# CPAP (Children's Positive Airway Pressure) Program Newsletter

Winter 2021/2022

Newsletter Date Volume 3



Kids deserve the best.



## Traveling with CPAP or BiPAP™

Is your family planning to travel\*? Don't forget to plan to bring your child's CPAP or BiPAP<sup>™</sup> machine with you! It's important for them to continue to wear their sleep therapy to feel their best. Here are some tips, especially if you are traveling by air:

- 1. Make sure the equipment, including the water chamber, is dry before you pack it to prevent mold and mildew or damage to the machine.
- If traveling by plane, don't check the machine. It could easily be lost or damaged. Rather, carry it on in its travel bag. Airlines must allow you to carry on the CPAP or BiPAP<sup>™</sup> as an extra carry-on.
- Bring a letter from your sleep doctor or nurse practitioner stating that this is medically necessary equipment. This can save confusion, since airlines might not be familiar with children or teens wearing CPAP or BiPAP<sup>™</sup>. Call or MyChart us for this letter.
- 4. If you have checked luggage, pack some distilled water to use when you get to your destination. If you only have carry-on luggage and can't get distilled water where you are staying, in a pinch, you can use regular bottled water in the humidifier. Just make sure to soak it with half white vinegar and half water when you get home to dissolve the mineral build-up. Or if you're driving, its easy to pack enough distilled water for the trip.
- 5. Consider bringing some mask wipes (available online or through your home care company) for easy mask cleaning.

\*Whether to travel or not during the COVID-19 pandemic is a personal and family decision.



### Inside this issue

Travel	1
New RT	2
Machine Maintenance	2
Child Taking Off Mask	2-3
Usage Tracking	3
Respironics Recall	4

### Special points of interest

• Meet the CPAP Program's new Respiratory Therapist, Karen!

## **Hello and Goodbye**

Children's Wisconsin CPAP Program is saying goodbye to Korina, one of our Respiratory Therapists . She's starting some new adventures, but will miss all of the wonderful children and families she's worked with over the years.

We're saying hello, however, to Karen, who is joining our CPAP Program! Some of you may already know Karen, since she has worked at night doing sleep studies for Children's Sleep Center for a number of years. She has been a Respiratory Therapist for over 35 years and is also a Sleep Technologist. She enjoys getting tattoos and living dangerously as a Bears fan here in Packer territory. Please join us in welcoming her when you come into clinic!



## Cleaning Corner—Taking Care of Your Child's CPAP or BiPAP™ Machine

Since CPAP and BiPAP<sup>™</sup> machines are expensive pieces of medical equipment, it's important to take good care of them so that they can last as long as possible. Here are some important tips:



- Empty out the water tank every day and allow to air dry. This prevents mold or mildew growing in the water chamber, which can make your child sick and ruin the machine.
- Once a week, unplug the machine and wipe the outside of the device with a cloth slightly dampened with water and a mild dish detergent. Let it dry completely before you plug it back in.
- We do not recommend using an ozone or ultraviolet light cleaner (like So-Clean) because they can actually harm your machine and make the warranty invalid.
- Don't let pets or young children have access to the machine.
- Regularly clean or replace the filter according to the manufacturer's directions. A dirty filter makes it harder for the machine to run.

Even if you regularly do the above, no machine lasts forever. That is one reason a respiratory therapist checks your child's machine every time you come to CPAP clinic. If you notice a problem with the machine, call your home care company right away. They will likely need to get an order from our office to repair or replace the machine. Typically, they will then provide you with a loaner machine to use until they know if your machine can be repaired or not. If the machine can't be repaired, they will submit to your insurance for authorization to provide a new machine.

# Parents Ponder—What can I do if my child takes the mask off in the night?

Does this sound familiar? Your child starts the night sleeping with the mask on as peacefully as the boy in the picture. But at some point in the night , the mask comes off. Parents frequently tells us about this problem. There are typically two possibilites: 1. Children and teens wake up and take the mask off because something is both-



ering them. 2. They take it off while sleeping.

It's easier to fix the first one, because the child can often tell us what is bothersome and we can try to fix it. For instance, they might have air blowing in their

#### Parents Ponder Continued:

eyes or the air pressure might feel like its blowing too hard. In this case, please contact one of our Respiratory Therapists at (414) 266-4924 for ideas.

In the second situation, it may still be because something is bothering the child. So, we would check a download to look for clues and check how the mask is

fitting. However, more often this happens when children and teens first start CPAP because they're just not used to it yet. The best solution? Make sure your child wears the mask *every night*. Most children will get used to it over time and be able to keep the mask on more hours. If you happen to be up in the night, you can put the mask back on. It can take a little longer for kids and teens to get used to CPAP or BiPAP<sup>™</sup>, but the health benefits are worth it!

# Ask a Respiratory Therapist—How can I track my child's CPAP or BiPAP<sup>™</sup> usage?





DreamMapper

This is a great question! Both of the major CPAP and BiPAP<sup>™</sup> manufacturers (ResMed and Respironics) have a free app that can connect with the modem in your child's machine. This allows you to access information like when your child or teen is wearing the mask and for how many hours, if the mask is leaking, and about how many breathing events they are having. You can also get coaching tips based on this data and daily feedback.

The app for ResMed is called **MyAir** and the app for Respironics is **DreamMapper**. If you don't have a smartphone or tablet or if you don't have room to download an app, you can also create an account and access the same data on an internet page.

After you download the app, it will ask you to create an account when you open it. You will need to enter the serial number from your child's machine so it can connect with the modem.

What are the benefits of tracking your child's usage? We know that you need your sleep too, and so can't stay up all night to check on your child's therapy. So, having the app will help you to be more in tune with your child's therapy while still getting your sleep. For instance, if your child is taking their mask off in the night (see previous article) you can find out how many hours they left it on. Many parents would like their teens to work on being independent with their CPAP, but still need to make sure they are using it regularly. These apps can help parents to monitor their teens and intervene when necessary, but still give them some space. The app can also be used to give kids positive feedback when they are doing well! "It can take a little longer for kids and teens to get used to CPAP or BiPAP™, but the health benefits are worth it!"

### **Vaccine Reminder**

With COVID-19 and influenza cases rising, it is more important than ever for kids and teens to get both vaccines or to get a booster, if eligible. Most children using CPAP, Bi-PAP, or a Non-Invasive Ventilator have underlying health issues leading to a higher risk of problems from COVID-19 or influenza. Vaccines are a proven way to reduce the risk of getting seriously sick. Visit childrenswi.org for more information or to schedule!





## Philips Respironics Recall Update

On June 14th, 2021, Philips Respironics announced a recall of millions of CPAP and BiPAP<sup>™</sup> machines. If your child has a machine made by ResMed, then they were not affected by this recall. However, families with children using a recalled machine were sent a letter from our office to notify them of the recall, ask them to register the machines, and to recommend continuing to use the machine.

Philips Respironics estimates that the process to replace the affected machines will take about 12 months to complete. They began to repair

or replace affected machines in September 2021.

Due to this recall and other supply chain issues, there is currently a global CPAP and BiPAP<sup>™</sup> shortage. Therefore, most home care companies are not able to replace a Respironics machine with one of a different manufacturer unless your machine is broken.

If you haven't registered your child's Respironics CPAP or BiPAP<sup>™</sup>, please visit <u>www.philips.com/SRC-update</u>right away to register and to find updates.

Children's Wisconsin CPAP Program 9000 W. Wisconsin Ave. Milwaukee, WI 53226 PLEASE PLACE STAMP HERE

Sleep Lab: (414) 266-2790 #1 CPAP RT: (414) 266-4924 Pulmonary: (414) 266-6730 Central Scheduling: (414) 607-5280

Website: childrenswi.org/CPAP



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