



AMERICAN SLEEP APNEA ASSOCIATION ANNUAL REPORT

FISCAL YEAR REPORTING FOR JULY 1, 2019 – JUNE 30, 2020

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WELCOME

Dear Patients, Caregiver, and Patient Advocates,

The COVID-19 pandemic has brought to light the most basic needs of all patients, their access to care, and support to maintain overall wellness. Racial and health disparities have been a main focus of American Sleep Apnea Association (ASAA) for the last few years. These have now come to the forefront of the healthcare discussion. And we were ready to engage in meaningful and in depth conversations about health disparities and help all the members of our community with the support and information they need.

During the early stages of the pandemic, our organization was quick to adjust and were one of the first patient communities to host a virtual Summit. Our AWAKE Angels campaign, created to help those in need during the 2017 Hurricane Harvey in Texas, was reignited to address the financial hardships patients were facing with the pandemic. ASAA's *Weekly Speaker Series* conveyed up-to-date knowledge of the latest developments about COVID-19 and sleep health.

Even through these difficult times, we did not lose focus on the importance of producing and promoting high-integrity, evidence-based information that comes from real-world research, guided by patients, caregivers, and the broader healthcare community. Our continued relationship with Patient-Centered Outcomes Research Institute (PCORI) and the recent publication of the SleepHealth Mobile App Study will propel ASAA into next year.

Because of you, and the other 8,000 community members who answered our surveys during the last two years, ASAA identified the **8 Unmet Needs of Sleep Apnea Patients**. This roadmap will set the course on how we can change systems which have not placed enough value on the one-third of our lives we spend sleeping. Our community deserves better outcomes for improved quality of lives for ourselves, our elders, and of course our children.

This Annual Report details the activities and achievements of our organization during the 2020 Fiscal Year ending June 30, 2020. Unless otherwise specified, reported outcomes reflect all activities for each program through the end of June 2020. We thank all of you for making ASAA part of your sleep journey, and we look forward to working with you to improve the lives of sleep apnea patients.

Sleep Well and Stay Safe,



Adam Amdur

ASAA Board Chair, Sleep Apnea Patient

MISSION STATEMENT

The American Sleep Apnea Association (ASAA) is a nonprofit organization that works to improve the lives of those affected by sleep apnea and leads the search for the elimination of this syndrome in future generations.

VISION STATEMENT

We envision a world in which no one suffers from sleep apnea. This syndrome is highly preventable and can be reversed if not eliminated through pediatric recognition and dynamic, multi-disciplinary interventions. To help those living with sleep apnea, we work relentlessly to promote affordable, convenient and highly effective diagnoses and treatments.



GUIDING PRINCIPLES

We are an organization of, by, and for patients. The needs and well-being of patients are always our first priority.

We strive to meet the highest standards of integrity, honesty, and transparency in all our actions.

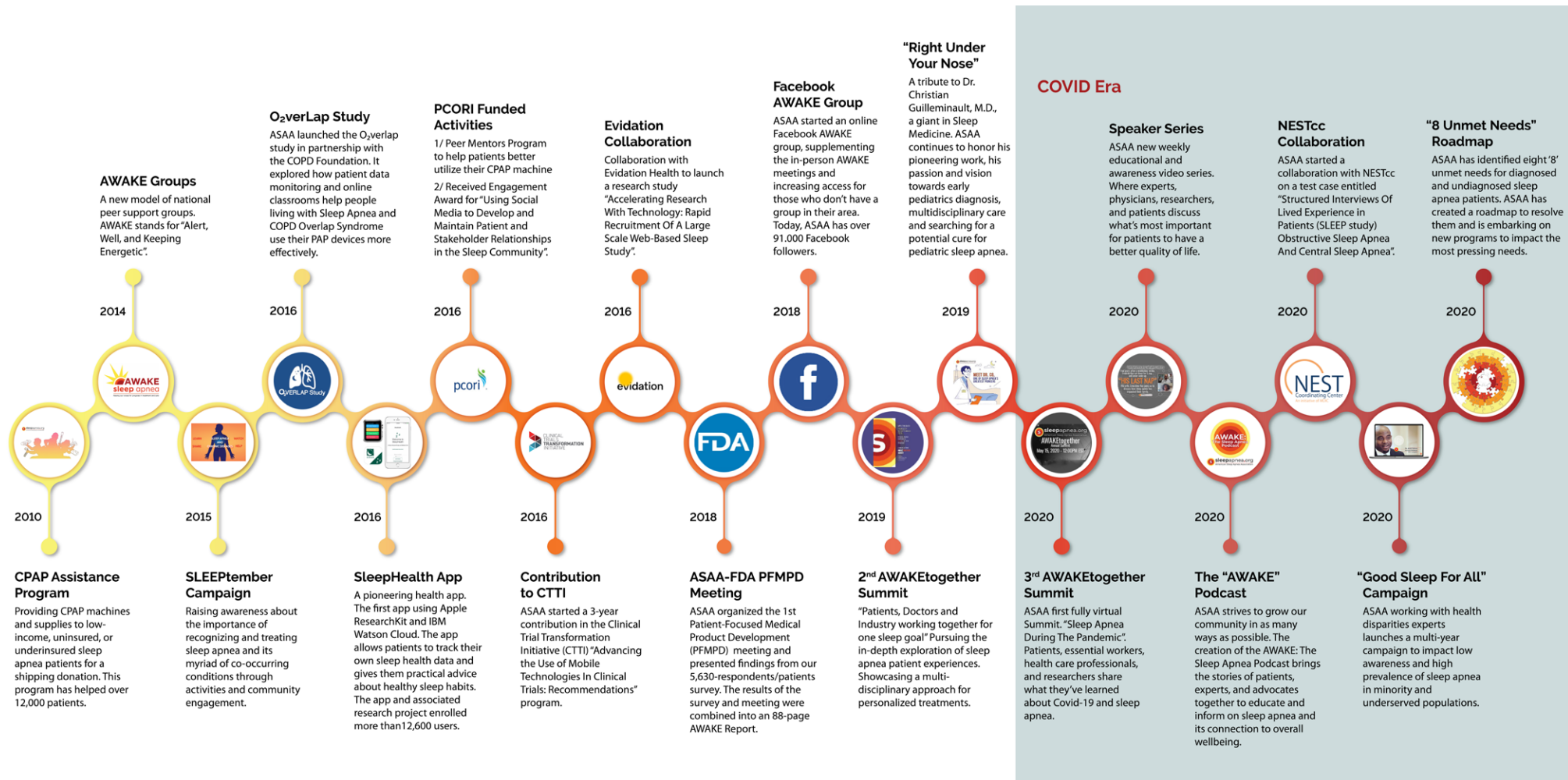
We are committed to providing accurate, scientific, evidence-based information.

We practice good stewardship of and accountability for the resources entrusted to us.

We welcome everyone affected by sleep apnea, regardless of color, national origin, citizenship status, age, physical or mental disability, race, religion, creed, gender, sex, sexual orientation, gender identity and/or expression, genetic information, marital status, status with regard to public assistance, veteran status, or any other characteristic protected by federal, state or local law. We commit to providing a safe space for people of all backgrounds to participate fully in all our activities.

OUR HISTORY TIMELINE

ASAA, founded in 1990, is a patient-driven organization committed to finding precise interventions, and making an impact on education, research and patient support. Here is a timeline of our recent achievements





ASAA PROGRAMS

EDUCATION & AWARENESS PROGRAMS

ASAA is committed to helping patients with sleep apnea and their caregivers improve their quality of life while living with this condition. Education and peer support are key strategies to achieving this goal, and ASAA has a wide array of programs to accomplish this.

Like most organizations, ASAA had to adapt our programming during the emergence of the COVID-19 pandemic, and our programming demonstrates a shift away from in-person activities to exclusively virtual content. Below is a report on our activities for Fiscal Year 2020.



The **"Alert, Well, and Keeping Energetic" (AWAKE) Network of support groups** provides in-person and online support for sleep apnea patients and caregivers. In Fiscal Year 2020, ASAA continued development of our official curricula modules for our AWAKE Network based on the needs, preferences, and interests expressed in our 2018 and 2019 AWAKESleepApnea surveys. This curriculum was rolled out to our in-person groups (during 2019), and presented entirely virtually to our community starting in March 2020.



1,505 AWAKE SleepHealth Forum Users

In addition to registered users (who can comment on posts) there were an additional 300 people per month who visited and read the forum.



1,245 Facebook Group Active Members

AWAKE Sleep Health Facebook group had 1,245 active members.



48 AWAKE Groups Nationwide

There were 48 active in-person AWAKE Groups across the country; which went virtual at the beginning of the pandemic.



10 Virtual Educational Events

ASAA provided 10 virtual educational events in our "AWAKE Speaker Series", where experts in sleep medicine and other related fields talked about sleep apnea and related topics. *See list to the right.*

VIRTUAL EDUCATIONAL EVENTS

TITLE	EXPERT	DATE
Peer Driven Care	Dr. Sairam Parthasarathy, Pulmonology/Sleep Specialist	5/5
The Immune System & COVID-19	Dr. Elana Oberstein, Rheumatology Specialist	4/28
The Relationship Between High Blood Pressure and Sleep Apnea	ASAA Education Leaders	4/23
Kidney Disease & COVID-19	Dr. Ashok Sastry, Nephrology Specialist	4/21
Mental Wellness and COVID-19	Dr. Michael Grandner, Asst Professor Univ. Arizona	4/14
Health Disparities and the current COVID-19 Pandemic	Dr. Aziz Seixas, Asst Professor NYU Langone	4/9
Narcolepsy and Similarities with Apnea	Dr. Mark Patterson, Pediatrician	4/7
COVID and Sleep Apnea	Dr. Craig Feied, board certification in clinical informatics and emergency medicine	4/2
Why Sleep Apnea Runs in Families	Dr. Kasey Li, ENT surgeon	3/17
The Relationship Between Heart Failure and Sleep Apnea	ASAA Education Leaders	2/18



AWAKE SLEEP APNEA PODCAST

ASAA is excited to announce the launch of our first podcast in February 2020, "AWAKE: The Sleep Apnea podcast. Between February and June 2020, **we presented 19 podcast episodes** sharing stories from patients and patient advocates. To date, we have had **6,445 downloads**. Podcasts can be viewed [here](#), and are available everywhere you listen.

AWAKE BLOG

Ensuring that ASAA continues to capture the patient perspective, we are happy to welcome **Eugena Brooks as our in-resident blogger**. Ms. Brooks's journey with ASAA started at the 2018 AWAKE Initiative where she participated in a patient panel. From there, her involvement grew and developed into a voice on the experiences of our apnea community, the hardships and triumphs we face, all with some humor and down to earth attitude. Nothing beats a first hand account of what living with sleep apnea and other co-occurring conditions is like. Follow our blog [here](#).





AWAKEtogether SUMMIT 2019

During fiscal year 2020, ASAA hosted two AWAKEtogether Summits. The first Summit was held during our annual SLEEPTember Campaign on September 19, 2019 in San Francisco, CA, and **256 people (75 in-person, 181 virtual) registered for the event**. The Summit was also **viewed live on Facebook by 1,692 people, and 856 people have watched** segments on ASAA's YouTube channel.

As in previous AWAKEtogether Summits, we had three panels in which patients shared their stories of sleep apnea with attendees. We also had presentations on sleep apnea and co-occurring conditions, sleep data tracking, sleep disorders and suicide risk, and a pioneering team-based approach to sleep apnea diagnosis and treatment. Expert speakers included Dr. Michael Grandner, Dr. Kasey Li, Dr. Stacey Quo, Dr. Shannon Sullivan, Dr. Anita Carmen Choy, Dr. Daniel Jin Blum, Christina Semonick, Bray Patrick Lake, Stacey Tiniatov, and Dr. Joe Borelli. At the Summit, ASAA conducted 14 patient and medical provider video interviews, highlighting stories for our Portraits of Sleep Apnea Series.

The 2019 AWAKEtogether Summit also featured an interdisciplinary "Round Robin", in which patients could talk one-on-one with a cross-section of medical specialists in fields closely related to sleep apnea. ASAA also launched our "Right Under Your Nose" campaign, a pediatric sleep apnea initiative building on the ideas of the late Dr. Christian Guilleminault, who passed away in summer 2019 and was honored posthumously at the event.



AWAKETOGETHER VIRTUAL SUMMIT 2020

Our 2020 AWAKEtogether Summit on May 15, 2020 was originally scheduled to be held in Florida, but went virtual due to the COVID-19 pandemic. Additionally, as the enormous health effects of the pandemic and “stay at home” orders became evident, ASAA quickly adapted our topics for the Summit to address these emerging issues in a virtual setting. The Summit was **attended by 282 live, online attendees, and over 1,200 people have watched** segments on ASAA’s YouTube channel.

Topics included some of the most pressing concerns for sleep apnea patients upon the emergence of COVID. Panelists and experts participated using a virtual platform for the following sessions: Confinement: Impact On Sleep Apnea & Sleep Quality, Future of Sleep Apnea Research & Advocacy in the COVID Era, Understanding the Impact of Excessive Daytime Sleepiness, Front Line / Essential Workers: Dealing With Sleep Apnea, The Role of Orexin in Sleep and Wakefulness, Closing Thoughts: ASAA Community Leaders Speak.

Expert speakers included:

Dr. Maurice Ohayon
Dr. Michael Vitiello
Dr. Sairam Parthasarathy
Dr. Elana Oberstein
Dr. Azizi Seixas
Dr. Danielle Hyman
Dr. Todd Swick
Dr. Michael Grandner

“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)

ASAA’s CPAP Assistance Program provides CPAP machines and masks to sleep apnea patients who otherwise could not afford them. Patients pay a small program fee to help support program expenses. In fiscal year 2020, ASAA **supplied 2,112 machines and 456 masks, with an average of 176 packages per month sent** out to patients.

From July 2019 until March 2020, ASAA **received 1,266 new or gently used machines and supplies** from individuals, durable medical equipment providers, and sleep labs, including an equipment donation from Fischer & Paykal. In April 2020, ASAA temporarily froze the collection of donated machines due to COVID-19 and possible transmission concerns.

AWAKE ANGELS

The COVID pandemic has placed many in our community in financial hardships. The AWAKE Angels campaign, originally created to help those in need during the 2017 Hurricane Harvey in Texas, was brought back to ensure that factory-sealed CPAP masks are given to those who need them. **For every \$50 our AWAKE Angels donated, we provided 2 masks to a person financially affected by COVID-19 for free.** Thanks to our Angel Donors, we are able to ship out masks to those who need them the most. Consider becoming an AWAKE Angel [today](#).

**Help those who need CPAP masks
Become an **AWAKE Angel** today!**





SLEEPTEMBER 2019

The signature event of SLEEptember 2019 was the AWAKEtogether Summit on Sept 19th in the Presidio of San Francisco. ASAA developed and distributed a survey about patients' sleep apnea experiences, available during the month-long campaign. The survey asked sleep apnea patients about their diagnostic odyssey; co-occurring conditions; current, past, and preferred treatments; experiences with healthcare providers and DMEs; CPAP cleaning practices; health data tracking, and more.

At 69 questions, the survey was over twice the length of our 2018 survey. Again, ASAA partnered with patient data company, Evidation, to promote and run the survey on their *My Achievement* platform. When the survey closed on September 30, 2019, there were **4,448 completed surveys**, providing us with a more detailed understanding of the needs of our community.

SLEEP APNEA AWARENESS DAY

March 20th is Sleep Apnea Awareness Day. This year with everyone at home due to the pandemic, we provided education and community engagement with an **11-part PSA video series** that provided quick tips for apnea patients and the general population about sleep health. The videos were 15 seconds in length and discussed things such as avoiding caffeine, finishing eating three hours before bedtime, maintaining regular bedtimes, etc.

CPAP APPRECIATION DAY

CPAP Appreciation Day is April 18th. As COVID brought lockdowns to many during that time, our **#SeeMyCPAP** virtual and social media campaign paid homage to the most widely used therapy to treat sleep apnea. We encouraged our community to share their stories and CPAP success through the #SeeMyCPAP hashtag and two videos showcasing [Show Me Your CPAP](#) and [How to Keep your CPAP Clean](#).



RESEARCH



O2VERLAP STUDY

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. The PCORnet demonstration [O2VERLAP study](#), conducted by the COPD Foundation and ASAA, investigated if an interactive online classroom will help people living with Overlap Syndrome use their sleep masks properly. This study closed in May 2019.

ASAA developed the CPAP curriculum used in the study, which targeted not only patients who were struggling with CPAP adherence, but also respiratory therapists who may not have worked with CPAP machines very often. The study also highlighted the problems of CPAP data collection and the ability to access information. Our experience connecting to over 300 DMEs nationally will better enable ASAA to articulate the patients’ needs to access their data, and how future research projects can overcome this hurdle.

We would like to thank the more than **300 people from around the US who participated in the study**. Details on the O2VERLAP Study can be found [here](#).

Special recognition should be bestowed upon the late John Walsh, Founder of COPD Foundation. Without his help and leadership, the O2VERLAP Study would not have happened.

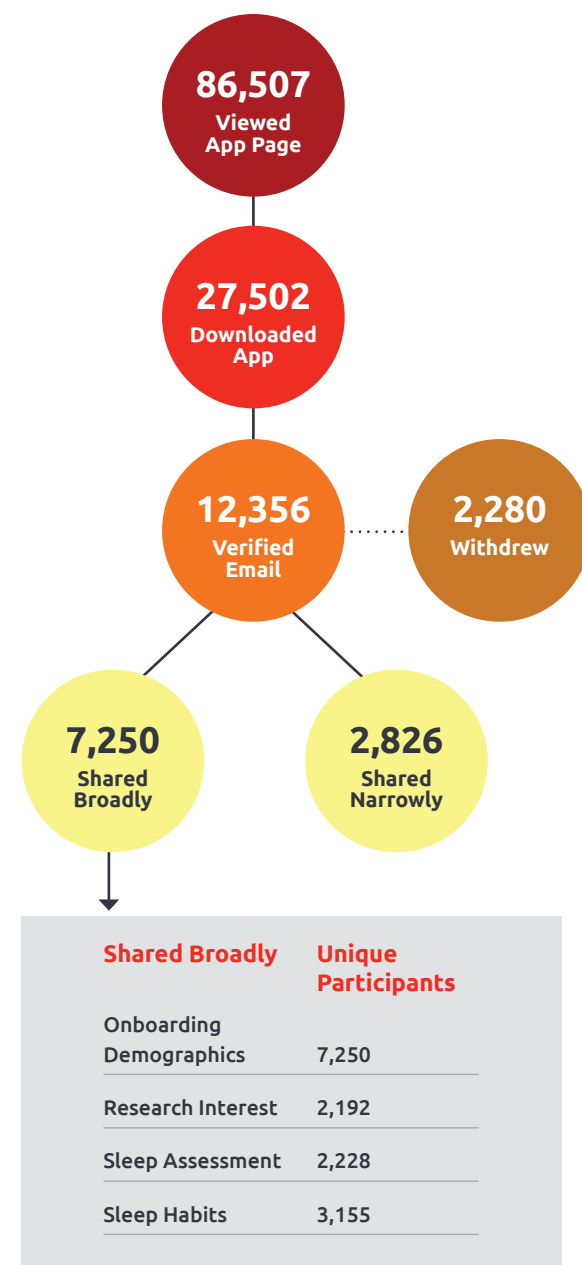


SLEEPHEALTH MOBILE APP

In 2016, ASAA sponsored and created the SleepHealth App, designed for Apple iPhone and iWatch. Working in conjunction with a researcher at University of California San Diego, and powered by Apple's ResearchKit, the SleepHealth App was a powerful patient-centered medical research tool helping patients gain greater insight into their sleep issues, learn how sleep is associated with other conditions they may have, and take charge of their health. ASAA is a pioneer user of ResearchKit among advocacy organizations. Other partners in the ResearchKit program included Mount Sinai Hospital, Stanford University and other major medical research hospitals and universities.

The goal was to learn to further develop the app into a personalized tool to help users gain knowledge into their sleep habits, next-day functioning, and general health/well-being. A secondary goal was to learn about how to use mobile apps to conduct research studies, which the Apple ResearchKit platform helped to foster. The study was closed in April 2020 with **over 12,000 enrolled and more than 7,000 sharing all of health data**.

This 4-year longitudinal study has been completed and a paper about the study's data descriptor has been accepted by *Scientific Data from Nature*. The titled paper "[Real World Longitudinal Data Collected from the SleepHealth Mobile App Study](#)" was published in November 2020. Open access to qualified researchers and our deidentified data sets will be made available on the Sage BioNetworks secured platform.





LOOKING AHEAD



AWAKE PEER MENTOR PROGRAM

The AWAKE Peer Mentor Program is the next step in virtual support for those using positive airway pressure (PAP) machines. This program provides one-on-one support to struggling PAP users matching them with experienced mentors to help them overcome any hurdle they are facing. This program was originally developed at the University of Arizona, Center for Sleep and Circadian Sciences. To learn more, or become a Mentor [click here](#).

INTERDISCIPLINARY ADVISORY COUNCIL

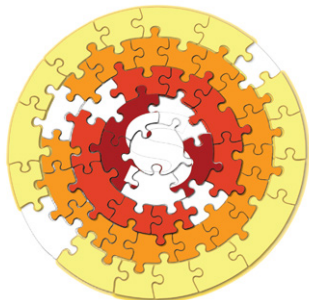
Because of the complex and often barrier-ridden journey to getting a diagnosis, treatment and support, a team of diverse medical and industry professionals are joining our mission. Visit our Interdisciplinary Advisory Council [here](#).

NESTCC

The study titled, Structured Interviews of Lived Experience in Patients (SLEEP Study) Obstructive Sleep Apnea and Central Sleep Apnea, aims to identify patient preferences related to the benefits, challenges, risks, and side effects felt when utilizing PAP management of Obstructive Sleep Apnea and Central Sleep Apnea.

Additionally, the study is assessing PAP design or delivery characteristics that patients feel would potentially benefit them the most to improve therapy. Finally, the study is assessing patient and parent/caregiver willingness to engage in such activities such as PAP design, regulatory approval process, device evaluations, and the collection of patient-generated data for safety and coverage decisions. Learn more about this study and the other organizations ASAA is working with [here](#).





8 UNMET NEEDS OF SLEEP APNEA PATIENTS

Real Patient Problems - Real Patient Data - Real Patient Evidence

More than **8,000 respondents to surveys** conducted by ASAA in 2018 and 2019 identified the 8 Unmet Needs of Sleep Apnea Patients. These needs will provide a roadmap for our future programming, education and awareness campaigns. View our roadmap [here](#).

- 1 Lack of Prevention**
Needed: Proactive and accurate diagnosis of sleep apnea in pediatric and non-typical patients.
 
- 2 Low Awareness**
Needed: Greater awareness of sleep apnea and its many co-occurring conditions among the general public and within the healthcare community.
 
- 3 Poor Detection**
Needed: Early attention to sleep issues in medical school curriculum and more training of healthcare professionals.
 
- 4 Imperfect Diagnosis**
Needed: Accurate home sleep testing devices. More attention to patient input for innovation.
 
- 5 Inadequate Treatment**
Needed: Better access to treatments for sleep apnea, fatigue and excessive daytime sleepiness.
 
- 6 Insufficient Coverage Policies**
Needed: Essential changes to medical coverage, reimbursement, and utilization policies to support effective patient care.
 
- 7 Inaccessible Patient-Generated Data**
Needed: Direct access to patient-generated data from medical devices, and much greater autonomy to control home care devices.
 
- 8 Systemic Health Disparities**
Needed: Essential changes to the health care ecosystem to achieve a culture of health for all.
 



PATIENT CONNECTION CAREGIVER PROGRAM

ASAA is proud to be a participant in the Patient and Caregiver Connection (PCC). This Program provides ASAA with an opportunity to share our patient experiences living with a condition or using medical devices with FDA's Center for Devices and Radiological Health (CDRH) staff who are focused on protecting and promoting public health.

CDRH developed the Patient and Caregiver Connection to obtain three types of patient feedback that can give context to the Center's regulatory activities:

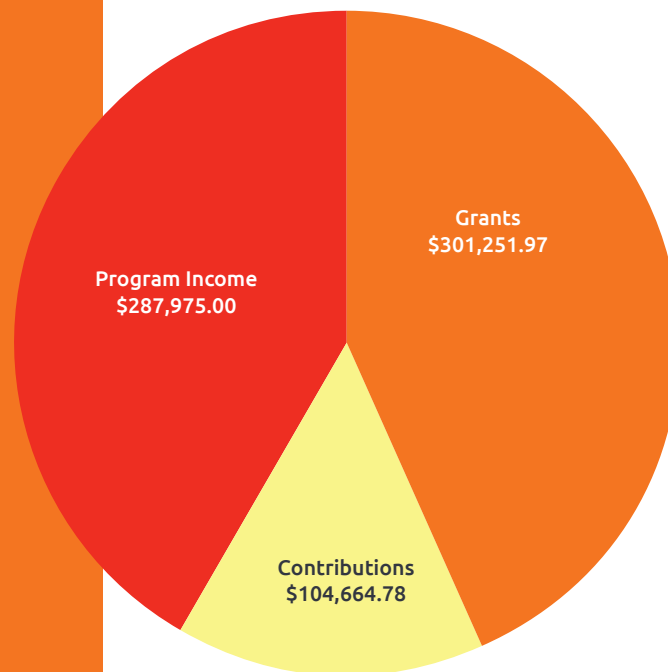
- Patients' experiences living with their specific condition
- Patients' experiences with devices used for the diagnosis, treatment, or management of their condition
- Current issues or trends related to medical devices that they use or may be treated with

This information could also provide insights that could be useful in medical device design, clinical studies to evaluate medical devices, and post-market medical device safety monitoring and product refinement. Learn more about this FDA Program and the other organizations ASAA is working with [here](#).

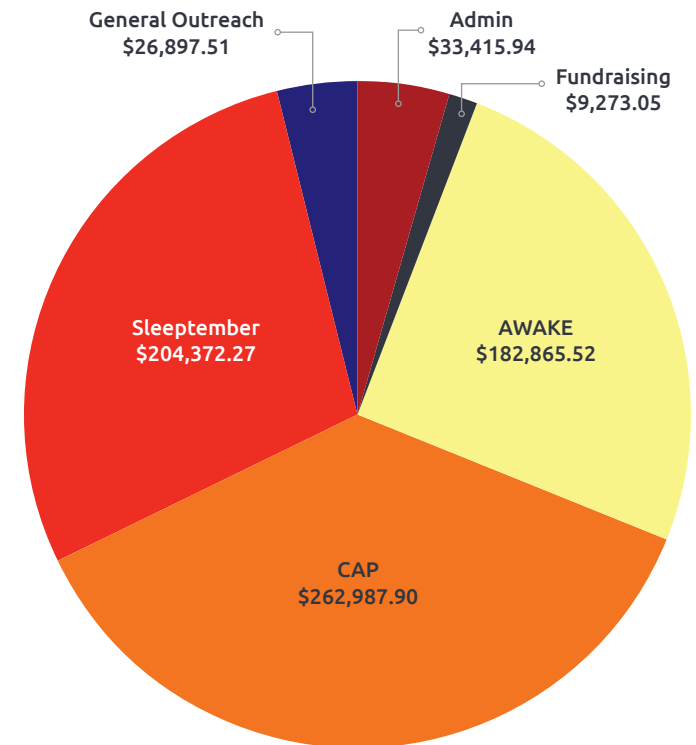
FINANCIALS

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

On behalf of the staff, volunteers and Board of Directors, ASAA extends our heartfelt thanks to all our generous donors and grantors! With your financial support, we are able to carry out our mission to improve the lives of those diagnosed with sleep apnea and to advocate for better sleep health for everyone. Thank you so much to everyone who has helped us continue to increase awareness and diagnosis, and to promote affordable, convenient and effective treatments for 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+)



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

Isabelle Amdur
Adam Amdur



SILVER SUPPORTERS (\$1,000 - \$9,999)

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Port Capital LLC
Wanda Kim
Zohar Geva

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A.W.A.K.E. Patient Support Network

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