



American  
Sleep  
Apnea  
Association

2018  
YEAR-END  
REVIEW

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# TABLE OF CONTENTS



PREFACE	04
A . W . A . K . E . PROGRAM	05
ONLINE EDUCATION / SOCIAL MEDIA / WEBSITES	15
CAP PROGRAM	19
SLEEPTEMBER PROGRAM	21
ORGANIZATION INFRASTRUCTURE	25
PEER-DRIVEN INTERVENTIONS	26
SOCIAL MEDIA DEVELOPMENT PROJECT	27
COPD / SLEEP APNEA O2VERLAP STUDY	29
SLEEPHEALTH APP	31
EVIDATION WEB-BASED SLEEP STUDY	33
CONCLUSION	34
DONOR LIST (APPENDIX)	35

**PREFACE :**

ASAA  
2018 YEAR-END REVIEW

**QUESTIONS?**

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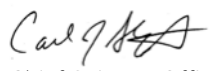
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**SLEEPAPNEA.ORG**

# THE AMERICAN SLEEP APNEA ASSOCIATION 2018 YEAR-END REPORT

The American Sleep Apnea Association (the ASAA), founded in 1990, is a patient-led nonprofit organization dedicated to the promotion of sleep health through research, advocacy and education. Our programs and research studies promote awareness of sleep apnea, provide low-cost PAP machines and supplies for patients, work for continuing improvements in treatments for this serious disorder, and advocate for the interests of sleep apnea patients.

This report details the activities and achievements of the ASAA during the 2018 calendar year, and will serve as the basis for our first official Annual Report, to be completed at the end of the ASAA's 2018/2019 fiscal year ending June 30, 2019. Unless otherwise specified, reported outcomes reflect all ASAA activities for each program through the end of October 2018.

  
Chief Science Officer

  
Chief Patient Officer





## PROGRAM OVERVIEW AND HISTORY

The “Alert, Well, and Keeping Energetic” (**A.W.A.K.E.**) Network of support groups was established in 1989 by a sleep technologist, Lucy Seger, with the support of a committee made up of Joyce Black, Nancy Kern, Jean Hardy, and Linda Napierala. Seger and the committee realized that patients living with sleep apnea could access an expert and impartial source of information on the condition, as well as benefit from a peer-to-peer support network.

The groups helped patients navigate the diagnosis and

treatment processes for sleep apnea, and the support group coordinators reported improved adherence to CPAP therapy among its participating members. The success of the **A.W.A.K.E.** groups was one of the main catalysts for the formation of the ASAA in 1990 – the organization formed to manage the **A.W.A.K.E.** groups and provide a clearing-house for information and education.

The **A.W.A.K.E.** program currently consists of a network of 71 in-person peer-to-peer support groups across America, guided by a curriculum developed by the ASAA, as well as an online [Facebook A.W.A.K.E. group](#). In 2018, the ASAA also conducted an **A.W.A.K.E.** survey, and shared the findings at a June conference with the FDA and in a report released in September.



THROUGHOUT THE YEAR, ASAA HAS TAKEN SEVERAL STEPS TO GROW THEIR **A.W.A.K.E.** COMMUNITY AND STRENGTHEN EXISTING **A.W.A.K.E.** GROUPS.

IN 2018, THE ASAA:

- 1 Developed the first official curricula modules for the peer support groups based on the needs, preferences, and interests expressed in the **A.W.A.K.E.** survey.  
  
Read **Survey, Conference, and Report** on [pg.10](#) to learn more.
- 2 Invited 1,800 healthcare providers from our database to start additional **A.W.A.K.E.** support groups.
- 3 Hosted a new webinar in which **A.W.A.K.E.** coordinators from our oldest and largest **A.W.A.K.E.** groups take turns providing education on **A.W.A.K.E.** group management to other local coordinators.
- 4 Worked with **A.W.A.K.E.** group facilitators to increase email sign-ups at meetings to bring patients into our online community.

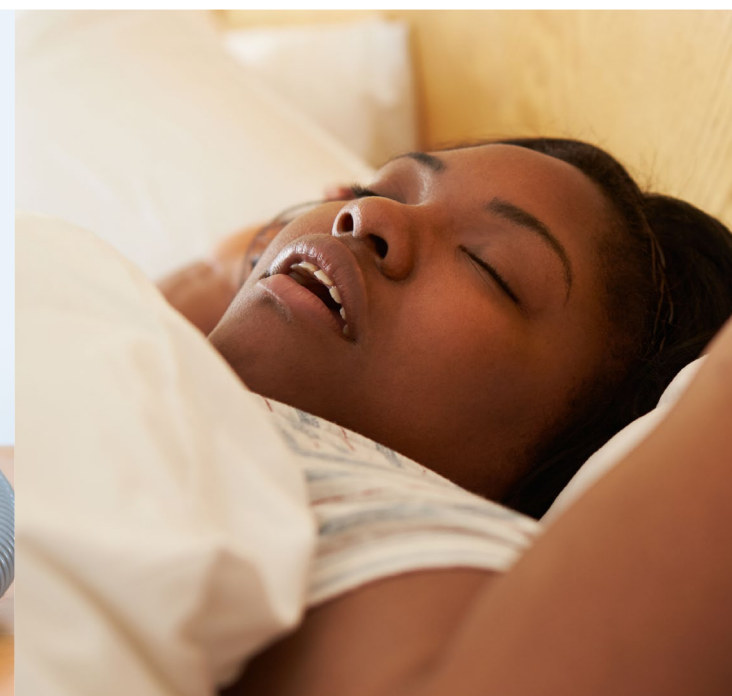
## 2018 ACTIVITIES AND ACHIEVEMENTS:

### **A.W.A.K.E.** PEER-TO-PEER SUPPORT GROUPS:

In-person peer-to-peer support groups are the heart of the ASAA's **A.W.A.K.E.** program. It is the ASAA's firm belief that patients have tremendous expertise and insight on the journey through diagnosis and treatment of their medical conditions, and are valuable resources and mentors for newly diagnosed patients experiencing sleep apnea. Last year, the ASAA

focused on growing and reinvigorating our **A.W.A.K.E.** program, including our peer-to-peer support groups.

Prior to 2018, participation in the **A.W.A.K.E.** support groups and formation of new groups had been waning for several years. During 2018, the ASAA reinvigorated the **A.W.A.K.E.** program, increasing the number of **A.W.A.K.E.** groups from 60 to 71 groups across the country, with an approximate average of 25 attendees (new and returning) per session. Meetings are held monthly or quarterly, depending on the location. These meetings provide a forum for patients to encourage each other and provide practical advice and tips to those new to sleep apnea.





## A.W.A.K.E. SURVEY, CONFERENCE & REPORT



In 2018, the ASAA was presented with the opportunity to participate in one of the Food and Drug Administration's (FDA's) Patient Focused Medical Product Development (PFMPD) meetings, in which the FDA learns about patient experiences through direct contact with patients.

In preparation for our June 8, 2018 "A.W.A.K.E. Sleep Apnea" conference with the FDA, the ASAA fielded a Patient & Caregiver Survey to capture a broad set of patient experiences and inform the discussion at the meeting. Patients were drawn from the ASAA's online network, and through patient-generated-data organization Evidation. When the survey period closed, 5,630 people had responded to the 32-question survey, 98% of whom were patients diagnosed with sleep apnea by a medical professional. The results of this report were presented at the

conference and then discussed by the audience.

The conference included two panels of 5 patients each, who were sponsored by the ASAA to attend the meeting and tell their stories to the audience. Patients were invited from around the country and represented a diverse cross-section of people living with sleep apnea (age, race, gender, income level, date of diagnosis, etc.) Each of these 10 panelists also worked with a video team to give one-on-one interviews about their experiences of living with untreated sleep apnea, being diagnosed, and working to find successful treatment(s). These videos, along with patient and practitioner interviews from other meetings, became our "Profiles of Sleep Apnea" series, available on the [ASAA's YouTube channel](#).

The A.W.A.K.E. conference was attended by 87 people in-person, and 378 people

participated via online live streaming. Since the conference, there have been 1,410 views of the full webcast, plus 420 views of the broken-out sessions on [YouTube](#). A live broadcast on Facebook reached 7,007 people, with 1860 views of the videos and 158 reactions/comments/shares.

During summer 2018, the ASAA collated and analyzed the survey data and reviewed the conference panels, and wrote an 88-page report about our findings. This report highlights several priority areas that the ASAA will focus on in 2019 and beyond, including:

- Getting Help: While 29% percent of patients sought treatment because of worsening symptoms, fully half were convinced by family or friends to seek treatment. Since sleep events occur while the patient is unaware, it is critical for caregivers to notice and mention symptoms.

- Treatment Impact: Prior to treatment, 44% of respondents reported moderate symptoms and 37% said their symptoms were severe. However, even after treatment, 29% of respondents still reported moderate symptoms and 5% still had severe symptoms. This indicates that while existing treatments help a lot of people, there are still people who need other options. People may also need help identifying other health conditions that can accompany sleep apnea.
- PAP is King: 69% of respondents were currently using a positive airway pressure machine (CPAP, APAP, BiPAP), while 12% had used one in the past but not anymore. Only 7% of respondents were using an oral appliance (down from 11% in the past).

- Barriers: PAPs can be hard to use. 53% of survey respondents found them uncomfortable, 48% said it's inconvenient, and 34% had financial issues with PAP treatment.
- Supportive Strategies: People used a number of supportive strategies to help them manage their sleep apnea. Top of the list was weight loss, with 51% of respondents working to shed some pounds. 33% of patients used sleep positioning, and 29% used alcohol avoidance. Extended sleep times, increased caffeine, relieving nasal congestion, and meditation/ mindfulness were also common strategies.

One of the ASAA's priorities for 2018 was to disseminate the **A.W.A.K.E.** report within our community of patients, healthcare providers, conference sponsors and partners, and the national media. The report's

dissemination and resulting publicity / metrics are summarized below.

- Report and press release emailed to over 8,000 media outlets across the country.
- Mailed full report to panelists, meeting sponsors, and meeting non-profit partners.
- Associated Press published an article by Carla K. Johnson on July 12, 2018 about the conference and sleep apnea.
- Email notifying 429 conference attendees that the report was available.
- A dedicated email was sent to our mailing list of 22,023 consented emails.
- The report announcement was included in our September eNewsletter sent to 22,219 recipients.
- Report announcements were posted on our [Facebook page](#) with 92,051

followers, 1,364 people reached, 37 likes, comments & shares, and 35 post clicks.

- The report announcement and link were posted to [awakesleepapnea.org](#) (96,554 unique users in September 2018) on Sept 5th and featured on 2 pages – these pages had 861 visits Oct 5th – Nov 15th, with an average of 2 minutes spent on the page.
- Webinar specifically to announce and discuss the report, 81 registered attendees, and broadcast on Facebook LIVE reached 3,531 people, had 1033 video views, and 80 likes, comments & shares. There were 18 additional views on [YouTube](#) after the live broadcast.

This webinar was promoted via several emails and social media for further reach and awareness.

- Posted several times to the 3 [ASAA](#) [Twitter](#) accounts with a total of

8,956 followers (although there is over-lap with followers across the different ASAA accounts), 16 retweets, 289 clicks.

- Report announcement posted on [LinkedIn](#) by Adam Amdur with 2,567 followers and the ASAA with 1,331 followers.
- Radio interview with WVOM Morning Drive Radio in Bangor, Maine (156 Market).
- Outbreak News podcast (hundreds to thousands of listeners worldwide).
- Diane Atwood "Catching Health" blog.
- Listicle for USA Today Patient Tips for Sleep Apnea - published Sept. 28, 2018, in print edition.

## A.W.A.K.E. FACEBOOK GROUP



In February 2018 the ASAA started a new **A.W.A.K.E. SleepHealth Facebook group**, which now has 1,241 members participating in an **A.W.A.K.E.** online community. This forum is a private group just for sleep apnea patients and caregivers. The group is growing rapidly: it has already gained over 250 new members since June 2018.

Starting in February 2018, the ASAA also launched a series of Facebook Live events to discuss various aspects of living with sleep apnea. The host, Kevin Bradley, is a RN by training, and

is currently a transplant coordinator, trainer, and CPAP user. The ASAA has hosted 7 Facebook Live events in 2018, growing from 155 participants in February to 1,600 by June. Topics included CPAP Masks and Fit, CPAP Pressure Setting, Discussion of June's **A.W.A.K.E.** Sleep Apnea Mtg, a Reconvene with the **A.W.A.K.E.** Sleep Apnea Panelists, and Sleptember 2018 Activities. Kevin also hosted a closed **A.W.A.K.E.** Network webinar to entice more groups to join, and to announce the four new curriculum modules.

## A.W.A.K.E. NEXT STEPS FOR 2019

1. Grow the number, size, and engagement in peer support groups.
2. Develop four more new curricula modules for peer support groups.
3. Work with **A.W.A.K.E.** group coordinators to track unduplicated participants and encourage participants to sign-up for the ASAA's email list.
4. Train **A.W.A.K.E.** group coordinators to help them optimize their **A.W.A.K.E.** groups.
5. Continue to distribute the **A.W.A.K.E.** Sleep Apnea report to patients, caregivers, healthcare providers, insurance companies, device manufacturers, pharmaceutical companies, regulators, and media outlets.
6. Write up the survey results into one or more peer-reviewed research papers for publication in medical journals.
7. Promote the **A.W.A.K.E.** [Facebook group](#) and continue the rapid expansion of members.

## ONLINE EDUCATION / SOCIAL MEDIA / WEBSITES



### OVERVIEW & HISTORY:

Social media and online content are essential mediums for communicating with our sleep apnea community, allowing us to reach a national audience without prohibitive expenses. The ASAA has a social media presence on [Facebook](#), [YouTube](#), [Twitter](#), [LinkedIn](#), and [Instagram](#) as well as a large email list and three difference websites ([Sleepapnea.org](#), [Sleeptember.org](#), and [Sleephealth.org](#)). We also host educational webinars monthly.

### 2018 ACHIEVEMENTS:

#### WEBSITES

The ASAA has three difference websites:

- [Sleepapnea.org](#) is our main online “home”, which provides general sleep apnea education and discusses all of the ASAA’s programs. In September 2018, the main ASAA website had 92,895 unique users and 147,396 page-views.
- [Sleeptember.org](#) is dedicated to our annual Sleeptember awareness and engagement campaign. Unfortunately, due to glitches with the Google Analytics coding on the Sleeptember website, we do not have metrics specific to the Sleeptember site. See the Sleeptember section below for additional details on Sleeptember activities and results.
- [Sleephealth.org](#) educates people about sleep health and encourages them to download and use our

SleepHealth app. Our [Sleephealth.org](#) website had 90,539 visits and 390,240 page-views. Please see the SleepHealth description in the “Research” section below for more information.

#### WEBINARS

Most months, the ASAA hosts at least one webinar on Zoom covering various topics related to co-occurring conditions, medical research, sleep mechanics, special populations’ experiences of sleep apnea, and more. Participants can listen to the expert discussion and submit their own questions to our presenters. Webinars cover a different topic each month, and the previous 12 months of webinars are available on our [YouTube](#) channel to watch on demand. From January to October 2018, the ASAA hosted 14 webinars, including (with number of attendees):

- REM Behavior (42)
- Brain on lack of sleep (10)
- Pediatric Apnea (1,000)
- Types of sleep apnea (1,900)
- Gender and LGBTQ in research (572)
- **A.W.A.K.E.** Initiative (405)
- Why Participate in Research? (539)
- Veterans & Sleep (382)
- **A.W.A.K.E.** Group – General Population (80)
- Sharing Research w/Patients (113)
- FDA Report Results (819)
- Insomnia (120)
- OTC Sleep Aids (150)
- **A.W.A.K.E.** Curriculum Roll-out (50)

#### EMAIL

The ASAA sends out a monthly eNewsletter to our mailing list of 22,023 consented emails. The e-mail list is continually growing, and provides updates on the ASAA’s activities, links to



research, articles with tips about living with sleep apnea, and other content of interest to patients, caregivers, and healthcare providers.

## FACEBOOK

The ASAA's main [Facebook page](#) has 92,051 followers, and the ASAA staff post articles, updates, quizzes, and other content multiple times per day. The ASAA also has a closed [A.W.A.K.E. SleepHealth Facebook group](#), described in the **A.W.A.K.E.** section.

## YOUTUBE

Our [YouTube](#) channel contains our 19 "Profiles of Sleep Apnea" interviews, webinars from the previous 12 months, sessions from the **A.W.A.K.E.** Sleep Apnea conference, overviews of our sleep research projects, and other informational videos about healthy sleep. There are currently 55 active videos available.

## TWITTER

The ASAA has three Twitter accounts ([ASAA's main account](#), the [Sleeptember](#) account, and the [SleepHealthApp](#) account) with a total of 8,956 followers (some duplicated). In September 2018, our Twitter accounts had 16,000+ tweets. Hashtags we're using include #ASAA, #sleephealthapp, #sleeptember, #apnea, and #sleephealth.

## LINKEDIN

The ASAA has 2,500 followers on [LinkedIn](#), including many healthcare professionals. This makes [LinkedIn](#) an excellent way to communicate with the healthcare community about our research projects, study findings, patient experiences, and other content that can help healthcare professionals provide more patient-centered care.



## INSTAGRAM

The ASAA uses [Instagram](#) to increase the reach of our visual content, including the Profiles of Sleep Apnea series, recorded webinars, infographics, and pictures.

## ONLINE NEXT STEPS FOR 2019:

With our communities' need for more instruction, we will continue to produce

engaging and educational content for [YouTube](#) with additional videos, including co-occurring condition information sessions. We will also continue our extensive online engagement via other social media platforms, including [Facebook](#), [Twitter](#), [Instagram](#), and [LinkedIn](#), in addition to our extensive e-mail list, and the [ASAA](#), [Sleeptember](#), and [Sleephealth](#) websites.

## CPAP PROGRAM OVERVIEW AND HISTORY:



### CPAP Assistance Program

Do you need a **CPAP** but can't afford it?  
We can help!

Do you have a **CPAP** you don't use?  
Donate it to help someone else.

In 2010, the ASAA started our CPAP Assistance Program, which provides low-cost CPAP machines and supplies to low-income, uninsured, or underinsured sleep apnea patients. No one should go untreated due to financial hardship or other issues. It is our goal to help as many patients as possible get the treatment that they need.

CAP offers patients with sleep apnea access to machines and resupplies at greatly discounted cost. CAP provides CPAP machines for a program fee of \$100, and offers CPAP masks for \$25 each. Anyone can apply for

the program if they need a machine or supplies, so long as they have a prescription from their doctor for a CPAP machine.

Some CPAP machines are donated to the program by Durable Medical Equipment providers such as ResMed, SecondWindCPAP, and Philips Respironics. We also accept private donations of new or gently used CPAP machines and new, sealed supplies.

### 2018 ACTIVITIES AND ACHIEVEMENTS:

The CAP program provides between 160 to 200 CPAP machines per month to patients, and receives about the same number of donated machines

monthly. Program fees defray the staff and administrative costs of running the program, helping ensure its sustainability, and help ensure patients' investment in using their new CPAP.

The CAP program receives a high volume of phone calls from patients inquiring about the program or following up on their CAP application. For example, over a two-week period in fall 2018, the CAP program received 297 calls; 31% requesting CAP information, 43% calling to discuss their CAP application status, 10% interested in making a CAP donation, 3% asking for equipment support, and 3% miscellaneous referrals.

### CAP NEXT STEPS FOR 2019:

- Expand supply of CPAP machines and supplies by increasing donations from individuals, medical device companies, and healthcare providers.

- Expand the variety of CPAP, Bi-PAP, and Auto-PAP machines and supplies that the ASAA has available through the CAP program.
- Increase awareness of the CAP program among sleep apnea patients, caregivers, and healthcare providers so that we can serve more people.



## SLEEPTEMBER OVERVIEW AND HISTORY:



The ASAA created Sleeptember in 2014 to engage our community and inform the public about sleep apnea. Over the last five years, the ASAA has tested a variety of techniques designed to increase patient participation in ASAA activities and raise awareness about sleep apnea in the general public. Some of these attempts were more successful than others. For example, the ASAA had a lot of success getting people to take a quiz that screened for sleep apnea symptoms. However, we did not see much engagement with our “Bedhead Selfie” initiative or our “Go Dark” campaign to power down devices at night and create a conducive sleep environment. We are

continually brainstorming new ideas for Sleeptember and working on the best messaging to communicate important information.

### 2018 ACTIVITIES AND ACHIEVEMENTS:

Each year, Sleeptember centers on a theme that ASAA has been working on that year. In 2018, our featured project was the creation and airing of 19 “Profiles of Sleep Apnea” video interviews with sleep apnea patients, caregivers, and providers. These videos were popular, with a combined total of 1,036 [YouTube](#) views.

Awareness e-mails were another important part of Sleeptember 2018 – the ASAA sent out five emails to our

mailing list, including two newsletters, two invites for Sleeptember webinars, and the unveiling of the **A.W.A.K.E.** Sleep Apnea report. These emails had higher than average open and click through rates, indicating a high level of community engagement with the materials.



- Newsletter - Sept 1: 17.2% open, 7.8% click through
- **A.W.A.K.E.** Sleep Apnea meeting report - Sept 5: 17.4% open, 5.7% click through
- Webinar invite: **A.W.A.K.E.** Sleep Apnea - survey results: 18.4% open, 4.8% click through
- Newsletter - Sept 19: 19.8% open, 5.9% click through

- Webinar invite: Insomnia: 17.5% open, 4.9% click through

[Facebook](#) engagement was also high for Sleeptember 2018, exceeding average monthly levels.

Video views were up 106%, post engagement was up 58%, the ASAA gained 220 new Sleeptember page followers, and reached 19,000 people. Patient stories averaged 800 reach on [Facebook](#) with an average of 40 engagements per post (likes, shares, comments etc.). We had 68 new email sign-ups through our [Sleeptember website](#). The ASAA also made 31 posts to [Instagram](#) for Sleeptember2018, and had 62,300 [Twitter](#) impressions for SleepApneaOrg. The hashtag #sleeptember2018 was used approximately 1,600 times across [Twitter](#) and [Instagram](#).



Unfortunately, website visitor data is not available for the Sleepتمبر 2018 website due to a technical issue.

In addition to featuring the “Portraits of Sleep Apnea” series of stories, the ASAA also invited community members to share their own stories throughout Sleepتمبر. This initiative had a small response rate in 2018, with 7 patients submitting stories during the month. The ASAA would like to substantially increase this number in 2019.

Donations are another area where the ASAA hopes to improve in future years. Dedicated fundraising asks

were not a formal part of Sleepتمبر 2018, but we did include soft asks for donations across several platforms.

While fundraising is a secondary goal for Sleepتمبر, we hope to make it a more formal and successful part of Sleepتمبر 2019.

The ASAA is extremely grateful to our partners who helped get the word out about Sleepتمبر 2018. These partners include Health-e-Heart Alliance, CMB Solutions, Atrial Fibrillation Support Forum, StopAfib, RemZzzzs, Paralyzed Veterans of America, Debbe McCall, F&P Healthcare, The PRIDE Study, Dr Michael

Grander, and many other individuals amplifying the reach of the campaign.

### **SLEEPTEMBER NEXT STEPS FOR 2019:**

Sleepتمبر has been successful as a tool for patient education. However, for 2019 the ASAA would like to increase the impact of Sleepتمبر by finding ways to engage patients and the public in more active ways. For example, we would like to see our community taking surveys, sending in pictures and stories, signing up for our email list or our SleepHealth app, and making donations to support the ASAA.



## ORGANIZATION INFRASTRUCTURE OVERVIEW AND HISTORY:

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There is tremendous demand for sleep health information within the sleep apnea community. In the last year, the ASAA received 17,000 phone calls from patients requesting sleep apnea information, resource referrals, or direct assistance. We also received at least six requests per day for information or assistance on Facebook, and additional daily requests through Twitter and email.

To meet this demand, the ASAA is increasing its infrastructure to respond to individual patient questions. We have added two (2) customer service

representatives to assist with this ever growing need. Our main telephone line has a dedicated person to answer calls and questions during regular business hours, this will allow for better customer service and less direct to voicemail calls. Another customer service addition has been focused on responding to inquiries via emails and online. Our efforts to respond, answer and assist our community is of the upmost importance.

Inquiries we receive from patients also generate topics for our online education, forming a feedback loop that keeps our education efforts relevant.

## PEER-DRIVEN INTERVENTIONS OVERVIEW AND HISTORY:

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In 2014, the ASAA collaborated with Dr. Sairam Parthasarathy, MD of the University of Arizona to initiate a PCORI-funded study looking at whether peer support could help encourage CPAP adherence (officially, the “Peer-Driven Intervention as an Alternate Model of Care Delivery and Coordination for Sleep Apnea” study). The study sought to determine whether peer driven interventions could increase patient satisfaction with care delivery and coordination, increase adherence to CPAP treatment and self-efficacy of patients, and improve patient outcomes.

Community health education volunteers (“peer-buddies”) who are experienced in managing their condition help newly diagnosed patients develop knowledge and confidence around using their CPAPs. Additionally, the project developed a telephone exchange that

improves access to healthcare providers, technicians, and home care companies. The study hoped to show that active community participation by experienced “lay individuals” assisted by the increased availability of cell phones can improve the reach and effectiveness of the healthcare system.

### 2018 ACTIVITIES AND ACHIEVEMENTS:

In July 2018, the research aspect of the project was concluded, and Dr. Parthasarathy started the process of analyzing the data and drafting a final manuscript.

### PEER-DRIVEN INTERVENTION

#### NEXT STEPS FOR 2019:

In 2019, Dr. Parthasarathy will complete the manuscript for publication in peer reviewed journals, and the ASAA will help to publicize the results of the study.

## SOCIAL MEDIA DEVELOPMENT PROJECT OVERVIEW AND HISTORY:

In March 2016, the ASAA was awarded funds from PCORI for its project “Using Social Media to Develop and Maintain Patient and Stakeholder Relationships in the Sleep Community”. The project ran from March 2016 to March 2018, and focused on growing our community, developing our messaging, and learning to create communications that resonated with our audiences, leading to the ASAA becoming a trusted and valued source of information.

Project activities included targeted social media campaigns, engaging the community in sweepstakes, and developing and executing webinars. These strategies were helpful for “warming” our community and building trust, leading to increased social media followers who were more engaged with our content. Social media is constantly evolving and the ASAA had to make adjustments to our strategies. Some social media lists were merged and/

or retired, while others were cultivated and expanded. Our virtual community looks much different now than it did in 2016, and is both larger and more efficient.

### 2018 ACTIVITIES AND ACHIEVEMENTS:

During the course of this project, which concluded in March 2018, the ASAA realized the following achievements and gained the following insights about our social media engagement:

- The ASAA saw community growth and increased engagement across many platforms, including Facebook, Twitter, LinkedIn, and Instagram.
- Previously separate email lists have been cleaned and merged, and are now maintained within Salesforce.
- The “warming” process of building relationships with a community takes a long time. It took the ASAA the full two years to really build a community that trusts our content and shares it with others.

- The ASAA refocused our definition of engagement on patients speaking to us, not just us speaking to them. Engagement became more about interactions and conversations instead of broadcasting a “one-size fits all” message. For example, the ASAA staff realized the webinar format is “one-way” with us presenting information and then hoping for questions or engagement at the end. These webinars also run the risk of being too technical for some audiences. The ASAA therefore launched Facebook Live events, which are more accessible presentations that engage participants in real-time.
- One interesting result we learned through survey deployment was that our community engages at different times, all hours, all days. This could be directly linked to our population, which keeps different hours related to sleep. Since this is atypical of online communities, we didn’t follow the traditional model of best times to send emails and surveys, but deployed a model that worked for our specific community.

- The ASAA learned that our patients are very engaged and possess a high level of social media sophistication. For a patient community to be active and engaged they need to know they are making a difference, and we are that voice/vehicle for them.
- Many patients cannot afford to help with donations and monetary support, but they can make a difference by sharing their knowledge and stories.
- Patient engagement must be personal, not automated, and tailored to meet the specific strengths of each social media platform. This can take a considerable amount of staff bandwidth and can be a challenge to maintain as our community continues to grow. In order to overcome this challenge, we are clarifying staff roles and hiring on new consultants and contractors as needed.

### SOCIAL MEDIA NEXT STEPS

#### FOR 2019:

In 2019, the ASAA will continue to apply the lessons learned from this study as we grow our social media community and adapt our social media strategy.



## COPD / SLEEP APNEA O<sub>2</sub>VERLAP STUDY OVERVIEW AND HISTORY:



About 60% of people with both COPD and obstructive sleep apnea (known as “Overlap Syndrome”) do not use their PAP machines as prescribed. This non-adherence limits the effectiveness of treatment, and increases the risk of flare-ups and hospitalizations.

To address this problem, in 2016 the ASAA and the COPD Foundation applied for and received a joint research

grant from PCORnet, the National Patient-Centered Clinical Research Network, which is an innovative initiative of the Patient-Centered Outcomes Research Institute (PCORI).

The project is titled “Monitoring and Peer Support to Improve Treatment Adherence and Outcomes in patients with Overlap Chronic Obstructive Pulmonary Disease and Sleep Apnea via a Large PCORnet Collaboration

(O<sub>2</sub>VERLAP).” The study investigates if PAP patient-generated data monitoring and an interactive online classroom will help people living with Overlap Syndrome use their PAP devices properly.

### 2018 ACTIVITIES & ACHIEVEMENTS:

- The ASAA has been actively promoting the research study and helping with recruitment throughout 2018. The study had 330 initial sign-ups, of which 165 enrolled.
- The ASAA assisted in creating the O2verlap curriculum, preparing 4 of the 7 curriculum modules (including an introduction to sleep apnea, two modules on CPAP usage and care, and a module on using oxygen with CPAP therapy).

### O<sub>2</sub>VERLAP STUDY NEXT STEPS

#### FOR 2019:

The recruitment phase of the study will close in April 2019, and the study

will conclude on July 31, 2019. Final deliverables will include a scientific paper analyzing the main study results. The principle investigators may also produce a second manuscript about the efficacy of using electronic methods to recruit research participants on a national level.

To **learn more** about the O<sub>2</sub>VERLAP study, please visit [o2verlap.org](http://o2verlap.org).

## SLEEPHEALTH APP OVERVIEW AND HISTORY:

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SleepHealth is a Mobile App Study and Wellness tool created by the ASAA and the University of California San Diego and powered by Apple's ResearchKit and IBM Watson Health Cloud. The app and study were designed and funded through the contributions of a small all-patient team of scientists, physicians, advocates and technology experts dedicated to health and data discovery in order to accelerate patient-centered and citizen research.

The SleepHealth app is a personalized tool that helps patients gain greater insight into their sleep habits and sleep issues, learn how sleep is associated with other conditions they may have, and take charge of their health. Patients can keep track of their daily physical activity, sleep habits and daytime alertness in order better understand

how their sleep impacts their health, safety, productivity and well-being. The app also provides daily checklists for getting a good night's sleep.

This study is unique in that it allows participants to be equal partners in both the monitoring of their symptoms and impact of sleep loss, as well as helping to direct future research through participating in our community forum at <https://www.sleephealth.org> or engaging with the [SleepHealth Blog](#).

### ACTIVITIES AND ACHIEVEMENTS:

In 2018, the SleepHealth app enrolled 1,711 new participants, and has been continually gathering data from study participants.

### SLEEPHEALTH APP NEXT STEPS FOR 2019:

The project is in the third year of the three-year study, which will conclude March 2019, though the app will continue uninterrupted after the study ends. Study results will then be analyzed and presented in a scientific article for publication in peer-reviewed medical journals. Study results will then be analyzed and presented in a scientific article for publication in peer-reviewed medical journals.

For 2019, the ASAA is looking to create the next iteration of the SleepHealth app. Specifically, the ASAA will evaluate moving the app away from its current research emphasis to a personal health monitoring focus. The revised app would include improvements to the user interface and a new focus on risk assessment and patient generated data (PGD) monitoring.



## EVIDATION WEB-BASED SLEEP STUDY OVERVIEW AND HISTORY:

In 2017, the ASAA collaborated with Evidation Health, a tech company specializing in online tracking of patient generated data, to launch a research study - "Accelerating Research with Technology: Rapid Recruitment of a Large-Scale Web-based Sleep Study". The aim of this study was to investigate a method for speeding up the recruitment process and maximizing participant engagement in sleep research using a novel approach, the Achievement Studies platform created by Evidation Health, Inc. Specifically, the study examined the relationship between participant sleep and daytime function.

Participants could access the web-based study platform at any time from any computer or web-enabled device to complete study procedures and track study progress. Eligible participants

enrolled and were then asked to connect a wearable device account through their study dashboard, which shared their device data with the research team. The data were used to provide objective sleep and activity metrics for the study. Participants were also sent a daily single-item Sleepiness Checker activity for 7 consecutive days at baseline and every 3 months thereafter for 1 year.

The ASAA helped Evidation recruit participants for the study through our patient database. 1,156 participants enrolled in the study within a 5-day recruitment window of March 24 – 29, 2017. 1,000 participants (86.5%) provided activity-specific wearable data and 982 (84.9%) provided sleep-specific wearable data.

### 2018 ACTIVITIES & ACHIEVEMENTS:

Ongoing data collection was concluded on March 31, 2018, and the researchers are now engaging in data analysis.

### EVIDATION NEXT STEPS FOR 2019:

The Achievement Studies platform allowed for rapid recruitment and high study engagement (survey completion and device data sharing). This approach to carrying out research appears promising. However, conducting research in this way requires that participants have internet access and own and use a wearable device. In 2019, the researchers will develop and publish a manuscript of their findings for publication in peer-reviewed journals.

## CONCLUSION:



**2018** has been a year of landmark firsts and rapid growth for the ASAA and its programs. We are particularly proud of the **A.W.A.K.E.** survey, conference, and report; the expansion of our **A.W.A.K.E.** peer support groups; the creation of 4 new **A.W.A.K.E.** curriculum modules; the creation and expansion of the **A.W.A.K.E. Facebook group**; stabilizing our CAP inventory and increasing the number of CAP monthly recipients; and the successful research partnerships with PCORI and the COPD Foundation. We look forward to continuing these initiatives into 2019!

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