ATSDR
AGENCY FOR TOXIC SUBSTANCES AND DISEASE REGISTRY

pennsylvania
DEPARTMENT OF HEALTH

March 2013

Polycythemia Vera and JAK2 Testing Information

Schuylkill, Carbon and Luzerne Counties, Pennsylvania

Summary

In 2008, the Pennsylvania Department of Health (PADOH) and the Agency for Toxic Substances and Disease Registry (ATSDR), a federal public health agency, identified an excess of polycythemia vera (PV), a rare blood disease with no known cause, in Schuylkill, Carbon and Luzerne counties. Most people develop PV later in life. The average age at diagnosis is about 60 years old.

In 2009, ATSDR and PADOH offered public health screening for a genetic marker known as JAK2. This genetic mutation has been observed in over 90 percent of patients with PV.

Although the meaning of a positive JAK2 test for someone who is in good health is not known, it is possible that people with this mutation may develop PV later in life. For persons with this mutation, health care providers may recommend that their blood counts and health status be more closely monitored.

The purpose of this fact sheet is to provide resources for individuals who would like to learn more about PV and other related diseases.

About the Agency for Toxic Substances and Disease Registry

The Agency for Toxic Substances and Disease Registry serves the public by using the best science, taking responsive public health actions, and providing trusted health information to prevent harmful exposures and diseases related to toxic substances.

What Is Polycythemia vera?

PV is a blood disorder in which the bone marrow makes too many red blood cells. This condition is sometimes referred to as "thick blood." Patients with PV may have few or no symptoms. However, patients with PV are prone to develop blood clots and are at increased risk of a heart attack or stroke.

What Is The JAK2 Test?

It is a blood test that determines the presence of the JAK2 genetic marker in blood cells.

This test provides information used to help diagnose PV in patients. People who have this genetic marker may already have or may develop PV or other related blood disorders known as myeloproliferative diseases or MPDs.

What Steps Should I Take?

If your health care provider thinks you are at risk of developing PV, or if you have a positive JAK2 screening result, he or she may refer you to a hematologist. A hematologist is a doctor who specializes in diseases of the blood and blood forming organs.

PV develops slowly. It may not produce signs or symptoms for years. PV is diagnosed based on signs and symptoms, medical history, a physical exam and test results. Early detection of PV, before signs or symptoms appear, could lead to medical care that prevents or delays complications of the disease.

While PV is not curable, appropriate treatment can help control the disease and its complications.

Important!

Having a positive JAK2 test does not mean that you have or will develop PV. However, the JAK2 genetic mutation has been observed in over 90 percent of patients with PV. If you have a positive JAK2 test, talk to your healthcare provider about the test, your health, and the need for additional evaluation.

Additional Resources:

The Myeloproliferative Diseases Foundation
Web site: *www.mpdfoundation.org*
Phone: 312-683-7243

The National Institutes of Health National Heart Lung and Blood Institute:
Web site: *www.nhlbi.nih.gov/health/dci/Diseases/poly/poly_whatis.html*
Phone: 301-592-8573

Leukemia & Lymphoma Society
Web site: *www.lls.org*
Phone: 914-949-5213800 OR 800-955-4572

Northeast Regional Cancer Institute
Web site: www.cancernepa.org
Phone: 570-970-6543 OR 800-424-6724

Local Specialists

The following is a list of specialists serving the tri-county area. This list is not an endorsement of these providers but, rather, is a listing based on geographical proximity to the area. Individuals are encouraged to use the health care provider that best meets their specific needs.

Geisinger Hazleton Cancer Center
Paul Roda, MD
Harsh Gandhi, MD
Jose Castillo, MD
1740 East Broad Street
Hazleton, PA
570-459-2901

Geisinger Medical Center ONC
Aneela Ali, MD
1175 E. Mountain Blvd.
Wilkes Barre, PA 18702
570-808-6150

Drs. Shah, Giangiulio and Ahmed
1240 S Cedar Crest Blvd
Suite 305
Allentown, Pennsylvania 18103-6218
Phone: (610) 821-2700

Dr. Shah
800 Mahoning Street
Suite F
Lehighton, PA 18235-1246
Phone: 610-377-5737

Lehigh Valley Physician Group
Hematology-Oncology Associates
Lloyd Barron II MD
Eliot Friedman, MD
1240 S Cedar Crest Blvd
Suite 103
Allentown, Pennsylvania 18103-6218
Phone: (610) 402-7880

Oncology Hematology of LV, PC
Neil Belman, DO
Yacoub Faroun, MD
701 Ostrum Street
Suite 403
Bethlehem, Pennsylvania 18015
Phone: (610) 821-2845

Geisinger Specialty Clinics - Wilkes-Barre
Arthur Meyer, MD
Charles White, MD
Paula Ronjon, MD
Albert Bernath Jr, MD

110 Trieble Road
Tunkhannock, PA 18657
570-996-2700
and
1000 East Mountain Blvd
Wilkes Barre, PA 18711
570-820-6150

Geisinger – Pottsville
Hematology – Oncology
Arthur Meyer, MD
Charles White, MD
Rodrigo Erlich, MD
Paula Ronjon, MD
Albert Bernasth, Jr., MD
529 Terry Reiley Way
Pottsville, PA 17901
570-624-4444

Geisinger Medical Center Hematology/Oncology
Maged Khalil, MD
100 N Academy Ave
Danville, PA 17822
570-271-6045

Pottsville Cancer Clinic
Satish Singla, MD
700 Schuylkill Manor Rd #7
Pottsville, PA
570-622-4113

Penn State Hershey Medical Center - Hematology/Oncology
Salah Almokadem, M.D.
David Claxton, M.D.
Leah Cream, M.D.
Joseph Drabick, M.D.
W. Christopher Ehmann, M.D.
Yixing Jiang, M.D.
Thomas Loughran, Jr. M.D.
Witold Rybka, M.D.

500 University Drive
Hershey, PA 17033-0850
800-243-1455
or 717-531-5076

CONTACT INFORMATION

For information about the screening:

Dr. Kenneth Orloff

Agency for Toxic Substances and Disease Registry

770-488-0735

For information about other ATSDR activities in the region:

Lora Siegmann-Werner
lkw9@cdc.gov
(215) 814-3141

ATSDR's PV Webpage:

www.atsdr.cdc.gov/sites/polycythemia_vera/index.html