LIVING WITH
POLYCYTHEMIA VERA (PV)

Information, resources, and support for wherever you are on your journey with PV.

For more information, visit PVvoices.com today.
POLYCYTHEMIA VERA
(polly-sigh-THEE-me-ah-VAIR-ah)

This brochure provides an overview of PV, including its symptoms, complications, and how you can take an active role in your care. Additional tools, information, and resources are available on PVvoices.com.
Polycythemia vera, or PV, is a rare, chronic blood cancer in which a person’s body makes too many red blood cells, white blood cells, and platelets. PV is part of a group of diseases called “myeloproliferative neoplasms” or MPNs. Every person with PV is unique and travels a unique path, but people may experience some common events along the way.

1 SOMETHING IS WRONG

The journey starts with the realization that something is wrong. Perhaps it was persistent, unexplained symptoms or elevated blood counts that were found during a routine check-up.
A hematologist, a specialist in blood diseases, may have been called in for evaluation. Testing may have taken time, with all the uncertainty that follows.

Diagnosis may have come as a shock, especially for people who didn’t have any symptoms. For people with symptoms, the diagnosis may have come as a relief. Finally, an explanation.

It may have been difficult to hear that PV is a chronic, slowly progressive disease, and that some people living with PV continue to get worse over time.

Treatment may have started with low-dose aspirin, but as the condition changed over time, phlebotomy or other medications that reduce red blood cell, platelet, and white cell counts may have been necessary. Dose adjustments, more frequent phlebotomy, and medication changes may have also been required. Overall, PV treatment may have had a major life impact.
MANAGING PV

Treatment may have helped lower blood counts and control symptoms for some time with regular monitoring and check-ins with a Healthcare Professional.

If the disease progressed, however, there may have come a point when blood counts and symptoms fell out of an acceptable range. Some patients continued to have an enlarged spleen or experience symptoms. And people with PV whose blood counts are too high have an increased risk of complications like heart attack or stroke.

Taking an active role in your care

Wherever you are in your journey, you can take an active role in your care. Regular monitoring and medical care can help detect any changes in your condition. Working with your Healthcare Professional and monitoring your blood counts can show if your condition is getting worse. You and your healthcare team can work to control your symptoms and reduce the risk of complications.

As a first step in taking a more active role, let’s learn more about PV on the following pages.
What is PV?

In PV, a person’s body makes too many red blood cells, white blood cells, and platelets (blood clotting cells). Thicker blood doesn’t flow as well, so organs may not get enough oxygen. Thicker blood also increases the risk of blood clots, which can cause heart attack or stroke.

What causes PV?

The cause of PV is not fully understood. Almost everyone with PV has a mutation of the Janus kinase 2 (JAK2) gene, but scientists are still studying the precise role of the mutation in the development of PV. The mutation (change) occurs in a stem cell in the bone marrow, which leads to uncontrolled blood cell production, especially red cells.
Who gets PV?

PV can occur at any age, but it is more common in people over 60 years of age. PV affects slightly more men than women. It is a rare disease. About 100,000 people in the United States are living with PV.

How serious is PV?

PV is a rare blood cancer that is chronic, which means it lasts a long time and may never go away. Some people with PV have no symptoms. Others have severe symptoms that interfere with their daily lives. PV is also a progressive disease. This means that it may get worse over time.

In a very small number of people, PV leads to other diseases such as myelofibrosis or leukemia. Additional complications of PV resulting from blood clots in your arteries or veins can include deep vein thrombosis, heart attacks, or strokes.

For more information and to register for periodic updates, visit PVvoices.com today. Don’t delay!
WHAT ARE THE SYMPTOMS OF PV?

Common PV symptoms

PV affects each person differently. Some people have no symptoms. In others, PV symptoms can interfere with daily life. Symptoms include:

- Tiredness (fatigue)
- Bone pain
- Muscle aches
- Sweating (at night or during the day)
- Blurred vision or blind spots
- Painful burning of the hands or feet
- Bleeding from the gums and heavy bleeding from small cuts
- Painful swelling in the big toe (a condition called “gouty arthritis”)
- Itching (especially after a warm shower)
Complications from an enlarged spleen

Your spleen helps your body fight infection and filter unwanted material, such as old or damaged blood cells. The increased number of blood cells caused by PV makes your spleen work harder than normal. This causes the spleen to get bigger. An enlarged spleen is known as splenomegaly (splee-nuh-MEG-uh-lee). Symptoms of an enlarged spleen can include:

• Pain or discomfort in your abdomen or under your left ribs
• Feeling full when you haven’t eaten or have eaten very little
Keeping your blood counts under control is important

Hematocrit is a measure of red cells in the blood and is stated as a percentage. A key sign that your PV is not being controlled is a hematocrit level above 45%. Having an elevated hematocrit level can increase the risk of serious health problems. These include heart attack and stroke.

Your Healthcare Professional may periodically order blood tests to monitor your condition. In addition to hematocrit, your Healthcare Professional may look at your red blood cell count, white blood cell count, and platelet count.

Keeping your blood counts — particularly your hematocrit — at the right levels is an important goal in managing PV. Stabilizing your blood counts can help lessen the chance of serious complications.
“My doctor and I are working to keep my hematocrit under 45.”
HOW CAN YOU **TAKE AN ACTIVE ROLE IN YOUR PV?**

Maintain a healthy lifestyle

Maintaining a healthy lifestyle is an important part of managing your PV. Taking small steps can add up to big changes over time. You can:

- Work toward a healthier diet by adding a fruit or vegetable to each meal
- Start walking or doing other physical activities, even for a few minutes a day at first
- Get a full night’s sleep as often as you can
- Get help breaking unhealthy habits (eg, cigarette smoking)

Pay attention to your symptoms

Many people with PV don’t realize that their symptoms may be caused by the disease. Fatigue may be attributed to getting older or conditions like high blood pressure or diabetes. Aches or pains may be attributed to aging or arthritis. Women may associate night sweats with menopause.
New or worsening symptoms may be a sign of uncontrolled PV. The earlier you are aware of your symptoms, the earlier you and your healthcare team can make any necessary changes in the management of your PV.

Talk to your Healthcare Professional

It is important to talk to your Healthcare Professional about any symptoms you have, even if you are not sure the symptoms are related to your PV. Talking to your Healthcare Professional about your symptoms helps you both:

- Understand how PV is affecting you
- Follow how your PV is changing over time
- Discuss options for managing your PV and its symptoms

Get help and support when you need it

Living with PV can be difficult, and everyone can benefit from help and support. You can join communities of people like you who are living with PV or caring for someone with the disease to ask questions, share stories, and share tips.

Take the first step in joining the PV community by visiting PVvoices.com.
Registering for resources

PV is a rare disease. You probably don’t hear it talked about much on the news. Many people have never heard of it. So where can you find out more about it? Visit PVvoices.com.

This website provides important information about PV and what people living with the disease can expect over time. You can also register to receive educational resources specific to PV. You will also find links that you can use to join the PV community and talk with other people like you who have PV or care for someone with PV.

Don’t wait. Visit PVvoices.com today.
Supporting PV Awareness

There are simple things you can do to show your support and raise awareness about PV. At PVvoices.com, you can get information and resources to help you:

SHOW IT!

Show your support and register for valuable tools and resources that can help you spread the word about PV.

WEAR IT!

Get free ribbons and bracelets to further the understanding about PV.

Colorful ribbons and bracelets are available—and you can order them for free. These ribbons and bracelets are great conversation starters, and they speak volumes about your commitment to PV awareness.

SHARE IT!

Join a virtual community eager to share experiences about living with PV or caring for someone who is affected by it. You can also share a PV awareness badge with your friends and family.
YOU CAN ALSO
ENGAGE WITH THE PV COMMUNITY

About Voices of MPN

Voices of MPN is an online community that provides information and resources to help make a difference in the care and support of people living with myeloproliferative neoplasms (MPNs), including PV, myelofibrosis, and essential thrombocytthemia.

Incyte Corporation has created Voices of MPN to provide a platform for the MPN community to share their stories, gain access to tools and resources, raise awareness of MPNs, and celebrate the MPN Heroes® in their lives.

Visit PVvoices.com today to learn more.

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