

Patient Education and Support Meetings



We are excited to hear that you are interested in hosting a Patient Education and Support Meeting in your local community. This is a valuable opportunity to bring patients, caregivers and supporters together to share common issues and to learn more about porphyria from an expert. Discussions often include medical explanations, information about current and emerging treatments, and an extended time for Q&A to answer specific questions. Bringing together a group facing similar issues in a social atmosphere is a meaningful and educational way to help individuals understand that they are not alone. We are here to help you coordinate your efforts.

MEETING DETAILS

To host a meeting:

- We encourage you to use a venue that is free of charge i.e. (Home, Church, Community Center)
 - Meeting attendance can range from 5 -50

The American Porphyria Foundation will:

- Send out invitations to your state and surrounding areas
 - Please allow us at least 2 months' notice to get invitations out with responses.
- Manage RSVP List
- Secure a Porphyria Expert or member of the Porphyria Research Consortium to speak
 - Depending on location – speaker on site, phone or Skype
- Provide educational materials and a *PorphyriaLive* DVD

Please fill out the information below and we will get back with you to map out planning details.

Name: _____

Porphyria Type: _____

Address: _____

City: _____ State: _____ Zip Code: _____

Phone: _____

Email: _____

When would you like to host this meeting? _____

Please return this form back to the American Porphyria Foundation by email at
edrinw@porphyriafoundation.org or by mail.