implementing their research findings. MPSER also serves to “match-make” patients and stakeholders to research projects. **We are looking for individuals interested in PCOR, who would be willing to have their name and email contact listed in the MPSER directory.** From time to time, you may receive a 250-word abstract of a new PCOR project, engagement, or educational initiative in sleep and circadian rhythm disorders that is being proposed. You can then decide if you are interested in committing 1-hour of your time every 6 months to provide non-binding input into the project. You also have the option of not volunteering for any given initiative and can simply ignore the email request. Participation in the directory will keep you aware of cutting edge research in sleep and circadian sciences and provide opportunities to collaborate with individuals sharing your common research and educational interests. If you are interested in this opportunity please contact Cody Havens ([chavens@email.arizona.edu](mailto:chavens@email.arizona.edu)).

#### **SLEEP<sup>2</sup> upcoming events**

Save the date – The next SLEEP<sup>2</sup> meeting will be held in Boston on June 3<sup>rd</sup>, 2017. The thematic focus will be on Narcolepsy and co-led by Project Sleep.

The SRN is a membership organization of sleep and circadian researchers that was created in 2008 by sleep and circadian researchers from institutions that had received the National Institutes of Health (NIH) Clinical and Translational Science Awards (CTSA).



#### **SRN Mission Statement**

The mission of the SRN is to promote sustainable, multi-institutional collaborations that address significant public health questions in sleep medicine and circadian biology, while also attracting and supporting training for the next generation of sleep medicine investigators. We address our goals through an annual meeting, network communications and project development, and collaborative grant applications.

#### **SRN Newsletter**

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