



Summer 2010

# Polycythemia Vera in Northeast Pennsylvania

## Schuylkill, Carbon and Luzerne Counties

### *Summary*

#### **About ATSDR**

ATSDR is part of the U.S. Department of Health and Human Services. It is a sister agency to the Centers for Disease Control and Prevention (CDC).

ATSDR gives information to the public to help you avoid contact with harmful materials. We use the best science we can to help you protect your health.

ATSDR has partnered with PADOH since 1989.

In 2008, the Pennsylvania Department of Health (PADOH) and the Agency for Toxic Substances and Disease Registry (ATSDR) confirmed more cases than expected of polycythemia vera (PV) in parts of Schuylkill, Carbon and Luzerne Counties in northeast Pennsylvania.

PV is a rare blood disease with no known cause. Over time, people with PV can develop headaches, tiredness, shortness of breath, blood clots and heart problems.

ATSDR and PADOH continue to assess the patterns and possible causes of PV in northeast Pennsylvania. This fact sheet is for people who have PV or who are concerned about PV. It provides information about PV in northeast Pennsylvania.

### *What Is Polycythemia Vera?*

PV is a rare blood disease. The bone marrow makes too many red blood cells, thickening the blood. That's why some people call PV "thick blood."

PV usually takes years to develop. Most people are diagnosed with PV later in life, most often around age 60 or older. People with PV might experience headaches, tiredness and shortness of breath. They are also at risk for getting blood clots, which can lead to heart attack and stroke.

At this time, there is no cure for PV. But treatment can control symptoms and avoid heart problems. Some people with PV do not need treatment. Even so, they should see their doctor regularly to remain as healthy as possible and catch problems early.

#### **Myeloproliferative Neoplasms**

Myeloproliferative neoplasms (MPNs) are blood disorders in which the bone marrow makes too many blood cells. PV is an MPN in which too many *red* blood cells cause health problems.

## *What Is JAK2?*

JAK2 is part of a signaling system (like a thermostat) that helps tell the bone marrow when to start and stop making blood cells. Most people with PV have an acquired mutation (change) in their JAK2, so the bone marrow makes too many blood cells. People are not born with the JAK2 mutation. We usually find the mutation in people over the age of 40.

People with the JAK2 mutation *might* have or develop PV or other MPNs. A positive test does not mean you will definitely get PV. People without the mutation probably will not develop PV (unless the mutation appears later in life).

A JAK2 blood test can help you find out if you have or might develop PV. To get a JAK2 blood test, ask your healthcare provider. They will draw a little blood to test, then contact you with the results.

## *How Common Is Polycythemia Vera?*

PV is rare. Each year, about one in 100,000 people are diagnosed with PV nationwide. In some parts of Schuylkill, Carbon and Luzerne counties, more people than expected have PV compared with other locations.

## *What Is Being Done?*

To learn more about PV in northeast Pennsylvania, PADOH is tracking the patterns of PV. ATSDR and its research partners are looking for trends and risk factors for PV. And the CDC is working to improve reporting systems for PV and other diseases. These groups are also giving information about PV to doctors, nurses, pharmacists and the public.

## *Should I Be Concerned About My Environment?*

Scientists cannot say for sure that anything in the environment causes PV. Even so, it is always a good idea to reduce your contact with harmful chemicals as much as you can, both at work and at home.

To learn more about reducing your contact with harmful chemicals in your home, visit the U.S. Department of Housing and Urban Development's Web page "Making Homes Healthier for Families" at:

<http://www.hud.gov/offices/lead/healthyhomes/index.cfm>

### **How Can I Learn More?**

- Ask your healthcare provider about JAK2 and PV.
- Visit ATSDR's Web page on PV: [www.atsdr.cdc.gov/sites/polycythemia\\_vera/index.html](http://www.atsdr.cdc.gov/sites/polycythemia_vera/index.html)
- Call ATSDR's toll-free PV information line: 866-448-0242

### ***MPN Tissue Bank***

*ATSDR is studying tissue samples from people with PV in the cluster area. If you have PV and live in this area, we invite you to participate. Please call:*

*Dr. Paul Roda, MD, FACP  
Geisinger/Hazleton Cancer Center  
Physician Liaison for Tissue Bank  
570-459-2901*

*Note: In the body, "tissue" is a group of cells that work together. An "organ" is a group of tissues that work together.*

### **PV and Your Environment**

ATSDR is trying to learn more about how things in your environment might alter the risk of getting PV. A few old studies suggested that PV might be caused by coming in contact with certain chemicals (benzene, embalming fluid, and petroleum products) or radiation. Other studies have not confirmed these findings.