

Acute Intermittent Porphyria: Sharing Your Journey to Diagnosis

Acute intermittent porphyria (AIP) is a serious disease. It's important to tell others, especially women who are related to you, about AIP. This form is designed to help you tell the story of your journey to your diagnosis of AIP. The prompts will help you share your experiences. Several prompts include blank lines so you can write in your own responses. If you prefer to write your story without using the prompts, you can use the "My own words" box at the end of the form.

1. I was _____ years old when I first had symptoms of AIP.

2. My first symptoms were (check all that apply):

Severe abdominal pain

Nausea or vomiting

Constipation

Muscle weakness

Pain in my legs, arms, back, chest, neck, or head

Fast heartbeat

High blood pressure

Emotional changes, such as feeling anxious, confused, or depressed

3. My symptoms tended to occur:

Every day

About once a week

About once a month

A few times a year

Once a year or less

4. My symptoms tended to last:

Less than an hour

Many hours

A day

Many days

5. The first doctor I saw about my symptoms was a:

General practitioner, internist, or family doctor

Neurologist

Gastroenterologist

Gynecologist

Cardiologist

Emergency room doctor

6. Before I was diagnosed with AIP, I saw _____ (number) specialists about my symptoms.
These specialists included:

Neurologist

Gastroenterologist

Hematologist

Cardiologist

7. Before I was diagnosed with AIP, the doctors I saw about my AIP symptoms diagnosed me with:

8. I went to the emergency room or was hospitalized about _____ (number) times before I was diagnosed with AIP.

9. I was _____ years old when I was diagnosed with AIP.

10. I was diagnosed with AIP by a:

General practitioner, internist, or family doctor

Neurologist

Gastroenterologist

Hematologist

Cardiologist

11. I was diagnosed with AIP on the basis of (check all that apply):

Symptoms alone

Urine or lab tests

Genetic testing

12. Besides me, the other people in my family who have shown signs of AIP or have been diagnosed with AIP are my:

_____	Shown signs	Diagnosed
_____	Shown signs	Diagnosed
_____	Shown signs	Diagnosed
_____	Shown signs	Diagnosed

My own words: