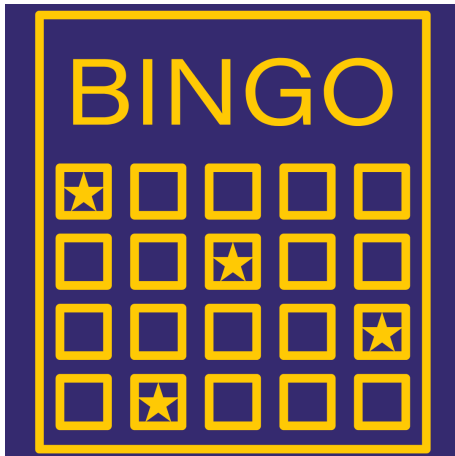


## The Future of Porphyria...



### PATIENT BINGO

This past weekend, United Porphyrias had the absolute pleasure of attending a Basket Bingo fundraiser that was organized by a patient's dedicated community to assist with medical bills and other out of pocket expenses.

It was truly and honor to attend and participate in such a fun and meaningful

event. UPA provided a customized handout and presented at the event.

If you are interested in hosting a fundraiser or awareness event and would like us to attend or provide custom handouts and information vetted by expert physicians, please email us at [info@porphyria.org](mailto:info@porphyria.org)

### WHAT'S UP, DOC?

Have you seen the [“What’s Up, Doc?”](#) section on our website? Every week, one of our expert physicians answers a question from YOU, the patient community. We have been flooded with questions from you all and we are having them answered one by one. If you have a question, please email it to [info@porphyria.org](mailto:info@porphyria.org) and stay tuned for your question is featured.



Please remember that you do not have to wait for your question to appear in What's Up, Doc – we'll be glad to engage the [UPA Expert Scientific Advisory Board](#) to support you at any time!

ASK A QUESTION



## CPAG MEETING

United Porphyrias is the designated patient advocacy group for the [Porphyrias Consortium](#) (PC), the network of expert porphyria doctors and scientists in the US. The PC is part of the NIH [Rare Disease Clinical Research Network \(RDCRN\)](#) which funds critical porphyria research. Each year, RDCRN hosts an annual meeting that engages all NIH-funded groups within the rare disease network.

This year, the meeting will take place on May 5-6.

We are proud that [Dr. Amy Dickey](#), Porphyria Specialist (MGH, Boston, MA) was selected to give a presentation related to novel research in the porphyrias and Kristen Wheeden, UPA, will moderate the concurrent 188-member Coalition of Patient Advocacy Group meeting.

[LEARN MORE](#)

## HOPE IN ACTION

Did you know our President, Kristen writes for [Porphyria News](#)? Have you seen her latest ["Hope in Action"](#) column?

This past week Kristen discussed having our Porphyria Experts, of the Porphyrias Consortium in town for our first in person meeting of 2022. Make sure to subscribe to Porphyria News, so you don't miss her column!



[PORPHYRIA NEWS](#)

## Let United Porphyrias help you celebrate Mother's Day!

Mother's Day 2022 is right around the corner, and we are here to help!

If you donate between now and **May 5th**, we'll send a Mother's Day card or e-



card to that important mother in your life.

Your donations allow us to continue our mission of improving the quality of life of the porphyria patient community.

**There are two ways to give:**

**1. Donate a one-time gift of \$30**

**OR**

**2. Sign up to give a \$10 minimum recurring donation**

Make sure to fill out the "special note" box with the recipient's name and mailing address OR their email address if they would prefer an e-card.

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**DONATE**

