



# HCSP FACT SHEET

HCV ADVOCATE

• EXTRAHEPATIC MANIFESTATION OF HCV •

## *Porphyria Cutanea Tarda (PCT)*

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### *Foreword*

**Porphyrins** are complex molecules in the body that combine with iron to produce heme, which is responsible for giving blood its red color. They combine with globin to form hemoglobin. **Porphyria** is the name of a group of diseases caused by an excess of porphyrins in the blood. **Porphyria Cutanea Tarda (PCT)** is one of the most common types of porphyria, triggered by a deficiency of an enzyme called uroporphyrinogen decarboxylase (UROD). The reduced activity of UROD leads to an overproduction and buildup of the protein uroporphyrinogen in the blood and urine of patients. This results in an abnormal production of heme, a compound found in all body tissues and especially in the liver, bone marrow, and red blood cells.

### **Causes of PCT**

PCT can be caused or triggered by hemochromatosis (accumulation of iron in the liver), heavy alcohol use, estrogens (oral contraceptives, and prostate cancer treatment), viral infections (HIV and HCV), and possibly smoking. Hepatitis C is the most common infection associated with viral infection. In fact, some studies have found that, in people who have PCT that can be traced to a viral infection, greater than 50% are the result of the hepatitis C virus. An inherited deficiency of UROD is responsible for about 20% of cases of PCT.

The number of people in the United States who have been diagnosed with all forms of PCT is unknown but it is estimated that about 1 in 10,000 to 25,000 have PCT. The rates of PCT are higher in some populations. PCT occurs in both sexes and it usually strikes in adulthood and can affect any racial or ethnic groups.



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The information in this fact sheet is designed to help you understand and manage HCV and is not intended as medical advice. All persons with HCV should consult a medical practitioner for diagnosis and treatment of HCV.

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## Porphyria Cutanea Tarda (PCT)

**Important note:** Everyone with hepatitis C should be evaluated and receive HCV treatment. Current treatment is very expensive, and some insurance companies and Medicaid/Medicare are restricting HCV treatment to people with the most severe HCV disease. One of the conditions that qualify people for HCV treatment is extrahepatic manifestations. Discuss any symptoms with your medical provider and have them recorded in your medical records. If you are not approved for the drugs to treat hepatitis C, you may qualify for free drugs or co-pay assistance through a pharmaceutical patient assistance program. More information is available at the end of this fact sheet.

### Symptoms

The symptoms of PCT are mostly confined to the skin. Skin lesions or blisters are most often seen on the hands, forearms, back of the neck and face and areas exposed to the sun. The skin may become red, blister and peel after exposure to the sun or minor trauma. PCT can also cause either darkening or lightening of the skin, increased facial hair, scarring, alopecia (hair loss), thickening of the skin, itching and premature aging of the skin. In severe cases calcium may be deposited in the skin causing non-healing ulcers.

Liver function enzymes can be abnormal although enzymes are usually only mildly elevated. A liver biopsy is generally performed to assess iron stores and to check for any damage caused by PCT.

### Diagnosis

PCT is usually diagnosed by a blood test

that measures porphyrins in the blood, and the diagnosis is confirmed by testing for porphyrins in the urine and feces.

### Management

The signs and symptoms of PCT can be managed, but there is no cure; however it is one of the easiest of the porphyria conditions to manage and treat.

The most common management techniques include:

- Phlebotomies (the removal of blood) to reduce iron in the liver. Phlebotomies are given until the level of serum ferritin (iron) is reduced to about 20ng/ml. Phlebotomies can also reduce the porphyrins to normal levels in the blood. Once levels of ferritin and porphyrins have normalized PCT does not usually recur.
- Avoiding the sun when possible, use sunscreen and protective clothing such as gloves, hats, pants, and long-sleeved shirts when outside.
- Low doses of chloroquine or hydroxy-chloroquine (drugs that are used to treat malaria).
- Restriction of foods that contain iron.
- Treatment of the underlying disease (HCV) has also been found to decrease skin lesions as well as the amount of UROD's found in urine.

Talk with your medical provider to find out if treatment of HCV is right for you.

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Related publications:

- **American Porphyria Foundation**  
www.porphyrifoundation.com
- **An Overview of Extrahepatic Manifestations**  
http://hcvadvocate.org/hepatitis/factsheets\_pdf/Extrahepatic.pdf
- **Patient Assistance Programs**  
http://hcvadvocate.org/hepatitis/factsheets\_pdf/Patient\_Assistance.pdf

For more information

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| <ul style="list-style-type: none"> <li>• <b>Americans with Disabilities Act</b><br/>www.ada.gov</li> <li>• <b>Centers for Disease Control and Prevention</b><br/>www.cdc.gov</li> </ul> | <ul style="list-style-type: none"> <li>• <b>Mayo Clinic</b><br/>www.mayoclinic.com</li> <li>• <b>MedlinePlus</b><br/>www.nlm.nih.gov/medlineplus</li> </ul> |
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www.hepatitistattoos.org

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