

PAH TODAY

Owning Her Health

Confidence and determination help Lauren take charge of her PAH

SODIUM AND YOUR HEART

Recognizing and Reducing Sodium in Your Diet

BEING YOUR BEST YOU: EXERCISE AND MENTAL HEALTH



PAH Initiative

Sponsored by United Therapeutics
Committed to Improving the Lives of Patients

WELCOME TO PAH TODAY!

From the PAH Initiative

Welcome to the third issue of the PAH Initiative magazine, *PAH Today!*

The PAH Initiative is sponsored by United Therapeutics as part of an ongoing commitment to improving the lives of patients and supporting all those who care for them. United Therapeutics was founded by the parents of a daughter living with pulmonary arterial hypertension (PAH), so we understand the challenges presented by this rare and complex disease.

In our third issue, we want to provide you with inspiring information regarding diet and nutrition with PAH, especially around the holidays. From tips about healthy lifestyles with PAH to insights from real-life patients, there's plenty in this issue to help you balance nutrition, exercise, and daily life with PAH.

When it comes to PAH, you're not alone. Our magazine is all about providing you with knowledge and inspiration as we navigate this journey together.

Sincerely,
The PAH Initiative

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Owning Her Health

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SODIUM AND YOUR HEART

Recognizing and Reducing Sodium in Your Diet

When thinking about what to incorporate in your PAH-friendly diet, it's important to think about your sodium intake. Let's take an in-depth look at the reasons moderating your sodium intake is important.

Where Do I Start?

If you have PAH and you're wondering whether you should reduce your sodium intake, it all depends on the person. According to the Food & Drug Administration (FDA), Americans average around 3,400 milligrams of sodium per day, which is far beyond the recommended daily amount of 2,300 milligrams. For those with high blood pressure, the American Heart Association recommends even less—no more than 1,500 mg per day.

Of course, it's best to discuss your goals with your healthcare team, including whether diet and nutrition changes will help you reach them. Your recommended sodium intake will be unique to you and aligned with your personal treatment goals. So, at your next visit, ask your healthcare provider what the recommended amount of sodium is for you.

What's the Difference Between Sodium and Salt?

Salt is what we add to our food. Sodium is what is *already* in our food. Sodium is prominent in processed foods containing preservatives. This is where it can get tricky because on nutrition labels, sodium may be listed as *salt, baking soda, sodium, sodium nitrate, sodium benzoate, or monosodium glutamate (MSG)*. This knowledge will come in handy when reading nutrition labels!

Get Familiar with Nutrition Labels!

Looking at nutrition labels is especially important for those living with PAH because there are many different ways a label can be misleading. Use the below table to better understand what those nutrition labels really mean when it comes to sodium and salt content:

- **Sodium-free:** less than 5 mg of sodium per serving
- **Very low sodium:** less than or equal to 35 mg of sodium per serving
- **Low sodium:** less than or equal to 140 mg of sodium per serving
- **Healthy:** less than 360 mg of sodium per serving
- **Unsalted, no salt added, or without added salt:** no salt has been added to the food; however, sodium may still be present in some ingredients

Sodium and Its Effect on Your Heart

Added sodium to your diet takes a toll on your heart, especially for those living with PAH. In fact, treatment guidelines include avoiding fluid retention as a key objective for a pulmonary hypertension treatment plan. With PAH, your heart is already working harder than normal,

so why add any more stress to your most important machine?

Eating a diet that is higher in sodium can upset the natural balance of fluid and sodium in your body, causing more fluid to be stored outside of your cells in blood plasma and fluid surrounding your cells. This extra fluid (which can also cause painful swelling of the ankles or other parts of the body) can lead to higher blood volume and blood pressure, forcing your overworked heart to be under even more strain.

So, How Can I Reduce My Sodium Intake?

Thinking about and moderating your dietary needs can be difficult, but here are some tips on ways to monitor and reduce your sodium intake:

- Read food labels for sodium content.
- Log your sodium intake daily in a journal or app.
- Speak with your dietitian about where to find low-sodium foods that you enjoy.
- Ask a loved one to help meal prep low-sodium meals for you to refrigerate or freeze and eat over the course of several days.
- Avoid fast foods, restaurant foods, and processed foods whenever you can.

It may be difficult to pull yourself away from eating higher-sodium foods—salt is all around us. However, getting yourself into a habit of reading food labels or logging your daily intake is a great way to start reducing the amount of sodium in your system. Your body—and most importantly, your heart—will thank you. 🍷

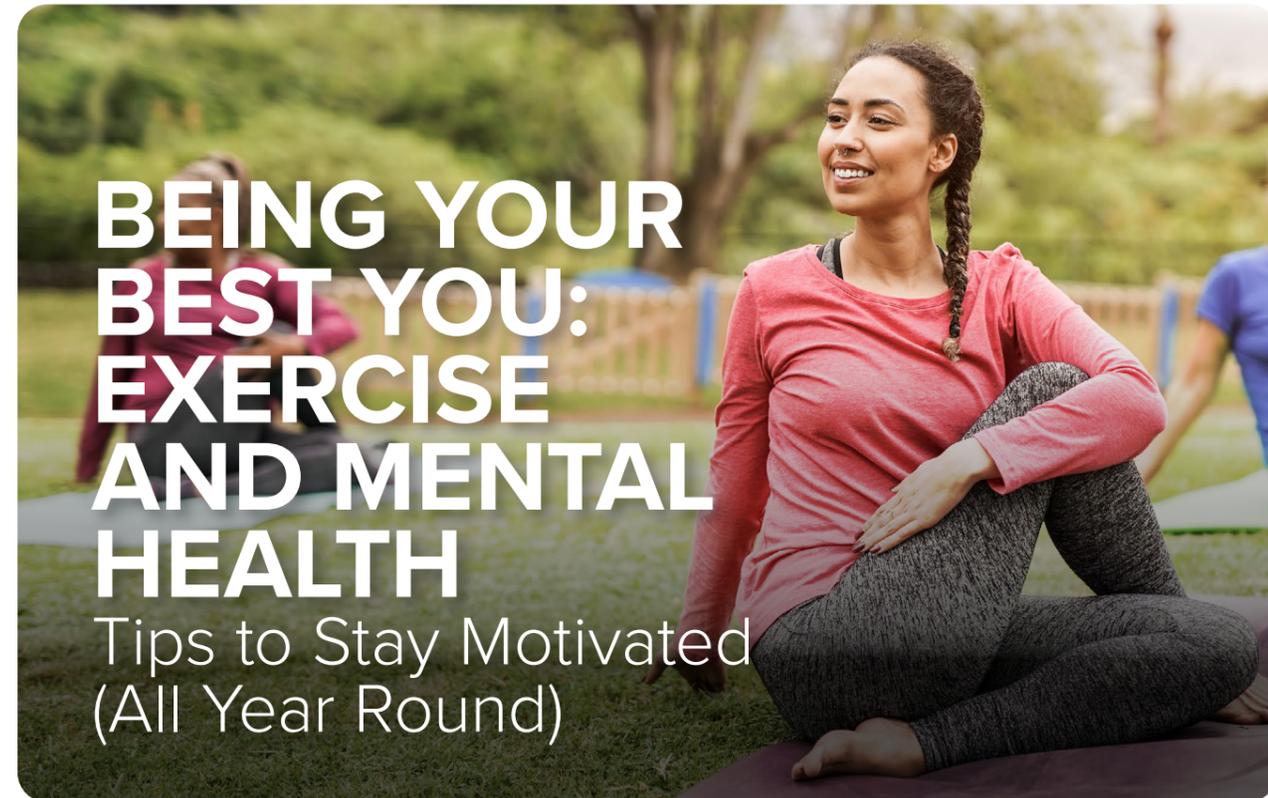
JOIN THE PAH INITIATIVE

Sign up to receive future magazines, the email newsletter, and other inspirational resources to help navigate life with PAH.



PAHNEWSLETTER.COM

Disclaimer: Always consult with your healthcare provider before starting an exercise routine. This article is offered for educational purposes only and is not a substitute for nor replaces professional medical advice, diagnosis, or treatment. If you act on information contained in this article you agree that you are doing so at your own risk. **IN THE EVENT OF A MEDICAL EMERGENCY, PLEASE CALL EMERGENCY SERVICES IMMEDIATELY.**



Once you've got an exercise routine going, it's important to keep it up. Consistency and motivation are key with workout programs. This can be tough around the holiday season, when things are a little more hectic than usual. We've all made New Year's resolutions and had trouble keeping them going once our initial enthusiasm started to run out.

Looking for ideas on how to stick with it? The following are some ways you can make sure to keep up your routine during the holiday season.

Set a specific time. By planning out a specific time for your workout, you can create a more comprehensive routine for your entire day. When you have a set time, it will be easier to keep going with your exercise routine, since you'll have a consistent "appointment" to keep with yourself.

Track your wins. Every little bit helps! One way to stay motivated is to capture those small wins. Write down what you did and break up your overall goal into levels. Don't forget to celebrate when you get to that next milestone!

Connect the challenge to something you enjoy. Tying exercise to an activity you enjoy—like watching TV or movies—can be a great way to connect something challenging to something you look forward to. Think about what that thing you love to do is. Could exercise be incorporated?

Check in with your buddy. When you're working out with another person, you have someone with you to keep you accountable and keep your workout routines consistent. Checking in regularly helps you both stay on track.

Write it down. Sometimes, committing a plan to paper can do wonders for follow-through. Write down your exercise goals—what you want to achieve by a certain time, and how you'd like to do it. Think about the barriers that get in the way and specific ways you can overcome them. Try using this format: "If I'm in this situation

_____ (name specific barrier), then I will

_____ (name action) that will help me achieve my goal."

Change it up. If your normal workout routine is getting a little stale, try incorporating some different moves. Check out the PAH Initiative website's PHitness video series, which features several six-minute workout videos. Work with your doctor to see what sort of additional exercises would work for you.



For more ideas on how to get started, scan this QR code for information on PAHInitiative.com.

Mental Health Tips and Tricks

When living with a condition like PAH, taking care of your mental health is also important. This is especially true during the holidays when we are not only busier but feel pressure to be "on" or just be on the go way more than we are used to. We're also prone to getting those holiday blues when things never quite seem to live up to our expectations. It's easy to get caught up in the hustle and bustle of your day and forget to take time for mental well-being. But spending time caring for your emotional health can be rejuvenating, restorative, and fulfilling. Here are some tips and tricks for keeping your mental health in a stable place with PAH.

Join a circle of support. Having people to talk to is critical to staying well. Engage with people who love you—these are often the people who can bring us the most comfort in our times of

need. With a strong support network, you can feel comfortable expressing your emotional needs and receiving the encouragement you deserve. Online support groups can also be a helpful resource.

Take a break. When you're feeling overwhelmed or overworked, take some time for yourself! Do something that brings you joy, like watching your favorite movie or taking a bath. Take your mind off whatever might be happening by changing your scenery or what you're physically doing. Getting a little respite with time to yourself can do wonders to restore your mental stamina.

Get ahead of the blues. Research shows that lifestyle choices may help decrease the chance that someone may have mental health issues. Getting regular physical activity, participating in activities with others, staying within the "normal" range for body mass index, not smoking, and keeping alcohol consumption low or moderate have all been shown to be linked with better mental health.

Understand PAH, understand yourself. Knowledge is power! By better understanding your condition, you can better understand what you need to feel good in your body and mind.

Talk to your doctor. It's imperative to let your doctor know what's going on with all facets of your health—including your mental and emotional well-being. When your doctor is in the loop, they are more able to help with what's happening in your life and recommend specific changes you can make.

With these tips and tricks in your back pocket, it will be easier to keep up your routine during the holiday season! If you want more information on PAH and exercise, visit PAHInitiative.com. 📍

FITNESS FOR YOU, 6 MINUTES AT A TIME

Are you ready to get fit? PAH Initiative provides PAH-friendly PHitness videos. Talk to your doctor about whether an exercise program is right for you. **Start getting PHit**



PAHFITNESS.COM

OWNING HER HEALTH

Confidence and determination help Lauren take charge of her PAH

For most of her life, Lauren has always been a mover, and she loves to stay active. If she isn't hiking, biking, or rock climbing, she is keeping her mind and body in check during a yoga session.

In 2010, Lauren was a 21-year-old aspiring nurse anxious to continue in her third year of nursing school. She was visiting her boyfriend (now-husband!) in South Korea, where he was teaching English. As a couple, they climbed mountains and hiked around the island he lived on. One day, during a hike, Lauren started to experience heart palpitations and shortness of breath. She found herself having to stop and catch her breath mid-hike more often than usual.

Lauren remembered thinking she should probably get checked out when she returned home to the U.S., but she wanted to live in the moment and enjoy time with her boyfriend. Her home state is relatively flat, and she was academically busy, so she thought she was likely just out of shape.

However, that was not the case.

Searching for Answers

About five days after Lauren returned home from South Korea, she attended an exercise class with a friend. They had just finished running up a flight of stairs when Lauren stopped at the top to catch her breath. The next thing she remembered was waking up on the floor with members of her class looking down on her to see if she was okay.

"I had just had my first syncopal episode, a fainting spell," Lauren said. "I was taken to the local emergency room, where they performed lab work and a CT scan on me. I didn't know what was wrong with me or what to expect."

Lauren's test results showed she had inflammation at the top of her lungs, so she was kept in the hospital overnight for further observation. An on-call cardiologist visited Lauren at her bedside the following morning to do an echocardiogram

with a bubble study, an imaging test that shows the heart's structure and involves the delivery of saline mixed with air into a vein.

After the study results came back, the cardiologist delivered the news to Lauren that she had an enlarged ventricle that potentially indicated pulmonary hypertension. The cardiologist referred Lauren to a PAH specialist at a hospital about 20 miles away so she could receive a PAH confirmation and further care.

"I knew in my head this was going to be a rough journey," Lauren said. "I felt that things were about

to turn very real and serious, but I was glad to be pointed in the right direction to get the answers I needed."

Adapting and Overcoming

Lauren immediately called her parents to inform them of the news. She tried to stay optimistic. She was then transferred to the specialty hospital for further testing and was discharged two days later because her college semester was starting.

Her diagnosis was confirmed by a right heart catheterization performed by the PAH specialist,

"I felt that things were about to turn very real and serious, but I was glad to be pointed in the right direction to get the answers I needed."

Continued on next page...



and Lauren trusted her from the start. Lauren said her specialist gave her every reason to believe this was a condition she could manage.

“She explained things very realistically to me, and she is very renowned in the PAH community with her research and expertise,” Lauren said. “Her primary goal was to allow me to live as normally as possible.”

Lauren started on intravenous (IV) therapy as her semester was starting, and she was unable to make it to class due to being inpatient. Her professors were not very accommodating, and Lauren was kicked out of nursing school because she missed two days of clinical. Lauren was devastated but vowed this setback wouldn’t keep her from being a nurse. Once she learned to manage her new disease and IV therapy, her parents and PAH specialist advocated for her so she could return to school within a matter of days.

Living with a central line was not an easy adjustment. Simple tasks such as showering became more difficult than before. She was determined to continue with her studies, though,

since she was only three semesters from finishing her bachelor’s degree.

“A lot of that semester was a blur because I felt like I had to perform at a higher academic level,” Lauren said. “I had a lot of nursing professors telling me I didn’t have what it took to be a good nurse. I passed that semester by 0.7%, and I had never been prouder of myself for overcoming all the mental and physical barriers life threw at me in a very fast four months. My confidence soared, and I knew I was stronger than I ever gave myself credit for.”

Finishing school wasn’t the only thing Lauren was afraid she wouldn’t accomplish after being diagnosed at such a young age. Over the last 12 years of her diagnosis, she has been able to work as a nurse full time, get married, start a family, and travel. She continues to grant herself the grace to see what her body will allow her to do each day.

With approval from her PAH specialist, Lauren set reasonable goals for herself to resume many of her previous hobbies. She still maintains her active lifestyle to the best of her ability.

Switching Things Up

Since adopting a son, Lauren and her husband have modified their activities to include their toddler. With approval from Lauren’s doctor, they walk at least four to five times every week, including one or more hikes and a few treks to the dog park. She’s also intent on maintaining her twice-a-week yoga practices.

“The trick to keeping a good routine is variety,” Lauren said. “If I am not feeling one type of activity, I switch it up to something different. Some days I am feeling the strength training, and other days I just want to take the dogs for a walk. The key is to not get too comfortable in anything—it really keeps things real. I always opt outside if possible because I really believe the sunshine and fresh air add endorphins to my body.”

Lauren does her best to eat as healthy as possible, especially during the holidays. She has been eating a more plant-based diet (with fish occasionally) for about four years. However, it is easy to go above her usual sodium allotment with all the potlucks and parties that come with the holiday festivities. She likes to savor fresh vegetables, hummus, or things that might be a better option than sweets or salty, processed foods. She enjoys cooking from scratch to help control what’s in her food as well.

After close to a decade on IV therapy, Lauren transitioned to subcutaneously infused therapy this past spring. She and her husband recently flew to Europe, where they spent two weeks visiting friends, hiking in Austria, and exploring German castles and vineyards with their son. Lauren paced herself and was sure to rest when she needed.

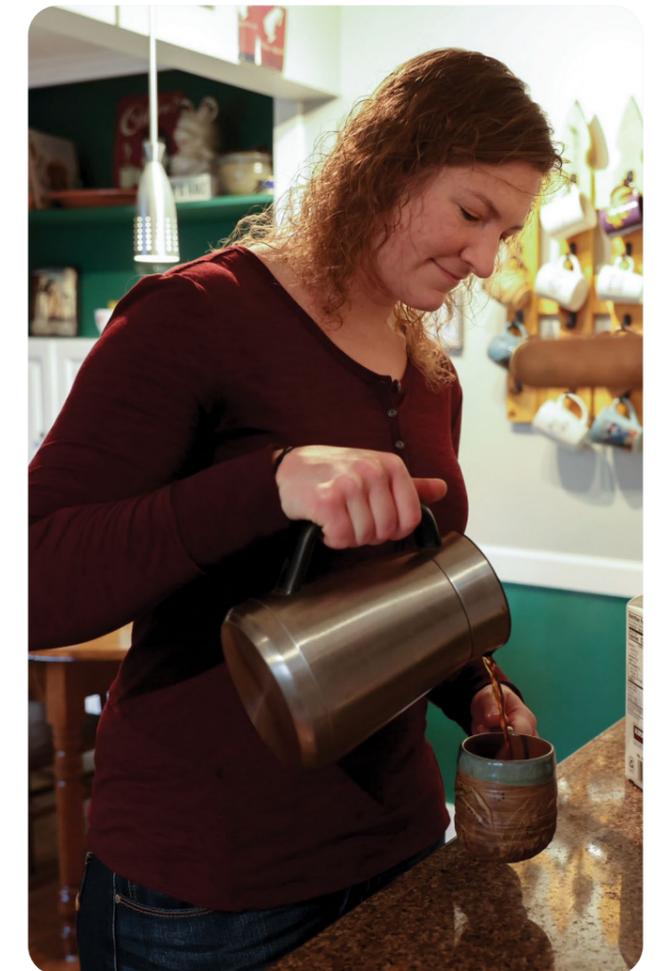
“I knew I was stronger than I ever gave myself credit for.”

Looking Toward a Brighter Future

Lauren plans to start graduate school to pursue a master’s degree in nursing education this winter. She is determined to teach at a university someday to help nursing students avoid having an experience like her own when dealing with a health issue.

Today, Lauren continues to keep a hopeful attitude. She sets goals for herself and adjusts as needed to best fit her lifestyle. Advocating is all about having your voice heard, and she tries to do it through her daily activities and encounters.

“Do everything in your power to own your health,” Lauren said. “This includes questioning things when necessary, living the healthiest you can, and educating yourself on current PAH happenings as best you can. Be your own best advocate. A mantra I like to live by is this: Do it while you can—nobody is guaranteed anything the next day.”





CARING FOR YOUR LOVED ONE—AND YOURSELF!

Ideas for the Long Road Ahead

As a caregiver to someone diagnosed with PAH, it might seem difficult to navigate caring for your loved one while balancing your own needs. Whether you are a family member or close friend, we're here to provide a few tips on how to better care for your loved one and for yourself!

Learn and Ask Questions

From the minute your loved one is diagnosed with PAH, there is a lot of information coming at you quickly. Trying to take it all in and learn as much as you can about PAH is key. Whether it's through their healthcare team, support groups, or your own research, your loved one will appreciate knowing that you're learning alongside them. It's also important to keep an open line of communication with your loved one's healthcare team. There may be times when you are unsure why something is being done a certain way or you notice your loved one is having new symptoms (or has stopped improving). You may want to ask about something that you read from a reputable source like the Pulmonary Hypertension Association or PAH Initiative. Speaking up and asking questions is a great way to advocate for your loved one and to be involved in their care.

Take Notes and Stay Organized

Consider having a binder, folder, or another organizational tool to keep all important documents in order. Keep records and your notes from all visits and medical paperwork together. Have a shared calendar or whiteboard with future appointments and questions you think of. It also may be helpful to document step-by-step processes, medication schedules, or daily caregiving activities in case you need someone

else to fill in for you. Lastly, make sure your family or extended family are up to date on plans and processes in case of emergency. It can be a lot to keep track of, but it will make things easier day to day if you are organized and ready for anything!

Value Your ME Time!

Many experienced caregivers will tell you: take breaks when you need them! That's easier said than done, of course, but it is important to step away occasionally, even for short periods of time. Recharging can help avoid burnout so you can provide the best care to your loved one. When you have the chance, do what you love most. Your loved one appreciates all the work you do for them, so when you have time to step away, take full advantage of it.

PAH will bring both good days and bad days. There will likely be times when you feel overwhelmed and need to take deep breaths. Remember, you are not alone. You are not expected to be everything or know everything. There are resources available, including support groups and other caregivers who have been where you are now. As you care for your loved one, remember to be their advocate and listen to their concerns. But don't forget to care for the caregiver! Your well-being and health are important, too. 🧡



EATING HEART HEALTHY

Tips for a Better Diet and Our Favorite Winter Pancakes

There are many aspects of maintaining a healthy lifestyle with pulmonary arterial hypertension (PAH). That means keeping up with any exercise routine you've set up with your doctor as well as keeping a healthy diet. A big part of eating heart-healthy is reducing salt and sodium in your diet.

Eating foods that are high in sodium causes the body to retain more water in blood plasma and the fluid surrounding your cells. This increased fluid volume can increase blood pressure, causing the heart to have to work harder to pump blood through the body. When your diet is lower in sodium, your heart doesn't have to work as hard. And if you take medicine for high blood pressure, a low-sodium diet might help the medicine be more effective. When your heart is already having to work harder due to PAH and narrowed blood vessels in the lungs, it needs all the help it can get!



Interested in learning more about how salt and sodium affect your body and other ideas for reducing sodium in your diet? Use the QR code to read more on the Living with PAH section of PAHInitiative.com

Making changes in your diet can feel intimidating—start small! Talk with your doctor, then consider starting with one positive change. You can make another change each week! Also, don't be too hard on yourself when you occasionally cheat. It happens, and being too hard on ourselves when we lapse can undermine our ability to keep going. Talk with your doctor about whether planning to have occasional cheat meals may help create a realistic plan you can stick with.

Although these changes may seem small, they will add up. Before you know it, you'll have made permanent change.

Here are some helpful ways to reduce sodium in your diet:

Get rid of the saltshaker. Keep the shaker out of the kitchen when you're cooking and off the table during meals. Out of sight, out of mind! Try substituting other herbs and spices instead, or flavored vinegar, sherry, wine, or lemon juice.

Limit salty foods. Some examples are pickles, olives, sauerkraut, processed or cured meats (ham, sausage, deli meats, hot dogs, and jerky), flavored or seasoned salts, canned soups, and salty snacks like chips, pretzels, and many nuts. If you can resist buying these at the store, you won't be tempted come mealtime!

Eat fresh food. Salt is a preservative, so it is often used to extend the shelf life of canned, preserved, or processed foods. Whenever you can, pick out fresh, whole foods. Some foods recommended by the American Heart Association are fruits and vegetables, whole grains, fat-free or low-fat dairy products, fresh legumes (peas, lentils, beans), lean meats, poultry, and fish.

Avoid fast food. It's easy to grab food on the go, but making fast food a part of your regular diet isn't advisable. According to dieticians, eating fast food regularly can increase your risk of depression, cancer, type 2 diabetes, and heart disease.

Recipe: Quick Pumpkin-Cranberry Pancakes with Maple Syrup

Looking for an easy breakfast recipe that's tasty and heart-healthy? Look no further than these easy pancakes — perfect for the holidays and cold winter weather. 🍷



Recipe CARD

NAME OF RECIPE	INGREDIENTS
Quick Pumpkin-Cranberry Pancakes with Maple Syrup	-1 cup whole wheat flour -3 tsp baking powder -2 tsp pumpkin seasoning (found in spice aisle) -1 cup 1% milk (can substitute skim milk) -2 egg whites -3 tbsp cinnamon applesauce -¾ cup unsweetened cranberries -Cooking spray -½ cup maple syrup
SERVES 2 4 6 8	PREPARATION
DIFFICULTY ● ● ● ● ●	1. In a medium bowl, mix flour, baking powder, and pumpkin seasoning. Next, add milk, egg whites, and cinnamon applesauce and beat until the batter is smooth. Once the mixture is complete, fold in cranberries with a mixing spoon.
TIME TO PREPARE 10 minutes	2. Spray griddle pan (or large frying pan) with cooking spray and place over medium-high heat for two minutes. Using a small ladle, make 4" pancakes and flip when the tops become bubbly. The second side will cook quickly, so be sure to monitor progress and remove once golden brown.
TIME TO COOK 15 minutes	3. Arrange four pancakes on each of four plates and top with 2 tbsp maple syrup.
COOKING TEMP Medium-high	

PAH Resources

Find support for PAH, nutrition, and fitness with these helpful resources

A low-sodium diet and regular exercise are two major components of living a healthy lifestyle, especially during the holiday season. That lifestyle might look different when you're someone living with PAH, but a PAH diagnosis doesn't mean you can't find a wellness routine that works for you. The PAH Initiative is proud to be a resource to you and your loved ones along with the organizations below that are committed to supporting the PAH community. We hope these resources help you find the support, education, and inspiration you've been looking for.



Nutrition and Fitness

The PAH Initiative: PAHInitiative.com has useful information and resources that you can use every day. Find out which foods and drinks could help or do harm, make lifestyle changes you can commit to, plus check out exercise videos for people with PAH at <https://www.pahinitiative.com/living-with-pah/pah-diet-exercise>.

The American Heart Association: Learn more about how to reduce sodium in your diet as well as tips for shopping for low-sodium foods, preparing food, and eating in a restaurant with resources from the American Heart Association. heart.org, search "low sodium."

Pulmonary Hypertension Association (PHA): The PHA is a great source of information on ways to cut back on salt, salty foods to avoid, hidden sources of sodium, how to interpret sodium content on food labels, and seasonings that can be substituted for salt. Visit phassociation.org.

Allina Health: Allina Health has lots of healthy recipes that are heart smart and low sodium. Allinahealth.org, search "recipes."



Knowledge, Community, and Financial Assistance

Pulmonary Hypertension News: Get the latest news coverage of PH science, medicine, and human-interest stories. Visit pulmonaryhypertensionnews.com.

phaware® Global Association: Stay #phaware by accessing digital content focused on PH education, resources, and knowledge, including the "Aware That I'm Rare" Podcast. Visit phaware.global.

Pulmonary Hypertension Association (PHA) Support Groups and Events: Learn more and find others in the PAH community by joining one of hundreds of virtual and in-person support groups or attending an event near you. Check out the PHA network at phassociation.org.

PHA List of Assistance Programs: Visit phassociation.org for a list of nonprofit, manufacturer, and specialty pharmacy assistance programs that may help you cover the cost of therapy.



PAH Initiative and United Therapeutics Resources

PAH Initiative: Stay informed about PAH through a variety of educational tools, resources, and information, including the PAH Initiative Learning Library. Visit pahinitiative.com.

PAH Initiative Facebook and Instagram: Connect with the PAH Initiative on Facebook and Instagram for more stories, information, and inspiration.



PAH Initiative Newsletter: Sign up to receive helpful information and updates from the PAH Initiative. Visit PAHnewsletter.com.

PHpal App: Explore an exciting new app developed by United Therapeutics that provides opportunities to be better informed and feel more in control of your PAH. Download the free PHpal App from the App Store or Google Play. Visit PHpalApp.com. 🍷





Where
knowledge
meets
inspiration

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