



UNITED PORPHYRIAS
ASSOCIATION

Advancing Awareness, Research & Therapies

SPECIAL UPDATE

Get the latest

Growing up with porphyria can be tough. We're thrilled to share resources for children and young adults with EPP and XLP... and their parents and caregivers too!

NEW SHADOW JUMPERS ADVENTURE!



Shadow Jumpers move from shadow to shadow to find the next safe place. This story follows Jackson and his friends, who have EPP. When an evil villain, UV man, threatens the world Jackson and the other Shadow Jumpers spring into action. Will the knowledge and power they've gained from their experiences with EPP be enough to save the day?

Read the comic online

Want your very own printed book?

We have a limited number of print copies available.

Please email us at info@porphyria.org to request your copy.



The Research Behind the Book



The Shadow Jumpers book is an evidence-based resource developed from [published research](#).

The study asked parents, young adults and children about their day-to-day experience of EPP. The research found that:

- EPP has a major impact on quality of life
- There was a need for more age appropriate information for children with EPP

[Read the study](#)

Special Thanks to Disc Medicine

We'd like to extend a huge thank you to [Disc Medicine](#) for supporting the development and printing of this book.



Disc Medicine is currently recruiting EPP patients for a clinical trial (ages 18+)- see the section below for more information on how to participate.

IT'S TIME TO THINK ABOUT SUMMER CAMP REGISTRATION!

For kids, having EPP can set you apart. Summer camps are a great way to have some fun with other kids who know what you're going through. Here are options that accommodate kids with EPP/XLP.



Camp Discovery (Burton, TX)

Camp Discovery is a one-week summer camp for kids with chronic skin conditions - perfect for those who cannot be outdoors during daylight.

The facility has a wonderful indoor space including a recording studio, climbing wall, challenge course and a large gym. Activities include hiking, swimming, and horseback riding at night!

- Dates: August 6-11, 2023
- [Referral form](#)
- For additional information, email jmueller@aad.org



Camp Wonder (Rutledge, GA)

Camp Wonder is a summer camp for children with any skin disease, ages 6 – 16.

Each year children and young adults take a break from being a patient for a week and focus on just being a kid. It is a unique environment of acceptance and support, to empower children to be themselves, not feel limited by their skin disease.

- Dates: June 18-23, 2023
- [Referral form](#)
- For additional information, email applications@cddf.org

Camp Sundown

Camp Sundown is not doing a summer session this year. Stay tuned for 2024 updates!

CHECK OUT OUR FRIENDS: SHADOW JUMPERS

Shadow Jumpers is an organization that provides meaningful experiences and a sense of community to individuals and families living with sun-related disorders and disabilities!

www.shadowjumpers.org





Looking for an expert to answer your porphyria questions?

Dr. Bruce Wang (Porphyria Expert, USCF and UPA Scientific Advisory Board Member) will be taking your questions live on **Saturday, February 18 at 1 PM ET** on our [Porphyria Together](#) Facebook group.

All porphyrias welcome. Be sure to join the [Porphyria Together group](#) in advance and we'll see you there!

[JOIN GROUP](#)

CURRENT RESEARCH OPPORTUNITIES

Participating in porphyria research is an important way that we can make a difference. Research gives us a better understanding of porphyria and is an important part of developing and testing new treatments.

Below are some current research opportunities. You can learn more about these and new opportunities [here](#) or by contacting **UPA at 1-800-868-1292** or info@porphyria.org.

EPP

DISC MEDICINE - BITOPERTIN

- Phase 2 Clinical Trial for patients with EPP.
- If you'd like more information, please [fill out this short form](#)

EPP/XLP

EPP/XLP Gene Modifier Study

- Study investigating genetic factors associated with differences in light sensitivity among patients with EPP and XLP.

CIMETIDINE

- Assessing treatment with Cimetidine in patients ages 15+ with EPP/XLP.
- Note: there is no longer a requirement to experience symptoms within 30-minutes of sunlight exposure.

ALL PORPHYRIAS

(EPP, XLP, CEP, VP, AIP, HCP, PCT, HEP, ADP)

LONGITUDINAL STUDY

- Long-Term Follow-Up Study to Better Understanding the Natural History of Porphyria.

Learn more about research opportunities [here](#)
OR
by contacting UPA at 1-800-868-1292 or info@porphyria.org.

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