

PAH TODAY

WINTER 2024 | #07

OWNING YOUR PAH

John shares the importance of advocacy, resilience, and support

REACHING HER MILESTONES

Gwen reveals her challenges and triumphs with PAH

A BALANCING ACT

The imbalances behind your PAH and what you can do about it

LOW ENERGY? UPSET TUMMY?

Recipes for different situations may be just what you need



PAH Initiative

Sponsored by United Therapeutics
Committed to Improving the Lives of Patients

WELCOME TO PAH TODAY!

FROM THE PAH INITIATIVE

Welcome to the 7th 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 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 this issue of PAH Today, you'll hear the perspectives of people living with PAH like you, including Gwen, who reflects on her journey that started before there were PAH medications, and John, who shared how he stays active and how he

didn't give up trying to find the right treatment plan. You'll also learn more about the role imbalances in natural substances play in PAH and its treatment. For those looking for inspiration in the kitchen, we hope the recipes will give you something new to try as well as new ways to think about how you can meet your nutrition goals, regardless of your situation.

When it comes to PAH, you're not alone. The PAH Initiative is here to provide you with knowledge and inspiration as we navigate this journey together.

Sincerely,
The PAH Initiative

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If you would like to provide feedback or suggestions for future issues of *PAH Today*, please visit PAHInitiative.com



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Gwen reveals her challenges and triumphs with PAH



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Owning His PAH

Working with his doctor helped John accept his disease and fight it at the same time

PAH: A BALANCING ACT

THE IMBALANCES CAUSING YOUR “BUMPY RIDE” WITH PAH



What if there was more you could do to feel better?

Imagine you're driving your car and one or more of your tires become unbalanced. Maybe there's too much or too little air in one or more of them. Your car isn't functioning the way it should, and you're in for a bumpy ride if you don't fix the imbalances in your tires. What would you do?

Just as a car needs balanced tires to run smoothly, your body relies on the right balance of four natural substances to keep your lungs healthy.

When you have pulmonary arterial hypertension (PAH), the blood vessels in your lungs become more narrow. These changes may cause the blood flow to the lungs to slow, causing PAH symptoms. It also strains the heart over time as it works harder to push blood through more narrow vessels.

The body produces several natural substances that are key to healthy blood vessels in the lungs. Having the right amount of each is important to allow blood to flow smoothly through the lungs.

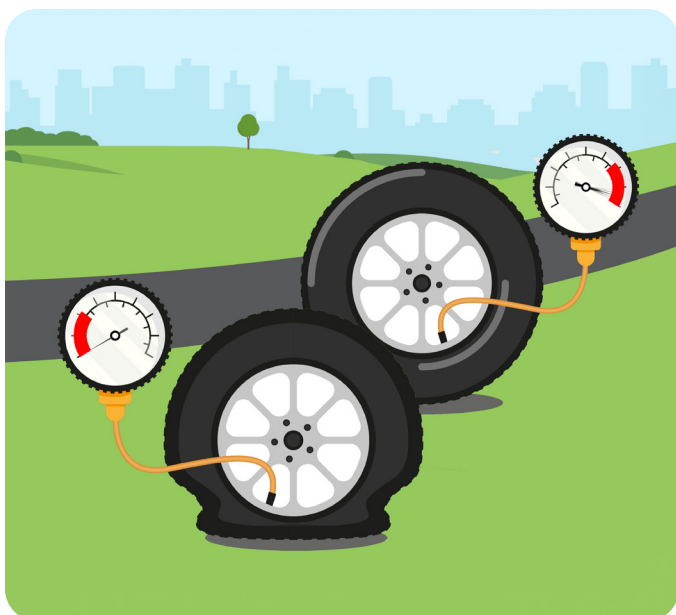
Just like a mechanic can adjust any tires that are out of balance, different kinds of PAH medications help fix one of the imbalances.

Each substance imbalance corresponds with what PAH experts call a treatment “pathway”.

The four treatable pathways are nitric oxide, endothelin, activin signaling, and prostacyclin.

PAH TREATMENT PATHWAYS

Nitric oxide	Helps blood vessels stay open and that blood is flowing properly. People with PAH may have too little nitric oxide.
Endothelin	Causes blood vessels to become narrow and the vessel walls to become thick. People with PAH may have too much endothelin.
Activin signaling	Involved in many body systems, including blood, bones, and muscles. In PAH, patients may have an imbalance in their activin signaling, which leads to the blood vessels in their lungs becoming too thick.
Prostacyclin	Helps blood vessels stay open, keeps vessel walls from becoming too thick, and helps prevent clotting. People with PAH may have too little prostacyclin.



Unfortunately, knowing which substances are imbalanced isn't as straightforward as fixing a tire. There's no gauge or test that can tell your specialist which substances are out of balance with your unique PAH. Although we can't see the "tires", we can still tell something may still be wrong because of the bumpy ride.

MOST PAH PATIENTS HAVE AT LEAST TWO IMBALANCES

Based on clinical studies, we do know that most people with PAH have more than two substances out of balance.

Researchers looked at multiple studies involving more than 4,000 patients and found that those who took only one PAH medication were at a higher risk of their PAH worsening. Their analysis also found that **taking at least two PAH medications:**

Helped patients walk farther
(improved six-minute walk distance)

Do more activities with fewer symptoms
(improved Functional Class)

Reduced risk for PAH-related hospital admissions

These results demonstrate why PAH experts think that most patients have more than one imbalance of natural substances in their lungs. **This is why PAH experts recommend that most patients take two or more medications to treat multiple imbalances.**

In fact, a combination of two or more medications—each working in their unique way— has become the standard of care in recent years.

If your PAH journey is still “bumpy”, it may be a sign that something is still wrong and that it’s time to try to fix another possible imbalance.

IS “GOOD ENOUGH” GOOD ENOUGH?

When you're living with PAH, it's natural to adapt your lifestyle to try and reduce your symptoms. You might limit your time playing with your grandchildren, stop working in the yard, or turn down invitations to go out to dinner with friends because exerting yourself makes breathing more difficult or you're just too tired.

What if there was more you could do to feel better? If your PAH journey is still “bumpy”, it may be a sign that something is still wrong and that it's time to try to fix another possible imbalance.

Adding a medication could help fix a remaining imbalance in one of your “tires” that’s still causing PAH symptoms, putting strain on your heart and keeping you from doing as much as you’d like.

We're learning more about PAH every day. Understanding the role multiple imbalances in natural substances play provides us with a new way to think about treating PAH.

Talk with your doctor about how the medications in your treatment plan work and whether there may be something else you can do. 🌱



HELPING OTHERS IS ALWAYS IN STYLE

HOW JULIA INSPIRES OTHERS WITH HER MESSAGE OF HOPE



Each issue of PAH Today features United Therapeutics' PAH Initiative Ambassadors, who are real people diagnosed with pulmonary arterial hypertension (PAH) or their caregivers. With a heart for the PAH community, these passionate advocates share their stories in a variety of ways to help others living with PAH find answers and support along their journeys from diagnosis to treatment.

Meet PAH Initiative's newest Ambassador, Julia.

Diagnosed with lupus as a teenager, Julia learned to advocate for her health at a young age. Years later, in 2021, while working as a full-time dispatcher, she began to experience breathlessness to the point where she felt like she was suffocating. After seeking a second—and then a third—opinion, Julia was diagnosed with PAH and started a treatment plan.

Discover what inspired Julia to join the PAH Initiative community and what she hopes to accomplish as an Ambassador.

PAH TODAY: Before your diagnosis, had you heard of PAH? How did you feel about your diagnosis?

JULIA: I didn't know about PAH, so I was very upset when I finally received my diagnosis. At first, it was overwhelming to know I had a second chronic disease that would require lifelong treatment. It took time for me to adjust, but with a treatment plan I can take deep breaths again. I feel like I can live life on my own terms.

PAH TODAY: Living with two chronic conditions must be difficult. How do you keep a positive outlook?

JULIA: I am a person of faith. My health conditions have kept me from seeing the world and doing everything I want to do, but I try to live day by day. I try to make the best I can with what I'm given with the time I'm given. There are other people who have it so much worse.

PAH TODAY: How would your friends describe you?

JULIA: I think they'd say I'm lively and fun. I'm a lovable person. I try to be honest with people. I'm a genuine and fun person. I'm as real as they come.

PAH TODAY: What is the hardest part of living with PAH?


JULIA: The hardest part is when people say, "You don't look sick. What's wrong with you?" They don't always understand why I can't consistently participate in activities or that I don't have the strength to go and do things all the time. It's hard when friends are upset because I'm late getting to dinner or whatever. They don't understand that it took me hours to get dressed. They don't know what it's like to be in my shoes—no matter how cute my shoes are!


That's one of the reasons I wanted to become a PAH Initiative Ambassador: I don't want people to be afraid to live with this disease. Your support system has to

INTERESTED IN BEING AN AMBASSADOR?

United Therapeutics proudly devotes its energy and resources to the PAH Initiative because, from the outset, PAH has been personal to us. United Therapeutics was founded by the parents of a daughter who was diagnosed with PAH. We understand the fears, hopes, and challenges that await people affected by PAH.

As part of this effort, we love hearing from people who are willing to share their stories as PAH Initiative Ambassadors. Interested in joining the Initiative as an ambassador?

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 PAHInitiative@mypatientstory.com



understand that you can't do certain things. I want people who are diagnosed with PAH to know your life isn't over—your life is just different. You can still have fun and live, you just have to live on your terms.

PAH TODAY: How did you become an Ambassador?

JULIA: I saw a few people on social media who had been diagnosed with PAH. I was curious about them and the educational programs they were involved with. I reached out to one of the people from the PAH Initiative posts, and they told me about the United Therapeutics PAH Initiative program. So I reached out to United Therapeutics, and they responded to me.

PAH TODAY: What are your goals as an Ambassador?

JULIA: I don't want people to live in fear. Just because you've been diagnosed with PAH, you don't have to stop living your best life. You might be on oxygen, but you can see the sunset and smell the flowers. You can't allow PAH to rule your life. My goal is to create a greater understanding of PAH. It's not an easy conversation to have with your friends and family. I want to encourage people to be curious rather than fearful.

PAH TODAY: What message do you want to share with others who are newly diagnosed and living with PAH?

JULIA: First, I want them to know that everyone who is diagnosed with PAH goes through the similar struggles. You are not alone.

Second, when you live with PAH, it's important to embrace it. Once you can accept what is, healing can come with this state of mind. You have to have a good mindset to be happy. It starts with you. Once you have accepted your diagnosis and are doing everything you can to help yourself, it's easier to receive help from your support team. And that support is important. We all need connection. 🧡

Individual patient results may vary.





OWNING HIS PAH

WORKING WITH HIS DOCTOR HELPED JOHN ACCEPT HIS DISEASE AND FIGHT IT AT THE SAME TIME

When John was diagnosed with pulmonary arterial hypertension (PAH), his pulmonologist said something he would never forget.

“My pulmonologist told me, ‘You have to own this disease, John. You’re not going to be successful in this journey unless you own it.’”

John didn’t know it at the time, but this statement would have a lasting effect on him.

He first started to notice that something was wrong during a family trip to Colorado for a college graduation. While walking up a hill, he became severely winded, more so than anyone else in his group. He had been a smoker for 30 years, so he chalked the breathlessness up to that and the high altitude of the Colorado mountains.

After returning home, John began finding himself out of breath more often than usual. The feeling

“My pulmonologist told me, ‘You have to own this disease, John. You’re not going to be successful in this journey unless you own it.’”

continued to get worse during the next few months. Then, one morning, while sitting in his car alone, John realized something was seriously wrong, so he went to a nearby urgent care center.

While at the care center, John was told that he needed to go to the hospital immediately. At the hospital, John received medical treatment, but still struggled with his health in the days that followed.

“I could hardly walk up two sets of stairs without feeling exhausted,” he said. “I knew something still wasn’t right.”

John knew he needed to advocate for himself, so on the following

Monday, he returned to the hospital, where he spent three and a half weeks, and additional testing determined his PAH diagnosis.

“I was a little pissed off,” he said of his diagnosis. “I’ve always been in really good shape, and this was something I never expected to hear.”

In response, John’s doctor started him on an oral medication that worked in the short term, but then his condition worsened—to the point where he couldn’t walk down an air-conditioned hallway without feeling exhausted. When he discussed this concern with his pulmonologist, John’s doctor administered some tests and discovered that his pressures were extremely elevated.

John’s pulmonologist then suggested he add a prostacyclin-class medication to his treatment plan. She recommended an inhaled formulation.

“When I approached my doctor, she told me she thought this would be a good option for me,” John said.

After starting the inhaled prostacyclin-class treatment, John slowly started to feel stronger. His pulmonologist recommended he exercise regularly, depending on how he felt. Exercise became a part of his treatment plan, and he started walking every day to rebuild his strength.

John’s wife, Lyndee, has been a huge support for him as he works to rebuild his strength, and she isn’t afraid to show him tough love when he needs it.

“My wife is my best friend,” John said. “We do everything together. I wouldn’t be where I am today without her support and that of my family, friends, and faith. It truly takes a village.”

With time, John started to take a more proactive approach to his health. He now walks at least a mile a day, with Lyndee by his side, of course. They love to take vacations to different locations in Florida to visit the beach as much as possible. They also relish in the moments they spend with their friends and family, most of which are spent in the summer, at the lake, on a boat.



John and his wife, Lyndee

“We’ve always been a water family,” John said. “Anytime I’m behind the wheel of that boat, I’m content.”

When John’s pulmonologist told him he needed to own his PAH, he wasn’t sure what to make of it at first. But thankfully, John’s PAH specialist is very personable, and he sees him about four times a year for routine check-ups.

The relationship John has built with his doctor has helped him recognize the need for a solid support system, and he feels fortunate to have a healthcare team that provides him with the support and guidance he needs.

“It’s really all about building relationships with others,” he said. “My pulmonologist really put me on the right path.”

When John accepted that he needed to make serious decisions to improve his overall health, his attitude toward his PAH diagnosis improved. He still experiences days when he feels frustrated about

having to take his medications, but he is thankful that the inhaled prostacyclin-class medication works for him.

John’s condition has not hindered his ability to continue working, but he hopes to retire early so he can spend more time focusing on his health and family.

“My advice to others who may be struggling with PAH is to not be afraid to go after your dreams,” he said. “Focus on what you want—not on what you don’t want—because that’s the first step to finding a way to get whatever that is.” 🌸

Individual patient results may vary.

“Don’t be afraid to go after your dreams, focus on what you want—not what you don’t want—because that’s the first step to finding a way to get whatever that is.”



Nancy, PAH Initiative Ambassador

COOKING FOR A CAUSE: RECIPES FOR DIFFERENT SCENARIOS

Managing a healthy diet is important for everyone, but patients living with pulmonary arterial hypertension (PAH) need to pay particular attention to what's on their plate. If you are living with PAH, you are likely already trying to limit your salt intake to reduce fluid retention, or edema. However, there may also be other special circumstances you consider when fine tuning your diet.

You and your PAH are unique. Please speak with your healthcare provider about the right dietary choices for you and your health.

Feeling sluggish? Try a smoothie. Feeling hungry between meals? Have some quinoa. Nauseous? Nibble on a small muffin. Designed specifically with PAH in mind by a nutritionist, the following recipes are low in salt but high in flavor. Cook with a cause in mind to maintain a healthy diet while living with PAH.

Enter this website address into your browser or scan the QR code on your phone to see each recipe on the PAH Initiative website.

PAH RECIPES

SCAN THE QR CODE
OR USE THE WEBSITE
ADDRESS BELOW

PAHrecipes.com



TUMMY TROUBLES

A side effect of some PAH medications can be upset stomach and other gastrointestinal issues like diarrhea. For centuries, people have turned to ginger as a natural way to settle the gastric system. Chicken is also easy to digest as it contains no fiber, which is good news for those with sour stomachs. Finally, nibbling on carbohydrates may help calm an irritated bowel. Small portions are the key—smaller meals are easier on the digestive system. Feel better because of the foods you choose eat!

Southern-Style, Slow-Cooked Chicken

Blueberry Ginger-Cinnamon Mini Muffins

Ginger Chicken Stir Fry with Noodles



Southern-Style, Slow-Cooked Chicken

INFLAMMATION AND ANTIOXIDANTS

Behold the humble banana blueberry smoothie! Whole fruit, honey, milk, spices, and ice are blended to create frothy perfection. While it makes an excellent breakfast, it can also be a refreshing drink on a hot summer day, and it's chock full of vitamins and antioxidants. Antioxidants are natural molecules that help neutralize

harmful free radicals in the body. There has been a link between neutralizing free radicals and reducing inflammation. By eating a variety of fresh fruits and vegetables, PAH patients may be able to bring down their inflammatory markers and absorb the vitamins and minerals they need to feel better.

Recipes packed full of fresh fruits and vegetables include:

Banana-Blueberry Smoothie

Spinach, Roasted Red Pepper, Goat Cheese, and Walnut Salad with Thyme Sesame Orange Dressing

Fish Tacos with Salsa Fresca and Spinach Sauté



FEEL FULLER, LONGER

There is nothing as mildly irritating as having a meal and then being hungry again two hours later. Stay fuller longer by eating whole grains, like steel-cut oats for breakfast or quinoa for lunch. By doing this, PAH patients can avoid reaching for overly processed snacks, which often have too much sodium. Eating whole grain provides protein, vitamins, and fiber to those dealing with a chronic disease.

Creamy Steel-Cut Oatmeal with Fresh Berries

Romaine Quinoa Salad and Tomato Coconut Soup

Spinach and Tomato Pasta with Fresh Basil



ENERGY WITH IRON

You might know of a certain fictional sailor who can pop open a can of spinach for instant strength, but there is a kernel of truth in that old cartoon. Leafy greens (such as spinach), legumes/beans, and seafood are excellent sources of iron. Protein too! When iron is depleted in your system, you may feel sluggish or tired. By eating fish with a salad, it is possible to feel fuller longer from the protein and to have more energy from the iron.

Seared Tuna with Colorful Wasabi Lime Asian Salad over Brown Rice Crisps

Easy Thai Beef Lettuce Wraps with Cucumber Salad

Quick Mini Spinach Quiches 🍷



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



PAHNEWSLETTER.COM

REACHING HER MILESTONES

Gwen never asked herself, “Why me?” Instead, she asked, “Why not me?” This perspective helped her keep the attitude she wanted as she forged a path for herself through unknown territory. Gwen focused on a lifestyle that included healthy eating. She changed her diet, cutting out salt and unhealthy foods. She also became a support group leader for others living with PAH.

NECESSITY IS THE MOTHER OF RESILIENCE

Have you ever been called resilient? Do you think of yourself as someone who is able to withstand or recover from difficult circumstances? The most resilient people are often born out of necessity. After all, how do you develop resilience if you never face any challenges?

Gwen learned about her own resilience through living with pulmonary arterial hypertension (PAH). She didn't begin her journey with resilience, even if she always had the determination to forge ahead.

TRAILBLAZING DOWN AN UNMARKED ROAD

When Gwen first experienced symptoms, she spent time in the hospital while doctors looked for the cause. Eventually doctors diagnosed Gwen with PAH—at the time called primary pulmonary hypertension. During that time, Gwen was a military wife, a mother to a preschooler, and just 25 years old. Her doctor told her there was little known about the condition due to lack of research and treatment. He sent her home and told her to get her affairs in order because he didn't think she would live past age 28.



But Gwen didn't go home and prepare to die. Instead, she went to the medical library and looked up her condition—only to find a single paragraph about it in all the medical literature she could find. She didn't know how to navigate her new situation; she only knew that she must.

WHY ME? WHY NOT ME?

Gwen never asked herself, “Why me?” Instead, she asked, “Why not me?” This perspective helped her keep the attitude she wanted as she forged a path for herself through unknown territory. Gwen focused on a lifestyle that included healthy eating. She changed her diet, cutting out salt and unhealthy foods. She also became a support group leader for others living with PAH.

Several years later, Gwen and her family were living in California when she began her first PAH treatment with calcium channel blockers, the only option available at the time.

Some years later, Gwen began to rely on oxygen and ended up in a wheelchair due to weakness. She felt that she was getting worse every day. Just as Gwen became sicker, a new drug trial began, and her doctor told her she was an ideal candidate.

The clinical trial team flew her and her family to the teaching hospital, where she met one of the first doctors conducting PAH research. Gwen admits that she was afraid—the medication would be delivered intravenously (IV) via a pump once they inserted a long, thin tube into a large vein above her heart. But her daughter encouraged her, telling Gwen she'd rather have her mom here with a tube in her than the alternative.



With those words, Gwen started on the medication and went back home, back to her life.

By the time she returned for a follow-up visit, she was no longer using oxygen and could walk without assistance. “I was able to do more—like clean my house. I had gotten some part of my life back,” says Gwen.

CIRCLE OF LIFE

Gwen imagines her healthcare team as her “circle of life.” Each person has a role and contributes to her care. In turn, she contributes, too, by being eager to learn, following their medical advice, and sharing openly with her healthcare providers. In her mind, the ideal way to manage her condition is to have this constant feedback loop of education, support, and humanity.

“I was able to do more—like clean my house. I had gotten some part of my life back.”

Gwen wants her team to see who she is, not what she is—because she is so much more than a PAH patient.

COMING HOME

A few years later, Gwen started to get sick again. She lost a lot of weight and was hospitalized. When she returned home from the hospital, she found that her →



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Presented by a nationally recognized expert in PAH, Dr. Lana Melendres-Groves, *PAH Today* broadcasts provide insights on today’s approaches to managing PAH.

PAHevents.com

REACHING HER MILESTONES

daughter had packed the house and prepared them for another cross-country move. It just so happened that the next up-and-coming, cutting-edge research was being conducted in Gwen's own original hometown. Every hour on the drive home, Gwen had to ask her daughter to stop the car so she could be sick.

But they made it home, and the next day, Gwen met a new doctor who would become her PAH specialist, growing into the trusting doctor-patient relationship that still exists years later.

BIG GOALS, LITTLE GOALS, AND ALL THE IN-BETWEENS

Over the years, despite the ups and downs of living with PAH, Gwen has celebrated many wins. She doesn't take life for granted. "Here I am years later doing better than I ever thought possible," she said.

Gwen has set little milestone goals over the years, such as getting off oxygen and losing weight, and has achieved these goals. She also decided that she wanted to go back to finish college and checked that off her list too. At one point, she just wanted to see her child grow up. The day her daughter graduated brought tears of joy and relief. Her daughter had reached a milestone, and so had Gwen. Each time she reached a new goal, she set another, hoping one day to see her daughter get married— and she did.

Recently, she shared with her doctor that she conquered something she'd always wanted to learn— to ride a bike. Worried about her health, he said, "Well, that is wonderful! Don't do it again!"

But the biggest milestone Gwen has accomplished in life is choosing to live without fear.

When Gwen thinks back to that single paragraph in the medical literature, or when she remembers that first doctor telling her to get her affairs in order, she is reminded that we never have guarantees in life. "When it's time, it's time," she says. "I'm thankful for the life I've had."

Resilience can come in many forms. For some, it's grinding through another day. For others, it's achieving milestones. By taking care of herself, having faith, trusting her doctors, always exploring new paths, and being open to solutions, Gwen is a poster child for resilience. 🌱

Individual Patient results may vary.



Did you know United Therapeutics is now a public benefit corporation?

In 2021, United Therapeutics converted to a public benefit corporation (PBC) and is the first public biotech or pharmaceutical company to do so.



Read more about our commitments to patients in our 2024 Corporate Responsibility and Public Benefit Report:

CORPORATERESPONSIBILITY.UNITHER.COM

PAH RESOURCES

Find information for all aspects of your PAH journey, from learning how to advocate for yourself, having positive conversations with your doctor, navigating insurance, and more!

While every patient's PAH is different, one aspect is always the same: the need for support. Having the right information and developing a proactive approach to maintaining your treatment goals can make those challenges easier. We've provided a list of helpful resources that will guide you in looking for healthy ways to treat and manage your PAH, building a PAH community, and navigating many aspects of living with PAH.



Learning more and talking with your doctor

Pulmonary Hypertension Association (PHA): The **PHA's website** is the most comprehensive resource on PH and PAH. Visit phassociation.org.

PAH Initiative: Whether you are recently diagnosed or have been living with PAH for years, there's always more to learn from PAH experts and other patients. Discover more about what's happening in your body, how it might affect you, and what you can do about it. Visit the **PAH Initiative website** for PAH knowledge and inspiration. Visit pahinitiative.com.

Pulmonary Hypertension News: Updated coverage of pulmonary hypertension science, news, columns written by other PH patients, and forums to connect with others. Visit pulmonaryhypertensionnews.com.

PAH Discussion Guide Tool: If you're unsure how to talk about your goals or your treatment plan with your healthcare provider, download this discussion tool, which can help make the conversation easier. Visit pahinitiative.com/discuss.



Stories for patients and caregivers like you, healthy living, and caring for yourself

Living with PAH: Visit this section of the PAH Initiative website for useful information and resources about living with PAH that you can use every day. From information about nutrition and fitness, caring for yourself (and your caregivers), and stories about patients like you, the PAH Initiative has the inspiration you're looking for. Visit pahinitiative.com/living-with-pah.



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Financial assistance programs

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



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