Could It Be Acute Intermittent Porphyria? A checklist for you and your doctor

Acute intermittent porphyria (AIP) is a rare inherited disorder caused by a partial lack of an enzyme needed to make heme, a substance that carries oxygen to all parts of your body. This enzyme deficiency results in the build-up of certain chemicals in your body, causing symptoms to develop. If not treated, AIP symptoms, also called AIP "attacks," can cause damage to your body such as to your brain and nervous system.

Recognizing AIP can be hard for two reasons. One, symptoms of AIP are similar to those of many conditions. And two, AIP is rare. So a more common diagnosis may be given.

Signs and symptoms that may point to AIP

During AIP attacks, people often have some of the signs and symptoms listed below. **Check and write in any symptoms you are having.**

- ☐ Severe abdominal pain
- ☐ Nausea or vomiting
- ☐ Constipation
- ☐ Dark or reddish urine
- ☐ Muscle weakness
- ☐ Pain in extremities, back, chest, neck, or head
- ☐ Fast heartbeat
- ☐ High blood pressure
- ☐ Mental symptoms, such as minor behavioral changes, anxiety, confusion, or depression

☐ Other: _____

Symptoms and family history

Symptoms of AIP can occur throughout life. AIP is inherited, so you are more likely to develop it if you have a relative with AIP. **Answer the questions below about your symptoms and family history.**

1. How often do you have symptoms?

_____

2. When was the first time you had symptoms?

_____

3. About how long do your symptoms last?

_____

4. Do you have any relatives with AIP or relatives who have symptoms listed above?

_____

Things that can trigger AIP attacks

AIP attacks are "acute" and "intermittent," meaning they tend to come and go. Certain things may trigger attacks. **Check and write in the things that seem to trigger your attacks.**

- ☐ The week or two before your period starts
- ☐ Dieting
- ☐ Smoking cigarettes
- ☐ Drinking alcohol
- ☐ Taking certain medicines: _____

_____

- ☐ Feeling stressed
- ☐ Having an illness or infection

☐ Other: _____

Diagnosing AIP

Diagnosis of AIP may involve:

- Laboratory tests of chemicals in your urine
- A genetic DNA test

Working with your doctor

If you are diagnosed with AIP, you should work closely with your doctor to manage your disorder. There is no cure for AIP, but treatment is available.

Indications and Usage

PANHEMATIN is a hemin for injection prescription medication used to relieve repeated attacks of acute intermittent porphyria related to the menstrual cycle in affected women, after initial carbohydrate therapy is known or suspected to be inadequate.

Limitations of Use

- Before giving PANHEMATIN, consider an appropriate trial of carbohydrates [i.e., 400 grams of glucose (a carbohydrate or sugar) per day for 1 to 2 days].
- Attacks of porphyria may progress to a point where irreversible nerve damage has occurred. PANHEMATIN therapy is intended to prevent an attack from reaching the critical stage of nerve breakdown. PANHEMATIN is not effective in repairing nerve damage that has already occurred.

Important Safety Information

PANHEMATIN is not for patients known to be allergic to this drug.

- Vein inflammation is possible. Use a large arm vein or a central line to administer PANHEMATIN to minimize the possibility of vein inflammation.
- Elevated iron levels may occur. Your doctor must monitor your iron levels if you receive multiple courses of PANHEMATIN.
- PANHEMATIN has a passing and mild blood thinning effect. Avoid blood thinners during PANHEMATIN therapy.
- Reversible kidney shutdown has occurred when too high a dose of PANHEMATIN was given in a single dose.
- PANHEMATIN may carry a risk of transmitting agents that can cause infections, such as viruses, and theoretically, the Creutzfeldt-Jakob disease (CJD) agent.
- Most common side effects are headache, fever, infusion site reactions, and vein inflammation.
- **To report SUSPECTED SIDE EFFECTS, contact Recordati Rare Diseases Inc. at 1-888-575-8344, or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.**
- When taking PANHEMATIN, do not take drugs such as estrogens (e.g., oral contraceptives), barbiturates (drugs that help with sleep and used to treat epilepsy) or steroids (body hormone-like drugs), because such drugs can trigger an attack or make an attack worse.

For more information, please see Full Prescribing Information at www.Panhematin.com.

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