



Tentative Agenda

SEPTEMBER 13-15, 2024

Chicago Hilton, CHICAGO, IL

FRIDAY, SEPTEMBER 13

- **4:00-7:00 PM: Welcome & Arrivals: The Prelude**
 - Warm welcome and introduction to Porphyriapalooza, complete with porphyria-safe amenities and an overview of the event's highlights.
 - **7:00 PM: Dinner & 'Chicago Stars' Evening: Opening Act**
 - Enjoy a themed dinner inspired by Chicago's culinary icons. The evening unfolds with 'Meet Your Porphyria Stars', an open mic session for shared stories and connections.
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SATURDAY, SEPTEMBER 14

- **7:00-10:00 AM: Breakfast and Optional Morning Activity: Sunrise Sessions**
 - Choose between a calming activity or an enlightening workshop on daily porphyria management, setting the tone for the day.
- **10:00 AM-12:00 PM: Porphyria Community Sessions: Band Together**
 - Engage in icebreakers and breakout sessions focused on each type of porphyria, led by a lineup of patient advocates and speakers. Includes the special session "Harmonizing Healthcare: Training Your Doctor & Connecting with Porphyria Experts"
- **12:00-2:00 PM: Lunch: The Mixtape**
 - A networking lunch designed for personal story-sharing and building connections in a relaxed, supportive environment.
- **2:00-5:00 PM: Afternoon Insights & Relaxation: Encore Workshops**
 - Dive deeper into workshops on nutrition, mental health, stress management, and advocacy, with a focus on the session "Empowerment Anthem: Being Your Own Best Advocate". A quiet room for rest and meditation is available, ensuring a comfortable space for all.
- **5:00-7:00 PM: Dinner: Culinary Remix**
 - A dinner that showcases the diverse flavors of Chicago!
- **7:00-10:00 PM: Porphyriapalooza: The Main Stage**
 - Celebrate our community coming together with a dance party featuring a DJ spinning upbeat dance music, interactive games, and a photo booth. Alternative movie night available for a more laid-back experience or for young guests.

SUNDAY, SEPTEMBER 15

- **7:00-9:00 AM: Breakfast: Acoustic Mornings**
 - A casual breakfast setting encourages attendees to mingle and share insights from the event.
- **9:00-11:00 AM: Empowerment Sessions: Final Chorus**
 - Wrap up with interactive sessions with something for everyone, including expressive art, somatic breathing, movement and exercise for stress management, and more...reinforcing the importance of self-care within the porphyria community.
- **11:00 AM-1:00 PM: Lunch & Learn Closing Session: Farewell Symphony**
 - Collaborative lunch where attendees share learnings, thoughts on Porphyriapalooza, and visions for the future of porphyria advocacy.
- **1:00-3:00 PM: Goodbyes & Departure: Encore Applause**
 - A heartfelt goodbye, leaving participants inspired, informed, and interconnected - with key takeaways to ensure you are ready to champion the cause of porphyria patients everywhere.

Throughout the Conference: Porphyria-Safe Haven

- **Patient-Friendly Space:** Your organizers will ensure a supportive environment with attention to light sensitivity, rest areas, safe foods, and immediate medical care access, fostering a comfortable and understanding atmosphere for all attendees.
- **Around the Clock Porphyria Hub:** This is your 24-hour sanctuary for spontaneous meet-ups and quiet chats. Perfect for those who find inspiration after dark or simply seek a calm corner for conversation, this space offers comfort and privacy around the clock, tailored to the needs of the Porphyria community. Whether you're up late or up early, the Porphyria Hub is your spot for connection and reflection, any time of day or night.
- **Patient Concierge:** Bring your needs and issues to our designated patient concierge, who will manage your requests related to porphyria or with this gathering with privacy and care.