

# This is #myporphyrria

## Campaign Toolkit

### The #MyPorphyria Awareness Campaign

On Global Porphyria Day 2024, the Global Porphyria Advocacy Coalition is launching the #MyPorphyria awareness campaign to highlight the realities of living with porphyria.

Porphyria is so much more than a list of symptoms. Each and every porphyria patient is unique and has their own story. #MyPorphyria promotes understanding by focusing on individuals' experiences of porphyria.

**The campaign will launch leading up to Global Porphyria Day on May 18, 2024, including:**

- Videos
- #MyPorphyria posts for Facebook, Instagram and Twitter
- Templates to create your own #MyPorphyria content
- A website to help direct patients, doctors and others to their national porphyria organizations

### How can I and my organization be involved?

1. Watch, like, comment on and share the #myporphyrria videos as they are released.
2. Encourage your members to share their own #myporphyrria story. Here are some ideas:
  - Print and fill out a #myporphyrria template, then post a photo with your #myporphyrria story
  - Post a photo of yourself and share a #myporphyrria experience in the caption
  - Use a blank template to share your #myporphyrria story
  - Don't forget to use the #myporphyrria hashtag so we can see what you've created!
3. Comment, share and like others' #myporphyrria stories



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**Custom materials:** If you represent a patient group and would like to customize the campaign materials (language, logo, colours or website) for your group, please contact us at [admin@gpac-porphyria.org](mailto:admin@gpac-porphyria.org)

### Campaign Materials- Videos

The first campaign video is live on the GPAC YouTube channel [@globalporphyria](https://www.youtube.com/@globalporphyria).

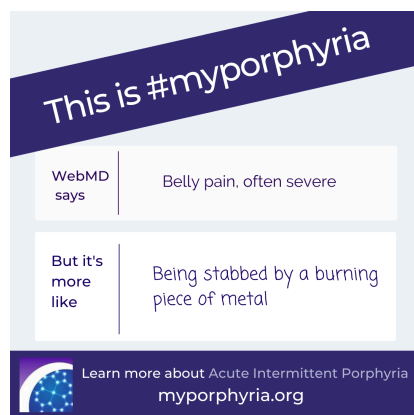
Additional videos featuring an in-depth look at different types of porphyria will be released leading up to

### Campaign Materials- Graphics

What is it really like to have porphyria? Use these templates to expand our understanding of porphyria beyond a list of symptoms:

- [Editable Canva posts](#)
- [Printable templates](#)
- [Posts and blank templates for different types of porphyria](#)
- Images and quotes of patients with porphyria

If you would like materials translated into a different language, or customized with your organization's logo, colours or website, please contact us at [admin@gpac-porphyria.org](mailto:admin@gpac-porphyria.org).



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### Campaign Materials- Sample Posts for Global Porphyrria Day Launch

#### **Not sure what to say? Here are some suggestions:**

As part of Global Porphyrria Day we're launching the #MyPorphyria awareness campaign to share how porphyria shapes our lives.

Join patients from around the world and share how porphyria impacts you. Visit [myporphyrria.org](http://myporphyrria.org) to find out how you can get involved.

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When talking about porphyria, let's go beyond what the textbooks say. The new #MyPorphyria campaign asks patients from around the world to share what porphyria is really like.

You can help us raise awareness! Find out how at [myporphyrria.org](http://myporphyrria.org). #porphyria

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What's it really like to have porphyria? For Global Porphyrria Day we asked patients from around the world to share how porphyria has shaped their lives. Here are some of their stories.

Learn more or share your #myporphyrria story at [myporphyrria.org](http://myporphyrria.org)

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Ever been told it's all in your head? Even though they can be invisible, the symptoms of porphyria are very real. Our new #MyPorphyria campaign shares the experiences of patients from around the world.

Find out how you can get involved at [myporphyrria.org](http://myporphyrria.org)

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Each and every porphyria patient is unique and has their own story.

We are very grateful to the patients who have shared their immensely personal stories of devastation, resilience and hope as part of #myporphyrria to awareness and ultimately generate better understanding and support for those impacted by porphyria!

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### Campaign Materials- Sample Text for Individual Posts

Porphyria can be hard to explain and the symptom list doesn't quite capture the reality. How have you learned to describe your porphyria?

We want to hear about your #myporphyria experience. Learn more at [myporphyria.org](http://myporphyria.org)

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The word "pain" doesn't even begin to capture how excruciating porphyria can be. Here is one way of explaining the pain of a porphyria attack. How would you describe your pain?

#myporphyria

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Porphyria can have a bewildering set of symptoms. What symptoms were you surprised to learn were part of your porphyria?

Share your #myporphyria experience. Learn more at [myporphyria.org](http://myporphyria.org)

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A porphyria diagnosis can take decades, and during that time you can wonder if it's all in your head. What was your diagnosis experience?

Share your #myporphyria experience. Learn more at [myporphyria.org](http://myporphyria.org)

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Porphyria can be lonely. Have you ever felt like your porphyria was keeping you apart?

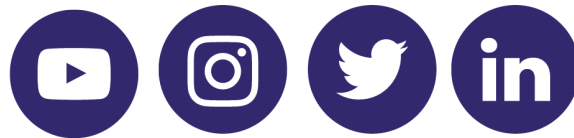
Share your #myporphyria experience. Learn more at [myporphyria.org](http://myporphyria.org)

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### Social Media Accounts

Don't forget to find, follow and tag us at **@GlobalPorphyria** on:



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