

# A Brief Introduction to the Hypersomnia Foundation (HF)

7<sup>th</sup> International Symposium on Narcolepsy  
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Beverly, MA USA



## Quality of Life: IH Patient-Identified Initiatives of Significance

- Shared Personal Stories in *SomnusNooze*
- Education Essentials for K-12 & College Students
- HF Patient Education Conferences
- Physician Directory
- Website IH Information & Publications
- Medical & Scientific Advisory Boards
- Patient Registry at CoRDS (Coordination of Rare Diseases at Sanford)

# Resources for Physicians, Researchers, Scientists & Advocates

- *Idiopathic Hypersomnia (IH) Standard Characteristics*
- Directory of IH Healthcare Providers
- Hypersomnia Foundation's (HF) Patient Registry at CoRDS
- HF Research Award Program
- Journal Article Summaries (vetted)
- Ongoing Research Studies for Patients with IH and Related Disorders
- Brochure about IH (vetted)
- Access to IH Expertise:  
Members, HF Medical & Scientific Advisory Boards



# The Way Forward: #BeyondSleepy

## ENGAGE

- PATIENTS in Research, Drug Discovery & Drug Development Process
- ACADEMIC & INDUSTRY Leaders
- PATIENT ADVOCACY Groups

## EXPAND

- International Patients, Providers, & Board Members
- Selectively Targeted Awareness Outreach

## EDUCATE

- Education & Workplace Issues and Resources
- Health, Disability & Insurance Issues and Resources
- Medication Access and Finance
- IH Medical Alert Card
- *Anesthesia Guide and Patient Care Plan*





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Type of Potential Conflict	Details of Potential Conflict
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