

# PAH TODAY

## Making a Difference in My PAH Journey

The Importance of Setting Goals with PAH

## How to Set (and Keep) Your PAH Goals

Having a clear goal greatly improves the likelihood that you'll reach it!

## Finding the Right Treatment Plan to Help Meet Your Goals

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 fifth 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 fifth issue of PAH Today, you'll get perspectives from real-life patients and caregivers

about finding their voice and advocating for their care. Read on to see how they set goals for their treatment and keep those goals, celebrating little wins along the way.

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

If you would like to provide feedback or suggestions for future issues of PAH Today, please visit [PAHInitiative.com](https://PAHInitiative.com)



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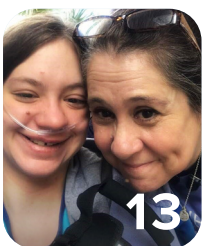
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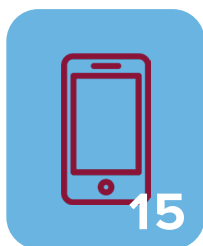
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## Making a Difference in My PAH Journey

The Importance of Setting Goals with PAH

# HOW TO SET (AND KEEP) YOUR PAH GOALS



**“IF YOU DON’T KNOW WHERE YOU ARE GOING, YOU MIGHT WIND UP SOMEWHERE ELSE.” – YOGI BERRA**

*Although Yogi Berra didn’t have pulmonary arterial hypertension (PAH), the longtime New York Yankees baseball player knew something about setting and reaching goals. The Hall of Fame catcher was an All-Star 18 times, won the World Series 10 times, and was the Most Valuable Player in Major League Baseball three times, after all.*

PAH is different than baseball, of course, and setting goals for your health is different than setting goals for other aspects of life. But there’s also something about goal setting that is universal, and it’s as true when

it comes to staying on top of your health as it is in baseball:

***Having a clear goal greatly improves the likelihood that you’ll reach it!***

The goals you and your doctor set will help you both determine whether your current treatment plan is working well enough, or if some adjustments need to be made to improve your symptoms.

## **HAVE YOU SHARED YOUR PERSONAL GOALS WITH YOUR PAH SPECIALIST?**

Someone living with PAH may have goals like having less fatigue or shortness of breath, spending less time in the hospital (or not being hospitalized at all), being more

active, spending more time with friends and family, and getting out more.

Your PAH specialist's goals may be improving your right ventricle heart function, having healthier blood vessels in your lungs, slowing your disease progression, and lowering your risk status.

Although your personal goals and your physician's goals may be different, they work hand in hand to improve your long-term prognosis and your day-to-day symptoms.

It's important to understand each other's goals, and this starts by having an open conversation with your doctor. If you haven't already done so, initiate a conversation and ask your specialist what their specific clinical goals are for you. This should give you an opportunity to also share your personal goals and come up with a plan to reach these goals together.

The PAH Initiative has discussion tools available such as the Waiting Room Questionnaire and the Doctor Discussion Tool to help you start these conversations.

**CLICK OR SCAN  
THE QR CODE**  
*TO START USING  
THESE TOOLS TODAY!*



## START WITH THE DESTINATION IN MIND

Committing a plan to paper can do wonders for follow-through. Write down your goals—what you want to achieve by a certain time. Ask your doctor what might be realistic and build in some wiggle room so you don't get discouraged.

Also think about (and write down) actions you will take and how you'd like to do them.

Think about the barriers that get in the way and specific ways you might 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.”***

## ARE YOU ON THE RIGHT ROAD TO GET TO YOUR DESTINATION?

While goals are an important part of living with PAH, keeping track of your progress can let you know whether you're on your way or if you're potentially off-track from reaching your goal.

You can keep track of your goals by keeping a journal. In this journal, you can document your symptoms, activities, and overall well-being to see if your condition is improving over time. You can bring this journal to your next doctor's appointment and share it with your doctor so you can evaluate your status as a team.

Keep an open line of communication with your physician; be transparent about what your goals are and ask your doctor if there are things you can do to help reach them.

## KEEPING YOUR PAH GOALS AND CELEBRATING THE LITTLE WINS

Every day isn't a winner, whether you live with PAH or play for the New York Yankees. Try not to get discouraged when setbacks occur or if you need to adapt to change your approach. Learning to take things as they come can help you stay motivated over the long term, which is important when dealing with a chronic disease like PAH.

When you reach a goal, celebrate it! Surround yourself with a community of people who will celebrate your wins with you! Whether that community is made up of other people living with PAH, your family, or your friends—or a combination of all three, having a supportive space to share your wins will help you sustain your positive mindset and provide you with the support needed to keep reaching for your goals.

Every milestone along the way to your destination is a triumph, so be sure to take time to look back on your journey and reflect on how far you've come before refocusing on how far you'll go.

Like Yogi Berra also said, ***“It ain't over 'til it's over!”*** 🗨️

***THINKING ABOUT YOUR  
GOALS? CHECK OUT THE PAH  
TREATMENT GOALS VIDEO FROM  
THE PAH INITIATIVE LEARNING  
LIBRARY TO LEARN MORE:  
WWW.PAHINITIATIVE.COM/PAH-  
INFORMATION-SUPPORT***

# FINDING THE RIGHT TREATMENT PLAN TO HELP MEET YOUR GOALS

**A**fter you've set your personal goals and discussed how these compare to your specialist's clinical goals for you, how can you work with your doctor to find the treatment plan that gives you a fighting chance to meet these goals?

Whether your goals are to reduce your symptoms and feel better, stay active, or improve your long-term prognosis, for individuals living with pulmonary arterial hypertension (PAH), the key to being on top of your condition includes monitoring your progress over time and working with your doctor to make changes if you're not where you want to be.

After all, the right treatment plan is something that often changes over time, and it varies from patient to patient.

## UNDERSTANDING RISK ASSESSMENT

One goal PAH patients and their specialists may share is to improve their risk status. A periodic risk assessment helps PAH specialists see a fuller picture of your unique PAH by combining the results of your individual test results into a single "risk status"—high, intermediate, or low risk.

Your PAH specialist can then use your risk status to help predict your life expectancy in the coming years, to help find the right treatment plan, or to know when it's time to make adjustments. For many patients, their goal is to reach low-risk status because it is associated with better outcomes. Getting regular risk assessments and lowering your risk status could also help you feel better and stay more active.

Having an intermediate or high-risk status, on the other hand, could be a sign it's time to adjust your treatment plan.

Ask your doctor about your risk status. If you're not at low risk or you're not making progress in improving your risk status, there may be more you and your healthcare team can do together.

*TO LEARN MORE ABOUT PAH RISK STATUS AND HOW PAH SPECIALISTS USE IT TO BETTER UNDERSTAND YOUR UNIQUE PAH AND TRACK YOUR PROGRESS, VISIT THE PAH INITIATIVE WEBSITE.*

## CONSIDERATIONS TO DISCUSS WITH YOUR PAH SPECIALIST

With PAH, blood vessels in the lungs become narrower, which creates increased pressure and makes the heart work harder to pump blood through them. These narrowed blood vessels are what cause PAH symptoms and the strain that damages the heart over time.

A key part of treating PAH effectively is to widen the blood vessels in the lungs. This will help reduce your symptoms and reduce the strain on your heart so you can feel better now and have better outcomes in the future.

To do this, you'll likely need to consider both medication and lifestyle changes as part of a treatment plan with your PAH specialist.



## Reaching low-risk status

## PAH MEDICATIONS COME IN DIFFERENT FORMS

PAH medications are taken in three different ways: orally (pill), inhaled into the lungs, or infused (pump therapy).

Many patients prefer one route of administration over another. Every form has its pros and cons, however, and it is important to understand the differences.



**Oral** (pill) medications come in capsule form and are taken by mouth.

Many patients find oral medications easier to take, but they deliver the medication in a less targeted way (i.e., the medication must pass through the stomach and GI system first). Some oral medications take longer before you start to feel better or know whether the medication is working. You may need to increase the dose slowly over time (“titrate”) to reach an effective dosage and manage side effects.



**Inhaled** medications are delivered directly to the lungs and generally work faster than oral medications. Inhaled medications require a device that is used throughout the day. Most patients start on a lower dose and titrate up until reaching an effective dose. This can often be done more quickly than with an oral medication.



**Infused** (pump) medications are delivered into the bloodstream and work faster than oral medications. Infused medications require a device that injects the medicine continuously, day and night. Infused medications can be administered intravenously (directly into a vein) or subcutaneously (under the skin). Titration to an effective dose with infused medications can be quite fast.

## THE WAY A TREATMENT WORKS IS AS IMPORTANT AS THE WAY YOU TAKE IT

PAH medications work to fix the narrowing of the blood vessels in your lungs in three different ways. Scientists and healthcare providers call these “pathways.” In PAH, these pathways are **nitric oxide**, **endothelin**, and **prostacyclin** pathways, each of which relates to a substance in your body that may be out of balance when you have PAH.

**There are medications available for each of these pathways to treat PAH.**

Medications for each pathway are available in oral form. Medications that treat the prostacyclin pathway are also available in inhaled and infused forms.

	Nitric Oxide	Endothelin	Prostacyclin
Oral	✓	✓	✓
Inhaled			✓
Infused			✓

People living with PAH generally respond better when more than one pathway is treated, which is one reason it’s suspected that many patients have multiple pathways out of balance.

## FINDING A TREATMENT PLAN WITH YOUR PAH SPECIALIST (IT’S MORE THAN JUST MEDICATIONS)

A treatment plan doesn’t just include the PAH medications you take. These are important, of course, but a treatment plan can also include things like your diet and activity level.

Adjustments to your treatment plan could include increasing your dosage, adding a medication, switching medication, or making lifestyle changes like diet and exercise.

Side effects and your ability to continue taking a certain medication over time are also important considerations. Side effects will be different depending on how the medication works and how you take it. Ask your doctor what to expect and if there are ways to help manage side effects.

Talk with your doctor about which medications and lifestyle changes may help you reach your goals! Remember...you’re the expert on you. You know your symptoms best. Don’t be afraid to talk to your healthcare provider about what else you can do to feel better. 🦋



# MAKING A DIFFERENCE IN MY PAH JOURNEY

THE IMPORTANCE OF SETTING GOALS WITH PAH



## FEELING INVISIBLE

**T**hekla has always been a goal-oriented person, setting goals and always finding ways to accomplish them. But when she was diagnosed with pulmonary arterial hypertension (PAH), that goal-oriented mindset began to shift into a lonely one.

“I was diagnosed with a disease no one knows about,” Thekla said.

Thekla went to the hospital to receive a heart catheter and left that appointment with a PAH diagnosis. Although Thekla was sent home after being diagnosed, her doctor at the time told her she should have never been discharged from the hospital because her pulmonary artery pressure was so high.

Thekla struggled immensely during her first year of living with PAH and felt like she lost control of her health. As she struggled with continued PAH symptoms, she spent much of that year going back and forth between her doctor and the specialty pharmacy to determine the right treatment and the right dosage.

**“I was scared to leave the house because I was afraid to pass out. I sat in my recliner and felt like there was nothing I could do.”**

Knowing this was no way to live, Thekla resolved to change it.

Thekla realized living with a rare disease meant she was going to need to advocate for herself. She couldn't just sit back and wait. She needed to begin setting goals for herself and learn about the disease—both how to live with it and how to treat it. She needed to know what was going on in her body and how she could fight it. She wanted to know everything she could about the treatment options.

Around the same time, someone from her support group explained how important it was to have a doctor who specialized in PAH. This disease was so rare that many pulmonologists and cardiologists did not know enough about it.

She became determined to find a specialist who really understood this disease and would help her develop a treatment plan for her PAH. Thekla found information on the Pulmonary Hypertension Association (PHA) website that helps individuals find a PAH specialist. Thekla did not have any luck finding one in her area, but she did find one in a different state.

Excited to find a doctor who had experience treating other PAH patients, Thekla booked an appointment and began her journey toward improvement.

## BE THE CHANGE

When Thekla arrived at her first appointment with this new specialist, he provided her with information about PAH she had never heard, including how this disease can affect the whole body. They discussed her goals, which included improving her symptoms, and together they established a treatment plan that gave her a fighting chance to reach them.

Thekla keeps track of her symptoms and her prescribed treatment plan and takes it with her to every appointment. Together with her specialist, they walk through Thekla's test results and assess her progress.

They have also added a prostacyclin-class medication to her existing PAH medications, taking every opportunity to help Thekla reach her goals.

Taking a prostacyclin-class medication came with its own challenges though. Thekla experienced a rash, headache, and pain in her arms, legs, and jaw, but with the help of her doctor, she learned to manage these and they subsided over time. She still experiences some of these side effects after increasing her dose of treatment, but overall, she feels like taking a prostacyclin-class

# IN JOURNEY

*TO FIND A SPECIALIST WITH REAL EXPERIENCE TREATING PAH, PLEASE VISIT [FINDAPAHDOCTOR.COM](https://findapahtreatment.com)*

*Disclaimer: United Therapeutics does not control and is not responsible for the content on this third-party site. United Therapeutics does not endorse any physician or treatment center.*

medication along with her other PAH medications is helping her achieve her goals, which makes it worth it.

### SETTING GOALS, ONE BREATH AT A TIME

Not wanting anyone else to have to go through this illness alone, Thekla called the PHA and asked how she could start a support group for other PAH patients in central Arkansas. Because no support groups existed there, she hadn't been able to connect to anyone who understood what she was going through. Now her support group can help other individuals living with PAH understand that they, too, are not alone. When she met the first person who attended her initial support session, they grabbed each other's hands and cried together. In that moment, they knew they weren't alone anymore. Together, they could support each other and start learning from each other, including discovering the ways they were reaching their individual goals.

Today, Thekla meets with doctors, pharmaceutical companies, and other patients to discuss what it's like living with PAH to spread awareness. She even helped a nurse who reached out to her and wanted to learn about PAH. This nurse asked many questions, and in return, she gave her all the information she could.

Thekla set a goal to raise awareness of PAH among healthcare professionals so patients can receive the correct care. When Thekla realized she could make a difference on a wider scale, she decided to meet with congressmen and state representatives to discuss a wide range of issues that affect individuals living with PAH.

### REACHING GOALS WITH PAH

Setting goals and taking action has allowed Thekla to accomplish things she didn't think would be possible again. Before her diagnosis, going on dates was a piece of enjoyment for her, and now, Thekla has been able to return to dating. She made a goal to live to see her grandchildren. Now she has six and has accomplished that goal, too.

Thekla knows she has PAH and that it affects her every single day. However, she does not let PAH define her or keep her from staying on track to meet her goals. She feels that PAH does not get in her way—she just does certain things differently these days.

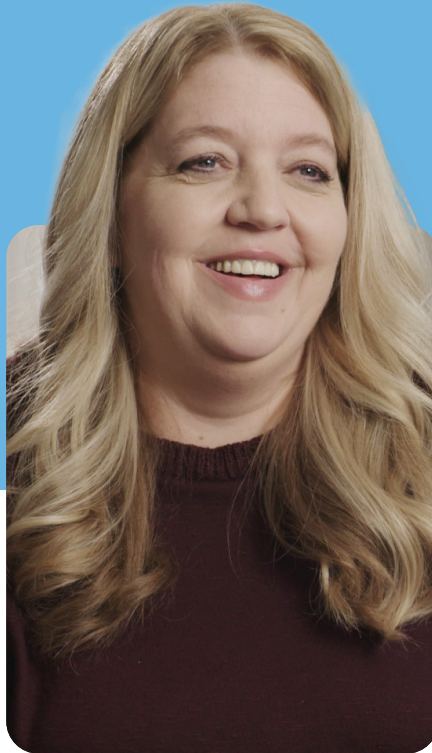
Thekla continues to set and reach goals, such as spreading awareness of PAH, continuing the work she does with her support group, and taking the

steps needed to meet her goals. She wants others to know that it's perfectly fine to seek a second—and even a third—opinion from a doctor if they feel as if their needs aren't being met.

***“I just wanted to help one person and I think we’ve done that,” Thekla said. “I’ve made friends, and I enjoy talking to patients like me, and I want to let them know, if they feel scared, it’s okay; they are not alone.”***



# PAH AMBASSADORS SHARE THEIR GOALS



*Those who have been diagnosed with pulmonary arterial hypertension (PAH) know that it's important for PAH patients to set goals and have productive discussions with their PAH specialists about how those goals can be met.*

**S**ometimes, though, even setting a goal may be hard when PAH can be so unpredictable each day. It can be helpful to know what goals other patients like you have set and how they achieved them.



PAH patient **Gwendolyn**, for example, set a goal of being able to get outside and ride her bike again. "I shared my goal with my doctor," she says, "and he sent me to pulmonary rehab. [That's where I learned how best to exercise for me, how to breathe better, and get my body in shape]. I also started taking walks with my family to get my legs stronger. Now, I've met my goal and I'm able to ride my bike again."

## PAH AMBASSADORS



**Denise**, a PAH patient, leans on both her loved ones and her doctor for support in setting and reaching goals in her PAH journey.

“For the past [nine] years, I feel like my husband and I have made a great team,” Denise says. “He knows when I’m having a bad PH day and steps up to help with anything needed for me or our fur babies. He has cheered me on, helping with my goals post-diagnosis as well as eating dietary-restrictive foods. My doctor and I

have also worked closely together over the years, setting goals and reaching different ones. My major goals are to feel better and to slow the progression of my disease. I feel like my body can handle more activities than I could in the beginning. I am able to walk farther than before, and I have more stamina in doing everyday tasks. I still get tired and may need breaks but I’m definitely better since starting my medications.”



**John**, another PAH patient, said the biggest challenge after his diagnosis was coming to terms with his disease and working toward a treatment goal. “The goal I talked about with my doctor was to keep my PAH from progressing as much as possible. I wanted to be as healthy as I could be.”

John doesn’t love having to take PAH medications but realizes they are needed until researchers find a cure. “Every time I take all my meds, I think to myself, ‘I never thought I’d be that guy that takes so many pills a day and an inhaled medication,’” John says. “But I’m also happy they helped me get where I am. Now I’m able to do a mile walk in the morning, five days a week.”

John explains that he tries to eat a healthy diet and exercises and works out consistently. “I don’t overly indulge with cheese, red

meat, and red wine—my weakest links and my loves. The hardest thing for me was to see other people, very out of shape, smoking like a chimney, eating a bunch of bad food, and having a smile on their face. All the while, I worked out and was in fairly good shape, but there I was—out of breath, carrying around oxygen on a dolly. I finally had to take the advice of my cardiologist, who told me in the very beginning that I have to own this. That was the most difficult part for me. But with the help of my wife and some tough love on her part, I came to grips with it.”

“In order to make it with PAH, it takes a lot of faith, friends that love you like family, family that love you like a dear friend, and some great doctors that care and are knowledgeable so they can steer you toward the right treatment plan,” John adds.

*We hope the examples shared here are a helpful starting point, but they’re just that: a starting point. Every patient is unique, and so is their journey with PAH. Only you know what you want to achieve. Talk with your doctor about what’s possible and how to get there. That’s why it’s so important to learn how to have open and honest conversations with your doctor. Talking to your doctor about your health and how you can manage PAH for the future is the first step in taking real action toward your treatment goals. 🍷*

# CAREGIVER CORNER

## HOW JANE HELPED HER LOVED ONE STAY ON TRACK

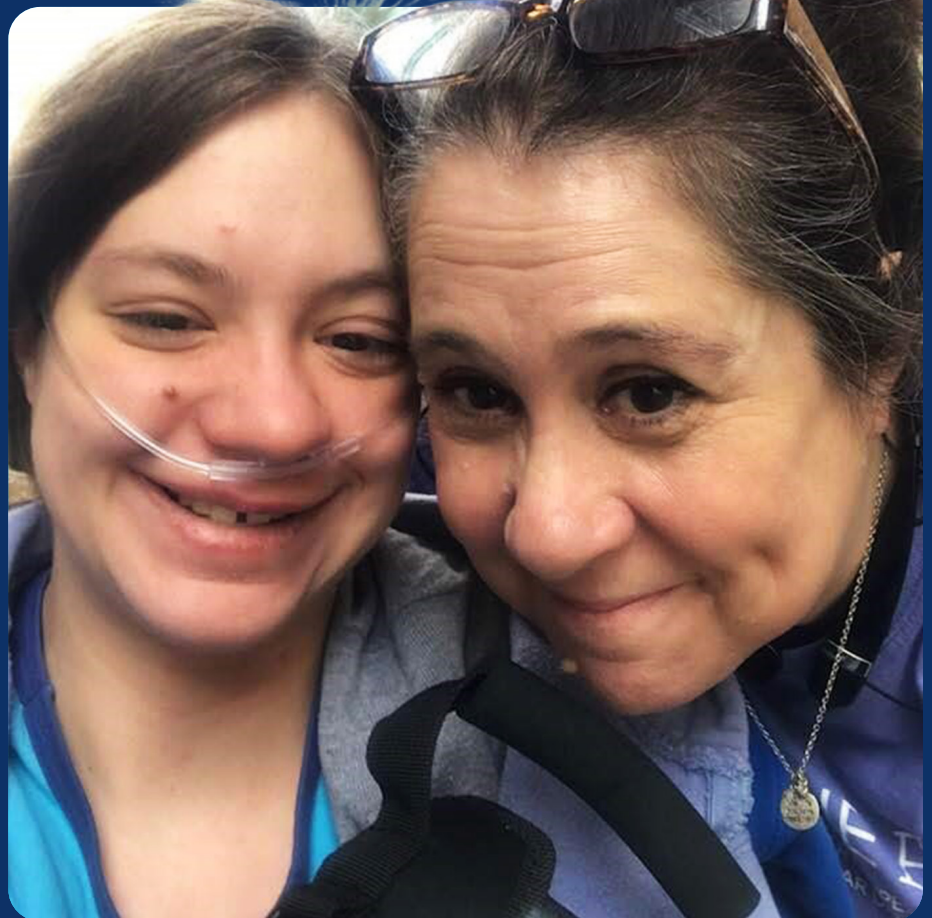
*One of the biggest challenges in goal setting can be finding the motivation to keep striving toward goals. For PAH patients, this is the perfect time for caregivers to lend a hand.*

Caregivers provide more than physical and emotional support to their loved ones. They can also help them stay motivated in tracking and keeping their personal goals as well as their PAH specialists' goals.

We asked one of our PAH Initiative Caregiver Ambassadors, Jane, to share how she supports her loved one by helping her track her goals.

Jane is a caregiver to her daughter Nicole, who was diagnosed with PAH when she was a teenager. Jane's caregiver role looks slightly different than it did when Nicole was younger, but she still stays involved in helping her track and meet her goals.

"At Nicole's request, I still take care of all the administrative aspects of her care, like keeping track of her records, scheduling her doctor's appointments, and making sure her prescriptions get filled," Jane said. "I still attend her doctor's appointments with her. Even though I don't speak up as much during them now, I still occasionally ask her doctor questions regarding her



care and treatment so I can help her keep track of her goals. And I'm happy to help her because she already has enough to get through in the day."

Being part of Nicole's treatment plan is a way that Jane is able to help her keep track of her goals. She also recommends organization as an important tool for caregivers to help their patients keep track of their goals and progress.

"I write everything down in a notebook and I keep Nicole's treatment information in a binder," Jane said.

Another tip Jane offers to caregivers for keeping their patients motivated is consistency.

"We actually got this idea from a nurse when Nicole was newly diagnosed. She suggested that Nicole keep a list of things to keep

track of and talk to her doctor about,” Jane said. “Nicole fills this list out every single day, and we look at it together. She keeps track of her vitals or every time she goes for walks. Every morning, I look at what she wrote so I know what her goals are.”

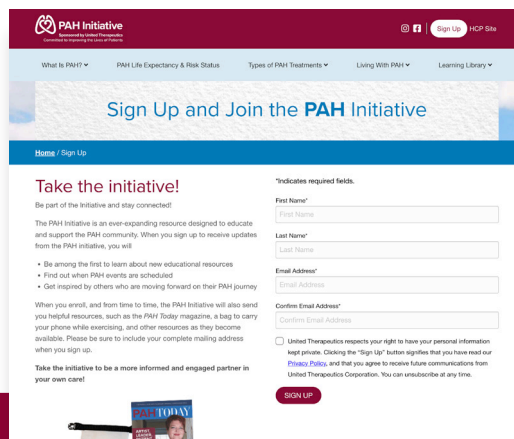
Jane says that keeping a list is a good way to keep track of their goals and compare it to their PAH specialist’s goals.

Caregivers can be the first to notice when something has changed. This could include early signals that things are improving. Sometimes, if patients are falling short of a goal, the caregiver may also have to have a difficult conversation with their loved one. Jane had to have that conversation with her doctor when it came to her doctor’s goals for her.

Nicole’s PH specialist advises her to walk every day, if she is able to, to get her heart rate up. In the summer when the weather is hot, Nicole prefers to walk her treadmill while Jane is in the room with her. When Nicole walks the treadmill, she’s often discouraged by the PAH symptoms she experiences, including chest and arm pain or shortness of breath.

“She gets so frustrated. I have tried to encourage her to focus on one area she can consistently work on and see improvement,” Jane said. “When she walks on the treadmill, the choices are distance, time, and speed. She finally made the choice to focus on time, so most days, she walks 20 minutes so she can improve on that and gradually work her way up. I can encourage her to do a little better, and each month she is walking a little bit longer, even if that is only five minutes more. A little progress is better than none.”

Jane encourages other caregivers to have open and honest discussions with their loved ones about tracking their goals. Support from a caregiver is an important part of a patient’s PAH journey and will help them feel motivated and encouraged to achieve their goals. 🧡



**JOIN THE PAH INITIATIVE**

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



**PAHNEWSLETTER.COM**



**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 2023 Corporate Responsibility and Public Benefit Report:

**CORPORATERESPONSIBILITY.UNITHER.COM**

# PAH RESOURCES

## FIND INFORMATION FOR ALL ASPECTS OF YOUR PAH JOURNEY, FROM NAVIGATING INSURANCE TO SETTING TREATMENT GOALS AND KEEPING THEM!

While every patient's PAH looks 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 help make those challenges easier. We've provided a list of helpful resources that could help 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.



### Goal-Setting Resources

**Short PAH Videos:** Don't have time for long videos? Hear from PAH experts and others living with PAH in these short videos at [youtube.com/@PAHInitiative](https://youtube.com/@PAHInitiative) and scroll to the Short PAH Videos playlist.

**PAH Initiative Facebook, Instagram, and YouTube:** Connect with the PAH Initiative on Facebook, Instagram, and YouTube 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 are recently diagnosed or have been living with PAH for years, there's always more to discover 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 newly updated 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:** Updated news coverage of pulmonary hypertension science, columns written by other PH patients, and forums to connect with others. Visit [pulmonaryhypertensionnews.com](https://pulmonaryhypertensionnews.com).

**phaware® Global Association:** Stay #phaware by accessing digital content focused on PH education, resources, and knowledge, including the "I'm Aware That I'm Rare" podcast. Visit [phaware.global](https://phaware.global).

**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](https://phassociation.org) and search "treatment access." 📄



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