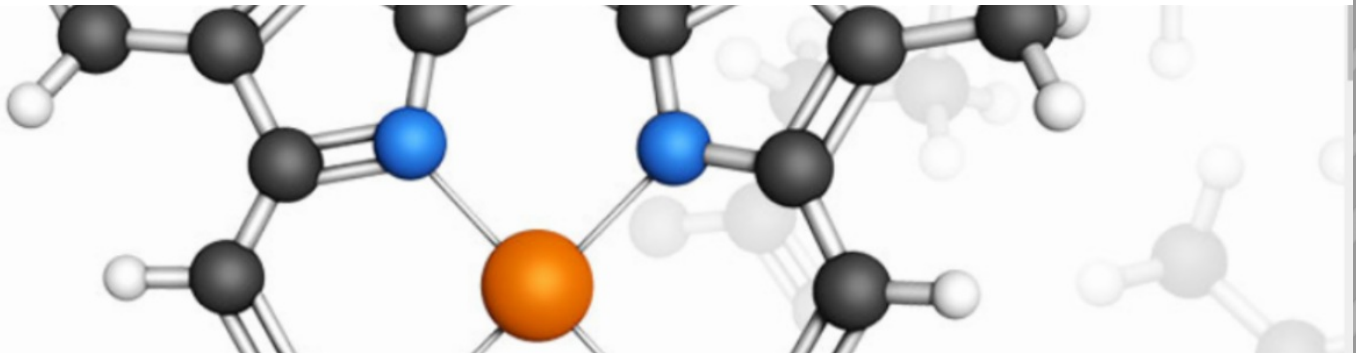




UNITED PORPHYRIAS
ASSOCIATION
Advancing Awareness, Research & Therapies

Get in Touch



Advancing Awareness, Research and Therapies

Hello Member,



EPP/XLP CIMETIDINE RESEARCH STUDY

Announcement: Recruiting volunteers for new EPP and XLP research study

Study Name: Effect of Oral Cimetidine in the Protoporphyrins

Dr. A. Dickey at Massachusetts General Hospital, **Dr. K. Anderson** at the University of Texas Medical Branch, and **Dr. H. Bonkovsky** at Atrium Wake Forest Baptist Health are currently recruiting patients with EPP who are 15 years of age or older for a study investigating whether taking oral cimetidine pills can affect your EPP or XLP symptoms. The study will test whether **Cimetidine** (a medication normally used to treat gastrointestinal issues such as ulcers or acid reflux) can reduce the level of protoporphyrin in your blood, and if it can affect your symptoms.

The entire study will last 9 months. For 4 months of the study, participants will be asked to wear a wearable light sensor and respond to brief surveys sent by text message. In some cases, the entire study may be able to be completed with telemedicine visits.

Please contact the United Porphyrrias Association (UPA) on 1-800-868-1292 or email info@porphyria.org for more information.

Get More Info



No issue is too small to bring to the UPA Scientific Advisory Board of expert physicians. Every single day, we are connecting patients with our expert doctors for information on the diagnosis, management, and treatment of the porphyrias. We often connect doctors for a peer-to-peer consult. Getting your questions and issues answered is our #1 priority. Don't hesitate to reach out for support – it's what we do!

The **UPA Scientific Advisory Board** is comprised of the foremost experts in the porphyrias and heme biosynthesis in the USA.

This Board reviews all materials and resources that are offered by the United Porphyria Association.

UPA is the designated patient advocacy group for the **Porphyrias Consortium** network which includes 6 Porphyria Centers and 8 Porphyria Satellite Centers across the US.

[Email Now](#)

RARE
ACROSS AMERICA

EVERY VOICE, IN EVERY DISTRICT, MATTERS

The United Porphyrias Association is excited to participate in this year's Rare Across America and encourage you to join us!

Rare Disease Legislative Advocates (RDLA) organizes meetings for rare disease advocates with Congress Members and/or their staff with the Member's in-state, district office. Meetings with Representatives will be in-person and meeting with Senators will be virtual. Advocates have the option of attending an in-person meeting with their Representative and/or virtual meetings with their Senators. You can choose to do both the in-person meeting with their Representative and the virtual meetings with their Senators.

The RDLA team also helps to prepare advocates for their meetings, provides legislative resource materials, and hosts pre-meeting training webinars. No prior advocacy experience is necessary. Don't miss out! Registration closes July 8th.

[Register Here](#)

Member Highlight

This month, we would love to introduce you to our friend, Victor! Victor is an amazing member of the UPA's Presidents Council and devoted to

helping those with EPP understand their diagnosis. Thank you, Victor for all that you do!

[Share Your Story](#)

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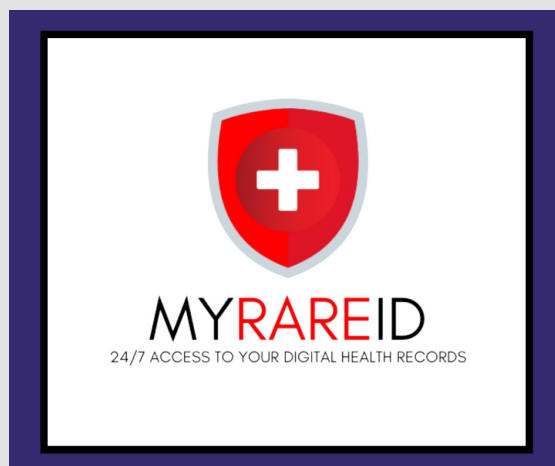
I WAS DIAGNOSED AT THE AGE OF 6 WITH EPP AFTER MY PARENTS NOTICED FROM OUR HOME MOVIES THAT EVERY TIME, I WAS OUTSIDE I WAS EXPERIENCING ANGUISHING DISCOMFORT.

I NEVER FULLY COMPREHENDED MY DIAGNOSIS UNTIL I WAS ABLE TO CONNECT WITH OTHER PATIENTS WHO HAVE HAD SIMILAR JOURNEYS SUCH AS MY OWN.

WITH THE HELP OF THE UNITED PORPHYRIAS ASSOCIATION, I WANT TO BE ABLE TO HELP OTHERS LIVE MORE COMFORTABLY WITH EPP AND SUPPORT THE VISION OF A WORLD WHERE PATIENTS ARE FREE FROM THE PAIN AND CHALLENGES OF PORPHYRIA.



VICTOR MEJIAS
ERYTHROPOIETIC
PROTOPORPHYRIA (EPP)



MY RARE ID

My Rare ID is a company that produces digital portable health records, and United Porphyrins is proud to be involved in their partner program. Whether it's a card to carry in your wallet, keychain or ID jewelry-- they can meet your needs. We will be working with them to create porphyria specific items. Email us today for our unique coupon code at info@porphyria.org

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