AMERICAN PORPHYRIA FOUNDATION
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RECORDATI RARE DISEASES
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ACUTE INTERMITTENT PORPHYRIA (AIP):

How can you better prepare for AIP attacks?

It's important to have a plan in place that can help you be more prepared for the challenges you may face if you have an AIP attack. Filling out this AIP attack preparation sheet can help you and your healthcare provider develop a detailed plan.

Check the boxes below to indicate the early warning symptoms and AIP attack symptoms you have experienced. You can also write in other symptoms you have had.

Early warning symptoms occurring hours or a few days before an AIP attack:

- ☐ Pain that is not just abdominal pain
- ☐ "Brain fog" or feeling mentally cloudy, confused, or unfocused
- ☐ Irritability
- ☐ Extreme tiredness
- ☐ Anxiety and/or agitation
- ☐ Headache
- ☐ Insomnia or trouble sleeping
- ☐ Other: _____

Symptoms occurring during an AIP attack:

- ☐ Severe abdominal pain
- ☐ Pain in the arms, legs, neck, chest, back, or head
- ☐ Vomiting
- ☐ Constipation, loss of bladder control, and/or diarrhea
- ☐ Dark or reddish urine
- ☐ Fast heart rate
- ☐ Muscle weakness
- ☐ High blood pressure
- ☐ Restlessness, anxiety, or confusion
- ☐ Other: _____

What steps should I take if I experience early warning symptoms or attack symptoms?

What friends or family members can I call to help me when I'm having an AIP attack and to potentially take me to a medical facility?

Name & phone number:

Name & phone number:

Name & phone number:

It will be helpful to share information about AIP and your experiences with AIP with your emergency contacts. This will help them understand what you are going through during an attack and how they can help you.

Whom should I call for medical advice if I suspect I am having an AIP attack?

Doctor name & phone number:

Nurse name & phone number:

Other office number:

After-hours number (nights, weekends, holidays):

What is my back-up plan if my doctor is not available?

Do I have an AIP Emergency Management Letter* ready that I can carry with me at all times? ◯ **Yes** ◯ **No**

If "No," then ask your doctor to write an AIP Emergency Management Letter.*

**An AIP Emergency Management Letter explains your diagnosis, should include results of genetic testing confirming your AIP diagnosis, provides instructions from your treating doctor on what to do if you have an AIP attack, and provides contact information for your treating doctor. A template for an AIP Emergency Management Letter is available HERE.*

Where should I go if I have an attack – which hospital, infusion center, or doctor's office?

Facility name & address and names of nurses or staff members who have been helpful during previous AIP attacks:

Facility name & address (back-up option):

Facility name & address (back-up option #2):

Do they have access to my medical records? ◯ Yes ◯ No

*If "No," then ask your doctor to write an AIP Emergency Management Letter.**

Does my health system have an app or patient portal where I can access my medical records? ◯ Yes ◯ No

If "Yes," I can access my medical records at:

If I have to go to the ER, which ER should I go to?

Facility name & address:

Facility name & address (back-up option):

Do they have access to my medical records? ◯ Yes ◯ No

*If "No," then ask your doctor to write an AIP Emergency Management Letter.**

**An AIP Emergency Management Letter explains your diagnosis, should include results of genetic testing confirming your AIP diagnosis, provides instructions from your treating doctor on what to do if you have an AIP attack, and provides contact information for your treating doctor. A template for an AIP Emergency Management Letter is available HERE.*

Living with AIP can be challenging, but having a plan in place will allow you to focus on getting the care you need if you have an AIP attack.

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