

INTERVIEW RESEARCH IN ACUTE PORPHYRIA (AP)

Sponsored by Alnylam Pharmaceuticals, in collaboration with Endpoint Outcomes, the American Porphyria Foundation and the British Porphyria Association

Are you an adult diagnosed with acute porphyria (AP)?

Have you experienced at least one porphyria attack in the past 2 years, but no more than 2 attacks-per-year in the past 2 years?

Participation



Interviews will be
scheduled
April - June, 2020

- We are looking for individuals with AP who do not currently receive prophylactic treatment to participate in a **90-minute in-person or telephone interview**.
- Our goal is to learn about your experience with AP. No medications will be given as part of this study.
- Your participation in the study will end upon completion of the 90-minute interview, which will be audio recorded, transcribed, and made anonymous.
- The aggregated results of the study, in which you will remain anonymous, may help explain the burden of AP and be published in a medical or scientific journal.

Compensation



- Eligible study participants will be paid \$150 upon interview completion via an electronic gift card.

Contact



If you are interested in participating, or would like more information about this study, **please contact us using the following e-mail address and include "AP" in the subject line.**

Recruitment is competitive and not all eligible participants may be invited to participate in an interview.

Email: research@endpointoutcomes.com

If you have other questions, please contact:

Endpoint Outcomes

11 Beacon Street, Suite 910, Boston, MA, 02108

Telephone: 617-607-3312

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