

# PAH TODAY

## Determination and Perseverance

Nathan's proactive  
approach to life with PAH

## Being Proactive in the Doctor's Office

How to Build a Better  
Relationship with Your  
PAH Specialist

## Building a Support System

How Joanne Found  
the Support She  
Needed



**PAH Initiative**

Sponsored by United Therapeutics  
Committed to Improving the Lives of Patients



# WELCOME TO PAH TODAY!

## From the PAH Initiative

Welcome to the fourth 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 fourth issue of PAH Today, you'll get perspectives from patients and caregivers who found their voice and advocated for their care. Read on to see how they built their support systems and navigated real-life challenges like working with PAH.

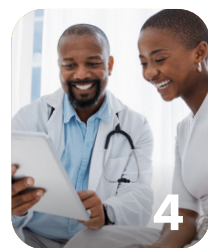
When it comes to PAH, you're not alone. The PAH Initiative is here to provide you with knowledge and inspiration as we navigate this journey together.

Sincerely,  
The PAH Initiative

Learn More: Visit [PAHInitiative.com](https://PAHInitiative.com) and follow the PAH Initiative on Facebook and Instagram



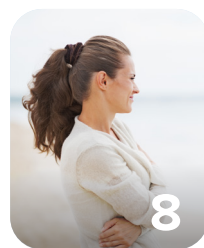
# CONTENTS



**Being Proactive in the Doctor's Office**  
How to Build a Better Relationship with Your PAH Specialist



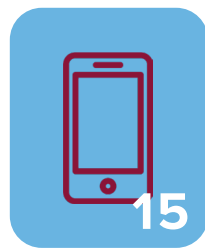
**Building a Support System**  
How Joanne Found the Support She Needed



**Working with an Invisible Illness**  
Thekla Got Ahead of The PAH Discussion With Her Boss and Colleagues



**Caregiver Corner**  
Nayda talks about her role as a caregiver to her husband, Nathan, who is living with pulmonary arterial hypertension (PAH)

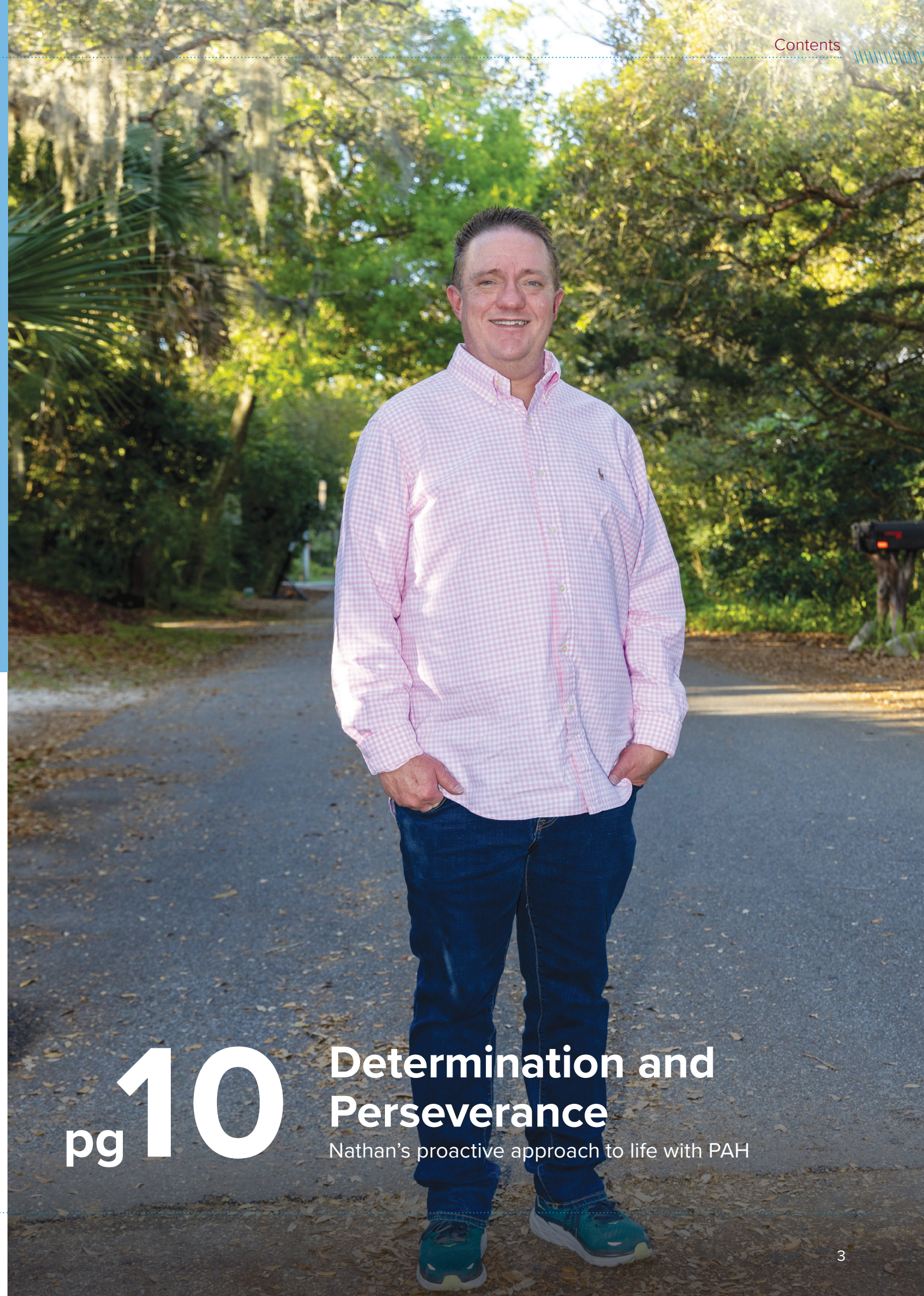


**PAH Resources**  
Find support for PAH, nutrition, and fitness with these helpful resources

pg **10**

## Determination and Perseverance

Nathan's proactive approach to life with PAH







# BEING PROACTIVE IN THE DOCTOR'S OFFICE

## How to Build a Better Relationship with Your PAH Specialist

If you have been diagnosed with pulmonary arterial hypertension (PAH), it's vital to monitor your progress and to work alongside your healthcare team to ensure you're on the right path. Of course, it all starts with finding the right doctor for you—ensure they are someone who is knowledgeable, prioritizes your needs, and has experience treating PAH patients. Pulmonologists and cardiologists who don't specialize in PAH may only see a handful of PAH patients in their careers. It's okay to ask your doctor how many PAH patients they support.

Once you've found a PAH specialist you feel comfortable with, how do you build that relationship and establish rapport? To start, frequency and consistency of visits is important. Establishing a set schedule for your appointments is crucial as you and your doctor become more familiar with each other. With each visit, your doctor will be able to monitor your progress, and you'll have an opportunity to share what has changed. Keeping your doctor informed will be helpful when making decisions about your treatment plan.

You and your PAH specialist are a team. Decisions about your treatment plan should be the result of a collaboration between you and your doctor, as each one of you should play an important role in this process. You should feel respected and listened to, just as you give your doctor and their team respect.

Part of having mutual respect is being honest about how your PAH is doing and not being afraid to ask questions. Many patients hold back the truth from their healthcare team; subconsciously, we don't want to "disappoint" our doctors, so we often put on a good face instead of being forthcoming. In fact, doctors want their patients to be candid. The more your PAH specialist knows, the more they can take that information into account to help you meet your goals.

Scan the QR code to find a PAH specialist near you!



Prior to each visit, think about how you can maximize your time with your doctor. Plan on asking questions about a specific topic, such as how your symptoms have changed, what progress you are making towards your goals, or questions about your treatment plan. Being proactive during and outside of your visit, such as doing your own research or getting involved in support groups, can help you stay on top of your PAH.

Try and get the most out of every conversation with your doctor and keep your goals in sight. If your needs are not being met, think about what changes you can make to build that relationship—or seek out a healthier one. After all, this is your life and your treatment! 🍷

Not familiar with PAH risk status? Learn more here:



*If you're struggling to come up with good questions to ask during your appointments, we've compiled a few questions to consider asking during your next doctor's visit:*

### Questions for your doctor



Have you noticed any changes in my progress since my last visit?



What actions can I take between now and my next appointment to help reach my goals?



What do my recent test results suggest about the status of my PAH?



What is my risk status? Is low-risk status the right goal for me?



How often should I have an echo to see how my right heart is doing?



Is there anything I can do to further reduce my symptoms?



What types of PAH medicine am I taking right now? Are there others I should consider?



What are the side effects of the medication you are recommending and how can I manage them?



# BUILDING A SUPPORT SYSTEM

## How Joanne Found the Support She Needed



One of the biggest challenges for patients diagnosed with pulmonary arterial hypertension (PAH) is figuring out who to disclose their condition to—and how to go about it. A strong and trustworthy support system

can help patients cope—both physically and mentally—with their symptoms and the challenges that come with a rare, chronic illness. Learning to accept support from others and how to have open and honest discussions can be a big adjustment. Fortunately, others in the PAH community who have been there can help.

Joanne, a PAH patient and PAH Initiative Ambassador, is passionate about helping others find support in friends, family, and the PAH community. Joanne has heritable PAH and is the third person in her family to be diagnosed with PAH. While she didn't have to teach her family about PAH, she quickly learned how challenging it can be to explain PAH to others.

"But you don't look sick!" How many times have PAH patients heard this? It can be frustrating

trying to explain that just because you look healthy, it doesn't mean you are able to do everything you used to. It's worth taking time with those you are closest with to share what you've learned about what's going on in your heart and lungs with PAH. After all, it might not be visible on the outside, but PAH symptoms can make activities more challenging.

When explaining PAH to others, Joanne says to keep it simple and not overwhelm people with too much science. She suggests, "PAH is essentially high blood pressure in the lungs. My heart has to work hard to push blood through the pulmonary artery to the lungs where it picks up oxygen, but because the blood vessels are so constricted, it pushes back on my heart, which becomes strained." Follow it up with how it makes the patient feel: "When I get short of breath, I feel like I'm going to faint."

Joanne advises patients to consider bringing those closest to them to PAH events or to doctor's appointments and ask the doctor to explain the condition in layman's terms.

The PAH Initiative YouTube page has a series of short videos perfect for sharing with others who would benefit from learning more about PAH:

[youtube.com/@PAHInitiative](https://youtube.com/@PAHInitiative)

Discussing PAH with friends and family may be daunting, but finding ways to educate others can be a proactive way to help others understand that you may not be able to do everything you used to.

### Through Good Days and Bad Days

Living with PAH may feel isolating at times, especially on days when you are unable to participate in activities with friends or family.

Having good days and bad days is something most PAH patients can relate to. "Couch days," as Joanne calls them, are days when patients feel tired, out of breath, and lacking energy. This is when having both physical and emotional support is especially important for a patient's health.

Though PAH affects each person differently, every patient can recognize what their limitations are. When speaking with someone newly diagnosed with PAH, Joanne cautions them to respect and acknowledge the down days—and perhaps take that time to rest or do things that take little energy, like catching up on email or paying the bills. Patients learn to work around their limits or adjust to their current status. On couch days, it's important to have a support system that understands their condition and can help them when they need it.

### Finding Support in the PAH Community

While it's important for patients to have a support system in their friends and family, talking to other patients with PAH can be invaluable. For patients who might not have loved ones living near them, coping with their diagnosis can be even more challenging. In these cases, finding a support group—as well as forming friendships and finding support with online friends—can be helpful.

Joanne helped form a support group in her area to give patients the opportunity to connect with

others. She believes there is nothing like seeing patients, families, and caregivers connect and form friendships over shared experiences.

If patients don't have a local support group, there are also national organizations they can join to find support and resources for their condition.

Looking for a support group? Visit the Pulmonary Hypertension Association website and find a virtual or in-person support group near you:

<https://phassociation.org/supportgroups/>

### Checking in on Your Support System

Many people living with PAH rely on a caregiver for support, but patients should also recognize the emotional and physical stress a caregiver may be going through. Joanne finds it important to check in on her caregiver to make sure that they are taking care of themselves, too. She remembers that while she wants to remain honest about her condition with her loved ones, she does not make her illness the center of her relationships.

The advice that Joanne likes to give to other patients is that while patients should be honest about their condition with their support system, they should also remember to show interest in what's going on in the lives of their loved ones. Most friends and families want to help, so it's okay for patients to let them—whether it's spending time together to catch up or picking up a few items at the store. If patients are going through a particularly hard time, they can ask for positive energy or prayers.

Joanne encourages patients to show gratitude to caregivers and their support system. Remembering to say "thank you" is a simple, but important way to make them feel appreciated for all that they do.

Building a support system is an important part of a patient's PAH journey. Having someone to rely on helps remind them that they're not going through this alone. 🌸



# WORKING WITH AN INVISIBLE ILLNESS

## Thekla Got Ahead of The PAH Discussion With Her Boss and Colleagues



Those who have been diagnosed with pulmonary arterial hypertension (PAH) likely recognize that unless they're wearing an oxygen tank, their condition isn't visible to others just by looking at them.

This is what's known as an invisible illness, and it presents a unique set of challenges for many PAH patients. Because of these circumstances, patients with this condition might struggle to cope with their diagnosis.

Thekla, a PAH patient and ambassador, knows firsthand about living with this invisible illness.

"For me, PAH can be a lonely disease," Thekla said. "No one understands unless you're on oxygen. I park in handicapped spaces sometimes, but I don't necessarily look like I need one. People have asked questions about why I park in these spots, but I just try to let it go."

Thekla has been living with PAH for 10 years. In January 2013, she started experiencing symptoms related to an upper respiratory infection and another illness. Breathing became significantly more difficult for Thekla over the next few weeks to the point where she couldn't stand up without passing out. Her symptoms started to affect her work, and she worked on and off for about two weeks until she was forced to stop altogether.

"It felt as if a seat belt was wrapped around my lungs," Thekla said. "It was very scary."

### Looking for Information

Thekla's doctor referred her to a cardiologist and PAH specialist who administered a series of tests, including an echocardiogram. The echocardiogram did not produce clear results, so the cardiologist proceeded with a right-heart catheterization, the only test that can definitively diagnose PAH. The results from Thekla's procedure confirmed her

pulmonary artery pressure was considerably high and that she had PAH.

When Thekla was diagnosed, there wasn't enough information available about this condition. She made it clear that she didn't want others to be sad for her. She does, however, want people to understand that PAH is a serious condition that deserves awareness.

"Average people do not understand this disease," Thekla said. "I do not look sick. People I've known for years know I have PAH but forget how serious it is."

"My PAH specialist and I discussed, in detail, how this disease can affect the heart and lungs

"Your employer should know that some days you may have to start later than others, or not at all," Thekla said. "The dependency on a full-time PAH patient working a stress-related, time-sensitive job would be very hard to do. PAH patients require rest, and some might need oxygen therapy at times."

### Planning Ahead

Because she uses an IV/pump medication as part of her treatment plan, Thekla has to be extra diligent with planning ahead. When preparing for an outing, for example, Thekla makes sure she has extra pump batteries everywhere she goes.

**"Average people do not understand this disease, I do not look sick. People I've known for years know I have PAH but forget how serious it is."**

and why managing the disease proactively is so important," Thekla said.

### Getting Ahead of "The PAH Discussion"

Thekla's employer was very understanding of her condition, but others might not have the same experience in the workplace. When it comes to creating an inclusive workplace culture, invisible illnesses are often overlooked.

An employee with an invisible illness might understandably choose to stay silent in the workplace for various reasons, including fear of discrimination and bias from colleagues who don't believe that they have a disability. But handled the right way and in the right environment, resetting expectations can help you get in front of the reality of living with PAH. Trying to hide the disease but inevitably needing to react when something goes wrong can make it even harder to find a reasonable working accommodation.

When Thekla was first diagnosed, there was no way she could see herself working a full-time job. She strongly encourages other patients living with an invisible illness to be up front with employers about how their symptoms might affect them in the workplace.

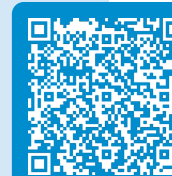
Effective planning also involves knowing your limits—not over-committing and being sure to build in enough time to rest and for a slower pace than others. PAH patients may also find they need to be more intentional about prioritizing the things they value most and not trying to please everybody all the time.

Every day looks different for patients living with invisible illnesses, and Thekla is no exception. Some days are better than others; some days are worse.

Nevertheless, Thekla refuses to let PAH control her. 🐾

## 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**



# DETERMINATION AND PERSEVERANCE

Nathan's proactive approach  
to life with PAH

Nathan was always active. In high school, he ran cross-country and went on to join the military shortly after graduating. He noticed that sometimes he was winded during basic training, but he didn't see it as much of a problem. As an adult, he was regularly tearing it up on the dance floor at the clubs on the weekends. He led a busy life, often burning the candle at both ends, and he liked it that way. Nathan was never one to sit still, but his life was about to change.

When he was 35 years old, Nathan and his then-fiancée, Nayda, went on a trip to Puerto Rico to visit her family. A few days into the trip, Nathan fell extremely ill. He could barely stand up straight and couldn't walk more than a few steps without feeling short of breath. In hindsight, he could see how he had been bloated and retained fluid but at the time had ignored it.

He went to the emergency room but it was difficult for doctors to figure out what was wrong; the language barrier didn't help. Nathan and Nayda flew back to the States to find medical care. The plane landed, and Nathan and his fiancée were both exhausted. Nathan just wanted to go home, but Nayda urged him to go straight to the emergency room, where he was admitted to the hospital and underwent many days of testing. He was then referred to a lung specialist at a medical facility, where he underwent even more extensive testing. After a right heart catheterization, Nathan was diagnosed with pulmonary arterial hypertension (PAH).

"I was confused and scared," Nathan said. "I thought I was going to die."

## Shocking News

Nathan and Nayda were married three days before the appointment where they were told that his status was extremely high risk. He was scared about the future.

"When the doctor told us that news, I felt like our world was coming to an end," Nathan recalls.

As someone who had always been active, Nathan felt shocked and confused. He was scared for what his future would bring. He could no longer work, so he quit his job and went on disability. The decision to quit his job was extremely difficult for Nathan, as he had been working ever since he was 16. The pain and burden of dealing with his disease caused him to lose his will to live for a time.

But Nathan didn't give up. He and his wife spent countless hours educating themselves on everything related to PAH. They researched various treatment methods and ways to manage symptoms as they looked desperately for something that would help him feel better. Nathan and his wife moved in with his parents at his childhood home for several months as they navigated doctor's appointments.

Throughout that time, Nathan also learned how to talk to doctors about his condition and ask questions about his risk status, goals, and treatment plan, which were his first few steps to becoming his own advocate. Nathan also started PAH treatment, which made an immediate difference in his PAH symptoms.

## Feeling Like He Could Do Better

For the first time in a while, Nathan had hope. He chose to live his life to the fullest and to not give up.

Over the next nine years, Nathan dealt with complications from medication interactions and errors in medical procedures that were performed poorly. He also learned that some foods didn't interact well with certain medications. While his initial treatment plan had helped, he couldn't help but feel like more was possible. Nathan and his wife made a point of educating themselves and researching every medication. He made sure to discuss treatment options with his doctor when he wasn't meeting his goals. He wanted to do everything he could to get better.

Nathan and his doctor decided to add another oral medication to his treatment plan, which Nathan felt was the right choice for him.

## Never Giving Up

Throughout his journey, Nathan has learned that despite his condition, he doesn't have to stop doing some of the activities he enjoys. While he no longer spends time on the dance floor, he has



found other ways to enjoy life, like going out to nice dinners with his wife, traveling, and going to the beach. He believes that patients with PAH should look for activities or hobbies that give them an outlet. He experienced firsthand how easy it is to focus on what you can't do and let worrying about PAH take over your life. In Nathan's experience, finding an activity that can help you smile again can also remind us that we have a lot to give to the world.

Nathan also investigated new careers that would work well for him living with PAH. He now sells insurance and is working toward building his own agency, which makes him smile. Going back to work was a life-changing moment for him.

Nathan joined support groups where he talks to other patients living with PAH and continued doing his own research on his condition. His wife has also been a huge support system in his life.

"I am grateful to have the positive emotional support of my wife, who is not only my caregiver, but my cheerleader, too," he says.

He has also learned that self-advocating and self-education are the keys to managing his condition properly so everyone—patient, caregiver, and doctors—can openly talk about their goals and how to meet them. Staying informed and educated gives him a better understanding of his condition and treatment plan, which allows him to have more productive conversations with his doctors.

Today, Nathan chooses to continue living his life to the fullest and spending time with his wife as much as he can.

"The biggest thing I have learned from my journey with PAH is that just because I have a chronic condition doesn't mean I have to stop enjoying life," he says. "Even though I have had to make lifestyle changes, I feel that life is still worth enjoying." 🌟

**"Just because I have a chronic condition doesn't mean I have to stop enjoying life."**

Learn more about Nathan's story:

[NathansPAHstory.com](https://NathansPAHstory.com)



## CAREGIVER CORNER

Nayda talks about her role as a caregiver to her husband, Nathan, who is living with pulmonary arterial hypertension (PAH)

Nayda is a caregiver to her husband, Nathan, who was diagnosed with PAH shortly after they met. Nayda and Nathan are a team, but Nayda knows when to take the time to care for herself, too.

**Q: How do you help Nathan stay proactive in his care?**

A: As a team, you must find the best way to stay positive, healthy, and proactive. Nathan and I attend his medical appointments together and have open and honest conversations with his healthcare team. I help him with his medications by using an app as an alarm that reminds him to take his medicine at specific times. I prepare homemade salt-free meals, make sure to monitor his legs for edema, and remind him to weigh himself daily. Working together is important because we strive for the same goal—keeping Nathan as healthy as possible.

**Q: In what ways do you take care of yourself?**

A: When I take a break, I do my manicure and pedicure or treat myself to some home beauty spa days to care for myself. Sometimes I relax by baking some cookies to make Nathan smile. Other times, we go out together to eat a nice

meal at a restaurant or just drive around while listening to some music and enjoy each other's company. Occasionally, when possible, we take a day trip to enjoy a long drive and see the beautiful landscapes.

**Q: How have you managed to build your own support system as your husband's caregiver?**

A: Nathan's healthcare team was always happy to educate me about PAH, especially during the first few years after his diagnosis. They showed me how to check Nathan for edema and how to connect his oximeter when he was in the hospital. Your loved one's healthcare team can be a great source of support when you are learning about PAH. As a couple, Nathan and I motivate each other, too. My love for him pushes me to stay positive.

I also took the time to learn about Nathan's childhood health by asking his mother questions. Nathan's brothers both have a medical



background and understanding, so they are more than willing to share their knowledge with me. My mother is my cheerleader, and my father and sister motivate me to stay positive as well.

**Q: How do you talk about PAH with others?**

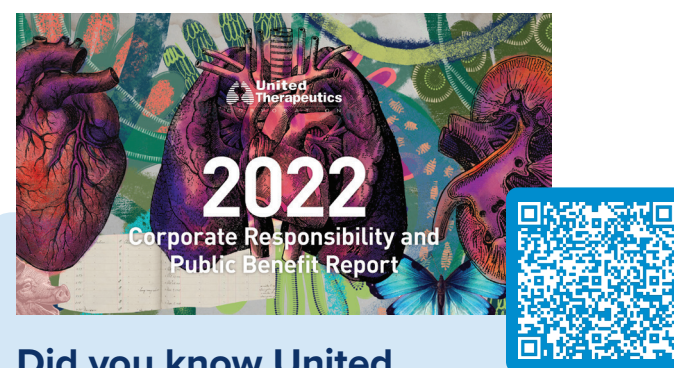
A: PAH is not only rare but is one of the many invisible illnesses a person could have. Any person who doesn't know about this condition might think someone with it doesn't look sick at all unless the person is wearing a nasal cannula and has portable oxygen with them. I visit PAH group pages and connect with other patients to learn about their experiences, help new patients, and motivate and encourage them to get connected. Whenever an opportunity arises for me to educate others about PAH, I educate them about how this condition affects the heart and lungs.

**Q: What advice would you give to other caregivers who may be struggling with their loved one's diagnosis?**

A: In our experience, PAH is a health condition that can be managed with a positive healthcare team and a treatment plan that adapts based on what's working, or not. There will be changes and sacrifices—and it is difficult—but all those changes will be for the well-being of your loved one, yourself (as a caregiver), and your family. Some days are better than others. Try to manage each day as it comes and don't give up hope.

Try to put yourself in your loved one's shoes. They might get upset or angry because they can't do what they used to do, but it's OK to ask what you can do to help them feel better. It is very important to have compassion, understanding of the situation, and lots of love for your partner, yourself, and your family.

There is a light, and you are not alone! 🌈



**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 2022 Corporate Responsibility and Public Benefit Report:

**CORPORATERESPONSIBILITY.UNITHER.COM**



# PAH Resources

## Find information for all aspects of your PAH journey, from navigating insurance to developing a support system

While every patient's PAH looks different, one aspect is always the same: the need for support. Having the right information and developing a support system can make those challenges easier. We've provided a list of helpful resources that will guide you in looking for support groups, building a PAH community, and navigating all aspects of life with PAH.

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.



**Support Resources**

**Pulmonary Hypertension Association (PHA) Support Groups:** Find others in the PAH community by joining one of hundreds of virtual and in-person support groups or by attending an event near you. Check out the PHA network at [PHAssociation.org/supportgroups](https://PHAssociation.org/supportgroups).

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



**Knowledge, News, and Financial Assistance**

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

**PAH Initiative:** Whether you have been recently diagnosed or have been living with PAH for years, there's always more to learn from PAH experts and other patients. Learn 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 information and inspiration.

**PAH Initiative Newsletter:** Sign up to receive helpful information and updates from the PAH Initiative. Visit [PAHnewsletter.com](https://PAHnewsletter.com).

**Pulmonary Hypertension News:** Get the latest news coverage of PH science, medicine, and human-interest stories. Visit [pulmonaryhypertensionnews.com](https://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](https://phaware.global).

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

**PHpal App:** Explore an exciting 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](https://PHpalApp.com).







Where  
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meets  
**inspiration**

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