



**UNITED PORPHYRIAS**  
ASSOCIATION  
Advancing Awareness, Research & Therapies

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## Advancing Awareness, Research & Therapies

**Hello Member,**



**THE UNITED PORPHYRIAS ASSOCIATION WISHES YOU A HEALTHY & PEACEFUL HOLIDAY SEASON!**

We bring 2022 to a close with deep gratitude for your tremendous support and an eye on all there is to accomplish in 2023! UPA will remain hyper-focused on our vision of a world without the pain and challenges of porphyria through advancing awareness, research & therapies.

**On behalf of our dedicated Board of Directors, Scientific Advisory Board, President's Council, and staff – have a joyous holiday season and we look forward to seeing you in the new year!**

**WITH APPRECIATION  
FOR OUR DEDICATED PHYSICIANS**

The expert clinicians and researchers of the NIH-Supported Porphyrrias Consortium, who dedicate their expertise to United Porphyrrias, have made significant contributions to the porphyria community. We acknowledge and appreciate their expertise and support!

**Karl E. Anderson, MD (Chair)**

University of Texas Medical Branch, Galveston, TX

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Jefferson Center for Genetic Metabolic Liver Disease,  
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**Gregory M. Vercellotti, MD, FACP**

University of Minnesota Med School, Minneapolis, MN

**Bruce Wang, MD**

UCSF Porphyria Center, San Francisco, CA

**Makiko Yasuda, MD, PhD**

Icahn School of Medicine at Mount Sinai, New York, NY

## PORPHYRIA PUBLICATION ALERT

Check out the latest article led by UPA Scientific Advisory Board Member Amy Dickey, MD (Massachusetts General Hospital) about porphyria in the **Journal of the American Academy of Dermatology**.



Entitled *Prospective observational pilot study of quantitative light dosimetry in erythropoietic protoporphyria*, this study explored novel strategies for measuring light tolerance in patients with EPP.

Stay tuned for a ***What's Up Doc?*** description on light dosimetry and why it matters!

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**Amy Dickey, MD**  
UPA Scientific Advisory  
Board Member

See the article: [Click here](#)



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**JOIN US FOR A FACEBOOK LIVE SESSION**



**PORPHYRIA  
TOGETHER**

The Porphyria Together Facebook group will host a **Facebook Live Q&A Session** with UPA Scientific Advisory Board Member Dr. Bruce Wang (Porphyria Expert, UCSF) on January 12, 2023. Take this opportunity to ask your porphyria questions to a physician expert. Details to be announced! Join the Facebook group [here](#).

**JOIN NIH RARE DISEASE DAY 2023!**



## **RARE DISEASE DAY** at NIH

Feb. 28, 2023 | #RDDNIH

**Rare Disease Day** is celebrated on the last day of February each year to raise awareness about rare diseases and their impact on patients and caregivers. The **National Institutes for Health (NIH)** hosts a terrific rare disease day event to initiate and discuss important topics in rare disease research, the people they impact, and the collaborations that are advancing critical research. The NIH-sponsored Porphyrrias Consortium, your team of expert physicians, is at the center of this important research!

The 2023 hybrid event will take place both online and in-person on the NIH main campus! This year, Rare Disease Day at NIH will feature a session including Porphyrria! UPA Member Jennifer Beck and UPA President Kristen Wheeden will discuss collaborations in research and the impact of therapeutics.

REGISTER AND VIEW AGENDA: [Click here to register](#)

**DONATE HERE**

Add United Porphyrrias **INSTA, FACEBOOK, TWITTER** to your social media feeds.



**UNITED PORPHYRIAS**  
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