Do your patients with acute intermittent porphyria (AIP) have an Emergency Protocol letter for AIP attacks?

Untreated AIP attacks may lead to serious consequences, including peripheral neuropathy, paresis, respiratory and bulbar paralysis, chronic neuropathic pain, renal impairment, and even death resulting from cardiac arrhythmia or paralysis during an attack.

That's why prompt recognition and treatment of AIP attacks is so important.

To assist patients in getting the care they need, the American Porphyria Foundation has collaborated with Recordati Rare Diseases to develop an EMERGENCY PROTOCOL letter template**.** This form can be used to help inform a physician treating a patient in an emergency situation of the patient's treatment protocol for AIP attacks.

The attached Emergency Protocol template provides a framework that you can modify to explain your patient's AIP diagnosis. There is also space to provide your recommended treatment plan if the patient presents with symptoms of an AIP attack and also for your contact information. You may want to encourage your patient to carry the completed letter with them at all times so that they can give it to physicians who may not be familiar with AIP.

Being able to provide the Emergency Protocol letter will help ensure your AIP patients get prompt and appropriate care.

Recordati Rare Diseases Inc. • Lebanon, NJ 08833
www.recordatirarediseases.com/us NP-PHT-US-0225

EMERGENCY PROTOCOL
ACUTE INTERMITTENT PORPHYRIA

Dear Colleague,

first and last name , DOB , is a patient of mine who has been diagnosed with acute intermittent porphyria (AIP).

AIP is a rare genetic disorder caused by a partial deficiency of the enzyme porphobilinogen deaminase (PBGD) in the heme biosynthetic pathway. This enzyme deficiency predisposes patients to the effects of precipitating factors that can increase the demand for hepatic heme and lead to a chemical buildup that may cause symptoms to develop.

The most common symptom of an AIP attack is **abdominal pain** that is neuropathic in origin and described as severe, unremitting, and diffuse. **Dark or reddish urine** is another common clinical feature that is suggestive of an attack. Other symptoms may include vomiting, tachycardia, constipation, paresis, pain in extremities, back, neck, or head, and psychiatric presentations.

AIP attacks are usually due to the additive effects of several exacerbating factors. If left untreated, these attacks may lead to serious and potentially fatal outcomes.

If this patient was admitted to your facility due to an emergency, please contact me directly:
phone/email .

Treating Physician's Recommended Treatment Plan for first and last name **During an AIP Attack:**

Please note that many commonly prescribed drugs may increase the demand for hepatic heme and disrupt the heme biosynthetic pathway. **These drugs may exacerbate an AIP attack and should be avoided.**
A comprehensive listing of safe/unsafe drugs can be found at **https://porphyriafoundation.org/for-healthcare-professionals/drug-safety/.**

Sincerely,