When Your Body Screams and Medicine Whispers:

The Hidden Crisis in Pulmonary Arterial Hypertension Diagnosis

A call to action for healthcare innovation, education, patient advocacy

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The Voice Note That Changed Everything

At 9 PM Australian time, two women joined our podcast from the other side of the world. One was a young mother who spent three years and nine months being told her deteriorating health was “just anxiety.” The other had survived 21 years with pulmonary arterial hypertension before receiving a lung transplant, but only after lying to her doctor to get the referral that saved her life.

As I listened to Jenna Mazor and Erin Baker share their stories with our team at electronRx, I felt something shift. We spend every working hour developing technologies for respiratory disease management, building solutions we believe can change lives. But that morning in Cambridge, hearing these women describe their journeys from symptoms to diagnosis, I realised we were confronting something more fundamental than technology gaps. We were witnessing a systemic failure of listening.

Jenna’s daughter was six months old when she noticed symptoms. By the time she received her diagnosis in 2024, that baby was six years old. Three years and nine months of medical appointments. Three years and nine months of escalating symptoms, heart palpitations so constant they became “a reminder that your body is yelling at you that something’s not right.” Three years and nine months of being told she was anxious, unfit, overreacting, irrational. Three years and nine months of a progressive disease advancing untreated.

“I still sometimes wonder if I didn’t demand to go see that cardiologist, would I still be undiagnosed with a progressive illness? Had I been diagnosed earlier, would my disease not have progressed as far?” recalls Jenna Mazor.

When Jenna finally demanded to see a cardiologist after her GP discouraged the referral, citing cost, the echo immediately showed pulmonary arterial hypertension. The physician who performed it had poor bedside manner for a reason: he “didn’t usually deal with patients.” He delivered the news bluntly: incurable heart and lung condition, medication for life, someone will call you in a couple of weeks.

Jenna went home and Googled her diagnosis. The first thing she read: two to five years to live. She looked at her four-year-old daughter and thought she wouldn’t see her grow up.

This Is Not An Isolated Story

Erin's mother was diagnosed with pulmonary arterial hypertension when Erin was three years old. Two years later, with no treatments available, her mother died. Erin grew up knowing she needed regular cardiac monitoring. She did everything right, saw cardiologists every few years, and stayed vigilant about her health.

Then, at age 16, climbing stairs after work, she suddenly couldn't breathe. She felt like she would collapse. She knew, instinctively, what was happening. She went to multiple GPs. Young and otherwise healthy, they told her she was unfit or anxious. Seven months earlier, she'd had a clear cardiology review. Surely nothing had changed.
But Erin knew her family history. She knew the stakes. So she did what she had to do: she lied. She told a new GP she was "due for a cardiology review" and demanded a referral to a specific cardiologist she'd researched.

The echo confirmed it. Nine months after her first symptoms, despite a fatal family history of PAH, despite seeing multiple physicians, and despite doing everything a young person could do, Erin finally had her diagnosis.

She would go on to spend 21 years managing the disease through oral medications, then IV therapy, and ultimately a lung transplant in October 2024. She is alive today because she advocated for herself when the system failed her.

Let me be clear about what that means: a teenage girl had to deceive medical professionals to access the diagnostic test that would reveal her life-threatening condition. This should horrify us. And it should mobilise us.

The Scale of the Problem: 1,200 Voices Saying the Same Thing

Jenna and Erin are members of an Australian PAH patient support group with 1,200 members. When new patients join, they typically share their "road to diagnosis" story. Erin told us directly: "A high percentage of those people would tell you that they've been delayed in diagnosis." Jenna confirmed: "We see it constantly."

Twelve hundred patients. A rare disease, pulmonary arterial hypertension affects roughly 1 in 100,000 people, yet in this single support community, the pattern is clear and consistent: diagnostic delay is not the exception. It is the norm.

Let that sink in. For a condition where early intervention can slow disease progression, where treatments have evolved from nothing (in Erin's mother's era) to sophisticated therapies that can extend life for decades, patients are spending years fighting to be heard.

The Medical Facts Are Straightforward:

- PAH can be identified through echocardiography
- Early treatment improves outcomes
- The disease is progressive without intervention
- Symptoms are measurable and distinct

Yet the Human Reality Is This:

Young women are told they're anxious

Objective findings (heart palpitations, elevated heart rates) are dismissed

Even a fatal family history doesn't trigger an urgent investigation

Patients must demand, deceive, or both to access specialist care

Geographic and financial barriers compound diagnostic delays

This is not a medical mystery. This is a system failure.

Why Diagnosis Delays Matter: The Compound Cost

When Jenna reflects on her journey, she asks questions that haunt her: "Had I been diagnosed earlier, would my disease not have progressed as far?" These aren't idle questions. They represent the compound cost of diagnostic delay:

1. The Clinical Cost

- Disease progression without treatment
- Worsening prognosis
- Reduced treatment efficacy
- Potentially irreversible damage

2. The Psychological Cost

- Medical gaslighting, being told your physical symptoms are mental health issues
- Erosion of trust in healthcare
- Anxiety about deteriorating health with no explanation
- Trauma of eventual diagnosis, often delivered poorly

3. The Financial Cost

- Years of ineffective treatments (antidepressants, anxiety medications)
- Multiple GP visits
- Lost work time
- For regional patients: travel costs to centers of excellence
- Many PAH patients become too unwell to work

4. The Social Cost

- Reduced quality of life
- Limited physical capacity affecting parenting, relationships, career
- Isolation from feeling unheard and dismissed
- Fear of being labeled as "difficult patient" when advocating for care

5. The Family Cost

- Jenna believed she had 2-5 years to live, that she wouldn't see her daughter grow up
- Children watching parents struggle without answers
- Inherited trauma (Erin lost her mother at age 5, then faced her own diagnosis at 16)

The Primary Care Education Gap: Why Good Doctors Miss PAH

Here is what we must acknowledge: the GPs who initially dismissed Jenna and Erin were likely not incompetent. They were under-educated about a rare condition that mimics common presentations.

Erin articulated this clearly: "Over the 21 years that I had PAH, I noticed that it was getting better with the actual specialists... They're doing well at that specialist level, but at the primary healthcare level, they're so far behind."

Consider the GP's Perspective:

- They see thousands of patients annually
- Anxiety and deconditioning are common, PAH is rare (1 in 100,000)
- Young, otherwise healthy women are low-risk demographics for cardiac disease
- Many GPs may never encounter a PAH case in their entire career
- Symptoms overlap with high-prevalence conditions

The question Jenna raised is critical:

- "My symptoms did mimic anxiety. At what point do you educate the GPs to send you off to a cardiologist?"
- This is not about blame. This is about education architecture.
- We Need Differentiation Protocols That Help Primary Care Distinguish Between:
- Anxiety presenting with cardiac symptoms
- Deconditioning causing breathlessness
- Pulmonary arterial hypertension in early stages

We Need Red Flags That Trigger Investigation:


Persistent symptoms despite treatment


Progressive worsening


Objective findings (elevated heart rate, palpitations) accompanying subjective complaints


Family history of PAH (this should be an automatic referral)


Symptoms that don't improve with fitness interventions

We need low-friction referral pathways. When doubt exists, specialist consultation must be accessible and financially reasonable. Most importantly, we need cultural change: when patients persistently report symptoms that aren't resolving, we need physicians trained to trust that persistence as a signal, not noise.

The Geographic and Access Crisis

Australia presents a particularly stark example of access inequality, but the pattern repeats globally.

- Centers of excellence for PAH exist primarily in capital cities:
- Sydney: 2+ centers
- Melbourne: 2+ centers
- Brisbane: 2 centers
- Perth: 1 center

For a country the size of Australia, this means many patients must travel by plane to access specialist care. For someone requiring regular monitoring every six months, or more frequently during disease progression,this becomes logistically and financially prohibitive.

Consider the Barriers:

- Flight costs
- Accommodation
- Time away from work (if able to work)
- Complexity of traveling with oxygen therapy
- No local support for monitoring between appointments

Jenna explained: “A lot of people with PAH may be too sick to work, so they can’t afford to fly to a centre of excellence to have regular monitoring... So there are so many factors in Australia that limit people from getting the initial diagnosis, but also from maintaining and monitoring the progression of their disease.”
This creates a two-tier system: those geographically fortunate enough to live near centers of excellence, and everyone else. In the 21st century, with telehealth capabilities and remote monitoring technologies, this should be unacceptable.

The Gender Dimension We Cannot Ignore

Both Jenna and Erin are women. Both were young when symptoms began. Both were told their symptoms were anxiety. This pattern appears repeatedly in medicine: women’s physical symptoms attributed to mental health or dismissed as exaggeration. The data on gender bias in diagnosis is extensive and troubling. Women wait longer for pain medication, are more likely to have cardiac symptoms dismissed, and face higher rates of misdiagnosis for autoimmune conditions.

In PAH Specifically:
When Jenna said her GP told her "it's probably just a case that you're unfit", despite working out five times a week, we're seeing the assumption that young mothers are sedentary overriding the objective evidence.

When Erin's symptoms at age 16 were attributed to being "unfit or anxious" despite fatal family history, we're seeing age and gender bias potentially overriding critical risk factors.

"You have this constant reminder because I was having heart palpitations almost constantly. Your body is yelling at you that something's not right, but you just constantly get brushed off and told that you're overreacting or you're being irrational and just sort of making it all up in your head" recalls Jenna.

We must name this. Not to shame individual physicians, but to recognise systemic patterns that cost lives.

What Success Looks Like: A Vision for Change

Imagine if Jenna's story had been different. When she reported elevated heart rate and chest pain at her six-month postpartum visit, imagine her GP had access to a simple decision-support tool: a checklist that said "persistent cardiac symptoms in new mothers: rule out postpartum cardiomyopathy, thyroid dysfunction, pulmonary arterial hypertension."

Imagine if the 24-hour heart monitor showing abnormalities triggered an automatic cardiology referral rather than reassurance.

Imagine if, between symptoms and diagnosis, the timeline was six weeks instead of three years and nine months.

Imagine if Erin's first GP, hearing "family history of fatal PAH" combined with "sudden breathlessness and chest pain," had immediately referred her to cardiology.

Imagine if she hadn't needed to lie to access appropriate care.

Imagine if the 1,200 patients in that Australian support group could share stories not of diagnostic odysseys, but of swift identification and early intervention.

This is not fantasy. This is achievable.

The Five Pillars of Change

1. Education Infrastructure

- Integration of rare disease presentations into primary care training
- Continuing medical education focused on diagnostic red flags
- Case studies from real patients (like Jenna and Erin) used in GP education
- Differential diagnosis tools for symptoms that mimic common conditions

2. Technology enablement

- Clinical decision support systems that prompt consideration of rare diseases
- Telemedicine access to specialist consultation
- Remote monitoring technologies for patients in regional areas
- AI-powered diagnostic assistance that recognises patterns humans might miss

3. Referral pathway optimisation

- Low-friction specialist referrals when red flags present
- Financial accessibility to specialist consultation
- Clear protocols for urgent investigation
- Patient empowerment to seek second opinions without stigma

4. Patient voice amplification

- Patient narratives integrated into medical education
- Support groups connected to healthcare systems for feedback
- Research that captures patient-reported pre-diagnosis
- experiences
- Advocacy training for patients to self-advocate effectively

5. Monitoring innovation

- Home monitoring tools that reduce travel burden
- Continuous or frequent data collection between appointments
- Early warning systems for disease progression
- Data sharing between regional GPs and specialist centers

Our Commitment: Technology in Service of Humanity

At electronRx, we've spent years developing respiratory monitoring technology, that we sometimes call "a Fitbit for lungs." It's smartphone-based, requiring just 60 seconds of passive recording to capture respiratory signatures that AI analyses to provide clinically meaningful data.

We built this technology because we believe continuous, accessible monitoring can transform chronic disease management. We envision a future where patients aren't alone between six-month appointments, where early deterioration is caught before crisis, where geographic distance doesn't determine quality of care. But listening to Jenna and Erin, I realised our technology, any technology, is only valuable if it's embedded in a system that listens to patients in the first place.

The Hard Truth:

- A monitoring tool is useless if it takes four and a half years to diagnose the condition being monitored
- Remote care is irrelevant if primary care physicians don't recognise when remote specialist consultation is needed
- Innovation without education is incomplete
- Technology without advocacy is insufficient

What We're Doing About It

So we're committing to more than product development. We're committing to:

1. Capturing Patient Stories

We're working with Jenna and Erin to document their journeys in detail, the symptoms, the dismissals, the specific language they used, the turning points. These will become educational resources for medical professionals and pharmaceutical companies.

2. Collecting Community Evidence

We're designing a simple way for the 1,200 patients in their support group to share 3-5 minute voice recordings of their pre-diagnosis experiences. This primary source data, potentially the largest collection of patient-reported diagnostic journey data for PAH ever assembled, can be analysed, published, and used to educate primary care physicians globally.

3. Enabling Remote Monitoring

We're piloting our technology with Jenna and Erin, working with their pulmonologists to demonstrate how home monitoring can provide reassurance, detect deterioration early, and reduce the burden of geographic barriers.

4. Advocating for Change

We're committing to putting these patient stories in front of people with the power to make systemic change: pharmaceutical companies with billions invested in PAH, medical education institutions, policy makers, and healthcare systems.

We're doing this because seven years ago, we decided to dedicate our professional lives to respiratory disease management. Not because it was easy or lucrative, but because it mattered. Because patients like Jenna and Erin deserve better.

A Call to Action: Who Will Listen?

This article is addressed to multiple audiences, each with the power to change outcomes:

To Pharmaceutical Companies

You've invested billions in developing PAH therapies. United Therapeutics, founded by a CEO whose daughter had the condition, has revolutionised treatment, extending lives from months to decades. But your medications only work if patients are diagnosed.
Every year of diagnostic delay is a year your innovations sit unused while disease progresses. Every misdiagnosed patient is someone whose life could be transformed by your products but who never gets the chance.

Action Items:

- Invest in primary care education programs
- Fund diagnostic awareness campaigns
- Support patient advocacy organisations
- Put patient stories in front of every GP in markets where your medications are available

The ROI isn't just financial, it's human lives.

To Medical Educators

Integrate patient narratives like Jenna's and Erin's into the curriculum. Not as footnotes, but as core case studies.

Action Items:

- Teach the differential diagnosis between anxiety and cardiac disease
- Train future physicians to trust persistent patient reporting
- Include rare disease presentations in primary care education
- Use real patient voices in clinical training

Create the doctors who will catch the next Jenna in six weeks instead of three years and nine months.

To Healthcare Systems

Build referral pathways that don't require patients to beg or lie to access specialist care.

Action Items:

- Implement clinical decision support tools that prompt consideration of rare diseases
- Make echocardiography accessible when cardiac symptoms persist
- Remove financial barriers between symptoms and diagnosis
- Create protocols for urgent investigation when red flags present
- Remove the barriers between symptoms and diagnosis

To Technology Companies

Build tools that extend specialist expertise to every corner of the globe.

Action Items:

- Create monitoring systems that empower patients between appointments
- Develop AI that helps time-pressured GPs consider diagnoses they might not otherwise think of
- Enable telemedicine that truly bridges geographic divides
- Design for accessibility, not just innovation
- Make geography irrelevant to quality care

To Policy Makers

Rare diseases collectively affect hundreds of millions globally. PAH may be 1 in 100,000, but across approximately 7,000 rare diseases, these aren't edge cases, they're a substantial population. They deserve diagnostic pathways that work.

Action Items:

- Fund education initiatives for primary care
- Support telemedicine infrastructure development
- Ensure financial accessibility to specialist consultation
- Create standards for diagnostic timelines in rare diseases

To Patients and Advocates

Your stories matter. Your persistence matters. The fact that you refuse to be dismissed, that Jenna demanded that cardiology referral, that Erin fabricated a review appointment, these acts of self-advocacy save lives.

Action Items:

- Share your stories
- Participate in research
- Push for change
- Connect with patient communities
- You are not being difficult. You are being heard.

To Fellow Innovators

Technology alone won't solve this. We need education, advocacy, policy change, and system redesign. But technology can be a powerful enabler ,if we build with deep understanding of patient needs.

Action Items:

- Embed solutions in clinical workflows
- Measure success in lives changed, not just metrics
- Build with patients, not for them
- Commit to addressing systemic issues, not just symptoms
- Let's build with purpose. Let's build with patients

The Future We're Building Together

Six months from now, I want to be writing a different story. I want to share:

Data from 1,200 patient testimonies, analysed and published in medical journals

GP training programs worldwide using this research

Pilot studies showing remote monitoring reducing diagnostic delays

Partnerships with pharmaceutical companies funding primary care education

Most importantly, I want to introduce you to the first patient who says: "I had persistent breathlessness and chest pain. My GP recognised the red flags, referred me immediately, and I was diagnosed with PAH in six weeks. I started treatment early. Because of that, my prognosis is excellent." That patient doesn't exist yet. But they could.

Jenna still wonders what her life would look like if she'd been diagnosed earlier, if her disease hadn't progressed as far before treatment began. Erin is alive because she fought for herself when the system failed her, but she shouldn't have had to fight.

The next generation of PAH patients deserves better. They deserve:

- A system that listens the first time
- Physicians educated to recognise rare diseases
- Technology that monitors them between specialist visits
- Access to care regardless of geography or finances
- They deserve what Jenna and Erin didn't get: to be believed.

An Invitation

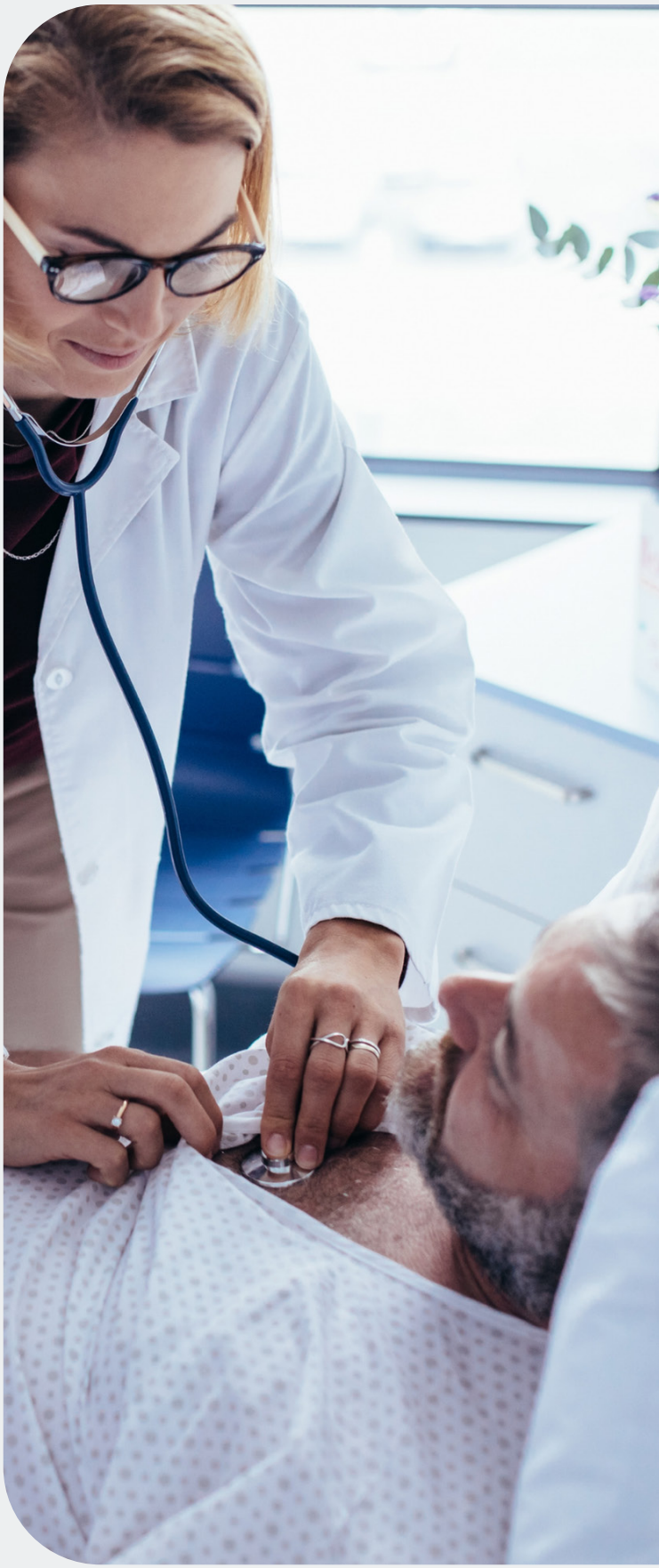
If you're a healthcare professional who wants to learn from patient stories, contact us. If you're a pharmaceutical executive who sees the value in diagnostic education, let's talk. If you're a PAH patient willing to share your pre-diagnosis experience, please reach out. If you're a technologist who wants to build solutions that matter, let's collaborate. If you're a policy maker, researcher, educator, or advocate who believes we can do better, you're right. We can. And we must.

This article is the beginning of a conversation, not the end. It's a call to action, not a conclusion. It's an acknowledgment of failure and a commitment to change. Jenna and Erin stayed up until 9 PM their time to talk with us, to share their stories, to help us understand. The least we can do is listen. And then, do something about what we've heard. Because somewhere right now:

- There's a young mother experiencing her first symptoms
- There's a teenager with a family history wondering if she should be concerned
- There's a patient seeing their GP for the third time, being told again that it's probably just anxiety

What happens next depends on all of us. Let's make sure their stories end differently.

Contact me at bpatel@electronrx.com to support our mission.



About The Author

Dr Bipin Patel is CEO of electronRx, a Cambridge-based healthcare technology company developing remote respiratory monitoring solutions. With over 30 years in healthcare innovation, Dr Patel and his team have spent the last seven years focused on creating accessible, smartphone-based respiratory monitoring technology,"a Fitbit for lungs", to empower patients and clinicians managing chronic respiratory diseases.

electronRx's mission is to make continuous respiratory monitoring available to hundreds of millions of people globally, removing geographic and financial barriers to quality care. The company's technology uses AI-powered analysis of smartphone recordings to provide clinically meaningful respiratory data without requiring complex equipment or forced breathing maneuvers.

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