

THE 8 UNMET NEEDS OF SLEEP APNEA PATIENTS

Real Patient Problems - Real Patient Data - Real Patient Evidence

Sleep apnea is a complex, multi-dimensional disorder. Improving understanding and treatment of this condition requires multidisciplinary expertise and a constant cooperation between patients, clinicians and scientists.

More than 8,000 respondents to 3 surveys conducted by ASAA in 2018-2019 identified the 8 main unmet needs experienced by sleep apnea patients. They are like the 8 missing pieces of a giant puzzle required to produce optimal care.

ASAA, always acting as a bridge between the patient community and healthcare professionals, has created a series of resources to help alleviate and resolve each of these unmet needs.

THE 8 UNMET NEEDS OF SLEEP APNEA PATIENTS

1

Lack of Prevention

Goal: Promote a universal, early, accurate and proactive diagnosis of sleep apnea in pediatric and non-typical patients.



2

Low Awareness

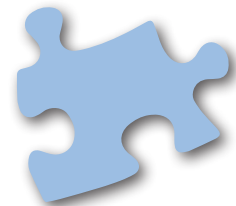
Goal: Develop much greater awareness of sleep apnea and its many co-occurring conditions among the general public and within the healthcare community.



3

Poor Detection

Goal: Promote much greater attention to sleep issues in medical and dentistry school curriculum and better training of healthcare professionals.



4

Imperfect Diagnosis

Goal: Achieve real person-centered testing; Promote easily available, cheap, connected and accurate Home Sleep Tests.



5 Inadequate Treatment

Goal: Facilitate better access to treatments for sleep apnea, fatigue and excessive daytime sleepiness.



6 Defective Coverage Policies

Goal: Push for essential changes to reimbursement to support effective patient care.



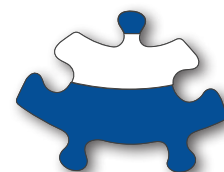
7 Inaccessible Patient-Generated Data

Goal: Direct access to patient-generated data from medical devices, and much greater autonomy to control home care.



8 Systemic Health Disparities

Goal: Promoting the essential changes to the healthcare ecosystem necessary to achieve a culture of sleep health for all.



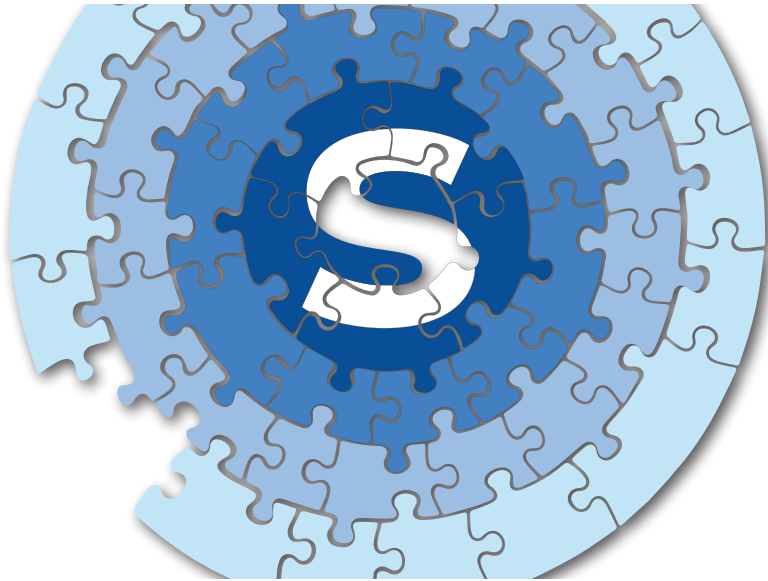


1 LACK OF PREVENTION

Goal:
Promote a universal, early, accurate and proactive diagnosis of sleep apnea in pediatric and non-typical patients.



Special efforts should be taken to erode the persisting stereotype that sleep apnea occurs only in overweight, middle-aged and older men. We must increase the recognition that sleep apnea occurs in children, in women, and in people of all body types.



While current messaging around prevention of sleep apnea is beneficial, many individuals develop sleep apnea even though they follow these practices.

We should better understand and address emerging sleep apnea in a milder state to help prevent or slow down progression and/or serious and costly consequences.

More proactive measures to monitor for early warning signs and address emerging sleep apnea in a milder state should be in place for those who may be at greater risk:

- People with physical features that form a vulnerable airway.
- People with family history.
- People who experience disruption of natural diurnal rhythms (as with night shift workers), safety-sensitive occupations (such as truck drivers, bus drivers, or rail operators).

To address this unmet need ASAA has created the following resources:

- **Portraits of Sleep Apnea** showcasing the patient story and the diverse community affected by sleep apnea
- **Outreach Campaigns:** Sleep Apnea Awareness Day and SLEEPtember
- **Speaker Series** providing the patient population educational access to experts that will address the non-typical patient and pediatrics
- **AWAKEtogether Summit** reaching out to the general populations to provide sleep education and awareness

"I knew my father, uncle, and cousins had it but I really didn't want to deal with the mask since I have anxiety about things on my face so I didn't tell my doctors.

I also didn't know all the symptoms or possible bad things that could happen or I would have told my doctor five years earlier."

— Female survey respondent



2 LOW AWARENESS

Goal:
Develop much greater awareness of sleep apnea and its many co-occurring conditions among the general public and within the healthcare community.



80% to 90% of people with sleep apnea are undiagnosed. Special efforts should be taken to improve recognition that sleep apnea is often associated with one of more serious chronic conditions (high blood pressure, diabetes, GERD / reflux and depression, among many others).



There is a serious need for greater awareness of sleep apnea among the general public and within the healthcare community.

In particular sustained efforts should be taken to improve recognition that sleep apnea is often associated with one of more serious chronic conditions (high blood pressure, diabetes, GERD / reflux and depression, among many others).

Awareness campaigns are needed to improve recognition and understanding of the risk factors that contribute to sleep apnea, its presenting signs and common symptoms, the potential benefits of effective therapy, and potential risks and consequences of non-treatment.

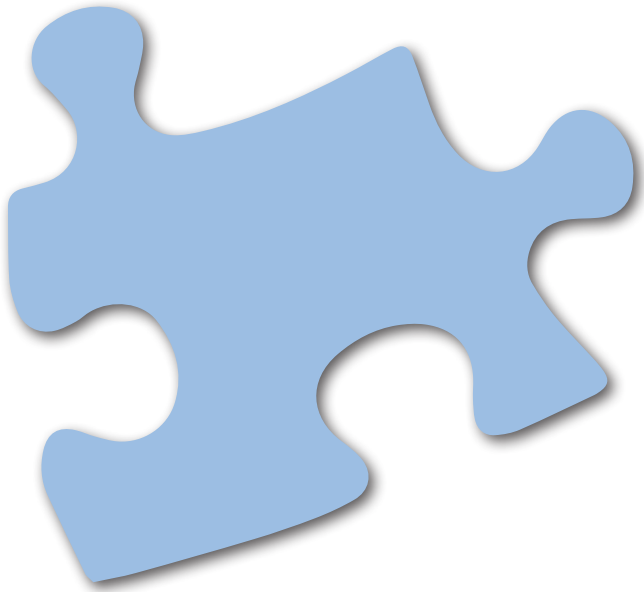
To address this unmet need ASAA has created the following resources:

- **Speaker Series** focusing on identified co-occurring conditions with our interdisciplinary advisors connecting sleep to overall health
- **Portraits of Sleep Apnea** detailing patients' story about common misconceptions and their difficult pathway to diagnosis
- **Outreach Campaigns:** Sleep Apnea Awareness Day, SLEEPtember, FOGust
- **AWAKEtogether Summit** educating all on the overlapping symptoms of sleep apnea



"I've wondered for many years whether I had sleep apnea. My husband, a physician, told me many times, 'There's no way you have sleep apnea; you're not obese.' Well, guess who has severe obstructive sleep apnea?"

— Female survey respondent



3 POOR DETECTION

Goal:

Promote much greater attention to sleep issues in medical and dentistry school curriculum and better training of healthcare professionals.



The importance of healthy sleep and better detection of sleep disorders warrants more attention in medical and dentistry school curricula and training of professionals in all health care settings. This need is made even more urgent as several leading sleep specialists are approaching retirement or have recently passed.



The growing understanding of the importance of healthy sleep must be associated with better detection as well as more understanding of the widespread impact of sleep disorders.

Breaking down the wall between medicine and dentistry will help better detect and address sleep disorders early, to prevent severe and/or lead to catastrophic outcomes

This is especially true in children, where symptoms and behaviors may be mis-identified as attention disorders, with opportunities for effective management delayed or missed entirely.

Standard attention to sleep as part of routine care would help to improve upon the relatively low rate of 20 percent of patients who spontaneously report sleep-related issues to their physician.

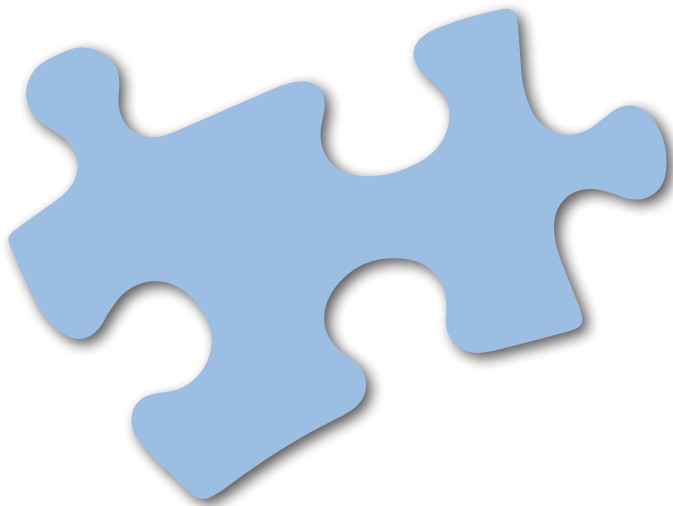
To address this unmet need ASAA has created the following resources:

- **Professional Summit** bringing the patient perspective and story directly to healthcare providers
- **Interdisciplinary Advisory Council** involvement in our outreach to and support of professional societies through educational materials and patient support
- **Speaker Series** targeted for medical and dental students



"The average amount of time spent educating a medical student about sleep is 18 minutes. The average medical resident gets three hours of instruction about sleep. So we need to do a better job as a nation on sleep education. It is one-third of our lives."

— Melissa Patterson, patient advocate



4 IMPERFECT DIAGNOSIS

Goal:

**Achieve real person-centered testing;
Promote easily available, cheap, connected and accurate Home Sleep Tests.**



Home Sleep Tests (HSTs) were developed to provide a less expensive, more convenient, less invasive and more immediate alternative to clinic-based overnight polysomnography. With the COVID-19 pandemic they have instantly become the de-facto sleep tests for most. We need better standards and quality for these devices.



Serious unmet needs along the path to diagnosis were revealed by survey participants. While home sleep tests (HSTs) were developed to provide a less expensive, more convenient, and more immediate alternative to clinic-based overnight polysomnography, there were reported shortcomings too.

Integrating patient perspectives in utilization policies may help to refine practices so that a wider range of short-term and long-term benefits and tradeoffs are considered. The experience of clinic-based tests warrants attention and innovation to become more patient-centered, much as the settings and procedures for childbirth have changed in response to women asserting their needs and expectations.

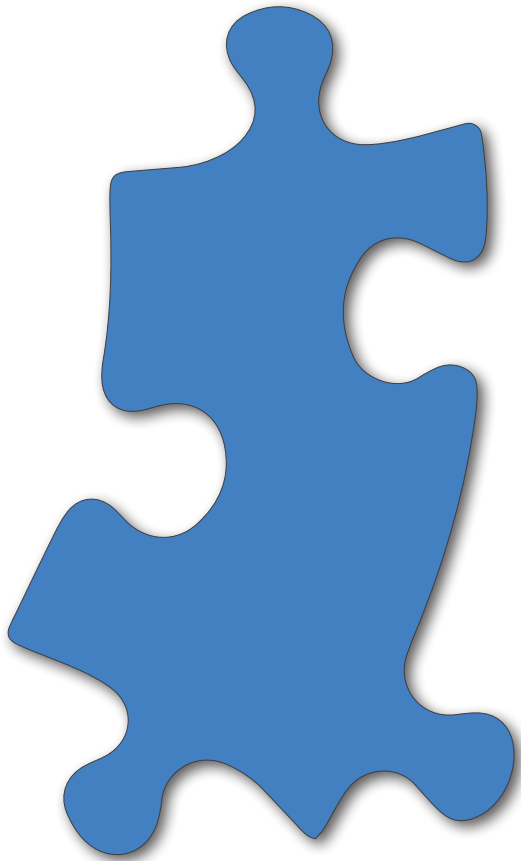
Criteria for sleep apnea and other conditions of sleep disordered breathing necessitate making considerations for borderline findings and sleeping abnormalities that may not be easily measured in a single night of sleep, under unfamiliar and observed conditions.

To address this unmet need ASAA has created the following resources::

- **Speaker Series** with device world experts speaking with patients
- **New Webinars** showcasing new devices, technologies and diagnostic choices for sleep apnea
- **AWAKEtogether Summit** to better engage and inform our community about new devices and options available
- **Outreach Campaigns:** Sleep Apnea Awareness Day and SLEEptember to

"As far back as 2003, I was really tired all the time and complained of symptoms, but doctors kept saying I was 'just depressed.' In 2008, I asked again. I was told I was "just depressed". A rheumatologist, without telling me, diagnosed fibromyalgia. In 2010 he ran out of things to prescribe so he sent for a sleep study. I got diagnosed with sleep apnea."

— Female survey respondent



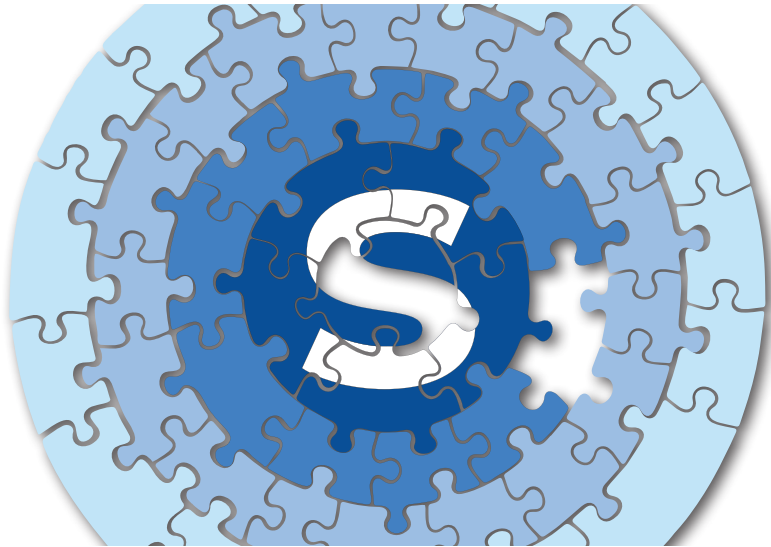
5 INADEQUATE TREATMENT

Goal:

Facilitate better access to treatments for sleep apnea, fatigue and excessive daytime sleepiness.



The top unmet medical need identified by ASAA real world surveys is for effective treatment of fatigue and excessive daytime sleepiness that often persists even in the setting of adherent PAP usage.



In spite of the array of treatment options, many individuals are untreated, undertreated or poorly treated.

The top unmet medical need identified in our surveys is for effective treatment of fatigue and excessive daytime sleepiness that persists even in the setting of adherent PAP usage.

We need a better understanding of:

- Weight gain resulting from long term PAP treatment.
- Contradictory experience with abstinence or use of caffeine and alcohol, various diets, and medications used to treat symptoms or concurrent conditions

It would help to refine treatment recommendations and could improve patient satisfaction, adherence, and health outcomes.

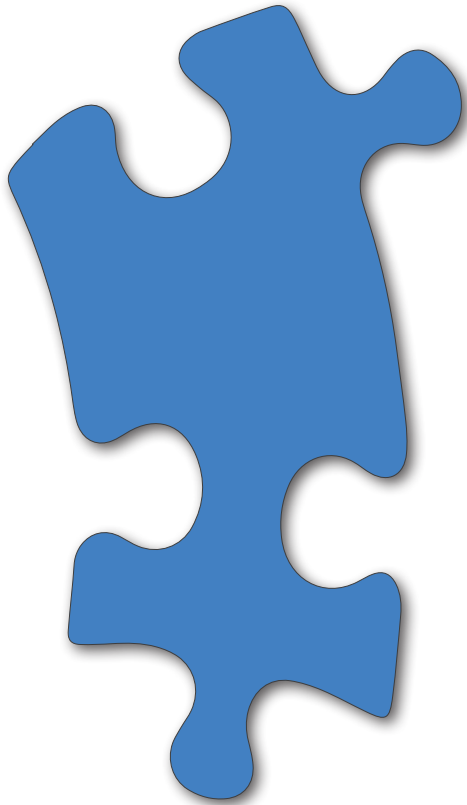
ASAA is addressing this unmet need via :

- **Outreach Campaigns:** CPAP Appreciation Day, FOGust, and SLEEPtember
- **Speaker Series** focused on articulating the persisting issues patients have even when adhering to their treatment
- **AWAKE Peer Mentor Program** to virtually assist patients with their treatment pathway



Sleep apnea has affected my overall health in so many ways. It contributed to erratic blood sugar levels and ultimately diabetes. It contributed to difficulty losing weight. The worst though is the exhaustion. It is so overwhelming and all consuming. I use my APAP machine 7 hours a night, 7 nights a week, but I'm still exhausted."

— Female survey respondent



6 DEFECTIVE COVERAGE POLICIES

Goal:
Effect essential
changes to
reimbursement to
support effective
patient care.



It is essential to evolve medical coverage, reimbursement, and utilization policies to support effective patient care, rather than punish non-compliance, or create additional obstacles to maintaining effective therapy.



It is essential to evolve medical coverage, reimbursement, and utilization policies to support effective patient care, rather than punish non-compliance or create additional obstacles to maintaining effective therapy.

Medicare may cover a 3-month trial of PAP therapy. Medicare and insurance companies may stop covering device for non-compliance even though the device is prescribed without providing any essential training of the user for proper usage.

There is a growing need to expand sources of financial support to help individuals overcome financial barriers to treatment, as evidenced by patient testimonies and the 17,000 calls for help received each year by ASAA's CPAP Assistance Program.

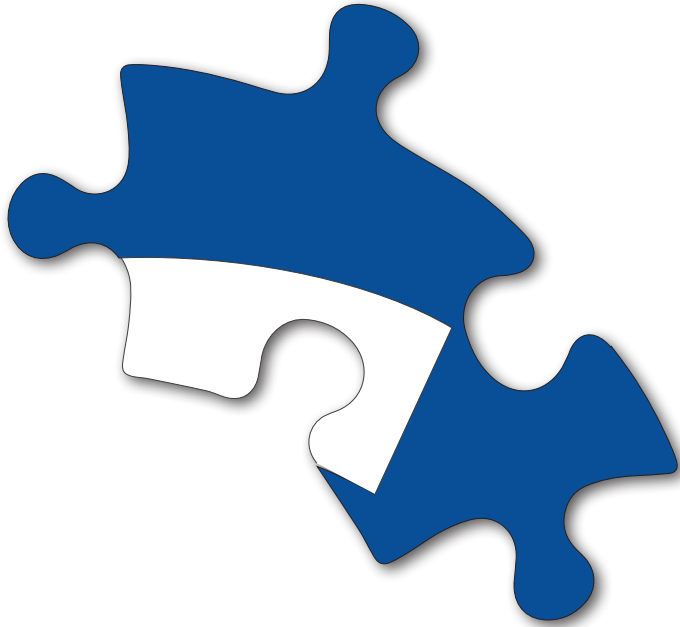
ASAA is addressing this unmet need via :

- **AWAKE Peer Mentor Program** to virtually assist patients with PAP therapy issues for their success in treatment
- **Mask Program** offering those that could not otherwise afford the necessary supplies
- **CPAP Assistance Program** is searching for factory sealed PAP machine inventory to bridge the gap in our healthcare cost system



"My insurance company stopped covering my CPAP equipment at 100% and I can no longer replace parts as they wear out because it is prohibitively expensive. My apnea used to be well managed with minimal side effects when I had functioning equipment; now many of my symptoms prior to treatment have returned."

— Female survey respondent



7 INACCESSIBLE PATIENT DATA

Goal:

Direct access to patient-generated data from medical devices, and much greater autonomy to control home care.



Patient-generated data sets from wearables and connected devices should serve to individually inform and fine-tune therapeutic and lifestyle decisions. These de-identified data sets should be gathered and aggregated to help conduct population-wide research.



People expectations are rapidly changing. Calls for direct access to patient-generated data from medical devices of all types are intensifying, as is the demand for more autonomy to control home care devices.

In 2020, current practice still limits the amount of PAP data exposed to patients and their ability to adjust machine settings. These restrictions should be lifted under certain conditions. The COVID-19 pandemic has accelerated the move to telehealth and patient direct involvement in their care.

More wearables and mobile applications (apps) now equip patients with easy means of recording and making sense of patterns in diet, physical activity, sleep quality, stressors, symptoms, and treatment outcomes.

These patient-generated data sets should serve to individually inform and fine-tune therapeutic and lifestyle decisions and practices as well as be gathered in de-identified form to help conduct population-wide research.

ASAA is addressing this unmet need via :

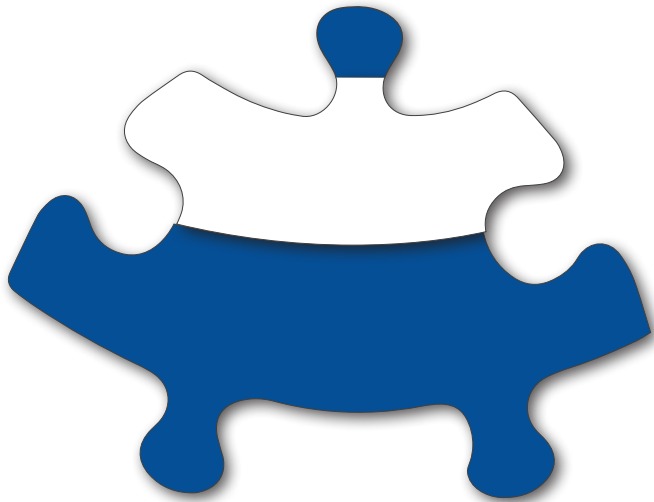
- **De-Identified Patient-Generated Data Bank** (planned)
- **SleepHealth Mobile App Study:** data set availability to qualified researchers
- **Increased Engagement** with wearable and apps to increase patient understanding of devices



"Not only are you entitled to your data, it is your data. It is our data coming from CPAP machines or wearables.

We shouldn't have to wait 90 days to see a clinician to verify if the device is setup optimally. We have to make technology and data work for us. We need to start using it jointly with our doctors in shared decision-making."

— Adam Amdur, ASAA's
Former Chief Patient Officer



8 SYSTEMIC SLEEP HEALTH DISPARITIES

Goal:

Promoting the essential changes to the healthcare ecosystem necessary to achieve a culture of sleep health for all.



Optimal sleep is integral to health but is commonly not obtained. An inadequate duration of sleep and poor-quality sleep are prevalent in minority and low-income populations, and may be fundamental to racial and socioeconomic status inequities that contribute to a range of health conditions, including cardiovascular disease (CVD).



While 50 to 70 million Americans have a chronic sleep disorder, there is low awareness of sleep health. There is a high prevalence of sleep apnea and short sleep duration in Blacks. There is a growing body of evidence it has the potential to magnify multiple chronic health conditions and Cardio Vascular Disease (CVD).

Although an inadequate duration of sleep and poor sleep quality may substantially contribute to inequities associated with race and socio-economic status for a wide range of health conditions, sleep health is understudied by researchers and underappreciated by the general public, policy makers, and other stakeholders

Current CVD prevention and management guidelines glaringly omit inclusion of CV behavioral predictors such as sleep, even though there is mounting epidemiological evidence it is an important predictor.

The omission of sleep is quite consequential for provider knowledge and clinical practice, patient and community health literacy, and patient-centered healthcare delivery.

To address this unmet need ASAA has created the following resources:

- **Sleep Health Disparities Advisory Council:** its diversity is a core element of its functions
- **Speaker Series** dedicated to issues related to sleep health disparities
- **Patient Stories** showing the real impact of systemic racism and sleep health disparities on underserved sleep apnea patients.
- **Participation in Research on Sleep Health Disparities**



“Individuals who have reported experiencing more discrimination have less stage 4 [deep] sleep and report experiencing greater physical fatigue than the general population.”

— Kamala S. Thomas

“Blacks and whites are characteristically different regarding the prevalence of inadequate sleep over the years.

— Girardin Jean-Louis