MSK Kids
Memorial Sloan Kettering

Sleep in children with OMAS: A to 💤 💤

Yasmin Khakoo, MD, FAAN, FCNS, FAAP (she/hers)

Child Neurology Director, MSK Kids

International Workshop on Opsoclonus Myoclonus Ataxia Syndrome, Oxford UK

April 10-12, 2025

THANK YOU

OMS *life* Foundation

- Patients, families/caregivers, colleagues
- OMSLife The Dancing Eyes Syndrome Support Trust and The OMSLife Foundation
- The sleep team of OMSLife (Kelsey, Scott, Bhavna, Hannah, Aaron, Tom, Mike)
- Dr. Wendy Mitchell

CHILD NEUROLOGY SOCIETY

Bringing CNS Members Together to Make Children's Lives Better

CONNECTING TO...	COLLEAGUES	CAREERS	CRAFT	CALLING	COMMUNITY

ROGER AND MARY BRUMBACK LIFETIME ACHIEVEMENT

Disclosures

OMSLife: Travel, support for studies

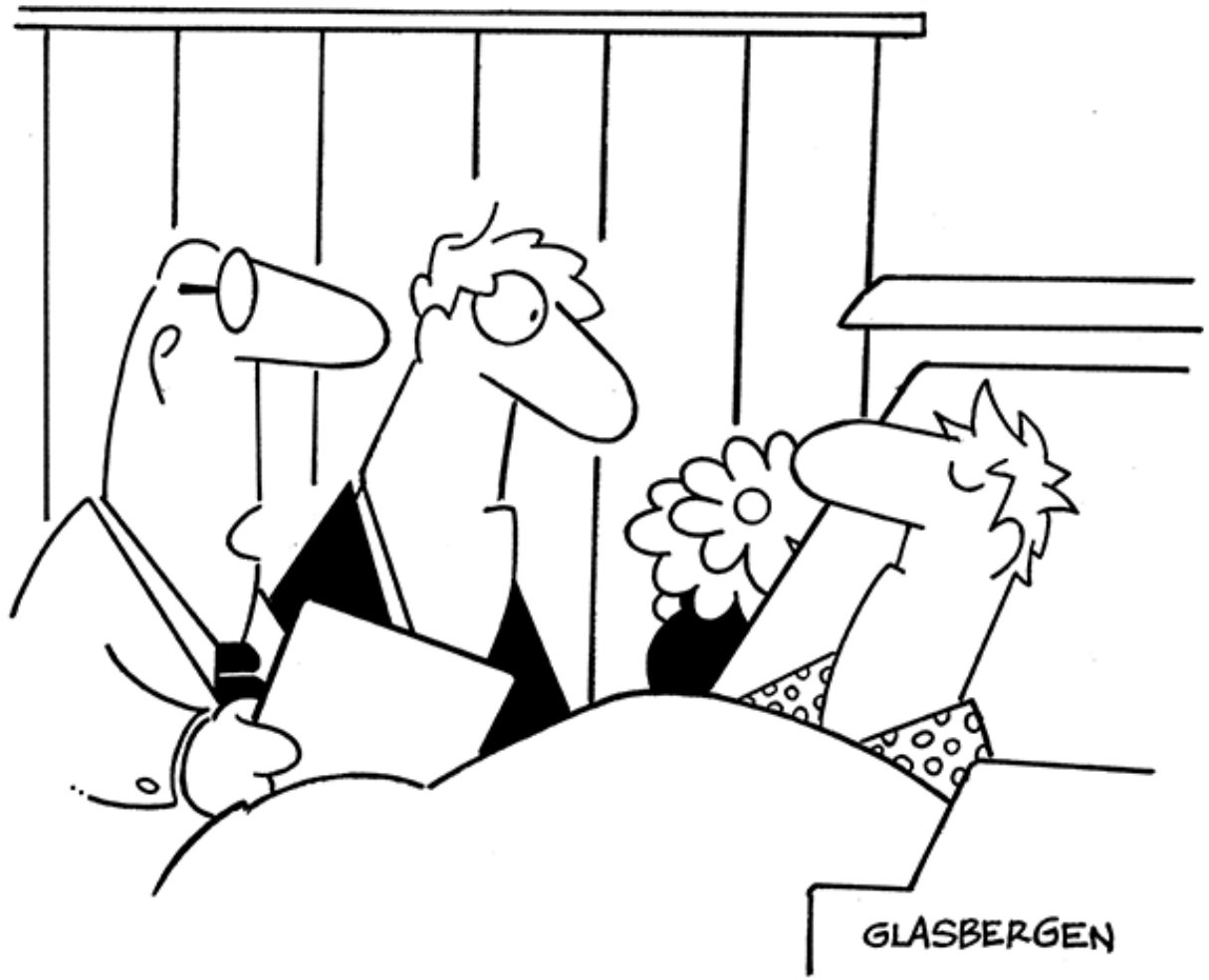
Little Eric's Foundation & Reid's Wolfpack support MSK Kids Neuro-oncology

NIH Award #R25CA020449 449 (MSK Summer/Pipeline Student)

Editor-in-Chief *Pediatric Neurology* Jan 2022-Dec 2025

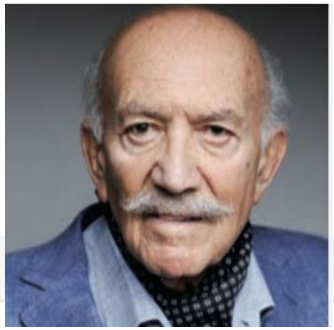
CancerCrusher Dec 2024-2025

Child Neurology Society President-Elect Oct 2024-Oct 2028



“He’s in a Powerpoint-induced coma.”

Solomon and Chutorian



(1929- 2025)

The New England Journal of Medicine NEJM Evidence NEJM AI NEJM Catalyst

The NEW ENGLAND JOURNAL of MEDICINE

CURRENT ISSUE SPECIALTIES TOPIC

MEDICAL INTELLIGENCE | ARCHIVE

Opsoclonus and Occult Neuroblastoma

Authors: Gail E. Solomon, M.D., and Abe M. Chutorian, M.D. Author Info & Affiliations

Published August 29, 1968 | N Engl J Med 1968;279:475-477 | DOI: 10.1056/NEJM196808292790907

VOL. 279 NO. 9

2023 Conference: Future directions: Obstructive sleep apnea

Consider sleep studies in children with residual attention/behavior

> Front Psychiatry. 2022 Jul 22;13:926153. doi: 10.3389/fpsyt.2022.926153. eCollection 2022.

Prevalence of high-risk for obstructive sleep apnea in attention deficit hyperactivity disorder children referred to psychiatry clinic and impact on quality of life

Tipkamol Prajsuchanai [1], Archwin Tanphaichitr [2], Tikumporn Hosiri [3], Kitirat Ungkanont [2], Wish Banhiran [2], Vannipa Vathanophas [2], David Gozal [4]

Affiliations + expand

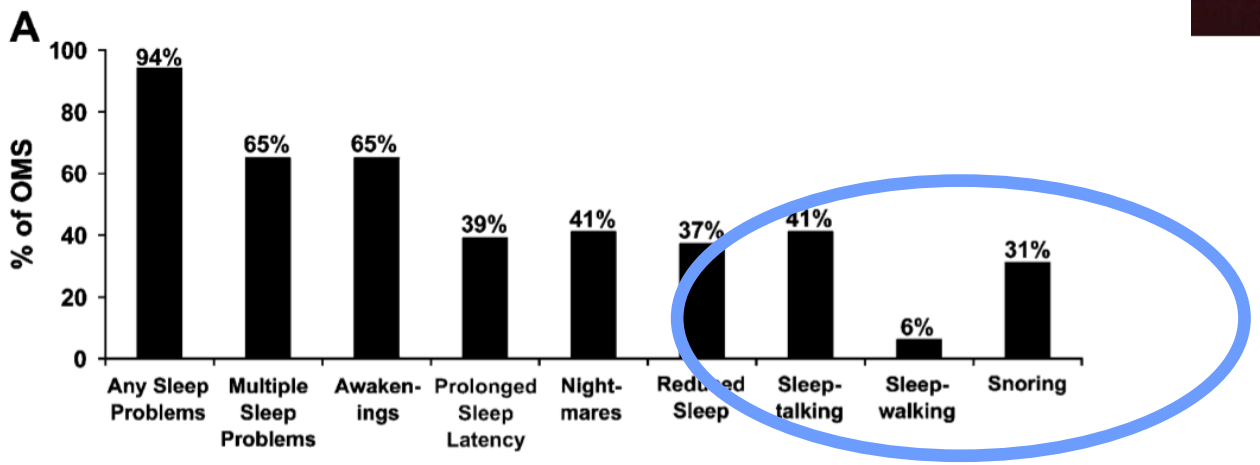
PMID: 35935414 PMCID: PMC9353399 DOI: 10.3389/fpsyt.2022.926153

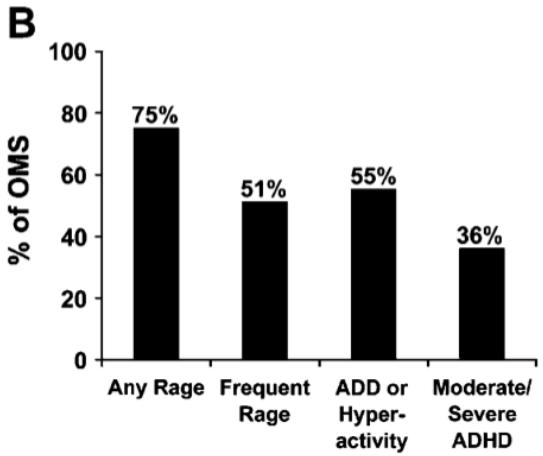
J Pediatr. 2005 Sep;147(3):372-8. doi: 10.1016/j.jpeds.2005.05.016.

Sleep disturbance and rage attacks in opsoclonus-myoclonus syndrome: response to trazodone

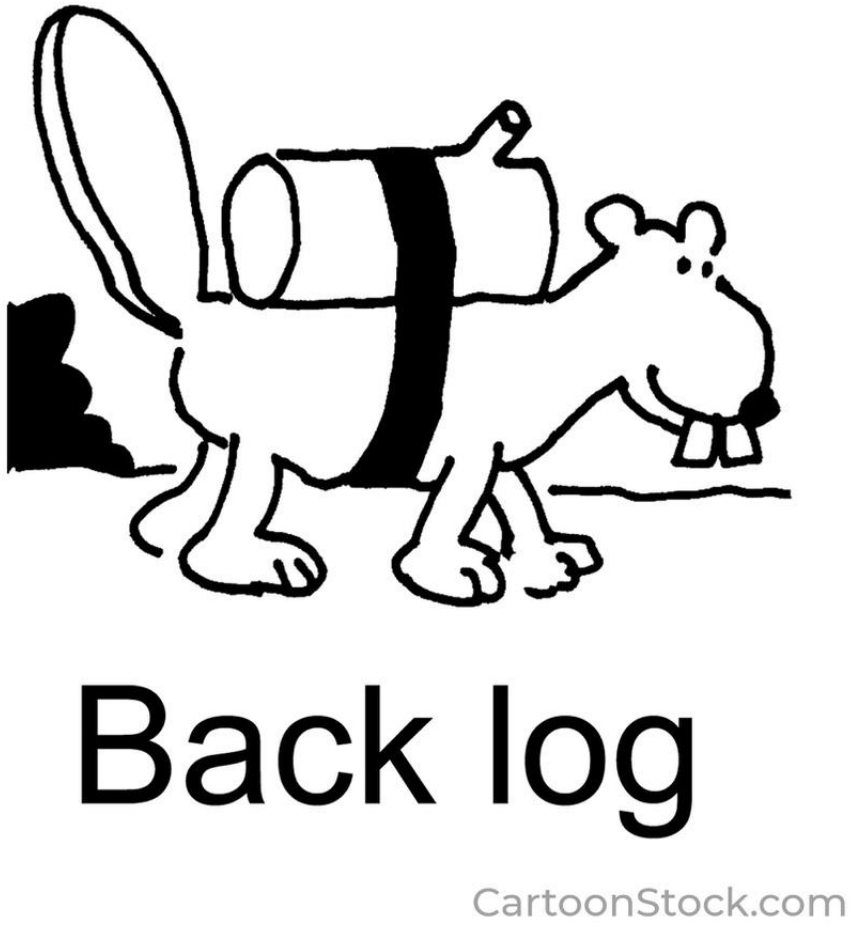
Michael R Pranzatelli [1], Elizabeth D Tate, William S Dukart, Mary Jo Flint, Michael T Hoffman, Amy E Oksa

1940-2018





Editor-in-Chief



POOMAS

Pediatric Neurology 158 (2024) 128–134

Contents lists available at ScienceDirect

Pediatric Neurology

journal homepage: www.elsevier.com/locate/pnu

Research Paper

Inaugural Patient-Reported Registry of Pediatric Opsocl Myoclonus-Ataxia Syndrome: Presentation, Diagnosis, a of 194 Patients

Sandra Jimenez Giraldo, MD [a, 1], Michael Michaelis, BS [b, 1], Lauren Kerr, Christopher Cortina, MS [d], Bo Zhang, PhD [c, d, *], Mark P. Gorman, MD [c,

[a] *Division of Child Neurology, Department of Pediatrics, Hasbro Children's Hospital, Warren Alpert School of Medicine, Brow Island*
[b] *The OMSLife Foundation, Cypress, Texas*
[c] *Department of Neurology, Boston Children's Hospital, Harvard Medical School, Boston, Massachusetts*
[d] *Biostatistics and Research Design Center, Institutional Centers for Clinical and Translational Research, Boston Children's Ho Boston, Massachusetts*

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Age, symptoms, and severity at OMAS onset (N = 166)

OMAS symptom onset (Table 4, Fig) peaked at age 12 to 18 months (27.8%) with an older age in females (22 months [15 to 31] vs 18 [14 to 23], $P = 0.0223$) and no significant differences between the tumor and no tumor subgroups. Ataxia was the most frequent symptom at onset (81.7%), followed by opsoclonus (58.9%), myoclonus (56.6%), sleep disturbances (43.4%), tremors (43.4%), temper tantrums (37.1%), and vomiting (22.3%). Myoclonus was more frequent in the tumor subgroup (65.9% vs 44.9%, $P = 0.0059$) (Supplemental Table 1). Nearly 40% of patients with OMAS did not have opsoclonus or myoclonus as one of the initial presenting symptoms. OMAS severity scale score was ≥15 in 41.8%, 10 to 14 in 28.9%, 5 to 9 in 13.9%, and 0 to 6 in 1.0% of patients. Severity of individual signs and symptoms did not differ between the tumor

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Editorial

Shaping Brighter Futures: The Transformative Impact of Sleep on Children and Adolescent Well-Being

Joanna Fong-Isariyawongse, MD[a,*], Sanjeev V. Kothare, MD[b,c]

[a] *Associate Professor of Neurology, University of Pittsburgh, Pittsburgh, Pennsylvania*

[b] *Division of Pediatric Neurology, Northwell, Cohen Children's Medical Center, New York, New York*

[c] *Professor of Neurology & Pediatrics, Zucker School of Medicine at Hofstra/Northwell, Hempstead, New York*

WHY SLEEP MATTERS FOR KIDS

SLEEP RECHARGES KIDS' BODIES AND BRAINS SO THEY CAN:

- Feel calm and refreshed.
- Make good choices.
- Have a healthy weight.
- Pay attention in school.

- Remember what they learned.
- Do better in sports.
- Avoid getting hurt.
- Feel good about themselves.

AFTER 1 OR 2 NIGHTS OF LESS SLEEP, YOUR CHILD MAY:

- Have more meltdowns.
- Make poor choices.
- Zone out in class.

- Forget what they learned.
- Have trouble with sports and games.
- Get into arguments.

KIDS WHO ARE SLEEP-DEPRIVED MAY:

- Feel sad, hopeless, or anxioius.
- Become overweight.

- Make risky choices.
- Use cigarettes, alcohol, and drugs.

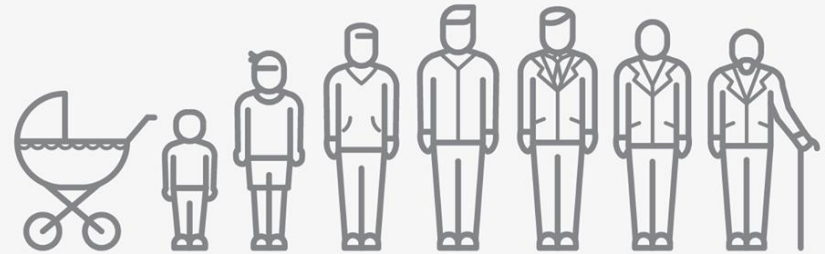
HOW MUCH IS ENOUGH?

9-12 hours for ages 6-12 8-10 hours for ages 13-18

Reviewed by Hansa Bhargava, MD, 1/17/2018

WebMD

How Sleep Changes With Age



Newborns (0-3 months) need **16-18 hours** — Sleep just a few hours at a time

Infants (4-12 months) need **12-16 hours** — The body's clock falls into a day/night pattern

Toddlers (1-2 years) need **11-14 hours** — Take fewer and shorter naps, and sleep longer at night

Preschool (3-5 years) need **10-13 hours** — May start to show "night owl" or "early bird" habits

School-age (6-12 years) need **9-12 hours** — Spend more time in deep sleep

Teens (13-18 years) need **8-10 hours** — Circadian rhythms shift to stay up later

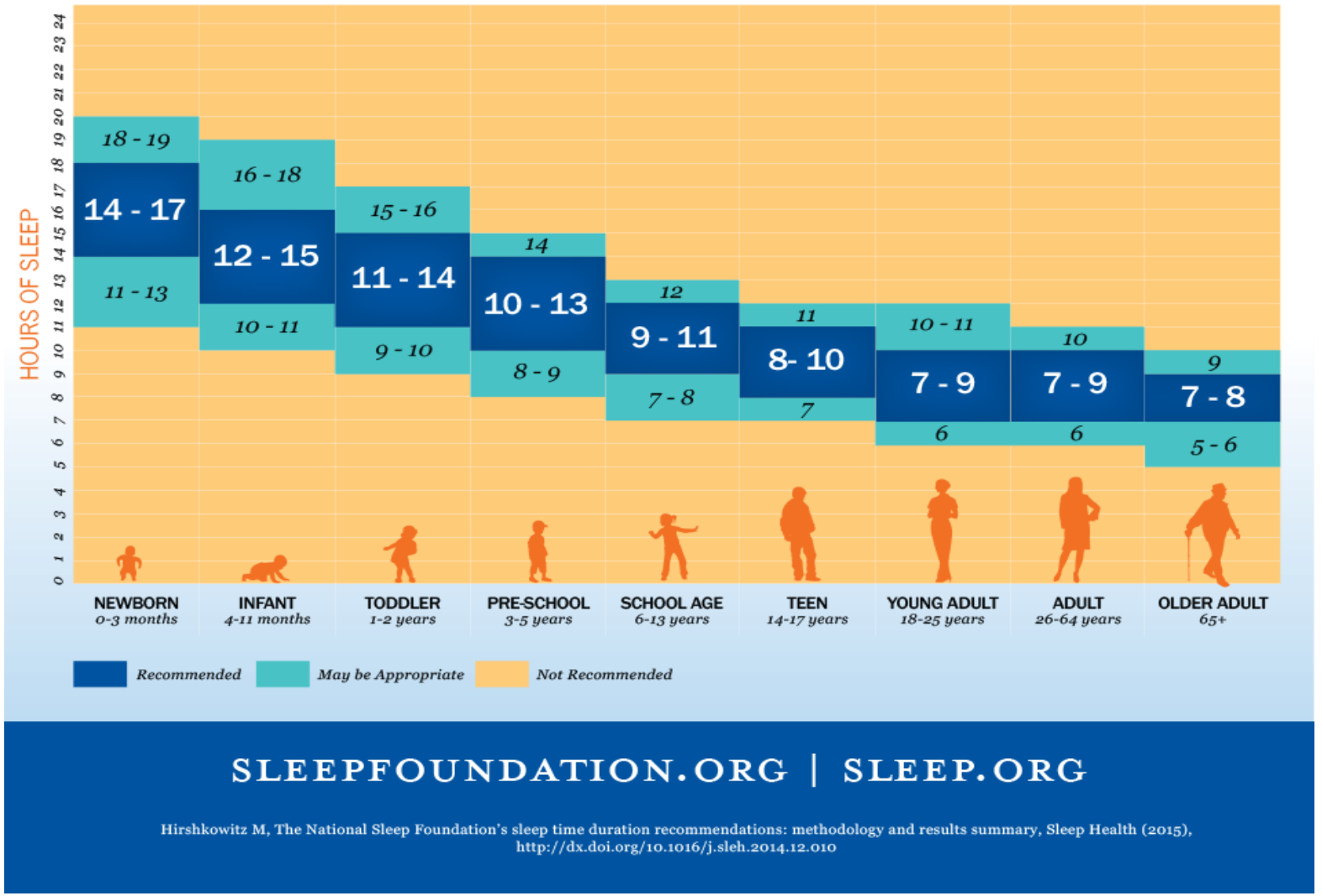
Adults need **7 or more hours** — Over time, get less deep and dream sleep, especially after age 65

Reviewed by: Neha Pathak, MD, 11/20/2018

SOURCES: CDC. National Academies Press. Harvard Medical School Division of Sleep Medicine. UCLA Health. Cleveland Clinic.

NATIONAL SLEEP FOUNDATION

SLEEP DURATION RECOMMENDATIONS



SLEEPFOUNDATION.ORG | SLEEP.ORG

Hirshkowitz M, The National Sleep Foundation's sleep time duration recommendations: methodology and results summary, Sleep Health (2015), http://dx.doi.org/10.1016/j.sleh.2014.12.010

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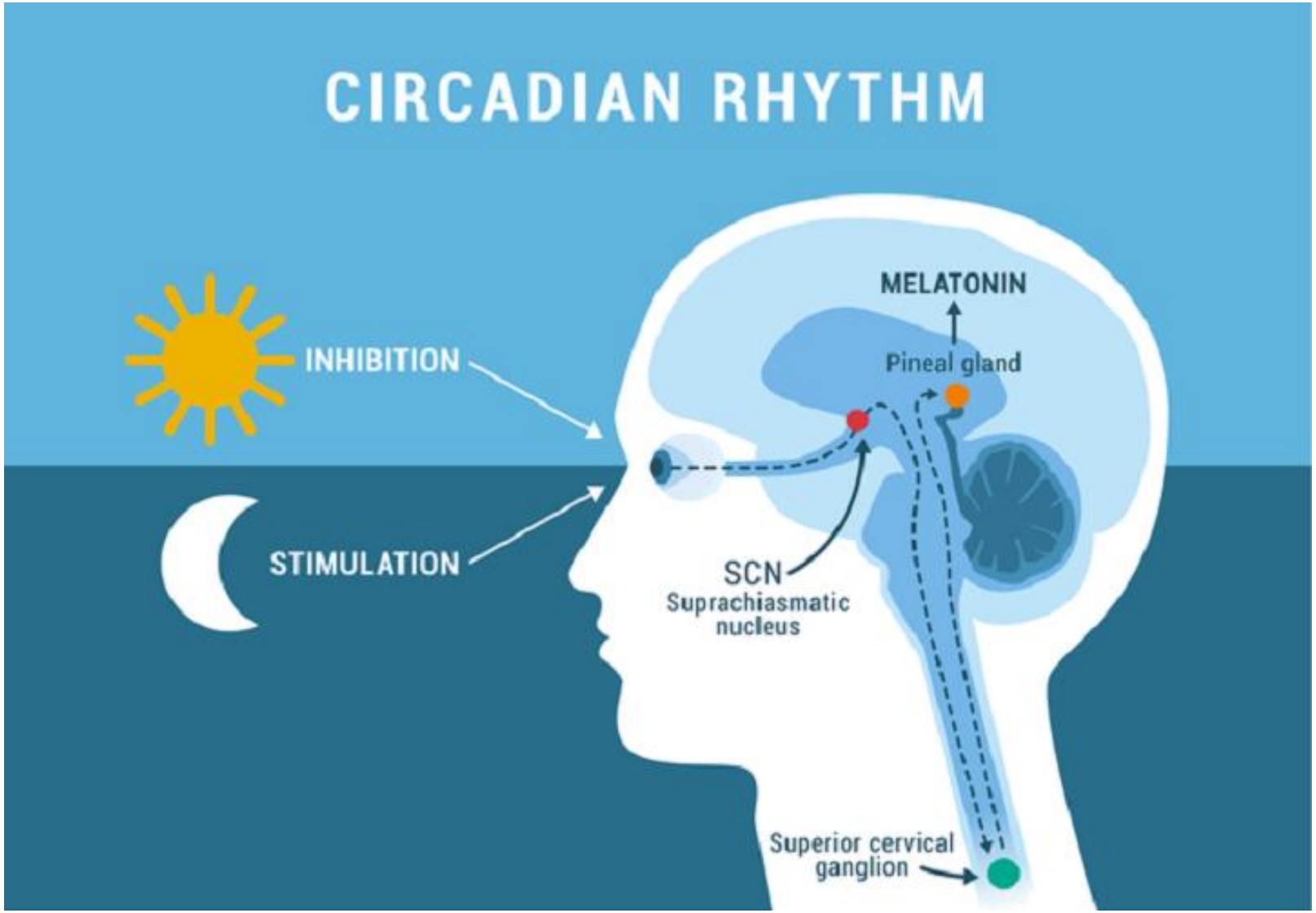
Slide courtesy of Dr. Sanjeev Kothare

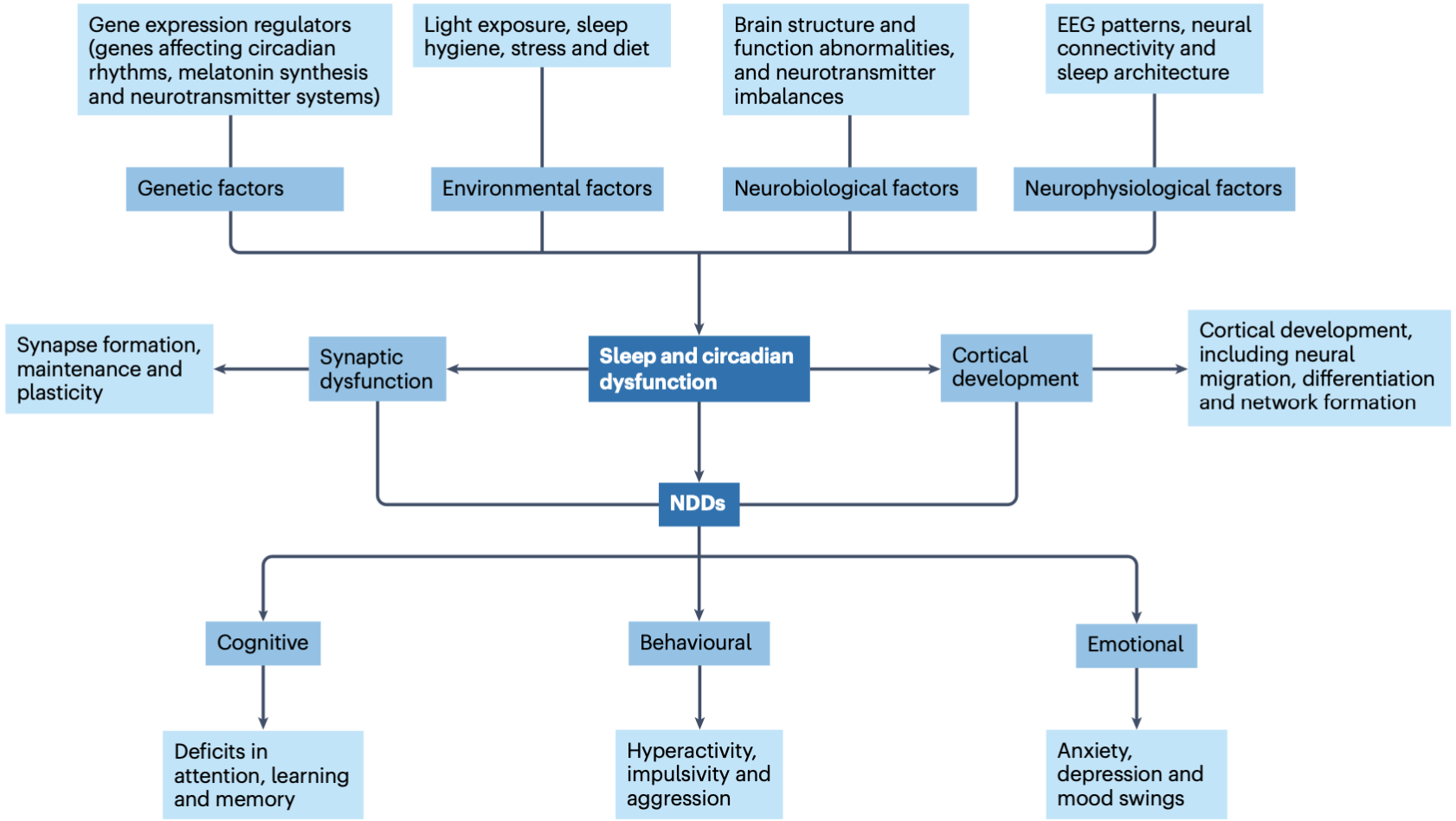
Circadian Rhythm



Sleep and circadian disturbances in children with neurodevelopmental disorders

Oliviero Bruni, Maria Breda, Valeria Mammarella, Maria Paola Mogavero & Raffaele Ferri

Nature Reviews Neurology **21**, 103–120 (2025) | Cite this article



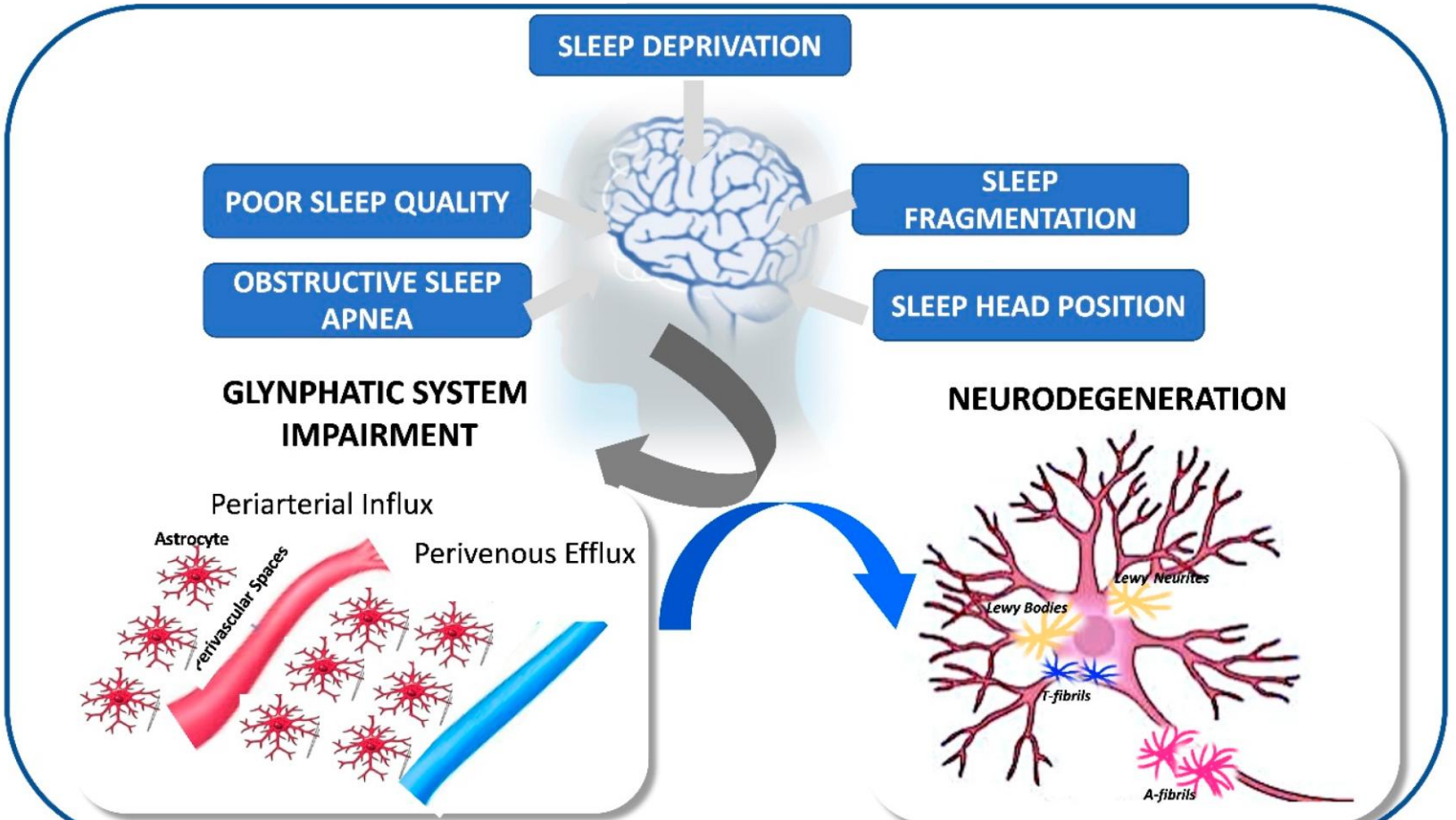
“Glymphatic” Neurodegeneration: Is Sleep the Missing Key?

by **Luigi Ferini-Strambi** [1,2,*] and **Maria Salsone** [1,3]

[1] Division of Neuroscience, Vita-Salute San Raffaele University, 20132 Milan, Italy
[2] Sleep Disorders Center, San Raffaele Scientific Institute, 20132 Milan, Italy
[3] IRCCS Istituto Policlinico San Donato, 20097 San Donato Milanese, Italy
* Author to whom correspondence should be addressed.

Clin. Transl. Neurosci. **2024**, *8*(2), 23; **https://doi.org/10.3390/ctn8020023**

Controversial: maybe **less** “brain cleaning” during sleep



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Obstructive sleep apnea (OSA)

Characterized by:

1. Episodes of complete (apnea) or partial (hypopnea)
2. Collapse of the upper airway ⟶ decreased O2 saturation or arousal from sleep
3. https://www.ncbi.nlm.nih.gov/books/NBK459252/

Obstructive Sleep Apnea

Jennifer M. Slowik; Abdulghani Sankari; Jacob F. Collen.

▸ Author Information and Affiliations

Last Update: March 4, 2025.

Risk factors for OSA

A. Hypotonia (OMAS? genetic conditions, metabolic disruptions)
B. Elevated BMI
    1) Steroids
    2) Decreased mobility 2° motor challenges
C. Tonsillar/adenoidal hypertrophy (seasonal allergies, chronic infections)

Signs of OSA

- Behavior issues, irritability
- Poor sleep, snoring, sleepwalking, choking
- Excessive daytime sleepiness (EDS)

Treatments of OSA

- Allergy medications
- CPAP machine
- BMI control (exercise, diet, GLP’s?)
- Tonsillectomy/adenoidectomy

Untreated OSA

- Hypertension/Cardiac failure

OMAS: A team sport

Pediatric Neuro-oncology

Khakoo/Fisher

2023 OMSLife Caregiver Conference