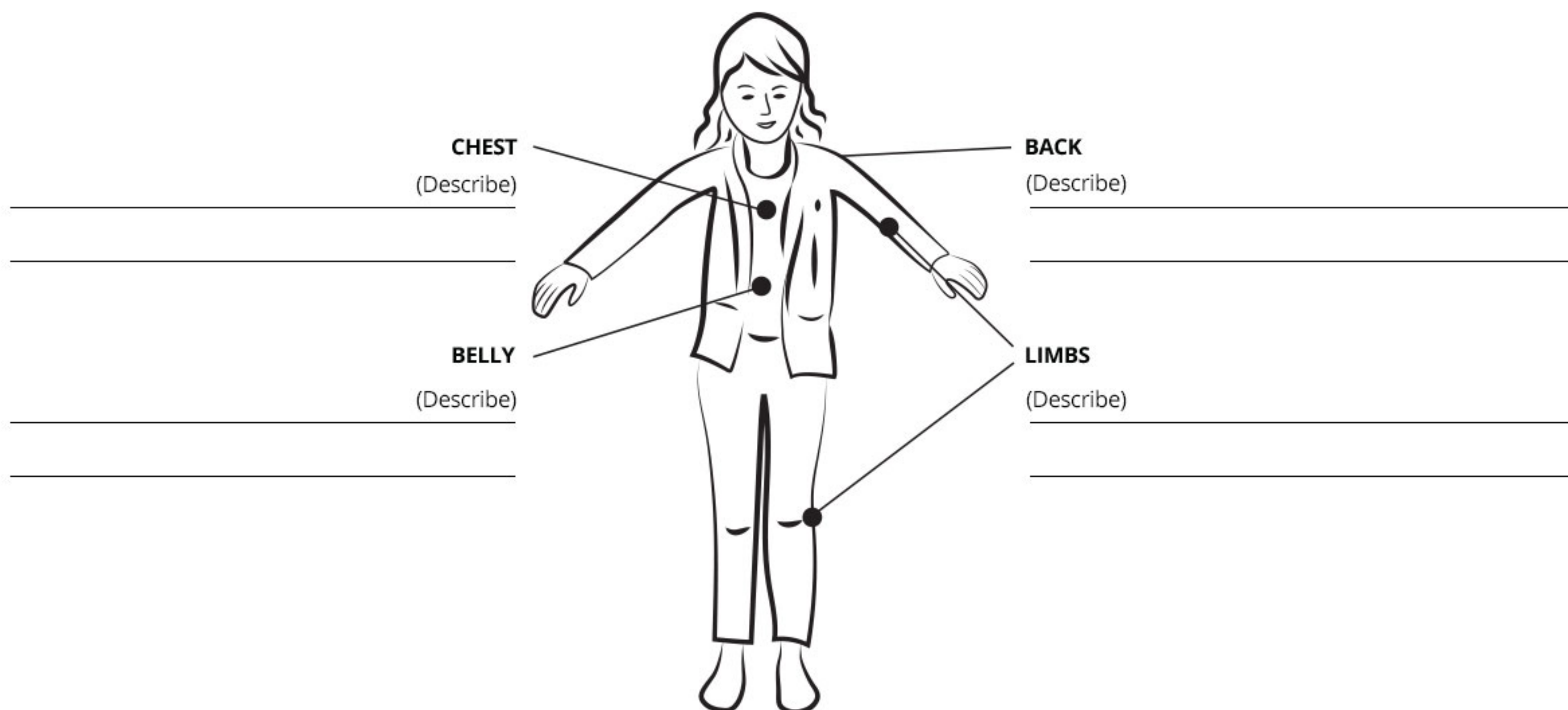


Use this discussion guide to help keep track of your signs and symptoms, and be sure to select all options that apply to your experience. During your next health visit, present this guide to your doctor to discuss if you should be tested for AHP.

## 1. Have you had severe, unexplained pain for more than one day in these areas?

Circle where you have experienced this pain and describe any details using the lines below.<sup>1</sup>



**CHEST**  
(Describe)

**BACK**  
(Describe)

**BELLY**  
(Describe)

**LIMBS**  
(Describe)

## 2. Have you experienced any of these signs and symptoms? Check all that apply<sup>1-5</sup>:

- |  |   |   |  |
|--|---|---|--|
| <input type="checkbox"/> Limb weakness or pain | <input type="checkbox"/> Confusion                | <input type="checkbox"/> Abdominal pain                           | <input type="checkbox"/> Dark or reddish urine |
| <input type="checkbox"/> Numbness              | <input type="checkbox"/> Anxiety                  | <input type="checkbox"/> Pain in back or chest                    | <input type="checkbox"/> Low blood sodium      |
| <input type="checkbox"/> Fatigue               | <input type="checkbox"/> Seizures                 | <input type="checkbox"/> Nausea and vomiting                      |  |
| <input type="checkbox"/> Tiredness             | <input type="checkbox"/> Insomnia                 | <input type="checkbox"/> Lesions or blisters on sun-exposed skin* |  |
| <input type="checkbox"/> Paralysis             | <input type="checkbox"/> Hallucinations           | <input type="checkbox"/> Rapid heart rate                         |  |
| <input type="checkbox"/> Respiratory paralysis | <input type="checkbox"/> Depression               | <input type="checkbox"/> High blood pressure                      |  |
| <input type="checkbox"/> Sensory loss          | <input type="checkbox"/> Constipation or diarrhea |   |  |

\*Hereditary coproporphyria and variegate porphyria only.

How long have you been experiencing these symptoms?

\_\_\_\_\_




Have your symptoms ever required you to go to the hospital?

Yes       No

Please write down any additional information you feel may be important to tell your doctor:

\_\_\_\_\_  
\_\_\_\_\_

### 3. Have you had any of the following diagnoses or surgeries? Check all that apply:

 <p><b>Gastrointestinal disorders<sup>5-7</sup></b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Irritable bowel syndrome (IBS)</li> <li><input type="checkbox"/> Acute gastroenteritis with vomiting</li> <li><input type="checkbox"/> Hepatitis</li> <li><input type="checkbox"/> Crohn's disease</li> </ul>	 <p><b>Neurological/neuropsychiatric disorders<sup>5,6</sup></b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Fibromyalgia</li> <li><input type="checkbox"/> Guillain-Barré syndrome</li> <li><input type="checkbox"/> Psychosis</li> </ul>	 <p><b>Abdominal conditions requiring surgery<sup>5</sup></b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Appendicitis (inflammation of the appendix)</li> <li><input type="checkbox"/> Cholecystitis (inflammation of the gallbladder)</li> <li><input type="checkbox"/> Peritonitis (inflammation within the abdomen)</li> <li><input type="checkbox"/> Intestinal occlusion (intestinal blockage)</li> </ul>
<p>After surgery, do you still have the same severe, unexplained pain?      <input type="checkbox"/> Yes      <input type="checkbox"/> No      <input type="checkbox"/> Not applicable</p>		

### 4. Have symptoms started within recent days after exposure to any of the following?

Check all that apply<sup>1</sup>:

					
<input type="checkbox"/> <b>SOME MEDICATIONS</b>	<input type="checkbox"/> <b>HORMONE CHANGES</b> including levels of estrogen and progesterone. These hormones fluctuate the most during the 2 weeks before a woman's menstrual cycle begins.	<input type="checkbox"/> <b>DRINKING ALCOHOL</b>	<input type="checkbox"/> <b>SMOKING</b>	<input type="checkbox"/> <b>STRESS CAUSED BY:</b> -Infections -Surgery -Physical exhaustion -Emotional exhaustion	<input type="checkbox"/> <b>FASTING</b> or extreme dieting

### 5. Have your symptoms disrupted parts of your life? Check all that apply<sup>8,9</sup>:

<ul style="list-style-type: none"> <li style="width: 50%;"><input type="checkbox"/> Sleep</li> <li style="width: 50%;"><input type="checkbox"/> Work</li> <li style="width: 50%;"><input type="checkbox"/> Eating</li> <li style="width: 50%;"><input type="checkbox"/> Socializing/Planning</li> <li style="width: 50%;"><input type="checkbox"/> Memory/Clear thinking</li> <li style="width: 50%;"><input type="checkbox"/> Completing tasks</li> <li style="width: 50%;"><input type="checkbox"/> Maintaining energy</li> <li style="width: 50%;"><input type="checkbox"/> Other: _____</li> </ul>	<p>How disruptive? <span style="display: inline-block; border-bottom: 1px solid black; width: 100px; margin: 0 10px;"></span>   1      5      10</p> <p>How frequently?   <input type="checkbox"/> Daily   <input type="checkbox"/> Weekly   <input type="checkbox"/> Monthly   <input type="checkbox"/> Yearly</p>
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### 6. Has anyone in your family been previously diagnosed with a type of AHP?

<input type="checkbox"/> Acute intermittent porphyria (AIP)	<input type="checkbox"/> Variegate porphyria (VP)	<input type="checkbox"/> Hereditary coproporphyrinemia (HCP)
<input type="checkbox"/> ALAD-deficiency porphyria (ADP)	<input type="checkbox"/> No	<input type="checkbox"/> Unsure

Please write down any additional information you feel may be important to tell your doctor:

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AHP refers to a family of rare genetic diseases characterized by potentially life-threatening attacks and, for some people, chronic debilitating symptoms that negatively impact daily functioning and quality of life.<sup>1,8</sup> The two most common techniques a doctor uses to determine if a person has AHP are a **urine test** and a **genetic test**.<sup>3,11</sup>

## Urine Test



- AHP can be diagnosed with a simple urine test of PBG (porphobilinogen), ALA (aminolevulinic acid), and porphyrin levels\*
- It is recommended to have a urine test during or shortly after an attack
- Porphyrin analyses may help identify the specific type of AHP, but are not used alone to diagnose AHP

## Genetic Test



- A genetic test using a blood or saliva sample may help to confirm a diagnosis or determine the specific type of AHP
- It can rule out AHP if there is not a genetic mutation
- A genetic test can be useful for family members of people with AHP who want to know if they carry the genetic mutation

\*PBG and ALA are substances that are produced when the liver makes heme. Increased levels of PBG and ALA can become toxic and have been associated with the symptoms and attacks of AHP.<sup>2,10</sup>

## One genetic testing option:

Doctors can request no-charge genetic testing through the AInylam Act<sup>®</sup> program for patients meeting certain criteria. While the program is sponsored by AInylam Pharmaceuticals, all services are performed by independent third parties.

For more information and program rules, download a brochure at [AInylamActAHP.com](https://AInylamActAHP.com).



AInylam Act

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