



UNITED PORPHYRIAS
ASSOCIATION

Advancing Awareness, Research & Therapies

TODAY IS #RAREDISEASEDAY!

Dear Member, did you know that there are 300 million people worldwide living with a rare disease, like porphyria?



[Rare Disease Day](#) takes place each year on the last day of February. During Rare Disease Day, we aim to raise awareness amongst the general public and encourage researchers and decision makers to address the needs of those living with rare diseases. The United Porphyrias Association is proud to celebrate Rare Disease Day and hope you will join us!

Learn more about how you can participate below.

LIKE, COMMENT AND SHARE











Use social media to raise awareness for Rare Disease Day and to share YOUR story. Be sure to like, comment, and share the UPA's Rare Disease Day posts on Facebook, Twitter, and Instagram to help us raise awareness for the rare disease community across the world!



JOIN US THIS AFTERNOON



Rare Diseases Therapeutics and the Role of Advocacy and Industry Collaborations

MODERATOR					
 Shazia Ahmad Senior Director, Head of Patient & Physician Services, UBC	 Sharon J. King Manager, Advocacy and Community Engagement, Aldevron	 Sandra Abrevaya, J.D. Rare Disease Caregiver; Co-Founder, I AM ALS	 Brian Wallach, J.D. Rare Disease Patient; Co-Founder, I AM ALS	 Kristen Wheeden, M.B.A. Rare Disease Caregiver; CPAG Representative, Porphyrias Consortium, RDCRN; President, United Porphyrias Association	 Jennifer Beck Erythropeitic Protoporphyrin Patient and Advocate
					
PANELISTS					

UPA President Kristen Wheeden and member Jennifer Beck (EPP) will speak on a *Rare Diseases Therapeutics and the Role of Advocacy and Industry Collaborations* panel during Rare Disease Day at the National Institutes of Health.

This session will explore the spectrum of advocacy–industry collaborations across the life cycle of therapeutic development and share how patient advocacy can play an important role in research efforts. Panelists from patient advocacy and industry will encourage participation in research and inspire hope for future treatments in more rare diseases. View the agenda and register to attend (in person or virtually) [here](#).

KICKING OFF RARE DISEASE WEEK!



Rare Disease Week on Capitol Hill

United Porphyrias will join the EveryLife Foundation on Capitol Hill with hundreds of rare disease advocates, including several porphyria friends, to make our voices heard by Members of Congress on policies impacting the rare disease community.

Learn more and attend virtually [here](#).



Rare Artist Returns to DC

Jennifer Virag, UPA member, will join Rare Disease Week as a former Rare Artist Award Winner and share issues related to the burden of living with porphyria.

View her winning work, Starry Burst, [here](#).

SPECIAL HOPE IN ACTION COLUMN



Joining forces is crucial to raising awareness of rare diseases |...

In my column, " Hope in Action," I write about porphyria and the lived experiences of those affected by this group of ultrarare diseases. But for Rare Disease Day today, I want to take a macro view of rare diseases. According to the National Organization for Rare Disorders, a disease is considered rare when it affects fewer than 200,000 Americans.

[Read More](#)

STAY IN TOUCH!

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