



Summit Centre for Education, Research, and Training
Conference 2019 Program

November 1st 2019

**Sleep in individuals with Autism :
etiology and avenues for intervention**

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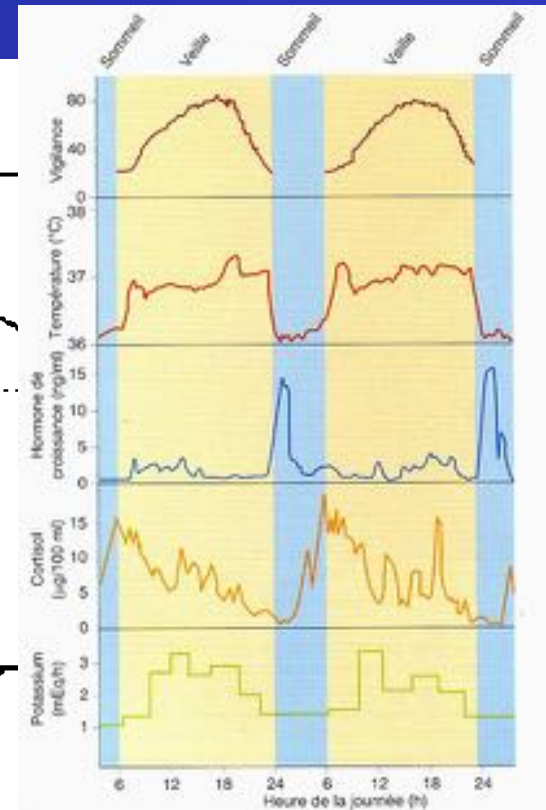
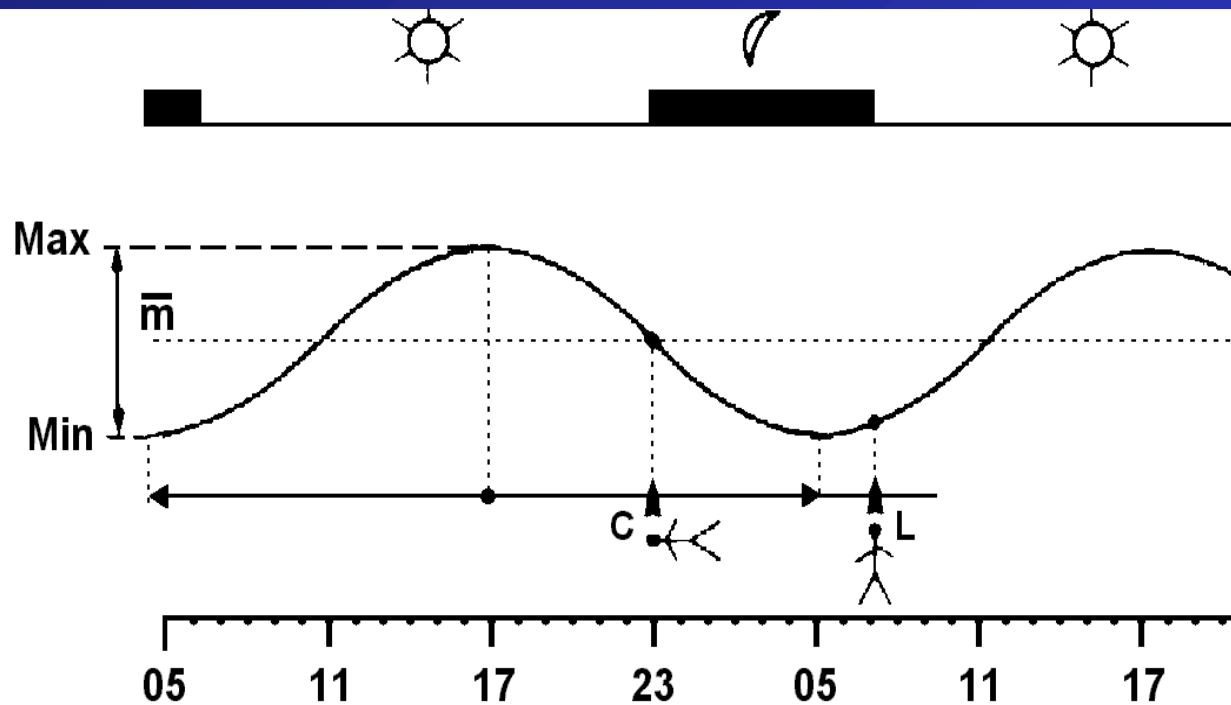
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PLAN



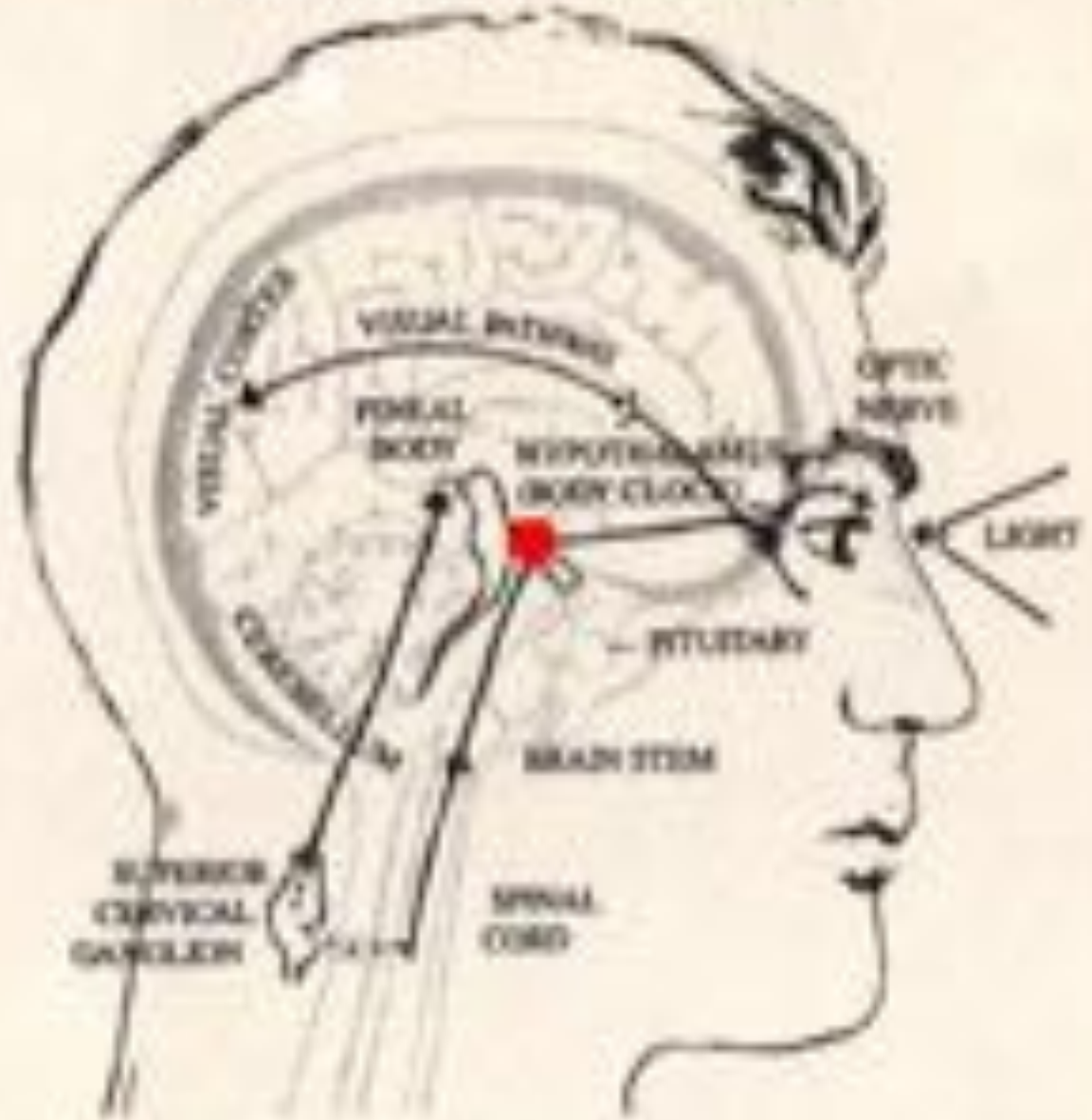
- 1. Typical organization of sleep**
- 2. Sleep disorders and their assessment**
- 3. Autism and sleep**
- 4. Autism and sleep**
- 5. Treatment avenues for sleep disorders in autism**

CIRCADIAN RHYTHMS



Intrinsic & extrinsic factors (or synchronizers) that modulate biological rhythms, including sleep

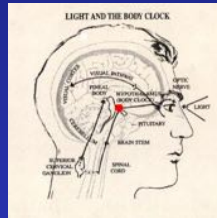
LIGHT AND THE BODY CLOCK



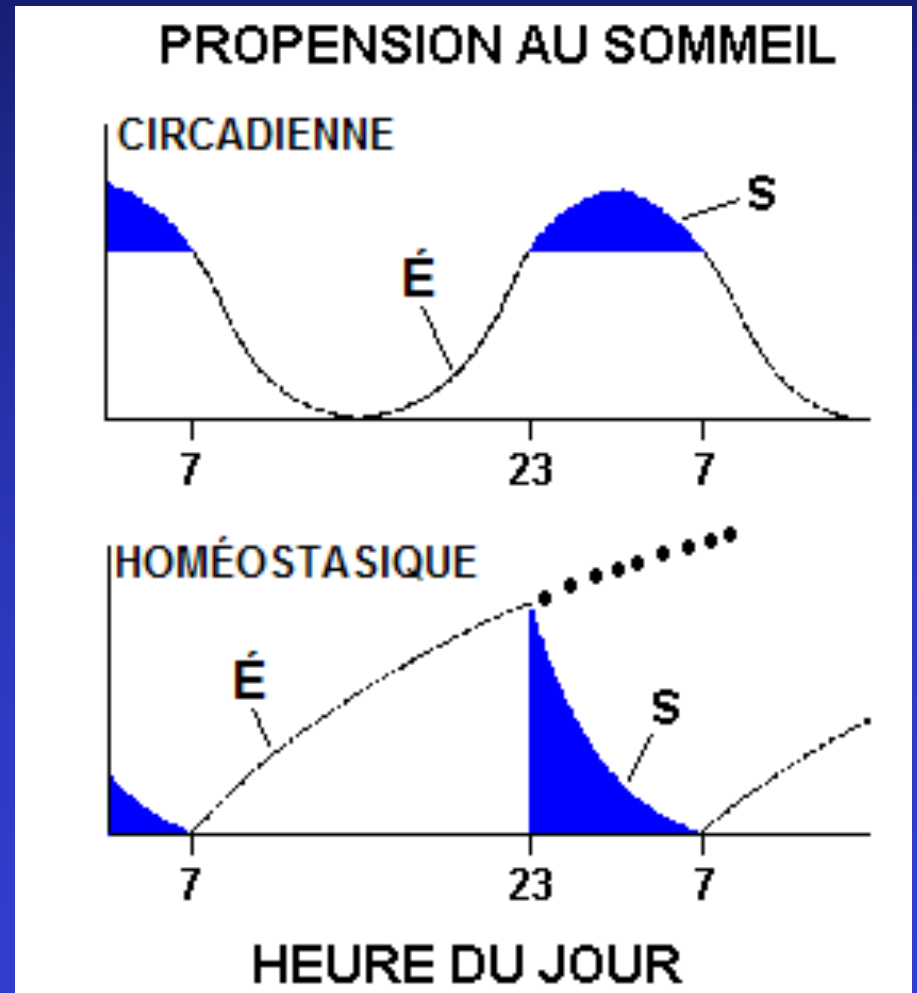
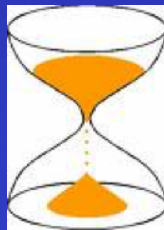
What determines us falling asleep and the maintenance of sleep?

Two influences:

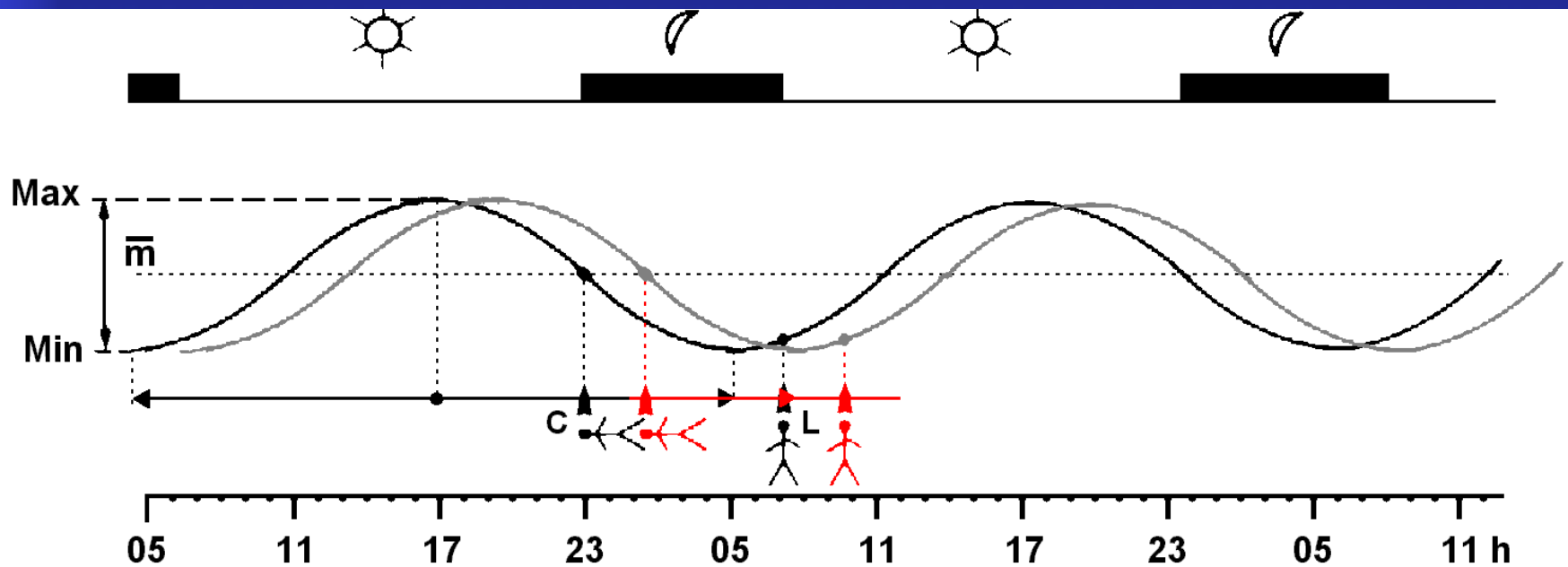
1) The circadian biological clock



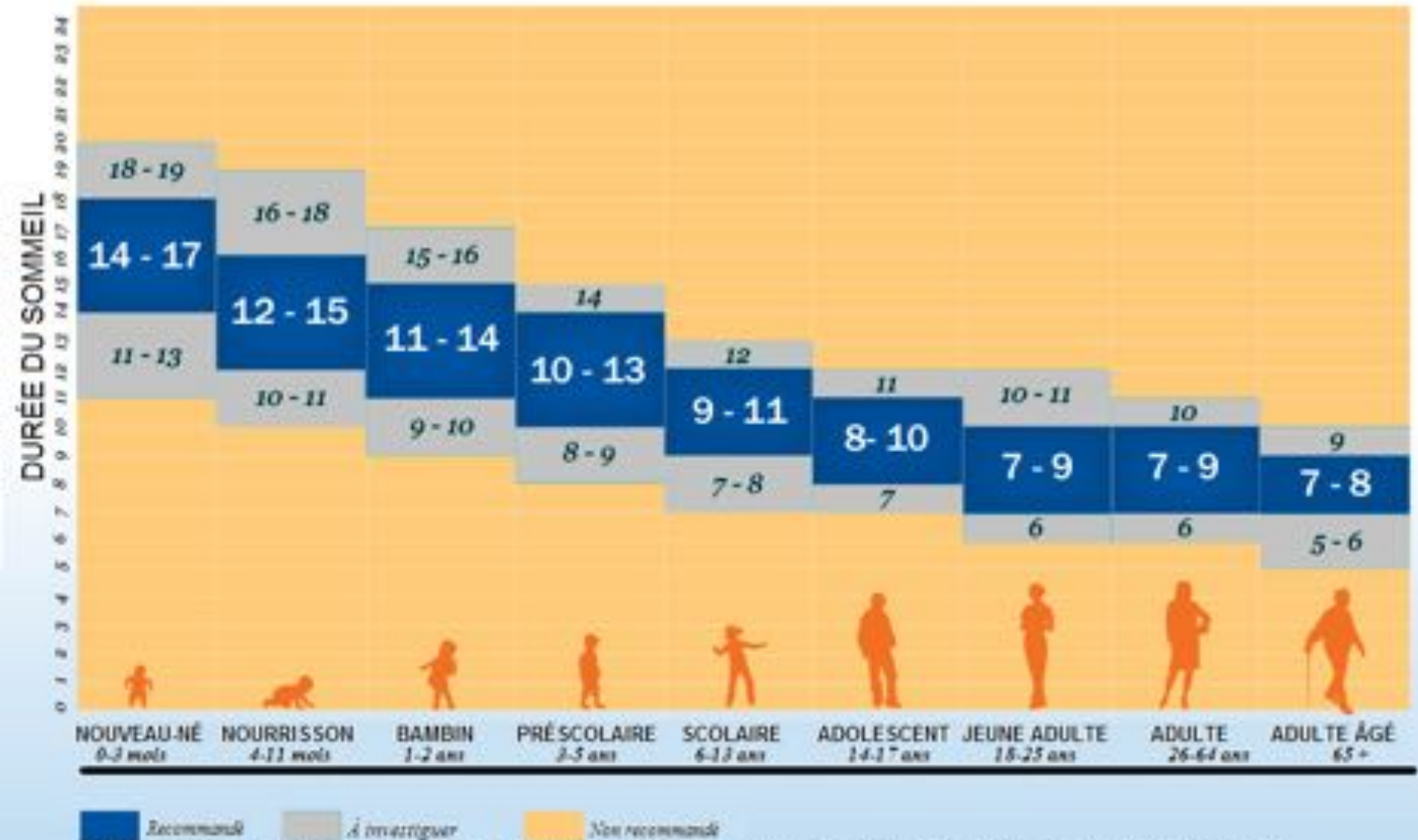
2) The accumulation of time awake



Night owl or early bird ?



Sleep time duration across ages (averages + deviations)



Two sources of information for assessing sleep

- 1- Subjective : sleeper's point of view (or partner, for example)
Person will say what he/she feels or does not feel anymore, the patient (or partner) will say what is wrong
- 2- Objective (« sleep disorders specialist's » point of view)
Equipment will measure what is detected, based on predetermined parameters (brain activity, cardiac rhythm ...), etc.

Conclusion :

→ Both sources reliable and useful but do not measure the same thing

TOOL USED FOR ASSESSING SLEEP

- Clinical scales and questionnaires
- Sleep journals
- Ambulatory methods:
 - Actigraphy, video recordings
- Laboratory-based investigations :
 - Polysomnography

Sleep questionnaires : advantages & disadvantages

- Allows to formalize the patient's complaint
- Existence of validated and normed questionnaires
- ... however :
- Don't allow for detection of « occult » sleep difficulties :
 - « light » sleep and partial/micro-awakenings
 - Sleep apnea
 - Periodic limb movements
 - abnormal EEG

5 BASIC QUESTIONS

Usually, during the last month:

1- How many minutes does it take before you fall asleep ?

2- How long do you night awakenings last ?

3- What time do you go to sleep :

Week-nights?

Week-ends?

4- At what time do you get up :

Week-nights?

Week-ends?

5- Are you satisfied with your sleep? Yes No

The « HIBOU »



NOM : _____ DATE DE NAISSANCE : _____

REPLI PAR : _____ DATE : _____

HIBOU

Échelle de dépistage des troubles de sommeil pédiatriques (2-17 ans)

Légende : 0 = jamais ; 1 = 1-2 x/ semaine ; 2 = 3-4 x/ semaine ; 3 = 5-7 x /semaine

H : Horaire irrégulier, hypersomnolence diurne

- Levé/couché trop tôt/trop tard, écart semaine/ fin de semaine de plus de 2 heures 0 1 2 3
- Somnolent le jour 0 1 2 3

I : Insomnie

- S'endort en plus de 30 minutes 0 1 2 3
- Incapable de s'endormir seul, présence des parents nécessaire 0 1 2 3

B : Bouge dans son sommeil

- Comportement ou mouvements inhabituels la nuit 0 1 2 3

O : Obstruction

- Ronflement, bruits ou pauses respiratoires pendant le sommeil 0 1 2 3
- Respiration buccale 0 1 2 3

U : Ultra vigilance

- Réveils nocturnes de plus de 20 minutes, plus de 2 fois par nuit 0 1 2 3
- Rejoint les parents dans leur lit la nuit 0 1 2 3

Total

→ Severity score :

- **weak** : do not refer, education, sleep hygiene
- **medium**: monitor (especially if 3 response on I and U questions)
- **high** : refer to sleep clinic

SLEEP JOURNAL

2 ½ year-old child w autism

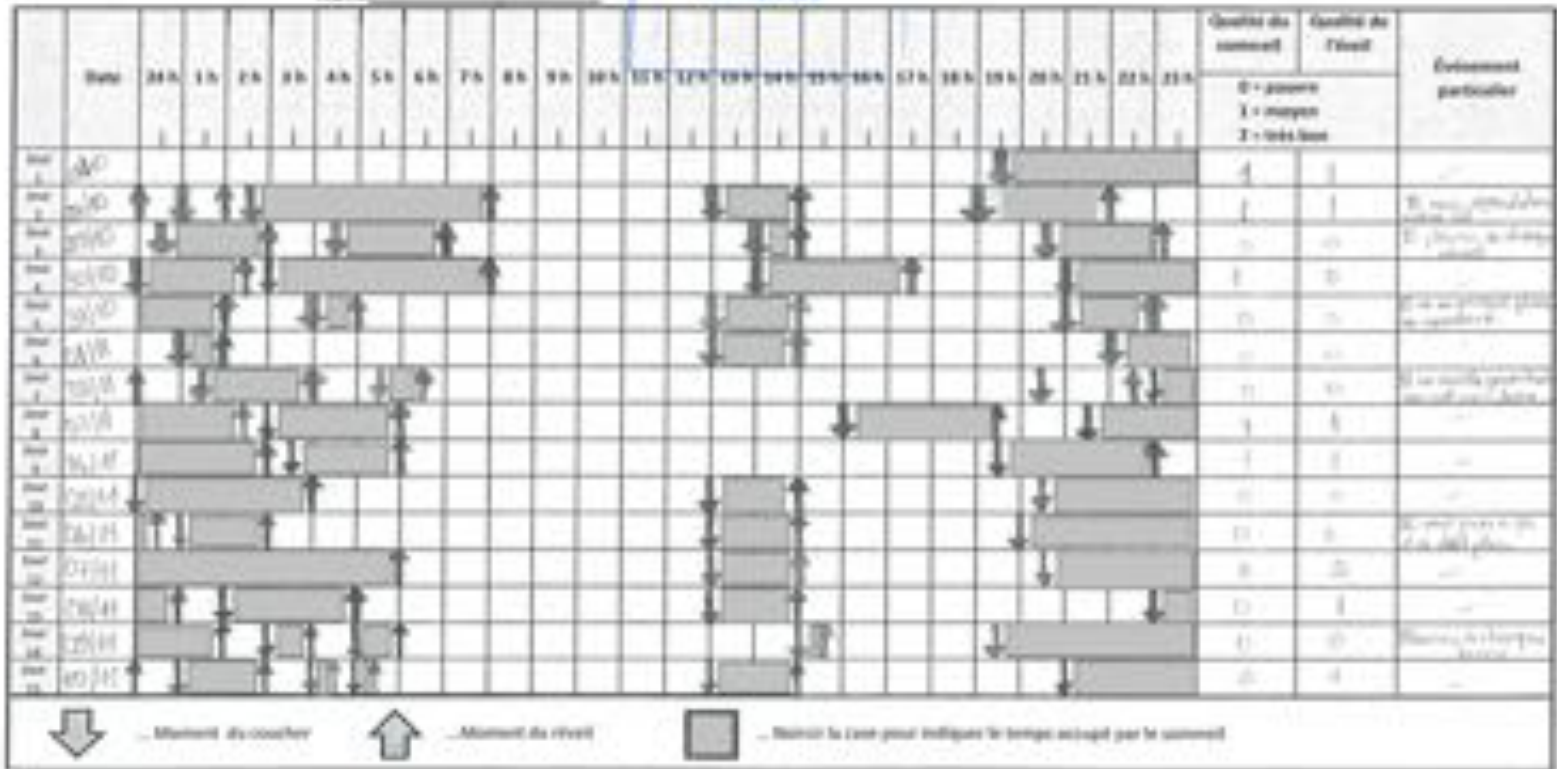


Service spécialisé Évaluation
diagnostique des troubles du sommeil

AGENDA DE SOMMEIL
Clinique spécialisée d'évaluation
diagnostique des troubles du sommeil

Nom: _____

20 sept. 2011



SLEEP ASSESSMENT TOOLS

- Clinical scales and questionnaires
- Sleep journal
- Ambulatory assessments :
 - Actigraphy, video recordings
- Laboratory-based assessments:
 - Polysomnography

AMBULATORY METHODS: Actigraphy

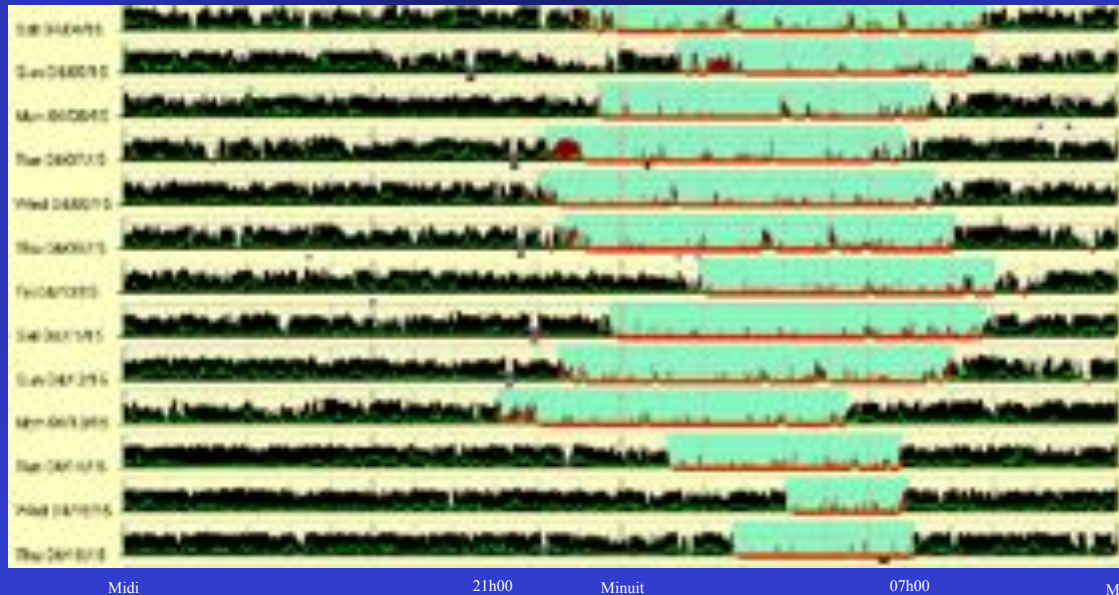


Bracelet worn on wrist of non-dominant hand

Sensitive to movement and light

Estimation of rhythmic activity / rest

Inferences made on awake and sleep periods (delay, duration, efficiency...)



VIDEO-SOMNOGRAPHY ENVIRONMENT & BEHAVIOUR

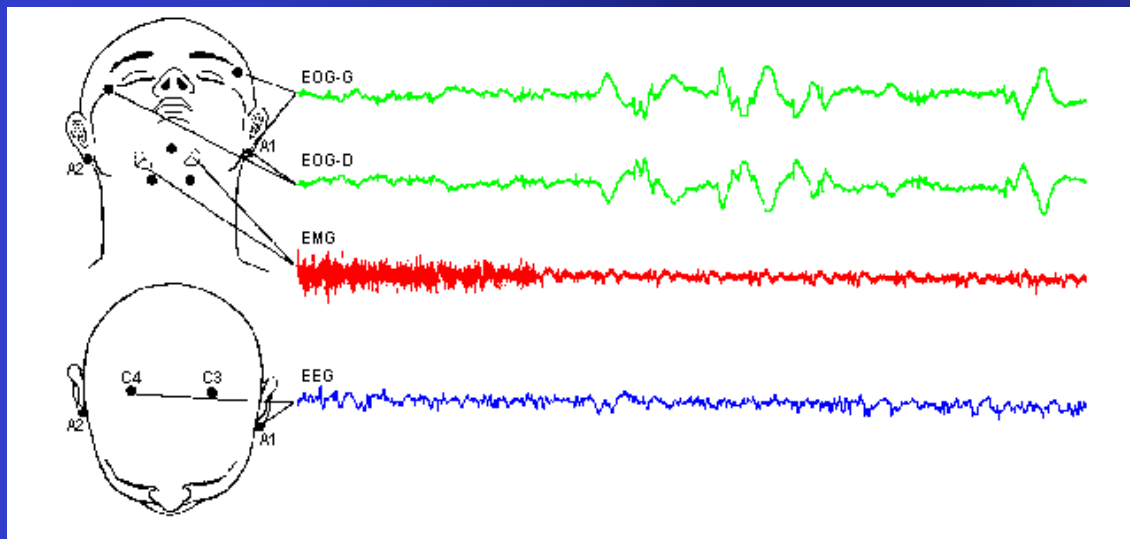


POLYSOMNOGRAPHY

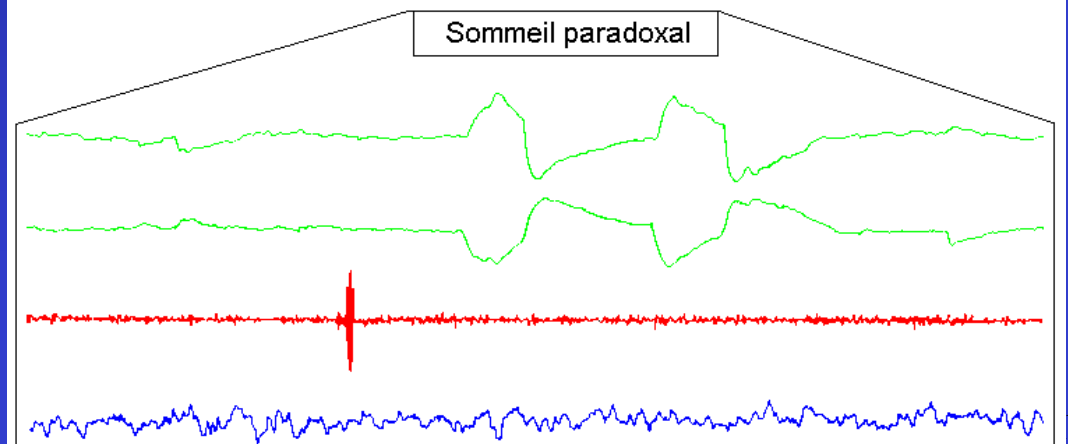
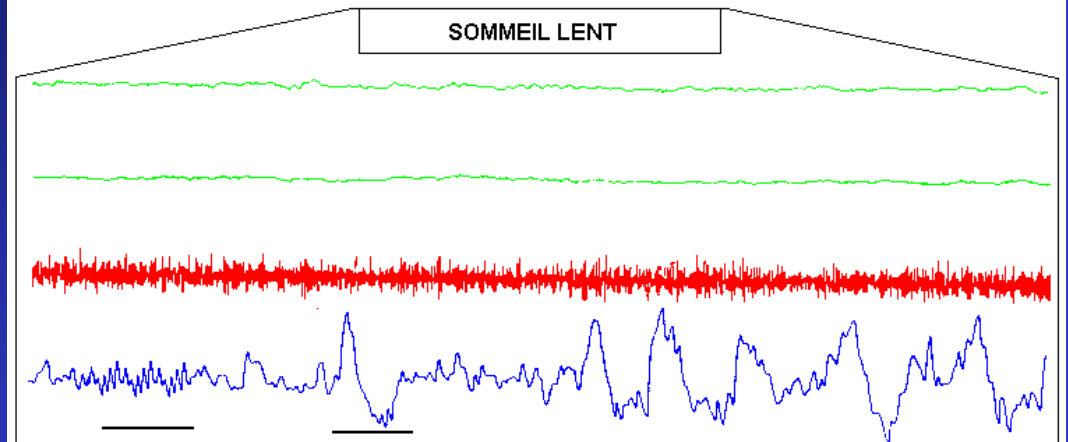
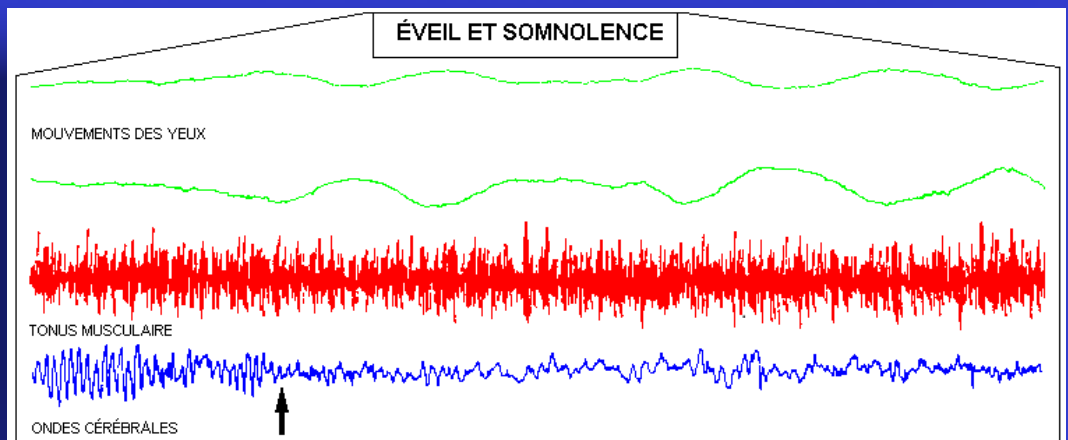
Mostly necessary for :

- ❖ sleep apneas ;
 - ❖ epilepsy \leftrightarrow parasomnia;
 - ❖ narcolepsy
- ✓ Ambulatory systems (apneas) : screening, difficult or distant cases

SLEEP IN THE LABORATORY : POLYSOMNOGRAPHY



The stages of sleep



THE STAGES OF SLEEP

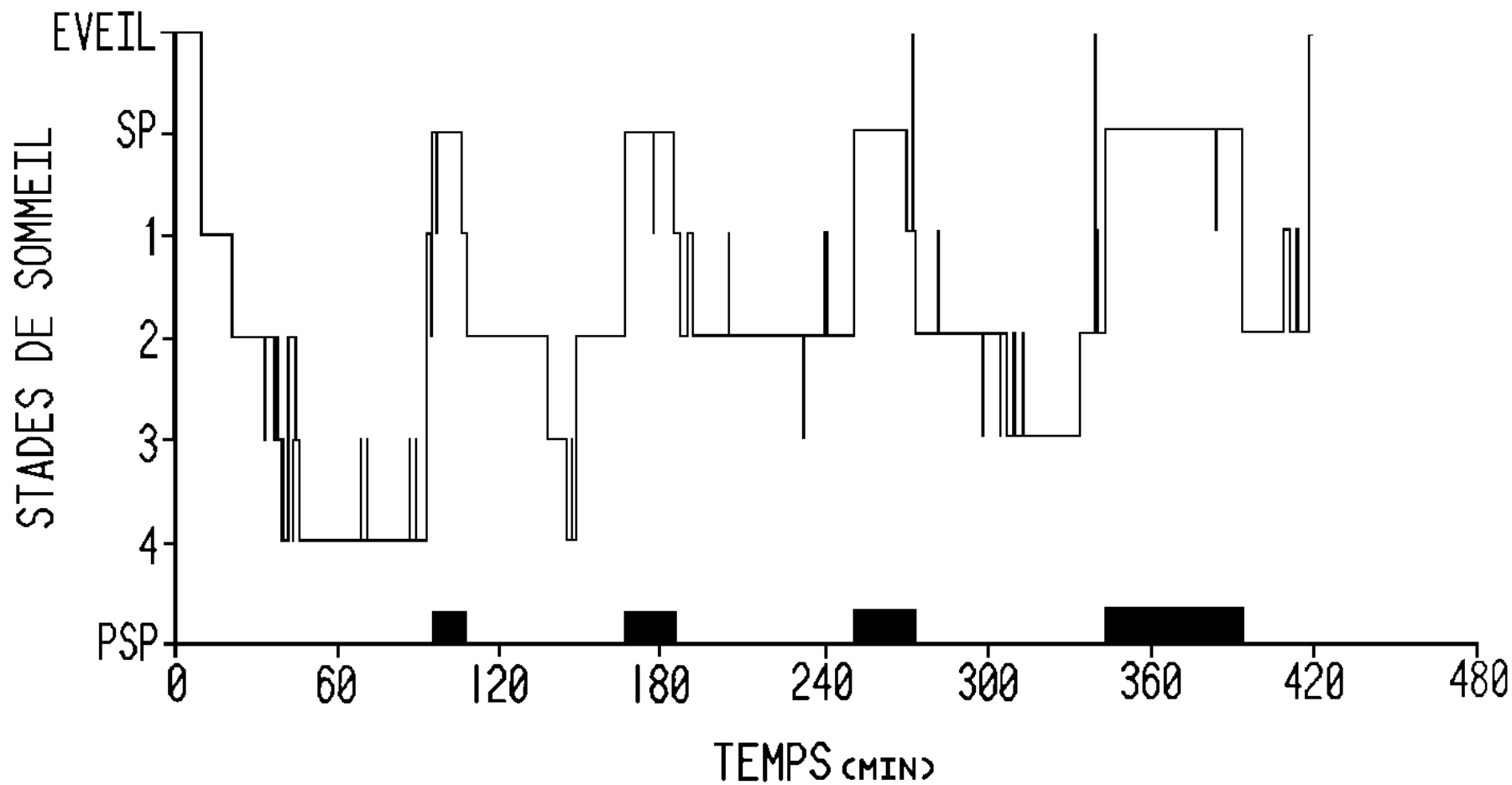


Fuseau de sommeil

Activité EEG lente après un complexe K



HYPNOGRAM



FONCTIONS OF SLEEP

« Slow-wave » sleep:

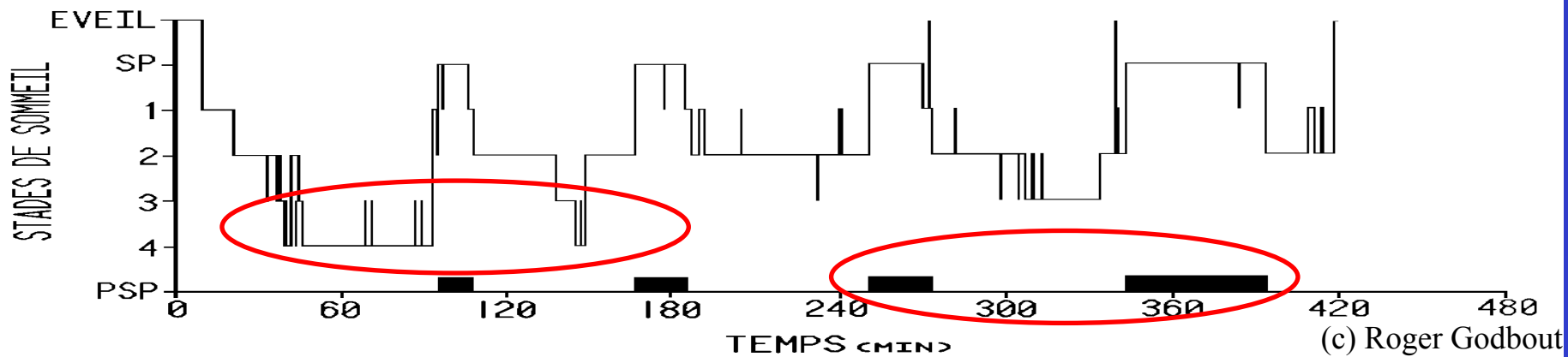
Somatic functions

- growth hormone secretion
- Immune activation
- Homeostasis (accumulated awakens, exercise)
- Spindle / slow waves

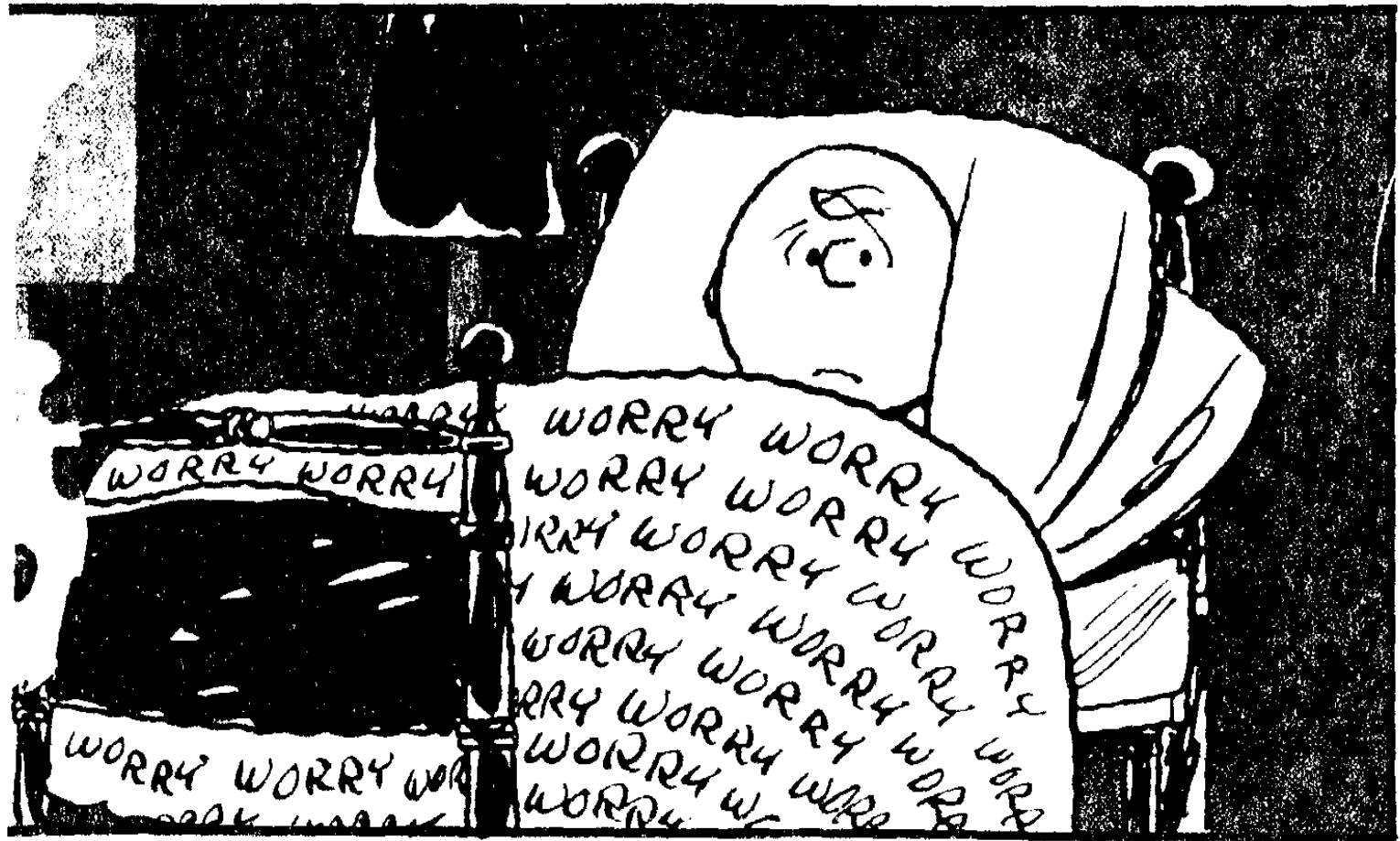
REM sleep :

neuro-cognitive functions

- Maturation du SNC, synaptogenesis
- Memory: encoding and recall
- Reactivation of information vital to survival
- Physiological support for dreams



SLEEP DISORDERS



CLASSIFICATION OF SLEEP DISORDERS ⁽¹⁾

- Insomnia
Difficulty inducing or maintaining sleep
- Hypersomnia
Difficulty inducing or maintaining awakeness
- Parasomnias
Episodic behavioural manifestations during sleep (sleepwalking, bruxism, sleep terrors, nightmares...)
- Dys-synchrony
Sleep-wake disorders
- Associated to medical conditions
Symptoms induced or accentuated by sleep

Sleep or psychiatric disorder : what to treat ?

Only about 1% of children with a sleep disorder are referred to a specialized sleep clinic. Two reasons :

- Are sleep disorders not a consequence of a psychiatric disorder ?
- Do we not have enough problems to resolve before addressing sleep?

SLEEP DISORDERS AND PSYCHIATRIC DIAGNOSIS

In a person with a psychiatric condition, is a sleep disorder :

- a consequence ? Not always !
- a co-occurrence ? Often !

According to the DSM-5, insomnia must be treated as a primary condition. A diagnosis of « secondary insomnia » no longer exists

Sleep disorders and psychiatric diagnosis: daytime functioning

- Aggravation of symptoms
 - \uparrow Sx = poor sleep; poor sleep = \uparrow Sx
- Hidden symptoms or new symptoms may appear
- Relations with family, authority, peers $\downarrow \downarrow$
- Performance at school $\downarrow \downarrow$
- Somnolence

Sleep disorders and psychiatric conditions : increased sensitivity

- Even at sub-clinical levels, « organic » sleep disorders (sleep apnea, « restless leg syndrome »...) have a significant effect on daytime functioning
- In infants and children, daytime sleepiness is manifested by
 - ✓ agitation
 - ✓ irritability
 - ✓ impulsivity
 - ✓ rigidity...



AUTISM AND SLEEP



AUTISM & SLEEP

Questionnaire studies

Children :

- Difficulty initiating and maintaining sleep reported by \approx 50-80% of parents
- ...compared to 9%-50% of parents of neuro-typical children

AUTISM & SLEEP

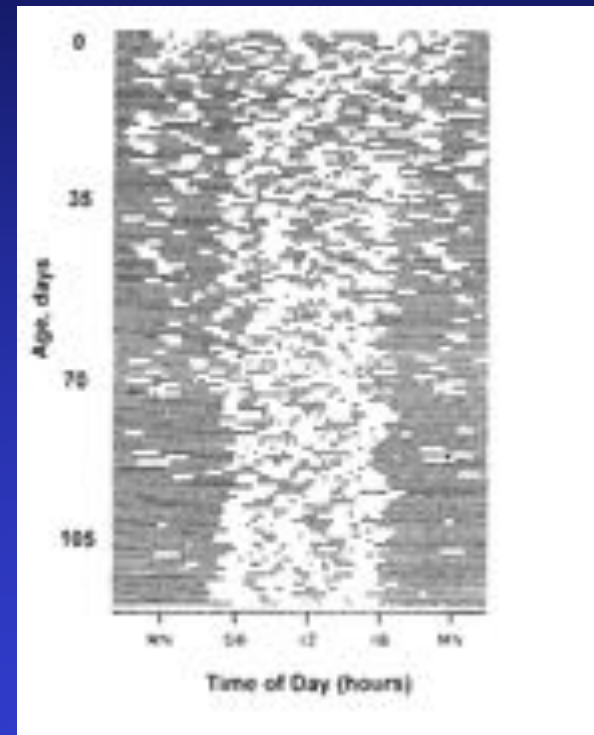
- Sleep profile:
 - Sleep-wake training difficulties
 - Difficulty initiating and maintaining sleep
 - Architectural parameters (sleep stages)
- Assessment:
 - Early screening / detection, about 2 years of age
 - Decreases with adulthood ?

AUTISM & SLEEP

LITERATURE REVIEW - 1/3

Organisation of sleep-wake cycle (questionnaires)

- Delay in the development of circadian rhythms (4 years vs < 6 months, typically)



AUTISM & SLEEP

LITTERATURE REVIEW - 2/3

Inducing and maintaining sleep

- Long delay before falling asleep
- Increase in nocturnal awakenings (number, duration)
- Short sleep duration

AUTISM & SLEEP

LITTERATURE REVIEW - 3/3

Sleep structure

- Stage 1 (light) : → elevated
- Stage 2 : → normal but few sleep spindles
- Deep sleep : → weak
- Paradoxical sleep : → normal

ETIOLOGY OF SLEEP DISORDERS IN AUTISM - 1/3

1- Circadian clock

- Melatonin : insufficient synthesis/transmission, altered sensitivity of receptors, gene mutation
- Secretion profile inverted / atypical in children with autism

ETIOLOGY OF SLEEP DISORDERS IN AUTISM - 2/3

2- Cortical protection mechanisms of sleep (EEG) : weak density and atypical distribution

- Sleep spindles
- Complex K
- EEG slow waves

ETIOLOGY OF SLEEP DISORDERS IN AUTISM - 3/3

3- Behaviour :

- Difficulty detecting external circadian signals :
time, light...
 - Imperfect associations regarding what appears /
is expected during the day vs night-time
 - Poor (acquired) habits
-
- Children with autism are first and foremost
children ... !

SLEEP DISORDERS IN AUTISM:

Impact on daytime functioning

Sleep disorders are associated with the intensification of autistic symptomology :

- Clinical scores
- Social abilities
- Stereotypical behaviours



Sleep Clinic @ HRDP

Team

- 2 part-time psychologists (+ co-ordinator)
- Clinical nurse specialist
- Developmental pediatrician
- Medical secretary
- Technicians
- Students, clinical trainees

Equipment

- 2 PSG rooms + 2 parent rooms
- ~15 actigraphs
- 6 portable “apnea” systems
- 2 infra-red cameras

Clients

- 90-100 new cases/year
- 0 to 17 years
- Psychiatric Dx or other medical Dx

The assessment process

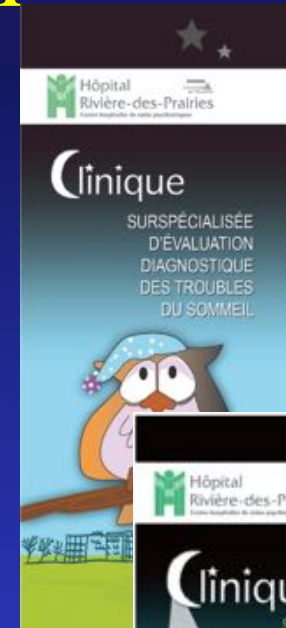
- ✓ Medical reference
- ✓ Eligibility; pre-interview questionnaire
- ✓ Analysis of results and team meeting
- ✓ Interview :
 - With parents, caregivers
 - Duration : ~ 90 minutes
 - Database
- ✓ 2nd Interview
 - Adolescents
 - If an objective assessment completed (polysomnography, video, ambulatory...)
- ✓ Follow up ~ 6-8 weeks, by telephone or e-mail
- ✓ Contacted before if necessary
- ✓ Dossier is closed if sleep problems addressed, if not we persevere

Pre-interview assessment

- Sleep journal x 2 weeks (incl. 2 weekends)
- Sleep habits (time, week-day vs week-ends / vacation)
- HIBOU[©]
- Sleep habit questionnaire
- Other questionnaires according to specific needs (daytime sleepiness, chronotype, behavioural scales, neuropsychological assessment...)

Treatment and follow-up

- ✓ Strategy established during interview
- ✓ Education (Sleep 101); flyers
- ✓ Support & instructions sent by e-mail
- ✓ Follow-up by nurse and psychologists (e-mail / telephone)
- ✓ Feedback and discussion with referring professionals : mental health, medication, etc....



AUTISM AND SLEEP

HOW TO INTERVENE ?

Two principal objectives :

- 1) Increase the perception of the day/night contrast
- 2) Develop autonomy regarding sleep hygiene

Three principal strategies:

- 1) Identify and treat comorbid factors (acid reflux, anemia, sleep apneas, anxiety,...); medication review
- 2) Establish sleep hygiene measures
- 3) Introduce supports geared at synchronising biological rhythms

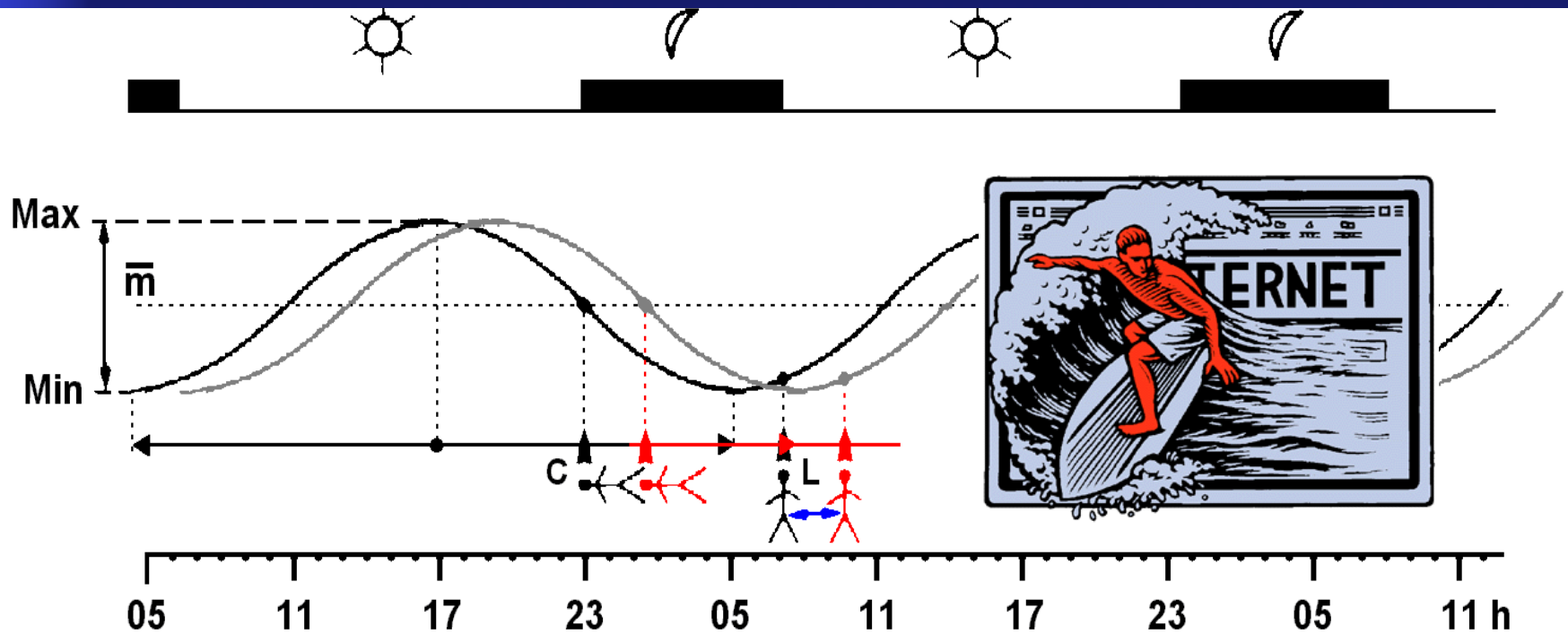
Treatment

- Pair/integrate treatment with that of other implicated professionals : differential diagnosis, tests and treatments
- Children : instill sense of teamwork w parents :
 - Compassion
 - Share knowledge
 - Build a relationship based on mutual trust
 - Engagement, mutual agreement
- Adolescents : sometimes a challenge
 - Draw up and sign contract together

SLEEP HYGIENE AND AUTISM

- Maintain a regular wake-up time.
Exposing quickly to daylight
- Maintain regular meal times,
especially supper
- Establish a relaxing routine in
preparation for bedtime
 - stable
 - predictable
 - repetitive (3-4 clear steps
taking 30-45 min.)
- Stabilize wake-up time : less than
1½ hours later for WE
- Keep bedroom dark and silent,
comfortable temperature and bed.
- Physical landmarks/references :
corner bed, body pillows
- Physical landmarks/references :
pictograms
- Do not use bed for functions other
than sleep, resting while sick
- Special place relaxation
- Avoid television, computer (games, e-
mails, typing...), & snacks in room :
these stimulate, don't help with sleep.

Phase delay (for adolescents)



Matthieu, a 5 (or an 11) year-old autistic boy with insomnia

- Poor sleep “since he was born”
 - Bedtime resistance
 - Very early morning awakening
- Other issues
 - Very sensorial: food texture, light
 - Rigid behaviors
 - Parents are separated, shared custody
- Will attend a standard school next September
 - He is stressed, his parents are stressed

Matthieu, cont'd:

Intervention

- Before the first meeting:
 - Received filled questionnaires, including sleep journal
 - Polysomnography (re: EEG, periodic leg movements...)
 - Retrospective chart review; other teams involved?
- First meeting (with both parents and Matthieu)
 - Reviewed questionnaires with parents, including medication: psychostimulant AM for “possible ADHD”)
 - Updated the complaints: no changes
 - Set objectives: early morning awakenings is #1
 - Team work!
 - Watched Matthieu during the meeting: anxious

Matthieu, cont'd:

Intervention steps

- First meeting, cont'd
 - Reviewed PSG results:
 - long sleep latency
 - a long awakening 2 hours later
 - high % stage N1
 - possible restless legs, definite periodic leg movements
- Reviewed the evening routine sequence:
 - Supper, iPad, bath, snack, legos, brush teeth, bed, massage, lights out
 - Pushed the bath just before bed and moved snack and tooth brushing earlier to better separate daytime-related and bedtime-related activities

Matthieu, cont'd:

Sleep 101

- Translated Sleep 101 knowledge in relation with PSG findings and routine:
 - The entry into the sleep zone needs to be planned according to Processes C (clock) and H (sleep debt).
 - Strong synchronizing signals are needed to help Matthieu's body and brain understand that sleep time is coming:
 - Warm bath just before going to the bedroom:
 - to help temperature lowers itself
 - to help Matthieu taking a break after a day full of pressure
 - Stop verbal interactions to let Matthieu's brain calm down
 - Slow massages are great!

Matthieu, cont'd:

Sleep 101

- Bedroom environment
 - Temperature $\sim 19^{\circ}\text{C}$, humidity $\sim 40\%$
 - White noise (table of floor fan)
 - Completely dark bedroom; no blue night lights
 - Melatonin:
 - Gives a strong biological signal to reinforce the clock
 - It is a time giver, not a sleeping pill
 - Like sunset: should be taken 7/7, at the very same time each night, no matter what, just before the bath
- The pediatrician reviewed the case with the child psychiatrist; psychostimulant medication was removed (evening snack was no longer needed)

Matthieu, cont'd:

Phasing out

- Next and last meeting in 6-8 weeks
- Both parents became experts about the sleep of Matthieu
- They can ask for advice anytime until Matthieu is 18 years old



Conclusion/Discussion

- Insomnia occurs frequently in ASD
- The circadian component frequently plays a major etiological role
- Psychiatric comorbidity also plays a role
- Knowledge of common autistic behavioral characteristics helps establishing a treatment schedule for insomnia.
- Parent often contribute significantly to fine tune the treatment.



SLEEP & AUTISM

1. Sleep disorders and autism are two independent conditions that are frequently associated.
2. Subjective complaints and objective measures each have their respective merit and value.
3. Medical and psychological interventions are both useful and necessary.



QUESTIONS?

