PLN PATIENT HANDBOOK

A GUIDE FOR PATIENTS, FAMIILIES, AND CAREGIVERS



Knowledge.

Community.

Hope.

PLN HEART FOUNDATION

NORTH AMERICAN CHAPTER

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YOUR PLN JOURNEY IS UNIQUE, BUT YOU ARE NEVER WALKING IT ALONE. EVERY APPOINTMENT, EVERY QUESTION, EVERY FAMILY MEMBER YOU INFORM, AND EVERY STEP YOU TAKE TOWARD UNDERSTANDING YOUR CONDITION CONTRIBUTES TO A HEALTHIER FUTURE, NOT ONLY FOR YOURSELF, BUT FOR GENERATIONS TO COME. WHILE THERE IS NOT YET A CURE, THERE IS HOPE. TOGETHER, THROUGH EDUCATION, RESEARCH, ADVOCACY, AND COMMUNITY, WE ARE MOVING CLOSER TO A WORLD WHERE PLN NO LONGER CHANGES LIVES.

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CHAPTER 1: WELCOME TO THE PLN COMMUNITY

Receiving a diagnosis of PLN R14del can bring many emotions, fear, uncertainty, confusion, or even relief at finally having answers. Whether you were diagnosed after experiencing symptoms, through family screening, or because of a loved one's diagnosis, know that you are not alone.

Although PLN is a rare inherited heart condition, you are now part of a global community of patients, families, researchers, physicians, and advocates working together to improve lives and find a cure. The PLN NA Foundation exists to provide education, support, resources, and hope every step of the way.

This handbook was created to help you better understand PLN, navigate your medical journey, support your family, and connect you with trusted information and a community that truly understands. You don't need to read it all at once, use it as a guide whenever questions arise.

Perhaps the most important thing to remember is that a positive genetic test does not define your future. Every person's journey with PLN is unique. While some carriers remain symptom-free, others develop heart disease at different ages and severities. Early diagnosis, regular cardiac monitoring, and ongoing research are changing lives and creating more hope than ever before.

Welcome to the PLN community. Together, through education, support, advocacy, and research, we are building a future where no family has to face PLN alone.

A LETTER FROM THE PLN NA FOUNDATION

Dear Friend,

If you're reading this, chances are that you, or someone you love, have recently been diagnosed with the PLN R14del mutation. First, we want you to know one thing: *You are not alone.*

A PLN diagnosis can bring a whirlwind of emotions. You may feel overwhelmed, frightened, confused, or uncertain about what comes next. You may have countless questions about your future, your family, and what this diagnosis means for your life. Those feelings are completely normal, and many of us have stood exactly where you are today.

The PLN NA Foundation was created because patients and families deserved more than uncertainty. We understand that living with a rare genetic heart condition can feel isolating, especially when many healthcare providers have never encountered PLN before. Our mission is to bridge that gap by providing reliable education, connecting patients with experts and one another, supporting groundbreaking research, and advocating for a future where no family has to experience the devastating effects of PLN.

Although PLN is considered a rare disease, you are part of a remarkable global community. Around the world, patients, caregivers, researchers, physicians, and volunteers are working together with a shared goal: to improve lives today while accelerating the search for tomorrow's cure. Every family that shares their story, participates in research, educates others, or simply supports another person facing this diagnosis helps move our entire community forward.

As you read through this handbook, remember that it was created with you in mind. Whether you are a newly diagnosed carrier, living with cardiomyopathy, caring for a loved one, or simply trying to understand your family's risk, we hope these pages provide clarity, reassurance, and practical guidance. You do not need to absorb everything at once. Take your time. Return to sections as questions arise, write notes in the margins, and use this guide as a resource throughout your journey.

Perhaps the most important message we want to leave you with is this:
A positive genetic test does not define your future. It is information, valuable information, that empowers you and your healthcare team to monitor your heart, make informed decisions, and take proactive steps to protect your health. While every person's journey with PLN is different, knowledge truly is one of the most powerful tools we have.

There has never been a more hopeful time in PLN research. Scientists around the world are making extraordinary advances in understanding this disease, developing targeted therapies, and exploring innovative treatments such as gene therapy and RNA-based medicine. Progress that once seemed impossible is now happening because of the strength and determination of patients and families like yours.

We also encourage you to lean on this community. Connect with other carriers. Ask questions. Share your story if and when you're ready. Celebrate milestones, no matter how small. The road ahead may have challenges, but it is one you never have to walk alone.

On behalf of everyone at the PLN NA Foundation, ***thank you*** for allowing us to be part of your journey. We are honored to stand beside you, as advocates, educators, researchers, and, above all, as a community united by hope. Together, we will continue raising awareness, supporting one another, advancing research, and moving closer to the day when PLN no longer changes the course of families' lives.

With hope,
The PLN North American (NA) Foundation

HOW TO USE THIS HANDBOOK

This handbook was created to support you and your family at every stage of your PLN journey. Whether you've just been diagnosed, have been living with PLN for years, or are caring for a loved one, you'll find trusted information, practical tools, and resources designed to help you feel informed and empowered.

You do not need to read this handbook from cover to cover in one sitting. Many people find it helpful to begin with the chapters that relate most to their current situation and return to others as new questions arise. Use the table of contents to navigate topics such as understanding PLN, building your healthcare team, treatment options, family screening, living with the condition, and ongoing research.

Throughout the handbook, you'll also find worksheets, symptom trackers, appointment preparation pages, medication logs, and space for personal notes. We encourage you to bring this handbook to medical appointments, write down questions for your healthcare team, and share relevant sections with family members or caregivers.

Medical knowledge and research continue to evolve. While every effort has been made to provide accurate and up-to-date information, this handbook is intended to complement, not replace, the advice of your cardiologist, genetic counselor, or other healthcare providers. Always discuss questions about your diagnosis or treatment with your medical team.

Most importantly, remember that you are not expected to navigate this journey alone. The PLN NA Foundation is here to provide education, connect you with others in the PLN community, and support you as research continues to bring us closer to better treatments and, ultimately, a cure.

YOU ARE NOT ALONE

One of the hardest parts of receiving a PLN R14del diagnosis is feeling like you're the only person going through it. Because PLN is a rare genetic condition, many people have never heard of it before, not even some healthcare professionals. It can feel isolating to explain your diagnosis to friends, family, or coworkers who may not fully understand what you're experiencing.

But the truth is, you are part of a much larger community.

Across North America and around the world, thousands of individuals and families are living with PLN. Some are newly diagnosed. Others have been living with the condition for decades. Some have implantable cardioverter-defibrillators (ICDs), some are caring for loved ones with heart failure, and others have undergone heart transplantation. Despite their different journeys, they all share one thing in common: they understand what it's like to live with PLN.

It is also important to remember that PLN is only one part of your story. A positive genetic test does not define who you are, your goals, or your future. Many carriers continue to work, travel, raise families, pursue careers, exercise within their physician's recommendations, and live meaningful, fulfilling lives. While the journey may look different than expected, it can still be filled with hope, purpose, and joy.

The PLN Foundation was built by patients, families, and advocates who understand these challenges firsthand. We are here to provide reliable education, connect you with others who truly understand, support research, and advocate for better treatments and, ultimately, a cure. Whether you have a question about your diagnosis, need help finding resources, or simply want to connect with another family, we encourage you to reach out.

There may be days that feel overwhelming, but you never have to face them alone. Lean on your healthcare team, your loved ones, and the PLN community. Ask questions. Share your story when you're ready. Accept support when it's offered, and know that your experiences may one day give hope to someone who is just beginning their own journey. Together, we are stronger than PLN. Every patient, every family, every researcher, and every act of support brings us one step closer to a future where no one has to face this disease alone.

WHAT IS PHOSPHOLAMBAN (PLN)?

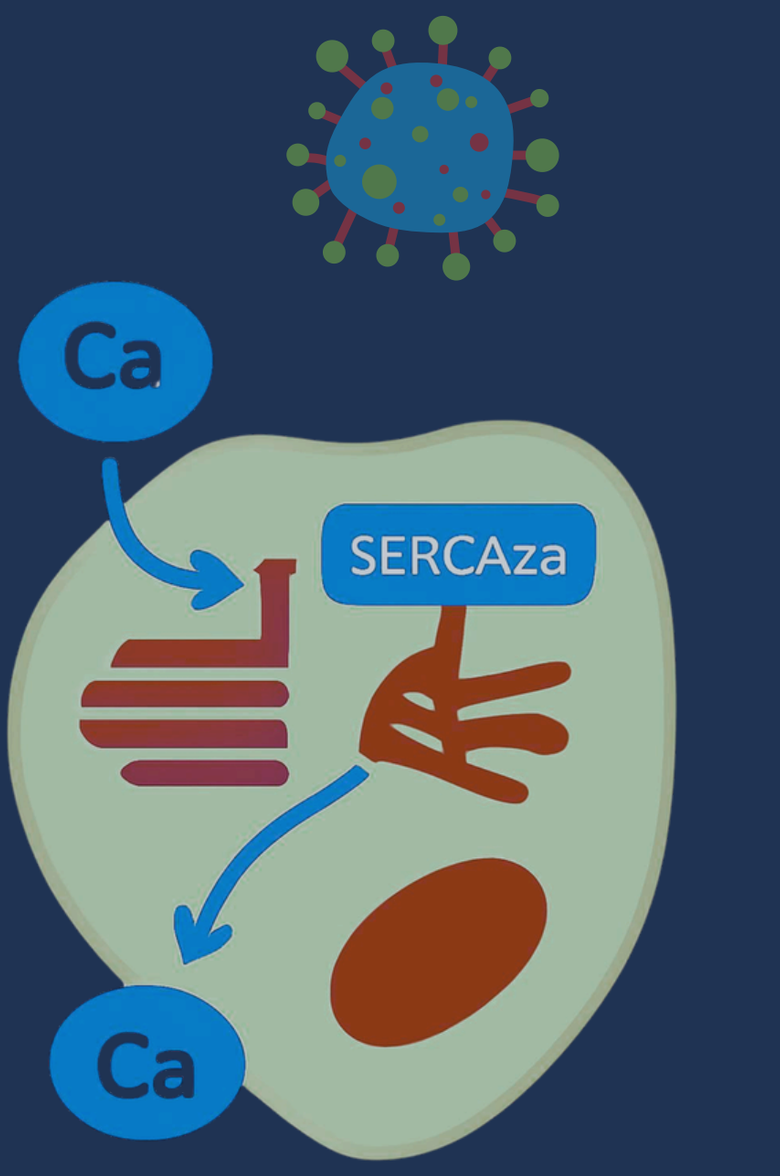
At the center of every heartbeat is a tiny but incredibly important protein called phospholamban (PLN). Although it is small, phospholamban plays a vital role in helping the heart contract and relax efficiently with every beat. Without it functioning properly, the heart cannot regulate calcium as effectively, which can affect both the strength of each heartbeat and the heart's electrical stability.

PLN: The Heart's Calcium Regulator

Every heartbeat depends on calcium. When calcium enters heart muscle cells, it triggers the release of calcium from an internal storage system (sarcoplasmic reticulum) and the overall calcium levels rise in the heart cells. This results in heart contraction, which pumps blood throughout the body. When calcium is removed from those cells, the heart relaxes and fills with blood again.

Phospholamban acts like a regulatory switch for this process. It controls the activity of a specialized calcium pump called SERCA2a (Sarcoplasmic Reticulum Calcium ATPase), which moves calcium back into storage after each heartbeat. This allows the heart muscle to fully relax before the next contraction.

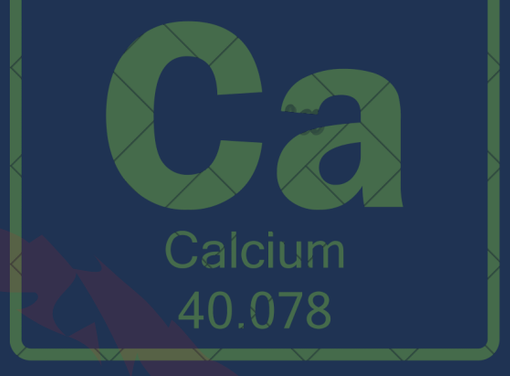
When phospholamban and SERCA2a work together properly, the heart beats efficiently, maintains a healthy rhythm, and responds appropriately during exercise, stress, and everyday activities.



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Think of PLN Like a Brake

An easy way to understand phospholamban is to imagine it as a brake controlling the flow of calcium. Just as a brake controls your car speed, phospholamban helps regulate when calcium should be released and when it should be stored again. This careful balance allows your heart to contract with enough force to pump blood while also relaxing completely before the next beat. If this system becomes disrupted, calcium is no longer handled as efficiently, placing stress on heart muscle cells over time.





YOUR HEART BEATS APPROXIMATELY 100,000 TIMES EVERY DAY, AND PHOSPHOLAMBAN HELPS REGULATE THE CALCIUM NEEDED FOR EVERY SINGLE HEARTBEAT!

Why Calcium Is So Important

Although calcium is often associated with healthy bones, it is equally important for the heart. Every heartbeat relies on carefully coordinated calcium movement. Healthy calcium regulation allows the heart to contract with enough strength to pump blood throughout the body, relax completely between heartbeats, maintain a steady and coordinated heart rhythm, and respond appropriately during exercise, illness, or emotional stress. When calcium regulation becomes impaired, the heart may gradually become weaker, develop abnormal electrical activity, or form scar tissue over time.

How Calcium Regulates Every Heartbeat

Every heartbeat begins with an electrical signal that travels through the heart. This signal tells the heart muscle cells that it is time to contract and pump blood to the rest of the body. But electricity alone doesn't make the heart squeeze, calcium does. Think of calcium as the "on" and "off" switch for every heartbeat. The movement of calcium into and out of each heart muscle cell is what allows your heart to contract, relax, and prepare for the next beat.

CALCIUM CYCLE IN A CELL

Step 1: The Signal Arrives



An electrical impulse spreads through muscle and reaches an individual heart cell. This electrical signal opens tiny gateways, called *calcium channels*, located on the surface of the cell.

Step 2: Calcium Enters the Cell



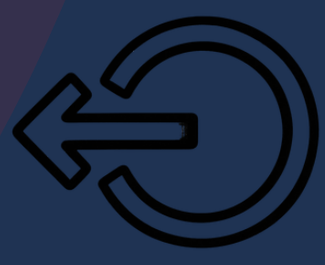
When these channels open, a small amount of calcium flows into the cell from the bloodstream. It acts like a spark that triggers a much larger release of calcium stored inside the cell. This stored calcium is released from a specialized internal calcium storage system called the *sarcoplasmic reticulum* (SR). Together, these two sources create a sudden surge of calcium inside the cell.

Step 3: The Heart Contracts



As calcium floods the cell, it binds to proteins within the muscle fibers, allowing them to slide past one another and shorten. This shortening is what causes the heart muscle to contract, squeezing blood out of the heart and into the circulation. Millions of heart muscle cells contract together in perfect coordination, producing one heartbeat.

Step 4: Calcium Must Leave Again



After the heart has pumped blood, it must completely relax before the next beat. To do this, calcium must be removed from the muscle fibers. Most of the calcium, about 70–90%, is pumped back into the SR by an important protein called SERCA2a. This pump stores calcium safely until the next heartbeat, allowing calcium levels inside the cell to return to normal.

Step 5: PLN Regulates the Process



This is where ***phospholamban*** plays its critical role. PLN acts like a brake on the SERCA2a pump. Under normal conditions, it carefully controls how quickly calcium is pumped back into storage. This regulation ensures that the heart contracts with enough force while also relaxing completely before the next beat. During exercise or times of stress, hormones such as adrenaline temporarily reduce PLN's braking effect. This allows SERCA2a to work faster, so calcium is recycled more quickly. As a result, your heart can beat faster and more forcefully to meet your body's increased demands.

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WHY RESEARCHERS STUDY PHOSPHOLAMBAN (PLN)

Because phospholamban is such an important regulator of calcium, scientists have spent decades studying how it functions and what happens when it does not work normally. Research has shown that changes in phospholamban can contribute to several forms of inherited cardiomyopathy. Understanding how this protein works has opened the door to exciting new treatments aimed at restoring healthy calcium regulation, including gene therapy, RNA-based therapies, and other forms of precision medicine currently under investigation. The better researchers understand phospholamban, the closer we move toward developing treatments that address the underlying cause of disease rather than simply managing its symptoms.

KEY TAKEAWAY

Phospholamban (PLN) is a small protein with a big responsibility. By regulating calcium movement inside heart muscle cells, it helps ensure that every heartbeat is strong, coordinated, and efficient. Although tiny in size, it plays a critical role in maintaining normal heart function throughout life.

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THE PLN R14DEL MUTATION

PLN R14del is caused by the loss of a single amino acid, but that tiny genetic change can significantly affect how heart muscle cells handle calcium over a lifetime.

Genes are the body's instruction manual. They tell our cells how to build proteins that allow the body to grow, function, and repair itself. The PLN gene contains the instructions for making *phospholamban*, a small protein responsible for regulating calcium movement inside heart muscle cells.

The most common disease-causing change in this gene is called **PLN R14del**. The name may sound complicated, but it simply describes what has changed:

- **R = Arginine (an amino acid, or building block of proteins)**
- **14 = The location of that amino acid within the protein**
- **del = Deletion (meaning it is missing)**

In other words, the PLN R14del mutation means one tiny building block (Arginine) is missing from the phospholamban protein.

Although only a single amino acid is missing, this small change alters the protein's shape and function. Instead of regulating calcium normally, the abnormal phospholamban protein interferes with the heart's ability to recycle calcium efficiently after every heartbeat.

Unlike some genetic conditions where the protein is simply absent, PLN R14del produces an abnormal protein that disrupts normal cellular function. Researchers believe this contributes to calcium imbalance, injury to heart muscle cells, the development of fibrosis (scar tissue), and an increased risk of dangerous heart rhythm disorders and cardiomyopathy.

Today, scientists around the world are studying this specific mutation to better understand why it causes disease and how targeted therapies, including RNA-based medicines, gene therapy, and gene editing, may one day correct its effects.

HOW PLN AFFECTS THE HEART OVER TIME

PLN is usually not a disease that develops overnight. Instead, it often progresses slowly over many years. Many carriers feel completely healthy during childhood and early adulthood while subtle changes are occurring within the heart. Because these changes happen gradually, regular cardiac screening is essential, even if you have no symptoms.



Stage 1: Silent Changes

The earliest changes occur at the microscopic level. Heart muscle cells begin handling calcium less efficiently, placing stress on the cells long before symptoms appear. Most people feel completely healthy during this stage.



Stage 2: Fibrosis Begins

Over time, chronic stress can injure heart muscle cells. As damaged cells die, they are replaced by fibrosis (scar tissue). Unlike healthy muscle, scar tissue cannot contract or conduct electrical signals normally. Fibrosis is often first detected on a cardiac MRI using late gadolinium enhancement (LGE), even when the heart's pumping function remains normal.



Stage 3: Electrical Changes

As scar tissue develops, the heart's electrical system becomes less organized. Importantly, dangerous arrhythmias may occur before the heart becomes enlarged or the ejection fraction decreases. This is one of the unique characteristics of PLN cardiomyopathy. This increases the likelihood of developing:

- **PVCs/ PACs (Premature Ventricular Contractions/ Premature Atrial Contractions)**
- **NSVT (Non-sustained Ventricular Tachycardia)**
- **Ventricular tachycardia**
- **Fibrillation**
- **Atrial arrhythmias**



Stage 4: Structural Changes

As more heart muscle becomes affected, the heart may begin to enlarge or weaken. Symptoms such as fatigue, shortness of breath, decreased exercise tolerance, dizziness, and swelling may begin to appear. Some individuals develop:

- Arrhythmogenic cardiomyopathy (ACM)
- Dilated cardiomyopathy (DCM)
- Hypertrophic Cardiomyopathy (HCM)
- Left ventricular dysfunction
- Reduced ejection fraction (EF)



Stage 5: Advanced Disease

For some individuals, heart disease may continue to progress despite medical therapy. Advanced disease can include:

- Severe heart failure
- Recurrent ventricular arrhythmias
- ICD therapies
- Ventricular assist device (LVAD)
- Heart transplantation

Fortunately, not every carrier progresses to this stage, and modern therapies have significantly improved outcomes.

Every Journey Is Different

One of the greatest challenges of PLN is that no two people experience it the same way. Some individuals remain symptom-free throughout life. Others develop heart disease in their twenties. Some experience arrhythmias first. Others develop heart failure years later. Even members of the same family carrying the exact same mutation can have dramatically different disease courses. Researchers continue working to understand why.

THE FIVE PHENOTYPES OF PLN



ASYMPTOMATIC

PREDOMINANTLY ARRHYTHMOGENIC PHENOTYPE

DILATED OR HYPERTROPHIC CARDIOMYOPATHY

MIXED PHENOTYPE

ARRHTHMOGENIC CARDIOMYOPATHY

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Asymptomatic: Genotype Positive / Phenotype Negative

These individuals carry the PLN mutation but show no evidence of heart disease on current testing. *They often have a normal ECG, normal ECHO, normal cardiac MRI, and show no symptoms.* Although they may feel completely healthy, regular surveillance remains important because heart changes can develop over time.

Arrhythmogenic Phenotype

For some carriers, the first sign of disease is an abnormal heart rhythm rather than weakened heart function. *Common findings include: PVCs, PACs, NSVT (Non-Sustained Ventricular Tachycardia), Sustained Ventricular Tachycardia, Syncope, ICD implantation, and/or Sudden Cardiac Arrest.* In PLN, dangerous arrhythmias can occur even when the heart's pumping function is relatively normal. With this phenotype, there is arrythmias with preserved cardiac structure/ function.

Dilated Cardiomyopathy (DCM) / Hypertrophic Cardiomyopathy (HCM) Phenotype

This phenotype is characterized by enlargement and weakening of the left ventricle (Dilated) or characterized by thickening and stiffening of the heart muscle (Hypertrophic). Features may include: reduced Ejection Fraction (EF), enlarged heart chambers, fatigue, shortness of breath, exercise intolerance, progressive heart failure, blood pressure issues, stroke, temperature dysregulation, and/or fibrosis. Many patients respond well to guideline-directed medical therapy.

Arrhythmogenic Cardiomyopathy (ACM) Phenotype

Some individuals primarily develop replacement of healthy heart muscle with fibrosis (scar tissue), leading to electrical instability. Common features include: Fibrosis on cardiac MRI, ventricular arrhythmias, palpitations, syncope, and/or increased risk of sudden cardiac arrest. This phenotype often requires careful rhythm monitoring and individualized risk assessment. This phenotype has arrythmias with structural myocardial disease/ fibrosis.

Mixed (Overlap) Phenotype

Many PLN patients do not fit neatly into one category. Instead, they develop both electrical and structural heart disease. They may experience: ventricular arrhythmias, fibrosis, reduced ejection fraction, heart failure, and/or progressive cardiomyopathy. This overlap phenotype is one of the reasons why individualized care is so important.

Looking Beyond the Phenotype

A phenotype describes how the disease appears today, not what it will necessarily look like tomorrow. Regular follow-up allows your healthcare team to detect changes early and adjust your care over time. As research advances, scientists continue to learn why some carriers remain symptom-free while others develop different patterns of disease. Understanding these differences is helping researchers develop more personalized treatments and move closer to targeted therapies for PLN.

Chapter 1 Summary

Understanding PLN begins with understanding phospholamban, the protein that helps regulate calcium inside heart muscle cells. When the PLN R14del mutation alters this protein, calcium handling becomes disrupted, placing stress on the heart over time. This can lead to fibrosis, arrhythmias, cardiomyopathy, heart failure, and an increased risk of sudden cardiac arrest. However, every person's journey is unique, some carriers remain symptom-free, while others develop heart disease at different ages and severities. Although there is currently no cure, advances in research and early detection continue to improve care and offer hope for the future.

Key Takeaways

- PLN is a protein that regulates calcium movement, allowing the heart to contract and relax normally.
- The PLN R14del mutation changes how this protein functions, affecting heart muscle cells over time.
- PLN may cause arrhythmias, cardiomyopathy, heart failure, and sudden cardiac arrest, but not all carriers develop symptoms.
- Regular cardiac screening is essential, even if you feel healthy.
- Every carrier's journey is different, making personalized care and lifelong monitoring important.
- Genetic testing and family screening can help identify other at-risk relatives.
- Ongoing research into gene therapy and targeted treatments offers growing hope for the future.
- ***You are not alone*. A global community of patients, families, healthcare professionals, and researchers are working together toward better treatments and, ultimately, a cure.**

CHAPTER 2:
YOUR JOURNEY BEGINS

Receiving a diagnosis of PLN R14del can feel overwhelming, but it is also the beginning of a journey built on knowledge, proactive care, and hope. While you may have many questions about what comes next, you don't have to navigate them alone. With the right medical team, regular cardiac monitoring, and a supportive community, you can take meaningful steps to protect your heart and make informed decisions for yourself and your family.

This chapter is designed to guide you through the first stages after diagnosis. You'll learn what to expect during your initial appointments, which diagnostic tests your cardiologist may recommend, how to build a healthcare team that understands inherited cardiomyopathies, and how to prepare for conversations about your long-term care. You'll also discover why early detection, routine monitoring, and family screening are among the most powerful tools we have in managing PLN.

Remember, this is not a race. You do not need to have every answer today. Take each step one at a time, ask questions, and use this handbook as a trusted resource throughout your journey. Every appointment, every test, and every conversation is another step toward understanding your health and taking control of your future.

"The journey of a thousand miles begins with a single step." – Lao Tzu

I Just Received My Diagnosis... Now What?

Hearing the words "You tested positive for the PLN R14del mutation" can feel overwhelming. It's completely normal to experience a wide range of emotions, including fear, confusion, sadness, anger, relief, or even numbness. You may have dozens of questions racing through your mind, wondering what this means for your health, your family, and your future.

The most important thing to remember is this:
A positive genetic test is not an emergency, it is information.

Your diagnosis provides valuable knowledge that allows you and your healthcare team to monitor your heart closely, identify changes early, and make informed decisions about your care. While there is currently no cure for PLN, advances in research, medications, cardiac devices, and monitoring have greatly improved the ability to detect and manage the disease before serious complications develop.

It is also important to remember that a positive genetic test is not the same as a diagnosis of heart failure or cardiomyopathy. Many individuals who carry the PLN mutation never develop symptoms, while others may not experience heart disease until much later in life. Because PLN affects everyone differently, your journey will be unique, and your care should be tailored specifically to you.

Rather than trying to learn everything at once, focus on taking one step at a time. Your next few weeks will likely include meeting with specialists, completing baseline cardiac testing, gathering your family medical history, and learning more about your diagnosis. Each appointment and each test provides another piece of the puzzle, helping your healthcare team better understand your heart and determine the best plan moving forward.

Your First Priorities

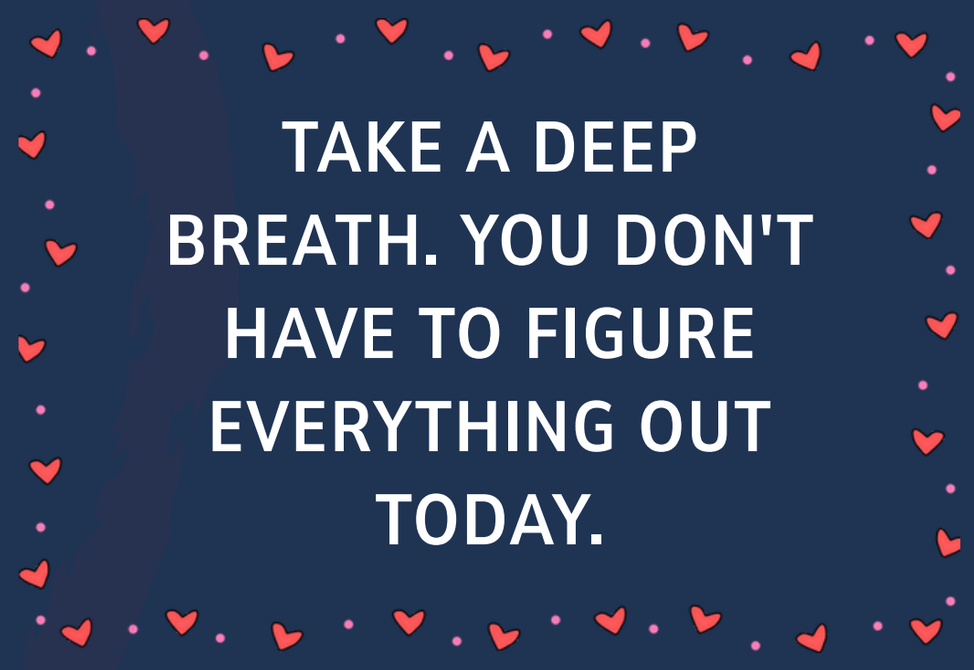
As you begin this journey, focus on these important first steps:

✔️ Find a cardiologist experienced in inherited cardiomyopathies and get genetic testing and baseline testing scheduled (ECHO, ECG, MRI)

✔️ Begin gathering your family's cardiac history and discuss genetic testing with biological relatives.

✔️ Learn about the warning signs that should prompt you to contact your healthcare provider.

✔️ Connect with the PLN Foundation and community for education, support, and trusted resources.



Try Not to...

It's easy to become overwhelmed after a diagnosis. While everyone's coping style is different, these tips can help during the first few weeks.

- Don't assume the worst based on someone else's story, every PLN journey is different.
- Don't rely solely on internet searches or social media for medical advice. Stick to reputable organizations and your healthcare team.
- Don't feel pressured to make major life decisions immediately.
- Don't hesitate to ask questions, send us an email, or seek a second opinion if something is unclear.
- Don't go through this alone. Lean on your family, friends, healthcare providers, and the PLN community.

RECOGNIZING SYMPTOMS

Listening to Your Body

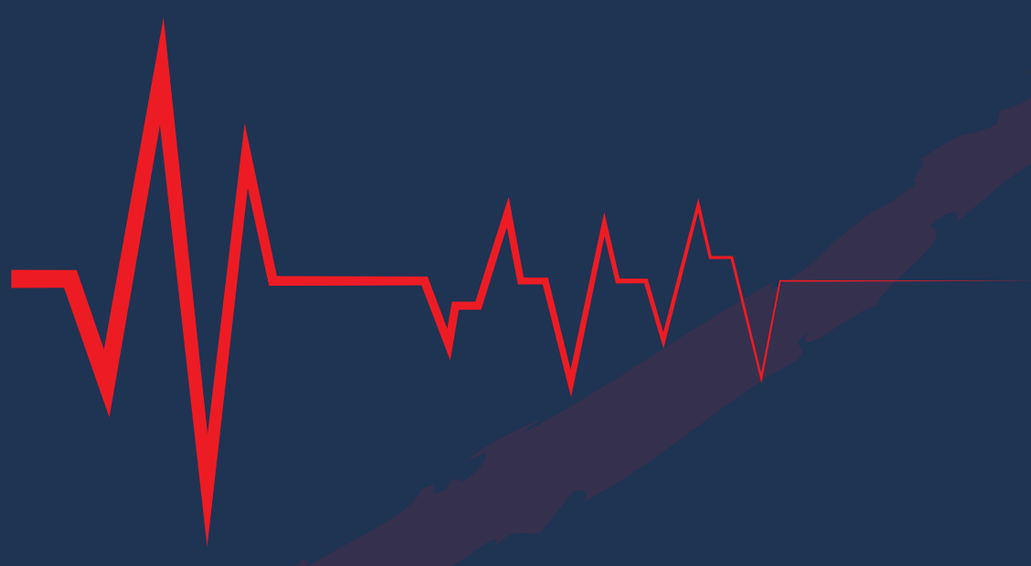
Not everyone with PLN will develop symptoms, and those who do may experience them at different ages and with varying severity. Becoming familiar with common warning signs can help you recognize changes early and seek medical care before symptoms become more serious. Remember, many of these symptoms can have causes other than PLN, but any new, persistent, or worsening symptoms should be discussed with your healthcare provider.

REMEMBER: YOU KNOW YOUR BODY BEST. IF SOMETHING FEELS DIFFERENT OR "JUST ISN'T RIGHT," TRUST YOUR INSTINCTS AND CONTACT YOUR HEALTHCARE PROVIDER. EARLY RECOGNITION AND TREATMENT CAN MAKE A SIGNIFICANT DIFFERENCE IN YOUR HEART HEALTH.

When to Contact Your Healthcare Team

Notify your cardiologist if you experience new or worsening symptoms, including increasing fatigue, more frequent palpitations, shortness of breath, swelling, dizziness, or decreased exercise tolerance. Seek emergency medical care immediately if you experience chest pain, fainting, severe shortness of breath, multiple ICD shocks, or symptoms of a stroke.

COMMON SYMPTOMS



PALPITATIONS

A sensation of fluttering, racing, pounding, or skipped heartbeats that may indicate an abnormal heart rhythm.

FATIGUE

Persistent tiredness or reduced energy that doesn't improve with rest and may make everyday activities more difficult.

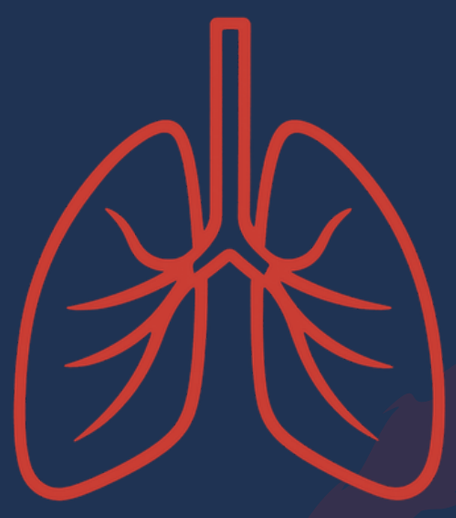


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SWELLING (EDEMA)

Fluid buildup causing swelling in the feet, ankles, legs, or abdomen, often accompanied by rapid weight gain.



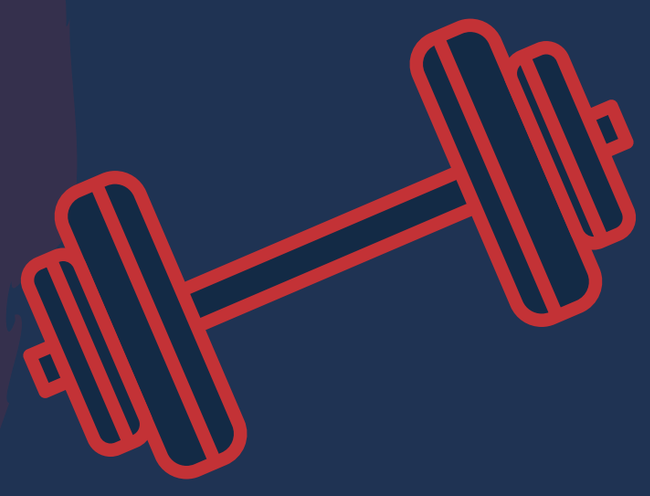


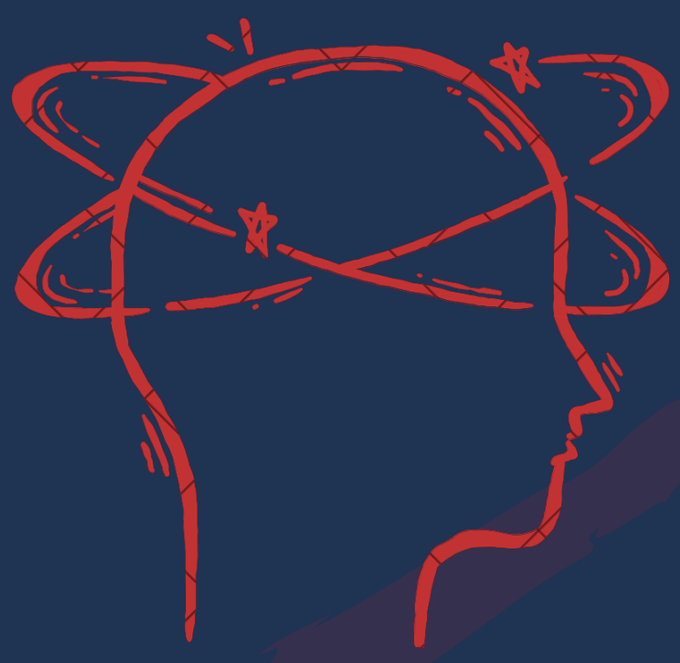
SHORTNESS OF BREATH

Difficulty breathing during activity, while lying flat, or at rest as the heart becomes less efficient at pumping blood.

EXERCISE INTOLERANCE

Becoming winded or fatigued more quickly during activities that were previously easy.





DIZZINESS OR SYNCOPE

Feeling lightheaded, nearly fainting, or losing consciousness, which may be caused by abnormal heart rhythms or reduced blood flow to the brain.

CHEST PAIN OR DISCOMFORT

Pressure, tightness, or pain that should always be evaluated, especially if severe or accompanied by shortness of breath or fainting.



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UNDERSTANDING YOUR RISK

Risk Does Not Equal Certainty

One of the most important things to understand about PLN R14del is that every carrier's journey is unique. Receiving a positive genetic test does not mean you will definitely develop heart disease, nor does it predict when symptoms may occur. Some carriers remain symptom-free throughout their lives, while others develop arrhythmias, cardiomyopathy, or heart failure at different ages and with varying severity, even within the same family.

This is because PLN demonstrates ***variable penetrance and variable expression.***

- **Variable penetrance means that not everyone who inherits the PLN mutation will develop signs or symptoms of disease.**
- **Variable expression means that those who do develop the disease can experience very different symptoms, ages of onset, and levels of severity.**

Age is only one piece of the puzzle. While many people develop symptoms later in adulthood, others may experience changes much earlier, while some never develop heart disease at all. Researchers continue to study why PLN affects individuals so differently.

Because there is currently no way to predict exactly who will develop symptoms or when, routine cardiac monitoring is recommended for all carriers, even if you feel completely healthy. Regular evaluations allow your healthcare team to identify changes early and intervene before complications become more serious.



REMEMBER: A POSITIVE GENETIC TEST MEANS YOU HAVE AN INCREASED RISK, NOT A GUARANTEED OUTCOME. KNOWLEDGE ALLOWS YOU AND YOUR HEALTHCARE TEAM TO BE PROACTIVE RATHER THAN REACTIVE.

PLN HEART FOUNDATION

YOUR FIRST 30 DAYS WITH PLN: ONE STEP AT A TIME

Receiving a PLN diagnosis can feel overwhelming, but you don't have to do everything at once. This timeline is simply a guide, not a checklist you must complete. Move at your own pace, ask questions, and remember that every step you take is a step toward better understanding your health.

WEEK 1

Your first week is about gathering information, not making major decisions. It's okay to feel overwhelmed, and it's okay if you don't have all the answers yet.

Goals for This Week:

✔️ **Learn what PLN R14del is and what it means for you.**

✔️ **Read Chapters 1 and 2 of this handbook.**

✔️ **Write down any questions that come to mind.**

✔️ **Contact the PLN NA Foundation if you need guidance or simply want to talk with someone who understands.**
[plnfoundation.na@gmail.com]

✔️ **Follow us on social media to stay informed about educational events, research updates, patient stories, and community news.**

✔️ **Sign up for the PLN Foundation newsletter to receive updates on new resources, research, webinars, and upcoming events.**

✔️ **Share your diagnosis only when you feel ready.**

WEEK 2

This week focuses on establishing your medical care and building your medical team.

Goals for This Week:

✔️ Schedule an appointment with a cardiologist experienced in inherited cardiomyopathy (or discuss PLN with your current cardiologist).

✔️ Meet with a genetic counselor if you have not already. If you need help locating one, email us!

✔️ Begin gathering your family medical history.

✔️ Schedule recommended baseline testing (ECG, echocardiogram, cardiac MRI, Holter monitor, etc.).

✔️ Start a folder or binder for your medical records.

✔️ Write down your symptoms, even if they seem minor.

HELPFUL TIP: BRING THIS, OR A, NOTEBOOK, TO YOUR APPOINTMENTS AND WRITE NOTES DIRECTLY IN IT.

WEEK 3

PLN is inherited, this week is a good time to begin thinking about your biological relatives.

Goals for This Week:

✔️ **Talk with close family members about your diagnosis when you feel ready.**

✔️ **Encourage relatives to discuss genetic counseling and testing with their healthcare providers.**

✔️ **Complete a family tree. It will also be helpful to include how deceased members passed to help link if PLN could be the cause. If you're interested in learning more about your ancestry or tracing your family's connection to PLN, email us at *plnfoundation.na@gmail.com* to learn about available genealogy resources through our team genealogist and how to get your reports.**

✔️ **Explore ConnectMyVariant, an international platform that helps individuals with rare genetic variants connect with others who share the same mutation. Participation is optional but can provide opportunities to contribute to research, connect with the global community, and learn from others with similar experiences. [*https://connectmyvariant.org*]**

WEEK 4

By now, you've taken some important first steps. While there may still be uncertainty, you are building a strong foundation for your future care.

Goals for This Week:

✔️ **Review your test results with your healthcare team and develop a personalized follow-up plan.**

✔️ **Continue tracking any symptoms or changes.**

✔️ **Join the PLN Facebook support group if you're interested.**

✔️ **Learn about ongoing PLN research and opportunities to participate in studies or clinical trials through our PLN NA Foundation newsletter and social media pages.**

REMEMBER:
THIS IS A LIFELONG JOURNEY, YOU DON'T HAVE TO KNOW EVERYTHING TODAY. TAKE TIME TO CELEBRATE HOW FAR YOU'VE ALREADY COME.

PLN HEART FOUNDATION

YOUR FIRST MONTH CHECKLIST

- ☐ Learned about PLN
- ☐ Contacted the PLN Foundation
- ☐ Signed up for the newsletter
- ☐ Followed the Foundation on social media
- ☐ Scheduled cardiology follow-up
- ☐ Completed or scheduled baseline testing
- ☐ Began family conversations
- ☐ Gathered family history
- ☐ Explored genealogy resources (optional)
- ☐ Learned about ConnectMyVariant
- ☐ Joined a support group (optional)
- ☐ Started symptom tracking
- ☐ Wrote questions for future appointments
- ☐ Read the next chapter

QUESTIONS TO ASK YOUR CARDIOLOGIST

No question is too small or unreasonable when it comes to your heart health. Writing down your questions before an appointment can help you make the most of your visit and ensure you leave feeling informed. Remember, every person's PLN journey is different, so not every question will apply to everyone. If a medical professional needs more information on PLN, please have them email us or visit our website. ***[PLNFoundationNA.com]***

UNDERSTANDING YOUR DIAGNOSIS:

- What does my PLN mutation mean for me specifically?
- Have I developed any signs of cardiomyopathy?
- Which phenotype of PLN best describes my current condition?
- Do I have any fibrosis (scar tissue) on my cardiac MRI?
- Is my ejection fraction (EF) normal?
- Are there any signs that my condition has changed since my last visit?
- How often should I have follow-up appointments?

CARDIAC TESTING

- Which tests do I need now?
- How often should I have an ECG, echocardiogram, cardiac MRI, or Holter monitor?
- Why is each test important?
- Are there alternatives if I cannot complete a particular test?
- What symptoms should prompt testing sooner than planned?
- If IVs are hard, ask for numbing cream to be applied an hour before needing the IV and/or an Ultrasound-guided IV placement
- Do I need to see an electrophysiologist too?

If I'm Claustrophobic...

- Are there wide-bore (large opening), open, or standing MRI scanners available nearby? *(Note: Open MRIs are generally not recommended for detailed cardiac imaging because image quality may be lower.)*
- Can medication be prescribed beforehand to help with anxiety?
- Can I wear headphones or listen to music during the scan? (Note: Most modern MRI-capable facilities provide headphones for the noise and can play music of your choice)
- May a family member stay in the MRI room if appropriate?

HEART RHYTHM MONITORING

- Do I need a Holter monitor?
- Would a longer event monitor or implantable loop recorder provide more information?
- If I have an Apple Watch, Fitbit, Garmin, Whoop, or another smartwatch, do I need a Holter monitor?
- What symptoms should I record if I experience palpitations?
- How many PVCs or PACs are considered concerning?
- When should I call the office instead of waiting for my next appointment?

GENETICS AND FAMILY SCREENING

- Should my parents, siblings, and children be tested? ***(Note: This is a personal and medical decision, some carriers are asymptomatic. Depending on the child's age, this could impact their health and life insurance. If you need additional guidance, please email us at [plnfoundation.na@gmail.com]***
- Can you refer me to a genetic counselor? ***(Note: The PLN NA Foundation can help locate resources for genetic counselors and FREE genetic testing you or medical professionals can order, if needed.)***
- If my provider is unfamiliar with PLN, can I seek a second opinion? ***(Yes, or email us to help educate them!)***
- I tested positive, but I am not showing symptoms. How often should I be screened?

MEDICATIONS

- Do I need medication now, or only if my heart changes?
- What are the benefits and possible side effects? *(Note: Each carrier's medicine journey will be different, it takes some time to find the right medication and dose. Be patient.)*
- Are there medications I should avoid?
- Can over-the-counter medications affect my heart?
- Should I avoid certain supplements or energy drinks?
- Are there any medication interactions I should know about?

IMPLANTABLE DEVICES

- Do I currently meet criteria for an ICD? If not, what changes would make one necessary?
- What type of ICD would be most appropriate for me? *(Note: You can also email us to get carrier stories. The EV-ICD is the newest device of the three, not all surgeons are trained with implantation of this device.)*
- Is my ICD MRI-compatible? If my ICD is MRI-compatible, are there any precautions before an MRI?
- What happens if I need an MRI but my device is not MRI-compatible?
- How often will my device need to be checked?
- What should I do if my ICD delivers a shock?

LIFESTYLE & EXERCISE

- What types of exercise are safe for me?
- Are there activities I should avoid?
- Can I continue strength training?
- Are there heart rate limits I should stay below?
- Is caffeine or alcohol safe for me?
- What should I know before traveling? Are there restrictions if I fly?

PREGNANCY & FAMILY PLANNING

- Is pregnancy safe for me?
- Should I meet with a maternal-fetal medicine specialist or genetic counselor before becoming pregnant?
- What reproductive options are available if I want to reduce or eliminatethe chance of passing on PLN? What options are covered by insurance?
- When should children in my family be evaluated?

LOOKING AHEAD

- What symptoms should prompt me to call your office immediately versus going directly to the ER?
- What are my biggest risk factors right now?
- What is our plan over the next year?
- If you were in my position, what would you focus on most
- Is there anything I can do to lower my risk?

DIAGNOSTIC TESTING

Electrocardiogram (ECG or EKG): A Snapshot of Your Heart's Electrical Activity

An ECG is one of the most common and important tests used to evaluate your heart. It is a quick, painless, and non-invasive test that records the heart's electrical activity. Every heartbeat begins with an electrical impulse that travels through the heart, telling it when to contract and pump blood. An ECG measures these electrical signals and displays them as a series of waves on a graph, allowing your healthcare provider to evaluate how your heart is functioning. For individuals with PLN, ECGs are especially valuable because changes in the heart's electrical system may occur before symptoms develop or before the heart muscle appears abnormal on imaging studies. While an ECG alone cannot diagnose PLN, it can provide important clues that help your cardiologist monitor subtle changes in your heart over time that could indicate disease progression.

An ECG helps your healthcare provider evaluate:

- Your heart rate (how fast your heart is beating)
- Your heart rhythm (whether it is regular or irregular)
- How electrical signals travel through the heart
- Signs of abnormal heart rhythms (arrhythmias)
- Evidence of previous heart muscle damage
- Conduction delays or electrical abnormalities
- Changes that may suggest cardiomyopathy or other heart conditions

What Happens During the Test?

An ECG is performed while you are lying comfortably on an examination table. A healthcare professional will place several small adhesive stickers, called electrodes, on your chest, arms, and legs. These electrodes are connected by wires to the ECG machine. The electrodes do not send electricity into your body. Instead, they simply detect and record the electrical signals naturally produced by your heart. Once the electrodes are in place, you'll be asked to remain still, breathe normally, and avoid talking for a few seconds while the machine records your heartbeat. The recording itself usually takes less than one minute, although the entire appointment is typically completed within 5–10 minutes. Afterward, the electrodes are removed, and you can immediately return to your normal activities.

Do I Need to Prepare?

One of the advantages of an ECG is that very little preparation is required. You can wear comfortable clothing that allows easy access to your chest. Avoid applying lotions, oils, or creams to your chest on the day of the test, as they can make it difficult for the electrodes to stick properly. You can continue taking your medications unless your healthcare provider specifically tells you otherwise. You do not need to fast before a routine ECG. You may eat and drink normally. Staying hydrated is encouraged. *If you have a hairy chest, small areas may occasionally be shaved so the electrodes adhere properly.*

What if My ECG Is Normal?

A normal ECG is reassuring, but it does not rule out PLN or other forms of inherited cardiomyopathy. Some carriers have normal ECGs for years before any changes become visible. Others may develop electrical abnormalities before symptoms occur. This is why your cardiologist will often combine the ECG with other tests to obtain a more complete picture of your heart health.

Can an ECG Detect Every Heart Problem?

No, an ECG records only a brief snapshot of your heart's electrical activity at the moment the test is performed. If an abnormal rhythm occurs only occasionally, it may not happen during those few seconds. If your symptoms come and go, your cardiologist may recommend longer-term monitoring such as: *Holter monitors (24–48 hours), event monitors (1 to 2 weeks), patch monitors, and/or an implantable loop recorder (months to years).*

Frequently Asked Questions

- Can I eat before? **Yes. There are no dietary restrictions for a routine ECG.**
- Can I take my medications? **Yes. Continue taking your medications unless your healthcare provider gives different instructions.**
- Can I drink coffee beforehand? **Yes, in moderation unless your provider advises otherwise. If you're having other tests on the same day, follow your provider's specific instructions.**
- Will I have to remove my clothes? **You'll usually remove clothing from the waist up and wear a medical gown to allow placement of the chest electrodes.**
- Will it hurt? **No, an ECG is painless; however, removal of the electrode adhesive pads might cause some discomfort. The test itself doesn’t cause discomfort.**
- How long does it take? **The recording itself takes less than one minute, and the full appointment usually lasts about 5–10 minutes.**
- Can I drive myself afterward? **Yes you can, there is no restrictions after a routine ECG**.

Echocardiogram (Echo): A Moving Picture of Your Heart

An echo is one of the most important tests used to evaluate the structure and function of your heart. It is a safe, painless, and non-invasive ultrasound that uses sound waves, not radiation, to create real-time images of your heart as it beats. Unlike an ECG, an echo shows how your heart is working mechanically. For individuals with PLN, this is an essential part of routine monitoring because they can detect changes in heart structure and pumping function long before symptoms become severe.

What Can an Echocardiogram Show?

- The size of your heart chambers and/or enlargement of the heart
- How well your heart muscle contracts and strength of the muscle
- Your ejection fraction (percentage of blood pumped out with each heartbeat)
- Heart valve function
- Signs of cardiomyopathy or heart failure
- Fluid around the heart (pericardial effusion)

For PLN carriers, serial echocardiograms allow your cardiologist to compare results over time and monitor for subtle changes that may indicate disease progression.

What Is Ejection Fraction (EF)?

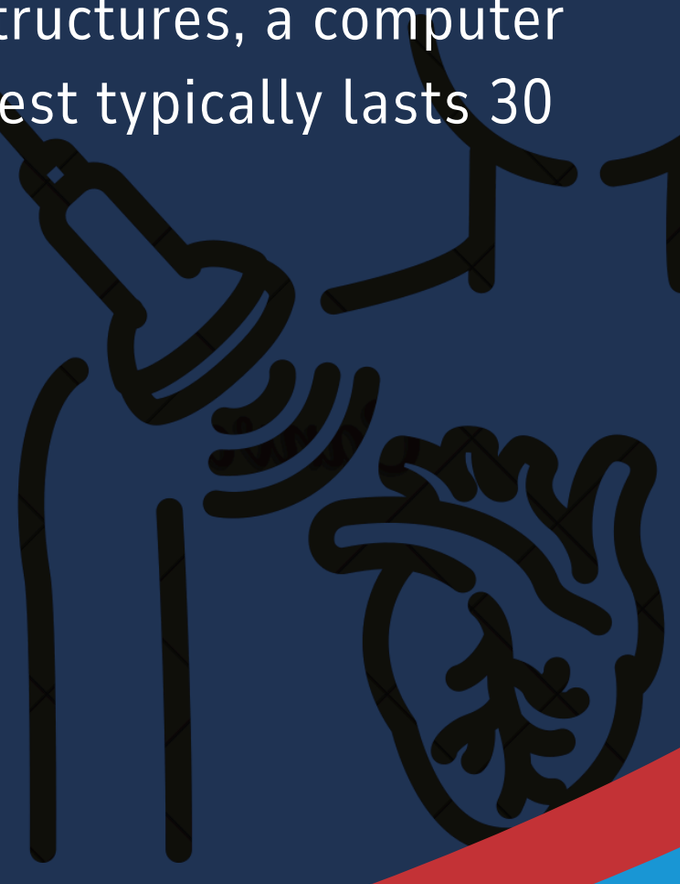
EF measures how much blood your left ventricle pumps out with each heartbeat. It is expressed as a percentage. *For example: If your heart fills with 100 mL of blood and pumps out 60 mL, your EF is 60%*. A normal EF generally ranges from 55–70%, although your cardiologist will interpret your results within the context of your overall heart health. It's important to remember that a normal EF does not always mean the heart is completely healthy. Some people with PLN develop dangerous arrhythmias or fibrosis before their EF declines.

What Happens During the Test?

During an echo, you'll lie comfortably on an examination table, usually on your left side. A trained sonographer will place a gel on your chest and move a handheld device called a transducer over different areas. The transducer sends harmless sound waves through your chest. As the sound waves bounce off your heart structures, a computer converts them into moving images displayed on a monitor. The test typically lasts 30 to 60 minutes.

The sonographer may ask you to:

- Change positions
- Hold your breath briefly
- Breathe normally
- Remain still while images are recorded



PLN HEART FOUNDATION

Do I Need to Prepare?
A routine echo requires little or no preparation. You can wear comfortable clothing. You can continue taking your medications unless your healthcare provider tells you otherwise. You do not need to fast before a standard transthoracic echo, and you can eat and drink normally. *If you are scheduled for a stress echocardiogram or a transesophageal echocardiogram (TEE), your healthcare team will provide different preparation instructions.*

Will It Hurt?
No. A standard echo is painless. You may feel gentle pressure from the transducer as the sonographer obtains different images, but the test itself is not uncomfortable. The ultrasound gel may feel cool when first applied.

Can an Echocardiogram Diagnose PLN?
No. An echo cannot diagnose the PLN mutation itself, only genetic testing can. Instead, it evaluates how the heart is functioning and whether PLN has caused changes in heart structure or pumping ability. Some PLN carriers have a completely normal echo many years. Because early fibrosis may not always be visible on an echo, your cardiologist may also recommend a cardiac MRI, which provides more detailed information about heart muscle tissue.

What If My Echo Is Normal?
A normal echo is reassuring, but it does not mean future monitoring is unnecessary. PLN can develop gradually, which is why routine surveillance remains important even when imaging is normal. Your cardiologist may recommend a repeat echo every few years, or more frequently if symptoms develop, changes are detected, or based on family history.

Frequently Asked Questions

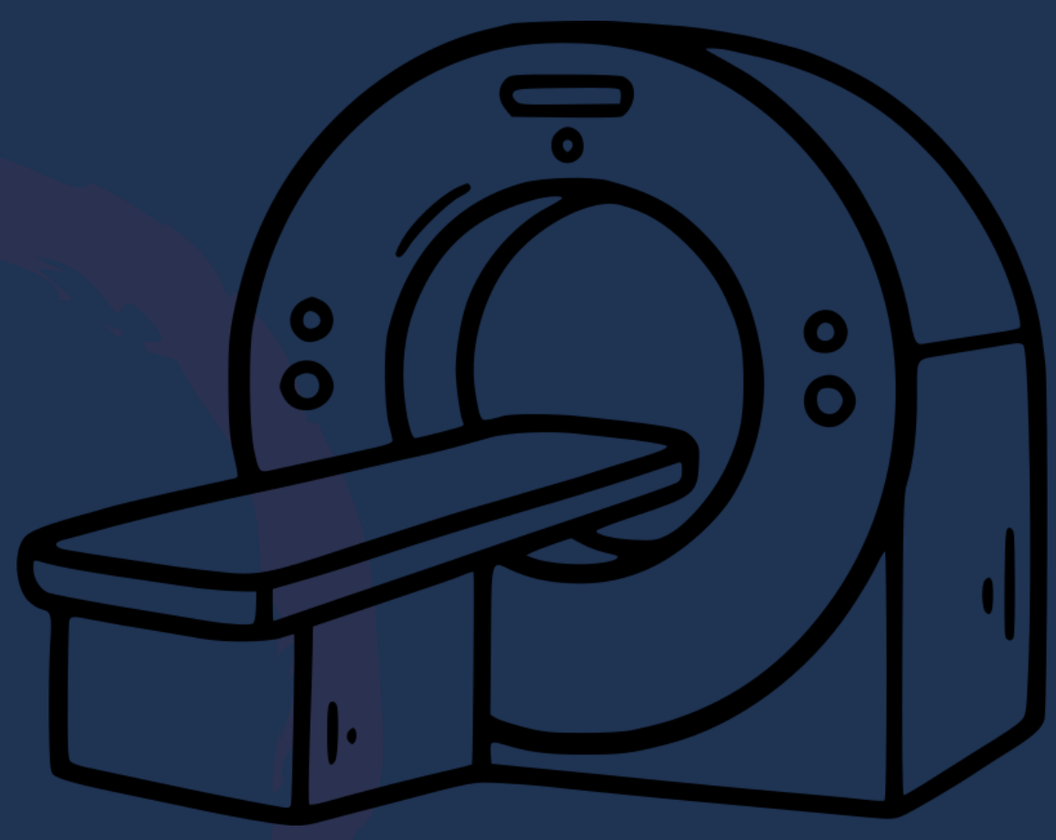
- Can I eat before an echo? **Yes. There are no dietary restrictions before a routine echo.**
- Can I take my medications? **Yes, unless instructed otherwise.**
- How long does the test take? **Most echos take 30–60 minutes.**
- Will I receive my results immediately? **Sometimes the sonographer can explain the process, but the images are typically reviewed by a cardiologist, who will discuss the results with you at a follow-up appointment or through your patient portal.**
- How often will I need an echo? **This depends on your age, symptoms, family history, and current heart function. Your cardiologist will determine the appropriate monitoring schedule.**

Cardiac Magnetic Resonance Imaging (MRI):

A cardiac MRI scan is one of the most advanced imaging tests available for evaluating the heart. It uses a powerful magnet, radio waves, and a computer to create highly detailed pictures of your heart's structure, function, and tissue. Unlike an echo, which evaluates how your heart pumps, a cardiac MRI provides incredibly detailed images of the heart muscle itself. For individuals with PLN, this test is especially valuable because it can detect fibrosis (scar tissue) and subtle changes in the heart before they become visible on an echo or before symptoms develop. Many cardiologists consider the cardiac MRI to be one of the most important tests for evaluating inherited cardiomyopathies like PLN.

What Can a Cardiac MRI Show?

- The size and shape of your heart
- Heart muscle thickness
- Structural changes
- Heart chamber size
- Pumping function (ejection fraction)
- Areas of weakened heart muscle
- Fibrosis (scar tissue)
- Inflammation
- Fatty replacement of heart muscle
- Blood flow through the heart
- Heart valve function



One of the most important reasons PLN patients undergo a cardiac MRI is to look for late gadolinium enhancement (LGE), an imaging technique that highlights areas of scar tissue. Research has shown that fibrosis can increase the risk of abnormal heart rhythms and may appear before the heart's pumping function declines.

Why Is This Test So Important for PLN?

PLN affects both the electrical system and the heart muscle. While ECGs detect electrical changes and echos evaluate heart function, a cardiac MRIs allows your healthcare team to examine the heart muscle itself.

What Happens During the Test?

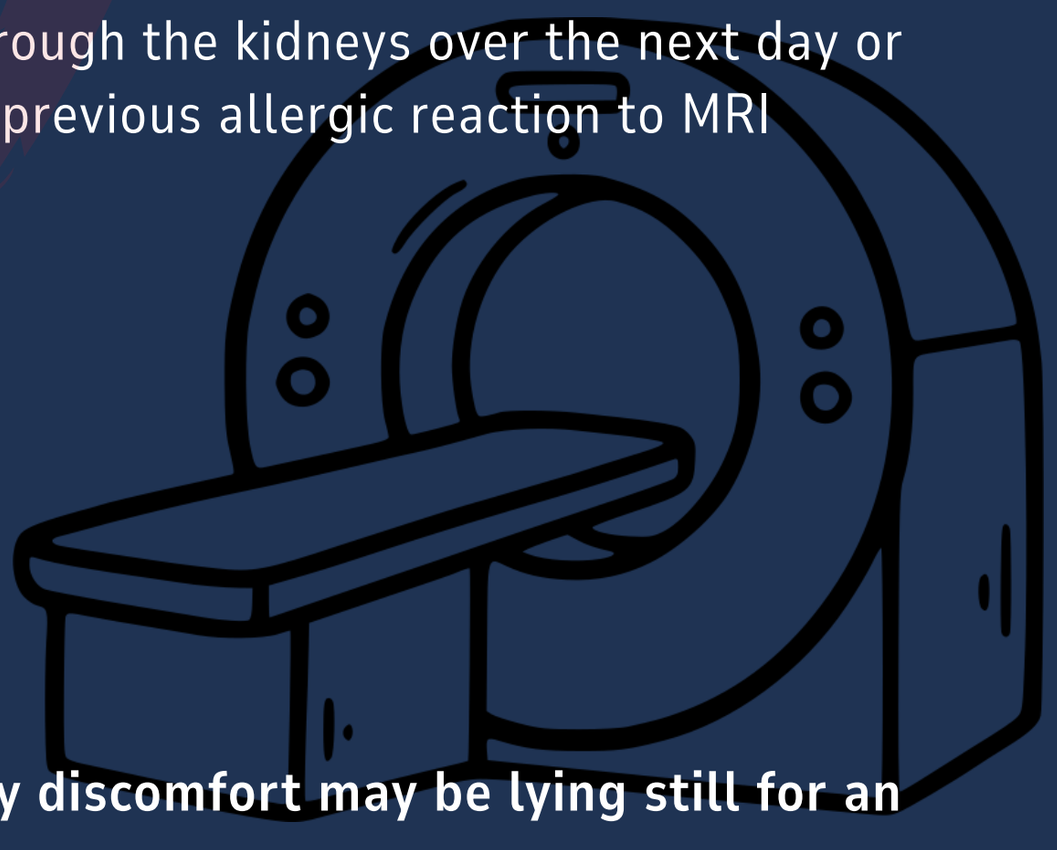
When you arrive, you'll be asked to remove jewelry, watches, hearing aids, credit cards, and any other metal objects. You'll change into a hospital gown and answer several safety questions regarding implants, previous surgeries, or metal fragments. An IV is often placed in your arm so that gadolinium contrast can be administered during part of the exam. This contrast helps highlight areas of scar tissue and improves image quality. You'll then lie on a narrow table that slowly slides into the MRI scanner. The scanner is open at both ends, but because it surrounds much of your body, some people feel confined. Headphones are typically provided to help with noise reduction of the loud knocking noises from the MRI and occasionally played preferred music. The technologist can see and hear you throughout the entire scan. You'll be asked to hold your breath for short periods (usually 5–15 seconds) while images are taken. It's very important to remain as still as possible to produce clear images. Most cardiac MRIs take 45–90 minutes.

Do I Need to Prepare?
MRI preparation is usually simple. Wear comfortable clothing without metal zippers or snaps. Continue taking your medications unless instructed otherwise. Most cardiac MRIs do not require fasting, although some hospitals may ask you not to eat for a few hours before the exam if contrast is being used. Stay well hydrated unless instructed otherwise. Tell your healthcare team if you have kidney disease, are pregnant, or have implanted medical devices.

What If I'm Claustrophobic?
Many people worry about feeling anxious inside the MRI scanner, and that's okay. If you have claustrophobia, tell your healthcare provider before your appointment. There are several ways to make the experience easier; mild anti-anxiety medications may be prescribed before the scan. Some hospitals have wide-bore MRI scanners, which have a larger opening and are often more comfortable. In certain situations, sedation may be available if necessary. Open MRI scanners are available at some facilities, but they generally do not provide the image quality needed for detailed cardiac imaging. If you're concerned about claustrophobia, ask your provider whether a wide-bore cardiac MRI is available instead.

Can I Have an MRI If I Have an ICD or Pacemaker?
In many cases, yes. Many modern pacemakers and ICDs are MRI-conditional, meaning they were specifically designed to allow MRI scans under carefully controlled conditions. Your cardiology team will determine whether your device is MRI-compatible. Your device may be temporarily adjusted before the scan. You'll be monitored throughout the procedure. After the MRI, your device will be checked and reprogrammed if needed. ***If your device is not MRI-compatible,*** your cardiologist will discuss whether an MRI can still be safely performed at a specialized center or whether another imaging test would be more appropriate. Always tell the MRI staff if you have any implanted device.

Is Gadolinium Safe?
Gadolinium is a contrast agent that helps identify scar tissue within the heart. For most people, gadolinium is very safe and is removed from the body through the kidneys over the next day or two. If you have significant kidney disease or have had a previous allergic reaction to MRI contrast, tell your healthcare provider before the scan.

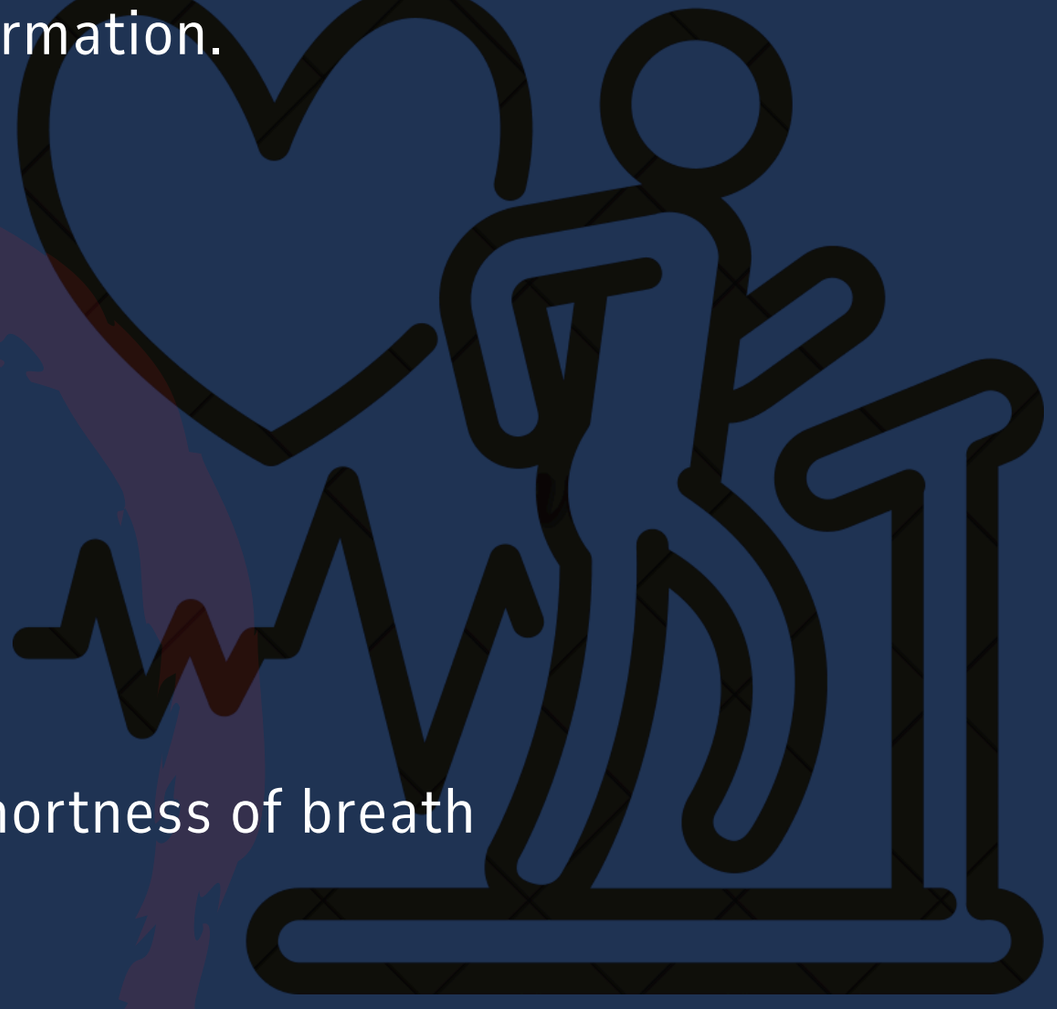


Frequently Asked Questions

- Will the MRI hurt? **No. The scan is painless. The only discomfort may be lying still for an extended period or having an IV placed.**
- Can I eat beforehand? **Usually yes, but always follow the specific instructions provided by your imaging center.**
- Can I take my medications? **Yes, unless your healthcare provider tells you otherwise.**
- How long does it take? **Most cardiac MRIs take 45–90 minutes.**
- Will I get my results immediately? **No. A specialized cardiologist or radiologist will carefully review your images before discussing the results with you.**

Exercise (Stress) Testing:
Evaluating How Your Heart Performs During Activity

An exercise stress test, sometimes called a treadmill test or cardiac stress test, evaluates how your heart responds to physical activity. Exercise places additional demands on your heart and can sometimes reveal abnormalities that aren't present during a routine ECG or echo. Stress testing can provide valuable information about your heart rhythm, exercise tolerance, blood pressure response, and overall cardiovascular fitness. It also helps your healthcare team make recommendations about physical activity and monitor changes over time. There is no ‘passing or failing’ this test. The goal is simply to gather information.



What Can an Exercise Stress Test Show?

- Your heart rate response to exercise
- If exercise-induced arrhythmias occur
- Blood pressure during activity
- Exercise capacity and endurance
- Changes in your ECG during exercise
- Symptoms such as chest pain, dizziness, or shortness of breath
- Recovery of your heart rate after exercise

Types of Stress Tests

1. **Exercise Stress Test:** This is the most common type of stress test. You'll walk on a treadmill and/or pedal a stationary bicycle while your speed and resistance gradually increase every few minutes. Throughout the test, your ECG, heart rate, blood pressure, and symptoms are continuously monitored. The goal is not to see how athletic you are, it is simply to observe how your heart responds to increasing levels of activity.

2. **Stress Echocardiogram**: A stress echocardiogram combines an exercise stress test with an echo. Images of your heart are taken before and immediately after exercise. This allows your cardiologist to compare how your heart pumps at rest versus during physical stress. A stress echo can identify areas of the heart muscle that may not be contracting normally during exercise.

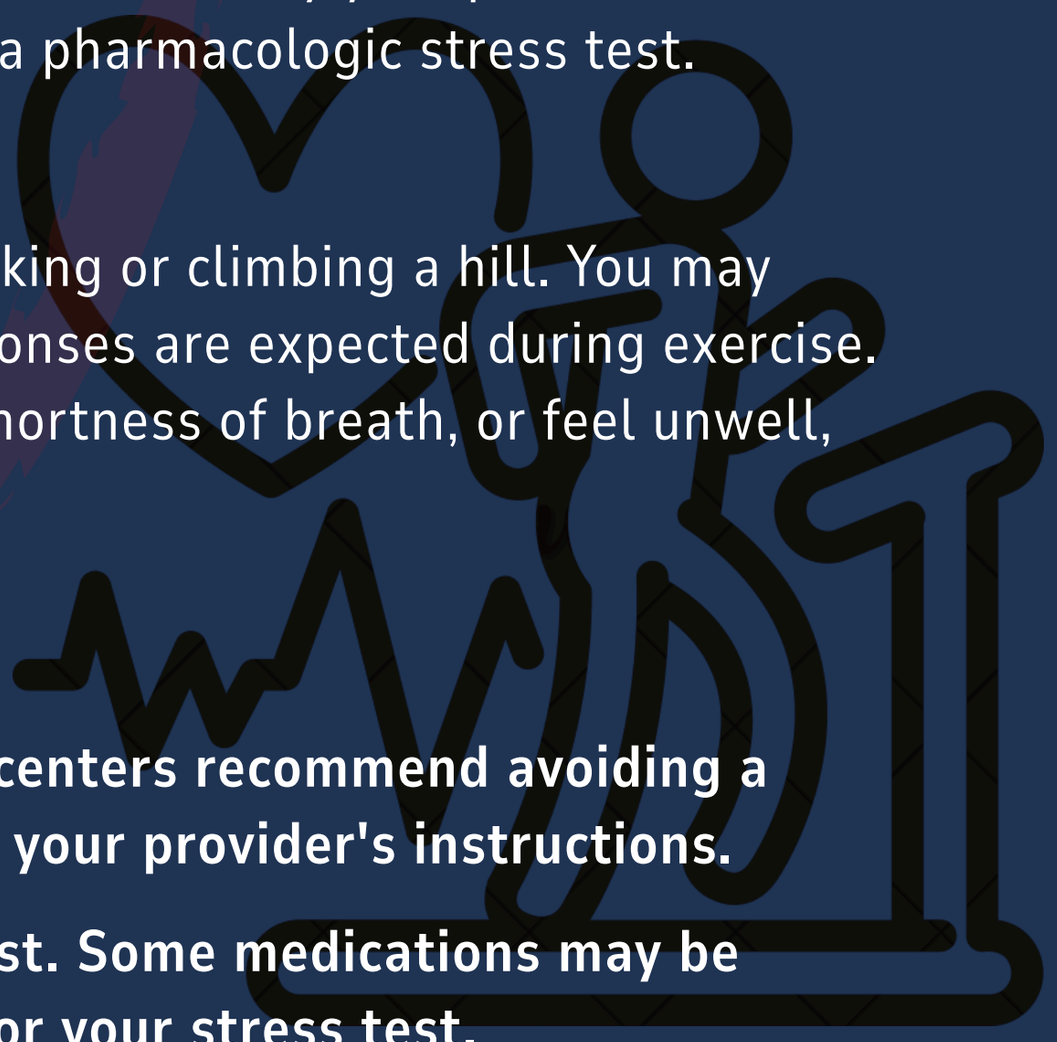
3. P**harmacologic (Medication) Stress Test**: Some individuals cannot safely exercise because of orthopedic conditions, neurological disorders, severe heart disease, or other medical concerns. Instead of walking on a treadmill, medications are given through an IV to temporarily make the heart work harder or increase blood flow, mimicking the effects of exercise. Although your heart experiences "stress," you do not have to exercise during this test.

What Happens During the Test?

Small ECG electrodes are placed on your chest. Your resting blood pressure and heart rate are measured. Your healthcare provider will explain the procedure. You'll then begin walking on a treadmill or pedaling a stationary bike. Every few minutes, the intensity gradually increases. During the test, you'll be asked how you're feeling and whether you've developed any symptoms. Depending on the facility, they might prick your finger every couple of minutes. Depending on the facility, you might have to wear a mouth piece that pushes specific gas mixtures into your body to help further evaluate how oxygen is moving through your body during exercise. The test is stopped if you've reached your target heart rate, you're too tired to continue, concerning ECG changes occur, your blood pressure changes significantly, and/or you develop symptoms that require stopping. After exercise, you'll continue to be monitored for several minutes while your heart rate and blood pressure return toward normal. The entire appointment usually lasts 30–60 minutes, although the exercise portion itself often lasts 8–15 minutes.

Do I Need to Prepare?

Preparation depends on the type of stress test you're having. Always follow your healthcare provider's specific instructions. You can wear comfortable clothing and walking shoes. Avoid heavy meals for several hours before the test. Stay hydrated unless instructed otherwise. Ask your healthcare provider whether you should take your usual medications before the test. Some medications, particularly certain heart medications like beta blockers, may need to be temporarily held because they affect your heart rate. Never stop a medication without medical guidance. If instructed by your provider, avoid caffeine before your test, especially if you are having a pharmacologic stress test.



Will It Hurt?

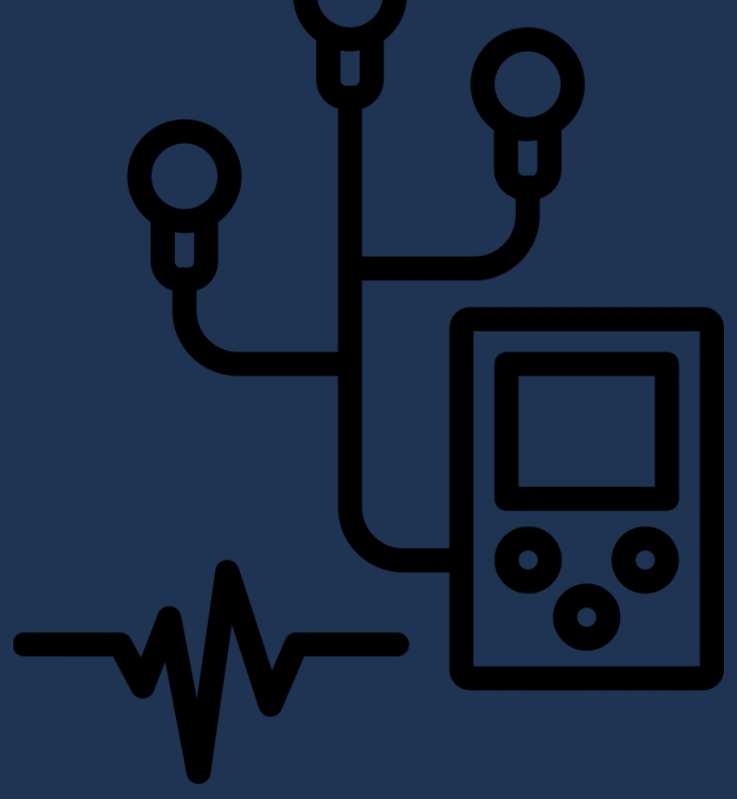
No. The exercise itself should feel similar to brisk walking or climbing a hill. You may become short of breath, sweaty, and tired; these responses are expected during exercise. If you develop chest pain, severe dizziness, unusual shortness of breath, or feel unwell, tell the healthcare team immediately.

Frequently Asked Questions

- Do I need to fast? **Usually not completely. Many centers recommend avoiding a large meal for 2–4 hours before the test. Follow your provider's instructions.**
- Can I take my medications? **Often yes, but ask first. Some medications may be temporarily adjusted depending on the reason for your stress test.**
- Can I drink coffee beforehand? **If you're having a treadmill stress test, your provider may recommend limiting caffeine beforehand. If you're having a pharmacologic stress test, you'll usually be asked to avoid all caffeine for at least 12–24 hours, as it can interfere with the medications used during the test.**
- What if I can't exercise? **That's okay, your healthcare provider may recommend a pharmacologic stress test.**
- Will I receive my results immediately? **The healthcare team performing the test can often tell you if the test was completed successfully, but your cardiologist will carefully review all of the data before discussing the results with you.**

Holter Monitor & Ambulatory Heart Rhythm Monitoring

An ECG records your heart's electrical activity for only a few seconds. But what if your palpitations, dizziness, or irregular heart rhythms happen only occasionally? That's where ambulatory heart rhythm monitoring, such as a Holter monitor, becomes valuable. A Holter monitor is a small, portable device that continuously records your heart's electrical activity while you go about your normal daily routine. Because many abnormal heart rhythms come and go, monitoring your heart over a longer period increases the chance of detecting rhythms that may not appear during a routine ECG. Holter monitors are an important tool for identifying arrhythmias, monitoring disease progression, evaluating symptoms, and helping determine the need for medications or implantable devices such as an ICD. Even with an ICD, some carriers might have a Holter monitor to further evaluate symptoms.



What Can a Holter Monitor Show?

- Your average heart rate over 24 hours or longer
- Heart rate during sleep, activity, and exercise
- Premature ventricular/ atrial contractions (PVCs/ PACs)
- Atrial fibrillation or atrial flutter
- Ventricular tachycardia (VT)
- Pauses or slow heart rhythms (bradycardia)
- Correlation between symptoms and heart rhythm

Types of Heart Rhythm Monitors

1. *24- or 48-Hour Holter Monitor:* This is the most common type of ambulatory monitor. Several adhesive electrodes are placed on your chest and connected to a small recording device worn around your neck, clipped to your waistband, or placed in a pocket. The monitor records every heartbeat continuously throughout the monitoring period.
2. *Patch Monitor*: Instead of several wires, a single waterproof adhesive patch is placed directly on your chest. Depending on the device, it may record your heart rhythm for 7–14 days, and sometimes even longer. Many patients find patch monitors more comfortable than traditional Holter monitors.
3. *Event Monitor:* An event monitor is worn for several weeks and records only when an abnormal rhythm is detected or when you press a button after experiencing symptoms.
4. *Implantable Loop Recorder (ILR)*: If symptoms are very infrequent, perhaps only once every several months, your cardiologist may recommend an implantable loop recorder. This small device is inserted just beneath the skin of the chest during a brief outpatient procedure and can continuously monitor your heart rhythm for up to 3–5 years.

What Happens During the Test?

A healthcare professional will clean your skin and place small adhesive electrodes on your chest. These electrodes connect to the recording device. You'll receive instructions about caring for the monitor, recording symptoms, returning the device, and keeping a symptom diary. During the monitoring period, you'll continue your normal daily activities unless your healthcare provider gives different instructions. In fact, it's helpful to perform your usual routine so the monitor captures your heart rhythm during typical activities. If you experience symptoms such as palpitations, dizziness, chest discomfort, or shortness of breath, record what you were doing, the time the symptoms occurred, how long they lasted, and what you felt.
This helps your healthcare provider compare your symptoms with your recorded heart rhythm.

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Do I Need to Prepare?
Preparation is minimal. Wear a two-piece outfit so your chest can be accessible. Avoid applying lotions, oils, or powders to your chest. Continue taking your medications unless instructed otherwise. You do not need to fast. Shower before your appointment if your monitor cannot get wet.

Frequently Asked Questions

- Can I Shower? **This depends on the type of monitor. Traditional Holter monitors usually cannot get wet, so you'll need to avoid showering, bathing, or swimming until the monitor is removed. Many newer patch or event monitors are water-resistant, allowing brief showers, but always follow your device's specific instructions.**

- Will It Hurt? **No. The monitor simply records your heart's electrical activity. Some people notice mild skin irritation from the adhesive stickers after several days, but otherwise the monitor should not be painful.**

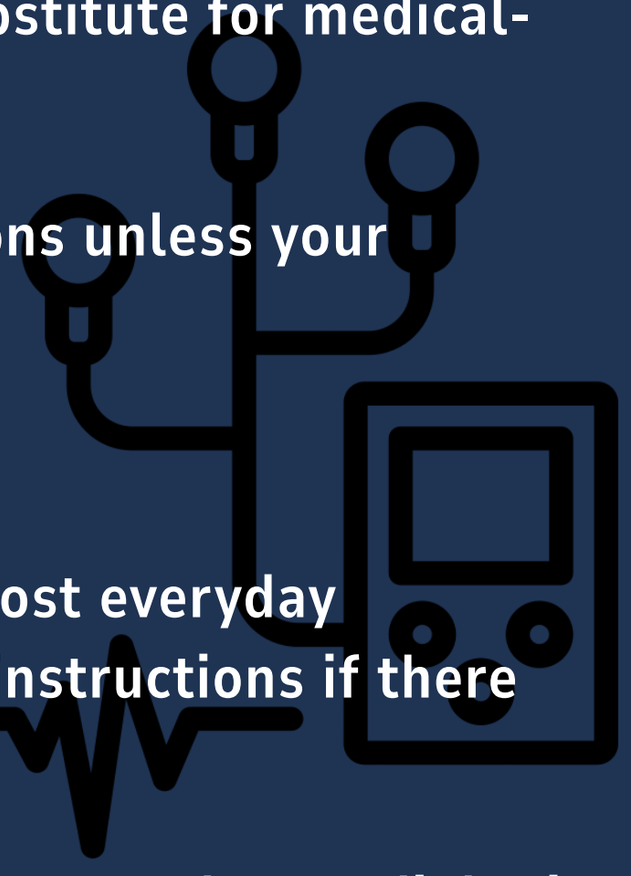
- Can I Exercise? **Usually yes, unless your healthcare provider advises otherwise, continue your normal activities, including exercise, so the monitor records how your heart behaves throughout your typical day. If exercise causes symptoms, make note of them in your symptom diary.**

- Can My Smartwatch Replace a Holter Monitor? **This is one of the most common questions patients ask. The answer is no. Devices such as the Apple Watch, Fitbit, Garmin, Samsung Galaxy Watch, Whoop, and other wearable technologies can be excellent tools for tracking heart rate and may even detect certain abnormal rhythms such as atrial fibrillation. However, they are not a substitute for medical-grade heart rhythm monitoring.**

- Can I take my medications? **Yes. Continue taking your medications unless your healthcare provider instructs you otherwise.**

- Do I need to fast? **No. You may eat and drink normally**.

- Will airport security or electronics interfere with the monitor? **Most everyday electronics are safe to use. Your healthcare team will provide instructions if there are any restrictions specific to your device.**



- Will I receive my results immediately? **No. After the monitor is returned, a cardiologist reviews thousands of heartbeats before preparing a report. Your provider will discuss the findings with you.**

- What if I don't have symptoms while wearing it? **That's okay. Even without symptoms, the monitor may detect rhythm abnormalities that occur silently. Some people experience silent arrhthymias without noticable symptoms.**

Blood Work

Blood work is a routine part of caring for your heart. While blood tests cannot diagnose PLN, they provide valuable information about your overall health and can help your healthcare team monitor how your heart and other organs are functioning. Blood tests may also help identify conditions that could contribute to symptoms or influence treatment decisions. Your cardiologist may order blood work when you are first evaluated, during routine follow-up appointments, before procedures, or if you develop new symptoms.

What Are They Looking For?

Depending on your situation, your healthcare provider may order tests to evaluate your kidney function (Important for medication management and before imaging tests that use contrast), liver function (Some heart medications can affect the liver), electrolytes (potassium, sodium, and magnesium levels which are all minerals help regulate your heart's electrical activity and rhythm). They will also look at your Complete Blood Count (checking for anemia, infection, and other blood disorders that may contribute to fatigue or shortness of breath), BNP or NT-proBNP (proteins released when the heart is under increased stress. Higher levels may suggest heart failure but are interpreted alongside your symptoms and other testing), thyroid function (thyroid disorders can affect heart rate and rhythm), and Cholesterol and blood sugar (To help assess your overall cardiovascular health and identify other conditions that may affect the heart). Your doctor may order additional tests based on your symptoms, medications, or medical history.

What to Expect

The process to collect blood through an IV typically takes only a few minutes, and you can return to your normal activities immediately afterward. Most routine blood tests do not require fasting, although certain tests, such as cholesterol or glucose testing, may. Your healthcare provider will let you know if any special preparation is needed. Continue taking your medications unless instructed otherwise.

If You Have Difficult Veins or Needle Anxiety

Many people are anxious about blood draws, and that's okay. Let the staff know if you've had difficult blood draws in the past or tend to feel faint. Several options may help make the experience more comfortable:

- **Numbing creams (such as lidocaine-based creams) can be applied before your appointment to reduce discomfort. These usually need to be applied 30–60 minutes beforehand, so ask your healthcare provider if they're appropriate for you.**
- **Many hospitals now use vein-finding devices, which use infrared light or ultrasound technology to help locate veins that may be difficult to see or feel.**
- **Staying well hydrated before your appointment (unless instructed otherwise) can make veins easier to access.**
- **If you've had success with a particular arm in the past, let your healthcare provider know.**

CHAPTER 2 SUMMARY

Receiving a PLN diagnosis is the beginning of a lifelong journey, not the end of one. While the weeks following diagnosis may feel overwhelming, taking one step at a time can help you gain confidence and take control of your heart health. Building a knowledgeable healthcare team, completing baseline cardiac testing, understanding your individual risk, and staying engaged in routine monitoring are all essential parts of managing PLN. Remember, every person's journey is different, and regular follow-up allows your healthcare team to detect changes early and provide the most personalized care possible.

Key Takeaways

- A positive genetic test does not predict your future. Every PLN carrier has a unique journey, and not everyone develops heart disease.

- Knowledge is empowering. Understanding your diagnosis and asking questions helps you become an active partner in your care.

- Baseline testing, including an ECG, echocardiogram, cardiac MRI, ambulatory heart rhythm monitoring, and blood work, provides important information about your heart's current health.

- Each diagnostic test serves a different purpose. Together, they help your healthcare team monitor both the electrical and structural health of your heart.
- Routine monitoring is essential, even if you feel well. Many changes can occur before symptoms develop.

- Bring questions to every appointment. Your healthcare team is there to help you understand your condition and make informed decisions.

- Family screening and genetic counseling can help identify other relatives who may benefit from testing and ongoing cardiac care.

- You don't have to navigate this journey alone. The PLN Foundation, your healthcare team, and the global PLN community are here to provide education, support, and hope every step of the way.

CHAPTER 3:
UNDERSTANDING YOUR HEART

How PLN Can Affect the Heart Over Time

Your heart is an incredible organ, beating more than 100,000 times each day to deliver oxygen and nutrients throughout your body. For most people, this happens effortlessly without a second thought. However, living with PLN R14del means understanding that the heart's electrical system and muscle can change over time, and that recognizing those changes is an important part of protecting your health.

The good news is that understanding your heart gives you power. By learning how PLN affects the heart, recognizing common symptoms, and understanding the purpose of different treatments, you'll be better prepared to work alongside your healthcare team and make informed decisions about your care.

This chapter focuses on what happens after a PLN diagnosis, including how the disease may progress, the symptoms to watch for, and the treatments available if changes occur. While some individuals remain symptom-free throughout their lives, others may develop arrhythmias, cardiomyopathy, or heart failure. Every journey is unique, which is why regular monitoring and individualized care are so important.

Most importantly, remember that heart disease is not inevitable, and even if changes do occur, there are many effective treatments available today. Advances in medications, implantable cardiac devices, heart failure therapies, and transplantation have dramatically improved outcomes for many people living with inherited cardiomyopathies. Researchers continue working every day toward therapies that target the underlying cause of PLN, bringing hope for an even brighter future. Knowledge doesn't create fear, it creates preparedness. The more you understand your heart, the better equipped you'll be to care for it.

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Arrhythmias: Abnormal Heart Rhythms

One of the hallmark features of PLN cardiomyopathy is its potential to affect the heart's electrical system. The heart relies on a carefully coordinated electrical signal to tell it when to beat. When these electrical signals become disrupted, the heart may beat too fast, too slow, or irregularly. These abnormal heart rhythms are called arrhythmias. Not every person with PLN will develop an arrhythmia, and not every arrhythmia is dangerous. Some may cause little or no symptoms, while others require close monitoring or treatment. Understanding these terms can help you better understand your condition and communicate with your healthcare team.

How Does a Normal Heartbeat Work?

In a healthy heart, an electrical signal begins in the sinoatrial (SA) node, often called the heart's "natural pacemaker." The signal travels through the upper chambers (atria), then passes through the atrioventricular (AV) node before spreading throughout the lower chambers (ventricles). This coordinated pathway allows the heart to beat in a steady, organized rhythm. In PLN, changes within the heart muscle, particularly fibrosis (scar tissue), can interfere with these electrical signals, increasing the risk of abnormal heart rhythms.

Common Arrhythmias

Premature Ventricular Contractions (PVCs)

PVCs are extra heartbeats that begin in the ventricles (the heart's lower chambers). Instead of following the heart's normal rhythm, an early beat occurs, often followed by a brief pause before the next heartbeat. PVCs are common and can occur even in healthy individuals. However, frequent PVCs may be an early sign of electrical irritation in the heart and are monitored closely in people with PLN. Many people describe PVCs as:

- A skipped heartbeat
- A flutter
- A flip-flop sensation
- A sudden "thump" in the chest

Premature Atrial Contractions (PACs)

PACs are similar to PVCs but begin in the atria (the upper chambers of the heart). Like PVCs, they are extra beats that occur earlier than expected and are often harmless.

Non-sustained Ventricular Tachycardia (NSVT)

NSVT is a short episode of very fast heartbeats originating in the ventricles. These episodes usually last less than 30 seconds and often stop on their own. Some people feel *palpitations, lightheadedness/ dizziness.* Others have no symptoms at all, and NSVT is discovered only during Holter monitoring. Because NSVT may increase the risk of more serious arrhythmias, it is an important finding in PLN patients.

Sustained Ventricular Tachycardia (VT)

VT occurs when the ventricles beat so rapidly that they cannot pump blood efficiently. Unlike NSVT, sustained VT lasts more than 30 seconds or requires medical treatment because symptoms develop. Symptoms may include *racing heartbeat, dizziness, chest discomfort, shortness of breath, and/ or fainting (syncope)*. Sustained VT is considered a ***medical emergency*** and often requires immediate treatment.

Ventricular Fibrillation (VF)

VF is one of the most serious heart rhythm disorders. Instead of pumping blood effectively, the ventricles quiver chaotically, preventing blood from reaching the brain and the rest of the body. Without immediate treatment, VF leads to sudden cardiac arrest. Treatment includes *CPR, AED or ICD shock, emergency medical care*. This is one reason some people with PLN are advised to receive an implantable cardioverter-defibrillator (ICD).

Atrial Fibrillation (AFib)

AFib is an irregular rhythm that begins in the atria. Instead of beating in an organized pattern, the atria quiver rapidly. Symptoms may include *fluttering heartbeat, fatigue, shortness of breath, and/or decreased exercise tolerance*. Some people have no symptoms at all. AFib is common in the general population and can also occur in individuals with PLN.

Can You Have an Arrhythmia Without Feeling It?

Yes. Many arrhythmias cause no symptoms whatsoever. Some people discover abnormal heart rhythms only after *a routine ECG, Holter monitor, Patch monitor, Smartwatch notification, and/or an ICD interrogation*. This is why routine monitoring remains important, even if you feel completely well.

When Should You Seek Medical Care?

Contact your healthcare provider if you notice more frequent palpitations, new dizziness, increased fatigue, exercise intolerance, and/or near-fainting episodes

Call 911 ***immediately*** if you experience loss of consciousness, chest pain, severe shortness of breath, multiple ICD shocks, and/or symptoms of sudden cardiac arrest

One of the unique characteristics of PLN cardiomyopathy is that dangerous ventricular arrhythmias can sometimes occur before the heart becomes enlarged or the ejection fraction decreases. This is why regular monitoring is recommended even if your heart's pumping function appears normal.

Cardiomyopathy: Understanding Diseases of the Heart Muscle

The word cardiomyopathy simply means "disease of the heart muscle." In people with cardiomyopathy, the heart muscle may become enlarged, thickened, stiff, weakened, or replaced by scar tissue. These changes can make it more difficult for the heart to pump blood efficiently and may increase the risk of abnormal heart rhythms. Not everyone with PLN develops cardiomyopathy, and those who do may experience different forms of the disease. Some people develop changes in the heart muscle itself, while others first experience abnormalities in the heart's electrical system. Because PLN affects everyone differently, your cardiologist will use imaging and/or genetic tests to help diagnose and monitor your heart over time.

The Three Main Types of Cardiomyopathy

Dilated Cardiomyopathy (DCM)

DCM occurs when the heart muscle becomes enlarged and weakened, making it more difficult for the heart to pump blood effectively. As the left ventricle stretches and enlarges, it loses some of its pumping strength, causing the EF to decrease. Over time, this can lead to symptoms of heart failure. DCM is one of the most common forms of cardiomyopathy associated with PLN and often develops gradually over many years. Common symptoms include *fatigue, shortness of breath, decreased exercise tolerance, swelling of the legs or ankles, and fluid retention.*

Arrhythmogenic Cardiomyopathy (ACM)

ACM primarily affects the heart's muscle and electrical system. In ACM, healthy heart muscle may gradually be replaced by fibrosis (scar tissue) and, in some forms of the disease, fatty tissue. Scar tissue disrupts the normal electrical pathways of the heart, increasing the risk of abnormal heart rhythms. One unique characteristic of PLN is that dangerous arrhythmias can sometimes occur before the heart becomes enlarged or weakened. This is why routine monitoring is so important, even when your EF is normal.Many people with ACM experience *palpitations, PVCs, PACs, ventricular tachycardia, syncope (fainting), and sudden cardiac arrest.*

Hypertrophic Cardiomyopathy (HCM)

Hypertrophic cardiomyopathy occurs when the heart muscle becomes abnormally thickened. Instead of stretching and enlarging, the muscle walls become thicker than normal, making it harder for the heart to relax and fill with blood between beats. Although HCM is generally caused by different genetic mutations than PLN, some individuals with PLN may develop features that resemble hypertrophic cardiomyopathy. Your cardiologist will use imaging studies to determine which type of cardiomyopathy is present and diagnose through genetic testing. Some people have no symptoms, while others experience chest pain, shortness of breath, dizziness, fainting, and exercise intolerance.

Can You Have More Than One Type?

Yes. Cardiomyopathy does not always fit neatly into one category. Many people with PLN develop an overlap phenotype, meaning they have features of both ACM and DCM. Some carriers might have ACM and HCM.

For example, someone may have:

- *Fibrosis on cardiac MRI*
- *Frequent ventricular arrhythmias*
- *A mildly enlarged heart*
- *A reduced ejection fraction*

How Is Cardiomyopathy Diagnosed?

Your healthcare provider may use several tests, including an ECG, Echo, Cardiac MRI, Holter monitor, exercise stress test, blood work, and genetic testing. No single test tells the entire story. Instead, your cardiologist combines information from all of these studies to determine how PLN is affecting your heart.

Can Cardiomyopathy Be Treated?

Although there is currently no cure for cardiomyopathy caused by PLN, there are many treatments that can help slow disease progression, reduce symptoms, and improve quality of life. Your treatment plan will depend on your individual heart function, symptoms, rhythm history, and overall health. Treatment may include heart medications, lifestyle modifications, Implantable cardioverter-defibrillators (ICDs), Pacemakers or cardiac resynchronization therapy (CRT), catheter ablation for certain arrhythmias, and/or heart transplantation or LVADs in advanced cases.

PLN cardiomyopathy is unique because it often combines features of both electrical disease and heart muscle disease. Some individuals experience dangerous arrhythmias before any obvious weakening of the heart muscle, while others develop both rhythm abnormalities and reduced heart function over time. This is why multiple tests, and regular follow-ups, are essential for understanding your individual risk.

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Heart Failure

The term heart failure can sound frightening, but it does not mean that your heart has stopped beating or is about to stop. Instead, heart failure means that the heart is not pumping blood as efficiently as it should to meet the body's needs. This can happen because the heart muscle has become weakened, enlarged, stiff, or damaged over time. For some individuals living with PLN, heart failure may develop gradually as cardiomyopathy progresses. Others may never develop heart failure at all. With today's medications, cardiac devices, and specialized care, many people with heart failure continue to live active and fulfilling lives.

How Does Heart Failure Develop?

A healthy heart pumps oxygen-rich blood throughout the body with each heartbeat. When the heart becomes weaker or stiffer, it must work harder to pump blood effectively. Over time, blood and fluid may begin to back up into the lungs or other parts of the body, leading to symptoms. Heart failure is usually a gradual process, and many symptoms develop slowly over months or years.

Common Symptoms of Heart Failure

Heart failure symptoms often develop gradually and may be mistaken for simply "getting older" or being out of shape. Symptoms can vary from person to person and may become more noticeable during periods of illness, stress, or fluid retention. Common symptoms include:

- Shortness of breath, especially during activity, when waking up, or while lying flat
- Fatigue or feeling unusually tired
- Exercise intolerance, becoming winded during activities that were once easy
- Swelling (edema) in the feet, ankles, legs, or abdomen
- Rapid weight gain from fluid retention
- Decreased appetite or feeling full quickly
- Difficulty concentrating or feeling mentally "foggy"

Recognizing Changes Early

One of the best ways to manage heart failure is to recognize changes early. Even small changes are worth discussing with your healthcare team, as early treatment can often prevent hospitalization. Ask yourself:

- Am I becoming more short of breath than usual?
- Am I more tired doing my normal activities?
- Have I noticed swelling in my feet or ankles?
- Have I gained 2–3 pounds in one day or 5 pounds in one week?
- Do I need more pillows to sleep comfortably?
- Am I waking up short of breath at night?

How Is Heart Failure Diagnosed?

Your cardiologist will use a combination of information to determine whether heart failure is present, including: Your symptoms, physical examination, Echo (to evaluate heart function and EF), Cardiac MRI, blood tests such as BNP or NT-proBNP, chest X-ray (when appropriate), ECG and heart rhythm monitoring. No single test alone diagnoses heart failure, the diagnosis is based on the complete clinical picture.

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REMEMBER: HEART FAILURE IS A MEDICAL CONDITION, NOT A LIFE SENTENCE. WITH EARLY RECOGNITION, REGULAR MONITORING, AND A PERSONALIZED TREATMENT PLAN, MANY PEOPLE WITH PLN CONTINUE TO WORK, TRAVEL, SPEND TIME WITH LOVED ONES, AND ENJOY THE ACTIVITIES THAT MATTER MOST.

How Is Heart Failure Treated?

Although heart failure is a chronic condition, there are many effective treatments available today. Treatment aims to reduce symptoms, slow disease progression, improve quality of life, and decrease the risk of hospitalization. Your treatment plan may include:

- Heart failure medications
- Diuretics ("water pills") to reduce fluid buildup
- Lifestyle modifications, including monitoring weight, sodium, and fluid intake
- Implantable devices such as an ICD or cardiac resynchronization therapy (CRT)
- Regular exercise within your healthcare provider's recommendations
- Ongoing follow-up with your cardiology team
- In advanced cases, an LVAD (left ventricular assist device) or heart transplantation may be considered.

Can Heart Failure Improve?

Yes. For many people, heart failure symptoms improve significantly with the right combination of medications, lifestyle changes, and regular medical care. In some cases, heart function may even improve over time. The goal of treatment is not only to help you feel better today but also to protect your heart for the future.

When Should I Seek Medical Care?

Contact your healthcare provider if you notice:

- Increasing shortness of breath
- New or worsening swelling
- Rapid weight gain
- Increasing fatigue
- Reduced ability to perform daily activities

Call **911** immediately if you experience:

- Severe shortness of breath at rest
- Chest pain
- Loss of consciousness
- Blue lips or fingertips
- Confusion or inability to stay awake

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Syncope (Fainting) & Near-Syncope

One of the symptoms that can occur in people living with PLN is syncope, the medical term for temporary loss of consciousness (fainting). Syncope happens when the brain does not receive enough blood flow for a brief period, causing a person to lose consciousness. Most episodes last only a few seconds to a minute, and many people recover quickly afterward. However, because syncope can sometimes be caused by a serious heart rhythm problem, it should always be discussed with your healthcare provider. Near-syncope is similar, but you do not actually lose consciousness. Instead, you may feel as though you are about to faint but recover before passing out. Both syncope and near-syncope deserve medical evaluation, especially in individuals with PLN.

Common Symptoms

People experience syncope and near-syncope differently. Some people have no warning signs at all, particularly if the episode is caused by a sudden abnormal heart rhythm. Warning signs may occur seconds to minutes beforehand and can include:

- Lightheadedness or dizziness, feeling as though you might “black out”
- Blurred or tunnel vision
- Feeling unusually warm or sweaty
- Nausea
- Ringing in the ears
- Weakness
- Pale skin
- A racing or pounding heartbeat



What Causes Syncope?

Not all fainting episodes are related to the heart. Common causes include:

- **Cardiac Syncope:** This occurs when the heart cannot pump enough blood to the brain, often because of a dangerous arrhythmia. In people with PLN, cardiac syncope is taken seriously because it may indicate an increased risk of ventricular arrhythmias and sudden cardiac arrest.
- **Vasovagal Syncope:** The most common type of fainting in the general population, vasovagal syncope occurs when the vagus nerve triggers a sudden drop in heart rate and blood pressure. It may be brought on by *pain, emotional stress, dehydration, standing for long periods, or overheating*. While usually not life-threatening, it can sometimes be difficult to distinguish from cardiac causes.
- **Orthostatic Hypotension**: This occurs when blood pressure drops suddenly after standing up, causing dizziness or fainting. It may be related to dehydration, certain medications, prolonged bed rest, or nervous system disorders.

How Is Syncope Evaluated?

If you experience syncope or near-syncope, your healthcare provider may recommend tests to determine the cause, including: *ECG, Holter or patch monitor, Implantable loop recorder, Echo, Cardiac MRI, Exercise stress testing, blood work, and/or a Tilt Table Test.* Depending on the suspected cause, you may also be referred to a neurologist or an electrophysiologist (cardiologist who specializes in heart rhythm disorders).

What Should I Do If I Feel Like I'm Going to Faint?

If you begin to feel faint, sit or lie down immediately. If possible, raise your legs above the level of your heart. Stay hydrated if dehydration may be contributing. Avoid driving or operating machinery until you've been evaluated. Let your healthcare provider know about the episode, even if you recovered quickly.If you lose consciousness, experience chest pain, severe shortness of breath, or are injured during a fall, seek emergency medical care immediately. Recovery after an episode can take hours or days.

Recognizing Warning Signs

Living with PLN means learning to recognize changes in your body. Many symptoms develop gradually, making them easy to dismiss or attribute to stress, aging, or being "out of shape." However, paying attention to new or worsening symptoms can help your healthcare team identify problems early, often before they become more serious. While not every symptom is caused by PLN, it's always better to report changes than ignore them. You know your body best, if something doesn't feel right, trust your instincts. You don't need to have all the answers to know when something feels different. It is always better to ask questions early than to wait until symptoms become more severe. Keep a journal to track blood pressure and heart rate, what happened during the symptoms, and activities to identify trends or patterns.

Monitor at Home

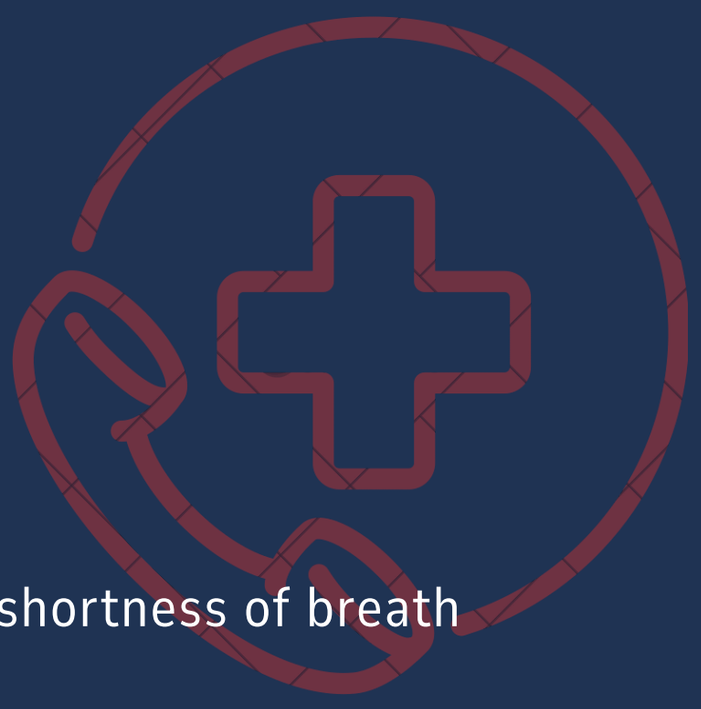
Keep track of symptoms and discuss them at your next appointment if they are mild and not worsening:

- Occasional palpitations that are brief and unchanged
- Mild fatigue after increased activity
- Stable exercise tolerance
- Mild swelling that improves with rest
- Gradual changes you've already discussed with your healthcare provider

Contact Your Cardiologist Soon

These symptoms do not always indicate an emergency but should be evaluated promptly. Call your healthcare team if you notice:

- More frequent or prolonged palpitations
- Increasing shortness of breath with everyday activities, especially when waking up
- New or worsening fatigue, especially during exercise or during daily activities
- Swelling in your feet, ankles, legs, or abdomen
- Rapid weight gain (2–3 pounds in one day or 5 pounds in one week)
- Dizziness or repeated episodes of near-fainting
- An ICD shock, even if you feel well afterward



Call 911 Immediately

Seek emergency medical care if you experience:

- Loss of consciousness (syncope)
- Chest pain that is severe, persistent, or accompanied by sweating or shortness of breath
- Severe difficulty breathing at rest
- Multiple ICD shocks or an ICD shock followed by ongoing symptoms
- Sudden weakness, facial drooping, difficulty speaking, or other signs of a stroke
- A racing heartbeat that does not stop and is accompanied by dizziness, chest pain, or fainting

Know Your Baseline

One of the best ways to recognize a problem is to know what is normal for you. Ask yourself:

- Can I do the same activities I could a month ago?
- Am I more tired or getting out of breath more easily than usual?
- Have my palpitations changed?
- Have I noticed new swelling?
- Has my weight increased suddenly?

Treatment Options

Medications

Although there is currently no cure for PLN, medications play an important role in protecting your heart. Depending on your symptoms, heart function, and risk of arrhythmias, your cardiologist may prescribe medications to help your heart pump more efficiently, reduce strain on the heart muscle, manage abnormal heart rhythms, decrease the risk of hospitalization, and improve long-term outcomes. Not every person with PLN will need medication immediately. Some individuals who have a positive genetic test but no evidence of heart disease may simply require regular monitoring. Others may benefit from starting medication early if changes in heart function or rhythm are detected. Your treatment plan is personalized and may change over time as your heart is monitored. Finding the right medication regimen may take time. If a medication causes side effects or doesn't seem to be working well for you, let your healthcare team know. Often, adjustments can be made to improve both your heart health and your quality of life.

Common Types of Heart Medications

Beta Blockers

Beta blockers help slow the heart rate and reduce the effects of adrenaline on the heart. This allows the heart to work more efficiently and may reduce the risk of certain abnormal heart rhythms. They are commonly prescribed to lower heart rate, reduce palpitations, improve heart function, help manage arrhythmias, and reduce the heart's workload. Common examples: Metoprolol, Carvedilol, Bisoprolol, Atenolol.

ACE Inhibitors & ARBs

These medications help relax blood vessels, making it easier for the heart to pump blood throughout the body. They may also help slow remodeling (changes in the heart muscle) that can occur with cardiomyopathy. They are commonly used to lower blood pressure, improve heart function, reduce progression of heart failure, and protect the heart over time. Common examples: Lisinopril, Enalapril, Losartan, Valsartan.

ARNIs (Angiotensin Receptor-Neprilysin Inhibitors)

ARNIs combine two medications into one and have become an important treatment for many people with heart failure and reduced EF. They help improve pumping efficiency, reduce hospitalization, improve survival, and reduce symptoms of heart failure. Common example: Sacubitril/Valsartan (Entresto).

Diuretics ("Water Pills")

Diuretics help your body remove excess salt and fluid through urination. They do not strengthen the heart itself, but they can significantly improve symptoms caused by fluid buildup. They are commonly used to relieve swelling in the legs or ankles, shortness of breath, fluid retention, and rapid weight gain. Common examples: Furosemide (Lasix), Torsemide, Bumetanide.

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Mineralocorticoid Receptor Antagonists (MRAs)

These medications help the body eliminate excess sodium while retaining potassium and may help reduce scarring within the heart. They may improve survival, reduce hospitalizations, and slow progression of heart failure. Common examples include: Spironolactone, Eplerenone.

SGLT2 Inhibitors

Originally developed to treat diabetes, these medications are now commonly used to treat heart failure, even in people without diabetes. They may reduce hospitalization, improve heart failure symptoms, protect kidney function, and improve quality of life. Common examples: Empagliflozin (Jardiance), Dapagliflozin (Farxiga).

Antiarrhythmic Medications

If you experience abnormal heart rhythms, your cardiologist may prescribe medications to help stabilize your heart's electrical activity. These medications may reduce episodes of arrhythmia, control heart rhythm, and/or reduce ICD shocks in some patients. Because these medications can have important side effects, they require close monitoring.

Can Lifestyle Replace Medication?

Healthy habits such as regular physical activity, a heart-healthy diet, maintaining a healthy weight, managing stress, and avoiding tobacco are all important. However, lifestyle changes should complement, not replace, your prescribed medications unless your healthcare provider advises otherwise.

Frequently Asked Questions

- Will I need medication for the rest of my life? **Not necessarily. Some medications are temporary, while others are intended for long-term use. Your treatment plan may change as your heart health changes.**

- What if I forget a dose? **Follow the instructions provided with your medication or contact your pharmacist or healthcare provider. Do not double your next dose unless specifically instructed**.

- Can I take over-the-counter medications? **Some cold medicines, decongestants, anti-inflammatory medications (NSAIDs), supplements, and herbal products can affect heart rhythm or interact with heart medications. Always check with your healthcare provider or pharmacist before starting anything new.**

- Can I drink alcohol while taking heart medications? **Alcohol may interact with certain medications and can worsen cardiomyopathy or heart failure. Talk with your cardiologist about what is safe for you.**

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Cardiac Devices

Pacemakers, ICDs, S-ICDs, EV-ICDs & Cardiac Resynchronization Therapy (CRT)

For some people living with PLN, medications alone may not be enough to manage the condition. If your heart beats too slowly, develops dangerous heart rhythms, or becomes weaker over time, your cardiologist may recommend an implantable cardiac device. These devices do not cure PLN, but they can help regulate your heartbeat, improve heart function, and, in some cases, save your life by treating life-threatening arrhythmias. Your healthcare team will recommend a device based on your individual heart rhythm, heart function, age, lifestyle, and overall health.

Pacemaker

A pacemaker is a small device implanted beneath the skin, usually below the collarbone. Thin insulated wires (called leads) connect the device to the heart.
A pacemaker continuously monitors your heartbeat. If your heart begins beating too slowly or pauses between beats, the pacemaker sends a small electrical impulse to restore a normal heart rate. Pacemakers do not treat dangerous fast heart rhythms such as ventricular tachycardia or ventricular fibrillation. A pacemaker may be recommended if you have:

- Symptomatic slow heart rate (bradycardia)
- Heart block
- Conduction disease
- Certain rhythm disorders

Implantable Cardioverter-Defibrillator (ICD)

An ICD is similar in size to a pacemaker but has additional lifesaving capabilities. Like a pacemaker, it continuously monitors your heart rhythm. If it detects a dangerous ventricular arrhythmia, the ICD can deliver painless pacing to interrupt certain fast rhythms and/or deliver a stronger electrical shock if needed to restore a normal rhythm. An ICD is designed to treat sustained ventricular tachycardia (VT) and ventricular fibrillation (VF). For many people with PLN who are at increased risk of sudden cardiac arrest, an ICD is one of the most effective treatments available.

Subcutaneous ICD (S-ICD)

A S-ICD provides protection against sudden cardiac arrest without placing leads inside the heart. Instead the device sits beneath the skin on the side of the chest. A single lead runs just beneath the skin along the breastbone. Because the leads never enter the heart or blood vessels, S-ICDs may reduce certain long-term complications associated with traditional ICD leads. However, S-ICDs cannot provide long-term pacing for slow heart rhythms or cardiac resynchronization therapy. They are often considered for younger patients who primarily need protection from dangerous ventricular arrhythmias.

Extravascular ICD (EV-ICD)

The EV-ICD is one of the newest advances in cardiac device technology. Like the S-ICD, the lead remains outside the heart and blood vessels, but unlike the S-ICD, it is positioned just beneath the breastbone. Because it combines some of the advantages of both traditional ICDs and S-ICDs, the EV-ICD may be an excellent option for certain patients. Your electrophysiologist can help determine whether it is appropriate for you. This unique location allows the EV-ICD to provide:

- Defibrillation for life-threatening arrhythmias
- Anti-tachycardia pacing (ATP) for some fast ventricular rhythms
- Temporary pacing after a shock if needed

Cardiac Resynchronization Therapy (CRT)

Sometimes heart failure causes the right and left sides of the heart to beat out of sync. A CRT device, sometimes called a ***biventricular pacemaker***, helps both ventricles contract at the same time, improving the heart's efficiency. CRT may improve symptoms of heart failure, increase exercise tolerance, improve quality of life, improve EF, and reduce hospitalizations. Some CRT devices also include a defibrillator and are called **CRT-D.**



RECEIVING A CARDIAC DEVICE CAN FEEL INTIMIDATING, BUT MANY PEOPLE DESCRIBE IT AS PROVIDING PEACE OF MIND. THESE DEVICES ARE DESIGNED TO PROTECT YOU, OFTEN QUIETLY WORKING IN THE BACKGROUND SO YOU CAN FOCUS ON LIVING YOUR LIFE RATHER THAN WORRYING ABOUT YOUR HEART.

How Is a Cardiac Device Implanted?

Most cardiac devices are implanted during a minimally invasive procedure performed by an electrophysiologist (EP). The procedure usually takes 1–3 hours and is performed under local anesthesia with sedation or, in some cases, general anesthesia. Most people return home the same day or after one overnight hospital stay. Following implantation, you'll receive a device identification card to carry with you at all times.

Living with a Cardiac Device

Most people return to their normal daily activities after recovering from implantation. You'll have regular follow-up visits so your healthcare team can check battery life, review recorded heart rhythms, adjust device settings if needed and ensure the device is functioning properly. Many devices can also be monitored remotely from home using a wireless transmitter or smartphone application.

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Frequently Asked Questions

- Will I feel the device working? **Most of the time, no. Pacemaker pacing is usually not noticeable. If an ICD delivers a shock, many people describe it as a sudden kick or thump to the chest. Although it can be startling, the shock is intended to restore a life-threatening rhythm.**

- Can I have an MRI? **Many modern pacemakers and ICDs are MRI-conditional, meaning MRI scans can be performed safely under specific conditions. Always tell your healthcare team and MRI staff that you have an implanted device.**

- Can I travel? **Yes. Airport security systems are generally safe, although your device may trigger metal detectors. Carry your device identification card whenever you travel.**

- Will my battery need to be replaced? **Yes. Most batteries last 7–15 years, depending on the type of device and how often it is used. Replacing the battery usually involves replacing the generator while leaving the leads in place if they are functioning well.**

- Can I use a cell phone or household electronics? Y**es. Most everyday electronics, including microwaves, televisions, computers, smartphones, and household appliances, are safe to use. Strong magnets should be kept several inches away from your device. Some devices have an alarm or vibration that will start if a strong magnet is too close to the device. Always ask your healthcare provider if you have questions about a specific device or occupation.**

- Which Device Is Right for Me? **There is no "best" device for everyone. Your EP considers many factors, including your diagnosis, heart function (EF), risk of ventricular arrhythmias, need for pacing, age, lifestyle, and/ or previous heart rhythm history. The goal is to choose the device that provides the greatest protection while meeting your individual needs.**



Advanced Heart Failure Therapies: LVADs & Heart Transplantation

Hearing terms like LVAD or heart transplant can feel overwhelming. These therapies are reserved for individuals with advanced heart failure, when the heart can no longer pump enough blood to meet the body's needs despite medications, lifestyle changes, and other treatments. If your cardiologist ever discusses these options with you, it does not mean there are no more choices, it means your healthcare team is exploring additional ways to help you live longer and feel better. Advances in mechanical heart support and transplantation have dramatically improved both survival and quality of life.

Left Ventricular Assist Device (LVAD)

An LVAD is a mechanical pump that helps the left ventricle, the heart's main pumping chamber, circulate blood throughout the body. Unlike a heart transplant, an LVAD does not replace your heart. Instead, it works alongside your own heart, taking over much of the pumping work when the heart has become too weak. Because the controller and batteries remain outside the body, individuals with an LVAD carry them in a shoulder bag, belt, or vest. The device includes:

- A pump implanted inside the chest
- A driveline (a cable that exits through the abdomen)
- An external controller (a small computer)
- Rechargeable batteries

Who May Need an LVAD?

An LVAD may be recommended for people with advanced heart failure who continue to have severe symptoms despite receiving the best available medical treatment. Your healthcare team will determine whether an LVAD is appropriate based on your overall health and heart function. An LVAD may be used as:

- **Bridge to Transplant**: Supports the heart while waiting for a donor heart.
- **Destination Therapy:** Long-term treatment for individuals who are not transplant candidates.
- **Bridge to Recovery**: In rare situations, temporarily supports the heart while it heals.

Living with an LVAD

Although adjusting to an LVAD takes time, many people return to activities they previously couldn't do because of severe heart failure. Living with an LVAD involves daily driveline care to prevent infection, carrying backup batteries and equipment, regular clinic visits, taking blood-thinning medications, and learning how to respond to device alarms. Many people return to traveling, spending time with family, exercising within their physician's recommendations, and enjoying hobbies after recovering from surgery.

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Heart Transplantation

A heart transplant is a surgical procedure in which a diseased heart is replaced with a healthy donor heart. For carefully selected patients, heart transplantation offers the opportunity for a longer, healthier, and more active life. Heart transplantation is considered when:

- Heart failure is advanced.
- Symptoms remain severe despite all available treatments.
- The heart can no longer meet the body's needs.

The Evaluation Process

Before being placed on the transplant waiting list, patients undergo a comprehensive evaluation by a multidisciplinary transplant team. The goal is to ensure that transplantation is both medically appropriate and that patients have the support needed for lifelong care after surgery. This evaluation may include *cardiac imaging, blood tests, lung function testing, dental evaluation, cancer screening, psychological evaluation, social work assessment, nutritional assessment, and financial counseling.*

Life After a Heart Transplant

Receiving a new heart is a cure from PLN, but it is the beginning of another lifelong journey.After transplantation, patients take immunosuppressant (anti-rejection) medications every day to prevent the immune system from attacking the donor heart. Regular follow-up appointments are essential and may include blood work, echos, heart biopsies (especially during the first year), medication adjustments, and infection monitoring. Many transplant recipients return to work, travel, exercise, raise families, and enjoy an excellent quality of life.

Frequently Asked Questions

- Will everyone with PLN eventually need an LVAD or heart transplant? **No. Some carriers never require advanced heart failure therapies. Many individuals remain stable for years with routine monitoring, medications, and, when appropriate, cardiac devices.**
- Can someone with an LVAD live a normal life? **While living with an LVAD requires daily care and lifestyle adjustments, many people experience significant improvement in their symptoms and quality of life.**
- How long can someone live after a heart transplant? **Many transplant recipients live 10–20 years or longer, with some living well beyond 20 years while remaining active and enjoying a high quality of life.**
- Can PLN return after a heart transplant? Because the donor heart does not carry the PLN mutation, the transplanted heart is not affected. However, transplant recipients still require lifelong follow-up to monitor for rejection, infection, and other transplant-related complications.

Hope for the Future

Advances in heart failure care continue to improve outcomes every year. New medications, improved LVAD technology, better transplant survival, and exciting research into gene therapy and targeted treatments for PLN are changing what is possible for patients living with inherited cardiomyopathies. If advanced therapies ever become part of your journey, you will be cared for by a team of specialists dedicated to supporting you every step of the way.

Emergency Preparedness

Living with PLN does not mean you should expect an emergency, but it does mean it's important to be prepared. Knowing what symptoms require immediate medical attention, understanding how to respond during an emergency, and making sure those around you know what to do can provide peace of mind and improve outcomes if an emergency ever occurs. Preparation isn't about living in fear, it's about feeling confident that you and your loved ones know what steps to take if they're ever needed.

When Should You Call 911?

Call 911 immediately if you or someone else experiences:

- Loss of consciousness (syncope) that is unexplained or prolonged
- Chest pain that is severe, persistent, or accompanied by sweating, nausea, or shortness of breath
- Severe difficulty breathing or inability to catch your breath
- Multiple ICD shocks or an ICD shock followed by ongoing symptoms
- A racing heartbeat accompanied by dizziness, fainting, or chest pain
- Symptoms of sudden cardiac arrest (collapse, no pulse, not breathing normally)
- Signs of a stroke, including sudden facial drooping, arm weakness, difficulty speaking, or confusion

Do not attempt to drive yourself to the hospital during a medical emergency. Emergency Medical Services (EMS) can begin lifesaving treatment on the way to the hospital.

CPR:

Every Minute Matters

If someone with PLN collapses, is unresponsive, and is not breathing normally, begin hands-only CPR immediately while someone else calls 911 and retrieves an AED. If you are trained in full CPR, follow your certification guidelines.
Consider taking a CPR certification course. Knowing these skills may one day save the life of a loved one, or even a stranger.

Hands-only CPR involves:

- **Call 911 immediately.**
- **Place your hands in the center of the chest.**
- **Push hard and fast at a rate of 100–120 compressions per minute (about the beat of Stayin' Alive by the Bee Gees).**
- **Continue until emergency responders arrive or the person begins breathing.**

Automated External Defibrillators (AEDs)

An AED is a portable device that can analyze the heart's rhythm and deliver a shock if a life-threatening rhythm such as VF or pulseless ventricular tachycardia (VT) is detected. AEDs are designed for use by both medical professionals and the general public. The device provides step-by-step voice instructions and will only deliver a shock if one is needed. If someone collapses, send someone to retrieve the nearest AED while CPR is started.

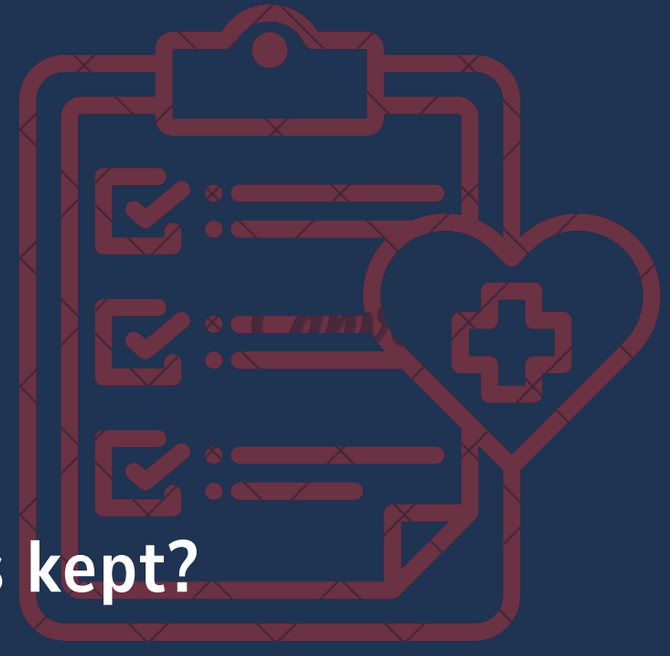
Using an AED If Someone Has an ICD

One of the most common questions people ask is whether it's safe to use an AED on someone who already has an ICD. The answer is yes. If a person with an ICD becomes unresponsive, is not breathing normally, and you suspect sudden cardiac arrest, ***call 911 immediately, begin CPR, and use an AED as soon as one is available***. Do not delay treatment because you're worried about the ICD. If the ICD has already restored a normal rhythm, the AED will recognize this and will not deliver a shock. If a shock is still needed, the AED will instruct you to deliver one. When placing the AED pads, avoid positioning them directly over the ICD, which is usually visible as a small bump beneath the skin below the collarbone. **Place the pad at least 1 inch (2.5 cm) away from the device.** Remember, an AED is designed to analyze the heart's rhythm and will only deliver a shock if it is appropriate. In an emergency, using an AED promptly, along with CPR, provides the best chance of survival, even for someone who already has an implanted cardiac device.

Create an Emergency Plan

Talk with your family, friends, coworkers, and caregivers about what to do in an emergency. Having a plan in place can reduce panic and help everyone respond more quickly. Emergencies are uncommon, but preparation saves lives. Taking a few simple steps today, learning CPR, knowing when to call 911, carrying medical identification, and having an emergency plan, can make all the difference if the unexpected ever happens. Consider discussing:

1. **Who should call 911?**
2. **Where is the nearest AED?**
3. **Who knows CPR?**
4. **Which hospital should you be taken to?**
5. **Who should be notified if you're hospitalized?**
6. **Where are your medications and medical records kept?**



Medical Identification

Consider wearing a medical ID bracelet or necklace or using the Medical ID feature on your smartphone. This information can help emergency responders provide faster, more appropriate care if you're unable to speak for yourself. Include information such as:

- **PLN cardiomyopathy**
- **ICD, pacemaker, or other implanted device (if applicable)**
- **Significant allergies**
- **Current medications**
- **Emergency contact information**



Know Your Local Resources

Before an emergency happens identify the nearest hospital with cardiology and emergency cardiac services. If possible, know which hospitals in your area have electrophysiologists, heart failure specialists, or transplant programs, particularly if you have advanced heart disease. Keep important phone numbers easily accessible, including your cardiologist, electrophysiologist, pharmacy, and emergency contacts. Planning ahead can save valuable time during an emergency.

Chapter 3 Summary

Understanding how PLN affects the heart is an important part of taking control of your health. While PLN can increase the risk of arrhythmias, cardiomyopathy, heart failure, and, in some cases, advanced heart disease, every person's journey is unique. Learning to recognize symptoms, understanding available treatments, and knowing when to seek medical attention can help you and your healthcare team detect changes early and provide the most effective care. Although these topics may seem overwhelming, today's medications, implantable devices, advanced therapies, and ongoing research have significantly improved outcomes and continue to provide hope for the future.

Key Takeaways

- PLN can affect both the heart's electrical system and heart muscle, increasing the risk of arrhythmias and cardiomyopathy.
- Not every carrier develops heart disease, and the severity and progression vary from person to person.
- Learn to recognize symptoms such as palpitations, dizziness, fainting, shortness of breath, swelling, fatigue, and decreased exercise tolerance, and report new or worsening symptoms promptly.
- Medications and implantable cardiac devices can effectively manage symptoms, improve heart function, and reduce the risk of serious complications.
- Advanced therapies, including LVADs and heart transplantation, are available for individuals with advanced heart failure, but most people with PLN will never require these treatments.
- Knowing when to call your healthcare provider, when to call 911, how to perform CPR, and how to use an AED can make a lifesaving difference.
- Regular follow-up and routine monitoring remain the best tools for detecting changes early and protecting your heart.

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Chapter 4: Living with PLN

A PLN diagnosis is only one part of your story, it does not define who you are or what your future holds. While living with an inherited heart condition may bring new challenges, it also offers an opportunity to become more intentional about your health, build meaningful relationships with your healthcare team, and prioritize the people and experiences that matter most. Living well with PLN isn't about putting your life on hold. It's about learning how to adapt, making informed choices, and finding confidence in what you can control. Many people with PLN continue to work, travel, exercise, raise families, pursue their passions, and live full, meaningful lives. Your journey may look different than someone else's, and that's okay. This chapter focuses on the day-to-day aspects of living with PLN. You'll learn about heart-healthy nutrition, staying physically active, pregnancy and family planning, mental and emotional well-being, caregiver support, and practical tips for navigating work, travel, and everyday life. You'll also discover that taking care of your heart means caring for your whole self, not just your diagnosis. Above all, remember that you are not alone. A growing community of patients, families, healthcare professionals, and researchers is walking this journey with you. Together, we continue to build hope for today and work toward a cure for tomorrow.

PLN may shape part of your journey, but it does not define your destination.

Living Well with PLN

A PLN diagnosis is only one part of your life, it does not define who you are or what you are capable of achieving. While living with an inherited heart condition may require adjustments, many people with PLN continue to work, travel, exercise, raise families, pursue careers, and enjoy meaningful relationships. The key is learning to listen to your body, work closely with your healthcare team, and make choices that support your long-term heart health. Rather than focusing on what PLN may take away, focus on what you can control. Small, consistent habits often have the greatest impact over time. Every person's journey is different, so it's important to build a lifestyle that works for your individual health, goals, and stage of life.

Daily Life

Living with PLN often means becoming more aware of your body and your symptoms. Some days you may feel completely normal, while other days you may need to slow down and rest. Learning your personal limits isn't a sign of weakness, it's an important part of protecting your heart. Continue attending routine medical appointments, take medications as prescribed, monitor your symptoms, and communicate openly with your healthcare team if something changes.

Exercise

Regular physical activity has many benefits, including improving energy, maintaining muscle strength, supporting mental health, and promoting overall cardiovascular wellness. However, exercise recommendations should always be individualized. Talk with your cardiologist about which activities are safe for you, whether there are heart rate limits you should follow, signs that you should stop exercising, and returning to sports or higher-intensity activities. The goal isn't to avoid activity, it's to exercise safely.

Work & School

Many individuals with PLN continue working or attending school without major limitations. Depending on your symptoms or occupation, some accommodations may be helpful. Don't hesitate to discuss flexible scheduling, time for medical appointments, temporary work modifications during recovery, and reasonable workplace accommodations if needed. If your job involves heavy physical labor or safety-sensitive work, talk with your healthcare provider about any necessary restrictions.

Travel

A PLN diagnosis does not mean you have to stop exploring the world.

Before traveling:

- Bring enough medications for your entire trip, plus a few extra days.
- Carry your medications in your carry-on luggage.
- Pack your ICD or pacemaker identification card (if applicable)
- Research nearby hospitals, especially if traveling
- Stay hydrated and take breaks to walk during long trips.

If you've recently had surgery, experienced an ICD shock, or have worsening heart failure symptoms, ask your cardiologist whether it's safe to travel.

Finding Balance

Living well with PLN means finding a healthy balance between staying informed and continuing to enjoy life. It's normal to think about your heart, but it's equally important to make time for the people, hobbies, and experiences that bring you joy. Celebrate milestones, make memories, pursue your passions, and allow yourself to live beyond your diagnosis. PLN may influence your journey, but it doesn't have to define your future.



Relationships

A PLN diagnosis does not mean you should put your life, or your heart, on hold. It's natural to wonder how someone else might react to your diagnosis, but don't let fear keep you from pursuing meaningful relationships. You are still the same person with the same personality, goals, values, and capacity to love. The right relationship is built on honesty, trust, mutual respect, and facing life's challenges together. Your diagnosis is one part of your story, it is not your entire story. Allow yourself to meet new people, dream about your future, and remain open to the possibilities that life has to offer.

Living with a chronic condition can bring new challenges to a relationship, but it can also strengthen communication and deepen your partnership. Open conversations about your diagnosis, symptoms, and needs help your partner better understand what you're experiencing, even on days when you look perfectly healthy. Share your diagnosis when you feel ready, involve your partner in appointments if you'd like, and don't be afraid to ask for help when you need it. Accepting support is not a sign of weakness, it's part of building a strong team. Remember, relationships thrive when both people support one another through life's highs and lows.

Pregnancy and Family Planning

Thinking about starting or growing your family after a PLN diagnosis can bring up many emotions. You may find yourself asking questions you've never had to think about before: "Can I safely become pregnant?", "Will I pass this on to my children?", "Should I even have children?", and/or "What options do I have?". There are no easy answers, and there is no one-size-fits-all path. The good news is that you have choices, and you don't have to make these decisions alone. Your cardiologist, genetic counselor, maternal-fetal medicine specialist, and reproductive endocrinologist can work together to help you understand your individual risks and options. **There is currently no research suggesting that pregnancy exacerbates or triggers PLN symptoms.**

Pregnancy Considerations

Pregnancy places significant demands on the heart. During pregnancy, your blood volume increases by approximately 40–50%, your heart beats faster, and your heart works harder to supply oxygen and nutrients to both you and your growing baby. For many women with PLN who have normal heart function, pregnancy may be possible with careful planning and close monitoring. However, for women with advanced cardiomyopathy, heart failure, significant arrhythmias, or reduced heart function, pregnancy can increase the risk of serious complications for both mother and baby. If you are considering pregnancy, talk with your cardiologist before becoming pregnant, even if you feel well. Pre-pregnancy planning allows your healthcare team to evaluate your heart, adjust medications if needed, see options covered by insurance, and discuss the safest approach for you. Some people choose to conceive naturally, while others prefer to reduce the chance of passing on the mutation. Options may include:

- Natural conception
- IVF with preimplantation genetic testing (PGT-M) to identify embryos that do not carry the PLN mutation
- Donor egg / donor sperm or adoption
- Choosing not to have children

There is no "right" or "wrong" choice. The best decision is the one that aligns with your health, your values, and your family's goals. None of these decisions make you a better or worse parent, partner, or person.
The goal isn't to make the "perfect" choice, it's to make an informed choice that feels right for you.

Nutrition & Lifestyle

There is no single diet or lifestyle plan that is right for everyone living with PLN, but healthy daily habits can reduce strain on your heart, improve your overall well-being, and help you recognize changes early. Nutrition and lifestyle choices work alongside your medications and medical care, they don't replace them. Always discuss significant dietary changes, supplements, or exercise plans with your healthcare team, as recommendations may vary depending on your heart function, medications, and symptoms.

Heart-Healthy Eating

A balanced diet provides your body with the nutrients it needs to support heart health and maintain energy. Focus on eating a variety of fruits and vegetables, whole grains, lean proteins (poultry, fish, beans, and legumes), and healthy fats (olive oil, avocados, nuts, and seeds). Limiting highly processed foods, added sugars, and foods high in saturated fat can also support overall cardiovascular health.

Sodium (Salt)

Too much sodium causes your body to retain extra fluid, making your heart work harder. This can contribute to swelling, shortness of breath, and worsening heart failure symptoms in some people. Many processed, packaged, canned, frozen, and restaurant foods contain surprisingly high amounts of sodium. Reading nutrition labels and preparing meals at home more often can help reduce your sodium intake. Your cardiologist may recommend a specific daily sodium limit based on your individual condition.

Hydration

Staying hydrated is important for everyone, but finding the right balance is especially important when living with PLN. Dehydration can contribute to dizziness, low blood pressure, and fainting, while drinking too much fluid may worsen swelling or heart failure symptoms in some individuals. Not everyone with PLN requires a fluid restriction. Your healthcare provider will recommend an amount that is appropriate for your heart function and medications.

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Caffeine

Many people with PLN can still enjoy caffeine in moderation. Current research suggests that moderate coffee consumption is generally safe for most people with stable heart disease, and for many individuals, it does not increase the risk of abnormal heart rhythms. However, everyone responds differently. If you notice that caffeine triggers palpitations, racing heartbeats, or other symptoms, discuss this with your healthcare provider. Energy drinks and highly caffeinated supplements should generally be avoided, as they contain much higher amounts of caffeine and other stimulants.



Alcohol

Alcohol can weaken the heart muscle and may worsen cardiomyopathy or heart failure over time. It can also interact with certain medications and increase the risk of some abnormal heart rhythms. For individuals with PLN, many cardiologists recommend avoiding or significantly limiting alcohol, particularly if cardiomyopathy or heart failure is present. Speak with your healthcare provider about what is safest for your individual situation.



Vitamins & Supplements

"Natural" does not always mean "safe." Some vitamins, herbal products, and dietary supplements can interfere with heart medications or affect your heart rhythm. Always tell your healthcare team about any vitamins, herbal remedies, or over-the-counter supplements you take before starting something new.



Daily Weight Monitoring

One of the simplest ways to monitor your heart health is by weighing yourself every morning. Weigh yourself at the same time each day, after using the restroom, before eating breakfast, and/or wearing similar clothing (or no clothing). A sudden weight gain may be one of the earliest signs of fluid retention. Contact your healthcare provider if you gain:
2–3 pounds (1–1.5 kg) in one day, or5 pounds (2–2.5 kg) in one week.
Keeping a daily log of your weight can help identify trends before symptoms become more noticeable.



Mental Health & Emotional Well-Being

A PLN diagnosis affects more than just your heart, it can also affect your emotions and outlook on the future. It's completely normal to experience a wide range of feelings, especially after diagnosis or during periods of changing health. You may feel overwhelmed one day, hopeful the next, or both at the same time. It changes more than your medical record, it can change the way you think about your future, your body, and even ordinary moments. Many people describe living with PLN as carrying an invisible weight that no one else can see. You may look healthy on the outside while privately wondering whether every new symptom means something serious. These thoughts are common. They don't mean you're weak, and they don't mean you're handling your diagnosis poorly. They mean you're human. Taking care of your mental health is not separate from taking care of your heart. Emotional well-being plays an important role in your overall quality of life, and seeking support is a sign of strength, not weakness.

Anxiety: "Is This Normal...or Is Something Wrong?"

Living with PLN often means becoming much more aware of your body. A skipped heartbeat, a moment of dizziness, or feeling more tired than usual can quickly lead to questions like "Was that just a normal palpitation?", "Should I call my cardiologist?", "Am I overreacting?", or "Is today the day something changes?" After experiencing symptoms or learning you carry a genetic mutation, it's natural for your brain to become more alert to every sensation. This is your mind trying to protect you, not trying to scare you. The challenge is learning the difference between being aware of your body and being consumed by it.

One of the hardest parts of PLN is that there isn't a timeline. You may wonder "Will I stay healthy for decades?", "Will I eventually need an ICD?" "Will I ever develop heart failure?", "Am I making plans for a future that might change?". The truth is, no one can answer these questions, not even your cardiologist. Uncertainty is uncomfortable because our brains naturally want certainty. But rather than asking, "What if something bad happens?" try asking: What if everything is okay today?, What if my next appointment is reassuring?, What if medical research continues to improve?, and What if I'm stronger than I think I am?. Your diagnosis deserves your attention. but it doesn't deserve every moment of your life.

Grief & Depression

Many people grieve after a PLN diagnosis. You may grieve the version of your future you imagined, feeling carefree, trusting your body without thinking about it, watching family members face the same diagnosis, and/or the loss of someone you love. Grief doesn't always look like crying. Sometimes it looks like exhaustion. Sometimes it looks like anger. Sometimes it looks like feeling emotionally numb. Healing doesn't mean pretending those feelings don't exist. It means allowing yourself to experience them while continuing to move forward. If sadness begins affecting your sleep, relationships, motivation, or daily life for more than a couple of weeks, reach out to your healthcare provider, email us, or a mental health professional. Asking for help is one of the strongest things you can do. Many of our members are carriers and can share personal experiences or relate to what thoughts are coming up. We are here for you and you are not alone. You are enough and worthy. PLN doesn’t define you.

Building Resilience

Resilience isn't waking up every day feeling positive. Resilience is going to your appointment even though you're nervous. It's taking your medications when you're tired of thinking about your heart. It's putting your walking shoes on after a difficult week. It's making future plans anyway. It's laughing with friends between doctor's appointments. It's choosing to keep living while acknowledging that life isn't guaranteed for any of us. Resilience isn't the absence of fear. It's deciding that fear doesn't get to make your decisions. One day, you'll realize there was a moment when PLN stopped being the first thing you thought about every morning. Not because it disappeared, but because you learned to carry it without letting it carry you. The goal isn't to live a life without uncertainty, it's to build a life so full of purpose, connection, and hope that uncertainty no longer gets the final word.

You Are More Than PLN

You are not simply a patient. You are someone's child, parent, sibling, spouse, partner, coworker, teammate, or best friend. You have talents, dreams, favorite songs, vacations you still want to take, people you still want to meet, and memories you haven't made yet. PLN is part of your life, but it is not your identity. Don't wait to celebrate birthdays, take the trip, apply for the job, fall in love, laugh too hard with friends, or chase the things that make you feel alive. Research continues to move forward. Treatments continue to improve. Hope continues to grow. Live your life while science keeps working.

Chapter 4 Summary

Living with PLN is about much more than managing a heart condition, it's about continuing to build a meaningful life while caring for your health. Although a PLN diagnosis may change some aspects of your future, it does not define who you are or what you can achieve. By making heart-healthy lifestyle choices, caring for your mental well-being, planning for the future, and leaning on your support system, you can continue to pursue your goals with confidence. Every person's journey with PLN is different, but no one has to navigate it alone. With knowledge, preparation, and hope, it is possible to live well, not despite PLN, but alongside it.

Key Takeaways

- PLN is one part of your life, it is not your identity. Continue pursuing your passions, relationships, career, and dreams.
- Healthy daily habits matter. A balanced diet, regular physical activity, taking medications as prescribed, and attending routine appointments all support long-term heart health.
- Listen to your body. Learn your normal, recognize changes early, and communicate concerns with your healthcare team.
- Your mental health deserves the same attention as your physical health. Feelings of anxiety, grief, or uncertainty are common, and seeking support is a sign of strength.
- Don't let fear make tomorrow's decisions today. Focus on what you can control while continuing to live fully in the present.
- Relationships, marriage, and parenthood are still possible. Open communication, thoughtful planning, and guidance from your healthcare team can help you make informed decisions about your future.
- Family planning is personal. Whether you choose natural conception, IVF with PGT-M, adoption, or another path, there is no single "right" choice only the one that is right for you.
- Stay connected. Family, friends, your healthcare team, and the PLN community can provide encouragement, understanding, and support throughout your journey.
- Research continues to move forward. Every year brings new discoveries, improved treatments, and growing hope for the future.

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LIVING WELL WITH PLN DOESN'T MEAN PRETENDING THE DIAGNOSIS DOESN'T EXIST. IT MEANS REFUSING TO LET IT BECOME THE CENTER OF YOUR STORY. SOME DAYS WILL BE HARDER THAN OTHERS, AND THAT'S OKAY. CONTINUE MAKING PLANS, CELEBRATING MILESTONES, BUILDING RELATIONSHIPS, AND CHASING THE LIFE YOU WANT. YOUR HEART MAY REQUIRE A LITTLE MORE ATTENTION, BUT IT IS STILL CAPABLE OF CARRYING YOU TOWARD A FUTURE FILLED WITH PURPOSE, JOY, AND HOPE.

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CHAPTER 5: FAMILY CONVERSATIONS

One of the first questions many people ask after a PLN diagnosis isn't about themselves, it's about the people they love; "Do my children have this?", "How do I tell my siblings?", "What if my parents don't want to know?", "How do I explain this to my partner?", "How can my family help?". Because PLN is an inherited condition, a diagnosis often affects an entire family, not just one individual. Sharing genetic information can feel overwhelming, and every family responds differently. Some relatives may want to be tested immediately, while others may need more time to process the information.

There is no perfect way to begin these conversations, but having them can give the people you love the opportunity to seek screening, understand their own health, and make informed decisions for the future. This chapter is also for the people walking beside you. Caregivers, partners, parents, siblings, children, and close friends often experience their own fears and uncertainties while supporting someone they love. Their well-being matters too. A strong support system is built not only through information, but through open communication, compassion, and understanding.

Remember, asking for help is not a sign of weakness. None of us were meant to navigate life's biggest challenges alone. Whether you're sharing your diagnosis for the first time, encouraging family members to pursue genetic testing, or learning how to support someone with PLN, every conversation has the potential to create greater understanding, and, in some cases, save a life. One conversation can change a family's future. Sharing your diagnosis isn't about creating fear, it's about creating opportunity: *the opportunity for early detection, informed decisions, and hope*. PLN may be inherited, but so is strength. Every conversation you have, every question you answer, and every family member who chooses to be screened creates an opportunity for earlier diagnosis, better care, and a healthier future for the generations that follow.

Family Conversations

One of the most difficult parts of receiving a PLN diagnosis isn't understanding what it means for you, it's figuring out how to tell the people you love. You may wonder "How do I tell my parents?", "What if my siblings don't want to know?", "How do I explain this to my children?", "What if I scare everyone?". These conversations can feel intimidating, but they are also incredibly important. Sharing your diagnosis gives your biological relatives the opportunity to learn about their own health, pursue genetic testing if appropriate, and begin cardiac screening before symptoms ever develop. While you can't control how others respond, you can provide them with information that could one day save their life. Remember that you don't have to explain everything in one conversation. Start where you feel comfortable, provide reliable resources, and allow your loved ones time to process the information.

Sharing Your Diagnosis

There is no perfect script or perfect time to tell someone you have PLN. Some people prefer to have an in-person conversation, while others feel more comfortable writing a letter, sending an email, or sharing educational resources from the PLN NA Foundation. Choose the approach that feels right for you. When talking with family members, try to focus on facts rather than fear. You might say: *"I recently learned that I have a genetic heart condition called PLN R14del Cardiomyopathy. Because it's inherited, my doctors recommend that close biological relatives consider talking with their healthcare provider or a genetic counselor about testing. I wanted to share this with you because I care about you and wanted you to have the opportunity to learn more."* Remember, sharing your diagnosis is an act of care, not a burden.

Talking with Children

Children often understand more than we realize, but they don't need every detail all at once. Use language that matches their age and maturity. Younger children may simply need reassurance that they are safe and that doctors are helping care for you. Older children and teenagers may have more questions about genetics, testing, and what PLN means for them. Encourage questions, answer honestly, and let them know it's okay if they don't understand everything immediately. If your child is old enough to benefit from cardiac screening or genetic counseling, your healthcare team can help guide those conversations in an age-appropriate way.
Most importantly, children look to the adults around them for reassurance. They don't need perfect answers, they need to know they are loved, supported, and not facing uncertainty alone.

Supporting Loved Ones

A PLN diagnosis often affects an entire family. Your loved ones may experience fear, sadness, guilt, confusion, or even denial after learning about the diagnosis. People process difficult news differently. Some will ask many questions. Some will immediately schedule testing. Some may need time before they're ready to talk. Try to meet people where they are. Listen without judgment, share reliable information, and remember that everyone copes differently. Encourage family members to seek information from trusted medical professionals, genetic counselors, and organizations like the PLN NA Foundation rather than relying solely on social media or internet searches.

Every Conversation Matters

Talking about a genetic condition can feel uncomfortable, but these conversations have the power to change lives. Because PLN can sometimes cause heart rhythm problems before symptoms appear, identifying at-risk family members early allows them to receive cardiac screening, ongoing monitoring, and treatment if needed. You don't have to convince anyone to be tested, but by sharing your diagnosis, you've given them the opportunity to make an informed decision. Sharing your diagnosis isn't about delivering bad news, it's about giving the people you love knowledge they didn't have before. That knowledge may allow them to seek care earlier, protect their health, and make informed decisions for themselves and future generations. Sometimes the hardest conversations become the most meaningful gifts we can give.

Key Takeaways

- **There is no "perfect" way to tell your family about a PLN diagnosis.**
- **Share information with honesty, compassion, and reliable educational resources.**
- **Talk with children using age-appropriate language and answer questions honestly.**
- **Give loved ones time to process the information in their own way.**
- **Encourage biological relatives to speak with their healthcare provider or a genetic counselor about screening and genetic testing.**
- **One conversation may lead to early diagnosis, earlier treatment, and the opportunity to prevent serious complications.**

Family Screening and Genetic Testing

When someone is diagnosed with PLN cardiomyopathy, it creates an opportunity to help protect the health of their biological relatives. Because PLN is inherited in an autosomal dominant pattern, parents, siblings, and children each have a 50% chance of carrying the same genetic variant. Family screening allows relatives to learn whether they may also be at risk and, if needed, begin cardiac monitoring before symptoms develop. One person's diagnosis has the potential to identify an entire family of individuals who may benefit from earlier care. This process is known as cascade testing. We have resources for **FREE** genetic testing, please email us with any questions.

What Is Cascade Testing?

Cascade testing is the process of offering genetic testing to biological relatives after a disease-causing genetic variant has been identified in one family member. It typically begins with the first person diagnosed in the family (often called the proband), testing of first-degree relatives (parents, siblings, and children), and if another relative tests positive, testing is then offered to their first-degree relatives. This step-by-step approach helps identify who carries the PLN variant and who does not, allowing healthcare providers to focus screening and provide long-term monitoring.

Building Your Family Pedigree

One of the most helpful tools for your healthcare team is a family pedigree, also known as a family tree. As you begin gathering family history, try to include:

- Parents, grandparents, siblings, children, aunts, uncles, and cousins
- Ages (or age at death)
- Heart disease diagnoses and/or heart failure
- Pacemakers or ICDs
- Heart transplants
- Sudden cardiac arrest or unexplained sudden death
- Stroke
- Fainting episodes

You may be surprised by patterns that become apparent once your family's medical history is written down. Even information that seems unrelated can help your healthcare team better understand your family's risk. If you need help creating an extended pedigree, contact us to connect with our team geneaologist!

Helping Relatives Get Tested

Not everyone will respond to the news of a genetic diagnosis in the same way. Some relatives may want testing immediately. Others may need weeks, months, or even years before they feel ready. Some may choose not to be tested at all. While you can encourage and educate your family members, the decision to pursue genetic testing belongs to each individual. Your role is not to pressure them, it's to provide them with the opportunity to make an informed decision. Many people find it helpful to share a copy of their genetic test result (if comfortable), educational materials resources from the PLN NA Foundation, information about genetic counselors, and resources for free or reduced-cost genetic testing programs. Sometimes hearing the information directly from a healthcare professional or genetic counselor can make these conversations less overwhelming.

What If Someone Tests Positive?

Testing positive for a PLN variant does not mean someone currently has heart disease, nor does it predict exactly what will happen in the future. Instead, it allows them to establish care with a cardiologist familiar with inherited heart disease, begin routine cardiac screening, learn about symptoms to watch for, make informed lifestyle and family planning decisions, participate in research or clinical trials if interested. Knowledge allows for proactive care rather than reactive care.

What If Someone Tests Negative?

If a biological relative tests negative for the known disease-causing PLN variant identified in the family, they generally cannot pass that specific variant to their children and usually do not require ongoing cardiac screening related to that familial PLN mutation. Receiving a negative result often provides significant reassurance, although their healthcare provider may still recommend routine medical care based on other personal or family health factors.

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Caregiver Corner

A PLN diagnosis affects more than one person, it affects families, partners, friends, and loved ones too. If you're caring for someone with PLN, you may find yourself attending appointments, helping manage medications, watching for symptoms, or simply providing a listening ear after a difficult day. While you may not have the diagnosis yourself, you are an important part of the care team. Your support, encouragement, and presence can make a tremendous difference. At the same time, it's important to remember that you cannot pour from an empty cup. Caring for yourself is one of the best ways to care for someone else.

Supporting Someone with PLN

One of the greatest gifts you can offer isn't medical knowledge, it's understanding. Living with PLN often means living with uncertainty. Some days your loved one may feel completely normal, while on other days they may be exhausted, anxious, or frustrated by symptoms that aren't visible to others. Sometimes they may need practical help, such as a ride to an appointment or assistance after a procedure. Other times, they may simply need someone to listen without trying to fix the situation. Helpful ways to offer support include attend appointments if they're comfortable with it, learn about PLN together, encourage healthy habits without becoming the "health police.", respect their independence while offering help when needed, celebrate the good days, not just focus on the difficult ones, and be patient. Living with a chronic condition can be physically and emotionally exhausting. One of the most meaningful questions you can ask is "What would be most helpful for you today?" The answer may change from day to day.

Caring for Yourself

Caregivers often spend so much time caring for someone else that they forget about their own needs. It's common to experience worry about the future, emotional exhaustion, feeling overwhelmed, guilt for taking time for yourself, and/or difficulty balancing work, family, and caregiving responsibilities. These feelings are normal. Taking care of yourself is not selfish, it's essential. Make time to attend your own medical appointments, get enough sleep, exercise and eat well, spend time with friends and family, continue hobbies that bring you joy, and ask for help when you need it. You don't have to carry everything alone.

Caregiving isn't about having the perfect words or always knowing what to do. It's about showing up, again and again, with patience, compassion, and love. Some of the most meaningful support comes from simply sitting beside someone and reminding them they don't have to face this journey alone. Together, you are stronger than either of you could be on your own.

Recognizing Emergencies

Knowing when to seek emergency medical care can help you feel more confident if an unexpected situation arises. Call **911** immediately if your loved one:

- Becomes unresponsive or loses consciousness.
- Is not breathing normally.
- Has severe chest pain.
- Experiences severe difficulty breathing.
- Receives multiple ICD shocks.
- Shows signs of a stroke, such as facial drooping, arm weakness, or difficulty speaking.

If someone collapses and is unresponsive and not breathing normally:

1. Call **911** immediately.
2. Begin hands-only CPR.
3. Send someone to retrieve an AED if one is available.
4. Continue CPR until emergency responders arrive.

Remember, if your loved one has an ICD, it is still safe to use an AED if needed. The AED will analyze the heart rhythm and only deliver a shock if one is appropriate.

Remember the Person Beyond the Diagnosis

While PLN may become part of daily life, it shouldn't become the only thing you talk about. Keep making memories. Celebrate birthdays. Take vacations when possible. Laugh together. Talk about things besides doctor's appointments. Watch movies. Go out for dinner. Dream about the future. The person you love is still the same person they were before the diagnosis. They may need more medical appointments, more medications, or more support, but they are still the person you know and love.

Chapter 6: Taking Charge of Your Health

Living with PLN means becoming an active partner in your healthcare. While your cardiologist, genetic counselor, nurses, and other specialists provide expert medical guidance, you are the one person present at every appointment, every test, and every stage of your journey. The more informed and organized you are, the more confident you'll feel making decisions about your care.

Taking charge of your health doesn't mean you need to know all the answers. It means asking questions, staying informed, keeping track of your symptoms, and feeling comfortable speaking up when something doesn't seem right. It means recognizing that your voice matters, your experiences are valuable, and you are an essential member of your healthcare team.

This chapter is filled with practical tools designed to make managing your health easier. From preparing for appointments and tracking medications to monitoring symptoms and organizing your family medical history, these resources will help you stay organized and make the most of every interaction with your healthcare team.

Remember, no one understands your body better than you do. Learning to advocate for yourself isn't about challenging your doctors, it's about working with them to make informed decisions that support your health and your goals.

"The best healthcare happens when informed patients and compassionate healthcare teams work together."

Tracking Your Health

One of the most valuable things you can do as someone living with PLN is become familiar with your own normal. No one knows your body better than you do. Tracking your medications, vital signs, weight, and symptoms helps you recognize changes early and gives your healthcare team a clearer picture of how you're doing between appointments. Think of these pages as a conversation with your future self. A symptom that seems insignificant today may reveal a pattern over weeks or months. Likewise, seeing months of stable blood pressures, heart rates, or weights can provide reassurance that your treatment plan is working. You don't need to record everything perfectly every day. The goal isn't perfection, it's consistency.

Medication Tracker

Keeping an updated medication list is one of the simplest ways to stay organized and avoid confusion during appointments, hospital visits, or emergencies. Use your medication tracker to record medication name, dose, time taken, reason for taking it, prescribing physician, start date, and side effects or notes. Whenever a medication changes, update your tracker and bring it with you to every appointment. Don't forget to include vitamins, herbal supplements, over-the-counter medications, and as-needed (PRN) medications.

Blood Pressure Log

Blood pressure naturally changes throughout the day, so one isolated reading rarely tells the whole story. If your healthcare provider recommends monitoring your blood pressure measure it around the same time each day, sit quietly for 5 minutes before checking it or standing for 10 minutes, keep your feet flat on the floor, rest your wrist at heart level, and record the date, time, reading, and any symptoms. If you experience dizziness, lightheadedness, or near-fainting, recording your blood pressure during or shortly after symptoms may provide helpful information for your healthcare team.

Heart Rate Log

Monitoring your heart rate can help you recognize changes over time and understand how your body responds to activity, medications, and illness. You may choose to record resting heart rate, heart rate during exercise (if recommended), highest and lowest heart rate of the day, and symptoms such as palpitations, dizziness, or shortness of breath. If you wear a smartwatch or fitness tracker, remember that wearable devices are helpful tools but are not medical devices. Always discuss concerning readings or symptoms with your healthcare provider rather than relying solely on your watch

Weight Tracker

Daily weight monitoring is especially important if you have heart failure or have been advised to watch for fluid retention. Weigh yourself every morning, after using the restroom, before eating or drinking, and wearing similar clothing each time. Sometimes a change in weight is the earliest sign that your treatment plan needs adjustment, even before you notice swelling or shortness of breath. Contact your healthcare provider if you notice:

- *A gain of 2–3 pounds (1–1.5 kg) in one day*
- *A gain of 5 pounds (2–2.5 kg) in one week*

Symptom Journal

Your symptoms matter, even if they seem small. Keeping a symptom journal helps you identify patterns and provides valuable information during appointments. Consider recording date and time, what you were doing when symptoms began, symptoms experienced, how long they lasted, severity (1–10), heart rate or blood pressure, if available, what helped the symptoms improve, and whether you contacted your healthcare provider. Examples of symptoms to track include palpitations, dizziness, near-fainting or fainting, chest discomfort, shortness of breath, fatigue, swelling, exercise intolerance, and ICD shocks or alerts.

Bring Your Records to Appointments

Your logs become even more valuable when you share them with your healthcare team. Bringing your records to appointments can help your providers identify trends over time, evaluate whether medications are working, decide if additional testing is needed, and better understand symptoms that aren't happening during your visit. You don't have to remember every detail, your journal does it for you.

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Questions to Ask Your Healthcare Team

Medical appointments can sometimes feel overwhelming. It's common to leave an appointment only to remember a question you meant to ask or realize you didn't fully understand something that was discussed. Preparing ahead of time can help you get the most out of every visit and leave feeling more confident about your care. Remember, there are no "bad" questions. Your healthcare team wants you to understand your diagnosis, your treatment options, and why recommendations are being made. The more informed you are, the more confident you'll feel making decisions about your health.

Preparing for Your Appointment

Before your visit, take a few minutes to prepare. Bring an updated medication list, your symptom journal, blood pressure, heart rate, and weight logs (if applicable), your most recent test results (if seeing a new provider), your device identification card (ICD, pacemaker, etc.), insurance information, a notebook or notes app for questions, and a family member or friend if you'd like another set of ears. Write your questions down before your appointment, you'll be less likely to forget them.

Questions About Your Diagnosis

Consider asking What type of PLN-related heart disease do I currently have?, What does my genetic test result mean?, Is my heart functioning normally? What is my ejection fraction? Am I showing any signs of cardiomyopathy? What symptoms should I watch for? How often should I be monitored? and What changes would make you concerned?

Questions About Testing

Understanding why tests are ordered can make them feel less overwhelming. You may want to ask Why are you recommending this test?, What information will it provide?, How should I prepare?, Will I need to fast or stop any medications? When will I receive my results?, If my results are normal, what happens next?, and If my results are abnormal, what are the next steps?

If you're having a cardiac MRI, you might also ask What if I'm claustrophobic?, Are there open or wide-bore MRI scanners available?, Is sedation an option? Is my ICD or pacemaker MRI-compatible?, and Does my device need to be checked before and after the scan?

Questions About Treatment

Ask your healthcare provider Why are you recommending this medication?, What are the most common side effects?, Are there medications or supplements I should avoid?, What should I do if I miss a dose?, How will we know if it's working?, and Are there lifestyle changes that could help my condition?

If a cardiac device is discussed, consider asking Why do you think I need this device?, What are the benefits and risks?, Will it change my daily activities?, Will I be able to travel?, and How often will it need to be checked?

Questions About Family

Because PLN is inherited, family discussions are an important part of your care. Consider asking Which family members should consider testing?, Can you refer me to a genetic counselor?, Should my children be screened?, When is the best time for children to undergo genetic testing?, Are there testing programs available for my relatives?, and How can I explain this diagnosis to my family?

Questions About Everyday Life

Don't hesitate to ask practical questions, including Is it safe for me to exercise?, Are there activities I should avoid?, Can I travel?, Is it safe to become pregnant?, Can I drink caffeine?, Should I avoid alcohol?, Can I continue working?, Should I wear a medical ID bracelet?, What symptoms should prompt me to call your office?, and When should I go directly to the emergency room?

Understanding Recommendations

If something isn't clear, ask for clarification. It's okay to say "Can you explain that another way?", "What does that medical term mean?", "Can you draw a picture or show me?", "Can you write that down for me?", "What would you recommend if I were your family member?", and "Is there another option we should discuss?". Healthcare providers use medical language every day. Asking questions helps ensure everyone is making decisions based on the same understanding.

Shared Decision-Making

The best healthcare decisions happen when patients and providers work together. Your healthcare team brings medical expertise. You bring something equally important: your goals, your lifestyle, your values, your concerns, your experiences, and your priorities.

Sometimes there may be more than one reasonable treatment option. Shared decision-making means discussing the benefits, risks, and alternatives together so that your treatment plan reflects not only the best medical evidence but also what matters most to you. Never feel rushed into making a decision you don't fully understand. It's okay to ask for time to think, seek a second opinion, or discuss your options with your family.

Before You Leave the Appointment

Before walking out the door, make sure you know:

- □ What was discussed today?
- □ Were any medications changed?
- □ Do I need additional testing?
- □ When should I schedule my next appointment?
- □ What symptoms should I watch for?
- □ Who should I contact if I have questions after I leave?

You don't have to become a cardiologist to be your own best advocate. Simply asking questions, staying curious, and speaking up when you don't understand something can make a tremendous difference in your care. Your voice matters, your questions matter, and together with your healthcare team, you are working toward the same goal: helping you live the healthiest life possible with PLN.

Frequently Asked Questions

Whether you've just been diagnosed or have been living with PLN for years, it's normal to have questions. This section addresses many of the concerns patients and families commonly ask. Remember that every person's situation is unique, so always discuss questions about your own care with your healthcare team.

- **Can I live a normal life with PLN?** ***For many people, yes. A PLN diagnosis does not mean you have to put your life on hold. Many individuals continue working, traveling, exercising, raising families, and pursuing their goals. Your experience will depend on your heart health, symptoms, and treatment plan, which is why regular follow-up is so important.***

- ***Can PLN skip generations?*** ***It may appear to skip generations because some individuals never develop symptoms or remain undiagnosed. However, a person who carries the mutation still has a 50% chance of passing it on to each biological child.***

- **Will I definitely develop heart disease because I carry a PLN mutation?** ***No. Carrying a PLN mutation does not guarantee that you will develop cardiomyopathy or arrhythmias. PLN has variable penetrance and variable expression, meaning some people never develop significant heart disease, while others develop symptoms earlier in life. Regular monitoring helps detect changes as early as possible.***

- **Should my family members be tested?** ***Because PLN is inherited, first-degree relatives should discuss genetic counseling and testing with their healthcare provider. Early identification allows for appropriate cardiac screening and ongoing monitoring if needed. We have resources for FREE genetic testing, contact us for more information.***

- **How often will I need to see my cardiologist?** ***This depends on your age, symptoms, test results, and overall heart health. Some people are monitored yearly, while others require more frequent visits. Your cardiologist will recommend a schedule that's appropriate for you.***

- **Can I exercise?** ***In many cases, yes, but the type and intensity of exercise should be individualized. Your cardiologist can recommend safe activities based on your heart function and risk profile. Regular movement is generally encouraged, but competitive or high-intensity sports may not be appropriate for everyone.***

- *Can I travel? Yes. Most people with PLN can travel safely with appropriate planning. Bring enough medications, carry your medical information and device identification card (if applicable), and know where the nearest hospital is if you're traveling far from home.*
- *Can I drink coffee? For many people with stable heart disease, moderate caffeine intake is acceptable. If caffeine triggers palpitations or other symptoms, discuss this with your healthcare provider. Energy drinks and concentrated caffeine supplements should generally be avoided.*
- *Can I drink alcohol? Alcohol may worsen cardiomyopathy, heart failure, or certain arrhythmias. Your cardiologist may recommend limiting or avoiding alcohol depending on your heart function and medical history.*
- **Can I have children?** *Pregnancy should be discussed with both your cardiologist and an obstetrician experienced in high-risk pregnancies before conception. Because PLN is inherited in an autosomal dominant pattern, each child has a 50% chance of inheriting the mutation. Options such as IVF with preimplantation genetic testing (PGT-M) are available for families who wish to reduce the chance of passing on the mutation.*
- **Will I need an ICD?** *Not everyone with PLN requires an implantable cardioverter-defibrillator (ICD). Your healthcare team will evaluate your heart function, rhythm history, imaging, family history, and overall risk before making recommendations.*
- **Can I have an MRI if I have an ICD or pacemaker?** *Many newer devices are MRI-conditional, meaning MRI scans can be performed safely under specific conditions. Always tell your healthcare providers about your implanted device before scheduling an MRI.*
- **Should I wear a medical ID bracelet?** *Many healthcare providers recommend wearing a medical ID bracelet or using your smartphone's Medical ID feature, especially if you have an ICD, significant heart disease, or take medications that emergency responders should know about.*
- **Can I take vitamins or supplements?** *Always discuss supplements with your healthcare provider before starting them. Some herbal products and over-the-counter supplements can interact with heart medications or affect heart rhythm.*

- *Can stress make my symptoms worse? Stress doesn't cause PLN, but it can make symptoms such as palpitations, fatigue, or anxiety feel more noticeable. Managing stress through exercise, counseling, mindfulness, hobbies, or connecting with others can improve overall well-being.*
- *Should I get a smartwatch? Smartwatches can be helpful for tracking heart rate, activity, and sometimes detecting irregular heart rhythms. However, they do not replace medical testing and should not be used as the sole basis for medical decisions.*
- **Is there a cure for PLN?** *Currently, there is no cure for PLN cardiomyopathy. However, treatments continue to improve, and researchers around the world are actively studying new medications, gene therapies, and other approaches that may change the future of care.*
- **Should I participate in research?** *Participation in research is a personal decision, but many patients choose to contribute because research helps improve understanding of PLN and may benefit future generations. If you're interested, ask your healthcare provider or the PLN North American Foundation about current research opportunities and clinical trials.*
- **What if I feel overwhelmed?** *You're not expected to have all the answers today. A PLN diagnosis is something most people learn to navigate over time, not overnight. Lean on your healthcare team, your loved ones, and the PLN community. Ask questions, take things one step at a time, and remember that you don't have to carry this alone.*
- *Can I have PLN if no one else in my family has it? Yes. Sometimes family members were never genetically tested, were misdiagnosed, or never developed symptoms despite carrying the mutation. In other cases, relatives may have experienced unexplained heart failure or sudden cardiac death before genetic testing was widely available. A detailed family history and genetic counseling can often provide additional answers.*
- *Can children have PLN? Yes. Children can inherit the PLN mutation, although many will not develop symptoms until adulthood. Families should discuss the appropriate timing of genetic testing and cardiac screening with a pediatric cardiologist and genetic counselor.*

- *Can athletes have PLN?* *Absolutely. Many people with PLN are healthy, active, and athletic before symptoms develop. In fact, because athletes are often in excellent physical condition, early symptoms like fatigue, dizziness, or palpitations may be overlooked or attributed to intense training. Being physically fit does not eliminate a genetic risk, which is why regular cardiac screening remains important.*

- *If I feel fine, do I still need yearly screening?* *Yes. Many people with PLN have no symptoms in the early stages of the disease. Routine ECGs, echocardiograms, cardiac MRIs, and other tests may detect changes long before symptoms appear. Early detection allows your healthcare team to monitor changes and begin treatment when appropriate.*

- *Does having PLN mean I will need a heart transplant?* *No. Most people with PLN will never require advanced therapies such as an LVAD or heart transplant. Many live long, active lives with routine monitoring, medications, and, when appropriate, implantable cardiac devices.*

- *Will I know if my heart is getting worse?* *Not always. Some people notice increasing fatigue, shortness of breath, swelling, or decreased exercise tolerance. Others have very few symptoms even when changes are occurring. That's why routine cardiac screening is just as important as paying attention to how you feel.*

- *Can I live a long life with PLN?* *Yes. Every person's journey is different, and no one can predict exactly how PLN will affect an individual. Fortunately, advances in cardiac imaging, medications, implantable devices, genetic testing, and research continue to improve outcomes. Many people with PLN live active, fulfilling lives for decades.*

Have a Question? Ask PLN! The PLN community is always growing, and so are the questions. If there's something you'd like us to answer, we'd love to hear from you. Submit your question through the PLN North American Foundation website or send us a message on social media. Your question could be featured in a future ASK PLN post and help educate families around the world. No question is too small. Every question asked helps someone else find answers too.

Final Thought

You may not remember every detail in this handbook, and that's okay. The goal isn't to memorize everything, it's to know where to find reliable information when you need it. As new questions arise, write them down, bring them to your appointments, and continue learning. Every question you ask is another step toward becoming an informed, confident partner in your own care. The only "wrong" question is the one you never ask. Your curiosity, your voice, and your willingness to learn are powerful tools in protecting your heart and helping you live well with PLN. When you're living with PLN, it's normal to have questions, sometimes even the ones you think might sound "silly." The truth is, if you're wondering about something, someone else probably is too. While these answers provide general guidance, every person's situation is unique. Always discuss your individual health and treatment decisions with your healthcare team.

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Chapter 7:
Finding Strength Through Community

No one chooses to become part of the PLN community, but once you're here, you'll discover something remarkable, you are surrounded by people who truly understand. People who know what it's like to wait for test results. People who have experienced the uncertainty of living with an inherited heart condition. People who have celebrated reassuring appointments, faced unexpected setbacks, received ICDs, cared for loved ones, participated in research, or waited for heart transplants. People who simply "get it."

One of the most powerful parts of the PLN community is the reminder that you don't have to explain everything to be understood. Whether you're newly diagnosed, supporting a family member, or have been living with PLN for many years, there is someone else who has walked a similar path, and many who are willing to walk beside you. This chapter is about connection. It's about finding people who can answer your questions, share their experiences, celebrate your victories, and encourage you through difficult days. It's also about recognizing that every story matters, including yours. By sharing your journey, participating in research, volunteering, or simply reaching out to another family, you become part of something much bigger than yourself. The future of PLN is being shaped by researchers, physicians, advocates, volunteers, caregivers, and patients around the world. Every family that shares their story, every individual who participates in research, and every person who chooses to educate others helps move us one step closer to better treatments, and one day, a cure. Hope grows stronger when it is shared. Together, we are more than patients and families, we are a community working toward a future where no one faces PLN alone.

The PLN community was built by people who chose to turn uncertainty into action and isolation into connection. Whether you need support today or are ready to support someone else tomorrow, there is a place for you here. Together, we share knowledge, inspire hope, and remind one another that while no one would choose this journey, none of us have to walk it alone.

Support Groups & Foundation Resources

You don't have to walk this journey alone; someone else understands exactly what you're going through. Whether you're newly diagnosed, have been living with PLN for years, or are supporting a loved one, connecting with others can provide reassurance, education, and hope. The PLN North American Foundation was created by patients, families, physicians, and researchers who share one common goal: improving the lives of people affected by PLN while advancing research toward better treatments, and ultimately, a cure. The Foundation is committed to raising awareness, supporting patients and families, educating healthcare professionals, and fostering collaboration among researchers worldwide.

Connect with the PLN Community

Connecting with others who understand your journey can make a tremendous difference. Whether you're looking for practical advice, emotional support, or simply reassurance that you're not alone, the PLN community is here for you. Through the PLN North American Foundation, you can connect with other patients and families, share your story (if and when you're ready), learn from people with lived experience, ask questions in a supportive environment, and stay informed about research and educational opportunities. Remember, you don't have to wait until you're struggling to reach out. Many lifelong friendships begin simply by introducing yourself to someone who understands. Please sign up for our newsletter to stay connected to news, other carriers, and your PLN Foundation family. Our newsletter sign up is located on our website. You can also send us an email and we can add you, and anyone else, to the electronic mailing list.

The PLN NA Foundation provides reliable, patient-friendly educational materials designed to help you better understand PLN and navigate each stage of your journey. Resources include patient education articles, the latest research updates, clinical trial information, educational handbooks and downloadable resources, frequently asked questions, patient stories, family education materials, and information about genetic testing and inherited heart disease. Whenever you have questions, start with trusted resources rather than relying solely on internet searches or social media.

REMEMBER: YOU DON'T HAVE TO BECOME A MEDICAL EXPERT OVERNIGHT. ONE QUESTION, ONE APPOINTMENT, ONE SYMPTOM LOG, AND ONE CONVERSATION AT A TIME CAN HELP YOU BECOME A CONFIDENT ADVOCATE FOR YOUR HEALTH. KNOWLEDGE GIVES YOU CONFIDENCE, ORGANIZATION GIVES YOU CONTROL, AND TOGETHER THEY HELP YOU TAKE AN ACTIVE ROLE IN YOUR PLN JOURNEY.

FOUNDATION RESOURCES

The PLN North American Foundation is here to support you and your family at every stage of your PLN journey. Whether you've just been diagnosed, are looking for educational materials, want to connect with other families, or are interested in research, the Foundation offers trusted resources designed specifically for the PLN community.

Our goal is simple: to ensure that no one faces PLN alone.

Visit Our Website: **www.PLNFoundationNA.com**

Follow Us on Social Media:

Instagram: @PLNGeneticHeartMutation
Facebook Page: @PLNGeneticMutationAwareness
Facebook Support Group: @PLNCardiomyopathySupport
LinkedIn: @PLN North American Foundation
YouTube: @PLNGeneticHeartMutation
TikTok: @PLNGeneticHeartMutation

Subscribe to our newsletter via the website or emailing us at plnfoundation.na@gmail.com, we look forward to hearing from you!

BELOW ARE FILLABLE WORKSHEETS TO PRINT OUT, FILL OUT, AND HELP ORGANIZE.

PLN HEART FOUNDATION

My PLN Journey Timeline

My Diagnosis:

Date Diagnosed:

Age at Diagnosis:

How was PLN discovered?

- □ Family screening
- □ Symptoms
- □ ECG/EKG
- □ Echocardiogram
- □ Cardiac MRI
- □ Genetic testing
- □ After a family member's diagnosis
- □ Other:

My PLN Variant:

Current Diagnosis (if known):

- □ Carrier only
- □ DCM
- □ ACM
- □ HCM
- □ Arrhythmia
- □ Heart Failure
- □ Other

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My Healthcare Team

Providers	Name	Phone Number
CARDIOLOGIST		
ELECTROPHYSICIOLOST		
GENETIC COUNSELOR		
PCP		
HEART FAILURE SPECIALIST		

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Test Result Tracker

Test	Date/Time	Doctor	Results
ECG			
ECHO			
MRI			
HOLTER			
STRESS TEST			
BLOOD WORK			

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Blood Pressure Log

Date/TIme	BP	HR	Symptoms

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Heart Rate Log

Date/TIme	HR	Activity	Symptoms

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Weight Log

Date/TIme	Weight	Swelling?	Notes

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Symptom Journal

Date/TIme	Severity (1-5)	Duration	Activity	Symptom(s)

HEART FOUNDATION

Questions for My Doctors

Questions:

1

2

3

4

5

6

7

8

9

10

Notes from Today's Visit:

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Appointment Preparation Checklist:

Before My Appointment:

- ☐ Medication list
- ☐ Insurance card
- ☐ ICD card
- ☐ Symptom journal
- ☐ Blood pressure log
- ☐ Weight log
- ☐ Family history
- ☐ Questions written down
- ☐ Previous testing
- ☐ Water/snack
- ☐
- ☐
- ☐
- ☐
- ☐
- ☐

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Emergency Information

Name:

DOB:

Blood Type:

Emergency Contact:

Cardiologist:

Hospital:

Genetic Mutation:

Current Medications:

ICD Information:

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Caregiver Notes

Things I noticed this week:

Questions for the doctor:

Appointments coming up:

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PLN Annual Review

This year I.....

- ☐ Had my ECG
- ☐ Had my Echo
- ☐ Had my MRI
- ☐ Met with my cardiologist
- ☐ Updated my medication list
- ☐ Updated my family history
- ☐ Talked to family members about screening
- ☐ Reviewed emergency plans
- ☐ Signed up for Foundation updates
- ☐ Participated in research
- ☐ Met someone in the PLN community

My biggest win this year:

My biggest challenge:

Goals for next year:

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Additional Notes

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YOUR PLN JOURNEY IS UNIQUE, BUT YOU ARE NEVER WALKING IT ALONE. EVERY APPOINTMENT, EVERY QUESTION, EVERY FAMILY MEMBER YOU INFORM, AND EVERY STEP YOU TAKE TOWARD UNDERSTANDING YOUR CONDITION CONTRIBUTES TO A HEALTHIER FUTURE, NOT ONLY FOR YOURSELF, BUT FOR GENERATIONS TO COME. WHILE THERE IS NOT YET A CURE, THERE IS HOPE. TOGETHER, THROUGH EDUCATION, RESEARCH, ADVOCACY, AND COMMUNITY, WE ARE MOVING CLOSER TO A WORLD WHERE PLN NO LONGER CHANGES LIVES.

PLN
HEART FOUNDATION

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