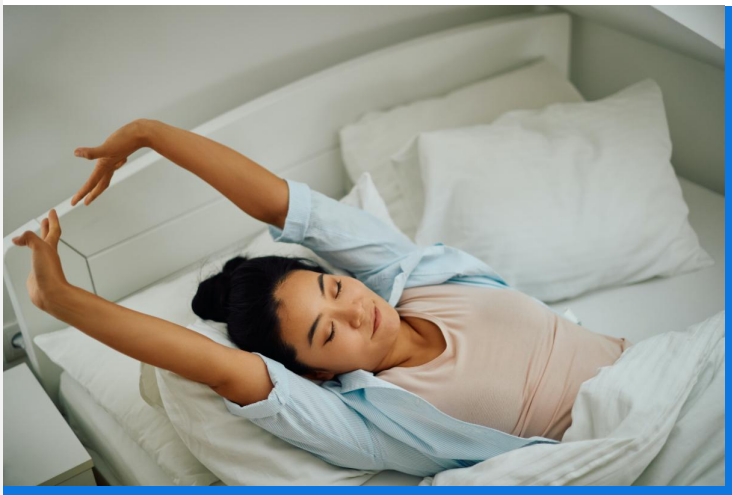
Alliance of Sleep Apnea Partners

DECEMBER 2023



Better Breathing. Better Sleep. Better You.

apneapartners.org

Executive Director's Letter: A Year of Growth and Gratitude

As the clock winds down on 2023, here at ASAP we're looking back on a remarkable year of growth that has help us raise the patients' issues and voice in more places, from conferences to publications to webinars. We know we couldn't have done it without our patient community and your support.

The Philips Respironics PAP recall, which continues to affect millions of patients nationwide, added even more urgency to our mission. Among our efforts on that topic this year, we secured a grant from the American Academy of Sleep Medicine Foundation for a project to identify gaps in care following the recall, highlight concerns of various stakeholders, and discuss actionable grassroots support to bridge the gaps in patient care.

We launched a webinar series seeking stakeholder experiences and perspectives on the recall. The series began with Philips Respironics Recall: Patient Perspectives, now available on demand on our YouTube channel.

These are part of our new patient-centered free webinar series, Breathing Room, a virtual forum to engage with the sleep apnea community. Through these regular webinars, we discuss lived experiences, what it means to be an informed patient, and how the apnea community can become more engaged and involved in advocacy with ASAP.
In 2023, ASAP also gained significant recognition from the medical and scientific communities at major conferences, such as the American Thoracic Society conference and SLEEP.

We've also grown our team and expanded our outreach with a communications director and a social media manager. We've developed new resources, including a Doctor

Dialogue, which helps women discuss sleep apnea with their primary care providers; a Women & Sleep Apnea toolkit produced in partnership with the Society for Women's Health Research and MyApnea.org; and new videos on our YouTube channel, including practical advice from longtime PAP support professional Laura DeFelice on using and caring for CPAP machines.

How You Can Help

To sustain and expand this impactful work, we seek your support. Your donation will enable us to enhance our outreach programs, provide vital resources, and advocate for individuals affected by sleep apnea. Together, we can make a meaningful positive difference in the lives of those living with sleep apnea.
Please contribute online today or contact us at info@apneapartners.org for more details.
Thank you for considering our cause, and we look forward to your continued support!

Monica Mallampalli, PhD

ASAP Executive Director

Donate Now

SAFETY AND RECALL ALERTS

This fall we have seen a number of product alerts affecting the sleep apnea patient community. These involved Philips Respironics, ResMed, and SoClean products.

Sign Up for Free FDA Recall Alerts

PHILIPS RESPIRONICS DREAMSTATION2

On Nov. 28, the Food and Drug Administration issued a safety communication about overheating in Philips DreamStation 2 CPAP machines. The communication calls on patients to carefully monitor these machines for signs of overheating and includes specific recommendations for patients, caregivers, and health care providers.

Read the FDA Notice and Recommendations

Visit the Philips Patient Portal

RESMED MASK WITH MAGNETS ON THE STRAPS

ResMed issued a safety notice regarding some of the company's most popular masks. This letter is applies to you if

- You have a medical implant or device, such as a pacemaker or defibrillator, or
- You will be within six inches of someone else with such an implant or device

If the notice applies to you, call your DME and keep using your CPAP unless your doctor advises you to stop.

*ASAP Executive Director Dr. Monica Mallampalli spoke with Sleep Review magazine about the safety notice. Read her comments **here** (in the article, scroll down to the section*

called "How the Magnet Contraindications Are Impacting Patients").

Read ResMed's Letters to Patients and Physicians

Learn More at ResMed's Informational Page

SOCLEAN VOLUNTARY RECALL

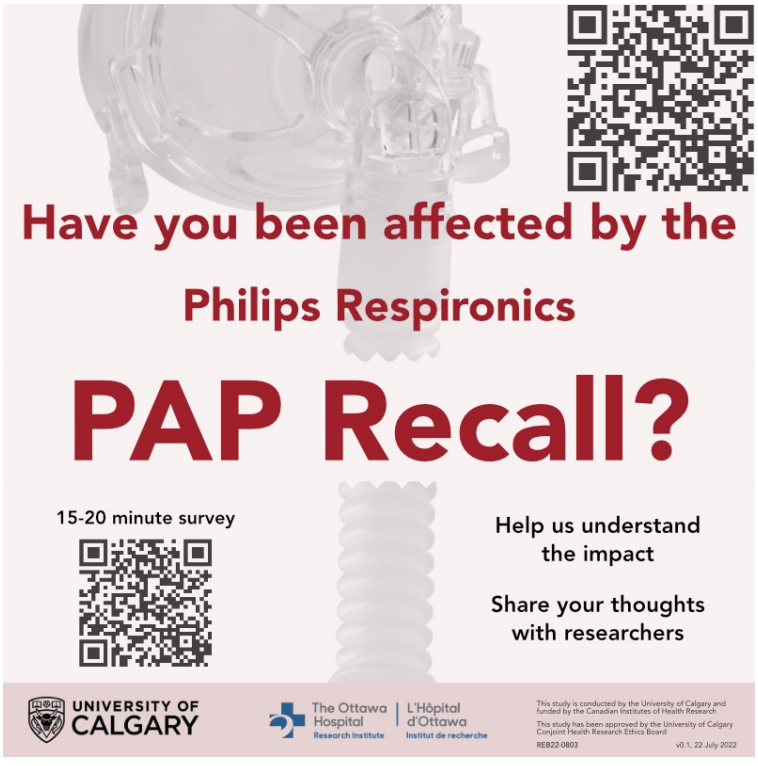
The FDA issued a safety communication following a voluntary recall of SoClean2 and SoClean3 equipment used to clean, sanitize or disinfect CPAP devices and accessories. The recall is intended to prevent potential health risks from exposure to ozone gas after use of this equipment.
The recall includes new instructions for device use, including the importance of using a hose and mask adapter provided by the company.

Read the FDA Notice and Recommendations

Have You Been Affected by the Recall of CPAP Devices?

Take This Online Survey.

In June 2021, Philips Respironics recalled a large number of CPAP and other positive airway pressure (PAP) medical devices over concerns about potential health risks.



Researchers from the University of Ottawa and University of Calgary are conducting a survey of patients from across the United States and Canada who have been affected by this recall.

We want to hear how the recall has impacted you, assess how the recall was communicated, and gather feedback for future improvement.
To access the online survey, scan one of the QR codes in the image above or click the button below.

The online survey will take about 15-20 minutes.

Take the Survey

ASAP NEWS

ASAP Welcomes Co-Founder Kathy Page as Board Chair

In November, ASAP elected Kathy Page to chair its board. Page, a co-founder and past president of ASAP, most recently had served as the nonprofit group's vice-chair. She succeeds Sarah Gorman, who has served as chair since 2021. Like Gorman, Page is a sleep apnea patient.

In addition to her work with ASAP, Page also serves on the board of MyApnea.org and is a member of the American Thoracic Society's Public Advisory Roundtable. She also has participated as a patient representative in Patient-Centered Outcomes Research Institute grant funding, has been active in various National Institutes of Health meetings on sleep apnea and restless leg syndrome, and has participated in three Food and Drug Administration grant processes as a patient specialist. She also participated in drafting the "Women & Sleep Apnea" toolkit jointly produced by the Society for Women's Health Research and ASAP.

Read the announcement.

ASAP Executive Director Dr. Monica Mallampalli with Project Sleep President Julie Flygare in Washington, D.C.

ASAP Joins Project Sleep for Sleep Advocacy in D.C.

ASAP brought sleep apnea patients' perspectives to Washington, D.C., in November, joining forces with Project Sleep and more than a dozen other advocacy organizations and professional societies at the Sleep Advocacy Forum. ASAP Executive Director Dr. Monica Mallampalli spoke at the forum's opening day, providing an overview of ASAP as an advocacy organization led by sleep apnea patients for sleep apnea patients and discussing its priorities.
The forum also included a visit with White House staff and members of Congress, which ASAP board member Ray Merrell attended.

Learn more about ASAP's mission and advocacy.

ASAP board member Ray Merrell (right) with New Jersey Rep. Tom Kean, Jr.

ASAP board member Ray Merrell (far right) visited the White House as part of Project Sleep's White House Sleep Equity Convening.

Apnimed Seeks Apnea Patients for Clinical Trials

Apnimed, a clinical-stage company focused on advancing oral medicines treat obstructive sleep apnea (OSA) and related disorders, is screening sleep apnea patients in the United States and Canada for Phase 3 clinical trials of AD109, its most advanced drug candidate for OSA.
AD109 is an investigational oral medication for OSA taken nightly at bedtime.
[See if you qualify for the study or refer a friend.]
[Learn more about Apnimed, its clinical trials, and who can participate.]

CATCH UP WITH ASAP WEBINARS ON YOUTUBE

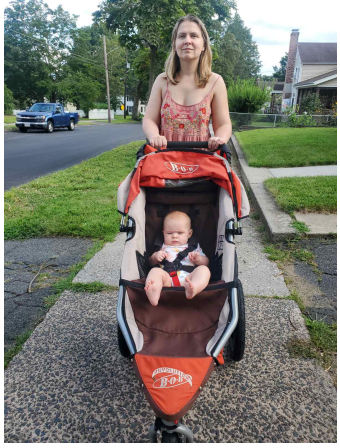
Watch webinars from our new "Breathing Room" series on demand at ASAP's [YouTube channel].
In the notes for each video you'll also find helpful links and information to help you find out more about the topic under discussion in the video.
The topics we're discussing include the Philips Respironics CPAP machine recall, including both patient and physician perspectives on the recall's impact, what went wrong, and how the sleep apnea healthcare system can be improved to support sleep apnea patients' wellbeing.

Watch ASAP Vidoes

Veeka Stanton's Patient Story: "I Just Had to Suffer Through It"

Veeka developed sleep-disordered breathing during pregnancy and was unable to arrange a diagnosis or treatment before giving birth. Her experience raises a number of questions, including whether people with untreated sleep-disordered breathing during pregnancy are at higher risk for sleep apnea and/or other cardiovascular conditions—and whether they

should see a sleep specialist even if the problem appears resolved after pregnancy.
[Read Veeka's story at apneapartners.org.]



We Want to Hear From You!

Do you have questions or concerns about sleep apnea? Do you have a sleep apnea story to share?
Email ASAP and let us know!

Email ASAP