



# AMERICAN SLEEP APNEA ASSOCIATION ANNUAL REPORT

FISCAL YEAR REPORTING FOR JULY 1, 2018 – JUNE 30, 2019

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# WELCOME

Dear Patients, Caregivers, and Patient Advocates,

It's been a momentous time here at the American Sleep Apnea Association (ASAA)! We started our fiscal year off gathering together the stories and data from our first ever AWAKE Sleep Apnea Survey and Summit. Patients told moving stories about their struggles with sleep apnea, and over 5,600 of you shared details of your sleep apnea journey through our 2018 survey. The AWAKE Sleep Apnea Report was released during our annual Sleepember awareness campaign, along with multi-media stories from patients. The rich data on patient experiences collected in this report will help guide our educational efforts and research goals for the next several years.

This fiscal year has seen the conclusion of several major research studies in which the ASAA was involved, such as our O2verlap study with the COPD Foundation and our SleepHealth App Study. We look forward to sharing results from this research with you in FY19/20. We are also proud to announce that the ASAA has launched a completely new website, with more content and new ways for patients to connect, share, learn, and get involved!

One of our focal themes this year has been to take a multi-disciplinary, holistic approach to sleep apnea diagnosis and treatment, and identifying issues where we can improve patient experiences and outcomes. Our fiscal year ended this summer with preparations for another AWAKE survey to gather patients' perspectives on these issues. The ASAA's AWAKETogether Summit in California focused on this interdisciplinary approach and patient-identified barriers to effective sleep apnea treatment.

This Annual Report details the activities and achievements of the ASAA during the 2018/2019 fiscal year ending June 30, 2019. Unless otherwise specified, reported outcomes reflect all ASAA activities for each program through the end of June 2019. We thank all of you for making the ASAA part of your sleep journey, and we look forward to working with you over the next year to improve the lives of sleep apnea patients!

Sincerely,



Adam Amdur  
ASAA Board Chair and Chief Patient Officer



Carl Stepnowsky, PhD  
Chief Science Officer





## ASAA PROGRAMS

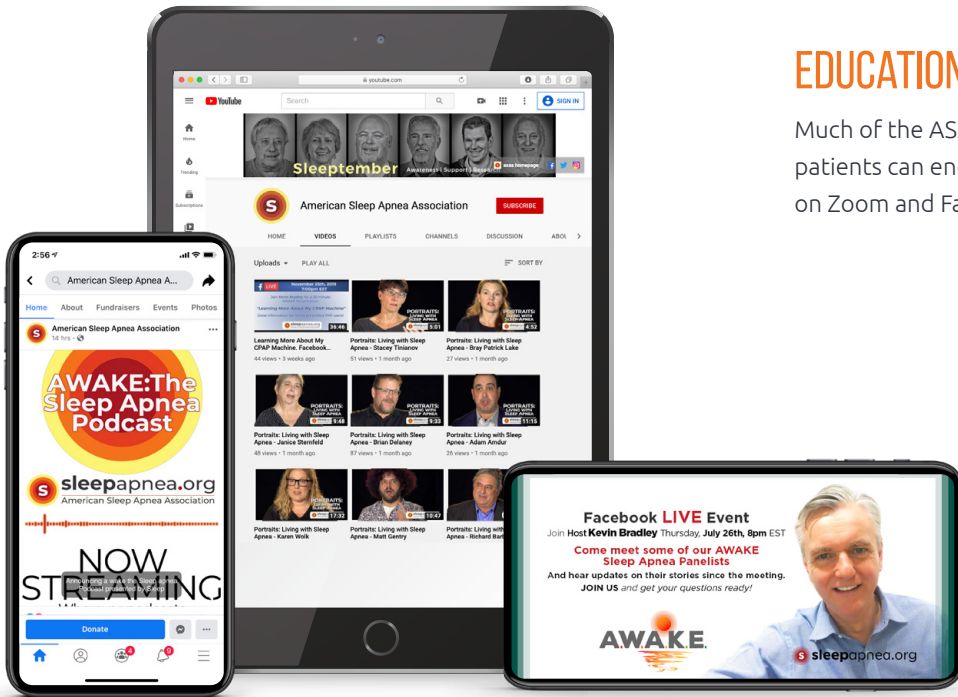
The mission of the American Sleep Apnea Association (ASAA) is to improve the lives of sleep apnea patients. We accomplish this mission through education, services, peer-support, research, and advocacy. At the ASAA, we envision a world in which no one suffers from sleep apnea because it is easily diagnosed and cured. In the meantime, we work towards a world in which sleep apnea is promptly diagnosed in adults or children; treatments are affordable, convenient, and highly effective; and patient voices are an essential element guiding healthcare delivery.



## AWAKE

The “Alert, Well, and Keeping Energetic” (AWAKE) Network of support groups provides in-person and online support for sleep apnea patients and caregivers. In FY18/19 the ASAA developed the first official curricula modules for the peer support groups based on the needs, preferences, and interests expressed in our 2018 AWAKESleepApnea Survey. This curriculum was rolled out to our in-person groups, and presented live to our AWAKE Sleep Health Facebook group. In FY18/19:

- The ASAA AWAKE website forum has **1,462 registered users**. In addition to registered users (who can comment on posts) there are an **additional 9,800 (average per quarter) users** who visit and read the forum.
- The AWAKE Sleep Health Group on Facebook had **1,421 active members**.
- There were **44 active AWAKE groups** across the country, including 10 added in FY 18/19. The ASAA actively supports our existing AWAKE groups and encourages more groups to join. As we propel the program forward, we are focusing our efforts on growing the online AWAKE community via our Facebook Group (AWAKE Sleep Health), our online Forum and through an increased output of registered webinars and events.



## EDUCATION & AWARENESS PROGRAMS

Much of the ASAA's educational materials are shared across our social media channels, where patients can engage and discuss the content within a community of peers. We also host events on Zoom and Facebook Live, which covered topics of interest to sleep apnea patients.



ASAA Facebook page has **92,357 followers**

AWAKE Sleep Health Group on Facebook has **1,421 active members**

Offered **12 LIVE events** on Facebook and Zoom, with an average attendance of **808 people**. Topics included Pain and Sleep; Sleep Aids; Learning About My CPAP; several AWAKE curriculum modules; and patient interviews



**1,309,472 visitors** to sleepapnea.org and **2,630,025 page-views** for the fiscal year



**2,685 LinkedIn group members** and **1,805 followers**



Grew YouTube channel subscribers from 17 to **141**, and views from 1,600 to **6,100**



**9,122 Twitter followers** @sleepapneaorg @sleepember @SleepHealthApp. Tweets gained **380K impressions** over the year



E-mail newsletter list of **31,810 subscribers**



Attended **10 sleep conferences**, including the 2019 AASM SLEEP conference, providing educational materials on sleep apnea to patients, academics, industry representatives, and medical professionals



“Thank-you very much,  
if it wasn’t for this  
program I wouldn’t  
be able to afford a  
replacement for my  
damaged machine  
for a very long time.”

– William M, NE



## CPAP ASSISTANCE PROGRAM (CAP)

The CPAP Assistance Program provides low-cost CPAP machines and supplies to low-income, uninsured, or underinsured sleep apnea patients. At the ASAA, we believe 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.

In FY18/19, the CAP program provided between 177 to 314 CPAP machines or supply packages per month, for a total of **2,684 CPAPs and supply packages shipped!**

The CPAP Assistance Program relies on donations of machines and supplies from equipment manufacturers, and donations of gently used machines from individuals. If you have a gently used CPAP machine or new supplies (in unopened packaging) that you would like to donate, please visit the CAP page on our website for [donation instructions](#).

We would like to thank ResMed for their **donation of 1,300 CPAP machines**, and AeroFlow/Moffit for their donation of 1,034 masks! If your company would like to donate CPAP machines or supplies, please contact our CAP Program Manager via email [manager@sleepapnea.org](mailto:manager@sleepapnea.org).





## SLEEPTEMBER 2018

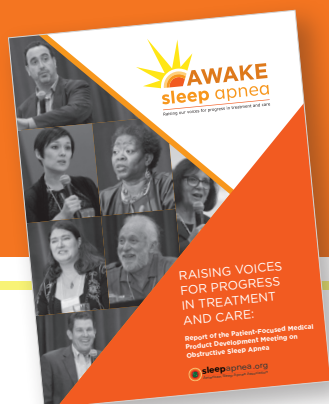
Sleeptember is the ASAA's annual, month-long September campaign to connect the dots between sleep and your quality of life. During Sleeptember 2018, we released our [AWAKESleepApnea Report](#), from our June 8, 2018, Patient-Focused Medical Product Development Initiative with the FDA. The report summarized the findings from our 2018 AWAKESleepApnea Survey of **5,630 patients and caregivers**.

The ASAA also hosted a "Profiles of Sleep Apnea" series for Sleeptember, with written stories, photographs, and video interviews of sleep apnea patients, caregivers, and physicians. We released a new portrait each day in September to highlight the diverse experiences of real people living with this disorder.

"Difficulty thinking and with memory was one of the scariest aspects of sleep apnea. I had difficulty recalling words. I was very forgetful about bringing things with me places or what my children had just asked me to do with them. Losing my cognitive ability was one of the things that

prompted me to seek out treatment."

– Erin Taylor, CO



< Click to read the full report



Click above to watch "Profiles of Sleep Apnea" series





## RESEARCH

In order to improve sleep apnea treatments and patient experiences, the ASAA partners with academic experts to conduct patient-centered research into sleep apnea and related conditions. Our two most prominent studies in FY18/19 were the O2verlap study, and our SleepHealth App.





## O2VERLAP

Did you know that about 60% of people with both Chronic Obstructive Pulmonary Disease (COPD) and obstructive sleep apnea (known as “Overlap Syndrome”) are not using their continuous positive airway pressure (CPAP) mask as prescribed? This is dangerous because it creates an increased risk for flare-ups and hospitalizations. The Overlap study, conducted by the COPD Foundation in conjunction with the ASAA, investigates if an interactive online classroom will help people living with Overlap Syndrome use their sleep masks properly. This study closed in May 2019. To see the results of the ASAA’s sleep apnea research, please visit our [website’s “Research” page](#) in early 2020.



## SLEEPHEALTH APP

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 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.

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

# LOOKING AHEAD....

We would like to take this opportunity to mention a few important highlights that took place after June 30, 2019.



## AWAKETOGETHER SUMMIT

The AWAKETOGETHER Summit held in the Presidio of San Francisco, CA on September 19, 2019, was the highlight of the 2019 SLEEPtember campaign. You can see the recordings of the patient focused event, speakers and topics covered [here](#). We will be hosting our 3rd Patient Summit in the Southeast US in May 2020, be on the lookout for more details soon.

## RIGHT UNDER YOUR NOSE CAMPAIGN

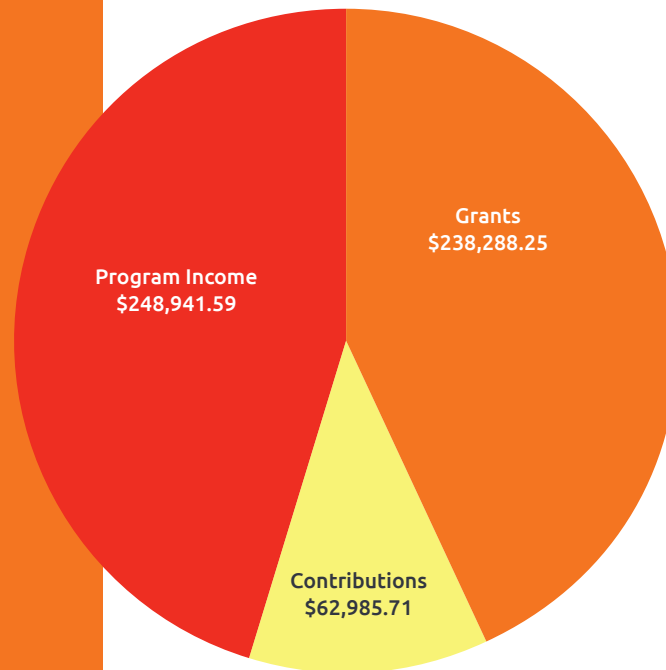
Right Under Your Nose Campaign in tribute to Dr. Christian Guilleminault. In step with honoring the work most important to Dr. Guilleminault (Dr. CG), the American Sleep Apnea Association will launch the "Right Under Your Nose" campaign which will continue Dr. CG's passion and vision towards early recognition in pediatrics, multidisciplinary care, as well as searching for a potential cure for pediatric sleep apnea. Learn more about Dr. CG and his his life's work [here](#).



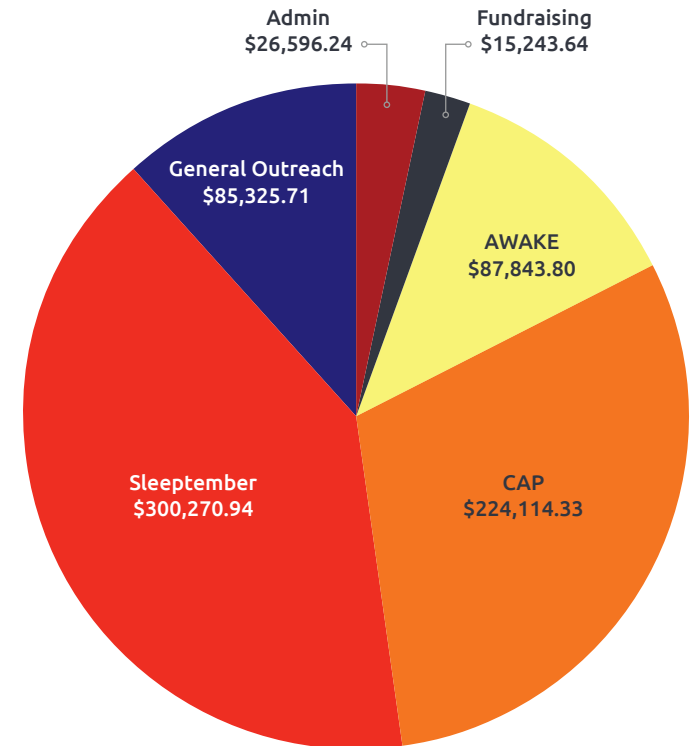
# FINANCIALS

The ASAA highly values fiscal responsibility, efficiency, and transparency. We are especially proud of our 5.7% overhead costs, allowing us to devote 94.3% of all income to our programs!

## INCOME SOURCES



## PROGRAM EXPENSES





# DONORS

The ASAA extends our heartfelt thanks to all our generous donors and grantors! Without your financial support, we would not be able to carry out our mission. Thank you so much to everyone who has helped the ASAA improve the lives of sleep apnea patients!

If you wish to support the critical, patient-centered work of the ASAA, please visit the donation page of our [website](#) to make your contribution today. Your contribution will improve the lives of patients living with sleep apnea!

The \* denotes supporting ASAA Board Members

## PLATINUM SUPPORTERS (\$50,000+)

Jazz Pharmaceuticals Inc.



## GOLD SUPPORTERS (\$10,000 - \$49,999)

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Adam Amdur\*

## SLIVER SUPPORTERS (\$1,000 - \$9,999)

Trailhead Institute  
Aaron B Cohen  
Susan Cummings

## BRONZE SUPPORTERS (\$1 - \$999)

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Adrienne Bond  
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Alfred Gysin  
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