WebMD REAL STORIES

PAROXYSMAL NOCTURNAL HEMOGLOBINURIA

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COMPLIMENTARY COPY
TAKE ONE HOME

SCAN ME

Read this article about "The Challenges of PNH." Use your smartphone camera to activate the QR code.

FALL 2025

INSIDE THE ISSUE

GETTY IMAGES

THE LATEST ON
PAROXYSMAL NOCTURNAL HEMOGLOBINURIA (PNH)

LIVING WELL WITH TARGETED THERAPIES

When it comes to managing rare conditions such as PNH, targeted therapies that block a specific immune protein have been shown to improve clinical outcomes. Researchers looked at the data of 783 adults in the U.S. who were receiving one of three targeted treatments (identified as complement inhibitors) and found that one option stood out. Nearly 99% of people stayed on this therapy as prescribed and for a much longer time period than those who received the other two therapies. Hospital stays significantly dropped by 45%, emergency room visits decreased by 40%, and outpatient visits declined by 19%. The need for blood transfusions also went down. These findings show how the right treatment can better support living well with PNH beyond the hospital setting.

SOURCE: *Blood*

30 to 40

Most common ages at which PNH is diagnosed.

SOURCE: National Library of Medicine

3,000 to 6,000

Estimated number of people with paroxysmal nocturnal hemoglobinuria in the U.S.

SOURCE: *Blood Reviews*

YOUR EXPERIENCE MATTERS

PNH can quietly affect your body, mind, and routine. Using online surveys and personal interviews, the everyday experiences of 61 people with PNH who were already undergoing treatment were analyzed in this U.S.-based study. Many reported facing ongoing challenges such as constant fatigue, difficulty in thinking clearly, and shortness of breath. These symptoms often disrupted their ability to work, maintain relationships, and manage daily tasks despite being on regular therapy. If these symptoms sound familiar, do not wait—consider talking to your doctor about how PNH may be interfering with your daily routine and ways to improve your quality of life.

SOURCE: *Annals of Hematology*

SUPPORT AT YOUR FINGERTIPS

It is not always easy to manage PNH on your own, but an app-based study conducted in the U.S. shows how technology can help. A phone app, which could help people track their daily symptoms, set medication reminders, and create health reports to share with their doctor, puts convenience first. In data collected during the first six weeks of the study, participants reported a wide range of disease-related symptoms and treatment experiences, showing how different the condition can be for each person. Researchers are turning these insights into a new app tailored specifically for people with PNH. Keep an eye out: Easier, more personalized care could be just a tap away.

SOURCE: *Blood*

DIMENSIONS/VIA GETTY IMAGES

This content was created using several editorial tools, including AI, as part of the process. Human editors reviewed this content before publication.

BEYOND PNH

Ask your doctor about FABHALTA, the first and only oral treatment for adults with PNH taken without infusions or injections

Patient portrayal.

FABHALTA® (iptacopan) 200 mg capsules

Approved Use

What is FABHALTA?

FABHALTA is a prescription medicine used to treat adults with paroxysmal nocturnal hemoglobinuria (PNH).
It is not known if FABHALTA is safe and effective in children.

Important Safety Information

What is the most important information I should know about FABHALTA?

FABHALTA is a medicine that affects part of your immune system and may lower your ability to fight infections.

- **FABHALTA increases your chance of getting serious infections caused by encapsulated bacteria,** including *Streptococcus pneumoniae, Neisseria meningitidis*, and *Haemophilus influenzae* type b. These serious infections may quickly become life-threatening or fatal if not recognized and treated early.
  - You must complete or update your vaccinations against *Streptococcus pneumoniae* and *Neisseria meningitidis* at least 2 weeks before your first dose of FABHALTA.
  - If you have not completed your vaccinations and FABHALTA therapy must be started right away, you should receive the required vaccinations as soon as possible.
  - If you have not been vaccinated and FABHALTA must be started right away, you should also receive antibiotics to take for as long as your health care provider tells you.
  - If you have been vaccinated against these bacteria in the past, you might need additional vaccinations before starting FABHALTA. Your health care provider will decide if you need additional vaccinations.
  - Vaccines do not prevent all infections caused by encapsulated bacteria. **Call your health care provider or get emergency medical care right away if you have any of these signs and symptoms of a serious infection:**
    - Fever with or without shivers or chills
    - Fever with chest pain and cough
    - Fever with high heart rate
    - Headache and fever
    - Confusion
    - Clammy skin
    - Fever and a rash
    - Fever with breathlessness or fast breathing
    - Headache with nausea or vomiting
    - Headache with stiff neck or stiff back
    - Body aches with flu-like symptoms
    - Eyes sensitive to light

Your health care provider will give you a Patient Safety Card about the risk of serious infections. Carry it with you at all times during treatment and for 2 weeks after your last dose of FABHALTA. Your risk of serious infections may continue for a few weeks after your last dose of FABHALTA. It is important to show this card to any health care provider who treats you. This will help them diagnose and treat you quickly.

FABHALTA is only available through a program called the FABHALTA Risk Evaluation and Mitigation Strategy (REMS). Before you can take FABHALTA, your health care provider must:

- Enroll in the FABHALTA REMS program.
- Counsel you about the risk of serious infections caused by certain bacteria.
- Give you information about the symptoms of serious infections.
- Make sure that you are vaccinated against serious infections caused by encapsulated bacteria and that you receive antibiotics if you need to start FABHALTA right away and you are not up to date on your vaccinations.
- Give you a **Patient Safety Card** about your risk of serious infections.

Who should NOT take FABHALTA?

Do not take FABHALTA if you:

- Are allergic to FABHALTA or any of the ingredients in FABHALTA.
- Have a serious infection caused by encapsulated bacteria, including *Streptococcus pneumoniae*, *Neisseria meningitidis*, or *Haemophilus influenzae* type b when you are starting FABHALTA.

FABHALTA® (iptacopan) 200 mg capsules **Pronounced [Fab-HALT-ah]**

HELPING REDEFINE THE STANDARD FOR PNH TREATMENT

Controls both types of hemolysis seen in PNH: intravascular hemolysis (IVH) and extravascular hemolysis (EVH)

Compared to adults who switched from SOLIRIS® or ULTOMIRIS® in a clinical study to see how FABHALTA impacted some of the most common challenges of PNH

"Since starting FABHALTA, I've been able to focus more on the moments that make me, 'me,' such as spending time with my pets and playing with my child."

— Garrett, a person living with PNH and taking FABHALTA, compensated for his time. Individual results may vary.

See what made people choose FABHALTA

Who should NOT take FABHALTA? (continued)

Before you take FABHALTA, tell your health care provider about all your medical conditions, including if you:

- Have an infection or fever.
- Have liver problems.
- Are pregnant or plan to become pregnant. It is not known if FABHALTA will harm your unborn baby.
- Are breastfeeding or plan to breastfeed. It is not known if FABHALTA passes into your breast milk. You should not breastfeed during treatment and for 5 days after your final dose of FABHALTA.

Tell your health care provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Taking FABHALTA with certain other medicines may affect the way FABHALTA works and may cause side effects.

Know the medicines you take and the vaccines you receive. Keep a list of them to show your health care provider and pharmacist when you get a new medicine.

If you have PNH and you stop taking FABHALTA, your health care provider will need to monitor you closely for at least 2 weeks after stopping FABHALTA. **Stopping treatment with FABHALTA may cause a breakdown of red blood cells due to PNH.**

Symptoms or problems that can happen due to breakdown of red blood cells include:

- Decreased hemoglobin level in your blood
- Blood in your urine
- Shortness of breath
- Trouble swallowing
- Tiredness
- Pain in the stomach (abdomen)
- Blood clots, stroke, and heart attack
- Erectile dysfunction (ED)

It is important you take FABHALTA exactly as your health care provider tells you to lower the possibility of breakdown of red blood cells due to PNH.

What are the possible side effects of FABHALTA?

FABHALTA may cause serious side effects, including:

- See **"What is the most important information I should know about FABHALTA?"**
- **Increased cholesterol and triglyceride (lipid) levels in your blood.** Your health care provider will do blood tests to check your cholesterol and triglycerides during treatment with FABHALTA. Your health care provider may start you on a medicine to lower your cholesterol if needed.

The most common side effects of FABHALTA in adults include:

- Headache
- Nasal congestion, runny nose, cough, sneezing, and sore throat (nasopharyngitis)
- Diarrhea
- Pain in the stomach (abdomen)
- Infections (bacterial and viral)
- Nausea
- Rash

Tell your health care provider about any side effect that bothers you or that does not go away. These are not all the possible side effects of FABHALTA. Call your doctor for medical advice about side effects.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Important Facts About FABHALTA on the following page.

NOVARTIS

Novartis Pharmaceuticals Corporation
East Hanover, New Jersey 07936-1080

5/25 FA-11416790

IMPORTANT FACTS ABOUT FABHALTA® (iptacopan)

USE

FABHALTA is a prescription medicine used to treat adults with paroxysmal nocturnal hemoglobinuria. It is not known if FABHALTA is safe and effective in children.

- FABHALTA is one capsule taken twice a day, every day, with or without food.

WARNINGS

FABHALTA is a medicine that affects part of your immune system. FABHALTA may lower the ability of your immune system to fight infections.

- **FABHALTA increases your chance of getting serious infections caused by encapsulated bacteria,** including *Streptococcus pneumoniae*, *Neisseria meningitidis*, and *Haemophilus influenzae* type b. These serious infections may quickly become life-threatening or fatal if not recognized and treated early.
  - You must complete or update your vaccinations against *Streptococcus pneumoniae* and *Neisseria meningitidis* at least 2 weeks before your first dose of FABHALTA. If you have not completed your vaccinations and FABHALTA must be started right away, you should receive the required vaccinations as soon as possible.
  - If you have not been vaccinated and FABHALTA must be started right away, you should also receive antibiotics to take for as long as your health care provider tells you.
  - If you have been vaccinated against these bacteria in the past, you might need additional vaccinations before starting FABHALTA. Your health care provider will decide if you need additional vaccinations.
  - Vaccines do not prevent all infections caused by encapsulated bacteria. **Call your health care provider or get emergency medical care right away if you have any of these signs and symptoms of a serious infection:** Fever with or without shivers or chills; fever with chest pain and cough; fever with high heart rate; headache and fever; confusion; clammy skin; fever and a rash; fever with breathlessness or fast breathing; headache with nausea or vomiting; headache with stiff neck or stiff back; body aches with flu-like symptoms; eyes sensitive to light.
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  - Enroll in the FABHALTA REMS program
  - Counsel you about the risk of serious infections caused by certain bacteria
  - Give you information about the symptoms of serious infections
  - Make sure that you are vaccinated against serious infections caused by encapsulated bacteria and that you receive antibiotics if you need to start FABHALTA right away and you are not up to date on your vaccinations
  - Give you a **Patient Safety Card** about your risk of serious infections

OTHER IMPORTANT INFORMATION

- **Do not take FABHALTA if you:** Are allergic to iptacopan or any ingredients in FABHALTA; have a serious infection caused by encapsulated bacteria, including *Streptococcus pneumoniae*, *Neisseria meningitidis*, or *Haemophilus influenzae* type b when you are starting treatment.
- **Increased cholesterol and triglyceride (lipid) levels in your blood.** Your health care provider will do blood tests to check your cholesterol and triglycerides during treatment with FABHALTA. Your health care provider may start you on a medicine to lower your cholesterol if needed.

Before you take FABHALTA, tell your health care provider about all your medical conditions, including if you:

- Have an infection or fever
- Have liver problems
- Are pregnant or plan to become pregnant. It is not known if FABHALTA will harm your unborn baby
- Are breastfeeding or plan to breastfeed. It is not known if FABHALTA passes into your breast milk. You should not breastfeed during treatment and for 5 days after your last dose of FABHALTA

COMMON SIDE EFFECTS

The most common side effects that occurred in patients treated with FABHALTA were headache, nasal congestion, runny nose, cough, sneezing, and sore throat (nasopharyngitis), diarrhea, pain in the stomach (abdomen), infections (bacterial and viral), nausea, and rash. **These are not all the possible side effects. Talk to the patient's doctor about any side effects that bother the patient or that don't go away.**

This information is not comprehensive.

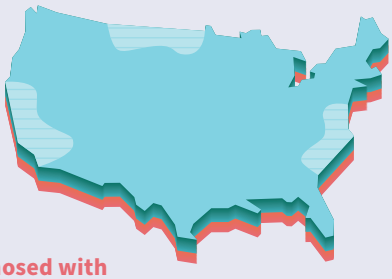
How to get more information: Talk to your health care provider or visit www.fabhalta.com to obtain the FDA-approved product labeling.

8/24 FA-11258903

STATS & FACTS

By Sonya Collins
Reviewed by Brunilda Nazario, MD, WebMD Chief Physician Editor, Medical Affairs

500



Number of people who are diagnosed with paroxysmal nocturnal hemoglobinuria (PNH) in the U.S. every year.

2 in 5

Number of people with PNH who report brain fog as one of their symptoms.

9 in 10

Number of people with PNH who take medicine for their condition.

75%

How much treatment advances in the last two decades have extended survival for people with PNH.

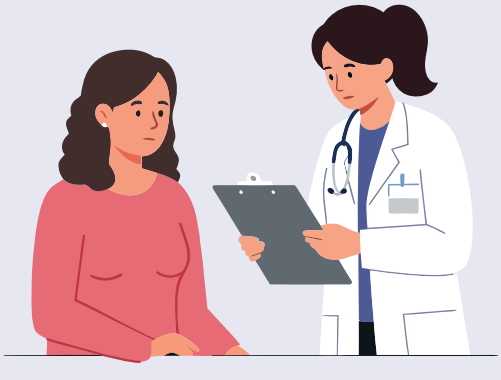
36

Average age when PNH is diagnosed.

2 in 5

Number of people with PNH who develop blood clots.

3 in 5



Number of people with PNH who report having a PNH-related doctor visit once or more per month.

VECTEEZY.COM

SOURCES: *Blood,* National Library of Medicine, AAMDS Foundation

GET THE **FACTS**

Learn more about PNH from two hematologists

By Sonya Collins **Reviewed by** Brunilda Nazario, MD, WebMD Chief Physician Editor, Medical Affairs


JOHNSON M. LIU, MD

Paroxysmal nocturnal hemoglobinuria (PNH) is a rare blood disorder that happens when your immune system attacks your red blood cells and platelets. The cells break down too easily, leaving blood in your urine and leaving you extremely fatigued. Here, two experts answer a few of the most common questions about the condition. Akriti Jain, MD, is a hematologist at Cleveland Clinic in Ohio, and Johnson M. Liu, MD, is section head of hematology at Mount Sinai Tisch Cancer Institute in New York.

Q:What causes PNH? Does genetics play a role?

JOHNSON M. LIU, MD: While a gene mutation causes PNH, you don't inherit it from your parents or pass it on to your children. It's a mutation in a gene called PIGA that only occurs in bone marrow stem cells.

AKRITI JAIN, MD: The PIGA mutation leads to an absence of or a deficiency in certain proteins that makes red blood cells more vulnerable to attack by the immune system. This results in the breakdown of red blood cells, also called hemolysis, leading to fatigue, dark urine, and other complications.

Q:Who gets PNH?

JAIN: PNH is estimated to occur in about 1 to 10 people per million. While it is typically diagnosed in adults in their 30s, it can affect anyone, regardless of age, race, ethnicity, sex, or geography.

LIU: PNH happens in two groups of people. One group has a complete failure of bone marrow cell production, called aplastic anemia, and they have a small number of PNH cells. The other group has a very large number of PNH cells, which typically causes an anemia that intermittently leads to red cell destruction and leakage of hemoglobin from the red cells into the urine during the night.

Q: What kind of impact does PNH have on your quality of life?

JAIN: Chronic fatigue is the most common symptom of PNH. You can also have pain from hemolysis—that's destruction of red blood cells—or blood clots. The combination of fatigue, pain, the need for ongoing treatments, and the potential for serious complications can limit personal, social, and professional activities. Patients may face both physical and psychological challenges, and the unpredictable nature of the disease can contribute to long-term stress and anxiety.

Q: How do you manage these difficult symptoms of PNH?

LIU: There are now therapies that directly prevent red blood cell destruction with antibodies that block the proteins causing the destruction. You get an infusion of the antibodies every two months. These therapies have significantly improved quality of life for people with PNH because their anemia and tendency for blood clots are significantly reduced.

AKRITI JAIN, MD

JAIN: Management of all aspects of PNH, beyond just physical symptoms and including the psychological challenges, requires a multidisciplinary team of psychologists, psychiatrists, pharmacists, and nutritionists.

Q: What is happening in PNH research?

LIU: One of the major research questions in PNH is why people acquire the PIGA gene mutation in their bone marrow. It's believed that the immune system plays a role in causing this, but we still don't have all the details and, hence, don't understand why PNH develops. That's an ongoing focus of research.

JOHNSON M. LIU, MD, PHOTO COURTESY OF MOUNT SINAI HEALTH SYSTEM; AKRITI JAIN, MD, PHOTO COURTESY OF CLEVELAND CLINIC

TREATMENT OPTIONS

Your choices for PNH management

By Rachel Reiff Ellis
Reviewed by Brunilda Nazario, MD, WebMD Chief Physician Editor, Medical Affairs

Treatment for PNH has come a long way in the last 20 years. In 2007, there was only one FDA-approved drug for PNH, an IV medication you took every two weeks.

"This was a major advance because it stopped thrombosis—the leading cause of death from PNH at the time—and improved anemia and quality of life," says Robert A. Brodsky, MD, past president of the American Society of Hematology and director of the Division of Hematology at Johns Hopkins University School of Medicine in Baltimore.

Now there are six FDA-approved medications for PNH, including injections, pills you take by mouth, and an IV therapy you take every eight weeks. In some cases, a bone marrow transplant is the best course of treatment, although advances in medications have made this less common.

COMPLEMENT INHIBITORS

All the approved drugs for treating PNH are in a class of drugs called complement inhibitors. These are targeted therapy drugs that have revolutionized PNH treatment over the last decade, says Keith McCrae, MD, director of benign hematology at the Taussig Cancer Institute in Cleveland.

"These drugs have substantially decreased the risk of blood clots, red blood cell destruction through hemolysis, and in many cases anticoagulation [taking drugs called drug thinners] is no longer needed after these inhibitors are initiated," McCrae says.

Your complement system's job is to help your body fight infection. When you have PNH, a mutation in a gene called PIGA keeps this system from working the way it should. With PNH, your complement system activates when it's not supposed to and causes damage to normal cells.

Complement inhibitors stop this process and keep your complement system from destroying red blood cells. Different complement inhibitors target different parts of the complement system pathway.

Most people tolerate complement inhibitors well, although the oral options may raise your cholesterol and triglycerides, Brodsky says.

"The major side effect of all of these drugs is that they make you more susceptible to infection from specific bacteria, with the biggest risk being meningitis," says Brodsky,

YAROSLAV ASTAKHOV/VIA GETTY IMAGES

who notes that anyone with PNH should get vaccinated against meningitis.

BONE MARROW/STEM CELL TRANSPLANT

A bone marrow or stem cell transplant is a procedure that replaces bone marrow (the soft, spongy tissue in the center of your bones) that's not working correctly with healthy stem cells—immature cells that grow into different types of blood cells.

Doctors may suggest this option in children with severe PNH, but other reasons can lead to this treatment path, too.

"We may undertake it for people with life-threatening and recurrent complications [unresponsive] to complement inhibitors," McCrae says.

You could also benefit from a transplant if you get a condition called aplastic anemia. This is a rare but serious blood condition that happens when your bone marrow can't make enough new blood cells for your body to work normally. PNH and aplastic anemia are closely linked—more than 10 out of every 100 people with aplastic anemia will develop PNH.

Depending on how closely the donor bone marrow matches yours, how severe your disease is, and complications, a transplant can be very successful, and even cure PNH. But with newer complement inhibitors targeting different parts of the complement pathway with success and fewer side effects, transplants are much rarer.

"Most patients with PNH can live a long and healthy life," Brodsky says.

MY TREATMENT JOURNEY

It was a long road, but I feel fortunate my body is not at war with itself anymore

By Jillian Stewart **Reviewed by** Brunilda Nazario, MD, WebMD Chief Physician Editor, Medical Affairs

In May 2019, I felt tired all the time. I'd get out of breath after just a handful of steps. One day while I was walking my dog, I lost feeling in my legs and had to sit down on the sidewalk.

The doctor chalked it up to typical college life and said I probably had mono or another infection. He prescribed antibiotics, ordered blood tests, and sent me home.

At midnight, the emergency department called—my hemoglobin levels were 4 grams per deciliter (normal is 12), and my platelet count was dismal. They said they didn't know how I was functioning. I packed my bags for the hospital.

After blood transfusions and multiple tests, they still didn't have a diagnosis. The last test was a bone marrow biopsy. I went home for two weeks to await the results, which felt like 50 years. Eventually they came back with an answer: I had PNH.

FINDING WHAT WORKED FOR ME

My doctor started me on a biweekly immunosuppressive infusion. He told me that since I was young and otherwise healthy, the medication would surely work.

While it was true that I was young, from my perspective, that meant facing a long lifetime of infusions and blood transfusions. And besides, I still didn't feel well at all. I couldn't go on a walk. I was pale and often faint. My skin was covered with bruises and tiny red dots.

I had to take a semester off from school to deal with it all. One day in the infusion center, I remember crying and asking my mom, "When am I going to feel better?" It felt like there was no answer.

I told my doctor I wanted to talk about a cure. I wanted to know more about bone marrow transplant.

THE PATH TO A TRANSPLANT

The transplant doctor was concerned that a transplant could cause more problems than it solved. She wanted to exhaust all medication options before going that route.

I tried an oral immunosuppressive and a bone marrow stimulant drug, but my liver enzymes became high and I got jaundice. Then I moved on to an antibody derived from horses or rabbits, a form of chemotherapy you get through a PICC line along with steroids to try to kick-start your bone marrow. (A PICC, or peripherally inserted central catheter, is a tube that's put into a vein in your upper arm. It's used to draw blood or give fluids.)

I was in the hospital for a week. I had more blood transfusions. I gained a lot of weight and had a moon face. The steroids boosted my energy and made me feel great, but when I stopped them, I felt terrible again.

At this point, my original doctor had retired. My new doctor came in with a fresh view. He looked at my medical history, and said, "This girl has a lot of life left to live, and I'm going to figure out how to help her."

AI IMAGE GENERATED BY FREEPIK AI; INSET PHOTOGRAPHY BY TRACY STEWART

SCAN ME

For additional treatment information, read "Life With PNH: What to Expect." Use your smartphone camera to activate the QR code.

JILLIAN'S TIPS

Living well with PNH

+ **Advocate for yourself**—you're the one living with the condition.
+ **Research** as much as you can so you're informed.
+ **Ask questions** until you understand the answer.

NEW LEASE ON LIFE

In 2021, the FDA approved an immunosuppressive injection that seemed to work well for me. Within two weeks of starting, my hemoglobin went up to 13. I graduated college, got a job. I felt young and healthy again. It was great.

Suddenly in November 2023, I got sick again. My liver enzymes were back up and my hemoglobin was down. I was having a hemolytic crisis—my PNH was overactive and attacking all my cells. My body had stopped responding to the medication.

My doctor told me we were out of options, and it was time to reconsult with the bone marrow transplant team. Not long after, they initiated a search to find me a match. This conversation started in December. I was incredibly lucky—they found an exact match, and she said yes. I had my transplant on Feb. 21, 2024. It was textbook, and I had no complications. It was the best possible outcome.

Recently, tests showed no evidence of PNH in my body. It was a long road, but I feel fortunate to have a body that's not at war with itself anymore.

LIFE WITH PNH

My advice? Build your community and listen to your body.

By Brandi Lewis
Reviewed by Brunilda Nazario, MD, WebMD Chief Physician Editor, Medical Affairs

I was diagnosed with PNH in 2016 at age 26. Before that, I had aplastic anemia that went into remission. When it came back six years later, my doctor said many people with aplastic anemia also have PNH. She ordered the test, and it came back positive. Suddenly, I had not one blood disorder but two.

I was more distraught and scared the second time around. I had no clue what PNH was or how I was going to tackle it. There wasn't a lot of research then or treatment options. I thought, 'Is this really going to slow my life down?' That was really my main question.

FINDING SUPPORT

When I was first diagnosed, I had a lot of support from my community in Homewood, Alabama. They wanted to know what it was that I had. I founded a nonprofit called Brandi's Blessings to support patients with blood disorders. I ran it for eight years. Facebook groups are another good place to find people who understand what it's like to have PNH.

Early on, my parents and I also went to NORD, the National Organization for Rare Disorders (RareDiseases.org). They had meetups for different rare blood disorders. You could meet other people in that same space.

Someone I met gave me a list of doctors she'd seen. We called or went to see those doctors for their opinions about what was going on with me. I found my doctor I have today from that list. He's in New York, which is another thing with rare disorders like PNH. It's hard to find a specialist in your area. Most of the time, you're going to have to travel.

SCAN ME

For another personal perspective, watch "When Words Don't Illustrate the Pain." Use your smartphone camera to activate the QR code.

MANAGING SYMPTOMS

A big thing with PNH is that the symptoms will never go away. You have brain fog, nosebleeds, bruising on your body, headaches. I'd say fatigue and brain fog are the worst for me. Somebody will tell you something, and five seconds later you don't remember anything that they said.

For me, working a full-time job, it's a challenge to remember things. I write things down just to remember them and make sure I'm meeting deadlines. I have a memorization app on my phone that I use.

FERMATE/VIA GETTY IMAGES; INSET PHOTOGRAPHY BY KRISTEN MORROW PUGH

LISTEN TO YOUR BODY

Fatigue is a tough one, too. Some days, it's like my body is telling me, 'I'm shutting down. I need you to rest.' During those times, I really don't fight my body. So if it's telling me, 'Hey, it's time to rest,' I'll lie on the couch and watch a good show. I've learned to really listen to my body with my blood disorders. My body really tells me what's going on, and, for me, if I try and fight any of that, it only gets worse in the end.

BRANDI'S TIPS

+ Find a doctor who you connect with and who makes you part of any decisions about your treatment options.
+ Fatigue can be hard to explain so people understand it's not laziness. Take the time with the people you truly care about, so they know what you're going through.
+ You can still achieve your goals and dreams. That's something I always tell people who are battling blood disorders. It gets better.

MEET YOUR PNH CARE TEAM

A strong and reliable team can make all the difference

By Kendall K. Morgan
Reviewed by Neha Pathak, MD, WebMD Chief Physician Editor

When you have paroxysmal nocturnal hemoglobinuria (PNH), it can be hard to make sense of all that's ahead or find others who really understand what you're going through. Having the right care team in place is an important first step.

"Having a strong and coordinated care team is very essential when living with PNH because it is a rare, chronic, and potentially life-threatening disease that affects multiple aspects of health," says Akriti Jain, MD, a hematologist at Cleveland Clinic in Ohio.

FIND AN EXPERT

Jain recommends finding a doctor with specific expertise and experience in treating PNH.

"There are newer therapies approved [for PNH] in the last one or two years, and only an expert in PNH will be able to keep up with newer therapies and provide them to patients," Jain says.

Hematologists specialize in blood disorders. But PNH can affect other parts of your body, including your immune system, kidneys, heart, liver, and lungs. It may come with neurological symptoms, too. In addition to your hematologist, Jain notes that you may benefit from seeing other specialists, such as a nephrologist, cardiologist, hepatologist, or neurologist.

BEYOND DOCTORS

In addition to your doctors, your PNH care team may include many others you can rely on and reach out to with questions or concerns, including:

+ Nurses
+ Nurse practitioners
+ Pharmacists
+ Social workers
+ Psychologists
+ Support groups
+ Nutritionists or dietitians
+ Physical therapists

PEOPLEIMAGES/VIA GETTY IMAGES

GENETIC COUNSELORS

PNH is caused by acquired mutations or changes in a particular gene. That means you didn't inherit it and can't pass it on to your kids. But a genetic counselor may be a good person to help you understand your condition better.

"A genetic counselor might be helpful if there is concern about related bone marrow failure syndromes, overlap with conditions like aplastic anemia, or to explain the pathogenesis of PNH mutations," Jain says.

PRIMARY CARE

It's good to keep your primary care doctor in the loop. They can help you navigate your PNH while keeping tabs on your overall health.

"Your PCP can help make sure overarching, comprehensive care is being provided rather than piecemeal with multiple specialists," Jain says.