

## Welcome to Beyond Sleepy 2023.

The Hypersomnia Foundation is delighted to host our conference for both in-person and virtual attendees. **The Whova App** gives you the opportunity to access presentations online should you miss a session and the opportunity to connect with each other throughout the duration of the conference. Refreshments are available as are our staff and board members should you have any questions about the conference or the Hypersomnia Foundation.

This weekend we are launching our new TikTok channel-- please visit the booth to participate and help spread awareness of IH. You can also keep up to date with our events and programs by following us on social media and signing up for our newsletter at [www.HypersomniaFoundation.org](http://www.HypersomniaFoundation.org).

I would like to thank our sponsors for supporting #BeyondSleepy and the incredible team of staff, volunteers, and board members who have dedicated themselves to this event. We hope you find connection, encouragement, information, and inspiration by being here this weekend and we look forward to also seeing you in Texas for #BeyondSleepy 2024.

Claire Wylds-Wright  
CEO

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HYPERSOMNIA FOUNDATION  
[info@hypersomniafoundation.org](mailto:info@hypersomniafoundation.org)

# #BEYONDSLEEPY CONFERENCE 2023

a conference for people  
with idiopathic  
hypersomnia, narcolepsy,  
and Kleine-Levin syndrome  
and their supporters.

JUNE 2-4 2023  
THE ALEXANDER HALL  
INDIANAPOLIS, INDIANA



# EVENT PROGRAM



## FRI JUNE 2 2023

- 3-5 PM Registration**  
Hotel Lobby
- 5-8 PM Meet & Greet**  
Market Table

## SAT JUNE 3 2023

- 8:10 AM Breakfast**  
Market Table
- 9:25 AM Opening Remarks** V  
**Claire Wylds-Wright** Hypersomnia Foundation  
Alexander Ballroom
- 9:35 AM Hypersomnia in Adulthood: What is the Role of the Family** V  
**Dr. Jennifer Mundt** Northwestern Center for Circadian and Sleep Medicine  
**Matthew Horsnell** Patient Advocate  
Alexander Ballroom
- 10:20 AM The Science Behind Orexin (Hypocretin) Agonists, and the Search for Potential New Treatments** V  
**Dr. Deborah Hartman** Centessa Pharmaceuticals  
Alexander Ballroom
- 11:05 AM Panel Discussion: Open Q & A** V  
**Claire Wylds-Wright** Hypersomnia Foundation  
**Dr. David Rye** Emory University  
**Victoria Kirby York** National Black Justice Coalition (NBJC)  
**Diana Kimmel** Hypersomnia Foundation  
Alexander Ballroom
- 12 PM Lunch**  
Market Table
- 1:15 PM Comorbidities and Overlapping Symptoms** V  
**Dr. Lynn Marie Trotti** Emory University  
Alexander Ballroom
- 2 PM Rising Our Voices** V  
**Elizabeth Terry** Patient Advocate  
**Julie Flygare** Project Sleep  
Alexander Ballroom
- 2:35 PM Rare Sleep Table Talk: Patient Centricity in Action** V  
**Veronica Moore, MA** Hypersomnia Foundation  
**Dr. Marsie Ross** National Black Justice Coalition (NBJC)  
**Rachel Radomski** Harmony Biosciences  
Alexander Ballroom

- 3:15 PM Breakout: An Origin Story for IH: "Let's Do What People with Other Diseases Do"**  
**Dr. Quinn Eastman** Emory University  
Alexander Ballroom
- Breakout: Panel Discussion - Alternatives to Stimulant Medications** V  
**Victoria Kirby York** National Black Justice Coalition (NBJC)  
**Rebecca King** Hypersomnia Foundation  
**Olivia Robbins** Patient Advocate  
Cityway Gallery
- Breakout: Avadel Session**  
**Dr. Anne Marie Morse** Janet Weis Children's Hospital  
**Katie Lancaster** Patient Advocate  
Fletcher Place
- Breakout: KLS Foundation- Stories of Hope: Life after KLS** K  
**Jenny Grossman** KLS Foundation  
**Glenn Marks** KLS Foundation Patient Advocate  
**Josh Riley** KLS Foundation Patient Advocate  
**Kayla Cross** KLS Foundation Patient Advocate  
Alexander Ballroom
- 3:55 PM Breakout: Pregnancy and IH** V  
**Dr. Lynn Marie Trotti** Emory University  
**Amy Desmarais** Hypersomnia Foundation  
Alexander Ballroom
- Breakout: Setting Yourself Up for Success in School**  
**Jessamine Griewahn-Okita** Patient Advocate  
**Olivia Robbins** Patient Advocate  
**Dr. Mary King** Patient Advocate  
Cityway Gallery
- Breakout: Jazz Session- Uncovering the Real-World Impact of Idiopathic Hypersomnia**  
**Dr. Marisa Whalen** Jazz Pharmaceuticals  
Fletcher Place
- 4:10 PM Breakout: KLS Community Social Meet and Greet** K  
Renaissance Place
- 4:35 PM Breakout: Reclaiming Our Worth - Requesting Accommodations for Every Part of Our Lives** V  
**Victoria Kirby York** National Black Justice Coalition (NBJC)  
Alexander Ballroom
- Breakout: Supporters Q & A Session**  
**Michael Sparace** Hypersomnia Foundation  
**Diane Powell** Hypersomnia Foundation  
Cityway Gallery
- 6:45 PM UNIGHT Session: Growing Your Support Village**  
**Matthew Horsnell** Patient Advocate  
**Shelly Gonzalez** Patient Advocate  
Alexander Ballroom

## SUN JUNE 4 2023

- 8:10 AM Breakfast**  
Market Table
- 9:25 AM Welcome Back** V  
**Claire Wylds-Wright** Hypersomnia Foundation  
Alexander Ballroom
- 9:30 AM Advocating for IH and Related Sleep Conditions while Leveraging Social Media- A moderated Q & A** V  
**Michael Sparace** Hypersomnia Foundation  
**Dr. Anne Marie Morse** Janet Weis Children's Hospital  
Alexander Ballroom
- 10:20 AM Breakout: Diagnosis and Management of Adolescents with Idiopathic Hypersomnia and Kleine-Levin Syndrome** V  
**Dr. Kiran Maski** Boston Children's Hospital, Harvard Medical School  
Alexander Ballroom
- Breakout: Panel- Impact on Relationships**  
**Michael Sparace** Hypersomnia Foundation  
**Diana Kimmel** Hypersomnia Foundation  
**Matthew Horsnell** Patient Advocate  
Cityway Gallery
- Breakout: Zevra Session**  
**Dr. Rene Braeckman** Zevra Pharmaceuticals  
**Dr. Christopher Drake** Henry Ford Health  
Fletcher Place
- 11:00 AM Latest Research in IH** V  
**Dr. Emmanuel Mignot** Stanford University  
Alexander Ballroom
- 11:50 AM Panel: Beyond Sleeping Beauty: What is Kleine-Levin Syndrome** V K  
**Arielle Poleg** KLS Foundation  
**Dr. Emmanuel Mignot** Stanford University  
**Dani Farber** KLS Foundation  
**Jenny Grossman** KLS Foundation  
**Josh Riley** KLS Foundation Patient Advocate  
Alexander Ballroom
- 12:45 PM Closing** V  
**Claire Wylds-Wright** Hypersomnia Foundation  
Alexander Ballroom

# #BEYOND SLEEPY