

FOR PEOPLE LIVING WITH PULMONARY ARTERIAL HYPERTENSION (PAH)

PAH TODAY

SUMMER 2024 | #06

NAVIGATING LIFE WITH PAH

Taking it one step at a time, Nancy is focused on what's ahead

ASKING THE HARD QUESTIONS

How to talk to your doctor about PAH risk assessment, life expectancy, and more

LIVING WELL, EATING RIGHT

What Karen has learned about managing her diet and living a healthier lifestyle



PAH Initiative

Sponsored by United Therapeutics
Committed to Improving the Lives of Patients

WELCOME TO PAH TODAY!

FROM THE PAH INITIATIVE

Welcome to the sixth 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 this issue of PAH Today, you'll hear the perspectives of patients and caregivers like you about being proactive with your or your loved one's health, working with your doctor to understand your risk status (and what to do about it), overcoming

side effects of medications, and making positive lifestyle decisions to improve overall wellbeing. Read on to see how United Therapeutics was founded and discover how real people living with PAH approach conversations with their doctors, accomplish their lifestyle goals, and celebrate 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 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



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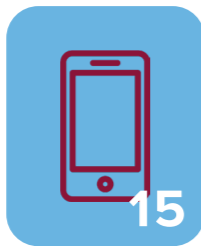
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THE UNITED THERAPEUTICS STORY: MISSION “I’M POSSIBLE”

HOW TWO PARENTS’ DETERMINATION TO SAVE THEIR DAUGHTER LAUNCHED A COMPANY WITH PAH AT ITS CORE



In 1994, Jenesis Rothblatt began having trouble breathing. Her lips turned blue. Even walking up the few steps to the hospital exhausted her. In the months that followed, Jenesis was diagnosed with a rare disease called pulmonary arterial hypertension (PAH). The specialist told her parents, Martine and Bina Rothblatt, that she would not survive more than three years without a lung transplant. There were no PAH-targeted treatments then.

At the time, Martine Rothblatt, was a highly successful entrepreneur and founder of Sirius XM Satellite Radio. But after her daughter’s diagnosis, none of those achievements mattered.

“I did research night after night after night,” Rothblatt said in a Forbes interview. “I decided that I had a new purpose in life. My previous purpose was to help humanity expand off the earth and into space, but my new purpose was to save my daughter’s life. And I didn’t care about anything else.”

As Rothblatt learned in her research, PAH causes blood vessels in the lungs to become narrower, which means the heart must work harder to push blood through these tighter passages. Not enough oxygen reaches parts of the body where it’s needed, causing shortness of breath and fatigue. Over time if not treated effectively, the narrowed lung vessels cause strain on the heart, which eventually cannot keep up and will begin to fail.

Racing against the clock, the determined mom discovered something that gave her hope: a molecule that relaxes the blood vessels, including those in the lungs, and thereby improves overall blood flow. But there was also a challenge: the molecule was already licensed to a pharmaceutical company, and it was not actively being developed for treatment. The company wasn’t focused on rare diseases like PAH and thought it would be impossible to manufacture the molecule into a treatment and gain FDA approval. Rothblatt looked for another company to take on the project. Over and over, the Rothblatts were told it was impossible. Unwilling to give up, Martine and Bina, embraced that challenge as an opportunity.

“When people say something is impossible, I just drive an axe right between the letter M and P. I say, ‘No; impossible means to me “I’m Possible.” And I’m going to figure out a way to slice this problem up into little pieces.”

And that’s just what they did.

In 1996, the Rothblatts started United Therapeutics to accelerate the development of that molecule into a treatment to help Jenesis and others diagnosed with PAH. United Therapeutics hired some of the world’s brightest scientific minds and got to work.

“Every company we approached to manufacture [the molecule] said it was impossible to do so to FDA standards,” Rothblatt says. “We finally found a chemistry professor at the University of Illinois, Dr. Robert Moriarity, who was willing to try, and fortunately succeeded.”

Once they had a treatment, the challenges didn’t end. The molecule needed to be continuously infused under the skin—this required a new kind of pump that did not exist at the time. Then came clinical trials and scrutiny by the FDA, a process that is notoriously prone to failure.

Since then, United Therapeutics has become a leader in championing the unmet needs of patients with rare diseases and end-stage lung diseases. But that’s not the end of this story.

After starting United Therapeutics, as the Rothblatts met other families facing similar challenges they learned more about the limited support options available for people impacted by PAH. They realized United Therapeutics could do more than create new treatment options. United Therapeutics could empower people living with PAH by providing help throughout their PAH journey. This insight led to the creation of the PAH Initiative and fuels United Therapeutics’ continued dedication to pursuing new ways to deliver treatments to patients with PAH and other chronic diseases.

Innovations continue at United Therapeutics. Every day, the company strives to transform impossible into

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“I’m possible.” Their ultimate goal is to reduce the progression of—and ultimately put an end to—end-stage organ disease altogether.

In 2021, United Therapeutics led the way again by becoming the first publicly traded biotechnology or pharmaceutical company to convert from a traditional corporation into a public benefit corporation (PBC). PBCs are different than other companies because they must balance commitments to shareholders with a mission to serve the public and operate in a sustainable manner. Being a PBC aligned with United Therapeutics’ core focus on patients and confirmed the way it has always operated.

“United Therapeutics has embraced uncertainty from our inception,” Rothblatt wrote in the company’s 2022 Annual Report. “We began as a parents’ quest to save their daughter’s life with a newly created chemical. There was huge uncertainty that this chemical would work for our daughter’s disease, or that it would even be safe. But we embraced that uncertainty as strongly as any parent embraces their children.”

Jenesis now works at United Therapeutics to help others like her who also face the uncertainty of PAH. Never underestimate the power of what’s possible with determination. 🧡

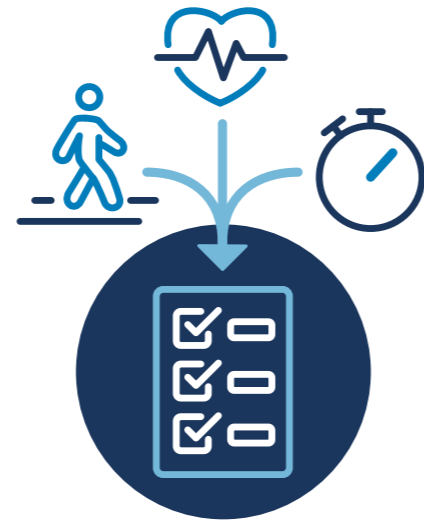


HOW WILL PAH AFFECT ME?

HOW ASKING HARD QUESTIONS MAY LEAD TO BETTER OUTCOMES

Our understanding of pulmonary arterial hypertension (PAH) has improved substantially since Jenesis Rothblatt was diagnosed with the disease. Today, with available treatment options and proactive monitoring, being diagnosed with PAH has a more positive outlook. But even with all the advances we've made, questions like, "How is PAH going to affect me?" and "What is my life expectancy with PAH?" are still tough—and the answers are different for everyone, depending on your unique PAH.

So how do PAH specialists answer these questions, and can those answers get better over time? Today, PAH specialists use an approach called "risk assessment" to answer these hard questions and ultimately help PAH patients live longer, feel better, and do more.



WHAT IS PAH RISK ASSESSMENT?

Risk assessment is an approach based on research and data from thousands of patients. Although every person living with PAH is unique, the patterns researchers have identified help specialists know how to combine your test results into an assessment called a "risk status" — low risk, intermediate risk, or high risk. The lower your risk status, the better, which is why getting to low risk is the goal PAH specialists want to see their patients achieve. Your risk status can tell your PAH specialist a lot, including how your current treatments are working, and your "prognosis" (how you'll do in the future including life expectancy/chance of survival in the coming years). With this assessment in hand, your PAH specialist uses this information to guide their recommendations for your treatment plan.

Low Risk	Intermediate Risk	High Risk
<p>Low risk means that:</p> <ul style="list-style-type: none"> • your PAH treatment plan is working • you may be walking further • you may have fewer symptoms • you may have a better life expectancy over the next 5 years 	<p>Intermediate risk means that:</p> <ul style="list-style-type: none"> • your PAH treatment plan may need adjustments • you may not be able to walk as far • you may have more symptoms • you likely have a more moderate life expectancy over the next 5 years 	<p>High risk means that:</p> <ul style="list-style-type: none"> • your PAH treatment plan should be adjusted urgently • you may not be able to walk without getting breathless • you may have more severe symptoms • you will likely have a lower life expectancy over the next 5 years

WHY IS KNOWING YOUR RISK STATUS IMPORTANT?

When it comes to PAH risk status, knowledge can be empowering, but simply having these tests done isn't enough. It's important to talk with your doctor about the results.

Risk status can change—it can get better, worse, or stay the same. Because your risk status can change, specialists recommend that people living with PAH receive a risk assessment every three to six months. While low-risk status is not achievable for some people, it is a goal for many patients because it leads to the best long-term outcomes.

FIND OUR MORE ABOUT RISK STATS.
 Watch "How do PAH specialists use risk status to help you?"



Once you know your risk status, you can take steps to improve your health—and your prognosis. Your treatment plan, diet, exercise, and PAH progression can all impact your risk status. If your risk status has not improved to low risk when your PAH specialist does a follow-up risk assessment, they may recommend making changes in one or more of these areas to help you improve.



HOW LAURA ASKED THE HARD QUESTIONS AND GOT BETTER OUTCOMES

As a PAH patient, a nurse, and Ambassador for the PAH Initiative, Laura is familiar with being on both sides of the "hard" conversation. Years later, she still remembers the feeling of uncertainty she felt when her diagnosis was

new. "For newly diagnosed patients, I think it's more of the initial shock of what you're being told," she says. "I had so many questions."

Today, Laura still has questions. She views every doctor's appointment as an opportunity to learn about PAH and improve her risk status. She does her homework and comes to each appointment prepared with questions and updates on her health. "Whenever I see my doctor, I ask her, 'What else can I be doing to improve my situation, to improve my condition?'" she says.

Knowing what questions to ask your doctor can be the first step to gaining a greater understanding of what you can do to improve your health. In fact, a recent survey of people living with PAH conducted by MyPHteam found that one of the most important things people living with PAH can do to help improve their health is to collaborate with their healthcare team. Patients who stayed in touch with healthcare providers, received regular risk assessments, and took their PAH medication as prescribed were less likely to have emergency room visits. Likewise, respondents whose PAH symptoms improved or stayed the same were more likely to have taken a proactive role in their healthcare.

Laura is grateful she recognized the need to ask the "hard questions" early on and thinks her candid, proactive approach is one of the reasons her status is now low-risk today. She values the open, ongoing dialogue she has with her healthcare team. "I didn't settle for good enough because I wanted better," she says. "I am my best advocate in the journey of my health." 🌸

NOT SURE WHERE TO START?

Here's a list of "hard questions" to ask your PAH Specialist

What do today's test results mean?

Do my test results from today suggest that my PAH is low, intermediate, or high risk?

What does my risk assessment reveal about my life expectancy?

Is low risk status the goal for me?

How frequently should I have risk assessments?

What can I do to improve my risk status?

Is there anything else I can do to improve my health and my life expectancy?



NANCY ON NAVIGATING LIFE WITH PAH

LIVING AN ENRICHED LIFE AFTER DIAGNOSIS

Novelists often divide their work into two parts, split at the point where the main character makes an enormous change, or must pivot direction to survive. Nancy thinks of her life in this way too. Part one consists of her life before her diagnosis with pulmonary arterial hypertension (PAH), and part two encompasses her life moving forward from that day.

Nancy was always a social person and an active member of her community. As an experienced elementary school teacher, she went above and beyond by hosting staff development opportunities and creating writing programs for English language arts.

“I call that my other life,” Nancy said. “It’s sad in some ways, but I’m not the kind of person who will just allow those doors to close.”

Nancy is no longer able to teach full-time in a classroom or take part in social activities like she used to, but she chooses to look forward, toward the future. After all, going back to her life before her diagnosis is not an option.

“There is a reason that the windshield is larger than the rearview mirror,” Nancy said. “It’s more important to focus on what’s ahead.”

The day Nancy received her diagnosis, she felt overwhelmed. It felt like she was handed an enormous book and told to read it quickly because this would encompass the rest of her life.

“My brain immediately went into panic mode,” Nancy said. “Would I get to see my youngest graduate college? Would I get to hold my grandbabies? My mind darted to my worst fears.”

Nancy realized that she needed to learn everything she could about PAH and the therapies that were available to reassemble her life in a way that was true to who she is. So that’s what she did. Since Nancy couldn’t learn everything about PAH all at once, she took her journey

one step at a time. Being open and honest with her doctors was an important first step.

OVERCOMING CHALLENGES WITH TREATMENT

Nancy feels very positive and confident about the way she manages her disease with her healthcare team. She regularly schedules appointments to track her progress, follows the advice that her doctors give to her, and asks questions frequently. It’s helpful for Nancy to compare current and past test results so that she can discuss concerns with her specialist.

“You have to know your body, and I do now. I know it so well,” Nancy said.

When Nancy started her treatment, her specialist recommended an infused medication delivered by a pump. Learning to live with it was one of the biggest challenges Nancy had to overcome. Carrying the necessary supplies in case of anything unexpected and getting used to sleeping and showering with it was difficult. Nancy’s PAH specialist was very supportive. He shared strategies that other patients found helpful, like wearing the pump instead of carrying it.

It helped that Nancy had her husband to assist with mixing medication cartridges, changing

her catheter bandage, and listening for any pump alarms. They often joked about their life becoming like a medical television show. Finding humor in an otherwise serious situation helped Nancy keep her head above water during her treatment process.

Nancy’s PAH specialist later switched her to an oral medication. This meant adapting to new side effects. The most difficult side effect for Nancy was headaches.

“My headaches definitely changed the way I live my life, and I talk about this with my doctor frequently,” Nancy said.

Communicating with her healthcare team lets Nancy and her doctors work through challenges together. Her specialist adjusted her dose in order to keep Nancy as comfortable as possible while working to improve her condition.

“PAH patients need to consider themselves an integral member of their own care team,” Nancy said.

She is grateful to her PAH specialist for teaching her what a good doctor-patient relationship is supposed to be like. Nancy and her specialist always discuss how she is feeling first at appointments, and she feels comfortable sharing her fears and asking hard questions. Nancy understands that it takes time for medications to show their potential, and she trusts her specialist to be forthcoming about

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what to expect with any given treatment option. Looking toward the next bend in the road with hope and humor helps Nancy persevere through the difficult moments.

FINDING JOY ON HER TREATMENT JOURNEY

For Nancy, the challenges she has faced during treatment have been worth it. Taking time to enjoy little things—like her beautiful flowers, her precious dogs, and playful birds flying past her window—reminds her of all the value in her life. Nancy’s journey has taught her a lot about her own strength, resiliency, and determination.

Nancy intentionally sets realistic limitations in her daily life. That means saying, “No” to lunch, dinner, and party plans most of the time and finding new ways to spend time with friends while listening to her body.

“It’s an intense way to live, but it’s a necessary way to live,” Nancy said. “My husband and I had to redefine ‘fun.’ Now, it involves more puzzles than parties, more healthy cooking at home than dinners out with friends, and more driving to interesting places than dancing.”

Nancy hopes to inspire others to be prudent about their care and find a medical team that is the right fit. She feels that every person living with PAH is unique and that patients can find comfort in each other’s experiences.

According to Nancy, “Therapy for PAH is not an event, it’s a journey.”

She believes that her journey is what she makes it and looking for the beauty and goodness in every day is important.

THE IMPORTANCE OF EDUCATION

Today, Nancy still feels like a teacher, only now she is working to build a different curriculum—a curriculum for PAH patients like herself. She believes that everything leading up to this point in her life was preparing her for what she’s supposed to do from this point forward. In the future, Nancy hopes to speak to patients who are newly diagnosed with PAH to offer support and help them adapt to the challenges they might face.

Nancy remembers feeling like a ‘deer in headlights’ when she was first diagnosed. She had a million questions and wished she could have spoken to a PAH patient. Now she hopes to be a person who can answer questions for newly diagnosed PAH patients.

She is determined to raise awareness of PAH and do whatever she can to help other individuals affected by this chronic disease.



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“We’ve got to get the word out to general practitioners about pulmonary hypertension.” Nancy said, “We also need to get the word out to the general population that there are people with diseases that might not be obvious on the surface but really do affect their lives.”

LOOKING BACK WHILE THINKING AHEAD

The only time Nancy looks back in the rearview mirror is to see how far she has come. She hopes that the way she chooses to live with her disease sets an example of courage and constant hope for others.

“In some ways, I like myself better now that I have my priorities straight and proved to myself what I can do, even in the face of my greatest fears,” Nancy said. “It sets me up for the excitement of what more I can do in the years to come, like holding more grandbabies.” 🧡



KAREN’S TIPS FOR LIVING WELL, EATING RIGHT WITH PAH

Sometimes Karen feels as if her life is built around food. What to eat, how much to eat, what to avoid, and how to plan for unexpected circumstances.

This wasn’t always the case, but when Karen was diagnosed with pulmonary arterial hypertension (PAH) in 2013, she had to make some changes for her health.

Karen has learned a lot over the years, making her a more creative cook and an even better mentor and friend to others living with PAH.

AVOIDING “FOOD ROULETTE”

Karen has a fairly routine morning. She often eats a hard-boiled egg and a piece of Hawaiian bread with her medicine. When she gets bored of that, she might have a yogurt and banana or a teaspoon of peanut butter and jelly. She’s careful to take her medication with food and explained, that for her, “I need a little fat and a little carbs to ease digestion.”

“The key is figuring out what works for you,” she said as she talked about the foods she no longer eats. With PAH, many people avoid high-sodium foods and carefully read labels.

Sodium can be found where you least expect it. “I had no idea there were 120 grams of sodium in a glass of milk!” Karen said.

Karen has given up on big chain restaurants that make it hard to cut down on her sodium intake. Her tastebuds are trained so well now that she says even a bite of pasta at a chain restaurant will turn her away. She prefers to dine at mom-and-pop establishments and local places that will modify food or deconstruct meals so that she can better control her sodium intake. “I hate to have to play “food roulette,” as I call it.” she stated. “But sometimes you learn the hard way.”

Now Karen knows her body well enough to know what to eat—and what to avoid.

When she joins a friend for breakfast, she avoids sausage and bacon. She recalled the last time she had bacon and remembered all too well how it made her feel. Now she avoids processed meats completely.

LIFEHACKS: FOOD EDITION

If Karen is planning a dinner out with friends, she makes careful choices all day, reserving her daily intake of sodium for the evening. “I eat before I go out,” she said, “That way I am not starving and eating all the bread and butter before the meal even comes.” Karen monitors and cuts back because one sodium-filled meal will be enough to ruin a perfectly good day.

The Vietnamese soup, pho, is a high-sodium no-go for Karen, but that doesn’t mean she can’t have other Asian food delights. She loves dumplings but opts out of the dipping sauce. Even light soy sauce carries too much sodium for Karen. Instead, she asks for a side of plain white vinegar and flavors it with wasabi. With just a touch of dumpling sauce added in, she has a flavorful

CLICK OR SCAN THE QR CODE TO LEARN ABOUT LOW-SALT DIETS!





low-sodium alternative. “I don’t care if anyone thinks my sauce is unusual,” Karen said. “At least I can still enjoy the dumplings.”

Portion control is another way Karen tackles ever-mounting sodium in many tasty treats.

If she ever finds herself sitting down for Mexican food, she mentally counts the sodium in the typical culprits: chips, refried beans, and everything in between! In these cases, Karen cuts the portion to decrease the sodium. It may be hard to pay for a full meal and eat half the portion, but Karen knows better than to pay with her health. She reminds herself often that no meal is worth that.

THE CREATIVE COOK

At home, Karen finds that having to watch her sodium intake has made her a more innovative cook. She refuses to settle for bland food, so she looks for ways to squeeze every bit of flavor out without sacrificing her wellbeing.

“Marinating gives a deeper flavor,” Karen said. “I find that if I marinate chicken or fish for even 15 or 20 minutes, it will change the resulting flavor after it’s cooked.” Sometimes she prepares it the day before, allowing it to marinate overnight.

Karen has a favorite salt-substitute seasoning that makes her forget she ever enjoyed salt. “It comes in flavors like lemon pepper, fiesta lime, and even spicy jalapeno.” She’s been known to have a container of salt-substitute in her purse from time to time.



Carefully reading recipes helps Karen see where she can edit them to meet her needs. The first thing to go is always the salt. But even better, Karen likes to find PAH-friendly recipes that are low-sodium in the first place.

Eating less processed food is one of her overall goals. Now that Karen has the hang of it, she prepares her own homemade salsa, uses salt-substitutes, and chooses whole foods.

FAST-FOOD FIXES

“Fast-food chains are fairly accommodating when it comes to unsalted french fries and all you have to do is ask,” Karen said. She has found that when making a request for unsalted fries, she often has to wait for a fresh batch, but then the result is worth it—hotter and fresher fries. But she says she is careful with the dipping sauces because even ketchup has a lot of sodium. At home, Karen uses low-sodium ketchup.

HANDLING CRAVINGS

Karen isn’t immune to cravings. Just because she makes healthy food choices most of the time, it doesn’t mean she never feels a longing for some of her old favorite comforts—like salt and vinegar chips or macaroni and cheese. She isn’t a fan of the repercussions that come with these foods but is certain that an all-or-nothing mindset doesn’t work for her.

Karen gets cravings out of her system by addressing them—not depriving herself. “I buy the one-dollar bag of chips and split it into three portions,” she said. “Then if I have a craving, I can eat 5–10 chips and solve it.”

Sometimes a small bit of her favorite sodium-laden snacks will satisfy a craving, or better yet, Karen will prepare a healthier alternative.

HYDRATION AND RELAXATION

At the end of the day, Karen likes to put her feet up. “Having experienced water retention in the past, I know the benefit of elevating my legs, plus there’s the added benefit of better circulation,” she said. Karen might watch TV, drink a cup of tea, and spend time with her dog while engaging in this self-care.

“Of course, there is a mental investment to thinking this hard about my food intake,” Karen said, reflecting on her lifestyle. She knows she has put a lot of effort into living healthier. But at the end of the day, she knows that paying the price of reading labels and carefully selecting and preparing food is going to serve her best.

Today, Karen leads a support group to pay it forward, helping others on their journey with PAH and sharing her tips and tricks to living well and eating healthy.



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](https://www.unither.com/corporateresponsibility)



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](https://www.pahnewsletter.com)

HOW NAYDA HELPED HER LOVED ONE STAY ON TRACK

Nayda shares how she supports, collaborates with, and advocates for her husband, Nathan, through his PAH journey.

HOW DO YOU SUPPORT AND ADVOCATE FOR NATHAN?

Nayda: We have a lot of love. I care for him so much. He's my everything. There are days he's not going to feel well at all. Those are the days when he needs a little more compassion and understanding. Frustration is not going to resolve anything. I try to put myself in his shoes. If he wants to do something, I say, "Yes, let's do it!"—so long as it doesn't hurt him. He wants to go back to school. I said, "Yes—the sky is the limit." It's all about being positive.

For every doctor visit, I will prepare a page full of questions. I present symptoms that Nathan has had with the medications, his reactions, and how he has been feeling. We talk to the doctor together, as a team.

WHAT ADVICE DO YOU HAVE FOR OTHERS CAREGIVING FOR THOSE WITH PAH?

Nayda: As caregivers, it's important to love yourself and care for yourself as well. Don't let the difficulties and sadness cause you to crumble and fall apart. Stop and take a break. Get a manicure and pedicure. Have that spa moment and lift up your spirits. I'm sure it will help. Seek other caregivers out to help motivate you as well. Go to support groups so you can reach out to them. Talk with others and share: This happened today, and I am sad. Get counseling if you need to. If you're emotionally drained, get help.

WHAT IS THE BIGGEST LESSON YOU HAVE LEARNED AND WISH YOU KNEW EARLIER?

Nayda: That the importance of research is to educate yourself about the condition and the types of medications. And don't let fear block you from speaking to the doctor about your concerns about medications or side effects.



HAVE YOU EVER HAD COMMUNICATION CHALLENGES WITH NATHAN'S HEALTHCARE TEAM?

Nayda: Oh, yes. As the caregiver, it can be frustrating when I am trying to share information with a healthcare professional when I feel like maybe they are not as understanding about his condition, both physically and emotionally, or are just not receptive to my input as a caregiver. I realized a long time ago that it is important to look for a second opinion when needed and always seek out doctors who really listen and are willing to work with my husband and me as a supportive team.

ANY FINAL HOPEFUL WORDS FOR YOUR FELLOW CAREGIVERS?

Nayda: I really hope they get the strength to provide the empathy, the compassion, the understanding, and the love that the patients really need. Our loved ones with PAH are going through a very difficult time. They think everything is going to crumble and fall apart. A caregiver needs to keep the patient grounded in love. 🍷

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.



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



Being successful on your treatment plan

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 and search "treatment access."



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knowledge
meets
inspiration

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