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“ASK ME ABOUT PORPHYRIA” CAMPAIGN BRINGS ATTENTION TO RARE, LIFE-THREATENING DISEASE

American Porphyria Foundation to Host Porphyria Awareness Week April 18-25, 2020

(BETHESDA, MD) – Porphyria affects fewer than 200,000 Americans. Due to the wide array of symptoms and the rarity of the condition, porphyria is often misdiagnosed and misunderstood by the medical community. The [American Porphyria Foundation](http://www.porphyriafoundation.org) is working to change that.

The non-profit porphyria research and advocacy organization is hosting [Porphyria Awareness Week](#) April 18-25 to spread the word about Porphyria.

“Porphyria Awareness Week has grown substantially in previous years and now represents a push for global awareness of porphyria research efforts and treatment,” says APF Executive Director, Kristen Wheeden.

Porphyria is not a single disease but a group of eight inherited genetic disorders that differ considerably from each other. A common feature in all the Porphyrias is the accumulation in the body of porphyrins or porphyrin precursors. These are normal body chemicals, but they normally do not accumulate. Precisely which of these chemicals builds up depends on the type of Porphyria.

Supporting the Porphyria community since 1983, the APF’s mission is to improve the health and well-being of all individuals and families impacted by Porphyria. The APF maintains a focus on education, advocacy, support services and research for the prevention, treatment and cure of the Porphyrias. Additionally, the APF serves as patient advocates to public, private, and government agencies interested in funding research and educational programs. The APF [Scientific Advisory Board](#) is comprised of the world's foremost experts in Porphyria diagnosis, management and treatment.

Throughout Porphyria Awareness Week, the APF will continue to educate others on porphyria by collecting and distributing awareness information from patients and the APF on [Twitter](#), [Instagram](#) and [Facebook](#). Visit the [Porphyria Awareness Week 2020 landing page](#) for more information, listing of special events, and a media kit.

[We are writing to ask you to join the Rare Disease Congressional Caucus in support of your constituents with Porphyria.](#) This bipartisan, bicameral Caucus is co-chaired by Representatives G.K. Butterfield (NC) and Bus Bilirakis (FL) and Senators Roger Wicker (MS) and Amy Klobuchar (MN).



Your participation in the Caucus will help give a voice to the more than 30 million Americans and their families affected by a rare disease. There are more than 7,000 rare disorders, however over 90% do not have treatments approved by the FDA. Since the Orphan Drug Act was enacted in 1983, however just over 500 treatments have received FDA approval. The science exists for many of these diseases to be treated; however, treatments may never be developed because of roadblocks in the development process, such as a lack of investment and a challenging regulatory environment.

I hope you will become a champion for the rare disease community and help seek solutions that can spur the development of life saving treatments for those who need it most. To join the Caucus, please contact Kyle Parker in Representative Butterfield's Office at Kyle.L.Parker@mail.house.gov or Elyssa Malin in Senator Klobuchar's Office at Elyssa_Malin@klobuchar.senate.gov.

For more information on Porphyrin, Porphyrin Awareness Week and the American Porphyrin Foundation, visit <https://porphyriafoundation.org>.

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