



Summer 2010

Reporting Polycythemia Vera

Information for Healthcare Providers Serving Carbon, Luzerne and Schuylkill Counties

About ATSDR

ATSDR 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.

ATSDR is a sister agency to the Centers for Disease Control and Prevention (CDC) and has partnered with PADOH since 1989.

Reporting Laws and Regulations

The two state laws that require reporting are:

- *Pennsylvania Cancer Control, Prevention and Research Act, 35 P.S. §5631 et seq.*
- *Disease Prevention and Control Law of 1955, 35 P.S. §521.1 et seq.*

PADOH regulations concerning Reporting of Communicable and Noncommunicable Diseases require healthcare providers to report cancer cases not referred to or previously admitted to a hospital or other healthcare facility for diagnosis or treatment of cancer.

Summary

In 2004, the Pennsylvania Department of Health (PADOH) identified more cases of polycythemia vera (PV) than expected in parts of Carbon, Luzerne and Schuylkill Counties. To further investigate the reason for this disease cluster, PADOH and the Agency for Toxic Substances and Disease Registry (ATSDR) need healthcare providers to report cases of PV to the Pennsylvania Cancer Registry (PCR). The PCR is a statewide data system with information on all new cases of cancer diagnosed or treated in Pennsylvania.

Pennsylvania laws and PADOH regulations require reporting of new cancer cases to the PCR. PADOH and ATSDR thank you in advance for your assistance.

This fact sheet provides information about procedures for reporting cases of PV.

Why Report

Two state laws require that hospitals and laboratories report all cases of cancer that are diagnosed and/or treated in these facilities. PADOH regulations require healthcare providers to report cancer cases that are *not* diagnosed or treated in these facilities.

Data reported to the PCR help public health officials:

- Answer questions about cancer incidence.
- Allocate limited cancer control resources to areas where they are most needed.
- Evaluate cancer control efforts.

PV has been on the list of diseases reportable to the PCR since 2001. In 2004, PADOH identified more PV cases than expected in parts of Carbon, Luzerne and Schuylkill Counties. Since then, PADOH and ATSDR have been investigating the reason for this disease cluster. At this time, no links have been established between PV and exposure to chemicals in the environment. But PADOH and ATSDR believe it is important to investigate further.

The initial PADOH/ATSDR investigation found that nearly half of confirmed PV cases had not been reported to the PCR. Moreover, a third of PV cases that were reported did not meet 2001 or 2008 World Health Organization (WHO) PV criteria.

PADOH and ATSDR are analyzing PCR data to learn more about the distribution of PV in northeast Pennsylvania and the characteristics (e.g., age, gender, ethnicity) of those diagnosed with PV. This analysis will enable PADOH and ATSDR to understand possible public health implications and make recommendations for follow-up or further investigation. For the results of the analysis to be meaningful, however, PCR data must be accurate and complete.

What to Report

The PCR collects information about:

- Occurrence of cancer.
- Types of cancers diagnosed and their locations within the body.
- Extent of cancer at the time of diagnosis.
- Treatment patients receive.

All malignant polycythemias are reportable to the PCR, including:

- Proliferative polycythemia.
- Polycythemia rubra vera.
- PV.

In addition, healthcare providers should report other myeloproliferative neoplasms, including:

- Essential thrombocytosis.
- Primary myelofibrosis.
- Chronic myelomonocytic leukemia.

Secondary polycythemia, such as that occurring in patients with emphysema or pneumoconiosis, is not a hematologic malignancy and should not be reported.

How to Report

Some physicians and laboratories already have a reporting mechanism established with the PCR. Those who do not have a reporting mechanism established with the PCR should contact the registry directly to discuss how to report PV cases. Please contact:

Robin Otto (Registry Manager) or other registry staff
Bureau of Health Statistics and Research
Pennsylvania Department of Health
Phone: 717-783-2548 or 800-272-1850

Most cancer cases reported to the state registry come from hospitalized patients. PV is rarely a reason for hospitalization and thus is frequently not reported through hospital registries. Therefore, it is critical that physicians' offices report PV.

Health Insurance Portability and Accountability Act (HIPAA)

Because the PCR is a public health entity, HIPAA allows the reporting of data to the PCR. Written informed consent from each cancer patient is not required.

Contacting ATSDR

In addition to the required reporting, physicians and patients are welcome to contact ATSDR informally when new cases of PV are diagnosed from Schuylkill, Carbon and Luzerne Counties:

***ATSDR PV information line
866-448-0242***

***Dr. Elizabeth Irvin-Barnwell
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Fax: 770-488-1537
Email: jcx0@cdc.gov***