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# **NARCOLEPSY & HYPERSOMNIA TRACK**

**FULL TRACK RUNS SATURDAY - WEDNESDAY** 

The Narcolepsy & Hypersomnia Track at World Sleep 2019 will include some of the biggest names in the field offering cutting-edge science and information.

# 23.25 HOURS OF NARCOLEPSY &

SEPTEMBER 20-25, 2019 · VANCOUVER,

**HYPERSOMNIA** content have been added to the final Scientific Program. Register today to learn more about narcolepsy & hypersomnia research and treatment options.

### **REGISTRATION OPTIONS:**

Course\$12	5
Affiliated Meeting + Course + Congress Registration	
(Member)\$52	0

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## NARCOLEPSY & HYPERSOMNIA TRACK OVERVIEW

TYPE	DAY	TITLE	HOURS
AFFILIATED MEETING	Saturday	Understanding narcolepsy and hypersomnia: Insights and perspectives	8:00am - 4:00pm
COURSE	Sunday	C16 Narcolepsy and other hypersomnias: Diagnostic approach and management	1:00pm - 5:00pm
SYMPOSIUM	Monday	S13: Sleepy Heads and Anesthesia: Anesthetic implications of disorders of daytime hypersomnolence	10:45am - 12:15pm
SATELLITE SYMPOSIUM	Monday	Waking up to narcolepsy: Strategies to improving outcomes	12:30pm - 2:00pm
SYMPOSIUM	Tuesday	S43: Genetic and epidemiological triggers of sleepiness: From natural variation to severe sleep disorders	3:00pm - 4:30pm
SYMPOSIUM	Tuesday	S45: New perspectives in the management of pediatric narcolepsy	3:00pm - 4:30pm
SYMPOSIUM	Wednesday	S63: Biology and biomarkers of unexplained hypersomnolence	10:45am - 12:15pm
SYMPOSIUM	Wednesday	S69: Is narcolepsy a spectrum disorder including IH, NT2 and NT1?	12:30pm - 2:00pm
SYMPOSIUM	Wednesday	S71: Neuroscience and neuroimaging insights into central disorders of hypersomnolence	12:30pm - 2:00pm
KEYNOTE	Wednesday	K12: From somnolence in the general population to narcolepsy	2:00pm - 2:45pm



# AFFILIATED MEETING | SATURDAY, SEPTEMBER 21 | 8:00AM - 4:00PM | ROOM 109

Wake Up Narcolepsy Education Day at Sleep Expo 2019 | In Collaboration with The Hypersomnia Foundation and World Sleep 2019

# UNDERSTANDING NARCOLEPSY AND HYPERSOMNIA: INSIGHTS AND PERSPECTIVES

#### PARTNERING TO ADVANCE PUBLIC SLEEP HEALTH





#### **Summary**

The number of patients presenting with symptoms of narcolepsy and hypersomnia disorders is increasing. This demonstrates a growing need to provide practitioners with an in-depth grasp of how these patients present and the trajectory of their symptoms. It also underlines the need for practitioners to be aware of specific treatment strategies and to understand when it is appropriate to refer patients to other sleep related specialists.

The overriding objective of the narcolepsy and hypersomnia education event is to provide an extensive and detailed knowledge base so that health care providers have the tools to make accurate diagnoses and informed decisions regarding treatment options.

The program will include the latest research, presented by leading experts in the field of narcolepsy and hypersomnias, as well as a panel discussion bringing together patient and practitioner perspectives related to the material presented.

#### Presentation

8:30am - 9:00am

Registration and coffee

9:00am - 9:15am

Welcome & introduction

Claire Crisp (United Kingdom); Diane Powell (United States)

9:15am - 10:00am

Current research in excessive sleepiness disorders

Yves Dauvilliers (France)

Coffee break

10:00am - 10:15am

10:15am - 11:00am

What sleepy mice tell us about sleepy people

Thomas Scammell (United States)

11:00am - 11:45am

Transitional care: The journey from childhood to adulthood

Brian Murray (Canada)

11:45am - 12:30pm

Lunch break

12:30pm - 1:15pm

Living with narcolepsy

Kelsey Biddle (United States)

1:15pm - 2:30pm

Managing depression associated with excessive sleepiness

Indra Narang (Canada)

2:30pm - 3:15pm

Non-pharmacologic strategies to manage excessive sleepiness disorders

Shelly Weiss (Canada)

3:15pm - 3:30pm

**Break** 

3:30pm - 4:15pm

### Panel discussion

Claire Crisp (United Kingdom); Thomas Scammell (United States); Yves Dauvilliers (France); Brian Murray (Canada); Kelsey Biddle (United States); Indra Narang (Canada); Shelly Weiss (Canada)



COURSE | SUNDAY, SEPTEMBER 22, 2019 | 1:00PM - 5:00PM | ROOM 122

# C16 Narcolepsy and other hypersomnias: Diagnostic approach and management

Chairs Merrill S. Wise (United States); Tomi Sarkanen (Finland)



# ADDITIONAL REGISTRATION REQUIRED

### **Summary**

The objectives of this half day course are to present current concepts regarding the assessment and diagnosis of narcolepsy and other hypersomnias of central origin, and to discuss the contemporary landscape of pharmacological and non-pharmacological treatment options. This course is directed towards practicing sleep medicine specialists and will focus on narcolepsy, idiopathic hypersomnia, periodic hypersomnia, and hypersomnia due to medical conditions in adults and children.

#### Presentation

1:00pm - 1:10pm Introduction

Merrill S. Wise (United States); Tomi Sarkanen (Finland)

1:10pm - 1:50pm

Narcolepsy: Presentation, assessment and diagnosis Tomi Sarkanen, Finland

1:50pm - 2:30pm

Idiopathic hypersomnia and other hypersomnias: Presentation, assessment and diagnosis Lynn Marie Trotti (United States)

2:30pm - 2:50pm

Coffee break

2:50pm - 3:25pm Narcolepsy in Children Merrill S. Wise (United States) 3:25pm - 4:10pm

Treatment of narcolepsy and other hypersomnias

Yves Dauvilliers (France)

4:10pm - 4:40pm

Psychosocial, academic and vocational aspects of hypersomnia Berit Hjelde Hansen (Norway)

4:40pm - 5:00pm

Conclusion / question and answer Merrill S. Wise (United States); Tomi Sarkanen (Finland)

### SYMPOSIUM | MONDAY, SEPTEMBER 23, 2019 | 10:45AM - 12:15PM | ROOM 219

S13: Sleepy Heads and Anesthesia: Anesthetic implications of disorders of daytime hypersomnolence 10:45am - 12:15pm | Room 219

### Chair

Mandeep Singh (Canada)

#### Summary

As more and more people undergo surgeries and require anesthesia, health care professionals are now caring for patients with a multitude of sleep disorders. Apart from obstructive sleep apnea, there is little familiarity amongst the health care providers and patients with anesthetic considerations for other sleep disorders that have potentially significant relationship with anesthetic management. One such example are disorders of daytime hypersomnolence, such as narcolepsy and idiopathic hypersomnia (IH). These patients present with unique symptom profile and pharmacological treatment warrants special anesthetic considerations. Theoretical complications include perioperative cataplexy or sleep paralysis episodes, status cataplecticus, drug interactions with anesthetic agents, prolonged emergence after general anesthesia and postoperative hypersomnia. Currently, little information exists regarding the perioperative anesthetic management and outcomes of narcolepsy or IH patients undergoing surgery.

This symposium is presented on behalf of the Society of Anesthesia and Sleep Medicine (SASM) educational initiative to raise awareness and provide a platform to discuss the

relationship between neurophysiological, neuropsychological and neuropharmacological function between sleep and anesthesia states.

10:45am - 10:47am

#### Introduction

10:47am - 11:07am

Unconsciousness, sleep and anesthesia: Shared mechanisms

Dennis Auckley (United States)

11:07am - 11:27am

Narcolepsy or idiopathic hypersomnia: What's the difference?

Lynn Marie Trotti (United States)

11:27am - 11:47am

Pharmacological treatment options and possible drug interactions with anesthesia management

Mandeep Singh (Canada)

11:47am - 12:07pm

Anesthetic considerations for patients with narcolepsy and idiopathic hypersomnia

David Hillman (Australia)

12:07pm - 12:15pm

Conclusion

# NARCOLEPSY & HYPERSOMNIA SATURDAY - WEDNESDAY



## SATELLITE SYMPOSIUM | MONDAY, SEPTEMBER 23, 2019 | 12:30PM - 2:00PM | BALLROOM A

# Waking up to narcolepsy: Strategies to improving outcomes

12:30pm - 2:00pm I Ballroom A

#### Chair

Michael Thorpy (United States)

#### Summary

Narcolepsy is a life-long disorder with the core symptoms of excessive daytime sleepiness (EDS), cataplexy, hypnagogic or hypnopompic hallucinations, sleep paralysis, and sleep disruption. Narcolepsy pathophysiology is linked to loss of signaling by hypocretin-producing neurons: an autoimmune etiology possibly triggered by an environmental agent may precipitate hypocretin neuronal loss. Narcolepsy is typically associated with a delay in diagnosis of approximately 8 to 15 years. The delay is related to numerous causes, such as mildness of symptoms, gradual onset, lack of recognition of the condition by the patient or clinician, and mistaken diagnosis because of alternative disorders of sleepiness such as sleep deprivation or obstructive sleep apnea. The high comorbidity burden in patients with narcolepsy with disorders that have symptom overlap with narcolepsy also contributes to the lack of recognition.

The delayed diagnosis leads to delayed treatment, which increases the burden of the disease with detrimental effects on health care resource use, employment, and quality of life.

In order to improve time to diagnosis, questions about the characteristic features of the sleepiness, sleepiness while sedentary, dreaming during naps, and the age of onset of sleepiness will help in identifying the patient with narcolepsy. Screening tools such as the Swiss Narcolepsy Scale (SNS) and Epworth Sleepiness Scale (ESS) can help identify problematic sleepiness and symptoms of narcolepsy. In order to effectively diagnose narcolepsy, a series of two in-lab diagnostic tests are performed: an overnight polysomnogram (PSG), followed by a Multiple Sleep Latency Test (MSLT). Because the diagnosis of narcolepsy relies heavily on the MSLT, it is essential that the test be performed under the correct conditions.

No cure for narcolepsy exists; therefore, treatment is targeted at symptom management. Non-pharmacologic management should be initiated in all patients. Good sleep habits with avoidance of sleep deprivation and/or irregular sleep patterns should be emphasized. Unfortunately, lifestyle changes are rarely sufficient to adequately control the symptoms of narcolepsy, and most patients require life-long medication to cope with the debilitating effects of the disorder.

Pharmacologic interventions include alerting medications for EDS, sodium oxybate (which treats both EDS and cataplexy), and antidepressants for cataplexy. Emerging therapies include solriamfetol, a selective dopamine and norepinephrine reuptake inhibitor (DNRI) for EDS, and pitolisant, a selective histamine 3 receptor antagonist/inverse agonist, for EDS and cataplexy.

Narcolepsy in the pediatric population is associated with impaired academic performance and reduction in social and

participatory activities. Narcolepsy is frequently not diagnosed and misdiagnosed, often due to the difficulty in diagnosing narcolepsy in children because atypical presentations of cataplexy and associated medical, sleep, and behavioral comorbidities can lead to misdiagnoses. Narcolepsy management in children involves behavioral and lifestyle changes along with pharmacologic therapy. Many of the medications used for treating narcolepsy in adults are used offlabel in children; sodium oxybate has recently been approved by the FDA for the treatment of cataplexy or EDS in pediatric patients with narcolepsy.

In this symposium, sleep clinicians will be provided with best practices in the diagnosis and treatment of narcolepsy in adults and children.

#### Presentation

12:30pm – 12:35pm Introduction Michael Thorpy (United States)

12:35pm - 1:00pm

Strategies for early and accurate diagnosis of narcolepsy Thomas Scammell (United States)

1:00pm - 1:25pm

Treatments for narcolepsy: Evaluating the landscape *Michael Thorpy (United States)* 

1:25pm - 1:50pm

Optimizing outcomes in pediatric patients Kiran Maski (United States)

1:50pm - 2:00pm

Take-home tips for clinical practice



# SCIENTIFIC PROGRAM NOW AVAILABLE

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### **SYMPOSIUM** | TUESDAY, SEPTEMBER 24, 2019

SYMPOSIUM | TUESDAY, SEPTEMBER 24, 2019

■ S43: Genetic and epidemiological triggers of sleepiness: from natural variation to severe sleep disorders 3:00pm – 4:30pm | Room 211

Chair

Hanna M. Ollila (United States)

#### Summary

This symposium will summarize the latest findings in sleepiness, the effect of sleepiness on diseases and the severe sleep disorders with core disease component of sleepiness (narcolepsy, excessive daytime sleepiness and Kleine-Levin Syndrome). In addition, we will present the triggering factors for natural and pathological sleepiness disorders and their recent discovered underlying biological mechanisms as well as unpublished work. This symposium comprises five talks that specifically address the following topics. 1) What affects normal variation in sleepiness in population level 2) What are the genetic and environmental triggers behind hypersomnia disorders 3) How is sleepiness connected with disease predisposition.

Finally, this symposium shows the known triggers and mechanisms in severe sleepiness, most notably in narcolepsy and Kleine-Levin Syndrome. Data presented comprises clinical cohorts, large scale population cohorts, electronic health records and functional biological assays where the exact disease mechanisms have been measured both in humans and in model organisms.

3:00pm - 3:02pm

Introduction

3:02pm - 3:18pm

Genetic association analyses for excessive daytime sleepiness

Heming Wang (United States)

3:18pm - 3:34pm

**USF1 ties metabolism to chronotype and sleepiness**Nasa Sinnott-Armstrong (United States)

3:34pm - 3:50pm

Kleine Levin Syndrome is strongly associated with variants at TRANK1 locus and genes involved in the regulation of rhythmic behaviours

Aditya Ambati (United States)

3:50pm - 4:06pm

Electronic health records define novel genetic and environmental triggers for sleepiness and narcolepsy Hanna M. Ollila (United States)

4:06pm - 4:22pm

CD8 T-cell autoreactivity in type 1 narcolepsy Birgitte Kornum (Denmark)

4:22pm - 4:30pm

Conclusion

S45: New perspectives in the management of pediatric narcolepsy 3:00pm – 4:30pm | Room 219

Chair

Michel Lecendreux (France)

**Summary** 

Narcolepsy is a chronic and disabling disorder affecting sleep and wakefulness, characterized by excessive daytime sleepiness (EDS), sudden sleep episodes and attacks of muscle atonia mostly triggered by emotions (cataplexy). Narcolepsy is a lifelong disorder, however not progressive, due to the loss of hypocretin neurons, and which occurrence during childhood is frequent. Among others, the occurrence of the disorder during childhood and adolescence should be taken into consideration. Narcolepsy in children and adolescents is still under-diagnosed and is often mistaken in its onset for other diseases or even neglected.

Young patients affected by the disorder often show dramatic and abrupt impairment in their social skills and academic performances due to excessive daytime sleepiness, fatigue and lack of energy. The goal of the symposium is to underlie the clinical characteristics of pediatric narcolepsy and to highlight the therapeutic outcome for the disorder.

All speakers are well known experts in the field of narcolepsy and pediatrics who will provide useful information from their clinical practice and/or specific research. For each topic, speakers will focus on clinical and therapeutic specificities in childhood and adolescent narcolepsy.

3:00pm - 3:02pm

Introduction

3:02pm - 3:18pm

Clinical features in the narcoleptic child: How clinical evaluation may orientate towards therapeutic decisions *Giuseppe Plazzi (Italy)* 

3:18pm - 3:34pm

Pediatric narcolepsy, auto-immunity and potential therapeutic outcomes

Lucie Barateau (France)

3:34pm - 3:50pm

Pediatric narcolepsy and psychiatric features and treatment issues

Paul Gringras (United Kingdom)

3:50pm - 4:06pm

Management of the pediatric narcoleptic patient Michel Lecendreux (France)

4:06pm - 4:22pm

Directions for the future, what can we expect regarding narcolepsy and other disorders of EDS based on current research?

Yves Dauvilliers (France)

4:22pm - 4:30pm

Conclusion



## **SYMPOSIUM** | WEDNESDAY, SEPTEMBER 25, 2019

# ■ S63: Biology and biomarkers of unexplained hypersomnolence

10:45am - 12:15pm | Room 211

#### Chair

David T. Plante (United States)

#### Summary

Unexplained hypersomnolence, in which patients are excessively sleepy, often with prolonged sleep duration, is commonly encountered in the practice of sleep medicine. Idiopathic Hypersomnia, the quintessential disorder of unexplained hypersomnolence, is likely a heterogenous disorder with multiple potential underlying causes.

This symposium will present cutting-edge research regarding the biology and biomarkers associated with unexplained hypersomnolence, with a primary focus on Idiopathic Hypersomnia (IH). As a collection of talks, this symposium will present emerging data that suggest potential biological processes that may be responsible for unexplained hypersomnolence. In addition, this symposium will suggest future research directions in this exciting area.

10:45am - 10:47am **Introduction** 

10:47am - 11:07am

### **GABA-related hypersomnolence**

Lynn Marie Trotti (United States)

11:07am - 11:27am

#### Neuroimaging findings in CNS hypersomnias

Nathan Cross (United States)

11:27am - 11:47am

Altered circadian period in idiopathic hypersomnia

Robert Thomas (United States)

11:47am - 12:07pm

Altered local slow wave activity in hypersomnolence

disorder: A transdiagnostic process?

David T. Plante (United States)

12:07pm - 12:15pm

Conclusion

# ■ S69: Is narcolepsy a spectrum disorder including IH, NT2 and NT1?

12:30pm - 2:00pm I Ballroom A

#### Chairs

Ulf Kallweit (Germany); Michael Thorpy (United States)

#### Summary

This symposium will address the possibility that some forms of Idiopathic Hypersomnia (IH) and Narcolepsy Type 2 (NT2) may have subtle loss of hypocretin neurons compared with Narcolepsy Type 1 (NT1) and therefore IH, NT2 and NT1 are part of a condition of a Narcolepsy Spectrum Disorder.

Hypocretin is integral to the pathophysiology of narcolepsy and we will review the current understanding of hypocretin in the control of sleep and wakefulness and discuss what is currently known about hypocretin loss in central neurological disorders of excessive sleepiness.

Should some forms of IH be considered a subtype of narcolepsy? Similarities in clinical presentation, electrophysiological similarities, and the association of REM sleep phenomena of IH, NT2 and NT1 with hypocretin loss will be discussed.

Are environmental triggers of narcolepsy similar in IH, NT2 and NT1, therefore leading to a similar pathophysiology? If IH, NT2 and NT1 are all part of a narcolepsy spectrum disorder, are excessive sleepiness and the degree of REM sleep abnormalities associated with the severity of hypocretin loss? Is the cataplexy of NT1 a manifestation of a high degree of neuronal hypocretin loss, and are the REM sleep manifestations of NT2, and the excessive sleepiness of IH due to lesser degrees of hypocretin loss?

12:30pm - 12:32pm

Introduction

12:32pm - 12:52pm

Hypocretin neurons in health and disease

Mehdi Tafti (Switzerland)

12:52pm - 1:12pm

The neuronal and csf hypocretin associations with REM sleep phenomena and narcolepsy

Thomas Scammell (United States)

1:12pm - 1:32pm

Environmental factors for the development of narcolepsy and IH

Fang Han (China)

1:32pm - 1:52pm

Similarities in the clinical features of IH, NT2 and NT1  $\,$ 

Yves Dauvilliers (France)

1:52pm - 2:00pm

Conclusion

# NARCOLEPSY & HYPERSOMNIA SATURDAY - WEDNESDAY

# **SYMPOSIUM** | WEDNESDAY, SEPTEMBER 25, 2019

# ■ S71: Neuroscience and neuroimaging insights into central disorders of hypersomnolence

2:00pm - 2:45pm I Room 121

#### Chair

Rolf Fronczek (The Netherlands)

#### Summary

Central disorders of hypersomnolence are characterized by excessive daytime sleepiness despite normal timing of nocturnal sleep. This symposium will cover the latest neuroscience and neuroimaging findings in these disorders: narcolepsy type 1 & 2 (NT1 & NT 2) and idiopathic hypersomnia (IH).

While NT1 originates from a selective loss of hypothalamic hypocretin-producing neurons, the pathophysiology underlying NT2 and IH remains to be fully elucidated. It is probable that different causes may lead to these phenotypes. All are diagnosed according to the current International Classification of Sleep Disorders - third edition (ICSD-3). This classification distinguishes NT2 and IH based upon one neurophysiological test: The Multiple Sleep Latency Test (MSLT). Clinically, the distinction between NT2 and IH is not clear. Furthermore, the current classification makes no distinction between IH with a short versus a long sleep time. The current classification might actually reflect the pathophysiology of distinct disease entities or might arbitrarily split a heterogeneous group of patients. More understanding of the psychophysiology of these disorders is thus very much needed.

This symposium will cover the latest neurobiological and neuromaging findings, which can help to improve classification and can shed light on the neural mechanisms involved in the regulation of sleep, vigilance and alertness. The chairperson and the proposed speakers represent clinical and fundamental experts in the field worldwide and together will highlight both findings of their recent research and provide an overview of the field.

12:30pm – 12:32pm **Introduction** 

12:32pm - 12:52pm

Central disorders of hypersomnolence: An integrated animal / human perspective

John Peever (Canada)

12:52pm - 1:12pm

Structural and functional MRI findings in narcolepsy Ysbrand Van Der Werf (The Netherlands)

1:12pm - 1:32pm

Is narcolepsy a progressive disorder? A neuroimaging perspective

Eunyeon Joo (Republic of Korea)

1:32pm - 1:52pm

Functional and structural neuroimaging of idiopathic hypersomnia

Thien Thanh Dang-Vu (Canada)

1:52pm – 2:00pm

Conclusion

# **KEYNOTE SPEAKER WEDNESDAY, SEPTEMBER 25, 2019**



K12: From somnolence in the general population to narcolepsy
Wednesday, September 25, 2019
2:00pm - 2:45pm | Room 211

Keynote

Yves Dauvilliers (France)

2:00pm – 2:02pm Introduction

2:02pm - 2:45pm

From somnolence in the general population to narcolepsy

PRESENTED BY





HOSTED B

