

## ACUTE HEPATIC PORPHYRIA PATIENT RESOURCES AND QUESTIONS FOR YOUR CLINICIAN

## **Patient Education Resources**

<u>American Porphyria Foundation – Patient Portal</u>

<u>American Liver Foundation – AHP Patient Information</u>

My Cleveland Clinic – Acute Hepatic Porphyria for Patients

## **Questions to Ask Your Clinician**

- Can you explain AHP to me in simple terms?
- How did I get AHP? Will my children get it?
- What is causing my symptoms?
- How can we figure out what triggers my symptoms?
- What can I do for the severe pain?
- What are other possible causes?
- What kinds of tests do I need?
- Are there alternatives to the approach you are recommending?
- I have another health condition. How can I best manage these together?
- Are there any precautions or restrictions I should follow?
- Do I need genetic testing? If so, should my family members be screened?
- Are there new therapies available?
- Are there new therapies in development?
- Are there clinical trials I should know about?
- Should I call you or go to the hospital if I'm having an attack?
- Will I be able to live a long life with AHP?

