PFIC Colors: Making Sense of PFIC with the PFIC Network

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Progressive Familial Intrahepatic Cholestasis (PFIC) can be a complex condition. Finding trusted information about PFIC shouldn't be. PFIC Colors is designed to help families make sense of these conditions and find the information and support they need, fast.

This complexity means PFIC can be difficult for families to understand, especially in the early stages after diagnosis. Families facing a PFIC diagnosis often describe the early days as overwhelming, confusing, and isolating. The condition's complexity and variable presentation from person to person can make it difficult for families to understand and find information that reflects their lived experience.

It can be a lonely and confusing time, filled with questions and uncertainty. In these moments, having access to trustworthy, community-developed resources can help bring clarity and light to what may otherwise feel like a daunting situation. This is exactly what families can find on the **PFIC Network website.**

Understanding PFIC through color

To help people navigate their way to factual, accurate and supportive information, Ipsen has joined with PFIC Network to develop an engaging and positive campaign that reaches out through digital channels, including social media, to find people who are searching for information on PFIC. Engagement is encouraged with the content using the positive, inspiring and simple concept of talking about PFIC as a disease of many colors.

This color-inspired initiative is designed to help make sense of PFIC's complexity by guiding families to the full spectrum of resources available on the PFIC Network website. It aims to bring color back into people's lives through clearer, more accessible information and meaningful connection with a community that understands their lived experience.

The importance of clarity, connection and community

Emily Ventura, co-founder and executive director of PFIC Network and mother to Cedar, who lives with PFIC, has experienced firsthand how challenging the early stages of diagnosis can be.

Emily shares more about this initiative in the video below, reflecting on why bringing clarity, connection and community to PFIC families is so important.

"When my daughter was diagnosed [with PFIC], back in 2012 we were not given any resources or contacts with any community for support, none existed yet. That left us feeling lonely, isolated and fearful of her diagnosis."

As Emily connected with other parents who were going through similar experiences, it became clear that many people were navigating PFIC without guidance or support. These shared realities led to the creation of PFIC Network, now a global community offering the full spectrum of trusted information and connection for people living with PFIC and those who care for them.

Explore the Colors of PFIC

The PFIC Colors approach is designed to help families navigate PFIC in a clearer, more accessible way. By organizing information into six colour-coded topic areas and grounding every section in lived experience, the PFIC Network helps families feel more confident and in control as they navigate their PFIC journey.

If you wish to find out more about PFIC, click on the individual topic boxes below to visit the dedicated section of the PFIC Network's website to learn more.

Visit **PFIC.org** for the full spectrum of information about PFIC.

This campaign was developed together by Ipsen and PFIC Network.

https://www.ipsen.com/stories/rare-diseases/pfic-colors-making-sense-of-pfic-with-the-pfic-network