

QUESTION:

Porphyria is a complex condition and it's hard for patients to put together a "team" of doctors to collaborate on our care, especially when we may not know the systems of our body to regularly monitor and evaluate.

Can you recommend a list of specialties for acute porphyria patients, and a list of specialties for cutaneous porphyria patients?

**FOR ACUTE HEPATIC PORPHYRIA PATIENTS:**

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| Hematologist | Internal medicine doctors or pediatricians who have extra training in disorders related to your blood, bone marrow, and lymphatic system. | For patients with frequent acute attacks, it is helpful to have a hematologist who can setup outpatient heme infusions to minimize emergency department visits and hospitalizations. |
| Neurologist | Doctors who diagnose and treat problems with the brain and nervous system. They don't do surgery. | This is recommended in AHP patients who have residual neurologic symptoms after acute attacks. |
| Nephrologist | Doctors who specialize in conditions that affect the kidney | This is recommended if an AHP patient develops reduced kidney function. |
| Pain specialist | A medical doctor (M.D.) or doctor of osteopathy (D.O.) who specializes in pain medicine. Pain medicine is a medical specialty that focuses on the evaluation, treatment, and prevention of pain. | This can be helpful in patients who have chronic pain issues. |
| Hepatologist | Medical doctors who diagnose, treat, and manage problems associated with your liver, gallbladder, bile ducts, and pancreas. | While routine monitoring of liver function can be done by your primary care physician, those AHP patients with evidence of chronic liver inflammation should be followed by a hepatologist. |

FOR ALL CUTANEOUS PORPHYRIA PATIENTS:

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| Dermatologist | A dermatologist is a doctor who specializes in diagnosing and treating a broad array of conditions that affect your skin, hair, and nails. | This is recommended for advice on proper wound management and skin care. |
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EPP PATIENTS:

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| Hepatologist | Medical doctors who diagnose, treat, and manage problems associated with your liver, gallbladder, bile ducts, and pancreas. | While routine monitoring of liver function can be done by your primary care physician, those AHP patients with evidence of chronic liver inflammation should be followed by a hepatologist. |
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CEP PATIENTS:

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| Ophthalmologist | An ophthalmologist is a medical or osteopathic doctor who specializes in eye and vision care. Ophthalmologists differ from optometrists and opticians in their levels of training and in what they can diagnose and treat. | For management of photodamage to the eyes. |
| Hematologist | Internal medicine doctors or pediatricians who have extra training in disorders related to your blood, bone marrow, and lymphatic system. | For management of phlebotomy treatment. |
| Dentist | Dentists are trained professionals who help care for the teeth and mouth. Dentist also diagnoses and treats problems of the gums, teeth, and mouth | For management of oral manifestations. |