



Do you have a plan for your next AIP attack?

Attacks of acute intermittent porphyria (AIP) can be very painful and also very serious. These symptoms may start suddenly, or they may begin more gradually and worsen over time.

Untreated attacks can damage your nervous system, leading to paralysis or even death.

That's why early diagnosis and treatment of AIP is so important.

To assist you in getting the care you need, the American Porphyria Foundation has collaborated with Recordati Rare Diseases to develop an EMERGENCY PROTOCOL letter template to help inform a doctor treating you in an emergency situation of your treatment protocol for AIP attacks.

Ask your doctor to write a letter following the attached template. This letter explains your diagnosis, provides instructions from your treating provider on what to do if you have an AIP attack, and provides contact information for your treating doctor. Carry the letter with you at all times so that you can give it to healthcare providers who may not be familiar with AIP.

AIP attacks can be scary, but having a plan in place can help you be more prepared for the challenges you may face.

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**EMERGENCY PROTOCOL
ACUTE INTERMITTENT PORPHYRIA**

Dear Colleague,

[redacted], [redacted], 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:

[redacted].

Treating Physician's Recommended Treatment Plan for [redacted] 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,