



THE
BRITISH PORPHYRIA
ASSOCIATION

Charity No. 1089609
www.porphyrin.org.uk

The Campaign #PorphyriaTogether

Dates 2-9 April 2022

Hashtags #PorphyriaTogether
#PAW2022
#PurpleForPorphyria
#Tell15

Raise awareness: Could you #Tell15 people about porphyria?

You could go a step further, and show one of three amazing documentaries (all aimed at different audiences: one on children and EPP, one on the acute porphyrias and one focused on EPP for adults) in school/work to really help raise awareness and get people talking – these documentaries really demonstrate the impact of porphyria on patients and their families.

We are a strong porphyria community, you are not alone, we are **#PorphyriaTogether**

Step-by-step guide: organise a porphyria film viewing

STEP 1: Decide which video (or videos) would be best for you to show

1. **Erythropoietic protoporphyria (EPP) film – aimed at all audiences and very suitable to children** (length: 7 minutes)

Dateline: Out of the Shadows – NBC News, piece by Andrew Finkelstein and Tommy Nguyen:

<https://www.nbcnews.com/dateline/video/full-episode--out-of-the-shadows-469336131891>

A wonderful awareness piece that speaks with children and their families from the USA. Summer is all about baseball games, laying out by the pool, barbecues in the sun. But there are a handful of kids who won't enjoy these activities this season, or at any time of the year.

2. **Erythropoietic protoporphyria (EPP) film – aimed at adults** (length: 20 minutes) **Overexposed: A film about light and erythropoietic protoporphyria:** <https://vimeo.com/359771483>

Andrea Minoglio's amazing moving documentary which uses a series of interviews and stories, included that of the filmmaker himself, to tell and show the strange 'love and hate' relationship that people suffering from EPP have with sunlight?

3. **Acute porphyria film – aimed at adults** (length: 25 minutes) **TWO OF ME: Living with Porphyria**

<https://www.porphyrin.com/patient-stories/documentary>

Alnylam Pharmaceutical's TWO OF ME: LIVING WITH PORPHYRIA film. It is 'A story of human strength, perseverance and survival, chronicling the lives of seven people around the world living with acute hepatic porphyria (AHP).' The film is directed by Emmy-nominated filmmaker Cynthia Lowen and sponsored by Alnylam Pharmaceuticals.

STEP 2: Decide on an event format

Decide whether you'd like to host your event in person or virtually.

In-person event

1. Decide how many people you would like to attend
2. Find a venue and reach out to them. Local schools, faith-based institutions, universities, libraries or community centres may be happy to provide a space for the event.

For further details on the BPA's Porphyria Awareness Week campaign
please contact: helpline@porphyria.org.uk

3. Make sure the venue is equipped with a projector and sound system. In the warmer seasons, consider outdoor movie spaces.
4. Decide whether you want to provide snacks, such as popcorn, or ask people to bring their own, or you might decide to make or buy food to sell – what about some purple-frosted buns?

Virtual event

1. Decide on a digital platform – such as Zoom or Teams.
2. Decide whether you will use the ‘share screen’ option to stream films for all participants or use the platform to bring your group together for introductions and then share a link to the film in the chat, so that everyone can watch on their own. (With this route, participants would mute to watch the film and then unmute to join the discussion again once the film is over).
3. Think about ways you could increase engagement – get people to dress in purple at home.

STEP 3: Invite people and promote your screening event

1. Post details or create an event page on social media
2. Ask for a few words to be included in community, school, work newsletters
3. Send email invitations
4. Print and hang/handout flyers around your business, campus, school
5. Ask people to wear purple [#PurpleForPorphyria](#)

STEP 4: Do a technical test

In-person event

1. Request technical screening assistance, and be sure the A/V equipment works and that the speakers can output at the necessary volume.

Virtual events

1. Test the streaming abilities on your platform before the event.
2. On Zoom, select “Share computer sound” when you enable your screen share.
3. To avoid sharing your entire screen (and content you may not want others to see), choose the correct screen share option. When you are prompted to choose a share option, you can choose to share your entire screen or share a specific program.

STEP 5: Send reminders

Make sure to send your audience reminders as the day approaches to keep your event top of mind.

STEP 6: Host your event

Screen the film to your audience and, after the film ends, instigate a conversation about the documentary. You could offer people the chance to ask you questions about how you are affected.

STEP 7: Let others know about ways they can help

1. Purchase porphyria awareness merchandise: <http://porphyria.org.uk/bpa-merchandise/>
2. Host a fundraising event: <http://www.porphyria.org.uk/wp-content/uploads/2017/01/Fundraising-Pack-2017.pdf> or take part in a sporting event. The BPA have places available for the Virtual London Marathon and the Great North Run, email for more details: helpline@porphyria.org.uk