PIECETOGETHERPV

PIECE TOGETHER PV GUIDE

A diagnosis of polycythemia vera (pol-e-sy-THEE-me-uh VEER-uh), or PV, can feel overwhelming—especially when you have more questions than answers. Learning about this rare, chronic blood cancer can help you see how the pieces fit together and empower you to take a proactive role in your care plan.

This guide includes:

- Key facts about PV
- Common symptoms
- Risks and complications

> **Advocate, advocate, advocate. Don't be satisfied with a watch and wait protocol. It's really important to research...to get ahead of your PV diagnosis to hopefully avoid disease progression.**

– Dana
Diagnosed with PV at age 29

Piecing together the facts about PV

What is PV?

PV is a rare, slow-growing cancer that starts in the bone marrow, where your stem cells make red blood cells, white blood cells, and platelets. It belongs to a group of blood cancers called myeloproliferative neoplasms (MPNs).

- In PV, the bone marrow makes too many red blood cells, and sometimes too many white blood cells and platelets
- This thickens the blood (hyperviscosity) and slows down blood flow, which can raise the risk of thrombotic events, including blood clots and strokes

What causes PV?

PV happens when stem cells in the bone marrow develop a mutation (or DNA change) that causes the overproduction of blood cells.

- Over 90% of people with PV have a mutation in the *JAK2* gene
- The *JAK2* gene makes a protein that promotes cell growth and helps control how many blood cells are made

Is PV genetic or inherited?

Typically, PV is not inherited. The *JAK2* mutation usually happens during a person's lifetime for reasons doctors don't fully understand yet.

How common is PV?

PV is estimated to affect about 4 to 6 people out of every 10,000 in the U.S.

Approximately 150,000 people in the U.S. may be living with PV.

PV is most commonly diagnosed in people aged 50 to 70 years.

However, people aged 15 to 39 years may now account for up to 20% of MPN diagnoses.

Speaking up about PV symptoms

Because PV symptoms can be vague, mild, or develop slowly, it can be easy to brush them off by saying “I’m fine,” when your doctor asks how you’re feeling. That’s one of the reasons why PV is sometimes only discovered during routine bloodwork.

Common PV symptoms

1 Head

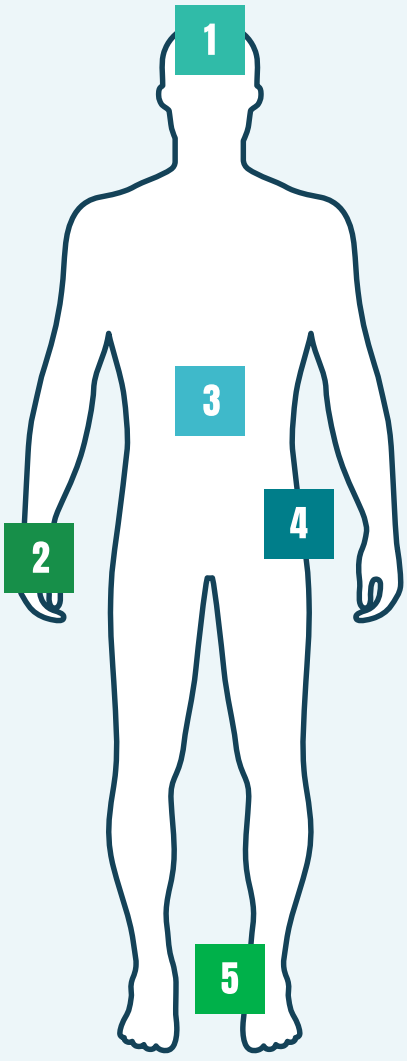
- Headache
- Dizziness
- Blurry vision
- Unusual bleeding or bruising, including nosebleeds or bleeding gums

2 Skin

- Itchy skin (pruritus), especially after a hot bath or shower
- A reddened or purplish skin rash, especially on the palms, ear lobes, nose, and cheeks

3 Stomach

- A feeling of fullness soon after eating
- Bloating or pain in your upper left abdomen



4 General

- Fatigue or low energy
- Shortness of breath and difficulty breathing when lying down

5 Joints/extremities

- Painful swelling of one joint (often the big toe)
- Numbness, tingling, or a burning sensation in the hands, feet, arms, or legs

Track how you’re feeling: Scan the QR code or visit PieceTogetherPV.com/resources for a doctor discussion guide with symptom tracker to help you prep for talking with your doctor about your symptoms and treatment options.

Making sense of risks and complications

Knowing the short- and long-term risks of PV can help you and your doctor create a plan to reduce the chance of serious problems like blood clots or disease progression.

Risk of blood clots with PV

Reduced blood flow due to thickening of the blood in PV can increase the risk of developing blood clots, which can cause stroke, chest pain (angina), heart attack, deep vein thrombosis (DVT), and pulmonary embolism.

- Blood clots occur in about 30% of people with PV even before the diagnosis is made
- Without treatment, 40%-60% of people may develop blood clots within 10 years of diagnosis

Progression to other cancers

With proper treatment, PV can usually be managed for many years. However, in some cases, it can progress to other cancers.

Myelofibrosis (MF)
Uncontrolled PV may transform into MF, a rare cancer that causes scarring in the bone marrow. When this this happens, the marrow can no longer produce healthy blood cells. Approximately 10% of people with PV may develop MF within 10 years of diagnosis.

Acute myeloid leukemia (AML)
In some people, PV can advance into AML, an aggressive type of blood cancer that grows quickly and results in too many immature white blood cells in the blood and bone marrow. AML affects between 2%-14% of people with PV within 10 years of diagnosis.

> **“I started seeking a second opinion because the more I started educating myself, I realized this is pretty serious and it’s progressive.”**
>
> **– Person with PV**

Other potential PV complications

Kidney stones

The high turnover of red blood cells with PV leads to higher-than-normal uric acid production, which is associated with kidney stones. Passing kidney stones can be extremely painful, but the stones usually don't cause permanent damage.

Enlarged spleen (splenomegaly)

The spleen often becomes enlarged in people with PV because it's working overtime to filter out a greater number of blood cells than normal. An enlarged spleen may:

- Cause a bloated or full feeling in the abdomen
- Lead to more frequent infections, anemia, and/or increased bleeding
- Rupture and cause life-threatening bleeding in the abdominal cavity

Gout

The high turnover of red blood cells with PV leads to higher-than-normal uric acid production, which can cause an inflammation of the joints called gout.

- Gout can cause intense joint pain, most commonly in the big toe, ankles, knees, elbows, wrists, and fingers
- As gout progresses, attacks may last longer and limit your range of motion

Peptic ulcers

Peptic ulcers are open sores on the lining of the gastrointestinal tract. Left untreated, they can cause internal bleeding, a hole in the stomach wall, or an obstruction in the digestive tract causing you to become full easily, vomit, and/or lose weight.

Keep connecting the pieces: Scan the QR code or visit PieceTogetherPV.com/resources for a downloadable doctor discussion guide, blood test tracker, and glossary of important terms.

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US-PV-2500053 (v2.0) 12/2025

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